

## Royal National Institute of Blind People (RNIB) Scotland Response to the NHS 24 Designing the Future Together - Phase One consultation

## Introduction

The Royal National Institute of Blind People (RNIB) Scotland is the country’s leading charity working with blind and partially sighted people. We support children and adults with sight loss and help them to live full and independent lives, campaigning for their rights.

In 2010, the date of the most recent figures published by the Scottish Government, the number of people registered as blind or partially sighted in Scotland was reported to be 34,492.[[1]](#footnote-1) Research suggests that around 10 per cent of eligible people do not register making the true figure closer to 40,000.

Around 178,000 people live with a significant degree of sight loss in Scotland, around 4,300 of which are children and young people.

This number could eventually double unless we act to prevent avoidable sight loss. The rise of sight threatening conditions such as diabetes and an aging population will increase the number of people affected by sight loss unless action is taken.

RNIB Scotland welcomes the opportunity to respond to this consultation to ensure that blind and partially sighted people have access to accessible health and social care services, which provide emotional and practical support to enable them to maintain an independent life.

RNIB Scotland considers it vital that during COVID-19 recovery and remobilisation of services, people with sight loss are at the forefront of decision making, leading to timely treatment and support.

The consultation poses a selection of questions; to highlight key points relating to sight loss we have replied to Question 2 and 3. The replies are based on previous RNIB/RNIB Scotland surveys, public consultation responses, literature review and specific consultation for this response.

## RNIB Scotland responses

### **Question 2. What could we improve on or do better?**

This could include how we deliver our services, our ways of working and/or your own experiences of working within our organisation

#### Accessible health information

Accessible health information is crucial and there needs to be inclusion of the requirements under the Equality Act 2010 and Patient Rights (Scotland) Act 2011, which sets out the responsibility of the NHS to provide accessible information, including the requirement that “Communication about a patient’s health and wellbeing is clear accessible and understood”.[[2]](#footnote-2)

A Charter of Patient Rights and Responsibilities[[3]](#footnote-3) accompanied the Act. This summarised the existing rights and responsibilities of patients using the NHS in Scotland, setting out that “You have the right to be given information about your care and treatment in a format or language that meets your needs.”

At present, however, Health Boards are not dealing consistently with how information is sent to blind and partially sighted people. Requests for accessible formats are not being correctly managed or not logged centrally to enable consistency.

This was discovered through research for our “Communication Failure?”[[4]](#footnote-4) report which found that blind and partially sighted people lacked confidence when considering requesting accessible formats from their health service. This was put down to feeling “a burden” or not wanting to be seen as “difficult”. They do not feel that they can enforce their rights to access information, as one respondent explained:

“No [I do not feel confident], because I worry I’m not worthy enough as I can just about manage with standard print for short lengths of time.”

Some respondents expressed a lack of trust in the health service and instead used their own supportive technology to make documents accessible at home, as one respondent explained:

“It’s easier to do it myself on a scanner so I don’t ask for information. If you’re ringing, they wouldn’t be there.”

Patients rely on good communication to ensure that they understand their health information and needs. For most people this is achieved through printed information, but for a person with sight loss, printed information is often inaccessible. Around 178,000 people live with a significant degree of sight loss in Scotland, so the need for accessibility is high.

People with sight loss should be informed about the accessible options available to them from the very beginning of their healthcare journey, giving them the opportunity to self-manage and control their own healthcare needs.

Accessing information online can provide blind and partially sighted people with valuable healthcare advice and empower them to better manage their health and wellbeing while supporting independent living. As more of our public services move online, digital inclusion has become more necessary than ever before.

Technology can reshape and improve services, support person-centred care, and improve outcomes.[[5]](#footnote-5) Furthermore, from 2019 - every public sector website and app including those of the Scottish health boards - will need to meet certain accessibility standards under new regulations.[[6]](#footnote-6)

However, a digital divide exists in Scotland.[[7]](#footnote-7) This is partially due to geographic barriers with around 25 per cent of rural households experiencing poor broadband speed.[[8]](#footnote-8) Those who do not have internet access at home need to use a public service computer which requires pre-planning and may mean lack of privacy.

Levels of digital uptake can be significantly lower for people with disabilities.[[9]](#footnote-9) Accessing online information, for example, filling in forms online, can be very time consuming or completely inaccessible.[[10]](#footnote-10) Visual barriers such as inconsistent font sizes prevent blind and partially sighted people from accessing information with ease. One respondent explained:

“Websites are very complex to navigate in general so when you have sight loss of any degree it becomes harder. It would be good to have a button to press so that the website becomes less busy and shows simple text.”

Due to a lack of awareness and understanding of what accessible health information is available to them, some blind and partially sighted people were left feeling disengaged and disempowered. More work must be done to ensure that all accessible options are clearly stated, providing people with sight loss with the information they need to manage their healthcare needs.

The effects of not receiving information in a preferred and accessible reading format should not be underestimated. This is leading to people with sight loss feeling unable to take control of their own health needs whilst their patient confidentiality can be compromised.

It is also worth noting that during the pandemic many blind and partially sighted people are currently receiving less support at home due to the risks posed by Coronavirus. This has led to individuals being home alone for a significant number of days during which health-related letters could be potentially left for weeks unread or put in the waste as junk mail.

### **Question 3. Where do you think the opportunities are for working differently in the future?**

RNIB has been delivering an Eye Clinic Liaison Officer (ECLO) service across the UK for over twenty-five years and brings with it a wealth of expertise and knowledge. 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.

Sight loss can have devastating consequences for individuals. Our RNIB Patient Experience Research[[11]](#footnote-11) suggests that many patients leave the eye clinic with little understanding of their eye condition, how best to maintain any functional vision they may have, and how best to live their lives with sight loss.As many as77 per cent of patients said they would not have found or accessed support outside the hospital without the ECLO.

The service works to ensure anyone with a sight loss diagnosis can access support at a time which is right for them, helping them to retain their independence, continue doing the things they want to do and continue to fully participate in society. After seeing the ECLO, 93 per cent of patients reported that they were either “well informed” or “very well informed” of support available. [[12]](#footnote-12)

RNIB is the only provider of ECLO services in the UK which has been nationally recognised by UKOA (UK Ophthalmology Alliance), which recognises ECLOs as integral to the patient pathway within Ophthalmology Services. RNIB ECLO services have also been peer-reviewed by the British Medical Journal.

We have also identified the cost savings to health and social care with the provision of an ECLO service by reducing falls, helping people to stay independent for longer, maximising their income and managing their sight condition and coming to terms with diagnosis. In addition, we have the potential to deliver these services remotely within communities, in a COVID-safe environment, which also offers greater flexibility.

ECLOs not only provide essential support to patients, ensuring they receive timely information on a range of topics which matter to them, but they are also indispensable to the functioning of the eye department. Ophthalmology departments in Scotland are under enormous pressure and demand will continue to increase as the number of people with sight loss in our ageing population goes up.

Early intervention can help maintain greater levels of independence and can help reduce the risk of longer-term depression. Through appropriate and timely referral to Low Vision Services, local societies’ resource centres and other local community-based services, the ECLO can support patients to access aids and adaptations, home improvements, training and support that can make a difference to their ability to maintain independence through best use of functional vision. Accessing these services as early as possible is recognised within the rehabilitation and health promotion fields to be crucial in improving longer term outcomes. Via ECLO intervention 84 per cent of patients were referred to services outside the hospital. Of these, 64 per cent had used the services and 27 per cent were intending to. [[13]](#footnote-13)

We value the opportunity to work in partnership with you to support blind and partially sighted people from diagnosis of sight loss.

### **For further information please contact:**

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3. Your health, your rights - The Charter of Patient Rights and Responsibilities, Scottish Government, 2012 <https://www2.gov.scot/Resource/0040/00407723.pdf> [↑](#footnote-ref-3)
4. Communication Failure? A review of the accessibility of health information for blind and partially sighted people, RNIB Scotland, 2020 <https://www.rnib.org.uk/scotland/reports-and-publications-rnib-scotland> [↑](#footnote-ref-4)
5. Scotland’s Digital Health and Care Strategy: enabling, connecting and empowering <https://www.gov.scot/publications/scotlands-digital-health-care-strategy-enabling-connecting-empowering/pages/3/> [↑](#footnote-ref-5)
6. The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018 <http://www.legislation.gov.uk/uksi/2018/852/contents/made> [↑](#footnote-ref-6)
7. Spreading the benefits of digital participation, The Royal Society of Edinburgh, April 2014 <http://www.rse.org.uk/wp-content/uploads/2016/09/Digital-Report-High-Res-EQ5.pdf> [↑](#footnote-ref-7)
8. Superfast broadband for Scotland, Audit Scotland 2018 <http://www.audit-scotland.gov.uk/uploads/docs/report/2018/nr_180920_broadband.pdf> [↑](#footnote-ref-8)
9. Op cit, The Royal Society of Edinburgh. [↑](#footnote-ref-9)
10. Ibid. [↑](#footnote-ref-10)
11. Eye Clinic Liaison Officer Evaluation Report, RNIB, March 2021: <https://www.rnib.org.uk/sites/default/files/UK-ECLO-Evaluation-Report-March-2021.pdf> [↑](#footnote-ref-11)
12. Eye Clinic Liaison Officer Evaluation Report, RNIB, March 2021: <https://www.rnib.org.uk/sites/default/files/UK-ECLO-Evaluation-Report-March-2021.pdf> [↑](#footnote-ref-12)
13. Ibid. [↑](#footnote-ref-13)