healthwatch

 Stoke-on-Trent

**An Insight Report: Access to Healthcare for People in Stoke-on-Trent Living with a Visual Impairment**

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# **Background**

Healthwatch Stoke-on-Trent is the city’s independent health and social care champion. We are here to listen to the experiences of local people using local health and care services and about the issues that matter to the people of Stoke-on-Trent.

**Accessible Information Standard**

The Accessible Information Standard was published by NHS England, following approval as a new ‘information standard’ for the NHS and adult social care system, in July 2015. Officially called DCB1605 Accessible Information (and formerly SCCI1605 Accessible Information), the Accessible Information Standard (‘the Standard’) directs and defines a specific, consistent approach to identifying, recording, flagging, sharing, and meeting individuals’ information and communication support needs, where those needs relate to a disability, impairment, or sensory loss. By law (section 250 of the Health and Social Care Act 2012), from 1st August 2016 onwards, all organisations that provide NHS care and/or publicly funded adult social care must follow the Standard in full. Organisations that commission NHS care and/or publicly funded adult social care, for example Clinical Commissioning Groups (CCGs) and local authorities, must also support implementation of the Standard by provider organisations.

The Accessible information standard is made up of 5 principles:

1. Ask - Find out if a person has any communication or information needs because of a disability or sensory loss and if so, what they are.
2. Record - Record those needs in a straightforward way that everyone agrees with. This could be done on a computer or on paper.
3. Highlight - Make sure that a person’s needs stand out whenever their records are checked. This means something can be done straight away.
4. Share - Include information about a person’s needs as part of data sharing and make sure it is in line with other information you have.
5. Act - Make sure that people get information which they can access and understand and get communication support if they need it.

Throughout January to March 2017, NHS England led a post-implementation review of the Standard, with the aim of assessing its impact and ensuring that it is and continues to be ‘fit for purpose’. The key themes which emerged as part of review were:

* There is widespread support for the overarching aims of the Standard, and for the Standard itself, although some organisations have concerns about costs.
* Patients, service users, carers and parents are clear that receiving accessible information and communication support is essential if they are to receive safe, high-quality care, to maintain their privacy and dignity, and to be involved in decisions about their care and treatment.
* Implementation of / compliance with the Standard is variable both across and within organisations, with particular (but differing) challenges identified by both large and small organisations of all types.

The most commonly raised implementation challenges relate to difficulty in adjusting electronic patient record systems (specifically as regards to recording and flagging of needs, and producing alternative formats), lack of awareness / the need for improved communications about the Standard and competing demands on staff time.

According to Staffordshire Sight Loss Association website, there are 16,020 people living with sight loss in North Staffordshire and this figure is expected to rise to 19,070 by 2030. We contacted the organisation to find out about the experiences of people living in Stoke on Trent with sight loss accessing services.

**Initial Contact**

In 2022 we visited Staffordshire Sight Loss Association (SSLA) to talk about the role of Healthwatch as a local health and care champion supporting individuals and groups to have their voice heard by decision makers involved in providing health and social care services and to use feedback to improve care and services. At the initial introductory meeting we heard from people who indicated to us some of the difficulties they encountered accessing health and social care services and told us of some of the main barriers they faced. As a result of this meeting, we decided to look further at the issues people with sight loss face when accessing services in Stoke on Trent and decided initially to focus on accessibility of the Ophthalmic outpatient services based in University Hospital North Midlands (UHNM).

**What we did**

In September 2023, we facilitated a focus group to seek their views on their experiences of accessing services. We engaged with nine members of the community. This was a face-to-face focus group session led by a member of the Healthwatch Stoke-on-Trent team.

We also arranged an observational visit to the eye clinic at The Royal Stoke University Hospital to find out more about the experience of somebody with sight loss attending local services.

# **Our Findings**

**Focus Group with Staffordshire Sight Loss Association (SSLA)**

**Information and Support**

Whilst everyone’s story of how they lost their sight was different, the common theme that everyone expressed was that once it had happened there was no help, support or guidance provided unless you go out of your way to find it yourself. People told us that when meeting with a consultant to get a diagnosis, it is no more than a diagnosis. All the group felt that they were left in limbo and expected to ‘just get on with it’ as best they could and find out for themselves what was out there in terms of help.

“Unless you ask the consultants, and I’ve seen hundreds of them, they don’t tell you anything. Take being registered for example – you've got to ask them if you’re eligible to be registered blind or partially-sighted. They’re not forthcoming at all.” – Member of SSLA.

One person shared with us that at one appointment, a consultant had informed them of the help desk and offered to take them there. However, due to the timing of the appointment, the help desk was closed.

People told us that when referrals are made on their behalf to other services, due to waiting lists and the lack of a clear pathway, people who are newly diagnosed are still left for some time without professional support or knowledge of what is happening. During this time, they are heavily reliant on others to help them in regain their independence. This can lead to strong feelings of helplessness.

“The consultant was lovely and was giving me the information, they had got but to me it was more of a form filling exercise. I felt they wanted to get the form done and get me out of the room as quickly as possible.” – Member of SSLA.

**Treatment**

A theme that emerged from the focus group was that people are generally treated the same way when attending the eye clinic whatever the condition and the cause of the impairment. They reported that they tended to go through the same routine eye tests reading the eye charts even those who had no sight left at all and people described this as being futile and humiliating. People described feeling like they were being treated as all the same and not as an individual with potentially different needs requiring different solutions.

“It’s as if the eye clinic had never met anyone with sight problems before.” – Member of SSLA.

**Accessibility**

The fifth principle of the NHS accessible information standard states that organisations should make sure that people get information which they can access and understand and get communication support if they need it. Through this focus group we heard that people attending the eye clinics were generally happy that their accessible information needs are being met via large print letters, people who require their information in braille said their needs were not being met. An individual had shared that any correspondence in braille coming from the NHS was squashed and illegible, however in comparison their bank has sent letter in braille without issue.

**Confidentiality and Independence**

Most of the people attending the focus group felt that NHS staff make an assumption that they will have family or friends who will step in and meet their needs to get to appointments, read letters, etc. Therefore, help is not often offered or enquired about. This again can feel very disempowering to people who do not have support available and takes away confidentiality and independence when they are forced to call upon friends or family to attend appointment with them.

“At the moment, I’ve got no faith in the NHS whatsoever.” – Member of SSLA.

**Observation Visit to University Hospitals of North Midlands NHS Trust (UHNM) Eye Clinic**

The second part of this work included an observational visit to the eye clinic at UHNM on the 30th November 2023. We had planned to carry out an observational visit with 2 people involved with Staffordshire Sight Loss Association. However, this visit had to be aborted due to issues of parking at UHNM having spent over 1 hour looking for parking. The visit was therefore carried out by Healthwatch Stoke-on-Trent staff over a 3-hour period.

**Access**

The Ophthalmology department is located on the ground floor of the main building in UHNM. Upon entry into the main building the enquiry desk is on the far left-hand side having moved from a more central point straight ahead of the entrance and is not so evident, especially if you have a visual impairment. There are volunteers based at the main desk to help guide people to the correct location, but no one was around at the time we visited so this would not have been evident. On our initial visit to the clinic, we attended the desk to ask for directions to the eye clinic but were not asked if we needed assistance and none was obviously available as we were directed to the clinic by pointing out the direction.

There are central digital check-in desks which provides people with visual problems the option of a large print facility for checking in. The signage guiding people to ward is above, high up on the wall, which according to the helpdesk is suitable for those who are visually impaired. The signage to the eye clinics is on a yellow background with black text, which is more accessible to those with visual impairments. However, signs to all other departments are, in most cases, white text on grey background so finding your way anywhere else in the hospital could be difficult. The assumption seems to be that if you are visually impaired, you only need to visit the eye clinic, or that those who are visually impaired have other means to access anywhere else, as alone it would be difficult.

Within the clinic itself signage is not always clear, as we found when we were left to wander from area to area unescorted. Patients were often sent to different seating areas after one part of their appointment procedure was completed but didn’t always understand terminology like ‘sub wait 5’. Some patients told us when asked what they were waiting for next were unsure saying that they were just told to go and wait there. A patient with severe sight impairment would be likely to struggle if they were unescorted trying to find their way around the 3 different waiting areas.

**Information**

The information displayed on the notice boards in each waiting area was clear and mostly in a user-friendly format. It was from observations all in English with no indication that it was available in other formats. Braille is not offered as an option but can be made available if a patient asks for it. As brought to our attention through the focus groups, there are some practical problems with providing information in braille due to the postal systems use of rollers which flattens the braille, but this is overcome in other sectors such as banking so it should be available through the NHS. Most patients told us that they received information and appointments by letter. For most this is not a problem as the hospital generally send out letters in the format requested. The hospital work with a 3rd part organisation who print off all letters in the format requested and most people said that this was fine, if they couldn’t read it themselves they would get family to read it for them, we did not meet anyone in clinic who had no sight so couldn’t gauge how they would manage if they needed alternative forms of information.

Information about the diagnosis and treatment and support available was not always given to people at the time and it appeared a bit hit and miss as to whether people got any information at all, and people were not all clear about where they should go for help. There was no clear pathway in place that ensured patients received information and support they needed to maintain and enhance independence. The most obvious place to direct patients seemed to be through the help desk and some patients are referred to them as a matter of course but others are not, and it is at the discretion of individual consultants and staff as to whether they think it is necessary and appropriate. A couple of people in the waiting room talked about issues around finances and knowing what help they could get because of not being able to work again and transport was raised as a concern which they would have liked help with. We were told by the helpdesk staff that telephone numbers are available but are not always given out to patients and it is often the consultant or other medical staff who makes the decision as to whether it is appropriate to tell patients depending upon their condition rather it seemed than personal circumstances.

**Communication**

Feedback to patients on progress of their condition was an issue that was raised several times by people we met in the waiting areas and from the group discussion. People reported that there were problems with communication upon and following diagnosis. Most people were happy with the format of the written information received but the level of information and support received following diagnosis was seen as requiring improvement. People in the waiting areas reported that information about their treatment and their progress was not good. One patient told us that they had asked the medical practitioner at the macular clinic how their treatment was progressing and were told that they would receive a response by letter but that this was never forthcoming, and they have never been given an answer even though they ask the same question at each appointment. The issue of certification and registration was also raised as an issue in which communication was not always clear and forthcoming.

Participants also suggested that the communication between services was not great and that the transition from diagnosis, to signposting, to support services was not consistent and led to lengthy delays for some in accessing the support they required. People reported that it would be helpful to have a clear pathway in place between diagnosis and support so that it wasn’t just left to the individual to search around and chase people to get the support they need.

Patients we spoke to in the waiting areas told us they would appreciate being communicated with about delays in appointments as they felt they are often left waiting for their appointment without being told that there was a delay. We learned that several appointments are made at the same time with the first being before the time the clinic starts but patients do not appear to know this which can cause some frustration when they receive no communication about delays.

**Next Steps**

Sight loss can be disempowering if people need to rely on others for help and support with many everyday activities. However simple, sensible, and empathetic actions can allow people with sight loss to live fuller and more independent lives.

The NHS Accessible Information Standard reflects the varied communication and accessibility needs of people with disabilities. The standard requires NHS services to identify, record, flag, share, and act on the information needs of patients. Full and widespread implementation of this standard will significantly help people with sight loss, but sustainable implementation relies on a regular review of the application of the standard to ensure it consistently meets and adapts to the needs of patients. From our findings, it appears there is a mixed picture of accessibility, information, and communication for people with sight loss and areas that could be improved quite easily in each area. This could be achieved by Ophthalmology services working closely with Staffordshire Sight Loss Association (SSLA) to identify actions that can be taken to improve the experience of patients from the perspective of those with lived experience of the service.

This small study focused on accessibility to a small area of the NHS specialist services. People with sight loss also access the whole range of services in primary and community care. It may be an area of work that could be expanded to look at how these services meet the needs of people with sight and other impairments who fall withing the Accessible Information Standard.

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We are committed to the quality of our information. Every three years we perform an in-depth audit so that we can be certain of this.

The contract to provide the Healthwatch Stoke-on-Trent service is held by Engaging Communities Solutions C.I.C.

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