

Accessible Information Standard Report

September 2022

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Introduction

The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. It simplifies the current laws and puts them all together in one piece of legislation. Also, it makes the law stronger in some areas. It was followed up in 2016 with the NHS Accessible Information Standard (DCB1605). The Standard aims to make sure that people who have a disability, impairment or sensory loss get information that they can access and understand, and that they get any communication support they need from health and care services. Since 1st August 2016, all organisations that provide NHS care and/or publicly-funded adult social care are legally required to follow the Accessible Information Standard, more commonly referred to as the NHS AIS. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

It means people with information needs can expect to contact and be contacted in accessible ways such as through email and text message. It also means that you should be supported at appointments, and information and correspondence should be provided in accessible ways. The Standard is far-reaching and applies to any condition which impairs an ability to communicate. Learning disability, acquired brain injury, Autism, Dementia, neurological conditions, strokes and mental health conditions can also be covered under the Standard, depending on an individual's circumstances.

In conjunction with Healthwatch Central Bedfordshire, we held a focus group to better understand experiences of the D/deaf community in accessing health and social care services. The *'Seen and Heard'* written report and BSL Exec Summary video highlight examples of negative experiences arising from key obligations of the Accessible Information Standard not being implemented.

NHS and social care organisations are expected to ask about communication needs and how these needs can be met. They are required by law to record those needs in a clear way, highlighting those needs in your files and are expected to act on them. Healthwatch England submitted Freedom of Information (FOI) requests to NHS Trusts in England asking them about how they do that. Healthwatch Bedford Borough then used the Trusts' responses in writing this report.

Methodology

Healthwatch England sent Freedom of Information (FOI) requests to all Trusts in England asking:

- How their patients are asked about their information needs
- How those information needs are recorded
- If there are barriers to compliance
- Do they carry out audits to assess compliance with the NHS Accessible Information Standard
- How many complaints they've had about not receiving information in an accessible format
- What is their annual spending on interpreting and translation

Healthwatch Bedford Borough used this information to look more closely at Trusts which care for Bedford Borough residents. We looked at the guidance on implementing the Accessible Information Standard. In particular, we highlighted the 'musts' or the obligations within the Implementation Guidance. When a Trust answered 'yes' to one of the Freedom of Information (FOI) questions, we then looked for supporting evidence and matched this against the obligations within the Standard.



Large Print



Braille



Easy Read



Email



British Sign Language



Audio



Our qualitative analysis of the findings concentrated on the following areas:

- Are individuals directly asked by staff about their information or communication support needs, on first contact but also in following appointments?
- Does the Trust make sure people can record their own communication needs and let them make changes?
- Does the Trust check the information they have is accurate, and how do they make sure it is reviewed?
- Do the Information Technology systems have ways of making the information 'highly visible'?
- Does the Trust actively seek consent for information to be passed on when there is a referral?
- Does the Trust actively seek consent for information to be passed to social care services at discharge?
- Does the Trust ensure that information is passed over on handover within the Trust?
- Does the Trust make sure that there are one or more communication methods that meet a person's needs?
- Does the Trust make sure that there are a number of accessible communication formats for people?
- How does the Trust ensure that standard format letters are not sent where they're not suitable for people with a disability, impairment or sensory loss?
- Does the Trust ensure that family members are only used as Interpreters when a person has explicitly asked for this, and if so, how is this recorded?

Our Findings

Asking about communication needs

The Freedom of Information (FOI) request put the question *'Does your Trust currently ask all patients whether they have any information or communication support needs?'* The Accessible Information Standard was intended to create a culture of proactively asking people their communication needs. Local charity organisations such as Access Bedford recognise that such a culture avoids communication breakdown. Such a breakdown can bring enormous worry for people with a disability, impairment or sensory loss and can result in missed appointments. Healthwatch Bedford Borough measured the answers against the implementation advice. We wanted to know whether they demonstrated their commitment to the Standard by asking people at their first interaction with the service but also on following interactions. (*Accessible Information Standard Implementation Guidance, Section 7.3 Methods for Identifying Needs*)

We found two hospitals did not meet the guidance as they relied solely upon information in the referral. They also said that they would act to meet communication needs if they were given information. This places all of the responsibility on the referrer which is usually a GP when the Accessible Information Standard is more of a 'belt and braces' approach giving multiple opportunities to ask the right questions. In fact, this response doesn't involve actively communicating with people at all. Our experience at Healthwatch Bedford Borough is that this is when communication breakdowns are most likely to happen.

We found two hospitals clearly met the guidance. One said **"The Trust's services are advised to request this information at referral, initial assessment or at the next review meeting."** This clearly gives people several opportunities to explain their needs. Another said **"Staff are requested to ask all patients whether they have any information or communication support needs and how we can meet those needs."** Healthwatch was pleased to see this improvement from a provider where we had previously questioned their reliance on referral forms. Other responses were unclear. Some responses said that patients can ask for different formats. However, this clearly places the responsibility on the patient to be proactive when the Standard expects this proactivity from the Trust. One Trust said that information is gained upon admission. However, it was not clear how this information was gained and what steps were taken to ask the person themselves directly.

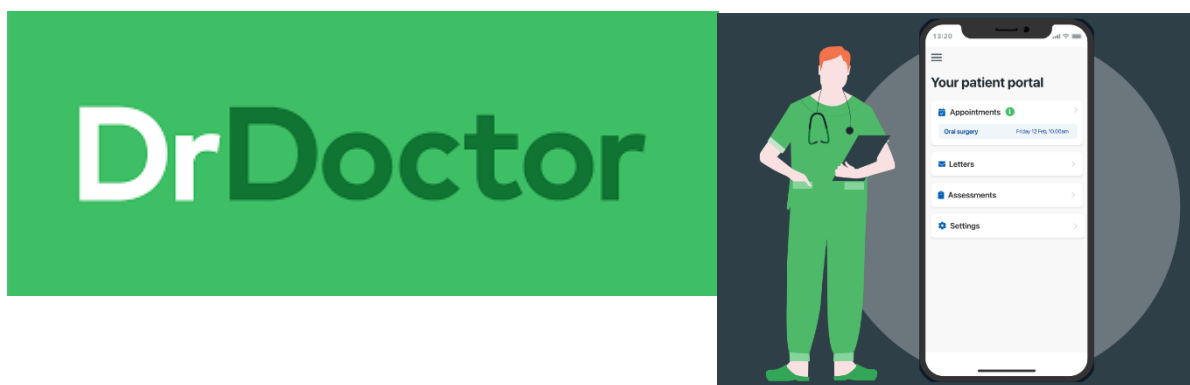
Recording own communication needs

The Implementation guidance for the Accessible Information Standard says that organisations **'should enable an individual to record their own communication and information needs'**.

SignHealth's report *'Review of the Accessible Information Standard'* highlights the possible consequences of communication breakdown including misdiagnosis, improper use of medication, mismanaged appointments, missed appointments, uninformed choice or consent, lack of confidentiality and disengaging from healthcare.

Clearly recording communication needs for oneself is the Gold Standard in terms of communication as it allows people themselves to state their needs without somebody else losing track of their meaning. By this we mean, that giving people the freedom to state their own needs is an experience against which other organisations would measure their performance.

In our report we did not find clear evidence of meeting this guidance. One Trust mentioned using the patient portal of **'DrDoctor'** but it was unclear what would happen for those patients with sensory needs.



Accuracy and Reviews

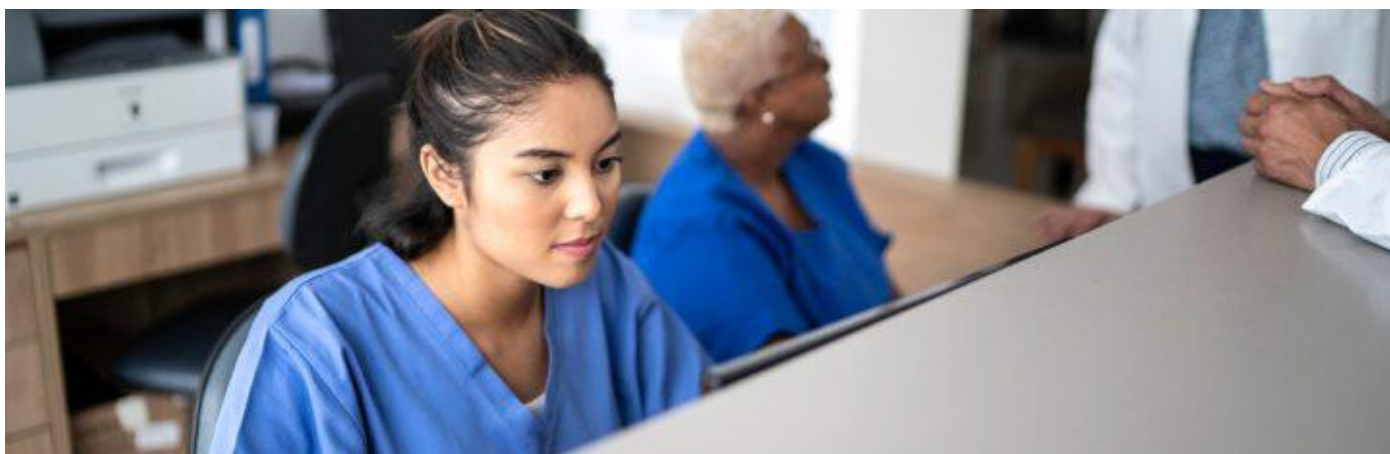
The Implementation Guidance for the Accessible Information Standard says that Trusts should have ways of checking the accuracy of the information that they have recorded and review it regularly. This is important as people's needs may have changed since their last appointment (for example their level of sensory loss may have changed) or meeting their needs may change over time. For instance, for some appointments, it may work to request information in large print but for other appointments a person may need a greater level of support.

We did not find any hospital Trusts which mentioned checking accuracy and reviewing the recorded information. Our experience at Healthwatch is that for those who receive a good standard of service from the NHS and social care services, they or a close relative have acted as an advocate for their own care. Again, this is putting the burden on the person with communication needs, whereas the Accessible Information Standard requires providers to check accuracy and have reviewing procedures.

‘Can’t miss it’ reminders on I.T systems

The Implementation Guidance for the Accessible Information Standard says that Trusts should not only have needs recorded but also have systems that make these notes **‘highly visible’**. Such ‘can’t miss it’ type reminders could take the form of pop-up alerts on patient management systems. With the Equality Act in place since 2010 and the Accessible Information Standard in place since 2016, hospitals have had more than enough time to implement this aspect of legislation.

We found that one Trust were not compliant. One Trust said that they were unable to flag-up any issues other than infection control issues within their patient management system and had no form of making notes highly visible. This means that staff need to read the notes of every person attending to check for communication needs. The hospital has developed a butterfly sticker system for people with Dementia within their paper records system. However overall, this has placed responsibility on people attending appointments in the hospital to remind staff. This clearly fails to meet both the letter and the intention of the Accessible Information Standard.



Another Trust gave details of how Clinicians could add notes but gave no information of how to make those notes visible.

For the remaining Trusts, compliance with this aspect was unclear with insufficient evidence given. One Trust had developed different colour flags for different communication needs such as learning disability. However, it was not clear whether these flags would be sufficiently visible for staff to notice them and whether the flags covered a full enough range of communication needs.

Another Trust had a flag system for Computer Aided Dispatch of ambulances. However, their policy was written before the Accessible Information Standard became law and focused on risks to staff. It's unclear how this system is implemented and whether this system covers a full range of communication needs.

Referral

For people living with multiple conditions, referral within the NHS is a common experience. The Healthwatch England report *'Your Care, Your Way'* notes the lack of flow between systems. Thus a referral may not include up-to-date information on what a person needs.

One Trust said that communication needs were a standard question for discharge paperwork. It wasn't clear what arrangements are in place for people who use British Sign Language (BSL) as their first language. In addition, the Trust gives the information that patients may not be able to give information on their communication needs in a face-to-face manner. This reliance on initial referral means that the information passed on may be out of date. For all other Trusts we recorded the response of unclear as insufficient information was given on how consent was gained, what information was gathered and whether people were consulted to update information if needed.

Discharge

Discharge has been a theme within our signposting service and a lack of understanding and communication were the most common explanations for poor responses. This was particularly distressing for people with elderly relatives who feared that a failure to record their relative's needs accurately would mean moving into a care home which could not meet their relative's care needs. One Trust said that the narrative or patient story should be included in the patient discharge

information. However, the hospital relied on primary care for information on communication needs and did not mention a system of reviewing information.

For the remaining Trusts we found compliance with the Information Standard in this respect was unclear.



Handover

None of the Trusts provided information on handover procedures. Thus, we found compliance with the Information Standard regarding handover was unclear.

One or more communication needs

Modern communication systems mean that people not covered by the remit of the Accessible Information Standard have several ways to communicate with Trusts. However, some of these methods such as reminder texts are not two-way which creates problems for people with communication needs who cannot use other communication methods to respond. This is a particular problem for people with sensory needs. For instance, people have explained that they have had problems cancelling or changing appointments as they are unable to use email or phone.

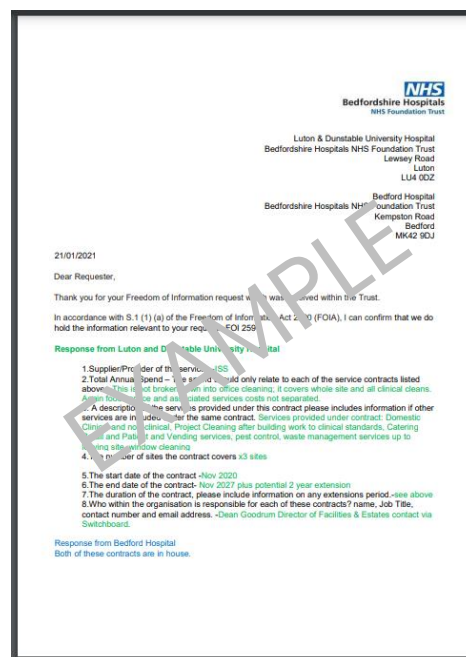
As none of the Trusts had carried out an audit of how the Accessible Information Standard is implemented, we did not receive any evidence on the number of communication methods available. We found compliance unclear for all Trusts.

Standard letters

The Sense Review of the Accessible Information Standard referred to the frustration of receiving standard letters when requests have already been produced letters in different formats. The Accessible Information Standard Implementation Guidance says that NHS organisations must not be sent where they are not suitable, or such letters are not in line with recorded needs.

As the Trusts involved had not carried out an audit of how the Standard is implemented, we do not have information available to us on compliance.

We found compliance in regard to written correspondence unclear for each Trust involved.



Using family members as Interpreters

Implementation Guidance on the Accessible Information Standard makes it clear that family members should only be used as Interpreters when this is an explicit preference for this and it conforms with the Standard as well as an individual's personal wishes. There should be a way of recording this and only when such a preference is recorded should family be invited to act as Interpreters.

Within the D/deaf community there are still reports of such requests being made by professionals without previously having been asked about their preferences.

As the Trusts involved had not carried out an audit of how the Accessible Information Standard is implemented, we do not have information available to us on compliance. We found compliance unclear for all Trusts involved.



Recommendations

- 1.** Our analysis showed none of the Trusts had carried out an audit in the last three years of how they were meeting their Accessible Information Standard legal obligations. We recommend that the BLMK ICB set out AIS requirements in all contracting arrangements. Contract monitoring arrangements should include a focus on AIS compliance within the Quality Improvement directorate. Providers should be asked to evidence their compliance with all aspects of the Accessible Information Standard.
- 2.** BLMK ICB should establish a lived experience panel representing the groups covered by the AIS to support a review of existing services and participate in ongoing review and monitoring of provision. The AIS Lead should support services to convene lived experience panels at neighbourhood level on an ad-hoc basis as part of quality improvement processes.
- 3.** Trusts mentioned that their I.T. systems did not allow them to highlight records in the way that the Standard requires. BLMK ICB should review AIS considerations and present recommendations on how to ensure that all digital systems support compliance with the AIS.
- 4.** The Standard recommends that people are empowered to write their own needs and review them. The Standard contains a link to information on patient portals. BLMK ICB should review portals and present recommendations on how these will empower people to record their own communication needs.
- 5.** Training on the Accessible Information Standard is seen as an add-on to Equality work. However, the Accessible Information Standard has its own administrative and technological components and so should be delivered separately by trained professionals. Training on Accessible Information should count as Continuing Professional Development (CPD) for all staff.
- 6.** Healthwatch England noted the response from the Ambulance Trust saying *'some other ambulance services have been much better at how they view their responsibilities under AIS (Accessible Information Standard).'* In common with other Trusts serving our area, East of England Ambulance Service NHS Trust have not carried out any audits in the last few years to assess their compliance against the Accessible Information Standard. We recommend that such an audit is carried out and that the Trust contacts other ambulance services to gauge what would be good practice within their service.

Next Steps

We have produced this report to draw attention to issues of inequality expressed through answers given to a Freedom of Information request. This report and its recommendations cover how local services could or ought to be improved. We will highlight this to the people that are responsible for the commissioning, providing, managing and scrutinising of local health and care services. The Commissioners and service providers are expected to respond to Healthwatch Bedford Borough within a period of no longer than 28 days. Their responses will explain what action they will take, or why they are not taking action. This report and its recommendations will also be shared with Healthwatch England, NHS England and the Care Quality Commission (CQC).





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