

---

# Review of the NHS Accessible Information Standard

**Urgent priorities for change,  
informed by patients' lived  
experience and NHS professionals.**

**“I wanted to be independent but  
there was no other option given.”**

---

# Summary

In late 2021, a coalition of charities surveyed NHS and social care professionals in England, as well as disabled people who have accessible information and communication needs, about the [NHS Accessible Information Standard \(AIS\)](#). More than 900 people gave responses.

- **After five years of the Accessible Information Standard, only 11 per cent of patients covered by the AIS have equitable access to the NHS.**
- **35 per cent of professionals reported that their organisation provides regular training linked to the AIS. 37 per cent report training has never occurred.**
- **67 per cent of Deaf people reported that no accessible method of contacting their GP has been made available to them.**
- **81 per cent of patients reported having an appointment when their communication needs were unmet.**
- **77 per cent of people with accessible information needs reported rarely or never receiving information in alternative formats.**
- **Only 41 per cent of complaints procedures were reported to be accessible by the professionals who filled in the survey.**

- **1 in 3 health and social care providers were unaware or unsure of the existence of the AIS.**

The AIS sets out clear steps that providers are required to take to meet information and communication needs, but our evidence suggests that this is not happening. The results highlighted significant actions that must be taken by providers to implement the AIS in full.

Responses 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 has serious practical, health and emotional consequences. Patients shared experiences of a lack of accessible communications as a barrier to:

- making appointments
- communicating with health professionals
- finding out test results
- receiving accessible information on discharge or medication instructions

These are areas where people with communication needs receive a lower quality of healthcare, including situations which could put patients at serious risk.

This important survey amplifies the voice of patients, sharing their lived experience of accessing health and social care and uncovering issues from the perspective of both providers and patients.

---

# Urgent Priorities

These priorities address the gaps in implementation and add the accountability necessary to embed and strengthen the AIS. As a coalition of user-led organisations and disability charities, we are ready to support implementation and improve access.

## Full implementation

Implementation of every aspect of the AIS is a requirement, but these areas have been identified as urgent priorities.

1. **Training:** staff must be informed of the AIS, its importance and how to meet it.
2. **Patient record systems:** a flag must be available and used to alert staff through a prominent notification on patient records. It should also transfer to referrals or handover documentation. The flag should notify staff, when an appointment is made or the record updated, what actions to take to meet the patient's needs. The system should be capable of actioning alternative formats, for example sending an email or a large print letter.
3. **Alternative contact methods:** Providers must not rely solely on phone systems for contact. Alternatives must be in place to meet patients' needs.

## Accountability and Monitoring

1. **Contracts:** Information accessibility must be written into provider contracts and monitored as part of minimum commissioning standards. This means:

- a. Embedding access costs in tenders and contracts
  - b. Accessibility is included as part of inspections, along with enforcement timelines and annual reporting
2. **Dedicated Lead:** An AIS lead in each service who is responsible for implementation and review.
  3. **Development:** Providers should also review their existing services alongside people with lived experience.
  4. **Accessible complaints procedures:** Including more accessible methods of promotion and availability in a range of alternative formats.

## Recommendations

1. **Email and Text Suggestion:** The majority of patients responding to this survey indicated that email and text message would be preferred methods of contact with their GP surgery. Providing and promoting these options could be a simple and cost-effective measure.
2. **Data oversight:** Allow patients to access their own records and make amendments to their accessible communication needs, in person or via NHS Health Access/Online portal.
3. **Video Relay Service:** BSL interpreters should be made available remotely via VRS and VRI, on-demand, 24/7 to provide communication support at short notice or in cases where agency provisions fail.

## Contents

<b>Summary</b> .....	<b>2</b>	Case study: Parent at Accident and Emergency Services.....	14
<b>Urgent Priorities</b> .....	<b>3</b>	Communication During Appointments	15
Full implementation.....	3	<b>Awareness of access to information as a right</b> .....	<b>15</b>
Accountability and Monitoring.....	3	<b>Current level of access</b> .....	<b>16</b>
Recommendations.....	3	<b>Best practice examples</b> .....	<b>17</b>
<b>Who took part?</b> .....	<b>5</b>	Case study: Test results and appointment reminders.....	18
Patients.....	5	<b>Consequences of poor access</b> .....	<b>19</b>
Providers.....	5	Misdiagnosis.....	19
<b>The NHS Accessible Information Standard</b> .....	<b>6</b>	Improper use of medication .....	19
<b>Review of implementation</b> .....	<b>7</b>	Case Study: Medication and Pharmacy .....	20
<b>No training</b> .....	<b>8</b>	Mismanaged appointments .....	21
Significant variation in training frequency .....	9	Missed appointments.....	21
Frequency of AIS training carried out by providers as reported by all professionals .....	9	Uninformed choice or consent .....	22
<b>Ongoing issues</b> .....	<b>9</b>	Confidentiality.....	22
Burden on the patient .....	9	Disengaging with healthcare.....	23
Complaints Procedures.....	10	Emotional impact.....	23
Issues reported in the survey by Deaf and blind people .....	10	Case study: Booking interpreters for operations .....	23
<b>Unmet need</b> .....	<b>11</b>	<b>Impact of the pandemic</b> .....	<b>24</b>
Contacting services.....	11	<b>Conclusions</b> .....	<b>25</b>
Alternative formats .....	11	<b>Methodology</b> .....	<b>26</b>
Professionals were asked ‘what alternative information formats are available to service users?’ .....	12	Breakdown of respondents.....	26
Communication Support.....	13	Age of patient respondents .....	26
		Roles of professional respondents....	26

# Who took part?

A coalition of user-led organisations and disability charities came together to review implementation. SignHealth partnered with the Royal National Institute of Blind people (RNIB), Sense, the Royal Association for Deaf people, Learning Disability England, Visionary, Macular Society, the Royal National Institute for Deaf People (RNID) and Healthwatch England to collect responses from patients and professionals.

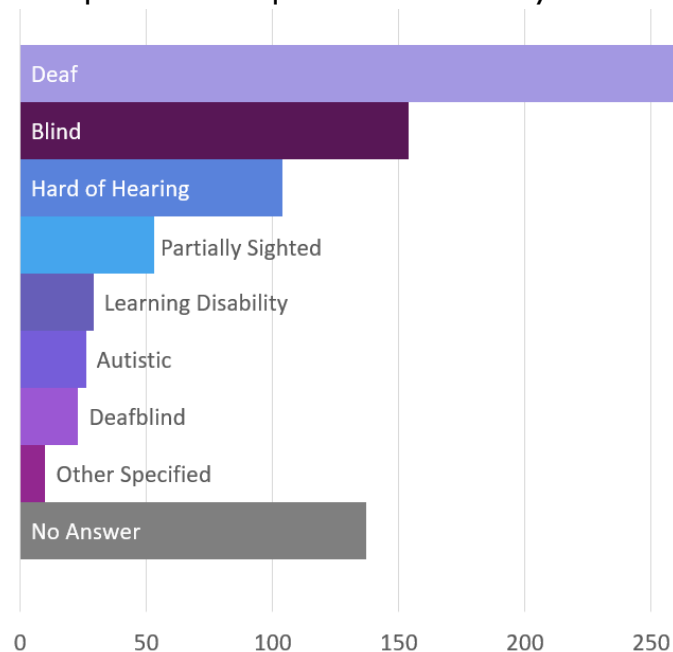
714 people with communications needs responded to the survey, as well as 196 professionals from health and social care provider organisations.

The anonymous online survey was in written English and British Sign Language (BSL).

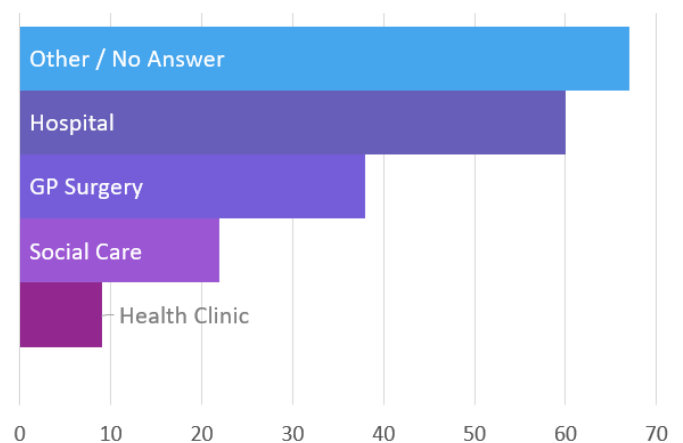
The survey was shared with professional networks linked to the charities involved and sent via email directly to all NHS service managers in England. This method of promotion means there is significant sampling bias, in particular the self-selection of respondents. It's difficult to know if, or which way, this would skew the data, but it would be reasonable to assume that professionals who decided to respond to what was essentially a "cold call" to fill in a survey about accessibility would also be the ones more likely to have awareness and work in services with better provisions in place. This assumption does carry some weight when analysing the disparity between professional responses and the experiences reported by patients.

## Patients

Note: Respondents were able to choose more than one option for this question in the survey.



## Providers



See page 26 for a further explanation of the survey methodology and respondents.

---

# The NHS Accessible Information Standard

By law, from August 2016 onwards, all organisations that provide NHS care and/or publicly funded adult social care must follow the Accessible Information Standard (AIS) in full.

Organisations that commission NHS care and/or publicly funded adult social care, for example Clinical Commissioning Groups (CCGs), Integrated Care Systems (ICS), and local authorities, must also support implementation of the AIS by provider organisations.

The AIS seeks to establish a clear, consistent approach to the information and communication support needs of patients, service users, caregivers, and parents with a disability, impairment, or sensory loss:

1. Ask
2. Record
3. Flag
4. Share
5. Meet

This includes autistic people and people with learning disabilities, Deaf people, people who are hard of hearing or have hearing loss, blind or partially sighted people, and deafblind people.

The AIS states that patients should:

- A. Be able to contact, and be contacted by, services in accessible ways, for example via email or text message.
- B. Receive information and correspondence in formats they can read and understand, for example in audio, braille, easy read or large print.
- C. Be supported by a communication professional at appointments if this is needed to support conversation, for example a British Sign Language interpreter.
- D. Get support from health and care staff and organisations to communicate, for example to lip-read or use a hearing aid.

---

# Review of implementation

The five steps of the AIS together consist of an accessible user journey through healthcare services. It is important to understand that while each step is significant and necessary, the AIS is only met when all five are implemented systematically and meeting a person's communication needs.

Responses from professionals indicated that **31 per cent** of the providers they work for have implemented all five steps. However, training is required in order for health professionals, administrators and receptionists to consistently and systematically meet communication needs, training that appears to very rarely, if ever, happen (see '[No Training](#)').

---

**“No training or resources, both in terms of people and tools people may need, have been put in place to support the implementation of the AIS.”**

**– NHS professional**

---

**1. Ask people if they have any information or communication needs and find out how to meet their needs.**

**77 per cent** of providers accounted for in the survey were reported to identify if people have information or communication

needs. Respondents frequently mentioned registration forms or the first appointment as the time when needs were identified. This may mean that existing patients, or patients whose needs change, will go unnoticed. A few professionals mentioned approaches for advertising access options, such as through posters or social media.

Without training, it is unclear if providers would be aware of the range of needs that might need to be identified and met.

Since a patient's needs can change over time, it is likely to be beneficial to allow patients to access their own records to make amendments to their information and communication needs.

**2. Record those needs clearly and in a consistent way.**

**68 per cent** of providers were reported to record information and communication needs.

Several professionals mentioned that systems limited what they could record but were in the process of being updated. A few conceded that needs were not recorded reliably.

**3. Flag or highlight in the person's file or notes so it is clear they have information and/or communication needs and how to meet those needs.**

Roughly half of providers indicated that there was a meaningful “alert” or pop-up of

---

some sort to flag patients' information or communication needs.

---

**“Four different electronic systems do have a flagging system – trouble is, staff do not read this or understand the importance of the requirements needed”**  
**– NHS professional**

---

**4. Share information about people's information and communication needs with other providers of NHS and adult social care, when consented or have permission to do so.**

**61 per cent** of providers were reported to routinely share information and communication needs across services as part of a referral or handover process.

---

**“Largely ignored by secondary and community care when GP includes this. Usual referral proformas do not include tick boxes for these.”**  
**- GP, East of England**

---

**5. Take steps to ensure people receive information they can access and understand and receive communication support if needed.**

Only **half** of patients with communication needs reported having an accessible method of contact with their GP.

**86 per cent** of providers were reported to have a process in place for booking communication support. A few mentioned the limited availability of interpreters meant they were sometimes unable to meet the needs of Deaf people.

Only **63 per cent** of providers were reported to have a process in place for delivering information in accessible formats, and not necessarily every required format.

## No training

Training is key to the implementation of any new approach to communication with patients. The NHS Accessible Information Standard (AIS) requires an understanding of the variety of communication needs or alternative formats that patients might require and then for actions to be taken by staff at a number of different points in a patient's journey. However, just **35 per cent** of professionals reported that their service provides regular training linked to the AIS, with **37 per cent** reporting training has never occurred.

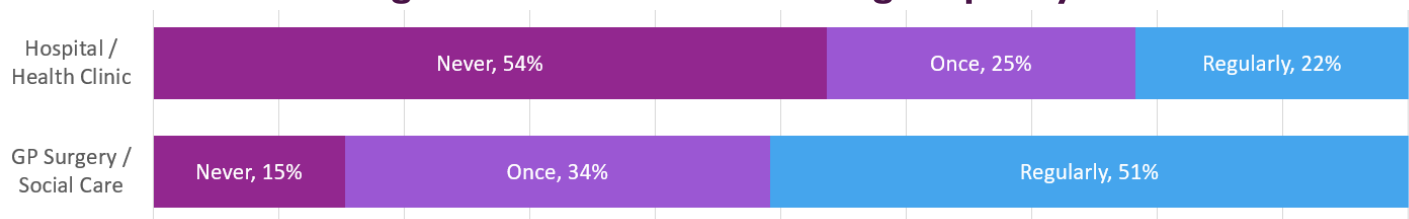
This is a disappointing finding as it indicates how poorly the AIS has been implemented.

People with communication needs responding to the survey also highlighted a number of issues linked to poor staff training and a lack of basic awareness of issues related to communication accessibility.

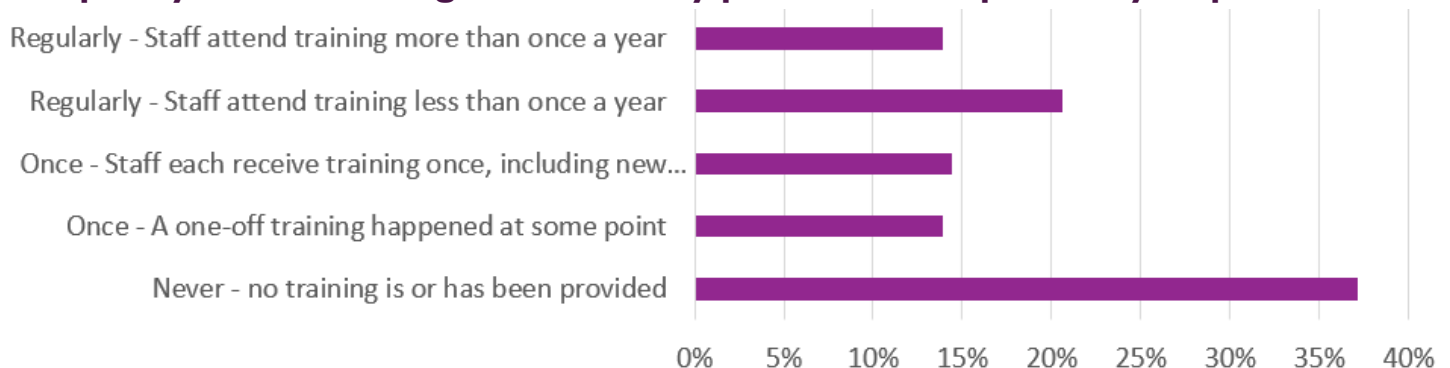


## Regularity of training linked to the AIS as reported by professionals:

### Significant variation in training frequency



## Frequency of AIS training carried out by providers as reported by all professionals



## Ongoing issues

### Burden on the patient

The Accessible Information Standard states: “Professionals and relevant staff should proactively prompt individuals to identify that they have information and/or communication needs and support them to describe the type of alternative format and/or support that they need, at their first or next interaction with the service.”

Despite this, **22 per cent** of professionals who responded to the survey, said that they do not, or are unsure if they, identify people’s communication and information needs.

Patients repeatedly referred to frustrations with how often they have requested their access needs to be recorded, or for interpreters to be booked, or for letters to be sent in alternative formats.

---

**“If I forget to ask for an interpreter, none is provided. Or if it is at short notice or an emergency appointment, no BSL interpreter is available. I am tired of having to ask and go through that hurdle every single appointment.”**  
- Deaf patient

---

Patients who shared positive examples of access often appear to have achieved this

through advocating for themselves over an extended period of time.

The provision of accessible information is the responsibility of providers, not patients.

## Complaints Procedures

**89 per cent** of providers were reported to ensure patients know how to complain. However, only **41 per cent** of complaints procedures were reported by professionals to be accessible.

A number of professionals described that their service has a complaints policy but may not have been taking any proactive measures to ensure access for patients.

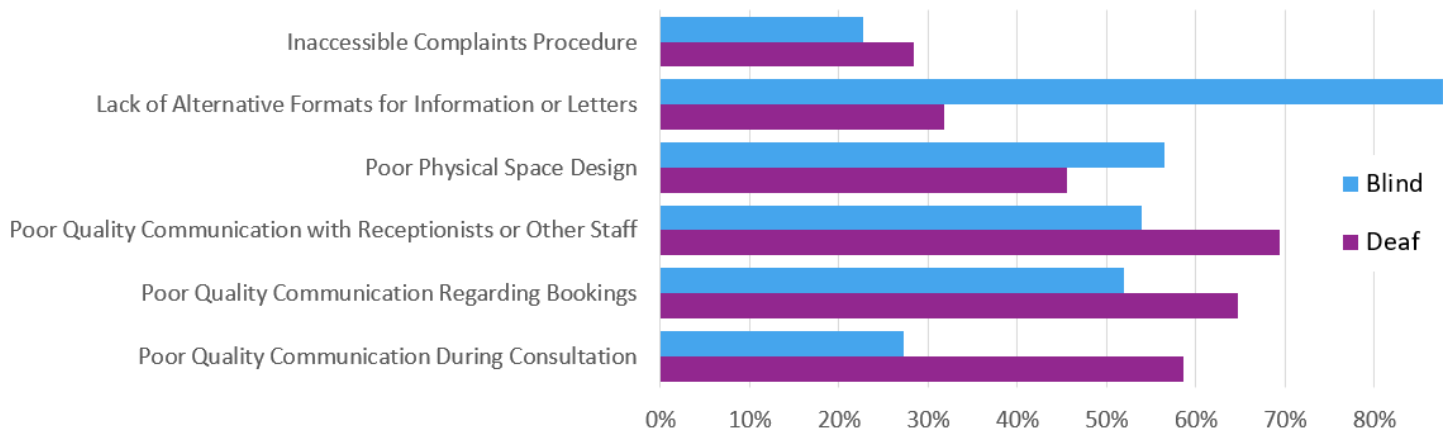
**55 per cent** of patients reported they were unsure or did not know how to make a complaint. **23 per cent** reported

experiencing an inaccessible complaints procedure.

The majority of explanations from professionals for how patients were informed about how to complain involved written resources (such as leaflets or posters in services), which may help explain why a higher percentage (**64 per cent**) of blind respondents were unsure of or did not know how to make a complaint.

Lack of complaints does not necessarily mean that providers are meeting their duties. Barriers in some complaints procedures, as well as potentially inaccessible methods of promotion, may both contribute to access failures going unnoticed.

### Issues reported in the survey by Deaf and blind people



---

# Unmet need

It is not enough to record a patient's communication needs; providers must meet those needs every time they see or communicate with a patient.

## Contacting services

The AIS clearly states that patients must 'be able to contact, and be contacted by, services in accessible ways, for example via email or text message.' However, contacting services, particularly GPs, is often dominated by the phone in terms of making and managing appointments, and this has worsened significantly during Covid-19.

**50 per cent** of patients reported still having to contact their GP using an inaccessible method. Having one system that every patient must use to book appointments may appear to be 'equal' treatment, but it is not necessarily fair or equitable access; alternative options must be provided to patients on an individual basis.

For Deaf people and others who need communication support, the lack of alternatives to phone was a frequently cited source of frustration in the survey.

**67 per cent** of Deaf people reported that no accessible method of contacting their GP has been made available to them. This is primarily due to providers relying on phone systems to book appointments. This is inaccessible when the patient cannot

properly hear the person on the other end of the line or may not be able to express their needs verbally. This, compounded with issues in communicating with the receptionists (especially when wearing masks), adds up to a failure to provide access otherwise afforded to hearing patients. This is likely to be a breach of the Equality Act in terms of the duty to make reasonable adjustments; disabled people should not be placed at a disadvantage when attempting to contact their healthcare providers.

**8 per cent** of patients reported that they visit the practice in person to contact their GP. This method has been discouraged since the beginning of the Covid-19 pandemic in the UK for the purposes of limiting the spread of the virus, however, for some patients, this method remains their only access to book an appointment.

## Alternative formats

The AIS states that patients should 'receive information and correspondence in formats they can read and understand, for example in audio, braille, easy read or large print.' However, **73 per cent** of blind people and others who need alternative formats reported their needs were rarely or never met.

**37 per cent** of providers lack a process for delivering any information in alternative

---

formats. **70 per cent** of providers were unable to deliver information in braille or in digital formats. **33 per cent** of providers could not deliver information in large print.

Some responses from professionals and patients suggested providers were reluctant to offer alternative formats. A few mentioned not providing them because they were so bespoke, expensive and potentially for very few patients.

---

**“There’s no funding for any of this though, the turnaround times are way too long and the process to access them not worth the effort.”**  
**– NHS professional**

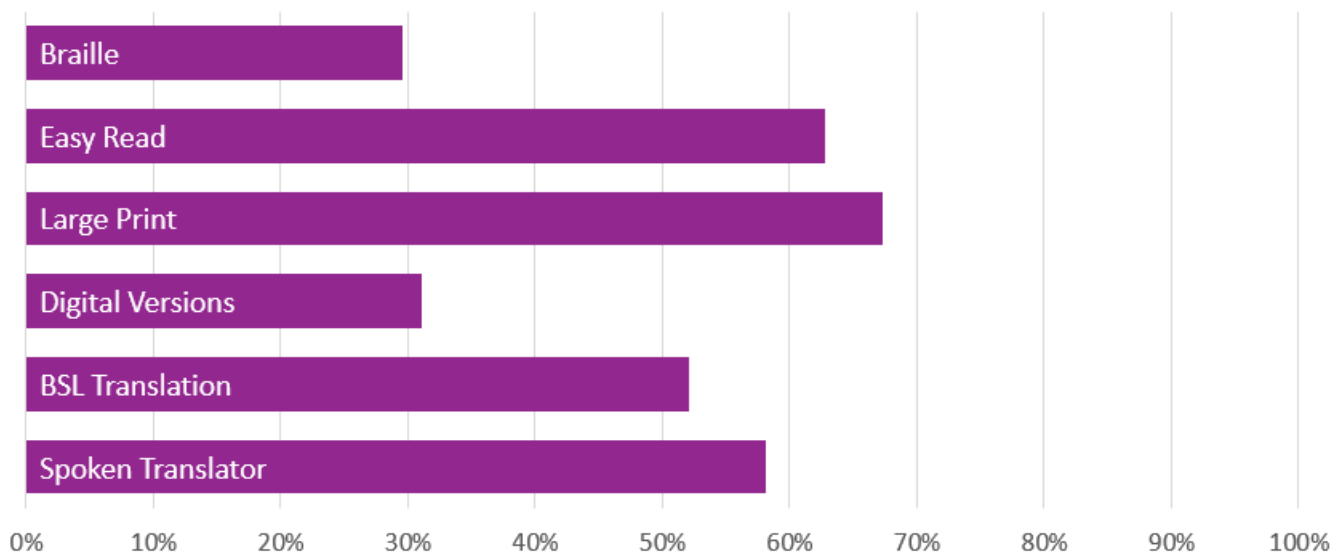
---

---

**“Was directed to the office manager at my GP surgery to get some information which had been given to me during an appointment in an alternate format, so that my screen reader could read it to me. He told me that he had 10,000 patients on his book and if everybody wanted this doing, he would have no time to do anything else. I told him that I did not care how many people he had on his books that it was my right to have this information in an alternate format as stated in the accessible information standard. He took a photograph of the information I had and provided it in a PDF format which could not be read by my screen reader he told me there was nothing else he could do and if that did not work then I would not get it.” - Blind patient, West Midlands**

---

**Professionals were asked ‘what alternative information formats are available to service users?’**



---

## Communication Support

**48 per cent** of Deaf people and others who need communication support reported that their needs were rarely or never met.

Availability of British Sign Language (BSL) interpreters (at least via contracted arrangements) seems to be a significant constraint according to providers. Specifically, that BSL interpreters could not be made available in the short timeframe that would be normal for a medical appointment. These contracts must be reviewed with meeting patients' needs placed at the forefront of decision-making.

---

**“Not able to get an interpreter at short notice. The agency they use need 2 weeks notice.”**

**- Deaf patient**

---

The AIS states that patients should ‘be supported by a communication professional at appointments if this is needed to support conversation.’ In instances where interpreters are needed at short notice or for urgent appointments, even for interactions outside of an appointment (like receiving test results or asking your

pharmacist a question) a qualified interpreter being made available via an on-demand video relay service would provide access in a timely and efficient manner.

---

**“When BSL Health Access was in use (it has closed now), it was life saving for us as family because it helped us to communicate with the paramedics.”**

**- Deaf patient, West Midlands**

---

Many providers in the experiences shared by patients did not seem to understand that requiring family or friends to interpret for the health professional is unacceptable and against guidance for a number of different reasons, including patient confidentiality, minimising safeguarding risk, patient's privacy and the accuracy and impartiality of the interpreting. Booking an interpreter allows family and friends to attend appointments and support the patient (emotionally and with decision-making) without the added pressure of needing to interpret. All interpreters booked should be registered, to ensure they are qualified, monitored and accountable.

## Case study: Parent at Accident and Emergency Services

I contacted NHS111 via SignVideo (a video relay service) after my son became unwell. NHS111 said they would contact me within 24 hours. I reminded them to contact me via text, email or use SignVideo as opposed to calling me. Upon waking the next morning, I saw they had tried to call me at around midnight which I wasn't aware of because I am deaf and can't hear or use the phone. I then took my son to A&E.

At reception, I wrote down that we would need a BSL interpreter in order to communicate. We went into triage and waited for someone to come and check my son. Staff refused to remove their masks for me to lip-read them, nor did they change their masks to clear masks. I could see from the movement on their masks that they were still speaking and repeatedly asked them to stop, because I could not understand anything. I also repeatedly asked them to write down what they were saying instead of speaking. They also tried to directly talk to my deaf son, which confused and distressed him. This made me very upset and angry, and so I video called my sister for assistance. She explained to the staff that it wasn't acceptable to rely on her for access because she is not a qualified BSL interpreter, and it is unethical to rely on family members to interpret. I could see the nurse/doctor were taken aback, and only then began to write down information for me.

My son had a blood test, and they told us to wait for an hour. We waited another 2 hours, at this point my son was desperate to go home after 6/7 hours in the hospital. Eventually, one of the nurses agreed to let us go home and said they would contact me with the blood test result and asked if they could call my sister instead of me. I questioned why they were stripping me of my independence, because I am his mother. Surely there are other means to contact me, via text or email. I gave my contact details, they apologised.

While we were waiting for the results at home, I called the hospital via Text Relay UK. They said they had never said they would contact me at home, only if something was serious. They also said that BSL interpreters weren't working on Boxing Day, which I know to be untrue. They also said that I had voluntarily discharged my son from hospital against their advice, which also wasn't true. I would have never left without their consent and medication.

This all demonstrated a complete lack of deaf awareness. I asked if someone couldn't speak English, would they provide a translator, at which point they interrupted me quickly and told me to make a complaint to PALS (which I have done). I don't want my son's generation to continue to face the barriers I have had all my life.

I want my story to impact the way staff are trained. This experience of communication failure needs to not be repeated. Enough is enough.

– Deaf parent, West Yorkshire

---

## Communication During Appointments

**81 per cent** of people with communication needs have had an appointment in which their communication needs were not met.

Significant numbers of Deaf and hard of hearing people reported:

- having over the phone appointments scheduled for them which were inaccessible
- providers refusing to book qualified BSL interpreters
- not being able to lip-read since staff did not wear clear masks or visors, or poor awareness of how to aid lip-reading (facing the patient, talking at a normal pace, etc.)
- several mentions of professionals being impatient with them
- not hearing name at reception
- hearing loops being unavailable or staff not knowing how to use them

---

**“I'm frequently handed information like forms or leaflets in formats I can't access. The GP will point at the screen. I can't even see where the screen is never mind read what is on it. I'm sat there with a white cane, or a guide dog and they just don't get it.”**

**– Blind patient, London**

---

## Awareness of access to information as a right

The AIS sets out access standards that NHS and publicly funded adult social care providers are required to provide. Although many providers have systems and procedures in place to improve general patient experience, it is still important for providers to be aware of the obligations specifically set out in the AIS that should guide decision-making and reinforce the importance of meeting the communication needs and preferences of every patient, carer and parent.

**1 in 3 health and social care providers were unaware or unsure of the existence of the Accessible Information Standard.**

**68 per cent** of professionals taking the survey responded that they were aware of the AIS, with fewer services then knowing its contents or how to apply it.

Also, interesting to note is that many respondents from services readily connected the AIS to the needs of Deaf people but may not have understood the significance of the AIS for other groups. Training would improve this situation considerably.

---

## Current level of access

Analysing the survey responses from disabled patients, we were able to roughly measure the level of access patients are receiving based on a variety of questions and particular to the needs of the patients responding. This included:

1. Is the patient able to contact their GP using an accessible method?
2. Are alternative formats regularly provided to the patient (if needed)?
3. Is communication support regularly provided to the patient (if needed)?
4. How accessible has communication been with doctors?



**Equitable Access:** This patient can contact their GP to book appointments. An interpreter is present during consultations, or health information and instructions are regularly provided in an accessible format. This patient is given the opportunity to explain symptoms or ask questions, and then to understand what the doctor is showing or saying. **Just 7 per cent of Deaf patients who need communication support and only 3 per cent of blind patients who need alternative formats have this level of access.**



**Poor Access:** This patient may experience particular barriers to accessible information, possibly when making initial contact, or during consultation, or the information sent to them is not readable. Alternatively, their access needs may be met very inconsistently. **59 per cent** of blind patients that need alternative formats experience this level of access.



**Very little access to healthcare:** This patient is unable to independently contact their GP or book appointments due to their preferred communication method not being offered. An interpreter is never or only occasionally provided and/or information or instructions are usually provided in a format in which they cannot read. Communication with doctors is often poor with misunderstandings. **57 per cent** of Deaf patients that need communication support have very little access to healthcare.

This analysis indicates that only **1 in 10** patients covered by the NHS Accessible Information Standard are currently provided equitable access to healthcare in England. This is unacceptable.



---

# Best practice examples

---

**“I had the most fantastic experience; I sent an email to audiology, and I sent it in a very large format and in bold because I cannot see it unless it's really bold. I got a reply in the same format that I sent my request. I was overjoyed because I had the most amazing email conversation with the person who was trying to arrange the appointment for me.”**

**- Deafblind patient**

---

---

**“Local ortho hospital have provided BSL interpreters for all my hydrotherapy appointments without fail. This has enabled me to access hydro where I can't use my hearing aid and hear nothing without it (I'm nearly profoundly deaf in most frequencies). The booking system they have for interpreters Just Works. Reception staff tick a box when appointments are booked (or added later) and the booking goes through to Comm Plus the local agency.”**

**- Deaf patient, West Midlands**

---

---

**“They couldn't have done more to help me making sure I had help getting about and that I understood all what was to happen.”**

**- Deafblind patient, East Midlands**

---

A few Deaf respondents commented on how BSL Health Access, a free on-demand 24/7 remote interpreting service, empowered and enabled Deaf people to engage with the NHS. This service not ensured Deaf people could have conversations with their GPs, but also with dental services, emergency services, hospitals, and hospices. It facilitated more equitable access to health services for Deaf people.

BSL Health Access was closed on 31 March 2021 as there was no further NHS funding available and SignHealth, who had set up the service as an emergency response to Covid-19, had already spent more than £800,000 on the service and could not afford to spend any more. The service received more than 4,000 calls in its final month of operation. No service has been put in place to take these calls since and many Deaf people are not able to contact NHS services.

---

## Case study: Test results and appointment reminders

The system at Addenbrookes I want to say is absolutely fantastic! When I go for a blood test, the next day I will get a notification sent to me by email saying my blood tests results are available. I can then log into the system and the way the results are presented is easy for my screen reader. I can also go back and look at past results and if your previous ones are similar then I know and so I am not going to worry about it. The consultant reviews them online and obviously if there's any issue, he phones me.

I also get an email telling me if I have a letter from the hospital. That has been amazing, particularly during Covid. Last week I had an email sent asking me to log into the system because you have a letter. I logged into the system and the letter was from my consultant saying I now need to have a booster Covid injection because I'm a clinically extremely vulnerable person. So, getting information so quickly in a format that I can read is fantastic. When I got the letter about the Covid injections, I didn't have to ask anyone else to read it to me. I just sort it all out myself. It empowers me.

When I have an appointment coming up, I get a notification telling me and asking me to log into the system. There might then be a questionnaire I need to complete before I go to my appointment. Everything is just so simple. Any changes go on to the Addenbrookes system. They send me an email to say this is now on the system, can you look at it and can you check it? Just so easy!

I think there are over 35 different alternative format options because they're considering learning disabilities, sight impairment, hearing impairment. Obviously, for me, it's by email, but it offers Braille if I would like.

– Blind patient, East of England

---

## Consequences of poor access

Failures to provide accessible information and communication lead to health inequalities. Previous research carried out by SignHealth found that Deaf people are twice as likely to have high blood pressure and four times as likely to be at risk of diabetes ([Sick Of It](#), 2014). This health inequality was explained by a lack of information, poor communication, and unnecessary barriers for patients to even meet with a GP, issues that still remain.

Each of the following sections highlight another area where people with accessible information or communication needs may be put at risk, disadvantaged or blocked entirely from healthcare.

### Misdiagnosis

The consequences of inadequate communication provision can include a risk of a misdiagnosis because the patient has difficulty understanding questions or communicating their symptoms. A condition could go unnoticed or identified incorrectly.

Appropriately planned and executed communication support would mean that the initial appointment would more likely lead to the correct diagnostic testing and results. The patient journey would continue to treatment and condition management with instructions that are then accessible to the patient. This would negate the need to

allocate more time for repeated follow-up appointments or unnecessary tests, treatments, or procedures.

### Improper use of medication

People are put at risk from medications when a lack of accessible information leads to a poor understanding of instructions of what to take and when.

---

**“I need additional time to process information but have often been denied a double appointment for this purpose. This has an impact, for example a GP prescribed me two different creams for different parts of my body but did not make clear which was which and the prescription directions were ‘use as directed.’” – Autistic patient**

---

People's needs sometimes require flexibility in what is usually a very rigid system. This can take the form of offering longer appointments, providing information in alternative formats and much more.

The assumption that everyone can access and understand the directions on a written prescription without explanation is inaccurate and discriminatory, and fails to meet patients' needs.

Several professionals and a number of patients mentioned pharmacies as lacking in provision for accessible communications and information.

---

## Case Study: Medication and Pharmacy

“I have no vision at all, I use assistive technology to read printed material, so my preferred format is always electronic. A couple of years ago I was given a course of 3 different antibiotics. These were very strong medicines and the instructions had to be followed carefully to ensure they were effective. My GP did not explain to me what the doses were, I was feeling so unwell, I did not think to ask.

A pharmacist handed the medication to me without any explanation of the dose or time it should be taken. I asked her about it, and she said that they had carefully colour coded the medicine so I could tell which one was which and handed me a sheet which apparently had large print details on it. Whilst this would have been helpful for people with some residual vision, I could not read it. No effort was made to ask me what my communication requirements were and how they could meet them.

The pharmacist rattled through the instructions for all the medicines in one go. Some you had to take with food, some you shouldn't drink with, and some were two tablets at a time. I couldn't remember the details by the end. There was nobody at home who could read this information to me. Luckily, I have some knowledge of braille, so once I peeled back the printed labels covering them, I was at least able to read the name of the medicine. I took a guess at which ones should be taken when.

The medicine made me feel dreadful, but I persisted as I knew how important it was not to stop antibiotics halfway through a course. When I neared the end of the two-week intensive treatment, I noticed that for one medicine there were still quite a few tablets left. I realised that I'd only been taking one tablet when it should have been two each time. I called the GP who said that I'd have to start the whole course of medication from scratch. This meant that I was on a huge dose of antibiotics for a month which was very stressful. This kind of thing has happened on many occasions.

I am a very independent person and I have the right to remain so for as long as I possibly can. Being able to read my own prescriptions would seriously improve my ability to manage my health conditions more effectively and safely. This would reduce the load on my doctors' surgery, who have had to pick up the pieces when I haven't been able to take the medicine as prescribed.”

- Blind Patient

---

## Mismanaged appointments

As mentioned previously, **81 per cent** of people with communication needs have had an appointment where communication needs were not met. This highlights instances when appointments were not conducted in the patient's best interests in terms of making an informed decision, thus limiting their agency.

Failure to meet a person's communication needs leads to a lack of autonomy, denies a person their right to be heard and is likely to constitute discrimination. Without equitable access, neither party - be it doctor or patient - can be fully assured that the appointment has been conducted to an acceptable standard.

A robust infrastructure is required to ensure the process of meeting communication and information needs is streamlined and efficient, providing full access which among other key benefits should also lead to far fewer appointments being mismanaged or repeated unnecessarily.

## Missed appointments

Survey responses from patients highlighted time and time again the number of appointments and procedures that were unable to take place, either because the patient was unaware of the appointment, was unprepared for the procedure due to inaccessible instructions, or where an

appointment had to be postponed due to no communication support available.

Delayed treatment can have significant consequences for the health of patients.

Services may also inappropriately end treatment or discharge patients due to patients missing appointments.

Missed appointments are a financial burden for providers, wasting precious time and resources for everyone involved.

---

**“The chronic pain clinic refused to send me email letters and told me they didn't have time to comply with the AIS. I asked how they expected me to read a printed letter, but they weren't interested. I did not know they had sent me appointments as I can't read the letters. Eventually I received a phone call saying I was being discharged from the clinic for missing appointments that I didn't even know I had. I reiterated that I needed email communication, not letters, but again they just didn't seem to care. It is extraordinarily frustrating.”**

**- Blind patient, East of England**

---

---

## Uninformed choice or consent

Blind and partially sighted patients often report that they are being provided with consent forms in inaccessible formats.

Consent from a patient must also be informed, which is impossible if communication needs are not met.

Inaccessible information about medications also deprives people of being able to make an informed decision about their health and treatment options.

---

**“I was released from hospital without any communication support. I had no idea what procedure I had done and no idea what medicines I was taking home. I text my support worker for help and when she rang up to ask when she could come and support the nurses said 'we are getting by.... she's not a bad lip reader!'”**  
**- Deaf patient with a learning disability, South East England**

---

The National Institute for Health and Care Excellence (NICE) guidance outlines how patients should be a part of decision-making, and ensure the patient understands the risks, benefits, and possible consequences of different options through discussion and information sharing. This is impossible when communication needs remain unmet.

## Confidentiality

The reliance that many of those with communication needs have on family members (or even friends/colleagues) to interpret or read out communications and information for them clearly undermines the principle of patient confidentiality.

---

**“I literally begged my GP to send me my smear test results in Braille; it did not happen. It happened that my father-in-law saw the paper and read it and it was so humiliating, no woman should experience this. My medical results are my private affair!”**

**- Blind patient**

---

This also erodes patient privacy and can entirely remove their ability to choose when to disclose their diagnosis. It could also put them in a position of increased vulnerability in situations of abuse.

---

**“Fed up always having to argue and say it's my right to have an interpreter - why have they for 18 years wanted my family to interpret for me! My health is my business.”**

**- Deaf patient**

---

---

## Disengaging with healthcare

Poor experiences of access sometimes result in patients deciding not to seek out medical care because they are uncertain about how they will be treated, listened to, and valued by health professionals. This in turn deepens the health inequality faced by many of the respondents.

---

**“I avoid seeking medical care because of the communication barriers. From the point of being ill, to getting better, it is a nightmare. Trying to seek advice is impossible. Booking the appointment, I have to physically attend, knowing the diagnosis and treatment plan is impossible for me to understand. And for any follow up care, I wouldn't have a clue what to do without BSL support.”**

**– Deaf patient**

---

---

**“I haven't seen a GP since 2015. That is to do with the fact that I find it difficult to access the service itself because I don't get the right support.”**

**– Deafblind patient**

---

Patients who are denied interpreters or the right communication support are effectively denied independent access to healthcare.

## Emotional impact

The importance of having full access to communication should not be understated. The additional stress of not having access exacerbates the already present stress of having to deal with medical or mental health issues. When communication barriers occur, it can have a profound emotional impact.

---

**“I didn't give any bloods, or anything so how have I been told I've got HIV? Turns out they put on the notes HIV and not hives! I was nearly crying; I didn't understand what was going on.”**

**– Hard of hearing patient, North West England**

---

A blind patient, who was due to become a new mother, reported having more anxiety than usual about the pregnancy because she was unable to browse and review independently the information provided in all the leaflets and materials from the midwives, which points to further barriers to information and autonomy.

**Case study: Booking interpreters for operations** [\[BSL Video Link\]](#)

Patients in hospital often experience feelings of vulnerability, uncertainty, or fear, but for those with additional communication needs, the experience can be made even more emotionally upsetting.

---

## Impact of the pandemic

The pandemic has led to more people than ever accessing healthcare online. There has been an increase in virtual appointments via video, booking GP appointments online and use of the NHS app. This can work well for many patients and can improve access for people with communication needs who are comfortable using technology. However, it is important to ensure that people who are digitally excluded also have their communication needs met.

In 2018, there were still 5.3 million adults who were “internet non-users”, 10 per cent of the UK adult population. Roughly 38 per cent of the total population with sight loss have never used the internet or have no internet access (Understanding Society (2020), Comparing the circumstances of people with sight loss to the UK population, Wave 8 2019).

When considering accessible formats and contact methods, non-digital alternatives must always be available for patients who are digitally excluded.

The use of face masks has had a serious, isolating effect on many Deaf and hard of hearing people. It is still unclear when clear face masks will be readily available in health settings, creating a significant barrier for patients who rely on lip-reading.

---

“[If I can’t] get things in my preferred format, I can’t access my own healthcare independently. Currently all my correspondence is being done remotely and by phone which I find very difficult to hear and understand. This is still being done despite deafblind being on my record, and my constant reminders. No alternative method, such as email, has been given. This means I cannot interact with consultants confidently or privately. I have to ask my parents to talk on my behalf. In person consultation is a must because then I’m physically in front of a person and can understand them better.”

- Deafblind patient

---

---

“Receptionist refused to remove her mask whilst talking to me. I explained I rely on lip reading; she just shrugged her shoulders at me. I wanted to make an appointment but left the surgery in tears and feeling embarrassed.”

- Hard of hearing patient

---



---

# Conclusions

The NHS Accessible Information Standard (AIS) clearly sets out the steps that providers must take to meet information and communication needs. Our evidence shows that this is not happening.

Providers must deliver training to staff to explain the AIS requirements and what steps to take. Staff should be appropriately trained in how to respond to the various needs and the alternative formats and communication support that should be offered to patients. Staff should understand how the system flags communication needs in advance of the appointment so that appropriate actions are taken, and support is provided. It is also imperative that a robust system is in place to implement or book the correct support.

Only **5 per cent** of patients surveyed are receiving equitable access to healthcare. Yet the responses from professionals indicated that **31 per cent** of providers have implemented the five steps outlined in the AIS. Much more emphasis must be focused on accountability and consistently embedding accessibility within services. This can be done by implementing review procedures which will in turn highlight issues and gaps in provisions. This will provide a clear pathway to resolving issues and ensuring equitable services are being provided.

There needs to be a clear and concise review of costings, timings and achievability/feasibility of provisions delivered by the services. This is needed in order to appropriately assign budgets and resources. If communication needs continue not to be met, the evidence will be there for review and comparison, so that appropriate actions can be taken.

As a coalition of disability organisations and user-led charities, we can support the NHS in implementing and meeting the Accessible Information Standard, through training, organising lived experience panels, advice, review, etc.

The NHS is a source of pride, created to provide universal access to health care to everyone at the point of need. According to the NHS Long Term Plan, every action will be taken to drive down health inequalities. To achieve this, the Accessible Information Standard must be fully implemented so that NHS services can support, listen to, and treat people to improve their health and wellbeing.

# Methodology

A coalition of charities devised a survey which was split into two parts. One for health professionals aimed to assess knowledge about AIS and what processes they had in place for their patients. The other part was for people with communication and alternative formats needs, to learn more about their experiences in health and social care settings. In both cases the survey was designed to be anonymous.

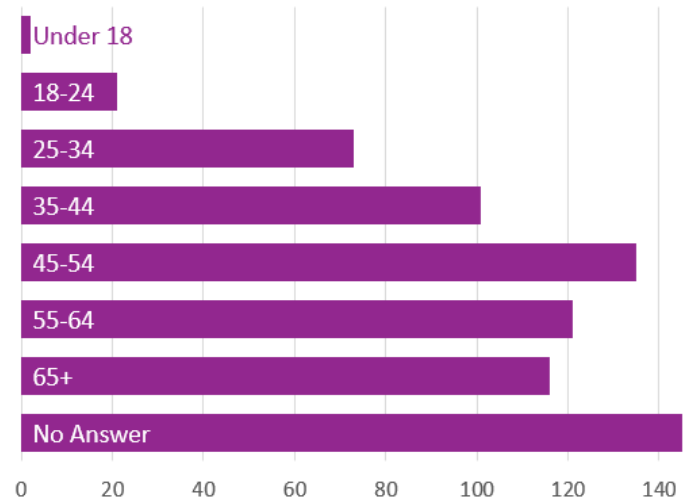
The questions were provided in written English and BSL video translations with subtitles to ensure that people with a variety of communication needs were able to respond to the survey in an accessible manner. Participants were also given the option of sharing positive and negative experiences of access in BSL by emailing their videos to the researchers.

This was an online survey advertised through websites, social media and emails, and as a result, we recognise that the survey is likely to have left out the experiences of persons who are unable to or don't use the internet.

## Breakdown of respondents

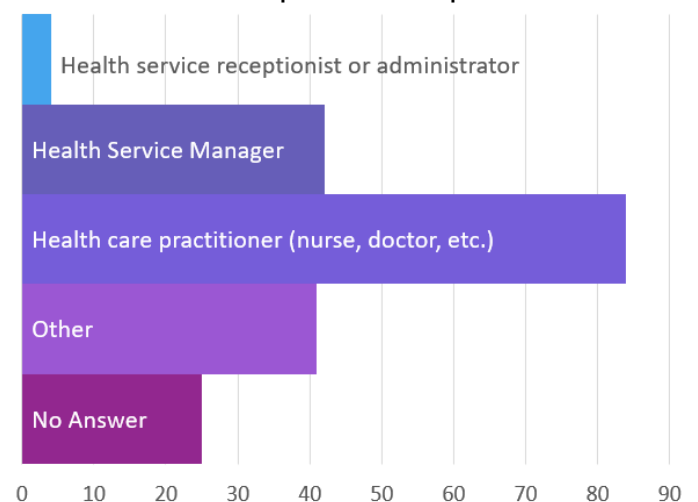
Patients responding to the survey were spread out geographically, and we believe covered all 42 integrated care systems. 87 per cent of patients who responded to the question recorded their race/ethnicity as white.

### Age of patient respondents



### Roles of professional respondents

Note: No responses from pharmacies



---

**THE DEAF HEALTH  
CHARITY  
SIGNHEALTH**

**R N I B**

—  
See differently



Royal Association for Deaf people



Learning Disability England



**healthwatch**

**RN  
I:D**