



AutismCRC

Draft Updated Guideline: Organisation Feedback Form

INSTRUCTIONS

Thank you for telling us what you think about the draft version of the updated National Guideline for Assessment and Diagnosis of Autism in Australia. Please follow these steps to share feedback on behalf of your organisation.

1. Read and complete the Participant Information Statement and Consent Form (attached in this document and in the online form).
2. Consult with relevant people within your organisation. It is expected that each person who contributes will read the Participant Information Statement (attached in this document), so that they understand the context for this feedback survey, as well as their individual rights, including the right not to contribute feedback.
3. Read and respond to the questions in the form and in the online survey to your satisfaction.
4. Ensure that your form is approved by the relevant officer/authorising person.
5. Lodge the form via the survey link – https://redcap.link/ADGupdate_public_consultation

If you have any questions about the process for providing feedback, please contact the research team at ADGupdate@griffith.edu.au

PLEASE NOTE: all feedback must be submitted by 4:00pm (AEST), 29 May 2023 to be considered.

No submissions after this time can be accepted. No extension requests can be granted.

Information Statement for the Research Project:

Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia: Community Feedback on the Draft Guideline (GU ref no:2022/780)

Part 1: Participation Information

What is this project about?

The Autism CRC is leading the update of the '*National Guideline for Assessment and Diagnosis of Autism Spectrum Disorders in Australia*'. A draft version of the updated Guideline has been developed based on both research and consultation with the community. The draft Guideline includes a set of Recommendations and Good Practice Points for practitioners that are intended to guide diagnostic decision-making and the comprehensive assessment of individual support needs.

Why are you being invited to participate?

We want to hear feedback from all community members on the draft version of the updated Guideline. You are invited to provide your feedback on the draft Guideline via an online form. Your feedback may inform revisions to the Guideline, to make it better.

Who can participate in the research?

We warmly invite feedback on the draft version of the updated Guideline from the following community members/groups, aged 18 years and over:

- People on the autism spectrum/autistic people.
- Parents, caregivers, and family members of individuals on the autism spectrum.
- Practitioners involved in assessment and/or diagnosis of autism across the lifespan.
- Members of organisations/bodies/groups that are involved in assessment and/or diagnosis of autism.
- Organisations/bodies/groups that are involved in assessment and/or diagnosis of autism.
- Other members of the autism community (e.g., informal support people, service providers, researchers).

How can I participate?

- You can submit your own response, as an individual.
- You can contribute to a shared response, within an organisation. If you contribute to a shared response within an organisation, you can still submit your own individual response as well.

What would I need to do?

1. Understand the project and your role

You are reading this Participant Information Statement, because your organisation is planning to submit a response that reflects the views of the organisation.

2. Read the draft Guideline

A copy of the draft version of the updated Guideline is available online via the Autism CRC.

The draft Guideline includes:

- An introduction about the purpose and scope of the Guideline, who the Guideline is intended for (i.e., target users), and information about how the draft Guideline was updated.
- A set of Recommendations and Good Practice Points relating to the following aspects of the assessment and diagnosis process:
 - Guiding principles
 - Foundations of assessment
 - Making a referral for assessment

- Comprehensive needs assessment
- Diagnostic evaluation

3. ***Providing feedback about the draft Guideline***

People within your organisation are responsible for (a) sharing this form with each person who is invited to contribute, (b) working out the best way to consult with people within the organisation, and (c) preparing and submitting the response.

Do I have to participate?

Participation in this research is entirely your choice. Only information collected from those who give consent will be included in this phase of the project. If you decide not to participate, this decision will not disadvantage you or impact your relationship with Griffith University or any other institutions affiliated with this research.

What happens if I change my mind?

If one or more people in the organisation change their mind after contributing feedback, it is expected that their responses will be removed prior to submitting. If a decision is made within the organisation to not submit feedback collected, do not submit the feedback. Once the feedback is submitted, if there is a change of mind, the authorising officer should contact the research team at ADGupdate@griffith.edu.au. The research team will endeavour to, but cannot make any guarantee that it will be able to, remove the submission from consideration. The research team will not accept a revised submission.

What are the benefits of participating?

We hope that it will be a positive experience for you, in helping to inform the updated Guideline. While you may not receive any direct benefits from participating in this research, the benefits of the research more broadly include an opportunity to improve the National Guideline for Assessment and Diagnosis of Autism in Australia.

Are there any potential risks?

We do not believe there are any direct risks associated with participation in this research.

Who are the researchers?

A/Professor David Trembath, Griffith University & Telethon Kids Institute
Dr Emma Goodall, Griffith University
Professor Andrew Whitehouse, Telethon Kids Institute & University of Western Australia
Dr Rhylee Sulek, Griffith University
Dr Kandice Varcin, Griffith University & Telethon Kids Institute
Dr Hannah Waddington, Victoria University of Wellington
Dr Nicole Dargue, Griffith University
Emma Hinze, Griffith University
Dr Rachelle Wicks, Griffith University
Dr Veronica Frewer, Griffith University

Who can I contact for further information?

You might be unsure if you are able to participate or unsure about how the research process works. We encourage you to contact the research team (ADGupdate@griffith.edu.au) to discuss this and anything else you might wish to talk about in relation to the project. This email address is monitored each working day by A/Prof David Trembath and members of the project team.

How can I receive information about the research results?

Regular updates regarding the progress and publishing of the Guideline will be provided on the Autism CRC website. Participants will be able to access a copy of the updated Guideline, once published. If you would like to discuss this further with the research team, you can do so via email (ADGupdate@griffith.edu.au).

How can I trust this research is safe for me?

This research is being conducted by skilled research staff and supported by a Guideline Development Group that includes people with a range of knowledge and experience, including autistic adults and family members of people

Draft Updated Guideline for the Assessment and Diagnosis of Autism in Australia: Organisation Feedback Form on the autism spectrum. The team has updated the Guideline based on international and national research and community consultation activities undertaken in Australia in 2022-2023. The team has also made available different options for you to share your feedback on the draft Guideline. For individual submissions, only anonymous feedback will be used and reported. For organisation submissions, only the name of the organisation will be published alongside the feedback.

Part 2: Ethical Information we must provide you.

What will be done with the information you provide?

1. **We will use it to revise the updated Guideline:** Feedback on each section and each Recommendation will be considered alongside the evidence collected through the original Guideline development process and the update process. We will read all written responses you provide using the designated online survey. To ensure that everyone providing feedback has the same opportunity, and to ensure that the Guideline Development Group considers all feedback equally, we will only consider feedback provided via the online form and we make no undertaking to review (and will not respond to) any further information referred to via links (e.g., weblinks, resources).
2. **We will provide a de-identified copy of all responses to the National Health and Medical Research Council.** This is a requirement for the development and update of clinical guidelines in Australia. All feedback collected from the community through this process will be submitted anonymously to the NHMRC. The NHMRC uses this information to evaluate how the Public Consultation occurred and how the information gathered was used, when they decide whether or not to approve the updated Guideline.
3. **We will publish your organisation's name, a copy of your feedback, and our response, when the updated Guideline is released.** This is **not** optional. By making a submission on behalf of an organisation you agree to the use of the information in this way. We will publish your responses verbatim, but reserve the right to redact any potentially personally identifying or defamatory information.

What type of feedback will you receive?

For organisational submissions, you will see a brief response from the Guideline Development Group to your feedback, when the updated Guideline is published. The Guideline Development Group will only provide feedback in this form and will not enter into additional correspondence regarding the feedback. By submitting feedback, you are acknowledging that this is the limit of feedback that will be provided.

How will privacy be protected?

The conduct of this research involves the collection, access, storage and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes, including publishing openly (e.g. in an open access repository). However, your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone (07) 3735 4375.

To further explain how your privacy will be protected, all of the data that is collected through the survey will be completely confidential. All data will be stored securely on an encrypted and password protected storage drive that will be accessible only by the members of the research team. This data will be stored securely for five years.

The ethical conduct of this research

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. Please feel free to contact the researchers if you have any questions (ADGupdate@griffith.edu.au). If you have any additional questions or concerns about ethical issues, please contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee (research-ethics@griffith.edu.au; 07 3735 4375).

**Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia: Community Feedback
on the Draft version of the updated Guideline
(GU ref no:2022/780)**

Community Feedback on the Draft version of the updated Guideline: Organisations

I confirm that I have read and understood the information sheet and I have noted that:

- I understand that my participation, and that of other people in the organisation, in this research will include:
 - Reviewing the draft version of the updated Guideline
 - Providing feedback on the draft version of the updated Guideline
- I understand that the feedback provided in the submission may be used to inform the final version of the National Guideline for assessment and diagnosis of autism in Australia.
- I understand that the feedback provided in the submission may be published alongside the final Guideline and include:
 - A summary of de-identified information about who participated (e.g., the variety of community members)
 - Direct quotes presented with the organisation name.
- I understand that by submitting feedback:
 - An identifiable copy of my feedback that includes the name of the organisation, will be provided to the National Health and Medical Research Council
 - The Guideline Development Group may contact the person submitting the feedback, to verify the submission
 - I will receive feedback when the updated Guideline is published, limited to a brief response from the Guideline Development Group
- I have read the Information Statement, or someone has read it to me in a language that I understand and the Participant Information Statement and Consent form have been made available to all people who contributed to the submission.
- I understand why this research is being conducted and how I can participate.
- I understand any risks as described above.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that I, other people who contributed to the submission, or the organisation can decide not to participate in this project.
- I am aware that once the submission is made, the research team will endeavour to, but cannot make any guarantee that it will be able to, remove the submission from consideration and publication and will not accept a revised submission.
- I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee if I have any concerns about the ethical conduct of this project (research-ethics@griffith.edu.au; 07 3735 4375).
- I agree to participate in the research.

***REQUIRED INFORMATION**

Authorising officer first and last name: Dr Zena Burgess
Organisation Name: Australian Psychological Society
Authorising officer position within the organisation: CEO
Contact email: zena.burgess@psychology.org.au

SECTION 1: Feedback on key sections within the Draft Guideline

The draft Guideline contains five key sections:

- Guiding principles
- Foundation of assessment
- Making a referral for assessment
- Comprehensive needs assessment
- Diagnostic evaluation

This set of items gives you the option to provide feedback on these overarching sections of the Guideline.

The next set of items (Section 2 of this form) gives you the option to provide feedback on specific Recommendations/Good Practice Points within each of the sections.

PLEASE NOTE: To ensure that everyone providing feedback has the same opportunity, and to ensure that the Guideline Development Group considers all feedback equally, we will only consider feedback provided via this form and we make no undertaking to review (and will not respond to) any further information referred to via links (e.g., weblinks, resources).

Feedback on Key Section: Guiding Principles

None.

Feedback on Key Section: Foundations of Assessment

Please provide your feedback (up to 150 words) on the 'Foundations of Assessment' section of the Draft Guideline. You can tell us what you like/support about this section or what could be improved.

Maximum word limit: 150 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 150 words).

Amend ^c in Table 2.1 (and throughout the Guideline) as follows:

To conduct a Lead Practitioner Diagnostic Evaluation, psychologists are recommended to have a relevant area of practice endorsement, and/or competence in the assessment and diagnosis of neurodevelopmental conditions as demonstrated by appropriate qualifications, training and experience.

The APS as the peak body for psychologists requests this change to ensure that clients have access to appropriately skilled psychologists who are competent to conduct the Lead Practitioner Diagnostic Assessment, noting that there are competent registered psychologists with advanced qualifications, training and experience in autism who do not have an area of practice endorsement or who have areas of practice endorsement other than clinical psychology, educational and developmental psychology or clinical neuropsychology.

Please reach out to the CEO through the national office on (03) 8662 3300 or by email at z.burgess@psychology.org.au should you wish to discuss this request.

Feedback on Key Section: Making a Referral for Assessment

Please provide your feedback (up to 150 words) on the 'Making a Referral for Assessment' section of the Draft Guideline. You can tell us what you like/support about this section or what could be improved.

Maximum word limit: 150 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 150 words).

We note that statements about the importance of early intervention have been removed from this section and it is unclear why this is the case. Diagnosis and intervention at any stage in the lifespan can be of value to people with autism and their families. However, research, policy and early intervention programs (e.g., NDIS early childhood approach for children under 7) all speak to the benefit of children with autism being identified and supported early in life. We recommend that early intervention is referred to in this section and practitioners be encouraged to discuss this with clients and families as part of the pros and cons for assessment and diagnosis.

Feedback on Key Section: Comprehensive Needs Assessment

None.

Feedback on Key Section: Diagnostic Evaluation

Please provide your feedback (up to 150 words) on the 'Diagnostic Evaluation' section of the Draft Guideline. You can tell us what you like/support about this section or what could be improved.

Maximum word limit: 150 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 150 words).

In Appendix 5.1, Possible differential or co-occurring diagnosis, add to the mental health assessment row: "psychiatric and psychological screening ."

SECTION 2: Feedback on Recommendations/Good Practice Points within the Draft Guideline

The draft Guideline contains 66 Recommendations. Many of these Recommendations also contain a set of Good Practice Points.

This set of items gives you the option to provide feedback on specific Recommendations (and associated Good Practice Points) within the draft Guideline. For the purposes of this form, we have included the Recommendation number and text. Please refer to the draft Guideline itself, for the associated Good Practice Points.

You can tell us (in up to 100 words) what you like/support about particular Recommendations, or what could be improved.

PLEASE NOTE: To ensure that everyone providing feedback has the same opportunity, and to ensure that the Guideline Development Group considers all feedback equally, we will only consider feedback provided via the survey and we make no undertaking to review (and will not respond to) any further information referred to via links (e.g., weblinks, resources).

Maximum word limit: 100 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 100 words).

Guiding Principles: Feedback on Recommendations

None.

Foundations of Assessment: Feedback on Recommendations

None.

Making a Referral for Assessment: Feedback on Recommendations

None.

Comprehensive Needs Assessment: Feedback on Recommendations

Recommendation 55

The Diagnostic Evaluation should involve practitioners with specified medical and/or allied health qualifications, combined with advanced training and/or experience relevant to the differential diagnosis of autism from a range of neurodevelopmental and behavioural conditions.

In 55.2, correct reference to the psychologist requirements for Lead Practitioner Diagnostic Evaluation to reflect the changes we have requested above in Feedback on Key Section: Foundations of Assessment and below in Other Feedback about Appendix 2.2

Diagnostic Evaluation: Feedback on Recommendations

None.

SECTION 3: Other Feedback

Please provide any other feedback that you feel is important for us to consider.

PLEASE NOTE: feedback provided in this section will be read and considered by the Guideline Development Group, however, it will not be published or responded to when the updated Guideline is released.

Maximum word limit: 150 words (to ensure equal opportunity, the Guideline Development Group will not read beyond 150 words).

Correct Appendix 2.2 to reflect Ahpra training, registration and protected title requirements.

- Training - change to: Successfully completed a six-year sequence of education and training which includes a 4-year Australian Psychology Accreditation Council (APAC) endorsed university degree, followed by: 2 years of supervised professional training, or a 5th and 6th year higher degree or a 5th year higher degree plus a 1-year internship. Psychologists who hold an area of practice endorsement (e.g., clinical psychology, educational and developmental psychology or clinical neuropsychology) have advanced training in a specific area of practice, having completed a postgraduate qualification and a registrar program in an approved area of practice.
- Registration or membership – remove from “OR” onwards as this essentially repeats the first statement and inadvertently suggests there are separate Ahpra registration requirements for the three named areas of practice endorsement.
- Three areas of practice endorsement as examples is appropriate in the context of this Guideline but must align with Ahpra-protected titles: educational and developmental psychology (not educational/development psychologist.)

A note from the Guideline Development Group (GDG)

Thank you very much for telling us what you think about the draft version of the updated Guideline for the Assessment and Diagnosis of autism in Australia. The information that you and others provide will be considered in the final version of the updated Guideline.

The next step for the research team will be to read, review and consider all of the information provided. The Guideline Development Group will then make the necessary amendments to the Guideline.

If you have not already done so, please register with the Autism CRC to receive updates about the Guideline. You can do so here <https://www.autismcrc.com.au/access/national-guideline/2022-update>.

Before we finish, we want to take a moment to acknowledge the time it takes to complete forms like this. While we are not able to send a personal response to each person and organisation who provides feedback, please know that we genuinely value the information you have provided and will be reading every word.

Thank you for helping to make the updated Guideline the best it can be.

We look forward to sharing the updated Guideline in due course, via the Autism CRC website.

Sincerely,

David, Emma G, Andrew, Hannah, Kandice, Rhylee, Emma H, Rachelle, and Nicole on behalf of the Guideline Development Group.