



Are you listening?

Access to health services for people who are deaf or hard of hearing in Scotland

By Florence Edmond, 2010

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Section 1

Executive summary

There are 758,000 people who are deaf or hard of hearing in Scotland. This means that one in seven patients visiting any GP practice, hospital or NHS dentist will be deaf or hard of hearing – a considerable proportion of the Scottish population.

RNID Scotland's report *Are You Listening?* explores the barriers people who are deaf or hard of hearing experience when accessing health care services in Scotland¹.

Previous research such as RNID's 2004 UK report *A Simple Cure*² showed that people who are deaf or hard of hearing experience significant barriers when accessing health care services. While more recently in Scotland, there has been evidence published about the barriers experienced by people with disabilities when using health care services, this report aims to present the current experiences of people who are deaf or hard of hearing using the Scottish NHS. The report

further aims to influence decision makers at national and local levels to challenge discrimination, change attitudes and break down barriers faced by people who are deaf or hard of hearing when using health care services.

Research underpinning the report was carried out between August and October 2009. We sent 595 questionnaires to a representative sample of RNID Scotland's members. We received 285 questionnaires back – a response rate of 48%. The majority of respondents (58%) were hard of hearing and a vast majority (85%) had one or two hearing aids. Most respondents were older people which reflects the profile of RNID Scotland's membership. A fairly high percentage of over-85s responded. This and the fact that the response rate was high indicate that access to health services is an important issue for people who are deaf or hard of hearing.



Key findings

Hearing loss is a barrier to accessing health services

The Disability Discrimination Act 1995 (DDA) requires public bodies such as the NHS to make reasonable adjustments for disabled people to access services. Yet, in 2009, RNID Scotland's research for *Are You Listening?* found that 43% of respondents agreed that "Being deaf or hard of hearing makes it hard for me to access health services."



The majority of respondents experienced a gradual deterioration in their hearing over a period of time, therefore, they have used the NHS before and after losing their hearing. The fact that 43% find that being deaf or hard of hearing makes it harder to access health services is therefore even more significant. By contrast, only 27% of respondents did not find that hearing loss is a barrier to accessing health services.

Respondents explained that there were two key barriers to accessing health services: staff are not deaf aware and there are no adaptations for people who are deaf or hard of hearing such as induction loops.

Difficulties making an appointment

Nearly half of the respondents who are deaf or hard of hearing (46%) phone to make an appointment and nearly a quarter (24%) make an appointment in person. This is primarily because these are the only options available to patients to make an appointment. However, a third of respondents said they had difficulties communicating with staff because staff did not speak clearly on the phone. Difficulties ranged from being unable to hear dates and times correctly to receptionists who spoke too quickly and too softly on the phone even when asked to slow down.

As a result, a quarter of people who are deaf or hard of hearing have to rely on a third party such as asking a relative or friend to phone on their behalf. But this can present difficulties as well, as one respondent told us:

"Hospital outpatient resists using Typetalk [now Text Relay³] so my husband has to phone for me (...) It is always difficult to communicate via a third person."

Having to rely on a third party undermines a patient's privacy and confidentiality as well as disempowering them from managing their own health. Making an appointment in person is just as difficult as staff lack deaf awareness. Over a third of respondents (36%) found that staff did not speak clearly in person. Receptionists shout or talk behind a glass partition and do not face the patients which means that patients cannot lipread. There is background noise in the waiting room/reception area and loop systems are often not available which means that people with a hearing aid cannot hear the receptionist.

Patients' hearing loss is often not recorded in the patients' notes. As a result, people who are deaf or hard of hearing have to constantly remind staff of their deafness. As a respondent told us:

“The GP’s computer has no way to record [that I am hard of hearing] so I have to report it every time I go”.



Difficulties during the appointment

Accessing communication support

While most respondents said they do not need communication support such as British Sign Language (BSL)/English interpreter or notetaker, nearly a quarter (24%) do not access communication support simply because they do not know they can ask for it.

Under the Disability Discrimination Act (1995), disabled people are entitled to reasonable adjustments to access public services such as the NHS, but people who are deaf or hard of hearing are unaware of their rights. Older respondents are less likely to be aware of their right to access communication support. 22% said they used alternatives such as lipreading or writing notes. Yet, a large number of respondents rely on relatives to act as their communication support worker. Again, this undermines a patient's confidentiality, privacy and independence.

In the waiting room

The main problem people who are deaf or hard of hearing experience when in a waiting room is not being able to hear their name called:

- 50% of respondents said they could not hear their name being called in GP practices.
- 40% of respondents said they could not hear their name being called when attending a hospital as an outpatient.
- 17% of respondents said they could not hear their name at NHS dentists.

The other main problem in waiting rooms is that there is no loop system or that it is not working. This is especially true in GP practices (15%), when visiting a practice nurse (10%) or when visiting a hospital as an outpatient (12%).

Communicating with staff

Respondents found it difficult to communicate with staff. 42% had experienced difficulties communicating with their GPs and half of the respondents had found it difficult to communicate with staff in hospital departments. One third had even found it difficult to communicate with staff working in audiology departments – the very place where staff should be deaf aware.

- 30% found staff did not speak clearly on the phone.
- 36% found staff did not speak clearly in person.
- 27% found that staff had not made sure they understood what was being said.
- 13% found that staff did not know to work the loop system.

As one respondent said: “[Staff] do not understand the needs of people with hearing loss (...) They do not read their notes before the appointment, if they did they wouldn’t shout up.”

Making a complaint

Although our research found that a significant proportion of respondents who are deaf or hard of hearing had problems accessing health services, nearly a quarter (23%) did nothing about it, they did not complain. Some people said they do not like to complain, whilst others said they did not have enough time or were too ill or tired to complain. Others felt it was useless and would not result in improving the situation.

Areas of good practice

There are, however, a few areas of good practice when compared with our UK-wide research in 2004.

The majority of respondents had not avoided any appointment because of being deaf or hard of hearing. This is an improvement since 2004 when RNID's research *A Simple Cure* found that 15% of people who are deaf or hard of hearing avoid going to their GP because of communication problems.

Most respondents understood what was wrong with them following an appointment with a health professional. However, respondents were slightly more likely to be in the dark when attending the hospital as an inpatient or outpatient.

The vast majority of respondents had also understood their treatment. They often double check to ensure they understand their prescription correctly, for example, asking their GP to write things down or double checking with the pharmacist. This is an improvement since 2004 when *A Simple Cure* found that 35% of people who are deaf or hard of hearing had been unclear about their condition because of a problem communicating with their GP or nurse.



Key Recommendations

In order to ensure equal access to health services in Scotland for people who are deaf or hard of hearing, RNID Scotland recommends:

1. The Scottish Government should ensure that health services train all health staff in deaf awareness.

All frontline staff should be trained in deaf awareness. This includes training in handling phone calls as well as communicating face-to-face with patients who are deaf or hard of hearing; and booking appropriate communication support.

Deaf awareness training refresher courses should be offered so that staff are given the opportunity to keep up-to-date with good practice in communicating with patients who are deaf or hard of hearing. Deaf awareness should also be a part of medical, nursing and dental students' training.

2. The Scottish Government and health boards should ensure that patients' records indicate a patient's hearing loss.

All patients' records should clearly indicate that a patient is deaf or hard of hearing and should include basic information about his/her preferred method of communication support.

3. Health boards, GPs and dental practices should provide – and staff should regularly test – technologies that can help patients who are deaf or hard of hearing.

All waiting rooms and consulting rooms should be equipped with induction loops. These should be tested regularly and staff should be trained on how to test induction loops.

Waiting rooms should be equipped with visual displays and these should operate in real time.

Alternative ways of making an appointment other than by telephone or in person such as SMS number; email or Text Relay should be made available and publicised.

4. Health boards, GPs and dental practices should raise awareness of communication support.

Health services should publicise the fact that patients who are deaf or hard of hearing are entitled to receive communication support. In particular, frontline medical staff should actively raise awareness of communication support services with patients who are deaf or hard of hearing.

5. Health boards, GPs and dental practices should ensure that patients are given opportunities to help improve health services by commenting on their experiences.

Health services should ensure that patients who are deaf or hard of hearing can comment and complain about the services through email or comment boxes.

Section 2

Introduction

There are 758,000 people who are deaf and hard of hearing in Scotland. This means that one in seven patients, who visit a GP, a practice nurse, a hospital (as an outpatient or inpatient, or in accident and emergency) or an NHS dentist is likely to be deaf or hard of hearing.

There are many reasons why some people are deaf or hard of hearing or lose their hearing. The most common reason is age-related deafness with more than half of people over the age of 60 with some hearing loss whilst 72% of over 70 year-olds have some hearing loss. Other people may lose their hearing because of exposure to noise at work or because of prolonged and repeated exposure to loud music. Deafness can be congenital

and there are also some conditions such as damage to the eardrum or inflammation in the middle ear that cause deafness. There is a broad spectrum of levels of a hearing loss ranging from people with mild deafness to people who are profoundly deaf.

Depending on their level of deafness and on when they became deaf or hard of hearing, people who are deaf and hard of hearing use a range of methods to communicate. Between 5,000 and 6,000 deaf people in Scotland use British Sign Language (BSL) as their preferred or first language; many rely on lipreading, others use note takers or rely on equipment such as hearing aids; and some use a combination of these.



2.1 Research methodology

Are You Listening? aims to find out the barriers experienced by people who are deaf or hard of hearing accessing health services in Scotland. The report has two key objectives:

1. Identify barriers people who are deaf or hard of hearing experience when using health care services – before, during and after appointments at GPs, practice nurses, hospitals (as outpatient/inpatient or carer), accident and emergency and NHS dentists.
2. Identify positive experiences of people who are deaf and hard of hearing when accessing health care services – including GPs, practice nurses, hospitals, accident and emergency and NHS dentists.

The research started in August 2009 with self-completion questionnaires sent to 595 RNID Scotland members living in all health board areas in Scotland. This represents a randomly selected sample of RNID Scotland's members. A freepost envelope was enclosed to ensure questionnaires could be returned easily and we received responses from 285 people, a response rate of 48%.



2.2 Respondents' profile

The majority of respondents (57%) said they were hard of hearing. 39% said they were deaf (although some people consider themselves both deaf and hard of hearing).

A vast majority (85%) have one or two hearing aids. A minority have a cochlear implant⁴ (3%); one respondent wears a Bone Anchored Hearing Aid (BAHA).

Respondents' hearing loss

Hearing loss	Number of respondents (%)
I am deaf	38%
I am hard of hearing	57%
I use British Sign Language (BSL)	2%
I use Sign Supported English (SSE)	1%
I have a cochlear implant	3%
I wear a hearing aid	85%
I wear a BAHA (Bone Anchored Hearing Aid)	0.4%
I have no hearing loss	2%
Other	2%

Total number of respondents: 285

Most respondents became deaf or lost their hearing between the age of 50 and 64 (26%) or between the age of 65 and 74 (15%). This tallies with RNID's general statistics that show hearing loss is often age-related (for example, 42% of people over the age of 50 are deaf or hard of hearing).



The vast majority of respondents said their first language was English (97%) with only 3% saying their first language was BSL.

Slightly more women (57%) than men (43%) responded to the questionnaire. This is probably due to the fact that life expectancy is higher for women and most of the respondents were in the 64 and over age brackets.

Respondents were mostly older people with 28% in the 64-74 age bracket; 31% in the 75-84 age bracket and 17% in the 85 and over age bracket. This reflects the profile of RNID Scotland's members. Interestingly though, a fairly high percentage of over-85s responded, often sending covering letters with additional qualitative information. This and the fact that the response rate (48%) was high indicate that access to health care services is an important issue for people who are deaf or hard of hearing in Scotland.

2.3 Policy context

Scottish Government policies have looked to remove the barriers experienced by people with disabilities when using health services. RNID Scotland's report *Are You Listening?* aims to find out to what extent those barriers still exist for people who are deaf or hard of hearing in Scotland.

2.3.1 Better Health, Better Care

The Scottish Government's Strategic Objectives, published in 2007, include Strategic Objective 2 to "help people to sustain and improve their health, especially in disadvantaged communities, ensuring better, local and faster access to health care."

The Scottish Government's strategy for a healthier Scotland *Better Health, Better Care*⁵ outlined the actions the Government will take to improve health. The central themes are patient participation, improved healthcare access, and a focus on improving Scotland's public health and tackling health inequalities.

2.3.2 Patients' Rights Bill

In *Better Health, Better Care*⁵, the Scottish Government announced there would be a consultation on a Patients' Rights Bill in 2008: "A mutual NHS provides the context for a legal framework that sets out what patients have a right to expect from their service, including individual waiting time guarantees appropriate to individual needs."

2.3.3 Modernisation of Audiology Services

The Audiology Services Modernisation project aimed to invest in new Digital Signal Processing (DSP) hearing aid technology, new infrastructure, information systems and training. As a result of the modernisation of audiology services, NHS patients in Scotland now receive a hearing aid with features that best overcome the consequences of their impairment (often a digital hearing aid) and the fitting and associated follow up should provide effective rehabilitation.

2.3.4 Quality standards for adult hearing rehabilitation services

RNID Scotland was part of the Scottish Government working group that developed the *Quality Standards for Adult Hearing Rehabilitation Services*⁶. The standards include issues such as accessing the correct audiology services, conveniently and as quickly as any other specialist medical service; timely and relevant information is provided to meet the needs of the patient in a format that suits their communication preference; there is a process of ongoing support and maintenance; and links with external agencies are in place to provide complementary service. The standards also cover recommendations to audiology services, for example all frontline staff with direct patient contact receive deaf awareness and communication training as part of their induction, which is then updated every three years.



Section 3

Hearing loss is a barrier to accessing health care services

“My main problem is general public awareness. Even when I explain my problem and ask people to speak slowly and clearly they may either nod, or they do it for a very short time and then resort to their previous way of speaking”

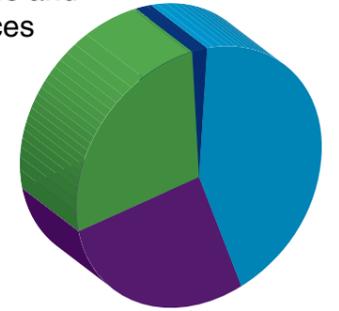
43% of respondents to RNID Scotland’s research *Are You Listening?* agreed with the statement: “Being deaf or hard of hearing makes it harder for me to access health services”⁷.

By contrast, only 27% disagreed with the statement.

Most respondents became deaf or hard of hearing later on in life, between the age of 50 and 64 (26%) or between the age of 65 and 75 (15%). As a result, most have used health services throughout their lives from both perspectives – both as hearing patients and as patients who are hard of hearing. The fact that 43% find being deaf makes it harder to access health services is therefore even more significant in terms of how they perceive the services they are receiving.

Chart 3.1 – Hearing loss and access to health services

43% Agree
27% Disagree
27% Neither agree or disagree
3% Don't know



Total number of respondents: 285

Throughout the questionnaire, respondents explained that the main barriers to accessing health services are linked to staff not being deaf aware and a lack of adaptations for people who are deaf or hard of hearing such as induction loops.

Patients’ hearing loss is often not recorded in their notes which means that people who are deaf or hard of hearing have to constantly remind staff of their deafness.

“Staff don’t know to look at me when speaking, they do not have a radio microphone, they talk too quickly. I have to explain I am hard of hearing, lipread and can’t hear when they walk away still talking. The GP’s computer has no way to record this information so I have to repeat it **every** time I go!”

Case study

Being profoundly deaf, Mr F. was concerned how he would fare in the hospital environment, but was assured by the hospital staff that they

“deal with deaf patients all the time”.

Mr F. recalls:

“The reality was somewhat different. The only concession to the needs of the deaf was to shout. If that failed, the volume was cranked up. The result was a complete lack of privacy and the other occupants of the ward knew more about my condition than I did myself. I became confused, angry and irritable.”

(Ward Misery, letter published in RNID magazine *One in Seven*, Issue 70, respondent to *Are You Listening?*)



RNID Scotland would like all frontline staff to be trained in deaf awareness. Deaf awareness training should be a compulsory part of frontline staff's induction training such as receptionists at GP practices, in hospital departments and at NHS dentist. Training should cover handling phone calls and communicating face-to-face.

Deaf awareness should also be part of medical, nursing and dental students' training⁸. We welcome the example of King's College, London that provides a programme of sensory awareness development and training as part of the undergraduate medical curriculum⁹. We would like deaf awareness training to be a significant part of medical students' curriculum.

In addition, deaf awareness training refresher courses should be offered so that staff are given the opportunity to keep up-to-date with good practice in communicating with patients who are deaf or hard of hearing.

Deaf awareness training

Deaf awareness training should cover:

- What causes deafness/hearing loss?
- Statistics and terminology.
- Effective communication tips, for example facing people who are deaf or hard of hearing so that they can lipread.
- Identifying accessibility issues that people who are deaf or hard of hearing face.
- The types of communication support available.
- Highlighting good and bad practice.
- Defining social and medical models of deafness.
- Understanding the Disability Discrimination Act (DDA).

3.1 Access to health services: Disabled people's experiences

RNID Scotland's *Are You Listening?* is the first report about the barriers faced by people who are deaf or hard of hearing when accessing health services in Scotland. Our findings reflect existing research about disabled people's experience of accessing health services in Scotland.

In November 2008, the Scottish Government published a report on progress towards equality of opportunity between disabled people and other people¹⁰ in which it quotes the baseline study of health boards carried out by Fair for All-Disability. This shows that

“Effort was concentrated on making services physically accessible, though with lesser apparent activity on other aspects of accessible service delivery and some of this appeared to arise from a lack of understanding about the definition of access to services.”

⁸ Paddock, M, O'Neill, B and Howell, 'Actions speak louder than words' BMJ, October 2008

⁹ describe a Sensory Awareness program that has been developed and implemented already as part of the medical curriculum in King's College London. Providing students with the skills necessary to enhance communication with patients who are deaf or hearing-impaired. This includes training in behaviours such as checking hearing aids and habits that maximise the communication of patients who rely on lipreading. This module additionally has a part named 'Deaf Awareness and British Sign Language', in year three.

¹⁰ Scottish Government (2008) Reporting on progress towards equality of opportunity between disabled persons and other persons made by public authorities in Scotland: the Scottish Ministers' Duties available at www.scotland.gov.uk/Resource/Doc/251584/0073692.pdf



RNID's *A Simple Cure*

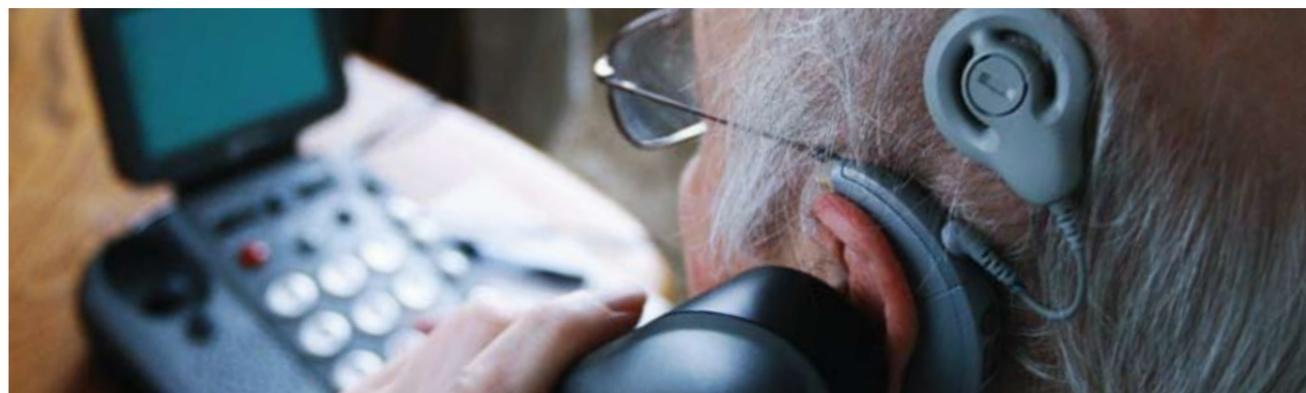
In 2004, RNID's report *A Simple Cure*¹² found that the level of services people who are deaf or hard of hearing receive in both GP surgeries and hospitals often falls short of what they could reasonably expect. Furthermore:

- 35% of people who are deaf or hard of hearing had experienced difficulty communicating with their GP or nurse.
- 32% found it difficult to explain their health problems to their GP.
- 24% of patients had missed an appointment with their GP because of poor communication (such as not being able to hear staff calling out their name) – 19% of whom missed more than five appointments.
- 15% of people who are deaf or hard of hearing said they avoid going to see their GP because of communication problems; this proportion doubles among British Sign Language users.
- 35% of people who are deaf or hard of hearing have been left unclear about their condition because of communication problems with their GP or nurse.

The same report quotes a survey by NOP for the Disability Rights Commission in 2003 which showed that 24% of disabled people polled in Scotland mentioned difficulties in the course of an appointment or visit to a hospital and 18% in accessing a dentist¹¹. For those with sensory impairments who had faced difficulties, barriers mentioned included staff attitudes and absences of induction loops.

3.2: Access to health services for people who are deaf or hard of hearing

Our research found that people who are deaf or hard of hearing in Scotland continue to experience barriers when accessing the Scottish health service. This mirrors previous research in the UK and England which showed that people who are deaf or hard of hearing experience significant barriers when accessing health services.



SignHealth's *Why do you keep missing me?*

In England, SignHealth published a report into deaf people's¹³ access to primary health care, *Why do you keep missing me?*¹⁴, in response to the GP Patient Survey in 2008. The 2008 GP Patient Survey included a question on deafness and provided some evidence of deaf people's experience of primary care.

The report shows two key results:

- People who are deaf are less happy with certain aspects of primary care. In particular, dissatisfaction among respondents who are deaf was far higher than for respondents who are hearing (21.7% compared to 16.9%).
- People who are deaf are also significantly less healthy than hearing peers. For example, the proportion of people referred to a specialist in the last six months was 36.6% among deaf people compared to 26% among hearing people. This suggests that people who are deaf are experiencing more illness requiring specialist input.

In 2009, SignHealth's report *Why are you still missing me?*¹⁵, following the publication of the GP Patient Survey in 2009, shows that there are still disparities between patients who are hearing and patients who are deaf. For example, only 7% of people who are deaf had no long-standing health condition, compared to 51% of the general population.

3.3 Conclusion

43% of respondents to RNID Scotland's research *Are You Listening?* agree that being deaf or hard of hearing makes it harder for them to access health services. Staff are not deaf aware, there is a lack of adaptations such as induction loops and hearing loss is not recorded in the patients' notes. Our findings mirror previous research in England and the UK.



¹³ Many people who are deaf whose first or preferred language is British Sign Language consider themselves part of the deaf community. They may describe themselves as Deaf with a capital D to emphasise their deaf identity.

¹⁴ SignHealth (2008) *Why do you keep missing me?* A report into Deaf people's access to primary health care

¹⁵ SignHealth, *Why are you still missing me?* A report following the publication of the GP Patient Survey 2009, September 2009, available from www.signhealth.org.uk/documents/Why%20%20final_web2.pdf

Section 4

Difficulties making appointments

“Email would be good but this service is not available. I was referred to the local hospital for physiotherapy so I went to make an appointment. The only way to do it was to phone the main hospital 30 miles away who would then allocate a time for me to see the person I was speaking to! She did offer to phone for me and put the appointment time in the post but it did not suit (This is a new arrangement!)”

“At my surgery to get an emergency appointment you must phone in the morning and a doctor will phone you back to assess you which is not good when you can't hear them”.

Nearly half of respondents (46%) phone to make an appointment while nearly a quarter (24%) make an appointment in person. Phoning or making an appointment

in person are often the only options to make an appointment for respondents leaving a quarter of them experiencing difficulties such as hearing all dates and times correctly on the phone or staff not facing them which means that they cannot lipread. As a result, people who are deaf or hard of hearing are left to rely on alternatives. A quarter of respondents have to involve a friend or relative to phone on their behalf, which goes against their right to privacy and confidentiality and disempowers them from managing their own health. Only a tiny minority (1%) use emails to make an appointment.

Table 4.1: Making an appointment

Making an appointment	Respondents (%)
In person	24%
By phone (myself)	46%
By phone (friend/relative)	25%
Textphone	3%
Text	1%
Email	1%

Total number of respondents: 285



Health services traditionally require patients to phone to make an appointment which leads to major communication difficulties for people who are deaf or hard of hearing. As one respondent explains: ‘I would prefer email but this is not always available. Put simply you do not have the aid of lipreading and body communication on the phone therefore it is stressful’. As a result, people who are deaf or hard of hearing tend to look for alternatives. The most frequent alternative is to ask a relative or a friend to phone on their behalf:

“My wife now makes the appointment and comes with me”.

“Sometimes I ask my daughter to make an appointment”.

“I need to have someone else do it for me”.

Other alternatives range from writing a letter or a fax to making the appointment in person and communicating in writing with the receptionist:

“I point at the letter of appointment and my personal diary for a specific date and time”.

“I ask to receive written confirmation on an appointment card to ensure I understand correctly. I often need to ask the receptionist to repeat”.

“The surgery receptionist is aware of the problem and writes things down”.

Some respondents find that phoning is alright either because they have an amplified phone or because they know their GP's receptionist and have raised awareness of their hearing loss at an earlier stage:

“Phone is OK as they know me”.

A few respondents use Text Relay:

“In person if possible, otherwise I use Text Relay”.

A few respondents stress that they simply cannot make an appointment. For example, one respondent told us that phoning is the only way to make an appointment, but:

“I can't make appointments. I am housebound and am unable to hear on the telephone”.

Options such as email or SMS messaging are not available:

“Hospital outpatient receptionists resist using Typetalk (now Text Relay) so my husband has to phone for me. I would prefer by email if that was supplied but our doctor's do not offer this service. It is always difficult to communicate via a third person.”

There should be alternatives to making appointments other than phoning or in person at GP practices, in hospitals and NHS dentists. These could include:

- an email address to make an appointment by email
- an SMS number so that people who are deaf or hard of hearing could text the surgery/department/NHS dentist
- or using Text Relay, a service that connects people using a textphone with people using a telephone or another textphone.

This should be advertised to all patients to ensure that those who prefer communicating in writing know that these alternatives exist.

In addition, frontline health staff should be aware that patients may use alternatives to the phone to make an appointment. They should be trained to check and reply to email or SMS messages and they should be aware that they may receive calls via Text Relay.



4.1 Problems when making an appointment

People who are deaf or hard of hearing face considerable barriers when making an appointment. 29% of respondents said they had difficulties communicating with staff because staff did not speak clearly on the phone. A number of respondents told us they found the receptionists spoke too quickly, too softly on the phone. Staff's lack of understanding and deaf awareness is obvious both on the phone and in person:

“Receptionists speak too quickly even when asked to slow down”.

“The person I call does not recognise Tynetalk (now Text Relay) and thinks it's advertising, cold calling!”.

“[My problem is] high pitched female receptionists who speak too quickly or softly (even after telling them that you are deaf)”.

Several respondents said they were anxious because it is harder to hear the details such as the times and dates accurately:

“I have to make sure I hear numbers correctly and do a lot of checking”.

“If an appointment is done by phone I can become anxious if I don't pick up the correct date and time”.

Another major difficulty when making an appointment on the phone are call-up options and pre-recorded messages:

“The message saying ‘press 5 for call back’ then saying ‘Sorry call-back is not available on this call’. Messages speak too fast”.

RNID Scotland would like frontline staff to be trained in deaf awareness and this should cover handling phone calls.

Good practice when talking to someone who is deaf or hard of hearing on the phone includes:

- speaking clearly, not too slowly
- keeping your voice at a normal level as it is uncomfortable for a hearing aid user if you shout
- avoiding background noise
- checking that the person you are talking to can follow you
- using plain language.



Making an appointment in person is just as difficult as staff lack deaf awareness. Receptionists shout or talk behind a glass partition and do not face the patients which means that they cannot lipread.

One respondent told us:

“The GP receptionist is sitting in poor light behind a reflective heavy glass screen. When she talks to you she is looking at her computer and does not face the patient.”

Background noise from the waiting room can prevent patients who are deaf or hard of hearing from hearing what staff are saying, and in some cases, a

“loop is available but not in use”.

On occasion, people who are deaf or hard of hearing feel they are considered a nuisance:

“People shout thinking you will hear people, as if you're an idiot.”

4.2 Examples of good practice

A few respondents said they had no problem making an appointment and some highlighted that some staff in health services are deaf aware. For example, one respondent said their GP uses email to allow patients to make an appointment. Another noted that staff at her surgery were deaf aware:

“Fortunately I normally have to deal with pleasant, reasonable people who don’t seem impatient when at times they are required to repeat information.”

“It’s OK once I explain I’m deaf ‘Please speak slowly.’”

“The surgery receptionist is aware of the problem and writes things down.”

However, these are a few positive comments compared to a third of respondents who commented on their negative experiences of making an appointment.



4.3 Conclusion

Nearly half of all respondents (46%) phone to make an appointment and nearly a quarter (24%) make an appointment in person. This is primarily because these are the only two options available to make an appointment. A third of respondents said they had difficulties in making an appointment, highlighting that staff lack deaf awareness.

“Dealing with organisations over the phone is made difficult because people insist on speaking so fast, I have to keep asking them to slow down and speak more clearly.”



Section 5

Difficulties during appointments

People who are deaf or hard of hearing also experience difficulties during appointments. Nearly a quarter (24%) do not receive communication support¹⁶, because they did not know they could ask for it. Under the Disability Discrimination Act (1995), disabled people are entitled to reasonable adjustments to access public services like the NHS but clearly people who are deaf or hard of hearing are unaware of their rights.



Other problems are:

50% of respondents cannot hear their name called at the GP’s practice, whilst 43% cannot hear their name called at the hospital.

44% of respondents had difficulties when communicating with staff at GP practices at least at some point and 49% when communicating with staff at hospitals.

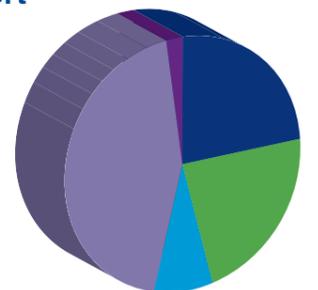
5.1 Accessing communication support services

Most respondents are hard of hearing and as a result, when asked if they need or are offered access to communication support, the vast majority (91%) do not use communication support on a regular basis. When respondents do get access to communication support, this is most likely to be as outpatients at hospital (where 13% receive communication support) and as inpatients at hospital (9% receive communication support).

Nearly a quarter are unaware of their rights to access communication support. Also, 22% said there was another reason (‘other’) and in the majority of cases, they said this was because they felt they did not need communication support, either because their hearing loss is ‘not bad enough’ or because they rely on alternatives such as lipreading or writing notes.

5.2 Reason for not accessing communication support

- 44% Other reason
- 24% I didn’t know I could ask
- 22% Staff didn’t know how to book communication support
- 8% Staff didn’t know I needed communication support
- 2% It was too short notice to book communication support



¹⁶ There are several types of communication support workers used by people who are deaf or hard of hearing, for example British Sign Language (BSL)/English interpreters for people whose first language is BSL, including video interpreting services; deafblind interpreters and communicator guides; lipspeakers; speech-to-text reporters; electronic notetakers; manual notetakers.

Several people said they did not feel they needed communication support:

“At present, I don’t need it if people speak clearly”,

“I can manage myself”.

A large number of respondents then rely on lipreading to understand:

“I tend to rely on lipreading but it is more a problem when dentists wear a face mask”, “I’m a good lipreader”.

Other people rely on alternatives such as writing things down:

“Hospital staff were happy to write things down for me”, ‘I often write notes and get the medical staff to write notes at an appointment’.

or telling staff that they are hard of hearing and asking them to slow down:

“I don’t think communication support is necessary if staff speak slowly and clearly. The tendency is to speak too quickly.”

“I can usually cope by telling them I’m deaf and make them slow down, speak clearly etc. But I sometimes miss things.”



Yet, a large number of respondents who gave other reason for not accessing communication support said they rely on relatives to act as their communication support worker:

“My wife is always with me to listen and make notes for me”,

“My daughter is excellent. She works as a disability officer, she provides me with communication support. Staff are clueless.”

‘My son accompanies me’.

This raises issues of confidentiality and dignity as people who are deaf or hard of hearing have to involve a third party to communicate with health care professionals.

One respondent stressed that she never received the relevant communication support. Whilst she is hard of hearing and needs access to an electronic notetaker, she explained that:

“All efforts in Scotland appear to be channelled towards BSL interpreters whereas the greater majority of hearing impaired people would benefit from notetakers and a campaign to make their availability known and people aware as to how to use them.”

Case study – Sign-Translate

Sign-Translate is a web-based communication program for people who are deaf available to all GPs in England free of charge. The program translates over 300 medical questions into BSL by means of short video clips. It also allows online access to BSL interpreters via webcam. Although not a replacement for interpreters, it is useful for when a patient who is deaf needs to see a doctor quickly and a face-to-face interpreter is not available.

Our research found that there is a correlation between the respondents’ age and the fact that they did not know they could access communication support services. In other words, older people are less likely to be aware of their right to communication support. Out of those who said ‘I didn’t know that I could ask for communication support’, 28% were aged 64-74; 27% were aged 75-84; and 20% were 85 and over.

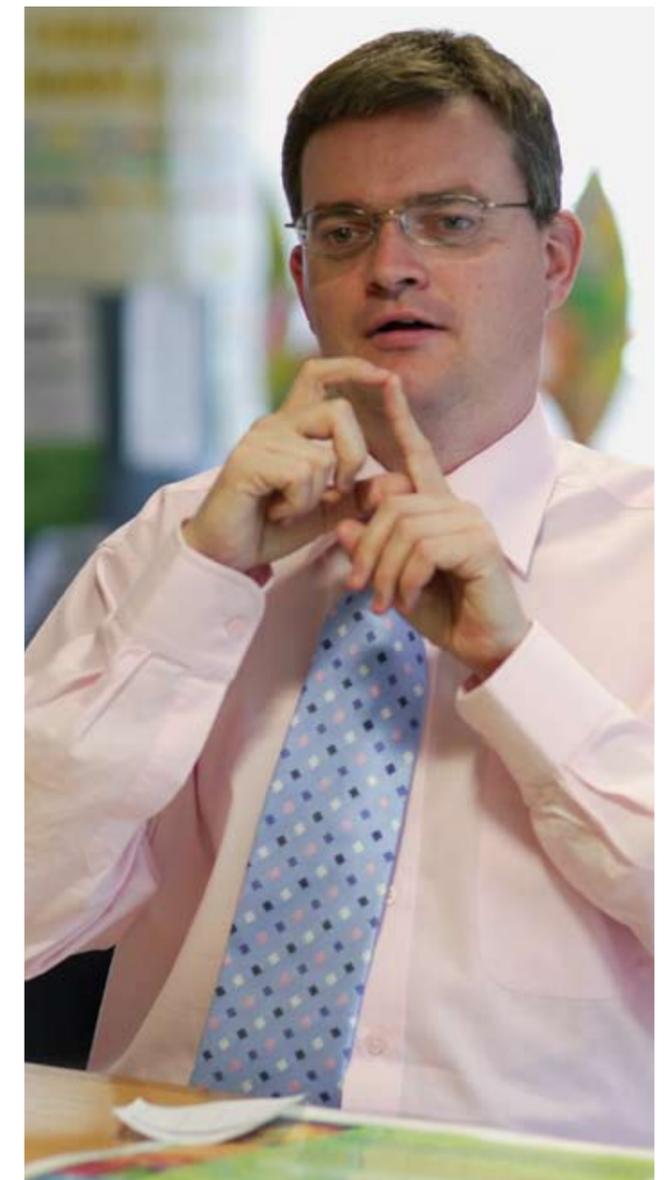
Table 5.1: Respondents’ age and lack of awareness of communication support

Age group	Number of respondents (%)
25-44	4%
45-54	6%
55-64	15%
65-74	28%
75-84	27%
85+	20%

Patients should be aware that they are entitled to receiving communication support. The Disability Discrimination Act (DDA) means that people who are deaf or hard of hearing are entitled to the same access to services

as a hearing person. Communication support should be booked when required in addition to other adjustments which might include induction loops.

Health boards should raise awareness among patients of their right to access to appropriate communication support.



5.3 In the waiting room

The main problem people who are deaf or hard of hearing experience in a waiting room is not being able to hear their name called. This is especially true in GP practices, where 50% of respondents said they could not hear their name being called, when visiting a practice nurse (31%) and when attending a hospital as outpatients (44%). 17% of respondents also mentioned they could not hear their name being called at the dentist.

This is an area that could and should be easily improved through staff being trained in deaf awareness. Patients' records should clearly indicate that a patient is deaf or hard of hearing and staff should be shown how to attract the attention of patients who are deaf or hard of hearing without calling their name.

The other main problem identified in our research is that there is no loop system or that it is not working. Again, this is especially true in GP practices (15%), when visiting a practice nurse (11%) or when visiting the hospital as an outpatient (12%).



- All waiting rooms and consulting rooms should be equipped with induction loops¹⁷. These should be tested regularly and staff should be trained on how to test induction loops.
- Instead of relying on calling a patient's name, virtual displays should be available in all waiting rooms and these should operate in real time to call the next patient in.

“I had a good experience at an outpatient hospital department. I informed the receptionist that I was deaf and she made sure I knew when the doctor called and also made sure the doctor knew I was deaf. The doctor checked to make sure I could hear him”.

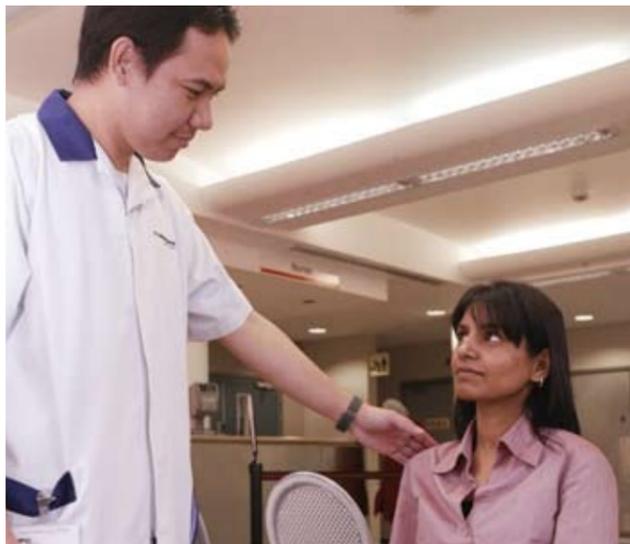


Table 5.2: Problems experienced in waiting rooms

	I could not hear my name being called.	A loop system was not available or not working.
GP	50%	15%
Practice nurse	31%	11%
Hospital as outpatient	44%	12%
Hospital as inpatient	11%	6%
Hospital as a carer/parent	5%	0%
A&E	12%	5%
NHS dentist	17%	7%

5.4 Communicating with staff

“Staff shouting at me, why?”

“I could not hear my name called at the GP’s practice but now the GP comes into waiting room as does the practice nurse.”

Most respondents experienced difficulties communicating with medical staff at some point. In particular, 42% of respondents said they

had experienced difficulties communicating with their GPs and 49% said they had found it difficult to communicate with staff at hospital.

Even more worrying, one third of respondents had experienced difficulties communicating with staff in audiology departments at some time – a department that should be demonstrating good practice in deaf awareness.

Good practice in deaf awareness in health services is achievable as the case study below demonstrates:

Case study – Louder Than Words

Louder Than Words is a best practice charter for organisations striving to offer excellent levels of service and accessibility for customers and staff who are deaf or hard of hearing.

The Louder Than Words qualification process has two parts: a benchmarking visit and an audit inspection. The assessment covers three aspects: communication with customers and staff; a safe and deaf-friendly environment; access to the organisation.

Health organisations that have been awarded Louder Than Words include Pfizer pharmaceuticals, a GP practice in Northern Ireland, the Royal Free Hospital in London and Brompton Hospital in London.



¹⁷ A loop system converts the sounds it picks up into magnetic inductive signals. When these signals reach the person's hearing aid, these are converted back into sound that the person who is deaf or hard of hearing can hear. A loop system consists of a long length of wire, which has both ends attached to the loop amplifier. An infrared system is an alternative to a loop system. The signal is transmitted by invisible infrared light rather than by magnetic field.

Table 5.3: Difficulties communicating with staff

Difficulties	
Staff did not speak clearly on the phone	29%
Staff did not speak clearly in person	37%
Staff did not make sure I understood what was being said	27%
I was not provided with CS	8%
There was no induction loop	15%
There was an induction loop but it was broken	7%
Staff did not know how to work the induction loop	13%
Other	12%

5.4.1 A lack of staff deaf awareness

Respondents who found it difficult to communicate with staff are more likely to have experienced 'human' problems such as staff not speaking clearly on the phone (29%); staff not speaking clearly in person (37%); and staff not making sure they had understood what was being said (27%). This proves the need for deaf awareness training for all frontline staff (for example, receptionists) as well as medical staff (GPs, nursing staff, and so on).

Respondents commented:

“Staff rarely understand your problem and are too busy to give you individual attention.”

“Staff generally are not aware that people may be deaf.”

“My GP had a computer in a corner and needed to turn away from me when he spoke to me, like he spoke with his back to me I could not hear.”

“Staff forget you are deaf and do not face you.”

“They do not understand the needs of people with hearing loss. Normally once they know you're deaf, they pay attention. They do not read their notes before the appointment, if they did they wouldn't shout up.”

However, a few respondents made positive comments such as

“Now I know to let the receptionist know that I am unlikely to make out my name when called. A note is made in front of my patient's notes.”



All medical staff should be trained in deaf awareness to be able to communicate clearly in person. Good practice when communicating with people who are deaf or hard of hearing face-to-face includes:

- making sure that you have the person's attention before starting to speak
- facing the person so they can lipread (not obstructing your face or turning away from the person)
- making sure that the light is on your face not the patient's
- speaking clearly, not too slowly
- using normal lip movements
- rephrasing rather than repeating
- checking that the person has understood.

5.4.2 Background noises and induction loops

Respondents also found it difficult to communicate with staff because of background noises ('In-house TV with sound which drowns voices. I did suggest subtitles but to no avail.')

14% of respondents said there was no induction loop in consultation rooms and 13% said staff did not know how to work the induction loop. This tallies with findings that there was no loop system or that it was not working in the waiting rooms. This is especially true in GP practices (15%), when visiting a practice nurse (11%) or when visiting the hospital as an outpatient (12%).

Respondents commented:

“Staff did not know where the loop was!”

“The induction loop was not in use”

“I now have my own loop 'contego' comfort audio listening device – have given up trying to find a loop that works. Functioning loop systems in the NHS must improve.”

“With reference to induction loops I have never really found these to be of any use. Although the signs for this facility are posted at reception in NHS establishments, I have not noticed it being used so I presume that like me others who are hard of hearing have found alternative ways of communicating such as asking for a written note.”

RNID Scotland's *Are You Listening?* found that people who are deaf or hard of hearing have difficulties accessing communication support, hearing their name called and communicating with staff. This reflects past research carried out in England and UK wide.

For example, Naish and Clark (1998) contacted 80 GPs in the Birmingham area using a questionnaire¹⁸. Questions referred to contact with deaf people both in practice and socially, deaf awareness training and methods of communication employed with deaf patients. The survey showed that GPs often wrote notes, spoke loudly and slowly or used hearing family members as interpreters. Naish and Clark also interviewed patients who are deaf or hard of hearing and they said the simple task of making an appointment is not easy with appointments made by relatives. Awareness is a recurrent theme in interviewing patients – they stated again and again that they wished doctors, nurses and receptionists were more deaf aware.

A study was carried out in Bedfordshire in 2002¹⁹ based on interviews with members of the deaf community, health professionals (doctors, dentists, opticians and pharmacists), reception and chemist counter staff.

Findings included:

- 50% of the surveyed population indicated they experiences problems with receptionists.
- People who are deaf or hard of hearing were unhappy about communication with health staff commenting:

“They don't try to understand, they are not patient with me”.

- The majority of health professionals were unaware how many deaf people they should expect to treat.
- 50% of health professionals said they had felt a deaf patient had not fully grasped their comments/diagnosis adequately.



Moreover, a study carried out in north-west England in 2005²⁰ interviewed 98 deaf adults about their experiences of consulting in primary care, and their preferences for, and use of communication support. On all questions for which comparative results were available for the general population, deaf patients as a group reported substantially less communication and less satisfaction with their primary health care provider. Around one in three left their last consultation uncertain if the doctor had managed their case correctly, gained no better understanding of their illness, and did not understand the doctor's advice on what to do next.

5.5 Conclusions

Most respondents do not access communication support such as BSL/English interpreters or notetakers. This is partly because they do not need communication support, for example they rely on a combination of their hearing aid and lipreading. But a quarter of respondents were unaware of their right to ask for communication support. Older people are less likely to be aware of communication support. Other respondents rely on alternatives such as asking relatives to act as intermediaries which goes against their rights of confidentiality and privacy.

In the waiting room, people who are deaf or hard of hearing cannot hear their name called. Half of the respondents did not hear their name called at the GP. People who are deaf or hard of hearing experience difficulties communicating with NHS staff mostly because staff are not deaf aware.

Case study

“I had a bad experience [with a doctor who knew I was profoundly deaf]. She banged my arm to wake me – get my attention, she didn't put on the light and wait for me to put my aids in. I said her communication techniques with deaf people were deplorable. I wrote to the hospital and suggested deaf awareness training would be good”.



Section 6

Making a complaint

Most people did not complain even when they had problems with health services. This is because some people who are deaf or hard of hearing lack confidence while others do not like to complain. In other cases, respondents did not complain because they felt it would make things worse or would be useless.

6.1 Making a complaint

The vast majority of respondents did not answer this question (for example, only 58 people said 'I complained in person at the time' and only one respondent said they had informed another charity). This is likely to be either because they did not feel there was a necessity to complain (namely they were happy with the service) or because they felt it was pointless or because they are not used to complaining (older respondents may not feel it appropriate to complain).

The majority of people who had problems accessing health services did not complain – a quarter of respondents did nothing. Those who complained did it in person (20%). A few respondents said they did not have any problem and therefore did not need to complain.



6.2 Reasons for not complaining

People who are deaf or hard of hearing do not complain because they lack confidence. This is particularly the case for a few respondents who have been deaf from birth:

“Difficult to change everyone’s attitude. Try to appear strong and calm, I will say if I am disappointed with the lack of respect from the person. I hope they will see me and the next deaf person and give more patience, respect and understanding. I try to put it behind me and move on but the memory and the hurt sometimes comes back and it affects confidence.”

“Deaf are not confident, also not communication support to assist in complaint, or unable to use phone or poor English skills.”

Some respondents do not like to complain or felt that if they complained, this might make the situation worse and feared a backlash:

“I don’t like complaining and I understand that all services cannot be perfect”; “It is difficult to complain without (a) making the relationship difficult in the future. (b) Without feeling a burden. Ideally you shouldn’t have to complain – facilities and support should automatically be in place to make this unnecessary”.

Other said they did not have enough time or energy to complain:

“It’s too much hassle on top of what the rest of life throws at you”



or they may feel too tired because of their illness:

“I felt too ill to complain”:

“Years ago, after an operation I was isolated by poor communications by ward staff, and the surgeon. I was discharged early as my husband felt I would be better at home. As time went on and I recovered I felt too weary to be bothered to complain in writing.”

“When I was an inpatient I was angry about lack of communication and I was too unwell to try to speak up for myself or try so hard to hear. By the time I was home and recovered I didn’t feel angry or upset enough to complain. I also work in the same hospital!”

Other respondents felt that complaining would not have any positive impact, that it would be 'useless':

“There were many times when complaining made little difference so I just gave up! For example asking the audiology department to install a loop system!”

“My complaint was completely ignored and the complaint made in person was useless. The staff tried to shift the blame on to me. This was in audiology.”

“You just feel nothing will be done about it anyway. Deafness is overlooked.”

“Hospital staff are too busy”.

One respondent said he had a meeting with the 'top boy' but was still not 100% satisfied.

These comments reinforce research carried out by the Scottish Health Council²¹. Their report found that only 18% of those who had experienced a problem with the NHS

said they had made a formal complaint, and almost two-thirds (64%) of those who said they did not take any further action said it was because they thought 'it would not make any difference.' Patients expressed concern that their feedback may not have been captured and feared being 'branded a troublemaker.'

RNID Scotland would like all GP practices, hospitals and NHS dentists ensure that patients who are deaf or hard of hearing can comment on the services they receive. Comments and suggestions boxes should be clearly visible in waiting rooms. There should also be an email address – clearly advertised in waiting rooms, on health boards' websites and on all literature aimed at patients – that people who are deaf or hard of hearing could use to comment about the services they receive.

6.3 Conclusion

Most people who are deaf or hard of hearing do not complain even when they had problems accessing health services. This is either because they do not like to complain, they did not have the time or felt too ill to complain, or because they feel this would not have any impact.



Section 7

Good practice

Most respondents understood what was wrong with them and the vast majority had understood their treatment with a marked improvement since our 2004 UK-wide research into access to health. In addition, very few respondents to our recent survey had avoided an appointment because of difficulties communicating with health professionals.

7.1 Understanding their condition

In 2004, RNID's research *A Simple Cure*²² showed that 35% of people who are deaf or hard of hearing had been unclear about their condition because of a problem communicating with their GP or nurse.

By contrast, most respondents to *Are You Listening?* understood what was wrong with them/their condition. Respondents were slightly more likely to be in the dark when attending the hospital as an outpatient (18%) or at a GP surgery (17%)

Table 7.1: Understanding their condition

	Yes	No
GP	17%	83%
Practice nurse	8%	91%
Hospital as outpatient	18%	82%
Hospital as inpatient	15%	84%
Hospital as a carer/parent	10%	90%
A&E	9%	90%
NHS dentist	9%	91%



7.2 Understanding their treatment

Nearly all respondents (98% over all health categories) had understood their treatment. Again, this is an improvement since 2004²³ when 33% of people who are deaf or hard of hearing said they had taken too small or large a dose of a particular medication because of a communication problem.

When asked for further comments, respondents said they often double check to ensure they understand their prescription correctly:

“I write down or I ask the GP to write down the outcome which can help.”

“I am a lawyer I double check everything with medical books.”

“I always double check with the pharmacy.”

One respondent gave an example of misunderstanding:

“I was given the wrong strength of pills and I never heard the directions for taking them.”

Another pointed out:

“I would not know (if this took place) that it was due to a communication problem.”

7.3 Avoiding appointments

In 2004, RNID published *A Simple Cure*²⁴ which showed that 15% of people who are deaf or hard of hearing said they avoid going to see their GP because of communication problems and this proportion doubled among British Sign Language (BSL) users.

In 2009, although a majority of respondents agreed that being deaf or hard of hearing makes it harder to access health services, the majority of respondents had not avoided any appointment because of being deaf or hard of hearing. Only 9% of respondents had avoided appointments at their GP and 9% had avoided outpatient appointments at hospital.



7.4 Conclusion

Most respondents understood what was wrong with them and understood their treatment. Only a few respondents had avoided appointments because of difficulties communicating with health staff. These are improvements since 2004.



Section 8

Conclusions and recommendations

8.1 Conclusions

RNID Scotland's report, *Are you listening?*, showed that people who are deaf or hard of hearing still experience considerable barriers when using health services in Scotland.

Nearly half of respondents (43%) said that being deaf or hard of hearing makes it harder for them to access health services.

Health care staff are not deaf aware. 30% of respondents said that staff did not speak clearly on the phone and commented on their difficulties when phoning to make an appointment such as hearing all the dates and times correctly. As a result, a quarter of respondents need to involve a friend or relative to phone on their behalf.

Patients also experienced difficulties communicating with staff face-to-face because staff lack deaf awareness. 36% found staff did not speak clearly in person and 27% found that staff had not made sure they understood what was being said.

A quarter of people who are deaf or hard of hearing do not know that they can ask for communication support services when accessing health services, which they are entitled to under the Disability Discrimination Act.

Often technologies such as induction loops or visual displays are not in use or do not work. 14% of respondents said they had experienced difficulties communicating with staff because there was no induction loop and 13% said staff did not know how the induction loop worked. As a result, a staggering 50% of respondents said they could not hear their name in GP practices. 43% said they could not hear their name when attending the hospital as outpatient.

Nearly a quarter (23%) of people who had problems accessing health services had done nothing about it. Some people explained they did not like to complain, others were too ill or tired to complain and others felt it would be useless to complain. Some respondents are reluctant to complain because they feel it would make matters worse.

However, there are a few areas of good practice such as most respondents understood their condition and their treatment. A number of respondents made positive comments, for example: "Staff are usually very responsive and understanding especially on the telephone." But these are only a few examples of good practice. By contrast, a quarter of respondents commented on their difficulties accessing health care services.



8.2 Recommendations

In improving access to health care services for people who are deaf or hard of hearing in Scotland, RNID Scotland recommends:

1. The Scottish Government should ensure that all health care staff should be trained in deaf awareness.

All frontline staff should be trained in deaf awareness. This includes training in handling phone calls as well as communicating face-to-face with patients who are deaf or hard of hearing; and booking appropriate communication support.

Deaf awareness training should be offered so that staff are given the opportunity to keep up-to-date with good practice in communicating with patients who are deaf or hard of hearing. Deaf awareness should also be a part of medical, nursing and dental students' training.

2. The Scottish Government and health boards should ensure that patients' records indicate a patient's hearing loss.

All patients' records should clearly indicate that a patient is deaf or hard of hearing and should include basic information about his/her preferred method of communication support.

3. Health boards, GPs and dental practices should provide – and staff should regularly test – technologies that can help patients who are deaf or hard of hearing.

All waiting rooms and consulting rooms should be equipped with induction loops. These should be tested regularly and staff should be trained on how to test induction loops.



Waiting rooms should be equipped with visual displays and these should operate in real time.

Alternative ways of making an appointment other than by telephone or in person such as SMS number; email or Text Relay should be made available and publicised.

4. Health boards, GPs and dental practices should raise awareness of communication support.

Health boards should publicise the fact that patients who are deaf or hard of hearing are entitled to receive communication support. In particular, frontline medical staff should also actively raise awareness of communication support services with patients who are deaf or hard of hearing.

5. Health boards, GPs and dental practices should ensure that patients help improve health services by commenting on their experiences.

Health boards should ensure that patients who are deaf or hard of hearing can comment/complain about the services through email or comment boxes.

Appendix 1

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