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## Views about Primary Care health checks for autistic adults: UK survey findings

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# Views about Primary Care health checks for autistic adults: UK survey findings

## ABSTRACT

### Background

Compared to the general population, autistic adults experience higher rates of physical and mental health conditions, premature morbidity and mortality, and barriers to healthcare. A health check for autistic people may improve their health outcomes.

### Aim

To establish the views of autistic people toward a primary care health check for autistic people.

### Design and setting

Cross-sectional questionnaire study.

### Methods

A questionnaire was sent to autistic adults with physical health conditions in England and Wales. 458 people (441 autistic adults and 17 proxy responders) completed the questionnaire.

### Results

Most respondents (72.9%, n=336) thought a health check is needed for all autistic people. Around half of the participants thought a health check should be offered from childhood and the health check appointment should last between 15 and 30 minutes. Autistic people were positive about providing primary care staff with contextual information regarding their health and the reasonable adjustments they would like prior to their health check appointment. Training about autism and the health check was considered important, alongside adequate time for discussions in the health check appointment (all by over 80% of respondents). Clinician's autism knowledge, seeing a familiar clinician, environmental adaptations, appropriate information, and accessible appointments were considered particularly important in making a health check accessible.

### Conclusions

Autistic people and relatives were supportive of a primary care health check for autistic people. Information gathered was used to support the design of a primary care health check for autistic adults.

### Keywords

Primary healthcare, autism, adults, survey, health checks, reasonable adjustments

### How this fits in

Compared to the general population, autistic adults experience higher rates of health conditions, premature morbidity and mortality, and barriers to effective healthcare. Strong support was found for a Primary Care health check for autistic adults, and important information was given about health check design and delivery. Most responders thought the health check should be available to

all autistic adults. Autistic people thought consideration of personalised reasonable adjustments would improve acceptability and access to the health check.

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## INTRODUCTION

Autism research has started to systematically investigate co-occurring mental and physical health conditions, and healthcare access for autistic people (1, 2). Large scale studies have found an increased prevalence of health conditions in autistic people versus population samples, independent of whether intellectual disability is present (3-7). For example, autistic adults seem more likely to experience premature mortality from neoplasms, endocrine conditions, and conditions of the nervous, circulatory, and respiratory systems (8, 9).

Studies highlight barriers faced by autistic adults accessing healthcare including: waiting areas that cause sensory overload (10, 11), problems with patient-provider communication (12), a lack of training about autism among healthcare providers (13), and cognitive difficulties (14, 15). For example, difficulties with executive functioning impacting on follow up of care, missing appointments due to memory difficulties, and translating medical care into concrete actions (15-17). These factors may increase distress throughout the healthcare experiences (e.g. when travelling to healthcare appointments, waiting for and during the appointment) that only reduces after returning home (11). Barriers likely contribute to difficulties identifying and treating autistic adults' health conditions. In the UK, adjustments to healthcare service provision may be available; however, a recent study showed a gap between adjustments autistic people want from services and what was received (18).

Annual health checks specifically designed for people with intellectual disability have been developed and evaluated in Randomised Controlled Trials (19, 20). In England, a health check for people with intellectual disabilities has been integrated into primary care. A review of health checks for people with intellectual disabilities found they consistently detected unmet health needs, and led to targeted actions to address needs (21). Autistic people with co-occurring intellectual disabilities may receive a health check for people with intellectual disabilities; however, this health check is not available to (and may not be appropriate for) the significant proportion of autistic people who do not have co-occurring intellectual disabilities. Recent healthcare policy in England has advocated for the development and evaluation of health checks specifically designed to meet the needs of all autistic people (NHS Long Term Plan and National Strategy for Autistic Children, Young People and Adults)(22, 23). A health check for all autistic adults that incorporates adjustments to healthcare may help to overcome barriers to access, reduce health inequalities, improve health, and reduce early mortality for autistic people with, and without, intellectual disability.

Our health checks research programme was conceived at a workshop to establish priority research areas to improve the physical health and wellbeing of autistic people (24). We aimed to investigate the views of autistic people about a specifically designed health check, the important features of design and delivery, and what would make accessing a health check easier (or more challenging). The study methods and materials were co-designed with autistic people and relatives as part of a wider programme of co-produced research (<https://research.ncl.ac.uk/autismhealthchecks>).

## METHOD

### Participants

Recruitment was through the Adult Autism Spectrum Cohort-UK (ASC-UK) (25), an ongoing, longitudinal study of the lived experiences of UK autistic adults; any UK based autistic person aged 16 years and over is able to participate. Cohort recruitment was through any source, including health

providers, voluntary sector, and community organisations. All ASC-UK participants aged 18 years and over, who provided baseline data identifying they had one or more physical health condition (e.g. diabetes, hypertension, asthma, arthritis), and lived in England or Wales were eligible to be contacted. All autistic adults with capacity to do so had given consent to be re-contacted; autistic adults who could not give informed consent for themselves were represented by a relative or carer authorised to act on their behalf (termed proxy responder) (25, 26).

## **Materials**

The research team (that includes autistic people) designed the survey, and autistic people who were not part of the study team were consulted about content and piloted the survey. Respondent's demographic information was available from ASC-UK (data access supported by ASC-UK Chief Investigator Parr). The survey included: items about a health check for autistic adults, including provision (do you think regular health checks for autistic people should be provided), delivery (at what age do you think health checks should be offered?, how often should they be carried out?, how long would you expect a health check for autistic people to last?, how would you like to be told what to expect from a health check specifically for autistic adults?, would you be happy to provide information about your health needs before the health check?, would you be happy to provide information about any reasonable adjustments you'd like before the health check). Questions also focused on health check delivery and implementation (what would make health checks easier for autistic adults or harder for autistic adults?).

Most questions offered fixed-choice responses; there were opportunities for free text-responses (e.g. to elaborate on reasons for response selection; or add information). Participants were asked to provide up to three free-text responses regarding what would make health check access easier and three free-text responses regarding what would make a health check harder).

## **Procedure**

Eligible participants were sent an information sheet and survey (post or e-mail). The electronic version of the survey was hosted on Qualtrics (27). Participants could contact the research team for assistance completing the questionnaire (one participant made use of this). A reminder was sent to eligible participants after one month.

## **Analysis**

Data from autistic people and proxy responders were grouped together for analysis.

To investigate representativeness, responders and non-responders were compared (using  $\chi^2$  square tests) on age (18-25 years, 26-40, 41-60, 61+), gender (male and female), and preferred contact method (post or e-mail).

Summary statistics were calculated for closed survey questions. Several questions allowed for multiple options to be selected so the number of responses could be greater than the number of participants. To explore systematic differences in responses, comparisons were made by: gender (male and female, 14 participants did not report a gender of male or female and were excluded from gender comparisons only); by age, and by intellectual disability. We did not carry out post-hoc comparisons because there were insufficient participants within groups.

Content analysis was completed for free-text responses; an inductive approach was used (29). HT read responses and created categories to organise data. HT and DM separately coded data, assigning responses to categories. Any differences in categorisation were discussed, and agreement reached.

Where responses did not fit into a category, further categories were created. HT and DM further reviewed the categories and condensed these into 17 final categories. Each response from each participant was coded separately. The number of responses within each category were expressed as a proportion of the total responses (excluding non-codable responses). Non-codable responses included expressions of uncertainty, ambiguous responses not attributable to a category, such as “pre-conceptions” or “lack of knowledge”, answers unrelated to the topic or those stating no opinion.

### **Ethics**

A positive opinion (approval) was given by an NHS Research Ethics Committee (REF: 18/WA/0191). Survey completion was taken as informed consent.

### **RESULTS**

1001 people (944 autistic adults and 57 proxy responders) were contacted. 458 people (46%) (N=441 autistic adults, and N=17 proxy responders) consented to take part. Participant characteristics are described in Table 1.

[Table 1 about here]

#### **Responders and non-responders**

Responders and non-responders were rather similar; nevertheless, due to group size, there were some statistically significant differences between the groups (see Table 2).

[Table 2 about here]

#### **Quantitative responses**

Responses relating to the importance and content of the health check are summarised in Table 3.

[Table 3 about here]

72.9% of participants (n=336) thought that a regular health check should be provided, with only 5.0% (n=23) and 11.9% (n=55) respectively not wanting a regular health check or being unsure. There were no differences in these proportions for gender (all  $\chi^2$  p-values  $\geq .05$ ), but there was a significant effect of age and intellectual disability. As part of a health check, the majority of participants (86.3%, n=398) were willing to provide information about their health needs. Similarly, 85.7% of respondents (n=395) said they would provide information on the reasonable adjustments they would like. There were no age, gender or intellectual disability effects associated with responses to these items (see Table 3 and Table 4).

[Table 4 about here]

Responses showed a clear preference for Primary Care staff to be trained in autism and delivering a health check for autistic people (rated ‘very important’ by 79.2% (n=365) and 70.3% (n=324) of respondents respectively). Autistic people thought that a health check should be available online and on paper, with only a minority thinking this was not important (15.6%, n=72, and 12.8%, n=59, respectively). Finally, over three quarters (76.7%, n=353) thought having adequate time for discussions was very important (Table 3). Although there were no age or intellectual disability effects

associated with these responses, there was a gender effect when participants were asked about the need for all staff involved in the health check to receive training about autism.

Most people (67.5%, n=299) wanted a health check to be for all autistic people, irrespective of whether they had intellectual disabilities. Only 9 responders (2.0%) reported that it should only be for people without intellectual disability. There were no differences in these proportions for gender (all  $\chi^2$  p-values  $\geq .05$ ), or intellectual disability, but there was a significant effect of age. 66.8% of respondents (n=308) thought a health check should be available from childhood or the teenage years; 5% (n=24) thought health checks should start from age 40 years or older.

There was a strong preference for an annual health check (60.1%, n=277). Half of the respondents (50.3%, n=232) thought a health check should last for 15-30 minutes (options ranged from < 15 minutes to over 45 minutes). Just over half of respondents wanted to be contacted about a health check by letter (54.2%, n=250). There were no age, gender or intellectual disability effects associated with these responses.

### **Open text responses and categories**

#### *Inter-rater reliability*

Cohen's Kappa was used to estimate inter-rater reliability. For both open text questions percentage agreement and Kappa statistic were high. For the facilitators question data Cohen's Kappa was 0.965 (96.9% agreement,  $p < .001$ ). For the barriers question data Cohen's Kappa was 0.904 (91.7% agreement,  $p < .001$ ).

#### *What would make a health check easier to access?*

Supplementary Table 1 lists the response categories and illustrative anonymised quotations for each of the categories. The most frequent responses about what would make a health check easier were factors relating to health professionals (e.g. a familiar clinician, and/or someone who knows about autism) (19.4%, n=171), environmental factors (e.g. low-level sensory stimulation especially in the waiting room) (18.8%, n=166) and providing information about the health check (e.g. who the participant will be seen by/photographs of the venue/staff and information about what will happen) (14.5%, n=128) (see Figure 1). Respondents also identified specific requirements of the health check (5.1%, n=45), including offering adjustments, doing health checks online, health professionals reviewing notes beforehand, and having a written summary detailing the outcomes of the appointment.

[Figure 1 about here]

#### *What would make a health check more challenging to access?*

The responses were consistent with those reported above, with health professionals and environmental factors listed as the biggest potential challenges to a health check (26.6%, n=215; and 18.2%, n=147 respectively) (see Figure 1). Responses indicated that health professionals could make health checks more challenging for reasons such as being "patronising" or "not knowledgeable about autism". Other factors included inaccessible appointments (e.g. inflexibility with appointment times and locations; 13.1%, n=106) and factors related to the organisation of the appointment, a lack of support or unclear communication. Only 6.8% (n=55) reported concerns about the health check appointment itself (e.g., being put on the spot to answer questions, being pressured to attend, long forms to complete on the day and undertaking physical assessments without seeking consent, such as measuring blood pressure).

## **DISCUSSION**

### **Summary**

The study represents a first step in our research programme to co-design and evaluate a health check for autistic adults, and to address this aim of the UK NHS Long Term Plan (23). Our findings suggest strong support from autistic people for a health check and provide useful information for its design, and delivery in primary care. The majority thought a health check should be available for all autistic people (irrespective of intellectual ability) and include consideration of personalised reasonable adjustments to improve access to healthcare with flexible delivery methods to maximise acceptability.

Open text responses identified some key factors relevant to a health check for autistic people, and these could apply more generally to healthcare encounters. Specifically, flexible ways of booking appointments (e.g. booking online avoiding a phone call) and providing advance information about the health check were perceived as facilitators for access. Incorporating these factors into the development of a health check for autistic adults may increase uptake.

### **Strengths and limitations**

Our large survey included autistic people from a wide age range including 62 people aged 61+ (14.0%), a group whose views are often missing from the autism literature (30, 31). Through ASC-UK recruitment we were able to include a large number of females. The age and gender distribution allowed us to investigate gender and age effects – although we could not consider both factors simultaneously. Demographic information, including gender, was gathered from ASC-UK and the response options were based on advice received from autistic people. As such, we are not able to comment on whether our findings are generalisable to people who do not report as male or female; this group may face additional challenges accessing healthcare and more research is needed to investigate what maximises good healthcare access. Finally, we included proxy responders in our analyses, but the views of those with intellectual disability are under-represented; Further exploration is needed to help inform health check implementation. The open text responses were necessarily brief; interviews and focus groups focusing on this topic are also part of the health check development process and are reported elsewhere (32).

### **Comparison with existing literature**

Our findings are in agreement with previous literature that finds some factors impact negatively on healthcare access (11, 12, 15). Autistic adults emphasised the importance of health professionals having a good understanding of autism (also identified elsewhere) (12). A lack of professionals' understanding may lead to autistic people being less satisfied with patient-provider communication (33) – to the extent that health conditions are not identified (31). A final consideration is continuity of GP or practice nurse seen. This is important in healthcare generally (34), but may be particularly relevant for autistic people (35).

### **Implications for research and practice**

Considering the aims of the NHS Long Term Plan and autistic adults' views here, evaluating a health check specifically designed for autistic adults is an appropriate next step. A subsequent trial of its clinical and cost effectiveness is planned, and if demonstrated, the study results will be important for those considering implementation in Primary Care. Future studies to investigate health check use for

autistic people in other countries will be important, as provision will need to be made appropriate for other health systems.

### **Funding**

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### **Ethical approval**

A favourable opinion for this study was given by Wales Research Ethics Committee 5 Bangor (18/WA/0191).

### **Competing interests**

There are no conflicts of interest with respect to the research, authorship, and/or publication of this article.

### **Acknowledgements**

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**Table 1. Participants characteristics**

Characteristic	N (%)
Total participants	458
Age	
18-25	47 (10.3)
26-40	148 (32.3)
41-60	202 (44.1)
61+	61 (13.3)
Gender	
Male	183 (40.0)
Female	244 (53.3)
Did not report as male or female <sup>a</sup>	14 (3.0)
Qualifications achieved <sup>b</sup>	
Postgraduate degree	74 (16.2)
Bachelor's degree	163 (35.6)
Diploma of higher education	59 (12.9)
Certificate of higher education	49 (10.7)
A-level or equivalent	245 (53.5)
General Certificate of Secondary Education (GCSE)	341 (74.5)
Basic skills	87 (19.0)
No formal qualifications	39 (8.5)
Other	76 (16.6)
Employment status	
Employed without support	142(31.0)
Employed with support	6 (1.3)
Self-employed	36 (7.9)
Volunteer	58 (12.7)
Unemployed	194 (42.4)
Retired	25 (5.5)
Other	78 (17.0)
Autism diagnosis	
Formal diagnosis	392 (85.6)
Suspected/unsure/awaiting assessment	66 (14.48)
Age at diagnosis: mean (SD) (range)	37.7 (15.6) (2.0-68.0)
SRS score by severity category <sup>c</sup>	
"Normal"	9 (2.3)
"Mild"	38 (9.6)
"Moderate"	121 (30.6)
"Severe"	227 (57.5)
Mean (SD)	116 (26)
Intellectual disability	
Formal diagnosis	28 (6.1)
Suspected	33 (7.2)
Type of secondary school attended <sup>b</sup>	
Mainstream school	424 (92.6)
Specialist schooling (at any time)	54 (11.8)
Statement of special educational needs	
Yes	60 (13.1)
No	362 (79.0)
Don't know	32 (7.0)

No response	4 (0.9)
Additional help with learning received at mainstream school	
No help	349 (76.2)
Classroom support	35 (7.6)
1:1 instruction	22 (4.8)
Extra time for exams	53 (11.6)
Special equipment	13 (2.8)
Quiet room	28 (6.1)
Support person	36 (7.9)
Support received currently <sup>b</sup>	
Home	135 (29.5)
Employment	45 (9.8)
Health	117 (25.5)
Finance	120 (26.2)
Social	67 (14.6)
Lifelong learning	56 (12.2)
Community	86 (18.8)
Organisation	70 (15.3)
Do not receive support	205 (44.8)
Support needed currently <sup>b</sup>	
Home	120 (26.2)
Employment	190 (41.5)
Health	161 (35.2)
Finance	202 (44.1)
Social	247 (53.9)
Lifelong learning	222 (48.5)
Community	136 (29.7)
Organisation	140 (30.6)
Do not want to receive support	61 (13.3)
Completion of survey	
On own	371 (81.0)
With help from somebody else	77 (16.8)
No response	11 (2.4)

<sup>a</sup> Not included in analyses of gender comparison; data included in all other analyses. <sup>b</sup> Respondents could tick more than one option, so percentages add up to more than 100%. <sup>c</sup> We report the SRS scores under the categories given by the SRS authors; however, we are aware that some autistic people may dislike this terminology and view it as pathologizing.

**Table 2. Comparison of survey responders and non-responders on age group, gender, and preferred contact method**

Variable	Responder N (%)	Non-responder N (%)	$\chi^2$ (p-value)	Effect size Cramer's V
Age				
18-25	47 (10.3)	78 (14.4)	16.35 (.001)	.128
26-40	148 (32.3)	211 (38.9)		
41-60	202 (44.1)	214 (39.4)		
61+	61 (13.3)*	40 (7.4)*		
Gender				
Male	183 (40.0)	247 (49.1)	6.15 (.046)	.081
Female	244 (53.3)	246 (48.9)		
Did not report as male or female <sup>a</sup>	14 (3.0)	10 (2.0)		
Preferred contact method				
Post	111 (24.3)	93 (17.3)	7.35 (.007)	.086
E-mail	346 (75.7)	444 (82.7)		

\* Indicates significant differences, based on chi-squared residuals. <sup>a</sup> not included in analyses of gender comparison; data included in all other analyses

**Table 3. Proportion of responses to quantitative survey questions about important aspects of the health check from autistic adults, and gender and age effects**

	Yes N (%)	No N (%)	Don't know N (%)	Gender effects Cramer's V (p-value)	Age effects Cramer's V (p-value)	Intellectual disability effects Cramer's V (p-value)
Do you think that:						
Regular health checks should be provided for autistic adults?	336 (72.9)	23 (5.0)	55 (11.9)	.06 (.557)	<b>.21 (.009)</b>	<b>.13 (.033)</b>
18-25	33 (93.4)	0 (0.0)	2 (5.7)			
26-40	104 (83.2)	9 (7.2)	12 (9.6)			
41-60	143 (78.6)	6 (3.3)	33 (18.1)			
61+	43 (78.2)	7 (12.7)	5 (9.1)			
Provide information about health needs before health check?	398 (86.3)	7 (1.5)	-	.02 (.689)	.04 (.877)	.01 (.850)
Provide information about reasonable adjustments before health check?	395 (85.7)	9 (2.0)	-	.01 (.796)	.12 (.147)	.01 (.916)
	Not important N (%)	Somewhat important N (%)	Very important N (%)			
Importance ratings for features of a health check for autistic adults:						
All staff receiving training about autism	2 (0.4)	39 (8.5)	365 (79.2)	<b>.15 (.011)</b>	.12 (.506)	.03 (.819)
Males	2 (1.3)	23 (14.5)	134 (84.3)			
Females	0 (0.0)	15 (6.8)	206 (93.2)			
Training about health checks for autistic adults	9 (2.0)	73 (15.8)	324 (70.3)	.09 (.245)	.18 (.050)	.06 (.520)
An online health check for autistic adults	72 (15.6)	144 (31.2)	182 (39.5)	.08 (.275)	.15 (.170)	.02 (.908)
A paper version of the health check	59 (12.8)	149 (32.3)	191 (41.4)	.06 (.489)	.15 (.200)	.08 (.284)
Having adequate time for discussions	3 (0.7)	49 (10.6)	353 (76.7)	.11 (.100)	.18 (.056)	.07 (.341)

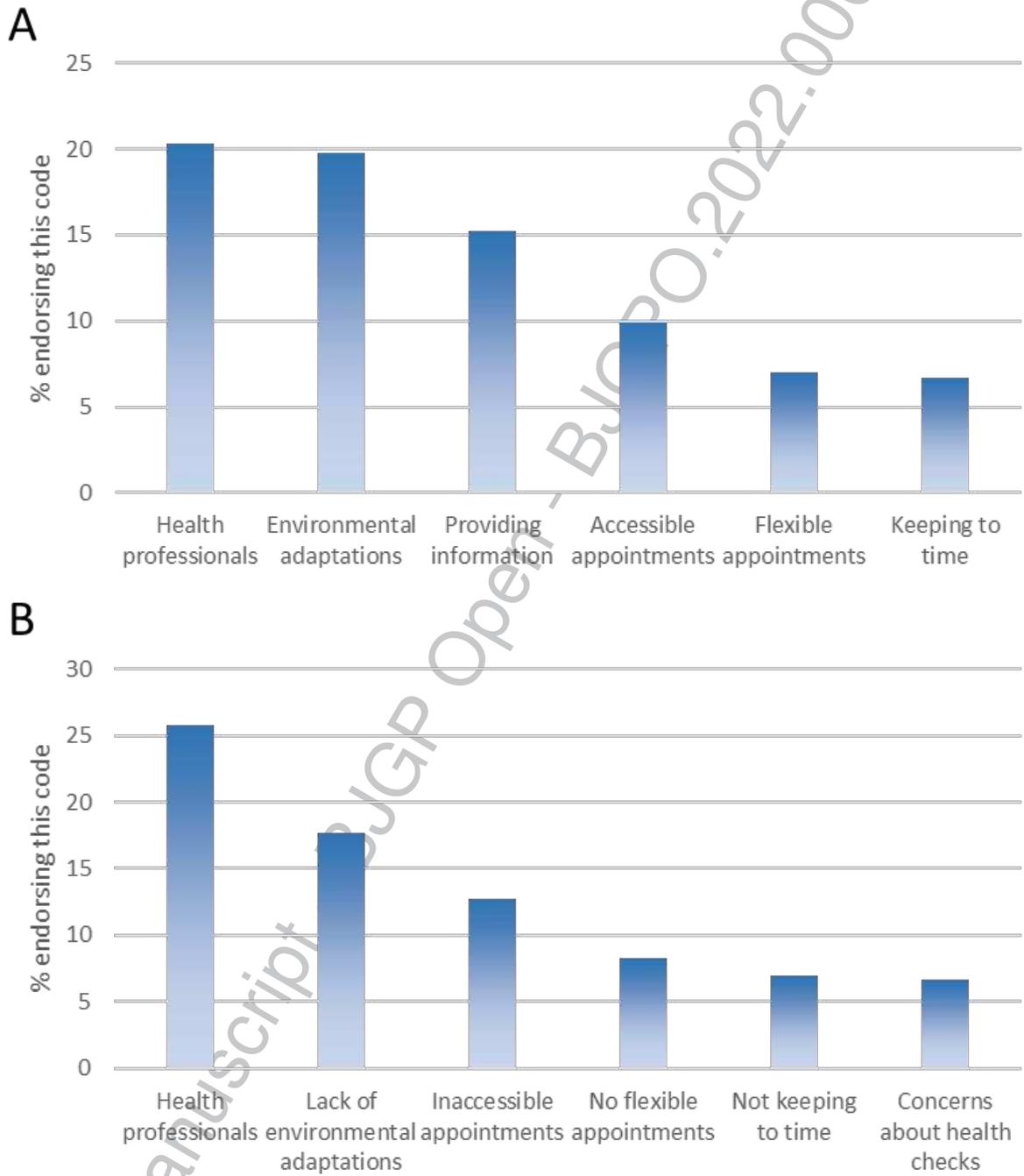
Statistically significant differences are marked in bold.



Only autistic adults without LD	0 (0.0)	5 (4.4)	2 (1.2)	2 (4.3)
Only autistic adults with LD	4 (11.8)	2 (1.8)	3 (1.8)	4 (8.5)
Don't know/Unsure	3 (8.8)	13 (11.4)	20 (12.2)	2 (4.3)

Statistically significant differences are marked in bold.

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**Figure 1: Representation of the categories for (A) “what would make a health check easier to access?” and (B) “what would make a health check more challenging to access?”**

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