

West Yorkshire & Harrogate Health and Care Partnership

Engagement mapping on the
communication needs for people
with a sensory impairment

November 2017

1.0 Introduction

The purpose of the report is to provide the digital inclusion pathfinder project running across West Yorkshire and Harrogate Health and Care Partnership (with Good Things Foundation and mHabitat), with feedback from engagement activity that has taken place across West Yorkshire and Harrogate in the previous years around the communication needs for people with sensory impairments.

The digital inclusion pathfinder project aims to find solutions on how we can make sure people with sensory impairments are not excluded from services. The project has already held some workshops with people with sensory impairments, which has provided valuable feedback to support the development of the project. And this report has been produced to understand what people with sensory impairments have previously told us.

2.0 Background

From 1st August 2016 onwards, all organisations that provide NHS care and / or publicly-funded adult social care are legally (section 250 of the Health and Social Care Act 2012) required to follow the Accessible Information Standard¹.

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.

The Standard was developed as many service users continue to receive information from health and social care organisations in formats which they are unable to understand and do not receive the support they need to communicate. This includes, but is not limited to, people who are blind or have some visual loss, people who are d/Deaf or have some hearing loss, people who are deafblind, and people with a learning disability. The impact of the lack of consistency and clarity around the identification, recording, flagging and sharing of individuals' information and communication support needs cannot be over-estimated.

Successful implementation of the standard will lead to improved outcomes and experiences, and the provision of safer and more personalised care and services to those individuals who come within the Standard's scope.

What does the Standard tell organisations to do?

As part of the Accessible Information Standard, organisations that provide NHS care or adult social care must do five things.

They must:

1. Ask people if they have any information or communication needs, and find out how to meet their needs.
2. Record those needs clearly and in a set way.

¹ <https://www.england.nhs.uk/wp-content/uploads/2017/08/accessible-info-specification-v1-1.pdf>

3. Highlight or flag the person's file or notes so it is clear that they have information or communication needs and how to meet those needs.
4. Share information about people's information and communication needs with other providers of NHS and adult social care, when they have consent or permission to do so.
5. Take steps to ensure that people receive information which they can access and understand, and receive communication support if they need it.

What does the Standard include?

The Standard says that patients, service users, carers and parents with a disability, impairment or sensory loss should:

- Be able to contact, and be contacted by, services in accessible ways, for example via email or text message.
- Receive information and correspondence in formats they can read and understand, for example in audio, braille, easy read or large print.
- Be supported by a communication professional at appointments if this is needed to support conversation, for example a British Sign Language interpreter.
- Get support from health and care staff and organisations to communicate, for example to lip-read or use a hearing aid.

To support the development of the Standard, NHS England carried out extensive engagement and consultation, this included events, workshops and focus groups held in Bradford and Leeds. City of Bradford Metropolitan District Council² and NHS Bradford City and Bradford Districts Clinical Commissioning Group³ were pilot sites for the draft Accessible Information Standard, and Leeds and York Partnership NHS Foundation Trust was one of the test partners.

3.0 Findings from engagement across West Yorkshire and Harrogate

A review has taken place of engagement and consultation activity held and collected across West Yorkshire and Harrogate that relates to the communication needs for people with a sensory impairment.

The mapping consisted of **35 documents**, including final reports and survey results. Some were produced by the CCGs, others came from Healthwatch, providers, voluntary and community sector and Local Authorities. See Appendix A for a full list of the documents reviewed.

² <https://www.england.nhs.uk/wp-content/uploads/2015/08/access-info-std-rep-bradford.pdf>

³ <https://www.england.nhs.uk/wp-content/uploads/2015/08/access-info-std-rep-nhs-bradford.pdf>

The documents were sourced via a review of documents held on websites of all key organisations, and previous engagement and consultation mapping documents produced for the West Yorkshire and Harrogate Health and Care Partnership.

Each document was summarised, and the key themes and details were written up in to an evidence summary. The majority of the work had already been thematically analysed, and in those cases, the themes were copied and summarised.

After summarising all of the documents, the key themes from those documents were reviewed and a list of the key themes was created. Consideration was given to how many pieces of work that theme had been mentioned in, how many people had taken part in the engagement activity that mentioned the theme, and how much discussion there had been around that theme by the people who had been involved in that engagement.

4.0 Key themes

Medical records

There needs to be a system in place so that the information about communication and access needs can be shared with all departments who need to know. This applies to Social Care as well. This should mean people get their access needs met from the outset. Also, importantly, staff should have had training to know what they should do.

People with sensory impairments would like to be asked by staff 'how would you like to be given information?' They should also ask if there is any extra help they would like to have for appointments, and this information should be recorded on their record.

Booking an appointment

- Currently if a deaf person wants to make a GP appointment, they often have to go to the surgery to book the appointment then take that to the interpreting service to see if there is an interpreter free at that time. Often a number of negotiations have to take place to get an appointment.
- GP appointments can only be booked 1-2 weeks in advance to accommodate those who need an interpreter. This is not always appropriate when a GP appointment is needed urgently.
- Patients with hearing loss or deafness should be able to use text messaging or online to book appointments. It would also be useful if deaf patients were able to book BSL interpreters whilst booking their appointments.
- Some people would benefit from a double appointment so that things can be properly explained, and it would be helpful if the surgery knew this when the patient is contacting them to make an appointment.
- Home visits are usually booked to schedule a BSL interpreter to attend at the same time, however on some occasions the nurse has not attended or arrived late and the interpreter has needed to wait or leave for another appointment. It would have

benefited both parties if the nurse was aware that a BSL interpreter would also be present.

Access to BSL interpreters

- There was a general feeling that no one seems to know who is responsible for booking and paying for BSL interpreters. For example, when booking appointments online there is no opportunity to request an interpreter. This often means that the responsibility for booking an interpreter for the appointment is left with the patient.
- There are not enough BSL interpreters when they are required, in particular for urgent and out of hour appointments. Deaf people often have to work round the availability of the BSL interpreters to book and attend appointments. There also seemed to be a problem with services using interpreters who are not appropriately skilled to interpret in a medical setting.
- Deaf or hard of hearing patients were reluctant to rely on friends and family, and wanted to have a qualified BSL interpreter, with the choice of whether the interpreter was male or female, particularly when they are attending appointments for highly sensitive issues. It was also pointed out that not all friends and family members are able to sign and could miss vital information about a deaf patient's medicines and treatment.
- There are situations where it is useful for all parties to engage a Deaf Relay Interpreter alongside a BSL interpreter, for example, if a person is deaf but unable to understand BSL.

Access to buildings and waiting areas

- For a blind or partially sighted person, steps into buildings are difficult if there is no highlighting of the edges. It can also be difficult to recognise door handles unless they are of a contrasting colour.
- There are some instances where a blind or partially sighted person with a guide dog have been refused access to services or facilities because of the presence of the dog.
- Access to buildings where there is an intercom system is difficult as patients with hearing loss or deafness are unable to hear the person at the other end, and a blind or partially sighted person is unable to locate the position of the unit on the wall or door.
- Reception staff are not always deaf aware, they do not speak clearly, often do not face people when speaking so that people who lip read are unable to see their face.
- Reception areas do not always have loop systems and even where they are in place staff do not always know how to use them.
- Reception staff need to speak slowly and clearly as blind or partially sighted people are unable to pick up the visual clues to what they are saying.
- The use of glass screens and partitions in reception areas can cause problems for partially sighted people because of the light reflection on the glass.
- Blind and partially sighted people often can't see the call board that lets patients know when it is their turn to go into the consulting room.
- Some patients with hearing loss or deafness reported missing appointments they had attended because they were verbally called in the waiting room and they couldn't hear their name being called. This was a particular issue in waiting rooms where the TV or

radio was on leading to greater difficulty hearing someone calling you in for your appointment.

- Some preferred to be collected by the clinician from the waiting room, or to have a display screen showing who was being called in for an appointment.

During the consultation

- It's important to be clear about the specific reasonable adjustment for that patient, for example, one profoundly deaf patient who ideally needed an electronic note taker, arrived at an appointment to find a BSL interpreter was there when she does not use BSL.
- Patients are concerned about missing important information about health conditions and medications because the doctor or nurse doesn't communicate clearly with them; key problems are medical staff not speaking clearly, or not facing the patient.
- Difficulties at the pharmacy were reported, when the pharmacist is trying to explain to a deaf person, without a BSL interpreter being present about their medication and how to take it.

Access to information

- Many raised the importance of giving people a choice about how they are communicated with, so that details of appointments or test results can be given by telephone or text message rather than by letter.
- Written information does not often provide details of whether it is possible to obtain the information in alternative formats, or if it is possible to contact the sender by text phones, fax or SMS. E-mailed documents are better for many blind people who have specialist computer software, however not all organisations are willing to e-mail out letters or forms.
- Letters are always sent out in normal 12 point type which is difficult for partially sighted people to read. Letters need to be in large print or available in audio format.
- Services often assume family members will read letters or information to the blind person without any regard to whether the information is sensitive or personal.

Access to technology

- Barriers to technology include the expense which restricts who can purchase it and having to purchase something before they know whether it is useful. People talked about the need to share knowledge and experiences about technology to help reduce concerns people may have, including information on cheaper alternatives to expensive items.
- Those with sight loss were less likely than people without disabilities to own mobile phones, particularly smart phones. With some people saying that their sight loss prevented them from using a mobile device.
- Blind and partially sighted people were less likely than people without disabilities to access the internet, and to have internet access at home. Most reported that their eyesight was the reason why they were not using the internet. Combined with low awareness of assistive technologies, many older people with sight loss do not regard the use of the internet as an activity that is open to them.
- GP websites should promote useful services for people with visual impairments. For example patients with sight loss may have little access to information about the medication they have been prescribed. A standard patient information leaflet in the pack

of medication may be of little use to them if they cannot read it. GP websites can promote/ provide a link to the RNIBs free phone Medicines Information Line, which the patient can call themselves and request for the leaflet in a format that is accessible to them such as in large print, Braille or an Audio CD.

Staff training

- There needs to be staff training to improve attitudes so that people with access needs get a positive first response from all staff, and people with needs are not made to feel like they are being a nuisance or being difficult.
- There is a lack of awareness regarding people's degrees of hearing loss and that deaf people have different communication requirements. For example not all deaf people can lip read, or use BSL, and not all deaf people can read English. There also appeared to be a lack of awareness to the different communication methods people may use.
- Staff are not always aware of Next Generation Text Service (formerly known as Text Relay and TypeTalk). It allows people with hearing loss to use a text phone to communicate and access any services that are available on standard telephone systems.
- Deaf awareness training should be provided for staff in health and social care settings. This preferably should be delivered by a Deaf person and should not be one off but a rolling programme of training.

Appendix A – Documents reviewed

1. Action on Hearing Loss (February 2014) *Making health and social care information accessible: workshop notes*
2. Airedale, Wharfedale & Craven, Bradford City and Bradford Districts CCGs (2015) *Piloting Accessible Information Standard Flagging Patient Access Needs in SystemOne: Progress Report*
3. Bradford Metropolitan Council (2015) *Bradford Council Pilot of draft accessible information standard*
4. Bradford Strategic Disability Partnership (January 2014) *Making health and social care information accessible: workshop notes*
5. Bradford Talking Media and Bradford Strategic Disability Partnership (October 2014) *Making health and social care information accessible: Consultation workshop*
6. Brainbox Research (March 2015) *Joined up Leeds*
7. Calderdale Council (May 2017) *All Age Disability Strategy Survey: March to May 2017*
8. Calderdale Council (August 2010) *Access issues faced by People with a Sensory Impairment*
9. GP Care Wakefield (September 2017) *Wakefield Extended Hours project: Patient engagement report*
10. Healthwatch Bradford and District (January 2014) *Invisible at the desk' Experiences and views of people using Primary Care services in Bradford and District*
11. Healthwatch Kirklees (February 2016) *An all age disability service for Kirklees*
12. Healthwatch Kirklees (February 2014) *Welcome to my world Issues affecting people in Kirklees who are Deaf and Hard of Hearing as they interact with Health Services- Full Report*
13. Healthwatch Kirklees (September 2014) *What do people want from their GP's website?*
14. Healthwatch Leeds (September 2014) *British Sign Language (BSL) Healthy Day*
15. Healthwatch Wakefield (2015) *Work with people who are deaf or hard of hearing: update*
16. Healthwatch Wakefield (September 2015) *Work with people who are deaf or hard of hearing: update*

17. Healthwatch Wakefield (2014) *Deaf people matter!*
18. Kirklees Council (2015) *Kirklees Blind and Low Vision Group Visual Impairment Strategy 2015 to 2020*
19. Local Healthwatch (September 2016) *Hear, see and treat: Engagement Report*
20. NHS Calderdale and Greater Huddersfield CCGs (November 2016) *Engagement and Equality Report of findings: Ophthalmology services provided in a hospital setting*
21. NHS Calderdale and Greater Huddersfield CCGs (September 2015) *Calderdale and Greater Huddersfield Hospital and Care Closer to Home Summary of findings from all engagement and pre-engagement Public, patients, carers and staff March 2013 – August 2015*
22. NHS England (October 2017) *Accessible Information Standard - Overview 2017/2018*
23. NHS England (August 2017) *Accessible Information: Specification v1.1*
24. NHS England (August 2017) *Accessible Information Standard Implementation Guidance*
25. NHS England (July 2017) *Accessible Information Standard: Post-Implementation Review – Report*
26. NHS England (March 2015) *Making health and social care information accessible Report of consultation 13 August – 09 November 2014*
27. NHS England (July 2014) *Making health and social care information accessible Report of engagement activity November 2013 – February 2014*
28. NHS Harrogate and Rural District CCG (July 2013) *Patient Involvement Forum Event “Seeking Your Experience”*
29. NHS Leeds West CCG (August 2015) *Ear, Nose and Throat (ENT), and ophthalmology community services and audiology and hearing aid services review: Engagement Update*
30. NHS Leeds West CCG (November 2014) *Ear, Nose and Throat (ENT), and ophthalmology community services and audiology and hearing aid services review: Patient Feedback Report*
31. NHS North Kirklees CCG and Healthwatch Kirklees (September 2015) *Adult Hearing Services in North Kirklees: Engagement Report*
32. RNIB (2015) *Service innovation to help people live well with diabetes and reduce sight loss*

33. RNIB (2014) *Communications technology and people with sight loss: A summary of Ofcom research*
34. RNIB (2012) *Tackling digital exclusion: Older blind and partially sighted people and the internet*
35. St Mark's Church (2014) *A snapshot of the unmet social support needs in Harrogate in 2014, and how those needs might be met.*

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