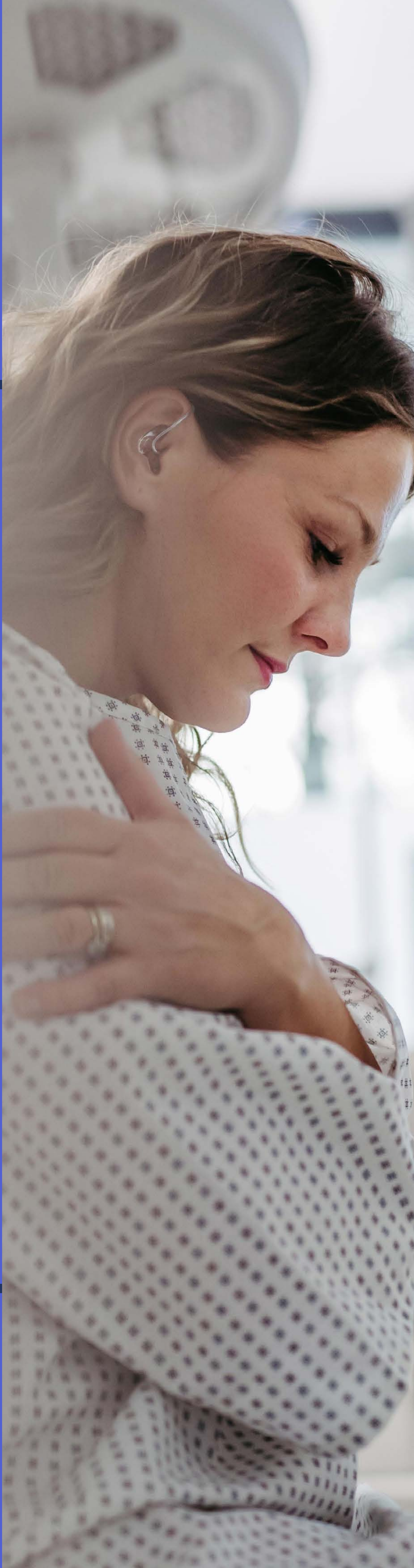
STILL IGNORED: THE FIGHT FOR ACCESSIBLE HEALTHCARE

2025 POLICY REPORT
ENGLAND



RNID Supporting people who are deaf, have hearing loss or tinnitus

THE DEAF HEALTH CHARITY SIGNHEALTH

Contents

Executive Summary

Equal access to healthcare is a human right. Deaf people and those with hearing loss have been failed by the NHS for too long. The healthcare system regularly neglects their communications needs.

In this report RNID and SignHealth demonstrate that the NHS does not have the systems in place to fulfil the right to accessible healthcare for people who are deaf or have hearing loss. Our new research shows that the NHS often fails to meet the fundamental needs of people who are deaf or have hearing loss, clearly violating the rights set out in the Equality Act over 15 years ago.

The consequences can be devastating, as we set out on pages 10-17. People who are deaf or have hearing loss are deterred from seeking NHS treatment, don't understand the information they are given and, ultimately, feel unable to manage their own physical and mental health because of the failures of the NHS to provide accessible healthcare.

The reasons why the NHS is often failing to provide those who are deaf or have hearing loss with equal access to healthcare are explored on pages 18-35. Importantly, awareness of the key regulation, the NHS Accessible Information Standard, is low amongst NHS staff. In addition, patient information often isn't recorded and shared accurately, and staff may not know how to access the information they need, or what action to take to ensure patients' communication needs are met. The result is a system with too many barriers, undermining the ability of people who are deaf or have hearing loss to access safe and effective treatment.

The findings in this report are not new. Whilst we present findings of serious and devastating failures across the NHS, they will not shock people who are deaf or have hearing loss and it would be worrying if anything in this report is a revelation to policymakers across the NHS. As we demonstrate on page 37, these NHS failures have been previously documented, and NHS England have commissioned reviews that have already identified solutions.

This cannot be just one more report on the failure of the NHS to meet the access needs of people who are deaf or have hearing loss. We need the Department of Health and Social Care (DHSC), NHS England, providers and commissioners to acknowledge their failings and agree a transformation plan which will deliver the rights that deaf people and people with hearing loss are entitled to, but have been deprived of, for too long. We set out the decisions and changes that would bring this about on pages 36-41 and 44-46.

In this report RNID and SignHealth demonstrate that the NHS does not have the systems in place to fulfil the right to accessible healthcare for people who are deaf or have hearing loss. Our new research shows that the NHS in England often fails to meet fundamental needs of people who are deaf or have hearing loss, clearly violating the rights set out in the Equality Act over 15 years ago.

Introduction

Making healthcare accessible to people who are deaf or have hearing loss isn't a small issue. It affects huge numbers of people and prevents the NHS from providing them with safe and effective care.

More than 15 million adults in England are deaf or have hearing loss. Around 6 million adults in England have hearing loss severe enough that they would have difficulty in noisy environments, whilst an estimated 1 million would not be able to hear most conversational speech.

In addition, there are an estimated 73,000 deaf BSL users. Deaf BSL users often experience language deprivation at an early age, leading to difficulty understanding and using written English. As a result, many deaf BSL users face significant additional communication barriers.

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.

The NHS systematically discriminating against people who are deaf or have hearing loss is a hidden national scandal.

It's time to end that scandal.

It's time to give deaf people more access and control over their physical and mental healthcare.

The legal right to accessible healthcare

THE EQUALITY ACT

Under the Equality Act 2010, health services like the NHS as well as social care services across the UK are required, by law, to make “reasonable adjustments” to remove barriers facing deaf people or people with hearing loss when accessing services, including providing information in an accessible format. For deaf people or people with hearing loss, a reasonable adjustment could include providing an accessible alternative to the telephone, or providing communication support, such as a qualified British Sign Language (BSL) interpreter.

Failure to make reasonable adjustments is classed as discrimination and is against the law. Health and social care services are also responsible for meeting the costs of any reasonable adjustments required.

The Equality Act also makes it clear that under the Public Sector Equality Duty (PSED) NHS bodies must consider what’s likely to be needed in advance and not simply respond to individual requests as they emerge.

There is therefore a clear and legally enforceable requirement for people who are deaf or have hearing loss to have their communication needs met when accessing NHS care. A failure to meet patients’ communications needs is a breach of the Equality Act.

"I had to go to A&E after a minor injury to my foot. I ended up relying on my husband to repeat lots of information for me. The doctor wasn’t speaking clearly, and they were wearing a mask, which made lip reading impossible. I explained that I have hearing loss and asked if they could lower their mask so I could see their lips. They half-lowered it but didn’t make any real effort to communicate clearly with me. Instead, they kept talking and relied on my husband to clarify information for me. I could tell he was uncomfortable – he felt I was being ignored and wanted to be there to support me, but not to be an interpreter. I felt so frustrated and invisible."

- Esther, 28 Warwickshire

THE ACCESSIBLE INFORMATION STANDARD

The 2012 Health and Social Care Act empowered the government to publish *information standards* – setting out how the NHS processes information.

The Accessible Information Standard (AIS) took effect in 2016. The AIS 'directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents, where those needs relate to a disability, impairment or sensory loss.'

In England, all providers of NHS or publicly-funded adult social care services should meet the legal requirements of the Accessible Information Standard. In this report, we have chosen to focus on access to NHS care.

In publishing the AIS, NHS England acknowledged that despite the Equality Act 'many service users continue to receive information from health and social care organisations in formats which they are unable to understand and do not receive the support they need to communicate'.[1]

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.

2. RECORD

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

3. FLAG

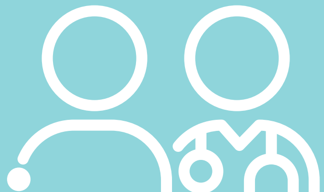
These details, while confidential, must be highly visible or linked to an electronic alert to prompt staff to take action.

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.



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[1] *DCB1605 Accessible Information: Specification v1.1 - section 4.2.*

The research

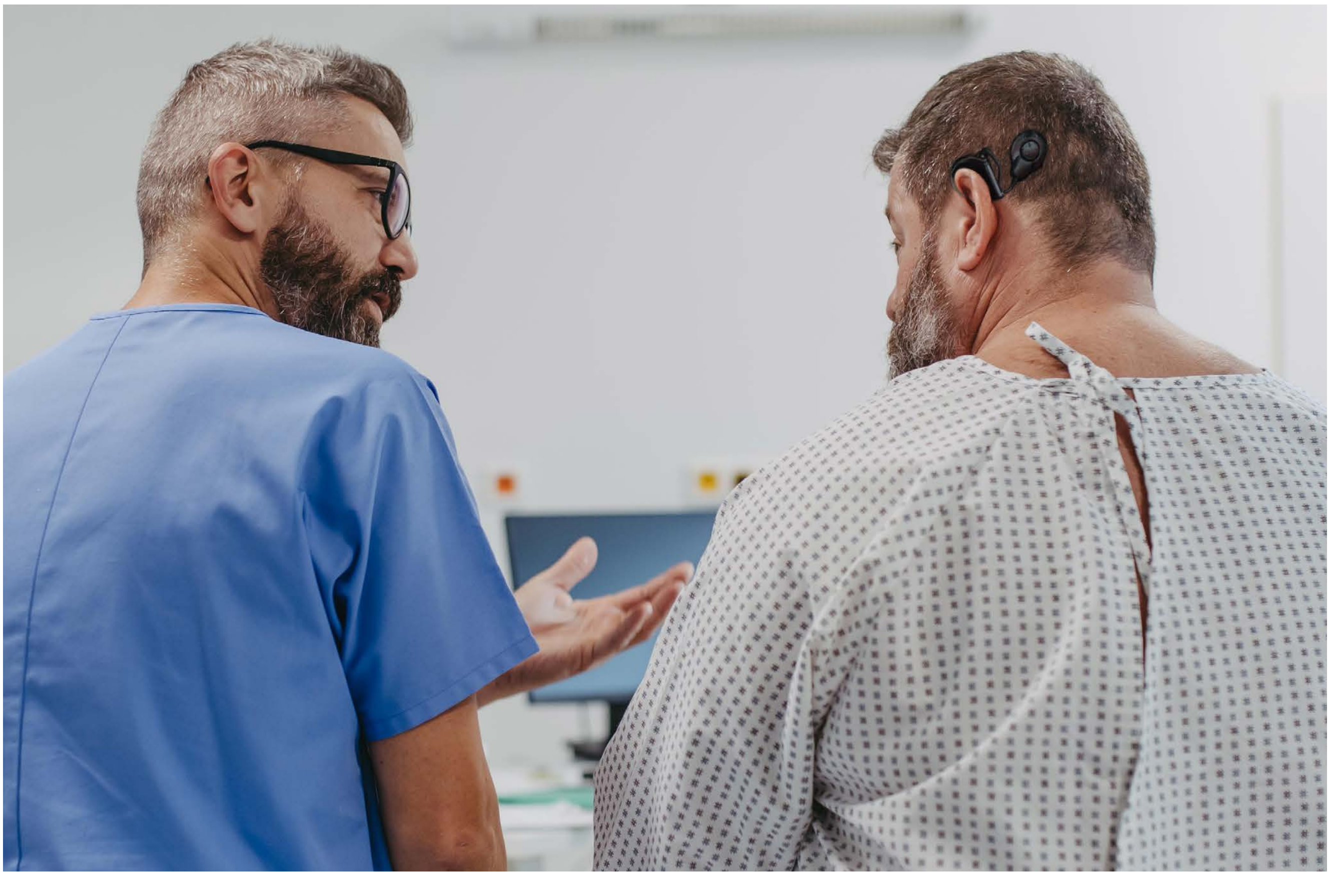
This report sets out the findings from new research which sheds light on the experiences of patients who are deaf or have hearing loss, and the perspective of professionals who are working in the NHS.

The research consisted of two parts: an online survey, which was open to those who are deaf or have hearing loss, and a survey of professionals in NHS healthcare settings.

The online survey was open to anyone aged 18 or over who is deaf or has hearing loss and lives in the UK. The survey was produced in written English and translated into British Sign Language (BSL). The data was collected between 13th November and 26th December 2024. This report is based on the data of the 1,114 responses from those living in England.

The survey of patient-facing professionals working in NHS healthcare settings in England, was conducted by Censuswide on behalf of RNID. The polling was conducted between 9th and 20th December 2024. 404 professionals took part, including at least 50 respondents from each of the following professional groups:

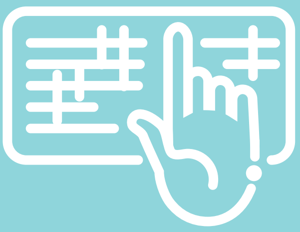
- General Practitioners (GPs)
- General practice administrators and receptionists
- District and general practice nurses
- Nurses and nursing associates working in hospital settings
- Doctors working in a hospital setting
- Hospital administrators and receptionists
- Healthcare support workers or clinical support staff
- Allied health professionals



Throughout this report we refer to three groups of people:

1. SIGN LANGUAGE USERS

people who say that sign language is their main or preferred language, this group is likely to need a BSL interpreter to access healthcare.



2. PEOPLE WHO NEED A COMMUNICATION SUPPORT PROFESSIONAL

people who are deaf or have hearing loss and need communication support professionals such as lipspeakers, Speech-to-Text-Reporters (STTR) and note takers (excluding sign language interpreters).

3. PEOPLE WHO ARE DEAF OR HAVE HEARING LOSS WHO NEED OTHER REASONABLE ADJUSTMENTS

people in this group will have access needs such as alternatives to the phone, not to have their names called in a waiting room, or for healthcare professionals to demonstrate good deaf awareness.

More detail on the methodology can be found in the accompanying research report.

The consequences of inaccessible healthcare

> ***"I have a chronic lung condition and need to use a steroid inhaler. I could not hear the instructions on how to use it. It is only when I found a video online that I used it properly. The impact is that for years I was using the inhaler but actually not receiving the dose I needed."***
>
> - Male, 75+, needs other reasonable adjustments

On a daily basis, people are being placed at risk by an NHS that systematically fails to meet its legal duty to provide accessible healthcare. NHS services are not putting in place the adjustments required by the Equality Act 2010 and the Accessible Information Standard (AIS), leaving deaf people and those with hearing loss excluded and unsafe.

Life-changing diagnoses are being delivered through unqualified family members acting as interpreters, because the NHS has not provided appropriate communication support. Treatment plans are misunderstood because healthcare staff fail to ensure patients have received information in an accessible format. Deaf patients have been left alone in hospital beds, unaware they are critically ill or dying, because there was no means for them to understand the information being given.

Others simply don't come forward for treatment, delaying diagnosis and care, because they are exhausted by the communication barriers they face when trying to engage with NHS services. Many people even avoid urgent care or A&E, knowing that the service won't be accessible to them.

Nearly 1 in 5 (19%) of people told us they require a communication support professional, such as a BSL interpreter, lipspeaker or notetaker to be to be present during an appointment. 67% of sign language users and 62% of people needing another type of communication support professional have been denied this at some point.

When the NHS fails to provide this legally required support, patients are left with no choice but to rely on family or friends to relay information or interpret at appointments (see Figure 1). This includes 15% who had to rely on their children for this support in an appointment. This strips deaf people of their autonomy, independence, and privacy. It also creates risks — family members are not trained interpreters, and mistakes can lead to misdiagnosis or unsafe care.

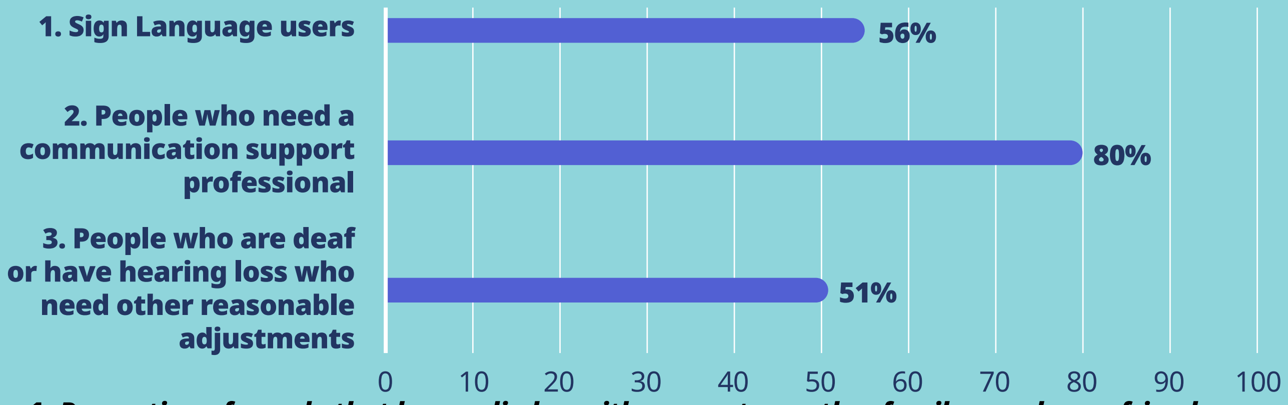
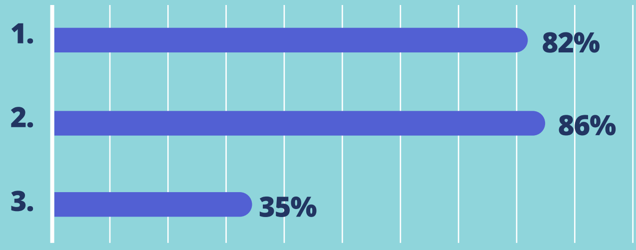
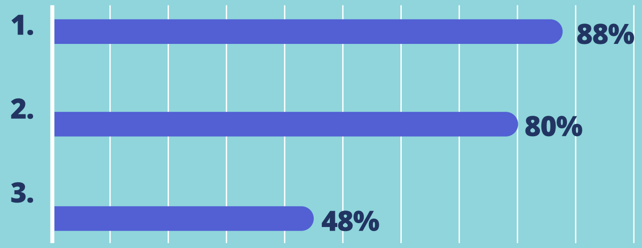


Figure 1: ***Proportion of people that have relied on either a partner, other family member or friend, or their children to interpret or relay information for them at appointments*** *(n=121 sign language users; 101 people who need a communication support professional; 892 people who need other reasonable adjustments)*

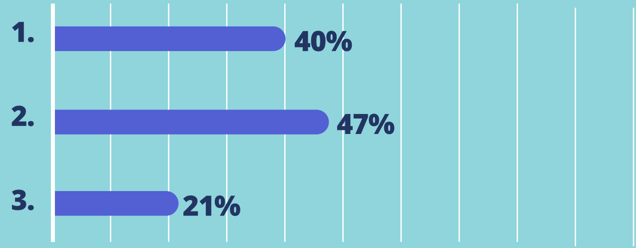
The impact of failing to meet the communication needs of deaf people and those with hearing loss is broad-ranging and serious, with significant threats to patient safety caused by missed diagnoses and disengagement from health services. It is directly contrary to attempts to improve population health by encouraging better health behaviours, earlier diagnosis and intervention, and to tackling health inequalities. Figure 2 illustrates people's feelings about the overall impact on their health, as well as how it affects their choices and behaviour.



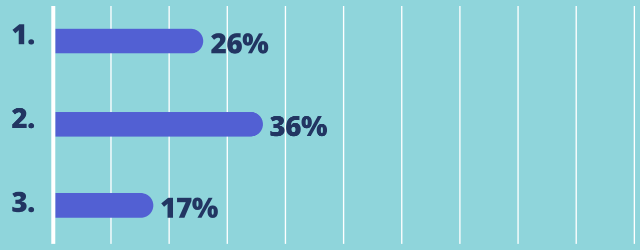
A lack of accessible communication makes it harder for me to maintain good physical health



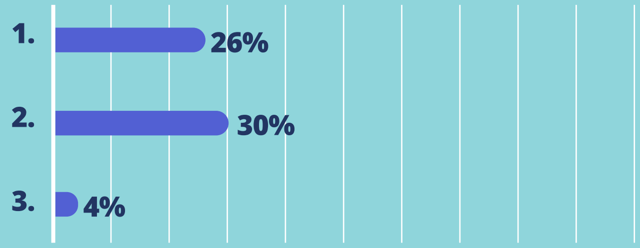
A lack of accessible communication makes it harder for me to maintain good mental health



I have avoided seeking help for a new health concern



I have avoided pursuing follow up or review appointments for existing health conditions



I have avoided calling an ambulance or attending A&E

1. *Sign Language users*
2. *People who need a communication support professional*
3. *People who are deaf or have hearing loss who need other reasonable adjustments*

Figure 2: ***Proportion of people who are deaf or have hearing loss agreeing with each statement*** *(n=121 sign language users; 101 people who need a communication support professional; 892 people who need other reasonable adjustments)*

> ***"As a 23-year-old woman, I do not want to rely on my family members or partner to make appointments for me and be involved with my health information as I want to be independent."***
>
> - Female, 18-24, needs other reasonable adjustments

People who need the NHS to make adjustments consistently receive lower quality care, demonstrated across our survey results. A clear finding of our research is that overall experiences of accessing healthcare are markedly worse for sign language users and those who need access to another type of communication support professional, with well over half rating it as 'poor' or 'very poor'. But nor are those who require other reasonable adjustments well-served by the NHS, with nearly one in three rating their access as poor or very poor.

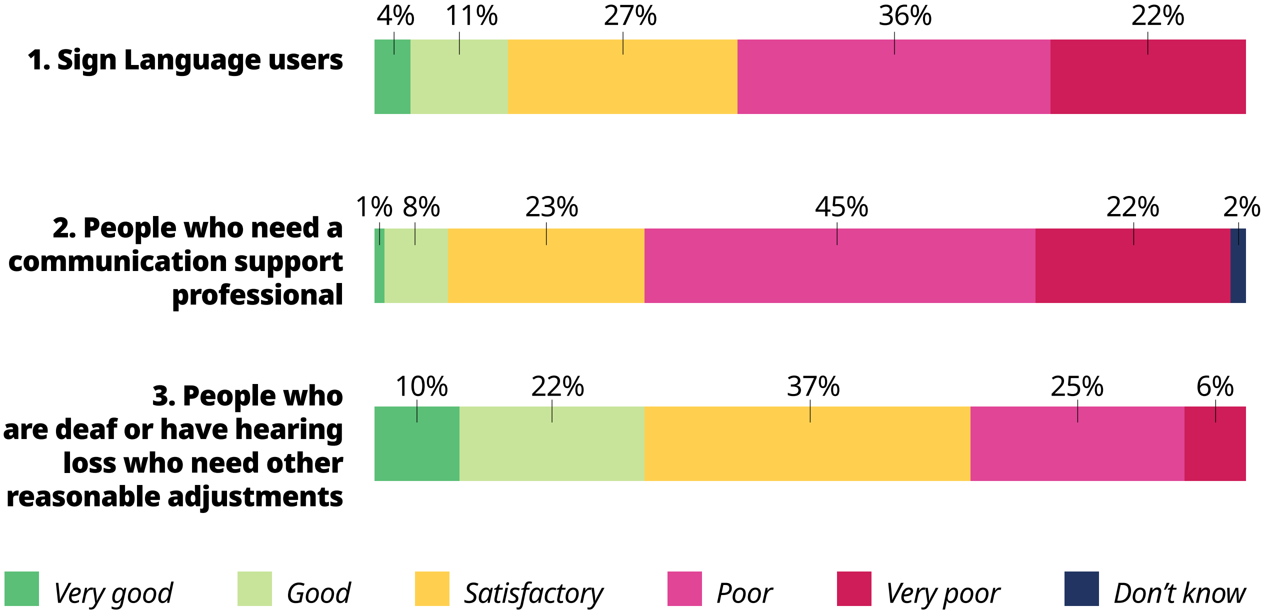


Figure 3: ***"Overall, how would you rate your experience of accessing healthcare?"***
(n=121 sign language users; 101 people who need a communication support professional; 892 people who need other reasonable adjustments)

This systemic gap can lead to harmful perceptions of deaf people as 'aggressive', when they are simply trying to ensure they receive the information they need to manage their health.

Unsurprisingly, this leads to feelings of mistrust. Fewer than one in five (17%) sign language users agree that deaf people can trust the NHS, alongside 13% of those who require another type of communication support professional, and 29% of those who need other reasonable adjustments.

It is clear that across the health service, people who need the NHS to make adjustments for them receive a lower quality of healthcare, which could put patients at serious risk. People who have been denied the information and communication support they need say it has resulted in situations including:

47%

Giving up trying to make an appointment

or missing an appointment

21%

A delayed or incorrect diagnosis

23%

33%

Failure to understand their diagnosis,

the outcome of their appointment

33%

or how to take medication or treatment prescribed

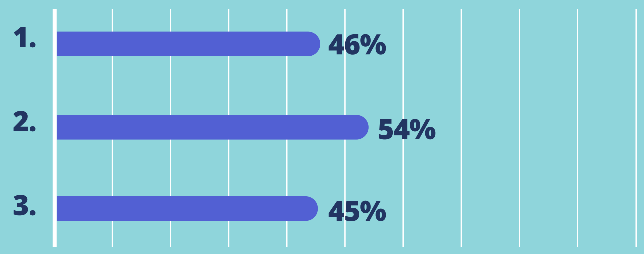
25%

44%

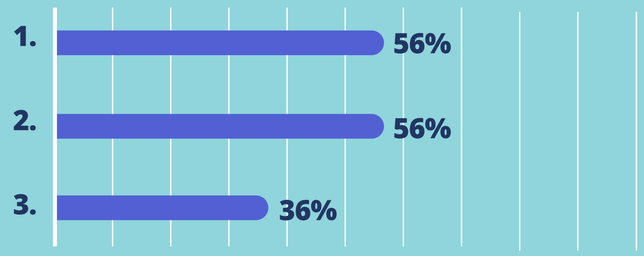
Almost half felt it has resulted in them not getting the follow-up care they need

> ***"They tell me I must have someone with me. They have robbed me of my independence and dignity and it is terribly upsetting. With reasonable adjustments I could manage my own healthcare but the NHS does not care."***
>
> \- Female, 55-64, needs other reasonable adjustments such as lipspeakers, Speech-to-Text-Reporters (STTR) and note takers

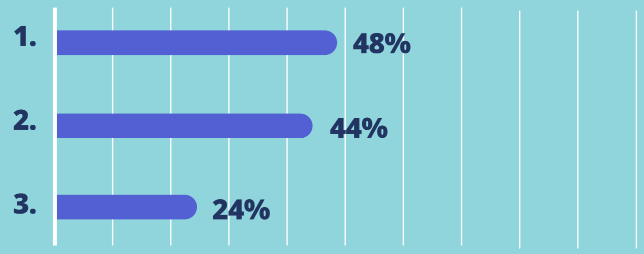
The consequences are particularly felt by those who use sign language and those who require a communication support professional – around half of sign language users report not understanding their diagnosis or how to take medication/treatment given.



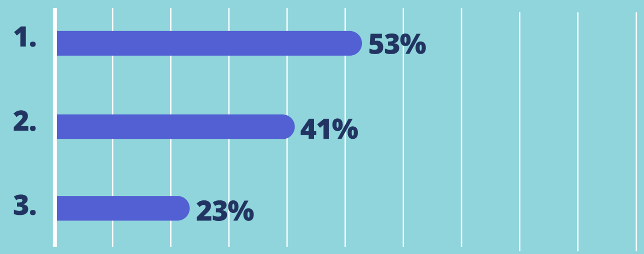
I gave up trying to make an appointment



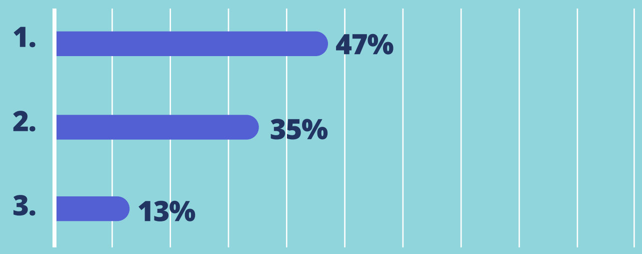
I did not get the follow up care I needed



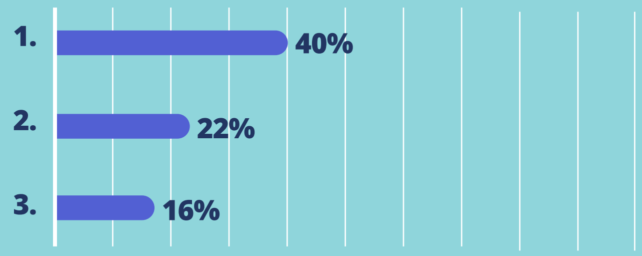
I did not understand my diagnosis



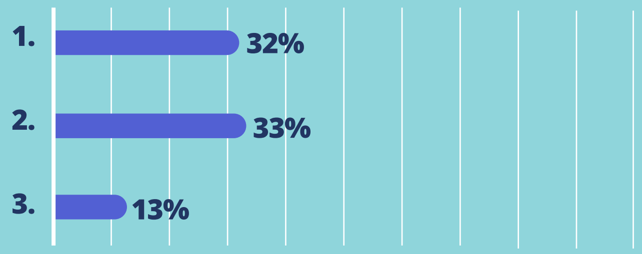
I did not understand the outcome of my appointment



I did not understand how to take the medication or treatment given



I did not recieve the correct diagnosis/diagnosis delayed



I missed an appointment

1. *Sign Language users*
2. *People who need a communication support professional*
3. *People who are deaf or have hearing loss who need other reasonable adjustments*

***Figure 4:* Consequences of not having information or communication needs met**
(n=81 sign language users; 63 people who need a communication support professional; 197 people who need other reasonable adjustments)

“I went into A&E for blood loss but no interpreters turned up after asking several times. I went through so many tests and wasn’t sure what it was all about. I was given medication, but I refused because I didn’t know why I needed them. The staff seemed gobsmacked, so I took it and was not sure how serious it was. The next thing a nurse took me into a bereavement room and sat me down with a leaflet that said ‘miscarriages’. I was in shock. They had not explained what the test was for. It was a massive misunderstanding and lack of communication.”

- Female, 35-44, sign language user

Further consequences of a lack of accessible healthcare include 1 in 7 (14%) people saying a health problem they were experiencing was made worse and 1 in 7 (14%) feeling that their health was put at risk.

These consequences are recognised by NHS staff, with some expressing similar concerns that a lack of communication support for their patients who are deaf or have hearing loss risked misdiagnosis, delayed treatment, and left patients not feeling fully informed about their health. Others suggest that patients who are deaf or have hearing loss simply do not get the quality of care that they deserve.

“I am unsure if I am giving them all of the information needed for them to make informed decisions.”

- District or practice nurse

“I am unable to diagnose accurately or have an accurate idea of the effectiveness of the treatment.”

- Allied health professional

Feeling disrespected and excluded

> ***“I could not get a blood test at hospital as I had to fill in details on a touch screen which I could not see. And then when a healthcare professional "helped" me complete it he shouted the questions at me which was embarrassing and also quite painful as loud noise hurts and then he repeated my private information so loudly everyone stared. It was such an insult to my privacy and dignity that I just wanted to crawl away. I cried for hours afterwards and avoided going back and refused medication that I know I need because it would require regular blood tests, and I just do not know how to manage these”.***
>
> - Female, 55-64, needs other reasonable adjustments.

In their accounts, many deaf people and those with hearing loss told of feeling “othered” (made to feel different to most people) by the healthcare system, disrespected or ignored, and, in some instances, of being treated as if they were stupid. Some said that they constantly had to fight to get the support they need across the NHS.

This is particularly true for those who need communication support professionals: 95% of sign language users find it stressful to access NHS services because they must fight for their communication needs to be met, in contrast to 46% of those who need other reasonable adjustments. This adds anxiety to what can already be stressful and unsettling times for people experiencing health concerns and may demotivate people from engaging with the health system.

In some cases, people described concerning attitudes from staff, for example feeling that “healthcare staff often seem annoyed after you tell them you can’t hear what they say”. Others described a distressing sense of loss of dignity and autonomy because of lack of communication support.

Some responses from professionals also reflect that outdated and offensive terminology is still in use in NHS systems. One reported that patients are indeed ***“registered as deaf or dumb”***.

> ***“It is such a struggle to get communication support in place. It causes so much anxiety and frustration. We can be portrayed as aggressive in our mannerisms just trying to access information and NHS services.”***
>
> - Female, 55-64, needs other reasonable adjustments.

Basic care

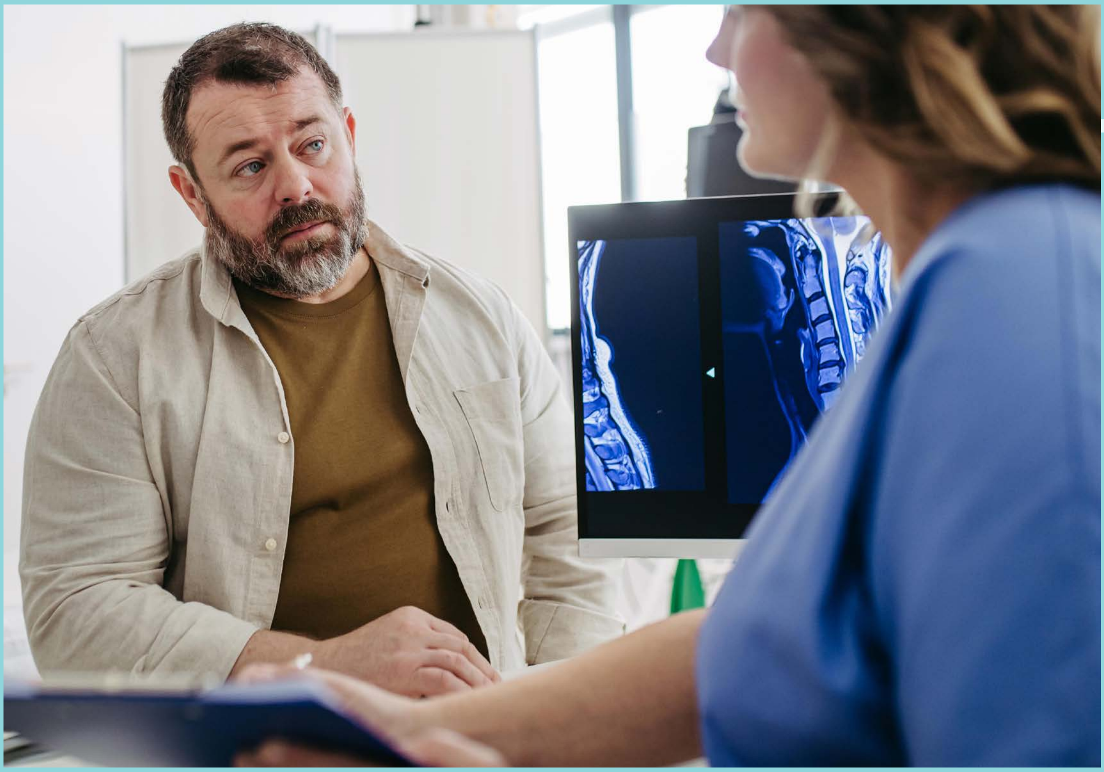
There is also evidence of a concerning failure to provide the most basic patient care. This is particularly true for hospital stays, and for those who require a sign language interpreter or other communication professional. People describe being frightened during their time in hospital, being unable to communicate other than by pen and paper, and their most basic needs not being met:

“I didn’t get food or water as apparently, I had been asked if I wanted anything, but I hadn’t heard them because they didn’t come to me for me to understand what they were asking.”

- Female, 65-74, needs other reasonable adjustments.

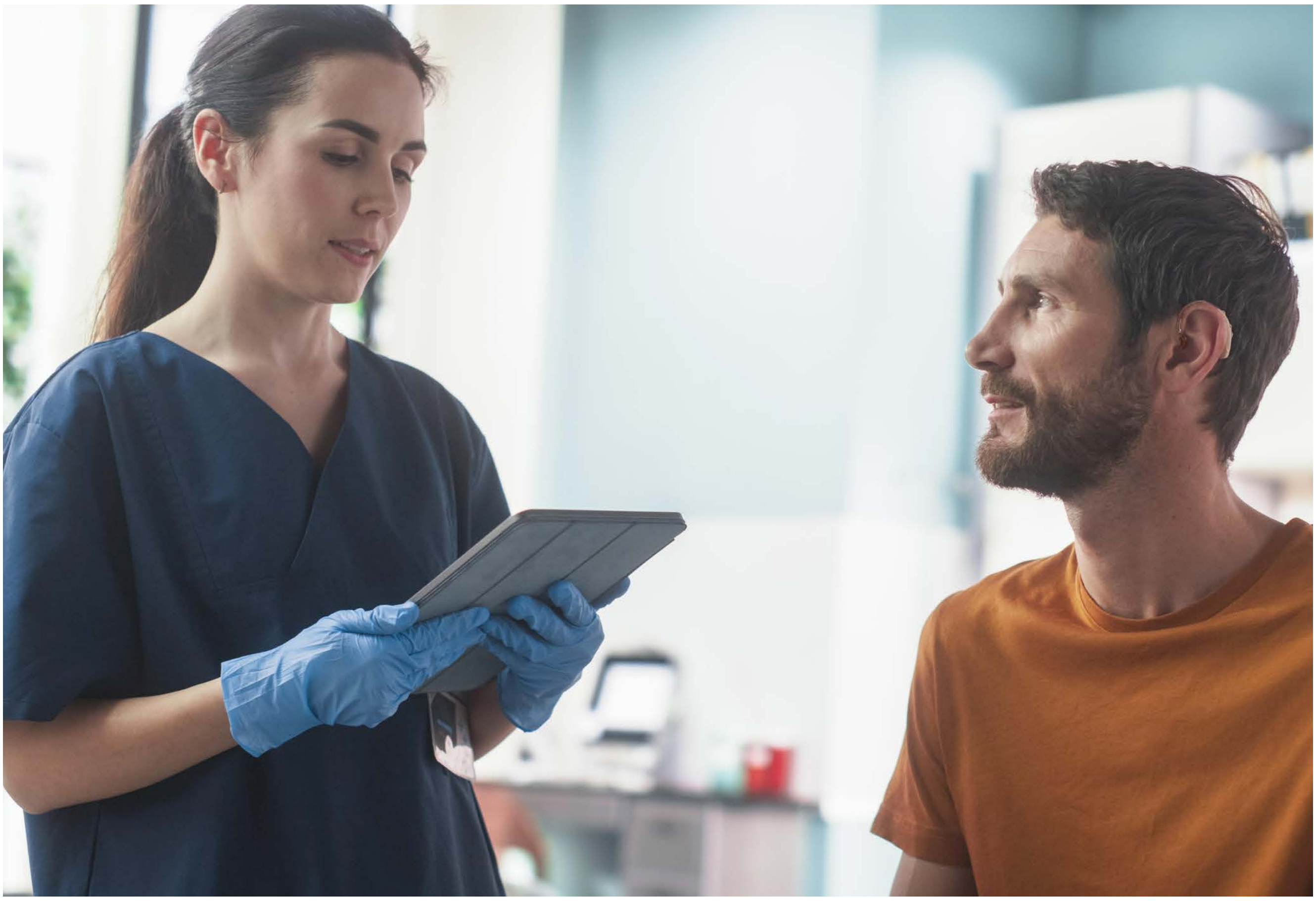
“I had to stay in hospital for six days and they never provided me with a BSL interpreter. I was stressed and panicked.”

- Male, 25-34, sign language user.



What's going wrong?

Almost 10 years after its launch, awareness of the AIS is poor.



Awareness of the Accessible Information Standard (AIS), and how it should be used to meet people's communication needs, is poor.

One-third of professionals (32%) are unaware of the AIS.

Of those who said they are aware of the AIS; most were able to correctly describe its purpose of allowing people with disabilities equal access to information and health care. However, some do not have a correct understanding of its purpose. The most common misunderstanding was mistaking the AIS with a patient's right to access their own medical records. Information Standards can be about information sharing and data protection, which some healthcare professionals understood – but without realising the key point of the AIS is about making communication accessible, this is an important distinction that healthcare professionals must adhere to.

Awareness among patients who are deaf or have hearing loss is even worse – overall, just 21% are aware of the AIS. Awareness is highest among sign language users.

For the AIS to be adhered to, patients, healthcare professionals and patient-facing administrative staff need to understand the five steps (see page 7) and need to be proactive, particularly so that patients' communication needs are registered, as the initial trigger which should see support follow them through the NHS.

It is ultimately the NHS's responsibility to proactively educate patients about their rights under the AIS and ensure that communication needs are identified and recorded at the earliest possible stage.

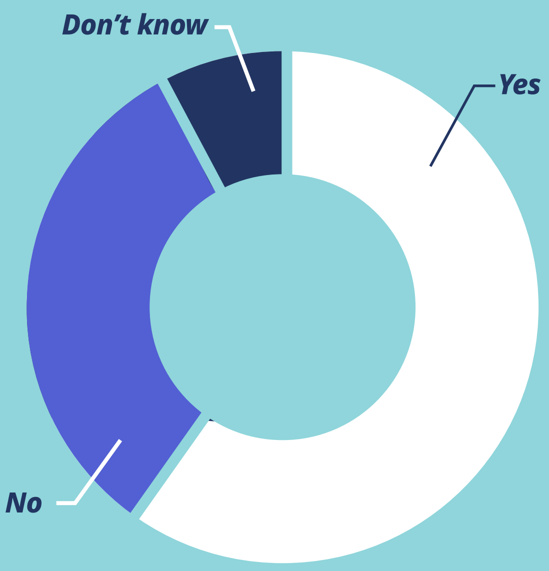


Figure 5: ***Awareness of the AIS among NHS staff***
(n=404)

32%

of NHS staff are unaware of the AIS.

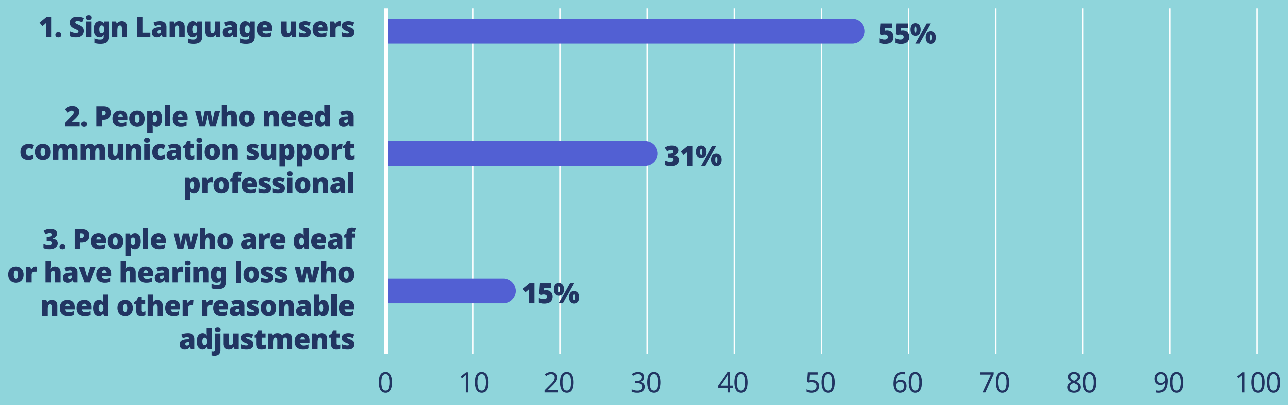


Figure 6: ***Awareness of the AIS among people who are deaf or have hearing loss*** *(n=121 sign language users; 101 people who need a communication support professional; 892 people who need other reasonable adjustments)*

RECOMMENDATION

DHSC should:
Provide patient facing information setting out patients' rights to equitable healthcare under the Equality Act and AIS, and the steps they can take to record their communication preferences. All information should be provided in multiple formats created through a process of co-production with service users.

NHS services are regularly failing to implement the five steps of the AIS

> ***"It doesn't matter how many times you make them aware of your deafness, the next nurse or Doctor on duty comes along and just starts speaking to you. It drives me crazy."***
>
> - Female, 45-54, needs other reasonable adjustment.

IDENTIFY

70% of people who are deaf or have hearing loss told us they have never been asked about their information and communication needs when accessing NHS care, as is required under the first step of the AIS.

RECORD, FLAG AND SHARE

Recording, flagging and sharing a patient's communication needs is essential – without this, NHS staff cannot proactively meet a patient's needs, for example by booking an interpreter or communicating by email instead of phone.

However, there is a clear mismatch between what professionals' report knowing how to do and what patients experience.

Most staff report knowing how to undertake these actions. 85% said they know how to find out whether a patient had communication needs. 79% said they know how to centrally record that information, and the same proportion said that they know how to add a flag to a patient's online record to make others aware of these needs.

Yet people who are deaf or have hearing loss are clear that their communication needs are often not being recorded and shared on NHS systems. More than three quarters (77%) of people told us that healthcare professionals have never or rarely been made aware of their information or communication needs before they meet with them.

MEET THE NEEDS OF ALL

The NHS frequently fails to meet the key requirements of the AIS to meet people's communication needs, as we demonstrated in figures 1-3.

These communication needs - or "reasonable adjustments" as set out under the Equality Act 2010 - include things like the ability to contact their GP practice by email or text rather than by telephone, healthcare staff facing them and speaking clearly to allow them to lip read, or the provision of a communication support professional such as a qualified BSL interpreter during an appointment.

These failures occur across many points in the patient journey.

Nearly half (45%) of people experience barriers when booking appointments. Many people commented on the fact that they cannot use the phone because they are deaf or have hearing loss and this leads to difficulties, particularly for accessing GP appointments.

At what points, if any, have you experienced barriers to information or communication when accessing healthcare?

WHEN BOOKING APPOINTMENTS:

74%
Sign language users

76%
People who need a communication support professional

37%
People who need other reasonable adjustments

WHEN BEING GIVEN A DIAGNOSIS:

64%
Sign language users

55%
People who need a communication support professional

27%
People who need other reasonable adjustments

WHEN BEING TOLD ABOUT MEDICATION AND TREATMENT:

67%
Sign language users

62%
People who need a communication support professional

28%
People who need other reasonable adjustments

> ***"I was in a doctors waiting room waiting and my name was called out and because I didn't hear it and because I'm not able to see, I wasn't aware that the doctor had come to call the next patient in and subsequently I missed my appointment. When I asked at reception, I was simply told that my name had been called but the next patient had taken my place as I didn't reply and I needed to rebook which I didn't bother doing and left feeling utterly ignored and unimportant."***
>
> Female 45-54, needs a communication support professional.

Some people report being told there are no alternatives to the phone. Others find there are alternatives, but this results in their care being delayed because the wait for a face-to-face appointment is longer.

When attending a face-to-face appointment, over two thirds of people (67%) experience barriers to information or communication when being called from the waiting room.

This often leads to increased stress and anxiety and can result in people being met with frustration from healthcare professionals when they don't hear their name being called.

Even when patients reach the stage of seeing a health professional, NHS systems and staff often fail to ensure effective communication, with two-fifths (42%) experiencing barriers trying to discuss and explain their symptoms or health problem.

Our evidence shows that the NHS is routinely failing to meet the core requirements of the AIS. Some of this failure may be down to local NHS processes. But the Department of Health and Social Care and NHS England can still do more to improve compliance with the AIS. Many of the steps that can be taken to improve patient and staff interaction with the AIS are about ensuring that ongoing changes to the NHS are designed and implemented with the needs of disabled people at the centre.

GETTING IT RIGHT - THE PROVISION OF ALTERNATIVE METHODS OF COMMUNICATION

People have a much more positive experience contacting health services and accessing health information when provided with alternative communication options. Where available, the NHS app clearly offers welcome advantages for booking appointments, seeing test results and receiving health information.

> ***“My GP health centre uses the NHS app for appointments and repeat prescriptions etc. which I can use on my smartphone. This makes things very accessible for me and I don’t have to use the dreaded phone to contact my GP.”***
>
> - Female 55-64, needs other reasonable adjustments

RECOMMENDATIONS

DHSC should:

- **In co-production with people with lived experience, design the NHS App to allow patients to record and share their communication needs across NHS systems, book communication support, and make appointments.**

- **Review best practice across the NHS of alternative contact methods and support commissioners and providers with guidance on enabling patients to contact them.**

ICBs should:

- **Require the providers they manage – whether in the NHS or private sector – to set out evidence of compliance with the Equality Act and AIS as a key part of their tendering and contract monitoring.**

- **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 to provide equitable access to appointments.**

Meet the specific needs of those who require communication support

> ***"Interpreters often don't turn up or cancel at the last minute. This practice is not helping deaf people's cause. Appointments are being cancelled at the last minute or family members are trying their best to interpret."***
>
> - Female, 35-44, needs a communication support professional

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In particular, people who require professional support to engage with the health service face constant issues with having access to BSL interpreters and other communication support professionals.

Of those who indicated they needed a communication support professional to be present during an appointment, only 7% say this is always provided for them. Over a quarter (27%) say this is rarely provided, and over a third (36%) say this support is never provided. In contrast, 78% of professionals told us they know how to book communication support, such as a BSL interpreter, when required. However, if needs are not identified, recorded, flagged or shared, this knowledge is of limited benefit.

Furthermore, 80% of sign language users have experienced instances when a communication support professional fails to turn up to an appointment, despite the patient being told they have been booked. It is not always clear if the healthcare provider or the communication support professional is at fault for this. This has also happened to nearly a quarter (24%) of those who need other forms of communication support professionals. Others report that appointments have been cancelled or pushed back because they are told that interpreters are not available.

These problems often stem from a critical misunderstanding embedded within NHS systems and processes. Most NHS services procure interpreting services through external agencies with Service Level Agreements (SLAs) that commonly stipulate a two-week notice period for booking interpreters. Requests made with less notice are treated as "best efforts," meaning agencies are under no contractual obligation to fulfil them.

Healthcare professionals are frequently unaware of this distinction. They believe that when they submit a request, it constitutes a confirmed booking – but in reality, it is often merely a request awaiting interpreter availability. As a result, patients are falsely reassured that an interpreter will be present, only to arrive at their appointment and discover no support is available.

An additional challenge is that the majority of interpreting agencies cover a wide range of languages, with BSL typically just 2% of their market. This creates a fundamental tension in how performance is measured and managed, meaning a supplier can still meet all their pre-agreed targets even if all BSL appointments are unfulfilled. Hence, there is often no real incentive to fill such appointments.

More than half (54%) of those who are deaf or have hearing loss have been forced to rely on either a partner, family member or friend to relay information or interpret for them at a healthcare appointment, at least some of the time.

EXPERIENCES OF VIDEO RELAY SERVICES (VRS)

VRS allows people who are deaf to make a video call to an interpreter. Just under a third of sign language users in our survey have used VRS interpreting to access a GP or hospital appointment (31%). Despite the small sample size (n=37), these figures have been included to give some insight into the experiences of those who have used VRS.

Disabled people are the experts in their own access needs, and while the use of VRS can be one of the adjustments offered to patients, it should not be compulsory or the only option. Communication support must address the needs and preferences of the patient, not the convenience of the provider.

35% report positive experiences, driven by the services' ability to facilitate 'some' communication, or that it is 'better than nothing'. Users often have a more positive experience when VRS is used for phone or video appointments rather than face-to-face. Some flag that it takes time to show healthcare staff how to use VRS, suggesting they are unfamiliar with the technology.

> ***"I'd be able to book appointments or ask questions about health stuff. It was really helpful because I had trouble understanding the text relay, but the VRS gave me confidence to get what I needed."***
>
> - Female, 25-34, sign language user

41% report negative experiences, largely related to screens freezing or the movements being slow due to poor video quality and connection. Interpreter availability via VRS was also raised. These negative experiences cause unnecessary stress to users and affects their confidence in using VRS.

> ***"I go for treatment every 4 weeks at the [hospital] and they refuse to provide a face to face interpreter. They have told me it's because they need to save money. They offer VRS but this is unsuitable for my needs and I have difficulty using it."***
>
> - Female, 45-54, sign language user

"I attend all my appointments with my mother. If the interpreter doesn't turn up my mother will help with communication because otherwise, the appointment can't go ahead until a later date."

- Female, 35-44, needs a communication support professional

Communication support professionals, such as BSL interpreters and lipspeakers, are vital for providing safe and effective healthcare for people who are deaf or have hearing loss.

There is a logistical challenge for commissioners and providers to ensure that the correct support is provided, particularly for emergency or unplanned appointments.

In 2021 a Rapid Review of commissioning arrangements for British Sign Language interpreting services was initiated by NHS England; this found that each ICB should provide consistent provision of BSL interpretations by bringing together all the provider led arrangements into one single ICB wide service. It is not clear whether this has been taken forward and NHS England has not driven such a reform from the centre.

There is a national role for DHSC and NHS England to support on best practice and ensure that communication support is integrated into workforce planning across the NHS.

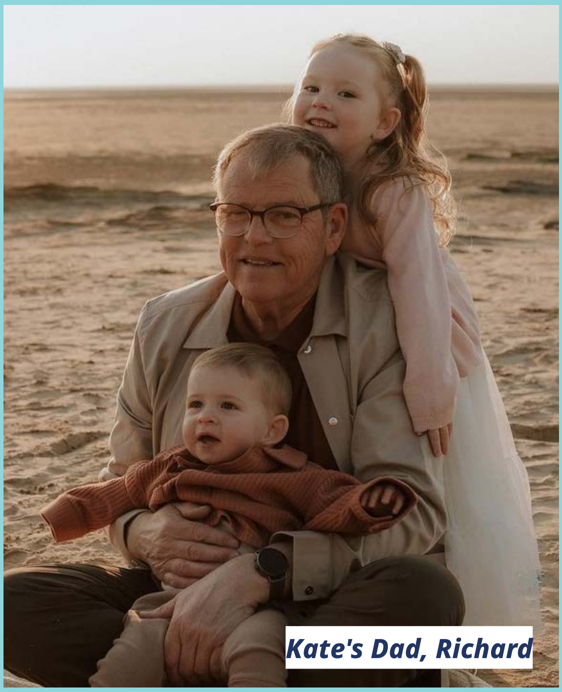
Kate 42, New Brighton shares her story about her father, Richard, who was born profoundly deaf.

Dad, a BSL user, face-timed me in a panic and said 'I can't see. Everything is black.' I drove him to a hospital which has an A&E especially for eyes – but no interpreter. They did lots of tests and at the end of the day they said to me: 'can you tell your dad he's got cancer?' So I told him. We went home in complete shock.

Dad was diagnosed with cancer in 2022 and passed away 23 November 2023. He was just 70 years old. He became disengaged with his care. It was like he felt he had no control over it. His personality just changed, and it killed us to see him slip away before he died. It wasn't because of the cancer. It was because of the access issues.

You always know from being within the deaf community how many barriers there are, but when you go through something so big as having a terminal illness, it really does bring to light how little access there is out there for a deaf person.

"I had to suppress every emotion to be able to interpret and that affected me. Even though we knew Dad was going to pass away, I don't feel like I said goodbye to him."

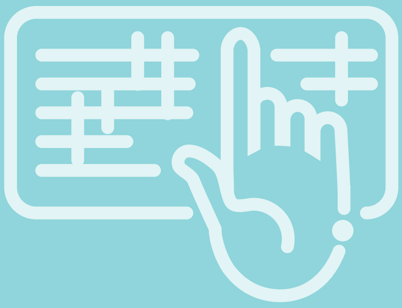


Kate's Dad, Richard

Image: Hannah Ainsworth Photography

GETTING IT RIGHT - PROFESSIONAL COMMUNICATION SUPPORT

Having the right communication support in place when attending appointments, such as a BSL interpreter, lip speaker or notetaker, is transformative for people’s experiences of care and their ability to fully engage with their own health and care plans.
It can increase confidence and empower patients to be in control of their care.



> ***“After some issues surrounding me needing help, I was allocated a lipspeaker. She was fabulous and I actually came away feeling that for once I fully understood what was being said to me about my condition and follow on treatment.”***
>
> - Female, 45-54, needs a communication support professional

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> ***“During chemotherapy, services were booked timely, and I had the same two BSL interpreters each time. I felt I was in control of my care.”***
>
> - Male, 45-54, sign language user

RECOMMENDATIONS

DHSC should:
- **Review the way in which providers and commissioners across the NHS procure communication support professionals to ensure patients receive timely access to healthcare, and then develop best practice guidance informed by input from service users.**
- **Work with the Women and Equalities Unit to understand whether there is an adequate supply of all types of registered communication support professionals and integrate this group into future NHS workforce planning.**

ICBs should:
- **Review and revise interpreting contracts to ensure they include separate performance metrics and targets for sign language interpretation that ensure high standards specifically for deaf clients.**

NHS systems fail to equip staff to meet the needs of patients

> *"If you can't communicate well, you can't fully understand the patient's need and give them the full care they require."*
>
> – District or practice nurse

Only a quarter of NHS staff feel confident that they can always meet the information and communication needs of patients who are deaf or have hearing loss. Staff consistently report that this low confidence is not due to a lack of willingness but because they are held back by poor systems, insufficient training, and time pressures

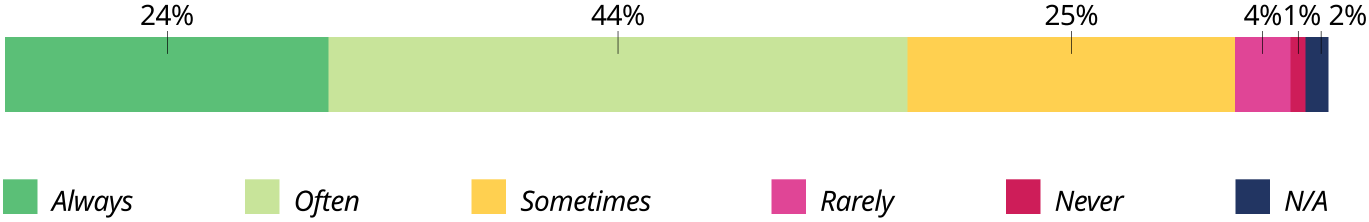


Figure 7: ***Frequency with which NHS staff feel that they can meet the information and communication needs of patients who are deaf or have hearing loss*** *(n=404)*

> *"The communication system for the deaf can be massively improved through providing training to staff and putting robust standardised systems in place."*
>
> - District or practice Nurse

NHS staff who do not feel confident that they can always meet patient needs face four main barriers:

34%

a lack of training

32%

a lack of time or capacity in workload

30%

a lack of functionality of IT systems

31%

a lack of standardised processes

NHS staff rely on systems and processes to provide them information on the communication needs of the patients they see – but these systems are clearly not fit for purpose. Staff are left on the back foot, trying to manage communication barriers in real time during appointments, which places both patients and professionals under avoidable strain. The rollout of Electronic Patient Records across the NHS has been a complicated process, although the Government has said it is committed to legislating for a single patient record. This provides a clear opportunity to think about the role that patient records can play in flagging communication support needs to health professionals.

RECOMMENDATIONS

DHSC should:

- **Audit the functionality of NHS IT systems to support the delivery of the AIS and ensure that the completion of the Electronic Patient Record roll-out includes all accessibility requirements to deliver the AIS.**

- **In co-production with people with lived experience, design the proposed 'Patient Passport' – where a patient record is stored digitally in one place – with deaf and disabled people who need communication support professionals to access NHS services.**

A lack of deaf awareness amongst NHS staff, and a need for training

The evidence on the extent to which the five steps of the AIS are being implemented reveals a clear disparity between how well professionals think they are meeting patients' communication needs, and what patients told us they actually experience.

In addition, 71% of professionals agree that deaf people and people with hearing loss are treated fairly by the NHS. However, only 20% of people who are deaf or have hearing loss agree that they are treated fairly.

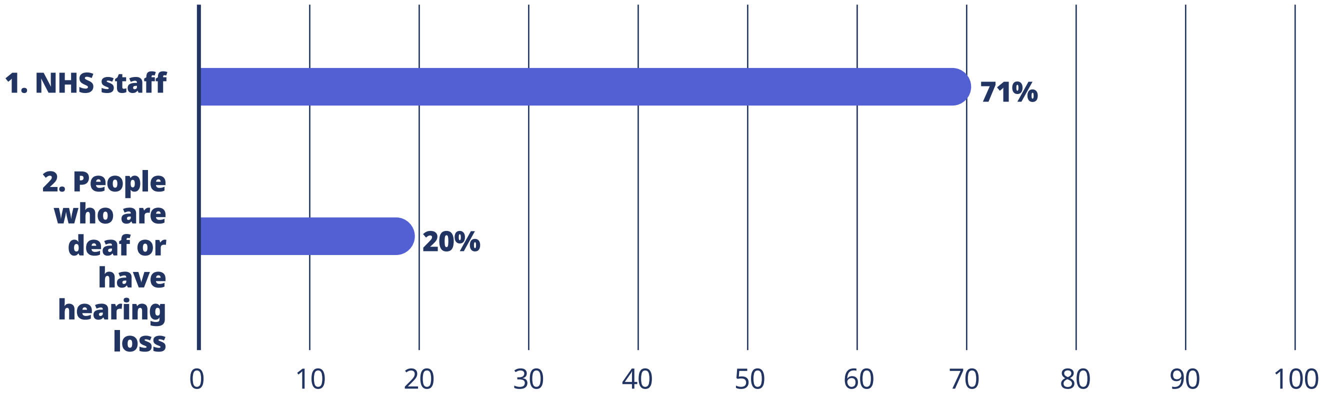
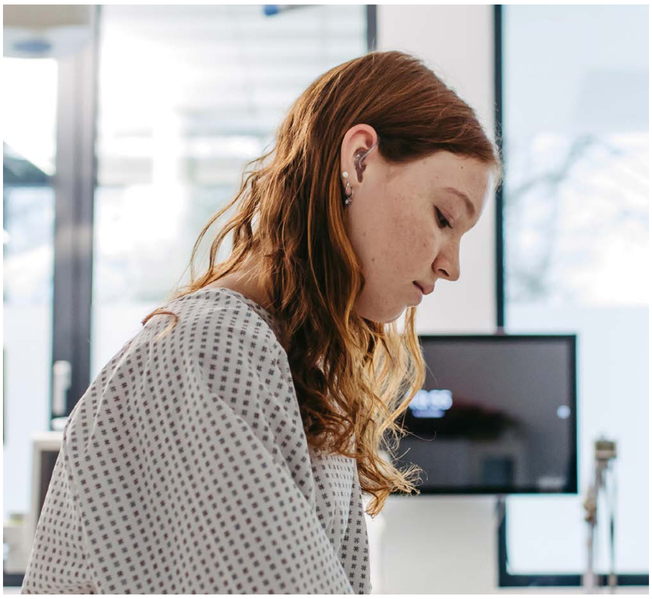


Figure 8: ***Agreement with the statement "Deaf people and those with hearing loss are treated fairly by the NHS"*** *(n=404 NHS staff; 1114 people who are deaf or have hearing loss)*

> ***"[There is a] total lack of deaf awareness. I am a lip reader and constantly have to ask to see the person's face when they speak to me and (ask them) not to put their hand over their mouth - I believe that all NHS staff would benefit from attending deaf awareness training."***
>
> \- Female, 75+, needs other reasonable adjustments

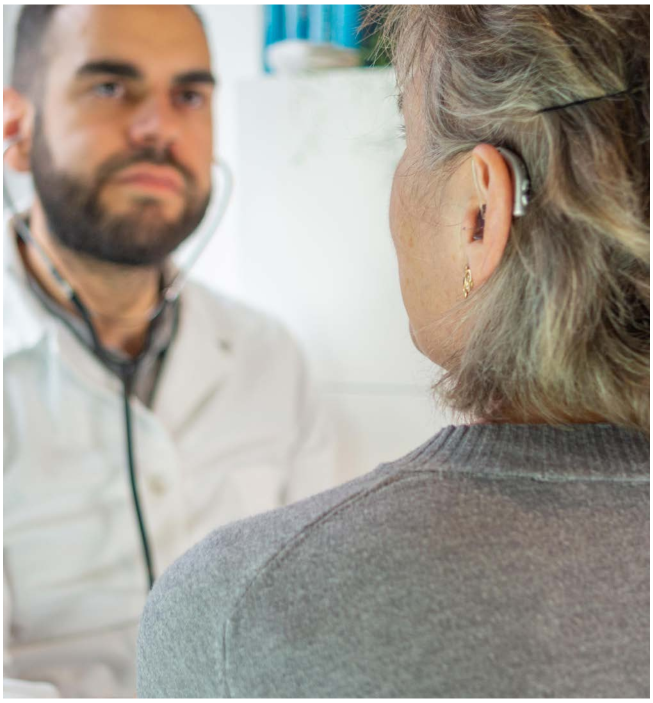
People who are deaf or have hearing loss are the definitive experts on their own experiences. The gap between their experience and the assumptions made by professionals shows a worrying lack of understanding from with the NHS about barriers deaf patients and patients with hearing loss face.

A core theme of comments from people who are deaf or have hearing loss is in relation to a lack of deaf awareness amongst staff. Many said the changes they require to access healthcare are actually very simple, for example, speaking clearly, facing the patient and not speaking too quickly. These are all skills covered by basic deaf awareness training. Others reflect a need for more knowledge about the requirements of the AIS itself.



"Everyone in the NHS needs to have a full understanding and knowledge of the AIS. Not all of them do."

- Male, 35-44, sign language user



There is a sense of frustration that little has changed over time regarding accessible communication. People expect better 'in this day and age' and some suggest accessibility is getting worse.

A desire for widely offered and better training on deaf awareness and the Accessible Information Standard is echoed by professionals.

Just 36% of NHS staff say they have received workplace training on the AIS. 46% have received training on supporting patients who are deaf or have hearing loss, and 39% have received training on deaf awareness. One-third (34%) say that a lack of training is the primary reason that providers are not meeting the communication needs of patients who are deaf or have hearing loss. Many say that they want more training, including training for specific staff groups like administrators and receptionists.

"I think there needs to be more training given everywhere. More and more people are coming in with hearing loss and sight loss and I think we all need to have more training in how to help these patients."

- GP

Levels of current workplace training on AIS and deaf awareness are consistently low (see Figure 9), with almost a third (31%) saying they had not received any of the training options. Where training has been received, satisfaction with the quality is generally low.

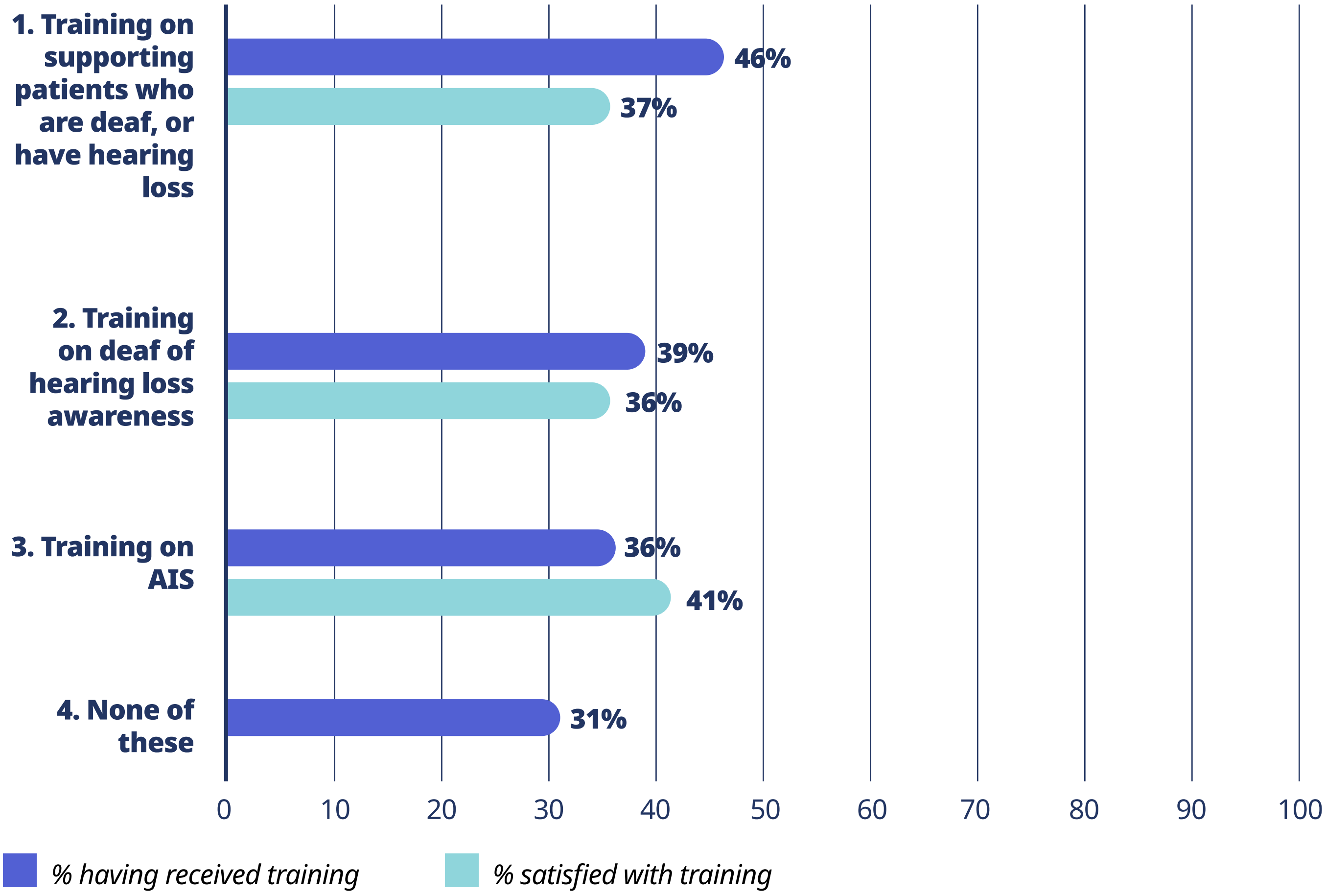


Figure 9: ***Proportion of NHS staff receiving different types of training and satisfaction with it***
(n=187 who received training on supporting patients who are deaf or have hearing loss; 157 who received training on deaf or hearing loss awareness; 145 who received training on the AIS)

Staff training is a key mechanism which can underpin delivery of the AIS. As well as understanding the general principles, staff need to know how to record, flag, share and access patients' communication needs, and book any necessary support, on the specific systems they use – this applies both to frontline medical staff as well as administration and management roles which facilitate people around the system. Our evidence shows that staff would benefit from both AIS and deaf awareness training, but this needs to be high quality and tailored to their role.

> ***"I consulted a doctor for a bad back. I told him that I had hearing problems and he was good at maintaining eye contact and speaking clearly. He also showed me the results of an MRI scan on a computer screen so that I could see what he was explaining verbally. It was a good experience".***
>
> - Female, 55-64, needs other reasonable adjustments

GETTING IT RIGHT - BEING DEAF AWARE

People appreciate when NHS staff adapt how they communicate in order to meet the needs of patients, such as facing them, speaking clearly, and ensuring their lips are visible to facilitate lip reading, or offering to remove their masks, for example. People also appreciate other adjustments, when appropriate, such as using written communication during appointments, or enabling longer appointments to ensure there is time to lipread and be confident that information has been understood.

Positive highlights include instances where healthcare professionals and administrative staff go out of their way to accommodate communication needs and ensure that a patient's needs are met, such as ensuring that patients knew when their names were being called in waiting rooms. It is also valued when professionals check they have been understood.

There is significant positive impact for deaf people and people with hearing loss when communication needs are met. It enables them to feel informed, reassured, and as though they matter:

> ***"In A&E the nurse was very good at facing me and making sure I understood what she was saying and what was happening. This enabled me to remain calm and feel in control of the situation."***
>
> Female, 65-74, needs other reasonable adjustments

RECOMMENDATIONS

DHSC should:

- **Work with professional bodies and the medical Royal Colleges to ensure that training curriculums and continuous professional development (CPD) requirements give clinical staff an understanding of the Equality Act, the AIS and deaf awareness.**

- **Introduce a requirement for all NHS staff, clinical and administrative, to undertake mandatory training on the AIS and deaf awareness, including on local systems to ensure a technical understanding of how to comply with the five steps.**

Complaints processes are often inaccessible and rarely lead to improvements

Nearly 1 in 5 (19%) have made a complaint to a healthcare provider about their communication needs not being met. A further 37% have had a good reason to complain but have not pursued it, usually because they feel it will not change anything or will not lead to change.

20% of those with cause to complain did not do so because the process was inaccessible and only 36% of those who did make a complaint found the process itself accessible to them as someone who is deaf or has hearing loss. This, along with the failure of the complaints process, with processes "dragging on" or feeling "too hard to pursue" can lead to people losing faith and giving up.

19%

have made a complaint to a healthcare provider about their communication needs not being met

> ***"I have made several complaints about my GP surgery (GP called it "too challenging" to deal with me via a helper). All my complaints have just been ignored. I have given up. I am too upset to press it further."***
>
> - Female, 55-64, needs a communication support professional

26%

say their complaint was successful

Just over a quarter of people (26%) say their complaint was successful. For some, changes have been made as a result of their complaint, including commitments to staff training, communication needs finally being properly recorded, and the provision of alternative contact methods. However, some of these provisions seem to be inconsistent or temporary.

> ***"I was listened to and my records amended to include my AIS needs. Unfortunately, this has now been undermined by an unclear phone system at the practice and the insistence on using texts which I regularly miss instead of e mail which I asked to be noted as my preferred communication needs. The use of e mail since the complaint has been inconsistent to say the least."***
>
> \- Male, 65-74, needs other reasonable adjustments

In contrast, 46% say their complaint was unsuccessful, often reporting it was ignored or dismissed, and many people say there has been no change or improvement following a complaint.

46%

say their complaint was unsuccessful

> ***"I got a response, an apology and promise to take on board the lessons learnt, but nothing changed - still the same problems when I went to the next appointment."***
>
> \- Female, 45-54, needs other reasonable adjustments

It is unacceptably ironic that people face a double barrier when they cannot complain about inaccessible healthcare because of an inaccessible complaints process. This not only denies them their right to have their issues understood and rectified, it denies the NHS the information it needs to identify ongoing problems and make systematic changes.

RECOMMENDATIONS

DHSC should:

- **Review the accessibility of NHS complaints systems.**
- **Ensure that complaints related to the Equality Act and AIS are flagged and reviewed in order to feed into future policy development.**

Deprioritised and ignored – the lack of accountability in providing accessible healthcare

The findings of this report suggest a routine failure by the NHS to meet the needs of people who are deaf or have hearing loss, including key requirements embedded in the AIS to identify and record people’s communication needs, share and flag them across NHS systems, and to make the necessary adjustments to meet those needs.

This finding that the NHS is not meeting the requirements of the AIS is not a new one. In recent years, a series of reviews, including a prior report from SignHealth, RNID, and other charities in 2022, have provided a strong evidence base that NHS providers are failing in this regard.

All these reviews made a series of careful and well-evidenced recommendations for change, highlighting areas of good practice to illustrate how improvements could be made. Yet several years on, the findings of this report show that the NHS is still routinely failing to meet the communication needs of people who are deaf or having hearing loss.

> ***“Legally, professionally and ethically, deaf insight training should be compulsory for all doctors. Right now, the experiences of deaf people and people with hearing loss are shocking. I have met patients who have been referred to palliative care services who have not understood that they will no longer be receiving cancer treatment – they haven’t understood that they are dying.”***
>
> - Dr Natasha Wilcock is a deaf doctor who works in palliative care.

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[1] Review Report: (https://www.england.nhs.uk/wp-content/uploads/2017/07/accessible-Info-std-review-report.pdf)
[2] https://www.england.nhs.uk/wp-content/uploads/2018/09/guidance-for-commissioners-interpreting-and-translation-services-in-primary-care.pdf)
[3] https://www.england.nhs.uk/long-read/the-review-report-equality-objectives-and-information-review-as-at-31-march-2023/

Accessible information: Fifteen years without progress

2010

The Equality Act comes into law – enhancing the rights that disabled people have across society, including within the NHS.

2012

The Health and Social Care Act 2012 allows the Government to publish the Information Standard – it sets out statutory guidance on how the NHS handles information.

2013

RNID published Access all Areas? The report showed that the Equality Act was failing to provide equitable access to healthcare.

2014

SignHealth published Sick of it, which showed that British Sign Language (BSL) users had worse health outcomes than the general population.

2015

NHS England approve the new 'Accessible Information Standard' and NHS organisations begin preparation for implementation of the Standard.[1]

2016

The AIS comes into force, with NHS organisations required to meet the five steps.

2017

January-March: NHS England leads a review of the Standard to assess impact and check its fitness for purpose.

August: Revised versions of the specification and Implementation Guidance are issued following a post-implementation review of the Standard.

2018

Guidance for commissioners on interpreting and translation services in primary care is issued.[2]

2019

Updated guidance for commissioners on interpreting and translation services in primary care.

2021

North East Commissioning Support consultancy undertake a Rapid Review of commissioning arrangements for British Sign Language interpreting services; it recommends NHS 111 to be broadened to provide VRS support for emergency, urgent and out of hours situations.

2022

Parliament passes the Health and Care Act 2022. The Bill contains an enabling mechanism allowing the Government to strengthen the required level of compliance required with information standards

February: SignHealth and RNID, alongside other charities, publish a Review of the NHS Accessible Information Standard for deaf and disabled people., showing a routine failure of NHS organisations in meeting the Standard.

NHS England commissions North of England Commissioning Support Unit (NECSU) to do a formal review of the Accessible Information Standard. This review makes 14 recommendations to support the redrafting of the AIS to be rolled out for implementation from April 2023[3]

2022/2023

Meetings with the AIS Programme Board made up of stakeholders and organisations representing those with lived experience, including Healthwatch, SignHealth, RNID, CQC, DHSC, local authority providers of care and others. An updated version of the Accessible Information Standard is expected, but not yet published.

2025

March: The Government announces the planned abolition of NHS England, meaning responsibility for the AIS will pass to the Department of Health and Social Care.

POOR ACCOUNTABILITY AND ENFORCEMENT OF THE ACCESSIBLE INFORMATION STANDARD

The essential reason that the AIS has not delivered for people who are deaf or have hearing loss is lack of accountability and enforcement across the NHS. There is no sufficient mechanism or framework in place to ensure that busy and stretched NHS organisations comply with the AIS; nor is there resource to support them to do so.

Whilst the AIS sets out people's right to accessible healthcare under the Equality Act 2010, the legal mandate of information standards like the AIS is currently weak.

There is also no proper monitoring by a regulatory body; whilst the Care Quality Commission looks at the performance of organisations in meeting people's communication needs as part of its ratings process, assessment of performance against the AIS within the CQC's single assessment framework appears piecemeal, and the Department of Health and Social Care have confirmed that compliance with the AIS is not directly assured by the Care Quality Commission.

Within the NHS itself there is no requirement for organisations to report on their compliance with the AIS. There is little accountability for commissioners and providers, and no local named lead with the responsibility to deliver the Standard. If patients wanted to consider the performance of a provider when choosing where to be treated, they would have no ability to compare existing compliance.

In early 2022, in light of concerns that NHS organisations were not always meeting AIS requirements, NHS England initiated a formal review of the AIS. They commissioned the North of England Commissioning Support Unit (NECSU) to carry out an initial assessment, which found that the requirements of the AIS were not being met across health and social care.

NHS England accepted the recommendations of this report for improving compliance with the AIS. It began a process of revising the AIS with the aim of having an updated and improved standard agreed by April 2023, with a focus on "improved implementation and accountability".

However, since then, the NHS's revision process for the AIS has been beset with repeated delays and inadequate plans to ensure that NHS providers will comply with the updated standard.

Almost 10 years after its initial publication, there is now an inescapable conclusion that the AIS and the communication needs of disabled people have been deprioritised and ignored by NHS England and the Department of Health and Social Care. The NHS is systematically disregarding the needs of millions of people and leaving them at risk of preventable harm.

THE LEGISLATIVE CONTEXT

The Accessible Information Standard comes from powers contained within the 2012 Health and Social Care Act, under which all NHS organisations ‘must have regard to’ the provisions within any information standard. This does not compel NHS organisations to implement an information standard like the AIS.

But the 2022 Health and Care Act contains “draft” legislation which, if activated, would allow the Government to increase the legal enforcement of the standards. Section 95 of that Act would replace the existing requirement for NHS bodies to ‘have regard to’ for information standards, instead, requiring that they ‘must comply” with an information standard. Section 95 also provides Ministers of Government with the power to compel the publication of documents, records or other evidence of compliance with an Information Standard.

At the moment, this legislation hasn’t yet been activated - although the Government have committed to doing this in 2025.

If this legislation that would make information standards like the AIS compulsory was activated - it would mean NHS England would have to publish a new version of the AIS. And yet, we know that the current process for updating the AIS has been beset by years of delay. It is therefore essential that the process to update the AIS is prioritised and sped up.

Once the power is in place Ministers need to utilise this to compel NHS bodies to provide and publish documents and other evidence of compliance with the AIS – this needs to be an evolving process which works with people who are deaf or have hearing loss to ensure the information published captures their experience.

OPPORTUNITIES FOR CHANGE

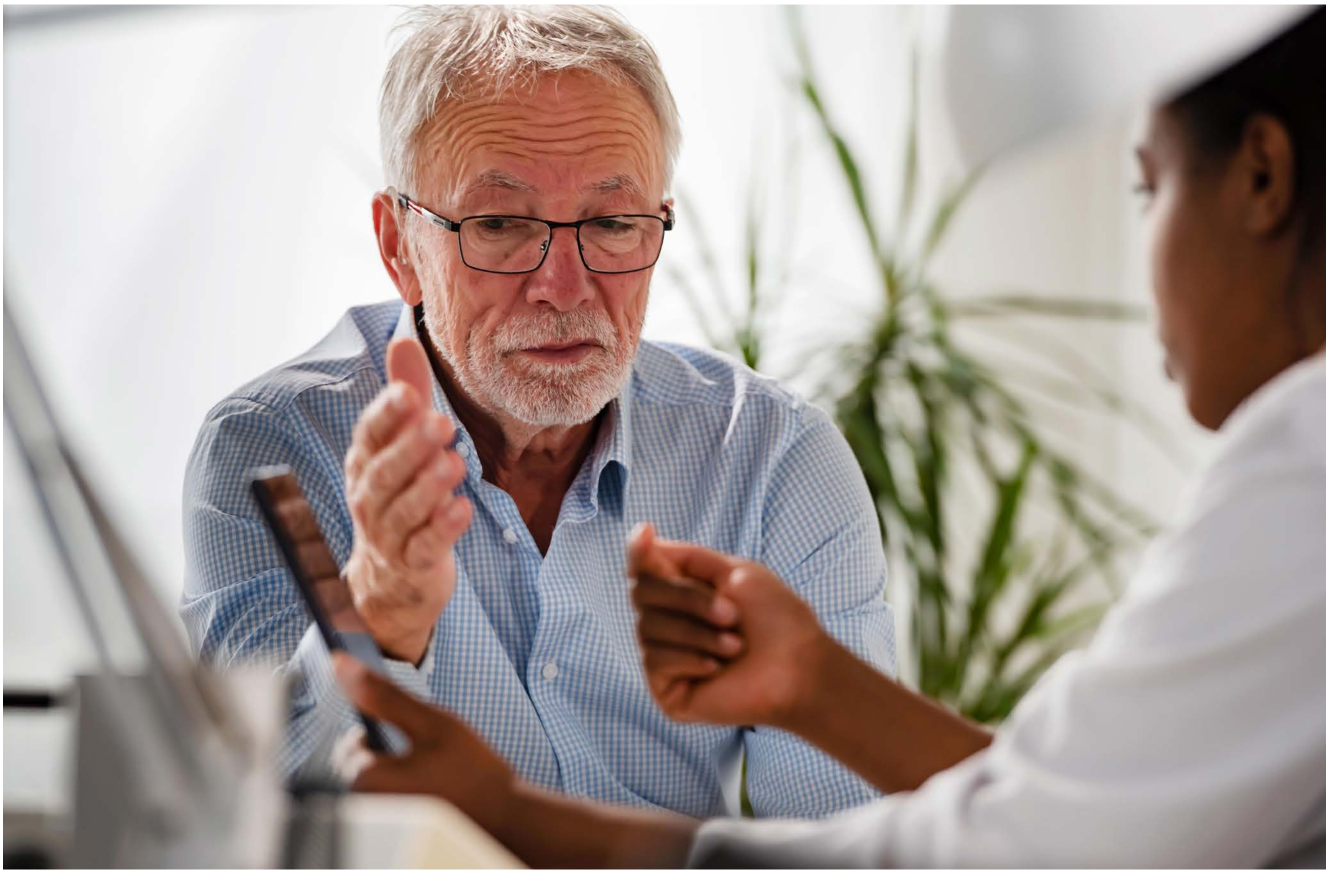
In this report, we have set out that the key reason for the NHS's failure to routinely meet people's communication needs is a failure to meet the AIS. We therefore make a series of recommendations to government on the enforcement of, and accountability for, the AIS.

Encouragingly, our research results – and those of previous AIS reports - suggest powerful opportunities for change.

In setting out its plan to abolish NHS England and restore 'democratic control' over the NHS, the Government has tacitly acknowledged the need to make the NHS more responsive to the concerns of patients. Our timeline (see page 37) has demonstrated that at no point has NHS England adequately responded to the concerns of patients who are deaf or have a hearing loss on the accessibility of NHS services. It is now clear that DHSC and Ministers will have direct responsibility for the problems people who are deaf or have hearing loss face within the NHS: the buck will stop with them.

The upcoming period of transition and reorganisation cannot, however, become a reason for further delays in passing the critical secondary legislation or strengthening the AIS. Likewise, the drive for efficiency savings across ICBs cannot become a reason why health services fail to improve their compliance with it. Rather, we hope DHSC and Ministers capitalise on this opportunity. to provide renewed leadership and coherence to the various processes, systems and policies which need to be brought together to make the NHS Accessible.

Improved use of technology and better electronic patient record systems should also be part of a plan for change. Draft proposals put forward by DHSC, as part of the upcoming NHS 10-year plan, for a single patient record to be held on the NHS App, should be designed to allow for patients to easily record and update their own communication needs, and allows for these needs to be shared and flagged easily across NHS trusts and GP surgeries. The NHS App should also be designed to allow patients to book communication support such as a BSL interpreters, as well as alternatives to booking appointments by telephone. It is important to include people with lived experience in the development of these plans and ensure there are mechanisms to meet the communication needs of people who are digitally excluded.



We also believe that the focus on workforce planning across the NHS is an opportunity to look at the inclusion of deaf awareness training and training on the AIS, both in the curriculums for those qualifying to practice and in the mandatory training for those working across the NHS.

Finally, people with lived experience of communication needs should be at the heart of plans for change. NHS providers should review the ability of services to meet the AIS alongside panels of people with lived experience.

RECOMMENDATIONS

DHSC should:

- **Acknowledge the past failure of the NHS to routinely meet the Accessible Information Standard, and work with NHS England and providers to agree on a transformation plan to deliver the right to healthcare to people with communication needs**

- **Make the AIS legally enforceable and mandate compliance by all NHS bodies by enacting Section 95 of the Health and Care Act 2022.**

- **Ensure that individual roles are assigned responsibility for implementation of the AIS at every level of the health and social care system – using the power granted by enacting Section 95 to the Health and Care Act 2022 to require evidence of compliance.**

- **Ensure that, during the two year transition period of responsibilities from NHS England to DHSC, the effective handover of work to revise and implement the AIS is properly resourced, and does not suffer further delays or become deprioritised.**

- **Direct the Care Quality Commission to improve the process by which it considers the performance of organisations in meeting people's accessible communication needs, with a specific section on the AIS to be included in CQC assessment frameworks, and set out the process by which the CQC may use its regulatory powers where an organisation is not meeting accessible communication needs.**

NHS England, before it is abolished, should:

- **Publish a revised and strengthened version of the AIS which outlines the steps that providers must take as an absolute requirement of the Standard to meet the communication needs of patients across the NHS.**

- **Develop a set of measurable metrics to allow progress on implementation of the AIS to be tracked and reported – with patients given information on individual providers to allow them to make a meaningful choice about where they access healthcare.**

Samantha Baines: *Advocating for better healthcare access for people who are deaf and have hearing loss*

Images: Louise Haywood-Schiefer

> ***"I have been navigating the NHS as a deaf person all my life and unfortunately, I have never had a positive experience of communication support within the NHS."***

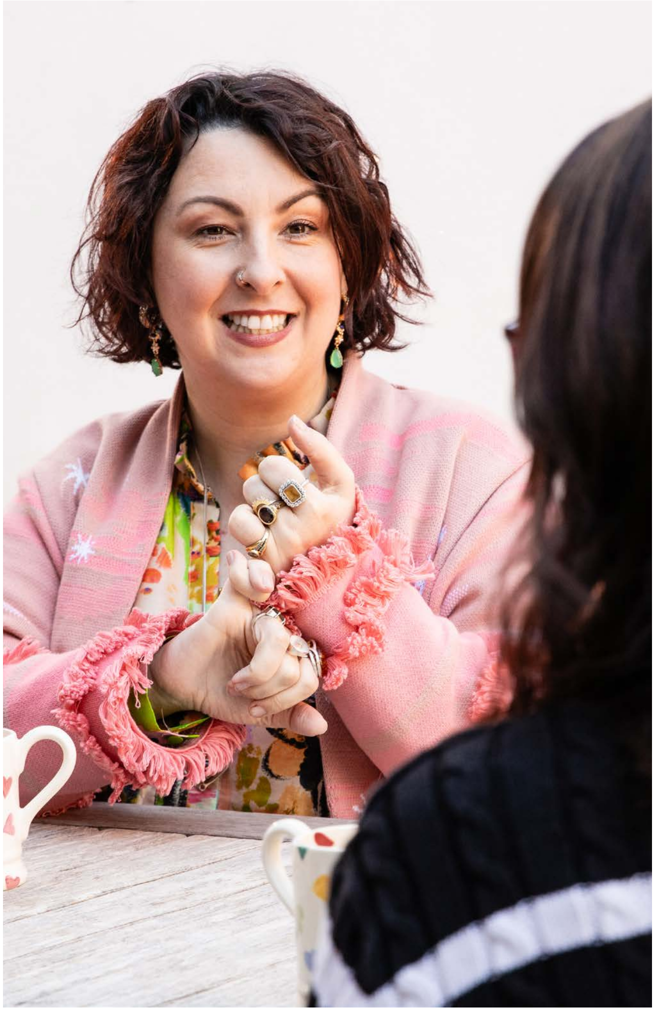
Actress, comedian, and author Samantha Baines is a passionate advocate for deaf awareness. As someone who is deaf and wears hearing aids, she has firsthand experience of the challenges that many deaf individuals face when accessing healthcare. One of the most difficult moments in her life—giving birth—was made even more stressful by a lack of appropriate communication support.

One of the most difficult experiences I had was during my NHS c-section. I had specifically requested a lipspeaker to be present so that I could follow what was happening. The staff had no idea what a lipspeaker was, and I had to repeatedly explain and even direct the midwife team to a website that explained how to book one. Eventually, a lipspeaker was arranged, but when my waters broke early, there wasn't one available. As a result, I didn't have one during my surgery. Fortunately, a nurse in the room had a deaf mother and was able to assist, but she had other responsibilities and couldn't solely focus on me. It left me feeling even more vulnerable in an already vulnerable situation.

This experience made me feel ignored and undervalued as a person simply because I am deaf. I had to fight at every stage of my difficult pregnancy just to have access to the support I needed. I was already exhausted from the pregnancy itself, and the added stress of constantly having to advocate for myself was overwhelming. All mothers deserve to be able to communicate and understand what is happening at all stages of their pregnancy—especially during the birth. The fact that deaf mothers are being denied this right is a serious human rights issue.

The NHS needs to make significant changes to improve communication accessibility for deaf patients. There should be better systems in place for recording communication needs, and these records should be checked before appointments to ensure communication needs are met. Staff also need proper training to understand what adjustments are required and how to implement them. Additionally, services should provide alternative communication options, such as email addresses instead of relying solely on phone calls.

I have been navigating the NHS as a deaf person all my life and unfortunately, I have never had a positive experience of communication support within the NHS. Despite multiple healthcare professionals recording my communication needs, only once has a staff member checked this information ahead of time. This failure to acknowledge and meet the needs of deaf patients is unacceptable and must change.



Recommendations

FOR THE DEPARTMENT OF HEALTH AND SOCIAL CARE (DHSC)

Implement legislation

- Make the AIS legally enforceable and mandate compliance by all NHS bodies by enacting Section 95 of the Health and Care Act 2022.
- Ensure that individual roles are assigned responsibility for implementation of the AIS at every level of the health and social care system – using the power granted by enacting Section 95 of the Health and Care Act 2022 to require evidence of compliance.

Leadership and Accountability

- Acknowledge the past failure of the NHS to routinely meet the Accessible Information Standard, and work with NHS England and providers to agree on a transformation plan to deliver the right to healthcare to people with communication needs.
- Ensure that, during the two-year transition period of responsibilities from NHS England to DHSC, the effective handover of work to revise and implement the AIS is properly resourced, and does not suffer further delays or become deprioritised.
- Direct the Care Quality Commission to improve the process by which it considers the performance of organisations in meeting people's accessible communication needs, with a specific section on the AIS to be included in CQC assessment frameworks. Additionally, set out the process by which the CQC may use its regulatory powers where an organisation is not meeting accessible communication needs.
- Review the way in which providers and commissioners across the NHS procure communication support professionals to ensure patients receive timely access to healthcare, and then develop best practice guidance informed by input from service users.
- Work with the Women and Equalities Unit to understand whether there is an adequate supply of all types of registered communication support professionals and integrate this group into future NHS workforce planning.
- Provide patient facing information setting out patients' rights to equitable healthcare under the Equality Act and AIS, and the steps they can take to record their communication preferences and how to complain if these rights are not met. All information should be provided in multiple formats created through a process of co-production with service users.

Training

- Work with professional bodies and the medical Royal Colleges to ensure that training curriculums and continuous professional development requirements give clinical staff an understanding of the Equality Act, the AIS and deaf awareness.

- Introduce a requirement for all NHS staff, clinical and administrative, to undertake mandatory training on the AIS and deaf awareness, including on local systems to ensure a technical understanding of how to comply with the five steps.

Complaints

- Review the accessibility of NHS complaints systems.

- Ensure that complaints related to the Equality Act and AIS are flagged and reviewed in order to feed into future policy development.

IT and the NHS APP

- Audit the functionality of NHS IT systems to support the delivery of the AIS and ensure that the completion of the Electronic Patient Record roll-out includes all accessibility requirement to deliver the AIS.

- In co-production with people with lived experience, design the proposed 'Patient Passport' – where a patient record is stored digitally in one place – with deaf and disabled people who need to be supported by communication support professionals to access NHS services.

- In co-production with people with lived experience, design the NHS App to allow for patients to record and share their communication needs across NHS systems, book communication support, and make appointments.

- Review best practice across the NHS of alternative contact methods and support commissioners and providers with guidance on enabling patients to contact them.

Recommendations

NHS ENGLAND

NHS England, before it is abolished, should complete some of its ongoing projects around the AIS. These are to:

- Publish a revised and strengthened version of the AIS which outlines the steps that providers must take as an absolute requirement of the Standard to meet the communication needs of patients across the NHS.

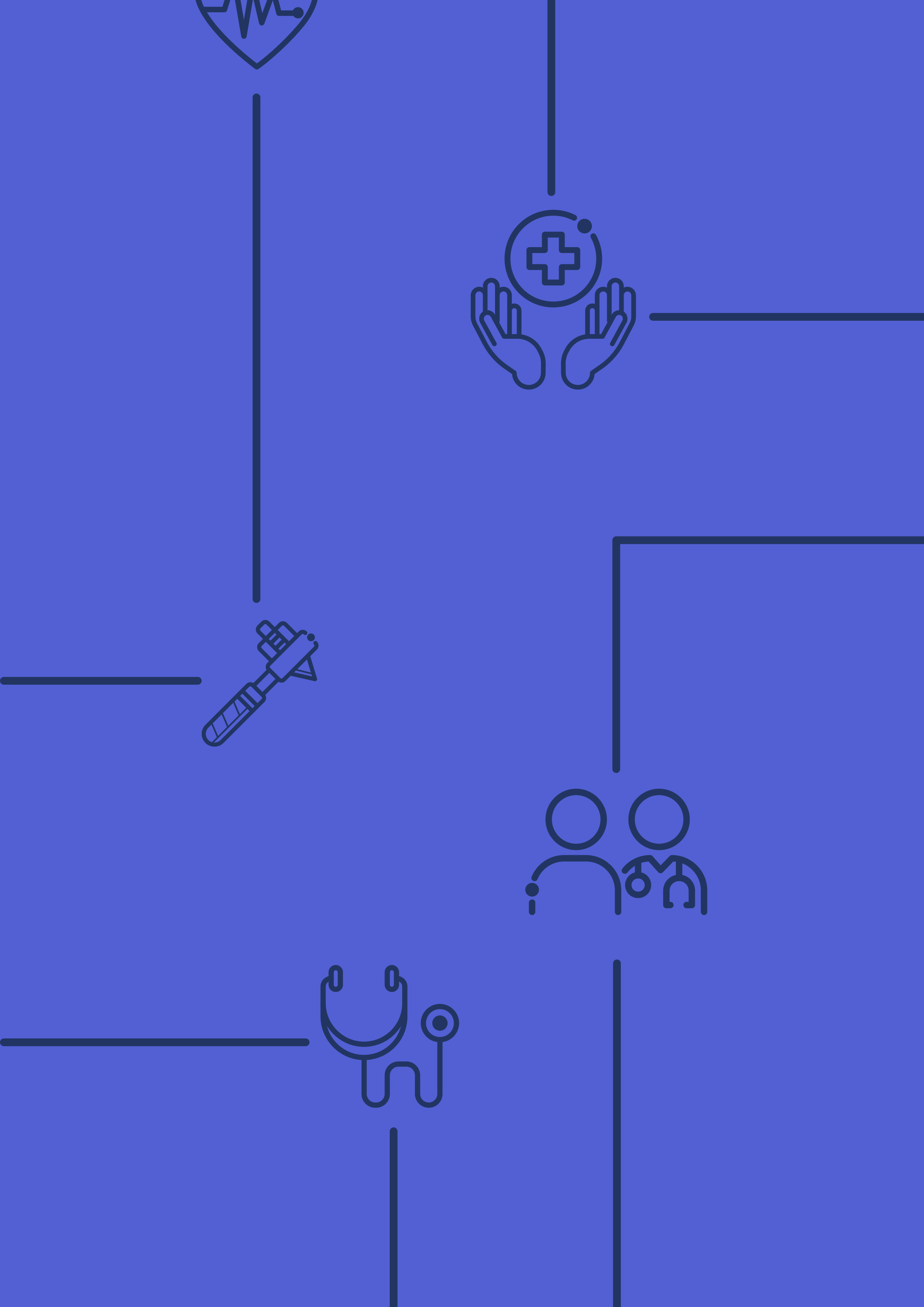
- Develop a set of measurable metrics to track and report progress on implementation of the AIS – with patients given information on individual providers to allow them to make a meaningful choice about where they access healthcare.

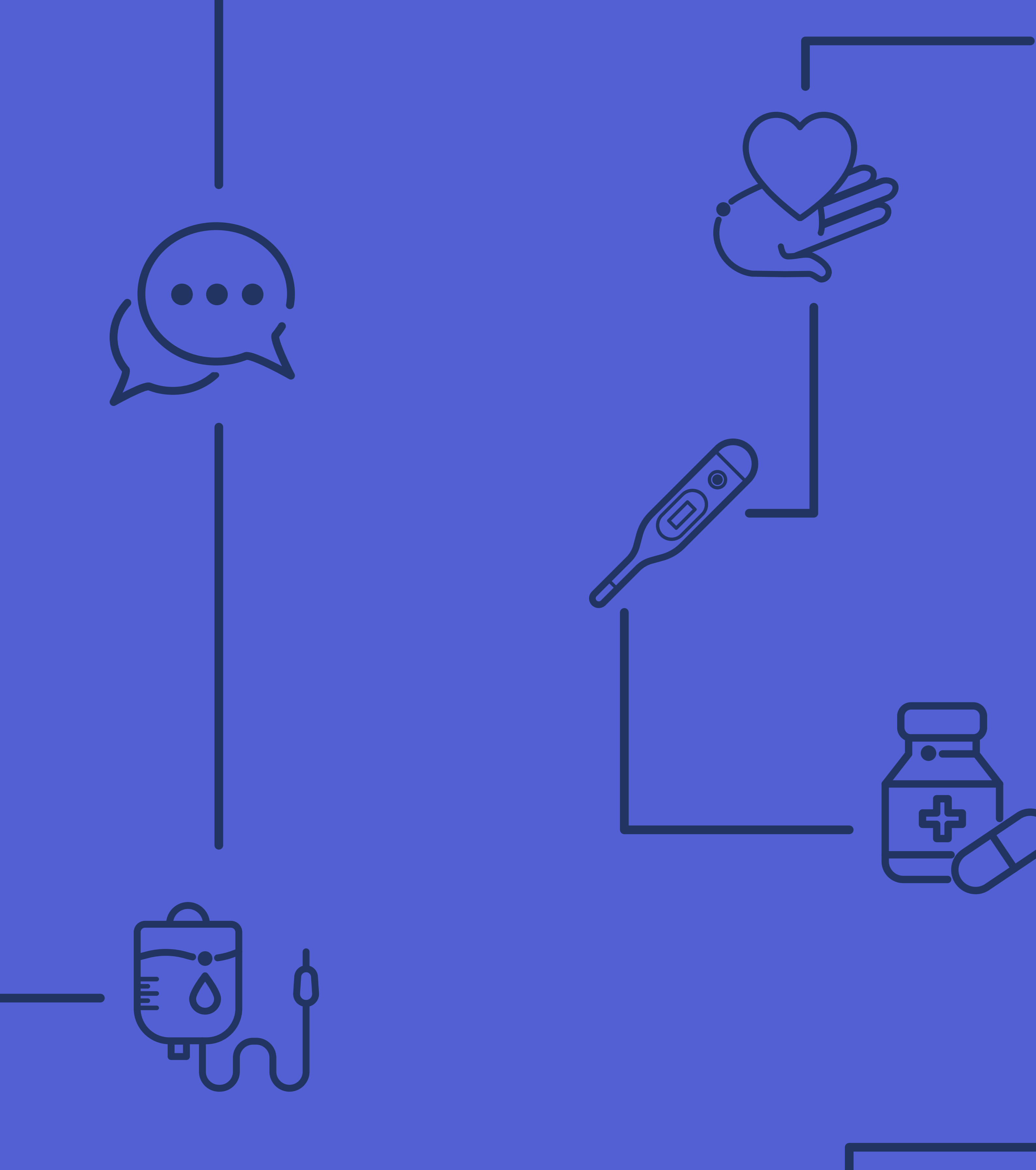
COMMISSIONERS

- Require the providers they manage – whether in the NHS or private sector – to set out evidence of compliance with the Equality Act and AIS as a key part of their tendering and contract monitoring.

- Consider contracting specialised BSL interpreting agencies with separate performance metrics and targets that ensure high standards specifically for deaf clients. These specialised agencies would help to ensure services are delivered on time, with fewer cancellations, and greater cultural awareness and accessibility.

- 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 to provide equitable access to appointments.





Supporting people
who are deaf, have
hearing loss or tinnitus

THE DEAF HEALTH
CHARITY
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