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Introduction

575,500 people are deaf or have hearing loss in Wales - that's equivalent to the populations of Cardiff and Swansea combined.

In 2013, the Welsh Government launched the **All Wales Standards for Accessible Communication and Information for People with Sensory Loss (The Standards)**, clearly laying out how NHS services would be delivered in an accessible way to people who are deaf or have hearing loss, blind, partially sighted or have dual sensory loss.

The then Health Minister, Mark Drakeford, said, "These standards – once fully implemented – will help to address the barriers that people with sensory loss face in accessing health services, particularly in helping staff to identify patients with sensory loss and meeting their needs."

In 2014, we spoke to more than 100 people in Wales who had a sensory loss, to find out the impact of The Standards, one year on. The picture painted was a grim one: people with sensory loss were still facing needless barriers when accessing health services, and still leaving hospital unsure of the meaning of the advice they'd been given.

Since then, we've undoubtedly seen some progress. Health Boards are spending time looking at their services for people with sensory loss and, in late 2017, the Sensory Loss Information Standard was introduced, meaning that all GP surgeries in Wales now have the technology to record the communication needs of patients with sensory loss – and their requirements.

However, it's now over four years since The Standards were introduced. And we've discovered there's a long way to go before patients get the increased accessibility they were promised.

of people still leave their GP surgery unclear about their diagnosis or how to take their medication.

38%

said doctors or nurses didn't speak clearly or spoke too quickly.

28%

said the appointment wasn't long enough to communicate properly.

52%

said doctors or nurses didn't check that they had been understood regarding diagnosis or medication.

SUMMM

29%

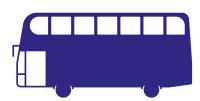
of people surveyed said that they have to ask a family member, friend or support worker to call their GP surgery on their behalf.

of Deaf British Sign
Language (BSL) users
said communication
at their appointment wasn't adequate
because they didn't have an interpreter.



Just 2% had been asked if they need support to understand written health information.

Only 4% of survey respondents said that their GP had asked them if they need support to contact them and understand what is said in their appointment.



36% of survey respondents have to travel to their GP surgery to book an appointment in person, as they can't use the phone.

46% said they had to rely on written notes.



What are the All Wales Standards for Accessible Communication and Information for People with Sensory Loss (The Standards)?

To meet the requirements of The Standards, NHS providers in Wales must:

- Ask patients how they prefer to communicate and record it on their health record.
- 2. Flag needs for support on patient records, to make sure they're highly visible, and prompt staff to meet those needs, such as speaking clearly to help people lipread or booking a BSL (British Sign Language) interpreter.
- 3. Make sure buildings are accessible for people with sensory loss; including clear signage and good lighting.
- **4.** Share a person's needs if they're discharged or referred elsewhere. Patients should not experience unreasonable delays due to their communication needs.
- 5. Give patients a choice of ways to make an appointment, including email, textphone or online.
- **6.** Train all staff in sensory loss awareness and how to communicate.
- 7. Install hearing loops in public rooms and train staff how to use and maintain them.

- **8.** Ensure people with sensory loss don't miss appointments: for example, a member of the reception team could ensure a person with sensory loss is collected and guided to their appointment.
- 9. Provide communication support to people with sensory loss who may be attending an appointment as a carer, or as the parent of a child.
- Recognise any other language need that a patient with sensory loss may have - for example, the Welsh language or minority languages.
- 11. Ask patients the best way to send them any written information for example, Braille or large print.
- **12.** Promote the different forms of communication available and encourage patients with sensory loss to use them.
- 13. Ensure that patients with sensory loss leave the healthcare setting having heard and understood everything they need to know about their healthcare.
- **14.** Seek advice and guidance from organisations that represent people with sensory loss.
- **15.** Emergency care staff should use specifically designed resources (such as the Pre-Hospital Communication Guide) to help communicate with people with sensory loss.

Methodology

Between September and October 2017, we surveyed people who are deaf or have hearing loss in Wales, to find out whether GP surgeries are meeting the requirements of The Standards. The survey was available online in English and BSL video, and we also posted letters and handed out paper copies of the survey. We received 384 responses to the survey in Wales.

To find out more about the survey results for England, Northern Ireland and Scotland, visit actiononhearingloss.org.uk/goodpractice

Contacting GP surgeries

Findings

Despite the requirements of The Standards, our findings suggest that people who are deaf or have hearing loss are still being forced to use the phone, go to their GP surgery in person or rely on other people to book appointments on their behalf:

- More than a third (36%) of survey respondents visit their GP surgery in person to book appointments, but only 17% said they prefer to book appointments in this way.
- More than a quarter (29%) said that they ask a family member, friend or support worker to call their GP surgery on their behalf. But a much smaller proportion, 18%, said they wanted other people to book GP appointments for them.
- Around a quarter (22%) of survey respondents said they experienced difficulties booking urgent same-day appointments or getting urgent medical advice when their GP surgery was closed.

When asked why they experienced difficulties:

- More than half (56%) said that this was because urgent same-day appointments can only be booked by phone.
- 15% of survey respondents also said they had experienced difficulties because they were offered a same-day phone consultation by their GP surgery.

Why accessibility matters...

Some people who are deaf or have hearing loss may struggle to follow conversations over the phone, which can lead to confusion over appointment times. Others who cannot use the phone at all may have to visit their GP surgery in person to book appointments or rely on other people to book appointments on their behalf, which may lead to reduced personal independence and privacy.

In recent years, many GP surgeries have also introduced remote consultations (either over the phone or online) to help them manage their workloads.



I've had a lot of problems trying to arrange BSL interpreters for my appointments. It's meant delays in getting to see my GP; sometimes I have to wait up to four weeks.

They also won't let me text or email to make appointments. I have to ask a friend or family member to phone for me, which sometimes means further delays.

Heather, Cardiff

Whilst these new types of consultation may be more convenient for some patients, phone consultations in particular may be inaccessible for many people who are deaf or have hearing loss. Without an accessible alternative to the phone, people who are deaf or have hearing loss may be forced to visit their GP surgery or other NHS services in person to get medical advice or clarify information about their treatment and care. This increases the demand for already stretched services – and costs the NHS money.

Recommendations for GP surgeries

- GP surgeries should offer a range of different contact methods for people who are deaf or have hearing loss, such as email, text/SMS message, textphone, Next Generation Text (NGT) Service and remote BSL video-interpreting services.
- Online access can also be a simple and accessible way for many people who are deaf or have hearing loss to contact their GP surgery, book appointments, order repeat prescriptions or receive test results. Many GP surgeries already offer online access for their patients and, given the accessibility benefits, they should consider promoting these services directly to people who are deaf or have hearing loss.
- GP surgeries should also ensure online services are accessible for people who are deaf. As a minimum, online information should be written in plain English. To ensure online services are accessible for everyone, GP surgeries should also consider producing BSL videos of key documents and other important information, such as complaints policies.

Visiting GP surgeries

Findings

Under The Standards, GP surgeries must ask people who are deaf or have hearing loss what support they need to communicate well and understand the information they're being given. The Standards say that this question should be asked when people who are deaf register with a GP surgery as an NHS patient or, opportunistically, when they next contact or visit their GP surgery.



I slipped and damaged my back, spending a night in hospital as an emergency. Staff realised I was deaf but there were no facilities to help.

After discharge, I was told I had broken my back and was referred to a specialist clinic in another hospital in another town. To book an appointment, I had to call a phone number. Despite me telling them I'm hard of hearing, they insisted that I either call or visit in person. I'm 81-years-old and I ended up taking a number of buses across town, with a severe back injury, just to book the appointment to begin my treatment including physiotherapy.

Kay, South West Wales

But our survey found:

- Only 4% of respondents said their GP surgery had asked them if they need support to contact GP services and understand what is said in appointments.
- Similarly, only 2% had been asked if they need support to understand written health information.

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

• Worryingly, two-fifths (42%) of survey respondents said that staff at their GP surgery are still calling their name out.

Hearing loop systems, which make speech clearer by reducing background noise, can also help people who use hearing aids hear more clearly in waiting areas.

- But 19% of survey respondents said a hearing loop system isn't available at their GP surgery and two-thirds (66%) didn't know if one is available.
- More than half (52%) of survey respondents said that their GP surgery has a visual display screen for appointments.
 But visual display screens should not be seen as a one-size-fits-all solution to improving accessibility, as they might not be accessible for everyone, especially if people have other needs, such as sight loss.



My GP has a touchscreen to check-in for my appointment and a display screen to let me know that it's my turn to be seen. This is better than trying to hear what's going on in a noisy reception area.

Roger, Llandrindod Wells

Only 4% said their GP surgery had asked them if they need support to contact GP services and understand what's being said

Why accessibility matters...

Poor communication in waiting areas causes considerable stress and anxiety for people who are deaf or have hearing loss and may put people off visiting GP surgeries altogether - forcing them to delay seeking help until their health gets worse and they can't wait any longer.

Recommendations for GP surgeries

- Have a clear, standardised approach for asking people
 who are deaf or have hearing loss what support they need
 to communicate well and understand information and for
 recording this information on patient records.
- GP staff should have deaf awareness training in worktime so that they can communicate properly. Poor deaf awareness in waiting areas causes considerable stress and anxiety for people who are deaf or have hearing loss.
- Ask people who are deaf or have hearing loss how they'd like to be notified when it's their turn to be seen by the doctor or nurse.
- Make hearing loops available on reception desks for everyone who needs them, and check them regularly to ensure they're working.
- Download our communication card to help people who are deaf or have hearing loss explain what support they need.
 To find out more, please visit <u>actiononhearingloss.org.uk/ontherecord</u>

Consultations

Findings

Worryingly, more than four years on since the introduction of The Standards, more than half (54%) of survey respondents said they're sometimes unclear about the information they're given at GP appointments.



A few years ago, my son was really ill and I had to text an ambulance in the middle of the night. When the paramedics came, they rushed him to hospital but no one could tell me what was happening.

My daughter was trying to interpret but she didn't understand the medical terms. I was so worried and upset. As a mother, I should have been the first person they informed, but I was the last. It wasn't until 4pm the next day that a BSL interpreter arrived to tell me my son had a burst ulcer and was going to be OK.

Fosia, Cardiff

When asked why, a high proportion of survey respondents with hearing loss identified the attitudes and behaviours of doctors or nurses as a particular problem:

- More than half (52%) said doctors or nurses did not check they had understood what had been said.
- More than a third (38%) said doctors or nurses did not speak clearly or spoke too quickly.
- More than a quarter (28%) said the appointment was not long enough to communicate properly.
- Almost half of Deaf BSL users (42%) said that this was because an interpreter was unavailable for their appointment.
 Another half (46%) said they had to rely on written notes.

Why accessibility matters...

- Poor communication at appointments may force people who are deaf or have hearing loss to go back to their GP surgery to clarify important information about their treatment and care; leaving without being clear about their medication may even be dangerous. The Ear Foundation estimates that, because of communication difficulties, people with hearing loss cost the NHS £76m in extra GP visits every year.
- Without access to a well-qualified communication professional, people who are deaf, in particular, are at risk of poor care and poor health. SignHealth estimates that missed diagnosis and poor treatment of people who are deaf costs the NHS £30m every year.

Recommendations for GP surgeries

- Doctors, nurses and other GP staff should follow simple communication tips such as speaking clearly, and avoid obstructing their lip movements (this is particularly beneficial for people who lipread).
- GP surgeries should also make sure that people who are deaf or have hearing loss have enough time to communicate in appointments; they should extend appointment times if necessary.

Missed diagnosis and poor treatment of people who are deaf costs the NHS £30m every year

- An appropriately qualified communication professional, such as a BSL interpreter, should be provided for everyone who needs one.
- Hearing loop systems should also be available in consultation areas for everyone who needs them, and should be checked regularly to ensure they're working.

Monitoring performance

The results from our survey suggest there is still some way to go before the benefits of accessible communication and information are fully realised for people who are deaf or have hearing loss. GP surgeries, the NHS in Wales and local health boards should work together to ensure services continue to improve – and that the requirements of The Standards are properly implemented and enforced.

GP surgeries should:

- Ensure all staff are trained in and regularly use the recently installed technology to meet the Sensory Loss Information Standard.
- Gather feedback from people who are deaf or have hearing loss on the provision of communication support and accessible information.
- Ensure people who are deaf or have hearing loss can give feedback or make a complaint about the quality of care in an accessible way.

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NHS Wales and local health boards should:

- Monitor the performance of GP surgeries against The Standards, publish the results annually and intervene if poor-performing GP surgeries do not improve.
- Provide funding, resources and training for GP surgeries to help them meet the requirements of The Standards.
- Take action to help poor-performing services improve.

Find out more...

GPs

If you work at a GP surgery and want to know what you can do to improve the accessibility of your services for people who are deaf or have hearing loss, take a look at Supporting People with Sensory Loss: Best-practice guide for GP surgeries, which we co-produced with RNIB Cymru.

We've also developed a toolkit for reception staff, containing top tips on the best ways to communicate with people who are deaf, have hearing loss or sight loss, or are deafblind.

To find out more, please visit: actiononhearingloss.org.uk/sensorywales

Access Solutions

If you work at a GP surgery or other NHS services, our Access Solutions team can offer a range of support and advice to help you meet the requirements of The Standards – and make your service more accessible for people who are deaf or have hearing loss.

To book an appointment with one of our consultants, to discuss our training courses or to find out more about the services we provide, call us and quote AIS:

Telephone: **0333 240 5658** Textphone: **0333 014 4530**

Email: access.solutions@hearingloss.org.uk Website: actiononhearingloss.org.uk/business

We've listed links to the services we provide below, but please do get in touch with us, as we can advise you on the most appropriate forms of support to meet your needs.

Deaf awareness training

actiononhearingloss.org.uk/training

E-learning packages

actiononhearingloss.org.uk/elearning

Hearing loop installation and maintenance

actiononhearingloss.org.uk/installation

Communication support

actiononhearingloss.org.uk/communication

Action on Hearing Loss (formerly RNID) is the largest UK charity helping people who are confronting deafness, tinnitus and hearing loss.

We give support and care, develop technology and treatments, and campaign for equality.

We rely on donations to continue our vital work.

To find out more, visit actiononhearingloss.org.uk

Contact our free, confidential Information Line:

Telephone 0808 808 0123

Textphone 0808 808 9000 SMS 0780 000 0360

(standard text message rates apply)

Email information@hearingloss.org.uk

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