

# Autistica Action Briefing: Health Checks

# AUTISTICA

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Autistica is the UK's autism research charity. This Action Briefing summarises ongoing work to develop a regular health check for autistic people, as already exists for people with learning disabilities. It was developed in collaboration with the project's leading researchers as well as autistic people with relevant experience to provide insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, services, regulators and research funders to act on this information. Enabling access to healthcare is a significant step in improving the lives of autistic people and reducing premature mortality. Commissioners, providers and policymakers now need to consider how to most effectively implement evidence-based health checks.

[www.autistica.org.uk/AutismStrategy](http://www.autistica.org.uk/AutismStrategy)

"For me, sitting in a doctor's surgery is like sitting in a black hole where I am not allowed to move until my name is called. Needless to say, I do not go to the doctors even when I am ill. But I would go if I received a letter telling me that I had an appointment." <sup>1</sup>

## What we know

"I don't use the phone so can't ring for an appointment. It's a barrier before I even get to the surgery." <sup>1</sup>

- **Autistic people die on average 16 years earlier than the general population.**<sup>2,3</sup> They experience poorer overall health outcomes<sup>4,5</sup> and are more likely to experience and die early from almost every cause of mortality that has been studied, including cardiovascular diseases, neurological conditions, mental health problems and suicide.<sup>5,6,7</sup>
- **International evidence suggests that autistic people are more likely to end up using emergency services and requiring hospital care than the general population.**<sup>8,9,10</sup> Problems that could be identified and managed early are often left to escalate, unnoticed by health professionals or even by autistic people themselves, until a crisis is reached.
- **Some autistic people are less likely to interpret signs of ill-health and many face barriers to accessing NHS services.** Alexithymia (difficulty identifying your own emotions), different responses to pain, sensory differences, anxiety-inducing uncertainty and mutual miscommunication are some of the issues that can avert autistic people from seeking healthcare when needed.<sup>1,11,12,13,14,15,16</sup>
- **Diagnosing health problems amongst autistic people is not always straightforward.** Autistic people are more likely to have a range of co-occurring conditions,<sup>5</sup> and communication differences can mean health problems are unnoticed, misunderstood or not investigated further.<sup>11,17</sup>
- **Health checks can help proactively focus support towards groups facing health inequalities.** Regular health checks are already offered to people with learning disabilities and other at-risk groups.<sup>18,19</sup> Implementing health checks for autistic people could provide GP practices with time and resource to provide a systematic and personalised approach to their autistic patients' needs, give autistic people a more certain route for accessing services, and build knowledge around autistic people which could improve accessibility and health outcomes more generally. It is possible that health checks will become highly cost-effective care for autistic people by reducing the need to access tertiary services.

## What we need to find out

"Everything needs to happen quicker, there appears to be a reactive response to mental health needs rather than proactive approaches" <sup>1</sup>

**Autistica are funding research at Newcastle University to design and test a health check for autistic adults.** The study is among the first ever to be completely co-designed with autistic people and will investigate a range of issues, including the barriers autistic people face in accessing primary care and the development of a pre-appointment digital tool to help deliver the health check. The research will be conducted as part of clinical practice, and consider the costs and value involved. Other research projects that could help to ensure health checks are implemented as effectively as possible include:

- How should health checks for autistic people be implemented? What is the impact of health checks on clinical outcomes (e.g. missed appointments, emergency admissions or misdiagnosis) and the cost-effectiveness of service delivery?
- Using existing secondary data, what are the rates of emergency admissions amongst autistic people in the NHS? What are the most common causes of hospitalisations, A&E attendance or visits to urgent treatment centres for autistic people?

- How can the health check currently in development be adapted for autistic children and young people?
- What public health campaigns are effective in driving uptake of health checks, including in harder-to-reach communities?
- Can elements of this health check be adapted to add value to the existing learning disability health check for autistic people with learning disabilities?
- How can services most effectively identify service users who could benefit from health checks, including those who may be undiagnosed?
- How can personalised support be delivered to autistic people after a health check, particularly with respect to common conditions?
- Can health checks be used to monitor wellbeing? How can measures of pain and wellbeing be used or adapted for autistic people through the annual health check?

## What we should do now

“Unless my appointment is specifically about autism it doesn’t seem to be on my file... Often they obviously don’t believe me.”<sup>1</sup>

- The NHS Long Term Plan<sup>20</sup> committed to *“pilot the introduction of a specific health check for people with autism, and if successful, extend it more widely”*. Autistica and the National Autistic Society have recruited a Policy Officer to tackle the practical and policy challenges in delivering health checks.

**NHS England should work with Autistica and National Autistic Society policy teams to deliver this commitment using an evidence-based approach with the involvement of the autism community.**

- Despite NICE recommendations, the digital infrastructure has not been prepared to enable GPs to invite local autistic people to health checks.<sup>21,22</sup> The NHS Long Term Plan commits to ensuring that *“clinicians can access and interact with patient records and care plans wherever they are”*.<sup>20</sup>

**NHS England and GP system providers need to ensure GPs can access information they need to invite autistic people for health checks, with relevant information possibly becoming part of the health record and accessible to individuals.**

- Autistic people’s diagnoses are so inconsistently coded across GP records that it would be difficult for practices to identify those in their area who should be invited for health checks.

**NHS Digital and NHS England should work closely with the Royal Colleges and autism community to produce a simplified list of codes and then support Integrated Care Systems and Sustainability and Transformation Partnerships to audit the quality of local records.**

- Implementing these health checks effectively in clinical settings will require time and resources from already overstretched health professionals, many of whom do not feel confident supporting autistic people.<sup>9,23</sup>

**NHS England should work with the Royal Colleges, Health Education England and others to agree how clinicians can be supported and incentivised to offer regular health checks for autistic people.**

- Every Primary Care Network area should have health professionals with expertise in the nuances of autistic people’s health to support other local areas in adjusting the care they provide. Currently we do not do enough to nurture that specialist expertise in the NHS.

**HEE and the Royal Colleges should consider ways to recognise members who develop expertise in the nuances of neurodivergent people’s health, including accrediting a General Practitioner with Extended Role (GPwER).**

- The CQC currently checks whether health checks for people with learning disabilities are delivered when it inspects GP practices.<sup>24</sup>

**CQC inspections should also look at whether practices are prepared to deliver health checks for their local autistic community.**

- 1 Autistica (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters, conducted in October 2018.
- 2 Autistica (2016). Personal tragedies, public crisis: The urgent need for a national response to early death in Autism. <[autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf](http://autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf)>
- 3 Hirvikoski T, et al. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 207(5), 232-8. <[ncbi.nlm.nih.gov/pubmed/26541693](http://ncbi.nlm.nih.gov/pubmed/26541693)>
- 4 Ryzewska E, et al. (2019) General health of adults with autism spectrum disorders – A whole country population cross-sectional study. Research in Autism Spectrum Disorders 60, 59-66. <[sciencedirect.com/science/article/pii/S1750946719300133](http://sciencedirect.com/science/article/pii/S1750946719300133)>
- 5 Croen L, et al. (2015) The health status of adults on the autism spectrum. Autism 19(7), 814-123. <[ncbi.nlm.nih.gov/pubmed/25911091](http://ncbi.nlm.nih.gov/pubmed/25911091)>
- 6 Bishop-Fitzpatrick L, et al. (2018). Using machine learning to identify patterns of lifetime health problems in decedents with autism spectrum disorder Autism Research 11(8). <[onlinelibrary.wiley.com/doi/abs/10.1002/aur.1960](http://onlinelibrary.wiley.com/doi/abs/10.1002/aur.1960)>
- 7 Autistica (2019). Recommendations for changes to the Autism Strategy. <[autistica.org.uk/AutismStrategy](http://autistica.org.uk/AutismStrategy)>
- 8 Zerbo O et al. (2018) Healthcare Service Utilization and Cost Among Adults with Autism Spectrum Disorders in a U.S. Integrated Healthcare System. Autism in Adulthood. <[doi.org/10.1089/aut.2018.0004](http://doi.org/10.1089/aut.2018.0004)>
- 9 Vohra R, et al. (2016) Emergency Department Use Among Adults with Autism Spectrum Disorders (ASD). Journal of Autism and Developmental Disorders 46(4), 1441-1454. <[ncbi.nlm.nih.gov/pmc/articles/PMC4845033/](http://ncbi.nlm.nih.gov/pmc/articles/PMC4845033/)>
- 10 Hand B, et al. (2018) Ambulatory Care Sensitive Admissions in Individuals With Autism Spectrum Disorder, Intellectual Disability, and Population Controls. Autism Research. <[onlinelibrary.wiley.com/doi/abs/10.1002/aur.2050](http://onlinelibrary.wiley.com/doi/abs/10.1002/aur.2050)>
- 11 Raymaker D, et al. (2017) Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. Autism 21 (8): 972-984. <[ncbi.nlm.nih.gov/pmc/articles/PMC5362353/](http://ncbi.nlm.nih.gov/pmc/articles/PMC5362353/)>
- 12 Westminster Commission on Autism (2016). A Spectrum of Obstacles: An inquiry into access to healthcare for autistic people. <[bit.ly/29dsAeE](http://bit.ly/29dsAeE)>
- 13 Nicolaidis C, et al (2013). Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. J Gen Intern Med. 28(6), 761-9. <[ncbi.nlm.nih.gov/pubmed/23179969](http://ncbi.nlm.nih.gov/pubmed/23179969)>
- 14 Sagr Y, et al. (2018). Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting. Autism 22(1), 51-62 <[ncbi.nlm.nih.gov/pubmed/28750547](http://ncbi.nlm.nih.gov/pubmed/28750547)>
- 15 Liptak G, et al (2006). Satisfaction with primary health care received by families of children with developmental disabilities. J Pediatr Health Care 20(4), 245-52. <[ncbi.nlm.nih.gov/pubmed/16831632](http://ncbi.nlm.nih.gov/pubmed/16831632)>
- 16 Bishop-Fitzpatrick L & Kind A (2017) A Scoping Review of Health Disparities in Autism Spectrum Disorder. J Autism Dev Disord 47(11), 3380-3391. <[ncbi.nlm.nih.gov/pmc/articles/PMC5693721/](http://ncbi.nlm.nih.gov/pmc/articles/PMC5693721/)>
- 17 Nicolaidis C et al. (2015) "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. Autism 19(7), 824-831. <[ncbi.nlm.nih.gov/pmc/articles/PMC4841263/](http://ncbi.nlm.nih.gov/pmc/articles/PMC4841263/)>
- 18 NHS (2018). Annual health checks: Learning disabilities. <[nhs.uk/conditions/learning-disabilities/annual-health-checks/](http://nhs.uk/conditions/learning-disabilities/annual-health-checks/)>
- 19 NHS (2016). NHS Health Check. <[nhs.uk/conditions/nhs-health-check/](http://nhs.uk/conditions/nhs-health-check/)>
- 20 NHS (2019). The NHS Long Term Plan. <[longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf](http://longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf)>
- 21 NICE (2017). NICE Quality and Outcomes Framework indicator NM153. <[bit.ly/2gGp8u4](http://bit.ly/2gGp8u4)>
- 22 NICE (2017). Autistic people will receive better care if GPs develop a national register, says NICE. <[bit.ly/2WMMNwu](http://bit.ly/2WMMNwu)>
- 23 Unigwe S, et al. (2017) GPs' confidence in caring for their patients on the autism spectrum: an online self-report study. J Gen Pract 67(659), e445-e452. <[bjgp.org/content/67/659/e445](http://bjgp.org/content/67/659/e445)>
- 24 CQC (2017). Guidance for providers > Nigel's surgery 53: Care of people with a learning disability in GP practices. <[bit.ly/2CWcFyd](http://bit.ly/2CWcFyd)>