

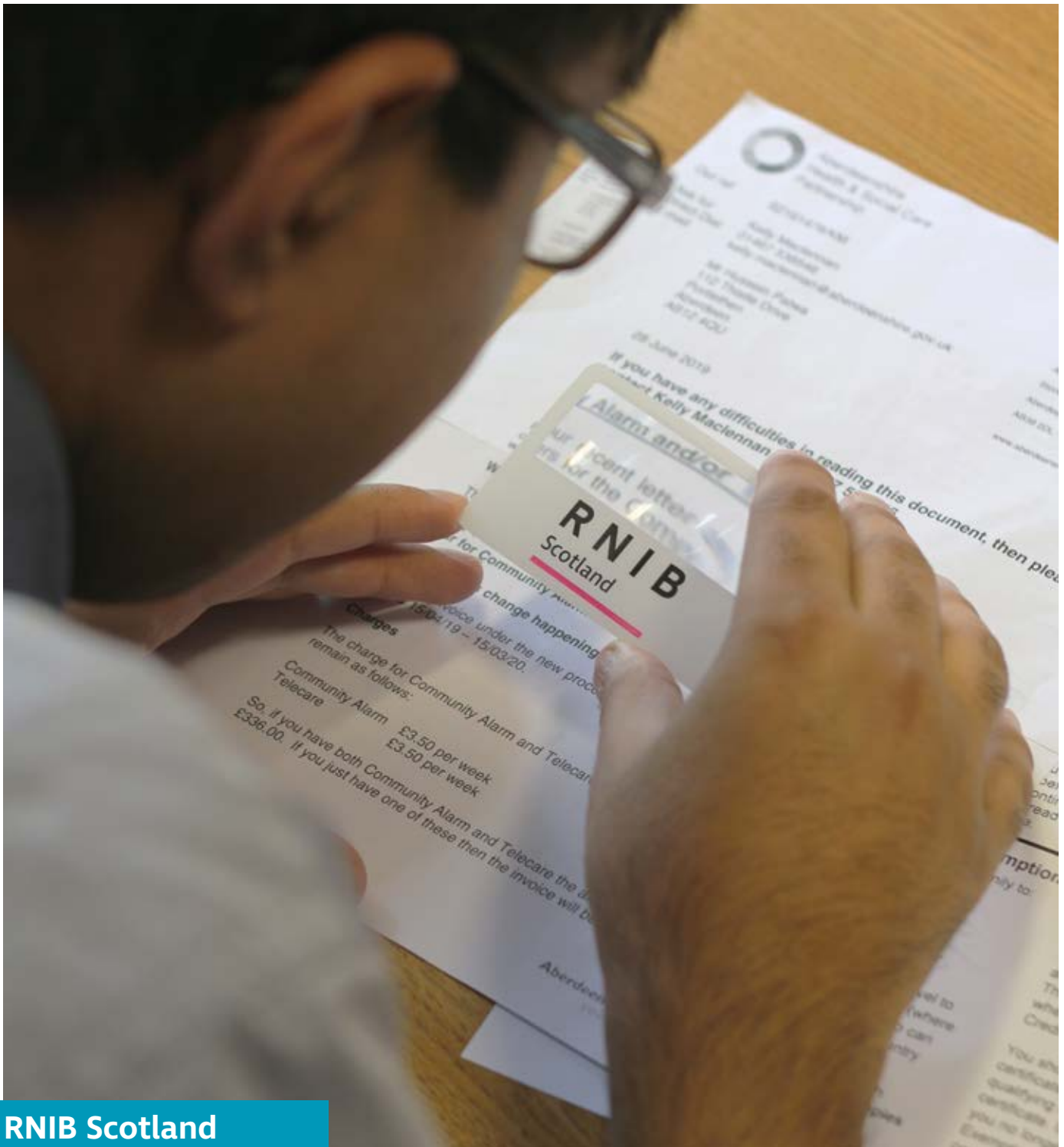
Communication Failure?

R N I B

Scotland

See differently

Review of the accessibility of health information for blind and partially sighted people in Scotland





Contents

3	Contents
4	Foreword
5	Executive Summary
5	Key findings include:
6	Recommendations
8	Section 1: Patients' perspective
9	Interview findings on accessible information
15	Hospitals and General Practitioners (GPs)
16	Medication
17	Case studies
19	Section 2: Scottish Health Boards
20	Scottish Health Board policies and procedures
23	Conclusion
24	Recommendations
25	Further information for blind and partially sighted people
25	Further information for Scottish Health Boards
26	Appendix 1: Report questions
27	Appendix 2: Scottish Health Boards
29	National policy references
32	Contact us

RNIB Scotland report compiled by:

Laura Jones Senior Policy Officer (Health and Social Care)

RNIB Scotland

12-14 Hillside Crescent
Edinburgh EH7 5EA

Email laura.jones@rnib.org.uk

Foreword

In 2010, RNIB Scotland produced a report on the **Accessibility of Health Information for Blind and Partially Sighted People**. [1]

This report found a lack of recognition of the specific additional needs of blind and partially sighted people within the health service. It showed that blind and partially sighted people did not experience the same patient confidentiality as sighted people as they were often forced to rely on others to give details of appointments, diagnosis and patient advice.

The Patient Rights (Scotland) Act 2011 and its accompanying Charter of Patient Rights and Responsibilities have since set out that:

“You have the right to be given information about your care and treatment in a format or language that meets your needs. [2]”

Each Health Board is now responsible for ensuring that **all NHS Health Scotland staff are aware of the level of accessibility [to] ... adhere to when producing information products.**

Around 170,000 people in Scotland have significant sight loss. Almost a decade since the passing of the Patient Rights legislation, RNIB Scotland wanted to review blind and partially sighted people's current experiences of patient health information.

Our key finding is that – whilst good policies may exist on paper – too often people with sight loss receive information in formats they can't read – even when healthcare providers know they have sight loss.

I urge all Health Boards to read this report, pay heed to the experiences cited and to implement its recommendations.

Sandra Wilson, Chair, RNIB Scotland



Executive Summary

Around 170,000 people in Scotland have significant sight loss. Being able to access and understand information on eye healthcare, and other healthcare services, is essential. Almost a decade since the passing of Patient Rights legislation, RNIB Scotland wanted to review blind and partially sighted people's experiences of patient health information.

..... This report is based on interviews with 32 people with sight loss, alongside information on policies and procedures on accessible information provided by NHS 24, State Hospital Lanarkshire and the nine Health Boards which replied to our requests for information.

..... Three case studies have been included within this report from individuals with sight loss. These personal experiences clearly demonstrate the huge impact on people's lives when they do not receive accessible information.

Key findings include:

1. Patient confidentiality is breached due to individuals relying on carers, relatives or friends to read appointment letters on their behalf.
2. Individuals are being put at risk of missing treatments, potentially leading to unnecessary sight loss, due to the lack of accessible documents.
3. Some individuals were told that they could cope without an accessible format so now feel unable to request their requirements.
4. Some people with sight loss did not feel 'worthy enough' to make requests and/or complain to their health service.

Recommendations

Accessing healthcare information

1. Each Scottish Health Board must ensure that they have accessible health information policies and procedures in place to support people with sight loss.
2. Each Scottish Health Board should understand the impact on patient confidentiality when health information is not sent in an accessible format.
3. Each Scottish Health Board must take more responsibility and accountability to provide timely information that is person-centred including the implementation of pending legislative requirements to ensure their websites are accessible for all.
4. There should be improved access to healthcare facilities and accessible information to direct blind and partially sighted people.
5. There is also a need for awareness raising and education amongst people with sight loss so that they are aware of their rights regarding receiving accessible health information.

Accessible care

1. Healthcare staff should receive training on the different types of blindness and the impact that this could have on communications with patients.
2. Enhanced awareness and professional development for healthcare staff should ensure that they know how to support the needs of blind and partially sighted people physically and emotionally.



Section 1: Patients' perspective

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. With 34,492 people formally registered as blind or partially sighted in Scotland [3], the need for accessibility is high.

Accessible health information is giving information in a way that is accessible to as many people as possible [4].

In 2010, RNIB Scotland produced a report on the **Accessibility of Health Information for Blind and Partially Sighted People** [5]. This report concluded that there was a lack of recognition of the specific additional needs of blind and partially sighted people within the health service.

Most shockingly, it highlighted that the patient confidentiality of blind or partially sighted people was being breached, as some had to rely on carers, relatives or friends to read appointment letters, medication or test results. This is a serious health inequality situation, where, in practice, blind and partially sighted people do not experience the same patient confidentiality as sighted people.

This section gives an update on blind and partially sighted people's experiences since 2010. We conducted interviews [6] with 32 people with sight loss, asking them specific questions about their personal encounters. Interviews were conducted face to face, over the phone and through an online survey.



Interview findings on accessible information

Question 1: Did you know that you can request health information in an appropriate format for your needs?

Accessible information must be in a format suitable for individual needs. The availability of alternative formats is often highlighted and displayed as a statement on healthcare documents, for example, **This letter can be made available in large print... other formats and languages can be supplied on request....** However, although this statement is clear, due to its placing in correspondence, it is often missed by people with sight loss as one respondent explained:

“Put, **If you can't read this** at the top of the letter rather than at the bottom.”

Blind and partially sighted people had varied experiences of finding out about their entitlement to access appropriate formats. Information about accessible documents did not always come directly from the health service, as one respondent told us:

“Yes [I did know I could request health information in an accessible format], but only because I was told by RNIB Scotland staff.”

Some people with sight loss confidently expressed their rights and needs directly to the health service; others were less inclined to or misinformed. A respondent declared:

“I knew about this [requesting accessible formats] but have been told I can manage without large print by some people which puts me off requesting it.”

Being told that you can cope with a format that you find inaccessible is undermining and might prevent individuals from requesting accessible formats in the future and / or raising concerns when trying to understand health content. It could also lead to individuals relying on carers, relatives or friends to read appointment letters, medication or test results, leading to a complete breach of patient confidentiality.

Overall, we found:

- 1.** There was low awareness about the option to request alternative formats, mainly due to the reference to 'other formats' being poorly situated on healthcare documents.
- 2.** Several individuals were not told directly by the health service that they could request alternative formats.
- 3.** Some were told that they could cope without an accessible format so now feel unable to request their requirements.
- 4.** Patient confidentiality is breached due to individuals relying on carers, relatives or friends to read appointment letters on their behalf.

Question 2: Do you feel confident to request and/or complain when you have not received your health information in the correct format? If not, could you tell us why?

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 say which accessible format they require and for this to be noted on their file for all future correspondence.

However, blind and partially sighted people told us about lacking 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**.

Blind and partially sighted people 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.”

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.

Overall, we found:

1. Some interviewees did not feel ‘worthy enough’ to request and/or complain to their health service.
2. Several relied on access to their own technology to make documents more accessible.

Question 3: If you have requested information in an alternative format, for example, easy to read or braille have your health providers delivered your requirements?

Managing blind and partially sighted people's requests for accessible formats, in a timely and consistent manner, creates clear communication and understanding between the individual and the health service. It can also prevent any unnecessary delays that could lead to a greater risk of sight deterioration for patients.

When requests have not been met, it can lead to people with sight loss feeling frustrated and misunderstood; as one respondent commented:

"Large print is yet to be managed [by Health Boards]."

Health literacy [7] is recognised as a potential barrier for individuals when understanding their healthcare. It is therefore crucial that blind and partially sighted people are given the information they need to make informed choices. Not getting information available in a suitable format could lead to devastating consequences, for example, missing important eyecare appointments or information about eye conditions that are irreversible and potentially life threatening.

Continuously receiving inaccessible documents can lead to individuals **giving up**, as one respondent explained:

"Little point after eight tries."

Receiving inaccessible health information puts blind and partially sighted people at risk of missing treatments; with some eye conditions being irreversible if treatment is not sought at an early stage. It can also lead to individuals feeling confused or misinformed about their healthcare needs.

Overall, we found:

- 1.** Patients said that alternative formats are, yet to be managed, by Health Boards.
- 2.** Some interviewees reported trying many times to request alternative formats to no avail.
- 3.** Individuals are being put at risk of missing treatments, potentially leading to unnecessary sight loss, due to the lack of accessible documents [8].

Question 4: Do you find it easy to access information in letter format and online? Do you have a preference? If so why?

Demand for healthcare services continues to increase and more people are waiting longer to be seen [9]. Ongoing challenges facing the NHS include increasing costs and growing demand, with these challenges continuing to intensify. Giving patients inaccessible information is only adding to this burden.

People with sight loss told us about the difficulty of consistently receiving healthcare documents in the same inaccessible format, even after expressing their requirements. It seemed that personal requests were not being correctly managed by the Health Board involved.

Blind and partially sighted people also experienced difficulties even after getting their preferred format due to font-size and type, colour and spacing, with all these severely affecting how easily a document can be read. For example, issues were raised about hard copy letters being difficult to read due to ink, **bleeding**, as one respondent explained:

“I prefer letter format, but it can be difficult to read... if the text is in bold I can manage for a short time but any bleeding ink or fading, it becomes almost impossible to read.”

Advancements in supportive technology now allow people with sight loss to scan text and use screen reading software to announce content using a synthesiser [10]. This has allowed some independent access

to information. However, access to supportive technology should not be taken for granted as not everyone has this support and equipment can be costly. For example, the current version of JAWS Home screen reading software for people with vision loss costs £699 and ZoomText screen magnifying software costs £575 [11].

People with other sensory impairments also require further consideration from the health service to give them the opportunity to manage their healthcare information independently. This was illustrated in the case of a respondent who had sight loss and was also hard of hearing:

“I find it easier [to receive documents] by e-mail. Print is no good as I am profoundly blind, and I am hard of hearing. I also don't find it easy to access the internet.”

Unless a robust central patient information system logs patients' requirements and requests, blind and partially sighted people will continue to receive inaccessible documents, despite frequent requests. This leads to people with sight loss not feeling valued by the health service.

Overall, we found:

1. Difficulties were reported in accessing documents online.
2. Personal preferences about preferred formats were not being met.
3. Electronic versions of health documents were sometimes considered more accessible by people with sight loss.

Question 5: When accessing information online did you find it easy to navigate on the Health Board's website? If you did, what made it accessible (font size, etc)? If you did not, what could have been better? Please provide examples.

Technology can reshape and improve services, support person-centred care, and improve outcomes [12]. 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 [13].

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.

However, a digital divide exists in Scotland [14]. This is partially due to geographic barriers with around 25 per cent of rural households experiencing poor broadband speed [15]. 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 [16]. Accessing online information, for example, filling in forms online, can be very time consuming or completely inaccessible [17]. 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."

Listening to people's experiences of accessible websites is a simple and inclusive way of identifying changes needed to ensure online information is accessible to all. It is important to carry out testing with end-users who use health services [18]. Checking for potential accessibility issues during web-building ensures that accessibility issues have been considered as one respondent agreed:

"[We need] Better user testing of websites."

Digital adaptations to healthcare are advancing in Scotland [19]. In the future this could reduce the need to attend physical appointments. There is an opportunity for blind and partially sighted people to be involved in future discussions about creating a fully accessible digital healthcare service. As one respondent suggested:

"Online vision services – to make a repeat prescription [online], could be considered or standardised."

Overall, we found:

1. Interviewees said that health service websites are difficult to navigate.
2. There could be a better use of online information, for example, to provide easily accessible vision support.
3. There should be the opportunity for people with sight loss to feedback user experiences of websites.

Further concerns

In addition to the formal interview-based questions, blind and partially sighted people also gave us comments on hospitals and GPs as well as on medication.



Hospitals and General Practitioners (GPs)

Accessible buildings give blind and partially sighted people the confidence to attend hospital and GP appointments independently. Further assistance such as clear audio announcements at reception is required when entering an unknown building to ensure that patients access the required department. In some cases, people with sight loss have not been greeted appropriately by healthcare staff leading to individuals being confused and frustrated. One respondent told us:

“Even when greeted at the eye clinic or hospital, there is no right guidance.”

The needs of people with sight loss should be considered before a health appointment. This not only gives visually impaired people the time to fully read and understand treatment information but allows them the opportunity to ask questions. Blind and partially sighted people are still being left in vulnerable situations due to the lack of accessible healthcare information before treatments, as one respondent explained:

“When having a new operation, everything was inaccessible, leaflets about the operation, food etc.”

Unless healthcare staff have good communication skills, it can be virtually impossible for people with sight loss to follow what is happening in their appointment. One respondent suggested:

“Training for health service staff about disability support.”

There are no hard and fast rules on how to assist people with sight problems; however, sight loss awareness training would assist healthcare staff when dealing with patients with sight loss [20]. Just being aware of the possibility that the person you are speaking to has sight loss and may also be hard of hearing would make a difference. For example, when healthcare staff know a patient has sight loss, a personal greeting can give reassurance.

Overall, we found:

1. Patients got inaccessible information before, during and after hospital and GP appointments.
2. There was dissatisfaction with the lack of accessible health documents about specific appointments such as surgery.
3. Interviewees recommended that all healthcare staff should receive basic sight loss awareness training.

Medication

All medication boxes should now display the name and the strength of the medicine in braille [21]. In 2013 RNIB co-wrote an impact report on braille standards for medicine packaging [22]. This found that out of 165 braille users, 96 per cent reported that they made use of braille labels on medicine packaging.

In addition, the patient information leaflet supplied should be in an accessible format. This aids independence and raises self-esteem in a person who has lost their sight.

However, blind and partially sighted people still experience difficulties in identifying the correct medication due to the lack of braille or the braille being covered by other labels as one respondent fed back:

“Braille is being covered on medication boxes by labels or the braille label is not on the medication box at all.”

There are obvious dangers in patients inadvertently taking the wrong dosage of medicines or at the wrong times. Lack of access to the right medication information could lead to devastating effects and preventable harm.

Overall, we found:

1. Some interviewees said that medication boxes did not include accessible information.
2. Respondents were unable to identify the correct medication due to the braille text being covered.

Case studies

Amanda

"When I went in to hospital for treatment, I received a printed letter explaining the procedure and the rules and what would happen. When I asked about having this sent to me via email they said that they can't do this owing to security. I waited around half an hour on the phone trying to call the number about accessible information, then when someone answered the phone they said that the person who used to deal with this is no longer there and there was no one to help so it was lucky my friend was able to spend time with me going over the document.

"I have always had difficulty getting material in accessible documents. When I started getting them via email they were in PDF format which isn't good for screen readers. I think it might help if you received a text or email reminder in respect of when your appointment is maybe a few days before your appointment, so you have a reminder of when it is."

Ken

"I registered for NHS Lothian's e-comms service and thought the problem with inaccessible information would have been fixed. However, the next time I visited the eye hospital, I mentioned the e-comms system and that I assumed that future correspondence would be sent via that system. The administration staff in the Ophthalmology department had never heard of e-comms and were unable to provide correspondence in an accessible format. As Ophthalmology is one

of the functions most likely to have patients who require alternative format information, I found this lack of awareness troubling and excluding.

"On registering for e-comms]... there were several stages to this process, and not all were accessible. ...my log in was confirmed via a letter, then I was required to prove I was not a robot by completing a Captcha. Both visual and audio Captcha codes are considered to be inaccessible, and after trying several of them, I would confirm that. I had to get sighted assistance to complete the process, which largely defeated the point of a system designed to provide accessible health information."

Hussein

"I was sent a letter offering me an initial appointment to discuss cataract removal at the Aberdeen Royal Infirmary Eye Clinic. ...The letter gave me seven days to acknowledge and confirm the appointment by phone. If not done so the letter said I would be placed at the end of the waiting list effectively adding another four months' delay before being able to see someone at the hospital. If I missed the deadline again, the entire case would be cancelled, and I would require a new referral from my optician.

"I suffer from a chronic pain condition and at the time was unable to use my scanner and assistive technology (screen reader/magnifier software) to read the letter. Eight days later someone visited me and was able to read the letter to me, by which time the period for confirming the appointment had lapsed. When I did call to confirm the appointment, it took some effort to convince the secretarial staff to offer me one and to understand that my not complying with their requirements was not deliberate or my fault. I felt as if I was having to justify my reason for having a disability and that I was not a lazy or irresponsible person."



Section 2: Scottish Health Boards

The Patient Rights (Scotland) Act 2011 sets out the responsibility of the NHS to provide accessible information, including the statement that.

Communication about a patient's health and wellbeing is clear accessible and understood [23].

A Charter of Patient Rights and Responsibilities [24] 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.**

In 2011, NHS Health Scotland produced an **Accessible Information Policy** which stated that 'All NHS Health Scotland staff are aware of the level of accessibility we must adhere to when producing information products.' Each Health Board is responsible for ensuring that this national policy is adhered to.

Section 2 of this report is based on responses to questions sent to the 14 Scottish health boards [25]. Nine Health Boards responded:

- NHS Ayrshire and Arran
- NHS Borders
- NHS Dumfries and Galloway
- NHS Grampian
- NHS Greater Glasgow and Clyde
- NHS Lanarkshire
- NHS Lothian
- NHS Orkney
- NHS Tayside

NHS 24 and the State Hospital, Lanarkshire also responded whilst NHS Fife, NHS Forth Valley, NHS Highland, NHS Shetland and NHS Western Isles did not reply.

Scottish Health Board policies and procedures

Understanding the process to requesting accessible formats within a Health Board gives blind and partially sighted people the information they need to make requests with confidence.

As part of this review, we asked each Scottish Health Board to provide us with further information about the specific policies and procedures for supporting individuals with accessible information requests.

The details given by the Health Boards which replied are summarised in Appendix 2 whilst the section below highlights some examples.

Question 1: What actions have been put in place to enable blind and partially sighted people to read and access their health information independently?

The actions taken to enable the access of health information independently included:

- A **Pre-admission specific needs form** (Example 1)
- A Referral Management System (Example 2)

Example 1: NHS State Hospital

A **Pre-Admission Specific Needs Form** is completed by one of the State Hospital's Consultant Psychiatrist. This pro-forma includes a section which highlights any barriers to communication, including sensory impairment.

Example 2: NHS Ayrshire and Arran

Our Referral Management Service is the main point of contact and can arrange to send particular letters in larger font or via alternative methods e.g. large font by email on receipt of a request from a patient or their representative. Some areas of the organisation, such as ophthalmology clinics and eye clinic services, are providing outpatients letters in font size 14 on yellow paper to increase accessibility for visually impaired patients.

Question 2: What processes are in place to ensure that there is consistency in sending information to individuals in their preferred format? For example, notes on their medical records.

How do you ensure that the actions undertaken have been effective in meeting the needs of blind and partially sighted people?

The processes in place to ensure consistency and action taken to provide preferred documents included:

- A patients' administration management system **TrakCare** (Example 1)
- Interpretation and Translation service (Example 2)

Example 1: NHS Tayside

If a patient has requested that they require information in a different format, then medical records will note this in TrakCare (patient administration management system) and the staff would put this in as an alert. The medical records staff will also note and document this on the waiting list comments section within TrakCare. Any appointment letters that require to be translated will be seen as an alert on the TrakCare system if the patient/clinical staff have informed medical records. Clinical staff can also put an alert on TrakCare so it is in the system for future access to our services. TrakCare can print appointment letters in large print and we know from information/statistics that Ophthalmology services have the highest request for large print.

Example 2: NHS Borders

We are happy to present information in braille and other formats and we have reminded our central booking staff of the means to do this through our Interpretation and Translation process (as a small health board we have no in-house resources). NHS Borders also operates a telephone reminder service for appointments. Staff in our Records Department add alerts to patients' TrakCare record when the GP has highlighted this in a section within the SCI gateway Referral programme. Our clinicians also record additional needs onto Trak which can then act as a trigger for future appointments.

Question 3: How do you ensure that NHS staff provide clear, accessible communication – verbal and non-verbal – about patients care and treatment? For example, clear guidelines about a medical condition which may result in them needing medication.

Respondent feedback regarding providing clear, accessible communication included:

- Communication skills training (Example 1)
- NHS Education for Scotland "Z" Card (Example 2)

Example 1: NHS 24

Communication skills training is provided at staff induction and through continuous professional development, including call review, coaching, peer support and levelling sessions. NHS 24 staff work within regulated codes and standards.

Example 2: NHS Grampian

As well as the inclusion of a section on disability, every participant is given their own personal copy of the NHS Education for Scotland "Z" Card entitled: **Sensory Impairment, Points for Good Communication**. This contains simple practical advice to improve communication with people who have a sensory impairment.'

Question 4: How do you ensure that patients are informed and involved in decisions about health care and services?

Means taken to ensure that patients are involved in decisions included:

- Patient Advocacy Services (PAS) (Example 1)
- A triage system (Example 2)

Example 1: NHS State Hospital

Patient Advocacy Services (PAS) provide a comprehensive service to all patients, to ensure they are fully involved in care and treatment planning and able to share their views as part of the Mental Health Tribunal process and 6 monthly care plan review meetings. We work closely with the Scottish Health Council Local Officers, who attend Patient Partnership Group (PPG) and are members of the Person Centred Improvement Steering Group. This external partnership supports the organisation to learn from the practice of other Boards who provide care for a larger number of visually impaired patients on a more regular basis.

Example 2: NHS 24

People who contact the 111 service and require care and advice when GP surgeries and pharmacies are closed are triaged. Recommendations are then made regarding the choices that are available to them. Staff members who are responding to the call have a duty to ensure that the person is in agreement with the outcome.

Question 5: How do you provide information to enable patients to make informed choices about their health care and treatment options?

Means of providing information to allow for informed choices included:

- Noting personal preferences on medical records (Example 1)
- Setting an alert for preferences (Example 2)

Example 1: NHS Orkney

We seek to meet all patient requests for alternative means of communication. To ensure staff are aware of a patient's preferred means of communication, a note of preference is placed on the patient's medical record when a deviation from the standard provision has been requested.

Example 2: NHS Greater Glasgow and Clyde

We do have the ability to flag patient preference on font/style at a patient level as an alert, thus supporting preferences and choices of our patient groups. This should then be acted upon by local staff requesting the letter/information in an accessible format through the Clear to All lead in the Equality and Human Rights Team.

Conclusion

Accessible health information can empower blind and partially sighted people to self-manage and control their own healthcare needs and some are beginning to take control of their own health information by using supportive technology. Although this is encouraging, we are clear that access to this should not be taken for granted. However, if people with sight loss do not have the access, motivation or skills to participate online, they will face growing exclusion from an increasingly digital society.

This section has highlighted that several good policies are in place on paper.

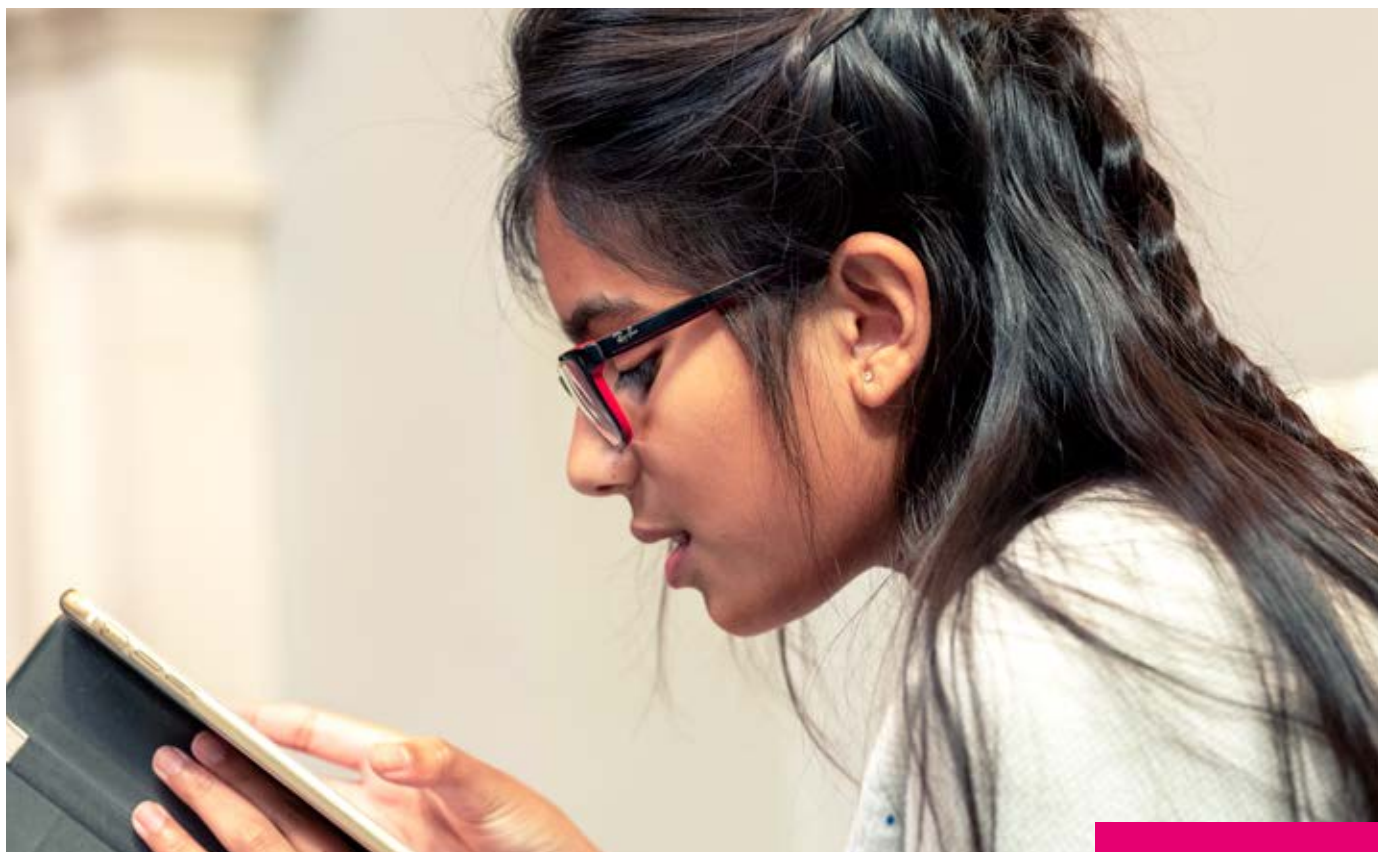
At present, however, Health Boards are not dealing consistently with how information is sent to blind and partially sighted people. Requests for accessible formats are not being correctly

managed or not logged centrally to enable consistency.

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.

Individuals should not have to consider if they're 'worthy enough' when requesting alternative formats from the health service.

Each Scottish Health Board must take more responsibility and accountability to provide timely information that is person-centred, including the implementation of legislative requirements to ensure their websites are accessible for all.



Recommendations

Accessing healthcare information

1. Each Scottish Health Board must ensure that they have accessible health information policies and procedures in place to support people with sight loss.
2. Each Scottish Health Board should understand the impact on patient confidentiality when health information is not sent in an accessible format.
3. Each Scottish Health Board must take more responsibility and accountability to provide timely information that is person-centred including the implementation of pending legislative requirements to ensure their websites are accessible for all.
4. There should be improved access to healthcare facilities and accessible information to direct blind and partially sighted people.
5. There is also a need for awareness raising and education amongst people with sight loss so that they are aware of their rights regarding receiving accessible health information.

Accessible care

1. Healthcare staff should receive training on the different types of blindness and the impact that this could have on communications with patients.
2. Enhanced awareness and professional development for healthcare staff should ensure that they know how to support the needs of blind and partially sighted people physically and emotionally.

Further information for blind and partially sighted people

Accessible Health Information Toolkit, Scotland

RNIB Scotland has put together a helpful toolkit for Scotland-based patients to make sure people can get their health information in their preferred format.

It provides useful background about Scottish legislation, how to complain to your health service and how to progress complaints further. We have also included letter templates to make it easy to submit a request.

The Accessible Health Information Toolkit can be accessed and downloaded on our RNIB Scotland website at rnib.org.uk/scotland/reports-and-publications-rnib-scotland

Further information for Scottish Health Boards

Courses and training

RNIB Scotland offers a variety of supportive courses and training that can provide additional development for professionals.

1. RNIB Learning Choices is an award-winning learning management system, offering a wide selection of online digital courses. It provides support to external organisations to create accessible online platforms [26].
2. RNIB's UK Training and Development Team provide tailored training designed to increase awareness and understanding of the impact sight problems have on people's daily life especially those with more complex needs [27].

Appendix 1: Report questions

Patient Interview Questions

1. Did you know that you can request health information in an appropriate format for your needs?
2. Do you feel confident to request and/or complain when you have not received your health information in the correct format? If not, could you tell us why?
3. If you have requested information in an alternative format, for example, easy to read or braille have your health providers delivered your requirements?
4. Do you find it easy to access information in letter format and online? Do you have a preference? If so why?
5. When accessing information online did you find it easy to navigate on the Health Board's website? If you did, what made it accessible (font size, etc)? If you did not, what could have been better? Please provide examples.

Health Board Questions

An initial request for information was sent out by email/letter but due to a disappointing response, the questions were reviewed and re-sent. In this report, we have summarised both sets of questions as follows:

1. What actions have been put in place to enable blind and partially sighted people to read and access their health information independently? This includes, appointment reminders, test results and medical information online and hard copy.
2. What processes are in place to ensure that there is consistency in sending information to individuals in their preferred format? For example, notes on their medical records.

How do you ensure that the actions undertaken have been effective in meeting the needs of blind and partially sighted people?

3. How do you ensure that NHS staff provide clear, accessible communication – verbal and non-verbal – about patients care and treatment? For example, clear guidelines about a medical condition which may result in them needing medication.
4. How do you ensure that patients are informed and involved in decisions about health care and services?
5. How do you provide information to enable patients to make informed choices about their health care and treatment options?

Appendix 2: Scottish Health Boards

Policies and procedures for supporting individuals with accessible information requests as supplied (and correct at the time of writing)

NHS Ayrshire and Arran

Main contact: The Referral Management Service is the main point of contact for alternative formats.
Telephone: **01563 827070**.

Process

- Ophthalmology clinics and eye clinic services are providing outpatients' letters in font size 14 on yellow paper to increase accessibility for visually impaired patients.
- NHS Ayrshire and Arran utilise a text reminder service for appointments and anecdotal feedback from visually impaired service users.
- Access support cards are aimed at supporting patients with sight loss by handing in the card to healthcare staff upon arrival at the health service.

NHS Borders

Main contact: The Interpretation and Translation process provides accessible formats through the Equality and Diversity Department.
Telephone: **01896 825560**.

Process

- A telephone reminder service is operated for appointments.
- Additional requirements are added onto the patients TrakCare (patient administration management system) record which acts as an alert.

NHS Dumfries and Galloway

Main contact: Patient Services provide and manage requests from patients for alternative formats.
Telephone: **01387 272733**.

NHS Grampian

Main contact: Corporate Communications provide alternative formats for patients.
Telephone: **01224 554400**.

Process

- Leaflets, booklets and other published material are written in minimum font size 14 or larger and contain details about requesting alternative formats.

NHS Greater Glasgow and Clyde

Main contact: The Clear to All lead in the Equality and Human Rights Team notes patient preferences.
Telephone: **0141 201 4560**.

Process

- Large print requests are noted by local healthcare staff.
- A statement, **If you require this information in an accessible format, such as large print or braille... please use the contact details on your patient information leaflet or letter**, is included on all appointment letters and pre-attendance information posted to the patient.

NHS Lanarkshire

Main contact: The General Enquiry Line can be used to request alternative formats.

Telephone: **0300 3030 243**.

Process

- Patient records contain an alert field for healthcare staff to know when a patient is blind or partially sighted.

NHS Lothian

Main contact: The Interpretation and Translation Service provides information in other reading formats on request.

Telephone: **0131 242 8181**.

NHS Orkney

No direct information was provided.

NHS Tayside

Main contact: An Interpretation and Translation service is alerted to patients' requests for alternative formats through the clinical staff.

Telephone: **01382 424138**.

Process

- Medical records will note accessible formats in TrakCare (patient administration management system) and healthcare staff put this in as an alert.
- TrakCare can print appointment letters in large print.
- The Patient Information Co-ordinator who, in conjunction with the Interpretation and Translation Service, arranges for leaflets to be provided in an appropriate media if requested.

NHS State Hospital

Main contact: The Consultant Psychiatrist completes a Pre-Admission Specific Needs Form which highlights any barriers to communication, including sensory impairment.

Process

- The Pre-Admission Specific Needs Form is scanned into the electronic patient record system. E-mail alerts are automatically generated to a number of healthcare staff.
- The Patient Advocacy Service (PAS) Manager will discuss any needs for patients in relation to barriers to communication. PAS are an independent organisation, based within the Hospital, whose key performance indicators include accessing and offering support to ensure all newly admitted patients understand their rights and the reason for their detention within five days of admission.

NHS 24

No direct information was provided.

National policy references

Patient Rights (Scotland) Act 2011

<https://www2.gov.scot/Topics/Health/Policy/Patients-Rights>

A Charter of Patient Rights and Responsibilities, NHS Scotland

<https://www2.gov.scot/Resource/0040/00407723.pdf>

NHS Health Scotland Accessible Health Policy

<http://www.healthscotland.scot/media/1606/accessible-information-policy-v30.pdf>

Access for All: Guide to Accessible Information, NHS Health Scotland

<http://www.healthscotland.scot/media/1135/think-access-for-all-your-guide-to-accessible-information-jul15.pdf>

Equality Act 2010

<https://www.gov.scot/publications/procurement-equality-duties/>

See Hear: A strategic framework for meeting the needs of people with a sensory impairment in Scotland, Scottish Government

<https://www.gov.scot/publications/see-hear-strategic-framework-meeting-needs-people-sensory-impairment-scotland/>

Making it Easier: A Health Literacy Action Plan for Scotland, NHS Scotland

<https://www2.gov.scot/Resource/0052/00528139.pdf>

Scottish Health Board Mainstreaming Report

Each Scottish Health Board produces a bi-annual Mainstreaming Report written by the in-house Equality and Diversity team. Each report contains further information on its work towards its **Accessible Information Policy**.

These reports are published on each Health Board website. Links to each Health Board can be found by visiting Health and Social Care Scotland:

<https://hscscotland.scot/hscps/>.

References

1. Accessibility of Health Information for Blind and Partially Sighted People, M. Thurston , A. Thurston and C. Henderson, RNIB Scotland, 2010 https://www.rnib.org.uk/sites/default/files/accessibility_healthcare_information.pdf
2. Your health, your rights – The Charter of Patient Rights and Responsibilities, Scottish Government, 2012 <https://www2.gov.scot/Resource/0040/00407723.pdf>
3. Registered Blind and Partially Sighted Persons, Scotland 2010, Scottish Government <https://www.gov.scot/publications/registered-blind-partially-sighted-persons-scotland-2010/>
4. Accessible Health Policy, NHS Health Scotland, 2018 <http://www.healthscotland.scot/media/1606/accessible-information-policy-v30.pdf>
5. Op cit, M. Thurston , A. Thurston and C. Henderson, RNIB Scotland, 2010 https://www.rnib.org.uk/sites/default/files/accessibility_healthcare_information.pdf
6. The interview questions are listed in Appendix 1 and form the section headings.
7. Making it Easier: A Health Literacy Action Plan for Scotland, Scottish Government, 2017-2025 <https://www2.gov.scot/Resource/0052/00528139.pdf>
8. See, for example, the case study on Hussein.
9. NHS in Scotland 2017, Audit Scotland https://www.audit-scotland.gov.uk/uploads/docs/report/2017/nr_171026_nhs_overview.pdf

10. Screen reading software, Technology resource hub, RNIB <https://www.rnib.org.uk/practical-help/technology/resource-hub>
11. Low Vision Software, Sight and Sound Technology
12. 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/>
13. The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018 <http://www.legislation.gov.uk/uksi/2018/852/contents/made>
14. 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>
15. Superfast broadband for Scotland, Audit Scotland 2018 http://www.audit-scotland.gov.uk/uploads/docs/report/2018/nr_180920_broadband.pdf
16. Op cit, The Royal Society of Edinburgh.
17. Ibid.
18. Website accessibility, RNIB <https://www.rnib.org.uk/rnib-business/website-and-apps/website-accessibility>
19. 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/>
20. Guiding a blind or partially sighted person, RNIB <https://www.rnib.org.uk/information-everyday-living-family-friends-and-carers/guiding-blind-or-partially-sighted-person>
21. Guideline on the readability of the labelling and package leaflet of medicinal products for human use, European Commission, January 2009 https://ec.europa.eu/health/sites/health/files/files/eudralex/vol-2/c/2009_01_12_readability_guideline_final_en.pdf
22. Impact report on Braille standard for medicine packaging, University of Birmingham and RNIB, July 2013 <https://www.rnib.org.uk/professionals/knowledge-and-research-hub/research-reports/reading-and-braille-research>
23. Patient Rights (Scotland) Act 2011, Scottish Government <https://www2.gov.scot/Topics/Health/Policy/Patients-Rights>
24. Your health, your rights – The Charter of Patient Rights and Responsibilities, Scottish Government, 2012 <https://www2.gov.scot/Resource/0040/00407723.pdf>
25. The questions are listed in Appendix 1 and form the section headings.
26. RNIB Learning Choices, RNIB <https://www.rnib.org.uk/rnib-business/business-services/training-services/rnib-learning-choices>
27. RNIB UK Training and Consultancy Services <https://www.rnib.org.uk/services-we-offer-learning-disability-services/uk-training-and-consultancy-services>

Contact us

For further information, please contact:

Laura Jones, Senior Policy Officer (Health and Social Care) on 07841 006 793 or email laura.jones@rnib.org.uk

Dr Catriona Burness, Parliamentary and Policy Manager on 07713 302 015 or email catriona.burness@rnib.org.uk

RNIB Scotland,
12 – 14 Hillside Crescent,
Edinburgh, EH7 5EA



facebook.com/rnibscotland



twitter.com/RNIBScotland

rnib.org.uk/Scotland