



Healthcare Barriers, Health Outcomes, and Annual Health Checks for Autistic Adults: A Cross-Sectional Study of General Practitioners' Knowledge, Attitudes and Practices

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Abstract

Various physical conditions appear with greater frequency in autistic individuals in comparison to non-autistic people and can lead to higher morbidity, lower quality of life, and lower life expectancy. A voluntary primary care annual health check (AHC) scheme is in place in the UK for patients with intellectual disabilities (ID), some of whom will also be autistic. We report the results of a study involving an online questionnaire disseminated via Twitter to investigate knowledge, attitudes, and practices of UK General Practitioners (GPs) concerning barriers and enablers to autistic adults accessing primary healthcare services. Amongst other matters, we found that (1) autistic people who are independent for the most part face the greatest struggles accessing primary healthcare, and (2) advocates of AHCs for autistic adults face the twin challenges of convincing extremely busy GPs to prioritise AHCs, and of advocacy on behalf of people with other conditions.

Keywords: Annual Health Checks; General Practitioners; Health Outcomes; Healthcare Barriers

Introduction

Various physical conditions appear with greater frequency in autistic individuals in comparison to their non-autistic peers and can lead to higher morbidity, reduced life expectancy and lower quality of life (Casanova et al., 2020; Hirvikoski et al., 2016; Sala et al., 2020). Casanova et al. (2020, p. 1) found that: 'The abundance of chronic conditions ... in modern medicine makes comorbidity the norm rather than the exception'; for example, about 42% of adult Americans had multiple chronic conditions in 2014'. Doherty et al. (2022) concluded that 'Autistic adults have poor physical and mental health compared to the general population'. Medical conditions such as diabetes, hypertension and obesity are common. Disparities in health outcomes between autistic and non-autistic populations were found by Bishop-Fitzpatrick and Kind (2017, p. 3380) to be likely to be exacerbated by intersectional factors such as a disadvantageous environment, ethnicity, and socioeconomic status. While these factors can disadvantage any population, increased anxiety and depression in autism is very likely to be a factor as a result of interaction between characteristics of autism and environmental conditions more suited to

neurotypical peopleⁱ. Greater health risks associated with autism necessitate investigation of measures to improve autistic healthcare. The main barriers to accessing primary healthcare facilities, including annual health checks (AHCs), emerging from our literature review are shown at Appendix A, mapped onto the barrier typology developed by Walsh et al. (2020) i.e., patient-level factors, provider-level factors, and system-level factorsⁱⁱ.

UK National Healthcare Strategy

The United Kingdom Government's national strategy for autistic people for 2021 to 2026 includes six themes, one of which is "tackling health and care inequalities for autistic people". The strategy states that 'Improving health and care staff's understanding of autism is crucial in enabling us to make progress on reducing health inequalities for autistic people.' Funding is to be provided to recruit autism champions. A voluntary AHC scheme is in place in UK primary care for patients with intellectual disabilities (ID), some of whom will be autisticⁱⁱⁱ. A primary care health check for all autistic adults will be trialled by the NHS in the Northeast^{iv}. The proposed Health and Care Bill is expected to include a provision for named regional executive leads for autism and learning disability.

A key focus of national healthcare policy has been improving the quality of primary care for people with intellectual disabilities (ID; also referred to as learning disabilities). This results from the extensive evidence that people with ID have significantly poorer healthcare and more unmet health needs than other groups (Chauhan, Courtenay, & Hoghton, 2020; Robertson et al., 2014). The Disability Rights Commission (DRC) (2006) recommended introducing AHCs for those with ID and mental health problems to address access barriers, identify undetected health problems, and improve prescribing and coordination with secondary care. The Michael Inquiry (2008) made a similar recommendation for learning disabilities^v. A national Directed Enhanced Service (DES)^{vi} was introduced in England in 2009 to fund surgeries to provide AHCs for adults with learning disabilities. The health check is intended to identify undetected health problems and improve prescribing and co-ordination with secondary care. Carey et al. (2017) identified that these AHCs were a reasonable adjustment under the Disability Discrimination Act (DDA) 1995. The Equality Act (2010) absorbed the duties of the DDA and continued the practice of reasonable adjustments. NHS England is clear about the importance of health checks for people with learning disabilities for early identification of

undetected health conditions, appropriateness of ongoing treatments and promoting health (e.g., by means of screening and immunisation).^{vii} Clinical evidence supports the value of health checks for hard-to-reach groups including those with (intellectual) learning disabilities and certain autistic individuals (Robertson, Roberts & Emerson, 2010; Robertson et al., 2014). Whilst acknowledging a lack of evidence of longer-term benefits, Robertson and her colleagues (2014, p. 1) reported that:

Health checks consistently led to detection of unmet health needs and targeted actions to address health needs. Health checks also had the potential to increase knowledge of the health needs of people with intellectual disabilities amongst health professionals and support staff, and to identify gaps in health services. Health checks are effective in identifying previously unrecognised health needs, including life threatening conditions.

Carey and his colleagues (2017) began to fill gaps in knowledge relating to longerterm impacts of ID with their study based on hospital admissions, reporting that ‘introduction of health checks for adults with ID may have reduced preventable emergency admissions to hospital during the study’ and ‘Encouraging practices to increase the uptake of health checks could reduce health inequalities for adults with ID, as well as ensuring better standardisation of the overall process’ (Carey et al., 2017, p. xxiii). However, the National Institute for Health Research states that they have not reduced overall emergency or elective hospital admissions.^{viii} Under the Royal College of General Practitioners’ (RCGP) curriculum^{ix} (2016), GPs are expected to ‘Understand the value of conducting regular (annual) health checks’ for adults with ID. A strong case for preventative healthcare for autistic adults via the use of AHCs was made by the Westminster Commission on Autism (Sharpe et al., 2019).

Annual Health Checks (AHCs)

GP surgeries are not obliged to offer AHCs. Although the gov.uk website^x states that most surgeries do offer them, the latest government statistics^{xi} show that just over half of those on GP learning disability registers took advantage of a health check, and those adults who qualify for a health check are on not necessarily on a register. Maddams and Pearson (2013) found that autistic patients identified ease of access to GPs (such as timing and location of visits and flexibility of appointment times), patient anxiety prior to a consultation, and communication between doctor and patient during a consultation as the most difficult issues prior to and during a consultation with their GP. Doherty et al. (2022) also identified these issues. Many GPs are likely to find it counter-intuitive that autistic people with no ID often have difficulty in accessing health care, many aspects of autism being difficult for non-autistic people to understand (Beardon, 2017). The difficulty accessing healthcare applies both to individuals who have received a formal diagnosis of autism and to those who have self-identified as autistic, and leads to adverse health outcomes (Doherty et al., 2022).

Difficulty fitting health checks in to a practice’s daily schedule is an issue for time poor GPs. Financial incentives have been used for ‘obtaining widespread “buy-in” to a new initiative from a fragmented, independent contractor primary care system’ (Stokes et al., 2016, p.10). An independent researcher and local self-advocacy group (Walmsley, Price, & Hoghton, 2011) investigated six practices in Oxfordshire, England during 2010,

following delivery of training for the participating GPs and their staff, which identified multiple issues relating to deployment of AHCs including the ‘key’ points listed at Appendix B.

We report here on the results of an autistic-led project to investigate the knowledge, attitudes, and practices of General Practitioners (GPs) in the UK concerning barriers and enablers to accessing this service by all autistic adults – that is autistic adults with and without ID. The project also encompassed investigation of autism training and attitudes to mandatory medical training the results of which will be reported elsewhere. Our study was designed by the second author who is the Research Lead for Autistic Doctors International (ADI)^{xii} and conforms to inclusive autism research practice as set out in the framework developed by Chown et al. (2017). With two exceptions, all co-authors of this article are neurodivergent, including three autistic medical doctors and an autistic researcher.

Methods

The first phase of our study was a structured literature review using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) literature search process. This was followed by an online survey to understand individual GP perspectives on AHCs for autistic adults. Following confirmation from the Health Research Authority that we were not required to seek ethical approval from them, we gained approval from the London South Bank University ethics committee (ETH2122-0023)^{xiii}. The online questionnaire-based survey results are reported here.

Our health check focused questionnaire sought to better understand what aspects of autism are at issue here and identify potential barriers and enablers to the success of an AHC programme for all autistic adults. The development of the questionnaire was an iterative process using the expert knowledge of the medical doctors and researchers in the project team. The questionnaire that emerged from this process was piloted successfully and the pilot version was used in the ‘roll out’ of the survey.

General Practitioners were recruited via Twitter, from Autistic Doctors International, and from the personal and professional networks of clinical staff contacts of the medical doctor members of the project’s Steering Group.

All data was analysed by the first and fifth authors (with contributions from the other co-authors) to ensure that, by using more than one pair of eyes, our data analysis and reporting properly reflected the data. Here, we report data concerning healthcare barriers, health outcomes, and annual health checks. We plan to report elsewhere on: (a) the analysis of our data concerning GP autism training, and (b) the results of the PRISMA analysis.

Results

Our online survey questionnaire produced 31 responses. Not all respondents answered every question hence the total responses vary question by question.

Demographics

Of 28 responses, 19 (68%) were either a GP partner or salaried GP and 21 (75%) have been a GP for more than five years. All but two respondents from Wales were based in England. Thirteen (46%) served a population of more than 10,000, nine (32%) had a

population of between 5,001 and 10,000, Four (14%) served a population of between 2,001-5,000, and the remaining two (7%) had no more than 2,000 patients. 23 of 25 (92%) stated that their practice participated in the current AHC programme for those with ID. Most (11/61%) respondents did not include a flag or other indicator for autism in their patient records and only seven respondents out of 28 (25%) had an autism registry or its equivalent. Fourteen (50%) reported seeing autistic patients weekly, eight (29%) said monthly, and three (11%) daily.

Thirteen of 21 respondents (62%) described having a particular interest in or knowledge of autism. Eight (38%) did not. Four disclosed being autistic and two others had an autistic child. One autistic GP wrote: ‘Recently diagnosed, just realising how important this may have been in the fact that I didn’t see my GP for years - realising that autistic patients need some vital adjustments made for them to help them use the system easier.’

The questions in our online survey questionnaire can be divided into the following categories: health outcomes, patient barriers, and annual health checks. We now report our main findings under these three headings. The italicised text prior to the narrative are survey questions.

Health Outcomes

What in your view would be the main reason(s) why autistic adults suffer worse health outcomes than non-autistic adults?

Responses which added to further insights to those recorded under other questions included:

- ‘Difficulty accessing primary healthcare and thus missing out on health promotion and early detection of disease processes’
- ‘Unspoken rule or not wanting to bother someone’
- ‘Difficulty with interoception so challenging to know if something is wrong’
- ‘They are idiots who don’t pay attention to anything but themselves’
- ‘Clinician making assumptions/stereotyping etc’
- ‘Atypical presentation of variety of conditions’
- ‘It’s possible treatments may be less effective if not tested specifically in a population’
- ‘Medication sensitivity’
- ‘Increased stress of life’

Patient Barriers

What challenges do you think autistic patients may face before, during, and after appointments?

Responses to patient challenges when booking an appointment included:

- Frequently occurring examples included issues with using the telephone
- Complex booking systems
- Communicating their needs clearly
- Conveying the seriousness of a situation
- ‘Some have very low symptom burden and access the surgery just as their neurotypical counterparts; some require a third party to act on their behalf.’

- ‘The patients with most challenges actually have carers booking for them. It is patients who are coping independently that struggle more.’
- Practical difficulties and anxieties around securing appointments such as:
 - ‘Having to compete with other callers who lie and game to secure appointments’
 - ‘Telephone lines are very busy, they may not have the persistence to get an appointment’
- ‘They don’t book appointments.’
- One respondent was ‘Far more open to electronic communication’ for the booking of appointments.

The heterogeneity in autism was reflected by one GP’s observation that autistic patients may prefer non-face-to-face appointments whilst another stated that ‘we try to book F2F appointments which they prefer’.

Responses to patient challenges when attending an appointment included:

- Issues in the waiting room environment
- Difficulty describing emotions □ Sensations and pain
- Other communication issues.
- Some patients may not want their autism acknowledged
- Patients reluctant to discuss mental health issues
- Preference to always see the same GP
- Requiring an advocate/someone to accompany them
- Need for quiet areas to wait

Responses to patient challenges following an appointment included:

- Patient uncertainty about follow-up (mentioned by nine respondents)
- Anxiety about feeling misunderstood
- Being unclear about what was agreed (including vagueness about follow-up or worsening symptoms)
- Processing and remembering what has been said, taking instructions literally
- Determining what to about potential complications which were not communicated during the consultation
- Difficulty getting prescriptions
- Lack of ‘sensory acceptable advice’ (e.g., if a patient cannot wear a support/brace, finds the taste of medicine unacceptable, or cannot swallow tablets)
- Long waiting times for secondary care services

Times when you have not been understood by an autistic patient. Some reasonable adjustments were suggested such as avoiding idioms, metaphors and jargon. “Non-verbal” individuals and those with “severe” ID were mentioned several times. One wrote ‘Difficult to judge what they could understand having 20-minute appointment and not having met them before’. Another commented on having to adjust the way they convey information ‘even when I know the patient well.’ Consultations with some autistic patients being very long ‘led to repetition and frustration on both sides’ for one GP with another stating ‘Every time. They hear only what they want to hear’

What, if anything, do you do to adjust your communication style with autistic patients?

Autistic respondents said: ‘Nothing- I am autistic myself’; ‘I’m autistic too, as are most of my family... so adjustments are usually unconscious’, and ‘Normal communication. I am autistic.’ Other respondents said adjustments were ‘Very dependant [sic] on the communication needs of the individual patient’ and that their autistic patients hear only what they want to hear ‘Yea, they don't really listen to ALL the words coming out of my mouth.’

Suggested adjustments to communication style included:

- ‘I have told patients it is fine to write down what they want to say/ask and just hand it to me, and have given written/drawn instructions and advice’
- ‘Allow for silences (for Patient to process and relax)’
- Having the final appointment so more time can be taken
- Talking more slowly, using simpler/direct language, and shorter sentences
- Asking patient if they prefer not to be looked at directly
- Checking understanding
- Allowing processing time
- Offering more visual cues and prompts
- Focusing on facts
- Writing things down
- ‘I talk slowly and repeat myself’
- ‘Not giving too much info at once re overload’

Have you noticed any sensory problems for autistic patients during consultation?

Respondents highlighted sensory issues, including lack of eye contact, fluorescent lights, noise distractions (including ‘Sudden, unknown [unexpected?] noise around [doors being slammed, other patients talking outside]’). One stated that they had only noticed sensory problems in children. Another described a patient ‘not wanting to be examined’.

Has anxiety been a significant issue for autistic patients during consultation?

Eighty-two percent of 22 respondents stated that anxiety was a significant issue at least “sometimes”, while (14%) did not agree. One suggested that this was particularly so at the first meeting while others observed that anxiety was most noticeable during examination and ‘usually most obvious in those with a carer including autistic children’. One respondent suggested that autistic patients ‘tend to feel more exposed than others. I think they are particularly modest. I also feel that they are aware that visiting a GP is more difficult for them than for neurotypicals, and that this fact makes them feel embarrassed, stupid.’ Out-of-hours, hospital waiting room environments were described as environments where many children became anxious ‘so I don’t know whether this has anything to do with being autistic.’

Do you think that annual health checks for all autistic patients would have the potential to improve health outcomes for these patients?

Most respondents (16/64%) felt that AHCs have the potential to improve health outcomes for autistic patients, but a sizeable minority (9/36%) disagreed.

What was your reasoning for participating/not participating in the learning disability health check programme?

Nine out of 23 respondents (39%) were not part of the decision-making process (e.g., being a locum). Four (17%) referred to financial reasons (either being paid or financial penalties if they did not participate). Six (27%), including two who also mentioned financial benefits, referred to autistic patients being a neglected, vulnerable, or hard-to-reach group. Others emphasised 'Enable promotion of equity', 'It sounds reasonable. It sounds ethical', 'Can see it provides real benefits for patients' and 'Good medical practice', and, intriguingly, 'Ethical need outweighs financial implications' (implying a financial disbenefit associated with participation). Further responses were 'Everyone gets treated the same', which could relate to a participating or a nonparticipating practice, and 'Health checks haven't been shown to reduce morbidity or mortality, why would autistic health checks be any different?'

Discussion

Our online questionnaire sought to identify GPs' knowledge, attitudes, and practices regarding health outcomes for autistic adults, the barriers they face in accessing primary healthcare including AHCs, during consultation and afterwards, reasonable adjustments to ameliorate or remove barriers, and the potential for AHCs to improve health outcomes.

Demographics

The extensive knowledge of autism revealed by many respondents to our survey reflects being either autistic themselves, having an autistic child (of any age, into adulthood), or other connections with autism. Given that autism is spread fairly evenly throughout the population, the gap between those who say they see autistic patients daily and those who see them monthly is of interest. Doherty et al. (2022) recently reported that 'doctors may underestimate... the number of autistic patients under their care.' Given that a significant number of our participants were either autistic, or displayed considerable knowledge of autism, this gap may reflect differences in understanding of autism. Over 90% of respondents stated that their practice participated in the AHC programme for those with ID. Most respondents (11/61%) did not include an indicator for autism in their patient records and only a quarter of respondents had an autism registry or its equivalent.

Health Outcomes

The literature indicates that autistic people have poorer health outcomes than their non-autistic peers (Bishop-Fitzpatrick and Kind, 2017; Croen et al., 2005; Hirvikoski et al.,

2016; Rydzewska et al., 2019). Having a diagnosis of autism is linked with increased mortality over many diagnostic categories and early death by up to 16 years, increasing to about 30 years where there is co-existing ID (Bilder et al., 2013, Hirvikoski et al., 2016); greater prevalence of multiple physical health conditions (Croen et al., 2015); increased psychiatric emergency department admissions (Vohra et al., 2016); and less use of cancer screenings (Nicolaidis et al., 2015) amongst other matters. In addition to identifying barriers discussed elsewhere in this paper, our participants referred to reasons for autistic individuals suffering poorer health outcomes than the general population previously identified by other researchers including atypical presentations (Diaz et al., 2021); differences in interoception (Fiene, Ireland & Brownlow, 2018); and medication sensitivity (Sockalingam et al., 2021).

Patient Barriers

The 31 responses to our online survey (of which 10% were from autistic GPs) demonstrated a recognition that autistic patients faced significant barriers before, during, and after consultations with a physician in primary care. Autistic people tend to be highly anxious for a considerable time prior to and after any social interaction event and often ruminate on what they can expect and undertake a 'post-mortem' afterwards (Beardon, 2022). The doctor's understanding of autism, the surgery environment, and system-related issues such as inadequate autism training and lack of diagnostic resources can exacerbate anxiety (Doherty et al., 2022). One respondent stated that when 'telephone lines are very busy, they may not have the persistence to get an appointment' although this could also be due to increasing anxiety rather than lack of persistence. The honesty often associated with autism (Atherton et al., 2019; Beardon, 2017) is reflected in the response from one GP who said that one of the challenges faced by autistic patients is 'having to compete with other callers who lie and game to secure appointments.'

Our survey revealed a belief that that autistic patients who are coping independently may struggle most as those with more obvious challenges tend to be supported by carers. It is not necessarily the case that independent autistic adults find accessing their doctor's surgery straightforward. Beardon (2022) considers that barriers are: not knowing that you need to go; making yourself accept that you need to go; and not being registered (achieving this in itself being a challenge for many independent autistic adults). It cannot be assumed that autistic adults will always present for care when unwell or will present in a timely manner (Doherty et al., 2022). As AHC uptake is poor for autistic adults with ID who are currently eligible and for whom GPs generally appreciate the necessity, there is a major barrier to convincing GPs that adults they expect to present when they need to may not do so. GPs do not learn enough about autism during their undergraduate and post-graduate training to understand the difficulties that otherwise capable autistic adults face in accessing healthcare (Unigwe et al., 2017).

Evidence of significant healthcare barriers for autistic adults, and their link with self-reported adverse health outcomes, is incontrovertible (Doherty et al., 2022) and points to a clear need for all GPs to be trained to an adequate level on the characteristics of autism and the ways in which autism can impact health and wellbeing. GP ongoing training needs to be cognisant of the barriers autistic adults without ID face in accessing primary healthcare, focus on the potential for improved health outcomes, and enable doctors to communicate more effectively with autistic patients. Our findings suggest that working

towards GP “buy in” may be more effective than making AHCs mandatory for all autistic patients. Although this may not be a quick fix, voluntary take-up is probably more likely to lead to efficacious health checking rather than perfunctory box-ticking. We suggest that AHCs for all autistic adults and appropriate GP training should be developed on a voluntary basis with an associated educational campaign to highlight the need and potential benefits. Further interesting perspectives included that some patients may not want their autism acknowledged, were not keen to discuss mental health issues, and preferred to see the same GP every time. This latter point could reflect a difficulty with unpredictability and getting used to ‘new’ people, although anecdotal evidence suggests that many people prefer to develop a long-term doctor/patient relationship.

The following comment possibly expresses a degree of exasperation. ‘Every time. They hear only what they want to hear’ (we do not understand how anyone can know this and it does not reflect our understanding of autism; had it been said in a focus group setting we could have enquired further). Responses from three autistic GPs – ‘Nothing- I am autistic myself’; ‘I’m autistic too, as are most of my family... so adjustments are usually unconscious’, and ‘Normal communication. I am autistic’ – support Milton’s double empathy hypothesis that communication difficulties between autistic and non-autistic people are bi-directional in nature rather than the ‘fault’ of the autistic person (Crompton et al., 2020; Milton, 2012).

Annual Health Checks

The ongoing debate about the efficacy of AHCs is reflected in our data where only about 60% of respondents thought that health checks could potentially improve health outcomes. However, NHS England emphasise the importance of health checks for people with ID for early identification of undetected health conditions, ensuring appropriateness of ongoing treatments and health promotion. Clinical evidence points to their value to hard-to-reach groups including those with ID and certain autistic individuals (Robertson et al., 2014; Warner, Parr & Cusack, 2019). AHCs also increase knowledge that clinical and support staff have about the health needs of people with ID and enable identification of gaps in health provision (Robertson et al., 2014).

Evidence of longer-term beneficial impacts for adults with intellectual disabilities (ID) is beginning to emerge (Carey et al., 2017; Emerson et al., 2017; Robertson et al., 2010; 2014). Indeed, it has been proposed that annual health checks for people with ID may represent a ‘reasonable adjustment’ under the Equality Act 2010 considering the difficulties in identifying health needs associated with this population (Robertson et al., 2010). There is sufficient evidence of the benefits on healthcare of annual health checks for adults with ID, many of whom are also autistic (Robertson et al., 2010; 2014), although further research is necessary, including longitudinal studies. The emerging evidence of benefits from the provision of AHCs, coupled with the difficulties autistic adults without ID often have accessing primary healthcare, is sufficient to conclude that GP practices should consider offering AHCs to *all* autistic adults. We also advocate further research into the efficacy of health checks for these hard-to-reach groups and especially longer-term research as there is a dearth of longitudinal studies designed to evaluate the sustained efficacy of AHCs over time.

We conclude with our finding that the medical model is still entrenched in relation to autism. This is not altogether unsurprising given that autism is included as a medical condition in the diagnostic manuals. There is increasing acceptance of the neurodiversity paradigm – which regards ADHD, autism, dyslexia, dyspraxia etc. as aspects of natural human cognitive difference – in some fields including higher education (Clouder et al., 2020) and high-tech businesses (Loiacono & Ren, 2018). Will medicine be a late adopter of this paradigm?

Strengths and Limitations

The primary strengths of this study are that it was autistic-led and that the research team included experienced medical doctors as well as researchers. All members of the research team were neurodivergent bar two, with the majority being autistic. Members of Autistic Doctors International – who bring the dual perspectives of lived experience of autism and their medical backgrounds – guided the development of the study from start to finish. One of the medical doctors on the team designed the original version of the study; although the design underwent some change (for purely pragmatic reasons) he guided the changes. The need for administrative support for the neurodivergent members of the team was recognised at the design stage. Admin support contributed significantly to successful completion. Our questionnaire emerged from a lengthy iterative course of development involving experienced qualitative researchers and medical doctors which we believe to have been a robust process.

There are also limitations to our study. Despite our extensive ‘marketing’ efforts our dataset is exceptionally small in relation to the number of GPs working in the UK. Unfortunately, our survey was undertaken during a pandemic when local practices were under extremely heavy pressure severely limiting time spent on non-essential matters. Nevertheless, our respondents have contributed valuable data which we think punches above its weight. Many respondents were either autistic and/or had a particular interest in autism. Although we are satisfied that the questionnaire captures the topic under investigation effectively, it was not subjected to a formal validation process by a psychometrician and principal components analysis was not undertaken. Our self-selecting contributors may well have significantly greater levels of understanding of autism than most GPs (Mazurek et al., 2021) which raises the likelihood of bias. Although our conclusions can only be indicative, the knowledge of autism demonstrated by many of our participants, represents a rich seam of expertise ripe for further mining. The project has identified next steps, subject to securing funding, which aim to operationalise the findings for the benefit of all autistic adults.

Next Steps

We hope to use GP focus groups to ‘drill down’ into our data and extend it in an interactive context. Some of the barriers reported in this study could be addressed reasonably easily and at little or no cost. We intend to identify ‘quick wins’ and create appropriate guidance on their implementation for dissemination to GPs. Further next steps, to be undertaken as separate projects, involve: (a) development of online autism training for GPs in conjunction with ADI to be made available free of charge after any initial unfunded development costs are recouped^{xiv}; and (b) research on financial incentives.

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Author Contributions

The second author designed the project methodology. The first author led the drafting of this manuscript. The first and fifth authors undertook data analysis separately. The other authors reviewed and commented on the data analysis and various drafts of the manuscript until all were satisfied that it reflected the project's survey data.

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Data Sharing Statement

The authors' data – all of which is fully anonymised – is available on request to the corresponding author.

Compliance with Ethical Standards

The authors have no conflicts of interest relevant to this article to disclose.

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Appendix A: Barriers for accessing primary healthcare for autistic adults

Patient-level factors
Not knowing that you need to go
Making yourself accept that you need to go
Not being registered
Knowledge that professional may not understand you, or believe you
Making an appointment
The terror of last time
Difficulty explaining healthcare concerns
Being alone
Fear of the unknown
Fear of the outcome
Lack of involvement in decision-making
Challenging procedures (including tactile issues)
Behavioural issues including fears
Sensory sensitivities/unfamiliar and challenging environments
Travelling/long waiting times/inadequate visit time
Communication issues including literal use of language ^{xv}
Lack of rapport between doctor and patient
Provider-level factors
GP lack of knowledge of autism/outdated knowledge
GP lack of diagnostic resources
Unfriendliness
Lack of positivity
Perception that GP is too busy to tend to needs
Co-existing conditions complicate assessment/diagnostic overshadowing
Communication issues including literal use of language
Lack of rapport between doctor and patient
System-level factors
Lack of access to autism specialists
Lack of training in autism

Appendix B: Issues relating to deployment of annual health checks

- (a) All the practices involved had problems identifying who was eligible for an AHC (with their lists often differing from those held by the Primary Care Trust;
- (b) Some GPs considered that these checks had the potential to improve healthcare but others stated that they already provided good care for these patients;
- (c) The recording of outcomes was patchy (only two of the six practices did this);
- (d) The recommended proforma screening tool – the Cardiff Health Check – needed improvement;
- (e) AHCs are not cost effective, especially if a home visit is necessary;
- (f) GPs were not properly trained to work with these patients;
- (g) Guidance on access to specialist advice was poor;
- (h) Advice on legal requirements was a particular need (e.g., the concept of “reasonable adjustments” under the Disability Discrimination Acts was poorly understood and no use of the Mental Capacity Act 2005 to test capacity was identified);
- (i) Community Learning Disability Nursing Teams (CLDTs)^{xvi} should be more proactive in *supporting* GPs and provide practices with a named contact. Extracted from Walmsley, Price, & Hoghton, 2011

ⁱ All environments are neurotypical environments – environments suited to non-autistic people – other than those specifically designed for autism such as the UK Autscope retreat-style conferences. ⁱⁱ Walsh et al. (2020) identified “social environment and attitudes” as a further category of barriers, listing complex family issues and attitudes towards conventional medicine under this category. ⁱⁱⁱ <https://www.england.nhs.uk/blog/the-importance-of-an-annual-health-check/>

^{iv} <https://managementinpractice.com/news/gp-practices-to-trial-health-checks-for-autistic-adults/>

^v The Michael Inquiry (2008, p. 59) covers autistic people ‘if they also have a learning disability but it excludes conditions such as Asperger’s syndrome amongst people with average or above average intelligence.’

^{vi} Of 270 assessed practices in the study undertaken by Buszewicz et al. (2014) 222 (82%) were incentivised practices i.e. were practices that carried out AHCs for their patients with an ID.

^{vii} <https://www.england.nhs.uk/blog/the-importance-of-an-annual-health-check/>

- ^{viii} <https://evidence.nihr.ac.uk/alert/annual-health-checks-for-people-with-intellectual-disabilitiesreduce-preventable-emergency-admissions/>
- ^{ix} https://www.gmc-uk.org/-/media/documents/RCGP_Curriculum_modules_jan2016.pdf_68839814.pdf
- ^x <https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/>
- ^{xi} The learning disability health check programme statistics are scheduled to be updated in July 2021.
- ^{xii} Autistic Doctors International is a group of over 500 autistic medical doctors ‘with a shared vision ... that autistic doctors bring a variety of strengths to healthcare, including an array of benefits for autistic patients. We adopt a neurodiversity-affirmative approach to our work, which centres around four core areas: Support, Advocacy, Research, and Education’ (<https://autisticdoctorsinternational.com/>). ^{xiii} The ethics approval covered this project and the related training project for ease of administration.
- ^{xiv} There is likely to be a small charge for access to the training until any unfunded costs have been covered. ^{xv} This barrier involves the patient and their doctor. It reflects the “double empathy” concept which proposes that communication difficulties between autistic and non-autistic people are bidirectional (Milton, 2012).
- ^{xvi} Whilst AHCs are for young people aged 14-17 as well as for adults, CLDTs work with adults only.