



Wales Eye Clinic Liaison Service Impact Report



yn cefnogi pobl ddall ac
â golwg rhannol

supporting blind and
partially sighted people



ARIENNIR GAN Y LOTERI
LOTTERY FUNDED

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1.0 Introduction

1.1 The challenge

With the number of people in the UK with sight loss predicted to double by 2050 (1), finding ways to reduce the economic impact and relieve pressure on hospital eye clinics is an urgent priority.

- Almost two million people in the UK are living with sight loss (2).
- Healthcare expenditure linked to eye health in Wales is nearly £120 million a year (3), but the indirect cost to the economy is more than double this amount (4).

1.2 The Wales eye clinic liaison service

The Wales eye clinic liaison service, developed by RNIB and partner organisations (see Appendix 1 for partner information), aims to reduce risk to the patients' physical and mental health, and increase their ability to live safely and independently. The service provides essential emotional support and practical advice at the point of diagnosis of sight loss, providing an effective link between health, social and community support services.

The eye clinic liaison service in Wales supported 6,730 patients in 2012/13.

The critical role of the eye clinic liaison service is widely recognised. Eye clinic liaison services are included in the Welsh Government eye care pathways for Age Related Macular Degeneration and Glaucoma. The Royal College of Ophthalmology recommends that Eye Clinic Liaison Officers (ECLOs) are part of a minimum service team (5).

Eye clinic liaison services in Wales are funded by Betsi Cadwaladr Health Board, the BIG Lottery, RNIB Cymru, Cardiff Institute for the Blind, and Sight Cymru (see Appendix 2 for service and funding details). The third sector has provided significant investment and pump priming to ensure services are available to patients across Wales. This funding is time limited and services will be at risk in the next 18 months.

The future provision of this critical service is at risk.

1.3 The policy context

Together for Health, the Welsh Government's five-year vision for the NHS, focuses on reduced health inequalities, improved access to services, an improved patient experience, and providing high quality care.

The Welsh Government's draft Eye Health Care Plan for Wales sets out five objectives in relation to eye health:

- Preventing poor eye health and visual impairment.
- Improving eye health outcomes.
- Ensuring early identification and intervention.
- Providing high quality, efficient services.
- Ensuring patient focused delivery of integrated services.

The eye clinic liaison service supports delivery of Welsh Government objectives. By providing information, advice, emotional and practical support to patients in a timely fashion, the service impacts positively on patients' health and wellbeing. ECLOs are an efficient and effective link between the eye clinic and the wider support and services which people need to live well with sight loss.

1.4 Summary: benefits of the eye clinic liaison service to the NHS in Wales

When people manage their conditions themselves they improve their quality of life and this reduces health care spending in the longer-term. The eye clinic liaison service can meet the needs of those living with long-term conditions by offering support for self-care and encouraging independence.

The service increases the efficiency of clinical staff through enabling them to focus their time most appropriately. This is achieved through reducing the time clinical staff need to spend with distressed patients, providing emotional support, assisting with the administration of Certificates of Visual Impairment and providing information on patients' eye conditions. Patient throughput is maximised and the stress felt in clinics can be reduced.

"Falls are a major cause of disability and death in older people in the UK, and result in significant human costs in terms of pain, loss of confidence and independence" (6). ECLOs provide information on fall prevention and support patients' timely access to low vision and rehabilitation services. There is a significant financial cost to health and

social care services associated with dealing with the results of falls (7). Helping reduce patients' risk of future falls can reduce the consequent cost to the NHS and Social Services.

The All Wales Mental Health Network's 2010 report estimated the cost of poor mental health in Wales to be more than £7.2 billion per year. Older people with sight loss who live alone are three times more likely to experience depression than those with normal sight (8). The eye clinic liaison service provides essential emotional support at the point of diagnosis and signposts to social and community support services, helping the patient adjust to living with sight loss.

2.0 The role of the Eye Clinic Liaison Officer (ECLO)

The service provided by the ECLO is person-centred emotional and practical support tailored to the needs of the patient. This is provided at an often traumatic and vulnerable time.

Support can include:

- providing information on the patient's eye condition and on good eye health
- referral to the Low Vision Service to enable patients to make better use of existing sight
- referral to statutory services including social services and rehabilitation services
- advice on falls prevention and safety in the home
- advice on certification and registration and support in completing the Certification of Visual Impairment
- referral to specialist services such as RNIB Cymru's welfare rights advice service, employment service, or education and transitions services for children and young people
- referrals to local and national voluntary services, including local support groups
- information on products and equipment to support independent living and personal safety
- support and information for friends, family and carers.

When people manage their conditions themselves they improve their quality of life and this reduces health care spending in the longer term (9). ECLOs meet the needs of those living with long-term conditions by offering information, advice and support for self-care, and encouraging independence.

Patient feedback on the RNIB Cymru eye clinic liaison service:

- 98 per cent felt their contact with the ECLO helped them to understand what other support and information is available to them outside of the hospital.
- 88 per cent thought they had a better understanding of their eye condition.
- 67 per cent said they had a better understanding of what things they could do to care for and treat their eye condition.

Case study

Mr D has age-related macular degeneration (AMD) and restricted mobility. After meeting with the ECLO a number of issues were identified that impacted upon his health and ability to maintain independent living. Referrals were made to the following services:

- Rehabilitation Officer for the Visually Impaired.
- Occupational therapy.
- Social Worker for the Hard of Hearing.
- IT Project Officer.
- Welfare Rights Officer.

Through the work of the ECLO and through contact with these services many of Mr D's issues were resolved. He was provided with small items of equipment to enable him to manage more safely at home. A volunteer driver was found to assist with shopping and attending appointments. Grab rails and handrails were installed indoors and outdoors to reduce the risk of falling and an occupational therapy assessment was speeded up.

The RNIB Cymru welfare rights service secured Higher Rate Attendance Allowance of £74 per week, which also gave entitlement to Pension Credit and Council Tax Benefit.

By seeing the ECLO at the eye clinic when he did, Mr D received the support and financial assistance at the best possible time and not at a time of crisis when his ability to manage may have deteriorated.

This patient's experience is in sharp contrast to the many patients who do not receive a service from an ECLO. The patient story on page 9 is from the RNIB report "Lost and Found" (2009) describes a visit to the eye clinic.

Judith's experience

"[After the first appointment] they said they would phone on the Monday or the Tuesday, and they didn't. They said they had taken my phone number down wrongly... the next time I went in for an appointment my right eye had 'gone'."

Judith wasn't offered any information on her eye condition or what it meant to lose one's sight. She would have liked to have been able to take information away with her so she and her husband could refer back to it in their own time. No one in the eye clinic spoke to Judith about her feelings or offered any practical advice on what to do now her sight loss was permanent.

"As far as the medical profession goes, there was nothing. When I went back to the waiting room, they gave me a cup of tea and left me with my husband. I was left for a while on my own."

"There needs to be something in eye hospitals soon after diagnosis. That has to change."

Call to RNIB Cymru office – May 2013

A lady called the office saying that she has lost the sight in one of her eyes. She was very distressed and worried about complete loss of sight. She had received no information or advice from the hospitals that she has been attending, nor had she been referred on to the ECLO by the clinic.

3.0 The benefits of the eye clinic liaison service to the NHS in Wales

The number of people with sight loss is expected to double over the next 25 years (10). The cost of sight loss in Wales is already estimated at £370m (11) and hospital eye clinics are struggling to cope with current demand. Innovative services that can help relieve the pressure on clinic staff and mitigate the impact of sight loss are urgently needed. The eye clinic liaison service can do this in a number of ways for a relatively low cost.

3.1 Ophthalmology

In a survey of 15 ophthalmologists all agreed that the eye clinic liaison service can increase clinical staff's efficiency by reducing time spent with distressed patients (12). This is corroborated by studies of eye clinic liaison services in other parts of the UK (13).

These studies have also found eye clinic staff valued the ECLO role in:

- increasing patient throughput/management
- reducing stress in the clinic
- improving patients' access to social services
- assisting with the administration and processing of Certificates of Visual Impairment
- increasing clinical staff efficiency by reducing the time spent with non-compliant glaucoma patients.

Of patients seen by the RNIB Cymru and Betsi Cadwaladr ECLOs:

- 70 per cent of 1,378 patients were given information and support around registering as blind or partially sighted.
- 79 per cent of 2,093 patients were provided with information on their eye condition.

3.2 Falls prevention

Falls are commonly associated with the need for health and community care services, as well as admission to residential or nursing care. Older people with sight loss have 90 per cent higher odds of multiple falls than a person with normal sight (14). A fall can have serious physical and psychological consequences, as well as significant resource implications for public services.

- Visual impairment is directly attributable to 47 per cent of the cost of falls in the population with visual impairment and 10 per cent of the cost of all falls in the UK (15).
- 5 per cent of all falls lead to a fracture and almost all hip fractures (92 per cent) are a result of a fall (16).
- The cost of treating hip fractures in 2005 was estimated to be £12,000 per patient (17).
- When admitted for any physical condition, blind and partially sighted people have an average length of stay in hospital two days longer than patients with normal sight (18).

Of patients seen by the RNIB Cymru and Betsi Cadwaladr ECLOs:

- 25 per cent of 1,007 patients said that they had had a fall.
- 26 per cent of 3,105 of those over 70 said they had had a fall.
- 47 per cent of 1,242 said that they feared a fall.

“By providing information on falls prevention and supporting patients’ timely access to rehabilitation services the ECLO service can help reduce a patient’s risk of future falls, and the consequent cost to the NHS and Social Services. If advice from an ECLO prevented just one or two falls associated with visual impairment that resulted in a fractured femur, the ECLO service would be cost neutral.” (19)

3.3 Mental ill health

Older people with sight loss who live alone are three times more likely to experience depression than those with normal sight (20). Eye clinic liaison services work predominantly with older people, with 90 per cent of patients seen by RNIB Cymru and Betsi Cadwaladr ECLOs being age over 50 years and 71 per cent aged 70 or over. ECLOs can help improve patients’ mental wellbeing and reduce the risks associated with poor mental health by providing emotional support at the point of diagnosis. Signposting to other health, social and community services will help the patient to live well with sight loss.

- Mental ill health is known to have a significant economic impact, costing Wales an estimated £7.2 billion a year (21).
- Nearly half of blind and partially sighted people report feeling “moderately” or “completely” cut off from people and things around them (22). This sense of isolation inevitably has an impact on people’s mental and emotional health.
- Sight loss has been identified as one of the top three causes of suicide in older people (23).

“Research evidences that providing practical and emotional support to people with health problems has multiple benefits – it increases people’s capacity to self-manage their condition, improves health outcomes, helps people live independently and reduces the burden on the health service by avoiding unnecessary hospital admissions” (25 and 26).

Of patients seen by the RNIB Cymru and Betsi Cadwaladr ECLOs:

- 76 per cent of 1,755 patients lived alone
- 98 per cent of 3,008 patients were referred to local services
- 96 per cent of 2,413 patients were referred to national services
- 90 per cent of 1,920 patients received information on low vision aids/assessments

3.4 Poverty, unemployment and impact on physical and mental health

The effects of poverty and unemployment on both physical and mental health are well documented. More than three quarters of older people with sight loss live in poverty (25) and 66 per cent of registered blind and partially sighted people of working age are not in employment (26). Patients of a working age are referred on to RNIB Cymru’s employment service, which supports individuals to retain or gain employment.

Many people with sight loss are not claiming the benefits to which they are entitled. By referring patients on to RNIB Cymru’s welfare rights service the ECLO ensures patients receive the financial support they are entitled to.

In 2012/13 RNIB Cymru and Betsi Cadwaladr ECLOs referred 81 per cent of 1,709 patients to the RNIB Cymru welfare rights service. Over 60 per cent of the individuals referred to the welfare rights service were not receiving the correct benefits. The service secured an average of £62.46 per week increase per successful outcome. This is £3,247 per annum.

Follow up interviews with welfare rights service clients evidenced the positive benefits to health and wellbeing arising from an increased income:

- 68 per cent of those interviewed reported an improvement in their mental health and emotional wellbeing.
- 68 per cent of those interviewed reported an improvement in their physical health, including falls prevention.
- 65 per cent of those interviewed reported an increased ability to be independent.

Case study – welfare rights service

Mr and Mrs W are a retired couple. Mrs W had recently been registered as sight impaired and her husband had extremely poor mobility due to various health problems.

When the couple were visited they were sitting in their lounge which had several buckets and containers on the floor as they had a number of leaks in their roof but could not afford to fix it. They were struggling financially and emotionally, feeling isolated and lacking support from friends and family. They were struggling due to the amount of money that they were paying out on general living expenses, which had increased due to their disabilities.

With the support of the service Attendance Allowance was awarded to both Mr W and Mrs W, Carers Allowance was obtained qualifying them for two carers' premiums on their pension credit, and they were also awarded the Couple Disability Premium Rate. Their income increased by £288.65 per week. With arrears of benefits and the support of Care and Repair they were able to repair their roof, vastly improving their living conditions and comfort.

4.0 Conclusion

The eye clinic liaison service is highly valued by patients, clinicians, social and community support services. The service helps mitigate the social, emotional and psychological impact of sight loss and helps to improve the health outcomes for individuals and families. The service in Wales assists the Welsh Government in the delivery of its stated policy objectives.

Universal coverage in Wales is currently under threat. The future provision of this critical service is at risk. RNIB Cymru is now urging Welsh Government, Health Boards and other partners to work together to ensure this vital service is not lost.

Patient experience

“I was registered sight impaired and diagnosed with ‘wet’ AMD, my vision deteriorated quite rapidly, which was a real shock. I also have other health problems. I live alone but was very independent and thought of as a strong individual who generally supported others rather than the other way round.

“Practical tasks became difficult and I had problems with my mobility out and about. I faced transport issues which were made worse by having no family living near.

“The ECLO explained registration and a variety of support services. She provided emotional support, referred me to the sensory team and arranged for a low vision assessment with volunteer transport to and from the centre. The ECLO also provided me with contact information on national and local support services such as Age Concern and RNIB.

“I was so very appreciative of the support provided.”

Appendix 1

Wales eye clinic liaison service partner details

The Big Lottery Advantage programme funds the Wales Eye Patient Advocacy Service. This project is led by RNIB Cymru and is delivered in partnership with:

- Abertawe Bro Morgannwg University Health Board
- Betsi Cadwaladr University Health Board
- BridgeVis Society for the Blind
- Cardiff and Vale University Health Board
- Cardiff Vale and the Valleys Institute for the Blind
- Cwm Taf Health Board
- Hywel Dda Health Board
- North Wales Society for the Blind
- The Royal College of Ophthalmologists
- Vision Impairment West Glamorgan (VIWG)

Sight Cymru provides eye clinic liaison services in Aneurin Bevan Health Board.

Appendix 2

Wales eye clinic liaison service and funders

The service is provided in 15 of the 16 eye clinics in Wales. RNIB Cymru and the Big Lottery fund a full time Wales ECLO Manager.

Hospital	Weekly hours	Current funder
Singleton Hospital, Swansea	Full time	RNIB Cymru
Royal Glamorgan, Pontyclun (1 day) Ysbyty Cwm Rhondda, Llwynypia (1 day) Prince Charles, Merthyr Tydfil (1 day)	21 hours	BIG Lottery. Wales Eye Patient Advocacy Service (Provided by RNIB Cymru)
Princess of Wales, Bridgend (2 days) Neath Port Talbot Hospital, Port Talbot (1 day)	21 hours	BIG Lottery. Wales Eye Patient Advocacy Service (Provided by RNIB Cymru)
Amman Valley, Ammanford (1 day) Glan Gwili, Carmarthen (1 day) Withybush, Haverfordwest (1 day) Prince Phillip, Llanelli (fortnightly)	21 hours in total	BIG Lottery. Wales Eye Patient Advocacy Service (Provided by RNIB Cymru)
Ysbyty Gwynedd, Bangor	21 hours	BIG Lottery. Wales Eye Patient Advocacy Service (Provided by RNIB Cymru)
University Hospital Wales, Cardiff	Full time	Cardiff Institute for Blind People
Royal Gwent, Newport Neville Hall, Abergavenny	Part time, flexible hours	Sight Cymru
The Stanley Eye Clinic, Abergele Hospital	4 days per week	Betsi Cadwaladr University Health Board
Wrexham Maelor, Wrexham	30 hours	Betsi Cadwaladr University Health Board with support from RNIB Cymru
North Road Eye Clinic, Aberystwyth	No service from April 13	Funding being sought

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