



Young People's Experiences of NHS Communication and Appointments Report

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Report written by:

Zoey Harries

Healthwatch West Sussex Manager

healthwatch
West Sussex

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Executive Summary

This report draws on the experiences of 51 young people.

Including 12 young people (aged 19–24) with disabilities (primarily ADHD, Autism, and learning difficulties), from Black and Black African backgrounds who access NHS services across primary and secondary care.

The aim of this work was to better understand the communication and access challenges, and how these can be improved by the NHS staff who engage with young people with additional needs.

Context

It is well documented by the **Royal College of Paediatrics and child health** that communication barriers can negatively affect how children and young people (CYP) experience NHS healthcare.

These barriers are often more pronounced for CYP from Black and global majority communities, particularly those with learning disabilities, neurodivergent needs, or life-limiting conditions.

As referenced by the **NHS race and health observatory**, discussed in the **Houses of Parliament** and featured in the **National Disability Strategy**, young people may face significant inequalities in both access to services and the quality of care received.

Project Aim

This project seeks to better understand the experiences and perceptions of CYP, particularly for those from Black and global majority communities of their interactions with NHS services.

It aims to identify barriers to effective communication and develop practical recommendations to improve engagement and inclusion in healthcare settings.

Approach & Methodology

1 Survey Design

A survey was co-designed with partners and CYP to explore communication experiences.

The survey was live from 3 June and closed on 31 October.

2 Targeted Engagement

Follow-up communications were used to recruit and engage 12 CYP participants from the target demographic.

This included contacting young people from the targeted group who have previously supported with Healthwatch projects and advertising the project on social media platforms, offering a £25 voucher incentive for involvement.



3

Flexible Data Collection

Feedback was gathered through a range of accessible methods: emails, online Teams calls, in-person interviews, and workshops-based on individual preferences and needs.

This was particularly important due to the varying communication needs of interviewees.

4

Analysis and Reporting

Insights from the survey and conversations were analysed and compiled into this final report.

This includes a set of clear, actionable recommendations for NHS services to improve communication and engagement with CYP from under represented communities.

5

Staff Information and Guidance Leaflet

A practical leaflet will be developed for NHS staff, offering tips, insights, and best practices for communicating effectively with CYP from Black and global majority communities who also have learning disabilities, neurodivergent needs, or life-limiting conditions.

The leaflet will draw directly from the lived experiences and suggestions of participants.

Thank you

We would like to thank all the young people who have completed our survey, had conversations, attended in-person interviews, and workshops and shared their stories to support this work.

Survey Results

The survey was answered by 51 young people, from varying ethnic diversities. It was designed to reach as many CYP that identify as having either a learning disability, neurodiversity, ADHD or autism.

This was to provide a context for further exploration with the target group from Black and global majority communities.

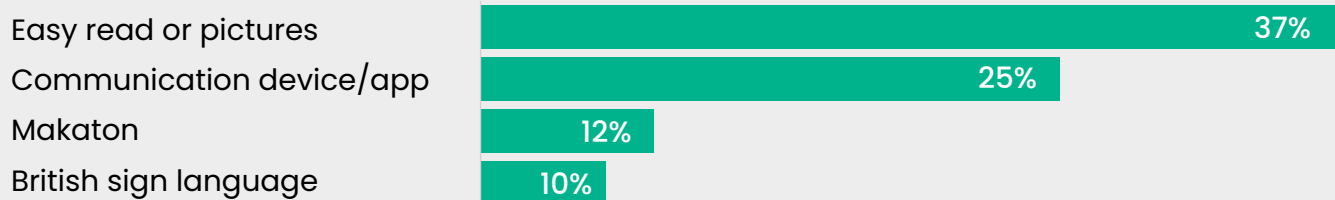
The survey was completed by CYP aged between 15 and 24.

It was reported that over half of respondents identify as having a learning disability and/or autism, **37% ADHD** and **14% with a life-limiting or long-term illness**.

67% have received a **diagnosis**, **18%** are on a **waiting list** and **4%** **consider themselves** to have a learning disability but are not seeking a diagnosis.

50% benefit from having someone else with them to help them talk or understand when communicating with NHS.

Other aids noted as being helpful include:



What would make you feel safer or more comfortable when you visit a doctor or hospital?

"Not to be rushed and to explain some words."

"Explain what is going on, be patient and give me time to understand the question before asking another one"

"Spare headphones in case I forget mine."

"Visual explanations and signs. A quiet waiting room, less transition."

"For the most part I feel and safe and comfortable when visiting a doctor or hospital, but occasionally I find that younger doctors don't understand old forms of treatment."

"Having someone who's experienced with autism and anxiety to help assist me around (especially around hospitals and specialist places as I do not know the places well)."

"The understanding of the disability and the fact they need to change their approach and have other means to help me understand and communicate."

"Knowing what was going to happen (i.e. come ready to have a blood test, so drink lots of water beforehand)."

"Less buzzy lights everything is bad but the constant buzzing lights is easy to change and quite a big thing that affects me."

"Having a quiet waiting area with fewer bright lights and noises would help me."

"A doctor who knows what is difficult for me."

"Maybe some fidget toys to use in the appointment."

"Warmer and nicer less clinical spaces. A comfortable environment."

"Reliable staff treatment."

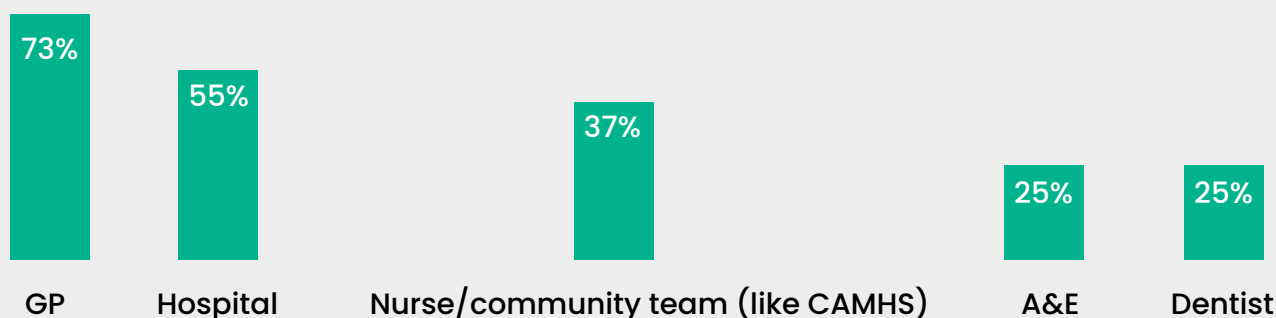
"If I am able to communicate my feelings without being interrupted and a friendly GP who understands my condition."

"I would appreciate being given effective and appropriate listening ears. No racism. Always feel that because you are black they are not providing the same help."

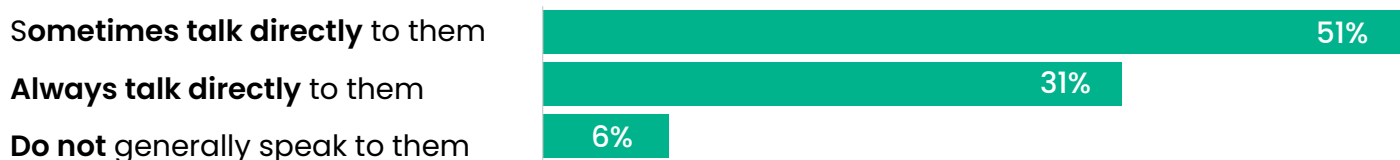
"I will like a hospital with workers who are well trained to handle people with my condition."

"If everybody was nice and patient."

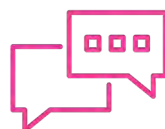
From most to least, respondents attended the following services in the last 12 months:



Young people told us when they go to appointments, staff:



No-one reported that they are never spoken to directly.



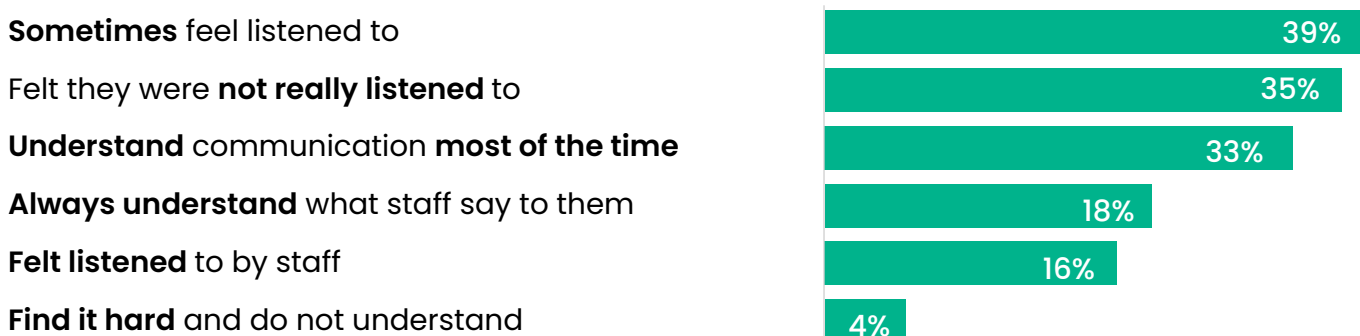
Do staff speak directly to you?

"Staff try to talk to ask me things, but I don't really understand what they say or mean except for basic yes no questions."

"Some staff speak directly to me and are kind, but others talk only to my mum. I wish they would give me more time to answer and speak more calmly."

"Now I am 16 they talk to me, but I want them to talk to mum."

"If I go with my parent, they talk mostly with my parent, but I am always asked a series of questions."



Do you feel listened to by Staff?

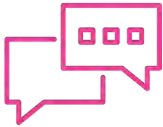
"The questions from GP's and nurses are completely inappropriate and not delivered in a way my daughter understands."

"They always start engagement asking how I am now and how I've been."

"I feel that they often think that I am being over dramatic or think that I am lying because I am young and have pain due to autism the permanent pain can be seen as lying."

"I feel listened to more when my mum is with me. On my own it's quite hard because I feel they don't take what I say seriously."

"I really wished they could listen more though."



Have you ever felt treated differently or unfairly because of your disability, illness, or how you communicate?

"Yes, sometimes not given the time in the appointment, or to be able to process the information. Lack of resources or signing to aid understanding of communication."

"Was talked to in a way that felt like I was being infantilised, then was talked to in a way that I couldn't understand as words were difficult to understand were used without clarification or explanation."

"Consultants did not understand the situation was urgent, I was admitted onto a ward and the neurology team did not see me even though the ambulance and A&E suggested that if I was admitted I would be seen."

"Didn't understand what GP was going on about, mum was trying to explain. GP was talking to mum like she was an idiot and didn't know what to do with a certain medication even though she has been on that medication all her life and the GP didn't understand my disability: understanding level or my difficulties."

"Many treat as though lesser."

"At one appointment, the doctor spoke only to my mum and ignored me the whole time. Another time, a receptionist got annoyed because I couldn't explain fast enough. It made me feel embarrassed and not want to go back."

"Doctor didn't understand how bad anxiety is and mum tried telling him that I need anaesthetic, but he said I don't because I'm 16 but I do because I am scared of needles and didn't understand."

"Way I was looked and spoken to sometimes wasn't fair."

"A health professional made mockery of my speech and was rude to me."

"A GP didn't understand me properly and he shouted at me. He said I was dumb."

"They thought my symptoms were just an act of stubbornness and they didn't bother to hear my side."

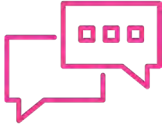
"Because I am slow in understanding what my doctor says, he gets frustrated and takes it out on me by raising his voice or ignoring me to attend to something else."

Sometimes staff talks in a way that works
Communication works for young people
Communication doesn't work for young people

57%

18%

16%



Do staff talk to you in a way that works for you?

"Only specialists do, not community health care professionals."

"I struggle with tone and understanding things and often have to ask for clarification and comparison to understand what I am being told."

"Simple, clear language speaking to me directly and asking my mum (carer) if that's clear and helpful."

"Due to processing issues I don't always understand and need to have my mum explain it."

"Many talk as though I am a young child and infantilise me despite being an older teen/ young adult and having a high comprehension and mental age equitable (if not higher) to my body."

"It would really help me if staff let me write things down because I need extra time to think before answering and that doesn't always happen."



Do you understand what staff say?

"Talk too fast and don't explain what medical words mean."

"They also always check to see if I want to ask any questions about anything they have said to make sure I've understood."

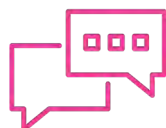
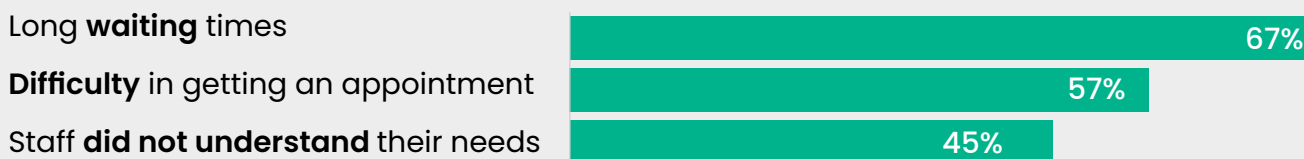
"I sometimes need help from a parent due to processing difficulties."

"It helps when they use clear words and speak slowly, sometimes I get overwhelmed and don't take everything in, but visuals help me understand better."

"I want them to talk to mum because I don't know what to answer."

75% have found it hard to get NHS care when needed.

The top three reasons being:



Have you found it hard to get NHS Care when needed?

"My daughter needs a parent or her P.A. to make an appointment. To get a GP appointment is virtually impossible."

"I struggle with understanding the options on the GP telephone when I ring them, and it's also really hard to get any help without going to the GP first which is already a struggle."

"It was hard to get an a CAMHS appointment when I really needed help with anxiety. I also find phone calls difficult so booking appointment difficult."

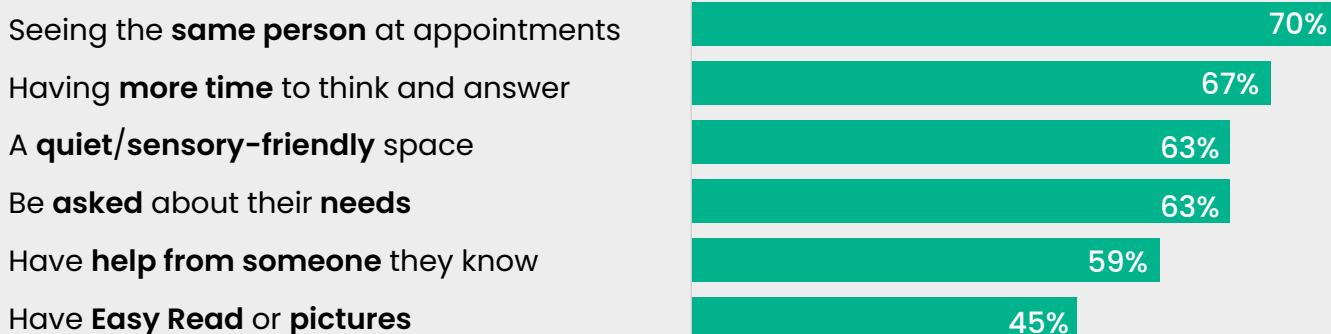
"I need help to order my medicine and I can't phone and doctor wants me to do the talking and not mum and I want them to talk to mum."

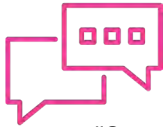
"My problems were not understood."

Over 60% of respondents felt that they **have been treated differently or unfairly** because of their disability, illness or how they communicate.

To feel more included and understood during appointments, young people selected a number of ways that could support them further.

This included:





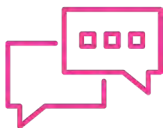
Is there anything else you want to say about NHS care and how you are treated?

"Some people are great some people are terrible"

"Overall, I've had positive experiences, and staff have listened very well and provided support."

"Ability to pay attention and listen more."

"I was discriminated against and that made me withdraw."



When respondents were asked if there was anything else they wanted to share in general, the following answers were provided:

"We have gone private for mental health support as the waiting list for CAHMS is so ridiculous."

"We dread A&E, plus as a teenager she will soon be in adult areas which will be dreadful. GP receptionist need training on special needs communication and needs."

"I am normally treated very well and with a great deal of kindness."

"Staff try to talk to ask me things, but I don't really understand what they say or mean except for basic yes no questions."

"GP services still don't like trying to work around my needs when I contact them for any reason, although, they do it eventually, but the biggest upset is my mum has. Deputyship and the GP surgery won't communicate with her, without me putting it in writing I give her permission every time we need to contact them, which I can't do with my mums help, but most of the receptionists are the worst with this and most say the Deputyship order from the court isn't worth the paper it's written on is the main thing, but if it's not that they say they have no record or the Deputyship on my records, when it's there."

"I've had outstanding treatment from GP and GP surgery clinicians and staff and also dentist. They keep me happy and healthy so I can avoid getting ill (good prevention) and avoid hospital visits unnecessarily."

"Sometimes I feel as though my mental health is treated the same as a paper cut. Like it doesn't actually matter and everyone has it and I'm annoying to have mental health struggles."

Reflections on Survey Results

It is recognised that the survey was answered by a small cross-section of CYP. Nevertheless, responses help to indicate general perceptions, experiences and needs.

Over half of respondents have more than one condition and identify as have a learning disability and autism or ADHD.

No two people experience learning disabilities, autism, ADHD, or life-limiting illnesses in the same way. For those living with more than one condition, the challenges and strengths intertwine, creating a unique and often more complex experience of daily life.

Respondents reported that having someone to support at NHS appointments helped with communication, although many felt able and had a desire to speak to staff directly to explain how they were feeling. Young people shared they do not always feel understood or listened to and sometimes come away from appointments disappointed and unheard.

Due to varying needs, the majority of young people felt that it would be easier to have the same member of staff when they attend appointments. The environment also plays a large role in terms of how comfortable they feel and how much they can listen to staff and not be distracted. The environment can affect respondents' ability to think clearly and say what they want to say in the moment. Having a quiet area can greatly benefit a number of young people with one or more conditions.

The survey results indicate that a wider range of communication methods and environmental changes could improve young people's experiences of healthcare.

It is noted that some respondents provided positive feedback about their experiences.

Young people shared their need to feel safe and more comfortable in doctors or hospital settings, as well as how they have previously been treated differently or unfairly.



This suggests a need to review these areas and include young people's experiences in changes made to improve healthcare settings appropriately.

Targeted Engagement

Interview Key Findings

It was initially challenging to identify ten participants which met the projects target group requirements to take part in the follow-up interviews. However, a few respondents kindly shared the opportunity with their friends and networks, which helped to build momentum and increase engagement. This collaborative effort enabled the completion of the survey and provided valuable insights for the project.

Recognising that the target group has a wide range of needs, participants were offered the choice of completing the questions either by email or through a Microsoft Teams video call, ensuring accessibility and comfort for all involved.

The responses have helped to provide a fuller picture of healthcare experiences and derive some suggested areas of focus and recommendations.

Communication Barriers	Neurodiversity-Sensitive Communication
<ul style="list-style-type: none">• Complex medical language, fast speech, and use of abbreviations made understanding difficult.• Lack of plain English and unfamiliar terminology confused and discouraged participation.• Tone of voice and staff attitude were frequently cited as reasons for distress or disengagement.• Several individuals felt that staff were rushed, inattentive, or dismissive.	<ul style="list-style-type: none">• Most respondents preferred:<ul style="list-style-type: none">◦ Easy Read materials, visual aids, or written notes◦ Yes/No questions◦ Being asked to repeat back information to check understanding• Having a trusted person present (e.g. parent, carer) was commonly requested, although some wanted to be addressed directly first.
Inclusion and Being Heard	Environment Preferences
<ul style="list-style-type: none">• Many young people reported being spoken about instead of to, particularly when with a carer.• Not being included in decisions or explanations made them feel invisible and disempowered.• Several preferred to be spoken to first, with their carers present only for support.	<p>Ideal settings were described as:</p> <ul style="list-style-type: none">• Quiet, low-stimulus rooms• Less bright lights• Same staff each time to build rapport• More time allocated for appointments
Best Experiences	Worst Experiences
<p>Occurred when:</p> <ul style="list-style-type: none">• Staff were patient, friendly, and engaged• Time was taken to explain clearly and check understanding• There was a strong emotional connection or warmth	<p>Included:</p> <ul style="list-style-type: none">• Being ignored, rushed or judged• Staff speaking to carers only• Discriminatory remarks (in 2 cases, related to race or disability)• Overstimulating environments with noise, crowds, and long waits

Recommendations

Adopt Inclusive Communication Practices

- Use Easy Read formats, visuals, and plain language
- Always check understanding using a youth-friendly approach
- Avoid medical jargon and acronyms
- Ensure the **NHS Accessible Information Standards** are being followed effectively

Train Staff in Neurodiverse & Culturally Sensitive Communication

Utilise **learning hub NHS training and resources**.

- Ensure front-line staff are trained to recognise different communication needs
- Address unconscious bias and improve cultural awareness
- Equip staff to communicate with warmth and emotional sensitivity

Design Accessible Appointment Environments

- Offer quiet spaces, more time per patient, and consistency of staff
- Reduce environmental stressors like noise and lighting

Empower Young People in Conversations About Their Care

- Always speak directly to the young person before involving carers
- Ask for and respect their preferred methods of communication

Improve Awareness of Rights and Services

Provide young people with information about:

- Their right to accessible communication
- What support tools are available (e.g. interpreters, advocates, Easy Read materials)

NHS Staff Checklist

Following the interviews, all respondents expressed a desire to support with the creation of a resource to help improve communication.

Initially an informative leaflet was discussed, although it was agreed that a checklist would be more engaging to help NHS staff consider and adapt to varying needs.

The feedback received from those interviewed formed the checklist and the young people reviewed a draft via email and provided feedback to improve the presentation.

There was consensus that the checklist could help to improve the experiences of other young people with similar needs.

Improving Communication with Young People NHS Staff Checklist



Adopt Inclusive Communication Practices

- ☐ Use Easy Read, visuals, and plain language
- ☐ Check understanding using youth-friendly methods
- ☐ Avoid medical jargon and acronyms

Train in Neurodiverse & Culturally Sensitive Communication

- ☐ Recognise and adapt to varied communication needs
- ☐ Address unconscious bias and cultural differences
- ☐ Communicate with warmth and emotional sensitivity (fun/informal approach)

Create Accessible Appointment Environments

- ☐ Offer quiet spaces and longer appointment slots
- ☐ Keep staff consistent for continuity
- ☐ Minimise bright lights, noise, and crowding
- ☐ Provide ear plugs or other sensory aids to help patients manage noisy environments

Empower Young People

- ☐ Always speak directly to the young person first
- ☐ Ask about and respect preferred communication methods
- ☐ Include carers for support — not substitution

Promote Awareness of Rights and Services

- ☐ Provide information about the right to accessible communication
- ☐ Share available tools (interpreters, advocates, Easy Read materials)

Clear, kind, and inclusive communication builds trust, reduces distress, and improves care experiences for all.

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This looks great. Every detail here is important and I believe it will help in the health sectors.

Thank you.

Conclusion

The data highlights both the struggles and the potential for improved, more personalised communication within NHS services.

Small changes in tone, time, and tools can significantly impact how safe, respected, and empowered young people feel when accessing care.

Implementing the recommended actions alongside the NHS staff checklist will have a positive and lasting impact on young people's experiences of healthcare.



By adopting inclusive communication practices, training staff in neurodiverse and culturally sensitive approaches, and creating more accessible environments, healthcare settings can become more welcoming and responsive to individual needs.

Empowering young people to take an active role in conversations about their care helps build trust, confidence, and independence, while greater awareness of rights and available support ensures that no one is left disadvantaged.

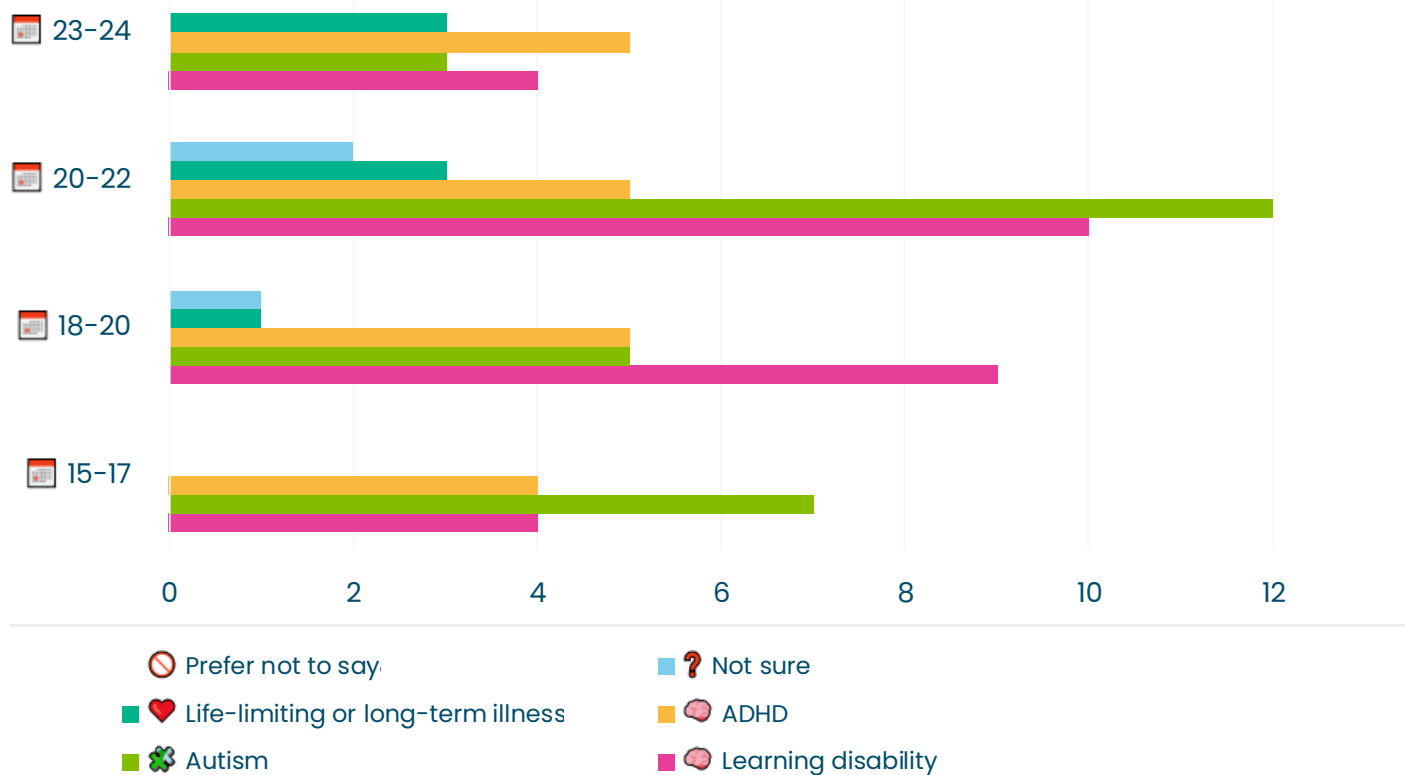


Collectively, these measures will promote equity, understanding, and meaningful engagement – leading to improved outcomes and a more positive healthcare journey for all young people.

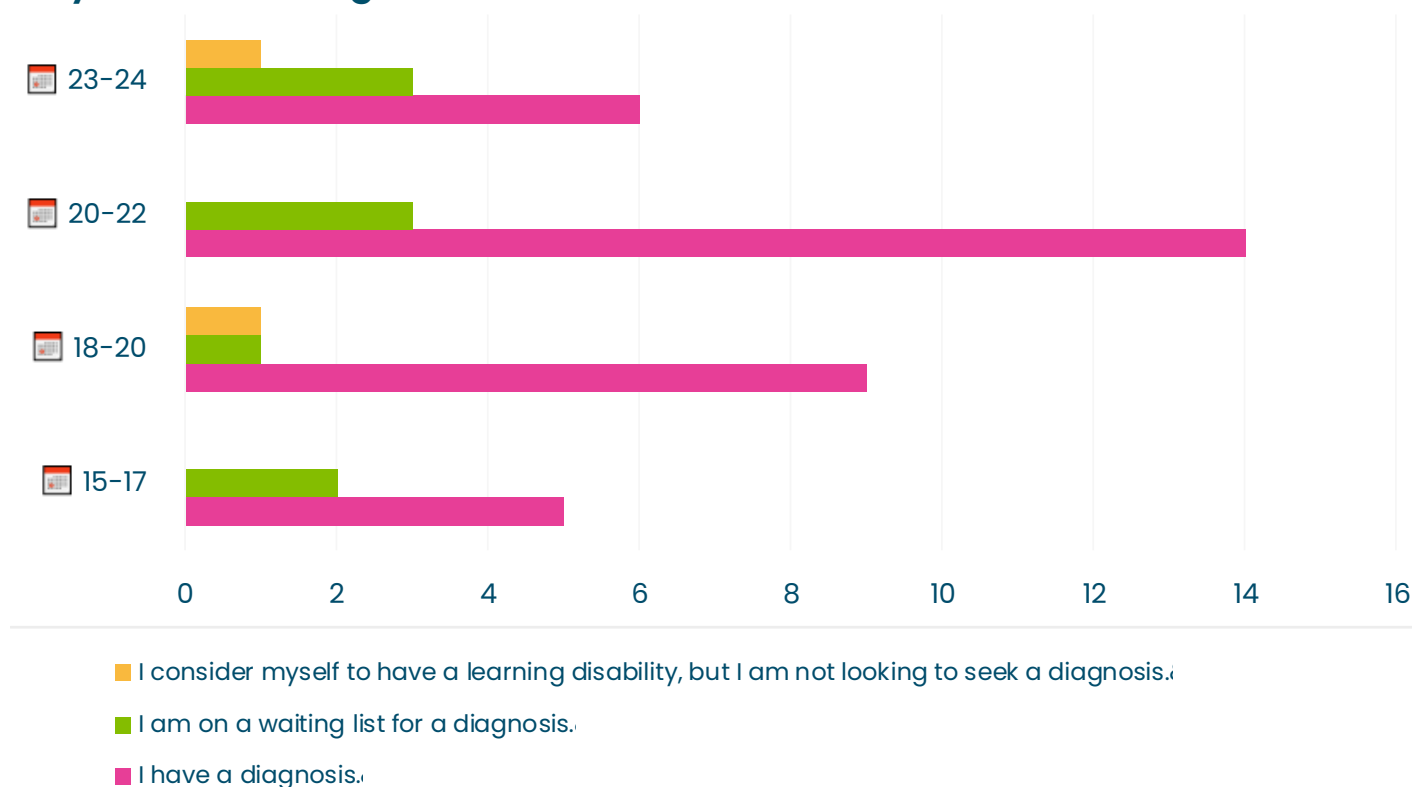
Survey Question Responses

How old are you?

Tick all that apply

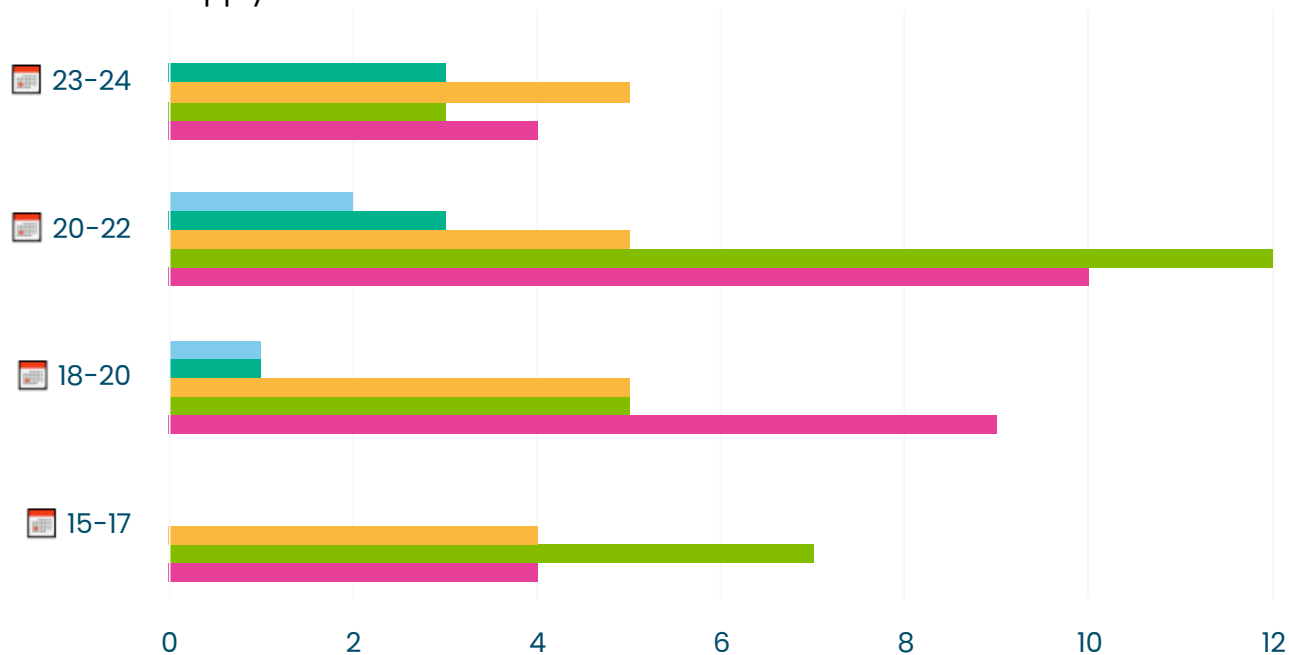


Do you have a diagnosis?



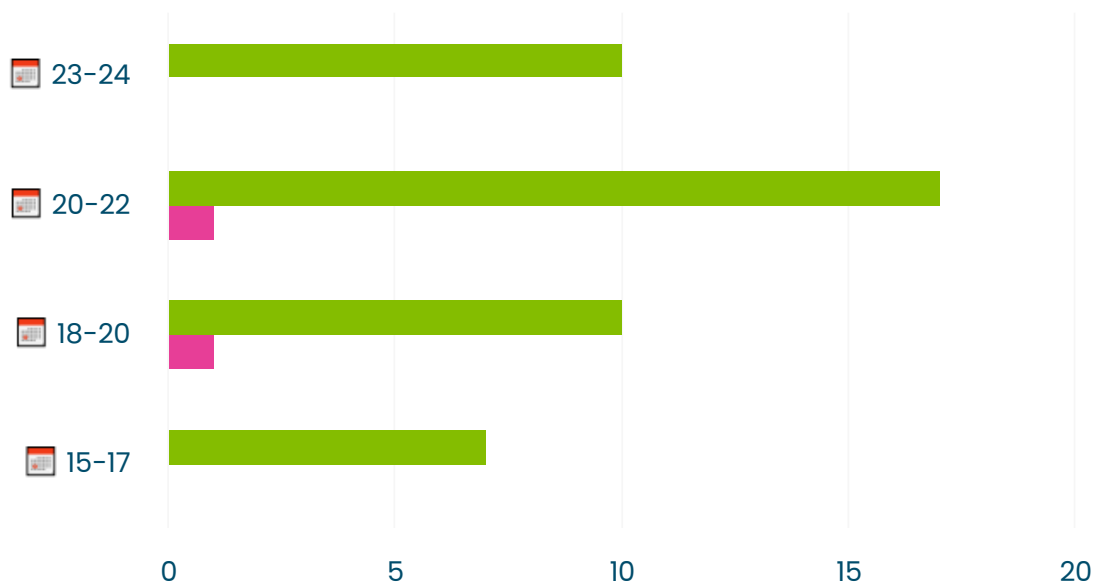
Do you use any of these to help you talk or understand?

Tick all that apply



- Prefer not to say
- Not sure
- Life-limiting or long-term illness
- ADHD
- Autism
- Learning disability

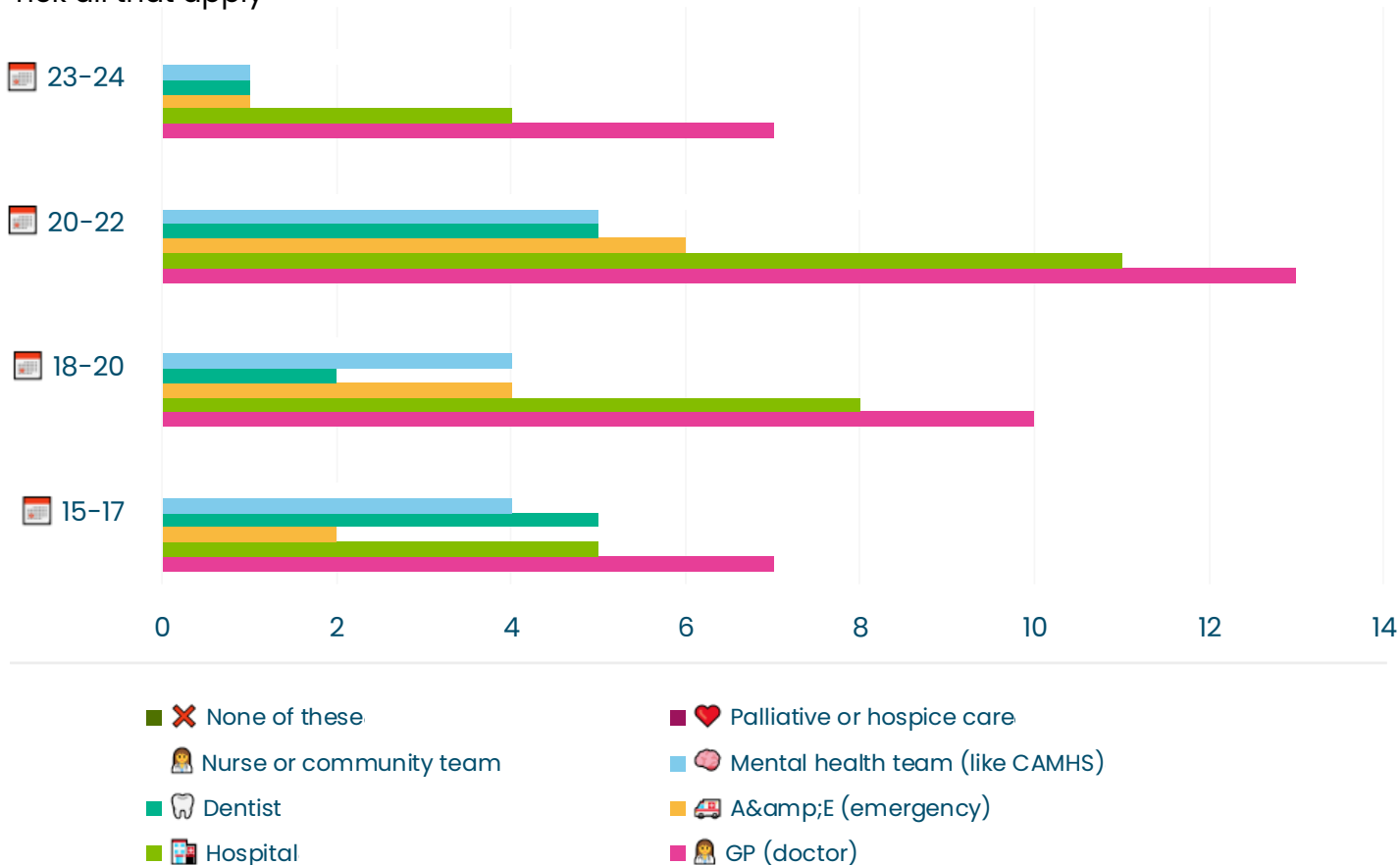
Do you speak a language at home that is not English?



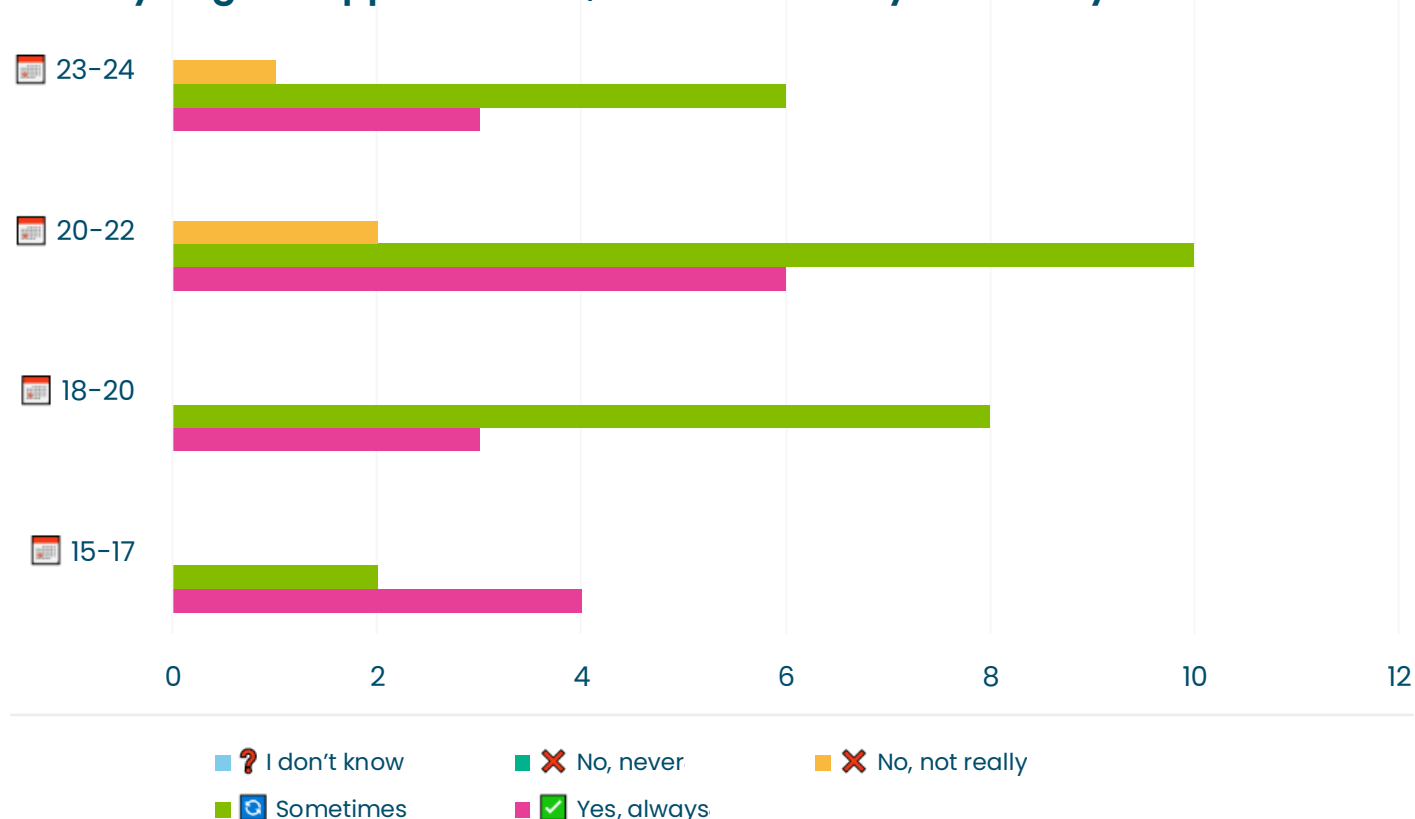
- No
- Yes

In the last year, have you seen or been treated by any of these?

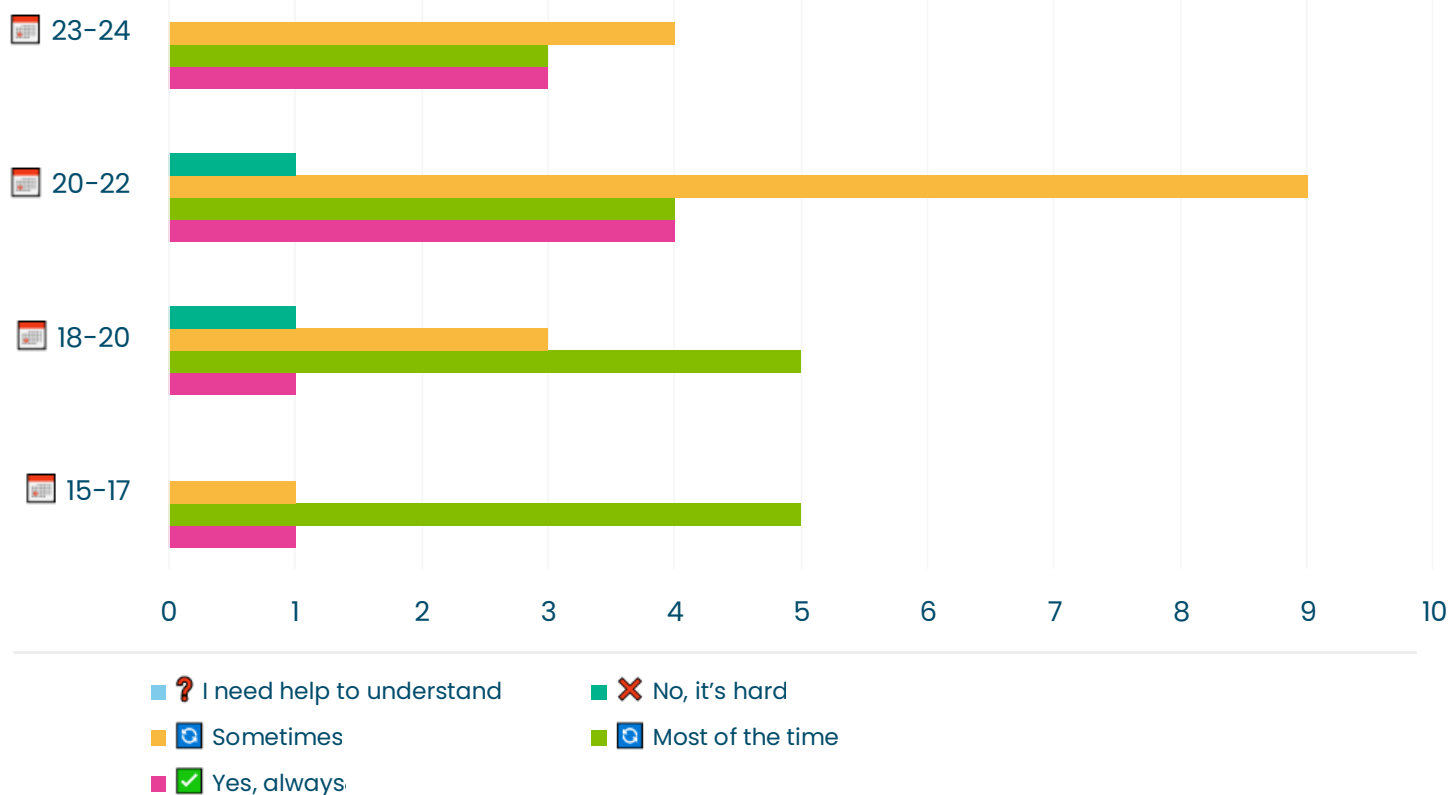
Tick all that apply



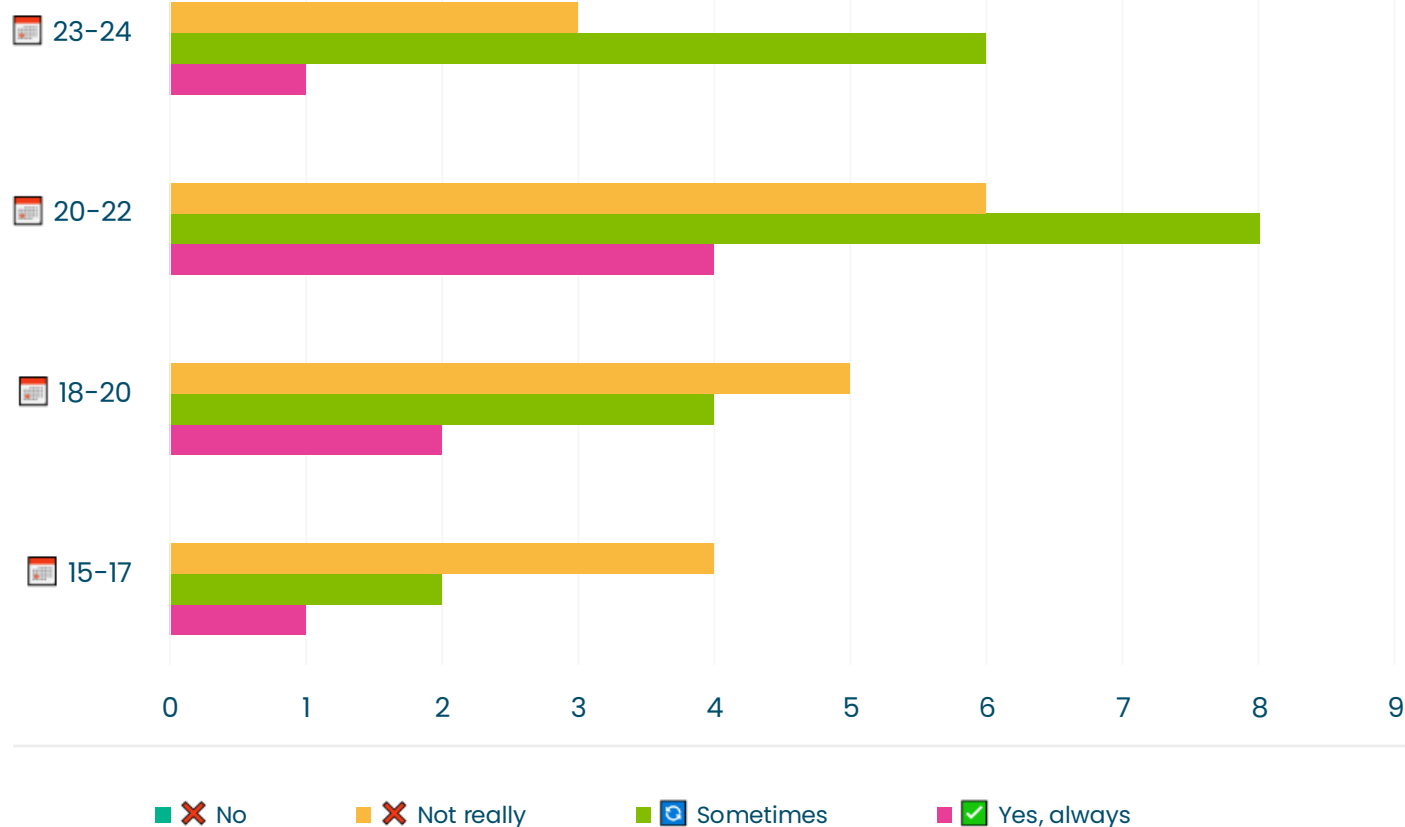
When you go to appointments, do staff talk to you directly?



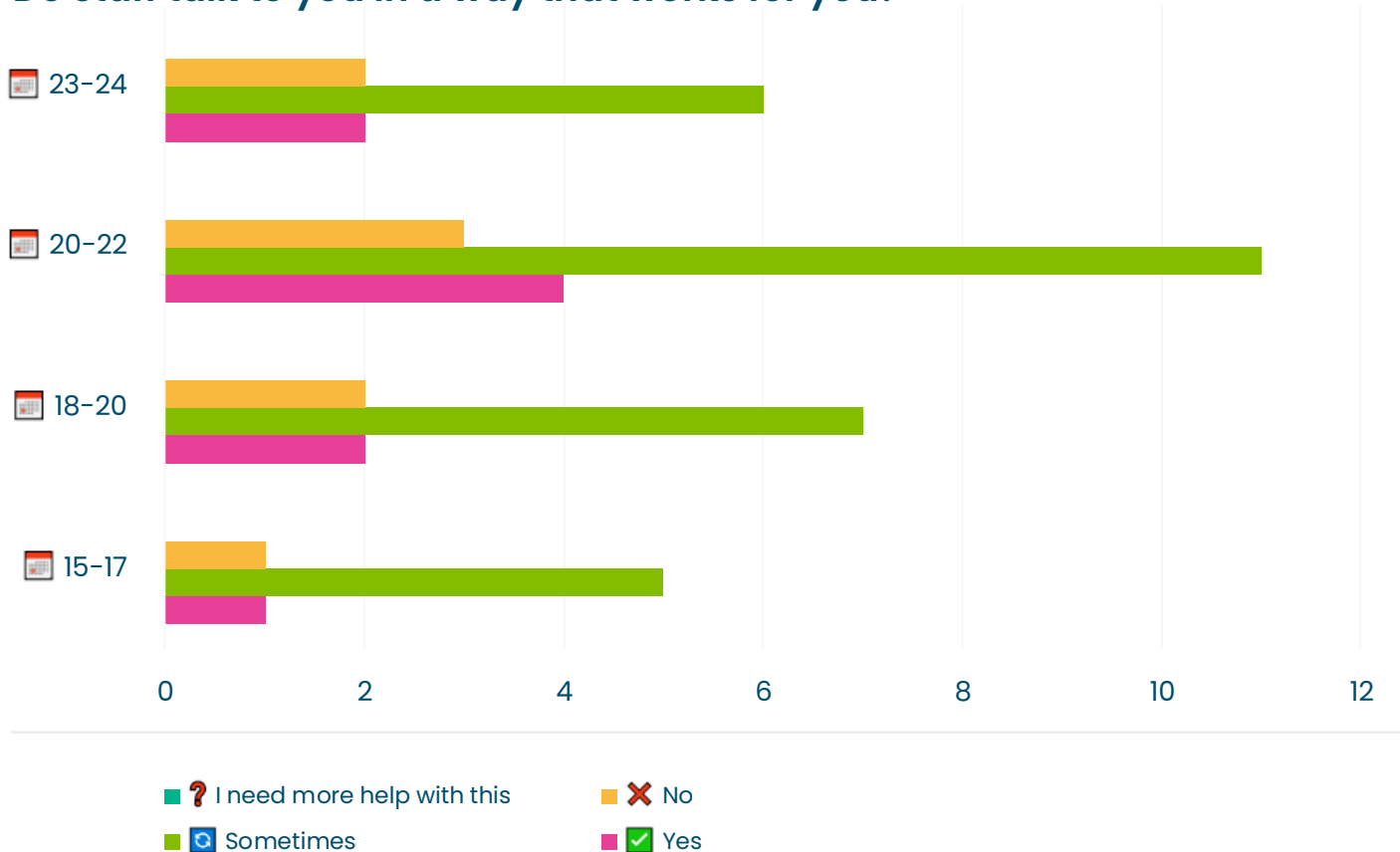
Do you understand what staff say to you?



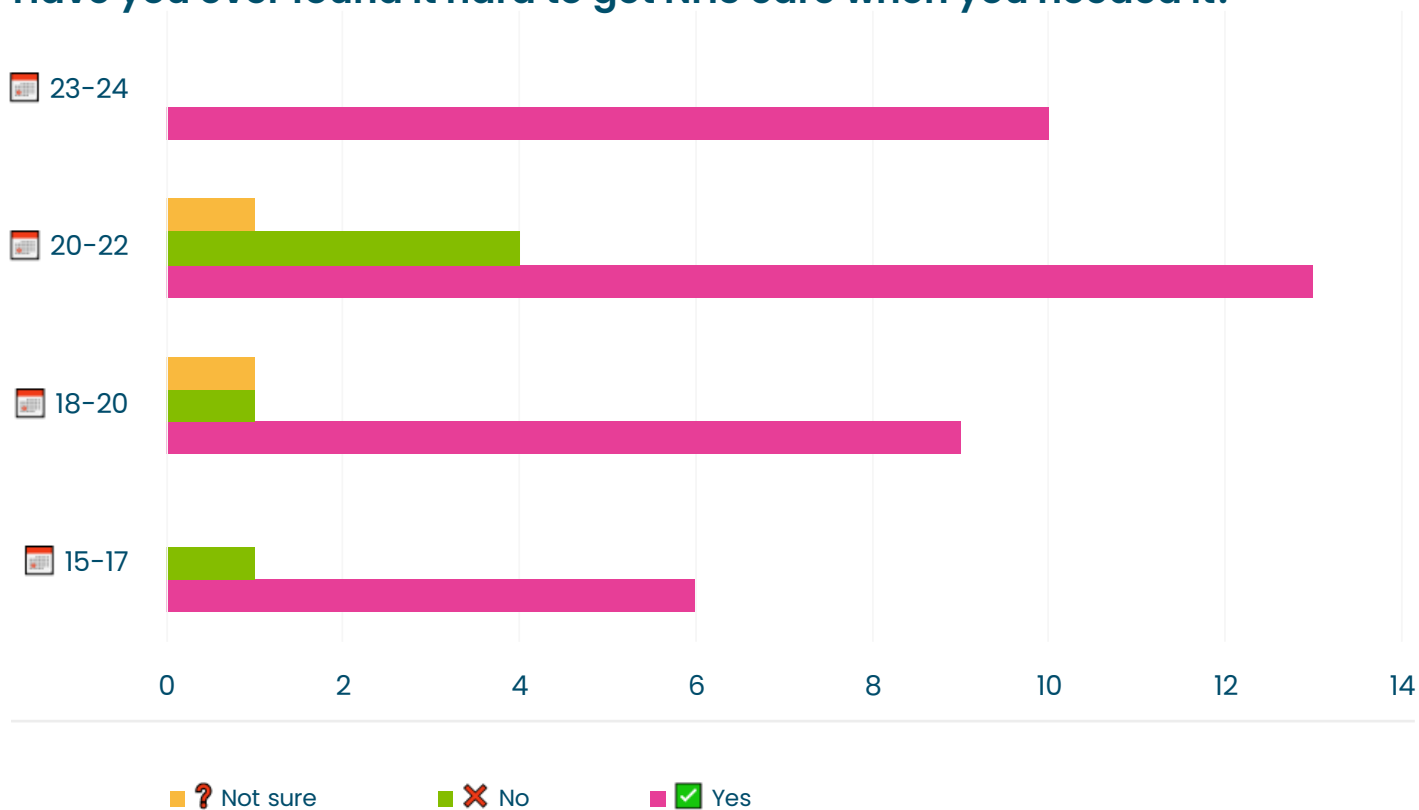
Do you feel listened to by staff?



Do staff talk to you in a way that works for you?

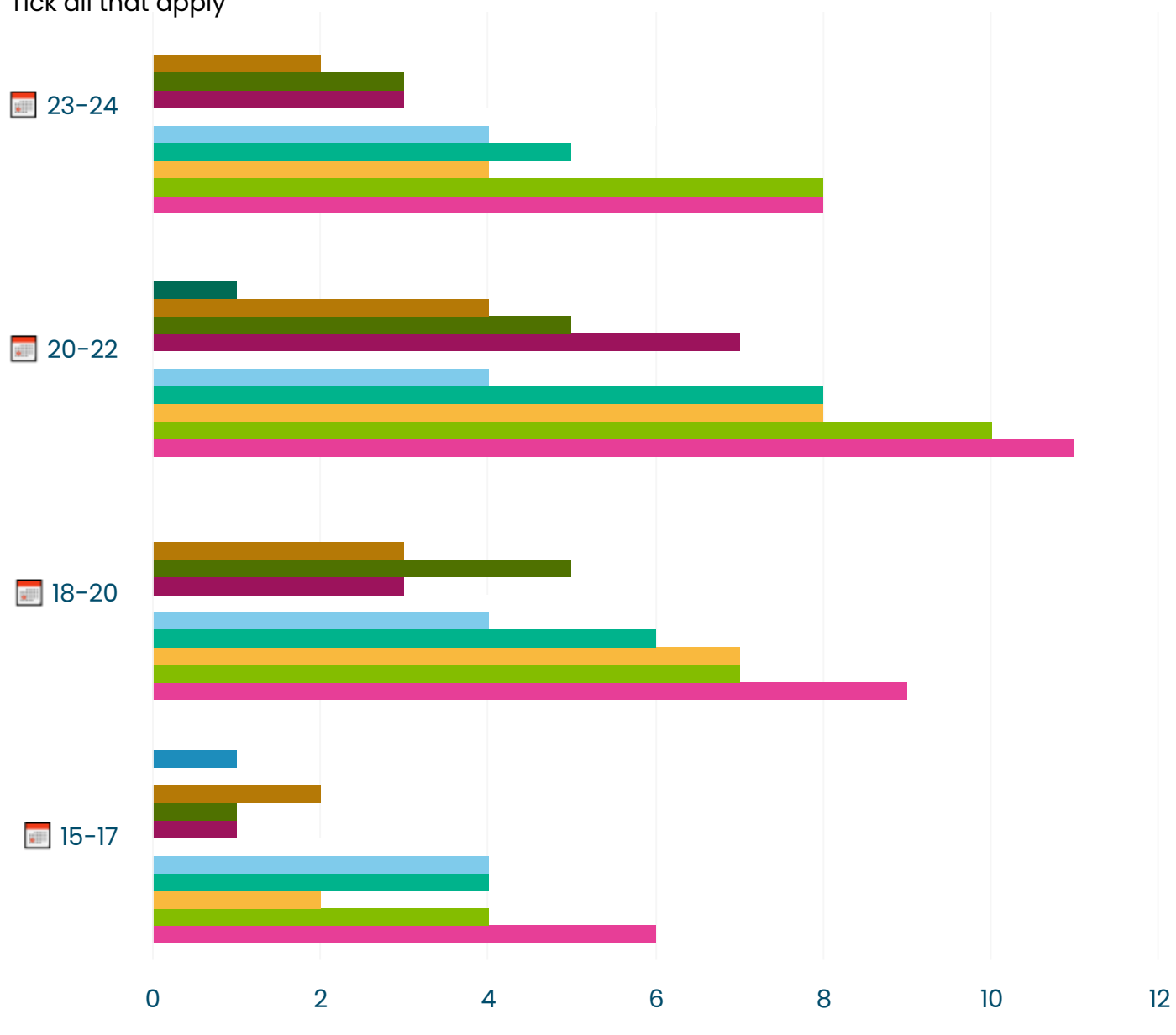


Have you ever found it hard to get NHS care when you needed it?



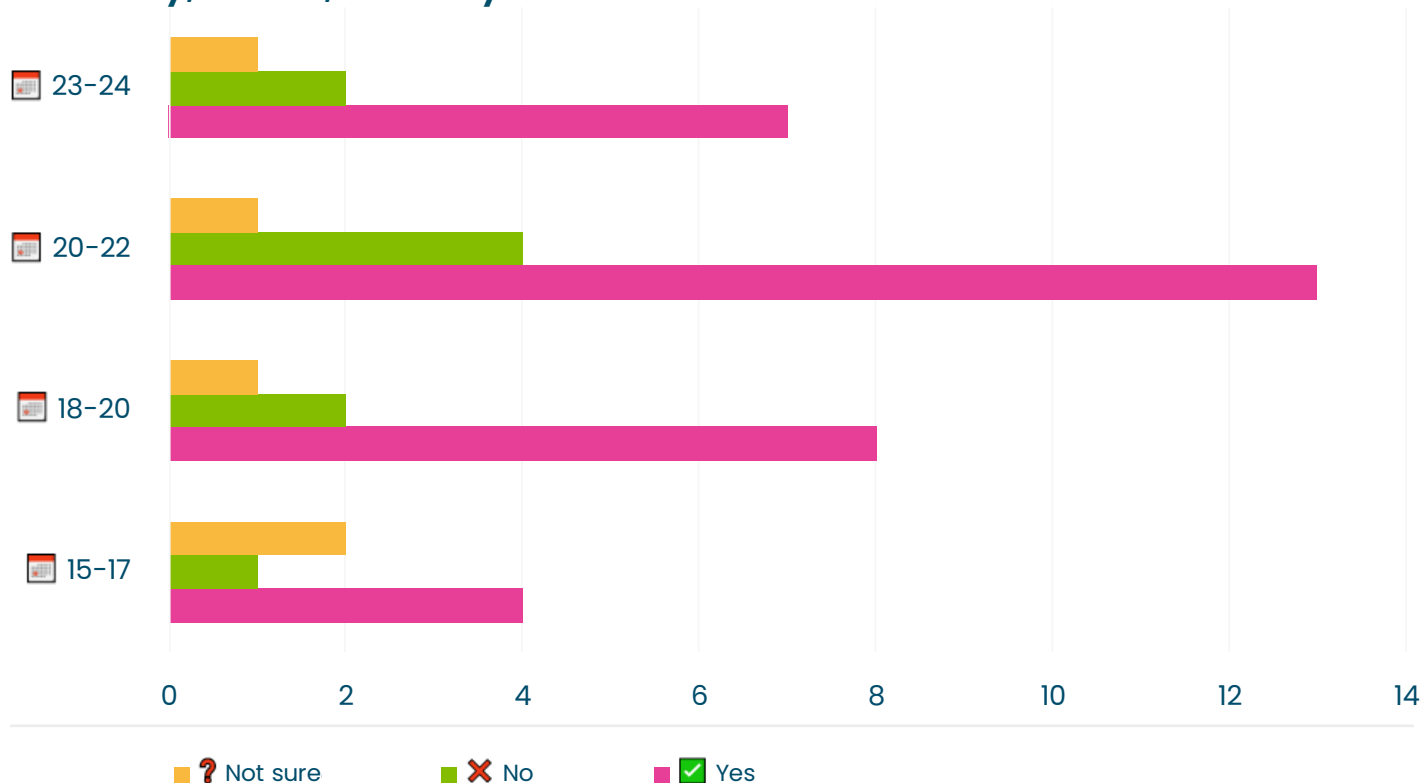
What made it hard?

Tick all that apply



- Other
- It was not hard
- Not sure
- Disability or health condition not understood
- Language or communication issues
- Treated unfairly
- Felt worried or unsafe
- Place was noisy or busy
- Staff didn't understand my needs

Have you ever felt treated differently or unfairly because of your disability, illness, or how you communicate?



What would help you feel more included and understood during NHS appointments?

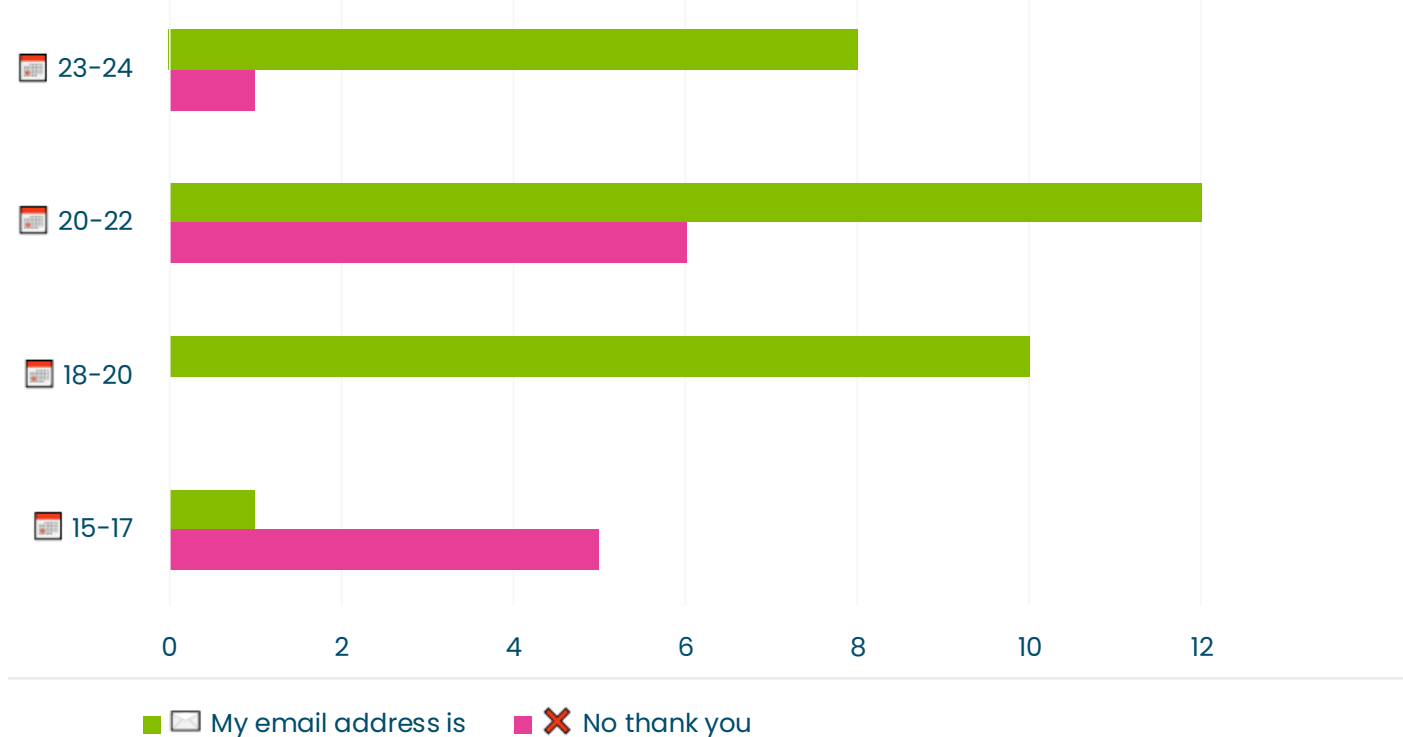
Tick all that apply



What is your ethnic background?



Would you like to share more information?



Interview Question Template



Children and Young People living with learning disability, neurodiversity or life-limiting illness communication survey.

This survey is only for 15–24 years who have a learning disability, neurodiversity (such as autism, ADHD, dyslexia, dyspraxia, tourette syndrome, OCD) or a life-limiting illness (such as Cancer (advanced or terminal stages), Motor neurone disease (MND), advanced heart failure, chronic obstructive pulmonary disease (COPD), end-stage kidney or liver disease).

Completing our survey

If you would like assistance or require a different format, please contact us via: helpdesk@healthwatchwestsussex.co.uk or call 0300 012 0122.

By completing our survey, you will be entered into a prize draw and the winner will receive a £25 One4All gift voucher!

This survey is confidential.

- This survey has been designed to ensure that responses provided are anonymous and cannot be used to identify you. However, there are free text boxes within the survey which we ask you to complete – please ensure you do not include any information which may be used to identify you.
- All questions are voluntary, and information will be used in our reports, updates on our webpage, and through our social media. To inform interested stakeholders, partners and local residents.

Healthwatch West Sussex is committed to protecting and respecting your privacy and security. Any information that you give will be held in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. Our Privacy statement sets out the data processing practices carried out by Healthwatch West Sussex.

We retain and use personal data (information that relates to and identifies living people) to help us carry out our role as the local independent champion for people who use health and social care services. For more information on how we use your information please see our Privacy Policy on our website.





Thank you for taking part!

Your NHS Healthcare Experience

We want to know about your visits to the NHS, like seeing a doctor, nurse, or going to the hospital. Your answers will help make healthcare better for everyone.







About You

1. How old are you?

- ☐  15-17
- ☐  18-20
- ☐  20-22
- ☐  23-24

2. Do you have any of these?

(Tick all that apply)







- ☐  Learning disability
- ☐  Autism
- ☐  ADHD
- ☐  Life-limiting or long-term illness
- ☐  Not sure
- ☐  Prefer not to say

3. Select one:


- ☐ I have a diagnosis.
- ☐ I am on a waiting list for a diagnosis.
- ☐ I consider myself to have a learning disability, but I am not looking to seek a diagnosis.

4. Do you use any of these to help you talk or understand?

(Tick all that apply)

- ☐  Makaton
- ☐  British Sign Language (BSL)
- ☐  Easy Read or pictures
- ☐  Communication device or app
- ☐  Help from someone else
- ☐  Prefer not to say

5. Do you speak a language at home that is not English?









- ☐  Yes
- ☐  No

If yes, which languages:

Your NHS Visits

6. In the last year, have you seen or been treated by any of these?

(Tick all that apply)






- ☐  GP (doctor)
- ☐  Hospital
- ☐  A&E (emergency)
- ☐  Dentist
- ☐  Mental health team (like CAMHS)
- ☐  Nurse or community team
- ☐  Palliative or hospice care
- ☐  None of these

7. When you go to appointments, do staff talk to you directly?

- ☐  Yes, always
- ☐  Sometimes
- ☐  No, not really
- ☐  No, never
- ☐  I don't know




Is there anything further you would like to share with us?

8. Do you understand what staff say to you?

- ☐  Yes, always
- ☐  Sometimes
- ☐  Most of the time
- ☐  No, it's hard
- ☐  I need help to understand

Is there anything further you would like to share with us?

9. Do you feel listened to by staff?

- ☐  Yes, always
- ☐  Sometimes
- ☐  Not really
- ☐  No

Is there anything further you would like to share with us?

10. Do staff talk to you in a way that works for you?

- ☐  Yes
- ☐  Sometimes
- ☐  No

Is there anything further you would like to share with us?

Challenges You Face

11. Have you ever found it hard to get NHS care when you needed it?


☐  Yes


☐  No


Is there anything further you would like to share with us?

12. What made it hard?


(Tick all that help or write your own)

☐  Long waiting times

☐  Hard to get an appointment


☐  Didn't understand what was happening


☐  Staff didn't understand my needs

☐  Place was noisy or busy

☐  Felt worried or unsafe

☐  Treated unfairly

☐  Language or communication issues

☐  Disability or health condition not understood

☐  Not sure

☐  It was not hard

☐  Other

13. Have you ever felt treated differently or unfairly because of your disability, illness, or how you communicate?

☐  Yes

☐  No








☐  Not sure

If yes, what happened?

Making Things Better

14. What would help you feel more included and understood during NHS appointments?

(Tick all that help or write your own)

- ☐  Easy Read or pictures
- ☐  More time to think and answer
- ☐  Seeing the same staff each time
- ☐  Quiet or sensory-friendly spaces
- ☐  Being asked about my needs
- ☐  Help from someone who knows me
- ☐  Nothing

☐  Other

15. What would make you feel safer or more comfortable when you visit a doctor or hospital?

(Optional)

16. Is there anything else you want to say about NHS care and how you are treated?

(Optional)


17. What is your ethnic background?

(Please select one. If you prefer, choose "Other" and describe)


- ☐ White
- ☐ Mixed or Multiple ethnic groups
- ☐ Asian or Asian British
- ☐ Black, Black British, Caribbean or African
- ☐ Arab
- ☐ Prefer not to say


☐ Other ethnic group (please specify):

Would You Like to Share More?

 We would like to hear more detailed feedback from children and young people, between the ages of 15 and 24 years old from Black, Asian and other ethnic minority groups who have a learning disability, neurodivergent needs (such as autism, ADHD, dyslexia, dyspraxia, Tourette syndrome, OCD) or life limiting illnesses (such as Cancer (advanced or terminal stages), Motor neurone disease (MND), advanced heart failure, chronic obstructive pulmonary disease (COPD), end-stage kidney or liver disease).


Sharing your experience can help other young people who need to communicate with the NHS about their healthcare. We can make a positive change to improve healthcare for others.

 If you would like to talk more (whether via email, Teams call, phone call or text messages) and receive an Amazon voucher as a thank you, please share your email address below.

 Your information will be kept private and only used to contact you about this survey.

18. I would like to share more information

(You can ask a parent or carer to help you if need)

☐  No thank you

☐  My email address is:

 Space for writing

Interview Question Responses



Ages:

- 19 years = 4 people
- 20 years = 1 person
- 21 years = 2 people
- 22 years = 2 people
- 23 years = 1 person
- 24 years = 2 people

Conditions:

- ADHD and have a learning disability = 4 person
- Autism and Learning disability = 3 person
- ADHD = 1 person
- ADHD and physical disability = 1 person
- Autism = 1 person
- Physical disability and Dyslexia = 1 person
- Dyslexia = 1 person

Ethnicity:

- Black African = 4 people
- Black = 8 people

"It shows staff are listening by"

Respondents said that is shows staff are listening when:

- They ask them questions (83%)
- Pay attention to just them (8%)
- Have eye contact (92%)
- Write down what they say (58%)
- Giving enough time for them to express their feelings (75%)
- Avoid interrupting whilst they are speaking (8%)

"What makes it easy to understand"

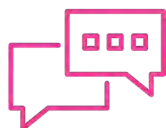
Respondents said that it helps to have:

- Pictures or easy read options (92%)
- Having someone they trust with them (83%)
- When they write things down (58%)
- When staff speak slowly and clearly and repeat information (75%)
- Have assistance from an application/device (25%)

"What makes it hard to understand"

Respondents feel that communication can be hard to understand:

- If a member of staff is too formal or does not use the right tone (33%)
- Use abbreviations, big words or medical terminology (58%)
- Speak quickly (42%)
- Being in a noisy environment (25%)



"I love being around people who make me feel less tense. It's always hard to also understand staff who are not soft spoken and considerate especially with people who have my condition."

"Check understanding by"

Respondents feel that it would help if staff:

- Could check their understanding by asking them directly if they understood (58%)
- Ask them to summarise in their own words (75%)
- Writing things down (50%)

"NHS Services used:"

In the last 12 months, respondents reported that they visited:

- A GP (100%)
- Hospital clinic (100%)
- Dentist (25%)
- Stayed in hospital (50%)
- Been to A&E (17%)
- The mental health team (17%)

"Time when staff did not listen"

All respondents provided an example of when they did not feel listened to in the last 12 months.

The main reasons provided included:

- Staff not paying attention (looking round the room, on their phone, on their computer)
- Feeling rushed
- Asked to repeat themselves
- Being in an open, busy environment

Respondents said that their experiences made them feel bad:

- They were unable to express themselves
- Disappointed about the outcome of the appointment
- Alone and neglected
- Dismissed
- Frustrated
- Unheard
- Overwhelmed



"I had an experience when a staff did not listen to me. I was explaining how I felt and she was engrossed on her phone and gave me very little attention. She made it seem like my problem wasn't a big deal meanwhile I was really down with the issue.

She kept on rushing me to speak faster not minding my disability. She used terms I was not familiar with. The session made me feel like I made a terrible decision and that I would not have gone to seek for such services.

The whole communication process lacked this connection I believe I usually feel when someone is really into helping me."

"Prefer staff to talk to"

All respondents expressed a need to lead on their own healthcare, with many wanting to speak directly with staff and a number of people more comfortable with staff speaking to their carer or parent(s) or to them both.

Due to varying and potentially changing preferences, most young people would like to be asked at the start of each appointment on their preference.

This may change, depending on how they may be feeling on the day in general and environmental factors such as noise/wait times and how this may make them feel.

One Tip to NHS Staff

When respondents were asked to provide one tip to NHS staff, they provided the following feedback:

- 1 Listen more and be more patient. Not to cut person off when they are talking.
Accepting belief of patient – how they feel and understand.
- 2 Accommodating, friendly and provide a good environment and be able to express self.
- 3 Follow up with patients and ask for anonymous feedback about individual staff members seen. Some are excellent and others need training.
Communicate with special needs.
Have the same person – love having a relationship and rapport with staff.
- 4 NHS staff should work on their communication skills. In my case, I like it when a staff is playful with me. You say sweet stuffs that makes me feel at ease.
I would not easily blend if a staff acts too official with me.
Being official is normal but for someone like me. It is necessary to make the space conducive and cool for me.
The staff should not be too fast with a patient, be attentive and must keep their tone in check.
- 5 Giving people like me more time to express ourselves and communicating with the language and tone that we understand.
Prefer NHS staff to use simple words to communicate rather than medical terms.
Prefer a calm tone when someone is speaking to me, rather than being too forward and not friendly.
Making the room lively and keeping a good attitude. This includes being playful and including jokes in communication.
- 6 To have appointments in good places with no crowds, no interruptions, no noise
- 7 Study before meeting and learn from your perspective.
- 8 Pay attention and write down what the person is saying.

9

I'd suggest speaking slowly and clearly, and checking if I've understood before moving on. Also, giving information in simple written form helps a lot.

10

If I had to pick one tip to help NHS staff communicate better with patients like me, it'd be to ask patients how they prefer to receive information.

NHS staff could ask, "How do you like me to explain things to you? Do you want me to write it down, or would you like someone with you to help understand?"

This helps tailor communication to the patient's style and helps patients grasp complex medical information better.

11

Trying to ask questions when necessary, especially to people like me and also to be patient

12

Less appointments.

Reduced people waiting.

More staff.

Summary of tips to NHS Staff to improve communication

How to Communicate Better

- **Listen actively** – don't interrupt or rush patients.
- **Be patient and understanding** – accept people's feelings and beliefs.
- **Use simple, clear language** – avoid medical jargon; speak slowly and clearly.
- **Check understanding** – ask if the patient has understood before moving on.
- **Adapt communication** – ask how each person prefers information (spoken, written, with support, etc.).
- **Use a calm, friendly tone** – avoid being too official or rushed.
- **Be approachable and kind** – a little playfulness, humour, and warmth help patients feel at ease.
- **Give people time** – to express themselves, especially those with special needs or communication difficulties.

Building Relationships

- **Consistency matters** – seeing the same staff helps build trust and rapport.
- **Follow up** – check in after appointments and gather anonymous feedback about individual staff.
- **Work on communication skills** – some staff are excellent communicators; others may need more training.

Environment and Practicalities

- **Create a comfortable space** – quiet, uncrowded, and without interruptions.
- **Be attentive** – take notes, pay attention, and show patients they're heard.
- **Prepare in advance** – learn about the patient's needs before the appointment.
- **Appointments and waiting times** – ensure enough staff to give proper attention and time.

In short

Young people want NHS staff to **listen, be patient, kind, and adaptable**, using simple language and a friendly approach in calm, comfortable settings. They value consistency, follow-up, and communication that meets their individual needs.



Talk to us

If you have questions about the content of this report, please either call 0300 012 0122 or email cheryl.berry@healthwatchwestsussex.co.uk

How this insight will be used?

We recognise that all health and care services are under pressure at this time and have had to adapt their ways of working. We will share this report with the local NHS, Local Government, and other providers to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps. We see this as a continuation of discussions taking place and will continue to use this fresh insight and the solutions presented to challenge for a better future.

For help, advice, and information or to share your experience

We also help people find the information they need about health, care and community and voluntary health and care support services in West Sussex.

Here to help you on the next step of your health and social care journey



You can review how we performed and how we report on what we have done by visiting our website www.healthwatchwestsussex.co.uk



Healthwatch West Sussex works with **Help & Care** to provide its statutory activities.

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