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'It seems like a luxury to be able to offer that': Factors influencing the implementation of annual health checks for autistic people in England

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Abstract

Autistic people in England face worse health outcomes than non-autistic people. Autism-specific annual health checks have been proposed as one solution to this issue. This study identified strategies to incentivise primary care providers to offer autism-specific annual health checks, using a behavioural science approach. In phase 1, we conducted interviews and focus groups with autistic people ($n = 10$) and primary care providers ($n = 11$). In phase 2, we conducted a national survey of primary care providers ($n = 196$). Qualitative data were analysed using a framework method and the Theoretical Domains Framework. Quantitative data were analysed descriptively, and comparisons between sub-groups of survey respondents were made using Mann–Whitney U and Kruskal–Wallis tests. The most salient theoretical domain was environmental context and resources. Participants identified lack of time and staff as key barriers to implementation. Delegating tasks to non-physician practitioners and automating processes were seen as key facilitators. Autism-specific knowledge was another relevant domain; education produced and delivered by autistic people was posited to increase health check uptake and quality. Overall, participants were enthusiastic about autism-specific annual health checks but were concerned about the practical aspects of implementation. We identified specific barriers and facilitators that can be addressed prior to policy adoption to maximise chances of success.

Lay abstract

Autistic people are more likely to have mental and physical health problems than non-autistic people. Annual health checks could reduce these problems by finding and treating them early. Annual health checks are yearly medical appointments where a primary healthcare provider (such as a doctor or nurse) can check things like a patient's weight and heart rate and ask if they have any worries about their health. In this study, we wanted to understand what might encourage primary healthcare providers to use annual health checks with their autistic patients. First, we spoke to 10 autistic people and 11 primary healthcare providers. Using the findings from these conversations, we created an online survey for primary healthcare providers in England. We used the findings from the interviews and survey to help us understand what would encourage primary healthcare providers to offer annual health checks for autistic people. Our participants said that a lack of time and staff would make it hard to provide health checks. To help, they said other members of staff (such as nurses and healthcare assistants) could do the health checks, rather than doctors. They also said parts of the process could be made automatic to save time (e.g. sending automatic reminders). Knowledge about autism was important too (e.g. knowing about the common conditions autistic people have, and how to best support autistic patients). Participants said training on these topics, produced and delivered with autistic people, could encourage them to use annual health checks with their autistic patients.

Keywords

autism, behavioural science, health checks, healthcare, policy, preventive care

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Autistic people face unique challenges when seeking and accessing healthcare. First, autistic people may be less likely to identify health issues that could be resolved through appropriate medical attention. For example, some autistic people display differences in interoception, meaning they may be less able to detect signs of ill health (DuBois et al., 2016; Williams et al., 2022). Furthermore, autistic people may not express pain or discomfort in the same way as non-autistic people, meaning such signs can be missed by parents, carers and/or medical professionals (Allely, 2013; D. J. Moore, 2015). Second, even when signals of ill health are identified, autistic people report finding healthcare inaccessible. For example, autistic people are likely to face difficulties using the telephone to book appointments with a general practitioner[1] (GP), and additional barriers exist related to the sensory environment when attending in-person appointments (e.g. noisy waiting rooms) (M. Doherty et al., 2022). Similarly, autistic people report experiencing significant challenges regarding communicating with clinicians and other personnel (e.g. reception staff) and suggest that traditional 10 minutes consultations provide a barrier to effective communication between GPs and their autistic patients (Brice et al., 2021; A. J. Doherty et al., 2020; M. Doherty et al., 2022). As a result, some autistic people avoid seeking medical advice until their health has deteriorated (Coleman-Fountain et al., 2020; A. J. Doherty et al., 2020; M. Doherty et al., 2022). Since regular, proactive contact with primary care professionals (PCPs)[2] may overcome some barriers autistic people face, annual health checks (AHCs) may improve health outcomes and healthcare experience for autistic people (Harper et al., 2019). AHCs are yearly bio-psycho-social health reviews that can help to identify health problems early. A recent study found that most (73.4%) autistic people and 'proxy' respondents (relatives and carers) think that a regular health check should be provided to autistic people (Mason et al., 2022).

AHCs in the English National Health Service[3]

In England, GP practices are private organisations that engage in contractual agreements with the National Health Service (NHS) to provide primary care services for a geographically defined population. These contracts outline which services the NHS will remunerate and under which circumstances. Currently, AHCs for the general population are not reimbursed by the NHS and, as such, are not typically offered as a standard service. Practices are, however, encouraged to offer AHCs to certain vulnerable populations (e.g. people with learning disabilities) as a Direct Enhanced Service. Direct Enhanced Services are outside the core offering of GP practices but are deemed by the NHS to be essential for certain demographic, geographic or clinical populations. The NHS will fund practices to offer these additional services in appropriate circumstances.

Where they have been implemented, AHCs result in (1) increased detection of unmet health needs, (2) reduced preventable hospital admissions, (3) increased patient quality of life and (4) increased knowledge about the health needs of specific groups (Bauer et al., 2019; Buszewicz et al., 2014; Carey et al., 2017; Robertson et al., 2014). Yet, adoption of AHC policies is generally low (only about half of those on the learning disability register receive AHCs), and varies widely geographically (from $<30\%$ to $>80\%$ across Clinical Commissioning Groups (CCGs);[4] Public Health England, 2020). The variation in take-up of AHCs, despite evidence of effectiveness, suggests implementation challenges. Proposed drivers of the implementation gap for AHCs include (1) inadequate time and resources, (2) inaccurate or inconsistent coding registers and (3) professionals' scepticism surrounding the effectiveness of AHCs (Krska et al., 2011; Mills et al., 2017; Shemtob et al., 2021; Walmsley, 2011).

Most autistic people do not have a co-occurring intellectual disability (Dunn et al., 2018) and are therefore not offered an AHC under the current scheme. An AHC specific to autistic people has recently been developed (Taylor et al., 2023), and a clinical trial will evaluate the effectiveness of the checks in identifying and responding to health needs of this group. However, the experience of other health checks leads us to anticipate that implementation challenges may limit access to autism-specific AHCs, even if they are shown to be effective.

Behavioural public policy design

The current study takes a behavioural science approach to investigate the implementation challenges associated with providing AHCs. We conceive of 'policy implementation' as a series of behaviour changes made by a defined group of actors, whose behaviour is influenced by both internal and external context. Here, we use the Theoretical Domains Framework (TDF) (see Supplemental Appendix A), which synthesises insights from 93 theories of behaviour change (Michie et al., 2011), to catalogue possible pathways to implementation. We define 'policy adoption' in this case as the decision to contract with NHS England to provide autism-specific AHCs. This decision is typically taken by GP practice leadership (i.e. the organisation's business leadership team, including GP partners[5]). The decision may involve consideration of, for example, patient-case mix and needs, resource capacity and anticipated (cost) effectiveness of the proposed policy. At a more granular level, adopting a new policy requires shifting resources and changing work patterns. This study explores the specific variables that may contribute to the decision to adopt autism-specific AHCs at GP practices in England.

Methods

This sequential, mixed-methods study was conducted in two phases. Phase 1 involved interviews and focus groups with PCPs ($n = 11$) and autistic people ($n = 10$) to explore attitudes towards autism-specific AHCs, and the perceived barriers and facilitators to implementation. Based on phase 1 findings, we refined a bespoke survey instrument for phase 2. The survey was completed by 196 PCPs and was used to confirm the most significant barriers and the most promising facilitators to implementing autism-specific AHCs. The TDF (Atkins et al., 2017; Cane et al., 2012) ensured full exploration of potential behaviour change mechanisms. The TDF has been used previously to investigate the implementation of NHS health checks for people aged 40–64 years (Atkins et al., 2020).

Ethical approval for this research was obtained at Institute of Education, University College London Faculty of Education and Society Research Ethics Committee (REC1492). Because we recruited healthcare professionals through their NHS workplaces in phase 2, additional approval for the survey was obtained through Integrated Research Application System (IRAS), the single system for applying for the permissions and approvals for health and social care/community care research in the United Kingdom (REF 298743).

Phase 1: interviews and focus groups

Participants. In phase 1, PCPs were recruited through the professional networks of the study authors and referrals from other participants. Recruitment materials indicated that we were interested in hearing the views of GPs in England regarding autism-specific AHCs and that participants did not need any prior knowledge or expertise about autism. During recruitment, one non-GP participant (an NHS commissioner) reached out to the research team to register their interest in participating. We chose to include them in the analysis as they had relevant experience and expertise. Formally diagnosed autistic adults (AAs) (aged 18 years or older), with no intellectual disability were recruited via the Autistica Network, a research participation database run by the UK charity, Autistica. Adults who self-identified as autistic were excluded given that, if recommended by NHS England, AHCs would be offered only to those with a formal autism diagnosis. Autistic people with an intellectual disability were also excluded as they are already eligible for AHCs in England.

Regarding PCPs, most ($n = 10$ of 11, 90.9%) of our participants in phase 1 were GPs. Most identified as women ($n = 8$, 72.3%) and were from a White ethnic background ($n = 7$, 63.6%). Over half were based in London ($n = 6$, 54.5%). Regarding their experience with autistic people, most PCPs reported occasionally ($n = 5$, 45.5%) or regularly ($n = 4$, 36.4%) interacting with autistic patients in their professional practice, and over half ($n = 7$, 63.3%) reported having a personal connection to an autistic person. When asked to rate their knowledge of autism on a 7-point Likert-type scale from 1 (low) to 7 (high), PCPs generally rated their knowledge as average (median rating = 4, range = 3–6). Furthermore, demographic information can be found in Table 1.

Regarding autistic participants, all were from a White ethnic background ($n = 10$, 100%) and the majority identified as female ($n = 7$, 70%). On average, autistic participants received their autism diagnosis at 37.7 years (standard deviation (SD) = 11.50), compared to the national average of 14.5 years (Russell et al., 2022). Most autistic participants ($n = 8$, 80%) reported thinking about health issues they would like to discuss with their GP three or more times within the last 6 months. However, only half ($n = 5$, 50%) had contacted their GP about a health issue at the same rate.

Materials and procedure. Prior to the interview/focus group, all participants completed a brief demographics questionnaire, including questions regarding their age, gender identity, ethnicity and geographical location. Autistic participants also provided information about the regularity of their contact with their GP, while PCPs provided information about their personal and professional experience with autistic people. Focus groups and interviews took place between July and October 2021. Individual interviews with PCPs ($n = 11$) and autistic people ($n = 3$) were conducted via Zoom. Two focus groups with autistic people ($n = 4$; $n = 3$) were conducted using Flock, an online written messaging platform. Interviews with PCPs took 29 min on average (range = 17–55 min). Interviews with autistic people took 19 min on average (range = 9–28 min[6]). Each online focus group lasted approximately 2 h.

Focus groups and interviews followed the same schedule, with interviews offering more time for in-depth probing of responses and focus groups allowing for group discussion between those with shared experiences. The content of the schedule was tailored to the participant group to ensure only relevant questions were asked (see Supplemental Appendix B). The schedule for PCPs covered (1) experiences of providing AHCs for other groups, (2) confidence in one's capabilities to provide AHCs, (3) perceptions surrounding the opportunities (and barriers) to provide autism-specific AHCs, (4) motivations for providing autism-specific AHCs and (5) potential intervention functions that may encourage PCPs to provide autism-specific AHCs. The schedule for AAs covered (1) beliefs around autism-specific AHCs, (2) experiences of accessing primary care and (3) beliefs surrounding whether GPs would want to, or would have the capacity to, provide AHCs. All participants received a £15 voucher for their participation.

Data analysis. Transcripts from phase 1 were analysed using a framework approach (Ritchie et al., 2013). The

Table 1. Phase 1 participant characteristics ($n = 22$).

	Autistic adults ($n = 10$)	Primary-care professionals ($n = 11$)
Gender identity		
Woman (including trans women)	7 (70%)	8 (72.7%)
Man (including trans men)	1 (10%)	3 (27.3%)
Non-binary	1 (10%)	0 (0.0%)
Prefer to self-describe	1 (10%)	0 (0.0%)
Age (in years)		
25–34	4 (40%)	4 (36.4%)
35–44	2 (20%)	4 (36.4%)
45–54	2 (20%)	2 (18.2%)
55–64	2 (20%)	1 (9.1%)
65–74	0 (0%)	0 (0.0%)
Ethnicity		
White	10 (100%)	7 (63.6%)
Asian/Asian British	0 (0%)	4 (36.4%)
Mixed/multiple ethnic groups	0 (0%)	0 (0.0%)
Black/African/Caribbean/Black British	0 (0%)	0 (0.0%)
Prefer not to say	0 (0%)	0 (0.0%)
Geographical location		
North East England	1 (10%)	0 (0.0%)
North West England	2 (20%)	1 (9.1%)
Yorkshire and the Humber	2 (20%)	0 (0.0%)
West Midlands	0 (0%)	0 (0.0%)
East Midlands	0 (0%)	0 (0.0%)
South West England	2 (20%)	4 (36.4%)
South East England	2 (20%)	0 (0.0%)
London	1 (10%)	6 (54.5%)
East England	0 (0%)	0 (0.0%)
Job role		
GP	N/A	10 (90.9%)
Nurse	N/A	0 (0.0%)
Practice manager	N/A	0 (0.0%)
Other	N/A	1 (9.1%)
Years in role		
<5 years	N/A	6 (54.5%)
5–10 years	N/A	2 (18.2%)
>10 years	N/A	3 (27.3%)
Professional interaction with autistic patients		
Rarely interact with autistic patients	N/A	1 (9.1%)
Occasionally interact with autistic patients	N/A	5 (45.5%)
Regularly interact with autistic patients	N/A	4 (36.4%)
Often interact with autistic patients	N/A	1 (9.1%)
Personal connection		
I have a personal connection to an autistic person (e.g. I am autistic or have an autistic friend/family member/colleague)	N/A	7 (63.6%)
I have little/no experience with autistic people	N/A	4 (36.4%)

GP: general practitioner.

analysis was led by J.D. who read and re-read the transcripts before assigning preliminary codes to the barriers and facilitators discussed, taking an inductive approach. Similar codes were grouped and summary 'themes' were inductively generated. The summary themes were organised into the TDF domain(s) that they were perceived to best represent. Analysis for each participant group (AAs and PCPs) was completed independently. J.D. and K.S. met on multiple occasions to discuss the coding framework and ensure there was a mutual understanding of how the TDF domains should be defined/applied in the context of the current research.

Phase 2: national survey

Participants. Interview data in phase 1 indicated that the delivery of health checks was often completed by different types of staff within different GP practices. For instance, in some practices, health checks were implemented exclusively by physicians, while in others, health checks were a more collaborative effort between different members of staff (e.g. GPs, nurses and healthcare assistants). As such, we invited anybody who worked in primary care in England and considered health checks within the scope of their job role to take part in phase 2. The 12 National Institute for Health and Care Research (NIHR) local Clinical Research Networks[7] (CRNs) circulated a call for participation to GP practices across England. Additional participants were recruited through the research team's professional and social networks, and snowball-recruited through phase 1 participants.

In total, 257 participants navigated to the survey. Of those, 61 (23.7%) were excluded, either because they were not eligible to take part (e.g. did not consider the implementation of autism-specific AHCs within the scope of their role) (n=34) or because they failed to answer any of the research questions (n=27). A total of 196 participants were included in the final analyses. The majority of participants identified as women (n=132, 67.3%) were from a White ethnic background (n=156, 79.6%) and worked as a GP (n=121, 61.7%). Most participants reported occasionally (n=103, 52.8%) or regularly (n=56, 28.7%) interacting with autistic patients in their professional practice, and almost two-thirds (n=121, 64.4%) had a personal connection to an autistic person. Self-reported knowledge about autism was average (median rating=4, range=1–7). See Table 2 for further information.

Table 2. Phase 2 participant characteristics (n=196).

Variable	*N* (%)
Gender identity	
Woman (including trans women)	132 (67.3%)
Man (including trans men)	63 (32.1%)
Non-binary	0 (0.0%)
Prefer to self-describe	1 (0.5%)
Age (in years)	
25–34	22 (11.2%)
35–44	66 (33.7%)
45–54	66 (33.7%)
55–64	37 (18.9%)
65–74	5 (2.6%)
Ethnicity	
White	156 (79.6%)
Asian/Asian British	34 (17.3%)
Mixed/multiple ethnic groups	3 (1.5%)
Black/African/Caribbean/Black British	1 (0.5%)
Prefer not to say	2 (1.0%)
Geographical location[b]	
North East England	7 (3.1%)
North West England	43 (22.1%)
Yorkshire and the Humber	7 (3.6%)
West Midlands	7 (3.6%)
East Midlands	16 (8.2%)
South West England	30 (15.4%)
South East England	27 (13.8%)
London	25 (12.8%)
East England	33 (16.9%)
Job role	
GP	121 (61.7%)
Nurse	34 (17.3%)
Practice manager	16 (8.2%)
Other[a]	25 (12.8%)
Years in role	
<5 years	54 (27.6%)
5–10 years	38 (19.4%)
>10 years	104 (53.1%)
Professional interaction with autistic patients[b]	
Rarely interact with autistic patients	26 (13.3%)
Occasionally interact with autistic patients	103 (52.8%)
Regularly interact with autistic patients	56 (28.7%)
Often interact with autistic patients	10 (5.1%)
Personal connection[c]	
I have a personal connection to an autistic person (e.g. I am autistic or have an autistic friend/family member/colleague)	121 (61.7%)
I have little/no experience with autistic people	67 (35.6%)

GP: general practitioner.

[a] Examples of other job roles includes healthcare assistant, paramedic practitioner, physician associate and care coordinator.

[b] n=195.

[c] n=188.

Materials and procedure. An initial survey prototype was developed by four of the authors (A.R., C.B., L.C. and K.S.) before formally commencing the research. The authors include researchers (with expertise in autism or behavioural public policy research) as well as a retired-GP with a specific interest in autism (C.B.). The authors used their prior knowledge and experience to develop statements related to the possible barriers and facilitators to implementation of autism-specific AHCs, and the possible factors that could be used to encourage their implementation. Following the analysis of data in phase 1, two authors (J.D. and K.S.) refined the survey. For example, adding additional statements and intervention functions (e.g. 'If annual health checks for autistic people were a QOF [Quality Outcomes Framework[8]] requirement') and rewording for clarity. The refined statements and intervention functions were assigned to the TDF domain they were perceived to best represent. For example, 'I have the time in my diary to provide annual health checks for all who need them' was assigned to the TDF domain 'Environmental Context and Resources'. The final survey was agreed upon by all co-authors. The survey took approximately 15 minutes to complete and was hosted on the online survey platform Qualtrics from October 2021 to February 2022 (see Supplemental Appendix C).

The final survey comprised a series of demographic questions (e.g. age, gender identity, ethnicity and geographical location) as well as employment-related questions (e.g. job role, years practicing and experience with autistic patients). Participants were then asked to rate their agreement with 31 randomised statements (e.g. 'I am motivated by performance targets, such as uptake goals') on a 5-point Likert-type scale from strongly disagree (1) to strongly agree (5). In the final section, participants saw 23 potential intervention functions (e.g. 'if I was educated about autism . . . ') in random order and were asked to rate the extent to which each statement would make them more or less likely to institute autism-specific AHCs on a 7-point Likert-type scale from (1) much less likely to (7) much more likely.

Data analysis. Quantitative data from the survey were analysed descriptively within SPSS Statistics version 27. To identify differences between sub-groups of survey respondents, we split and compared the sample in three ways. First, we assessed if responses differed based on whether participants had a personal connection to autistic people (yes vs no) using Mann–Whitney U tests. Second, we assessed if responses differed as a function of job role (GP vs non-GP), using Mann–Whitney U tests. Finally, we assessed whether responses differed as a function of self-reported knowledge about autism using Kruskal–Wallis tests. Post hoc Dunn's tests were employed following significant results and adjusted for multiple comparisons. Participants who rated their autism knowledge between 1 and 3 on a 7-point Likert-type scale (where 1 is low and 7 is high) were categorised as having low knowledge about autism, ratings of 4 were categorised as average knowledge, and ratings between 5 and 7 were categorised as high knowledge. All analyses were adjusted for the number of comparisons made using a Bonferroni correction ($p < 0.001$).

Open-ended responses to the survey questions were analysed using the same framework analysis approach as phase 1 data (Ritchie et al., 2013). However, more emphasis was placed on inductive generation of micro-level codes in the second phase, to allow the authors to explore specific experiences and interventions in more depth. The process took the same form as above, with J.D. leading the analysis and discussing with K.S. where necessary.

Synthesis

The TDF was used as an organising framework to systematically identify potential barriers and facilitators of providing autism-specific AHCs. Inductive codes from phase 1 transcripts were organised thematically by theoretical domains. These codes and themes were used to revise the phase 2 survey instrument, which was developed a priori, by adding or revising items as appropriate. The analysis of both phases was conducted independently. The findings from both phases were then compared to identify areas of overlap and inconsistency. The findings from both phases formed the basis for policy recommendations set out in the discussion.

Community involvement

No autistic people were involved in designing or conducting this research. However, insights generated from autistic participants in phase 1 did inform the development of the survey in phase 2. Regarding the expertise of the authors, C.B. is a GP and was the Royal College of General Practitioners clinical representative for autism at the time of the research. C.B. is also the parent of an autistic person. C.B. inputted specifically to the design and development of the study, supported with, and advised on recruitment, contributed to the interpretation of the findings and critically reviewed the published report, from the perspective of a GP and parent of an autistic person.

Results

This was a sequential, mixed-methods study with a hypothesis-generating first phase and a hypothesis-testing second phase. Phase 1 was an in-depth qualitative exploration of perceptions towards autism-specific AHCs and the feasibility of their implementation within the primary healthcare context in England. Phase 2 used a comprehensive online survey to confirm initial findings and provide further insight into the perspectives of a wide range of PCPs across England. Below, we present the qualitative findings from phase 1, organised by the five key domains that were perceived to be most well-represented. Second, we present the quantitative and qualitative findings from the national survey, highlighting the key perceived barriers and potential facilitators of implementation. Finally, we integrate the findings across both phases to generate recommendations for policy and practice.

Phase 1 findings

Five key TDF domains were represented (1) environmental context and resources; (2) knowledge; (3) memory, attention and decision processes; (4) skills and (5) social/professional role and identity. Within each domain, subthemes link granular codes to larger theoretical constructs. The ID of participants indicates if they were an AA or a PCP.

Environmental context and resources

Staff shortages. Participants indicated that they did not have enough staff to provide autism-specific AHCs.

Indeed, one PCP stated, 'it seems like a luxury to be able to offer that [AHCs]' (PCP-05). Specific concerns included the growing number of people receiving an autism diagnosis, and the impact this may have on capacity for autism-specific AHCs: '[My colleagues] would worry about the capacity because there's a growing number of people being diagnosed with autism. And so that's a lot of extra people to do [health checks] on' (PCP-07).

Time pressures. Resource shortages manifested as a lack of time and a sense of increasing responsibilities. Indeed, participants highlighted the need to 'prioritise acutely ill patients' (PCP-03) with prevention strategies, such as AHCs, perceived to be less of a priority. With such limited time, PCPs expressed concerns about the possible trade-offs associated with autism-specific AHCs: 'what service are you taking away to provide this new service?' (PCP-05).

Capabilities and capacity of non-GP staff. Participants shared concerns regarding the financial cost associated with GPs conducting AHCs: 'the cost of taking a GP out [to do AHCs] is a lot higher [than other members of staff]' (PCP-04). As a result, participants proposed the possibility of non-physician members of staff taking on the responsibility of autism-specific AHCs to reduce the GP burden. Indeed, one GP explained, 'lots of annual reviews are done by our really amazingly capable nursing staff . . . maybe if we can train a nurse . . . they offer freeing up time for GPs' (PCP-09).

Knowledge

Lack of autism education in clinical training. Many PCPs reflected that they had only received basic autism education. Perhaps a result of this perceived lack of education, some felt unable to identify autistic patients that did not fit the taught stereotype:

> [GPs] knowledge is not as good as people think it is, particularly [with] something like autism. I have a rough idea in my head of what someone with autism is like, but realistically that's based it's based on a medical model of someone with very severe[9] autism . . . a lot of GPs would struggle to pick up mild autism, you know that doesn't affect someone functionally day to day. (PCP-07)

Relatedly, PCPs reported uncertainty about common conditions that co-occur with autism ('what [would] these patients be vulnerable to?'; PCP-10). Indeed, autistic participants felt autism understanding among PCPs was poor, detrimentally impacting their quality of care, and thus their health: 'GP knowledge and skills around many issues (neurodiversity, mental health, etc) is often quite lacking . . . it [autism] just either doesn't get noticed or they don't know what it is' (AA-03).

Lack of knowledge regarding autism-related challenges to seeking healthcare. PCPs reported particular challenges in identifying the barriers to primary care for autistic people: 'I wouldn't really feel very confident knowing actually what is difficult for [autistic patients]. Do they find it really difficult getting an appointment with us? Do they find it really difficult going to hospital for their referrals?' (PCP-11). As a result, some PCPs did not see the need for AHCs for autistic people without a co-occurring intellectual disability: 'there's a subset of people diagnosed with autism where they still have family, they still have jobs . . . [they can] live a normal life, and so, for them, [AHCs] seem a bit over the top' (PCP-07). Yet, AAs (all without a co-occurring intellectual disability) identified multiple barriers to accessibility, for example, phone-only scheduling systems ('It's not an accessible system for someone who struggles on the phone'; AA-01), short appointments ('it takes a lot of autistic people a lot of time to explain what they mean . . . but they don't have that time [in a 10 minute consultation]'; AA-08) and the overall perceived inaccessibility of GP practices:

> [I struggle] making the initial call, [I] worry that my health issue doesn't warrant seeing a GP, having to speak to the receptionist, [the] waiting room often very busy, not knowing how to communicate my issue to the GP effectively . . . I'll leave having covered everything up and feeling frustrated that I didn't get what I needed because I could not advocate for myself. (AA-04)

Lack of knowledge regarding autistic manifestations of illnesses. Autistic participants also shared concerns that PCPs are not knowledgeable about autistic presentations of pain and/or specific conditions, which was perceived as a potential barrier to the meaningful implementation of autism-specific AHCs. For example, one participant shared:

> I was having an investigation and the nurse didn't tell me she was assessing my pain . . . I don't show pain really in a way to somebody else might . . . when I got off the table and was dressed again, [the nurse] said, well, it didn't seem to be a problem . . . I said it was excruciatingly painful and she didn't believe me. (AA-02)

Memory, attention and decision processes

Automation and leveraging existing processes. PCPs indicated that they had 'good processes [in place] for the other health checks' (PCP-06) and pointed to existing processes as opportunities to facilitate implementation of autism-specific AHCs: 'if you've already got a set pathway for LD [learning disability AHCs] to then add in autism in the same pathway is a lot easier' (PCP-05). Similarly, embedding funding for autism-specific AHCs into existing frameworks was seen as an enabler: 'the incentives to do it would [it being] part of QOF [the Quality and Outcomes Framework] or [offered] as a Direct Enhanced Service . . . because it is additional work, so it needs to be paid for' (PCP-03). Participants indicated that such integration, along with process automation, would reduce their time and resource burden, thus encouraging implementation: 'it would be great if there was something in the process that [was] automatically sent out . . . [if] there is a pre-health screening questionnaire that we could send all our patients [that would be useful]' (PCP-04). Promisingly, autistic participants also suggested they would endorse elements of automation:

> If someone's going to basically run through a checklist on you, you should have that checklist in advance . . . that would help a lot of autistic people go in with the information that's needed . . . or chart to fill in or something to bring to the appointment to say I've been keeping my records, here it is . . . we'd be only too happy to have a framework that's standardised. (AA-02)

Current tools and guidance do not reflect workflow. While participants felt that guidance documents were useful in facilitating the effective implementation of AHCs, concerns were raised about existing materials. For example, participants reflected a lack of awareness of guidance materials and, in some cases, unnecessary duplication. Those that were aware of existing materials acknowledged flaws such as misalignment between documents: 'it doesn't make sense when you have one thing that tells you what to do, but then the actual template is in a whole different order and doesn't allow you to do the same thing' (PCP-04). As such, participants recommended that guidance be standardised to reflect the workflow required.

Skills.[10]

Ability to effectively communicate with autistic patients. Some PCPs expressed concerns about their and/or their colleagues' ability to effectively communicate with their autistic patients. For example, one participant explained 'I find [communicating with autistic patients] quite challenging to be totally honest, which I think is mostly [a lack of] experience, and then not having that confidence in doing it' (PCP-11), while another noted that they found it 'really difficult to form a bond with [their autistic patients]' (PCP-10). This sentiment was echoed by autistic participants who felt that PCPs 'just don't seem to know how to communicate effectively with us' (AA-09).

Training in working with autistic patients. As above, some PCPs did not feel confident in their knowledge about autism, their knowledge about the specific challenges autistic people face in accessing primary care or their ability to communicate effectively with autistic patients. Relatedly, both PCPs and autistic participants highlighted the importance of professional training to bolster skills for effective implementation of AHCs: 'Education is the most important [thing] . . . if somebody could teach us what to do and then give us some support that would be the best way forward' (PCP-10).

Social/professional role and identity

Provision of evidence-based care. PCPs saw it as part of their professional duty to provide care that is 'evidence-based' (PCP-05). While some were confident that autism-specific AHCs would result in positive outcomes, many highlighted the need for a clear evidence base: 'you need some statistics and numbers to say . . . [these are] the benefits in the longer term, and for the wider health system . . . and it's always powerful to have people with lived experience, case studies' (PCP-02). Indeed, one participant suggested 'it needs to be framed as something that's really beneficial for the patient . . . if it's framed [like that] then I think practices, particularly the forward-thinking practices, will be more inclined [to implement them]' (PCP-11).

Dedicated member of staff with health checks responsibility and/or autism expertise. Recognising the divergent needs and communication styles of autistic patients, some participants recommended that a dedicated member of staff conduct AHCs: 'having [a] nominated person to do it at all . . . they can get a lot of job satisfaction doing that, they've got a list of things that they have sorted . . . [and] it means that people don't get missed' (PCP-06). They suggested that these non-GP professionals could be further supported with 'training in autism or neurodivergence' (AA-05) and a wider organisational culture that accepts AHCs as standard care for vulnerable populations.

Essential role of patient voice. Both autistic and PCP participants shared concerns regarding the reception of AHCs by autistic people: 'Some autistic people have suffered a lot of iatrogenic harm (harm caused through experience of medical treatment) and might not welcome it' (AA-07). This translated into concerns about measuring policy success: 'the difficulty with [uptake targets] is that if a few don't turn up, it can significantly skew your percentage . . . it's a bit of a double-edged sword' (PCP-08). Such concerns were shared by autistic participants:

> I worry it will become a tick-box exercise . . . there are autistics that wouldn't want to attend a health check for fear of the being seen as different from their peers but are somehow pressured to attend but it isn't done for their benefit more for so for the practices benefit. (AA-04)

Participants emphasised the importance of working with autistic patients in order to reduce some of these barriers. For example, autistic participants emphasised the importance of autistic involvement in the delivery of training for PCPs and other medical professionals: 'training should be developed involving autistic people and [people with] lived experiences' (AA-09). Autistic participants also emphasised the need for more representation of autistic people within the NHS more broadly to ensure their voices are heard and needs are met: '[there should be] greater involvement of people with ASD with CCGs [clinical commissioning groups] etc' (AA-08).

Phase 2 findings

Quantitative findings: possible barriers and facilitators to implementation. Most participants ($n=149$ of 195,[11] 76.4%) said they would be likely to implement autism-specific AHCs should they be recommended by NHS England. Participants generally agreed that they could identify the advantages and disadvantages of autism-specific AHCs as well as the challenges autistic people may face in accessing primary health care. However, there was less agreement in terms of knowledge of how to adapt AHCs for autistic people. While participants neither agreed nor disagreed that they had the staff or financial resources to provide AHCs for all who need them, they generally disagreed that they had time in their diary to provide AHCs for all who need them. See Table 3 for a breakdown of responses.

Personal connection versus no personal connection. Participants who had a personal connection with an autistic person were significantly more likely to be able to name some of the common co-occurring diagnoses associated with autism ($U=2410$, $p<0.001$). No other differences remained significant after adjusting for multiple comparisons.

GP versus non-GP. Compared to non-GPs, GPs were significantly less likely to report having the staff ($U=2311$, $p<0.001$), financial resources ($U=2404$, $p<0.001$) or time in their diary to provide AHCs for all who need them ($U=2054$, $p<0.001$). Further, significant findings are highlighted in Table 3.

Low versus average versus high knowledge. There was a significant association between self-reported autism knowledge and participant's confidence in communicating with autistic patients ($H(2)=18.527$, $p<0.001$), with participants with high knowledge reporting being more confident in communicating with autistic patients than those with low knowledge ($p<0.001$). Self-reported knowledge also impacted participant's ability to name the advantages and disadvantages of AHCs for autistic people: $H(2)=17.561$, $p<0.001$. Participants with high knowledge were more likely to be able to name the advantages and disadvantages of autism-specific AHCs than those with low knowledge ($p=0.003$) and those with average knowledge ($p=0.001$). There was also an effect of self-reported knowledge on participants' ability to name common co-occurring conditions associated with autism: $H(2)=26.042$, $p<0.001$. Specifically, participants with high knowledge were more likely to be able to name common co-occurring conditions than those with low knowledge ($p<0.001$) and those with average knowledge ($p=0.010$). Finally, there was an effect of autism knowledge on the likelihood of participants knowing who their autistic patients are ($H(2)=15.747$, $p<0.001$), with those with high knowledge being more likely to know who their autistic patients are, compared to those with low knowledge ($p<0.001$).

Quantitative findings: possible intervention functions. As shown in Table 4, no intervention function was perceived as having a possible negative impact on implementation. Only one intervention (the electronic health record of the patient not closing unless AHC data are added) was perceived to have neutral impact on implementation. All other possible intervention functions were perceived to increase implementation. Intervention functions that were perceived as most favourable across the sample included (1) statistics that show an increase in health issues identified, (2) a recommendation of autism-specific AHCs by National Institute for Health and Care Excellence (NICE)[12] and (3) autistic people saying that AHCs would make them feel more comfortable contacting their GP in future.

Personal connection versus no personal connection. No differences in the endorsement of intervention functions, based on whether one had a personal connection with an autistic person, remained significant following the adjustment for multiple comparisons.

GP versus non-GP. Compared to non-GPs, GPs were significantly less likely to be motivated by autistic people saying that AHCs would make them feel more comfortable in contacting their GP in future ($U=2309.5$, $p<0.001$) or training on how to run effective consultations for autistic people ($U=2169$, $p<0.001$). Conversely, GPs were significantly more likely than non-GPs to be motivated by bonus payments ($U=2064.5$, $p<0.001$). All significant differences are highlighted in Table 4.

Low versus average versus high knowledge. No differences in endorsement of the intervention functions based on self-reported knowledge about autism were identified. In acknowledgement of the imperfect nature of how knowledge was categorised (i.e. scores of 1–3 = low, 4 = average and 5–7 = high), we reran the analysis using alternative grouping (scores of 1 or 2 = low, 3–5 = average and 6 or 7 = high). However, there were still no differences in endorsement of the intervention functions based on self-reported knowledge. As such, we can be more confident that there was no meaningful effect of knowledge on the endorsement of intervention functions.

Table 3. Participants' agreement (from 1 = strongly disagree to 5 = strongly agree) with a series of statements regarding health checks ($n = 182$), split by personal connection, job role and self-reported autism knowledge.

Statement	Median score	Range	Personal connection[a]			Job role			Self-reported autism knowledge[b]			
			Personal connection Median	No personal connection Median	*p*	GP Median	Non-GP Median	*p*	High Median	Average Median	Low Median	*p*
I am familiar with guidelines on providing health checks[c]	4.00	2–5	4.00	4.00	0.696	4.00	4.00	0.422	4.00	4.00	4.00	0.028
I know how to administer health checks[c]	4.00	2–5	4.00	4.00	0.926	4.00	4.00	0.140	4.00	4.00	4.00	0.021
I can name the advantages and disadvantages of providing annual health checks for the general population[c]	4.00	1–5	4.00	4.00	0.554	4.00	4.00	0.055	4.00	4.00	4.00	0.058
I conduct annual health checks regularly[c]	4.00	1–5	4.00	4.00	0.968	4.00	4.00	0.154	4.00	4.00	4.00	0.272
I know where to find guidance on how to provide annual health checks	4.00	1–5	4.00	4.00	0.536	4.00	4.00	0.742	4.00	4.00	4.00	0.128
I can identify the challenges autistic people may face in accessing primary health care[c]	4.00	1–5	4.00	4.00	120	4.00	4.00	0.884	4.00	4.00	4.00	0.001
Autistic people would benefit from annual health checks[d]	4.00	1–5	4.00	4.00	0.575	**4.00**	**4.00**	**<0.001**	4.00	4.00	4.00	0.189
Annual health checks would improve autistic patients' health outcomes[d]	4.00	1–5	4.00	4.00	0.777	**4.00**	**4.00**	**<0.001**	4.00	4.00	4.00	0.317
I have observed colleagues/mentors interacting with autistic patients in a positive way	4.00	1–5	4.00	4.00	0.126	4.00	4.00	0.968	4.00	4.00	4.00	0.004
Health checks for autistic people are as high a priority as health checks for other populations[c]	4.00	1–5	4.00	4.00	0.013	4.00	4.00	0.001	4.00	4.00	4.00	0.209
Annual health checks would improve autistic patients' satisfaction with primary healthcare	4.00	1–5	4.00	4.00	0.863	4.00	4.00	0.041	4.00	4.00	4.00	0.248
Population health would improve if more people got annual health checks[d]	4.00	1–5	4.00	4.00	0.054	**4.00**	**4.00**	**<0.001**	4.00	4.00	4.00	0.129
I am confident in my ability to communicate with my autistic patients	4.00	1–5	4.00	4.00	0.048	4.00	4.00	0.019	**4.00**	**4.00**	**3.00**	**<0.001**
I can name the advantages and disadvantages of providing annual health checks for autistic people	4.00	1–5	4.00	3.50	0.010	4.00	4.00	0.138	**4.00**	**4.00**	**4.00**	**<0.001**
The existing guidance on how to provide annual health checks is helpful in assisting me to conduct annual health checks	4.00	1–5	4.00	4.00	0.331	4.00	4.00	0.002	4.00	4.00	4.00	0.629
I can name some of the common co-occurring conditions associated with autism[c]	4.00	1–5	**4.00**	**3.00**	**<0.001**	4.00	4.00	0.204	**4.00**	**4.00**	**3.00**	**<0.001**
I communicate easily with consultants when I need to refer my patients on[c]	4.00	1–5	4.00	4.00	0.928	4.00	4.00	0.010	4.00	4.00	4.00	0.654
I am motivated by performance targets such as uptake rates[d]	3.50	1–5	4.00	3.00	0.833	3.00	4.00	0.605	3.00	4.00	3.00	0.611
I would know how to adapt an annual health check for an autistic person	3.00	1–5	4.00	3.00	0.027	3.00	4.00	0.014	4.00	3.00	3.00	0.002
I know who my autistic patients are	3.00	1–5	4.00	3.00	0.009	4.00	3.00	0.209	**4.00**	**3.00**	**3.00**	**<0.001**
Annual health checks would only be worthwhile if they were proven to be cost-effective[c]	3.00	1–5	3.00	3.00	0.754	3.00	3.00	0.003	3.00	3.00	3.00	0.554
I communicate easily with social services when I need to refer my patients on[d]	3.00	1–5	3.00	3.00	0.159	**2.00**	**4.00**	**<0.001**	3.00	3.00	3.00	0.630
My practice has the financial resources to be able to provide annual health checks for all who need them[c]	3.00	1–5	3.00	3.00	0.944	**2.00**	**3.00**	**<0.001**	3.00	2.00	3.00	0.290
My practice has enough staff to be able to provide annual health checks for all who need them	2.50	1–5	2.00	3.00	0.139	**2.00**	**3.00**	**<0.001**	3.00	2.00	3.00	0.360
When I see a patient who looks well, I am worried they may have a problem I've missed[c]	2.00	1–5	3.00	2.00	0.854	2.00	3.00	0.011	2.00	2.00	3.00	0.423
When I see a patient who looks well, I am concerned about my liability if I get something wrong[d]	2.00	1–5	2.00	2.00	0.849	2.00	3.00	0.032	2.00	2.00	3.00	0.212
Conducting annual health checks for autistic people would be a poor allocation of resources[c]	2.00	1–5	2.00	2.00	0.242	2.00	2.00	0.008	2.00	2.00	2.00	0.061
I have time in my diary to provide annual health checks for all who need them	2.00	1–5	2.00	2.00	0.697	**2.00**	**3.00**	**<0.001**	2.00	2.00	2.00	0.224
Providing annual health checks for autistic people would have a negative impact on other patients	2.00	1–5	2.00	2.00	0.399	**2.00**	**2.00**	**<0.001**	2.00	2.00	2.00	0.093
It is important for annual health checks to be completed by a GP (as opposed to other primary health care professionals)	2.00	1–5	2.00	2.00	0.613	2.00	2.00	0.007	2.00	2.00	2.00	0.800
There would be negative consequences for autistic people if they received annual health checks[c]	2.00	1–5	2.00	2.00	0.693	2.00	2.00	0.335	2.00	2.00	2.00	0.390

GP: general practitioner.

Significant group differences are indicated in bold text and highlighted cells.

[a] Participants who reported knowing at least one autistic person (e.g. a friend/family member), being autistic themselves, or having professional autism expertise were categorised as being 'familiar' with autism. Participants who reported having 'little/no experience with autistic people' were categorised as being 'unfamiliar' with autism.

[b] Participants who reported an autism knowledge score of between 1 and 3 were categorised as having 'low' autism knowledge. Participants who reported a knowledge score of 4 were categorised as having 'average' autism knowledge. Participants who reported a knowledge score of between 5 and 7 were categorised as having 'high' autism knowledge.

[c] $n = 181$.

[d] $n = 180$.

Table 4. Participant endorsement of intervention functions, from (1) much less likely to implement to (7) much more likely to implement ($n = 171$), split by personal connection, job role and self-reported autism knowledge.

Statement	Median score	Range	Personal connection[a]			Job role			Self-reported autism knowledge[b]			
			Personal connection Median	No personal connection Median	*p*	GP Median	Non-GP Median	*p*	High Median	Average Median	Low Median	*p*
If I was shown statistics that show an increase in identified health issues in the autistic population[c]	6.00	3–7	6.00	6.00	0.313	6.00	6.00	0.194	6.00	6.00	6.00	0.698
If annual health checks for autistic people were recommended by NICE	6.00	3–7	6.00	5.00	0.153	6.00	6.00	0.025	6.00	6.00	6.00	0.572
If autistic people said they wanted annual health checks	6.00	2–7	6.00	6.00	0.020	6.00	7.00	0.011	6.00	6.00	6.00	0.344
If I had protected time in my schedule to conduct annual health checks	6.00	1–7	6.00	6.00	0.878	6.00	6.00	0.746	7.00	6.00	6.00	0.201
If the goal for uptake of the health check was realistic	6.00	1–7	6.00	6.00	0.730	6.00	6.00	0.118	6.00	6.00	6.00	0.650
If autistic people said that annual health checks would make them feel more comfortable in contacting their GP in future	6.00	1–7	6.00	6.00	0.028	**6.00**	**7.00**	**<0.001**	7.00	6.00	6.00	0.079
If annual health checks for autistic people were a QOF requirement	6.00	1–7	6.00	6.00	0.171	6.00	7.00	0.419	6.00	6.00	6.00	0.813
If I was provided standardised documents to assist with the annual health check (e.g. a checklist)	6.00	1–7	6.00	6.00	0.868	6.00	6.00	0.037	6.00	6.00	6.00	0.977
If I was provided with clear, concise documents that told me how to conduct annual health checks	6.00	1–7	6.00	6.00	0.819	6.00	6.00	0.069	6.00	6.00	6.00	0.932
If other, non-physician, members of the team could conduct the annual health checks	6.00	1–7	6.00	6.00	0.777	6.00	6.00	0.003	6.00	6.00	6.00	0.977
If I was given training on how to run effective consultations for autistic people	6.00	1–7	6.00	6.00	0.737	**6.00**	**7.00**	**<0.001**	6.00	6.00	6.00	0.990
If I was given training on how to conduct effective annual health checks for autistic people	6.00	1–7	6.00	6.00	0.448	6.00	6.00	0.002	6.00	6.00	6.00	0.804
If I was shown case studies that show the qualitative improvement in individuals' lives following annual health checks	6.00	1–7	6.00	6.00	0.796	6.00	6.00	0.124	6.00	6.00	6.00	0.708
If some of my other duties were taken away so I could focus on providing health checks	6.00	1–7	6.00	5.50	0.351	6.00	6.00	0.384	6.00	6.00	5.50	0.165
If I was educated about benefits of annual health checks for autistic people	6.00	1–7	6.00	6.00	0.595	6.00	6.00	0.007	6.00	6.00	6.00	0.336
If I was given bonus payments for completing annual health checks for autistic people	6.00	1–7	6.00	5.00	0.130	**6.00**	**4.00**	**<0.001**	6.00	5.00	6.00	0.453
If I was educated about autism	6.00	1–7	6.00	6.00	0.134	5.00	6.00	0.004	5.00	6.00	6.00	0.223
If autistic patients were sent automatic appointments for their annual health checks	5.00	1–7	5.00	5.00	0.304	5.00	5.50	0.174	5.00	5.00	5.00	0.763
If I was shown evidence of the cost-effectiveness of annual health checks for autistic people	5.00	1–7	6.00	5.00	0.073	6.00	5.00	0.139	5.00	6.00	5.00	0.766
If I was shown statistics that show an increase in health seeking behaviour in the autistic population	5.00	1–7	6.00	5.00	0.322	5.00	6.00	0.120	6.00	5.50	5.00	0.859
If I was penalised for not offering annual health checks to my autistic patients	5.00	1–7	5.00	5.00	0.536	5.00	4.00	0.715	5.00	5.00	4.50	0.707
If other local practices were also conducting annual health checks for autistic patients	5.00	1–7	5.00	5.00	0.802	5.00	4.50	0.997	5.00	5.00	5.00	0.921
If my electronic health record would not let me close a patient's file until I added health check data[c]	4.00	1–7	4.00	4.00	0.260	4.00	4.00	0.004	4.00	4.00	4.00	0.362

GP: general practitioner; NICE: National Institute for Health and Care Excellence; QOF: quality and outcomes framework.

Significant group differences are indicated in bold text and highlighted cells.

[a] Participants who reported knowing at least one autistic person (e.g. a friend/family member), being autistic themselves, or having professional autism expertise were categorised as being 'familiar' with autism. Participants who reported having 'little/no experience with autistic people' were categorised as being 'unfamiliar' with autism.

[b] Participants who reported an autism knowledge score of between 1 and 3 were categorised as having 'low' autism knowledge. Participants who reported a knowledge score of 4 were categorised as having 'average' autism knowledge. Participants who reported a knowledge score of between 5 and 7 were categorised as having 'high' autism knowledge.

[c] $n = 170$.

Qualitative findings. Participants in phase 2 identified potential barriers and facilitators in the five TDF domains, outlined in phase 1: (1) environmental context and resources; (2) knowledge; (3) memory, attention and decision processes; (4) skills and (5) social/professional role and identity. Quotes are labelled by participant number so that those from the same participant can be identified.

Regarding the environmental context and resources, participants discussed the perceived lack of resources within primary care, both regarding staff and time, with one participant highlighting: 'we are 7,000 GPs short, and the NHS is broken. It can't do more. The big question is what will we not do in order to do this?' (P086). Participants also identified the possible opportunity for non-GP members of staff to implement autism-specific AHCs: 'how about a non-GP service run by knowledgeable people like yourselves, with time, carrying out these annual health checks?' (P031). Some participants also highlighted some potential gaps in knowledge, with one participant suggesting that autism-specific AHCs would involve 'hugely time-consuming consultations – probably made worse by lack of expertise of clinicians' (P090). Similarly, while participants in this phase did not explicitly acknowledge any gaps in knowledge regarding autism-related challenges to seeking healthcare, several questioned the necessity of AHCs for autistic people who 'function extremely well' (P040), indicating a possible lack of knowledge about the healthcare experiences of autistic people without a co-occurring intellectual disability. Regarding memory, attention and decision processes, participants endorsed the integration of autism-specific AHCs into existing processes such as the Quality Outcomes Framework (QOF): 'If the practice was paid to do them (e.g. as part of QOF) it would improve compliance' (P009). Participants also identified some areas for improvement in relation to the skills required to successfully implement autism-specific AHCs. For example, participants identified specific barriers regarding their ability to communicate with their autistic patients and suggested that successful implementation would be contingent on 'structured whole team education/training and support from [a] specialist team' (P065). Finally, participants discussed highlighted the importance of their social and professional role and identity as evidence-based clinicians, highlighting a clear evidence base as integral for the successful implementation of autism-specific AHCs: 'I would want to see hard evidence that it significantly improves health outcomes before embarking on this' (P062).

Synthesis

As seen in Table 5, the qualitative findings in phase 2 largely map onto the phase 1 findings, and the TDF domains previously identified. No participants in phase 2 of the research, however, discussed a lack of knowledge regarding autistic manifestations of illness, and when asked if they would know how to adapt an AHC for an autistic person, participants neither agreed nor disagreed (median score = 3 out of 5, range: 1–5). Similarly, no participants in phase 2 identified issues with the current tools and guidance regarding health checks, and quantitative data suggested participants generally found existing guidance helpful (median score = 4 out of 5, range = 1–5). Finally, while participants in phase 2 did not discuss the potential utility of having a designated member of staff responsible for the health checks, quantitative data from this phase indicated protected time to conduct AHCs would be well-endorsed (median score = 6 out of 7, range = 1–7). For a full comparison of findings from both phases, see Table 5.

Discussion

This study identified a series of potential barriers and facilitators to the implementation of autism-specific AHCs, as well as possible interventions that could encourage implementation. The barriers and facilitators outlined in phase 1 were categorised within five theoretical domains: environmental context and resources; knowledge; memory, attention and decision processes; skills and social and professional role and identity. Findings from phase 2 confirmed the perceived salience of these domains, and the potential utility of interventions targeting these issues. Indeed, while participants in phase 2 were generally enthusiastic about autism-specific AHCs, concerns were shared about the practical aspects of implementation, including a perceived limited capacity, and a lack of knowledge about autism. Based on these findings, we make recommendations for policy elements that cut across the identified TDF domains to either circumvent barriers or unlock facilitators to providing autism-specific AHCs.

The primary barrier of concern among participants was the environmental context and resources to provide AHCs alongside other primary care commitments. Yet participants consistently recognised that nurses, care assistants and other members of the primary care workforce had both the capacity to take on the extra tasks associated with autism-specific AHCs, and the professional expertise to do so competently. As a professional development incentive, AHCs could become part of the formal job description for certain roles. In addition to dedicated time for AHCs, this could be accompanied by specialised training or a formal qualification in, for instance, neurodivergence or AHCs. By contrast, GPs were more likely to say that they personally did not have the time or resources to take on this new service. Thus, we recommend that, if autism-specific AHCs are offered, they become part of the remit of the non-GP primary care workforce.

Another key barrier identified related to memory, attention and decision processes. For example, our participants

Table 5. Overlap between the qualitative findings in phase 1 and phase 2.

TDF domain	Theme	Barrier/ facilitator	Illustrative quote from phase 1 (interviews)	Illustrative quote from phase 2 (national survey)	Illustrative survey question from phase 2	Survey response, median (range) scores on a 5-point Likert scale
Environmental context and resources: (any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour)	Staff shortages	Barrier	'I guess it's a manpower problem as well, we just haven't got the capacity'. (PCP-07)	'Ultimately, we are 7,000 GPs short, and the NHS is broken. It can't do more. The big question is what will we not do in order to do this?' (P086)	My practice has enough staff to be able to provide AHCs for all who need them.	2.50 (1–5)
	Time pressures	Barrier	'I think I would be worried about the challenges we already have, which is about timing and resources, I think the 20 minutes that was already given for the learning disabilities is . . . it's very hard to fill and do a comprehensive review in that 20 minutes, and so it does become . . . lots of people cut corners'. (PCP-04)	'We currently would have the will to implement these health checks, but nothing like the resources–not remotely enough people or time to coordinate and run these checks'. (P037)	I have time in my diary to provide AHCs for all who need them.	2.00 (1–5)
	Capabilities and capacity of non-GP staff	Facilitator	'Lots of annual reviews are done by our really amazingly capable nursing staff . . . maybe if we can train a nurse . . . they offer freeing up time for GPs'. (PCP-09)	'We just don't have time. Every specialty/ person with an interest in an area is quite happy to dump more and more work on general practice. How about a non-GP service run by knowledgeable people like yourselves, with time, carrying out these annual health checks?' (P031)	It is important for AHCs to be completed by a GP (as opposed to other primary health care professionals).	2.00 (1–5)
Knowledge: (an awareness of the existence of something)	Lack of autism education in medical training	Barrier	'[GPs] knowledge is not as good as people think it is, particularly [with] something like autism. I have a rough idea in my head of what someone with autism is like but realistically that's based it's based on a medical model of someone with very severe autism'. (PCP-07)	'[autism-specific AHCs would be] hugely time consuming consultations–probably made worse by lack of expertise of clinicians'. (P090)	I know who my autistic patients are.	3.00 (1–5)
	Lack of knowledge regarding autism-related challenges to seeking healthcare	Barrier	'I wouldn't really feel very confident knowing actually what is difficult for [autistic patients]. Do they find it really difficult getting an appointment with us? Do they find it really difficult going to hospital for their referrals?' (PCP-11)	'[Implementation] depends on autism severity. I think many people with autism function extremely well; those who have more complex needs usually have care systems in place'. (P040)	I can identify the challenges autistic people may face in accessing primary health care.	4.00 (1–5)
	Lack of knowledge regarding autistic manifestations of illness	Barrier	'I had anorexia but because of sensory issues. But they [PCPs] only approached it from a weight perspective'. (AA-04)	N/A	I would know how to adapt an AHC for an autistic person.	3.00 (1–5)
Memory, attention and decision processes: (the ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives)	Automation and leveraging existing processes	Facilitator	'If you've already got a set pathway for LD [learning disability AHCs] then to then add in autism in the same pathway is a lot easier'. (PCP-05)	'If the practice was paid to do them (e.g., as part of QOF [Quality Outcomes Framework]) it would improve compliance'. (P009)	I would be more likely to provide AHCs . . . if AHCs for autistic people were a QOF [Quality Outcomes Framework] requirement	6.00^a (1–7)
	Current tools and guidance do not reflect workflow	Barrier	'There has to be some cohesiveness between both [the checklist and the electronic health record, EHR^b] as well when it's formulated and some sort of reason as to why something's here and not there'. (PCP-07)	N/A	The existing guidance on how to provide AHCs is helpful in assisting me to conduct AHCs.	4.00 (1–5)
Skills: (an ability or proficiency acquired through practice)	Ability to effectively communicate with autistic patients	Barrier	'A few years ago I had a couple of autistic people and it was really difficult to form a bond with them, and so I had to go away and do my own learning . . . although I had qualified as a doctor, I didn't know how and had to do some extra research'. (PCP-02)	'Barriers [include] . . . [the] lack of experience of some clinicians on how to adapt and communicate with [autistic] patients'. (P037)	I am confident in my ability to communicate with my autistic patients.	4.00 (1–5)
	Training in working with autistic patients	Facilitator	'I would be very surprised if you offer training and support that it would be declined'. (PCP-02)	'[Implementation] would require structured whole team education/ training and support from [a] specialist team to deliver quality care'. (P065)	I would be more likely to provide AHCs . . . If I was given training on how to conduct effective AHCs for autistic people.	6.00^a (1–7)
Social and professional role and identity: (a coherent set of behaviours and displayed personal qualities of an individual in a social or work setting)	Provision of evidence-based care	Facilitator	'I would want to know that it has been helpful and how it's been helpful before . . . I think a little bit of anecdotal evidence, but actually sort of proper actual research evidence and statistical evidence would be better'. (PCP-03)	'I would want to see hard evidence that it significantly improves health outcomes before embarking on this. There is no good evidence in real live populations that annual checks on those with severe mental illness improves physical health outcomes and all-cause mortality'. (P062)	I would be more likely to provide AHCs . . . If I was shown statistics to show an increase in identified health issues in the autistic population	6.00^a (3–7)
	Dedicated member of staff with health checks responsibility and/or autism expertise	Facilitator	'Part of my role is to roll out the program of annual health checks, make sure they are completed, make sure that we have got the whole cohort of patients that fall under that category . . . it gives it some standardisation. You'll find that if you can run a clinic and where you're doing one after another, all the forms and things that come with it are more easily produced and done'. (PCP-07)	N/A	I would be more likely to provide AHCs . . . If I had protected time in my schedule to conduct AHCs.	6.00^a (1–7)
	Autistic people as experts by experience	Facilitator	'Training should be developed involving autistic people and [people with] lived experiences'. (AA-09)	'It is imperative that the literature with the appointment invitation is suitable and sensitive towards the needs of the patient. We have similar experiences with patients who have certain mental health conditions whom refrain from attendance because there is a lack of understanding of what is to be expected during their appointment and the anxieties this creates'. (P127)	I would be more likely to provide AHCs . . . If autistic people said they wanted health checks	6.00^a (2–7)

TDF: Theoretical Domains Framework; GP: general practitioner; AHC: annual health check.

[a] Intervention functions were evaluated on a 7-point Likert-type scale from 1 = much less likely to implement to 7 = much more likely to implement.

[b] Electronic health records are electronic records of patients' medical and treatment histories.

cited overly complicated procedural guidance, a lack of integration with the electronic health record software and a lack of understanding of clinical workflow as barriers to providing high-quality AHCs efficiently. By contrast, eliminating or reducing some of these hurdles was seen as key to making AHCs routine. Indeed, participants recommended automating scheduling and documentation using co-designed templates within the electronic clinical record. On the business side, participants supported the integration of reimbursement for autism-specific AHCs into existing payment structures such as the QOF. Participants also noted that AHCs do not need to be completed either (a) by one single health professional or (b) all at the same time. To address the time-related barriers of AHCs, some practices may find that dividing responsibilities for various aspects of the AHCs among multiple professionals to be an alternative solution.

Many PCPs saw it as part of their professional role and identity to provide care that is evidence-based. Relatedly, some felt that the evidence for AHCs – for autistic people or more broadly – is lacking and were reluctant to support a widespread policy for AHCs until more concrete evidence of impact is available. Conversely, they recognised that they may lack knowledge and skills regarding communicating with autistic people, recognising autism-specific barriers to access and responding to autistic manifestations of illness. Indeed, autistic participants spoke about the challenges they experience accessing primary care, and how AHCs would circumvent those challenges. They were cognisant of the time and resource pressures practices face, and that there may be valid reasons for some patients to reject AHCs. This pointed to the availability of nuanced expertise among people with lived experience, which should be harnessed when crafting policy. We recommend involving autistic people in the development of training materials, implementation guidance and evaluation studies.

While this study dealt specifically with the question of implementing autism-specific AHCs in English general practice, we believe our approach has implications for policy design and implementation more broadly. Our recommendations were intended to be concrete yet not overly prescriptive, to allow for differences in context (Hauser et al., 2018; Schmidt & Stenger, 2021). A strength of this study is that the TDF allowed us to tie high-level policy recommendations to specific mechanisms of behaviour change. While previous studies have used the TDF to investigate implementation problems (Atkins et al., 2017), including those specific to AHCs (Atkins et al., 2020), we are unaware of other studies that have used the tool prospectively in this way.

Within broader behavioural approaches to public policy, much focus has been on choice architecture, defaults and 'nudging' to anticipate and in some ways harness people's cognitive biases to improve decision-making in real time (Chapman et al., 2016; Dai et al., 2021; Organisation for Economic Co-operation and Development, 2017). As the TDF clarifies, however, these approaches respond to only a narrow set of barriers that influence in-the-moment decision-making (primarily in the domain of memory, attention and decision processes). The degree of complexity that surrounds health service delivery interventions has been well-documented (Alageel et al., 2018; Jorm et al., 2021; Plsek & Greenhalgh, 2001), revealing the limits of both traditional behavioural policy tools (Lambe et al., 2020; MacKay & Quigley, 2018) and traditional evaluation methods (Marchal et al., 2013).

Recent work has recognised a broader set of influences on behaviour and conceptualised them to include choice infrastructure alongside choice architecture (Schmidt, 2022). Choice infrastructure comprises standards, process mechanisms, accountability, culture within systems and evaluative and iterative feedback. The recommendations resulting from this study can be understood as supporting the infrastructure to provide autism-specific AHCs, by clarifying professional roles and standards, simplifying processes and iteratively building the evidence base. Involving AAs in an ongoing way could also shift the culture of medical practice towards one more accommodating of neurodivergence.

Anticipating implementation issues and designing policies to proactively avoid them will have tangible consequences for service users. Autistic participants in this study cited both practical barriers to access (e.g., requiring appointments to be made via phone and loud waiting areas) and challenges to receiving appropriate care (e.g., miscommunication and lack of GP understanding), which align with previous findings (Brice et al., 2021; A. J. Doherty et al., 2020; M. Doherty et al., 2022). These issues are associated with poor outcomes, including delays in care, misdiagnosis and reduced quality of life (Cashin et al., 2016; Coleman-Fountain et al., 2020; Croen et al., 2015; Rydzewska et al., 2019). Other research suggests that the 'burden of treatment' and the 'work of being a patient' can be significant even without the additional barriers that autistic people face (Boehmer et al., 2016; May et al., 2014). Elsewhere, a lack of support for providers to implement new policies dampens efforts to improve quality of care for patients (Doran et al., 2017). As such, we believe this approach to systematically identifying barriers and facilitators to policy implementation can be adapted to support the care of other vulnerable groups.

Limitations

This study is limited in scope given that we explored the implementation of a proposed policy for autism-specific AHCs in GP practices in England. Variability in practice configurations, access to resources and local culture around AHCs means that the extent to which our recommendations will be salient will vary (Bates & Glennerster, 2017). We were also limited by conducting this study at the height of the coronavirus pandemic, which affected recruitment by both taking longer and yielding fewer participants than anticipated. While we achieved good representation in terms of demographic factors such as job role, age and location, we engaged a relatively small sample of autistic people ($n=10$) and PCPs ($n=207$ across the interviews and survey) which could have implications for the generalisability of our findings. The lack of diversity in our autistic sample is a particular limitation: all autistic participants reported being from a White ethnic background. Yet, people from ethnic minority groups face persistent health inequalities (Byrne et al., 2020; Germain & Yong, 2020). As such, autistic people from ethnic minority groups may be disproportionately disadvantaged when it comes to accessing healthcare. Given that prevalence of autism appears to be highest among Black children (Roman-Urrestarazu et al., 2021), this issue should be addressed in future research as a priority. A further caveat is that while this policy has been proposed, it has not yet been implemented. Specific elements of the AHC policy may not have been anticipated by this study. Our findings are also based on participants' ability to consider and predict which factors may become barriers/facilitators to the implementation of autism-specific AHCs. The limitations associated with cognitive biases in self-reports and hypothetical situations have been documented elsewhere (Featherston et al., 2020; Fitzsimons & Shiv, 2001; S. G. Moore et al., 2012; Stone et al., 2007). Finally, these recommendations have been submitted but not (yet) been taken up. The present study cannot speak to the effectiveness of the strategies we have proposed, and further research will be required.

Conclusion

Our autistic and PCP participants generally supported the proposal of autism-specific AHCs. Nonetheless, they also identified potential barriers to successful implementation, including a lack of knowledge, resources and key skills among PCPs. If autism-specific AHCs are to be recommended, we suggest delegating their facilitation to non-GPs, automating the process and educating PCPs with autistic people as experts-by-experience.

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Supplemental material

Supplemental material for this article is available online.

Notes

1. General practitioners (GPs) in England are the first line of contact for patients, treating all common medical conditions or, where necessary, referring patients to other medical services for urgent and specialist treatment.
2. Throughout this report, we use the term primary care professional (PCP) to be inclusive of non-physician healthcare providers working in primary care environments, many of whom conduct annual health checks (AHCs) in whole or in part.
3. The National Health Service (NHS) is a government-funded health care service in the United Kingdom. Each UK country has a devolved NHS, resulting in policy differences. This study focuses on England. The NHS is free at the point of use, meaning citizens pay for their care via taxes, as opposed to at the point of requiring care.
4. Clinical Commissioning Groups (CCGs) were clinically led NHS bodies, responsible for the planning and commissioning of health care services in their local area. In April 2021, there were 106 CCGs in England. CCGs were replaced in July 2022 by Integrated Care Boards, as part of the restructuring of the NHS into Integrated Care Systems.
5. GP partners are practicing GPs that have additional administrative and business responsibilities, over and above their clinical duties (e.g. staffing, performance management and accounts).
6. Note, one interview with an autistic participant was uncharacteristically short (9 min). We did, however, complete the interview schedule and generate findings that we felt were appropriate to include in this report.
7. Local Clinical Research Networks (CRNs) are regional networks that provide the infrastructure for clinical research to take place within the NHS. For example, CRNs work with researchers to distribute research opportunities to relevant groups.
8. The Quality Outcomes Framework (QOF) is a pay for performance and quality bonus programme for GP practices, which has been in place in the NHS since 2004.
9. We have endeavoured to use respectful language throughout the reporting of our findings, which adheres to best practice guidance for avoiding ableism in reporting on autism

research (e.g. Bottema-Beutel et al., 2021). However, we quote participants verbatim to reflect how language is used in practice.

10. Note: the TDF differentiates between knowledge (understanding of concepts and the existence of phenomena) and skills (ability to do something, to operationalised knowledge). We organise our results accordingly.
11. One participant did not respond to this question.
12. The National Institute for Health and Care Excellence (NICE) is an independent public body, sponsored by the Department of Health and Social Care in England. NICE provides evidence-based recommendations for health and care in England.

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