Icon

Description automatically generated

Consultation Response

Scottish Government

Call for views: Long Term Conditions Strategy Consultation

July 2025

Questionnaire

1. Do you agree that Scottish Government should move from a condition-specific policy approach to one that has a balance of cross-cutting improvement work for long term conditions alongside condition-specific work?

**Yes**/No. **Why do you say this?**

 We are grateful for the opportunity to respond to the Scottish Government's proposals for a move towards a balanced approach that combines cross-cutting improvements with condition-specific work. If done well, we agree that this presents an opportunity to enhance care coordination whilst ensuring specialist services continue to meet complex needs.

 It is not clear whether the Scottish Government considers visual impairment as a long-term condition within this framework. We see that visual impairment can be a long-term condition in itself (such as progressive conditions like glaucoma), or it could come as the result of other long-term conditions (like diabetic retinopathy), or it may exacerbate the management of other long-term conditions (affecting medication management, appointment attendance, and self-care). This complexity means the framework must consider how visual impairment intersects with long-term conditions across all these scenarios.

While visual impairment is a health-related condition, the biggest impact we see are the social implications - mobility, independence, employment, and community participation. Therefore, we cannot divorce the health and social care aspects of visual impairment. Any integrated approach must recognise that effective support requires seamless coordination between medical treatment, rehabilitation services, social care, and community support. The framework's success will depend on how well it bridges these different but interconnected aspects of care.

1. Are there any improvements in prevention, care or support you have seen in a long term condition you have, or provide care and support for, that would benefit people with other long term conditions?

Scotland's provision of free NHS eye examinations for everyone demonstrates how early detection approaches developed for one area can benefit broader long-term conditions prevention. This universal screening model could inform similar initiatives for other conditions where early detection prevents or delays long-term complications.

The role of Eye Clinic Liaison Officers (ECLOs) illustrates this integration approach, providing a bridge between clinical teams and rehabilitation services. They help people navigate from medical diagnosis to practical support, ensuring seamless transitions between hospital-based treatment and community-based rehabilitation. This model of having dedicated liaison roles could benefit other long-term conditions where people need support moving between medical care and social support services.

This integrated approach is essential because achieving independence requires coordinated support across multiple domains—mobility training, assistive technology, employment support, and emotional wellbeing. These examples show how approaches developed for visual impairment - universal screening, liaison roles, and coordinated support - could strengthen long-term conditions services across the board, and we would be happy to share our learning on this.

1. Do you have any thoughts about how areas for condition-specific work should be selected?

The Scottish Government needs clear principles for deciding which conditions require specialist approaches alongside the generic framework.

First, it is important to recognise that some conditions have unique requirements that simply cannot be met through generic services. Without acknowledging these differences, people will inevitably fall through cracks in the system.

Second, particular attention should be given to conditions that significantly impact how people manage other health issues. Visual impairment exemplifies this - it affects everything from healthy lifestyle, reading medication labels to attending appointments for other conditions. If visual impairment support is inadequate, it can undermine treatment across multiple conditions such as diabetes, heart disease, or stroke recovery.

Finally, prevalence shouldn't be the main factor in these decisions. We need to consider the broader impact – how does poor management of one condition affect the whole healthcare system. A less common condition that creates significant barriers to managing other conditions may well deserve targeted attention to ensure the integrated approach works properly for everyone.

1. What would help people with a long term condition find relevant information and services more easily?

Emphasis should be placed on making information and services accessible to all. People with visual impairment often face challenges accessing information due to access and communications barriers. What we need is accessibility standards for all health information, including large print, audio, and digital formats. A single point of contact for visual impairment services might improve the ability of people with a visual impairment to navigate complex service structures.

The enhanced role of the Eye Clinic Liaison Officers/Patient Support Workers across all health boards represent a proven approach to supporting navigation of complex health systems. Scottish Government research confirms "anecdotal reports suggest under-provision and inequality of low vision services across Scotland with access delayed by geographical location and long waiting times. Improved integration between NHS, local authority, and third sector services with clear referral pathways could address these inequalities.

Community engagement for this consultation for example, has been problematic, with consultation materials lacking accessible formats and using technical language, making it difficult for people with visual impairment to understand proposed changes.

1. What would help people to access care and support for long-term conditions more easily?

Accessible patient portals which are compatible with screen reading technology would help ensure people with visual impairment can engage with digital health services. Standardised visual impairment assessments shared across relevant services could reduce duplication and improve care coordination. Scotland's unique strength in providing free NHS eye tests could be better supported with consistent rehabilitation and support services across all health board areas.

1. How could the sharing of health information/data between medical professionals be improved?

Scotland operates its own [Certificate of Vision Impairment](https://www.gov.scot/policies/social-care/) (CVI) system for people aged 16 and over, replacing the earlier BP1 form. For children under 16, Scotland uses the [Visual Impairment Network](https://www.nss.nhs.scot/) for Children and Young People (VINCYP) pathway.

However, Scotland currently lacks a consistent national approach to vision impairment registration. Health boards each decide how they complete Certificates of Vision Impairment, while local authorities separately maintain their own registration records. This fragmented system creates inconsistencies across the country and makes it difficult to share information between services. A standardised CVI process across all health boards would improve data collection and enable better coordination between NHS services, local authority support, and third sector organisations.

Moreover, current service models often don't address the interconnected nature of visual impairment with other conditions. Without reliable data, Health and Social Care Partnerships cannot accurately assess population needs or allocate resources effectively. More work needs to be done to consider how a data that would give a more comprehensive picture of individual and collective needs for support with vision impairment could be collected.

1. What services outside of medical care do you think are helpful in managing long term condition(s)? You may wish to comment on how these services prevent condition(s) from getting worse.

The social model of disability recognises that people with long-term conditions often benefit more from addressing the barriers society creates than from medical treatment alone. For people with visual impairment, this means tackling the environmental and social barriers that prevent full participation in life.

Post-diagnosis support is essential and includes rehabilitation services that teach orientation and mobility skills, training in daily living activities, assistive technology support, employment services with workplace adjustments, peer support networks, mental health services, and housing adaptations. These services address the real-world challenges people face rather than just the medical aspects of their condition.

This approach prevents deterioration in ways that medical care alone cannot. Good rehabilitation promotes prevention approaches (i.e. supporting people to be more physically active), reduces fall risks and maintains independence. Peer support and employment services combat isolation and preserve mental health. Accessible housing and technology enable people to remain active contributors to their communities rather than becoming dependent on expensive care services.

Without these non-medical services, we see a predictable pattern - people with visual impairment become isolated, lose confidence, and ultimately require much more intensive and costly support. The integrated framework must recognise that preventing this decline requires investment in social and environmental solutions, not just medical management.

1. What barriers, if any, do you think people face accessing these (non-medical) services?

A number of barriers prevent people with a visual impairment from getting the support the need. Funding is inconsistent across council areas, creating geographical inequalities. Third sector organisations supporting communities in underserved areas rarely receive sustainable funding, putting services at risk.

There's a serious shortage of qualified staff, particularly rehabilitation workers, meaning long waiting lists. Services are poorly coordinated, so people fall through gaps or get assessed multiple times. Many generic service providers don't understand vision impairment needs, leading to inaccessible and inappropriate support**.**

Specialistvision rehabilitation services are provided by local authorities in Scotland. We would encourage the Scottish Government to consider how a more co-ordinated approach might help improve vision rehabilitation provision, particularly through supporting the development of quality standards for vision rehabilitation services across Scotland and more effective workforce planning. We would also suggest reviewing the National Occupational Standards used by many vision rehab service providers to ensure they remain relevant and appropriate for the Scottish context, and that specialist staff provider vision rehabilitation across Scotland are working to consistent, up-to-date standards.

1. What should we know about the challenges of managing one or more long term conditions?

[BMC Medicine](https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-014-0181-7) research shows the interconnected nature of the relationship vision impairment with other long-term conditions. In Scotland, hypertension affects over half (55.6%) of people with visual impairment, making it the most prevalent comorbidity, followed by coronary heart disease (28.8%) and diabetes (25.9%).

However, the complexity of managing visual impairment alongside these conditions is often underestimated, highlighting the need for coordinated care approaches that address both sight loss and these significant health challenges together.

Visual impairment can affect every aspect of daily life, from medication management to appointment attendance. Generic services often lack understanding of these pervasive impacts. Evidence shows low vision impacts every part of a person's life, being associated with falls, reduced capacity for everyday activities, and representing one of the strongest risk factors for functional decline.

1. What would strengthen good communication and relationships between professionals who provide care and support and people with long-term condition(s)?

Strong professional relationships require better integration between health and social care services. Visual impairment affects both medical and social aspects of life, so professionals need understanding of how these interconnect. Visual impairment awareness training for health professionals could address knowledge gaps, alongside longer appointment times to accommodate communication needs. Consistent care teams where possible would help build relationships over time.

Digital tools need full accessibility from the outset rather than retrofitted features. Investment in accessible platforms working with assistive technologies would help, alongside recognition that digital exclusion disproportionately affects older people with visual impairment.

1. What digital tools or resources provide support to people with long-term conditions?

Eyes.nhs.scot is Scotland's comprehensive eye health resource, providing guidance on screen-reading software and navigation apps, connecting users with Patient Support Workers/ECLOs. Scottish charities provide crucial support: RNIB Scotland offers "Chats about apps" podcast series and Technology for Life consultations; Sight Scotland Veterans provides IT instruction at dedicated centres; Triple Tap Tech offers peer support from people with visual impairments.

1. What new digital tools or resources do you think are needed to support people with long-term conditions?

It's not just about the digital tools themselves - it's about thinking through how people who need to navigate the system will actually access and use these services. Many people with visual impairment face barriers precisely because they are digitally excluded, so the Scottish Government cannot rely solely on digital solutions when digital exclusion is itself a significant barrier. Local support must be available through non-digital channels including face-to-face services, telephone helplines, and community-based assistance to help people navigate both digital and non-digital services effectively.

However, where digital tools are developed, we need them designed to be accessible from the outset rather than retrofitted later. Priority areas include patient portals that work seamlessly with screen readers, appointment systems allowing longer time allocations for people needing extra support, health monitoring apps with voice interfaces, and telehealth platforms compatible with existing assistive technologies. Better digital infrastructure connecting health and social care records would stop people repeatedly explaining their conditions to different services and will help with resource allocation and coordination.

1. How do you think long-term conditions can be detected earlier more easily?

Better distribution of community optometry provision and stronger links to secondary care are the key to improving early detection. Scotland's current system shows significant gaps, with services clustered in urban areas while rural communities remain badly underserved, creating a postcode lottery for specialist care access.

Scotland has a major advantage with free NHS eye examinations for everyone, but we're not maximising this opportunity. Only around 40% of eligible people currently use these free services, so much better promotion is essential. More importantly, we need enhanced community optometry services with direct referral pathways to rehabilitation support - this could transform early intervention if properly developed and promoted.

In example the See4School Programme screened 167,962 children with 85.5% coverage, detecting visual impairment in 2.42%, demonstrating that systematic early detection is both effective and cost-effective. We need similar systematic approaches for adults.

Training healthcare professionals to better recognise visual impairment symptoms and understand their broader health impacts would address current knowledge gaps. Combined with stronger integration between primary care and specialist services, this could ensure timely referral and intervention, potentially preventing much avoidable visual impairment that complicates management of other long-term conditions.

1. What barriers do people face making healthy decisions in preventing or slowing the progress of long-term condition(s)?

People with visual impairment face fundamental barriers accessing health information. Most health promotion materials remain unavailable in accessible formats, whilst public health campaigns rely heavily on visual media. Nutrition labels, medication instructions, and health monitoring equipment are typically inaccessible without specialist adaptations.

Fear of falls and lack of confidence navigating unfamiliar environments prevents engagement in physical exercise. Visual impairment impacts employment opportunities, with many facing poverty limiting healthy food choices, whilst additional costs of accessible technology, transport and support with daily activities strain budgets. The mental health impact creates additional barriers, with depression and anxiety rates significantly higher among people with vision impairment, affecting motivation for self-care**.**

Social isolation, particularly acute in Scotland's rural communities, removes the peer support that helps maintain healthy behaviours.  In remote areas, people with visual impairment may be the only person with their condition in their village or small town, cutting them off from others who understand their experiences and can share practical advice about managing daily challenges. This isolation is compounded by limited public transport, making it difficult to travel to support groups or social activities in larger towns.

Without peer networks, people lose access to informal health education - the kind of practical tips about managing medications, staying active, or adapting homes that come naturally from conversations with others facing similar challenges. Rural isolation also means less access to community resources like accessible exercise classes, talking book groups, or technology training sessions that help people maintain independence and confidence in self-care.

1. Is there anything currently working well within your community to prevent or slow progression of long-term conditions?

Scotland leads the UK with free NHS eye examinations for all. The See4School Programme exemplifies successful population-level prevention, whilst partnership working between Sight Scotland, RNIB Scotland, Guide Dogs, and Visibility Scotland creates prevention pathways no single organisation could deliver alone. The visual impairment community has developed strong peer support networks including Sight Scotland Veteran Forums, Sight Scotland Policy Group and Sight Loss Councils. These groups can contribute to prevention policy development by providing lived experience expertise and support the development of effective dissemination strategies.

Good collaboration between organisations in our sector enables better outcomes for people with visual impairment. In example assistive technology training and support provided across the sector enables independent health monitoring and medication management, whilst digital accessibility improvements during COVID showed the potential for remote prevention support. Audio description services for health information can also increase engagement with prevention messages.

1. How can the Scottish Government involve communities in preventing or slowing the progress of long term conditions?

Prevention strategy development teams could include people with visual impairment from diverse backgrounds, recognising that lived experience provides expertise professional training cannot replicate. Community engagement could use accessible formats as standard, requiring plain English and extra response time. Funding visual impairment organisations to facilitate genuine community involvement recognises the role as trusted intermediaries.

Embed visual impairment considerations in all prevention policies from inception, using impact assessment tools that specifically consider sensory impairment. Create cross-government working groups including visual impairment expertise to ensure joined-up approaches.

1. Are there additional important considerations for people with long term conditions:

* who live in deprived areas and rural and/or island areas?
* with protected characteristics e.g., race, disability (see paragraph 84 above)?
* who are in inclusion health groups e.g., homelessness?
* who experience stigma due to perceptions of their long term condition e.g., people with dementia?

The intersection of poverty and vision impairment creates spirals of disadvantage. [Scottish research reveals](https://www.nature.com/articles/s41433-021-01536-8) children in deprived areas are less likely to access appropriate spectacle correction, establishing lifelong inequality patterns. Geographic inequalities mean rural regions remain systematically underserved whilst urban areas cluster services.

Age discrimination occurs when older people are told vision loss is simply "part of ageing" rather than treatable. For minority ethnic communities, language barriers compound communication challenges. Women experience certain eye conditions more frequently yet access services less often. The framework could address these intersections explicitly, recognising that generic equality approaches don't suffice.

Assumptions of incompetence pervade interactions, with healthcare professionals failing to involve people with visual impairment fully in care decisions. The "invisible" nature of many visual impairments leads to disbelief and inadequate support. When professionals assume incompetence and lack accessible information formats, they provide less information and make decisions "in the person's best interest" without consultation.

1. Given that racism and discrimination are key drivers of inequalities, what specific actions are necessary to address racism and discrimination in healthcare?

The most effective approach is putting people with lived experience at the centre of decision-making. This means actively including people who face multiple forms of discrimination - such as those experiencing both visual impairment and racial discrimination - in designing services and training programmes from the start, rather than making assumptions about what they need.

Healthcare staff need training that addresses how different types of discrimination intersect and compound each other. In example for someone who is both visually impaired and from a minority ethnic background, barriers can multiply - language differences combined with inaccessible formats, cultural misunderstandings alongside assumptions about capability, or lack of culturally appropriate peer support networks.

Services should collect and publish data on who accesses visual impairment support by ethnicity to identify where inequalities exist. Funding community-led organisations to provide culturally safe spaces and peer advocacy within minority communities would help address gaps that mainstream services often miss. Most importantly, any anti-discrimination training must be designed and delivered with meaningful involvement from people who actually experience these intersecting forms of discrimination, ensuring solutions address real barriers rather than well-meaning assumptions.

1. Is there anything else you would like to raise that was not covered elsewhere in the consultation paper?

The Long-Term Conditions Framework presents both opportunity and risk for visual impairment services in Scotland. Done well, it could end fragmentation and postcode lottery currently affecting our community. Done poorly, it could undermine specialist expertise and leave people with visual impairment worse off.

Integration is a positive direction, but visual impairment needs to maintain visibility within the broader framework. We remain committed to working constructively with the Scottish Government to ensure this framework delivers improvements for people with visual impairment across Scotland, recognising this requires partnership, adequate resourcing, and understanding that some services may need to remain specialist to be effective.