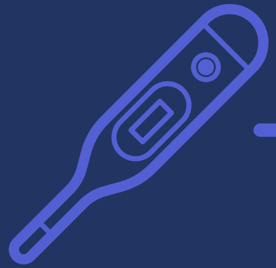
STILL IGNORED: THE FIGHT FOR ACCESSIBLE HEALTHCARE

2025 RESEARCH REPORT

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

THE DEAF HEALTH CHARITY SIGNHEALTH

Contents



Introduction

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.

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 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' communication needs is a breach of the Equality Act.

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 AIS. 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].

In late 2021, a coalition of charities including RNID and Sign Health surveyed NHS and social care professionals in England, as well as disabled people who have accessible information and communication needs, about the AIS[2]. The findings indicated a lack of training, and a poor understanding of communication access as a patient right and of providers' responsibility to follow the AIS. Poor implementation of the AIS was found to have serious practical, health and emotional consequences. In addition, research from Parmar et al. (2025), sets out similar findings.[3] Building on our previous research, RNID have collaborated with Sign Health to improve and update our current evidence base on the barriers to accessing NHS healthcare for people who are deaf or have hearing loss.

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

[2] SignHealth (2022) Review of the NHS Accessible Information Standard

[3] Parmar B, Henshaw H, Howe S, Dickinson AM, Rolfe C, Le Mere P, Blondiaux-Ding E, Musker Z, Stevenson R, Hughes SE, Calvert S, Stapleton E, Turton L. "I always feel like I'm the first deaf person they have ever met:" Deaf Awareness, Accessibility and Communication in the United Kingdom's National Health Service (NHS): How can we do better? PLoS One. 2025 May 7;20(5):e0322850. https://doi.org/10.1371/journal.pone.0322850

This report sets out the findings of this new research. It 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 and demonstrates that the NHS does not have the systems and processes in place to fulfil the right to accessible healthcare for people who are deaf or have hearing loss.

The consequences can be devastating. People who are deaf or have hearing loss avoid 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 failures of the NHS to provide accessible healthcare.

Awareness of the key regulation amongst NHS staff is low, patient information isn't being recorded and shared accurately, staff do not know how to access the information they need, or what action to take to ensure the needs of patients 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.

Together, RNID and SignHealth set out recommendations from this research in our policy report, ***Still ignored: the fight for accessible healthcare*** which urges government to take note, grasp the opportunity and end the discrimination that people who are deaf or have hearing loss face when accessing NHS services.

The Accessible Information Standard

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.

Method

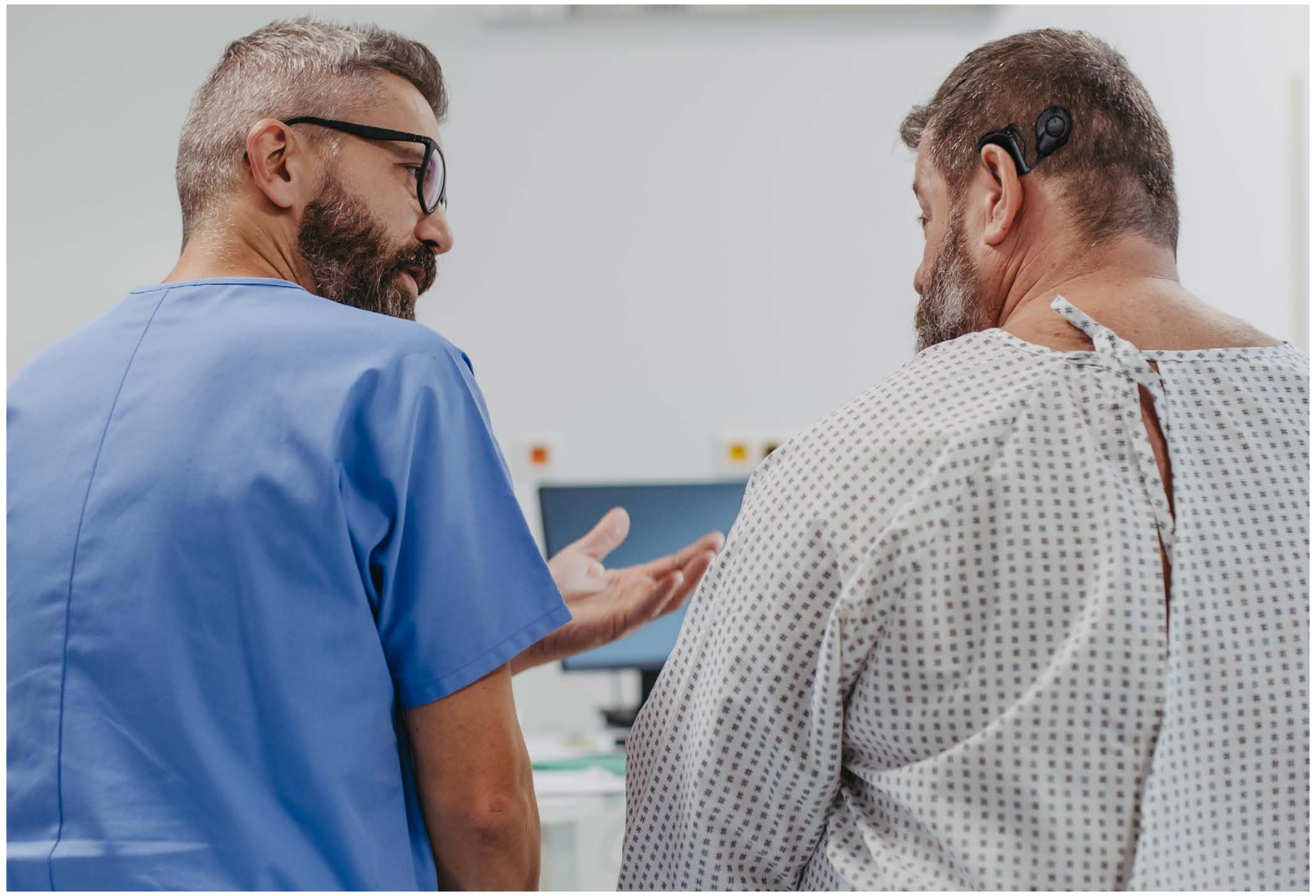
1. Polling of healthcare professionals

In December 2024, RNID and SignHealth conducted polling of patient-facing healthcare professionals with Censuswide to explore their understanding of the AIS and its implementation, as well as their experiences of working with patients who are deaf or have hearing loss.

The polling of patient-facing NHS staff spanned a range of professional groups and healthcare settings. The polling was conducted between 9th December and 20th December 2024.

PROFILE OF NHS STAFF
In total, 404 NHS staff in patient-facing roles aged 18 and above in England were sampled with a quota of 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

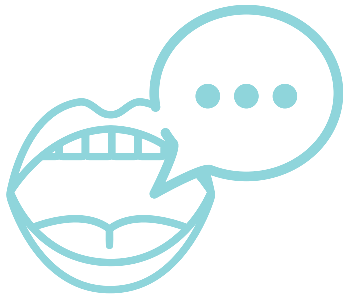


Method

2. Survey of people who are deaf or have hearing loss

An online survey reached a sample of 1,114 people who are deaf or have hearing loss and live in England.

Within our sample, 19% of those surveyed need a communication support professional, such as a BSL interpreter, lipspeaker or notetaker to be present during an appointment.



19%

of those surveyed need a communication support professional, such as a BSL interpreter, lipspeaker or notetaker to be present during an appointment.

Table 1: ***Do you need a communication support professional to be present for you to access a GP or hospital appointment? For example, a BSL interpreter, lipspeaker or notetaker*** *(n=1114)*

Yes	19%
No	75%
Don't know	6%
Prefer not to say	1%

The most common type of communication support professional needed is a BSL interpreter (58%), followed by a notetaker (25%) and a lipspeaker (22%). Other types of communication support were also used, but were less common, such as Speech-to-Text Reporters (17%), relay interpreters (9%) and deafblind interpreters (2%).

Table 2: ***What type of communication support professional do you need?*** *(n=208)*

BSL interpreter	58%
Notetaker	25%
Lipspeaker	22%
Speech-to-text reporter	17%
Other	12%
Relay interpreter	9%
Other sign language interpreter	6%
Deafblind interpreter	2%
Prefer not to say	1%

The data was collected between 13th November 2024 and 26th December 2024, promoted through RNID's Research Panel, Campaigns Network, Charity Newsletter and social media channels, as well as through SignHealth's networks and communication channels.

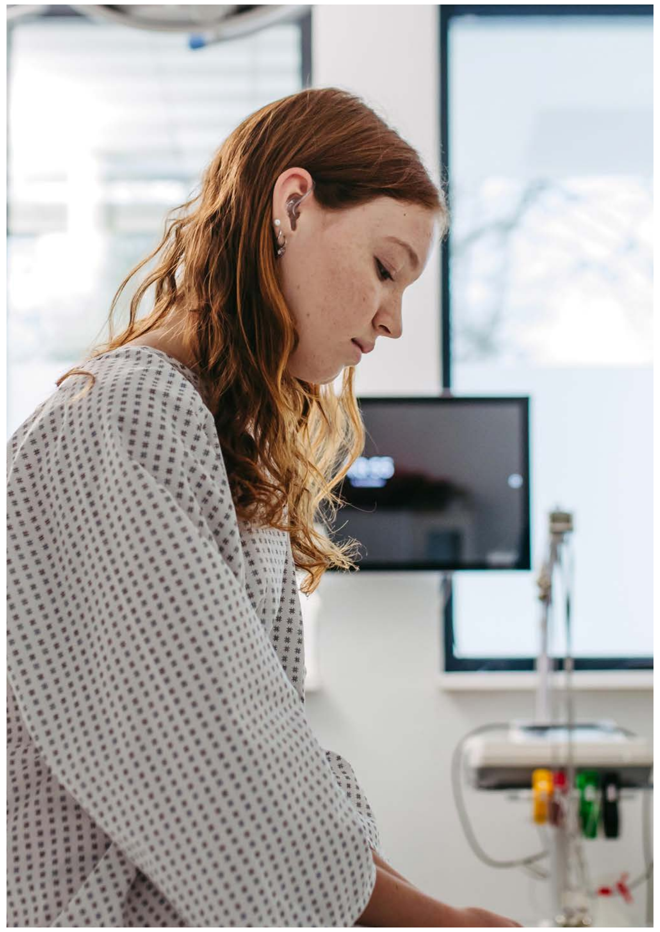
The questions and answers were provided in written English and BSL video translations with subtitles to ensure the survey was accessible to BSL users. There was also the option for BSL users to provide a signed response to any open-ended questions with instructions provided about how to submit their response to a member of the Insight and Evidence Team at RNID.

Data Analysis

1. NHS staff

The data in this report outlines overall totals collected from the polling data of NHS staff, and provides breakdowns by job role, where relevant. The job roles were combined into the following categories for analysis and reporting purposes, which includes staff members across both community and hospital settings in patient-facing roles:

- Admin staff (administrators and receptionists)
- Allied healthcare professionals
- Clinical support staff and healthcare support workers
- Doctors (including GPs and hospital doctors)
- Nurses and midwives



2. Survey of people who are deaf or have hearing loss

The data in this report outlines overall totals for England, and provides breakdowns into the following groups:

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.

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).

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.

This breakdown reflects the evident differences in healthcare access experiences among sign language users, those who need a communication support professional for GP or hospital appointments, and those who need other reasonable adjustments.

The survey included several open-ended questions which allowed respondents to expand on their answers and provide more detailed insights into their experiences. This qualitative data was analysed using thematic analysis and has been incorporated into the report where appropriate.

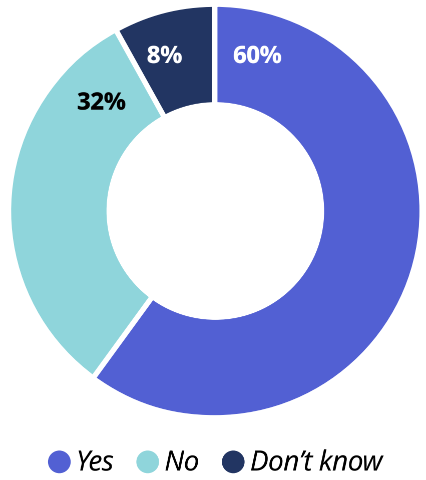
Results

Section 1: Awareness and understanding of the AIS

AWARENESS OF THE AIS AMONGST NHS STAFF

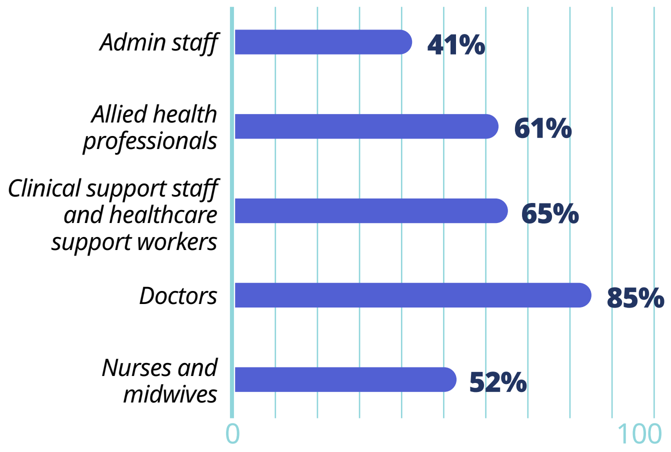
Nearly ten years after its implementation, awareness of the AIS and how it should be used to help meet people's communication needs, remains poor. Almost one third (32%) of the NHS staff surveyed say they are unaware of the AIS.

Figure 1: ***Awareness of the AIS among NHS staff*** *(n=404)*



Significant variations in levels of awareness of the AIS were evident amongst NHS staff, where 85% of doctors were aware of the AIS compared to just 41% of admin staff, indicating inconsistencies in exposure to the AIS across the NHS.

Figure 2: ***Awareness of the AIS according to job role*** *(n=110 admin staff; 51 allied health professionals; 51 clinical support staff and healthcare support workers; 100 doctors; 102 nurses and midwives)*

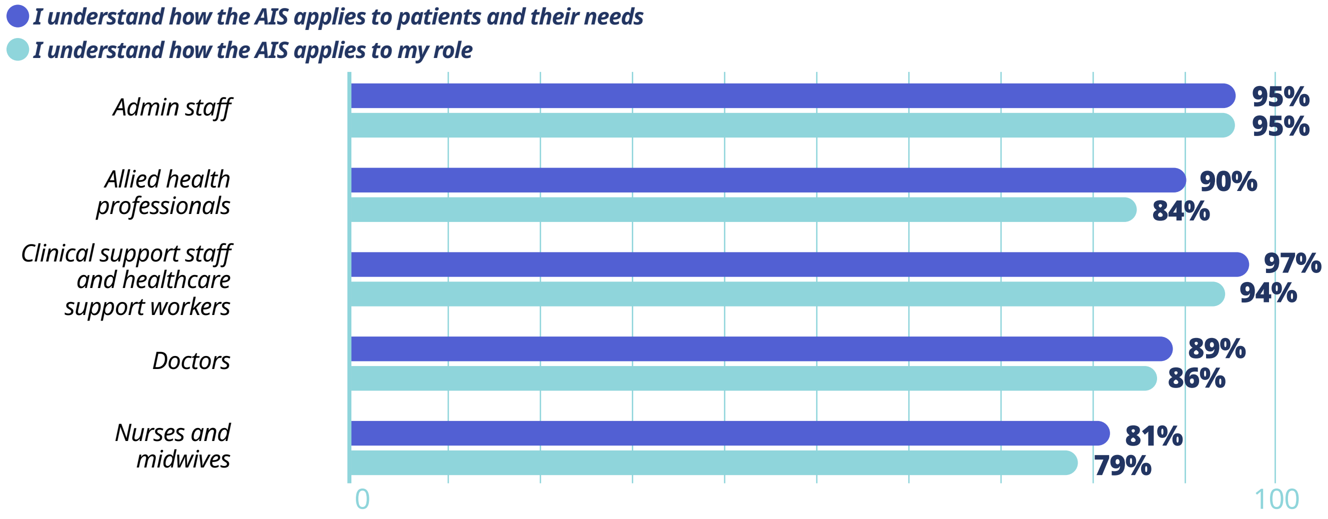


For those NHS staff who say they are aware of the AIS, there appears to be a high degree of confidence in how it applies to their patients. Indeed, 90% say they understand how the AIS applies to patients and their needs, and a similar number (87%) say they understand how the AIS applies to their role.

Yet there are observable differences once again between staff groups. Understanding of how the AIS applies to patients and their needs is highest among clinical support staff and healthcare support workers (97%), as well as admin staff (95%), whereas the lowest levels of understanding are found among nurses and midwives at 81%.

Similarly, 95% of admin staff and 94% of clinical support staff and healthcare support workers say they understand how the AIS applies to their role whereas, again, the lowest levels of understanding are found amongst nurses and midwives at 79%.

Figure 3: ***Proportion of NHS staff across a range of job roles that were aware of the AIS and their levels of agreement with each of the statements*** *(n=41 admin staff; 31 allied health professionals; 33 clinical support staff and healthcare support workers; 85 doctors; 53 nurses and midwives)*

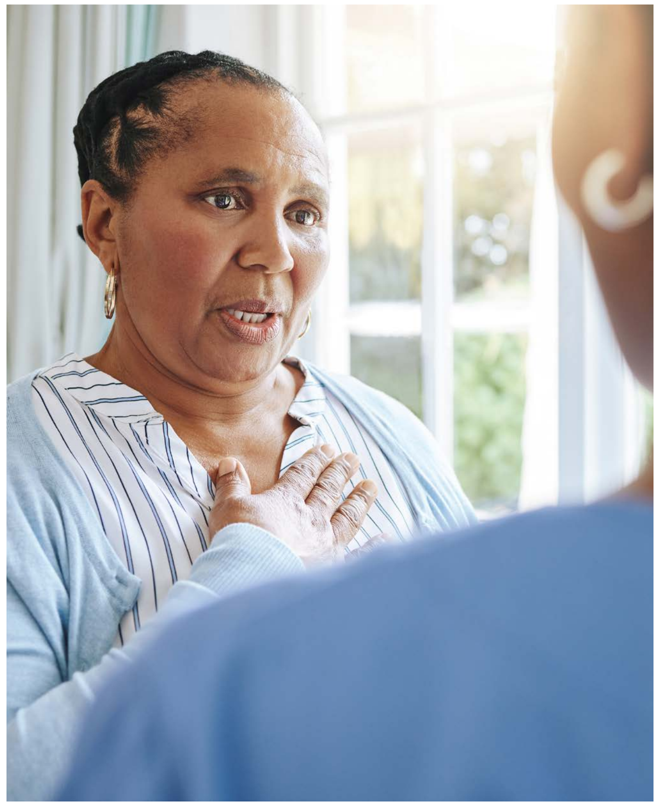


Of those NHS staff who say they are aware of the AIS, most were able to correctly describe its purpose of allowing disabled people equal access to information and healthcare when asked to explain the purpose of the AIS in their own words. Many responses focused on the notion of providing information in a way that 'people can understand', with NHS staff specifically mentioning the AIS in relation to people with learning disabilities and sensory loss:

> ***"A rule that ensures that people with disabilities or impairments can receive information in a way that they can easily understand."***
> GP administrator/receptionist

> ***"The standard aims to make sure that people who [have a] disability, impairment or sensory loss are provided with information."***
> Healthcare support worker

> ***"Ensures equal access to information for all, regardless of your disabilities."***
> GP



However, some NHS staff do not have a correct understanding of the purpose of the AIS. 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 that the AIS is about making communication accessible:

"It's part of the freedom of information act."
District or practice nurse

"Being able to access your healthcare information by sending in a written request to the hospital."
GP administrator/receptionist

"We are all entitled to see our own health care records."
Nurse working in a hospital

"Patients should be able to see their medical records easily."
Hospital administrator/receptionist

Additionally, some framed the AIS as part of data protection and patient privacy, which further suggests some confusion between the AIS and other responsibilities such as patient confidentiality:

"To make sure that only people who have a genuine need can access patient information. They should only look at what is totally necessary for the patients care at that time."
Hospital administrator/receptionist

"It is to protect the privacy of patients."
Hospital administrator/receptionist

"To safeguard the sensitive information of patients and only reveal it on a need-to-know basis."
Healthcare support worker

AWARENESS OF THE AIS IN OUR COMMUNITIES

Levels of awareness of the AIS are worryingly low among people who are deaf or have hearing loss, with 70% saying they are not aware of the AIS. Only 21% say they are aware of the standard.

Sign language users have the highest levels of awareness of the AIS at just over half (55%), whereas less than a third (31%) of people who need a communication support professional are aware of the AIS. This figure drops to only 15% for people who need other reasonable adjustments.

Of all those who are aware of the AIS, only 31% feel they have a good understanding of how it applies to them as someone who is deaf or has hearing loss. Half (50%) feel they have some understanding, whereas almost 1 in 5 (19%) say they either don't have much understanding or don't have any understanding of how the AIS applies to them.

This demonstrates that even where patients who are deaf or have hearing loss are aware to some extent of the AIS, they are not equipped with the information and knowledge they need to understand how it applies to them, or how they can exercise their rights and use it to demand the communication support or adjustments they need.

Case Study

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

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.


Image: Louise Haywood-Schiefer

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."

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.

Section 2: Implementation of the AIS

For the AIS to work, patients, healthcare professionals and patient-facing admin staff need to be proactive in ensuring that patients' communication needs are recorded in the first place, as this is the initial trigger which should see support follow them through the NHS pathway. Without this in place, even those NHS staff members who are pro-actively looking for the information and communication needs of patients won't be able to find it, and will therefore be unsuccessful in meeting their needs.

Our findings highlight a discrepancy between what NHS staff are saying and what people who are deaf or have hearing loss are actually experiencing - that NHS services are regularly failing to implement the five steps of the AIS and are therefore failing to meet their needs.

IDENTIFY

Despite 85% of NHS staff saying they know how to find out if a patient has communication needs, worryingly, 70% of people who are deaf or have hearing loss say they have never been asked about their information or communication needs when accessing healthcare, as is required under the first step of the AIS.

For those who have been asked, this was mainly in standardised correspondence such as a referral letter, with people who are deaf or have hearing loss rarely being asked about their information and communication needs during in-person interactions, such as during an appointment (9%) or when checking in (5%).

Table 3: ***In which situations, if any, have you been asked about your information or communication needs?*** *(n=1114)*

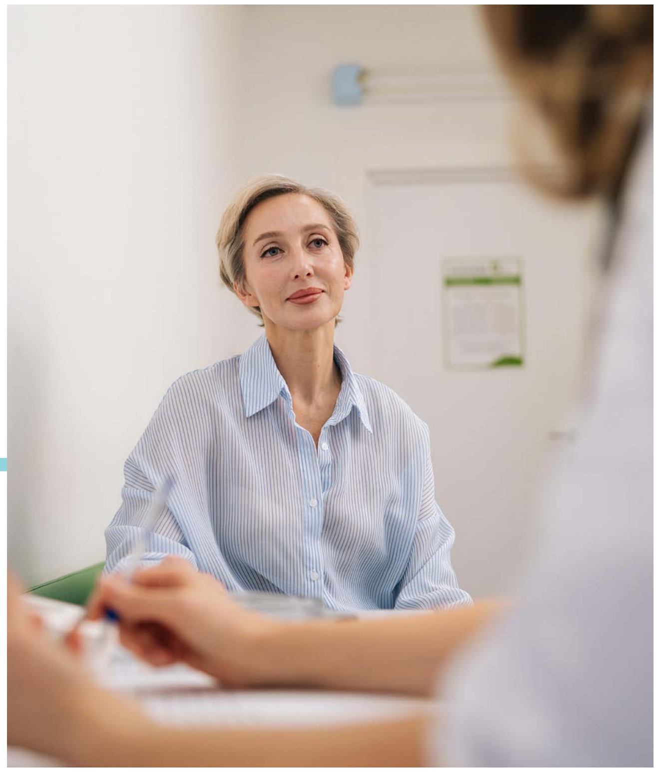
I have never been asked about my information or communication needs	70%
When receiving a letter about a referral to a hospital or other service	15%
When booking an appointment	9%
During an appointment with a healthcare professional	9%
When registering as a new patient	6%
When checking in for an appointment	5%
When presenting at a service for urgent medical care (this may include attending Accident and Emergency, an Urgent Treatment Centre or a Walk in Centre)	4%
Other	3%
Don't know	2%

It appears that little has changed over time since the implementation of the AIS. When asked to reflect on how often they are asked about their information and communication needs now, compared to ten years ago, only 13% agree that they are asked more frequently now than they were ten years ago.

These findings demonstrate how little has changed over time regarding accessible communication since the implementation of the AIS.

Table 4: ***Level of agreement with the statement: 'Healthcare professionals ask me about my information and communication needs more frequently than they did ten years ago'*** *(n=1114)*

Agree (net)	**13%**
Strongly agree	3%
Agree	10%
Neither agree nor disagree	22%
Disagree	34%
Strongly disagree	22%
Disagree (net)	**55%**
Don't know	4%
Not applicable	5%



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. Yet, there is a clear mismatch between what NHS staff report knowing and whether this actually happens or not, based on what patients are reporting.

Despite almost a third (32%) of NHS staff being unaware of the AIS, most report knowing how to undertake these actions. Specifically, 79% say they know how to centrally record a patient's communication needs, and how to add a flag to a patient's record to make others aware of their communication needs. This also extends to knowing how to share information about a patient's communication needs with other NHS staff (87%).

This demonstrates a consistently high level of stated knowledge among NHS staff about how to undertake the various requirements of the AIS.

Table 5: ***Levels of agreement with the following statements:*** *(n=404)*

I know how to centrally record what a patient's communication needs are

Agree (net)	79%
Disagree (net)	7%

I know how to add a flag to a patient's online record to make others aware of their communication needs

Agree (net)	79%
Disagree (net)	8%

I know how to share information about a patient's communication needs with other healthcare professionals during a handover or referral

Agree (net)	87%
Disagree (net)	2%

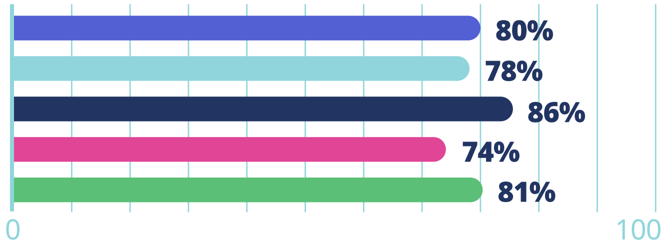
However, there are again some differences between staff groups. For instance, knowledge of how to add a flag to a patient's online record to make others aware of their communication needs is highest among clinical support staff and healthcare support workers at 88% and lowest among allied healthcare professionals, as well as nurses and midwives, at 75%.

Similarly, knowledge of how to share information about a patient's communication needs with other healthcare professionals is, again, highest among clinical support staff and healthcare support workers at 94%, compared to only 77% of admin staff.

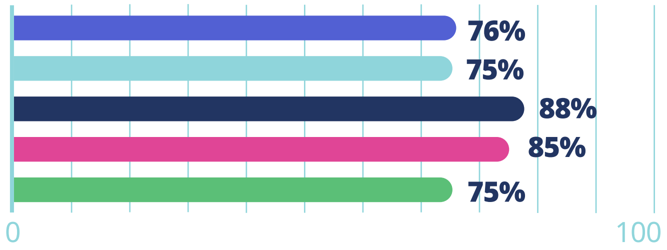
Figure 4: ***Proportion of NHS staff across a range of job roles that agree with each of the statements*** *(n=100 admin staff; 51 allied health professionals; 51 clinical support staff and healthcare support workers; 100 doctors; 102 nurses and midwives)*

● Admin staff ● Allied health professionals
● Clinical support staff and healthcare support workers
● Doctors ● Nurses and midwives

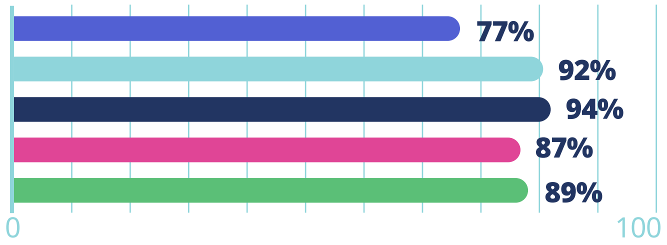
I know how to centrally record what a patient's communications needs are



I know how to flag a patient's online record to make others aware of their communication needs



I know how to share information about a patient's communication needs with other healthcare professionals during a handover or a referral



Yet, although a significant proportion of NHS staff report knowing how to record and share information about patients' communication needs, this knowledge is not translating into practice.

Less than a third are always made aware of the communication needs of patients who are deaf or have hearing loss before appointments, potentially leading to challenges in providing accessible care. The fact that nearly one in ten NHS staff members are rarely or never informed of a patient's needs suggests gaps in processes or training that need to be addressed.

Table 6: ***When working with patients who are deaf or have hearing loss, how often, if ever, are you made aware of their communication needs before you meet with them (for example, if they need a BSL interpreter to be booked)?*** *(n=404)*

Always	27%
Often	39%
Sometimes	21%
Rarely	7%
Never	2%
Not applicable	4%

Of those NHS staff who say they are made aware of this information, it is provided in a range of ways. It can appear as an alert or a flag on a new patient registration form, booking form or record, or it can be proactively sought by NHS staff.

While 41% of NHS staff say one of the ways they find this information is by proactively seeking it themselves by looking through a patient's record, this means that 59% of NHS staff are therefore relying solely on the information being made visible automatically on records or other relevant documents, or are reliant on patients self-identifying their communication needs to them and having to advocate for themselves.

Table 7: ***How are you made aware of this information?*** *(n=381)*

It is attached to the booking information or referral	54%
It appears as an alert or flag as soon as I open the patient's record	50%
Patients self-identify their communication needs	45%
I find this information myself by looking through their record	41%
It is on their new patient registration form	40%
Other	1%

The experiences of people who are deaf or have hearing loss also reflect this gap between knowledge and practice. More than three quarters (77%) of people who are deaf or have hearing loss say that NHS staff have either never or rarely been made aware of their information or communication needs before meeting with them (see Table 8).

Only 2% say that NHS staff have always been made aware of their information and communication needs before meeting with them.

"It doesn't matter how many times you make them aware of your deafness, the next nurse or Dr on duty comes along and just starts speaking to you. It drives me crazy."

Female, 45-54, needs other reasonable adjustments

Table 8: ***How often do you find that healthcare professionals (such as doctors or nurses) have already been made aware of your information or communication needs before you meet with them?*** *(n=1114)*

Always	2%
Sometimes	13%
Rarely	35%
Never	43%
Rarely or never (net)	**77%**
Don't know	8%

MEET THE NEEDS OF ALL

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.

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 lipread, or the provision of a communication support professional such as a qualified BSL interpreter during an appointment.

GETTING IT RIGHT – REASONABLE ADJUSTMENTS

When NHS staff make adjustments for patients who are deaf or have hearing loss to ensure their needs are being met, this has a significant impact on patient experience. This can include ensuring patients are able to lipread and taking additional time to check that patients have understood the information they've been given:

"Recently attended a nurse appointment at my GP surgery. I asked reception to let the nurse know I am profoundly deaf. When she came to call me she spoke clearly and faced the waiting room (other staff were calling from their doorways). Once in the room she faced me when speaking and clarified when I couldn't understand. I left feeling that I mattered whereas I often feel frustrated and angry after a medical appointment."

Female, 65-74, needs other reasonable adjustments

"When I gave birth in 2019 my maternity unit were very understanding and made sure all care providers were aware. They made accommodations such as standing next to my 'good' ear, spoke clearly so I could lip read. They would wave round the side of the privacy curtain and wait for me to respond rather than calling my name, this allowed me to relax and maintain my privacy."

Female, 35-44, needs a communication support professional

"I was sent to A&E with a suspected retina tear. I didn't have help so explained my problem to the receptionist who didn't help at all. I got up when no one else answered a call and fortunately it was for me. Once the doctor realised my deafness he took me into a quiet space and removed his mask to speak to me. He was extremely kind and at the end he escorted me up to eye casualty and checked me in and told them my communication needs. I will always be grateful to him for treating me with such kindness."

Female, 65-74, needs a communication support professional

NHS staff suggest there are a wide range of ways a patient who is deaf or has hearing loss can contact their service. The most commonly available methods are via email (68%) or in person with communication support (68%). There appears to be some, albeit limited, familiarity and availability of methods such as Video Relay Service (26%) and Relay UK (22%).

Table 9: ***Which, if any, ways can a patient who is deaf or has hearing loss contact your setting?*** *(n=404)*

Email	68%
In person (with communication support such as video relay interpreting or BSL interpreter)	68%
Text message or SMS	62%
Online form	50%
In person (with no additional communication support)	35%
Video Relay Service	26%
Phone	24%
Relay UK	22%
Other	1%
Don't know	2%

Yet despite the range of methods of communication that NHS staff say patients can use to contact their service, a quarter (25%) of people who are deaf or have hearing loss say they are not able to contact their GP in a way that is accessible to them.

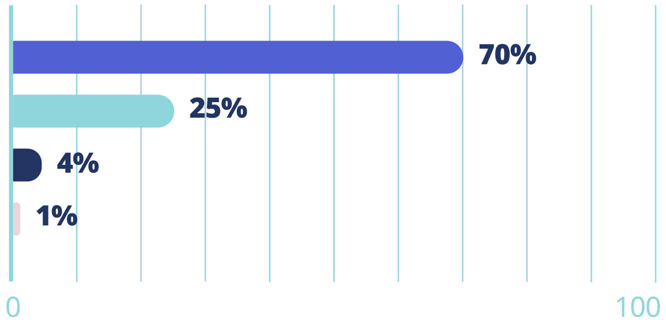
Similarly, just over half (59%) of people who are deaf or have hearing loss say their GP contacts them in a way that is accessible to them, whereas nearly a third (32%) say this is not the case and are instead contacted through an inaccessible method for someone who is deaf or has hearing loss.

It is perhaps unsurprising, therefore, that overall, 39% of people who are deaf or have hearing loss say they do not feel confident contacting their GP.

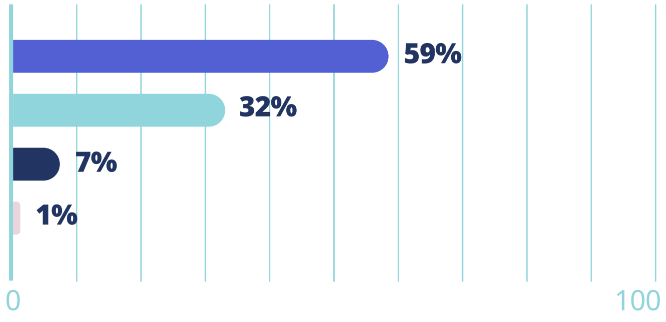
Figure 5: ***Level of agreement with each statement*** *(n=1114)*

● *Yes* ● *No* ● *Don't know* ● *Prefer not to say*

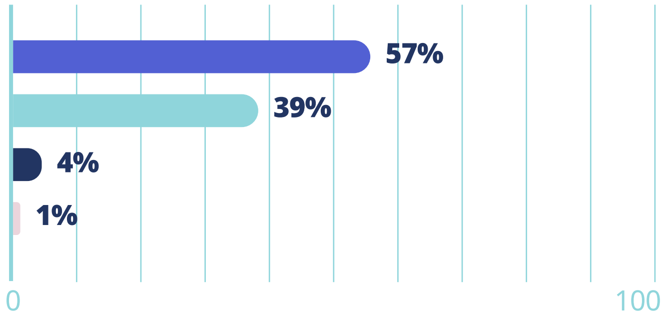
I can contact my GP in a way that is accessible to me



My GP contacts me in a way that is accessible



I feel confident contacting my GP



However, when we break down these results, the extent of the lack of equitable access is further highlighted.

Half (50%) of sign language users and 52% of those who need a communication support professional report being unable to contact their GP in an accessible way. Additionally, 18% of people who need other reasonable adjustments face the same issues.

The challenges extend to how GPs reach out to patients as well. Six in ten (61%) sign language users and 59% of people who need a communication support professional say their GP does not contact them in a way that is accessible to them, along with 25% of people who need other reasonable adjustments.

Figure 6: ***I can contact my GP in a way that is accessible to me*** *(n=1114)*

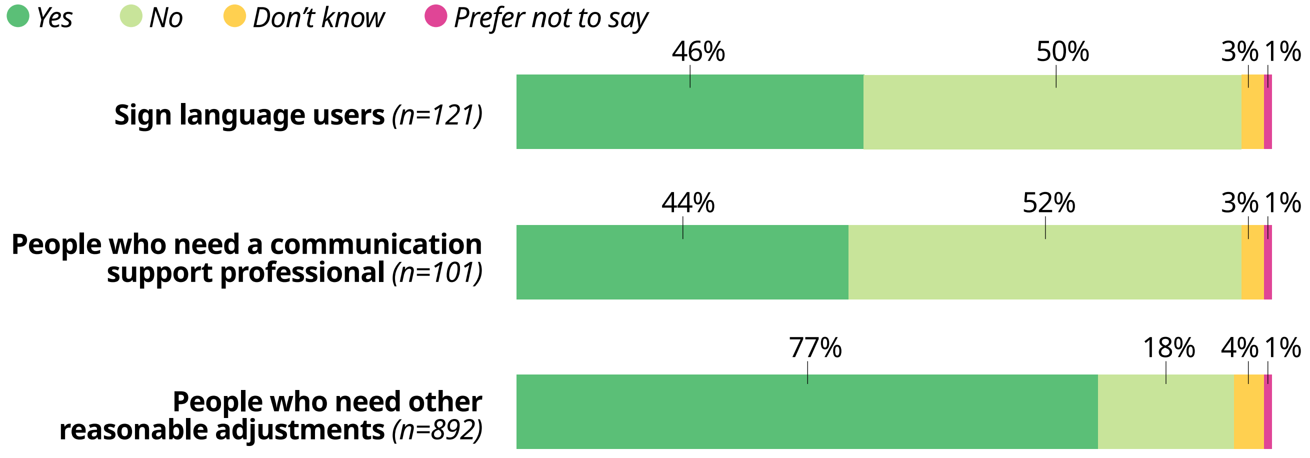


Figure 7: ***My GP contacts me in a way that is accessible to me*** *(n=1114)*

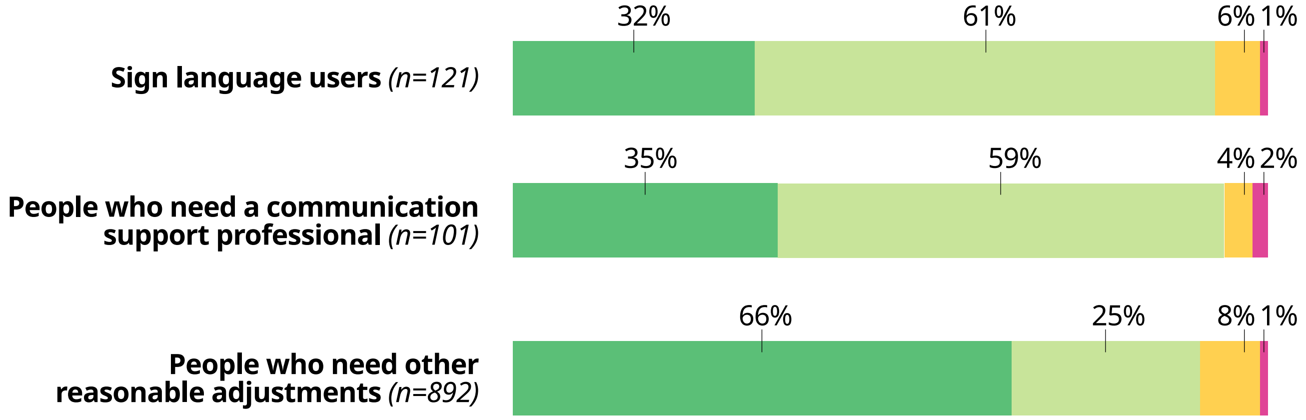
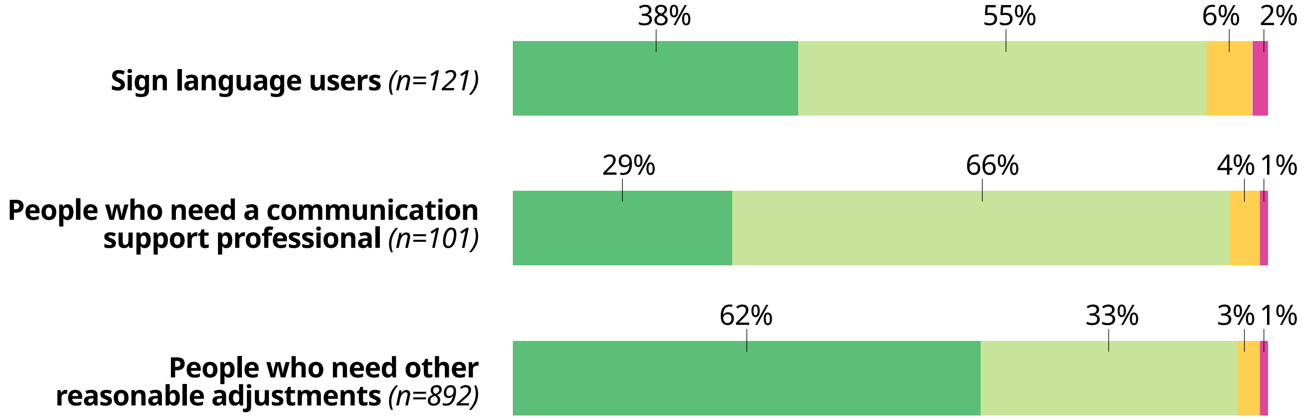


Figure 8: ***I feel confident contacting my GP*** *(n=1114)*

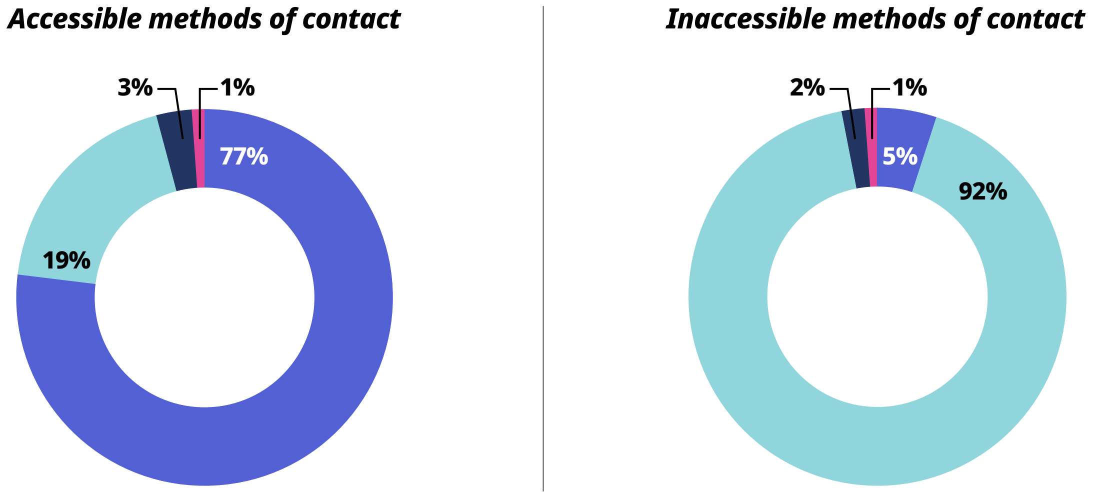


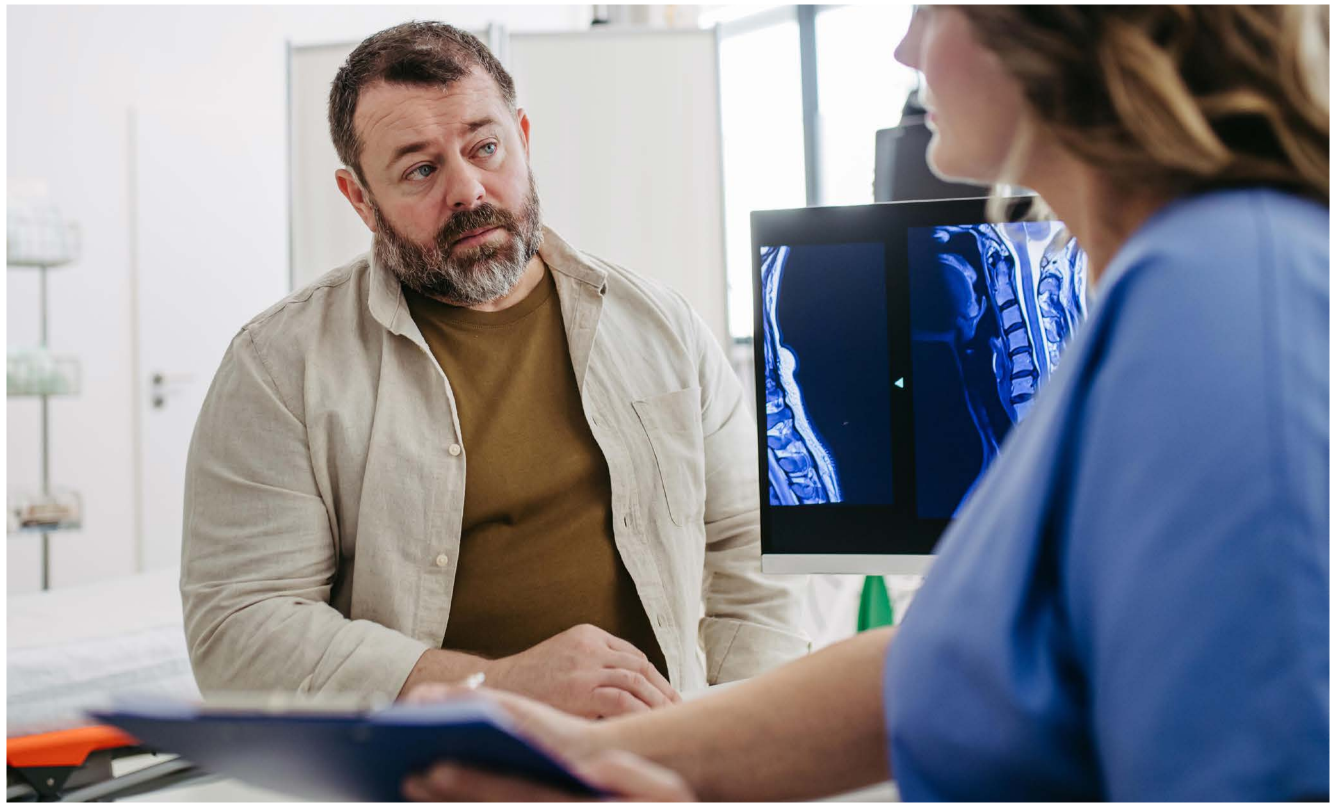
This highlights that a significant proportion of people who are deaf or have hearing loss still experience barriers when communicating with their GP, both when reaching out for care and when being contacted by their practice.

The benefits of accessible methods of communication on patient confidence are clear, as evidenced by the finding that over three quarters (77%) of those people who can contact their GP in a way that is accessible to them, also feel confident contacting their GP.

Conversely, 92% of those who cannot contact their GP in a way that is accessible to them, say they do not feel confident contacting their GP, demonstrating the adverse impact this can have on a patient's ability to seek care.

Figure 9: ***Proportion of people who feel confident contacting their GP depending on whether they can contact their GP in a way that is accessible to them or not*** *(n=783 accessible methods of contact; 277 inaccessible methods of contact)* ● *Confident* ● *Not confident* ● *Don't know* ● *Prefer not to say*





Many people commented that they find it difficult to contact healthcare providers and book appointments due to a continued dominance of telephone-based communication, without effective alternative methods in place. This can lead to their care being delayed because the wait for a face-to-face appointment is longer or having to resort to a telephone appointment with help from family and friends. This also leaves patients at risk of missing important information:

"Telephone appointments are extremely stressful. It is the need to constantly ask people to speak up and to speak more slowly. You are never sure if you have taken in information accurately."
Female, 65-74, needs other reasonable adjustments

"It is challenging getting an appointment. I live on my own with no family in this town. The surgery phones, despite my notes saying I am deaf."
Female, 55-64, needs other reasonable adjustments

"I am unable to use the phone. It is very embarrassing having to use my husband as a go between, repeating what [the] GP is saying."
Female, 55-64, needs other reasonable adjustments

"When I raised a valid concern about my ability to access a GP appointment in an accessible way (other than by telephone) I was told that there was no scope to be able to email the surgery directly. Instead, I have to attend the surgery in person at 8am in order to book in person. This is very difficult for me as I am a full-time carer for my disabled son."
Female, 45-54, needs other reasonable adjustments

"I had a persistent cough and went to the surgery to request an appointment. I was told if I couldn't do a telephone consultation I would have to wait a month. When the appointment finally came round the GP told me off for leaving it so long! I have asked several times for them to adapt things for us deaf people, but nothing changes. It's easier to not go unless you are desperate!"
Female, 65-74, needs a communication support professional

Section 3: Barriers at every stage of the patient journey

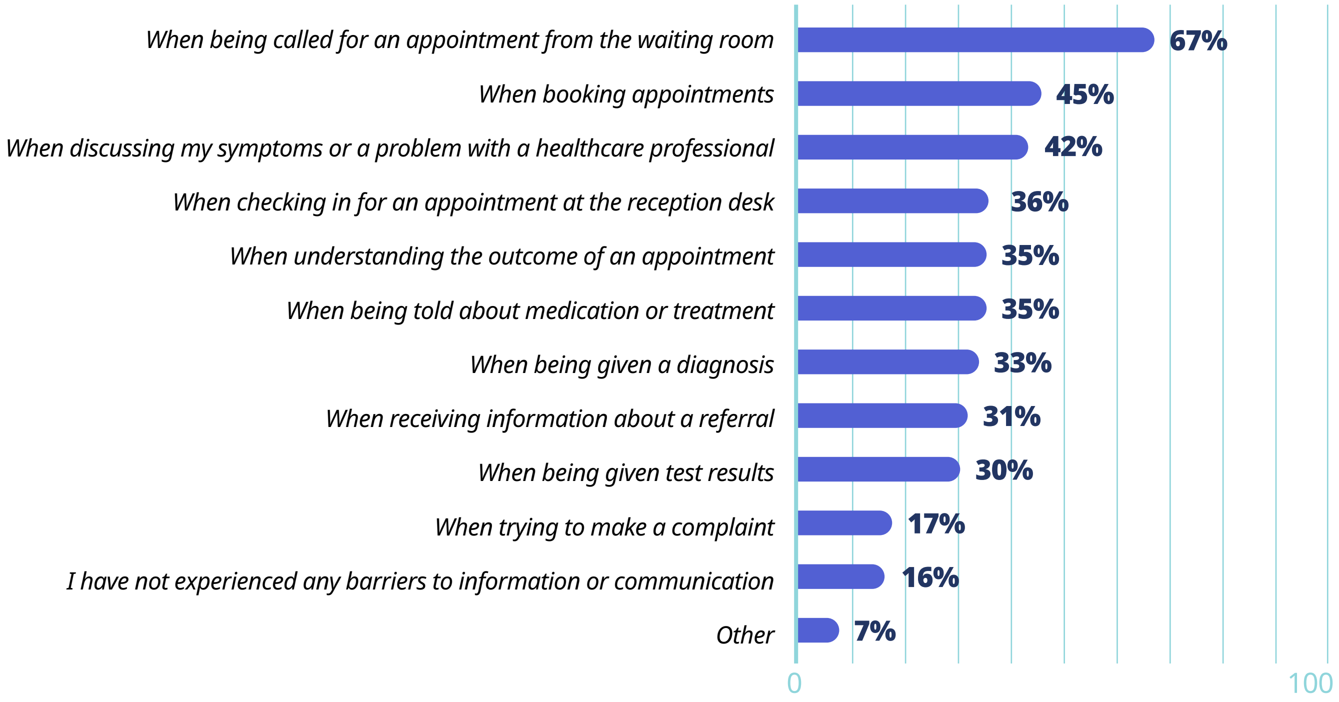
Beyond being able to contact NHS services when they need to, disabled people and those with sensory loss must be able to communicate well during appointments and understand the information they are given.

For many people who are deaf or have hearing loss, there are evident failures across every point in the patient journey. Nearly half (45%) encounter barriers when booking an appointment, and over a third (36%) struggle to check in at the reception desk. Even something as simple as being called from the waiting room presents difficulties for more than two-thirds (67%) of patients.

Once inside the consultation room, these barriers continue. Nearly half (42%) find it difficult to communicate their symptoms or concerns with a healthcare professional. A third face obstacles when receiving a diagnosis (33%), when learning about a medication or treatment (35%), or understanding test results (30%). Even after the appointment, clarity on next steps remains a challenge, with 35% struggling to understand the outcome of their appointment, and 31% experiencing barriers when receiving information about a referral.

With only 16% of people who are deaf or have hearing loss reporting no issues accessing healthcare, it is clear that barriers need addressing at every stage of the patient journey.

Figure 10: ***Points where people have experienced barriers to information and communication when accessing healthcare*** *(n=1114)*



One recurring experience is people not hearing their name when being called from the waiting room. This leads to increased stress and anxiety, but there are also reports of being met with frustration from NHS staff when they don't hear their name being called:

"I was in a doctors waiting room waiting for my appointment 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 why I hadn't been called in by the doctor 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

"It makes me anxious that I have to keep my eyes peeled to get visual clues for when my appointment is being called in waiting rooms."

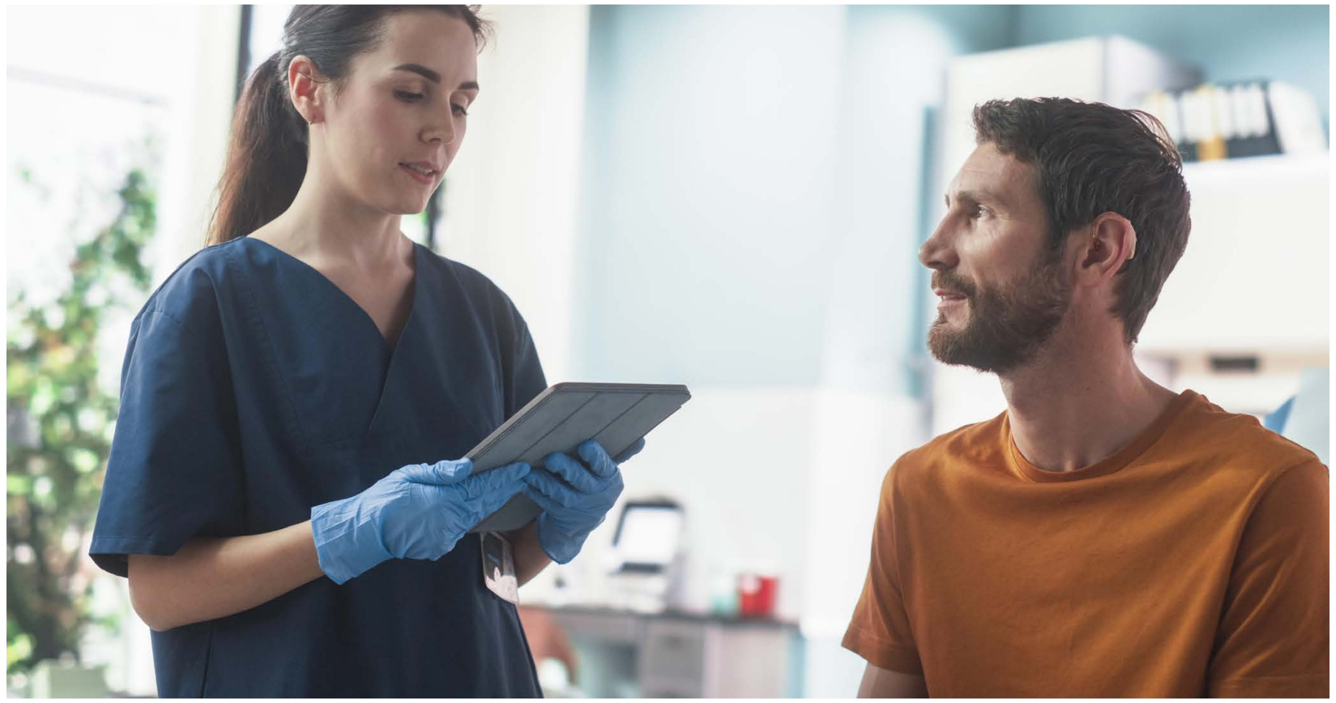
Female, 75+, needs other reasonable adjustments

"I knew I would not be able to hear my name being called. I was alone so didn't have a friend to listen out for me. I told the receptionist but she assured me that the Doctor would call my name several times and look for me if I didn't respond as they knew I was there waiting. I asked which room I would be called to so that I could sit near to it and face it so I could lip read when names were called but was told it wasn't necessary. I eventually realised I was being called by a doctor who was very irate as apparently, I'd been called earlier and didn't respond. His manner didn't improve when I apologised and explained I'm deaf. The appointment was very unpleasant! I was made to feel stupid and a time waster. I dread going back there."

Female, 65-74, needs other reasonable adjustments

Sign language users and those people who need a communication support professional report experiencing significantly more barriers when accessing healthcare.

Table 10: ***At what points, if any, have you experienced barriers to information or communication when accessing healthcare?*** *(n=1114)*	Sign language users (n=121)	People who need a communication support professional (n=101)	People who need other reasonable adjustments (n=892)
When being called for an appointment from the waiting room	75%	80%	65%
When booking appointments	74%	76%	37%
When being told about medication or treatment	67%	62%	28%
When discussing my symptoms or a problem with a healthcare professional	66%	62%	36%
When checking in for an appointment at the reception desk	59%	63%	30%
When being given a diagnosis	64%	55%	27%
When understanding the outcome of an appointment	56%	59%	29%
When being given test results	58%	57%	23%
When receiving information about a referral	57%	54%	24%
When trying to make a complaint	46%	33%	11%
I have not experienced any barriers to information or communication	4%	1%	19%
Other	10%	13%	6%
Don't know	1%	1%	2%



GETTING IT RIGHT – ALTERNATIVE METHODS OF COMMUNICATION

By providing patients who are deaf or have hearing loss with options for alternative methods of communication when accessing healthcare, this reduces anxiety for the patient and ensures they understand the information they are being given about their health:

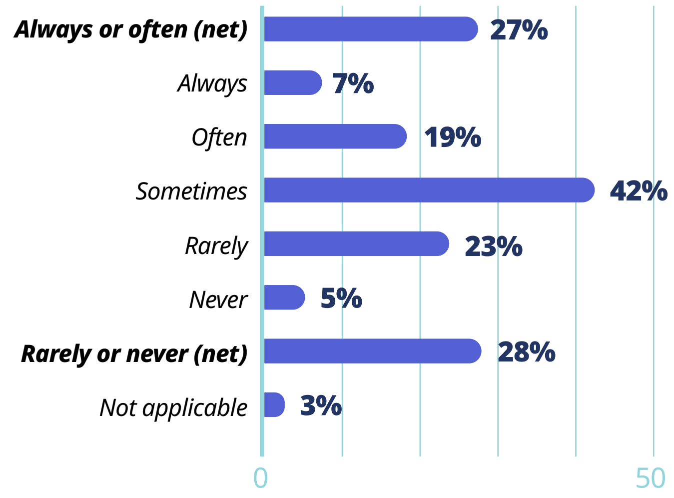
"One of the GPs at my practice has been accommodating when I have requested video calls to facilitate lip reading and this was much better for me than having to arrange for someone to help me get to the medical centre. It meant I was less physically tired, anxious and stressed and therefore the consultations were more productive."
Female, 55-64, needs other reasonable adjustments

"During surgery under local anaesthetic this summer, the theatre assistant kept writing notes for me to read to make sure that I was not in pain and comfortable during the procedure. Very impressive!"
Female, 75+, needs other reasonable adjustments

"When I was able to email a Neuropsychologist, I was able to fully explain my problems and background to the problems. It is not always possible to say everything you need to say in a 15-minute appointment. But an email can be read in their own time. A lot of appointment time is taken up by not being able to fully hear the doctors and asking them to repeat everything. So being able to communicate by email, gave me a lot more time during the appointment to discuss what was in the email. A lot more efficient and less likely to mishear someone. When we can't fully hear something our brains try to fill in the missing details and doesn't always get it right. But emails/digital communication, makes it a lot easier to follow."
Male, 45-54, needs other reasonable adjustments

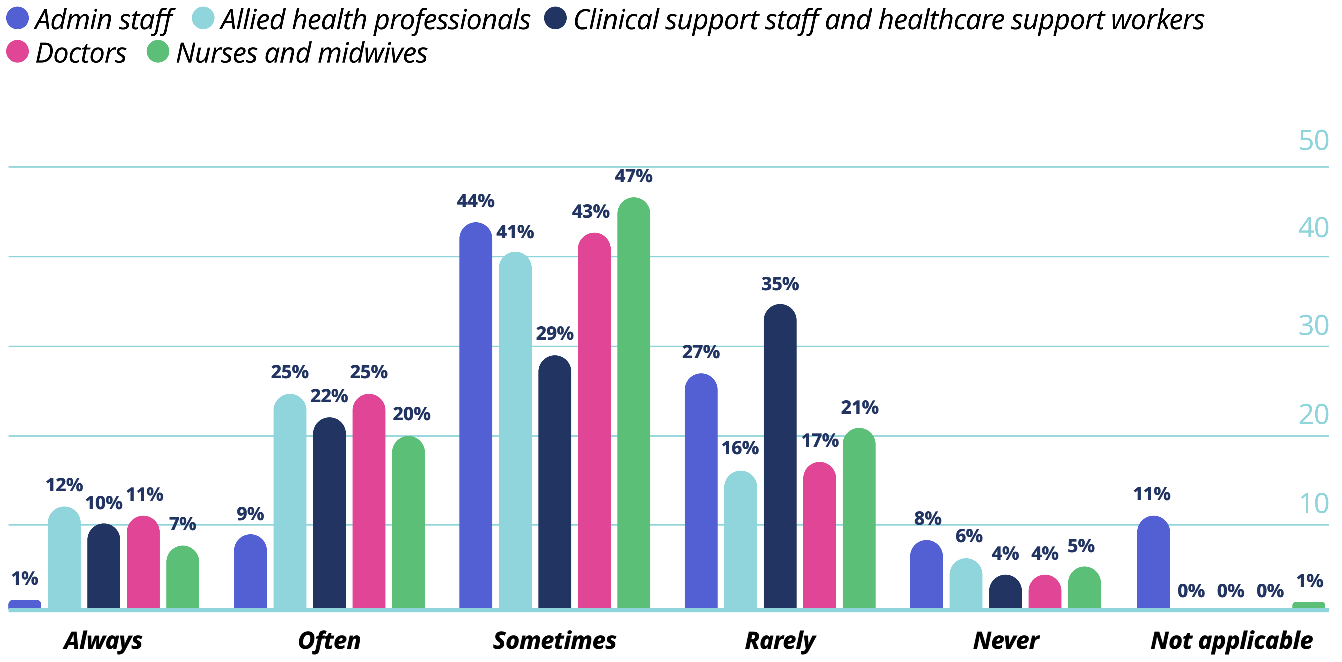
Despite the widespread barriers that people who are deaf or have hearing loss tell us they are facing, only 27% of NHS staff say they always or often experience communication barriers when working with these patients. In contrast, just over a quarter (28%) of NHS staff say they rarely or never experience communication barriers, showing a disconnect between the experience of patients and the perceptions of NHS staff.

Figure 11: ***Frequency that NHS staff experience communication barriers when working with patients who are deaf or have hearing loss*** *(n=404)*



The net values of those NHS staff roles who said they always or often experience communication barriers when working with patients who are deaf or have hearing loss are highest among allied health professionals (37%), compared to only 10% of admin staff.

Figure 12: ***Proportion of NHS staff across a range of job roles and how often they feel they experience communication barriers when working with patients who are deaf or have hearing loss*** *(n=100 admin staff; 51 allied health professionals; 51 clinical support staff and healthcare support workers; 100 doctors; 102 nurses and midwives)*



Given the extent of the communication barriers that people who are deaf or have hearing loss are reporting, it is unlikely that admin staff are not meeting patients who are encountering these barriers. Rather, it could be indicative of variations in awareness and understanding among different NHS staff groups about when and how these communication barriers are being experienced when interacting with patients who are deaf or have hearing loss, as well as variations in how they need to adjust to meet people's needs.

> ***"Information can be lost in translation. It can cause delays in treatment and discharge."***
> Hospital administrator/ receptionist

Section 4: Unmet communication support needs

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. Nearly 1 in 5 people in our survey (19%) say they need a communication support professional to be in attendance at an appointment.

THE POSITIVE IMPACT OF PROFESSIONAL COMMUNICATION SUPPORT

Having the right communication support in place when attending appointments, such as a BSL interpreter, lipspeaker or notetaker is transformative for people's experiences of care and their ability to fully engage with their own health and care plans. It increases their confidence and enables them to feel empowered and in control of their care:

> ***"After some issues surrounding me needing help, I was allocated a lip speaker. 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

> ***"When treated for my breast cancer, I was given a lip speaker who was wonderful to have with me. I needed this lip speaker as my family were unable to stay with me during my chemotherapy treatments."***
> Female, 65-74, needs a communication support professional

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

> ***"I was able to request an interpreter by name, the booking was confirmed, I accessed the appointment fully and understood the treatment plan. I felt empowered and equal to others."***
> Non-binary, 45-54, sign language user

While three quarters of those in our survey (75%) say they do not need a communication support professional to be in attendance at an appointment, demonstrating the varied needs of people who are deaf or have hearing loss, this should not be taken as an indication of not having any information and communication needs.

Indeed, a reliance on partners, family members or friends to interpret or relay information in appointments emerged, highlighting that information and communication needs are being fulfilled by people other than communication support professionals.

More than half (54%) have been forced to rely on either a partner, other family member, friend or their children to relay information or interpret for them at an appointment due to a lack of access. This includes 15% who had to rely on their children for this support in an appointment.

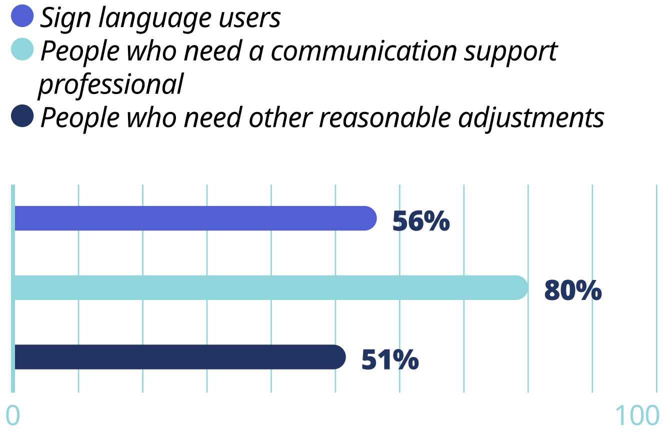
Table 11: ***In which of the following ways, if any, has a lack of accessible communication impacted you?*** *(n=1114)*	Overall	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
I have relied on my partner to relay information or interpret for me at an appointment	40%	27%	53%	41%
I have relied on other family members or friends to relay information or interpret for me at an appointment	18%	34%	37%	14%
I have relied on my children to relay information or interpret for me at an appointment	15%	18%	31%	12%
Net (reliance on a partner, other family member, friend or children)	**54%**	**56%**	**80%**	**51%**

Those people who need a communication support professional demonstrate the greatest reliance on others to relay information or interpret for them at an appointment, where a staggering 80% have relied on either a partner, other family member, friend or child in the past.

Furthermore, over half (51%) of those people who need other reasonable adjustments have had to rely on others during an appointment due to lack of access. This reinforces how pervasive this issue is across all sections of the deaf and hearing loss communities.

This reliance on family and friends could be due to lack of access but could also indicate a lack of awareness among some people who are deaf or have hearing loss that communication support professionals should be available to them.

Figure 13: ***Proportion of people that have relied on either a partner, other family members, friends, or their children to interpret or relay information for them at appointments***
(n=121 sign language users; n=101 people who need a communication support professional; 892 people who need other reasonable adjustments)



By having to rely on family and friends, this limits people's autonomy, independence and privacy. It also creates risks - family members and friends are not trained interpreters, and mistakes can lead to misdiagnosis or unsafe care.

"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 a communication support professional

"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

"It's embarrassing having to go through a family member for something personal."
Female, 55-64, needs other reasonable adjustments

"I have to take my wife with me now to help me. I dread to think how I would cope if anything happened to my wife."
Male, 65-74, sign language user

"I rely on my husband being available to come to all appointments with me. I feel disempowered because of this. My husband is extremely good and I'm grateful but I do feel a burden to everyone and this puts me off seeking appointments."
Female, 65-74, needs other reasonable adjustments

"A Consultant ended up ignoring me, the patient, and communicated with my husband - I may as well not have been at the appointment. I felt like a child, whose parent was talking to the Consultant. So humiliating."
Female, 55-64, needs other reasonable adjustments

There are consistent issues with access to the communication support professionals that people who are deaf or have hearing loss need.

Despite more than three quarters (78%) of NHS staff saying they know how to book communication support for a patient, such as a BSL interpreter, only 7% of people who need a communication support professional to be present to access an appointment say this is always provided for them.

Overall, nearly two thirds (63%) say a communication support professional is rarely (27%) or never (36%) provided for them, despite needing one present to be able to access a GP or hospital appointment.

For those who need a communication suport professional, their communication needs appear to go unmet to an even greater extent than those of sign language users.

Specifically, while almost half (48%) of sign language users say a communication support professional is rarely or never provided for them, over three quarters (78%) of those who need a communication support professional say the support they need is rarely or never provided.

It is important to note that there were 14 sign language users who stated they do not need an interpreter or communication support professional or don't know if they need one in order to be able to access an appointment. These people were therefore not included in the analysis in the following section. However, we see this as further evidence to suggest a potential lack of awareness among people who are deaf of have hearing loss about the communication support they are entitled to in order to be able to access an appointment, as well as a reliance on friends and family to provide this support for them in the place of professionals.

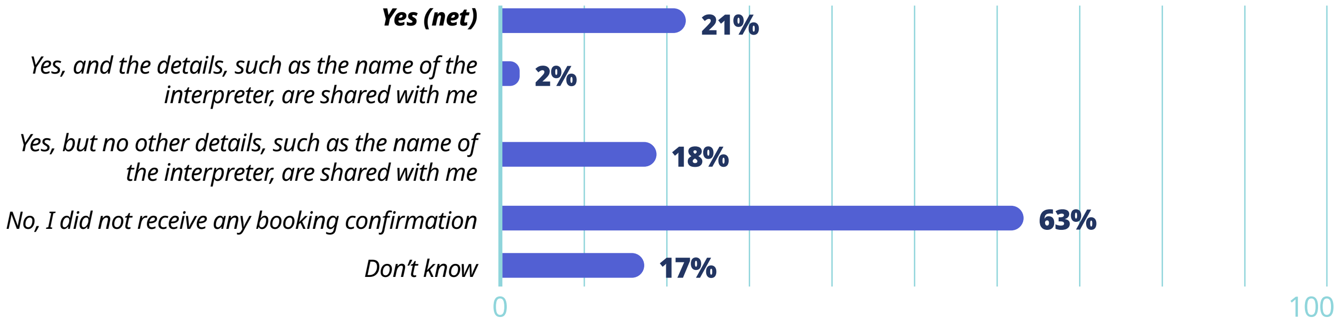
Table 12: ***How often is this communication support professional provided for you when you attend a GP or hospital appointment?*** *(n=208)*

	Overall total *(n=208)*	Sign language users *(n=107)*	People who need a communication support professional *(n=101)*
Always	7%	11%	2%
Sometimes	28%	40%	15%
Rarely	27%	30%	24%
Never	36%	18%	54%
Rarely or never (net)	**63%**	**48%**	**78%**
Don't know	3%	3%	5%

Only 1 in 5 patients (21%) who ask for communication support to be booked receive any confirmation before attending an appointment. Only 2% receive confirmation where details such as the name of the interpreter are shared with them, whereas 18% say they do receive confirmation but have no further information given to them prior to the appointment.

Nearly two thirds (63%) of those who need communication support professionals to be booked do not receive any confirmation that the booking has been made before they attend the appointment. This means they are turning up to appointments without knowing whether the communication support they need to access the appointment will be in place for them or not.

Figure 14: ***Proportion of people who have received confirmation of a communication support professional being booked for them before an appointment or not*** *(n=208)*



While nearly a third (32%) of sign language users receive some form of confirmation that a communication support professional has been booked for them before they attend an appointment, only 9% of people who need a communication support professional receive any confirmation.

Table 13: ***When you ask for this communication support professional to be booked for an appointment, do you receive confirmation of this before the appointment?*** *(n=208)*

	Sign language users *(n=107)*	People who need a communication support professional *(n=101)*
Yes (net)	**32%**	**9%**
Yes, and details, such as the name of the interpreter, are shared with me	3%	2%
Yes, but no other details, such as the name of the interpreter, are shared with me	29%	7%
No, I do not receive any booking confirmation	64%	60%
Don't know	4%	31%

More than half (53%) have experienced communication support not turning up to an appointment, despite being told it had been booked, with nearly a quarter (24%) saying this happens often.

Table 14: ***Have you ever experienced a communication support professional not turning up to an appointment even though you were told they had been booked?*** *(n=208)*

Yes (net)	**53%**
Yes – often	24%
Yes – occasionally	29%
No – never	21%
Don't know	26%

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

80% of sign language users have experienced a communication support professional not turning up to an appointment, despite being told one had been booked

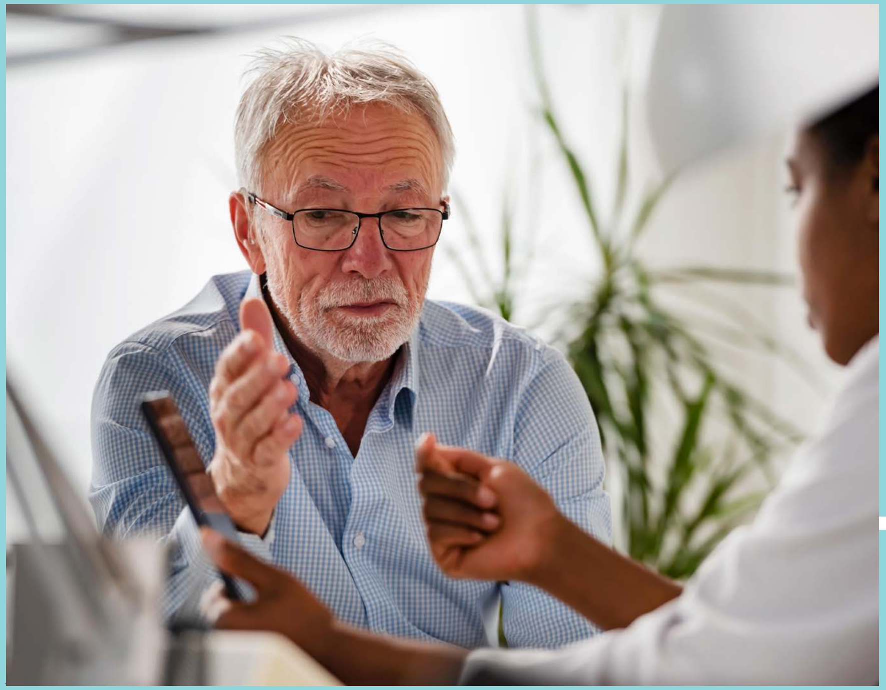
> ***"Interpreters often don't turn up or cancel at the last minute. This practice is not helping deaf people's cause. Appointments are being cancelled at the last minute or family members are trying their best to interpret."***
>
> Female, 35-44, needs a communication support professional

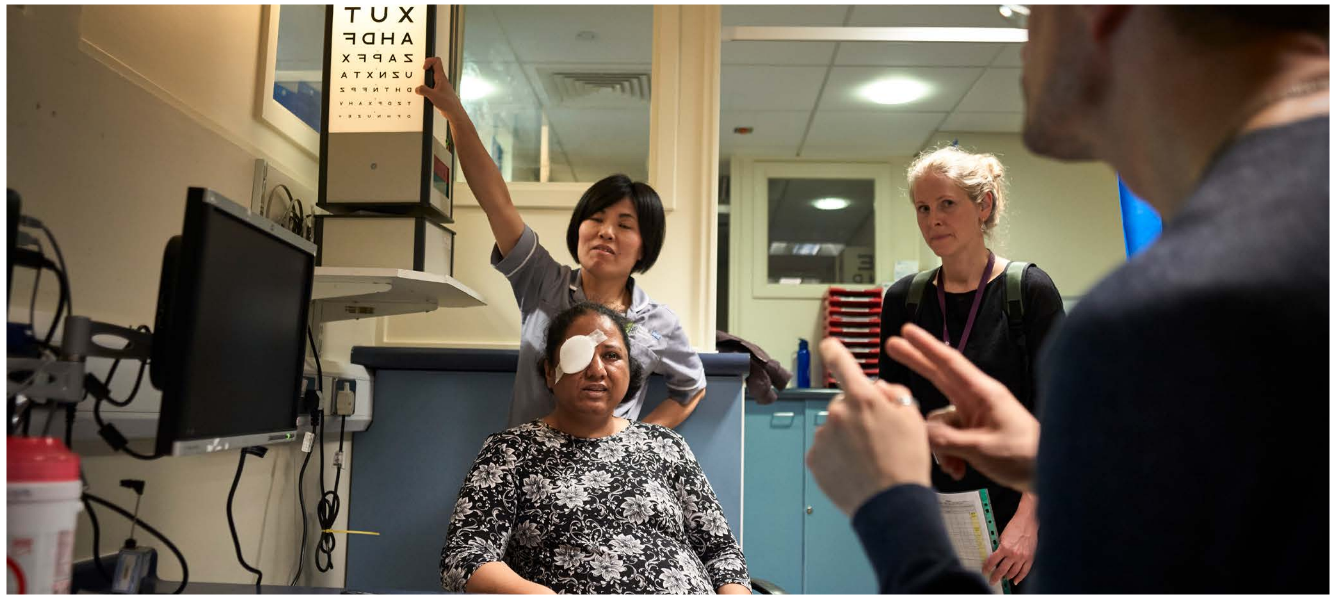
NHS SYSTEMS FOR BOOKING COMMUNICATION SUPPORT PROFESSIONALS

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.

Some healthcare professionals may not be aware of this distinction, erroneously believing that when they submit a request, it constitutes a confirmed booking – in reality, it is often merely a request awaiting interpreter availability. As a result, patients may be falsely reassured that an interpreter will be present, only to arrive at their appointment and discover no support is available.

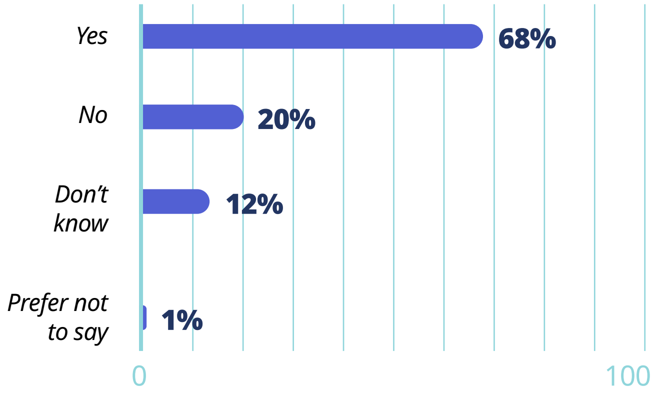
An additional challenge is that the majority of interpreting agencies cover a wide range of languages, with BSL typically just 2% of their market. This creates a fundamental tension in how performance is measured and managed, meaning a supplier can still meet all their pre-agreed targets even if all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





Over two thirds (68%) of sign language users say they would prefer a system where people have the choice to book a BSL interpreter or other sign language interpreter themselves using an online system, with 84% of those saying they would feel more confident that the booking had been confirmed. Only 20% would not prefer to book one themselves using an online system.

Figure 15: ***Proportion of sign language users who would prefer to book a BSL or other sign language interpreter themselves using an online system to select an interpreter*** *(n=121)*



However, it is important to note that as the method of data collection used was an online survey, digital literacy may be higher than average in this sample. This could have been a factor in the level of interest in being able to book a BSL interpreter using an online booking system, which may not be replicated in samples with lower digital literacy.

Table 15: ***Which, if any, of the following reasons describe why you would want to do this?*** *(n=82)*

I would be more confident that the booking had been confirmed	84%
I would be able to book an interpreter who can meet my needs or preferences (for example, a male or female interpreter)	74%
It would give me more control over my appointment	70%
I would be able to book the same interpreter for all my appointments	68%
Other	6%
Don't know	1%

For those who said they would not prefer this system, this is mainly because they do not feel it is their responsibility as a patient to book it themselves, or they would not feel confident using an online booking system, as well as concerns that it might take longer to schedule an appointment if they requested a specific interpreter.

EXPERIENCES OF VIDEO RELAY SERVICES

Video Relay Services (VRS) allow people who are deaf to make a video call to an interpreter. 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.

Just under a third (31%) of sign language user in this sample have used VRS interpreting to access a GP or hospital appointment. Despite the small sample size (n=37), these figures have been included to provide some insight into the experiences of those who have used VRS.

It is evident that experiences of VRS are mixed, with just over a third (35%) saying they would rate their experience as positive, whereas 41% would rate their experience of using VRS to access a GP or hospital appointment as negative.

Table 16: ***How would you rate your experience using VRS to access a GP or hospital appointment*** *(n=37)*

Positive (net)	**35%**
Very positive	11%
Positive	24%
Neither positive nor negative	24%
Negative	22%
Very negative	19%
Negative (net)	**41%**
Don't know	0%

N.B. Small sample size of n=37 for this routed question.

When asked to expand further on why their experiences were positive or negative, those who had positive experiences expressed that VRS enabled 'some communication' or was 'better than nothing'. VRS appears to be a more positive experience when used for appointments which are via phone or video call, rather than those in person. However, people did still experience problems such as the screen freezing and issues with the internet or bandwidth. Others commented that it takes time to show NHS staff how to use VRS, suggesting they are unfamiliar with the technology:

✓

"At least I had some communication. Unfortunately, the screen can freeze."
Female, 55-64, sign language user

"I was able to speak with [the] consultant and understand the results and next steps. Plus, the appointment was via call not in-person and that was where VRS was best suited."
Male, 35-44, sign language user

"When no interpreter is booked due [to] miscommunication between NHS and the agency, I use my own VRS. It helps but not always good due [to] Wi-Fi connection or the GP is not aware what it is! Time to explain how it works [is] so annoying but at same time VRS saves my time to rearrange another appointment!"
Female, 55-64, sign language user

Negative experiences of VRS were also largely related to screens freezing or the movements being slow due to poor video quality and connection, as well as a lack of interpreter availability via VRS. These negative experiences of VRS have caused unnecessary stress to users and has affected their confidence in using VRS; some reflected that they would prefer face-to-face appointments instead:

✗

"It was an emergency at the children's hospital with my baby, then 10 days old. The only available communication was relay service. The internet kept freezing, buffering, was slow, it disconnected. It was left for my mother to communicate who was also stressed and worried about the situation."
Female, 25-34, sign language user

"Most of the time it is a poor signal system and it does not move around, for example, when I am having an eye treatment or mouth check or they tend to move around and that means they have to move VRS around too and the doctors get annoyed or impatient with it. It is very off-putting and knocked my confidence."
Female, 45-54, sign language user

These negative experiences are reflected in the finding that over half (54%) of those who had used VRS do not think it is suitable to use in a healthcare setting in place of an in-person interpreter.

Table 17: ***VRS is suitable to use in a healthcare setting in place of an in-person interpreter*** *(n=37)*

Agree (net)	**24%**
Strongly agree	14%
Agree	11%
Neither agree nor disagree	24%
Disagree	22%
Strongly disagree	32%
Disagree (net)	**54%**
Don't know	0%

N.B. Small sample size of n=37 for this routed question.

While nearly a third (32%) say they would be equally as happy using VRS as they are using in-person interpreting, 38% disagree.

Table 18: ***I am equally happy using VRS as I am using in-person interpreting in a healthcare setting*** *(n=37)*

Agree (net)	**32%**
Strongly agree	11%
Agree	22%
Neither agree nor disagree	27%
Disagree	11%
Strongly disagree	27%
Disagree (net)	**38%**
Don't know	3%

N.B. Small sample size of n=37 for this routed question.

Similarly, there are mixed feelings as to whether VRS should be used more in healthcare settings. While 43% of those who have used VRS would want it to be used more, 43% would not.

Table 19: ***I would like VRS to be used more in healthcare settings*** *(n=37)*

Agree (net)	**43%**
Strongly agree	22%
Agree	22%
Neither agree nor disagree	16%
Disagree	19%
Strongly disagree	24%
Disagree (net)	**43%**
Don't know	0%

N.B. Small sample size of n=37 for this routed question.

However, 59% did report that VRS gives them confidence that they can have sign language access to healthcare at short notice or in an emergency. Therefore, whilst the provision of an in-person interpreter should always be the priority for sign language users who request an interpreter, patients find it reassuring that if an issue occurs, VRS is available to provide them with access in the absence of an in-person interpreter.

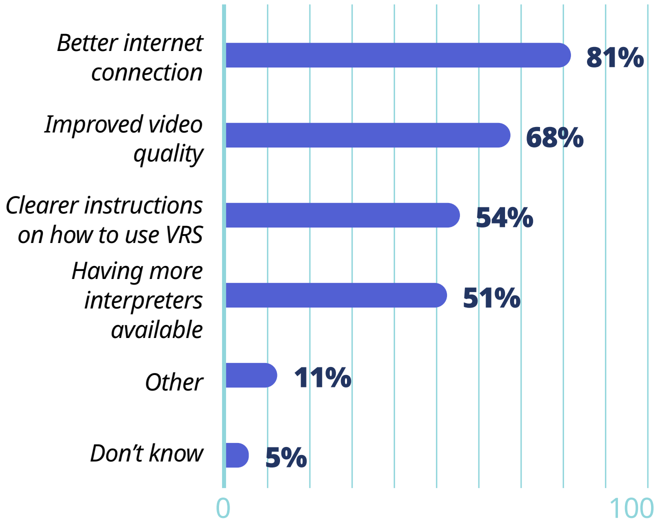
Table 20: ***VRS gives me confidence that I can have sign language access to healthcare at short notice or in an emergency*** *(n=37)*

Agree (net)	**59%**
Strongly agree	22%
Agree	38%
Neither agree nor disagree	22%
Disagree	8%
Strongly disagree	14%
Disagree (net)	**22%**
Don't know	3%

N.B. Small sample size of n=37 for this routed question.

When asked what would help to improve the experience of using VRS, in line with earlier responses, 81% say better internet connection and more than two thirds (68%) want improved video quality.

Figure 16: ***Ways in which VRS could be improved*** *(n=37)*



INFORMATION PROVISION

It is not only in 'live conversation' that some sign language users require support. Deaf BSL users often experience language deprivation at an early age, leading to difficulty understanding and using written English.

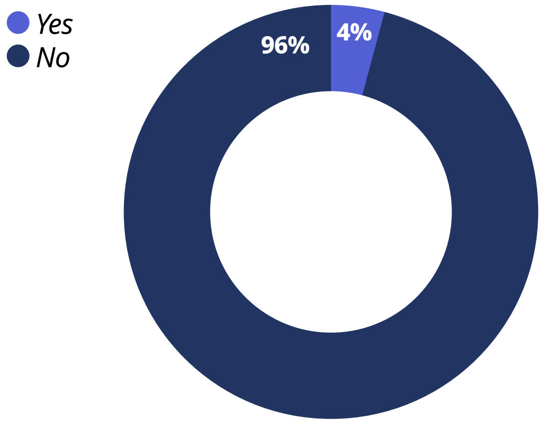
The majority of NHS staff (86%) report giving patients information to take home following an appointment or consultation, for example a link to online information or giving patients a physical leaflet or information sheet, with only 10% saying they do not give patients information to take home and 4% saying they do not know.

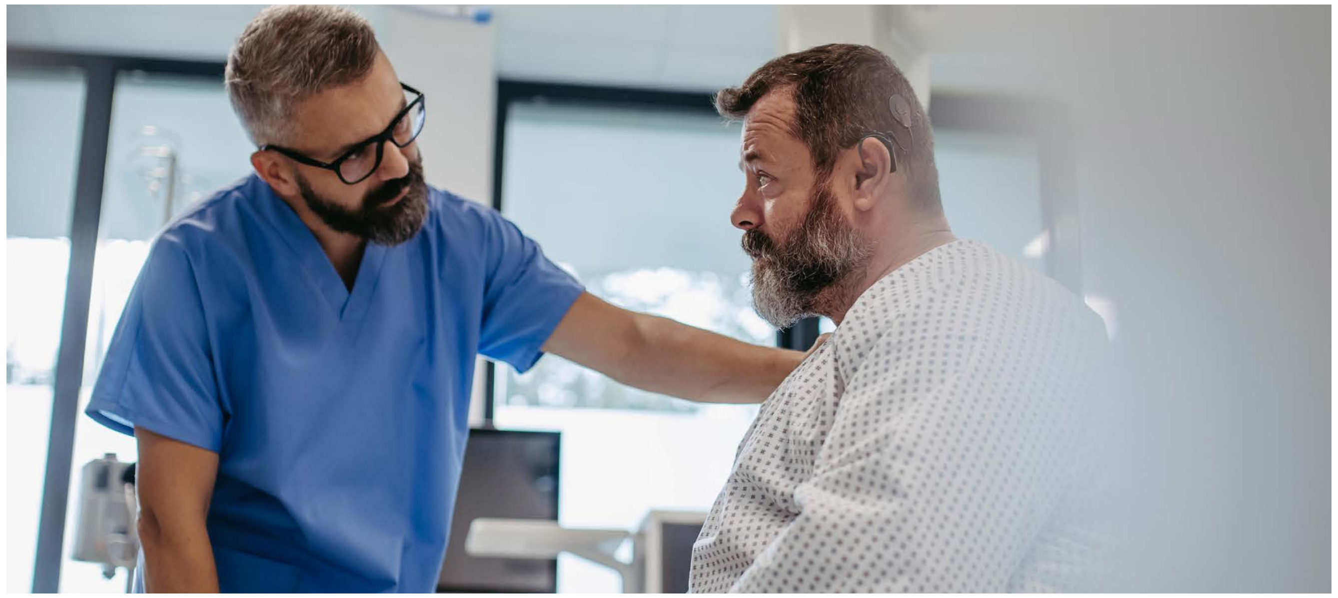
When asked specifically about information provision for BSL users, of those who report giving patients information to take home, two thirds (66%) report that deaf patients who use BSL are offered take-home information translated into BSL. Only 19% report that they are not offered this information translated into BSL and 16% say they do not know.

Almost two thirds (63%) of the sign language users in our sample have been offered written information to take home after an appointment. However, 96% of those have never been offered written information translated into BSL, despite sign language being their main or preferred language. The discrepancy between what NHS staff report is happening versus the experience of patients is stark.

Furthermore, 64% of those who had not been given any information in BSL say they felt less confident in the information they had been given about their health as a result.

Figure 17: ***Proportion of sign language users that have been offered written information translated into BSL*** *(n=76)*





Section 5: The impact of unmet needs

Overall, people who are deaf or have hearing loss report poor experiences of accessing healthcare. However, it is evident that the experiences are markedly worse for those who need access to a communication support professional. This impacts their ability to maintain good physical and mental health, as well as their ability to manage other health conditions.

Two thirds (66%) of those people who need a communication support professional rate their experience as poor, as do 58% of sign language users and nearly a third (31%) of people who need other reasonable adjustments.

Only 15% of sign language users would rate their experience as good, with this figure dropping even further to just 9% of people who need a communication support professional.

Table 21: ***Overall, how would you rate your experience of accessing healthcare?*** *(n=1114)*

	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
Good (net)	**15%**	**9%**	**32%**
Very good	4%	1%	10%
Good	11%	8%	22%
Satisfactory	27%	23%	37%
Poor	36%	45%	25%
Very poor	22%	22%	6%
Poor (net)	**58%**	**66%**	**31%**
Don't know	0%	2%	0%

Nearly ten years on after the initial publication of the AIS, little has changed to improve the experiences of people who are deaf or have hearing loss. Only 16% of people agree that healthcare is more accessible to them now than it was ten years ago, prior to the implementation of the AIS.

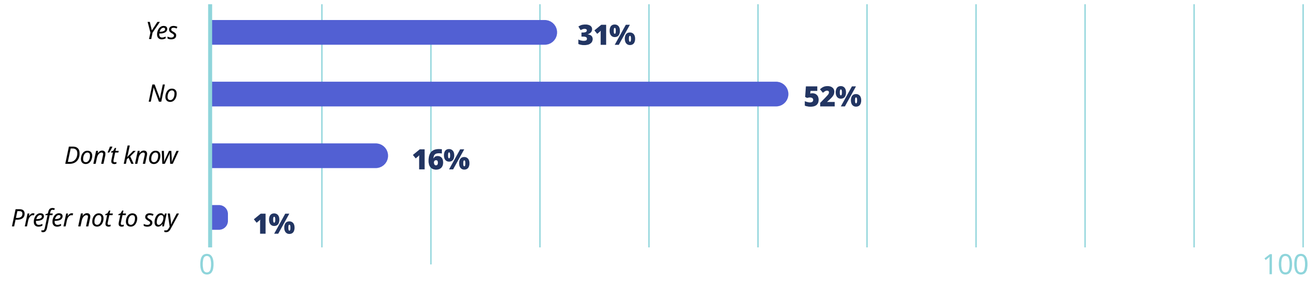
Similarly, only 17% of people agree that healthcare professionals meet their information and communication needs more now than they did ten years ago.

Table 22: ***Level of agreement with the following statements*** *(n=1114)*	Healthcare is more accessible to me than it was ten years ago	Healthcare professionals meet my information and communication needs more often than they did ten years ago
Agree (net)	**16%**	**17%**
Strongly agree	3%	3%
Agree	13%	14%
Neither agree nor disagree	28%	29%
Disagree	28%	26%
Strongly disagree	21%	17%
Disagree (net)	**49%**	**44%**
Don't know	3%	4%
Not applicable	4%	6%

Our evidence demonstrates that, rather than there being improvements in patient experience since the AIS was introduced, people who are deaf or have hearing loss are actually being denied their information and communication needs, which is a clear failure of the NHS to meet the key requirements of the AIS.

When asked explicitly, almost a third (31%) of people say they have been denied the information and communication support they need in order to access health services.

Figure 18: ***Proportion of people who say they have been denied the information and communication support they need*** *(n=1114)*



This figure rises to over two thirds (67%) of sign language users and 62% of people who need a communication support professional.

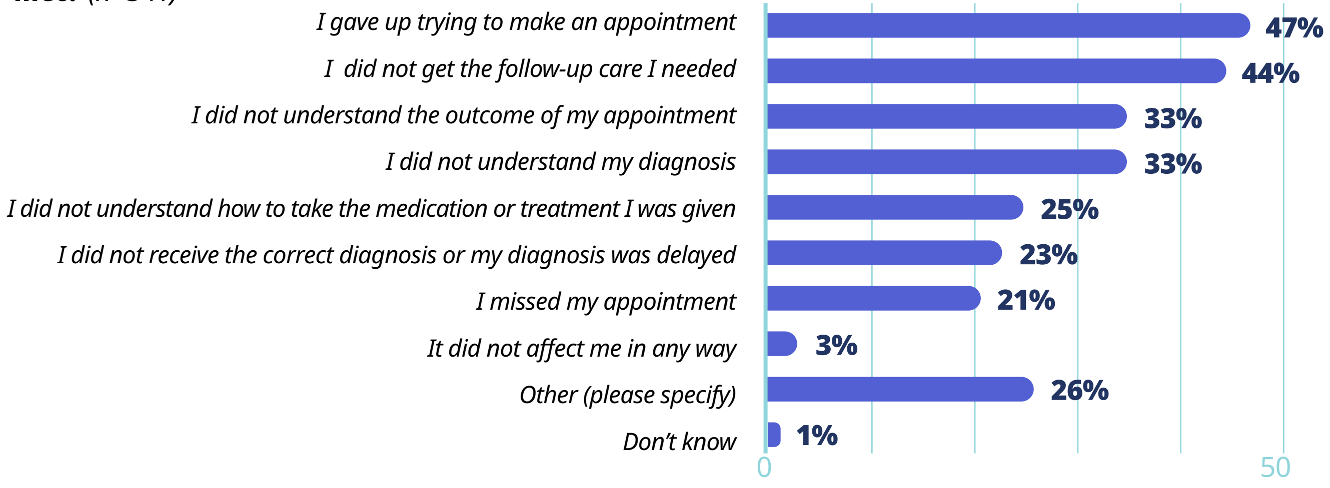
Table 23: ***Have you ever been denied the information and communication support you need?*** *(n=1114)*

	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
Yes	67%	62%	22%
No	21%	16%	61%
Don't know	10%	19%	16%
Prefer not to say	2%	3%	1%

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

- Giving up trying to make an appointment (47%) or missing an appointment (21%)
- A delayed or incorrect diagnosis (23%)
- Failure to understand their diagnosis (33%), the outcome of their appointment (33%) or how to take prescribed medication or treatment (25%)
- Almost half felt it has resulted in them not getting the follow-up care they need (44%).

Figure 19: ***What happened as a result of not having your information and communication needs met?*** *(n=341)*



The consequences are particularly felt by sign language users and those who require a communication support professional, where over half (53%) of sign language users did not understand the outcome of their appointment and 56% did not get the follow-up care they needed as a result of their information and communication needs not being met.

Table 24: ***What happened as a result of not having your information or communication needs met?*** *(n=341)*	Sign language users *(n=81)*	People who need a communication support professional *(n=63)*	People who need other reasonable adjustments *(n=197)*
I gave up trying to make an appointment	46%	54%	45%
I did not get the follow-up care I needed	56%	56%	36%
I did not understand my diagnosis	48%	44%	24%
I did not understand the outcome of my appointment	53%	41%	23%
I did not understand how to take the medication or treatment I was given	47%	35%	13%
I did not receive the correct diagnosis or my diagnosis was delayed	40%	22%	16%
I missed my appointment	32%	33%	13%
Other (please specify)	15%	30%	29%
It did not affect me in any way	2%	3%	3%
Don't know	4%	0%	1%

For those who selected 'other', many went on to talk about some of the longer-term impacts. Here, people explained how they no longer feel able to attend appointments on their own and now rely on others to accompany them to appointments to support with communication. Others spoke about the emotional impact, stress and anxiety they have felt as a result. Some explained they lost confidence in their GP practice and now look for health information from other sources or have chosen to change their GP practice as result.

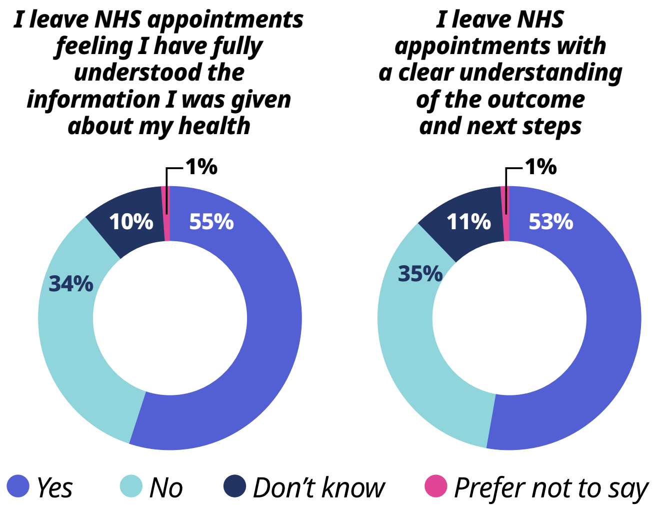
Others spoke of avoiding seeking help or trying to book appointments, with some suggesting they have stopped continuing to engage with a service. For some, the fact they need face-to-face appointments has led to delays in them receiving care, whereas others did not get the diagnostic tests or treatment agreed due to communication breakdowns.

The impact of not meeting the communication needs of people who are deaf or have hearing loss is broad-ranging and serious, with effects on patient safety, including missed diagnoses and disengagement from health services. It runs contrary to attempts to improve population health by encouraging better health behaviours, earlier diagnosis and intervention, and to tackling health inequalities.

LACK OF UNDERSTANDING OF CRITICAL INFORMATION

Only around half (55%) of patients say they leave NHS appointments feeling they fully understand the information they are given about their health and with a clear understanding of the outcome and next steps following NHS appointments (53%).

Figure 20: ***Proportion of people who agreed with the statements outlined*** *(n=1114)*



Those who need a communication support professional experience particularly poor outcomes. Half (50%) of sign language users and 56% of people who need a communication support professional leave NHS appointments feeling they do not fully understand the information they are given about their health, as do 29% of people who require other reasonable adjustments.

And again, nearly half (49%) of sign language users and 58% of people who need a communication support professional do not leave NHS appointments with a clear understanding of the outcome and next steps, as do nearly a third (31%) of people who require other reasonable adjustments.

Figure 21: ***I leave NHS appointments feeling I have fully understood the information I was given about my health*** *(n=1114)*

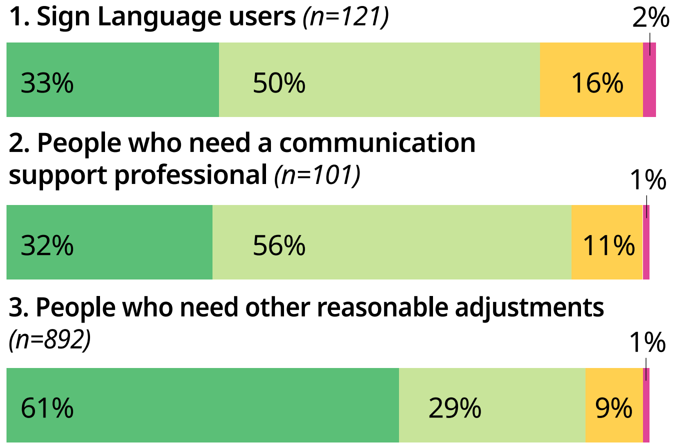
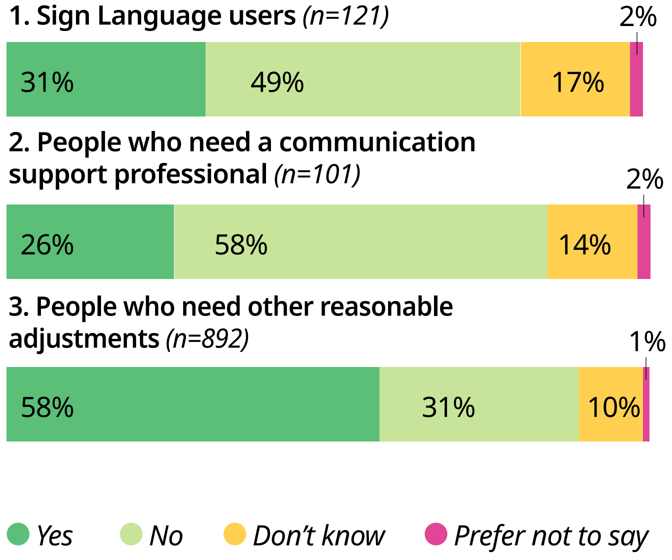


Figure 22: ***I leave NHS appointments with a clear understanding of the outcome and next steps*** *(n=1114)*



GETTING IT RIGHT – ENSURING PATIENT UNDERSTANDING

When communication needs are met, patients who are deaf or have hearing loss feel informed and in control of their health:

“A physiotherapist made sure she had a clear visor on so that I could lip read her. She checked that I had heard everything and was very patient with answering questions that I had to check my understanding of what she was saying.”

Female, 55-64, needs other reasonable adjustments

“A locum understood my hearing needs immediately and whizzed his chair round to be opposite me and explained really carefully to me about a skin cancer I had so I understood. He was so proactive and I felt very cared for because he was very happy to do this and didn’t judge me or get annoyed.”

Female, 65-74, needs other reasonable adjustments

“I recently met with an ENT medic who clearly made a conscious effort to speak clearly, whilst sitting right in front of me face on. This was done in a non-patronising way... For example, he didn’t speak overly loud or shout. They listened to all my concerns and clearly addressed all of them. They came up with a clear plan, that was explained to me. I felt really listened to and that I had all the information I had wished for, along with being reassured.”

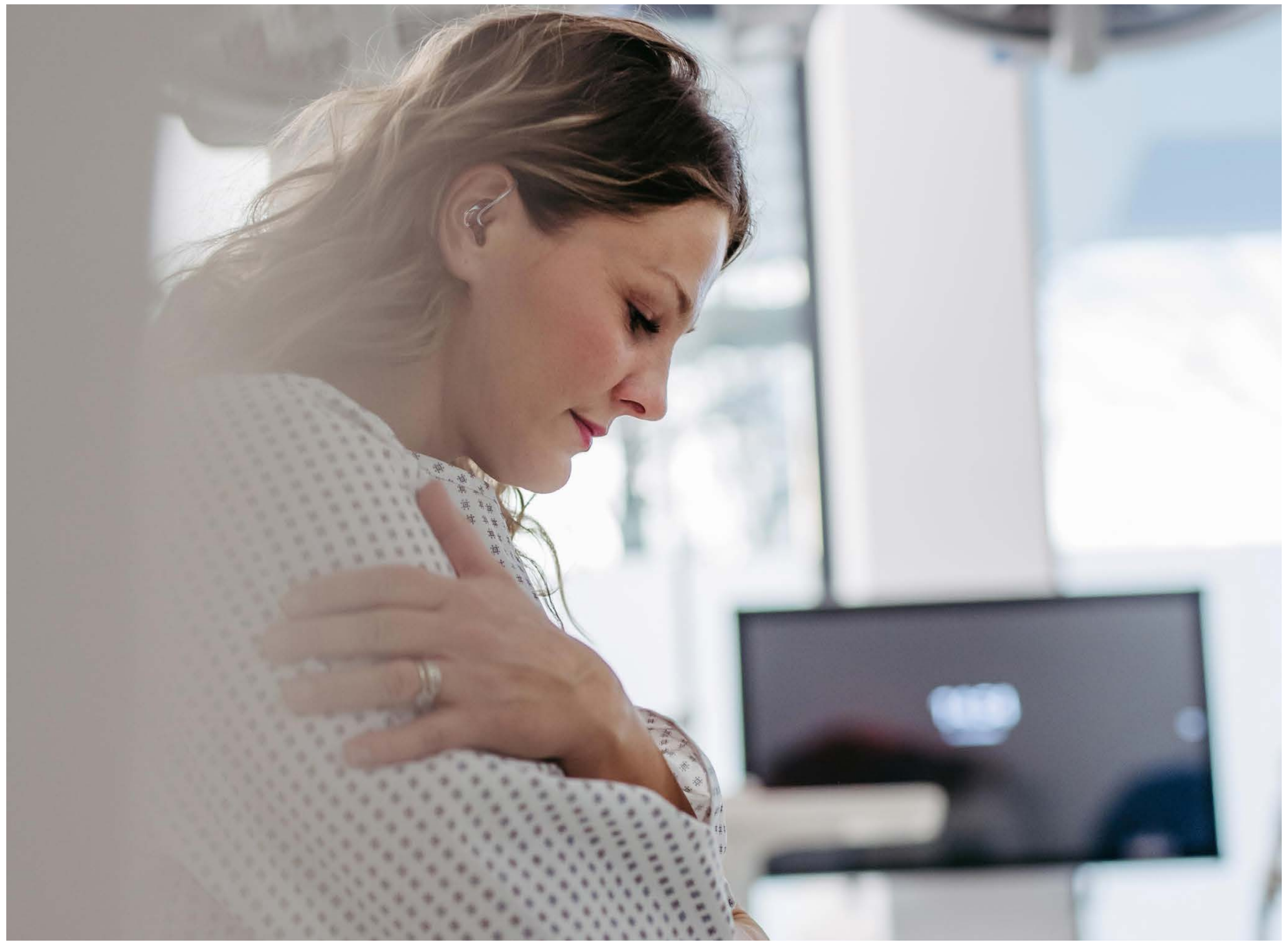
Female, 45-54, needs other reasonable adjustments

“I had a GP appointment and the GP messaged me and asked if I’d like a 20 minute appointment, instead of a 10 minute appointment, so that they could take the time to talk to me face to face. This way I would be able to lipread them, understand what was going on and not have to read my GP notes after the appointment. This GP has now left but they took the time and care to notice that I had accessibility issues, they addressed it rather than me and they tried to take action. I know it’s still a long way to go but these little steps are still steps in the right direction.”

Female, 25-34, needs other reasonable adjustments

“Being able to read clearly what was going on made me feel that I was being treated with respect, as a partner in my care, and it gave me the sense that I was important - that these people actually wanted me to know and understand the information they were giving me. I didn’t feel as though I was being spoken down to or treated like I was dumb. I felt as I did before I lost much of my hearing - I felt like I was treated as a person.”

Female, 45-54, needs other reasonable adjustments



PATIENTS ARE BEING PUT AT RISK

The proportion of people who are deaf or have hearing loss that leave appointments without fully understanding the information they are given about their health or the outcome of their appointment is unacceptable.

For sign language users in particular, inaccessible communication has left them feeling that their health was put at risk (43%) or an existing health problem was made worse (32%).

Table 25: ***In which of the following ways, if any, has a lack of accessible communication impacted you?*** *(n=1114)*

	Overall total *(n=1114)*	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
I felt that my health was put at risk	14%	43%	31%	8%
A health problem I was experiencing was made worse	14%	32%	36%	10%

The impact of needs not being met includes people missing important information about their health and treatment as well as the risk of misdiagnosis:

“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

“I recently saw a consultant who I’d been referred to because I keep falling. I did not know that he discharged me until I received a copy of the letter to my GP. I kept telling him I could not hear but I gave up.”

Female, 65-74, needs other reasonable adjustments

“I had to ask them to repeat what she said over and over and, in the end, gave up and hoped for the best. I had an IV canula into which she inserted a small amount of a clear liquid. She told me what it was, but I could not understand so just trusted that it was water or something similar. This didn’t seem right to me, but I was fed up asking for things to be repeated.”

Female, 75+, needs other reasonable adjustments

“Misunderstood care plan for osteoarthritis which was severe, and I thought I was having an amputation which was very distressing for me and my family. What was said was the opposite of that and that took a while to clarify.”

Male, 65-74, needs other reasonable adjustments

There were some accounts that demonstrated the serious and often dangerous impact of communication needs not being met due to a failure of BSL interpreter provision. There is also evidence of a concerning failure to provide the most basic patient care:

“I had to stay in hospital for 6 days and they never provided me with a BSL interpreter. I was stressed and panicked.”

Male, 25-34, sign language user

“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 me.”

Female, 65-74, needs other reasonable adjustments

Some NHS staff who face communication barriers with patients who are deaf or have hearing loss are also concerned about them not getting the quality of care they deserve, with concerns raised about the risk of misdiagnosis, delayed treatment or patients not feeling fully informed about their health:

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

District or practice nurse

“If you can’t communicate well, you can’t fully understand the patient’s needs and give them the full care they require.”

District or practice nurse

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

Allied health professional

“I could misdiagnose them.”

District or practice nurse

“It makes it harder to deliver quality care.”

Allied health professional

“We struggle to meet needs and provide person-centred care.”

Healthcare support worker

Without access to interpreters, sign language users are left feeling uninformed about their health treatment and consequences, which were described as frightening, worrying and traumatic experiences:

“I am often not clear on what the medication is or does at the time of prescribing. I have to research myself when I get home. Sometimes the label on medication is not clear on dosage, I again research it and guess.”

Female, 25-34, sign language user

“I had an appointment for suspected breast cancer, no interpreter arrived so I had to resort to using pen and paper at a very worrying time.”

Female, 45-54, sign language user

“I went into A&E for blood loss, 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

THE EMOTIONAL IMPACT OF UNMET NEEDS

The emotional impact of consistently not having communication needs met when accessing healthcare is clear. In their accounts, many people who are deaf or have hearing loss told us of feeling 'othered' by the healthcare system, disrespected or ignored, and, in some instances, of being treated as if they were stupid:

"Lack of information makes me feel like I don't count."

Male, 75+, needs other reasonable adjustments

"People think that you are stupid."

Female, 55-64, needs other reasonable adjustments

"I would like to be treated with respect and like a human being."

Female, 35-44, needs a communication support professional

"In the last two years, I have had two stays in hospital where 'Deaf and Dumb' has appeared on my patient notes."

Male, 35-44, sign language user

"I feel like a second-class citizen."

Female, 55-64, sign language user

When communication needs are not met in situations of crisis, it can be a deeply stressful situation, which further exacerbates the anxiety and distress that patients are already facing:

"Recently my windpipe made it difficult to breathe and I was fast track[ed] to a hospital bed. I laid there thinking I did not understand exactly what going on; my anxiety shot up through roof and I laid in bed on my own crying. I felt so alone and in the dark. My partner cannot retain information and therefore he struggled to relay what was being said back to me."

Female, 35-44, needs a communication support professional

"When attending hospital for an ultrasound scan, I found the technicians were poor at communicating what they needed me to do when they prepared me for the scan. As a result, I felt insecure and confused. I have experienced this on several different occasions."

Female, 75+, needs other reasonable adjustments

In some cases, people described a distressing sense of loss of dignity and autonomy as a result of a lack of communication support, with implications for future engagement with the healthcare system:

"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 a communication support professional

FIGHTING FOR COMMUNICATION NEEDS TO BE MET

Having to fight for their communication needs to be met is stressful in and of itself. It adds anxiety to what can already be stressful and unsettling times for people experiencing ill health or health concerns.

Nearly half (46%) of those who need other reasonable adjustments say they find it stressful to access NHS services because they have to fight for their communication needs to be met. This figure rises to 89% of people who need a communication support professional and 95% of sign language users.

Table 26: ***It is stressful to access NHS services because I must fight for my communication needs to be met*** *(n=1114)*

	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
Agree (net)	**95%**	**89%**	**46%**
Strongly agree	75%	57%	18%
Agree	20%	33%	28%
Neither agree nor disagree	2%	3%	28%
Disagree	1%	4%	16%
Strongly disagree	1%	2%	8%
Disagree (net)	**2%**	**6%**	**24%**
Don't know	1%	3%	3%

"Every appointment I have, I have to tell them about my hearing loss and wearing hearing aids. It is tiring and it makes me feel invisible."

Female, 25-34, needs other reasonable adjustments

"Sometimes it is like climbing a mountain, it's exhausting."

Female, 75+, needs other reasonable adjustments

"You have to be assertive and tell the healthcare professional what they can do for you. You may need to contact the setting before your appointment to get the access you need."

Male, 45-54, needs other reasonable adjustments

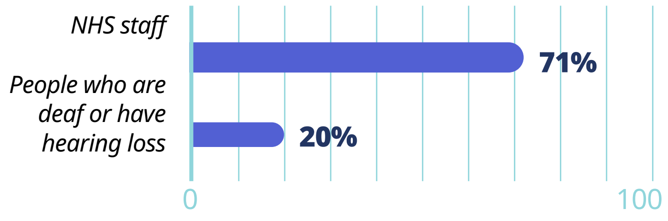
Section 6: Longer-term impacts

AN EROSION OF TRUST

When it comes to being treated fairly and the trust that patients have in the NHS, once again, there is a clear disparity between how well NHS staff think they are meeting patients' communication needs and the stark realities of the patient experience for deaf people and people with hearing loss.

While 71% of NHS staff agree that deaf people and people with hearing loss are treated fairly by the NHS, only 20% of people who are deaf or have hearing loss feel they are treated fairly. This indicates that NHS staff are unaware of the extent of the unfair treatment that deaf people and people with hearing loss are facing.

Figure 23: ***Levels of 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)*



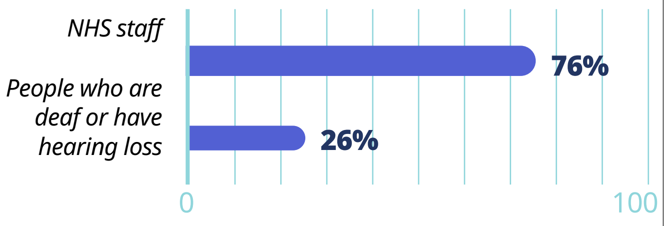
Indeed, 70% of people who need a communication support professional do not think that deaf people and people with hearing loss are treated fairly by the NHS, as do 68% of sign language users. People who need other reasonable adjustments are more ambivalent and uncertain in their views.

Table 27: ***Deaf people and those with hearing loss are treated fairly by the NHS*** *(n=1114)*

	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
Agree (net)	**19%**	**7%**	**21%**
Strongly agree	13%	2%	5%
Agree	7%	5%	16%
Neither agree nor disagree	12%	20%	34%
Disagree	31%	38%	28%
Strongly disagree	36%	33%	9%
Disagree (net)	**68%**	**70%**	**37%**
Don't know	3%	5%	9%

NHS staff also seem unaware of any cause for distrust; over three quarters of staff (76%) say that deaf people and people with hearing loss can trust the NHS compared to 26% of people who are deaf or have hearing loss.

Figure 24: ***Levels of agreement with the statement 'Deaf people and those with hearing loss can trust the NHS'*** *(n=404 NHS staff; 1114 people who are deaf or have hearing loss)*



Over half of sign language users (55%) and people who need a communication support professional (52%) do not think deaf people and people with hearing loss can trust the NHS. Again, those who need other reasonable adjustments are both more positive and more ambivalent about whether or not they can trust the NHS (see Table 28 below).

However, it is not just about the 'institution' as an entity. Overall, 22% of people who are deaf or have hearing loss say they have lost trust in healthcare professionals as a result of a lack of accessible communication, which increases to 42% of sign language users and 40% of people who need a communication support professional. This demonstrates an erosion of trust in the NHS particularly among those people who need communication support in order to be able to access an appointment.

Figure 25: ***Proportion of people that agree with the statement 'I have lost trust in healthcare professionals'*** *(n=1114 overall total; 121 sign language users; 101 people who need a communication support professional; 892 people who need other reasonable adjustments)*

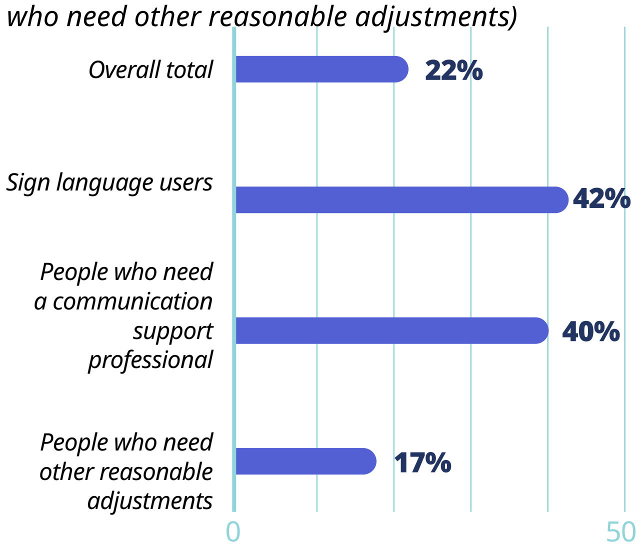


Table 28: ***Deaf people and those with hearing loss can trust the NHS*** *(n=1114)*

	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
Agree (net)	**17%**	**13%**	**29%**
Strongly agree	10%	3%	6%
Agree	7%	10%	24%
Neither agree nor disagree	26%	32%	43%
Disagree	22%	26%	16%
Strongly disagree	32%	27%	6%
Disagree (net)	**55%**	**52%**	**21%**
Don't know	2%	3%	7%

However, when NHS staff were asked if they feel deaf people and people with hearing loss are being let down by the NHS, the results were more divided. Here, 37% agree that deaf people and people with hearing loss are being let down by the NHS.

Therefore, despite believing that deaf people and people with hearing loss are being treated fairly by the NHS and can trust the NHS, there is some apparent level of recognition among NHS staff that the NHS is not doing enough for deaf people and people with hearing loss.

Table 29: ***Levels of agreement among NHS staff with the statement 'Deaf people and people with hearing loss are currently being let down by the NHS*** *(n=404)*

Agree (net)	**37%**
Strongly agree	12%
Agree	25%
Neither agree nor disagree	23%
Disagree	17%
Strongly disagree	18%
Disagree (net)	**35%**
Don't know	5%
Prefer not to say	0%

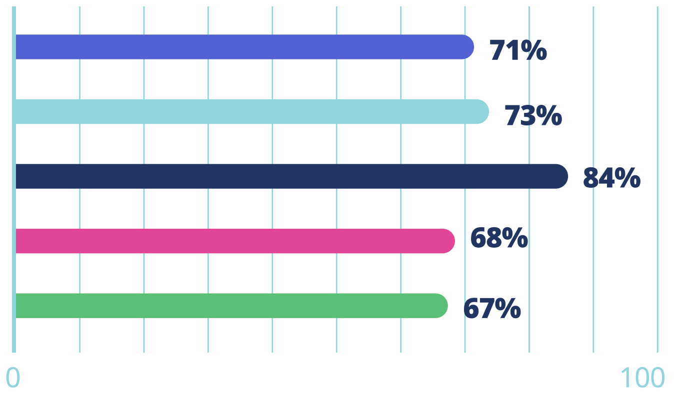
There are marked differences between NHS staff, where 84% of clinical support staff and healthcare support workers feel that deaf people and people with hearing loss are being treated fairly by the NHS, compared to only 67% of nurses and midwives.

Clinical support staff and healthcare support workers demonstrate the highest levels of agreement with the statement that deaf people and people with hearing loss can trust the NHS (92%) compared to only 70% of doctors.

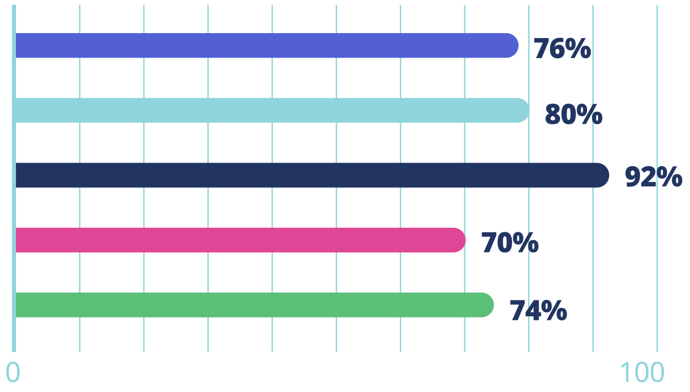
Over half (53%) of allied health professionals feel that deaf people and people with hearing loss are being let down by the NHS, compared to only 18% of admin staff. This may be indicative of greater awareness or indeed personal experience amongst allied health professionals of instances where the needs of deaf people and people with hearing loss have not been met to account for such disparate views.

Figure 26:. ***Proportion of NHS staff across a range of job roles that agree with each statement*** *(n=100 admin staff; 51 allied health professionals; 51 clinical support staff and healthcare support workers; 100 doctors; 102 nurses and midwives) (n=1114)*

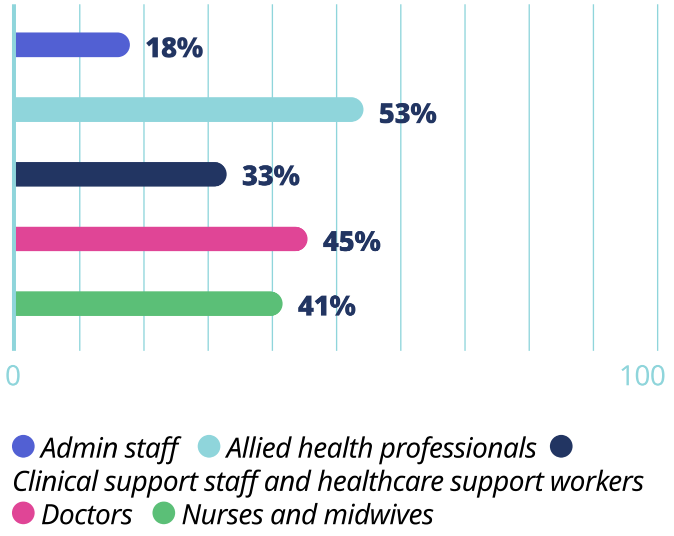
Deaf people and people with hearing loss are being treated fairly by the NHS



Deaf people and people with hearing loss can trust the NHS



Deaf people and people with hearing loss are currently being let down by the NHS



DISENGAGEMENT FROM HEALTHCARE SERVICES

As demonstrated, the failure to meet the communication needs of patients who are deaf or have hearing loss has immediate impacts at the point of interaction. It then continues to impact the ongoing care and outcomes for a patient in terms of the specific health concern or condition that had triggered engagement with the health service.

Beyond this, however, it can have significant impacts on an individual's ability to proactively manage their health and wellbeing, and their willingness to engage with health services in the future.

Those people who need a communication support professional show the highest levels of disengagement with healthcare services. For instance, nearly half (47%) of people who need a communication support professional avoided seeking help for a new health concern, as have 40% of sign language users.

Table 30: ***In which of the following ways, if any, has a lack of accessible communication impacted you?*** *(n=1114)*

	Overall total *(n=1114)*	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
I have avoided seeking help for a new health concern	25%	40%	47%	21%
I have avoided pursuing follow up or review appointments for existing health conditions	20%	26%	36%	17%
I have avoided calling an ambulance or attending Accident and Emergency (A&E)	9%	26%	30%	4%

Although they have not yet needed the service, a few people also raised concerns about contacting 999 if they needed help in an emergency as they did not think it would be accessible to them:

> ***"I am independent and live alone. It's difficult for me and my main concern is in an emergency calling 999 or 111."***
>
> Female, 65-74, needs a communication support professional

> ***"I've not needed emergency services [but] as I live alone and am profoundly deaf, I am unsure how effective 999 service will be in the event I need it. I can hardly test it out to understand how I can communicate my emergency issues quickly."***
>
> Male, 65-74, needs other reasonable adjustments

THE IMPACT ON PHYSICAL HEALTH AND MENTAL WELLBEING

The government has identified improving the population's health and preventing long-term illness as critical to reducing health inequalities – it has placed this at the heart of the NHS Long Term Plan. Prevention is a key work area within the plan. This means encouraging people to adopt healthy behaviours and seek early help for health concerns.

However, as a result of a lack of accessible communication, people who are deaf or have hearing loss say that this is difficult for them to do. Specifically, 82% of sign language users and 86% of those who need a communication support professional agree that it is harder for them as someone who is deaf or has hearing loss to maintain good *physical* health.

Table 31: ***A lack of accessible communication makes it harder for me as someone who is deaf or has hearing loss to maintain good physical health*** *(n=1114)*

	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
Agree (net)	**82%**	**86%**	**35%**
Strongly agree	53%	47%	9%
Agree	29%	40%	27%
Neither agree nor disagree	14%	9%	35%
Disagree	1%	3%	19%
Strongly disagree	2%	2%	8%
Disagree (net)	**3%**	**5%**	**27%**
Don't know	2%	1%	3%

It is also harder for people who are deaf or have hearing loss to maintain good *mental health* and wellbeing due to a lack of accessible communication. While just under half (48%) of those who need other reasonable adjustments agree that it is harder for them as someone who is deaf or has hearing loss to maintain good mental health and wellbeing, this figure rises to 80% of people who need a communication support professional and 88% of sign language users.

Table 32: ***A lack of accessible communication makes it harder for me as someone who is deaf or has hearing loss to maintain good mental health and wellbeing*** *(n=1114)*

	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
Agree (net)	**88%**	**80%**	**48%**
Strongly agree	57%	51%	14%
Agree	31%	30%	34%
Neither agree nor disagree	6%	11%	27%
Disagree	2%	3%	17%
Strongly disagree	2%	2%	6%
Disagree (net)	**5%**	**5%**	**23%**
Don't know	2%	4%	3%

> ***"It's impossible to manage your health when you don't fully understand it because of communication breakdowns again and again. I'm an adult (23 years old) and I still feel like a child because lots of healthcare professionals ignore me and only talk to my mum and make me feel invisible. I feel like I can't manage my own health."***
>
> Female, 18-24, needs a communication support professional

THE IMPACT ON MANAGING OTHER HEALTH CONDITIONS

For those who are managing other disabilities or long-term health conditions, a lack of accessible communication negatively impacts their ability to manage their existing health conditions.

Two thirds (66%) of those surveyed are managing another disability or long-term health condition.

Of those with another health condition or disability, over two thirds (69%) agree that when their communication needs are not met, it makes it harder for them to manage their existing health conditions.

Table 33: ***When my communication needs are not met, it makes it harder for me to manage my existing health conditions*** *(n=730)*

Agree (net)	**69%**
Strongly agree	28%
Agree	41%
Neither agree nor disagree	21%
Disagree	5%
Strongly disagree	2%
Disagree (net)	**7%**
Don't know	3%

> ***"I avoid contact with the GP whenever possible, so I have little support for existing conditions."***
>
> Female, 45-54, needs other reasonable adjustments

> ***"Because I find hearing on the phone difficult, if I have a problem, like a flare up with my joints, I just try to cope."***
>
> Female, 75+, needs other reasonable adjustments

> ***"They usually have very little patience with someone who cannot understand them straightaway. It is difficult to understand medical terms, so I neglect health conditions unless a relative can be there to assist me."***
>
> Female, 75+, needs a communication support professional

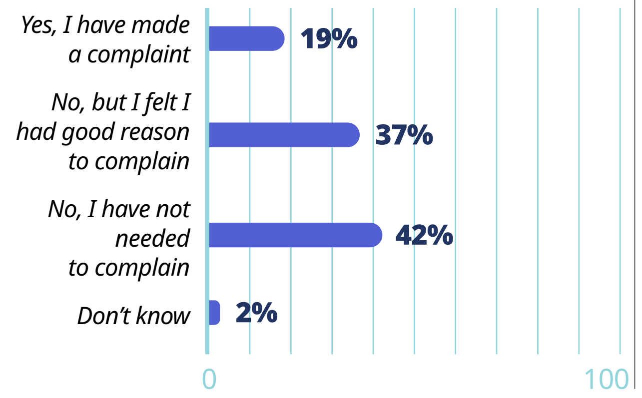
Section 7: Complaints about lack of equal access to healthcare

People who feel that their information and communications needs are not being met have the right to complain. In the first instance, they should complain to the service provider, such as the hospital or GP practice.

Given the barriers that people who are deaf or have hearing loss face when accessing healthcare, it is ironic that even the complaints process itself was often found to be inaccessible and rarely leads to improvements.

Nearly 1 in 5 (19%) of those people surveyed have made a complaint about their access to healthcare as a result of their information and communication needs not being met. While a further 37% felt they had good reason to complain, they decided against pursuing a complaint.

Figure 27: ***Proportion of people that have made a complaint about their access to healthcare as a result of their information and communication needs not being met*** *(n=1114)*



Of those who did pursue a complaint, over two thirds (67%) complained to the NHS service provider directly and 11% complained to the service commissioner.

It was found that 13% said they had complained to the Patient Advice and Liaison Service (PALS). However, as PALS is not a formal complaint mechanism, this suggests a lack of understanding among people who are deaf or have hearing loss about what the complaints process actually is.

For those who answered, 'other', they had complained directly to an NHS staff member at the time, for example "the staff at the audiology department", "hospital staff" and "the consultant", with some of these referred to as "informal complaints". A small number of people said they left comments online or took their complaint to their MP.

Table 34: ***Who did you complain to?*** *(n=210)*

NHS service provider directly. For example, a GP practice, dentist surgery or hospital	67%
The commissioner of the service which is the body that pays for the NHS services you use. For example, the Clinical Commissioning Group (CCG) or Integrated Care Board (ICB)	11%
Patient Advice and Liaison Service (PALS)	13%
Other	9%

It was therefore decided to remove those people from the analysis who had not made complaints to the NHS service provider or the commissioner of the service, as this would skew the results for the success rates of complaints. By removing those who said they made a complaint to PALS or selected 'other', this means that in fact only 15% had made a formal complaint. The results for the remainder of this section will focus specifically on this 15%.

There is a lack of awareness of advocacy services that could assist people with their complaint, with only 12% of people using one to assist them with their complaint, and over a third (34%) saying they are not aware of any advocacy services.

Those who had complained to the NHS provider directly were more likely to say they did not use an advocacy service (71 out of 141 respondents), compared to people who had complained to the commissioner of the service (8 out of 23 respondents). They were also more likely to say they weren't aware of any advocacy services (52 out of 141 respondents) compared to those who had complained to the commissioner of the service (4 out of 23 respondents).

Table 35: ***Did you use any advocacy services to assist with your complaint?*** *(n=164)*

Yes	12%
No	48%
I wasn't aware of any advocacy services	34%
Other	5%
Don't know	1%

Just over a quarter of people (26%) say their complaint was successful. For some, changes were made as a result of their complaint including commitments to staff training, communication needs finally being recorded, and the provision of alternative contact methods:

"A clear note was put on file with my accessibility needs."
Female, 55-64, needs other reasonable adjustments

"I can now write to my consultant and GP and specialist nurses by email."
Female, 65-74, needs other reasonable adjustments

"To some extent they admitted problems with their systems and promised to resolve them."
Male, 45-54, needs other reasonable adjustments

However, some of these provisions seem to be inconsistent or temporary, with many patients suggesting there had been no long-term change or improvement as a result of their complaint:

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

"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

"The outcome of the complaint was OK, but I don't have the feeling that they really changed their procedure as a result of my protests."
Male, 75+, needs other reasonable adjustments

"Nothing much happened to change anything. A bit of grovelling and apologies, but nothing else really."
Female, 75+, needs other reasonable adjustments

In contrast, 46% say their complaint was unsuccessful, often reporting it was ignored or dismissed:

"I was ignored and heard nothing more despite trying to chase it up."
Female, 45-54, needs a communication support professional

"Eventually I was seen [regarding] the complaint. It was dismissed, ignored."
Female, 75+, needs other reasonable adjustments

Table 36: ***Was your complaint successful?***
(n=164)

Yes	26%
No	46%
Don't know	27%

For those people who do not know if their complaint was successful, this was often due to the complaints process still being ongoing and awaiting a decision, whereas others indicated a breakdown in the complaints procedure that has left them unsure of the outcome of their complaint, with some stating they never received a response:

"Still awaiting the results, it has dragged on for a year."
Female, 45-54, needs a communication support professional

"No outcome, no response."
Female, 45-54, sign language user

"I have never heard back from my complaint even though I followed their process to the exact detail."
Female, 45-54, needs a communication support professional

Instances of patients not knowing the outcome of their complaint were higher among those people who complained to the commissioner of the service (10 out of 23), compared to those who complained to the NHS provider directly (35 out of 141).

In those instances where the complaint was unsuccessful, only 20% decided to take further action, compared to 80% who decided against taking any further action.

"Nothing has changed - I am still in the same position I was before and struggling to book appointments. I just didn't have the strength to pursue it."
Female, 45-54, needs other reasonable adjustments

"My concerns were noted, but the constraints of the service meant there could be no favourable outcome for me."
Female, 75+, needs other reasonable adjustments

The Parliamentary and Health Service Ombudsman (PHSO) independently investigates complaints about the NHS in England. Where patients have reached the end of the complaints process and they are unhappy with the organisation's final decision, a complaint can be made to the PHSO to further investigate.

However, only 46% of those who made a complaint that was unsuccessful say they are aware of the PHSO. This apparent lack of knowledge could have been an influencing factor in people's decision to not take any further action – they may simply not have known who to turn to.

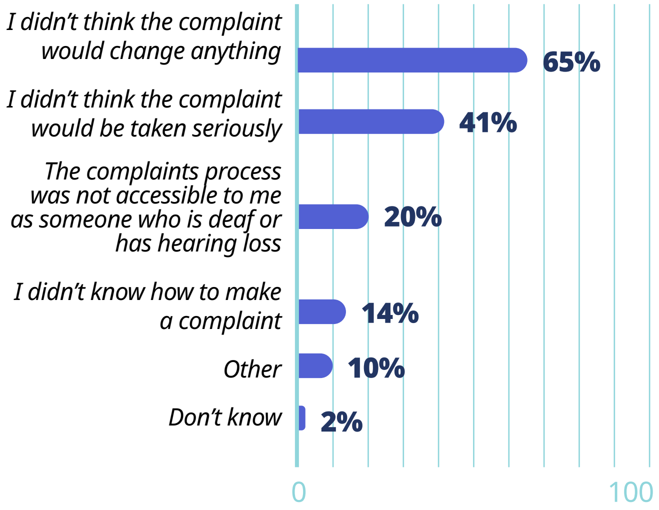
Those who complained to the NHS provider directly were also more likely to say they were not aware of the PHSO (67 out of 141) compared to those who complained to the commissioner of the service (1 out of 23).

Table 37: ***Are you aware of the Parliamentary and Health Service Ombudsman?***	Total who made a formal complaint *(n=164)*	Made an informal complaint* *(n=46)*	Made a complaint that was successful *(n=43)*	Made a complaint that was unsuccessful *(n=76)*	Don't know if their complaint was successful *(n=45)*
Yes (net)	**54%**	**43%**	**60%**	**46%**	**62%**
Yes, and I broadly understand what they do	25%	26%	33%	22%	22%
Yes, I have heard of them but are not sure what they do	29%	17%	28%	24%	40%
No, I have not heard of them	45%	57%	40%	54%	36%
Don't know	1%	0%	0%	0%	2%

**This includes those people who made a complaint to PALS (n=27) or selected 'other' (n=19), for example, people who complained directly to the NHS staff members themselves at the time*

For the 37% of patients who are deaf or have hearing loss that felt they had grounds to complain but decided not to make a complaint, this was mainly because they didn't think the complaint would change anything or they didn't think the complaint would be taken seriously. However, 20% of those who had cause to complain did not pursue it because the complaint process itself was not accessible to them as someone who is deaf or has hearing loss.

Figure 28: ***Reasons why people decided not to pursue a complaint*** *(n=416)*



The lack of an accessible complaints process not only prohibits patients from being able to make a complaint in the first place, but may even be influencing the success or failure of the complaint. Critically, only 36% of people who made a formal complaint actually found the complaints process itself to be accessible to them as someone who is deaf or has hearing loss.

Table 38: ***Did you find the complaints process accessible to you as someone who is deaf or has hearing loss?*** *(n=164)*

Yes	36%
No	57%
Don't know	7%

For those people who complained to the commissioner of the service, they were also more likely to say that the complaints process was not accessible to them as someone who is deaf or has hearing loss (16 out of 23) compared to those who complained to the NHS service provider directly (78 out of 141).

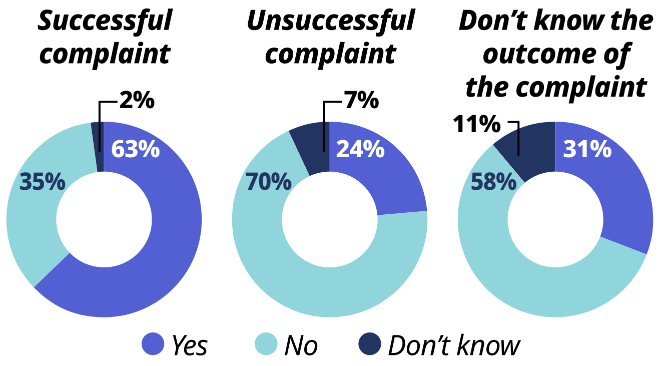
Although not a formal complaints mechanism, the majority of those people who used PALS (n=27), said they did not find the complaints process accessible (16 out of 27).

> ***"I have made complaints, and all have failed and been full of further access problems. For example, PALS say 'if you wish to discuss this further, please call' when a large part of it was around no access to email communication."***
> Female, 35-44, needs a communication support professional

Drilling down further into how accessible patients found the complaints process to be and whether their complaint was successful or not, there is evidence to suggest higher rates of unsuccessful complaints amongst those who found the process to be inaccessible.

Specifically, while 63% of those whose complaint was successful found the complaints process accessible to them, 70% of people who had unsuccessful complaints did not find the complaints process accessible.

Figure 29: ***Proportion of people who found the complaints process accessible or not and the outcome of their complaint*** *(n=43 successful complaints; 76 unsuccessful complaints; 45 don't know the outcome of their complaint).*



It is unacceptable that people who are deaf or have hearing loss face a double barrier when they cannot complain about inaccessible healthcare because of inaccessible complaints processes. This not only denies them of their right to have their issues understood and rectified, but it also denies the NHS the information it needs to identify ongoing problems and make systematic changes.

Section 8: Systemic challenges

People who are deaf or have hearing loss are the definitive experts on their own experiences. The gap between their experiences and the assumptions made by NHS staff shows a worrying lack of understanding from within the NHS about the barriers that patients who are deaf or have hearing loss face and the systemic challenges that urgently need addressing.

When NHS staff were asked how effective they feel their organisation, specifically, is in meeting the information and communication needs of patients who are deaf or have hearing loss, over three quarters (78%) agreed that **their organisation** is effective in meeting the information and communication needs of patients. Only 8% disagreed with this statement, indicating that most NHS staff members feel their organisation is doing a good job at meeting needs.

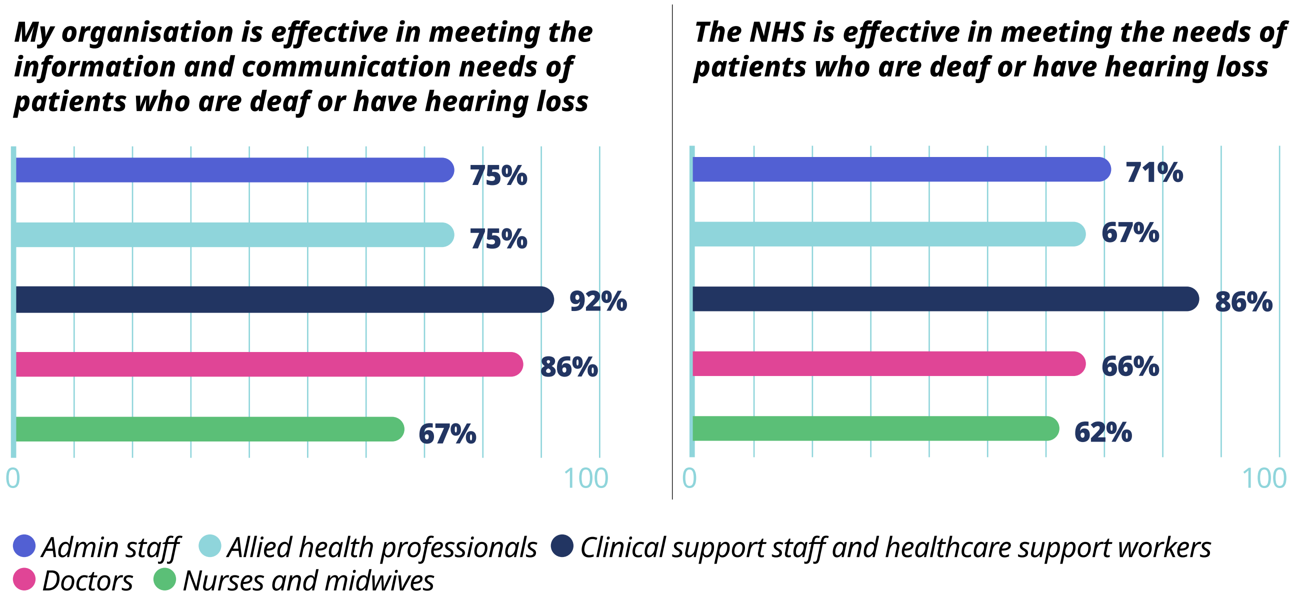
Whereas the number of NHS staff who say **the NHS** is effective in meeting the information and communication needs of patients is slightly lower. Here, just over two thirds (69%) agree with this statement compared to 12% who disagree, perhaps indicating slightly less confidence in the ability of the NHS to meet the needs of patients who are deaf or have hearing loss.

Table 39: ***Levels of agreement with the following statements by NHS staff:***

	My organisation is effective in meeting the information and communication needs of patients who are deaf or have hearing loss *(n=404)*	The NHS is effective in meeting the information and communication needs of patients who are deaf or have hearing loss *(n=404)*
Agree (net)	**78%**	**69%**
Strongly agree	32%	27%
Agree	46%	42%
Neither agree nor disagree	13%	17%
Disagree	7%	10%
Strongly disagree	2%	2%
Disagree (net)	**8%**	**12%**
Don't know	1%	2%
Not applicable	1%	0%

Clinical support staff and healthcare support workers demonstrated the highest levels of agreement that their organisation is effective in meeting the information and communication needs of patients who are deaf or have hearing loss (92%) and that the NHS is effective in meeting the needs of patients who are deaf or have hearing loss (86%), whereas levels were lowest among nurses and midwives.

Figure 30. ***Proportion of NHS staff across a range of job roles that agree with each statement*** *(n=100 admin staff; 51 allied health professionals; 51 clinical support staff and healthcare support workers; 100 doctors; 102 nurses and midwives)*



My organisation is effective in meeting the information and communication needs of patients who are deaf or have hearing loss

The NHS is effective in meeting the needs of patients who are deaf or have hearing loss

Yet in stark contrast, people who are deaf or have hearing loss do not feel that they get equal access to the NHS as hearing people. Nearly three quarters (71%) of people who need a communication support professional do not feel they have the same access to the NHS as hearing people, as do 64% of sign language users and 40% of people who need other reasonable adjustments.

Table 40: ***As someone who is deaf or has hearing loss, I feel I have the same access to the NHS as hearing people*** *(n=1114)*

	Sign language users *(n=121)*	People who need a communication support professional *(n=101)*	People who need other reasonable adjustments *(n=892)*
Agree (net)	**29%**	**18%**	**37%**
Strongly agree	22%	11%	11%
Agree	7%	7%	26%
Neither agree nor disagree	6%	7%	22%
Disagree	20%	25%	29%
Strongly disagree	44%	47%	11%
Disagree (net)	**64%**	**71%**	**40%**
Don't know	3%	4%	3%

There is a clear contrast between how well NHS staff feel they are meeting patients' communication needs and the perceptions of people who are deaf or have hearing loss.

Nearly a quarter (24%) of NHS staff say they can always meet the needs of patients who are deaf or have hearing loss. Only 4% say they rarely can, and just 1% say they never can.

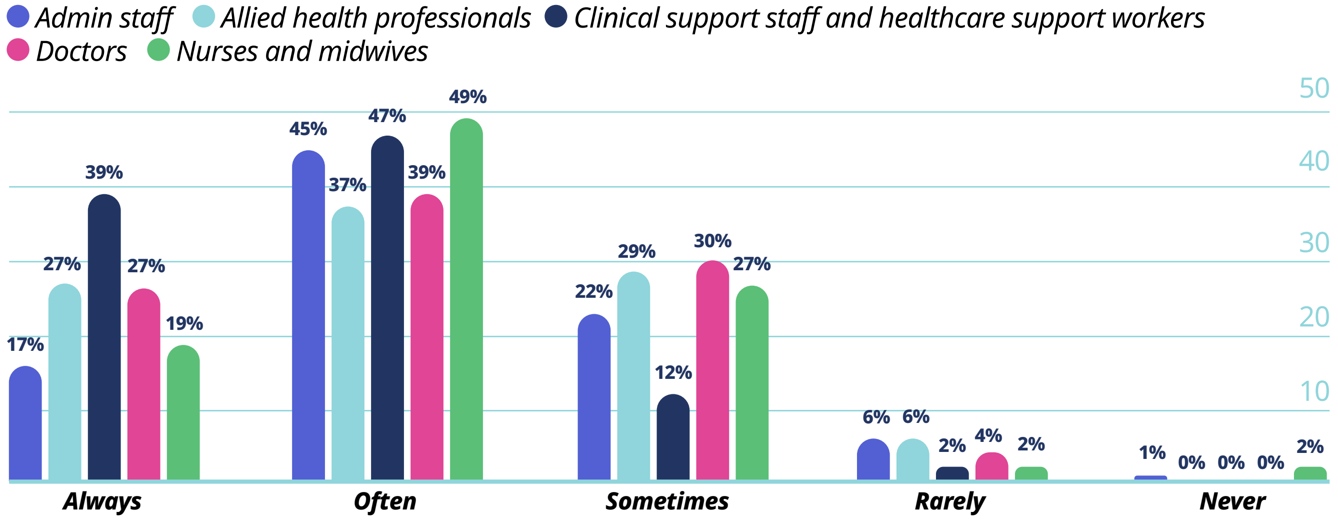
Table 41: ***How often, if at all, do you feel that you can meet the information and communication needs of patients who are deaf or have hearing loss?*** *(n=404)*

Always	24%
Often	44%
Sometimes	25%
Rarely	4%
Never	1%
Not applicable	2%

Only 17% of admin staff and 19% of nurses and midwives feel they can always meet the information and communication needs of patients who are deaf or have hearing loss, compared to 39% of clinical support staff and healthcare support workers.

Indeed, the proportion of clinical support staff and healthcare support workers that feel they can always or often meet the information and communication needs of patients who are deaf or have hearing loss is significantly higher compared to all other NHS staff roles at 86%.

Figure 31: ***Proportion of NHS staff across a range of job roles and how well they feel they can meet the information and communication needs of patients who are deaf or have hearing loss*** *(n=100 admin staff; 51 allied health professionals; 51 clinical support staff and healthcare support workers; 100 doctors; 102 nurses and midwives)*



Staff who do not always feel able to meet the communication needs of patients who are deaf or have hearing loss, attribute this to four main barriers: a lack of training, a lack of time or capacity in workload, a lack of standardised processes, and a lack of functionality of IT systems.

Table 42: ***You said that you do not always feel able to meet the information and communication needs of patients who are deaf or have hearing loss. What, if any, are your reasons for this?*** *(n=297)*

Lack of training	34%
Lack of time or capacity in workload	32%
Lack of standardised processes	31%
Lack of functionality of IT systems	30%
I do not understand how to meet the needs of patients who are deaf or have hearing loss	10%
No reasons in particular	9%
Other	3%
It is not part of my job role to meet the needs of patients who are deaf or have hearing loss	3%
Don't know	1%

NHS staff talked about issues with slow systems, or having to use multiple systems which can impact their ability to meet the needs of patients who are deaf or have hearing loss, while others mentioned time constraints and lack of resources, as well as highlighting a need for more training:

> ***"Having multiple notes systems means their needs aren't always shared."***
> District or practice nurse

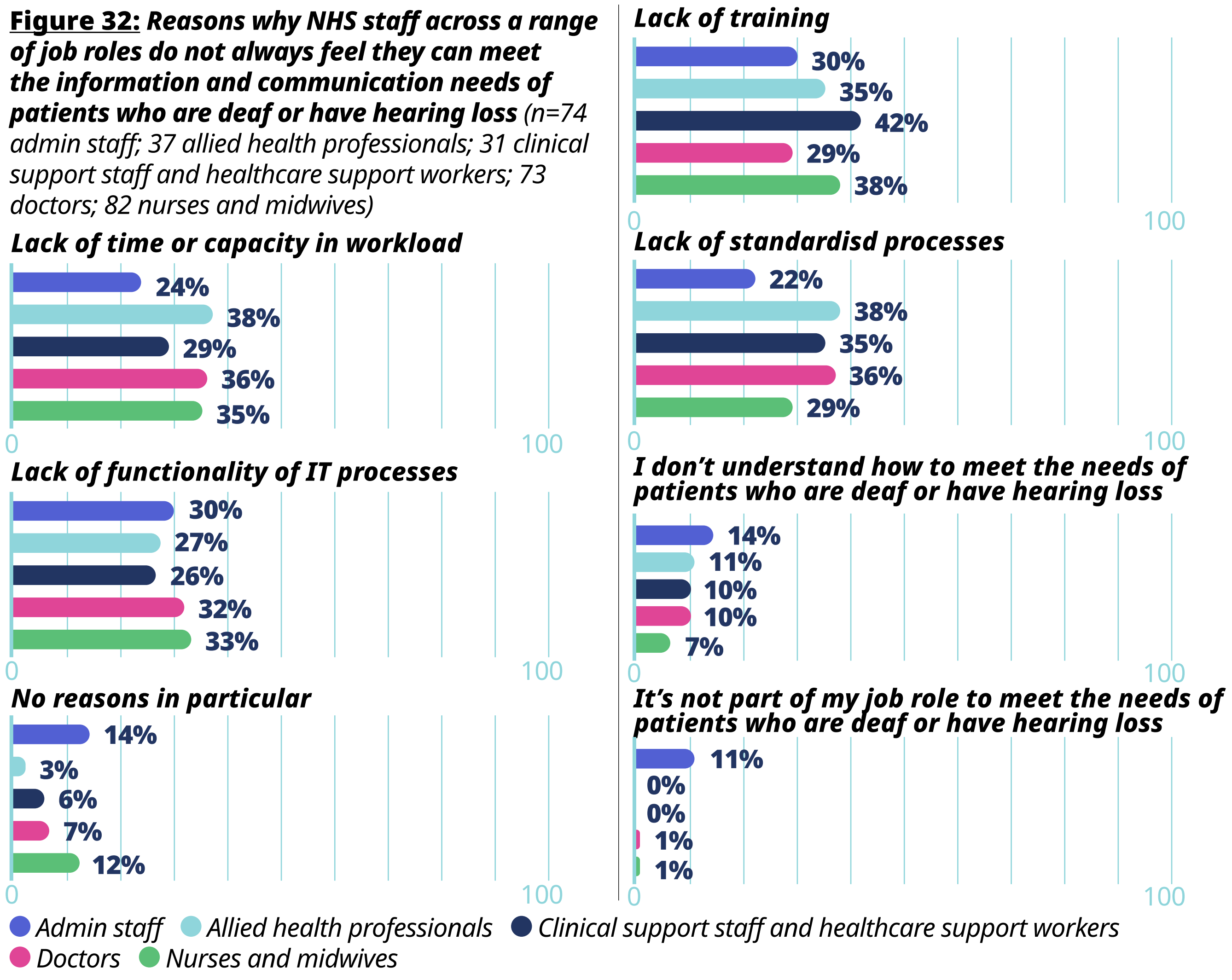
> ***"If the system is running very slow or if nobody replies to my emails from the referring member of staff, this can cause immense delays and stress."***
> GP administrator/receptionist

> ***"Working with patients who are deaf or have hearing loss has highlighted the importance of clear, accessible communication. While tools like interpreters and relay services are helpful, challenges often arise due to time constraints or a lack of resources. Improved training for staff and greater availability of communication aids could enhance the patient experience and ensure equal access to care."***
> Nurse working in a hospital

Clinical health staff and healthcare support workers in particular feel that a lack of training means they cannot always meet the information and communication needs of patients who are deaf or have hearing loss (42%).

While 30% of admin staff also cite a lack of training, 14% say they do not understand how to meet the needs of patients who are deaf or have hearing loss, and 11% say they do not feel it is part of their job role to meet the needs of patients who are deaf or have hearing loss, despite being in a patient-facing role.

Figure 32: ***Reasons why NHS staff across a range of job roles do not always feel they can meet the information and communication needs of patients who are deaf or have hearing loss*** *(n=74 admin staff; 37 allied health professionals; 31 clinical support staff and healthcare support workers; 73 doctors; 82 nurses and midwives)*



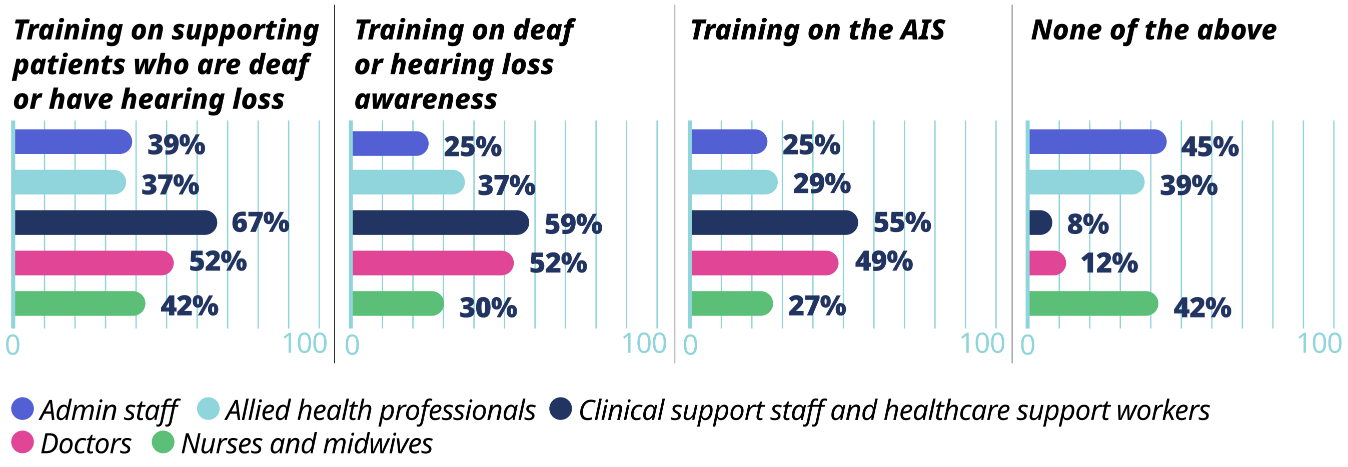
TRAINING PROVISION

Indeed, levels of workplace training on the AIS, and broader training on deaf awareness or how to support patients who are deaf or have hearing loss were found to be consistently low. Less than half (46%) had received training on supporting patients who are deaf or have hearing loss. 39% had received training on deaf or hearing loss awareness, and 36% had received training on the AIS specifically. Almost a third (31%) say they had not received any of the training outlined.

NHS admin staff, as well as nurses and midwives, reported having received comparatively less training compared to those in other roles, with 45% of admin staff saying they have received none of the training outlined, as did 42% of nurses and midwives.

In contrast, levels of training were highest among clinical support staff and healthcare support workers across all types of training, which may go some way to explain why the NHS staff members in these roles felt they could always meet the needs of patients who are deaf or have hearing loss to a greater extent than NHS staff in other roles.

Figure 33: ***NHS staff across a range of job roles and the training they have received*** *(n=100 admin staff; 51 allied health professionals; 51 clinical support staff and healthcare support workers; 100 doctors; 102 nurses and midwives)*



Of those who had received training, levels of satisfaction were low across the board and did little to help NHS staff feel better able to meet the needs of patients who are deaf or have hearing loss.

Table 43: ***Type of training received by NHS staff and their agreement with the following statements:***	Training on supporting patients who are deaf or have hearing loss *(n=187)*	Training on deaf or hearing loss awareness *(n=157)*	Training on the AIS *(n=145)*
The training I received improved my confidence in supporting patients who are deaf or have hearing loss	58%	67%	57%
The training I received was relevant to my job role	50%	52%	61%
I was satisfied with the quality of the training I received	37%	36%	41%
The training made me feel better able to meet the needs of patients who are deaf or have hearing loss	32%	31%	30%
None of the above	2%	1%	2%

NHS staff talked about the need for training across all staff roles to ensure that the needs of patients who are deaf or have hearing loss are being met:

"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

"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

"Training should be extended to admin staff as well as clinical."
District or practice nurse

The need for better training for NHS staff was echoed in comments made by people who are deaf or have hearing loss. Many people, particularly those who need other reasonable adjustments said the changes they need to be made to access healthcare are actually very simple, including things like speaking clearly, facing the patient and not speaking too quickly. These are all skills covered by basic deaf awareness training, while others reflect a need for more knowledge about the requirements of the AIS itself:

"[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, 55-64, needs other reasonable adjustments

"It's hard work and I still find it surprising that healthcare professionals seem to have little or no understanding of deafness and how it affects their patients."
Female, 75+, needs other reasonable adjustments

"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

Staff training is a key mechanism which can underpin the 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 admin and management roles which facilitate people around the system. Our evidence shows that NHS staff would benefit from both AIS and deaf awareness training, but this needs to be high quality and tailored to their role.

GETTING IT RIGHT – BEING DEAF AWARE

When NHS staff demonstrate deaf awareness by adapting their communication in order to meet the needs of people who are deaf or have hearing loss, this can have a powerful impact:

"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. I wrote to say thank you afterwards as I believed that this would show him how useful it was to someone with hearing loss."
Female, 55-64, needs other reasonable adjustments

"I went to see the nurse and she adjusted the chairs in the room so that light fell on her face. She also spoke clearly. That was all I needed at that time, but not every health professional does it."
Female, 65-74, needs other reasonable adjustments

"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

"Attended my first mammogram test and told the healthcare worker I needed to lipread. She was brilliant and only spoke to me when the light was fully on and pulled down her mask to speak. I was nervous before the appointment but her deaf awareness and flexibility made me feel more confident."
Female, 45-54, needs other reasonable adjustments

"It's rare, but when it happens it's like a miracle! That sounds a bit over the top but seriously, it's such a massive relief to have someone understand the daily struggle we experience just attempting to have a normal conversation. I had an appointment with a neurological specialist and he actually read my notes and noted that I have hearing loss and asked if his voice was clear to me; he tried to face me at all times and apologised if he turned away. He wrote some notes for me and then sent a very concise follow up letter highlighting all points we had covered in the clinical and ongoing treatments. That meant the world to me. I have been experiencing progressive hearing loss for over 30 years - these kind of positive experiences with the medical profession are incredibly rare. I have had far more appalling experiences than I can recount."
Female, 55-64, needs a communication support professional

Concluding Remarks

The findings of this report suggest a routine failure by the NHS to comply with the Equality Act and 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[3], 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 have hearing loss.

Almost ten 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.

On the following page is a summary of RNID and SignHealth's recommendations arising from this research. For a more detailed discussion of the policy context, see our accompanying policy report, **Still ignored: the fight for accessible healthcare**, which sets out our recommendations to Government and NHS England on the enforcement of, and accountability to, the AIS.

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[3] Signhealth (2022) Review of the NHS Accessible Information Standard

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 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 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.
- 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.

Appendix

The following tables outline the demographic data for the survey of people who are deaf or have hearing loss, which consisted of a sample of 1,114 people who live in England.

DEMOGRAPHIC DATA

Table i. Are you: *(n=1114)*

Female	66%
Male	33%
Non-binary	<1%
Prefer not to say	<1%

Table ii. How old are you? *(n=1114)*

18-24	1%
25-34	4%
35-44	7%
45-54	13%
55-64	20%
65-74	24%
75+	30%
Prefer not to say	1%

Table iii. How would you describe your ethnicity? *(n=1114)*

Asian or Asian British	1%
Black, African, Caribbean or Black British	1%
Mixed or Multiple Ethnic Groups	1%
White	96%
Other ethnic group	<1%
Prefer not to say	2%

Table iv. How would you describe yourself? *(n=1114)*

I am Deaf	18%
I am deaf	26%
I have hearing loss	62%
I am deafblind	1%
I prefer another term	3%

Table v. Is sign language your main or preferred language? *(n=1114)*

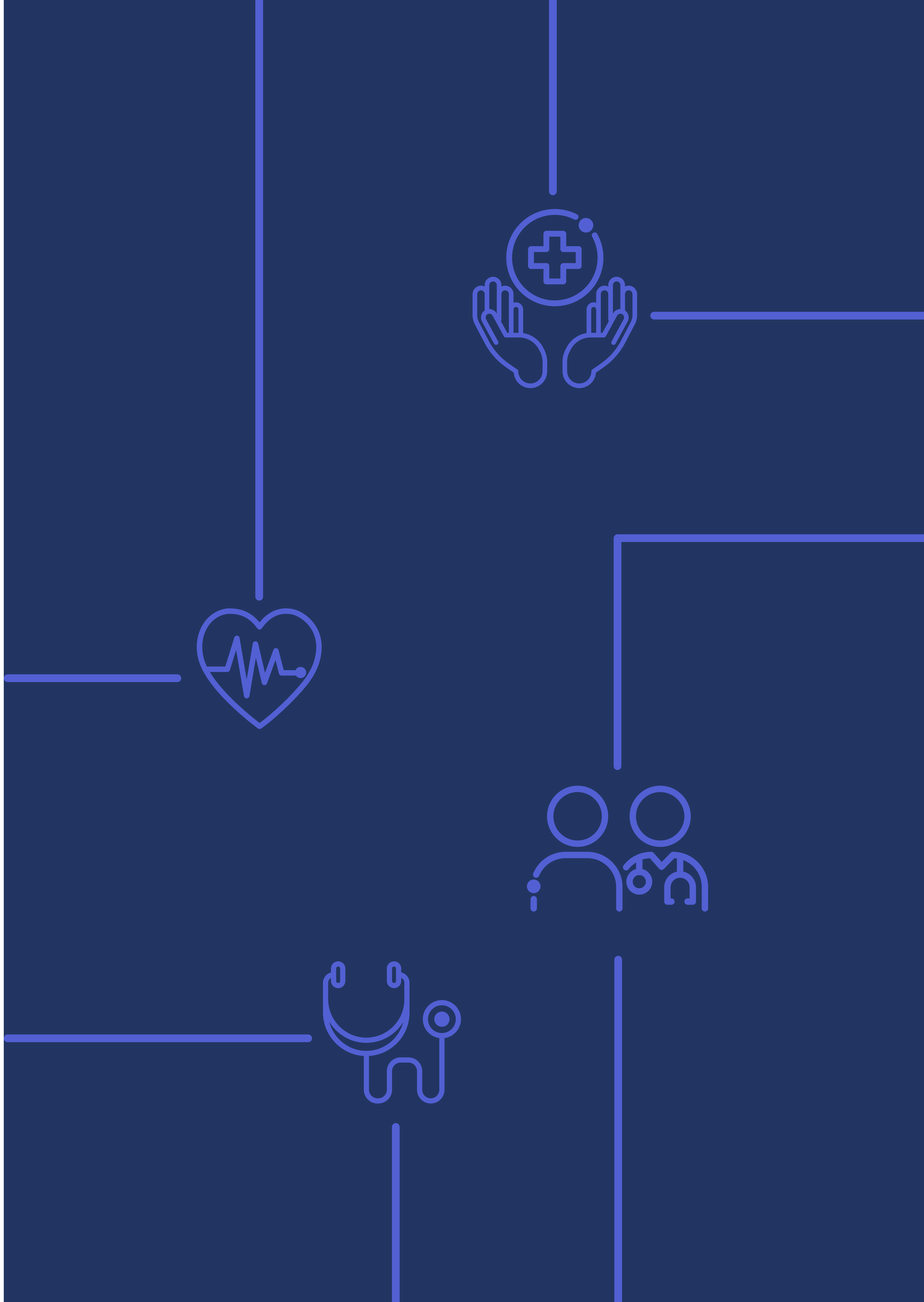
Yes	11%
No	89%

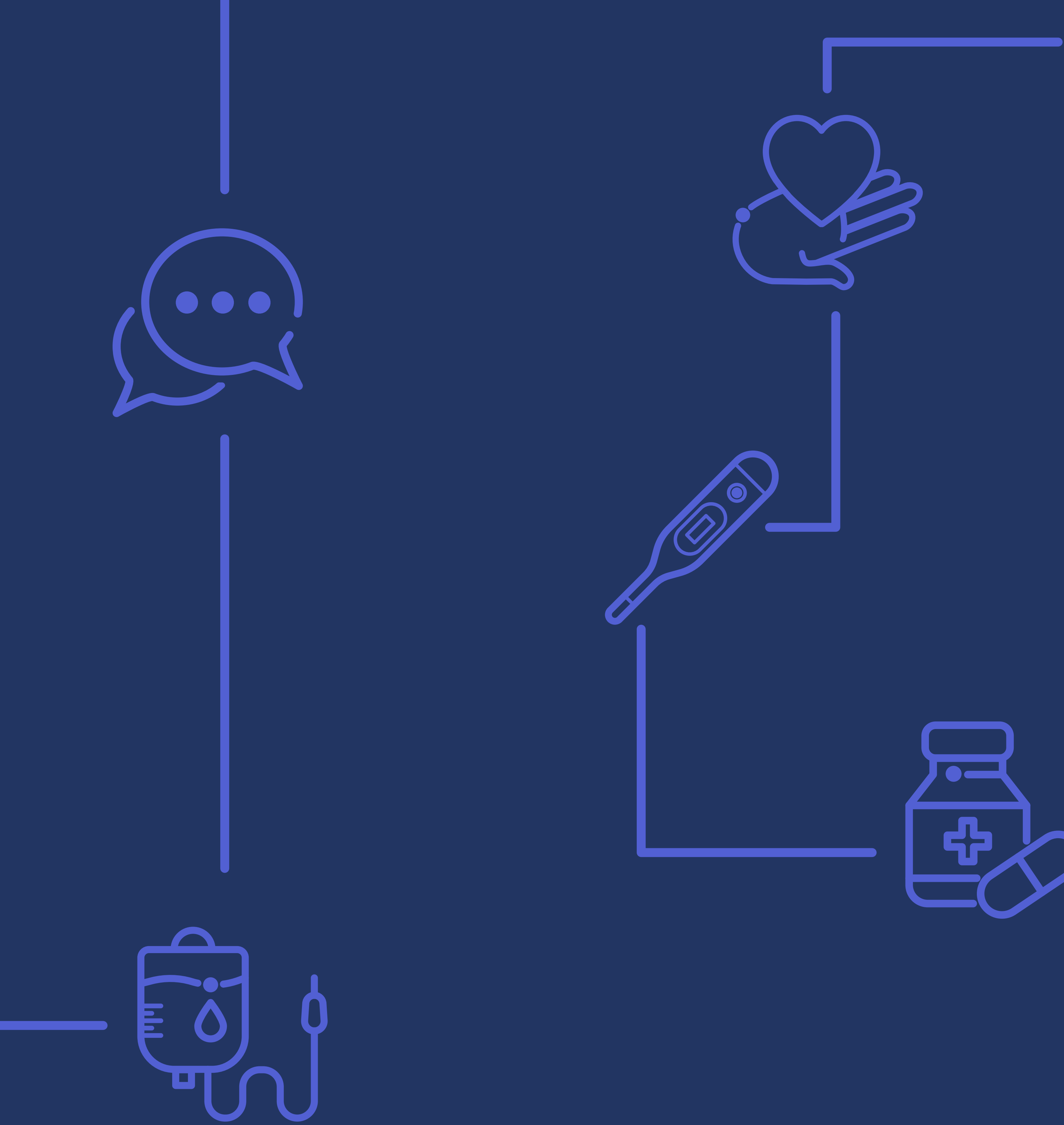
Table vi. Which of these languages do you use? *(n=121)*

British Sign Language	97%
Irish Sign Language	0%
International Sign	7%
Other Sign Language	12%

Table vii. Where do you currently live? *(n=1114)*

England – North East	4%
England – North West	11%
England – Yorkshire and The Humber	8%
England – East Midlands	9%
England – West Midlands	11%
England – East of England	10%
England – Greater London	10%
England – South East	23%
England – South West	14%





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

THE DEAF HEALTH CHARITY SIGNHEALTH

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