**Access to Health and Social Care Policy Statement**

**July 2019**

**Contents**

1. [**Introduction**](#Introduction)
2. [**Legal and policy context**](#Context)
3. [**Evidence**](#Evidence)
   1. [Contacting services](#Contactingservices)
   2. [Visiting services](#Visitingservices)
      1. [Waiting areas](#Waitingareas)
      2. [Appointments](#Appointment)
   3. [Communication support](#Commsupport)
   4. [Communication in mental health settings](#MHsettings)
   5. [Communication in social care settings](#SCsettings)
   6. [Monitoring services and gathering feedback](#Monitoring)
      1. [Self-assessment](#selfassessment)
      2. [Commissioner monitoring](#commissioners)
      3. [National monitoring](#National)
4. [**Recommendations**](#Recommendations)
5. [**Appendices**](#Appendix)
   1. [Recommendations (full list)](#Fullrecommendations)
   2. [Communication tips](#appendix2)

**1. Introduction**

This policy statement presents key issues people with hearing loss face when accessing health and social care services. We outline our stance on accessible communication and information and set out the actions that should be taken by Government, NHS organisations and health and social care service providers across the UK. Acting on these recommendations will enable more people with hearing loss to contact services when they need to, communicate well and understand the information they are given when using the services that are so crucial to their health and wellbeing.[[1]](#footnote-1)

We use the term 'people with hearing loss', throughout this statement to refer to people with all levels of hearing loss, including people who are profoundly deaf and those who use British Sign Language (BSL), or other forms of sign language, as their first or preferred language.

**2. Legal and policy context**

Under the Equality Act 2010 (and the Disability Discrimination Act 2005 in Northern Ireland) health and social care services across the UK are required, by law, to make reasonable adjustments if people with hearing loss face substantial difficulties when accessing services. For people with hearing loss, a reasonable adjustment could include an accessible alternative to the telephone or the provision of communication support, such as a qualified British Sign Language (BSL) interpreter. Failure to make reasonable adjustments is classed as discrimination and is against the law. Health and social care services are also responsible for meeting the costs of any reasonable adjustments required.

What is considered reasonable for an organisation will depend on factors such as the cost of making the adjustment, the effectiveness of the adjustment, and the organisation’s size and resources. The Equality and Human Rights Commission (EHRC) also highlight that the duty is ‘anticipatory’, meaning an organisation cannot wait until a person with disabilities wants to use its services, but must think in advance (and on an ongoing basis) about what support people with disabilities may need. More information can be found on the EHRC website: <https://www.equalityhumanrights.com/en/multipage-guide/using-service-reasonable-adjustments-disabled-people>

In England, NHS England’s *Accessible Information Standard*[[2]](#footnote-2) sets out clear guidance on what NHS providers and providers of publicly-funded adult social care must do to make their services accessible for people with disabilities and sensory loss, including people with hearing loss. The Standard, which became a legal requirement in 2016, establishes a clear framework to ensure people with hearing loss (and their parents, guardians and/or carers) are able to communicate well and understand the information they are given. Compliance with the Standard is a legal duty under section 250 of the Health and Social Care Act[[3]](#footnote-3) and the Department of Health and Social Care’s *Care and Support Statutory Guidance*. [[4]](#footnote-4) The Standard undergoes review by the Patient Experience team at NHS England every three years, with the next review scheduled for 2020.

The Standard sets out a standardised approach for asking people with hearing loss what support they need to communicate well and understand information, and ensure these needs are recorded and met. It states that any decisions about adjustments to meet an individual’s information and communication needs should be based on a conversation with the individual themselves. While the Standard highlights the legal duty organisations have to provide at least one accessible method of communication, it’s clear that organisations should be mindful of individual preferences and that those using services are best placed to decide how their needs can best be met. Therefore, service providers should make every effort to accommodate preferences, as long as it reasonable to do so.

The Standard is part of a wider effort to improve the quality of care for people with hearing loss. The legal duty set out in the Standard is reinforced by the National Institute of Health and Care Excellence (NICE) *Hearing Loss in Adults* guideline,[[5]](#footnote-5) which states that GP surgeries and other NHS services should take steps to make sure that people with hearing loss can participate fully in discussions about their care and treatment. NHS England’s *Action Plan on Hearing Loss*[[6]](#footnote-6) similarly highlights the importance of promoting inclusion and participation by ensuring all public services are accessible and that there is adequate provision to meet language and communication needs.

In Wales, NHS Wales’ *All Wales Standards for Accessible Information and Communication for People with Sensory Loss*[[7]](#footnote-7) provides guidance on what people with sensory loss should expect when accessing health services. The Standards state that people with hearing loss should be able to contact health services when they need to, communicate well with NHS staff and receive information in a format they can understand. As part of the Standards, Local Health Boards (LHBs) and NHS Trusts are required to monitor and review compliance regularly. In 2018, the Standards were updated[[8]](#footnote-8) and a plan was published for all GP surgeries in Wales to be equipped with the technology to record the communication needs of patients with sensory loss and their requirements in a consistent manner. Phase 2 of this roll out has been completed, meaning that all systems across GP surgeries in Wales can now transfer information on communication needs between primary and secondary care.[[9]](#footnote-9)

In Scotland, the Patients’ Rights (Scotland) Act (2011) required the Scottish Government to publish *The Charter of Patient Rights and Responsibilities[[10]](#footnote-10)* which sets out what everyone, including people who are Deaf or have hearing loss, can expect when they use NHS services and receive NHS care in Scotland. This includes the right to be given information in an accessible format and the right to request support, for example a sign language interpreter or other communication support. The Scottish Government introduced new *Health and Social Care Standards* in June 2017,[[11]](#footnote-11) setting out the kind of experience everyone should expect to have when making use of health and social care services. These standards are not specific to improving accessibility for people with sensory loss, but are instead human-rights based standards of care for everyone.

Following the introduction of the *British Sign Language (Scotland) Act* in 2015,[[12]](#footnote-12) the Scottish Government published its first BSL National Plan[[13]](#footnote-13) in October 2017, setting out Scotland’s ambition to be the best place in the world for people who use BSL to live, work and visit. The National Plan outlines ten long term goals for BSL in Scotland and 70 actions Scottish Ministers will take by 2020, including a key action to improve access to health care and mental health services in BSL. As part of the plan, public bodies including local authorities and NHS organisations were required to publish their first BSL Local Action Plans by 2018, demonstrating how these goals will be achieved regionally. Local plans are expected to be revised every six years showing how they will promote and support BSL, and a national progress report is due to be published in 2020. The progress report will highlight poor performance and key areas for improvement. People who use BSL are encouraged to work with public bodies via their comments and complaints procedures to improve and contribute to local BSL plans.[[14]](#footnote-14)

In Northern Ireland, although no formal accessibility standard currently exists, guidance provided by Action on Hearing Loss and RNIB[[15]](#footnote-15) on making primary care services more accessible to people with sensory loss has been supported by the Health and Social Care Board and distributed to all GP practices. It sets out the legal responsibilities primary care services have to support people with sensory loss under the Disability Discrimination Act (1995) and the United Nations Convention of the Rights of People with Disabilities. The guidance also offers practical advice on how best to meet the needs of this group, for example through the use of simple communication tips for staff and an overview of the different kinds of communication support available.

Despite existing laws and guidelines, research shows that people with hearing loss struggle to access the support they need from health and social care services, facing unnecessary and costly barriers to communication. These barriers are resulting in a poorer quality of care for people with hearing loss, as well as increasing pressure on already stretched NHS and social care services (see below).

**3. Evidence**

People with hearing loss often need support to contact services, understand information and communicate well in appointments. Unfortunately, research suggests this is rarely provided, preventing people with hearing loss from fully accessing and benefitting from the services they need.

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 with hearing loss when accessing GP surgeries. A separate survey, exploring the experiences of people with hearing loss when accessing all NHS services, was also carried out in Scotland. We received 1,411 responses in total to the survey sent out in England and Wales and Northern Ireland, and of these 744 were from people with hearing loss living in England.

The results presented in the following sections are for survey respondents who live in England only (unless otherwise specified), as this constituted the single largest group. As sample sizes were different across the nations, direct comparisons may not be representative of national differences. The results for survey respondents who live in Northern Ireland, Scotland and Wales are published in separate reports, which are available for download from the Action on Hearing Loss website. For survey results and recommendations specific to each nation, please use the following links.

England: <https://www.actiononhearingloss.org.uk/how-we-help/information-and-resources/publications/research-reports/good-practice/>

Scotland: <https://www.actiononhearingloss.org.uk/how-we-help/information-and-resources/publications/research-reports/equal-treatment-scotland/>

Wales: <https://www.actiononhearingloss.org.uk/how-we-help/information-and-resources/publications/research-reports/good-practice-wales/>

Northern Ireland: <https://www.actiononhearingloss.org.uk/how-we-help/information-and-resources/publications/research-reports/good-practice-northern-ireland/>

The recommendations made based on this evidence are relevant to all four nations of the United Kingdom, and have the potential to drastically improve access to, and experience of, health and social care services for people with hearing loss.

***3.1. Contacting services***

People with hearing loss may find it difficult or impossible to use the telephone to book appointments, order repeat prescriptions, receive test results or contact emergency or out of hours services. They may benefit from other contact options such as email, SMS Text, online booking and Next Generation Text service (NGT). Without an accessible alternative to the phone, some people with hearing loss may be forced to visit their GP surgery in person to get medical advice or clarify information about their treatment and care, increasing demand on already-stretched services and costing the NHS money.

Despite the requirements of NHS England’s Accessible Information Standard, ourresearch[[16]](#footnote-16) shows that many people with hearing loss are forced to struggle with the phone or go in person to book a GP appointment, due to the lack of accessible contact methods:

* Nearly half (44%) of survey respondents use the phone to book GP appointments, but less than one-quarter (23%) want to communicate in this way;
* Nearly half (47%) visit their GP surgery in person, but only one in seven (14%) said this was how they preferred to communicate;
* One-quarter (26%) 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 one in 12 (7%), said they wanted other people to book GP appointments for them.

When booking urgent, same-day appointments or getting urgent medical advice, the barriers to accessing help in primary care appear to be even worse:

* More than one-third (37%) of survey respondents reported that they had experienced difficulties over the past year;
* Nearly six out of ten (59%) respondents said this was because urgent, same-day appointments can only be booked by phone;
* Almost one in five (19%) survey respondents said they had experienced difficulties because they were offered a same-day phone appointment by their GP surgery.

Telephone appointments have become increasingly common in primary care in recent years as a way of helping GPs to increase the amount of time they have to see patients. NHS England’s *GP Patient Survey[[17]](#footnote-17)* highlighted that of those patients who were offered appointments, almost one in ten (9%) went on to have a telephone consultation. Other GPs have introduced telephone consultations as a way of sorting requests for face-to-face appointments and deciding which patients should be seen first. In England, national primary care policy and practice has emphasised telephone as a way of helping GPs manage multiple demands on their time. NHS England’s General Practice Development Programme, which was established as part of the *General Practice Forward View*,[[18]](#footnote-18) lists the introduction of new communication methods, such as phone and email, for consultations as one of the ten ‘high impact’ actions GP surgeries can take to increase capacity.

**Whilst these new consultation types 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 with hearing loss and may further increase the health inequalities they face**. A survey by the Royal College of General Practitioners (RCGP) found that more than half (56%) of GP surgeries in England have introduced remote consultations of this type (RCGP, 2017),[[19]](#footnote-19) but research indicates that telephone-first triage systems may be a source of anxiety for this group of patients.[[20]](#footnote-20)

There are accessible methods of communication that already exist and are being used to positive effect in some services.In England, NHS 111 offer an online BSL Video Relay Service (VRS) to help people who use BSL to access care and advice in non-emergency situations. BSL VRS involves a BSL interpreter translating what is being said from English to BSL and vice versa via an online video link, which may be especially helpful for people who use BSL and cannot fluently read or write English, or find it difficult to use English-based text relay services. In June 2019, the Scottish Government made a brief announcement about the expansion of contactSCOTLAND-BSL, a VRS provided in Scotland. The Scottish Government committed to providing additional funding for contactSCOTLAND-BSL, and as of 1st June 2019 the service has expanded to include calls to private numbers, in addition to public and third sector. The service hours have also increased to 24 hours a day and 365 days a year.[[21]](#footnote-21)

**Online technology is a simple and easy way for many people with hearing loss to contact services or get health advice. Often providing these alternative communication methods doesn’t require expensive or complex changes to the way in which practices are run**. In recent years, national policy in England has promoted online access to primary care which may have specific benefits for patients with hearing loss. In 2014, NHS England launched the Patient Online programme to support GP surgeries to offer and promote online services to patients. These services include booking and cancelling appointments, ordering repeat prescriptions, and having access to GP patient records. From 2014, GP surgeries have been required under the General Medical Services (GMS) contract to offer and promote online access to their patients where they have access to nationally funded and approved IT systems. In Scotland, as part of the digital transformation of services in primary care and the implementation of the 2018 GP Contract, the Scottish Government has made technology available which, by March 2018, had resulted in 94% of GP Practices offering an online means of booking appointments or requesting repeat prescriptions.[[22]](#footnote-22)

However, evidence suggests that more could be done to promote online services to people with hearing loss. A significant proportion of respondents to our *Good Practice* survey didn’t know whether they could access these services online, suggesting staff in practices could be doing more to highlight the communication options available to those who may benefit most from them. For example, almost one-quarter (24%) of survey respondents didn’t know if they could order repeat prescriptions online and half (49%) didn’t know if they could use online GP services to get test results.

These results are reinforced by the latest *GP Patient Survey.[[23]](#footnote-23)* When asked which online services their practice offered (booking online appointments, ordering repeat prescriptions, accessing medical records), more than half (51%) of respondents answered ‘none of these / don’t know’. This demonstrates a considerable lack of awareness amongst a significant number of patients. Despite their accessibility benefits, it is also important to note that online services may be unsuitable for people who are not comfortable using technology or who don’t use the internet. This is a particular consideration for people with hearing loss, as ONS research shows that 20% of people with a disability have never used the internet, and that older people are less likely to use the internet, particularly those over 75 years of age. [[24]](#footnote-24)

**Recommendations**

GPs and other NHS services should ensure their polices for booking appointments, remote consultations or accessing other routine services such as ordering repeat prescriptions are consistent with the requirements laid out in national accessibility guidance and quality standards. A range of different accessible contact methods should be available, and GPs and other NHS services must work with people with hearing loss to understand the barriers they face and how these may be overcome. Many solutions already exist, such as online services, but there must be greater promotion of the options available to people with hearing loss to increase awareness and uptake. Decisions about accessible methods of contacting services should always be based upon a conversation with the person concerned, and wherever possible, should reflect the preferences of the person with hearing loss.

*For a full list of recommendations, please see* [*appendix 1.*](#Fullrecommendations)

“Since I lost my hearing, I have been unable to hear on a phone. I have had to make considerable adjustments to my lifestyle, and one area of particular concern to me has been how to contact my GP surgery.

After reading information about the Accessible Information Standard, I contacted my practice manager to ensure my communication needs were recorded on my patient record. I agreed with my practice that my husband would be nominated to communicate on my behalf. Whilst I now had a means of contacting my GP surgery, I felt this solution reduced my privacy and personal independence.

I decided to contact my practice manager again to try to find a better solution, not just for my own benefit, but also for all other patients with hearing loss registered at the surgery. I suggested that use of the BT Next Generation Text (NGT) service might be a way to overcome this issue.

Once my practice manager had assessed the viability, he emailed me with the exciting news that my surgery had just completed trialling the NGT service and was in the process of training staff and implementing an awareness campaign.

I booked an appointment to test the system and it worked perfectly. The receptionist was most helpful and the conversation went smoothly. I can honestly say that I felt a huge sense of relief in the knowledge that I could finally communicate in person with the Surgery. In fact, it has had a beneficial impact on my self-esteem.

I hope that our story of successful collaboration will encourage other GP surgeries to follow suit.”

***Sylvia,******Hertfordshire***

***3.2. Visiting services***

When visiting health services, people with hearing loss may need additional support to communicate well with staff and know when it’s their turn to be seen. It’s good practice for staff to ask people about their communication needs and make sure these needs are recorded and acted upon. Without this support, people with hearing loss may be left unclear about the information they’ve received, leading to poor treatment and increased costs on other parts of the health and social care system. Asking people with hearing loss what support they need to communicate well and understand information is a requirement under national accessibility guidance and standards. Our research shows that this still isn’t happening in practice, with only one in ten (10%) survey respondents reporting that their GP surgery had asked them about their communication needs.[[25]](#footnote-25) In Wales, fewer than 1 in 20 (4%) people reported that their GP had asked them if they need support to contact GP services and understand what is said in appointments.[[26]](#footnote-26)

*3.2.1. Waiting areas*

Reception staff should be aware of the support people with hearing loss may need to help them communicate and there should be a hearing loop system installed on reception desks, so people who use hearing aids can communicate with reception staff when they need to. However, our *Good Practice?* report shows that waiting areas are often not accessible for people with hearing loss:

* One-quarter (26%) of respondents said a hearing loop system isn’t available at their GP surgery, and more than half (58%) didn’t know if one is available;
* More than two-fifths (43%) said that staff at their GP surgery call their name out when it’s their turn to be seen by the doctor or nurse;
  + The situation is better in **Northern Ireland,** where eight out of ten 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 just 16% said that practice staff call out their name.

Visual display screens can be useful if people with hearing loss miss important information about their appointment when they arrive at reception, but 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. For some people, the solution may be as simple as letting them know face-to-face when they can go in for their appointment. This highlights the importance of services having a clear process in place for asking people what support they need to communicate and making sure this information is recorded and acted upon (see above).

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 their condition needs urgent attention. In addition, our *Access All Areas*[[27]](#footnote-27) research shows that one in seven (14%) survey respondents had missed an appointment because they didn’t hear their name being called in the waiting area. NHS England[[28]](#footnote-28) estimates that this costs the NHS £14 million every year – a substantial sum that could be saved by making reception desks and waiting areas more accessible for people with hearing loss.

*3.2.2. Appointments*

Our research shows that people with hearing loss may struggle to hear what is being said by health professionals, due to poor deaf awareness and the lack of communication support in consultation areas, which may lead to confusion over their diagnoses and ineffective care.

We asked people with hearing loss whether they ever leave their GP appointments feeling unclear about what they’ve been told by the doctor or nurse:

* Nearly two-thirds (64%) of survey respondents said they feel unclear about the information they’ve been given at their GP appointments, at least some of the time;
* Almost half (45%) of people with hearing loss felt unclear because their doctor or nurse didn’t speak clearly. When asked why they felt unclear, more than half (52%) of survey respondents said doctors or nurses spoke too quickly or didn’t check whether they’d been understood;
* More than half (57%) of survey respondents who use BSL said they felt unclear about their health advice because a sign language interpreter was unavailable for their appointment. More than one in eight (13%) also said that the quality of sign language interpretation wasn’t good enough.

Research also shows that many pharmacies are similarly inaccessible for people with hearing loss. Our *Access All Areas*[[29]](#footnote-29) research shows that just over a third (35%) of respondents said their pharmacy consultation took place in a private room (private rooms are important for patient confidentiality but can also aid communication by reducing background noise) and only a small proportion (8%) said that a hearing loop system was available.

In Scotland, an e-learning module on British Sign Language (BSL) and Tactile BSL has been available for NHS staff in recent years to improve communication with Deaf and Deafblind patient, but there has been very low take-up of the course. In an attempt to increase the number of health and social care staff taking the course, the Scottish Government has made the course freely available to everyone (including members of the public) who register.[[30]](#footnote-30)

**Poor communication in appointments may force people with hearing loss to go back to their GP surgery again to clarify important information about their treatment and care and may even be dangerous if they leave their appointment feeling unclear about how to take their medication**. The Ear Foundation[[31]](#footnote-31) has estimated that, because of communication difficulties, people with hearing loss cost the NHS £76m every year in extra GP visits. The survey results and comments we received as part of our *Good Practice* research demonstrate that the poor deaf awareness of practice staff in waiting areas causes considerable stress and anxiety for people with hearing loss. However, with the right support, the risks and impact of poor communication in NHS appointments can be significantly reduced.

**Recommendations**

Health and social care providers must take basic steps to improve accessibility for service users with hearing loss. For many people with hearing loss, following simple communication tips such as speaking clearly or making sure lip movements are clearly visible can make a huge difference. Other people with hearing loss may require support from a communication professional, such as a qualified British Sign Language (BSL) interpreter (see [Section 3.3](#Commsupport) below). Health and social care professionals should follow the processes set out in national accessibility standards, meaning they should be asking about communication needs, recording these and responding to them appropriately. This is critical to improve the experiences of people with hearing loss visiting services and to ensure people with hearing loss can get the care they need.

*For a full list of recommendations, please see* [*appendix 1.*](#Fullrecommendations)

“In my experience, the combination of my severe hearing loss and the fact that I am a very senior citizen can often lead to GPs and other NHS staff incorrectly assuming that I am suffering from age-related dementia.

Recently, a GP whom I had not met before spoke to me with his back turned so that I could not see his face. I found it hard to understand what he was saying, so he told my regular GP that I was losing my wits. I was then asked the standard set of diagnostic questions, which I answered without any difficulty. After discussion with my GP, I have suggested to the practice manager that someone from Action on Hearing Loss should be invited to a staff meeting to talk about the problems that patients with hearing loss experience, and encourage them to ensure they face patients when speaking to them.”

***Liz, Norwich***

***3.3. Communication support***

During appointments, some people with hearing loss may require support from communication professionals, such as speech-to-text reporters (STTR) or lipspeakers. For people who use British Sign Language (BSL), English may not be their first or preferred language and they may need a qualified BSL interpreter to get the most out of their appointments. In practice, evidence suggests this is rarely provided, resulting in poor access to services and limited understanding of health information being shared. As highlighted in [Section 3.2.2](#Appointment), when asked why they felt unclear after their GP appointment, more than half of people who use BSL said this was because a sign language interpreter was unavailable for their appointment.

The Standards in both England and Wales state that people with hearing loss should have access to a National Registers of Communication Professionals working with Deaf and Deafblind people (NRCPD)-registered communication professional if they need one, as this provides assurance that professionals hold suitable qualifications, hold enhanced disclosure from the Disclosure and Barring Service (DBS) and engage in continuing professional development. The Standards are clear that family and friends should not be used as interpreters unless the person with hearing loss explicitly asks for their help to communicate.

Two high-profile legal cases have drawn attention to the provision of communication support in recent years. Two separate patients treated in Scottish hospitals in 2014 and 2016 were not given access to BSL interpreters during inpatient treatment lasting several days. The Equality and Human Rights Commission (EHRC) Scotland supported both cases and the Scottish Public Services Ombudsman ruled that reasonable adjustments were not made, resulting in a failure to adhere to the Equality Act.[[32]](#footnote-32) This highlights the ongoing difficulties in this area, with patients left for days with no way of communicating with healthcare professionals. This is clearly dangerous and distressing for those patients involved, and is completely unacceptable.

**Without a properly qualified communication professional and accessible information, people who use BSL in particular are at risk of worse care and poor health**. Research by the charity SignHealth shows that over a third (34%) of people who use BSL 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.[[33]](#footnote-33) This suggests that people who use BSL may not be getting the care they need due to problems with communication and understanding. SignHealth estimates that the missed diagnosis and poor treatment of people who use BSL costs the NHS £30m every year.[[34]](#footnote-34)

When people with hearing loss are accessing planned care, such as advance GP or outpatient appointments, there should be adequate time to make reasonable adjustments and arrange the provision of the person’s preferred type of communication support. Planning communication support in advance is especially important, given the high level of unmet need for communication support in general. The latest figures from NRCPD show that there are only 1,098 NRCPD registered BSL interpreters,[[35]](#footnote-35) compared with at least 24,000 people who use BSL across the country.[[36]](#footnote-36) This highlights the importance of communication needs being consistently recorded and flagged, to ensure staff are prompted to book communication support as soon as an appointment is scheduled (see [Section 3.2.2](#Appointment)).

In instances of unplanned and emergency care, however, communication support may be unavailable at short notice. In these circumstances, remote BSL interpreting services may help people who use BSL communicate with health and social care professionals. Remote BSL services work in a similar way to remote BSL Video Relay Service (VRS) (see [Section 3.1](#Contactingservices)) and both services involve a BSL interpreter translating what is being said from English to BSL and vice versa via an online video link. Although useful in emergencies, remote BSL interpreting services should not be seen a full replacement for face-to-face communication support. Remote BSL interpreting services may also be unsuitable for people with sight loss or for sensitive discussions about a patient’s treatment and care. Similarly, such services may be inappropriate for people who are not comfortable using technology or who don’t use the internet. As highlighted in [Section 3.1](#Contactingservices), this is a particular consideration for this patient group, as ONS research[[37]](#footnote-37) shows that 20% of people with a disability have never used the internet and that those in older age groups tend to have the lowest rates of internet access and use.

In addition, more needs to be done to improve the availability of health information in BSL video. Under accessibility standards in England and Wales, patients with hearing loss have the right to receive information a format they can understand and this includes information in BSL video if this would best meet their needs. This doesn’t mean that GPs and other NHS services have to provide information in BSL video themselves; instead, it is only a requirement for them to ensure patients have access to information in an accessible format. However, at present, sources of health information in BSL video are few and far between. Only 6 of the 420 videos available on the NHS website are available in BSL – that’s just over 1%.[[38]](#footnote-38) It is hoped that the NHS accessibility guidance and standards, and new legislation such as the British Sign Language (Scotland) Act, will drive improvement in this area in future. However, to be effective, it is vital that this guidance and legislation is properly implemented and enforced.

**Recommendations**

Providers of health and social care must act to ensure that the provision of communication support is always based on a discussion with the person receiving support, in line national accessibility guidance and standards. New technologies have the potential to improve access to health and social care services for more people with hearing loss, and should be explored where appropriate*.* However, if the person in need of communication support thinks that face-to-face support is the best way of meeting their communication needs, health and social care services should make every effort to accommodate this. Crucially, services must ensure that communication support professionals used are registered and appropriately qualified.

*For a full list of recommendations, please see* [*appendix 1.*](#Fullrecommendations)

***3.4. Communication in mental health settings***

People with hearing loss, and people who use BSL in particular, face specific challenges in accessing and benefitting fully from treatment for mental health conditions. In particular, low levels of literacy in a written language, poor access to appropriate communication support and a lack of cultural awareness may make it impossible for people who use BSL to access talking therapies.[[39]](#footnote-39)

Without appropriate support, people with hearing loss may experience a worsening of their condition and may become increasingly vulnerable. This is especially important given that people with hearing loss are more likely to experience mental ill-health compared to hearing people, so the risks of not addressing the significant unmet need in this area are high.

Unaddressed hearing loss has been linked with depression, anxiety and other mental health problems.[[40]](#footnote-40) For example, research shows that hearing loss doubles the risk of developing depression.[[41]](#footnote-41) Evidence also suggests that the prevalence of mental health problems in the Deaf community lies somewhere between the range of 30% and 60%.[[42]](#footnote-42) It’s vital therefore that all services providing NHS-funded mental healthcare provide appropriate support to ensure people with hearing loss can contact their services in an accessible way and communicate well during appointments (see Sections [3.1](#Contactingservices) and [3.2](#Visitingservices)), in line with requirements set out in national accessibility guidance and standards.

People with hearing loss may also encounter additional challenges in accessing mental health care, and these need to be taken into account by GPs and other NHS services. People who use BSL and present with mental health difficulties may face barriers in their initial referral from primary care. It is common to be directed to self-refer into Improving Access to Psychological Therapies (IAPT) services, but this process requires the completion of several online assessments in order to be considered for therapy.[[43]](#footnote-43) This may prove impossible without additional support for people who use BSL, and for whom English is not their first or preferred language, and may prevent them from receiving vital treatment.

Engaging with talking therapies may also be difficult for people with hearing loss. It may be beneficial to have longer sessions as a result of the time needed for interpretation or for people to clarify that they’ve understood their health advice correctly. Our research carried out in Wales highlights that more than a quarter (28%) of people with hearing loss say their medical appointments aren’t long enough to communicate properly.[[44]](#footnote-44) Alternative avenues for referral should be in place to avoid people with hearing loss missing out on psychological support, and longer appointment times should be considered, in line with national accessibility standards and guidance, especially where interpreters are being used and may need to be briefed before and after the session.[[45]](#footnote-45)

In addition, people who use BSL have unique needs that to be taken into account when providing mental health care. Standard tests and mental health measures may be ineffective for people who use BSL if they are unable to communicate well in English. Inappropriate assessments can overlook vital clues about a person’s mental state, leading to misdiagnosis or ineffective treatment.[[46]](#footnote-46) Although the availability of culturally appropriate mental health care is out of scope for the purposes of this policy statement, it is important to highlight the benefits to service users of good knowledge and understanding of BSL and Deaf culture among staff working in these settings.

**Recommendations**

Providers of mental health services must ensure that staff interacting with service users with hearing loss have appropriate deaf awareness. People with hearing loss should be consulted about how they can be supported to access the help they need and get the most out of the care on offer to them. Where necessary, support should be offered to understand written information and complete forms and assessments. If the person seeking help feels that a therapist fluent in BSL is best placed to meet their needs, every effort should be made to accommodate this. Communication needs should be recorded centrally, shared where appropriate and consistently planned for and met.

*For a full list of recommendations, please see* [*appendix 1.*](#Fullrecommendations)

***3.5. Communication in social care settings***

People with hearing loss constitute an increasingly significant number of those receiving social care and support. Age-related hearing loss is the single biggest cause of hearing loss[[47]](#footnote-47) and, due to the ageing population, the number of people in need of support is projected to grow in coming years. By 2032, there will be an estimated 620,000 older people living in care homes in England and of these, almost half a million will have hearing loss.[[48]](#footnote-48)

In the absence of effective treatment and management, hearing loss can seriously impact upon a person’s health and quality of life.[[49]](#footnote-49) Evidence suggests that if older people who use BSL cannot communicate in a meaningful way with care staff and other care home residents, this can result in deterioration in personal wellbeing and loss of cultural identity. [[50]](#footnote-50) Older people who use BSL value being able to have proper conversations in BSL with care staff and other people living in care homes, and this has been shown to help maintain signing skills and promote personal independence.46 Meeting people’s communication and information needs is therefore crucial for improving the wellbeing of people living in care homes or receiving support in their own homes.

In England, The Care Quality Commission’s latest *State of Care* report[[51]](#footnote-51) found that awareness of responsibilities in line with the Standard is particularly low amongst publicly-funded adult social care providers, in part because central mechanisms for communicating the requirements of the Standard don’t exist in this sector, compared with health settings. This is concerning given that more than 80% of older people living in care homes will require support for their hearing loss to maximise their independence and wellbeing.[[52]](#footnote-52)

**Recommendations**

Social care providers must meet the needs of the growing numbers of people with hearing loss who rely on their services. It’s vital that social care services follow the general principles set out in national accessibility guidance and standards to ensure people with hearing loss can contact services when they need to and can communicate well with care staff (see Sections [3.1](#Contactingservices) and [3.2](#Visitingservices)). Following simple communication tips, such as facing the person with hearing loss so they can lipread (see [appendix 2),](#appendix2) and installing hearing loops in communal areas can make a big difference to the experiences of people living with hearing loss in care homes. With appropriate support and staff training, people with hearing loss receiving social care and support will be better able to communicate well and participate fully in the activities they enjoy.

*For a full list of recommendations, please see* [*appendix 1.*](#Fullrecommendations)

For more information on the issues facing people with hearing loss who need social care and support, please see our Social Care Policy Statement: <https://www.actiononhearingloss.org.uk/how-we-help/information-and-resources/publications/policy-statements/health-and-social-care/social-care/>

***3.6. Monitoring services and gathering feedback***

Monitoring performance plays a critical role in driving improvement in the accessibility of health and social care services for people with hearing loss. Whilst there is currently no requirement for organisations to report on their adherence to the accessibility standards in England and Wales, organisations in England are required to publish or display an accessible communications policy which explains how they will follow the Standard, and an accessible complaints policy. The inclusion of these requirements is intended to support compliance assessments by interested organisations, and to ensure that people with information and communication support needs are able to provide feedback to organisations about their experiences.

In January 2017, NHS England launched a review to gather evidence on the impact of the Standard and to identify any changes that may improve its effectiveness. The full findings from the review were published as a report, which is available for download from the *Accessible Information Standard* website: [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)

We worked closely with NHS England to make sure the views of people with hearing loss were properly represented in the review process. The report we produced as part of this process found that although some people with hearing loss have experienced improvements in accessibility, others had felt little change since the Standard was implemented or were not even aware of it:

* More than two thirds (67%) of those surveyed had not been asked about their information and communication needs when using or contacting NHS services over the last six months;
* More than half (53%) had not noticed any improvement in getting accessible information or communication support from NHS services over the last six months;
* Almost three quarters (73%) had not been asked to provide feedback on their experiences in an accessible way;
* More than two fifths (44%) had not heard of the Standard; almost a third (32%) felt the impact of the Standard was neither good nor bad (neutral); around one in seven (15%) felt that the impact of the Standard had been good or very good.

We found similar results when we assessed the impact of the Welsh Standards one year after their launch.[[53]](#footnote-53) Of the 120 people with sensory loss from across Wales who were surveyed about their experiences over the previous 12 months, the vast majority were not feeling the effects of the Standard:

* The vast majority (91%) of people asked were not aware of any improvements in the way healthcare services communicate and share information with them;
* Only around one in five patients had been asked about their communication and/or information needs by healthcare services across both primary and secondary care settings;
* More than half (58%) of respondents said that they did not know how to report a concern or complaint.

People with hearing loss are still not feeling the intended benefits of national accessibility standards, demonstrating the need to monitor progress more carefully to better understand persisting barriers to accessibility. People with hearing loss should be involved in service planning decisions and should be able to give feedback on quality of care in accessible way. Monitoring should be occurring at multiple levels simultaneously.

*3.6.1. Self-assessment*

Under the Standard, providers of NHS services and publicly-funded adult social care services in England must gather feedback from people with disabilities and sensory loss on the provision of communication support and accessible information. There is also an organisational duty in England and Wales to have an accessible complaints process should patients want to feedback their experiences. This is crucial if services are to be able to monitor their own performance and understand what is working, as well as what isn’t, since people with sensory loss are best placed to comment on the impact of any adjustments made.

A survey of health and social care professionals carried out by NHS England as part of their review of the Standard in 2017 found that only half (49%) of organisations had an Accountable Officer responsible for the Standard and around two fifths (37%) said compliance with the Standard is not monitored. Services should be monitoring their performance against the Standard, and gathering feedback from service users about accessibility, but this does not seem to be happening consistently.

Action on Hearing Loss have produced a range of resources to help services better understand obligations and meet the requirements of the Standard. Information specific to improving the accessibility of GP surgeries, hospital, urgent and emergency care services and social care services can be found on our website: <https://www.actiononhearingloss.org.uk/how-we-help/health-and-social-care-professionals/standards-for-accessible-information-and-communication/accessible-information-standard/>

*3.6.2. Commissioner monitoring*

Clinical commissioning groups (CCGs) in England are required to monitor their performance against the Standard to ensure compliance. Commissioners must also seek assurance from NHS and publicly-funded adult social care providers in their local area that they are meeting the requirements of the Standard. Compliance with the Standard is also included as requirement in 2019/20 Standard Contract, which is mandated by NHS England for use by commissioners for all contracts for healthcare services in England other than primary care.[[54]](#footnote-54)

In 2016, we wrote to all CCGs in England to find out what steps they were taking to ensure NHS providers in their area were following the requirements of the Standard. The feedback we received suggests that NHS services have not achieved full compliance with the Standard and CCGs are not monitoring progress towards implementation in a consistent way. Whilst most CCGs reported that they were aware of the Standard and monitoring compliance with the Standard as part of their service contracts, few provided any detailed information on how they were going about this. Only a small number said they published the results of local monitoring exercises or gathered feedback on the accessibility of services directly from people with hearing loss.

These findings suggest that more work is needed to promote the Standard to all those who could benefit from it. NHS providers, commissioners and NHS England should do more to promote the Standard to people with hearing loss and gather feedback on the provision of communication support and accessible information. Crucially, a consistent approach to evaluating performance against the standard is required if compliance is to be effectively monitored and regional variations reduced.

*3.6.3. National monitoring*

National monitoring is crucial for developing a national picture of adherence to the Standard, and identifying variation between areas, as well as different services. The Equality Act 2010 (the Disability Discrimination Act 2005 in Northern Ireland) sets out the legal requirement for health and social care services across the UK to make reasonable adjustments if people with hearing loss face substantial difficulties when accessing services. National bodies have a responsibility to ensure this is the case and act where services are not meeting their legal requirements.

In Scotland, a report is due to be published in 2020 on progress against the BSL Action Plan.In many areas local plans are still not available, despite a national requirement for them to be published in 2018. At present, there is nothing legally binding to ensure compliance. Of the 32 local authority areas, three have produced no plan and a further three have produced a written document without a BSL version. Additionally, of the 14 NHS areas, only seven have produced both a BSL and written version of their local BSL action plan, with two areas publishing no plan at all.[[55]](#footnote-55) For more information, see the local plans page on the BSL Act website: <http://bslscotlandact2015.scot/plans/>.

The Scottish Government intends to publish a report by 2020 on what progress has been made towards the national plan. It’s difficult to see how this will be accurately measured if public services are yet to develop their plans for implementation at a local level and there is no standardised reporting mechanism or targets in place. Although the progress report will be laid before the Scottish Parliament and will therefore be subject to scrutiny, the Act itself does not provide for direct legal remedy or recourse.[[56]](#footnote-56)

In Wales, guidance states that the Standards should be subject to regular review and monitoring, and that arrangements should be made for a designated senior officer to report to the Board on the progress made on improving access to health and social care for people with sensory loss. Again, there is no standardised reporting mechanism or targets in place, and little to encourage compliance.

In March 2017, the Care Quality Commission (CQC) publicly committed to monitor compliance with the Standard in England as part of their inspection work. CQC’s [Equality Objectives for 2017-19](https://www.cqc.org.uk/sites/default/files/20170321_equality_objectives_2017-19.pdf) include a specific objective on ‘Accessible Information and Communication’ and CQC inspection frameworks have been updated to include specific references to the Standard. CQC have also trained their inspectors to ensure they have a good knowledge of the Standard and know how to apply it in their inspection work. All CQC inspection reports should now include information on how NHS and adult social care services are implementing the Standard.

As part of their Equality Objectives, CQC has also committed to improve the way it communicates with people with disabilities and sensory loss. As part of this, CQC will review its information to ensure it is clear, concise and uses plain English. They will also provide appropriate support to make sure all people with disabilities and sensory loss are able to communicate with them in an accessible way.

In their latest *State of Care* report,[[57]](#footnote-57) the CQC highlights the need for more to be done to meet the requirements of the Standard. Of trusts who provided feedback to the CQC on how they’re responding to the introduction of the Standard, the majority stated that they either had or were in the process of procuring or upgrading electronic systems that will allow them to record and flag specific communication needs. This suggests that many trusts are currently not capable of meeting fundamental requirements of the Standard.

Whilst all these changes should go some way to improve the way compliance with equality law and national accessibility guidance and standards are monitored, more needs to be done to ensure poor performing services are identified and encouraged to improve. In particular, the findings from NHS England’s review and the CQC’s State of Care report suggests further monitoring is needed to ensure the Standard is properly implemented and enforced in England. The CQC should continue to monitor and enforce compliance with the Standard as part of their inspection work and NHS England should establish a national dataset or reporting mechanism for the Standard that can be applied consistently across different areas, with the results being published.

National patient and service users’ surveys, such as the *GP Patient Survey,[[58]](#footnote-58)* also provide a good opportunity to ask people with hearing loss about their experiences when accessing health and social care services. As well as requiring only simple amendments to an existing tool, this would enable an annual overview of how services are performing, and allow for comparison between areas and service providers.

**Recommendations**

In order to meet the aims of national accessibility guidance and quality standards, more must be done to monitor service performance and gather feedback from people with hearing loss. Monitoring should be occurring at multiple levels simultaneously:

* Providers of health and social care services must meet their commitments under national legislation to gather feedback from people with hearing loss on the provision of communication support and accessible information. They should also meet their organisational duty to have an accessible complaints process should patients want to feedback their experiences;
* Commissioners must do more to monitor performance in their area. A consistent approach to evaluating performance against the standard is required if compliance is to be effectively monitored and regional variations reduced;
* National bodies must do more to encourage standardised reporting and encourage compliance with national guidance.

*For a full list of recommendations, please see* [*appendix 1.*](#Fullrecommendations)

1. **Appendix**

**Appendix 1: Recommendations (full list)**

**Governments, commissioners and NHS organisations across the UK should:**

* Enforce the Equality Act (and the Disability Discrimination Act in Northern Ireland) to make sure people with hearing loss are protected from discrimination and to ensure health and social care services make reasonable adjustments;
* Raise awareness of equalities legislation amongst health and social care providers and the public;
* Make sure mandatory standards for accessible communication and information are in place and properly enforced. Performance against standards should be routinely monitored, including through inspections, and results should be published;
  + In England, NHS England should provide funding, resources and training to help services meet the requirements of the Standard. They should also work with commissioners, providers and IT suppliers to remove barriers preventing effecting sharing of information between services. NHS England should commit to working with a range of stakeholders in an accessible way to carry out a full, robust review of the Standard, and should work with bodies such as the Care Quality Commission (CQC) and Healthwatch England to enforce regulations;
  + In Wales, Local Health Boards (LHBs) should set out and enforce a timetable for implementation to make sure the requirements of theStandards are met, and a legally binding status should be sought for the Standards. Plans to roll out the necessary technology to equip GP surgeries with the tools to adequately record the communication needs of patients with sensory loss should be completed at the earliest possible opportunity;
  + In Scotland, the *Health and Social Care Standards* and the *British Sign Language (Scotland) Act* should be enshrined in law and enforced appropriately. More needs to be done to ensure the publication of outstanding local BSL plans and progress towards the national BSL plan;
  + In Northern Ireland, an Accessible Information Standard should be introduced, with legally binding status, as in England;
* Sources of health information available to the public, such as the NHS website, NHS Direct and NHS Inform, should be accessible to people who use BSL;
* Establish a national dataset or reporting mechanism for the Standard that can be applied consistently across different areas to monitor the performance of services against the Standard and publish the results annually. There should be a process in place to intervene if poor-performing services do not improve;
* Continue to provide funding, resources and training to make sure services meet the requirements of the Standard;
* Proactively gather feedback from patients and service users on the provision of communication support and accessible information.

## Health and social care regulators should:

* Ensure the issues facing people with hearing loss, when accessing health and social care services, are taken into account during inspections;
  + In England, the Care Quality Commission (CQC) should meet the commitments set out in their Equality Objectives for 2017–19 to: ensure CQC staff have good knowledge of the communication and information needs of people with hearing loss;
* Provide accessible contact options to help people with hearing loss give feedback on the quality of care;
* Take action to help poor-performing services improve.

**Providers of health and social care services should:**

* Make sure the communication needs of people with hearing loss are identified, recorded and met, in line with national accessibility guidance and standards;
* Provide a range of contact methods such as SMS, email, online booking and Next Generation Text (NGT) for people with hearing loss who find it difficult or impossible to use the telephone;
* Provide deaf awareness training for staff and make sure waiting rooms and communal area are accessible for people with hearing loss. For example, hearing loop systems should be available for people who use hearing aids;
* Ensure communication professionals, such as qualified BSL interpreters, are available for everyone who needs one, in line requirements set out in national accessibility guidance and standards;
* Provide information in accessible formats to make sure people with hearing loss, including people who use BSL, understand information on health, social services and social care. This includes health promotion campaigns;
* Ensure people with hearing loss can give feedback or make a complaint about the quality of care in an accessible way;
* Ensure self-referral processes and methods of assessment are accessible and appropriate for people who use British Sign Language (e.g. in mental health settings);
* Take into consideration the preference of service users with hearing loss and trying to accommodate this wherever possible (e.g. by providing a therapist fluent in British Sign Language, rather than an interpreter, in mental health settings).

## Action on Hearing Loss will:

* Work with health and social care services to remove barriers to communication faced by people with hearing loss;
* Support the Patient Experience team at NHS England to review the implementation of the Standard, providing advice and suggesting improvements as members of the ongoing Accessible Information Advisory Group;
* Continue to work closely with other charities to ensure CQC inspection frameworks take account of the communication and information needs of people with hearing loss;
* Continue to raise awareness of people’s rights under the Standard to ensure people with hearing loss know what to expect when accessing health and social care services and know how to complain if their needs are not met;
* Provide resources to help people with hearing loss give feedback or make a complaint about the quality of care.

**Appendix 2: Communication tips (taken from the** [**Guidance for Supporting Older People with Hearing Loss in Care Settings**](https://www.actiononhearingloss.org.uk/how-we-help/health-and-social-care-professionals/guidance-for-supporting-older-people-with-hearing-loss-in-care-settings/) **page of our website)**

**Communicating well with residents who have hearing loss**

Follow these simple tips to improve communication with residents who are deaf or have hearing loss. Remember, even if someone is using hearing aids, it doesn’t mean they can hear you perfectly.

* Start by asking the resident if they need to lipread.
* Make sure you have face-to-face contact, so the resident can easily see your lip movements.
* Get the resident’s attention before you start speaking, by gently tapping them on the arm.
* Find a place to talk that has good lighting, away from noise and distractions (where possible).
* Speak clearly, not too slowly, and use normal lip movements, facial expressions and gestures.
* Get to the point: use plain language and don’t waffle.
* Keep your voice down: it’s uncomfortable for a hearing aid user if you shout, and it looks aggressive.
* Make sure what you’re saying is being understood.
* If the resident doesn’t understand what you’ve said, don’t keep repeating it – try saying it in a different way instead.
* Use assistive equipment – for example, a conversation listener – if available.
* Be patient and take time to communicate properly.
* Writing may help if you are having difficulty communicating – avoid capital letters and use a thick pen if a resident has sight problems.

It’s particularly important to use the above tips if a resident has or may have dementia. Hearing loss can make dementia worse, particularly if one or both of the conditions are undiagnosed.

1. Please note that, like many policy documents, this statement reflects the issues relevant at the time of writing. Over time, this may be subject to change, such as new legislation being introduced, and we may review and amend the document. [↑](#footnote-ref-1)
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