

**The Delivery of the Accessible
Information Standard in South West
London GP Practices**

Contents

Contents.....	2
About the Accessible Information Standard	3
Why did we do this?	5
What We Did?	6
Key Findings.....	7
Recommendations.....	11
Who we spoke to	16
What we found out: Key themes (Patients and carers).....	22
What we found out: Key themes (GP staff)	59
About the authors.....	78

About the Accessible Information Standard



The Standard sets out how Health and Care services must meet the communication and information needs of people with certain disabilities. In relevant cases, it also covers carers and parents with disability, who support a person who may or may not be disabled.



Some examples of conditions covered under the Standard:

1) Sensory loss (for example, vision or hearing)



2) Certain neurological conditions (for example Parkinson's disease)



3) People who are neurodiverse and/or have a learning disability (for example autism)



About the Accessible Information Standard

Standard



The 5 steps:

1) **Identify:** ask about communication needs



2) **Record:** store the identified communication needs



3) **Flag:** highlight communication needs in the general system where they have been recorded



4) **Share:** provide a way for communication needs to be shared with other services



5) **Meet:** provide information in a format that people with communication needs can receive



Why did we do this?

The South West London Healthwatch collaborative worked on this with people covered by the Standard. We also worked with local charities.



The aims of the project were:

- To **listen** to people with communication needs and their carers to see how well GP practices meet their needs.
- To **understand** what helps or stops GP practices from using the Standard in their services.
- To **support** discussions between GP staff, people with communication needs and carers, and find ways to improve.



What We Did?

Patients and carers: We shared surveys with people who have communication needs and carers of people with communication needs.



We had 10 combined focus groups and interviews for patients and carers, held online and in person.



GP service staff: We shared surveys among GP practice managers, clinicians, and other staff.



We joined their regular meetings to learn about the challenges and things that help with using the Accessible Information Standard.



Key Findings

We received:

- 144 combined responses were collected through surveys, focus groups, and interviews with patients and carers.
- 82 responses from GP staff were collected through surveys and small focus groups to learn about their experience with the Accessible Information Standard (AIS).



People with communication needs:

- 73% of people with communication needs shared that they did not know what the AIS is.
- People mostly had a good experience sharing their communication needs, but many said they had to repeat them often.
- People shared that their GP services provided a wide range of communication tools, such as easy read formats and Plain English documents.



- Across different communication needs, people said they often depend on family or community organisations to help them talk to GP services. Without this help, they might lose contact with GPs and miss out on proper care.



- People with communication needs shared the importance of having information shared in an accessible way to maintain independence and communicate directly with GP staff.



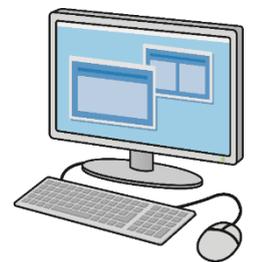
Carers of people with communication needs:

- Carers of people with communication needs said it's important for GP services to understand their role in speaking up for the person they care for. This should be considered alongside a patient's ability to be independent.
- Carers said that seeing the same GP staff helps avoid repeating communication needs. This saves time during appointments and allows more focus on health issues.



GP staff and the Accessible Information standard:

- Most GP staff had some level of awareness of the AIS.
- GP staff had some training in the AIS but some staff shared that it would help to have experts, resources, and support to use the right communication tools.
- GP practices recorded communication needs in different ways. Some staff said the system for flagging these needs can be overwhelming, as a lot of different flags can appear on a patient's record. These often get missed because of workflows and limited time in appointments.
- GP staff shared that it is important to monitor how well a practice is changing to help people with communication needs and to provide a continual feedback system between patients and practices.



Across all three groups, the importance of training, longer appointments, and not assuming the communication needs of people was a consistent theme.

A note about terminology

We use the word 'carer' throughout this report to mean the parent or carer of someone living with a disability that makes communication difficult.

While some of the carers we spoke with also had a relevant disability, in most cases the carers that we spoke with were not covered under the Accessible Information Standard.

Recommendations

For Healthwatch, voluntary sector, South West London Integrated Care Board (ICB), and GP Practices

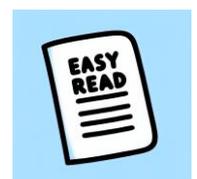
Awareness

Awareness about the Accessible Information Standard among patients, carers, and GP staff is low. Healthwatch, the voluntary sector, ICB, and GP practices could **support communication campaigns to inform people of their rights** and enable GP practices to communicate more effectively with patients and carers (see Page 25 for patient/carer findings. See page 64 for GP staff findings).



For the South West London Integrated Care Board

1. GP practices shared that they have limited knowledge and time to create accessible communication for people with disabilities, such as easy read materials. GP practice staff request that the ICB send information that is standard, across all patients. This includes general and public health information (for example, vaccine availability) in easy read, BSL, and other accessible versions, for sharing on waiting room screens, posters, and websites (see page 74 to 76 for findings).



2. As of 1 October 2024 (after this research was conducted), there is a new provider for **BSL interpretation in SWL GP practices**. It is important that this **service be evaluated** against measures that matter to people who use BSL (see page 27 & 43 for experiences of BSL interpretation).
3. GP practice staff shared concerns that too many ‘flags’ in EMIS (the nationally-provided patient record system), and receptionist workflow within EMIS, cause patient communication needs to be missed. In December 2024 (after this research was conducted), South West London ICB rolled out a new reasonable adjustments flagging system that may, alongside practice cultural shifts, improve practice staff’s recognition of people’s communication needs. The impact of this new system on people having their communication needs met should continue to be evaluated (see page 65 to 66 findings).



For GP practices

1. Disability equality **training** and Accessible Information Standard training are available. It is helpful for staff to undertake these trainings **regularly** (see page 67 to 70 for findings).
2. While not everyone will need one, many people say they need extra time to understand information or to express themselves. It is important to nurture an environment where people know longer appointments are available



and can express their wishes for one (see page 40 and 43 for findings).

3. **Providing timely updates** about BSL interpreter booking is valuable. **Deaf and hard of hearing patients** said they often have to follow up to make sure BSL interpreters are booked for appointments, adding to the 'invisible extra work' many people with disabilities need to do to access care (see page 27 & 43 for experiences of BSL interpretation).



For further consideration

For the South West London Integrated Care Board

For GP practices

1. Practice staff should aim to make **patients as independent** as possible by meeting their stated communication needs and by speaking directly with the patient where possible. Some patients may require their **carer** to be present during their appointments, and a **careful balance** must be taken to ensure that both feel listened to and respected while ensuring that the focus remains on the patient (see page 44 & 52 to 57 for findings).



2. Practice staff should aim to **avoid using medical jargon** and provide documents in **Plain English**, as people who have disabilities that affect communication find **Plain English** easier to follow. **Easy read** documents can also be helpful, especially for people with learning disabilities (see page 43 to 45 for findings).



3. Some people with neurodiverse conditions may find it difficult to stay in the waiting room and/or in the clinical area for very long. It is important to work with patients and, where appropriate, their carers to develop a **personalised strategy before they come for an appointment** that can minimise discomfort and maximise the value of your time together (see page 41 to 42 for findings).



4. It is important to support patients in connecting with the **same GP practice staff** who are familiar with their needs. This includes reception as well as clinical staff (see page 36 to 39 for findings).



5. Consider having an **accessibility champion** associated with each practice, who is best trained in the Standard and its legal requirements and can support other staff in its delivery.



6. Consider how you can use data from your existing **feedback systems** to learn about and improve the experiences of people with communication needs.



Patients, carers, and AIS



Who we spoke to

Codes: Survey numbers,
Focus group and
interview numbers

We collected 144 responses from:

- Croydon (n=10)(n=7),
- Kingston (n=30) (n=8)
- Merton (n=9) (n=7)
- Richmond (n=18) (n=7)
- Sutton (n=19) (n=6)
- Wandsworth (n=9) (n=9)
- Unreported (n=3)



Survey responses:

- Total = 95 responses from:
- 54 carers of people with communication needs
- 41 people with communication needs



Communication needs:

- Hearing loss (n=6)
- Learning disability (n=26)
- Neurodiversity (n=43)
- Neurological condition (n=10)
- Sight loss (n=6)
- Other condition that affects communication (n=4)



Focus Group and interview responses*:

- 10 Focus groups
- 15 carers of people with communication needs
- 29 people with communication needs
- *3 additional people did not report their patient or carer status



(Additional demographics can be found in Annex 1)

The following organisations worked with us to hold a focus group:

- Express CIC (Supports people and their carers with autism)
- Integrated Neurological Services (Neurological conditions)
- SignHealth (Deaf and hard of hearing)
- Merton Vision (Blind or visually impaired)
- The Baked Bean Charity (Learning disabilities)
- Nickel Support Group (Learning disabilities)
- Advocacy for ALL (Learning disabilities and autism)
- DeafPLUS (Deaf and hard of hearing)
- Rethink (Learning and sensory disabilities)
- Remark! (Deaf and hard of hearing)



Patient Story

This story shares the experience of a woman with a neurological condition, how she communicates with GP services, and how her family's support helps her get the care she needs.



Living with a Neurological Condition



“ You're trying to tell them, please make these adjustments, note it in the system, but it sounds like they're not actually taking that on board.

[At] certain [times] there's over-communication, so I get quite confused. So I tend to get loads of text messages. I don't know whether it's for the same thing.

And so, for me to read this sentence, I need somebody else to explain it, because by the time I've got to the end of the sentence, I've forgotten the beginning.

There have been times where I have tried to give feedback, but then if you see you're not being listened to, you just shut down and then maybe ignore the next few appointments, because you don't know what's the use.

[But] actually, when I see the GP, they're very empathetic. I do sometimes get locums, sometimes I get a regular GP. When I call, I do



ask for the regular GP, only because she knows me, she knows my background.

And then around the sensory side of things When it's on a screen, I can't stare at a screen for too long...It's like everything moves all the time. So I need a lot of concentration, which then takes my energy, and I'll probably get fatigued.

So that doesn't help, but I never got told, what format would you like? It's just on the system, so you just get told. And also I find when I do call up reception, I do ask them, "can you please speak slower?"

Because [there are] times where I can't see their lips, I can't see their mouth, I can't see it. It's just on the phone. It's a bit more difficult.

And my hearing either goes super high, so I'm super sensitive, or really low. So the thing is, I'm being proactive by asking them, saying, "can you please speak slower?" And sometimes I've just had to ask them, "can you please repeat, can you please repeat?"

I think their reception staff has changed, compared to before."

Interviewer: "How different do you think your experience would have been with your GP if you didn't have your family around to help?"

“I wouldn't be in contact with them. I'd probably be at home. I might even be dead.”

What we found out: Key themes (Patients and carers)

We grouped the findings from our patient and carer surveys and focus groups into themes.

Theme 1: Knowledge of the Accessible Information Standard



Theme 2: Overall satisfaction with GP practices



Theme 3: Sharing communication needs with GP staff and your experience about whether GP practices remembered these needs



Theme 4: Providing accessibility tools



Theme 5: Communication for booking appointments



Theme 6: Importance of seeing the same GP staff



Theme 7: Waiting room and appointments



Theme 8: Referrals

Theme 9: Support for communication needs from family, friends, and charities

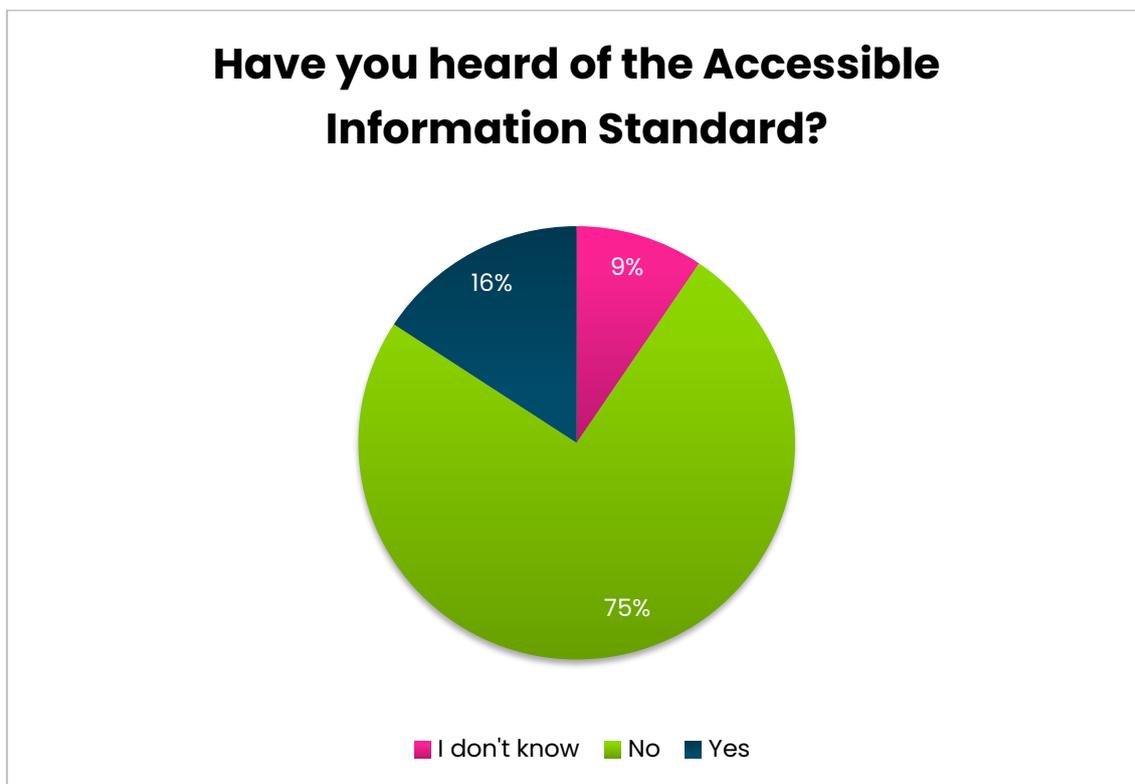


Links with Accessible Information Standard steps:

- Theme 2 links with the Accessible Information Standard steps 1 -3 ('identity,' 'record, and flag.')
- Theme 8 links to step 4 ('share').
- All other themes link to step 5 ('meet').

Theme 1: Knowledge of the Accessible Information Standard

Survey Responses



- 80 (84%) people said that they either had not heard of or were unsure if they had heard of the Accessible Information Standard.
- Of those who had heard of the Standard (n=15), only 1 person reported knowing 'a lot' about it.



Theme 2: Overall satisfaction with GP practices



- 76 (80%) people were generally satisfied (responded 'okay' or better) with how practices met communication needs. 29 (31%) people felt that practices did an 'excellent' or 'good' job.
- Neurodiverse people and their carers were less likely to be satisfied (67% versus 83% or more for all other disabilities).



Focus Group Responses

Patient experience

Across different communication needs, people shared mixed responses towards sharing their communication needs with GP staff. Some felt that GP staff, especially doctors, were helpful and took their needs seriously, while others felt their needs were not taken into consideration.



Deaf or hearing impaired:

One deaf person said that her BSL interpretation needs weren't met. This made her anxious and uncertain about whether her health needs were understood.

"I think it's the whole human interaction, it's nerve-wracking, you feel nervous. Have I said the right thing? Do they understand where I'm coming from?" Deaf person



Neurodiversity and/or Learning Disability:

"Well, they think they understand, but technically they don't. They say they do, but they're only just saying that. So, you can get seen quicker." Person with a learning disability



Neurological condition:

“He [doctor] ticks it off on my diary for me, he writes notes for me. If there's a prescription he'll give me the prescription in paper to take with me to the pharmacy.” Person with a neurological condition



Carer experiences

Some people said it's important for GP practices to recognise that carers help speak up for the communication needs of those they care for. They felt that sometimes their role is met with pushback, and staff expect patients to share their needs without extra help. Some people said that some staff didn't know about patients' communication needs, which affected their care.



Neurodiversity and/or Learning Disability:

- “It's the idea that you will identify something's wrong, be assertive, initiate contact, be assertive again...if you are reasonably able, you know, you're going to have to argue your head off to get that appointment. Yeah, my kid wouldn't pick up the phone.” Parent of a person with autism



“And with our son at the moment, he's got quite a complex problem. It almost seems like you're being talked down to sometimes.” Parent of a person with a learning disability

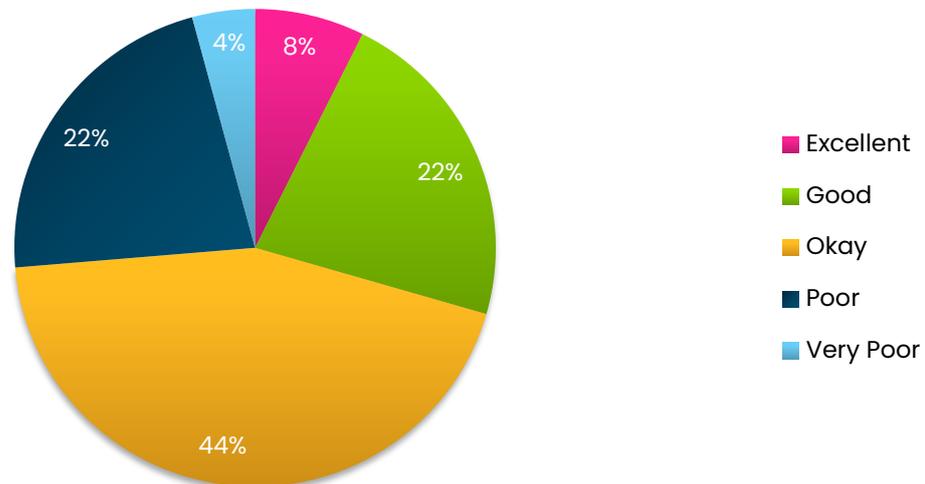


“So there's a lack of kind of looking at notes and listening to the patient, and then a lack of kind of recognising if there are just communication differences, you know.” Parent of a person with a learning disability



Theme 3: Sharing your communication needs with GP staff and your experience about whether GP practices remembered these needs

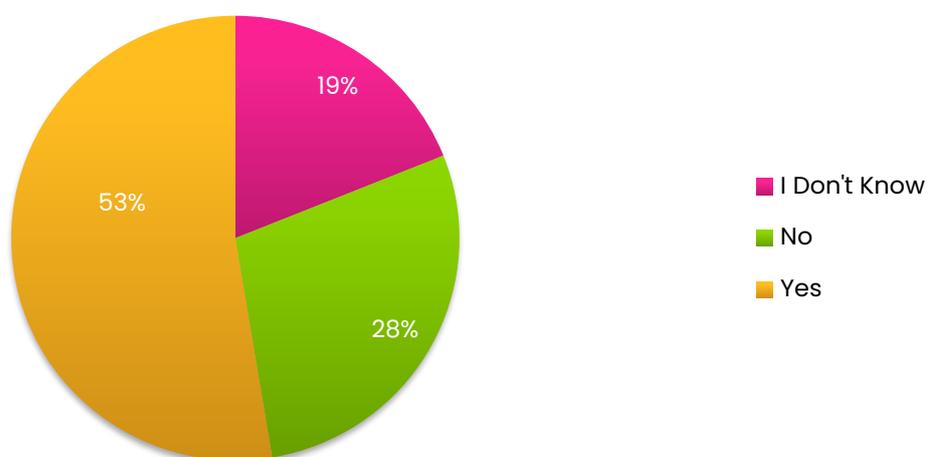
What is your experience of sharing your communication needs?



- 70 (74%) people with communication needs and carers of people with communication needs indicated that they have had satisfactory experiences sharing the patient's communication needs with GP staff.



Do you have to regularly repeat these communication needs?



- Over half (53%) of the people who responded said they had to repeat their communication needs often. 27 (28%) people responded that they do not need to regularly repeat communication needs to the GP practice.



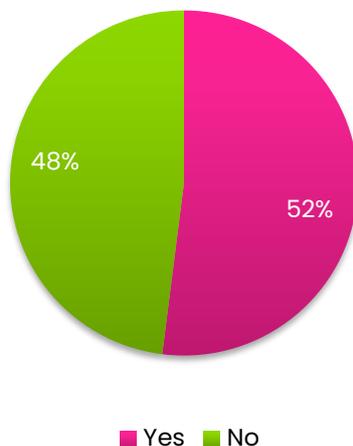
Survey Responses

- 8 people (8%) recalled being asked to complete an AIS questionnaire at their GP practice.
- 21 (22%) people felt confident that their GP practice had recorded patient's communication needs.



Theme 4: Providing accessibility tools

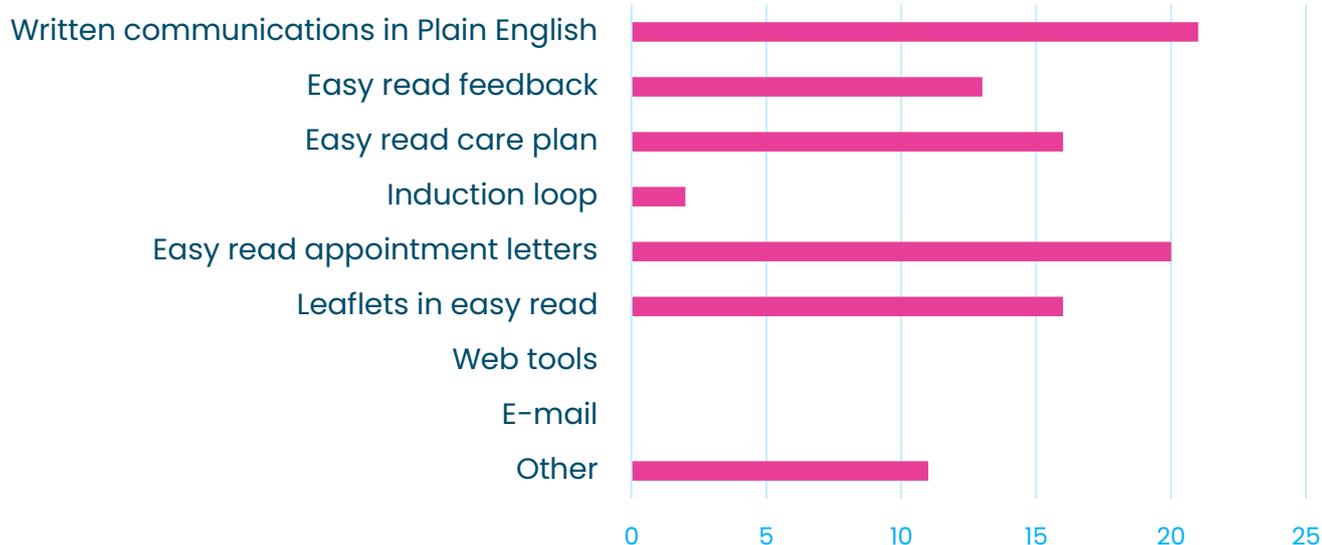
Does the GP practice provide at least one method of accessible information?



- Of the 94 people who answered the questions about whether, and how, GP practices used accessible methods to communicate with patients, 49 (52%) people shared that the GPs used at least one method, with examples shown in the bar graph below:



What accessible formats do GP practices use?



Theme 5: Communication for booking appointments

Focus Group Responses

Patient experience

Across the different groups we spoke to, people said they preferred booking appointments in person. People also shared about what communication was like between appointments.



Blind or visually impaired:

- "I'll tell you what, it's a very complicated system, when you phone they say phone again tomorrow." Blind person

"I would prefer they phone me up more." Blind person



Deaf or hearing impaired:

- "Yeah we did try in the past, texting, but they didn't respond. I tried emailing and they didn't respond... I don't know if they didn't get the email or if they ignored it so I just tend to just go in and as I said they're quite good." Deaf person



“I do receive a call...luckily my phone transfers it to a message, so I use that, but it's me phoning them, it's difficult, I have to use text to talk, sometimes people hang up when I use Text Talks.” Deaf person

“My doctors do provide interpreters, no problem, but realistically, one of the biggest issues is saying “I have an issue, I want a booking” [they'll say] “no, you have to wait two weeks”, and that's not right. Say in those two weeks I deteriorate, things get worse, if it's an urgent issue, I should be able to get care and access it as quick as possible, there shouldn't be a delay.” Deaf person



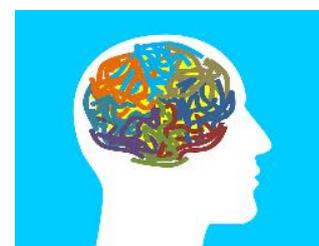
Neurodiversity and or Learning Disability:

- “I prefer to book in the place and my key worker always calls in.” Person with a learning disability



Neurological condition:

- “I went into the surgery, she said there's no appointment for him this month... so I came home, and I thought, well, I'll try the app, I did it on the app, the next day they phoned up and said you can have an appointment tomorrow.” Person with neurological condition



Carer experiences

Some carers preferred to go in person to book appointments on behalf of the patient, while others preferred to call the GP. Some carers shared that it can be hard for the person they care for to book appointments alone because the system doesn't always support their communication needs.



Neurodiversity and or Learning Disability:

- “Without us doing it, my daughter [is] on her own.
How are they making it accessible for my daughter?”
Parent of a person with a learning disability



Theme 6: Importance of seeing the same GP staff

Focus Group Responses

Across both patient and carer experiences people shared that seeing the same GP staff meant that less time was spent in appointments explaining communication needs and more time was spent investigating the health needs that the appointment was booked for. This made the medical process easier for people.



Patient experience

People generally shared a more positive experience when they saw the same GP staff who knew their communication needs and made the necessary adjustments. For example, people felt that their doctors were more caring towards their communication needs when they saw the same doctors.



Deaf or hearing impaired:

- “It's always the same receptionist as well so they don't seem to have much of a change around so again they've got that familiarity with me.” Deaf person



- “I always have new faces [and] I have to explain.”

Deaf person

Neurodiversity and or Learning Disability:

- “Seeing the same GP is important to me, because I get the extra help.” Person with a learning disability



Neurological condition:

- “When I call, I do ask for the regular GP, only because she knows me, she knows my background.” Person with a neurological condition
- “I tend to go to the doctor who knows me but I have also had to be with locums and in the practice that I go to they have been absolutely amazing but with a locum they don't know my background so they don't know that I am forgetful, obviously they can't you know read through everybody's timelines before they see a patient and you wouldn't necessarily know that I had that problem because I am very verbal so that in itself can lead to a problem” Person with a neurological condition



Carer experiences

Carers talked about the importance of seeing the same doctors regularly. This helps them get better care and means they don't have to keep explaining the needs of the person they're caring for. Carers shared that if they don't see the same doctor, that doctor might not know the patient's history or how they usually act during visits. Because of this, the doctor could miss important changes in the patient's health.



Blind or visually impaired:

- “We had one doctor and she was our doctor, now they have this system whoever is available we go see them. Admittedly I have all the information online, but they don't know us as our previous doctor knew all our history. So I think that's a negative aspect. They have to catch up with everything when the patient comes along.” -Spouse of a blind person



Neurodiversity and or Learning Disability:

- “Well, I think we do need to see the same doctor, if possible. Because then your young person is familiar with that doctor. There's that continuity of care.”. - Parent of a person with a learning disability



- “If you talk to a doctor, you get to know the doctor, and your child gets to know that doctor, so they open out more to that person, don't they?” -Parent of a person with a learning disability
- “You haven't got one person you're dealing with, you know, it's appalling. It makes it very difficult, and actually, you're repeating yourself.” Parent of a person with a learning disability



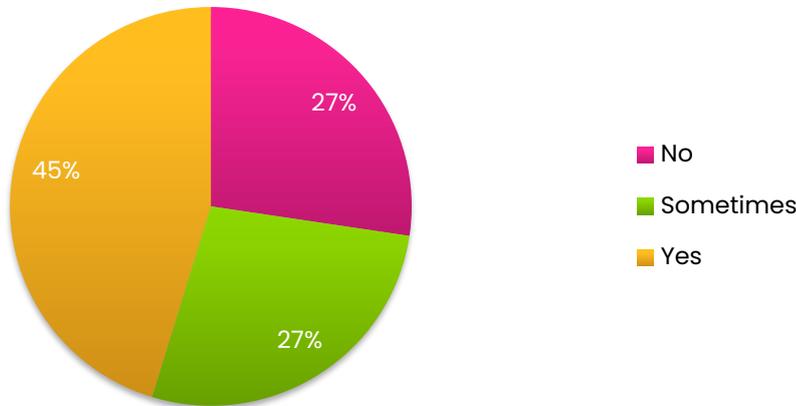
Theme 7: Waiting room and appointments

43 people (45%) said in the survey that appointment times were usually long enough. However, both patients and carers mentioned that having longer appointments would give them more time to understand the information shared by the doctors. The importance of seeing the same GP staff was shared in theme 3 and may affect how time is used in a GP appointment.



Survey Responses

Are GP appointments long enough?



Focus Group and survey open-ended responses

Across both patient and carer groups, people shared what they found helped or did not help with their communication when in the waiting room at a GP practice and when they were with a member of staff during an appointment.



What participants found helpful or unhelpful in the waiting room

- **Reception Staff attitudes:** "When I go there I think the receptionist is usually really nice they try their best I think to fit me in." -Deaf person



“There doesn't seem to be any recognition at reception that, like my son's on the learning disability register there should be some difference in terms of accommodating that.” Carer of a person with a learning disability



- **Announcements over an audio speaker:** “They all have it spoken as well as going up on the screen.” Spouse of a blind person



- **Announcements made on an electronic screen:** “When I see the screen and my name comes up on there and the room number, it's like, great!” Deaf person



- **Staff physically approaching patient when it's time for an appointment:** “Everyone [GP staff] just comes up to us and just says your name.” Person with a learning disability



What Participants found helpful or unhelpful during a GP appointment

- **Flexibility of GP staff:** “[I] ask my GP, “If you're looking at anything on the screen, can you angle it towards me so I can see it, so I can read it myself?” Deaf Person



- **Lack of BSL interpreters:** “The doctor and me write back and forth to each other. It's not good enough. I want to be able to have more access to language, more information there, because I'm not very good with English!” - Deaf participant



- **Extra time during appointments:** “She knows that I need a little bit more time to explain what's wrong sometimes, and she always gives me that time.” Person with a learning disability



- **Medical Jargon:** “They don't explain it [medical jargon] in a way that everybody understands.” Carer of a person with a learning disability



- **How fast or slow staff speak:** “Sometimes they can speak to me fast” – Participant with a learning disability



- **Dismissive approach of staff due to appointment time constraints:** “I don't know how long the time scale is with your GP and obviously I'm not saying that it should be long but you can[t] make a judgment in just a few minutes about the situation...so what does a parent do if you know like my daughter she has dyspraxia... they'll [say] but she'll grow out of it she'll grow out of it so it's you know it's kind of... I don't know you feel quite patronised by it.” Carer of a person with a learning disability



- **GP staff not speaking directly to patients:**

“When my support worker, takes me to my appointment, [and I] get to be seen, and they [GP staff] don't talk to me they to talk to my key worker, they [should] be talking to me.” Person with a learning disability



- “They don't listen, they speak to my carer. They sometimes get things wrong because of it.” – Person with a learning disability

- **Information that is presented in a non-simplified manner:** “She finds it difficult to read as well and form sentences and retain information so everything will have to be broken down but then I don't think professionals would do that.” Carer of a person with a learning disability



- **Flexibility of GP staff** “He [the doctor] ticks it off on my diary for me, he writes notes for me if there's a prescription he'll give me the prescription in paper to take with me to the pharmacy” Person with a neurological condition



- **Lack of flexibility and consideration for patient communication needs:** “My husband has Parkinson's and he has a difficulty actually walking and so the GP suggested well next time we can do a telephone consultation [but] because of Parkinson's his voice is very soft, very quiet. So that doesn't work out.” Carer of a person with neurological condition



Patient Story



While the Accessible Information Standard does not cover digital information (this is covered under a different law), we heard about people’s experiences with digital services since these are important for how some people book appointments and get information from their GP practices.

NHS App accessibility

Alex is registered blind and has no central vision. He has two young children. His mornings are very busy getting ready for work and daycare.

One morning, Alex’s son became ill. He tried to use the NHS App to make an appointment with the GP. He uses special tools to see the screen, which increases the amount of time he needs to successfully enter the information to book an appointment. He found that he kept losing his preferred times as other patients more quickly used the App, leapfrogging over his place in the virtual queue.

Alex thinks this could be fixed if the NHS App worked more like a concert ticket platform, where your reservation is held for a fixed amount of time as you complete the check-out process.

He also says that his experience has wider learnings for the NHS as they continue to rollout the App and other digital platforms.

First, **the NHS App should not be promoted as the only digital solution for all people**, if the way it works currently creates barriers for some users.

Second, Alex noted that in his experience, **GP practice website triage forms tend to be more accessible** and where they are not, there is more opportunity to work with the practice to make changes to the website. This is very difficult to do for a large, nationally controlled system, like the NHS App. He recommends that practices should consider sharing feedback, if they're not already, about best practices in making their digital platforms accessible.

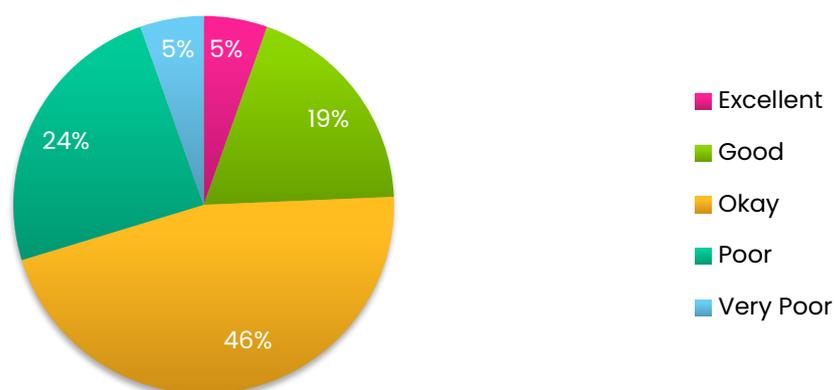
Finally, Alex emphasised that all steps in the individual patient's journey to care need to be understood. If any of these steps are inaccessible – anything from booking an appointment to understanding a prescription – then patients will risk having **worse health outcomes and poorer overall experience**.

Alex works at Community Action Sutton. Previously, he worked for Sutton Council for 10 years. His professional background gives him a strong understanding of how digital systems like the NHS App work. **He chose to share his story because he knows that if he has trouble with accessibility, others will as well.**

Theme 8: Referrals

Survey Responses

How was your experience of having your accessibility needs shared as part of your referral?



- Among those who have been referred by their GP to secondary care, 52 (70%) people reported that the experience of having their accessibility needs shared was satisfactory.
- However, among people who have been referred by their GP to secondary care, only 21 (28%) people were confident that their communication needs had been shared with the provider they had been referred to, conflicting with the earlier survey response.



Open-ended question Survey Responses

People had mixed views about how GPs share communication needs when a patient is referred to other health services. Some said GP services were excellent, but others felt there was not enough communication between GPs and other NHS services about their communication needs.



“There is a clear disconnect between NHS hospitals, GPs and community services. Whilst the system may be adequate for many it is entirely unsuitable for carers who are managing a patient’s often complex multifunctional needs.” – Carer of a person with a neurological condition

Focus Group Responses

Patient experience

Across the groups we spoke to people shared that they often have to speak up to make sure their GP shares information with other services they are referred to. At times, they don’t know why an appointment has been booked because the health service hasn’t explained it clearly.



Deaf or hearing impaired:

- “I’m basically getting two different things from the GP and the hospital. So next time I said, you know, can you please write it down, give me something to take to the hospital. So the GP can give me something as proof that when I get to the hospital I’ve been told to go there by a GP. And that’s much easier and much quicker when I’ve got something written down as evidence.” Deaf person



Neurological condition:

“There have been times where it’s not under their control, where my dosage has changed. I’ve said to the pharmacy, my dosage changed. They said, “oh no, you need to let the GP know”. I said, well, “I’ve already got a consultant letter to say it’s changed. It’s been written to the GP. Have they not given you that?” They said no. So that’s where, again, it’s a bit of to-ing and fro-ing.”
Person with a neurological condition



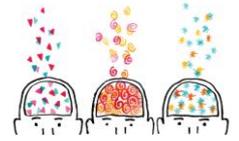
Carer experiences

Carers said that sometimes communication between their GP and other NHS services about communication needs isn’t always good. Carers often have to speak up for the person they care for, this can lead to missing information and a negative medical experience.

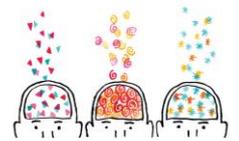


Neurodiversity and or Learning Disability:

- “They are so busy that once you've walked out the door, you're forgotten and on to the next thing. So unless we, as carers, keep chasing up things, nothing, get[s] done.” – Carer of a person with a learning disability



“When I go and see a GP and my child looks fine and I shouldn't have to then explain, actually, he has a psychiatrist and occupational therapist and all of these other professions are involved because he needs this care and there should be some continuity and something joined up to... Coordination. That's the word I was looking for...But yeah, it would be useful if it was flagged up on the thing.” Carer of a person with a Learning disability



Neurological condition:

- “We hardly have any communication if my husband goes to see a consultant and [when] the consultant recommends something I have to chase it ...I have to pick up the phone [and ask] “have you seen the letter?”” Carer of a person with a neurological condition



Theme 9: Support for communication needs from family, friends, and charities

Focus Group Responses

Both patients and carers said that outside support was very important in helping them get information from their GP, especially when the GP practice didn't provide the right support. This was even more of an issue when information from the GP wasn't given in an accessible format.



Blind or visually impaired:

- “When a letter is sent to my address, a relative comes and reads it for me...my younger brother...[or] one of my children.” Blind person

“Well, I am all right, because I don't do the booking. My husband does the booking.” Blind person



Deaf or hearing impaired:

- “There was no interpreter there, but my sister interpreted for me...I haven't had interpreters in the past. So when I go to the GP, I normally go with my sister. I always go with my sister. Because there [are] no interpreters” Deaf person

“My wife helps me a lot, and we write things down back and forth with them.” Deaf person



“If they phone me, I'm deaf, I can't be in communication with them. So they'll contact [my] daughter instead who will then communicate with me.” Deaf person



Neurodiversity and or Learning Disability:

- “Sometimes when they call me, I tell them to speak to my mum, if I don't understand it, because of my learning difficulties, if I don't understand it, I let them talk to my mum.” Person with a learning disability



“My house [supported accommodation] phones up to make an appointment. But I don't do it.” Person with a learning disability



“My dad reads my documents, but I don't read them.” Person with a learning disability

“Well, I have autism and a learning disability and I can't book appointments myself because you have to go onto their website and you have to book it through there. I've tried doing it once before but it didn't work, so my mum does it for me.” Person with autism

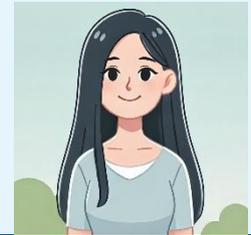


“It's hard when I go to the doctors, because they say, well, what tablets do you take? What medication? I wouldn't have a clue. My mum does all my tablets for me. She makes sure I take them daily. She rings me up, checks, because I live on my own, and I have



a carer as well, and I wouldn't know. I wouldn't have a clue. So, you know, with the GPs, they always ask, well, what medication will the hospital ask if I ever go there? And I don't know." Person with autism

Personal story: A person with autism reflecting on an appointment she attended with her mum



"And sometimes they can get a bit rude when I can't understand something [...] I went into a surgery once, and they said to me to lay on the bed, to check my stomach, and they said lay on the bed, and I laid on the bed, but then they said, could you put your legs up?

So my mum was showing them how to do it to me. She was saying, you just lift your legs up like that. And the GP had a go at her and said, I'm the GP here, can you not tell her what to do?

And she said, well, I know my daughter, and she can't do that. And then, you know, and then she didn't communicate to get off the bed. And she started talking to me and asking me questions.

And I was still laying on the bed, and so I got up and I stood next to her. And my mum said, just sit there. And she said, no, I'm the GP, I'll tell her to sit down.

So I sat down, but she was very, very rude to me and my mum. And, you know, it was the lack of communication that I didn't like. You know, now when we go into the surgeries, my mum has to be a little bit cautious of what she says, because in case, they have a go."

Neurological condition:

- "I'm ok with having information from the GP I go to [an organisation that supports people with neurological conditions] and I get a lot of information there and I've got a wife and three kids as well so they can all help me I'm lucky." Person with a neurological condition



Carer experiences

Carers talked about how important it is to speak up for the people they care for. Some carers face some difficulty being the voice of the people they care for, with some GP staff overlooking carers to talk to the people they care for directly, even though the person may not be able to communicate well with the doctor without the carer's help.



Blind or visually impaired:

"I have to ask my son for him to explain it [online medical results] and read it [online medical results], isn't it? Because you can't read it. Luckily, my son lives in the same apartment as we live down below. So we have a great help with him. He's very smart. He knows about everything." Spouse of a person who is blind

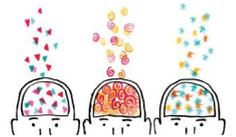


"I have to keep an eye on the appointment. [participant name] wouldn't know what to do. Because he cannot see." Spouse of a person who is blind



Neurodiversity and or Learning Disability:

- "If I wasn't there being his advocate and pushing it all the time, you know, that's the thing. He would have been waiting a long time. It's quite frightening." Parent of a person with a learning disability



"I find, as a carer, you're stuck sometimes because you'll take your child to the doctor because you know what's best for them and then they'll go, well, I'll just ask her what she thinks...Am I speaking on behalf of my young person or aren't I, because you can't have both. We are either acting in their best interest or we're not. I find that frustrating sometimes." Parent of a person with a learning disability



"Without me being able to lay out those clear boundaries, would that happen? I don't know that the awareness is really there to understand the processing, the time that's needed, you know, and the different type of communication that [is needed]" Parent of a person with a learning disability



Neurological condition:

- "Another thing is about the 10 minutes the GPs have as well we went to get some prescription for his medication because the GPs are under time pressure all the time she only looked at the first line of the medication and prescribed totally wrong proportions. So I looked at the directions and the composition, and I noticed this is just wrong that's terrible potentially catastrophic." Spouse of person with a neurological condition



"You don't have the wherewithal to remember and also my husband couldn't do it for himself so it just puts extra time and pressure and everything on me." Spouse of a person with a neurological condition



GP Staff & AIS



GP staff & the Accessible Information Standard

We shared a survey with GP staff and joined their regular meetings to hold 'mini focus groups'.



These were quick 10-15 minute discussions to find out what GP staff thought was helpful or not helpful about following the Accessible Information Standard. In total, we spoke to 82 GP staff during these sessions.



We also asked them a question to see how much they knew about the Accessible Information Standard.



We heard from 23 people through our surveys, from across the six boroughs in South West London.



A wide range of staff responded, including GPs, nurses, practice managers and other managers, receptionists, and a social prescriber.

We also spoke to 59 people in our mini-focus groups held in five London boroughs. However, we didn't note down the job titles of the people who joined the focus groups.



What we found out: Key themes (GP staff)

Several key themes emerged from the GP staff focus group and surveys:

Theme 1: Knowledge of the Accessible Information Standard and how it should be used



Theme 2: Identifying and reviewing communication needs



Theme 3: System flags and alerts



Theme 4: Staff training



Theme 5: Staff attitudes and awareness



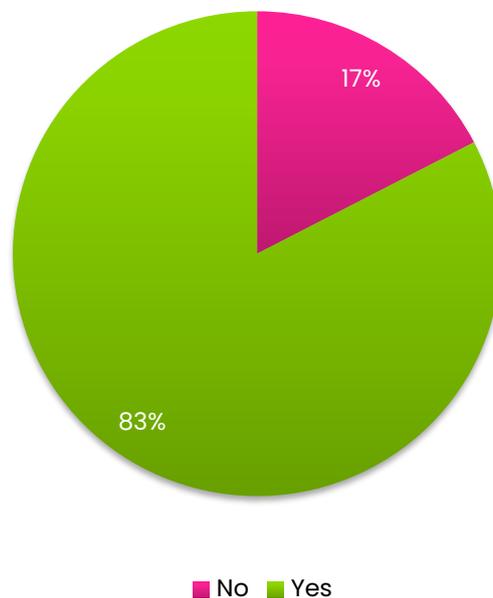
Theme 6: Communication tools used in practices



Theme 1: Knowledge of the Accessible Information Standard and how it should be used:

Survey responses

Are you aware of the Accessible Information Standard?

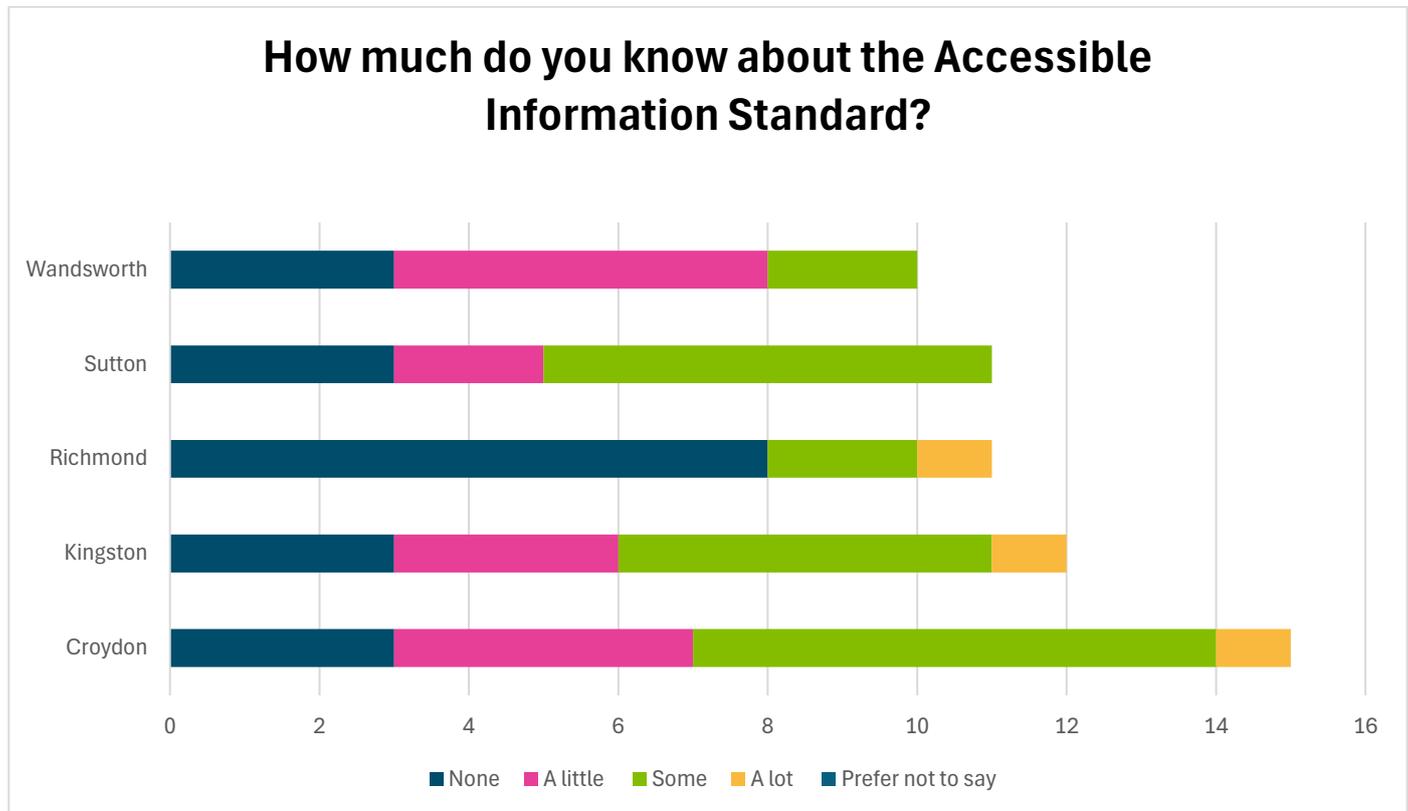


- 83% of staff who responded to the survey shared that they were aware of the Accessible Information Standard.



Mini focus group responses

Awareness of AIS Question Responses from mini focus groups



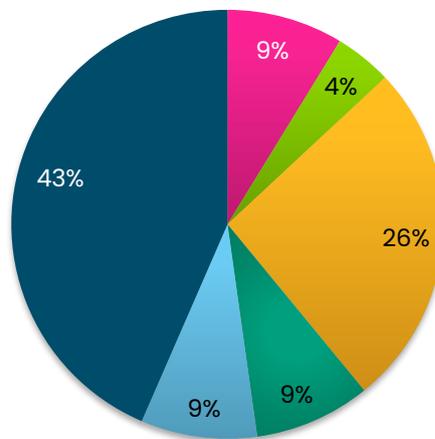
- In the mini-focus groups, GP staff took an anonymous poll to see how much they knew about the Accessible Information Standard. Some staff had some knowledge of the Accessible Information Standard, but many staff had little or no knowledge about it.



Theme 2: Identifying and reviewing communication needs

Survey responses

How often are new patients given the 'Accessible Information and Communication Support Needs' questionnaire?

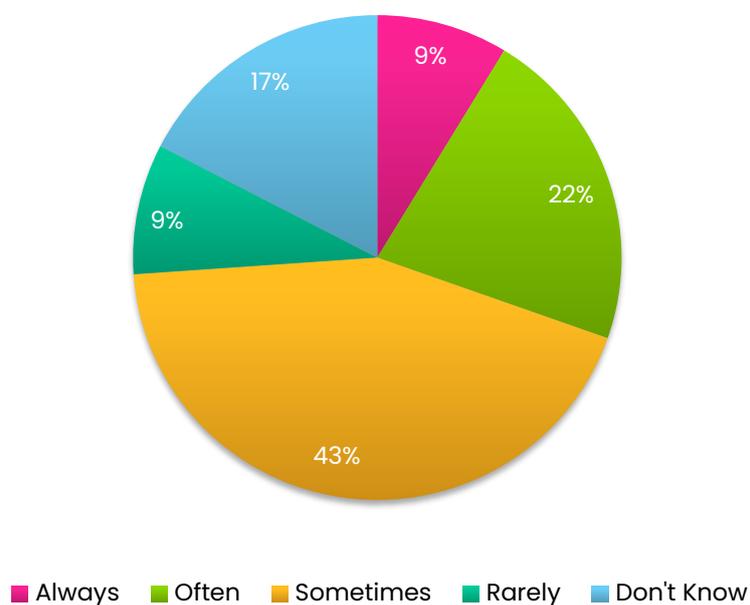


Always Often Sometimes Rarely Never Don't Know

- Just under half (43%) of GP staff who responded to the survey, shared that new patients were not given questionnaires to understand how their needs could be supported.



How often are the communication needs of patients reviewed?



Out of the GP staff who answered the survey, 31% said they regularly review patients' communication needs. About 43% said they review patients' communication needs "sometimes".



Follow-up question: If never or rarely, why is that so?

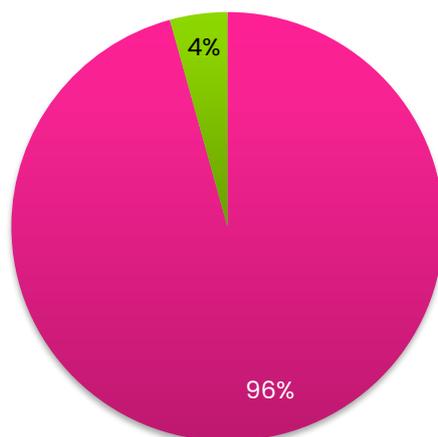
- GP staff shared that in the past, patients did not always respond to the questionnaire used to record their communication needs.



Theme 3: System flags and alerts

Survey responses

Are there system alerts or flags set up for patients who require additional support for their communication needs?



■ Yes ■ No

- 96% of staff who responded to the survey shared that there are flags and system alerts that show when a patient needs additional support.



Follow-up question: If never or rarely, why is that so? If yes, what type of system alerts/flags are used?

GP staff said that administrators check all new applications and use these alerts and flags:

- Clinical alerts and pop-ups on medical records
- Screen messages attached to medical records
- Warnings/codes on notes



Mini focus group responses

During the mini-focus groups, GP staff shared what they found helpful or unhelpful when it came to system flags and alerts.



System flags and alerts

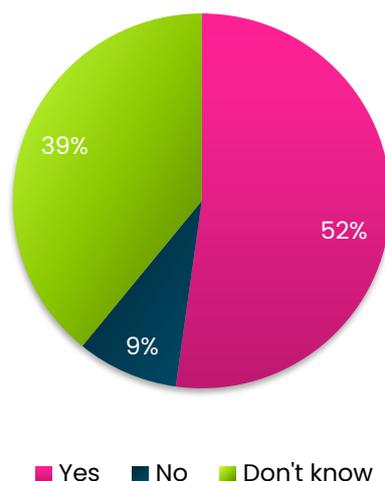
- **Helpful:** In Balham, new patient forms are used to record disability needs. There is a system that alerts the receptionist if a patient has a disability.
- **Unhelpful:** Staff in Kingston said that pop-ups or flags are not always easy to see or can be missed because too many flags are shown at once.
- In Croydon, GP staff said there isn't a good way to record patients' communication needs in the system. This means staff don't always know what patients need and can't make the right adjustments. They also said there's no way to know the communication needs of patients who don't make themselves known to services.
- Staff in Croydon said that some patients don't want labels on their records. They explained that it's important to reduce stigma and make patients feel confident that recording their communication needs will help them get better care.



Theme 4: Staff training

Survey responses

Are patient-facing staff in your surgery trained in how to implement the Accessible Information Standard?



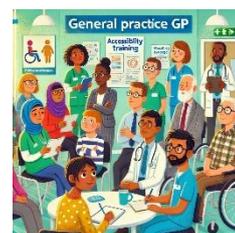
- 52% of staff who responded to the survey shared that staff within their practices had been trained on how to use the Accessible Information Standard.



Follow-up question: If yes, what type of training is provided?

GP staff shared the following types of training:

- Yearly online training
- Warnings/codes on notes
- Disability awareness training
- In-house training



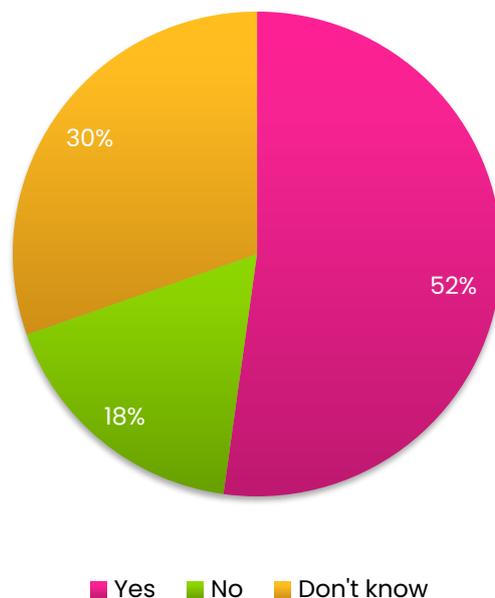
Follow up question: If no, why are staff not trained?

GP staff shared the following challenges to staff training:

- Not enough time
- When staff do not stay in their roles for a long time



Are there specific staff members that oversee how the AIS is being implemented?



- 52% of staff shared that they have a specific staff member in their practice who makes sure the Accessible Information Standard is being followed.



Mini focus group responses

Staff shared their experiences of receiving training on the Accessible Information Standard and what they found helpful or unhelpful.



Staff training

Helpful: In Balham, staff learn about the Accessible Information Standard (AIS) when they start their jobs. Training is done using the website

<https://www.bluestreamacademy.com/>.



- Staff in Kingston shared that they receive yearly online training in AIS.
- Staff in Croydon said it would be helpful to have the AIS in a format that is easy to access and understand, along with a toolkit to help use it.



Unhelpful: In Kingston staff said that they receive many different types of training on different topics, which means it can be easy to forget the information from the yearly AIS online training.



- Staff were also unsure who in the practice needed to receive training in AIS. Staff suggested that it would be helpful to have someone in the practice or a connection with local organisations that could regularly advise them on the AIS.



- Staff in Kingston said that specialist support is needed for people with communication needs, and this should be the same in all practices.



Partnering with VCSE organisations

- **Helpful:** In Balham GP practices use materials from VCSE organisations to make their practice more accessible.



Theme 5: Staff attitude and awareness

Mini focus group responses

GP staff shared their experiences of staff attitudes towards the Accessible Information Standard.

Staff attitude and awareness

- **Helpful:** Staff in Croydon said it is important to check how well a practice is helping people with communication needs and to have a system for getting ongoing feedback from users.
- **Unhelpful:** Staff in Kingston said that assuming what patients or carers need can be unhelpful to providing accessible information, because different communication needs require different approaches.



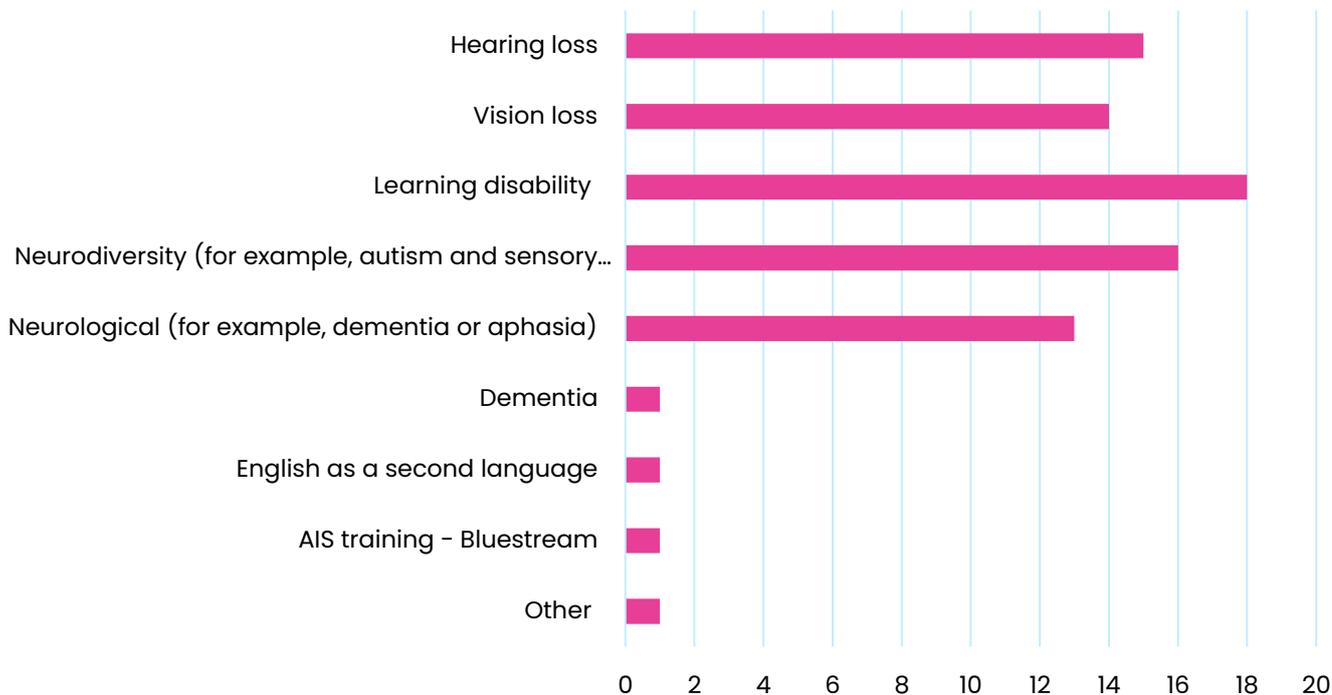
Theme 6: Adaptations and communication tools used in practices

Survey responses

GP staff were asked to share that they received training to help them communicate better with patients who have the conditions listed in the chart:



For which of the following groups of conditions/disabilities have staff been provided with accessibility or awareness training to better meet patients' communication needs?



Follow-up question: Are there any adaptations that have been provided for patients with communication needs within your practice?

GP staff shared these tools and changes used in the practice to help patients::

- Clear signs in the GP office
- Receptionists that help people with reading or writing problems
- Hearing loops for better sound
- Access to interpretation services
- Written communication
- Text messages/calls/emails/letters
- Adjusted text size
- Longer appointment times
- Braille signs



Follow-up question: Have any tools been developed to help with the implementation of the Accessible Information Standard? If so, please describe these and link to them if possible

GP staff said these tools would help use the Accessible Information Standard:

- Having standard document templates



- Learning Disability explanation sheets

Follow-up question: Are there any factors that have helped with the implementation of the Accessible Information Standard?

GP staff said these things have helped with using the Accessible Information Standard:

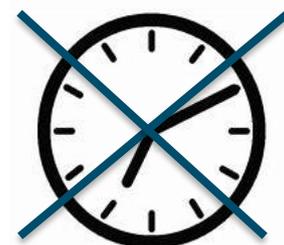
- The introduction of the Accessible Information Standard, which has raised awareness
- Training
- Patient and carer feedback
- Regular reviews by GP staff
- Clear and consistent recording of patient communication needs
- Having staff trained in British Sign Language (BSL)
- Hiring staff with special knowledge of communication needs or sensory loss



Follow-up question: Are there any barriers to implementing the Accessible Information Standard?

GP staff said the following things make it hard to follow the Accessible Information Standard:

- Difficulty getting resources to translate information into Braille
- Limited time and resources



- Building problems: When GP practices share a building, it can be hard to find a quiet space for patients whilst waiting for an appointment
- Changes in staff
- Not knowing how to make texts and emails easy to read
- Lack of training on how to make easy-read documents
- Text messaging services that are hard to use



Mini focus group responses

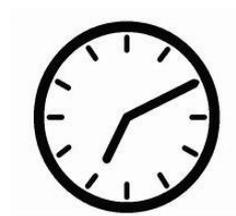
Communication tools used in practices

In the focus groups, staff talked about some of the communication tools mentioned in the survey. They also shared what helped or didn't help in meeting the communication needs of patients.



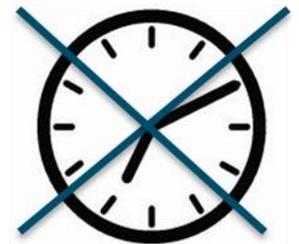
Helpful:

- In Balham, one practice used visual aids to help guide people with dementia around the building.
- In Sutton, practices check patients' communication needs every year and offer longer appointments for those who need them. They also book patients with the same doctor each time.
- At a focus group in Kingston, staff saw that text messages helped make information clearer for patients after an appointment.



Unhelpful:

- In Wandsworth, staff said it's hard to make text messages easy to read, and although BSL interpreters are available, they often cancel at the last minute.
- In Kingston, a recent change in BSL interpretation services to match other services in South West London has made BSL interpretation less reliable for face-to-face appointments.
- In Croydon, staff said there is not enough funding for BSL interpreters.
- In Sutton, even though they offer longer appointments and send information before appointments, some patients still don't show up.



Limitations to our engagement

- We did not collect information from parents and carers who have disabilities, or who support people without disabilities. This group is covered under the Accessible Information Standard and may have different experiences from those described here.
- Given the unique nature of the population we focused on in this research, it was a challenge to get a large number of responses. We do not have enough participants to meaningfully compare patient and carer experiences by borough or race/ethnicity. We also spoke to only a few participants who were visually impaired or d/Deaf (see Annex 1).
- GP practice staff were also hard to recruit because of the pressure on health services, and we don't have enough staff responses to compare results by borough.



Other work around AIS, GP services, communication needs

Additional Healthwatch community engagement findings

- [Including Communities: Engagement Report March 2022 to October 2023 | Healthwatch Kingston](#) (informed by 334 people)
- [Including Digitally Excluded Communities: Engagement Report | Healthwatch Kingston](#) (informed by 137 people)
- [Patient Experiences of General Practice in Richmond](#) (informed by 2700 people)
- [Your Care, Your Way campaign](#) | Healthwatch England



Reports/briefs by our charity collaborators

- <https://signhealth.org.uk/resources/research/aisreview/>
- <https://signhealth.org.uk/with-deaf-people/campaigns/still-sick-of-it/#keydocuments>
- <https://www.ruils.co.uk/article/same-day-gp-appointment-access-guide/>
- <https://leder.nhs.uk/images/resources/Action-From-Learning-Report-2021-22.pdf>

About the authors

Report authorship

This report was written by [Iyinoluwa Oshinowo](#), South West London Healthwatch Engagement Coordinator, and [Alyssa Chase-Vilchez](#), South West London Healthwatch Executive Officer, who can be contacted with any questions or comments. Iyinoluwa and Alyssa led the design and implementation of this project.

About South West London Healthwatch

South West London Healthwatch is a collaborative of six independent Healthwatch organisations (Healthwatch Croydon, Merton, Kingston-upon-Thames, Richmond-upon-Thames, Sutton, and Wandsworth). Since 2022, they have collaborated to gather insights across the Integrated Care System's footprint in South West London, to ensure that people have a voice in NHS decision-making. The lead officers of each of these organisations played a consultative role on this project



healthwatch

Healthwatch Croydon: <https://www.healthwatchcroydon.co.uk/>

Healthwatch Kingston: <https://www.healthwatchkingston.org.uk/>

Healthwatch Merton: <https://www.healthwatchmerton.co.uk/>

Healthwatch Richmond: <https://www.healthwatchrichmond.co.uk/>

Healthwatch Kingston: <https://www.healthwatchkingston.org.uk/>

Healthwatch Wandsworth: <https://www.healthwatchwandsworth.co.uk/>