

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 one 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.