

## Royal National Institute of Blind People (RNIB) Scotland Response to the NHS Dumfries and Galloway consultation on the “Strategic Commissioning Plan for Health and Social Care 2022-2025

## 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 6, 11 and 12. 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 6: Do you have any comment to make about the model of health and social care and support shown in Section 3 of the SCP?

We are pleased to see that a human rights-based approach is core to the model of health and social care. In addition, the Equality Act 2010[[2]](#footnote-2) promotes the need for all service providers to make “reasonable adjustments” to support disabled people, including providing information “in an accessible format”.

We would like to suggest adding an additional point about “ensuring that information and support is accessible for all”.

### **Question 11: Is there anything about adult health and social care that you think should be included in the document but is not?**

#### 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”.[[3]](#footnote-3)

A Charter of Patient Rights and Responsibilities[[4]](#footnote-4) 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?”[[5]](#footnote-5) 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.[[6]](#footnote-6) 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.[[7]](#footnote-7)

However, a digital divide exists in Scotland.[[8]](#footnote-8) This is partially due to geographic barriers with around 25 per cent of rural households experiencing poor broadband speed.[[9]](#footnote-9) 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.[[10]](#footnote-10) Accessing online information, for example, filling in forms online, can be very time consuming or completely inaccessible.[[11]](#footnote-11) 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.

#### Emotional and practical support

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[[12]](#footnote-12) 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.77 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. 93 per cent of patients reported that they were either “well informed” or “very well informed” of support available after seeing the ECLO. [[13]](#footnote-13)

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 the UK 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. 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. [[14]](#footnote-14)

Emotional and mental wellbeing are central to the Strategic Commissioning Plan model of health and social care support, so we value the opportunity to work in partnership with you to support blind and partially sighted people upon diagnosis.

### **Question 12: Is there any other comment that you would wish to make?**

#### Prevention and falls assessments

In 2014, the Scottish Government’s “The Prevention and Management of Falls in the Community: A Framework for Action for Scotland 2014/15” [[15]](#footnote-15) acknowledged the link between sight loss and falls by including under Action 4.6:

“Level 3 assessment and interventions offered are in line with current and emerging evidence… assessment and management of visual impairment.”

In 2018, an output from the “Falls and Fragility Fracture Strategy for Scotland Consensus and Commitment Workshop” led by the Falls Programme received feedback from attendees to “Consider funding services within acute care to respond to people with a high risk of falls - including people with a visual impairment”.

“The Place Standard: How Good is Our Place?” [[16]](#footnote-16) which was developed by NHS Health Scotland and Architecture and Design Scotland, aims to allow communities to work together to assess the quality of their place and prioritise areas for action. “The Place Standard Tool Strategic Plan for 2020-2023” states:

“A place-based approach, also referred to as place-based working, is a holistic approach to identifying opportunity and needs within a particular place and addressing issues through collaboration across services and sectors.” [[17]](#footnote-17)

It emphasises maximising the potential of the physical and social environment to support health, wellbeing, and a high quality of life.

Within the health context, this encourages a collaborative approach, being applied prior to hospital discharge, to adapt surroundings that are suitable for a person with sight loss. However, a central issue here is that most falls prevention assessments are not nearly so effective for people with sight problems; they may in fact be counterproductive. Moving furniture or removing rugs may increase the risk of falls for people who rely on those “markers” to help them negotiate the room, or even to help them balance.

Carers should be included in home adaption conversations when appropriate. As mentioned within the Strategy, “many people at risk of falls are not in a position to organise their own health and social care, so carers often take this responsibility on their behalf”. The Carers (Scotland) Act 2016, clearly states that “taking account, so far as it is reasonable and practicable to do so, of any views given by the carer in making decisions relating to the discharge of the cared-for person”.

We welcome the action by the Scottish Government within “Age, Home and Community: Next Phase” [[18]](#footnote-18) to “…commit… to delivering at least 50,000 affordable homes over the lifetime of the current… which can be adapted for… people with physical disabilities”. Acknowledging the needs and requirements for people with physical disabilities, including people with sight loss, can ensure that there are necessary preventive measures put in place from the onset to stop unnecessary falls at home.

We would like to see a stronger focus on the need for falls and fractures prevention presented within the Strategic Commissioning Plan.

#### Maintaining strength

Maintaining strength, balance and bone health can reduce risks of falls and harm from falling. Exercises should therefore be encouraged, within an inclusive environment, to allow people with sight loss to maintain strength. We are pleased that the “Active Scotland Delivery Plan” [[19]](#footnote-19) reinforces this message by stating that “We will work to ensure everyone has access to opportunities to be active, regardless of their… disability.”

Sensory impairment is also recognised within “The Key to Life Strategy”[[20]](#footnote-20) which emphasises the importance of additional support for individuals with more complex needs:

“…in terms of prevention, people with learning disabilities are also less likely to exercise and eat healthily than the general public because they may not always have the knowledge or understanding to make healthy choices and are reliant on others for support and communication.”

In 2016, Public Health Information for Scotland (ScotPHO) released its/the “Scottish Burden of Disease Study”.[[21]](#footnote-21) This demonstrates that neck and lower back pain was the second leading cause of disease burden in Scotland that year. This accounts for a high proportion of years lived with a disability for people 65 years and older.

Maintaining a level of exercise is important to people with sight loss, however, barriers still need to be addressed. There is still a need to increase physical activities for people with sight loss and adapting the environment. When exercise programmes do take place, they tend to rely on an instructor who gives visual ‘cues’ or demonstrates the movements.[[22]](#footnote-22)

**Isolation and loneliness**

RNIB Scotland offers a wide range of online and remote resources to help people with sight loss build new connections - from our Living with sight loss course, to Talk and Support, and our Advice and Helpline.

We want to ensure that people feel connected to their communities and have voice, choice, and control of their lives. Loneliness and isolation can affect people at different stages of their life. So too can sight loss, from being born blind, being registered blind or partially sighted as a younger person, to losing sight during older age.

Yet people with sight loss face barriers every day, as we underlined in our consultation response to the “A Connected Scotland: our strategy to tackling social isolation and loneliness and building stronger social connections”.[[23]](#footnote-23)

We are pleased that people with a visual impairment were acknowledged in the “Analysing responses to 'A Connected Scotland' - the Scottish Government's draft strategy to tackle social isolation and loneliness” [[24]](#footnote-24), and that there is a key action within the Strategic Commissioning Plan to address loneliness and isolation in Dumfries and Galloway.

### For further information please contact:

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