

# Autistic People's Experiences of GP Services in Hertfordshire

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## About Healthwatch Hertfordshire

Healthwatch Hertfordshire represents the views of people in Hertfordshire on health and social care services. We provide an independent consumer voice evidencing patient and public experiences and gathering local intelligence to influence service improvement across the county. We work with those who commission, deliver and regulate health and social care services to ensure the people's voice is heard and to address gaps in service quality and/or provision.

## About the Hertfordshire and West Essex Integrated Care System

The Hertfordshire and West Essex Integrated Care System (ICS) was established as a statutory body on 1<sup>st</sup> July 2022. Integrated Care Systems are geographically based partnerships that bring together providers and commissioners of NHS services with local authorities and other local partners to plan, coordinate and commission health and care services<sup>1</sup>. The Hertfordshire and West Essex ICS is made up of two key bodies – an Integrated Care Board (ICB) and Integrated Care Partnership (ICP).

### Integrated Care Board (ICB)

The Integrated Care Board (ICB) is an NHS organisation responsible for planning and overseeing how NHS money is spent across Hertfordshire and West Essex, with the aim of joining up health and care services, improving health and wellbeing, and reducing health inequalities. The board of the ICB includes representation from NHS trusts, primary care and from Hertfordshire County Council and Essex County Council<sup>2</sup>.

This report will be sent to the Hertfordshire and West Essex ICB Primary Care Board to inform how it can further support people to look after their heart health.

### Integrated Care Partnership (ICP)

The Integrated Care Partnership (ICP) is made up of representatives from different organisations involved in health and care. This includes NHS organisations, local authorities and the Voluntary, Community, Faith and Social Enterprise (VCFSE) sector. The partnership is responsible for developing an Integrated Care Strategy which will set out the priorities for Hertfordshire and West Essex for the next 10-20 years<sup>3</sup>.

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<sup>1</sup> [Integrated care systems: how will they work under the Health and Care Act? | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/insights-and-analysis/healthcare-reform/integrated-care-systems)

<sup>2</sup> [Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System \(hertsandwestessexics.org.uk\)](https://www.hertsandwestessexics.org.uk/)

<sup>3</sup> [Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System \(hertsandwestessexics.org.uk\)](https://www.hertsandwestessexics.org.uk/)

# Hearing Patient Views about Primary Care in Hertfordshire and West Essex

Healthwatch Hertfordshire and Healthwatch Essex have been commissioned by the Hertfordshire and West Essex Integrated Care Board (ICB) Primary Care Workstream to undertake a series of engagement projects. The aims of the engagement projects include:

- Gathering lived experiences to feed directly into the Hertfordshire and West Essex ICS Primary Care Workstream
- Supporting and enabling the Hertfordshire and West Essex ICS to achieve wider participant engagement
- Engaging patients and the public on programmes covering key priorities and areas of importance at a regional and local level
- Making recommendations to the Hertfordshire and West Essex ICS Primary Care Workstream so improvements can be implemented

Using patient and public feedback, this engagement project will focus on improving the relevant services within different areas of primary care by making recommendations to the Hertfordshire and West Essex ICB Primary Care Board.

From May to August 2023, the Director of Primary Care Transformation at the ICB has requested that Healthwatch Hertfordshire explore autistic people's experiences of GP services, with a focus on<sup>4</sup>:

- Their experiences of contacting and visiting their GP practice, and the challenges they may face when accessing their GP practice
- Their awareness of reasonable adjustments and whether GP practices support in offering and implementing reasonable adjustments
- Whether autistic people feel understood by reception staff and healthcare professionals within their GP practice
- What GP services are currently doing to support autistic people
- How GP services could improve to better meet the needs of autistic people

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<sup>4</sup> The term 'autistic people' has been used throughout this report as the preferred term for most autistic people, in accordance with research and guidance from the National Autistic Society:  
[https://dy55nndrxkelw.cloudfront.net/file/24/xT2FqU\\_xTh5\\_JA5xTMYZxb.dfV0x/NAS\\_How%20to%20talk%20and%20write%20about%20autism.pdf](https://dy55nndrxkelw.cloudfront.net/file/24/xT2FqU_xTh5_JA5xTMYZxb.dfV0x/NAS_How%20to%20talk%20and%20write%20about%20autism.pdf)

# Background

## Autism

*“Autism is a lifelong developmental disability which affects how people communicate and interact with the world. More than one in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK.”*

- National Autistic Society<sup>1</sup>

The signs and characteristics of autism can vary greatly between people – every individual will have a different profile from a wide range of traits and range of severity. Nevertheless, in addition to their individual strengths, there are some shared difficulties that autistic people may face that can be helpful in understanding and identifying autism. These include: social communication and social interaction challenges, repetitive and restrictive behaviour, over- or under-sensitivity to light, sound, taste or touch, highly focused interests or hobbies, extreme anxiety, and meltdowns and shutdowns. Not every autistic person will experience these, and many autistic people will also face other challenges not listed<sup>5</sup>. It is also common for autistic people to experience co-occurring conditions such as ADHD, dyslexia, dyspraxia, insomnia, mental health problems, learning disabilities, epilepsy and hypermobility. Autistic people will therefore also have varying needs in terms of education, healthcare and overall support in day-to-day life.

## Healthcare

Currently, autistic people have poorer health outcomes and on average, die 16 years earlier than non-autistic people<sup>6</sup>, with suicide being a leading cause of death. Autistic people are less likely to identify and seek help for health problems, meaning they often present late with healthcare needs. Further to this, poor or inconsistent understanding of autism amongst healthcare staff can mean that signs and symptoms of illness are missed, and autistic people are more likely to have to use emergency services when a crisis point has been reached<sup>7</sup>.

Autistic people also often have different responses to pain and can have difficulty identifying emotions<sup>8</sup>. As such, diagnosing health conditions in autistic people can be difficult, particularly when there is a broad range of co-occurring conditions. When these factors are coupled with mutual miscommunication, serious symptoms can be unnoticed, dismissed or underestimated and can mean that treatment is prolonged or complicated.

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<sup>5</sup> [What is autism](#)

<sup>6</sup> [The national strategy for autistic children, young people and adults: 2021 to 2026 \(publishing.service.gov.uk\)](#)

<sup>7</sup> [Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf](#)

<sup>8</sup> [Increased pain sensitivity and pain-related anxiety in individuals with autism - PMC \(nih.gov\)](#)

In healthcare, unfortunately it is typically the case that autistic people's needs are not sufficiently met, or that, for a multitude of reasons, they face barriers in accessing the right healthcare for them<sup>9</sup>. Research from 2022 found that 80% of autistic people faced difficulties when visiting a GP, in comparison to 37% of non-autistic respondents. The most common barrier cited was deciding whether symptoms required a GP visit (72%), followed by having difficulties using the telephone to make an appointment (62%). In the same research, just 16% of non-autistic respondents reported that they had particular difficulty using the telephone system<sup>10</sup>. Other factors, also experienced by over half of autistic respondents were not feeling understood by their doctor, having difficulty communicating with their GP and trouble with the waiting room environment. The research found that, as a result of these barriers, autistic people experienced adverse outcomes such as untreated mental or physical health conditions, late presentation to specialist referral or screening programmes and life-threatening conditions going untreated. 60% of respondents from the study were told that they should have attended primary care sooner<sup>11</sup>.

## **Mental health**

Not only do autistic people have poorer physical health outcomes, they are also more likely to experience mental health problems, and more likely to die by suicide. They are recognised as a high-risk group by the 2018 NICE guidelines on suicide prevention<sup>12</sup>. Just 1% of people in the UK are diagnosed autistic, whereas 11% of people who die by suicide are autistic<sup>13</sup>. It is thought that mental health problems among autistic people could, in part, be because they are more likely to experience social isolation, unemployment, trauma, and abuse. Further to this, as highlighted, autistic people are more likely to face barriers to timely and appropriate healthcare, including mental health care, meaning they miss out on preventative measures<sup>14</sup>.

## **Parents and Carers**

It has been evidenced that parents go through high levels of stress and intense emotion during an autism diagnosis for their child, and that difficult relationships between parents and healthcare professional are often continued beyond diagnosis<sup>15</sup>.

Parents and carers of autistic people are often required to advocate for their child in the healthcare system and are often frustrated by their experiences. Research has shown that parents also experience poor communication from healthcare professionals, in addition to

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<sup>9</sup> <https://www.autism.org.uk/advice-and-guidance/professional-practice/research-gps>

<sup>10</sup> [Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study | BMJ Open](#)

<sup>11</sup> [Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study | BMJ Open](#)

<sup>12</sup> [Preventing suicide in community and custodial settings \(nice.org.uk\)](#)

<sup>13</sup> [Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf](#)

<sup>14</sup> [Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf](#)

<sup>15</sup> [A meta-synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis - Boshoff - 2019 - Health & Social Care in the Community - Wiley Online Library](#)

feeling like they don't have a voice in their child's care. Furthermore, many parents feel that health care professionals do not have an individualised approach, perhaps due to lack of understanding about autism<sup>16</sup>. Many parents said their experience of healthcare services with their children would be improved if they were able to be more involved in a collaborative way with doctors, as experts on their child<sup>17</sup>.

## General Practice

General Practitioners (GPs) are the first port of call for any non-urgent health need, so they are in a position to support their autistic patients with their overall health, and refer them to specialist providers where necessary. However, evidence suggests that many GPs have not received any training on autism, and those without any experience of autism in their personal lives do not feel very confident in their ability to support their autistic patients<sup>18</sup>. There are also other factors to consider such as system-level barriers and what the role of the GP is in identifying and supporting autistic patients. Ultimately, research currently suggests that many autistic people are unable to visit their GP, or do not have a good, or even acceptable experience when they do go<sup>19</sup>. A lack of identification, awareness and understanding also means that necessary reasonable adjustments are not being put in place to ensure autistic people are able to access the right medical care.

## Statutory responsibilities

Many autistic people have sensory needs such as sensitivity to light and sound that make visiting GP surgeries distressing and anxiety inducing, and these are often not mitigated or addressed<sup>20</sup>. Other sensory differences for autistic people include touch sensitivity and sensory or information overload<sup>21</sup>. They will also often have specific communication needs, which is particularly important when interacting with healthcare professionals.

The 2010 Equality Act dictates that the NHS puts reasonable adjustments in place for people with disabilities to ensure that they have equal access to healthcare. Examples of reasonable adjustments that autistic people might need in healthcare environments are:

- Quiet waiting room
- Flexibility in appointment times
- Communication support
- Longer or double appointments
- Continuity or choice of practitioner

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<sup>16</sup> [A meta-synthesis of how parents of children with autism describe their experience of accessing and using routine healthcare services for their children - Boshoff - 2021 - Health & Social Care in the Community - Wiley Online Library](#)

<sup>17</sup> [A meta-synthesis of how parents of children with autism describe their experience of accessing and using routine healthcare services for their children - Boshoff - 2021 - Health & Social Care in the Community - Wiley Online Library](#)

<sup>18</sup> [Supporting GPs working with autistic patients \(autism.org.uk\)](#)

<sup>19</sup> [Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study | BMJ Open](#)

<sup>20</sup> [NHS England – Midlands » NHS helps to create sensory-friendly GP surgeries to support autistic people](#)

<sup>21</sup> [Sensory differences - a guide for all audiences \(autism.org.uk\)](#)

- Choice of communication method
- Ability to have a parent/carer/friend present

Reasonable adjustments should be anticipatory, meaning that the service should be aware of, and put in place, the reasonable adjustments somebody needs prior to their appointment. This requires that GP surgeries include the individual requirements of their patients in their patients' records<sup>22</sup>.

It is also legally required that NHS and social care providers follow the Accessible Information Standard (2016). This legislation commits to "identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss."<sup>23</sup> The standard requires NHS providers to<sup>24</sup>:

- Ask people if they have any information or communication needs, and find out how to meet their needs.
- Record those needs clearly and in a set way.
- Highlight or 'flag' the person's file or notes so it is clear that they have information or communication needs and how those needs should be met.
- Share information about people's information and communication needs with other providers of NHS and adult social care, when they have consent or permission to do so.
- Take steps to ensure that people receive information which they can access and understand, and receive communication support if they need it.

Autistic people's communication needs vary to a great extent, but many autistic people will have difficulty communicating effectively with their GP, particularly if they are unfamiliar or the environment is difficult. It is therefore especially important that healthcare professionals understand each autistic patient's needs and requirements so that both parties are giving and receiving important health-related information in a way that is mutually helpful.

Despite these two legal requirements being in place, many autistic people are still experiencing unequal and life-shortening obstacles when accessing healthcare<sup>25</sup>.

## National Strategy

In 2021, the Government published '*The national strategy for autistic children, young people and adults: 2021 to 2026*'. This strategy follows several previous strategies dating back to the Autism Act 2009. The 2021 document sets out a vision for the years 2021-2026, and includes several priorities to improve autistic people's lives, one of which is 'tacking health and care

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<sup>22</sup> [Reasonable Adjustment Flag - NHS Digital](#)

<sup>23</sup> [NHS England » Accessible Information Standard](#)

<sup>24</sup> [NHS England » Accessible Information Standard comes into force](#)

<sup>25</sup> [Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf](#)



inequalities<sup>26</sup>. As part of this, in addition to tackling diagnostic waiting times, the strategy aims to improve support and healthcare following diagnosis.

In the Health and Care Act 2022, the Oliver McGowan Mandatory Training on Learning Disabilities and Autism became mandatory for health and social care staff. It was developed after the avoidable and untimely death of an autistic person due to a lack of awareness and understanding from the staff caring for him. This training aims to ensure that the “health and social care workforce have the right skills and knowledge to provide safe, compassionate and informed care to autistic people”. With the training now mandatory, it is hoped that it will help to support healthcare professionals and support staff to offer more personalised, appropriate, and safer care to their autistic patients.

The 2021 document also commits to developing a better understanding of autistic people’s experiences of healthcare. It also plans to develop and trial programmes such as autism health checks that are intended to improve autistic people’s health, with the organisation Autistica partnering with NHS England to ensure every autistic adult receives an annual health check by 2030<sup>27</sup> and in Hertfordshire, autism health checks have started to be piloted in a selection of GP practices. Another key priority in this strategy is the development of ‘digital flags’ on patient records, to enable healthcare professionals to better tailor their support to the needs of their autistic patients.<sup>28</sup>

## Local picture

It is evident that there are huge nationwide problems in healthcare for autistic people, leading to them experiencing a health inequalities gap. Steps are being taken to better support autistic people, but it will still take more time, commitment, and willingness to learn and adapt, in order to reach our shared healthcare goal for the autistic community.

In 2020, there were estimated to be over 8900 adults with Autism Spectrum Disorder living in Hertfordshire<sup>29</sup>. However, in 2015 there were just 2,615 people recorded on GP registers as being autistic, indicating a huge gap in the knowledge of GP practices. This severely limits their capacity to support and treat their autistic patients in a suitable way, with reasonable adjustments and considerations. By 2025, it is estimated that the number of autistic adults in Hertfordshire will have risen to over 9600 and this number is only likely to increase<sup>30</sup>. In terms of children and young people, in 2020, the rate of autistic children known to schools was 16.7 per 1,000. This does not include those who are waiting for a formal diagnosis, so the number is likely to be higher still<sup>31</sup>.

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<sup>26</sup> [The national strategy for autistic children, young people and adults: 2021 to 2026](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/101422/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf) ([publishing.service.gov.uk](https://publishing.service.gov.uk))

<sup>27</sup> [Health-Checks-Plan.pdf](https://autistica.org.uk/health-checks-plan) ([autistica.org.uk](https://autistica.org.uk))

<sup>28</sup> [The national strategy for autistic children, young people and adults: 2021 to 2026](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/101422/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf) ([publishing.service.gov.uk](https://publishing.service.gov.uk))

<sup>29</sup> [autism-spectrum-disorder-jsna.pdf](https://www.hertfordshire.gov.uk/autism-spectrum-disorder-jsna) ([hertfordshire.gov.uk](https://hertfordshire.gov.uk))

<sup>30</sup> <https://www.hertshealthevidence.org/microsites/jsna/jsna-documents/autism-spectrum-disorder-jsna.pdf>

<sup>31</sup> <https://www.hertshealthevidence.org/microsites/jsna/jsna-documents/autism-spectrum-disorder-jsna.pdf>

## Aims of the Research Project

- To explore the experiences of autistic people when contacting and visiting their GP practice
- To understand the barriers that autistic people face when accessing their GP practice, and the impact of these barriers on them
- To identify whether autistic people are aware of reasonable adjustments, and if this support is being offered and/or implemented by their GP practice
- To understand whether autistic people feel understood by reception staff and/or healthcare professionals within their GP practice
- To consider parent/carer perspectives on navigating GP services for the autistic person they care for
- To explore any improvements GP practices could make to be more autism-friendly, from the perspective of autistic people

## Methodology

The aims of this research were explored through an online survey for autistic adults to complete, although this was sometimes completed with the support of a parent or carer. This methodology was chosen in order to be sensitive to communication preferences and to reach a greater number of participants. People who completed the survey were given the option to leave an email address and be contacted for an interview should they wish. The survey was also available in different formats, but this was not requested at any point.

To support the survey, we also offered interviews with the parents and carers of autistic children and adults. This approach meant that we captured the experiences of children, in addition to parents and carers' perspectives on GP Services.

The engagement period for the online survey ran from May – July 2023. The survey was promoted via social media and shared with the NHS, other statutory services, and the Voluntary, Community, Faith and Social Enterprise sector across Hertfordshire to distribute via their networks, contacts and social media channels. These stakeholders also received a digital flyer to support with promotion.

# Key Findings

Most respondents found accessing GP Services to be very **stressful, difficult** and to cause great **distress** and **anxiety**, meaning some avoided it altogether or did not benefit from their appointment.

The **barriers** respondents commonly faced included:

- Not being able to contact the practice through a communication method suitable for them.
- Feeling dismissed or treated rudely by reception staff.
- Finding waiting areas incredibly difficult environments, which increased anxiety prior to an appointment.
- Experiencing significant anxiety from waiting itself, either on the phone or in-person, which often contributed to communication difficulties at the appointment.
- Not being supported with, or even being refused reasonable adjustments such as longer appointments, seeing a familiar clinician or a choice of appointment type.
- Experiencing a lack of kindness, patience and understanding from both clinical and non-clinical staff, meaning that respondents felt rushed, like a nuisance, or not safe to express their needs.
- A lack of awareness and knowledge of autism from clinical staff, such that respondents felt misunderstood and that the care they receive was not suitable or appropriate to their needs.

Some respondents did share examples of **good experiences** of GP Services, where particular members of staff had been especially kind and accommodating, which made a significant difference to their experience. Others said that they had received **reasonable adjustments**, and that these had a positive impact on how they were able to manage making and attending an appointment.

**66%**

were not aware of the reasonable adjustments they're entitled to

**48%**

didn't feel very or at all understood by their GP

**69%**

said they would benefit from an Autism Health Check

## Demographics:

Overall, this research heard from **131** autistic people via a survey, and a further **6** people via interview, who were either autistic themselves, or a parent/carer of an autistic person. The survey was also filled in by parents/carers on behalf of an autistic person they care for.



### Age:

- 18–24 years: **24%**
- 25–34 years: **18%**
- 35–44 years: **18%**
- 45–54 years: **18%**
- 55–64 years: **9%**
- 65–74 years: **1%**
- 75+ years: **1%**
- I'd prefer not to say: **9%**



### Gender:

- Male: **46%**
- Female: **44%**
- Non-binary: **1%**
- I'd prefer not to say: **5%**
- Other: **3%** (1 transwoman, 1 transman, 1 trans man/non-binary)



### Ethnic background:

- White: British/English/Northern Irish/Scottish/Welsh: **71%**
- I'd prefer not to say: **9%**
- White: Irish: **4%**
- White: Any other White background: **3%**
- Black/Black British: African: **2%**
- Mixed/Multiple ethnic groups: Black Caribbean and White: **2%**
- Mixed/Multiple ethnic groups: Any other mixed/multiple ethnic backgrounds: **2%**
- Asian/Asian British: Indian: **1%**
- Asian/Asian British: Pakistani: **1%**
- Asian/Asian British: Any other Asian/Asian British background: **1%**
- Black/Black British: Caribbean: **1%**
- White: Polish: **1%**



### Other:

- Are a carer: **26%**
- Have a disability: **54%**
- Have a long-term condition: **40%**
- None of the above: **3%**
- I'd prefer not to say: **9%**

*\*Please see appendices for number of survey respondents per GP Practice\**

## All Findings

### Overall support

When asked to describe the overall support respondents received from their practice:

**42%** said it was **good or very good**

**34%** said it was **neither good nor bad**

**24%** said it was **bad or very bad**

#### **Examples of positive experiences included:**

- Clinicians being friendly, patient and understanding.
- Provision of reasonable adjustments e.g. quiet waiting rooms, well signposted
- Feeling listened to
- Accommodating of their individual needs.
- Able to see the same clinician/continuity of care

#### **Examples of negative experiences included:**

- Lack of understanding
- Rude and unkind reception staff and clinicians
- Poor care and treatment
- Lack of choice - appointment times, type of appointment, seeing the same GP
- Lack of reasonable adjustments
- Poor communication from clinicians

Respondents choosing neither good nor bad could be a result of limited interaction with their GP practice due to access difficulties or barriers. Many will also have their parent or carer supporting them, which might improve their experience.

Whilst these statistics are an initial indication of findings and show that some GP practices are providing good support to autistic people, the remainder of the report presents individual's thoughts and experiences in more detail as to both what their GP practice is doing well, and what improvements need to be made.

## **GP Patient Records**

**64%** of respondents said that their GP practice knows that they are autistic. **13%** said their GP practice does not know, and **22%** were unsure.

Of the **64%**, the majority (**47%**) said that this does not improve their experience of accessing their GP practice in any notable way, and **30%** were not sure if it did.

For those whose experience it did not improve, this was sometimes due to inconsistent knowledge amongst reception staff and clinicians, and confusion as to whether or not their autism has been flagged on their patient records.

*"I don't think they even read and acknowledge the individual notes of their patients. So they just treat him like any other patient. Never once have I felt like my child's needs have been noted."*

*"They seem not to pay attention or take that into consideration during appointments, causing access barriers."*

Others felt that it made no difference in how they accessed their GP practice, as they were refused accommodations and reasonable adjustments. Providing reasonable adjustments is a legal requirement for NHS and social care services, so they can ensure people who have additional needs can have equal access to healthcare.

*"I don't feel that [my children] are given any kind of priority care or offered any support, when it is critical because they are already disadvantaged. I feel like they get disadvantaged more, when it should be the other way round to prevent further harm."*

*"My son is, but they seem not to pay attention or take that into consideration during appointments, causing access barriers."*

Some respondents found that they or the person they care for were not treated kindly or with any additional understanding, despite the fact that their GP practice knew they were autistic.

*"They already know – but I rarely see the same person twice. I would prefer that I saw maybe 2-3 doctors who actually KNOW me well. The uncertainty of who I will get is horrible. There is 1 doctor I refuse to see and another one I try to avoid because she shouted at me once."*

*"Some doctors at the practice treat him like he is a nuisance and ignore me even when I share with them that he is autistic. I believe GP'S have no training regarding autistic children."*

In contrast, some respondents felt that their needs should still be taken into account despite a lack of formal diagnosis, particularly in light of long diagnostic waiting lists.

*"I have told them. But the whole lack of a formal diagnosis means they don't/won't document it because they won't acknowledge self-diagnosis"*

*"In the defence of GPs, not everyone has a diagnosis of autism, but that does not mean that some individuals have autistic tendencies and this also needs to be recognised."*

**23%** of people felt their experience was improved as a result of their GP knowing they were autistic. For some, respondents this was because awareness of their autism meant that reasonable adjustments were able to be put in place, for example, priority appointments, a quiet space to wait, or be able to bring someone to support to appointments.

*"My autistic daughter's GP is fantastic with her and will even alter an appointment so she is seen first in the GP's clinic/session so that my daughter isn't waiting around too long in a crowded waiting room."*

*"I always obtain an appointment"*

*"My mum and dad can make appointments for me and come with me for support"*

Some respondents found that clinicians were more patient and understanding with them when they were aware of their autism, which often meant they had a far more positive experience when accessing their GP practice.

*"I feel they treat me patiently."*

*"My doctor has known me when I born and my Mum before she died and so he always says hello and talks to me"*

*"They let me express how I feel about my body"*

*"It helps them to be clear when they speak and to understand that I am very literal. That I don't like being touched unless it's essential."*

*"Since I was diagnosed I've noticed some GPs have taken more time to listen to what I'm saying and not jump to conclusions."*

Other respondents shared that because the GP practice was aware of their autism, they were able to see the same GP consistently, which improved the quality and continuity of their care.

*"GP very aware I will only talk to him, no other Doctors"*

*"It helps me to see the same GP when I need an appointment as a new person is difficult because of the Autism, and extra tiring because of the M.E. My mental health in particular is managed through the same GP as he has a psychiatric background."*

*"Once we get past the initial call to the surgery and speak to a GP, our son is given a prompt appointment with his named GP."*

However, for some respondents the support or understanding they received was inconsistent and their experience tended to vary dependent on the reception staff they spoke to or the clinician they saw.

*"Sometimes. On one occasion a doctor asked if I would prefer the lights off which I found respectful and understanding."*

*"Sometimes, depends on who you see and for what."*

Nevertheless, **77%** of respondents said that they would like their GP practice to know that they are autistic so that they could be more accommodating of their needs. Those few who were not sure or would not like them to know did not give a reason for this.

*"Yes it would help them understand I need quiet areas to wait and be more understanding of me"*

*"Yes, I think it would help both parties to keep the diagnosis in mind"*

## **Making an appointment**

**Over half** of respondents faced barriers when making an appointment with their GP practice. Whilst some of these challenges reflected the difficulties faced by the general public, including limited availability of appointments and long waiting times on the telephone, these factors have a significantly greater negative impact on autistic respondents, particularly given the challenges they often face with social interaction and communication.

Many commented that the process of making an appointment is highly stressful and often induces anxiety, which is only exacerbated when reception staff are impatient and/or lack understanding of their needs.

*"I dread every time I have to contact my GP surgery. It is always a negative experience and always leaves me in tears, it's like a trauma response. It's just so HARD."*



*"I don't like using a phone and having to wait increases my anxiety and makes me reluctant to call."*

*"I would be too nervous/anxious to book one for myself."*

*"The whole prospect of going to the doctors terrifies me. Even the event of having to deal with a receptionist or be in a waiting room."*

### Reception staff

Given that receptionists are the first interaction people have when contacting the GP practice, they play a pivotal role in supporting people to get the help they need, particularly when making appointments. However, the majority of respondents (**51%**) said that reception staff were not understanding or accommodating to them. A few respondents shared that reception staff don't have a good enough understanding of autism and were therefore not sensitive to their needs.

*"Not at all. Awful. Had awful experiences as they cannot understand that it is a social communication disorder."*

*"Not always. It very much depends individual to individual. Usually, they can be quite challenging and rarely accommodate the need for an in-person appointment... nearly always they insist on calling using the telephone; which I find really hard, as I rarely use the telephone."*

Several respondents said that reception staff had been rude, unkind and unhelpful which led to them feeling distressed and dismissed, and feeling reluctant to contact the practice in the future.

*"No not at all, they are in general rude and unhelpful."*

*"No, I am always distressed when speaking with Reception staff as I find they are impatient and rude, more often than not. It is the part I find most stressful when going to the doctors."*

*"They are rude, and won't explain things I don't understand."*

Other respondents noted that reception staff did not seem to read patient records, so were not aware of their autism and therefore did not accommodate their needs appropriately or think to offer reasonable adjustments. Many respondents found it incredibly difficult to get to the stage of interacting with reception staff, and that challenging reception staff was then another obstacle to overcome in order to see a GP.

*"They're not accommodating of the needs of neurotypicals, why would we be different?"*

*"Due to difficulties in accessing services in the NHS a lot of the time access to information is dependent on asking the rights questions which one might not know of. It would be helpful if information was readily shared rather than dependent on people asking the right questions in order to access help and support."*

*"Information to help patients with the process is not made available unless you ask, and even then staff are often impatient and intolerant of people not knowing what to do."*

In contrast, **25%** of respondents felt that receptionist staff were understanding and accommodating of their needs as an autistic person. Several respondents shared that they found reception staff to be patient, kind and helpful, whether or not they are aware of the patient's autism.

*"The reception staff do come across as caring and I've not had any problems with the reception staff. They aren't discriminating. I find that they are very understanding and efficient."*

*"They treat my daughter the same as other patients. They are always kind and professional."*

*"Yes, the receptionists are always super kind and helpful if I go in person."*

Other respondents found that reception staff were able to support with providing them reasonable adjustments or trying to meet their needs in a personalised way.

*"Yes, if I ask for help then they provide help."*

*"Some receptionists understand the need for a bookable appointment."*

*"They help my Mum to get quick appointments for me."*

*"Offering phone appointments between specific times"*

*"They make a reasonable adjustment"*

*"They provide rooms to wait and chat in"*

*"Autism is logged on the system and there seems to be a good understanding of individual needs. We have been able to book appointment for health check with a named doctor."*

**13%** felt that this was only sometimes the case, or that it depended very much on the receptionist they spoke to and/or the mode of interaction.

*"When talking face to face with them, yes, they seem very accommodating. But when on the phone, no not really."*

*"If I go in person yes, but not on the phone."*

*"Depends on the staff."*

**10%** felt that reception staff would not necessarily know that they are autistic and have additional needs, while others said they do not have much interaction or contact with receptionists, either because they do not access their GP practice very often or because their parent, carer or support worker contacts the GP practice on their behalf.

*"Unless I say anything it is unlikely they know...I don't seem to see regular staff at the desk so it's not like they know me. It is difficult to know if I trust them."*

*"Because autism is a hidden disability, I don't think they really know I have it to be honest, they just see me as a normal person walking in. Some of them can be nice but others tend to be grumpy."*

*"I don't think they know. I don't tell reception staff."*

### Contacting the practice

At **36%**, most respondents preferred to make a GP appointment online. Respondents commented that they often find making an appointment online much easier, and limited feelings of stress and anxiety for some.

*"I hated the phone at 8am system! But I am glad to just fill in an online form now. If I do need to contact for other things then my husband/carers does this on my behalf for the most part."*

*"Yes, the nightmare of automated phone systems. However, I can book online which helps but still means waiting for a call at an unspecified time."*

*"I'm glad they have the online triage system now as I used to dread phoning in the mornings, waiting and the receptionists were always really busy and fast and I would get anxious and muddled."*

However, booking an appointment online does not suit everyone. Some respondents emphasised that they find eConsult difficult to use, noting that there are too many questions to fill in and is complicated to complete.

*"Online consult is a barrier - there are too many screens to click through"*

*"I don't use the eConsult form as I find this particularly hard - it tires me and makes me extremely anxious. I am allowed to ring for appointments instead. The staff there are very nice indeed."*

*"Long, repetitive questions on the online forms."*

In comparison, a few respondents would prefer to make an appointment online but are only able to contact their GP practice by telephone. A few respondents suggested that if they could book an appointment online, then they might not need to ask their parent or carer for support.

*"The barriers are the eConsult which I cannot access and is also an issue for my carer."*

*"My mum does it for me. I do not like to wait on the phone. If I could book online it would help."*

*"I can't talk on the phone and no appointments online so I have to get someone else to make them."*

**28%** of respondents make an appointment on the phone. However, it is important to again emphasise that for many respondents this is the only way they can contact their GP practice and is not necessarily their preference.

*"I would prefer online but it all needs to be done by phone."*

*"I'm not given a choice. Mostly it's via the phone."*

*"We are only able to make appointments over the phone."*

This lack of choice is particularly problematic, given such a large proportion of respondents expressed just how distressing contacting by telephone is for them. Respondents shared that interacting and communicating with reception staff and waiting on hold can be incredibly challenging and causes stress and anxiety for many.

*"I find phone calls stressful, I feel like I'm being shunted along with little regard for how I'm feeling, or if have I understood the information."*

*"If I have to phone to make an appointment, and it takes around 30 minutes on hold to get through. Often I am so anxious that I hang up before I get through. It's made worse when staff are rude to me if I ask questions."*

*"I hate having to call at 8:00am and sit on hold for 20 minutes and then be talked down by reception...I get very stressed...I hate using the phone period."*

It is evident that for many respondents, the stress of having to call for an appointment means they are either reluctant or avoid accessing their GP practice entirely.

*"To make an appointment you usually have to phone at certain times or go into the doctors which can be stressful. I struggle with phone calls and so often avoid making appointments."*

*"I find the incessant hold music triggering when I'm trying to ring for an appointment, to the point that I avoid it at costs, and often end up in A&E with much more serious health conditions which could have initially been dealt with at the GP had it of been easier to get an appointment."*

*"I am unable to phone them as I don't feel comfortable using the phone. There are never any appointments available online."*

**17%** of respondents prefer to make an appointment by visiting their GP practice in-person. Of these respondents, many commented that they find this a much easier and quicker way of getting an appointment. Although, a few shared that having to disclose the reason for their appointment in public can make them feel very uncomfortable and takes away their privacy.

*"We're lucky we can walk to our GP surgery, I often find that's the best way to do it, because it's hard to get through on the phone"*

*"If I make an appointment at reception, the staff want to loudly discuss why I need an appointment, in front of all the other people waiting."*

**19%** said they make an appointment through other means. Of this group, the majority said that they ask their parent, carer or support worker to contact their GP practice on their behalf. For some, this is simply their preference, while for others this is because they find contacting their GP practice themselves too challenging and inaccessible.

*"I have to phone up for an appointment and that can be incredibly challenging, I often have to get my mum to do it for me."*

*"My Mum does it, I can't stand the hold music and can't get what I need online."*

*"I can't use the telephone system, so someone has to ring on my behalf."*

*"I can't talk on the phone and no appointments online so I have to get someone else to make them. It's always hard to get an appointment with the doctor I know."*

The above findings about different ways to make an appointment demonstrate the diversity of needs and preferences among autistic people. It is clear that above all, there needs to be a choice in how autistic patients are able to contact their surgery.

### **Visiting the practice**

**39%** of respondents stated that they faced barriers when visiting their GP for an appointment.

*"Overall, I find visiting the doctors a hugely stressful experience. From booking the appointment to picking up a prescription I find the whole process overwhelming and feel that information to help patients with the process is not made available unless you ask, and even then staff are often impatient and intolerant of people not knowing what to do. Whilst I appreciate that a doctors is a busy place, I do not feel that patients are made comfortable in the environment and this is even more true for autistic people. I dread visiting the doctors as I feel that every interaction is pressured and rushed and that I am just causing a problem. I never seem to have a consistent GP who I see regularly and so I have to re-explain everything each time I go to the doctors."*

### **Waiting rooms and times**

One of the most significant barriers faced by the majority of respondents was the anxiety and stress around waiting rooms. Respondents described waiting rooms and the environment of GP practices as too loud, public, and busy and often causing a sensory overload a result. For many autistic people, the build up to the appointment can be so stressful and anxiety-inducing that when it is time for the appointment, they feel unable to express themselves sufficiently or take in any information given.

*"Waiting room. Do not cope with waiting but public waiting room is a huge barrier."*

*"The waiting room is a really difficult sensory environment for me. "*

*"I have to wait in an open room and I get anxious round strangers."*

*"I get so anxious in the waiting room that I often can't fully articulate my needs when I see the GP."*

*"There is no quiet space to wait and I can't use headphones to block out the sound as then I won't hear the alert to call me to the room."*

Likewise waiting to be seen by a clinician was mentioned as a barrier by some respondents. They shared that delays and long waiting times made an already challenging situation even more difficult and only added to their discomfort and distress.

*"I get anxious going in there, and waiting makes me more and more anxious."*

*"Waiting due to GP running late. I get anxious."*

### Staff attitudes

The second most significant barrier mentioned was the attitude of clinicians, with respondents noting that clinicians are not understanding, patient, or accommodating. Many have had a negative experience during their appointments, in which they felt rushed, judged, misunderstood or dismissed. A few commented that clinicians treat them "like a child" or as if they "do not understand" and felt clinicians do not take the time to listen to them or their needs.

*"Impatient, not understanding of going non-verbal, not listening, refusing referrals."*

*"Fear, judgement, not believing me, treating me as difficult and making it obvious that they don't want to deal with me."*

*"I never see the same doctor and not all of them understand my disabilities and they treat me like a child once they realise I'm disabled."*

*"My GP won't read the symptoms etc I write down and always seems rushed. I feel I'm treated like I don't understand and it is assumed I don't take care of my help or know the information to choose to."*

*"In the past I have felt judged by the GP."*

Similarly, respondents shared that clinicians do not seem to have an adequate understanding

of autism, and will often speak to their carer, parent or support rather than directly to them, which many find disrespectful.

*"Autism is completely ignored."*

*"GP don't have much understanding of autism...GP rely a lot on the staff who are supporting...GP rely so much on home staff, there is no interaction from GP to the individuals."*

It is then unsurprising that most respondents did not feel very understood by their GP:

**14%** felt very understood by their GP  
**18%** felt mostly understood by their GP  
**26%** didn't feel very understood by their GP  
**22%** felt not at all understood by their GP  
**20%** weren't sure

Likewise, some parent and carer participants voiced concerns that their GP seemed to have very little knowledge of autism at all. This can cause issues and barriers to support outside of healthcare too:

*"The GPs know next to NOTHING about Autistic people. And even when we need referrals from them for specialist intervention, they are unable to help. I had to personally "teach and educate" my GP in order to help my child. Many a time Local Authorities request information from GP before help is given, but that is next to impossible if the GP does not even recognise the need of my child."*

### Communication barriers

Communication was another barrier raised by respondents, with some emphasising that their communication needs were not understood or taken into account. Some respondents commented that the clinician did not understand that autistic people may become anxious and as a result non-verbal or have difficulties communicating their needs. Others said that clinicians tend use complicated language and terminology which they find difficult to understand. For autistic people, communication barriers can stop them from attending appointments, or mean that appointments are not as helpful as they could be.

*"I feel overwhelming anxiety which can cause me to go non-verbal"*



*"Talking to me in speech I do not understand, not simplified language. Being cold towards me not friendly even when I explained communication disorder (autism, learning difficulties) they still treat me beyond my means, which makes me feel unwelcome. Hate seeing doctors, I will not go."*

*"Yes, I am extremely anxious and nervous and struggle to communicate my needs."*

One respondent gave an example of when clinicians were not accommodating or flexible in their communication with her husband:

*"The expression was 'how are you doing XXX', and he said 'how am I doing what?' he doesn't understand. They asked him 'why can't you answer the questions properly'"*

Communication barriers between respondents and their GPs were particularly evident when considering pain and 'pain scales'. Several respondents felt that the clinician was not aware of the known difference in pain sensitivity and presentation for autistic people, in addition to the difficulty some autistic people face in describing feelings, sensations or pain<sup>32</sup>. Respondents felt that if clinicians were more aware of these factors, then they would be able to probe or find other way for the patient to communicate their symptoms effectively, rather than using the standardised pain scales.

*"Understand that we experience pain differently, so we might look fine but if we are telling you that something hurts, even though we aren't screaming, we could still be in agony with something seriously wrong. We also don't necessarily know how to convey what's wrong and we may need some help describing or getting there e.g. does the pain feel like this or like that, can you point to what's wrong"*

*"It would helpful for the kids if the GP was aware of their presentation. Because I think obviously autism is such a wide spectrum, you know you've got children who are hypersensitive, and then you've got children who just don't respond, and it's helpful for the adult to know where that child is on the spectrum. My son had a broken wrist and it took him two days to tell me his arm was hurting. That's something that medical practitioners need to know. My kids would never say anything higher than 2 out of 10 on a pain scale. I think a purple folder could be useful, but I don't think the GP would actually even acknowledge it, so I haven't bothered. The message still hasn't got across that every autistic person is different, and they present in a different way, with different needs."*

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<sup>32</sup> [Increased pain sensitivity and pain-related anxiety in individuals with autism - PMC \(nih.gov\)](#)

Lastly, a few respondents mentioned that their GP practice is not physically accessible and/or has poor signage, meaning respondents do not know what to do, where to go, or where to sit, which they can find very stressful.

*"Not always sure where I should wait."*

*"The parking is often an issue, even with my blue badge. The accessible door to the practice is rarely working and I struggle with my crutch to open it. I find standing in line very difficult and painful and have to sit down."*

*"Booking in. Anxiety about where to sit etc."*

**13%** of respondents said that they only sometimes faced barriers, and often this was because their parent/carer/support staff with them mitigated these barriers, although they mentioned they would struggle to access and visit their GP practice without this support.

*"I take my mum as I can't take in a lot of information - I would prefer them to write it down"*

*"I would struggle without my carer (mother)"*

*"It is OK if my mother can come. She can speak to the receptionist and the doctor."*

Some respondents said they find it too difficult to visit their GP practice and/or have had previous poor experiences which have made them hesitant or reluctant to revisit. Not being able or comfortable to use GP services means that autistic people are at a higher risk of not receiving the right healthcare at the right time.

*"Yes, I have Chronic Fatigue Syndrome too, so am too exhausted, and sensory overloaded. I rarely see GP and don't like the appointments so avoid it whenever I can. I haven't seen GP in a very long time. My Mum does my health needs."*

*"I never visit my GP, they only offer phone appointments"*

*"He should really get a medication review because he takes a lot of medication but we don't engage with services, we haven't engaged with the GP for a long time. If he had to, I would go with him, but he's had such bad experiences we don't go."*

*"I avoid going to the doctor because I am anxious and scared of being prodded or poked or sent for more appointments."*

Positively, **40%** of respondents said that they didn't face any particular barriers when visiting the GP. Sometimes this was because the staff members were particularly friendly and helpful, and had a good understanding of their needs and/or autism.

*"My experience with my son visiting the GP surgery has always been very positive."*

*"They're brilliant."*

*"Staff are always friendly and helpful."*

*"My GP Practice is fantastic and patient and supportive in general. So I am very lucky."*

Others found that the environment was manageable, and information was clear which was helpful.

*"They are very well sign posted, and the waiting room is usually quiet unless there are children there."*

*"No because it's quiet"*

However as mentioned above, some respondents did not report facing challenges in accessing their GP practice because they were able to have a parent, carer or other support with them to help mitigate the barriers.

*"I take my mum as I can't take in a lot of information - I would prefer them to write it down."*

*"I always have staff with me. I would ask the receptionist if I went on my own."*

Some of these barriers are similar to those that the general population face, due to well-documented pressures on GP services<sup>33</sup>. However, it is very clear from this research that these barriers have such a significantly detrimental impact on autistic people's access to, and experience of GP Services and contribute to their poorer health outcomes.

## **Mental health and wellbeing**

As has been made clear in previous research, autistic people are more likely to experience mental health problems, but often face difficulties in receiving support for them in a timely and appropriate manner. Autistic people can be particularly vulnerable to anxiety and depression

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<sup>33</sup> [Pressures in general practice | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/pressures-in-general-practice)

but might have difficulty in identifying or expressing their feelings<sup>34</sup>. If GPs and other clinicians are not alert to this, it can mean that diagnoses and support is missed or delayed.

Just **32%** respondents said that their GP had discussed their mental health with them.

*"Yes, in one appointment"*

*"Yes, medication was prescribed"*

*"Yes, [mental health] is the primary topic of our conversations."*

Although mental health and wellbeing had been discussed for some respondents, they did not always find that this was helpful. Often, this was because the clinician's lack of awareness and understanding of autism meant that the support they offered with mental health problems was not appropriate to the respondent.

*"Briefly discussed. With assumptions and no understanding of impact of neurodivergent conditions on mental health and employment."*

*"They have not done anything to help me."*

*"We saw the mental health practitioner at the surgery. She was not the best, to be fair I don't think she had much understanding of autism. She was just saying things like 'try not to think about these things' and I was thinking well you don't really get it, he can't help his obsessions, and that's often the way with people with autism."*

Similarly, one respondent shared their frustration that each symptom, problem or diagnosis was considered in isolation, and their healthcare was not holistic enough.

*"This is something that is overlooked and not managed. Everything is in isolation which causes issues."*

Lastly, some respondents shared the feeling that their mental health was overlooked or dismissed, even when they were clearly expressing a need for support.

*"I told them I am not well in my mind, and they told me I can go online to read things."*

*"I have been on Citalopram for over 20 years but no discussions about my mental health or wellbeing since."*

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<sup>34</sup> [Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf](#)

*"When I was suicidal, all I had was a phone call for less than 5 minutes."*

A few respondents did have a positive experience when speaking with primary care clinicians about mental health and wellbeing. This parent found her son's GP to be particularly kind and patient, treating him as a 'proper individual'.

*"When we have seen the GP recently it's been for a couple of mental health issues and the GP was really really good with him. I was so impressed that I emailed the surgery to say how lovely she'd been with him. I was just impressed that she treated him as a proper individual, you know, talked to him, rather than sort of, going via me. She was really kind with him, he asked a lot of questions and it didn't faze her."*

However, many respondents also stated that they or their parent/carer often initiated the discussion about their mental health and wellbeing, rather than being prompted by the GP to talk about this.

*"Only when prompted by my parent."*

*"Yes, but only when I have asked for it. I have had experiences at another surgery where my mental health issues were not supported at all."*

*"Mental health and well-being is only discussed if I choose to bring it up during my appointment. I never seem to have a consistent GP who I see regularly and so I have to re-explain everything each time I go to the doctors."*

*"Not unless I have come with an issue around it."*

*"I discuss it with my GP. They do not pro-actively prompt."*

This patient-led approach could mean that the mental health needs of autistic people who struggle to identify and communicate their emotions and feelings are missed, because the topic has not been directly addressed with them or their carer. Given the poor mental health outcomes and suicide rates for autistic people, early identification and intervention is really important. This respondent shared the barriers faced that make it difficult for the person they care for to communicate their mental wellbeing.

*"When the GP says to him 'how do you feel?', it takes him time to formulate how he feels, and he may not know, and there's never that time in a consultation to get that across."*

Concerningly, **43%** of respondents had never spoken to their GP about their mental health, despite many clearly expressing a desire or need for this. Some respondents had faced resistance from practitioners about discussing their health – whether that be physical and/or mental.

*“They will barely discuss my physical health. I was told that I cannot book an appointment for an ongoing or chronic condition, and that I should go to A&E if I require even routine care, as appointments are only for new and chronic conditions.”*

*“No just the bare minimum of ticking boxes over yearly disability checkup. I am seeing a psychiatrist for my anxiety. When I’ve tried to talk to the doctors about it you get nothing no understanding whatsoever it’s like they don’t want to see me or help.”*

Other respondents felt that they had been dismissed or misunderstood by clinicians, despite reaching out for help.

*“No. Although during a recent visit to discuss about issues with menopause was given anti-anxiety and depressants instead.”*

*“I have been misdiagnosed for years when reaching out for help.”*

One parent felt that if her son had a consistent GP who understood autism, they would have been more likely to pick up on any mental health needs.

*“No! They have never discussed it. They could if they “realised” or know and understand [my child] is Autistic. However, they do not. Plus, he is seen by different doctors. So... ”*

## **Reasonable adjustments**

### Awareness

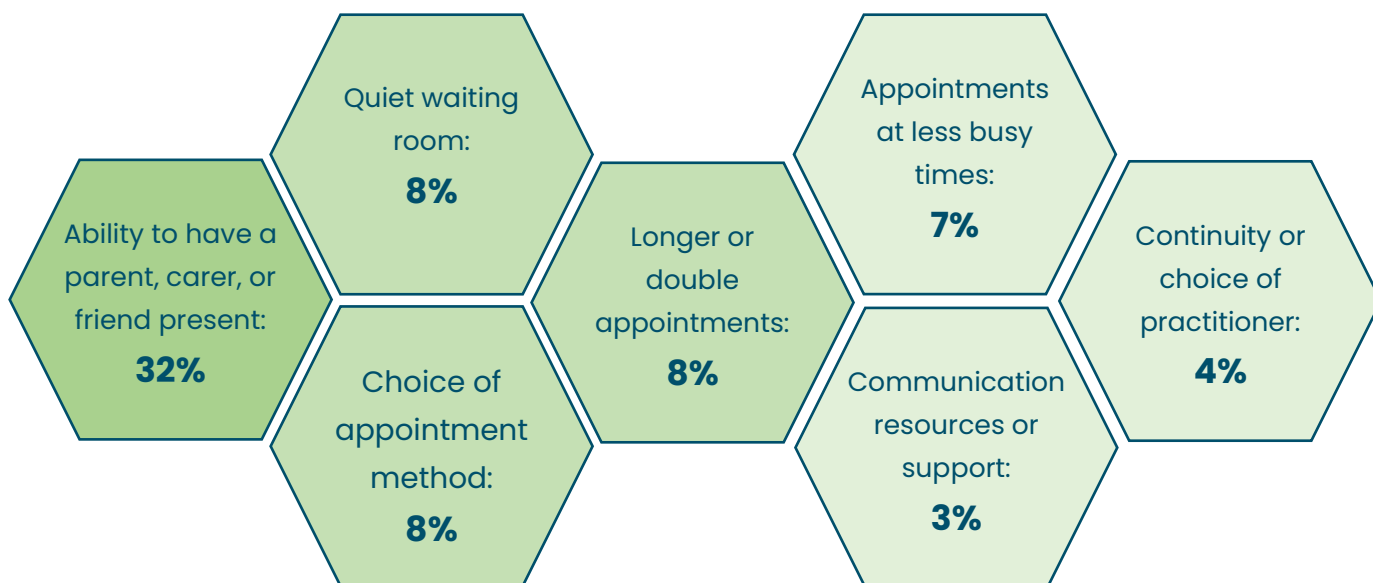
Under the Equality Act (2010) GP practices must ensure that services are accessible by implementing reasonable adjustments to ensure everyone has equal access to health services<sup>35</sup>.

**42%** of survey respondents were aware that GP practices were required to offer them reasonable adjustments as an autistic person. **45%** said that they were not aware of the requirement for reasonable adjustments to be made, and **13%** unsure.

Awareness of each reasonable adjustment was very low, at **under 10%** for all except for the ability to have another person present at appointments:

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<sup>35</sup> [Reasonable adjustments for people with a learning disability - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/guidance/reasonable-adjustments-for-people-with-a-learning-disability)



Concerningly, **66%** of respondents were not aware of **any** of the above adjustments listed in the survey, and did not realise that it is their right to receive accommodations to ensure their access to healthcare is equal.

*"I'm shocked after reading this!"*

*"I know nothing about these."*

*"Are all of these available to me??"*

Furthermore, **70%** of respondents had never been offered any of the above reasonable adjustments, and **14%** were not sure or could not remember if they had been. Worryingly, a few respondents commented that they have asked for reasonable adjustments but were refused.

*"I have asked for several of the above but been refused on several occasions."*

*"I've asked but have been met with confusion and resistance."*

*"They don't do this as far as I know."*

*"None of these are provided or offered."*

For the **15%** who had been offered reasonable adjustments, it was mostly that they were allowed to have a parent, carer or support worker come into their appointments. A few mentioned that they had been given a longer appointment, were able to see their named GP,

were able to request a particular type of appointment, and had access to a quieter waiting room.

*"I have asked for telephone appointments, longer appointments, named GP."*

*"Time was changed so that my daughter had less waiting time in the waiting room for her appointment."*

*"They ask if I need my dad with me"*

However, several respondents had to explain their situation and advocate for themselves or their child every time.

*"My mum has asked for a longer appointment when I needed a lot of vaccinations done - it took a month to get approval. My mum had to do this as there was no way I could do this at all. We didn't know they had to do this, it was just what she rang and asked for but was told no, so she had to push for it."*

*"We have to ask and explain our son's disabilities and special needs, every time we call."*

*"I complained and made them adjust in some level and accept telephone appointment and accept my mum contacting my GP."*

Some respondents also mentioned that although their own GP was accommodating, there was variation between staff members and the support they offer.

*"Every person I've spoken to is different. Some nurses and doctors are very understanding. Others don't seem to understand or care very much."*

*"Doctors who have known me since I was a baby are more understanding and accommodating."*

*"Dr XXX is great. He is calm and get it. No one else is like this."*

### Waiting rooms and waiting

When asked what reasonable adjustments would improve their experience of visiting the GP, **most** respondents said that they would benefit from a quiet, calm waiting room and/or the ability to book an appointment when the GP practice is less busy to help manage and reduce their anxiety and the risk of sensory overload.

*"Quiet/dark waiting room"*



*"Quiet waiting room. Appointments at less busy times."*

*"Appointments at less busy times e.g. at the end of the day."*

*"separate room to wait, quiet times for appointments."*

Linked to this, respondents said they would like waiting times to be shorter and/or to be kept updated regarding their appointment time, emphasising that this would help them to manage their anxiety.

*"My daughter who is autistic finds it difficult to wait so less waiting times."*

*"Being kept more up-to-date with my own waiting time."*

*"To know rough waiting time so I could go in later if there's a long wait."*

### Other reasonable adjustments

The next **three** top adjustments that autistic respondents would benefit from are:



The opportunity to have a longer or double appointment, so that they do not feel rushed and can have enough time to communicate their needs. Respondents also commented that having a longer appointment would enable them to discuss multiple concerns at once, saving them from having to book another appointment.

*"Covering as much as possible in as few appointments as possible, because I find it really stressful."*

*"Allowing more than one issue to be discussed in an appointment. These are often related. Whilst I understand time pressures there is little attention for holistic care."*

*"Extended appointments would make a huge difference. I get so distressed about trying to fit in everything I need to say, that I end up not able to say anything of importance at all. Then I feel rushed and come out feeling worse than when I went in."*

*"I find normal, short appointments very hard to cope with. I am given double appointments generally, but if I need a quick appointment for a particular problem I get a random GP and under 10 minutes with them. I need a double appointment for this too, ideally. The short appointment makes me very anxious, and because I haven't taken everything in during the appointment, and haven't asked all the questions I have (about a medication I will have to take, how the illness will develop and get better etc.) I often have to recontact the surgery and speak to them more than once in order to get all the detail I require. (I really require detail!!) I end up taking up more of their time overall because they rush me to begin with."*

2

A consistent, familiar GP for all their appointments who knows the patient. This continuity of care is important to autistic people and enables them to build communication, trust and rapport. It also means that they do not need to keep repeating their needs and/or medical history.

*"Continuity of care would make a huge difference. It's really hard when you see a strange face every time."*

*"Seeing the same doctor, not needing to speak to other people."*

*"To be able to choose a Dr to see and to see the same person."*

*"Only being offered to see certain doctors as not all are friendly or explain themselves very well, that leaves me stressed or upset."*

One respondent has a particular good relationship with her children's GP and shared how much of a positive difference it makes both emotionally and clinically.

*"It can be difficult having to wait for the child to be seen by the same GP – that's a big issue, it has to be the same GP, but often there's no availability, you have to wait a month or more.*

*Our own GP is very sensitive and very caring and very knowledgeable, it comes across as highly sincere and she's keen to refer us to any services whatsoever that we ask for. It means an awful lot, it means a huge amount.*

*She is highly understanding of the condition and other related conditions, and it's really helpful. She is very understanding when anything related is pointed out, because she's made herself knowledgeable. The major positive is that she went away and took the time to look into the condition, she took time out to understand it – I thought that was very nice of her. But that's just one GP, and the rest of them don't know that much. That's why I find it best to see her."*

3

Although it does not typically fall under reasonable adjustments specifically, it was very clear from most respondents that more understanding, patience, sensitivity and respect from clinicians was really important and would make a huge difference to them. Many respondents felt that these were often absent and made them feel like uncomfortable, misunderstood and as if they are a burden.

*"Extra time, patience and sensitivity towards me."*

*"Extra care in how they talk to me and treat me."*

*"It would help me if they did not treat me as a pet animal."*

*"Most importantly someone that doesn't treat you as freak of nature and burden."*

*"Treating us with respect. Doctors talk to me in technical terms and even though my carer is saying he has a communication disorder and deciphering what they're saying, they still don't make an effort. It feels like they just don't care you're made to feel uncomfortable."*

*"Just try to understand us and be kind. We are all different. Going out does not fix things with autism."*

*"Better training for staff. There is a lack of understanding for severe learning difficulties and people that cannot communicate or understand."*

This included respondents wanting reception staff to be more understanding and aware of the needs of autistic people and the reasonable adjustments they can be offered.

*"Better informed reception staff with an understanding of how autism affects people."*

*"Reception staff being aware that I'm autistic and being less aggressive (although I understand their job is stressful.)"*

*"For each receptionist to be aware of the reasonable adjustments required rather than having to ask all the time."*

Respondents made lots of other suggestions which they felt would help them and other autistic people to use and access their GP practice. This included the ability to choose the type of appointment, whether this be face-to-face, online or by telephone to accommodate their individual communication needs and/or preferences.

*"Being able to request in person appointments rather than not having a choice and only being offered phone appointments."*

*"Getting an in-person appointment, not a telephone call to my mum."*

*"The eConsult system and submitting photos does not work for autistic people or anyone with a social communication disorder, it needs to be face to face."*

Similarly, when offered a telephone appointment, respondents would prefer if an exact time could be given rather than a large time window. Not having an exact time can increase anxiety and prevent autistic people from being able to sufficiently communicate their needs and in some cases, lead them to avoiding the telephone call entirely.

*"If I get a phone appointment, I need to know who I will be speaking to and when they will call, but reception won't tell me this, and will only tell me 'between 9 and 2' for a phone call. This makes me so anxious that I can't usually articulate my needs to the GP."*

*"Not always knowing when they will contact me can lead me to avoid it completely."*

Respondents also mentioned that they would like clinicians to communicate in a way that is accessible to them, including speaking more slowly, using different words and using alternative ways of interacting. Others suggested that receiving written information before and after the appointment would help them to manage their anxiety and enable them to feel reassured and prepared.

*"I have trouble talking about my body, so a different way to communicate."*

*"Written information telling me what I should do after seeing them about something."*

*"Understanding of my needs and that language used is very important."*

Respondents felt that better signage in GP practices would improve their experience of accessing their GP practice, and would help them to navigate an environment which might feel uncomfortable and distressing.

*"Extra information would be extremely useful as I get anxious when I feel I don't have all the information I need. Information to show if appointments are running late would be useful to reduce stress and clear signage to point me to where I would need to go would help to reduce anxiety."*

*"Extra signage would be useful, last time I thought the automatic door work and I have waited outside for it to work until someone came and pushed it."*

*“Better signage, I got used to the names of the waiting rooms, then they changed them to colours, but I cannot remember where to go now and this is stressful.”*

Lastly, respondents would like to be able to bring someone to support them at their appointments, as some noted this request has been denied. They would also like to be able to easily nominate someone to act on their behalf in making appointments, but also in receiving test results and other types of information.

*“Ability to have a friend present (I usually have to take someone but sometimes this isn’t allowed).”*

*“Easy way to nominate someone to act on my behalf making appointments or getting results/information.”*

It is worth noting that a few respondents could not think of any reasonable adjustments or personalised care they would like to be put in place, largely because their GP practice is already very supportive and accommodating.

*“I can’t think of any. My GP practice is fantastic and patient and supportive in general. So I am very lucky.”*

*“I think my practice does very well in accommodating me.”*

## **Autism health check**

Pilots are currently taking place in the NHS to implement Autism Health Checks with the GP which are specifically for autistic people in order to identify any health needs earlier, and to improve their overall health.

**69%** of respondents said that they would find a health check specific to autistic people helpful. Just **9%** would not find a health check helpful, and **23%** weren’t sure if they would.

*“Basically time to discuss all aspects of health care, so we can bring up minor issues but as part of a holistic check as I really struggle with making appointments for one issue when often many issues overlap.”*

*“An Autistic child may not be able to tell you their needs even if they are verbal. Routine check-ups can help diagnose any anomalies and issues with them.”*

*"If nothing else, it would mean they're not slipping out of the system otherwise, because it is quite easy to do so. They just need that little extra help to make sure that somebody's looking out for them, otherwise it would be quite easy for them to get missed, or maybe not go to the GP at all, because it's that first step of making communication"*

For those who would like an Autism Health Check, the majority would like a holistic approach to their health to be taken, and for this to include:

- A basic health examination (blood pressure, height and weight)
- Review of medication
- Dietary information and weight management support
- Mental health and emotional wellbeing
- Signposting information, including social and wellbeing support such as employment, education and housing
- Information on how to check for signs of cancer
- Blood tests
- Conditions typically more common in autistic people

*"Definitely help with diet. My diet is absolutely awful and that's because of all the sensory taste and texture difficulties I have with my autism. Weight management support would be useful. Checks to do with my heart rate and blood pressure too. Physical exam, or instructions on how to check for physical changes. Like breast checks and examinations. There are lots of things I should be doing for myself now I am an adult but I am not sure what."*

*"Physical health. I'm never really sure if my body is working well."*

*"Weight check (as long as the individual is comfortable with that), making sure the person is keeping up with their dental/eye check-ups, asking if there are any other concerns, potential sign posting, blood tests."*

*"Mental health, wellbeing, being offered any support that is available as its hard to find on my own, time to raise any concerns I might have."*

*"Just general physical wellbeing check, and mental health review."*

*"Standard tests such as height, weight, blood pressure and question about any health worries,*

*"Co-occurring conditions, diet, mental health, signposting to other things in the community, checking any other health problems."*

*"Medical risk factors associated with Autistic people."*

Respondents also felt that having a regular review of health would enable them to build a relationship with a GP.

*"An opportunity to build a relationship with the GP as wanted to build trust which is very difficult nowadays."*

These suggestions from autistic people about what they would like to be included in an autism health check show that having a GP who knows them and understands autism would make a significant difference to their wellbeing. Furthermore, having the opportunity to see their GP every year for an extended appointment would mean that autistic people feel more confident visiting their GP at other times, and would be supported in a holistic way that takes into account their individuality and specific needs.

### **"Autistic children are always left behind"**

Sam is the mother of a 13-year-old autistic boy who shared her experience of GP services for her son. She has had to constantly advocate for her child to receive the care that he needs.

**"The support is nothing, zero. They don't recognise him as having autism, so..."**

**"A GP Surgery should be safe space for an autistic person. They should be more friendly, more accommodating, more open, more welcoming so that parents can find it easy to communicate the needs of their children and not feel like they are being a bother and that GPs are doing them a favour."**

She shared multiple poor experiences with GP services:

**"I've had a doctor tell me... for example, he wasn't sitting still and they said, 'can you tell him to sit still?', and I said, 'but he's autistic...', they said, 'yeah, but tell him to sit still'. And I said, 'it's not him' - I have tears in my eyes as I'm saying this - I said 'he's not doing it deliberately, it's just who he is', and they just ignored me and carried on. As mothers, there's nothing you can do, you cry and pick yourself up and carry on."**

On the barriers to receiving reasonable adjustments, Sam said:

**"You can only ask for these things if there's that room to manoeuvre, that safe space for you to say something, to feel free to request such services. But when you feel like you're getting on their nerves, you're made to feel uncomfortable. Because of that, I don't even take him to the surgery unless it it's really really really needed."**

Sam shared that GP staff need more training on autism:

**"I feel strongly that the GPs need to be educated. They need to be trained. I feel that they are not trained, I've been to a few who are nice, there was one who was accommodating, but even him, I went back to him for a referral to CAMHS, and he didn't know what to do. He didn't know what to write in the referral. No clue what to do. So I realised that they are not trained, so they don't know how to handle our children with autism, they don't know. I was expecting that it would be in his notes, but they don't know. They need to be trained to understand that everyone is different. They don't know, and they don't care to know, like 'it's none of our business'. They don't take the time to know *these* children, or patients, adults, they don't take the time to know them in a holistic way."**

**"It should be a requirement for them to know these patients. Not just the GPs, the receptionists should know too, because they are the first port of call. They've been given so much power to decide what to do, so they should also know the patients and their requirements."**

She felt that an autism health check would be very beneficial:

**"Parents up and down the country like me say why bother, they don't even want to take care of you anyway, they won't listen to you. If we had a routine check every year, you'd know that someone cares enough to listen, to do something about it. The way it is now, no-one cares enough to listen. you just resign yourself to the situation and you conserve your energy to look after [your child], instead of going and being slapped in the face every time with 'no, no, no, no, no'. So if there was something like an autism health check put in place, that would be amazing. They should know that they can call their GP and get help."**

**"The strength that you have is to look after your child, not to be fighting [the doctors]. They are not taking who he is into consideration, to meet his needs. It shows that they**

## **Support and improvements**

63% of respondents said their surgery wasn't doing anything to support autistic people, or they didn't know what they were doing to support them.

*"Not heard of any support really, I asked for an OT assessment and was rejected, for mental health support, was rejected, however they did refer me to Mind, an organisation that offered me discounted Talking Therapy sessions"*

*"I'm not sure it really is. One doctor offered to turn the lights off as they were painful for me. I haven't seen any other direct help."*

*"I do not feel anything has been put in place to support autistic people and, if there is, it has not been made readily available to patients."*



However, some respondents shared some positive experiences, including examples of particularly caring and understanding staff members, and accommodations such as faster appointments or separate waiting rooms.

*"My doctor is understanding and is patient when I get stuck on words or find it difficult to speak."*

*"They are generally very supportive."*

*"Our GP practice is super at looking after my daughter's autistic needs. I do think this is more driven by her actual GP rather than the practice itself though."*

Many respondents' experiences were often dependent on being able to speak to the right person or GP, rather than being able to rely on the whole system to meet their needs.

*"There are individuals who are patient and try to accommodate you within I'll fitting systems and processes... but this is fairly rare."*

*"Once I can speak to my son's named GP everything goes very well."*

## **Suggestions for better care**

When asked how GP practices could better support autistic people, the top three improvements suggested were:

1

Clinicians and reception staff to receive training and education about autism and the needs of autistic people, so that their understanding, awareness and the care they give is improved.

*"Training their staff to understand the challenges autism presents in situations like these."*

*"They should all be trained to know, acknowledge and understand autism."*

*"Be better educated about autism, from reception and including GPs."*

*"A little bit more understanding and read and educate themselves on autism."*

2

Receptionists and clinicians to treat autistic people with more kindness, respect and empathy, and be willing and proactive in accommodating for their individual needs.

*"I think some extra consideration of the idea that 'not all disabilities are visible' would go a long way, not just for autistic people but for others too."*

*"To not be discriminating and take their needs seriously. The support they need is paramount and prevents harm. It's not optional, the support that they need is critical to help them thrive and live their best lives without further impairment. It's sad that it's not more important within modern day society. It should be. They deserve to live full lives like everybody else, but they can only do that with the correct support. It should not be put on hold like it's unimportant, because it's detrimental."*

*"As long as an ASD person is treated as an individual with their presenting challenges being recognised and supported, they are listened to and then signposted to services available in the community for ASD people, then things should go well."*

*"If they treated me as a human being."*

3

GP practices to offer and accommodate for reasonable adjustments, including being able to bring someone to support, choice in the type of appointment given, choice in clinician, a longer appointment, and having a quiet area to wait in.

*"Having a quiet room, so they can feel calm before seeing the doctor."*

*"Be aware of the special needs/reasonable adjustments up front."*

*"Allow me to nominate my parents to act for me."*

*"An extended appointment time."*

*"Somewhere quiet to wait would be super, if we could wait in the car... if I went in and registered to say we're here, and then sit in the car and wait, and then get a quick call to say it's your turn to come in, that would be great, it reduces anxiety."*

Some respondents suggested that patient records should clearly state if someone has autism. They felt that having this information immediately flagged would help reasonable adjustments be put in place and offered, and also prevent autistic people from having to keep repeating their diagnosis and medical history.

*"Read, recognise and know their patients' history and notes."*

*"Flag up on top of the file that someone is autistic. So everyone you see knows you have a disability...I should not have to keep saying every time I ring up that I am special needs...you should be letting me know what you know and what you can do to help me but instead I have to keep telling people this so that you would understand and be kinder."*

*"Acknowledge who they have on their records with autism."*

Having multiple ways to book an appointment was also important to respondents, with many commenting that they would like the option to contact their GP practice online rather than having to rely on the telephone, particularly as this interaction can be very distressing for autistic people.

*"Having ways to make appointments without using the phone."*

*"Offering a range of ways to book and attending appointments."*

*"Make it easier to communicate with them online or via email and make it easier to book appointments online."*

Autism Health Checks were also important, with respondents commenting that having a regular review of their health with a clinician they can build a rapport with would be useful and encourage them to access health and care services.

*"Regular reviews would be welcome."*

*"Regular checks even when healthy to allow trust so when health issues arise anxiety is lower and support can be accessed."*

## Summary

There is such a variety of needs and experiences within the autistic community, and this project has really focused on understanding and highlighting the breadth and depth of people's experiences. Autistic people's voices are seldom heard in such detail, and the stories shared in this research emphasis and communicate the lived experience of autistic people in a tangible way.

A core theme to recognise from this work is the extent to which the problems that many people face when accessing their GP practice are completely debilitating, scary and anxiety-inducing for many autistic people. Several respondents shared that the entire process of accessing and visiting their GP practice was so difficult and caused such distress that they avoided it completely, which puts their health at risk. Common reasons for this were due to difficulties communicating, unmanageable waiting times and environments, and feeling dismissed or rushed by staff. Positively though, some respondents shared experiences where individual GPs or other staff members had made an effort to be supportive and extra-patient, and these seemingly small acts made a big difference to their comfort and experience.

The positive experiences some autistic people had were most often the result of front-line staff taking the individual initiative to meet the needs of their patients. Their actions do not appear to be well enough supported or encouraged by the network within which they operate and the impetus cannot solely be on clinicians (and autistic people and their parent/carers) to stretch and shape the system in order for autistic people to receive basic primary healthcare.

The findings have also shown the importance of putting a clear emphasis on understanding how individualised autism is. Each autistic person deserves to be asked what their specific needs are, and for those needs to be met. For example, many respondents could not use a telephone, but preferred to make an appointment online. Conversely, others would benefit from being able to make an appointment over the phone instead of using the online system. Offering reasonable adjustments requires GP practices and staff to adapt to the needs of the patient concerned, rather than providing a cover-all approach. It would also help autistic people and their parents or carers to feel confident in requesting for their needs to be met.

The findings of this research highlight the inflexibility present in some areas of GP practices – when the workings of the system are prioritised above the individual needs of its patients, it's often the most vulnerable groups who fall through the net or aren't adequately supported. Whilst this inflexibility is a frustration for many patients, for autistic people, it has an extreme and directly detrimental effect on their lives and their health. For some autistic people, these barriers mean that they don't receive any healthcare until it's urgent, and their quality and length of life are reduced as a result.

## Recommendations

It is well understood that General Practice is facing significant pressure due to a combination of system factors, patient factors and supply-side issues<sup>36</sup>. However, it is particularly important that people who are already at a disadvantage, such as autistic people, do not suffer more as a consequence of these pressures on services. As such, based on the findings of this research, we advise Hertfordshire and West Essex ICB Primary Care Board to implement the following recommendations:

### Identification

- Support the implementation and promotion of the 'digital flag' for autistic people to add to patient records that indicate their eligibility for reasonable adjustments and enable the GP to be aware of the diagnosis.
- Reception staff should be proactive in reading patient records and checking whether any additional support is needed.

### Reasonable adjustments

- Ensure that all GP Practices are proactive in offering reasonable adjustments and are making patients aware of their right to ask for them. Any support requested must be implemented and not denied.
  - Of particular importance are:
    - Longer or double appointments
    - Appointments at less busy times
    - A quiet or private place to wait
    - Ability to see their named GP
    - Ability to choose the type of appointment they have
    - Ability to bring someone to support them at their appointment

### Communication

- As stated under the Accessible Information Standards (2016) clinicians should ensure they are communicating with autistic people in a way that is accessible to them, and providing information in a range of formats.

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<sup>36</sup> [Pressures in general practice | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/pressures-in-general-practice)

## Flexibility of Appointments

- Improve flexibility in the methods available to make an appointment to take into account individual needs and preferences – there should always be more than one way to book an appointment.

## Training and awareness

- Ensure the provision of autism and neurodivergence awareness training for all clinical and non-clinical staff working in GP practices.
- Clinical staff should take a holistic approach when interacting with patients, examining both their physical health as well as their emotional wellbeing.
- Clinical and non-clinical staff should treat autistic people with respect, dignity and understanding, and play a proactive part in supporting autistic people to communicate their needs and concerns.

## Autism Health Checks

- Continue to pilot Autism Health Checks across GP practices in Hertfordshire, and find out from autistic people what works well, what could be better, and what checks should be included.

## Appendices

Respondents were patients at the following GP Surgeries:

District	GP Practice	Respondents
Broxbourne	Park Lane Surgery	2
	Valley View Surgery	1
Dacorum	Rothschild Surgery	2
	Highfield Surgery	1
	Lincoln House Surgery	1
	Everest House Surgery	4
	Parkwood Drive Surgery	1
East Herts	New River Health	3
	Marymead & Knebworth Surgery	2
	Hanscombe House Surgery	1
	South Street Surgery	1
	Wallace House Surgery	2
	Dolphin House Surgery	1
	Church Street Surgery	1
	Helix Medical Centre	2
	Puckeridge & Standon Surgery	1
Hertsmere	Manor View Practice	6
	Attenborough Surgery	2
	Grove Medical Centre	1

	Schopwick Surgery	1
	Fairbrook Medical Centre	1
North Herts	Birchwood Surgery	2
	Sollershott Surgery	1
	Nevels Road Surgery	2
	Bancroft Medical Centre	1
	Regal Chambers Surgery	3
	Portmill Surgery	1
	Baldock Surgery	4
	Whitwell Surgery	1
	Garden City Surgery	1
	Buntingford Medical Centre	2
	St. Albans	Parkbury House
Maltings Surgery		8
Elms Medical Practice		2
The Lodge Surgery		3
Midway Surgery		1
Hatfield Road Surgery		1
Summerfield Health Centre		1
The Village Surgery		3
Stevenage	King George Surgery	2
	Stanmore Medical Group	5
	Chells Surgery	1
	Manor House Surgery	1
Three Rivers	Abbotswood Medical Centre	1
	Vine House Surgery	1
	The Consulting Rooms	1
	Gade Surgery	2
	Baldwins Lane Surgery	1
	New Road Surgery	1
Watford	Bridgewater Surgeries	4
	Watford Health Centre	3
	Suthergrey House Medical Centre	1
	Garston Medical Centre	1
	Sheepcot Medical Centre	1
	Callowland Surgery	1
Welwyn Hatfield	Lister House Surgery	2
	Moors Walk Surgery	2
	Garden City Practice	3
	Potterells Medical Centre	1
	Burvill House Surgery	1
	Hall Grove Surgery	1
	Bridge Cottage Surgery	2
Other	University of Hertfordshire Medical Centre	1