

## Accessible Information report summary

“Ask me what helps me and do something about it.”

The Accessible Information Standard (AIS) was introduced in August 2016. It is a legal requirement to provide information in the format that someone needs. The AIS applies to all organisations that provide NHS care and / or publicly-funded adult social care. 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’.

Healthwatch North Yorkshire and Healthwatch York have worked together to understand if the AIS has made any difference in how people receive information. North Yorkshire County Council supported us in speaking to forums and groups with whom they engage, and is undertaking its own internal project to ensure good practice in accessible information is embedded within the organisation and it is providing information in appropriate formats to local people.

Through surveys, focus groups and conversations, we heard from more than 300 people who shared their experiences of getting information in a format they can access and understand from a wide range of organisations, including health and social care organisations, colleges and workplaces. We found some examples of good practice but too often people aren't getting information in the right format to meet their needs. Two thirds of survey respondents said they had never been asked what format they needed.

The feedback we received fell into a number of themes:

### **I want to be independent**

Many people felt robbed of their independence as a result of not getting health and care information in a way they could read themselves. Many organisations send information in a standard letter format. These often only offer a phone number for queries, to change appointments or to carry out phone appointments with a GP or consultant.

However, some people with sight loss, a learning difficulty or other conditions cannot access or understand a standard print letter and rely on others to read it out to them. Similarly, some people who are D/deaf, people who are neurodiverse, or have speech issues cannot use the phone. With no other option to contact services, they have to rely on someone else to have conversations on their behalf.

We all have rights in health and care. Most of us take for granted that we are the first people to know the news about personal health or care issues. This is not the case for many people who need information in a different format.

## **Inaccessible information makes me feel: frustrated, sad and angry**

We asked people how they feel when they don't get information in their chosen format.

The overwhelming response was to say frustrated, followed by sad, angry and annoyed. Some people said they felt ignored, belittled and discounted and a few people were resigned to the fact of never getting information in the way they want it.

The feedback is a powerful challenge for organisations to do better.



## **Listen and respond**

It is vital that organisations ask people what they need, and as the title of our report states, that this leads to action. Many of the organisations we asked said they do ask people and note their needs in some way. However, our feedback shows, if this is happening it isn't always consistent or followed up.

We heard from people who know their medical notes include information about not phoning them up, yet the default is still for them to get a phone call or be told to phone up. Others said that they don't look at text messages, but appointment updates are sent by text, which they can't access.

Our respondents were also clear that assumptions only lead to problems. Not every person with a particular condition wants information in the same way. Some people are keen on using technology, others aren't. Everyone needs to be asked.

## **It's not just about format, it's about the whole experience**

The wording of any document is important. You can't just add images to a document to make it Easy Read. Wording needs to be in Plain English and easy to understand. In reality, Plain English is appreciated by everyone.

We heard that screen readers used by people with sight loss can't always read a pdf document. So it is important to make sure information sent can be accessed by any technology someone uses. So, Word or plain text documents should be the default with an explanation given for any images or charts.

It is not just about sending information. Services need to be accessible and take into account someone's needs when they attend an appointment. There is no point asking someone with sight loss to respond to visual information or someone who is D/deaf to hear when their name is called out. Accessible information extends to providing BSL (British Sign Language) interpreters when people need them, having information in Easy Read formats and having the skilled staff to talk to all people and make sure they understand what is being said in any health or care environment.

## **Learning from good practice**

We did find some examples of good practice and heard that a quarter of our survey respondents felt things had improved in the past six years since the AIS was introduced.

It is important that organisations work together and work across departments to learn from each other and better support people using their services. Each organisation will face similar challenges, so it makes sense to share ideas and possible solutions.

## **Get experts involved to find solutions**

Many of the people we heard from want to help organisations improve things. They have the experience and they want solutions. So it is vital that every organisation listens to and involves people with lived experience in developing and delivering action plans that lead to improvements. The best people to help shape health and care services are those using them.

## **Principles**

From the many personal experiences that people have shared with us we would encourage all health and social care organisations to take on board the principles below. If these are followed, we are confident that if we ask people in another six years, they will be getting information in the right format and they will feel positive, independent and empowered.

- Ask what helps and do something about it. Put the user first.
- Make Accessible Information an organisational priority from the top down and ensure everyone knows why it is important. Have understanding, committed staff championing this at all levels.
- Ensure that you ask people about their information and communication needs. Record this and use it to provide information in a person's preferred format. There is no point in having a flag on a record which is ignored.
- Once identified, share people's information needs within organisations. Information about people's needs should only be recorded once for people to get the right format from all parts of that organisation.
- Involve people with lived experience to help find pragmatic answers.

- Provide choice. Don't assume that everyone with a particular issue needs information in the same format or that everything is accessible. Digital is not the solution for everyone.
- Each organisation should have one contact/team who works across that organisation to find solutions to accessible information needs quickly and effectively.
- Seek and share good practice. Providing information in accessible formats isn't always easy, but lots of organisations are trying. Share progress and challenges so that things are constantly improving.
- Review what you're doing to make sure it is working and learn from what is and isn't going well.

Thank you to everyone who worked with us on this project, responded to our survey or attended one of our focus groups and contributed feedback.

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