FILLING THE GAP WHERE PATIENTS USED TO FALL:

EVALUATING THE ROLE AND IMPACT OF EYE CLINIC LIAISON OFFICERS AND OTHER VISION SUPPORT WORKERS ACROSS THE UNITED KINGDOM

Final Report

for Royal National Institute of Blind People

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Research led, Analysis Driven, Real World Perspective

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Most importantly, we are immensely grateful to those people who took the time to engage with the study – whether eye clinic liaison officers (ECLOs), clinicians or others working across ophthalmology, those in social services or voluntary sector organisations or groups, or individual patients themselves. Without their willing engagement in the study, our work would have been greatly limited – the study is much richer for their contribution.

We trust that the findings will contribute usefully to ongoing discussions about the developing role and value of ECLOs as they support people with sight loss. It should be noted that this report is entirely the work of the study team and the analysis and conclusions we have come to have been arrived at independently of any outside influence.

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GLOSSARY OF TERMS

AMD	Age-Related Macular Degeneration
Anti-VEGF	Anti Vascular Endothelial Growth Factor
CVI	Certificate of Vision Impairment
DES	Discrete Event Simulation
DR	Diabetic Retinopathy
ECLO	Eye Clinic Liaison Officer
EQ-5D-5L	EuroQoL (Quality of Life) 5-Dimension, 5-Level questionnaire (cited as EQ-5D herein)
ESaC	Emotional Support and Counselling Services
ELVR	Enhanced Low Vision Rehabilitation
HRQoL	Health-Related Quality of Life
ICER	Incremental Cost-Effectiveness Ratio
LVAs	Low Vision Aids
LVL	Low Vision Leaflet
LVR	Low Vision Rehabilitation
NICE	National Institute for Health and Clinical Excellence
QALY	Quality-Adjusted Life Year
QoL	Quality of Life
RNIB	Royal National Institute of Blind People
RVI	Referral of Vision Impaired Patient Letter
SCHE	Swansea Centre for Health Economics, Swansea University
SI	Sight impairment
SSI	Severe Sight Impairment
VAS	Visual Analogue Scale
WIHSC	Welsh Institute for Health and Social Care, University of South Wales
WLVS	Wales Low Vision Service

1 EXECUTIVE SUMMARY

The Royal National Institute of Blind People (RNIB) commissioned the Welsh Institute for Health and Social Care (WIHSC), University of South Wales working in partnership with the Swansea Centre for Health Economics (SCHE), Swansea University, to evaluate the impact that patient information and support services in UK NHS ophthalmology departments makes for patients, the clinic and on services more generally.

RNIB were interested to understand the difference that those that provide patient information or support services (most typically called eye clinic liaison officers – ECLOs, or vision support officers) make where they are present in clinics – whether defined in health-related quality of life outcomes (HRQoL) for people with sight loss, capturing or quantifying other benefits that they bring to the running of the clinic.

1.1 TERMS OF REFERENCE AND METHOD

The study was required to answer several key questions, structured around three areas of impact:

Impact on patients

- How does the ECLO 'value add' for the patient?
- How does contact with the ECLO impact on the HRQoL for patients?
- Are ECLOs targeting the right people?

Impact on clinics

- How do ECLOs operate within the clinic setting?
- What is the impact of an ECLO on clinic activity?

Impact on services

- What are the service benefits for having an ECLO present in clinic?
- Are there cost-savings to the NHS when an ECLO is part of the care team?
- What would happen if ECLO services were expanded?

The study was undertaken through an analysis of existing RNIB/Action for Blind People data on ECLO activity, complemented by 30 site visits to UK NHS ophthalmology outpatients. Our original 'typology' of sites based on presence or absence of an ECLO proved too simplistic. Instead, we used the experience described by patients divided into four categories: a) patients who said that they had support needs that were a) not met as no support was offered or requested; b) met by an ECLO; c) met by another person (whether nurse, doctor, volunteer etc. but not by an ECLO); or d) patients who said that they had no support needs. It is important to recognise that all four categories of patient could be present in each of the sites. The complex nature of ophthalmology departments meant that no two sites or ECLO services in the study were the same as organisations arranged their services to reflect local priorities.

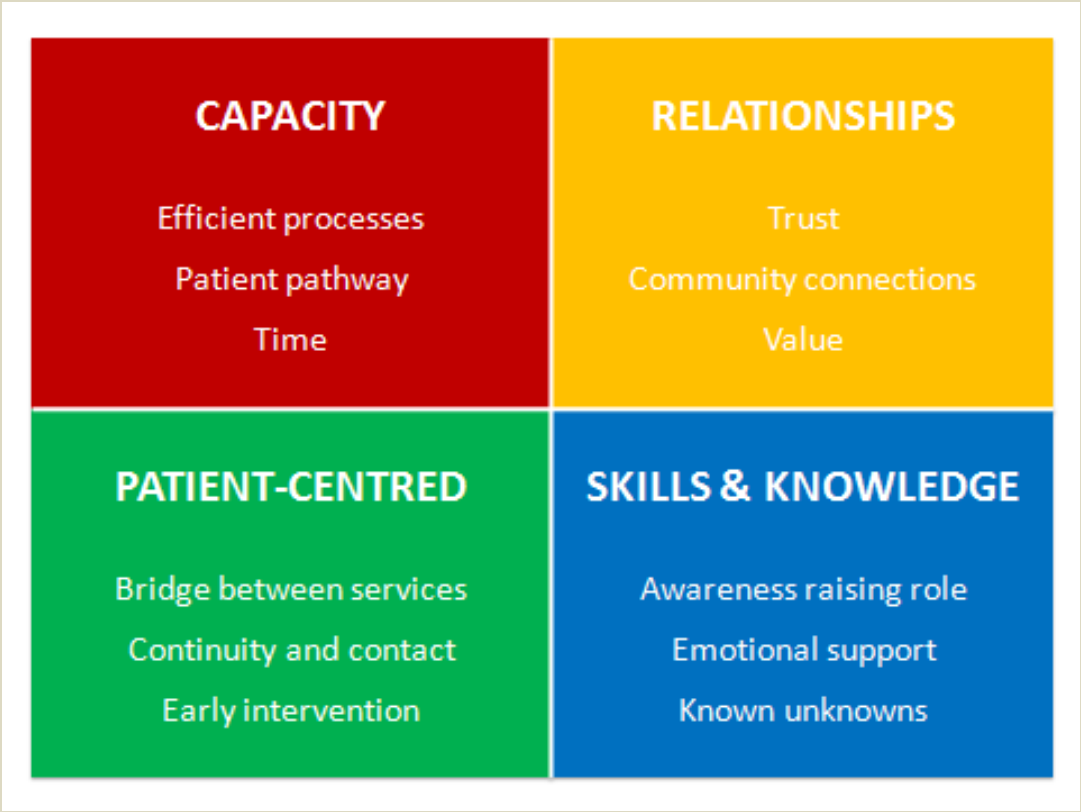
The visits to outpatient departments were designed to gather:

- HRQoL data from patients using National Institute of Health and Care Excellence (NICE) preferred measures, which were then followed-up after three months;
- Patient experience data;
- Staff data on the time spent on tasks that they undertake similar to ECLOs; and
- Interviews with a range of individuals including ECLOs, consultant ophthalmologists, clinic/ directorate managers, optometrist, commissioners, rehabilitation officers for visual impairment; orthoptists, registrars and medical secretaries.

1.2 RESULTS OF QUALITATIVE ANALYSES

There were four main categories in our coding framework (Figure 1.1) which evolved throughout the research project, namely: Capacity, Patient-centred, Skills and Knowledge, and Relationships.

FIGURE 1.1 · Coding framework - summary



1.2.1 CAPACITY

'They're like a little cog that makes all the others spin. They're a central link that the patient can go to and the ECLO can start all the other cogs spinning for them' [Operations manager]

The themes that became apparent under this category include the ways in which ECLOs affect the capacity of each service: that they add to the capacity in clinics and services and work in the most efficient, patient-centred manner possible. ECLOs also have positive effects on fundamental issues such as applying for a CVI, or impact on the various pathways that have to be negotiated by patients. ECLOs often have both networked power and networking power, the former being the means to enact, interact and facilitate core aspects of the 'care' system for those losing their sight, such as completing the CVI process. The latter, networking power, would be the use of tools such as referral

and signposting to activate other relationships across the various networks in which ECLOs operate, and in which they are important nodes.

The CVI process

- ECLOs have made CVI processes more efficient compared to previous systems that were in place. Many of our interviewees, professionals working alongside ECLOs, reiterated that ECLOs seem to have 'sorted out' the CVI pathway, in a comprehensive manner, in many of the sites visited.
- ECLOs ensure that all eligible patients are supported through the CVI process in a timely manner so that they access preventative support from their local council.
- ECLOs have more time to explain the significance of the Certificate clearly – it is an opportunity to offer support in what can be an emotional process for the patient. Crucially, ECLOs are able to follow up the process, including setting up any further support from that point onwards.

Time saving, streamlining processes and pathways to care

- Many of our interviewees were convinced that having an ECLO in post saves a lot of clinical time. We heard this from clinical managers, matrons, nurses, consultants and others. This assertion is no less valid as a finding for having been established qualitatively. However the quantitative study found that staff in non-ECLO clinics do not spend much time per patient performing as 'ECLO-like' staff. The ECLOs provide extra time and support for patients, rather than delivering support that other staff give.
- Interviewees from ophthalmology clinics acknowledged that ECLOs save them time primarily by taking pressure off them. The medical staff are required to move people through the system quite quickly, more so with ever tightening budgets: *'it releases some of the time for the trained staff to do what they trained for'.*
- Overwhelmingly, interviewees believe that ECLOs contribute to the smooth running of eye clinics. They would seem to enhance efficiency within clinics and streamline processes to release capacity, not only through the CVI process as outlined, but by referring and signposting appropriately and according to the needs of patients, in a timely way: *'…[referring to an ECLO...is] about putting the patient in the right place for the right reasons at the right time – that's how it works' [Orthoptist]; '[I]t definitely does have an impact on the smooth running of the clinic and that's how it saves money' [Clinical Lead]*
- Many interviewees are of the opinion that time is also saved for other staff through ECLOs taking ownership of the CVI process. Inappropriate referrals are avoided. In more than one account it was stated that if there is early engagement with patients (e.g. pre-CVI), people will impact less, further down the line. Part of an ECLO job is early intervention and prevention, not waiting until the patient is registered.
- Giving patients time to talk and get used to their diagnosis is a key function of ECLO practice. Most interviewees recognize this, and this was a comment made by many across the nations and regions. By giving this time to talk, an ECLO allows other clinical staff to carry on with their tasks.

1.2.2 PATIENT–CENTRED

'We fill the gap where patients used to fall, and give them the help to remain independent' [ECLO]

Another major category developed in our data was that of 'patient-centred' practice. By being 'patient-centred', there is slight shift in emphasis in ECLO practice, where the focus is on the need of the patient rather than the needs of the service.

Bridge between clinical and non-clinical services

- ECLOs are clearly the bridge between services both within the clinical environment and services outside of the hospital, and this is a key practice – linking the health service and the wider world – whether that is to social services, social care, local sight loss charities or other voluntary sector groups. By linking services together, this benefits patients, their families and carers. It also enables care to continue once medical options have been exhausted.
- As we have seen, there are clear examples of when the ECLO takes over in the clinic for 'non-clinical' work e.g. certification, but also raising patient awareness in other ways.

Emotional support

- Providing a wide range of emotional support is obviously a key practice for ECLOs. They provide support for patients who are anxious about their condition including those whose symptoms are mild and are anxious about their future, and are able to manage expectations.
- ECLOs fill a gap in services. In clinics without ECLOs, and before existing ECLOs were in post, the capacity to provide emotional support was limited: *'The really tough patients, the patients that really need a lot of emotional support, there's no way we would be able to provide it without [the ECLO], no way at all' [Optometrist]*
- In many clinics people who are anxious about their condition are referred to an ECLO immediately. Both clinicians and ECLOs perceive this saves time in the clinic and gives the clinicians 'permission' to move to the next patient.

Developing emotional resilience and enabling

- ECLOs are enabling in the sense that they help patients to get on with their lives outside of the clinic, and help them develop the necessary coping mechanisms, what is now commonly called emotional resilience. The clinician is able to refer the patient with confidence – their needs will be seen to as fully as possible by the ECLO, beyond the starkness of the diagnosis and details of the treatment: *'It's the quality you can bring to a patient's life I think, the quality service, a way of life, a coping strategy. It is just a good experience, an all-round experience, and it is part of our patient care, and it enhances the patient experiences and enhances their lives I would say' [ECLO]*

Preventative work - early intervention

- Many ECLOs are proactive, not reactive, often working to fill gaps and provide the patient with tools to take things further. In this sense, ECLOs add value because if they spot a patient earlier (not at the point of CVI), more work can be done to help. We heard several times during our interviews how delays in the system can have knock on consequences for the patient and that early intervention by the ECLO can avoid some of this: *'Getting things in place so that they cope with the visual impairment before they fall and become an inpatient...We felt it was important to say to the doctors we've made contact with every new person should they need it' [ECLO]*
- Several Rehabilitation Officers for Visually Impaired people (ROVIs) interviewed were of the opinion that ECLOs are a real help to engagement, and they prefer it when the ECLO refers to them, because they can explain fully what ROVIs do: *'when they find out that you're not a social worker, you're a rehab worker and you're there to teach them to stay independent, you find that they will take the service up' [ROVI]*
- By linking to the outside world, ECLOs often facilitate early intervention and rehabilitation, and the 'work' starts before they see the ROVI, for instance.

Maintaining engagement and continuity of care

- Engagement with patients can be an opportunistic process; ECLOs have to be able to improvise and be flexible with the time it takes. An ECLO needs to be there at the precise point when the patient asks for help, which might be immediately, or because of circumstances or attitudes towards support, later on. Either way, this can be a commitment that lasts for many months.
- Another aspect to this is the follow-up, to maintain that engagement, and many interviewees indicated that it is often the ECLO who does a lot of the follow up work to make sure that care continues beyond the medical care of the clinic. By supporting the patient early on in their journey, we heard how it then helps other professionals in the local eye health network to maintain their engagement: *'You've not left the patient to go home wondering if they're safe, but you pass over to a person who is more specialised to follow it up. Whereas the doctors and nurses they don't have the time and they don't have the skills just for that purpose because there are so many other things clinically to do. If I have a patient, I do encourage them to speak with [the ECLO]. It makes a difference and you feel safer' [Clinic manager]*

Quality of service

- ECLOs have made a major improvement to services across the nations and regions of the UK. The feedback from many clinicians was clear about the benefit to patients: *'Given the very positive feedback we've had about their support, there is a direct service quality and patient benefit argument for having one in any clinic' [Consultant Ophthalmologist].*
- Many interviewees stated that an ECLO adds to the quality of care offered: *'Our service would be very incomplete without the ECLO component: people need to know how to live their lives after walking through the door – this is what an ECLO brings' [Consultant Ophthalmologist].*

1.2.3 SKILLS AND KNOWLEDGE

This is a very wide category and encompasses descriptions of a range of practices, from the awareness raising or administrative roles to advocacy and communication with external stakeholders.

Admin and paperwork

- Apart from the CVI process, which seems central to everyday practice, we heard how ECLOs also have a fair amount of administration and other paperwork to complete, both for internal audit and tracking functions but also, more importantly, on behalf of the patient.
- We detected that there were differences of emphasis in the systems used across the nations, regions and local authority areas, depending on local need e.g. some adapted the way that ECLOs had to record contacts because many of the ECLOs are partially sighted.

Advocacy

- ECLOs advocate for patients on a regular basis. We heard how this could be both within the clinical system and other external pathways. Because their practice is patient-centred, they often reduce stigma, and ensure people aren't ignored as they try to navigate complex systems and frameworks of rights and entitlements, whilst at the same time experiencing profound changes in their eye health status.
- By helping people to deal with their worries and concerns, we found evidence through our interviewees that they often demystify challenging situations, and encourage people to benefit from the offer of support that exists: *'We have a lot of patients who don't want to have social*

services involved, especially the very elderly, because they think it's an intrusion and [the ECLO] will have more time to explain to them that they're there to help and it's, they don't have to come to your house and intrude, you know, it's just the help that's there' [Clinic Manager]

Communication

- The ECLO role is very much about communication between patient and community as they get used to the diagnosis: *'Patients at least need to be much clearer about what they can do, and how to live their life after they walk through the door, and that's the big difference that the ECLO can bring' [Consultant Ophthalmologist]*
- Good internal communication is also part of ECLO role – they often make sure that parts of the eye care team, and the eye care system as a whole, work together. The continual arrival of new staff in clinics means that there is always a need for ECLOs to educate staff about what they do.
- The evidence suggests that there is a very 'embodied' nature to the role of ECLO; it became evident from many of the accounts heard that the ECLO role is a very physical presence in the clinic. We heard how much easier it is if they're physically there in the clinic, not only to help immediately with those who are upset, but to connect the various part of the team.

Awareness raising role

- Fundamentally, ECLOs help people by providing a lot of information. We heard how they are often able to explain the eye condition in terms that are understood by patients, and how they have an important role in the internal workings of teams and training for medical professionals.
- Their awareness raising role can be quite varied. For example in some places, the ECLO is part of the induction process for medical staff – in at least one place, this included taking part in the mandatory training on falls prevention for all doctors.
- We heard also that some ECLOs are very involved in patient awareness initiatives such as how to administer drops, which in some places, meant saving a certain amount of clinical time for others.

Experience and background

- ECLOs come from a wide variety of backgrounds. There is a whole range of background in our interviews, from those with nursing experience, to those who have the lived experience of sight loss, to others who have spent years in the voluntary sector.
- Most ECLOs have a degree of clinical knowledge but the vast majority aren't formally trained as clinicians. As mentioned, for a minority, having a background in nursing is seen as an important component in the team 'makeup', and gives another way of experiencing the gaps in the system.
- Many of those interviewed have completed a lot of training to become ECLOs in the first place, with some able to add value by being able run things such as low vision clinics, for example.

Knowledge of local services/ local knowledge

- Having good local knowledge of services available in several sectors, and being able to maintain that knowledge through networks, would seem to be a key skill for ECLOs. As we've explored previously, ECLOs act as a bi-directional node, with knowledge about local services coming into clinical teams also through the role.

Referral and signposting

'It would be a disaster in clinic without the ECLO – patients would not be directed to the proper

places' [Senior Doctor]

- Referrals seem to be the most common way that patients come to ECLOs, and for many, a key point of contact, enabling support to begin.
- In general, ECLOs are trained to signpost after helping the patient gain some understanding of their condition and they signpost for a diverse group of patients, from older people with macular degeneration, to young diabetics. What we heard from several ECLOs was that because it's constantly changing, one of the main challenges for ECLOs is to keep up with what's happening locally through their networks, and having strong relationships within those networks is key.

1.2.4 RELATIONSHIPS

Building and maintaining a strong network of relationships with other services both within the clinical environment and outside the clinic with other sectors would seem to be a key ECLO role: *'The ECLO isn't just about lending an ear –it's about efficiently liaising with services' [Outpatients Sister]*

Connections with the community

- Having good relationships with local eye health networks is a fundamental part of ECLO practice. This means constantly having to update information about what's going on in the local community or voluntary sector, for a wide range of patient ages and interests, and maintaining those relationships over time.
- Many clinicians admitted in our interviews that ECLOs make the connections that are very difficult for them to make, and therefore they complete the care needed for their patients. Patients are referred to the ECLO because clinicians recognise they provide holistic rather than medical care and so add value to the service.

Connections with social services

- ECLOs save waiting time for patients in making connections with social services. In some places, this relationship is quite formalised and meetings will take place on a regular basis. We heard how ECLOs help with the important background work that's needed so people are more open to getting their rights and entitlements as patients/citizens.

Connections with the voluntary sector

- ECLOs signpost to a very wide range of voluntary sector organisations, from the small local groups to services offered by large charities. Again, this is an important part of their practice and they have to keep up with what's going on locally, often through the relationships built up in their own networks.

Trust and value

- As a trusted link between clinical services and other sectors, ECLOs do the necessary support work, beyond the clinical work. Many clinicians noted that without the ECLO it would be really difficult to offer the emotional support to people who are having a tough time with their diagnosis.
- ECLOs thrive on relationships of trust, and some believe that being identified as part of the NHS means that they are seen more as a 'trusted' member of the clinic staff: *'When my badge said I worked for a charity, people didn't want to see you. The minute that badge changed my numbers trebled, because they know you're trained, they know you are a trained professional, they know that you'll be telling them the proper stuff. The NHS see you as a professional' [ECLO].*

1.3 RESULTS OF QUANTITATIVE ANALYSES

1.3.1 ECLO ACTIVITY

The ECLO activity data included the outcomes of the meeting with the patient in three categories: 'Informed about' relates to providing information related to patients' main concerns, such as giving leaflets to patients; 'Signposted to' relates to providing specific source of support or services that patients can seek help from; and 'Referred to' relates to making referrals for patients with the purpose of getting further specific support.

- During the 12 months of the study period (April, 2015 – March, 2016) a total of 16,887, 2,934, 2,341 and 4,126 meetings with ECLOs were recorded in England, Wales, Scotland and Northern Ireland respectively.
- Overall, Welsh patients tended to re-visit the ECLOs more than the other three UK countries, and in each country, women and people between the ages of 60 and 89 years are the main age groups seen by the ECLOs.
- While living with family members was the most frequently recorded living arrangement for patients in all four countries, over half of patients of age 80 years and above reported living alone.
- Age-related macular degeneration (AMD) was the most commonly seen eye condition among the patients ECLOs see.
- Various interaction types between the ECLOs and patients were used, including face-to-face meetings and phone calls (most frequent type of interaction) and email, letters, and texts.
- In most cases, ECLOs spent 16-30 minutes either face to face or telephone with patients and also another half an hour undertaking activities on behalf of patient if it was necessary.
- Of patients aged 60 years and above who reported to the ECLO they had a fall, 60% reported a previous fall.
- Overall rates for patients aged 60 years and above in terms of fear of falling shows that they have higher rates than the general population, with the highest prevalence in Wales (60%).
- Following patient contact, the data indicate that up to 70% of patients receive information about eye related services, with referrals to services provided less often.
- The main concerns patients express at ECLO meetings relate to their independence and reading ability. Up to 90% of patients received emotional support from the ECLOs.

1.3.2 PATIENT SURVEY

Data collected from the patient survey includes HRQoL outcomes (using the EQ-5D 5L instrument) from a number of perspectives revealing differences in HRQoL between different eye conditions, types of support required, received and not received, and time since diagnosis, scores of the different dimensions of HRQoL, and differences between the groups of the people that responded to the patient survey.

- The "robustness" (i.e. how confident we can be of the results) of these differences in HRQoL between these patient conditions and support categories were then tested via statistical tests (i.e. Student t-tests).
- The p-values of the t-tests indicate the probability that the samples do not differ; however trends

are seen that suggest differences.

- Trends can be observed in the data however, the patient numbers at follow up are smaller than those who contributed at baseline, further data collection could strengthen the data and confirm the observed trends.
- HRQoL (mean EQ-5D scores – utility scores) were lowest for Diabetic Retinopathy patients (mean 0.751, Standard Deviation (SD) 0.322), and these patients were recorded as receiving the lowest level of support from either and ECLO or other staff. For other eye conditions (Dry and Wet AMD, and Glaucoma) those receiving ECLO support had slightly lower HRQoL than those seen by other staff.
- Patients supported by ECLOs or non-ECLOs showed a decline in HRQoL captured in the utility scores at follow-up (0.011 and 0.07 respectively for the utility scores). However, the VAS scores showed a small increase at follow-up for those seeing an ECLO, with differences not being statistically robust and thus warranting further study with larger patient samples sizes.
- The patient survey revealed a significant proportion of patients at ECLO supported clinics who stated they needed support but did not receive it. This may be a signal that there may be a case for provision of more ECLO support in some centres.
- While there was a trend suggesting a small overall decline in HRQoL scores at follow-up for patients supported by an ECLO or other staff, the decline was less for those patients attending an ECLO site in comparison to non-ECLO sites, possibility indicating that having an ECLO on-site may reduce the size or rate of the decline in patients' HRQoL. The staff survey data suggest that it may be that having an ECLO on-site may influence an improvement in the environment of support in general within eye clinics.
- When changes to HRQoL after diagnosis were examined, a small improvement in HRQoL over the first 6 months post-diagnosis, followed by a small decline in the following 6 months was shown. This may suggest that the effect of diagnosis and initial treatment helps to improve HRQoL, but a later decline may be due to a decline in the eye condition itself, or that patient care has a lesser impact over time.
- The differences of scores for the 5 domains of the EQ-5D between the whole study participant population and those who have received ECLO support indicates there is a proportion of all study patients that have moderate to severe problems with mobility, self-care, their usual activities, pain and discomfort, and depression and anxiety. In addition, data shows that the ECLO service is providing support to patients with these needs.
- Of all study patients recording moderate and severe problems with anxiety/depression (n = 29 and 11 respectively); over half had support from an ECLO, and of those reporting extreme problems (n=2), all received ECLO support, suggesting that the ECLOs are targeting the patients with self-reported anxiety/depression who need support and potentially those needing support are engaging with ECLOs.
- For the four other domains of the EQ-5D (mobility, self-care, usual activities, and pain and discomfort) ECLOs see less than half of the study population that report moderate to severe levels of these impairments, suggesting that there may not be enough ECLOs to meet demand and to actively find and engage with patients who want support need for more ECLO or ECLO-type support.

1.3.3 THE COST OF AN ECLO IN THE NHS SETTING

We looked at whether the ECLO might release cash or capacity in the NHS clinic setting by

understanding what the staff in the absence of an ECLO might cost the NHS.

We also looked at the data from the staff survey, to assess how much of staff time is spent providing the kinds of support to patients that ECLOs provide, so that this could be compared between sites and crucially act as inputs to the economic model which explored the potential of the ECLO to release staff capacity.

- From the ECLO activity data it is conservatively estimated that an ECLO spends 76 minutes per client, overall, of which a little under half (35 minutes) is spent on behalf of the client. Given a 35 hour working week, 4,877 ECLOs would be required to deliver this level of service. At NHS staff rates (see Table 5.19) an ECLO operating in band 5 unit costs (£36 per hour) a UK wide ECLO service costs the NHS total £7.8m per year.
- An estimate of £17.94 per patient per ECLO contact was reported in the literature; furthermore, approximately £247.76 for ECLO intervention over a person's lifetime was estimated for proportions of people registered as severely sight impaired at each age group, assuming an ECLO is seen once per year. However these figures do not give the whole picture The opportunity cost to the NHS of not having an ECLO is the staff member who would otherwise be employed and/the equivalent NHS pay band.

In total 30 study sites were visited through the course of the study, from which 20 contributed to the staff survey. Analyses were conducted on time spent by staff in providing emotional support, advocacy and certification and registration.

For the category *Emotional Support* ("I have spent time listening to patients/carers, talking through their worries or concerns"):

- Consultant ophthalmologists at ECLO sites reported provided marginally more patients per week with emotional support than non ECLO sites; clinical nurse specialists and ophthalmic nurses at ECLO sites reported providing more patients per week with emotional support than non ECLO sites.
- Staff nurses and sisters at ECLO sites reported seeing fewer patients per week for emotional support than non ECLO sites but spent more time providing emotional support in those contacts than non ECLO sites.

For *Advocacy* ("I have helped people to have their voices heard; to secure their rights and to obtain the support they need"):

- Consultant ophthalmologists at both ECLO and non ECLO sites reported low or no levels of advocacy; both clinical nurse specialists and ophthalmic nurses and staff nurses and sisters at ECLO sites reported low levels of advocacy support per week for patients with on average less than 1 patient receiving support of this nature, while non ECLO sites did not report advocacy support.

On *Certification and Registration* ("I have informed and advised patients about Certification and Registration and its benefits. I have helped patients in a practical way by helping to fill in forms, for example"):

- Consultant ophthalmologists and staff nurses and sisters at both ECLO and non ECLO sites saw a similar number of patients per week, supporting certification and registration but ECLO sites reported more time spent supporting patients with practical help such as form filling; clinical nurse specialists and ophthalmic nurses at ECLO sites reported marginally more support for patients per week supporting certification and registration than non ECLO sites.

1.3.4 BURDEN OF FALLS AND DEPRESSION

While a number of studies have attempted to investigate the impact of the ECLO on falls reduction, our study attempts to pursue exploration of this further in order to better estimate the impact of the ECLO on NHS costs overall. We used data from our study and from the literature to estimate the potential impact of the ECLO service on both falls and depression which, aside from the personal impact on individuals, are both costly to the healthcare system.

The literature indicates that the rate of falls and risk of falls and depression in people with sight loss is unequivocally linked. Thus the role of the ECLO, alert to the impact of a fall on a person with sight loss, is vital in making the connection between these risks, the patient and services available in the region.

- The literature indicates that the rate of falls and risk of falls and the rate of depression in people is unequivocally linked with sight loss. The role of the ECLO, who is alert to the impact of a fall on a person with sight loss, is vital in making the connection between these risks, the patient and services available in the region. Using the quantitative data collected in our study, combined with costs and prevalence data on falls and depression from the literature, deterministic modelling was conducted to estimate the potential impact of the ECLO service on both falls and depression.
- We estimated that the presence of ECLOs could lead to a 13.3% reduction in falls, overall in the prevalent cohort; equivalent to approximately 28,000 fewer falls, based on the 2013 UK population of people with sight loss: a reduction in the total fall rate from 25% to 21.7%.
- Cost implications of ECLO provision for fall reduction was estimated at an incremental cost per fall avoided of £2,813 when an ECLO is supporting patients at risk of falls. Should the percentage of patients able to see an ECLO increase, a proportional saving increase should also ensue.
- The DEPVIT study reported that 43% of those presenting to low vision rehabilitation clinics have significant depressive symptoms.
- Our estimates suggest that the ECLO could prevent approximately 43,000 interventions from NHS services for depression, a reduction of 11.9% compared to a situation where no ECLO action was taken. At an average costs of £2,509 per depression episode per person, an estimated saving of £107.6m in avoided referrals to depression services is estimated.
- After accounting for the total cost of the estimated 112 full-time ECLOs required, a total saving of £101m is estimated, equivalent to 11.2% saving compared with care without an ECLO. This represents an incremental cost per referral avoided of £2,361. Increasing the percentage of patients able to see an ECLO would result in a proportional saving increase.

1.3.5 COST-UTILITY ANALYSIS

Cost-effectiveness analysis (CEA) is a form of economic evaluation that utilises a single, specific, one-dimensional, health or clinical outcome to evaluate competing health interventions. In CEA, the ultimate measure of interest is the incremental cost-effectiveness ratio (ICER), which is the ratio of the difference in costs and the difference in outcomes for one intervention compared with another.

Cost-utility analysis (CUA) is a special type of CEA in which multidimensional health outcomes (e.g. depression and mobility) are reduced to a single dimension (score) reflecting individuals' preferences for health outcomes. The outcome in cost-utility analysis is the quality adjusted life year (QALY).

Valuation of a healthcare intervention is made by measuring the additional cost per additional outcome ratio (e.g. an incremental cost/QALY ratio). This ratio is then compared with that to an

external threshold to evaluate the value of the new intervention with ratios for other interventions.

- A simple cost-effectiveness of the impact of ECLOs compared with no ECLO was evaluated using CUA. The analysis spanned a time period of 12 months, and was from the perspective of the NHS.
- Inputs to the analysis included the EQ-5D utility scores from the patient survey and the costs to the NHS of an ECLO employed at the equivalent of NHS salary Band 4 and Band 5 - the most usual bandings for a NHS employed ECLO.
- The incremental cost- per 'QALY sustained' showed that the patients seen at an ECLO site generated an incremental cost per 'QALY sustained' of £2,883 for an ECLO paid at Band 4 compared with patients attending the non – ECLO site. When the cost of the ECLO increased based on Band 5, the incremental cost- effectiveness ratio (ICER) increased to £3,517 per 'QALY sustained' compared with patients attending a non ECLO site.
- For patients who received support at an ECLO site compared with patients who needed support but did not receive support, at an ECLO site, the cost per 'QALY sustained 'was £3,348 for an ECLO with a Band 4 salary compared with patients not getting support at an ECLO site. This increased to £4,102 per 'QALY sustained' compared with patients who did not get support, when the Band 5 was used.
- While the CUA was limited by the small patient numbers at follow up, a similar picture of small QALY losses across time was seen for unsupported patients, but the magnitude of differences is small and showed weak statistical significance.
- ECLO support for patients could potentially be regarded as cost-effective when compared to a 'world without ECLO support' by commonly accepted norms. These trends show promise but additional data collection would strengthen the statistical analysis.

1.4 KEY MESSAGES FROM FINDINGS

1.4.1 IMPACT ON PATIENTS

ECLOs help those patients experiencing sight loss with the greatest needs. Evidence suggests that they may contribute to maintaining patient HRQoL over time. They provide a wide range of well-targeted, well-appreciated services. In particular:

- The ECLO 'adds value' for the patient by recognising the critical issues for them and providing the appropriate support and signposting/referring.
- Contact with the ECLO may impact positively on health-related quality of life for patients in a number of ways.
- ECLOs target the right people but some people may be 'missing out', either due to lack of an available ECLO, or because they do not access an ECLO where one is present.
- ECLOs integrate services, securing immediate clinical needs for patients and also long-lasting rights and entitlements; the needs of people are well served by ECLOs integrating health, social services and others.
- ECLOs are proactive patient-centred advocates, reducing stigma, and ensuring people aren't ignored as they move through a complex system; in part through developing relationships, networks and trust, and standing up for patients, as constants at a time of change.
- ECLOs help people to deal with their worries and concerns, demystifying challenging situations,

and reducing stigma and anxiety and allowing people to benefit from the offer of support that exists.

- ECLOs develop relationships, networks and trust, instigating and inculcating local eye heath networks, bringing together professionals in two-way information flows.
- ECLOs thrive on relationships of trust, becoming key members of the clinic 'staff' which is crucial to them being able to work effectively, whether or not they have a clinical background.

1.4.2 IMPACT ON CLINICS

Across the UK, we can describe seven broad types of valued service and support provided by ECLOs, working in ways which reflect the individual circumstances of different clinics and hospitals (see Figure 1.2).

FIGURE 1.2 · Seven domains of ECLO practice

ECLOs are effective in doing this as follows:

- ECLOs improve and streamline the processes which operate within clinics, helping others provide quality services by aiding the smooth running of the clinic, and making administrative processes more efficient.
- ECLOs develop quality services, catalysing and expediting change; they are experts in joining the dots and raising the profile of patients' needs and their 'soft power' effects are significant; they

work with staff to make clinics better places for patients through raising awareness of what they need with staff and what represents good practice.

- ECLOs enhance the profile of services through their added-value; by turning the routine into the efficient, and the regular into the effective; they stimulate change that improves the offer of clinics bringing up the overall quality of the clinic by looking beyond the vision and the visual.
- ECLOs are proactive catalysers of change through developing effective relationships both within and without the clinic.
- Whilst many ECLOs are working in the earlier stages of the patient journey to good effect, they also provide safe and meaningful 'departure points', taking the pressure off the system by offering a positive place for patients to reside towards the end of the treatment and clinical care pathway; they are an alternative to the binary choices of clinicians (continue treatment or stop treatment).
- ECLOs provide continuous specialist expertise in how to emotionally support people during medical treatment and once that treatment ends, ensuring that people make meaningful contact between different services, within and without the hospital.
- Training and continuing professional development for ECLOs could take account of these domains of practice.

1.4.3 IMPACT ON SERVICES

ECLOs enhance and broaden the care which clinical services provide, thereby potentially reducing patients' longer-term care needs, and release NHS staff to perform their role. They add capacity and contribute to the increasing quality of the service offered in clinics; and they make a contribution to various other NHS objectives relevant to all four nations:

- The principal benefit for having an ECLO present in clinic is in providing support that others do not/cannot provide. ECLOs have a specific role; they provide a valued added service and they do not substitute for other clinic staff.
- Hence there are no evident cost-savings within the clinic when an ECLO is part of the care team but there may be to the wider NHS in terms of reduced burden of falls, depression and anxiety.
- If ECLO services were expanded, expressed needs may be met for more patients and through the ECLO referrals, negative impacts on health and social functioning may be addressed.

This study confirmed that from a commissioner's perspective it is '*all about the evidence*' and that evidence should relate to the local health economy, patient health outcomes, well-being and experience rather than a more general reduction in costs to the NHS.

The ECLO activity data is a valuable resource and has been fundamental as a source of evidence for this research. It has power to provide evidence to commissioners on how the ECLO impacts the services and outcomes. Enriching the data collection without overburdening ECLOs and ensuring it is gathered consistently across the UK is worthy of consideration.

2 INTRODUCTION AND METHODOLOGY

The RNIB commissioned the Welsh Institute for Health and Social Care (WIHSC), University of South Wales working in partnership with the Swansea Centre for Health Economics (SCHE), Swansea University, to evaluate the impact that patient information and support services in UK NHS ophthalmology departments makes for patients, the clinic and on services more generally.

RNIB were interested to understand the difference that those that provide patient information or support services (most typically called eye clinic liaison officers – ECLOs, or vision support officers) make where they are present in clinics – whether defined in health-related quality of life outcomes for people with sight loss, or a quantification of other benefits that they bring to the running of the clinic.

2.1 INFORMATION ABOUT ECLOs

The ECLO role was established to provide person-centred emotional advice and support tailored to the need of the patient, and to act as a bridge between health and social care services. The ECLO (who may also be known as a sight loss adviser or vision support officer, or indeed by other similar titles) works directly with people with sight loss to provide information and advice, emotional support and assistance in achieving an appropriate referral to community based services. The first ECLO began their work in February 1995.

ECLOs are key in helping patients understand the impact of their diagnosis and providing them with emotional and practical support for their next steps. They provide those with an eye condition with the practical and emotional support which they need to understand their diagnosis, deal with their sight loss and maintain their independence. Most importantly, ECLOs have the time to dedicate to patients following consultation, so that they can discuss the impact the condition may have on their life.

Role of RNIB in training non-RNIB ECLOs

RNIB offers training and provides ongoing support to all those in ECLO or similar roles across the UK, from any organisation. The Accredited Eye Clinic Support Studies course is open to anyone performing an ECLO role (or very similar) in an ophthalmology department. RNIB offers resources to support ECLOs in post including an Induction pack for managers, a range of Good Practice Guides are available, as well as information about integrating into an eye department, and a set of referral guidelines aimed at clinical staff to help them in making appropriate patient referrals to the ECLO. RNIB provides networks specifically for ECLOs including the Early Intervention Support Network, an email based forum for ECLOs to ask questions and share expertise.

There is Continuing Professional Development for ECLOs three times a year at seminars, and RNIB has developed a Quality Framework and Practice Guidelines, which can be used as a quality assessment tool for ECLO services. All these resources are available to RNIB and non-RNIB trained ECLOs alike.

Current number of ECLOs

Tables 2.1 and 2.2 below provide the latest information RNIB holds on the current headcount and full-time equivalent number of ECLOs across the UK. It gives information on both RNIB provided accredited ECLOs and other provider accredited ECLOs.[1]

TABLE 2.1 · RNIB provided accredited ECLOs – UK (as at September 2016)

Country	FTE	Headcount	Funder
UK	**44.7**	**54**	**-**
England	28	32	RNIB / NHS trusts / local authorities / local societies[2]
Northern Ireland	7.7	9	RNIB / Lottery
Scotland	4.8	8	Health boards
Wales	4.2	5	RNIB / Health boards / Novartis

TABLE 2.2 · Other provider RNIB accredited ECLOs – UK (as at September 2016)

Country	FTE	Headcount	Funder
UK	**28.9**	**37**	**-**
England	24	29	NHS trusts / local authorities / local societies
Northern Ireland	-	-	-
Scotland	3.9	7	RNIB partnership / local charities / health boards
Wales	1	1	Health board / Sight Cymru

2.2 TERMS OF REFERENCE

The Terms of Reference for the study were originally outlined in the project specification and covered the following key research questions:

- Does an ECLO release staff capacity to perform activities requiring their level of skill (substitution)?
- Does the reallocation of resources save money and/or offset wastage in the clinic? Is there a cost saving or simply a reallocation of resources?
- What is the impact of an ECLO on the delivery of care against quality standards and guidance?

[1] It should be noted that the funding situation for many ECLO posts is not simple, as there may be many different organisations funding a single post and the funding ratios can change each year.

[2] Local societies include, for example, Kent Association for the Blind, Sight for Surrey, and VISTA.

- What is the impact of an ECLO on the health and social care cost of conditions associated with sight loss (e.g. risk of falling; increased isolation)?
- What are the patient reported benefits of an ECLO?

At the outset of the study, it was posited that there would be a marked difference between what might be defined as 'ECLO sites' where ECLOs were present and 'non-ECLO sites' where they were not. This initially led to an over-simplistic way of thinking about the complexities of service delivery, but in the early stages of the study, the project was comprised of a combination of intervention sites (i.e. with an ECLO present in the hospital) and comparison sites (i.e. an ECLO not present). This thinking evolved over time (as described in section 2.3 below) and after several iterations, a data 'long-list' was identified which captured all of the key metrics that the study would analyse (see Table 2.3).[3] Emanating from this work, and building on the original specification, the following questions became central to the study, organised against three headings:

Impact on patients	– How does the ECLO 'value add' for the patient? – How does contact with the ECLO impact on the quality of life for patients? – Are ECLOs targeting the right people?
Impact on clinics	– How do ECLOs operate within the clinic setting? – What is the impact of an ECLO on clinic activity?
Impact on services	– What are the service benefits for having an ECLO present in clinic? – Are there cost-savings to the NHS when an ECLO is part of the care team? – What would happen if ECLO services were expanded?

2.3 SITE VISITS AND CATEGORISATION

In order to gather the data needed to answer the questions above, the study team undertook 30 site visits (across all four countries of the UK), to hospital-based ophthalmology outpatient clinics. The visits to each site had a number of activities designed to meet the project objectives, details of which are provided in section 2.4 below.

2.3.1 PILOT

In order to inform the substantive phase of the study, a pilot was undertaken. This included three site visits – one to a site with an ECLO employed by RNIB/Action, one to a site with an ECLO employed by the health organisation, and one to a site with no ECLO. In these visits, it was possible to test the study methodologies, interview schedules and much was learned to improve the substantive phase of the

[3] This list was derived after the pilot phase of the study.

study. 45 participants were engaged in completing patient outcome questionnaires, and 11 staff took part in interviews. The pilots were undertaken in both England and Wales.

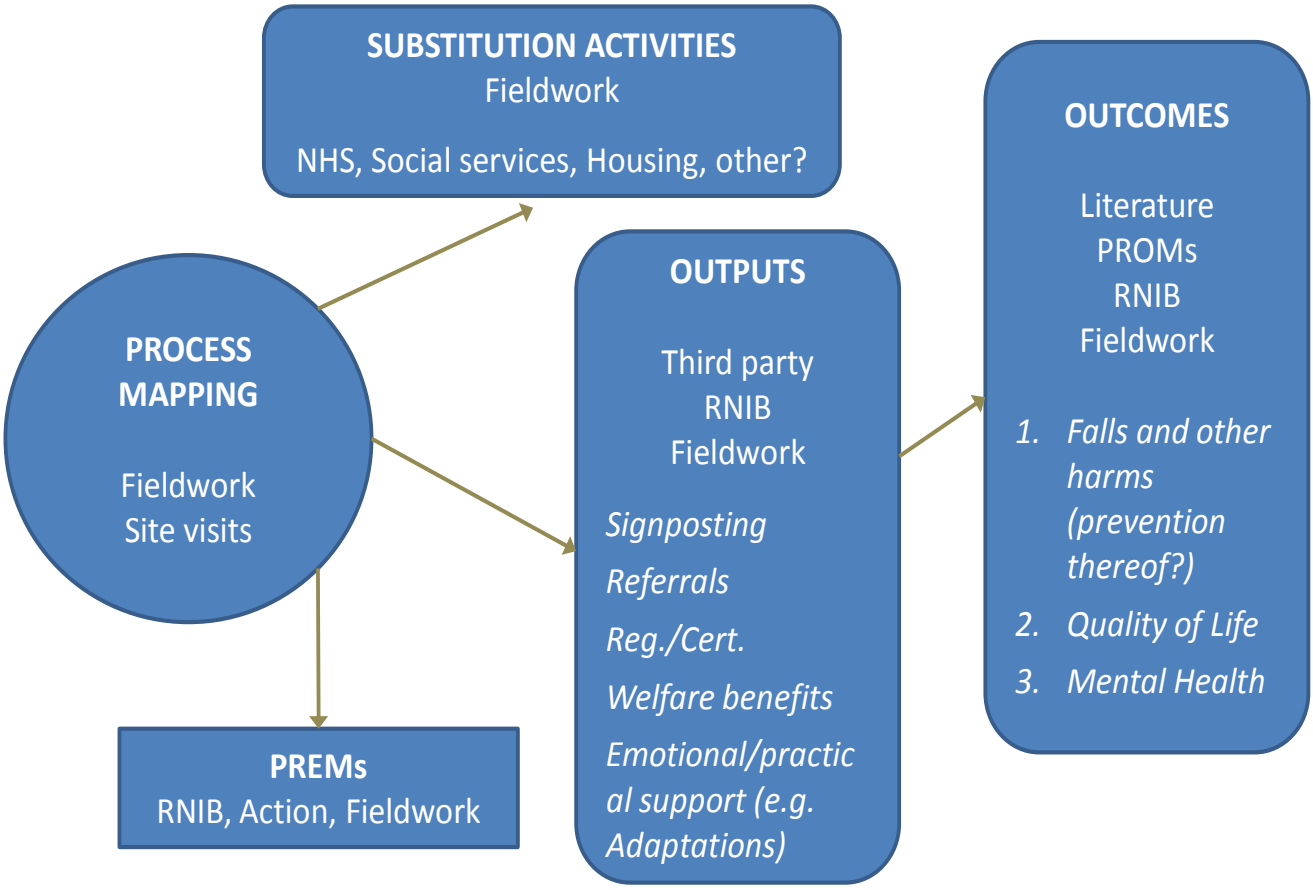
TABLE 2.3 · Key data and sources

Data item	Source	Status
Impacts on quality of life for those supported by ECLOs, those supported by other staff and not supported at all (either when they identified they needed to be, or when they didn't need to be) – Demographics of participants and postcode – Nature of sight loss/eye condition – Fear of and experience of falls, signposting to falls prevention services and possible prevention thereof – Satisfaction measures with the service received - PREMs – Impacts on the mental health of patients (EQ-5D instrument) – Impact on Quality of Life (EQ-5D instrument) – Practical/emotional/family support received – amount and impact	Patient Outcome Questionnaires (incl. EQ-5D) with a longitudinal dimension (tracking changes over 6 months) – and triangulated with RNIB/Action data *[WIHSC primary research]* Linked data from the four countries of the UK *[RNIB/Action]*	GREEN AMBER
Understanding the models of support – How do the ECLO typologies differ (or not) between sites? – How might support vary between different types of diagnoses? – What impact might the length of the ECLO's tenure make? – How do the non-ECLO sites function (where they both provide and do not provide support)? – What are the relationships between ECLOs and clinical staff? Who determines a patient needs to see an ECLO? – Who signposts to ECLO and who does the ECLO signpost to? – What are the referral and signposting flows and how large are these flows? – What does good look like for an individual and for the service, and how would success be recognised?	Interviews, observations with ECLOs and key stakeholders, especially clinical, social services and third sector staff. *[WIHSC primary research]*	GREEN
Understanding the impact of ECLOs on key stakeholders – What are the 'soft power' effects of ECLOs? – No. clinicians who use ECLO support and no. who don't (per site) – Types of activities that ECLOs are requested to undertake by colleagues – How well are ECLOs working with / signposting to personal and social services and other existing third sector and other organisations, and what are the possible duplications? – Degree of integration between ECLOs and other relevant third sector organisations		GREEN
Service data from ECLO and non-ECLO sites – by period, and from England, Wales, Scotland and Northern Ireland – No. of those patients who need the support of an ECLO (but who do not get to see an ECLO) – No. of those patients who need the support of an ECLO (who then get to see an ECLO) – No. referrals received and from whom – No. days (WTE) ECLO is at clinic – No. (capacity) of ECLO 'slots' (where ECLOs are present) – No. of patients who fill those slots – i.e. the annual capacity of an ECLO – No. Certificates issued and Registrations made and role of ECLOs in them – DNA rates for clinics and whether these are impacted upon by ECLOs – Proportion of staff and amount of time that clinical and other staff spend undertaking roles that duplicate with and substitute for ECLOs where ECLOs do not exist – Waiting list nos. for appointments and length of wait – No. (capacity) of outpatients clinics slots (ideally disaggregated by eye conditions) – No. of patients who fill those outpatients clinics slots (ideally disaggregated by eye conditions) – No. patients signposted on to other services, and to which services	Staff pro forma *[WIHSC primary research]* Clinic data is not uniformly collected across sites but wherever it is available we will access this *[Clinical data from sites]* Linked data from the four countries of the UK *[RNIB/Action]*	GREEN AMBER
Economic impacts of ECLOs – Secondary literature review of costs of falls (and imputing saving attached to preventing them), depression (related to vision problems) and other effects that might be attributed to ECLOs as described above – Modelling work to estimate cost benefit/cost consequence/social return on investment (depending on final data set) of ECLO the effects and impacts identified above into context – Substitution/capacity increase effects of ECLOs – whether on clinical staff or others – Potential impact of increasing/decreasing ECLO-type service	Literature review and modelling of impacts *[SCHE]* Staff pro forma *[WIHSC primary research]*	GREEN

GREEN	These sources are within the gift of the research team to collect and/or analyse
AMBER	These sources are important but there is an impediment currently in collecting and/or analysing them
RED	These items, whilst theoretically possible to collect and/or analyse, are not practical given the budget or timescale for this study

Figure 2.1 provides a 'schematic' detailing the key components of each of the initial site visits – in effect we were trying to understand the relationship between the care provided within the clinic setting (whether with or without an ECLO) and a series of patient reported experience measures (PREMs), patient reported outcome measures (PROMs), outputs, and potential substitution activities. The figure also provides a source for each of these different data.[4]

FIGURE 2.1 · Diagrammatic representation of site visits



This led to the team developing an initial 'typology' for ECLO provision across the UK, which formed the basis of the pilot for the study (see Table 2.4). This typology was developed following initial discussions with RNIB, and tried to build on the division between sites that had ECLOs (Types 1-3) and those sites that did not have ECLOs (Types 4-5).

This typology was tested and refined during the pilot period. Importantly for the study as a whole, one of the key lessons from the pilot was that the binary distinction between 'ECLO sites' and 'non-ECLO sites' did not reflect the complexity of patient pathways into and out of the ophthalmology department. As such, the team developed a more nuanced approach to categorising patient pathways which was crucial to the analysis of data.

[4] It should be noted that this represented the approach at the outset of the study, and that the analysis of the data in the subsequent chapters has to extent superseded this diagram, although the core components remained.

TABLE 2.4 · Initial typology of sight loss support provision across the UK

	Type 1	Type 2	Type 3	Type 4	Type 5
Employer	RNIB Action for Blind People	Local arrangements	Local arrangements 'Formal' volunteer-led	'Informal' volunteer-led	No formal ECLO/vision support functions provided
Name(s)	ECLO Vision support worker Sight loss advisor	ECLO Vision support worker Sight loss advisor	ECLO Vision support worker Sight loss advisor	May not have a title	
Trained as an ECLO by RNIB?	Yes	Maybe	No	No	

2.3.2 PATIENT CATEGORISATION

The team recognised that there were in effect four possible categories of patient experience, based on whether they felt that they had support needs on arrival at the clinic, and whether those needs had been met (by an ECLO or someone else) or not.[5] These four categories are as follows, and are represented in Figure 2.2:

- Patients who said that they had support needs, but that no support to them was offered or provided (A);
- Patients who said that they had support needs, and that those support needs were met by an ECLO (B, only applicable to 'ECLO sites');
- Patients who said that they had support needs, and that those support needs were met by another person (C, whether nurse, doctor, volunteer etc. but not by an ECLO); and
- Patients who said that they had no support needs (D).

These categories are used in the chapters below as a unit of analysis for comparing between different groups of patients.

Linked to this was the need to review and revise the original 'typology' of sites given that the simplistic distinctions between sites that had or did not have ECLOs was much less important than recognising that in each of the sites, all four categories of patient could theoretically be present.[6] This was not a formal re-categorisation, but Figure 2.3 attempts to show the overlaps between the previous typology (Table 2.4) and that all four categories of patient experience (as represented by Figure 2.2) could be present in any one site.

[5] These needs were self-reported and determined during the interviewer-led patient outcome questionnaire completion process.

[6] Except of course for those that had their support needs met by an ECLO, as this is only possible in ECLO sites.

FIGURE 2.2 · Categories of patient used during the study

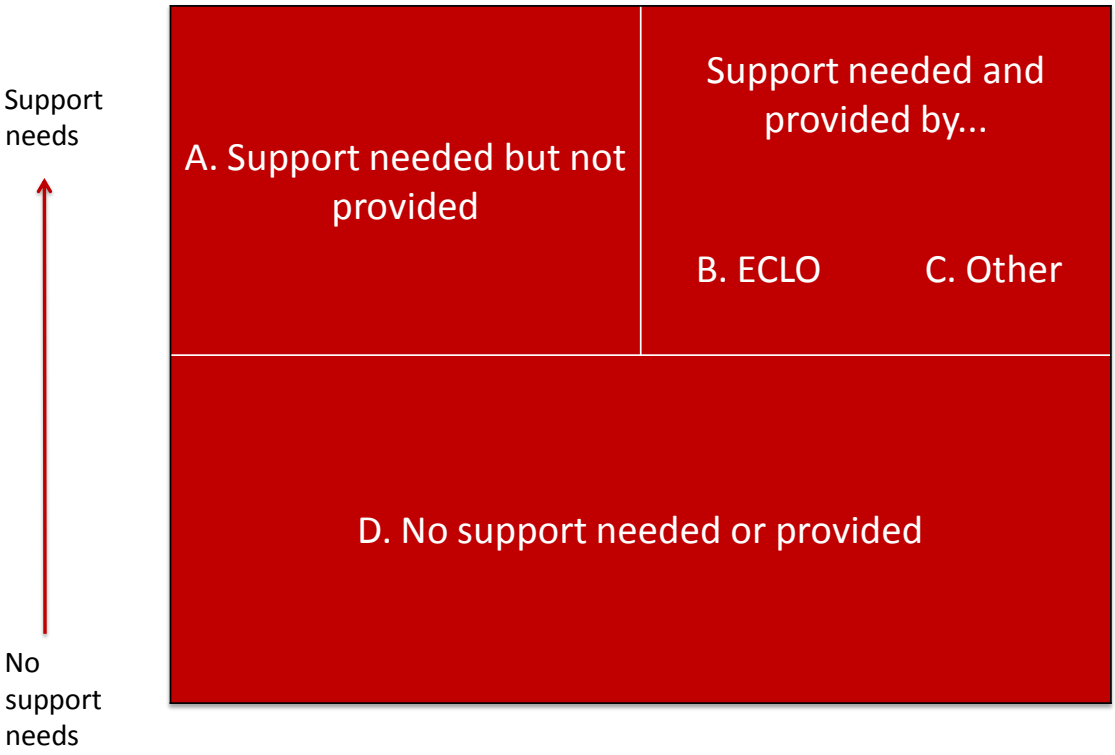
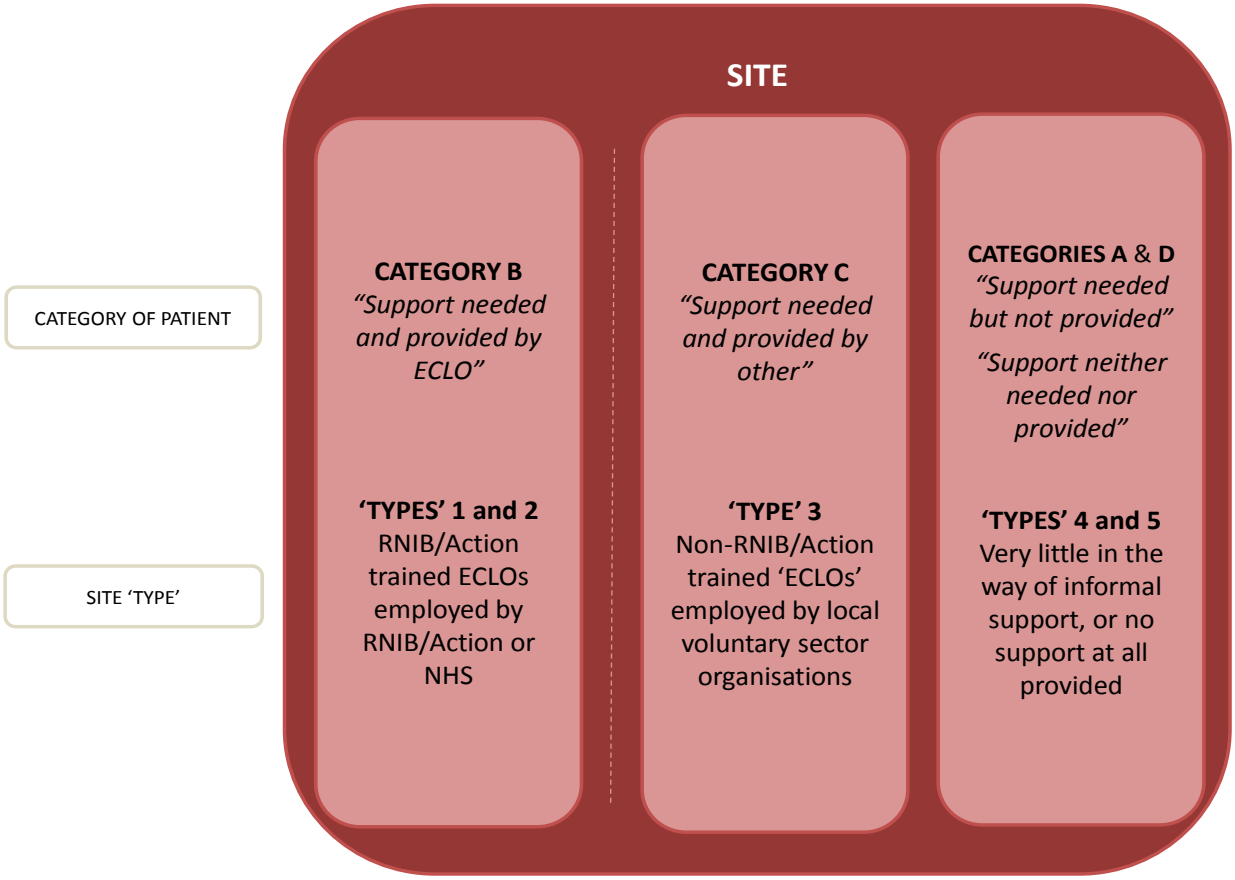


FIGURE 2.3 · Revised typology of sites to reflect categories of patient



2.3.3 SITE VISITS

Having learned from the pilots, the study team continued to iterate the methodology before undertaking the remaining 27 site visits. In total, of the 30 site visits (completed between September 2015 and April 2016), 24 were undertaken in sites with an ECLO present, and 6 without. Similarly, 21 of the site visits were undertaken in English sites, and three in each of Wales, Scotland and Northern Ireland. That said, for the purposes of the analysis all 30 sites will be treated as one case, although we will comment on differences between the types of site where relevant.

2.4 STUDY DESIGN AND METHODS

During the site visits a number of methods were adopted to gather relevant data in order to answer the study questions above.

2.4.1 INTERVIEWS

In order to gauge the impact of the ECLO (or equivalent role) on the clinic, we conducted 141 semi-structured interviews with key staff such as ophthalmic consultants, ophthalmic nurses, administrative staff, ECLOs, and rehabilitation officers for visual impairment among others. Prior to the interview, informed consent was obtained and typically took place on the day of the site visit by the evaluation team. A smaller number were completed over the telephone at a different time. Interviews ranged in length from five minutes to two hours, but usually lasted around half an hour. Interviews were transcribed and analysed by the researchers (described in more detail in chapter 5). Table 2.5 provides an account of who the researchers spoke to during the course of the study.[7]

2.4.2 PATIENT OUTCOMES QUESTIONNAIRE

The purpose of the patient survey was to evaluate the patient experience and outcomes of the ECLO service where it existed, and clinic staff where no ECLO service was available. The survey was administered in a 1:1 interview by the researcher at the site (see Appendix 1). We also used the survey to get a baseline value of health-related quality of life (HRQoL) following that up after three to four months with another survey (data collected via a phone call). The survey was administered after obtaining informed consent (all patients were given time to read the information sheet and consent form prior to survey administration by the researcher).

The patients were asked if they are willing to complete a brief survey about any support services they have received. In order to collect HRQoL outcomes, the EuroQoL-5D-5L (EQ-5D) was administered at the same time. As many participants had visual impairments, they completed the survey with a member of the evaluation team in the clinic. The evaluation team member went through the information sheet with the patient if they were unable to read it themselves. Patients were also asked to take part in a

[7] Interviews with patients were not undertaken as part of this study given that at the outset of the work RNIB stated that they had collected much qualitative data from patients. Instead they wanted to prioritise gathering the views of those professionals who interact with ECLOs.

follow-up questionnaire and were contacted at a later date to complete the survey over the telephone three to four months after the initial contact.

TABLE 2.5 · Number and role of interviewees[8]

Role of interviewee	Number of interviews
ECLO	26
Nurse	28
Consultant	24
Clinic/directorate manager	13
Optometrist	12
Commissioner (health and/or social services)	9
Rehabilitation Officer for Visual Impairment	8
Orthoptist	6
Registrar/other doctor	5
Medical secretary	5
Others (including family members and volunteers)	5
TOTAL	**141**

Background to the EQ-5D Questionnaire

The EQ-5D 5L (EQ-5D) is a HRQoL questionnaire that captures patient-reported outcomes in two ways. Firstly, patients are asked to report their assessment of their health state on 5 dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression at five levels ranging from 'no problems' to 'severe problems'. These patient responses generate a 5-figure profile that is converted to an individual utility score that represents that person's current HRQoL which is used for health economic evaluation to enable estimation of quality adjusted life years (QALYs). The resulting EQ-5D utility scores range from 1 (perfect health) to worst possible health (-0.594). A Visual Analogue Scale (VAS) is also included in this questionnaire, which is a thermometer-type scale that requires a self-rated valuation of the health state experienced by the respondent on a scale of 0 to 100.[9] The utility scores are derived from a survey of the general public and represent a preference based valuation of a health state

[8] It should be noted that whilst this table records the overall number of interviews undertaken, participants were asked to consent to recordings being made of the discussion, and/or noted being taken during the interview. A small number of interviewees (n=11) did not consent to their interview being recorded or notes being taken (this number incidentally included a relatively high proportion of commissioners). Accordingly, the study team did not have permission to produce a transcript from these interviews from which to quote evidence.

[9] This was an interviewer-led process in this study, and *in situ* the researchers were instructed by participants as to how they wished to record their scores on the VAS.

characterised by the EQ-5D. This in effect is the 'tax payers' valuation. The VAS score however is a self-rated valuation and represents the respondent view of their health state and how it affected their life on the day.[10]

Various validation studies of the EQ-5D have been carried out for patients with sight loss and for patients with other conditions.[11] This generic questionnaire can be administered in a variety of ways, on paper as a self-completed survey or interviewer administered (as we used it here). It is quick and easy to complete (reduced patient burden) and is NICE's (National Institute for Health and Care Excellence) preferred method of gathering HRQoL data for economic evaluations (cost effectiveness and cost utility analyses, using QALYs). NICE has outlined their requirements for the methods and conduct of carrying out economic evaluations on their website.[12] Particularly relevant is Section 5.3, which states NICE's preferred methods of assessing HRQoL for economic evaluations, and confirms its validity on a range of patient populations. Essentially, this instrument enables 'before' and 'after' comparisons for health-related interventions (services, treatments, etc.) to be made and also enables the NHS and NICE to make comparisons of cost effectiveness and HRQoL differences within and between a wide range of health conditions. In the current study, EQ-5D and VAS patient responses are gathered at baseline and at follow up in order to record any changes in general HRQoL over time. They are also used to describe the study population in terms of their self-reported HRQoL to explore whether ECLOs and other staff are engaging with those patients who most need support.

Eligibility criteria

Patients eligible for the survey included those with sight loss and an eye condition and/or who have a CVI, who could receive support from an ECLO (such as those with AMD, glaucoma, diabetic retinopathy).

2.4.3 STAFF SURVEY

In addition to the interviews, clinical staff were also asked to complete a pro-forma which aimed to assess how much of their time is spent providing the kinds of support to patients that ECLOs provide, so

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[10] For a sample copy of the EQ-5D-5L, go to: http://www.euroqol.org/fileadmin/user_upload/Documenten/PDF/Products/Sample_UK__English__EQ-5D-5L_Paper_Self_complete_v1.0__ID_24700_.pdf

Useful academic references on EQ-5D-5L include: Devlin N, Shah KK, et al (2016) *Valuing Health-Related Quality of Life: An EQ-5D-5L Value Set for England*. HEDS Discussion Paper Series (16.02), Health Economics and Decision Science, School of Health and Related Research, University of Sheffield , Sheffield; Igarashi A, Fukuda T, et al (2015) *Development of a national tariff for EQ-5D-5L in Japan*. EuroQol Proceedings, Krakow, 10-09-2015; Kiadaliri AA, Eliasson B and Gerdtham UG (2015) 'Does the choice of EQ-5D tariff matter? A comparison of the Swedish EQ-5D-3L index score with UK, US, Germany and Denmark among type 2 diabetes patients' *Health Qual Life Outcomes*, 13145, 01-01-2015; Van Hout B, Janssen MF, et al (2012) 'Interim Scoring for the EQ-5D-5L: Mapping the EQ-5D-5L to EQ-5D-3L Value Sets' *Value in Health* 15, pp.708-715; Janssen MF, Pickard AS, et al (2013) 'Measurement properties of the EQ-5D-5L compared to the EQ-5D-3L across eight patient groups: a multi-country study' *Quality of Life Research*, 22.7, pp.1717-1727

[11] Longworth L, Yang Y, Young T, et al (2014) 'Use of generic and condition-specific measures of health-related quality of life in NICE decision-making: a systematic review, statistical modelling and survey' *Health Technology Assessment*, 18.9, NIHR Journals Library: Southampton (see: http://www.ncbi.nlm.nih.gov/books/NBK261619/)

[12] See *Guide to the methods of technology appraisal* (2013): https://www.nice.org.uk/article/pmg9/chapter/the-reference-case#framework-for-estimating-clinical-and-cost-effectiveness

that this could be compared between sites and crucially act as inputs to the economic model which explored the potential of the ECLO to release staff capacity. The pro forma is included in Appendix 2.

The clinic staff varied by site but were usually ophthalmologists consultants, registrars and senior doctors, ophthalmic nurses, optometrists, orthoptists, imaging technicians, administrative staff and health care assistants. Additionally, the qualitative interviews with staff were used to collect data to evaluate the staff mix in clinic and how staff spent their time performing activities typically undertaken by an ECLO. The survey at each site was conducted over one day and the staff willing and available at the time of survey completed the pro forma regarding the level of support they were able to provide the patients attending their clinic. Staff were also asked to report their role, employment band and contract type i.e. whole time equivalent (WTE) or other.

2.4.4 OPHTHALMOLOGY OUTPATIENTS DATA

Further, the study team had a short questionnaire which was left with an administrator asking about typical clinic staffing and the number of appointments per clinic, per month. The purpose of this was to inform the economic analyses.

2.4.5 ECONOMIC EVALUATION METHODS

The health economic objectives of the study were:

- To establish the resources used and costs related to the ECLO service comprising:
  - The impact of the ECLO service on the ophthalmology clinic services and the patients using the service; and
  - The relative cost and consequences of providing the ECLO service compared with the *status quo.*

The perspective adopted for this study was the UK NHS. The scope of the study did not include looking at the wider societal perspective.

Sources of ECLO activity data

In addition to the data collected by survey, two sources of routinely collected data were utilised for our analyses. The first was the dataset relating to the daily activities of each RNIB ECLO, throughout the UK. This dataset contained records from one calendar year split by the constituent countries in the UK. Whilst there have been moves to address this since, at the time of the study each country in the UK collected different data in a different way but every effort was made to attain consistency, largely through the efforts of the staff of RNIB and Action for Blind People. A second source of data related to England alone and contained information relating to the time spent on completing certificates of vision impairment (CVI) and information on the patients who are given them. These data inform the cost-consequence analysis of the ECLO role and an analysis of the impact of the ECLO on patient outcomes and the eye clinic.

Resource utilisation and costs

The costs and consequences framework used for this study identified both the direct costs of the range of ECLO roles and those employed by the NHS that provide support services in the absence of ECLOs.

These were evaluated in relation to the outcomes which can be affected at sites with and without an ECLO. The costing exercise involved estimating the NHS salaries required in order to perform ECLO activities by ECLOs or substitute staff. Unit costs for staff (hourly rates) were derived from the PSSRU's Unit Costs of Health & Social Care[13] and NHS Reference Costs (2014-15)[14] based on costs by professional roles and include salary on-costs (employers' National Insurance contributions, superannuation, etc) as well as ongoing training and qualifications, indirect and capital overheads.

Unit costs for community-based scientific and professional staff[15] were used to guide the calculation of ECLO salary on-costs and overheads, etc. For NHS staff undertaking support services in sites where no ECLO role existed, unit costs were derived according to their NHS role/band/grade. Self-reported assessments of time spent on support services (from the staff pro forma) were used to inform the analysis. These resources and associated costs were used to compare the costs of the ECLOs and those performing similar support roles elsewhere, and the sources of costs are fully referenced to aid transparency of the analysis (see in particular Table 5.19 in chapter 5 below).

Health economic modelling

A model-based analysis was undertaken to assess the impact of the provision of the ECLO service compared to the other clinical and non-clinical staff covering the work. The analyses were conducted using a de-novo discrete event simulation (DES) model developed in SIMUL8. The model reflects the clinical pathway for patients defined and agreed by the project team based on the ECLO services (Intervention) and no access to ECLO services (Comparator). The model follows a patient through the pathway (with/without the ECLO service) over a 12 month period. The model was informed by:

- Population- Adults aged 18 years and over with low vision ;
- Intervention: ECLO support
- Comparator: No ECLO support
- Perspective: UK NHS
- Outcomes: The main impacts of the service for the NHS and patients

Questionnaire data from the study (as described in section 2.4.2 above) and data from the RNIB ECLO activity dataset were used to populate the model. Where necessary, data from the review of the literature 'spot- searches' of the previous systematic reviews/ epidemiological/HRQoL literature were used to inform 'gaps' in the model. These inputs were validated as appropriate by the RNIB project team prior to final analysis. Where data were unavailable, assumptions were made and verified by the RNIB project team prior to inclusion.

Study Outcomes for the Economic Analyses

The main outcomes utilised for the economic analysis were:

[13] Curtis L and Burns A (2015) *Unit Costs of Health & Social Care*. Personal Social Services Research Unit, The University of Kent, Canterbury

[14] Department of Health (2015) *Reference Costs 2014-15* – accessed from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/477919/2014-15_Reference_costs_publication.pdf

[15] Curtis and Burns (2015), op. cit, p.164

- Patient demographics and cause of sight loss;
- The EQ-5D (utility and VAS scores) at baseline and follow up;
- The mean overall scores, VAS scores and domain scores for patients at baseline and follow up and percent of population reporting problems and no problems;
- Patient mean scores and change scores (baseline to follow up) whether seen by an ECLO, and whether at an ECLO or non ECLO site;
- Utility and VAS scores and change scores in patients at baseline and follow up who had contact with an ECLO and those who did not, those who had their support needs met and those who did not .

ECLO activity data included:

- The number of people reporting falls and/or fear of falls at baseline and within the follow up period;
- Rates of provision of advising, signposting and referral to services provided by ECLOs;
- The rates of Certificate of Vision Impairment (CVI) generation under a variety of scenarios;
- Costs of providing ECLO services;
- Consequences of providing ECLO support for patients and NHS. These are:
  - Capacity of service and estimated changes and resource release the ECLO services may deliver;
  - Impact of changing level of ECLO services;
  - Impact on health related quality of life; and
  - Potential impact of falls and mental health when an ECLO is giving support.

Data were analysed using STATA and MS Excel software packages. Distributional analysis was undertaken using Stat:Fit. The DES model was run in Simul8. A plausibility check on the dataset and preliminary findings was undertaken by the health economics team. Prior to statistical analysis, the data were reviewed. Sub group analyses were also performed comparing the three main eye conditions where sight loss may occur and where the availability of an ECLO may be most beneficial: age related macular degeneration (AMD), glaucoma and diabetic retinopathy (DR). Also, age subgroups were also used. The time horizon employed for the study was 12 months. A base-case analysis for the model was undertaken based on the collected data. The findings from the collected data were used to model the likely effects over the particular time horizons and costs and effects were discounted at 3.5% where appropriate (i.e. a time horizon over 12 months). All assumptions included in the model were agreed *a priori* with the RNIB project team.

Sensitivity Analyses

Univariate sensitivity analysis and scenario analysis were used to examine the best case (i.e. where the most optimistic inputs are used) and in the worst case (i.e. where the worst inputs are used).

2.5 ETHICS AND GOVERNANCE

Ensuring compliance with research governance and ethical principles was a very important consideration for the study. In the first instance, the methodology and approach was presented to the University of South Wales Faculty of Life Sciences and Education Ethics Committee for guidance. In conjunction with their view, and the guidelines produced by the National Research Ethics Service, the study was determined to be a 'service evaluation'. This meant that no formal ethical review was needed, but rather the study team had to approach the research governance officers of the individual NHS health trusts and health boards in order to satisfy their local arrangements for such study. These requirements varied across the UK, and the study was successfully registered with all 30 sites.[16]

2.6 CONTEXTUAL FACTORS

As with all such service evaluations, this study is inevitably limited by the lack of formal controls on the 'interventions' that we observed. That said, the fact that one fifth of the site visits were in places where no ECLO was present, provide us with the ability to make meaningful comparisons between different types of circumstances. We would however need to bear in mind the points raised in Section 2.3.2 above as in practice the differences between the four groups of patients proved to be a more relevant unit of analysis for the study than between 'ECLO' and 'non-ECLO' sites.

It is also very important to note the complex nature of ophthalmology outpatient departments. No two sites in our study were the same, as organisations chose to arrange their services in ways that clearly reflected their local priorities and circumstances. As such, no two ECLO services (where we encountered these) were the same and a large part of the study was focused on encountering and dealing with that complexity.

2.7 STRUCTURE OF THE REPORT

This report follows with a literature review which covers both the existing evidence on the role of the ECLO and other similar roles, and the economic and health outcomes of such services. There follows a substantive chapter on each of the qualitative and quantitative findings derived through the course of the evaluation. The qualitative data is structured into four areas – concerning the capacity, patient-centred, skills and knowledge and relationship-based nature of their service. The quantitative chapter focuses on activity data associated with ECLOs, information on health-related quality of life, and the economic implications of ECLO services. A discussion chapter follows which considers the overall impact on patients, clinics and services, and the conclusions summarise the findings whilst reflecting on how this study builds on previous knowledge.

[16] A copy of the Study Protocol that was sent to all research and development offices of the sites is included in Appendix 3.

3 LITERATURE REVIEW

There are two foci for the review of the literature. Firstly, there is a review of the literature regarding the role of the ECLO; and secondly, a review of the literature on health and economic related to ophthalmology and those experiencing sight loss.[17]

3.1 ROLE OF THE ECLO

3.1.1 SIGHT LOSS IN THE UK

More than two million people are living with sight loss that has a significant impact on their daily lives in the UK. According to a 2009 report commissioned by RNIB, the leading causes of sight loss are uncorrected refractive error, age-related macular degeneration, cataract, glaucoma and diabetic retinopathy.[18] The same report also estimates that the number of people in the UK with sight loss is set to increase in the future. The prevalence of sight loss increases with age, and the UK population is ageing. It is predicted that by 2020 the number of people with sight loss will increase to over 2,250,000. By 2050, the number of people with sight loss in the UK will double to nearly 4 million.[19]

Since 2005 in England and 2007 in Wales, registration as blind or partially sighted has been initiated by completion of a designated certificate – the Certificate of Vision Impairment (CVI) in England and the CVI-W in Wales.

For England and Wales between April 2012 and March 2013, 24,009 CVI certificates were received, of which 10,410 were people certified with severe sight impairment (blindness; SSI) and 13,129 certified with sight impairment (partial sight; SI). A total of 22,647 forms were completed in England and 1362 in Wales. An additional 470 (2%) forms did not state whether or not the individual was SSI or SI. Although AMD was the most commonly recorded main cause of certification for SSI, AMD has decreased as a proportionate cause of sight impairment, from 58.6 to 50% for SSI and from 57.2 to 52.5% for SI. Glaucoma remains the second most common cause (11% SSI; 7.6% SI) but hereditary retinal disorders overtook diabetes as third leading cause of SSI. Thus, diabetes was displaced into fourth position being responsible for 5.4% of SSI certifications in 2013 compared to 6.3% in 2007–2008.[20] In an analysis of blindness certifications in working-age adults (age 16-64 years), the main causes of CVIs were hereditary retinal disorders (20.2%), DR/maculopathy (14.4%) and optic atrophy (14.1%).[21]

[17] It should be noted that a review of the clinical guidelines impacting on ECLOs, or services that ECLOs provide, is contained in Appendix 6.

[18] Access Economics (2009) Future Sight Loss UK 1: The economic impact of partial sight and blindness in the UK adult population. London: RNIB

[19] Ibid.

[20] Quartilho A, Simkiss P, Zekite A, Xing W, Wormald R, and Bunce C (2016) 'Leading causes of certifiable visual loss in England and Wales during the year ending 31 March 2013' *Eye* doi: 10.1038/eye.2015.288

[21] Liew G, Michaelides M and Bunce C (2014) 'A comparison of the causes of blindness certifications in England and Wales in working age adults (16–64 years) 1999-2000 with 2009-2010' *BMJ Open* 4:e004015: doi:10.1136/bmjopen-2013-004015

It has been suggested that many eligible patients may not be registered but also that many of those registered may not meet the clinical criteria for registration.[22] However, current guidelines for completion of CVI forms state that the criteria should be interpreted in the context of the patient's functional status rather than as strict cut-offs because the purpose of the CVI is to initiate registration with social services, thereby providing a reliable route for someone with sight loss to formally be brought to the attention of local social service departments for assessment and early intervention. Registration is voluntary but enables the individual to access a range of support including financial concessions and the loan of aids and equipment.

However, access to benefits and social services is not dependent on registration. The Referral of Vision Impaired Patient (RVI) letter can also be used where registration is not appropriate or where the patient has declined registration but wants advice and information about the difficulties caused by loss of vision. The Low Vision Leaflet (LVL) is for optometrists to enable people to self-refer to social services if they wish to be contacted for help. Unlike CVIs, there appears to be no national datasets about the number of RVIs or LVLs received by social services. One study that profiled seven different low vision services in England reported that 40-50% of social services referrals came via CVIs. One traditional (optometry-led) hospital service reported an additional 15% of their referrals from RVI and LVL combined. LVL referrals from local optometrists made up a very small percentage of total referrals (2% in one externally purchased and multi-agency service; "very small" in a traditional hospital service and an orthoptist led service). The exception was the social services led service where around 20% of referrals came from LVLs, mostly coming from the optometrists specifically involved in the low vision scheme operating in that area.[23]

3.1.2 INFORMATION AND SUPPORT NEEDS OF PEOPLE WITH SIGHT LOSS

The impact of sight loss has been well documented, with significant effects on psychological wellbeing, social isolation, depression, mobility, being able to live independently, financial difficulties, employment, and daily activities such as travel, shopping, cooking, reading, watching television, and using technology.[24,25,26,27,28] The need for information and support services for those living with sight loss has also

[22] Barry RJ and Murray PI (2005) 'Unregistered visual impairment: is registration a failing system?' *British Journal of Ophthalmology* 89, pp.995-998: doi:10.1136/bjo.2004.059915

[23] Dickinson C, Linck P, Tudor-Edwards R, Binns A, Bunce C, Harper R, Jackson J, Lindsay J, Suttie A, Wolffsohn J, Woodhouse M, Margrain T (2011) 'A profile of low vision services in England: the Low Vision Service Model Evaluation (LOVSME) project' *Eye* 25, pp.829-831: doi:10.1038/eye.2011.112

[24] Hodge S and Eccles F (2013) *Loneliness, social isolation and sight loss: a literature review conducted for Thomas Pocklington Trust* Lancaster: Lancaster University

[25] Cimarolli VR, Boerner K, Brennan-Ing M, Reinhardt JP, and Horowitz A (2012) 'Challenges faced by older adults with vision loss: a qualitative study with implications for rehabilitation' *Clinical Rehabilitation* 26, pp.748-757

[26] Rees G, Tee HW, Marella M, Fenwick E, Dirani M and Lamoureux EL (2010) 'Vision-specific distress and depressive symptoms in people with vision impairment' *Investigative Ophthalmology & Visual Science* 51.6, pp.2891-2896

[27] Surrey Social and Market Research (2009) *Understanding the needs of blind and partially sighted people: Their experiences, perspectives and expectations* University of Surrey

[28] Thetford C, Robinson J, Mehta J, Knox P and Wong D (2008) *The changing needs of people with sight loss: Final report for Thomas Pocklington Trust* Liverpool: Health and Community Care Research Unit, University of Liverpool; and Thetford C, Robinson J, Knox P, Mehta J, Wong D (2011) 'Long-term access to support for people with sight loss' *British Journal of Visual Impairment* 29.1, pp.46-59

received growing attention. There is considerable variation in the level of service provision across the UK. Following certification or referral to social services individuals may be offered a range of low vision services including rehabilitation, mobility training, low vision aids, advice about welfare benefits, and emotional support. Again there is variation in the way these services are configured in the UK, with a variety of providers delivering rehabilitation using different strategies to operate between the health, social care and voluntary sectors.[29] It can therefore be difficult for people to negotiate the complex networks of agencies involved in delivering these services, with people not knowing what is available and who to contact.[30] There is also evidence that registration status, visual function, and support needs change over time and that people should be given multiple opportunities to receive information and support for their visual impairment.[31] People often access support and rehabilitation through clinical services and once they are discharged because nothing can be done for them clinically, they may not receive any information about other services that could benefit them. Therefore, access to services is often largely dependent on the initiative of the service user.[32] This may be especially true for those who do not have a CVI, which is often the key to accessing vital financial, practical, and social support.

3.1.3 EVALUATIONS OF LOW VISION AND VISION SUPPORT SERVICES

Patients are able to access a range of clinical services in hospital eye clinics, including: medical diagnosis, treatment, and advice by ophthalmic and optometric professionals. Patients might also receive non-medical support and advice. This type of service may be formal or non-formal and may be staffed by, for example, nurses, rehabilitation workers, or volunteers. One study which interviewed health professionals from nine eye clinics in England found that services within the eye clinic differed from each other in terms of having clear paths of referral within the eye clinic, clear links with social services (or equivalent), and keeping detailed records.[33] All the services provided a 'link service' referring patients onto others beyond the eye clinic. Since the publication of this study over 10 years ago, more formalised early intervention services have expanded in UK eye clinics, including the growth of the role of ECLOs, who can provide initial support and advice including signposting and referral to other sources of support. ECLOs can also therefore be thought of as providing a link service for patients between health care, social care and the voluntary sector. Other models of service delivery for eye clinic patients have also been developed, such as an emotional support and counselling (ESaC) service delivered within an integrated low vision service.[34, 35]

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[29] Dickinson et al. (2011), op. cit

[30] Thetford et al. (2011), op. cit

[31] Hodge S, Thetford C, Knox P and Robinson J (2015) 'Finding your way around: Experiences of health and social care provision for people with a visual impairment in the United Kingdom' *British Journal of Visual Impairment* 33.3, pp.200-211

[32] Ibid.

[33] Douglas G, Spurgeon P and Pavey S (2005) 'An exploratory study of the impact of non-medical eye clinic support services (ECSS) in hospital eye clinics' *International Congress Series* 1282, pp.105-108

[34] Hodge S, Barr W, Bowen L, Leevan M and Knox P (2012) 'Exploring the role of an emotional support and counselling service for people with visual impairments' *British Journal of Visual Impairment* 31.1, pp.5-19

[35] Barr W, Hodge S, Leeven M, Bowen L and Knox P (2012) 'Emotional support and counselling for people with visual impairment: Quantitative findings from a mixed methods pilot study' *Counselling and Psychotherapy Research* 12.4, pp.294-302

All clients who attended the low vision service were given information about the ESaC service and, if the service was taken up by the client, they were offered individual counselling from a qualified counsellor for up to 12 sessions lasting up to 50 minutes each. Improvements in psychological well-being were seen during the course of the treatment which ranged from counselling to less formalised emotional support depending on the needs of the client.[36] A systematic review of low vision services reported that improvements in psychological status may be seen in low vision services, even without the provision of a specific counselling component,[37] however there was limited evidence to support this as most studies see greater improvements in functional status than psychological status. This could be because most conventional optometrist-led low vision rehabilitation services in UK hospital eye clinics are primarily focused on minimising limitations in activities by providing low vision aids (LVAs), usually magnifiers, and teaching people about the importance of controlling illumination. One trial compared (a) conventional low vision rehabilitation (LVR) for people with AMD as provided by the hospital eye service, (b) conventional LVR "enhanced" by home visits from a rehabilitation officer for the visually impaired (ELVR), and (c) conventional LVR supplemented by home visits from a community care worker. The latter arm was intended to act as a control for the contact time with subjects allocated to ELVR. This trial found no evidence of benefit from the model of enhanced LVR, compared with conventional LVR in terms of vision specific QoL, general health-related QoL, and psychological adjustment to vision loss.[38]

In 2004, the primary care based Welsh Low Vision Service (WLVS) was established to improve access to low vision services in Wales. The WLVS exists alongside hospital-based services but is located in accredited community-based optometric practices. At the WLVS a patient's vision is assessed, low vision aids are provided on loan, advice is given about lighting and other methods of enhancing vision, and signposting and referral to other services is provided where necessary (e.g. social services or ophthalmology). In the year after the WLVS was implemented, an additional 127 optometry practices provided low vision services and the number of NHS funded low vision appointments increased by 51.7%. The proportion of patients waiting for less than 2 months for an initial LVA increased from 11% to 60%. Journey times for patients also decreased. Visual disability scores also decreased significantly and of the patients who had been prescribed magnifiers, 92% had used at least one in the previous week.[39] When the community-based low vision service was compared with the hospital-based low vision service, there were no significant differences in patient satisfaction, use of low vision aids and visual acuity, suggesting that they are both effective methods of service provision in Wales.[40]

A recent report on vision rehabilitation services in the UK showed that there is a wide variety of vision

[36] Ibid.

[37] Binns AM, Bunce C, Dickinson C, Harper R, Tudor-Edwards R, Woodhouse M, Linck P, Suttie A, Jackson J, Lindsay J, Wolffsohn J, Hughes L and Margrain TH (2012) 'How effective is low vision service provision? A systematic review' *Survey of Ophthalmology* 57.1, pp.34-65

[38] Reeves BC, Harper RA and Russell WB (2004) 'Enhanced low vision rehabilitation for people with age related macular degeneration: a randomized controlled trial' *British Journal of Ophthalmology* 88, pp.1443-1449

[39] Ryan B, White S, Wild J, Court H and Margrain T (2010) 'The newly established primary care based Welsh Low Vision Service is effective and has improved access to low vision services in Wales' *Ophthalmic and Physiological Optics* 30.4, pp.358-364

[40] Court H, Ryan B, Bunce C and Margrain TH (2011) 'How effective is the new community-based Welsh low vision service?' *British Journal of Ophthalmology* 95, pp.178-184

rehabilitation provision across England, in terms of the type of providers, specialism within the teams, case loads and waiting times.[41] The two predominant types of providers are local authority in-house providers (61% of services) and voluntary sector providers (28% of services). The most common type of team found within local authority in-house providers was a sensory impairment team (57%); 75% of voluntary sector providers were specialist vision rehabilitation teams. In terms of the type of training and support offered to service users, independent living skills, orientation and mobility and training in the use of aids, adaptations and equipment were predominant types of training offered.

Self-management courses were provided for service users in just over a third of services. Other types of training which services mentioned included low vision aid, confidence building and training in accessibility issues. In terms of support, provision of aids, adaptations and equipment (99%), and an information/signposting role (100%) were most commonly reported, followed by emotional support for service users (79%) and support for partners and carers (80%). Counselling was less likely to be offered (24%). Benefits/financial advice was offered in 59% of services and support for leisure/social activities in 65%. Respondents were asked to rank how easy it was to work with other organisations and professionals involved in supporting service users. 68% of services ranked ECLOs as 'easy' to work with, whereas other health professionals such as GPs were rated as 'easy' to work with by 23%. This study also highlighted the importance of offering rehabilitation intervention in the early stages of sight loss. A general view was that rehabilitation officers could achieve much better outcomes when the clients still had some vision. However, participants reported that they did not always get to know about the clients (for example, through the ECLO, the eye health personnel or a GP) at early stages of their sight impairment. Clients were often not referred until after they had been registered, by which time they could have suffered for a long time and lost a lot of vision and hope.

An exploratory trial is underway in Wales to explore the impact of a Visual Rehabilitation Officer on self-reported visual function, depression, well-being, loneliness, adjustment to visual loss and generic health-related quality-of-life outcomes in individuals with low vision.[42] The aim of the rehabilitation (which will be provided by two experienced Visual Rehabilitation Officers based at the Sight Cymru rehabilitation service) is to promote independence by helping individuals learn new skills or regain lost skills and rebuild confidence following sight loss. This support may be implemented by the provision of information, equipment, encouragement, training and/or referral to other agencies.

3.1.4 FACILITATING ACCESS TO VOLUNTARY AND COMMUNITY SERVICES

A crucial part of the ECLO role is providing a link for patients from healthcare settings to other statutory, community and voluntary sector organisations. In this way ECLOs could be seen as facilitating 'social prescribing' defined as "a mechanism for linking patients with non-medical sources of support within the community".[43] Very few social interventions, like social prescribing schemes, have been empirically

[41] Rabiee P, Parker G, Bernard S and Baxter K (2105) *Vision Rehabilitation Services: what is the evidence?* Social Policy Research Unit: University of York – accessed from: http://www.york.ac.uk/inst/spru/research/pdf/VIrehabTPT.pdf

[42] Acton JH, Molik B, Binns A, Court H and Margrain T (2016) 'Effect of rehabilitation worker input on visual function outcomes in individuals with low vision: study protocol for a randomised controlled trial' *Trials* 17, p.105: doi:10.1186/s13063-016-1235-2

[43] CentreForum Mental Health Commission (2014) *The Pursuit of Happiness: A new ambition for our mental health* London

evaluated. A scoping review to understand the effectiveness of linking schemes from healthcare providers to community resources to improve the health and well-being of people with long-term conditions identified only seven papers.[44]

The aim of the review was to identify the types and benefits of linking mechanisms adopted by social interventions to support people in healthcare settings access wider community-based resources. This review highlighted enablers and barriers to implementing social interventions. Almost all interventions were facilitator-led. The facilitators helped to engage participants through being flexible, trustworthy, empathetic and accessible. Developing relationships with both clinical staff and voluntary and community groups was also considered important. Having a single point of contact based within the general practice was reported by healthcare staff as making the referral process easy and straightforward.

The physical proximity of the facilitators was also important to ensure engagement of healthcare staff. Recognised barriers included ambiguity of the facilitator role, inappropriate referrals to the services, clinicians apprehensions about referring to voluntary organisations and the sustainability of services. One of the studies included in the review measured cost-effectiveness and reported that the mean cost of the intervention arm was significantly greater than normal GP care, but that there were also significant improvements in levels of anxiety, ability to carry out everyday tasks, feelings about general health and quality of life.[45]

3.2 ECONOMIC AND HEALTH OUTCOMES

Prior to the analysis, a rapid review of the health economics literature related to the likely health and economic outcomes of the ECLO on patients with low vision was conducted to inform the report and to identify possible candidate models for adaptation and data inputs (e.g. the costs and benefits of the outcomes) to inform the model where additional data (alongside findings from the questionnaires) are required. The aim of the literature review was to identify the key outcomes associated with sight-loss, comprising psycho-social effects and injuries from falls, potentially influenced by and avertable by ECLOs support, and their economic implications to the NHS and humanistic implications to patients. In addition, further pragmatic structured searches to identify literature to inform relevant health outcomes were undertaken as issues emerged requiring more understanding as the research progressed.

3.2.1 SCREENING PROCESS

Titles and abstracts of all citations initially identified were screened against predefined exclusion criteria listed below. Citations not of interest were eliminated accordingly, these included:

- Qualitative studies

[44] Mossabir R, Morris R, Kennedy A, Blickem C and Rogers AA (2015) 'Scoping review to understand the effectiveness of linking schemes from healthcare providers to community resources to improve the health and well-being of people with long-term conditions' *Health & Social Care in the Community* 23, pp.467-484: doi: 10.1111/hsc.12176

[45] Grant C, Goodenough T, Harvey I and Hine C (2000) 'A randomised controlled trial and economic evaluation of a referrals facilitator between primary care and the voluntary sector' *BMJ* 320, pp.419-423

- HRQoL validation studies
- Inpatient outcomes (costs or HRQoL)
- Editorials
- Animal or *in vitro* (non-human) studies
- Diseases and disabilities other than vision-related
- Non-English language
- Outcome not in scope

Most of the cost studies identified originate from the UK, with HRQoL, where relevant to the remit of the report, also from western European countries, the US and Canada.

TABLE 3.1 · PICO approach to guide search strategy

Population	Interventions	Comparison	Outcomes (Health and Economic)
Adults aged 18 years and over with low vision impairment All settings/countries will be considered	Eye liaison clinic officers Low vision services No intervention	All other interventions e.g. usual care	Mortality Morbidity Outcome rates (e.g. fall rates, depression rates) Health-related quality of life Cost Cost-effectiveness Cost-consequences Cost-benefit Cost-utility

3.2.2 DATA ABSTRACTION

Data were abstracted and reviewed manually in a two-step process. Initially, key article statistics were abstracted into an Excel database. Selected articles (full-text) were then reviewed thoroughly and a narrative output produced. The adopted approach was subject-driven, such that the output represents a review of key economic and HRQoL topics insofar as they are supported by articles, rather than an explicit review of each article.

3.2.3 LITERATURE SELECTION

All data inputs for the model were extracted and summarised in an MS Excel spread-sheet as part of the 'look-up' tables for the model. All inputs that were obtained from the literature review used the best possible evidence and where required, point estimates and variances (e.g. standard deviation, 95% confidence intervals) utilised.

On a human level, sight loss, its consequences and its incident morbidity create important effects to health-related quality of life (HRQoL) and economic well-being; especially for those in paid employment who are unable to continue with their vocation due to reduced visual function, further burden is appreciable[46] and added to the societal toll of sight loss in those beyond their employable years.

The body of literature investigating the epidemiologic, economic and humanistic burden of sight loss has informed healthcare prioritisation decision-making from global[47] to local levels,[48] for both prevention and treatment pathways as well as supportive services, and its growing size is representative of the heightened concern by healthcare policy makers and society of the increasing population-wide risks and consequences of sight loss. Such studies emanate from investigators and institutions world-wide, some of which have been summed by recent systematic reviews[49,50,51,52,53,54,55,56,57] to establish economic burden,[58,] with one identifying up to 390 related studies.[59] In such surveys in particular, direct costs of treatment or service provision and indirect or intangible effects related to blindness and severe visual impairment have been surveyed, with the latter ensuing as most critical in the cost equation, and

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[46] Hirai FE, Tielsch JM, Klein BE and Klein R (2012) 'Relationship between retinopathy severity, visual impairment and depression in persons with long-term type 1 diabetes' *Ophthalmic Epidemiology* 19.4, pp.196-203

[47] World Health Organization (2014) *Universal Eye Health: a global action plan 2014-2019* – accessed from: http://www.who.int/blindness/AP2014_19_English.pdf?ua=1

[48] Tian Y, Thompson J, Buck D and Sonola L (2013) *Exploring the system-wide costs of falls in older people in Torbay* The King's Fund – accessed from: http://www.King'sfund.org.uk/sites/files/kf/field/field_publication_file/exploring-system-wide-costs-of-falls-in-torbay-King'sfund-aug13.pdf

[49] Royle P, Mistry H, Auguste P, Shyangdan D, Freeman K, Lois N and Waugh N (2015) 'Pan-retinal photocoagulation and other forms of laser treatment and drug therapies for non-proliferative diabetic retinopathy: systematic review and economic evaluation' *Health Technology Assessment* 19.51

[50] Mowatt G, Hernández R, Castillo M, Lois N, Elders A, Fraser C, Aremu O, Amoaku W, Burr J, Lotery A, Ramsay C, Azuara-Blanco A (2014) 'Optical coherence tomography for the diagnosis, monitoring and guiding of treatment for neovascular age-related macular degeneration: a systematic review and economic evaluation' *Health Technology Assessment* 18.69

[51]Frampton G, Harris P, Cooper K, Lotery A and Shepherd J (2014) 'The clinical effectiveness and cost-effectiveness of second-eye cataract surgery: a systematic review and economic evaluation' *Health Technology Assessment* 18.68

[52] Bourne RR, Jonas JB, Flaxman SR, Keeffe J, Leasher J, Naidoo K, Parodi MB, Pesudovs K, Price H, White RA, Wong TY, Resnikoff S and Taylor HR (2014) 'Vision Loss Expert Group of the Global Burden of Disease Study. Prevalence and causes of vision loss in high-income countries and in Eastern and Central Europe: 1990-2010' *British Journal of Ophthalmology* 98.5, pp.629-38

[53] Pearson I, Rycroft C, Irving A, Ainsworth C and Wittrup-Jensen K (2013) 'A systematic literature review of utility weights in wet age-related macular degeneration' *Journal of Medical Economics* 16.11, pp.1307-16

[54] Bennion AE, Shaw RL and Gibson JM (2012) 'What do we know about the experience of age related macular degeneration? A systematic review and meta-synthesis of qualitative research' *Social Science and Medicine* 75.6, pp.976-85

[55] Tosh J, Brazier J, Evans P and Longworth L (2012) 'A review of generic preference-based measures of health-related quality of life in visual disorders' *Value Health* 15.1, pp.118-27

[56] Binns AM, Bunce C, Dickinson C, Harper R, Tudor-Edwards R, Woodhouse M, Linck P, Suttie A, Jackson J, Lindsay J, Wolffsohn J, Hughes L and Margrain TH (2012) 'How effective is low vision service provision? A systematic review' *Survey of Ophthalmology* 57.1, pp.34-65

[57] Peto T and Tadros C (2012) 'Screening for diabetic retinopathy and diabetic macular edema in the United Kingdom' *Current Diabetes Reports* 12.4, pp.338-45

[58] Soubrane G, Cruess A, Lotery A, Pauleikhoff D, Monès J, Xu X, Zlateva G, Buggage R, Conlon J and Goss TF (2007) 'Burden and Health Care Resource Utilization in Neovascular Age-Related Macular Degeneration: Findings of a Multicountry Study' *Archives of Ophthalmology* 125.9, pp.1249-1254

[59] Köberlein J, Beifus K, Schaffert C and Finger RP (2013) 'The economic burden of visual impairment and blindness: a systematic review' *BMJ Open* 7.3

consistently pointing to outcomes such as depression, emotional distress, loss of independency, loss of HRQoL, limitations in activities of daily living and physical hazards and injuries particularly from falls.

To this end, the aim of this targeted secondary research was to inform, with a summarisation of these indirect outcomes largely focussed on the UK where relevant and possible, the valuation of ECLO services in the care pathway of people who have vision impairments. With falls and psycho-social effects being the most prevalent indirect outcomes of sight-loss, it is expected that any enhancements in supporting patients to reach related services, as that provided by ECLO services, that reduce these outcomes can bring significant value to both the NHS and patients and carers.

3.2.4 FALLS RELATED TO VISUAL IMPAIRMENT

Epidemiology of falls

While population-level health risks related to the aging UK demographics are well established, the significance of falls in particular in the older age groups was brought to the fore by the Royal College of Physicians and NICE Falls Prevention Guidelines[60] highlighting that annually, over 500,000 older people attend UK emergency departments following a fall and account for over 4 million bed days per year in England alone. Falls in the over-65 age group amount up to 200,000 fractures and the leading cause of disability and accidental death in this age group in the UK.[61] Furthermore, the Royal Society for the Prevention of Accidents (RoSPA) estimates that one in three people aged 65 years and over experience a fall at least once a year – rising to one in two among 80 year olds and older.[62,75]

Although the causes of falls are often multifactorial, increased risk of falling in the elderly is compounded by visual impairment causing poor balance and reduced depth perception which can lead to trips over obstacles or on stairs due to reduced central and/or peripheral vision or eye movement disorders.[63] The relative risk of a fall in people whose visual impairment is caused by visual field loss or glaucoma particularly high[64,65]

Outcomes of falls: resource use and cost

The economic implications of falls in the UK have been established at national and regional levels, and acute hospital settings. On a national level, costs of falls to the NHS in 2011 were estimated at more than £2.3 billion per year,[66] while direct cost estimated to the NHS of falls associated with visual

[60] NICE (2013) *Falls in older people: assessing risk and prevention* Clinical guideline [CG161], June 2013 – accessed from: https://www.nice.org.uk/guidance/cg161

[61] Scuffham P and Chaplin S (2002) *The incidence and costs of accidental falls in the UK: Final Report* York: York Health Economic Form Consortium, University of York

[62] RoSPA – accessed from: http://www.rospa.com/home-safety/advice/older-people/ (accessed 8 Oct 2016)

[63] College of Optometrists (2014) *Focus on Falls* – accessed from: http://www.college-optometrists.org/filemanager/root/site_assets/commissioning/falls/focus_on_falls_report_240414.pdf (accessed 8 Oct 2016)

[64] Dirani M, Crowston JG, Taylor PS, Moore PT, Rogers S, Pezzullo ML, Keeffe JE and Taylor HR (2011) 'Economic impact of primary open-angle glaucoma in Australia' *Clinical and Experimental Ophthalmology* 39.7, pp.623-32

[65] College of Optometrists and British Geriatrics Society (2013) *The Importance of Vision in Preventing Falls* London: College of Optometrists

[66] Snooks H, Cheung WY, Gwini SM, Humphreys I, Sanchez A and Sirwardena N (2011) 'Can older people who fall be identified in the ambulance call centre to enable alternative responses or care pathways?' *Emergency Medicine Journal* 28.3.1

impairment specifically was at least £25.1 million per annum, without accounting for wider and longer-term community and social care.[67] Average acute costs per fall, on the other hand, have been estimated at £1,088 and £15,133 for falls leading to a hip fracture.[68]

While now dated, analysis of 1999 healthcare records by Scuffham et al revealed that there were 647,721 A&E attendances and 204,424 admissions to hospital for fall-related injuries in 1999 in the UK population aged 60 years or over.[69] The associated cost of these falls to the NHS was £908.9 million and 63 per cent of these costs were incurred from falls in those aged 75 years and over, and £269 million was spent on the population with visual impairment and £128 million was directly attributable to visual impairment. However, the 2013 report published by the King's Fund[70] was critical in revealing the true extent of healthcare costs, beyond the inpatient cost of the core event itself, and decomposed by health, community and social services costs. The report was aimed to assist commissioners across health and social care to better understand where the costs of treating patients are incurred across health, community and social care services for making more integrated commissioning decisions for this group of patients. Data were from Torbay for 421 patients in each of the 12 months before and after the fall event, from Torbay's seven linked health and social care data sets. It was the first detailed analysis of the cost to the health and social care system in relation to falls patients in England. The following cost breakdown of falls to the health and social care system suggest that on average, the cost of hospital, community and social care services for each patient who fell were almost four times as much in the 12 months after admission for a fall as the costs of the admission itself (Figures 3.1 and 3.2).

- Over the 12 months that followed admission for falls, costs were 70% higher than in the 12 months before the fall. (Figure 3.1)
- Comparing the 12 months before and after a fall, the most dramatic increase was in community care costs (160%), compared with a 37% increase in social care costs and a 35% increase in acute hospital care costs. (Figure 3.2)
- While falls patients in the study accounted for slightly more than 1% of Torbay's over-65 population, in the 12 months that followed a fall, spending on their care accounted for 4% of the whole annual inpatient acute hospital spending, and 4% of the whole local adult social care budget.
- The majority of the costs of caring for patients after a fall are outside the acute hospital setting; this is not always recognised by commissioners, because data on costs is never brought together.

[67] Boyce T (2011) *Falls: costs, numbers and links with visual impairment* London: RNIB

[68] Iglesias CP, Manca A and Torgerson DJ (2009) 'The health-related quality of life and cost implications of falls in elderly women' *Osteoporosis International* 20.6, pp.869-78

[69] Scuffham PA, Legood R, Wilson ECF et al (2002) 'The incidence and cost of injurious falls associated with visual impairment in the UK' *Visual Impairment Research* 4.1, pp.1-14

[70] Tian et al (2013), op. cit

FIGURE 3.1 · Costs of the core event, and other health and social care costs in the 12 months before and after the event (permission for use of figure to be obtained from authors)[71]

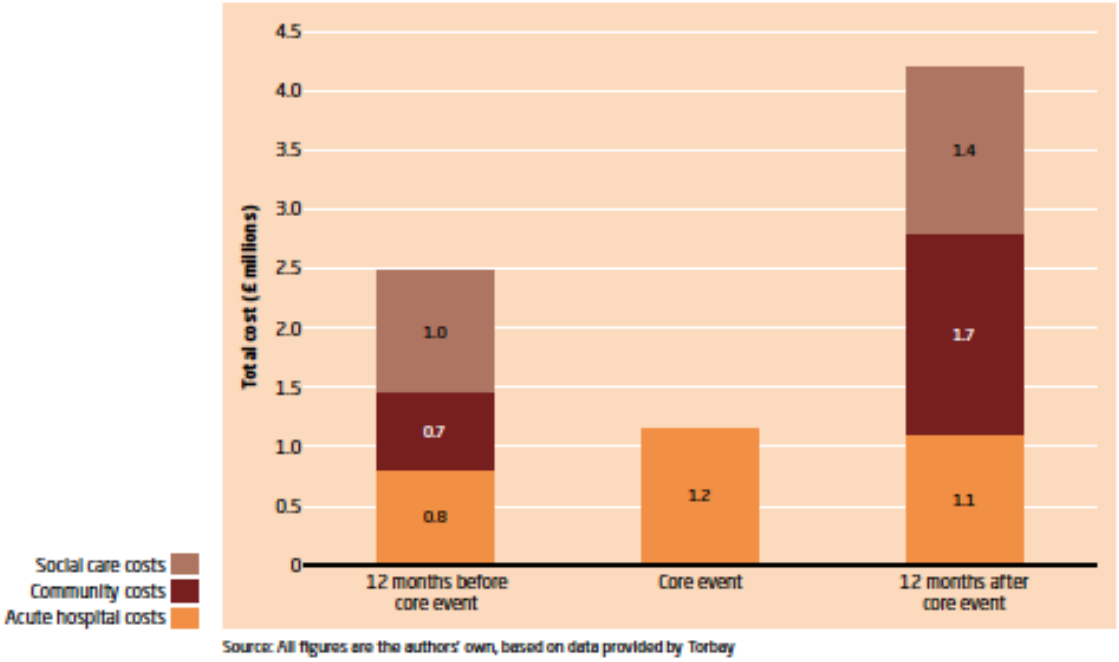
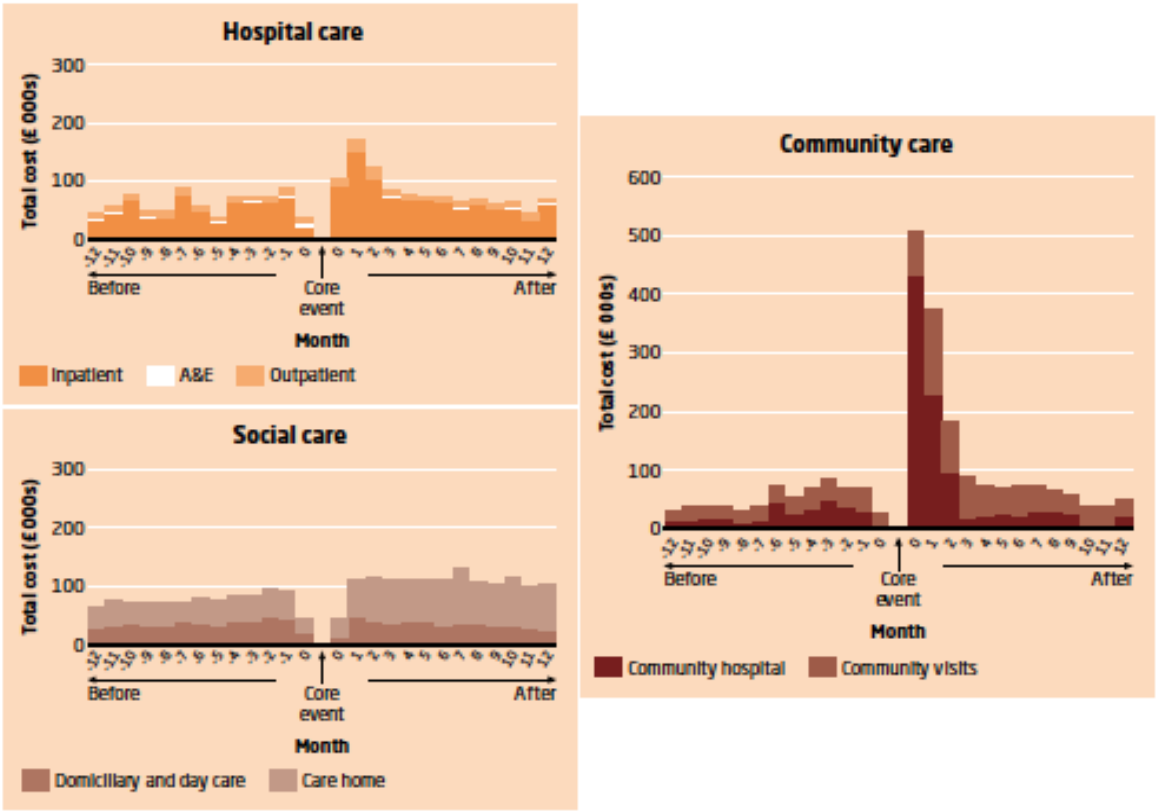


FIGURE 3.2 · Total cost of hospital, community and social care by month in relation to the core events (permission for use of figure to be obtained from authors)[72]



[71] Tian et al (2013), op. cit.

[72] Ibid.

The comprehensiveness of the Torbay health services data presented in the King's Fund report[73] will likely have captured the wide range of outcomes associated with falls as classified in the NICE 2013 Guidelines on assessment and prevention of falls in older people[74] including:

- hypothermia
- pressure-related injury
- infection
- loss of mobility, leading to social isolation and depression
- increase in dependency and disability
- further psychological effects, for example, a fear of falling and loss of confidence in being able to move about safely[75]

In addition to primary prevention of falls, the guidelines also consider secondary prevention strategies, including:

- improving the diagnosis, care and treatment of those who have fallen
- rehabilitation and long-term support
- ensuring that older people who have fallen receive effective treatment and rehabilitation
- ensuring that patients and carers receive advice on prevention, through a specialised falls service.

Impact of falls on HRQoL

Apart from costs related to health services, the human cost of falling by the elderly is deep in terms of HRQoL as well as wide-reaching to family and informal carers. HRQoL consequences such as distress, pain, loss of confidence, anxiety/fear of falling[76], loss of independence and mortality are significant.[75]

Furthermore, physical and psycho-social debilitation is not precluded in minor falls, these even cause losses of confidence and falling fears, creating further reduced mobility, further isolation and increased dependency on others. These issues are particularly heightened in those with sight loss.[77,78,79,80,81]

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[73] Tian et al (2013), op. cit

[74] NICE (2013) *Falls Assessment and prevention of falls in older people* NICE guidance number 161 – accessed from: https://www.nice.org.uk/guidance/cg161/evidence/falls-full-guidance-190033741

[75] Ibid.

[76] Cumming RG, Salkeld G, Thomas M and Szonyi G (2000) 'Prospective study of the impact of fear of falling on activities of daily living, SF-36 scores, and nursing home admission' *Journals of Gerontology, Series A: Biological Sciences and Series B: Medical Sciences* 55

[77] Friedman SM, Munoz B, West SK, Rubin GS and Fried LP (2002) 'Falls and fear of falling: which comes first? A longitudinal prediction model suggests strategies for primary and secondary prevention' *Journal of the American Geriatrics Society* 50, 1329

[78] White UE, Black AA, Wood JM and Delbaere K (2015) 'Fear of falling in vision impairment' *Optometry and Vision Science* 92.6, pp.730-735

[79] Nguyen AM, Arora KS, Swenor BK, Friedman DS and Ramulu PY (2015) 'Physical activity restriction in age-related eye disease: a cross-sectional study exploring fear of falling as a potential mediator' *BMC Geriatrics* 15.64

[80] Van Landingham SW, Massof RW, Chan E, Friedman DS and Ramulu PY (2014) 'Fear of falling in age-related macular degeneration' *BMC Ophthalmology* 28.14.10

[81]Ramulu PY, van Landingham SW, Massof RW, Chan ES, Ferrucci L and Friedman DS (2012) 'Fear of falling and visual field loss from glaucoma' *Ophthalmology* 119.7, pp.1352-1358

The construct of 'fall fear' is also considered a predictor in the likelihood of having a future fall, sharing a complex relationship with other psychological consequences of falling, such as depression and anxiety.[77] Importantly, fear of falling can lead to activity restriction and avoidance, which contribute to functional declines, social isolation, depression, falls, and institutionalization, in the general elderly population[82,83,84,85] but particularly in the elderly with sight loss.[78]

The prevalence of fall fears across various vision impairments has been examined in the literature, as recently surveyed.[64] Visual field loss has been implicated to have association with increased levels of fall fears, as particularly observed in studies of older adults with glaucoma.[81,86] Similarly, reduced contrast sensitivity has similar association with fear of falling[81,87,88] and fear related activity restriction.[82,87,89,90,91]

3.2.5 PSYCHO-SOCIAL IMPACTS OF VISUAL IMPAIRMENT

Epidemiology psycho-social impacts

The large and growing size of the literature on psycho-social outcomes related to visual impairment[92,93,94] reflects the recognition by society, health providers, and researchers on the degree that a patient's life changes after reaching even the initial stages of visual impairment, and its far

[82] Deshpande N, Metter EJ, Bandinelli S, Lauretani F, Windham BG and Ferrucci L (2008) 'Psychological, physical, and sensory correlates of fear of falling and consequent activity restriction in the elderly: the InCHIANTI study' *American Journal of Physical Medicine and Rehabilitation* 87, pp.354-62

[83] Friedman SM, Munoz B, West SK, Rubin GS and Fried LP (2002) 'Falls and fear of falling: which comes first? A longitudinal prediction model suggests strategies for primary and secondary prevention' *Journal of the American Geriatrics Society* 50, pp.1329-1335

[84] Lachman ME, Howland J, Tennstedt S and Jette A (1998) 'Fear of falling and activity restriction: the survey of activities and fear of falling in the elderly (SAFE)' *Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 53, pp.43-50

[85] Howland J, Lachman ME, Peterson EW, Cote J, Kasten L and Jette A (1998) 'Covariates of fear of falling and associated activity curtailment' *Gerontologist* 38, pp.549-55

[86] Yuki K, Tanabe S, Kouyama K, Fukagawa K, Uchino M, Shimoyama M, Ozeki N, Shiba D, Ozawa Y, Abe T and Tsubota K (2013) 'The association between visual field defect severity and fear of falling in primary open-angle Glaucoma' *Investigative Ophthalmology and Visual Science* 54, pp.7739-7745

[87] Wang MY, Rousseau J, Boisjoly H, Schmaltz H, Kergoat MJ, Moghadaszadeh S, Djafari F and Freeman EE (2012) 'Activity limitation due to a fear of falling in older adults with eye disease' *Investigative Ophthalmology and Visual Science* 53, pp.7967-7972

[88] Van Landingham SW, Massof RW, Chan E, Friedman DS and Ramulu PY (2014) 'Fear of falling in age-related macular degeneration' *BMC Ophthalmology* 14.10

[89] Black AA, Wood JM and Lovie-Kitchin JE (2011) 'Inferior field loss increases rate of falls in older adults with glaucoma' *Ophthalmology and Visual Science* 88, pp.1275-1282

[90] Wood JM, Lacherez P, Black AA, Cole MH, Boon MY and Kerr GK (2011) 'Risk of falls, injurious falls, and other injuries resulting from visual impairment among older adults with age-related macular degeneration' *Investigative Ophthalmology and Visual Science* 52, pp.5088-5092

[91] Lord SR and Dayhew J (2001) 'Visual risk factors for falls in older people' *Journal of the American Geriatrics Society* 49, pp.508-515

[92] Senra H, Barbosa F, Ferreira P, Vieira CR, Perrin PB, Rogers H, Rivera D and Leal I (2015) Psychologic adjustment to irreversible vision loss in adults: a systematic review' *Ophthalmology* 122.4, pp.851-61

[93] Nyman SR, Dibb B, Victor CR and Gosney MA (2012) 'Emotional well-being and adjustment to vision loss in later life: a meta-synthesis of qualitative studies' *Disability and Rehabilitation* 34.12, pp.971-81

[94] Pinquart M and Pfeiffer JP (2011) 'Psychological well-being in visually impaired and unimpaired individuals: a meta-analysis' *British Journal of Visual Impairment* 29.1, pp.27-45

reaching consequences thereafter as expressed by the variety of emotional, cognitive, behavioural and social responses to loss of sight.[95,96,97, 98] It is comparable to the grief experienced by terminally ill persons.[99,100]

Feeding into these constructs, functional disability[101] and the loss of leisure activities and hobbies, impaired self-esteem, being socially less active and experiencing challenges with regard to interpersonal relationships and communication have been implicated in the toll of sight loss on patient mental health, especially depression and anxiety,[102,103,104,105], and predictors of suicide in the elderly.[106,107,108]

In the UK, the prevalence of depression in people with sight loss, as informed by large-scale epidemiologic studies, has been estimated at 13.5%, up to 3 times greater than the 7.4% prevalence of depression measured in the general population.[109]

Recently, screening results of the DEPVIT study, which sought to establish the prevalence of significant depressive symptoms in people attending visual rehabilitation centres in the UK. The aim of the study was to conduct an exploratory trial to assess whether problem solving treatment or physician referrals were effective at reducing depression in people with impaired vision and significant depressive symptoms. In those accessing the low vision rehabilitation study centres, the prevalence of depression,

[95] Stevelink SA and Fear NT (2016) 'Psychosocial impact of visual impairment and coping strategies in female ex-Service personnel' *Journal of the Royal Army Medical Corps* 162.2, pp.129-33

[96] Stevelink SA, Malcolm EM and Fear NT (2015) 'Visual impairment, coping strategies and impact on daily life: a qualitative study among working-age UK ex-service personnel' *BMC Public Health* 12.15.1118

[97] Pinquart M and Pfeiffer JP (2011), op. cit

[98] Sturrock BA, Xie J, Holloway EE, Hegel M, Casten R, Mellor D, Fenwick E and Rees G (2016) 'Illness Cognitions and Coping Self-Efficacy in Depression Among Persons With Low Vision' *Investigative Ophthalmology and Visual Science* 57.7, pp.3032-8

[99] Schilling OK and Wahl HW (2006) 'Modelling late-life adaptation in affective well-being under a severe chronic health condition: the case of age-related macular degeneration' *Psychology and Aging* 21.4, pp.703-14

[100] Bergeron CM and Wanet-Defalque M (2013) 'Psychological adaptation to visual impairment: the traditional grief process revised' *British Journal of Visual Impairment* 31.1, pp.20-31

[101] Hochberg C, Maul E, Chan ES, et al (2012) 'Association of vision loss in glaucoma and age-related macular degeneration with IADL disability' *Investigative Ophthalmology and Visual Science* 53.6, pp.3201-3206

[102] Casten RJ and Rovner BW (2013) 'Update on depression and age-related macular degeneration' *Current Opinion in Ophthalmology* 24.3, pp.239-243

[103] Casten R, Rovner BW, Leiby BE and Tasman W (2010) 'Depression despite anti-vascular endothelial growth factor treatment of age-related macular degeneration' *Archives of Ophthalmology* 128.4, pp.506-508

[104] Hayman KJ, Kerse NM, La Grow SJ, Wouldes T, Robertson MC and Campbell AJ (2007) 'Depression in older people: visual impairment and subjective ratings of health' *Optometry and Vision Science* 84.11, pp.1024-1030

[105] Schilling and Wahl (2006), op. cit.

[106] Osborn DPJ, Fletcher AE, Smeeth L, Stirling S, Bulpitt CJ, Breeze E, Ng ESW, Nunes M, Jones D and Tulloch A (2003) 'Factors associated with depression in a representative sample of 14,217 people aged 75 and over in the United Kingdom: results from the MRC trial of assessment and management of older people in the community' *International Journal of Geriatric Psychiatry* 18.7, pp.623-630

[107] Waern M, Rubenowitz E, Runeson B, Skoog I, Wilhelmson K and Allebeck P (2002) 'Burden of illness and suicide in elderly people: case–control study' *British Medical Journal* 324.7350, pp.1355-1357

[108] Cimarolli VR, Casten RJ, Rovner BW, Heyl V, Sörensen S and Horowitz A (2015) 'Anxiety and depression in patients with advanced macular degeneration: current perspectives' *Clinical Ophthalmology* 30.10, pp.55-63

[109] Evans JR, Fletcher AE and Wormald RPL (2007) 'Depression and anxiety in visually impaired older people' *Ophthalmology* 114.2, pp.283-288

at up to 43%, was observed to be higher than previous cross-sectional studies had indicated. Of those who screened positive, 75% were not receiving any treatment for their depressed mood.

One important finding from the DEPVIT study was that the prevalence of significant depressive symptoms in visual rehabilitation clinics in Britain, at 43%, is among the highest reported anywhere in the world, in particular, compared with the rates measured in North America (22% to 38%).[110,111] Such a rate is noted to be comparable with rates for depressive symptoms in people with a cancer diagnosis at initiation of chemotherapy – estimated at 45%.[112] The investigators also note that while people seeking help for their sight loss are a high-risk group for depression, the fact that three-quarters of those who screened positive were not receiving any form of treatment suggests that depression is being routinely overlooked in this vulnerable group, which is conceivable given that there are currently only two low vision services in Britain that screen people regularly for depression.[113]

The increased burden of depression in the sight impaired people compared with those with no impairment in the UK has also been underlined.[114] These investigators found in their secondary analysis of national survey data that the sight-impaired vs those with no impairment, respectively, are up to seven times more likely to have been feeling unhappy or depressed a lot more than usual (14% vs 2%); nine times more likely to have been feeling worthless recently a lot more than usual (9% vs 1%); three times more likely to not feel optimistic about the future (9% vs 3%); nine times more likely never to feel useful (9% vs. 1%); five times more likely to never feel close to others (5% vs. 1%).

3.2.6 HEALTH-RELATED QUALITY OF LIFE OUTCOMES OF DEPRESSION

The significance of untreated depression having a profound negative impact on HRQoL and reducing life expectancy in the general aged population is well-recognised in the literature.[115,116,117,118] The association between depression and HRQoL in the visually impaired, in particular has recently been

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[110] Horowitz A, Reinhardt JP and Boerner K (2005) 'The effect of rehabilitation on depression among visually disabled older adults' *Aging and Mental Health* 9, pp.563-570

[111] Margrain TH, Nollett C, Shearn J, Stanford M, Edwards RT, Ryan B, Bunce C, Casten R, Hegel MT and Smith DJ (2012) 'The Depression in Visual Impairment Trial (DEPVIT): trial design and protocol' *BMC Psychiatry* 6.12.57

[112] Bellera CA, Rainfray M, Mathoulin-Pelissier S et al (2012) 'Screening older cancer patients: first evaluation of the G-8 geriatric screening tool' *Annals of Oncology* 23, pp.2166-2172

[113] Margrain et al (2012), op. cit

[114] McManus and Lord (2012) cited in Pybis J, Thurston M, Dennison CM, Broom M, and Miller A (2016) 'The nature of emotional support and counselling provision for people with sight loss in the United Kingdom' *British Journal of Visual Impairment* 34.2, pp.167-176: doi: 10.1177/0264619616633884

[115] Adamson JA, Price GM, Breeze E, Bulpitt CJ and Fletcher AE (2005) 'Are older people dying of depression? Findings from the medical research council trial of the assessment and management of older people in the community' *Journal of the American Geriatric Society* 53, pp.1128-1132

[116] Nollett CL, Bray N, Bunce C, Casten RJ, Edwards RT, Hegel MT, Janikoun S, Jumbe SE, Ryan B, Shearn J, Smith DJ, Stanford M, Xing W and Margrain TH (2016) 'Depression in Visual Impairment Trial (DEPVIT): A Randomized Clinical Trial of Depression Treatments in People With Low Vision' *Investigative Ophthalmology and Visual Science* 57.10, pp.4247-4254

[117] Covinsky KE, Fortinsky RH, Palmer RM, Kresevic DM, and Landefeld CS (1997) 'Relation between symptoms of depression and health status outcomes in acutely ill hospitalized older persons' *Annals of Internal Medicine* 126, pp.417-425

[118] National Institute for Health and Clinical Excellence (2010) *Depression in Adults With a Chronic Physical Health Problem: Treatment and Management* NICE Clinical Guidelines No. 91: London

established via systematic review of 13 studies implementing HRQoL and depression measures in studies in visually-impaired populations. Comparison of HRQoL scores between participants with and without depression (Cohen's d) and correlations between depression and HRQoL (Pearson's r) were examined. The evaluation revealed that lower health-related or vision-related HRQoL was associated with greater symptoms of depression.[119]

3.2.7 OUTCOMES OF INTERVENTIONS

Psychological interventions such as self-management programmes and problem solving treatment incorporated into low vision rehabilitation to potentially reduce depression in visually impaired older adults is based on the notion that functional ability and depression are closely related in this group.

The results of the DEPVIT study[99] indicated that problem solving treatment and referring people to their physician achieved higher scores on the Beck Depression Inventory measure than doing nothing for the treatment of depression in people with low vision, however, the results were not compelling and attributed to potential flaws in treatment delivery. Yet, the results of this trial added to those of other similar trials recently published, for example, on a stepped care approach, which comprised watchful waiting, guided self-help based on cognitive behavioural therapy, problem-solving treatment, and referral to a general practitioner significantly reduced the risk (relative risk 0.63) of a depressive dysthymic and/or anxiety disorder at 24 months. Investigators suggest that 'stepped care' seems to be a promising way to deal with depression and anxiety in visually impaired older adults which could lead to standardised strategies for the screening, monitoring, treatment, and referral of visually impaired older adults with depression and anxiety.

An online survey of the provision of emotional support and counselling for people affected by sight loss was recently conducted;[120] their aim was to evaluate the need for a national standardised framework for the provision of emotional support and counselling services for the blind and partially sighted people in the UK. The sample comprised voluntary sector organisations and parts of the NHS across the United Kingdom. The survey revealed that services providing counselling relied mostly on self-referral; emotional support was most likely to receive referrals via self-referral or via an eye clinic; and services providing both counselling and emotional support similarly received the majority of their referrals via these routes, and also via vision rehabilitation officers. While numerous unmet needs of the visually impaired were revealed, the investigators concluded on a clear need for both emotional support and counselling to be available at both, the point of diagnosis as well as when needed and as such "embedded into the sight loss care pathway". The investigators also noted that for these needs to be met, collaborative working among all professionals supporting people who are affected by sight loss, from GPs to ECLOs to ophthalmologists was clearly warranted.

3.2.8 PSYCHO-SOCIAL OUTCOMES ON CAREGIVERS

The wider psycho-social impacts of visual impairment have been shown on caregivers. Reviews of the

[119] Renaud J and Bédard E (2013) 'Depression in the elderly with visual impairment and its association with quality of life' *Clinical Interventions in Aging* 8, pp.931-43

[120] Pybis et al (2016), op. cit

literature on caregivers for the visually-impaired has revealed demonstrable association of depression and burden with communication theory, emotional contagion, and care burden. Caregiving is also associated with greater hours of supervision to the patient, multiple chronic conditions in the patient or caregiver, the patient not completing vision rehabilitation, and female gender of the caregiver cited as implicating factors.[121] By identifying those at risk for decreased HRQoL outcomes, health care providers may be able to alter the management of the visually impaired, such as advocating the use of vision rehabilitation clinics in order to minimize the caregiver burden and depression.[122]

3.2.9 RESOURCE USE AND COSTS OF PSYCHO-SOCIAL FACTORS

Estimates of overall resource use and costs in the UK directly related to psycho-social factors of visual impairment are limited. However, the DEPVIT study measured total health and social care costs, incurred by those in the treatment waiting-list, referral, and problem solving treatment arms of the trial during the 6-month study period and found them to be,£1444 (Standard Deviation £1941), £1362 (SD £1842), and £962 (SD £1051), respectively. Furthermore, the treatment of vision-impairment associated depression via problem solving treatment ranged between £1176 in Wales and £1296 in London (see Table 3.2).[123]

In the 2013 study of the forms of provision and cost of ECLO services,[124] while depression *per se* was not captured or evaluated, it might be inferred that the emotional support provided by ECLO services (as absorbed in the time and costs of the service) addressed the needs of patients with depression. An estimate of £17.94 per patient per ECLO contact was reported; furthermore, approximately £247.76 for ECLO intervention over a person's lifetime was estimated for proportions of people registered as severely sight impaired at each age group, assuming an ECLO is seen once per year. The literature also points to some indirect costs of depression, in terms of the impact on vision care and costs thereof, particularly for age-related macular degeneration and diabetic retinopathy. It is suggested that increased healthcare costs via reduced treatment outcomes are due to the negative attitudes toward and related lowered adherence to treatments caused by depression.[125]

[121] Kuriakose RK, Khan Z, Almeida DR and Braich PS (2016) 'Depression and burden among the caregivers of visually impaired patients: a systematic review' *International Ophthalmology* July 29

[122] Ibid.

[123] Nollett et al (2016), op. cit

[124] Gillespie-Gallery H, Subramanian A and Conway ML (2013) 'Micro-costing the provision of emotional support and information in UK eye clinics' *BMC Health Services Research* 13.482: DOI: 10.1186/1472-6963-13-482

[125] Chen X and Lu L (2016) 'Depression in Diabetic Retinopathy: A Review and Recommendation for Psychiatric Management' *Psychosomatics* 57.5, pp.465-71

TABLE 3.2 · Mean NHS and Local Authority Costs (£) (over 6 months by group)[126]

Health Care Service Use	Control (n=27)*		GP Referral (n=26)*		PST (n=22)*		PST vs. Control†	PST vs. GP Referral†
GP consultation (surgery)	156	(271)	138	(129)	122	(119)	-34	-16
GP consultation (home)	10	(32)	4	(14)	49	(209)	39	45
Practice nurse consultation	25	(58)	24	(76)	43	(67)	18	19
Primary care antidepressant prescribing	1	(4)	3	(11)	<1	(1)	-1	-3
TOTAL PRIMARY CARE	**192**	**(303)**	**169**	**(137)**	**214**	**(222)**	**22 (-124 TO 162)**	**45 (-48 TO 158)**
Community health workers‡	124	(642)	353	(1302)	212	(908)	88	-141
Mental health support services§	0	(0)	71	(172)	20	(94)	20	-51
Occupational therapy	3	(11)	2	(5)	4	(14)	1	2
Social services	21	(63)	74	(202)	51	(159)	30	-23
Physical rehabilitation services**	33	(116)	36	(94)	43	(136)	10	7
Other	21	(30)	214	(930)	85	(235)	64	-129
TOTAL COMMUNITY SERVICES	**202**	**(761)**	**750**	**(1540)**	**415**	**(948)**	**213 (-273 TO 705)**	**-335 (-1066 TO 349)**
TOTAL LOCAL AUTHORITY DAY CARE SERVICES	**68**	**(351)**	**38**	**(194)**	**0**	**(0)**	**-68 (-248 TO 89)**	**-38 (-404 TO 267)**
Ophthalmology inpatient	0	(0)	0	(0)	75	(351)	75	75
Ophthalmology outpatient	138	(385)	110	(232)	103	(168)	-35	-7
Low vision assessment	30	(49)	7	(24)	20	(47)	-10	13
Inpatient (other)	601	(1824)	166	(601)	0	(0)	-601	-166
Outpatient (other)	202	(371)	107	(158)	128	(228)	-74	21
Day case (other)	0	(0)	15	(76)	0	(0)	0	-15
Accident and emergency	11	(41)	0	(0)	4	(20)	-7	4
Therapy/counselling services	0	(0)	0	(0)	3	(12)	3	3
TOTAL SECONDARY CARE	**982**	**(1826)**	**405**	**(622)**	**333**	**(583)**	**-649 (-1421 TO 4)**	**-72 (-404 TO 267)**
TOTAL SERVICE USE COST AND INTERVENTIONAL COST	**1444**	**(1941)**	**1362**	**(1842)**	**1775**	**(1044)**	**331(-554 TO 1099)**	**413 (-439 TO 1193)**

[126] Taken from Nollett et al (2016), op. cit PST = problem solving treatment. All costs rounded to nearest £.* Reported as Mean (SD). † Reported as mean difference (bootstrapped 95% confidence interval, where appropriate). ‡ District nurse or health visitor. § Psychologist, therapist or counsellor, or psychiatric nurse. ** Physiotherapist or chiropodist, dietician, optician, dentist, or meals on wheels.

4 QUALITATIVE FINDINGS

In this chapter, we will outline some of the main findings from the qualitative work carried out as part of the research. We will also seek to illuminate two fundamental questions, namely:

- How does the ECLO 'value add' for a service and for the patient?
- What is the impact of an ECLO on clinic activity?

We will attempt this through exploring the main themes generated in the interviews and which formed the basis of our coding of those interviews, our thematic framework. We will use extensive quotation throughout, because we feel it is important to hear the voices of those who gave their time to our research, and were often very passionate about the way they saw the ECLO role in their local context. However, we have restricted the details of who said what (and where) to the generic job title of the interviewee, thereby preserving anonymity but also extracting as far as possible the general from the local context of what it means to be an ECLO.

That said, the local context here is key to an extent, because a qualitative framework will evidently produce a different form of data and analysis from the quantitative work that forms part of this report. This evidence, by its very nature is contingent, locally based and often reflects the extensive professional expertise that the local health and social care systems offer across the nations and regions of the UK. Our evidence base is the words given in the accounts, the lived experiences of those who were interviewed; but these words were spoken by as wide a pool as possible of ophthalmologists, nurses, rehabilitation officers for visual impairment (ROVIs), commissioners, optometrists, clinical leads, consultants, support workers, volunteers, managers, health care assistants– and of course the ECLOs themselves.

Undoubtedly, some interviews stood out for us as we became more familiar with the field, and developed a feel for the subject matter: many of our interviewees were very articulate and passionate about the role of the ECLO. Though we had a semi-structured interview schedule, we felt that it was important to let the interviewees speak at length when they wanted to, though the time pressures in a clinical environment can preclude this. However, we are as confident as it is possible to be that through our months of analysis, we have found enough consistent categories and themes to give a meaningful response to the research questions as posed, and provide a substantial picture of the growing importance of ECLO practice in all its forms.

Given the size and breadth of our sample – 141 interviews across 30 sites in four countries – we're confident also that we've been able to capture the dynamic nature of ECLO practice in these local contexts. We've attempted to give voice to those everyday practitioners within the multiple systems and frameworks which ECLOs operate, and hope that we have listened as closely and as systematically as possible to what is being said. As experienced field researchers in health and social care, we are not 'neutral' - we bring our own fields of expertise to this – but we've sought to look with fresh eyes at what is familiar to those lived professional experiences in each site.

We would also like to bring attention to how we refer to possibly the most important people not in the data to an extent, namely the people who are living with sight loss. Having discussed this as a team, we

will refer to them in this chapter as 'patients' but also 'patient/citizens' interchangeably, as we felt that a key aspect of ECLO practice was the support they give to people who cannot be thought of as purely subjects of medical care. In fact, this is a major point of definition: we felt that ECLOs offer a way of continuing care as people who are visually impaired often have to navigate a new set of frameworks, rights and entitlements as visually impaired citizens, outside of purely medical care.

4.1 METHOD AND APPROACH TO ANALYSIS

In this section, we will outline our approach to the qualitative data collection and analysis. In total, 141 interviews were completed the length and breadth of the nations and regions of the UK, with a wide range of practitioners, not least ECLOs themselves. The fieldwork was completed over 12 months, and we visited 30 sites during the study.[127]

We devised a topic guide which would orientate each researcher without being too prescriptive, and which we felt would set out to answer our key questions. The practicalities of fieldwork were such that the researchers often had to be able to interview in clinical environments, which were by their very nature very busy; although many interviews were pre-arranged, we were keen also to take opportunities, where possible, to speak to as many members of a clinical team as possible in each site. We felt that this snowball approach meant that, on occasion, we were able to speak to more people and gain more insights as to the worKing's of a given site.

Once collected, interviews were transcribed verbatim. To manage such a large qualitative dataset, it was decided to use NVivo 11 software, using a framework analysis approach[128] that by now is commonly used with such large qualitative datasets. This method takes into consideration pre-identified issues that the researchers wish to investigate in accordance with the research questions, but allows flexibility for new themes.

We felt the framework approach was appropriate to help us explore the data as systematically as possible, given the multiple contexts and number of researchers who did the fieldwork and analysis, and the sheer amount of data that was generated. Getting the interpretation right, when such qualitative data is so voluminous and discursive, meant that the team had to maintain an analytical dialogue throughout. In this way, the subsequent construction of the thematic framework and other stages of analyses were agreed by all authors.

4.1.1 THE FRAMEWORK PROCESS

In essence, framework analysis seeks to condense the sometimes unwieldy amount of thematic coding that can be generated when we look at so many interviews. By doing so, it helps to clarify the key themes which emerge, and to compare cases across those themes. NVivo 11 has a built in facility to aid

[127] As noted in Section 2.4, Interviews with patients were not undertaken as part of this study given that at the outset of the work RNIB stated that they had collected much qualitative data from patients. Instead they wanted to prioritise gathering the views of those professionals who interact with ECLOs.

[128] Ritchie J and Spencer L (1994) 'Qualitative Data Analysis for Applied Policy Research' in A Bryman and R Burgess (eds) *Analyzing Qualitative Data* London: Sage, pp. 173-194

this approach, but we were keen not to be over reliant on the software; analytical memos, field notes and mind maps, often separate and on paper were used in combination with the data management tool. However, the five stages of analysis used in the framework approach are usually:

1. **Familiarisation** - gaining an overview of the literature, research objectives and data (including proposal, literature review, interview topic guides, sample characteristics, interview and observation and themes found in the interview transcripts). Around thirty scripts were read at this stage with direction given from the interviewing team. Codes and themes were developed using a combination of software and paper-based notes. We also double coded some interviews, using more than one researcher, so that we could check for consistency of interpretation.
2. **Identifying a thematic framework** - this was constructed from the codes and notes developed in the familiarisation stage. This was then verified with the rest of the research team in terms of relevancy and how far the themes would answer the research questions.
3. **Indexing** - systematic coding of all interview transcripts using the thematic framework. Indexing can be done manually or by using a qualitative software package to code sections of data against the thematic framework. Indexing was carried out at this stage using the software.
4. **Charting** - creating a set of thematic charts for each theme using a matrix format, using the software. Within each matrix, each interviewee is assigned a row and each sub-theme is allocated a separate column. The data were further condensed, linking the coded data to a synopsis. As noted, this stage allows researchers to identify any recurrent themes across the dataset, and add to any analytical notes for the final interpretation of the data. It also becomes apparent at this stage which themes are redundant or can be amalgamated with others.
5. **Mapping and interpretation** - reviewing the charted data and analytical notes, comparing and contrasting participants' accounts, identifying patterns and connections in the data and seeking explanations for these within the data. As in previous stages, the findings of this stage are shared across the research team.

As will be explored in the next chapter, the key categories which we identified from our dataset were: Capacity, Relationships, Patient-centred and Skills and Knowledge, and within each one of these, there were further themes which we will also explore in that chapter.

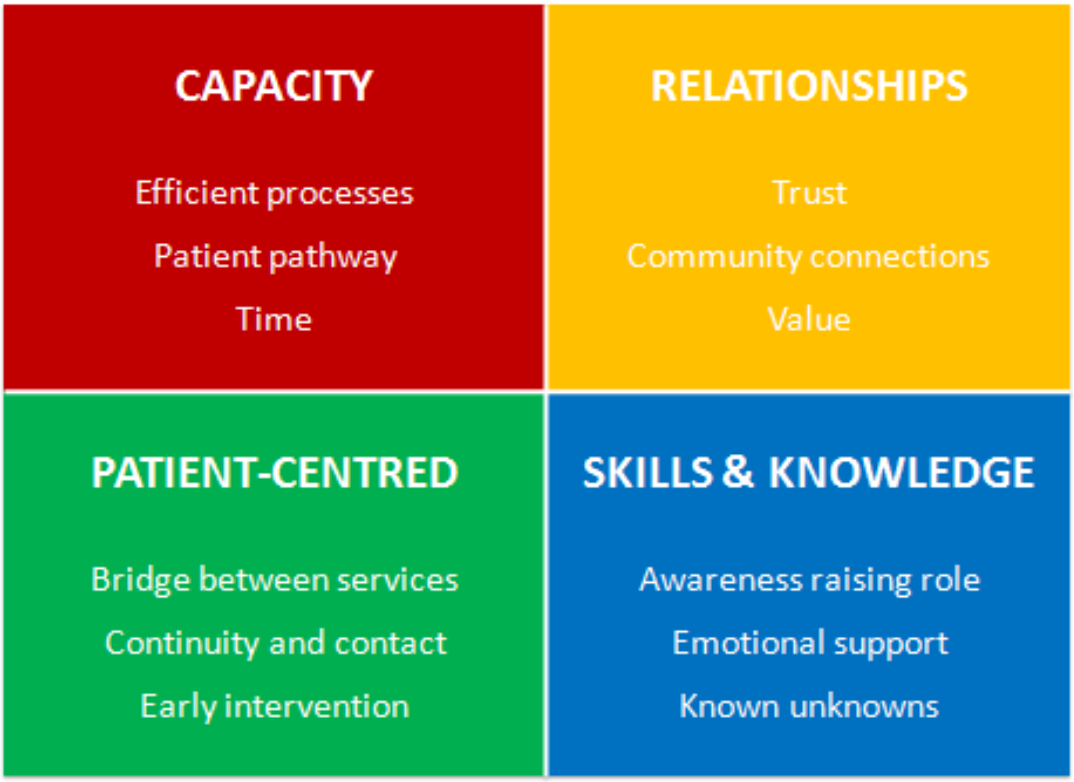
4.2 FINDINGS BASED ON THE THEMATIC FRAMEWORK

These constitute the main findings which came under the four most prominent categories in our coding framework, which evolved throughout the research project, namely Capacity, Relationships, Patient-centred and Skills and Knowledge. Using the framework analysis approach, we developed our coding framework as systematically as possible. This included double coding some interviews – having more than one researcher code the same data – to make sure our categories are as grounded as possible in the accounts given by our interviewees, and to try and achieve a degree of consistency in a task which is necessarily about the interpretations of each researcher.

From the initial ‘free’ coding and familiarization stage, which generated many themes, we then reduced the data to the essential ones we felt were relevant to our research questions. After further coding, it

became apparent that some of these themes were either redundant, or could be amalgamated with others.

FIGURE 4.1 · Coding framework - summary[129]



As noted, the corpus of interviews used for analysis is large, another reason for using the framework analysis approach as a means of managing it all. Our analysis ran alongside the data management from the start. Field notes, analytical memos and mind maps were all used to help interpret what was being said, as we took into account factors such as time, place, busyness of the clinic etc. Through regular meetings, we maintained lively internal discussions about interpreting the data throughout the project. We therefore feel confident that we are providing as accurate a picture as possible of the data, but furthermore, we have sought to interpret what was seen and heard through our own 'lenses' of academic, professional, expertise.

So in this chapter, we will explore the main categories included in our coding framework, and we've highlighted the most relevant themes in each one.

4.3 CAPACITY

> *'They're like a little cog that makes all the others spin. They're a central link that the patient can go to and the ECLO can start all the other cogs spinning for them' [Operations manager]*

[129] It is important to note that when we talk about 'efficiency' in this chapter, we do not mean it in the technical sense of reducing waste and time as we will be used in chapter 5. Rather it is used here in the sense that respondents meant – as a general way of describing the ability to do things well, successfully and in a more streamlined manner.

This category encompasses the myriad of ECLO practices that seem to be common and everyday within clinical and other services, and which ECLOs might be reasonably expected to perform. The themes that became apparent under this category include questions about how ECLOs affect the capacity of each service: whether or not they add or subtract from that capacity in each clinic or service to work in the most efficient, patient-centred manner, and what are the effects ECLOs have on fundamental issues such as CVI registration, or the various pathways that have to be negotiated by patients.

We examined issues such as time-saving or identifying the complexities of the various pathways, as well as the more systems-wide position of the ECLO, recognizing that they often act within more than one dynamic system e.g. clinical and social care, and act as a critical point or node of bi-directional information between various communities of practice.

As we discuss in chapter 6, it would seem that ECLOs often have both networked power and networking power, the former being the means to enact, interact and facilitate core aspects of the 'care' system for those losing their sight, such as completing the CVI process. The latter, networking power, would be the use of tools such as referral and signposting to activate other relationships across the various networks in which ECLOs operate, and in which they are important nodes. We also coded for feedback given by others about how they perform or are perceived within these systems, as well as how integrated the ECLOs felt they were within the systems.

4.3.1 THE CVI PROCESS

> *'Historically people would be told I'm registering you blind today, you're losing your eyesight and they just go home. I can't bear to think of anybody doing that and not knowing that there's tons of help out there. I'm thankful that I do have all these services to pass people onto' [ECLO]*

> *'Everything's now filled out properly and there's proper processes in place for everything and that is really important especially for the doctors. That's because they can get on and see patients quicker, so they can register the patient and then any patient that patient wants to ask they can go straight to [the ECLO] and she can take them away from the doctor and the doctor can get on with his patients' [Senior Nurse]*

> *'You often would find in the olden days piles of CVIs waiting in the consultant's office – that doesn't happen anymore' [Head of Optometry]*

> *'…how could the secretary fill that in if they don't have any patient involvement?' [ECLO]*

ECLOs have made CVI processes more efficient compared to previous systems that were in place. As noted already, the process of registration for CVI is probably one of the most fundamental practices in the eye clinic, one that is often life changing for the patient. Our research would suggest it is increasingly carried out by ECLOs, wherever they are: they would seem to be taking the bulk of the administrative burden.

Furthermore, many of our interviewees, professionals working alongside ECLOs (e.g. managers, ophthalmologists, consultants), reiterated that ECLOs seem to have 'sorted out' the CVI pathway, in a comprehensive manner, in many of the sites visited. Repeated accounts were given of how the CVI process had previously been severely blocked in many places. We heard of *'piles of CVIs waiting to be processed'*, or other inefficiencies such as people *'slipping through the system'* e.g. driving when they

shouldn't be, or not being assessed at home – potentially therefore putting others at risk. With an ECLO in place, we heard that many of these problems simply don't exist anymore.

In several areas, it was suggested that without ECLO support, this process wouldn't get done in a timely way, which apart from the risks highlighted above, also had implications in terms of getting the appropriate support for things that can make a real difference in people's lives, such as finances, for example. We heard how ECLOs in clinics often facilitate the smooth running of the CVI pathway in practical ways, right from the start, by making sure the doctors have the right forms, or by flagging up registration requests which haven't happened. Often, it is an ECLO who completes the majority of the form, thereby saving time for others in the clinic.

We also heard that in some places, they can initiate the CVI process, though more often than not, they get them through referrals. In some places, other staff or volunteers help with this process also.

Equally importantly, it would seem that ECLOs have more time to explain the significance of the document clearly – it is seen as an opportunity to kick off and consolidate support, in what can be an emotional process for the patient. Crucially, ECLOs are also more likely to follow up on the process, including setting up any further support from that point onwards e.g. with social services or others. When there are perceived blockages in this system, we heard accounts from people from within and outside the team e.g. ROVIs, that they turn to the ECLO for help; in many localities they are the trusted first port of call. By taking more time to explain the process, we heard how this reduces the stigma felt by some, especially older patients, if there's a referral to social services.

It is useful at this stage to reflect on the nature of the findings above, and that follow. There was a clear view among participants that ECLOs have made a significant contribution to the efficient running of clinics, but (as will be seen in chapter 5) hard metrics to evidence this are difficult to control for, measure and attribute. We would assert though that a near universal qualitative finding from our participants that efficiency has been improved by ECLOs is compelling.

4.3.2 TIME SAVING

> *'[Before] the person could sit there with no contact at all, on this waiting list, for, you know three months, six months, nothing….What the difference is that the ECLO has been in my opinion, is it's caught a lot of people before certification. And they've had contact… she'd put in a referral, 'oh I've referred, I've had a conversation with a lady, she's agreed for it to be a referral to yourself, but what I've done as well, I've made a referral to raise with regards to benefits'… So that kind of rehabilitation sometimes has actually started already, and then the person comes to us, and then they sit you know three months on the waiting list, but that rehabilitation process and connection, in my opinion, has actually started' [ROVI]*

Many of our interviewees were convinced that having an ECLO in post saves a lot of clinical time. We heard this from clinical managers, matrons, nurses, consultants and others, and it is a theme that appears throughout this section, not just as a standalone theme here. As commented on above, these proved difficult to measure in a quantitative sense (see chapter 5 below), but are no less valid as findings for having been established qualitatively.

Generally speaking, many interviewees acknowledged that they save time primarily by taking pressure off the medical staff, who themselves are often under pressure to move people through the system quite quickly, more so with ever tightening budgets. ECLOs also do a lot of follow up e.g. phoning patients months later to see if anything's changed. As one interviewee pointed out '*it releases some of the time for the trained staff to do what they trained for'.*

Some ECLOs are even able to order equipment and post it out directly for people, so people are able to get things they need quickly instead of waiting. We also heard how they save time *outside* the clinic – initial contact from ECLO, working closely with a patient can facilitate further work by ROVI, making it quicker and easier, for instance.

4.3.3 EFFICIENT PROCESSES AND PATHWAYS TO CARE

> *'I would suggest to people that ECLOs have an impact on the throughput of a clinic and allow us to see as many people as possible, and also that given the very positive feedback we've had about their support, that there is a direct service quality and patient benefit argument for having one in any clinic' [Consultant Ophthalmologist]*
>
> *'So it definitely does have an impact on the smooth running of the clinic and that's how it saves money. I think falls is a classic example, because falls do come with poor sight and most of these people have falls, apart from being frail and drugs they may be taking, poor vision is a huge contributory factor' [Clinical Lead]*
>
> *'I think the ECLOS have a fantastic role in that they take away the patient from the clinical side…where the treatment has been given or terminated or could not be completed for one reason or other…and they get them prepared for life after. So from being sympathetic as to what their clinical condition is they quickly move onto what is available and accessible outside…and also what is available here in the hospital…' [Consultant Ophthalmologist]*
>
> *'…[referring to an ECLO] it's not the case of passing the buck, it's about putting the patient in the right place for the right reasons at the right time – that's how it works' [Orthoptist]*
>
> *'I think that it's a poor service without an ECLO, having someone 'on tap' makes a big difference' [Consultant Ophthalmologist]*

Overwhelmingly, most interviewees believe that ECLOs contribute to the smooth running of eye clinics. They would seem to enhance efficiency within clinics and streamline processes to release capacity, not only through the CVI process as outlined, but by referring and signposting appropriately and according to the needs of patients, in a timely way.

As we have already pointed out, many interviewees are of the opinion that time is also saved for other staff through ECLOs taking ownership of the CVI process. Inappropriate referrals are avoided. In more than one account it was stated that if there is early engagement with patients (e.g. pre-CVI), people will impact less, further down the line. Part of an ECLO job is early intervention and prevention, not waiting until the patient is registered.

Without the ECLO, the system slows down to the sum of its parts. In some places that operated without an ECLO, we heard of staff at times struggling to keep up with the emotional and support requirement of patients, and being unable to offer the kind of specialized advice e.g. around benefits, which ECLOs

often give. Any advice given was 'ad hoc'. For many sites operating without an ECLO, it was suggested that having an ECLO would vastly improve their service; some were in the process of recruiting, and we talked to consultants who were looking forward to having one as part of their team.

Some interviewees indicated that ECLOs also could have a positive effect on pathways such as falls care, for example. Several anecdotal examples of this were given, but ECLOs in various localities were also involved in glaucoma care, diabetic or pediatric pathways.

However, falls is a major area of concern and cost - proactive ECLOs probably have an effect on this primarily by registering people at the right time, but also raising awareness among clinical teams of what the ECLO service can do to help e.g. among junior doctors. We heard how fully embedded ECLO practice helps clinics to function better by linking to outside world and the services available locally. Often other members of clinical teams are not as aware of processes and support available in the outside the clinic e.g. the role of ROVIs, or right and entitlements in the welfare system.

We noted in several interviews that ECLOs often work well with ROVIs, through good efficient communication, joint working, shadowing roles, and ultimately being able to give people an all-round care package that extends into their lives outside of the clinic. This relationship also works in terms of queries and scrutiny, a way of checking the quality of service as a whole: if there is a blockage in terms of registration, for example, we heard repeatedly how ECLOs sort things out. It is a natural feedback loop between systems.

It was noted that, according to our interviewees, when it is difficult to convey all the information around diagnosis, often because of time constraints, ECLOs communicate more effectively. They often link the patient to the community support needed in a timely way. They also often have an advocacy role for the patients within the pathways, especially relevant in large hospitals, with patients potentially on several different pathways.

4.3.4 FEEDBACK AND HOLISTIC SERVICES

> *'We used to say 'sorry there is nothing we can do for you' – now we can send them to [the ECLO] for support. We have a moral duty to give patients the best possible treatment and it's nice to give them something positive in the form of ongoing support from the ECLO' [Consultant Ophthalmologist]*
>
> *'When we refer them to you [the ECLO], it means we haven't finished with the patient and it means that we don't have the expertise…' [Consultant Ophthalmologist]*
>
> *'In the low vision clinic sometimes the barriers are down a bit more because you really are getting into people's proper world, but I feel because of the confidence I've got in the ECLO, we can relax a bit and dig deeper knowing I can follow through' [Orthoptist]*
>
> *'If the ECLO weren't here and I was being thick-skinned, I'd say that the impact on me wouldn't be very much. I'd spend all the time I had available with patients and then it'd be out the door and off you go, and to say to patients "if you have any questions, ask me at the next clinic". From my point of view that would be a very incomplete service – patients at least need to be much clearer about what they can do, and how to live their life after they walk through the door, and that's the big difference that the ECLO can bring' [Consultant Ophthalmologist]*

As we are already indicating, when asked, most feedback given about ECLOs in our research were positive, either from clinical colleagues or other outside partners. Nevertheless, some of the ECLOs interviewed were also very keen on trying to evaluate their own services, primarily to make sure that they were giving people the service that they need, but also to make sure that funders knew what they were getting locally.

However, it was noted that there is no overarching evaluative framework or national standard by which they can measure this as yet. Some ECLOs have carried out patient satisfaction exercises in the past, though certainly not all. Many are keen to be able to evaluate own services to maintain funding and justify service levels.

As noted also in the previous theme, within the system(s) that they operate, it could be argued that ECLOs, in conjunction with others also act as a feedback loops e.g. linking Social Services and clinical teams, but also able to spot any potential problems through the often close joint working that they do, and their extensive knowledge of the local eye health network.

It was also pointed out in interviews that people are at most need of support when there's no more clinical support to be given, and this is often what ECLOs provide. By doing this, many of our interviewees believe that the presence of ECLOs in clinical eye services makes them more of a 'complete' service, in contrast to pre-ECLO times where there was less support, and the support was less structured when offered. Joint working e.g. with ROVIs is far easier, so looking at a more integrated model of health and social services for visually impaired citizens, ECLOs are key to delivering some of this.

4.3.5 TIME TO TALK

> *'We've given her a slot [in the Bardet-Biedls syndrome clinic] as part of our ophthalmology slot, so that even if it is just to introduce herself or if there's something that they need that we pick up on, she's got that time allocated within the clinic programme to actually have a consultation which is really good' [Clinical Nurse Specialist]*

Giving patients time to talk and get used to their diagnosis is a key function of ECLO practice. Most interviewees recognize this, and this was a comment made by many across the nations and regions. Many skilled ECLOS will be able to talk to patients about anything and everything which might worry them in terms of work, how they'll manage etc. and understand the deep emotional need for this, to '*enable people to live life after they walk out of the door*'. However, in this category, it should be understood that by giving this time to talk, an ECLO also releases capacity, allowing other clinical staff to carry on with their tasks i.e. see more patients.

4.3.6 INTEGRATION AND NEED FOR ADDITIONAL ASSISTANCE

It became apparent in interviews that some ECLOs often feel more integrated in teams when they are funded by NHS. Some already come from nursing backgrounds, and work part-time as an ECLO, so already feel integrated in clinical services. For many ECLOs there is a constant need to remind clinical colleagues of the existence of the service.

In some clinics, as demand has grown, some ECLOs felt also that they needed some additional assistance to keep up with administrative work. In many areas, the very success of the service has meant that

demand for it has grown also; ironically, what was once, in some senses, an additional service assisting more clinical services, now needs assistance in some places because it's reaching capacity. We heard of volunteers providing this in some places.

4.4 PATIENT–CENTRED

'We fill the gap where patients used to fall, and give them the help to remain independent' [ECLO]

Another major category developed in our data was that of 'patient-centred' practice. By being 'patient-centred', there is slight shift in emphasis in ECLO practice, where the focus is on the need of the patient/citizen rather than the needs of the service. It could be argued that giving time to talk to patients could also fall under this category: the very act of doing so not only has implications in terms of day to day capacity for a clinic, but also in providing a more holistic service for the patient, where all the needs are met as fully as possible. If one of the fundamental ECLO domains is that of planning for the future of people who are visually impaired, then their role as enablers, in developing emotional resilience once people lose their sight, is an important one. The themes developed here also take into consideration once more where the ECLOs sit in relation to other services.

4.4.1 BRIDGE BETWEEN CLINICAL AND NON-CLINICAL SERVICES

'I'm a bridge between the health service and the wider world – whether that's on social care or voluntary sector groups or whatever it is. Financially I think if we can catch people early and support them, I think they won't then be a drain on the external services quite as much. It's difficult to build that argument though – there isn't a robust case that I'm aware of to be honest' [ECLO]

'She [the ECLO] has got much more access to social services which before I'd just literally be phoning up and trying to find the appropriate person and she has all this at her fingertips where she knows someone that can help' [Clinical Nurse Specialist]

ECLOs are clearly the bridge between services both within the clinical environment and services outside of the hospital, and this is a key practice – linking the health service and the wider world – whether that is to social services, social care, local sight loss charities or other voluntary sector groups. By linking services together, this benefits patients, their families and carers. It also enables care to continue once medical options have been exhausted. Above all, we found in our interviews that ECLOs give practical support – each one will be different in how they do it - but at base they will always link them up with other people and services. To an extent, an ECLO will be as good as their network of connections allows them to be, and their network will constantly be evolving and changing.

As we have seen, there are clear examples of when the ECLO takes over in the clinic for 'non-clinical' work e.g. certification, but also raising patient awareness around things like the Amsler grid, vitamins. But equally, the work that is needed outside of the clinic is dealt with by the ECLO. One of the prime examples of this is that they are an important point of contact for making sure that benefit issues are dealt with. Previously, without an ECLO in place, we heard how this would often be the responsibility of low vision nurses, but with an ECLO in place they are free to concentrate on their own clinics. We also heard how in clinics that did not have an ECLO, these issues tended to be dealt with in an ad hoc

manner, resulting in poorer outcomes for patients. We would also stress that in a real sense, when we talk of patients, we are also talking of patient/citizens; by being a bridge and support to the outside world, ECLOs often ensure that rights and entitlements of the patient/citizens are cared for.

Many of our interviewees indicated that ECLOs often refer to local rehab officers and sensory teams where available, and that this is often a key relationship locally in terms of the eye health care network. With early intervention and encouragement from the ECLO, rehab officers often get people doing practical tasks early on, so that people gain a gradual awareness of the difficulties they can face. The service also gives support to relatives and carers connecting them to local networks also. They offer support around employment transitions, assistive technology or benefits, as well as emotional support.

4.4.2 EMOTIONAL SUPPORT

> *'The really tough patients, the patients that really need a lot of emotional support, there's no way we would be able to provide it without [the ECLO], no way at all. Thankfully we seem to have a good clinic setup and a good team in that we don't have that many patients where we need to get her involved but it's really useful to know that there's a backup there if someone's very upset, say they've just developed glaucoma and they're not understanding the context that we're putting it in for them then we need [the ECLO] to be the shoulder to cry on' [Optometrist]*
>
> *'I tick emotional support for everyone that I see on the spreadsheet because ultimately that is what we do for everyone, even if it's seems like something quite small, it can help them with their feelings and whether they feel down' [ECLO]*
>
> *'People in need aren't interested in titles or uniforms…they just want someone who is genuine, who is interested in them and will help them whenever they need help' [Ophthalmic Nurse]*

Providing a wide range of emotional support is obviously a key practice for ECLOs. They provide support for patients who are anxious about their condition, even when it's relatively mild, and are able to manage expectations. Many are trained to deal with giving people bad news, and we heard how RNIB courses were an essential part of training to prepare for this aspect of practice.

ECLOs fill that gap in services which meant that people weren't been given enough emotional support previously; we heard in our interviews how this used to be the case, pre-ECLO, and in clinics without ECLOs, the impression was that the time needed to sit with people wasn't there. That's not to say that it didn't happen, just that the capacity was less.

As we have already indicated, ECLOs are able to save time of other staff by 'mopping up' the emotional support needed by patients. Psychological adaptation to visual impairment is often compared to the grief process, but people often need some kind of emotional support as they have to navigate other administrative processes and frameworks also. We heard of ECLOs helping out with the work of applying for benefits, and getting more support in the outside world.

But by having an ECLO in the clinic, when people are really upset, we heard several accounts of how the ECLO takes over, which both clinicians and ECLOs perceive saves time in the clinic and gives the clinicians permission to move to the next patient. We heard how people who are anxious about their condition are referred to ECLO immediately in many clinics, and that they will often sit with a patient as long as it takes if they're upset: this is accepted practice in many clinics. Eventually, they also offer

signposting to other emotional support, but that initial support and the fact that they provide time and space for a detailed conversation in the clinic is very important.

In addition, by being able to explain and interpret the diagnosis, on occasion we heard how they're also able to calm things down when the communication is difficult between the clinician and patient. An ECLO, herself sight impaired, described how it's fundamental to make people realise that they are not alone, right from the start: *'that it's not the end for them, it's the start of a new part'.*

4.4.3 DEVELOPING EMOTIONAL RESILIENCE AND ENABLING

> *'It's the quality you can bring to a patient's life I think, the quality service, a way of life, a coping strategy. It is just a good experience, an all-round experience, and it is part of our patient care, and it enhances the patient experiences and enhances their lives I would say' [ECLO]*
>
> *'The practical support is just that – the things that we do like writing letters, or making phone calls, or linking them up with people and services. It might be showing them equipment, and I only do a very basic demonstration of the basics. You see again, every ECLO is different as to how they do it, so I don't make too much of this – I touch on some of the household stuff, but I don't go anywhere near the equipment that needs to be prescribed. I'm not an expert in that so I leave it to the people who prescribe the equipment to show them how it works, like magnifiers' [ECLO]*
>
> *'We have a lot of patients who don't want to have social services involved, especially the very elderly, because they think it's an intrusion and [the ECLO] will have more time to explain to them that they're there to help and it's, they don't have to come to your house and intrude, you know, it's just the help that's there. A lot of people don't know what's on offer' [Clinic Manager]*

ECLOs are enabling in the sense that they help patients to get on with their lives outside of the clinic, and help them develop the necessary coping mechanisms, what is now commonly called emotional resilience. The clinician is able to pass on the patient with confidence - their needs will be seen to as fully as possible by the ECLO, beyond the starkness of the diagnosis and details of the treatment.

Leading on from our previous theme, some clinicians said that they wouldn't be able to provide the emotional support for the 'really tough patients', without the ECLO. In addition, we heard how some patients want to show the doctor that they're doing well, and don't want to feel a burden on clinical time. Having an ECLO in the clinic gives them other options, other types of non-medical support and above all, the space to talk. ECLOs therefore give patients the space to express their emotions about their condition, and then provide the support needed. However, some clinicians acknowledged also that communication is also part of their role, not just the ECLO, and that it shouldn't be a straightforward split between them and the ECLO's pastoral role in that sense: clinicians also need to have the listening skills.

However, we also heard how ECLOs can be enabling on a practical level: we heard how some, with a background perhaps in low vision clinics, were able to help with showing how equipment can be used, with day-to-day, practical tools e.g. bump-ons, technologies which help with living life. We heard that through doing the initial work of supporting patients, they make people more open to further support outside of the clinic, for example, into the helping hand of the ROVI. As one ROVI put it, ECLOs often help ROVI services to *'get past the gate'* i.e. clients will have developed some resilience and acceptance

of condition before ROVI begins helping them. By breaking down barriers, and sometimes the stigma associated with asking for help, they make people more accepting of ROVI help. Some of our key interviews revealed that the relationship between ROVIs and ECLOs can be pivotal locally. Several ROVIs interviewed were of the opinion that ECLOs are a real help to engagement, and they prefer it when the ECLO refers to them, because they can explain fully what ROVIs do:

'when they find out that you're not a social worker, you're a rehab worker and you're there to teach them to stay independent, you find that they will take the service up' [ROVI]

4.4.4 PREVENTATIVE WORK - EARLY INTERVENTION

'You see him talking to patients and hopefully he captures them ideally before they get to the point of registration which is what we want now so when they are registered it's not such a massive thing. Their life hasn't fallen apart quite so much. Before it used to be that people had the information at the point of registration. So now we give them that information so that when they do get to that point their life's come together' [Ophthalmic Nurse]

'In the macular or diabetic clinics I'll have a look through the files and flag people that have got a little bit of reduced vision that could potentially hinder their everyday life. Usually I'll put a flyer in so that the nurses know I'd like to have a chat with them and they'll talk to the patients to say 'we've got Julie here if you're having any difficulties, would you like to have a chat?' If they say yes then they come to me. That usually happens after they've had their visions done and while they're waiting for their scan. They all get given a leaflet so sometimes they self-refer back again at a later date if things change' [ECLO]

'Part of an ECLO job I feel is early intervention and prevention not waiting until the patient is registered. Getting that patient before they get to the registration stage. Getting things in place so that they cope with the visual impairment before they fall and become an inpatient...We felt it was important to say to the doctors we've made contact with every new person should they need it' [ECLO]

'….at the end of the day, I want to be cautious and say 'you're certified', and can always take it back, rather than say 'no, no, no' and then something serious happened' [ECLO]

Many ECLOs are proactive, not reactive, often working to fill gaps and provide the patient/citizen with tools to take things further. We detected an approach from some ECLOs that could be seen as analogous with a 'harm reduction' approach, often found in preventative work in other health and social care fields. We heard, for example, that some ECLOs will look at files in macular and diabetic clinics for people with a bit of reduced vision, and who are potentially experiencing some 'hindrances' – clinics can then raise or suggest meeting with ECLO for more support.

In this sense, ECLOs add value because if they spot a patient earlier (not at the point of CVI), more work can be done to help. We heard several times during our interviews how delays in the system can have knock on consequences for the patient e.g. with mental health, and that early intervention by the ECLO can avoid some of this. At least one of our interviewees was also keen to point out that early registration in the CVI process can have a beneficial effect for some – a 'belt and braces' approach even if the sight loss hasn't completely gone, can enable adjustment and the preventative support to be put

in place: this very experienced ECLO was adamant that this is an approach which saves money in the long term because it lessens the likelihood of falls and other mishaps, which are more costly to the systems – both health and social care.

So by linking to the outside world, ECLOs often facilitate early intervention and rehabilitation, and the 'work' starts before they see the ROVI, for instance. Likewise, getting financial help early, as part of their support, means that things will be easier later on, with less anxiety and associated psychological effects.

4.4.5 MAINTAINING ENGAGEMENT AND CONTINUITY OF CARE

> *'ECLOs mean that you feel that the patient is safer - you pass over to a person who is more specialised to follow up, and it also saves time' [Consultant Ophthalmologist]*
>
> *'You've not left the patient to go home wondering if they're safe, but you pass over to a person who is more specialised to follow it up. Whereas the doctors and nurses they don't have the time and they don't have the skills just for that purpose because there are so many other things clinically to do. If I have a patient, I do encourage them to speak with [the ECLO]. It makes a difference and you feel safer' [Clinic manager]*

Engagement with patients can be an opportunistic process; ECLOs have to be able to improvise and be flexible with the time it takes. This again is analogous with the 'harm reduction' approach we've explored in subsequent themes. Some patients are long-term, and might be on the books for years, others might only be seen the once. An ECLO needs to be there at the precise point when the patient/citizen asks for help, which might be immediately, or because of circumstances or attitudes towards support, later on. Either way, this can be a long-term commitment.

We heard from interviewees that when people find it difficult to accept their diagnosis, often the day-to-day reality of running a clinic is that there's no more clinical time to help them, so it often up to the ECLO to step in. As we've also indicated, ECLOs often reach parts which ROVIs can't: our framework analysis pointed to examples of long-term clients whose sight gets worse suddenly are helped with joint working approaches between both ECLO and ROVI, and of ECLOs who had patients on their books for many years, even though the majority were often helped within months.

Another aspect to this is the follow-up, to maintain that engagement, and many interviewees indicated that it is often the ECLO who does a lot of the follow up work to make sure that care continues beyond the medical care of the clinic. By supporting the patient/citizen early on in their journey, we heard how it then helps other professionals in the local eye health network to maintain their engagement.

Equally important, because of the bi-directional nature of the ECLO within the system, engagement with the world outside of the clinic is made available to the rest of the clinical team: we heard of how many ECLOs were proactive in providing updates on subjects such as changes to benefits, changes to the local voluntary sector provision or any other services available outside of the clinic. We then heard how this can then translate into practical help being offered by the whole team, not just the ECLO.

4.4.6 QUALITY OF SERVICE

> *'Our service would be very incomplete without the ECLO component: people need to know how to live their lives after walking through the door – this is what an ECLO brings' [Consultant Ophthalmologist]*
>
> *'Given the very positive feedback we've had about their support, there is a direct service quality and patient benefit argument for having one in any clinic' [Consultant Ophthalmologist]*

From most of our interviewees, it would seem that ECLOs, where in post, have been a major improvement to services across the nations and regions of the UK. As discussed, ECLOs have a real impact on the throughput of a clinic, and allow clinicians to see more people, the feedback from many clinicians was clear-sighted about the patient benefit argument for having one in a clinic. The major points made in several interviews were that patients are being referred at a better point in treatment, making a difference to their quality of life, and that they free up other resources e.g. the low vision nurses to concentrate on the things that matter - making sure that patients get the right courses according to needs.

Though some services measure this quality through key performance indicators, this is by no means a consistent feature of ECLO posts across the UK. Rather than concentrate on those managerial and accounting features in this chapter, we think that the breadth of experience and expertise in our interviewees speaks the loudest when we've asked about the nature of having a high quality service; barring one or two exceptions, there was almost universal agreement that an ECLO adds to the quality of care offered.

4.5 SKILLS AND KNOWLEDGE

Under our 'Skills and knowledge' category, we were able to look at other aspects of day-to-day ECLO practice. It is a very wide category and encompasses descriptions of a range of practices, from the awareness raising or administrative roles to advocacy and communication with external stakeholders. Again, there are plenty of overlaps with previous themes to be found here, but we feel that this category illuminates aspects that might not be covered elsewhere.

4.5.1 ADMIN AND PAPERWORK

Apart from the CVI process, which seems central to everyday practice, we heard how ECLOs also have a fair amount of administration and other paperwork to complete, both for internal audit and tracking functions but also, more importantly, on behalf of the patient/citizen.[130]

This includes what was called by one interviewee the *'light touch stuff'* as well. Examples included the BT195 form, cinema cards, arranging fire safety checks, blue badges – 'practical' work which gets services, ensures the rights of patients/citizens and enables them to live fully and safely with their condition.

[130] Not all of these processes apply in Scotland.

We detected that there were differences of emphasis in the systems used across the nations, regions and local authority areas, depending on local need e.g. some adapted the way that ECLOs had to record contacts because many of the ECLOs are partially sighted.

We also found that some ECLOs are keen on documenting everything (for audits, key performance indicators etc), and that depending on funding arrangements, we detected that this was in part because they felt insecure: there seemed to be more pressure on some to justify their roles, and this translated into more time taken recording outcomes. However, we also heard very practical reasons for keeping detailed reports, such as having a job share: *it's far easier to hand over to colleagues if detailed records and notes are kept*.

As indicated, the CVI process itself is seen as a starting point for some in terms of getting a conversation going with patients, and we heard how before ECLOs were in place, a large part of this work was done by secretaries. Some ECLOs divided their workflow by having dedicated admin days, as they have a lot of referrals, stats and other paperwork to keep up with. We heard also how some use OneVision, and they maintained that this generated more evidence of activity than others systems they had tried.

4.5.2 ADVOCACY

> *'There's often situations with benefits where benefits have been cut or changed or job issues where things are getting very awkward for the person because the visions failing due to visual field defects and their workplace isn't being overly helpful, so our ECLO is very good with that, she can get involved and help them and get some benefits for them' [Optometrist]*
>
> *'It would be terrible for patients if there were no ECLO. Patients would lose out financially and we don't have the skills for either helping people with their benefits or counselling' [Orthoptist]*
>
> *'What the ECLO service does, is that by actually providing that advice, information and guidance at the point of diagnosis, or deterioration or crisis, they're able to connect people and identify what those maybe critical or urgent at that time and being able to advocate for the patient. To ensure that they get that support rather than just a CVI document being completed and going into the local authority, then being sat in somebody's in-tray because they haven't got the capacity to deal with the weight of referrals because of the budget cuts and the change in their sort of set-up' [Consultant Ophthalmologist]*

ECLOs advocate for patient/citizens on a regular basis. We heard how this could be both within clinical system and pathways – so perhaps sitting with patient when she's talking to the consultant to make sure that they're not too anxious – or outside the clinic. It might be making sure that somebody is registered at the right point, in a timely manner. ECLOs will also advocate in the workplaces of people with failing sight, as well as when benefit issues come up. Because their practice is patient-centred, they often reduce stigma, and ensure people aren't ignored as they try to navigate complex systems and frameworks of rights and entitlements, whilst at the same time going through profound changes in health status.

By helping people to deal with their worries and concerns, we found evidence through our interviewees that they often demystify challenging situations, and encourage people to benefit from the offer of support that exists:

'We have a lot of patients who don't want to have social services involved, especially the very elderly, because they think it's an intrusion and [the ECLO] will have more time to explain to them that they're there to help and it's, they don't have to come to your house and intrude, you know, it's just the help that's there. A lot of people don't know what's on offer' [Clinic Manager]

4.5.3 COMMUNICATION

'Patients at least need to be much clearer about what they can do, and how to live their life after they walk through the door, and that's the big difference that the ECLO can bring' [Consultant Ophthalmologist]

The ECLO role is very much about communication between patient and community as they get used to the diagnosis. Equally, it would seem from our interviewees that good internal communication also part of ECLO role – they often make sure that parts of the eye care team, and the eye care system as a whole, work together. Internal communication between teams is essential to keep up to date with what's going on locally also, and as indicated previously, ECLOs provide that link to local provision and services.

The evidence suggests that there is a very 'embodied' nature to the role of ECLO; it became evident from many of the accounts heard that the ECLO role is a very physical presence in the clinic. We heard how much easier it is if they're physically there in the clinic, not only to help immediately with those who are upset, but to connect the various part of the team. Also, for patients, we heard how it is often essential that ECLOs are able to communicate clearly about the diagnosis, and that some patients were more prepared to talk with ECLOs than the doctor because the ECLO was trained to use language which could be understood by all.

However, we heard from some clinicians that they are anxious that communication isn't something that can be exclusively left to the ECLO and some recognise that they still need to improve their own skills. As part of the advocacy role, ECLOs can also improve the communication that happens between clinical staff and patients, especially if people are upset about their diagnosis.

We heard that high staff turnover in clinics can present a challenge to ECLOs and can sometimes mean that people are unaware of what ECLOs offer, so there is a continual need to educate staff about what they do.

4.5.4 AWARENESS RAISING ROLE

'I'm sure if you can increase awareness and go to departments where there isn't an ECLO and ask them first how do you manage with all this information and do you have the time? I can tell you 99% would say no, we are absolutely stretched but we have to do it or we do it patchily or I just give them the booklet' [Clinical Lead for Ophthalmology]

'It is important to have someone who knows about the patient's condition so that they can give them the appropriate information. Not to take over from the doctor, but to support the patient on their terms' [Consultant Ophthalmologist]

In our interviews, we heard how ECLOs are trained to help people understand their condition, identify problems and signpost them on, and provide ongoing support outside clinic. Fundamentally, they help

people by providing a lot of information, *'tools to take things further'*, and as mentioned, having good communication skills for this is key. We heard how they are often able to explain the eye condition in terms that are understood by patients. We also heard of how they have an important role in the internal workings of teams and training for medical professionals.

Their awareness raising role can be quite varied. For example in some places, the ECLO is part of the induction process for medical staff – in at least one place, this included taking part in the mandatory training on falls prevention for all doctors. Introducing the ECLO is part of the staff induction process can be crucial because *'if you don't make the connections you just won't get the referrals'*. As was indicated in the previous section, *'it needs a constant education to new staff and to keep pressing the message across'*, and this can include activities such as giving blind awareness talks to medics. In some places, we heard that because of high staff turnover, there is a continuous need to *'bang the drum'* about the ECLO service.

We heard also that some ECLOs are very involved in patient awareness initiatives such as how to administer drops, which in some places, meant saving a certain amount of clinical time for others. One interviewee maintained that by explaining the day-to-day reality of processes such as anti-vascular endothelial growth factor (anti-VEGF) treatments, they are able to put the patients mind at ease. Some ECLOs also get involved in awareness raising and facilitation roles outside of the clinic, a form of outreach as well as providing practical help: we heard of several who were running 'Sight Loss' courses in the community, for example.

4.5.5 EXPERIENCE AND BACKGROUND

> *'I was always a nurse, and someone who believed in this but it is hard for ECLOs because we don't all share a common identity. We're not quite like Macmillan nurses but it'd be good if we were' [ECLO]*

ECLOs come from a wide variety of backgrounds. There is a whole range of background in our interviews, from those with nursing experience, to those who have the lived experience of being partially sighted, to others who have spent years in the voluntary sector, working for social enterprises or as Independent Living Coordinators. Some of those with nursing backgrounds still maintained their nursing practice on a part time basis.

A lot have a previous background in working with people who are visually impaired, but many do not have any formal medical background; this is seen as a strength by some, but some ECLOs value the nursing experience, and are still practicing nurses on a part time basis; they also felt that somehow this was more reassuring to patients.

In one or two cases, it was indicated from other health professionals that this was somehow important to them also, that those from a nursing background would be trusted more by clinical colleagues – but this was a minority view.

We heard that most ECLOs have a degree of clinical knowledge but the vast majority aren't formally trained as clinicians. As mentioned, for a minority, having a background in nursing is seen as an important component in the team 'makeup', and gives another way of experiencing the gaps in the system. It is a moot point whether or not this then equips the ECLO with the skills which are necessary to network *beyond* the clinical environment, which as we have seen is a key skill. Either way, many of

those interviewed seemed to have completed a lot of training to become ECLOs in the first place, with some able to add value by being able run things such as low vision clinics, for example.

4.5.6 KNOWLEDGE OF LOCAL SERVICES/ LOCAL KNOWLEDGE

Having good local knowledge of services available in several sectors, and being able to maintain that knowledge through networks, would seem to be a key skill for ECLOs. As we've explored previously, ECLOs act as a bi-directional node, with knowledge about local services coming into clinical teams also through the role. From our interviews it would seem that one of the starting points for the role is to communicate often with the social services in general and rehab teams in particular, and build up some good working relationships.

We will explore this further below, but equally important are the local networks of voluntary sector, community-focused, and advocacy groups. From our interviews with some, it would seem to be that ECLOs need to be in touch with a vast range of services outside of the clinic.

A couple of interviewees pointed out that, in particular, local services for young people were very important as they are often overlooked because the visually impaired population tends to be older, as it was important to have connections to services that help people living with diabetes, or financial help, for those more worried about their bills, for example if they couldn't work as sight loss progressed.

4.5.7 OUTREACH

ECLO outreach services would seem to be more common in rural areas, so it became apparent that not all ECLO practice is based in a single acute hospital.[131] We interviewed ECLOs who could be better described as peripatetic, and who move from clinic to clinic in rural areas as well as those that practice in non-hospital based community settings. This practice can include going out to talk to groups about sight loss, as well as running courses in the community, thereby raising awareness of help available. In contrast, we heard how in some rural areas, services have been brought into a central, non-acute hospital-based clinic, though it was unclear whether this was an attempt to improve services or cut costs. As we indicated in a previous section, some ECLOs try to anticipate future needs of patients e.g. by doing diabetic clinic work, and thereby making sure that people are aware of their services long before they might need it, so they can self-refer if needed. More referrals are generated through the awareness raising/staff training work, as well as through talking to voluntary services locally.

4.5.8 REFERRAL AND SIGNPOSTING

> *'Referrals can come from the staff in this building, from word of mouth, the internet. I get a lot of emails these days from people enquiring about services for their parents. We've just done a presentation with community optometrists last week to try and encourage them to refer. Any avenue we can reach people, that's what we're going for' [ECLO]*
>
> *'It would be a disaster in clinic without the ECLO – patients would not be directed to the proper places' [Senior Doctor]*

[131] It should be noted that for this reason, in Scotland and elsewhere, the term ECLO is not always used – Vision Support Workers or Sight Loss Adviser is preferred in certain places.

Referrals seem to be the most common way that patients come to ECLOs, and for many, a key point of contact, enabling support to begin. As we've already established, ECLOs are very focused on connecting people, so when they get referrals, from whatever source, they often refer on to other services also. Some of those interviewed used the terms 'referrals' and 'signposting' interchangeably, and saw signposting as a form of 'onwards referral' to the appropriate service.

Some ECLOs maintained that the CVI itself constitutes a referral. We heard how ECLOs in some areas receive them through a variety of avenues: through the post, from different clinics, from primary care. Many patients are referred because they're being registered. That constitutes the referral from the consultant that's registering them. We also heard that the ECLO, because of their connections and network e.g. with rehab teams, can often speed up the whole referral system. As discussed, they can act as a feedback loop which discourages blockages in the system: if a ROVI knows that a patient has been referred, but cannot act until the registration is completed, they will contact the ECLO to sort this out.

In general, ECLOs are trained to signpost after helping the patient gain some understanding of their condition and they signpost for a diverse group of patients, from older people with macular degeneration, to young diabetics. What we heard from several ECLOs was that because it's constantly changing, one of the main challenges for ECLOs is to keep up with what's happening locally through their networks, and having strong relationships within those networks is key.

4.6 RELATIONSHIPS

Finally in this chapter, we touch upon the fourth key theme in our framework – that of relationships. Building and maintaining a strong network of relationships with other services both within the clinical environment and outside the clinic with other sectors would seem to be a key ECLO role.

> *'The ECLO isn't just about lending an ear –it's about efficiently liaising with services' [Outpatients Sister]*

In fact, we would argue that ECLOs play a very important role as critical nodes within what could be called the local eye health network; their ties to this network, and the strength of their ties not only provides one of the fundamental ways in which they 'add value' to clinical services, but also helps to integrate and align the care pathway for patients/citizens across different systems.

4.6.1 CONNECTIONS WITH THE COMMUNITY

> *'[The ECLO] communicates between the patient and the community, often when people have had a little time to get used to the diagnosis' [Clinic Manager]*

> *'[The ECLO] gives them information about what financial support, what other services are available, what other support is out in the community as well, it's not just in-house, she has a whole remit out there where she can give patient connections…It's a holistic approach really because not only does she give the visual aids and the internal support, she's got the connections outside as well and she gives a lot of information. And she also helps me with other things in clinics, gaining information for other specialties and things like that' [Matron]*

Having good relationships with local eye health networks is a fundamental part of ECLO practice. This means constantly having to update information about what's going on in the local community or voluntary sector, for a wide range of patient ages and interests, and maintaining those relationships over time.

As we heard from our interviewees, this can be a challenge in itself, because things are constantly changing: staff turnover, charities that open or close, budget cuts affecting services. However, we would maintain that this is a fundamental part of ECLO practice, reflected strongly in our interviews, and it represents an important point of difference and added value that ECLOs bring to the overall care of patients/citizens. Many clinicians admitted in our interviews that ECLOs make the connections that are very difficult for them to make, and therefore they complete the care needed for their patients. Patients are handed over to the ECLO not so much because clinicians can do no more for them, but because the job of care isn't finished.

4.6.2 CONNECTIONS WITH SOCIAL SERVICES

> *'As an ECLO you have to keep your networks with social workers as up to date as you possibly can. They change relatively quickly so you need to keep abreast of any changes that they are making to the referral process' [ECLO]*

ECLOs save waiting time for patients in making connections with social services. In some places, this relationship is quite formalised and meetings will take place on a regular basis. We heard how ECLOs help with the important background work that's needed so people are more open to getting their right and entitlements as patients/citizens.

Not only do they signpost or refer to rehab teams if they are present locally, but they also do the preparatory groundwork so that people feel confident in engaging with these services, often at a time of life when they feel very vulnerable. Social services are usually part of a package offered by ECLO, involving the voluntary sector, practical help and so forth, but in our interviews, it was the connection to ROVI that seemed to be key.

4.6.3 CONNECTIONS WITH THE VOLUNTARY SECTOR

We heard how ECLOs signpost to a very wide range of voluntary sector organisations, from the small local groups to services offered by large charities. Again, this is an important part of their practice and they have to keep up with what's going on locally, often through the relationships built up in their own networks. We also heard of the important contribution that volunteers from charitable organisations make in some places, helping out with running clinics, but also able to help with some of the increasing administrative burden that success has brought to some ECLOs.

4.6.4 TRUST AND VALUE

As a trusted link between clinical services and other sectors, ECLOs do the necessary support work, beyond the clinical work. We heard in our interviews how clinicians often rather refer to the ECLO first than straight to other places e.g. local rehab teams, social services.

Many clinicians reiterated that without the ECLO it would be really difficult to offer the emotional support to people who are having a tough time with their diagnosis. On a one-to-one level also, some maintained that people are more likely to be honest with an ECLO - not to try to *'please the white coat'.*

As noted previously, however, some ECLOs believe that being identified as part of the NHS means that they are more trusted, but in general it would seem that ECLOs thrive on relationships of trust – so being a 'trusted' member of the clinic staff is important for them to be able to work effectively:

> *'When my badge said I worked for a charity, people didn't want to see you. The minute that badge changed my numbers trebled, because they know you're trained, they know you are a trained professional, they know that you'll be telling them the proper stuff. The NHS see you as a professional' [ECLO]*

5 QUANTITATIVE FINDINGS

This chapter presents quantitative analyses on the ECLO's impact on patients, clinics and NHS services. These were conducted on data for ECLO activity, patient experience, HRQoL and a staff survey. On ECLO activity, data were examined for two data sets, one from English patients only and the other from patients in Wales, Scotland and Northern Ireland. Descriptive analyses for all data are followed by the main findings of the economic analysis and modelling based on these ECLO, patient and staff data.

5.1 ECLO ACTIVITY DATA

5.1.1 SUMMARY

Background

The ECLO activity data discussed in this section include information on the key aspects of first and follow-up appointments with the eye clinic patients in England, Wales, Scotland and Northern Ireland, covering information on new and returning patients, patient enquiries, interactions between ECLOs and patients, and appointment outcomes. The data reported here covers the 12 months from April 2015 to March 2016.

Other than in England where data are aggregated, the ECLOs record the outcomes of the meeting with the patient on three categories: 'informed about' relates to providing information related to patients' main concerns, such as giving leaflets to patients; 'signposted to' relates to providing specific source of support or services that patients can seek help from; and 'referred to' relates to making referrals for patients with the purpose of getting further specific support.

Key findings

- During the 12 months of the study period (April, 2015 – March, 2016) a total of 16,887, 2,934, 2,341 and 4,126 meetings with ECLOs were recorded in England, Wales, Scotland and Northern Ireland respectively.
- Overall, Welsh patients tended to re-visit the ECLOs more than those in the other three UK countries, and in each country, women and people between the ages of 60 and 89 years are the main age groups seen by the ECLOs
- While living with family members was the most frequently recorded living arrangement for patients in all four countries, over half of patients of age 80 years and above reported living alone.
- Age-related macular degeneration (AMD) was the most commonly seen eye condition among ECLOs' patients.
- Various interaction types between the ECLOs and patients have been adopted, including face-to-face and via phone (most frequent type of interaction) and email, letters and texts. In most cases, ECLOs spent 16-30 minutes either face to face or on the telephone with patients and also another half an hour undertaking activities on behalf of patients where necessary.

- Overall rates of falls in patients age 60 years and above show that 60% reported a previous fall. By country, 29% of patients from Wales claimed at least one previous fall, up to four times more than reported in Scotland (7%) and seven times more than reported in Northern Ireland (4%). Overall rates for fear of falling in patients aged 60 years and above shows that the over-60s have higher rates of a fear of falling than the general population, with the highest prevalence in Wales (60%).
- Following patient contact, the data indicate that up to 70% of patients receive information about eye related services, with referrals provided less often. The main concerns patients express at ECLO meetings relate to their independence and reading ability. Up to 90% of patients received emotional support from the ECLOs.

After each visit ECLOs record the key aspects of their appointments with the eye clinic patients in England, Wales, Scotland and Northern Ireland. These data were collated by RNIB and sent to the researchers. We received the RNIB ECLO activity data from the routine activity data collected by ECLOs after their appointments with patients in all four countries. The data were provided as four separate datasets over the study period. English data have been sorted into six files in MS Excel, showing new and returning patients, their enquiries, interactions between ECLOs and patients, and appointment outcomes. Each file contained patients' ID and contact date that are used as an identifier to merge the files together (see Appendix 4 for further detail). For the other three countries, one single file was created in MS Excel for each country and variable names are recorded consistently, therefore, the three files can be appended. Simply speaking, there are two ECLO data sets, one contains English patients only and the other contains patients in Wales, Scotland and Northern Ireland. We believe that this inconsistency in recording data has now been resolved.

The data analysis reported here covers the 12 months April 2015-March 2016. Data were anonymised prior to sending from the RNIB and aggregated. The data contains patients' demographic information, including age, gender, education status and ethnicity, living status, employment status, CVI certificate status, patients' eye conditions and main issues concerned. During the contact with patients, the ECLOs record the referral source of patients, their interaction types with patients, location of meeting, time spent with patients and on behalf of patients, and their meeting outcomes, such as the type of support given, and any other sources the patients have been signposted to, referred to or informed about. The data are recorded at every visit and are categorised as a follow up appointment or a first appointment. Unfortunately there were no identifiers that enabled linking the same patient through the series of appointments in Wales, Scotland and Northern Ireland.

Compared with the other three UK countries, some differences exist in data collected in England in both the content and recording methods. For example, regarding patients' falls, only patients' fear of falling is recorded by the ECLOs in England but not the history of falls. The English data do not contain information on patients' main concerns and ECLO's support to patients, either emotional or practical. English data collection had also been reduced to alleviate the burden on ECLOs, and there is an assumption that giving emotional and practical support is assumed being intrinsic to the ECLO role.

Other than in England, the ECLOs record the outcomes of the meeting with the patient on three categories; 'informed about' relates to providing information to address patients' main concerns, such

as giving leaflets to patients; 'signposted to' relates to providing specific source of support or services that patients can seek help from; and 'referred to' relates to making referrals for patients with the purpose of getting further specific support.

In England, appointment outcomes, on the other hand, are recorded in a different way. These differences somewhat limited the extent to which we could use UK data to inform our analyses.

5.1.2 DESCRIPTIVE DATA

The following tables summarise the ECLO activity data and; clearly this restricted our reporting to only clinics with ECLOs in place. Unfortunately, there were no sources of data, other than our survey data reported in section 4.3.1 that reveals the activities in these categories that staff other than ECLOs, undertake in eye clinics. During the 12 months of the study period (April, 2015 – March, 2016) a total of 16,887, 2,934, 2,341 and 4,126 meetings with ECLOs were recorded in England, Wales, Scotland and Northern Ireland respectively, summarised in Table 5.1.

TABLE 5.1 · Demographics of patients

	England		Wales		Scotland		Northern Ireland	
	N	%	N	%	N	%	N	%
Total appointments	16,887	-	2,934	-	2,340	-	4,126	-
Returning patients	2,657	15.73	520	17.72	287	12.20	395	9.57
Age range (in years)								
0-16	609	3.61	36	1.23	49	2.09	75	1.82
17-25	340	2.01	26	0.89	57	2.44	66	1.60
26-39	647	3.83	65	2.22	83	3.55	166	4.02
40-59	1,854	10.98	226	7.70	267	11.41	557	13.50
60-69	1,425	8.44	183	6.24	270	11.54	487	11.80
70-79	2,636	15.61	383	13.05	499	21.32	1,045	25.33
80-89	4,956	29.35	691	23.55	785	33.55	1,186	28.74
90+	2,055	12.17	234	7.98	238	10.17	276	6.69
Missing information	*2,365*	*14*	*1090*	*37.15*	*92*	*3.93*	*268*	*6.50*

Overall, Welsh patients tend to re-visit the ECLOs more than the other three UK countries. In each country, women and people between the ages of 60 and 89 years are the main age groups seen by the ECLOs. Table 5.1 also presents the age distributions of patients, with over 50% of patients' falling into the age categories between 60 and 89 years old. Table 5.2 presents information on patients' living arrangement and age distributions for patients who live alone.

TABLE 5.2 · Patients' living status and age distributions of patients living alone

Living status	England		Wales		Scotland		Northern Ireland	
	N	%	N	%	N	%	N	%
Live alone	2,595	15.37	663	22.59	923	39.3	1,239	30.03
Residential home	-	-	102	3.48	137	5.9	167	4.05
Live with family members	2,895	17.14	996	33.94	928	39.6	1,920	56.53
Others	431	2.55	18	0.61	284	12.1	26	0.63
Age range of patients who live alone (in years)								
0-16	7	0.27	-	-	-	-	-	-
17-25	10	0.39	4	0.6	2	0.22	3	0.24
26-39	40	1.54	19	2.87	28	3.03	19	1.53
40-59	222	8.55	36	5.43	74	8.02	121	9.77
60-69	137	5.28	49	7.39	87	9.43	115	9.28
70-79	409	15.76	120	18.1	163	17.66	317	25.59
80-89	1,117	43.04	302	45.55	407	44.1	516	41.65
90+	576	22.2	127	19.16	156	16.9	124	10.01
Missing information	*77*	*2.97*	-	-	-	-	-	-
TOTAL	**2,595**		**663**		**923**		**1,239**	

While living with family members is the most frequently recorded living arrangement for patients in all four countries over half of patients of age 80 years and above reported living alone.

The patients' main eye conditions can be found in Table 5.3.[132]

TABLE 5.3 · All patients' main eye conditions

Main eye conditions	England		Wales		Scotland		Northern Ireland	
	N	%	N	%	N	%	N	%
AMD	3,394	20.1	975	33.23	1,034	44.19	1,265	30.66
Glaucoma	1,389	8.22	70	2.39	72	3.08	167	4.05
Diabetic Retinopathy	405	2.4	206	7.02	191	8.16	1,084	26.27
Others	4,440	26.29	557	18.98	1,043	44.57	1,158	28.07
Missing information	7,259	42.99	1,126	38.38	/	/	452	10.95
TOTAL	**16,887**		**2,934**		**2,340**		**4,126**	

[132] It is common that patients have more than one eye disease, and in the data supplied for Wales, Scotland and Northern Ireland, patients' eye conditions are recorded as the main eye condition and also other eye conditions. Data for England is slightly different that patients' eye conditions are all recorded under the same category; therefore the main eye condition for English patients is defined as the first one recorded.

Age-related Macular Degeneration (AMD) is the most commonly seen eye condition among ECLOs' patients. Please note that as a person may have more than one eye condition and not all patients have records of their eye condition the totals will not always add to 100%. Information about patients' eye condition is recorded more completely in Scotland, as shown in Table 5.3, the total percentage of the four eye conditions are 100% meaning there is no missing data. From Table 5.3, the Scottish data suggest that over 40% of patients that ECLOs contact with have AMD.

ECLO interactions with patients

Various interaction types between the ECLOs and patients are adopted, including face to face, on the phone and via email, letters and texts. The most frequently recorded types of interaction are meeting face to face and communicating on the phone. Table 5.4 also reports the time intervals that the ECLOs spend with patients and on behalf of patients.[133]

TABLE 5.4 · Interaction type and ECLO's time with patients

ECLO interaction type	England		Wales		Scotland		Northern Ireland	
	N	%	N	%	N	%	N	%
Face to face	5,093	30.16	955	32.54	1,522	65.01	2,180	52.84
Telephone	4,457	26.39	907	30.90	722	30.84	1,310	31.75
Email/letters/text	1,029	3.13	9	0.31	19	0.81	7	0.17
Time spent with clients								
0-15 mins	4,498	26.63	401	13.66	509	21.74	586	14.2
16-30 mins	4,334	25.66	1,145	39.01	799	34.13	2,050	49.68
31-59 mins	2,663	15.77	242	8.25	602	25.72	798	19.34
1-2 hours	166	0.98	12	0.41	261	11.15	126	3.05
2+ hours	21	0.12	4	0.14	84	3.59	9	0.22
Time spent on behalf of clients								
0-15 mins	-	-	136	4.63	666	28.46	1,063	25.76
16-30 mins	-	-	818	27.87	983	42.01	1,479	35.85
31-60 mins	-	-	720	24.53	360	15.38	878	21.28
1-2 hours	-	-	57	1.94	119	5.09	199	4.82
2+ hours	-	-	3	0.10	125	5.34	13	0.32
TOTAL	**16,887**		**2,934**		**2,340**		**4,126**	

It can be seen that in most cases, ECLOs will spend 16 minutes to half an hour with patients and also another half an hour undertaking activities on behalf of patient if it is necessary. In Table 5.5, ECLOs'

[133] Time spent on behalf of patients is not recorded by ECLOs in England.

TABLE 5.5 · ECLOs' time spent with patients, by interaction types

Interaction types by country		Mean	Standard deviation	Min.	Max.
England	Face to face	2.19	0.78	1	5
	Telephone	1.72	0.75	1	5
Wales	Face to face	2	0.65	1	5
	Telephone	1.86	0.57	1	4
Scotland	Face to face	2.56	1.13	1	5
	Telephone	2.1	0.84	1	5
Northern Ireland	Face to face	2.16	0.72	1	5
	Telephone	2.12	0.75	1	5

time spent with patients has been further specified by interaction types, i.e. face to face and telephone.[134] The time range typically spent with patients in the four countries, either face to face or telephone, is 16-30 minutes.

Patients' history of falls and fear of falling

Tables 5.6 to 5.9 present the patients' history of falls and fear of falling, by age and living status. No statistics are filled in for England as data recorded in England only contains information on fear of falling but not on the history of falls.

From Table 5.6, it can be seen that overall, for patients age 60 years and above, over 40% reported they had no previous fall. However, but in Wales, 29% of patients claimed that they had at least one previous fall before, the rate three four times greater higher than that in Scotland (7%) and six seven times bigger higher than that in Northern Ireland (4%). Table 5.7 presents information on fear of falling for all patients, and patients aged 60 years and above It can be seen that the rates of fear of falling increases with age as with the this older age group of patients in the four UK countries have higher rates than patients overall, with the highest prevalence for this age group in Wales (60%).

Patients' main concern and emotional support from ECLOs

Table 5.10 summarises the main concerns patients express when they see the ECLO; this excluded English data since these were not collected in England. For the other three UK countries, variations in the patient concerns are observed. For patients in Wales the main concern r related to their independence; for patients in Scotland and Northern Ireland the main concern related to their reading ability. [135]

The information on provision is not available in England. The other three countries' data are summarised in Table 5.10.

[134] As time is originally recorded as intervals, time categories are created during data analysis. The order of categories created are those presented in Table 5.4. For example, time interval 1 is 0-15 minutes.

TABLE 5.6 · Number of falls for all patients and patients aged 60 years and above

Number of falls for all patients	England		Wales		Scotland		Northern Ireland	
	N	%	N	%	N	%	N	%
None	-	-	769	26.21	1,087	46.45	1,512	36.65
1	-	-	512	17.45	144	6.15	141	3.42
2	-	-	87	2.97	99	4.23	35	0.85
3	-	-	14	0.48	42	1.79	63	1.53
More than 3	-	-	67	2.28	76	3.25	45	1.09
N/A	-	-	*144*	*4.91*	*563*	*24.06*	*308*	*7.46*
Missing information	-	-	*1,341*	*45.71*	*329*	*14.06*	*2,022*	*49.01*
TOTAL	**-**		**2,934**		**2,340**		**4,126**	
History of falls for all patients aged 60 and above								
None	-	-	602	40.38	861	48.05	1,230	41.08
1	-	-	425	28.5	123	6.86	109	3.64
2	-	-	69	4.63	74	4.13	21	0.7
3	-	-	12	0.8	29	1.62	30	1
More than 3	-	-	52	3.49	52	2.9	21	0.7
N/A	-	-	*119*	*7.98*	*435*	*24.27*	*162*	*5.41*
Missing information	-	-	*212*	*14.22*	*218*	*12.17*	*1,421*	*47.46*
TOTAL	**-**		**1,491**		**1,792**		**2,994**	

TABLE 5.7 · Fear of falling for all clients and clients aged 60 years and above

Fear of falling for all patients	England		Wales		Scotland		Northern Ireland	
	N	%	N	%	N	%	N	%
No	9,287	54.99	398	13.57	931	39.79	232	5.62
Yes	670	3.97	1,155	39.37	716	30.60	533	12.92
Don't know	-	-	158	5.39	535	22.86	190	4.60
Missing information	*6,930*	*41.04*	*1,223*	*41.68*	*158*	*6.75*	*3,171*	*76.85*
TOTAL	**16,887**		**2,934**		**2,340**		**4,126**	
Fear of falling for all patients aged 60 and above								
No	6,670	60.24	398	19.99	737	41.13	173	5.78
Yes	561	5.07	940	63.04	540	30.13	338	11.29
Don't know	-	-	128	8.58	423	20.36	118	3.94
Missing information	*3,841*	*34.69*	*125*	*8.38*	*423*	*23.6*	*2,365*	*78.99*
TOTAL	**16,887**		**1,491**		**1,792**		**2,994**	

TABLE 5.8 · History of falls for patients age 60 and above, by living status

History of falls for patients age above 60 years of age	Live alone		Live with family members		Residential home		Other living circumstances	
	N	%	N	%	N	%	N	%
Wales								
None	250	41.81	313	43.53	32	33.68	1	11.11
1	158	26.42	223	31.02	40	42.11	3	33.33
2	39	6.52	28	3.89	2	2.11	-	-
3	8	1.34	4	0.56	-	-	-	-
More than 3	20	3.34	29	4.03	2	2.11	-	-
N/A	*43*	*7.19*	*57*	*7.93*	*9*	*9.47*	*2*	*22.22*
Missing information	*80*	*13.38*	*65*	*9.04*	*10*	*10.53*	*3*	*33.33*
TOTAL	**598**		**719**		**95**		**9**	
Scotland								
None	446	54.86	335	53.86	45	48.39	29	12.78
1	79	9.72	37	5.95	7	7.53	-	-
2	39	4.8	31	4.98	3	3.23	1	0.44
3	14	1.72	13	2.09	2	2.15	-	-
More than 3	21	2.58	25	4.02	5	5.38	1	0.44
N/A	*129*	*15.87*	*118*	*18.97*	*21*	*22.58*	*162*	*71.37*
Missing information	*85*	*10.46*	*63*	*10.13*	*10*	*10.75*	*34*	*14.98*
TOTAL	**813**		**622**		**93**		**227**	
Northern Ireland								
None	506	47.2	591	47.66	64	41.83	9	69.23
1	49	4.57	40	3.23	13	8.5	-	-
2	11	1.03	6	0.48	4	2.61	-	-
3	8	0.75	22	1.77	-	-	-	-
More than 3	17	1.59	4	0.32	-	-	-	-
N/A	*60*	*5.6*	*90*	*7.26*	*10*	*6.54*	*1*	*7.69*
Missing information	*421*	*39.27*	*487*	*39.27*	*62*	*40.52*	*3*	*23.08*
TOTAL	**1,072**		**1,240**		**153**		**13**	

TABLE 5.9 · Fear of falling for patients age 60 and above, by living status

Fear of falling	Live alone		Live with family members		Residential home		Other living circumstances	
	N	%	N	%	N	%	N	%
England								
No	2,349	90.52	2,658	91.81	-	-	371	86.08
Yes	246	9.48	237	8.19	-	-	60	13.92
Don't know	-	-	-	-	-	-	-	-
Missing information	-	-	-	-	-	-	-	-
TOTAL	**2,237**		**1,815**		**-**		**-**	
Wales								
No	109	18.23	171	23.78	11	11.58	1	11.11
Yes	398	66.56	461	64.12	73	76.84	4	44.44
Don't know	48	8.03	61	8.48	8	8.42	3	33.33
Missing information	*43*	*7.19*	*26*	*3.62*	*3*	*3.16*	*1*	*11.11*
TOTAL	**598**		**719**		**95**		**9**	
Scotland								
No	355	43.67	304	48.87	36	38.71	35	15.42
Yes	302	37.15	195	31.35	34	36.56	9	3.96
Don't know	114	14.02	106	17.04	21	22.58	171	75.33
Missing information	*42*	*5.17*	*17*	*2.73*	*2*	*2.15*	*12*	*5.29*
TOTAL	**813**		**622**		**93**		**227**	
Northern Ireland								
No	81	7.56	68	5.48	5	3.27	2	15.38
Yes	155	14.46	162	13.06	13	8.5	1	7.69
Don't know	47	4.38	61	4.92	8	5.23	1	7.69
Missing information	*789*	*73.6*	*949*	*76.53*	*127*	*83.01*	*9*	*69.23*
TOTAL	**1,072**		**1,240**		**153**		**13**	

TABLE 5.10 · Patients' main issue and emotional support

Patients' main issue	England		Wales		Scotland		Northern Ireland	
	N	%	N	%	N	%	N	%
Anxiety/emotional distress	-	-	455	15.51	286	12.22	150	3.64
Loss independence	-	-	896	30.54	551	23.55	288	6.98
Reading	-	-	599	20.42	682	29.15	759	18.4
TOTAL	**-**		**2,934**		**2,340**		**4,126**	
Emotional support given to all patients								
No	-	-	277	9.44	546	23.33	97	2.35
Yes	-	-	1,471	50.14	1,651	70.56	3,182	77.12
Missing information	-	-	*1,186*	*40.42*	*143*	*6.11*	*847*	*20.53*
TOTAL	**-**		**2,934**		**2,340**		**4,126**	
Emotional support given to patients have fear of falling								
No	-	-	98	8.5	114	15.9	28	5.3
Yes	-	-	1017	88.0	577	80.6	485	90.9
Missing information	-	-	*40*	*3.5*	*25*	*3.5*	*20*	*3.8*
TOTAL	**-**		**1,155**		**716**		**533**	
Emotional support given to patients have anxiety/emotional distress (of appointments)								
No	-	-	10	2.2	7	2.5	1	0.7
Yes	-	-	413	90.8	273	95.4	143	95.3
Missing information	-	-	*32*	*7.0*	*6*	*2.1*	*6*	*4.0*
TOTAL	**-**		**455**		**286**		**150**	

For those patients reporting anxiety/emotional distress[136], the majority (over 90% in Wales, Scotland and Northern Ireland) received emotional support from the ECLOs.

Consequences for patients after contact with ECLO

Table 5.11 presents the outcome after contact with ECLOs in Wales, Scotland and Northern Ireland by the categories: informed about, signposted to and referred to, and further refined into 7 categories, including RNIB services, eye related services, health related services, CVI information and registration, rehabilitation, falls support and other services/support.[129]

The summaries in Table 5.11 show that the ECLOs inform patients about eye related services. Particularly in Northern Ireland, over 70% of patients received information about eye related services.

[136] The anxiety/emotional distress the patients report to the ECLOs may not be clinically diagnosed.

The more 'interventional' category – 'referred' is provided less often. This may relate to the ECLO perception of patient need or the ability of the ECLO to make a referral in a direct sense, whereas 'informing about' and 'signposting to' are more easily accomplished. Especially in Wales, referral rate to all services or support are lower than 12% and only 6.5% of patients are referred to eye related services.

TABLE 5.11 · All patients appointment outcomes: Wales, Scotland and Northern Ireland

Appointment outcomes	RNIB services	Eye related services	Health related services	CVI info and registra-tion	Rehabili-tation	Falls support	Other services or support
Wales							
Informed about	14.72	31.14	0.99	20.41	17.99	5.72	39.91
Signposted to	7.67	14.62	3.10	0.92	1.43	1.06	11.45
Referred to	11.72	6.41	2.49	1.09	9.27	0.10	10.57
Scotland							
Informed about	21.02	33.75	0.26	12.05	24.99	2.22	40.90
Signposted to	13.50	14.78	1.88	1.07	9.10	0.51	46.07
Referred to	12.47	11.62	0.94	1.20	15.63	1.15	44.69
Northern Ireland							
Informed about	25.45	74.77	0.02	17.62	42.07	0.82	51.45
Signposted to	3.13	18.13	0.12	3.78	6.93	0.22	17.23
Referred to	20.87	32.72	0.19	10.52	22.49	0.07	22.78

Although data collected in England does not categorize the outcomes, it records information on patients' CVI completion status as one of the outcomes, which is not collected in the other UK countries. From the English data we see that the rate of CVI completion and time spent on completing patients' CVI is seen. From Table 5.12, it can be seen that 22% of patients in England have their CVI completed during their contact with an ECLO and this process takes on average 30 minutes to finish. There is no reason to believe that this will vary in any other UK country.

TABLE 5.12 · CVI completion and time spent: England

Time spent with clients (in mins)	"Yes"/total	%	Mean	Std. Dev.	Min	Max
CVI completed	2712/11970	22.66	31.38	18.78	5	210

5.2 PATIENT SURVEY DATA: HEALTH RELATED QUALITY OF LIFE

5.2.1 SUMMARY

Background

Data collected from the patient survey includes HRQoL outcomes (including EQ-5D-5L) from a number of perspectives revealing differences in HRQoL between different eye conditions, types of support required, received and not received, and the time since diagnosis, scores of the different dimensions of HRQoL, and the differences between the sub groups of the people that responded to the patient survey.

The "robustness" (i.e. how confident we can be of the results) of these differences in HRQoL between patient conditions and support categories were then tested via statistical tests (i.e. Student t-tests). The p-values of the *t*-tests indicate the probability that the samples have the same mean value (i.e. are similar). Typically, a maximum p-value cut-off of 0.05 (i.e. 95% probability) is used as the basis of accepting the robustness of the differences of the data; hence a p-value above this threshold (i.e. less than a 95% probability) suggests that the differences are not significant enough to accept with confidence. However, this may also be influenced by the size of the patient population, with larger sizes providing more robust outcomes.

Whilst the results may suggest particular findings, it is important to note that the patient numbers responding initially to the survey were large, the patient numbers at follow up are smaller than those who contributed at baseline. Thus, where trends can be observed this suggests that further data collection may be worthwhile to get enough data to be able to confirm the observed trends.

Key findings

- HRQoL (mean EQ-5D scores) were lowest for Diabetic Retinopathy patients (mean 0.751, SD 0.322), and these patients were recorded as receiving the lowest level of support from either and ECLO or other staff. For other eye conditions (Dry and Wet AMD, and Glaucoma) those receiving ECLO support had slightly lower HRQoL than those seen by other staff.
- Patients supported by ECLOs or non-ECLOs showed a decline in HRQoL captured in the utility scores at follow-up (0.011 and 0.07 respectively for the utility scores). However, the VAS scores showed a small increase at follow-up for those seeing an ECLO, with differences not being statistically robust and thus warranting further study with larger patient samples sizes.
- For those patients who stated they needed support but did not receive it, and how they fared at the point of follow-up, those stating they needed support had lower baseline HRQoL (EQ-5D utility and VAS scores) compared with those not needing it. This may suggest that there are patients attending the eye clinics who expressed a need for support and did not receive it who are missing out on the ECLO services and support.
- While there was a small (non-significant) decline in HRQoL scores at follow-up for patients supported by an ECLO or other staff, the decline was lower for those visiting an ECLO site in comparison to non-ECLO sites, possibility indicating that having an ECLO on-site may reduce the size or rate of the decline in patients' HRQoL – and that having an ECLO on-site may influence an improvement in the environment of support in general within eye clinics.

- When changes to HRQoL after diagnosis were examined, a small improvement in HRQoL over the first 6 months post-diagnosis, followed by a small decline in the following 6 months was shown. This may suggest that the effect of diagnosis and initial treatment helps to improve HRQoL, but a later decline may be due to a decline in the eye condition itself, or that patient care has a lesser impact over time.
- The differences of scores for the 5 domains of the EQ-5D between the whole study participant population and those who have received ECLO support indicates there is a proportion of all study patients that have moderate to severe problems with mobility, self-care, their usual activities, pain and discomfort, and depression and anxiety. In addition, data show that the ECLO service is providing support to patients with these needs.
- Of all study patients recording moderate and severe problems with anxiety/depression (n = 29 and 11 respectively), over half have received support from an ECLO, and of those reporting extreme problems (n=2), all received ECLO support, suggesting that the ECLOs are targeting the people who need support and potentially people needing support are engaging with ECLOs.
- For the four other domains of the EQ-5D (mobility, self-care, usual activities, and pain and discomfort) ECLOs see less than half of the study population that report moderate to severe levels of these impairments, suggesting that there are patients who may need help who have no ECLO contact, and that there is a need for more ECLO or ECLO-type support at study sites.

In this section, we report data collected from the patient survey; this HRQoL outcomes (including EQ-5D) from a number of perspectives revealing differences between HRQoL between different types of eye conditions, types of support required, received and not received, and the f the time since diagnosis. We also report the scores of the different domains of the EQ-5D (mobility, self-care, usual activities, pain/discomfort and depression/anxiety) and the differences between the sub groups of the people that responded to the patient survey.

Within the analysis, we also looked at the robustness of the differences in HRQoL between patient conditions and ECLO support categories. This measure of robustness was obtained via a statistical test termed the Student t-test. The resulting p-values of the t-tests indicate the probability that the samples have the same mean value (i.e. differences in means are 'not statistically significant'). Typically, a maximum p-value cut-off of up to 0.10 is used as the basis of accepting the robustness of the differences of the data; hence a p-value above this threshold suggests that the differences in means between the groups are not 'statistically significant enough' to accept with confidence. However, this measure of robustness may also be influenced by the size of the patient population, with larger sizes enabling stronger evidence.

Whilst the results may indicate particular findings, it is important to note that the patient numbers responding initially to the survey were large, the patient numbers at follow up are smaller than those who contributed at baseline. This was due to study closure which resulted in truncated data. The patient numbers reduced even further after sub-grouping the patients further. Thus some of our findings are tentative and should be considered with some caution. This is important when interpreting the results from a statistical standpoint, as comparing small numbers means that statistical power to detect 'true' differences between groups is lost. However, where trends can be observed this suggests

that further data collection may be worthwhile to get enough data to be able to confirm the observed trends.

5.2.2 EYE CONDITION AND SUPPORT TYPE

Tables 4.13a and 4.13b show the number of participants, their main eye condition and whether they received support from an ECLO or that this support was substituted by another member of staff.

EQ-5D scores show that those with Diabetic Retinopathy have the lowest mean score (mean 0.751, SD 0.322) indicating that, on average, these patients have a lower HRQoL than those with other visual impairments. The number of Diabetic Neuropathy patients recorded as receiving support is relatively small, whether by an ECLO (n=8) or other staff member (n=1). However, this indicates that EQ-5D scores for those with Diabetic Retinopathy receiving support is far lower than other patients, indicating that those who have a much lower HRQoL are receiving ECLO support (mean 0.542) or seeing other staff (mean -0.016).

For other eye conditions (Dry and Wet AMD, and Glaucoma) it appears that those receiving ECLO support had a slightly lower HRQoL than those seen by other staff although these are not greatly different. These scores (ranging from mean 0.726 to 0.853) are also comparable to the national UK population average EQ-5D scores of 0.81.[137]

The findings of note between Table 5.13a reporting the EQ-5D utility scores and Table 5.13b reporting the VAS scores are the way the two sets of scores are recorded and calculated. The EQ-5D utility score is calculated with a scoring algorithm which is derived from surveys of the general population whereas the VAS score is a direct representation of how individual patients score their state of health on a scale of 1-100 on the day. It seems for the survey respondents that patients tend to rate themselves with a far lower score with the VAS than is indicated by the 5-dimension EQ-5D utility score. VAS scores represent an individual's perception of their own health state so the data we see here shows that the general population valuation of the health states that visually impaired people experience is higher than

ECLO and non-ECLO Support

Tables 4.14a and 4.14b provide a baseline and follow-up results for those receiving ECLO and non-ECLO support. Both patients supported by ECLOs and non-ECLOs show a decline in HRQoL captured in the utility scores at follow-up (0.011 and 0.07 respectively for the utility scores). However, the VAS scores (i.e. the subjective experience of the respondent) show a small increase at follow-up for those seeing an ECLO. Whilst these are interesting results which suggest positive impacts of ECLOs, none of these differences are statistically significant– that is, they are not robust and we cannot be sure without certainty that they have not occurred by chance. Thus further research will be needed in order to assess whether the decline in EQ-5D scores are 'tempered' or strengthened as a direct influence of ECLO support. Subsequent analysis in this report explores this further.

[137] Janssen B and Szende A (2014) 'Population norms for the EQ-5D – Self-Reported Population Health: An International Perspective based on EQ-5D' *Springer* pp.19-30

TABLE 5.13a · Baseline EQ5D scores for patients according to their main eye condition[138]

	All					Support received from ECLO					Support from other staff				
	N	Mn	SD	Min	Max	N	Mn	SD	Min	Max	N	Mn	SD	Min	Max
Diabetic Retinopathy	23	0.751	0.322	-0.016	1	8	0.542	0.326	0.149	1	1	-0.016	/	-0.016	-0.016
Dry AMD	17	0.807	0.173	0.294	1	12	0.790	0.193	0.294	1	5	0.848	0.123	0.661	1
Wet AMD	125	0.803	0.245	-0.015	1	25	0.739	0.224	0.125	1	27	0.853	0.251	0.061	1
Glaucoma	27	0.787	0.221	0.203	1	9	0.726	0.222	0.335	1	2	0.849	0.214	0.698	1
Other	65	0.823	0.235	-0.062	1	18	0.713	0.248	0.19	1	2	0.394	0.645	-0.062	0.85

TABLE 5.13b · Baseline VAS scores for patients according to their main eye condition

	All					Support received from ECLO					Support from other staff				
	N	Mn	SD	Min	Max	N	Mn	SD	Min	Max	N	Mn	SD	Min	Max
Diabetic Retinopathy	23	58.870	24.558	10	95	8	43.000	27.087	10	80	1	40.000	/	40	40
Dry AMD	17	55.294	25.585	5	100	12	47.917	26.238	5	100	5	73.000	13.038	60	90
Wet AMD	125	66.344	18.201	20	100	25	62.320	17.016	35	95	27	66.481	19.700	30	100
Glaucoma	27	67.667	17.422	25	100	9	61.667	21.065	25	100	2	80.000	14.142	70	90
Other	67	70.597	22.422	10	100	18	63.400	27.157	10	100	2	52.500	31.820	30	75

[138] Mn = Mean value, SD = Standard Deviation.

TABLE 5.14a · Patients' EQ-5D scores for those receiving support from ECLO and other staff

EQ-5D	Support received from ECLO					Support received from other staff				
	Mean	St. Dev	Median	Min	Max	Mean	St. Dev	Median	Min	Max
Baseline	0.710	0.247	0.758	0.125	1	0.804	0.300	1	-0.062	1
TOTAL	**73**					**37**				
Follow-up	0.699	0.222	0.683	0.076	1	0.735	0.302	0.747	-0.122	1
TOTAL	**35**					**17**				
Difference	-0.011	0.208	-0.085	-0.397	0.51	-0.070	0.274	0	-0.831	0.396
T-TEST OF DIFFERENCE	**0.207**					**0.306**				

TABLE 5.14b · VAS for those receiving support from ECLO and other staff

VAS	Support received from ECLO					Support received from other staff				
	Mean	St. Dev	Median	Min	Max	Mean	St. Dev	Median	Min	Max
Baseline	58.667	24.146	60	5	100	66.622	19.474	70	30	100
TOTAL	**73**					**37**				
Follow-up	64.800	25.430	70	0	100	64.706	23.417	70	20	95
TOTAL	**35**					**17**				
Difference	6.133	37.587	0	-100	95	-1.916	24.618	-5	-70	40
T-TEST OF DIFFERENCE	**0.38**					**0.274**				

Support required and received

Table 5.15 shows EQ-5D utility and VAS scores in relation to the support patients require and receive.

TABLE 5.15 · Patients numbers by category, EQ-5D

Patient numbers	N	%	EQ-5D Scores Baseline (Mean)	VAS
Receive support from ECLO	73	28.29	0.710	58.667
Support needed and receive from other staff	37	14.02	0.804	66.622
Support needed but not received	30	11.36	0.756	65.667
Support not needed	118	44.7	0.865	71.263

This indicates that those who see an ECLO have the lowest average utility and VAS scores (mean utility = 0.710, mean VAS = 58.667), indicating that ECLOs are seeing those with a lower HRQoL, which suggests appropriate targeting of the ECLO activity. This table also shows that there are a number of patients with the lower mean utility scores who reported that they needed support but had not received it (n=30, mean utility scores = 0.756, mean VAS =66.622). These patients report lower scores than those receiving support from other substitute staff, although this difference should be viewed with caution as it does not reach statistical significance at the 0.1 (90%) or 0.05 (95%) levels.

Tables 4.16a and 4.16b provide further information for those patients who stated they needed support but did not receive it, and how they fared at the point of follow-up. Those stating they needed support having lower baseline scores (EQ-5D utility = 0.756, VAS = 65.667 compared with those not needing support (EQ-5D utility = 0.865, VAS = 71.663), which suggests that there are patients attending the eye clinics who expressed a need for support and did not receive it and have a lower HRQoL than those who did not need support.

TABLE 5.16a · Patients' EQ-5D scores, support not received and not needed

EQ-5D	Support not received					Support not needed				
	Mean	St. Dev	Median	Min	Max	Mean	St. Dev	Median	Min	Max
Baseline	0.756	0.274	0.857	-0.015	1	0.865	0.196	1	0.175	1
TOTAL	**30**					**118**				
Follow-up	0.679	0.288	0.692	0.161	1	0.873	0.169	1	0.427	1
TOTAL	**10**					**42**				
Difference	0.051	0.247	0.000	-0.445	0.444	-0.013	0.169	0	-0.416	0.416
T-TEST OF DIFFERENCE	**0.529**					**0.616**				

TABLE 5.16b · Patients' VAS scores, support not received and not needed

VAS	Support not received					Support not needed				
	Mean	St. Dev	Median	Min	Max	Mean	St. Dev	Median	Min	Max
Baseline	65.667	17.307	72.5	35	100	71.263	18.228	75	10	100
TOTAL	**30**					**118**				
Follow-up	67.000	13.375	72.5	50	85	80.886	16.868	80	40	100
TOTAL	**10**					**44**				
Difference	1.333	15.986	5	-25	30	9.623	14.179	5	-25	40
T-TEST OF DIFFERENCE	**0.349**					**0.004**				

While the EQ-5D utility scores show a small decline in HRQoL at follow-up, for those who had not received support, the VAS scores show a small increase, however, without statistical significance. For those patients who do not require support, the VAS scores show an increase over the study period with a relatively high degree of statistical robustness.

ECLO and non-ECLO sites

In order to explore the explore the effect of having an ECLO on-site in an eye clinic, the results summarised in Table 5.17a shows the HRQoL of patients over the study period at ECLO and non-ECLO sites. While the previous data show there was a small (non-significant) decline in utility scores at follow-up for patients supported by an ECLO or other staff, results in Table 5.17a shows that this decline is attenuated for those visiting an ECLO site (mean EQ-5D utility score = -0.016, no significant evidence of difference between visits) in comparison to non-ECLO sites (mean EQ-5D utility = -0.076 weak evidence of significance differences between visits). This may indicate that having an ECLO on-site may reduce the size or rate of the decline in patients' HRQoL – further suggesting that having an ECLO on-site may influence an environment of support in general within eye clinics.

TABLE 5.17a · Patients EQ-5D scores for those attending an ECLO site and non-ECLO site

EQ-5D	ECLO site					Non-ECLO site				
	Mean	St. Dev	Median	Min	Max	Mean	St. Dev	Median	Min	Max
Baseline	0.782	0.236	0.836	-0.015	1	0.844	0.263	1	-0.062	1
TOTAL	**185**					**73**				
Follow-up	0.777	0.237	0.829	-0.122	1	0.759	0.244	0.826	0.161	1
TOTAL	**84**					**20**				
Difference	-0.015	0.213	0	-0.831	0.51	-0.076	0.191	-0.084	-0.445	0.32
T-TEST OF DIFFERENCE	**0.508**					**0.089**				

Time of Diagnosis

The following table (Table 5.17b) provides results on the change in HRQoL over the study period between those recently diagnosed in the previous 3 months, 4-6 months, 7-12 months and beyond 12 months previously. The purpose of this analysis is to explore the difference in the effect of the time since diagnosis on patients' HRQoL.

The main observation of these results is the change in EQ-5D utility scores for the four groups (change in HRQoL for diagnosis at <3months = 0.086, 4-6months = 0.118, 7-12months = -0.080, >12months = -0.047). This shows that there is an initial small improvement in HRQoL over the first 6 months post-diagnosis, followed by a small decline in the following 6 months, which may suggest that the effect of diagnosis and initial treatment helps to improve HRQoL. The subsequent decline, albeit minor, may be due to a decline in the eye condition itself, or that patient care has a lesser impact over time.

TABLE 5.17b · Patients' EQ-5D time from diagnosis

EQ-5D	Eye condition diagnosed in the past three months					Eye condition diagnosed 4-6 months ago				
	Mean	St. Dev	Median	Min	Max	Mean	St. Dev	Median	Min	Max
Baseline	0.784	0.248	0.879	0.203	1	0.814	0.271	1	0.125	1
TOTAL	**28**					**20**				
Follow-up	0.887	0.190	1	0.427	1	0.932	0.098	1	0.784	1
TOTAL	**10**					**5**				
Difference	0.086	0.192	0.061	-0.163	0.416	0.118	0.222	0	0	0.51
EQ-5D	**Eye condition diagnosed 7-12 months ago**					**Eye condition diagnosed more than 12 months ago**				
	Mean	St. Dev	Median	Min	Max	Mean	St. Dev	Median	Min	Max
Baseline	0.870	0.189	0.953	0.149	1	0.789	0.252	0.848	-0.062	1
TOTAL	**34**					**166**				
Follow-up	0.865	0.138	0.837	0.654	1	0.739	0.253	0.787	-0.122	1
TOTAL	**9**					**74**				
Difference	-0.080	0.131	0	-0.346	0.028	-0.047	0.217	-0.004	-0.831	0.444

Domains of EQ-5D

The following table and charts (Table 5.18 and Figure 5.1) shows each of the 5 domains of the EQ-5D and the differences between the whole study participant population and those who have received ECLO support. Primarily, these tables and figures show that there is a proportion of all study patients that have moderate to severe problems with mobility, self-care, their usual activities, pain and discomfort, and depression and anxiety – and that the ECLO service is providing support to patients with these needs.

As we are aware from the literature recorded in this report, depression and anxiety can significantly affect those with vision impairment, thus, our results are interesting. Of all study patients recording moderate and severe problems with anxiety/depression (n = 29 and 11 respectively), over half have received support from an ECLO, and of those reporting extreme problems (n=2), all received ECLO support. This suggests that the ECLOs are targeting the people who need support and potentially people who identify themselves as needing support are engaging with ECLOs. For the four other domains of the EQ-5D, ECLOs see less than half of the study population that report moderate to severe levels of

TABLE 5.18 · Dimensions of the EQ-5D

EQ5D Mobility	All patients		Patients with contact with ECLOs	
	N	%	N	%
None	161	62.16	41	56.16
Slight	36	13.9	12	16.44
Moderate	38	14.67	12	16.44
Severe	20	7.72	6	8.22
Extreme	4	1.54	2	2.74
TOTAL	**259**	**100**	**73**	**100**

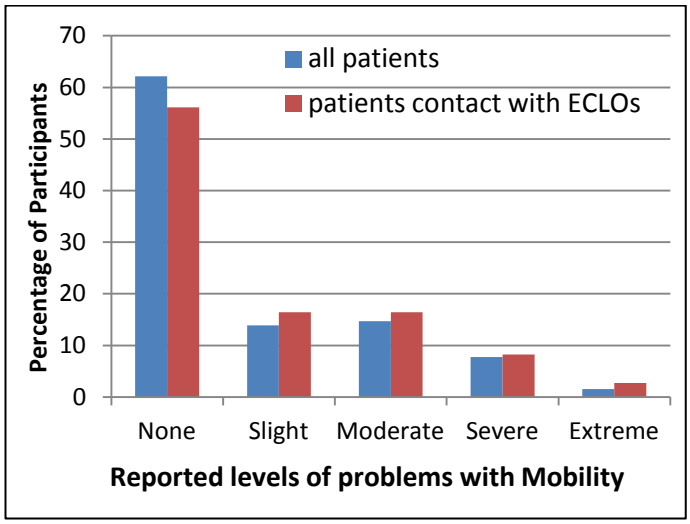
EQ5D Self care	All patients		Patients with contact with ECLOs	
	N	%	N	%
None	212	81.85	54	73.97
Slight	21	8.11	7	9.59
Moderate	20	7.72	9	12.33
Severe	2	0.77	2	2.74
Extreme	4	1.54	1	1.37
TOTAL	**259**	**100**	**73**	**100**

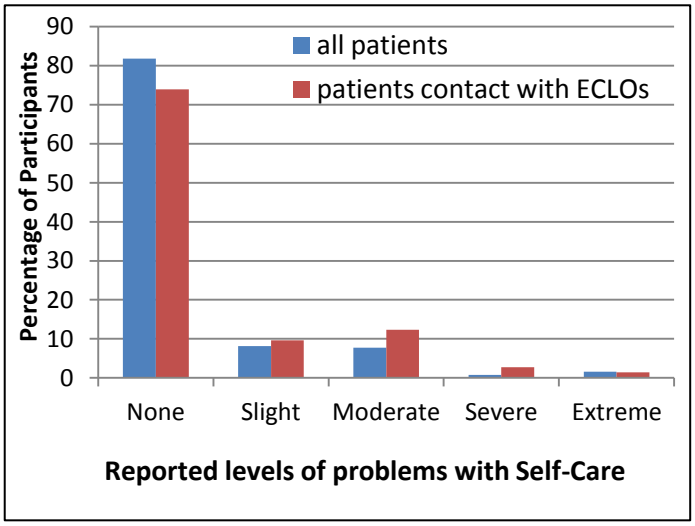
EQ5D Usual Activities	All patients		Patients with contact with ECLOs	
	N	%	N	%
None	172	66.41	36	49.32
Slight	45	17.37	18	24.66
Moderate	27	10.42	10	13.7
Severe	8	3.09	6	8.22
Extreme	7	2.7	3	4.11
TOTAL	**259**	**100**	**73**	**100**

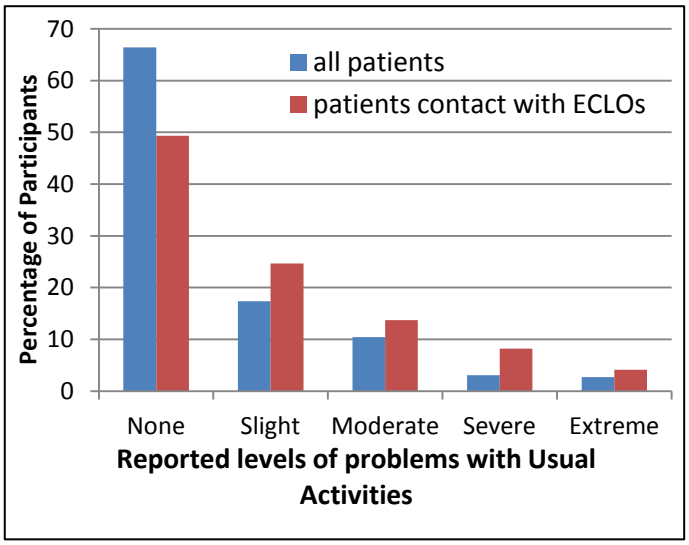
EQ5D Pain / Discomfort	All patients		Patients with contact with ECLOs	
	N	%	N	%
None	177	68.34	41	56.16
Slight	31	11.97	17	23.29
Moderate	29	11.2	8	10.96
Severe	20	7.72	6	8.22
Extreme	2	0.77	1	1.37
TOTAL	**259**	**100**	**73**	**100**

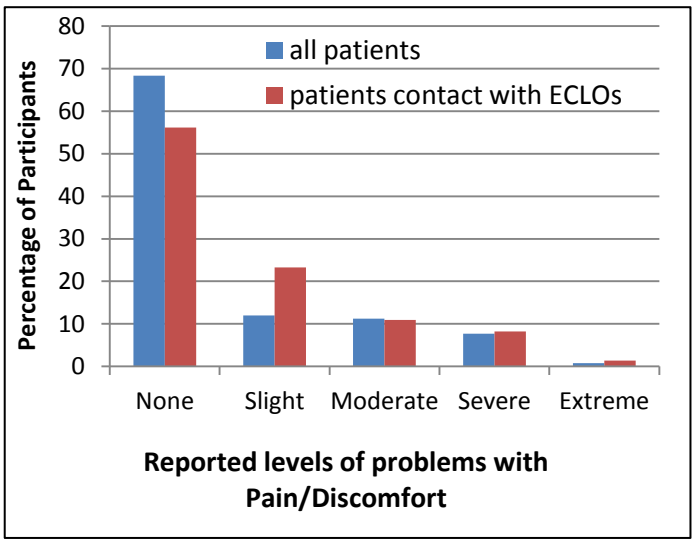
EQ5D Anxiety / Depression	All patients		Patients with contact with ECLOs	
	N	%	N	%
None	185	71.71	39	54.17
Slight	29	11.24	7	9.72
Moderate	31	12.02	18	25
Severe	11	4.26	6	8.33
Extreme	2	0.78	2	2.78
TOTAL	**258**	**100**	**72**	**100**

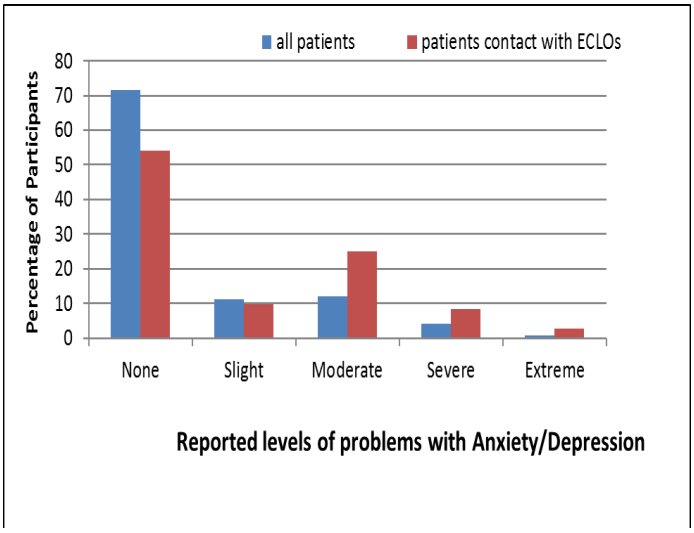
FIGURE 5.1 · Dimensions of the EQ-5D











mobility, self-care, usual activities, and pain and discomfort, suggesting that there may be patients who may need help who have no ECLO contact, and that there is a need for more ECLO or ECLO-type support at study sites. These results need to be viewed with caution as within this population may be people who have stated they do not need support. Nevertheless, we have some signals as we observe from other results provided in this report, it may be that ECLOs help to maintain the level of HRQoL for those with (worsening eye) conditions, and this table indicates that the domains of HRQoL that may be key signalling the need for the involvement of ECLOs in preserving these levels.

5.3 THE COST OF AN ECLO IN THE NHS SETTING

5.3.1 SUMMARY

Background

The objective of this section was to explore how and if the ECLO might release cash or capacity in the NHS clinic setting by understanding what the staff in the absence of an ECLO might cost the NHS.

We also looked at the data from the staff survey, to assess how much of staff time is spent providing the kinds of support to patients that ECLOs provide, so that this could be compared between sites and crucially act as inputs to the economic model which explored the potential of the ECLO to release staff capacity.

Key findings – cost to NHS

- An estimate of £17.94 per patient per ECLO contact was reported in the literature; furthermore, approximately £247.76 for ECLO intervention over a person's lifetime was estimated for proportions of people registered as severely sight impaired at each age group, assuming an ECLO is seen once per year. However these figures do not give the whole picture.
- There is a somewhat different cost issue as we are looking at a substitution of ECLOs for NHS staff and existing clinics to deliver 'ECLO type' support. Thus the opportunity cost to the NHS of not having an ECLO is the staff member who would otherwise be employed and/the equivalent NHS pay band.

Key findings – staff survey

In total 30 study sites were visited through the course of the study, from which 20 contributed to the staff survey. Analyses were conducted on time spent by staff in providing emotional support, advocacy and certification and registration. Data collected in each category is described below:

- Emotional support ("I have spent time listening to patients/carers, talking through their worries or concerns")

  Consultant ophthalmologists at ECLO sites reported provided marginally more patients per week with emotional support than non ECLO sites; clinical nurse specialists and ophthalmic nurses at ECLO sites reported providing more patients per week with emotional support than non ECLO sites. Staff nurses and sisters at ECLO sites reported seeing fewer patients per week for emotional support than non ECLO sites but spent more time providing emotional support in those contacts than non ECLO sites.

- Advocacy ("I have helped people to have their voices heard; to secure their rights and to obtain the support they need")

  Consultant ophthalmologists at both ECLO and non ECLO sites reported low or no levels of advocacy; both clinical nurse specialists and ophthalmic nurses and staff nurses and sisters at ECLO sites reported low levels of advocacy support per week for patients with on average less than 1 patient receiving support of this nature, while non ECLO sites did not report advocacy support.

- Certification and registration ("I have informed and advised patients about Certification and Registration and its benefits. I have helped patients in a practical way by helping to fill in forms, for example").

  Consultant ophthalmologists and staff nurses and sisters at both ECLO and non ECLO sites saw a similar number of patients per week, supporting certification and registration but ECLO sites reported more time spent supporting patients with practical help such as form filling; clinical nurse specialists and ophthalmic nurses at ECLO sites reported marginally more support for patients per week supporting certification and registration than non ECLO sites.

To explore whether the ECLO might release cash or capacity in the NHS clinic setting we need to understand what the equivalent of an ECLO might cost the NHS compared if they undertook those 'ECLO-like' activities (the opportunity cost). The Personal Social Services Research Unit (PSSRU) produce an annual account – Unit Costs of Health and Social Care – of the roles within the NHS and their mean salaries and salary on-costs, overheads, etc. based on the average of over 230 English hospitals and NHS institutions.[139] This seems the most appropriate source to establish these substitution costs. We acknowledge that there are wide variations throughout the UK, but this is considered as a representative guide for deriving an hourly rate for staff that reflects the overall cost to the NHS. The rates shown in Table 5.19 here are taken from this source.

For some of the roles in the eye clinic cost per patient contact has been calculated where the average time spent per patient is relatively consistent (i.e. the role of nurses). For others, a cost per working hour is used as there is a wide variation in the time spent on their patient-related activities. Unlike nurse rates, the hourly rates for 'community-based scientific and professional staff' which equate to ECLO NHS rates reflect time that an ECLO has spent at the clinic including the various salary on-costs and overheads that apply, and is also the rate used for work done on behalf of the client (including phone calls, paperwork like CVI registration, travel, etc.) that may take place at other community-based institutions.

It should also be considered that, when ECLOs are working in the clinic environment, they will be affected by the some of the salary on-costs and overheads of the hospital, raising their hourly rate. The hourly rate presented here is an underestimate of the true cost of the 'NHS employed' ECLO.

[139] Curtis and Burns (2015), op. cit – accessed from: http://www.pssru.ac.uk/project-pages/unit-costs/2015/

TABLE 5.19 · Unit costs of ECLO and NHS staff[140]

ANNUAL & UNIT COSTS	Community-based scientific and professional staff (p.165)						Hospital-based staff (p.277)			(p.233)	(p.234)	(p.235)
	Band 4	Band 5	Band 6	Band 7	Band 8a	Band 8b	Nurse: Band 6	Nurse: Band 7	Nurse: Band 8a	Registrar Doctors	Associate Specialist	Consult'nt Surgical
Wages/salary	£21,248	£23,284	£31,070	£38,525	£46,038	£55,276	£31,914	£38,332	£45,240	£37,329	£78,217	£87,229
Salary on-costs	£4,809	£5,375	£7,540	£9,612	£11,701	£14,269	£7,774	£9,558	£11,479	£9,279	£20,646	£23,152
Overheads: Management, admin and estates staff	£6,384	£10,948	£9,459	£11,794	£14,146	£17,038	£7,677	£9,257	£10,980	£9,741	£20,662	£23,070
Overheads: Non-staff	£9,954	£14,014	£14,749	£18,388	£22,056	£26,566	£16,687	£20,121	£23,865	£22,792	£48,344	£53,976
Capital overheads	£4,370	£4,370	£4,370	£4,370	£4,370	£4,370	£3,687	£3,687	£3,687	£4,244	£4,244	£5,101
Working time	42.4 weeks per year, 37.5 hours per week (1590 hours)			42.4 wks per year, 48 hrs per week			42.4 wks per year, 40 hrs per week			42.4 wks per year, 43.3 hrs per week		
Cost per working hour	**£29**	**£36**	**£44**	**£52**	**£62**	**£74**	**£45**	**£54**	**£63**	**£41**	**£101**	**£105**
Cost per patient contact	-	-	-	-	-	-	**£109**	**£131**	**£154**	-	-	-

NOTE: Hourly and patient contact rates do NOT include qualification costs or travel expenses

[140] Curtis L and Burns A (2015) *Unit Costs of Health & Social Care* Personal Social Services Research Unit, University of Kent, Canterbury

Where employed by the NHS, ECLOs are typically banded at Grade 4 or 5. As we can see in Table 5.20 below, the rates for nurses and community professional staff (including the ECLOs) are very similar (e.g. Band 6 nurse and community professional = £44 and £45 respectively) so when similarly graded NHS staff are doing the 'ECLO-like activities' at a clinic, the cost difference will be negligible. In cases where, for example, a Band 6 nurse (£45/hour) is 'released' by use of a Band 4 ECLO (£29/hour), this implies that there would be a cost saving for that hour. However, in terms of opportunity cost and from the economic perspective, this represents a release of resources if this nurse can carry on other duties with that time. A release of cash is only available if the nurse has hours reduced and no salary costs are incurred. Thus the time released must be a meaningful and useful amount of time in which another task or activity can be delivered or sufficient time that would mean that a staff member can be released from working in the clinic and the staffing costs avoided.

At the practical level while some of this hour may be released from this nurse's time, during the clinic it is likely that the nurse may still continue to provide a similar service to patients and that the ECLO provides additional support to these patients. Therefore, assumptions of ECLOs releasing time for other NHS staff should be considered with caution, as the ECLO may provide additional value to these patients in this time while freeing-up a short amount of time for substitute staff. It may be that ECLOs would need to carry out a number of hours work at the clinic in order to free-up a meaningful length of time for the nurse role – for example 2-3 hours (or the duration of the clinic) so that the nurse can perform a series of other activities in the clinic or elsewhere.

The literature review highlighted a study undertaken in 2013 of the forms of provision and cost of ECLO services.[141] An estimate of £17.94 per patient per ECLO contact was reported; furthermore, approximately £247.76 for ECLO intervention over a person's lifetime was estimated for proportions of people registered as severely sight impaired at each age group, assuming an ECLO is seen once per year. We did not use these figures as we have a somewhat different cost issue in front of us; we are looking at a substitution of ECLOs for NHS staff and existing clinics, into which the ECLO service would be added/increased. Thus the opportunity cost to the NHS is the staff member who would otherwise be employed and/the equivalent NHS pay band. Additionally the ECLO activity data suggests more frequent meetings (between 9% and 17% meetings reported in the data over the 12 months were 'follow up' meetings) with patients than the one per year suggested in this publication.

5.3.2 STAFF SURVEY - DESCRIPTION

In total 30 study sites were visited through the course of the study, from which 20 contributed to the staff survey. The survey was opportunistic and depended very much on the busyness of the clinic and the willingness of staff to engage with the researchers. The respondents to the survey are summarised in Table 5.20 which also shows how we grouped the staff from the survey responses to role and grade.

Table 5.21 reports the number of staff responses per staff group by 'ECLO' and 'no ECLO' site and shows that 78 members of staff contributed from ECLO sites compared to 20 members of staff from sites without ECLO. Analysis of the nine areas of patient support offered to patients by clinics was only conducted for staff groups where 5 or more members of staff provided responses to questions.

[141] Gillespie-Gallery et al (2013), op. cit

TABLE 5.20 · Analysis of staff groups responding to the survey

Staff Group for analysis	Free Text response to survey	Staff grade
Consultant Ophthalmologist	Consultant, Consultant Ophthalmologist	No grade was entered
Clinical Nurse Specialist /Ophthalmic Nurse	Matron, Nurse clinic manager, Nurse manager, Nurse practitioner, Ophthalmology nurse, Senior charge nurse Clinical nurse specialist, Ophthalmic nurse Senior nurse, Ophthalmic nurse, Sister eye clinic	Grades 5,6,7,8
Senior Optometrist / Optometrist	Head Optometrist, Head Optometrist, Senior Optometrist, Optometrist	Grade 6 and 8
Senior Orthoptist / Orthoptist	Head orthoptist, Manager orthoptics, Deputy head orthoptics, Orthoptist, Senior orthoptist, Specialist orthopist	Grades 5,6,7,8
Specialist Doctor/Registrar	Associate specialist ophthalmology, Clinical fellow doctor (CF), Doctor (GPST2), Registrar (ST1), Speciality doctor (medical grade non-consultant), ST5 ophthalmology (ST)	Grades in brackets
Staff Nurse / Sister	Senior sister, Staff nurse, Jr Sister, Nurse Outpatient sister, Staff nurse	Grades 4,5,6
Ophthalmic Technician	Ophthalmic technician	Grade 3
Medical Photography / Imaging Technician	Digital imaging technician, Imaging technician Lead imaging technician, Medical photography	Grades 3,4,5
Healthcare Assistant	HCA, Healthcare Assistant, Senior HCA	Grades 3,4
Medical Secretary	Medical secretary	Grade 3

Therefore, the descriptive analysis of resource use by 'ECLO' compared and 'no ECLO' sites was undertaken for consultant ophthalmologists, clinical nurse specialists and ophthalmic nurses, senior optometrists and optometrists, senior orthoptists and orthoptists (although response rates were just under 5), and nurses and for ECLO sites only specialist doctors and registrars are reported.

Responses were reported in numerical form but occasionally in a free text format e.g. "*five to ten minutes"* and therefore needed to be collated and converted into numerical data for analysis. The following rules were applied to non-numerical responses:

- Responses entered as a range, for example 1 to 5 minutes were converted into an average value, in this case for example 2.5 minutes;
- Responses indicating less than 1 per week or more than 1 per week were classified as 1 e.g. 1 patient or 1 minute;
- Responses such as 35+ were conservatively classified as 35; and
- Responses indicating that patient support was only provided occasionally or to 1 or 2 patients per year were classified as 0 patients.

TABLE 5.21 · Number of staff who responded to the questionnaire

Staff Group	Number of staff providing an answer Sites with ECLO		Number of staff providing an answer Sites without ECLO	
	N	%	N	%
Consultant Ophthalmologist	20	25.6	5	25
Specialist doctor / Registrar	7	9	0	0
Clinical Nurse Specialist/Ophthalmic Nurse	13	16.7	3	15
Senior optometrist /optometrist	7	9	3	15
Senior orthoptist /orthoptist	7	9	2	10
Staff nurse / sister	10	12.8	4	20
Healthcare Assistant	4	5.1	2	10
Medical secretary	2	2.6	1	5
Medical photography / Imaging technician	5	6.4	0	0
Ophthalmic technician	2	2.6	0	0
ECLO	1	1.3	0	0
TOTAL RESPONDENTS	**78**	**100**	**20**	**100**

It should also be noted that where responses indicating the amount of time supporting a patient was minimal such as "approx. 1 minute" this often referred to handing out an information leaflet or making a referral to another healthcare specialist so whilst brief could have had a meaningful impact. At one site the ECLO also responded to the questionnaire but is not included here as it was not within the scope of this survey.

5.3.3 RESULTS OF STAFF SURVEY

Staff were asked to list any other types of support offered to patients that were not included in the survey. No other types of support were listed. As staff response rates were relatively low for some staff groups the analysis is centred on consultant ophthalmologists and nurse groups and the time spent giving emotional support, advocacy, certification and registration (data from other staff groups is presented in Appendix 5). All the responses relate to patients seen in a typical week. The number of patients of course would depend on the number of clinics held at the centre per week.

Consultant ophthalmologists

Emotional Support: Question – I have spent time listening to patients/carers, talking through their worries or concerns.

Consultant ophthalmologists at ECLO sites reported providing marginally more patients per week with emotional support than non ECLO sites (Table 5.22):

- ECLO sites reported seeing between 0 and 23 patients and spent between 2 and 20 minutes (mean 6.82 minutes) providing emotional support; and
- Non ECLO sites reported seeing between 0 and 10 patients and spent between 3 and 7.5 minutes (mean = 5.13 minutes) providing emotional support.

Advocacy: Question – I have helped people to have their voices heard; to secure their rights and to obtain the support they need.

Consultant ophthalmologists at both ECLO and non ECLO sites reported low or no levels of advocacy.

Certification and registration: Question I have informed and advised patients about Certification and Registration and its benefits. I have helped patients in a practical way by helping to fill in forms, for example.

Consultant ophthalmologists at both ECLO and non ECLO sites saw a similar number of patients per week, supporting certification and registration but ECLO sites reported more time spent supporting patients with practical help such as form filling:

- ECLO sites reported seeing between 0 and 7 patients advising about certification and registration and spent between 1 and 15 minutes (mean = 5.07 minutes) offering advice. They also reported seeing between 0 and 5 patients offering practical help such as form filling and spent between 1 and 15 minutes (mean = 6.40 minutes) supporting patients; and
- Non ECLO sites reported seeing between 1 and 2 patients advising about certification and registration and spent between 3 and 10 minutes (mean = 5.50 minutes) offering advice. They also reported seeing between 0 and 2 patients offering practical help such as form filling and spent between 1 and 3 minutes (mean = 2.00 minutes) supporting patients.

Clinical Nurse Specialist / Ophthalmic Nurse

Emotional Support: Question – I have spent time listening to patients/carers, talking through their worries or concerns.

Clinical nurse specialists and ophthalmic nurses at ECLO sites reported providing more patients per week with emotional support than non ECLO sites (Table 5.23):

- ECLO sites reported seeing between 0 and 100 patients and spent between 3 and 25 minutes (mean 11.0 minutes) providing emotional support; and
- Non ECLO sites reported seeing between 0 and 5 patients and the one response to the question regarding time spent, reported spending 10 minutes supporting a patient.

Advocacy: Question – I have helped people to have their voices heard; to secure their rights and to obtain the support they need.

Clinical nurse specialists and ophthalmic nurses at ECLO site reported low levels of advocacy support per week for patients with on average less than 1 patient receiving support of this nature, while non ECLO sites did not report advocacy support.

TABLE 5.22 · Support provided by Consultant Ophthalmologist

Type of support provided by Consultant Ophthalmologist		No. of patients to whom you've provide this service in the last week					Average time spent per patient (minutes)				
		N	Mean	SD	Min	Max	N	Mean	SD	Min	Max
I have spent time listening to patients/carers, talking through their worries or concerns.	Site with ECLO	19	3.63	6.39	0	23	11	6.82	5.19	2.0	20
	Site without ECLO	5	3.40	4.22	0	10	4	5.13	1.84	3.0	7.5
I have provided information about further, non-clinical support, local and/or national.	Site with ECLO	19	1.11	1.86	0	6	7	4.21	2.69	1	7.5
	Site without ECLO	5	0.70	1.10	0	3	2	1.75	1.06	1	2.5
I have provided eye health information to patients, family members and others.	Site with ECLO	18	5.39	6.93	0	20	10	3.15	2.35	1	7.5
	Site without ECLO	5	7.90	4.96	2	15	5	2.20	1.64	1	5
I have helped people to have their voices heard; to secure their rights and to obtain the support they need.	Site with ECLO	18	0.22	0.73	0	3	0	-	-	-	-
	Site without ECLO	5	0	0	0	0	0	-	-	-	-
I have made contact with referrers on behalf of patients.	Site with ECLO	19	0.95	2.46	0	10	4	5.75	2.90	4	10
	Site without ECLO	5	0	0	0	0	0	-	-	-	-
I have informed and advised patients about Certification and Registration and its benefits.	Site with ECLO	19	1.55	1.55	0	7	15	5.07	3.74	1	15
	Site without ECLO	5	1.30	0.45	1	2	5	5.50	2.74	3	10
I have helped patients in a practical way by helping to fill in forms, for example.	Site with ECLO	18	0.72	1.41	0	5	5	6.40	6.07	1	15
	Site without ECLO	5	0.70	0.67	0	2	3	2.00	1.00	1	3
I have followed up with patients that I've referred on to other services to check that satisfactory progress has been made.	Site with ECLO	18	0.31	0.99	0	4	2	10.5	0.71	10	11
	Site without ECLO	5	0	0	0	0	0	-	-	-	-
I have engaged and consulted with patients to evaluate our services and to support continuous service improvement	Site with ECLO	18	0.14	0.41	0	2	1	11	-	11	11
	Site without ECLO	5	0	0	0	0	0	-	-	-	-

TABLE 5.23 · Support provided by Clinical Nurse Specialists / Ophthalmic Nurse

Type of support provided by Clinical Nurse Specialists / Ophthalmic Nurse		No. of patients to whom you've provide this service in the last week					Average time spent per patient (minutes)				
		N	Mean	SD	Min	Max	N	Mean	SD	Min	Max
I have spent time listening to patients/carers, talking through their worries or concerns.	Site with ECLO	12	16.50	28.85	0	100	8	11.0	7.82	3	25
	Site without ECLO	3	1.67	2.88	0	5	1	10.0	-	10	10
I have provided information about further, non-clinical support, local and/or national.	Site with ECLO	12	2.38	4.90	0	15	4	6.0	5.05	2	12.5
	Site without ECLO	3	0	0	0	0	0	-	-	-	-
I have provided eye health information to patients, family members and others.	Site with ECLO	13	6.77	7.34	0	20	9	6.56	4.75	1.5	15
	Site without ECLO	1	1.50	-	2	2	1	5.0	-	5	5
I have helped people to have their voices heard; to secure their rights and to obtain the support they need.	Site with ECLO	13	0.81	1.55	0	5	2	8.75	1.77	8	10
	Site without ECLO	3	0	0	0	0	0	-	-	-	-
I have made contact with referrers on behalf of patients.	Site with ECLO	11	0.68	2.26	0	8	1	7.50	-	8	8
	Site without ECLO	3	0	0	0	0	0	-	-	-	-
I have informed and advised patients about Certification and Registration and its benefits.	Site with ECLO	12	0.75	1.60	0	5	3	7.0	1	1	15
	Site without ECLO	3	0.33	0.58	0	1	1	5.0	-	5	5
I have helped patients in a practical way by helping to fill in forms, for example.	Site with ECLO	12	0.83	1.95	0	5	2	5.0	-	5	5
	Site without ECLO	3	0.33	0.58	0	1	1	2.0	-	2	2
I have followed up with patients that I've referred on to other services to check that satisfactory progress has been made.	Site with ECLO	12	0.42	1.44	0	5	1	5	-	5	5
	Site without ECLO	3	0	0	0	0	0	-	-	-	-
I have engaged and consulted with patients to evaluate our services and to support continuous service improvement	Site with ECLO	12	1.0	2.89	0	10	2	5.0	-	5	5
	Site without ECLO	3	0	0	0	0	0	-	-	-	-

Certification and registration: Question I have informed and advised patients about Certification and Registration and its benefits. I have helped patients in a practical way by helping to fill in forms, for example.

Clinical nurse specialists and ophthalmic nurses at ECLO sites reported marginally more support of patients per week supporting certification and registration than non ECLO sites.

- ECLO sites reported seeing between 0 and 5 patients advising about certification and registration and spent between 1 and 15 minutes (mean = 7.0 minutes) offering advice. They also reported seeing between 0 and 5 patients offering practical help such as form filling and spent 5 minutes supporting patients; and
- Non ECLO sites reported seeing between 0 and 1 patients advising about certification and registration and spent 5 minutes offering advice. They also reported seeing between 0 and 1 patient offering practical help such as form filling and spent 2 minutes supporting patients.

Staff Nurse / Sister

Emotional Support: Question – I have spent time listening to patients/carers, talking through their worries or concerns.

Staff nurses and sisters at ECLO sites reported seeing fewer patients per week for emotional support than non ECLO sites but spent more time providing emotional support than non ECLO sites (Table 5.24)

Advocacy: Question – I have helped people to have their voices heard; to secure their rights and to obtain the support they need.

Staff nurses and sisters at ECLO site reported low levels of advocacy support per week for patients with on average less than 1 patient receiving support of this nature, while non ECLO sites did not report advocacy support.

Certification and registration: Question I have informed and advised patients about Certification and Registration and its benefits. I have helped patients in a practical way by helping to fill in forms, for example.

Staff nurses and sisters at ECLO and non ECLO sites saw a similar number of patients per week and spent a similar amount of time supporting certification and registration but ECLO sites reported more time spent supporting patients with practical help such as form filling:

- ECLO sites reported seeing between 0 and 2 patients per week advising about certification and registration and spent between 3 and 15 minutes (mean = 7.75 minutes) offering advice. They also reported seeing between 0 and 5 patients offering practical help such as form filling and spent approx. 30 minutes supporting patients.
- Non ECLO sites reported seeing between 0 and 2 patients advising about certification and registration and spent approx. 15 minutes offering advice. They also reported seeing between 0 and 1 patient offering practical help such as form filling and spent approx. 2 minutes supporting patients.

TABLE 5.24 · Support provided by Staff Nurse / Sister

Type of support provided by Staff Nurse / Sister		No. of patients to whom you've provide this service in the last week					Average time spent per patient (minutes)				
		N	Mean	SD	Min	Max	N	Mean	SD	Min	Max
I have spent time listening to patients/carers, talking through their worries or concerns.	Site with ECLO	9	7.44	6.12	0	16	7	14.14	11.39	4	30
	Site without ECLO	4	13.75	13.77	0	30	3	6.17	3.40	3.5	10
I have provided information about further, non-clinical support, local and/or national.	Site with ECLO	8	1.94	2.18	0	5	4	8.75	4.79	5	15
	Site without ECLO	4	4.25	4.35	0	10	3	2.17	1.04	1	3
I have provided eye health information to patients, family members and others.	Site with ECLO	8	6.81	5.40	0	15	6	6.83	6.46	1	15
	Site without ECLO	3	8.33	2.89	5	10	3	3.83	3.18	2	7.5
I have helped people to have their voices heard; to secure their rights and to obtain the support they need.	Site with ECLO	6	0.67	1.63	0	4	1	30.0	-	30	30
	Site without ECLO	4	0	0	0	0	0	-	-	-	-
I have made contact with referrers on behalf of patients.	Site with ECLO	7	0.86	1.57	0	4	3	17.5	10.90	10	30
	Site without ECLO	4	0.25	0.50	0	1	1	10.0	-	10	10
I have informed and advised patients about Certification and Registration and its benefits.	Site with ECLO	8	0.81	0.53	0	2	6	7.75	5.67	3	15
	Site without ECLO	4	0.50	1.0	0	2	1	15.0	-	15	15
I have helped patients in a practical way by helping to fill in forms, for example.	Site with ECLO	7	1.00	1.92	0	5	2	30.0	-	30	30
	Site without ECLO	4	0.25	0.50	0	1	1	2.0	-	2	2
I have followed up with patients that I've referred on to other services to check that satisfactory progress has been made.	Site with ECLO	8	0.25	0.71	0	2	2	22.50	10.61	15	30
	Site without ECLO	4	0	0	0	0	0	-	-	-	-
I have engaged and consulted with patients to evaluate our services and to support continuous service improvement	Site with ECLO	8	3.50	8.75	0	25	3	8.33	4.73	3	12
	Site without ECLO	4	0	0	0	0	0	-	-	-	-

5.4 ECONOMIC MODELLING

5.4.1 SUMMARY

Background

While a number of studies have attempted to investigate the impact of the ECLO on falls reduction, we have attempted to pursue this further to quantify the impact of the ECLO on NHS costs overall. Deterministic modelling was used to analyse the data collected from our study combined with the literature to estimate the potential impact of the ECLO service on both falls and depression which, aside from the personal impact on individuals, are both costly to the healthcare system. In order to undertake these analyses, the relevant input variables were identified from the literature review and the analysis of the data collected within this study. Discreet event simulation was employed to explore clinic flows and substitution effects of ECLOs on staff capacity in a typical hospital eye clinic.

Key findings

- The literature indicates that the rate of falls and risk of falls and the rate of depression in people is unequivocally linked with sight loss. The ECLO, alert to the impact of a fall on a person with sight loss, is vital in making the connection between the risks, the patient and services available in the region. Using the quantitative data collected in our study, combined with costs and prevalence data on falls and depression from the literature, deterministic modelling enabled estimation the potential impact of the ECLO service on both falls and depression.
- We estimated the ECLO service might lead to a 13.3% reduction in falls, equivalent to approximately 28,000 fewer falls, with a reduction in the total fall rate from 25% to 21.7%, based on the 2013 UK prevalent population of people with sight loss.
- Cost implications of ECLO provision for fall reduction was estimated at an incremental cost per fall avoided of £2,813 when an ECLO is supporting patients at risk of falls. Should the percentage of patients able to see an ECLO increase, a proportional saving increase should also ensue.
- The DEPVIT study reported that 43% of those presenting to low vision rehabilitation clinics have significant depressive symptoms. Our estimates suggest that the ECLO could prevent approximately 43,000 interventions from NHS services for depression, a reduction of 11.9% compared to a situation where no ECLO action was taken. At an average costs of £2,509 per depression episode per person, an estimated saving of £107.6m in avoided referrals to depression services is estimated.
- After accounting for the total cost of the estimated 112 full-time ECLOs required, a total saving of £101m is estimated, equivalent to 11.2% saving compared with care without an ECLO. This represents an incremental cost per referral avoided of £2,361. Increasing the percentage of patients able to see an ECLO would result in a proportional saving increase.

5.4.2 BURDEN OF FALLS AND DEPRESSION

It is clear from the qualitative and quantitative data collected and reported from this study that ECLOs have a vital role to play enabling people with sight loss to adjust to their diagnosis and optimise their

ability to cope and have as full a life as possible post diagnosis. This section of the report addresses two aspects of sight loss that have significant impact on people: falls and depression. As the literature review (section 3.2) suggests, the rate of falls, the risk of falls and risk of depression in people with sight loss is unequivocally linked. The role of the ECLO, alert to the impact of a fall or the risk of depression on a person with sight loss, is vital in making the connection between these risks, the patient and services available in the region.

A number of studies have quantified the impact on the NHS of falls reduction. Our study attempts to pursue this further, in order to quantify the potential impact of the ECLO on NHS costs, overall. Using the data collected in this study we used deterministic modelling approaches to estimate the potential impact of the ECLO service on both falls and depression which, aside from the personal impact of these problems on individuals, are both costly to the healthcare system. The models for falls and depression are presented in Appendix 6 and Appendix 7 respectively.

In order to undertake these analyses, appropriate variables including incident rates, ECLO resource usage, and costs were identified from the literature review and statistical analysis of the data collected within this study. Because some information is not available and some data are limited we have also had to make estimates based on informed and reasonable assumptions for some of the calculations. Care and discretion are essential in selecting appropriate variables and conservative assumptions to avoid criticism of overestimating the impact an ECLO service can make. Any assumptions made to facilitate our estimates have been explained. Whilst assumptions are not 'evidence' or fact they can enable scenarios to be constructed and 'what if' estimates to be created. We have taken this approach to explore 'what if... ECLOs presently or in future initiate a chain of events that reduces the impact of falls or depression'. At present the assumptions are informed by our understanding of reality but the objective evidence is not available. In the fullness of time, data may be available to replace our assumptions and these estimates can be re-calculated.

The impact of falls and depression in the NHS is sizable. Research undertaken for the King's Fund estimated the cost of falls to the NHS - that is falls overall, not just related to sight loss - to exceed £2 billion[142]. The cost of depression, overall, in England was estimated at £1.7 billion by McCrone and colleagues.[143]

We hypothesised that the presence of ECLOs in the ophthalmology clinics improves the rate of risk identification, contact and referral for those that require further support for these (latent) problems. Through an appropriate intervention (listening, empathising, giving emotional support, informing, signposting, referring etc.) by the ECLO, it is assumed that fewer incidents of falls and depression would occur, reducing the financial burden on the healthcare system. To explore this hypothesis we have had to bring together data from various sources to enable us to make estimates of the potential impact of ECLOs on the costs of falls and depression.

[142] Tian Y, Thompson J, Buck D and Sonola L (2013) *Exploring the system-wide costs of falls in older people in Torbay* The King's Fund – accessed from: www.King'sfund.org.uk/publications/exploring-system-wide-costs-falls-older-people-torbay

[143] McCrone P, Dhanasiri S, Patel A, Knapp M and Lawton-Smith S (2008) *Paying the Price: the cost of mental health care in England to 2026* The King's Fund – accessed from: http://www.King'sfund.org.uk/publications/paying-price

The Wales Eye Clinic Liaison Report conducted by RNIB Cymru[144], an assessment of the impact of the ECLO service in Wales reported that the service supported 6,730 patients in 2012/13. A report from Access Economics published in 2009,[145] estimates that 1.8m individuals in the UK have sight loss. Of the 53.5% reported by Access Economics, to have sight loss due to uncorrected refractive error (RE), which would typically be corrected by High Street optometrists with the use of glasses or contact lenses. The remaining 46.6% - equivalent to approximately 838,000 people - would require support from secondary care based clinics for issues including age-related macular degeneration (AMD), cataract, diabetic retinopathy (DR), glaucoma and other rare eye diseases. This is a prevalent population which is the basis for our estimates. This is perhaps a smaller number than is prevalent in the present day as numbers of people with eye conditions related to older age is increasing. These are also broad assumptions and a simplification of reality as secondary care support may be required for those with severe RE related sight loss but not required for those with mild sight loss related to other conditions. And of course people with RE may also have eye conditions that would be treated in secondary care.

In order to get an estimate of the people in the UK that would have contact with an ECLO (accepting that some people may be in need of support but not get it due to lack of service) we have worked up a series of informed estimates. We have also assumed that once contact is made with an ECLO the support is open ended, though in reality there may be a finite number of initial contacts which tail off as things settle for an individual. Assuming an equal prevalence rate of sight loss across UK regions, and a Welsh population of 4.8%[146] of the UK total, a total of 87,000 individuals in Wales are estimated to have sight loss. Of the Welsh sight loss population, 46.6%, equivalent to approximately 40,500 people, have conditions other than RE and thus require secondary care interventions. This is the population of interest for our model and resulting estimates.

We used the RNIB Cymru Eye Clinic Liaison Report data published in 2013, [147] which reports 6,730 patients were supported by an ECLO in 2012/3, to give us a rate of 16.7% for people with sight loss in Wales receiving secondary care support in this time period. From a UK perspective, for 2012/13, scaling these estimates using the 16.7% rate would equate to 139,500 patients both requiring support and getting it from an ECLO. This is a conservative estimate as the patient survey data reported in section 5.2 suggests a higher percentage of 28% patients attending an ECLO supported clinic want and get support.

Based on the ECLO activity data reported in section 5.1 we have conservatively estimated that an ECLO spends 76 minutes per patient, overall, of which a little under half the time (35 minutes) is spent undertaking activities on behalf of the patient, the rest of the time in contact with the patient. As stated above, 139,500 patients are estimated to receive support from an ECLO, in 2012/13, which means that they utilised a total 170,689 hours of ECLO time. In order to estimate the costs of an ECLO service supporting this prevalent population we estimated the salary costs at NHS rates based on a 37.5 hour

[144] RNIB Cymru (2013) *Eye Clinic Liaison Report* – accessed from: http://www.rnib.org.uk/wales-cymru-publications/reports

[145] Access Economics (2009) op. cit

[146] ONS mid-year population estimates 2012 https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesanalysistool

[147] RNIB Cymru (2013) *Eye Clinic Liaison Report* – accessed from: http://www.rnib.org.uk/wales-cymru-publications/reports

working week, and 42.4 week working year (1590 hours per year). A total 112 full time ECLO's would be required to deliver this level of service. Using the equivalent NHS rates (see Table 5.19) an ECLO funded in Band 4 costs £29 per hour so we can estimate that provision of this level of service costs total £5.1m per year. It should be noted that by no means all ECLOs are funded by the NHS, but in many ways from many sources – though the benefits of employing ECLOs accrue to NHS patients and services.

As we now have an estimate of what ECLO resource and cost it might take in terms of ECLO provision, based on 2012/13 data, to influence outcomes for people with sight loss, we can estimate what the economic impact of this for falls and depression – two common problems for people with sight loss.

Falls

Having analysed data related to falls for 421 patients from Torbay, Tian et al[148] report a total cost to the NHS associated with these falls of £1.2m, or £2,850 per fall which we can use to help with our estimates. Inflating from 2013 prices to 2016 prices, the cost per fall is estimated to be £2,997.[149]

Data from the same Wales Eye Clinic Liaison Report[150] estimates that 25% of those with non RE sight loss ultimately have falls. As stated above, if approximately 838,000 people in the UK require support for sight loss, using this rate, we estimated that of these people 209,400 will experience falls, equating to an estimated cost to the NHS of £628 million per year.

Our next steps were to estimate how much the ECLO services can impact and reduces this substantial amount of money.

Based on the ECLO activity data reported in Section 5.1, fear of falling and actually having a fall, subsequently, has a relationship, so we can bring this knowledge into our calculations on rates of falling. As described above, we assumed that 16.7% of the UK population with sight loss had contact with an ECLO, equivalent to approximately 139,500 patients; we assume based on the ECLO activity data reported in section 5.1, that of these 47%, have a fear of falling. In order to explore the potential for the ECLO service to influence the rate of falls for these people we have to make some assumptions alongside using reported data.

From the RNIB Cymru Wales Eye Clinic Liaison report,[151] it is noted that 47% of those with sight loss have a fear of falling, which scaled up is equivalent to 393,700 UK patients. This is within the range reported by the ECLO activity data in Table 5.7 where the fear of falling across the four UK countries ranges from 77% in Northern Ireland, 41% in England and Wales and 7% in Scotland (rounded percentages). An assumption has been made that whilst some people who fall would not have had a prior fear of falling, the majority would have a fear of falling, given their condition or a previous history of falls. In the absence of available evidence linking the number of falls to those with a fear of falling we made an assumption that, of the people reported to fall in the RNIB Cymru Wales Eye Clinic Liaison

[148] Tian et al (2013) op. cit

[149] Bank of England Inflation Calculator – accessed from: http://www.bankofengland.co.uk/education/Pages/resources/inflationtools/calculator/default.aspx

[150] Ibid.

[151] RNIB Cymru (2013) op. cit

report[152], 80% also had a fear of falling prior to the fall, with the remaining 20% of falls were experienced by people with no fear of falling. From these assumptions it has been estimated that 167,500 (42.6%) of the 'fear of falling' group ultimately have a fall. In addition, because there will be some people who have no fear of falling may have a fall, based on the ECLO activity data rates, we estimate that 41,900 (9.4%) of the people who have no fear of falling ('non-fearers') actually do have a fall.

Table 5.11 shows that the ECLO referral rate to falls services was surprisingly low, given the remit of ECLOs. We queried this with the managers of ECLOs with RNIB and Action for Blind People. The explanation for the rate seemed to be related, in some areas, to lack of availability and means of access to falls services. An informal survey with ECLOs undertaken by RNIB suggests that once the ECLO identifies the risk, if there is limited access to falls services, the referrals go via GPs or the ophthalmology clinic and are therefore not captured as a referral to falls services. The real rate of people being referred through the action of an ECLO is thought to be much higher than captured in the activity data. Based on this information we assume that an ECLO referral rate to falls services of 30% will occur for people who have stated that they have a fear of falling, but we assume a reduced referral rate of 5% for people with no explicitly expressed fear of falling, but where the ECLO recognises that a risk does exist and something needs to be done to address the risk.

Our next assumption is that referral to relevant services is deemed to be effective and reduce the likelihood of falls with some reports identifying a significant reduction in the fall rate following intervention of approximately 1/3. This is supported by published research by Close and colleagues.[153] Based on this evidence, we can assume a reduction in the likelihood of falls of 1/3 following referral, leading to estimates of fall rates amongst ECLO referred patients of 28.4% and 6.3% for the 'fearing fall' and 'not fearing fall' groups respectively. Assuming that ECLOs make appropriate referrals, the fall rate amongst those who receive support from an ECLO, yet are not subsequently referred to falls services, is assumed to be very low; however we have to assume some failure in the system, so conservatively our calculations assume a residual fall rate of 1% for these patients. The fall rate for those people not seen by ECLOs is assumed to remain unchanged relative to the background rate of falls.

If we put all this information together in our model of the potential impact of the activity of ECLOs, we estimate that this could lead to a 13.3% reduction in falls, equivalent to 28,000 fewer falls across the UK, with a reduction in the total fall rate from 25% to 21.7% (see Appendix 6 for the detailed calculations). However ECLO service cost implications have to be taken into account.

As described earlier, the costs of providing ECLOs that can support the 139,500 patients is estimated at £5.1m. At an average cost per fall of £2,997[154], the estimated cost of 181,500 falls related to sight loss, is estimated to cost £544m. Assuming the ECLO service reduces the overall number, rate and cost of falls; for each fall avoided the NHS benefits by saving £2,813 compared with the 'no ECLO' situation. This reduction, equivalent to a 12.5% saving to the health services, relative to the cost to the NHS in a

[152] RNIB Cymru (2013) op. cit

[153] Close J, Ellis M, Hooper R, Glucksman E, Jackson S and Swift C (1999) 'Prevention of falls in the elderly trial (PROFET): a randomised controlled trial' *Lancet* Jan 9th, 353.9147, pp.93-7

[154] Tian et al (2013) op. cit

situation where either clinics are not supported by an ECLO service or for other reasons a patient does not get access to an ECLO. Should the percentage of patients able to see an ECLO increase, a proportional saving increase will occur.

Depression

A similar deterministic approach was also used to evaluate the potential impact of the ECLO service on depression. Those with sight loss are reported to have a higher risk of developing depressive symptoms, with the recent DEPVIT study presenting results on the observed rate of depression in people attending low vision clinics (43%)[155] and the RNIB Cymru Report claiming that older people living alone were up to three times more likely to demonstrate depressive symptoms in comparison to those with normal sight.

Using the same approach for estimating the impact on falls, the calculations exclude the 53.5% of sight loss patients with RE, and assumes that 100% of those with other sight loss conditions have contact with the eye services in secondary care. From a UK perspective this equates to approximately 838,000 patients. The DEPVIT study[156] reported that 43% of those presenting to low vision rehabilitation clinics have significant depressive symptoms. Using this figure in our calculations would mean that the equivalent to 360,000 of the population may be in need of support because of depressive symptoms. The cost of services that are in place to support people who have depressive symptoms suggested by recent literature indicates that average service costs of £2,085 relating to managing depression are reported by McCrone and colleagues;[157] at 2016 prices our estimates suggest that this corresponds to a total service cost amongst the sight loss population in excess of £900 million if they all at some point accessed these services.

Using the same methodology when we looked at the impact of falls for people with sight loss, we assume that 16.7% of the population seeking support got time with an ECLO, equivalent to 139,500 patients, of which we estimated 60,000 have depressive symptoms, using the DEPVIT rate of 43%. Based on the ECLO activity data reported in section 5.1.data, we know that ECLOs provide emotional support to approximately 95% of the patients seen; equivalent to 57,000 patients of the estimated number of people who have sight loss and depressive symptoms. In addition to providing emotional support for those people ECLO's can then choose whether to inform, signpost or refer these patients to services or resources that can potentially avert the onset of clinical depression. Assuming (based on informal advice) that the ECLO onward referral rate for people showing symptoms of depression is 30% of those receiving emotional support and that these people are subsequently referred to a service that can help the patients' depression symptoms, we can then estimate the potential impact of the ECLOs on depression rates. Our assumption that 30% of those receiving emotional support from the ECLO, equivalent to 17,000 patients, are enabled through referral or signposting to gain access to depression services, such as Improving Access to Psychological Therapies (IAPT) to achieve resolution of symptoms and/or avoid clinical depression.

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[155] Nollett CL, Bray N, Bunce C, Casten RJ, Edwards RT, Hegel M, Janikoun S, Jumbe SE, Ryan B, Shearn J, Smith DJ, Stanford M, Xing W and Margrain TH (2016) 'High Prevalence of Untreated Depression in Patients Accessing Low-Vision Services' *Ophthalmology* 123.2, 440-2014

[156] Ibid.

[157] McCrone et al (2008) op. cit

Using these estimates we can suggest that ECLOs, in the course of giving emotional support and subsequent actions could prevent approximately 43,000 interventions from NHS services for depression, a reduction of 11.9% of costs compared to a situation where no ECLO action was taken. At an average NHS costs of £2,509 per depression episode per person, there is the potential to have an estimated saving of £107.6m from avoided referrals to depression services. After accounting for the total cost of having 112 Band 4 ECLOs in place, in the UK, an estimated total saving of £102m, equivalent to 11.9% reduction is possible, compared with a situation where ECLOs are not in place. This represents an incremental cost per referral avoided of £2,389 (see Appendix 7 for detailed calculations). Increasing the percentage of patients able to see an ECLO would result in a proportional saving increase.

By utilising previously cited estimates of incident prevalence and costs, and making a series of informed, conservative assumptions regarding the ECLOs actions and consequences of these actions, a reduction in sight loss related falls and depression referrals have been calculated with the potential cost savings to the NHS estimated. The estimates presented in this section, calculated using deterministic modelling methods, are not objective evidence of the impact of ECLOs – rather they are informed estimations that indicate the potential benefit of the ECLO service of the healthcare system. These estimates are based on a number of assumptions and the likelihood that there is a relationship between the support provided by an ECLO and actions the ECLO takes on behalf of their client and the outcomes for the consequent actions. It is important to exercise caution with these figures which are based on the premise that there is a sufficient number of ECLOs who take action appropriately and this action leads to a reduction in adverse outcomes for their clients.

The value of these estimates, and the scenarios we have created, are that they provide a focus on where the ECLO can make a difference and where data collection could provide objective evidence of these specific ECLO activities.

5.4.3 SERVICE MODELLING

The discreet event simulation (DES) model we developed was designed to replicate a typical ophthalmology clinic, the number of patients, number of appointments and staff at the clinic are based on observations from the earlier site visits and guidance from RNIB at the start of the project. The patient pathway was based on what we learned from the initial site visits and was validated by RNIB. The premise on which the model was established was that where ECLOs are not in place, or not available due to part time working or being occupied with other patients, clinic staff would be undertaking tasks which the ECLO would normally undertake to give patients support. Once we had the staff survey results it was clear, from those centres at least, that this was not a valid assumption.

5.4.4 MODEL STRUCTURE

Patients enter a 'waiting room' within the model structure and wait (in the model) for their appointments with the clinic staff. The first appointment in the model flow is with the clinical specialist – the 'consultant' – though this could be a specialist registrar or other clinically qualified specialist. The time given to patients by ECLOs was based on the ECLO activity data reported in section 5.1. Based on this information the simulation in the model assumes that 29 patients arrive in the clinic for any type of appointment, per hour. The time spent in the appointment is based on the staff survey and it is assumed (on the basis of discussion) that the consultant appointments follow a normal distribution, with

a mean of 10 minutes per appointment (S.D = 2.5) allowing for the intrinsic variation due to the different appointment types encountered at the ophthalmology clinic.

The ECLO cannot substitute for any of the 'consultant' roles other than giving emotional support, and/or signposting/informing about or referring to specialist services. One important activity undertaken by the ECLO is a contribution to the CVI completion (over and above the information which it is mandatory for the consultant to complete and sign). This can take an ECLO on average 30 minutes. According to the staff interviews this activity is important added information to make things easier for the administration subsequent to the receipt of the form but is not mandatory, compared with the part of the form which the consultant has to do (to do takes approximately 10 minutes). However the staff survey reveals that in the absence of an ECLO no one undertakes the 'added value' role completing the 'nice to do' rather than 'consultant must do' parts of the CVI.

Once a patient has been seen by the consultant for their appointment, in the model the patient remains with the consultant for a set period of time and then goes on to see a nurse. The nurse has specific activities that relate to patient care but may also hypothetically, experience a situation where an ECLO is not available (a site without an ECLO or an ECLO is not available at the clinic at the time) may spend time giving emotional support, inform, signpost or refer patients to other services as the model is concerned with the amount of time that a nurse spends doing an ECLO role. Once patients reach this point, they are divided into those which require support and those which do not. This routing is governed by a percentage obtained from the patient survey data. These data, as used in the model, are summarised below in Table 5.25.

TABLE 5.25 · Patient need for support (source Patient Outcome Questionnaire)

Patients statement about 'needing support'	**%**
Yes	55
No	45
Patients reporting 'needing support but not receiving it'	**%**
Not received	21
Received	79
Patients who received support: who provided support	**%**
ECLO	68
Other staff	32

Patients who do not require support have the simplest route in the model: they are simply counted and leave the model and are '*sent home*'. They are given an EQ-5D value to represent the HRQoL experienced as they enter and leave the model as well as some values for categorical variables relating to their mental health, their fear of falling, and their capability of undertaking their usual activities. The remainder of the patients, 55% at baseline, according to the survey say that they needed support. The

pathway that these patients adopt is far more complex in nature and differs depending upon whether the hospital is an ECLO or a non-ECLO site.

Considering ECLO sites first, the patients first of all are routed through the simulation by whether they receive support (from someone) or are sent home without receiving support. The latter group are the patients who "fall through the net" and their needs are not met and we assume no further support from the ECLO or other staff. As with other patients, they are assigned EQ-5D scores based on the patient survey as well as the values for the categorical outcomes as above.

The percentage of patients who require support and do receive support from the ECLO was obtained directly from the patient questionnaire data (68%) and the remainder have contact with other staff. The ECLO will then spend a set amount of time with each patient (on average 30 minutes based on the ECLO activity data) and then a further set amount of time as they are active on behalf of the patient outside of the face to face contact, also based on the ECLO activity data. Once they have done this, a certain proportion of patients (23.85% based in the English ECLO activity data) will have a CVI supplemented and completed by the ECLO. This will take a set amount of time, on average 30 minutes, also based on the ECLO activity data, and once the ECLO has completed this, they are free to see the next patient. The original patient can also be referred to falls services, or just given information by the ECLO. These individual times are added up to see the amount of time that an ECLO is busy on behalf of that patient arising from the contact.

If the patient is seen by another member of staff rather than the ECLO, the time they spend with the patient is assumed to be the same as the time that the ECLO would spend with the patient, but they do not spend any time on behalf of the patient nor do they complete CVIs for the patients, as this is a senior medical task. This assumption is based on the staff survey results and the qualitative data collection. The number of patients who would have had a CVI fully completed if they had seen the ECLO is counted and noted in the results. The patients are also referred, if necessary, to falls services or given information. This is an assumption since we have no data based on the other support staff, but since this is in an ECLO site, information in terms of leaflets and telephone numbers should be readily available for the patients and since the ECLO has demonstrated best practice in terms of referrals to rehabilitation officers and falls services, it is assumed that the other support staff will follow the same pattern.

For non-ECLO sites, the situation is simpler yet dependent on more assumptions since very little is known about what provision in terms of patient support is present, other than the staff survey data.

To begin with, patients are split into those who received support and those who do not although they do require support. Of these, 79% received support (as for the ECLO site) and 21% do not. Those 21% are *sent home* and are assigned outcomes as outlined above. Of the 79% who receive support, if the support staff are busy then they go home without getting any support. In many ECLO sites, if the ECLO is busy the names of the patients requiring follow up are noted and the ECLO will follow them up at a convenient time. This is not inconsistent with the survey data which suggests that some patients do leave the clinic without their support needs being met (at that time). However, it does give us difficulty in representing this pathway in the model, so this is handled by the patients who fall into this category remaining in the 'waiting room' and the time in the waiting room building up. In our simulations some patients remain indefinitely in the waiting room suggesting that in a typical clinic represented by our

model it is likely that one ECLO may not see all patients who have needs in the clinic on the day of the clinic.

The time spent with the patients at this stage was difficult to quantify. If the support staff are nurses or consultants, their times are already accounted for in the earlier stage of the model. Since we are interested in the consequences of the ECLOs activity we have used the patients' questionnaire data: when patients were asked who supported them if it was not an ECLO, it was reported that either healthcare professionals or people from the voluntary sector supported the patients in their various needs. When their needs were practical in nature, social services, low vision services would also aid in the provision of these needs. However, since the focus is on resource and costs from an NHS perspective, these are accounted for already in the model.

In terms of referrals from other support staff, since these hospitals are non-ECLO sites, we can assume that the support staff do not complete CVIs as an ECLO would and therefore anyone requiring a CVI will get one that has the minimum data and a consultant sign off or get one at the next visit. The model adds these patients up and reports this outcome.

On inspection of the patient questionnaire data (section 5.3.2), and the qualitative data (section 4.3.1) we find that although the clinic staff do provide information and some signposting/referrals, they do not refer directly to social services (there may be a social services officer available to support them in the clinic but they do not have such a direct route into the social care system as an ECLO has at an ECLO site). Also there is no mention of any referrals to falls services from these support staff members. Therefore, the model does not allow such referrals from support staff at non-ECLO sites and patients are only given advice and information. The model was designed and validated prior to the completion of the survey data collection and the last of the completed site visits in order to comply with timelines and be ready to run when the data was cleaned and analysed. On receipt of the final data the model was populated with the survey data and simulations created.

To explore the impact on HRQoL for patients falling into the different categories at the ECLO supported sites, EQ-5D utility scores based on the patient survey data, for both baseline and follow-up are fitted with distributions and estimated by the model for the various simulated pathways. For those patients for whom support is not required, a small increase in the EQ-5D scores is observed from a baseline of 0.869 to 0.877 (0.015) at follow up. By contrast, for those patients for whom support is required, a fall in the simulated EQ-5D utility values are observed. For those patients receiving support, the fall in the ECLO group, from a baseline value of 0.710 to 0.695 (0.07) at follow-up is smaller than that observed for the other staff group, falling from 0.816 to 0.746. Nevertheless, these reductions in scores are substantially smaller compared to the group requiring support but not receiving any, with EQ-5D utility score falling from 0.764 at baseline to 0.677 (0.087) at follow-up.

Additionally, outcomes were simulated for the people who have a fear of falling: The percentage of patients with a fear of falling ranges between 21.4% and 22.6% at baseline and follow-up for all four groups. However, our simulations suggest that whereas the number of patients with a stated fear of falling increases for those receiving support from other staff or requiring support but not receiving any, small reductions in stated fear of falling are observed for the ECLO supported group and those not requiring support. In a non-ECLO site the people with a fear of falling, there is little change in percentages between baseline and follow-up estimated for both the supported by other staff and the

support required but not received groups. The results from the simulations are helpful in validating our findings based on other analyses, in that we have signals that the ECLO supported individuals have a positive change in the trajectory of their outcomes, whether for EQ-5D scores or fear of falling.

In addition to the explorations described above, one of the main reasons for choosing DES as the modelling approach was to enable the team to explore the potential for ECLO substitution for clinic staff, based on the hypothesis that the ECLOs freed clinic staff time because clinic staff were delivering patient support in the same manner as ECLOs would. However, it was apparent from the simulations that the ECLOs were not substituting for any clinic staff activity, as seen in the staff survey results. Additionally, given the level of ECLO support in the clinics where the staff completed the survey, on average, there were no simulations where the needs of patients were not met by existing ECLO staffing levels. This does seem counter intuitive to the patient survey where needs were not met – an important illustration of patient expressed needs differing to objective provision of ECLO support. The patient survey data does not reveal whether the lack of support was directly due to an ECLO not being available and this may deserve further exploration. It may be that the clinics (20 of the 30 visited) may be the less pressured clinics given they had time to respond to the survey.

There was no way of knowing within the survey data used in the modelling which are services that have very little ECLO time allocated, and which site had the greater proportion of patients who 'had needs but received no support', as the centre data was anonymised. The case seems to be that patients in these no ECLO sites simply miss out on ECLO like support. The analysis of the qualitative data supports the findings of the model.

5.5 COST UTILITY ANALYSIS

5.5.1 SUMMARY

Background

Cost-effectiveness analysis (CEA) is a form of economic evaluation that utilises a single, specific, one-dimensional, health or clinical outcome for competing health interventions. In CEA, the ultimate measure of interest is the incremental cost-effectiveness ratio (ICER), which is the ratio of the difference in costs and the difference in outcomes for one intervention compared with another. And intervention can be a single drug or a complex health care intervention or service.

Cost-utility analysis (CUA) is a special type of CEA in which multidimensional health outcomes are reduced to a single dimension reflecting individuals' preferences for diverse health outcomes. The most commonly used outcome in cost-utility analysis is the quality adjusted life year (QALY).

The value of a health intervention is made by measuring the additional cost per additional outcome compared with the alternative (e.g. an incremental cost/QALY ratio). This ratio is then compared with an external threshold (in the UK this is the threshold set by the National Institute for Health and Care Excellence) to evaluate the value of the new policy with ratios for other policies.

Key findings

- A simple cost-effectiveness of the impact of ECLOs compared with no ECLO was evaluated using CUA. The analysis spanned a time period of 12 months, and was from the perspective of the NHS.
- Inputs to the analysis included the EQ-5D utility scores from the patient survey and the costs to the NHS of an ECLO employed at the equivalent of NHS salary Band 4 and Band 5 - the most usual bandings for an NHS employed ECLO.
- The incremental cost- per 'QALY sustained' showed that the patients seen at an ECLO site generated an incremental cost per 'QALY sustained' of £2,883 for an ECLO paid at Band 4 compared with patients attending the non – ECLO site. When the cost of the ECLO increased based on Band 5, the incremental cost- effectiveness ratio (ICER) increased to £3,517 per 'QALY sustained' compared with patients attending a non ECLO site.
- For patients who received support at an ECLO site compared with patients who needed support but did not receive support, at an ECLO site, the cost per 'QALY sustained 'was £3,348 for an ECLO with a Band 4 salary compared with patients not getting support at an ECLO site. This increased to £4,102 per 'QALY sustained' compared with patients who did not get support, when the Band 5 was used.
- While the CUA was limited by the small patient numbers at follow up, a similar picture of small QALY losses across time was seen for unsupported patients, but the magnitude of differences is small and showed weak statistical significance.
- ECLO support for patients could potentially be regarded as cost-effective when compared to a 'world without ECLO support' by commonly accepted norms, such as the NICE thresholds of £20,000 - £30,000 per incremental QALY gained. These trends show promise but additional data collection would strengthen the statistical analysis.

Cost-effectiveness analysis (CEA) is a form of economic evaluation that utilises a single, specific, one-dimensional, health or clinical outcome for competing health intervention. Cost-utility analysis (CUA) is a special type of cost-effectiveness analysis where multidimensional health outcomes are reduced to a single dimension reflecting individuals' preferences for the diverse health outcomes. The most commonly used outcome in cost-utility analysis is the quality adjusted life year (QALY). Both forms of analyses are incremental analyses comparing an intervention with the alternative(s) For CEA and CUA, value for money is identified using a measure of the additional cost per additional outcome ratio (e.g. an incremental cost/QALY ratio). This ratio is then compared with that of an external threshold, like that of NICE, to evaluate the value of the new policy with ratios for other policies.

QALYs combine quantity and quality of health to calculate outcomes based on treatment or services or other activities that influence health. Life years are weighted by the values (utilities) ascribed to the health states and are generally derived from surveys or research studies. This provides a method of measurement for the impact of disease or treatment on an individual's ability to function and how that impacts HRQoL. The utility scale ranges for from 0 (death) to 1 (perfect health); however, it is possible to have a minus score for a state worse than death.

In this section, a CUA using patients' EQ-5D utilities scores and the cost to the NHS of an ECLO employed at Band 4 is reported. The cost of an ECLO at Band 5 salary is used for sensitivity analysis. The time horizon for this CUA analysis is 12 months.

5.5.2 COST EFFECTIVENESS OF ECLOS

The results of the costs per QALY analyses are reported in two ways. The first analysis compared patients only within the ECLO sites compared with patients within the non- ECLO sites. The second analysis compared patients who saw an ECLO compared with those who did not see the ECLO intervention (but had self-expressed needs for support). The base-case for both analyses is based on the cost of providing an ECLO at a clinic at a Band 4 salary. In order to assess the impact of different staff costs (as these could differ in usual practice); a sensitivity analysis was undertaken by increasing the cost of an ECLO to a Band 5 salary. We assumed no other costs for providing ECLOs, and that the ophthalmology clinic would not incur any extra costs by provision of ECLO. In reality this may not be true if additional office space was required or other facilities were needed to enable an ECLO to function.

Table 5.26 shows patients' EQ-5D scores derived from the survey at the ECLO sites and non-ECLO sites, as well as patients receiving support from the ECLOs and those who reported that they needed support but not did not receive it (from anyone). A fuller explanation of the patient types, defined by their responses can be found in section 5.2. As reported in Table 5.26, the average baseline EQ-5D score for patients attending non-ECLO sites is higher (i.e. better HRQoL) than for patients attending ECLO sites. However, the magnitude of difference between EQ-5D scores at follow up, compared with baseline, was greater in patients attending the non-ECLO site, than for those patients attending the ECLO supported sites.

A similar pattern was seen when comparing patients receiving support from an ECLO compared with those who did not receive support, but needed it i.e. baseline utilities were higher in the latter group but decreased further when assessed at follow up. These differences reveal an interesting trend, but the differences were not statistically significant, which may have been due to low patient numbers.

5.5.3 INCREMENTAL COSTS

To estimate the cost of providing the ECLO service, we used the ECLO activity data that patients had on average, over the 12 month period, 76 minutes (1.27 hours) of ECLO support some of which would be personal contact with patients and the rest where the ECLO works on behalf of the patient.

From Table 5.19, we took the average unit cost per hour for community based professional staff (the equivalent staff definition and banding in which an NHS ECLO is employed) as £29 and £36 for band 4 and band 5 respectively, therefore the total incremental cost for the ECLO over and above the usual cost of running a clinic is £36.83[158] using an NHS band 4 staff cost and £45.72based on NHS band 5 staff cost.

Our assumption, for the purpose of costing, based on the qualitative evidence and the staff survey data, is that ECLOs have a specific role and provide a valued added service and they do not substitute for

[158]Using band 4 salaries which are £29 per hour, the incremental cost would be £29*1.27=£36.83 for one complete visit to ECLO, and £36*1.27=£45.72 using band 5 salaries.

other clinic staff. Thus the analysis is based on the assumption that the ECLO cost is all additional and that there is no substitution effect. We have taken a conservative approach to this analysis. We assumed that after the follow up survey, the EQ-5D scores flattened out remaining at the level of the follow up score, for the remaining months in the 12 month period. This is a conservative assumption because the reality might be that patients whose values fell because they did not see an ECLO might have further diminution of their HRQoL and this utility score would also diminish. It might also be the case that HRQoL in the patients seen by the ECLO might have an increase in HRQoL and their utility score rise. Either or both of these scenarios might increase the difference between groups and amplify the QALY gain.

5.5.4 INCREMENTAL COST EFFECTIVENESS

ECLO site and non-ECLO sites

The QALY estimations over time are presented in Table 5.27. This is based on the baseline utilities derived from the 185 patients attending the ECLO supported clinics and 73 attending non ECLO clinics, of those 84 patients from the ECLO clinics and 20 from the non ECLO clinics were re-interviewed at 3-4 months. The analyses presented in Tables 5.27 to 5.30 are incremental analyses; the definition of the ECLO and patient activity is shown in the upper row comparator for the analysis is shown in the lower row and the incremental QALY, incremental costs and the incremental cost per QALY shown in the three right hand rows.

TABLE 5.27 · Incremental cost per QALY sustained with patients at ECLO and non-ECLO site, using Band 4 costs (base-case analysis)

Site	Time period	EQ-5D score	Change over time	Incremental QALY	Incremental cost of ECLO	Cost per QALY
Patients at ECLO site	Baseline	0.78	-	0.013	£36.83	**£2833.08**
	Follow up	0.77	-0.001			
Patients at non-ECLO site	Baseline	0.84	-			
	Follow up	0.76	-0.014			

TABLE 5.28 · Incremental cost per QALY sustained with patients at ECLO and non-ECLO site, using Band 5 costs (sensitivity analysis)

Site	Time period	EQ-5D score	Change over time	Incremental QALY	Incremental cost of ECLO	Cost per QALY
Patients at ECLO site	Baseline	0.78	-	0.013	£45.72	**£3516.92**
	Follow up	0.77	-0.001			
Patients at non-ECLO site	Baseline	0.84	-			
	Follow up	0.76	-0.014			

TABLE 5.26 · EQ-5D scores for patients at ECLO sites and non-ECLO sites and patients receiving support from the ECLOs and not receiving support (independent of site type)

EQ-5D	ECLO site						Non-ECLO site					
	Mean	SD	Median	Min	Max	95% confidence intervals	Mean	SD	Median	Min	Max	95% confidence intervals
Baseline	0.78	0.24	0.84	-0.02	1	(0.748 0.816)	0.84	0.26	1	-0.06	1	(0.783 0.905)
TOTAL	**185**						**73**					
Follow up	0.77	0.24	0.83	-0.12	1	(0.726 0.828)	0.76	0.24	0.83	0.16	1	(0.645 0.873)
TOTAL	**84**						**20**					
DIFFERENCE (P VALUE)	**-0.01 (0.51)**						**-0.08 (0.09*)**					

EQ-5D	Support received from ECLO						Support needed but not received					
	Mean	SD	Median	Min	Max	95% confidence intervals	Mean	SD	Median	Min	Max	95% confidence intervals
Baseline	0.71	0.25	0.76	0.13	1	(0.625 0.768)	0.76	0.27	0.86	-0.02	1	(0.654 0.858)
TOTAL	**73**						**30**					
Follow up	0.70	0.22	0.68	0.08	1	(0.622 0.775)	0.68	0.29	0.69	0.16	1	(0.473 0.885)
TOTAL	**35**						**10**					
DIFFERENCE (P VALUE)	**-0.01 (0.21)**						**-0.08 (0.53)**					

*Indication of 'weak' statistical significance i.e. 91% sure that the difference did not arise by chance

TABLE 5.29 · Cost per QALY sustained for patients receiving support from ECLOs and those who needed support but did not receive it, using Band 4 costs

Type of patient	Time period	EQ-5D score	Change over time	Incremental QALY	Incremental cost of ECLO	Cost per QALY
Patients who receive support from ECLOs	Baseline	0.71	-	0.011	£36.83	**£3,348.18**
	Follow up	0.70	-0.002			
Patients needing support but not received	Baseline	0.76	-			
	Follow up	0.68	-0.013			

TABLE 5.30 · Cost per QALY sustained with patients receiving support from ECLOs and those who needed support but did not receive it, using Band 5 costs

Type of patient	Time period	EQ-5D score	Change over time	Incremental QALY	Incremental cost of ECLO	Cost per QALY
Patients who receive support from ECLOs	Baseline	0.71	-	0.011	£45.72	**£4,101.82**
	Follow up	0.70	-0.002			
Patients needing support but not received	Baseline	0.76	-			
	Follow up	0.68	-0.013			

The incremental cost per QALY shown in Tables 5.27 and 5.28 suggest that compared with patients attending non-ECLO clinics, there will be £2,883 extra cost to help patients maintain one year of perfect health when an ECLO is paid at Band 4 salary and £3,517when an ECLO is paid at Band 5 salary.

Patients who received support compared with patients who needed support but did not receive support

Seventy-three patients received support from ECLOs, of which 35 had complete survey forms at follow up. As described above, the incremental costs were based on the different salary costs for the ECLO. Tables 5.29 and 5.30 report the QALY change over time for the two groups through reporting the ICER.

This estimates that in patients who received support from an ECLO the cost per 'QALY sustained 'was £3,348 which increased to £4,102when the higher salary band was used (Table 5.30). However, there are a number of important limitations to this analysis. Aspects of selection bias and response bias need to be acknowledged in terms of the overall quality of the evidence on which these estimations of costs and outcomes were derived. The impact of an ECLO on health and social services have not been taken into consideration, leading to an underestimation of the total benefits and costs: an ECLO doing a good job could increase uptake of social services in short term as well as save costs to NHS downstream.

At the time of undertaking the analyses; the final UK population norms for the EQ-5D 5L had yet to be published thus the recommended 'cross–walk' algorithm to the EQ-5D 3L version from the EuroQoL group was used to derive utilities (http://www.euroqol.org/about-eq-5d/valuation-of-eq-5d/eq-5d-5l-value-sets.html) from the patient survey data.

The calculation of the QALY has been undertaken in a simplistic manner. It has been derived directly from the utilities derived at baseline and follow-up used to report QALY gain/loss over time with no consideration of the impact of truncated data taken into account. An important consideration is the baseline differences in utilities which could be down to a variety of factors as this was a non-randomised sample. Thus any comparison attributed to an 'intervention' effect on utilities and subsequent QALYs is problematic to interpret and further examination is needed to explore and deal with such baseline imbalances.

The sensitivity analysis undertaken has only considered the impact of changing one parameter variation (cost) as part of different scenarios. As shown in Table 5.26 there is wide variation in the 95% confidence intervals in the utility estimates and further data collection is needed to reduce these and assess the impact on the findings.

In summary; while the two analyses undertaken are exploratory and limited by the small patient numbers at follow up, they revealed a similar picture of small QALY losses across time for unsupported patients. While these differences were weak (i.e. results were not statistically robust), the results suggest economic benefits, in addition to the patient benefits of an ECLO.

The lack of statistically significant difference seen in the other sub groups is not evidence of no difference, but may be a function of sample size. The original sample size estimates were based on a straightforward comparison between ECLO and non-ECLO sites but as our research progressed we came to understand that there were other important comparisons to make to explore differences between patients attending ophthalmology clinics – particularly those who stated they had needs but were not seen. However, we see some suggestion that ECLO support for patients could potentially be regarded as cost-effective when compared with usual care; with the sensitivity analysis showing that altering the costs of the ECLO would impact on the ICER but would still remain within the NICE 'threshold' based on a societal willingness to pay threshold of £20,000- £30,000 per QALY gained. However, such an interpretation should be considered with appropriate caution within the strengths and limitations of the analysis.

6 DISCUSSION

In this section, we will discuss the three fundamental areas for exploration identified at the beginning of the study in light of our findings and explore options for moving forward in light of this research. By doing so, we will hopefully shed further light on how our evidence demonstrates that ECLOs can have a positive impact on patients, optimise management of ophthalmology clinics, and how ECLOs enhance and broaden the care which clinical services provide, thereby potentially reducing patients' longer-term care needs.

We also describe how we believe that, informed by the findings from this project; there are seven broad types of valued service and support provided by ECLOs, working in ways which reflect the individual circumstances of different clinics and hospitals.

In other parts of this report we indicate that the evidence of ECLOs impact on overall service costs, productivity and efficiency is less clear; however from the accounts that have been captured during the project, we believe that they make a contribution to various other NHS objectives relevant to all four UK nations. We approach this discussion from the broadest possible consideration using a range of evidence to ensure our conclusions are linked to, informed by and relevant to those involved in the provision of ECLOs across the UK. One of the strengths of the study is that the team have considered the impact of their role in a number of ways, by interrogating the different sources of data – for example, the strength of the qualitative work alongside the economic analysis adds value because in context people value different things differently.

6.1 WHAT IS THE IMPACT OF ECLOs ON PATIENTS?

6.1.1 HOW DOES THE ECLO 'ADD VALUE' FOR THE PATIENT?

As we have reported, in many instances ECLOs are a link between health services, social services, and wider community and voluntary sector groups. They point to a vision of more integrated services and systems which look after the needs of the visually impaired patient/citizen (as opposed to just 'patient'), securing not only the immediate clinical needs but also their rights and entitlements as citizens. Equally importantly, to many we interviewed, they represent a welcome development in the overall care of those who are sight impaired.

There is not a settled, one-size-fits-all model for ECLO activity; we would maintain that each service, while conforming to certain common values, actually reflects local needs and priorities to a greater or lesser extent. For example, whereas the majority of ECLOs are based in single acute hospital clinic, others we talked to were peripatetic, and cover a large geographical area, visiting several clinics. Whereas some ECLOs come from a nursing or medical background, and are often able to spend part of the week in those roles, other ECLOs come from a variety of backgrounds including the voluntary sector, or other care services, and being an ECLO is their full-time role. Some also have the lived experience of sight loss. This lack of a common professional pathway means that ECLO practice at present is heterogeneous in certain aspects, and can be shaped to a degree by those in post, wherever they are.

In terms of capacity, our findings suggest very strongly that having an ECLO service, in whichever guise, usually adds to the capacity of clinical teams by enhancing the efficiency of those teams, ensuring that patient pathways and other processes work more efficiently and in a timely manner for the patient. Furthermore, the services offered would seem to be more holistic, linking both the patient and the clinical services to the outside world through information management that uses referral and signposting as its day-to-day tools, but is primarily based on the relationships, networks and trust built up by each ECLO.

Broadly speaking, whether formally or informally, they are an important part of the local eye health network, which includes clinical services, social services, private providers and the voluntary sector. By developing critical relationships, networks and trust, ECLOs can often be instigators and critical nodes in these local eye health networks, e.g. by bringing together professionals, making sure that information flows properly form place to place. They can have a stabilising effect on the network, because they can act as a feedback loop that indicates the health of that local system: if there are blockages e.g. in the CVI registration, which in turn might affect other systems, then they will sort things out. The information flow is often bi-directional; they not only refer out into other services, but they also bring in information to clinical teams about services available. This is reflected in the excerpt below from one of our interviews:

> *INV: So you refer people to them that aren't just, that aren't registered as well?*
>
> *ECLO: Yeah, we also have the people who are not actually eligible for registration if we think they're struggling and they need extra…*
>
> *INV: Yeah*
>
> *ECLO: We have another form from Social Services or we can just ring them up, and anybody who's at risk, you know and needs help urgently; we can ring them up and highlight them, so...we're pretty good with that.*
>
> *INV: Yeah, so is that so that patients you're particularly concerned about, they get prioritised?*
>
> *ECLO: Yes. I mean at one point our social services, I mean quite a few years ago, were nearly two years behind.*
>
> *INV: Right.*
>
> *ECLO: And then I think they're about, I think they're about two or three months behind now*

ECLOs thrive on building collaborative relationships; becoming trusted 'members' of the clinic staff was is seen as crucial to ECLOs being able to work, whether or not they have clinical training. They need the clinical teams to refer to them with confidence.

ECLOs are fundamentally patient-centred in their approach. They provide the sort of immediate emotional support in the clinic setting which clinical colleagues might find difficult to offer. Not only is this support anticipatory, in the sense that they are uniquely placed to see what support might be needed for certain conditions, but we have heard how they also help develop emotional resilience in what can be life-changing circumstances for patients. Some ECLOs take an approach that can loosely be modeled on 'harm reduction' – to reduce the risks of harms through deteriorating vision; they will

instigate support at a very early stage if possible. We could further connect this harm reduction approach to the practice of outreach by some ECLOs or indeed others who have similar roles or skills: by going out to the community, engaging in Sight Loss courses or giving talks to groups, they are potentially making clinical and other services more accessible.

Through our interviews it also became apparent to us that with severe sight loss at the heart of the CVI registration, for example, giving people the time to effectively 'grieve' means that ultimately they might be able to cope better. Whilst ECLOs do engage with people at every stage of their sight loss, for those who are reaching the end of their treatment, the ECLO is especially important. When the limits of medical expertise are reached, the ECLO helps to support and guide so that life can be made bearable.

Related to this, we have heard many accounts of how ECLOs can be proactive in their approach and will seek to engage early on in patient pathways such as diabetic care or falls care. ECLOs seek to help those patients with the greatest needs maintain their health-related quality of life by providing a wide range of well-targeted, well-appreciated services. They will often seek out the best practical options for life outside the clinic to support these care pathways. By trying to engage early on, they contribute to preparing the patient emotionally, developing their coping skills:

> *'It's the quality you can bring to a patient's life I think, the quality service, a way of life, a coping strategies. It is, it is just a good experience, an all-round experience, and its part of our patient care, and it enhances the patient experiences and enhances their lives I would say' [ECLO]*

We heard how many ECLOs will use the CVI process productively. Far from being just another administrative task, it is an opportunity to offer help and further information that is relevant to the individual needs of the patient:

> *'The majority of patients are referred to me because they're being registered. That constitutes the referral from the consultant that's registering them. I will talk to them about everything. For example, what problems does their sight loss pose to them at work? Do they live alone? If so, how do they manage? Of if they live with someone what sort of tasks are they having to pass on to their partner, mum, dad, son?...All sorts of reasons why they come, but they all get asked the same questions, but with registration they get extra information about what registration means' [ECLO]*

Those who had longstanding clinical experience and expertise, and the institutional memory both within clinical teams and in other support roles, gave multiple examples of how the CVI system had improved as the ECLO role had developed:

> *'So as an in between us they're very good, but it's not only just between health and social care, it's also between health and the community, because the ECLOs in that link to local societies and to other support groups. Again, you know if a person wanted to … is struggling to get the support or whatever, they can always go back to the ECLO and they then can help to try and sort out the referral to them' [ROVI]*

> *'The ECLOs are good here because they've got connections that it's really difficult for us to make…' [Ophthalmic Nurse]*

The ECLO is a trusted and valued part of the provision:

'They usually remind the consultant that they need to be sending off the documentation, which is good because then we can get it faster than normal' [Medical Secretary]

'The ECLOs usually let us know that/if the document's there. The other side of the coin too is if they need background information on somebody, say because the information that came through from the person themselves is not 100% accurate, the ECLOs can act as a link between us and the consultants, so we can get some background checks on, make sure that we've got the eye conditions right and everything else' [ROVI]

As we discussed in the previous section, ECLOs often have an awareness raising role to play within teams also. In some accounts, this included being part of the induction process for doctors, or having input into falls prevention teams. This need to 'bang the drum' for the ECLO role, making sure that everyone is aware of who they are and what they can do, is essential if the right referrals are to be made.

But in some clinics, they also have a varied awareness raising role as patient-facing staff, ranging from explaining the realities of anti-VEGF treatments to showing the patients the correct way to administer drops. This can also mean time saved for other clinical staff:

'The main thing that patients value is for the ECLO to explain the process of anti-VEGF treatments, and the 'reality' of this and what it will mean for them. That is reassuring for them to know how this will go, what it will feel like as they have their treatment. This is priceless for them to have some education on this. Without an ECLO this would take longer, and mean that there would be much greater time spent in the clinic for patients and mean that we can maximise the number of people that we can see. It helps to optimise the running of the clinic, and the 10-15 minutes that I would have to spend with that person can be reallocated and I can do other things' [Optometrist]

Some also have an awareness raising role outside of the clinic environment e.g. running or taking part in Living with Sight Loss courses in the local community. It would seem to be part of the core ECLO skills, being able to explain the various types of eye condition in terms which can be understood.

The point at which an individual's low vision reaches a stage where they are eligible for CVI and registration is either an opportunity to access social services or a perceived threat from these services - 'being put in a home' or admission of 'loss of independence' that may make a person reluctant to engage with services and the CVI process. There are also practical tasks that can be daunting; claiming benefits, understanding what allowances are available and how to access these. The ECLO is in a unique position to engage with a person as they attend an ophthalmology clinic and provide support – whether that be practical, emotional or both.

6.1.2 HOW DOES CONTACT WITH THE ECLO IMPACT ON THE QUALITY OF LIFE FOR PATIENTS?

As detailed in our literature review, the evidence points to the significant impact low vision can have on in individuals, particularly in terms of the increased risk of falling, the fear of falling and actual fall events that may isolate people socially, and the high rates of depression experienced by the people attending low vision rehabilitation services reported in the DEPVIT study.[159] It is also well documented that all of

[159] Nollett et al (2016), op. cit

these factors and others, contribute to a relatively lower HRQoL for people with low vision than a similarly aged person in the UK.

Our data show some tentative indications that the support of an ECLO can maintain health related HRQoL, which otherwise deteriorates in the absence of ECLO support. Our data collection was limited by the study timeline; if a routine EQ-5D data collection could be enabled in partnership with ophthalmology services these analyses could be strengthened. Healthcare providers and commissioners are becoming more engaged in enabling outcomes data to be collected and analysed and value this information; this could be the right time to initiate discussions using this research and these data as an example of how this can be facilitated.

6.1.3 ARE ECLOs TARGETING THE RIGHT PEOPLE?

Our survey data reporting the EQ-5D scores, split by domain, show that the survey respondents experience problems with anxiety/depression, reinforcing the DEPVIT findings for patients attending general ophthalmology clinics (the DEPVIT study surveyed patients attending low vision rehabilitation services). Our analyses indicate that the ECLO does see the patients experiencing problems measured in all the EQ-5D domains, including anxiety and depression and those who expressed the need for support and received it, suggesting that ECLOs are able to 'target' the right patients, but questions must be asked about the respondents who said they needed help and did not receive it. We assured the study sites that we would maintain anonymity so cannot identify the sites where people fell through the gaps but overall our data suggest that there are not enough ECLOs to meet demand and to actively find and engage with patients who want support.

6.2 WHAT IS THE IMPACT OF ECLOs ON CLINICS?

6.2.1 WHAT IS THE IMPACT OF AN ECLO ON CLINIC ACTIVITY?

The qualitative data is unequivocal about the value of the ECLO and how they 'oil the wheels' of the clinic and how they support patients. One of the objectives of this project was to identify and quantify the economic impact of the ECLO. One of the ways we hypothesised the ECLO might deliver economic benefits was through relieving other clinic staff of 'ECLO-like' patient support activities releasing capacity within the clinic. A critical input to the economic analyses and the simulation model was the clinic staff data collection and the ECLO activity data collection.

Contrary to the hypothesis that was developed in part by clinicians themselves, it has not been possible to prove in quantifiable terms that the presence of an ECLO does specifically free clinic staff to carry out more clinical activity. This somewhat paradoxical result is simply explained by the fact that clinics without ECLOs apparently provide less non-clinical support 'ECLO-like'– the clinical staff are too busy to offer much of such support. The presence of ECLOs therefore generally *enhances* provision, rather than improving efficiency *per se* by freeing clinical staff to do what only they can do. In fact we see indications in the data that in ECLO sites staff spend a little more time on emotional support and other non-clinical activities, such as signposting to services etc. than at non-ECLO sites. On closer inspection of our findings, this is not surprising – it is clear that ECLOs are enabling and adding quality and value, and in the judgement of those working in clinics, do much to make the clinic more cohesive and streamlined.

However in an environment where resources are stretched very thinly and there is a significant need for the ECLO activities we can understand why our survey findings do not reveal any substitution capacity – time is short and not much is spent on patients doing anything but the clinically necessary. Thus the reality of the staff data collection suggests that in non-ECLO clinics the staff do not spend much time per patient on performing as 'ECLO-like' staff.

In a small number of centres the interviews for the qualitative research found that their ECLOs explicitly take on tasks such as supporting people to gain confidence in the self-administration of eye drops – here a substitution of the ECLO for clinic staff is evident. However this activity is relatively rare in our study sample and the RNIB advised us that this type of work was not central to the ECLOs' role as currently configured, unlike giving emotional support. This drives up the quality of care based on what matters most to people with sight loss.

We also learn from the ECLO activity data, the staff survey and the qualitative work that CVI completion is best done in partnership with the ophthalmologist and the ECLO as a team – that way the most comprehensive and accurate information is collected and subsequently social services are best enabled to support the patients. The ECLOs provide extra time and support for patients, rather than delivering support that other staff gives. In fact, our data suggests that in a clinic setting where there is an ECLO, the staff provide the same amount of time supporting patients as in a non-ECLO site, or more, on ECLO like support activities. It may be that the ECLO service supports a culture of patient centred care, or that clinics that have been successful in engaging an ECLO to support the service have a more patient centred culture than those who do not (or simply have more funding). These questions may warrant further investigation; however, it is clear from our research that the ECLOs provide considerable added value and potentially and contributing to maintaining HRQoL for a patient who is attending an ophthalmology clinics.

The ECLO activity data is a valuable resource and has been fundamental as a source of evidence for this research. We acknowledge that its primary function may not be for research but we cannot overlook its power to provide evidence to commissioners as to where and for whom the ECLO service is targeted and how the ECLO impacts services and outcomes. Enriching the data collection without overburdening the ECLOs is something to consider if its utility for research and evidencing the impact of ECLOs is desired.

From our research, we would suggest that ECLOs have a beneficial and welcome impact on the activities of most clinics. They are often involved in key processes and pathways which have a large impact on helping patients to progress and receive the care needed in the various systems that they have to negotiate. From the accounts given, ECLOs would seem to speed up and take the pressure off certain aspects of clinic activity, thereby freeing clinicians to see more patients. For example, many are involved in the CVI registration process; what was seemingly quite an ad hoc system in many places has been largely improved.

Likewise, time spent giving 'emotional support' (which covers a whole range of activities) is the core part of the ECLO practice within the clinic. ECLOs can also improve the communication that happens between clinical staff and patients, especially if people are upset. It is obvious that communication isn't something that can be exclusively left to the ECLO, and some recognise that they still need to improve their own skills. Further that depending on local context, there will likely be value added by the ECLO –

for example in respect of having good quality discussions with people at length – over and above what may be provided by the clinic staff:

> *'Communication with patients is part of our CPD and part of our role. It shouldn't be that it's split between us doing a particular role and [the ECLO] doing the pastoral care. It's an integral part of my job and if I can't do it very well then I need to learn how to do it. It's just continually developing. A patient will come in you'll discuss their eye condition, ask them how do you feel your eyes are? You're asking them general questions and gauging their reaction, how much they understand about their condition, what drops they are using. You tell them information as you're going and try and gauge the retention and understanding of it and you just change depending. You may get another patient coming in who clearly doesn't understand their condition and is very distressed by it and they may need 10 minutes of my time just talking about it. It's very difficult to put a figure on it' [Optometrist]*

As noted, the ECLO role is very much about communication between patient and community as they get used to the diagnosis, but also about good internal communication – they make sure that parts of the eye care team work together.

In some of our accounts, we heard that this communication is bi-directional – information flows out through the ECLO in terms of referrals to other services e.g. ROVI, but also the information about services and what's available locally flows back in to the clinical teams through the ECLO. When a ROVI needs to check on a referral which might be needed to take things forward outside clinic, then the ECLO is the point of contact and can hurry things along in terms of getting everything signed and ready. The ECLO can also be kept up to date about what's going on locally in terms of social services, rehab team provision etc. through the ROVI, and pass this information on to colleagues.

> *INV: 'In terms of convincing the people in the hospital that this was an investment that they should be making – were those processes ever questioned or negotiated or was is straightforward?'*
>
> *ECLO: 'No I think quite quickly because of patient feedback to the consultant – "thanks for referring me to the ECLO service because this has happened" – and I very quickly as well started to chip in education at the clinical audits in the hospital – so if there as a change in benefits I would ask for a slot and start to update them on what was changing and patients are likely to come in and ask for this information and this is why. So they were feeling well this is informing us – this is helping us deliver a better service to patients. So it depends on how good your ECLO is, but merely the fact that you've got an ECLO means that there is a lot of stuff that you don't have to do in the clinic apart from the bare essentials that you have to do.'*

We would argue that ECLOs stimulate change, provide a valuable feedback loop in terms of the health of systems, and improve the offer of clinics in general. By connecting everything that needs to be connected for the patient/citizen, they lift the overall quality of the clinic by looking beyond the vision and the visual:

> *'Because I've never not had one so I don't know why you would not have one. The role for doctors here is just to see patients and treat them and not really consider what happens beyond. I think they wouldn't think of the role of ECLO…but if you are going to give the whole package as I call it from not just looking at their visual needs but looking at more than just their visual needs, I think the ECLO role is indispensable…they are essential' [Consultant Ophthalmologist]*

6.2.2 CORE ECLO ACTIVITIES AND THE SEVEN DOMAINS OF ECLO PRACTICE

Although ECLO practice differs across sites and the UK nations, certain 'domains' of activity emerge from this research, which offer a useful framework for considering the role.[160] We were able to discern seven domains of ECLO practice which seemed to be common and reflect some underlying characteristics of the role, depending on those local contexts, needs and the skill-set brought to the role by individual practitioners. We would contend that that there is a dynamic element to ECLO practice which enables the role to evolve according to local needs – and this adaptability might be a valuable feature of the role – but there are also domains of practice which came through in the data and seem worth examining. These are mainly indicative categories, and in no way mutually exclusive i.e. an ECLO's day-to-day practice might have elements of all these activities at different times and with different patients (see Figure 6.1).

FIGURE 6.1 · Seven domains of ECLO practice

The enabling aspect here is key. As we have heard in the interviews, when one set of (healthcare professionals may have said that they can do no more, an ECLO can be the gateway to other options in terms of help and support. In this way they build a capacity for care which is not only restricted to the clinic, but is networked across the local eye health support network. As in social work and other

[160] Bowker GC and Star SL (2000) *Sorting things out: classification and its consequences* Cambridge, MA: MIT Press

professions, ECLOs often have both networked power and a networking power. [161] In the former, ECLOs interact and facilitate aspects of the 'care' network e.g. by taking charge of the CVI process. In the latter, ECLOs use the tools of referral and signposting to activate other relationships. ECLOs help their 'clients' to navigate several different systems and frameworks: clinical, welfare, social care – their networking power is central to how they do this, as they build up their local knowledge and contacts.

Core ECLO activities

By this we mean the activities which seem to be ubiquitous in the data when interviewing the whole range of those who participated - like providing emotional support, expediting certification and registration processes, engaging in signposting and referral, seeing people as people and undertaking an 'embodied' practice where connection at a basic human level is valued and practised. These are seemingly values which are common in the data regardless of funding, geography and other circumstance. If care here is fundamentally about learning to live life with disease ('coping'), then ECLOs enable care to take place. It is also 'holistic' activity, in the sense that they very often 'complete' the service of caring for the patient, when clinical options for the effective treatment of patients have come to an end.

To an extent, the core activities have been explored quite thoroughly in the preceding sections of this report, but we would reiterate that they would seem to revolve around the main categories of capacity building, relationships, patient-centred practice and a skills and knowledge base which encompasses the awareness raising role(s), which often fosters resilience through emotional support, as well as other types of practical help. Although nominally both the health and social care systems are about helping the patient/citizen to thrive in the face of disease, 'care' involves a range of people: the patients themselves/family, professionals, and because it is integral to daily life it is necessarily complex, sometimes hard to identify and measure.

The following descriptions are of aspects of ECLO practice that came to the fore in our interviews, and which individual ECLOs might display a particular tendency towards – or else, might display a combination of these approaches as part of their palette of skills.

Pastoral

In the pastoral aspects of practice, ECLOs use expertise in guiding the patient/citizen through the various clinical and non-clinical systems which might be needed to provide care for the citizen and that potentially might help them adjust to sight loss, by providing the best possible care. It would seem from our interviews that some ECLOs were particularly adept at this, and even though it could be argued that this is in effect a key characteristic, it is a domain which some seemed to emphasise more as part of their professional practice. This includes advocating in the benefits system, making sure that people are getting all entitlements – beyond just signposting to outside agencies. There is a sense in which ECLOs act as pastoral 'shepherds' – one ECLO calls her patients her 'flock' – actively guiding them through with a calm and expert hand. ECLOs also operate as quasi-religious 'pastors', offering time and a listening ear to the troubles and challenges of those in difficulties. They can further act in a 'confessional' mode, hearing people talk in confidence - many patients are more comfortable talking about their lives to

[161] Smith R (2012) 'Castells, power and social work' *British Journal of Social Work* p.73: doi: 10.1093/bjsw/bcs073

non-medical staff. Pastoral ECLOs tend to make time for long-term engagement with patients where needed, so that help and support is given at the point at which the patient/citizen is ready to accept it (as much as needing it).

Advocate

By advocate ECLO practice, we would draw attention to those who are concerned with making sure that patient/citizen's right and entitlements are fully met, and are able to advocate for these not only within the clinical system, but also with employers or aspects of the welfare system. Superficially, there are similarities here with the pastoral domain, but we would emphasise the ability to go beyond referral or signposting to agencies outside of the clinical environment. Equally important is the ability to advocate on behalf of the patient/citizen within the clinical system or pathway.

Experiential

The experiential or lived experience ECLOs are those who bring to the ECLO role relevant lived experience of sight loss, or their professional experience in a closely related caring profession such as nursing. In some of our interviews, there was a sense that there were insights offered by those who had trodden the same path which gave a greater sense of passion and empathy. There are some nurses who are ECLOs, and they can bring a more specialised clinical knowledge to offer the patient, as well as already being more integrated into the NHS system locally. Others' experiences are different and will have different strengths to bring. It is also important to state that some ECLOs' personal experience of sight loss is a crucial part of their professional practice and their skills of empathy are highly valued by patients.

Awareness-raiser

We have already examined the awareness raising aspect of ECLO practice, but we would suggest that some ECLOs have a particular interest in making sure that colleagues within the clinical environment especially are kept up to speed with the ECLO role, and with making sure that information from outside of the clinical sphere e.g. about changes in benefits which might affect the patient/citizen, are widely disseminated, or that any new members of a clinical team are made aware of the ECLO role. This domain also covers those who have an outreach role or are able to offer courses in the community, for instance.

In-betweener

The description of ECLOs being an 'in-betweener' service came from an interview with a ROVI, and we thought that it effectively described how some ECLOs are very adept at linking to all kinds of services and agencies. As a key part of the local eye health network, the ECLO is that node of information that enables networked power, and is able to connect the services necessary for the care of the patient/citizen. They navigate people successfully through the complex and challenging pathways that face them. Some ECLOs literally place themselves in-between clinics, and tend to be more peripatetic – often travelling to other clinics. They are also increasingly concerned with other outreach activities which might be giving talks with outside groups and agencies. Where clinical judgments will necessarily involve a 'scientific' assessment of the individual's health (and further options accordingly), the ECLO's

options (for the patient/citizen) are more networked and dependent on multiple relationships and systems into which the individual might integrate in the world outside the clinic.

Harm-reduction

The harm-reduction approach is an aspect of ECLO practice which emphasises taking a belt-and-braces approach in terms of processes such as CVI registration, so preventative action is prioritised with a view to preventing further more serious harms later on. 'Harm reduction' ECLOs are proactive in the sense that they will be interested in seeking out those who might end up with significant sight loss before they get to that stage e.g. by targeting work around glaucoma and diabetes pathways, and in-patients admitted for stroke, for example. They might also be more open to early engagement with the certification/registration process, reasoning that the sooner that a person is entitled to the maximum amount of help, and that these benefits are in place, then there will be less harm later on, thus potentially saving the health and social care system money in the long run.

Entrepreneur

The entrepreneur ECLO recognises the need to create awareness and value for their role as an important part of the clinical pathway, and uses a range of skills to identify or create opportunities to 'sell' the value of the service to those who have influence. This behaviour is often centred on ensuring the maximum number of patients are made aware of their service, and can then be supported by them. It is also the case however, that entrepreneur ECLOs are adept at identifying the key 'levers' of power and aligning themselves with decision-makers to raise the profile of their service. Their system knowledge is excellent and they are able to grow their service successfully, to the benefit of patients.

6.3 WHAT IS THE OVERALL IMPACT ON SERVICES?

6.3.1 WHAT IS THE IMPACT OF THE ECLO SERVICE ON UK NHS COSTS?

The qualitative research reported here gives clear evidence as to how the ECLO is valued as part of the team. What is their impact on patient outcomes? Any data on the contribution the ECLO makes to outcomes through giving emotional as well as practical support and how that impacts mental health and well-being for a person with sight loss, is relevant. Given the disturbing findings of the DEPVIT study[162] the impact of the ECLO in providing emotional support to people with low vision is timely.

Another important area of ECLO activity within the clinic is intervening for the patient to reduce the risk of falls though facilitating advice, contact with services and building patient confidence in getting out and about safely. As we see from the analyses reported in the chapters above, falls and their consequences are not only an unwelcome and potentially catastrophic event for the patient: the impact on NHS services and funds is very high. Any action the ECLO takes to help a person avoid a fall must therefore be important. However, the ECLO data reports very limited activity in referrals to falls services. Informally, through the RNIB project team, we understand that these data are not reported well by the ECLOs, potentially because falls services are few and far between. We understand that

[162] Nollett et al (2016), op. cit

ECLOs take action in other ways to achieve intervention on behalf of the patient, for example suggesting the patient sees their GP to ask for a referral to falls services.

Whilst falls services may be in short supply, under-reporting this ECLO activity in the ECLO activity data seems a missed opportunity. Additionally, any 'brief intervention' that ECLOs can be trained to give regarding falls avoidance/building confidence over and above what they do at present and capturing this activity may further build the case for the ECLO not only as a 'value added' service for patients but also pay back through reductions in falls in the low vision population.

Research undertaken in Northern Ireland, reported by Robinson et al suggests that the ECLO is well placed to give advice to the patient on falls prevention and suggests that ECLOs be trained in falls risks, falls prevention and post fall management techniques.[163] Our estimates reported in section 4.5 suggest that any evidenced link to impact of ECLOs in this area could reduce NHS costs. For example, if ECLOs could take on the additional training suggested in the report and evidence an active role - perhaps delivering a 'brief intervention' to patients they anticipate to be at risk or who explicitly express a fear of falling - the link between the ECLO activity and a decrease in fall rates gains. The value to the patient, confidence in engaging with life and the reassurance this intervention might give them may also play through to HRQoL gains. Equally as we have such strong evidence that the ECLOs are connected to services in the community they may have a role, as Robinson et al suggest,[164] in educating staff working in falls services about the strong link between low vision and falls. The College of Optometrists report gives guidelines as to how this can be done.[165]

Similarly, there may be an opportunity for the ECLO to be trained further in recognising the signs of depression and proactively facilitating and enabling the patient to access support. The speculative estimations in section 4.5 show how a small reduction in rate of depression in people with low vision - through an ECLO facilitated action – can reduce the burden on services and NHS funding, releasing it for other services. Research undertaken by Pybis et al[166] suggested that there is a clear need for both emotional support and counselling to be available at both the point of diagnosis as well as when needed and *"embedded into the sight loss care pathway"*. Given that there is evidence that the ECLO is providing emotional support, there is a case for care pathways to recognise this explicitly and measure the impact. It is therefore difficult to establish evidence for a causal link between ECLO interventions and their impact on either rates or levels of depression, or the incidence of falls. These links are highly plausible, given the evidence marshalled here from a variety of sources about what ECLOs do and how it is received, but further data is needed of the types described above.

6.3.2 WHAT ARE THE SERVICE BENEFITS FOR HAVING AN ECLO?

Our research shows how, from diverse modes of action, that ECLOs can have a positive impact on patients, ease the pressure on ophthalmology clinics and broaden the care which clinical services provide, which may play through to patients' longer-term care needs.

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[163] Robinson L, Casey J, Stinson M, Hull A and Crawford S (2015) *Effectiveness of an ECLO Service Provision in Reducing the Incidence of Falls in People with Visual Impairment* RNIB: Northern Ireland

[164] Ibid.

[165] College of Optometrists (2014), op. cit

[166] Pybis et al (2016), op.cit

Although it is clear that the ECLO cannot completely substitute for the consultant in the CVI process, there is evidence that the ECLO's involvement can speed the process, and improve the quality of information collected. Their involvement therefore enables a more useful CVI for the downstream users and potentially allows a better uptake and deployment of social services for the patient, and an opportunity to engage with the patient and focus on their individual needs.

We looked for other service benefits that were economically important when an ECLO is present. However, the ECLO does not appear to be directly cost saving for the provider (the organization that would pay the salary). In the few cases where an ECLO (at band 4 or 5) takes on a specific role that a band 6 nurse may otherwise deliver (such as training in the administration of eye drops), there may be some potential to release capacity. Where this happens the ECLO has to release a meaningful and 'releasable' amount of time reliably and regularly for the nurse and his/her salary budget to be redeployed in another capacity - probably a 'clinic session' of time on a regular basis. We don't have any evidence of this happening, but recognition that this task 'eases pressure' on the clinic staff.

In addition to their obvious within, the role and impact of the ECLO is felt outside of the world of the clinic; ECLOs are a link between health services, social services, and wider community and voluntary sector groups. They enable more integrated services and systems support the overall care of those who are sight impaired.

6.3.3 WHAT WOULD HAPPEN IF ECLO SERVICES WERE EXPANDED?

ECLO services optimise the capacity of clinical teams by streamlining the work of those teams, ensuring that patient pathways and other processes can work more in a more timely manner for the patient. The question is, is more (ECLO) better?

Thinking about patients, the patient survey revealed a significant proportion of patients at ECLO supported clinics feel they need support but don't receive it. There are signs in the data that these patients are at risk of diminishing HRQoL. This is a signal to us that there may be a case for provision of more ECLO support in some centres. The data are not strong enough given the limitations of sample size in this sub grouping, and lack of knowledge of the level of ECLO service at that specific clinic, to be concrete evidence of cause (not enough ECLO) and effect (patients whose HRQoL diminishes) but it is perhaps the case, locally, that services know where patients are not having their needs met and repeating the patient outcome questionnaire in the clinic might be enlightening for service managers.

6.4 STUDY LIMITATIONS

An intervention or service that is cost effective is delivering more benefit for more cost, compared with the *status quo*. We have some tentative evidence, based on our QALY estimates, of cost effectiveness – but the sample sizes of the patient groups are small and confidence intervals wide. Further data collection may strengthen this evidence. In a wider setting we can see that where the additional cost of the ECLO is invested, a host of benefits that are not easily measured, are realised. However the links between 'cause' – the ECLO – and reduced falls, fewer cases of depression – 'effect' – are very weak. Again a thoughtful, targeted data collection may strengthen the case for ECLOs not only to be cost effective but potentially contribute to a reduction in rates and costs overall to the NHS. This study

confirmed that from a commissioner's perspective, it is '*all about the evidence'* and that evidence should relate to the local health economy, patient health outcomes, well-being and experience rather than just a more general *'reduction in costs to the NHS'.*

7 CONCLUSIONS

This project has provided a breadth and depth of evidence at 'grass roots' level to add to what is currently known about the role of the ECLO. It now concludes by reflecting on three areas. Firstly, we conclude an overview of the findings. Secondly, we consider how the study builds on what is already known about information and support provision in eye clinics, and finally, we offer a series of different perspectives on the commissioning and implementation of ECLO services.

7.1 SUMMARY OF FINDINGS AND CONCLUDING POINTS

In this final part of the report, we provide a concise summary of the key findings across all of the different sources of data – summarising the impact on patients, clinics and services.

7.1.1 IMPACT ON PATIENTS

ECLOs help those patients experiencing sight loss with the greatest needs. Evidence shows they appear to maintain their health-related quality of life over time. They provide a wide range of well-targeted, well-appreciated services. In particular:

- The ECLO 'adds value' for the patient by recognising the critical issues for them and providing the appropriate support and signposting/referring.
- Contact with the ECLO may impact positively on health-related quality of life for patients in a number of ways.
- ECLOs target the right people but some people may be 'missing out', either due to lack of an available ECLO, or because they do not access and ECLO where one is present.
- ECLOs integrate services, securing immediate clinical needs for patients, and also long-lasting rights and entitlements; the needs of people are well served by ECLOs integrating health, social services and others.
- ECLOs are proactive patient-centred advocates, reducing stigma, and ensuring people aren't ignored as they move through a complex system; in part through developing relationships, networks and trust, and standing up for patients, as constants at a time of change.
- ECLOs help people to deal with their worries and concerns, demystifying challenging situations, and reducing stigma and anxiety and allowing people to benefit from the offer of support that exists.
- ECLOs develop relationships, networks and trust, instigating and inculcating local eye heath networks, bringing together professionals in two-way information flows.
- ECLOs thrive on relationships of trust, becoming key members of the clinic 'staff' which is crucial to them being able to work effectively, whether or not they have a clinical background. Some ECLOs believe that being identified as part of the NHS means that they are seen more as a 'trusted' member of the clinic staff: '*When my badge said I worked for a charity, people didn't want to see you. The minute that badge changed my numbers trebled, because they know you're trained, they know you are a trained professional, they know that you'll be telling them the proper stuff. The NHS see you as a professional' [ECLO].*

7.1.2 IMPACT ON CLINICS

Across the UK, we can describe seven broad types of valued service and support provided by ECLOs, working in ways which reflect the individual circumstances of different clinics and hospitals. ECLOs are effective in doing this as follows:

- ECLOs improve and streamline the processes which operate within clinics, helping others provide quality services by aiding the smooth running of the clinic, and making administrative processes more efficient.
- ECLOs develop quality services, catalysing and expediting change; they are experts in joining the dots and raising the profile of patients' needs and their 'soft power' effects are significant; they work with staff to make clinics better places for patients through raising awareness of what they need with staff and what represents good practice.
- ECLOs enhance the profile of services through their added-value; by turning the routine into the efficient, and the regular into the effective; they stimulate change that improves the offer of clinics bringing up the overall quality of the clinic by looking beyond the vision and the visual.
- ECLOs are proactive catalysers of change though developing effective relationships both within and without the clinic.
- Whilst many ECLOs are working in the earlier stages of the patient journey to good effect, they also provide safe and meaningful 'departure points', taking the pressure off the system by offering a positive place for patients to reside towards the end of the treatment and clinical care pathway; they are an alternative to the binary choices of clinicians (continue treatment or stop treatment).
- ECLOs provide continuous specialist expertise in how to emotionally support people during medical treatment and once that treatment ends, ensuring that people make meaningful contact between different services, within and without the hospital.
- Training and continuing professional development for ECLOs could take account of these domains of practice.

7.1.3 IMPACT ON SERVICES

ECLOs enhance and broaden the care which clinical services provide, thereby potentially reducing patients' longer-term care needs, and release NHS staff to perform their clinical roles. They add capacity and contribute to the increasing quality of the service offered in clinics; and they make a contribution to various other NHS objectives relevant to all four nations:

- The principal benefit for having an ECLO present in clinic is in providing support that others do not/cannot provide. ECLOs have a specific role; they provide a valued added service and they do not substitute for other clinic staff.
- Hence there are no evident cost-savings within the clinic when an ECLO is part of the care team but there may be to the wider NHS in terms of reduced burden of falls, depression and anxiety.
- If ECLO services were expanded, expressed needs may be met for more patients and through the ECLO referrals, negative impacts on health and social functioning may be addressed.

7.2 HOW DOES OUR WORK BUILD ON EXISTING KNOWLEDGE?

An RNIB Campaigns report recently summarised the evidence available at that time in relation to the range of contributions which ECLOs can make to the totality of service provision.[167] These were grouped under seven headings:

- Enhancing the patient experience
- Improving service efficiency
- Ensuring positive patient outcomes
- Providing a cost-effective service
- Streamlining the CVI process
- Bridging the gap between health and social care
- Improving staff satisfaction

This report confirms that ECLOs do indeed contribute to most if not all of these seven areas, and the evidence presented herein adds to that previously summarised by the RNIB. The one exception relates to the extent to which provision is 'cost effective'. Here the evidence is more nuanced and requires more careful consideration, as explained above.

7.3 PERSPECTIVES ON IMPLEMENTING ECLO SERVICES

Finally, we feel that it would be useful to add into these conclusion some observations that have been made during the course of the study on the ways in which ECLO services have been implemented in a number of different contexts.

ECLO provision offers a variety of different benefits, which potentially have more or less relevance to different stakeholders – including NHS and social services commissioners, NHS providers, clinicians and patients. They can perhaps be summarised under five headings:

1. Meeting quality standards

   Some specific national clinical quality standards are mandated within the four UK nations, but this arrangement is unusual, and often resisted by services anxious to ensure that they have local discretion to meet local need. More commonly, national 'guidance' on services is issued, and a number of national quality standards documents already reference ECLOs (see Appendix 6 for details), although their influence is more one of persuasion rather than mandate.

2. Ensuring equity from a commissioning perspective

   Commissioners will share a concern to minimise variation in provision, and will wish to ensure that all eye clinics enjoy a similar level of evidence-based provision in relation to need.

[167] RNIB (2015) *See the need: Sight loss advisers, improving patient outcomes through cost-effective care* – accessed from: https://www.rnib.org.uk/sites/default/files/See%20the%20need,%20Sight%20loss%20advisers%20improving%20patient%20outcomes%20through%20cost-effective%20care.pdf

3. Ensuring equity from a provider perspective

   Most NHS provider organisations will themselves wish to ensure that the service they provide their patients is the best possible within the resource made available to them (irrespective of the specific requirements of their commissioners). They will therefore wish to include ECLOs alongside other evidence-based provision, and often have sufficient discretion within commissioning arrangements to ensure this. Outside England, of course, there is no formal purchaser-provider split, and this considerably simplifies arrangements.

4. Clinical aspiration

   Individual clinicians, especially those with clinical leadership roles within ophthalmology, have the ability to influence business plans and the direction of services within their clinics. Aspirational clinicians who see their peers enjoying the benefits of working with ECLOs elsewhere can be effective champions of the need to implement such services.

5. Cost effectiveness

   Commissioners, providers and clinicians usually share a desire to maximise the benefit derived from the available resources, and are receptive to services which can demonstrate a greater benefit from the same resource, or similar/greater benefit from less resource. This can be derived in the form of cash-releasing savings, or (perhaps more commonly) by enabling services to cope with rising demand. The evidence on the cost-effectiveness of ECLO services has been presented and discussed at length.

There is much evidence in these pages. We trust that this will allow RNIB and a range of other stakeholders to gather new insights into the ECLO service and the impact that it has. This study has covered much new and existing territory through its primary research. It has confirmed much of the evidence that previously existed about ECLOs, and it has expanded our knowledge about the impact that ECLOs make into new areas.

APPENDICES

APPENDIX 1 · **PATIENT OUTCOMES QUESTIONNAIRE**

An evaluation of patient information and support services in UK eye clinics

Welsh Institute for Health and Social Care, University of South Wales and Swansea Centre for Health Economics, Swansea University

Questionnaire for patients

Study site:

Thank you for taking the time to consider participating in our survey.

We would like to know if you have been given information and support in the eye clinic to help you cope with poor vision in your daily life and how you feel about your quality of life. We would also like to know if any information and support you have received has made any difference over a period of time and would like to contact you again in three months time. If convenient we will arrange a telephone call to go through similar questions we will ask you today.

ABOUT YOU

Study participant number:

- Gender: ☐ Male ☐ Female
- Date of birth: (dd/mm/yy):
- Postcode:
- Marital status:

☐ Single ☐ Divorced

☐ Married ☐ Civil Partnership

☐ Widowed ☐ Co-habiting

- Who do you live with:
  - ☐ Partner/spouse
  - ☐ Other family members
  - ☐ Live on own
  - ☐ Residential/ nursing care
  - ☐ Sheltered accommodation
  - ☐ Other _____
- Main eye condition:
  - ☐ Age-related macular degeneration (AMD) (if known ☐ wet ☐ dry)
  - ☐ Diabetic Retinopathy
  - ☐ Glaucoma

- ☐ Other (please specify) _____

- When was your eye condition was first diagnosed in the eye clinic?
  - ☐ In the last 3 months
  - ☐ 4 to 6 months ago
  - ☐ 7 to 12 months ago
  - ☐ 13 to 18 months ago
  - ☐ More than 18 months ago
  - ☐ Don't know

- Do you have a Certificate of Visual Impairment (CVI)?
  - ☐ Yes, sight impaired (partially sighted)
  - ☐ Yes, severely sight impaired (blind)
  - ☐ No
  - ☐ Don't know

- Do you have any long-standing illness or disability in addition to your visual impairment?
  - ☐ Yes (details) _____
  - ☐ No

In the following section, we would like to know about your experience of the eye clinic support services (either through an ECLO or other person) that you have received. These services will have been the kinds of things to help you adapt to your sight condition and maintain your quality of life.

- Have you received any of the following?

Further information on your eye condition	☐ Yes ☐ No, I don't need it ☐ No, but I do need it	If yes who from Who referred/signposted
Emotional support to talk through worries or concern	☐ Yes ☐ No, I don't need it ☐ No, but I do need it	If yes who from Who referred/signposted
Informed about or given visuals aids such as magnifiers	☐ Yes ☐ No, I don't need it ☐ No, but I do need it	If yes who from Who referred/signposted

Information about welfare benefits	☐ Yes ☐ No, I don't need it ☐ No, but I do need it	If yes who from Who referred/signposted
Information about the certification (CVI) /registration process	☐ Yes ☐ No, I don't need it ☐ No, but I do need it	If yes who from Who referred/signposted
Support for any employment issues	☐ Yes ☐ No, I don't need it ☐ No, but I do need it	If yes who from Who referred/signposted
Support for a family member or carer	☐ Yes ☐ No, I don't need it ☐ No, but I do need it	If yes who from Who referred/signposted

If yes to any of the above continue. If no to all go to Q17.

Record who Q 11-16 refers to……..

- When did you first have contact with the support services?
  - ☐ In the last 3 months
  - ☐ 4 to 6 months ago
  - ☐ 7 to 12 months ago
  - ☐ More than a year ago
  - ☐ Don't know
- How did you have contact with the support services?
  - ☐ Telephone
  - ☐ Face to face
  - ☐ Written correspondence (e.g. letter or email)
- **After contact** with the support services, **do you feel more** informed about the support available to help you live with sight loss?
  - ☐ A lot more informed
  - ☐ A bit more informed
  - ☐ No difference

- **After contact** with the support services do you think you have a better understanding of the following:
- Your eye condition:
  - ☐ Yes
  - ☐ No
  - ☐ Don't know
  - ☐ Not applicable
- How you care for and treat your eye condition:
  - ☐ Yes
  - ☐ No
  - ☐ Don't know
  - ☐ Not applicable
- The range of support that is available to you outside the hospital:
  - ☐ Yes
  - ☐ No
  - ☐ Don't know
  - ☐ Not applicable

Thinking about the support that you received from the support services, can you tell us:

- Did the support services give you the practical support you needed? For example: supporting you on how to use aids and adaptations, or telling you about services or support available outside of the eye clinic.
  - ☐ Yes, all the support I needed
  - ☐ Yes, most of the support I needed
  - ☐ Neither enough nor too little support
  - ☐ No, I would have liked more support
  - ☐ No, I would have liked considerably more support

- How helpful was the support and/or information you received from the support services?
  - ☐ Very helpful
  - ☐ Helpful
  - ☐ Neither helpful nor unhelpful
  - ☐ Unhelpful
  - ☐ Very unhelpful

- As a result of speaking to the support services, do you feel more or less able to seek further support yourself?

  ☐ Much more able

  ☐ More able

  ☐ No different

  ☐ Less able

  ☐ Much less able

- Have you had any problems with mobility (e.g. experiencing falls) or accidents (e.g. burns or other harms) as a result of your vision loss?

  ☐ No (go to Q18)

  ☐ Yes

- If yes, were these:

  ☐ Falls

  ☐ Burns

  ☐ Other (please describe)_____

- How many times in the past 12 months have you needed medical treatment as a result of a fall or other accident due to your sight loss?

  _____

- Do you feel more at risk of falling today than you did 6 months ago?

  Yes, agree

  No, disagree

- Have you had any adaptations to your home or training (as a result of your contact with support services)?

  No

  Yes (please describe, include provider) _____

In this section, we would like to know about the impact that the service you received had on your quality of life. When answering, please think about the service you were offered and the difference that made to you. Please place a tick in ONE box for each of the five groups below.

Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY

I have no problems in walking about ❑
I have slight problems in walking about ❑
I have moderate problems in walking about ❑
I have severe problems in walking about ❑
I am unable to walk about ❑

SELF-CARE

I have no problems washing or dressing myself ❑
I have slight problems washing or dressing myself ❑
I have moderate problems washing or dressing myself ❑
I have severe problems washing or dressing myself ❑
I am unable to wash or dress myself ❑

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ❑
I have slight problems doing my usual activities ❑
I have moderate problems doing my usual activities ❑
I have severe problems doing my usual activities ❑
I am unable to do my usual activities ❑

PAIN / DISCOMFORT

I have no pain or discomfort ❑
I have slight pain or discomfort ❑
I have moderate pain or discomfort ❑
I have severe pain or discomfort ❑
I have extreme pain or discomfort ❑

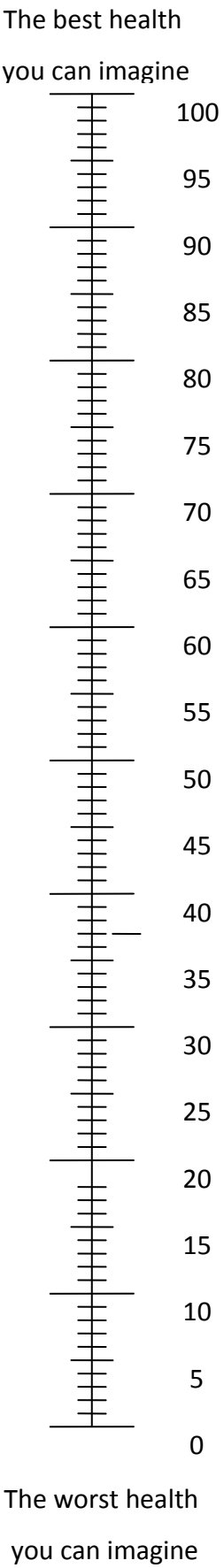
ANXIETY / DEPRESSION

I am not anxious or depressed ❑
I am slightly anxious or depressed ❑
I am moderately anxious or depressed ❑
I am severely anxious or depressed ❑
I am extremely anxious or depressed ❑

We would like to know how good or bad your health is TODAY.This scale is numbered from 0 to 100.

- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =



APPENDIX 2 · NON-CLINICAL SUPPORT FOR PATIENTS IN EYE CLINICS – STAFF PRO FORMA

An evaluation of patient information and support services in UK eye clinics

NON-CLINICAL SUPPORT FOR PATIENTS IN EYE CLINICS

As part of the evaluation of patient information and support services in UK eye clinics, we are interested in how much time you spend providing non-medical support to patients, such as referring patients to other services. Please complete the table below as far as possible by estimating for how many patients and how much time you spend on the various tasks below in an average week.

Job title: **Employment band/grade:** **WTE:**

Task	Description	No. of patients to whom you provide this service in an average week	Average time spent per patient
Emotional support	I have spent time listening to patients/carers, talking through their worries or concerns.		
Information-giving / signposting	I have provided information about further, non-clinical support, local and/or national.		
	I have provided eye health information to patients, family members and others.		
Advocacy	I have helped people to have their voices heard; to secure their rights and to obtain the support they need.		
Professional networks / relationships	I have made contact with referrers on behalf of patients.		

Certification and registration	I have informed and advised patients about Certification and Registration and its benefits.		
	I have helped patients in a practical way by helping to fill in forms, for example.		
Monitoring and follow up of patient progress	I have followed up with patients that I've referred on to other services to check that satisfactory progress has been made.		
Evaluation / impact measurement	I have engaged and consulted with patients to evaluate our services and to support continuous service improvement		
Other non-medical support	(Please list, continuing overleaf if needed)		

Do you refer patients to the ECLO (or other services)?

How many per week?

What type of patients do you refer?

Does the ECLO save you time in clinic?

If yes how much time?

What would be the impact of there not being an ECLO in clinic?

-On patients?

- On clinic?

An evaluation of patient information and support services in UK eye clinics
Data collection protocol

Evaluation team

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STUDY SPONSOR AND ETHICAL CONSIDERATIONS

The University of South Wales is the sponsor for this evaluation in line with the Research Governance Framework for Health and Social Care (2005). All documentation, including consent forms, information sheets, patient surveys and interview schedules have been approved by the University Research Ethics Committee. Although this is considered to be a service evaluation using the NHS Health Research Authority criteria (see below), the evaluation is being conducted with full consideration of ethical issues in line with good clinical practice. We are contacting all R&D departments at each site to gain the appropriate approvals.

This study is considered to be solely service evaluation as the participants will not be randomised to different groups. We are examining how standard care is delivered and the evaluation protocol does not demand changing treatment/ patient care from accepted standards for any of the patients involved. Also the findings are not going to be generalisable - we will produce outcomes that are only of interest to the specific clinical area being considered.

BACKGROUND

RNIB has funded a service evaluation to explore the effectiveness and cost-benefit of Eye Clinic Liaison Officers (ECLOs) – also known as Sight Loss Advisers or Vision Support Officers. The study is being undertaken by the Welsh Institute of Health and Social Care, University of South Wales (WIHSC) and the Swansea University Centre for Health Economics (SCHE). The ECLO role was established to provide person-centred emotional and practical support tailored to the needs of patients with sight loss, and to act as a bridge between health and social care services. The ECLO works directly with people with sight loss to provide information and advice, emotional support and assistance in achieving an appropriate

referral to community based services. This study is attempting to answer questions relating to the role of ECLOs in hospital eye clinics, such as:

- What is the impact of an ECLO on clinic activity?
- Are there cost-savings to a department/wider NHS when an ECLO is part of the care team? For example, does the support of an ECLO reduce falls and other hospital admissions?
- What are the patient benefits of having an ECLO present in an eye clinic?

The evaluation team from WIHSC and SCHE will collect data from hospital sites where a RNIB qualified ECLO is present in the eye clinic and, as a comparison, from sites where there is no ECLO present. At these comparison sites, a range of other third sector information and support services may be provided, or no such provision maybe available for patients. This evaluation aims to provide much needed information as to the cost-effectiveness and impact on patients of having a trained ECLO available in hospital eye clinics. Information will be collected at a patient and service-wide level.

METHOD

The evaluation team intends to conduct site visits to around 30 ophthalmology departments across the UK to gather data from a range of clinics where trained ECLOs are present, where other voluntary support is available, and where no formal support is provided. Data collection at each site will compose of:

- **Patient survey to evaluate the impact of the service on patient outcomes such as quality of life**. With informed consent (all patients will be given time to read the information sheet and consent form) patients will be asked if they are willing to complete a brief survey about any support services they have received. As patients may have visual impairments, patients will be able to complete the survey with a member of the evaluation team in the clinic. The evaluation team member will also go through the information sheet with the patient if they are unable to read it themselves. Patients can also simply consent to take part in the evaluation and will be contacted at a later date to complete the survey over the telephone. Eligible patients include those with an eye condition or who have a certificate of visual impairment, who would be eligible for support from an ECLO (such as those with AMD, glaucoma, diabetic retinopathy etc). The evaluation team aim to recruit around 10-20 patients from each site. Patients will be asked to consent to a follow-up phone call in 3 months time, where the survey will be repeated. Patients will be informed that their participation is entirely voluntary and that they are able to withdraw from the evaluation at any time without giving a reason. The care and treatment they receive from the NHS will not be affected whether they choose to take part or not. All consent forms will be kept in a locked cupboard in the evaluation team office which is only accessible to the team. All participants will remain anonymous and no identifiable information will be published in study reports or publications.
- **Interviews with key staff.** In order to qualitatively gauge the impact of the ECLO or equivalent on the clinic, we will conduct semi-structured interviews with key staff such as ophthalmic consultants, ophthalmic nurses, administrative staff, and ECLOs. Interviews will be conducted with fully informed consent and will take place on the day of the site visit by the evaluation team or over the telephone at a convenient time. Interviews are expected to last no more than 20 minutes. Clinical staff can also complete a proforma which aims to assess how much of their time is spent providing various forms of support to patients, so that this can be compared between sites. Interviews will be transcribed and analysed by the researchers. All interviewees will remain

anonymous and any identifying information will not be provided in any reports or publications. Participation by staff is entirely voluntary and they will be free to withdraw their contribution at anytime without giving a reason.

These results will feed into a cost-consequence analysis of the ECLO role and an analysis of the impact of the ECLO on patient outcomes and the eye clinic. The outcomes and impact of the ECLO model will be compared with other forms of information and support provision.

IMPACT AND DISSEMINATION

The evaluation of the ECLO role is crucial because ECLOs are funded either by RNIB, the NHS, social services, other third sector organisations, or a mixture of these. From a national perspective, the unique nature of the ECLO role and substantial funding makes it obligatory that learning from the programme is maximised so that we know what models of working are most effective for patients and which are most cost-effective. From a local perspective, the local health community and commissioners require robust evaluation to inform decisions on funding these services and their long-term sustainability.

APPENDIX 4 · **ECLO ACTIVITY DATA**

In addition to the data collected by survey, two sources of routinely collected data were utilised. The first is a dataset relating to the daily activities of each RNIB ECLO throughout the UK. This dataset contains records from one calendar year split by the constituent countries in the UK. The ECLOs are responsible for collecting information on patients' demographic background, personal information such as living arrangements, fear of falling, eye conditions, disabilities and etc. Interaction types and meeting durations are also recorded into the data by the ECLOs.

Unfortunately, each country in the UK collects data in a different way but every effort will be made to attain consistency. All patients in each country will be firstly located an ID number and identified as new or returning patients by the ECLOs. The difference is, only patients in England can be tracked with the uniquely located ID. Nevertheless, some data are not collected in England as they do in Wales, Scotland and Northern Ireland, for example, patients' history of falls, main issue, emotional support and practical support. Usually patients have multiple concerns regarding their eye condition, life issues such as reading and driving, registration of certificate of vision impairment (CVI), anxiety and emotional distress, welfare etc., three main concerns are recorded by the ECLOs followed by support from the ECLOs, emotional and practical.

A second source of data relates to England alone and contains information relating to the time spent on completing CVI and information on the patients who are given them. These data inform the cost-consequence analysis of the ECLO role and an analysis of the impact of the ECLO on patient outcomes and the eye clinic. Actual time that the ECLOs spend with patients are recorded in English data rather than time intervals in the rest three countries, and 'CVI completed' is an outcome option in the outcome category so that we can track the patients who have their CVI completed. Although ECLOs' time spent with patients and appointment outcomes are recorded in different files, they can be matched using patients' uniquely allocated IDs.

The following table lists variables in the data set of four countries.

Table A4.1. List of variables in ECLO activity data

Variable name	Variable description
said	Patients' ID
DOC	Date of contact
year	Year of collecting
quarter	Quarter of collecting
neworreturning	New or returning patients
interactiontype	Interaction type (face to face, phone, text, email, etc.)
locationofmeeting	Location of meeting (ECLOs office, waiting room, etc.)
referralsource	Referral source (Doctor, eye clinic, self, etc.)

gender	Gender
agerange	Patients' age range
localauthority	Local authority
educationstatus	Education status
additionaldisability1,2,3	Patients' other disabilities
ethnicity	Patients' ethnics
fearoffalling	Patients' fear of falling
historyoffalls	Patients' history of falls
livingstatus	Patients' living status
caringstatus	Patients' caring status
employmentstatus	Patients' employment status
maineyecondition	Patients' main eye condition
othereyecondition	Patients' other eye conditions
firstdiagnosedwitheyecondition	Date of patients' eye condition first diagnosed
certificatestatus	Patients' CVI status
clientissue1,2,3	Patients' main concern (three recorded)
timespendwithclients	ECLOs' time spend with patients
timespendonbehalfofclients	ECLOs' time spend on behalf of patients
informedabout1,2,3,4,5	Patients' outcome, informed about from the ECLOs (up to five are recorded)
signpostedto1,2,3,4,5	Patients' outcome, signposted to other source (up to five are recorded)
referredto1,2,3,4,5	Patients' outcome, referred to other source (up to five are recorded)
emotionalsupportgiven	Emotional support given to patients (not in English data)
practicalsupportgiven	Practical support given to patients (not in English data)
familysupportgiven	Family support given to patients (not in English data)
outcometype	Outcome type for England patients
outcomecategory	Specific outcome for England patients, including CVI completion

APPENDIX 5 · **STAFF SURVEY RESULTS FOR OTHER OPHTHALMOLOGY STAFF**

TABLE A5.1 · Support provided by Senior Optometrist / Optometrist

Type of support provided by Senior Optometrist / Optometrist		No. of patients to whom you've provide this service in the last week					Average time spent per patient (minutes)				
		N	Mean	SD	Min	Max	N	Mean	SD	Min	Max
I have spent time listening to patients/carers, talking through their worries or concerns.	Site with ECLO	7	5.50	3.93	2	12	7	7.5	3.08	4	12.5
	Site without ECLO	3	4.00	3.61	1	8	3	6.67	2.89	5	10
I have provided information about further, non-clinical support, local and/or national.	Site with ECLO	7	2.43	2.15	0	5	6	2.17	1.47	1	5
	Site without ECLO	3	2.00	1.00	1	3	3	1.67	0.58	1	2
I have provided eye health information to patients, family members and others.	Site with ECLO	6	0.83	1.60	0	4	2	3.50	2.12	2	5
	Site without ECLO	0	-	-	-	-	0	-	-	-	-
I have helped people to have their voices heard; to secure their rights and to obtain the support they need.	Site with ECLO	6	0	0	0	0	0	-	-	-	-
	Site without ECLO	3	0	0	0	0	0	-	-	-	-
I have made contact with referrers on behalf of patients.	Site with ECLO	6	0.50	1.23	0	3	1	1.0	-	1	1
	Site without ECLO	3	0.67	0.58	0	1	2	10.0	7.07	5	15
I have informed and advised patients about Certification and Registration and its benefits.	Site with ECLO	7	0.71	0.76	0	2	4	7.50	6.14	2	15
	Site without ECLO	3	0.67	0.58	0	1	2	3.50	2.12	2	5
I have helped patients in a practical way by helping to fill in forms, for example.	Site with ECLO	7	0	0	0	0	0	-	-	-	-
	Site without ECLO	3	0.33	0.58	0	1	1	1	-	1	1
I have followed up with patients that I've referred on to other services to check that satisfactory progress has been made.	Site with ECLO	7	0	0	0	0	0	-	-	-	-
	Site without ECLO	3	0	0	0	0	0	-	-	-	-
I have engaged and consulted with patients to evaluate our services and to support continuous service improvement	Site with ECLO	7	0.14	0.38	0	1	1	5.0	-	5	5
	Site without ECLO	3	0	0	0	0	0	-	-	-	-

TABLE A5.2 · Support provided by Senior Orthoptist / Orthoptist

Type of support provided by Senior Orthoptist / Orthoptist		No. of patients to whom you've provide this service in the last week					Average time spent per patient (minutes)				
		N	Mean	SD	Min	Max	N	Mean	SD	Min	Max
I have spent time listening to patients/carers, talking through their worries or concerns.	Site with ECLO	4	5.75	4.03	1	10	4	10.0	4.08	5	15
	Site without ECLO	3	4.00	3.61	1	8	3	6.67	2.89	5	10
I have provided information about further, non-clinical support, local and/or national.	Site with ECLO	4	1.50	1.92	0	4	2	10.0	7.07	5	15
	Site without ECLO	3	2.00	1.00	1	3	3	1.67	0.58	1	2
I have provided eye health information to patients, family members and others.	Site with ECLO	3	4.67	5.03	0	10	2	10.0	7.07	5	15
	Site without ECLO	0	0	0	0	0	0	-	-	-	-
I have helped people to have their voices heard; to secure their rights and to obtain the support they need.	Site with ECLO	3	0	0	0	0	0	-	-	-	-
	Site without ECLO	3	0	0	0	0	0	-	-	-	-
I have made contact with referrers on behalf of patients.	Site with ECLO	2	0	0	0	0	1	10.0	-	10	10
	Site without ECLO	3	0.67	0.58	0	1	2	10.0	7.07	5	15
I have informed and advised patients about Certification and Registration and its benefits.	Site with ECLO	4	1.50	1.73	0	4	3	5.67	4.04	2	10
	Site without ECLO	3	0.67	0.58	0	1	2	3.50	2.12	2	5
I have helped patients in a practical way by helping to fill in forms, for example.	Site with ECLO	4	0	0	0	0	0	-	-	-	-
	Site without ECLO	3	0.33	0.58	0	1	1	1.0	-	1	1
I have followed up with patients that I've referred on to other services to check that satisfactory progress has been made.	Site with ECLO	4	0	0	0	0	0	-	-	-	-
	Site without ECLO	3	0	0	0	0	0	-	-	-	-
I have engaged and consulted with patients to evaluate our services and to support continuous service improvement	Site with ECLO	4	0	0	0	0	0	-	-	-	-
	Site without ECLO	3	0	0	0	0	0	-	-	-	-

TABLE A5.3 · Support provided by Specialist Doctor / Registrar (non consultant) – ECLO sites only

Type of support provided by Specialist Doctor / Registrar (non consultant) – ECLO sites only		No. of patients to whom you've provide this service in the last week					Average time spent per patient (minutes)				
		N	Mean	SD	Min	Max	N	Mean	SD	Min	Max
I have spent time listening to patients/carers, talking through their worries or concerns.	Site with ECLO	6	1.75	2.36	0	5	4	26.75	42.30	2	90
I have provided information about further, non-clinical support, local and/or national.	Site with ECLO	6	4.92	9.88	0	25	4	5.75	4.92	1	10
I have provided eye health information to patients, family members and others.	Site with ECLO	6	4.17	6.83	0	18	4	8.00	4.49	2	12.5
I have helped people to have their voices heard; to secure their rights and to obtain the support they need.	Site with ECLO	6	0	0	0	0	6	-	-	-	-
I have made contact with referrers on behalf of patients.	Site with ECLO	6	0.33	0.52	0	1	2	5.50	6.36	1	10
I have informed and advised patients about Certification and Registration and its benefits.	Site with ECLO	7	0.86	0.85	0	2	4	8.63	7.91	2	20
I have helped patients in a practical way by helping to fill in forms, for example.	Site with ECLO	6	0.17	0.41	0	1	1	5.0	-	5	5
I have followed up with patients that I've referred on to other services to check that satisfactory progress has been made.	Site with ECLO	6	0	0	0	0	0	-	-	-	-
I have engaged and consulted with patients to evaluate our services and to support continuous service improvement	Site with ECLO	6	0	0	0	0	0	-	-	-	-

APPENDIX 6 · **DETERMINISTIC ECONOMIC MODELLING OUTPUT - FALLS**

	Sight Loss [1,2]	Refractive Error (%)[1]	Other Eye Conditions	Seek Support (SS) (%)	Estimated	Fear Fall (% Pop.)[3]	Fear of Fall (SS. Pop.)	No Fear of Fall	Fall (% SS Pop.)[3]	Fall (Tot. Pop.)	Fallers having Fear of Falling	Fearers Falling	Non-Fearers Falling	Fall Rate Fearers	Fall Rate Non-Fearers
UK	1,800,000	53.5%	837,633	100%	837,633	47%	393,687	443,945	25%	209,408	80%	167,527	41,882	42.6%	9.4%
WALES	86,858	53.5%	40,420	100%	40,420	47%	18,997	21,422	25%	10,105	80%	8,084	2,021	42.6%	9.4%

	Seek Support/ See ECLO (%)[3]	SS Pop. See ECLO	SS Pop. (Other Staff)	Fear Fall See ECLO	Fear Fall No ECLO	No Fear of Falls See ECLO	No Fear of Fall No ECLO	Total Patients Seen by ECLO
UK	16.7%	139,468	698,164	65,550	328,137	73,918	370,027	139,468
Wales	16.7%	6,730	33,690	3,163	15,834	3,567	17,856	6,730

	ECLO Referral to Falls - Fearers	Fearers Referred	Referral to Falls - No Fear	Non-Fearers Referred	Referral Reduction in Fall Rate [4]	Fall Rate - Referred Fearers	Falls - Referred Fearers	Fall Rate - Referred Non-Fearers	Falls Referred Non-Fearers	Fall Rate - Non-Referred Fearers/Non-Fearers	Falls - ECLO Non-Referred Fearers	Falls - ECLO Non-Referred Non-Fearers	Non-ECLO Falls - Fearers	Non-ECLO Falls - Non-Fearers
UK	30%	19,665	5%	3,696	33%	28.4%	5,579	6.3%	232	1.0%	459	702	139,633	34,908
Wales	30%	949	5%	178	33%	28.4%	269	6.3%	11	1.0%	22	34	6,738	1,684

	Total Falls Fearers	Total Falls Non-Fearers	Total Falls	Reduction in Falls	Reduction in Falls	Estimated Fall Rate
UK	145,670	35,843	181,513	27,895	13.3%	21.7%
Wales	7,029	1,730	8,759	1,346	13.3%	21.7%

	ECLO Time - With Client (mins)	ECLO Time - On Behalf of Client (mins)	Total ECLO Client Time (mins)	Total ECLO Time (mins)	Total ECLO Time (Hours)	Total (FT) ECLO's Required	ECLO Cost (per hr) [5]	ECLO Cost per Client	Total ECLO Cost
UK	40.69	35.40	76.09	10,611,747	176,862.45	112	£ 29.00	£ 36.78	£ 5,129,011
Wales	40.69	35.40	76.09	512,067	8,534.44	5	£ 29.00	£ 36.78	£ 247,499

	Cost per Fall [6,7]	Total Falls (CONTROL)	Total Fall Cost (CONTROL)	Total Falls (with ECLO)	Total Fall Cost (with ECLO)	Reduction in Falls	Reduction in Falls Cost	Falls Saving %
UK	£ 2,997	209,408	£ 627,596,306	181,513	£ 543,995,533	27,895	£ 83,600,773	13.32%
Wales	£ 2,997	10,105	£ 30,284,470	8,759	£ 26,250,340	1,346	£ 4,034,130	13.32%

	Total Fall Cost (with ECLO)	Total ECLO Cost	Total Cost	Saving	Saving %
UK	£ 543,995,533	£ 5,129,011	£ 549,124,544	£ 78,471,762	12.50%
Wales	£ 26,250,340	£ 247,499	£ 26,497,839	£ 3,786,631	12.50%

	Incremental Cost per Fall Avoided
UK	-£ 2,813
Wales	-£ 2,813

From Literature	Estimated	Assumed	ECLO Results

REFERENCES

1. Access Economics (2009)
2. ONS mid-year population estimates. 2012
3. RNIB Cymru (2013), Eye Clinic Liaison Report
4. Close, J. et al. (1999), 'Prevention of falls in the elderly trial (PROFET): a randomised contolled trial' *Lancet* Jan 9th, 353.9147, pp.93-7
5. Curtis, L., Burns, A. (2016), Unit Costs of Health and Social Care 2016, Personal Social Services Research Unit, University of Kent.
6. Tian et al. (2013), *Exploring the system-wide costs of falls in older people in Torbay*, The Kings Fund
7. Bank of England Inflation Calculator, 2016.

APPENDIX 7 · **DETERMINISTIC ECONOMIC MODELLING OUTPUT - DEPRESSION**

	Sight Loss [1,2]	Refractive Error (%)[1]	Other Eye Conditions	Seek Support (SS) (%)	Estimated	Depression Prevalence [3]	Depression Population	Average Depression Service Costs[4,5]	Total Control Service Costs
UK	1,800,000	53.8%	837,633	100%	837,633	43%	360,182	£ 2,509	£ 903,696,800
WALES	86,858	53.8%	40,420	100%	40,420	43%	17,380	£ 2,509	£ 43,607,616

	Seek Support/ See ECLO (%)[6]	Population Seen by ECLO	Depression Population Seen by ECLO	Depression Population Seen by Other Staff	ECLO Emotional Support (%)	ECLO - Emotional Support	ECLO - No Emotional Support	Referral to Services (ECLO - Emotional Support)	Referral to Services (ECLO - No Emotional Support)	ECLO - Emotional Support - Referrals	ECLO - No Emotional Support - Referrals	TOTAL ECLO REFERRALS
UK	16.7%	139,468	59,971	300,211	95%	56,973	2,999	30%	0%	17,092	-	17,092
Wales	16.7%	6,730	2,894	14,487	95%	2,749	145	30%	0%	825	-	825

	Total Depression Service	Reduction in Depression Service Users	Percentage Reduction
UK	317,303	42,880	11.90%
Wales	15,311	2,069	11.90%

	ECLO Time - With Client (mins)	ECLO Time - On Behalf of Client (mins)	Total ECLO Client Time (mins)	Total ECLO Time (mins)	Total ECLO Time (Hours)	Total (FT) ECLO's Required	ECLO Cost (per hr)[7]	ECLO Cost per Client	Total ECLO Cost
UK	40.69	35.40	76.09	10,611,747	176,862	112	£ 29.00	£ 36.78	£ 5,129,011
Wales	40.69	35.40	76.09	512,067	8,534	6	£ 29.00	£ 36.78	£ 247,499

	Depression Service Costs[4,5]	Depression Referrals (CONTROL)	Depression Cost (CONTROL)	Depression Referrals (with ECLO)	Depression Cost with ECLO	Saving	Saving Percentage
UK	£ 2,509	360,182	£ 903,696,799.71	317,303	£ 796,112,074	£ 107,584,726	11.90%
Wales	£ 2,509	17,380	£ 43,607,616.38	15,311	£ 38,416,148	£ 5,191,468	11.90%

	Total Depression Cost (with ECLO)	Total ECLO Cost	Total Cost	Saving	Saving
UK	£ 796,112,074	£ 5,129,011	£ 801,241,085	£ 102,455,715	11.34%
Wales	£ 38,416,148	£ 247,499	£ 38,663,647	£ 4,943,970	11.34%

	Incremental Cost per Referral Avoided
UK	-£ 2,389.39
Wales	-£ 2,389.39

From Literature	Estimated	Assumed	ECLO Results

REFERENCES

1. Access Economics (2009)
2. ONS mid-year population estimates. 2012
3. Nollett et al. (2016), 'High prevalence of untreated depression in patients accessing low-vision services' *Opthamology* 123.2, 440-441
4. McCrone et al. (2008) 'Paying the Price: the cost of mental health care in England to 2026' *The Kings Fund*
5. Bank of England Inflation Calculator
6. RNIB Cymru (2013), Eye Clinic Liaison Report
7. Curtis, L., Burns, A. (2016), Unit Costs of Health and Social Care 2016, Personal Social Services Research Unit, University of Kent

APPENDIX 8 · CLINICAL GUIDELINES RELEVANT TO THE ECLO SERVICE

The table below provides information about guidelines and recommendations that are relevant to the ECLO service. These include the NICE Clinical Guideline for Glaucoma; guidelines published by the Royal College of Ophthalmologists; and the UK Vision Strategy.

The first column contains the reference to the guideline. The second column contains the section of the guidance that is relevant to the ECLO service. Comments about the relevance of the guideline to the ECLO service are in the third column.

Guideline	Recommendation	Relevance to ECLO service
NICE guidelines [CG85] Glaucoma: diagnosis and management[168]	1.6 Provision of information 1.6.1 Offer people the opportunity to discuss their diagnosis, prognosis and treatment, and provide them with relevant information in an accessible format at initial and subsequent visits. This may include information on the following: – their specific condition (OHT, suspected COAG and COAG), its life-long implications and their prognosis for retention of sight – that COAG in the early stages and OHT and suspected COAG are symptomless – that most people treated for COAG will not go blind – that once lost, sight cannot be recovered – that glaucoma can run in families and that family members may wish to be tested for the disease – the importance of the person's role in their own treatment – for example, the ongoing regular application of eye drops to preserve sight – the different types of treatment options, including mode of action, frequency and severity of side effects, and risks and benefits of treatment, so that people are able to be active in the	– Some ECLOs educate patients in the importance and technique of applying eye drops

[168] https://www.nice.org.uk/guidance/cg85

	decision-making process – how to apply eye drops, including technique (punctal occlusion and devices) and hygiene (storage) – the need for regular monitoring as specified by the healthcare professional – methods of investigation during assessment – how long each appointment is likely to take and whether the person will need any help to attend (for example, driving soon after pupil dilatation would be inadvisable) – support groups – compliance aids (such as dispensers) available from their GP or community pharmacist – Letter of Vision Impairment (LVI), Referral of Vision Impairment (RVI) and Certificate of Vision Impairment (CVI) registration – Driver and Vehicle Licensing Agency (DVLA) regulations.	– ECLOs are well placed to provide information about local and national support groups – ECLOs can provide information about CVIs and referrals to social services sensory rehabilitation teams
The Royal College of Ophthalmologists Age-Related Macular Degeneration: Guidelines for Management September 2013[169]	12.1 The diagnosis session in clinic – general remarks a. Breaking bad news. Patients report that after receiving news that their eye condition is not treatable, they tend not to hear further information during the consultation. It is therefore important that patients are given written information at the end of the consultation concerning their eye condition, available rehabilitation services and useful contact numbers. b. Avoid 'diagnose and immediate discharge'. Patients with macular disease who have lesions which are not treatable with current therapies are often seen only once in the eye clinic and then discharged. They can be unaware of what to expect in the future or where they can obtain relevant information or how to find their way through the maze of services and organisations. Although there may seem little advantage in seeing the patient a second time, because most are not able to take in information after receiving bad news, a follow up visit is of benefit to receive further information and ask questions. They must be given contact details of someone they can come back and talk to. This may be an Eye Clinic Liaison Officer (ECLO) who may be available at the time of diagnosis also.	– Patients whose eye condition is not treatable can be referred to an ECLO to access support and information. Potentially saving a follow-up visit with the clinician

[169] https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013-SCI-318-RCOphth-AMD-Guidelines-Sept-2013-FINAL-2.pdf

	c. The clinic experience at time of diagnosis has an impact on the way patients deal with their diagnosis and visual impairment. Patients frequently report that the diagnosis was given in an uncaring manner. A good initial experience at the hospital will almost certainly help the patient's future outlook, expectations and achievements. A satisfactory patient experience can only be achieved by good training. d. Importance of signposting. Receiving a diagnosis without the follow up information leaves patients feeling lost and isolated. They should be given appropriate information about support services such as visual rehabilitation officers and low vision services. Charities such as local societies, the RNIB, and the Macular Society offer wide range of services such as telephone advice and counselling services and local support groups. e. Provide literature in the clinic. Patients appreciate being given information regarding their condition that can be read at leisure. It should be the responsibility of staff in the clinic to make information leaflets available and ensure that patients are offered them before leaving. The Macular Society and others have a wide range of materials in large print and audio. Smoking is a recognised risk factor for both dry and wet AMD. All patients with macular degeneration/ dystrophy should be advised to stop smoking. Interventions which can help the individual come to terms with their sight loss, retain their independence, and improve their function and quality life include information about the condition and prognosis, emotional support, counselling, a low vision assessment and practical input such as rehabilitation covering daily living skills, mobility and the benefits of lighting, colour and contrast in maximising the use of residual sight. Some awareness of the research in the area of retinal repair is helpful as many patients will wish to discuss the current research strategies; two examples are stem cells and electronic eye research. 12.3 Referral to rehabilitation and low vision services a. If an individual has sight loss then it is vital that they be offered the opportunity of accessing low vision support and advice at an early stage. Advice and use of task lighting and magnifiers reduce the early impact of sight loss and the risk of falls. Do not wait until all treatment options have been explored or until an individual's vision deteriorates to a level that registration as blind/ severely sight impaired or as partially sighted/ sight impaired becomes appropriate; before considering referring an individual to low vision and rehabilitation services. b. Early advice and support means that an individual can learn how to use their remaining vision more	– ECLOs can improve patient satisfaction – ECLOs play a role in signposting patients to support services and local societies – ECLOs are often instrumental in keeping literature and leaflets up-to-date in the eye clinic. – ECLOs can refer patients to appropriate interventions including rehabilitation and low vision assessments

	effectively, retaining independence and confidence. It is also far easier to learn the principles of using optical low vision aids with the lower powers and the skills can be transferred to the higher powers later if needed. The longer it is left the more difficult it is to help a person overcome any loss of confidence in their abilities and the more likely that depression will occur. General information from the NHS on living with low vision can be found at: http://www.nhs.uk/Livewell/Eyehealth/Pages/Livingwithlowvision.aspx c. Find out where and what low vision services are available locally and refer your patients with low vision as soon as possible. Some may well be hospital based and others may be community based. d. It should no longer be the case that access to a low vision service is certification/ registration led. e. The NHS Eyecare Services Programme sets out what should be expected from a Low Vision Services, and is available online. The principles: · Access to rehab and low vision support will vary according to local arrangements. Clinicians should be present or represented on their local low vision committee. All local systems should adhere to these principles: · Low vision services must reflect a multi-disciplinary, multi-agency approach that co-ordinates with other health and social care providers in the area, including services provided at the client's residence at the time. This methodology ensures efficient and professional delivery of services. · The services delivered must be based upon needs identified by clients and be sufficiently flexible to meet the disparate needs of its client group. There should be evidence of user participation in agreements on the setting up and implementation of pathways and protocols. · Registration as sight impaired or severely sight impaired should not be a pre-requisite to accessing low vision services. · Locally designed guidelines, pathways and protocols should be underpinned, whenever possible, by evidence based knowledge and accepted guidance. This must conform with and contribute to local clinical governance arrangements. · Assessment. There should be a tailored needs-based assessment for each client following referral to the low vision service. A low vision assessment should always offer: o An eye health examination or evidence of recent examination or referral for examination according to local	– ECLOs can refer patients to rehabilitation services before the point of registration

	protocols. o A functional visual assessment · After assessment the following should be offered, as appropriate, to the user: o Prescription/provision of appropriate optical/non-optical aids. The sale of some low vision aids is restricted to certain professionals or requires appropriate supervision. The supply/loan of aids should be governed by local protocol. o Advice on lighting, contrast and size, filters, tactile aids, electronic aids and other non-optical aids. o Training and/or therapy to enable optical and non-optical aids and other techniques to be used effectively. o Links to broader rehabilitation services, such as home assessment and mobility as well as possible referral to structured therapy programmes and counselling. o A review of benefits, welfare rights, concessions, support groups, (both local and national) o Advice on access to the full range of low vision equipment available for purchase through local society resource centres or the RNIB or direct from retailers. If an individual is experiencing difficulties because of problems with their sight they are entitled to an assessment of need by social services – they do not need to be registered as severely sight impaired or sight impaired. The level of support offered once an assessment of need has taken place will depend on locally decided criteria, but social services will be able to provide the client information as to the advice and support that is available in an area for people with sight loss and on any services for which they may be eligible. In some areas social services will contact patients via the sensory impairment team rehabilitation officers for the visually impaired. Rehabilitation officers can provide training and support to a person with sight loss in their homes and local environment to cover daily living and mobility skills. The aim is to help an individual to retain their independence. They can also provide practical advice on how to use remaining vision effectively including the use of lighting, colour and contrast, which can be extremely beneficial even when there is minimal reduction to visual quality. It does not take long for people to lose confidence in their abilities as their sight deteriorates and for many this can lead to depression. 12.4 Registration a. What is registration? Practices may vary in different devolved administrations in the UK: region specific information will be available from the local macular unit. In England each local council keeps a register of sight impaired and severely sight	

	impaired people living in its area. The register is held by the social services or social work department, or by a local voluntary agency. The Certificate of Visual Impairment (CVI) was introduced in 2003 and is used to certify people as sight impaired or severely sight impaired. Concessions are calculated from the date of examination. Hospital eye services can download the Word version of the CVI form for tailoring with their own contact details from the NHS web, or by emailing OPDEnquiries@dh.gsi.gov.uk. This form formally certifies someone as sight impaired or severely sight impaired so that the local council can register him or her. Its second purpose is to record a standard range of diagnostic and other data that may be used for epidemiological analysis. b. Why register somebody as severely sight impaired or sight impaired? · Recent figures for the numbers of people registered as severely sight impaired or sight impaired have dropped significantly since the introduction of the (CVI). There may be many reasons for this, but it certainly does not reflect a drop in the numbers of people experiencing sight loss. · If anything evidence based on the aging population predicts a sharp increase in the numbers of visually impaired individuals in the coming years. The services for people with sight loss are decreasing in some areas because of this drop in the numbers of people being registered. · Epidemiology and prevalence data in the UK is based on the information contained within processed CVIs. If they are not completed for whatever reason then the future planning of health and social care services will be flawed. · Social Services still base their budget allocations for support to people with sight loss on the number of CVIs that they receive. A reduction in registrations means that funding is allocated elsewhere. Many visually impaired people may not choose to be or are never offered the opportunity to become registered · Certification is also the trigger for a review of benefits that an individual may receive, though these may vary in different devolved administrations in the UK. 12.5 Signposts to others who will provide support a. “Signposting” to others who can provide information, support and advice is vital. Not knowing how to access information or what help is available is cited by people with sight loss as the biggest barrier to coming to terms with their sight loss. b. Signposting may be the provision of contact details so the individual can find out further information for themselves. Useful details to pass on would include: · contact number for local sensory impairment teams – most councils have a single entry point duty telephone number	– ECLOs can signpost patients to local support,

	· Local VI society contact details · Knowledge of local low vision services referral mechanisms and access criteria · The Macular Society: – the national charity providing support for people with macular degeneration	information and advice services.
The Royal College of Ophthalmologists Diabetic Retinopathy Guidelines December 2012[170]	SECTION 14: COMMISSIONING FOR DIABETIC RETINOPATHY 14.3 RESOURCE REQUIREMENTS IN CONTEMPORARY DIABETIC EYE DISEASE SERVICE DELIVERY 14.3.1 Personnel The contemporary management of diabetic eye disease requires teamwork with the retinal specialist leading each team. The most important aspect of diabetic eye disease management is the prompt and correct diagnosis of the condition, especially regarding the retinal involvement due to diabetes. This means that there should be an effective retinopathy screening service to detect retinopathy in the community, and trained personnel who would decide which patients need referral to the eye hospital for further management., It is crucial that there be well defined pathways for patients to access care services in the hospital after being referred by screening for retinopathy in the community. The ENSPDR has refined the referral pathway recently introducing virtual triage set up for hospital referrals. Furthermore, the management of particular patients may change from time to time, including switching from one treatment to another, or multi-modality treatment. To provide the service, greater personnel resources are required. (Level B) – Ideally, a maximum of ten to twelve patients should be seen per clinic, i.e. not more than 20-24 patients for a 2-session day. There should be appropriate adjustment in clinic booKing's for trainees and their supervising ophthalmologists. – The following minimum service team would be required (for each clinical session) for a population of 300,000: – 2x doctors (one consultant with retinal expertise and one non-consultant) – 2x trained nurses – 1 x ophthalmic photographer/technician	

[170] https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013-SCI-301-FINAL-DR-GUIDELINES-DEC-2012-updated-July-2013.pdf

	– 1 x healthcare assistant – 1 x administrative coordinator – 1 x data collection and management support staff – 1x eye clinic liaison officer (ECLO) 14.3.9 ECLO The eye clinic liaison officer will provide the vital link between diabetic retinopathy treatment, and rehabilitation (LVA) and support (social) services and allow better integration of care. Patients who do not respond to treatment need direction to appropriate low vision services. The ECLO, where available, should ensure smooth transition from healthcare to social care. In hospitals without an ECLO, effective measures need to be in place to ensure that patients are directed to available support at a time of their choice. Specialists need to ensure that they offer patients the option of registration as visually impaired or severely visually impaired as soon as patients reach the thresholds for registration. Whilst registration remains a crucial gateway to support (low vision rehabilitation, provision vision devices, counselling, benefits etc.), it is important to encourage eye health professionals to raise awareness of available support services even before patients reach the level of registration in order to maximize the chances of patients adjusting to their sight loss with minimal trauma.	– Guidelines specifically refer to the provision of an ECLO within the diabetic retinopathy service
Adult Community Optical Low Vision Community Service Pathway[171] Issued by Local Optical Committee Support Unit	Appendix 2 Information to be provided as part of the low vision assessment: • ECLO – contact details (Eye Clinic Liaison Officer) • ILCO – contact details (Independent Living Coordinator) • Rehabilitation Officer for Visual Impairment – contact details • Other local social services, what they can offer and contact details • Local Blind Society(s), what they can offer and contact details • Local Visionary (if different), what they can offer and contact details	

[171] http://www.locsu.co.uk/uploads/enhanced_pathways_2013/locsu_adult_low_vision_pathway_rev_nov_2013.pdf

April 2011	• Action for Blind People team (part of the RNIB group), what they can offer and contact details • Local Citizen's Advice Bureau - contact details • Local tax office – contact details • Local benefits office – contact details • Local housing office – contact details This information should be supplied to low vision practices by the service commissioners, CCGs and local authority social service. The information should be checked at least annually for currency and accuracy	
Commissioning better eye care: clinical commissioning guide from The College of Optometrists and The Royal College of Ophthalmologists[172] Adults with low vision November 2013	Recommendations – Every part of the country should have access to a low vision service. – Low vision services should not only be open to people who meet visual acuity thresholds or who register as sight impaired. Low vision services can mitigate the practical, emotional and occupational or educational impacts of sight loss for people who do not meet the criteria to register as sight impaired. – Access to low vision services should be prompt and flexible. Early intervention is key to getting the best outcomes. Flexibility means service users can access the service from multiple routes and should be entitled to reassessments as their vision changes. – Integration is particularly important for low vision services. Effective low vision services adapt to individual needs and work as seamlessly as possible with other services, including hospital eye units, education, social care, voluntary organisations and stroke, rehabilitation and fall teams. Serious consideration should be given to the provision of an eye care liaison officer (ECLO) in every eye clinic in order to facilitate this. – Commissioners should ensure low vision services have dedicated funding in their programme budget for eye health and explore the possibility to jointly fund and provide the service with health, local authority and voluntary sector resources.	– Specifies provision of an ECLOS in the service delivery model

[172] http://www.college-optometrists.org/filemanager/root/site_assets/policies_and_postition_papers/joint_college_glaucoma_final_20_3_13.pdf

Commissioning better eye care: clinical commissioning guide from The College of Optometrists and The Royal College of Ophthalmologists[173] Age-related macular degeneration November 2013	Objectives: Patients have emotional and practical support to cope with their condition Services should help AMD patients adapt to their condition and improve visual functioning and well being. Examples, include Eye Care Liaison Officers (ECLO) and/or a Low Vision service Discharging patients Patients with dry AMD should be offered low vision support if visual loss is impacting upon their independence and lifestyle. Patients who meet the criteria for a certificate of visual impairment should offered one. Decisions on when to discharge patients with wet AMD are more complex but should be at clinicians' discretion and based on how stable the condition is and if treatment will bring any further benefits to the patient. Again, patients should be offered low vision support and a certificate of visual impairment if appropriate.	• Specifies provision of an ECLOS in the service delivery model – Low vision support and information about CVIs/registration can be provided by the ECLO
UK Vision Strategy 2013-2018[174]	Strategy Outcome 1 Everyone in the UK looks after their eyes and their sight In the next five years, we will work to: • raise awareness and understanding of eye health, particularly focusing on people most at risk of eye disease • encourage every individual to develop personal responsibility for their eye health and sight • raise awareness of eye health and the impact of sight loss among health and social care practitioners and ensure the early detection of sight loss and prevention where possible. Strategy Outcome 2 Everyone with an eye condition receives timely treatment and, if permanent sight loss occurs, early and appropriate services and support are available and accessible to all In the next five years, we will work to: • improve the co-ordination, integration, reach and effectiveness of eye health and eye care services • ensure that, when permanent sight loss occurs, emotional support, habilitation and/or rehabilitation will be	– ECLOs can play an educational role with patients in terms of looking after their eye health. Also ECLOs can work to raise awareness of the impact of sight loss among health and social care professionals. – ECLOs can help to ensure patients are signposted and

[173] http://www.college-optometrists.org/filemanager/root/site_assets/guidance/amd_guidance_25_11_13.pdf

[174] http://www.ukvisionstrategy.org.uk/sites/default/files/UK%20Vision%20Strategy%202013-18%201.0.pdf

	provided in a timely fashion, enabling people to retain or regain their independence. Strategy Outcome 3 A society in which people with sight loss can fully participate In the next five years, we will work to: • improve attitudes, awareness and actions within education, employment and other services • ensure that children and young people with sight impairment can take their place in society • achieve improved compliance with equality legislation	referred to services efficiently. – ECLOs work with patients with sight loss to maintain and gain employment. ECLOs also work with children and young people in eye clinics.
Adult UK Eye Health and Sight Loss pathway Vision 2020[175]	This pathway specifies the requirement for Early Intervention (Advice, information & emotional support) e.g. Eye Clinic Liaison Officer (ECLO), Vision Support Service or similar in the service delivery for adults as they progress along the eye health and sight loss pathway.	– ECLOs are well placed within eye clinics to provide early intervention to address patients' needs.
Eye Health Network for London: Achieving Better Outcomes[176]	Recommendation 1 The important role of the Eye Clinic Liaison Officer (ECLO) should be included as part of the service specification. Recommendation 3: Age-related Macular Degeneration Ensure that all patients who have visual loss have access to an ECLO service and services which provide support and visual rehabilitation. Recommendation 8: Low Vision Integration is particularly important for low vision services. Effective low vision services need to adapt to	– Specifies provision of an ECLO as part of the service

[175] http://www.vision2020uk.org.uk/download/Adult-UK-eye-health-and-sight-loss-pathway-Word-with-charts-revised-January-2015_2.pdf

[176] http://www.londonsenate.nhs.uk/wp-content/uploads/2015/07/Item-5-2015-07-21-LCSC-Final-London-Eye-Health-Network-Achieving-Better-Outcomes.pdf

	individual needs and work as seamlessly as possible with other services, including hospital eye units, education, social care, voluntary organisations and stroke, learning disability, rehabilitation and falls teams. There should be an ECLO service in every eye clinic in order to facilitate this. VISION 2020(UK) Ophthalmic Public Health Outcome measures Portfolio Eye Specific Indicator 9 "Eye Care Liaison (ECLO) Service. Every Commissioning Organisation (e.g. CCGs in England) to have commissioned an ECLO Service to be provided within HES, community or both"	
Action on AMD[177]	Key Recommendations 1. Appropriate funding and resources must be made available now that treatment is possible 2. There should be no compromise in the standard of service provision, or quality or frequency of intravitreal treatment administration 3. Continued evaluation and adaptation/redesign of local wet AMD NHS service is required 4. Recruitment 5. Prioritisation/stratification of patients 6. Virtual clinics 7. Use of other community spaces such as mobile units, polyclinics or GP clinics 8. Multi-disciplinary clinics—staff training / development, flexible role, and appropriate use of staff 9. Use of community optometrists for monitoring 'stable' patients (at low risk of needing treatment) 10. Electronic referrals from community optometrists 11. Electronic medical records 12. Employment of an Eye Clinic Liaison Officer to guarantee a holistic service that takes account of the emotional support needs of patients and helps secure a smooth transition from health to social care and other support services as required	– Specifies provision of an ECLO as part of the AMD service

[177] Amoaku W, Blakeney S, Freeman M, Gale R, Johnston R, Kelly SP et al (2012) 'Action on AMD: optimising patient management: act now to ensure current and continual delivery of best possible patient care' *Eye* 26, s2-s21

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