

Supplementary Material

A trial of the AASPIRE healthcare toolkit with Australian adults on the autism spectrum

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Supplementary material

Demographic Questionnaire for Adults on the Autism Spectrum

Personal information

1. Date of birth (DD/MM/YYYY)

2. Country of birth:

Australia

Other, please specify

.....

3. Gender:

Male

Female

Other, please specify

.....

4. Which one or more of the following best represents your ethnic background? (Tick all that apply)

Caucasian

Asian

Hispanic

African

Middle Eastern

Aboriginal or Torres Strait Islander

- Other, please specify

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5. Which of the following best describes your marital status?

- Single
- Married
- De facto
- Never married
- Widowed
- Divorced and now single
- Divorced and now remarried or with de facto
- Separated
- Other, please specify

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6. What is your usual/normal living situation? (Tick all that apply)

- Living alone (with or without children)
- Living together as a couple (with or without children)
- Living with parents
- Living with other relatives
- Living with others
- Other, please specify

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7. What is your current residential postcode?

*Diagnosis***8. Did you undertake a formal diagnostic assessment of Autism?**

- Yes
- No
- I don't know

a) If yes, who provided your diagnosis?

- Paediatrician
- Psychiatrist
- Psychologist and Speech Pathologist
- Other, please specify
.....
- I don't know

b) Description of diagnosis:

- Autism spectrum disorder/condition
- Autistic disorder
- Asperger's Disorder/Syndrome
- Pervasive Developmental Disorder-Not Otherwise Specified
- High Functioning Autism
- Childhood Disintegrative Disorder
- Infantile Autism
- Other, please specify

c) Year of diagnosis of autism:

9. Below are some specific diagnoses or syndromes that are sometimes associated with Autism. Please tick any that apply to you:

- Down syndrome
- Prader-Willi syndrome
- Intellectual disability
- Fragile X syndrome
- Cerebral palsy
- Cornelia de Lange syndrome
- Smith-Magenis syndrome
- Rett syndrome
- Tuberous sclerosis
- Angelman syndrome
- Seckle syndrome
- Cri du Chat syndrome
- PKU (Phenylketonuria)
- Tourette's syndrome
- Fetal Alcohol syndrome
- Meningitis
- Brain injury
- Prenatal infection
- Other, please specify

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Communication

10. What is your dominant language?

- English
- Other, please specify

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11. In general, how would you describe your ability to understand what people say?

- I usually can understand spoken language well.
- I often have a hard time understanding or processing what people say.
- I understand very little spoken language.
- Other, please specify

.....

12. In general, how would you describe your ability to speak?

- I usually can speak well.
- I can speak, but often have a hard time saying what I want to say.
- I have a very hard time speaking (for example, I only can use short phrases).
- I have little or no ability to speak.
- Other, please

specify.....

13. What types of alternatives to speech do you use, if any?

- Text-based alternatives to speech (text-based AAC, typing, written notes, iPhone app)
- Picture-based alternatives to speech (picture-based AAC, picture boards, drawing)
- Other signs, gestures, or behaviours, please specify
- None

I would prefer to conduct the interview using the following method(s)

.....

14. What can the researchers do to help you understand them better?

- Use simple words and short sentences.
- Use very precise language, even if it means using longer sentences or advanced vocabulary.
- Be very concrete and specific.
- Show me diagrams, pictures, or models whenever possible.
- Ask me to repeat what you said in my own words.
- Write down important information or instructions for me.
- Give me very detailed information.
- Focus only on the most important information.
- Be patient with me if I need to ask a lot of questions.

- Give me extra time to process what you have said and check to make sure I am ready to move on.
- Do not try to talk to me while there are other noises (for example, beeping sounds, outside noises, people talking, or babies crying).
- I don't need accommodations to help me understand the researchers.
- Other, please specify
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15. What else do you want the researchers to know about your communication?

- I may have a hard time communicating, even if my speech sounds fluent.
- I can be involved in decisions about my care, even though I have difficulty speaking.
- I often take language too literally.
- In general, I can read better than I can understand spoken language.
- In general, I can write or type better than I can speak.
- I may have difficulty understanding tone of voice, facial expressions, or body language.
- My ability to communicate changes a lot, depending on the situation.
- If I seem rude, I don't mean it. I'm just really direct.
- I have a hard time using the telephone.

There isn't anything related to my communication that my provider needs to be aware of.

Other, please specify

.....

16. Most of the time, if I don't understand something and/or can't find my answer, I find it easiest to

Go silent

Say I don't know

Say the first thing that comes into my head

Say what I think the other person wants to hear

Ask the other person to explain (for example use different words, use gestures, visual cue card)

Other, please specify

.....

Health service use

17. Which of the following health professionals have you seen in the past 12 months?

(Tick all that apply)

General practitioner

Doctor

Nurse

Occupational therapist

- Physiotherapist
- Speech pathologist
- Social worker
- Other, please specify

18. What is the name of your current health professional that you would like to nominate to participate in the study?

What is their profession?

What is the name of their practice?

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What is the address of the practice?

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What is the practice telephone number?

What is the practice email address?

19. a) How many times did you visit the health professional mentioned in Question 18 in the past 12 months?

- Less than 5 times
- 5 – 10 times
- 10 – 20 times
- I don't know

b) How many minutes did these visits last on average?minutes

20. Does someone usually accompany you to your healthcare appointments?

Yes

No

If yes, what is the name of the person likely to accompany you to your appointment, that you would like to nominate to participate in the study?

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What is their relationship to you?

What is their contact telephone number?

What is their email address?

Thank you for taking the time to complete this questionnaire and for participating in the “A trial of the AASPIRE healthcare toolkit with Australian adults on the autism spectrum” study.

Our research team will now contact your nominated health professional/s and support person/s about participating in this study. Please inform the research team if you do not wish for this to occur.

Do you have any feedback about the questionnaire? (*Optional question*)

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Interview Guide for Adults on the Autism Spectrum

General

- What was your first impression of the Healthcare Toolkit?
- Can you tell me about how you used the Healthcare Toolkit?
 - o Which parts of the Healthcare Toolkit did you use?
 - o How did you use the Healthcare Toolkit when you saw your healthcare provider?
 - o Which healthcare provider did you use the Healthcare Toolkit with?
- How did your visit with your healthcare provider go?
 - o Did using the Healthcare Toolkit make a difference in how the visit went?
 - o What effect, if any, do you think the Healthcare Toolkit had on your relationship with your healthcare provider? (e.g. communication, adaptations to the environment etc.)

Usability

- How easy was it to use the Healthcare Toolkit (with help if needed)?
 - o How much of the information in the Healthcare Toolkit was easy to understand (with help if needed)?
- How long did it take for you to get used to using the Healthcare Toolkit?
 - o How much help, if any, did you get while you were using the Healthcare Toolkit?
- When you used the Healthcare Toolkit, which parts of the toolkit did you use most?

Acceptability

- How important is the information in the Healthcare Toolkit?

- Was the information in the Healthcare Toolkit relevant (in an Australian context)?
- How useful was the information in the Healthcare Toolkit?
 - What did you find most useful about the Healthcare Toolkit?
 - What did you like least useful about the Healthcare Toolkit?

Future Use

- Would you use the Healthcare Toolkit again?
 - Would you recommend the Healthcare Toolkit to a friend?
 - Would you recommend the Healthcare Toolkit to healthcare providers?
- What would make it easier for you to use the Healthcare Toolkit?
- Do you think this toolkit should be widely implemented within Australian healthcare?
 - Why or why not?