

# **Healthwatch Shropshire:**

# An analysis of the implementation of the NHS Accessible Information Standard

By
Janki Gore, Chun Wai Wong, Alex Cawley



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## Introduction

Healthwatch Shropshire is the independent consumer champion for social and health care in Shropshire. It aims to ensure that people across Shropshire have an opportunity to voice their opinions on the social and health care services which affect them. It was established by the Health and Social Care Act 2012 and has been commissioned by Shropshire Council. [1]

By engaging with individuals, voluntary and community groups they aim to gain an understanding of peoples' experiences and use this feedback to share best practice across service providers throughout the country.

From 1<sup>st</sup> August 2016 onwards, all organisations that provide NHS care and/or publicly funded adult social care are legally required to follow the NHS Accessible Information Standard. 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. Hence, we are interested to gather the views of local residents with special communication needs and make recommendations about how services could better meet their health needs by following the Standard. [2]

# <u>Aim</u>

To look at the implementation of the NHS Accessible Information Standard with various objectives including:

- Learning about the Standard.
- Understand the need for the Standard speak to people with communication needs and gather experience.
- Assess its implementation within an NHS setting.
- Identify recommendations and improve implementation.

## Method

After discussion with the Healthwatch Shropshire team we decided that the best way to gather information to better understand peoples experience and look for recommendations would be to conduct semi-structured interviews with questionnaires.

Our questionnaire covers four main areas:

- > Patients understanding of Accessible Information Standard.
- Patients experience with Primary Care.
- > Strengths in the system.
- Improvements and recommendations.

To ensure that we gathered the views of individuals with a broad range of communication needs, our target population included people with visual impairment, hearing impairment and learning disabilities. A number of patients with communication needs from 3 different practices were identified and interviewed. In addition to speaking to the patients, their carers, GPs and receptionist at the practices were interviewed to find out their understanding regarding the Accessible Information Standard. We gathered their general feedback and suggestions for improvement. The computer system at each practice was accessed to determine if patients were flagged up appropriately to notify the attending GP and receptionists regarding their communication needs.

To collect views from the community outside the practice, we visited two local community groups – the Sight Loss Opportunity Group (SLOG) in Oswestry that was attended by visually impaired and partially deaf people. As well as the Shropshire Autism Hub in Shrewsbury which was attended by individuals with autism spectrum disorder.

Once the results were gathered, the data was analyzed to identify themes, strengths and improvements. Based on the findings we were able to formulate appropriate recommendations and evaluations.

# **Results**

## **Demographics**

We gathered data from 28 participants, 10 each from the SLOG and Shropshire Autism Hub, with the remaining 8 recruited from different practices. 17 participants have a learning disability, 7 have visual impairment and 6 have hearing impairment.

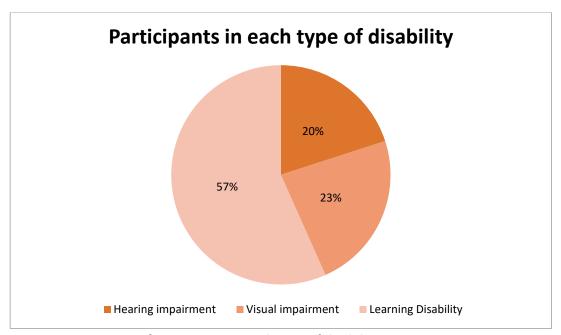


Figure 1. Percentage of participants in each type of disability.

#### **Knowledge of Accessible Information Standard**

Participants generally had a poor knowledge of the Accessible Information Standard with only 2/28 understanding that they have the right to be asked regarding their communication needs. Unfortunately, most of the participants also felt that GPs did not actively ask the patients if they had any communication needs. However, it is important to mention that in one practice there is a nurse in charge of patients with learning disability and she would go through the extra needs required by them, including social requirements as well.

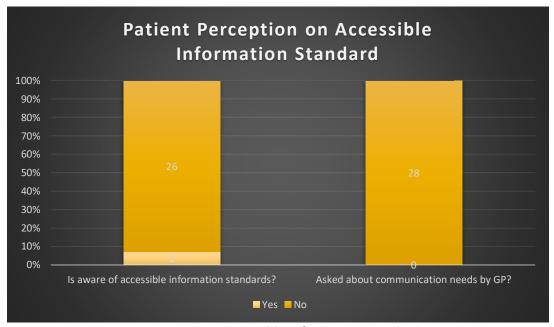


Figure 2. Participant perception on Accessible Information Standard.

# **Appointments**

64% of the patients said that their appointments were made by their carers or partners especially if they have moderate learning disability or severe hearing impairment. The most common method of booking is by phone.



Figure 3. Methods of appointment booking by participants.

## **Themes**

#### Arrival at GP

Upon arrival at practice, some patients encountered an issue with booking in. For example, one blind patient described a previous unpleasant experience attending her practice when the receptionist failed to realise that she is blind and instructed her to use the self-check in machine even though she had a guide dog with her. Also, many patients only felt comfortable coming with a carer, who would help them book in. In one practice, we found receptionists would go through the patient list in the morning and make note of patients with extra needs to facilitate their booking in and healthcare experience.

#### Environment in GP

While in the practice, a majority of the participants have no issue finding their way in the waiting room or accessing the toilet as they often attend with someone else. For participants who attended alone, they reported no issues in requesting help from the receptionists if they needed to use the toilet.

However, a commonly preventable issue for this group of participants is the lack of awareness of the patient's status when the GP calls patient in. Both visually impaired and hearing-impaired patients had raised the problem with the call in systems in different

practices. For example, practices that use screen monitors to inform patients which room to enter are not appropriate for patients with visual impairment. A blind participant shared her previous experience where she was called in through the speaker system. She described an embarrassing moment as she did not know the direction to the consultation room and had to shout, 'can I get some help?' to get the staffs' attention. After consultations, some visually impaired participants complained that they were expected to leave the room themselves as the GP was busy updating notes, failing to realise they needed help.

For patients with hearing impairment, some mentioned that they might miss the announcement if they are sitting far away from the speaker system or from the spot where GPs call for patients. These problems tend to occur more frequently with locum GPs thus most participants prefer to see their usual GP which is not always possible.

Many Patients with Autism felt that long waiting time is an issue. They felt that they were not comfortable with the lighting and settings in the practice. Some patients mentioned that at certain practices they have to wait up to an hour to be seen. One patient with visual impairment felt that on a few occasions he has had to wait for a long time in the waiting room. He commented 'I felt very anxious as the waiting room is full of people at the moment and I was sitting in anticipation waiting for my name to be called'.

#### **IT Consultation**

Based on conversations with GPs at our practices, patients with extra needs (i.e. visually impaired, hearing impaired, learning disability) will have a pop up alert on the bottom right corner of the screen when the GP access their notes. The alert is not specific for communication needs, it may include an alert for blood pressure monitoring, flu vaccination, diabetes review, cholesterol lowering, smoking cessation etc. Hence there is a risk that the patient status (blind/deaf/learning disability) could be overlooked in the vast information provided in the alert pop up.

#### **GP Consultation**

Another issue raised by participants with learning disability is that they find the 10 minutes consultation too short and were not able to understand or retain the information provided by the GP. One participant on the mild spectrum of ASD with epilepsy mentioned that she takes about 10 tablets daily and is managing okay but would appreciate if more information could be given, preferably in written form. Another young participant with ASD mentioned that he was asked to leave the consultation when he asked for sick note and told to get a job. He felt that some GPs do not understand autistic patients as their disability is not often manifested physically. Similar thoughts were mentioned by other participants in the Autism Hub.

Some patients on the spectrum of ASD felt that insufficient information was provided by the GP when they were referred to secondary care for certain further investigations or

treatment. For example, one patient was due to have a colonoscopy at the hospital, he felt that he was very anxious when the hospital had explained what the procedure was going to involve.

#### Secondary care

Other feedback that was a common theme included, hospital staff being unaware of patient's communication needs when patients attend health appointments in hospital. Fortunately, many of the participants do not attend hospital appointments alone therefore they have support when attending consultations.

# **Recommendations**

#### **Environment in General Practice**

After speaking to patients, many felt that waiting times could be reduced. A way to ensure this would be to accommodate to these patients by either placing them first in the morning or afternoon lists. In addition, a calm waiting room, which would be a friendly environment for ASD patients, where the lighting could be adjusted to their needs.

Seating patients with communication needs closer to the receptionist could reduce their anxiety, as they would have easier access to the consultation room, or trying to sit them where they felt comfortable.

Another avenue to explore would be to possibly have text messages sent to patients with visual impairment or deaf people which could vibrate to notify them that they are being called in.

To ensure reception staff are aware of patients with communication needs, a standardized system could be implemented where a notification should pop up on their computer screen and with the expectation of the patients' arrival, the staffs could focus on their needs and minimise any issues that could potentially cause the patients to feel uncomfortable. For visually impaired patients, the GP should personally call the patients in the waiting area and walk them to the consultation room.

#### **IT System**

More central, larger and possibly longer lasting flag up when accessing the electronic note of patients with communication needs. We suggest a flag up box that would appear in the middle of the screen that would only indicate the patient's communication needs and possibly with picture illustration.

#### Secondary care

As sharing communication needs and information about patients between primary and secondary care is a legal requirement, it is important to establish who has this responsibility. Our participants felt this was the role of the GP and as such we would recommend the implementation of an additional proforma, to include communication needs to be sent with the referral letter.

#### **GP** consultations

Participants in the Shropshire Autism Hub, suggested to have a GP with special interest or had special training in Autism placed in practices that has a significant number of ASD patients. This might not be possible in terms of cost effectiveness but perhaps LD/ASD patients could make appointment to see a GP with more experience treating those patients. This would enhance the long-term patient-doctor relationship and patients would be more likely to disclose their health issues. Besides, double appointment slots should be booked for these patients as they often need more time understand the management plan.

## **Evaluation**

Our study has several strengths in that we gathered a wide variety of views and feedback from both the primary care setting and patient focus groups. Furthermore, we were able to interview doctors, receptionist staff and carers in order to establish a wider array of opinions and various challenges faced. We were also able to include participants with different forms of disability, which enabled our results to be more generalizable for the local population.

However, our study had various limitations, firstly we interviewed participants at each practice who were selected by the practice manager, which could have introduced selection bias in to our research and not reflect the population of disabled patients within each practice. Furthermore, a small sample size of 28 patients could mean that we could have missed important points from the disabled community. Finally, we interviewed a disproportionate number of patients with a learning disability compared to hearing or visual impairment which could have possibly skewed our results.

# **References**

- 1. Healthwatch Shropshire Information. <u>http://www.healthwatchshropshire.co.uk/content/find-choose-services</u>
- 2. NHS England Accessible Information Standard. https://www.england.nhs.uk/ourwork/accessibleinfo/

# **Appendix**

# **Questionnaire – NHS Accessible information**

#### Accessible Information Questions

1. Do you know what the accessible information standard is?

#### Specific Questions about the standard

- 1. Have you ever been asked if you have any communication or information needs? Was it recorded properly?
- 2. Was this information properly shared with relevant healthcare professionals i.e outside of the practice?
- 3. Have your practice taken steps to ensure that you can assess and understand the information and receive communication support if you needed it.

#### Specific questions about practice

- 1. Are the healthcare staffs aware of your arrival and your needs?
- 2. Are you shown to your seat if required?
- 3. Are you shown the toilet?
- 4. Are you walked round to the appointment door if required?
- 5. How do you us usually make the appointment?

#### **General Questions**

- 1. What works well?
- 2. What doesn't work well?
- 3. Are there any gaps in the system?
- 4. Any improvements that you feel are needed in the system?

# **Record of engagement**

Dates of Engagement	Activity
August 29th 2017	Introductory session
5th September 2017	Deciding on structure of interviews
19th September 2017	Completing Questionnaires
26th September 2017	Deciding on Groups to visit and arranging meetings
3rd October 2017	Attended the Sight Loss Group Oswestry
10th October 2017	Collecting results from groups visited and our own practices
31st October 2017	Discussing results
7th November 2017	Meeting with Shropshire Autism Hub
15th November 2017	Working on the report
21st November 2017	Discussing results/editing report
28th November 2017	Working on the presentation
30th November 2017	Presentation Day
1st December 2017	Report hand in

## **Data summary**

#### <u>Sight Loss Opportunity Group (SLOG) – visually impaired participants</u>

- 2/6 have heard of the accessible info but only 1 knew what it stands for.
- 4/6 were not asked about their communication needs.
- Appointment booking: 1/6 use app (with partner help) the rest use phone.
- General feedback: prefer partner to book appointments.
- Hospital unaccommodating with large font and was told no availability of brail letters.
- Unless visiting their own specific GP, patients impression is that most doctors are unaware of their communication needs.
- On arrival: 4/6 attend with partner hence no issues. 2/6 with guide dog: one had issue with receptionist, was asked to use self check in system and felt offended.
- After booking in, most participants not shown where to sit.
- When being called in: generally called in by doctor and works well but Locum doctors have had problems and missed patient's disability and caused issues.
- After consultations, sometimes doctors start typing and didn't realise patients need help leaving.

#### Sight Loss Opportunity Group (SLOG) - partially deaf participants

- 1/4 have heard about accessible information standard.
- All of them were not asked about communication needs.
- Appointment booking: 2/4 book via phone by themselves. 2/4 by partner due to difficulty hearing.
- On arrival at GP: generally don't have an issues with booking in. Might need to ask the receptionist to speak louder or repeat.
- After booking in, most participants have no issues finding their own way in the waiting room.
- When being called in, they might miss the announcement. Doctor needs to be more aware.

#### **Shropshire Autism Hub**

- o 10 participants with Autistic Spectrum Disorder.
- o 0/10 heard of accessible info standard.
- 0/10 asked about communication needs.
- 1/10 went to GP alone, felt his GP doesn't understand his Autism and because of this he doesn't like to go to any healthcare professional.
- o 'too noisy in the waiting room'.
- Most appointments cooked by carers.
- Felt doctors rushed through the consultations too quick.
- Patients have very short attention spam, hence trying to get appointment by phone call is very difficult to wait it often takes at least 20mins to be done.

• When attending secondary care, some patients don't think the hospital were aware that they have learning disability.

#### Riverside Practice – 4 LD patients (2 also have hearing impairment)

- 4/4 unaware of what accessible information standard is.
- None of the asked about their communication needs by GP.
- o Have a nurse in charge of LD patients who go through all their needs in detail.
- All make appointment by phone call themselves.
- Receptionists aware of patient arrival and provided support for booking in and guided them to toilet if required.
- o 3/4 usually come alone.
- 2/4- have hearing aid.
- When attending secondary care, 3/4 felt hospital unaware of their communication needs.
- Sometimes letters too complicated for some patients to read. Doctors might need to use simpler language.
- o All 4 patients comfortable going to GP alone

#### Much Wenlock and Cressage

- 3/4 unaware of accessible information standards.
- All 3 LD patients have their appointments made by carers.
- A visually impaired patient make appointment by phone call.
- Reception staffs make note in the morning when patient with communication needs are coming in.
- All of the patients called in by doctors personally.
- All patients with communication needs are called on a regular basis to see how they are doing.

# **Acknowledgments**

We would like to thank Healthwatch Shropshire for all their support and help, a particular mention to Adelle and Jane who have been very supportive throughout this project.