

# What we're hearing about accessible information and reasonable adjustments

October 2025





"I went to a GP appointment where I asked for a BSL (British Sign Language) interpreter to support me. The doctor advised they could understand me and therefore I don't need one. My request wasn't for them, it was for ME. Why am I being told what support I do or don't need? Isn't that my decision?"

If you would like a paper copy of this document or require it in an alternative format, please get in touch with us.



### **Background**

Under the <u>Equality Act 2010</u> anyone with a disability, impairment or sensory loss has the right to request reasonable adjustments. Reasonable adjustments include:

- Providing letters, leaflets or forms in large print, braille, audio or Easy Read formats.
- Supplying BSL (British Sign Language) interpreters or lip speakers for meetings or events.
- Offering clear, plain-language explanations or extra time to go through information.
- Offering a quiet space to wait for people with sensory sensitivities.

The <u>Accessible Information Standard</u> (AIS) sets out how providers and commissioners of NHS and publicly funded adult social care services should ensure disabled people and people with impairments or sensory loss:

- Can access and understand information about NHS and adult social care services
- Receive the communication support they need to use those services.

All organisations that provide publicly funded NHS care or adult social care – and commissioners of NHS or social care services – must adhere to this standard.



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#### Who have we heard from?

In the past 6 months 42 Surrey residents have talked to us about requesting and trying to access reasonable adjustments and accessible information. They have shared their experiences via our Helpdesk and/ or at community engagement events.

Out of the 42 people who have spoken to us about reasonable adjustments and accessible information...

- 15 people identified as having a long-term health condition, with
   12 of the 15 people identifying as having multiple disabilities.
- 7 people told us they identified as neurodivergent and had a long-term condition.
- 9 people had a sensory impairment, such as a hearing or vision impairment.
- The most common age range we heard from were working-age adults (13 experiences from people aged 25-64).
- We heard mostly about people's experiences in Surrey hospitals, (18 people); 12 people spoke to us about their experiences with their GP practice.

### **Recommendations**

Healthwatch surrey recommends that all providers take steps to review whether they're complying with the AIS effectively.



# Reasonable adjustments not being implemented

Surrey residents reported that even when they had adjustments recorded on their notes, the adjustments were not always followed or acted upon.

Of the **42** experiences we heard, only **6** people knew that their reasonable adjustments had been recorded or had a hospital passport. However, these people told us that the reasonable adjustments were not acted upon by staff.

"I said to the receptionist that I have it on my record that I need reasonable adjustments and the receptionist said, 'Oh so you expect me to read notes from 2017?'"

230941, Surrey Resident

"I also have PTSD about hospitals and sometimes it's hard for them to understand my needs. I have a hospital passport and sometimes they don't even look at it."

230862, Reigate and Banstead Resident

"I recently had to attend A&E as an immunocompromised chemotherapy patient. Despite presenting the staff with my alert card indicating that I needed to be isolated, I was repeatedly placed in areas not suitable for my condition."

230734, Surrey Resident



# Unmet needs: the voices of people who are neurodivergent or have a learning disability.

Surrey residents reported feeling misunderstood and unheard when communicating the adjustments they needed to access services.

**9** people whose primary reason for requesting reasonable adjustments or accessible information be put in place was due to them being neurodivergent or having a learning disability (1 person).

# Lack of reasonable adjustments leads to difficulties accessing services

People with neurodivergent conditions or learning disabilities told us that a lack of reasonable adjustments meant that they struggled to access the services they required. In some cases this led to a delay in accessing clinical care and a worsening of their conditions.

"My autistic daughter was referred in year 7 to our local CAMHS (Child and Adolescent Mental Health Services) in January 2023. She has been unable to attend school since November 2022. We were offered counselling in late September 2023. My daughter is unable to leave the house. We agreed to the counselling and asked for online or in person counselling to take place in our home. We had 2 online sessions and my daughter was then discharged as she is unable to come into the GP practice to meet the CAMHS counsellor. We have received no mental health or mentoring support since."

230939, Surrey Resident

"Our son has Downs Syndrome and a severe disability diagnosis; we are having issues getting him to do blood tests. We received support when he was under paediatrics, but now he's an adult, nothing is happening. Our GP is also



not really being proactive about advising us how to get past the barriers."

#### 230829, Waverley Resident

"I did not receive any reasonable adjustments for treatment at [the hospital]. I was told I was not eligible for IV antibiotics because I did not have a learning disability, even though I am autistic and find hospital environments very difficult to manage. I was treated so badly without reasonable adjustments that I went without antibiotics and ended up with sepsis. My support workers, their manager and my GP all fought for me to get IV antibiotics, which I really needed due to high-risk infection, but they didn't do it, and their words were 'she doesn't have a learning disability, so we won't do it or don't have to do it. They even said that 'I don't have a learning disability I 'just' have autism'"

#### 230725, Surrey Resident

"Appointments at my GP have been cancelled without any notification, causing confusion and delays in care. Despite being a high-needs patient, I am rarely prioritised and am often told to attend walk-in centres or A&E. In several cases, this delay has worsened my condition and led to emergency care. As a vulnerable individual managing multiple health conditions, I feel unsupported, dismissed and let down by those meant to care for me."

230872, Woking Resident

### Confused, distressed and unheard

Neurodivergent Surrey residents reported experiencing increased anxiety, distress and confusion about their care due to adjustments not being made. In some cases, this led to them no longer trusting the service they were receiving care from.

"My little boy is 9 and autistic. He needed to have an urgent MRI, which was booked in for 1pm the following day. When they booked in the MRI, they said he would need to be



sedated for the procedure to keep him calm and so they can get the images they need. I kept on reminding the nurses on the ward that he needed to be sedated, however this never happened. A porter just came and took him down for the MRI without any warning. It was horrific, he was screaming and wriggling the whole time and has been traumatised by the experience. Due to this experience we said we no longer felt safe at the hospital and asked to be transferred to the Royal Surrey."

#### 230893, Woking Resident

"[The hospital] have failed to make reasonable adjustments for my disability; I am now being penalised because I had an autistic meltdown and took too much pain relief.

Communication from the department is not existent and now I have to wait another year for surgery, and nobody will listen to me."

230967, Guildford Resident



# Seeking support: the voices of people with sensory impairments

We heard from 9 Surrey residents whose primary reason for requesting reasonable adjustments was due to them being hard of hearing, deaf, partially sighted or blind.

### Challenges due to information not being accessible

For many, communications not being in an accessible format led to frustration and anxiety that they would not be able to fully understand the information being communicated to them, vital when engaging with health care services.

"I went to a GP appointment where I asked for a BSL interpreter to support me. The doctor advised that they could understand me and therefore I didn't need one. My request wasn't for them; it was for ME. Why am I being told what support I do or don't need? Isn't that my decision? I have anxiety around going to medical appointments because I know they may call my name and I won't hear them, then I may not understand the terms they use or what the doctor is actually saying. This has caused some conditions to become worse than they should be because the health care professionals either can't be bothered to make adjustments for me or they just don't care."

### 230663, Woking Resident

"I have been waiting over 14 months for an appointment. Originally, I went all the way to [the hospital] not realising my outpatients appointment was in the next year - because the letter was not in my required format. Now I have had no further communication from the hospital or GP practice. It feels like nobody cares."

230763, Reigate & Banstead Resident



"I am blind and disabled. We have had to apply to the ICB [Integrated Care Board] for funding for me to attend a specific clinic. When I tried to research this online, I was unable to access the information because it is not accessible for those who are visually impaired."

#### 230706, Surrey Heath Resident

"I have been sent an appointment letter, which I can't respond to by [the hospital] outpatient appointments team. The letter has the message: 'To rearrange this appointment please call us on [telephone number]'. I am unable to lipread on the phone so I can't reply to say I am unable to attend the consultation as they do not have an option to communicate by SMS or email."

#### 230667, Surrey Resident

"For deaf people, who are unable to use voice phone, an additional anxiety arises. How will I be told of my appointment? Over and over 'registration' forms insist on a phone number. Fortunately, I have one but use it exclusively for data. Anyone trying to make a voice call to it will simply find it rings and rings. So, if I start getting calls, I can't answer, they may be someone trying to contact me about a medical appointment. I have no way of knowing. Its extraordinarily stressful!"

230881, Surrey Resident

# Difficulties accessing services due to a sensory impairment

For some people with sensory impairments, lack of reasonable adjustments make accessing services a challenge.

"I am blind and have a physical disability. I have been called to have a scan as part of a preventative program. When I was contacted by the local provider, they gave me a list of times and dates for my appointment, but I was unable to attend any of them as I need to arrange support from my



carers to attend these appointments. When I said this to the person booking the appointment, they said that I would have to wait a further 8 weeks to attend an appointment, or I may not be able to attend at all."

#### 230899, Surrey Heath Resident

"I have a hearing impairment from birth and my lipreading skills are of no use on the phone, so calling 119 to make an appointment and check that a vaccination venue has a hearing loop is not possible. Therefore, when I saw that there are drop-in clinics in Redhill and Guildford for the 75+ cohort, I decided to attend without needing to ask someone to phone and book for me. I expected to find that they would be accessible to our age group, but they were not. There was no hearing loop available at a clinic designed for a cohort most likely to be hearing aid users?"

230750, Surrey Resident



# Lack of understanding: the voice of people with mental health conditions

We heard from 5 people whose primary reason for requesting reasonable adjustments was a mental health condition, such as anxiety, depression or PTSD.

# Lack of understanding from staff causes barriers to care and personal distress.

People who have a diagnosis of PTSD or anxiety told us they struggled to get reasonable adjustments implemented and this greatly impacted their ability to access services, as well as their emotional wellbeing. They also reported a lack of knowledge from staff about trauma informed care having a direct impact on their experience within the service they were attending.

"I had a very bad experience recently when I went for a smear test. Due to the nature of my trauma, I asked for reasonable adjustments to make it easier, which they didn't do. The nurse also began to ask me about my past trauma, which caused me to become triggered and leave crying. There needs to be more done for women who have trauma to access smear tests. After that I didn't see a doctor for a while, but eventually I saw my GP to catch up on all the things I missed when I felt like I couldn't go to them. I brought up the issues I experienced when I had my smear test, but the GP was quite dismissive and didn't take them seriously."

230857, Guildford Resident

"I have PTSD about hospitals as I nearly died there previously. When I enter the hospital, I have selective mutism. They are not good about this - I've had awful experiences there. To be fair the doctors at A&E have been



good and tell me to take my time, but the receptionists and other staff are not kind. I try and write it on my phone to explain and recently when I went to the receptionists, they rolled their eyes at me while other staff were laughing about it in another room. I feel stupid enough as it is. They treat me like I am making it up and it makes me feel really anxious."

#### 230863, Reigate and Banstead Resident

"I have been referred for an MRI but I am really claustrophobic. I have already been once and couldn't do it – I actually banged my head as I was panicking and asking to come out – I just couldn't cope. I don't know why it has to be a full body MRI when it's only my foot, but they've said it has to be. I have explained but it seems like they've just sent the same information again. I have another appointment, but I know I won't be able to do it."

#### 230922, Guildford Resident

"When I receive health texts I am usually expecting them. To receive one unexpectedly triggers me thinking that something terribly bad (like cancer) has come through for my health...This triggered my complex-PTSD as I was given no option and felt trapped and my health put at risk. Their system and staff are not responsive, respectful or supportive to patients like me who are invisibly disabled. I asked the GP admin to email me with the response, but still, they call me and are curt and abrupt. I was so ill I could barely speak and just said 'You need to email me' and she said, 'Oh email, right' and the phone was put down on me. I am yet to receive an email."

230824, Surrey Resident



# The importance of reasonable adjustments: the voice of people with long term health conditions

We heard from Surrey residents who identified as having a long-term health condition which impacted on their mobility, processing and retaining information, or physically being able to access services.

### Lack of adjustments delayed access to clinical care

People with long term health conditions told us that a lack of reasonable adjustments or accessible information increased their anxiety around the care they would receive and, in some cases, delayed that care.

"I had a fall in April, and a paramedic came out and assessed I was fit to stay home. A couple of days later I contacted my GP because I had bloodshot eyes and didn't feel right. The GP on the phone was dismissive of my access requirements and told me to go to A&E. I told her I couldn't get to A&E as I am housebound, and I wouldn't call an ambulance for bloodshot eyes. She then told me I needed to come to the practice to have my blood pressure taken. I told her again I couldn't get there. The next day someone from the GP practice arrived to take my blood pressure."

230957, Reigate and Banstead Resident

Healthwatch Surrey have recently completed a project looking at whether healthcare services are accessible/available to, and meeting the needs of, people who are classified as being housebound, and what improvements can be made to better meet these needs. Read more in our report - Home is where the care is? Experiences of people receiving care in their home - September 2025 | Healthwatch Surrey.



"Due to my disability, I am unable to attend the surgery in person. They only offered me a telephone consultation, not the face-to-face appointment I requested 4 weeks ago. Due to there not being a face-to-face appointment, they are refusing to release a letter I need... I raised these concerns with the practice manager. I then received a text to say a GP would attend my home. However, this message was inadequate and did not give me the name of the attending GP, date, time of appointment or allow for me to notify them on how to access my key safe."

#### 230959, Surrey Resident

"I was so confused about the whole thing. First off, I was referred to [Named Medical Centre] which was difficult for me to get to because I don't drive. Then they didn't give me any information about what to expect from the procedure apart from wound care post excision... After a multidisciplinary meeting took place, which I was not aware my case was being taken to, they notified me that I would have to have a further procedure as a preventive measure. They booked me in an appointment, but I have cancelled it because I don't understand the situation fully. They have not provided me with any information other than through QR codes which I can't access because my phone doesn't support them. They also didn't signpost me to any support services for post cancer diagnosis, so I have been trying to process all of this on my own."

231007, Guildford Resident



# Positive impact on people when reasonable adjustments are put in place

Out of the 42 experiences we heard across 6 months about accessing reasonable adjustments, none were positive. However, in a video we previously produced about the impact of reasonable adjustments, a parent and teenager discuss the different times when the daughter's reasonable adjustments have been met and when they haven't. In the video, the parent highlights the real difference that having reasonable adjustments can make to her daughter's experience.

"I spoke to the hospital twice before my daughter's appointment and spoke to the sister who will be on duty the day of my daughter's procedure. She was wonderful and asked what we can do to make my daughters appointment easier for her. On the actual day, she remembered what I had said. They let my daughter be treated first so she didn't have to wait, they also let her have her own room and they played pet shop boys as she went under anaesthetic and when she woke up. This helped my daughter be more comfortable for her procedure."

**Surrey Resident** 

Watch the <u>full video about their experiences</u>.



### Sharing our insight and raising concerns

This report is designed to highlight the themes we have been hearing about and includes quotes from local people to provide context on these themes. Whilst this report accurately reflects what we hear from the individuals we speak to, we are aware that it may not be representative of everyone's views of a particular service. Multiple references to a specific service may be due to where our community engagement has recently taken place.

Any urgent or concerning experiences within this report have been escalated to the appropriate teams. All appropriate information and signposting has already been given.

If you would like more information or examples of what people have shared, please get in touch.

### **About Healthwatch Surrey**

Healthwatch Surrey champions the voice of local people to shape, improve and get the best from NHS, health and social care services. We are independent and have statutory powers to make sure decision makers listen to the experiences of local people.

We passionately believe that listening and responding to local people's experiences is vital to create health and social care services that meet the needs of people in Surrey. We seek out people's experiences of health and care services, particularly from people whose voices are seldom heard, who might be at risk of health inequalities and whose needs are not met by current services. We share our findings publicly and with service providers and commissioners to influence and challenge current provision and future plans.

We also provide reliable and trustworthy information and signposting about local health and social care services to help people get the support they need.



#### **Contact us**

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We are proud to be shortlisted in 2025, and commended in 2024, for the National Healthwatch Impact Awards recognising our work helping to improve local NHS and social care.



We are committed to the quality of our information. Every 3 years we perform an audit so that we can be certain of this.



The Healthwatch Surrey service is run by Luminus Insight CIC, known as

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