Understanding people's experiences of accessing support for ADHD

September 2025

healthwatch Gloucestershire

Contents

About Us

Healthwatch Gloucestershire is the county's health and social care champion.

We're here to listen to your experiences of using local health and care services and to hear about the issues that really matter to you. We are entirely independent and impartial, and anything you share with us is confidential. We can also help you find reliable and trustworthy information and advice to help you to get the care and support you need. As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care. This report is an example of how your views are shared. Healthwatch Gloucestershire is part of a network of over 150 local Healthwatch across the country. We cover the geographical area of Gloucestershire County Council, which includes the districts and boroughs of Cheltenham, Cotswold, Forest of Dean, Gloucester, Stroud, and Tewkesbury.

Background

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental condition characterised by difficulties with concentration, energy levels, impulsiveness, or a person's ability to manage their time.

Recently, there has been a massive rise in demand for assessment, diagnosis and support for ADHD. As a result of local Healthwatch raising concerns with Healthwatch England about the state of ADHD services, they commissioned YouGov to run two rounds of polling about adults' experiences of ADHD. They also ran their own survey, asking people with both diagnosed and possible ADHD to share their experiences: www.healthwatch.co.uk/report/2025-05-28/how-improve-adhd-support-people

The following findings show what respondents living in Gloucestershire wanted to say about their experiences of accessing support for ADHD which largely reflect the findings of the national report.

Key messages

- The impact that ADHD has on people's lives can be profound, affecting work, relationships and day to day functioning, often resulting in people experiencing poor mental health.
- Getting an ADHD diagnosis can be life-changing – giving people a better understanding of themselves and access to medication, and improving their ability to manage their health and wellbeing.
- Despite requesting a Right to Choose pathway, choice of provider in Gloucestershire is very limited, and people are still being told that the waiting list is between two and five years long.
- People want support while they wait for an ADHD assessment, but most aren't getting any.
- Some people are put off from seeing their GP to get a referral to an ADHD assessment because of concerns about being overwhelmed and the long wait times involved in getting an assessment.
- People with ADHD or suspected ADHD can be reluctant to speak to their employers about support. Those that had, felt that their employer could not meet their needs in a meaningful way, highlighting a lack of practical support.

Recommendations

To improve access and provide more consistent support to those waiting for assessment, we have called on NHS decision-makers to:

- Move ADHD assessments to the community. This includes providing NHS teams with the training and resources they need to deliver care closer to people's homes. This shift will require collaboration between NHS, social care, education, employment and criminal justice stakeholders.
- Provide better and more consistent support to people waiting for ADHD assessments, including keeping people updated with clear and accessible communication from the NHS. Experts by Experience should be included in developing this support.
- Provide easily accessible information about statutory and VCSE services that can offer counselling, peer support and life coaching.

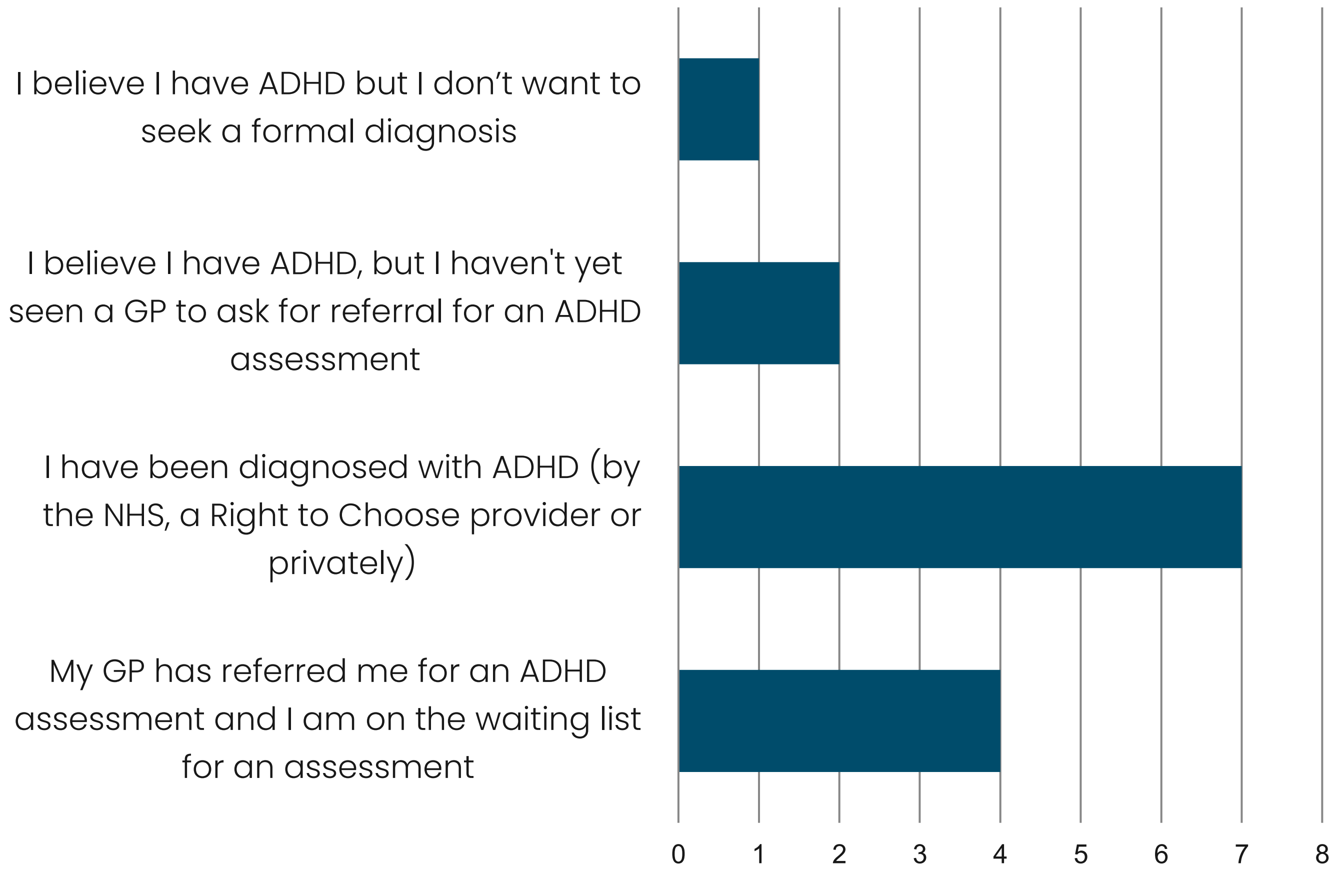
- Explore options to increase the number of providers that can carry out assessments under a Right to Choose pathway.
- Improve employers' support for those with ADHD through raising awareness and training, and proactive offers of reasonable adjustments.

Who we heard from

14 respondents to the national survey lived and accessed services in Gloucestershire. Demographic information is included as Appendix 1.

ADHD Status

People were asked to describe their ADHD status. Seven had received an ADHD diagnosis, four were on a waiting list for an assessment having been referred by their GP and three believed that they had ADHD but had not requested a referral for assessment through their GP or had not sought a formal diagnosis.



What we found

The following findings are laid out according to ADHD status.

I believe I have ADHD, but I haven't yet seen a GP to ask for referral for an ADHD assessment/ but I don't want to seek a formal diagnosis

Two respondents gave the following reasons for not asking their GP for a referral for assessment:

> "The process of getting a normal GP appointment is difficult - it's a telephone lottery every morning and I get stressed - so it feels like I'm asking too much to be seen for something non-emergency. I have got a GP appointment for next week though and I'm hoping to start the process"
>
> "Not sure what's to gain from it"

A further respondent had chosen not to seek a formal diagnosis for the following reason:

> "I am a female in my 50s and know how long it can take to get a diagnosis as an adult. I believe I have inattentive ADHD and understanding what this means for me has helped me make sense of why I have reacted to things throughout my life. Now things are making sense I am happy not to seek a formal diagnosis."

My GP has referred me for an ADHD assessment, and I am on the waiting list for an assessment

The 4 respondents that were on a waiting list were asked what impact this was having on them:

> "Being unable to access right to choose or shared care so that you can access shorter waiting time. Found a provider but GP would not refer as Gloucestershire ICB has its own rules. In the meantime, in limbo waiting for an assessment which could be up to two years whilst trying to negotiate further education and movement into a degree"

“Been told it's a five year wait. I'm in my early fifties and had NO idea about ADHD until I stumbled across an article and it has changed my life. In some ways much makes sense now and I am trying to regulate all sorts of elements of my life. In other ways, knowing is making it harder. I am too often falling apart and am going to have to give up my job. Suffering from burnout, unmasking and overwhelm.”

“Have ground to a halt in every aspect of my life and can barely function”

“I've had huge struggles with my mental health including dozens of suicide attempts over last 7 years. ADHD was never even mentioned by health professionals until I did online test and realised that this was the probable cause. Had to fight to get referred for assessment. Been on list 3 years and no sign of assessment. This has caused issues all my life.”

These comments highlight significant issues being faced by people in terms of their mental health and day to day functioning, which is compounded by the long waiting times for an assessment. However, when asked if they had received any support while on the waiting list for an assessment, all 4 respondents said they had not.

The impact of the lack of support was explored further:

“It is more about getting a diagnosis so that you can then get support.”

“Health and relationships are key and taking all my time and energy right now. It's devastating being told I have to wait Five Years, and I'll have to bring a parent along ?!?!”

“Condition worsened considerably. Was made unemployed in no small part due to condition”

“Severe anxiety and depression with suicidal actuation. Have had considerable input from mental health teams but has been 7 years of misery and still going.”

The survey asked the respondents to describe what kind of support they felt would be useful for them to have:

“You can use right to choose and shared care for any other avenue of healthcare. But when it comes to mental health, shared care then becomes an issue.”

“Trauma therapy, ADHD life coaching”

“To be believed and not treated like I'm jumping on the bandwagon for the sake of it. It would help to have some idea of timeframes but have only had 1 letter in all that time.”

Regarding what the communication had been like with services, there was mixed responses:

“The service has been very good with updates.”

“Awful. I asked for right to choose, was told it would be 6 months. Then I received a text message letting me know it would be five years! I had a letter saying sufficient information was received to have me assessed but it's a long wait and don't expect to hear from us anytime soon. I asked my Dr if I'm still on right to choose, he said I'd get an answer within 24 hrs. Three weeks later I rang to ask, two days later I received a text I couldn't open (had to forward to someone else's computer) which is a copy of a letter I was sent in October and not the answer to my question.”

“Only one letter confirming I'm on the list. Nothing since then. Have no idea how long it will be. Not offered any other support or signposted to any other help.”

One of these 4 respondents had asked their GP to refer them to a provider based on a Right to Choose pathway however this had been declined, stating that there are guidelines for GPs depending on where you live.

“Have had to carry on with a provider of GP choice with very long wait. Disappointing to ask for help, done all the leg work to find a provider yourself then get told no.”

I have been diagnosed with ADHD (by the NHS, a Right to Choose provider or privately)

In contrast, the 7 respondents who had received a diagnosis of ADHD shared the difference it had made to their lives:

"Being diagnosed with ADHD at 36 has changed my life. It's made me learn so much about myself and improved my ability to concentrate at work 10-fold."

"It really helped me feel validated after suffering mental health difficulties for decades. I can now understand myself and my behaviour and use coping skills to make life easier."

"Allows me to be kinder to myself. To accept that I need to set reminders for everything, to understand why I have a strong sense of injustice, which I take things personally etc"

"Absolutely life changing. Medication has meant that I have been able to start building and normal and potentially happy life rather than being constantly burnt out and in crisis."

"After diagnosis and medication, it felt like switching to 'Story Mode', when you've been fighting by the skin of your teeth on 'Ultra Hard Mode', for your whole life. I felt a stillness that I have never before experienced. I could hear my thoughts for so much more time, and with such improved clarity. I was less exhausted, because I wasn't constantly moving in some way. I was able to re-frame past experiences, and come to terms with how my undiagnosed self, has played on 'Hard Mode', for all of those difficult, damaging, decades."

"I've been crippled by my ADHD my whole life. My dopamine chase has led my weight to creep up to 138kg. I've had to have a stomach bypass a year ago. I've got fibromyalgia, other comorbid conditions, have been wrongly medicated as my symptoms were not recognised by the GP as they do not have the training to connect the dots. They only look at a problem as an isolated issue, rather than look for the bigger picture."

"Before my assessment and diagnosis, I was suicidal. Getting a diagnosis helped me to not only understand but also accept myself. The biggest impact has been on my health and wellbeing. I now have a better understanding of burn out / hyperfocus cycles and allow myself to rest without guilt. I have completed an MA since my diagnosis. I needed medication to enable me to retain focus and manage my anxiety. There is no way I could have completed this without the diagnosis."

Impact of ADHD

All 14 respondents were asked to describe the impact that ADHD had on their lives and there were many common themes that became apparent:

“My quality of life has been greatly affected as has that of my children.”

“Really struggle to remember things - appointments, meetings, and anything outside of the normal weekly routine is difficult.”

“Struggling with emotional regulation difficulties means I struggle to keep friends.”

“Struggled to get through GCSE’s. Finding it extremely difficult to navigate interviews currently. Really want to do a degree apprenticeship but can’t get organised or motivated”

“My job is crumbling and I am letting myself and others down.”

“Everything is disorganised and messy and I feel like I can't cope. I've got a degree in fine art but I find the idea of running a business from that unrealistic and overwhelming so I work minimum wage in a craft shop I am often depressed and lonely.”

“Relationships, family members moods drastically effect mine, can’t tell people how I feel.”

“I have been told that I come across as unapproachable - this has been upsetting as I feel I am a fair and honest person. I have had to work hard to improve my people skills.”

“I have noticed that I stim quite a lot particularly rubbing my fingertips together and hair twirling.”

“I’ve been successful but at the expense of my physical and mental health as everything has felt a huge effort, like wading through treacle. My mental health was awful despite working really hard in therapy- turns out all I needed was medication to treat my ADHD- my anxiety disappeared instantly when I started medication.”

Impact on Employment

Respondents were asked whether they had requested reasonable adjustments at work. Only three had spoken to their employers. Those that hadn’t requested reasonable adjustments gave the following reasons:

“Currently at college. I don’t have a diagnosis so can’t access exam changes”

“I told last employer, was let go within 2 weeks”

“I feel like I should be capable because I'm intelligent, and for the most part in my low difficulty job, that's fine. I don't progress.”

“I feel it’s my problem, I need to sort this, I need to try harder to overcome”

“To be honest unless I present proof of formal diagnosis of ADHD my line manager will not support any requests for reasonable adjustments.”

“It’s been a turbulent time in the business and I’ve changed department and line manager at the same time I was privately diagnosed. HR is understaffed and has other bigger fish to fry at the moment”

The 3 respondents who had spoken to their employers highlighted a lack of practical support, even if their employers were well meaning and understanding:

“I often get the same old “you’re the problem” or “we cannot disadvantage others by making your life easier” which is ridiculous as I don’t want an easier life, I want a level playing field.”

“Employer has good intentions but no idea how to actually support people. Provision of Ras (reasonable adjustments) is slow to non-existent. Because I work in the civil service I cannot access the government’s Access To Work scheme and receive less support than friends working in the private sector who can apply to this fund for support.”

> “Sensitive, kind and understanding, but no practical help. IT is a total pain and I've asked for help. The work is becoming overwhelming.”

One person felt that they did not need reasonable adjustments made and two people were self-employed:

> “I am the founder and owner of a company. This one is currently 2.5 years old.”

People were asked if they would like to comment further on their experiences of ADHD

The responses can be categorised into demands on a person’s mental and physical health, issues with Right to Choose and Shared Care Agreements, and a lack of understanding on the part of healthcare professionals.

Mental and Physical health concerns

> “It sucks, I'm physically, mentally and emotionally exhausted from it”
>
> “Everyone presenting with mental health issues should be reviewed for both asd and adhd. This currently has never happened with me even when I advised I was sure I had both, despite a family history of both in subsequent generations”
>
> “Thinking about it categorically like this is very upsetting for me. It's hard to fight your corner when it brings you to tears. I think just not knowing whether medication would help is the worst thing - I want to try to make things better.”
>
> “Before being diagnosed and medicated privately for ADHD, I did suffer with anxiety and mild depression. This has now been resolved”
>
> “We always mask. And, we are exhausted, stressed, and depressed.”
>
> “Untreated ADHD was clinically indistinguishable from anxiety/depression/cPTSD for me. Conventional therapies for those conditions

were never going to work for me and so much time and money was wasted trying. Had I been able to access a diagnosis sooner, or had someone been looking out for me as a child/ young person, my life would have been immeasurably different.”

“I didn’t understand that I’ve always been highly anxious until I took ADHD medication and I noticed it by its absence. I hide who I am a lot professionally to get by as there is a lot of judgment against ADHD.”

Issues with Right to Choose and Shared Care Agreements

“With the NHS waiting list so long I sought a private diagnosis for myself and my teenage daughter. I would like to try medication and give that option to my daughter, but my GP surgery won’t accept the private diagnosis so i would need to pay privately. I therefore need to pursue an NHS diagnosis - why not accept the private diagnosis to save NHS resources and avoid adding to already long waiting lists?”

“Also it’s incredibly frustrating that my county only allows shared care with PsychiatryUK. I sought a private diagnosis due to being in crisis and unable to wait 18months, yet whilst some GPs do shared care with my provider, mine won’t (ADHD people are easy targets for GPs who want to decline work to make a point about their funding - they’ve told me as much), so I now need to wait 12-18months for a second, repeat NHS assessment, at the taxpayer’s expense, so my GP can delay taking on this official workload. In the county next door, other right to choose providers have wait times of as little as two weeks, and offer shorter, reduced cost assessments for people with an existing diagnosis. But Gloucestershire ICB and GPs block people from accessing this life-saving care because they can’t be bothered to engage or innovate.”

A lack of understanding of ADHD

“Finding out new things every day. The current system is absolutely not fit for purpose. It is ageist and sexist. Some doctors have zero understanding of the condition. Its name needs changing, we have dysregulation - both over and under.

Hard things: sensory overload, directional dysregulation (directions), tired and 'peopled out', overwhelm / burn out, finding easy things hard, anxiety, masking, procrastination, total chaos; surroundings and busy mind too, self doubt

The super power side can be amazing; hyper focus, intuition, sensitivity, connection to nature and animals, creativity, finding some hard things easy, childlike understanding / appreciation, gentle/ compassionate, quirky / eccentric, spotting neurodivergence in others

Fully understand that the NHS is at breaking point, that the funding isn't there and neither are the numbers of clinicians needed to address the backlog, especially as awareness spreads and the fast paced, consumer world makes it harder and harder for us to fit in. I am reading everything I can and am particularly interested in the large number of women finding out during perimenopause / menopause.”

Stakeholder response

One Gloucestershire Integrated Care System

Dr Mala Ubhi, Clinical Lead for All-age Mental Health, Neurodivergence, Learning Disabilities and Inequalities, NHS Gloucestershire

Dr Becky Parish, Associate Director, Engagement and Experience, NHS Gloucestershire ICB

Thank you to Healthwatch Gloucestershire (HWG) for giving NHS Gloucestershire Integrated Care Board (ICB) the opportunity to provide a stakeholder comment for inclusion in the published Healthwatch Gloucestershire report entitled: Understanding people's experiences of accessing support for ADHD in Gloucestershire. Please find our comments below:

We welcome the insight presented in this report and offer the following comments:

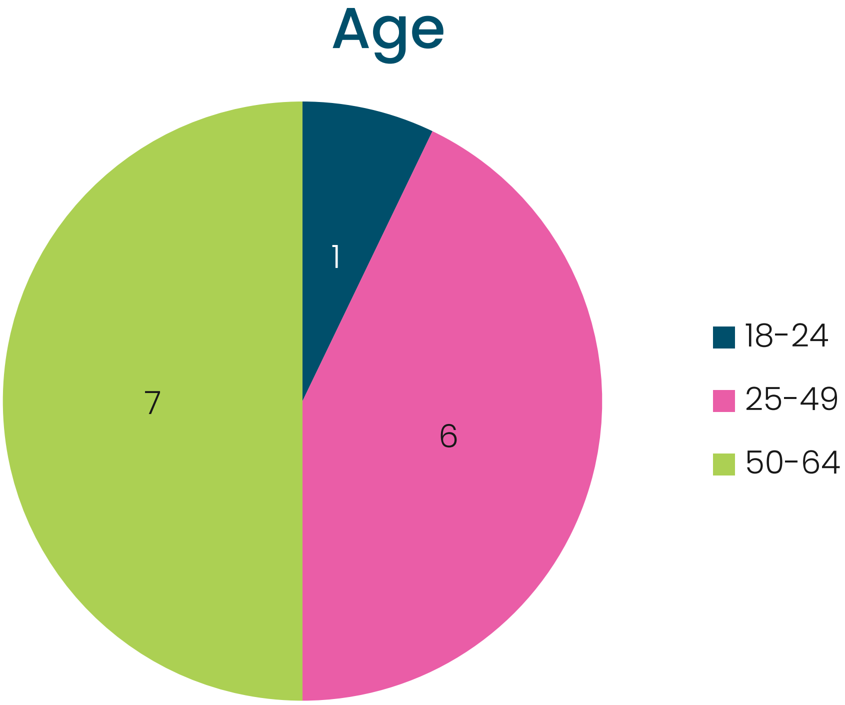
- We understand the difficulties for people seeking ADHD diagnoses in Gloucestershire and understand this reflects the national picture.
- We note that there is overlap between the recommendations within the HWG report with NHS England's ADHD Taskforce Interim Report. All recommendations are being discussed by healthcare partners across the One Gloucestershire system.
- We would like to take this opportunity to draw attention to the support that is currently available whilst individuals wait for their specialist appointment through Firstly, there is The Owl's national offering: https://www.waitingwell.co.uk/ as well as a local Neurodiversity website commissioned by the ICB: https://www.ghc.nhs.uk/our-teams-and-services/children-and-young-people/camhs/support-a-childs-neurodiversity/. This website is designed for children and young people but much of the information may help young adults and families with much of the information being relevant for adults too. In addition there is information about wider support available, e.g. local advocacy groups on Your Circle https://www.yourcircle.org.uk/. Finally, the local Partnership Board also has information about local support available: https://www.gloucestershire.gov.uk/health-and-social-care/disabilities/autism-and-neurodivergence-partnership-board/
- We are working together with system partners to improve the process THROUGH the new self-referral pathway for adults to Gloucestershire Health and Care NHS Foundation Trust. The improvements enable adults who are suspecting ADHD to bypass a GP appointment. Children and young adults are

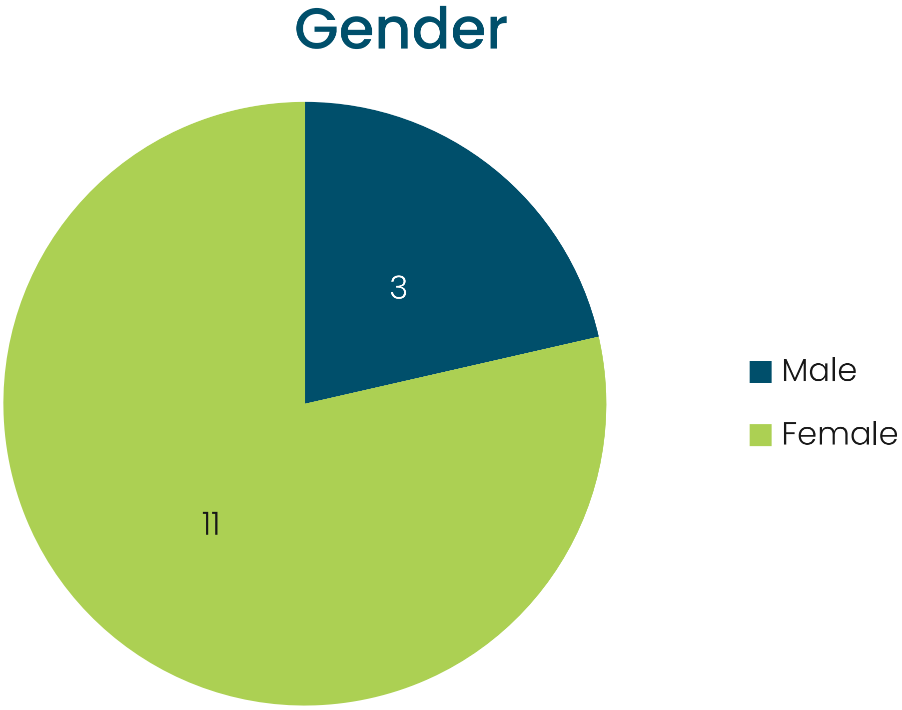
already able to bypass a GP appointment as schools and their SENDCo can access the referral pathways directly.

- All patients seeking ADHD diagnoses, if they meet the pre-assessment criteria, have the Right to Choose. There is a non-exhaustive list of providers on the ADHD UK website. Many Right To Choose assessments offer a remote option which does not inhibit access based on geography.
- Individual issues with GP access or referrals should be raised with the individual GP surgery in the first instance. The ICB Patient Advice and Liaison Service (PALS) can also offer support to individuals.
- We look forward to working with Healthwatch Gloucestershire over the coming months as we work to understand the experience of people accessing support for ADHD in Gloucestershire.

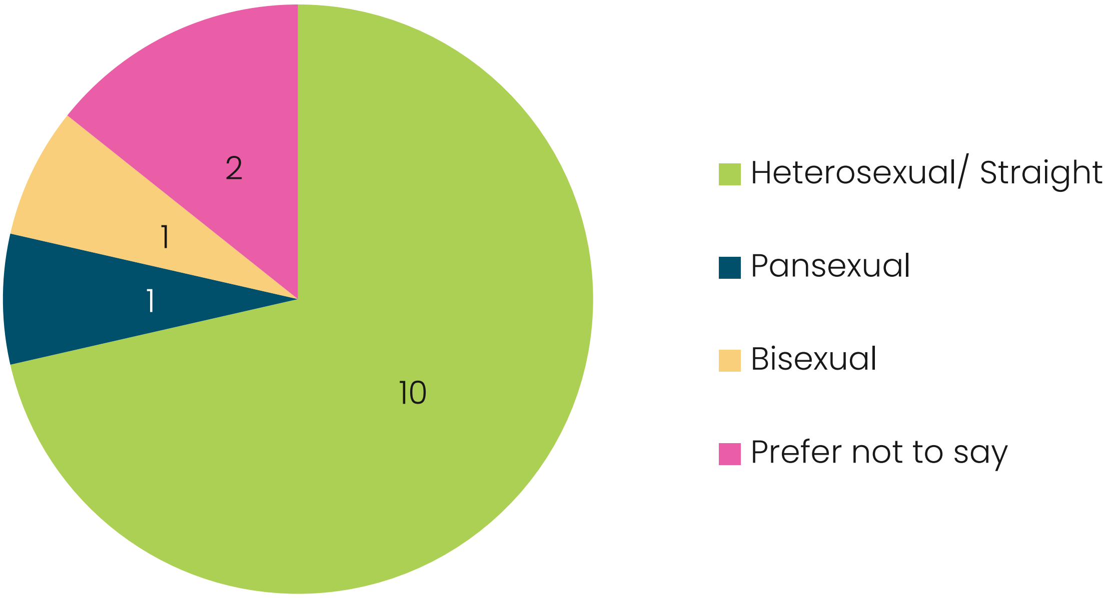
Appendix 1

Demographics

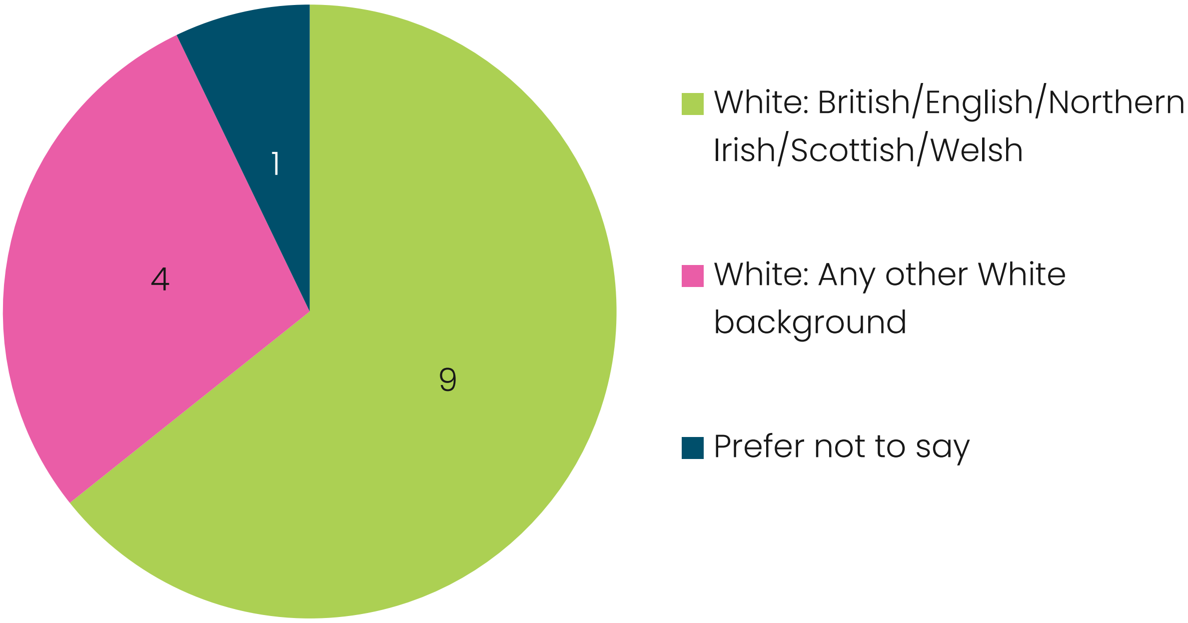




Sexual orientation



Ethnicity



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