Accessible Information Standard (AIS)
Consultation response

This document contains insight gathered by local Healthwatch as the AIS was being developed, implemented and post implementation. This paper forms our response to NHS England’s review of the AIS, conducted in early 2017.
Executive summary

In July 2015, the Accessible Information Standard (AIS) was approved to ensure people with a disability, impairment or sensory loss can access information and communicate effectively with health and care services.

Health and social care providers were given a year to implement the new standard and have been legally required to follow the AIS from 1 August 2016¹.

The AIS is important because it aims to reduce the disparity between care provided to people without any disabilities and people with sensory and communication impairment.

This document looks at what local Healthwatch have been hearing over the last two years from people with sensory and communication impairment about their experiences.

It contains insight gathered by local Healthwatch as the AIS was being developed and implemented, as well as post implementation. More insight is being shared with Healthwatch all the time but we hope this snapshot proves useful to NHS England as it assesses what progress has been made.

This document draws on the work of 41 local Healthwatch, incorporating the views of more than 700 people and includes evidence from visits to 50 healthcare providers.

While local Healthwatch have clearly supported the AIS, including working with local partners to emphasise its importance and, in some cases, providing training on how to implement it, the majority of experiences shared by local people suggest the new standards are yet to have a significant impact on experience. However, more comprehensive research is required to assess the impact of the AIS across the country.

The key areas people told local Healthwatch they wanted to see improve were:

- **Access to information and services**
  - Information is not provided in an appropriate form to meet people’s specific needs
  - Building signage and infrastructure is not always designed in a way that is accessible to people with sensory impairments

- **Staff attitudes and understanding**
  - People require more awareness training about how to communicate effectively with people who have different needs
  - People who have sensory impairments should be involved when service providers are making new decisions about accessibility

- **Patient records**
  - Flagging people’s needs is part of the standard but is not always implemented

- **Support**
  - People require support from the point of diagnosis

Understanding the issue

The Accessible Information Standard was introduced by NHS England to “make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand and with support so they can communicate effectively with health and social care services.”

The standard was introduced after a confidential inquiry into premature deaths of people with learning disabilities (CIPOLD) was undertaken in 2013. This inquiry showed that there was a further need to:

“identify people with learning disabilities in a healthcare setting, and to record, implement and audit the provision of ‘reasonable adjustments’ to avoid serious disadvantage.”

Early work by the Healthwatch network also highlighted the need to address issues around the accessibility of information and the way in which the NHS and care services meet the communication needs of all those they serve.

In 2014, a group of 13 local Healthwatch across North, Central and East London carried out a number of Enter and View visits in Emergency Departments (ED) across London. These took place over a period of 7 months.

There were some key findings across all of these emergency departments which included:

- There was a general uncertainty amongst staff about the procedures to follow when dealing with a person with sensory or communication impairments.
- They all had hearing loop systems in place, however, there was a lack of information available in large print, braille, easy read, or audio format.
- Receptions at ED were generally not set up so that people with hearing impairments were able to lip read easily.
- Staff were very keen on the idea of further training to improve knowledge and awareness.

---

2 https://www.england.nhs.uk/ourwork/accessibleinfo/
3 https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/finalreportexecsum.pdf
The AIS sets out the requirements all health and care providers must meet across five key areas:

1) Identification of needs
2) Recording of needs
3) Flagging of needs
4) Sharing of needs
5) Meeting of needs

NHS England is carrying out a post-implementation review, since the standard was introduced last year, and wants to find out what impact the standard has had.

This briefing therefore gathers information from local Healthwatch published reports and daily feedback to help NHS England assess if any change has been experienced since the AIS was implemented.

When the standard was first approved, a group of local Healthwatch worked together to produce a toolkit to help the network and others hold providers to account.

“It has been created to support and inform local Healthwatch activity around the provision of accessible information. This includes a methodology for undertaking Enter & View visits that support adherence to the Accessible Information Standard”

This toolkit was developed with support from NHS England, Healthwatch England, The Alzheimer’s Society, Surrey Coalition of Disabled People, Sight for Surrey, NHS Coastal West Sussex CCGs, Barchester Healthcare and Cranleigh Medical Practice.

This group of local Healthwatch, support by Healthwatch England, has also started to provide ‘Train the Trainer’ training to enhance Healthwatch volunteer understanding of the AIS.

In addition to this specific work, local Healthwatch have also been looking in more detail at what they have been hearing from users with sensory impairments, learning disabilities and communication challenges. Although there are specific issues in certain areas of the country, the overarching issues that arise include:

- Access to information and services
- Staff attitudes and understanding
- Patient records
- Support

Although it is still early days, the experiences people have shared with local Healthwatch have not shown any significant impact since the AIS came into force. However, further research should be carried out in order to gain a better understanding of whether service providers are meeting the needs of people with sensory and communication impairment.

---

What people said

In this section, we look into what local Healthwatch heard from their communities about the need for the AIS and more detail about the areas that require improvement.

The four key points are:

- Access to information and services
- Staff attitudes and understanding
- Patient records
- Support

Access to information and services

*Healthwatch Lincolnshire* (September 2015, after the standard was approved) asked people to complete a questionnaire about access to information. When asked how confident people felt about contacting health and social care providers to make appointments, many of the comments were negative. These included:

- “I cannot see the phone to make calls”
- “As a deaf-blind person, it is difficult to make appointments”
- “Because I can’t see, I panic and stutter with unknown people making things very difficult for me”

*Healthwatch Northumberland* (January 2016) highlighted that:

> “The design of the premises, access to services and information provided can all create barriers for people with sensory impairment. The lack of availability of information in appropriate formats to meet individual needs is a particular issue of concern.”

In March 2016, *Healthwatch Wokingham Borough* carried out some mystery shopping across 10 dental practices using deaf volunteers. It was made clear that receptionists need to be made more aware of the process of booking BSL interpreters. Recommendations included providing registration forms for new patients in easy read and large print formats.

*Healthwatch Bristol* engaged with people in April 2016 and heard that more trained sign language interpreters are needed. In particular, family members, carers and friends felt that they should not have to be responsible for acting as interpreters. People said they want a choice of male or female interpreters for when patients are discussing personal details with doctors. It was also recommended that booking a BSL interpreter should always be possible without the use of a phone.

The group of 13 local Healthwatch across North, East and Central London have continued their work around the accessibility of information and reported that their local Emergency Departments are looking further into visual displays to notify patients when they are ready to be seen. There needs to be a way of achieving this without breaking confidentiality.
They have also highlighted how poor signage around hospitals makes it difficult for some patients to find their way. Many hospitals across North, East and Central London said that there will be ongoing work to improve this and, in the meantime, volunteers will be used to help guide people around hospitals.

Receptionists in Emergency Departments generally sit behind glass screens, which makes it difficult for Deaf people to lip read. Many hospitals responded to these findings that they will look into a solution to this issue.

One piece of daily feedback shared with Healthwatch Kent in December 2016, after the AIS was introduced, was that a patient kept being unable to attend appointments because nobody had booked a BSL interpreter. Another example from Healthwatch Cornwall, from March 2017, said that a person could only receive letters for appointments in small print and was informed that the system does not allow any other options or methods of contact.

A mother of a teenage boy who is deaf told Healthwatch about an appointment with her son’s consultant. During the appointment, the mother had to translate what the consultant was saying into sign language for her son to understand. When the doctor broke the news of the son’s diagnosis, the mother started to cry before she could sign to her son the news. Both mother and son shared how distressing this situation was.

(Healthwatch Bristol, March 2015)

Staff attitudes and understanding

People often expressed to local Healthwatch the need for receptionists to be aware that they are the first impression that people have of any health provider. With more training and encouragement, receptionists would be able to feel more confident in approaching and helping people with sensory or communication impairments.

A survey Healthwatch Northumberland carried out in January 2016 found that:

“The results of the survey indicate that there is a lack of understanding of the communication needs of some of the groups that we worked with. Many respondents identified the waiting room to be a particularly problematic area, particularly for those with sensory impairment.”

Healthwatch Enfield and Healthwatch Camden both said that people with sensory and communication impairments should be involved when healthcare providers are looking to improve services.

Healthwatch Wokingham Borough’s work on dental practices reported very mixed experiences when it came to how receptionists welcomed its volunteers into the practice. Some were very helpful, but others were unwelcoming and unsure about how to communicate effectively and in a respectful way.
**Healthwatch Enfield** (March 2015, before the standard had been approved) highlighted four key themes that were important to the deaf people they engaged with. These were:

- Access to BSL interpreters.
- Making healthcare staff more aware of the issues that people face and how to deal with them in an appropriate and sensitive manner.
- Making sure that there are ways of accessing information and services in an appropriate way.
- Having more deaf people involved in Patient Participations Groups (PPGs). PPGs should try to actively involve sensory impaired people in order to improve services.

Healthwatch Enfield (March 2015, before the standard had been approved) recommended that having more deaf people involved in PPGs would improve how services work best for people with sensory impairment.

In December 2016, post-implementation of the AIS, **Healthwatch Bristol** carried out follow-up engagement work and came to a similar conclusion. It was recommended that deaf people should be involved in decision making over webcam BSL services.

> “At my GP there is a complete lack of awareness training among the reception staff.”

*(Healthwatch Camden, June 2016)*

**Patient records**

One of the requirements of the AIS is for providers to record and appropriately flag people’s needs so that they don’t have to remind the NHS continually about their requirements. However, a number of local Healthwatch heard about slow progress against this objective.

**Healthwatch Northumberland** (January 2016), in its ‘Access to Healthcare’ report, found that, in general, the number of providers identifying or recording patients who have a sensory impairment, physical or learning disability and required adjustments, was very low.

In a report published by **Healthwatch Camden** in June 2016, one quote said:

> “There’s no flagging system of my support needs when I check in at reception. If they had some system to flash up that I am visually impaired it would help a lot.”

**Healthwatch Birmingham** (draft report awaiting publication) carried out research to find out how prepared Trusts and Commissioners were for implementation of the AIS. One of the key findings was:

> “There is a considerable disparity in the interpretation of the requirements of the Accessible Information Standard across the main provider Trusts and Commissioners in the city.”
Only one of the Trusts that responded to Healthwatch Birmingham had shared a detailed assurance process plan so they can track if they are meeting the standards including recording and flagging people’s needs.

Healthwatch Bristol (December 2016) carried out follow-up work and found that one of the challenges with flagging records in hospital is that they receive patient records from GP practices that are not flagged in a way to indicate a person’s needs.

In one positive case Healthwatch Hampshire (March 2017) has worked together with their local voluntary sector, local council, and West Hampshire CCG to produce a ‘Communications Alert Card’. This card can be collected from local engagement events and allows people with special communication needs to alert service providers to their requirements. The holder of the card simply has to present it when booking an appointment and their needs will be flagged on their records. The card was designed because there was found to be a lack of consistency between GP and hospital appointments. People were fed up with having to keep explaining their needs multiple times. This concept is still in the early stages but it is being used in the local community. Healthwatch Hampshire will carry out an evaluation later this year but hope it will be rolled out to a wider area in the future.

Support

Healthwatch Lincolnshire (September 2015), carried out a survey involving over 300 people who are often under represented. This report included people with sensory and communication impairments.

One of the areas the survey explored was the level of social care and mental health support offered to those who received a sensory impairment diagnosis. Two thirds (67%) of those of who responded said they felt this was inadequate.

One individual reported that when she was diagnosed as being permanently blind she was told “go home and learn to live with it”.

Another respondent was told “Nothing more can be done so sorry and goodbye. We will need to take your driving licence away from you soon.”

Healthwatch Camden carried out work in June 2016 (just before the standard was due to be implemented) and looked at the access to GP services for people with communication support needs. They spoke to people with learning disabilities, visual impairment and hearing impairment.

“I don’t think they all understand what support people with a learning disability need.”

In November 2016, post-implementation, the daily feedback we received at Healthwatch England from local Healthwatch highlighted a number of experiences from visually impaired people. For example, Healthwatch Bromley heard that there was no support available to people when they needed to have worked done on their home, and that they felt very vulnerable. Healthwatch Somerset heard from one blind person who had recently been widowed who reported a long delay in getting support. In the interim, no support was made available to help with cooking at home.
Thank you

Thank you to everyone who has shared their experiences

Thanks also to the following local Healthwatch whose work has informed this document:

About us

We are the independent consumer champion for health and care. Our job is to make sure that those who run local health and care services understand and act on what really matters to people.

A local Healthwatch exists in every area of England. We support them to find out what people want from health and care services and to advocate for services that work for local communities. Local Healthwatch also act as our eyes and ears on the ground, telling us what people think about local health and social care services. We use the information the network shares with us and our statutory powers to ensure the voice of the public is strengthened and heard by those who design, commission, deliver and regulate health and care services.

Contact us.

Healthwatch England
National Customer Service Centre
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

www.healthwatch.co.uk
t: 03000 683 000
e: mailto:enquiries@healthwatch.co.uk
@HealthwatchE
facebook.com/HealthwatchE