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Good Practice?

Why people who are deaf or have hearing loss in Northern Ireland are still not getting accessible information from their GP

by Tom Bailey and Claire Lavery

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About us

Action on Hearing Loss, formerly RNID, is the UK's largest charity working for people with deafness, hearing loss and tinnitus. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose, enabling them to take control of their lives and removing the barriers in their way. We give people support and care, develop technology and treatments and campaign for equality.

We have been established in Northern Ireland since 1991. We provide a range of support services, including practical hearing aid support, specialist tinnitus support, and befriending and employment services, supported by a large number of committed volunteers.

Introduction

People who are deaf or have hearing loss may find it difficult to communicate with friends, family and health and social care professionals, and have an increased risk of other health problems.

In 2010 our Northern Ireland report ***Is It My Turn Yet?*** found that many GP practices needed to give their staff training in sensory disability – and to invest in equipment such as hearing loops. Crucially, our research demonstrated that healthcare providers wanted to improve their accessibility.

We responded to this by producing a detailed guide for GP practices, in partnership with RNIB, on how to improve access for people with sensory disability. hscboard.hscni.net/download/PUBLICATIONS/PHYSICAL%20AND%20SENSORY%20DISABILITY/best-practice-guidance-primarycare.pdf

Our ***Access All Areas*** report (Ringham, 2013) shows that people who are deaf or have hearing loss may find it difficult to access GP surgeries when they need to, due to the lack of accessible alternatives to the telephone, poor deaf awareness amongst practice staff, or the lack of communication support.

Four years on, we carried out another survey to explore how people who are deaf or have hearing loss usually contact GP surgeries to book appointments and communicate with practice staff. We wanted to know whether the guidance we provided to GP practices in Northern Ireland had resulted in any improvements in the way GP surgeries communicate.

Our comprehensive research has resulted in this report. Section 1 provides background information on the prevalence and impact of deafness and hearing loss, and identifies the communication barriers people face when accessing GP surgeries. Section 2 sets out the aims and methodology of the research.

The next three sections present the results of the survey across three areas:

- contacting GP surgeries
- visiting GP surgeries
- what improvements people who are deaf or have hearing loss would like to see.

Finally, we discuss the implications of the research findings and set out our practical recommendations for action.

Throughout this report, we use the term ‘people with hearing loss’ to refer to people with acquired hearing loss, which could be caused by a number of factors, including age, exposure to loud noise or genetic predisposition. This term is intended to be inclusive of those who identify as hard of hearing or deaf. We use the term ‘people who are deaf’ to refer to people with severe or profound levels of hearing loss who describe themselves as d/Deaf and use British or Irish Sign Language (BSL/ISL) as their first or preferred language.

Section 1. Background

Prevalence and impact of deafness and hearing loss

Almost 300,000 people have hearing loss in Northern Ireland – that’s one in six of us (Action on Hearing Loss, 2015). Due to the ageing population, the number of people with hearing loss is set to grow. We estimate that, by 2034, there will be 400,000 people with hearing loss in Northern Ireland; around one-fifth of the population.¹ Some people who are severely or profoundly deaf may use British or Irish Sign Language (BSL or ISL) as their first or preferred language and may consider themselves part of the Deaf community, with a shared history, culture and language. There are estimated to be around 4,500–5,000 people in Northern Ireland who use BSL or ISL as their first or preferred language (British Deaf Association, 2018).

1. This is calculated using prevalence estimates from Davis A, 1995. *Hearing in Adults*. London: Whurr, updated with ONS national population projections, 2014-based.

Unaddressed hearing loss can lead to feelings of loneliness, emotional distress and withdrawal from social situations (Arlinger, 2003; Gopinath et al, 2013; Héту et al, 1993; Monzani et al, 2008; Pronk, 2011). People with hearing loss also have an increased risk of depression (Saito et al, 2010; Monzani et al, 2008) and dementia (Lin et al, 2011).

Older people who are deaf or have hearing loss are also likely to have other age-related conditions such as sight loss, dementia or cancer; so diagnosing and managing hearing loss is crucial for good communication and care (Action on Hearing Loss, 2013).

A review of academic literature shows that people who are deaf have an increased risk of mental health problems (Fellinger et al, 2012). Poor awareness of sign language and deaf culture may also lead to misdiagnosis or under-diagnosis of mental health problems in people who are deaf (Department of Health, 2002; Department of Health, 2005).

Research shows that people who are deaf or have hearing loss often struggle to access GP surgeries and other NHS services when they need to. Our **Access All Areas** report (Ringham, 2013) shows that:

- One in seven (14%) of survey respondents had missed an appointment because they didn't hear their name being called in the waiting room.
- After attending an appointment with their GP, more than a quarter (28%) had been unclear about their diagnosis and nearly one-fifth (19%) had been unclear about their medication.
- Two-thirds (68%) of survey respondents who asked for a BSL interpreter for their GP appointment didn't get one and two-fifths (41%) felt the quality of interpretation was not good enough.

Research by SignHealth (2014) also shows that more than one-third (34%) of people who are deaf were unaware they had high or very high blood pressure and more than half (55%) of those who said they had cardiovascular disease were not receiving appropriate treatment - suggesting problems with communication and access.

Section 2. Aims and methodology

Aim of research

Under the Disability Discrimination (NI) Act 1995, people have the right to expect reasonable adjustments to be made if they face substantial difficulties accessing services due to their deafness and hearing loss.

Despite this legal protection, our **Access All Areas** report and other research (see Section 1) shows that people who are deaf or have hearing loss often struggle to book appointments when they need them, and to communicate well when visiting GP surgeries.

Further legislation has been introduced in other parts of the UK that will strengthen the requirements for health service providers to make reasonable adjustments to meet the communication needs of people with hearing loss.

In 2016, in England, the Accessible Information Standard was introduced into law. It requires GP and NHS services to record their patients' communication needs, share that information with other services, and provide accessible communication methods.

In Wales, the All Wales Standards for Accessible Communication and Information for People with Sensory Loss makes clear that people with sensory loss in Wales should, as needed, be provided with appropriate support to contact services. This ensures they can communicate well during appointments and understand any information they're given.

In Scotland, the British Sign Language (Scotland) Act 2015 requires local authorities, including Scotland's NHS health boards, to publish British Sign Language Action Plans by October 2018. This may help improve access to health services for sign language users.

In Northern Ireland, guidance provided by Action on Hearing Loss and RNIB on how to make primary care services more accessible has been distributed to all GP practices, but the impact of that guidance on patient experience is not being monitored. So we've returned to the subject area of our original **Access All Areas** report, to explore the experiences of people who are deaf or have hearing loss when accessing GP surgeries since the introduction of our guidance.

We decided to focus on GP surgeries because people who are deaf or have hearing loss frequently tell us that improving the accessibility of GP surgeries is a key priority for them. For example, almost all the participants in focus groups carried out to support the development of the 2018-23 strategic plan (Action on Hearing Loss, 2017) identified the accessibility of GP surgeries and the attitudes of practice staff as a particular problem. We also believe that our findings and recommendations will be useful for other NHS services.

Methodology

Between September and December 2017, Action on Hearing Loss carried out a survey in England, Wales and Northern Ireland to gain a better understanding of the experiences of people who are deaf or have hearing loss when accessing GP surgeries. A separate survey, exploring the experiences of people who are deaf or have hearing loss when accessing all NHS services, was also carried out in Scotland.

Both surveys were available online via the Survey Monkey website. Links to the online survey were emailed to people who have signed up to receive updates about Action on Hearing Loss campaigning and were also included in e-newsletters. The survey was also promoted online on our social media accounts and shared by other organisations. All the survey questions were available in a BSL and ISL video and we also gave people who are deaf the opportunity to book appointments with us to give their answers in BSL or ISL over Skype or Facetime. Paper copies of the survey were given out at drop-in sessions and at other Action on Hearing Loss events.

We received 1,411 responses in total to the survey sent out in England, Wales and Northern Ireland. Of these, 100 were from people who are deaf or have hearing loss who live in Northern Ireland. A full breakdown of the individual characteristics of survey respondents living in Northern Ireland can be found in the Appendix.

The results we present in the following sections are for survey respondents who live in Northern Ireland. The results for survey respondents who live in England, Scotland and Wales are published in separate reports, which you can download from the Action on Hearing Loss website. To find out more, please visit: actionhearingloss.org.uk/goodpracticeNI

At the end of the survey, we asked respondents if they had any other comments on the accessibility of GP surgeries. We've included some of their comments and personal stories as extended quotes in the last section of this report.

Please note: the percentages in the results do not always equal 100. This is either due to rounding decimals up or down, or because survey respondents could choose multiple answers for each question. Not all survey respondents answered each question and some questions were hidden from respondents using the online survey form, on the basis of previous answers they gave.² The results presented in this report are for survey respondents who are deaf or have hearing loss combined, unless otherwise specified.

Section 3. Contacting GP surgeries

In the first section of the survey, we asked people who are deaf or have hearing loss how they usually contact their GP surgery to book appointments, get urgent medical advice, order repeat prescriptions and receive test results.

Booking appointments

First, we asked people who are deaf or have hearing loss how they usually contact their GP surgery to book appointments and, also, how they would like to book appointments, even if they can't book appointments in this way at the moment.

Almost half of respondents (45%) phone their GP surgery themselves to book appointments, with a slightly lower number (38%) saying the phone was their preferred method of communication.

A quarter (26%) of survey respondents visit their GP surgery in person to book appointments, but only 7% said they prefer to book appointments this way.

Over a third (35%) of survey respondents said that they ask a family member, friend or support worker to call their GP surgery on their behalf, but a much smaller proportion, less than a fifth (18%), said they wanted other people to book GP appointments for them.

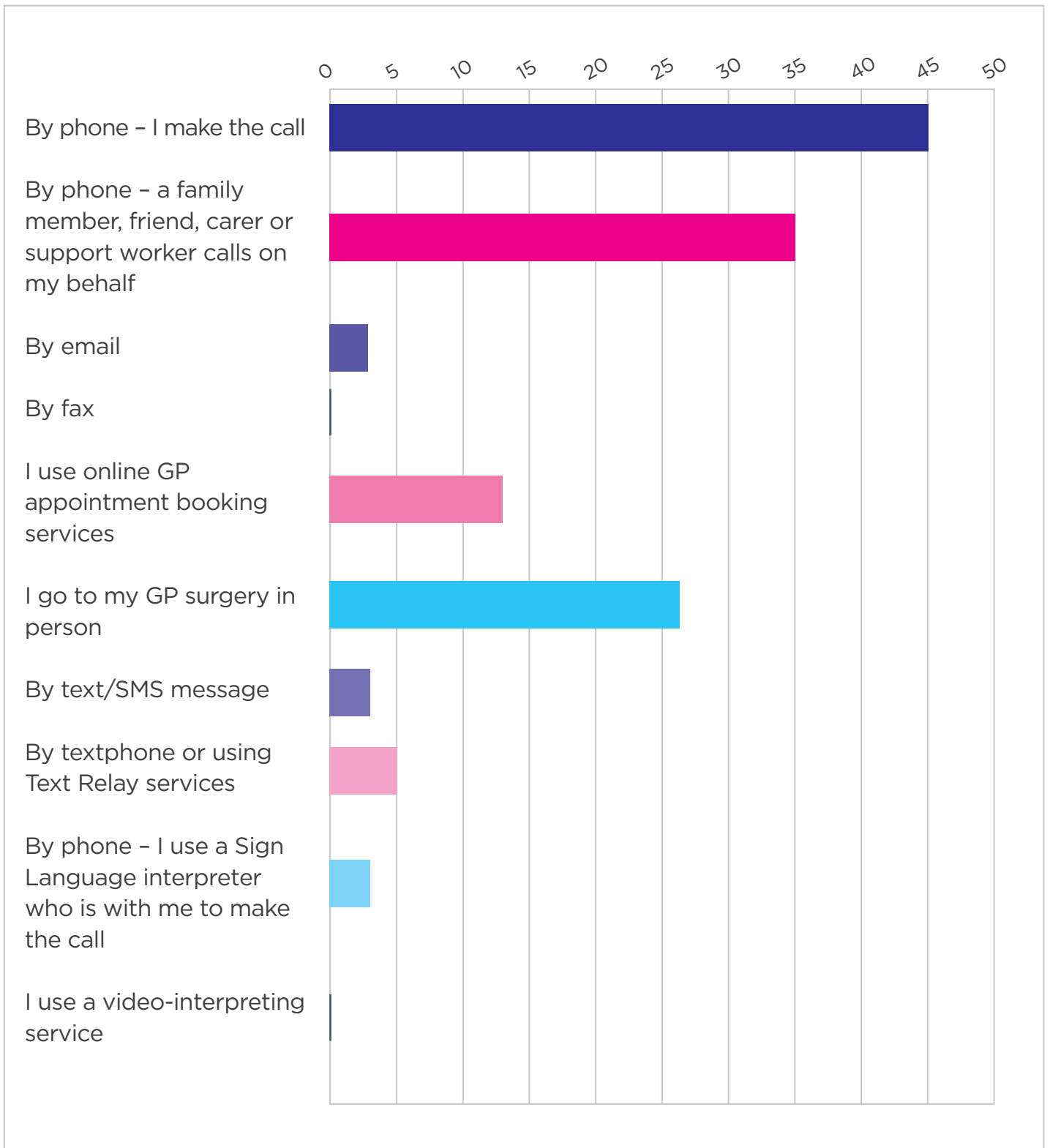
Currently, a very small number, 2%, of respondents contact their GP practice by SMS. More people (13%) would prefer to use this method.

13% of survey respondents said they use online GP services to book appointments – suggesting that some people who are deaf or have hearing loss are already benefiting from improved online access to GP surgeries. A similar proportion also said that online access was their preferred contact method for booking appointments.

These findings suggest that many people would prefer not to have to visit their GP practice in person, use the telephone or rely on family and friends to make appointments on their behalf. Their preference is to use SMS, email or online booking systems.

2. Different versions of the paper survey questionnaire were also given out to people at drop-in sessions and other events, depending on whether they were deaf or have hearing loss.

Figure 1: How do you contact your GP surgery to book an appointment?



**Table 1: How do you contact your GP surgery to book an appointment?
(All respondents)**

Respondents could choose more than one answer

	Number of respondents	Percentage (%)
By phone - I make the call	44	45
By phone - a family member, friend, carer or support worker calls on my behalf	34	35
By email	3	3
By fax	0	0
I use online GP-appointment booking services	13	13
I go to my GP surgery in person	25	26
By text/SMS message	2	2
By textphone or using Text Relay services	5	5
By phone - I use a Sign Language interpreter who is with me to make the call	2	2
I use a video-interpreting service	0	0
Other - please explain	8	8
Total number of responses	97	

Figure 2. How do you prefer to contact your GP surgery to book an appointment?

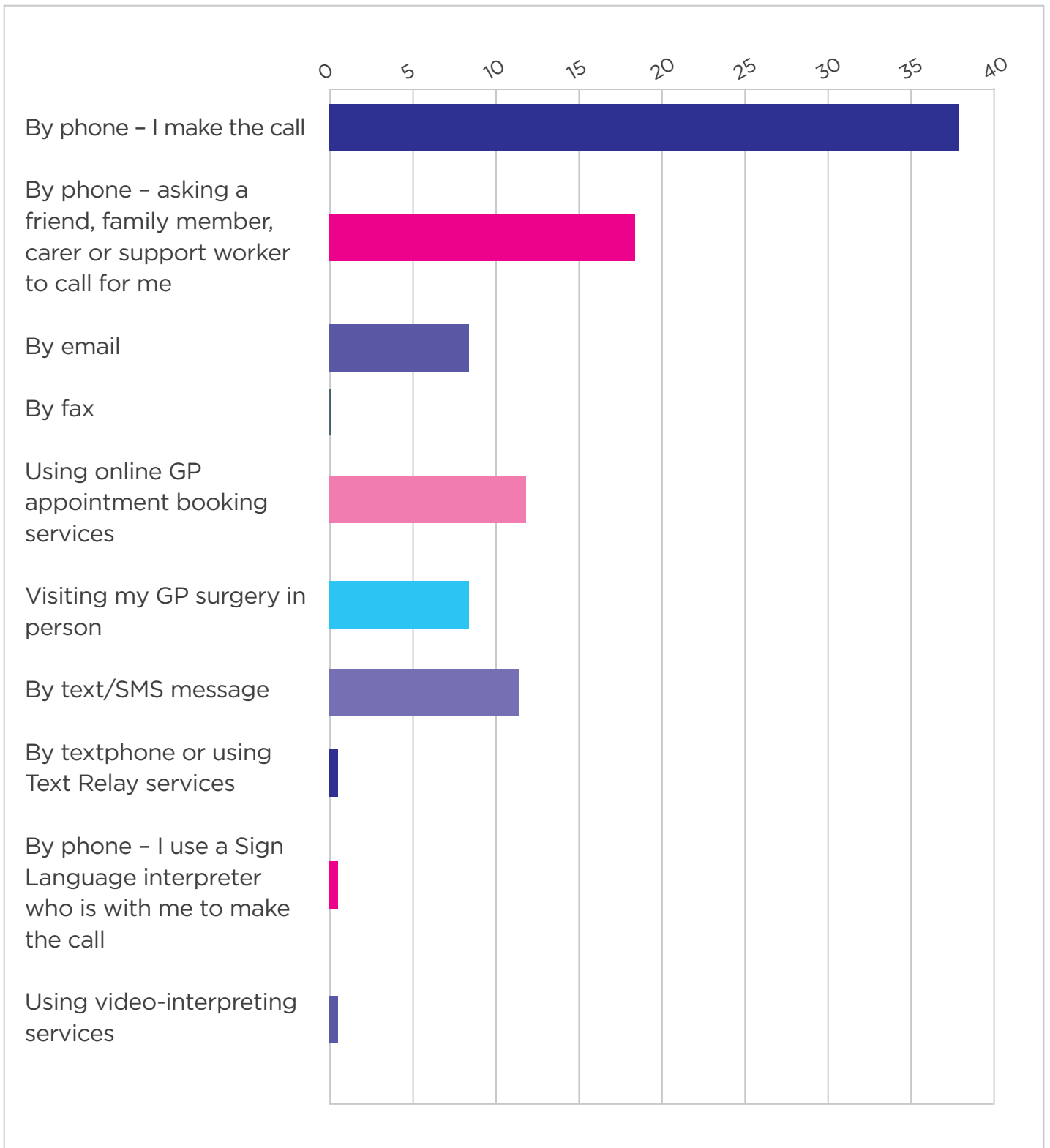


Table 2: How do you prefer to contact your GP surgery to book an appointment? Say your first choice, even if you can't do this with your GP surgery at the moment. (All respondents)

Respondents could choose one answer only

	Number of respondents	Percentage (%)
By phone - I make the call	37	38
By phone - asking a friend, family member, carer or support worker to call on my behalf	18	18
By email	7	7
By fax	0	0
Using online GP-appointment booking services	13	13
Visiting my GP surgery in person	7	7
By text/SMS message	13	13
By textphone or using Text Relay services	1	1
By phone - I use a Sign Language interpreter who is with me to make the call	1	1
Using video-interpreting services	1	1
Total number of responses	98	

We asked people who are deaf or have hearing loss whether their GP surgery sends them text/SMS messages to remind them about their GP appointments.

The majority (90%) of survey respondents said that this service wasn't available. This compares unfavourably with the experience in England, where over half (53%) of respondents said they do receive SMS reminders from their GP surgery.

“90% of Northern Ireland respondents say they don't get text/SMS reminders from their GPs. In England, more than half do.”

Text/SMS message reminders can be helpful for people who are deaf or have hearing loss if they don't hear their appointment time properly over the phone. Our findings suggest that there is a high level of unmet need for these services.

Table 3: Does your GP surgery send you text/SMS messages to remind you about your appointments? (All respondents)

	Number of respondents	Percentage (%)
Yes	7	7
No	87	90
Don't know/I don't have a mobile phone	3	7
Total number of respondents	97	

Ordering repeat prescriptions and getting test results

We asked people who are deaf or have hearing loss what contact options they can use to access other services at their GP surgery.

More than four out of five (89%) survey respondents said they can order repeat prescriptions by visiting their GP surgery in person and 85% can also get test results in this way. More than two-thirds (71%) said they could order repeat prescriptions over the phone and 80% can get test results by phone.

Almost half (47%) of survey respondents said they order repeat prescriptions online, but only 6% can get test results in this way – suggesting there are substantial variations in terms of the scope of online GP services offered to patients.

A high proportion of survey respondents **didn't know** if they could use online services to order repeat prescriptions or get test results:

- Almost one-quarter (22%) of survey respondents didn't know if they could order repeat prescriptions online.
- Over a third (36%) didn't know if they could use online GP services to get test results.

Almost one-quarter (22%) didn't know if they could order repeat prescriptions by email, rising to 38% who didn't know if email access was available for getting test results. Over half, however, also said email access is unavailable for these services.

**Table 4: How can you order prescriptions from your GP surgery?
(All respondents)**

	Number of respondents	Yes	No	Don't know
By email	51	27%	51%	22%
Using online GP services	58	47%	31%	22%
By fax	41	7%	51%	41%
By letter	47	28%	43%	30%
By phone	68	71%	22%	7%
By visiting my GP in person	62	89%	3%	8%
Total number of respondents	100			

**Table 5: How can you get test results from your GP surgery?
(All respondents)**

	Number of respondents	Yes	No	Don't know
By email	48	2%	60%	38%
Using online GP services	50	6%	58%	36%
By fax	47	0%	60%	40%
By letter	54	31%	37%	31%
By phone	74	80%	15%	5%
By visiting my GP in person	72	85%	7%	8%
Total number of respondents	100			

Booking urgent, same-day GP appointments or getting urgent medical advice

We asked people who are deaf or have hearing loss if they had experienced any difficulties over the past year when booking urgent, same-day appointments or getting urgent medical advice.

Almost half (45%) of survey respondents had experienced difficulties, almost a quarter (23%) had not experienced any difficulties in the past year, and a third (32%) had not used these services in the last year.

Table 6: In the past year, have you experienced any difficulties when trying to book urgent, same-day GP appointments or get urgent medical advice when your GP surgery is closed (out-of-hours GP services)? (All respondents)

	Number of respondents	Percentage (%)
Yes	44	45
No	23	23
I haven't used these services in the past year	31	32
Total number of respondents	98	

When asked why they had experienced difficulties over the past year, almost half (48%) of survey respondents said that this was because urgent, same-day appointments can only be booked by phone, and almost two-fifths (39%) said they had to ask a family member or support worker to call on their behalf.

Arranging a home visit by a doctor or nurse when the GP surgery is closed presented a difficulty, because either the patient had to make the booking by phone (16%), or the surgery wanted to contact the patient by phone to make a booking (11%).

11% said their GP surgery wanted to contact them by phone when they tried to book an urgent, same-day appointment or get urgent medical advice, and this wasn't accessible for them.

In recent years, many GP surgeries have introduced remote consultations (either over the phone or online) to improve the way they manage their workloads and increase the amount of time they have to see patients.

Our findings suggest that people who are deaf or have hearing loss may find it more difficult to get same-day appointments. This is because of the communication difficulties they experience when contacting GP surgeries – irrespective of the severity of their health condition or the availability of same-day appointments.

“People who are deaf or have hearing loss may find it more difficult to get same-day appointments.”

More than one-quarter (27%) of survey respondents gave other reasons for experiencing difficulties when trying to book urgent, same-day appointments or get urgent medical advice out of hours. Most of the reasons provided were unrelated to deafness and hearing loss. For example, many survey respondents said that same-day appointments were very limited or unavailable at their GP surgery.

Some respondents said they experienced difficulties because GP out-of-hours services use a call-back system to book appointments: this isn't accessible for people with hearing loss.

“GP out-of hours services use a call-back system – this isn't accessible for people with hearing loss.”

**Table 7: If you answered ‘yes’ to the previous question, why was this?
(Respondents who have experienced difficulties in the last year only)**

Respondents could choose more than one option

	Number of respondents	Percentage (%)
I usually go to my GP surgery in person to book an appointment, but I was too ill to travel	3	7
Urgent, same-day GP appointments can only be booked by phone	21	48
I experienced difficulties using Text Relay services	1	2
I had to ask a family member, friend, carer or support worker to call my GP surgery or other NHS services for me	17	39
My GP surgery offered me an urgent, same-day phone appointment with a doctor or nurse, but I can't use the phone	2	5
My GP surgery wanted to contact me by phone to arrange my urgent, same-day GP appointment, but I can't use the phone	5	11
When my GP surgery is closed, home visits by a doctor or nurse can only be booked by phone	7	16
When my GP surgery was closed, my GP surgery or other NHS services offered me a phone appointment with a doctor or nurse, but I can't use the phone	4	9
When my GP surgery was closed, my GP surgery or other NHS services wanted to contact me by phone to arrange a home visit by a doctor or nurse, but I can't use the phone	5	11
Other - please explain	12	27
Total number of respondents	44	

Section 4. Visiting the GP surgery

In the second section of the survey, we asked people who are deaf or have hearing loss about the attitudes of practice staff and the accessibility of GP surgery waiting areas and consultation rooms.

Asking people about their communication and information needs

First, we asked people who are deaf or have hearing loss if staff working at their GP surgery have asked them what support they need to communicate well and understand information.

Our findings suggest that the vast majority of people who are deaf or have hearing loss haven't been asked about their communication needs or information needs by their GP surgery. Only 9% of survey respondents said that practice staff had asked them if they need support to contact their GP surgery and to understand what is said in GP appointments. Similarly, only 3% had been asked if they needed support to understand written health information.

“Only 9% of survey respondents said that practice staff had asked them if they need support to contact GP services – and to understand what’s said during appointments.”

**Table 8: Have staff at your GP surgery ever asked you if you need support to contact them and understand what is said in GP appointments?
(All respondents)**

	Number of respondents	Percentage (%)
Yes	9	9
No	87	88
Don't know	3	3
Total number of respondents	99	

Table 9: Have staff at your GP surgery ever asked you if you need support to understand written health information? (All respondents)

	Number of respondents	Percentage (%)
Yes	3	3
No	89	91
Don't know	6	6
Total number of respondents	98	

Waiting areas

We asked people who are deaf or have hearing loss how receptionists, or other practice staff, let them know when it's their turn to be seen by the doctor or nurse.

Eight out of 10 people (81%) said that their GP surgery has a visual display screen that lets patients know when it's their turn to be seen, whilst 16% said that practice staff call out their name.

One in seven (13%) survey respondents said that practice staff at their GP surgery let them know when it's their turn to be seen in other ways. These respondents were asked to provide more information. Most said that their doctor came into the waiting area and called out their name. Others said that appointments are announced on a PA (public address) system. Many survey respondents commented that they often struggle to hear their name being called in waiting areas.

As a result of these difficulties, some survey respondents said they feel anxious about missing their appointment when they visit their GP surgery. Here are some of their comments:

“I find it very hard to hear when my name is called as there is also music playing in the waiting room. I am always afraid of missing my name.”

“I can't make out the loudspeaker.”

But, more encouragingly, some respondents benefit by being known by the staff or, in one case, because the GP can communicate in basic sign language:

“Sometimes I stay in reception and the doctor comes to get me! I am well known to staff through work.”

“Sometimes my doctor comes out as she signs Level 1, which is great for me!”

Figure 3. How do staff at your GP surgery let you know when it's your turn to be seen by the doctor or nurse?

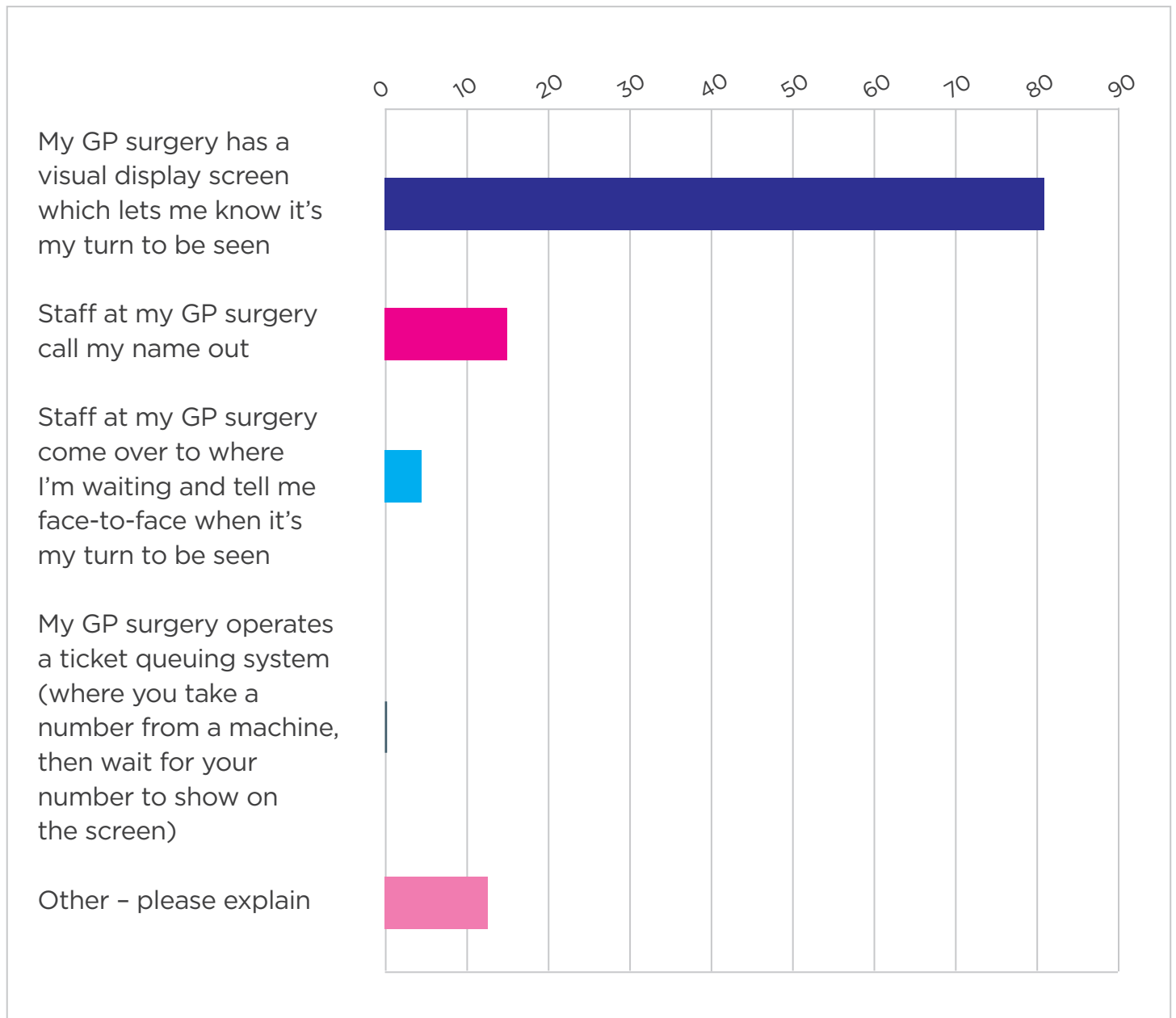


Table 10: How do staff at your GP surgery let you know when it's your turn to be seen by the doctor or nurse? (All respondents)

Respondents could choose more than one option

	Number of respondents	Percentage (%)
My GP surgery has a visual display screen which lets me know it's my turn to be seen	80	81
My GP surgery operates a ticket queuing system (where you take a number from a machine, then wait for your number to show on the screen)	0	0
Staff at my GP surgery call my name out	16	16
Staff at my GP surgery come over to where I'm waiting and tell me face-to-face when it's my turn to be seen	5	5
Other - please explain	13	13
Total number of respondents	99	

Hearing loops

We asked people who are deaf or have hearing loss if a hearing loop system is available for them to use on the reception desk of their GP surgery.

Hearing loop systems make speech clearer for hearing aid users by reducing the level of background noise. Providing hearing loop systems on reception desks should ensure people who use hearing aids don't miss important information about their appointment or other aspects of their treatment and care.

Over one third (35%) of survey respondents said a hearing loop system isn't available for them to use and only 4% said a hearing loop system is available. More than half (61%) said they didn't know if a hearing loop system was available and/or they don't use hearing loop systems.

This demonstrates that, in the majority of cases, either a loop system is not available or, if available, is not promoted to patients.

Table 11: Is a working hearing loop system available on the reception desk of your GP surgery? (All respondents)

	Number of respondents	Percentage (%)
Yes	4	4
No	34	35
Don't know/I don't use hearing loop systems	60	61
Total number of respondents	98	

Consultations

We also asked people who are deaf or have hearing loss whether they ever leave their GP appointments feeling unclear about the health information they've been given.

Our previous research shows that people who are deaf or have hearing loss often miss important information during their GP appointment because of the poor deaf awareness of doctors, nurses or other practice staff, or because of the lack of communication support such as a BSL interpreter (see Section 1). Our **Access All Areas** report (Ringham, 2013) highlighted that, after attending an appointment with their GP, more than a quarter (28%) of respondents to our previous survey had been unclear about their diagnosis and nearly one-fifth (19%) had been unclear about their medication.

We wanted to find out whether the guidance we issued through the Health and Social Board in 2014 has led to any improvements in the way doctors, nurses or other practice staff communicate with people who are deaf or have hearing loss, during consultations.

More than one-third (32%) said they are always clear about the information they're given after their GP appointments and a third (31%) said they're clear most of the time.

Whilst we welcome the fact that a high proportion of respondents (63%) said they get all the information they need during GP appointments most or all of the time, our findings suggest that there is still room for improvement, in the way doctors, nurses and other GP staff communicate with people who are deaf or have hearing loss. Nearly two-thirds (68%) of respondents said they feel unclear after GP appointments at least some of the time.

Figure 4. After your GP appointments, do you ever feel unclear about the information you are given?

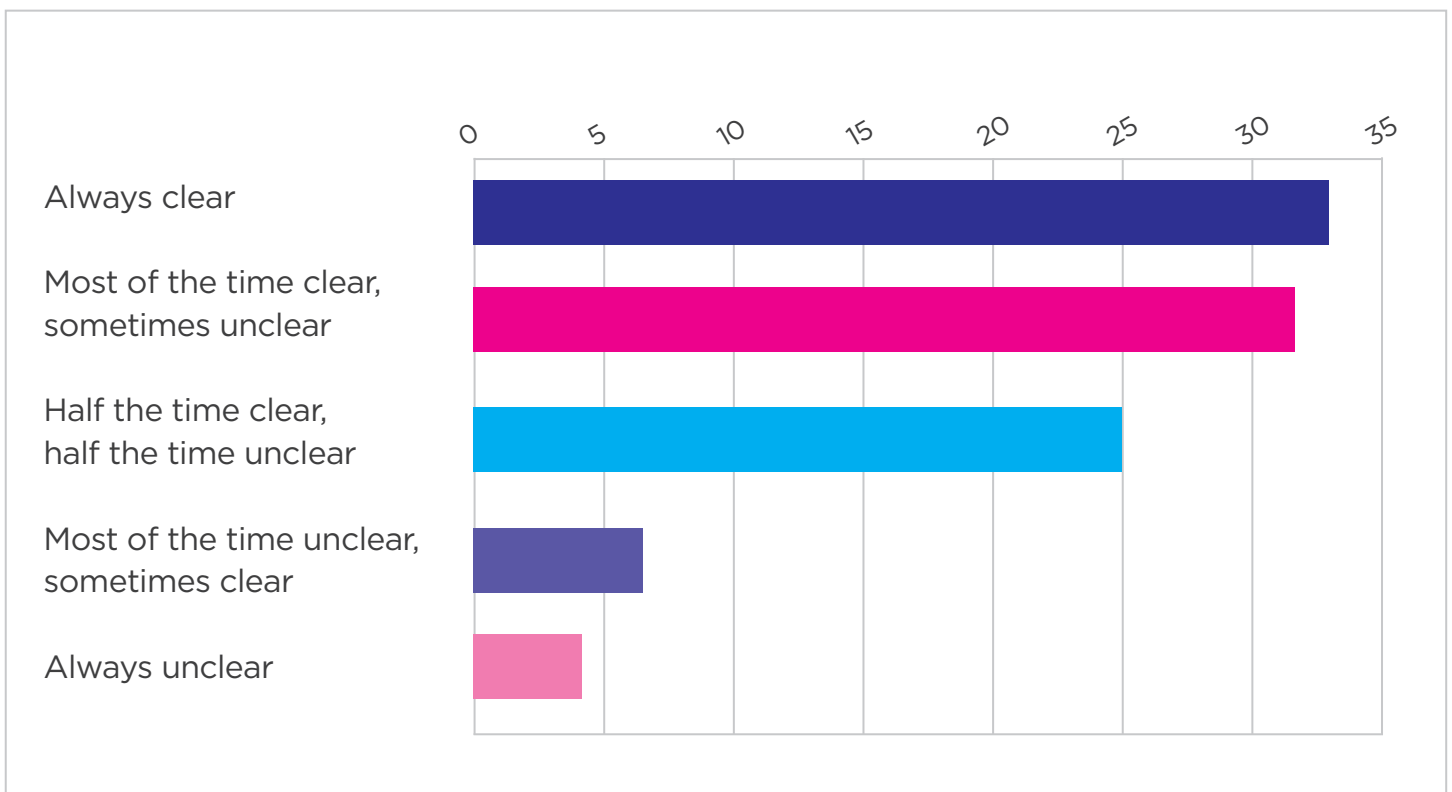


Table 12: After your GP appointments, do you ever feel unclear about the information you are given? For example, you are unclear about what is wrong with you, what you have to do next or what medicine you need and how to take it? (All respondents)

	Number of respondents	Percentage (%)
Always unclear	4	4
Most of the time unclear, sometimes clear	7	7
Half the time clear, half the time unclear	24	25
Most of the time clear, sometimes unclear	30	31
Always clear	31	32
Total number of respondents	96	

We also asked people who are deaf or have hearing loss why they feel unclear after GP appointments. Survey respondents saw one of two lists of answer options on the online survey form or paper questionnaire, depending on whether they said they use English or Sign Language³ as their first or preferred language.

A high proportion of survey respondents with hearing loss identified the attitudes and behaviours of doctors or nurses as a particular problem during appointments:

- Over a third (33%) said doctors or nurses did not speak clearly.
- 35% said doctors or nurses did not face them.
- 41% said doctors or nurses spoke too quickly and 47% said their doctor or nurse did not check they had understood what had been said.

These findings show that, in most cases, doctors and nurses could improve the way they communicate with people with hearing loss during GP appointments by following simple communication tips such as facing the person, speaking clearly and checking that the person's understood what's been said.

3. This included people who said they use British Sign Language (BSL), Sign Supported English (SSE) - which incorporates both BSL and English - or Irish Sign Language (ISL) as their first or preferred language.

More than one-quarter (29%) of survey respondents with hearing loss said their GP appointment wasn't long enough and they didn't have time to communicate properly. This finding suggests that doctors, nurses and other GP staff should recognise that people with hearing loss may need longer appointments to communicate properly; and ensure that people with hearing loss have the opportunity to ask questions or check they have understood their health advice correctly.

22% of survey respondents with hearing loss said they were unclear because a hearing loop system was unavailable for their appointment. As stated previously, hearing loop systems can help people who use hearing aids hear more clearly by reducing the level of background noise, so it's vital that they should be available in GP consultations for everyone who needs them.

14% of survey respondents with hearing loss said they felt unclear after their GP appointment for other reasons. Respondents who chose this answer were asked to provide more information. Some respondents said they felt unclear because doctors and nurses had to rely on the information being passed on by family and friends.

Many survey respondents said that they felt they didn't have enough time at their GP appointments to discuss their health issues properly. However, in most cases, it was not clear whether this was due to hearing loss or more general concerns about the quality of their appointments.

Here are some of their comments:

“At times I find they don't show an interest. They seem to be in a rush to get to the next patient.”

“I find especially with hospital consultations I think I have heard and understood more than I did. I take someone with me and it's only then I discover I have missed a lot of what has been said. As I have cancer I need to hear treatment options etc. Ultimately, people really do not understand hearing loss, especially its impact on [one's] ability to determine speech. [It's] like putting a jigsaw puzzle together to hear.”

“GP/nurse usually leave it to the people who support me to provide me with accessible information after my appointment.”

Figure 5. If you ever feel unclear about the information you are given after your GP appointments, please tell us why this is

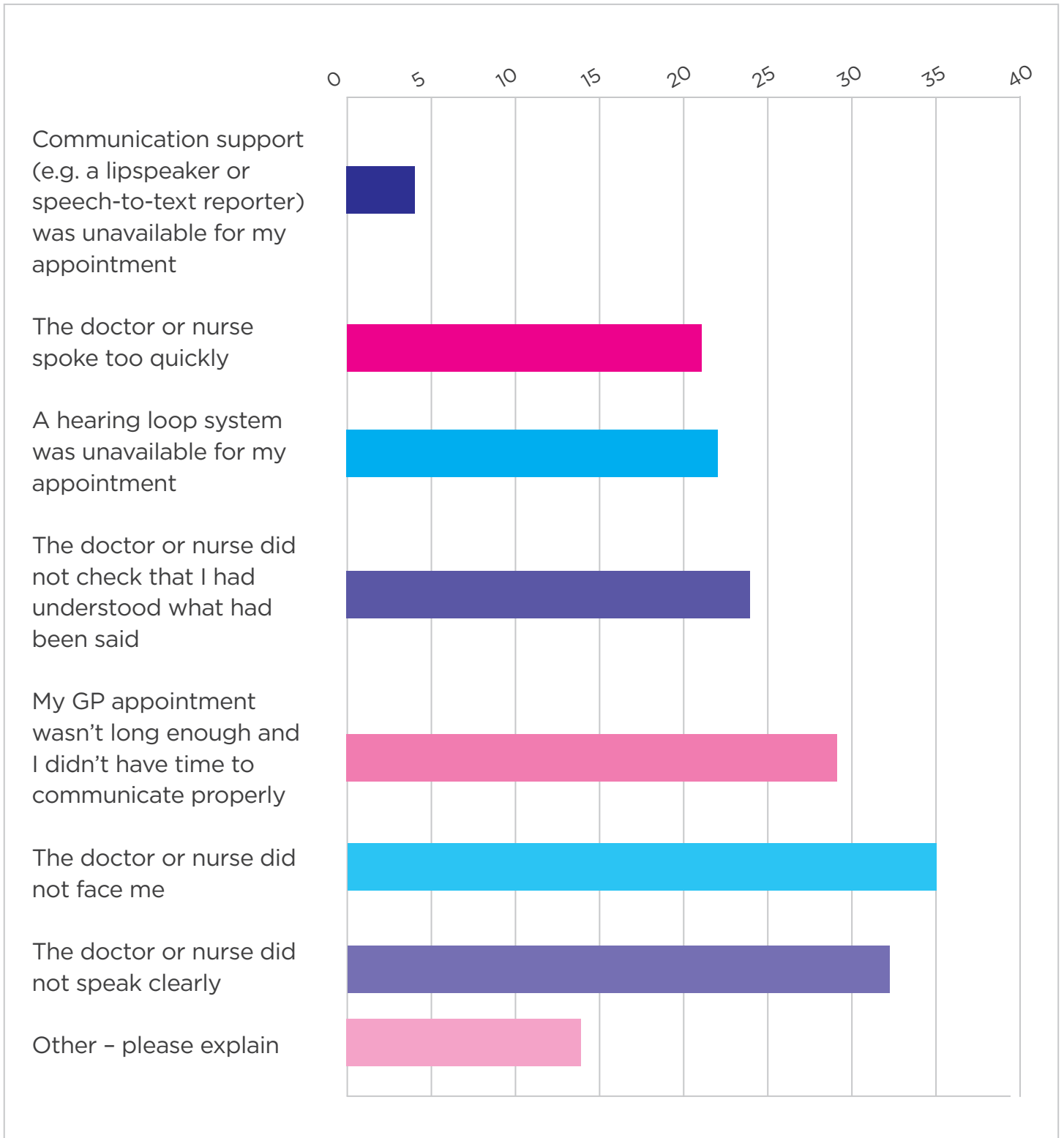


Table 13: If you ever feel unclear about the information you are given after your GP appointments, please tell us why this is. (All respondents)

Respondents could choose more than one answer

	Number of respondents	Percentage (%)
The doctor or nurse did not speak clearly	17	33
The doctor or nurse did not face me	18	35
The doctor or nurse spoke too quickly	41	21
The doctor or nurse did not check that I had understood what had been said	47	24
A hearing loop system was unavailable for my appointment	11	22
Communication support (for example, a lipspeaker or speech-to-text reporter) was unavailable for my appointment	2	4
My GP appointment wasn't long enough and I didn't have time to communicate properly	15	29
Other - please explain	7	14
Total number of respondents	51	

When asked why they felt unclear after their GP appointment, almost half (47%) of survey respondents who are deaf said that this was because no sign language interpreter was available to help them communicate.⁴

More than one-third (35%) of survey respondents said they felt unclear because their appointment wasn't long enough and they didn't have time to communicate properly. Another third (29%) said they felt unclear because their doctor or nurse did not check they had understood what had been said. 24% of survey respondents who are deaf said they had to rely on written notes during their GP appointments.

These findings suggest that doctors, nurses or other GP staff could do more to support good communication during GP appointments.

4. Some of the figures for this question are based on a small number of survey responses and, as such, should be treated with caution.

Figure 6. If you ever feel unclear about the information you are given after your GP appointments, please tell us why is this? (Respondents who use BSL, SSE or ISL)

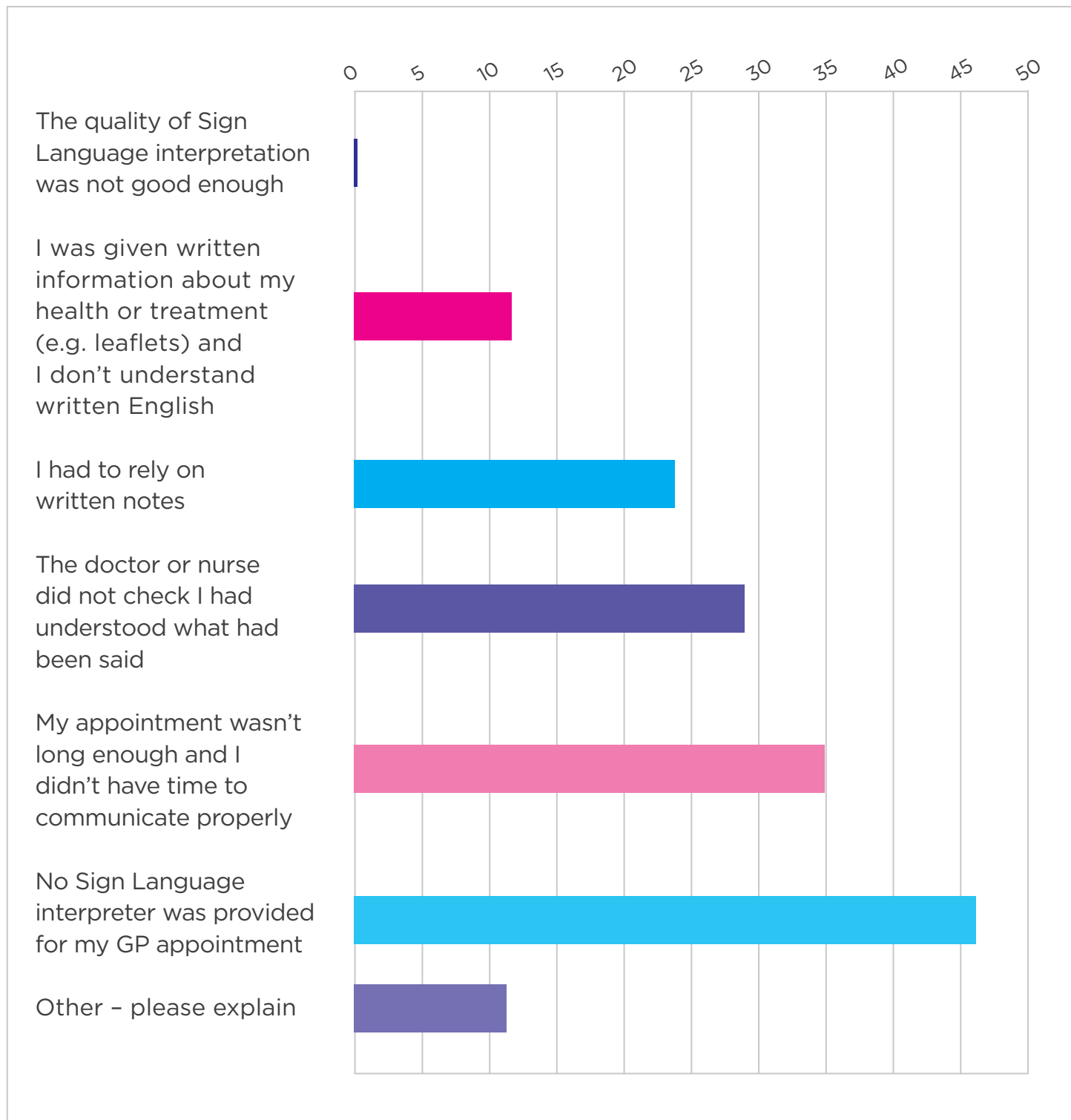


Table 14: If you ever feel unclear about the information you are given after your GP appointments, please tell us why is this (respondents who said they use BSL, SSE or ISL as their first or preferred language)

Respondents could choose more than one answer

	Number of respondents	Percentage (%)
No sign language interpreter was provided for my GP appointment	8	47
The quality of sign language interpretation was not good enough	0	0
My appointment wasn't long enough and I didn't have time to communicate properly	6	35
I had to rely on written notes	4	24
The doctor or nurse did not check I had understood what had been said	5	29
I was given written information about my health or treatment (for example, leaflets) and I don't understand written English	2	12
Other - please explain	2	12
Total number of respondents	17	

Awareness of receptionists and other GP staff

We asked people who are deaf or have hearing loss how receptionists and other practice staff communicate with them, and whether they know how to give feedback or make a complaint.

More survey respondents disagreed than agreed with positive statements on practice staff knowledge of deafness and hearing loss, and good communication. Over two-fifths of respondents disagreed that receptionists, doctors and nurses who work at their GP surgery:

- understand their deafness and hearing loss (42%)
- know how to support them (44%).

“Nearly half the people surveyed said that practice staff don't know how to support them.”

These results support earlier findings in this report about the barriers to communication some people who are deaf or have hearing loss face in waiting areas and consultation rooms, because of the poor deaf awareness of practice staff.

Only half (49%) of survey respondents agreed with the statement about knowing how to give feedback and make a complaint. A clear, accessible complaints policy is crucial for ensuring people who are deaf or have hearing loss know how to give feedback about the quality of care.

It's important to note, however, that a third of survey respondents also said that they neither agreed nor disagreed with these statements. This could suggest that some people who are deaf or have hearing loss did not see the questions as relevant to them and/or they have had both good and bad experiences when communicating with practice staff or making a complaint.

Table 15: Please tell us how much you agree or disagree with the following statements. (All respondents)

	Number of respondents	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Receptionists, doctors and nurses who work at my GP surgery understand my deafness and hearing loss	94	7%	16%	33%	29%	14%
Receptionists, doctors and nurses who work at my GP surgery know how to support me	92	7%	16%	32%	34%	12%
I know how to give feedback and make a complaint	93	15%	35%	22%	14%	14%
Total number of respondents	95					

Section 5. Priorities for improvement

In the last section of the survey, we asked people who are deaf or have hearing loss what improvements they would like to see at their local GP surgery.

36% of respondents said that their top priority would be to have more ways to contact their GP surgery that are accessible to them, such as email and SMS. More than a third (37%) of survey respondents also chose improving online access as one of the top three changes they wanted their GP surgery to make to improve accessibility.

One-fifth (21%) felt that improving receptionists', doctors' and nurses' knowledge of deafness and hearing loss more generally would improve their experience.

18% of respondents said that improving the way receptionists, doctors and nurses communicate with people who are deaf or have hearing loss was important.

More than three-quarters (78%) of people who are deaf said that increasing the range of accessible contact methods was one of their top three priorities for improving the accessibility of GP surgeries, and 61% of deaf respondents felt that improving the availability of communication support (for example, BSL interpreters or speech-to-text reporters) for GP appointments is a priority.

These results support earlier findings in this report suggesting that more needs to be done to change the way in which patients can contact their practice, to include the use of technology such as emails and SMS. There is also a desire to see improved communication and deaf awareness among practice staff, and more available communication support for deaf people.

Table 16: What are the three most important things for you for making access and communication easier? (All respondents)

Respondents could choose one answer in each column

	Number of respondents	1st choice	2nd choice	3rd choice
More ways to contact GP surgeries that are accessible to you (email, SMS text, video-interpreting services)	52	36%	11%	10%
More information about health issues available in sign language	10	4%	2%	4%
Improving the availability of communication support (for example, British Sign Language (BSL) interpreters or speech-to-text reporters) for GP appointments	20	7%	8%	8%
Making it easier to book appointments online	34	10%	13%	14%
Improving the availability of hearing loop systems	15	3%	4%	9%
Improving the way receptionists, doctors and nurses communicate with people who are deaf or have hearing loss	60	18%	29%	19%
Improving knowledge of deafness and hearing loss more generally among receptionists, doctors and nurses	50	21%	18%	15%
Total number of respondents	92			

Table 17: What are the three most important things for you for making access and communication easier? (Respondents who said they use British Sign Language (BSL), Sign Supported English (SSE) or Irish Sign Language (ISL) as their first or preferred language only)

Respondents could select one option in each column

	Number of respondents	1st choice	2nd choice	3rd choice
More ways to contact GP surgeries that are accessible to you (email, SMS text, video-interpreting services)	14	50%	22%	6%
More information about health issues available in sign language	5	11%	6%	11%
Improving the availability of communication support (for example, BSL interpreters or speech-to-text reporters) for GP appointments	11	22%	17%	22%
Making it easier to book appointments online	8	11%	11%	22%
Improving the availability of hearing loop systems	0	0%	0%	0%
Improving the way receptionists, doctors and nurses communicate with people who are deaf or have hearing loss	7	6%	11%	22%
Improving knowledge of deafness and hearing loss more generally among receptionists, doctors and nurses	3	0%	11%	6%
Total number of respondents	18			

Section 6: Knowledge and rights

In Northern Ireland we asked three additional questions, to find out if people who are deaf or who have hearing loss are aware of their right to ask for and receive information in an accessible way, as stated in the United Nations Convention on the Rights of People with Disabilities. This right to a reasonable adjustment to how information is provided is also protected under the Disability Discrimination (NI) Act 1995.

65% of respondents said they did not know that they have the right to receive information in a way that is accessible to them.

Unsurprisingly, given that most people are not aware of this right, 83% have never asked their GP surgery to give them information in an accessible way.

Action on Hearing Loss, in partnership with RNIB and the Health and Social Care Board, issued guidance to all GP surgeries in Northern Ireland in 2014, giving detailed and practical support on how to ensure their services were accessible to people with sensory disabilities. The final question in our survey sought to find out if patients had noticed any improvements over the past three years in the way GPs, nurses or other health and social care professionals communicate with them, to assess the impact of this guidance.

70% of survey respondents said that they haven't noticed any improvements over the past three years in the way GPs, nurses or other health and social care professionals communicate with them.

Table 18: Before taking this survey, did you know you have the right to receive information from your GP surgery in an accessible way? (All respondents)

	Number of respondents	Percentage (%)
Yes	34	35
No	64	65
Total number of respondents	98	

Table 19: Have you ever asked your GP surgery to give you information in an accessible way? (All respondents)

	Number of respondents	Percentage (%)
Yes	17	17
No	81	83
Total number of respondents	98	

Table 20: Over the past three years, have you noticed any improvements in the way GPs, nurses or other health and social care professionals communicate with you? (All respondents)

	Number of respondents	Percentage (%)
Yes	17	17
No	69	70
Don't know	13	13
Total number of respondents	99	

Section 7. Discussion and recommendations

In this last section, we discuss the findings of the survey and present our recommendations for future work.

Contacting GP surgeries to book appointments, order repeat prescriptions and get test results

Our findings suggest that people who are deaf or have hearing loss would prefer to have more options for communicating with their GP practice to book appointments, order repeat prescriptions and get test results. Many people would prefer not to have to visit their GP practice in person, use the telephone or rely on family and friends to contact their practice.

Forcing people to visit their GP surgery in person, or rely on other people to book appointments on their behalf, reduces personal independence and makes it more difficult for people who are deaf or have hearing loss to look after their own health.

A high proportion of survey respondents chose increasing the number of accessible contact methods, including use of email and SMS, as one of their top three priorities for improving the accessibility of GP surgeries.

At the moment, most Northern Ireland GP practices don't offer SMS as a method of contacting patients. This compares unfavourably with the experience in England, where over half of respondents to our survey said they do receive SMS reminders from their GP surgery.

“My doctor and receptionist aren't very clear when trying to explain things to me. I would like them to improve their communication skills on how to speak to a deaf person, especially when the hearing person is phoning on your behalf.”

Booking urgent, same-day appointments and getting urgent medical advice

In recent years, many GP surgeries have introduced remote consultations (either over the phone or online) to improve the way they manage their workloads and increase the amount of time they have to see patients.

Our findings suggest that a significant proportion of people who are deaf or have hearing loss are experiencing difficulties booking urgent, same-day appointments or getting urgent medical advice as often they're only offered phone appointments, or appointments arranged by phone.

This presents a barrier to people who are deaf or have hearing loss – particularly when contacting out-of-hours services.

“The out-of-hours GP always wants me to phone, whether for a home visit or to attend a centre. I can speak but find it exceptionally difficult to hear. I drove to the contact centre without an appointment the last time as I gave up!

Utter discrimination and, because I can speak, the staff think I can hear. I have been accused of being rude/abusive/shouting and I'm sick of it.”

Whilst these new types of consultation may be more convenient for some patients and increase the amount of time doctors, nurses and other practice staff can spend on patient care, phone consultations, in particular, may be inaccessible for many people who are deaf or have hearing loss and may further increase the health inequalities they face (see Section 1).

Some people who are deaf or have hearing loss may find it impossible to use the phone, or struggle to follow phone conversations with their doctor or nurse. Without an accessible alternative to the phone, some people who are deaf or have hearing loss may be forced to visit their GP surgery in person to get medical advice or clarify information about their treatment and care. This increases demand for already stretched services and costs the NHS money.

Identifying communication and information needs

Our findings also suggest GP surgeries need to be more proactive in terms of helping people who are deaf or have hearing loss explain what support they need to communicate well and understand information. Having a clear process in place for asking people who are deaf or have hearing loss what support they need to communicate well and understand information is crucial for ensuring these needs are accurately recorded on patient records – so practice staff know when and what action to take.

In doing so, GP surgeries have an important role to play in promoting accessible contact methods and communication support, as some people who are deaf or have hearing loss (particularly those who have acquired hearing loss later in life) may be unfamiliar with the different forms of support available to help them communicate well and understand information.

GP staff should use a standardised list of questions or prompts to help people articulate their requirements when they register as new patients or when they next get in touch to book an appointment. GP surgeries should not make assumptions about the different forms of support that people who are deaf or have hearing loss may need without consulting the individual concerned or, where appropriate, their parent, guardian or carer.

Waiting areas

Our findings show that most GP practices in Northern Ireland are operating a visual display system to call patients for their appointments.

Although visual display screens can be useful if people who are deaf or have hearing loss miss important information about their appointment when they arrive at reception, they should not be seen as a 'one-size-fits-all' solution to improving accessibility. Visual display screens might not be accessible for everyone, especially if people have other conditions, such as sight loss.

Our findings demonstrate that, in the majority of cases, either a loop system is not available in the reception area or, if available, is not promoted to patients.

While there are instances where GPs themselves have some basic understanding of sign language, a third of survey respondents felt that communication could be improved if practice staff in general had a better knowledge of deafness and hearing loss.

Poor communication in waiting areas may lead to missed appointments and may put people off visiting GP surgeries altogether; forcing them to wait until their health gets worse and they can't wait any longer. In England, the cost of people who are deaf or have hearing loss missing appointments – because they didn't hear their name being called in the waiting room – is estimated to be as high as £15m every year (NHS England, 2017a).

“The acoustics in the waiting room are poor, not helped by a TV constantly on. It's impossible to hear.”

“I usually make a point of letting people know I cannot hear well. I ask the receptionist where I should sit for the GP/nurse. I ask the person I'm with to look at me and speak slowly and clearly. Sometimes, however, I am overwhelmed and just sit and miss my name being called.”

Consultations

The high proportion of survey respondents saying that they sometimes leave their appointments unclear about the information they're given, suggests that more work needs to be done in terms of improving the way doctors, nurses and other GP staff communicate with people who are deaf or have hearing loss.

Poor communication in appointments may force people who are deaf or have hearing loss to go back to their GP surgery again to clarify important information about their treatment and care. It may even be dangerous if, for example, they leave their appointment feeling unclear about how to take their medication. The Ear Foundation (2014) has estimated that, because of communication difficulties, people who are deaf or have hearing loss cost the NHS £76m every year in extra GP visits.

“If staff would speak face to face it would help, rather than turn away or write etc. I often miss the end of sentences because of this. Also speaking clearly doesn't mean speaking 'down' to people, when the one with poor hearing is left feeling a bit of an idiot when something has to be repeated.”

“Despite me telling GPs and other staff I am deaf, I don't find any difference in how they address me. I'm not thick or stupid but, when I can't hear them, I feel very isolated and that I'm not receiving important or useful information.”

Our findings suggest that doctors, nurses and other GP surgery staff could improve the way they communicate with many people with hearing loss if they followed communication tips, or by allowing more time for appointments with people with hearing loss to ask questions and check their understanding.

It's also vital that GP surgeries meet their commitments under the Disability Discrimination (NI) Act 1995 to make reasonable adjustments for people who are deaf – our findings suggest that, in particular, people who are deaf still experience difficulties in terms of accessing high-quality communication support for their appointments. Without support from a well-qualified communication professional, people who are deaf may be at risk of poor care and poor health. SignHealth estimates that the missed diagnosis and poor treatment of people who are deaf costs the NHS £30m every year (SignHealth, 2014).

“Too many times when I see my GP – even though they know I am Deaf – they never ask me if I need an interpreter. I have to ask them to book one.”

Although it may be difficult to secure the services of communication professionals at short notice, there are other options GP surgeries could explore (such as remote video-interpreting services) to ensure people who are deaf are able to access their services in urgent or emergency situations.

In each case, the provision of support should be built around the needs and preferences of the patient. Communication professionals who have the appropriate qualifications will be registered with the National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD). Providing an NRCPD-registered communication professional will ensure people who are deaf or have hearing loss receive high-quality communication support – and don't miss any important information about their treatment and care.

Doctors, nurses and other practice staff should also work together with communication professionals to make sure the format of GP appointments supports good communication. For example, doctors, nurses and other practice staff should allow more time for information to be translated into BSL and for checking it has been understood by the patient.

Recommendations

The Department of Health should:

- introduce an Accessible Information Standard for Northern Ireland
- establish independent monitoring and reporting mechanisms to measure performance against the Standard and publish the results annually
- provide funding, resources and training for GP surgeries to help them meet the requirements of a Standard.

Commissioners of GP services should:

- ensure that GP surgeries are providing accessible services to people who are deaf or have hearing loss
- monitor the implementation of best practice, measure the impact on patients and take action to ensure that services improve

- provide funding, resources and training for GP surgeries to help them improve accessibility.

GP surgeries should:

- provide a range of different contact options such as email, text/SMS message, textphone or Next Generation Text (NGT) and promote these to people who are deaf or have hearing loss
- offer and extend online access for booking appointments, ordering repeat prescriptions and getting test results. GP surgeries should also ensure these online services are accessible for people who are deaf or have hearing loss
- have a clear, standardised approach for asking people who are deaf or have hearing loss what support they need to communicate well and understand information, and record this information on patient records
- book deaf awareness training for all practice staff, to take place during work hours
- ensure waiting areas are accessible for people who are deaf or have hearing loss
- ensure hearing loop systems are available for people who use hearing aids in waiting areas and consultation rooms
- provide appropriately qualified communication professionals, such as a BSL interpreter, for everyone who needs one
- ensure that people who are deaf or have hearing loss have enough time to communicate in appointments; and extend appointment times if necessary
- ensure people who are deaf or have hearing loss can give feedback or make a complaint about the quality of care in an accessible way.

Action on Hearing Loss Northern Ireland will:

- work with GP surgeries and other NHS services to improve the accessibility of their services for people who are deaf or have hearing loss
- lobby government for the introduction of an Accessible Information Standard for Northern Ireland
- provide information and guidance, so that people who are deaf or have hearing loss know what to expect when they access GP surgeries – and what action they can take if their needs are not met.

Section 8. Appendix – overview of respondents

We also asked survey respondents some specific questions about themselves.

Almost half (46%) of survey respondents said they have hearing loss. Over one-third (36%) described themselves as hard of hearing and 26% said they're deaf. Just over a third (33%) said they have tinnitus.

Almost four out of five (78%) survey respondents said they use hearing aids and more than a third (33%) have tinnitus. Three-quarters (85%) use English as their first or preferred language and one in 5 (19%) use British or Irish Sign Language (BSL/ISL).

We had more female respondents than male: almost two-thirds (65%) of survey respondents are female and over one-third (35%) are male.

Table 21: Which of the following statements describe you? (All respondents)

Respondents could choose more than one answer

	Number of respondents	Percentage (%)
I have hearing loss	46	46
I am deaf	26	26
I am hard of hearing	36	36
I am deafened	1	1
Other – please explain	13	13
Total number of respondents	99	

Table 22: More about you... (All respondents)

Respondents could choose more than one answer

	Number of respondents	Percentage (%)
I wear hearing aid(s)	75	78
I have cochlear implant(s)	12	13
I wear a bone-anchored hearing aid (BAHA)	2	2
I have tinnitus	32	33
I have Ménière's disease	3	3
I have balance problems	22	23
Other (including other conditions) - please explain	16	17
Total number of respondents	96	

Table 23: What is your first or preferred language? (All respondents)

	Number of respondents	Percentage (%)
BSL (British Sign Language)	17	18
ISL (Irish Sign Language)	1	1
Sign Supported English (SSE)	2	2
English	72	75
Other - please explain	4	4
Total number of respondents	96	

Table 24: Are you...? (All respondents)

	Number of respondents	Percentage (%)
Male	34	35
Female	62	65
Non-binary	0	0
Total number of respondents	96	

Table 25: How old are you? (All respondents)

	Number of respondents	Percentage (%)
16-24	2	2
25-44	19	19
45-54	18	18
55-64	19	19
65-74	18	18
75-84	18	18
85+	4	4
Total number of respondents	98	

Table 26: Which of the following ethnic groups do you belong to? (All respondents)

	Number of respondents	Percentage (%)
Asian/Asian British	0	0
Black/African/Caribbean/Black British	0	0
Mixed/Multiple ethnic groups	0	0
White	99	97
Other - please explain	1	1
Total number of respondents	98	

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