

**Accessible
Information
Standard (AIS)
Report
August 2022**

Your care, Your Way

Accessible Information Standard

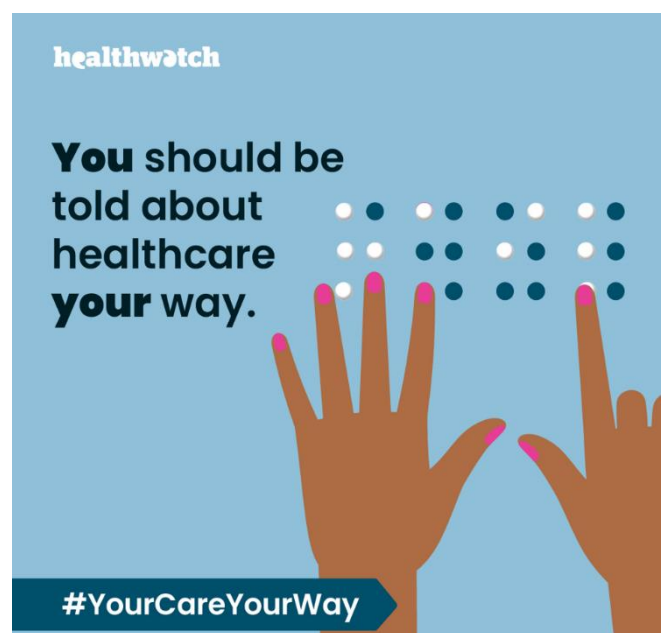
Introduction

Medical and healthcare information can be complex. However, if you are disabled or have sensory loss you have a legal right, under the Accessible Information Standard (AIS), to health and social care information in a way you understand, and communication support if you need to do so.

What rights do you have?

If you have a disability, impairment, or sensory loss, or are a parent or carer of someone who does, you should expect:

1. To contact and be contacted by services in ways you find accessible.
2. Services to give information and correspondence in formats you can read and understand.
3. To be supported at appointments if needed.
4. Health and care services to support you to communicate.



What do health and care organisations have to do?

- 1.** Ask if you have any communication needs, and how these needs can be met.
- 2.** Record your needs in a clear and set way and highlight these needs in your file or notes so people are aware and know how to meet them.
- 3.** Share information about your communication needs with other providers of NHS and adult social care, when they have consent or permission to do so.
- 4.** Deliver information to you in a way you can access and understand, with the option for communication support if needed.

So...what should you expect?

If you're speaking to a dentist, doctor, care home manager or any other provider of health and social care, here's what you can expect:

- 1.** You should be able to contact, and be contacted by, services in accessible ways, for example via email or text message.
- 2.** Information and correspondence should be given in formats you can read and understand, for example in audio, braille, easy read or large print.
- 3.** You should be supported by a communications professional at appointments if this is needed to support conversation, for example, a British Sign Language interpreter.

Health and care staff and organisations should support you to communicate, for example, to lip-read or use a hearing aid.

The AIS has been a **legal requirement** since 2016, but sadly many NHS Trusts are not supporting equal access to care for deaf and blind patients. Therefore, in February 2022, Healthwatch England launched a new campaign 'Your care, your way'.

Our campaign 'Your care, Your way' aims to:

1. Find out how well health and care services are delivering the Accessible Information Standard.

2. Make sure that, if the standard covers you, you know your rights.

3. Find out who else has problems understanding information about their healthcare and needs to be covered by the standard.

This report reviews the results of our survey which aimed to find out how well health and care services in Lincolnshire are delivering the accessible information standard.

Methods

We heard from 58 people via an online survey from February to April 2022.



Who took part?

71% of respondents were women.
23% were men.

77% were white: British / English / Northern Irish / Scottish / Welsh.
11% were white: Any other White background.

94% could speak, understand and read English well.
3% (1) could not speak, understand or read English at all.



6% Had sight loss



15% Had hearing loss

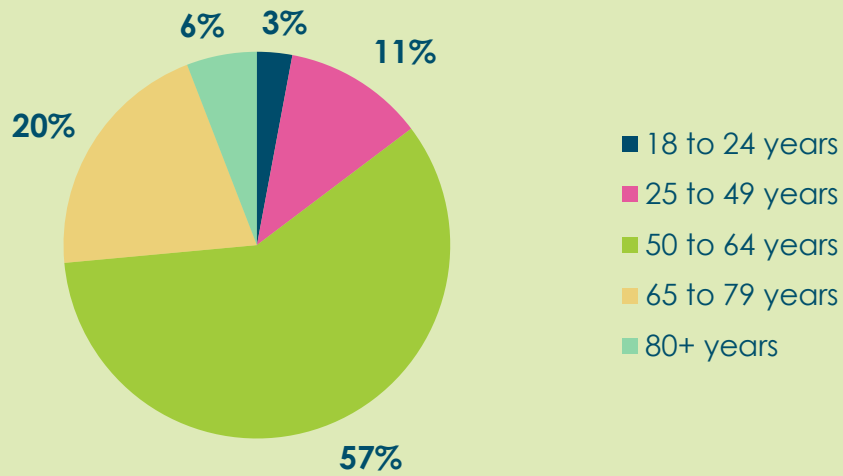


6% Had a mental health condition which affects ability to communicate or understand information



6% Had a learning disability that affects ability to communicate or understand information

Age of respondents



Respondents were most commonly between 50 to 64 years old.

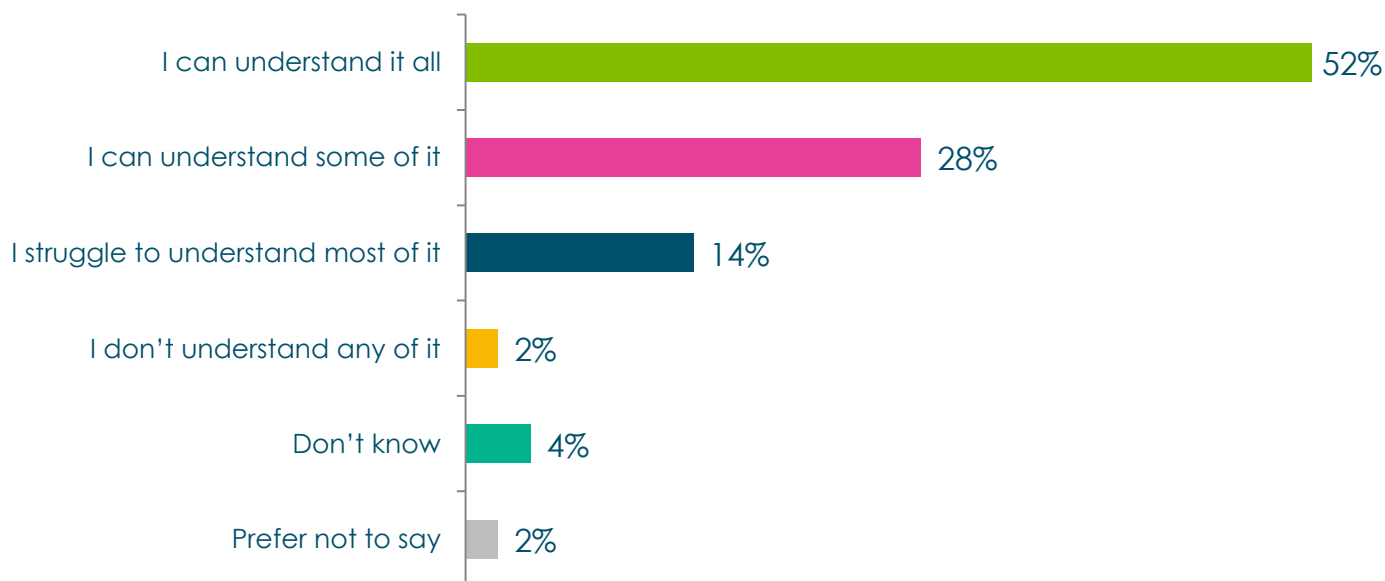
- 14%** Boston Borough
- 23%** East Lindsey District
- 9%** Lincoln City
- 14%** North Kesteven District
- 9%** South Holland District
- 26%** South Kesteven District
- 6%** West Lindsey District



Findings

How would you describe your ability to understand any information about your healthcare you are given by services?

Examples of healthcare information could include appointment letters, face-to-face consultations, leaflets or information on a website



52% felt they could understand any information given to them by services about their healthcare.

16% struggled to understand most or all of the information given to them about their healthcare.



When using health and care services, have you ever asked for support to help you understand health or care information that you have received?



41% Yes



49% No

When using health and care services, have you ever asked for support to help you contact health or care services?



41% Yes



53% No

“Could never get through to surgery so treated myself and put up with it have given up trying to get through to surgery.”

When using health and care services, have you ever asked for support to help you communicate with healthcare staff / services?

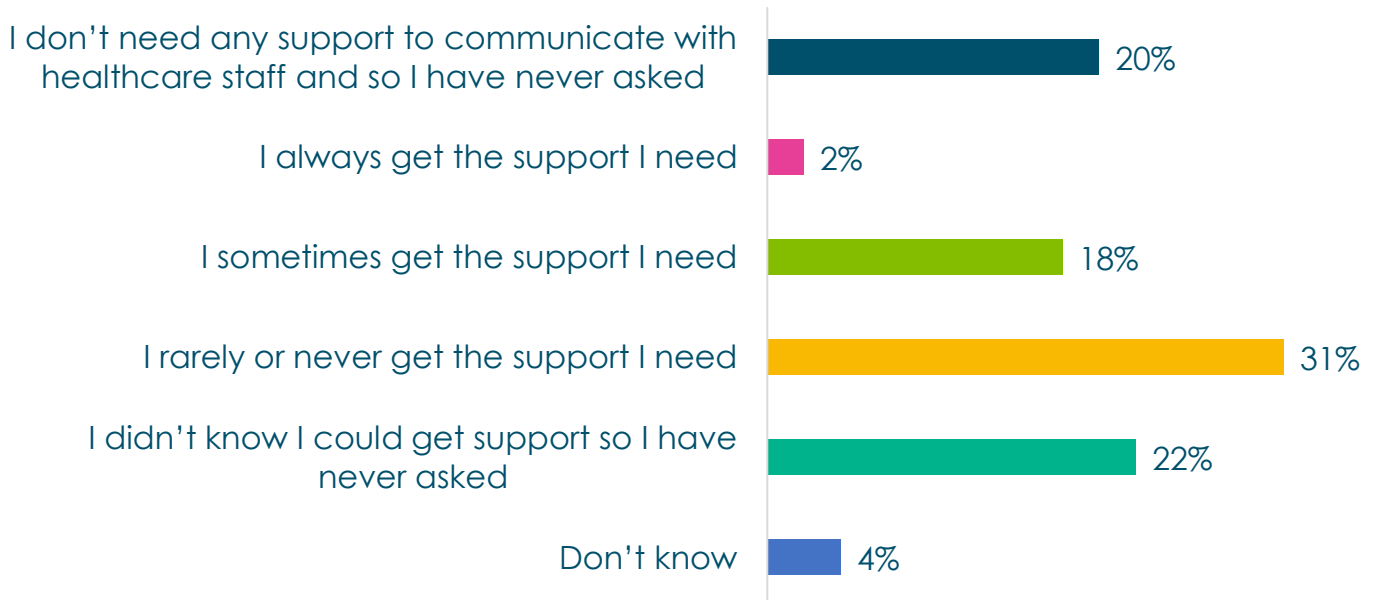


41% Yes



53% No

How would you describe your attempts to get support from health and care services with understanding information, contacting services or communicating with staff?



2% (1 person) felt they always got the support they need.

31% felt they rarely or never got the support they need.

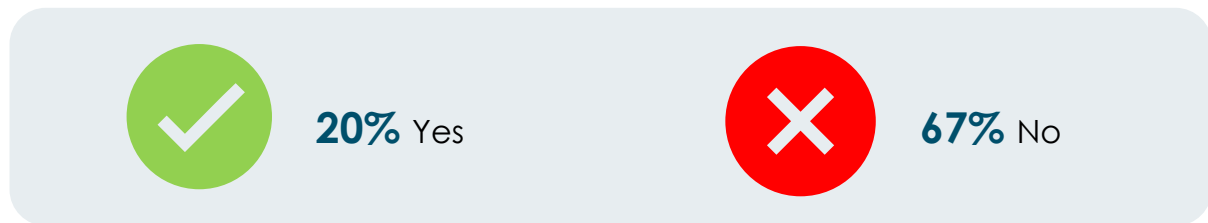
22% did not know they could get support so never asked.

"It was frustration at not being given the information and then having to use NHS website or Google for answers or specialist charity websites."

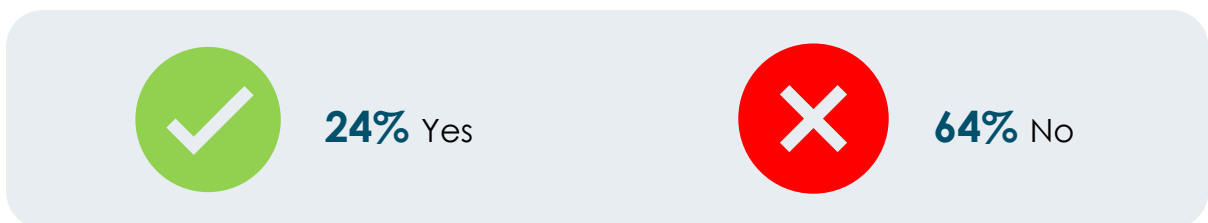
"On occasion some health workers have been less than polite and seem unwilling to treat me as a person seeing me as just another number on the list to do. Many are caring and will spend the time needed to help. its a bit luck of the draw and being over worked is no excuse for bad manners and lack of bedside manners."

"I can understand if I'm well, I just can't speak due to severe symptoms flare, so I need help at that time. The biggest issue I have with medical information generally, is that Medics will often say one thing, but then write something else in the medical notes. I have to take someone with me now to every appointment, because of previous bad experiences."

Have you ever been refused healthcare information in a format and/or language you needed, even though you asked for it?



Have you ever been refused a request for support to understand healthcare information that you have been given, even though you asked for it?



What was the impact of not being provided with healthcare information you could understand or access?



5% I missed my appointment



33% I could not contact the service that I needed



14% I could not understand how to take my medication

What was the impact of not being provided with healthcare information you could understand or access? Continued.



5% I got the wrong medication



14% I could not understand and communicate with health care staff



19% I missed out on important information about my health



9% I did not know what I needed to do to keep safe during the COVID-19 pandemic

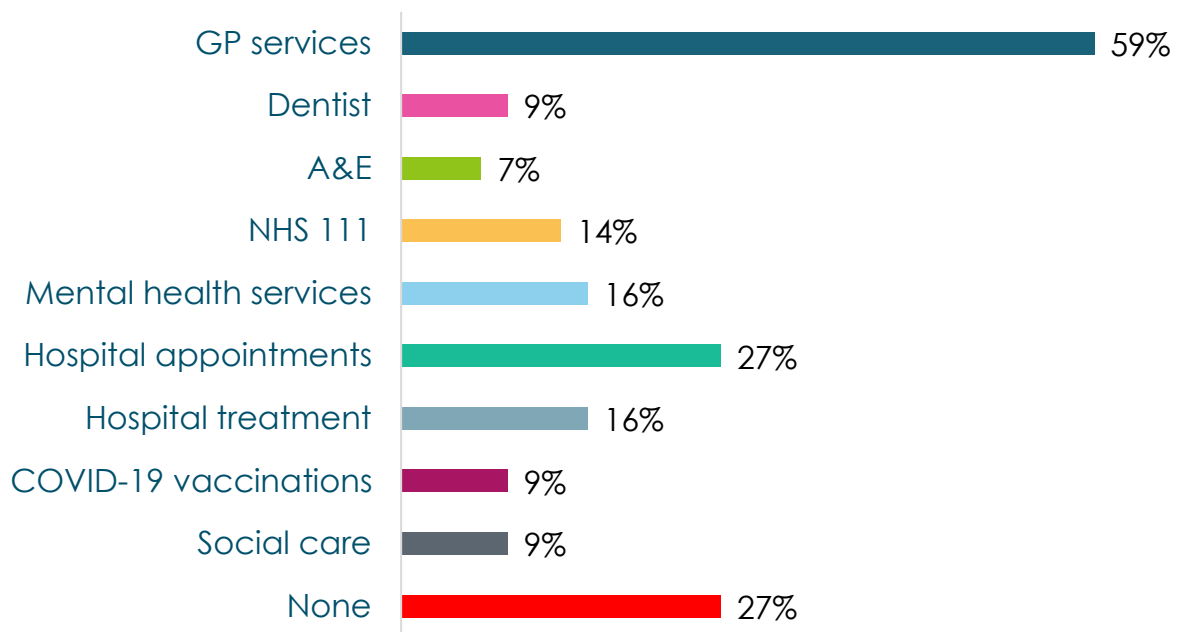


28% It affected my mental health and wellbeing

33% It did not affect me in any way

“I requested information in my notes after a medical procedure had gone wrong, but they said they had lost them. It prevented me getting the right treatment going forward, its devastating. I have been so traumatised by previous episodes of care, and misinformation that I've been told regarding diagnosis, that has made it almost impossible to access new care going forward.”

Which, if any, health or care services have you struggled to access as a result of communication problems?



59% struggled to access GP services the most as a result of communication problems.

Access to hospital services including both appointments and treatments was selected by **43%** of people and the next most affected by poor communication.

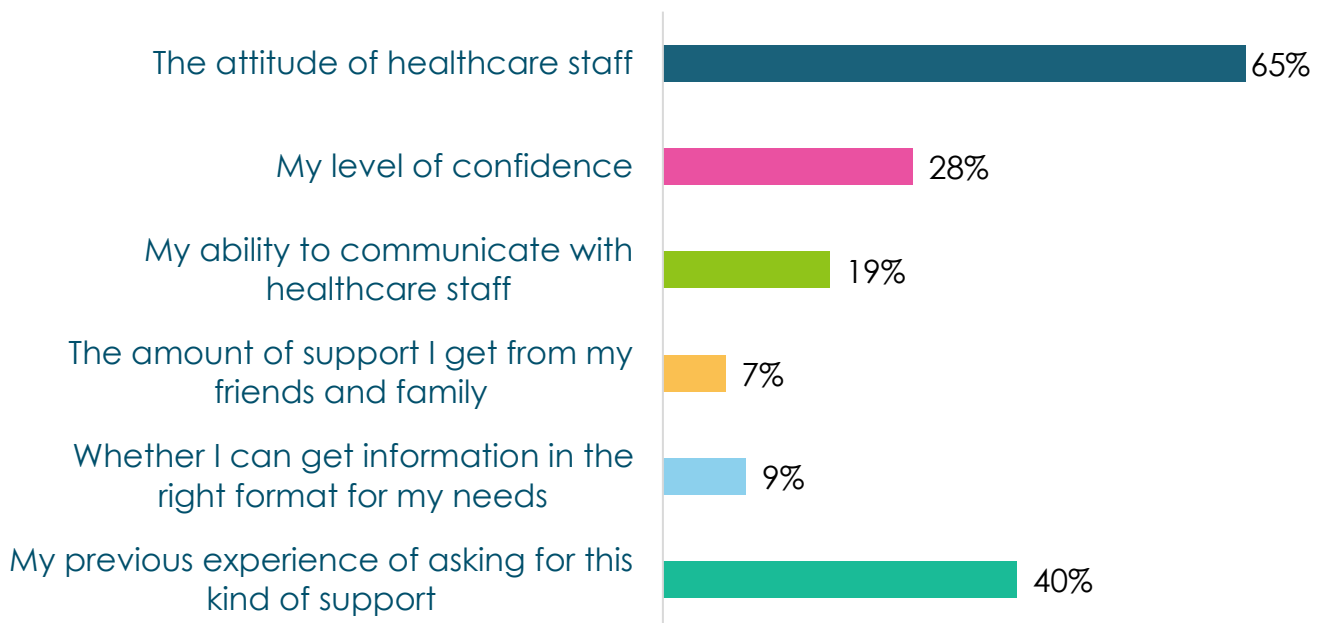
How do you feel about asking health or care services to provide information in a way that you can easily understand?

44% felt very comfortable asking health services to provide information in a way they could understand.

37%, by contrast, felt uncomfortable asking health services to provide information in a way they could understand.

"I'm am a pretty straight forward polite talking person but my confidence has been knock out of me over the past 3 years. We know everyone/or some people in the health service are trying the best but I am not a rude person but I most certainly have come across many rude staff in the NHS. I am now fed up of thinking well they are under a lot off stress because I am as well and I am managing to stay polite well I was but now I am at a loss with my health that I'm now don't care.

Which of the following affect your ability to ask health services to provide information or communicate with you in a way that you can easily understand?



The attitude of the health care staff affected the ability of **65%** of respondents' ability to ask health services to provide information or communicate in a way they could easily understand.

For **40%**, previous experiences of asking for support deterred them from asking for help again.

“If one could communicate with the GP surgery it would be a start.

“Being able to write to GP via 'ask my GP' service has improved things tremendously. Because I can write information as opposed to talk, which is much better. And the GP writes the information directly back to you, as opposed to telling you something, then writing something different in the notes or letter to you/me.”

Do you know how to complain if you are not given information in the format or language you need or support to understand information?



35% Yes



47% No

What can you do if your communication needs are not met?

If you do not receive information about your health and care in a format that suits you, you can:

1. Remind service staff that they have a legal duty to provide accessible information under the Accessible Information Standard.
2. Make an informal complaint to the nearest Patient Advice and Liaison Service which can help you to resolve issues informally.
3. Make a formal complaint. If you're thinking about making a complaint, you are entitled to support from the independent NHS Complaints Advocacy Service.
4. Share your experience with your local Healthwatch, who will feed back to local services and decision-makers, as well as feed into Healthwatch England's national advocacy work.
5. Get involved with your local Patient Participation Group or patient reference group – groups of patient volunteers which work to represent the voices of patients and improve services.

What change have you noticed about the way in which health and care services communicate with you since the COVID-19 pandemic started?

The overwhelming majority, **51%**, felt the way health and care services communicate with them had got a lot worse since the start of the COVID-19 pandemic. Just **5%** felt they had seen an improvement in communication and **12%** reported no change.

“Whilst there has been no change in the way services communicate with me, this isn’t a good thing.”

Freedom of Information Requests

As part of the national survey and campaign Healthwatch England sent all NHS trusts a freedom of information request, in Lincolnshire we received responses from LPFT and LCHS, no response was received from ULHT.

Q. At the point of registration/referral, in line with the Accessible Information Standard, does your trust currently ask all patients whether they have any information or communication support needs, and find out how to meet those needs?

- **LCHS** - This is asked at the initial referral and followed up in the initial assessment in more detail.
- **LPFT** - This is information which is put in correspondence to patients which asks them to let us know if they have any of the above needs so that we can make reasonable adjustments. Examples may be: information in different format; Interpreter service; Correspondence in a different language.

Following identification from the patient that they require information in a different format, this is recorded as an alert on the Trust’s clinical record system, RiO

Once identified, this will be highlighted to any other organisation / teams so that they are aware they will need to make any reasonable adjustments.

No barriers to compliance of the Accessible Information Standard were identified for both LCHS and LPFT.

Q. In the last three full financial years (2020/21, 2019/20 and 2018/19), have you undertaken any audits to assess your compliance against the Accessible Information Standard or the provision of accessible information generally? If yes, please share any resulting reports/findings.

- **LPFT** - No audits have been undertaken.
- **LCHS** - No, however, we are presently applying an audit to assess where LCHS is with AIS and developing an action plan to further embed the AIS.

LPFT shared they have had 2 complaints over the last three financial years relating to patients not receiving information in accessible formats. LCHS felt due to the nature of the information sought, including the sensitivity and low numbers held they engaged section 40 relating to personal data to withhold the information from disclosure.

Statistical data which relate to fewer than five people could lead to the identification of individuals – especially when coupled with information already in the public domain, thus breaching Section 24(1) of the Data Protection Act 2018 and Article 21 of the UK General Data Protection Regulation. Therefore, consider this information exempt from disclosure under Section 40(2) of the Freedom of Information Act 2000.

Q. Please provide figures for your trust's spending on interpreting and translation into non-English languages (if possible, excluding British Sign Language (BSL) interpreting and translation of materials into easy read) for the last three full financial years (2020/21, 2019/20 and 2018/19) together, if possible, with the number of requests for interpreting/translation that this represents.

LCHS

2020/21 - £55.7k - 396 Requests

2019/20 - £38.2k - 708 Requests

2018/19 - £26.5k - 554 Requests

Information regarding breakdown of whether these include any BSL is not held.

LPFT - From data taken from their 2020/21 Equality report

	2018/19	2019/20	2020/21
Telephone Interpretation	£3,333.42	£1,870.56	£10,872
Documentation Interpretation	£7,690.42	£5,831.25	£7,446.72
Face to Face Interpretation	£29,693	£33,298	£12,754
Video interpretation			£9,082.80
Use of British Sign language Interpretation	£3186.87	£6490.86	£2340

Other comments

Throughout the responses to this survey, we heard repeatedly that individuals were struggling to get appointments at their local GP practice. Others highlighted their worries over the reliance on telephone consultations. Both of these concerns have been continually raised to us over the past few years. Several people were frustrated about long waiting times for specialist appointments, with there being little communication during the wait. Poor communication between services and to patient was also a concern, one we have also heard repeatedly during the past year and beyond.

Recommendations

While our work has been focused on health services, we are clear that the Accessible Information Standard (AIS) applies equally to social care services, and that NHS England's review of the standard should consider how all of these recommendations will translate to social care.

1. Health and care services to be made accountable for fully delivering the standard.

The Department of Health and Social Care, NHS England and the Care Quality Commission (CQC) should ensure that all individual health and care services meet their duties as set out under the AIS.

This new framework for accountability should maximise commissioning, contracting and performance management processes, and regulation at all levels to set clear expectations and monitor progress.

To support this and create clear accountability through the 42 new Integrated Care Systems (ICSs), we recommend that local boards appoint a member of the board responsible for ensuring that services meet communication needs of all their local citizens. This should include a role to gather more and better feedback from users on a continual basis and report back to the board annually.

Outcomes:

- Individual services and ICSs have a clear accountability system in place and can report back on how services support people who have communication needs.
- They can identify broader trends in people's experiences of accessible information and put in place measures to address areas of concern.
- New CQC assessments of ICSs become effective at holding service providers accountable for working together to meet the standard.

Responsible: Department for Health and Social Care, NHS England, CQC, other Arm's Length Bodies and leaders and ICS level, NHS Digital.

2. Every health and care service to have an accessibility champion.

Every health and care service should appoint an Accessible Information Champion to receive additional training and identify local challenges, barriers and best practices. These champions should report on how services deliver the standard back to ICS board lead.

Outcomes: Health and social care staff know who is responsible for leading local accessible information policy and delivery. All staff are aware they must comply with the standard.

Responsible: ICS leaders, health and care providers

3. Better IT systems so that patients can update services with their communication needs.

As part of the AIS review, NHS England should review current IT systems and present recommendations to ensure they comply with the AIS. The review should also address barriers to sharing information on patients' communication needs between services. Ultimately, IT systems should store data on patients' communication needs centrally so that services can access it whenever they need it rather than getting it through referrals as they currently do.

The NHS App should allow people to log their communication needs and update them if they change.

Outcomes:

- People can easily update services with their communication needs.
- People's communication needs and preferences are part of their care records.
- Services have systems in place to share patients' communication needs.
- Services have access to a central database.

Responsible: NHS England, NHS Digital

4. Involving people with communication needs in designing better services

People with communication needs are essential to informing and creating change. Each integrated care system should establish a panel representing people with accessible information needs. They should involve the panels in reviewing existing services and monitoring how local services act on the AIS. Only services that include people in implementing the standard should be considered outstanding when assessed by the CQC.

NHS England should also work with the panels to develop national commissioning standards for communication support and ensure local services meet them.

Outcomes:

- People with accessible information needs can regularly feedback on their experiences as part of quality improvement.
- Health and care services know where to go if they need input from people with communication needs on how best to support them.

Responsible: NHS England, ICS leaders

5. Mandatory training on accessible information for all health and care staff

Health and care providers should make detailed training on accessible information mandatory for all staff and recommend improving quality and consistency in delivering it. Training on accessible information should count towards professional development and be part of teaching curricula for students progressing to clinical careers.

Outcomes:

- Staff understand the standard. They regularly provide information in the formats patients need and proactively ask about their communication needs.
- Staff are aware of the training available to them and extra local support.

Responsible: ICS leaders, the medical profession.

Summary

The Accessible Information Standard (AIS) was introduced to ensure that those with a disability or sensory loss are able to access information in a way they understand and receive communication support if needed. The AIS became a legal requirement in 2016, but sadly, many NHS Trusts are not supporting equal access to care. Therefore, in February 2022, Healthwatch England launched a new campaign 'Your care, your way'. The campaign aimed to gain insight into how well health and care services are delivering AIS, who else has problems understanding information about their healthcare, and ensure that you know your rights. To do this we conducted a survey online from February to April 2022. We heard from 48 people.

Around half of respondents understood all the information provided by services about their healthcare. 41% of respondents had asked for support to help understand health or care information, contact and communicate with services. However, subsequently, just 2% felt they got the support they needed and 31% felt they rarely got the supported they needed. It is also important to note that 22% did not know they could ask for support. This highlights that individuals need to be made more aware that they are able to ask for support to understand information and help to communicate with services.

The most difficult services to access as a result of problems with communication were GP and hospital services. 37% of individuals felt uncomfortable asking for help. Staff attitudes and previous experiences deterred people from asking for support.

However, for those who had asked for accessible information or help understanding information, 1 in 5 people were refused. As a result of the AIS not being followed, individuals could not contact the services they needed, which in some cases led to a deterioration in health which could have been prevented if help could have been sought earlier on. Furthermore, individuals felt they had missed out on important information about their health meaning they could not manage their condition or make informed decisions. All of this had a negative impact on mental health and wellbeing.




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Call us: 01205 820892
Email us: info@healthwatchlincolnshire.co.uk**

The results of this survey highlight that despite the AIS being a legal requirement, many are still struggling to access the support they need in order to understand information about their health and care and communicate with services. Many are unaware that they are able to ask for support, but for those that do services and staff are not always receptive. Such issues and previous experiences deter people from asking for support in the future. This lack of support is having a negative impact on people being able to access health and care services and make informed decisions which in turn negatively impacts people's physical and mental health. It is therefore crucial that not only are people made aware of the AIS and their rights as outlined in this report, but that health and care organisations play their part in ensuring equitable access to information and services.

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