

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Gynllun Llywodraeth Cymru i drawsnewid a moderneiddio gofal a gynlluniwyd a lleihau rhestrau aros](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [Welsh Government's plan for transforming and modernising planned care and reducing waiting lists](#)

PCWL 18

Ymateb gan: | Response from: RNIB Cymru



RNIB Cymru's response to the Health and Social Care Committee consultation on the Welsh Government's plan for transforming and modernising planned care and reducing waiting lists

About RNIB

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.

1. Will the plan be sufficient in addressing the backlogs in routine care that have built up during the pandemic, and reduce long waits.

1.1 RNIB Cymru welcomes this plan and the concerted effort by Welsh Government to reduce waiting lists. It's crucial, however, that improvements to services happen at pace as backlogs in planned care are leading to sight loss.

1.2 As of March 2022, there are currently just over 130,000 people in Wales assessed with the highest risk of sight loss. Half of them (65,000) are waiting beyond the target for their clinical appointment and are at immediate risk of going blind.¹

1.3 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.

1.4 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.

1.5 By 2050, the number of people with sight loss is expected to double.²

1.6 A recent Wales Audit Office report³ 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.

1.7 We know that the pandemic has exacerbated waiting lists and has had a substantial impact on theatre capacity, with around 20,000 operations per month currently taking place compared to almost 30,000 pre-covid.

1.8 Since 2018, eye care in Wales has taken a risk-based approach by introducing Eye Care Measures. This is the first service to do so. The Eye Care Measures assign patients a "Health Risk Factor", based on the severity of their condition and also a target date which they need to be

¹ [Patients waiting for an ophthalmology outpatient appointment \(gov.wales\)](#)

² RNIB sight loss data tool

³ [Tackling the Planned Care Backlog in Wales | Audit Wales](#)

treated by, in order to reduce the risk of irreversible sight loss. The highest is HRF1, which means that there is “Risk of irreversible harm or significant patient adverse outcome” if patient target date is missed. Essentially, patients could go blind or suffer significant sight loss if treatment is delayed.

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

1.10 As a result, we are concerned that the Welsh Government's plan for transforming and modernising planned care and reducing waiting lists does not directly address the Eye Care Measures or how Health Boards will be held accountable around meeting the targets set out by the Measures. RNIB Cymru believes this is crucial for supporting the identification of pain points within the patient pathway.

Recommendations

- Welsh Government should publish its plans around how it will hold health boards to account around their performance against the Eye Care Measures
- Welsh Government should publish a timeline of when it will expect HBs to meet the targets

2. Whether the plan strikes the right balance between tackling the current backlog, and building a more resilient and sustainable health and social care system for the long term?

2.1 RNIB Cymru very much welcomes 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. These changes will enable high street optometrists to provide services that go

well beyond eye tests, with the aim of reducing hospital eye care waiting lists by 'a third'.⁴

2.2 However, as well as planning for the future, as mentioned above, it's crucial that the immediate risks and challenges are addressed with urgency as patient pathways are transformed. For example, the absence of Eye Care Measures is very noticeable in the section around clinical prioritisation (page 22), as we're now in the situation where the vast bulk of the waiting list is categorised as the highest risk of irreversible sight loss/harm. Every person on that list is a priority and needs to receive treatment urgently.

Recommendations:

- Eye Care Measures must now be properly embedded in Health Board practice and action plans be developed to tackle performance and backlog. A national review at this point would be a timely and important exercise in supporting the Welsh Government and NHS to prioritise funding and action.
- Welsh Government and health boards must also develop a robust capacity and demand analysis of patients by sub-speciality, through extending ECM reporting to include data by condition.
- Welsh Government and health boards should also expediate implementation of the earlier recommendations of the Wales Audit Office's 2018 report into the management of outpatientsⁱ, and the Public Accounts Committee's subsequent 2019 inquiry (ii), in particular to bring forward proposals for recording occasions when patients have come to harm as a result of waiting for a follow up outpatient appointment or treatment.

⁴ [Statement: NHS Planned Care Recovery Plan](#) – Tuesday, April 26

3. Whether the plan includes sufficient focus on:

3a. Supporting people who are waiting a long time for treatment, managing their expectations, and preparing them for receiving the care for which they are waiting, including supported self-management;

3.1 We know that patients often feel unsupported whilst waiting for treatment. They may not be given the advice or information to effectively self-manage their condition or may not be aware that they're in a category which puts them at significant risk of harm. This could then impact on their behaviour, for example, they may not think it important to attend outpatient appointments or take all of the precautionary measures recommended to manage their condition.

3.2 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. ECLO's have told us that they are seeing more complex cases due to patients waiting up to a year for treatment, this leads to them spending more time with patients and offering increased levels of emotional support.

3.3 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. 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 can 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.

Recommendations:

- The Welsh Government should 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.
- Welsh Government and NHS Wales should launch an awareness campaign to increase patients' understanding of optometrists' new role as a result of eye care services being moved to the community. There should also be ongoing communication with patients around how this will change the way their eye care is delivered.
- In terms of preparing eye care patients to receive their care, HBs should provide information intended to reassure patients of the importance of attending their appointment; the importance of arriving on time to reduce the number of patients waiting in the clinic; and how to contact the Eye Clinic Liaison Officer (ECLO) if they have any concerns. This could help reassure patients of the need to attend their appointments and could reduce the high number of patients who do not attend.
- Welsh Government plans for the recovery and transformation of planned care should reflect the Health and Social Care Committee's recommendation around the need for a focus on supporting patients to wait well. This includes information being provided in accessible formats to meet the patients' communication needs while they wait, as well as promoting awareness of, and ensuring access to, the most appropriate interim practical and emotional support.
- The ECLO role needs to be embedded in any future patient pathways.
- It's crucial that counselling services are robustly resourced to meet current and future demand, and that they are accessible to people with sight loss.

- RNIBs counselling service specifically addresses the issues arising from sight loss and it's crucial that there are good referral and signposting links to this service, and that the service is resourced.
- Welsh Government should support the role of RNIB's accredited training module, which has been developed for the counselling professions in the UK.
- Further detail is required around how the Welsh Government and NHS Wales will deliver targeted support and signposting to people living in more deprived areas, people with learning disabilities, ethnic minority communities and any other groups that face additional barriers to accessing eye care.

3b. Meeting the needs of those with the greatest clinical needs, and those who have been waiting a long time;

3.4 As mentioned above, clarity is needed around how health boards and Welsh Government are going to prevent HRF1 patients (and particularly those waiting over target) from going blind.

3.5 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 Vision Rehabilitation support. This raises concerns that when a person's wait for a very low priority procedure exceeds a length of time, a person's condition can deteriorate significantly. Patients in the low priority categories may rarely get to the front of the queue unless there is dedicated capacity for them.

3.6 While we welcome the recognition that local authority rehabilitation services, including vision rehabilitation services, have a key role to play in improving personal independence, and in the recovery of services, we regret the lack of specific proposals to improve the quality and equity of provision. This is especially crucial as there are significant delays in eye care patients receiving timely treatment.

3.7 As detailed in the Wales Council for the Blind's report "Addressing a workforce crisis in Wales", there are areas with waiting lists of more than a year for vision rehabilitation support after referral with a CVI. Vision rehabilitation is a vital element in blind and partially sighted people regaining and maintaining independence following a sight loss diagnosis. 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.

Recommendation

- The strategy needs to make 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.
- Health Boards should ensure 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.

3c. Improving patient outcomes and their experience of NHS services

3.8 It's crucial that the information patients need to keep safe and well is accessible. We welcome the Welsh Government's emphasis on the importance of making sure that support and information is easily accessible to those who are waiting, however, changes need to happen at pace.

3.9 Many blind and partially sighted people in Wales report that they are not currently able to understand and make informed decisions about their own healthcare because:

- i. Information about their health is not given to them in an appropriate format
- ii. They are not routinely communicated with in a way that is appropriate to their needs.

3.10 Ineffective communication with patients with sensory loss is a patient safety issue. Patients are at risk by not receiving the right support to enable them to engage in and fully understand consultations with healthcare professionals.

3.11 We have also heard from ECLOs that patients have been removed from waiting lists or moved to the bottom of lists as the communications they've received have been inaccessible.

Recommendations

- Welsh Government should audit Health Boards' adherence to the All Wales Standards for Accessible Communication and Information with people with Sensory Loss, and implement an action plan to ensure this is standard practise within eye clinics.
- All health boards should also be mandated to include accessibility as a standing item on Eye Clinic Collaborative Group agendas.
- We would also like to request an update around a recommendation accepted by the Welsh Government on 23 September 2020, which called for the appointment of an accessibility lead within the Welsh Government to oversee the production of all key public health and other information in accessible formats, including implementation of and compliance with the standards.⁵ Despite this recommendation being made and accepted, we know that there is no appointed Welsh Government lead for the All Wales Standards.
- NHS services should ensure that people with sight loss are asked about their communication needs and that any information is provided in their preferred accessible format.
- NHS IT systems and infrastructure must be available to support the collection and delivery of accessible information to people with sight loss.
- Key staff within health boards should receive training to better understand the communication needs of blind and partially sighted people and how to meet their communication preferences.
- Health boards should also undertake a comprehensive review of health board patient management systems to stop resource waste

⁵ Health and Social Care Committee, Waiting well? The impact of the waiting times backlog on people in Wales (April 2022)

and ensure the well-being, dignity and safety of the patient.

- 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.

4. Whether the plan provides sufficient leadership and national direction to drive collective effort, collaboration and innovation-sharing at local, regional and national levels across the entire health and social care system (including mental health, primary care and community care)?

4.1 A regional approach to eye care has been recommended to increase service capacity. This would help create fundamental change in the way eye care services are delivered as they recover. We are aware that three new regional clinical leads for eye care have been appointed which is to be welcomed, however, no regional groups for eye care have been established so it's unclear how this regional working will be delivered. 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.

Recommendations:

- Welsh Government should also ensure that the Ophthalmic Planned Care Board examines the scope of more regional planning and identifies where pressures can be off-set or where risk-sharing can be enabled, and progress recommendations.

5. Is it sufficiently clear which specialties will be prioritised/included in the targets?

5.1 The absence of the Eye Care Measures from the document means that it's difficult to get a sense of measurable, realistic and achievable

timescales and targets. A delivery plan specific to Eye Care recovery should be developed and published.

5.2 Evidence suggests around 10% of new patients are at risk of irreversible sight loss compared to about 90% of follow-up patients. The current Referral to Treatment Time (RTT) in eye care is 24 weeks, which means the target of 'No one waiting longer than a year for their first outpatient appointment by the end of 2022' included in the plan is irrelevant in terms of eye care.

5.3 We do, however, welcome the plan's commitment to developing targets and performance management alongside a real-time, visibility of the waiting list by sub speciality, robust demand and capacity plans that will enable teams to work effectively. RNIB Cymru has repeatedly called for this for several years.

6. Do you anticipate any variation across health boards in the achievement of the targets by specialty?

6.1 The plan outlines the importance of a fair and equitable approach to patient prioritisation to minimise health inequalities.

6.2 However, 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, Betsi Cadwaladr UHB and Hywel Dda UHB have more than half of their HRF1 (the highest risk category of patients) over target and beyond what is clinically safe. Cardiff & Vale UHB is the better performing of the larger health boards with 30% of patients over target, however Cwm Taf Morgannwg is the worst performing – with 63% of patients, almost two-thirds of their highest risk patients, over target.

6.3. We are aware that gaps in the consultant workforce is leading to the exacerbation of some speciality waiting lists in some Health Boards, for example due to specialist shortages there is a huge backlog in Glaucoma patients. A workforce plan and a clear approach to regional working are essential to ensuring equity of service across Wales.

Recommendation

- Health Boards should share examples of good practice and learn, this is particularly important as such large variations exist across Wales in terms of patient access and outcomes.

7. Does the plan adequately address health and social care workforce pressures, including retention, recruitment, and supporting staff to work flexibly, develop their skills and recover from the trauma of the pandemic?

7.1 Whilst we welcome the plan's focus on how it will address the immediate as well as long-term workforce challenges by moving eye care services into the community, it does not detail how it intends to upskill the optometry workforce or how the eye care workforce across primary and secondary care will see greater recruitment and retention. This is crucial to ensuring the challenges and backlogs are addressed at pace.

7.2 We know that the ophthalmic consultant workforce is ageing and there is an existing shortage. Recruiting and retaining a future proof workforce remains a challenge for Wales. Further work is needed to incentivise doctors to train and remain in Wales. Given too that the Royal College of Ophthalmology estimates that demand on services will increase by 40% in next 20 years (as mentioned above). The nursing workforce also faces many challenges including the appropriate training for eye care services.

7.3 We welcome the plan's commitment to developing multidisciplinary teams around the needs of patients, by ensuring that all members of the team have the support and professional development they need to use their skills and work at the top of their license to deliver their role effectively. As part of this, it's crucial that within the multidisciplinary team there are a sufficient number of health and social care professionals with skills and knowledge of sight loss and other disabilities.

7.4 Whilst some individual Health Boards are demonstrating good examples of workforce planning on a local scale, if we are to achieve service redesign and deliver additional capacity to meet current and future demand within the eye care system right across Wales, the pace of change must increase, and the work must be overseen by

government at a national level. There are also many key local recruitment issues that need urgent tackling in the short term.

Recommendation

To deliver the changes needed, we must see Welsh Government and HEIW develop a pan-Wales integrated and sustainable eye care workforce plan that is clearly linked to capacity and demand data.

This plan must:

- robustly hold health boards to account for developing local and regional plans which reflect local pathways,
- ensure that all health board IMTPs reflect and plan for workforce challenges,
- work with health boards to audit current workforce skills, map the resource implications of expanding future demand, and ensure the necessary sub-speciality workforce capacity.

8. Is there sufficient clarity about how digital tools and data will be developed and used to drive service delivery and more efficient management of waiting times?

8.1 Consultants have told us that the Electronic Patient Record (EPR) currently being rolled out is essential to delivering timely treatment and for improving eye care patient prioritisation.

Recommendation

- We recommend a review of the operational roll out and the ongoing impact of EPR.

For further information, please contact Liz Williams (Policy and Public Affairs Manager, RNIB Cymru)

ⁱ [Wales Audit Office, *Management of Follow-up Outpatients Across Wales, 2018.*](#)

ⁱⁱ [Public Accounts Committee Inquiry, *Management of follow up outpatients across Wales, National Assembly for Wales, 2019.*](#)