

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy'n aros am ddiagnosis neu driniaeth](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment](#)

WT 01

Ymateb gan: | Response from: RNIB Cymru

R N I B

Cymru

Golwg gwahanol

See differently

RNIB Briefing for the Health and Social Care Committee: inquiry into the impact of the waiting times backlog on people in Wales waiting for diagnosis or treatment.

Sight Loss in Wales

Every day in Wales, nearly 4 people start to lose their sight and one in five people will live with sight loss in their lifetime.

Eye health care services are some of the busiest in Wales with hospital ophthalmology clinics seeing 11% of all outpatient appointments - and this is expected to increase by 40% in the next 20 years.

Over the next 20 years demand is projected to increase by 16% for conditions such as glaucoma, 47% for age related macular degeneration, 50% for conditions such as cataract, and up to as high as 80% for diabetic retinopathy.

Eye Care in Wales

Since 2018, eye care in Wales has taken a risk based approach – the first service to do so. Eyecare patients are allocated a “Health Risk Factor”, according to the seriousness of their condition. The highest is HRF1, which is that there is “Risk of irreversible harm or significant patient adverse outcome” if patient target date is missed. Essentially that **patients could go blind or suffer significant eyesight loss** if treatment is delayed.

As a result of that, the National Eyecare Measures are that 95% of HRF1 patients are seen within their clinical waiting time (or within a defined period afterwards).

However, the latest figures, according to StatsWales at September 2021, are that there are 126,565 patients in Wales with a HRF1 rating. It is now estimated that **HRF1 patients make up around 70%** of the total number of patients.

More than half of all HRF1 patients in Wales (65,410 patients) now waiting over time for their clinical appointment.

Pre-pandemic, the introduction of the Eye Care Measures had already increased awareness of poor waiting list management and the substantial shortfall in capacity.

The Eye Care Measures now also show that there is a **significant postcode lottery** to Health Board performance in terms of outpatient waiting times. For example, one third of HRF1 patients in Cardiff & Vale UHB (33.3%) are waiting beyond their clinical target, while almost two-thirds of HRF1 patients are over target in neighbouring Cwm Taf Morgannwg UHB (63.1%).

The backlog in secondary care is leading to sight loss. RNIB Cymru very much welcome the Welsh Government’s efforts to encourage Health Boards to move more services in to the community and the significant changes to optometry that are underway. However as patient pathways are transformed, it is important the backlog doesn’t keep building as this is rolled out. This change needs to happen at pace but Health Boards must also have clear plans and deadlines for improvement against the Eye Care Measures.

RNIB Cymru is also **concerned that many patients may not be aware that they are in a category which is at significant risk of harm**, and that this may impact upon their behaviour, for example, not attending scheduled outpatient appointments.

It is essential that patient satisfaction with the service is collected. With the increased DNA (do not attend) and CNA (cannot attend) rates, understanding and learning from patient experience is vital to improving the clinical and patient service. Health Boards must collect, analyse, use and learn from patient feedback for quality improvement. It is unclear how this is being done at present.

Concerningly too, due to the waiting list backlog, we are now hearing of cataract patients meeting the threshold for a CVI (certificate of visual impairment) and being referred to Rehabilitation support. This raises concerns that when a person's wait for a very low priority procedure reaches such a point, then it becomes a more significant harm in itself. Patients in the low priority categories may rarely get to the front of the queue unless there is dedicated capacity for them.

Emotional support

RNIB research into the experiences of blind and partially sighted people shows that the following are the top daily barriers encountered:

- 1) getting out and about whether navigating external environments or taking public transport,
- 2) employment - just 54% of the working age population with sight loss are in employment which contributes so much to sense of self-worth. – Getting support is key so people can stay in their jobs,
- 3) opportunities to take part in social activities or exercise. Around half say they are not able to participate as much as they would like – but this is so crucial to avoid feelings of isolation.

It is no surprise that the challenges and frustrations people with sight loss face in their daily lives can take an emotional toll as they struggle to come to terms with their visual impairment. **56% told us they feel anxious about the future, and 47% feel isolated and cut off from other people.** Feedback 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.

Patients accessing the RNIB Counselling service tell us that it is vitally important that when the time comes to deal with the emotional impact of

sight loss, that the support they get comes from someone who has knowledge and understanding about sight loss conditions, as well as the range of support that can be offered as sight fails, and alternative coping mechanisms to cope both emotionally and physically with everyday life. RNIB currently offers counselling to 73 people per year affected by sight loss in Wales. There are often specific challenges faced by people who live in rural settings where transport links to services and be an issue. To lose your sight in an isolated environment can add a level of complexity and lead to increased levels of anxiety and isolation. Despite the dedicated resources we still have a number of people on our waiting list in Wales, with a current waiting time of 9 months. The demand outstrips the current resources.

Third sector and social care

With more people likely to lose sight, given the backlog and demographics, it is crucial that health pathways strengthen the connection with social care and third sector to ensure that patients can access support.

Eye Clinic Liaison Officers

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 Board eye care teams, ECLO services enable patients to access critical early intervention support to help them to remain independent, manage their sight condition and to access both local and national support services. RNIB patient experience research found **that as many as 77 per cent of patients said they would not have found or accessed support outside the hospital without the ECLO.** The ECLO service has also been found to reduce falls, help people stay independent for longer, maximise their income and manage their sight condition while coming to terms with diagnosis. Early intervention can help maintain greater levels of independence and can help reduce the risk of longer-term depression. The ECLO role needs to be supported in any future patient pathways.

Vision Rehabilitation

The importance of the specialist **Vision Rehabilitation** service is also not fully recognised in social care and this became very clearly during the pandemic. Vision rehabilitation services are crucial to ensuring blind and partially sighted people remain as independent as possible. Rehabilitation is more than just acute care, it is a preventative measure

for maintaining quality of life at home. There is a worrying shortfall in the Vision Rehabilitation workforce in Wales which will exacerbate an already challenging situation whereby Covid restrictions have created both a backlog and additional cases due to lost skills and the impact of reduced services in primary and secondary healthcare. The service needs to be supported and accessible for all those in need within reasonable timeframe.

Recovery plans needs to specifically recognise bringing health and social care together to keep patients healthy and well.

Patient Communications

In addition to the concerns about patients' own awareness of their risk factor as detailed above, the pandemic has shone a stark light on how inaccessible much of NHS communications is. Failings have been found with not receiving accessible information – such as shielding letters and vaccine invitations. The Senedd's Equality, Local Government and Communities Inquiry into Covid-19 found deficiencies in the provision of information and guidance in accessible formats during the pandemic. It called for the appointment of an accessibility lead within the Welsh Government to oversee production of all key public information in accessible formats. RNIB supports this call but is concerned that no appointment has yet been made. Patients need to be provided with vital, accessible information to keep themselves well and safe.

We have seen an increase in messaging to the public about importance of attending appointments. However, patients continue to report to us their anxiety about attending services, not only fears about covid, but changes to social distancing, to streets layouts, clinics, public transport – the world has changed incredibly when you have sight loss.

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Contact:

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