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Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study.

Barriers to healthcare for autistic adults

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Abstract

Objectives:

Autistic people experience significantly poorer physical and mental health along with reduced life expectancy. Our aim was to identify self-reported barriers to primary care by autistic adults compared to non-autistic adults and to link these barriers to self-reported adverse health consequences.

Methods:

Following consultation with the autistic community at an autistic conference, *Autscape*, we developed a self-report survey which we administered online through social media platforms.

Results:

The 52-item online survey was completed by 507 autistic adults and 157 control subjects. Eighty percent of autistic adults and 37% of controls reported difficulty visiting a GP. The highest-rated barriers by autistic adults were deciding if symptoms warrant a GP visit (72%), difficulty making appointments by telephone (62%), not feeling understood (56%), difficulty communicating with their doctor (53%) and the waiting room environment (51%). Autistic adults reported a preference for online or text based appointment booking, facility to email in advance the reason for consultation, the first or last clinic appointment and a quiet place to wait. Increased adverse health outcomes reported by autistic adults correlated with difficulty attending, and these included untreated physical and mental health conditions, not attending specialist referral or screening programmes, requiring more extensive

treatment or surgery due to late presentations, and untreated potentially life threatening conditions.

Conclusions*:*

Reduction of healthcare inequalities for autistic people requires that healthcare providers understand autistic perspectives, communication needs and sensory sensitivities. Adjustments for autism specific needs are as necessary as ramps for wheelchair users.

Strengths and limitations of this study

Autistic people face barriers accessing the healthcare system, followed by difficulties interacting with healthcare providers, which may contribute to known healthcare disparities including increased morbidity and mortality.

Our study arose from a community-identified need to develop autism awareness training for healthcare providers and benefited from an autistic-led research team including autistic doctors, using participatory methods.

This cross sectional study compared the difficulties experienced by autistic and non-autistic adults when visiting a General Practitioner, but as we used a convenience sample and self-report survey, generalisability of the data may be limited.

We linked access barriers to self-reported adverse outcomes and our data indicated that autistic help-seeking may occur later in the natural course of an illness.

Common healthcare access barriers for autistic patients are described along with practical suggestions to promote access, which may help to reduce morbidity and excess mortality for autistic adults.

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Introduction

Autism is a common neurodevelopmental condition affecting 1-2% of the population.[1] Most autistic people are adult, do not have intellectual disability and are likely to be undiagnosed.[2] Doctors may underestimate the number of autistic patients under their care.[3.4] Autistic adults have poor physical and mental health compared to the general population.[5] Most medical conditions are more prevalent in the autistic population,[6,7] including diabetes, hypertension and obesity.[8] Autistic people experience premature mortality.[9,10,11] Life expectancy is reduced by 16-30 years, with increased mortality across almost all diagnostic categories[9]. In-hospital mortality is also increased.[12] Autistic people are three times more likely to use emergency departments, to require inpatient admission, and to die after attending emergency care.[13]

Alongside increased health needs, autistic people report a greater likelihood that their needs are unmet.[14] Pervasive, multifactorial barriers to healthcare access are experienced.[15] Some are shared by other disabled people, but autistic patients experience additional autism-specific barriers.[16] Patient-provider communication, sensory sensitivities, executive functioning/planning difficulties, and prior negative experiences with healthcare providers are important barriers.[17,18]

In response to primary legislation[19] and statutory guidance[20] The Royal College of General Practitioners (RCGP) developed an Autism Patient Charter.[21] This recommended: staff awareness and training; autism friendly environment; reasonable adjustments following disclosure or clinical suspicion of autism; patient-tailored communications; and behaviour-sensitive accommodations.[21] Despite efforts to champion autism, proposals to formalise autism training[18,22] and specific awareness-raising interventions,[21] almost 40% of general practitioners (GPs) report no formal training in autism.[22] They also report limited confidence in managing autistic patients.[22] Greater autism awareness exists where GPs have personal knowledge of autism, either through a relative or friend on the autistic spectrum, or because they themselves are autistic.[22] Communication skills training for health care providers may be the most pressing need.[4] GPs[22] and hospital specialists[3] self-report difficulties communicating with autistic patients. Only 25% of primary healthcare providers reported high confidence in communicating with autistic adult patients, or identifying and making necessary accommodations.[4]

This study aimed to identify self-reported barriers to primary health care faced by autistic adults with a focus on autism-specific communication, sensory issues and procedural considerations. We captured self-reported consequences to add a narrative frame to the existing evidence base around disparities in health outcomes. This is to our knowledge the largest study of primary healthcare barriers to date and benefits from a high degree of participatory design by the autistic community.

Methods

Conception and design

Here, we present part of a larger cross-sectional study. This work was inspired by a quality improvement project designed to inform autism training for local healthcare providers as part of an "Autism Friendly Town" initiative by AsIAm, Ireland's National Autism Charity.[23,24] In 2018, MD attended *Autscape*,[25] an annual conference by and for autistic people. Participants of all ages are welcome at *Autscape*, including those who are non-speaking, have high support needs or require full-time care, although the majority typically have low to moderate support needs. Whilst there, MD distributed a qualitative questionnaire entitled "What do you wish your GP knew about autism?" MD reviewed the 75 responses and grouped these under broad themes. That project formed the inspiration and basis for the study reported in this paper. Using the data gathered at *Autscape*, MD developed an online survey to investigate barriers to primary healthcare in a larger sample of autistic adults, compared with a non-autistic adult control group. Nine autistic adults assisted with refining the survey. The resulting survey contained a mix of quantitative questions and free comment boxes. Quantitative questions included yes-no responses, single- and multiple-item selections from a list, and Likert scales. We asked about specific barriers encountered accessing healthcare, reasons for delaying or avoiding a visit, and difficulties booking, planning or waiting for a GP visit. We explored the challenges during a consultation, including communication, sensory and organisation issues as well as available social supports. We also explored the impact of such barriers including self-reported consequences of failure to access healthcare and the reasonable adjustments to standard care which facilitate access. We used Google Forms to host the survey.

Piloting and refinement

We piloted the survey in 2018. Preliminary analysis revealed a recurring theme of total non-engagement with healthcare providers, despite expressed healthcare needs. Consequently, we altered the survey to add response options applicable to non-attenders. Our research team, comprising autistic and non-autistic GPs, experienced academics, and other autistic individuals, adapted and refined the survey into its final 52-item form.

Sampling, recruitment and data collection

Autistic adults were recruited using a convenience sampling approach, through Twitter, Facebook and the AsIAm website. We recruited non-autistic controls (without autistic children) through personal and professional contacts of research team members, local area groups and parenting groups on social media. Recruitment took place in August 2019. We provided participant information, with informed consent implied through subsequent completion of the questionnaire. We asked respondents, particularly those who were parents, to respond specifically about seeking healthcare for themselves. For those identifying as autistic, we asked if they were formally diagnosed or self-identified.

Data analysis

We used the statistical package 'R' to assess significance of between-group associations using a test of proportions and a Wilcoxon-Mann-Whitney U test. Participants who skipped questions were omitted from the analyses of those questions. We intend to present our qualitative results elsewhere.

Patient and Public involvement

Our study was conducted by an autistic-led research team including autistic doctors, using participatory methods. Nine autistic individuals assisted with developing and refining the survey into its final form.

Results

Participants

We are reporting 664 responses to the online survey: 507 autistic and 157 control (Table 1). Unless otherwise specified, results relate to primary care.

Table 1. Participant Data		
	Autistic	Control
Participants (n)	507	157
Age		
Median (Range)	38 (17 - 73)	38 (18 - 70)
Gender		
Male	99 (20%)	16 (10%)
Female	311 (62%)	132 (85%)
Non-binary	83 (17%)	7 (5%)
Prefer not to say	9 (2%)	1 (1%)
Location		
UK	330 (65%)	67 (43%)
Ireland	77 (15%)	63 (40%)
North America	44 (9%)	20 (13%)
Other	56 (11%)	7 (4%)
Formal diagnosis of autism	77%	
By psychiatrist	25%	
By clinical psychologist	48%	
By multidisciplinary team	26%	
Age at diagnosis		
Median (Range)	33 (2 - 67)	

Barriers to access

The most common reason for a GP visit was a physical condition or illness in both groups (86% vs 92%, n.s.). Autistic individuals were more likely to attend for mental health difficulties (61% vs 27%, difference 34%, 95%CI[25.2%,42.3%] p<0.001). Twenty-two percent of the autistic respondents usually attended for issues directly related to autism. Compared to 37% of controls, 80% of autistic respondents reported difficulty visiting a GP when needed (difference 43% 95%CI[34.4%,51.9%], p<0.001). While difficulty deciding if symptoms warrant a visit was a barrier for both groups (72% vs 65%, n.s.), the most notable difference related to difficulties using the telephone to book an appointment (62% vs 16%, difference 46%, 95%CI[38.5%,53.5%], p<0.001). Not feeling understood was a reason to avoid or delay for 56% of autistic respondents compared to 13% of controls (difference 42%, 95%[CI 35.2%,49.7%] p<0.001). Difficulty communicating with the doctor during the appointment was a barrier for 53% of the autistic group but only 6% of controls (difference 46.7%, 95%CI[40.5, 52.9%], p<0.001). See Supplementary Table 1 for specific barriers in order of frequency.

Communication

Alongside difficulty using the telephone, not feeling understood and difficulty communicating with the doctor, autistic respondents reported difficulty communicating with reception staff more often than controls (46% vs 8%, difference 38%, 95%CI[31.5%,44.6%], p<0.001). Fifty nine percent of autistic respondents reported difficulty communicating during a consultation "all the time" or "frequently" compared to 12% of controls (p<0.001). Seventy eight percent of autistic adults reported that "anxiety makes it harder to communicate."

Autistic respondents reported avoiding the telephone (78%), voicemail (61%) and face-to-face verbal communication (30%). Forty one percent reported that it is "easier for me to communicate in writing" (Table 2).

Table 2 Communication Barriers

Reasons to avoid or delay GP visit (Communication)				
	Autistic n (%)	Control n (%)	Difference (95% Confidence Interval)	p value
Difficulty using the telephone to book an appointment	314 (62%)	25 (16%)	46% (CI 38.5%,53.5%)	p<0.001**
Not feeling understood	283 (56%)	21 (13%)	42% (CI 35.2%,49.7%)	p<0.001**
Difficulty communicating with the doctor during the appointment	269 (53%)	10 (6%)	47% (CI 40.5%,52.9%)	p<0.001**
Difficulty communicating with the reception staff	235 (46%)	13 (8%)	38% (CI 31.5%,44.6%)	p<0.001**
Communication preferences				
Telephone generally avoided where possible	395 (78%)	59 (38%)	40% (CI 31.5%,49.1%)	p<0.001**
Voicemail generally avoided where possible	311 (61%)	61 (39%)	23% (CI 13.3%,31.6%)	p<0.001**
Verbal, face-to-face communication generally avoided where possible	152 (30%)	12 (8%)	22% (CI 16.2%,28.5%)	p<0.001**
It is easier for me to communicate in writing	208 (41%)	13 (8%)	33% (CI 26.3%,39.2%)	p<0.001**
Communication challenges				
Anxiety makes it harder to communicate	395 (78%)	42 (23%)	51% (CI 42.9%,59.4%)	p<0.001**
Sensory issues make communication more difficult	156 (31%)	2 (1%)	30% (CI 24.7%,34.3%)	p<0.001**
I need extra time to process what is being said	286 (56%)	12 (8%)	49% (CI 42.4%,55.2%)	p<0.001**
I can't describe my pain or symptoms accurately	272 (54%)	36 (23%)	31% (CI 22.4%,39.0%)	p<0.001**
Verbal communication is difficult	234 (46%)	11 (7%)	39% (CI 32.8%,45.5%)	p<0.001**
I express emotions differently e.g. I can appear angry when I am afraid or in pain	227 (45%)	6 (4%)	41% (CI 35.3%,46.6%)	p<0.001**
I have difficulty prioritising when describing medical symptoms	333 (66%)	34 (22%)	44% (CI 36.0%,52.1%)	p<0.001**
I need to give the whole story and not leave anything out	332 (66%)	18 (12%)	54% (CI 47.1%,60.9%)	p<0.001**

None of the above (Communication)	11 (2%)	58 (37%)	-35% (CI -42.8%,-26.7%)	p<0.001**

Sensory processing

The waiting room environment was a barrier for 51% of autistic respondents, but only 8% of controls (difference 43%, 95%CI[36.4%,49.3%], p<0.001). Specific sensory barriers are detailed in Table 3. Sensory issues made communication more difficult for 31% of the autistic group (Table 2). Only 10% of autistic respondents marked "none of the above" to sensory questions compared to 71% of controls (difference 61%, 95%CI[-69.2%,-53.3%], p<0.001).

Table 3: Sensory Barriers

Reasons to avoid or delay GP visit (Sensory)	**Autistic n (%)**	**Control n (%)**	**Difference (95% Confidence Interval)**	**p value**
The waiting room environment	256 (51%)	12 (8%)	42.8% (CI 36.4%,49.3%)	p<0.001 **
Specific sensory challenges	**Autistic n (%)**	**Control n (%)**	**Difference (95% Confidence Interval)**	**p value**
Noise in the waiting room from other patients	319 (63%)	19 (12%)	51% (CI 43.8%,57.8%)	p<0.001 **
Crowded waiting area	299 (59%)	22 (14%)	45% (CI 37.6%,52.3%)	p<0.001 **
Bright or fluorescent lights	268 (53%)	14 (9%)	44% (CI 37.3%,50.6%)	p<0.001 **
Uncomfortable furniture	195 (39%)	11 (7%)	32% (CI 25.2%,37.7%)	p<0.001 **
Unexpected touch	193 (38%)	9 (6%)	32% (CI 26.3%,38.3%)	p<0.001 **
Music playing in the waiting room	172 (34%)	9 (6%)	28% (CI 22.3%,34.1%)	p<0.001 **
Smells in the waiting room	171 (34%)	8 (5%)	29% (CI 22.9%,34.4%)	p<0.001 **
Touch during examination	160 (32%)	11 (7%)	25% (CI 18.5%,30.7%)	p<0.001 **
Noise from the reception desk	140 (28%)	4 (3%)	25% (CI 20.0%,30.1%)	p<0.001 **
Smells in the doctor's office	104 (21%)	6 (4%)	17% (CI 11.7%,21.7%)	p<0.001 **
None of the above (Sensory)	51 (10%)	112 (71%)	-61% (CI -69.2%,-53.3%)	p<0.001 **

Perceived Stigma

Only 3% of autistic respondents stated they did not feel anxious going to the doctor, compared to 33% of controls (difference 30%, 95%CI[-37.7%,-21.8%] p<0.001). Autistic respondents reported being "concerned I won't be taken seriously when I describe my symptoms" (67%); worried about "wasting the doctor's time" (66%) and "being considered a hypochondriac" (65%). They also reported difficulty "asking for help" (63%) and "discussing mental health" (59%). Autistic respondents reported that unusual behaviour or stimming elicited negative reactions from other patients (15%) reception staff (9%) or medical staff (7%) (Supplementary Table 2).

Planning and Organising

Autistic respondents reported difficulties with summarising when describing medical problems, with 66% noting the "need to give the whole story and not leave anything out" compared to 12% of controls (difference 54%, 95%CI[47.1%,60.9%], p<0.001). Autistic respondents reported difficulties with organisation and planning for healthcare, including difficulties "making an appointment in advance" (59%), "prioritising my health issues" (58%) and "making changes to my lifestyle or habits" (56%). Forty five percent reported forgetting a medical appointment and 30% had attended on the wrong day. (Supplementary Table 3).

Predictability and control

Autistic respondents reported more difficulty with uncertainty than controls. Particular difficulties included not knowing the wait duration (70% vs 30%, difference 40%, 95%CI[31.5%,48.7%], p<0.001), what would happen during the consultation (63% vs 16%,

difference 47%, 95%CI[39.7%,54.7%], p<0.001), which doctor they would see (58% vs 24%, difference 33%, 95%CI[25.0%,41.8%], p<0.001) and the consultation length (40% vs 8%, difference 32%, 95%CI[25.6%,38.4%] p<0.001).

Support needs

Autistic adults reported physical mobility needs (16%), and unmet support needs in primary care e.g. “needing a support person to come with me” (21%). This extended to secondary care: 17% had no one to support unexpected hospital admission, collection from hospital (20%), or home care following discharge (26%). (Supplementary Table 4).

Adverse consequences

Autistic respondents reported adverse consequences more frequently than controls, including untreated mental (69%) and physical (63%) health conditions. Notably 60% were told they “should have seen a doctor sooner” and 47% “did not attend referral to a specialist”. Thirty-six percent “required more extensive treatment or surgery” and 34% did not access treatment for a “potentially serious or life threatening condition”. Additionally, they were less likely to “attend on schedule for screening programmes" than the control group (39% vs 21%, difference 18%, 95%CI[9.8%,26.2%], p<0.001) (Figure 1).

Compared to autistic respondents who had no difficulty visiting a doctor, those who experienced difficulty (80%) reported more untreated mental and physical health conditions (p<0.001). They were also more likely to not attend specialist referral (p<0.001), to need more extensive treatment (p=0.009), to experience untreated life-threatening conditions (p=0.006) and to not attend screening (p=0.028) (Figure 2). The autistic respondents who did

not attend any doctor at all (4%) differed from the controls (5%) in two areas: all had difficulty visiting the doctor when needed, compared to 50% of controls (p=0.002); and 95% of autistic non-attenders had experienced at least one delayed treatment outcome, compared to 43% of non-attending controls (p=0.01). There were no significant differences in difficulty attending, barriers experienced or adverse outcomes between formally diagnosed and self-identified autistic respondents.

Facilitators

While most respondents (67% vs 65%) reported booking an appointment online would facilitate access, autistic patients selected a need to "email my doctor in advance with a description of the issue I need to discuss" (62%), "wait in a quiet place or outside until my turn" (56%), and "book an appointment by text" (41%). Some autistic individuals would benefit if they "could book the first or last appointment" (41%) or had a "sensory box available in the waiting room" (16%) (Supplementary Table 5).

Despite the outlined difficulties of visiting their doctor, autistic individuals felt their relationship with their GP was "very important" or "important" significantly more than controls (70% vs. 56%, p=0.001), but only 33% of autistic respondents reported a good relationship with their doctor(p<0.001). Only 62% of autistic individuals reported that their doctor knew they were autistic. Twenty two percent were unsure whereas 16% hadn't disclosed their diagnosis. Autistic respondents appreciated GPs who ask direct questions, give clear explanations, are honest about not understanding autism but know that autism isn't a mental illness.

Discussion

Our study describes the results of a survey of autistic adults and compares their experiences with non-autistic adults. It highlights barriers faced by autistic people accessing and engaging with primary healthcare. In our study these included greater difficulties deciding when to seek care, reluctance to bother their GP, difficulties planning appointments and greater communication difficulties – with particular emphasis on telephone use. Communication was also impaired by anxiety and sensory issues. We linked those barriers to self-reported adverse outcomes. Our data indicated that autistic help-seeking may occur later in the natural course of an illness. Autistic participants reported reduced attendance for screening, late presentations, missed opportunities for early detection and more extensive therapy being required. They also delayed or avoided healthcare because they didn't feel understood by their doctors. Furthermore, a substantial minority of autistic adults did not disclose their autism diagnosis which may impede identification of their autism-specific needs. These barriers may have real consequences, as evidenced in reduced life expectancy, and higher levels of physical and mental health conditions amongst autistic people.

Comparison with existing literature

This study confirms the findings of Nicolaidis,[14] Raymaker[16] and several recent reviews[15,17,26], which all identified three groups of barriers: (1) patient-level factors; (2) provider-level factors; and (3) system-level factors. Our study stratifies individual barriers from the perspective of autistic individuals. We couple these barriers to self-reported adverse consequences, highlighting factors which may lead to excess morbidity and mortality in the autistic population.

Strengths and limitations

Our study arose from a community-identified need to develop autism awareness training for healthcare providers. It benefited from an autistic-led research team including autistic doctors, using participatory methods. This increased the likelihood of genuine responses being received. Our study provided a unique picture of autistic adults' healthcare experiences, including those entirely excluded from healthcare due to access barriers. In particular, we highlighted the difficulties with using the telephone which is a distilled, concentrated essence of verbal communication.

As we used a convenience sample and self-report survey, generalisability of the data may be limited. Respondents required the ability to complete the survey which excluded those with reduced ability to self-report. Whilst we did not set out to create a validated tool, our survey may have benefited from some validity and reliability testing. As the initial quality improvement questionnaire was undertaken in the United Kingdom, we did not include issues specific to other healthcare systems, such as cost or insurance. Our analyses did not account for potential confounding factors, such as ethnicity or socio-economic status. Female participants were over-represented in both groups which is not unusual for online surveys, but is interesting given the higher rate of autism diagnosis in males. Whilst we noted significant gender differences in relation to non-binary participants, these participants were almost all autistic and we were therefore unable to attribute differences to gender identity or autism with any degree of certainty. Furthermore, as this is a cross-sectional study, whilst we can identify associations, we cannot confirm causality.

Implications for Research

Our study suggests a need for personalised healthcare access plans. A prior study investigated using a pre-visit telephone call to identify individualised accommodations.[27] Our data suggest that this could be problematic for autistic adults. The AASPIRE Healthcare Toolkit[28] includes a publicly available online program which generates a computerised report of required healthcare accommodations. Adaptation of such a toolkit in NHS General Practice should be considered and researched. Social care interventions and healthcare facilitators in general practice have shown benefit with a vulnerable population,[29] similar approaches could benefit an autistic population. The significant difficulties amongst the small number of autistic people not registered with any GP indicate a need for further research into this group.

Implications for Clinical Practice

Figure 3 outlines our proposed elements of an autism friendly practice. Such adjustments may minimise anxiety, manage sensory issues, and ensure mutual understanding – promoting clear, unambiguous communication. Autism friendly practices should employ a personalised approach, with a healthcare access needs assessment and, where possible, a specialist liaison nurse or facilitator.

Implications for Policy

Given the identified barriers, the extension of annual health checks to autistic adults[30,31] and the recently announced Oliver McGowan Mandatory Training in Learning Disability and Autism[32] are welcome. These will likely bring important benefits provided they are informed by the autistic community and autistic healthcare providers. Autism registers in GP practice

have been recommended.[33,34] The success of such initiatives will likely depend on greater awareness by medical practitioners of autistic culture and communication needs. Specific training for GPs during core training and continuing professional development may be beneficial. GPs with a special interest in autism should be facilitated to develop their skills, but management of general health needs and co-occurring conditions fall within the remit of every GP. Implementing existing autism legislation or development where lacking is required in order to reduce health inequities for autistic people.

Conclusions

Autistic people face barriers accessing the healthcare system, followed by difficulties interacting with healthcare providers, which may contribute to known healthcare disparities including increased morbidity and mortality. Progress towards eliminating healthcare inequalities for autistic people may be achieved by understanding the healthcare experiences and access barriers for this vulnerable patient group. These barriers represent not so much a failure to deliver or to avail of healthcare, but a lack of intersection between the communication patterns of autistic healthcare users and non-autistic providers. This phenomenon is described by The Double Empathy Problem.[35] Reasonable accommodations are legally[36] and morally required. Adjustments for communication needs are as necessary for autistic people as ramps for wheelchair users.

Ethical approval: We obtained ethical approval from SJH/TUH Research Ethics Committee, Tallaght University Hospital, Dublin.

Competing interests: None.

Data availability statement: Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplementary information. Should further details or materials be required, please contact the corresponding author.

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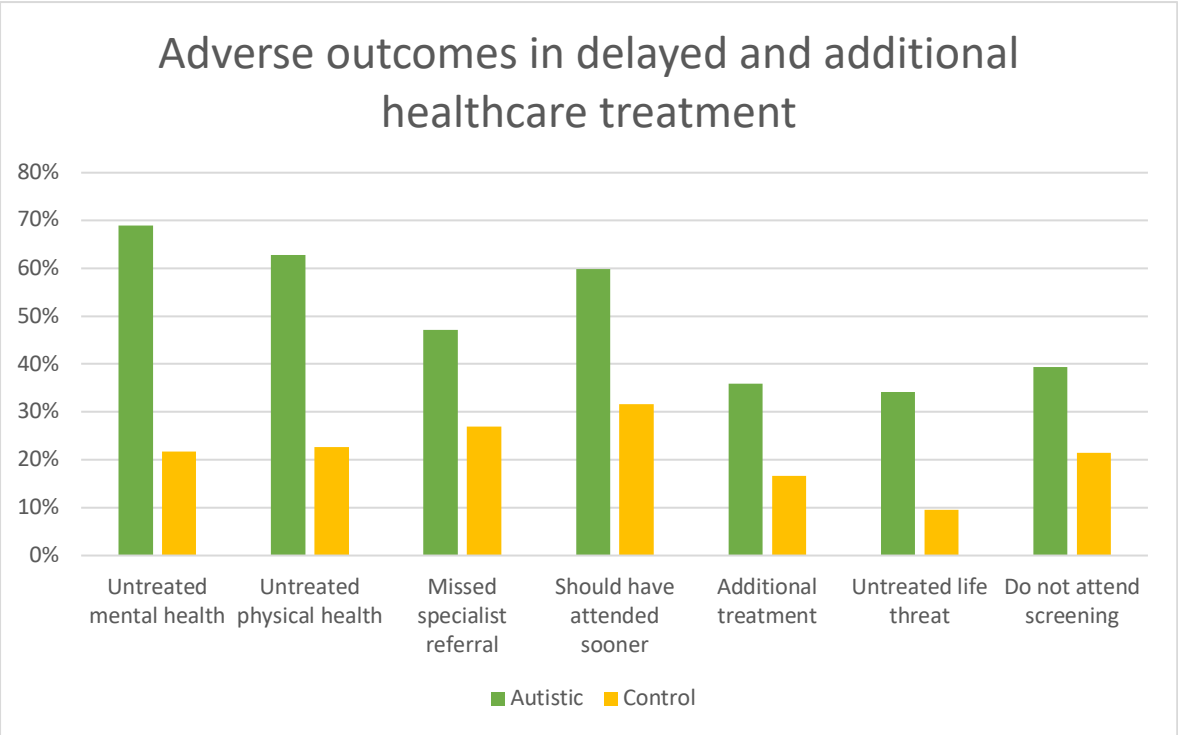

Figure 1. Adverse Healthcare Outcomes
For all comparisons between autistic and control groups p<0.001.

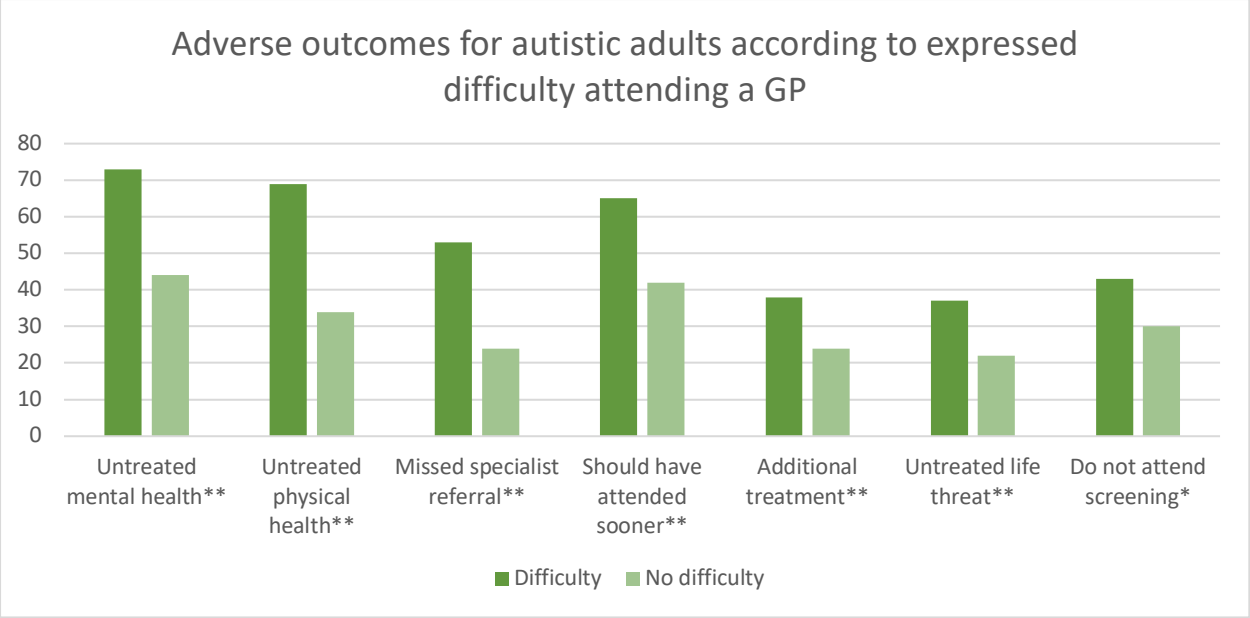

Figure 2. Adverse outcomes according to difficulty attending a GP
**p<0.001
* p<0.05
Note y-axis = N

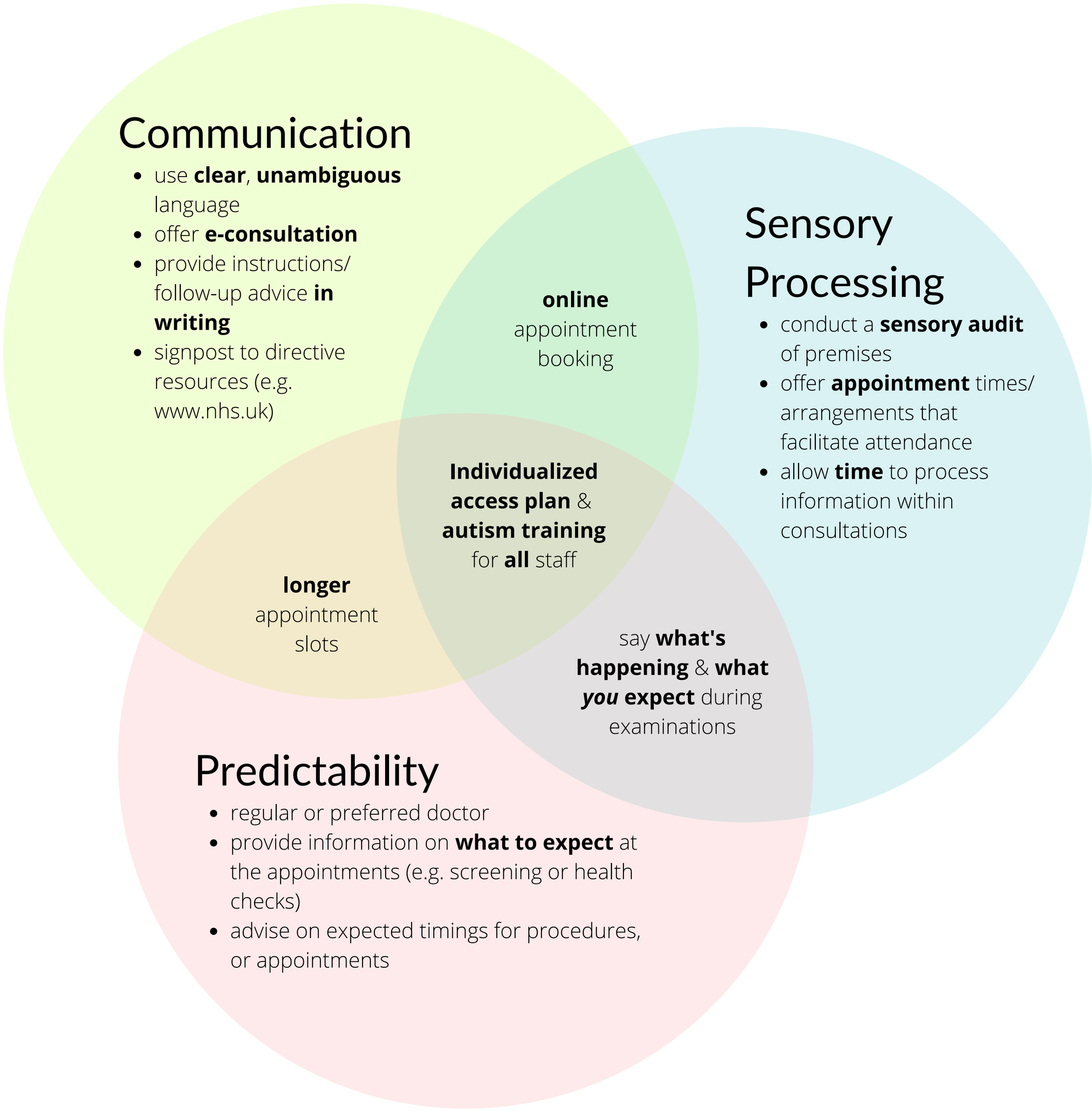
Communication
use clear, unambiguous language
offer e-consultation
provide instructions/ follow-up advice in writing
signpost to directive resources (e.g. www.nhs.uk)
online appointment booking
Sensory Processing
conduct a sensory audit of premises
offer appointment times/ arrangements that facilitate attendance
allow time to process information within consultations
Individualized access plan & autism training for all staff
longer appointment slots
say what's happening & what you expect during examinations
Predictability
regular or preferred doctor
provide information on what to expect at the appointments (e.g. screening or health checks)
advise on expected timings for procedures, or appointments

Table S1 Access Barriers to Healthcare

Which of the following would cause you to delay or avoid seeing your doctor when you need to?

	Autistic n (%)	Control n (%)	Difference (95% Confidence Interval)	p value
Difficulty deciding if symptoms warrant a GP visit	366 (72%)	102 (65%)	7% (CI -1.6%,16.1%)	p=0.102 ns
Difficulty using the telephone to book appointment	314 (62%)	25 (16%)	46% (CI 38.5%,53.5%)	p<0.001**
Not feeling understood	283 (56%)	21 (13%)	42% (CI 35.2%,49.7%)	p<0.001**
Difficulty communicating with the doctor during the appointment	269 (53%)	10 (6%)	47% (CI 40.5, 52.9%)	p<0.001**
The waiting room environment	256 (51%)	12 (8%)	43% (CI 36.4%,49.3%)	p<0.001**
Long wait to get an appointment	251 (50%)	70 (45%)	5% (CI -4.4%,14.2%)	p=0.324 ns
Difficulty planning an appointment in advance	243 (48%)	51 (33%)	15% (CI 6.5%,24.4%)	p<0.001**
Inability to see a known or preferred doctor	241 (48%)	35 (23%)	25% (CI 17.0%,33.5%)	p<0.001**
Difficulty communicating with the reception staff	235 (46%)	13 (8%)	38% (CI 31.5%,44.6%)	p<0.001**
Not having enough time to visit the doctor	174 (34%)	61 (39%)	-5% (CI -13.6%,4.6%)	p=0.346 ns
No online booking system	160 (32%)	35 (23%)	9% (CI 1.2%,17.3%)	p=0.033*
Waiting to see the doctor is too difficult	114 (23%)	7 (5%)	18% (CI 12.7%,23.3%)	p<0.001**
Needing a support person to come with me	106 (21%)	7 (5%)	16% (CI 11.2%,21.7%)	p<0.001**
There is an online booking system but it's confusing	102 (20%)	9 (6%)	14% (CI 8.9%,19.8%)	p<0.001**
Not having anyone to look after my child	66 (13%)	18 (12%)	2% (CI -4.6%,7.8%)	p=0.708 ns
None of the above	6 (1%)	17 (11%)	-10% (CI -15.0%,-4.3%)	p<0.001**

Table S2 Perceived Stigma

Going to the doctor, I am anxious :	**Autistic n (%)**	**Control n (5)**	**Difference (95% Confidence Interval)**	**p value**
I won't be taken seriously when I describe my symptoms	341 (67%)	54 (34%)	32.9% (CI 24.0%,41.8%)	p<0.001 **
I might be wasting the doctor's time	333 (66%)	53 (34%)	31.9% (CI 23.0%,40.8%)	p<0.001 **
I might be considered a hypochondriac	330 (65%)	42 (27%)	38.3% (CI 29.8%,46.8%)	p<0.001 **
about asking for help	318 (63%)	28 (18%)	44.9% (CI 37.2%,52.6%)	p<0.001 **
about discussing mental health	301 (59%)	37 (24%)	35.8% (CI 27.5%,44.1%)	p<0.001 **
that there might be something wrong	217 (43%)	55 (35%)	7.8% (CI -1.3%,16.8%)	p=0.102 ns
I don't feel anxious going to the doctor	17 (3%)	52 (33%)	-30% (CI -37.7%,-21.8%)	p<0.001 **

Is stimming a problem for you at the doctors' office?	**Autistic n (%)**	**Control n (%)**	**Difference (95% Confidence Interval)**	**p value**
Unusual behaviours or stimming elicit negative reactions from other patients	74 (14.6%)	4 (2.5%)	12% (CI 7.7%,16.4%)	p<0.001 **
Unusual behaviours or stimming elicit negative reactions from other reception staff	44 (8.7%)	1 (0.6%)	8% (CI 4.9%,11.2%)	p=0.001 **
Unusual behaviours or stimming elicit negative reactions from other medical staff	37 (7.3%)	2 (1.3%)	6% (CI 2.7%,9.3%)	p=0.009 **
I feel comfortable with stimming at the doctors' office	101 (19.9%)	74 (47.1%)	-27% (CI -36.2%,-18.2%)	p<0.001 **
I do not feel comfortable with stimming at the doctors' office	4 (0.8%)	5 (3.2%)	-2% (CI -5.7%,0.9%)	p=0.061 ns
No need to stim at the doctors' office	133 (26.2%)	0 (0.0%)	26% (CI 22.0%,30.5%)	p<0.001 **
I don't understand the term "stimming"	29 (5.7%)	62 (39.5%)	-34% (CI -42.1%,-25.4%)	p<0.001 **

Table S3 Planning and Organising

	Autistic n (%)	Control n (%)	Difference (Confidence Interval)	p value
I find it difficult to prioritise when describing my medical problems	333 (66%)	34 (22%)	44% (CI 36.0%,52.1%)	p<0.001 **
I need to give the whole story and not leave anything out	332 (66%)	18 (12%)	54% (CI 47.1%,60.9%)	p<0.001 **
I find it difficult to make appointments in advance	300 (59%)	45 (29%)	31% (CI 21.8%,39.2%)	p<0.001 **
Making changes to my lifestyle or habits is difficult for me	282 (56%)	36 (23%)	33% (CI 24.4%,41.0%)	p<0.001 **
I have forgotten to attend a medical appointment	230 (45%)	34 (22%)	24% (CI 15.5%,31.9%)	p<0.001 **
I need to write things down	227 (45%)	17 (11%)	34% (CI 27.0%,40.9%)	p<0.001 **
I find waiting difficult	221 (44%)	15 (10%)	34% (CI 27.3%,40.8%)	p<0.001 **
I have difficulty making decisions about my health	222 (44%)	20 (13%)	31% (CI 23.9%,38.2%)	p<0.001 **
I have turned up for a medical appointment on the wrong day	151 (30%)	16 (10%)	20% (CI 13.0%,26.2%)	p<0.001 **
It is difficult to arrange someone to come with me	103 (20%)	2 (1%)	19% (CI 14.7%,23.4%)	p<0.001 **
I have forgotten why I made the appointment	54 (11%)	1 (1%)	10% (CI 6.6%,13.4%)	p<0.001 **
None of the above	13 (3%)	64 (41%)	-38% (CI -46.4%,-30.0%)	p<0.001 **

Table S4 Support Needs

Do you visit your doctor:	Autistic n (%)	Control n (%)	Difference (95%CI)	p value
Alone, by choice	306 (60%)	134 (85%)	-25% (CI -32.4%,-17.6%)	p<0.001 **
Alone, but would prefer to have a support person	165 (33%)	10 (6%)	26% (CI 20.2%,32.2%)	p<0.001 **
With a parent, partner or support person	137 (27%)	9 (6%)	21% (CI 15.6%,27.0%)	p<0.001 **
With a parent, partner or support person but I would prefer to go alone	12 (2%)	0 (0%)	2% (CI 0.6%,4.1%)	p=0.109 ns
With a support animal	5 (1%)	0 (0%)	1% (CI -0.3%,2.3%)	p=0.471 ns
To support an autistic adult	26 (5%)	0 (0%)	5% (CI 2.8%,7.5%)	p=0.008 *
As a parent to access healthcare for my child	78 (15%)	30 (19%)	-4% (CI -11.0%,3.6%)	p=0.327 ns
With my child, but I would prefer to go alone	6 (1%)	12 (8%)	-7% (CI -11.1%,-1.8%)	p<0.001 **

If you were suddenly admitted to hospital, who would be able to bring your personal belongings to you?	Autistic n (%)	Control n (%)	Difference (95%CI)	p value
Spouse or partner	234 (46%)	106 (68%)	-21% (CI -30.3%,-12.4%)	p<0.001 **
Parent	168 (33%)	70 (45%)	-11% (CI -20.7%,-2.2%)	p=0.012 *
Other family member	96 (19%)	72 (46%)	-27% (CI -35.8%,-18.0%)	p<0.001 **
Friend	118 (23%)	57 (36%)	-13% (CI -21.8%,-4.2%)	p=0.002 *
Neighbour	17 (3%)	14 (9%)	-6% CI -10.7%,-0.4%)	p=0.008 *
Paid support person or carer	15 (3%)	1 (1%)	2% (CI -0.0%,4.7%)	p=0.174 ns
Volunteer support person or carer	6 (1%)	0 (0%)	1% (CI -0.2%,2.5%)	p=0.375 ns
Nobody available	88 (17%)	5 (3%)	14% (CI 9.5%,18.9%)	p<0.001 **

If you were admitted to hospital for a day case surgical procedure, who would be available to collect you afterwards?	Autistic n (%)	Control n (%)	Difference (95%CI)	p value
Spouse or partner	208 (41%)	100 (64%)	-23% (CI -31.7%,-13.6%)	p<0.001 **
Parent	176 (35%)	73 (47%)	-12% (CI -21.0%,-2.5%)	p=0.010 *
Other family member	96 (19%)	75 (48%)	-29% (CI -37.8%,-19.9%)	p<0.001 **
Friend	116 (23%)	67 (43%)	-29% (CI -37.8%,-19.9%)	p<0.001 **

Neighbour	17 (3%)	8 (5%)	-2% (CI -5.9%,2.5%)	p=0.446 ns
Paid support person or carer	17 (3%)	0 (0%)	3% (CI 1.4%,5.3%)	p=0.042 *
Volunteer support person or carer	3 (1%)	0 (0%)	1% (CI -0.5%,1.7%)	p=0.776 ns
Nobody available	99 (20%)	3 (2%)	18% (CI 13.1%,22.1%)	p<0.001 **

If you needed assistance at home after an operation, who would be available to provide that care?

	Autistic n (%)	Control n (%)	Difference (95%CI)	p value
Spouse or partner	219 (43%)	101 (64%)	-21% (CI -30.2%,-12.1%)	p<0.001 **
Parent	152 (30%)	74 (47%)	-17% (CI -26.3%,-8.0%*)	p<0.001 **
Other family member	83 (16%)	61 (39%)	-23% (CI -31.2%,-13.8%)	p<0.001 **
Friend	74 (15%)	43 (27%)	-13% (CI -20.8%,-4.8%)	p<0.001 **
Neighbour	14 (3%)	8 (5%)	-2% (CI -6.5%,1.8%)	p=0.241 ns
Paid support person or carer	30 (6%)	3 (2%)	4% (CI 0.6%,7.4%)	p=0.071 ns
Volunteer support person or carer	4 (1%)	0 (0%)	1% (CI -0.4%,2.0%)	p=0.599 ns
Nobody available	131 (26%)	13 (8%)	18% (CI 11.4%,23.7%)	p<0.001 **

If you are a parent and you were unable to care for your child due to illness, who would be available to provide that care to your child?

	Autistic n (%)	Control n (%)	Difference (95%CI)	p value
Spouse or partner	110 (22%)	64 (41%)	-19% (CI -28.0%,-10.2%)	p<0.001 **
Parent	37 (7%)	40 (26%)	-18% (CI -25.8%,-10.6%)	p<0.001 **
Other family member	40 (8%)	40 (26%)	-18% (CI -25.2%,-10.0%)	p<0.001 **
Friend	21 (4%)	27 (17%)	-13% (CI -19.6%,-6.5%)	p<0.001 **
Neighbour	4 (1%)	8 (5%)	-5% (CI -8.2%,-0.4%)	p<0.001 **
Paid support person or carer	5 (1%)	9 (6%)	-5% (CI -8.9%,-0.6%)	p<0.001 **
Volunteer support person or carer	1 (1%)	0 (0%)	0% (CI -0.4%,0.8%)	p=1.000 ns
Nobody available	34 (7%)	6 (4%)	3% (CI -1.2%,7.0%)	p=0.256 ns
I don't have a child requiring care	274 (54%)	78 (50%)	4% (CI -5.0%,13.7%)	p=0.387 ns

Table S5 Facilitators

Visits to my doctor would be easier if:	Autistic n (%)	Control n (%)	Difference (95% Confidence Interval)	p value
I could book an appointment online	339 (67%)	102 (65%)	2% (CI -7.0%,10.8%)	p=0.732 ns
I could email in advance with a description of the issue I need to discuss	316 (62%)	35 (22%)	40% (CI 31.9%,48.2%)	p<0.001 **
I could wait in a quiet place or outside until it was my turn	284 (56%)	13 (8%)	48% (CI 41.2%,54.3%)	p<0.001 **
I could book the first or last appointment of the day	210 (41%)	38 (24%)	17% (CI 8.8%,25.6%)	p<0.001 **
I could book an appointment by text	209 (41%)	44 (28%)	13% (CI 4.6%,21.8%)	p=0.004 **
There was a sensory box available in the waiting room	80 (16%)	4 (3%)	13% (CI 8.8%,17.7%)	p<0.001 **
None of the above	16 (3%)	34 (22%)	-19% (CI -25.5%,-11.5%)	p<0.001 **

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Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study.

Barriers to healthcare for autistic adults

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Abstract

Objectives:
Autistic people experience poor physical and mental health along with reduced life expectancy compared to non-autistic people. Our aim was to identify self-reported barriers to primary care access by autistic adults compared to non-autistic adults and to link these barriers to self-reported adverse health consequences.

Design:
Following consultation with the autistic community at an autistic conference, *Autscape*, we developed a self-report survey which we administered online through social media platforms.

Setting:
The 52-item, international, online survey.

Participants:
507 autistic adults and 157 non-autistic adults.

Primary and secondary outcome measures:
Self-reported barriers to accessing healthcare and associated adverse health outcomes.

Results:
Eighty percent of autistic adults and 37% of non-autistic respondents reported difficulty visiting a General Practitioner (GP). The highest-rated barriers by autistic adults were deciding if symptoms warrant a GP visit (72%), difficulty making appointments by telephone (62%), not feeling understood (56%), difficulty communicating with their doctor (53%) and the waiting room environment (51%). Autistic adults reported a preference for online or text based appointment booking, facility to email in advance the reason for consultation, the first or last clinic appointment and a quiet place to wait. Self-reported adverse health outcomes experienced by autistic adults were associated with barriers to accessing healthcare. Adverse outcomes included untreated physical and mental health conditions, not attending specialist referral or screening programmes, requiring more extensive treatment or surgery due to late presentations, and untreated potentially life threatening conditions. There were no significant differences in difficulty attending, barriers experienced or adverse outcomes between formally diagnosed and self-identified autistic respondents.

Conclusions*:*
Reduction of healthcare inequalities for autistic people requires that healthcare providers understand autistic perspectives, communication needs and sensory sensitivities. Adjustments for autism specific needs are as necessary as ramps for wheelchair users.

Strengths and limitations of this study

Our study arose from a community-identified need to develop autism awareness training for healthcare providers and benefited from an autistic-led research team including autistic medical doctors, using participatory methods.

To date, this large cross-sectional study is the first to explore the associations between barriers to accessing healthcare and self-reported adverse health outcomes for autistic adults.

As we used a convenience sample and self-report survey, generalisability of the data may be limited.

As the initial pilot questionnaire was undertaken in the United Kingdom, we did not include issues specific to other healthcare systems, such as cost or insurance, in this study.

Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study.

Introduction

Autism is a common neurodevelopmental condition affecting 1-2% of the population.[1] While autism is lifelong and heterogeneous in presentation, most autistic people are adult, do not have intellectual disability and are likely to be undiagnosed.[2] Doctors may underestimate the number of autistic patients under their care.[3,4] Autistic adults have poor physical and mental health compared to the general population.[5] Most medical conditions are more prevalent in the autistic population,[6,7] including diabetes, hypertension and obesity.[8] Autistic people experience premature mortality.[9,10,11] Life expectancy is potentially reduced by 16-30 years, with increased mortality across almost all diagnostic categories[9]. In-hospital mortality is also increased.[12] Autistic people are three times more likely to use emergency departments, to require inpatient admission, and to die after attending emergency care.[13]

Alongside increased health needs, autistic people report a greater likelihood that these needs are unmet.[14] Pervasive, multifactorial barriers to healthcare access are experienced.[15] Some are shared by other disabled people, but autistic patients experience additional autism-specific barriers.[16] Patient-provider communication, sensory sensitivities, executive functioning/planning difficulties, and prior negative experiences with healthcare providers are important barriers.[17,18]

In response to primary legislation[19] and statutory guidance,[20] the Royal College of General Practitioners (RCGP) developed an Autism Patient Charter.[21] This recommended: staff awareness and training; autism friendly environment; reasonable adjustments following disclosure or clinical suspicion of autism; patient-tailored communications; and behaviour-sensitive accommodations.[21] Despite efforts to champion autism, proposals to formalise autism training,[18,22] and specific awareness-raising interventions,[21] almost 40% of general practitioners (GPs) report no formal training in autism.[22] They also report limited confidence in managing autistic patients.[22] Greater autism awareness exists where GPs have personal knowledge of autism, either through a relative or friend on the autistic spectrum, or because they themselves are autistic.[22] Communication skills training for health care providers may be the most pressing need.[4] GPs[22] and hospital specialists[3] report difficulties communicating with autistic patients. Only 25% of primary healthcare providers reported high confidence in communicating with autistic adult patients, or identifying and making necessary accommodations.[4]

This study primarily aimed to identify self-reported barriers to accessing primary health care faced by autistic adults with a focus on autism-specific communication, sensory issues and procedural considerations. Secondary aims included capturing self-reported adverse health outcomes and the associations between these and reported healthcare access barriers, adding a narrative frame to the existing evidence base around health disparities. This is to our knowledge the largest study of primary healthcare access barriers to date and benefits from a high degree of participatory design by the autistic community.

Methods

Ethical approval

We obtained ethical approval from SJH/TUH Research Ethics Committee, Tallaght University Hospital, Dublin.

Conception and design

Here, we present part of a larger cross-sectional study. This work was inspired by a quality improvement project designed to inform autism training for local healthcare providers as part of an "Autism Friendly Town" initiative by AsIAm, Ireland's National Autism Charity.[23,24] In 2018, MD attended *Autscape*,[25] an annual conference by and for autistic people. Participants of all ages are welcome at *Autscape*, including those who are non-speaking, have high support needs or require full-time care, although the majority of attendees typically have low to moderate support needs. Whilst there, MD distributed a qualitative questionnaire entitled "What do you wish your GP knew about autism?" MD reviewed the 75 responses and grouped these under broad themes. That project formed the inspiration and basis for the study reported in this paper. Using the data gathered at *Autscape*, MD developed an online survey to investigate barriers to primary healthcare in a larger sample of autistic adults, compared with a non-autistic adult comparison group (see Supplement 1). Nine autistic adults assisted with refining the survey. The resulting survey contained a mix of quantitative questions and free comment boxes. Quantitative questions included yes-no responses, single- and multiple-item selections from a list, and Likert scales. We asked about specific barriers encountered accessing healthcare, reasons for delaying or avoiding a visit, and difficulties booking, planning or waiting for a GP visit. We explored the challenges during a consultation, including

communication, sensory and organisation issues as well as available social supports. We also explored the impact of such barriers including self-reported consequences of failure to access healthcare and the reasonable adjustments to standard care which facilitate access. We used Google Forms to host the survey.

Piloting and refinement

We piloted the survey in 2018. Preliminary analysis revealed a recurring theme of total non-engagement with healthcare providers, despite expressed healthcare needs. Consequently, we altered the survey to add response options applicable to non-attenders. Our research team, comprising autistic and non-autistic GPs, experienced academics, and other autistic individuals, adapted and refined the survey into its final 52-item form.

Sampling, recruitment and data collection

Autistic adults were recruited using a convenience sampling approach, through Twitter, Facebook and the AsIAm website. We recruited non-autistic controls (without autistic children) through personal and professional contacts of research team members, local area groups and parenting groups on social media. Recruitment took place in August 2019. We provided participant information, with informed consent implied through subsequent completion of the questionnaire. We asked respondents, particularly those who were parents, to respond specifically about seeking healthcare for themselves. For those identifying as autistic, we asked if they were formally diagnosed or self-identified.

Data analysis

We used the statistical package 'R' to assess significance of between-group associations using a test of proportions and a Wilcoxon-Mann-Whitney U test. Participants who skipped questions were omitted from the analyses of those questions. We intend to present our qualitative results elsewhere.

Patient and Public involvement

Our study was conducted by an autistic-led research team including autistic medical doctors, using participatory methods. In addition, nine autistic individuals assisted with developing and refining the survey into its final form.

Results

Participants

We are reporting 664 responses to the online survey: 507 autistic adults and 157 non-autistic adults (Table 1). Unless otherwise specified, results relate to primary care.

Table 1. Participant Data

	Autistic	Non-autistic
Participants (n)	507	157
Age		
Median (Range)	38 (17 - 73)	38 (18 - 70)
Gender		
Male	99 (20%)	16 (10%)
Female	311 (62%)	132 (85%)
Non-binary	83 (17%)	7 (5%)
Prefer not to say	9 (2%)	1 (1%)

Location		
UK	330 (65%)	67 (43%)
Ireland	77 (15%)	63 (40%)
North America	44 (9%)	20 (13%)
Other	56 (11%)	7 (4%)
Formal diagnosis of autism	77%	
By psychiatrist	25%	
By clinical psychologist	48%	
By multidisciplinary team	26%	
Age at diagnosis		
Median (Range)	33 (2 - 67)	

Barriers to access

The most common reason for a GP visit was a physical condition or illness in both groups (86% vs 92%, n.s.). Autistic individuals were more likely to attend for mental health difficulties (61% vs 27%, difference 34%, 95%CI[25.2%,42.3%], p<0.001). Twenty-two percent of the autistic respondents usually attended for issues directly related to autism. Compared to 37% of non-autistic respondents, 80% of autistic respondents reported difficulty visiting a GP when needed (difference 43%, 95%CI[34.4%,51.9%], p<0.001). While difficulty deciding if symptoms warrant a visit was a barrier for both groups (72% vs 65%, n.s.), the most notable difference related to difficulties using the telephone to book an appointment (62% vs 16%). Not feeling understood was a reason to avoid or delay for 56% of autistic respondents compared to 13% of non-autistic respondents. Difficulty communicating with the doctor during the appointment was a barrier for 53% of the autistic group but only 6% of non-autistic respondents. See Supplementary Table 1 for specific barriers in order of frequency.

Communication

Alongside difficulty using the telephone, not feeling understood and difficulty communicating with the doctor, autistic respondents reported difficulty communicating with reception staff more often than non-autistic respondents (46% vs 8%, difference 38%, 95%CI[31.5%,44.6%], p<0.001). Fifty nine percent of autistic respondents reported difficulty communicating during a consultation "all the time" or "frequently" compared to 12% of non-autistic respondents (p<0.001). Seventy eight percent of autistic adults reported that "anxiety makes it harder to communicate."

Autistic respondents reported avoiding the telephone (78%), voicemail (61%) and face-to-face verbal communication (30%). Forty one percent reported that it is "easier for me to communicate in writing" (Table 2).

Table 2 Communication Barriers

Reasons to avoid or delay GP visit (Communication)				
	Autistic n (%)	Non-autistic n (%)	Difference (95% Confidence Interval)	p value
Difficulty using the telephone to book an appointment	314 (62%)	25 (16%)	46% (CI 38.5%,53.5%)	p<0.001
Not feeling understood	283 (56%)	21 (13%)	42% (CI 35.2%,49.7%)	p<0.001
Difficulty communicating with the doctor during the appointment	269 (53%)	10 (6%)	47% (CI 40.5%,52.9%)	p<0.001
Difficulty communicating with the reception staff	235 (46%)	13 (8%)	38% (CI 31.5%,44.6%)	p<0.001
Communication preferences				
Telephone generally avoided where possible	395 (78%)	59 (38%)	40% (CI 31.5%,49.1%)	p<0.001
Voicemail generally avoided where possible	311 (61%)	61 (39%)	23% (CI 13.3%,31.6%)	p<0.001
Verbal, face-to-face communication generally avoided where possible	152 (30%)	12 (8%)	22% (CI 16.2%,28.5%)	p<0.001

It is easier for me to communicate in writing	208 (41%)	13 (8%)	33% (CI 26.3%,39.2%)	p<0.001
Communication challenges				
Anxiety makes it harder to communicate	395 (78%)	42 (23%)	51% (CI 42.9%,59.4%)	p<0.001
Sensory issues make communication more difficult	156 (31%)	2 (1%)	30% (CI 24.7%,34.3%)	p<0.001
I need extra time to process what is being said	286 (56%)	12 (8%)	49% (CI 42.4%,55.2%)	p<0.001
I can't describe my pain or symptoms accurately	272 (54%)	36 (23%)	31% (CI 22.4%,39.0%)	p<0.001
Verbal communication is difficult	234 (46%)	11 (7%)	39% (CI 32.8%,45.5%)	p<0.001
I express emotions differently e.g. I can appear angry when I am afraid or in pain	227 (45%)	6 (4%)	41% (CI 35.3%,46.6%)	p<0.001
I have difficulty prioritising when describing medical symptoms	333 (66%)	34 (22%)	44% (CI 36.0%,52.1%)	p<0.001
I need to give the whole story and not leave anything out	332 (66%)	18 (12%)	54% (CI 47.1%,60.9%)	p<0.001
None of the above (Communication)	11 (2%)	58 (37%)	-35% (CI -42.8%,-26.7%)	p<0.001

Sensory processing

The waiting room environment was a barrier for 51% of autistic respondents, but only 8% of non-autistic respondents. Specific sensory barriers are detailed in Table 3. Sensory issues made communication more difficult for 31% of the autistic group (See Table 2). Only 10% of autistic respondents marked "none of the above" to sensory questions compared to 71% of non-autistic respondents.

Table 3: Sensory Barriers

Reasons to avoid or delay GP visit (Sensory)	**Autistic n (%)**	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
The waiting room environment	256 (51%)	12 (8%)	42.8% (CI 36.4%,49.3%)	p<0.001

Specific sensory challenges	Autistic n (%)	Non-autistic n (%)	Difference (95% Confidence Interval)	p value
Noise in the waiting room from other patients	319 (63%)	19 (12%)	51% (CI 43.8%,57.8%)	p<0.001
Crowded waiting area	299 (59%)	22 (14%)	45% (CI 37.6%,52.3%)	p<0.001
Bright or fluorescent lights	268 (53%)	14 (9%)	44% (CI 37.3%,50.6%)	p<0.001
Uncomfortable furniture	195 (39%)	11 (7%)	32% (CI 25.2%,37.7%)	p<0.001
Unexpected touch	193 (38%)	9 (6%)	32% (CI 26.3%,38.3%)	p<0.001
Music playing in the waiting room	172 (34%)	9 (6%)	28% (CI 22.3%,34.1%)	p<0.001
Smells in the waiting room	171 (34%)	8 (5%)	29% (CI 22.9%,34.4%)	p<0.001
Touch during examination	160 (32%)	11 (7%)	25% (CI 18.5%,30.7%)	p<0.001
Noise from the reception desk	140 (28%)	4 (3%)	25% (CI 20.0%,30.1%)	p<0.001
Smells in the doctor's office	104 (21%)	6 (4%)	17% (CI 11.7%,21.7%)	p<0.001
None of the above (Sensory)	51 (10%)	112 (71%)	-61% (CI -69.2%,-53.3%)	p<0.001

Perceived Stigma

Only 3% of autistic respondents stated they did not feel anxious going to the doctor, compared to 33% of non-autistic respondents (difference 30%, 95%CI[-37.7%,-21.8%] p<0.001). Autistic respondents reported being "concerned I won't be taken seriously when I describe my symptoms" (67%); worried about "wasting the doctor's time" (66%) and "being considered a hypochondriac" (65%). They also reported difficulty "asking for help" (63%) and "discussing mental health" (59%). Autistic respondents reported that unusual behaviour or stimming elicited negative reactions from other patients (15%) reception staff (9%) or medical staff (7%) (Supplementary Table 2).

Planning and Organising

Autistic respondents reported difficulties with summarising when describing medical problems, with 66% noting the "need to give the whole story and not leave anything out" compared to 12% of non-autistic respondents (difference 54%, 95%CI[47.1%,60.9%], p<0.001). Autistic respondents reported difficulties with organisation and planning for healthcare, including difficulties "making an appointment in advance" (59%), "prioritising my health issues" (58%) and "making changes to my lifestyle or habits" (56%). Forty five percent reported forgetting a medical appointment and 30% had attended on the wrong day. (Supplementary Table 3).

Predictability and control

Autistic respondents reported more difficulty with uncertainty than non-autistic respondents. Particular difficulties included not knowing the wait duration (70% vs 30%, difference 40%, 95%CI[31.5%,48.7%], p<0.001), what would happen during the consultation (63% vs 16%, difference 47%, 95%CI[39.7%,54.7%], p<0.001), which doctor they would see (58% vs 24%, difference 33%, 95%CI[25.0%,41.8%], p<0.001) and the consultation length (40% vs 8%, difference 32%, 95%CI[25.6%,38.4%] p<0.001).

Support needs

Autistic adults reported physical mobility needs (16%), and unmet support needs in primary care e.g. "needing a support person to come with me" (21%). This extended to secondary

care: 17% had no one to support unexpected hospital admission, collection from hospital (20%), or home care following discharge (26%). (Supplementary Table 4).

Adverse consequences

Autistic respondents reported adverse consequences more frequently than non-autistic respondents, including untreated mental (69%) and physical (63%) health conditions. Notably 60% were told they "should have seen a doctor sooner" and 47% "did not attend referral to a specialist". Thirty-six percent "required more extensive treatment or surgery" and 34% did not access treatment for a "potentially serious or life threatening condition". Additionally, they were less likely to "attend on schedule for screening programmes" than the non-autistic respondents (39% vs 21%, difference 18%, 95%CI[9.8%,26.2%], p<0.001) (Figure 1).

[FIGURE 1 GOES HERE]

Compared to autistic respondents who had no difficulty visiting a doctor, those who experienced difficulty (80%) reported more untreated mental and physical health conditions (p<0.001). They were also more likely to not attend specialist referral (p<0.001), to need more extensive treatment (p=0.009), to experience untreated life-threatening conditions (p=0.006) and to not attend screening (p=0.028) (Figure 2). Four percent of autistic respondents reported no access to primary healthcare and did not attend any doctor at all. This group differed from the non-autistic respondents who reported no access to primary healthcare (5%) in two areas: all had difficulty visiting the doctor when needed, compared to 50% of non-attending non-autistic respondents (p=0.002); and 95% of autistic non-attenders had experienced at least one delayed treatment outcome, compared to 43% of non-

attending, non-autistic respondents (p=0.01). There were no significant differences in difficulty attending, barriers experienced or adverse outcomes between formally diagnosed and self-identified autistic respondents.

[FIGURE 2 GOES HERE]

Facilitators

While most respondents (67% vs 65%) reported booking an appointment online would facilitate access, autistic patients selected a need to "email my doctor in advance with a description of the issue I need to discuss" (62%), "wait in a quiet place or outside until my turn" (56%), and "book an appointment by text" (41%). Some autistic individuals would benefit if they "could book the first or last appointment" (41%) or had a "sensory box available in the waiting room" (16%) (Supplementary Table 5).

Despite the outlined difficulties of visiting their doctor, autistic individuals felt their relationship with their GP was "very important" or "important" significantly more than non-autistic respondents (70% vs. 56%, p=0.001), but only 33% of autistic respondents reported a good relationship with their doctor (p<0.001). Only 62% of autistic individuals reported that their doctor knew they were autistic. Twenty two percent were unsure whereas 16% hadn't disclosed their diagnosis. Autistic respondents appreciated GPs who ask direct questions, give clear explanations, are honest about not understanding autism but know that autism isn't a mental illness.

Associations between barriers and outcomes for autistic respondents

Table 4: Barriers and Outcomes Associations for Autistic Respondents

	Untreated mental health condition	Untreated physical health condition	Specialist referral missed	Told they should have presented sooner	More extensive treatment or surgery required	Serious or life threatening condition
Difficulty using the telephone to book an appointment	**p<0.001**	**p<0.001**	**p=0.036**	**p=0.015**	n.s.	**p=0.007**
Difficulty with advance planning	**p=0.020**	**p=0.032**	**p<0.001**	**p=0.030**	n.s.	n.s.
Difficulty communicating with reception staff	**p<0.001**	**p<0.001**	**p=0.008**	**p<0.001**	**p=0.041**	**p=0.004**
Difficulty communicating with the doctor during the appointment	**p<0.001**	**p<0.001**	**p<0.001**	**p=0.003**	**p=0.003**	**p=0.002**
The waiting room environment	**p=0.007**	**p<0.001**	n.s.	**p=0.010**	**p<0.001**	n.s
Inability to see a known or preferred doctor	**p<0.001**	**p=0.003**	n.s.	**p=0.027**	n.s.	n.s
Waiting to see the doctor is too difficult	**p=0.018**	**p=0.001**	n.s.	n.s.	**p=0.026**	n.s.
Not feeling understood	**p<0.001**	**p<0.001**	**p<0.001**	n.s.	n.s.	**p=0.026**
Needing a support person to come with me	n.s.	**p=0.002**	**p=0.004**	n.s.	**p=0.009**	**p=0.002**

Table 4 outlines associations between reported barriers and outcomes for autistic respondents. There were no significant associations between any adverse outcomes and difficulty deciding if symptoms warrant a GP visit, not having an online booking system, having a confusing online booking system, having a long wait to get an appointment, or having enough time to visit a doctor. In contrast, difficulty communicating with reception staff and difficulty communicating with the doctor during appointments were both significantly associated with all adverse outcomes.

Difficulty using the telephone to book an appointment was significantly associated with all adverse outcomes apart from having to undergo more extensive treatment or surgery than if they had attended sooner. Challenges with the waiting room environment were significantly associated with all adverse outcomes apart from missing specialist referrals and having a potentially serious or life threatening condition for which they did not access treatment. Difficulty planning an appointment in advance was significantly associated with all adverse outcomes apart from having a potentially serious or life threatening condition for which they did not access treatment, and having to undergo more extensive treatment or surgery than if they had attended sooner. Needing a support person to attend appointments was significantly associated with all adverse outcomes apart from having had a mental health condition remain untreated due to difficulties accessing healthcare and being told they should have presented sooner. Not feeling understood was significantly associated with all adverse outcomes apart from being told they should have presented sooner and having to undergo more extensive treatment or surgery than if they had attended sooner. Needing a support

person to attend with them was significantly associated with all adverse outcomes apart from having untreated mental health conditions and being told they should have presented sooner.

The inability to see a known or preferred doctor was significantly associated with having both untreated mental and physical health conditions. It was also significantly associated with being told they should have presented sooner. Finding waiting to see a doctor too difficult was significantly associated with having both untreated mental and physical health conditions. It was also significantly associated with having to undergo more extensive treatment or surgery than if they had attended sooner.

Reporting no barriers to access healthcare had no significant associations with any of the adverse outcomes.

Discussion

Our study describes the results of a survey of autistic adults and compares their experiences with non-autistic adults. It highlights barriers faced by autistic people accessing and engaging with primary healthcare. In our study these included greater difficulties deciding when to seek care, reluctance to bother their GP, difficulties planning appointments and greater communication difficulties – with particular emphasis on telephone use. Communication was also impaired by anxiety and sensory issues. We linked those barriers to self-reported adverse outcomes. Our data indicated that autistic people may present for healthcare later in the natural course of an illness. Autistic participants reported reduced attendance for screening,

late presentations, missed opportunities for early detection and more extensive therapy being required. They also delayed or avoided healthcare because they didn't feel understood by their doctors. Furthermore, a substantial minority of autistic adults did not disclose their autism diagnosis which may impede identification of their autism-specific needs. These barriers may have real consequences, as evidenced in reduced life expectancy, and higher levels of physical and mental health conditions amongst autistic people.

Comparison with existing literature

This study confirms the findings of Nicolaidis,[14] Raymaker[16] and several recent reviews[15,17,26], which all identified three groups of barriers: (1) patient-level factors; (2) provider-level factors; and (3) system-level factors. Our study stratifies individual barriers from the perspective of autistic individuals. We couple these barriers to self-reported adverse consequences, highlighting factors which may lead to excess morbidity and mortality in the autistic population.

Strengths and limitations

Our study arose from a community-identified need to develop autism awareness training for healthcare providers. It benefited from an autistic-led research team including autistic doctors, using participatory methods. Our study provided a unique picture of autistic adults' healthcare experiences, including those entirely excluded from healthcare due to access barriers. In particular, we highlighted the difficulties with using the telephone which is a distilled, concentrated essence of verbal communication.

As we used a convenience sample and self-report survey, generalisability of the data may be limited. Respondents required the ability to complete the survey which excluded those with reduced ability to self-report. Whilst we did not set out to create a validated tool, our survey may have benefited from some validity and reliability testing. As the initial quality improvement questionnaire was undertaken in the United Kingdom, we did not include issues specific to other healthcare systems, such as cost or insurance. Our analyses did not account for potential confounding factors, such as ethnicity or socio-economic status. Female participants were over-represented in both groups which is not unusual for online surveys, but is interesting given the higher rate of autism diagnosis in males. Whilst we noted significant gender differences in relation to non-binary participants, these participants were almost all autistic and we were therefore unable to attribute differences to gender identity or autism with any degree of certainty. Furthermore, as this is a cross-sectional study, whilst we can identify associations, we cannot confirm causality.

Implications for Research

Our study suggests a need for personalised approaches to healthcare access. A prior study investigated using a pre-visit telephone call to identify individualised accommodations.[27] Our data suggest that this could be problematic for autistic adults. The AASPIRE Healthcare Toolkit[28] includes a publicly available online program which generates a computerised report of required healthcare accommodations. Adaptation of such a toolkit in NHS General Practice should be considered and researched. Social care interventions and healthcare facilitators in general practice have shown benefit with a vulnerable population,[29] similar approaches could benefit an autistic population. The significant difficulties amongst the small number of autistic people not registered with any GP indicate a need for further research into this group.

Implications for Clinical Practice

Figure 3 outlines our proposed elements of an autism friendly practice. Such adjustments may minimise anxiety, manage sensory issues, and ensure mutual understanding – promoting clear, unambiguous communication. Autism friendly practices should employ a personalised approach, with a healthcare access needs assessment and, where possible, a specialist liaison nurse or facilitator.

[FIGURE 3 GOES HERE]

Implications for Policy

Given the identified barriers, the extension of annual health checks to autistic adults[30,31] and the recently announced Oliver McGowan Mandatory Training in Learning Disability and Autism[32] are welcome. These will likely bring important benefits provided they are informed by the autistic community and autistic healthcare providers. Autism registers in GP practice have been recommended.[33,34] The success of such initiatives will likely depend on greater awareness by medical practitioners of autistic culture and communication needs. Specific training for GPs during core training and continuing professional development may be beneficial. GPs with a special interest in autism should be facilitated to develop their skills, but management of general health needs and co-occurring conditions fall within the remit of every GP. Implementing existing autism legislation or development where lacking is required in order to reduce health inequities for autistic people.

Conclusions

Autistic people face barriers accessing the healthcare system, followed by difficulties interacting with healthcare providers, which may contribute to known healthcare disparities including increased morbidity and mortality. Our study has highlighted a variety of specific barriers to accessing primary healthcare for autistic adults, including use of the telephone to book appointments, not feeling understood, and difficulty communicating with doctors as well as sensory and organisational issues which impede healthcare access. We identified a variety of significant associations between self-reported barriers to healthcare access and adverse outcomes for autistic respondents. One of our most impactful findings was the lack of any significant differences between formally diagnosed and self-identified autistic respondents in difficulty attending a GP, barriers experienced, or self-reported adverse healthcare outcomes. Progress towards eliminating healthcare disparities for autistic people may be achieved by understanding the healthcare experiences and access barriers for this vulnerable patient group. These barriers represent not so much a failure to deliver or to avail of healthcare, but a lack of intersection between the communication patterns of autistic healthcare users and non-autistic providers. Reasonable accommodations are legally[35] and morally required. Adjustments for communication needs are as necessary for autistic people as ramps for wheelchair users.

Figure legends

Figure 1. Adverse Healthcare Outcomes
For all comparisons between autistic and non-autistic groups p<0.001.

Figure 2. Adverse outcomes according to difficulty attending a GP
**p<0.001 *p<0.05
Note y-axis = N

Figure 3. Autism Friendly General Practice

Author Contributions

Conception and design of study: M Doherty, S Neilson, J O'Sullivan, with contributions from those listed in acknowledgements.
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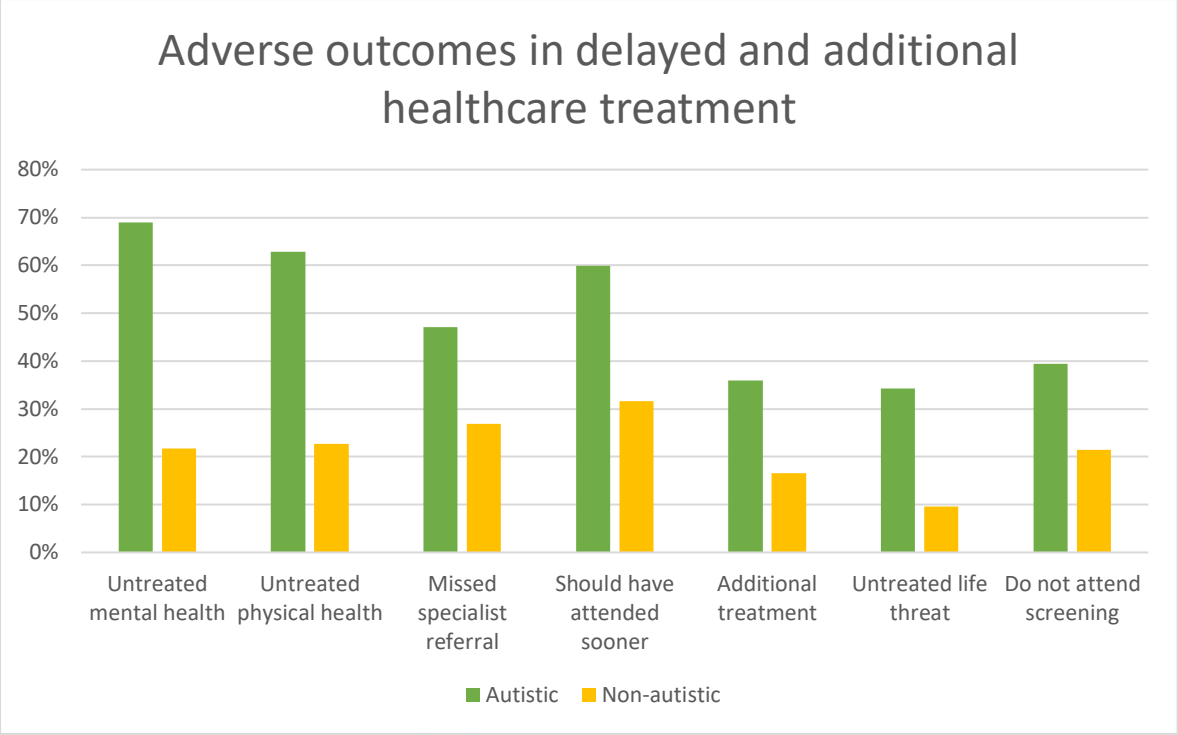


Figure 1. Adverse Healthcare Outcomes
For all comparisons between autistic and non-autistic groups $p<0.001$.

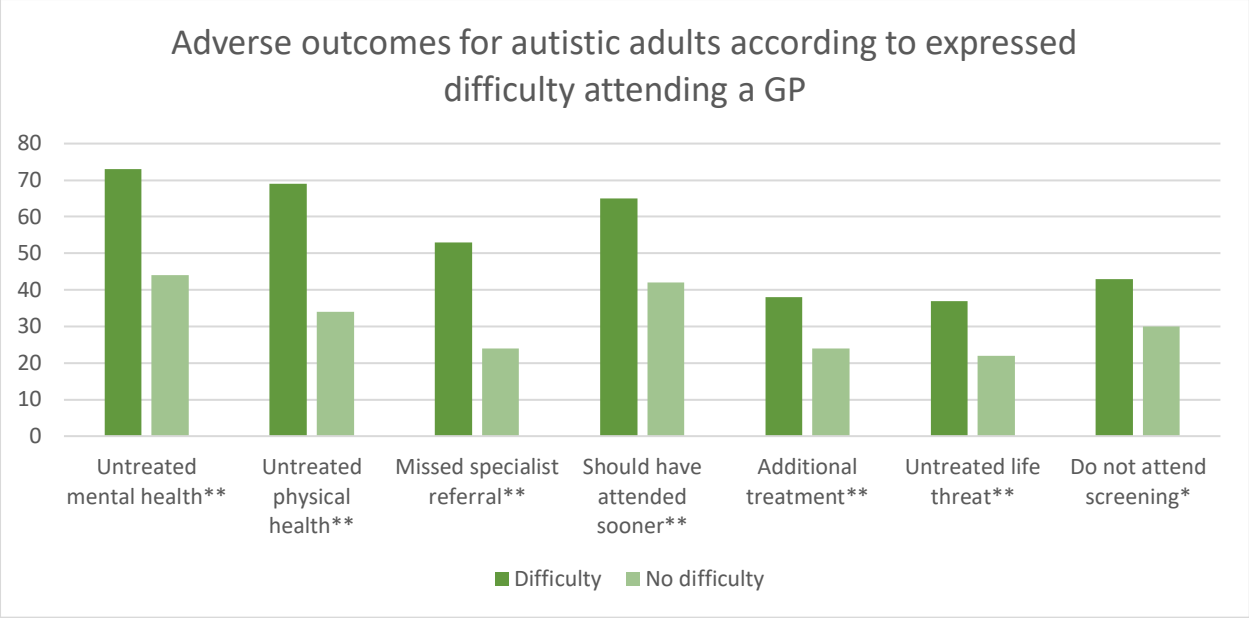
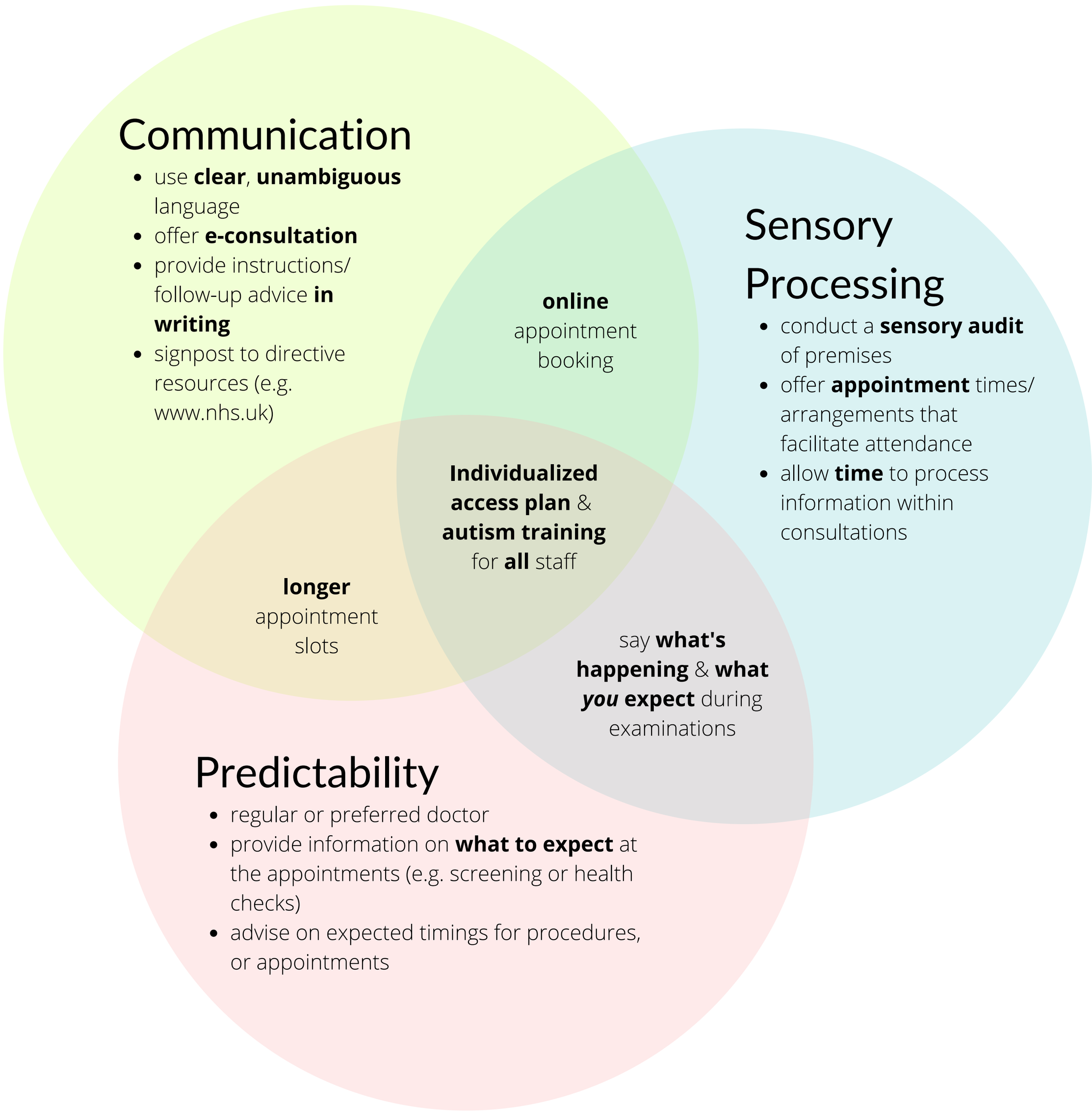


Figure 2. Adverse outcomes according to difficulty attending a GP
**p<0.001 *p<0.05
Note y-axis = N


Communication
use clear, unambiguous language
offer e-consultation
provide instructions/ follow-up advice in writing
signpost to directive resources (e.g. www.nhs.uk)
online appointment booking
Sensory Processing
conduct a sensory audit of premises
offer appointment times/ arrangements that facilitate attendance
allow time to process information within consultations
Individualized access plan & autism training for all staff
longer appointment slots
say what's happening & what you expect during examinations
Predictability
regular or preferred doctor
provide information on what to expect at the appointments (e.g. screening or health checks)
advise on expected timings for procedures, or appointments

Supplement 1

Barriers to accessing healthcare for autistic adults: online survey

1. Are you autistic?
Includes Autism, Autistic Spectrum Conditions, Asperger Syndrome, self-diagnosed or formally diagnosed.
☐ Yes
☐ No

2. Do you usually attend the same medical practice?
☐ Yes
☐ No
☐ I don't attend any medical practice

3. Do you usually see the same doctor?
☐ Yes
☐ No
☐ I don't attend any doctor

4. Do you have difficulty visiting your doctor when you need to?
☐ Yes
☐ No

5. Which of the following would cause you to delay or avoid seeing your doctor when you need to?
Please check ALL THAT APPLY
☐ Difficulty deciding if symptoms warrant a GP visit
☐ Difficulty using the telephone to book appointment
☐ No online booking system
☐ There is an online booking system but it's confusing
☐ Difficulty planning an appointment in advance
☐ Difficulty communicating with the reception staff
☐ Difficulty communicating with the doctor during the appointment
☐ The waiting room environment
☐ Inability to see a known or preferred doctor
☐ Long wait to get an appointment
☐ Waiting to see the doctor is too difficult
☐ Not feeling understood
☐ Not having enough time to visit the doctor
☐ Needing a support person to come with me
☐ Not having anyone to look after my child
☐ None of the above

6. Which of the following is the most difficult part of booking an appointment?
Please choose the <u>one</u> issue which is MOST DIFFICULT for you

- [ ] Using the telephone to book an appointment
- [ ] No online booking system
- [ ] There is an online booking system but it's confusing
- [ ] None of the above

7. Which of the following is the most difficult part of planning a visit?
Please choose the one issue which is MOST DIFFICULT for you

- [ ] Deciding if your symptoms warrant a GP visit
- [ ] Long wait to get an appointment
- [ ] Planning an appointment in advance
- [ ] Inability to see a known or preferred doctor
- [ ] Not having enough time to visit the doctor
- [ ] Arranging for someone to come with me
- [ ] If you are a parent, not having anyone to look after your child
- [ ] None of the above

8. Which of the following is most difficult during an appointment?
Please choose the one issue which is MOST DIFFICULT for you

- [ ] Communicating with the reception staff
- [ ] Communicating with the doctor during the appointment
- [ ] The waiting room environment
- [ ] Not feeling understood
- [ ] Waiting to see the doctor is difficult
- [ ] None of the above

9. Do you visit your doctor...
Check ALL THAT APPLY

- [ ] Alone, by choice
- [ ] Alone, but would prefer to have a support person
- [ ] With a parent, partner or support person
- [ ] With a parent, partner or support person but I would prefer to go alone
- [ ] With a support animal
- [ ] To support an autistic adult
- [ ] As a parent with my child

10. Why do you usually visit your doctor?
Check ALL THAT APPLY

- [ ] Physical condition or illness
- [ ] Mental health difficulties
- [ ] Issues directly related to autism
- [ ] Other

11. How much do you value your relationship with your GP?

- [ ] It is very important to me
- [ ] It is important to me
- [ ] It is neither important nor unimportant to me
- [ ] It is not very important to me

☐ It is not at all important to me

12. Do you have a good relationship with your doctor?
☐ Yes
☐ Sometimes
☐ No
☐ Not currently, but had good relationship with GP in past

13. Do you find it difficult to communicate during a consultation?
☐ All the time
☐ Frequently
☐ Sometimes
☐ Rarely
☐ Not at all

14. Which of the following communication issues cause you problems during a consultation?
Check ALL THAT APPLY
☐ Verbal communication is difficult
☐ Sensory issues make it harder to communicate
☐ Anxiety makes it harder to communicate
☐ It is easier for me to communicate in writing
☐ I'm scared of the receptionist
☐ I have difficulty asking for help
☐ I have difficulty prioritising my health issues
☐ I am concerned I might be labelled a hypochondriac or malingerer
☐ Vague or open ended questions are difficult
☐ I can't describe my pain or symptoms accurately
☐ I express emotions differently (e.g. I can appear to be angry when I am afraid or in pain)
☐ I need extra time to process what is being said
☐ I am concerned I won't be taken seriously when I describe my symptoms
☐ None of the above
☐ Other

15. Which communication issue causes you the MOST problems during a consultation?
Please choose the one issue which is MOST DIFFICULT for you
☐ Verbal communication is difficult
☐ Sensory issues make it harder to communicate
☐ Anxiety makes it harder to communicate
☐ It is easier for me to communicate in writing
☐ I'm scared of the receptionist
☐ I have difficulty asking for help
☐ I have difficulty prioritising my health issues
☐ I am concerned I might be labelled a hypochondriac or malingerer
☐ Vague or open ended questions are difficult
☐ I can't describe my pain or symptoms accurately
☐ I express emotions differently (e.g. I can appear to be angry when I am afraid or in pain)
☐ I need extra time to process what is being said

- [ ] I am concerned I won't be taken seriously when I describe my symptoms
- [ ] None of the above
- [ ] Other

16. Is stimming a problem for you at the doctors' office?
Check ALL THAT APPLY
- [ ] My unusual behaviours or stimming elicit negative reactions from other patients
- [ ] My unusual behaviours or stimming elicit negative reactions from reception staff
- [ ] My unusual behaviours or stimming elicit negative reactions from medical staff
- [ ] I feel comfortable stimming at the doctors' office
- [ ] I do not feel comfortable stimming at the doctors' office
- [ ] I don't feel a need to stim at the doctors' office
- [ ] I don't understand the term "stimming"

17. Do you experience any of the following?
Check ALL THAT APPLY
- [ ] I find it difficult to make appointments in advance
- [ ] I have turned up for a medical appointment on the wrong day
- [ ] I have forgotten to attend a medical appointment
- [ ] I find it difficult to prioritise when describing my medical problems
- [ ] I need to give the whole story and not leave anything out
- [ ] I have forgotten why I made the appointment
- [ ] I find waiting difficult
- [ ] It is difficult to arrange someone to come with me
- [ ] I need to write things down
- [ ] I have difficulty making decisions about my health
- [ ] Making changes to my lifestyle or habits is difficult for me
- [ ] None of the above

18. Do you experience sensory issues which make it difficult to visit your doctor?
Check ALL THAT APPLY
- [ ] Bright or fluorescent lights
- [ ] Noise in the waiting room from other patients
- [ ] Music playing in the waiting room
- [ ] Noise from the reception desk
- [ ] Smells in the waiting room
- [ ] Smells in the doctor's office
- [ ] Crowded waiting area
- [ ] Uncomfortable furniture
- [ ] Touch, such as during examination
- [ ] Unexpected touch
- [ ] None of the above
- [ ] Other

19. How would you describe your pain threshold?
- [ ] Very high
- [ ] High

☐ Neither particularly high nor low
☐ Low
☐ Very low
☐ I don't know

20. What communication methods do you use?
Check ALL THAT APPLY
☐ Verbal, face-to-face
☐ Verbal, telephone
☐ Voicemail
☐ Text messaging
☐ Online messaging
☐ Email
☐ Other online method
☐ Written
☐ Alternative communication device
☐ Sign language
☐ Other

21. What communication methods do you AVOID if possible?
Check ALL THAT APPLY
☐ Verbal, face-to-face
☐ Verbal, telephone
☐ Voicemail
☐ Text messaging
☐ Online messaging
☐ Other online method
☐ Email
☐ Written
☐ Alternative communication device
☐ Sign language
☐ Other

22. If your GP offered options for making an appointment, which would you be most likely to use?
☐ Verbal, face-to-face
☐ Verbal, telephone
☐ Voicemail
☐ Text messaging
☐ Email
☐ Online booking system
☐ Alternative communication device
☐ Other

23. My doctors are really good for me because they are...
Check ALL THAT APPLY
☐ Patient

- [ ] Good listeners
- [ ] Understanding
- [ ] Supportive
- [ ] Kind
- [ ] Friendly
- [ ] Efficient
- [ ] Familiar
- [ ] Not condescending
- [ ] Aware of my needs
- [ ] Honest about not understanding autism
- [ ] None of the above

24. My doctors are really good for me because they...
Check ALL THAT APPLY

- [ ] Ask direct questions
- [ ] Give clear explanations
- [ ] Accept written or email communication
- [ ] Use printed information and diagrams
- [ ] Value my opinion
- [ ] Accept my right to make decisions regarding my health
- [ ] Know that autism is not a mental health condition
- [ ] Do home visits
- [ ] Have reception staff who are trained regarding autism
- [ ] Remind me to make my next appointment before leaving
- [ ] None of the above

25. Do you find it difficult not knowing...
Check ALL THAT APPLY

- [ ] Which doctor you will see
- [ ] How long you will wait
- [ ] How long the consultation will last
- [ ] What will happen during the consultation
- [ ] None of the above

26. When going to the doctor, what causes you to feel anxious?
Check ALL THAT APPLY

- [ ] asking for help
- [ ] discussing mental health
- [ ] that there might be something wrong
- [ ] that I might be considered a hypochondriac
- [ ] that I might be wasting the doctor's time
- [ ] I don't feel anxious going to the doctor

27. Do you have mobility needs which make visiting your doctor difficult?

- [ ] Yes
- [ ] No

28. My doctor is knowledgeable about physical conditions:
- ☐ Strongly agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly disagree

29. My doctor is knowledgeable about mental health conditions:
- ☐ Strongly agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly disagree

30. My doctor is knowledgeable about autism:
- ☐ Strongly agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly disagree

31. Visits to my doctor would be easier if…
Check ALL THAT APPLY
- ☐ I could book an appointment online
- ☐ I could book an appointment by text
- ☐ I could book the first or last appointment of the day
- ☐ I could wait in a quiet place or outside until it was my turn
- ☐ I could email my doctor in advance with a description of the issue I need to discuss
- ☐ There was a sensory box available in the waiting room
- ☐ None of the above
- ☐ Other

32. Have you ever had a mental health condition remain untreated due to difficulties accessing healthcare?
- ☐ Yes
- ☐ No
- ☐ Possibly
- ☐ Other

33. Have you ever had a physical health condition remain untreated due to difficulties accessing healthcare?
- ☐ Yes
- ☐ No
- ☐ Possibly
- ☐ Other

34. Have you even been referred to a specialist but did not make an appointment or did not attend?
☐ Yes
☐ No

35. Have you ever been told you should have seen a doctor sooner?
☐ Yes
☐ No

36. Have you ever had to undergo more extensive treatment or surgery than if you had attended sooner?
☐ Yes
☐ No

37. Have you ever had a potentially serious or life threatening condition for which you did not access treatment?
☐ Yes
☐ No

38. If you answered yes to any of the last 6 questions, would you like to give more details?

39. Do you attend on schedule for screening programmes applicable to you?
Includes cervical screening, sexual health screening, breast check, colon screening etc.
☐ Yes
☐ No
☐ Sometimes

40. If you were suddenly admitted to hospital, who would be able to bring your personal belongings to you?
Check ALL THAT APPLY
☐ Spouse or partner
☐ Parent
☐ Other family member
☐ Friend
☐ Neighbour
☐ Paid support person or carer
☐ Volunteer support person or carer
☐ Nobody available
☐ Other

41. If you were admitted to hospital for a day case surgical procedure, who would be available to collect you afterwards?
Check ALL THAT APPLY
☐ Spouse or partner
☐ Parent
☐ Other family member
☐ Friend

- [ ] Neighbour
- [ ] Paid support person or carer
- [ ] Volunteer support person or carer
- [ ] Nobody available
- [ ] Other

42. If you needed assistance at home after an operation, who would be available to provide that care?
Check ALL THAT APPLY

- [ ] Spouse or partner
- [ ] Parent
- [ ] Other family member
- [ ] Friend
- [ ] Neighbour
- [ ] Paid support person or carer
- [ ] Volunteer support person or carer
- [ ] Nobody available
- [ ] Other

43. If you are a parent and you were unable to care for your child due to illness, who would be available to provide that care to your child?
Check ALL THAT APPLY

- [ ] Spouse or partner
- [ ] Parent
- [ ] Other family member
- [ ] Friend
- [ ] Neighbour
- [ ] Paid support person or carer
- [ ] Volunteer support person or carer
- [ ] Nobody available
- [ ] I don't have a child requiring care
- [ ] Other

44. Do you identify as autistic?
Includes Autism, Autistic Spectrum Conditions, Asperger Syndrome, self-diagnosed or formally diagnosed.

- [ ] Yes
- [ ] No
- [ ] Possibly

45. Do you have a formal diagnosis? *

- [ ] Yes
- [ ] No

46. If you have a formal diagnosis, was it provided by:

- [ ] Psychiatrist
- [ ] Clinical Psychologist

- [ ] Multidisciplinary Team
- [ ] Other

47. Does your doctor know you are autistic? *
- [ ] Yes
- [ ] No
- [ ] I don't know

48. What is your age?

49. What age were you when you were diagnosed?
If applicable

50. Which country do you live in?
- [ ] England
- [ ] Scotland
- [ ] Wales
- [ ] Northern Ireland
- [ ] Republic of Ireland
- [ ] United States
- [ ] Canada
- [ ] Other:

51. What is your gender?
- [ ] Male
- [ ] Female
- [ ] Non-binary
- [ ] Prefer not to say

52. Please give any further information or suggestions here.

Table S1 Access Barriers to Healthcare

Which of the following would cause you to delay or avoid seeing your doctor when you need to?

	Autistic n (%)	Non-autistic n (%)	Difference (95% Confidence Interval)	p value
Difficulty deciding if symptoms warrant a GP visit	366 (72%)	102 (65%)	7% (CI -1.6%,16.1%)	p=0.102 ns
Difficulty using the telephone to book appointment	314 (62%)	25 (16%)	46% (CI 38.5%,53.5%)	p<0.001
Not feeling understood	283 (56%)	21 (13%)	42% (CI 35.2%,49.7%)	p<0.001
Difficulty communicating with the doctor during the appointment	269 (53%)	10 (6%)	47% (CI 40.5, 52.9%)	p<0.001
The waiting room environment	256 (51%)	12 (8%)	43% (CI 36.4%,49.3%)	p<0.001
Long wait to get an appointment	251 (50%)	70 (45%)	5% (CI -4.4%,14.2%)	p=0.324 ns
Difficulty planning an appointment in advance	243 (48%)	51 (33%)	15% (CI 6.5%,24.4%)	p<0.001
Inability to see a known or preferred doctor	241 (48%)	35 (23%)	25% (CI 17.0%,33.5%)	p<0.001
Difficulty communicating with the reception staff	235 (46%)	13 (8%)	38% (CI 31.5%,44.6%)	p<0.001
Not having enough time to visit the doctor	174 (34%)	61 (39%)	-5% (CI -13.6%,4.6%)	p=0.346 ns
No online booking system	160 (32%)	35 (23%)	9% (CI 1.2%,17.3%)	p=0.033
Waiting to see the doctor is too difficult	114 (23%)	7 (5%)	18% (CI 12.7%,23.3%)	p<0.001
Needing a support person to come with me	106 (21%)	7 (5%)	16% (CI 11.2%,21.7%)	p<0.001
There is an online booking system but it's confusing	102 (20%)	9 (6%)	14% (CI 8.9%,19.8%)	p<0.001
Not having anyone to look after my child	66 (13%)	18 (12%)	2% (CI -4.6%,7.8%)	p=0.708 ns
None of the above	6 (1%)	17 (11%)	-10% (CI -15.0%,-4.3%)	p<0.001

Table S2 Perceived Stigma

Going to the doctor, I am anxious :	**Autistic n (%)**	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
I won't be taken seriously when I describe my symptoms	341 (67%)	54 (34%)	32.9% (CI 24.0%,41.8%)	p<0.001
I might be wasting the doctor's time	333 (66%)	53 (34%)	31.9% (CI 23.0%,40.8%)	p<0.001
I might be considered a hypochondriac	330 (65%)	42 (27%)	38.3% (CI 29.8%,46.8%)	p<0.001
about asking for help	318 (63%)	28 (18%)	44.9% (CI 37.2%,52.6%)	p<0.001
about discussing mental health	301 (59%)	37 (24%)	35.8% (CI 27.5%,44.1%)	p<0.001
that there might be something wrong	217 (43%)	55 (35%)	7.8% (CI -1.3%,16.8%)	p=0.102 ns
I don't feel anxious going to the doctor	17 (3%)	52 (33%)	-30% (CI -37.7%,-21.8%)	p<0.001

Is stimming* a problem for you at the doctors' office?	**Autistic n (%)**	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Unusual behaviours or stimming elicit negative reactions from other patients	74 (14.6%)	4 (2.5%)	12% (CI 7.7%,16.4%)	p<0.001
Unusual behaviours or stimming elicit negative reactions from reception staff	44 (8.7%)	1 (0.6%)	8% (CI 4.9%,11.2%)	p=0.001
Unusual behaviours or stimming elicit negative reactions from medical staff	37 (7.3%)	2 (1.3%)	6% (CI 2.7%,9.3%)	p=0.009
I feel comfortable with stimming at the doctors' office	101 (19.9%)	74 (47.1%)	-27% (CI -36.2%,-18.2%)	p<0.001
I do not feel comfortable with stimming at the doctors' office	4 (0.8%)	5 (3.2%)	-2% (CI -5.7%,0.9%)	p=0.061 ns
No need to stim at the doctors' office	133 (26.2%)	0 (0.0%)	26% (CI 22.0%,30.5%)	p<0.001
I don't understand the term "stimming"	29 (5.7%)	62 (39.5%)	-34% (CI -42.1%,-25.4%)	p<0.001

*Stimming refers to repetitive motor movements or vocalisations which are commonly used by autistic people as a self-regulatory mechanism.

Table S3 Planning and Organising

	Autistic n (%)	Non-autistic n (%)	Difference (95% Confidence Interval)	p value
I find it difficult to prioritise when describing my medical problems	333 (66%)	34 (22%)	44% (CI 36.0%,52.1%)	p<0.001
I need to give the whole story and not leave anything out	332 (66%)	18 (12%)	54% (CI 47.1%,60.9%)	p<0.001
I find it difficult to make appointments in advance	300 (59%)	45 (29%)	31% (CI 21.8%,39.2%)	p<0.001
Making changes to my lifestyle or habits is difficult for me	282 (56%)	36 (23%)	33% (CI 24.4%,41.0%)	p<0.001
I have forgotten to attend a medical appointment	230 (45%)	34 (22%)	24% (CI 15.5%,31.9%)	p<0.001
I need to write things down	227 (45%)	17 (11%)	34% (CI 27.0%,40.9%)	p<0.001
I find waiting difficult	221 (44%)	15 (10%)	34% (CI 27.3%,40.8%)	p<0.001
I have difficulty making decisions about my health	222 (44%)	20 (13%)	31% (CI 23.9%,38.2%)	p<0.001
I have turned up for a medical appointment on the wrong day	151 (30%)	16 (10%)	20% (CI 13.0%,26.2%)	p<0.001
It is difficult to arrange someone to come with me	103 (20%)	2 (1%)	19% (CI 14.7%,23.4%)	p<0.001
I have forgotten why I made the appointment	54 (11%)	1 (1%)	10% (CI 6.6%,13.4%)	p<0.001
None of the above	13 (3%)	64 (41%)	-38% (CI -46.4%,-30.0%)	p<0.001

Table S4 Support Needs

Do you visit your doctor:	**Autistic n (%)**	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Alone, by choice	306 (60%)	134 (85%)	-25% (CI -32.4%,-17.6%)	p<0.001
Alone, but would prefer to have a support person	165 (33%)	10 (6%)	26% (CI 20.2%,32.2%)	p<0.001
With a parent, partner or support person	137 (27%)	9 (6%)	21% (CI 15.6%,27.0%)	p<0.001
With a parent, partner or support person but I would prefer to go alone	12 (2%)	0 (0%)	2% (CI 0.6%,4.1%)	p=0.109 ns
With a support animal	5 (1%)	0 (0%)	1% (CI -0.3%,2.3%)	p=0.471 ns
To support an autistic adult	26 (5%)	0 (0%)	5% (CI 2.8%,7.5%)	p=0.008
As a parent to access healthcare for my child	78 (15%)	30 (19%)	-4% (CI -11.0%,3.6%)	p=0.327 ns
With my child, but I would prefer to go alone	6 (1%)	12 (8%)	-7% (CI -11.1%,-1.8%)	p<0.001

If you were suddenly admitted to hospital, who would be able to bring your personal belongings to you?

	Autistic n (%)	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Spouse or partner	234 (46%)	106 (68%)	-21% (CI -30.3%,-12.4%)	p<0.001
Parent	168 (33%)	70 (45%)	-11% (CI -20.7%,-2.2%)	p=0.012
Other family member	96 (19%)	72 (46%)	-27% (CI -35.8%,-18.0%)	p<0.001
Friend	118 (23%)	57 (36%)	-13% (CI -21.8%,-4.2%)	p=0.002
Neighbour	17 (3%)	14 (9%)	-6% CI -10.7%,-0.4%)	p=0.008
Paid support person or carer	15 (3%)	1 (1%)	2% (CI -0.0%,4.7%)	p=0.174 ns
Volunteer support person or carer	6 (1%)	0 (0%)	1% (CI -0.2%,2.5%)	p=0.375 ns
Nobody available	88 (17%)	5 (3%)	14% (CI 9.5%,18.9%)	p<0.001

If you were admitted to hospital for a day case surgical procedure, who would be available to collect you afterwards?

	Autistic n (%)	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Spouse or partner	208 (41%)	100 (64%)	-23% (CI -31.7%,-13.6%)	p<0.001

Parent	176 (35%)	73 (47%)	-12% (CI -21.0%,-2.5%)	p=0.010
Other family member	96 (19%)	75 (48%)	-29% (CI -37.8%,-19.9%)	p<0.001
Friend	116 (23%)	67 (43%)	-29% (CI -37.8%,-19.9%)	p<0.001
Neighbour	17 (3%)	8 (5%)	-2% (CI -5.9%,2.5%)	p=0.446 ns
Paid support person or carer	17 (3%)	0 (0%)	3% (CI 1.4%,5.3%)	p=0.042
Volunteer support person or carer	3 (1%)	0 (0%)	1% (CI -0.5%,1.7%)	p=0.776 ns
Nobody available	99 (20%)	3 (2%)	18% (CI 13.1%,22.1%)	p<0.001

If you needed assistance at home after an operation, who would be available to provide that care?

	Autistic n (%)	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Spouse or partner	219 (43%)	101 (64%)	-21% (CI -30.2%,-12.1%)	p<0.001
Parent	152 (30%)	74 (47%)	-17% (CI -26.3%,-8.0%)	p<0.001
Other family member	83 (16%)	61 (39%)	-23% (CI -31.2%,-13.8%)	p<0.001
Friend	74 (15%)	43 (27%)	-13% (CI -20.8%,-4.8%)	p<0.001
Neighbour	14 (3%)	8 (5%)	-2% (CI -6.5%,1.8%)	p=0.241 ns
Paid support person or carer	30 (6%)	3 (2%)	4% (CI 0.6%,7.4%)	p=0.071 ns
Volunteer support person or carer	4 (1%)	0 (0%)	1% (CI -0.4%,2.0%)	p=0.599 ns
Nobody available	131 (26%)	13 (8%)	18% (CI 11.4%,23.7%)	p<0.001

If you are a parent and you were unable to care for your child due to illness, who would be available to provide that care to your child?

	Autistic n (%)	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Spouse or partner	110 (22%)	64 (41%)	-19% (CI -28.0%,-10.2%)	p<0.001
Parent	37 (7%)	40 (26%)	-18% (CI -25.8%,-10.6%)	p<0.001
Other family member	40 (8%)	40 (26%)	-18% (CI -25.2%,-10.0%)	p<0.001
Friend	21 (4%)	27 (17%)	-13% (CI -19.6%,-6.5%)	p<0.001
Neighbour	4 (1%)	8 (5%)	-5% (CI -8.2%,-0.4%)	p<0.001

Paid support person or carer	5 (1%)	9 (6%)	-5% (CI -8.9%,-0.6%)	p<0.001
Volunteer support person or carer	1 (1%)	0 (0%)	0% (CI -0.4%,0.8%)	p=1.000 ns
Nobody available	34 (7%)	6 (4%)	3% (CI -1.2%,7.0%)	p=0.256 ns
I don't have a child requiring care	274 (54%)	78 (50%)	4% (CI -5.0%,13.7%)	p=0.387 ns

Table S5 Facilitators

Visits to my doctor would be easier if:	Autistic n (%)	Non-autistic n (%)	Difference (95% Confidence Interval)	p value
I could book an appointment online	339 (67%)	102 (65%)	2% (CI -7.0%,10.8%)	p=0.732 ns
I could email in advance with a description of the issue I need to discuss	316 (62%)	35 (22%)	40% (CI 31.9%,48.2%)	p<0.001
I could wait in a quiet place or outside until it was my turn	284 (56%)	13 (8%)	48% (CI 41.2%,54.3%)	p<0.001
I could book the first or last appointment of the day	210 (41%)	38 (24%)	17% (CI 8.8%,25.6%)	p<0.001
I could book an appointment by text	209 (41%)	44 (28%)	13% (CI 4.6%,21.8%)	p=0.004
There was a sensory box* available in the waiting room	80 (16%)	4 (3%)	13% (CI 8.8%,17.7%)	p<0.001
None of the above	16 (3%)	34 (22%)	-19% (CI -25.5%,-11.5%)	p<0.001

*A sensory box contains items to manage sensory stress, such as sunglasses, ear defenders or ear plugs, items providing tactile sensory input such as fidget tools and olfactory input such as scented items.

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Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study

Barriers to healthcare for autistic adults

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Abstract

Objectives:
Autistic people experience poor physical and mental health along with reduced life expectancy compared to non-autistic people. Our aim was to identify self-reported barriers to primary care access by autistic adults compared to non-autistic adults and to link these barriers to self-reported adverse health consequences.

Design:
Following consultation with the autistic community at an autistic conference, *Autscape*, we developed a self-report survey which we administered online through social media platforms.

Setting:
The 52-item, international, online survey.

Participants:
507 autistic adults and 157 non-autistic adults.

Primary and secondary outcome measures:
Self-reported barriers to accessing healthcare and associated adverse health outcomes.

Results:
Eighty percent of autistic adults and 37% of non-autistic respondents reported difficulty visiting a General Practitioner (GP). The highest-rated barriers by autistic adults were deciding if symptoms warrant a GP visit (72%), difficulty making appointments by telephone (62%), not feeling understood (56%), difficulty communicating with their doctor (53%) and the waiting room environment (51%). Autistic adults reported a preference for online or text based appointment booking, facility to email in advance the reason for consultation, the first or last clinic appointment and a quiet place to wait. Self-reported adverse health outcomes experienced by autistic adults were associated with barriers to accessing healthcare. Adverse outcomes included untreated physical and mental health conditions, not attending specialist referral or screening programmes, requiring more extensive treatment or surgery due to late presentations, and untreated potentially life threatening conditions. There were no significant differences in difficulty attending, barriers experienced or adverse outcomes between formally diagnosed and self-identified autistic respondents.

Conclusions*:*
Reduction of healthcare inequalities for autistic people requires that healthcare providers understand autistic perspectives, communication needs and sensory sensitivities. Adjustments for autism specific needs are as necessary as ramps for wheelchair users.

Strengths and limitations of this study

Our study arose from a community-identified need to develop autism awareness training for healthcare providers and benefited from an autistic-led research team including autistic medical doctors, using participatory methods.

To date, this large cross-sectional study is the first to explore the associations between barriers to accessing healthcare and self-reported adverse health outcomes for autistic adults.

As we used a convenience sample and self-report survey, generalisability of the data may be limited.

As the initial pilot questionnaire was undertaken in the United Kingdom, we did not include issues specific to other healthcare systems, such as cost or insurance, in this study.

Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study

Introduction

Autism is a common neurodevelopmental condition affecting 1-2% of the population.[1] While autism is lifelong and heterogeneous in presentation, most autistic people are adult, do not have intellectual disability and are likely to be undiagnosed.[2] Doctors may underestimate the number of autistic patients under their care.[3,4] Autistic adults have poor physical and mental health compared to the general population.[5] Most medical conditions are more prevalent in the autistic population,[6,7] including diabetes, hypertension and obesity.[8] Autistic people experience premature mortality.[9,10,11] Life expectancy is potentially reduced by 16-30 years, with increased mortality across almost all diagnostic categories.[9] In-hospital mortality is also increased.[12] Autistic people are over twice as likely to use emergency departments,[13] and to die after attending emergency care and three times as likely to require inpatient admission.[14]

Alongside increased health needs, autistic people report a greater likelihood that these needs are unmet.[13] Pervasive, multifactorial barriers to healthcare access are experienced.[15] Some are shared by other disabled people, but autistic patients experience additional autism-specific barriers.[16] Patient-provider communication, sensory sensitivities, executive functioning/planning difficulties, and prior negative experiences with healthcare providers are important barriers.[17,18]

In response to primary legislation[19] and statutory guidance,[20] the Royal College of General Practitioners (RCGP) developed an Autism Patient Charter.[21] This recommended: staff awareness and training; autism friendly environment; reasonable adjustments following disclosure or clinical suspicion of autism; patient-tailored communications; and behaviour-sensitive accommodations.[21] Despite efforts to champion autism, proposals to formalise autism training,[18,22] and specific awareness-raising interventions,[21] almost 40% of general practitioners (GPs) report no formal training in autism.[22] They also report limited confidence in managing autistic patients.[22] Greater autism awareness exists where GPs have personal knowledge of autism, either through a relative or friend on the autistic spectrum, or because they themselves are autistic.[22] Communication skills training for health care providers may be the most pressing need.[4] GPs[22] and hospital specialists[3] report difficulties communicating with autistic patients. Only 25% of primary healthcare providers reported high confidence in communicating with autistic adult patients, or identifying and making necessary accommodations.[4]

This study primarily aimed to identify self-reported barriers to accessing primary health care faced by autistic adults with a focus on autism-specific communication, sensory issues and procedural considerations. Secondary aims included capturing self-reported adverse health outcomes and the associations between these and reported healthcare access barriers, adding a narrative frame to the existing evidence base around health disparities. This is to our knowledge the largest study of primary healthcare access barriers to date and benefits from a high degree of participatory design by the autistic community.

Methods

Ethical approval

We obtained ethical approval from SJH/TUH Research Ethics Committee, Tallaght University Hospital, Dublin.

Conception and design

Here, we present part of a larger cross-sectional study. This work was inspired by a quality improvement project designed to inform autism training for local healthcare providers as part of an "Autism Friendly Town" initiative by AsIAm, Ireland's National Autism Charity.[23,24] In 2018, MD attended *Autscape*,[25] an annual conference by and for autistic people. Participants of all ages are welcome at *Autscape*, including those who are non-speaking, have high support needs or require full-time care, although the majority of attendees typically have low to moderate support needs. Whilst there, MD distributed a qualitative questionnaire entitled "What do you wish your GP knew about autism?" MD reviewed the 75 responses and grouped these under broad themes. That project formed the inspiration and basis for the study reported in this paper. Using the data gathered at *Autscape*, MD developed an online survey to investigate barriers to primary healthcare in a larger sample of autistic adults, compared with a non-autistic adult comparison group. Nine autistic adults assisted with refining the survey. The resulting survey contained a mix of quantitative questions and free comment boxes. Quantitative questions included yes-no responses, single- and multiple-item selections from a list, and Likert scales. We asked about specific barriers encountered accessing healthcare, reasons for delaying or avoiding a visit, and difficulties booking, planning or waiting for a GP visit. We explored the challenges during a consultation, including

communication, sensory and organisation issues as well as available social supports. We also explored the impact of such barriers including self-reported consequences of failure to access healthcare and the reasonable adjustments to standard care which facilitate access. We used Google Forms to host the survey.

Piloting and refinement

We piloted the survey in 2018. Preliminary analysis revealed a recurring theme of total non-engagement with healthcare providers, despite expressed healthcare needs. Consequently, we altered the survey to add response options applicable to non-attenders. Our research team, comprising autistic and non-autistic GPs, experienced academics, and other autistic individuals, adapted and refined the survey into its final 52-item form.

Sampling, recruitment and data collection

Autistic adults were recruited using a convenience sampling approach, through Twitter, Facebook and the AsIAm website. We recruited non-autistic controls (without autistic children) through personal and professional contacts of research team members, local area groups and parenting groups on social media. Recruitment took place in August 2019. We provided participant information, with informed consent implied through subsequent completion of the questionnaire. We asked respondents, particularly those who were parents, to respond specifically about seeking healthcare for themselves. For those identifying as autistic, we asked if they were formally diagnosed or self-identified.

Data analysis

We used the statistical package 'R' to assess significance of between-group associations using a test of proportions and a Wilcoxon-Mann-Whitney U test. Participants who skipped questions were omitted from the analyses of those questions. We intend to present our qualitative results elsewhere.

Patient and Public involvement

Our study was conducted by an autistic-led research team including autistic medical doctors, using participatory methods. In addition, nine autistic individuals assisted with developing and refining the survey into its final form.

Results

Participants

We are reporting 664 responses to the online survey: 507 autistic adults and 157 non-autistic adults (Table 1). Unless otherwise specified, results relate to primary care.

Table 1. Participant Data

	Autistic	Non-autistic
Participants (n)	507	157
Age		
Median (Range)	38 (17 - 73)	38 (18 - 70)
Gender		
Male	99 (20%)	16 (10%)
Female	311 (62%)	132 (85%)
Non-binary	83 (17%)	7 (5%)
Prefer not to say	9 (2%)	1 (1%)

Location		
UK	330 (65%)	67 (43%)
Ireland	77 (15%)	63 (40%)
North America	44 (9%)	20 (13%)
Other	56 (11%)	7 (4%)
Formal diagnosis of autism	77%	
By psychiatrist	25%	
By clinical psychologist	48%	
By multidisciplinary team	26%	
Age at diagnosis		
Median (Range)	33 (2 - 67)	

Barriers to access

The most common reason for a GP visit was a physical condition or illness in both groups (86% vs 92%, n.s.). Autistic individuals were more likely to attend for mental health difficulties (61% vs 27%, difference 34%, 95%CI[25.2%,42.3%], p<0.001). Twenty-two percent of the autistic respondents usually attended for issues directly related to autism. Compared to 37% of non-autistic respondents, 80% of autistic respondents reported difficulty visiting a GP when needed (difference 43%, 95%CI[34.4%,51.9%], p<0.001). While difficulty deciding if symptoms warrant a visit was a barrier for both groups (72% vs 65%, n.s.), the most notable difference related to difficulties using the telephone to book an appointment (62% vs 16%). Not feeling understood was a reason to avoid or delay for 56% of autistic respondents compared to 13% of non-autistic respondents. Difficulty communicating with the doctor during the appointment was a barrier for 53% of the autistic group but only 6% of non-autistic respondents. See Supplementary Table 1 for specific barriers in order of frequency.

Communication

Alongside difficulty using the telephone, not feeling understood and difficulty communicating with the doctor, autistic respondents reported difficulty communicating with reception staff more often than non-autistic respondents (46% vs 8%, difference 38%, 95%CI[31.5%,44.6%], p<0.001). Fifty nine percent of autistic respondents reported difficulty communicating during a consultation "all the time" or "frequently" compared to 12% of non-autistic respondents (p<0.001). Seventy eight percent of autistic adults reported that "anxiety makes it harder to communicate."

Autistic respondents reported avoiding the telephone (78%), voicemail (61%) and face-to-face verbal communication (30%). Forty one percent reported that it is "easier for me to communicate in writing" (Table 2).

Table 2 Communication Barriers

Reasons to avoid or delay GP visit (Communication)				
	Autistic n (%)	Non-autistic n (%)	Difference (95% Confidence Interval)	p value
Difficulty using the telephone to book an appointment	314 (62%)	25 (16%)	46% (CI 38.5%,53.5%)	p<0.001
Not feeling understood	283 (56%)	21 (13%)	42% (CI 35.2%,49.7%)	p<0.001
Difficulty communicating with the doctor during the appointment	269 (53%)	10 (6%)	47% (CI 40.5%,52.9%)	p<0.001
Difficulty communicating with the reception staff	235 (46%)	13 (8%)	38% (CI 31.5%,44.6%)	p<0.001
Communication preferences				
Telephone generally avoided where possible	395 (78%)	59 (38%)	40% (CI 31.5%,49.1%)	p<0.001
Voicemail generally avoided where possible	311 (61%)	61 (39%)	23% (CI 13.3%,31.6%)	p<0.001
Verbal, face-to-face communication generally avoided where possible	152 (30%)	12 (8%)	22% (CI 16.2%,28.5%)	p<0.001

It is easier for me to communicate in writing	208 (41%)	13 (8%)	33% (CI 26.3%,39.2%)	p<0.001
Communication challenges				
Anxiety makes it harder to communicate	395 (78%)	42 (23%)	51% (CI 42.9%,59.4%)	p<0.001
Sensory issues make communication more difficult	156 (31%)	2 (1%)	30% (CI 24.7%,34.3%)	p<0.001
I need extra time to process what is being said	286 (56%)	12 (8%)	49% (CI 42.4%,55.2%)	p<0.001
I can't describe my pain or symptoms accurately	272 (54%)	36 (23%)	31% (CI 22.4%,39.0%)	p<0.001
Verbal communication is difficult	234 (46%)	11 (7%)	39% (CI 32.8%,45.5%)	p<0.001
I express emotions differently e.g. I can appear angry when I am afraid or in pain	227 (45%)	6 (4%)	41% (CI 35.3%,46.6%)	p<0.001
I have difficulty prioritising when describing medical symptoms	333 (66%)	34 (22%)	44% (CI 36.0%,52.1%)	p<0.001
I need to give the whole story and not leave anything out	332 (66%)	18 (12%)	54% (CI 47.1%,60.9%)	p<0.001
None of the above (Communication)	11 (2%)	58 (37%)	-35% (CI -42.8%,-26.7%)	p<0.001

Sensory processing

The waiting room environment was a barrier for 51% of autistic respondents, but only 8% of non-autistic respondents. Specific sensory barriers are detailed in Table 3. Sensory issues made communication more difficult for 31% of the autistic group (See Table 2). Only 10% of autistic respondents marked "none of the above" to sensory questions compared to 71% of non-autistic respondents.

Table 3: Sensory Barriers

Reasons to avoid or delay GP visit (Sensory)	**Autistic n (%)**	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
The waiting room environment	256 (51%)	12 (8%)	42.8% (CI 36.4%,49.3%)	p<0.001

Specific sensory challenges	**Autistic n (%)**	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Noise in the waiting room from other patients	319 (63%)	19 (12%)	51% (CI 43.8%,57.8%)	p<0.001
Crowded waiting area	299 (59%)	22 (14%)	45% (CI 37.6%,52.3%)	p<0.001
Bright or fluorescent lights	268 (53%)	14 (9%)	44% (CI 37.3%,50.6%)	p<0.001
Uncomfortable furniture	195 (39%)	11 (7%)	32% (CI 25.2%,37.7%)	p<0.001
Unexpected touch	193 (38%)	9 (6%)	32% (CI 26.3%,38.3%)	p<0.001
Music playing in the waiting room	172 (34%)	9 (6%)	28% (CI 22.3%,34.1%)	p<0.001
Smells in the waiting room	171 (34%)	8 (5%)	29% (CI 22.9%,34.4%)	p<0.001
Touch during examination	160 (32%)	11 (7%)	25% (CI 18.5%,30.7%)	p<0.001
Noise from the reception desk	140 (28%)	4 (3%)	25% (CI 20.0%,30.1%)	p<0.001
Smells in the doctor's office	104 (21%)	6 (4%)	17% (CI 11.7%,21.7%)	p<0.001
None of the above (Sensory)	51 (10%)	112 (71%)	-61% (CI -69.2%,-53.3%)	p<0.001

Perceived Stigma

Only 3% of autistic respondents stated they did not feel anxious going to the doctor, compared to 33% of non-autistic respondents (difference 30%, 95%CI[-37.7%,-21.8%] p<0.001). Autistic respondents reported being "concerned I won't be taken seriously when I describe my symptoms" (67%); worried about "wasting the doctor's time" (66%) and "being considered a hypochondriac" (65%). They also reported difficulty "asking for help" (63%) and "discussing mental health" (59%). Autistic respondents reported that unusual behaviour or stimming elicited negative reactions from other patients (15%) reception staff (9%) or medical staff (7%) (Supplementary Table 2).

Planning and Organising

Autistic respondents reported difficulties with summarising when describing medical problems, with 66% noting the "need to give the whole story and not leave anything out" compared to 12% of non-autistic respondents (difference 54%, 95%CI[47.1%,60.9%], p<0.001). Autistic respondents reported difficulties with organisation and planning for healthcare, including difficulties "making an appointment in advance" (59%), "prioritising my health issues" (58%) and "making changes to my lifestyle or habits" (56%). Forty five percent reported forgetting a medical appointment and 30% had attended on the wrong day. (Supplementary Table 3).

Predictability and control

Autistic respondents reported more difficulty with uncertainty than non-autistic respondents. Particular difficulties included not knowing the wait duration (70% vs 30%, difference 40%, 95%CI[31.5%,48.7%], p<0.001), what would happen during the consultation (63% vs 16%, difference 47%, 95%CI[39.7%,54.7%], p<0.001), which doctor they would see (58% vs 24%, difference 33%, 95%CI[25.0%,41.8%], p<0.001) and the consultation length (40% vs 8%, difference 32%, 95%CI[25.6%,38.4%] p<0.001).

Support needs

Autistic adults reported physical mobility needs (16%), and unmet support needs in primary care e.g. "needing a support person to come with me" (21%). This extended to secondary

care: 17% had no one to support unexpected hospital admission, collection from hospital (20%), or home care following discharge (26%). (Supplementary Table 4).

Adverse consequences

Autistic respondents reported adverse consequences more frequently than non-autistic respondents, including untreated mental (69%) and physical (63%) health conditions. Notably 60% were told they "should have seen a doctor sooner" and 47% "did not attend referral to a specialist". Thirty-six percent "required more extensive treatment or surgery" and 34% did not access treatment for a "potentially serious or life threatening condition". Additionally, they were less likely to "attend on schedule for screening programmes" than the non-autistic respondents (39% vs 21%, difference 18%, 95%CI[9.8%,26.2%], p<0.001) (Figure 1).

[FIGURE 1 GOES HERE]

Compared to autistic respondents who had no difficulty visiting a doctor, those who experienced difficulty (80%) reported more untreated mental and physical health conditions (p<0.001). They were also more likely to not attend specialist referral (p<0.001), to need more extensive treatment (p=0.009), to experience untreated life-threatening conditions (p=0.006) and to not attend screening (p=0.028) (Figure 2). Four percent of autistic respondents reported no access to primary healthcare and did not attend any doctor at all. This group differed from the non-autistic respondents who reported no access to primary healthcare (5%) in two areas: all had difficulty visiting the doctor when needed, compared to 50% of non-attending non-autistic respondents (p=0.002); and 95% of autistic non-attenders had experienced at least one delayed treatment outcome, compared to 43% of non-

attending, non-autistic respondents (p=0.01). There were no significant differences in difficulty attending, barriers experienced or adverse outcomes between formally diagnosed and self-identified autistic respondents.

[FIGURE 2 GOES HERE]

Facilitators

While most respondents (67% vs 65%) reported booking an appointment online would facilitate access, autistic patients selected a need to "email my doctor in advance with a description of the issue I need to discuss" (62%), "wait in a quiet place or outside until my turn" (56%), and "book an appointment by text" (41%). Some autistic individuals would benefit if they "could book the first or last appointment" (41%) or had a "sensory box available in the waiting room" (16%) (Supplementary Table 5).

Despite the outlined difficulties of visiting their doctor, autistic individuals felt their relationship with their GP was "very important" or "important" significantly more than non-autistic respondents (70% vs. 56%, p=0.001), but only 33% of autistic respondents reported a good relationship with their doctor (p<0.001). Only 62% of autistic individuals reported that their doctor knew they were autistic. Twenty two percent were unsure whereas 16% hadn't disclosed their diagnosis. Autistic respondents appreciated GPs who ask direct questions, give clear explanations, are honest about not understanding autism but know that autism isn't a mental illness.

Geographical variations

Some barriers to access for autistic respondents varied by geographical location (UK vs elsewhere in the world). Autistic respondents from the UK had more difficulty using the telephone to book appointments (66% vs 54%, p=0.012), more difficulty communicating with reception staff (52% vs 37%, p=0.002), and were less likely to experience no barriers to access at all (0.3% vs 2.8%, p=0.038). Autistic respondents from the UK also found it harder to see a known or preferred doctor (58% vs 29%, p<0.001), reported longer waits to get appointments (59% vs 33%, p<0.01), and found their online appointment booking systems more confusing (26% vs 10%, p<0.001). However, they were less likely to report no access to online booking systems compared to those from elsewhere in the world (26% vs 42%, p<0.001). There were no other significant differences for autistic respondents by geographical location.

There was only one significant geographical variation in self-reported adverse outcomes. For autistic respondents, those in the UK were less likely than those from elsewhere in the world to miss / not attend specialist referrals (43% vs 55%, p=0.019).

Associations between barriers and outcomes for autistic respondents

Table 4: Barriers and Outcomes Associations for Autistic Respondents

	Untreated mental health condition	Untreated physical health condition	Specialist referral missed	Told they should have presented sooner	More extensive treatment or surgery required	Serious or life threatening condition

Difficulty using the telephone to book an appointment	**p<0.001**	**p<0.001**	**p=0.036**	**p=0.015**	n.s.	**p=0.007**
Difficulty with advance planning	**p=0.020**	**p=0.032**	**p<0.001**	**p=0.030**	n.s.	n.s.
Difficulty communicating with reception staff	**p<0.001**	**p<0.001**	**p=0.008**	**p<0.001**	**p=0.041**	**p=0.004**
Difficulty communicating with the doctor during the appointment	**p<0.001**	**p<0.001**	**p<0.001**	**p=0.003**	**p=0.003**	**p=0.002**
The waiting room environment	**p=0.007**	**p<0.001**	n.s.	**p=0.010**	**p<0.001**	n.s
Inability to see a known or preferred doctor	**p<0.001**	**p=0.003**	n.s.	**p=0.027**	n.s.	n.s
Waiting to see the doctor is too difficult	**p=0.018**	**p=0.001**	n.s.	n.s.	**p=0.026**	n.s.
Not feeling understood	**p<0.001**	**p<0.001**	**p<0.001**	n.s.	n.s.	**p=0.026**
Needing a support person to come with me	n.s.	**p=0.002**	**p=0.004**	n.s.	**p=0.009**	**p=0.002**

Table 4 outlines associations between reported barriers and outcomes for autistic respondents. There were no significant associations between any adverse outcomes and difficulty deciding if symptoms warrant a GP visit, not having an online booking system, having a confusing online booking system, having a long wait to get an appointment, or having enough time to visit a doctor. In contrast, difficulty communicating with reception staff and difficulty communicating with the doctor during appointments were both significantly associated with all adverse outcomes.

Difficulty using the telephone to book an appointment was significantly associated with all adverse outcomes apart from having to undergo more extensive treatment or surgery than if they had attended sooner. Challenges with the waiting room environment were significantly associated with all adverse outcomes apart from missing specialist referrals and having a potentially serious or life-threatening condition for which they did not access treatment. Difficulty planning an appointment in advance was significantly associated with all adverse outcomes apart from having a potentially serious or life-threatening condition for which they did not access treatment, and having to undergo more extensive treatment or surgery than if they had attended sooner. Needing a support person to attend appointments was significantly associated with all adverse outcomes apart from having had a mental health condition remain untreated due to difficulties accessing healthcare and being told they should have presented sooner. Not feeling understood was significantly associated with all adverse outcomes apart from being told they should have presented sooner and having to undergo more extensive treatment or surgery than if they had attended sooner. Needing a support person to attend with them was significantly associated with all adverse outcomes apart from having untreated mental health conditions and being told they should have presented sooner.

The inability to see a known or preferred doctor was significantly associated with having both untreated mental and physical health conditions. It was also significantly associated with being told they should have presented sooner. Finding waiting to see a doctor too difficult was significantly associated with having both untreated mental and physical health

conditions. It was also significantly associated with having to undergo more extensive treatment or surgery than if they had attended sooner.

Reporting no barriers to access healthcare had no significant associations with any of the adverse outcomes.

Discussion

Our study describes the results of a survey of autistic adults and compares their experiences with non-autistic adults. It highlights barriers faced by autistic people accessing and engaging with primary healthcare. In our study these included greater difficulties deciding when to seek care, reluctance to bother their GP, difficulties planning appointments and greater communication difficulties – with particular emphasis on telephone use. Communication was also impaired by anxiety and sensory issues. We linked those barriers to self-reported adverse outcomes. Our data indicated that autistic people may present for healthcare later in the natural course of an illness. Autistic participants reported reduced attendance for screening, late presentations, missed opportunities for early detection and more extensive therapy being required. They also delayed or avoided healthcare because they didn't feel understood by their doctors. Furthermore, a substantial minority of autistic adults did not disclose their autism diagnosis which may impede identification of their autism-specific needs. These barriers may have real consequences, as evidenced in reduced life expectancy, and higher levels of physical and mental health conditions amongst autistic people.

Comparison with existing literature

This study confirms the findings of Nicolaidis,[14] Raymaker[16] and several recent reviews[15,17,26], which all identified three groups of barriers: (1) patient-level factors; (2) provider-level factors; and (3) system-level factors. Our study stratifies individual barriers from the perspective of autistic individuals. We couple these barriers to self-reported adverse consequences, highlighting factors which may lead to excess morbidity and mortality in the autistic population.

Strengths and limitations

Our study arose from a community-identified need to develop autism awareness training for healthcare providers. It benefited from an autistic-led research team including autistic doctors, using participatory methods. Our study provided a unique picture of autistic adults' healthcare experiences, including those entirely excluded from healthcare due to access barriers. In particular, we highlighted the difficulties with using the telephone which is a distilled, concentrated essence of verbal communication.

As we used a convenience sample and self-report survey, generalisability of the data may be limited. Respondents required the ability to complete the survey which excluded those with reduced ability to self-report. Whilst we did not set out to create a validated tool, our survey may have benefited from some validity and reliability testing. As the initial quality improvement questionnaire was undertaken in the United Kingdom, we did not include issues specific to other healthcare systems, such as cost or insurance. Our analyses did not account for potential confounding factors, such as ethnicity or socio-economic status. Female participants were over-represented in both groups which is not unusual for online surveys,

but is interesting given the higher rate of autism diagnosis in males. Whilst we noted significant gender differences in relation to non-binary participants, these participants were almost all autistic and we were therefore unable to attribute differences to gender identity or autism with any degree of certainty. Furthermore, as this is a cross-sectional study, whilst we can identify associations, we cannot confirm causality.

Implications for Research

Our study suggests a need for personalised approaches to healthcare access. A prior study investigated using a pre-visit telephone call to identify individualised accommodations.[27] Our data suggest that this could be problematic for autistic adults. The AASPIRE Healthcare Toolkit[28] includes a publicly available online program which generates a computerised report of required healthcare accommodations. Adaptation of such a toolkit in NHS General Practice should be considered and researched. Social care interventions and healthcare facilitators in general practice have shown benefit with a vulnerable population,[29] similar approaches could benefit an autistic population. The significant difficulties amongst the small number of autistic people not registered with any GP indicate a need for further research into this group.

Implications for Clinical Practice

Based on supplementary table 5 and the lived experience of the autistic members of our research team, Figure 3 outlines our proposed elements of an autism friendly practice. Such adjustments may minimise anxiety, manage sensory issues, and ensure mutual understanding – promoting clear, unambiguous communication. Autism friendly practices should employ a personalised approach, with a healthcare access needs assessment and, where possible, a specialist liaison nurse or facilitator.

Implications for Policy

Given the identified barriers, the extension of annual health checks to autistic adults[30,31] and the recently announced Oliver McGowan Mandatory Training in Learning Disability and Autism[32] are welcome. These will likely bring important benefits provided they are informed by the autistic community and autistic healthcare providers. Autism registers in GP practice have been recommended.[33,34] The success of such initiatives will likely depend on greater awareness by medical practitioners of autistic culture and communication needs. Specific training for GPs during core training and continuing professional development may be beneficial. GPs with a special interest in autism should be facilitated to develop their skills, but management of general health needs and co-occurring conditions fall within the remit of every GP. Implementing existing autism legislation or development where lacking is required in order to reduce health inequities for autistic people.

Conclusions

Autistic people face barriers accessing the healthcare system, followed by difficulties interacting with healthcare providers, which may contribute to known healthcare disparities including increased morbidity and mortality. Our study has highlighted a variety of specific barriers to accessing primary healthcare for autistic adults, including use of the telephone to book appointments, not feeling understood, and difficulty communicating with doctors as well as sensory and organisational issues which impede healthcare access. We identified a variety of significant associations between self-reported barriers to healthcare access and adverse outcomes for autistic respondents. One of our most impactful findings was the lack

of any significant differences between formally diagnosed and self-identified autistic respondents in difficulty attending a GP, barriers experienced, or self-reported adverse healthcare outcomes. Progress towards eliminating healthcare disparities for autistic people may be achieved by understanding the healthcare experiences and access barriers for this vulnerable patient group. These barriers represent not so much a failure to deliver or to avail of healthcare, but a lack of intersection between the communication patterns of autistic healthcare users and non-autistic providers. Reasonable accommodations are legally[35] and morally required. Adjustments for communication needs are as necessary for autistic people as ramps for wheelchair users.

Figure legends

Figure 1. Adverse Healthcare Outcomes
For all comparisons between autistic and non-autistic groups p<0.001.

Figure 2. Adverse outcomes according to difficulty attending a GP
**p<0.001 *p<0.05
Note y-axis = N

Figure 3. Autism Friendly General Practice

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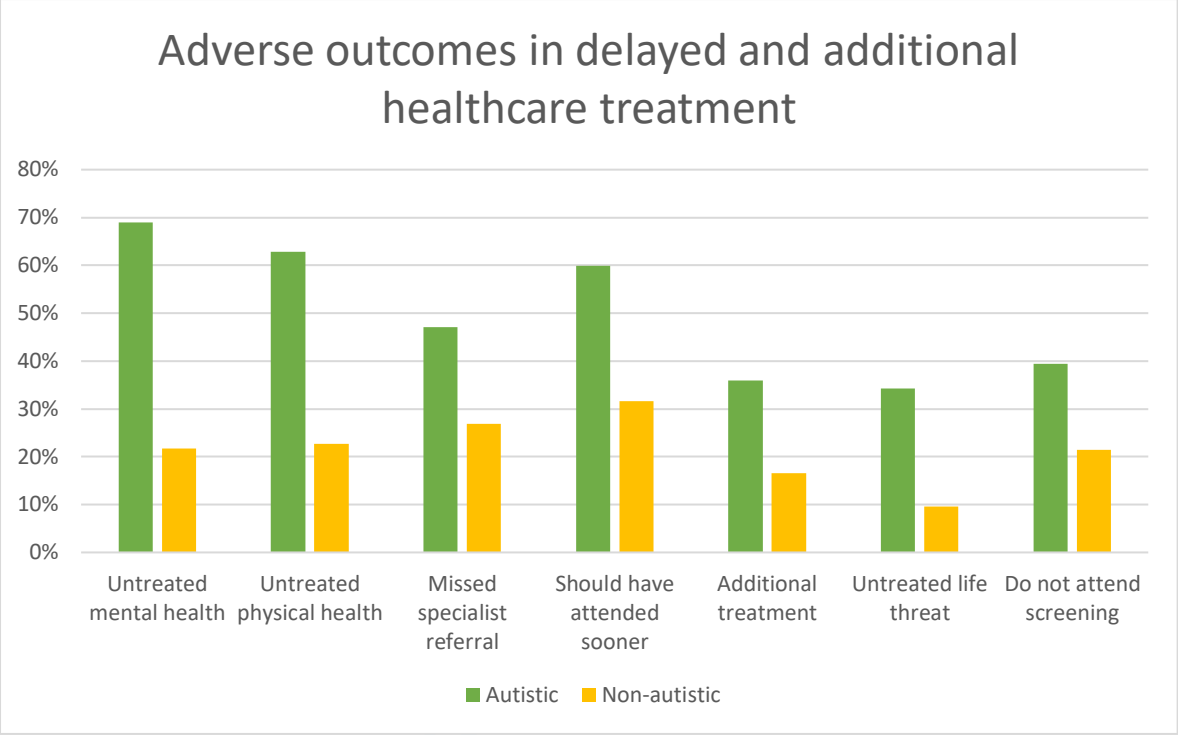

Figure 1. Adverse Healthcare Outcomes
For all comparisons between autistic and non-autistic groups $p<0.001$.

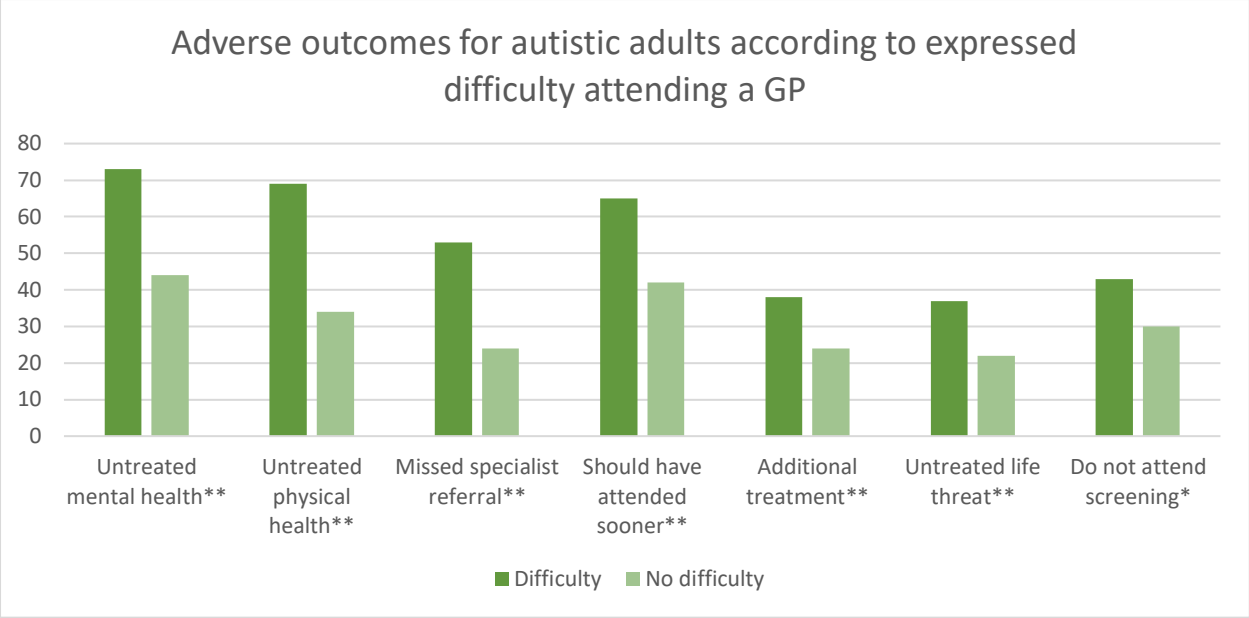

Figure 2. Adverse outcomes according to difficulty attending a GP
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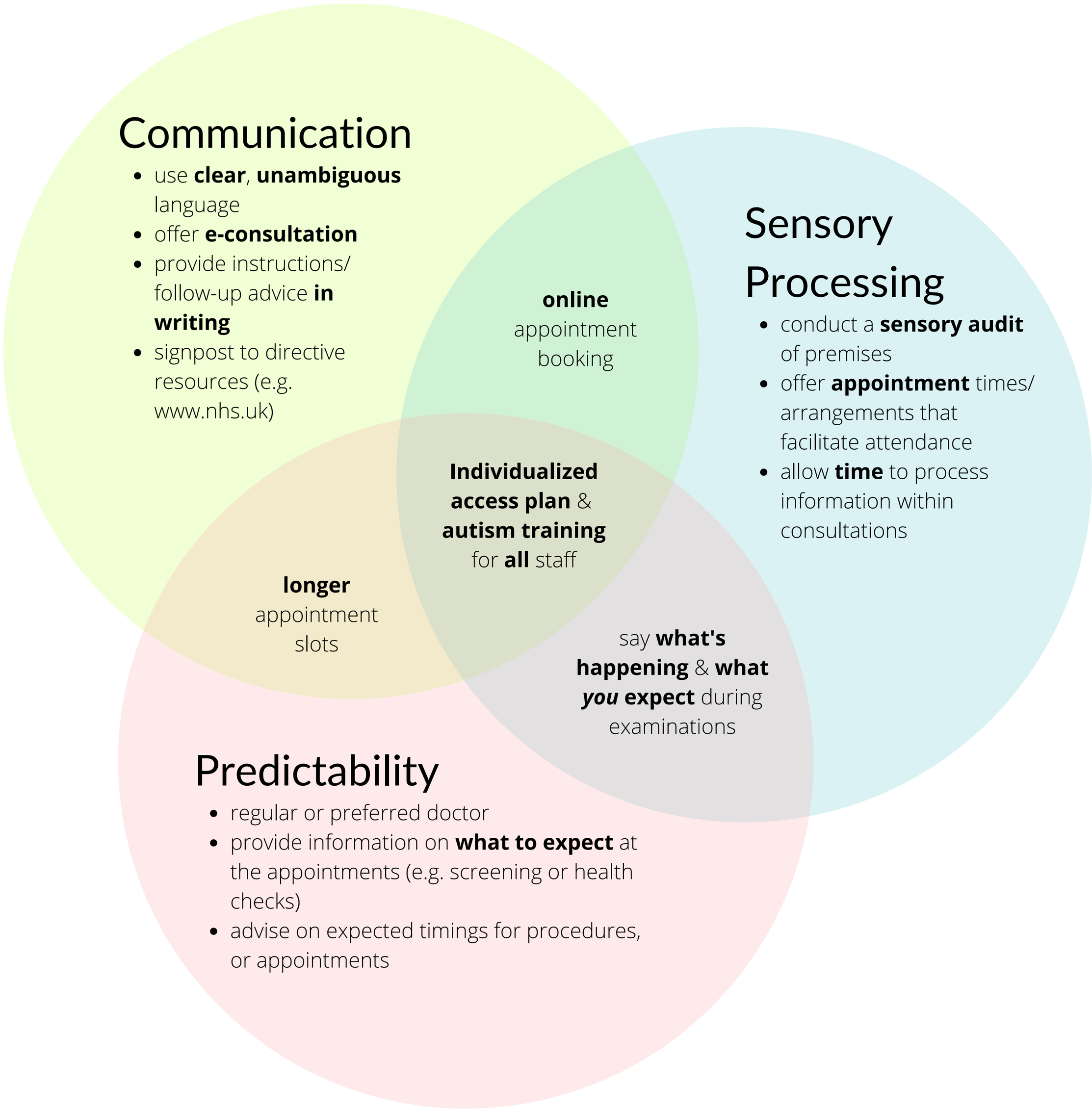
Communication
use clear, unambiguous language
offer e-consultation
provide instructions/ follow-up advice in writing
signpost to directive resources (e.g. www.nhs.uk)
online appointment booking
Sensory Processing
conduct a sensory audit of premises
offer appointment times/ arrangements that facilitate attendance
allow time to process information within consultations
Individualized access plan & autism training for all staff
longer appointment slots
say what's happening & what you expect during examinations
Predictability
regular or preferred doctor
provide information on what to expect at the appointments (e.g. screening or health checks)
advise on expected timings for procedures, or appointments

Supplement 1

Barriers to accessing healthcare for autistic adults: online survey

1. Are you autistic?
Includes Autism, Autistic Spectrum Conditions, Asperger Syndrome, self-diagnosed or formally diagnosed.
☐ Yes
☐ No

2. Do you usually attend the same medical practice?
☐ Yes
☐ No
☐ I don't attend any medical practice

3. Do you usually see the same doctor?
☐ Yes
☐ No
☐ I don't attend any doctor

4. Do you have difficulty visiting your doctor when you need to?
☐ Yes
☐ No

5. Which of the following would cause you to delay or avoid seeing your doctor when you need to?
Please check ALL THAT APPLY
☐ Difficulty deciding if symptoms warrant a GP visit
☐ Difficulty using the telephone to book appointment
☐ No online booking system
☐ There is an online booking system but it's confusing
☐ Difficulty planning an appointment in advance
☐ Difficulty communicating with the reception staff
☐ Difficulty communicating with the doctor during the appointment
☐ The waiting room environment
☐ Inability to see a known or preferred doctor
☐ Long wait to get an appointment
☐ Waiting to see the doctor is too difficult
☐ Not feeling understood
☐ Not having enough time to visit the doctor
☐ Needing a support person to come with me
☐ Not having anyone to look after my child
☐ None of the above

6. Which of the following is the most difficult part of booking an appointment?
Please choose the <u>one</u> issue which is MOST DIFFICULT for you

- [ ] Using the telephone to book an appointment
- [ ] No online booking system
- [ ] There is an online booking system but it's confusing
- [ ] None of the above

7. Which of the following is the most difficult part of planning a visit?
Please choose the one issue which is MOST DIFFICULT for you

- [ ] Deciding if your symptoms warrant a GP visit
- [ ] Long wait to get an appointment
- [ ] Planning an appointment in advance
- [ ] Inability to see a known or preferred doctor
- [ ] Not having enough time to visit the doctor
- [ ] Arranging for someone to come with me
- [ ] If you are a parent, not having anyone to look after your child
- [ ] None of the above

8. Which of the following is most difficult during an appointment?
Please choose the one issue which is MOST DIFFICULT for you

- [ ] Communicating with the reception staff
- [ ] Communicating with the doctor during the appointment
- [ ] The waiting room environment
- [ ] Not feeling understood
- [ ] Waiting to see the doctor is difficult
- [ ] None of the above

9. Do you visit your doctor...
Check ALL THAT APPLY

- [ ] Alone, by choice
- [ ] Alone, but would prefer to have a support person
- [ ] With a parent, partner or support person
- [ ] With a parent, partner or support person but I would prefer to go alone
- [ ] With a support animal
- [ ] To support an autistic adult
- [ ] As a parent with my child

10. Why do you usually visit your doctor?
Check ALL THAT APPLY

- [ ] Physical condition or illness
- [ ] Mental health difficulties
- [ ] Issues directly related to autism
- [ ] Other

11. How much do you value your relationship with your GP?

- [ ] It is very important to me
- [ ] It is important to me
- [ ] It is neither important nor unimportant to me
- [ ] It is not very important to me

☐ It is not at all important to me

12. Do you have a good relationship with your doctor?
☐ Yes
☐ Sometimes
☐ No
☐ Not currently, but had good relationship with GP in past

13. Do you find it difficult to communicate during a consultation?
☐ All the time
☐ Frequently
☐ Sometimes
☐ Rarely
☐ Not at all

14. Which of the following communication issues cause you problems during a consultation? Check ALL THAT APPLY
☐ Verbal communication is difficult
☐ Sensory issues make it harder to communicate
☐ Anxiety makes it harder to communicate
☐ It is easier for me to communicate in writing
☐ I'm scared of the receptionist
☐ I have difficulty asking for help
☐ I have difficulty prioritising my health issues
☐ I am concerned I might be labelled a hypochondriac or malingerer
☐ Vague or open ended questions are difficult
☐ I can't describe my pain or symptoms accurately
☐ I express emotions differently (e.g. I can appear to be angry when I am afraid or in pain)
☐ I need extra time to process what is being said
☐ I am concerned I won't be taken seriously when I describe my symptoms
☐ None of the above
☐ Other

15. Which communication issue causes you the MOST problems during a consultation? Please choose the <u>one</u> issue which is MOST DIFFICULT for you
☐ Verbal communication is difficult
☐ Sensory issues make it harder to communicate
☐ Anxiety makes it harder to communicate
☐ It is easier for me to communicate in writing
☐ I'm scared of the receptionist
☐ I have difficulty asking for help
☐ I have difficulty prioritising my health issues
☐ I am concerned I might be labelled a hypochondriac or malingerer
☐ Vague or open ended questions are difficult
☐ I can't describe my pain or symptoms accurately
☐ I express emotions differently (e.g. I can appear to be angry when I am afraid or in pain)
☐ I need extra time to process what is being said

- [ ] I am concerned I won't be taken seriously when I describe my symptoms
- [ ] None of the above
- [ ] Other

16. Is stimming a problem for you at the doctors' office?
Check ALL THAT APPLY
- [ ] My unusual behaviours or stimming elicit negative reactions from other patients
- [ ] My unusual behaviours or stimming elicit negative reactions from reception staff
- [ ] My unusual behaviours or stimming elicit negative reactions from medical staff
- [ ] I feel comfortable stimming at the doctors' office
- [ ] I do not feel comfortable stimming at the doctors' office
- [ ] I don't feel a need to stim at the doctors' office
- [ ] I don't understand the term "stimming"

17. Do you experience any of the following?
Check ALL THAT APPLY
- [ ] I find it difficult to make appointments in advance
- [ ] I have turned up for a medical appointment on the wrong day
- [ ] I have forgotten to attend a medical appointment
- [ ] I find it difficult to prioritise when describing my medical problems
- [ ] I need to give the whole story and not leave anything out
- [ ] I have forgotten why I made the appointment
- [ ] I find waiting difficult
- [ ] It is difficult to arrange someone to come with me
- [ ] I need to write things down
- [ ] I have difficulty making decisions about my health
- [ ] Making changes to my lifestyle or habits is difficult for me
- [ ] None of the above

18. Do you experience sensory issues which make it difficult to visit your doctor?
Check ALL THAT APPLY
- [ ] Bright or fluorescent lights
- [ ] Noise in the waiting room from other patients
- [ ] Music playing in the waiting room
- [ ] Noise from the reception desk
- [ ] Smells in the waiting room
- [ ] Smells in the doctor's office
- [ ] Crowded waiting area
- [ ] Uncomfortable furniture
- [ ] Touch, such as during examination
- [ ] Unexpected touch
- [ ] None of the above
- [ ] Other

19. How would you describe your pain threshold?
- [ ] Very high
- [ ] High

☐ Neither particularly high nor low
☐ Low
☐ Very low
☐ I don't know

20. What communication methods do you use?
Check ALL THAT APPLY
☐ Verbal, face-to-face
☐ Verbal, telephone
☐ Voicemail
☐ Text messaging
☐ Online messaging
☐ Email
☐ Other online method
☐ Written
☐ Alternative communication device
☐ Sign language
☐ Other

21. What communication methods do you AVOID if possible?
Check ALL THAT APPLY
☐ Verbal, face-to-face
☐ Verbal, telephone
☐ Voicemail
☐ Text messaging
☐ Online messaging
☐ Other online method
☐ Email
☐ Written
☐ Alternative communication device
☐ Sign language
☐ Other

22. If your GP offered options for making an appointment, which would you be most likely to use?
☐ Verbal, face-to-face
☐ Verbal, telephone
☐ Voicemail
☐ Text messaging
☐ Email
☐ Online booking system
☐ Alternative communication device
☐ Other

23. My doctors are really good for me because they are...
Check ALL THAT APPLY
☐ Patient

- [ ] Good listeners
- [ ] Understanding
- [ ] Supportive
- [ ] Kind
- [ ] Friendly
- [ ] Efficient
- [ ] Familiar
- [ ] Not condescending
- [ ] Aware of my needs
- [ ] Honest about not understanding autism
- [ ] None of the above

24. My doctors are really good for me because they...
Check ALL THAT APPLY

- [ ] Ask direct questions
- [ ] Give clear explanations
- [ ] Accept written or email communication
- [ ] Use printed information and diagrams
- [ ] Value my opinion
- [ ] Accept my right to make decisions regarding my health
- [ ] Know that autism is not a mental health condition
- [ ] Do home visits
- [ ] Have reception staff who are trained regarding autism
- [ ] Remind me to make my next appointment before leaving
- [ ] None of the above

25. Do you find it difficult not knowing...
Check ALL THAT APPLY

- [ ] Which doctor you will see
- [ ] How long you will wait
- [ ] How long the consultation will last
- [ ] What will happen during the consultation
- [ ] None of the above

26. When going to the doctor, what causes you to feel anxious?
Check ALL THAT APPLY

- [ ] asking for help
- [ ] discussing mental health
- [ ] that there might be something wrong
- [ ] that I might be considered a hypochondriac
- [ ] that I might be wasting the doctor's time
- [ ] I don't feel anxious going to the doctor

27. Do you have mobility needs which make visiting your doctor difficult?

- [ ] Yes
- [ ] No

28. My doctor is knowledgeable about physical conditions:
- ☐ Strongly agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly disagree

29. My doctor is knowledgeable about mental health conditions:
- ☐ Strongly agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly disagree

30. My doctor is knowledgeable about autism:
- ☐ Strongly agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly disagree

31. Visits to my doctor would be easier if…
Check ALL THAT APPLY
- ☐ I could book an appointment online
- ☐ I could book an appointment by text
- ☐ I could book the first or last appointment of the day
- ☐ I could wait in a quiet place or outside until it was my turn
- ☐ I could email my doctor in advance with a description of the issue I need to discuss
- ☐ There was a sensory box available in the waiting room
- ☐ None of the above
- ☐ Other

32. Have you ever had a mental health condition remain untreated due to difficulties accessing healthcare?
- ☐ Yes
- ☐ No
- ☐ Possibly
- ☐ Other

33. Have you ever had a physical health condition remain untreated due to difficulties accessing healthcare?
- ☐ Yes
- ☐ No
- ☐ Possibly
- ☐ Other

34. Have you even been referred to a specialist but did not make an appointment or did not attend?
☐ Yes
☐ No

35. Have you ever been told you should have seen a doctor sooner?
☐ Yes
☐ No

36. Have you ever had to undergo more extensive treatment or surgery than if you had attended sooner?
☐ Yes
☐ No

37. Have you ever had a potentially serious or life threatening condition for which you did not access treatment?
☐ Yes
☐ No

38. If you answered yes to any of the last 6 questions, would you like to give more details?

39. Do you attend on schedule for screening programmes applicable to you?
Includes cervical screening, sexual health screening, breast check, colon screening etc.
☐ Yes
☐ No
☐ Sometimes

40. If you were suddenly admitted to hospital, who would be able to bring your personal belongings to you?
Check ALL THAT APPLY
☐ Spouse or partner
☐ Parent
☐ Other family member
☐ Friend
☐ Neighbour
☐ Paid support person or carer
☐ Volunteer support person or carer
☐ Nobody available
☐ Other

41. If you were admitted to hospital for a day case surgical procedure, who would be available to collect you afterwards?
Check ALL THAT APPLY
☐ Spouse or partner
☐ Parent
☐ Other family member
☐ Friend

- [ ] Neighbour
- [ ] Paid support person or carer
- [ ] Volunteer support person or carer
- [ ] Nobody available
- [ ] Other

42. If you needed assistance at home after an operation, who would be available to provide that care?
Check ALL THAT APPLY

- [ ] Spouse or partner
- [ ] Parent
- [ ] Other family member
- [ ] Friend
- [ ] Neighbour
- [ ] Paid support person or carer
- [ ] Volunteer support person or carer
- [ ] Nobody available
- [ ] Other

43. If you are a parent and you were unable to care for your child due to illness, who would be available to provide that care to your child?
Check ALL THAT APPLY

- [ ] Spouse or partner
- [ ] Parent
- [ ] Other family member
- [ ] Friend
- [ ] Neighbour
- [ ] Paid support person or carer
- [ ] Volunteer support person or carer
- [ ] Nobody available
- [ ] I don't have a child requiring care
- [ ] Other

44. Do you identify as autistic?
Includes Autism, Autistic Spectrum Conditions, Asperger Syndrome, self-diagnosed or formally diagnosed.

- [ ] Yes
- [ ] No
- [ ] Possibly

45. Do you have a formal diagnosis? *

- [ ] Yes
- [ ] No

46. If you have a formal diagnosis, was it provided by:

- [ ] Psychiatrist
- [ ] Clinical Psychologist

☐ Multidisciplinary Team
☐ Other

47. Does your doctor know you are autistic? *
☐ Yes
☐ No
☐ I don't know

48. What is your age?

49. What age were you when you were diagnosed?
If applicable

50. Which country do you live in?
☐ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ Republic of Ireland
☐ United States
☐ Canada
☐ Other:

51. What is your gender?
☐ Male
☐ Female
☐ Non-binary
☐ Prefer not to say

52. Please give any further information or suggestions here.

Table S1 Access Barriers to Healthcare

Which of the following would cause you to delay or avoid seeing your doctor when you need to?

	Autistic n (%)	Non-autistic n (%)	Difference (95% Confidence Interval)	p value
Difficulty deciding if symptoms warrant a GP visit	366 (72%)	102 (65%)	7% (CI -1.6%,16.1%)	p=0.102 ns
Difficulty using the telephone to book appointment	314 (62%)	25 (16%)	46% (CI 38.5%,53.5%)	p<0.001
Not feeling understood	283 (56%)	21 (13%)	42% (CI 35.2%,49.7%)	p<0.001
Difficulty communicating with the doctor during the appointment	269 (53%)	10 (6%)	47% (CI 40.5, 52.9%)	p<0.001
The waiting room environment	256 (51%)	12 (8%)	43% (CI 36.4%,49.3%)	p<0.001
Long wait to get an appointment	251 (50%)	70 (45%)	5% (CI -4.4%,14.2%)	p=0.324 ns
Difficulty planning an appointment in advance	243 (48%)	51 (33%)	15% (CI 6.5%,24.4%)	p<0.001
Inability to see a known or preferred doctor	241 (48%)	35 (23%)	25% (CI 17.0%,33.5%)	p<0.001
Difficulty communicating with the reception staff	235 (46%)	13 (8%)	38% (CI 31.5%,44.6%)	p<0.001
Not having enough time to visit the doctor	174 (34%)	61 (39%)	-5% (CI -13.6%,4.6%)	p=0.346 ns
No online booking system	160 (32%)	35 (23%)	9% (CI 1.2%,17.3%)	p=0.033
Waiting to see the doctor is too difficult	114 (23%)	7 (5%)	18% (CI 12.7%,23.3%)	p<0.001
Needing a support person to come with me	106 (21%)	7 (5%)	16% (CI 11.2%,21.7%)	p<0.001
There is an online booking system but it's confusing	102 (20%)	9 (6%)	14% (CI 8.9%,19.8%)	p<0.001
Not having anyone to look after my child	66 (13%)	18 (12%)	2% (CI -4.6%,7.8%)	p=0.708 ns
None of the above	6 (1%)	17 (11%)	-10% (CI -15.0%,-4.3%)	p<0.001

Table S2 Perceived Stigma

Going to the doctor, I am anxious :	**Autistic n (%)**	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
I won't be taken seriously when I describe my symptoms	341 (67%)	54 (34%)	32.9% (CI 24.0%,41.8%)	p<0.001
I might be wasting the doctor's time	333 (66%)	53 (34%)	31.9% (CI 23.0%,40.8%)	p<0.001
I might be considered a hypochondriac	330 (65%)	42 (27%)	38.3% (CI 29.8%,46.8%)	p<0.001
about asking for help	318 (63%)	28 (18%)	44.9% (CI 37.2%,52.6%)	p<0.001
about discussing mental health	301 (59%)	37 (24%)	35.8% (CI 27.5%,44.1%)	p<0.001
that there might be something wrong	217 (43%)	55 (35%)	7.8% (CI -1.3%,16.8%)	p=0.102 ns
I don't feel anxious going to the doctor	17 (3%)	52 (33%)	-30% (CI -37.7%,-21.8%)	p<0.001

Is stimming* a problem for you at the doctors' office?	**Autistic n (%)**	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Unusual behaviours or stimming elicit negative reactions from other patients	74 (14.6%)	4 (2.5%)	12% (CI 7.7%,16.4%)	p<0.001
Unusual behaviours or stimming elicit negative reactions from reception staff	44 (8.7%)	1 (0.6%)	8% (CI 4.9%,11.2%)	p=0.001
Unusual behaviours or stimming elicit negative reactions from medical staff	37 (7.3%)	2 (1.3%)	6% (CI 2.7%,9.3%)	p=0.009
I feel comfortable with stimming at the doctors' office	101 (19.9%)	74 (47.1%)	-27% (CI -36.2%,-18.2%)	p<0.001
I do not feel comfortable with stimming at the doctors' office	4 (0.8%)	5 (3.2%)	-2% (CI -5.7%,0.9%)	p=0.061 ns
No need to stim at the doctors' office	133 (26.2%)	0 (0.0%)	26% (CI 22.0%,30.5%)	p<0.001
I don't understand the term "stimming"	29 (5.7%)	62 (39.5%)	-34% (CI -42.1%,-25.4%)	p<0.001

*Stimming refers to repetitive motor movements or vocalisations which are commonly used by autistic people as a self-regulatory mechanism.

Table S3 Planning and Organising

	Autistic n (%)	Non-autistic n (%)	Difference (95% Confidence Interval)	p value
I find it difficult to prioritise when describing my medical problems	333 (66%)	34 (22%)	44% (CI 36.0%,52.1%)	p<0.001
I need to give the whole story and not leave anything out	332 (66%)	18 (12%)	54% (CI 47.1%,60.9%)	p<0.001
I find it difficult to make appointments in advance	300 (59%)	45 (29%)	31% (CI 21.8%,39.2%)	p<0.001
Making changes to my lifestyle or habits is difficult for me	282 (56%)	36 (23%)	33% (CI 24.4%,41.0%)	p<0.001
I have forgotten to attend a medical appointment	230 (45%)	34 (22%)	24% (CI 15.5%,31.9%)	p<0.001
I need to write things down	227 (45%)	17 (11%)	34% (CI 27.0%,40.9%)	p<0.001
I find waiting difficult	221 (44%)	15 (10%)	34% (CI 27.3%,40.8%)	p<0.001
I have difficulty making decisions about my health	222 (44%)	20 (13%)	31% (CI 23.9%,38.2%)	p<0.001
I have turned up for a medical appointment on the wrong day	151 (30%)	16 (10%)	20% (CI 13.0%,26.2%)	p<0.001
It is difficult to arrange someone to come with me	103 (20%)	2 (1%)	19% (CI 14.7%,23.4%)	p<0.001
I have forgotten why I made the appointment	54 (11%)	1 (1%)	10% (CI 6.6%,13.4%)	p<0.001
None of the above	13 (3%)	64 (41%)	-38% (CI -46.4%,-30.0%)	p<0.001

Table S4 Support Needs

Do you visit your doctor:	**Autistic n (%)**	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Alone, by choice	306 (60%)	134 (85%)	-25% (CI -32.4%,-17.6%)	p<0.001
Alone, but would prefer to have a support person	165 (33%)	10 (6%)	26% (CI 20.2%,32.2%)	p<0.001
With a parent, partner or support person	137 (27%)	9 (6%)	21% (CI 15.6%,27.0%)	p<0.001
With a parent, partner or support person but I would prefer to go alone	12 (2%)	0 (0%)	2% (CI 0.6%,4.1%)	p=0.109 ns
With a support animal	5 (1%)	0 (0%)	1% (CI -0.3%,2.3%)	p=0.471 ns
To support an autistic adult	26 (5%)	0 (0%)	5% (CI 2.8%,7.5%)	p=0.008
As a parent to access healthcare for my child	78 (15%)	30 (19%)	-4% (CI -11.0%,3.6%)	p=0.327 ns
With my child, but I would prefer to go alone	6 (1%)	12 (8%)	-7% (CI -11.1%,-1.8%)	p<0.001

If you were suddenly admitted to hospital, who would be able to bring your personal belongings to you?

	Autistic n (%)	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Spouse or partner	234 (46%)	106 (68%)	-21% (CI -30.3%,-12.4%)	p<0.001
Parent	168 (33%)	70 (45%)	-11% (CI -20.7%,-2.2%)	p=0.012
Other family member	96 (19%)	72 (46%)	-27% (CI -35.8%,-18.0%)	p<0.001
Friend	118 (23%)	57 (36%)	-13% (CI -21.8%,-4.2%)	p=0.002
Neighbour	17 (3%)	14 (9%)	-6% CI -10.7%,-0.4%)	p=0.008
Paid support person or carer	15 (3%)	1 (1%)	2% (CI -0.0%,4.7%)	p=0.174 ns
Volunteer support person or carer	6 (1%)	0 (0%)	1% (CI -0.2%,2.5%)	p=0.375 ns
Nobody available	88 (17%)	5 (3%)	14% (CI 9.5%,18.9%)	p<0.001

If you were admitted to hospital for a day case surgical procedure, who would be available to collect you afterwards?

	Autistic n (%)	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Spouse or partner	208 (41%)	100 (64%)	-23% (CI -31.7%,-13.6%)	p<0.001

Parent	176 (35%)	73 (47%)	-12% (CI -21.0%,-2.5%)	p=0.010
Other family member	96 (19%)	75 (48%)	-29% (CI -37.8%,-19.9%)	p<0.001
Friend	116 (23%)	67 (43%)	-29% (CI -37.8%,-19.9%)	p<0.001
Neighbour	17 (3%)	8 (5%)	-2% (CI -5.9%,2.5%)	p=0.446 ns
Paid support person or carer	17 (3%)	0 (0%)	3% (CI 1.4%,5.3%)	p=0.042
Volunteer support person or carer	3 (1%)	0 (0%)	1% (CI -0.5%,1.7%)	p=0.776 ns
Nobody available	99 (20%)	3 (2%)	18% (CI 13.1%,22.1%)	p<0.001

If you needed assistance at home after an operation, who would be available to provide that care?

	Autistic n (%)	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Spouse or partner	219 (43%)	101 (64%)	-21% (CI -30.2%,-12.1%)	p<0.001
Parent	152 (30%)	74 (47%)	-17% (CI -26.3%,-8.0%)	p<0.001
Other family member	83 (16%)	61 (39%)	-23% (CI -31.2%,-13.8%)	p<0.001
Friend	74 (15%)	43 (27%)	-13% (CI -20.8%,-4.8%)	p<0.001
Neighbour	14 (3%)	8 (5%)	-2% (CI -6.5%,1.8%)	p=0.241 ns
Paid support person or carer	30 (6%)	3 (2%)	4% (CI 0.6%,7.4%)	p=0.071 ns
Volunteer support person or carer	4 (1%)	0 (0%)	1% (CI -0.4%,2.0%)	p=0.599 ns
Nobody available	131 (26%)	13 (8%)	18% (CI 11.4%,23.7%)	p<0.001

If you are a parent and you were unable to care for your child due to illness, who would be available to provide that care to your child?

	Autistic n (%)	**Non-autistic n (%)**	**Difference (95% Confidence Interval)**	**p value**
Spouse or partner	110 (22%)	64 (41%)	-19% (CI -28.0%,-10.2%)	p<0.001
Parent	37 (7%)	40 (26%)	-18% (CI -25.8%,-10.6%)	p<0.001
Other family member	40 (8%)	40 (26%)	-18% (CI -25.2%,-10.0%)	p<0.001
Friend	21 (4%)	27 (17%)	-13% (CI -19.6%,-6.5%)	p<0.001
Neighbour	4 (1%)	8 (5%)	-5% (CI -8.2%,-0.4%)	p<0.001

Paid support person or carer	5 (1%)	9 (6%)	-5% (CI -8.9%,-0.6%)	p<0.001
Volunteer support person or carer	1 (1%)	0 (0%)	0% (CI -0.4%,0.8%)	p=1.000 ns
Nobody available	34 (7%)	6 (4%)	3% (CI -1.2%,7.0%)	p=0.256 ns
I don't have a child requiring care	274 (54%)	78 (50%)	4% (CI -5.0%,13.7%)	p=0.387 ns

Table S5 Facilitators

Visits to my doctor would be easier if:	Autistic n (%)	Non-autistic n (%)	Difference (95% Confidence Interval)	p value
I could book an appointment online	339 (67%)	102 (65%)	2% (CI -7.0%,10.8%)	p=0.732 ns
I could email in advance with a description of the issue I need to discuss	316 (62%)	35 (22%)	40% (CI 31.9%,48.2%)	p<0.001
I could wait in a quiet place or outside until it was my turn	284 (56%)	13 (8%)	48% (CI 41.2%,54.3%)	p<0.001
I could book the first or last appointment of the day	210 (41%)	38 (24%)	17% (CI 8.8%,25.6%)	p<0.001
I could book an appointment by text	209 (41%)	44 (28%)	13% (CI 4.6%,21.8%)	p=0.004
There was a sensory box* available in the waiting room	80 (16%)	4 (3%)	13% (CI 8.8%,17.7%)	p<0.001
None of the above	16 (3%)	34 (22%)	-19% (CI -25.5%,-11.5%)	p<0.001

*A sensory box contains items to manage sensory stress, such as sunglasses, ear defenders or ear plugs, items providing tactile sensory input such as fidget tools and olfactory input such as scented items.

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No.	Recommendation	Page No.	Relevant text from manuscript
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	Pg 2	Lines 4 - 10
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	Pg 3	Lines 13 – 17 & 30-46
Introduction				
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Pg 5 - 6	Lines 17 (pg 5) - 37 (pg 6)
Objectives	3	State specific objectives, including any prespecified hypotheses	Pg 6	Lines 42 - 52
Methods				
Study design	4	Present key elements of study design early in the paper	Pg 7 - 8	Lines 17 (pg 7) - 28 (pg 8)
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Pg 8	Lines 32 - 52
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	Pg 8	Lines 33 - 43
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case		
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	N/A	
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Pg 8	Lines 33 - 53
Bias	9	Describe any efforts to address potential sources of bias	Pg 8	Lines 33 – 43, & 47 - 53
Study size	10	Explain how the study size was arrived at	Pg 8	Lines 33 - 43

Continued on next page

Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Pg 9	Lines 9 - 11
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	Pg 9	Lines 3 - 9
		(*b*) Describe any methods used to examine subgroups and interactions	Pg 9	Lines 3 - 6
		(*c*) Explain how missing data were addressed	Pg 9	Lines 6 - 9
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	N/A	
		(*e*) Describe any sensitivity analyses	None	
Results				
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Pg 9	Lines 35 - 38
		(b) Give reasons for non-participation at each stage	N/A	
		(c) Consider use of a flow diagram	N/A	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Pg 9-10	Lines 42 (pg 9) – 21 (pg 10)
		(b) Indicate number of participants with missing data for each variable of interest	N/A	
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)		
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time		
		Case-control study—Report numbers in each exposure category, or summary measures of exposure		
		Cross-sectional study—Report numbers of outcome events or summary measures	Not reported	
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Pg 10 - 16	Lines 25 (pg 10) – 55 (pg 16)
		(*b*) Report category boundaries when continuous variables were categorized	N/A	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A	

Continued on next page

Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Pg 17 - 20	Lines 3 (pg 17) – 15 (pg 20)
Discussion				
Key results	18	Summarise key results with reference to study objectives	Pg 20	Lines 25 - 52
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Pg 21 - 22	Lines 43 (pg 21) – 14 (pg 22)
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Pg 20 Pg 23 - 24	Lines 52 - 57 Lines 46 (pg 23) – 23 (pg 24)
Generalisability	21	Discuss the generalisability (external validity) of the study results	Pg 21	Lines 43 - 46
Other information				
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Pg 25	Lines 6 - 7

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.