

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

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## ABSTRACT

**Background.** Autistic adults experience barriers to accessing health care, such as service provider communication not meeting their needs, healthcare facilities causing sensory discomfort and feeling fear or anxiety regarding their healthcare visit. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) developed and trialed an online healthcare toolkit to reduce such barriers and improve healthcare interactions between autistic adults and their primary care providers in the United States. This preliminary study aimed to explore experiences of autistic adults using the AASPIRE Healthcare Toolkit in Australia. **Methods.** Semi-structured interviews were conducted with six autistic adults about their experiences and perceptions of utilising the toolkit in an Australian healthcare setting. **Results.** Participants identified that the toolkit facilitated their interactions with health professionals by providing structure to appointments, supplementing new knowledge and increasing individual confidence. They also offered suggestions to tailor the toolkit for use in Australia. **Conclusions.** Future research should seek to explore the experiences of autistic adults using a version of the toolkit adapted for Australian use, as well as exploring the views of health professionals utilising it.

**Keywords:** adult, autism spectrum disorder, autistic, health resource, health services, qualitative content analysis, qualitative description, qualitative research.

## Introduction

The healthcare needs of autistic<sup>1</sup> adults are often considerable. They have higher rates of physical and mental health conditions than the general population (Croen *et al.* 2015; Vohra *et al.* 2017), as well as decreased life expectancy (Hirvikoski *et al.* 2016; Hwang *et al.* 2019). They have more outpatient visits for primary care and mental health than the general population, with rates of use increasing with age (Zerbo *et al.* 2019).

Many autistic adults report barriers when accessing health care (Mason *et al.* 2019). These include individual factors such as sensory issues (Dern and Sappok 2016; Gerber *et al.* 2017), difficulties with emotional regulation and/or communication (Raymaker *et al.* 2017) and previous negative healthcare experiences (Vogan *et al.* 2017). Barriers to health care also include social factors such as stigma and isolation (Singh and Bunyak 2019) and the cost of services (Raymaker *et al.* 2017; Singh and Bunyak 2019); and environmental factors such as healthcare system navigation (Raymaker *et al.* 2017; Vogan *et al.* 2017), and lack of accessible facilities (Dern and Sappok 2016). In addition, health professionals often report feeling unprepared when interacting with autistic adults due to limited professional knowledge and training (Warfield *et al.* 2015; Zerbo *et al.* 2015; Urbanowicz *et al.* 2020).

Resources that can identify and reduce general and autism-specific barriers to health care are vital for improving healthcare experiences for autistic adults (Raymaker *et al.* 2017). The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit is an online resource, developed with autistic adults,

<sup>1</sup>This paper uses identity-first language (i.e. autistic adult) or neutral language (i.e. on the autism spectrum) as preferred by many autistic adults and their allies.

which aims to improve interactions with health professionals (Nicolaidis *et al.* 2016). The toolkit aims to increase healthcare self-efficacy of autistic adults, decrease barriers to accessing health care and improve patient–provider communication (Nicolaidis *et al.* 2016). The toolkit was evaluated in the US with 259 autistic adults and 51 primary healthcare professionals in a mixed methods study, with autistic adults reporting less barriers to health care and increased healthcare self-efficacy and satisfaction regarding health communication (Nicolaidis *et al.* 2016). Health practitioners also reported that the toolkit was beneficial in clarifying clients’ needs and enabling self-advocacy (Nicolaidis *et al.* 2016). Although the toolkit has been evaluated in the US, there has been limited qualitative research into the experience of autistic adults using the toolkit and it has not yet been evaluated in other countries.

There is a paucity of published research on the healthcare experiences of autistic adults living in Australia. However, due to similarities within health systems globally, it is likely that many healthcare experiences of autistic adults are universal. Therefore, based on promising findings from the US-based study, the AASPIRE Healthcare Toolkit may potentially benefit autistic adults during healthcare interactions in Australia. This preliminary study aimed to explore the user experience of the AASPIRE Healthcare Toolkit in Australia from the perspectives of autistic adults.

## Methods

This study used a qualitative description research design, as described by Sandelowski (2000, 2010), comprising semi-structured interviews with autistic adults. This design is the preferred approach when straight descriptions of phenomena are desired (Sandelowski 2000). It aims to provide a low inference, detailed summary of events in lay terms (Sandelowski 2000).

## Participants

Autistic adults were included if they reported a diagnosis of autism, were aged  $\geq 18$  years, lived in Australia and could speak and read in English. Convenience sampling was used to identify potential participants within the Queensland Centre for Intellectual and Developmental Disability (QCIDD) and the Cooperative Research Centre for Living with Autism (Autism CRC) networks. Study flyers were posted on each organisation’s social media and websites. Autistic participants from previous Autism CRC research studies exploring autism in adulthood were also emailed about participating in the current study.

Thirty-one autistic adults expressed interest in participating, with 13 consenting to participate. However, only six participants went on to access the toolkit, complete the

**Table 1.** Participant characteristics.

	No. respondents (%)
<b>Gender</b>	
Female	2 (33)
Male	4 (66)
Age range (years)	23–72
<b>Autism diagnosis reported by participants</b>	
Asperger’s Disorder/Syndrome	5 (83)
High Functioning Autism	1 (17)
<b>Ethnicity</b>	
Caucasian	6 (100)
<b>Born in Australia</b>	
Yes	5 (83)
No	1 (17)
<b>Marital status</b>	
Married or de facto	5 (83)
Single	1 (17)
<b>Living situation</b>	
With partner (with or without children)	5 (83)
Alone (with or without children)	1 (17)
<b>In general, how would you describe your ability to understand what people say?</b>	
I usually can understand spoken language well	4 (66)
I often have a hard time understanding or processing what people say	0
I understand very little spoken language	0
Other (e.g. If there is a lot of background noise I can’t follow or retain information)	2 (33)
<b>In general, how would you describe your ability to speak?</b>	
I usually can speak well	4 (66)
I can speak, but often have a hard time saying what I want to say	1 (17)
I have a very hard time speaking (e.g. I only can use short phrases)	0
I have little or no ability to speak	0
Other (e.g. I find speaking to or with more than one person difficult)	1 (17)

demographic questionnaire and participate in an interview. People who provided consent, but did not go on to access the toolkit or complete the demographic questionnaire, were followed up once or twice. It was not feasible or appropriate to follow up potential participants more than twice. Four men and two women participated in this study, ranging in age from 23 to 72 years (Table 1).

## Study procedure

Study documents were developed in conjunction with two autistic adults not participating in the study. These adults advised the research team and provided feedback on draft study documents including the information sheet and consent form. Their input resulted in the development of an easy read information sheet for potential participants who may prefer simpler language and less detail.

Potential participants were provided with an information sheet and consent form and were encouraged to ask any questions prior to consenting. Once signed consent was received from the participants themselves, they were provided with a demographic questionnaire and directed to the AASPIRE toolkit website and, if requested, were posted a printed copy of the toolkit.

### AASPIRE healthcare toolkit

The toolkit was developed using community-based participatory research methods in the United States, with autistic adults having direct input into the development and evaluation of the toolkit (Nicolaidis *et al.* 2016). The toolkit provides access to basic health information, rights, diagnosis information, checklists, worksheets (e.g. Making an Appointment) and the Autism Healthcare Accommodations Tool (AHAT) (Nicolaidis *et al.* 2016). Although the toolkit is designed to be accessed mainly via the website, worksheets and documents can be downloaded and printed. Two participants in this study requested such printouts.

Participants were asked to review the toolkit and use any section/s they wanted with their chosen healthcare provider (e.g. general practitioner, psychologist). Following this, interviews were scheduled.

## Data collection

Demographic questionnaires and semi-structured interviews were completed. The questionnaire collected information regarding the participants' autism diagnosis, age, gender, living arrangements and communication (see Supplementary material). Semi-structured interviews were selected as the interview format to provide a focused exploration of topics, but also allow participants to elaborate as desired. Interviews were conducted by the first author and explored topics including participants' first impression of the toolkit, its ease of use, whether it made a difference to their healthcare interaction and what could be changed for an Australian context (see Supplementary material). The interview guide was piloted via video conference with two autistic adults not participating in the study to gain feedback on the structure of the questions. They provided feedback that the questions asked were appropriate and no changes were required. Participants could complete the demographic questionnaire electronically through Qualtrics (Qualtrics 2018, 'Qualtrics') or via hard copy. All except one participant completed it online. Participants could

complete the interview through various mediums (in person, or via video conference, phone or email), which is best practice in autism research (Nicolaidis *et al.* 2019). All participants elected to complete their interviews via email. The interview guide was emailed to participants, who were instructed to email their responses to the research team, answering follow-up questions from a researcher as required.

## Data analysis

Interview data were analysed using qualitative content analysis (Zhang and Wildemuth 2005). Initially, the first author read and re-read the transcripts and inductively developed codes describing the participants' experiences with the toolkit. The other authors then met to collaboratively review, revise and agree on an initial coding scheme. The first author then reviewed all transcripts using the revised codes and began to group these codes into categories, with a focus on highlighting findings that would help us understand whether the toolkit should and could be used in Australia, and what changes, if any, were needed. These categories were iteratively reviewed over several meetings by the entire author team before coming to agreement on findings.

## Ethics approval

The study was approved by the School of Health and Rehabilitation Sciences in accordance with the ethical review process of The University of Queensland (#2018SHRSOCT002). Potential participants were provided with an information sheet and consent form and were encouraged to ask any questions prior to consenting. Once signed consent was received, participants were provided with a demographic questionnaire and directed to the AASPIRE toolkit website and, if requested, were posted a printed copy of the toolkit.

## Results

Six autistic adults completed email interviews. Among the six, four utilised the toolkit with either their general practitioner, psychiatrist, psychologist or dietitian, whereas two declined to use it and provided feedback on why they chose not to. Participant responses were grouped into five main categories describing their user experience of the AASPIRE healthcare toolkit.

### Usefulness of the AASPIRE healthcare toolkit

Participants described the most useful aspects of the toolkit for them. Harry said the toolkit 'would be useful if I need[ed] to see a new primary healthcare provider, as an introduction'. Leon suggested it would be useful for adults on the spectrum who are 'new to the diagnosis and hav[ing] a rudimentary understanding of autism' and for him in

educating others such as family and colleagues – through the ‘helpful suggestions for how to manage my anxiety in certain situations when engaging with my family members’ and ‘to show to people I work with to give them a basic understanding of how I interact and why I behave in certain ways’.

One way to use the toolkit with a healthcare provider is through the development of a Personalised Accommodations Report using the AHAT. Ned stated that he would recommend the toolkit to health professionals because ‘not every healthcare provider makes such accommodations and having it spelt out explicitly in the AHAT is really beneficial’. He explained that ‘people fall through the cracks as having a tantrum or being rude, when that is far from the case. An individualised report can really assist in getting providers and patient on the same page’. All participants who used it stated they would recommend the toolkit to autistic friends.

### Developing capacity

Participants were able to prepare for their appointment using the toolkit, using resources such as the ‘Making An Appointment’ worksheet and becoming aware of issues to raise. Jim wrote, ‘[I] made a paper list of all the issues I wanted to cover, then memorised them. Then [I] rehears [ed] the discussion in my head so I wouldn’t forget any salient points’. Kelly stated that the toolkit ‘prompted me to think about what I wanted from the appointment with my doctor’ and ‘made me more aware of what I needed to do before, during and after an appointment so that I didn’t miss bringing up issues that I would have otherwise forgotten’.

The toolkit also provided ‘structure to questions’ during the appointment. Kelly felt that the toolkit ‘reminded [her] to think about what was happening in the appointment and to listen more carefully and follow up what [she] was asked to do e.g. mak[ing] an appointment to have blood taken’. Leon explained that it was ‘a useful tool to ensure salient points were addressed’.

According to participants, the toolkit facilitated communication between them and their health professionals. Leon noted that, when using the toolkit within a healthcare interaction, it provided him with ‘more information so we [he and his psychiatrist] were communicating as equals, which my psychiatrist does well anyway but it enhanced this communication’. Leon also reported that it increased his confidence as it ‘prepares the autistic person with enough confidence and skill to seek aid in whatever field he/she needs’.

### Ease of use

Participants discussed the presentation of the toolkit, including its format and content. Kelly perceived it as lengthy and Leon wrote that it was ‘heavily text based’ and that the ‘volume of text also made it slightly overwhelming’. In contrast, Jim stated that the ‘toolkit was complete and

detailed so that all aspects were made available for consideration’, while expressing that there ‘seem[ed] to be a lot of repetition’ in it. He also perceived that it had ‘too many acronyms’ which ‘made reading the content confusing and fragmented’.

Two participants suggested several changes to the toolkit. Leon proposed that ‘the content could potentially be ‘chunked’ or broken down a bit further’ using ‘clear headings’. Jim suggested ‘reducing the number of sections...’. Leon suggested using video presentations to break up the ‘volume of text’. Two participants, Leon and Ned, described how the website was not easily accessible on a mobile device, suggesting it be available via an app, mobile website option or a chat bot.

### Personal factors associated with using the toolkit

Participants who used the toolkit identified individual characteristics such as their vocabulary, preferred method of accessing information and personal preference as factors influencing their use of it. When viewing the toolkit, Jim said that, due to his vocabulary, he took longer to understand the meaning intended by its authors. In addition, Kelly described difficulty remembering things which were new to her, requiring practice and time before getting used to the toolkit. Ned stated it took him ‘a few weeks’ to get used to using the toolkit, ‘1–2 days to digest and read information, then introduce it over [the] next appointment, follow up on it in a subsequent appointment to evaluate does it work well for me’.

Harry, who did not use the toolkit with a health professional, explained that the toolkit ‘seems to list things I already do before and after an appointment with a healthcare provider’. This also included being familiar with their existing healthcare professional. As Kelly described, ‘I have been going to Dr [A] and Dr [B] for about 3 years and Dr [C] for 5 years. I found a lot of the things to take were not necessary’. This reiterates previously noted comments by Harry, who felt the toolkit would be useful with a newer healthcare provider.

### Implementing the toolkit in Australia

All participants expressed that the toolkit could be implemented in Australia with some adaptations. They emphasised that US-specific information, such as the legal rights information, certain terminology and linked websites, needed to be changed to include information relevant to Australia. The US-specific information was a barrier to actually using the toolkit for Jean who did not use it with a health professional, explaining ‘I do not feel it [toolkit] [is] relevant to use due to its US bias and irrelevant links’.

Participants stated several barriers to its potential implementation. Leon noted that the information presented in the toolkit may appear ‘basic’ to healthcare professionals who

are 'already dealing with patients who have autism as they would have their own experience in this field'. Jim also noted that using it alongside a health professional may be interpreted as 'a blight on professionalism'. He explained:

If a client said to a professional that 'you are not addressing my needs', or 'you are not being clear enough in your explanation', [it] might put the professional on the defensive and appear that the client deemed him/her to be unprofessional.

## Discussion

The AASPIRE Healthcare Toolkit was developed in the US to improve primary healthcare experiences of autistic adults (Nicolaidis *et al.* 2016). This preliminary study explored the experiences of a small group of autistic adults using the toolkit. The six participants were mostly male, partnered and able to understand spoken language well and speak well. All participants reported either a diagnosis of Asperger's Disorder/Syndrome or High Functioning Autism, and all were Caucasian. The lack of diversity in our sample limits the transferability of our findings to the broader population of autistic adults. Nevertheless, this study is an initial step in developing an understanding of whether the toolkit should and could be used in an Australian context. It is the first study of the AASPIRE Healthcare Toolkit in Australia, to focus solely on the qualitative experience of users and to explore the use of the toolkit in a naturalistic setting, in that participants accessed the toolkit as they would have if they were a community member accessing it and had choice and control over what sections to use, and with what health professional.

The four participants who used the toolkit in our study expressed that they were able to use the toolkit independently and it improved their capacity and confidence during healthcare interactions with a variety of health professionals including general practitioners, psychiatrists, psychologists and dietitians. Difficulty communicating with healthcare providers can impact on satisfaction with healthcare services for autistic adults (Gerber *et al.* 2017) and resources that can assist them in explaining their symptoms, and interpreting and acting on medical advice may be of benefit (Nicolaidis *et al.* 2016). Participants felt that the toolkit filled knowledge gaps, enabled them to remember things during and after the appointment, provided detailed information for them to refer to, and improved their healthcare interactions. Similarly, autistic adults in the study by Nicolaidis *et al.* (2016) were able to use the toolkit to clarify their needs during appointments, helping them to form the right words, which enabled self-advocacy.

Participants who used the toolkit in our study also felt that it reduced the power imbalance between themselves and their healthcare providers. This aligns with the concept

of power sharing in health care, in which patients are viewed as experts and acknowledged as holding individualised knowledge on themselves (Townsend and Polatajko 2013). Encouraging power sharing through mutual trust, respect, acceptance and patient education can contribute to positive experiences of the patient-provider relationship, contributing to improved quality of interpersonal interactions and healthcare outcomes (Kelley *et al.* 2014).

Another finding that emerged from our participants' experiences was how the toolkit could potentially be useful for adults newly diagnosed as autistic or when seeing a new health professional for the first time. Research reports those diagnosed as autistic in adulthood, experience difficulties finding and accessing support post-diagnosis (Jones *et al.* 2014; Baldwin and Costley 2016). The toolkit could potentially be used as a reference point for these adults.

In addition, participants in our study indicated that the presentation of the toolkit influenced how it was used. To illustrate, the toolkit, which at present contains primarily text-based content, was challenging to process for three participants. Many adults on the spectrum have atypical cognitive processing speeds and different preferences for learning (Friedman and Bryen 2008; Williams *et al.* 2015). Although the toolkit was originally developed with the participatory involvement of autistic adults (Nicolaidis *et al.* 2016), our findings suggest there may be room for ongoing development of the toolkit. Participants from our study recommended improvements to the toolkit, including having multimodal features (such as a combination of video and text) on various platforms (such as apps or a mobile version) and simpler headings that separate 'chunks' of information. This could potentially lead to increased accessibility for those who may have difficulty processing larger amounts of information or find it hard to discriminate visual information. This is congruent with research that states that using visual cues (e.g. pictures, icons and graphics), enabling grouping of information using headings, and multimodal websites combining text, audio and visual, is a step towards universal design, as it provides adaptability to individual user needs and preferences (Cline and Haynes 2001; Friedman and Bryen 2008; DeWalt *et al.* 2011). Additional research is recommended to further explore the usability of the toolkit and modifying the presentation of information to provide a more accessible format.

## Limitations

Although this study provides valuable insights, the findings should be viewed with caution due to a number of limitations. A key limitation of the study is the low number of participants included in the analysis. It was not feasible or appropriate to follow up more than twice with potential participants and it was not feasible to extend our recruitment time. Additionally, our small convenience sample lacked diversity, limiting the transferability of our findings.

Furthermore, only those with internet access were targeted, as all participants were required to access the internet at some point during the study. Despite the small and narrow sample, our preliminary study sheds light on the potential benefits of the toolkit and future areas of research. Future research should seek to explore the perceptions of health professionals using the toolkit, recruit a more diverse sample of autistic adults (e.g. younger adults or those with complex communication needs), and focus more on the integration of the toolkit within primary care systems.

## Conclusion

This was a preliminary study aimed at exploring the user experience of the AASPIRE Healthcare Toolkit from the perspective of autistic adults in Australia. The four participants in this study who used the toolkit reported that they were able to obtain knowledge and information, which benefited their interactions with their health professionals including general practitioners, leading to increased confidence and empowerment. An Australian-adapted healthcare toolkit may potentially improve the healthcare experiences of autistic adults living in Australia.

## Supplementary material

Supplementary material is available [online](#).

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**Data availability.** The data that support this study cannot be publicly shared due to ethical or privacy reasons.

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