

Unheard Voices

Experiences of using Health and Care Services by those who are D/deaf and Hard of Hearing



About us

Healthwatch Bolton is your local health and social care champion. We exist to listen to your feedback about your experiences of using your health and care services. If you access GPs and hospitals, dentists, pharmacies, care homes or other NHS support services in your area, we want to hear about your experiences. As an independent statutory body, we have the power to make sure NHS leaders and other decision-makers listen to local feedback to help shape and improve standards of care. We can also help you to find reliable and trustworthy information and advice, through in-depth signposting to services and organisations, that can offer help and support.

About this project

As part of our workplan and obligations to listen to the views of people whose voices we seldom hear, we set about to make links with our D/deaf community with a view to opening a continuous dialogue, to gather feedback about experiences of using health and care services in Bolton (and Greater Manchester where appropriate).

Background

There are some 46,500 deaf, Deaf and hard of hearing people in Bolton, 15.7% of the local population. We met with the Chief Executive of Bolton Deaf Society – John Hesketh, who told us about some of the issues and barriers that D/deaf people face with using all public services, not just health and care. It was clear that people are still facing barriers that have been highlighted many times over the years, about the struggles D/deaf people have when accessing services.

In 2014 the Deaf Health charity -Sign Health¹, did some research into the health of D/deaf people in the UK. The report – 'Sick of It', found that:

Findings on medical care:

- ♣ Deaf people have generally healthier lifestyles than the rest of the population in terms of smoking and alcohol, but, are more likely to be overweight.
- High blood pressure was almost twice as common in Deaf people as in the rest of the population.
- ♣ Deaf people are twice as likely as hearing people to have high blood pressure which has not been diagnosed. They may also be more likely to have undiagnosed diabetes, high cholesterol and cardiovascular disease.
- ≠ Even when Deaf people have been diagnosed, they are less likely than hearing people to be adequately treated for these conditions (high blood pressure, high cholesterol, diabetes and cardiovascular disease).
- ♣ Under-diagnosis and under-treatment of potentially serious conditions is more common in Deaf people.
- ♣ Together these may put Deaf people at risk of preventable heart attacks and strokes, and diabetic complications such as kidney failure and blindness.
- As these conditions cause long-term ill-health, disability, and death, urgent measures are needed to address this marked health inequality.

Findings on access

- Deaf people are being denied access to health services.
- Services are not allowing Deaf people to communicate in their preferred language (BSL).
- ♣ Health information is not accessible to Deaf people.
- ♣ Most of the necessary actions are simple and cost-neutral, or cost-saving, in terms of improving access to services, communication with health staff, and improved management of long-term conditions.
- ♣ There is a large, avoidable cost to the NHS because of these health inequalities (in excess of £30m/ year).

¹ https://signhealth.org.uk/resources/report-sick-of-it/

The 'Sick of It' report helped inform and shape policy decisions leading to the Accessible Information Standard², and although some progress has been made, many issues still remain.

Working with Bolton Deaf Society

We discussed with John Hesketh, the best way to start working with the D/deaf community. We also met with some of the D/deaf advocates who shared some feedback with us about what the main issues and barriers people face when using health and care services.

With the help of the D/deaf advocates, we produced a video in British Sign Language (BSL), that explains what we do at Healthwatch Bolton. The video was uploaded to You Tube on our channel. The intention was to use this video with the D/deaf community and to allow them to talk about their experiences by making their own videos using BSL and sharing them with us.

We agreed that we would hold regular meetings throughout the year, with members of the D/deaf society to gather feedback from them. We also encouraged people who may not be members of the D/deaf Society to get in contact with us via our newsletter articles and video on You Tube.

Our video in BSL can be accessed here:

What is Healthwatch Bolton in BSL



² https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/

What People Told Us

Meeting with D/deaf Advocates - 13th December 2023

Our Engagement Officer – Yasmin, met with the D/deaf advocates – Philip Bridge and Ruth Malkin, and discussed feedback that members of the D/deaf Society had shared which is as follows:

Barriers to Health and Care Services

- Turning up at A & E and relying on family members because there are no interpreters.
- Not being able to access a GP practice during lockdown because they
 locked the door and used an inaccessible intercom system to let
 patients in. Relying on a hearing patient to use the intercom to get
 attention, and then the GP receptionist came down with pen and paper
 to communicate through the door.
- When interpreters are booked for appointments and the patient turns up early, the consultant wants to see the patient, but they have to wait for the interpreter.
- There is no way of communicating with Bolton Hospital by text but the Northern Care Alliance, that covers Salford, Bury, Rochdale and Oldham, have text numbers for D/deaf people to check their appointments etc.
 Why does Bolton not have text numbers for patients?
- There is still an inconsistency where places have screens where your name comes up when it's your appointment, but sometimes receptionists and nurses are still resorting to calling people's name out in waiting rooms which is not appropriate for D/deaf people.
- Some things are improving the use of iPads for Sign Live is very handy.
 But not every service has iPads. Technology helps but it needs to be available.

The advocates also told us that Bolton Deaf Society were presently booking interpreters for some medical appointments. They were also training GPs in deaf awareness.

A card has been designed for D/deaf people to help people communicate their access requirements very clearly:: NCA Hospital Communication Tool

Meeting with members of Bolton Deaf Society – 28th May 2024

We engaged with members of one of Bolton Deaf Society's social groups. We asked the group for their comments and feedback on their experiences of using health and care services. The following feedback was received:

Service Area	Comment
Primary Care - GP	"When the GP calls my name out, it makes me feel embarrassed because I am deaf. There's better ways to do it. There should be electronic signs where you name appears across the top."
Primary Care - GP	"The GP practice should have a flag [on your health record] that says a patient is deaf."
Primary Care - GPs	"My GP practice has changed. Whenever someone comes out to get you, they signal for the patient that it is their consultation." "my GP always comes out and opens the door"
Primary Care - GP	"Waste of time trying to book an appointment so complex and hard work going through 3 different people" "Going through a third party is hard work"
Primary Care – Unsworth Group – Peter House GP Interpreter	"Four/five weeks ago, the interpreter came [for my GP appointment], but they were a trainee interpreter. She was 10 mins late. She told me that she only had 20 minutes. We saw the GP. It was very rushed I complained. I told the GP that I need a fully qualified interpreter. They should have a yellow badge."
Primary Care – Pikes Lane GP practice Interpreter	"When you phone, you get a text to say you need an interpreter. You have to keep repeating yourself. It's complex going through three different people. You waste a lot of time going through a third party. Then you're waiting for a long time. When you get through, you're told there are no interpreters. The doctors tells me I have to bring a family member or friend. But I don't want to because my health issues are confidential."
Primary Care – Unsworth Group Practice	"I went to the doctors because I have restless legs. They gave me tablets. The tablets are not working. I need an interpreter to

Service Area	Comment
Communication & Interpreters	enable communication. All doctors need to be deaf aware. I never see the same doctor we go."
Primary Care – Lever Chambers GP Communication & interpreters	"Last Tuesday [21.05.2024], I went to book an interpreter. I waited and waited and waited. The interpreter never came. I am still unwell. Today [28.05.2024], I have another GP appointment. It is difficult to give feedback/complaints because I am deaf."
	Lever Chambers - "Last week I booked an Interpreter waited 20 mins no one turned up, had to re book" "Difficult to feedback complaints when people don't sign"
Royal Bolton Hospital – Interpreter booking	"I went to the hospital Thursday [23.05.2023] regarding a gallstone problem. I got a letter from the hospital saying that I need to book an interpreter – specifically that my GP practice needs to book an interpreter. My GP said that hospital needs to book an interpreter otherwise the GP practice will get the invoice."
NHS Dentistry	"Whose responsibility is it to book an interpreter???" "Me and my wife were at a regular NHS dentist in Little Hulton (Walkden). The practice has told us that they can no longer see
Specsavers - Interpreters	us and that we need to find an NHS dentist." "I was really surprised they [Specsavers] had an interpreter."
Interpreters – general comments	Problem with interpreters cancelling – "they don't care about me" "Waste of time sometimes" "Need to be a team of interpreters within NHS"
Social Care – Social workers	"There are no social workers for deaf communities anymore. Since 2008, all social worker jobs for the deaf have gone. Deaf clubs have been close down. There used to be deaf clubs in every town, and they have closed them down." "Social workers don't exist for the deaf, they have all closed down"

Service Area	Comment
Social Care –	Now, most deaf clubs have set up advocacy services. We need
Social Workers	to replace the social workers at Local Authorities so people can
	access their rights."

Other areas in Greater Manchester

Service Area	Comment
Northern Care Alliance	"Salford Northern Care Alliance came to my flat. I waited and waited for an interpreter to come for 10am. It got to 11am. Often you have to wait a long time for an interpreter. We did a Face Time call. I needed something for the bathroom. It's impossible to communicate without an interpreter. It's the person [patient] who is important. It's easier for the hearing world. Deaf people suffer a lot more."
Hospital waiting times Patient lives in Bury	"The NHS are always delaying things. My wife is very frustrated, she has been waiting for surgery for three/four years. We have gone private. We pay our taxes. We also pay for interpreter. It makes you very depressed and frustrated."

Other Comments

Service Area	Comment
News Bulletins	There are no interpreters for sharing news. Especially during Covid- 19. Scotland had news interpreters. Other countries have them, England has never caught up."
General Election 2024	"No interpreters to inform us."
Personal Independence Payments	"Having problems with PiP. Does anyone know what the new changes are?"
Healthwatch in Greater Manchester	"I know we have the 10 HW, can they work together?" "I feel like we have gone backwards, information gets missed, can we have something where we work together".
General comments	"Most people don't have good English, everyone has different levels and communication needs"

Summary of findings

Interpreters

Communication is the main theme of the feedback received. Clarity is needed for both patients, service users and organisations to understand who is responsible for the booking of British Sign Language interpreters when a patient is needing treatment. All staff involved in the care of the patient should be aware of the procedure to book BSL interpreters. NHS and social care organisations need to ensure they abide by the Equality Act, and the Accessible Information Standard at all times.

Wasted Appointments/impact on health

Appointments are being wasted due to the confusion and lack of information and clarity around the booking of appointments for interpreters. Appointments are also problematic if a patient has to try to communication with more than one member of staff. This is not only wasteful for the NHS, but it is also detrimental to the health of the patient.

Patient Rights

Under the Equality Act 2010³, and the Disability Discrimination Act 1995 in Northern Ireland, people who are D/deaf or have hearing loss have the right to equal access to services. There is also the Accessible Information Standard⁴, which states that all NHS dentists, doctors, hospitals, opticians and public social care providers must follow the Accessible Information Standard. Health providers must ask patients what their communication and information needs are. The NHS must record this information. Their system must flag up the needs of the patient each time, and share this information with other NHS professionals involved in the patient's care.

³ https://www.legislation.gov.uk/ukpga/2010/15/contents

Recommendations

- There must be clear information about who is responsible for booking interpreters and to ensure all health and care staff are aware of the process. Both primary and secondary care organisations and social care organisations, need to work together to ensure there is a straightforward process.
- 2. Health and care organisations should provide easily accessible information that outlines the process when someone needs an interpreter.
- 3. Ensure **qualified** interpreters are booked.
- 4. Simplify the process to book an interpreter so that people are not forced to communicate with more than one person, where possible.
- 5. Ensure that interpreters are booked at the correct time and place.
- 6. GPs or other clinicians should not be asking patients to bring **family members** to appointments with them. GP practices need to ensure that patients can access a BSL interpreter for every appointment they need.
- 7. Medical records should indicate that the patient is either D/deaf or Hard of Hearing, so that the proper communication methods can be used.
- 8. All health and care premises should not rely on audio information to alert patients, but, should also use video technology to alert patients to their appointment and other information.
- 9. Health and care organisations must ensure they abide by the Equality Act and the Accessible Information Standard.
- 10. Bolton Hospital and other care providers need to explore the use of texting to communicate with D/deaf patients.
- 11. Ensure communication tools are used and available when patients are using health and care services.
- 12. Healthwatch should share the experiences of the D/deaf community with Healthwatch colleagues in Greater Manchester and work together to improve experiences.

Thanks and Acknowledgements

We would like to thank Bolton Deaf Society staff, advocates and volunteers for their invaluable help and support for this piece of work. We would also like to thank all the group members who warmly welcomed us, and shared their experiences of health and social care.

Next Steps

This report will be shared with NHS health and social care commissioners and providers, who will be asked to respond to the recommendations. We will share the responses with Bolton Deaf Society in due course.

We will continue to arrange engagement sessions with Bolton Deaf Society to ensure members have a voice in sharing their experiences of health and care services. Anyone can share their feedback with us by any of the communication methods below:

By Post: PO Box 822, Wigan, WN1 9XF

Text only: 07893 943577

WhatsApp: 07946 094057 – if you wish, you can send a

video in BSL.

Email: info@healthwatchbolton.co.uk

Website: Share Your Views

Contact Details:

Tel: 01204 394603

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