

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

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# **RNIB Cymru response to the Senedd Health and Social Care Committee inquiry into Supporting people with chronic conditions**

## **About RNIB Cymru**

RNIB Cymru is the largest sight loss charity in Wales, providing support and services to blind and partially sighted people, their families, friends, and carers. We aim to improve lives and empower people to adapt to sight loss and keep their independence. We work in partnership with public, private and third sector bodies across Wales to deliver projects, training, services and give information, advice, and guidance.

We challenge inequalities by campaigning for social change and improvements to services. We believe that timely treatment should be available to all to prevent avoidable sight loss, and that the right support is there for people when prevention isn't possible. We raise awareness of issues facing blind and partially sighted people on a daily basis. Whether you have full, some, little or no sight, everybody should be able to lead independent and inclusive lives, without facing inequity and discrimination.

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## **NHS and social care services**

- **The readiness of local NHS and social care services to treat people with chronic conditions within the community;**

The Welsh Government has begun work on an ambitious programme of reform of Optometry services. Community-based optometrists will play a greater role in eye health treatment, diagnosis and aftercare. This will help to free up the capacity of Ophthalmologists to focus on the treatment of chronic eye disease that only they can treat, with the aim of reducing hospital eye care waiting lists by 'a third'.<sup>1</sup>

RNIB Cymru welcomes this initiative, but full implementation will take a number of years and patients continue to be being put at real risk of avoidable, permanent sight loss. Currently demand for hospital Ophthalmology services is far outstripping capacity, and it's crucial that the immediate risks and challenges are addressed with urgency as patient pathways are transformed. Optometry reform will not solve this crisis in and of itself.

The Eye Care Measures for NHS Outpatients in Wales (ECM) were introduced in 2019 after concerns were raised that Ophthalmology services across Wales were struggling to manage key issues around capacity and demand. Patients were waiting far too long from initial referral from primary care to follow-up assessment and treatment. This caused significant numbers of patients with chronic but treatable conditions to permanently lose their sight. Were these patients to be seen within a clinically appropriate timeframe, their sight could have been saved.

Wales was the first country in the UK to introduce these dedicated clinical prioritisation targets for Ophthalmology. Introduction of the ECM aimed to shift the focus away from traditional Referral to Treatment (RTT) targets in favour of a more prudent approach to waiting list management. Unlike RTT, the ECM allows for clinical capacity to be directed to the most clinically urgent cases to ensure that patients with the highest levels of risk associated with their condition are treated in a safe and clinically appropriate timeframe. This is important because a significant number of Ophthalmology patients need to be seen much sooner than the 26 week RTT target in order to mitigate the risk of irreversible harm or blindness. Conversely, patients with less urgent conditions can be seen later than 26 weeks without risking permanent, irreversible sight loss.

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<sup>1</sup> [Our programme for transforming and modernising planned care in Wales and reducing the waiting lists \(gov.wales\)](https://www.gov.wales/our-programme-for-transforming-and-modernising-planned-care-in-wales-and-reducing-the-waiting-lists)

In Wales, over half of Ophthalmology patients who are categorised as being most at risk of permanent sight loss are not being seen within a clinically appropriate timescale. Latest available ECM data from March 2023 shows that just 49.1 per cent of the 140,110 patients categorised as being at the highest risk of permanent sight loss are being seen within their target date.<sup>2</sup>

With one in two of the highest risk patients at immediate risk of going blind, tackling performance against the ECM must be a priority for health boards and the Welsh Government.

As a result, it is crucial that Welsh Government urgently publishes a plan for how they will ensure a high quality, sustainable eyecare services that drive progress against the ECM.

The plan should:

- Outline how they will ensure a high quality, sustainable eyecare services that guarantee that people with chronic eye conditions such as AMD and Glaucoma receive appropriate and timely treatment to prevent avoidable and irreversible sight loss.
- Include a robust demand and capacity analysis of patients by sub-speciality, through extending ECM reporting to include data by condition.
- Outline how health boards in Wales will be held accountable around meeting the targets set out by the Measures.

In addition to improved provision of eye care services, local authority vision rehabilitation services play a vital role in supporting people with sight loss to maintain their personal independence and to learn new skills enabling them to lead full and active lives with their chronic sight condition.

We regret the lack of specific proposals by Welsh Government to improve the quality and equity of vision rehabilitation provision. This is especially crucial as there are significant delays in eye care patients receiving timely treatment.

As detailed in the Wales Council for the Blind's 2021 report "Addressing a workforce crisis in Wales", there are many areas with waiting lists of

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<sup>2</sup> Eye care measures for NHS outpatients: March 2023 | GOV.WALES

more than a year for vision rehabilitation support. Only 6 local authorities in Wales currently meet the Association of Directors of Adult Social Services and Social Services Improvement Agency's minimum standard of 1 ROVI per 70,000 of the population.

Vision rehabilitation is a vital element in blind and partially sighted people regaining and maintaining independence following a sight loss diagnosis.

Despite the critical role vision rehabilitation plays in supporting people with sight loss to live independently in the community, there are currently 30.3 FTE out of the recommended 44.9 ROVIs and set to fall to less than 10 by 2030 if no action is taken.

The inevitable result of delayed or absent provision is a loss of confidence and income for an individual, and an increased dependence on carers or care needs assessed services.

- **Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people;**

RNIB Cymru regularly receives complaints from blind and partially sighted people about the barriers they face to accessing essential services and ongoing treatment, in both primary and secondary care.

In December and January, we undertook research to understand the scale of the problem and to build a picture of the lived experiences of blind and partially sighted people across Wales.

It shows:

- One in three (32 per cent) blind and partially sighted people have missed a healthcare appointment or had their healthcare affected because they did not receive information that they could read.
- More than half of the people that participated in our research said they had received information about their healthcare from their GP (56 per cent) or hospital (54 per cent) in a format they couldn't read.
- Nearly nine in 10 respondents have never been asked by their GP or hospital about their communication preferences.

According to patients with sight loss, a lack of accessible communications in health settings is a barrier to:

- Making appointments
- Reading appointment confirmation letters
- Understanding their consultations with healthcare professionals
- Finding out test results
- Receiving accessible information on discharge, medication instructions or their condition
- Using home screening kits
- Complying with advice and instructions for medication.

Inaccessible health information is a patient safety issue and can lead to poorer health outcomes by creating a barrier to timely and appropriate treatment.

- **Support available to enable effective self-management where appropriate, including mental health support;**

It's vital that health services provide patients with adequate and appropriate information about their level of clinical need and the degree of urgency with which they need to receive treatment. In terms of eye care, this means that patients are aware of the health risk factor rating (HRF). Patients should know who they can contact and the support they should expect when waiting over target.

To ensure that patients 'wait well' and can access appropriate and timely practical and emotional support, it's crucial that they are provided with information in their required format. For some, this could mean receiving information in large print, braille, telephone, text or digital formats.

Every sight loss diagnosis will be associated with a significant emotional impact, with the experience of adjusting to sight loss often being likened to that of grief.

The feedback we receive regularly from blind and partially sighted people is that at the time of diagnosis, there is a lack of understanding of the impact their condition will have on their lives, what support is available to them and how to access it.

This means blind and partially sighted people are not receiving sufficient emotional support or being referred to mental health services.

RNIB has been delivering an Eye Clinic Liaison Officer (ECLO) service across the UK for over twenty-five years giving a wealth of expertise and knowledge. Working with Health Boards, ECLOs play a crucial role in providing practical and emotional support for people diagnosed with sight loss. Yet we know through our research that, UK wide, people are not routinely signposted to ECLO services at the point of diagnosis. In our latest tracker survey, only 21% of respondents were referred to emotional support services such as ECLOs when they were first diagnosed. Nearly 8 out of 10 were not offered any emotional support at all. Early intervention is key to help maintain greater levels of independence and to help reduce the risk of mental health deteriorating. The ECLO role needs to be supported in any future patient pathways.

In addition, referral rates in Wales to RNIB counselling services are the lowest amongst the four nations of the UK.

To reduce the mental health inequalities facing blind and partially sighted people in Wales, we have a series of recommendations that we would like to see adopted across Wales:

- A comprehensive training plan should be developed to support the mental health of patients with sight loss. Such training should be delivered to NHS counsellors, GPs, and all clinicians working at every point of the patient journey for those with sight loss
- To encourage eye health professionals to have conversations about the emotional impact of sight loss
- To encourage eye health professionals to screen for anxiety and depression for early intervention
- Specialist training for psychiatrists to better understand the emotional needs and impact of sight loss
- The development of a marker system for GP's records that will alert them if their patient has sight loss and training to support GP's to routinely check in on the mental health of their patient.

### **Multiple conditions**

- **The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation;**

Living with sight loss is often an unseen disability and it can be very difficult for older people to get the help they need when they need it. In

Wales there are 112,000 people living with sight loss which is expected to rise to 146,000 by 2030.

People with sight loss are highly likely to have co-morbidities as the prevalence of sight loss increases with age. Care home residents suffer from unusually high rates of poor eyesight, with the RNIB estimating that as many as over half of older residents in care homes have some form of sight loss.<sup>3</sup>

Poor eyesight can have significant repercussions for health and quality of life for care home residents. As well as potential complications from the eye condition itself, it can increase the risk of falls and contribute to depression and isolation. There are significant associated costs with these health problems. For example, falls directly relating to sight loss in the UK are estimated to cost £128m a year in medical costs alone.<sup>4</sup>

It is therefore critical that all services are equipped to meet the needs of people with sight loss by:

- Ensuring all staff receive training on sight loss.
- Ensuring the physical environment is accessible to blind and partially sighted people, including considerations for colour contrast and lighting.
- Ensuring the provision of accessible information is available so people can understand their needs and care plans.

### **The interaction between mental health conditions and long-term physical health conditions;**

Research has consistently found that blind and partially sighted people are more likely to experience poor mental health outcomes, such as depression and anxiety in their lifetime, compared to their sighted peers.

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<sup>3</sup> Older people's experiences of sight loss in care homes  
<https://www.brighton.ac.uk/pdf/research/ssparc/older-peoples-experiences-of-sight-loss-in-care-homes-final-report.pdf>

<sup>4</sup> The economic impact of sight loss and blindness in the UK adult population  
<https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-2836-0>



Research from the latest Understanding Society study found that compared to non-disabled people, visually impaired people were:

- More than twice as likely to have experienced moderate or severe psychological distress
- More likely to say they are unhappy or depressed and had experienced symptoms associated with anxiety
- More likely to report a lack of confidence and feelings of worthlessness
- More likely to feel dissatisfied with their lives

The relationship between mental health and sight loss is multifaceted, as people with sight loss can experience poor mental health for a variety of reasons. This can include the emotional distress associated with adjusting to sight loss, but it can also be a result of more indirect consequences of sight loss that can exacerbate poor mental health. For example, a loss of independence, loss of identity, difficulties adjusting to everyday activities or experiencing barriers finding and staying in work.

While the emotional impact of sight loss is well documented, in practice it is often overlooked as treatment and support is more focussed on the physical impacts of sight loss. This leaves many blind and partially sighted people having to cope with mental health problems, such as depression and anxiety, on their own. As a result, there needs to be greater recognition of the emotional impact of sight loss from the point of entry at diagnosis and throughout an individual's sight loss journey, so they can access the right support at the right time.

### **The impact of the pandemic on quality of care across chronic conditions;**

Ophthalmology is one of the busiest outpatient specialisms in the health service<sup>5</sup>. A 2022 report by Audit Wales found that ophthalmology is one of the specialisms that will likely take far longer to recover than others because they were already hugely stretched before the impact of the COVID-19 pandemic.<sup>6</sup>

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<sup>5</sup> Latest available data for March 2023 shows 86,910 Ophthalmology patients are currently waiting to start treatment. This amounts to one in every nine patients on the NHS Wales waiting list.

<sup>6</sup> Audit Wales (2022) [Tackling the Planned Care Backlog in Wales](#)

We know that before the COVID-19 pandemic, health boards in Wales were making progress in terms of the numbers of HRF1 patients being treated within the target date or within 25 per cent beyond the date. For example, in April 2019, almost 66 per cent of patients being treated within their target date or within 25 per cent beyond the date. However, by October 2020, just 44 per cent of HRF1 patients were seen within their target date or within 25 per cent beyond the date

An analysis of the Eye Care Measure data shows that since July 2020, there has not been a single month when over half of R1 patients have been seen within their clinically safe target date.

We know that Ophthalmology services in Wales are not currently sustainable, and that huge shortfalls in capacity means that patients are not being prioritised by their clinical need and treated in a timely manner. Every patient waiting over target is at risk of irreversible sight loss. As a result, we are incredibly concerned about the absence of a clear action plan to address this waiting list backlog at pace, and we know that Optometry Reform alone is not enough to address this serious issue.

A regional approach to eye care has been recommended to increase service capacity. Three regional centres of excellence have been recommended across Wales, which would encourage new recruitment and allow for Ophthalmic capacity, expertise, and technologies to be pooled to ensure an efficient and sustainable service. Each centre would deliver specialist visiting services in surrounding areas to enable people with conditions that require frequent treatments to access these closer to home.

This would help create fundamental change in the way eye care services are delivered as they recover. As a result, we seek clarity on the progress around the development of regional eye care services, which will need to be allocated significant and sustainable resource and investment.

In addition, the pandemic highlighted significant shortcomings in the provision of accessible patient communication and shone a light on the importance of making accessible information standard practice.

For example, shielding letters, which were sent to the 130,000 people in Wales at highest risk of severe illness from COVID-19, were not sent out in accessible formats for people with sight loss, despite containing potentially life-saving information.

Digital communications from official sources were - and in some cases still are - not fully accessible, particularly for screen reader users.

While most organisations responded promptly, the fact that third sector organisations had to be reactive and bring this to their attention, highlights the reality that accessible information is not standard practice for many public sector organisations.

In April 2022, the Health and Social Care Committee's report, 'The impact of the waiting times backlog on people in Wales' referenced RNIB Cymru evidence, which "shone a stark light on how inaccessible much of NHS communications is". It noted that important communications about shielding and vaccination had not always been provided in accessible formats, with implications for patient safety. The committee then called for Welsh Government to provide an update on progress made on the implementation of recommendation 37 in the 'Into sharp relief' report. Once again, this recommendation was accepted by the Welsh Government.

Despite the fact that this recommendation was made in two separate inquiries and was accepted by Welsh Government, no appointment has yet been made.

### **The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing**

RNIB Cymru recently surveyed over 110 blind and partially sighted people across Wales, to understand the experiences of blind and partially sighted people during the cost of living crisis.

Because of increases in the cost of living, blind and partially sighted people are more likely to be:

- cutting back on non-essential journeys (56 per cent compared to 40 percent)

- using less fuel such as gas or electricity in their homes (77 per cent compared to 62 per cent)
- spending less on food and other essentials (62 per cent compared with 42 per cent)

They are more likely to be financially vulnerable.

- Over half live in a household which could not afford an unexpected but necessary expense of £850 (56 per cent compared to 31 per cent)
- One in ten (12 per cent) are more than a month behind with paying their household bills and most are not confident they will be able to clear this debt within the next six months.

- **The extent to which services will have the capacity to meet future demand with an ageing population**

Eye care services are some of the busiest in Wales, with hospital ophthalmology clinics seeing 11% of all outpatient appointments. The Royal College of Ophthalmology estimates that this will increase by 40% in the next 20 years.

Over the next 20 years ophthalmology demand is expected to increase by 16 per cent for conditions such as Glaucoma, 47 per cent for Age related Macular degeneration, 50 per cent for conditions such as cataract, and up to as high as 80 per cent for diabetic retinopathy.

By 2050, the number of people with sight loss is expected to double.<sup>7</sup> A Wales Audit Office report highlights that Ophthalmology is one of the specialities which could take far longer to recover than others because it was stretched even before the pandemic.<sup>8</sup>

With demand outstripping capacity, and a clear lack of progress against the Eye Care Measures across all Health Boards in Wales, radical action is needed now to meet future demand.

## **Prevention and lifestyle**

- Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating);

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<sup>7</sup> RNIB sight loss data tool

<sup>8</sup> [Tackling the Planned Care Backlog in Wales | Audit Wales](#)

It is absolutely crucial that patients are given all of the information they need, in their required format, to ensure they can keep themselves as well and informed as possible while they wait for treatment. Patients need to be aware of their clinical need, including their risk of going blind as a result of waiting over target.

For example, Wet Age-related Macular Degeneration (AMD) is a condition that can cause irreversible harm to patients if they wait beyond their target date for treatment. Patients with Wet AMD can experience rapidly progressing, permanent sight loss over the course of weeks or even days. Patients should also be made aware of how to manage their condition and the importance of attending appointments, particularly for patients with chronic conditions which are at high risk of permanent, avoidable sight loss. Patients should also be signposted to appropriate practical and emotional support in the interim.

As mentioned earlier in this response, it's crucial that Welsh Government invests in Vision Rehabilitation services to ensure that people can maintain their independence and confidence and therefore prevent their needs from escalating and requiring further interventions.

We need a strategy for Vision Rehabilitation that:

- Makes it clear how to signpost to and ensure integration of, local authority rehabilitation services, including more specialist rehabilitation services that work alongside those that provide hospital discharge reablement/rehabilitation.
- Ensures that referrals into local authority vision rehabilitation services are made in a timely and systematic way, and that there is an equity of high-quality provision across Wales.