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**Survey Responses from Deaf people
(British Sign Language):**

Gathering views about using digital
technology to speak to a GP

Collated by Dawn Marshall (Becoming Visible) on behalf of Sunderland, County Durham
and South Tyneside CCG — July 1st, 3rd and 14th 2020



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Background information

There are approximately 5,000 Deaf people who use British Sign Language in the North East of England* (<https://bda.org.uk/help-resources/#statistics>). Bear in mind, many Deaf people are also parents of children who are not Deaf but for whom they have guardianship for. With guardianship comes responsibility and decision making and these responsibilities are often extended to other family members who may be elderly and vulnerable and require support; so, the figure of 5,000 may appear a higher number than initially thought.

This is a large group of people who are usually classed as 'vulnerable', 'hard to reach' and the majority of NHS workers do not use British Sign Language and even less that use it fluently, therefore, the thoughts and real-live experiences of these people do not get included into service planning and delivery. This report is designed to do just that, take on board people's experiences in order to shape future NHS delivery in within the General Practitioner's (GP's) environments.

For the majority of Deaf people, who use British Sign Language, written English is usually not an option as a means of accessing information. A lack of confidence and ability in written English goes beyond simple 'reading ability' and, as such, an enormous barrier is created that inhibits people from trying to contact their GP, talk with their GP, read any material that their GP may offer them to supplement their medical diagnosis and, as we have found, understanding instructions in taking their medicine. The risks that this invisible barrier places upon the doctor and the patient are enormous.

There are numerous case examples and background information for purchasers and providers of NHS services found here (<https://signhealth.org.uk/wp-content/uploads/2019/12/THE-HEALTH-OF-DEAF-PEOPLE-IN-THE-UK-.pdf>) to give some idea of the various barriers faced by Deaf people. This introduction is set in a way to provide some background reading and in understanding the feedback from Deaf patients living in the Sunderland, Country Durham and South Tyneside areas in the context of current and potential barriers we face using NHS services whether at the GP or elsewhere.

Methodology

As agreed with Sunderland CCG's Involvement and Engagement Manager, Lisa Anderson, Becoming Visible would advertise a Zoom meeting to take place on 1st July 2020 with a view to translate the survey in BSL and collate people's viewpoints. It was found that many elderly deaf people did not want to use technology to give feedback, instead wanting to give feedback face to face and in person. Obviously, due to Covid-19 and social distancing restrictions at the time this was not feasible. As an alternative It was agreed that BV would have appointments time slots with individuals, via videocalls, as this was deemed to be a more manageable way for some to be involved and to give the feedback they wanted.



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In total, 11 Deaf people came forward to offer their views. It was evident that more time to engage with a larger demographic was important and that the NHS needs to consider a variety of different and accessible ways to engage with more of the local/regional Deaf people be that in consultations, surveys and/or design/ delivery of services.

Survey results - Gathering views about using digital technology to speak to a GP

Summary of individual's responses

Male	4
Female	7
I live in the following area:	County Durham = 3 South Tyneside = 1 Sunderland = 7
Age range	16-17 = 0 18-24 = 1 25-34 = 1 35-44 = 1 45-54 = 3 55-64 = 0 65-74 = 1 75 or older = 3 Prefer not to say = 1
Does your gender identity match your sex as registered at birth?	Yes = 11
Are you currently pregnant or have you been pregnant in the last year? Are you currently...?	No = 11 Cohabiting = 1 Divorced or civil partnership dissolved = 0 In a civil partnership = 0



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	<p>Married = 4</p> <p>Prefer not to say = 0</p> <p>Separated (but still legally married or in a civil partnership) = 1</p> <p>Single (never married or in a civil partnership) = 4</p> <p>Widowed = 1</p>
Do you have a disability, long-term illness, or health condition?	<p>No = 4 (they do not regard being Deaf as a disability)</p> <p>Yes = 7</p>
Do you have any caring responsibilities?	<p>None = 5</p> <p>Primary carer of a child or children (between 2 and 18 years) = 3</p> <p>Primary carer or assistant for an older person or people (65 years and over) = 1</p> <p>Secondary carer (another person carries out main caring role) =</p>
Which race or ethnicity best describes you?	<p>White (British, Irish, European, or other) = 11</p>
Which of the following terms best describes your sexual orientation?	<p>Gay woman or lesbian - 1</p> <p>Heterosexual or straight - 8</p> <p>Prefer not to say - 2</p>
What do you consider your religion to be?	<p>Christianity - 9</p>



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	No religion - 2
What is the first half of your postcode?	SR5 SR5 SR6 SR2 NE37 NE37 SR 1 NE32 DH1 DL14 DL14



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<p>Have you contacted your GP practice since the coronavirus lockdown on the 23rd March 2020?</p>	<p>Have not contacted my GP since lockdown = 1</p> <p>No = 1</p> <p>Rather not say = 0</p> <p>Yes, for a family member = 4</p> <p>Yes, for myself = 4</p> <p>Yes, for myself and a family member = 1</p>
<p>If you have contacted your GP practice, how did you make this initial contact?</p>	<p>By completing an online form (also known as a online consultation) = 0</p> <p>By telephone = 0</p> <p>Does not apply – have not contacted my GP = 1</p> <p>Other:</p> <p>1 = asked my mam to call on my behalf as there is no way for me to contact the surgery on my own, eg. Text messaging (I cannot read emails so has to be brief like a text)</p> <p>1 = Had to physically call into the surgery but was told not to go in and shooed me away. I felt small and really anxious/ worried about how I was going to get help so felt ill and ended up going to A&E</p> <p>6 = Had to ask someone to call for me. Did not like it because no privacy. But no choice.</p> <p>2 = Used NHS 111 video interpreting service to call in BSL</p>



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<p>What happened as a result of your contact with your GP practice?</p>	<p>Does not apply – have not contacted my GP = 1</p> <p>I received my sick note/ prescription without an appointment = 3</p> <p>I was offered an appointment for a face to face, telephone or video consultation = 5</p> <p>I was provided with some information so I could self-care = 0</p> <p>I was signposted to another service = 1</p> <p>Other:</p> <ul style="list-style-type: none">a) I was sent away because I was not allowed in the surgery but there was no help and I felt really distressed and upset. Eventually I went to A&E – but no interpreter so it was back to square 1 = 1b) One lady was told she would be called back by her GP but they obviously couldn't so she ended up calling an ambulance for her friend when she wanted a face to face appointment with an interpreter.c) Couple: It was a little different for us as there were different situations. In the first instance we telephoned for an appointment for a GP consultation and that would be arranged with an interpreter. I always get a voice message back and I can't access it because I am deaf. So, I end up having to ring them back via NHS access BSL to say, "you've phoned me, but I can't hear your message". In the second situation, it was the same problem again. It was for a GP consultation, the surgery contacted an interpreter and gave the interpreter my number and the interpreter then contacted me via facetime, asked me to wait while they contacted the GP surgery and the appointment carried on from there. That happened quite recently, in fact, that was the last appointment we had with our GP. I was concerned about my data being shared because my mobile number was given to the interpreter without my consent.
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<p>If you were offered an appointment, what type of appointment were you offered?</p>	<p>Does not apply – have not contacted my GP = 1</p> <p>Does not apply – was not offered an appointment = 1</p> <p>Face to face – (I went into the GP Practice) = 2</p> <p>Telephone – 3 (then realised it didn't work!)</p> <p>Video – 2 (I spoke to a healthcare professional using a video camera)</p> <p>Other – home visit (shielding) – 2</p> <p>Comment here from a participant:</p> <p>In normal circumstances I would go to the GP surgery myself as the receptionist there is able to sign. Due to the pandemic, I wasn't able to physically go to the surgery so under these circumstances I needed my mam to ring them on my behalf. If my mam wasn't able to do this for me, then I would be completely lost and I wouldn't be able to access services. I am aware you can now do this online via video interpreting in some cases but I am not very good at using online services and so I would struggle. If my mam passed away, I would need to rely on my neighbours for support. I know there is no privacy doing it this way but if it is just for a prescription then I am ok with that. However, if it was a more personal, private matter, I would look at an alternative way to get support but I couldn't do this online as I don't know how to?</p>
<p>Were you given a choice of how you could have an appointment with a healthcare professional?</p>	<p>Does not apply – have not contacted my GP = 1</p> <p>Don't know/ can't remember = 1</p> <p>No, I did not have a choice = 8</p> <p>Yes, I had a choice = 1</p>



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<p>How likely would you be to recommend these methods of consultation to a family member or friend?</p> <p>This became a discussion point as with other other questions. What follows is a summary of the discussion points.</p> <p>Online Consultation</p> <p>Recommend this and views?</p>	<p>All disagree.</p> <p>The general consensus was that access to the English language would be a problem.</p> <p>What if the GP just uses medical jargon, it wouldn't be very accessible? They felt that there was little awareness of British Sign Language and how it functions as a language thereby impacting upon how GPs communicate with Deaf people. "Our first language is British Sign Language (BSL). It would be very frustrating as you wouldn't have any access to emotive language. It could also make you feel quite low if you had to access communication in this way."</p> <p>"I disagree with the use of online forms as it can be difficult to describe symptoms. However, the good thing about it is it's in black in white and you will be able to access your medical records and see what has been said. I have emailed my practice before to set up a telephone consultation and waited a while for a response. However, I had the email as evidence and could chase it up if I needed to. This was a positive action but not necessarily a satisfactory outcome."</p>
<p>Telephone Consultation</p> <p>Recommend this and views?</p>	<p>All disagreed.</p> <p>"We are Deaf!"</p> <p>It was felt that it would not be suitable for GPs to contact patients and discuss their health via the telephone as there would be no opportunity for Deaf people to 'see' the GP's faces, reading their body language and vice versa.</p> <p>"If someone calls me or leaves me a voice message, I just ignore it"</p> <p>The general consensus was that there is no one solution fits the situation and so there needs to be some flexibility and choice as to how the patients wish to be seen/ treated.</p>



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<p>Video Consultation</p> <p>Recommend this and views?</p>	<p>There were mixed responses to this.</p> <p>“It depends what the benefit would be for video calls. To make appointments, yes but not to discuss physical problems as this still need to be done face to face.”</p> <p>“I have mentioned to the GP that they should contact me via videocall but they keep saying that they can’t, what’s the problem? Before the pandemic they couldn’t and now they can, it’s not a problem but they need to get it right first”.</p> <p>“I would accept video calls with my Doctor if there was a streamlined process in place that guaranteed privacy, had an interpreter that I was familiar with and that everyone was able to feel confident in that process.”</p> <p>“I do find using technology difficult and I am young-ish so I do worry for older people who are not tech-savvy and would feel absolutely stressed out with using technology”</p> <p>“No, I would prefer to still go into the surgery face to face to have a proper consultation. What if there were technical issues with equipment and I couldn’t finish my consultation, I would find that very difficult. There are different scenarios but I would still prefer to have my consultations in the surgery.”</p> <p>“I would feel ok with video calls but it would depend on the quality of the call and using good technical equipment. Sometimes the picture can freeze or get stuck. If they say they will still carry out face to face consultations but only with a face mask and the interpreter isn’t allowed in, then how would that work?</p> <p>“Video calls are ok but what if I am in physical pain, you can’t see me then how will they diagnose the problem? Sometimes you need a physical examination to diagnose the problem and that can only be done face to face.”</p> <p>“Not everyone has access to technology”.</p> <p>“If you are describing symptoms virtually it can be very hard to see and explain what the problem is but face to face you can show the area of the body that is affected. When I had my</p>
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video call with the GP recently, I could only see the interpreter as the GP was on the phone to the interpreter. This meant the interpreter had to relay the issue without the doctor seeing us, that is very hard to do? I had to point to the issue I was having and the interpreter then had to translate it, did the interpreter translate the issue effectively and clear enough for the doctor to understand? We don't know if this happened, this is why it is crucial for a consultation to take place face to face while everyone is in the same room.

"If doctors are going to conduct video call consultations then the doctor and the interpreter must be on screen at the same time. This is so I can identify the issue and know that the interpreter has translated this correctly."

"Simple queries or minor ailments could be done via video calls but anything physical or more in-depth would need to be face to face."

"Whether the consultation is a video call or any other method, when the health professional opens your records it should have in bold red letters "DEAF/ BSL". Then doctors should be prepared to book an interpreter so that access is fluid and automatic. The problem is they sometimes expect the patient to call up but I can't do that as I am Deaf and I do wonder why this process is so difficult at times!

"I am ok using NHS 111 services but I don't think it is suitable for the elderly population. If you know how to use technology that's fine but a lot of people don't and there should be alternative methods."

"Also, NHS 111 uses interpreters from all around the country not necessarily using local signs and this will affect the deaf community as well as the added complication of using technology."

"I would recommend using the NHS 111 service as it is a solution for the deaf community rather than trying to use the telephone but yes, the interpreter on screen can be a problem. The 111 service tends to use the same interpreter all the time and I don't like that, I would much prefer to have access to a range of interpreters. If you ring up to complain there is the



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interpreter on screen and when you ring again on a separate occasion it's the same interpreter again. I just tend to put up with it as I need access to the service."

"Sometimes you want a specific interpreter due to the nature of the call i.e. women's issues and I wouldn't want to use a male interpreter. In these situations, I will hang up and see if a different interpreter comes on screen."

"You have both used video calls to communicate. I haven't as I find it a little bit scary, especially if I made a mistake, I don't have the confidence to make video calls. It was the same with using zoom, my friend had to help me out and tell me what to do as I was a bit dubious about how to use it. It's very hard for me to know how to make video calls, maybe could set up some training?"

"My friend was rushed to hospital by ambulance four times in May, when she was discharged home, she had no idea what happened (and still doesn't) as an interpreter wasn't booked. The doctor was fully aware she is Deaf and she cannot access English language spoken or written but no interpreter was provided! They inserted an intravenous canula in her arm to give her fluid antibiotics but didn't ask her permission to do so, they just went ahead and did it. That's dangerous!"

"If the NHS needs to move to digital platforms then they need to invest in patients by providing them with equipment and training to support them. This is only fair! I do worry for elderly patients who are extremely vulnerable and are more likely to be going to the GP than younger patients!"



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<p>Before completing this survey or before contacting your GP practice since the coronavirus lockdown on the 23rd March 2020, were you aware that you could speak to a healthcare professional at your GP practice through these methods?</p> <p>Online Consultation</p>	<p>No = 9 Not sure = 0 Yes = 2</p>
<p>Telephone Consultation</p>	<p>No = 11 Not sure = 0 Yes = 0</p>
<p>Video Consultation</p>	<p>No = 11 Not sure = 0 Yes = 0</p>
<p>How would you describe your overall views about these methods of consultation?</p> <p>Online Consultation</p>	<p>Don't know/ no opinion = 0 Fairly negative = 1 Fairly positive = 0 Neither positive or negative = 0 Very negative = 10 Very positive = 0</p>



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<p>Telephone Consultation</p>	<p>Don't know/ no opinion = 0 Fairly negative = 0 Fairly positive = 0 Neither positive or negative = 0 Very negative = 11 Very positive = 0</p>
<p>Video Consultation</p>	<p>Don't know/ no opinion = 2 Fairly negative = 7 Fairly positive = 2 Neither positive or negative = 0 Very negative = 0 Very positive = 0</p>
<p>How happy would you be to use these consultation methods, or to use them again, if a healthcare professional felt it was appropriate for your medical concern?</p> <p>Online Consultation</p>	<p>Don't know/ No opinion = 0 Fairly happy = 0 Fairly unhappy = 0 Neither happy nor unhappy = 0 Very happy = 0 Very unhappy = 11</p>
<p>Telephone Consultation</p>	<p>Don't know/ No opinion = 0 Fairly happy = 0 Fairly unhappy = 0 Neither happy nor unhappy = 0 Very happy = 0 Very unhappy = 11</p>



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<p>Video Consultation</p>	<p>Don't know/ No opinion = 2 Fairly happy = 0 Fairly unhappy = 0 Neither happy nor unhappy = 9 Very happy = 0 Very unhappy = 0</p>
<p>What do you think the benefits are of using these consultation methods?</p>	<p>The general consensus was that these 11 people felt that there should be CHOICE in how they would like to contact their GP and that the process should be streamlined, 2 way and accessible for all with local people involved in this set up. They felt that unless GPs and practices were Deaf aware there would continue to be barriers to healthcare.</p>
<p>What problems do you think people may experience with these consultation methods?</p>	<ul style="list-style-type: none"> • Lack of Deaf Awareness and Lack of understanding the issues around access to healthcare for Deaf people and BSL as a language • Lack of understanding how interpreters and the process takes place of using interpreters whether in the surgery or online • Poor wi-fi connection • Poor screen quality – low pixels and freezing pictures on screen • Use of regional dialects in BSL – poor interpreters affecting the interpreting process • No access to English language or voice calls • Lack of equipment at home (or surgery) • Lack of training for patients • Elderly community do not have access to wi-fi or mobiles • Connectivity issues such as power cuts (which happened in Sunderland twice in a week!)



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What do you think would encourage more people to use these consultation methods in the future?

- It's frightening, if the NHS see this working then it could diminish the use of interpreters, it's dangerous. It's ok to give patients a choice of how they would like to conduct their appointments and expand the resources they have available to them but not to reform the current system.
- When you attend appointments with an interpreter it is more interactive but when it is a video call it seems to be less engaging and a little flat. In a real-life situation, it is easier to be expressive but it's not so easy on a screen. Doing appointments remotely, you don't walk anywhere and there's not interaction, it feels a bit forced.
- I recently tried to encourage more people to use video calls but they were all reluctant to use it and didn't like the idea. They don't like to use technology and it is just because they don't know how to use it. They like to rely on their own ways of communicating and that is using a face to face interpreter.
- In the future if facetime was three dimensional, I would prefer it as it would be much easier and much clearer to see.
- If the CCG decided to promote the use of video calls in the future, then I would ask that local interpreters be provided for patient choice. I would prefer not to use national interpreters as I don't know who they are and I am not familiar with their use of signs. I would prefer to have a choice of local interpreters.
- If local interpreters are being booked and they can see by my name that I am a woman then I would expect female interpreters to be booked and not male interpreters given the nature of the appointment. I lose confidence when male interpreters are booked, and the appointment always needs to be rescheduled. This is a waste of money as the NHS has to pay twice for an interpreter. If it's a male patient, then it's a male interpreter but if it's a female patient then it must be a female interpreter.



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	<ul style="list-style-type: none">• Yes, give the patient the choice as there has never really been any choices for Deaf patients have there?!
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<p>What do you think would encourage more people to use these consultation methods in the future?</p>	<p>They all felt that there should be choice. The use of local resources such as local organisations, local companies, local training and support. Including the use of equipment.</p>
<p>Flu vaccinations</p> <p>Where would you find it most suitable to get your flu vaccination?</p>	<p>They all felt that it would be fantastic to have the flu vaccination at a local Deaf Club where NHS resources could be used more effectively. For example, book an interpreter all day which would be more cost effective for the NHS but also for Deaf people to feel comfortable in their own environment which was Deaf friendly.</p> <p>If not this, then post to home and for them to watch a BSL video on how to apply the jabs themselves.</p>



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Any other comments

- Streamlined processes - If attending an appointment, I would like to see staff who can sign to communicate with me when I first arrive as to make this experience really personal and welcoming.
- Covid-19 - There is a member of the deaf community who is fearful of attending medical appointments as doctors are wearing face masks. That is a huge issue for the deaf community, some people cannot remove their masks but there lies an issue for us as we cannot lip-read them. The deaf community is worse off because of this situation and the health profession needs to look into how they can improve this situation. A solution maybe the use of a visor as it would be clearer and you would be able to see the other person's face.
- PPE - I have been to the hospital and all the nurses and doctors are wearing face masks in the outpatient's department. An interpreter was also there wearing a face mask but forgot to bring her visor. So she borrowed the doctor's visor!
- The waiting rooms in Sunderland Hospital is awful and the nurse always calls the patient name out but because of how it is set up it is difficult to see her. They shout the patient name from behind a corner before they come out in full view. They then repeat the name again, when I realise it is me, they always say I said your name twice and I have to remind them that I am deaf.
- All staff, doctors and nurses need deaf awareness. Whether they are new starters or have been there for a while they need to run refresher sessions, possibly every five years. It would be lovely if they could use basic sign language, be more visual, waiting areas should be open plan without any barriers.
- I have been using my GP practice for a number of years now, but it has only been in the last two years when a new receptionist was employed that she learnt to sign. She always greets me with a smile and that has boosted



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	<p>my confidence. I asked for an appointment as I discovered a lump in my neck and straight away, she asked if I wanted an interpreter. She's also teaching other staff that they need to book interpreters for deaf patients and is currently undertaking BSL level two. I really appreciate her, but she only started there two years ago.</p> <ul style="list-style-type: none">• (Interpreters) I used their agency about three years ago and they supplied me with a cowboy interpreter. I explained the situation to the doctor's manager and they wrote a complaint to Sunderland CCG and then fed back to me that I would be entitled to use an interpreter of my choosing. Deaf people need to know that you need to complain to your local CCG if you are not happy. That's why my GP appointments are much better now but other GP's who have deaf patients are still having issues. But CCGS do not know how to engage with the Deaf community and they should be doing so much more than they do now.• I have had a lot of issues with XX company for interpreters, the problem is I don't want to cancel the appointment when the interpreter turns up and I don't know who to complain to? Can you pass on this information to the CCG as deaf people need a platform to where they can raise issues and complaints if they are not happy with the service they have received including issues with interpreters. Who do we contact? As before today I didn't know you could complain to the CCG. Now I know that you can but that information needs to be readily available to the deaf community.• Can we have a Deaf Community/ Service Users Improvement and Feedback Group for the CCGs to help them improve services for us?
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Summary

Although Becoming Visible was not asked to provide recommendations for the CCGS to consider, there have been some suggestions organically generated by those who participated in the discussions. We would suggest that these are incorporated into the future planning, service design and delivery for digital services within GPs in the future.

DM – Becoming Visible – 15 July 2020