Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

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.

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

BMJ Open

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

Supplemental material
BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance
placed on this supplemental material which has been supplied by the author(s)
BMJ Open

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.