



# IGNORED: IGNORED: THE FIGHT FOR ACCESSIBLE HEALTHCARE

2025 POLICY REPORT WALES



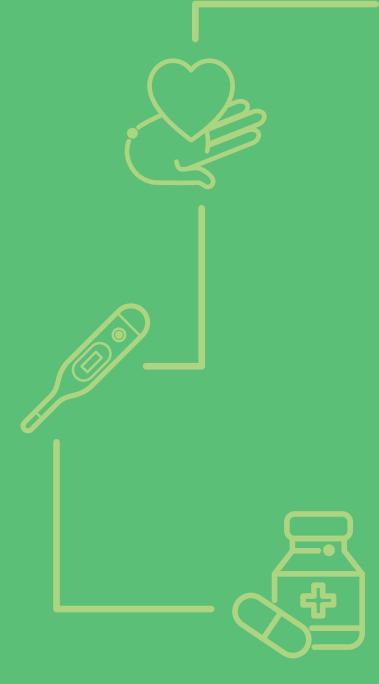
Supporting people who are deaf, have hearing loss or tinnitus



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about access to healthcare



## Introduction

Equal access to healthcare is a human right. Yet for too long, deaf people and people with hearing loss have been failed by an NHS that regularly neglects their communication needs.

In this report, we demonstrate how NHS Wales services are failing to meet the communication needs of people who are deaf or have hearing loss, and still lack the systems and processes needed to fulfil people's right to access healthcare. This means that people who are deaf or have hearing loss face significant barriers to healthcare, from being unable to book a GP appointment, to not understanding what is happening to them in emergency care.

This is despite the introduction of Standards in 2013 that aim to address this inequality and set out the standard of care that people with sensory loss should receive. The All Wales Standards for Accessible Communication and Information for people with Sensory Loss (referred to throughout as the All Wales Standards or AWS)1, were developed in conjunction with organisations representing people with sensory loss specifically to tackle these issues, but more than a decade on, little has changed. This treatment also goes against the rights set out in various legislation including the Equality Act 2010<sup>2</sup>, and the principles of the Wellbeing of Future Generations (Wales) Act 20153.

Our new research looks at the experience of deaf people and people with hearing loss in Wales trying to access the NHS, as well as the NHS staff who provide those services, to understand where the barriers lie.

80%
f natients surveyed said they

of patients surveyed said they are not aware of the All Wales Standards.

**73**%

still say they have never been asked about their information or communication needs

Only 1 in 5

(18%) agreed that their information and communication needs needs are met more often now than a decade ago

The impact of unequal access is devastating and can have significant consequences, not just on the healthcare and treatment patients receive, but also on patients' understanding and autonomy over their own health. This is a patient safety issue that means deaf patients and patients with hearing loss are too often unable to make informed decisions about their own healthcare, placing them at significant risk of harm. This also directly contradicts Welsh Government priorities of improving equal access to healthcare and taking a prevention-based approach to improving health and wellbeing.

This is happening because NHS Wales is failing to prioritise accessible care, including the digital and physical infrastructure needed to record and meet patient needs, and the training and awareness for NHS staff to ensure deaf people and people with hearing loss have equal access to care.

This is not a small or niche issue. 1 in 3 people in Wales are deaf or have hearing loss (more than 900,000 people), and we

estimate that at least 300,000 of those have a degree of hearing loss where they are likely to require adjustments be made in healthcare settings, or at the least, for staff to act with a good level of deaf awareness. We estimate that 60,000 people would not be able to hear most conversational speech. With an ageing population, this figure is set to increase, so NHS Wales must be prepared to meet these needs.

There are also estimated to be between 4,000-7,200 British Sign Language (BSL) users in Wales.<sup>4</sup> Deaf BSL users often experience language deprivation at an early age, which can lead to difficulty understanding and using written English or Welsh. This means that many deaf BSL users face significant communication barriers and may rely on interpreters or translators to communicate with hearing people. But we know that these needs are not always met, as highlighted in our report.

A failure to meet the communication needs of people who are deaf or have hearing loss across the NHS is a breach of the Equality Act and a form of discrimination.



4Bowen, R., & Holtom, D. (2020). Independent Review of BSL Provision for Adults in Wales (Government Social Research No. 4/2020). Welsh Government. https://www.gov.wales/sites/default/files/statistics-and-research/2020-01/independent-review-of-bsl-provision-for-adults-in-wales.pdf

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This means that NHS Wales is systematically discriminating against people who are deaf or have hearing loss. This is a hidden scandal. It's time to end that scandal.

Some progress has been made in recent years. Welsh Government has committed to a review and revision of the All Wales Standards, working closely with organisations supporting people with sensory loss and NHS Wales delivery partners to shape this work, which is ongoing. However, timeframes are unclear, and change is urgently needed to end the unequal access to NHS Wales services. Welsh Government and NHS Wales must act now to end the discrimination.

It's time to ensure that people who are deaf or have hearing loss have full access to NHS Wales services and are empowered to manage their own physical and mental health.

### RECOMMENDATION



Welsh Government must publicly restate their commitment to the ongoing work to revise, strengthen and enforce the All Wales Standards, and publish the Action Plan with clear timeframes.

# The legal right to accessible healthcare in Wales

Deaf people and people with hearing loss have a legal right to accessible healthcare, underpinned by various legislation.

This right entitles patients to have reasonable adjustments made to deliver equal access to health and social care to remove barriers people face. These can include providing information in an accessible format, communicating in a different way – for example via email rather than telephone – or providing professional communication support, such as a qualified British Sign Language (BSL) interpreter.

This is an anticipatory duty, requiring NHS Wales to be proactive in making adjustments to meet patients' needs. Failure to make reasonable adjustments is classed as discrimination and is against the law.

In Wales specifically, there is additional legislation and guidance which further enforces patients' legal rights to accessible healthcare, including the principles of the Wellbeing of Future Generations Act 2015, the Health and Care Quality Standards<sup>5</sup>, the Welsh Government's commitment to incorporating the UN Convention on the Rights of Persons with Disabilities<sup>6</sup> into Welsh Law, and the All Wales Standards.

The All Wales Standards for Accessible Communication and Information for People with Sensory Loss were specifically developed and introduced in 2013 to tackle barriers to accessing care. These came about as the result of a report into Accessible Healthcare for People with Sensory Loss in Wales, convened by experts across health and social care, alongside Welsh Government, NHS Wales, Healthcare Inspectorate Wales (HIW), and charities including RNID (Formerly Action on Hearing Loss Cymru), RNIB

Cymru and Sense Cymru.

Additionally, in 2018, Welsh Government also embedded the NHS England Accessible Information Standard (AIS), to ensure effective capture and communication of sensory loss communication and information needs between NHS staff in Wales.

The AIS sets out how the communication and information needs of patients with sensory loss should be recorded. This Standard was issued via a Welsh Health Circular to all NHS bodies, health boards and trusts that commission or provide health services.

However, guidance on the Public Health Wales website itself states that "The success of the Accessible Information Standard will largely rely on the awareness of GP practices of their responsibility to capture and record this information, and the willingness of patients to share their communication needs with their surgeries."

In our timeline, we have highlighted the key legislation, guidance, reports, campaigning activity, progress and setbacks relating to improving access to healthcare for deaf people and people with hearing loss in Wales that have taken place throughout the last decade and more.

Further expansion into the legislative and policy context of access to healthcare for deaf people and people with hearing loss in Wales can be found at the end of this report in Annex 1.

Despite the introduction of the All Wales Standards in 2013, the AIS being mandated in Wales in 2018, and the pre-existing underpinning legislation, our research in 2025 continues to show that awareness of, and compliance with the Standard is limited. This means that deaf people and people with hearing loss in Wales are continually being failed by inaccessible NHS services and are facing the same barriers as they did more than a decade ago.

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### **Timeline of the All Wales Standards**

### 2010-

The Equality Act is passed, requiring health services to make reasonable adjustments for patients to ensure equal access to care.

### 2012

Welsh Government establishes a Task and Finish Group to take forward the report's recommendation.

### 2014

RNID (then Action on Hearing Loss Cymru) alongside RNIB Cymru and Sense Cymru publishes the *One Year On* report initially assessing the impact of the introduction of the All Wales Standards.

### 2020

The Welsh Parliament Equality and Local Government Committee inquiry into Covid-19 found deficiencies in the provision of information and guidance in accessible formats. Their report called for the appointment of an Accessibility Lead within Welsh Government to oversee production of all key public information in accessible formats.

### 2023

 Welsh Government convene workshops to understand barriers to implementation, and begin work to revise and review the All Wales Standards in response to our campaigning.
 The Minister for Health and Social Services approves the Action Plan developed by the All Wales Standards workshops.

### 2023-24

Work to revise the All Wales Standards and deliver the accompanying Action Plan is paused due to budget pressures.

### 2011

The Accessible Healthcare for People with Sensory loss in Wales report recommends the development of an Accessible Information Policy for all health boards.

### 2013

- The All Wales Standards for Accessible Communication and Information for People with Sensory loss are developed and published.
- The All Wales Sensory Loss Senior Officers Group (Standards Steering Board) is established.

### 2018

- The Centre for Equality and Human Rights publishes its first report on implementation of the Standards.
- Welsh Government issues a Welsh Health Circular to all health boards mandating compliance with the NHS England Accessible Information Standard and introducing technology to flag communication needs on a patient record. At the same time, a plan for roll out across all GP surgeries in Wales is published.

### 2022

- The Welsh Parliament Health and Social Care Committee reinforced the 2020 call in their 'Waiting Well' report.
- Welsh health boards ceased their annual RAG rating of their implementation of the Standards. All health boards but one were rated as not meeting the Standards at this time
- RNID and RNIB Cymru write to then Minister for Health and Social Services, Eluned Morgan MS, to express concerns about this end to reporting and call for urgent action.

### 2024

Work to revise and effectively enforce the Standards resumes.

### The research

This is not the first report of its kind. RNID has previously and consistently published research and evidence about the severe impact of the NHS' failure to provide accessible healthcare. Just a year after the introduction of the All Wales Standards (2014), RNID assessed the immediate impact. Of the 120 people with sensory loss surveyed across Wales, the vast majority were not feeling any change<sup>8</sup>:

- 91% of patients were not aware of any improvements in the way healthcare services communicate and share information with them.
- Only one in five patients had been asked about their communication and/or information needs by healthcare services across both primary and secondary care.
- More than half (58%) said that they did not know how to report a concern or complaint.

Concerningly, more than 10 years on, only 15% of our survey respondents agree there has been any improvement in how often they are **asked** about their information and communication needs compared to a decade ago, and only 18% agree that these needs are **met** more often now than a decade ago.

In this report, we set out the findings of our new research on the experience of patients who are deaf or have hearing loss, and the perspective of NHS Wales staff who deliver care.

The survey of people who are deaf or have hearing loss had a sample size of 106 people who live in Wales, of which 18% said sign language is their main or preferred language.

The data was collected between 13th November 2024 and 20th January 2025.

A survey was also conducted with NHS staff in Wales. Given the low response rate and small

sample size of n=47, we would urge that this data is treated with caution as it is not representative of the views of NHS staff across Wales. We did, however, feel it was important to share the data collected, despite the small sample size, to provide a snapshot of some of the experiences and concerns of those who provide care for people who are deaf and have hearing loss.

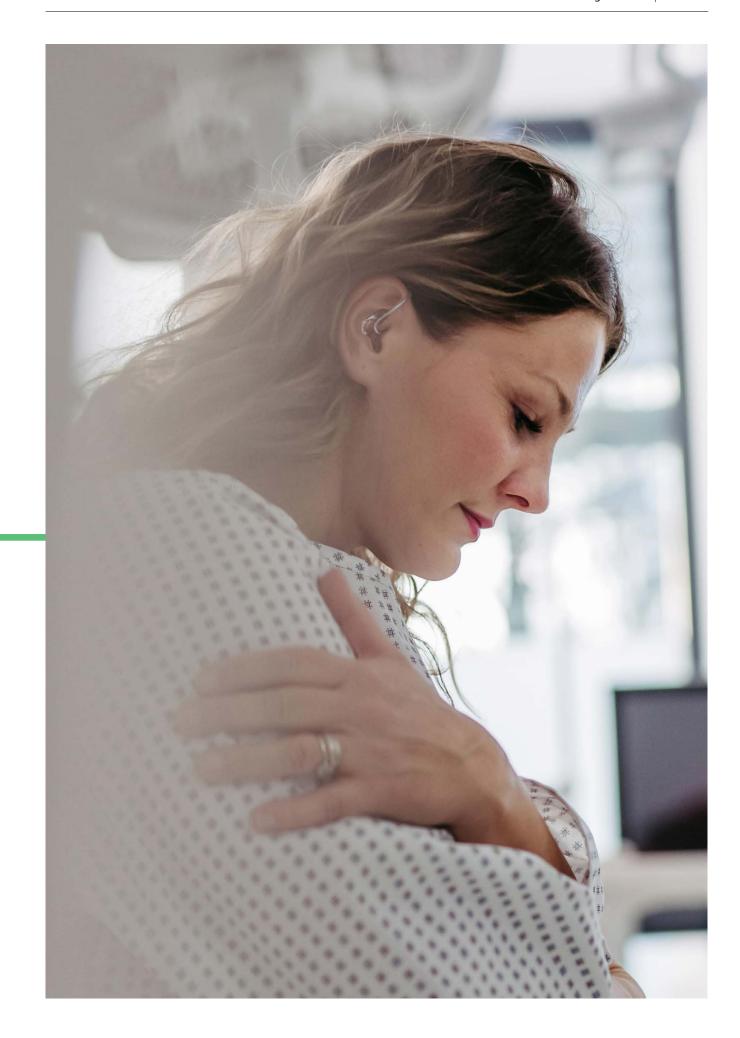
More than 10 years on...



agree they are asked about their information and communication needs more often.



agree that these needs are met more often now.



# Research findings

#### Awareness of All Wales Standards and access to GPs

Our survey of patients who are deaf or have hearing loss paints an extremely worrying picture: **80% said they are not aware of the All Wales Standards.** 

One third (30%) report still not being able to contact their GP in a way that's accessible to them but 44% said their GP does not contact them in a way that's accessible to them, this shows a contrast in accessibility when contacting or being contacted by a GP. This suggests that perhaps initial steps have been taken to improve accessibility, for example, by making contacting a surgery accessible, but not embedding this change for on-going communication, so GP's themselves continue to contact patients in inaccessible ways.

"There is still a lack of understanding and empathy. No clear masks, no checking of understanding. Little patience, there is more awareness of deafness but usually an assumption is made on the need for sign."

- Female, 55-64

In terms of patient confidence, 42% do not feel confident contacting their GP. And only 56% said they have left NHS appointments feeling they had fully understood the information they were given about their health – 38% have not.

Only 55% said they have left NHS appointments with a clear understanding of the outcome and next steps – 37% do not.

Despite the All Wales Standards and guidance which have been in place for more than a decade, 73% still say they have never been asked about their information or communication needs.

Similarly, 74% say that NHS staff have either never, or have rarely, been made aware of their information and communication needs before meeting with them; almost half (48%) said they are never made aware. Shockingly, only 4% of patients said NHS staff are always made aware before meeting with them.

still say they have never been asked about their information or communication needs.

74%

say that NHS staff have either never, or have rarely, been made aware of their information and communication needs before meeting with them.

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"All I want is to be able to text message my surgery when I want an appointment. I want them to read the text message, reply and give me an appointment - it appears to no longer happen although it did used to happen, so the service has got worse."

#### - Female, 65-74

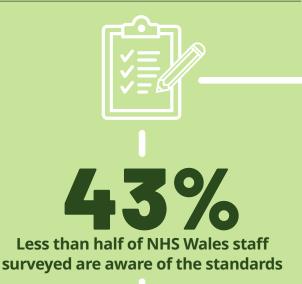
Among the small sample of NHS Wales staff we surveyed, levels of awareness of the All Wales Standards (AWS) are mixed – with less than half (43%) saying they are aware, and the same proportion saying they aren't, with a further 14% saying they don't know. Only 45% say they understand how it applies to patients and their needs and only half (50%) say they understand how the All Wales Standards applies to their job role.

More positively, 81% of NHS staff say they know how to find out if a person has communication needs, while only 2% disagree. However, we must be cautious about this figure given the significant contrast in the experiences reported by deaf people and people with hearing loss. Further investigation is needed into this disparity to understand why, if NHS staff are aware of how to access this information, they are either not doing so or why it is not translating into improving patient care.

These experiences reveal that patient communication needs are not being recorded, flagged or met as they should be, and that staff awareness of the AWS is low, despite guidance being introduced in 2013, and digital infrastructure to enable this being issued in 2018. Patients are being failed at their first checkpoint with the NHS Wales, and communication barriers affect them immediately when accessing care.

Unfortunately, this is just the beginning of the barriers people who are deaf or have hearing loss face accessing NHS Wales services.

This results in dangerous gaps in patients' understanding about their care and treatment. A third (34%) said they have experienced barriers when being told about medication or treatment, 31% when understanding the outcome of an appointment, 30% when being given a diagnosis, 28% when receiving information about a referral, and 35% when receiving test results.



### RECOMMENDATIONS



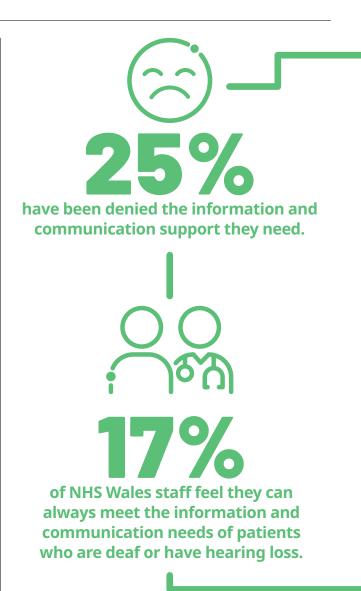
- NHS Wales must review staff awareness and understanding of their duties under the All Wales Standards and Accessible Information Standard.
- Welsh Government must undertake a communications campaign to promote patients' legal rights and the standard they should expect when accessing NHS services.

# Communication support

However, barriers to access extend beyond the physical environment and appointment booking systems. Many deaf people and people with hearing loss require communication support to access NHS services. This can vary significantly from person to person; it can include basic deaf awareness, such as clinicians facing the patient while speaking, removing face coverings and speaking slowly; to accessing communication support professionals. Concerningly, one in four patients (25%) have been denied the information and communication support they need.

Almost one in five of our survey respondents need a communication support professional to be present to access a GP or hospital appointment, and the most common form of support professional required is a BSL interpreter. However, other support professionals mentioned included notetakers, speech to text reporters (STTRs), lip speakers and others. While the sample of those requiring communication support professionals is too small (n=19) to report in depth, our results show consistently poor experiences. These include:

- Communication support professionals not being provided at appointments as requested.
- Patients not receiving any information about their communications professional ahead of the appointment, including whether the booking was confirmed or not.
- Communications support professionals not showing up at appointments, despite bookings.



"Even though interpreters are booked, they do not always turn up. Also, when they do turn up, they often turn up at the same time as the patient, so there is no time to discuss what the appointment is for or some of the questions that we might ask."



This poor provision of communication support could be down to several points of failure: lack of NHS staff understanding and awareness; issues in communication with interpretation services; or, poor systems in place to book communication support.

Indeed, NHS staff understanding of how to record, flag and meet patient needs, including the provision of communication support, is poor: only 57% know how to record a patients' communication needs, and less than half (48%) know how to add a flag to a patient's online record to make others aware of a patient's communication needs. While nearly two thirds (62%) say they know how to book communication support for a patient, such as a BSL interpreter. There is also a worryingly low figure (17%) of NHS staff feeling they can always meet the information and communication needs

of patients who are deaf or have hearing loss.

As a result of these negative experiences, most people said they would prefer to book their own communication support rather than rely on the NHS provider to do this for them, to give them greater control, information and certainty ahead of their medical appointments or treatment. However, some feel strongly that this is not their responsibility as a patient.

Booking of interpreters for NHS Wales appointments and care is provided by Wales Interpretation and Translation Service (WITS), which initially held a contract with Cardiff Council, and was then extended to a pan-Wales service. WITS is not a specialist provider of communication support for people with hearing loss - they also provide interpreters and translators for foreign languages, in addition to BSL interpreters.

### **RECOMMENDATION**



 Review the way communications support is provided to NHS Wales Services through WITS, working with people who use this service and organisations who represent them to understand how this service can be improved.

# The impact of barriers to accessing healthcare

The impact of NHS Wales failing to provide accessible communication and information to patients who are deaf or have hearing loss means that 56% have had to rely on either a partner, children, family or friends to interpret or relay information for them at an appointment. This introduces risk, as most of these individuals, despite best intentions, will not be qualified to convey complex medical information and ensure it has been understood and received as intended. Moreover, it is an affront to a patient's privacy, dignity, and right to ownership of their own health and care.

56%

have had to rely on either a partner, children, family or friends to interpret or relay information for them at an appointment.

"I have to take my husband with me all the time. This has destroyed my confidence and independence and to be honest deters me from seeing the doctor unless I really have to."

- Female, 55-64

The knock-on impact is also a loss of faith and trust in NHS services – 21% say they have lost trust in NHS staff as a result of a lack of accessible communication, and this has real implications for how individuals prioritise their health and care. A quarter (25%) say they have avoided seeking help for a new health concern, or pursuing follow up or review appointments (24%).

21%

say they have lost trust in NHS staff as a result of a lack of accessible communication.



"I went to A&E for chest pain issues a few years ago. Staff there didn't know how to book an interpreter and were rude to me when I tried to ask for one. I made a formal complaint, but they never followed it up. I lost trust in the complaints process and don't bother with complaints anymore."

- Female, 35-44, Sign Language User

This results in significant risks to patients' health and wellbeing. Almost one in five (18%) said a health condition was made worse due to this lack of accessible communication, and 11% feel their health was put at risk. Almost one in 10 (8%) said they have even avoided calling an ambulance or attending A&E as a result. This demonstrates a complete failure of NHS Wales services to provide an equal quality of care for deaf patients and patients with hearing loss, going against the legal standards patient should expect.

said a health condition was made worse due to this lack of accessible communication.

"I previously met a consultant to discuss a cochlear implant. They refused to provide a captioner and I struggled to hear the information provided. I had to request detailed notes, and it took 6 months for them to arrive. I did not go ahead with the cochlear implant at that time because I felt I didn't have full access to ask questions and get answers that I needed."

# **Unequal access**

When asked to consider the equality of their experience of healthcare, nearly half of people (47%) agree that it is harder for them as someone who is deaf or has hearing loss to maintain good physical health because of a lack of accessible communication. And more than half (57%) agree it is more difficult for them to maintain good mental health and wellbeing. This is particularly worrying given that Wales is the only UK country without a specialised deaf mental health service.<sup>9</sup>

In some situations, it seems that barriers to accessing health and care could exacerbate individuals' poor mental health and wellbeing, with more than half (53%) of patients saying they find it stressful to access NHS services because they have to fight for their communication needs to be met.

There is a clear view amongst deaf people and people with hearing loss in Wales that they do not have the same access to the NHS as hearing people (48% do not think they have the same access as hearing people), and only a quarter (26%) agree that deaf people and people

with hearing loss are treated fairly by the NHS.

Despite the clear negative impact unequal access to healthcare has on deaf people and people with hearing loss, levels of NHS staff training are low. This includes training on how to support patients who are deaf or have hearing loss, deaf awareness training, or training specifically on the All Wales Standards.

More than half of NHS Wales staff we surveyed (56%) said they have not received any training on either the All Wales Standards, on how to support patients who are deaf or have hearing loss, or training on deaf or hearing loss awareness.

do not think they have the same access as hearing people.

"As a D/deaf member of staff with a cochlear implant this is a very important topic. I do feel the NHS could do a lot more with the resources available such as Relay UK - we know about it but can't cross the line on getting it approved for use. Staff awareness, more training needs to be done."

- Allied Health Professional

"It is infuriating that hospitals lose people's hearing aids when they are inpatients. Staff are not trained to routinely check and clean hearing aids; in fact, I doubt they get any training on this at all."

- Allied Health Professional

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Our survey respondents included staff from different parts of NHS Wales, as poor access to healthcare is an issue deaf people and people with hearing loss suffer across the whole of the NHS.

"Within wider healthcare and healthcare organisations, there is a lack of awareness of the impact of these issues, leading to the potential for unmet needs and possible unsafe care. More needs to be done to raise awareness of the impact, improve compliance and accountability and ultimately reduce the risk of poor care"

- Healthcare Scientist

It is crucial that this is not viewed as the responsibility of one part of the NHS or for one department, but as a whole system challenge that needs a whole system approach to improvement.

### "We need a whole staff approach to sensory losses and its importance"

- Healthcare Scientist



# **Complaints**

These barriers persist even through the complaints process, where patients should be able to express their concerns and dissatisfaction with their treatment. 20 people told us they had made a complaint and, of those, only half found the process to be accessible.

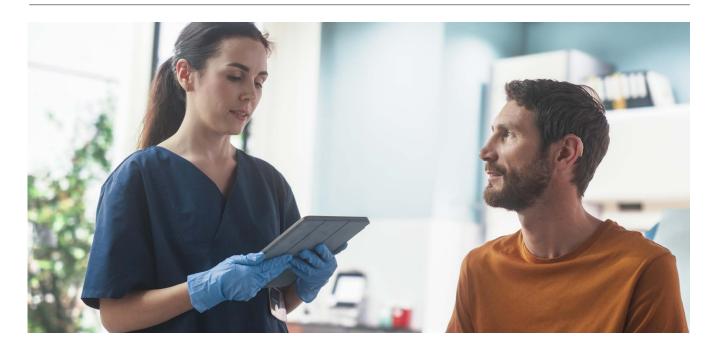
A further 42 people decided not to make a complaint despite having good reason to. RReasons for this include: they didn't think the complaint would change anything (26 out of 42); they didn't think the complaint would be taken seriously (18 out 42); didn't know how to complain (7 out of 42); or, the process was not accessible as someone who is deaf or has hearing loss (5 out of 42).

It's also important to note the double burden many patients face; many cannot complain, or have a negative experience of complaining, about lack of access to NHS services, due to the complaints process being inaccessible. One patient highlights this succinctly:

# "I don't know what the outcome [of my complaint] was because they tried to call me then never emailed or texted so I couldn't find out."

- Female, 25-34, sign language user

This will also be affecting decision-makers' awareness of the scale and urgency of this problem. If issues accessing NHS Wales for deaf people and people with hearing loss are widespread, but patients either cannot or are not motivated to complain, this information is being lost and cannot inform decision-making.





The severity and scale of this problem, and the impact that poor access to healthcare has on deaf people and people with hearing loss must not be overlooked or understated.

However, while the impact of poor access to healthcare is significant; the changes needed to make improvements do not have to be. While there is a need for larger-scale changes, including with digital infrastructure, the smallest changes – like staff being more deaf aware, taking time to check a patient has understood or has everything they need in order to understand – can make a substantial difference.



"I had major surgery recently and not once was I given support during the whole experience. I think it's because they thought I could hear and understand. I had no idea I had nearly died until a family member told me."

- Male, 45-54, sign language user

### **RECOMMENDATION**



NHS Wales must work with Welsh Government and the Public Services
 Ombudsman to review the NHS complaints procedures, including the Putting
 Things Right guidance and the Once for Wales Concerns Management
 System and make changes to ensure accessibility for patients who are deaf
 or have hearing loss.

## Conclusion

The findings of this report suggest a routine failure by NHS Wales services, including health boards, to meet the needs of people who are deaf or have hearing loss. This includes failing to meet key requirements through the All Wales Standards, AIS and Equality Act to record and meet people's communications needs across NHS Wales systems, and make the necessary adjustments to meet those needs.

This finding is not a new one. Multiple reports, by RNID, other charities, public bodies, Welsh Government and Senedd committees, have highlighted these issues and added to the wealth of evidence about the scale of this problem. We expand on some of these in the annex and highlight their calls for change, many of which mirror our own. Despite this, progress has been extremely limited. We cannot continue this way. We cannot allow the same barriers that deaf people and people with hearing loss experience when accessing NHS Wales to persist for another decade or more.

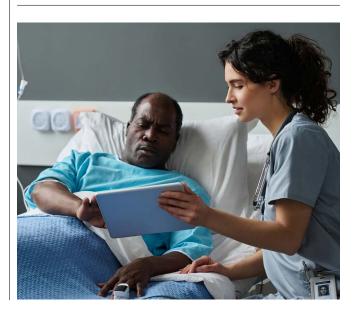
Welsh Government has made clear its commitments to equal access to healthcare, a prudent approach to delivering NHS Wales care, and a preventative approach to improving the health of people in Wales. The evidence we have highlighted demonstrates how NHS Wales is actively undermining these Welsh Government priorities. The lack of compliance with, and effective enforcement of, the Standards and other legislation over the past decade is contradicting and threatening progress to the Welsh Government's commitment to improve the wider and wellbeing of people in Wales. The issue must be addressed now.

Throughout this report, and highlighted at

the end, we make a series of recommendations to Welsh Government, NHS Wales and other public bodies to improve access to healthcare for deaf people and people with hearing loss.

Despite the extremely worrying picture, there are powerful opportunities for change, and progress is already underway through the work of the Welsh Government Accessible Communications Implementation Group, as well as areas of good practice across Wales. But we are clear that strong leadership and a renewed commitment to the urgency of tackling this issue is needed to drive progress and maintain the engagement of all relevant stakeholders to deliver the change needed.

Improvements to digital infrastructure and technology must also be central to this process, with this being a clear priority for Digital Health and Care Wales (DHCW). Improvements to the patient record, and the ongoing development



and expansion of features on the NHS Wales App must also prioritise work to ensure the needs of deaf patients and patients with hearing loss are recorded, flagged and met in healthcare settings. Further consideration is needed of how this can be prioritised in the DHCW workplan and what functionality can be explored to, for example, request communications support and record the details of any booking in-app. Patients with lived experience must be included in the development of these plans, and we must also ensure there are mechanisms to meet the communication needs of people who are digitally excluded.

Lack of training fo for NHS Wales staff has also been a core theme throughout this work. As set out in the ongoing Action Plan to revise and renew the All Wales Standards, we would like to see mandatory training for NHS staff on deaf awareness and on the Standards themselves. There are many examples of good training that exists already across Wales, including an online deaf awareness training course developed specifically for nurses by Dr Julia Terry at Swansea University. This existing training needs to be mapped in order to explore opportunities for roll out across Wales as well as any gaps for additional training.





### RECOMMENDATIONS



- Improving access to NHS Wales should be a central priority in Digital Health and Care Wales' (DHCW) workplan, including improving digital infrastructure; like the patient record, the NHS Wales app, and other IT to ensure NHS staff have the resources and information needed to provide accessible care.
- DHCW must explore whether digital systems, including the NHS Wales app for example, could include the functionality to request communications support at appointments, and for information regarding bookings to be recorded in-app.
- DHCW must consult and engage with people who are deaf or have hearing loss and require communication support to inform these plans.
- Welsh Government and NHS Wales to map and review existing available training options on deaf awareness, the All Wales Standards and providing communication support etc and explore good practice, gaps in provision, opportunities to roll this out across Wales.

# Recommendations

### WELSH GOVERNMENT

- **1.** Welsh Government must publicly restate its commitment to the ongoing work to revise, strengthen and enforce the All Wales Standards, and the importance of ending the inequality experienced by patients who are deaf or have hearing loss.
- **2.** Welsh Government must publish an updated timeframe for implementing the action plan developed by the Accessible Communications Implementation Group, to ensure the strengthened All Wales Standards are effectively rolled out and enforced.
- **3.** Welsh Government and NHS Wales must ensure that new governance, enforcement and monitoring mechanisms included in the revised All Wales Standards are robust and will effectively report progress, or flag issues with implementation, allowing for partners to take immediate action to resolve issues or delays.
- **4.** Welsh Government and NHS Wales must review the way providers and commissioners procure communication support professionals, and the current support provided through WITS, to assess how it meets the needs of deaf patients and patients with hearing loss, and NHS staff.
- **5.** Welsh Government and NHS Wales must review existing and in-development training for NHS staff that covers topics including: deaf awareness; the All Wales Standards; using IT systems to record, flag and meet patients needs; and, booking and providing communication support This will allow Welsh Government to to identify gaps in provision and consistency across the whole of Wales and the NHS Wales Workforce. This training must be mandated for NHS Wales staff.
- **6.** Welsh Government must work with NHS Wales alongside Llais and the Public Services Ombudsman to review accessibility of the NHS Wales complaints system. This must include review of the *Putting Things Right* guidance and the Once for Wales Concerns Management System and making the changes needed to ensure accessibility for patients who are deaf or have hearing loss.
- **7.** Welsh Government must undertake a communications campaign to promote patients' legal rights to accessible healthcare, and the standard they should expect when accessing NHS Wales services.

### NHS WALES. HEALTH BOARDS. TRUSTS AND OTHER PUBLIC BODIES:

- **8.** All key delivery partners, including Digital Health and Care Wales (DHCW), Public Health Wales (PHW), Health Education and Improvement Wales (HEIW), Wales Interpretation and Translation Service (WITS) and others must commit to the work needed to improve accessibility of NHS Wales services and clearly demonstrate this in their strategies and workplans.
- **9.** NHS Wales must review staff awareness and understanding of their duties under the All Wales Standards and Accessible Information Standard.
- **10.** NHS Wales should review best practice of alternative contact method (for patients to contact healthcare settings, including GPs) across healthcare settings and support commissioners and providers with guidance on enabling patients to contact them.
- **11.** NHS Wales must audit GP practices to ensure proactive identification and recording of patients' communication needs, and as the front door to the NHS, offer alternatives to the phone which provide equitable access to appointments and ensure this is embedded throughout patient communication.
- **12.** Digital Health and Care Wales (DHCW) must co-produce developments in the NHS Wales App with patients who have reasonable adjustments recorded on their patient record, to ensure that the App supports patients by empowering them to take control of their access needs across NHS Wales.
- **13.** DHCW must also explore whether digital systems, including the NHS Wales app, could include the functionality to request communications support at appointments, and for information regarding bookings to be recorded in-app and shared with patients.
- **14.** NHS Wales must work with health boards to review the way communications support is provided across NHS Wales services and through WITs, working with patients who use this service and organisations who represent them to understand how their needs can be better met.
- **15.** As part of this, they should consider contracting specialised BSL interpreting services with separate performance metrics and targets that ensure high standards specifically for deaf patients. These specialised services would help to ensure services are delivered on time, with fewer cancellations and greater cultural awareness and accessibility.
- **16.** NHS Wales should include communications support professionals in NHS workforce strategies to ensure patient needs are met and incorporated into planning.
- **17.** NHS Wales must require all commissioned services whether in the NHS or private providers to set out evidence of compliance with the All Wales Standards, AIS and Equality Act as a key part of tendering and monitoring throughout the contract.

# Annex 1: The policy and legal framework underpinning patients' right to accessible healthcare

# The right to accessible healthcare for deaf people and people with hearing loss is a legal right.

The 2010 Equality Act requires that reasonable adjustments be made to deliver equality of access to healthcare and social care services for disabled people to remove the barriers people face. These can include: producing information in an accessible format; communicating in a different way such as via email rather than telephone; or, providing professional communication support such as a qualified British Sign Language (BSL) interpreter.

This is an anticipatory duty, which means that health providers such as NHS Wales are required to be proactive in making adjustments to ensure patients' needs are met. Services are also responsible for meeting the costs of any reasonable adjustments required. Failure to make reasonable adjustments is classed as discrimination and is against the law.

In Wales, ensuring that healthcare is accessible to people who are deaf and have hearing loss also aligns with the principles of the Wellbeing of Future Generations (Wales) Act 2015. A key goal of the Act is to create 'A Healthier Wales'. Achieving this goal requires an equitable and inclusive healthcare system, ncluding ensuring that NHS Wales communication is accessible to all patients, and that all patients can fully understand their health conditions, treatment options and care plans.

The Health and Care Quality Standards were introduced on 1 April 2023 as part of the Duty of Quality through the Health and Social Care (Quality and Engagement) (Wales) Act 2020. The standards apply to all NHS Wales services and set the expectation that everyone should attain their full potential for a healthy life which does not vary in quality by organisation or personal characteristics.

Additionally, the Welsh Government has

made clear its commitment to incorporate the UN Convention on the Rights of Persons with Disabilities into Welsh law, which provides an international standard for disabled people's human rights. Effective and appropriate communication is identified as fundamental to ensuring services are delivered in ways that promote dignity and respect.

Finally, the All Wales Standards were specifically developed and introduced in 2013 to tackle barriers to accessing care. These came about as the result of a report into Accessible Healthcare for People with Sensory Loss in Wales, convened by experts across the health and social care sphere alongside Welsh Government, NHS Wales, Healthcare Inspectorate Wales, and charities including RNID, RNIB Cymru and Sense Cymru.

This report recommended that all Health Boards in Wales have an Accessible Information Policy, and as a result, the All Wales Standards were co-produced. The Standards were warmly welcomed, and at the time Welsh Government was the first in the UK to adopt this approach towards ensuring healthcare is accessible. The Standards sets out the service delivery that people should expect to be met and includes guidance to:

- Ensure all patient information leaflets and documents are accessible.
- Ensure patient areas are assessed to be accessible – hospital wards, outpatient areas, A&E, and primary care – and that this should be assessed alongside people with lived experience.
- That health services must "understand and meet" the information and communication needs of patients.

rnid.org.uk

### The Standards span what is required to deliver accessible care across primary care, secondary care, emergency and unscheduled care. This covers:

- Asking patients about their communication needs and flagging this on a patient record to
  ensure it is communicated between departments. This specifically states that patients
  should not have to keep repeating their needs.
- Considering the access environment: lighting, colour, background noise, the need for loop systems for hearing aid users.
- Using a variety of contact methods for making, communicating about, or rearranging appointments email, text messaging, text phone and websites.
- Training for all appropriate staff to develop awareness of the need for different forms of communication, and how to communicate effectively with patients with sensory loss.
- A proactive approach to ensuring arrangements are in place ahead of patients' arrival in care, to ensure appointments are not missed.
- Promotion of different forms of communication available to patients to encourage uptake.
- That every patient who requires communications support should have this need met, and NHS staff are responsible for making sure patients understand everything they need to know about their care.
- The concerns and feedback process should be accessible and provide a variety of contact methods, and data on patient concerns about access should be captured and monitored to identify patterns.

Regular review and monitoring of health boards' implementation and compliance was previously a key element of the Standards. This was initially overseen by the Centre for Equality and Human Rights (now Public Health Wales), and Health Boards were required to report progress towards implementing the Standards through an annual RAG rating. However, a decision was made by health board Chief Executives to cease this in 2022, without consultation with relevant partners or patients, and no alternative system of monitoring the Standards was put in place. When this decision was made, all but one health board was rated as not meeting the Standards.

It is clear that a lack of ownership and accountability of the national Standards led to a lack of drive and ambition to implement the Standards fully and improve outcomes for patients. This has led to minimal progress being made, with NHS Wales services continually failing to meet the needs of deaf patients and

patients with hearing loss.

Since 2022, significant progress has been made. Welsh Government responded to urgent calls for action by RNID and RNIB Cymru by facilitating a series of workshops in 2023 to review the Standards, compliance with them, and whether they are still fit for purpose. This brought together NHS Wales Equality Leads from all seven health boards, key Welsh Government stakeholders, other delivery partners and charities representing people with sensory loss. The result of the workshops was an action plan, approved by the Welsh Government Health Minister, to review and revise the standards, including a more robust mechanism of monitoring implementation. This also included a recommendation to broaden the Standards to apply to anyone in Wales with additional communication and information needs, widening the scope of patients that the Standards would positively impact.



### The Accessible Information Standard in Wales

It's also important to note that in addition to the All Wales Standards, in 2018, Welsh Government also embedded the NHS England Accessible Information Standard (AIS), to ensure effective capture and communication of sensory loss communication and information needs between NHS staff in Wales.

This Standard for how information and communication needs of patients with sensory loss must be recorded was issued by Welsh Government via a Welsh Health Circular to all NHS bodies, health boards and trusts that commission or provide health services in Wales in September 2018.

This Welsh Health Circular required the following immediate actions:

- All relevant staff be made aware of their responsibilities for recording information
- All systems in procurement or for future procurement must comply with the Standard with immediate effect
- All relevant actions must be taken to comply with the implementation plan

Under the AIS, NHS organisations must take five key steps:

### 1. IDENTIFY

They must ask people with a disability and/or sensory loss if they need support to be contacted, to communicate well, and to understand written information.



They must record individuals' communication and information needs in a standardised way.



### 3. FLAG

These details, while confidential, must be highly visible or linked to an electronic alert to prompt staff to take action.

### 4. SHARE

They must share an individual's communication and information needs with other services as part of a routine referral, or discharge and handover process, in line with data protection requirements.

### 5. MEET

Disabled people and those with sensory loss must be able to contact NHS services when they need to, communicate well during appointments and understand information they're given.

The Welsh Health Circular provided technical information and guidance for GP practices and individuals on how to meet these duties and standards, including details of a new digital system to flag patient communication needs. It also laid out a plan for this to be rolled out across all GP surgeries in Wales.

However, guidance on the Public Health Wales website itself states that "The success of the Accessible Information Standard will largely rely on the awareness of GP practices of their responsibility to capture and record this information, and the willingness of patients to

share their communication needs with their surgeries."

Despite the introduction of the All Wales Standards in 2013, the AIS being mandated in Wales in 2018, and the pre-existing underpinning legislation, our research in 2025 continues to show that awareness of, and compliance with the Standard is limited. This means that deaf people and people with hearing loss in Wales are continually being failed by inaccessible NHS services, and are facing the same barriers as they did more than a decade ago.

# Annex 2: Additional policy reports about access to healthcare

We are also not the only organisation to raise the urgency of this issue. In 2023, RNIB Cymru published their Make it Make Sense report, highlighting how inaccessible healthcare information is putting patients with sight loss at risk, and calling for immediate action to fully implement and monitor the All Wales Standards.

A recent report by the Public Services
Ombudsman for Wales, Equality Matters,
highlighted how lack of reasonable adjustments
have led to serious failings in patient care,
highlighting the case of a deaf individual
who was the primary carer for her mother.
An investigation identified failings in the care
provided to the individual's mother and an
apology was issued, recognising the barriers she
had faced as a deaf carer.

Another report by the Older People's Commissioner for Wales on <u>Access to GP</u> <u>practices</u> highlighted many similar themes, such as:

- Patient information, including sensory loss, not being shared or having to be provided several times.
- Practices not making adjustments for sensory loss despite being informed about them.
- Difficulty using the telephone to communicate with the practice or understanding automated announcements.

The report also documented patients experiencing "sensory overload" in GP practice environments, as well as "having to shout/being unable to hear". The Commissioner highlighted the impact this has on patients' mood and confidence in accessing care.

Therefore, there is a wealth of evidence about the scale and impact of this issue on our communities and others who require communications support or reasonable adjustments when accessing healthcare. This is a hidden scandal affecting hundreds of thousands of people within Wales and must be urgently addressed.







Supporting people who are deaf, have hearing loss or tinnitus

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