# healthwatch

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

**Summary version** 

# About the Accessible Information Standard

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**



#### 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

- 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).
- Training
- 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).





 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.



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