Accessible Information as Standard

Improving access to health and care for people with a sensory or learning disability.

Contents

This report brings together the findings of two separate projects that looked at the experiences of people who need accessible information when they use health or care services.

These started under Healthwatch Cambridgeshire and Healthwatch Peterborough, who combined on 1 April 2017 and now work together as one organisation.

Nothing smaller than 14 point

Key findings

Between October 2016 and the summer of 2017, our Healthwatch spoke to over 180 people about their experiences of getting accessible information when they used health or care services.

Overall, we found low levels of awareness about the Accessible Information Standard.

The themes that emerged from what people told us were similar in both areas and for most people.

Most people are getting some level of accessible information support. This is variable and even those getting some support are not getting all the support they need.

We found that it is likely that people are being given treatment without consent as they do not understand what they are consenting to. This is of great concern.

Staff attitudes are mostly positive towards providing accessible information. However, frontline NHS and care staff would benefit from training in disability awareness and their responsibilities under the Accessible Information Standard.

Communication between NHS providers could be better to make sure people's needs are recorded and shared.

You should have accessible information as standard.

That's the law!

About the Accessible Information Standard

The Accessible Information Standard came into effect from 1 August 2016. Minor changes were made in August 2017, after a review by NHS England.

Organisations that provide publicly-funded care and health services need to provide information in a way that people with a sensory or learning disability can understand.

They must also provide communication support where necessary, for example, a British Sign Language (BSL) interpreter.

Organisations must do these five things

1. Ask you if you have any information or communication needs and find out how to meet your needs.

2. Record your needs clearly and in a set way.

3. Highlight or flag your file or notes so it is clear you have information or communication needs, and how to meet those needs.

4. Share information about your information and communication needs with other providers of NHS and adult social care. They will need your consent to do this.

5. Take steps to make sure that you get information which you can access and understand, and get communication support if you need it.

The Standard applies to patients and carers who need this support.

Why we looked at this

People told our Healthwatch that they were not always getting information in a way they could understand, or the communication support they needed. This meant they could not always understand what health or social care staff said to them. As a result, they may not be able to manage and make informed decisions about their own care or treatment.

What we did

As the projects started when we were two separate organisations, there are key differences in what we did in each area.

Healthwatch Cambridgeshire looked at the impact on people with a hearing loss and those who identified themselves as Deaf.

Healthwatch Peterborough looked at a wider group of people. This included people with a visual impairment, a hearing loss, people who are Deafblind and people with a learning disability.

Both Healthwatch used a broadly similar survey, working with local voluntary sector organisations to gather people's experiences.

Healthwatch Peterborough also carried out a '15 Steps Challenge' assessment at Peterborough City Hospital and an observational visit at the hospital. They also visited nine local groups to find out about people's experiences.

Healthwatch Cambridgeshire attended several drop-ins run by Cambridgeshire Hearing Help, and two events organised by Cambridgeshire Deaf Association (CDA). CDA also arranged a further event in Peterborough.

Healthwatch Cambridgeshire looked at all of the available websites for Cambridgeshire GP practices to see what information there was about the Accessible Information Standard.

What people told us

People highly value accessible information when it is given to them.

The most popular resource needed in Peterborough was someone to speak up for the person. This is mostly provided by family members and support workers rather than a professional advocate*.

People with a hearing loss in Cambridgeshire were often accompanied to appointments by a family member or friend.

The second most popular resource requirement in Peterborough was for a qualified British Sign Language (BSL) interpreter. There was some evidence that family members are used as interpreters.

In Cambridgeshire, there is still pressure on family members to act as interpreters for d\Deaf** people, either for routine or emergency appointments.

Telephone calls, texts and emails to patients have improved communication about appointment dates and reminders. However, not being able to text back causes problems for people who cannot use a telephone or want to check that a BSL interpreter or advocate has been booked for them.

The lowest level of provision was identified within GP practices.

There was also mixed information on GP websites. In Cambridgeshire, just under a third of GP websites had no information about the Accessible Information Standard, nor any sort of accessibility provision.

Several people in Cambridgeshire told us that hearing aids improved their quality of life.

d/Deaf** people frequently said they felt that they were treated less well than people without a hearing loss.

* We use the term 'professional advocate' to distinguish from support given by friends and families.

** People in the deaf community often use d/Deaf to differentiate between those who are deaf (who are hard of hearing) and Deaf (sign language users).

From people who need a hearing loop

'I do ask a lot questions and ad lib - sometimes I get things wrong but I am getting better.'

'My husband can't hear things very well even with his hearing aids he misses things, I always go with him.'

From people who need an Easy Read format

'I don't like it if I can't read things for myself. My dentist and optician phone me when I have an appointment.'

'I get frustrated when communication doesn't work. Easy read format and an advocate would help as I don't get to know people properly.'

From people who need a professional advocate or someone to speak up for them

'I have a learning disability and require text messages, easy read and an advocate. I get an advocate from the Volunteer Centre, I find this very useful, it kept me calm when I had to have an injection, I can't always understand things. I get phone calls from the hospital when I need an appointment.'

'My son acts as my advocate and reads my letters for me.

From people who need large print
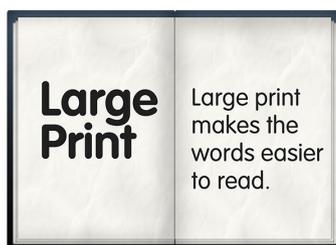
'It is a relief to be able to read things for myself otherwise my daughter has to read this information for me.'

From people who need a BSL interpreter

'I have had to wait longer for appointments until a BSL interpreter can do my appointment. Having an interpreter explaining results has helped me.'

'...at A&E I have problems as they don't have interpreters. I know they can phone and I will have to wait two or three hours. A nurse will come and I will say, sorry I cannot. So then, I have to try and write for the doctor. It is hard to read, I cannot lip read very well. It makes it hard.'

'In the last bit (of the letter), it will say about parking and it does say that if you have communication needs to phone them to let them know. So, because we are deaf, we cannot phone.'

'(I) don't understand the doctor. I cannot lip read. Really important to have interpreter and this makes me really angry. This is difficult.''You get a text about an appointment but you cannot text back on the same number.'

Communicate

'Two months ago, I asked a dentist receptionist to book an interpreter but they said no because there was nobody to pay for it.'

Choice

What needs to change

Healthwatch Cambridgeshire and Peterborough recommend that:

1. Staff working for services who provide health and care understand what the Accessible Information Standard is and how it applies to what they do. This could include services changing procedures and giving training.

2. Services providing health and care have clear guidelines and procedures for booking qualified interpreters or other communication support. Consideration should be given to commissioning an on-call service for qualified BSL interpreters.

3. Services providing health and care make sure they can provide evidence that 'informed consent' has been given by patients.

4. Services providing health and care make sure patients can communicate with them in an accessible way, for example, being able to reply to appointment text reminders to check that communication support has been booked.

5. Where there are fixed or portable hearing loops in health and care premises, they work. There should be staff available who know how to use them.

6. Services providing health and care (such as GPs) update their websites with clear information about the Accessible Information Standard. This could be a role for Patient Participation Groups and hospital Patient Experience Groups.

7. Commissioners check that health and care services they commission are carrying out their duties under the Accessible Information Standard. This should be contained within any contract or Service Level Agreement.

8. Services providing health and care consider how they assess their implementation of the Accessible Information Standard as part of their internal monitoring processes.

What we will do to monitor and support improvements

We will continue to ask people with information and communication support needs about their experiences of health and care services.

We will support local health and care service providers to set up a monitoring process that looks at how the Accessible Information Standard is being implemented.

We will contact the GP practices where there is currently no information on the practice website about the Accessible Information Standard and ask them to review and update their website.

We will ask the Clinical Commissioning Group, Peterborough City Council and Cambridgeshire County Council how they monitor the relevant service contracts.

We will follow up the 15 Steps Challenge at Peterborough City Hospital that included the Accessible Information Standard check, and report back on the findings.

We will look at how the Accessible Information Standard can be included in our Enter and View Programme.

Thank you

We want to thank all the people who shared their experiences of using health and care services with us, and the organisations who supported this project.

In particular, we want to thank Cambridgeshire Deaf Association, Cambridgeshire Hearing Help, Inspire Peterborough, DeafBlind UK, Peterborough Association for the Blind, Family Voice, Turning Point, The Helping Hands group, and Goldhay Arts.

This report is available in other formats, including large print, BSL and Easy Read.

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