

Deaf and disabled people's experience of primary care

What Deaf and disabled people would do to improve
primary care access



Background

SignHealth consulted with deaf and disabled people using an online survey. The survey was entirely focused on access to primary care, and people's recommendations for improvement. There were over 150 respondents, the majority of whom were deaf. A number of respondents had a learning disability. There was a geographic spread and the survey was also printed and circulated so it was accessible to people not connected to the internet.

Overview

The accounts people gave of trying to access primary care were extremely valuable. We always hear anecdotal tales of appalling practice, but it's hard to get the exact detail. Here, possibly for the first time, some of those worst fears were confirmed. Examples include: GPs refusing to book interpreters because they cost too much, patients leaving with no idea what is wrong with them, people not understanding their medication and taking the wrong amount.

However, there were also examples where people felt respected and happy with access. Indeed, in some cases it was clear that staff had made a conscious effort to adapt to the patient's needs. It is a shame this flexibility and respect is hard to measure and incentivise. This does present a dilemma. It is reasonably straightforward to say that all patients with a particular profile need to have an annual blood pressure check. This can be easily measured and fits with modern systems. Asking doctors to discuss access problems with their patients and treat them with respect is harder to benchmark and quantify.

A clear message from the responses was that 'one size fits all' solutions are not appropriate. This should, perhaps, not be a great surprise as there is huge diversity among deaf and disabled people. Many deaf people made suggestions that would let them know when the doctor was ready to see them. However, these solutions often relied on visual methods, which blind respondents obviously found useless. Even among deaf respondents there was a lot of variety. Some could access no services without communication support (usually an interpreter), whereas others were happy to lipread if they had a doctor who spoke clearly. It would be a waste of time to provide the lipreader with an interpreter, and pointless to provide the British Sign Language (BSL) user with a doctor who spoke clearly. Individual need and preference is all important. Flexible, personalised care is crucial.

A lot of respondents with a learning disability were clearly reliant on carers or support workers to facilitate their access.

Access problems

We crudely constructed a pathway for respondents to help them think about access, and to structure the replies.

Booking an appointment

Many of the respondents gave replies that would not be uncommon among hearing people. For instance, there was frustration about not being able to book advance appointments. But these 'normal' difficulties were clearly compounded. Many people resent the 8.30am telephone lottery, but this is a game deaf people struggle to even join.

Many Deaf people tried to use TypeTalk or a Textphone but had limited success. The growth of automated switchboards has made it quite difficult to 'get through'. Callers through TypeTalk are also finding the line going dead. This could be because of a lack of training, or because reception staff are pressured and don't want to 'waste time' with a tricky call. Either way, deaf people are being denied access.

It was surprising how many people relied on visiting their surgery to book an appointment. While some were happy to do this, there was obviously a concern that when ill this is either impossible or difficult. People are also relying heavily on other people to call and book an appointment for them. If a hearing person was told they would have to ask a work colleague to call on their behalf they would be livid. Unfortunately, many deaf and disabled people 'accept' that is what they have to do.

Out-of-hours services seemed particularly difficult to use, with the doctor sometimes calling back (voice) to a mobile number. For the majority of the week, access to the NHS is by telephone. This must be addressed.

Before your appointment, e.g. reception, waiting room

This part of the pathway yielded some unexpected responses. We know that deaf people often get overlooked and miss their appointment. There were plenty of examples of that happening. However, what was interesting was the amount of stress the waiting room engendered. A number of respondents actually used the word "stressed" and clearly hated the experience. The stress arose from a fear that they would not hear their name being called. Many people try to sit in a seat where they can see the person calling names, and then try to lipread the names being called. Others may have asked the receptionist to get them, but aren't confident that this will happen (the receptionist may be dealing with someone else at the time).

SignHealth has in the past emphasised the importance of receptionists for the patient experience. This is something that *No patient left behind* recognised and is certainly borne out by this consultation.

During the appointment

There were no big surprises here. Some people were 'lucky' and had a GP who they regularly saw and had an established method of communication. Some GPs had been given a crash course in Deaf awareness from their patients, and this made a difference. Not all patients were as fortunate (or as confident).

Many Deaf patients relied on trying to lipread. This was made more difficult by doctors who had an accent (and so had different mouth patterns). Medical language also hindered understanding.

A lot of patients used a pen and paper to communicate. Amazingly, some doctors had refused to use a pen-and-paper, and some were not able to find any spare paper. This is a worry. Even where pen-and-paper communication is used, low levels of English meant this did not always work efficiently. Medical terminology was not understood and the patient was unsure.

In cases where interpreters were provided there was concern that they did not always turn up, and that appointments had to be booked on the basis of interpreter availability (so the interpreter was booked first and then the patient was told when the appointment would be).

It's clear that a lot of patients who would like an interpreter are not being offered one – or are being refused one. In light of the Disability Discrimination Act this is hard to justify. Regardless of the DDA there are clinical issues which should encourage staff to practice safely by using an interpreter. Some GPs are concerned about the cost, but are probably unaware that online interpreting is available (through SignTranslate), which is particularly useful for short-notice bookings.

After the appointment, e.g. getting prescription

Some pharmacists are extremely important to their deaf and disabled patients. In some cases there was a sense that the pharmacist would explain to the patient what they had not understood during the GP consultation.

Some people said they couldn't understand the instructions from the pharmacist, or the written instructions.

Recommendations

Respondents were very 'reasonable' in their recommendations. Nobody suggested improvements that were unrealistic. The most 'extreme' suggestion from a couple of people was that all GPs and receptionist learn BSL to at least Stage One. While this may be impractical it is certainly something that could be encouraged or made possible.

The main concerns and solutions arose again and again. We have adapted them slightly to make them more widely applicable. It is encouraging that most of the recommendations are simple and largely cost-neutral. Indeed, when compared to some of the financial losses currently experienced (missed appointments, repeat appointments, etc.) then a small investment would probably bring large financial and clinical benefits.

The recommendations are contained in [Appendix A](#).

Brief quotes for the responses

Sometimes I don't know why I'm ill or what's wrong with me.

...waiting my turn is a very stressful experience.

They talk to their computers rather than their patients.

They need to face who they are speaking to and not just keep watching their PC.

It is just so stressful in the waiting room!

How wonderful it would be to use e-mail!

So I always have to be on the alert for my name to be called which can be stressful.

My GP has introduced on-line booking which is the most fantastic thing ever as it gives me independence to book my own appointments and not have to rely on other people telephoning.

A little flexibility in dealing with unusual situations would be helpful.

I'm just Deaf, not simple-minded.

They call names over a tannoy system which is very very nerve wracking for me.

...but all GP call names, we must sit in front and watch lipreading... they not aware.

Some doctors just write very briefly and shoo me away with prescription and I don't really understand and feel confused.

Normally I am not sure why my illness happened and when it will be better. Mostly I don't bother with doctors as it's just frustrating.

Sometimes they forget [to let me know], it is stressful especially as I can't read magazine in case I miss someone announcing my name.

Spent over an hour in waiting room. Turned out I had been called twice but due to my deafness completely missed it. Now my medical records say I am deaf and this has made a difference.

Some flexibility please!

I hate this part of the visit [waiting room].

I struggled to explain using written English and the doctor did not understand what I was saying.

I need an interpreter. Sometimes I do not understand what I am getting and how to take it.

I receive a lot of information in the post which I do not understand what for. I have received three of the same things about cancer, which makes me think why me? This type of information which turns up in the post just makes me angry, why are they bothering me?

Changing attitudes will change lives.

I have been to the doctor and he was laughing about something and I have no idea why? It is very confusing.

The doctor communicates with me only with gestures and paper and pen, but I do not understand English very well, because I use BSL. Most of the time I am not sure what he means and get confused. They never provided me with a BSL interpreter which I need. I leave the doctor uncertain of what is the problem and what I am to do with my medication.

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When I am with the GP he can look very serious, and as I do not understand what he has written, I think there may be something serious wrong with me. The GP writes very complicated words which I do not understand. I would like to have an interpreter at the surgery with me so I can understand fully what is being said. The surgery had previously said that interpreters are too expensive, and paper and pen should be enough.

Appendix A – recommendations from Deaf and disabled people to improve access

1	<p>Surgeries allow booking of appointments by text/SMS, internet or e-mail; and attention is given to out-of-hours services.</p> <p>Response after response asked, “Why can’t I use e-mail or SMS?” It seems that technological advances have worked against Deaf and disabled people: automated switchboards with options are particularly annoying. We gather from suppliers of patient record software that the capability is already available to a large number of practices. There is also a cost saving involved in introducing electronic booking (EMIS estimate 69p per booking).</p>
2	<p>Staff receive Deaf Awareness, BSL training or wider disability training.</p> <p>There were numerous reasons given for providing training. Sometimes it was the attitude of staff. Often it was the practical barriers created by ignorance, e.g. glass screens making lipreading impossible, doctors talking to their computer screen, staff assuming written English is okay. In the case of Deaf Awareness there are qualified trainers throughout the country. Many were involved in delivering a programme tailored for health services in 2005.</p>
3	<p>All patients to be asked how they should be informed that it is their turn to see a doctor or nurse.</p> <p>Most respondents had an issue with being called for their appointment. Their proposed solutions differed. Some liked the idea of screens, although these were not always successful as the patient had to sit ‘glued’ to the screen in case they missed it. Some liked visual ‘number’ systems. One surgery used pagers, which seemed particularly effective and also worked for those with impaired vision. Systems that relied on the doctor or receptionist sometimes grounded when the people involved changed. Solutions need to be tailored to the individual patient.</p>
4	<p>The patient to be asked whether they would like support, what kind of support they would like.</p> <p>One approach will not work for all Deaf and disabled people. Adjustments need to be made on an individual basis, i.e. surgeries should not book interpreters for all deaf people, because not all will use BSL. Health centres need to be prepared to have a dialogue with their patients to see what they want. Some people said they would like an interpreter for some appointments, but not necessarily all of them. A lot of respondents did not feel confident about asking for support.</p>
5	<p>Patients’ notes to clearly state the person’s deafness or disability, and any associated adjustments required and preferred communication method – this should be a clear flag on electronic systems.</p> <p>Many people said staff seemed unaware of their deafness or disability. Patient administration systems allow this to be solved and create a system of support: rather than being reliant on staff knowing that Mr Smith is Deaf and needs an interpreter, either face-to-face or online. The interface between the GP practice and secondary care seems to create a lot of problems, with the hospital being unaware that the patient is Deaf or has a disability. If this information is not in the referral letter then it needs to be on patient administration systems. We are told by the developers of computer software that most systems already allow for “auto alerts” to be easily created. Again, this seems to be an example of the potential solution being in place, but not being utilized.</p>