



Access & Inclusion (Health) Review:

Impact and influence on health care
services between Deaf British Sign
Language users and service
providers in Scotland



Scottish Government
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We would like to thank those Deaf people in Scotland who gave their time to share their views and experiences.

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I Introduction and Background

In 2013, the Scottish Government Section 16b funded the British Deaf Association (BDA) Scotland with the aim of ensuring that Deaf people have equal and direct access to all forms of health care and health promotion across the whole of Scotland.

As an objective within the Deaf Health Challenge Project, which became the remit of the Access and Inclusion (Health) Officer, BDA Scotland was tasked with devising and carrying out a Deaf Health Challenge survey. The survey sought to gather and collate health related information from British Sign Language (BSL) users across Scotland, to include their own assessments of their experiences of accessing health services.

In addition, a survey was undertaken to establish the current provision of health services for Deaf patients, in particular, focusing on issues of accessibility.

This report presents our findings. Included in the report are a number of quotes from Deaf community participants. These have been added to evidence service gaps relating to the key health challenges identified, as well as to assist with recommendations and guidelines for health services.

The BDA is the largest Deaf organisation in the UK that is run by Deaf people; united by shared experiences, history, and, most importantly, by British Sign Language (BSL).

Since 1890, the BDA's long-standing commitment has been to ensure that the language, culture, community and heritage of Deaf people are effectively protected. Beyond this, the BDA recognises the rights of Deaf people to full participation and inclusion in wider society and the contribution its members can make as equal and valued citizens. Indeed, the BDA wishes to see a society in which BSL users have the same rights, responsibilities, opportunities and quality of life as everyone else. According to the 2011 census, an estimated 12,500 people in Scotland (0.24 per cent of the population aged 3 or over) use BSL at home.

The BDA's mission is to achieve a world in which the language, culture, community, diversity and heritage of Deaf people in the UK is fully protected, leading to the social inclusion of Deaf people. We strive to achieve this by:

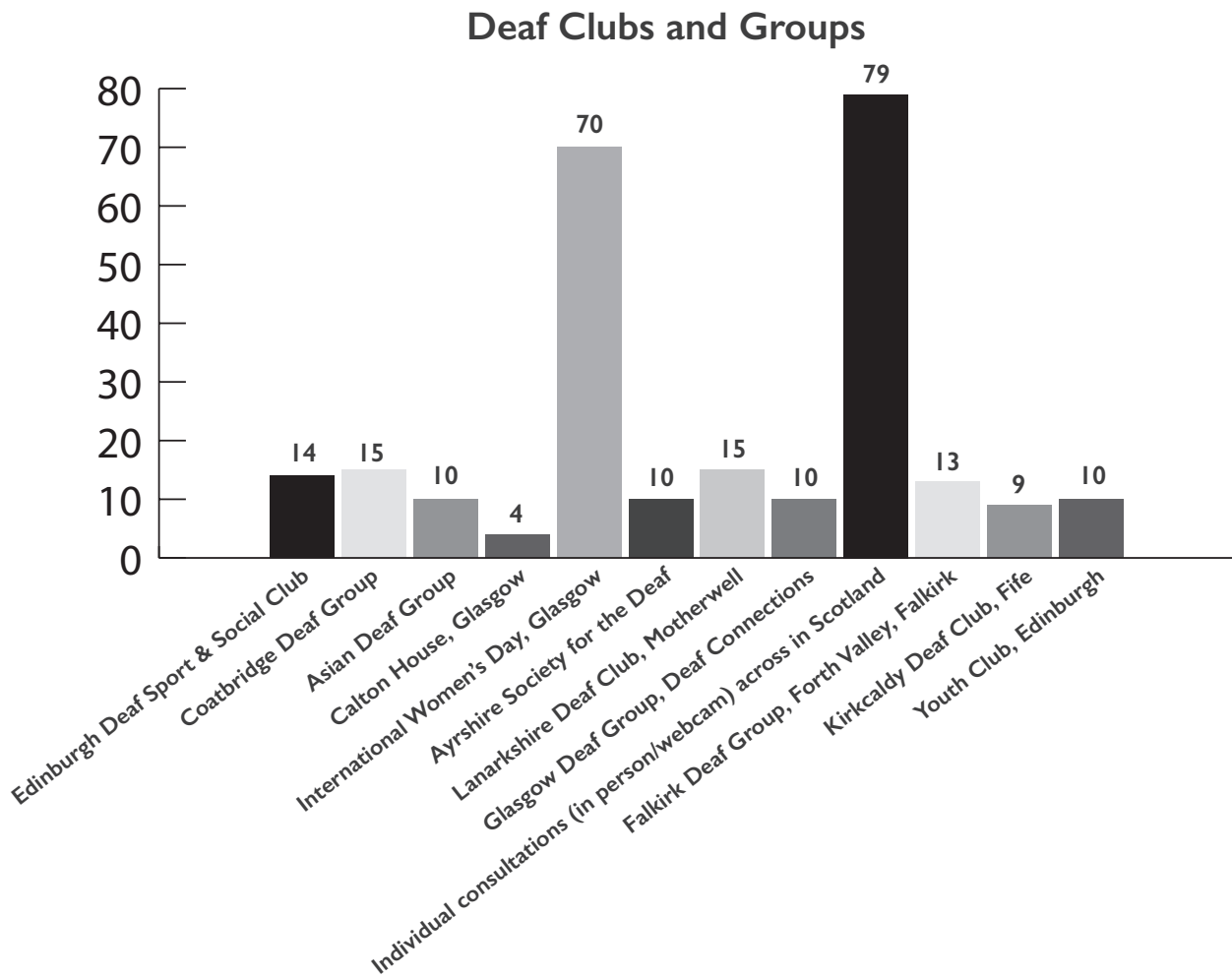
- Improving quality of life by empowering Deaf individuals and groups;
- Enhancing freedom, equality and diversity;
- Protecting and promoting BSL;
- Establishing bilingual education for Deaf children.

Over the course of this 3-year project, the BDA Scotland consulted with a diverse mixture of 636 Deaf BSL community members.

Society recognises Deaf people as a minority culture in the world, with their own language, social norms and culture. The BDA promotes Deaf people's right to collective space within society to pass on their language and culture to future generations.

The BDA Scotland has found, as we have consulted with Deaf people, that Deaf culture intersects with nationality, education, race, ethnicity, gender, class, sexual orientation and other identity markers, leading to a culture that is at once quite small and also tremendously diverse. It may even be that a Deaf person may identify with their nationality first. This may occur especially in the case of Deaf children being born to hearing parents.

This survey was developed to establish the impact and influence of health care services and patient relations. The Access & Inclusion (Health) Officer organised consultation events in **12** Deaf clubs and groups – total is **259** participants. This proved an effective way of engaging with individuals from Scotland's Deaf community. The Deaf clubs/groups were:



The Access & Inclusion (Health) Officer contacted **25** different services; **14** of them responded. Subsequently, the Access & Inclusion (Health) Officer organised consultations (by email/phone/in person) with the below Health organisations:

- NHS Ayrshire and Arran
- NHS Greater Glasgow and Clyde
- NHS Lanarkshire
- NHS Orkney
- NHS Shetland
- NHS24
- Golden Jubilee National Hospital
- The State Hospital, Carstairs
- NHS Education for Scotland
- Chest Heart & Stroke Scotland
- Diabetes Scotland
- Prostate Scotland
- Action on Depression
- Alzheimer Scotland

Main Findings

Through NHS engagement with Deaf organisations such as the BDA Scotland, it has been noted that some improvements have been made to all areas of health services for Deaf people. These include the booking of BSL/English interpreters, NHS staff receiving BSL/Deaf Awareness training, and an increase in health related BSL and Plain/Easy Read English publications.

Main Recommendations

As this report shows, there is still a great deal of work to be done to ensure Deaf and Deafblind patients, including those with Usher Syndrome and young people, get the same level of treatment that hearing patients do.

To achieve this, we recommend building on the fine work that has been done, by:

- NHS services continuing to engage with Deaf organisations and the Deaf community, working together to improve the standard of health care for the Deaf community in Scotland.
- Improving the level of communication systems between staff and patients, and also inter departmental communication, to ensure that Deaf people have the communication systems they need for initial and subsequent appointments.
- Building the confidence that Deaf people have regarding NHS services, by giving them full involvement in decisions about their care and medication, and giving them a fuller understanding of health issues through BSL videos and Plain/Easy Read English publications.
- Continually building information publications for Deaf and Deafblind people in BSL version.

Main Solutions

The main solutions in improving the standard of health care are:

- For the NHS to engage with Deaf organisations to support and guide them in improvements in communication systems for Deaf people.
- To increase the use of technology as it becomes available, e.g. contactSCOTLAND-BSL, and building BSL health videos.
- To establish BSL/Deaf Awareness training programmes for all Primary and Secondary Care staff, with a refresher course every 2 to 3 years, in line with procedures such as First Aid, health and safety training and communication policy.

Impact that this project has made over 3 years:

- 1.** The most encouraging achievement is that a good relationship has been built between Deaf patients, the NHS and BDA Scotland to improve access to health services.
- 2.** Through Deaf organisations, the NHS now has a support mechanism that they can call on to assist them with Deaf patients and receive BSL/Deaf Awareness training and guidance on communicating with Deaf people.
- 3.** Deaf patients are becoming more confident with their engagement with the NHS, from making appointments to spending time in hospital, along with the increasing help they have in understanding their medical conditions through BSL videos.
- 4.** The Access & Inclusion (Health) Officer provided BSL/Deaf Awareness training to Primary Care and Secondary Care staff, and encouraged them to learn about Deaf issues.
- 5.** The Access & Inclusion (Health) Officer worked with voluntary health organisations to produce 12 health factsheets, created BSL video clips for the BDA website, and promoted health information to the Deaf community in Scotland.
- 6.** The NHS is more aware about contactSCOTLAND-BSL (online BSL/English interpreting service) that allows Deaf BSL users contact health services directly.

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Research findings from consultations with Deaf BSL users

This section sets out a summary of our research findings from the consultation events held in the **12** Deaf clubs and groups mentioned in Section 2, which involved **259** participants altogether. The headings below correspond to the questions presented to participants.

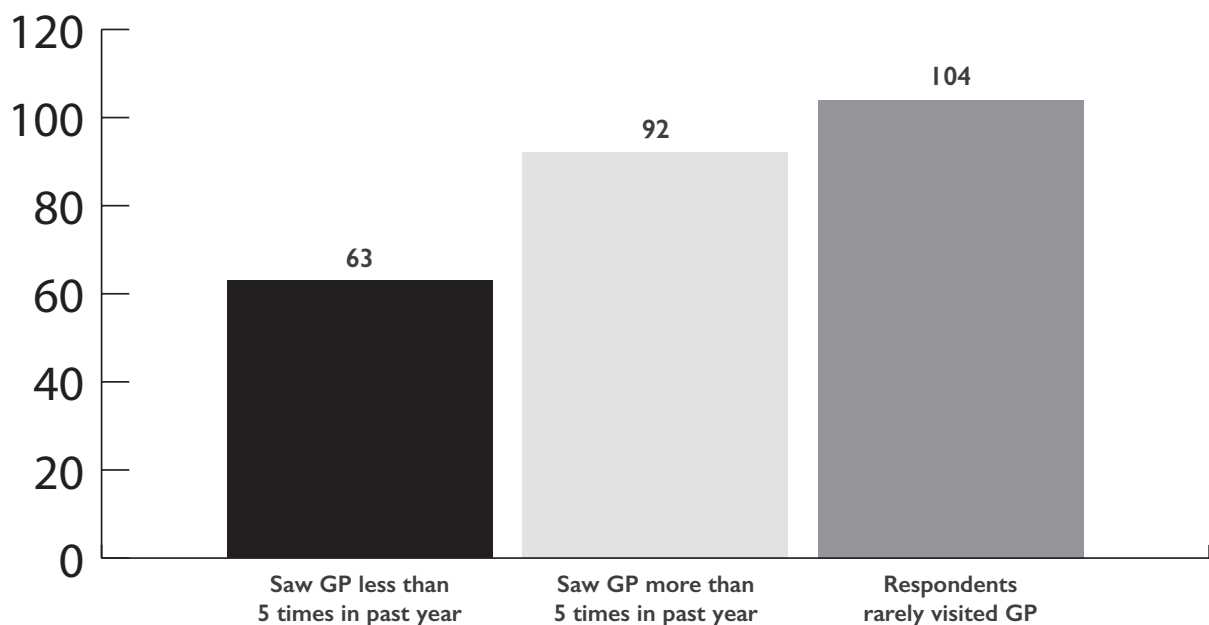
Not all attendees at the consultation events were willing to contribute. Therefore, numbers responding to questions have been used in the main, and **259** participants have been used only if the views of all participants were expressed. This was done in order to ensure information was clear and understandable.

Question 1:

Over the last 12 months, how many appointments have you had with your local GP service (Primary Care) and within NHS services (Secondary Care)?

Primary Care:

It was found that the majority of participants attended appointments with Primary Care services.



63 of the **259 (24.3%)** participants commented that they had rarely seen their GPs because they did not have any health issues. However, they stated that if they did have a health issue they would go and see their local GP less than 5 times in past year.

“Really, it’s very rare for me to go and see my GP. But if I have a health problem, I will go and see the doctor to talk about my health issue.” **Deaf man, Ayrshire**

92 of the **259 (35.5%)** participants stated that they had often been to appointments with their GPs within the last 12 months; for regular check-ups, follow up appointments relating to their health e.g. blood tests (blood pressure and diabetes), or to receive repeat prescriptions more than 5 times in past year.

“I always go to my GP for a check-up every 3 months, to make sure that my blood pressure is OK, as I have problem with high blood pressure. I always take my tablets for it.”

Deaf woman, Scottish Borders

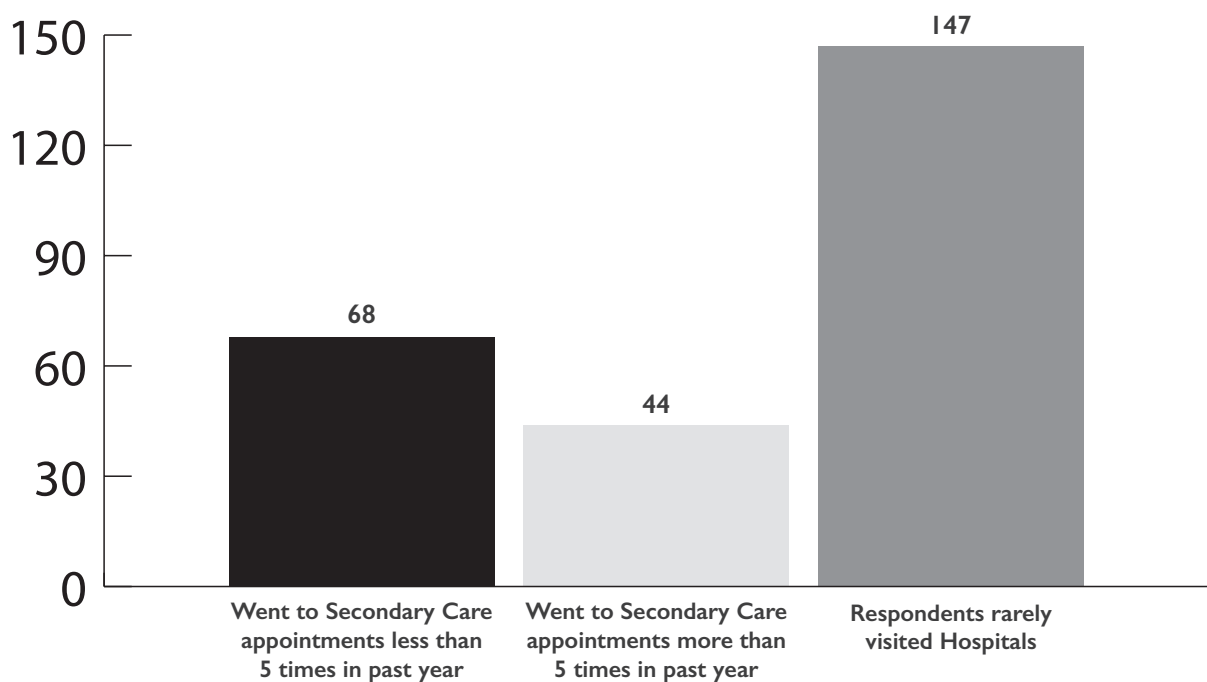
“I go to my doctor for appointment with my family for communication support.”

Deaf Asian woman, Glasgow

104 of the **259 (40.2%)** participants rarely visited their GP.

Secondary Care:

Participants attended appointments with Secondary Care services.



68 of the **259 (26.3%)** participants stated that they attended referral appointments within Secondary Care services (at hospitals, clinics or different departments) to follow up with their health issues less than 5 times in past year.

44 of the **259 (17%)** participants said they often went to Secondary Care referral appointments to follow up with their health issues more than 5 times in past year.

“I go to hospital for regular check-ups to make sure my eyes are OK every 6 months, as I have diabetes.” **Deaf woman, Glasgow**

Participants stated that they always attended hospital for treatment if they had specific medical issues (stroke, diabetes, physiotherapy).

Participants mentioned that they regularly went to audiology departments (Secondary Care) to have check-ups relating to their hearing aids/cochlear implants.

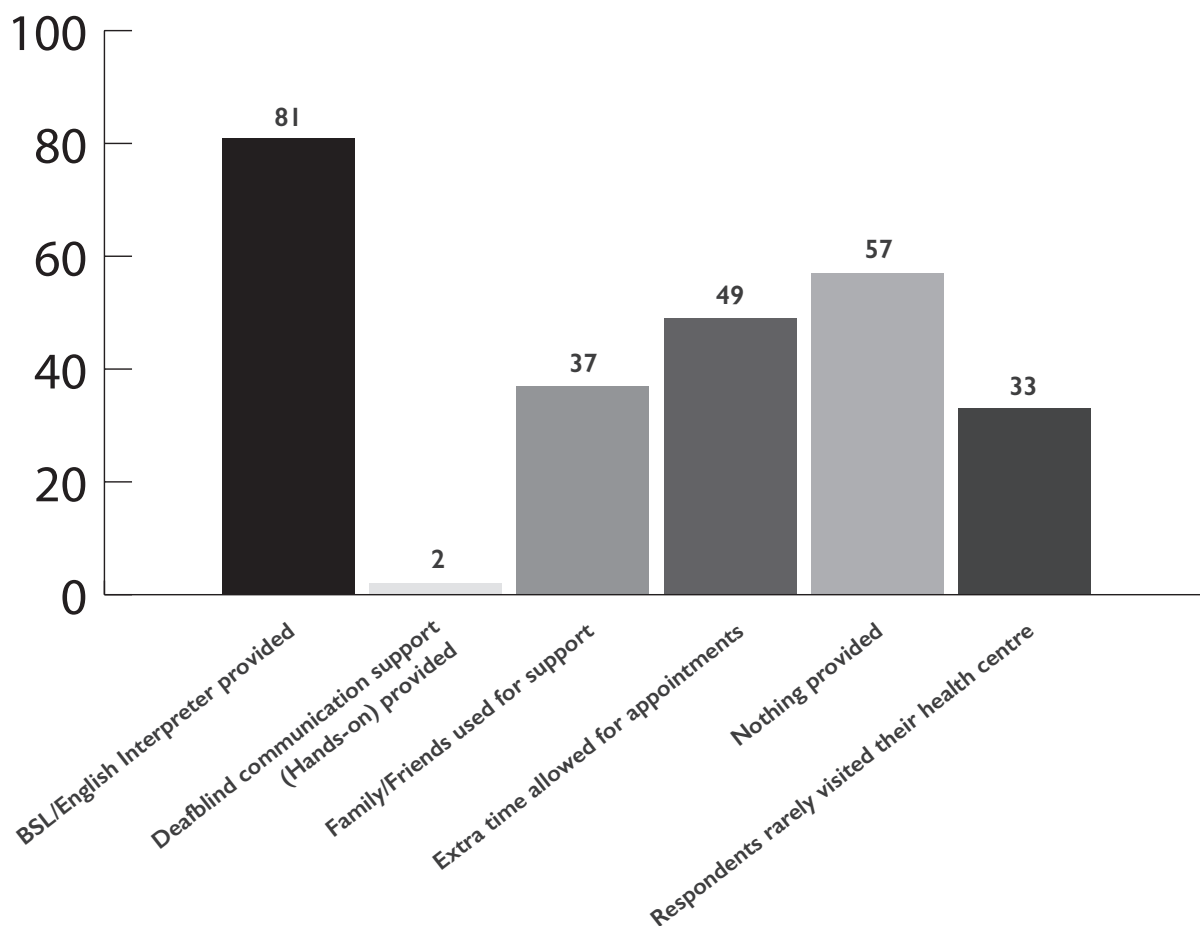
“I always go to audiology for checks to my cochlear implant to make sure that everything is OK. Sometimes, I have found it difficult to communicate with the audiology staff when my cochlear implant was switched off; I felt lost as I couldn’t hear what she said and I relied on my mother for communication support.” Deaf young person, Edinburgh

“Sometime, I went to hospital for check-up but I do find difficult to communicate with doctor about my health. I rely on my mother to tell me what they saying.” Deaf Asian woman, Glasgow

147 of the 259 (56.8%) participants rarely visited Secondary Care services (Hospitals).

Question 2:

Do you feel that the health care practitioner was prepared for your visit? For example, did they book a BSL/English interpreter or give you extra time for your appointment?



81 of the **259 (31.3%)** participants stated that their GPs always provided BSL/English interpreters for their appointments.

“My GP surgery always provides BSL/English interpreters for my appointments, no problem, as they are Deaf aware.” **Deaf man, Edinburgh**

Participants had asked their GP surgeries for BSL/English interpreters for their appointments, but stated that they preferred to know which BSL/English interpreters had been booked, or wanted to be able to request specific BSL/English interpreters who had experience with their medical history. Furthermore, they stated that they would like to have the ability to select the gender of their BSL/English interpreters.

“I asked reception staff for BSL interpreters for my appointments but didn’t know who had been booked to interpret. I would rather know who it is because sometimes my health issues relate to being a woman, so I would rather have a female interpreter but sometimes I get a male one.” **Deaf woman, South Lanarkshire**

Participants felt that some hospitals provided a better service than others across Scotland. These services provide a BSL/English interpreter automatically without the BSL user having to request this, which saves valuable time and reduces the need to rebook appointments, or attend the appointment without a BSL/English interpreter. The impact of having a robust system for ensuring BSL/English interpreters are consistently booked reduces stressful situations for the BSL user and ensures appointments run smoothly.

2 of the **259 (0.8%)** participants were Deafblind and stated that they needed to have a tactile hands-on BSL/English interpreter present at all appointments. This is particularly important due to the specific needs of Deafblind BSL users.

“My GP surgery does know how to use a BSL/English interpreter and Deafblind communication guide for my appointments. I’d like to emphasise that I think Deafblind people have greater barriers than Deaf and hearing people; sometimes we face double barriers to accessing services.” **Deafblind woman, Fife**

The participant went on to explain the importance of having access to BSL/English interpreters and communication guides who have specific knowledge of working with Deafblind BSL users. It is also essential that medical staff have awareness of how to work with a Deafblind patient, as it takes considerably longer to deliver information between a doctor or nurse and the Deafblind person. Using this collaborative approach will significantly impact the quality of service for Deafblind BSL users.

37 of the **259 (14.3%)** participants mentioned that they always brought a member of their family or a friend to appointments because they were unsure if their GP would provide a BSL/English interpreter or not.

“I always bring one of my family members to my appointments because I’m not sure if they have booked a BSL interpreter as they never inform me. So I make sure I have someone with me just in case – sometimes a BSL interpreter isn’t booked or doesn’t turn up for my appointment.” **Deaf woman, East Ayrshire**

Participants commented on the standard of service received whilst attending A&E. They stated that they found significant issues relating to communication. This is due to NHS staff who still do not have any knowledge of how to use BSL/English interpreter booking systems. This inevitably results in BSL using patients having to rely on their families and friends for communication support. They went on to state that this is problematic, as they have no other choice than to ask for help; however, they felt this was not allowing them their privacy and right to live independently.

Participants felt it was acceptable to use a family member/friend to support communication, but felt that they did not receive enough information because they did not know how to interpret medical terminology.

Youth participants mentioned that they often used their family members for communication purposes for example – lip-reading, because they felt that they do not understand what GP or consultant saying as they felt that sometime they talking too fast, mumbles and misses out information. They prefer to have their family for communication as they will explain to them what doctor or consultant saying.

49 of the **259 (18.9%)** participants say that they had extra time to attend appointments, being given double or triple appointment slots because communication purpose via BSL/English interpreter and/or communication guide support for Deafblind person.

Participants mentioned that their GP surgeries were aware of ensuring BSL users patients who use BSL/English interpreters are given extended appointments to allow time for full discussion to take place regarding their health issues.

Participants stated that their GP surgeries or Community Psychiatric Nurse (CPN) always gave them more time during appointments to discuss their health, due to the important nature of their particular health issues.

“My CPN always makes sure a BSL interpreter is booked for appointments and there is extra time available because it is important to talk about my health and we always have to review my medication.” **Deaf man, Edinburgh**

57 of the **259 (22%)** participants commented that their health care practitioner never booked a BSL/English interpreter for appointments, nor allowed for extra time during the appointment.

Participants stated that whilst they had requested that a BSL/English interpreter was booked for their appointment, their requests were not fulfilled and no BSL/English interpreters were booked. This resulted in patients having to attend their appointments with no BSL/English interpreters. The Access and Inclusion (Health) Officer asked them how they communicated

with medical staff; they replied that they had to use the following methods:

- Writing notes on paper
- Lip-reading
- Using gestures

They went on to state that this was potentially detrimental to their health issues as information was not clear and they did not have enough time to clarify any points they were unsure of.

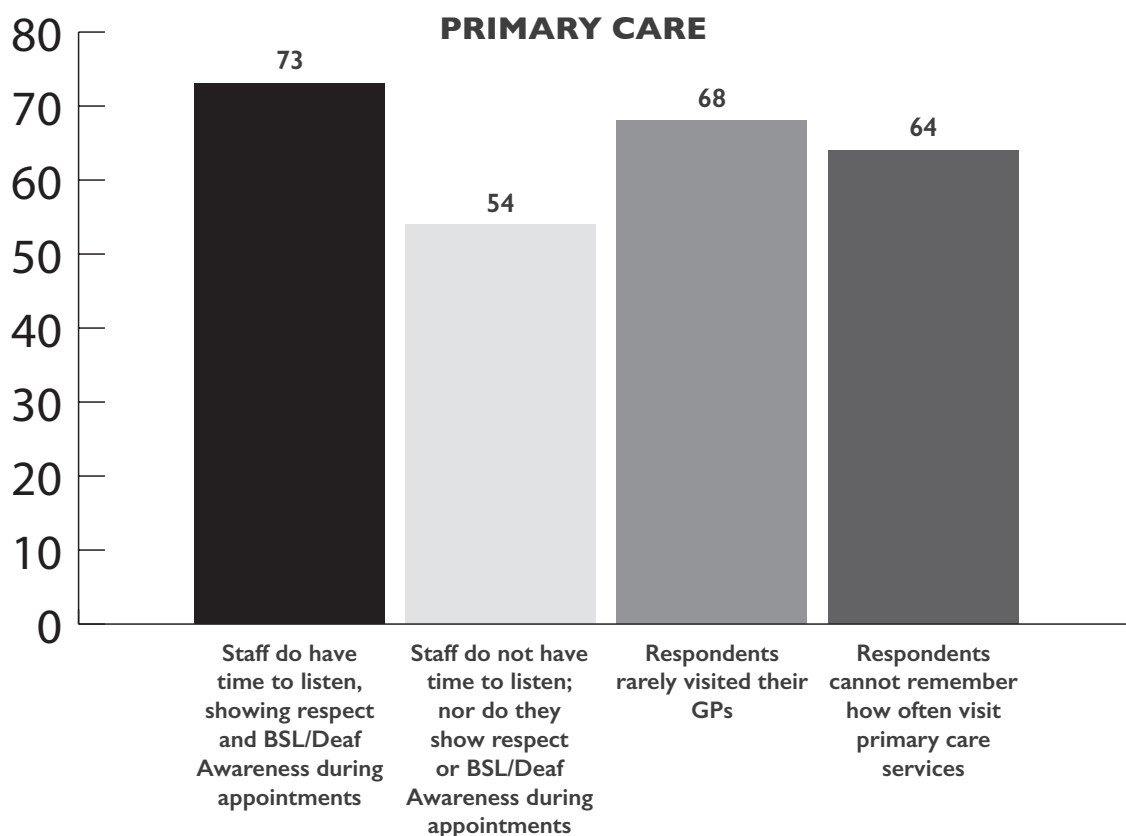
“I have problem with using a BSL interpreter for any appointment as I know that myself is BSL user but I do also have Hindi spoken language for my family so I would like to have Asian BSL interpreter.” **Deaf Asian man, Glasgow**

“Sometimes, I use a notepad for communication, but I don’t feel that’s good enough because I want to say something about my problem but it’s difficult for me to write it down as I am not very good at English and I worry about whether the doctor will understand what I’ve written on paper or not.” **Deaf woman, Perthshire**

33 of the **259 (12.7%)** participants were unsure about this question. The Access & Inclusion (Health) Officer asked them about their services, provided BSL/English interpreters, extra time but they respond that they rarely visit their health centre for any appointment.

Question 3:

Did the health care professional (staff) listen to you carefully, treating you fairly and with respect? Did they understand/have awareness about Deaf-related issues and how they affect your life?



73 of the **259 (28.2%)** participants felt that Primary Care staff did have time to listen or treat them fairly and with respect during appointments. Participants mentioned that some staff had BSL/Deaf Awareness, which makes it easier for BSL patients to feel more comfortable.

Participants stated that having consistency with the medical staff, attending the same doctor or nurse etc. for appointments, resulted in their appointments being easier, as there is better rapport, and the medical staff begin to understand how to interact with them during appointments. Other participants felt that attitudes vary depending on the doctor; e.g. some of them will be patient, have a good attitude, have respect and listen, whilst others seem more focused on ensuring appointment times are completed on time whether full information has been given or not.

“My local GP is fine as they have Deaf Awareness, understanding what Deaf people want. For example, they know how to book BSL interpreters for appointments and how to work with them, and pay attention when the Deaf person is talking. They always make sure that everything is covered before I leave the room.” Deaf woman, Edinburgh

Participants noticed that their GP had a BSL/Deaf Awareness of how to converse with Deaf people, e.g. they used the right position and faced the Deaf person whilst the BSL/English interpreter was in the room. Their rooms were bright and the GP had plenty of time to explain things to the Deaf person. Participants mentioned that they found bringing a piece of paper with key points written down assisted them in remembering the particular issues related to their health problems.

Participants stated that their GP surgeries had knowledge about Deaf related issues concerning communication barriers, such as contacting the surgery (phone calls) and BSL/English interpreter booking systems.

Participants commented that on occasion their GP might have a medical student (shadowing a doctor or nurse) with them in the room and asked for consent for the student to observe the consultation. The participants believed that this is valuable for medical students' training; experiencing it during their courses can improve services in future. Participants said that GPs or nurses should always ensure that Deaf people understand what is happening at the consultation, give them support, and take time to talk about their health issues.

One participant recalled a positive experience in which an on call doctor visited a Deaf person who was unwell at home. The doctor requested an ambulance to come and take the Deaf person to hospital (A&E), and ensured that there was a BSL/English interpreter booked and waiting when the patient arrived at the A&E department. However, other participants spoke of experiences in which staff would not use BSL/English interpreters, but instead used paper and a pen to explain health issues, which caused a breakdown in communication and understanding of the implications of the health issue.

“When I was unwell that day, I had to call my doctor out to check on me, then he decided to call an ambulance to take me to hospital. At the same time, I asked my doctor about a BSL interpreter – he told me that he had already arranged for someone to turn up at hospital (A&E). At first, I didn’t believe it as it’s impossible to get a BSL interpreter at short notice, but when I arrived at A&E I saw the interpreter there and was gobsmacked!” **Deaf man, Falkirk**

Participants commented that they had used contactSCOTLAND-BSL (online BSL/English Interpreter) for appointments. They thought medical staff knew about this service and would use it when necessary.

54 of the **259 (20.8%)** participants felt that Primary Care staff involved in their health care had no awareness about Deaf issues. They felt the staff were impatient and did not book extended appointments to allow full information to be delivered. They went on to state that despite explaining that they were Deaf and requesting to be prompted when their appointments were ‘called’, staff still forgot to inform the Deaf person when they were called, causing frustration.

Participants commented that when they received medication from their GP, sometimes the doctors did not take time to fully explain it, e.g. the dosage, the length of the course and what it was for.

“I have health problem myself, depression. My Doctor gave me tablets to help me to feel better but still have problem. I explained to my doctor but he still doesn’t understand what I’m talking about. I don’t want to ask my sister to get involved because it’s private.” **Deaf Asian woman, Glasgow**

Conversely, other participants mentioned that their doctors always make sure that they do understand, giving a full explanation before they leave the consultation room.

Another area of difficulty discussed by participants related to attending the chemist. Participants felt that staff had no awareness about Deaf related issues; the Access & Inclusion (Health) Officer asked them to explain more. The participants stated that when collecting medication, staff spoke too fast, which added to their stress, as lip-reading can cause a breakdown in communication. When asked to slow down, staff did not seem to understand how to do this. Some participants experienced difficulty when the staff called out their names when their prescriptions were ready to be collected, as they could not hear the call.

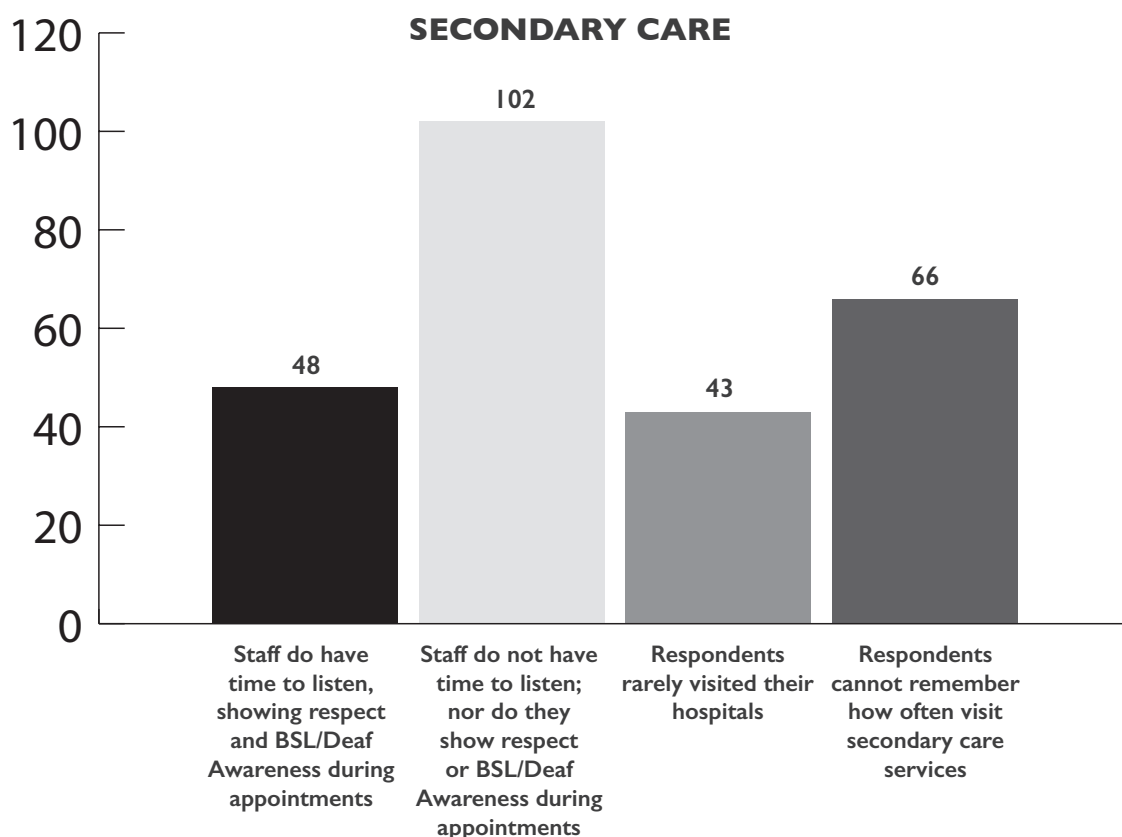
“I have problems with the chemist as I find it difficult to communicate with staff there, because they always ask for my name, address and date of birth. It is hard for me to explain and ask for a pen and paper, wasting the staff’s time and other people in the queue stare at me. That makes me feel small – I wish all the staff could sign and it would go smoothly with no problems!” **Deaf woman, Motherwell**

68 of the **259 (26.3%)** participants rarely visited their GP services for any appointments.

64 of the **259 (24.7%)** participants were unsure how to respond to this question. The Access & Inclusion (Health) Officer asked them about this question, they felt they could not respond to this question because they cannot remember how often they have visited Primary Care services.

Question 3:

Did the health care professional (staff) listen to you carefully, treating you fairly and with respect? Did they understand/have awareness about Deaf-related issues and how they affect your life?



48 of the **259 (18.5%)** participants believe that Secondary Care staff made time to listen and treat patients fairly and with respect when they attend appointments in hospital. They also commented that some staff do have an awareness of how to communicate with Deaf people, e.g. using basic BSL, using gestures etc. The participants suggested that NHS staff should learn more BSL/Deaf Awareness.

Participants felt that, on occasion, NHS staff know how deal with Deaf patients and Deaf family members of hearing patients, providing a BSL/English interpreter to communicate with the Deaf person. On other occasions, staff resort to using gestures or write things down on paper to communicate with the patient or family member.

“I always bring one of my family members along when I was in the hospital ward, because although I did ask staff to book a BSL interpreter for me, they weren’t sure how to do that. I gave up and used my family for communication, or sometimes wrote things down, but I don’t feel that was good enough.” **Deaf woman, Coatbridge**

102 of the **259 (39.4%)** participants thought that NHS staff did not have any knowledge about Deaf related issues. They felt this was directly related to the high turnover of staff. If BSL/Deaf Awareness training is only delivered every two years, then new staff will have no awareness, which affects Deaf community life.

Participants felt that specialist services related to mental health did have BSL/Deaf Awareness, but there were still gaps. The participants went on to explain that whilst some professionals knew some BSL to communicate with Deaf people, it would be more desirable for staff within these specialist services to be fluent BSL users of the language, which would allow for full communication.

Participants further commented that within mental health services, some specialist doctors would arrange reviews with the Deaf person to discuss their health and medication. During one of these consultations, the specialist doctor made the decision to change the patient's medication due to it not being suitable. However, the doctor failed to inform the Deaf patient of the change of medication. The Deaf patient therefore, was unaware of the new medication and was not given full information, or the right to ask questions relating to the change of medication.

Young Deaf participants discussed issues when attending appointments within audiology departments for check-ups relating to their hearing aids/cochlear implants. They commented that they found it difficult to understand what staff were saying when their hearing aids were removed or their cochlear implants were switched off. Some young Deaf participants further commented that some staff had no BSL/Deaf Awareness, like facing them so that they could lip-read, which caused difficulty in understanding them. Most of the time, they relied on their family for communication support. Also, they felt that it would be of benefit for all NHS staff to learn something about Deaf people, BSL and lip-reading.

Participants discussed other departments in which they had experienced difficulty; notably dental departments or ophthalmology (treatment of disorders and diseases of the eye), where they had found it hard to understand what was being discussed. It was felt that staff had no knowledge about Deaf related issues. When the Access & Inclusion (Health) Officer asked them to explain in more detail, the participants explained that staff used protective coverings, such as masks to cover their mouths, which means the Deaf patient cannot lip-read. In ophthalmology (Eyes) appointments, the room is darkened while staff conducts their testing. This means that the Deaf patient is unable to see the BSL/English interpreter and constant requests to put the lighting back on create longer appointment times.

When Deaf participants had been admitted to hospital, they commented that they found this hard to cope with, feeling very isolated. This was mainly due to the limited communication they had with staff, and the poor provision of BSL/English interpreters. Participants also felt that although there seemed to be plenty of staff working in the wards, no effort was made to converse with the Deaf patient, which added to the feeling of isolation and loneliness during a time of illness and stress.

One participant had a personal experience of having been admitted to NHS Ayrshire and Arran hospital for a 7-week period. She requested a BSL/English interpreter but none were provided.

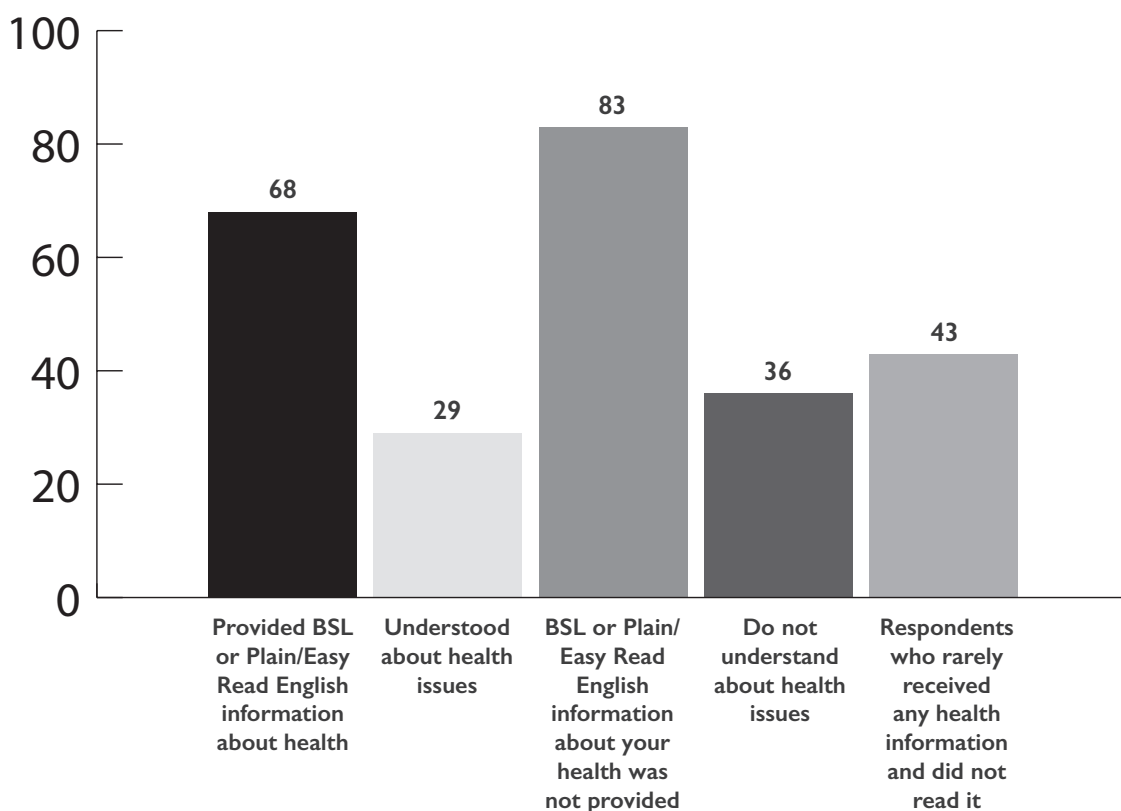
Participants felt that when attending counselling via hearing organisations, the counselling professionals did not have awareness about Deaf related issues, which caused difficulty when the Deaf patient was attempting to engage with them. Participant mentioned that few services did offer to provide a BSL/English interpreter for appointments, but this was also felt to be problematic as some people found it difficult to have a third person in the room during these sessions. They would like more Deaf BSL using counsellors, who they would find easier to access when in need of support.

43 of the **259 (16.6%)** participants rarely visited hospital for any appointments.

66 of the **259 (25.5%)** participants were unsure how to respond to this question. Access & Inclusion (Health) Officer asked them about this question, they felt they could not respond to this question because they cannot remember how often they visited Secondary Care services.

Question 4:

Were you given BSL or Plain/Easy Read English information to help you to understand your health problem? If so, was it clear and easy to understand?



68 of the **259 (26.3%)** participants mentioned that they always got BSL or Plain/Easy Read English information about their health. They further stated that they could access BSL/English interpreters to assist them with translating the information into BSL.

29 of the **259 (11.2%)** participants mentioned that whilst they managed to understand the general meaning of the information, they did not feel they had a full and complete understanding. They stated that if they were not sure about certain concepts, they would look

online or in a dictionary to find out the meaning of certain words. If they were still unsure of the information then they would see their GP and ask for an explanation.

83 of the **259 (32%)** participants stated that they felt information given to them about health conditions was difficult to understand and confusing, and they often felt unsure about it due to the use of jargon and the structure of the English. It was also felt that there are not enough BSL translated health resources.

“I always rely on my family/friends for help with translating health information, but I have noticed that I am not only one, as other Deaf people feel the same about information about their health issues. I don’t think we have any confidentiality.” Deaf woman, Edinburgh

36 of the **259 (13.9%)** participants felt that health information was difficult to understand, stating that they used search engines such as Google to gain more information about conditions and medication.

There was a discussion about how, during surgical procedures, information was given to Deaf patients regarding medication. Leaflets stating what medication should be taken and what cannot be taken were unclear, and as such the Deaf patient may attend the pre-operation consultation having taken medication that they should not have taken. The operation will then have to be rescheduled to a different date. This is, of course, very stressful for all involved.

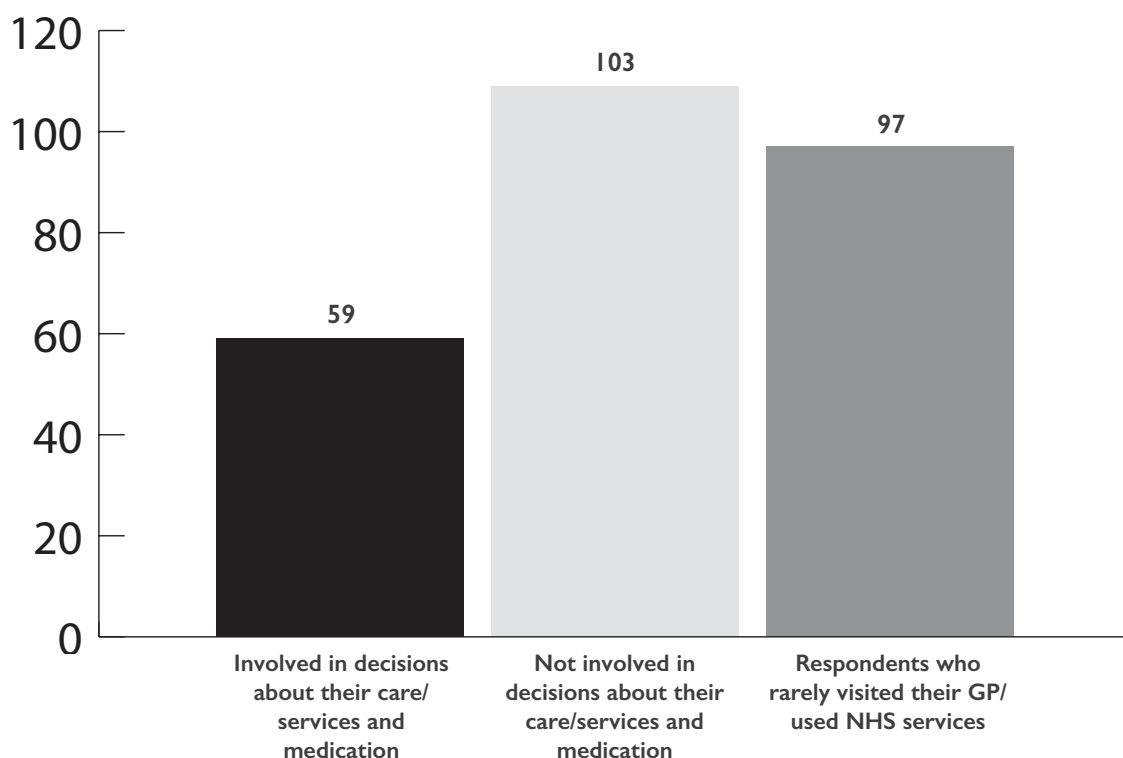
“I received a pre-operation letter from the hospital, saying which medication to take or not take, but I was not sure about it. On the day, I realised I should not have taken the medication. Appointment was postponed.” Deaf woman, Glasgow

Participants stated that doctors or nurses would give them information that was neither in large print nor visual. Deafblind participants were unable to see the writing, which was frustrating.

43 of the **259 (16.6%)** participants rarely received health information. The Access & Inclusion (Health) Officer asked them about this question, they explained that they received information about health but did not read it, as they were not relevant to them.

Question 5:

Do you feel involved in decisions about your care and services and the medication you receive from your GP/the NHS?



59 of the **259 (22.8%)** participants said they always felt involved in any decisions with their care/services and medication they received from their GP or elsewhere in the NHS when using BSL/English interpreters. Most of them felt that it is important to be involved because they have the right to know about their health.

Participants said that if their health issue required treatment which may include medication or a blood test, it is vitally important to receive information.

Participants felt it was important to have BSL/English interpreters for appointments within mental health settings, to allow them to discuss issues related to their health.

“I think all mental health services should provide BSL interpreters for appointments.”
Deaf man, Edinburgh

103 of the **259 (39.8%)** participants felt that they were not involved with decisions relating to their health, due to lack of support, not enough information from staff via BSL/English interpreters, or using families/friends for communication support.

Participants expressed concern about their rights regarding decisions relating to health issues. They felt that there were issues with the quality of BSL/English interpreters provided, as some participants were continually asking for clarification of information to ensure they had full and correct understanding and awareness of the specifics of their illness.

Participants mentioned that they felt excluded from decisions when they attended GP/hospital appointments and used their families/friends for communication support. If they tried to contribute to the conversation, or ask for an explanation of what was being discussed, health professionals would often say they would explain later. However, later, they did not receive the full information; rather they got an edited version of what was discussed about them. The participants continued to express that they felt left out of the conversations that occurred between their family members and health professionals, without being allowed to contribute.

“When I had a hospital appointment, I didn’t feel involved in the discussion about my health because I used my family for communication support and didn’t feel that I’d received full information. When I asked my sister to explain to me, she said she would tell me after the appointment had finished; then she explained briefly. I still wasn’t happy!”

Deaf man, Motherwell

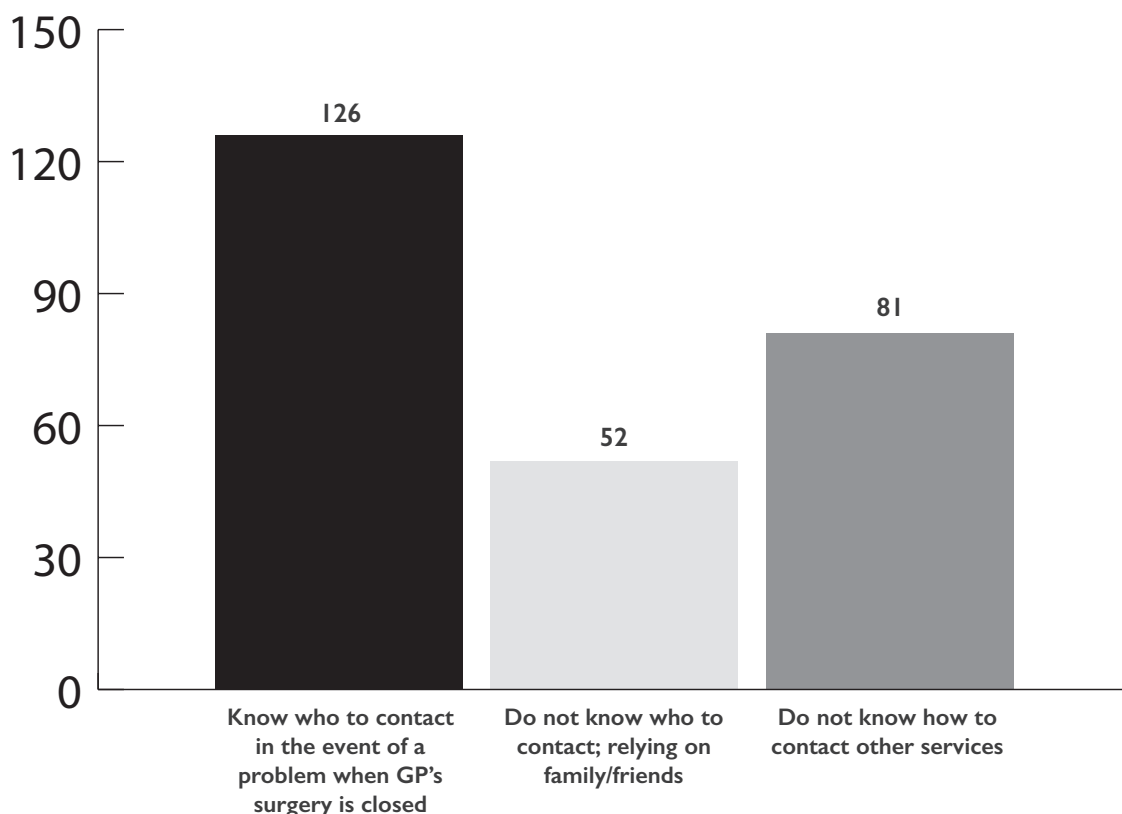
Participants felt that although they often received medication, they were unsure if it was suitable or correct for them.

“Sometime, I get new medication from my doctor but I am not sure about it – I always ask my daughter to explain it to me.” **Deaf woman, Ayrshire**

97 of the **259 (37.5%)** participants who rarely visited their GP / used NHS services.

Question 6:

Do you know who to contact if you have a problem when your GP's surgery is closed? If not, why not?



126 of the **259 (48.6%)** participants said they knew to how to contact other services when their GP's surgery was closed. When the Access & Inclusion (Health) Officer asked them which methods they used to contact the out-of-hours services, the following contact methods were cited:

- Text relay (by using the text to speech rely service)
- contactSCOTLAND-BSL (online BSL/English interpreting)
- Family members
- Friends/neighbours
- Fax
- Email

Participants stated that to arrange an appointment to see a GP, they must call first thing in the morning. If they cannot wait due to the serious nature of their illness, they would go to their local A&E department.

"I would rather to go my GP to arrange an appointment to see the doctor by myself but they always ask me to phone them in the morning so I have to rely on my son to deal with this."
Deaf woman, Fife

Participants stated that they preferred to contact health services themselves as they did not want others to have access to their personal medical issues.

It was noted that three GP surgeries were open on Saturdays.

52 of the **259 (20.1%)** participants stated that they did not know how to contact health services and relied on family members/friends to support them if they required access to health services. Some participants highlighted continuing problems with contacting GP surgeries. These surgeries only allowed appointments to be booked over the telephone, and would not allow a text messaging service / email to be used. Participants explained that in order to make an appointment they had to wait until the surgery opened and attend in person to make the appointment. However, when they did this, certain surgeries refused to accept their bookings as they only accepted telephone bookings. This has created significant barriers.

Participants suggested the option of GP surgeries extending their opening hours (8am to 8pm) which would allow Deaf people to attend appointments any time during that day, further allowing more opportunity to book BSL/English interpreters.

Participants noted that when making an appointment with their GP and asking for a BSL/English interpreter, they were given the appointment 2 weeks in advance to allow the surgery to secure a BSL/English interpreter. If they required an appointment urgently, then they were advised to use a family member or friends for communication support.

“I will go and ask for an appointment on the same day, but they always arrange to get a BSL interpreter in 2 weeks’ time, not that day. Waiting for an appointment for that long feels pointless, so I have told them go ahead with an appointment on the day, and have had to write things down instead.” **Deaf woman, Glasgow**

Participants discussed how they found it extremely difficult to use NHS24 (Call on 111) due to the endless questioning, which can take up to 30 minutes. They felt the questions were difficult to understand and could become confusing, then upon arrival at hospital, they were further questioned. This barrage of questions can be frustrating.

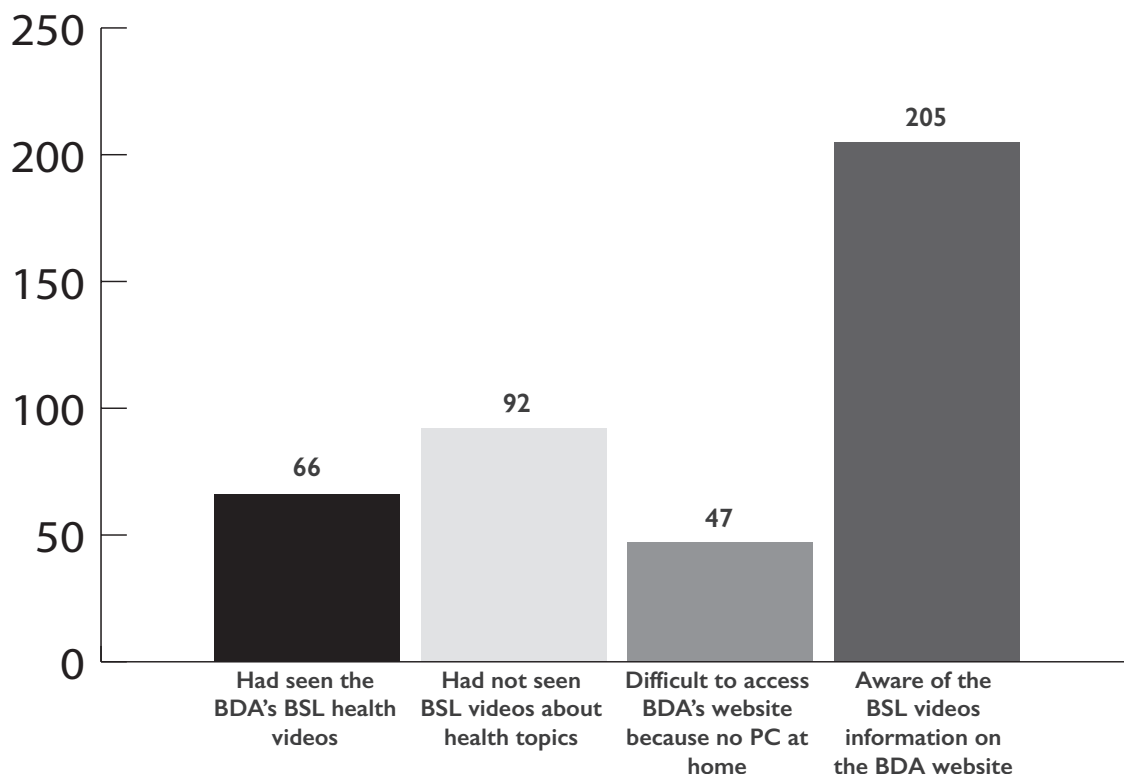
Participants mentioned they had to use NHS24 (Call on 111) used by contactSCOTLAND-BSL (online BSL/English interpreter) to deal with health issues, especially in the North of Scotland (rural area). The contactSCOTLAND-BSL service is problematic at times due to weak signals or poor weather. However; if the connection is good, they feel the service is helpful.

“I have used contactSCOTLAND-BSL to arrange an appointment. I do find it a useful service useful for the Deaf community.” **Deaf man, Glasgow**

81 of the **259 (31.3%)** participants mentioned that they do not know to contact other services.

Question 7:

The BDA's website has BSL videos about different health topics (dementia, stroke, depression, pancreatic cancer and multiple sclerosis – MS).



The Access & Inclusion (Health) Officer asked participants if they had watched the BSL videos or not; and if so, whether they thought they were useful and had made an impact on the Deaf community or not.

66 of the **259 (25.5%)** participants stated that they had looked at the BDA website's BSL videos about different health topics (dementia, stroke, depression, pancreatic cancer and MS). They found it useful to have the information in BSL, and in the linked health factsheets.

Participants felt that they got a better understanding of the information from the BSL video clips, which gave clearer explanations than the leaflets which were in English, thus difficult to understand. They mentioned that they preferred the BSL translations as BSL is their first language.

"I found the COPD factsheet really useful because I have had a problem with COPD for a long time; my GP and hospital gave me a booklet about COPD but I didn't understand it because the amount of reading involved was overwhelming. I then watched the BSL video clip, which I was really happy with." **Deaf woman, Aberdeenshire**

Participants who are Deafblind or have Usher Syndrome mentioned that whilst the BDA's health videos contained really good information for the Deaf community, the creators of the clips needed to rethink the background they used, which was too dark. They need to create more contrast to help people who are Deafblind/have Usher Syndrome see the signing properly. It was suggested that there should be a discussion with Deafblind people/those who have Usher Syndrome, regarding the best way forward. English text could be provided so that they can read it, or use Braille/moon, etc.

The participants agreed that it was important to have translated information to ensure engagement with the Deaf community, and to encourage Deaf people to learn about different health issues. It is also important to influence health organisations and charities to create BSL videos on health topics for the Deaf community from now on, particularly with consideration for the BSL (Scotland) Act 2015 for health issues.

“It’s important to have BSL videos about health issues and make other health services aware of them – it’s what Deaf people need; to understand information about health in an accessible way.” **Deaf man, Aberdeenshire**

92 of the **259 (35.5%)** participants agreed that when they received information about their health issue from the NHS or their GP, they felt very confused by the English used, which contained technical medical words; they felt they lacked understanding. They said that they had looked at the BDA website for information, but only saw the translated video clips once. When the Access & Inclusion (Health) Officer asked them what the issues were, they responded that they found it difficult to navigate to find the BSL health videos, because there were too many signposts, making it difficult to access health information. Other participants mentioned that they lacked the time to look at the BDA’s website.

“I have seen it once, but it was difficult to find the relevant videos on the BDA website. After that, I gave up. I wish it was easier to access health information on the BDA website.”
Deaf woman, Glasgow

47 of the **259 (18.1%)** participants, especially elderly people who did not have their own computers, mentioned that they never used computers at home and did not know how to do so. They said it was difficult for them to access information online, which resulted in a lack of information on important health topics, such as the warning symptoms of an illness. The Access & Inclusion (Health) Officer explained to these participants that BDA Scotland staff always email people information about events and health topics. These emails include links to the BDA website and Facebook page every month.

Web link: www.bda.org.uk/health-and-well-being-info

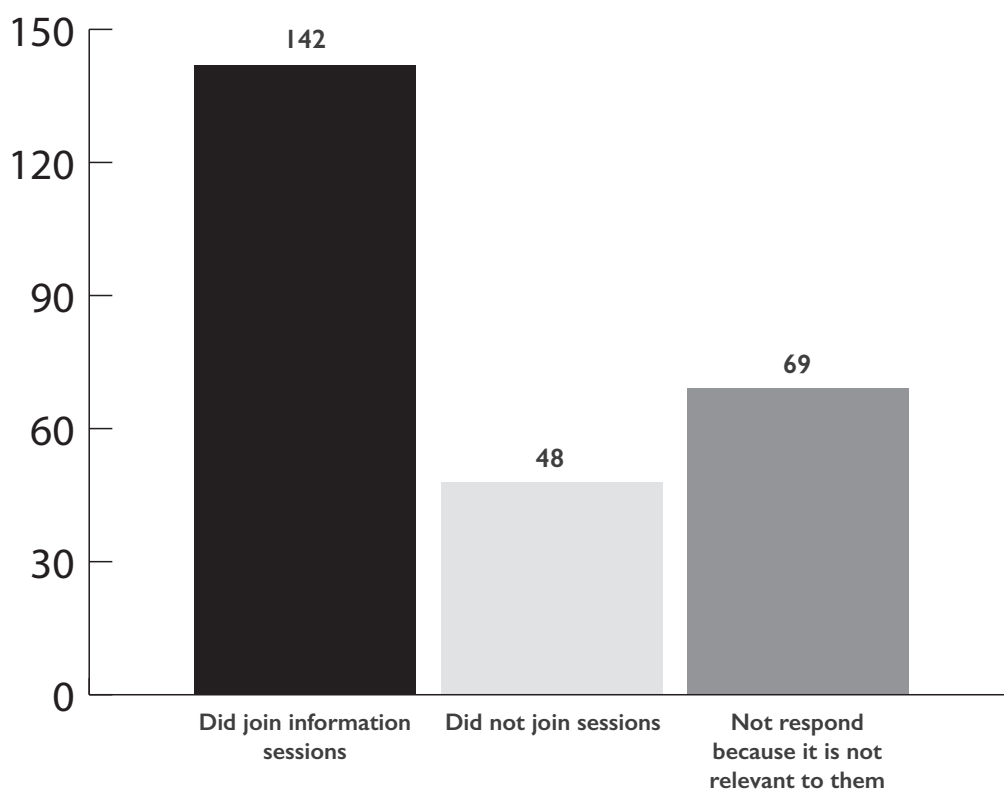
- **Bipolar Disorder:** www.bda.org.uk/health-bipolar-disorder
- **Chronic Obstructive Pulmonary Disease (COPD):**
www.bda.org.uk/health-copd-chronic-obstructive-pulmonary-disease
- **COPD Pathway:** www.bda.org.uk/health-copd-chronic-obstructive-pulmonary-disease
- **Dementia:** www.bda.org.uk/health-dementia-scot
- **Depression:** www.bda.org.uk/health-depression
- **Glaucoma:** www.bda.org.uk/health-glaucoma
- **Myalgic Encephalomyelitis (ME):** www.bda.org.uk/health-me
- **Multiple Sclerosis (MS):** www.bda.org.uk/health-ms
- **Migraine:** www.bda.org.uk/health-migraine
- **Pancreatic Cancer:** www.bda.org.uk/health-pancreatic-cancer
- **Parkinson’s Disease:** www.bda.org.uk/health-parkinsons-disease

- **Pneumonia:** www.bda.org.uk/health-pneumonia
- **Rheumatoid Arthritis (Osteoarthritis):** www.bda.org.uk/health-rheumatoid-arthritis
- **Stroke:** www.bda.org.uk/health-stroke

205 of the 259 (79.2%) participants were aware of the translated information on the BDA website.

Question 8:

Did you think the BDA’s information sessions (on depression and stroke) or steering groups (on dementia, MS, ME and stroke) were useful and informative? If not, why not?



142 of the 259 (54.8%) participants mentioned that they had been involved in the BDA’s information sessions in the past, and felt that the information given about depression, stroke and International Women/Men’s Days were very useful. Furthermore, it was felt that having the opportunity to engage and share information on the experiences of the Deaf community with services and organisations was of benefit. Having the opportunity to ask questions and being directly involved was seen as positive.

“Before I came here, I had always thought that depression was related to having an unhappy life. I didn’t realise that different kinds of problems link with depression. Now, I have learnt something new about depression – which is very useful!” Deaf man, Edinburgh

“Very interesting and useful but I’d like more details. The two presentations were very emotional and really had an impact on me.” Deaf woman, Glasgow

48 of the 259 (18.5%) participants said they were not interested in engaging with the BDA's information sessions. The Access & Inclusion (Health) Officer asked them why; they replied that they were not relevant to them, or were held at the wrong time.

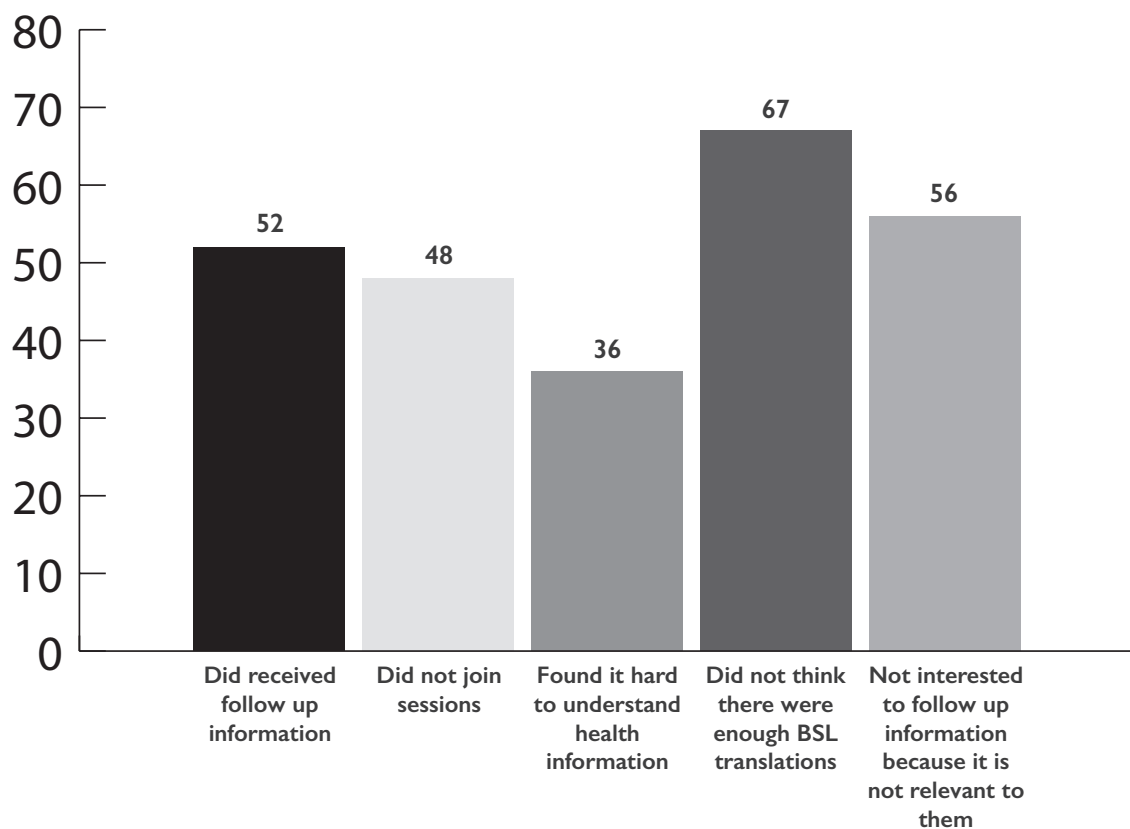
Participants (youth, Deafblind people, those with Usher Syndrome) said they found it difficult to attend information sessions/steering groups due to travel issues or support from their families/friends/carers. Furthermore, some Deafblind / Usher syndrome participants stated that whilst they had an interest in being involved with the Deaf community sessions, there were issues in accessing communication guides to assist them in attending.

"I would love to join in any information sessions, but I do find it difficult because I am Deafblind, so it will be problematic to access information without communication support. If I want to go, I have to arrange for a communicator guide to be with me on the day."
Woman with Usher, Fife

69 of the 259 (26.6%) participants at the consultation events felt they were unable to contribute. Access & Inclusion (Health) Officer asked them that they are not interested to respond this question because they felt that it is not relevant with them.

Question 9:

After information sessions (on depression and stroke), did you receive follow up information? If yes, what?



52 of the 259 (20.1%) participants agreed that while they did receive follow up information after the BDA's information sessions/steering groups, they found it hard to understand because most of this information contained a lot of technical medical information in English. They commented that there was not enough BSL translated material relating to health issues.

Participants commented that some information sessions had BSL translation available, which was easier for them to access and gave clearer information.

“I have attended some information sessions because there were BSL interpreters or Deaf speakers, which made it easier to discuss health issues, and I could share things with other Deaf people too.” **Deaf man, Glasgow**

Participants mentioned that they had attended an information session/steering group with a hearing organisation, which unfortunately did not provide a BSL/English interpreter, so they found it hard to get involved. This was particularly frustrating; the participants stated that they would have liked to have learned something about health issues/personal experiences from the hearing people involved, but due to the environmental barriers, this was very difficult to achieve.

“I went to a steering group – a hearing organisation provided it. I asked them to provide BSL interpreters and they did so once, but then nothing happened because they couldn’t afford it.” **Deaf woman, Scottish Borders**

48 of the **259 (18.5%)** participants stated that they never attended the BDA’s information sessions, due to the sessions not being relevant to their health needs, or held at an inconvenient time or day.

56 of the **259 (21.6%)** participants at the consultation events felt they could not contribute. Access & Inclusion (Health) Officer asked them why not interested to follow up information, they mentioned not interested to not follow up information because sometimes health information is not relevant to them.

Question 10:

Do you think this Deaf Health Challenge project will make a difference and help health services to improve their provision for the Deaf community? How?

153 of the **259 (59.1%)** participants said they thought this project should continue. By engaging with health services, the Deaf community can influence the improvement of their provision to the benefit of all. They felt that 3 years funding for this project was not enough, and that more funding was needed to ensure health services continued to improve services for Deaf BSL users.

Deaf participants said they would like to see:

- More BSL/Deaf Awareness training for NHS staff (Primary and Secondary Care)
- Provision of BSL/English interpreters for all appointments
- All health information in Plain/Easy Read English
- BSL translations of information on different health issues
- More research/surveys on the Deaf community
- More information sessions for the Deaf community
- More meetings with third sector/voluntary organisations to improve provision/work together as partners

- Health provision and services improvements in line with the BSL (Scotland) Act 2015
- Accessible BSL translated information (leaflets/video clips) from health services
- Improvements in mental health services across Scotland

“I have been involved in the work of the Access & Inclusion (Health) Officer for 3 years. I have shared my experiences as I am happy to help, to exemplify Deaf people’s experiences with health services and encourage the services to improve and engage with the Deaf community. It’s important to carry on with this project because Deaf people need it.” Deaf woman, Edinburgh

Participants thought it should be mandatory for all staff (Primary and Secondary Care) to attend a BSL/Deaf Awareness refresher course every 2 to 3 years, in line with procedures such as First Aid, health and safety training and communication policy.

Participants felt that all services (Primary and Secondary Care and voluntary organisations/the third sector) should have more involvement with Deaf organisations such as BDA Scotland and the Deaf community. Using a collaborative approach, services can improve and impact the standard of care for the Deaf community across Scotland.

106 of the **259 (40.9%)** participants at the consultation events felt unable to contribute to this question. Access & Inclusion (Health) Officer asked them why not to join this questionnaire; they responded this question that they are new to this project.

5

Research findings from consultations with Health Boards / Health organisations

To establish the current systems in place within existing health services, BDA Scotland contacted **14** service providers and received completed questionnaires from a total of **14** of the **25 (56%)** different health care providers across Scotland. Individuals were consulted and were asked to answer six questions relating to service provision.

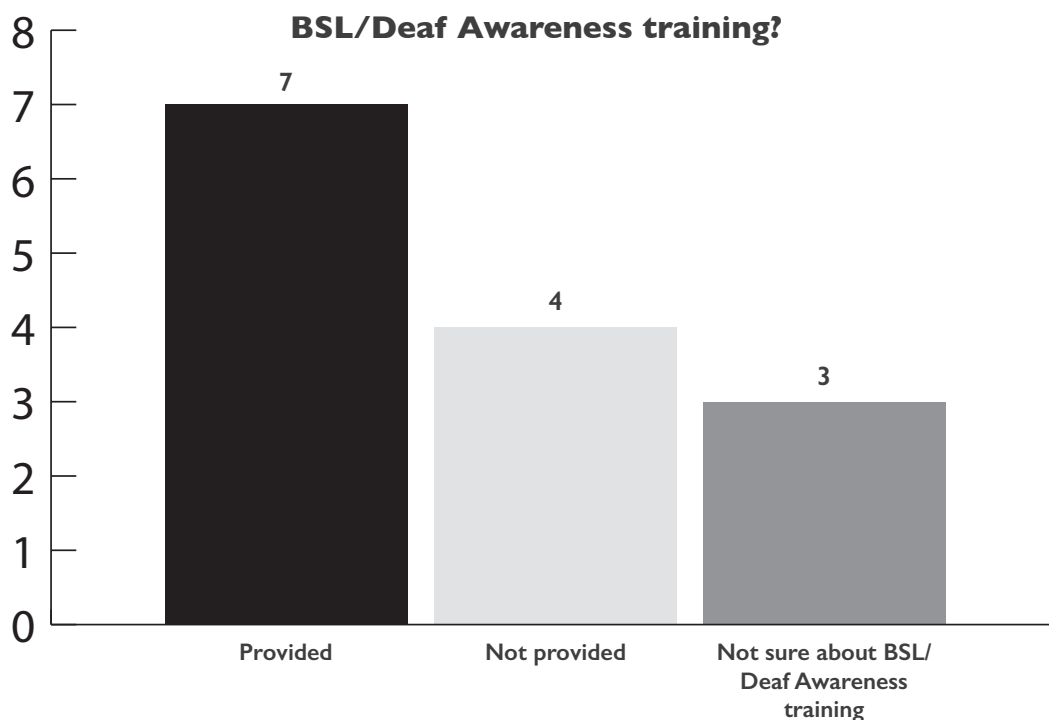
Question 1:

Over the last 12 months, what percentage of NHS staff have had BSL/Deaf Awareness training, and how did this help to give a better service for Deaf patients?

7 of the **14 (50%)** respondents provided BSL/Deaf Awareness training for their service providers.

4 of the **14 (28.6%)** respondents did not provide BSL/Deaf Awareness for their service providers.

3 of the **14 (21.4%)** respondents were unsure if they had provided any training.



Staff who provided training did so either as an online course, as part of the induction process for new staff, or as group training.

One respondent commented, “Although we delivered training to staff, we had no Deaf BSL users within the facility.” Another commented, “It is of great benefit to Deaf BSL service users.”

Question 2:

What system do you have for ensuring that a qualified and registered BSL/English interpreter is booked automatically for each new appointment for a Deaf person?

8 of the **14 (57.1%)** respondents stated that they had systems for booking qualified and registered BSL/English interpreters.

Respondents from different services mentioned that they do know how to use booking BSL/English interpreters systems whenever Deaf patient need it for their appointment as they will provide one BSL/English interpreter.

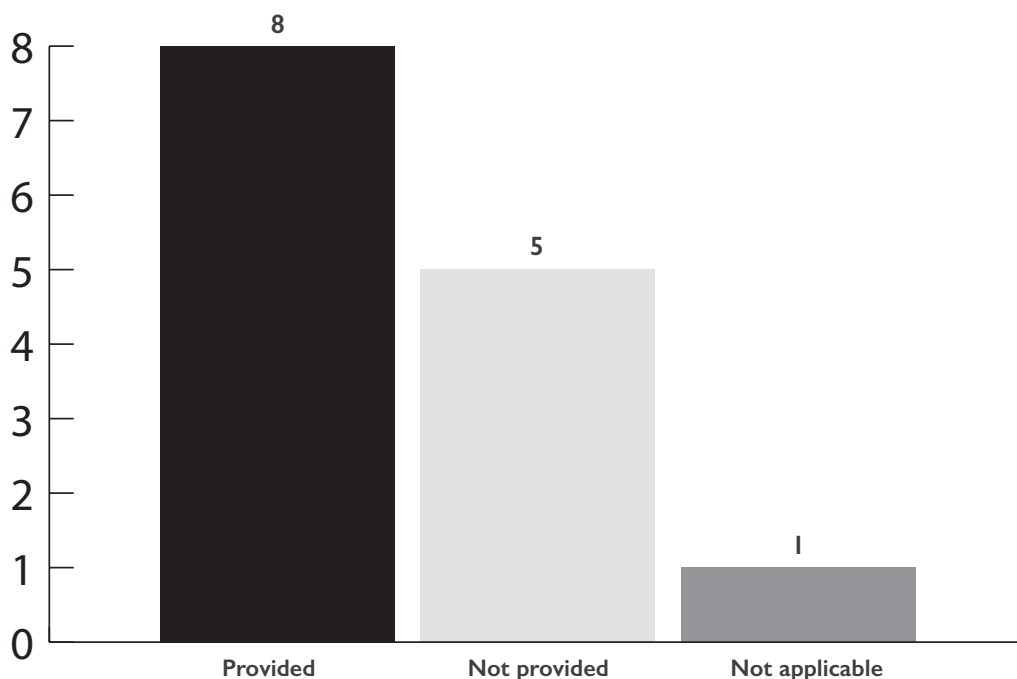
5 of the **14 (35.7%)** respondents stated that they did not provide BSL/English interpreters for any appointments.

Respondents mentioned that they did not provide BSL/English interpreters because Deaf patient did not asking for one; some of them mentioned that not sure to how to use systems for book BSL/English interpreter because not aware about information about BSL/English interpreters.

1 of the **14 (7.1%)** respondent stated that this was not applicable to their services.

Most of the respondents who stated that they had systems to book BSL/English interpreters said that they had policies which were adhered to. However, one respondent stated that for follow up consultations, information may not be supplied to state that a Deaf patient needed the services of a BSL/English interpreter. This was identified as an issue, as central bookings would not be aware of the need to arrange interpreting services for the appointment.

Are BSL/English interpreter provided for appointments?



Question 3:

Do you (Health Boards / Health organisations) know of alternative BSL/English interpreter services e.g. contactSCOTLAND-BSL and would you consider using them to ensure a Deaf person has a full medical service?

7 of the 14 (50%) respondents knew of the contactSCOTLAND-BSL (online BSL/English interpreting) service.

Respondents mentioned that they knew about contactSCOTLAND-BSL (online BSL/English interpreting) service because Deaf patient use it regarding appointments.

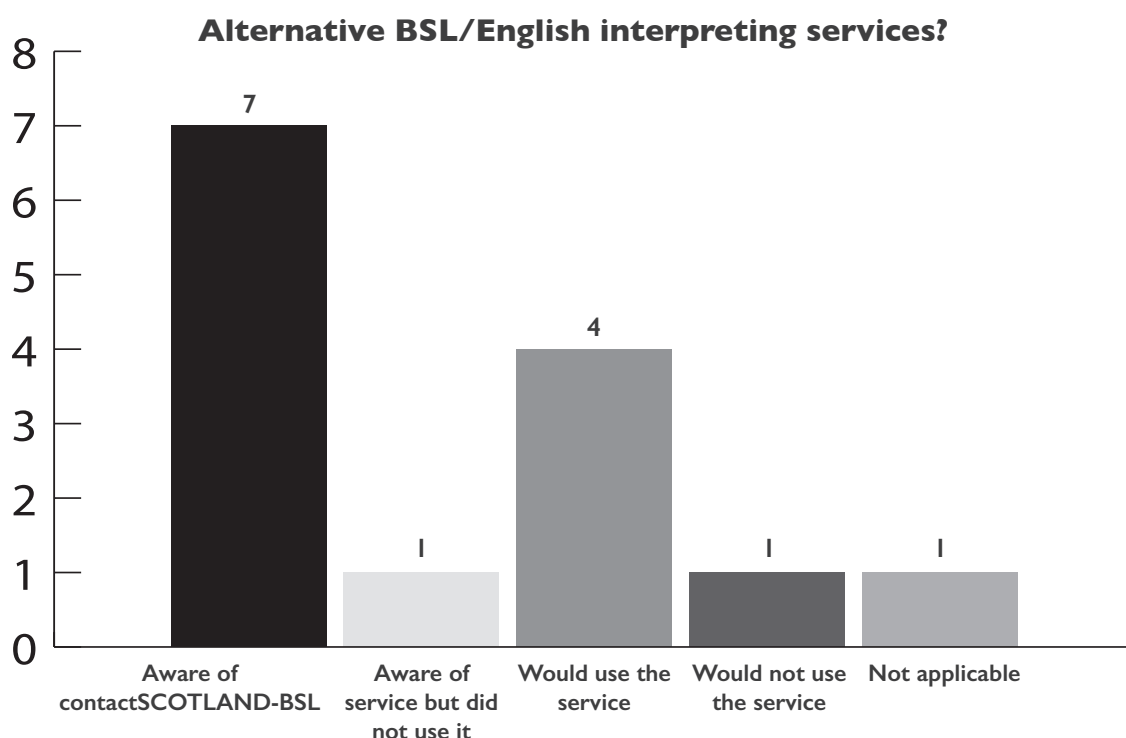
1 of the 14 (7.1%) respondents stated that although they were aware of the service, it did not hold any relevance to their services.

Respondent knew about these services but never use it. In the future, they would consider using it for Deaf community to access their health services.

4 of the 14 (28.6%) respondents would use the service to provide a full medical service.

1 of the 14 (7.1%) respondents said they would not use the service.

1 of the 14 (7.1%) respondents stated that it was not applicable to their service.



Question 4:

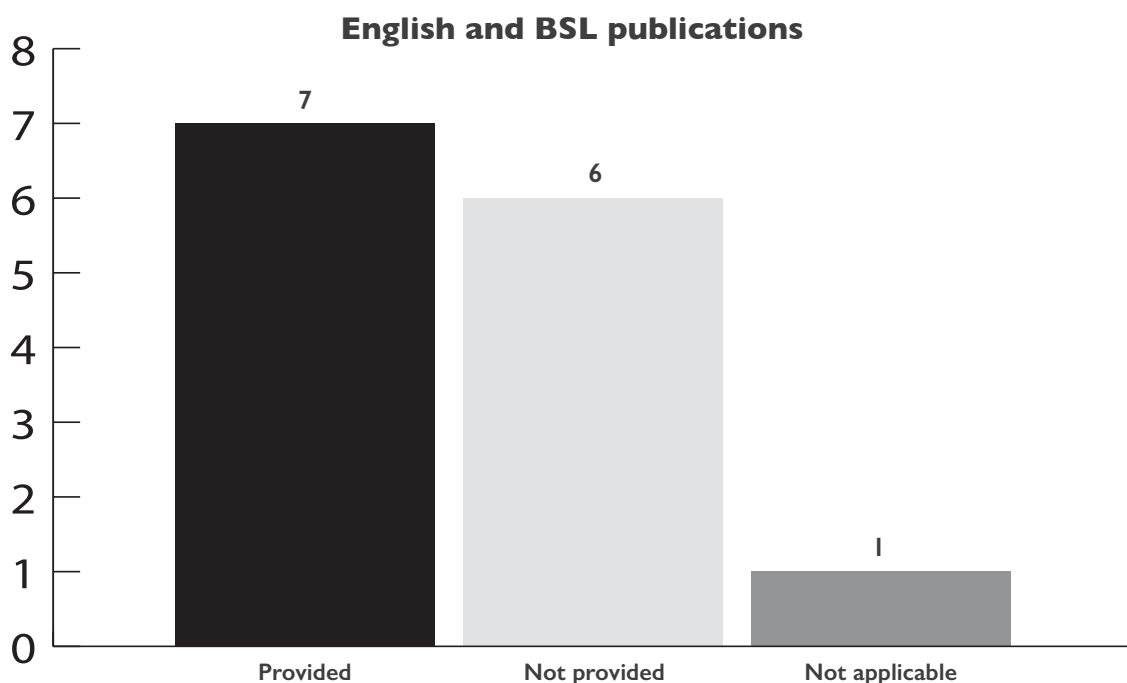
What kind of Plain/Easy Read English and BSL publications do you have, and how would a Deaf person know how to locate them?

7 of the 14 (50%) respondents service providers stated that they had Plain/Easy Read English and BSL publications available.

6 of the 14 (42.9%) respondents stated that they did not provide this service.

1 of the 14 (7.1%) respondents stated that it was not applicable.

It must be noted that most participants commented that the translation of publications into BSL was done on an ad hoc basis, due to materials being continually updated, and that a low number of patients required this information in comparison to the cost implications.



Respondents mentioned that their services do have resources/materials of Plain/Easy Read English and BSL publications for Deaf community but need to more promote to Deaf community that their services do have resources/materials link with Plain/Easy Read English and BSL translated. 7 respondents mentioned that have been work with Access & Inclusion (Health) Officer to promote health information link with information sessions and steering group and factsheet of health topics on website.

Question 5:

Do you (Health Boards / Health organisations) have any information for Deaf people about how to make a complaint?

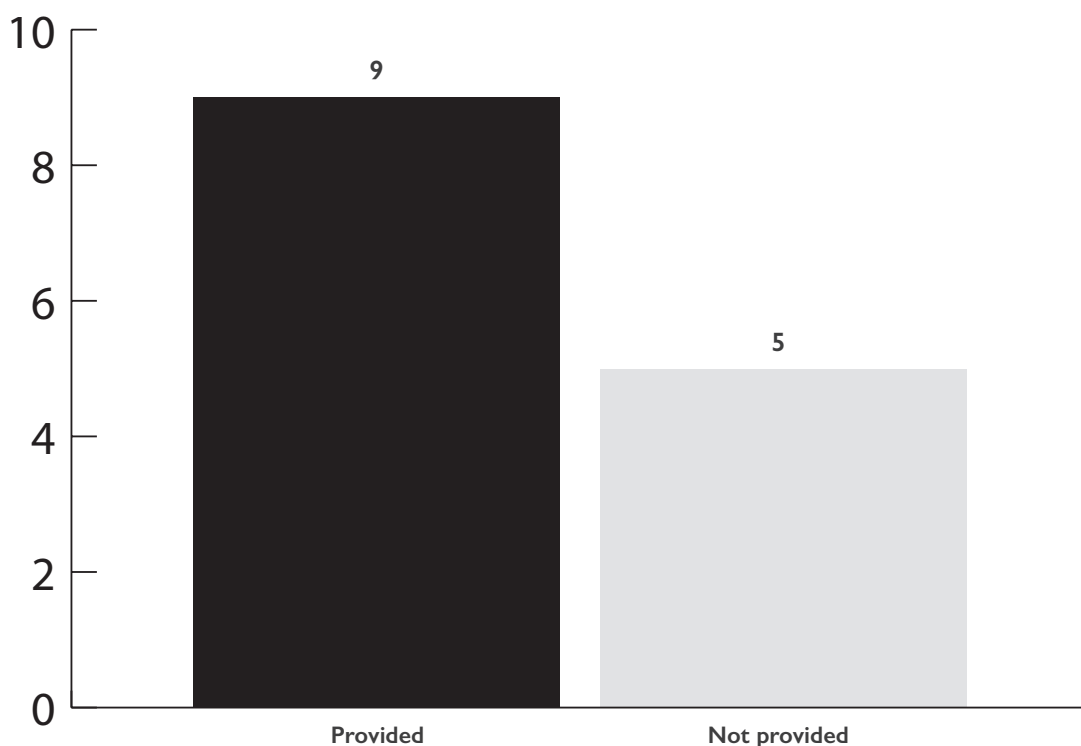
9 of the 14 (64.3%) respondents stated that they had clear information for Deaf people about how to make a complaint.

Respondents stated that they delivered information about how to make a complaint to Deaf community groups, and that they were happy to adapt their current systems if necessary to meet the needs of BSL service users.

5 of the 14 (35.7%) respondents did not have information for Deaf people about how to make a complaint.

Respondents stated that their complaints procedures were undertaken online via written English; however, they were also happy to accept other formats.

Information for Deaf people about how to make a complaint?



Question 6:

Do you (Health Boards / Health organisations) allow more time for Deaf patients at appointments to ensure they get full information regarding their treatment and medicines?

6 of the 14 (42.9%) respondents stated that they allowed extra time when a Deaf BSL user was attending an appointment.

Respondents mentioned that Deaf patients always have double appointments for seeing their doctor, also with BSL/English interpreter. And, they want to make sure that Deaf patient receive full information about their health (treatment and medicines).

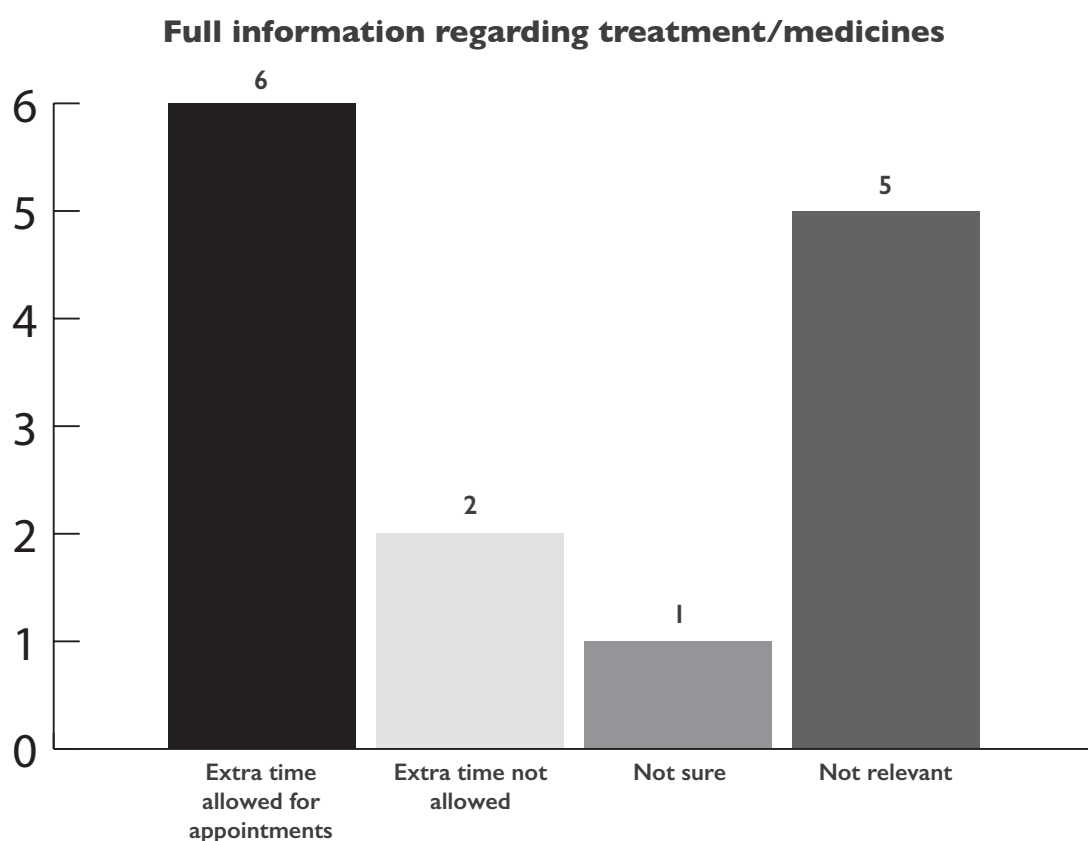
2 of the 14 (14.3%) respondents stated that they did not allow for extra time.

Respondents mentioned that their services did not allow for extra time because time limit for seeing doctor or difficult to get BSL/English interpreter for appointment. Some Deaf patients never asking for double appointment.

1 of the 14 (7.1%) respondents was unsure if their service provided double appointments.

It should be noted that several of the respondents stated that, although their policies allowed for double appointments, in reality this rarely happened due to a lack of BSL/Deaf Awareness when booking appointments.

5 of the 14 (35.7%) respondents said they could not respond to this question because it was not relevant to their services.



1. Using a comparative approach between the Deaf, Deafblind, Usher Syndrome, Asian and Youth community's living experiences of health care provision and the services offered by health providers within the NHS has granted us the ability to clearly identify gaps in service provision within health services.
2. Consultations with people who were Deaf, Deafblind, Usher Syndrome, Asian and Youth community members proved successful, with 259 participants engaging with the process:
 - a) Year 1 and Year 2 of this project focussed on Deaf people only, but in Year 3, we have had 259 consultations with Deafblind people, those with Usher Syndrome, Deaf youth community members and Asian Deaf group.
 - b) We found that these new consultations could not be treated in the same way. For example, Deafblind people must be consulted individually, and the level of care and support they need depends on how severe their hearing and vision problems are. They require special requests for Deafblind patients who need hands-on BSL/English interpreters with additional skills in tactile BSL.
 - c) Deaf youths are more technologically aware.
3. This would indicate that our findings that issues surrounding communication between Primary and Secondary Care services continue to persist. Systems should be improved to ensure communication needs are identified.
4. Although there has been some improvement in health services' provision of some BSL/Deaf Awareness training, this would indicate these needs to be extended to all health service providers. This training should be provided on a regular basis and refresher courses should be given, in line with First Aid or health and safety course updates include communication related.
5. For participants to understand their health issues, this would indicate that they need more information in BSL or Plain/Easy Read English. Although there are more sources of this, e.g. the BDA's website, Deaf community need to be directed to where this information is.
6. As the BDA Scotland interacts more with Primary and Secondary Care health services, improvements and influence seem to be made to health services for Deaf people. This would indicate that ensuring these services engage more with Deaf organisations and the Deaf community is a primary method of improving the standard of health care for the Deaf community.

7. Participants feel most vulnerable when they do not understand or are not involved in their medical care packages from their GPs and other NHS services. This is something we have found is widespread throughout Primary and Secondary Care services.
8. An important weakness we have found in health services is that current systems such as making complaints, booking appointments and booking BSL/English interpreters for appointments is creating a great deal of stress and wasted time both for health services and their Deaf patients.
9. Participants felt that Out of Hours services should be easier to access via contactSCOTLAND-BSL (online BSL/English interpreting service).

Recommendations

1. Communication between Primary and Secondary Care should be improved. A systematic approach should be implemented, which ensures that information about Deaf patients' communication needs is shared between departments, such as the consistent provision of BSL/English interpreters as well as special requests for Deafblind patients who need hands-on BSL/English interpreters with additional skills in tactile BSL.
2. Consideration must be made in relation to NHS computer systems. Systems must ensure that all computer records for Deaf patients are clearly marked "Deaf – BSL user" to indicate that the patient is likely to have additional access and support requirements which require action. Additionally, files should also contain the patient's preferences; for example, a female or male BSL/English interpreters. These systems should ensure that all follow up appointments automatically send a request to the central booking service, which is responsible for booking a BSL/English interpreter.
3. Ensure that staff within Secondary Care, receive regular BSL/Deaf Awareness training, to enhance communication with Deaf patients. This training should be updated every 2-3 years, in line with First Aid or health and safety updates.
4. All Deaf patients should be involved with decisions about their care, services and their medication. Health professionals should ensure this is achieved regardless of whether family members are present or not.
5. Consideration should be made for GP surgeries extending their opening hours (e.g. from 8am to 8pm), which would allow Deaf, Deafblind, Usher Syndrome and young people to attend appointments any time during the day, and allowing more opportunities to book BSL/English interpreters.
6. Health providers should research, promote and create BSL videos on relevant health topics; Plain/Easy Read English should be provided too.
7. Existing health promotion resources covering health issues of concern to BSL participants. It is recommended that a single access point for accessing health promotion material is established, and publicised within Deaf community and health services to ensure Deaf patients are signposted to this information.
8. All services (Primary and Secondary Care and voluntary organisations and the third sector) should ensure they engage with Deaf organisations such as BDA Scotland and the Deaf community. Using a collaborative approach, services can improve, influence and impact upon the standard of care for the Deaf community across Scotland.
9. Health services should ensure they have a robust system which allows Deaf BSL users

patients to make complaints. Information on complaints procedures should be developed and the ability to submit complaints in the Deaf person's preferred format (BSL, written English, face-to-face) should be incorporated to existing complaints procedures.

- 10.** Health services have stated that they have clear policies and procedures for booking double appointments for patients who use BSL/English interpreter services. A lack of BSL/Deaf Awareness results in this policy not being adhered to. As stated in recommendation link with Number 3, all staff should receive regular BSL/Deaf Awareness training to ensure they are able to comply with policy and procedure within their organisation.
- 11.** Charities' information should be accessible in BSL and Plain/Easy Read English; online and in leaflets. They should also provide information sessions with BSL access, for example, via BSL/English interpreters, for further support and access to information.

Solutions on way forward

- On Deaf patients' notes, enter information about what their communication needs are. This information would indicate that a BSL/English interpreter is needed each time an appointment is made.
- Give regular BSL/Deaf Awareness training to Primary and Secondary Care staff, to enhance communication with Deaf patients.
- Continue to work with Deaf organisations to research and create BSL videos and Plain/Easy Read English publications on relevant health topics.
- Have regular meetings with Deaf organisations such as BDA Scotland to influence and improve the standard of care for Deaf people.
- Create a central booking system that would ensure a BSL/English interpreter is booked for new and follow up appointments.
- Alter complaints procedures to allow Deaf people to make a complaint in their preferred format (BSL, written English, face-to-face).

8

Appendix I: Questionnaire for Deaf BSL users

1. Over the last 12 months, how many appointments have you had with your local GP service (Primary care) and within NHS services (Secondary Care)?
2. Do you feel that the healthcare practitioner was prepared for your visit? For example, did they book a BSL/ English interpreter or give you extra time for your appointment?
3. Did the healthcare professional (staff) listen to you carefully, treating you fairly and with respect? Did they understand/have awareness about Deaf-related issues and how they affect your life?
4. Were you given BSL or Plain/Easy Read English information to help you to understand your health problem? If so, was it clear and easy to understand?
5. Do you feel involved in decisions about your care and services and the medication you receive from your GP/the NHS?
6. Do you know who to contact if you have a problem when your GP's surgery is closed? If not, why not?
7. The BDA's website has BSL videos about different health topics (dementia, stroke, depression, pancreatic cancer and multiple sclerosis – MS).
8. Did you think the BDA's information sessions (on depression and stroke) or steering groups (on dementia, MS, ME and stroke) were useful and informative? If not, why not?
9. After information sessions (on depression and stroke), did you receive follow up information? If yes, what?
10. Do you think this Deaf Health Challenge project will make a difference and help health services to improve their provision for the Deaf community? How?

Appendix 2: Questionnaire for Health Boards / Health organisations

1. Over the last 12 months what percentage of NHS staff have had BSL/Deaf Awareness training, and how did this help to give a better service for Deaf patients?
2. What system do you have for ensuring that a qualified and registered BSL/English interpreter is booked automatically for each new appointment for a Deaf person?
3. Do you (Health Boards / Health organisations) know of alternative BSL/English interpreter services e.g. contactSCOTLAND-BSL and would you consider using them to ensure a Deaf person has a full medical service?
4. What kind of Plain/Easy Read English and BSL publications do you have, and how would a Deaf person know how to locate them?
5. Do you (Health Boards / Health organisations) have any information for Deaf people about how to make a complaint?
6. Do you (Health Boards / Health organisations) allow more time for Deaf patients at appointments to ensure they get full information regarding their treatment and medicines?

Appendix 3: List of Deaf clubs and groups

- Asian Deaf Group, Glasgow **(10)**
- Ayrshire Society for the Deaf **(10)**
- Calton House, Glasgow **(4)**
- Coatbridge Deaf group **(15)**
- Edinburgh Deaf Sport & Social Club **(14)**
- Falkirk Deaf group, Forth Valley **(13)**
- Glasgow Deaf group, Deaf Connections **(10)**
- Individual consultations (in person/webcam) across Scotland **(79)**
- International Women's Day, Glasgow **(70)**
- Kirkcaldy Deaf club, Fife **(9)**
- Lanarkshire Deaf Club, Motherwell **(15)**
- Youth club, Edinburgh **(10)**

Total: **259** participants who have been interviewed with this report.



Appendix 4: List of Health Boards / Health organisations

This services contacted were as follows:

- Action on Depression
- Alzheimer Scotland
- Chest Heart & Stroke Scotland
- Diabetes Scotland
- Golden Jubilee National Hospital
- NHS Ayrshire and Arran
- NHS Education for Scotland
- NHS Greater Glasgow and Clyde
- NHS Lanarkshire
- NHS Orkney
- NHS Shetland
- NHS24
- Prostate Scotland
- The State Hospital, Carstairs

Total: **14** services who have been interviewed with this report.

Glossary and Additional Information

BSL/English Interpreter

This refers to a qualified and registered interpreter proficient in both English and British Sign Language (BSL).

Deaf (upper case 'D')

This term refers to someone with a strong cultural affinity with other Deaf people and whose first or preferred language is BSL. The BDA uses the capital 'D' to denote adults who have BSL as their first or preferred language and have Deaf culture.

deaf (lower case 'd')

Because many Deaf people do not use BSL while at school, we tend to use the lower case 'd' for children. This is also used for people with significant hearing loss who tend to use exclusively speech and lip reading to communicate as English is their first language.

DeafBlind Scotland

Deafblindness is a low incidence disability with increasing prevalence being identified. Common issues can be that accessibility features and assistance for someone with a single sensory impairment are often not suitable for those with severe dual sensory loss. This can mean that Deafblind people can become isolated from the community in which they live.

Deafblind Scotland's aim is to enable Deafblind people to live as rightful members of their own communities.

Deafblind Scotland offers a variety of services such as communication and linguistic access advice, advice navigating self-directed support, information and formatting services, welfare rights support, accredited training and a guide/communicator service.

FaceTime

An application supported by Apple products that allow people to video chat to each other in real time. Both parties need to have Apple products to enable this interaction as well as an internet connection.

Hearing

This is a term used by Deaf people to denote those who are non-deaf.

Sign Translate

Sign Translate offers a commercial online BSL/English interpreting service for GPs and hospitals as a subsidiary of SignHealth. For more information please see: www.signtranslate.com. See

Video Interpreting Services (VIS) below for a full explanation of how this works plus a list of companies offering VIS services.

Primary Care

Primary care is your first point of contact with the NHS. This involves contact with community based services such as general practitioners (GPs), community nurses, allied health professionals such as physiotherapists and occupational therapists, midwives and pharmacists.

Secondary Care

A patient who has been provided with primary care may be referred to a secondary care professional; a specialist with expertise on the patient's issue. These are consultant-led services which include psychology, psychiatry and orthopaedics.

Secondary care is usually (but not always) delivered in a hospital/clinic, with the initial referral being made by the primary care professional.

Registration:

- **Scottish Association of Sign Language Interpreters (SASLI)** is the only Scottish based registering and membership body for BSL/English interpreters. The Association sets minimum entry qualifications and skills that are to be met for registration. The register also includes Deafblind Manual Interpreters, Lipreaders and Guide Communicators.

SASLI Registered and Registered Trainee members agree to adhere to the following policies:
SASLI's Code of Conduct and Professional Practice Policy
SASLI's Complaints Policy and Procedure
SASLI's Continuing Professional Development Policy (as a condition to continued registration).

The policies reassure service purchasers and service users that SASLI Registered and Trainee members are expected to work in a professional manner. Additionally, the Continuing Professional Development Policy ensures that SASLI members maintain and develop further their skills and expertise.

SASLI emphasises the importance of using Registered and Trainee members to work to improve communication between BSL users and hearing people. SASLI works to provide equality of linguistic access for Deaf and Deafblind people to develop a fully inclusive society.

SASLI is also a Professional Association, providing support, advice and training to its members.

Web link: www.sasli.org.uk

- **The National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD)** is a UK wide regulator of sign language interpreters, sign language translators, speech to text reporters, lipspeakers, notetakers and interpreters for deafblind people.

Registrants, such as Registered Sign Language Interpreters (RSLI), are fully qualified. NRCPD also regulates trainees, such as Trainee Sign Language Interpreters (TSLI). All Registrants and Trainees have to follow the Code of Conduct. If you believe they have not followed the Code of Conduct then you can make a complaint to NRCPD.

Registrants tend also to be members of a professional representative body. However, membership of a professional association does not guarantee someone is qualified. You should always ask to see their NRCPD badge.

Web link: www.nrcpd.org.uk

Videophone

This is usually used online, via a webcam, or by using stand-alone videophone equipment that uses the telephone system to transmit visually in addition to audio calls.

Video Interpreting Services (VIS):

There are two types of Video Interpreting Services:

- Video Relay Service (VRS)
This is used when the Deaf person and the hearing person are in separate locations. The BSL/English Interpreter is in a different location to both parties. BSL/English interpreter relays the conversation back and forth between the two people using a telephone link to the hearing person and a video-phone link to the Deaf person.
- Video Remote Interpreting (VRI)
Takes place when the Deaf person visits an establishment to meet a hearing person. They use a BSL/English interpreter using an online video link to communicate with each other – no telephone call is involved. Some local authorities are experimenting with this as a way to improve access for BSL users.

Web link: <http://deafcouncil.org.uk/deaf-access-to-communications/vrs-vri/>

The British Deaf Association's British Sign Language Charter

The purpose of the Charter for British Sign Language (BSL Charter) is to promote better access to public services for Deaf people who use BSL and in doing so; enable public agencies meet their legislative duties under the Equality Act 2010.

The UK Government ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2009. Local authorities, public services and agencies should follow the intentions of the UNCRPD. One way this can be achieved is by adopting the BSL Charter.

Under the Equality Act 2010, Deaf people have the right to equal access to services through a variety of access provision including BSL/English interpreters when required. The Deaf community is a linguistic community with a rich history, identity, language and culture. The BDA believes equal opportunities can be achieved by working with the Deaf community, rather than by taking decisions and designing services decided on their behalf.

The BSL Charter sets out five pledges:

1. Consult formally and informally with our local Deaf community on a regular basis
2. Ensure access for Deaf people to information and services
3. Support Deaf children and families
4. Ensure staff working with Deaf people can communicate effectively using British Sign Language
5. Promote learning and high quality teaching of British Sign Language.

The expectation is that by adopting these pledges, public services can achieve the following objectives:

- Remove direct and indirect discrimination against Deaf people
- Resolve conflicts between service providers and Deaf people
- Increase awareness of Deaf issues and BSL issues
- Empower local Deaf people to be more participative in the wider community
- Provide better educational options for Deaf children.

The BDA recognises that public services will have different priorities for the areas they serve and it is expected that each public agency will consider the number of pledges that it can sign up to. For some, this may be a minimum of one pledge towards achieving equality for Deaf people in their areas while others will sign up for all five pledges.

For more information: www.bda.org.uk/project/bsl-charter

What is British Sign Language (BSL)?

British Sign Language (BSL) is the first or preferred language of many Deaf people in the UK. It is a language of space and movement using the hands, body, face and head.

BSL is the sign language of the Deaf community in the UK (in Northern Ireland, Irish Sign Language (ISL) is also used). BSL is a real, full and living language that is part of a rich cultural heritage. It is one of the UK's indigenous languages; other includes English, Welsh, Scottish Gaelic and Cornish. Many hearing people also use BSL; it has more users than other indigenous languages such as Welsh or Gaelic.

It is a language that has evolved in the UK's Deaf community over hundreds of years. There is considerable research evidence that shows Deaf children who are exposed to BSL early can develop linguistically at the same rate and to the same linguistics levels as hearing children with spoken language. This kind of early access to language ensures the ability for learning throughout life, leading to improved life opportunities.

BSL is not just a language; it is also a gateway to learning, a path towards a sense of Deaf identity, and the means whereby Deaf people survive and flourish in a hearing world.

The British Deaf Association (BDA)

The BDA stands for **D**eaf **E**quality, **A**ccess and **F**reedom of choice

Vision

Our vision is Deaf people fully participating and contributing as equal and valued citizens in wider society.

Mission

Our Mission is to ensure a world in which the language, culture, community, diversity and heritage of Deaf people in the UK is respected and fully protected, ensuring that Deaf people can participate and contribute as equal and valued citizens in the wider society. This will be achieved through:

- Improving the quality of life by empowering Deaf individuals and groups;
- Enhancing freedom, equality and diversity;
- Protecting and promoting BSL.

Values

The BDA is a Deaf people's organisation representing a diverse, vibrant and ever-changing community of Deaf people. Our activities, promotions, and partnerships with other organisations aim to empower our community towards full participation and contribution as equal and valued citizens in the wider society. We also aim to act as guardians of BSL.

- 1. Protecting our Deaf culture and Identity** – we value Deaf peoples' sense of Deaf culture and identity derived from belonging to a cultural and linguistic group, sharing similar beliefs and experiences with a sense of belonging.
- 2. Asserting our linguistic rights** – we value the use of BSL as a human right. As such, BSL must be preserved, protected and promoted because we also value the right of Deaf people to use their first or preferred language.
- 3. Fostering our community** – we value Deaf people with diverse perspectives, experiences and abilities. We are committed to equality and the elimination of all forms of discrimination with a special focus on those affecting Deaf people and their language.
- 4. Achieving equality in legal, civil and human rights** – we value universal human rights such as the right to receive education and access to information in sign language, and freedom from political restrictions on our opportunities to become full citizens.
- 5. Developing our alliance** – we value those who support us and are our allies because they share our vision and mission, and support our BSL community.

**To contact the British Deaf Association please look at our website: www.bda.org.uk
Email: bda@bda.org.uk • ooVoo: [bda.britdeafassoc](https://voo.com/rooms/bda.britdeafassoc) • Skype: [bda.britdeafassoc](https://www.skype.com/rooms/bda.britdeafassoc)**

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