

Autistica Health Checks Workshops



Summary of findings

Autistica is the UK's autism research charity. Our visionary and ambitious 2030 Goals will help us achieve our mission to see all autistic people live happier, healthier, longer lives. This document summarises the findings of a project which engaged stakeholders in interactive workshops to drive our shared vision outlined in our 2030 Health Checks Goal. This goal is aimed at ensuring all autistic adults have access to a holistic health check from healthcare specialists by 2030 to improve detection and treatment of preventable health conditions that contribute to health inequalities.

By 2030, every autistic adult will be offered a yearly, tailored health check

Autistic people with and without learning disabilities, including those perceived to have lower support needs, are on average at higher risk of physical and mental health conditions¹⁻⁷. Many autistic people find accessing healthcare difficult or even impossible, whether due to having to make a phone call, having difficulty communicating symptoms to providers or experiencing sensory overload in healthcare settings⁸⁻¹⁰. These barriers to access mean many autistic people receive help later when problems have worsened, which can lead to worse health. Poorer health contributes to worse quality of life, lack of opportunities such as employment, and early death.

Autistica and NHS England are looking at ways of offering all autistic adults an **annual health check** at their GP surgery to help detect health problems earlier before the point of crisis. Our Health Checks Goal Plan sets out the work done so far, and what is needed, to drive progress on this goal. Autistica have funded researchers to co-design and pilot test an annual health check and to gather insights from healthcare providers and patients about their views on the health check¹¹⁻¹³.

Key research insights

- Over 70% of a large and diverse sample of autistic people think a primary care health check would be worthwhile.
- Health professionals were in favour of updating the healthcare offer for autistic adults and receiving additional training about autism in adults.
- Healthcare professionals do not always recognise the barriers autistic people face in healthcare that lead to health inequalities.

There is much work to be done to find out the best models of health check delivery to maximise uptake, quality and consistency of health checks. We want to help autistic people feel confident to use health services and attend health checks, knowing that their needs will be understood and accommodated, whether attending independently or with a supporter and whatever the level of support needed. We also want to ensure primary care professionals have enough resources and training needed to carry out health checks effectively.

In January 2023, we brought together different stakeholders, including autistic people, their supporters, health service commissioners and policymakers, GPs and researchers, in two interactive online workshops. People involved in the workshops gave us their views on how the issues affect them and may create barriers to delivering or accessing health checks. The groups discussed solutions to help answer the questions that are not being directly addressed by the current research studies.

What will Autistica do with the findings from workshops?

- **Research** – We apply for grants to support research, so if any ideas require further research we can find the best researchers and support them to achieve these aims.
- **Policy** – We will work with NHS England to explore, trial, develop and test feasible solutions to a tailored health check for autistic people. We will lobby the government to continue to tackle health inequalities affecting autistic people.
- **Information** – We will coproduce patient information and campaigns focused on raising awareness of the importance of health checks and helping autistic people make informed choices and advocate for their needs in healthcare.

Workshop topics

Reducing the workload for health check delivery

Autistica's aim: Listen to suggestions from healthcare providers and patients on how to introduce more efficient systems and how to do this without compromising accessibility or quality for autistic people.

Identifying who needs a health check and reaching underserved groups

Autistica's aim: Advise decision-makers on adapting materials and procedures and to consider the most vulnerable autistic people a priority in delivery of health checks, to ensure no group is underserved or invisible. We want to build trust, agency and empowerment for autistic people around the use of diagnostic and health data in identifying who to invite for a health check.

Finding out which health check models best support communication and accessibility needs

Autistica's aim: Inform commissioners, GPs and primary care practices on accessible communication for autistic people and continue to campaign for more digital and remote options.

Creating accessible information about health checks

Autistica's aim: Coproduce campaigns and information to guide and motivate autistic people and GPs about the need for health checks and what to expect.

Workshop findings

Barriers and facilitators to healthcare

Communication

“If we get communication right for autistic people, we get it right for everybody”
- Workshop participant

Too many services still rely on telephone as the main form of communication and access. This is not accessible for many autistic people who can experience anxiety, uncertainty and difficulty speaking when making phone calls. Online alternatives can be limited - they might not offer the same choices as the phone service.

Autistic people find their health problems can be overlooked, downplayed or misinterpreted by healthcare professionals because they may use different words, facial expressions and physical responses to other people. This led some people to doubt their own judgement.

It is currently up to autistic people to communicate their needs, as they are not routinely asked about adjustments that could be made to their care. Communication in healthcare doesn't just involve communicating with doctors, but also with other staff such as receptionists.

What helps?

- Online options that are well-implemented and offer an equal service to other formats.
- Being able to use photos, drawings or text to describe a problem.
- Some changes made during Covid-19 made healthcare more accessible – for example, less crowded environments help with processing and communication.

Automated systems

“[During Covid] what GPs said was impossible was suddenly possible. But now these options are closing down.”

- Workshop participant

Some automated systems, such as appointment reminders and online questionnaires, can make using healthcare a more positive experience. Systems need to be well-tested to make sure they work as intended and do not create additional barriers. Participants had had problems with faulty web links, incompatible devices, emails going into their spam inbox or needing to phone their GP to access an online resource. Providers of health services and researchers who attended the workshops noted that some systems used by health services have limitations when trying to create new tools to use with patients, such as having default instructions to patients that do not match providers' needs.

What helps?

- Automated check-in screens can remove some of the unpredictability of talking to a person.
- Automatic reminders for appointments and check-ups which can be personalised to the patient's preferred format – for example, some autistic people wanted to receive calendar invitations they could download to their phone, while others wanted reminders via a phone call to a carer or supporter.
- Having to opt out of an appointment or service rather than opt in made it more likely that people would attend.
- Two-way communication options (rather than 'no reply' numbers/email addresses).
- Systems that can be tailored towards a specific patient group or need.

Views on health checks: Information and accessibility

What to expect from health checks

Workshop contributors discussed what types of information would make them feel at ease about attending the health check.

- Video walkthroughs were often a useful tool which were often produced during the peak of the Covid-19 pandemic to help the public to know what to expect from services when their procedures changed. Autistic people and their family members in the workshops felt that having more video walkthroughs for routine procedures would put them at ease, reducing anxiety about attending appointments.
- Autistic people also felt they would need detailed information as early as possible about what the health check is for and what is involved – they would be less likely to respond if they received a letter or text telling them only that they were invited for a health check.

- They also valued step-by-step instructions and explanations, but noted the information they received often had steps missing. For example, if a letter tells a person to 'make an appointment to book their health check', this fails to mention the steps involved in making the appointment such as how to get in contact with the surgery.

Concerns about health checks

Even though the proposed health check has been developed with input from the autistic community, it is important to listen to people's concerns to provide the best possible information and find ways to overcome remaining barriers.

- Some participants worried that the broad scope of the proposed health check, which looks at physical health, mental health, social care and many other aspects of a person's life, might be overwhelming or distressing when reviewed in a single appointment. They felt this could put them at risk of going into crisis. They might be more at ease if they could choose which parts of the health check they wanted to focus on.
- Participants also worried that there was a lack of services and support to address new concerns that may be identified in the health check appointment. They also felt there would be stigma around discussing some issues such as mental health and how health intersects with areas like gender.
- Participants felt that more work would need to be done to offer health checks to people who find healthcare harder to access, including those with no fixed address, people who work or whose carers/supporters work, people who have less access to digital resources, and people with higher communication needs

What helps?

- A range of appointments/clinic times.
- Involving advocates to help people communicate with services.
- Using resources creatively to reach people who have less contact with health services. For example, involving social prescribers (practitioners with knowledge about local networks and connections with the charity and community sector) to reach people in communities who have less contact with primary care services.
- Information in different formats (e.g. posted letters).

Recommendations

"It doesn't have to be perfect, it just has to be good enough"
- Workshop participant

1. Coproduction

Coproduction is when services involve their target population in creating materials and processes. This can help to make services more relevant and increase engagement.

- Diverse groups of autistic people should be involved in the design, testing and review of all materials and processes involved in the health check.
- Autistic people who have had a health check or contributed to its implementation could be involved in communicating about the health check to the wider autistic community. This may help to build trust in the health check compared to communication only coming from the health service.
- All information should follow accessibility standards, taking account of autistic people's different communication and processing styles. Easy read information may be important for some autistic people and all materials should avoid jargon and use visual prompts, such as images, alongside written information.

- The health service should work more closely with the autistic community to build trust in the health system so that people feel more confident about having an autism diagnosis recorded on their medical records. They can only be invited to the health check if this is recorded accurately.
- Making universal adjustments to healthcare, such as reducing the impact of the sensory environment and improving communication methods, will benefit everybody, not just autistic patients.

2. Training

“Even in a city, I asked for recommendations of a GP with autism experience, and all the ones people mentioned wouldn’t take me as I was outside their practice area (even though they are very nearby).”

- Workshop participant

- Participants suggested that having an easy way to recognise a clinician who has had appropriate training about autism would help put them at ease about their appointment, such as displaying a certificate or lanyard that could indicate this.
- Training for clinicians carrying out health checks, and working with autistic patients more generally, should cover areas of importance to the autistic community. In these workshops, these included:
 - » Alexithymia (difficulties some autistic people experience with interpreting emotions and associated physical sensations)
 - » Masking (conscious or unconscious suppression of autistic traits) and more subtle presentations of autism
 - » Behavioural differences (for example, lack of eye contact as a neutral rather than negative behaviour)
 - » Sensory issues
 - » Professionals’ unconscious biases about autism and nurturing empathy towards autistic people and their supporters
 - » Mental health literacy (specifically in autistic people)
 - » Stress involved in healthcare interactions for autistic people and their supporters
- Demonstrating neurodiversity awareness, such as assigning staff who have training or lived experience to be Autism Champions, as well as posters, symbols (e.g. infinity sign) and evidence of coproduction and involvement in the tailoring of processes to neurodiversity.
- More work should be done to engage harder to reach GPs and health professionals in receiving autism training. GPs involved in the health checks trial have been positive about training and the need for health checks, but they represent a sub-group who are more engaged with this research. All clinicians in every sector of the health service will come into contact with autistic people and should be trained appropriately, but many may not recognise that they are not always able to tell which of their patients are autistic.

3. Information about health checks

- Information should be available in a range of formats, and individual preferences noted in patients’ records. Different formats may be useful for different stages of the health check (for example, an initial letter may be best for introducing the health check and setting out the options available for booking the appointment, with the ability to ask questions by phone or email, or look up more information online. Appointment reminders may be best offered as text messages).
- Inform patients about consent and sharing procedures involved in the health check – even though these may be the same as for other NHS services, it is important to build continual trust with autistic community, especially those in communities who are underserved or marginalised. Patients should also be able to choose what personal or medical information from the health check can be shared on with other services.
- Involve people in discussions between teams and services.

- Raise awareness of changes coming into NHS around reasonable adjustments flagging, improvements to medical records and the increasing functionality of the NHS App¹⁴⁻¹⁶.
- Patients should be told how they can best prepare for the health check appointment, such as what they will need to bring with them.

4. Carrying out health checks

- Consider if parts of the health check can be carried out in different ways, such as discussing health concerns using an online consultation and booking a separate appointment at the surgery or at home to conduct physical tests.
- Use digital systems that store previous responses to health check questions, so that information can be updated at the following year's appointment rather than entered from scratch – this will reduce the appointment time and the effort required for staff and patients.
- Use systems people are already familiar with, such as the NHS App.
- Allow patients to select the clinician they would like to carry out their health check, such as a familiar GP or the practice nurse.
- Professionals referring patients on to other services after identifying health concerns should check those services are appropriate and the patient is eligible to use them, to avoid them being bounced back to general practice.
- Tools, such as NHS England's digital reasonable adjustments flag, will support health checks, but need to be used correctly and consistently across services.
- Health checks should incorporate a safety plan that can be followed if patients experience any distress.
- Some parts of the health check could be optional so that people can choose what areas they would like to focus on.
- The health check could be offered across more than one appointment to reduce the risk of overwhelming patients.

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