

healthwatch Peterborough





Accessible Information as Standard Background Information: Cambridgeshire



Improving access to health and care people who are Deaf or hearing impaired



Contents

Key findings	3
Why the Accessible Information Standard is important	3
What we did	4
What people told us	5
Thank you 1	12

Healthwatch Cambridgeshire and Peterborough* is an independent 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.

We listen to what people like about services and what could be improved.

We share what people tell us with those with the power to make change happen. We encourage services to involve people in decisions that affect them. We also help people find the information they need about services in their area.

Key findings

- ✓ Many people with hearing loss rely on family members or friends accompanying them to appointments.
- ✓ A number of people told us that hearing aids had improved their quality
 of life.
- ✓ There is still pressure on family members to come along to interpret for Deaf people, either for routine or emergency appointments
- ✓ It is likely that patients are being treated without consent, as they do not understand what they are consenting to. This is of great concern.
- ✓ D/deaf people frequently said they felt that they were treated less well than people without hearing loss.
- ✓ There are varying levels of information for patients about the Accessible Information Standard on GP websites.

Why the Accessible Information Standard is important

NHS England's Accessible Information Standard gives disabled people who need information in particular formats or help with communication support the right to have this provided when accessing NHS health services and publically-funded care services. It came into force on 1 August 2016.

If people cannot get information in a way they can understand, it is much harder for them to understand their health condition, or take medication as they should, or manage their care

Patients had previously told us of situations when family members had to read out letters with details of test results.

We also heard about people missing important information about their condition and treatment because they were trying to lip-read and staff would not look at them.

Another Deaf patient told us that when they asked to have email communication they were told their partner (who was hearing) had to phone to make an appointment for them.



We also heard from a professional advocate (note 1), who said 'I know that when I went to see a client, the information was very basic, but the hearing people got lots of information.'

One Deaf person told us, 'When you arrive and there is no interpreter, nobody lets me know but they let the hearing people know. They should send a message to say it is cancelled, maybe a text message.'

What we did

We decided to look at how different groups of people were affected by the introduction of the Accessible Information Standard. The group we looked at for this report were people who identify as d/Deaf (note 2) or who have hearing loss.

We chose this group for several reasons:

- ✓ We had previously heard stories from people who struggled to understand because staff did not know how to communicate with them.
- ✓ We had established relationships with key local organisations Cambridgeshire Hearing Help (CHH) and Cambridgeshire Deaf Association (CDA).
- ✓ The 'Sick of it' report (note 3) published by SignHealth in 2014 highlighted problems in accessing British Sign Language (BSL) interpreters, and we wanted to see if improvements had occurred.

We spoke to Cambridgeshire Hearing Help about their drop-ins. They run many drop-in sessions across Cambridgeshire. Here, people can have NHS hearing aid maintenance - such as new batteries and re-tubing. They can also get information and advice.

Note 1: We use the term 'professional advocate' to distinguish from support given by friends and families

Note 2: The term D/deaf is used to describe people who are 'Deaf' (sign language users) and deaf (who are hard of hearing but who have English as their first language and may lipread and/or use hearing aids).

Note 3: http://www.signhealth.org.uk/health-information/sick-of-it-report/sick-of-it-in-english/



In total 117 surveys were completed, most with support from Healthwatch staff and volunteers.

We decided to visit a relatively small number of these in person to speak with patients and carers. This was due to guidance from CHH, and staff and volunteer capacity. We also met with CDA and they arranged meetings in Cambridge and Huntingdon. British Sign Language (BSL) interpreters were booked to enable people to communicate effectively.



We only spoke to a small number of people at these meetings, but we heard similar experiences and issues.

We also looked at 63 Cambridgeshire GP websites to see what information they had about the Accessible Information Standard.

What people told us

People with hearing loss

Very few people seem to have been asked about their preferred format for information, and if they needed communication support.

Conversely, most people reported that they did get the information or support they needed. However, many people told us they 'always' took a family member or friend with them to help them understand what was being said.

People with hearing loss told us that they will respond positively to being asked what is helpful, e.g. eg where should I stand?

People using the community audiology service (provided by Specsavers) were unhappy that the only contact method for appointments was a central call centre.

Some people commented that they did not think the hearing loops worked or were effective (for example in GP practices).

Support with using aids

The Hearing Help sessions were picking up quality issues in the fitting of hearing aids.

There was a lack of information given to patients about use and care of hearing aids when they are first fitted.

Deaf people

Information format and communication support.

GP receptionists did not always seem to be aware of their responsibilities in booking BSL interpreters.

CDA had devised yellow cards explaining the basic facts about the Accessible Information Standard, but some receptionists reportedly handed them straight back to the patient.



Cambridgeshire Deaf Association Deaf Card

Patients attending the Emergency Department (A&E) had a poorer experience than people without hearing loss. Patients often had a significantly longer wait, due to waiting for an interpreter.

One patient told us:

'I was scared to leave the waiting area to get any food or drink in case I missed the interpreter arriving'.

This patient waited over 5 hours for an interpreter. Another person told us,

"...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."

Some Deaf people told us they had a SignHealth app on their phone, but were not allowed to use the hospital wi-fi. This meant a longer wait for an interpreter to arrive.



There can be pressure for hearing family or friends to come and translate:

'They told me I had to come immediately as my partner was in A&E'

Health and social care staff sometimes expect Deaf advocates to both interpret and represent their clients which is not their role.

It is particularly difficult for people who are in-patients if there is no interpreter.

'I was in (name of hospital) for nine weeks. Have a cochlear implant trying to listen. But no interpreter. The nurse would do simple gesture, like are you alright. I just had to say, please can I go home, I just want to go home.'

'That has happened to me about a month ago, lots of waiting, doctor explained without an interpreter. Thought that I was going home, but then I had to wait until four o'clock. When I got home and got my bag, I thought what is all this about? It wasn't clear. I didn't know what to do with it.'

There can be a lack of continuity of care in in-patient settings due to frequent staff changes:

'Shift changes, you establish a relationship with someone and then they have gone.'

Understanding information

Changes in medication present a real risk to Deaf patients if they do not understand how to take it. CDA told us about a person who was recently re-admitted to hospital seriously ill just a few days after discharge. This was because they did not understand the instructions for taking their medication.

Writing information in plain English will help many patients, not just those for whom English is a second language. People who have BSL as their first language can struggle with written English.

'Sometimes they write things down but I don't always understand this, it is too hard.'



Staff need to understand lip reading is not a precise art. Some people told us if was more difficult to lip-read staff who do not have English as their first language. Not all Deaf people can lip read.

One patient told us:

'(I) don't understand the doctor. I cannot lip read. Really important to have interpreter and this makes me really angry. This is difficult.'

Appointments

Appointment letters have contact details to alert hospital of access needs, this is an improvement. However, patients said they often do not receive a response to their email, so until they arrive they do not know if an interpreter will be present.

Some letters still ask Deaf people to telephone:

'In the last bit, 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.'

'Transport issues - now have to phone a number to book hospital transport. Deaf people cannot.'

Health care providers can be reluctant to book interpreters for short appointments.

Text reminders for appointments are helpful, but patients wanted to be able to text back to cancel an appointment or to check that an interpreter had been booked.

'You get a text about an appointment but you cannot text back on the same number.'

Dentists

A few people had seen some improvements in provision, one commented that a family member had a BSL interpreter booked by their dental practice for the first time in 30 years.

We also heard about dentists who removed their masks to enable patients to lip-read.



In some cases, the communication support needed was clearly recorded:

'I have been to the dentist at (name of practice) and I have had an interpreter, and it has been finished and will do it on the computer to book another appointment and also book an interpreter.'

However, some dentists are clearly not aware of their responsibilities:

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

'Never had an interpreter at the dentist.'

In several cases, patients relied on CDA staff to help make the arrangements:

'When I went, I gave them my yellow card, I filled in the form. There was an interpreter there. Matt phoned the dentist to arrange this beforehand.'

Positive stories

We heard about the difference an interpreter can make:

'With an interpreter, I get the full information and can understand and make sure that it is the right tablet and stuff.'

Provider information

GPs are key to accessing other health services, so we looked at what information Cambridgeshire GP practices had on their websites about the Accessible Information Standard.

We first looked at the sites in February 2017, and again in June 2017. We chose this indirect approach due to the number of practices involved. We thought that by seeing what information there was, we could gain an indication of how aware they were of the standard.

This approach identified a number of themes.

✓ Where there was information on GP websites about the Accessible
Information Standard, it was not always easy to find. Several websites
called it 'Accessibility Information'.



- ✓ Some combined it with information on how to change the appearance of the website, e.g. changing font sizes. Quite a few added it to the section which described physical access such as disabled parking availability and ramps. One surgery had good information but it was in a tab on the footer named 'Accessibility'.
- ✓ It was implied that it was the patient's responsibility to tell the surgery if they needed information in a particular format or communication support. However, the Accessibility Information Standard states that patients should be directly asked about their needs. Not all patients will have access to the website or will easily find the information.

Disappointingly, out of the 63 websites we looked at, only 11 made specific reference to the Accessible Information Standard. 20 had no information about any type of accessibility.

The remainder had some information but mostly about physical access, such as parking and ramps or lifts. Most also had information about hearing loop provision. However, several of our survey responses indicated that hearing loops were not working.

There were some examples of good practice. Some practices explained what the Standard meant, for example, a few of the websites had a section which said:

'We want to get better at communicating with our patients. We want to make sure you can read and understand the information we send you. If you find it hard to read our letters or if you need someone to support you at appointments, please let us know.

We want to know if you need information in braille, large print or easy read. We want to know if you need a British Sign Language interpreter or an advocate.

We want to know if we can support you to lipread or use a hearing aid or communication tool.'

Other practices tried to find better titles for their section on accessible information, such as 'Clearer information for patients'.



Lessons for us

Whilst doing this study we have also taken on board that we need to improve how easy we make it for people to communicate with us. We are currently investigating how we can make our services more accessible.

Recommendations and future actions

Our recommendations will be published as part of a joint summary report. This will pull together recommendations from this work and from a similar project undertaken in Peterborough. These two projects were designed and started before Healthwatch Cambridgeshire and Healthwatch Peterborough merged on 1 April 2017.

Thank you

Thank you to all the staff and volunteers from Cambridgeshire Hearing Help and Cambridgeshire Deaf Association for their interest, time and help with this project.

Thank you too to all the people who shared their experiences or completed the survey.

Thanks to Lizzie, our Research Volunteer for her assistance.



Let us know if you would like to get this information in a different way.

This background information is published by Healthwatch Cambridgeshire and Peterborough CIC who retain the copyright. Healthwatch Cambridgeshire and Peterborough is using the Healthwatch mark under license from Healthwatch England. You can read and share this report free of charge.

You can get a free copy from our website or by contacting our office. Healthwatch Cambridgeshire and Peterborough is a Registered Community Interest Company No. 08516179.

Registered office: The Maple Centre, 6 Oak Drive, Huntingdon, PE29 7HN. (© Healthwatch Cambridgeshire and Peterborough, 2017)



healthwetch

Cambridgeshire

Phone: 0330 355 1285 (local call rate number)

Email: enquiries@healthwatchcambridgeshire.co.uk

Website: www.healthwatchcambridgeshire.co.uk

healthwetch

Peterborough

Phone: 0330 355 1285

Email: info@healthwatchpeterborough.co.uk Website: www.healthwatchpeterborough.co.uk

