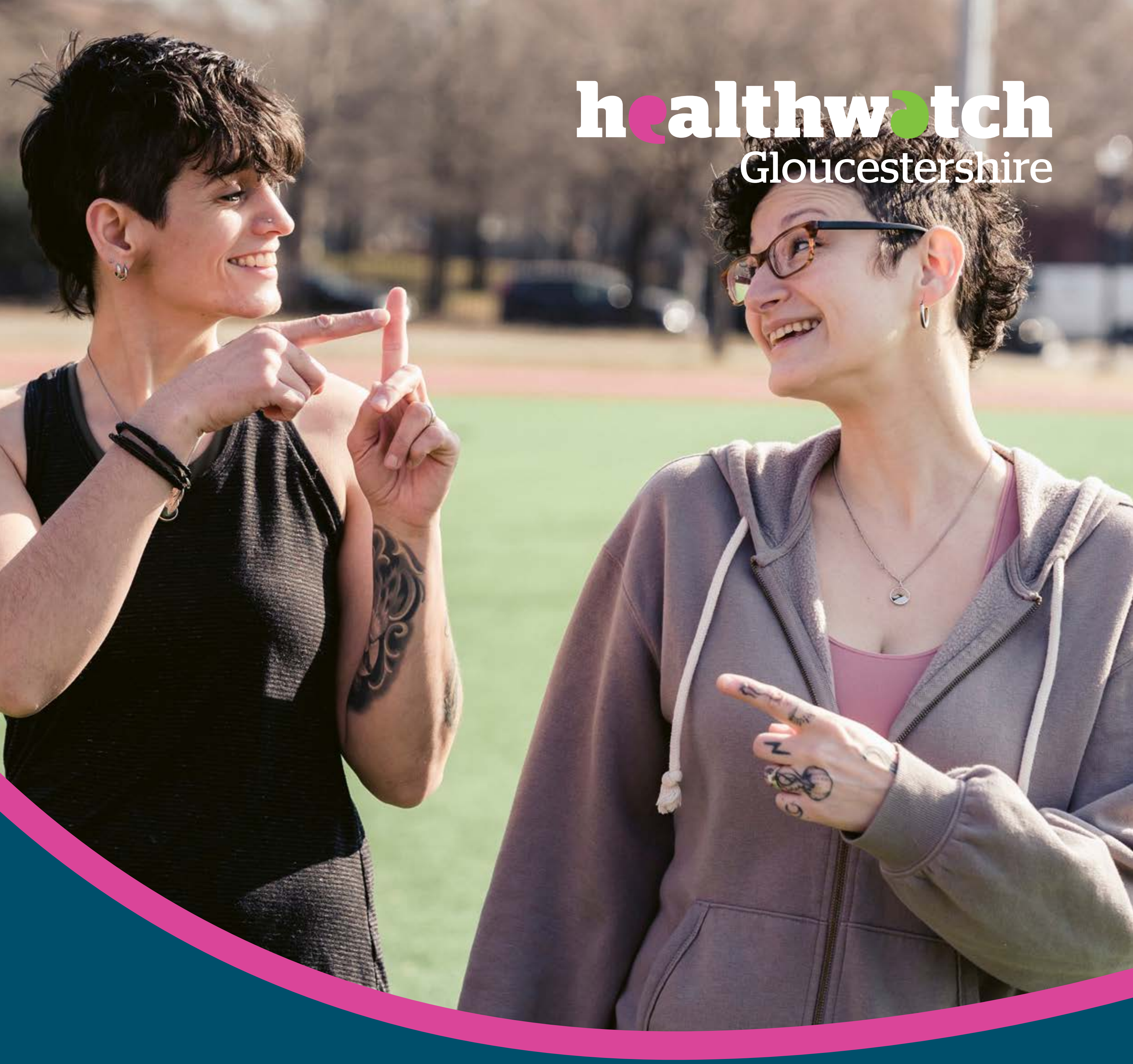


healthwatch Gloucestershire

Promoting the voices of the Deaf community in Gloucestershire

Working with the Care Quality Commission to tackle inequalities in health and social care

May 2022

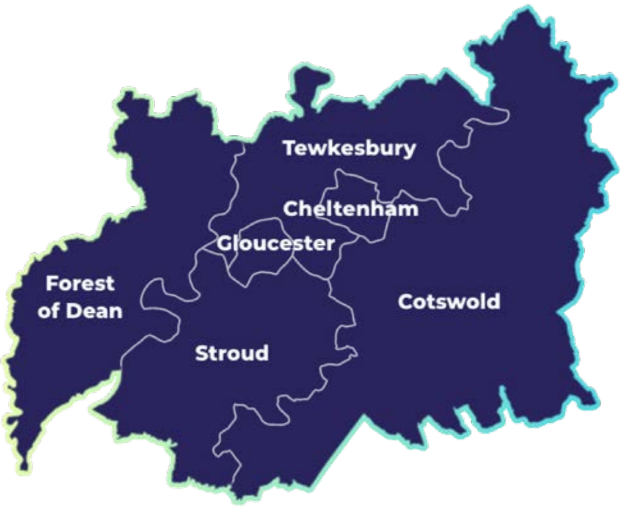
About us

Healthwatch Gloucestershire is the county's health and social care champion.

We're here to listen to your experiences of using local health and care services and to hear about the issues that really matter to you. We are entirely independent and impartial, and anything you share with us is confidential. We can also help you find reliable and trustworthy information and advice to help you to get the care and support you need.

As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care. This report is an example of how your views are shared.

Healthwatch Gloucestershire is part of a network of over 150 local Healthwatch across the country. We cover the geographical area of Gloucestershire County Council, which includes the districts and boroughs of Cheltenham, Cotswold, Forest of Dean, Gloucester, Stroud, and Tewkesbury.



Any enquiries regarding this publication should be sent to us at info@healthwatchgloucestershire.co.uk

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Background

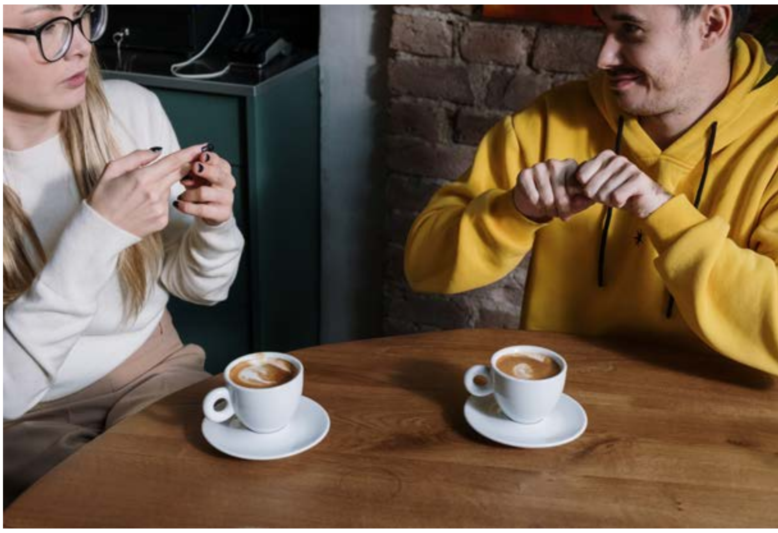
The Care Quality Commission (CQC) is the independent regulator of health and adult social care in England. It makes sure health and social care services provide people with safe, effective, compassionate, high-quality care and it encourages care services to improve.

In June 2021, the CQC launched its new strategy, which aims to provide the public with independent assurance on the quality of care in their area and to tackle inequalities in health and social care by improving access to services, patient experiences and health outcomes for everyone.

The CQC has highlighted the need to raise awareness of its work among people in seldom heard groups and communities, where it acknowledges there are specific challenges around understanding, accessing, and using services. Some of these challenges include digital deprivation, inaccessible services, and a fear of expressing views on the quality of care. In some situations, people are not aware that they have rights to expect and receive health and care support, or they do not know what good care looks like.

Aim of the project

The CQC asked us to undertake an engagement project with the Deaf community and people who are hearing impaired. They wanted to know which health and social care services people use, what they expect from those services, what barriers and challenges they face when trying to access them, and what changes they would like to see to improve access to health and care services. The CQC also wanted to know what the Deaf community and hearing impaired people know about the CQC, and how they might be encouraged to share their experiences and feedback about health and care services.



What we did

We worked closely with the Gloucestershire Deaf Association (GDA) to plan and promote this project.

We held a focus group discussion in July 2021, to explore people's views and experiences in depth. The discussion was supported by two British Sign Language (BSL) interpreters.

We promoted the event on social media and through the GDA; they created and shared a signed version of our event poster.

Six people took part in the focus group, five people who use BSL, one person who is hearing impaired, and a representative from the GDA.

The discussion was focused around nine questions (see Appendix).

What people told us

Focus group discussion

1. Which health and social care services do you use on a regular basis?

('Regular' could mean appointments every few months if there is an ongoing issue, a six-monthly review, or an annual appointment.)

Some of the group have regular appointments with GPs and hospitals including blood tests, audiology appointments, and diabetes checks, although these had been less frequent during the pandemic.

2. How do you access these services?

The group had different ways of accessing these appointments, with some using relatives or asking the GDA to help them, and others using specific packages such as the 'Whereby' video app or text-to-speech software.

3. What challenges do you encounter when trying to access services?

Everyone had a story to share about the challenges they have encountered and which they continue to experience. A few people described their experiences of visiting GP practices since new COVID-19 procedures were introduced.

Face masks

Since summer 2020, we have all been required to wear face masks when visiting GPs and other health services. Masks have increased the communication challenges experienced by people who are Deaf and hearing impaired because they prevent lip reading. We were told that masks have become a huge barrier to communication and many people now feel more isolated than ever.

We heard that very few GP practice staff, if any, wear clear masks that enable lip reading. In addition, even when staff are wearing clear masks they will turn around and keep talking, so the patient cannot see them to lip read.

Intercoms

People talked about how difficult it is if they have to speak to someone on an intercom before being allowed into the GP practice. This is impossible as they cannot hear the other person speaking. Often, they have to wait for someone who is leaving or arriving at the building to let them in to the GP practice. They felt that this is not good enough and that no provision had been made for their needs; their frustration was palpable.

In the waiting room

One person described the challenge of waiting to be called through to see the GP. They told us that they keep an eye on the door to see if they can recognise the GP who might have come to collect them. And, when someone appears at the door, they will look around to see if any other patients stand up. If not, they will stand up themselves and hope they are the person being called through.

Use of communication systems

We heard that sometimes systems have been set up to enable the GP to communicate with the patient via an interpreter, but the GP does not know how to use them.

> **An interpreter had been booked for my GP appointment through the Whereby System, but the doctor could not use it and I was just sat there waiting.**

One person described having two hospital appointments booked three days apart, and they happened to have the same interpreter for both. The hospital had told the interpreter about the second appointment, but they had not told the patient. The interpreter told the patient about the second appointment, though an appointment letter was received from the hospital on the following day.

> **The interpreter knew about my appointment before I did.**

Phone calls and answerphone messages

Another frustration and annoyance raised during the focus group is the number of phone calls made to people at home, or messages left on answerphones. People who are Deaf or hearing impaired cannot listen to voice messages or hear people talking on the phone.

One person described having a hospital appointment where an interpreter was used, and they were told that follow up appointments were needed. The patients email address was provided so that the hospital could send the dates and times for the next appointments. A few days later they noticed their phone flashing with voicemail messages, and they recognised the hospital telephone number. They asked the GDA to ring the hospital to find out what the messages said. The hospital did apologise and accepted they should have done better.

> **Why can't they use a flag system on their records, which identifies me as having a hearing impairment. It would be one extra field to complete but would make a huge difference to all of us.**

One person described seeing the GP for an ear infection, where they were given some medication and advised a referral to the hospital was required. They were told to expect an appointment letter or text message from the hospital, but they were still waiting nine months later with no communication, despite the GP chasing and the GDA getting involved.

> **I am told I am top of the list, but I am still waiting for some communication from them!**

4. What expectations do you have of health and social care services?

The group appeared to have little expectation of services working in a way that would benefit them, and they felt "this is just the way it is for us".

One of the group said that they have been trying to improve services for the Deaf community for the past 30 years, but nothing ever seems to change. Others in the group recognised this sentiment.

> **My expectation is medium to low, really.**

> **We would like fairness for all people; we want the staff to have adequate training to know how to work with Deaf people**

5. What would improve your experience of using these services?

Staff training

The most common issue mentioned by everyone in the group is the need for staff awareness and training. This is across the board, in all health and care settings, such as GP practices, hospitals, dental practices. However, everyone acknowledged that there is often a high staff turnover, which makes this difficult.

People feel that many staff just do not think; they will look away whilst talking, wear a cloth mask, or look down at their computer screen during a conversation, so the person is unable to lip read.

> **We want them to be prepared for any Deaf person who presents in their services and to know how to communicate with them.**

> **It should be in their induction training that they have Disability Awareness Training.**

Support the communication needs of Deaf and hearing impaired people

A flag system (or similar) was suggested, to identify on patients' records if they are Deaf or have a hearing impairment, and to highlight the most appropriate way to contact them, such as sending an email or text message.

It was also suggested that someone could be waiting to greet Deaf and hearing impaired patients when they arrive for their GP appointment. This would mean they are not left waiting outside, unable to use the intercom, until someone else lets them in or speaks on their behalf.

There is anxiety around the arrival process for medical appointments. People with a hearing impairment might not know where to sit or if the receptionist is aware they are waiting, and they may be unsure about how they will be called to the appointment.

> **I don't feel comfortable coming into that environment.**

Use of interpreters

Ensuring Interpreters are automatically booked for each appointment would improve the experience for people who are Deaf and hearing impaired.

Sometimes interpreters are used online to communicate with the patient, but this is only as good as the technology. We heard that there are places in all hospitals where the internet signal can be unpredictable and this causes issues when the screen freezes, or the signal drops out.

> **The Wi-Fi can't always get through every part of the building and the technology should be there.**

Everyone agreed that since the GDA took over the contract to supply interpreters, things have improved, and can be actioned more quickly. However, the service is only as good as the information provided to the GDA, and this can be patchy.

Continuity of care was also discussed. If an interpreter is booked for an appointment and a follow-up appointment is needed, the next booking should be automatic. It was suggested that the flag system on patients' records could support this.

> **Deaf people should not be an add-on, and we should be a part of the everyday.**

6. Have you had a bad experience when trying to access a service, and if so, what action did you take?

Communication breakdown after surgery

One person described going to hospital for an operation, where an interpreter had been booked to attend during the operation. This went well and the interpreter left. However, the patient had to stay in hospital, and this is where things were not so well managed.

> **I had to stay in the hospital and a little later the doctors and nurses ran over and were talking to me, but I had no idea what they were saying and there was a complete communication breakdown. No one thought to bring in another interpreter to help and instead they wrote notes to me, despite me feeling dizzy and dazed.**
>
> **They were explaining that my heart was racing, and I was really emotional and upset as I didn't know what this really meant. I messaged the GDA, and they organised an interpreter straight away; one of the staff actually drove over to be with me. I cried when the interpreter arrived as I was so happy that I would finally be able to communicate with the hospital staff.**
>
> **The interpreter explained to me what had happened and explained to the doctors and nurses that I could not read the notes they were trying to use. It was only at this point they realised their mistake and that they should have arranged for another interpreter.**
>
> **I did not even think to complain about this as it is fairly normal for us to experience these situations.**

Nearly missed appointment

Another person described going to an audiology appointment and almost missing it because they didn't know they were being called. They felt this difficulty arose because staff did not use BSL or clear face masks to enable lip reading.

> **You can see them talking, but you do not know what they are saying. It is really embarrassing to get up and walk towards them and then have to turn around and sit down again, as they were not calling you. The Audiology Department in a hospital should be the most accessible one for Deaf and hard of hearing people, but often they turn out to be the worst.**

Deafness is not just a medical issue

> **The hospitals often look at Deafness as a medical issue. They see that we have 'broken ears' and they want to fix them, but I don't want to become hearing and I am proud to be Deaf.**

Language deprivation

Often, people who are born Deaf have language deprivation, because, unlike hearing people, they are unable to 'pick up' language by listening to others as they are growing up. This in turn means "they don't know, what they don't know" and until the need arises, many words and phrases are unknown.

Requests for GDA support

The whole group were aware and extremely grateful for the help and assistance they receive from the GDA on a regular basis.

We also heard that the workload of the GDA, and particularly a specific member of staff, has increased significantly since the start of the COVID-19 pandemic. This is largely because it is so much harder for Deaf people and those who are hearing impaired to phone and speak to health professionals such as GPs, pharmacists, and hospitals, and the GDA help them with this. In addition, there are occasions when an interpreter has not been booked and the GDA is then required to help with very little or no notice.

The GDA have a very good relationship with their commissioner who is very supportive and even went to the hospital and spoke to them about being more Deaf aware and they took it all on board. However, shortly after this happened, a Deaf patient went to a pre-booked appointment at the hospital and an interpreter had not been booked, but this appears to happen quite a lot.

> **These sorts of incidents are frequent and frustrating for all of us.**

The GDA has spoken to the commissioner about having a dedicated health and wellbeing officer in the hospitals to assist Deaf and hearing impaired patients. This would be a peripatetic role, where they would move around hospital departments as required. The commissioner acknowledged this as a positive step.

The Barnwood Trust reports that in Gloucestershire there are 11,000 people with learning difficulties and 43,000 people who are Deaf or hard of hearing, and although there is a learning disability liaison officer in the hospitals, there is no one yet to support Deaf patients through their care and treatment

The GDA reported that sometimes, when interpreters are not booked by hospitals, family members (often young children) are used to interpret. They commented that this is not acceptable because it puts a huge responsibility on the family member to make sure their interpretation of the conversation and medical references is correct.

It takes seven years to train as an Interpreter and they are trained well and are extremely professional. They are also trained in jargon too, so they have a full understanding of what is being said and the way to pass the medical information on in the correct manner. All interpreters are covered by professional liability insurance, which is not the case if a member of the family is having to do this.

Use of display screens

One person told us that she had asked why none of the GP practices or hospitals she had visited in Gloucestershire use a screen to display the patient's name and which room they need to go to when it is time for their appointment. The response was that this does not comply with General Data Protection Regulations (GDPR). This made her wonder why a new hospital in Bristol does this and why they think it's fine to say someone's name out loud, but not to display it on a screen: "It doesn't make sense and I do not understand why this is the case."

Another participant commented that their GP practice had used screens in the past, but has now reverted to calling the patient's name, even for a Deaf person, which is useless.

7. Are you aware of the CQC and do you know what their role is?

Only one member of the group was aware of the CQC, which they had used to check care home ratings when finding a home for their mother.

Another person asked if CQC information was available in BSL and if so, how could this be accessed.

8. Have you ever had any dealings with the CQC?

The one person who had used the CQC to check care home ratings, thought their website is fantastic. They particularly liked the traffic light system used by the CQC as they felt this made it simpler and easier to find a suitable care home for their mother.

9. Would you ever consider sharing your experiences of health and social care with the CQC?

The person who had used the CQC to view care home ratings, did not know that they could contact the CQC directly and wondered why this would be necessary. They felt that, if there was a problem with the care home, they would first go through the care home's own complaints department. They also said that they would be more likely to contact Healthwatch Gloucestershire as they had heard of us. They thought it was unlikely that any Deaf person would contact the CQC as they are almost completely unknown.

When we explained to the group what the CQC does, they said that they would be more likely to contact the Patient Advice and Liaison Service (PALS) or the GDA for information.

> **For people who are born Deaf, and experience language deprivation, it is likely they may not have the knowledge to know what an organisation is about, nor what it can do for them; this only changes when they need to know.**
>
> **The Deaf community learn through life experience, until forced to learn and understand something new. It is very common in Deaf culture to share information and thereby teach others, whether it be about a hospital department, service, or anything else.**
>
> GDA staff member

Case study: Sarah's story

Sarah's hearing is deemed profound in one ear and severe in the other, although she is able to hear fairly well with hearing aids, but as soon as these are removed, she cannot hear anything.

"A recent experience for me is regarding an appointment with an eye consultant at Gloucestershire Royal Hospital. The appointment was set up as a telephone consultation, despite me asking from the outset for an in-person consultation due to my hearing condition. In addition to this, they have changed the date three times, but did not take account of my request for a face-to-face appointment. Every time a new date has been sent to me, it is always as a telephone consultation which is just not appropriate or acceptable. I contacted the hospital to ask for an email address to enable me to deal directly with the consultant's PA and was advised the email address could not be shared due to GDPR.

"In order to try to sort this out, I contacted them again when my husband was around and following a number of transfers to different people, I finally spoke to the consultant's PA and the appointment is now in person, but it has taken a lot to arrange this and I still do not have an email address to enable me to communicate with anyone.

"I always try to make calls when my husband is with me so he can hear the conversation and if needs be, he can take over for me, as access only via the telephone is not ok for me.

"Saying I cannot have an email address to me would be the same as bringing a wheelchair user to the steps of the hospital and then telling them to walk up the steps to access it.

"My second experience relates to the Audiology Department in the hospital. When attending a recent appointment I approached the reception desk and could see they were sitting behind a clear screen, which was fine. However, all of them had cloth masks on and when I approached, the Receptionist asked me a question, but I could not hear what she was saying, nor could I lip read due to the cloth mask. After three times of asking me a question and me trying to explain I could not hear her, I was met with was an eye roll and then she wrote down what she was saying. In addition to this, what I find even more incredible, is that this department, of all departments, has a system of staff coming out to reception and calling your name when they are ready for you! The individual calling you then wonders why no one is coming forward, as though this is a surprise. These staff are also wearing cloth face masks, which ensures no one is able to lip read either. Once in the appointment, all the Audiologists are also wearing cloth masks, which is just no good.

"Surely at the very least, the staff in the Audiology Department should be wearing clear masks. Eye rolling at patients is not acceptable. Given this service is for people who cannot hear, I was very surprised at the lack of thought or provision.

“I have found it very difficult to communicate with my GP practice and this is yet another example of the lack of patient care due to them only offering telephone contact. I have access to SystmOnline, but I am not able to book an appointment through this, or indeed request a repeat prescription. Once again I have asked for an email address to be able to write to them, but they will not give this to me. I am left having to complete their online form every time I want to make contact with them which asks lots of unnecessary questions and takes time to complete, when a simple message is all I need to send.

“Myself and others who have a hearing impairment often have a preferred way to make contact with services and this needs to be taken into account and noted on our records. For example, I prefer to make contact via email as this enables me to express everything I want to say and there are never any issues with misinterpretation.

“Communication with the medical world has been especially hard since everyone started to wear masks and even when I ask if they can remove them to enable me to lip read, very few people are willing to do this.

“Staff training on how to communicate and treat patients who are hearing impaired should be standard.

“No one should feel they are a nuisance and should be treated with the same respect as everyone else.

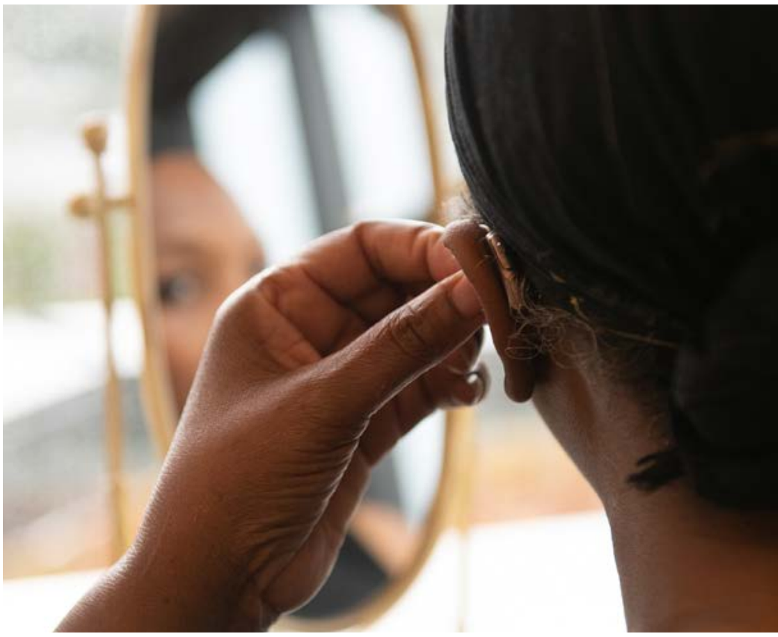
“On different occasions in the past, I have complained following my experiences of trying to access services, although it seemed to make little to no difference. If possible, I like to have my husband near, or with me, to ensure he hears everything being said and he can then explain it to me. However, there was one time recently when he was not there and I could not hear so asked the staff member if they would remove their mask and was told no, because ‘you can hear some of what I say, so you are not really Deaf’.

“I am aware of the Care Quality Commission, although I am not really sure what they are meant to do. I did have dealings with them when a relative died, and I would consider sharing my experiences with them.

“As a member of the Deaf and hearing impaired community, I often think there could be some simple solutions which would make a huge difference to us.”

Key messages

The CQC asked us to investigate the challenges and barriers experienced by people who are Deaf and hearing impaired when using health and care services in Gloucestershire.



Based on the feedback we gathered, we identified the following key messages.

- English is not the first language for many Deaf people.
- Small adjustments, such as the use of screens and clear masks, can have a huge and positive impact on their experience.
- Ensuring a methodical system is in place for the booking of interpreters.

Recommendations

We have made the following recommendations to help the CQC advance its work to help tackle inequalities in health and care.

- To work with the Association of BSL Interpreters on a national level to understand the challenges Deaf and hearing impaired people face.
- To use an easily identifiable symbol on patient records to identify they have access requirements and need reasonable adjustments.
- To use plain English and ensure easy access to alternative ways of communication.
- To ensure all medical settings use screens and other ways of communicating with the Deaf and hearing impaired.
- Staff training in communicating with the Deaf community in all NHS settings.

Case study recommendations

- GDPR becomes an issue to many patients when trying to make contact with the medical professionals, so there needs to be a generic email address for use to communicate with the different departments.
- Having a screen in the waiting room to show the name of the next patient would be an easy solution.
- On arrival for an appointment, give the individual a 'pager' (for example, like the ones given when you are waiting for food in a pub or café) and then when it is time for the appointment, it would light up and vibrate, so the person knows it is their time.

Next steps

We have shared our findings with the CQC to help complement their new strategy, and to help them achieve their core ambition to tackle inequalities in health and social care. The CQC are confident that this work will feed into many different future work streams.

Stakeholder response

Care Quality Commission
Ellen Fernandez, Public Engagement and Insight

- Public Insight Team (my team)– we are able to use this report to influence. For example we run the CQC Access Able panel, which is to allow colleagues to test content and build their accessibility skill set knowledge base by regularly working in partnership with people who use services and experts by experience. We hope that this will improve the accessibility of content and engagement of people who use services.
- Transformation Team – they are developing policies and new ways of working and regulating services. A large part of the public engagement strategy focuses on improving our accessibility. The following was part of an annex shared with our Transformation Board:

  People's experiences and people at the centre

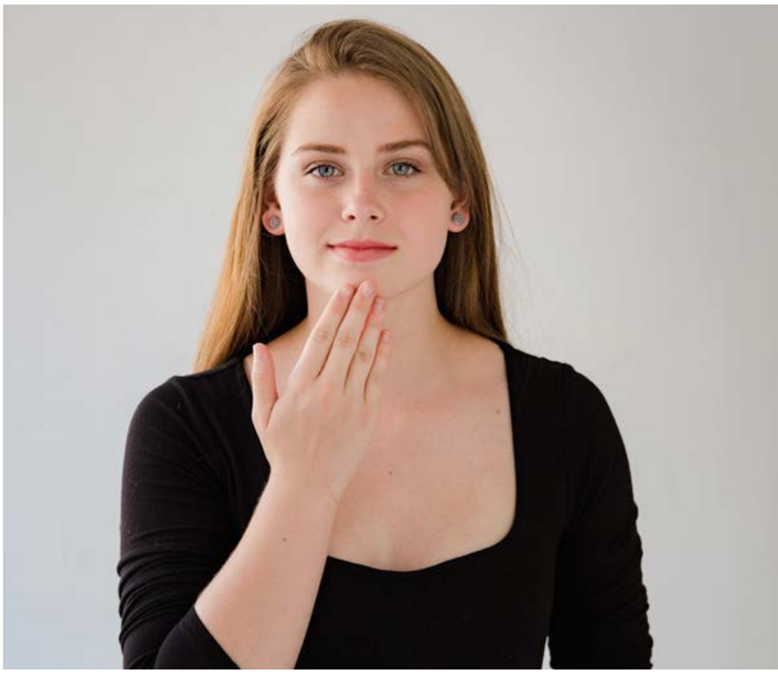
  Seldom-heard groups represented by local Healthwatch shared their views on how we work. Some themes are relevant to developing our new approach, for example, importance of accessibility and alternative formats; clarity of wording; explanations for how to navigate the system; importance of including the voices of carers and family; support useful to help certain groups to share their experiences.

  - Inspection teams – although no services are named it's helpful for the inspection teams to have sight of issues and positive practices in their patches.
  - National service centre – our call centre which takes calls and queries. We do have a BSL interpreter facility, which is why I have given them sight of the report.

Thank you again for completing the engagement on our behalf. We will continue to use the report to influence.

Thank you

Thanks to those who shared their experiences with us. Without you, we would not be able to do the work that we do. A special thanks to Sarah (not her real name), who shared her story with us. We would also like to thank the Gloucestershire Deaf Association for all their help and support with this project.



Appendix

Focus group questions

1. Which health and social care services do you use on a regular basis?
2. How do you access these services?
3. What challenges do you encounter when trying to access services?
4. What expectations do you have of health and social care services?
5. What would improve your experience of using these services?
6. Have you had a bad experience when trying to access a service, and if so, what action did you take?
7. Are you aware of the CQC and do you know what their role is?
8. Have you ever had any dealings with the CQC?
9. Would you ever consider sharing your experiences of health and social care with the CQC?

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