



Our Hands Tied

Barriers to Health Care Access that Deaf people face



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Introduction

Healthwatch is the independent consumer champion for health and social care in England.

Healthwatch's function is to engage with local people to seek views about locally delivered services, to signpost service users to relevant information and to influence the design of local health and social care provision.

Healthwatch Hampshire is part of a network of local Healthwatch across 152 local authority areas that launched in April 2013 to ensure local voices are heard and enable them to influence the delivery and design of local services. Our sole purpose is to understand the needs, experiences and concerns of people who use health and social care and to speak out on their behalf. Healthwatch have statutory powers, as stated in the Health and Social Care Act 2012, to ensure the consumer's voice is strengthened and heard by those who commission, deliver and regulate health and care services. Local Healthwatch helps people get the best out of their local health and social care services; whether it's improving them today or helping to shape them for tomorrow.



<https://youtu.be/BamBVZLxjpU>

In England, it is estimated that around 900,000 people have severe or profound deafness. Members of the Deaf community tend to view deafness as a difference in human experience not a disability. Most of the Deaf community sees being deaf as a positive attribute and is not considered as a medical condition that needs to be fixed. 95% of Deaf people are born to hearing parents, so most members do not acquire their cultural identities from parents.

For some, the experiences associated with deafness, particularly communication difficulties, are so damaging that they reach adult life with many social and behavioural difficulties like

- loss of confidence
- low self- esteem
- embarrassment
- they may become withdrawn
- they may become dependent upon other people, resulting in limited lifestyles and restricted opportunities.

Deaf people and their families cope with changing abilities such as the capacity to make decisions about major life events as well as day-to-day situations. NHS England and Department of Health jointly published The Commissioning Services for People with Hearing Loss framework for Clinical Commissioning Groups (CCGs) in July 2016, which set standards for access and outcomes.



NHS England and the Department of Health state that there are five outcomes CCGs would be expected to monitor:

- **Reduced communication difficulties**
- **Improved quality of life**
- **Proportion of patients continuing with their choice of hearing aid and or other intervention(s)**
- **Proportion of patients reporting hearing intervention has helped**
- **Service user satisfaction with their choice of intervention**



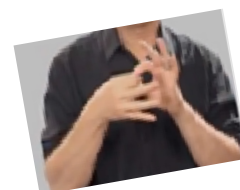
British Sign Language

- This is recognised as a language in its own right
- It is the first or preferred language of around 125,000 deaf adults and 20,000 deaf children
- Other people who are not deaf also use sign language such as people with non-verbal communication skills, hearing relatives, interpreters and the wider society
- The term 'sign language' is just one part of Deaf Culture. Deaf culture is recognized under article 30, paragraph 4 of the United Nations Convention on the Rights of Persons with Disabilities, which states that "Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture."
- Deaf Services Team, Hampshire County Council stated that there are a wide range of issues faced by Deaf BSL service users
- People are often misdiagnosed as having learning difficulties, having been assessed by people with whom they are unable to communicate effectively
- Recent studies have found that 38% were experiencing some form of mental distress
- Deaf people experience higher rates of problems such as depression or anxiety than hearing people



Facts and Figures

There are over 11 million people in the UK with some form of deafness



British Sign Language (and Spoken Signed English) is the first or preferred language of over 125,000 deaf adults and 20,000 deaf children

Health Economists at the University of East Anglia, commissioned by SignHealth, 2014, stated that “Missed diagnosis and poor treatment is costing the NHS £30m a year.”

When used as a cultural label, the word deaf is often written with a capital D and referred to as “big D Deaf” in speech and sign. When used as a label for the audiological condition, it is written with a lower-case d.

Action on Hearing Loss states that research shows that hearing loss doubles the risk of depression, anxiety, other mental health issues as well as physical health issues such as dementia, diabetes, cardiovascular disease, stroke and obesity.

SignHealth reported that 70% of Deaf people who haven't been to their GP recently wanted to but didn't go mainly because there was no interpreter

There are many deaf social and support groups across Hampshire- Deaf led on a voluntary basis



References

Deaf Sensory Services, Hampshire County Council

SignHealth www.signhealth.org.uk

Action on Hearing Loss www.actiononhearingloss.org.uk



Outreach Project

Healthwatch Hampshire was approached to raise the voices of the d/Deaf Community and BSL interpreters regarding their experiences of accessing various NHS services.

Throughout this project we have worked closely with providers and commissioners including West Hampshire CCG, North East Hampshire & Farnham CCG and Hampshire County Council Sensory Services team, as well as some borough councils.

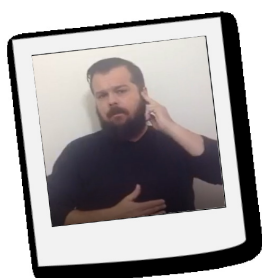
The way services are provided and delivered has been under significant scrutiny nationally for ensuring the Accessible Information Standard is being met.

We worked with focus groups of Deaf service users and BSL interpreters to develop key questions for two online surveys. We identified issues and had follow up conversations, to develop an understanding of existing service users and interpreters' experiences to support the development of new recommendations. We included feedback about wellbeing, beyond health and social care service delivery, also enabling interpreters to raise wider issues that affect their wellbeing such as confidentially boundaries or mental

health wellbeing. In total, we spoke to over 250 people.

Examples of experiences are shown in a video (BSL/SSE/Subtitles available)

<https://youtu.be/BamBVZLxjpU>



- Surveys were rolled out to the d/Deaf community and to BSL/English interpreters to capture their experiences of using NHS services. 67% of the respondents use sign language (Either or both BSL and Sign Supported English- SSE) as their preferred language, and some respondents also had other disabilities including autism, CHARGE, cerebral palsy and blindness.**
- Both surveys show that d/Deaf people and BSL interpreters have used or accessed health services across Hampshire.**
- Deaf people aged 16 to 85+ years old completed the survey, a range of services were accessed: GPs, hospitals, mental health services, audiology, eye clinics, and many more.**
- Interpreters who responded have worked using BSL/ English, Lip speaking and interpreting for someone who is Deafblind.**

As a result of this work Healthwatch Hampshire will be making recommendations to commissioners and providers to improve experiences for Deaf people and interpreters. This report details the five key findings, highlights representative case studies and celebrates good practice already taking place throughout the county.



Project feedback

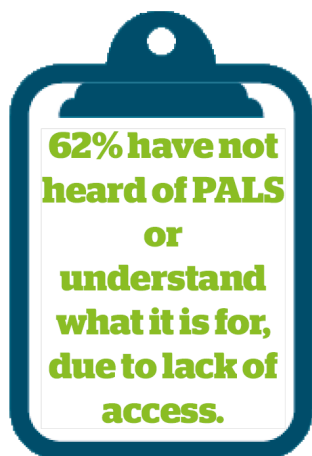
1. Complaints

51% of deaf respondents do not know how to give feedback or make a complaint about any NHS service.

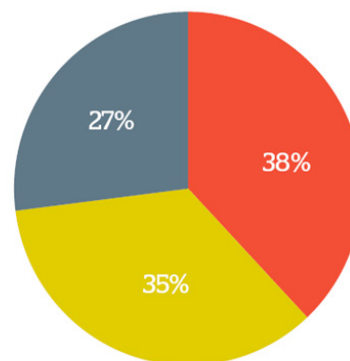
“One interpreter turned up and they were banned from the NRCPD register. I refused to have the appointment with them, but the Doctor ignored my wishes and called them back in anyway.”

NRCPD registration protects both fully qualified BSL interpreters and Deaf patients from interpreters who may not have the relevant experience and training.

NHS staff need to be aware of this registration to avoid the risk of misconduct, grievance, serious incidents or safeguarding. For example, a banned GP would not be able to practice/work in a health setting, putting patients at risk and this principle applies to interpreters. Health care settings should be able to provide information to Deaf patients including which agency interpreters are booked through, they should also be given information about how to formally complain to the said agency if it is necessary.



We asked the Deaf Community in Hampshire about the Accessible Information Standard;



■ Not heard of the AIS ■ Not sure what the AIS is or understand it ■ Know of it

24% of Deaf respondents reported having their needs met.

Follow up conversations found that patients had complained to PALS and were not happy with the response or the lack of it. One commented on the refusal to accept a complaint in British Sign Language format. This was challenged during a local forum meeting, focused on access to Frimley Park Hospital;

“From the floor: What about people just who don’t have English, who can’t explain it? Would they be able to do something with BSL and you take that video on board and so it is from that first language, to you.

Response from panel: I have not come across that before.”

52% of the respondents understood PALS and its purpose. Some respondents said they had no follow up regarding action taken or progress with raising their complaint.



Case Studies

“I have complained to PALS about my after-care, I was discharged by a nurse after a back operation on the same day, I thought it was odd as I had no bandages or anything covering my stitches, and I had no communication support to ask questions as they didn’t understand me when I asked. My husband had to ring for an ambulance later that night as the stitches came undone and I was bleeding everywhere. My complaint was put in July 2017 and I had no response since then, it’s now April.”

“I put in a complaint about the attitude of a doctor and their refusal to provide an interpreter for me and told me that I do not need it. I thought it was unacceptable and I complained about this. I had no response and all I was told is that they were investigating, and this was 14 months ago.”

“I can’t see very well, and I was told by gestures of the doctor that I had to take new tablets. I went to pick them up in a pharmacy bag full with other meds. After being sick and faint on a day out, St John’s First Aiders called A&E ambulance out to me and I was in hospital for three days. All because the pharmacy gave me someone else’s medication with their name and address on and everything. I couldn’t read the labels either until my son noticed this and had to show this to A&E doctors. I put in a complaint 7 months ago and I had no apology, nothing.”

“I had to go into A&E for bad kidney pain, they told me to sign a yellow paper to say yes to let them do an operation to stop

the pain- I had no communication support either and right there I didn’t understand or care, as long they took the pain away. Hours later after no food or drink, they told me that my operation was cancelled. I was back in again two weeks later as the pain was still there, the A&E doctor on duty was confused and said why I had pain when I have finished the operation. I had to explain it was cancelled and she said my notes said I have had my operation when I didn’t. Even had to show her my body to prove I had no marks from being cut open! Complained about this and I never had a sorry. All I keep getting is they are investigating but I bet they won’t get back to me.”



Recommendation

Healthwatch recommends that patients should be able to give their feedback in an accessible way, which includes accepting admissible complaints in British Sign Language (BSL) format and other languages, with response to their complaint in a timely manner in the format the person has requested.

Internal policies needs to be reviewed to ensure the Accessible Information Standard is met.



Project feedback

2. Choice

Family, friends and unqualified interpreters are not to be used as this leads to potential misdiagnosis, confusion about who is held accountable for the misdiagnosis and potentially places the patient in a vulnerable position.

“I used my family member to interpret as they struggled to book an interpreter. It ended up in a family communication breakdown as I didn’t want my health information shared with the whole family, but they did”

“My family don’t know signs, we have home signs which is not reliable”

42% of deaf respondents said that they rely on carers to cancel or change appointments.

13% used NHS staff members who are not NRCPD registered as interpreters for their bookings.



The survey has found that deaf respondents wanted to make a choice about which interpreters to use in certain bookings due to potential conflicts of interest. (For example- a colonoscopy with an interpreter attending and knowing the patient in a different working relationship capacity)

21% of those who were uncomfortable explained reasons for this; not knowing whether the interpreter is male or female, knowing the interpreter in a different manner such as a working environment, attitudes and privacy.

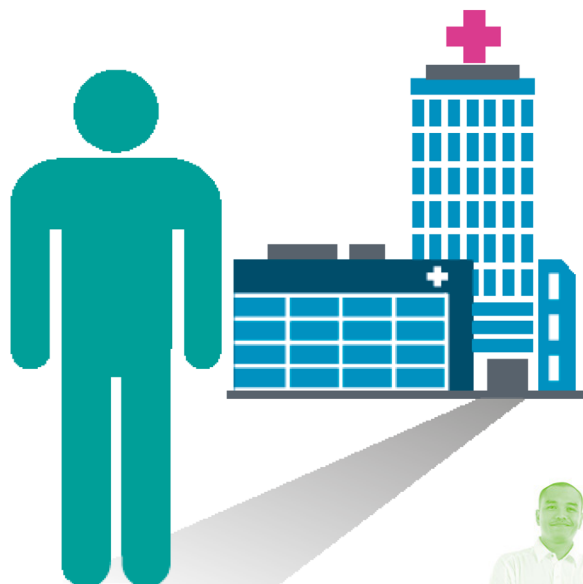
One interpreter responded to say that Deaf patients are left disappointed that the interpreter they prefer is not booked. The relationship between agencies and interpreters could be improved.

“I didn’t know if my interpreter was male or female for my appointment. I asked, and I needed to know as I had a very personal appointment.”





Only 8% say that their local hospital has offered support or advice to understand spoken or written information in the format they prefer



35% of interpreters that responded to our survey said that they have never received or occasionally received the name of the client to establish whether there is conflict of interest.

43% of deaf respondents said that they had to ask a family member or friend to call and change or cancel their appointments and 31% use text relay for this. A few responded to say that it takes several attempts to get through as the other person has no understanding of using the text relay system and puts the phone down. This follows with a face to face visit to the place where they will be having the appointment.

Recommendation

Healthwatch recommends that there should be flexibility when selecting NRCPD registered interpreters to meet the patient's needs- such as female/male preference or switching interpreters due to conflict of interest.

To meet the Accessible Information Standard, NHS services need to provide patients with communication support if they need it to access and understand information.



Project feedback

3. Training and Accountability



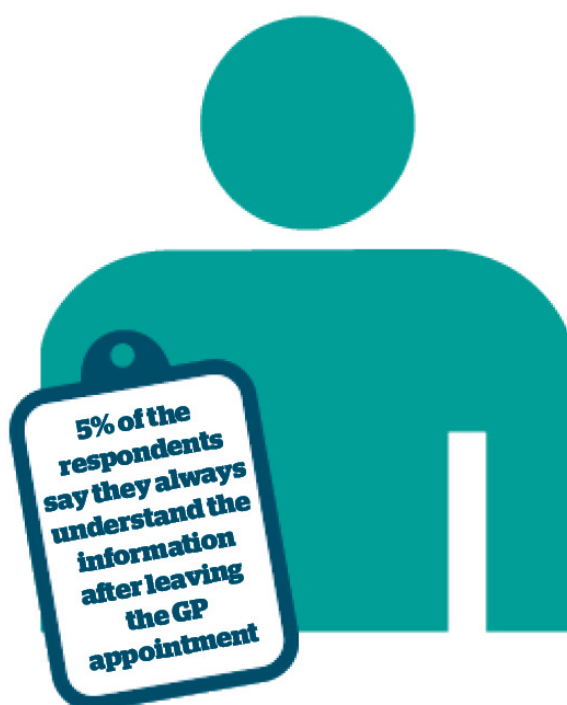
Nearly 60% of Deaf respondents feel that both GP surgeries and hospital staff do not understand their deafness or needs

70% of deaf respondents said they had not been offered support by staff at their GP surgeries to contact them to help understand what was said in their GP appointment. 87% were not offered support to understand written health information by GP surgery staff if they needed support.

“It put me on edge”

“Lipreading is a difficult skill”

“Once- a GP hardly spoke a word, just gave me forms for tests. When I asked them what they were for, they looked shocked. I made a formal complaint against them.”





Deaf respondents shared examples of why they had left GP appointments without fully understanding what had been said





WAITING ROOM



How do staff at your GP surgery let you know when it's your turn to be seen by the doctor or nurse?



They come over to where I am waiting and tell me face-to-face when it's my turn to be seen

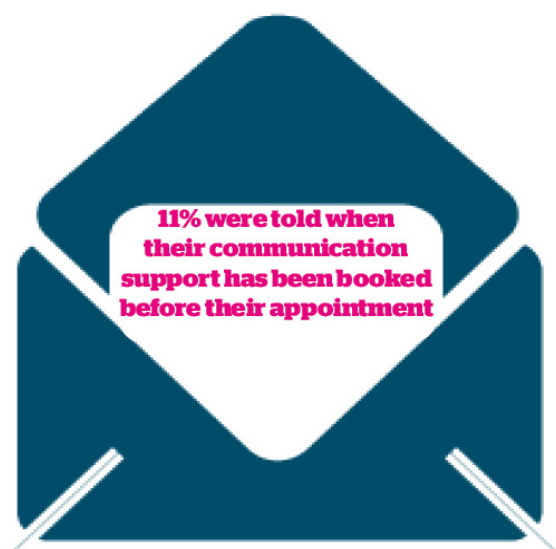
They call out my name



They operate a ticket queuing system (where you take a number from a machine, then wait for your number to show on the screen/called out

8% of deaf respondents had been offered support by staff at their hospital, if they do not understand what was said in their appointments. 8% were offered support to understand written health information by staff at their local hospital.

NHS staff have a duty of care to ensure their patients have been given the right diagnosis and treatment. This applies through the use of interpreters whose accountability lies in the registration. With no registration, you risk misdiagnosis, conflict of interest, confidential information shared with anyone.



Interpreters comply with their governing body Code of Conduct and each booking is confidential. This can result in their emotional and mental health being affected as they cannot disclose information to their peers. More information about this can be found in the Useful Links.

One interpreter stated;

“I would like the NHS to realise that the same as their staff follows rules of confidentiality of their patients so do we of our clients.”

The wellbeing of interpreters is just as important as the patients they are interpreting for. 50% interpreters surveyed said that they have had Safeguarding training and 70% received or know where to access specialist training to help with patients, particularly around areas such as mental health. Interpreters should be given the name of the patient and the department they are going into- for example an interpreter would be able to turn down a maternity booking if they have had experience of a traumatic childbirth,

or a chemotherapy booking if they have had experience of dealing with loved ones' cancer treatments. Their wellbeing affects the way they work as well as the potential need to use mental health services in the same locality as patients themselves. This was highlighted by d/Deaf respondents around conflict of interest;

“I didn't know who was booked then at the reception I saw who it was- I had an issue with a specific interpreter. I still preferred to have this interpreter than none but would have liked to be informed who is booked as I have preference. Some interpreters understand me better and I understand them better.”

Conflict of Interest

20% of interpreters are given information about the nature of the booking, prior to accepting or declining.

“Massive conflict of interest, for example, one of interpreter is really lovely she was used by my play worker while training to become fully qualified, so once when she fully qualified, and she interpreted for me while I gone through legal things with the police. I felt emotional, worried when seeing her again in health situation because I thought she will share information into the community...”



An interpreter stated, “I had a staff member tell the Deaf patient they were a cancer staff member and then left the room!”, leaving the interpreter in a difficult situation with no explanation of what the appointment was for and nor were they prepared for potentially bad news.

85% of interpreters said that they ask the receptionist to identify their Deaf patient when arriving for the GP or hospital appointment.

Interpreter respondents state their experience of identifying the Deaf patient could be improved by having a photo on patients’ records or their photo to show the patient themselves. Both parties say they experience difficulties identifying each other when using an electronic system.



There have been issues raised by interpreters in follow up conversations to their survey responses;

“Particularly around procedures is hospitals not being realistic with the length of time that the interpreter is required for. This is especially a concern with Deaf and Deafblind people that need to undergo general anaesthetic. Deafblind people, especially, in my experience, can take a very long time to come round. Hospitals also have a very bad habit of giving patients after care advice in recovery. Shortly after they have woken up and this is very problematic where someone has had a cataract operation and may only have the use of one eye. It is my experience that within a few minutes of being given the information they have forgotten what they have been told and will be asking me to repeat it, which isn’t how it should be as I can’t answer any questions they may have. Deaf and Deafblind people don’t have the sense of hearing to back-up what they also see, they are relying on their vision (and that’s limited for people with Ushers) or hands-on techniques for Deafblind people and giving them information immediately after coming round is ineffective. In some cases, the hospitals have booked me to be there just for the start of the operation with no regard for giving after care information immediately after coming round or they have based the timing on how long it might typically take for a hearing person to go through the procedure. One patient that requested my services had a cataract operation and they have Ushers. The hospital booked me 8am to 12pm. I was clear from the start that this would need to be an all-day booking, but the hospital was adamant that this person would be done by 12pm. In my experience the order of the patients often gets changed so most of the period can be taken up with waiting to go in. I will then need to wait for the patient to recover and it is likely that the whole process will take longer than 4 hours. I am freelance, and I cannot take half day bookings on the basis that something might massively overrun.



Despite arguing this through the agency (who were very supportive) the hospital refused to book an interpreter for a minimum day rate and I had to leave at 12pm to go to another booking at 1pm and squeeze some lunch in. Consequently, the patient had only just woken up and having Ushers, information cannot be given to them quickly and it left me with no time to be there to interpret questions later on or for them to be discharged. I had to leave, and a family member had to take over and this is completely unacceptable. The patient was there into the evening, which is what I predicted and had tried to advise the hospital ahead of booking.”

Interpreters have been trained for approximately 7 years before becoming fully qualified which includes the ability to carry out an informed decision based on the nature of the booking and advise whenever necessary. Many NHS staff disregard the expertise and advice given by interpreters utilising their experience.



Recommendation

Healthwatch recommends that there should be training provided to NHS frontline staff on;

- d/Deaf awareness
- use of interpreters and relevant technologies
- understanding accountability
- preventing barriers
- signposting to accessible formats to meet the needs of the patient

77% of interpreters also responded to say they have experienced barriers or other difficulties when dealing with NHS staff. Respondents say this was around;

- **Attitude**
- **Lack of Deaf awareness**
- **Not allowing the interpreter to give full instructions before a procedure**
- **Lack of information**
- **Telling the interpreter that they can manage without them and being dismissive of the Deaf patient's choice**
- **Staff not knowing how to book interpreters or the procedure to do this**
- **Consultants not understanding the value of interpreters or their legal requirements**
- **Delay of bookings to cancel other bookings- chain reaction effect**
- **NHS staff lacking knowledge of the Accessible Information Standard**
- **NHS staff speaking to interpreters as if they are a family member of the Deaf patient**
- **Unreasonable expectations**
- **NHS staff instructing interpreters and not giving the Deaf patient the choice**



It is also stated by interpreters that Deafblind patients get overlooked. Interpretation for deafblind requires more time to relay information in the format they require.

“When I was in the ward I missed the food trolley on 2 occasions. I couldn’t get a newspaper, a chocolate bar, a drink or anything and day 4 when I finally saw it, it is only a little thing, but I was really upset because I was sat there and didn’t get what everyone else got. I did cry, and they said what is wrong. I said I did not know that the trolley was there. The nurses are busy, they forget. I had to keep looking out.”

An interpreter responded, “I was asked to have a chat with a Deaf 15/16-year-old as he might get angry and aggressive if I sign what is being said in the meeting, he had additional needs I had not been informed about. He didn’t want to know what they were talking about and didn’t want to watch but it means the hospital and mother will look like they have provided an interpreter when it hasn’t happened.”

“A few years ago, it happened to a Deaf person who had an incident, they were sectioned under the Mental Health Act. They were profoundly Deaf and using a vocal manner in a Deaf way. And three months later it was like ‘oh you are deaf sorry’ and they were released. It is dangerous.”

Healthwatch Hampshire asked Deaf respondents if they are aware of a working hearing loop system available at their GP surgery. 59% responded to say that they do

not use the hearing loop system, which shows not every deaf person will adapt to this format.



52% Deaf parents/carers that responded were not provided the communication format they needed, to make decisions for the person they are caring for

Children and babies

Children and babies are not able to give consent without their parents/ guardians’ permission. When the care giver is not given access to the format they need, they are unlikely to give consent as they do not understand what is happening, no matter how genuine the treatment may be. This potentially puts the young patient and their care giver in a vulnerable position, and ultimately becomes a safeguarding matter.



Project feedback

4. Access and Information

RECEPTION

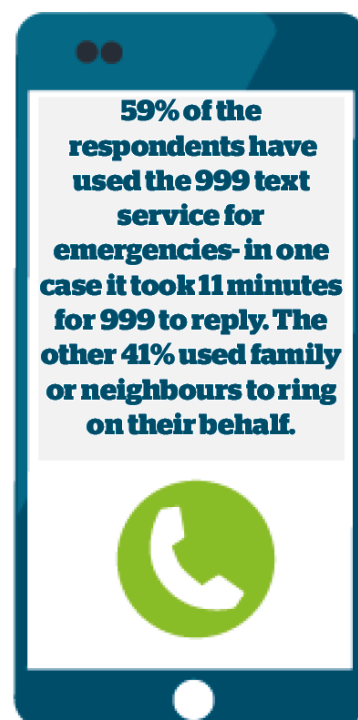


55% currently go in face to face or use text relay (NGT) to book an appointment with their GP. Most respondents said they would prefer to book through an online system or continue to use text relay if staff were trained.

57% of deaf respondents have received text messages from their GP surgeries as a reminder- they have found it useful and clear though they stated they could not reply if they had an enquiry or wish to change/cancel the appointment. A good example of this;

Dear Mr [REDACTED] this is a reminder for your appointment at 15:50 on Mon 26 Feb at [REDACTED] Surgery. To cancel this appointment send CANCEL to [079035\[REDACTED\]](tel:079035[REDACTED])

Ordering repeat prescriptions and receiving test results are done in the same way, going into a GP surgery, which expresses the importance of using the patient's preferred method of communication.



One patient's experience left her in hospital for three days after being admitted to A&E. The patient was given new medication, and without the ability to communicate nor read due to blindness, she was prescribed the wrong medication.

Respondents say in both surveys that perhaps a photo of each interpreter and patient is listed for recognition when trying to find each other prior to an appointment.

When a GP or hospital appointment has been changed or cancelled, 26% said that they receive a phone call though they cannot answer or hear on the phone, 31% receive a letter and 18% find out on the day when arriving for their appointment. This highlights the importance of recording and acting upon patients communication needs.



15% of interpreters say they get told when an appointment gets cancelled.

Cancellations lead to confusion. Patients receive letters about their appointments being cancelled or changed and interpreters are not being notified. Patients reported they have attended changed appointments with no interpreter attending, and this was a concern for them as they are conscious of the result in lost appointment time that could have been fulfilled and costing NHS in time and money. Interpreters have reported to say they have turned up for the appointment, resulting in lost time where other patients need their communication to be fulfilled and NHS paying for their time in accordance to their cancellations' terms and conditions.



“I went to hospital for surgery with an interpreter. The doctor said I need another surgery in four weeks, so the interpreter said they were available to book and the doctor said it had to be done their way. I went for that appointment and find they did not book the interpreter! The nurse said it was fine they will look after me, but I was very nervous, I couldn't understand what was going on during that appointment.”



Recommendation

Healthwatch recommends that NHS frontline staff should be provided with information and access to the appropriate resources to comply with the Accessible Information Standard

Staff should also use other formats and links of access if the NHS cannot provide this- such as MacMillan's BSL information about cancer or Deaf Diabetes UK




Project Feedback


5. Other key findings

- SignHealth produced the “Sick of It” report in 2014, which correlates with many of the issues in this report.
- One key finding was around conflict of interest between the Deaf patient and the communication support, whether it is a BSL interpreter or a Lip-speaker. This could be a lack of understanding, safeguarding, gender choice, or conflict of interest.
- Interpreters say that they are not given enough information and have to chase their agency for the Deaf patient’s name. For example, one agency, will not disclose any names until an interpreter agrees to do the booking, once agreed, the interpreter is not able to refuse the booking. They also state that direct bookings are preferred, and they can refuse instead of being tied into a contract where there is potential for conflict.
- One interpreter respondent summed up the issues that they have;
 - with me/someone I don’t want to work with.”
 - “Medical area, Location, Duration? Where along in the treatment process this is- i.e. is this the 5th of 10? Physios? and I have no clue what they’ve done so far? Will there be blood? Will they be given really bad news? Do I know them personally? Can I be strong for them? Will I need supervision afterwards? Will it upset me? Can I keep impartial and not get upset or grossed out? Am I good enough for this? Do I know the medical team, and can I ask them lots of questions if I need to? Will we be waiting for ages? or Be seen quickly? Can I stay later if I need to? Can I/ should I go for a cup of tea with them afterwards if it’s bad news and they want to talk a bit?”
 - 17% of interpreters say their agency (If working as an inhouse agency interpreter) provide support or debrief after interpreting a medical/health booking.

“Trying to get information about the booking, particularly if it is a procedure (so I can prep). Some agencies won’t give out the name of the client (citing confidentiality) so I don’t know who they are and whether it might be someone that I’d want to get some information about their medical history or some that might not want to work







Not all Deaf respondents were registered for the 999-text service, some people are worried about using the text system and still rely on their family or neighbours to call instead. One respondent stated they have tried to use the text service and it took 11 minutes to respond. Another found using Skype 999 service too lengthy with their questions and found they would respond quicker when they asked a neighbour to ring on their behalf.

Deaf patients who had experience of the ambulance services said they either used pen and paper or a neighbour but with great difficulty. One patient said that they had a great experience with two paramedics who had Deaf awareness training and found it an easier experience.

Interpreters' insight

Interpreters have had experience and insight to the changes of legislation and access;

“Having been an interpreter for 20 years, I’ve seen a lot of shifts in how interpreters are provided and why. Back in the 90’s, the fear of the DDA was so great that a real corner was turned with the provision of interpreters. The Equality Act has really weakened that, and I am shocked to come across Deaf people who are still getting Community Support Workers (CSWs) or people with Level 2 provided in place of interpreters in medical appointments. Lots has improved around attitude towards provision, but it is still shocking when there is an incorrect assumption or poor attitude. Cost being a big factor these days, is having a massive impact on good provision and using frameworks is very much to blame. Deafinite Interpreters, a specialist agency, went under this week and 10 years ago I worked for a good 20 specialist agencies, now those are rare, and they are at the risk of closing because spoken language/non-specialist agencies have the contracts and pay themselves too much or more is lost in subcontracting to the specialist agencies. I am also worried about the interest in Video Relay Service (VRS) as it is just not appropriate and is not fit for purpose in health settings. There seems to be a lot of legislation and guidance around about use of registered interpreters and Deaf people’s rights to this but the mechanisms that are meant to supply this are wrong. Interpreters always respond to consultations to say ‘don’t go down the route of frameworks’ and we give lots of good reasons as to why this does not work, but we know the decision has already been made and that’s exactly what will happen. It’s good that interpreters now have National Union of British Sign Language Interpreters (NUBSLI). This isn’t just about protecting our pay it’s also about Deaf people getting good and sustainable access. It shocks me that this is the point of the provision, but it gets lost in contracting a cost. In health, Face-to-Face should be the main consideration and VRS could always have been contracted for separately since it is less used than face-to-face. It is a shame that the reality for the interpreters are not taken into consideration.”



• Fees and/or Terms and Conditions for interpreters are not being met (including cancellation periods), leaving them with limited choice to refuse any health bookings from agencies, for the fear of no income, no information or consideration for conflict of interest.

• Issues over interpreters' fees leaves the Deaf patient, in urgent cases, with no reassurance of an interpreter being booked. Some bookings are made without specific information which questions the interpreter's relevant skill set for the appointment.

• Regardless of the fees, interpreters responded that they provide interpretation out of hours (Between 8pm to 8am) and every respondent would be willing to work out of hours.

• Interpreters responded to say why face to face interpretation and using video relay are different, using face to face at its' advantage;

“Rapport management, better service to client around time. No issues of tech whether my end or usually at clients end. Faster. Sometimes clients have told me outside in reception that they have an issue, then go in and it was a different reason e.g. prescription review. As mentioned outside can appropriately prompt at end e.g. anything they want to raise. With one patient, this prompt meant that it went on as a diagnosis of bowel cancer. Would not have got this as a VRS interpreter.”



“VRS has its place, I agree that the Deaf Community should have equal access to telecommunications but BSL is a life size 3D language

and it is always better to be present than remote.”

“Feel ‘listened to’. Don’t feel alone. Clear communication (no need to worry about technical glitches or Wi-Fi failing).”

“I believe it has good applications in some domains, but health is not one of them, with the exception of being better than nothing in an emergency situation. It’s lovely not to have to travel but I believe that that is part of the job that I signed up to do.”



• Interpreters •

You can find out more about British Sign Language (BSL) interpreters through the Association of Sign Language Interpreters (ASLI) or The National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD) websites

*Website addresses are in Useful Links

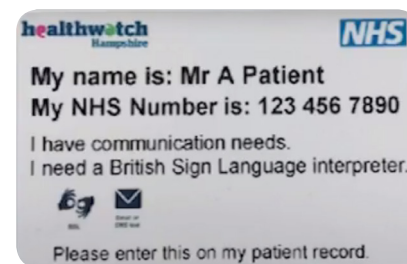


Spotlight on...

As part of the outreach carried out for this project we discovered a huge amount of innovative work taking place throughout the county that is aimed at improving experiences for the d/Deaf community. This section of the report puts a spotlight on some of that good practice.

Communication Needs Card

Shaped and integrated by West Hampshire CCG Equality and Diversity Officer. For their Communication Needs Card project- they are looking at accessibility on a wider scale; reaching out to various communities including those who speak English as their second language; for example, the Nepalese and Polish communities, across West Hampshire. The card is designed to identify and declare a patient's communication needs on the card, along with their NHS number for staff to record this for future appointments, ensuring their needs are being met. On the back of the card, there is a reminder to comply with the Accessible Information Standard. We have been part of the data collection and follow ups of the development of the communication needs card, evidencing all issues and good practice via a survey, before expanding to other health services and areas. North East Hampshire and Farnham CCG are keen to carry out this work, with the d/Deaf community within their locality with a Communication Needs card pilot. Healthwatch Surrey will work with us to carry out the pilot in the Surrey locality too.



The BSL video link to this -
<https://youtu.be/iZL7BrYtO2k>

GP Surgeries' Deaf and Disability Awareness Training

Shaped and developed together with West Hampshire CCG Equality and Diversity Officer, Healthwatch Hampshire supports the training by approaching GP Practice Managers of the Communication Needs Card pilot scheme through the West Hampshire CCG locality, ensuring GP surgeries have the Accessible Information Standard information, awareness of Healthwatch Hampshire's aims, and resources are made available to support them in their role. The Project Officer and Equality and Diversity Officer has approached West Hampshire's Practice Managers and giving them an opportunity for further resources for their staff. Through this, issues at some surgeries were identified immediately and quickly rectified. By this, the access for any form of communication is greatly improved.

GPs across Hampshire are invited to be involved in this project to move forward working together with d/Deaf patients and third-party support such as Lip-speakers or BSL interpreters.



Frimley Park Hospital

We have been working with Frimley Park, Wexham and Heatherwood Hospitals, focusing on the development of an integrated health, social care and wellbeing system which will put the person at the centre of their care, ensuring they are understood with the preferred form of access.

This includes;

- A Hybrid system to generate accessible formatted letters, using alerts and flagging up communication requirements
- Training approach to include more awareness on Accessible Information Standard and the use of Text Relay (NGT), or the importance of using SMS communications for any queries and to include on the patient's letters
- BSL video on their website to explain how to make a complaint/feedback
- An audit of patients who are d/Deaf, Blind/Visually Impaired, deafblind or have a learning disability to be carried out and ensuring the "flagging" system is updated
- List of communication needs to be cross checked with BSL interpreter bookings
- Universal symbols to identify communication needs with the patient's permission to be used behind the patient's bed and form as part of the handover between staff
- BSL supplier contracted to provide fully-qualified and NRCPPD regulated BSL Interpreters
- BSL supplier fulfilment rate to be reviewed regularly and a report on Complaints-identifying any issues and advise on corrective action
- Carry out quality assurance to ensure support or information provided meets patient's needs



Sir Andrew Morris, CEO of Frimley Park Hospital has stated at the Forum held in March 2017;

“Anyone in hospital who is deaf, we should always provide an interpreter. We have got some, a lot of work to do to educate our staff that that is the normal course of events. This is not about money, this is about providing service. So, we spend 670 million pounds! So, this is a very small but very important part of what we do, and we should support people when they are in hospital and they are deaf. Clearly, sitting there for a period of time and not having access to an interpreter must make people feel very vulnerable. I apologise for that, and that is something that we must improve upon.”



Other support

Healthwatch Hampshire utilised the support of numerous organisations whilst carrying out the engagement work for this project. Despite one of the key findings of this report highlighting a lack of signposting to support, we witnessed numerous support groups for d/Deaf people living in Hampshire. Some of the groups we visited or worked with, included:

deafPLUS Hampshire- Provides social and cultural opportunities to overcome isolation, health workshops and materials, skills training, volunteering opportunities, information, advocacy and advice.

SignHealth- SignHealth works to improve the health and wellbeing of people who are Deaf. They provide some services directly in British Sign Language (BSL), and working in partnership with the NHS, also campaigning for change.

Royal Association for Deaf people (RAD)- creating access and promoting equality for Deaf people through the provision of accessible services.

National Deaf Children's Society (NDCS)- supporting Deaf children and their families to overcome barriers in local and national services.

Association of Sign Language Interpreters (ASLI)- a professional membership association and support network for British Sign Language (BSL) interpreters in the UK.

National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD)- exists to protect the public by regulating communication and language professionals who work with deaf and deafblind people.





Summary & Recommendations

As a result of this work Healthwatch Hampshire are asking commissioners and providers of health and social care services that effect d/Deaf to consider the following recommendations.

This report will be sent to relevant professionals for a direct response. All responses and feedback will be published alongside this report on our website: www.healthwatchhampshire.co.uk



Key themes for d/Deaf people

- Q Lack of knowledge about availability of services (BSL videos not readily available for specific health information like cancer, diabetes or glaucoma support).
- Q Difficulties in accessing BSL interpreters/lipspeakers. Poor communication between service users, NHS staff and agencies responsible for booking BSL interpreters/lipspeakers.
- Q Unnecessary and inappropriate use of family and friends as interpreters.
- Q Misdiagnosis with no appropriate support can lead to serious consequences of wrong medical treatment
- Q Problems with making complaints. Patient Advice and Liaison Services (PALS) not being accessible. Often complaints are required in writing, which some people struggle with when English is not their first language.
- Q Conflicts of interest with interpreters. Knowing the interpreters in a personal or other professional setting.
- Q d/Deaf parents/carers report not being provided the communication format they need to make decisions for the person they are caring for.
- Q Not understanding complex medical information (diagnosis, treatment options, medication) leading to difficulty in providing consent for treatment. This often puts the patient in a vulnerable position.



Key themes for interpreters

- Q Health and care professionals not fully understanding the importance of interpreting services for patients
- Q Use of hours - Professional interpreters usually have a minimum booking time. Health and care services routinely fail to recognise this resulting in bookings that could be used in more cost-effective ways. It was also reported that bookings were often not used effectively to serve the needs of patients. (e.g. ensuring interpreting services are available both pre and post surgery)
- Q Poor communication between health and care services and interpreters about booking times, locations, delays and needs of patients. This can result in patients not able to access interpreting services when they need them.
- Q Use of trainees or interpreters that are not [National Registers of Communication Professionals working with Deaf and Deafblind people](#) (NRCPD) registered.

Recommendations

Complaints

- Q Health and care settings should review all internal policies to ensure the Accessible Information Standard is complied with;
- Q Hospitals should review their PALS complaints procedures;
 - Information and process must be available in a format that is accessible to all.
 - Complaints procedures must be carried out with appropriate provision to meet patients accessibility requests in a timely manner
 - Responses to complaints must be in the format requested by patients
 - Allow complaints to be given in formats other than written (e.g. BSL)

Choice

- Q Allow patients and carers flexibility when selecting NRCPD registered interpreters to meet the patient's needs. To include preference over female/male interpreters or switching interpreters due to conflict of interest.

Training and Accountability

- Q Provide NHS frontline staff with training on the following;
 - d/Deaf awareness
 - The use of text relay (for example [NGT system](#)) and how to use it
 - Safeguarding and understanding accountability (Duty of care)
 - Understanding the use of interpreters
 - Barriers that could be prevented
 - Signposting to accessible formats to meet the needs of the patient



Access and Information

- Q Provide NHS frontline staff with information and access to the appropriate resources to comply with the AIS
- Q Signpost appropriately to other sources of information in appropriate formats (if services cannot provide this directly) such as [MacMillan's BSL information](#) about cancer or [Diabetes UK BSL information](#).

We would also ask commissioners and providers of services that are for, or could effect, d/Deaf or Hard of Hearing people to carefully consider all aspects of this report, not just the above recommendations. It is clear that there is a large amount of good work being carried out throughout the county but we are still receiving feedback about poor experiences of accessing services and support. Healthwatch are ultimately

accountable to local people and prioritise the work we do to reflect the intelligence and evidence we have gathered from local people. Our independence from the NHS and local authorities mean that we are not bound to adopt the priorities or messages of those bodies. We would always encourage commissioners and providers to carry out their own consultation and engagement to support their decision making processes.



Useful links

URGENT Contacts

NHS 111 BSL service <http://interpreternow.co.uk/nhs111>

Text Relay- 18001 111

Emergency services- text 999

NHS Accessible Information Standard (All documents- Easy Read, BSL, Summary, etc):
www.england.nhs.uk/ourwork/accessibleinfo

NHS Principles for high quality interpretation and translation services:
www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/03/it_principles.pdf

For information about caring for someone with communication difficulties:
www.nhs.uk/conditions/social-care-and-support/communication-problems-carers

Text relay (Known as NGT or Next Generation Text) To call a patient who uses this- ring 18002 before their number. More information is found here: <https://ngts.org.uk>

Details of local BSL interpreters in Hampshire and borders: www.bslsouthcentral.com

NRCPD regulated and qualified BSL interpreters (You can check their registration and other guidance here): www.nrcpd.org.uk

NRCPD Code of Conduct: www.nrcpd.org.uk/code-of-conduct

National Union of British Sign Language Interpreters (NUBSLI)-
<http://nubsli.com>

NUBSLI's Campaign for the use of qualified interpreters- <http://nubsli.com/guidance/why-nubsli-are-campaigning-for-the-use-of-qualified-bslenglish-interpreters/>

The following charities and third sector organisations also provide further support and information:

deafPLUS - www.deafplus.org

SignHealth - www.signhealth.org.uk

Royal Association for Deaf people - www.royaldeaf.org.uk

NDCS - www.ndcs.org.uk





Contacts and useful links

Signed Videos

How to make a complaint to any NHS in England: www.england.nhs.uk/ourwork/accessibleinfo

“What is Healthwatch Hampshire?”: <https://www.youtube.com/watch?v=Oo2RnOSyMyQ>

Communications Needs Card information: <https://www.youtube.com/watch?v=iZL7BrYtO2k>

NHS Accessible Information Standard Overview 2017/2018:

https://www.youtube.com/watch?v=WWrZIEu_KhQ

Macmillan cancer information in BSL:

https://www.youtube.com/results?search_query=macmillan+cancer+bsl

Understanding diabetes in BSL: <https://www.youtube.com/watch?v=rxAUvIwmFAI>

Advice for Deaf Carers: <https://www.signhealth.org.uk/advice-for-deaf-carers-also-in-bsl/>

Other

Ushers: www.sense.org.uk/get-support/information-and-advice/conditions/usher-syndrome/

Equality Act: <http://www.legislation.gov.uk/ukpga/2010/15/contents>

What is a CSW and why the Deaf community do not use one:

<https://www.reference.com/business-finance/community-support-worker-ab8876899f7725a>

VRS- https://en.wikipedia.org/wiki/Video_relay_service

The link to the BSL interpreters survey: <https://www.surveymonkey.co.uk/r/HBV9WCY>

The link to the Deaf individuals survey: <https://www.surveymonkey.co.uk/r/DJZYLVF>

Sick of it Report by SignHealth:

<https://www.signhealth.org.uk/health-information/sick-of-it-report/sick-of-it-in-english/>

Resources:

www.england.nhs.uk/ourwork/patients/accessibleinfo/resources/

To download a copy of this report or to share feedback and experiences about health and social care services in Hampshire get in touch with us at Healthwatch Hampshire.





Thanks

A special thank you to the Deaf community, BSL interpreters and Lip-speakers for dedicating their time to share their experiences.

Thank you to the Deaf volunteers who were willing to get in front of the camera and tell someone's story, it helped to show people in the language you use!

Thank you to the BSL interpreters who have committed their time to research legislation, information, fact finding, and reaching out further to the Deaf Community and their colleagues.

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