



GP surgery care when you're Deaf, deaf or hard of hearing

May 2023



What we did

Our latest research project focused on people who are Deaf, deaf or hard of hearing.

In line with SignHealth guidance, we use the terms 'deaf', 'Deaf' and 'hard of hearing' as follows in this report:

- deaf used to describe or identify anyone who has a severe hearing problem
- Deaf used refer to people who have been deaf all their lives, or since before they started to learn to talk
- hard of hearing used to describe people with less severe hearing problems.

We asked about their experiences of booking and attending appointments at their GP surgery in Buckinghamshire.

We developed a survey which was online from 7 February to 30 April 2023. The survey was publicised via social media, and community and service providers' newsletters. We also held three focus groups.

Key findings

90 people told us about their experiences of accessing GP surgery care in Bucks when Deaf, deaf or hard of hearing.

- + People want to communicate using their first language wherever possible, including when this is British Sign Language (BSL).
- + Few people knew they could ask for their GP records to be 'flagged' with their communication needs.
- + Many people were very frustrated by having to remind people inside the surgery (and then in secondary care if they were referred) that they had a degree of hearing loss.

- + Few Deaf people had experience of BSL interpreters in a GP surgery because they said it took too long to book, and/or Sign Live or similar apps were not generally used. Most of these would prefer to have a BSL interpreter present at an appointment.
- + Many people who are hard of hearing or Deaf find making appointments by phone or receiving speech calls from GP surgeries difficult. Remote phone consultations by phone were particularly unpopular.
- People who were able to communicate with their GP surgeries by text, and whose surgeries responded in a timely way, found communication between appointments straightforward.
- + While booking appointments online was an option for some, not everyone could or knew how to do this. People also told us that this was not suitable for urgent, same day appointments which could only be obtained by phone.
- + Half of the people we spoke to were happy with the use of speech at an appointment, as many could lip read or took someone to help them. However, several wanted to know why technology such as hearing loops or apps such as Sign Live could not be routinely offered.
- + While several people asked family members, friends and/or social workers to help them book appointments and/or communicate with medical staff, some felt that this did not allow them to keep aspects of their medical history private.
- + Some people told us that not being able to communicate in a way that suited them left them confused, frustrated, ill-informed or they felt the experience affected their self-esteem in a negative way.
- + Many people felt surgery staff were not deaf aware. People told us many members of staff did not give them enough time to communicate. Staff might obscure their mouths with masks, sit so they were backlit or have their face pointed away from the patient so the latter could not lip read.

Our recommendations

We recommend that Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) encourages Buckinghamshire GP surgeries to sign up to the Healthwatch Bucks **Deaf and Hearing Loss GP Practice Charter** (Appendix 4).

This sets out a commitment to reducing inequalities in access to GP surgery care that may affect people who are Deaf, deaf or hard of hearing. This should be displayed in the GP practice and on its website. By signing up to this Charter, GP practices would

help demonstrate that they are committed to meeting their requirements under the Accessible Information Standard (Accessible Information Standard - RNID).

What the project was about

Background

As of 1st August 2016, all organisations that provide NHS care and/or publicly funded adult social care are legally required to follow the <u>Accessible Information Standard</u>. This gives rights to people who have information and communication needs to due to a disability, impairment or sensory loss.

Providers are required to identify, record, flag, share, and meet the information and communication support needs of these patients, parents and carers. People who have a disability, impairment or sensory loss should be provided with information they can easily read and understand, and also with support so they can communicate effectively with health and social care services.

"The word deaf is used to describe or identify anyone who has a severe hearing problem. Sometimes it is used to refer to people who are severely hard of hearing too. We use Deaf with a capital D to refer to people who have been deaf all their lives, or since before they started to learn to talk... It is an important distinction, because Deaf people tend to communicate in sign language as their first language. For most Deaf people English is a second language and understanding complicated messages in English can be a problem." (SignHealth)

In February 2022, SignHealth published their Review of the NHS Accessible Information Standard. In this, 67% of Deaf people reported that no accessible method of contacting their GP was made available to them. Only 7%. Of respondents who needed communication support had equal access to NHS services in comparison with people who do not have hearing loss. The report highlighted that, in this regard, little had changed since the publication of the 'Sick of It' report.

In June 2022, The BSL Act came into force. This recognises BSL as an official language in its own right in England, Scotland and Wales. The 2021 Office for National Statistics census showed 0.03% of people living in Buckinghamshire said their main language was BSL. That is around 166 people. However, the British Deaf Association and

SignHealth both estimate that BSL is the preferred language of three times that many people. Based on these statistics, as many as 500 people in Bucks may prefer to use BSL as opposed to a spoken or other language.

In 2022, we started to get more feedback from people who are Deaf, deaf or hard of hearing in Bucks about the issues they were experiencing with accessing health care. We were aware that some of the issues faced by them would also be faced by those who are hard of hearing.

"In the UK there are 12 million adults with hearing loss greater than 25 dBHL (mild hearing loss). This is equivalent to one in five adults.... " (RNID)

The Royal National Institute for Deaf People's (RNID) 'Hearing Matters' report states that approximately 900,000 people have severe hearing loss or profound deafness. They estimated that in the UK, more than 40% of people over 50 years old have hearing loss, rising to more than 70% of people over the age of 70. The last census (2021) showed 18.7% of Buckinghamshire's population are over 65. This means that around 5000 Bucks residents may have some hearing loss.

Our aims

We wanted to know what a good experience of primary care would look like for those who are Deaf, deaf or hard of hearing. We also wanted to know how support for the Deaf community might be improved in Bucks.

The project looked to:

- Enable people who are Deaf, deaf or hard of hearing to share their views with the providers of primary care in Bucks
- Give further insight into the issues that are particular to those who are Deaf, deaf or hard of hearing.

Who talked to us

Nine members of Aylesbury Deaf Coffee Morning Club attended one focus group and 20 members of the Winslow, and Chiltern, Hard of Hearing Groups attended two others. A BSL interpreter accompanied us to the first group. Several members of the second group used a hearing loop, while the third group used speech to text technology to help with communication.

We followed a similar set of questions to those in the online survey with all groups. Full details about who talked to us can be found in Appendix 2.

All respondents were registered with a GP surgery in Bucks.

We found the following:

- 34% of respondents said they were Deaf or had profound hearing loss
- 15% said their first language was BSL or Sign Supported English (SSE), and all preferred to use this language
- 91% identified as White: British
- 68% identified as a woman and 32% as a man
- The median age was 68.

What we heard

This report reflects the views of the 90 people who attended the focus groups or completed our survey.

Hearing loss

Two thirds of respondents (61) told us they had experienced hearing loss in adulthood.

14 had hearing loss from birth and ten from childhood.

We asked them to describe their level of hearing.

Table 1 shows that we heard from people with a wide range of hearing loss.

Level of hearing	Total
Deaf (complete hearing loss)	11
Profound hearing loss (you may use hearing aids, cochlear implants, BSL and/or lip-reading)	18
Severe hearing loss (severe difficulty following speech without a hearing aid, may depend on lip reading)	20
Moderate hearing loss (some difficulty following speech even with a hearing aid)	27
Mild hearing loss (some difficulty following speech in noisy environments)	10
Total	86

Table 1 - How would you describe your level of hearing?

We also asked each person what they considered to be their first language. 13 people (all Deaf or with profound hearing loss) said this was BSL or SSE. Everyone else told us English was their first language. Everyone said their first language was the one they preferred to use to communicate.

Flagging your GP record

Only 21% of people knew a flag could be put on their GP record highlighting their communication needs, hearing loss or to note they were Deaf, deaf.

"I wish I had known a flag could be put on my medical records instead of having to explain EVERY time I see someone that I have severe hearing loss."

Only 11 people said they had asked for a flag to be put on their record. However, some of these people did make further comments implying that whether their records were flagged or not made no difference to the way people inside the surgery communicated with them.

"I have to keep reminding them I'm Deaf even though I've told them."

"The receptionists are variable in attitude to deafness. I don't think they have deaf awareness training. I have to explain I have hearing problems each time as, although there is a note on my records, the software is not enabled for the flag to appear automatically on screen."

"They don't check their records; they still ring me by phone even though I'm Deaf."

Some people also asked why GP surgeries did not pass communication needs onto hospitals when referrals are needed.

"If a GP refers someone to a hospital then the GP should tell the hospital that you're Deaf, so staff know before you arrive."

Making an appointment

We asked people how they made their last appointment at a GP surgery. Full details can be found in Appendix 3.

The top three answers were:

- By phone (54%)
- In person (18%)
- Using an app (13%).

How did you find this

There was an almost even split between those who found making an appointment easy or very easy and to those who told us it was difficult or very difficult. Full details can be found in Appendix 3.

It was very easy

- Two people with mild or moderate hearing loss made their appointments by phone.
- Three people with profound hearing loss had either booked their appointments online, by e-mail or had turned up in person.
- No one identifying as Deaf said making an appointment was very easy.

It was easy

- Only one Deaf person said the process was easy.
- 16 people used the phone and most said they had mild or moderate hearing loss.
- Four people with severe or profound hearing loss used the phone.
- 15 others, all of whom had moderate to profound hearing loss, didn't use the phone.
 Six of these turned up in person, five used an app or went online, and three asked others to help them to make the appointment.

One person told us they only found it easy because they have hearing aids that are connected to their mobile phone using Bluetooth.

"I am fortunate to be able to afford private hearing aids which connect to my mobile. I can have difficulty hearing if anyone rings on our home phone."

It was difficult

"It's taking too long to make sure GPs work better with deaf patients."

 20 people used the phone to make the appointment. Many told us that this was the method the GP surgery had told them they had to use.

"The surgery (and other NHS departments) are very slow to help deaf people, all you get is Phone us!"

"Everything has to be booked by phone with no consideration as to how difficult that is for someone with hearing loss."

Another seven physically went to the surgery to book an appointment.

"We're told the only way to get an appointment is to book online, which we don't know how to do, or phone. We can't ring up at 8am and get an appointment like everyone else, as we can't hear. So, I turn up and hold out a piece of paper to ask to talk to my doctor..."

Many people with different levels of hearing loss told us that they felt they had no choice but use the phone, as other options were not made available to them.

"There's a new booking system but it is totally dependent on phoning up and I can't use it as I can't hear the options."

Many said they found this particularly difficult if they wanted an urgent appointment that day. They felt that unless they turned up to the GP surgery or got someone else to phone on their behalf, they couldn't see a GP.

"I contact the surgery by e-mail to get an appointment. I have to wait for the receptionist to respond. This means I can never get the emergency morning appointments because they have gone to hearing patients before the receptionist gets back to me. They are slow to text me. It's not fair as hearing people get a better service. It feels unfair."

"Having to book an appointment on the phone on the day of is near impossible for me as I struggle to hear on the phone/find it much harder to communicate effectively. If I can, I will always book appointments in person which is fine for blood tests etc but not an option for doctors' appointments."

Some people found ways around this by turning up to the surgery in person, or by asking friends or family to ring on their behalf. However, many did not see why they had to do this if they didn't want to. Others wondered what those who lived on their own did.

"A lot of deaf people depend on family to phone - but how do you manage when children grow up and leave home?"

Many asked why appointments could not be arranged by text or e-mail, including same day ones.

"...why do I always go through the same hoops, why is the website rubbish with nothing specifically for HoH [hard of hearing] people, why don't they embrace technologies other than the phone. I HATE THE TELEPHONE!!!"

"[The] doctor's surgery should embrace technology, not resist it. Email is more secure than the phone and helpful for hearing loss people. They send text messages, but we can't do the same."

People are not always clear as to when and how surgeries can contact patients by text, which can lead to misunderstandings. Many surgeries only seem to use outgoing texts, and don't allow incoming messages.

"Why can't they text? They text us frequently about admin such as when the surgery hours are changing."

However, a few Deaf people had experience of using technology to book appointments and they had not always found this successful. One person told us that Minicom has its disadvantages; for example, text disappearing off the phone screen too quickly to enable someone to write the appointment details down in time. In addition, alternatives to the phone only worked if staff at the GP surgery fully embraced them.

"When I complain that the receptionist never picks up Type Talk, they say it's because they're too busy. So it's a waste of time."

Three people told us they ask someone to phone on their behalf.

One Deaf person said that they would prefer to get an appointment themselves but making a speech call was the only option offered by their GP.

"I get X to ring. It's too tiring for me to go to the surgery in person to make an appointment. It's very frustrating. There's no accommodation for being Deaf."

It was very difficult

- Seven people who were severely or profoundly hard of hearing or Deaf said they found making a GP surgery appointment by phone very difficult.
- Another person, identifying as profoundly deaf, told us:

"Really hard to book appointments, can't use the phone, have to go in person, often appointments run out before you get to front of queue."

Communication at the appointment

We asked about the main way in which respondents had communicated with people at the GP surgery. Full details can be found in Appendix 3.

The top three answers were:

- Speech (56)
- Lip reading (11)
- Took a friend or support worker with me to help (8).

Two people, who usually had their partners accompany them to any appointment, both said that the GP always addressed them, the patient, resisting the temptation to speak just to the hearing person.

Only three of the Deaf respondents had used an in-person interpreter and / or Sign Live on a phone. One Deaf person suggested that all GPs should have the latter. They said it worked successfully for them - although at the moment, as the GP does not have Sign Live, they use the app on the patient's phone. This means that the patient has to pay for the service/cost of the call.

Most respondents said speech was the way they wanted people to communicate with them inside the surgery. Many people who identified as having a mild to severe hearing loss told us this worked for them.

Those whose hearing aids can be hearing loop enabled preferred to use a hearing loop rather than just depend on lip reading. However, not every GP surgery has a hearing loop - and even if they do, not all staff know where the equipment is kept or how to use it.

"Until recently they had no working Loop system, then some staff did not know how to work it. COVID gets the blame for everything but it's mostly a case of lack of thought, training or just not engaging with the issue."

One focus group also wanted to know why GPs seemed unwilling to try new technology that cost very little or nothing at all. This group were trialling a phone app linked to a monitor on which text appeared when any person nearby spoke.

Most Deaf people told us they would prefer to communicate with the assistance of a BSL interpreter. While seven wanted an interpreter in person, three were happy to have one present via an app at an appointment.

"I can lipread most people, but some are difficult, so I need a BSL interpreter. If it's a minor pain etc. I lipread, but if severe I use BSL"

Most Deaf people had not been offered either a BSL interpreter or use of an app such as SignLive. Several people we spoke to had not heard of SignLive. However, many of the Deaf respondents agreed that booking BSL interpreters often took too long to make their involvement beneficial.

"It's really difficult to get an interpreter if you want an appointment within a few days. If you insist on an interpreter then the GP delays your appointment and often you're better before that appointment comes around."

Some Deaf people said that sometimes the benefits of having an interpreter outweighed the disadvantages.

"Having an interpreter is quicker and saves time. Some people can't lip read. If you get something you can't understand, you need additional help or at least people with patience and time."

In the waiting room how do you know if the nurse/doctor was ready to see you?

The top three answers were:

A staff member collects me (21).

"It depends on the GP. Some come out to collect me if they are deaf aware."

• A staff member calls out my name (21).

"There's no screen so someone comes out and shouts. If there are only a few people waiting and no one moves, I can ask the person calling if it is for me."

However, some deaf or people with hearing loss find this difficult.

"When I'm called by a nurse, I can't hear them. They haven't checked my records to see I am deaf. The nurse announces the name behind a mask, so I have no chance to lip read either"

I watch a visual display screen (20).

"My name, the waiting room and the name of the GP come up on a screen I can see easily."

Several people also told us that, if they are accompanied by a relative, partner, friend or social worker, they let them know that a medical professional is ready to see them.

"If I have an interpreter with me, they tell me that my name has been called."

Difficulties which stop you communicating effectively with staff

55% of respondents, with different levels of hearing loss, told us there were other difficulties which stopped them communicating effectively with staff.

"1.1.2 Ensure that factors such as physical or learning disabilities, sight, speech or hearing problems and difficulties with reading, understanding or speaking English are addressed so that the patient is able to participate as fully as possible in consultations and care."

We received 37 additional comments about what these difficulties were. We have summarised these by theme.

 10 people said they struggled with GP surgeries' staff not giving them time or not actively listening to them. Some told us people spoke too quickly.

"Doctor/s talk too fast and do not enunciate clearly. I frequently have to ask them to speak up and speak slowly. They do this for a bit and then I have to remind them again. This applies both in surgery and on the phone. They may be busy, but in the end the consultation takes longer through repeated repetition. Receptionists better than doctors!"

 Others found lip reading difficult because of the direction a medical professional faced.

"Receptionists and doctors often keep their heads down which make lip reading impossible."

"Why do all GPs sit with the light behind them and as soon as we talk they turn way to look at their computers. We can't lip read like that."

- Eight people told us about the difficulties they face when staff wear masks, particularly non-transparent ones. This might be because voices become muffled or because they inhibit lip reading.
- Seven people said background noise and screens at a reception desk made it more difficult to communicate effectively.
- Five people repeated the fact that they found it too difficult to use a phone.

"Sometimes they forget I am deaf. There needs to be more deaf awareness as I sometimes receive phone calls despite me telling them I cannot use the phone..."

 Four people told us about the lack of technology used in a GP surgery to aid communication. "They don't use the available technologies - I email (you can't text) - they phone, which is hopeless. Why don't they at least use a system with a visual display. 'Whats App/ Facetime etc. The 'Friends' of the practice have funded hearing loops - the staff don't use them other than badly at the reception desk..."

"No email address or text number to try and book appointments, especially emergency ones. Online is good for non-urgent but those appointments are weeks away."

Three people left general comments.

The importance of communicating in the right way

We found care could be affected negatively if people were unable to communicate in a way that they liked. This was even the case for those who said that they found booking an appointment easy or very easy.

"We [Deaf people] seem to wear invisibility cloaks unless we have an interpreter with us."

Figure 1 shows how people felt their GP care was affected, and represents their comments summarised by theme. Some people commented on more than one theme, so the number of comments is greater than the number of people who responded.

Almost a third of comments related to poor communication that negatively affected the patient's self-esteem. Some people said that, because of their hearing loss, they felt vulnerable and anxious when seeking help from their surgery.

"I feel isolated and made to feel stupid."

"It is soul destroying, humiliating and always causes more problems than the appointment solved..."

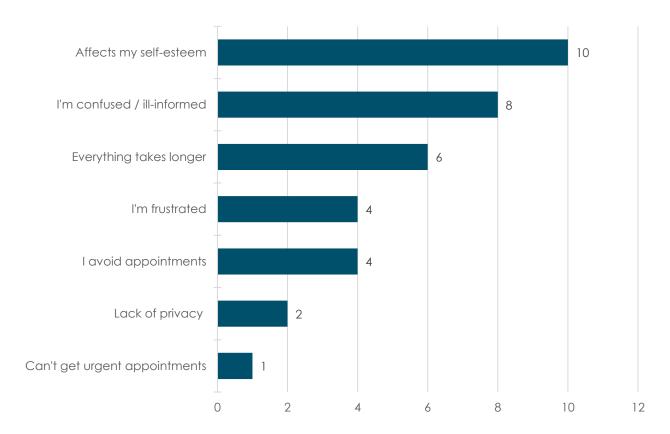


Figure 1 - If people can't communicate with you in the way you like, how does that affect you / your visit to the GP surgery?

Almost a quarter of the comments related to people feeling confused or ill-informed because the surgery did not make allowances for their hearing loss.

"Find it stressful and can lead to misunderstandings."

"Not being able to see someone's lips when talking to them means that I have to keep asking people to repeat themselves/has meant there has been confusion during the appointment."

Some people expressed a concern that people's health or safety could be compromised because they don't understand written English.

"It's a hidden disability. Not all deaf people are educated and can read English writing." "My mother is 96 and deaf. She has a nurse visit every day but there's never an interpreter. Everything is provided in written English which we don't often understand."

One person also said they were accused of being racist because they were from a different ethnic background to the medical professional.

"I'm used to continually asking people to speak slower. I have been accused of being racist. I had to say that I wasn't but that I was hard of hearing."

A couple also mentioned that shouting louder often distorted speech and, rather than making it easier to understand, this made it more difficult.

Six people also told us that everything in an appointment or a phone call usually takes much longer because people can't communicate with them in a way that they would like. Sometimes this also compromises the patient's privacy.

"It makes the visit longer and I am aware that other people can hear the conversation."

Four people said their experiences had led them to avoid using NHS GP surgeries because they were obliged to make or have appointments by phone.

"The problem is not with a visit to the surgery but with the telephone consultations that they insist on. This has made me unwilling to try to get an appointment since Covid. I have paid for a private GP appointment twice so that I can speak face to face."

Remote appointments

Many people also took the opportunity here to tell us about the issues they had with remote appointments. Many would have preferred in-person appointments.

"No problem if you can obtain a face to face appointment but this seems very hard to achieve."

Again, people repeated the difficulties they had following the conversation and being sure they had heard and understood everything.

"I have a particular problem using the telephone and find following complicated discussions very difficult even with amplification. I did not have this problem in my face to face discussion with the GP."

"It was telephone consultation - ironically because I needed a referral for new hearing aids."

"Phone consultations are no use to me. They ask if my other half can help. But not everyone has another half and not everyone wants their other half to hear everything you have to say."

Missed appointments

Despite our findings, very few people (14% of all respondents) told us they had missed an appointment in a GP surgery because of miscommunication, or because no interpreter was available.

Communication between appointments

We asked people to think about the last time the GP surgery had communicated with them, and how they had done this. Almost half said they'd received an SMS text message. These are often bulk texts to all patients informing them of a training day or new service. Most other respondents told us they had received a voice / phone call from the surgery. Five people had received e-mails.

This suited me

18 (of the 72 respondents) said the method of communication used by the surgery was completely suitable for them. Again, these respondents had a wide range of hearing loss although none were deaf.

For many, this was because they received texts, which gave them control as well as a record of any conversation.

"Using texts and uploads is really helpful and I can get my message across easily. I understand what is being told to me, or what is asked."

"If it's text I can read it for myself. I still get letters saying "we have tried to contact you on several occasions by phone"

This suited me to a certain extent

43 people (60% of respondents) said the GP surgery had, to a certain extent, communicated in a way suitable for them. Many left comments clarifying what worked and what didn't.

Positive comments

 The majority of these were again because they related to being able to communicate by text with the GP surgery.

"My nurse texts me which works."

"I can read, whereas the phone is more difficult"

 However, one person said that different professionals within a surgery might use different communication tools. Consistency would be more helpful.

"Doctor's appointment is texted, but nurse appointment was not..."

Two people also told us about their experience of SignLive.

"I've used SignLive. A GP had it on his laptop. All GPs should have a SignLive contract."

• A few said the phone worked for them, although some did qualify what this meant.

"So long as the caller speaks slowly and distinctly I can usually follow the conversation."

"Confirmation of appointment is ok this way. More detailed information no good this way."

Staff attitudes also influenced people's responses.

"My GP has a deaf sister and that really helps and makes for a different experience to other GPs."

Negative comments

 Four people complained about being contacted by phone when they are hard of hearing.

"I found an e-mail address to do with the surgery and sent them a message. They responded by phoning me even though the email said I couldn't hear."

 Four people said that their surgery's use of the phone affected their independence and privacy.

"I still have to get help from my mum to understand."

"I want to be independent of my daughter, but she makes all my calls for me. She knows everything about me. I have no privacy."

Two people told us the GP would phone a relative to pass on results to a patient. One said they hadn't given permission for this.

"[the] GP phoned my parent as next of kin to inform me via BSL"

Another family member said that, while it was acceptable to act as an interpreter in a GP appointment, they felt it wasn't appropriate to give the results of a test by phone when they could send the results by letter or e-mail directly to the deaf patient.

Three people were worried about the increased use of technology.

"Following a text conveying only information is no problem, but texts requiring further access to the internet or sending a photograph to the GP often fail from my lack of dexterity on a small smart phone"

A few people told us that written communication often included too much jargon.
 Medical staff need to be aware of using non-medical language and the need to give clear explanations when communicating by e-mail.

"The doctor doesn't communicate very well. When writing in English, they need to use smaller words. 'approximately' should be replaced with 'about.' They need to make adaptations especially when using medical jargon... Using complex English just generates more questions..."

Others, living alone, didn't feel supported by the surgery.

"They say they will reply to you within three days for your blood test results. But I don't know if they have rung or not. It's very stressful.

Hearing people get their tests results by phone, but I don't get them..."

"Living life profoundly hoh [hard of hearing] is tough. It often is the worst experience in clinical settings – where tolerance and compassion is lacking. I wish they never have to experience the awful communications ("don't worry I'll speak louder" OR "don't worry I can hear you"... it's rude, unhelpful and condescending."

This did not suit me

Only 11 people told us that the communication method used was not the most suitable for them. Again, they reiterated the fact that they couldn't communicate well over the phone - which was frequently the method they were forced to use.

"It's almost as if they didn't care. From a caring profession, you would have thought they'd have thought about this..."

"I would like the Surgery to recognise that I have moderate to severe hearing problems and to communicate face to face so that I can lipread. Also I would like to be able to always arrange my appointments online or be email/text... I cannot communicate on the phone unless I'm in a quiet environment. Hearing loss is a hidden disability and there is not enough awareness of our needs, especially in hospital environments and when dealing with the surgery."

One person also restated the issues around getting an appointment online.

"I needed to make an appointment, but nothing was available on line...

The system does not allow for me to communicate by text or email,
although I do receive routine text messages - e.g. regarding Covid
vaccinations. Also the GP can organise for a text message to be sent to
me but there is no way I can text back."

There was frustration because e-mail, text, Signed video etc was not used enough by GP surgeries as an alternative to the spoken word.

"A GP needs to think of simpler ways like using Sign Video; something more empathetic for the patient."

"My GP won't use e-mail. I suspect they don't want me to keep bothering them."

"Deaf people rely on e-mail and text. I have to make appointments face to face as my GP has stopped text communication."

 A Deaf person repeated the need to recognise that both parties needed to understand how and why a non-verbal communication tool was being used, and react within an agreed time if phoning was not an option.

"The GP told me to e-mail but I wait hours for a response by e-mail."

If people who are hard of hearing send 'written' messages (whether by letter, e-mail or text for example), staff need to act on the communication needs of the patient as well as their health needs.

"I found an e-mail address to do with the surgery and sent them a message. They responded by phoning me even though the email said I couldn't hear."

Any other comments?

We received 41 additional comments which we have split by provider and summarised these by theme.

GP Surgeries

 27 comments were about GP surgeries and covered many of the same issues already explored.

"We hope communication with Deaf people will improve in time."

Hospitals

"1.5.15 Ensure that mechanisms are in place to alert services of any need for interpreters and non-standard formats to be available when patients move between services." (National Institute for Health and Care Excellence – NICE

 Several people commented that communication for those who are Deaf, deaf or hard of hearing was often worse at hospitals. Patients told us that this often started at the referral process and continued with remote appointments and when trying to get test results.

"PLEASE can an effective method of flagging patient's records regarding hearing loss be developed? I have had two hospital stays in the past few months and EVERY time I spoke to someone I had to remind them that I couldn't hear. I cannot fault the treatment I had but having to remind people every time added to what was already a stressful situation."

"It's easier to drive to the hospital to pick up X-ray results rather than sitting on the phone. But we have to pay for the petrol to drive there and for the parking. Why can't the X-ray department find a different way to help deaf patients."

"My worst experience was having a telephone appointment with a consultant ... I found it very difficult to tell what he said and felt stupid."

- Several people said they hadn't missed any appointments at a GP surgery, but had at a hospital.
 - "... at the hospital when the interpreters often fail to turn up."
- One person who is hard of hearing said that no allowance is made to understand the issues people face while waiting for a hospital appointment in a large, busy area.

"It's much worse at Stoke Mandeville because there are so many people waiting for different clinics in the same room. I can't heat anyone shout my name out in the waiting room and can't guess either. Luckily, I usually take my wife and she can hear."

However, one person was very positive about Stoke Mandeville hospital.

"I think the audiologists at Stoke Mandeville need to give the doctors lessons in clear speech. I never have problems at Stoke Mandeville."

Other healthcare

- Several people told us that, now they have to pay to get ear wax removed, this was proving very expensive.
- We received two comments about opticians. One person said their optician would not provide a BSL translator.

"My other healthcare, audiologist and dentist provides BSL interpreter, but Vision Express stopped the interpreting service and asked me to provide one."

Another said that not all opticians have sound proof booths for hearing tests. If you are partially deaf, you can hear interference from outside the room.

Acknowledgements

We thank all the people who met us and told us about their experiences. We also thank our volunteers and the BSL interpreters involved in the project. We are also grateful to organisations publicised our survey, particularly Aston Hearing, Bucks Vision and BOPAG for the articles published in their newsletters.

Disclaimer

Please note this report summarises what we heard and what we saw. It does not necessarily reflect the experiences of all service users.

Appendix 1

More about our approach

Who we included

We set up an online survey to seek feedback from people who were registered with a Buckinghamshire GP surgery or lived in Buckinghamshire. Anyone not registered in this way, or who did not live in Buckinghamshire, was excluded.

In this report we have summarised the free text feedback offered by people according to the categories used across the Healthwatch network. We have added some specific themes as well. These summaries should be regarded as an indication of how often a theme was mentioned rather than an exact count. Some feedback offered views on more than one theme, so the number of results can be more than the number of responses. People may have made a similar comment in response to different questions. The numbers for each theme reported under each question should not be added together. People could do the survey more than once, so the total number of responses may be more than the number of individuals who responded.

Where suggested by the data, we looked to see if there were any differences in the answers between some groups. We focused on statistically significant findings in the main body of the report. Our statistical findings are in Appendix 4.

Who we will share our findings with

We will share our findings with the Care Quality Commission and Healthwatch England, the independent national champion for people who use health and social care services. We also share all our reports with the Buckinghamshire Council Health and Wellbeing Board and the Health and Adult Social Care Select Committee.

We will also share our findings with the Buckinghamshire Oxfordshire and Berkshire West Integrated Care Board (BOB ICB).

How we follow up on our recommendations

We will request a formal response to our recommendations from BOB ICB. We will follow up this formal response to confirm what changes have been made.

Appendix 2

Who did we hear from?

What age group are you in?

Age Group	Total
18 – 25 years	2
26 – 35 years	5
36 – 45 years	2
46 – 55 years	3
56 – 65 years	14
66 – 75 years	25
76 – 85 years	26
86 and over	4
Total	81

Are you a:

Gender	Total
A man	29
A woman	61
Total	90

Is your gender identity the same as your sex recorded at birth?

Gender Identity	Total
Yes	82
Total	82

What is your sexual orientation?

Sexual Orientation	Total
A gay man	2
Asexual	1
Bisexual	2
Heterosexual / Straight	59
Lesbian / Gay woman	1
Prefer not to say	3
Prefer to self-describe	1
Total	69

How would you describe your pregnancy status?

Pregnancy Status	Total
Currently breastfeeding	1
Not applicable	77
Prefer not to say	1
Total	79

How would you describe your marital or partnership status?

Marital or Partnership Status	Total
Cohabiting	4
Divorced / Dissolved civil partnership	5
In a civil partnership	1
Married	31
Separated	2
Single	10
Widowed	14
Prefer not to say	2
Total	69

What is your religion or belief?

Religion / Belief	Total
Christian	38
Jewish	1
Muslim	1
No religion	18
Other	2
Prefer not to say	5
Total	65

How would you describe your ethnic group?

Ethnic Group	Total
Any other ethnic group	2
Asian / Asian British: Indian	1
Asian / Asian British: Pakistani	1
Asian / Asian British: Any other Asian / Asian British	1
White: British / English / Northern Irish / Scottish / Welsh	74
White: Irish	1
Prefer not to say	1
Total	81

Do you consider yourself to be a carer?

Are you a carer?	Total
No	68
Prefer not to say	1
Yes	10
Total	79

Postcode

Postcode	Total
HP5	2
НР7	7
HP8	2
НР9	1
HP10	2
НР11	1
HP12	2
HP13	1
HP14	3
HP15	2
HP16	3
HP17	2
HP18	10
HP19	1
HP20	1
HP21	4
HP22	6
HP27	1
LU7	1
MK2	1
MK4	1
MK17	1
MK18	10
SL1	2
Total	67

Do you have a disability?

Do you have a disability?	Total
No	19
Prefer not to say	1
Yes	47
Total	67

Which of the following disabilities apply to you?

Which disabilities?	Total
Physical or mobility impairment	10
Sensory impairment	30
Neurodevelopmental condition	3
Mental health condition	1
Long term condition	10
Other	9
Total	

Do you have a long-term health condition?

Do you have a long-term health condition?	Total
No	25
Prefer not to say	2
Yes	41
Total	68

Which of the following long-term conditions?

Which long-term health conditions?	Total
Asthma, COPD or respiratory condition	6
Cancer	3
Cardiovascular condition (including stroke)	6
Deafness or severe hearing impairment	23
Diabetes	6
Hypertension (high blood pressure)	15
Learning disability	2
Mental health condition	2
Musculoskeletal condition	6
Other	7
Prefer not to say	1
Total	

Have you been diagnosed with any of the following?

Have you been diagnosed with	Total
Autism (ASD)	1
Total	

Appendix 3

What did people tell us?

When did you first experience hearing loss?

Timeframe for hearing loss	Total
From birth	14
In childhood	10
In adulthood	61
I do not have hearing loss	5
Two Total	90

Did you know that a note (a flag) can be put on your NHS records to tell people the best way to communicate with you?

Did you know?	Total
Yes	19
No	64
Don't know	6
Total	89

Have you asked for a note (a flag) can be put on your GP surgery record to say you are Deaf / deaf or have a hearing loss, and note the best way of communicating with you?

Did you know?	Total
Yes	11
No	5
Don't know	1
Total	17

How did you book your last appointment?

Method	Total
In person	14
Online / Website	4
Using an app	8
By text	0
By e-mail	3
By phone	41
Asked a friend, relative or support worker to make the appointment	5
Other	1
Total	76

How easy did you find this?

	Total
Very easy	8
Easy	35
Difficult	33
Very Difficult	7
Total	83

What was the main way in which you communicated with people inside the surgery?

Method	Total
Via a BSL interpreter (in person)	3
Via a BSL interpreter (on an App)	0
Lip read	11
Use a hearing loop	1
Used Type Talk	2
Wrote things down to communicate	3
Took a friend, relative or support worker with me to help	8
Speech	56
Other	1
Total	85

In the waiting room, how would you know that a doctor/nurse was ready to see you?

Method	Total
I watched a visual display screen	20
A staff member collected me	21
I was given a buzzer / vibrating pager	1
It was a video consultation	0
Other	29
Total	71

Are there any other difficulties which stop you communicating effectively with staff at your doctor's surgery?

Did you know?	Total
Yes	31
No	28
Don't know	2
Total	56

Thinking about the last time your doctor's surgery communicated with you, how did they do so?

Method	Total
SMS Text	41
Voice call	33
E-mail	5
Letter	1
Other	3
Total	83

Is the way the GP surgery communicated suitable for you?

Did you know?	Total
Yes completely	18
Yes, to a certain extent	43
No	11
Total	72

Have you missed an appointment because of problems with communication or because no interpreter was available?

Did you know?	Total
Yes	9
No	54
Don't know	1
Total	64

Appendix 4

Deaf and Hard of Hearing GP Practice Charter

(Insert GP Practice name) is committed to meeting the needs of our patients who are Deaf or hard of hearing. We will:

- Ensure our records show that you have hearing loss or are Deaf and highlight your preferred methods of communication.
- Act on these communication and information needs.
- Ask you whether we can share your communication needs with other NHS services such as hospitals.
- Ensure our staff have completed Deaf Awareness Training and select a member of our team to act as a Hearing Loss Champion.
- Help you to contact us in several ways, including online, and where possible by email and text.
- Ensure you can request a BSL interpreter (in person or via an app such as SignLive),
 via our receptionists, our online consultation system or website, whether for a video or face-to-face appointment.
- Ensure our broadband is reliable enough to maintain communication, including with an online BSL interpreter if used, throughout a conversation.
- Try to provide you with a video consultation with live captions for remote appointments, rather than conduct these by phone,.
- Ensure that when we meet with you, we look at you directly and speak clearly, and at a reasonable speed, to help you understand what is being said.
- Offer to use a speech-to-text app and / or hearing loop.
- Ensure someone will collect you from the waiting room or provide you with a nonaudio prompt which will tell you when a member of staff is ready to see you.
- Ensure that face masks, where necessary and not removable, are transparent.

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If you require this report in an alternative format, please contact us.

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