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Make it Make Sense

Inaccessible information: a health inequality





An ECLO advising a client

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Summary: Inaccessible healthcare information is putting patients with sight loss at risk

Blind and partially sighted people face unique challenges every day, and many are unable to access vital services, like healthcare, on an equitable basis.

Everyone has the right to access their own personal and confidential health information independently. This includes being able to read the details of an upcoming appointment, fill out a form at the GP surgery or read a test result or diagnosis.

It's been 13 years since the Equality Act 2010 put a duty on public bodies to proactively ensure that people's access and communication needs are met.

It has also been a decade since the All Wales Standards for Accessible Communication and Information for People with Sensory Loss (All Wales Standards) were introduced by the Welsh Government. The All Wales Standards set out the level of service delivery that people with sensory loss should expect when they receive healthcare. This includes receiving written information in accessible formats.

However, our research has found that personal and confidential information is consistently provided to blind and partially sighted people in a standardised, written format that they cannot read.

It shows:

- One in three (32 per cent) blind and partially sighted people have missed a healthcare appointment or had their healthcare affected because they did not receive information that they could read.
- More than half said they had received information about their healthcare from their GP (56 per cent) or hospital (54 per cent) in a format they could not read.
- Nearly nine in 10 respondents have never been asked by their GP or hospital about their communication preferences.

According to patients with sight loss, a lack of accessible communications in health settings is a barrier to:

- Making appointments
- Reading appointment confirmation letters
- Understanding consultations with healthcare professionals
- Finding out test results
- Receiving accessible information on discharge, medication instructions or their condition
- Using home screening kits
- Complying with advice and instructions for medication.

Inaccessible health information is a patient safety issue and can lead to poorer health outcomes. It also impacts people's right to privacy. In many cases, people with sight loss are forced to rely on others (friends, family members, even strangers) to read sensitive medical information for them, undermining their independence and compromising confidentiality.

It is unacceptable that these rights are consistently being denied to blind and partially sighted people. However, in some cases, the solutions are simple. For some this could be receiving information in an email or text – rather than a written letter – allowing them to use screen reader technology to read the information. For others, their requirement may be to receive letters in a larger font or braille.

There are also significant benefits in terms of improved health outcomes and reducing the number of missed appointments, saving valuable financial and staff resource in the NHS.

We are working to fully understand the practical barriers to recording and actioning required patient formats, as well as the steps needed to secure meaningful change for blind and partially sighted people accessing healthcare in Wales.

We need action now to make accessible healthcare a reality for blind and partially sighted people.



All RNIB leaflets and letters use a 14 point minimum size, often larger!

Our findings and key messages

A barrier to care, a cost to NHS Wales

Perhaps the most concerning finding from our research is that one in three (32 per cent) blind and partially sighted people have missed a healthcare appointment, or had their healthcare affected because they did not receive information in a format they could read.

This shows that inaccessible health information can be a significant barrier to receiving timely care and treatment.

One focus group participant told us they had been removed from an NHS waiting list because they failed to respond to a letter in time. The letter, which they were not able to read, told them to confirm in writing whether they still needed the appointment. It was only once they telephoned the hospital to ask why they had not heard about their appointment that they discovered they had been taken off the waiting list.

“When I realised I had missed an appointment, I felt frustrated and annoyed. I phoned the contact number and got an answering machine, so I left a message explaining that I couldn’t read the letter but have had no contact since. What do you do next?”

A waste of NHS Wales resources

As well as directly impacting people’s access to healthcare, missed appointments are also a waste of valuable NHS resources. Each missed outpatient or GP appointment costs the NHS an estimated £160. The latest available data for March 2023 shows that 734,721 patient pathways are waiting to start treatment. This amounts to 23.64 per cent of the total population of Wales (bit.ly/45YbhHs). With waiting lists at near record levels and demand far outstripping capacity, it is crucial that health services make the most of their available resource.

Ophthalmology is one of the busiest outpatient specialisms in the health service, accounting for nearly 12 per cent of all patients on the NHS Wales waiting list (bit.ly/43zzCBu).

A 2022 report by Audit Wales found that ophthalmology is one of the specialisms that will likely take far longer to recover than others because they were already hugely stretched before the COVID-19 pandemic (bit.ly/43oXGqK).

All ophthalmology patients will have experienced some degree of sight loss. With large numbers of people with sight loss waiting for treatment, it is vital that they can access the information they need. This will maximise their chances of making their appointment and enable them to manage their condition while waiting for treatment.

Latest available data from 2018-19 showed that 7.7 per cent of hospital outpatient appointments were recorded as 'Did Not Attend' (DNA) (bit.ly/3WTnwRt). However, this data was paused during the pandemic and has not resumed. This makes it difficult to know how addressing missed appointments could reduce waiting list backlogs. Our conversations with health boards suggest that DNA rates are now much higher than they were before the pandemic.

Up to date DNA data would help NHS Wales to understand the scale of the problem. Further work is needed to identify why people are missing their appointments, but our research clearly shows that inaccessible information is a key factor.

Improvements to patient communication could go a long way towards reducing wasted appointments and maximising the capacity of the health service, delivering the dual benefit of saving NHS costs and improving outcomes for patients.

Intrusive and dangerous: the impact of inaccessible health information

More than half of the people we surveyed have received information from their GP (56 per cent) or hospital (54 per cent) in a format they could not read. This has serious practical, health and emotional consequences.

A risk to patient safety

Inaccessible health information is contributing to deepening health inequalities and puts people at serious risk of harm.

Participants in our research told us that not being able to read their own health information is a huge barrier to making and attending appointments, understanding the results of a test, diagnosis or screening, complying with medical advice, taking medication correctly, and preparing for operations or other procedures.

One member of our patient panel told us that she could not read information about her repeat prescription so was not aware that her medication dosage had changed. She told us that "if it wasn't for my mum looking at the package and realising the dosage had actually gone up, then I could've ended up overdosing because I couldn't read it myself."

The impact on mental health and wellbeing

Blind and partially sighted people have told us about the frustration, anxiety and depression they have experienced as a direct result of not receiving their health information in a format they can read. Others told us that they felt as though they had lost their dignity, and were being treated differently, because of their sight loss.

“It plays on your mind. Why can’t I have my information? Why is it difficult? Why am I different? Why should I be different to anybody else?”

Another person told us: “It goes round in circles, and these become vicious cycles that then become worry cycles. It becomes more and more frustrating, leads to anxiety, depression, might lead hospital admissions, and then that has a cost impact on society.”

Compromising confidentiality and independence

Too many blind and partially sighted people are forced to rely on loved ones, or in some cases, strangers to read letters and complete forms for them.

A member of our patient panel told us that she had to ask her mother to read a letter detailing a referral to a mental health counsellor. This led to her mother becoming worried and questioning why it was happening. This experience left her feeling “embarrassed”, “humiliated” and that her right to make personal decisions independently and confidentially had been breached.

She said:

“I’ve always had someone with me, and it feels like [doctors think] ‘it’s all right, they’ll read it to you.’ Well, no it’s not. I’m an adult. It’s really intrusive. I now tense up immediately when my mum says I have a letter. I run through it in my head thinking: ‘have I got anything coming up that I don’t want her to see?’ She asks me if I want her to read it out and I’m thinking: ‘well it’s not like I’ve got any other choice’, because it’s in print.”

Why training and awareness matter

Nearly nine in 10 respondents have never been asked by their GP (88 per cent) or hospital (86 per cent) about their preferred method of communication and how they'd like to receive information.

"I have never been asked for my preferred format by my GP. I've been with them over 16 years."

These responses demonstrate a lack of understanding of the needs of blind and partially sighted people among frontline NHS staff. This is disappointing, as the 2018 Welsh Health Circular, (bit.ly/43dXhaN) mandated GPs to ensure effective capture and communication of patients' information needs between healthcare professionals.

Patients told us some of the reasons they have been given as to why they were unable to be communicated with in their preferred format. We have heard that health board staff are not always aware of blind and partially sighted people's rights to accessible health information, are not familiar with their duty to make reasonable adjustments or the All Wales Standards. Many reported being told that NHS IT systems lack the functionality to record and action required formats. Others said that health board staff cited GDPR and data security concerns as reasons they could not receive accessible communications.

"I've never had [information in my required format]. Whenever I've mentioned it, I've been told 'we'll look into it', 'we can't do that' or 'we've looked into it, but we can't do it because it's a security risk!'"

Most respondents indicated that staff were able to communicate well with them when they attended their GP surgery (88 per cent) or hospital appointment (82 per cent).

However, some described difficulties navigating around NHS buildings to find the correct department or the reception desk. Others were given instructions that require vision to be able to follow, such as asking for a reference number from a letter, having their name called out and being given no additional directions or being told their appointment is "in that room" or "over there".

One member of our patient panel told us that this was the result of medical professionals not understanding their needs: "You've got to explain yourself all the time to doctors when you do get to meet them. They don't seem to understand that you can't see. They're pointing at things or giving you leaflets... it means nothing to me at all."

Another member of the patient panel feels that they are treated differently by medical professionals because of their condition:

“If I take someone with me to help me find my way to a doctor’s appointment, they’re talking to them instead of talking to me. It can be quite frustrating, as you can imagine.”

Simple and cost-effective solutions

We asked 135 blind and partially sighted people to tell us what their required format is for receiving health information. Respondents were able to select more than one option.

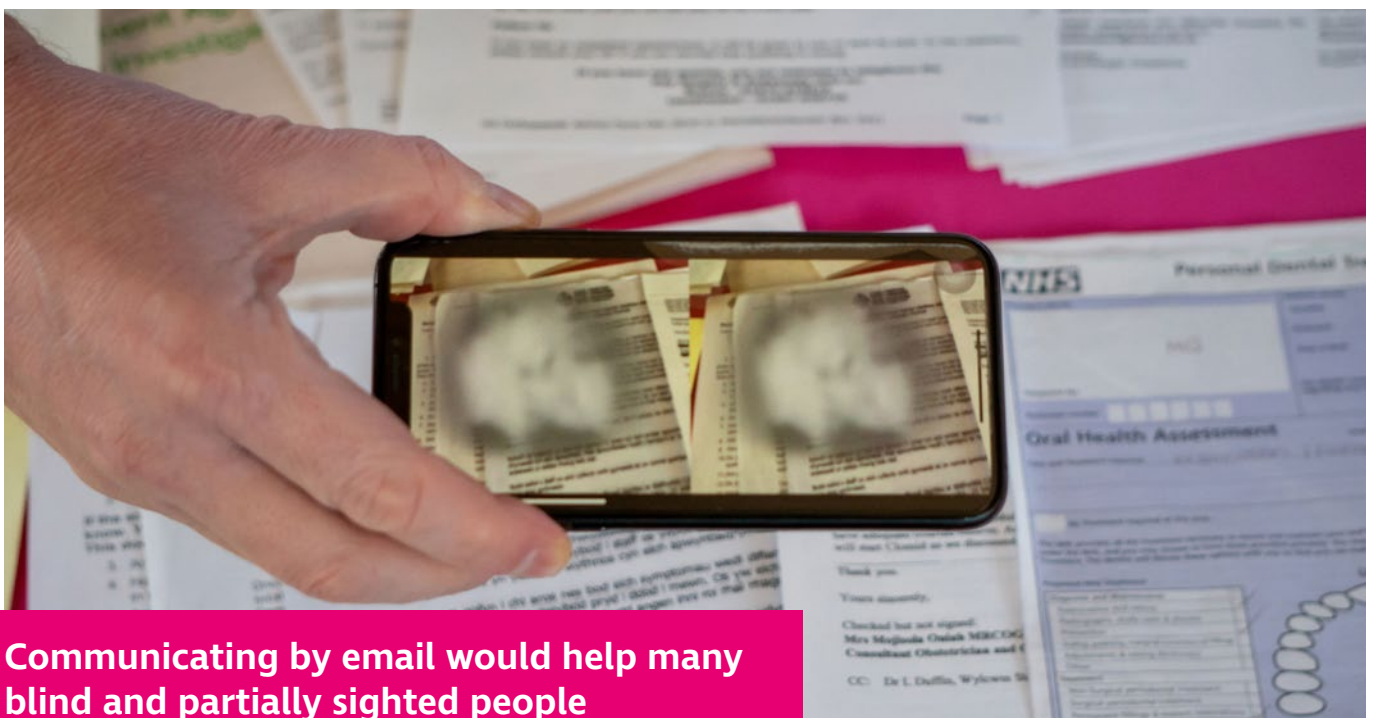
The most popular responses were:

- Email (79 respondents)
- Large print (78 respondents)

- Telephone (50 respondents)
- Text (44 respondents)

The two most popular answers, email and large print, are simple solutions that would allow a large number of blind and partially sighted people to access their information independently. Increasing the font size on letters and other written documents to size 14 or 16 could be implemented immediately and with little additional cost.

Likewise, if health board communication systems allowed patients to be sent information by email and text, this would save postage and printing costs, contributing towards net zero initiatives while improving accessibility. We know that some health boards do offer this level of service to their patients, but this is currently not a consistent offer across Wales.



Communicating by email would help many blind and partially sighted people

Our recommendations

We recommend that the Welsh Government

1. Works with NHS Wales on a national strategy to review, update and fully implement the All Wales Standards for Accessible Communication and Information for People with Sensory Loss (bit.ly/42hrPHp).
2. Appoints a dedicated Welsh Government Accessibility Lead to oversee the production of all key public health and other information in accessible formats, including implementation of and compliance with the All Wales Standards.
3. Uses the upcoming incorporation of the United Nations Convention on the Rights of Disabled People (UNCRPD) into Welsh law to guarantee the rights of disabled people to receive information on an equal basis through the format of their choice.
4. Ensures that health service IT systems have the functionality to automatically and routinely record and action a patient's required format, for example sending an email, text, a large print letter or braille.
5. Recommence the publication of data on the number of appointments recorded as 'did not attend', disaggregated by health board and specialism.

We recommend that NHS Health Boards and Trusts in Wales

1. Accelerate action to fully review and implement The All Wales Standards, including ensuring they are monitored and reported on.
2. Appoint named senior leads to hold responsibility for the implementation and compliance with The Standards.
3. Initiate a campaign to raise awareness among patients with sensory loss of their rights to reasonable adjustments within healthcare settings. This should include raising awareness of the complaints procedures.
4. Review their complaints, concerns and reporting methods to ensure that these systems are accessible, and that people can easily access information about how to report concerns and complaints.
5. Ensure all relevant staff are given the necessary training to understand the communication and information needs of people with sensory loss, as well as how to record and action required formats.

Policy and legal context

■ All Wales Standards

The Welsh Government introduced All Wales Standards in 2013 to ensure that the communication and information needs of people with a sensory loss are met when accessing healthcare services.

Every Health Board and NHS Trust in Wales is required by the standards to develop an implementation plan that is led by a designated senior officer and sets out clear timescales and actions for delivery.

■ Equality Act 2010

Under the Equality Act 2010 public services, including health and social care providers, have a responsibility to make sure that disabled people can access services on an equal basis to non-disabled people. This is known as the 'duty to make reasonable adjustments.'

This duty is 'anticipatory', meaning that service providers should anticipate what adjustments disabled people are likely to require and make adjustments in advance, rather than waiting for a person to experience and report the disadvantage.

For example, rather than waiting for a blind or partially sighted person to report that they are receiving important medical information in a format they are unable to read, health providers should anticipate this need and take steps to ensure that they proactively provide information in an appropriate accessible format.

Successful legal challenges to inaccessible information

Leadbetter (2021) v Department of Health and Social Care (bit.ly/3oFQgQW).

In March 2021, Sarah Leadbetter, who is registered blind, brought a judicial review against the UK Government Department of Health and Social Care (DHSC) for failing to provide her with accessible shielding information.

Ms. Leadbetter had a number of health conditions which meant she was considered clinically extremely vulnerable to COVID-19. Throughout the pandemic, she received four hard copy letters from DHSC containing vital information that she needed in order to keep herself safe. She was not able to read any of these letters independently and only discovered that she was on the shielded patients list after her mother read the letters for her.

Sarah argued that a failure to provide accessible shielding correspondence to blind and partially sighted people was unlawful disability discrimination, a breach of her human rights, and a failure to comply with the UK Government's own Accessible Information Standard.

Sarah's case, which was supported by RNIB and the Equality and Human Rights Commission, was settled out of court. The DHSC agreed to review its practice of sending hard copy letters to patients that are not individually tailored to their communication preferences and to commission work to improve their patient communication systems.



Sarah Leadbetter, who is registered blind, brought a judicial review against the UK Government

United Nations Convention on the Rights of Disabled People (UNCRPD)

Effective and appropriate communication is fundamental to ensuring services are delivered in ways that uphold the rights of disabled people and promote the values of dignity and respect.

The UNCRPD provides the international standard for protecting and upholding the human rights of disabled people. The UK ratified (agreed to follow) the Convention in 2009.

Article 21 of the Convention calls on states that have ratified the UNCRPD to take all appropriate measures to ensure that disabled people can exercise the right to freedom of expression and opinion. This includes the right to receive and impart information on an equal basis

with others and through all forms of communication of their choice.

In practice, this means providing information in a person's required accessible format in a timely manner and without additional cost to them.

The United Nations Committee on the Rights of Persons with Disabilities (the Committee) periodically monitors how well the UNCRPD is being put into practice in the countries that have signed up to it. In the most recent review of the UK (which includes the devolved governments of Wales, Scotland and Northern Ireland) the Committee raised concern that public services do not provide enough accessible information, and that legal standards for ensuring the accessibility of communications are insufficient (bit.ly/3POS2XL).



Committee on the Rights of Persons with Disabilities, Geneva. Photo by Violaine Martin

Methodology

Between December 2022 and January 2023, we surveyed 135 blind and partially sighted people from all over Wales about their experiences of receiving information from their GP and hospital services. Respondents were asked questions about their demographic profile, including their age, disability, ethnicity and health board area. We also asked them about their language and communication preferences and whether they used the internet.

This was a self-selecting online survey advertised through email and social media. But we know that people with sight loss are twice as likely to be digitally excluded when compared to the general population. To attract participants who may be digitally excluded, we also partnered with Sight Life, a charity that provides a wide range of local services to blind and partially sighted people across most of South Wales.

Sight Life promoted the survey through their own networks and supported people who attended in-person events to complete the survey. As a result, our survey has a higher uptake from the South Wales population. Of the 135 total responses, 97 lived in the Cardiff and Vale, Cwm Taf or Aneurin Bevan health board areas. However, there were respondents from every health board in Wales.

Of those who took part in the survey, 46 per cent are blind and 53 per cent are partially sighted people. 27 per cent are deaf or hard of hearing in addition

to being blind or partially sighted. Two respondents did not indicate their level of sight loss.

People who took part in our survey were less likely to be internet users. 76 per cent reported using the internet compared to 92 per cent for the general UK population. They were less likely to be Welsh speakers. 12 per cent of respondents were Welsh speakers, compared to 17.8 per cent of the Welsh population.

Our survey was somewhat representative of the ethnic demography of Wales. 94 per cent of respondents described their ethnic group as white, compared to 93.8 per cent of the Welsh population. 3.7 per cent of respondents were of mixed ethnicity, compared to 1.6 per cent of the Welsh population and 2.2 per cent were Asian or Asian British, compared with 2.9 per cent of the Welsh population.

Our survey is also more representative of working age blind and partially sighted people. While around a fifth of the general population of blind and partially sighted people are of working age, 48 per cent of respondents to the survey were under 65 years old.

We also hosted a focus group to provide additional qualitative insights to supplement the survey findings in more detail. During the focus group, we asked six blind and partially sighted people to discuss their experiences in more detail in order to build our understanding. We also asked them to share their ideas for potential solutions. Findings and quotes from this session have been included in this report.

Contact us

If you have questions, or want advice, just get in touch with RNIB Cymru and we'll do our best to help.

RNIB Cymru

Jones Court, Womanby Street,
Cardiff CF10 1BR



CymruCampaigns.Mailbox@rnib.org.uk



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