

The Experiences of Deaf People Accessing Health & Social Care in Sheffield

This report provides a snapshot of the barriers Deaf people experience in using health and social care services in Sheffield.

It sets out how we identified the problems and what we have done in response.

We have made recommendations to providers and commissioners of health and social care services, and, in particular, those who have a lead role in the implementing the Accessible Information Standard.

Throughout the report we are using the term Deaf to mean a person who is pre-lingually and profoundly deaf and communicates in British Sign Language (BSL).

We worked in partnership with Citizens Advice Sheffield and Disability Sheffield in carrying out this investigation and making the recommendations.

Margaret Kilner, Chief Officer, Healthwatch Sheffield

Who we are

Healthwatch Sheffield – We're here to help adults, children and young people influence and improve how services are designed and run. We are completely independent and not part of the NHS or Sheffield City Council. You can tell us about your experience of:

- Health services (GPs, dentists, opticians, pharmacies and hospitals)
- Social care services (care at home, residential and nursing homes, personal budgets etc)

We collate the feedback you give us so we can provide evidence-based recommendations to the organisations that design, pay for, and run our local services.

Citizens Advice Sheffield – Deaf Advice Team is a specialist team of Deaf and hearing staff and volunteers all of whom are fluent BSL users.

Originally established in 1987 by members of the Sheffield Deaf community we offer the following advice provision;

Drop-in advice on Monday and Wednesday 10am-2pm

Peer Support appointments Tuesdays 10am-2pm.

Skype advice on Thursdays 10am-2pm.

Advice appointments Fridays 10am-2pm.

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Disability Sheffield – a pan disability organisation, managed by disabled people. Established in 2003 they provide a range of services to support independent living for disabled people. Their advocacy and information service includes a service specifically for members of the Deaf community provided by an advocate who is themselves Deaf.

Recommendations

The experiences shared during the course of this investigation have left us in no doubt that Deaf people face many continual barriers to accessing health and social care in Sheffield. These are not isolated incidents, and we hope that in presenting our findings to local commissioners and provider, they will take steps to ensure equal access for Deaf people.

We have made five recommendations, using the powers given to local Healthwatch, and based on the findings of our investigations. Our recommendations are for local commissioners and providers, including NHS Sheffield Clinical Commissioning Group, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield Health and Social Care NHS Foundation Trust, Sheffield City Council and local GPs. We will ask each organisation to provide a response to the recommendations.

Although our investigation has focused on the experiences of Deaf people, acting on the recommendations is likely to benefit those with hearing loss and those who are Deafblind. Full implementation of the Accessible Information Standard would have much further reach, in improving healthcare for local people with individual communication needs.

Recommendation 1:

Providers of NHS and Social Care should recognise the legal requirement to meet the five elements of the Accessible Information Standard (Identify, Record, Flag Share, Meet) and ensure they are embedded and consistently applied within their organisations.

Immediate actions required:

- a) Establish a written protocol within each service describing how and in what circumstances an interpreter should be booked, with staff trained in the process.
- b) Monitor the number of appointments where a BSL interpreter is required but has not been booked (and whether this leads to cancellation/rebooking).
- c) Write appointment letters to Deaf people in simple language, with confirmation that an interpreter has been booked.
- d) Enable two way text or email communication.

- e) Develop a written protocol and training for staff on the appropriate use of SignLive, in conjunction with Deaf people. An accompanying BSL video should be made available for Deaf service users.

Recommendation 2:

Commissioners should consider the use of measures and/or incentives to ensure the Standard is being implemented by providers.

Recommendation 3:

Contract monitoring of LanguageLine Solutions should include the experiences and views of Deaf people.

Recommendation 4:

Providers should ensure health and social care staff have at least a basic understanding of the needs of, and the problems experienced by, Deaf people and are aware of their responsibilities under the Equality Act 2010.

Recommendation 5:

Local providers should act to ensure information about their complaints and concerns process is accessible and available in BSL, including information about NHS complaints advocacy.

We would like to thank all of the people who contributed to this report, who attended workshops, told us their stories, and provided insight and guidance.

Why Healthwatch Sheffield decided to investigate

According to the most recent Department of Health figures, 990 people living in Sheffield are registered as Deaf and 560 are registered as hard of hearing (People Registered as Deaf or Hard of Hearing - England, Year ending 31 March 2010, <https://digital.nhs.uk/catalogue/PUB00594>)

Citizens Advice Sheffield's Deaf Advice Team, contacted Healthwatch Sheffield about a significant increase in the number of complaints they were being asked to help Deaf service users make about the provision of British Sign Language (BSL) interpreters at NHS appointments (see Appendix 3 for summary of complaints).

This increase followed a joint tendering process by NHS Sheffield Clinical Commissioning Group (CCG), Sheffield City Council and Sheffield Teaching Hospitals NHS Foundation Trust. The contract for the supply of BSL interpreters was awarded to LanguageLine Solutions.

After the contract was awarded, LanguageLine Solutions reduced the pay of BSL interpreters by cutting the minimum booking time from three to two hours. This led to a dispute which was followed by strike action.

We wanted to understand how Deaf people had been involved in the tendering process, whether their experiences or views had been considered, and how the dispute had affected them.

Advocates from Disability Sheffield were also supporting Deaf people who described being excluded from their own healthcare. They contributed to our understanding of the problems people were facing, and were involved in planning and facilitating the subsequent workshops.

Through listening to the concerns of our partners at Citizens Advice Sheffield and Disability Sheffield, we recognised that many of the problems service users were experiencing could be addressed by proper implementation of the Accessible Information Standard and the Equality Act 2010.

The findings of our recent report 'My Health, My Say', which gathered the views of people with a Learning Disability, also highlighted the potential of the Accessible Information Standard to improve the experience of health and social care for people with individual communication needs.

Since August 2016, providers of NHS or adult social care services have been required by law to apply the Accessible Information Standard in full. The Standard aims to 'make sure that people who have a disability, impairment or sensory loss get information that they can access and understand, and any communication support that they need from health and care services' (for an overview of the Standard, see Appendix 4).

Under the Equality Act 2010, providers of public services are legally responsible for making adjustments to ensure that people with disabilities are not excluded from accessing care (<https://www.legislation.gov.uk/ukpga/2010/15/section/149>).

However, the 2016 report, 'The Equality Act 2010: the impact on disabled people' (<https://publications.parliament.uk/pa/ld201516/ldselect/ldseqact/117/117.pdf>) criticised the NHS, amongst others, for failing to act proactively on behalf of disabled people to prevent discriminatory practices.

Communication was cited as a 'major issue', with disabled people often being unaware of their rights as they are not presented to them in a way that they can understand.

Within this context we wanted to give a voice to Sheffield's Deaf community to explore whether, in failing to seek to understand the needs and experiences of local Deaf people in the commissioning and monitoring of BSL interpreting services, these criticisms need to be addressed by providers and commissioners in Sheffield.

Quote: 'If all those responding to the needs of disabled people engaged with them, listened to them, and took account of their views, all would benefit.'

Equality Act 2010: the impact on disabled people, March 2016

How did we investigate?

At our initial meeting with Citizens Advice Sheffield and Disability Sheffield, we met Sharon Hirshman, a Social Worker who lives in Sheffield and works in Rotherham. Sharon is Deaf and advocates for the rights of Deaf people to be recognised and met.

Sharon had secured funding from South Yorkshire Community Forum and there was agreement to hold three workshops to find out more.

The aims of the workshops were to:

- Develop a greater understanding of Deaf people's experiences of using health and social care services
- Bring Deaf service users together with providers and commissioners
- Identify ways in which access to care and information for Deaf people can be improved

As a local Healthwatch we felt that we could add value to these workshops through our relationships with health and social care providers and commissioners, by providing staff to help run the workshops and by writing up the findings into this report. Sharon and our partners have in depth knowledge and lived experience, so it was right that they led on the design and content of the workshops.

We publicised the meeting as widely as possible within the Deaf community and we asked for representation from the adult NHS trusts (Sheffield Teaching Hospitals NHS Foundation Trust and Sheffield Health and Social Care NHS Foundation Trust), Primary Care Sheffield, NHS Sheffield Clinical Commissioning Group (CCG) and Sheffield City Council.

We were keen to bring a cross section of people together, and sought participation from commissioners of interpreting services, leads for the Accessible Information Standard, Quality and/or Governance Leads, operational leaders and frontline staff, as well as Deaf and hard of hearing service users and BSL interpreters.

Sharon asked Tom Bell from Sign Live to attend. Sign Live is an online video interpreting service, subcontracted by LanguageLine Solutions.

Tom, who is Deaf, gave a brief presentation at each of the workshops to explain why and how Sign Live can be used.

Members of staff from the Citizens Advice Sheffield and Healthwatch Sheffield helped to facilitate the sessions and took notes of all the issues that were raised.

We spoke to approximately 75 people over the three workshops.

Key Themes from the Workshops

- The communication needs of Deaf people are not routinely recorded and flagged by providers of NHS or Adult Social Care.
- The communications needs of Deaf people are not routinely shared between primary and secondary care.
- The problems that Deaf people experience are not being addressed in a meaningful way.
- Written information received by Deaf service users from NHS providers and Sheffield City Council isn't adjusted to the needs of Deaf people, for example, in an easy read format.
- NHS letters do not state whether an interpreter has been booked for appointments, causing uncertainty, anxiety and adding to the demand on support services who make phone calls on behalf of service users.
- It is very rare that two way text or email communication is an option available to Deaf service users.
- Provision of interpreters is inconsistent and unreliable, causing people to disengage from services and to suffer unnecessary distress.
- Interpreters are needed at every stage; in planned and emergency settings, inpatient and outpatients, at discharge and for Deaf carers.
- Health and Social Care professionals often have little awareness of how to best communicate with Deaf people and don't appear to understand their legal obligations under the Accessible Information Standard.

- Providers welcomed the opportunity to find out more about the experiences of Deaf service users but were unable to say when any of these issues will be addressed.

Workshop 1

A small group attended an evening session on Wednesday 11th October, with only one representative from health and social care, the Quality Manager for Patient Experience at Sheffield CCG.

We decided to run this session as a focus group to gain a more detailed understanding of people's experiences. People were asked to tell us their own stories of accessing health and social care. Staff from the Citizens Advice Sheffield, Disability Sheffield and BSL interpreters were invited to share some of their experiences. See Appendix 1 for summaries of the individual stories that were shared.

A common theme was the lack of clarity around booking interpreters, who is responsible for making sure an interpreter is booked and when should they do it? Deaf people asked for confirmation that an interpreter has been booked when they receive their appointment letter, and emphasised the importance of booking the interpreter in advance to ensure the booking.

Deaf people attend appointments not knowing whether an interpreter will be there, and this hasn't improved over time.

People felt that more should be done to avoid cancelling appointments on the day. The interpreters present said that the provider should contact the agency, a local BSL interpreter may be available at short notice. Sign Live could be a useful back up but people were clear that it shouldn't be the first choice for detailed consultations.

Our CCG representative was keen to find out what the process should be, particularly with regard to sharing information between GPs and hospital, and was concerned that she hadn't realised the extent of the problems people were facing despite attending Sheffield Teaching Hospitals' Patient Experience Committee.

She also asked service users whether they were asked about their experiences by health professionals. Sharon explained that there are barriers to Deaf people giving feedback, as it's only be possible if they are asked using BSL or plain English.

Similarly, the complaints system is challenging to Deaf people. An option for receiving complaints via a BSL video clip or text message would be more accessible.

Sheffield Teaching Hospitals' website has a BSL video explaining how to make a complaint about the NHS (<http://www.sth.nhs.uk/patients/patient-experience/feedback/how-to-make-a-complaint>) but it is not local so some information is very general.

Workshop 2

The workshop in the morning on Thursday 12th October 2017 was well attended, with service users who were Deaf and hard of hearing participating.

Sheffield Teaching Hospitals were represented by the lead for Equality and Diversity and colleagues from Patient Experiences as well as an out-patient nurse and a cancer nurse from Weston Park Hospital. Sheffield Health and Social Care Trust was represented by a nurse from the Memory Clinic and Sheffield City Council by their Customer Services Manager and Sensory Care Manager.

Participants introduced themselves to each other and discussed the barriers facing Deaf and hard of hearing people in groups.

The groups fed back some very similar problems to those discussed in detail at the first workshop.

What BSL users told us:

- Lack of basic Deaf awareness amongst health and social care staff - people described being shouted at.
- Lack of understanding of the role of the interpreter and what's important to BSL users.
- Reception staff don't know the procedure for booking interpreters.
- Reliance on written notes during consultations with GPs isn't equitable and 'not good enough'.
- The patient records system doesn't flag if a person's Deaf so the staff don't know.
- Interpreters not being present despite assurances that they would be booked, this happens at both physical and mental health appointments.
- Family members being used as interpreters is not appropriate.
- Information not passed from GP to hospital so hospital staff are unaware the patient is Deaf at the first appointment.
- Appointments/treatment delayed due to interpreter availability.
- Waiting for hours at the hospital for an interpreter that didn't arrive, the appointment had to be re-arranged.
- Wasting time checking if an interpreter has been booked, it should be an automatic process.
- Using Sign Live can be challenging if the screen is small, its not suitable for everyone.
- It would be helpful to be able to text and receive texts from all providers, some dentists do this and it works.
- People don't understand that a telephone consultation is not appropriate - Deaf people need face to face communication.
- Letters from the council don't take account of people's communication needs - they get thrown away or have to be taken to a support service for them to interpret.

What hard of hearing people told us:

- Social isolation is a problem for people who become Deaf in old age.
- Lack of visual cues to come into appointments is also a problem for hard of hearing people.

What interpreters told us:

- Sometimes they turn up and the appointment has been cancelled but no one cancelled the interpreter, and other times the patient doesn't attend, its a waste of time and money.
- The cuts to NHS funding shouldn't impact on provision of interpreters because of the National Framework Agreement.

What health and social care staff told us:

- Communication needs can be recorded on the new electronic patient record system (Lorenzo) at Sheffield Teaching Hospitals but staff don't know how to use it yet.
- The needs of Deaf and hard of hearing people aren't always prioritised even though individuals are trying to push it further up the agenda.
- It's not easy (for staff) to use alternative methods of communication, eg. text and email, infrastructure is needed to enable this.
- 'Personalisation' is a challenge - some people will want BSL but other will want other forms.
- There are huge training needs for staff, yet Deaf awareness is not mandatory.
- Staff don't know enough about the options available, for example, Sign Live.
- Other Sheffield NHS Trusts use Enable2 (another interpreter agency) and they struggle to recruit BSL interpreters.

At the end of the workshop, Jo Evans, Patient Information Manager from Sheffield Teaching Hospitals took the opportunity to update participants on how the Trust plans to address the problems people have experienced. Jo apologised that Sign Live had been introduced in a hurry in a response to the lack of face to face interpreters and not in the best way.

Jo said that she plans to invite Tom to deliver training to staff on Sign Live and she is keen that they address the issues that people have raised so that service users still have the opportunity to benefit from Sign Live.

Workshop 3

The final workshop took place at Farm Road Sports and Social Club with the Over 50's Deaf Group on Thursday 2nd November 2017.

At this event we heard from a wide range of people who described the barriers they have faced and the impact on them, including Deaf Blind service users. They described the barriers they have faced and the impact this had on them.

The stories we heard were consistent with the previous two workshops. We also heard greater detail about the importance of responding to individual communication needs and some of barriers to understanding that hearing people may be unaware of. See Appendix 3 for direct quotes.

For example:

- A Deaf person may continue to use BSL after a cochlear implant is fitted, and require an interpreter.
- BSL interpreters are not appropriate for Deaf Blind service users.

- A Personal Assistant (PA) or family member cannot provide the same level of interpreting as a professional interpreter for medical appointments.
- BSL has regional dialects which can make using a national service such as SignLive difficult.
- Deaf people want to be independent, relying on friends and family is a barrier to independence.
- Health and social care professionals do not always take the needs of Deaf people seriously – we heard about a doctor laughing at a patient when they explained that his beard and moustache made lip reading difficult.
- Health and social care staff don't understand that being Deaf can be a barrier to written communication – written English is considered by some to be a second language.

Follow up

We will invite all providers and commissioners to respond to the findings and recommendations of this investigation.

We plan to arrange a follow up workshop in February 2018 where we will invite providers and commissioners to provide updates on the progress that they've made in response to the overwhelming examples of poor communication practice we have summarised in this report.

As GPs were not represented at the workshops, we plan to approach the CCG and Local Medical Committee to seek their support in involving GPs in the next stages of this work. We hope to understand how GPs ensure that they are meeting the needs of Deaf service users.

At the next workshop we will share a leaflet, designed to be a brief guide for health and social care professionals on the 'do's and don'ts' for communicating with Deaf people.

We will produce a BSL video summarising our recommendations and the responses from providers, to help Deaf people understand what they can expect.

Recommendations

1. Providers of NHS and Social Care should recognise the legal requirement to meet the five elements of the Accessible Information Standard (Identify, Record, Flag, Share, Meet) and ensure that they are embedded and consistently applied within their organisations.

Immediate actions required:

- a. Establish a written protocol within each service describing how and in what circumstances an interpreter should be booked, with staff trained in the process.
- b. Monitor the number of appointments where a BSL interpreter is required but has not been booked (and whether this leads to cancellation/re-booking).
- c. Write appointment letters to Deaf people in simple language, with confirmation that an interpreter has been booked.
- d. Enable two way text or email communication.
- e. Develop a written protocol and training for staff on the appropriate use of SignLive, in conjunction with Deaf people. An accompanying BSL video should be made available for Deaf service users.

2. Commissioners should consider the use of measures and/or incentives to ensure the Standard is being implemented by providers.
3. Contract monitoring of LanguageLine Solutions should include the experiences and views of Deaf people.
4. Providers should ensure health and social care staff have at least a basic understanding of the needs of, and the problems experienced by, Deaf people and are aware of their responsibilities under the Equality Act 2010.
5. Local providers should act to ensure information about their complaints and concerns processes is accessible and available in BSL, including information about NHS complaints advocacy.

We would like to thank all of the people who contributed to his report, who attended workshops, told us their stories, and provided insight and guidance.

Appendix 1

Experiences shared at the Deaf Access Workshop, Wednesday 11th October 2017

Advocate (this person is Deaf)

There is a lack of basic understanding in the NHS about how to communicate with Deaf people.

It can be really difficult for Deaf people to read written English. BSL as a first language is very different to spoken English. Deaf people receive letters to say interpreters have been booked but there is no interpreter at the appointment.

Appointments are sometimes cancelled by letter, with people asked to phone the hospital to re-book the appointment. There is no understanding that the person is Deaf and can't use the phone.

One patient was lacking confidence in communicating with a stranger and he had his own way of communicating with his wife due to a slight learning disability so he did not really understand what was being translated. His wife was told by the consultant not to be involved in the conversation and was asked to wait in the waiting area despite her explanation that her husband would not fully understand. So when the interpreter asked questions, the combination of the Deaf person's nervousness and failure to understand due to his learning disability resulted in an incorrect pre-op questionnaire being carried out and the operation being delayed once the wife read the pre-op notes and reported it as incorrect.

Communication methods need to be at a level suitable to Deaf patients – it is not a simple case of straight forward BSL.

Advocate (this person is Deaf)

I supported a Deaf lady who asked me for help. She wanted to explain to her GP why she needed to be able to text them (because she can't use the phone). I really had to fight to get a meeting with the Practice Manager and I had to involve Voice-ability.

Eventually the practice did start accepting texts but it took a lot of time and effort. Being able to text is really important to Deaf people but not many places offer it.

I also heard from a Deaf person who had been refused an interpreter at A&E, and the staff also refused to use Sign Live.

On another occasion, Sign Live was used but inappropriately, at a consultant appointment. The staff hadn't been trained to use it and it wasn't explained to the service user.

Really Sign Live should just be used for short interactions or in an emergency when a face to face interpreter isn't available. Deaf people and staff both need training.

I'm worried that Sign Live is seen a cheap, easy substitute to booking an interpreter.

Deaf people need to have a choice, Sign Live won't always be suitable, for example, when the lighting is bad or when people are fearful of technology.

A lot of people accept that the right interpreter service isn't available. Some staff say they will book an interpreter but they don't or they don't know how. I've been told there is no interpreter available

but when I checked there was an available interpreter. I'm assertive but not everybody is, we need to help those people too.

I know someone who was told that because they have a PA they should use the PA as an interpreter, the PA had basic sign language but couldn't interpret medical terminology. The staff realised eventually.

People need to be aware that they have a choice, you shouldn't have to ask at every appointment, it should be recorded on the system what a person's communication preference is and whether they need a BSL interpreter. Some people are hard of hearing and prefer hearing loops.

As a Deaf carer I need an interpreter, if I'm attending an appointment with my elderly father, I need to understand how to feed him, how to take care of him.

Service representative (this person is hearing)

It's very common for Deaf service users to have to come to the Deaf Advice Team just to find out about appointment arrangements.

A high number of our enquiries are about whether an interpreter has been booked for an appointment. Couldn't it say so in the letter?

The Accessible Information Standard is in place so why isn't information recorded? A Deaf person is always going to be Deaf, they're always going to need an interpreter.

The process needs to be much clearer. I asked the hospital if someone could book their own interpreter and was told no.

Service user (this person is Deaf)

I recently went to see the eye consultant at the Hallamshire Hospital to have a check up after an operation. An interpreter hadn't been booked and the reception staff had no clue about Sign Live. I was stuck. And disappointed as I would have been happy to use Sign Live. Staff need to be aware of Sign Live. I do think that a long, in depth appointment needs a face to face interpreter, but in this case I was happy to use it. The receptionist eventually found a nurse with Level 2 British Sign Language - it was not appropriate.

At first I wasn't worried when there was no interpreter because I knew about Sign Live. Why didn't reception know?

Can't it go on my file that I'm Deaf and I use BSL? It's not appropriate to cancel appointments.

My GP at Crystal Peaks has a notification system so my name comes up when it's my turn but I have to constantly watch, I can't do the things other people do.

I heard about the parents of a hearing child who were told there was no need for an interpreter because the child is hearing.

Service user (this person is Deaf)

I went to hospital and took my sister with me. I told the receptionist I was Deaf but it wasn't recorded on my file that I was Deaf. Information wasn't transferred onto the new system. I'm Deaf and I need an interpreter - this information shouldn't be missing.

When I go to the GP, the receptionist calls me in and I'm dependent on other people in the waiting room to let me know. My neighbour let me know that the receptionist had called my name quietly.

Interpreter (this person is hearing and from a Deaf family)

I am the only hearing person in my family. My parents never used me as an interpreter and I had a happy childhood, but when my father became ill he was admitted to hospital (in York) for two weeks and an interpreter was only booked for the conversation with the consultant. The interpreter that had been booked knew my dad because my dad was well known in the Deaf community, and he was in tears.

He had 92 appointments without an interpreter being booked. I was told when I asked that there wasn't an interpreter available but later I found out that this wasn't the reason. On his records it did say he was profoundly Deaf, but he was always happy and didn't complain so the staff didn't book interpreters. I should have been there as a son, supporting my dad but instead I had to interpret at every appointment, I resent that. I wasn't qualified at that time but I had to interpret and I told my dad 'you are going to die'.

Since then I've trained and now I'm a BSL interpreter. I'm an ex-police officer. As a police officer I had a legal responsibility to book an interpreter so who governs it in the NHS? The receptionist?

I've been involved with Healthwatch in York and the reports always say the same things but the way the system is designed, it doesn't seem to make any difference.

Service representative (this person is Deaf)

My wife is Deaf and our three children are Deaf. They have lots of appointments at audiology and I always check every time we get an appointment for myself and my three children whether an interpreter has been booked because I don't trust what's in the letter. It takes hours of time and I'm often told 'thanks for reminding me'. It can cause anxiety and uncertainty, now knowing whether we will be able to attend.

Appendix 2

Experiences shared at the Over 50's Deaf Group, Thursday 2nd November 2017

Experiences in a variety of care settings

'I have recently had a cochlear implant. However, this does not mean that I am suddenly a 'hearing' person, but the doctors now treat me as such. I still require an interpreter but they don't provide one.'

'I was an inpatient on a hospital ward. My carer left me so I had no way of communicating – I felt extremely isolated while there, I had no idea what was going on.'

'I had an interpreter for a doctor's appointment but they weren't able to stay for a sufficient amount of time, they had to leave and go somewhere else.'

'My son had to take time off work to accompany me to medical appointments.'

'My doctor had a huge moustache and beard, so I couldn't lip read. When I told him this, he laughed and didn't do anything to help me understand.'

'The people at the doctors expect me to be able to use Google, they don't understand that English is my second language, and Google is all in English.'

'I didn't know that there was a form like this* (*Communication needs) where we could fill in our preferences.'

'GPs don't know how to book interpreters, there is no up to date information about provision, and where interpreters are provided from.'

'I can't be independent in my own Healthcare; I have to rely on my family and my friends. They have to play piggy in the middle on my behalf.'

'Doctors don't think about the fact that a back and forth conversation with an interpreter and a Deaf person takes much longer than one with a hearing person.'

'There is a lack of understanding at my GP practice. I requested a BSL interpreter, but they didn't know what it was or how to book one. I rely on my Mother and Father but they are both elderly.'

'When the interpreter doesn't turn up, as a Deaf person, I don't know what to do and why they haven't arrived.'

'I need a Deaf Blind interpreter, but I only ever get booked BSL.'

'Sometimes they book an interpreter, sometimes they don't, and I get by.'

'One person usually thinks that an interpreter has been booked, another doesn't; this means that usually an interpreter doesn't turn up. There is an issue with consistency.'

'Carers who don't sign can't interpret; mine struggles to understand.'

'When I go to my doctors at Norfolk Park, there is often no interpreter. I think that this workshop is a really good idea, I'm happy for you to share my story.'

'Some interpreters have a bad attitude, this doesn't help.'

'Royal Hallamshire never provide an interpreter, I'd rather have my PA and an interpreter there, I need both – The PA can clarify, but the PA needs information from the interpreter.'

'If it is an emergency, I have to manage without an interpreter, although usually one gets booked.'

'I am a PA and when I go to the doctors with my client, they will ask me to interpret but I shouldn't be doing that, it's not my job so it shouldn't be me.'

'My son and my daughter in law have to come to appointments with me. My daughter in law has experienced problems at work because of this necessity. I live alone in a flat, I don't know what services to use or who to go to. It's really hard, It's really difficult on my own.'

'When I go to appointments, it's all over the tannoy or shouted. When I was younger, they used to hold a card up; I wish they would give me a card number and hold it up as well as shouting.'

'I went to A&E, but there was no interpreter, and I ended up going home at 5AM without being seen.'

'I am taken to the Drs by my husband. My husband doesn't sign, he doesn't tell me what the doctor is saying – this means I'm unaware of my own health, I only sign a little bit anyway. The doctor just talks to my husband as if I'm not there.'

'A couple of years ago, I had an accident and ended up in hospital, there was no interpreter there and they still aren't regularly providing interpreters now, it's not good enough. My Mum had to come to the hospital to help, after 24 hours they still hadn't provided an interpreter. For my aftercare, they said, 'We've got a nurse who can sign a bit' they insisted on using this nurse who only had Level 2 or 3 BSL.'

Booking appointments

'When I'm booking a doctor's appointment, I rely on using text and on getting a reminder from them but sometimes they don't text me. There isn't consistency.'

'I don't want to have to ask my husband to phone my GP for an appointment – Sometimes it's private but I have to get him to do it, usually.'

'When I try and book, Type Talk is engaged constantly.'

'I know that the surgery has a text facility, all Sheffield hospitals need consistency with how they use email and text message.'

'There is no reply function for text reminders, but I need this to be able to communicate.'

'I am not sure how to make sure an interpreter will be booked. Preferences should be recorded on a patient's record, so it is done automatically each time.'

'I would like to be able to send an SMS to my GP but I can't.'

'My referral was last minute so I couldn't arrange to go to hospital with my carer/interpreter, but because I am Deaf Blind it is necessary for them to be there.'

Experiences of Sign Live

'I have used it before but I couldn't understand it. I would prefer having an interpreter in the room.'

'When I used it, because of the regional signs and dialects, I couldn't understand. It was a Scottish interpreter.'

'Some interpreters are uncomfortable relaying information with Sign Live, they don't have the patience.'

'I can't use Sign Live from home; I am an older person, and I can't use that level of technology.'

'My Doctor didn't know about Sign Live.'

Appendix 3

Examples of complaints made about provision of interpreters and Sign Live at NHS appointments in the past 12 months.

- Deaf patient attended the hospital with heart symptoms. There was no BSL interpreter at the appointment so it was cancelled and rearranged for two weeks later. The Trust acknowledged their oversight in not booking an interpreter.
- Sign Live was used inappropriately in a consultant appointment. The communication was so poor that the Deaf patient was unclear on what was happening. We were told that the consultant was also unhappy with the communication level of Sign Live and is raising their own concern to the Trust. We were told that other consultants are unhappy with video interpreting being used for their appointments.
- A Deaf patient attended an appointment at the eye clinic for a consultant appointment and was asked to use the Sign Live. This was not appropriate due to the patient's poor eyesight, with the picture of the interpreter on the screen being so small. The Deaf patient struggled to see and could not understand the consultant. The BSL Interpreter on Sign Live made no attempt to make sure Deaf patient understood. The patient walked away from appointment confused.
- A Deaf patient travelled out of area for specialist eye treatment. The patient was gone for the day and travelled by train with a support worker. The BSL interpreter did not attend and the appointment had to be re-arranged for two weeks later in which Deaf patient made a return journey with a support worker.
- A Deaf parent attended a behavior assessment appointment for their child for possible autism/ADHD. The appointment was cancelled as there was no BSL interpreter present and was re-arranged for four months later.
- A patient's wife who is Deaf arrived at hospital looking for her husband who is also Deaf. Hospital staff struggled to communicate with her and took her to the wrong patient who had the same name.
Eventually the patient's wife was directed to the Intensive Care Unit. It had not been explained to her that her husband was in Intensive Care Unit and this left her very upset, frightened and worried.
- A Deaf patient struggled to follow what was going on during a consultation using SignLive. The interpreter repeatedly told the consultant to stop but the Deaf patient thought they were being told to stop. This confused the patient because the interpreter was looking at the patient to explain, (because the interpreter is on screen) and talking to the consultant at the same time. In a face to face setting the interpreter would turn round and ask the consultant to slow down and turn back to the Deaf patient. BSL is a method of communication that requires the use of body language, hand shapes, face expressions and use of emotional expressions.
- Several occasions when Deaf patients have attended an A&E only to miss their name being called, despite informing receptionists of their disability, causing delays to treatment and prolonging their pain unnecessarily.

- Two Deaf patients had their diabetes reviews cancelled and were given new appointment dates for the following month only to have them cancelled again due to lack of interpreters.
- A Deaf patient had his dental appointment re-arranged five times because the dental practice could not get a BSL interpreter, leaving the Deaf patient in considerable pain. The Dental Practice also made their own complaint regarding the lack of interpreters.
- A Deaf patient attended a consultant appointment and brought his PA with him to be on the safe side after previous experience with interpreters not being provided. Use of Sign Live was enabled but the patient found this to be such a bad experience that the nurse made a complaint. He feels his needs have not been taken into consideration
- A Deaf patient attended a hospital appointment. She took a family member just in case there was no interpreter and was right to do so because the booked BSL interpreter didn't turn up. The family member had to interpret for her which she found totally unacceptable.
- A Deaf patient attended a hospital appointment. She wasn't happy with her communication with the consultant at her appointment and she complained. She received a letter of reply stating that the consultant has agreed and written a letter to the Trust not to use Sign Live for this patient.
- A patient who had previously made a complaint against an interpreter, was given the same interpreter for her appointment. If she had a choice, this wouldn't happen.
- A Deaf patient had a full day appointment. The letter confirmed that a BSL interpreter had been booked. The patient arrived on the day to find interpreter did not turn up. The patient and her husband were very angry and complained.
- A Deaf patient was discharged from hospital without an interpreter, with no information about self care. The Trust responded that someone new was now in post who will be making training available to staff.

Appendix 4

Accessible Information Standard – Overview 2017/2018

Summary

The Accessible Information Standard aims to make sure that people who have a disability, impairment or sensory loss get information that they can access and understand, and any communication support that they need from health and care services.

The Standard tells organisations how they should make sure that patients and service users, and their carers and parents, can access and understand the information they are given. This includes making sure that people get information in accessible formats.

The Standard also tells organisations how they should make sure that people get support from a communication professional if they need it, and about changing working practices to support effective communication.

By law (section 250 of the Health and Social Care Act 2012), all organisations that provide NHS care or adult social care must follow the Standard in full from 1st August 2016 onwards.

Organisations that commission NHS care and/or adult social care, for example Clinical Commissioning Groups (CCGs), must also support implementation of the Standard by provider organisations.

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.
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.

More information

There is more information about the Accessible Information Standard on the NHS England website at www.england.nhs.uk/accessibleinfo

For more information please email NHS England at england.nhs.participation@nhs.net

or telephone 0300 311 22 33.

Or you can write to

Accessible Information Standard, NHS England, 7E56, Quarry House, Quarry Hill, Leeds, LS2 7UE

<https://www.england.nhs.uk/wp-content/uploads/2017/10/accessible-info-standard-overview-2017-18.pdf>