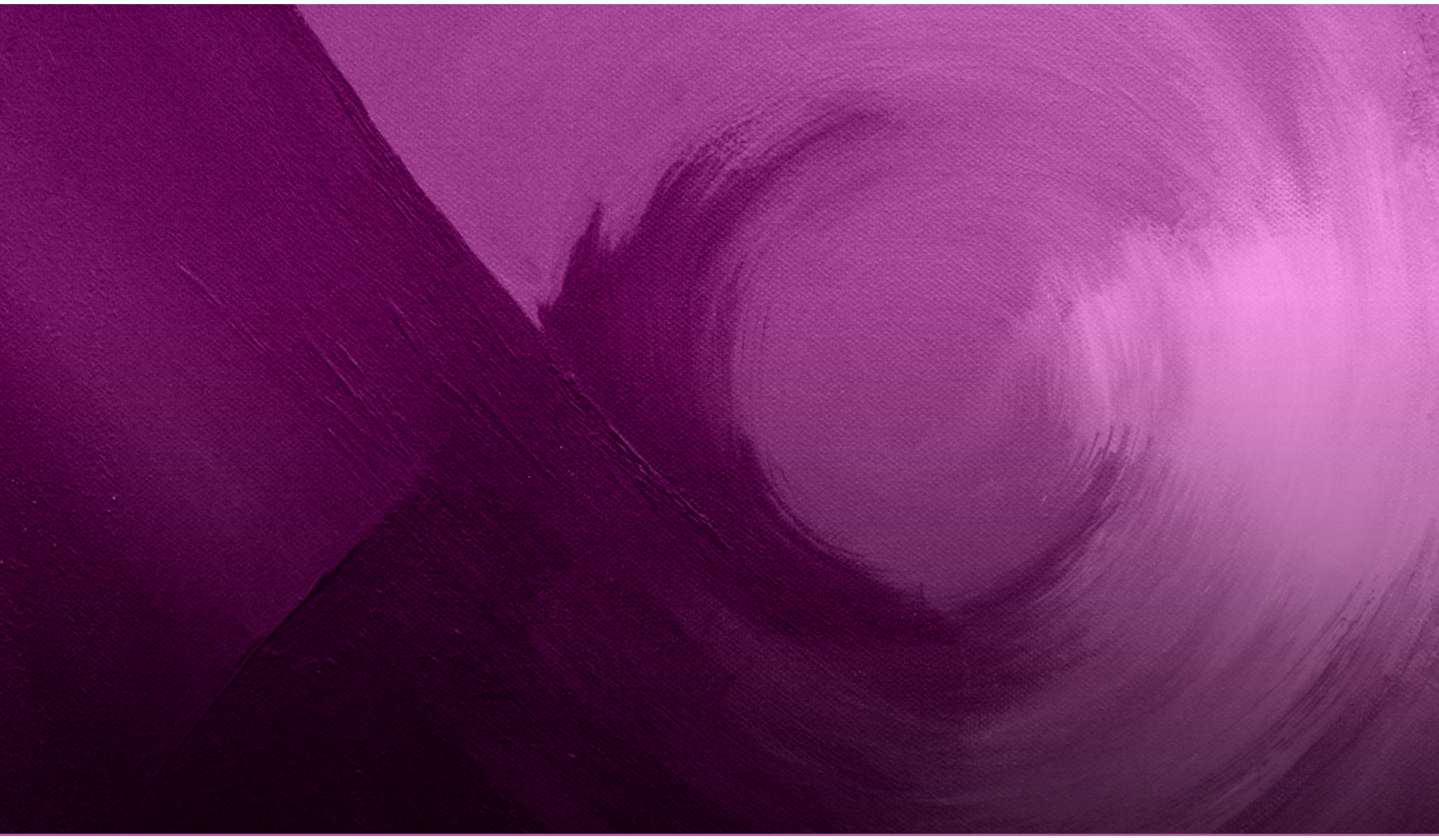
Administration and Technical Report

National Guideline

For the assessment and diagnosis of autism in Australia

PUBLISHED 2018 | UPDATED 2023



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Copyright and disclaimer

Citing this Guideline

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Acknowledgements

The Guideline Development Group warmly acknowledges the following people who have contributed to the development of the Guideline.

Autistic people, families, and community

We warmly acknowledge and thank all members of the autistic and autism communities who have so generously shared their experiences, insights, views, and expertise to inform the original, and update of, this Guideline. This includes participation in the original studies included in the systematic reviews undertaken as part of the development and update, participating in the community consultation activities, and providing feedback on draft versions of the Guideline.

Original Guideline Development Group

We warmly acknowledge the efforts of the members of the Guideline Development Group that was responsible for developing the original Guideline in 2018, including the Research Executive Committee – Andrew Whitehouse, Kiah Evans, Valsamma Eapen, Margot Prior, and John Wray. We extend this acknowledgement to the many people who supported their work, and who are identified in the original Guideline document.

Research Support

We warmly acknowledge and thank Veronica Frewer (Griffith University) who provided project coordination support and contributed to the research activities, along with Katie Brooker (University of Queensland), Briohny Dempsey (Telethon Kids Institute), Amy Giesberts (University of Queensland), and Libby Groves (Griffith University) who supported the research activities.

Reference Group

We warmly acknowledge and thank the members of the Reference Group, each of whom represented an organisation that is relevant to assessment and diagnosis of autism in Australia. The names of all members of the Reference Group, and the organisations they represent are included in the Guideline.

Further Assistance

We warmly acknowledge and thank the following people who provided additional assistance in updating the Guideline. Justina Sparks (Telethon Kids Institute) and Felicity Rose (Telethon Kids Institute) provided expert input regarding current, and planned, Guideline implementation activities. The following people at Autism CRC contributed to sharing information with the community about the Guideline development process and preparing the documents (graphic design, copyediting): Cally Jackson, Jason Kotzur, Darcy Maguire, Braeden Monnier, and Sally Vidler.

Common abbreviations

Abbreviation	Full term
DRWG	Draft Recommendations Working Group
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth edition
EtD	Evidence to Decision
GDG	Guideline Development Group
GRADE	Grading of Recommendations Assessment, Development and Evaluation
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
PICO	Population-Comparison-Intervention-Outcome framework
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SR	Systematic Review

1. Introduction

This chapter outlines the purpose and contents of this report.

1.1 Purpose of this report

The purpose of this report is to outline the administrative aspects of the process for updating the 2018 Guideline and includes a detailed summary of the methods used.

This report acknowledges, but does not repeat, the information contained in the Guideline and supporting documents (including the Administration and Technical Report) for the original 2018 release of the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia* (Whitehouse et al., 2018a, b).

1.2 Overview of information presented

This report comprises the following chapters:

1. **Introduction**
2. **Project Administration.** This chapter provides a summary of the Guideline questions, the people involved in its development, project governance, and the Public Consultation process.
3. **Research Methodology.** This chapter provides a summary of the systematic process used to move from Guideline questions to the collection and synthesis of evidence from a variety of sources, through to the formulation of recommendations and the production of the Guideline and associated documents.
4. **Recent evidence in relation to assessment and diagnosis for autism: An umbrella review.** This chapter presents the aims, method, and results of this umbrella review (review of reviews) regarding the following aspects of assessment and diagnosis for autism: (a) existing guidance; (b) clinical tools and processes; (c) considerations regarding personal and environmental factors; and (d) experiences of the autistic and autism communities.
5. **Community Consultation: Online Survey.** This chapter presents the aims, method, and results of this study seeking the views of all members of the autistic and autism communities.
6. **Community Consultation: Focus Groups.** This chapter presents the study aims, method, and results of this study seeking the views and experiences of autistic people, family members, and practitioners.

2. Project Administration

2.1 Chapter overview

This chapter provides a summary of how the Guideline update project was administered. It begins with a statement of the purpose of the Guideline, scope, and target users to provide context for readers, drawing on the same information presented in the Draft updated Guideline document. This chapter also includes a summary of the people involved in the Guideline update process and project governance.

2.2 Guideline Purpose and Objectives

This Guideline was developed to support clinicians involved in clinical assessment that may result in a diagnosis of autism spectrum disorder (ASD) according to the Diagnostic and Statistical Manual of Mental Disorders which is currently in its 5th edition (DSM-5-TR; American Psychiatric Association, 2022) and the World Health Organization's International Statistical Classification of Diseases and Related Health Problems, which is currently in its 11th edition (ICD-11; World Health Organization, 2019). The specific objectives were to develop a Guideline that:

1. Describes a rigorous framework for accurately determining whether an individual meets the criteria for a clinical diagnosis of autism.
2. Outlines a comprehensive approach to identify related support needs.
3. Contains sufficient flexibility to apply to the assessment of a child, adolescent or adult of any age, gender, cultural or language background, communication or intellectual capacity, and medical complexity, living anywhere in Australia.
4. Describes a feasible process for clinical service providers to administer across the full breadth of community settings in Australia, including public and private healthcare settings.
5. Meets the needs and expectations of individuals being assessed and their caregivers.

2.3 Scope

The Guideline is focused on assessment that is conducted where a clinical diagnosis of autism is being considered. The process includes making a referral, Assessment of Functioning, Medical Evaluation, and Diagnostic Evaluation. The scope of the Guideline update – which is unchanged from the original Guideline - was determined prior to the commencement of the research and community consultation activities, and is summarised in Table 2.1.

Table 2.1. The scope of the Guideline.

Aspect	In Scope	Out of Scope
Recipients of services	Children, young people, and adults of all ages, for whom a clinical diagnosis of autism may be relevant.	Children, young people, and adults not meeting this criterion.
Focus of assessment	Assessment where a diagnosis of autism is being considered. This includes assessment of individual characteristics, strengths, and supports needs, whether or not the assessment leads to a diagnostic evaluation and decision.	Assessment where a diagnosis of autism is not being considered, or that focuses solely on goal setting and/or support planning.
Outcomes of assessment	Sharing and documentation of findings, as well as recommendations for supports where relevant.	The provision of supports following assessment and diagnosis, irrespective of whether a diagnosis of autism was given.

In presenting the scope, two considerations are highlighted:

1. People access medical and allied health assessments for a variety of reasons. For example, a person may seek an assessment if they have a difference or delay in development, are experiencing restrictions and/or barriers in life activities, and/or may have a diagnosable condition. A person may also access an assessment to better understand their experience of the world, but not be seeking a clinical diagnosis. In each case, the practitioner would work within their scope of practice to meet the client's needs. The Guideline, rather than attempt to account for all possible reasons for assessment, and provide Recommendations for all aspects of practice, focuses specifically on clinical diagnosis of autism.
2. It is critical that an assessment for autism takes place in the context of a broader neurodevelopmental and behavioural assessment. This Guideline is intended to operate within the assessment processes applicable for children, adolescents, and adults presenting with characteristics of a broad range of neurodevelopmental conditions.

2.4 Target users

The primary target users of this Guideline are Australian practitioners who conduct assessments that may result in a clinical diagnosis of autism.

Secondary target users of this Guideline include the following groups:

1. Individuals who have characteristics that may be explained by autism diagnosis, as well as others (e.g., partners, family) can use this Guideline to understand how to initiate, and what to expect from, assessment for autism.
2. Australian medical, nursing, allied health, and education professionals and organisations who work with children, young people, and/or adults who show characteristics of autism can use the Guideline to know when and how to make a referral for autism assessment.
3. Australian medical, nursing, allied health, and education professionals and organisations who work with autistic people can use this Guideline to understand what assessment should involve to ensure recommendations are implemented and duplication of services is avoided.
4. Australian training providers, including peak bodies and tertiary institutions, can use this Guideline to tailor educational and clinical resources, courses, and qualifications to ensure participants achieve the learning outcomes required to contribute to assessment for autism, where doing so will be within their scope of practice and consistent with Guideline Recommendations.
5. Australian funding bodies can use this Guideline to align resource allocation with the recommended process for assessment and diagnosis of autism.

2.5 Guideline funding

The Guideline was developed (2018) by Autism CRC with support from the National Disability Insurance Agency, including funding to support the coordination of the project (by Dr Kiah Evans), for the public consultation activities and for an honorarium to the Steering Committee members. The authors who led the original release - Andrew Whitehouse, Valsamma Eapen, Margot Prior and John Wray - received no personal financial or other remuneration for their involvement in the project.

As part of NHMRC methodological review, they will assess whether funding source for dissemination and implementation has been identified. David Trembath (Griffith University; Telethon Kids Institute) and Emma Goodall (Griffith University) were appointed Co-chairs of the Guideline Development Group, and Griffith University and Telethon Kids Institute received funding from Autism CRC to support this work. David's contributions were in-kind, with funding used to employ Emma Goodall and research fellows/assistants to support the work, to support community consultation activities, and to pay honoraria to the GDG members.

2.6 Process for ensuring editorial independence from funders

The GDG had complete editorial independence from Autism CRC in updating the Guideline, with each entity having clearly defined roles and responsibilities. In chronological order, the mechanisms to ensure editorial independence included:

Conceptualisation: The GDG responsible for the 2018 release of the Guideline recommended that it be updated within 5 years, consistent with NHMRC requirements.

Commissioning: Autism CRC released a call for applications for funding to lead the update of the Guideline in 2022. The call was open to all Autism CRC member organisations. David Trembath led an application that was successful. Autism CRC invited David Trembath and Emma Goodall to Co-chair the update of the Guideline. David Trembath and Emma Goodall consulted with Autism CRC regarding aims, scope, and representation, but retained complete independence in all aspects of the proposal.

Funding agreements: Autism CRC engaged Griffith University and project partners involved in the update (Telethon Kids Institute, University of Queensland, Victoria University of Wellington) via formal funding agreements. The funding agreement stipulated that each party would ensure that research was conducted in accordance with the Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council [NHMRC], 2018), which highlights the importance of honesty, rigor, and transparency: all of which rely on editorial independence.

Conduct: The GDG were responsible for all aspects of project design and delivery. Autism CRC involvement was limited to (a) receiving updates on progress towards agreed project milestones in accordance with the funding agreements and (b) facilitating the community consultation through sharing information (e.g., overview of activities, invitations to participate) via the Autism CRC website and database, and via social media. The GDG were responsible for drafting the information that Autism CRC shared with the community. All research activities were approved by the Griffith University Human Research Ethics Committee and implemented using Griffith University research infrastructure (e.g., Microsoft Teams for focus groups, REDCap for online surveys). Autism CRC was not involved in evidence synthesis nor formulation or refinement of the recommendations.

External consultation: The GDG were responsible for all consultation regarding the contents of the Guideline, including liaising with and incorporating feedback from the Reference Group.

Draft Guideline: The GDG were responsible for drafting the Guideline. Autism CRC had access to a copy of the Draft Guideline as it was developed to assist with formatting and graphic design. Autism CRC had authority to make changes to the formatting (e.g., organisation branding) and phrasing (e.g., in order to prepare plain language summaries in consultation with the GDG and to improve accessibility) but did not have authority to make changes to the meaning of any statement or recommendation in the Guideline.

2.7 Guideline Development Group

The Guideline Development Group was established in accordance with the NHMRC (2011) requirements to lead the research and community consultation process.

Terms of Reference

The Terms of Reference are presented in Appendix 2.1 and include the following information about the project:

- Background.
- Purpose of the Guideline Development Group.
- Anticipated timeline.
- Membership of the Guideline Development Group.
- Appointment of Chair.
- Responsibilities of Project Team Members.
- Meetings.
- Code of conduct for the Project Team.
- Reporting.

The Terms of Reference were signed by each GDG member. Meetings were held monthly from October 2022 to March 2023, and will continue to June 2023.

Recruitment

The members of the GDG were identified and appointed via a three-stage process.

- In the first stage, the Co-chairs identified a range of perspectives that were critical to updating the Guideline. These perspectives included lived expertise (autistic people, family members), clinical expertise (medical and allied health), expertise in human ethics, and the lived expertise of one or more Aboriginal and/or Torres Strait Islander person/s. The Co-chairs also identified research expertise that would be relevant, including in relation to co-designed research, systematic reviews, community consultation, and Guideline development. Finally, the Co-chairs considered the need for continuity from the 2018 release of the Guideline through the update, to ensure the accurate interpretation of the original context, questions, evidence, and Recommendations.
- In the second stage, the Co-chairs identified people who had knowledge, skills, and experience relevant to each of these required perspectives, and distributed invitations via email. Consideration was given to ensuring diversity within the GDG. The email included an introduction to the project and Terms of Reference. The Co-chairs made themselves available to meet with invitees to discuss the Terms of Reference.
- In the third stage, the invitees returned the signed Terms of Reference to confirm their role within the GDG.

Members

The members of the GDG, including name, position, affiliation, role, and expertise are presented in Table 2.2.

Table 2.2. Members of the Guideline Development Group.

Name	Position, role, and expertise
Mr Gary Allen	Gary Allen is the Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. Gary has worked in the human research ethics area since 1997, working with a number of research institutions, state and federal departments, private companies and research ethics committees internationally. He also has a degree in education and a professional doctorate in social sciences. Gary brings extensive experience in regards to the national and international governance of ethical conduct in research.
Dr James Best	Dr James Best is a General Practitioner and Chair of the Child and Young Person's Health, Faculty of Special Interests Group, within the Royal Australian College of General Practitioners. He brings experience working with children and families in the areas of behaviour, parenting and autism, and is extensively published in medical and mainstream publications on these and other child health topics.
Dr Nicole Dargue	Dr Nicole Dargue is a Lecturer within the Autism Centre of Excellence, School of Education and Professional Studies at Griffith University. Her research interests include factors impacting learning and communication in autistic individuals, with a focus on nonverbal communication including gestures. She is an accredited Clinical Neuropsychologist who brings experience working with autistic individuals of all ages when navigating the diagnostic process.
Prof Valsamma Eapen	Professor Valsamma Eapen is the Chair of Infant, Child and Adolescent Psychiatry at the University of New South Wales. An internationally-recognised child psychiatrist and researcher, Valsamma's expertise combines extensive experience in childhood mental health and developmental disorders from a clinical and basic science research perspective.
Dr Kiah Evans	Dr Kiah Evans coordinated the development of the first Guideline from 2016 to 2018. She has held leadership roles in multiple research projects over the past six years that have focussed on exploring the perspectives of autistic adults, caregivers, clinicians and other key stakeholders in relation to assessment of functioning and diagnostic processes related to autism and other neurodevelopmental conditions. This included a large program of research to investigate the psychometric properties of existing assessment of functioning measures and supervision of doctoral research projects to develop new measures based on the ICF. Kiah co-led community consultation to evaluate the comparable guideline in New Zealand and was an international consultant for the development of a

	comparable guideline in Vietnam. She has qualifications and teaching experience in the field of health professions education.
Dr Emma Goodall **(Co-chair)**	Dr Emma Goodall is an autistic author, advocate, qualified meditation and mindfulness teacher and adjunct research fellow at the University of Southern Queensland. She is the Manager for Content & Research for Positive Partnerships and also runs Healthy Possibilities, a consultancy offering personal life coaching alongside autism specific continuing professional development for educators and families and National Disability Insurance Scheme (NDIS) services (many with a link to interoception). Emma speaks widely on the topic of interoception and the role mindful body awareness plays in emotional regulation. Dr Emma Goodall was Co-chair of the Guideline Development Group for this Guideline.
Ms Emma Hinze	Emma Hinze is a PhD candidate within the School of Applied Psychology at Griffith University. She brings lived experience as a parent and caregiver to her autistic son, as well as knowledge gained through her research and work with autistic adolescents and adults.
Mr Will Foster	Will Foster is an autistic adult who enjoys spending time with family and friends, building various Lego projects, engaging in the community, and enjoys making puppets, cooking, and exercising.
Dr Mandira Hiremath	Dr Mandira Hiremath is a general paediatrician at Western Health, is a board director for the Neurodevelopmental and Behavioural Paediatric Society of Australasia and has also completed further studies in public health. She has extensive clinical experience in the diagnosis of autism spectrum disorder in children and additionally supporting children and their families through a range of mental health and developmental concerns.
Dr Wenn Lawson	Dr Wenn Lawson is an Adjunct Associate Professor at Curtin University, WA. Wenn is a Senior Researcher in the area of autism and supports PhD students thought supervision, works on various projects, and is a member of the Curtin Autism Research Group (CARG).
Dr Rhylee Sulek	Dr Rhylee Sulek is a Research Fellow within the School of Health Sciences and Social Work, Griffith University and Honorary Research Associate at CliniKids, Telethon Kids Institute. She brings experience in working with young autistic children and their families when receiving early supports and therapies, and the inclusion of key stakeholders in the co-production of research.
Dr Samarra Toby	Dr Samarra Toby is a First Nations Medical Doctor who specialises in General Practice. Dr Toby has an interest in nutritional and environmental medicine, aerospace medicine, medical ecology and First Nations Translational Health Research.
A/Prof David Trembath **(Co-chair)**	David Trembath is an Associate Professor in Speech Pathology at the Menzies Health Institute Queensland, Griffith University and Honorary Research Fellow at CliniKids, Telethon Kids Institute. He brings over 20 years of clinical-research experience working with autistic children and

	their families. David was Co-chair of the Guideline Development Group responsible for developing the Autism CRC's National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia. David was the Co-chair of the Guideline Development Group for this Guideline update.
Dr Kandice Varcin	Dr Kandice Varcin is a Research Fellow at the Menzies Health Institute Queensland, Griffith University and Honorary Research Associate at CliniKids, Telethon Kids Institute. She is also a registered psychologist who brings experience and expertise in research focused on autism, early development and the evaluation of therapies and supports for young children and their families.
Dr Hannah Waddington	Dr Hannah Waddington is a Senior Lecturer at Victoria University of Wellington and the Clinic Lead of the Victoria University of Wellington Autism clinic. She is also a practicing educational psychologist who brings experience in provision of early support to autistic children and their families.
Prof Andrew Whitehouse **(Co-chair)**	Andrew Whitehouse is a Speech Pathologist and Angela Wright Bennett Professor of Autism at the Telethon Kids Institute and the University of Western Australia. Andrew is also the Director of CliniKids, a clinical research centre of excellence for autistic children, and is the Autism CRC's Research Strategy Director. He brings over 20 years' clinical research experience in working with autistic children and their families. He also brings experience in Guideline development, having chaired the development of the original version of the National Guideline for the Assessment and Diagnosis of Autism in Australia, and co-chaired the development of the National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia.
Dr Rachelle Wicks	Dr Rachelle Wicks is an autistic research fellow within Griffith University's Autism Centre of Excellence. She brings lived experience as a late-diagnosed woman and professional experience in early literacy and assessment for young autistic children, as well as knowledge of the varied perspectives and needs of individuals within the autistic and autism communities gained through her research and work with autistic children, their families, and service providers.

Roles within the GDG

All members of the GDG contributed to decision-making in relation to the design, development, and delivery of the Guideline and associated documents. This included reviewing materials, engaging in discussion at monthly GDG meetings, and endorsing the final versions of these documents.

Within the GDG, nine members were responsible for developing and progressing the core research and development activities, including designing and completing systematic reviews, community consultation activities, and the Evidence to Decision (EtD) process (described in subsequent chapters): Nicole Dargue, Emma Goodall, Emma Hinze, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse, and Rachelle Wicks. Emma Goodall, Emma Hinze, Hannah Waddington, and Rachelle Wicks held salaried positions, while Nicole Dargue, Rhylee Sulek, David Trembath, Kandice Varcin, and Andrew Whitehouse made in-kind contributions. Each member contributed to all activities, while taking leadership of one or more activities. Specifically, Nicole Dargue and Hannah Waddington led the systematic review of existing guidelines. Rhylee Sulek led community consultation involving the online survey and focus groups. Kandice Varcin led the public consultation. Rachelle Wicks led coding of the qualitative data from community consultation, and preparation of evidence summaries. Emma Hinze led coordination of the analysis of qualitative data in systematic reviews and data collected during community consultation activities.

Declaration of Interests

The following process was adopted to ensure the declaration and management of any competing interests, in accordance with the NHMRC Guidelines for Guidelines (2016):

Develop a conflict-of-interest policy

The following information constitutes the conflict-of-interest policy used in the development of the Guideline.

Determining if an interest is a conflict of interest

Members of the GDG who were directly responsible for the design and conduct of research activities (Emma Goodall, Nicole Dargue, Emma Hinze, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse, Rachelle Wicks) each disclosed conflicts of interest using the International Committee of Medical Journal Editors (ICMJE) Disclosure of Potential Conflicts of Interests form (**https://journals.sagepub.com/pb-assets/cmscontent/HPQ/coi_disclosure.pdf**) at the outset of the project, and these forms were made available to one another to review. No major conflicts of interest were identified. All members of the GDG were required to complete the same form prior to having input into the drafting of Guideline recommendations. GDG Co-chairs reviewed all forms and identified processes that would be put in place if required (e.g., self-abstaining or asking group member to abstain from one or more aspects of the guideline development process).

Appoint an independent chair

Autism CRC invited Emma Goodall and David Trembath to act as Co-chairs based on their experience and demonstrated track record of co-designed and ethical research in related projects that included the National Disability Insurance Agency commissioned synthesis of evidence for non-pharmacological supports for autistic children and their families (Whitehouse et al., 2020) and developed of the Autism CRC National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia (Trembath et al., 2022). The Co-chairs had no financial interests relevant to update the Guideline to declare.

Select development group candidates

As indicated above, members of the GDG were selected through a process that involved the Co-chairs first identifying perspectives and expertise that are critical to the development of the Guideline, and then inviting relevant people.

Disclose interests throughout development

All GDG and Reference Group members were required to declare any potential conflicts of interest that arise during the guideline development process by (a) updating their form and (b) notifying the Co-chairs at the start of the following meeting (standard agenda item). GDG members were advised to notify the Co-chairs of any changes in their declarations, prior to providing feedback on any documents outside of GDG meetings (e.g., feedback on the Draft Guideline). The exceptions to this approach were members of the GDG directly involved in day-to-day work on the Guideline (Emma Goodall, Nicole Dargue, Emma Hinze, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse, Rachelle Wicks) who were required to notify this same group of any new disclosures as they arose and no later than the next weekly working group meeting.

Manage conflicts of interest

It was planned that conflicts arising would be managed according to recommendations in the NHMRC Guidelines for Guidelines (2016) including members recusing themselves and/or being excluded from aspects of the guideline development process, removing a member from the GDG should a serious breach in relation to disclosures occur, and refusing sponsorship where a conflict exists. All decisions were to have been discussed and documented within the GDG and published in the technical manual that accompanies the Guideline. It is noted that these actions have not been required during the update of the Draft Guideline.

Publish declarations of interest in the Guideline

The declarations of interests for all GDG members are provided in Appendix 2.2.

Guideline Development Group meetings

The GDG met via videoconference on a monthly basis from October 2022 to March 2023. Additional monthly meetings are scheduled for April, May, and June 2023. Each meeting followed an agenda, focusing on (a) updates on Guideline activities and (b) discussion and decision-making within the GDG. Minutes of each meeting, along with a rolling record of actions arising and any supporting documents, were circulated between meetings.

The primary focus of each meeting was:

- October 2022: Introduction of members, project overview, discussion of GDG functioning, and overview of current GDG priorities.
- November 2022: Progress report on community consultation and umbrella review, discussion of timeline, and overview of the NHMRC and GRADE Evidence to Decision process.

- December 2022: Progress report on community consultation and umbrella review, and discussion of Australian context and language choices.
- January 2023: Progress report on community consultation and umbrella review, and discussion of method for analysing Expression through Art submissions
- February 2023: Update on method for analysing Expression through Art submissions and reviewing draft updated Recommendations.
- March 2023: Review of Recommendations and Evidence to Decision Judgements.

2.8 Reference Group

To support its work in community consultation, the GDG formed a Reference Group, comprising of representatives from organisations with members that play a critical role in assessment and diagnosis of autism or support and reflect the views of autistic people and family members; that represent Aboriginal and Torres Strait Islander Peoples, and represent Culturally and Linguistically Diverse communities; or that were from a relevant Government Department (Department of Social Services, Department of Health) or agency (National Disability Insurance Agency). Terms of reference

- The Terms of Reference are presented in Appendix 2.3 and include:
- Background (to the project).
- Purpose (of the Guideline Development Group).
- Anticipated timeline for the project.
- Membership of the Reference Group.
- Appointment of Chair.
- Responsibilities of Project Team Members.
- Meetings.
- Code of conduct for the Project Team.
- Reporting.

The Terms of Reference were signed by each Reference Group member ahead of the first of three meetings held during the Guideline development process in December 2022 and March 2023. A further meeting is scheduled for June 2023.

Recruitment

The members of the Reference Group were identified and appointed via a three-stage process.

- In the first stage, the Co-chairs identified a range of perspectives that were critical to updating the Guideline. The Co-chairs also identified the need for representation of Aboriginal and Torres Strait Islander Peoples, representation of culturally and linguistically diverse communities, and representation from the key Government agency: the National Disability Insurance Agency.

- In the second stage, the Co-chairs identified organisations, peak bodies, and agencies that are relevant to each of the aspects identified and sent an email invitation to a representative (typically CEO) of each organisation, peak body, or agency inviting their participation and requesting they nominate a representative to attend Reference Group meetings. The email included an introduction to the project and Terms of Reference. The Co-chairs made themselves available to meet with invitees to discuss the Terms of Reference.
- In the third stage, the nominees returned the signed Terms of Reference to confirm their role within the Reference Group.

Members

The members of the Reference Group are presented in Table 2.3.

Table 2.3. Members of the Reference Group.

Stakeholder group	Organisation	Representative	Position
Autistic people	Autistic Self Advocacy Network – Australia and New Zealand	Cheryl Koch	Board member
Family members of autistic people	Autism Awareness Australia	Nicole Hurley	Head of fundraising and partnerships
First Nations peoples	National Aboriginal Community Controlled Health Organisation (NACCHO)	Jess Styles	Director, Programs
Culturally and linguistically diverse communities	Australian Multicultural Health Collaborative	Daniel Coase	Senior Advisor
Focusing on health	Neurodevelopmental and Behavioural Paediatrics Society of Australasia	John Wray	Member
Focusing on health	Royal Australian College of General Practitioners	Alison Palmer	Member

Focusing on health	Royal Australian and New Zealand Colleague of Psychiatrists	Matthew Sellen	Member, RANZCP Section of Psychiatry of Intellectual and Developmental Disabilities
Focusing on social-communication functioning	Speech Pathology Australia	Amy Fitzpatrick	Senior Advisor - Disability
Focusing on physical functioning	Australian Physiotherapy Association	Kristy Nicola	APA Paediatric National Group – Deputy Chair
Focusing on cognitive functioning and mental health	Australian Psychological Society	Catriona Davis-McCabe	APS President
Focusing on sensory functioning and occupations	Occupational Therapy Australia	Gaynor Gray	Divisional Manager (QLD) Occupational Therapy Australia
Focusing on rural health	National Rural Health Alliance	Susanne Tegen	Chief Executive
Representing service providers (peak body)	Australian Autism Alliance	Frances Scodellaro	Member
Representing researchers	Australasian Society for Autism Research	Josephine Barbaro	Treasurer
Government	Australian Government Department of Education	Susan Aitkin	Improving Student Outcomes Division
Government	Department of Social Services	Angela Warner	Assistant Director, Autism Policy Team, Disability Support Branch

Government	National Disability Insurance Agency	Sam Bennett	General Manager Policy, Advice and Research

Declared Interests

The process for declaring interests and managing conflicts of interest was the same as outlined in relation to the GDG above. This included members completing declaration of interests forms that will be published with the final version of the updated Guideline. Given that the Reference Group did not input into the formation of the draft Recommendations, some flexibility was given for members to complete their Declarations of Interest forms.

Reference Group Meetings

The Reference Group met via videoconference on two occasions (November 2022, March 2023) with a third meeting scheduled for June 2023. Each meeting followed an agenda, focusing on (a) updates on Guideline activities and (b) discussion of these activities. Minutes of each meeting, along with a rolling record of actions arising and any supporting documents, were circulated between meetings.

The primary focus of each meeting was:

- November 2022: Introduction of members, project overview, confirming processes for governance and communication, overview of methodology, and review of proposed timeline.
- March 2022: Summary of progress towards update of the Guideline, including research and community consultation activities, and review of upcoming stages of Guideline development.

2.9 Other people who contributed to the Guideline update.

Table 2.4 presents the names, roles, expertise, and organisational affiliation of additional people who contributed to the Guideline update.

Table 2.4. Additional contributors to the Guideline update.

Name	Discipline/Expertise	Organisation	Role
Briohny Dempsey	Occupational therapy	Telethon Kids Institute	Research assistant
Veronica Frewer	Speech pathology	Griffith University	Research assistant
Libby Groves	Speech pathology	Griffith University	Research assistant

Justina Sparks	Guideline implementation	Telethon Kids Institute	Consulted in relation to current, and planned future, Guideline implementation activities.
Felicity Rose	Guideline implementation	Telethon Kids Institute	Consulted in relation to current, and planned future, Guideline implementation activities.
Cally Jackson	Marketing and Communications	Autism CRC	Community engagement regarding Guideline
Jason Kotzur	Marketing and Communications	Autism CRC	Community engagement regarding Guideline
Darcy Maguire	Marketing and Communications	Autism CRC	Community engagement regarding Guideline
Braeden Monnier	Marketing and Communications	Autism CRC	Community engagement regarding Guideline
Sally Vidler	Marketing and Communications	Autism CRC	Community engagement regarding Guideline

2.10 Consumer representation

The following processes were used to ensure consumers (i.e., members of the autistic and autism communities) were involved in the update of the Guideline.

Guideline Development Group: Multiple people with lived expertise of autism were invited to be members of the GDG. Four members are autistic, 3 members are parents of autistic children, and others have family members who are autistic.

Reference Group: Two organisations were specifically invited to join the Reference Group. The Autistic Self Advocacy Network – Australia and New Zealand is run by and represents autistic people. Autism Awareness Australia is run by and represents parents and other family members of autistic people.

Community consultation activities: A series of research studies were conducted as part of the Guideline update process to inform the recommendations. These were separate to the Public Consultation on the Draft updated Guideline and were used to gather evidence to inform the revising of recommendations. The activities included:

- Focus groups for autistic people, family members of autistic people, and practitioners.
- An online community survey that was open to all members of the community including autistic people, family members, practitioners and organisations.

2.11 Involvement of Aboriginal and Torres Strait Islander Peoples and culturally and linguistically diverse communities

For a Guideline to serve the needs of all Australians, it is critical that the guideline development process includes proper consideration of issues relating to Aboriginal and Torres Strait Islander Peoples and culturally and linguistically diverse communities. These considerations include recognising the enduring impact of historical injustices, discrimination, and marginalisation of Aboriginal and Torres Strait Islander Peoples; the importance of understanding and embracing culturally-bound understandings of family practices and disability; and the need to ensure that every Australian has access to culturally-responsive and appropriate health and education services, delivered by people with appropriate knowledge, skills, understanding, and experience. The GDG took the following steps to ensure the Guideline Recommendations were responsive to these and other considerations relevant to these peoples and communities. First, the Guideline Development Group included Aboriginal representation. Second, the Reference Group included representatives from the peak organisation serving the health of Aboriginal and Torres Strait Islander Peoples: The National Aboriginal Community Controlled Health Organisation (NACCHO).

3. Guideline Update Methodology

3.1 Introduction

The methodology and findings that contributed to the development of the original Guideline are outlined in detail in the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia (2018)* full Guideline document and the supporting Administrative and Technical Report.

This report focuses on the methodology used to update the Guideline. This chapter focuses on the application of the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) framework that was used to update the Guideline. The detailed methodology and findings of each of the research activities completed as part of the Guideline update process are presented in subsequent chapters (Chapters 4-6).

3.2 NHMRC Guidelines for Guidelines

At the time of the Guideline update, the NHMRC did not yet have published guidelines for Guideline updates. As such, the Guideline update process adhered closely to the approach described in the *Guidelines for Guidelines* handbook used for the development of Guidelines (NHMRC, 2016).

The phases of updating the Guideline included *planning, revising*, and *reviewing* the Guideline. The phases of *implementing* and further *updating* the Guideline will be outlined in the final version of the updated Guideline. In adhering to the handbook, the Guideline Development Process also met the NHMRC Standards for Guidelines:

- Standard 1 – Be relevant and useful for decision making
- Standard 2 – Be transparent
- Standard 3 – Be overseen by a guideline development group
- Standard 4 –Identify and manage conflicts of interest
- Standard 5 – Be focused on health and related outcomes
- Standard 6 – Be evidence informed
- Standard 7 – Make actionable recommendations
- Standard 8 – Be up-to-date
- Standard 9 – Be accessible

3.3 GRADE

GRADE provides a systematic approach for developing practice recommendations (Schünemann et al., 2013). The process involves (a) identifying clinical questions, (b) collecting relevant research evidence, (c) using the evidence to answer the clinical questions, and (d) in doing so formulate recommendations. In determining the grade of recommendations, the GDG must consider the certainty of evidence for the recommendation, the benefits and risks, the values and preferences of the people whom the recommendation will affect, resource implications, impact on health inequities, acceptability to the people whom the recommendation will affect, and feasibility of implementation. These steps, as they were applied in this Guideline update process, are outlined below.

3.4 Guideline development process

Step 1: Establishing the Guideline Development Group (GDG)

Purpose: The GDG was responsible for reviewing and refining the guideline questions, gathering updated evidence through a systematic review and community consultation, and using the updated evidence, alongside the original evidence, to revise – and then grade the strength of - recommendations using an Evidence to Decision (EtD) process. The GDG will also be responsible for considering community feedback on the Draft updated Guideline during the consultation period, making revisions if appropriate, and endorsing the final version of the updated Guideline for public release.

Process: The process for determining the roles, and people who ultimately filled those roles, is presented in Chapter 2. Briefly, it included three stages, the first of which was to identify relevant perspectives to inform the Guideline development process, to identify people who could contribute those perspectives, and then invite participation including agreement with the Terms of Reference.

People involved: A detailed description of the seventeen-member GDG is provided in Chapter 2. Briefly, among the 17-member group were autistic adults; parents and other family members of autistic children, including individuals with complex support needs; an Aboriginal person; a person with expertise in ethics and research integrity; practitioners with experience across government and non-government sectors; and researchers with expertise in the guideline development process, including community consultation.

Step 2: Revising Guideline questions

Purpose: Asking relevant questions is critical to the development and update of a useful Guideline.

Process: The GDG reviewed questions that formed the basis of the original version of the Guideline and considered whether any changes were required. In considering possible changes, the GDG reflected on (a) whether the questions remained relevant, (b) if any new questions should be added to reflect changes in the community and practice, and (c) if re-wording and/or organisation of questions could improve readability and reduce repetition within the Guideline. The updated Guideline questions were as follows:

Section	Question
Guiding principles	What guiding principles should be followed in the assessment and diagnosis of autism?
Foundations of assessment	What should be the process for assessment and diagnosis of autism in the Australian context?
	What knowledge, skills, training, support, and regulation are required to conduct components of the Comprehensive Needs Assessment and Diagnostic Evaluation?
	What settings are appropriate for assessment?
	How should information be collected in an assessment?
	How should information be shared?
	When should referral for health, education, disability, social, and/or community supports be considered?
	How should the quality and safety of the assessment and diagnostic process be optimised?
Making a referral for assessment	When should a referral for autism assessment be initiated?
	Who should initiate a referral for autism assessment?
	What information should be collected?
	What should be the outcome once a referral for assessment has been considered?
Comprehensive Needs Assessment	When should an Assessment of Functioning be conducted?
	Who should conduct an Assessment of Functioning?
	What information should be collected as part of an Assessment of Functioning?
	What should be the outcomes of an Assessment of Functioning?
	When should a Medical Evaluation be conducted?
	Who should conduct a Medical Evaluation?

	What information should be collected in a Medical Evaluation?
	What should be the outcomes of a Medical Evaluation?
Diagnostic Evaluation	When should a Diagnostic Evaluation be conducted?
	Who should conduct a Diagnostic Evaluation?
	What information should be collected in a Diagnostic Evaluation?
	What information should be considered in making a diagnosis?
	How should a diagnostic decision be made?
	What should be the outcomes of a Diagnostic Evaluation?

Within GRADE, questions are typically asked using a consistent format that specifies the *population* (P = population of interest), *intervention* (I = intervention/support/assessment that is being trialled), *comparison* (C = the alternative to the intervention/support/assessment), and *outcome* (O = the outcome of interest). Such questions should be relevant to the community. For instance, a question that seeks to answer whether one type of assessment is more effective than another in accurately diagnosing autism, could be framed as “In people seeking an assessment for autism (Population), is *Assessment A* (Intervention) more accurate than *Assessment B* (Comparison), in diagnosing autism (Outcome)?” To answer this question, there must be sufficient studies involving the specific population, types of assessments, and outcome of interest to enable a meta-analysis to be completed, which involves quantitatively combining data from across studies. However, this situation is uncommon in relation to research involving autistic people for several reasons including:

- Few or no studies available to answer questions that are most relevant to practice.
- Where studies are available, they vary in terms of the participant characteristics; assessments examined; and how outcomes of interest are measured.
- Where studies are available, they also vary in terms of methodological quality including the clear and complete reporting of data needed to complete meta-analyses.

The challenge with using the Population, Intervention/Assessment, Comparison, Outcome (PICO) format extends beyond consideration of whether empirical evidence is available to answer a particular question. Two broader challenges that were particularly relevant to the update of this Guideline were as follows:

- Many questions parents and practitioners want answered do not align with the PICO format, such as “What guiding principles should be followed in the assessment and diagnosis of autism?” Conceivably, if there were two or more studies comparing different guiding principles used in the assessment and diagnosis of autism and the impact of these on client experience and diagnostic accuracy, it would be possible to compare the approaches to see which was more appropriate. However, doing so would rely on there being existing sets of guiding principles to compare, and then there being sufficient empirical evidence to compare them. At the same time, taking this approach would limit the answer to this question to consideration of just principles that have been compared, whereas consulting the autistic and autism communities is likely to yield far more diverse views and preferences in relation to what constitutes appropriate guiding principles and how should they be selected.

- Related to the previous point, answering PICO questions relies on quantitative data. Yet, when it comes to understanding the views and experiences of autistic people, their families, and the broader autistic and autism communities, qualitative data are just as important. Therefore, questions need to be asked in a way that allows people to share a broad range of, at times differing, views and experiences.

Given these challenges and limitations with adopting the PICO format, the GDG elected to formulate questions in a way that would prioritise their relevance to everyday practice. Doing so was consistent with the NHMRC Standard 1 (Be relevant and useful for decision making) to ensure Standard 7 (Make actionable recommendations) could be achieved. For this same reason, the Recommendations included in the Guideline are consensus-based recommendations, drawing on evidence from the research literature, combined with evidence collected through detailed community consultation from the original Guideline development and through the Guideline update process.

People involved: The questions were developed and endorsed by the GDG.

Step 3: Gathering evidence

Purpose: For a Guideline to be relevant it must be evidence-based. For the updated Guideline, evidence-based refers to being consistent with an *evidence-based practice* framework, that combines the best available research evidence, with evidence from clinical practice, and the views and priorities of autistic people. The purpose of gathering new evidence was to ensure that recommendations were relevant and/or could be revised in a systematic way, consistent with GRADE, and reflecting multiple converging sources of evidence.

Process: The GDG designed a series of research activities to gather recent, best available evidence from the published research literature and from the community. This involved undertaking a systematic review of recent published evidence as well as two community consultation activities. Ethical approval for the consultation activities was granted by the Griffith University Human Research Ethics Committee (2022/780).

The research activities were:

1. An umbrella review of recent evidence in relation to assessment and diagnosis of autism (Chapter 4). This was a systematic review of systematic reviews that examined evidence relating to: (a) existing guidance for assessment and diagnosis, (ii) clinical tools and processes, (b) considerations regarding personal and environmental factors, and (c) experiences of the autistic and autism communities.

2. An online survey designed to understand experiences and current views and preferences of the autistic and autism communities regarding assessment and diagnosis of autism in Australia (presented in Chapter 5). The survey was open to all members of the autistic and autism communities (including children).
3. A series of focus groups designed to provide an opportunity for autistic adults, family members, and practitioners to reflect on and discuss their experiences, views and preferences regarding assessment and diagnosis of autism in Australia (presented in Chapter 6).

The research and consultation activities were designed such that, across the collective set of activities, the GDG was able to collect evidence from all key stakeholders, including autistic children and adults, as well as members of the broader autistic and autism communities (i.e., organisations, support people, researchers, educators). The populations represented by each evidence source are summarised in Table 3.1.

All evidence collected through the research and consultation activities was used to inform the revision and update of recommendations through the Guideline.

Table 3.1. Sources of evidence and populations represented.

Sources of evidence (i.e., research activity)	**Populations represented**						
	Autistic children	Autistic young people	Autistic adults	Family members	Practitioners	Organisations	Other community members
Systematic review of recent evidence	✓	✓	✓	✓	✓		✓
Online survey	✓	✓	✓	✓	✓	✓	✓
Focus groups			✓	✓	✓		

People involved: The research activities were developed by the GDG and informed by the research consultation activities undertaken as part of the development of (i) the original version of the Guideline (Whitehouse et al., 2018a) and (ii) the National Guideline for supporting autistic children and their families (Trembath et al., 2022). The day-to-day work of gathering and synthesising evidence was undertaken by nine members of the GDG (Nicole Dargue, Emma Goodall, Emma Hinze, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse, Rachelle Wicks). The coding and analysis of data was undertaken by these same nine members of the GDG, with additional research support for qualitative data coding provided by Libby Groves, Veronica Frewer, Briohny Dempsey, and Amy Giesberts.

Step 4: Reformatting the Guideline Text

The original Guideline was developed according to NHMRC *Guidelines for Guidelines* handbook (2016) but did not use the GRADE method for moving from evidence to Recommendations. To ensure that GRADE could be applied when updating the Guideline, some reconfiguring of Recommendations and accompanying text was required, prior to applying GRADE. The process of reconfiguring the text also provided an opportunity to align formatting with the approach taken with Autism CRC's *National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia* (2022). Aligning the formatting in this way should help practitioners in moving seamlessly from one Guideline to the other when working with autistic children and will lay the foundation for similar consistency for other Guidelines in the future.

The process of reconfiguring the Recommendations and accompanying text involved five steps. First, all text from the original Guideline was transferred to a Microsoft Excel spreadsheet and organised according to the original Guideline questions. Second, this text was re-organised according to the updated Guideline questions. Third, the Recommendations and accompanying text related to each of the updated Guideline questions was reviewed, individually and as a group. Fourth, the text was reconfigured into a set of revised Recommendations, Good Practice Points, and if relevant accompanying text. At this point, no changes in the scope or meaning of the Recommendations was allowed, only changes to the way the information was presented. Fifth, the Chair of the original Guideline Development Group (Andrew Whitehouse) reviewed the original and reconfigured text to ensure continuity in scope and meaning of Recommendations between the original Guideline and updated draft Recommendations, Good Practice Points, and accompanying text.

Step 5: Moving from evidence to Recommendations

An iterative process, built around an Evidence to Decision (EtD) framework, was used to move from evidence to recommendations (Alonso-Coello, Oxman et al., 2016; Alonso-Coello, Schünemann, et al., 2016). The process was led within the GDG by a Draft Recommendations Working Group (DRWG; Nicole Dargue, Emma Goodall, Emma Hinze, Rhylee Sulek, David Trembath, Kandice Varcin, Hannah Waddington, Andrew Whitehouse, Rachelle Wicks) with support from research staff (Veronica Frewer, Libby Groves) to analyse data from the community consultation activities and review the draft updated Recommendations in light of the evidence generated.

Evidence review and preparation of draft 1 of updated Recommendations

Members of DRWG and research staff reviewed the draft updated Recommendations against evidence from the umbrella review and community consultation activities. In doing so, they considered if each Recommendation should be retained in its original form, be revised based on new evidence, or be removed based on new evidence. The team also considered whether one or more new Recommendations should be added. Proposed edits, along with the supporting evidence from the umbrella review and/or community consultation were documented first in an excel spreadsheet that contained the evidence summary for each Recommendation, and second in the draft updated Guideline. One co-Chair reviewed the proposed edits and either endorsed them immediately or sought further clarification and consensus with the team before endorsing. The second Co-chair and all members of the DRWG reviewed the edits and any disagreements were discussed until consensus was achieved.

Guideline Development Group review of Draft 1 of updated Recommendations

The DRWG shared the draft updated Recommendations and Good Practice Points with the GDG. The GDG provided feedback at the monthly meeting and via suggestions in shared documents.

Grade of Recommendation judgements and preparation of Draft 2 of updated Recommendations

Members of the DRWG incorporated feedback provided by GDG members to further update Recommendations and Good Practice Points. The DRWG also independently completed a review and judgement of each Recommendation against the seven criteria required within the GRADE Evidence to Decision framework (Alonso-Coello, Oxman et al., 2016; Alonso-Coello, Schünemann, et al., 2016). The judgements related to certainty of evidence, benefits and risks, values and preferences, resource implications, equity considerations, acceptability, and feasibility. The judgements occurred over five rounds, with the first involving independent review, followed by consensus review, and then review by the broader GDG.

Based on the judgements, each Recommendation was then classified as either a ‘strong’ Recommendation or a ‘conditional’ Recommendation, as per the GRADE process and reflecting the confidence in the clarity of the balance between desirable and undesirable consequences. In the case of this Guideline, ‘conditional’ Recommendations indicated: uncertainty around alignment with values and preferences of autistic people and their family; a possible reduction in health equity across populations; uncertainty around the acceptability of the Recommendation for practitioners; and/or a possible lack of feasibility in implementation. The classifications reflect the judgements of the GDG, based on the available evidence and other relevant considerations such as alignment with international conventions. The complete set of judgements is provided in the Supporting Evidence document accompanying this Guideline.

The grade of Recommendations does not reflect whether a Recommendation should be implemented or prioritised. All Recommendations within the Guideline represent good practice and should be implemented. Rather, the grade of Recommendations (strong, conditional) is intended to support users in considering a range of factors when implementing a given Recommendation, such as the benefits and harms, resources needed, and the acceptability to individuals, families, and practitioners. A grading of a Recommendation as ‘conditional’ reflects a judgment that there are key factors to consider during implementation. Further information on the grading of each Recommendation is provided in the Supporting Evidence document.

The DRWG prepared the Draft updated Guideline and shared it with the GDG. The document was reviewed and then discussed by members at a meeting of the GDG. The GDG endorsed the documents, subject to further minor edits and formatting.

Step 6: Public consultation on Draft updated Guideline

The GDG prepared the Draft updated Guideline and supporting documents (Summary of Evidence, Administration and Technical Report, and Easy Read summary) for public consultation.

Ahead of public consultation

The public consultation on the draft updated Guideline complied with Section *74A of the Commonwealth National Health and Medical Research Council Act 1992* and accompanying regulations. The following activities were undertaken ahead of the public consultation period:

- Autism CRC updated its webpage devoted to the Guideline update to reflect the upcoming consultation period and the invitation to participate.
- Autism CRC announced the upcoming public consultation period, via an email distributed to people who had registered specifically for updates on the Guideline, as well as people who were on the Autism CRC communications database more broadly. Key professional and consumer organisations were identified through the Reference Group and were invited to provide feedback. Further announcements were made via Autism CRC social media, and then re-posted by GDG members.
- A Co-chair of the GDG emailed the Office of the Director General, Chief Executive or Secretary of each state, territory, and Commonwealth Health Department to prepare those offices for the publication of the Draft updated Guideline.

3.5 Recommendations and Good Practice Points

The Evidence to Decision (EtD) process resulted in a set of Recommendations and Good Practice Points, which were formulated and presented in a way that met the following requirements:

Consensus-based Recommendations

Using the GRADE methodology, recommendations may be described as evidence-based or consensus-based. Evidence-based recommendations are typically based on evidence derived from one or more systematic reviews containing meta-analyses of empirical data, that are relevant to one or more clinical questions presented using the PICO format. Consensus-based recommendations are typically based on sources of evidence, other than those described for evidence-based recommendations, such as through non-systematic reviews, evidence derived through consensus-based processes (e.g., Delphi studies), and qualitative data pertaining to relevant stakeholders' views and experiences.

For this Guideline, the GDG was unanimous in endorsing the formulation of consensus-based recommendations, for the following reasons (also explained in Section 3.4):

- The questions that are most relevant to professional practice rarely align with the PICO format.
- There is a lack of empirical evidence on which to make judgements, even if the PICO format was deemed appropriate.
- The GDG determined that it was critical to gather evidence from all relevant stakeholders across the autistic and autism communities, including autistic children, their families, and practitioners to ensure the Recommendations are relevant, acceptable, and feasible.

All Recommendations are clearly labelled as Consensus-Based Recommendations.

Recommendations are defined as “Key elements of practice that must be followed for a practitioner to deliver evidence-based supports.”

Good Practice Points were linked to specific Recommendations and defined as “Elements of practice that provide critical context to that Recommendation, such as how a Recommendation should be operationalised in clinical practice, or how it is applied to a specific population or under specific circumstances.”

3.6 Language used in formulating Recommendations and Good Practice Points

In drafting the Recommendations and Good Practice Points, the GDG adhered to the following three requirements:

- The wording must be in plain English, specific, unambiguous, employ consistent terminology, and accessible to autistic people, family members, and practitioners.
- The wording must convey one or more specific actions that practitioners should take.
- The wording must reflect the evidence on which the Recommendation or Good Practice Point is based, in terms of both strength and precision.

4. Recent evidence in relation to assessment and diagnosis for autism: An umbrella review

4.1 Background

A synthesis of existing research evidence is critical to the development and update of any Guideline. This evidence can be used to inform the recommendations and to identify factors (e.g., certainty of evidence, feasibility) that should be considered when they are implemented (NHMRC, 2016).

4.2 Aims

The aims of this umbrella review were to synthesise data from existing systematic reviews regarding the following aspects of assessment and diagnosis for autism: (a) existing guidance; (b) clinical tools and processes; (c) considerations regarding personal and environmental factors; and (d) experiences of the autistic and autism communities.

4.3 Research Questions

The umbrella review aimed to answer the following research questions:

1. What recommendations have been made to guide medical and allied health practitioners in assessing and diagnosing autism?
2. What clinical tools and processes contribute to timely and accurate assessment and diagnosis for autism?
3. What were the considerations regarding personal and environmental factors in assessment and diagnosis for autism?
4. What were the views and experiences of the autistic and autism communities regarding assessment and diagnosis for autism?

4.4 Design

This project was an umbrella review, which involved systematically searching for and selecting relevant systematic reviews, then synthesising and presenting data from the selected reviews. This umbrella review was conducted in accordance with the procedures outlined in the Joanna Briggs Institute manual for evidence synthesis (Aromataris et al., 2020) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Page et al., 2021).

4.5 Method

Eligibility

Systematic reviews (SRs) were included in the umbrella review if they met all the following criteria:

1. The SR was a meta-analysis or a narrative synthesis (i.e., a SR without a meta-analysis). A review was considered "systematic" if it: (1) included a clear statement of the purpose of the review; (2) described the search strategy (e.g., key search terms, multiple relevant databases, specification of search limits); (3) indicated the criteria used to select studies for inclusion; (4) presented all findings relevant to the main purpose of the SR; and (5) used a method of quality appraisal for each included study.
2. The SR reported on assessment and diagnosis for autism. SRs including diagnosis for other conditions in addition to autism could be included if results were reported separately for autistic individuals.
3. The SR focused, at least in part, on one of the following four areas:
    a. Recommendations to guide medical and allied health practitioners in assessing and diagnosing autism.
    b. Clinical tools and processes that contribute to timely and accurate assessment and diagnosis for autism (e.g., consideration of diagnostic accuracy, location of assessment, single vs. multidisciplinary team, professional knowledge and experience etc.).
    c. Considerations regarding personal (e.g., gender, age) and environmental (e.g., residential location, financial resourcing) factors in assessment and diagnosis for autism.
    d. The views and experiences of the autistic and autism communities regarding assessment and diagnosis for autism.
4. The results of the SR were relevant to one or more of the following questions related to guiding clinicians' practice in assessment and diagnosis:
    a. What guiding principles should be followed in the assessment and diagnosis of autism?
    b. In making a referral, conducting a functional, medical, and/or diagnostic assessment:
        i. When should this be considered?
        ii. Who should be involved?
        iii. In what settings should it occur?
        iv. What knowledge, skills, training, and support were required?
        v. What information should be collected?
        vi. How should information be collected

        vii. How should decisions be made?
        viii. What should be the outcomes?
        ix. How should information be shared?
    c. How should the quality and safety of assessment and diagnostic services be ensured?
5. The SR was published as a thesis, conference paper, scientific report, or peer-reviewed journal article.
6. The SR had a full-text copy available in English.
7. The final literature search was conducted in the last 6 years (2017-2022). If the search end date was not stated, then the SR was published in the last 6 years.

There were no restrictions placed on the design of the studies included within each SR. SRs were excluded if they met any of the following criteria:

1. The SR failed to meet one or more of the above inclusion criteria.
2. The article was an umbrella review or "review of reviews".
3. The SR incorporated theoretical studies, text, and opinion as their primary source of evidence.
4. The article was a protocol for a SR only.
5. The SR focused exclusively on research related to understanding aspects of autism outside of the assessment and diagnostic process (e.g., aetiology, neuroimaging techniques, prevalence, developmental trajectories, factors impacting likelihood of autism including biomarkers, accuracy of screening tools and universal screening programs).
6. The SR had been superseded by an updated version of the same review (completed after full-text review of all SRs for all other eligibility criteria)
7. The SR was presented in a report, that has since been superseded by a scholarly publication (completed after full-text review of all SRs for all other eligibility criteria).

Search Strategy

A literature search was conducted in October 2022 using the following databases: PsycINFO, Education Resources Information Centre (ERIC), Medline, PubMed, EMBASE, CINAHL, Cochrane Database of Systematic Reviews, Scopus, EBSCO Education Source, Web of Science, and Epistemonikos.

The search terms were: (Autis* OR ASD* OR Asperger* OR pervasive developmental disorder* OR PDD* OR pervasive child development disorder* OR pervasive childhood developmental disorder* OR PCDD* OR disintegrative disorder*) AND (diagnos*) AND (systematic review* OR systematic literature review* OR evidence synthes* OR meta-analy* OR meta-regress*). The full search strategy for each database is provided in Appendix 4.1.

Ancestral searches were also completed for the reference lists of included SRs.

Study Selection

All studies retrieved from the database searches were imported into the Covidence software platform. Duplicates identified by the software were automatically removed prior to screening. Two reviewers (Rahcelle Wicks and either Hannah Waddington or Nicole Dargue) independently screened the titles and abstracts of the studies against the inclusion/exclusion criteria and excluded articles if they met one or more exclusion criteria. Any disagreements were discussed and resolved via consensus. If an agreement could not be reached, another member of the research team was consulted (David Trembath). The percentage of agreement [agreements/(disagreements + agreements) × 100] for the title and abstract screening was 87.6%.

Next, two reviewers (Rachelle Wicks and either Hannah Waddington or Nicole Dargue) independently screened the full-text reports of all potentially relevant articles according to the eligibility criteria. Once the authors finished individually screening all full-text reports they also reviewed all SRs to determine whether they (a) had been superseded by an updated version of the same review or (b) were reports which have been superseded by a scholarly publication and should thus be excluded. No reviews were excluded for this reason. Again, any disagreements were discussed and resolved via consensus with another member of the research team if needed. The percentage of agreement for the full-text 87.2%.

Data Extraction

Characteristics of the Included Systematic Reviews

Two reviewers (Libby Groves, Rachelle Wicks) read the SR in full, including supplementary material relevant to answering one or more of the Guideline questions. These reviewers extracted the following information about the SR characteristics: (a) title, (b) authors, (c) year of publication, (d) aim(s)/objective(s) of the SR, (e) the type of SR (i.e., meta-analysis with narrative synthesis), (f) search details, (g) number of studies included, (h) population/s included, (i) concept/context, (j) design/s of included SRs, (k) quality of included studies including the assessment tool used, (l) sources of funding and conflicts of interest, (m) location(s) in which data for included studies was collected. The full list of extraction questions is included in Appendix 4.2.

The reviewers then categorised the SR into one or more of the following four categories, based on the focus of the review: (a) SR focused primarily on recommendations to guide medical and allied health practitioners in assessing and diagnosing autism (*Recommendation focused*), (b) SR focused primarily on clinical tools and processes that contribute to timely and accurate assessment and diagnosis for autism (*Process focused*), (c) SR focused primarily on the considerations regarding personal and environmental factors in assessment and diagnosis for autism (*Factor focused*), and (d) SR focused primarily on the views and experiences of the autistic and autism communities regarding assessment and diagnosis for autism (*Experience focused*).

Any disagreements were discussed and resolved via consensus between the two reviewers. The percentage of agreement [agreements/(disagreements + agreements) × 100] for the title and abstract screening was 78.6%.

Qualitative Evidence from Systematic Reviews related to Guiding Clinicians' Practice

Coding framework

Following the Framework method of analysis (Gale et al., 2013), a coding framework was developed to be used across all research activities (umbrella review and community consultation activities) undertaken as part of the Guideline update. The codes within the framework reflected the guiding principles that should be followed by practitioners and the processes engaged in during the assessment and/or diagnosis of autism. A series of codes were developed for each Guideline question, with more than one code able to be applied where relevant. For guiding principles, a preliminary set of codes was developed, drawing on the guiding principles used in the National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia (Trembath et al., 2022), and preliminary screening of the first 100 participants who responded to the community consultation survey (see Chapter 5) by members of the working group (Emma Hinze and David Trembath). In applying the coding framework, the coding team had the option of applying an 'other' code to any comment that they felt did not fit with an existing code. This ensured that novel, including contrasting, views could be accounted for in the coding process.

Adopting a coding framework meant that the GDG could code responses in a consistent manner across the umbrella review, and community-consultation activities (i.e., online survey and focus groups), thereby ensuring that views and experiences could be compared and contrasted during the process of formulating Recommendations and making judgements within the evidence-to-decision framework. The code book, that contains the complete framework, along with instructions to coders (addressed below) is provided in Appendix 4.3.

Coding process (all research activities)

Two members of the Working Group (Emma Hinze, Rachelle Wicks) with three research assistants (Briohny Dempsey, Veronica Frewer, Libby Groves), completed the coding of evidence collected as part of the Guideline update. The team comprised people with a combination of relevant professional experience and, for two members, lived experience of autism. Most members of the coding team had prior experience coding the National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia (Trembath et al., 2022).

The following processes were used to support the coding team to complete the coding:

- David Trembath (Co-chair) and Emma Hinze (GDG) worked together, supported by the GDG, to establish the processes that would be used to code the data and support the coding team in their work. The code book was created along with all administrative processes required to securely and reliably manage the data and coding processes.

- Research assistants (Briohny Dempsey, Veronica Frewer, Libby Groves) were invited to participate in the project via email, which briefly outlined the Guideline project and their proposed contributions. A variation to Griffith University Human Research Ethics Committee to support each person's involvement was granted.
- David Trembath and Emma Hinze met with the coding team to:
    - Provide an overview of the project.
    - Review the processes that would be used in data management and coding.
    - Review the codes relevant to each person's role in the coding.
    - Answer any questions arising.
- Each member of the coding team was then given access to the code book and relevant data. Emma Hinze was responsible for coordinating data management and fielding queries on a daily basis, with David Trembath available to support Emma Hinze at all times.
- All members of the coding team had previously received training in NVivo which was used to support the coding process.
- The instructions that were to be followed are presented in Appendix 4.3, but in brief included:
    - Reviewing the code book
    - Within NVivo, reviewing evidence (either from SRs or community consultation) and coding according to the framework
    - Completing memos in which the coding team was asked to reflect on any patterns they were seeing in the data (e.g., prominent themes); differences, contrasts, and/or contradictions in the responses; any challenges they were experiencing in assigning codes; suggestions for possible new or revised codes; reasons for why they may have coded a specific way or anything else that they, at that time, felt was important. These memos (reflections) were used to help create an audit trail, to inform the coding process and interpretation of the data, and to support the coding team in their work.
- During coding, the coding team met on a weekly basis to discuss the coding process, as well as to discuss their experience of completing the coding. This meeting was open to all members of the GDG involved in data gathering and coding. The rationale for this meeting was two-fold. First, the meetings provided an additional opportunity to ensure fidelity within the coding process (i.e., in addition to standardised training, standardised coding, and on-call support at all times). Second, the meetings provided an opportunity for team members to share and debrief about their experiences. It became apparent, from the first day of data gathering and coding, that the personal insights and experiences shared by members of the autistic

and autism communities in the community consultation activities were often very confronting in terms of the challenging circumstances people had found themselves in, were experiencing currently, or foresaw themselves and their loved ones experiencing in the future. The focus of the debrief was to share individual feelings, support each other, and identify if any further support was required. Doing so ensured each team member was supported, and in doing so ensured the process was carried out with fidelity.

Coding process and credibility (umbrella review)

One reviewer (Rachelle Wicks) read the Abstract and Results section of each SR, and coded evidence relevant to the Guideline questions using the coding framework described above. All sections of the coding framework could be applied.

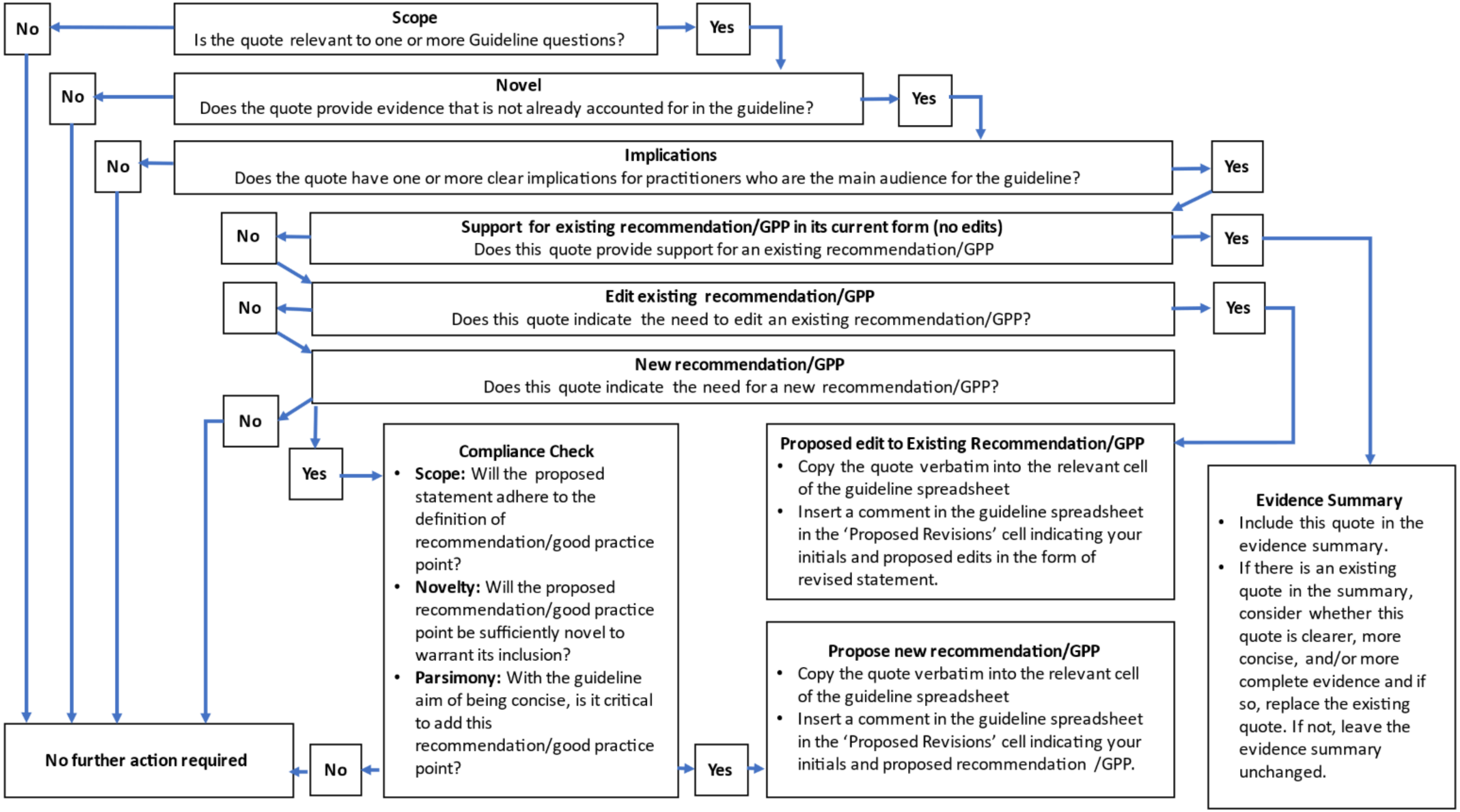
A quote matrix was created using a list of quotes exported from NVivo to Microsoft Excel.

To check the reliability and credibility of the data extraction, the second reviewer (Libby Groves) read the Abstract and Results section of each SR, and identified and coded any relevant text that was not picked up by the first reviewer (Rachelle Wicks). These quotes were then exported to Excel and reviewed by the first reviewer. The percentage agreement (number of quotes with agreement/total number of quotes × 100) for this coding was 100%. The second reviewer also checked that each quote extracted by the first reviewer in the quote matrix related to the allocated Guideline question. Again, agreement for this coding was 100%.

Applying codes in the development of evidence summaries for Recommendations and Good Practice Points (all activities).

The following process was developed, and implemented by members of the GDG (Emma Hinze, Rhylee Sulek, David Trembath, Kandice Varcin, Rachelle Wicks) and research assistants (Veronica Frewer, Libby Groves) to ensure that qualitative data gathered during the research activities could (a) be considered in a systematic manner when supporting and formulating Recommendations and Good Practice Points and (b) used to populate the evidence summaries for each Recommendation in a consistent manner. Implementation of the process with fidelity was supported by (a) documenting the process, (b) producing a video to explain the process that was used to support implementation (including worked examples), and (c) daily interaction with Microsoft Teams to support implementation. Each person involved in this process was assigned a section of the guideline and provided with associated evidence drawn from the research activities. Figure 4.1 presents the decisions each panel member made when reviewing the evidence for their assigned section, in relation to each code, and determining if/how it would inform revisions to existing Recommendations, the formulation of new Recommendations, and the development of Good Practice Points. Those involved in the development of evidence summaries also reviewed any evidence coded as ‘other’, to ensure that information that did not fit within the coding framework was considered collectively (when viewed alongside the complete set of data) to ensure that novel Recommendations and Good Practice Points could emerge. Following application of the process outlined in Figure 4.1 draft Recommendations and Good Practice Points were then reviewed by the GDG.

Figure 4.1 Applying codes in the development of evidence summaries for Recommendations and Good Practice Points.



Scope
Is the quote relevant to one or more Guideline questions?

Novel
Does the quote provide evidence that is not already accounted for in the guideline?

Implications
Does the quote have one or more clear implications for practitioners who are the main audience for the guideline?

Support for existing recommendation/GPP in its current form (no edits)
Does this quote provide support for an existing recommendation/GPP

Edit existing recommendation/GPP
Does this quote indicate the need to edit an existing recommendation/GPP?

New recommendation/GPP
Does this quote indicate the need for a new recommendation/GPP?

Compliance Check

- **Scope:** Will the proposed statement adhere to the definition of recommendation/good practice point?
- **Novelty:** Will the proposed recommendation/good practice point be sufficiently novel to warrant its inclusion?
- **Parsimony:** With the guideline aim of being concise, is it critical to add this recommendation/good practice point?

Proposed edit to Existing Recommendation/GPP

- Copy the quote verbatim into the relevant cell of the guideline spreadsheet
- Insert a comment in the guideline spreadsheet in the ‘Proposed Revisions’ cell indicating your initials and proposed edits in the form of revised statement.

Propose new recommendation/GPP

- Copy the quote verbatim into the relevant cell of the guideline spreadsheet
- Insert a comment in the guideline spreadsheet in the ‘Proposed Revisions’ cell indicating your initials and proposed recommendation /GPP.

Evidence Summary

- Include this quote in the evidence summary.
- If there is an existing quote in the summary, consider whether this quote is clearer, more concise, and/or more complete evidence and if so, replace the existing quote. If not, leave the evidence summary unchanged.

No further action required

Study Quality Assessment

Risk of Bias was independently assessed by two reviewers (Libby Groves and Rachelle Wicks) using an adapted version of the Critical Appraisal Checklist for Systematic Reviews and Research Syntheses (CACSRRS; Appendix 4.4) created by the Joanna Briggs Institute (2020). The form comprises 11 items related to the quality of: (a) the review question, (b) the inclusion criteria, (c) the search strategy, (d) the sources and resources, (e) the criteria for appraising the studies, (f) agreement between raters on extraction and quality appraisal, (g) the methods used to combine studies, (h) the likelihood of publication bias, (i) recommendations for policy and/or practice, and (j) directives for new research. Any disagreements were discussed and resolved via consensus, without input from a third reviewer. The percentage of agreement [agreements/(disagreements + agreements) × 100] for quality assessment was 81.3%.

The original CACSRRS was developed to assess SRs pertaining to supports/interventions. The review questions for these SRs could, thus, be answered using a Population-Intervention-Comparison-Outcome (PICO) format. However, the research questions being addressed in this Umbrella Review, and thus the eligibility criteria adopted, mean that PICO was not relevant to the majority of the included SRs. Therefore, the reviewers instead determine if the review presents one or more aims/questions that specify the population, concept, context (PCC approach; Peters et al., 2020). For example, an SR focussing on experiences should detail (a) the types of participants sought for inclusion, (b) the specific experience(s) examined by the SR, and (c) the settings in which they were assessed and/or diagnosed, if relevant.

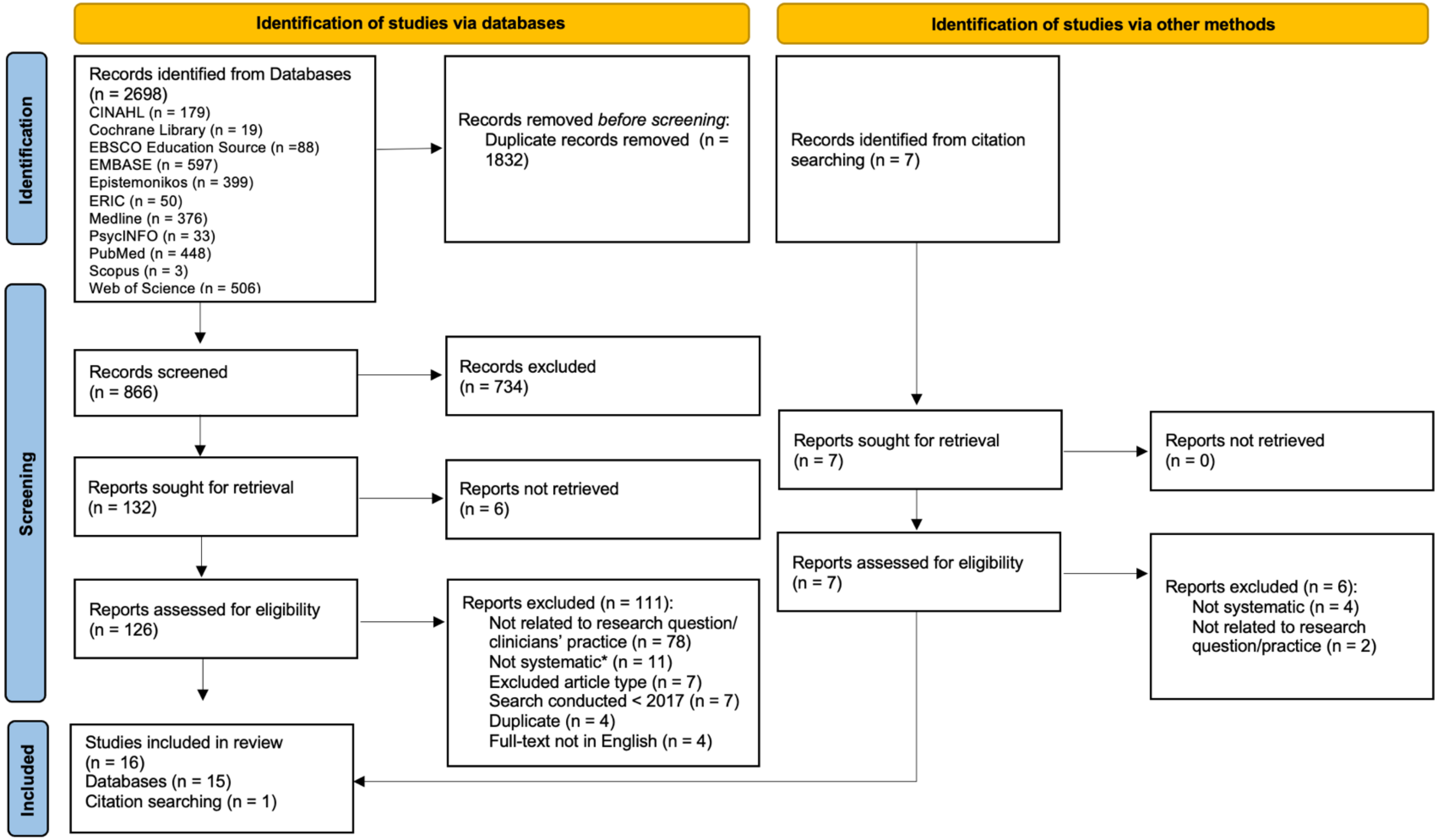
Each item was rated dichotomously, with “yes” indicating a low risk of bias for that item, and “no” indicating a high risk of bias for that item. The item regarding the likelihood of publication bias was rated for meta-analyses only and was rated ‘not applicable’ for all other SRs. SRs were not excluded based on methodological quality. A summary rating of ‘high’ was awarded for systematic reviews that meet ≥80% of items using the CACSRRS. Systematic reviews that meet fewer than 80% of items using the CACSRRS were rated as low.

4.6 Results

Study selection

The PRIMSA flow diagram in Figure 4.2 represents the study selection process (Page et al., 2021). The database search yielded 2,698 records across databases and 866 records once duplicates were automatically removed. One-hundred-and-thirty two articles proceeded to full-text review and 105 articles were excluded at this stage (see Appendix 4.5). The most common reason for exclusion was the article was not relevant to either the research question or to guiding clinicians' practice. During extraction, 6 additional articles were excluded because they did not contain quality assessments and, therefore, were not deemed to be systematic. This resulted in the inclusion of 15 SRs from the database searches. Citation searches identified seven additional potentially relevant records, of which six were excluded (see Appendix 4.6). This resulted in the inclusion of a total of 16 SRs in the umbrella review (See Appendix 4.7).

Figure 4.2 PRISMA flow diagram



*Six of these were excluded during extraction.

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Study characteristics

Of the 16 SRs included in the umbrella review, three (19%) were meta-analyses with narrative synthesis, and 13 (81%) were narrative syntheses. The majority of SRs (n = 13; 73%) were published in 2021 and 2022, with the remainder (n = 3, 19%) published in 2018 or 2019. The number of studies included in SRs ranged from 6 (Dorlack et al., 2018; Guan et al., 2022) to 56 (van't Hof et al., 2020), with a median of 20. Each SR specified the final year of the search, and 13 (73%) SRs mentioned the presence or absence (i.e., since database inception) of a starting year limit. Of these, 10 (77%) placed a limit on date, whereas 3 (23%) included all prior published research. The authors of 12 SRs (75%) provided information regarding sources of funding to conduct the SR and sources of funding were declared for seven of these (44%). The authors of 10 SRs reported that they had no conflicts of interest, while the remaining authors did not report on this. A detailed outline of study characteristics is provided in Appendix 4.8.

Focus of reviews

Eight SRs (50%) had a sole focus and the remaining eight SRs (50%) focussed on two areas related to assessment and diagnosis for autism. As such, the sum of the below exceeds 16. Five SRs (31%) examined recommendations to guide practitioners in assessing and diagnosing autism (Recommendation-focussed). Nine SRs (56%) focussed on clinical tools and processes that contribute to timely diagnosis for autism (Process-focussed). Four SRs (25%) examined considerations regarding personal and environmental factors in assessment and diagnosis for autism (Factor-focussed). Finally, six SRs (38%) focused on the views and experiences of the autistic and autism communities (Experience-focussed).

Study designs

Ten SRs (63%) specified the design of at least one of the included studies. There was considerable variation in the designs of the studies included in the SRs. Four SRs (40%) included studies that used qualitative approaches only (e.g., thematic analysis, grounded theory, phenomenological analysis), four SRs (40%) included studies that used quantitative approaches only (e.g., analyses of longitudinal cohort data, randomised controlled trials, pre-post study designs), and two SRs (20%) included studies that used either qualitative or quantitative approaches.

Participants

All SRs provided some detail about the participants in the original studies. Eight SRs (50%) included studies involving children, adolescents, and/or adults with an autism diagnosis or at high likelihood of receiving an autism diagnosis. Eight SRs (50%) included studies involving parents and/or family members of individuals with an autism diagnosis, such as mothers, fathers, grandparents, and aunts. Seven SRs (44%) included practitioners involved in assessment, diagnosis, and/or provision of support for autism. There was wide variation in practitioner roles, which included paediatricians, psychologists, educators, speech language pathologists, and nurses. One SR (6%) included general 'community members'.

Some SRs are included in the above frequencies multiple times due to including studies involving individuals from more than one of the above categories. Only six SRs (38%) stated the total number of included participants which ranged from 342 (Legg & Tickle, 2019) to 120,540 individuals (included in the narrative synthesis; Loubersac et al., 2021).

Study location

Thirteen SRs (81%) provided information about the geographical locations at which the original studies had been conducted. Twelve SRs (92%) included studies conducted in North America or Europe. This was followed by six SRs (46%) which included studies conducted in Australia, and five (38%) which included studies conducted in Asia. Three SRs (23%) included studies conducted in Africa or the Pacific. Finally, only one SR included studies conducted in South America/the Caribbean (8%). Note that some SRs are included numerous times in the above frequencies due to including studies from multiple geographical locations.

Quality of SRs

The quality of SRs, assessed using a modified version of the CACSRRS (Joanna Briggs Institute, 2020), yielded scores of 5 to 7 out of 11 for the three included meta-analyses, and 2 to 10 out of 10 (mode = 8) for the 13 narrative syntheses. Seven SRs (44%) were considered "high quality" because they met ≥ 80% of the items, and the remaining nine SRs (56%) were considered "low quality". The only SR to score maximum points was conducted by Legg et al. (2019). A full summary of item scores and totals for each SR is provided in Appendix 4.9.

Common areas of strength (criterion met for ≥80% of SRs) were in the inclusion of a clear statement of the review question (Item 1), appropriate inclusion criteria (Item 2), the use of independent reviewers to assess critical appraisal (Item 6), appropriate methods for combining study findings (Item 8), and suggestions for future research (Item 11). Common areas of weakness (criterion met for < 80% of SRs) related to the absence of a clear search strategy (Item 3), appropriate sources including grey literature (Item 4), lack of an appropriate critical appraisal tool (Item 5), adoption of methods to minimise extraction errors (Item 7), and well-supported recommendations for policy/practice (Item 10). Of the three SRs (65%) that included a meta-analysis, only one included an assessment of potential publication bias (Item 9).

The quality of studies included within SRs was assessed by the original review authors using a variety of tools (see Appendix 4.8). The most common of these were Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, 2019) tool for qualitative studies which was used in five studies (31%). The Scientific Merit Rating Scale (National Autism Center, 2015), and the Quality Assessment of Diagnostic Accuracy Studies (Whiting et al., 2011) were each used in two SRs (13%), while the remaining tools were only used in one SR. Eleven SRs (69%) were identified as including at least one study at high risk of bias, three (19%) as including at least one study with moderate risk of bias, and two (13%) as only including studies at low risk of bias.

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The quantitative summary of the quote matrix is included in Appendix 4.10. Thirteen SRs included at least one quote pertaining to Principles. The number of SRs with quotes related to each principle ranged from one for ‘evidence-based’ to ten for ‘timely and accessible.’ No quotes were extracted from any of the SRs for the ‘neurodiversity-affirming’, or ‘respecting Australia’s First Nations Peoples’ principles. All 16 SRs included at least one quote related to the process of assessment and/or diagnosis. The number of SRs with quotes related to each aspect of the process ranged from three for ‘decision making’, ‘outcomes, ‘other’, and ‘when’ to 13 for ‘knowledge and training’. No quotes were extracted from any of the SRs for the Quality and Safety domain. Full lists of the evidence quotes for the Principles and the Process of Assessment and/or Diagnosis are included in Appendices 4.11 and 4.12 respectively.

5. Community Consultation: Online Survey

5.1 Background

Integral to the update of the Guideline was consultation with the autistic and autism communities. Consistent with the recommendations in the Guidelines for Guidelines handbook (NHMRC, 2016), community consultation was conducted to ensure that all relevant stakeholders within Australia were provided with the opportunity to inform the update of the Guideline. This was key to enhancing the relevance and acceptability of the updated Guideline to the autistic and autism communities. The consultation process was also conducted to (a) complement other research evidence, and (b) gather information and insight from relevant stakeholders where research evidence is currently lacking.

This consultation activity adopted an online survey methodology. This approach was used to enable broad participation and input from all relevant stakeholders, including children, young people and adults, who identified as members of the autistic and/or autism communities.

5.2 Aim

The aim of the online survey was to understand the experiences, views, and preferences of the autistic and autism communities regarding assessment and diagnosis of autism in Australia.

5.3 Research questions

- What are the experiences, views, and preferences of the autistic and autism communities regarding the assessment and diagnosis of autism in Australia?
- What are the autistic and autism communities' views on best practice for the assessment and diagnosis of autism in Australia?
- What are the autistic and autism communities' views on the current version of the Guideline? Is there anything that should be changed or addressed in the updated version?

5.4 Design

An online survey methodology was adopted. This was a one-off survey, accessed via a link on the Autism CRC website and hosted on Griffith University REDCap. Participants had flexibility and autonomy in choosing what questions they would like to answer. They were able to complete the survey independently or with support. The survey included speech-to-text and text-to-speech functionality as well as the option to submit an artwork instead of text responses.

The survey was open to individuals of any age for 4 weeks, from 7th November to 5th December 2022.

5.5 Method

Ethical approval for this community consultation activity was provided by Griffith University Human Research Ethics Committee (2022/780).

Eligibility

All relevant stakeholders across the autistic and autism communities were eligible to participate in the online survey, including

- Autistic people of any age (with or without a formal diagnosis)
- Parents, caregivers, and family members of individuals on the autism spectrum
- Practitioners involved in assessment and/or diagnosis of autism
- Members of organisations/bodies/groups that have an interest in the assessment and/or diagnosis of autism
- Any other relevant stakeholders (e.g., informal support people, researchers, educators)

Recruitment

Participant recruitment for community consultation activities was predominantly facilitated by Autism CRC. Autism CRC initially advertised the community survey by emailing members on their mailing list (n=25,432 recipients) and posting information on their social media channels (Twitter, Facebook). The Guideline Development Group also shared the invitation to participate in the community consultation activities with (a) organisations who had provided feedback (during the public consultation period) on the National Practice Guideline for supporting autistic children and their families (n=39), and (b) organisations that support or represent Aboriginal and Torres Strait Islander Peoples (n=10).

Over the 4-week community consultation period, Autism CRC sent two reminders of the community consultation activities via email to people on their mailing list. In addition, Reference Group members were kindly requested to advertise the community consultation activities through their organisations/members. Members of the GDG also promoted the community consultation activities throughout their professional networks and social media pages.

After accessing the online survey link, prospective participants were presented with a short video outlining what participation in the survey would entail and highlighting accessibility features of the survey platform. Following this, participants were presented with a Participant Information Statement and Consent Form. All participants were required to provide informed consent before accessing the survey questions. For individuals who were under the age of 18, or could not provide informed consent independently, a parent or guardian was asked to provide consent on their behalf and assist them (as necessary) to complete the survey.

Tools

The development of the draft online survey was informed by: (i) the structure and content of the online community consultation activities used as part of the development of the National Practice Guideline for supporting autistic children and their families in Australia (Trembath, 2022), (ii) the content of the Delphi survey used as part of the development of the 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders' (Whitehouse et al., 2018a,b), and (iii) the set of questions developed by the Guideline Development Group guiding the update to the Guideline (see Chapter 2).

An iterative approach was taken to the design of the online survey. Members of the Working Group (Rhylee Sulek, David Trembath, Kandice Varcin) led the initial drafting of the survey. All members of the Working Group were invited to provide input on the draft survey. The draft version was then sent to the broader GDG for review and feedback. The Working Group members addressed feedback from the GDG and made changes to the survey, as appropriate. The revised version of the survey was coded in REDCap (a secure web-based application for survey development and distribution) and piloted by members of the Working Group for clarity and functionality. Feedback provided through the piloting process led to further minor modifications before the final survey was finalised ahead of distribution.

The survey was intended to be able to collect the views, preferences and experiences of as many members as possible of the autistic and autism communities (of all ages) with an interest in the assessment and/or diagnosis of autism. In addition to demographic information, the final survey (see Appendix 5.1) included open-ended questions that were structured to collect information related to: (i) people's current views and/or experiences of assessment and/or diagnosis in Australia (which could be submitted as text or as piece of art), (ii) important considerations for each aspect of the assessment and/or diagnosis process covered by the Guideline (i.e., guiding principles, referral, assessment of functioning, medical evaluation, diagnostic assessment, safety and wellbeing), and (iii) the original Guideline and the update (e.g., anything that should be changed or addressed, and barriers and enablers to implementation of the Recommendations).

Participants were provided with multiple pathways to navigate through the survey, including the capacity to skip sections and/or exit the survey at multiple points. In addition to the option to submit views and perspectives on assessment and/or diagnosis as text or artwork, there were other accessibility features enabled in the survey. These included speech-to-text and text-to-speech options throughout the survey, the option to save and return as many times as someone needed, and the option to complete the survey with support or independently.

The final survey was estimated to take between 10 to 60 minutes to complete depending on which questions participants chose to answer.

Analysis

Coding process and credibility (community consultation activities)

Qualitative data gathered via the online survey were analysed using the coding framework outlined in Chapter 4. The coding team (Briohny Dempsey, Veronica Frewer, Libby Groves, Emma Hinze, Rachelle Wicks) were each assigned a set of survey questions, and coded all participant responses for their assigned section/s. Members of the coding team applied the relevant section of the coding framework to participant responses (i.e., coding team member assigned the Principles questions applied the codes outlined under the corresponding section of the codebook).

While section three of the online survey (i.e., participant views about the existing guideline) was originally intended to be coded against ‘Principles’ it became apparent that many pieces of evidence were being coded as ‘other’. A decision was made to read each participant response individually to determine whether the evidence supported already identified Recommendations and Good Practice Points. Where new evidence was emerging, these quotes were used to either (1) support proposals for new Recommendations and Good Practice Points, or (2) support introductory or guiding text featured throughout the Guideline.

As indicated in Chapter 4, multiple approaches were used to help ensure the credibility of the coding process (i.e., akin to *reliability* in quantitative research) including employing people with relevant expertise (i.e., previous coding of the Supporting Children’s Guidelines), using a standardised code book and training procedures, ensuring on-call support on a daily basis and weekly team meetings for fidelity and support purposes, and ultimately presenting evidence using people’s own words in preparing the evidence summaries. In addition, a credibility check was completed for every quote identified during the coding process was developed.

The credibility check was intended to (a) ensure that quotes were attributed to codes accurately and (b) ultimately provide readers of the Guideline with information to inform their interpretation of the data. The instructions were to:

- Review the contents (quote/s) one cell (participant) at a time.
- Ask yourself “Is this quote relevant to the code that has been applied?”
- If the answer is yes, proceed to next step. In some cases, you may find that the quote is ambiguous because you are only reviewing part of a participant’s more expansive response or due to the participant’s expression. It is not intended that each quote will be a complete and cohesive statement in relation to the code, and so provided that in your judgement the quote appears to be relevant, it can be marked yes.
- If the answer is no, ask yourself “Is this quote potentially relevant to addressing one or more other guideline questions?
- If yes, highlight the quote in yellow.

- If no, highlight the quote in red, indicating that the quote does not appear to fit the current code, and does not appear relevant to addressing one or more guideline questions.

This approach resulted in the classification of each quote in each code as either ‘relevant to the Guideline and code,’ ‘relevant to the Guideline, but cannot establish relevance to code,’ or ‘does not appear to be relevant to the Guideline.’ The proportion of responses related to each classification is provided in the Results section for each community consultation study. It is important to note that the person completing the credibility check was reviewing the coded data, not the original transcripts. Accordingly, they did not necessarily have knowledge of the context (e.g., broader statement) from which the quotes had been extracted, which may account for some of the disagreements.

5.6 Results

Participant characteristics

One thousand people accessed the online survey. Of those, 810 participants provided informed consent to participate. Amongst those, five people provided informed consent, however, indicated in response to the final survey question that they would not like their information to be used. As such, the final number of participants who provided consent for their information to be used was 805.

Participants brought a range of (and often, multiple) perspectives to the survey including 232 people who identified as autistic/person on the autism spectrum, 325 parents/caregivers/family members of someone on the autism spectrum, 298 practitioners, 115 members of organisations/bodies/groups that have an interest in the assessment and/or diagnosis of autism, and 72 people that identified as bringing ‘other’ perspectives.

Demographic information for each group (as self-identified by the person completing the survey) is presented in Tables 5.1 – 5.5.

Autistic people/people on the autism spectrum

Table 5.1 Demographic information for people who identified as autistic/on the autism spectrum in the online survey (n=232).

Demographic group	Participation information
Other perspectives	Autistic people/people on the autism spectrum brought the following additional perspectives: • Parent/caregiver/family member of someone on the autism spectrum: n=93 • Practitioner: n=47

	- Member of an organisation/body/group that has an interest in the assessment and/or diagnosis of autism: n=22 - Other: n=27
Age	Autistic people/people on the autism spectrum were in the following age brackets: - 0-12 years (child): n=4 (2%) - 13-17 years (adolescent): n=1 (0.4%) - 18-25 years: n=27 (11.6%) - 26 years or older: n=198 (85%) 2 (1%) participants did not provide a response.
Aboriginal and/or Torres Strait Islander Peoples	6 (2.6%) autistic people identified as Aboriginal. 222 (95.7%) autistic people did not identify as Aboriginal and/or Torres Strait Islander. 4 (1.7%) participants did not provide a response.
State/Territory	Autistic people resided in the following States/Territories within Australia: - Australian Capital Territory: n=13 (6%) - New South Wales: n=54 (23%) - Northern Territory: n=0 (0%) - Queensland: n=54 (23%) - South Australia: n=18 (8%) - Tasmania: n=8 (3%) - Victoria: n=61 (26%) - Western Australia: n=19 (8%) 3 (1%) participants were not currently residing in Australia (and as such, were unable to progress any further through the survey). 2 (0.9%) participants did not provide a response.
Autism diagnosis	172 (74%) people had received a formal diagnosis of autism. 10 (4%) people were currently being assessed for a possible diagnosis of autism. 36 (16%) people self-identified as autistic but had not received a formal diagnosis of autism. 7 (3%) people chose not to share additional information about their diagnosis. 7 (3%) people did not provide a response.
Age at autism diagnosis	Of those who had received a formal diagnosis, 169 (98%) people reported their age at diagnosis, with the average age 35.98 years (SD = 14.8), and ages ranging from 2 years to 78 years. 3 (2%) participants who had received a formal diagnosis did not provide a response.
Level of support - diagnosis	Of people with a formal diagnosis, the following levels of support were reported by participants to participate in everyday activities at the time of their diagnosis:

	• 66 (38%) people reported Level 1 (required some support). • 66 (38%) people reported Level 2 (required substantial support). • 3 (2%) people reported Level 3 (required very substantial support). • 23 (13%) were unsure. • 10 (6%) preferred not to say. 3 (2%) participants did not provide a response. For people that specified a level of support (as Level 1, 2 or 3): • 28 (21%) selected that level as they felt it was most appropriate at the time they were diagnosed • 105 (78%) selected that level as it was the level assigned by the practitioner at the time of diagnosis 2 (1%) participants did not provide a response.
Level of support - current	The following levels of support were reported by participants to participate in everyday activities at the current time: • 74 (32%) selected Level 1 as most representative. • 69 (30%) selected Level 2 as most representative. • 9 (4%) selected Level 3 as most representative. • 44 (19%) were unsure. • 19 (8%) preferred not to say. 17 (7%) participants did not provide a response.
Familiarity with the National Guideline for the Assessment and Diagnosis of Autism in Australia	Of autistic people/people on the autism spectrum completing the online survey: • 106 (46%) had read or used the previously published 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (2018) • 122 (53%) had not read or used the previously published 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (2018) 4 (0.4%) participants did not provide a response.

Parents, caregivers or family members of people on the autism spectrum

Table 5.2. Demographic information of parents, caregivers or family members of people on the autism spectrum (n=325).

Parents, caregivers or family members of people on the autism spectrum	
Other perspectives	Parents, caregivers or family members of people on the autism spectrum brought the following additional perspectives: • Autistic person/person on the autism spectrum: n=93 • Practitioner: n=61 • Member of an organisation/body/group that has an interest in the assessment and/or diagnosis of autism: n=31 • Other: n=27
Relationship	Family members of people on the autism spectrum self-identified as: • Parents/caregivers: n=277 • Kinship carers/foster carers: n=2 • Children of autistic parents: n=8 • Spouses: n=12 • Grandparents: n=8 • Aunts/uncles: n=7 • Siblings: n=15 • Other/non-specific relation (e.g., support person, family member): n=3 19 (6%) participants did not provide a response.
Age of people completing the survey	Parents, caregivers or family members of people on the autism spectrum, completing the survey, were in the following age brackets: • 18-25 years (young adult): n=12 (4%) • 26 years or older (adult): n=256 (79%) 4 participants (1%) did not provide a response. *It appeared that there was an error in reporting on this question in some age brackets. 36 (11%) people indicated that they were 0-12 years of age and 17 (5%) indicated that they were 13-17 years of age. However, upon closer inspection of the data, it appeared that these respondents had provided the age of their child (rather than their own age).
Age of family members on the autism spectrum contributing to	28 family members indicated that their family member/s on the autism spectrum contributed to the responses in the survey. The family members on the autism spectrum contributing responses were the following ages: • 0-12 years (child): n=10 (29%)

responses in the survey	- 13-17 years (adolescent): n=12 (34%) - 18-25 years (young adult): n=7 (20%) - 26 years or older (adult): n=6 (17%)
Aboriginal and/or Torres Strait Islander Peoples	12 parents, caregivers or family members (4%) identified as Aboriginal and/or Torres Strait Islander. 306 parents, caregivers and family members (94%) did not identify as Aboriginal and/or Torres Strait Islander. 7 (2%) participants did not provide a response.
State/Territory	Parents, caregivers and family members of autistic children resided in the following States/Territories within Australia: - Australian Capital Territory: n=12 (3.5%) - New South Wales: n=66 (20%) - Northern Territory: n=5 (1.5%) - Queensland: n=73 (22%) - South Australia: n=18 (5.5%) - Tasmania: n=10 (3%) - Victoria: n=71 (22%) - Western Australia: n=59 (18%) 5 (1.5%) participants were not currently residing in Australia (and as such, were unable to progress any further through the survey). 6 (2%) participants did not provide a response.
Family members on the autism spectrum	301 parents, caregivers and family members provided information about 425 family members on the autism spectrum. 5 (1.5%) parents, caregivers or family members chose not to share additional information about their family member's diagnosis. 19 (6%) participants did not provide a response to these items. Of those that did provide information, family members on the autism spectrum were in the following age brackets: - 0-12 years (child): n=201 (47%) - 13-17 years (adolescent): n=96 (23%) - 18-25 years (young adult): n=55 (13%) - 26 years or older (adult): n=72 (17%) 1 (0.2%) participant did not provide a response.
Family members autism diagnosis	Of the 425 family members on the autism spectrum, 358 (84%) had received a formal diagnosis of autism. 67 (16%) had not yet received a formal diagnosis.

Family members age at autism diagnosis	Of the 358 family members on the autism spectrum that had received a formal diagnosis, the average of diagnosis was 9.25 years (SD = 9.39), with ages ranging from 1 year to 73 years. 7 participants did not provide their family member's age at diagnosis.
Family members level of support - diagnosis	Of those with a formal diagnosis, the following levels of support were reported by their family members to participate in everyday activities at the time of their diagnosis: • 63 (18%) people reported Level 1 (required some support). • 199 (56%) people reported Level 2 (required substantial support). • 66 (18%) people reported Level 3 (required very substantial support). • 23 (6%) were unsure. • 5 (1%) preferred not to say. 2 (0.5%) participants did not provide their family member's level of support. For family members that specified a level of support (as Level 1, 2 or 3): • 64 (20%) selected that level as they felt it was most appropriate at the time their family member was diagnosed • 260 (79%) selected that level as it was the level assigned by the practitioner at the time of their family member's diagnosis 4 (1%) participants did not provide a response.
Familiarity with the National Guideline for the Assessment and Diagnosis of Autism in Australia	Of parents, caregivers and family members of people on the autism spectrum completing the online survey: • 170 (52%) had read or used the previously published 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (2018) • 146 (45%) had <u>not</u> read or used the previously published 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (2018) 9 (3%) participants did not provide a response.

Practitioners

Table 5.3. Demographic information of practitioners involved in the assessment and/or diagnosis of autism (n=298).

Practitioners	
Other perspectives	Practitioners brought the following additional perspectives: • Autistic person/person on the autism spectrum: n=47 • Parent/caregiver/family member of someone on the autism spectrum: n=61 • Member of an organisation/body/group that has an interest in the assessment and/or diagnosis of autism: n=39 • Other: n=10
Profession	Practitioners included: • Aboriginal and Torres Strait Islander Health Worker or Health Practitioner: n=2 • Audiologist: n=1 • Board Certified Behaviour Analyst: n=3 • Developmental educator: n=3 • Educator (early childhood): n=3 • Educator (primary school): n=6 • Educator (high school): n=4 • General Practitioner: n=4 • Nurse: n=7 • Nurse practitioner: n=1 • Occupational therapist: n=23 • Paediatrician: n=25 • Physiotherapist: n=1 • Psychiatrist: n=7 • Psychologist: n=164 • Social worker: n=7 • Speech pathologist: n=44 • Support worker: n=1 • Other: n=13 2 (0.7%) participants did not specify their profession.

Aboriginal and/or Torres Strait Islander Peoples	3 (1%) practitioners identified as Aboriginal. 280 (94%) practitioners did not identify as Aboriginal and/or Torres Strait Islander. 15 (5%) participants did not provide a response.
State/Territory	Practitioners resided in the following States/Territories within Australia: • Australian Capital Territory: n=5 (1.5%) • New South Wales: n=93 (31%) • Northern Territory: n=2 (0.5%) • Queensland: n=46 (15%) • South Australia: n=18 (6%) • Tasmania: n=8 (2.5%) • Victoria: n=74 (25%) • Western Australia: n=38 (13%) 12 (4%) participants were not currently residing in Australia (and as such, were unable to progress any further through the survey). 2 (0.5%) participants did not provide a response.
Involvement in assessment and/or diagnosis process	4 (1%) people chose not to share additional information about their role. 23 (8%) participants did not provide a response. Of practitioners that chose to provide additional information about their role (n=271), they were involved in the assessment and/or diagnosis of autism in the following ways: • Referral: n=107 (39%) • Conducting assessments: n=187 (69%) • Assessments and diagnosis: n=164 (61%) • Provision of services after a diagnosis: n=177 (65%) • Other: n=12 (including supervision and training in assessment, development of organisational guidelines for assessment, consultation and support for people referring and assessing) (4.4%)
Involvement in specific aspects of assessment and/or diagnosis	Of practitioners that chose to provide additional information about their role (n=271), they reported being involved in the following specific aspects of assessment and/or diagnosis: • Medical evaluation: n=43 (16%) • Assessment of functioning: n=195 (72%) • Single clinician diagnostic evaluation: n=143 (53%) • Consensus team diagnostic evaluation: n=182 (67%) • None of these aspects: n=10 (4%) 3 (1%) participants did not provide a response.

Years of experience in assessment and/or diagnosis	Practitioners had on average 10.04 years (*SD* = 7.52) experience in the assessment and/or diagnosis of autism. Years of experience ranged from 1 year to 43 years. 7 (2.5%) participants did not provide a response.
Years of experience in clinical practice	Practitioners had on average 13.07 years (*SD* = 8.38) experience working in clinical practice with people on the autism spectrum. Years of experience ranged from 0 year to 43 years. 11 (4%) participants did not provide a response.
Organisation type	210 practitioners worked in private organisations (including non-government organisations) and 99 worked in government organisations (including hospitals and health services). 3 (1%) participants did not provide a response.
Service setting for assessment and/or diagnosis	Practitioners provided assessment and/or diagnostic services across the following settings: • Hospital (inpatient/outpatient): n=38 (14%) • Community clinic (including private practice): n=210 (77%) • University clinic: n=15 (5.5%) • Other: n=33 (12%) 4 (1.5%) participants did not provide a response.
Age groups for assessment and/or diagnostic services	Across their career, practitioners had provided autism assessment and/or diagnostic services across the following age brackets: • 0-12 years (children): n=242 (89%) • 13-17 years (adolescents): n=210 (77%) • 18-25 years (young adults): n=139 (51%) • 26 years and older (adults): n=117 (43%) • Does not provide assessment and/or diagnostic services: n=5 (2%) 4 (1.5%) participants did not provide a response.
Familiarity with the National Guideline for the Assessment and Diagnosis of Autism in Australia	Of practitioners completing the online survey: • 255 (86%) had read or used the previously published ‘National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia’ (2018) • 30 (10%) had <u>not</u> read or used the previously published ‘National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia’ (2018) 13 (4%) participants did not provide a response.

Members of organisations/bodies/groups

Table 5.4. Demographic information of members of organisations/bodies/groups that have an interest in the assessment and/or diagnosis of autism (n=115).

Members of organisations/bodies/groups	
Organisational level response	Members of organisations/bodies/groups responded to the online survey as: • Individual members (i.e., the views were that of the individual): n=81 (70%) • The nominated representative of the organisation/body/group (i.e., submitting on behalf of the organisation as a whole): n=31 (27%) 3 (2%) participants did not provide a response.
Other perspectives	For those people providing feedback as individual members of organisations/bodies/groups (n=81) with an interest in the assessment and/or diagnosis of autism, they brought the following additional perspectives: • Autistic person/person on the autism spectrum: n=19 • Parent/caregiver/family member of someone on the autism spectrum: n=28 • Practitioner: n=34 • Other: n=17
State/Territory	Organisations/bodies/groups provided services in/across the following States/Territories within Australia: • Australian Capital Territory: n=22 • New South Wales: n=43 • Northern Territory: n=19 • Queensland: n=33 • South Australia: n=32 • Tasmania: n=23 • Victoria: n=43 • Western Australia: n=32 6 (5%) participants did not provide a response.
Familiarity with the National Guideline for the Assessment and Diagnosis of Autism in Australia	Of members of organisation completing the online survey: • 93 (81%) had read or used the previously published 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (2018) • 14 (12%) had not read or used the previously published 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (2018) 8 (7%) participants did not provide a response.

‘Other’ Participants

Table 5.5. Demographic information of participants who indicated that they brought ‘Other’ perspectives (n=72).

Other	
‘Other’ description	Individuals who indicated that they brought ‘Other’ perspectives described themselves/their interest in the assessment and/or diagnosis of autism as: • Advisory group member: n=1 • Advocate: n=1 • Autistic person: n=1 • Behaviour support: n=2 • Consultant: n=1 • Coordinator: n=1 • Educator: n=1 • Facilitator/moderator of online group: n=1 • Friend: n=1 • Health professional: n=1 • Manager at a service: n=2 • Member of an organisation: n=1 • Mental health clinician: n=1 • Music therapist: n=1 • Neurpsychologist: n=1 • Occupational therapist: n=3 • Parent: n=3 • Psychologist: n=5 • Researcher: n=12 • Social worker: n=1 • Speech pathologist: n=1 • Spouse: n=2 • Student (at university): n=3 • Student teacher: n=1 • Support person: n=1 • Support worker: n=6 • Teacher: n=6 • Therapy assistant: n=1 • Work with autistic young people: n=1 12 (17%) participants did not provide a response.

Other perspectives	People who selected 'other' brought the following additional perspectives: - Autistic person/person on the autism spectrum: n=27 - Parent/caregiver/family member of someone on the autism spectrum: n=27 - Practitioner: n=10 - Member of an organisation/body/group that has an interest in the assessment and/or diagnosis of autism: n=17
Age	People who selected 'Other' were in the following age brackets: - 13-17 years (adolescent): n=1 (1%) - 18-25 years: n=7 (10%) - 26 years or older: n=63 (88%) 1 (1%) participant did not provide a response.
Aboriginal and/or Torres Strait Islander peoples	0 (0%) of people who selected 'Other' identified as Aboriginal and/or Torres Strait Islander. 68 (94%) people did not identify as Aboriginal and/or Torres Strait Islander. 4 (6%) participants did not provide a response.
State/Territory	People who selected 'Other' resided in the following States/Territories within Australia: - Australian Capital Territory: n=1 (1%) - New South Wales: n=16 (22%) - Northern Territory: n=0 (0%) - Queensland: n=19 (26%) - South Australia: n=3 (4%) - Tasmania: n=0 (0%) - Victoria: n=19 (26%) - Western Australia: n=11 (15%) 3 (4%) participants were not currently residing in Australia (and as such, were unable to progress any further through the survey).
Familiarity with the National Guideline for the Assessment and Diagnosis of Autism in Australia	Of people who selected 'Other' completing the online survey: - 47 (65%) had read or used the previously published 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (2018) - 22 (31%) had <u>not</u> read or used the previously published 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (2018) 3 (4%) participants did not provide a response.

Qualitative data

Survey text responses

A total of 5,229 references (i.e., participant quotes) were coded using the framework, with the distribution of references (i.e., quotes) for each participant group presented in Table 5.6. These quotes, where relevant to updating the Recommendations and Good Practice Points, feature in the corresponding Evidence Summaries.

Table 5.6. Summary of codes and references for each participant group.

Codes	**Number of Coding References for Each Participant Group**				
	Autistic Person	Family	Practitioner	Organisations	Other
Principles					
Appropriate	88	86	86	32	26
Competent	158	179	158	54	43
Comprehensive	42	86	132	31	21
Coordinated	8	25	54	16	4
Culturally Safe	2	4	3	4	2
Ethical	16	11	27	10	5
Evidence-based practice approach	40	77	113	32	20
Helpful	102	144	86	45	23
Holistic	73	99	91	36	20
Individual and Family Centred	51	79	47	27	26
Neurodiversity-affirming	56	47	72	38	13
Principles – Other	118	153	143	60	34
Respecting Australia's First Nations People	2	2	2	3	2
Strengths focused	37	52	68	16	10
Timely and Accessible - Equity	113	144	74	35	19

Comprehensive Needs Assessment					
Decision Making	0	0	0	0	0
Information Collected – How	41	52	72	28	10
Information Collected – What	35	49	60	28	6
Information Sharing	6	6	7	4	2
Knowledge and Training	83	92	83	29	20
Outcomes	7	7	9	5	2
Setting	4	24	21	8	2
When	0	1	1	0	0
Who	0	6	7	1	1
Other	13	7	6	4	4
Referral					
Decision Making	9	8	10	5	2
Information Collected – How	16	18	22	7	6
Information Collected – What	23	40	50	15	9
Information Sharing	11	15	29	5	2
Knowledge and Training	82	97	89	28	24
Outcomes	13	22	25	12	8
Setting	0	0	0	0	0
When	7	10	5	1	0
Who	7	8	5	4	0
Other	3	2	8	0	1
Diagnostic Evaluation					
Decision Making	1	2	11	5	2
Information Collected – How	36	49	68	25	15

Information Collected – What	17	23	31	11	6
Information Sharing	3	7	13	4	3
Knowledge and Training	54	59	82	30	13
Outcomes	3	8	19	6	4
Setting	1	13	12	5	3
When	0	0	0	0	0
Who	14	27	36	11	6
Other	6	5	3	1	1
Quality and Safeguarding					
Decision Making	0	0	0	0	0
Information Collected – How	12	13	21	7	3
Information Collected – What	11	11	33	7	4
Information Sharing	25	30	31	11	6
Knowledge and Training	62	90	102	39	22
Outcomes	18	21	19	11	6
Setting	22	25	31	13	8
When	1	2	1	0	0
Who	4	11	20	4	4
Other	6	6	7	4	0
Medical Evaluations					
Decision Making	1	0	0	1	0
Information Collected – How	16	23	23	13	4
Information Collected – What	32	41	51	18	9
Information Sharing	8	11	7	5	3
Knowledge and Training	58	77	84	30	17

Outcomes	7	9	7	5	1
Setting	2	1	3	3	1
When	0	1	0	1	0
Who	8	14	22	10	1
Other	1	1	2	0	0

As indicated above, credibility checks were completed for all quotes that featured in the analysis of qualitative data from the community survey. 99% were classified as ‘relevant to the guideline and code,’ <1% were classified as ‘relevant to the guideline, but cannot establish relevance to code,’ and 0% were classified as ‘does not appear to be relevant to the Guideline. Readers are reminded that the person completing the credibility check was reviewing the coded data, not the original transcripts. Accordingly, they did not necessarily have knowledge of the context (e.g., broader statement) from which the quotes had been extracted.

Artwork submissions

As part of the community consultation process, participants were invited to submit an artwork instead of and/or alongside providing written responses to questions presented in the community survey. A total of eight artwork submissions were received, with two excluded from analysis (due to containing only text responses). The remaining six artworks were analysed according to the coding scheme presented in Appendix 4.3 (i.e., the coding scheme applied across all community consultation activities). Two autistic members of the working group jointly viewed and discussed potential coding for each submission until consensus was reached. The results from the artwork submissions analysis are included in Table 5.6.

6. Community Consultation: Focus Groups

6.1 Background

Integral to the update of the Guideline was consultation with the autistic and autism communities. Consistent with the recommendations in the Guidelines for Guidelines handbook (NHMRC, 2016) community consultation was conducted to ensure that all relevant stakeholders within Australia were provided with the opportunity to inform the update of the Guideline. This was key to enhancing the relevance and acceptability of the Guideline to the autistic and autism communities. The consultation process was also conducted to (a) complement the current research evidence, and/or (b) gather information and insight from relevant stakeholders where research evidence is currently lacking.

This consultation activity was conducted to ensure that the experiences, views, and preferences of autistic individuals, their family members, and practitioners involved in the assessment and/or diagnosis of autism were captured in the update of the Guideline.

6.2 Aim

The aim of the focus groups were to understand the experiences, views, and preferences of (a) autistic people, (b) family members of autistic people, and (c) practitioners regarding assessment and/or diagnosis of autism.

6.3 Research question

What are the experiences, views, and preferences of autistic people, family members, and practitioners regarding assessment and/or diagnosis of autism in Australia?

6.4 Design

A qualitative methodology approach was adopted, with a series of nine online focus groups run between November 15th to December 2nd, 2022. Three of the focus groups were open to autistic adults, three were open to family members of autistic individuals and three were open to practitioners.

6.5 Method

Ethical approval for this community consultation activity was provided by Griffith University Human Research Ethics Committee (2022/780).

Eligibility

Autistic adults, family members, and practitioners were eligible to participate in the focus groups. To participate, all individuals had to be aged 18 years or over and reside in Australia.

Recruitment

Participant recruitment for the focus groups was predominantly facilitated by Autism CRC. An invitation to register interest in attending a focus group was distributed to members of Autism CRC mailing lists. In addition, links to access the focus group registration survey were made available via the social media (Facebook and Twitter) accounts of Autism CRC. Members of the GDG also promoted the focus groups throughout their professional networks and social media pages. After following the registration link, prospective participants were presented with a Participant Information Statement and Consent Form and required to indicate consent before providing their details and preferences to attend an online focus group.

The registration survey for the first round of focus groups was closed following a two-day recruitment period, due to total registrations exceeding available places (n=142 registrations for 72 positions). Registered individuals were allocated to a focus group based on their preferences and in consecutive order of receiving their registration, with 12 individuals allocated to each of the six groups and five waitlist positions available. A further three focus groups were advertised due to overwhelming demand, with recruitment occurring over a five-day period. Individuals who were not allocated to a group in the first round were contacted and provided an opportunity to indicate their preferences to attend one of the additional groups. A random number generator was then used to assign the remaining registered individuals (n=104 new registrations, n=5 individuals from round one) to one of the three additional groups, with 12 individuals allocated to each of the six groups and five waitlist positions available.

All registered participants were emailed to indicate their assignment to a focus group, waitlist, or to direct them to the online survey if they were not allocated. A total of nine focus groups were conducted, three for each participant group.

Tools

Participants completed a demographic survey (see Appendix 6.1) upon registering (round one) or were sent a link to the demographic survey following assignment to a group (round two). The demographic surveys were coded in REDCap (a secure web-based application for survey development and distribution).

Focus Group Question Guide

A semi-structured question guide was developed and used across all nine focus groups. The questions developed for the focus groups covered the same three overarching questions posed to participants who completed the online survey:

1. What is, or was, good about the way assessment and/or diagnosis happens in Australia?
2. What is, or was, bad about the way assessment and/or diagnosis happens in Australia?
3. What would like to see change in the way assessment and/or diagnosis happens in Australia?

Thinking to the future

- What principles are important for the assessment and diagnosis process?
- What can practitioners do to help ensure the safety and wellbeing of individuals and their families?

Focus group facilitation

Each focus group was facilitated, via Microsoft Teams, by two members of the GDG across a three-week period (15th November – 2nd December 2022). Each group was facilitated by a co-chair (either David Trembath or Emma Goodall), while the second facilitator alternated between different GDG members (Nicole Dargue, Rhylee Sulek, Kandice Varcin, Hannah Waddington, Andrew Whitehouse). The first facilitator was responsible for (a) coordinating the meeting, (b) introducing the Guideline development process and providing an orientation to the Focus Group, (c) facilitating the discussion, and (d) summarising and concluding the meeting. The second facilitator was responsible for facilitating the discussion via the 'chat' comments (an option available to all participants throughout the entirety of the focus group, as an additional or alternate method of contributing).

Participants were invited to have their video function turned on for the focus group, but this was not a requirement. Participants were also invited to share information in the way they preferred (i.e., through verbal discussion or writing responses using the 'Chat' function).

Each focus group followed the same schedule:

- Fifteen minutes prior to the meeting, the two facilitators joined Microsoft Teams to review planning for the focus group.
- At the scheduled start time, participants were admitted to the meeting.
- Facilitator 1 presented the introduction to the Guideline development process and focus group orientation (15 minutes).
- Facilitator 1 presented the three focus group questions, one at a time (allowing approximately 30 minutes per question).
- Facilitator 1 invited the participants to briefly introduce themselves the first time they shared responses to posed questions.
- Facilitator 1 presented a summary of the focus group outcomes, an overview of the next steps, and thanked the participants for their contribution (10 minutes).

A copy of the PowerPoint presentation that was used for all eight focus groups is provided in Appendix 6.2.

Analysis

Coding process and credibility

Focus group transcriptions were auto generated by the Microsoft Teams platform. Transcriptions were deidentified by a research assistant prior to analysis. De-identified transcriptions files were uploaded to NVivo software for analysis. 'Chat' comments and any further information provided to the facilitators following focus groups were copied from Microsoft Teams into a Word document and deidentified for analysis.

Information collected during the focus groups were coded according to the 'Principles' section of the coding framework outlined in detail in Chapter 4. This approach – rather than coding according to each section of the code book (e.g., making a referral, conducting an assessment) was adopted *a priori* in the first instance, given that focus groups – by their nature of encouraging discussion – may see participants talk in relation to more than one aspect of the Guideline at once (e.g., a person simultaneously talking about the referral process and their experience of diagnosis at the same). However, to ensure that no specific insights, experiences, or suggestions that may be relevant to formulating Recommendations and Good Practice Points were missed, the GDG also reviewed every transcript (discussion and chat) generated from the groups in full to ensure that all information was considered in relation to all Guideline questions, Recommendations and Good Practice Points.

The processes to ensure credibility of the coding undertaken were identical to those outlined in Chapter 5.

6.6 Results

Participant characteristics

A total of 246 registrations for 96 focus group positions (i.e., 12 slots across 8 focus groups) were received. Of these, 68 participants attended their allocated focus group. One participant was excluded from all analysis following their participation in a focus group as they did not meet criteria for inclusion (i.e., were not an Australian resident). While many participants held multiple perspectives (e.g., an autistic individual who was also a practitioner, see Figure 6.1), 21 (31.3%) participants attended focus groups where the common shared experience was being an autistic adult, 19 (28.4%) participants attended focus groups where the common shared experience was being a parent or caregiver of a child on the autism spectrum, and 27 (40.3%) participants attended focus groups where the shared experience was being a practitioner who provides assessment and/or diagnostic services to individuals on the autism spectrum.

Of the 67 participants who were included in analysis, 66 provided some details about themselves, and their child(ren) where relevant, through the online demographic survey (see Table 6.1).

Figure 6.1 Unique and shared perspectives of focus group participants.

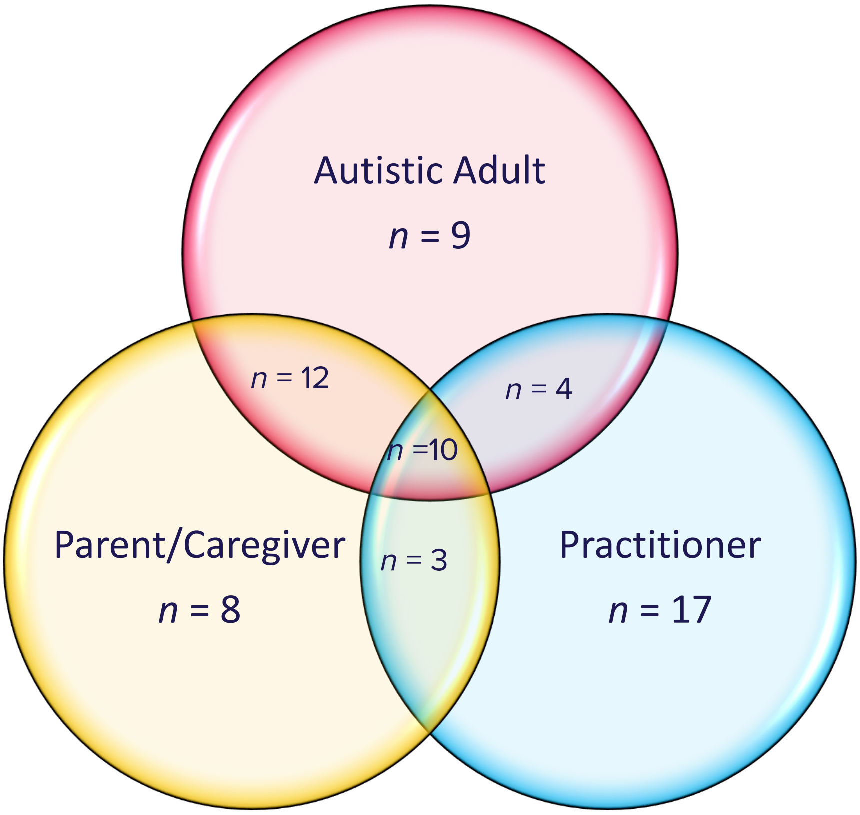

Table 6.1. Demographic information for people who attended the focus groups and provided some demographic information (n=66).

Demographic group	Participation information
Perspectives	Participants attending the focus groups brought the following perspectives: • Autistic person/person on the autism spectrum: n=35 • Parent/primary caregiver/family member of someone on the autism spectrum: n=34 • Practitioner: n=34 Other: n=10
Age	Participants were in the following age brackets: • 18-21 years: n=1 (1.5%) • 26 years and over: n=63 (95.5%) 2 (3%) participants did not provide a response.
Gender identity	55 (83%) participants identified as female, 4 (6%) identified as male, 4 (6%) as non-binary, and 2 (3%) preferred not to say. 1 (1%) participant did not provide a response.

Aboriginal and/or Torres Strait Islander Peoples	2 (3%) participants identified as Aboriginal and/or Torres Strait Islander. 3 (5%) participants did not provide a response.
State/Territory	Participants resided in the following States/Territories within Australia: • Australian Capital Territory: n=2 (3%) • New South Wales: n=20 (30%) • Northern Territory: n=2 (3%) • Queensland: n=13 (20%) • South Australia: n=3 (5%) • Tasmania: n=1 (1%) • Victoria: n=19 (29%) • Western Australia: n=5 (8%) 1 (1%) participant did not provide a response.

Table 6.2. Participants who identified as autistic.

Autism diagnosis	29 (44%) people had received a formal diagnosis of autism, and 4 (6%) people self-identified as autistic but had not received a formal diagnosis of autism. 2 (3%) participants did not provide a response.
Age at autism diagnosis	Of those who had received a formal diagnosis, the average age of diagnosis was 40.8 years (SD = 9.31), with ages ranging from 24 years to 55 years.
Level of support - diagnosis	Of people with a formal diagnosis, the following levels of support were reported by participants to participate in everyday activities at the time of their diagnosis: • 12 (41%) people reported Level 1 (required some support). • 12 (41%) people reported Level 2 (required substantial support). • 0 (0%) people reported Level 3 (required very substantial support). • 3 (10%) were unsure. • 2 (7%) preferred not to say.
Level of support – current	The following levels of support were reported by participants to participate in everyday activities at the current time: • 14 (40%) selected Level 1 as most representative. • 14 (40%) selected Level 2 as most representative. • 1 (3%) selected Level 3 as most representative.

	• 2 (6%) were unsure. • 3 (8%) preferred not to say. • 1 (3%) participant did not provide a response.

Table 6.3. Participants who identified as parents/caregivers/family members.

Family members on the autism spectrum	33 family members provided information about 56 family members on the autism spectrum. 1 family member chose not to share additional information about their family member's diagnosis. Of those that did provide information, family members on the autism spectrum were in the following age brackets: • 0-12 years (child) = 20 (36%) • 13-17 years (adolescent) = 18 (32%) • 18-25 years (young adult) =13 (23%) • 26 years or older (adult) = 5 (9%)
Family member autism diagnosis	Of the 56 family members on the autism spectrum, 47 (84%) had received a formal diagnosis of autism. 9 (16%) had not yet received a formal diagnosis.
Family members age at autism diagnosis	Of the 47 family members on the autism spectrum that had received a formal diagnosis, the average age of diagnosis was 9.05 years (SD = 9.39), with ages ranging from 2 years to 39 years.
Family members level of support – diagnosis	Of those family members with a formal diagnosis, the following levels of support were reported by their family members to participate in everyday activities at the time of their diagnosis: • 11 (23%) people reported Level 1 (required some support). • 27 (57%) people reported Level 2 (required substantial support). • 7 (15%) people reported Level 3 (required very substantial support). • 1 (2%) person was unsure. • 1 (2%) person preferred not to say.

Table 6.4. Participants who identified as practitioners.

Profession	Practitioners included: • Nurse practitioner: n=2 • Occupational therapist: n=1 • Paediatrician: n=1 • Psychologist: n=24 • Speech pathologist: n=4 • Other: n=2
Involvement in assessment and/or diagnosis	Of practitioners that chose to provide additional information about their role (n=34), they were involved in the assessment and/or diagnosis of autism in the following ways: • Referral: n= 15 (44%) • Conducting assessment: n = 24 (71%) • Assessment and/or diagnosis: n = 24 (71%) • Provision of services after a diagnosis: n= 25 (74%) • Other: n= 4 (12%, including the training and supervision of other practitioners).
Involvement in specific aspects of assessment and/or diagnosis	Of practitioners that chose to provide additional information about their role (n=34), they reported being involved in the following specific aspects of assessment and/or diagnosis: • Medical evaluation: n=2 (6%) • Assessment of functioning: n=25 (74%) • Single clinician diagnostic evaluation: n= 22 (65%) • Consensus team diagnostic evaluation: n= 26 (76%) 2 practitioners indicated they were not involved in the processes outlined above.
Years of experience in assessment and/or diagnosis	Practitioners had on average 12.76 years (SD = 10.00 years), experience in the assessment and/or diagnosis of autism. Years of experience ranged from 1.5 years to 29 years.
Years of experience in clinical practice	Practitioners had on average 12.76 years (SD = 8.18) experience working in clinical practice with people on the autism spectrum. Years of experience ranged from 2 years to 30 years.
Organisation type	28 practitioners worked in private organisations (including non-government organisations) and 10 worked in government organisations (including hospitals and health services).

Service setting for assessment and/or diagnosis	Practitioners provided assessment and/or diagnostic services across the following settings: • Hospital (inpatient/outpatient): n=4 (12%) • Community clinic (including private practice): n=30 (88%) • University clinic: n=2 (6%) • Other: n=3 (9%)
Age groups for assessment and/or diagnostic services	Across their career, practitioners had provided autism assessment and/or diagnostic services across the following age brackets: • 0-12 years (children): n=29 (85%) • 13-17 years (adolescents): n=24 (71%) • 18-25 years (young adults): n=20 (59%) • 26 years and older (adults): n=20 (59%) • Does not provide assessment and/or diagnostic services: n=2 (6%)

Qualitative data

A total of 1052 references (i.e., quotes) were coded using the framework. The distribution of references for each code for each group are presented in Table 8.2. These quotes, where relevant to the formulation of Recommendations and Good Practice Points, feature in the corresponding Evidence Summaries.

Table 6.5. Summary of codes and references for the three types of focus groups.

Codes	Autistic Adults	Parents	Practitioner	Other
Principles				
Appropriate	84	84	69	30
Competent	112	89	86	48
Comprehensive	23	27	26	13
Coordinated	23	33	30	8
Culturally Safe	6	5	3	7
Ethical	14	7	11	8
Evidence-based practice approach	8	12	5	5
Helpful	81	73	50	32
Holistic	54	33	27	19

Individual and Family Centred	56	67	32	26
Neurodiversity-affirming	36	30	25	15
Principles – Other	43	23	17	19
Respecting Australia’s First Nations People	1	1	1	0
Strengths focused	27	29	19	10
Timely and Accessible - Equity	51	72	50	7

Credibility checks were completed for all quotes that featured in the analysis of qualitative data from the focus groups. 100% were classified as ‘relevant to the guideline and code,’ 0% were classified as ‘relevant to the guideline, but cannot establish relevance to code,’ and 0% were classified as ‘does not appear to be relevant to the Guideline.’ Readers are reminded that the person completing the credibility check was reviewing the coded data, not the original transcripts. Accordingly, they did not necessarily have knowledge of the context (e.g., broader statement) from which the quotes had been extracted.

7. References

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8. Appendices

The appendices have been prepared for the Draft Administration and Technical Report in draft form. These documents will be further updated and formatted prior to the release of the final updated Guideline.

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Appendix 4.3	Qualitative Codebook
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Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 2.1	Guideline Development Group – Terms of Reference

Update: National Guideline for Assessment and Diagnosis of Autism Spectrum Disorders in Australia
Terms of Reference for the Guideline Development Group

Background

In 2018, Autism CRC published the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia*. This was the first national practice guideline in Australia, and has underpinned fundamental changes in the way autism is understood, assessed, and diagnosed in the Australian community. The Guideline, herein referred to as the Assessment and Diagnosis Guideline (ADG) for brevity, was endorsed by the National Health and Medical Research Council and a range of relevant professional associations. Autism CRC has also supported the implementation of the ADG through a range of implementation activities, along with the efforts of an Expert Reference Group commissioned by the Australian Government Department of Social Services to inform its implementation and evaluation. Given that nearly 5 years has passed since publication, as per NHMRC requirements, it is important that the ADG be updated. This process will occur in a manner consistent with the NHMRC Standards for Guideline Development.

In June 2022, Autism CRC made a call for applications for investment to support the update of the ADG. A group of five organisations – Griffith University, Telethon Kids Institute, Autism New Zealand, Victoria University of Wellington, and University of Queensland – were successful in an application to undertake this work, which will occur between 01/09/22 and 30/06/23. The process for updating the ADG will be led by a Guideline Development Group (GDG). The GDG will bring together members with diverse lived and professional expertise relevant to the Guideline, in keeping with NHMRC Guidelines for Guidelines Process.

The GDG will be responsible for overseeing the update of the GDG. The role of a GDG member includes providing input into planning, advice in relation to Guideline activities, feedback on summarised information gathered through research and community consultation activities, and feedback on draft documents. Additional roles, where relevant, may be negotiated with the co-Chairs based on members' interests, experience, and expertise. Each member of the GDG will be responsible for abiding by the Terms of Reference, attending monthly meetings, reviewing documents, and providing endorsement or otherwise of the final documents. The specific role, responsibilities, and accessibility will be considered in an individualised way for each GDG member.

Purpose

Autism CRC has asked A/Prof David Trembath and Dr Emma Goodall to form a GDG that will be responsible for leading the update of the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia. The GDG will exist for the duration of the project.

Anticipated timeline for the project

The project commenced on 01/09/22 and will be completed on 30/06/23. The initial phase of the project involves establishing the GDG. The work of each individual GDG member will commence on the date of signing and returning (via email) this Terms of Reference and conclude on 30/06/23.

Membership of the Guideline Development Group

Membership of the Guideline Development Group is informed by the 'Guideline for Guidelines' recommendations provided by the National health and Medical Research Council. The Guideline Development Group will comprise A/Prof David Trembath (co-chair) and Dr Emma Goodall (co-chair), autistic people, family members of autistic people, at least one First Nations person, clinicians, clinician-researchers, an expert in ethics, and at least one original author of the ADG.

Appointment of Co-Chairs

The co-chairs of the Guideline Development Group are A/Prof David Trembath and Dr Emma Goodall., who will each have clearly delegated duties.

Responsibilities of Project Team Members

A/Prof Trembath (co-Chair) will:

- Assume overall responsibility for governance and delivering the project.
- Guide and contribute to the day-to-day research activities for the project.
- Coordinate and chair meetings with the Reference Group.
- Coordinate engagement with stakeholders external to the Guideline Development Group, including (but not limited to) the Reference Group, the Autism CRC, the National Health and Medical Research Council, and the National Disability Insurance Agency.
- Line manage staff employed by Griffith University to work on the Guideline.

Dr Emma Goodall (co-Chair) will:

- Contribute to Governance of the GDG.
- Guide and contribute to the day-to-day research activities for the project.
- Chair meetings of the Guideline Development Group.

Other members of the Guideline Development Group:

- Attend meetings as required throughout the duration of the project (all).
- Provide input in the areas of expertise and experience they bring to the Guideline Development Group.
- Respond to ‘out of meeting’ emails from co-Chairs requesting guidance.
- Provide feedback on documents that are prepared for the Guideline within agreed. timeframes (typically 5-10 business days).

Meetings

The Guideline Development Group will meet monthly via videoconference. A quorum will be a majority of the Members present via videoconference, including one of the co-Chairs.

Code of conduct for the Project Team

The Guideline Development Group recognises that this is a sensitive project that requires completion within a relatively short timeframe. As such, the Guideline Development Group agrees to the following:

- Conflicts of interest will be declared at the outset of the project, and be updated as any new potential conflicts emerge.
- All communication between Guideline Development Group members will be conducted in a respectful, constructive and cooperative way, and avoiding self-interest.
- The guideline generated by the Guideline Development Group will be based on a balanced evaluation of the strength of the evidence.
- All discussions within the Project Team will remain confidential to that Project Team until the conclusion of the project.

Reporting

The Project Team reports to the Autism CRC Ltd Board.

By signing below, I indicate that I agree to these Terms of reference.

Name	
Signature	

Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 2.2	Guideline Development Group – Declaration of Interests

Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	6 February 2023
First Name:	Gary
Surname:	Allen

Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (https://www.icmje.org/disclosure-of-interest/)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf)

Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the update of the Autism CRC National Guideline for Assessment and Diagnosis of Autism Spectrum Disorders in Australia (herein referred to as the *guideline*). "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

1. Support for your involvement in the update of the guideline.

This section asks for information about your role in the update of the guideline. The time frame for this reporting is that of the work itself, from the point at which you became involved in the update. If you worked on the original Guideline, you will have disclosed your interests related to that work previously, and so please focus on your involvement in the update in this form.

The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you will receive an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds you will receive. The honorarium for members of the GDG who will be accepting an honorarium is $2,000 (AUD).

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Pine Rivers and Samford Community Grant DESBT, Queensland Government Moreton Bay Council	$8,500 $29,200 $3,500
Consulting fee or honorarium	Various Australian universities and research institutions. As well as institutions in Aotearoa New Zealand, the UK, Kazakhstan and across Asia.	
Support for travel to meetings for the guideline or other purposes		
Other	Fiverr Outcomes Australia	$27,000 $4,000

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	Name all entities with whom you have this relationship or	Specifications/comments (e.g., description of support,

	indicate none (add rows as needed)	**if payments were made to you or your institution)**
Grants or contracts from any entity (if not indicated in item #1 above).		
Royalties or licenses		
Consulting fees	Silver Chain	To AHRECS
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events	Paid member of the Australian Health Ethics Committee of the NHMRC. Paid member of the National Statement Review Committee Paid member of both the NEA and the Health Ethics Application form. Paid trainer of the NHMRC. Paid member of the National Mutual Acceptance advisory committee	Me personally
Payment for expert testimony		
Support for attending meetings and/or travel		
Patents planned, issued or pending		
Participation on a Data Safety Monitoring Board or Advisory Board		
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	CEO and Co-Founder of Enabled.vip	
Stock or stock options		
Receipt of equipment, materials, drugs, medical writing, gifts or other services		

3. **Relevant other activities or relationships, including non-financial relationships (no time limit)**

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**

Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	Editor of the AHRECS resource library and Co-editor of the Research Ethics Monthly Senior consultant and trainer at AHRECS
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	Senior consultant and trainer at AHRECS
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	
Other (please make any further declarations that may be relevant)	

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than ‘none’ to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	1/2/2023
First Name:	JAMES
Surname:	BEST

Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (https://www.icmje.org/disclosure-of-interest/)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf)

Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the update of the Autism CRC National Guideline for Assessment and Diagnosis of Autism Spectrum Disorders in Australia (herein referred to as the *guideline*). "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

1. Support for your involvement in the update of the guideline.

This section asks for information about your role in the update of the guideline. The time frame for this reporting is that of the work itself, from the point at which you became involved in the update. If you worked on the original Guideline, you will have disclosed your interests related to that work previously, and so please focus on your involvement in the update in this form.

The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you will receive an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds you will receive. The honorarium for members of the GDG who will be accepting an honorarium is $2,000 (AUD).

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline? NO

Please add more rows if necessary.

Support	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant		
Consulting fee or honorarium		
Support for travel to meetings for the guideline or other purposes		
Other		

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome. NIL

Activities	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).		
Royalties or licenses		
Consulting fees		
Payment or honoraria for lectures, presentations,		

speakers' bureaus, manuscript writing or educational events		
Payment for expert testimony		
Support for attending meetings and/or travel		
Patents planned, issued or pending		
Participation on a Data Safety Monitoring Board or Advisory Board		
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid		
Stock or stock options		
Receipt of equipment, materials, drugs, medical writing, gifts or other services		

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify. NO

Activity	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional	

preparation programs that include training in assessment and diagnosis of autism)	
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	
Other (please make any further declarations that may be relevant)	

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

Junction Street
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Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	08/11/2022
First Name:	Nicole
Surname:	Dargue

Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (https://www.icmje.org/disclosure-of-interest/)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf)

Instructions

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Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

1. Support for your involvement in the update of the guideline.

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	**Name all entities that provided support (or indicate none)**	**Description of support (e.g., amount of funding, time in lieu)**
Grant	Autism CRC Limited paid to Griffith University	Total project value $252,025 paid to Griffith University
Consulting fee or honorarium	none	
Support for travel to meetings for the guideline or other purposes	none	
Other	none	

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	**Name all entities with whom you have this relationship or indicate none (add rows as needed)**	**Specifications/comments (e.g., description of support, if payments were made to you or your institution)**
Grants or contracts from any entity (if not indicated in item #1 above).	none	
Royalties or licenses	none	
Consulting fees	none	
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events	none	
Payment for expert testimony	none	
Support for attending meetings and/or travel	none	

Patents planned, issued or pending	none	
Participation on a Data Safety Monitoring Board or Advisory Board	none	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	none	
Grants or contracts from any entity (if not indicated in item #1 above).	none	
Royalties or licenses	none	
Consulting fees	none	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	none	
Payment for expert testimony	none	
Support for attending meetings and/or travel	none	
Patents planned, issued or pending	none	
Participation on a Data Safety Monitoring Board or Advisory Board	none	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	none	
Stock or stock options	none	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	none	

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	no
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training	no

manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	no
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	no
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	no
Other (please make any further declarations that may be relevant)	none

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than ‘none’ to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	31.01.23
First Name:	Valsamma
Surname:	Eapen

Origin of Form

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- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (https://www.icmje.org/disclosure-of-interest/)
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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant		
Consulting fee or honorarium	Autism CRC	$2000
Support for travel to meetings for the guideline or other purposes		
Other		

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	Director, Autism CRC and research lead for Autism Surveillance program via GP clinics	CRC grant
Royalties or licenses		
Consulting fees		
Payment or honoraria for lectures, presentations,		

speakers' bureaus, manuscript writing or educational events		
Payment for expert testimony		
Support for attending meetings and/or travel		
Patents planned, issued or pending		
Participation on a Data Safety Monitoring Board or Advisory Board		
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	DSS Expert Advisory group for the implementation of National Autism Guideline	Committee member
Stock or stock options		
Receipt of equipment, materials, drugs, medical writing, gifts or other services		

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	Watch Me Grow Electronic platform – development and evaluation
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	No
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	Teaching material, publications and presentation slides on the topic of assessment and diagnosis of neurodevelopmental disorders including autism
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional	No

preparation programs that include training in assessment and diagnosis of autism)	
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	No
Other (please make any further declarations that may be relevant)	Nil

Declaration

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Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	11 November 2022
First Name:	Kiah
Surname:	Evans

Origin of Form

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Please add more rows if necessary.

Support	**Name all entities that provided support (or indicate none)**	**Description of support (e.g., amount of funding, time in lieu)**
Grant		
Consulting fee or honorarium	Autism CRC	$2,000 (AUD) honorarium
Support for travel to meetings for the guideline or other purposes		
Other		

2. Relevant financial activities outside the guideline (2019-2022)

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Activities	**Name all entities with whom you have this relationship or indicate none (add rows as needed)**	**Specifications/comments (e.g., description of support, if payments were made to you or your institution)**
Grants or contracts from any entity (if not indicated in item #1 above).	Autism CRC	Chief Investigator and actively involved in the following grants that were either awarded or work was undertaken during this period: • 'Reliability, Validity and Usability of Assessment of Functioning Tools for Autism Spectrum Disorder and Developmental Delay in the Australian Context' • 'Autism Spectrum Disorder Diagnostic

		Inconsistencies in New Zealand' - 'Development of an Assessment of Functioning Tool Based on the ICF Core Sets for ASD' Other grants in which I was a named investigator during this period that may be considered related include: - 'A Multistate Trial of an Early Surveillance Program for Autism within General Practices in Australia' - 'Development of an Autism Specific Quality of Life Assessment for Use with Autistic Adults'
Grants or contracts from any entity (if not indicated in item #1 above).	NDIA	Contributing researcher on the following grant that was awarded and completed during this period: - 'Review of the information requirements of the NDIS Act 2013 (the Act) and associated Rules'
Grants or contracts from any entity (if not indicated in item #1 above).	Telethon Kids Institute	Chief or contributing investigator on the following grants that were awarded and/or completed during this period: - 'Working Towards a Shared Framework in the Diagnosis of Neurodevelopmental Disorders in Australia: A Gap Analysis' - 'Precision Pathways for Children at Risk of Neurodevelopmental Disorders'
Grants or contracts from any entity (if not indicated in item #1 above).	WA Child Research Fund – Government of Western Australia: Department of Health	Named investigator on the following grant that was awarded and/or commenced during this period: - 'ORIGINS of neurodevelopmental risk and resilience: Examining neurodevelopmental trajectories of infants in the ORIGINS cohort'

Royalties or licenses	No	
Consulting fees	Centre for Creative Initiatives in Health and Population (Vietnam), using funding obtained from USAID	Named and contributing investigator on: • 'I – Thrive: Interdisciplinary Rehabilitation Services Supporting Children with Intellectual and Developmental Disabilities to Thrive' Description of engagement: • Technical expert (guideline development process, desk review of autism identification, assessment, intervention and management – based on existing guidelines) • Supported development of 'Ministry of Health. (2022). Guidelines for diagnosis and intervention for children with autism spectrum disorder (1862/QD-BYT). Author: Hanoi, Vietnam.' • Funds were paid directly to my employer at the time (Telethon Kids Institute) in compensation for my time spent on the project (e.g. salary, on-costs, infrastructure). A small proportion of these funds were distributed to a project code that I could use for discretionary costs (e.g. professional development, conference travel).
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events	No	
Payment for expert testimony	No	
Support for attending meetings and/or travel	Telethon Kids Institute	As mentioned above, consultancy payments from the project with Vietnam resulted in some discretionary funds that I plan to use to pay for travel expenses to attend an international conference

Patents planned, issued or pending	No	
Participation on a Data Safety Monitoring Board or Advisory Board	No	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	No	
Stock or stock options	No	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	No	

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	The following publications report on the evaluation of assessment of functioning tools (projects listed above): • Evans, K., Chamberlain, A., D'Arcy, E., Hayden-Evans, M., Girdler, S., Milbourn, B., Taylor, S., Bölte, S., & Whitehouse, A. (2020). Reliability, Validity and Usability of Assessment of Functioning Tools for Autism Spectrum Disorder and Neurodevelopmental Conditions in the Australian Context. Brisbane: Autism CRC. [Please note that journal manuscripts are under development based on this report] • D'Arcy, E., Wallace, K., Chamberlain, A., Evans, K., Milbourn, B., Bölte, S., Whitehouse, A., & Girdler, S. (2021). Content validation of common measures of functioning for young children against the International Classification of Functioning, Disability and Health and Code and Core Sets relevant to neurodevelopmental conditions. Autism, https://doi.org/10.1177/13623613211036809. • Hayden-Evans, M., Milbourn, B., D'Arcy, E., Chamberlain, A., Afsharnejad, B., Evans, K., Whitehouse, A., Bölte, S., & Girdler, S. (Manuscript Submitted). An evaluation of the overall utility of measures of functioning suitable for school-aged children on the

	autism spectrum: A scoping review. International Journal of Environmental Research and Public Health, https://doi.org/10.3390/ijerph192114114. Related to these publications, I am a co-supervisor for the following two Curtin PhD students who are conducting research to develop and evaluate assessment of functioning tools: • Emily D'Arcy • Maya Hayden-Evans I have developed, piloted and utilised research tools to assess functioning and support needs as part of my Autism CRC grants listed above. Many of the above co-authors / collaborators are involved in other research projects related to assessing functioning (including tools).
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	No
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	• I delivered numerous professional presentations to single discipline and interprofessional groups about the original Guideline (during my role as coordinator of this project) • My PhD students delivered a conference workshop for occupational therapists on assessments of functioning, which I assisted to develop • I worked with Autism CRC to develop an implementation toolkit and resources for the original Guideline (https://www.autismcrc.com.au/access/national-guideline) • I have held informal conversations with UWA staff who deliver the Graduate Certificate in Autism Diagnosis and are developing related micro credentials about the autism assessment and diagnostic process, which may have contributed to their educational resources
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	No
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	No

Other (please make any further declarations that may be relevant)	• I was employed as the coordinator of the original Guideline (which was paid for via an Autism CRC grant and in-kind salary from Telethon Kids) and as a result was a co-author of the final documents. • I have published numerous articles and delivered numerous conference presentations about the autism assessment and diagnostic process in Australia and New Zealand (I would be happy to provide details on request) • I have been a peer reviewer for numerous journals for manuscripts submitted about the autism assessment and diagnostic process

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than ‘none’ to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	30/01/2023
First Name:	Will
Surname:	Foster

Origin of Form

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	Autism CRC	$2,000
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

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Activities	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations,	None	

speakers' bureaus, manuscript writing or educational events		
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	Mother part of the GDG
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the	

guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	
Other (please make any further declarations that may be relevant)	

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than ‘none’ to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	15/12/2022
First Name:	Emma
Surname:	Goodall

Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (https://www.icmje.org/disclosure-of-interest/)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf)

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	**Name all entities that provided support (or indicate none)**	**Description of support (e.g., amount of funding, time in lieu)**
Grant	Autism CRC project grant.	$317,336
Consulting fee or honorarium		
Support for travel to meetings for the guideline or other purposes		
Other		

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	**Name all entities with whom you have this relationship or indicate none (add rows as needed)**	**Specifications/comments (e.g., description of support, if payments were made to you or your institution)**
Grants or contracts from any entity (if not indicated in item #1 above).	no	
Royalties or licenses	no	
Consulting fees	no	
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events	no	
Payment for expert testimony	no	
Support for attending meetings and/or travel	no	

Patents planned, issued or pending	no	
Participation on a Data Safety Monitoring Board or Advisory Board	Yes – unpaid CRC biobank access committee	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	Yes – exec committee Australian Society for Autism research unpaid, co-chair Australian Autism Alliance unpaid.	Unpaid positions
Grants or contracts from any entity (if not indicated in item #1 above).	Yes – contract as National Manager Content & Research Positive Partnerships.	Salaried position
Royalties or licenses	no	
Consulting fees	no	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	no	
Payment for expert testimony	no	
Support for attending meetings and/or travel	no	
Patents planned, issued or pending	no	
Participation on a Data Safety Monitoring Board or Advisory Board	no	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	no	
Stock or stock options	no	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	no	

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	no
A personal relationship with another person (e.g., spouse, family member) involved in the	no

development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	no
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	no
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	no
Other (please make any further declarations that may be relevant)	I am autistic and have an NDIS service provider registered company – however I currently only offer life coaching to autistic adults or parents of autistic children through this.

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than ‘none’ to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	30/01/2023
First Name:	Emma
Surname:	Hinze

Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (https://www.icmje.org/disclosure-of-interest/)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf)

Instructions

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1. Support for your involvement in the update of the guideline.

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	**Name all entities that provided support (or indicate none)**	**Description of support (e.g., amount of funding, time in lieu)**
Grant	None	
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	**Name all entities with whom you have this relationship or indicate none (add rows as needed)**	**Specifications/comments (e.g., description of support, if payments were made to you or your institution)**
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations,	None	

speakers' bureaus, manuscript writing or educational events		
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the	

guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	Autistic Son
Other (please make any further declarations that may be relevant)	

Declaration

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Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	8/11/2022
First Name:	MANDIRA
Surname:	HIREMATH

Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (https://www.icmje.org/disclosure-of-interest/)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf)

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	Autism CRC	funds: $2000
Support for travel to meetings for the guideline or other purposes		
Other	None	

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	Autism CRC - microcredentialling funding	
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events	Melbourne University	payment for teaching
Payment for expert testimony	None	
Support for attending meetings and/or travel	Western Health	CME for attending meetings

Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	NBPSA	on board of directors & funding
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	Western Health	Salary - clinical role
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events		
Payment for expert testimony	as above	
Support for attending meetings and/or travel		
Patents planned, issued or pending		
Participation on a Data Safety Monitoring Board or Advisory Board		
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid		
Stock or stock options		
Receipt of equipment, materials, drugs, medical writing, gifts or other services		

3. **Relevant other activities or relationships, including non-financial relationships (no time limit)**

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	N/A.
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training	N/A

manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	as above
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	n/a
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	Yes - 2 children of mine with autism accessing therapy
Other (please make any further declarations that may be relevant)	N/A.

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than 'none' to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

8/11/22

Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	09/11/2022
First Name:	Wenn
Surname:	Lawson

Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	**Name all entities that provided support (or indicate none)**	**Description of support (e.g., amount of funding, time in lieu)**
Grant		
Consulting fee or honorarium	CRC	$2000.00
Support for travel to meetings for the guideline or other purposes		
Other		

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	**Name all entities with whom you have this relationship or indicate none (add rows as needed)**	**Specifications/comments (e.g., description of support, if payments were made to you or your institution)**
Grants or contracts from any entity (if not indicated in item #1 above).	no	
Royalties or licenses	no	
Consulting fees	no	
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events	no	
Payment for expert testimony	no	
Support for attending meetings and/or travel	no	

Patents planned, issued or pending	no	
Participation on a Data Safety Monitoring Board or Advisory Board	no	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	no	
Grants or contracts from any entity (if not indicated in item #1 above).	no	
Royalties or licenses	no	
Consulting fees	no	
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	no	
Payment for expert testimony	no	
Support for attending meetings and/or travel	no	
Patents planned, issued or pending	no	
Participation on a Data Safety Monitoring Board or Advisory Board	no	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	no	
Stock or stock options	no	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	no	

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	no
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training	no

manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	no
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	no
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	no
Other (please make any further declarations that may be relevant)	no

Declaration

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Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	11/11/2022
First Name:	Rhylee
Surname:	Sulek

Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (https://www.icmje.org/disclosure-of-interest/)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf)

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1. Support for your involvement in the update of the guideline.

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	None	
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	In-kind support through current position at Griffith University	

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	None	
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	

Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	None
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	None
Other (please make any further declarations that may be relevant)	None

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than ‘none’ to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	11/11/22
First Name:	David
Surname:	Trembath

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	**Name all entities that provided support (or indicate none)**	**Description of support (e.g., amount of funding, time in lieu)**
Grant	Autism CRC project grant.	$317,336
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

2. Relevant financial activities outside the guideline (2019-2022)

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Activities	**Name all entities with whom you have this relationship or indicate none (add rows as needed)**	**Specifications/comments (e.g., description of support, if payments were made to you or your institution)**
Grants or contracts from any entity (if not indicated in item #1 above).	Autism CRC	Project funding awarded to Griffith University (CIA, 2022-2022, $250,800) to support the development of the National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia.
	CliniKids, Telethon Kids Institute	I hold a joint appointment between Griffith University and CliniKids, Telethon Kids Institute. My substantive position is at Griffith University, with salary

		support from CliniKids, Telethon Kids Institute (2022 – Current)
	NHMRC/Medical Research Future fund	Project funding awarded to Griffith University (CIC, 2022-2025, $579,747) to support a project aimed at *Enhancing Quality of Life through an early InTervention co-developed with the autistic communitY (E-QoL-ITY)*
	Autism CRC	Project funding awarded to Griffith University (CIA, 2020-2020, $121,000) to support the synthesis of evidence for autism early intervention approaches.
	Queensland Government, Australia	Advance Queensland Industry Research Fellowship. $150,000. Optimising telepractice service delivery for individuals on the autism spectrum and their families. (2021-2022)
	Griffith University, Australia	Research grant, $71,112.86, funding for research aimed at laying the foundations for the development of a clinical decision support system for children on the autism spectrum and their families. Trembath, D., Wee-Cheung Liew, A., Whitehouse, A., & Upson, G. (2021-2021)
	Commonwealth Department of Health	Consultancy/commercial research. Alcohol, Tobacco and Other Drugs – Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Services – 4-GO41V23. Dawe, S., Harnett, P., Trembath, D. (2021-2024)
	Griffith University, Australia	Research grant. $228,000. Funding to support the development of the Child Health, Learning, and Disability Network at Griffith University (CIA, 2019-2021)
	Channel 7 Children's Foundation Grant	Project grant. $100,000. Evaluation of Lego Robotics program for autistic students (AI, 2020-2022)
	Menzies Health Institute Queensland	Research grant, $50,000. Promoting Knowledge Translation in Teachers of

		Students with Autism through Peer-to-Peer Professional Development: A Collaborative Interdisciplinary Project. Paynter, J., Adams, D., Simpson, K., Clark, M., Trembath, D., & Westerveld, M. (2018-2019)
	Australian Government Department of Social Services, $232,961.	Research grant, $232,961. Supporting Best Practice in the Assessment and Treatment of Minimally Verbal Children with Autism. Trembath, D., Tucker, M., et al. (2017-2019)
	Menzies Health Institute Queensland	Research grant. $160,000. From Cell to Community: New Frontiers in Integrative Restorative Neurorehabilitation. Lloyd D, Coppieters M, St John J, McConnel H, Zeeman H, Grant G, Thiel D, Trembath D, Pizzolato C, Foster M, Buys N, Lakhani A, Potter L, Canning S. (2018-2019)
	Department of Social Services	Research Grant, $89,445.43. Debunking Autism Treatment Myths. Paynter, J., Keen, D., Trembath, D., Fordyce, K., Joosten, A., Hoppenbrouwers, G., DeBlassio, A., Ecker, U., & Imms, C. (2016-2019)
	Education Queensland Horizon Grants Scheme	Research grant, $96,645.61. Listening to the evidence: Using what works to improve educational outcomes for students with autism. Keen, D., Paynter, J., & Trembath, D. (2017-2019)
	Autism CRC	Research grant, $661,989 Longitudinal Study of Students with Autism (LASA), Roberts, J., Trembath, D., Westerveld, M., Keen, D., Simpson, K. Paynter, J., Adams, D. & Howlin, P. (2016-2021)
	Autism CRC	Research grant, $49,986. "How was your day?" Home conversations about their school day in children with Autism Spectrum Disorder. Stirling, L., Dissanayake, C., Sofronoff, K., Westerveld, M.,

		Trembath, D., & Ashburner, J. (2015-2019)
	Autism CRC	Research grant, $25,000. Relate: Technology Supporting Communication in Children on the Autism Spectrum. Trembath, D., Iacono, T., Cox, J., Johnson, R., Rose, V. (2016-2019)
Royalties or licenses		
Consulting fees	Speech Pathology Australia	Honorarium for role as Project Officer responsible for leading the revision of the Speech Pathology Australia Position Statement and Practice Guideline for working with individuals on the autism spectrum (2020-2021, $7,500)
	Humanity Health Group	Griffith University consultancy and commercial research (CCR) to provide professional development to Humanity Health Group (2021, $2500).
	Speech Pathology Australia	Honorarium for preparation of self-guided learning package relating to Autism CRC synthesis of evidence report (2021, $1,400)
	Speech Pathology Australia	Honorarium for presentation of professional development event (webinar) relating to Autism CRC synthesis of evidence report (2021, $840)
	Charles Sturt University (2022) University of Sydney (2021) Deakin University (2021) Macquarie University (2021) Victoria University (2019) Curtin University (2019)	Thesis examination (approximately $500 on each occasion)
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events		
Payment for expert testimony		
Support for attending meetings and/or travel	Australian Swim Schools Association	Complementary associate membership to attend webinar titled 'Teaching children with Autism' for research purposes. 2022.
	Griffith University	Registration support to attend the Aspect Research Centre for Autism Practice Conference. 2021.

	Association for Applied Behaviour Analysis Australia	Registration to enable access to online platform to deliver invited address (no exchange of funds), 2021.
Patents planned, issued or pending		
Participation on a Data Safety Monitoring Board or Advisory Board	National Health and Medical Research Council	Committee fees for work as member of the Grant Management Solution Working Group as per NHMRC schedule.
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	Australasian Society for Autism Research	Executive Committee member (unpaid)
	AEIOU	Member of Research Advisory Committee (unpaid)
	Augmentative and Alternative Communication (journal)	Associate Editor (unpaid)
	Journal of Research in Autism Spectrum Disorders (journal)	Extended Editorial Board Member (unpaid)
	Department of Social Services	Member representing Speech Pathology Australia on the Expert Reference Group to implement the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia (unpaid)
Stock or stock options		
Receipt of equipment, materials, drugs, medical writing, gifts or other services		

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Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	I led the adaptation of the ELSA-T language sampling methodology for Australian children as part of a research project. I have no financial interest in this regard.
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or. technology that may be relevant to assessment and diagnosis of autism	

Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	Since 2004, I have contributed to the development and/or delivery of speech pathology professional preparation programs at the University of Sydney, La Trobe University, and Griffith University. I have also acted as an external reviewer (accreditation) for the Massey University speech pathology program in New Zealand. From 2018-2020, I was tasked with developing and acting as Program Director for two programs in Applied Behaviour Analysis (Graduate Certificate, Masters) at Griffith University.
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	I have family members who access services with funding from the National Disability Insurance Scheme.
Other (please make any further declarations that may be relevant)	

Declaration

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Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	10/11/2022
First Name:	Kandice
Surname:	Varcin

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Autism CRC	Project funding awarded to Griffith University ($252,000) for a Guideline project. Dr Varcin did not receive any salary or other financial support for this project. Dr Varcin's contribution was in-kind.
Consulting fee or honorarium	None	None
Support for travel to meetings for the guideline or other purposes	None	None
Other	None	None

2. Relevant financial activities outside the guideline (2019-2023)

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Activities	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	Autism CRC & Griffith University	Autism CRC funding provided to Griffith University which served as salary support for my Research Fellow position on an evidence synthesis project commissioned by NDIS from June 2020-December 2020.

	Autism CRC & Griffith University	Autism CRC funding was provided to Griffith University which served as salary support for my Research Fellow position on the development of the National Practice Guideline for supporting autistic children and their families (2021-2022). Amount: $65,531
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events	La Trobe University	Payment made to a research account at CliniKids, Telethon Kids Institute for the provision of ADOS-2 training services.
Payment for expert testimony	None	
Support for attending meetings and/or travel	None	
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

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Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	Specifications/comments (e.g., description of the relationship/activity/organisations involved)
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	I am a qualified trainer on the Autism Diagnostic Observation Schedule-2 and I have delivered numerous courses (in-kind and for-fee) for researchers and practitioners in Australia.
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may	None

be relevant to assessment and diagnosis of autism	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	None
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	None
Other (please make any further declarations that may be relevant)	I currently hold a conjoint position between Griffith University and CliniKids, Telethon Kids Institute. I am supervised in this position by A/Prof David Trembath and Prof Andrew Whitehouse - both of whom have relationships with Autism CRC.

Declaration

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Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	11.11.22
First Name:	Hannah
Surname:	Waddington

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Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	Name all entities that provided support (or indicate none)	Description of support (e.g., amount of funding, time in lieu)
Grant	Autism CRC	Autism CRC research funding provided to Victoria University of Wellington as salary support for Research Fellow position on the development of the update of the assessment and diagnosis guideline. Amount: AUD$52,000
Consulting fee or honorarium		
Support for travel to meetings for the guideline or other purposes		
Other		

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/comments (e.g., description of support, if payments were made to you or your institution)
Grants or contracts from any entity (if not indicated in item #1 above).	Royal Society of New Zealand, Discovery Fellowship	Transforming the clinical pathway for young autistic children in Aotearoa. (P.I., 2023 – 2027, NZD$800,000) **Waddington H.**
	Health Research Council of New Zealand	Randomised controlled trial examining low intensity therapy and parent coaching

		for young autistic children (PA, 2020-2023, NZD$300k). **H. Waddington,** Whitehouse, A. J. O.
	Cure Kids, New Zealand	Randomised controlled trial comparing naturalistic developmental behavioural intervention, acceptance and commitment therapy, or a combination of these approaches on outcomes for young autistic children and their families (AI, 2022-2023, NZD$500k). McLay, L., Emerson, L., **Waddington, H.,** Macfarlane, S.
	Victoria University of Wellington	Funding to explore the effect of teaching non-autistic older siblings to interact with their autistic younger sibling through play (PI, 2020-2022, NZD$29k). **H. Waddington.**
	IHC Foundation, New Zealand	Funding to develop an autism diagnostic clinic together with Autism New Zealand (AI, 2021-2022, NZD$34k). L. van der Meer, D. Dougan, **H. Waddington**
	IHC Foundation, New Zealand	Funding for further training in the early start Denver model (AI, 2020-2021, NZD$78k). L. van der Meer, D. Dougan, **H. Waddington**
	Auckland University of Technology, New Zealand	Funding to train Auckland Well Child Tamariki Ora Nurses to identify early signs of autism (AI, 2019-2020, 20k). D. Shepherd, L. van der Meer, **H. Waddington.**
	IHC Foundation	Funding for delivery of community therapy based on the early start Denver model (AI, 122k, 2019-2020). L. van der Meer, D. Dougan, **H. Waddington**
	Victoria University of Wellington	Research establishment grant-training Wellington Well Child Tamariki Ora nurses to identify early signs of autism (PI, 10k, 2018). **H. Waddington.**
Royalties or licenses	None	
Consulting fees	None	
Payment or honoraria for lectures, presentations,	None	

speakers' bureaus, manuscript writing or educational events		
Payment for expert testimony	None	
Support for attending meetings and/or travel	Autism CRC	Support to attend the Autism CRC participant day in Brisbane, 2022 (NZD$1332)
	Victoria University of Wellington	Support to virtually attend the International Society for Autism Research Conference, 2021 (USD$375)
	Victoria University of Wellington	Support to attend the Australasian Society for Autism Research Conference, 2022 (NZD$1,200)s
Patents planned, issued or pending	No	
Participation on a Data Safety Monitoring Board or Advisory Board	No	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	Autism New Zealand	Member of research advisory group (unpaid)
	Autism Intervention Trust	Victoria University of Wellington Representative (unpaid)
	University of Canterbury	Member of New Zealand Research Priorities advisory group (unpaid)
	Victoria University of Wellington	Clinic Lead, Victoria University of Wellington Autism Clinic (unpaid)
	Advances in Neurodevelopmental Disorders (journal)	Extended editorial board member (unpaid)
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	I am trained in the SACS-R and have helped to coordinate SACS-R training in New Zealand.
A personal relationship with another person (e.g., spouse, family member) involved in the	None

development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	I lecture about early identification and diagnosis in several programmes at Victoria University of Wellington.
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	No.
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	No.
Other (please make any further declarations that may be relevant)	No.

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than ‘none’ to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	31st January 2023.
First Name:	Andrew
Surname:	Whitehouse

Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (https://www.icmje.org/disclosure-of-interest/)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf)

Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the update of the Autism CRC National Guideline for Assessment and Diagnosis of Autism Spectrum Disorders in Australia (herein referred to as the *guideline*). “Related” means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

1. Support for your involvement in the update of the guideline.

This section asks for information about your role in the update of the guideline. The time frame for this reporting is that of the work itself, from the point at which you became involved in the update. If you worked on the original Guideline, you will have disclosed your interests related to that work previously, and so please focus on your involvement in the update in this form.

The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you will receive an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds you will receive. The honorarium for members of the GDG who will be accepting an honorarium is $2,000 (AUD).

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	**Name all entities that provided support (or indicate none)**	**Description of support (e.g., amount of funding, time in lieu)**
Grant	Yes	The Telethon Kids Institute (which supports salary for Andrew Whitehouse) received funding for a researcher to assist the coding of responses received during the community consultation for this project.
Consulting fee or honorarium	None	
Support for travel to meetings for the guideline or other purposes	None	
Other	None	

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	**Name all entities with whom you have this relationship or indicate none (add rows as needed)**	**Specifications/comments (e.g., description of support, if payments were made to you or your institution)**
Grants or contracts from any entity (if not indicated in item #1 above).	Since 2020, Andrew Whitehouse has received research funding from the following organisations: National Health and Medical Research Council (NHMRC), Autism CRC,	Research funding received that is specific to autism intervention: 1. NHMRC Investigator Grant (CIA Whitehouse, APP1173896). Improving clinical outcomes for children with autism spectrum disorder: A research

	the Waterloo Foundation, the National Disability Insurance Agency, Griffith University, the New Zealand Health Research Council, the Western Australian State Government (Telethon-Perth Children’s Hospital Research Fund), and the Angela Wright Bennett Foundation.	program spanning basic, clinical and implementation science. 2020-2024. 2. Telethon-Perth Children’s Hospital Research Fund (CIB Whitehouse). A randomised-controlled trial of group-based very early intervention for infants with autism risk behaviours 2018-2020. or developmental delay 2016-2018. 3. Angela Wright Bennett Foundation (CIA Whitehouse) Funding provided as part of Whitehouse’s Chair position, which has been used to trial a new intervention for newborns with a family history of autism. 2019-2024. 4. Commonwealth Department of Social Services, via Autism CRC (CIA Whitehouse). Implementation of the National guideline for the Assessment and Diagnosis of Autism in Australia. 2021-2022. 5. Health Group Seed Grant Scheme, Griffith University (CIB Whitehouse) Laying the foundation for optimal clinical decision-making for children with autism spectrum. 2020-2021. 6. New Zealand Health Research Council (CIB Whitehouse, 20/581) Low-intensity therapy and parent coaching for young children with ASD: An RCT. 2020-2023. 7. National Disability Insurance Agency, via Autism CRC (CIA Whitehouse 1.077RC). Synthesis of evidence for early autism intervention approaches 2020. 8. Waterloo Foundation (CIB Whitehouse) Exercise intervention in developmental coordination disorder. 2020-2022.
Royalties or licenses	Pearson Publishing, UWA Publishing	Andrew Whitehouse is the co-author of the Communication Checklist - Adult (2009) and Communication Checklist -

		Self Report (2009) and in receipt of small royalties based on sales (<\$5,000p.a). Andrew Whitehouse is the author of a book with UWA Publishing (*Will Mozart make my Baby Smart*) and in receipt of small royalties based on sales (<\$5,000p.a).
Consulting fees	None	Andrew Whitehouse is the Research Strategy Director for the Autism CRC. This is an honorary position and is not supported by any financial remuneration.
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events	None	
Payment for expert testimony	None	
Support for attending meetings and/or travel	Autism CRC	Andrew Whitehouse received support for travel and accommodation to attend the Autism CRC Participant Day in April 2022.
Patents planned, issued or pending	None	
Participation on a Data Safety Monitoring Board or Advisory Board	None	
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	Autism Awareness Australia, Kids are Kids, Ocean Heroes, Australasian Society for Autism Research, Furthering Autistic Children's Education And Schooling	1. Non-Executive Director of Autism Awareness Australia (https://www.autismawareness.com.au/). Role is unpaid. 2. Non-Executive Director of Ocean Heroes: https://oceanheroes.com.au/ . Role is unpaid. 3. President, Australasian Society for Autism Research from 2021-2022 (https://asfar.org.au/). Role is unpaid. 4. Director of Furthering Autistic Children's Education and Schooling Inc. Role is unpaid. 5. Patron of 'Kids are Kids' (www.kidsarekids.org.au/) which is a service provider for children with developmental difficulties, including autism. Role is unpaid.

		6. Invitee to the Expert Reference Group to implement the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia. Role is unpaid.
Stock or stock options	None	
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	Chair of the development of the original version of the "National guideline for the Assessment and Diagnosis of autism in Australia". Co-owner of Intellectual Property for the iBASIS intervention. Director of CliniKids, an arm of the Telethon Kids Institute that provides clinical services to children with neurodevelopmental conditions.
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	None
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	None
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	Andrew Whitehouse has first degree family member who is a participant within the National Disability Insurance Scheme.
Other (please make any further declarations that may be relevant)	None

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than ‘none’ to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

Autism CRC Update: Assessment and Diagnosis Guideline

Disclosure of Interests

Date:	11/11/2022
First Name:	Rachelle
Surname:	Wicks

Origin of Form

This form has been adapted (including direct replication of text where relevant) from:

- The International Committee of Medical Journal Editors (ICMJE) disclosure of interest form (https://www.icmje.org/disclosure-of-interest/)
- The Cochrane Collaboration Disclosure of Potential Conflicts of Interest form (https://community.cochrane.org/sites/default/files/uploads/EPPR/Cochrane-COI-disclosure-form.pdf)

Instructions

The purpose of this form is to provide readers of your review with information about your other interests that could influence how they receive and understand your work. We ask you to disclose all relationships/activities/interests listed below that are related to your involvement in the update of the Autism CRC National Guideline for Assessment and Diagnosis of Autism Spectrum Disorders in Australia (herein referred to as the *guideline*). “Related” means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the guideline. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. Please think broadly when disclosing all relationships/activities/interests that may be relevant to your involvement in the guideline. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

Each person will be asked to complete their own form and you are responsible for the accuracy and completeness. In submitting this form, you certify that you have answered every question and have not altered the wording of any of the questions on this form.

If new interests arise during the project, you are required to submit an updated form.

1. Support for your involvement in the update of the guideline.

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The requested information is about resources that you received, either directly or indirectly (via your institution), to enable you to complete the work. Writing "None" means that you did the work without receiving any financial support from any third party -- that is, the work was supported by funds from the same institution that pays your salary and that institution did not receive third-party funds with which to pay you. If you or your institution received funds from a third party to support the work, such as a government granting agency, charitable foundation or commercial sponsor, then provide the details. For example, if you will receive an honorarium from Autism CRC in relation to your involvement, you would name Autism CRC and then indicate the amount of funds you will receive. The honorarium for members of the GDG who will be accepting an honorarium is $2,000 (AUD).

Did you or your institution at any time receive payment or services from a third party for any aspect of your involvement in the development of the guideline?

Please add more rows if necessary.

Support	**Name all entities that provided support (or indicate none)**	**Description of support (e.g., amount of funding, time in lieu)**
Grant	None	None
Consulting fee or honorarium	None	None
Support for travel to meetings for the guideline or other purposes	None	None
Other	Griffith University	Salary

2. Relevant financial activities outside the guideline (2019-2022)

This section asks about your financial relationships with entities in the field of autism that could be perceived to influence, or that give the appearance of potentially influencing, your involvement in the the guideline. These relationships may include clinical service providers; companies that sell products that autistic people, their families, or service providers may purchase; and organisations that represent and/or advocate for autistic people, their families, and/or service providers. You should disclose interactions with ANY entity that could be considered broadly relevant to the work. Report all sources of revenue paid (or promised to be paid) directly to you or your institution on your behalf over the 36 months prior to commencing work on the update of the guideline, and up until the point it will be submitted to Autism CRC (i.e., 2020-2023). This should include all monies from sources with relevance to the guideline, not just monies from Autism CRC which sponsored the research. Please note that your interactions with Autism CRC that are outside the guideline should also be listed here. If there is any question, please disclose the relationship. For grants you have received for work outside the guideline, you should disclose support only from entities that could be perceived to be affected financially by the published work, such as Government departments and agencies (e.g., National Disability Insurance Scheme), service providers, companies, business (including where self-employed), or foundations supported by entities that could be perceived to have a financial stake in the outcome.

Activities	**Name all entities with whom you have this relationship or indicate none (add rows as needed)**	**Specifications/comments (e.g., description of support, if payments were made to you or your institution)**
Grants or contracts from any entity (if not indicated in item #1 above).	None	None
Royalties or licenses	None	None
Consulting fees	None	None
Payment or honoraria for lectures, presentations, speakers' bureaus, manuscript writing or educational events	None	None
Payment for expert testimony	None	None
Support for attending meetings and/or travel	Autism QLD – Advisory Committee member	Receive $50 for attending quarterly meetings.

Patents planned, issued or pending	None	None
Participation on a Data Safety Monitoring Board or Advisory Board	None	None
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	None
Grants or contracts from any entity (if not indicated in item #1 above).	None	None
Royalties or licenses	None	None
Consulting fees	None	None
Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	None	None
Payment for expert testimony	None	None
Support for attending meetings and/or travel	None	None
Patents planned, issued or pending	None	None
Participation on a Data Safety Monitoring Board or Advisory Board	None	None
Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	None	None
Stock or stock options	None	None
Receipt of equipment, materials, drugs, medical writing, gifts or other services	None	None

3. Relevant other activities or relationships, including non-financial relationships (no time limit)

Are there other relationships or activities that readers could be perceived to have influenced, or that could give the appearance of potentially influencing, your involvement in the guideline? If so, please specify.

Activity	**Specifications/comments (e.g., description of the relationship/activity/organisations involved)**
Development, delivery, evaluation, and/or distribution of any clinical tools, training manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	None
A personal relationship with another person (e.g., spouse, family member) involved in the development, delivery, evaluation, and/or distribution of any clinical tools, training	None

manuals, resources, and/or technology that may be relevant to assessment and diagnosis of autism	
Development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	None
A personal relationship with another person (e.g., spouse, family member) involved in the development and/or delivery of professional preparation programs that may be relevant to the guideline (e.g., allied health professional preparation programs that include training in assessment and diagnosis of autism)	None
Personal and/or family interest in assessment and diagnosis, such as accessing clinical services that may be covered in the guideline	None
Other (please make any further declarations that may be relevant)	None

Declaration

If your answer is different from 'No' to any of the questions above, you may have a competing interest which should be declared. These will be reviewed by the co-Chairs of the Guideline Development Group. If the co-Chairs have answered other than ‘none’ to any of the questions above, these will be reviewed by three members of the Guideline Development Group. In each case, appropriate processes will be put in place to manage any conflicts arising.

Appendix 2.3	Reference Group – Terms of Reference

Update: National Guideline for Assessment and Diagnosis of Autism Spectrum Disorders in Australia

Terms of Reference for the Reference Group

Date distributed: 19/10/22

Background

In 2018, Autism CRC published the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia*. This was the first national practice guideline in Australia, and has underpinned fundamental changes in the way autism is understood, assessed, and diagnosed in the Australian community. The Guideline was endorsed by the National Health and Medical Research Council and a range of relevant professional associations. Autism CRC has also supported the implementation of the Guideline through a range of implementation activities, along with the efforts of an Expert Reference Group commissioned by the Australian Government Department of Social Services to inform its implementation and evaluation. Given that nearly 5 years has passed since publication, as per NHMRC requirements, it is important that the Guideline be updated. This process will occur in a manner consistent with the NHMRC Standards for Guideline Development.

In June 2022, Autism CRC made a call for applications for investment to support the update of the ADG. A group of five organisations – Griffith University, Telethon Kids Institute, Autism New Zealand, Victoria University of Wellington, and University of Queensland – was successful in an application to undertake this work, which will occur between 01/09/22 and 30/06/23.

The update of the Guideline will be led by a Guideline Development Group (GDG), which will bring together members with diverse lived and professional expertise relevant to the Guideline, in keeping with NHMRC Guidelines for Guidelines Process.

A Reference Group, made up of representatives of key stakeholder organisations from the autistic and autism communities, will also support the update of the Guideline. The Reference Group will provide key stakeholder organisations with a direct way to engage in the update process, including (a) sharing the organisations' views, (b) ensuring the organisations' members are aware of opportunities to participate in community consultation activities, and (c) providing feedback (as organisations and/or feedback from individual members) on the draft updated Guideline when it is ready for Public Consultation. The Reference Group will provide advice and support in relation to these matters, but will not have any direct input into the revision process (e.g., revising specific Recommendations).

Purpose

Autism CRC has asked Dr Emma Goodall and A/Prof David Trembath to form a GDG that will be responsible for leading the update of the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia. The GDG will exist for the duration of the project.

Anticipated timeline for the project

The project commenced on 01/09/22 and will be completed on 30/06/23. The initial phase of the project involves establishing the Guideline Development Group and Reference Group. The involvement of organisations (and their representatives) in the Reference Group will commence on the date of signing and returning (via email) this Terms of Reference and conclude on 30/06/23.

Membership of the Reference Group

Stakeholder organisations represented in the Reference Group will be determined by the co-chairs of the project (Dr Emma Goodall and A/Prof David Trembath), informed by the 'Guideline for Guidelines' recommendations provided by the National health and Medical Research Council. Stakeholders will be asked to nominate one individual to represent their organisation on the Reference. A proxy may attend a meeting if the nominated individual is unable to attend. The Chair must be informed of the substitution at least one working day prior to the scheduled nominated meeting.

Appointment of Meeting Chair

Dr Emma Goodall and/or A/Prof David Trembath will Chair the Reference Group meetings.

Responsibilities of the Reference Group Members

The responsibilities of the members are as follows:

- Complete a written Declaration of Interest form at the commencement of involvement, and update the Co-Chairs of any changes during the term of the Reference Group.
- Share the views of the organisations and members they represent, on issues that are relevant to the update of the Guideline.
- Help to ensure their organisation's members are aware of opportunities to participate in community consultation activities, such as through publicising opportunities to members.
- Provide feedback on the draft updated Guideline.

Meetings

The Reference Group will meet on three occasions. It is anticipated that these meetings will occur in November 2022, March 2023, and June 2023. Notifications of these meetings will be distributed to members upon return of a signed copy of these Terms of Reference. A quorum for meetings will be a majority of the Members present via videoconference, including one of the co-Chairs.

Other correspondence

The work of the Reference Group will occur primarily in the scheduled meetings. Reference Group members may be invited by the Co-Chairs to offer feedback on documents or issues arising between meetings. This correspondence may occur via phone or online. Any additional activities (e.g., providing feedback on documents) will be voluntary, as will any communication outside of meetings (e.g., Co-Chair inviting a phone call to follow up on an issue raised in a scheduled meeting when time has not allowed for complete discussion of the issue).

Code of conduct for the Project Team

The Reference Group members agree to the following:

- Conflicts of interest will be declared at commencement of their involvement, and be updated as any new potential conflicts emerge.

- All communication between Reference Group members will be conducted in a respectful, constructive, and cooperative way, and avoiding self-interest.

- All discussions within the Reference Group will remain confidential to that group until the conclusion of the project, unless permission to discuss meeting content is provided by the Co-Chairs.

Reporting

The Reference Group reports to the Autism CRC Ltd Board.

By signing below, I indicate that I agree to these Terms of reference.

Name:	
Position:	
Organisation:	
Signature:	

Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 4.1	Database search strategy

CINAHL

Ab((Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”)) AND Ti((Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”))
Limit to: Published Date 20170101; English language

Cochrane

(Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) in Title Abstract Keyword AND (diagnos*) in Title Abstract Keyword AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”) in Title Abstract Keyword-with Cochrane Library Publication Date from Jan 2017 to Present.

Education Source

TI ((Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”)) AND AB ((Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”))
Limit to 2017-01-01 to present.

EMBASE

(Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “metaanaly*” OR “meta-regress*”) AND English language AND (2017:py OR 2018:py OR 2019:py OR 2020:py OR 2021:py, OR 2022:py)

Epistemonikos

(title:(Autis* OR ASD* OR Asperger* OR "pervasive developmental disorder*" OR PDD* OR "pervasive child development disorder*" OR "pervasive childhood developmental disorder*" OR PCDD* OR "disintegrative disorder*") OR abstract:(Autis* OR ASD* OR Asperger* OR "pervasive developmental disorder*" OR PDD* OR "pervasive child development disorder*" OR "pervasive childhood developmental disorder*" OR PCDD* OR "disintegrative disorder*")) AND (title:(diagnos*) OR abstract:(diagnos*)) AND (title:("systematic review*" OR "systematic literature review*" OR "evidence synthes*" OR meta-analy* OR meta-regress*) OR abstract:("systematic review*" OR "systematic literature review*" OR "evidence synthes*" OR meta-analy* OR meta-regress*)) Limit 2017 to 2022

ERIC

Ab((Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”)) OR Ti((Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”))
Limit to yr=”2017-current, English language only

Medline

Ab((Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”)) AND Ti((Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”))
Limit to: Published Date 20170101-; English language

PsycInfo

(Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
Limit to yr=”2017-current”, English language only

PubMed

(TITLE-ABS (Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND TITLE-ABS-KEY (diagnos* AND TITLE-ABS-KEY (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “metaanaly*” OR “meta-regress*”)) AND (LIMIT-TO (PUBYEAR, 2017)

Scopus

TITLE-ABS-KEY (Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) AND TITLE-ABS-KEY (diagnos*) AND TITLE-ABS-KEY (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”) AND PUBYEAR >2016 AND (LIMIT-TO (LANGUAGE, ‘English)

Web of Science

TI = ((Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”)) OR AB = ((Autis* OR ASD* OR Asperger* OR “pervasive developmental disorder*” OR PDD* OR “pervasive child development disorder*” OR “pervasive childhood developmental disorder*” OR PCDD* OR “disintegrative disorder*”) (diagnos*) AND (“systematic review*” OR “systematic literature review*” OR “evidence synthes*” OR “meta-analy*” OR “meta-regress*”))
Index Date 2017-01-01 to 2024-01-01

Appendix 4.2	Extraction Items for Characteristics of Included Systematic Reviews

Publication details

1. Title
2. List of all authors
3. Year of publication
4. Aims
5. Type of review (Narrative synthesis only; Meta-analysis with narrative synthesis)
6. Databases searched
7. Search start date
8. Search end date
9. Number of included systematic reviews
10. Number of autism-specific systematic reviews included
11. Continents where research was conducted

PCC and Design Characteristics

12. Population (e.g., parents of autistic children aged 0-12, autistic adolescents and adults, physicians).
13. Number of participants
14. Concept/Context
15. Design

Additional information

16. Name of quality appraisal instrument
17. Lowest quality of included studies
18. Sources of funding specified
19. Sources of funding
20. Conflict(s) of interest specified
21. Conflict(s) of interest

Focus

22. Primary focus of systematic review (recommendation, process, factor, experience)
23. Secondary focus/es of systematic review

Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 4.3	Qualitative Codebook

Update of the Autism CRC Guideline for Assessment and Diagnosis of Autism

Coding Manual for Umbrella Review and Community Consultation

Version 1.2 (last modified 23/11/22)

Instructions for Coding

1. Before starting coding for the day, please review the '*Coding Questions & Comments'* Tab in Teams to see if there have been any updates
2. Find the file you have been allocated in Teams. Your file will be located in your own Teams folder located in the *'Data Files NVIVO*' folder. Your files will be dated, so please take note to select the most recent file (This should be the file available)
3. Save the file in a folder on your computer that is safe and can be easily found and deleted when coding is complete.
4. Open NVIVO - (If you have not already setup your NVIVO settings, please ensure the settings are set to remind you to save the file at least every 15 minutes and add a two letter initials for identifying purposes. For example, David would add DT in the initial sections.)
5. Check which questions you are required to code (see colour coding below, the upload notification will confirm the questions requiring coding) and have a printed copy of the code book beside you for your reference.
6. Review the codes and definitions to clarify your understanding.
7. You might find coding one column (i.e., participants' responses to a question) at a time to be easier, as each column will have a specific set of codes to consider within the coding framework. Therefore, double check you are coding each response to the correct codes assigned.
8. In situations where the participant's response appears relevant to the question they were asked, but does not clearly meet the definition of one or more codes, then code as 'other.'
9. Please write a journal/reflection on the process, during each coding session. This should be done in NVIVO memo feature. Please reflect on any patterns you are seeing in the data (e.g., prominent themes); differences, contrasts, and/or contradictions in the responses; any challenges you experienced in assigning codes; suggestions for possible new or revised codes; reasons for why you may have coded a specific way or anything else that you, at that time, felt was important. These memos not only provide you with a great way to document the process and a source for recalling what you did and why, but are also a key aspect of the methodology and thus important to analysing and interpreting the data.
10. Once you have finished coding all responses in your file, save the file and upload into your Teams Data Files NVIVO Return folder. There is no need to change the file name.
11. Please notify Emma, in the Teams channel '*Data Management*' or in chat when you have completed and uploaded your assigned response. Likewise, this channel also notifies when a new data file for coding ready for each coder.
12. ***IMPORTANT*** – Please <u>DO NOT</u> change any of the comments and responses. Only assign codes, as any changes to the text will impact file merging.

If you have any questions with coding, please ask via the ''*Coding Questions & Comments'* Tab in Teams in the first instance, as this will provide us with a central and consistent way of documenting and responding to these questions. You can share a chat message via the Teams chat or contact Emma/David directly if you want to alert them to the new question/comment. Please do not hesitate to any questions or share comments as this is an important part of the process.

Coding the Online Survey

- The sections and corresponding questions of the online survey that are to be coded are outlined below in Table 1.
- See column 'D' for codes to be applied to each section
- Codes are defined in Table 4.

Table 1. Coding the online questionnaire

A. Section	**B. Question Number**	**C. Question Label**	**D. Coding framework to be applied**	**Coding Instructions**
1. Sharing views and experiences of assessment and diagnosis	1	What do you think is/was **good** about the assessment and/or diagnostic process?	• Code for principles • If responses do not map to existing principles, code as "Principles - other" • Code at 'other' if not related to principles but relevant for consideration	The same coder should code each participant's responses to each of these three questions (i.e., reviews on good, bad, and change), using the *Principles* codes presented below.
1. Sharing views and experiences of assessment and diagnosis)	2	What do you think is/was **bad** about the assessment and/or diagnostic process?	• Code for principles • If responses do not map to existing principles, code as "Principles - other" • Code at 'other' if not related to principles but relevant for consideration	
1. Sharing views and experiences of assessment and diagnosis	3	What do you think should be done **better**?	• Code for principles • If responses do not map to existing principles, code as "Principles - other" • Code at 'other' if not related to principles but relevant for consideration	

2. Sharing your views about specific aspects of assessment and diagnosis	1	What are the *most important principles* (e.g., evidence based, strengths focused) that practitioners should follow in the assessment and diagnosis of autism?	• Code at principles • If responses do not map to existing principles, code as "Principles - other"	Code according to *Principles* codes presented below.
2. Sharing your views about specific aspects of assessment and diagnosis	2	What are the most important considerations for practitioners when *making a referral* for assessment and possible diagnosis of autism?	Code at • When • Who • Settings • Knowledge + training • Info collected • Decision making • Outcomes • Info sharing • Other	Coding explanation in tables below
2. Sharing your views about specific aspects of assessment and diagnosis	3	What are the most important considerations for practitioners when conducting an *assessment of functioning** that may lead to a diagnosis of autism?	Code at • When • Who • Settings • Knowledge + training • Info collected • Decision making • Outcomes • Info sharing • Other	Coding explanation in tables below
2. Sharing your views about specific aspects of assessment and diagnosis	4	What are the most important considerations for practitioners when conducting a *medical evaluation** as part of a possible diagnosis of autism?	Code at • When • Who • Settings • Knowledge + training • Info collected • Decision making • Outcomes • Info sharing • Other	Coding explanation in tables below
2. Sharing your views about specific aspects of assessment and diagnosis	5	What are the most important considerations for practitioners when conducting a *diagnostic assessment** as part of a possible diagnosis of autism?	Code at • When • Who • Settings • Knowledge + training • Info collected • Decision making • Outcomes • Info sharing	Coding explanation in tables below

			• Other	
2. Sharing your views about specific aspects of assessment and diagnosis	6	What are the most important considerations for practitioners to ensure the *safety and wellbeing* of individuals during the assessment and diagnostic Process?	Code at • When • Who • Settings • Knowledge + training • Info collected • Decision making • Outcomes • Info sharing • Other	Coding explanation in tables below
3. Views about existing guideline	7	If you haven't already identified these, what are the barriers to implementing the Recommendations in the existing guideline?	• Code for principles • If responses do not map to existing principles, code as "Principles - other" • Code at 'other' if not related to principles but relevant for consideration	Code according to Principles codes presented below.
3. Views about existing guideline	8	If you haven't already identified these, what are the enablers to implementing the Recommendations in the existing guideline?	• Code for principles • If responses do not map to existing principles, code as "Principles - other" • Code at 'other' if not related to principles but relevant for consideration	Code according to Principles codes presented below.

Coding focus group transcripts

- The questions and corresponding codes are outlined below in Table 2.
- See column ‘D’ for codes to be applied to each section
- Codes are defined in Table 4.

Table 2. Coding focus group transcripts

A. Section	**B. Question Number**	**C. Question Label**	**D. Coding framework to be applied**	**Coding Instructions**
1. Sharing views and experiences of assessment and diagnosis	1	What do you think is/was **good** about the assessment and/or diagnostic process?	• Code for principles • If responses do not map to existing principles, code as “Principles - other” • Code at ‘other’ if not related to principles but relevant for consideration	The same coder should coder should code the whole transcript (i.e., responses to all questions) using *Principles.*
1. Sharing views and experiences of assessment and diagnosis)	2	What do you think is/was **bad** about the assessment and/or diagnostic process?	• Code for principles • If responses do not map to existing principles, code as “Principles - other” • Code at ‘other’ if not related to principles but relevant for consideration	
1. Sharing views and experiences of assessment and diagnosis	3	What do you think should be done **better**?	• Code for principles • If responses do not map to existing principles, code as “Principles - other” • Code at ‘other’ if not related to principles but relevant for consideration	

Coding Systematic Reviews

- The sections and corresponding codes are outlined below in Table 3.
- See column ‘D’ for codes to be applied.
- Codes are defined in Table 4.

Table 3. Coding systematic reviews

A. Section	**B. Question Number**	**C. Question Label**	**D. Coding framework to be applied**	**Coding Instructions**
Abstract and *Results*	N/A	N/A	All codes presented in Table 4 may be used.	The same coder should code the abstract and results for each systematic review. More than one code may be applied to a section of text in the systematic review.

Codes and Definitions

Table 4 presents a list of codes and their definitions that should be used when coding information gathered through the umbrella review and community consultation activities.

Table 4. Codes and definitions.

	Code	Definition
Principles		
	Individual and Family Centred:	Assessments should be individual and family-centred, with their unique reasons for seeking assessment, preferences, and circumstances respected, valued, and supported.
	Strengths-focused:	Assessments and the sharing of findings should focus on the individual's strengths including personality traits, interests, functional skills, and supports that are personally meaningful to them and promote their learning, participation, and wellbeing.
	Holistic:	Assessments should seek to understand all aspects of the individual, their family, and context, their life history and future aspirations, to the extent that is relevant to the purpose of the assessment and that they are comfortable to share.
	Comprehensive:	Assessments should involve the gathering of all relevant information from all relevant people.
	Appropriate:	Information should be gathered and shared in ways that are valid, accurate, respectful, and relevant for the individual, their family, and the context.
	Helpful:	Assessments should answer the questions individuals and families have, provide a pathway to supports where relevant, and involve sharing findings in ways that are relevant to the people and for the purpose intended.
	Ethical:	Assessments should be conducted in ways that are ethical, to protect the rights of individuals and their families.
	Evidence Based:	Assessment and diagnosis practices should reflect the best available evidence from research, evidence from clinical practice and lived experience, and the preferences and priorities of the individual and their family.
	Culturally safe:	Practitioners should acknowledge and respect the values, knowledge, preferences and cultural perspectives of the individual and their family; adopt culturally safe practices; and reflect on their own cultural knowledge and competency in their practice.
	Neurodiversity-affirming:	Assessment and diagnosis should be neurodiversity-affirming, embracing each person's unique understanding of other people and the world around them.
	Respecting Australia's First Nations Peoples:	[To be developed – for the SCG we had Supports should be culturally safe for Aboriginal and Torres Strait Islander Peoples, built on an acknowledgment of the barriers to accessing supports that they may experience, an understanding of current and

		historical truths and their enduring impact; and respect for deep connection to Country, language, customs, and traditions.]
	Competent:	Practitioners involved in assessment and diagnosis should have qualifications, knowledge, skills, experience, supervision, and professional regulation that is relevant to assessment and differential diagnosis of autism.
	Timely and Accessible:	Every person should be able to access assessment and diagnostic services in a timely accessible manner, regardless of who they are, where they live, or how much money they have.
	Coordinated:	Practitioners should contribute to a coordinated approach to assessment and diagnosis, that increases access and reduces burden for individuals and their families.
	Other	Please code as other when there is evidence for a principle that is not accounted for by one or more existing principles above.
Process of Assessment and/or Diagnosis		
	When	Evidence is presented in relation to **when should this be considered?**
	Who	Evidence is presented in relation to **who should be involved?**
	Settings	Evidence is presented in relation to **in what settings should it occur?**
	Knowledge + training	Evidence is presented in relation to **what knowledge, skills, training, and support are required?**
	Info collected_what	Evidence is presented in relation to **what information should be collected?**
	Info collected_how	Evidence is presented in relation to **how should information be collected?**
	Decision making	Evidence is presented in relation to **how should decisions be made?**
	Outcomes	Evidence is presented in relation to **what should be the outcomes?**
	Info sharing	Evidence is presented in relation to **how should information be shared?**
	Other	Please code as other when there is evidence that is relevant to purpose of the Guideline but does not align with any of the codes above.
Quality and Safety		
	Quality	Evidence is presented in relation to **how should the quality of assessment and diagnostic services be ensured?**
	Safety	Evidence is presented in relation to **how should the safety of assessment and diagnostic services be ensured?**

Appendix 4.4	JBI Critical Appraisal Checklist

NB: A ‘Yes’ decision requires all checkboxes under a single item to be met, unless the criteria specifically state otherwise (i.e., use an ‘OR’ qualifier). If all checkboxes are not met, a ‘No’ decision should be specified.

CODING: Yes (Low Risk of Bias); No (High Risk of Bias); Not applicable (Item 9 only)

1. **Is the review question clearly and explicitly stated?**
   - ☐ The review presents one or more aims/questions that specify the population, concept, and context.

2. **Were the inclusion criteria appropriate for the review question?**
   - ☐ The PCC elements and design were clearly defined in the inclusion and/or exclusion criteria.
   - ☐ The PCC elements were relevant to the objectives of the review and/or the research questions

3. **Was the search strategy appropriate?**
   - ☐ The search strategy included key words and/or index terms that specified the key PCC elements
   - ☐ Date and language limits appropriate and/or justified

4. **Were the sources and resources used for the study adequate?**
   - ☐ Included at least two major bibliographic databases relevant to the review question, from the following list: Medline, CINAHL, PsycINFO, PubMed, EMBASE, Scopus, Web of Science, and ERIC
   - ☐ Attempt to search for grey literature (e.g. websites relevant to the review question, thesis repositories, trial registries)

5. **Were criteria for appraising the studies appropriate?**
   - ☐ Clear statement that critical appraisal was conducted
   - ☐ Details of the items that were used to assess the included studies (within methods, appendix, or further reference) were outlined and appropriate for the relevant study design

6. **Was critical appraisal conducted by two or more reviewers independently?**
   - ☐ Critical appraisal was conducted by two reviewers working independently from each other and conferring when needed to make a decision; OR
   - ☐ Two reviewers conducted critical appraisal with at least 10% of eligible studies and achieved good agreement (at least 80% or Cohen’s kappa = 0.6 or greater), with the remainder extracted by one reviewer

7. **Were there methods to minimise errors in data extraction?**
   - ☐ All data extraction was conducted by two reviewers working independently; OR

  - ☐ Two reviewers extracted data with a sample of eligible studies and achieved good agreement (at least 80% or Cohen's kappa = 0.6 or greater), with the remainder extracted by one reviewer

8. Were the methods used to combine studies appropriate?

- Meta-analyses
  - ☐ A statement about the extent to which the studies were appropriate to be combined
  - ☐ Assessment of heterogeneity
  - ☐ Explanation for heterogeneity that may be present
- Narrative synthesis
  - ☐ Methods for data synthesis are congruent with the stated methodology
  - ☐ Adequate information is provided to support the synthesised findings
- Meta-analyses and narrative synthesis
  - ☐ Summary/extraction tables were structured to provide sufficient information to ascertain the key PCC elements and design for each included study

9. Was the likelihood of publication bias assessed? (meta-analyses only)

  - ☐ Publication bias was assessed (e.g., a funnel plot for 10 or more studies, Egger's test Begg test, or Harbord test)
  - ☐ N/A

10. Were recommendations for policy and/or practice supported by the reported data?

  - ☐ Clear link made between the results of the review and recommendations for policy and practice
  - ☐ The strengths of the findings and the quality of the research considered in the formulation of the review recommendations

11. Were the specific directives for new research appropriate?

  - ☐ Indication of directions for further research

Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 4.5	Articles excluded during full-text screen and extraction with reasons

*Indicates an article excluded during extraction

Exclusion reason: Does not address research question (n = 56)

Alqaysi, M. E., Albahri, A. S., & Hamid, R. A. (2022). Diagnosis-based hybridization of multimedical tests and sociodemographic characteristics of autism spectrum disorder using artificial intelligence and machine learning techniques: A systematic review. *International Journal of Telemedicine and Applications*, 3551528. https://doi.org/10.1155/2022/3551528

Ansel, A., Posen, Y., Ellis, R., Deutsch, L., Zisman, P. D., & Gesundheit, B. (2019). Biomarkers for autism spectrum disorders (ASD): A Meta-analysis. *Rambam Maimonides Medical Journal*, *10*(4), e0021. https://doi.org/10.5041/RMMJ.10375

Ayoub, M. J., Keegan, L., Tager-Flusberg, H., & Gill, S. V. (2022). Neuroimaging Techniques as Descriptive and Diagnostic Tools for Infants at Risk for Autism Spectrum Disorder: A Systematic Review. *Brain Sciences*, *12*(5), 602-614. https://doi.org/10.3390/brainsci12050602

Boterberg, S., Charman, T., Marschik, P. B., Bölte, S., & Roeyers, H. (2019). Regression in autism spectrum disorder: A critical overview of retrospective findings and recommendations for future research. *Neuroscience and Biobehavioral Reviews*, 102, 24–55. https://doi.org/10.1016/j.neubiorev.2019.03.013

Bourson, L., & Prevost, C. (2022). Characteristics of restricted interests in girls with ASD compared to boys: A systematic review of the literature. *European Child & Adolescent Psychiatry*, 1-18. https://doi.org/10.1007/s00787-022-01998-5

Brignell, A., Albein-Urios, N., Woolfenden, S., Hayen, A., Iorio, A., & Williams, K. (2017). Overall prognosis of preschool autism spectrum disorder diagnoses. *Cochrane Database of Systematic Reviews*, *8*, 1-124. https://doi.org/10.1002/14651858.CD012749.

Canu, D., Van der Paelt, S., Canal-Bedia, R., Posada, M., Vanvuchelen, M., & Roeyers, H. (2020). Early non-social behavioural indicators of autism spectrum disorder (asd) in siblings at elevated likelihood for asd: a systematic review. *European Child & Adolescent Psychiatry*, *30*(4), 497–538. https://doi.org/10.1007/s00787-020-01487-7

Cavus, N., Lawan, A. A., Ibrahim, Z., Dahiru, A., Tahir, S., Abdulrazak, U. I., Hussaini, A., & Torres, E. B. (2021). A systematic literature review on the application of machine-learning models in behavioral assessment of autism spectrum disorder. *Journal of Personalized Medicine*, *11*(4), 229-245. https://doi.org/10.3390/jpm11040299

Clairmont, C., Wang, J., Tariq, S., Sherman, H. T., Zhao, M., & Kong, X. J. (2022). The value of brain imaging and electrophysiological testing for early screening of autism spectrum disorder: A systematic review. *Frontiers in Neuroscience*, *15*, 1-20. https://doi.org/10.3389/fnins.2021.812946

Conti, E., Scaffei, E., Bosetti, C., Marchi, V., Costanzo, V., Dell'Oste, V., ... & Battini, R. (2022). Looking for "fNIRS Signature" in Autism Spectrum: A Systematic Review Starting From Preschoolers. *Frontiers in Neuroscience*, *16*. https://doi.org/10.3389/fnins.2022.785993

de Belen, R. A. J., Bednarz, T., Sowmya, A., & Del Favero, D. (2020). Computer vision in autism spectrum disorder research: A systematic review of published studies from 2009 to 2019. *Translational Psychiatry*, *10*(1), 333-353. https://doi.org/10.1038/s41398-020-01015-w

DeBoth, K. K., & Reynolds, S. (2017). A systematic review of sensory-based autism subtypes. *Research in Autism Spectrum Disorders*, *36*, 44–56. https://doi.org/10.1016/j.rasd.2017.01.005

Demetriou, E. A., Lampit, A., Quintana, D. S., Naismith, S. L., Song, Y. J., Pye, J. E., ... & Guastella, E. A. (2018). Autism spectrum disorders: A meta-analysis of executive function. *Molecular psychiatry*, *23*(5), 1198-1204. https://doi.org/10.1038/mp.2017.75

Diniz, N. L. F., Parlato-Oliveira, E., Pimenta, P. G. A., Araújo, L. A. D., & Valadares, E. R. (2022). Autism and Down syndrome: Early identification and diagnosis. *Arquivos de Neuro-Psiquiatria*, *80*, 620-630. https://doi.org/10.1590/0004-282X-ANP-2021-0156

Engstrand, R. Z., Klang, N., Hirvikoski, T., Westling Allodi, M., & Roll-Pettersson, L. (2018). Reporting of cultural factors in autism research publications in Sweden: Application of the gap-reach checklist. *Review Journal of Autism and Developmental Disorders*, *5*(4), 390–407. https://doi.org/10.1007/s40489-018-0147-3

Frye, R. E., Vassall, S., Kaur, G., Lewis, C., Karim, M., & Rossignol, D. (2019). Emerging biomarkers in autism spectrum disorder: A systematic review. *Annals of Translational Medicine*, *7*(23), 792-813. https://doi.org/10.21037/atm.2019.11.53

Gargot, T., Archambault, D., Chetouani, M., Cohen, D., Johal, W., & Anzalone, S. M. (2020). P. 114 Automatic assessment of motors impairments in autism spectrum disorders: A systematic review. *European Neuropsychopharmacology*, *40*, S71-S72.

Gautam, R., & Sharma, M. (2020). Prevalence and diagnosis of neurological disorders using different deep learning techniques: A meta-analysis. *Journal of Medical Systems*, *44*(2), 49-73. https://doi.org/10.1007/s10916-019-1519-7

Gillett, G., Leeves, L., Patel, A., Prisecaru, A., Spain, D., & Happé, F. (2022). The prevalence of autism spectrum disorder traits and diagnosis in adults and young people with personality disorders: A systematic review. *Australian & New Zealand Journal of Psychiatry*, 20220819. https://doi.org/10.1177/00048674221114603

Grove, J., Carey, C., & of the Psychiatric, A. W. G. (2022). 5.“Are we there yet?” Reporting on a GWAS of autism. *European Neuropsychopharmacology*, *63*, e46.

Guo, B.-Q., Ding, S.-B., & Li, H.-B. (2020). Blood biomarker levels of methylation capacity in autism spectrum disorder: A systematic review and meta-analysis. *Acta Psychiatrica Scandinavica*, *141*(6), 492–509. https://doi.org/10.1111/acps.13170

Gurau, O., Bosl, W. J., & Newton, C. R. (2017). How useful is electroencephalography in the diagnosis of autism spectrum disorders and the delineation of subtypes: A systematic review. *Frontiers in Psychiatry*, *8*. https://doi.org/10.3389/fpsyt.2017.00121

Hosseinzadeh, M., Koohpayehzadeh, J., Bali, A. O., Rad, F. A., Souri, A., Mazaherinezhad, A., Rezapour, A., & Bohlouli, M. (2020). A review on diagnostic autism spectrum disorder approaches based on the internet of things and machine learning. *The Journal of Supercomputing: An International Journal of High-Performance Computer Design, Analysis, and Use*, *77*(3), 2590–2608. https://doi.org/10.1007/s11227-020-03357-0

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Exclusion reason: Not systematic (n = 11)

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Exclusion reason: Search conducted before 2017 (n = 7)

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Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 4.6	Articles excluded during extraction with reasons

Exclusion reason: Not related to research question/practice (n = 2)

La Valle C, Johnston E, Tager-Flusberg H. A systematic review of the use of telehealth to facilitate a diagnosis for children with developmental concerns. (2022). *Research in Developmental Disabilities*, *127*, 104269. https://doi.org/10.1016/j. ridd.2022.104269.

Vuijk R, Deen M, Sizoo B, Arntz A. Temperament, character, and personality disorders in adults with autism spectrum disorder: a systematic literature review and meta-analysis. (2018). *Review Journal of Autism and Developmental Disorders*, *5*, 176-197. https://doi.org.10.1007/s40489-018-0131-y]

Exclusion reason: Not systematic (n = 4)

Desideri L, Pérez-Fuster P, Herrera G. Information and communication technologies to support early screening of autism spectrum disorder: A systematic review. (2021). *Children*, *8*(2), 93. https://doi.org/10.3390/child ren8020093.

Marlow M, Servili C, Tomlinson M. A review of screening tools for the identification of autism spectrum disorders and developmental delay in infants and young children: recommendations for use in low- and middle- income countries. (2019). *Autism Research*, *12*, 17699. https://doi.org/ 10.1002/aur.2033

Stewart LA, Lee L-C. Screening for autism spectrum disorder in low and middle-income countries: A systematic review. (2017). *Autism*, *21*, 52739. https://doi.org/10.1177/1362361316677025

Stavropoulos KK-M, Bolourian Y, Blacher J. (2022). A scoping review of telehealth diagnosis of autism spectrum disorder. PLoS ONE*, 17*(2), e0263062. https://doi.org/10.1371/journal.pone.0263062

Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 4.7	Included Articles

Included Articles

Boshoff, K., Gibbs, D., Phillips, R. L., Louise Wiles, L., & Porter, L. (2019). A meta-synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis. *Health and Social Care in the Community, 27*(0), e143-e157. https://doi.org/10.1111/hsc.12691

Brown, M., Marsh, L., & McCann, E. (2021). Experiences of fathers regarding the diagnosis of their child with autism spectrum disorder: A narrative review of the international research. *Journal of Clinical Nursing*, 30, 2758–2768. https://doi.org/10.1111/jocn.15781

Clarke, L & Fung, L. K. (2022). The impact of autism-related training programs on physician knowledge, self-efficacy, and practice behavior: A systematic review. *Autism*, 1-15. https://doi.org/10.1177/13623613221102016

Dorlack, T. P.,Orrin B. Myers, O. B., & Piyadasa W. Kodituwakku, P. W. (2018). A Comparative Analysis of the ADOS-G and ADOS-2 Algorithms: Preliminary Findings*. Journal of Autism and Developmental Disorders*, *48*(0). 2078–2089. https://doi.org/10.1007/s10803-018-3475-3

Ellison, K. S., Guidry, J., Picou, P., Adenuga, P., & Davis III, T. E. (2021). Telehealth and Autism Prior to and in the Age of COVID-19: A Systematic and Critical Review of the Last Decade. *Clinical Child and Family Psychology Review*, *24*, 599–630. https://doi.org/10.1007/s10567-021-00358-0

Guan, X., Zwaigenbaum, L., & Sonnenberg, L. K. (2022). Building Capacity for Community Pediatric Autism Diagnosis: A Systemic Review of Physician Training Programs. *Journal of Developmental and Behavioral Pediatrics*, *43*(1), 44-54. https://doi.org/10.1097/dbp.0000000000001042

Howes, A. E., Burns, M. E., & Surtees, A. D. R. (2021). Barriers, Facilitators, and Experiences of the Autism Assessment Process: A Systematic Review of Qualitative Research with Health Professionals. *Professional Psychology: Research and Practice*, *52*(5), https://doi.org/10.1037/pro0000413

Lebersfeld, J. B., Swanson, M., Clesi, C. D., & O'Kelley, S. E. (2021). Systematic Review and Meta-Analysis of the Clinical Utility of the ADOS-2 and the ADI-R in Diagnosing Autism Spectrum Disorders in Children. *Journal of Autism and Developmental Disorders*, *51*(11), 4101-4114. https://doi.org/10.1007/s10803-020-04839-z

Legg, H & Tickle, A. (2019). UK parents' experiences of their child receiving a diagnosis of autism spectrum disorder A systematic review of the qualitative evidence. *Autism*, *23*(8), 1897-1910. https://doi.org/10.1177/1362361319841488

Lockwood Estrin, G., Milner, V., Spain, D., Happé, F., & Emma Colvert, E. (2021). Barriers to Autism Spectrum Disorder Diagnosis for Young Women and Girls: a Systematic Review. *Review Journal of Autism and Developmental Disorders*, *8*(0), 454–470. https://doi.org/10.1007/s40489-020-00225-8

Loubersac, J., Michelon, C., Ferrando, L., Picot, L. M, & Baghdadli, A. (2021). Predictors of an earlier diagnosis of autism spectrum disorder in children and adolescents: a systematic review (1987–2017). *European Child & Adolescent Psychiatry*. https://doi.org/10.1007/s00787-021-01792-9

Meimei, L & Zenghui, M. (2022). A systematic review of telehealth screening, assessment, and diagnosis of autism spectrum disorder. *Child and Adolescent Psychiatry and Mental Health*, *16*(0), 1-15. https://doi.org/10.1186/s13034-022-00514-6

Rivera-Figueroa, K., Marfo, N. Y. A., & Eigsti, I. M. (2022). Parental Perceptions of Autism Spectrum Disorder in Latinx and Black Sociocultural Contexts: A Systematic Review. *American Journal on Intellectual and Developmental Disabilities*, *127*(1), 42-63. https://doi.org/10.1352/1944-7558-127.1.42

Sainsbury, W. J., Carrasco, K., Whitehouse, A. J. O., McNeil, L., & Waddington, H. (2022). Age of Diagnosis for Co-occurring Autism and Attention Deficit Hyperactivity Disorder During Childhood and Adolescence: a Systematic Review. *Review Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s40489-022-00309-7

Valentine, A. Z., Sophie S Hall, S. S., Emma Young, E., Brown, B. J., Groom. M. J., PhD; Chris Hollis, C., & Charlotte L Hall, C. L. (2021). Implementation of Telehealth Services to Assess, Monitor, and Treat Neurodevelopmental Disorders: Systematic Review. *Journal of Medical Internet Research*, *23*(1), e22619. https://doi.org/10.2196/22619

van ’t Hof, M., Tisseur, C., van Berckelear-Onnes, I., van Nieuwenhuyzen, A., M., Daniels, A. M., Deen, M., Hans W Hoek, H. W., & Ester, W. A. (2021). Age at autism spectrum disorder diagnosis: A systematic review and meta-analysis from 2012 to 2019. *Autism*, *25*(4), 862-873. https://doi.org/10.1177/1362361320971107

Appendix 4.8	Characteristics of included systematic reviews

Author (year)	Characteristics of Systematic Reviews	Characteristics of Included Studies
Boshoff et al. (2019)	**Type:** Narrative synthesis **Focus:** Experience **Objectives:** 'to consolidate in-depth qualitative data from parents of their experience of advocating for their child with autism, during the process of diagnosis.' **Number of included studies:** 22 **Search limit (years):** Inception - 2017 **Quality (systematic review):** Low (7/10) **Sources of funding:** Not specified **Conflict of interest:** Not specified	**Participants:** Parents and family members of children with an autism diagnosis aged 2–14years (n = 1178) **Concept/Context:** 'Experience of parents of children with autism of advocating for their children during the process of diagnosis.' **Design(s):** Grounded theory, Descriptive qualitative, Phenomenology, Hermeneutic phenomenology, Qualitative design, Ethnography, Narrative, Narrative and observation used in case study, Collective case study, Questionnaire with themes **Locations of included studies:** Asia; Europe; North America **Quality appraisal tool (included studies):** Critical Appraisal Skills Programme tool **Quality (included studies):** Low-quality/high risk of bias and above
Brown et al. (2021)	**Type:** Narrative synthesis **Focus:** Experience **Objectives:** 'to highlight the views and experiences of fathers regarding their child's autism spectrum disorder (ASD) diagnosis and to identify their care and support needs.' **Number of included studies:** 9 **Search limit (years):** 2000 - 2020 **Quality (systematic review):** High (8/10) **Sources of funding:** Not funded **Conflict of interest:** No conflict(s)	**Participants:** Fathers of children with autism aged 20 months - 36 years old (n = 298). **Concept/Context:** **'**The views and experiences of fathers in relation to their child's ASD diagnosis and [sic] their care and support needs'. **Designs(s):** Qualitative (semi-structured interviews), Qualitative (in-depth interviews), Mixed methods (survey and interviews), Quantitative (survey) **Locations of included studies:** Africa; Asia; Australia; Europe; North America **Quality appraisal tool (included studies):** Critical Appraisal Skills Process tool **Quality (included studies):** High-quality/low risk of bias
Clarke & Fung (2022)	**Type:** Narrative synthesis **Focus:** Process **Objectives:** 'to examine the impact that autism-specific training programs have on improving physician knowledge, self-efficacy, and practice behavior related to caring for autistic patients...and identify gaps in the literature that should be addressed in future studies to provide a stronger foundation for the efficacy of these specialized training programs.' **Number of included studies:** 17	**Participants:** General pediatricians, family medicine physicians, nurse practitioners, family practitioners, pediatricians, general practitioners, family practice physicians, physicians and staff at pediatric and family medicine practices, child psychiatrists, and psychologists, third-year medical students, residents in pediatrics, medicine-pediatrics, and neurology, pediatric or medicine-pediatric residents, internal medicine-pediatrics physicians, physician assistants, psychiatrists, developmental and behavioral

	Search limit (years): Not specified - 2021 **Quality (systematic review):** Low (7/10) **Sources of funding:** Not funded **Conflict of interest:** Not specified	pediatricians, pediatric neurologists, pediatric nurse practitioners, medical students, physicians, community pediatricians (n = 917) **Concept/Context:** 'The impact of specialized training programs on physicians' knowledge of autism and their self-efficacy and practice behavior related to caring for autistic patients'. **Designs(s):** Single group pre-test and post-test, Single group post-test, Randomized control trials **Locations of included studies:** Not stated **Quality appraisal tool (included studies):** Medical Education Research Study Quality Instrument (MERSQI) **Quality (included studies):** Low-quality/high risk of bias and above
Dorlack et al. (2018)	**Type:** Meta-analysis with Narrative synthesis **Focus:** Process **Objectives:** 'to analyze the sensitivity and specificity of the ADOS-G and ADOS-2 algorithms, Modules 1–3...and report preliminary findings on the relative merits of the two versions, with a view of informing the design of future comparative studies of the ADOS.' **Number of included studies:** 6 **Search limit (years):** 2000 - 2017 **Quality (systematic review):** Low (7/11) **Sources of funding:** Study funded (National Center for Advancing Translational Sciences of the National Institutes of Health [UL1TR001449]). **Conflict of interest:** No conflict(s)	**Participants:** Children referred for assessment and evaluation who met an identifying score to qualify as either "autism/ASD" or "non-autism/ASD" by the ADOS-G and ADOS-2 diagnostic algorithm cutoff scores (number of participants specified). **Concept/Context: '**Diagnostic accuracy of standardised diagnostic assessments (i.e., sensitivity and specificity of the ADOS-G and ADOS-2 algorithms, Modules 1–3).' **Designs(s):** Not specified **Locations of included studies:** Not stated **Quality appraisal tool (included studies):** Quality Assessment of Diagnostic Accuracy Studies-2 (QUADAS-2) tool **Quality (included studies):** Low-quality/high risk of bias and above
Ellison et al. (2021)	**Type:** Narrative synthesis **Focus:** Process **Objectives:** 'to examine the evidence base, methodology, and outcomes of studies that have used telehealth for assessment and/or intervention with children and adolescents with ASD as well as their families over the last decade. Further, the goal is to highlight the advances in telehealth and its use with this special population.' **Number of included studies:** 55 **Search limit (years):** 2010 - 2021	**Participants:** Children diagnosed with autism aged 29 months to 12 years (n = 104) and their parents (n = 41), teachers (n = =9) or care staff (n = 3), children with developmental delays (n = 10), typically developing children (n = 6) **Concept/Context:** 'The evidence base, methodology, and outcomes of studies that have used telehealth for assessment and/or intervention with children and adolescents with ASD as well as their families.' **Designs(s):** Method comparison design, Random assignment to either in-person or interactive VC assessment, Multi-element

	Quality (systematic review): Low (5/10) **Sources of funding:** Not specified **Conflict of interest:** No conflict(s)	design; Randomized assignment to either the TELE-STAT or TELE-ASD-PEDS groups, Teacher implementation comparisons, Participant comparisons, Multiple-baseline design across participants with embedded multielement designs, Nonconcurrent multiple-baseline design **Locations of included studies:** Not stated **Quality appraisal tool (included studies):** Scientific Merit Rating Scales (SMRS) **Quality (included studies):** Moderate quality/moderate risk of bias and above
Guan et al. (2022)	**Type:** Narrative synthesis **Focus:** Process **Objectives:** 'to identify and summarise published studies that included ASD diagnostic training for primary care providers (PCPs) and aims to guide future training and evaluation methods.' **Number of included studies:** 6 **Search limit (years):** Inception - 2020 **Quality (systematic review):** High (9/10) **Sources of funding:** Study funded (Resident Trainee Research Grant by the Department of Pediatrics and Women and Children's Health Research Institute at the University of Alberta) **Conflict of interest:** No conflict(s)	**Participants:** Community-based primary care providers (general pediatricians, speech-language pathologists, psychologists, family physician, nurse practitioner (n = 67; one included study did not provide details) and pediatric patients assessed for a possible autism diagnosis (n = 279) **Concept/Context:** 'ASD diagnostic training programs for primary care providers [in community settings]' **Designs(s):** Nonrandomized trial study design, Pre-post study design **Locations of included studies:** Europe; North America **Quality appraisal tool (included studies):** National Institutes of Health Quality Assessment Tool for Before-After (Pre-Post) Study Checklist (NIH Checklist) and the Cochrane risk assessment tool **Quality (included studies):** Low-quality/high risk of bias and above
Howes et al. (2021)	**Type:** Narrative synthesis **Focus:** Experience **Objectives:** 'to identify and summarise the literature on the experiences and perceptions of diagnosing ASD for health professionals, and to support future health professionals by summarising the facilitators and barriers to diagnosing ASD'. **Number of included studies:** 7 **Search limit (years):** 1994 - 2019 **Quality (systematic review):** High (8/10) **Sources of funding:** Not specified **Conflict of interest:** Not specified	**Participants:** Health professionals who diagnose ASD, including clinical psychologists, pediatricians, educators, educational psychologists, psychiatrists, speech and language therapists, specialist early years practitioners, general practice pediatricians, child and adolescent psychiatrists, child neurologists, disability physicians, nurses, specialist teachers, and other (n = 200). **Concept/Context: '**The experiences and perceptions of health professionals who diagnose ASD'. **Designs(s):** Qualitative interviews, Mixed methods **Locations of included studies:** Europe; North America **Quality appraisal tool (included studies):** Critical Appraisal Skills Programme tool

		Quality (included studies): High-quality/low risk of bias
Lebersfeld et al. (2021)	**Type:** Meta-analysis with Narrative synthesis **Focus:** Process **Objectives:** ‘to determine the accuracy and clinical utility of the ADOS-2 and the ADI-R [for the purpose of an initial diagnostic evaluation in a clinical or research setting for children under 18 years]’ **Number of included studies:** 22 **Search limit (years):** 2007 – 2018 **Quality (systematic review):** Low (5/11) **Sources of funding:** Not specified **Conflict of interest:** Not specified	**Participants:** Children under 18 years referred for an initial diagnostic evaluation in a clinical or research setting (n = 9060) **Concept/Context:** ‘The efficacy of [the ADOS-2 and ADI-R] for initial diagnostic evaluation in a clinical versus research setting’. **Designs(s):** Prospective, Retrospective, Cross-sectional, and Longitudinal study designs **Locations of included studies:** Europe; North America **Quality appraisal tool (included studies):** Quality Assessment of Diagnostic Accuracy Studies-2 (QUADAS-2) **Quality (included studies):** Low-quality/high risk of bias and above
Legg & Tickle (2019)	**Type:** Narrative synthesis **Focus:** Experience **Objectives:** ‘to systematically identify, appraise, and synthesise qualitative research concerning UK parents’ experiences of their child receiving a diagnosis of autism spectrum disorder’. **Number of included studies:** 11 **Search limit (years):** N/A - 2018 **Quality (systematic review):** High (10/10) **Sources of funding:** Not funded **Conflict of interest:** Not specified	**Participants:** Parents whose child received a diagnosis of ASD or Asperger syndrome (AS) [before 18years of age] (n = 342) **Concept/Context: ‘**The experience of parents whose child receives a diagnosis of autism spectrum disorder [in the UK]’. **Designs(s):** Inductive thematic analysis, Discourse analysis, Long-table approach, Interpretive phenomenological analysis, Thematic analysis, Thematic content analysis, Grounded theory, Content analysis, Modified form of constant thematic analysis incorporating elements of comparative method, Combination of structural and thematic narrative analysis **Locations of included studies:** Europe **Quality appraisal tool (included studies):** Critical Appraisal Skills Progamme tool **Quality (included studies):** Low-quality/high risk of bias and above
Lockwood Estrin et al. (2021)	**Type:** Narrative synthesis **Focus:** Experience **Objectives:** ‘to identify key barriers to obtaining an ASD diagnosis in girls and young women under 21 years.’ **Number of included studies:** 20 **Search limit (years):** Inception - 2018 **Quality (systematic review):** Low (7/10) **Sources of funding:** Study funded (Sir Henry Wellcome Postdoctoral fellowship [Wellcome Trust grant number:	**Participants:** 23, 760, including females with a diagnosis of ASD (n = 3197), 92 parents/family members of girls/young women diagnosed with ASD (n = 92), and professional providers (n = 3) **Concept/Context:** ‘the barriers to ASD diagnosis in girls and young women (aged 21 or younger) from the perspectives of (a) autistic individuals, (b) their parents and family members, (c) teachers, and (d) health professionals’. **Designs(s):** Qualitative - In-depth semi-structured interviews, Field notes, observations, and artefacts, Focus group discussions

	204706/Z/16/Z] and an Economic and Social Research Council Research Grant [ES/M011488/1]). **Conflict of interest:** No conflict(s)	Quantitative - Secondary data analysis of a population-based study of the prevalence of ASD, Retrospective secondary data analysis of a longitudinal cohort study, Population-based study, Survey, Observational, cross-sectional study, Experimental, cross-sectional study, Secondary data analysis from an online survey, Observational, multiple centre cross-sectional study, Observational study, clinical comparison of caregiver's concerns, Longitudinal cohort study, Secondary data analysis from UK database, Secondary data analysis across multiple cross-sectional studies, Secondary data analysis from an RCT **Locations of included studies:** Australia; Europe; North America **Quality appraisal tool (included studies):** Qualitative Critical Appraisal Skills Programme (CASP) checklist, or an adapted CASP checklist for quantitative research studies **Quality (included studies):** Low-quality/high risk of bias and above
Loubersac et al. (2021)	**Type:** Narrative synthesis **Focus:** Factor **Objectives:** 'to identify clinical, social, and environmental factors associated with the age at which the diagnosis of ASD is confirmed in children.' **Number of included studies:** 50 **Search limit (years):** N/A - 2019 **Quality (systematic review):** Low (5/10) **Sources of funding:** Not funded **Conflict of interest:** No conflict(s)	**Participants:** Children with confirmed ASD diagnosed according to the ICD or DSM classifications (n = 97,719) **Concept/Context: '**the clinical, socioeconomic, and environmental factors associated with the age at which a diagnosis of ASD is formally established in childhood according to the criteria of international classifications.' **Designs(s):** Not specified **Locations of included studies:** Africa; Asia; Australia; Europe; North America **Quality appraisal tool (included studies):** Newcastle Ottawa Scale (NOS) **Quality (included studies):** Low-quality/high risk of bias and above
Meimei & Zenghui (2022)	**Type:** Narrative synthesis **Focus:** Process **Objectives:** 'to provide ASD screening and diagnosis application options for use in daily practice by relevant healthcare practitioners and researchers to help diagnose various conditions and suggest possible future research directions.' **Number of included studies:** 26 **Search limit (years):** 2000 - 2022	**Participants:** Children/individuals with and without autism aged 2 months to 42 years (autism: n = 10,689; without autism: n = 1,611) **Concept/Context:** 'to provide ASD screening and diagnosis application options for use in daily practice by relevant healthcare practitioners and researchers to help diagnose various conditions.' **Designs(s):** Specific study designs not specified; states that all types of empirical study designs were included

	Quality (systematic review): Low (2/10) **Sources of funding:** Not funded **Conflict of interest:** No conflict(s)	**Locations of included studies:** Australia; Pacific; Europe; North America **Quality appraisal tool (included studies):** Scientific Merit Rating Scale **Quality (included studies):** Moderate-quality/moderate risk of bias and above
Rivera-Figueroa et al. (2022)	**Type:** Narrative synthesis **Focus:** Experience **Objectives:** 'to present a systematic review of parental and community perceptions of ASD in Latinx and Black American communities, discuss the clinical implications of these perceptions; and provide recommendations to facilitate better research and clinical practice, and to increase equitable access to care'. **Number of included studies:** 50 **Search limit (years):** 2005 - 2019 **Quality (systematic review):** High (8/10) **Sources of funding:** Study funded (Portions funded by NIMH R01MH112687-01A1, NSF 1144399, and by a UConn Provost's Research Award). **Conflict of interest:** Not specified	**Participants:** Latinx and Black American parents/caregivers of children with ASD, community members, and healthcare providers (number of participants not specified) **Concept/Context:** 'Parental and community perceptions of ASD within Latinx and Black American communities and key factors that contribute to ASD-related health inequities in Latinx and Black American communities in the United States.' **Designs(s):** Cross-sectional, Descriptive, Mixed methods, Qualitative **Locations of included studies:** North America **Quality appraisal tool (included studies):** Let Evidence Guide Every New Decision (LEGEND) system **Quality (included studies):** Low-quality/high risk of bias and above
Sainsbury et al. (2022)	**Type:** Narrative synthesis **Focus:** Process **Objectives:** 'to elucidate whether there is a significant difference in the age of ASD diagnosis for children and adolescents with ASD only and co-occurring ASD+ADHD, compare the age of ASD diagnosis for children and adolescents with ASD only and co-occurring ASD+ADHD, and examine quantifiable factors which may contribute to differences in the age of diagnosis between groups'. **Number of included studies:** 12 **Search limit (years):** 2015 - 2020 **Quality (systematic review):** High (8/10) **Sources of funding:** Study funded (Open Access funding enabled and organized by CAUL and its Member Institutions, an internal	**Participants:** Children with ASD, ADHD, or ASD+ADHD diagnoses (n = 41,382), including 14,584 diagnosed with ASD only, 12,689 diagnosed with ADHD only, and 14,109 diagnosed with ASD+ADHD. **Concept/Context:** 'The age at which children/adolescents were diagnosed with both ASD and ADHD, compared to the age of primary diagnosis of ASD or ADHD, and quantifiable factors which may contribute to differences in age of diagnosis.' **Designs(s):** Not specified **Locations of included studies:** Asia; Europe; North America **Quality appraisal tool (included studies):** Hoy et al.'s (2012) guidelines. **Quality (included studies):** Moderate-quality /moderate risk of bias and above

	research grant provided by The University of Victoria, Wellington [225668], and an Investigator Grant National Health and Medical Research Council [1173896]). **Conflict of interest:** No conflict(s)	
Valentine et al. (2021)	**Type:** Narrative synthesis **Focus:** Process **Objectives: '**to highlight how telehealth has been used with clinical samples in the neurodevelopmental field, including patients with neurodevelopmental disorders (NDDs), their families, and health care professionals and identify which technologies show the greatest potential for implementation into health services.' **Number of included studies:** 42 **Search limit (years):** 2014 - 2019 **Quality (systematic review):** High (8/10) **Sources of funding:** Study funded (National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care East Midlands). **Conflict of interest:** No conflict(s)	**Participants:** People with NDDs or parents, carers or health care professionals who worked with people with NDDs (number of participants not specified) **Concept/Context:** 'The clinical/service effectiveness, economic impact, and user impact (i.e., feasibility/acceptability) of telehealth to aid in assessment, diagnosis, monitoring, and treatment with clinical samples within the neurodevelopmental field prior to the COVID-19 pandemic'. **Designs(s):** Not specified **Locations of included studies:** Australia; Pacific; Europe; North America **Quality appraisal tool (included studies):** Oxford Centre for Evidence-Based Medicine Levels of Evidence **Quality (included studies):** Low-quality/high risk of bias and above
van't Hof et al. (2020)	**Type:** Meta-analysis with **n**arrative synthesis **Focus:** Process **Objectives:** 'to conduct a systematic review of age at ASD diagnosis from studies published between 2012 and 2019 and perform a meta-analysis of the age at ASD diagnosis reported in these studies to specify the current age at diagnosis.' **Number of included studies:** 20 **Search limit (years):** 2012 - 2019 **Quality (systematic review):** Low (6/11) **Sources of funding:** Study funded (Sarr Expert Centre for Autism, Lucertis Child and Adolescent Psychiatry). **Conflict of interest:** No conflict(s)	**Participants:** Children, adolescents, and adults aged 0-85 years with diagnosis of autism spectrum disorder, autistic disorder, Asperger's syndrome, PDD, or PDD-NOS (narrative review: n = 120,540; meta-analysis: n = 66,966) **Concept/Context: '**The age at ASD diagnosis from studies published between 2012 and 2019, the current age at diagnosis (via meta-analysis), and possible influencing factors on age at ASD diagnosis.' **Designs(s):** Not specified **Locations of included studies:** Africa; Asia; Australia; Pacific; Europe; South America/Caribbean; North America **Quality appraisal tool (included studies):** 'An RoB tool based on items from several standardized critical appraisal tools developed by the Joanna Briggs Institute (2020)' **Quality (included studies):** Low-quality/high risk of bias and above

Appendix 4.9	Quality Appraisal

	1. Review question stated	2. Inclusion criteria appropriate	3. Search strategy appropriate	4. Sources and resources adequate	5. Quality appraisal appropriate	6. Independent critical appraisal	7. Minimised errors in data extraction	8. Methods to combine studies appropriate	9. Publication bias assessed (meta-analyses only)	10. Policy and/or practice recommendations	11. Directive for the research appropriate	Total	Overall quality
Boshoff et al. (2019)	Yes	Yes	No	No	Yes	Yes	Yes	Yes	N/A	No	Yes	7/10	L
Brown et al. (2021)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	N/A	No	Yes	8/10	H
Clarke & Fung (2022)	Yes	Yes	No	No	Yes	Yes	No	Yes	N/A	Yes	Yes	7/10	L
Dorlack et al. (2018)	No	Yes	Yes	No	Yes	Yes	No	Yes	Yes	No	Yes	7/11	L
Ellison et al. (2021)	Yes	Yes	No	No	No	Yes	No	Yes	N/A	No	Yes	5/10	L
Guan et al. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	N/A	Yes	Yes	9/10	H
Howes et al. (2021)	Yes	Yes	Yes	No	Yes	Yes	No	Yes	N/A	Yes	Yes	8/10	H
Lebersfeld et al. (2021)	No	Yes	Yes	No	Yes	No	Yes	No	No	No	Yes	5/11	L
Legg & Tickle (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Yes	10/10	H
Lockwood Estrin et al. (2021)	Yes	Yes	No	No	Yes	Yes	Yes	Yes	N/A	No	Yes	7/10	L
Loubersac et al. (2021)	Yes	Yes	No	No	No	Yes	No	Yes	N/A	No	Yes	5/10	L
Meimei & Zenghui (2022)	No	No	No	No	Yes	No	No	No	N/A	No	Yes	2/10	L
Rivera-Figueroa et al. (2022)	Yes	Yes	Yes	Yes	No	Yes	No	Yes	N/A	Yes	Yes	8/10	H
Sainsbury et al. (2022)	Yes	No	No	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Yes	8/10	H
Valentine et al. (2021)	Yes	Yes	Yes	No	No	Yes	Yes	Yes	N/A	Yes	Yes	8/10	H
van't Hof et al. (2020)	Yes	Yes	Yes	No	Yes	No	Yes	No	No	No	Yes	6/11	L

Note: L = Low Quality <80%; H = High Quality ≥80%

Appendix 4.10	Quantitative summary of quote matrices.

	Dorlack et al. (2018)	Valentine et al. (2021)	Rivera-Figueroa et al. (2022)	Loubersac et al. (2021)	Lebersfeld et al. (2021)	Ellison et al. (2021)	Clarke & Fung (2022)	Legg & Tickle (2019)	Boshoff et al. (2019)	Meimei & Zenghui (2022)	van't Hof et al. (2020)	Sainsbury et al. (2022)	Lockwood Estrin et al. (2021)	Howes et al. (2021)	Guan et al. (2022)	Brown et al. (2021)	**Number of SRs covering theme**
Principles	**0**	**4**	**8**	**7**	**0**	**1**	**3**	**32**	**40**	**3**	**0**	**3**	**20**	**35**	**2**	**10**	**13**
Appropriate	0	0	0	0	0	0	0	1	3	2	0	0	0	1	0	0	**4**
Competent	0	0	1	0	0	0	3	3	4	0	0	0	2	5	0	4	**7**
Comprehensive	0	0	0	0	0	0	0	2	0	1	0	0	1	0	0	0	**3**
Coordinated	0	0	0	0	0	0	0	1	2	0	0	0	0	7	0	0	**3**
Culturally safe	0	0	4	0	0	0	0	0	2	0	0	0	0	1	0	1	**4**
Ethical	0	0	2	0	0	0	0	1	0	0	0	0	0	7	0	0	**3**
Evidence-based	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	**1**
Helpful	0	0	2	0	0	0	0	18	19	0	0	0	2	14	0	6	**6**
Holistic	0	0	0	1	0	0	0	2	1	0	0	0	16	1	0	0	**5**
Individual and Family Centred	0	1	3	0	0	0	0	7	17	0	0	0	1	6	1	0	**7**
Neurodiversity affirming	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**0**
Respecting Australia's First Nations Peoples	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**0**
Strengths-focused	0	0	0	0	0	0	0	1	2	0	0	0	0	0	0	1	**3**
Timely and Accessible	0	3	1	6	0	0	0	5	16	0	0	3	2	7	1	1	**10**
Process of Assessment and/or Diagnosis	**14**	**5**	**3**	**16**	**7**	**6**	**10**	**17**	**11**	**6**	**72**	**8**	**54**	**40**	**5**	**8**	**16**
Decision making	0	0	0	0	0	0	0	0	0	0	0	0	1	6	2	0	**3**
Info Collected - How	0	3	1	0	0	4	0	0	1	3	0	0	0	3	0	0	**6**
Info collected - What	0	0	1	0	0	0	0	0	1	1	0	0	5	3	0	0	**5**
Info Sharing	0	0	0	0	0	0	0	10	6	0	0	0	0	18	0	3	**4**
Knowledge and Training	14	0	3	14	7	0	10	0	2	6	72	8	54	10	3	5	**13**
Outcomes	0	0	0	0	0	0	0	2	0	0	0	0	0	6	1	0	**3**
Setting	0	4	0	0	0	6	0	0	1	3	0	0	0	1	1	0	**6**
When	0	0	0	0	0	0	0	2	1	0	0	0	0	2	0	0	**3**
Who	0	1	0	0	0	3	0	4	0	0	0	0	0	6	3	0	**5**
Other	0	0	0	2	0	0	0	0	1	0	0	0	0	4	0	0	**3**
Quality and Safety	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Quality	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**0**
Safety	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	**0**
Number of themes coded to SR	**2**	**7**	**11**	**6**	**2**	**6**	**4**	**16**	**18**	**8**	**2**	**4**	**11**	**21**	**9**	**9**	**24**

Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 4.11	Umbrella Review Evidence Quotes - Founding Principles

Principle	Systematic review	Evidence quotes
1. Client and family-centred	Boshoff et al. (2019)	Parents’ relationships with professionals were negatively affected by a perceived lack of acknowledgement of their concerns. Parents described feeling unheard with dismissal of their concerns, resulting in distress, anger, humiliation, and frustration (Frye, 2016; Ryan & Salisbury, 2012). At times, parents reported that the concerns they raised were deferred at more than one visit, resulting in a delay in the eventual diagnosis. Marginalisation, silencing of their concerns, and lack of support were reported, as well as health professionals not acknowledging the importance of parents’ concerns (Bultas & Pohlman, 2014). Parents report hesitation by health professionals with parents feeling that their concerns were not being taken seriously, resulting in losing valuable time for early intervention. The process of negotiating knowledge was considered to be a continued struggle to advocate for their child’s needs (Carlsson et al, 2016).
	Legg & Tickle, (2019)	Parents mostly reported positive interactions with assessing clinicians but remained aware, and in some respects cautious, of clinicians’ power. Parents seeking support have a need to be taken seriously by professionals when raising concerns about their children. This point offers professionals the first opportunity to build a positive relationship with parents. Good communication from professionals towards both parents and children promoted good relationships between parents and professionals. Such relationships are likely to have been containing for parents who have concerns about their children and promote positive engagement in the assessment process.

		Parents are likely to be more satisfied when assessments include more time building relationships between the professional and the child and when information is provided to the parents, including through observation of assessments. Fathers may have additional or alternative support needs to mothers following diagnosis. It is possible this in part arises from their sense of being excluded earlier in the process and that more inclusive relationships with professionals could promote later emotional adjustment.
	Lockwood Estrin et al. (2020)	Parents also expressed frustration, knowing their daughter was developing atypically, yet not receiving validation from medical professionals about their concerns.
	Rivera-Figueroa et al. (2022)	Parents report feeling discomfort in sharing concerns with healthcare providers and community members, fearing that their children will be judged or shunned and that their parenting skills will be questioned.
2. Strengths-focused	Boshoff et al. (2019)	Parents also described that the methods by which health professionals assessed their child were compromised. Assessments were typically conducted in environments unfamiliar to the child, which impacted on the opportunity to observe the child's full potential (Carlsson, Miniscalco, Kadescjo, & Laakso, 2016). Parents experienced the use of overt medical language and an over-emphasis on negative outcomes when communicating with professionals.
	Brown et al. (2021)	This was further compounded by a lack of accessible information about ASD supports available and the insensitive way some healthcare professionals disclosed the diagnosis, with an overemphasis on the negative aspects of the condition (Burrell et al., 2017; Potter, 2017).
	Legg & Tickle (2019)	Delivery of diagnosis was criticised for being too brief with a lack of sensitivity and a focus on negative aspects.
3. Holistic	Boshoff et al. (2019)	Parents recognised that the characteristics of autism contributed to the issues they faced in obtaining an appropriate diagnosis and support. Parents stated: "Because he looks like a normal child, people don't see the autism and don't understand" (Midence, 1999, p. 280) and "It was a battle getting anyone to understand our problems and believe that she was something other than naughty." (Tissot, 2011, p.

		7). Parents described this process as trying to make the invisible characteristics of their child visible (Hoogsteen, 2013).
	Howes et al. (2021)	It was noted by some professionals that there was a lack of family support available, although, some services offered "whole family support needs" but this was not consistent across all the services discussed within Crane et al. (2018, p. 3768) study.
	Legg & Tickle (2019)	Some fathers had not felt sufficiently included in the diagnostic process.
	Lockwood Estrin et al. (2020)	Arguably, this could be framed as females diagnosed with ASD needing additional behavioural problems to improve their chances of receiving a diagnosis. It would seem that social difficulties became more pronounced in girls over time, or that compensatory mechanisms such as camouflaging are less successful, against the higher social demands of teenagers. The study also included the parent-completed Social Communication Questionnaire (SCQ), on which current communication skills were reported to be significantly better for ASD boys than girls. This again indicates greater problems for diagnosed girls and the possibility of girls needing more ASD traits than boys to gain an ASD diagnosis. Salomone et al. (2016) found that for verbally able individuals (i.e. those with phrase speech) in a population-based sample, girls had a significantly higher age of diagnosis than boys. This gender difference was not seen for non-verbal or minimally verbal children. These results indicate that verbally able girls may be waiting longer for a diagnosis, thereby supporting Dworzynski et al.'s (2012) suggestion that additional language (or other) difficulties are often necessary for girls to receive an ASD diagnosis in contrast to boys. Studies indicated that males show more RRBIs than females (Duvekot et al. 2017; Tillmann et al. 2018), and that RRBIs are more predictive of an ASD diagnosis in males compared to females.

		The number of stereotyped behaviours in boys significantly decreased between five and 10 years of age, whereas it remained at a consistent level across these ages in girls with ASD. Tillmann et al. (2018) found that girls with an ASD diagnosis exhibited fewer RRBIs than boys, however non-verbal intellectual functioning accounted for and attenuated these differences. Boys who had an additional diagnosis were diagnosed significantly later than boys who did not. When observing social interactions from a distance, girls with ASD behaved like neurotypical girls, i.e.' spending a significant amount of time talking and weaving in and out of groups; yet, it was only upon closer inspection of the quality of interaction with peers that social challenges were perceived. By contrast, it was easier to identify social challenges in boys with ASD at a distance. The authors argued that using camouflaging techniques to mask social difficulties makes girls with ASD more vulnerable and less likely than boys to be identified within a school setting. Girls with an additional diagnosis were diagnosed later than girls who did not have an additional diagnosis. It has also been suggested that cognitive impairment increases the likelihood of having a documented ASD diagnosis for boys, but not for girls. Girls with an IQ of 70 or less were less likely than boys with an IQ of 70 or less to have a documented ASD diagnosis. This may suggest that once a cognitive impairment had been identified in a female, it is less likely that an ASD assessment will take place. Another paper using in-depth interviews, this time with parents, adolescent autistic daughters, and siblings, suggested that ASD females are less likely to be identified until the social demands they experience exceed their compensatory strategies.

		Mothers interviewed in one further paper, by Cridland et al. (2014), reported negative consequences from their daughters imitating social behaviours during assessment, and clinicians therefore being unable to identify their autistic behaviours. Parental reports of RRBI symptoms were significantly less predictive of an ASD diagnosis for females than for males, indicating that even with high scores in this domain, there was less of a link to diagnosis for females. Boys were more likely than girls to have a diagnosis of ASD even when both sexes had documented ASD symptoms in educational and clinical records. They concluded that this may result from an 'interpreting bias', where the observed experiences differ from the expected behaviours dependent on sex bias. They highlighted that clinicians evaluating girls, compared to boys, with a complex developmental profile may be more likely to exclude a classification of ASD if other conditions are present, due to this bias.
4. Helpful	Boshoff et al. (2019)	Our findings highlight the intense emotional journey for parents during identification of their initial concerns and the formal process of diagnosis, and their perceptions of not being supported by others on this journey. Marginalisation, silencing of their concerns, and lack of support were reported, as well as health professionals not acknowledging the importance of parents' concerns. Some parents described the formal process of diagnosis as a struggle, initiating a pattern of persistent behaviour by parents and a sense of distrust with medical professionals. Although parents described feeling empowered at the end point of this process, they also described feeling alone. Despite obtaining the knowledge they needed, they still needed to process the accompanying emotions and resulting decisions.
	Brown et al. (2021)	Some fathers described healthcare professionals not discussing the diagnosis and prognosis with them, with a need to provide information in language they could understand (Manor-Binyamini, 2019).

	Howes et al. (2021)	Multidisciplinary teams were thought to support parents' experience of the diagnostic process, as they allowed parents "time to talk" and gave clarity about the diagnostic process. The professionals from Rogers et al. (2016) wanted to offer long-term support to people with autism, but acknowledged that this is not possible for many services and that in-service support was also lacking for people who had received a diagnosis.
	Legg & Tickle (2019)	Professionals were represented as withholding information and scrutinising parents and child as well as providing help, guidance and support. Parents admired the professionals' expertise and were grateful for the service received. Diagnostic process was hard to understand, and parents did not understand roles of professionals. Parents were unaware of potential support available following diagnosis. Frequent criticisms were lack of support during and after assessment. Parents wanted a quicker, easier process with more coherent structure and content. Parents suggested information leaflets provided at the time of diagnosis could be valuable. Parents suggested they would like more information about the range of intervention and educational programmes available and local support groups. Delivery of diagnosis was criticised for being too brief with a lack of sensitivity and a focus on negative aspects.

		Lack of adequate information and support at the time and following diagnosis was highlighted. Some parents reported feeling abandoned by services after the diagnosis was given, leading to disappointment and frustration: Following my son's diagnosis, I received a leaflet and that is all. Any help and support I have subsequently received, I have sought out and paid for myself … (Potter, 2017, p. 101)
	Rivera-Figueroa et al. (2022)	Parents with limited English-proficiency are more likely to endorse distrust in the HCP as a barrier to service use (Zuckerman et al., 2017); to report receiving conflicting information that is not explained clearly (Stahmer et al., 2019); and to describe feeling discriminated against by professionals for not speaking English (Burke et al., 2019).
5. Evidence-based	Ellison et al. (2021)	All of the assessment studies included in this review demonstrate the feasibility of using telehealth to accurately assess not only for diagnostic purposes, but to also conduct other forms of assessments with children with ASD.
6. Culturally safe	Boshoff et al. (2019)	Parents from a Latino background described the specific issues they faced as a result of communication difficulties (Blanche et al., 2015). In their experience, service providers did not emphasise the need for a diagnosis and access to services, which they perceived may have been due to language barriers. Parents from different cultural backgrounds reported communication (Luong et al., 2009) and interaction difficulties (Jegatheesan et al., 2010), perceived to significantly impact on the relationship between parents and provider
	Brown et al. (2021)	An awareness of ASD from a cultural perspective is required, with the need for further research reflecting the range of experiences and essential cultural perspective.
	Howes et al. (2021)	Language or cultural differences were reported to increase the difficulty of diagnosing, such as needing a translator if there was a language barrier.
	Rivera-Figueroa et al. (2022)	Latinx and Black American parents are often met with providers who suggest a ''wait and see'' approach and normalize their behavioral concerns; Spanish-speaking and

		Black American caregivers often understand this to be a reaction to their race or culture and feel invalidated. Racial and ethnic disparities are exacerbated by a lack of culturally competent healthcare.
7. Respecting Australia’s First Nations Peoples.	Nil	Nil
8. Neurodiversity affirming	Nil	Nil
9. Competent	Boshoff et al. (2019)	“When I first presented with my children, I had to tell them what to do and that was the frightening part…could not tell me what to do with them...We lost tremendous amount of time.”
	Brown et al. (2021)	It was reported that some health professionals lacked detailed knowledge about ASD and the implications arising from the condition, thereby provoking emotions including denial, confusion, shame and disbelief in some fathers. Fathers also detailed how they struggled with the limited knowledge about and implications of an ASD diagnosis and prognosis by some healthcare professionals (Manor-Binyamini, 2019; Potter, 2017).
	Clark & Fung (2022)	The results reported by these studies suggest that by completing specialized training programs related to autism, physicians were more knowledgeable on topics related to the condition, more confident in their ability to provide care to autistic individuals, and more likely to screen their patients for autism spectrum disorder. Studies measuring self-efficacy found significant improvements in the outcome measure following the completion of a specialized autism training program. For example, one study found that physicians became more comfortable with identifying the symptoms of ASD, making appropriate diagnoses and referrals, and providing care to autistic children.

		Another study found that levels of self-efficacy remained increased six months following the completion of a training program (van ‘t Hof et al., 2021), suggesting that these educational programs are able to have a lasting impact on physicians’ confidence in their ability to provide care to autistic individuals.
	Howes et al. (2021)	A perceived lack of knowledge of how a person with autism presents was suggested to cause a delay in autistic traits being noticed. A lack of facts on ASD meant that some professionals felt they could not convey clear messages to parents about the diagnosis. Penner et al. (2017) described that professionals experienced diagnosis of both very young children and older children to be more challenging, and that girls were felt to be more difficult to diagnose, due to the differences in their presentation.
	Legg & Tickle, (2019)	Highlighted need for early diagnosis and better recognition of developmental problems by health professionals.
	Lockwood Estrin et al. (2020)	Reports of healthcare professionals being reluctant to diagnose a female as autistic and a lack of awareness of ASD in females due to a perceived higher incidence of ASD in males. Mademtzi et al. (2018) reported a parent feeling the need to exaggerate their daughter’s impairments to gain a diagnosis; ‘I felt that I needed to make my daughter look more impaired than she actually was, in order to get diagnosis and needed services’.
10. Timely and Accessible	Boshoff et al. (2019)	Positive relationships with professionals were reported by parents who experienced a timely diagnosis. The need to take action was reported as more challenging for parents from socioeconomic disadvantage or with cultural backgrounds different to that of the professionals (Luong et al., 2009), as well as for those living in rural areas (Divan et al., 2012).

		For rural families, complications included access to services, limited local expertise in autism, needing to attend multiple consultations, and not receiving satisfactory answers (Divan et al., 2012). Parents described the time of waiting as very difficult as they were overwhelmed with worry and concern for their child. "…It just seems to take an awfully long time to diagnose and its valuable time early on. A lot of time is wasted"
	Guan et al. (2022)	Two studies evaluated the change in wait time before and after implementing the training program. These 2 studies compared the wait time to see an ASD specialist versus the wait time to seeing a trained PCP. Another study evaluated the change in time to diagnosis by measuring the number of days from receipt of the parent-completed intake package to the date the final diagnostic International Classification of Diseases code was entered. All 3 studies reported the wait time to see a trained PCP was approximately 50% the length of the wait time to see the traditional assessment team.
	Howes et al. (2021)	Some professionals discussed how the appointment time slots were not "adequate to assess an autistic spectrum," which was a recurrent perspective in professionals who diagnosed other conditions in their practice. Additionally, the time taken to diagnose was further scrutinized under the context of services lacking the capacity to meet the demand, such that people are referred into services but then wait a long time to be assessed and receive a diagnosis. The time taken to be seen by other professionals, for participants who did not make the diagnosis alone, was discussed as a barrier and professionals stated that this impacted their ability to diagnose early.

		When faced with long referral times, some professionals chose to diagnose themselves, rather than refer to a specialist (Penner et al., 2017). They explained that getting support for people with autism as quickly as possible was a key priority.
	Legg & Tickle (2019)	While some parents were satisfied with timing of referral or assessment, others found the process overly long and this had an emotional impact on them. Time delays in assessment likely contributed to ongoing concerns and confusion and further added to parents' emotional difficulties.
	Lockwood Estrin et al. (2020)	Families experienced difficulty obtaining early diagnosis and problems having to justify requests for services. Strict diagnostic criteria also led to delayed diagnosis for females, with one parent saying their daughter was declined diagnosis because 'she's two points above the cutoff score'.
	Loubersac et al. (2021)	The diagnosis of ASD was, on average, earlier in areas with a higher median income. A significant 15-month age difference at diagnosis was reported by Thomas et al. [33] between children who live in a zone with a high median income (> $90,000) and those living in a zone with a lower median income (< $30,000). Those children living in a high median income area also received more assessments, which may have contributed to their earlier diagnosis. African American children were diagnosed approximately 1.4 years later than Caucasian children, with the difference being identical after adjusting for gender and socioeconomic status. Living in an "urbanized" area to be associated with a lower age at diagnosis of ASD. Children residing in rural or semi-urban areas were mostly diagnosed later, after the age of seven years (85%).
	Sainsbury et al. (2022)	Hatakenaka et al. (2016) found that the ASD + ADHD group waited 5 months longer than the ASD only group for a diagnosis of ASD after the first visit, and the ADHD only

		group waited 8 months longer than the ASD group for a diagnosis (no statistical analysis performed). Stevens et al. (2016) found that the ASD + ADHD group waited 1.3 years longer than the ASD only group for a diagnosis after first seeking medical assistance.
	Valentine et al. (2021)	Investigated referrals before and after the introduction of a telehealth service. They found that implementing a diagnostic consultation service for ASD, in partnership with an early intervention service, increased referrals for diagnostic evaluation and the likelihood of families attending appointments. Families from rural areas reported geographical and time barriers to accessing traditional healthcare. These barriers were reduced with remote diagnoses, leading to high levels of satisfaction.
11. Coordinated	Nil	Nil

Appendix 4.12	Umbrella Review Evidence Quotes – Process of Assessment and/or Diagnosis

Research question		
When – Evidence is presented in relation to **when should this be considered?**	Legg & Tickle (2019)	Highlighted need for early diagnosis and better recognition of developmental problems by health professionals. Information would support both professionals and parents to recognise differences in language, communication and behaviour as possible indicators of autism as early as possible.
	Boshoff et al. (2019)	Parents described occasions where their concerns were dismissed or ignored by paediatricians, resulting in parents pressuring their pediatricians into referrals and further assessments until they obtained a diagnosis. (Stoner et al., 2005). Parents' persistence was rewarded by obtaining a diagnosis.
	Howes et al. (2021)	When faced with long referral times, some professionals chose to diagnose themselves, rather than refer to a specialist (Penner et al., 2017). They explained that getting support for people with autism as quickly as possible was a key priority. Some professionals also used a "wait and see" approach toward diagnosis, due to the worry that putting a family through the diagnostic process and the outcome not being ASD is "not a wonderful thing to go through".
Who – Evidence is presented in relation to **who should be involved?**	Valentine et al. (2021)	Families could be coached to complete ASD assessment activities with young children via videoconferencing and clinicians could make accurate diagnoses remotely.
	Ellison et al. (2021)	Video conferencing was utilized to coach parents in implementing modified Autism Diagnostic Observation Schedule (Lord et al., 2002)-Module 1 activities and presses with their children compared to an in-person autism assessment utilizing these same presses. No difference between diagnostic consistency was found between groups; inter-rater agreement was not significantly different on the ADI-R and only one significant difference for an item on the ADOS was found. Further, high parent satisfaction was reported for both conditions.

		After radonmized group assignment, remote assessors randomly provided prompts to parents using an adaptation of the Screening Tool for Autism in Toddlers and Young Children (Stone et al., 2000) via VC or used the TELE-ASD-PEDS to guide parents to lead specific social tasks with their children (Corona et al., 2021). Both of these telehealth administrations were used to establish diagnostic accuracy; across the sample, diagnostic accuracy was 86–77% of parents reported that they would prefer both to play and observe the child during the remote assessment instead of just playing with the child or just observing (Corona et al., 2021). Remote real-time coaching was effective in having parents administer the functional analysis and was successful with identifying the social function of the behaviors consistently (Wacker et al., 2013). Results were comparable to previous functional analysis studies where theses assessments were conducted in-home with parents but the telehealth administration was a more cost-effective strategy
	Legg & Tickle (2019)	Diagnostic process was hard to understand, and parents did not understand roles of professionals. Some fathers had not felt sufficiently included in the diagnostic process. Fathers felt excluded. Fathers may have additional or alternative support needs to mothers following diagnosis. It is possible this in part arises from their sense of being excluded earlier in the process and that more inclusive relationships with professionals could promote later emotional adjustment.
	Howes et al. (2021)	Professionals reported difficulties with consistency of diagnostic categorization, and that the different sources of expertise on ASD were difficult to integrate into one uniformed view.

		The benefits of multidisciplinary teams were noted. Multidisciplinary teams helped compensate for the clinical setting of a formal diagnostic assessment, by allowing observations to take place in a variety of environments. Multidisciplinary teams were thought to support parents' experience of the diagnostic process, as they allowed parents "time to talk" and gave clarity about the diagnostic process. Parental understanding was understood to impact assessment processes. Participants in Finke et al. (2010) acknowledged the importance of listening to parents as their awareness of their child's behaviors could be important in heightening the professional's "concern" that a diagnosis should be explored. When faced with long referral times, some professionals chose to diagnose themselves, rather than refer to a specialist (Penner et al., 2017). They explained that getting support for people with autism as quickly as possible was a key priority. Professionals in the Finke et al. (2010) study indicated a preference of which specialists they would refer to, but a lack of these specialists meant this was not always possible.
	Guan et al. (2022)	A small number of patients were included in studies that reported accuracy (n 5 14–38). Diagnostic agreement between the trained providers and the expert teams ranged between 74% and 100%. Notably, each of these studies reported absolute agreement, without adjustment for chance agreement; the rates of ASD diagnosis by the expert teams ranged from 41% to 78%. PCPs reported their impression as to whether the child had ASD and stated the specific DSM IV diagnostic subtype. Full agreement between the trained PCP and the expert teams was 92% for the presence/absence of ASD and 87% for specific subtypes.

		There were no significant differences in respect to parents' perception of shared decision making or family-centered care between the traditional model and the trained PCP model.
Settings – Evidence is provided in relation to **in what settings should it occur?**	Valentine et al. (2021)	Families could be coached to complete ASD assessment activities with young children via videoconferencing and clinicians could make accurate diagnoses remotely. Juarez et al [21] reported on 2 studies, of which 1 compared a telediagnosis to a face-to-face assessment. This study demonstrated that, compared to gold-standard tools, remote ASD diagnostic consultations resulted in clinicians correctly diagnosing 78.9% (15/19) of children. No children were inaccurately diagnosed with ASD. Following referral, 56 (89%) of the 63 families chose to receive further appointments via telehealth services rather than face-to-face services. These barriers were reduced with remote diagnoses, leading to high levels of satisfaction.
	Ellison et al. (2021)	Findings, although still emerging, encouragingly suggested that services via telehealth were equivalent or better to services face-to-face. Results support the benefits to using telehealth with individuals with ASD. Video conferencing was utilized to coach parents in implementing modified Autism Diagnostic Observation Schedule (Lord et al., 2002)-Module 1 activities and presses with their children compared to an in-person autism assessment utilizing these same presses. No difference between diagnostic consistency was found between groups; inter-rater agreement was not significantly different on the ADI-R and only one significant difference for an item on the ADOS was found. Further, high parent satisfaction was reported for both conditions. After radonmized group assignment, remote assessors randomly provided prompts to parents using an adaptation of the Screening Tool for Autism in Toddlers and Young Children (Stone et al., 2000) via VC or used the TELE-ASD-PEDS to guide parents to

		lead specific social tasks with their children (Corona et al., 2021). Both of these telehealth administrations were used to establish diagnostic accuracy; across the sample, diagnostic accuracy was 86–77% of parents reported that they would prefer both to play and observe the child during the remote assessment instead of just playing with the child or just observing (Corona et al., 2021). Based on these two studies, it does appear that well-established diagnostic measures of ASD (i.e., ADOS and ADI-R), as well as other measures of ASD symptomology, can be used via telehealth successfully as accurate alternatives for identifying children with ASD rather than solely relying on in-person assessments. Remote real-time coaching was effective in having parents administer the functional analysis and was successful with identifying the social function of the behaviors consistently (Wacker et al., 2013). Results were comparable to previous functional analysis studies where theses assessments were conducted in-home with parents but the telehealth administration was a more cost-effective strategy. All of the assessment studies included in this review demonstrate the feasibility of using telehealth to accurately assess not only for diagnostic purposes, but to also conduct other forms of assessments with children with ASD.
	Boshoff et al. (2019)	Parents also described that the methods by which health professionals assessed their child were compromised. Assessments were typically conducted in environments unfamiliar to the child, which impacted on the opportunity to observe the child's full potential (Carlsson, Miniscalco, Kadescjo, & Laakso, 2016). Other parents also reported that they did not feel that the communication style used with their child was optimal. One parent said "Maybe they are good at it, but I don't always agree with what they say, that's what it feels like … I see him in so many other situations than they do, so it doesn't feel like the way they describe him always applies." (Carlsson et al., 2016, p. 333).

	Meimei & Zenghui (2022)	Reese et al.'s study found that there was still excellent diagnostic agreement between clinicians and other teams in the video conferencing setting. Real-time videoconferencing achieved the same results (sensitivity = 0.84, accuracy = 0.88) as the psychometric properties of in-person assessments (sensitivity = 0.88, accuracy = 0.78), consistent with a previous review Juárez et al. studied the preliminary feasibility, accuracy, and clinical utility of diagnosing ASD via televideo conferencing. This study showed that telemedicine procedures were as capable as in-person assessments at identifying children diagnosed with ASD. Although the TELE-ASD-PEDS is not designed for screening and diagnosing ASD, preliminary data suggest that it is a useful and valid ASD diagnostic tool. The benefits of multidisciplinary teams were noted. Multidisciplinary teams helped compensate for the clinical setting of a formal diagnostic assessment, by allowing observations to take place in a variety of environments.
	Guan et al. (2022)	Two of the 6 studies included self-reported changes in provider practice and perceptions.21,23 The first found that the providers' comfort level for discussing ASD diagnosis increased. They also noted a large, statistically significant shift in reports of practice behavior, with 68% of providers reporting that they were more likely to conduct ASD assessments within their practice at the end of the training program.
Knowledge and training – Evidence presented in relation to **what knowledge, skills, training, and support are required?**	Dorlack et al. (2018)	For Module 1, pooled sensitivity was similar for the ADOS-G algorithm (Pooled Random Estimate = 0.87, 95% CI 0.84–0.90), the ADOS-2 algorithm administered to children with no words (0.90, 95% CI 0.87–0.93), and the ADOS-2 algorithm administered to children having some words (0.88, 95% CI 0.82–0.94, Table 2). Pooled specificity estimates for the Module 1 algorithms of the ADOS-G, ADOS-2 used with children having no words, and ADOS-2 used with children having some words were 0.71 (95% CI 0.60–0.81), 0.62 (95% CI 0.43–0.81), and 0.79 (95% CI 0.70–0.88), respectively.

		Paired comparisons found that specificity of the ADOS-2 algorithm used with children having some words increased by 7% (0.07, 95% CI 0.10 to 0.25), while specificity of the ADOS-2 algorithm used with children having no words decreased by 8% (− 0.08, 95% CI 0.36 to 0.21), although neither of these measures were statistically significant. Sensitivity measures remained similar across the ADOS-G and ADOS-2 algorithms, with observed changes < 3%. For Module 2, pooled sensitivity was 0.72 (95% CI 0.57–0.87) for the ADOS-G algorithm, 0.77 (95% CI 0.63–0.90) for the ADOS-2 algorithm administered to children < 5 years old, and 0.89 (95% CI 0.67–0.92) for the ADOS-2 algorithm administered to children older than or equal to 5 years of age. Pooled specificity estimates for these three administrations were 0.90 (95% CI 0.83–0.97), 0.90 (95% CI 0.84–0.96), and 0.77 (95% CI 0.66–0.88), respectively. Paired comparison analyses found that sensitivity for the ADOS-2 algorithm used with children < 5 years old remained unchanged from ADOS-G (0.01, 95% CI 0.24 to 0.26). Sensitivity of the ADOS-2 algorithm used with children 5 years and older was increased by 9% from the ADOS-G (0.09, 95% CI 0.03 to 0.21), although it was not statistically significant. Specificity measures were reduced by 8% for the ADOS-2 algorithm used with children < 5 years old (− 0.08, 95% CI 0.21 to 0.05) and by 10% for the ADOS-2 algorithm used with children 5 years of age and older (− 0.10, 95% CI 0.28 to 0.07). However, none of these differences were statistically significant. For Module 3, pooled sensitivity was 0.75 (95% CI 0.66–0.84) for the ADOS-G

		algorithm and 0.82 (95% CI 0.75–0.90) for the ADOS-2 algorithm. Pooled specificity estimates for the Module 3 ADOS-G and ADOS-2 algorithms were 0.79 (95% CI 0.68–0.90) and 0.72 (95% CI 0.57–0.87), respectively. Paired comparison analyses found that sensitivity of the ADOS-2 algorithm was significantly improved by 8% (0.08, 95% CI 0.03–0.13) from ADOS-G. Specificity of the ADOS-2 algorithm was decreased by 7% (− 0.07, 95% CI 0.26 to 0.12) from ADOSG, although it was not significant.
	Rivera-Figueroa et al. (2022)	They report that HCPs lack cultural knowledge and implicitly criticize or question child-rearing practices and competence (Burkett et al., 2015). Clinicians (a) are less likely to recognize the signs and symptoms of ASD in Latinx children (Zuckerman et al., 2013). The most widely used ASD assessment tools are normed on predominantly White samples, and administration guidelines have little guidance regarding cultural considerations (Harris et al., 2014).
	Loubersac et al. (2021)	The results suggest that the diagnosis of ASD occurs earlier if there is a delay in social communication or the presence of intellectual disability. Two studies found a significant association between more severe impairment in social communication, as measured by the ADI-R [50, 72], and an earlier diagnosis of ASD, whereas two other studies found no significant association. A significant association was not found between the AoD and higher scores in the area of social interaction disruption measured by the ADOS. One study [40] found that children with a higher score in the RRB domain of the ADI-R were diagnosed earlier, whereas another study found opposite result [50] with a higher score in the RRB domain of the ADI-R associated with a later AoD. One study

		[42] found no significant association using the same tool. Furthermore, the RRB score measured with the ADOS did not appear to be significantly related to the AoD [50, 58]. An association between delayed intellectual development and an earlier diagnosis of ASD was found in seven [36, 40, 49, 55, 66, 74, 75] of the ten studies [28, 36, 38, 40, 49, 55, 58, 66, 74, 75] that analyzed this factor. Children with ASD and comorbid ADHD were diagnosed more than one year after those without comorbid ADHD. Lower language level (measured by PLS-4) was significantly associated with earlier diagnosis. Children who only started using sentences after 33 months of age were diagnosed approximately three years before those without a language delay. Darcy-Mahoney et al. (2016) [39] found a significant association between the AoD and the mother's marital status, with children of mothers who were married being diagnosed earlier (mean AoD = 53 months) than those who are divorced (mean AoD = 63 months). Valicenti-McDermott et al. (2012) [34] found no link between AoD and bilingualism in the home. African American children were diagnosed approximately1.4 years later than Caucasian children, with the difference being identical after adjusting for gender and socioeconomic status. Bickel et al. (2015) [37], who studied the association between the AoD and having a sibling with ASD, found that the presence of sibling with ASD is a significant predictor

		of earlier AoD. Living in an “urbanized” area to be associated with a lower age at diagnosis of ASD.
	Lebersfeld et al. (2021)	ADOS-2 performance was stronger than the ADI-R. ADOS-2 sensitivity and specificity ranged from .89-.92 and .81-.85, respectively. ADOS-2 accuracy in research compared with clinical settings was mixed. ADI-R sensitivity and specificity were .75 and .82, respectively, with higher specificity in research samples (Research = .85, Clinical = .72). Estimates of overall Se (.89–.92) and Sp (.81–.85) of the ADOS-2 as well as individual estimates for identified articles. When all articles were included, the DOR was higher for research compared with clinical samples; however, inclusion of the setting covariate was not significant (p =.071). Exclusion of the outlier had little effect on Se of the clinical sample but increased the Sp of the clinical sample from .80 to .90, which is higher than specificities reported in research samples (.81 and .83; Table 4). Interpretation of the SROC plot (Fig. 3) for all three setting types (clinical, research, and both) when all articles were included in the analysis and the Gotham et al. (2007, 2008) ASD vs. NS accuracy estimates were used (Approach 1) suggests research samples have higher levels of accuracy compared with clinical samples and combined clinical and research samples. When the outlier (Sp =.44) was removed from the analysis (Fig. 4), and the ASD vs. NS accuracy estimates were used (Approach 3), visual inspection of the SROC curve suggests there was not a difference between accuracy of the ADOS-2 in research and clinical settings, and accuracy of the ADOS-2 for studies including both research and clinical evaluations was lower than either research or clinical settings individually. The ADI-R pooled Se was .75, Sp was .82, and individual articles ranged widely (Se =.33–1.00, Sp =.61–1.00.

		Clinical and research samples had comparable Se (clinical = .71, research = .73) but articles utilizing both research and clinical samples had higher Se (.82). Sp was higher for research samples (.85) compared to clinical samples (.72) and those including both research and clinical evaluations in the study (Se =.85–1.00; Sp =.44–1.00) are presented in Table 4 and Fig. 5. These estimates were generally comparable to published algorithms (Table 5).
	Clark & Fung (2022)	The results reported by these studies suggest that by completing specialized training programs related to autism, physicians were more knowledgeable on topics related to the condition, more confident in their ability to provide care to autistic individuals, and more likely to screen their patients for autism spectrum disorder. Despite the variations in training duration and frequency, all of the studies that utilized the ECHO training model reported some level of positive outcomes (Bellesheim et al., 2020; Giachetto et al., 2019; Mazurek et al., 2019; Mazurek, Parker, et al., 2020; Mazurek, Stobbe, et al., 2020); however, not all of the studies showed the same level of success. Two of the three ECHO studies that measured knowledge and self-efficacy reported significant changes to both outcome measures (Giachetto et al., 2019; Mazurek, Parker, et al., 2020), but another was only able to significantly increase self-efficacy and had no impact on knowledge. Of the 17 included studies, 10 (59%) measured physician knowledge, eight (47%) measured physician self-efficacy, and 11 (65%) measured some aspect of physician behavior, mostly related to ASD screening. Most studies reported improvements in one or more of these outcome measures, and these improvements were seen across all participant groups regardless of their training level. Medical students saw improvements in symptom identification and diagnostic accuracy following an online-only training program.

		One study utilized the Autism Spectrum Disorder Knowledge Questionnaire–Physician Edition (AKQ-P) to show that an educational program led to an initial increase in both general autism knowledge and physician-specific autism knowledge. While physician-specific autism knowledge remained increased at six months post-training, general autism knowledge did not (van ‘t Hof et al., 2021). Another study measured both the objective and self-assessed knowledge of residents and found that both had been significantly increased after they participated in a case-based training program. Studies measuring self-efficacy found significant improvements in the outcome measure following the completion of a specialized autism training program (Table 1). For example, one study found that physicians became more comfortable with identifying the symptoms of ASD, making appropriate diagnoses and referrals, and providing care to autistic children. Another study found that levels of self-efficacy remained increased six months following the completion of a training program (van ‘t Hof et al., 2021), suggesting that these educational programs are able to have a lasting impact on physicians’ confidence in their ability to provide care to autistic individuals.
	Boshoff et al. (2019)	A prominent parental experience amongst studies was reports of experiencing problems with first line health professionals in the early identification of children with ASD and access to services. Parents reported being presented with a variety of unsatisfactory explanations as alternatives to autism (Altiere & von Kluge, 2009).
	Meimei & Zenghui (2022)	Reese et al.’s study found that there was still excellent diagnostic agreement between clinicians and other teams in the video conferencing setting. Real-time videoconferencing achieved the same results (sensitivity = 0.84, accuracy = 0.88) as

		the psychometric properties of in-person assessments (sensitivity = 0.88, accuracy = 0.78), consistent with a previous review. Juárez et al. studied the preliminary feasibility, accuracy, and clinical utility of diagnosing ASD via televideo conferencing. This study showed that telemedicine procedures were as capable as in-person assessments at identifying children diagnosed with ASD. Although the TELE-ASD-PEDS is not designed for screening and diagnosing ASD, preliminary data suggest that it is a useful and valid ASD diagnostic tool. All diagnostic tools used a comprehensive set of observables. The DSM-5 diagnostic criteria were used by NODA, TeleNP, and the tool proposed by Juárez et al. to diagnose ASD. Although BOSA uses a standardized coding manual developed in-house, the score still corresponds to the DSM-5 checklist and the ADOS-2 score. Moreover, TeleNP also used the childhood autism rating scale (CARS-2), the NEPSY second edition (NEPSY-II), Delis-Kaplan executive function system (DKEFS), vineland adaptive behavior scales, third edition (VABS-3), and autism diagnostic observation schedule, second edition (ADOS-2). Juárez et al. used STAT, clinical best estimate (CBE), Mullen scales of early learning (MSEL), VABS-2, and ADOS-2 as other observables. The most commonly used diagnostic tool is the ADOS-2. Assessment tools such as the TELE-ASD-PEDS and the study by Reese et al. also used a full range of observables, both of which used the ADOS-2; Reese et al. also used the Autism Diagnostic Interview-Revised (ADI-R) for assessments. Among the studies reporting psychometric information (n = 15), 8 reported sensitivity and specificity values equal to or greater than 75%. However, it should be noted that sensitivity values below this threshold may not indicate poor psychometric properties as the tool may be reliable for detecting specific subgroups of ASD patients. The study by Dow et al. had a better sensitivity (0.86–0.96) than that by Reese et al.

		[37] (0.88), while the application studied by NODA and Juárez et al. [19] presented a sensitivity between 0.79 and 0.85. However, both NODA and Juárez et al. [19] reported specificities greater than 0.94, while the specificity of BOSA fluctuated between 0.70 and 1.
	van't Hof et al. (2021)	Results showed the current mean age at diagnosis to be 60.48 months (range: 30.90–234.57 months) and 43.18 months (range: 30.90–74.70 months) for studies that only included children aged ⩽10 years. Numerous factors that may influence age at diagnosis (e.g., type of autism spectrum disorder diagnosis, additional diagnoses and gender) were reported by 46 studies, often with conflicting or inconclusive results. Multiple studies indicated that autistic disorder is associated with a lower age at diagnosis and Asperger's syndrome with a higher age. Comorbid attention deficit hyperactivity disorder (ADHD) diagnosis, along with ASD, is associated with a higher age at ASD diagnosis. In 17 studies, there was no difference between the age at diagnosis for boys and girls, whereas five studies reported a higher age at diagnosis for girls. We included 56 studies that reported the mean and/or median age at ASD diagnosis, of which 46 reported an overall ASD mean age at diagnosis between 30.9 and 574.4 months. Of the 56 studies, 24 reported an overall ASD median age at diagnosis (only or combined with mean age at diagnosis score) between 28 and 96 months. Several studies reported the age at ASD diagnosis for distinct ASD subtypes. For instance, the mean age at diagnosis for autistic disorder (eight studies) ranged between 33.8 and 194 months and the median age at diagnosis (nine studies) between 30 and 68.1 months.

		For Asperger's syndrome, the reported Christensen mean age at diagnosis (seven studies) was between 59.5 and 316 months and the median age at diagnosis (nine studies) was between 30 and 84 months. For pervasive developmental disorder-not otherwise specified (PDD-NOS), the reported mean age at diagnosis (eight studies) ranged between 34.60 and 211 months and the median age at diagnosis (five studies) ranged between 61 and 114 months. Four studies reported a median age at diagnosis between 49 and 56 months for PDD-NOS and ASD-other together. One study reported that the median age at diagnosis for autistic disorder and PDD-NOS combined was 34.8 months. For ASD-other (two studies), the mean age was between 43.1 and 50.7 months and a median age at diagnosis was between 33 and 47.0 months. In total, the meta-analysis included 35 papers (reporting on 55 study samples with a total study population of 66,966 individuals with ASD) across 35 countries that led to a mean age at diagnosis between 30.90 and 234.57 months. The meta-analysis shows a mean age at diagnosis of 60.48 months (95% CI: 50.12–70.83). Of the 35 studies, nine reported age at diagnosis estimates ranging from 30.90 to 74.70 months in 23 countries (26 study samples with a total study population of 18,134). Mean age at diagnosis of 43.18 months (95% CI: 39.79–46.57) for children aged ⩽10 years.

		The exclusion of three studies with the 95% CI bars well outside the range of the main group in the forest plot in Figure 2 (Begeer et al., 2013; Kentrou et al., 2019; Rutherford et al., 2016) lowered the age at diagnosis to 52.48 months (95% CI: 47.47–57.49) for all included studies instead of 60.48 months (range: 30.90–234.57 m). Regarding children aged ⩽10 years, the exclusion of one study with the 95% CI bars well outside the range of the main group in the forest plot (Hrdlicka et al., 2016) resulted in a lower age at diagnosis of 41.99 months (95% CI: 39.39–44.59) instead 43.18 months (range: 30.90–74.70 m). a wide variety of factors that could affect the average age at diagnosis of ASD. These factors are: (1) clinical characteristics, (2) sociodemographic characteristics, (3) parental concern, (4) interactions of healthcare and education systems, (5) geographic region and associated characteristics, and (6) cohort and period effects. Four studies found that children/adolescents with autistic disorder were diagnosed the earliest, followed by children with PDD-NOS and children with Asperger's syndrome were diagnosed the latest. The lowest age at diagnosis for children with autistic disorder, followed by children with PDD-NOS/Other ASD and children with Asperger's syndrome. Later age at diagnosis for children with Asperger's syndrome than those on the autism spectrum (Crane et al., 2016) and autistic disorder and PDD-NOS. No differences were reported in the adult population. Three studies reported differences in age at diagnosis based on ASD severity. Two of these showed that ASD severity is negatively associated with age diagnosis, indicating an earlier diagnosis is made in children with higher severity scores.

		Moderate ASD is being diagnosed earlier than mild and severe forms of autism. Children with Asperger's syndrome or Pervasive developmental disorder, unspecified, were referred for diagnostic assessment later than children with Atypical autism. High functioning children (i.e. with Asperger's syndrome) were diagnosed at a later age (Hagberg & Jick, 2017) and children with a high ADOS-2 comparison score tend to be diagnosed earlier than children with a minimal to low score (Höfer et al., 2019). A diagnosis of attention-deficit/hyperactivity disorder (ADHD) and major congenital anomaly was associated with a older age at ASD diagnosis. Children with additional diagnoses, especially those with ADHD, dyslexia or dyspraxia, were diagnosed later than children without these conditions. Children with an ADHD diagnosis were often three (Wei et al., 2018) or four years older (Miodovnik et al., 2015) when they were diagnosed with ASD. Children with more complex diagnoses (with ADHD before ASD diagnosis, and those diagnosed with ADHD at the same time as their ASD or later) were more likely to be diagnosed with ASD after age 6 years compared to children with only ASD. Some children with a later ASD diagnosis were more likely to have co-occurring ADD/ADHD than children without ASD; this was true only in non-Hispanic-white and non-Hispanic black children (NHB), but not in Hispanic-English or other Hispanics. Age at diagnosis was younger for children with ASD and comorbid disorders (epilepsy, auditory deficits, genetic/metabolic disorders) than children not on the autism spectrum. Children who spoke in only single words or echoing were diagnosed earlier than children with better verbal skills.

		Epilepsy and Cerebral palsy had no effect on the age at diagnosis of ASD. Children with Gilles de la Tourette syndrome and ASD were diagnosed at an older age than children with only ASD but not Tourette syndrome. Lower age at diagnosis in children with ID (IQ<70) than in children without ID (IQ>70). Another study found that an ASD diagnosis in children with IQ<85 was made earlier than in children with IQ>85 (Höfer et al., 2019). Frenette et al. (2013) found a significant lower mean age at diagnosis in children without ID than with ID, but this disappeared in regression analyses. Cognitive impairment was associated with a younger age at diagnosis (Montiel-Nava et al., 2017). However, Brett et al. (2016) found that learning/intellectual disability did not affect the age at diagnosis in a regression model controlling for multiple covariates. There was conflicting evidence from studies on verbal skills and age at diagnosis. One found that age at diagnosis was significantly higher for children who used complex sentences than for both non-verbal- and minimally verbal children. However, they found no differences in the age at diagnosis of non-verbal children and minimally verbal children (Salomone et al., 2016). Children who spoke in only single words or echoing were diagnosed earlier than more verbal children, and language delay explained 8% of the variance in age at diagnosis (Brett et al., 2016) Positive association between verbal (and composite) IQ score and age at diagnosis, indicating that children with no language delay were diagnosed significantly later (by 3 years) than children with language delay (Goodwin et al., 2017).
Info collected – What Evidence is presented in relation to **what**	Rivera-Figueroa et al. (2022)	The most widely used ASD assessment tools are normed on predominantly White samples, and administration guidelines have little guidance regarding cultural

information should be collected?		considerations (Harris et al., 2014). Racial and ethnic disparities are exacerbated by a lack of culturally competent healthcare.
	Bashoff et al. (2019)	Due to the invisible nature of autism, professionals often need to take parents' word for reported observations which may not be displayed during consultations (Midence & O'Neill, 1999).
	Meimei & Zenghui (2022)	All diagnostic tools used a comprehensive set of observables. The DSM-5 diagnostic criteria were used by NODA, TeleNP, and the tool proposed by Juárez et al. to diagnose ASD. Although BOSA uses a standardized coding manual developed in-house, the score still corresponds to the DSM-5 checklist and the ADOS-2 score. Moreover, TeleNP also used the childhood autism rating scale (CARS-2), the NEPSY second edition (NEPSY-II), Delis-Kaplan executive function system (DKEFS), vineland adaptive behavior scales, third edition (VABS-3), and autism diagnostic observation schedule, second edition (ADOS-2). Juárez et al. used STAT, clinical best estimate (CBE), Mullen scales of early learning (MSEL), VABS-2, and ADOS-2 as other observables. The most commonly used diagnostic tool is the ADOS-2. Assessment tools such as the TELE-ASD-PEDS and the study by Reese et al. also used a full range of observables, both of which used the ADOS-2; Reese et al. also used the Autism Diagnostic Interview-Revised (ADI-R) for assessments.
	Lockwood Estrin et al. (2020)	Girls with ASD used gestures more vividly than boys. Girls with ASD made significantly more mistakes than boys on an emotion recognition test. Watson (2014) found that all participants (n = 13 females with a clinical ASD diagnosis) reported having a co-occurring condition (e.g., ADHD), with 10 out ofthe 13 participants receiving their co-occurring diagnosis prior to ASD. Boys who had an additional diagnosis were diagnosed significantly later than boys who did not.

		Girls with an additional diagnosis were diagnosed later than girls who did not have an additional diagnosis. It has also been suggested that cognitive impairment increases the likelihood of having a documented ASD diagnosis for boys, but not for girls (Giarelli et al. 2010). Girls with an IQ of 70 or less were less likely than boys with an IQ of70 or less to have a documented ASD diagnosis. This may suggest that once a cognitive impairment had been identified in a female, it is less likely that an ASD assessment will take place.
	Howes et al. (2021)	Professionals reported difficulties with consistency of diagnostic categorization, and that the different sources of expertise on ASD were difficult to integrate into one uniformed view. Parental understanding was understood to impact assessment processes. Participants in Finke et al. (2010) acknowledged the importance of listening to parents as their awareness of their child's behaviors could be important in heightening the professional's "concern" that a diagnosis should be explored. Standard assessments need to be supplemented with a personal approach to decide what works for the child.
Info collected – How Evidence is presented in relation to **how should information be collected?**	Valentine et al. (2021)	Families could be coached to complete ASD assessment activities with young children via videoconferencing and clinicians could make accurate diagnoses remotely. Juarez et al [21] reported on 2 studies, of which 1 compared a telediagnosis to a face-to-face assessment. This study demonstrated that, compared to gold-standard tools, remote ASD diagnostic consultations resulted in clinicians correctly diagnosing 78.9% (15/19) of children. No children were inaccurately diagnosed with ASD. Stainbrook and colleagues investigated referrals before and after the introduction of a telehealth service. They found that implementing a diagnostic consultation service for ASD, in partnership with an early intervention service, increased referrals for diagnostic evaluation and the likelihood of families attending appointments.

	Rivera-Figueroa et al. (2022)	The most widely used ASD assessment tools are normed on predominantly White samples, and administration guidelines have little guidance regarding cultural considerations (Harris et al., 2014).
	Ellison et al. (2021)	One study (Reese et al., 2013), randomly assigned participants to either the in-person administration group or VC administration group. Both groups were administered the Autism Diagnostic Interview-Revised (Rutter et al., 2003). Video conferencing was utilized to coach parents in implementing modified Autism Diagnostic Observation Schedule (Lord et al., 2002)-Module 1 activities and presses with their children compared to an in-person autism assessment utilizing these same presses. No difference between diagnostic consistency was found between groups; inter-rater agreement was not significantly different on the ADI-R and only one significant difference for an item on the ADOS was found. Further, high parent satisfaction was reported for both conditions. After radonmized group assignment, remote assessors randomly provided prompts to parents using an adaptation of the Screening Tool for Autism in Toddlers and Young Children (Stone et al., 2000) via VC or used the TELE-ASD-PEDS to guide parents to lead specific social tasks with their children (Corona et al., 2021). Both of these telehealth administrations were used to establish diagnostic accuracy; across the sample, diagnostic accuracy was 86–77% of parents reported that they would prefer both to play and observe the child during the remote assessment instead of just playing with the child or just observing (Corona et al., 2021). Based on these two studies, it does appear that well-established diagnostic measures of ASD (i.e., ADOS and ADI-R), as well as other measures of ASD symptomology, can be used via telehealth successfully as accurate alternatives for identifying children with ASD rather than solely relying on in-person assessments. Primarily, all of the assessment studies included in this review demonstrate the feasibility of using telehealth to accurately assess not only for diagnostic purposes, but to also conduct other forms of assessments with children with ASD.

	Boshoff et al. (2019)	Parents also described that the methods by which health professionals assessed their child were compromised. Assessments were typically conducted in environments unfamiliar to the child, which impacted on the opportunity to observe the child's full potential (Carlsson, Miniscalco, Kadescjo, & Laakso, 2016). Other parents also reported that they did not feel that the communication style used with their child was optimal. One parent said "Maybe they are good at it, but I don't always agree with what they say, that's what it feels like … I see him in so many other situations than they do, so it doesn't feel like the way they describe him always applies." (Carlsson et al., 2016, p. 333).
	Meimei & Zenghui (2022)	Reese et al.'s study found that there was still excellent diagnostic agreement between clinicians and other teams in the video conferencing setting. Real-time videoconferencing achieved the same results (sensitivity = 0.84, accuracy = 0.88) as the psychometric properties of in-person assessments (sensitivity = 0.88, accuracy = 0.78), consistent with a previous review Juárez et al. studied the preliminary feasibility, accuracy, and clinical utility of diagnosing ASD via televideo conferencing. This study showed that telemedicine procedures were as capable as in-person assessments at identifying children diagnosed with ASD. Although the TELE-ASD-PEDS is not designed for screening and diagnosing ASD, preliminary data suggest that it is a useful and valid ASD diagnostic tool.
	Howes et al. (2021)	Tools and professionals judgments and individual differences were acknowledged frequently in Some professionals stated that weaknesses in diagnostic tools and guides meant that tools were often not "subtle" enough (Rogers et al., 2016, p. 827) when trying to diagnose someone with an atypical presentation. Standard assessments need to be supplemented with a personal approach to decide what works for the child

Decision making: Evidence is presented in relation to **how should decisions be made?**	Lockwood Estrin et al. (2020)	Strict diagnostic criteria also led to delayed diagnosis for females, with one parent saying their daughter was declined diagnosis because 'she's two points above the cutoff score'.
	Howes et al. (2021)	Tools and professionals judgments and individual differences were acknowledged frequently in professionals felt that mediation between the outcome of the diagnostic tools and their own professional judgment was necessary. This process was discussed by two professionals in Karim et al. (2014, p. 118) as necessary, due to the "subjective impressions" that were being "objectified" by the diagnostic tools. When faced with long referral times, some professionals chose to diagnose themselves, rather than refer to a specialist (Penner et al., 2017). They explained that getting support for people with autism as quickly as possible was a key priority. Additionally, the professionals perceived parental readiness to receive an ASD diagnosis as closely related to their understanding of ASD. In cases of diagnostic uncertainty, professionals would put the needs of the child and family first, such as giving a "false positive diagnosis" (Rogers et al., 2016, p. 827), due to diagnosis being a gateway for some services. Within the postdiagnosis topic, the difficulties with support services were acknowledged, along with the satisfaction of both the professionals and families. Diagnosis was described as an entrance ticket to services and it was suggested that professionals may feel coerced to make an ASD diagnosis due to the link between diagnosis and service support.
	Guan et al. (2022)	PCPs reported their impression as to whether the child had ASD and stated the specific DSM IV diagnostic subtype. Full agreement between the trained PCP and the expert teams was 92% for the presence/absence of ASD and 87% for specific subtypes.

		There were no significant differences in respect to parents' perception of shared decision making or family-centered care between the traditional model and the trained PCP model.
Outcomes: Evidence is presented in relation to **what should be the outcomes?**	Legg & Tickle (2019)	Having a diagnosis gave access to support and helped with adjusting future expectations. Parents need to be taken seriously from the first point of seeking help. The relationship with the diagnosing professional makes a real difference to parents and it is important fathers are included in this where they wish to be. Parents also wish to maintain contact with services as they adjust to the diagnosis. It is likely that such relationships could contain parents and help them to manage their emotional reactions, which is likely to benefit both their well-being and that of their child.
	Howes et al. (2021)	Too little parental knowledge was a barrier to giving a diagnosis because it would mean additional time was needed to explain the diagnosis, while too much knowledge of the challenges a child with autism might face could indicate that the family would not accept a diagnosis if it was given. Professionals felt that mediation between the outcome of the diagnostic tools and their own professional judgment was necessary. This process was discussed by two professionals in Karim et al. (2014, p. 118) as necessary, due to the "subjective impressions" that were being "objectified" by the diagnostic tools. The family response was a crucial experience for professionals, with Jacobs et al. (2018) identifying a dual effect where parents who had actively pursued an ASD diagnosis were relieved when they received the diagnosis, but not giving a diagnosis for these parents was seen as bad news. Additionally, some professionals acknowledged that parents viewed the practical use of the diagnostic label, such as an explanation for why their child might behave in a certain way, to be more important than it being an explanation of their child's condition.

		The professionals in the Finke et al. (2010) study stated that a discussion around the worries of the causes of ASD, such as vaccines, was crucial to informing the family of a diagnosis. Professionals in Rogers et al. (2016) recognized the need to communicate both the positive and negatives of the ASD diagnosis with both the person with autism and their family. Within the postdiagnosis topic, the difficulties with support services were acknowledged, along with the satisfaction of both the professionals and families. Diagnosis was described as an entrance ticket to services, and it was suggested that professionals may feel coerced to make an ASD diagnosis due to the link between diagnosis and service support.
	Guan et al. (2022)	A small number of patients were included in studies that reported accuracy (n 5 14–38). Diagnostic agreement between the trained providers and the expert teams ranged between 74% and 100%. Notably, each of these studies reported absolute agreement, without adjustment for chance agreement; the rates of ASD diagnosis by the expert teams ranged from 41% to 78%.
Info sharing: Evidence is presented in relation to **how should information be shared?**	Legg & Tickle (2019)	Feedback session was anxiety provoking and had significant emotional impact. Structured and focussed approach was valued. Diagnostic process was hard to understand, and parents did not understand roles of professionals. Parents were unaware of potential support available following diagnosis. Delivery of diagnosis was criticised for being too brief with a lack of sensitivity and a focus on negative aspects. Lack of adequate information and support at the time and following diagnosis was highlighted. Some expressed disappointment in the way diagnosis was communicated.

		Parents had mixed views, with some seeing assessments as comprehensive and others expressing disappointment that clinicians did not spend more time or show them recordings of assessments: It did seem really short [session where clinician interacted with son] it didn't … I mean it was only about fifteen minutes … and I don't see how you can make a judgement just within half an hour of watching a child, because surely it would take a bit longer. (Griffith et al., 2013, p. 64). Those parents who received it valued information and support from professional services after diagnosis: The child psychologist gave us, you know, she was very good, she gave us, a massive great book actually on, you know, various exercises that might help developmental wise. (Evans, 2010, p. 68). Good communication from professionals towards both parents and children promoted good relationships between parents and professionals. Such relationships are likely to have been containing for parents who have concerns about their children and promote positive engagement in the assessment process. Parents are likely to be more satisfied when assessments include more time building relationships between the professional and the child and when information is provided to the parents, including through observation of assessments.
	Boshoff et al. (2019)	Parents reported being presented with a variety of unsatisfactory explanations as alternatives to autism (Altiere & von Kluge, 2009). Through the process of reaching a diagnosis for their child, parents experienced confusion as a result of professionals often providing various alternative suggestions to a diagnosis of autism (Altiere & von Kluge, 2009). They also described receiving information through a standard brochure rather than individual support. These parents reported that had the health professionals used a warmer and more personal interaction style in their communications, it would have made hearing the formal diagnosis much easier (Jegatheesan et al., 2010). Parents from different cultural backgrounds reported communi- cation (Luong et al., 2009) and interaction difficulties (Jegatheesan et al., 2010), perceived to significantly impact on the

		relationship between parents and providers, leaving parents with a preference to consult with doctors from a similar cultural and linguistic background. “She said, from there, there is really nothing more that you can do … Goodbye and good luck’, ‘What she gave was sort of nothing … no hope.” “That is how he is, he is going to go down, and you are going to be stuck with this, let’s say, vegetable’”
	Howes et al. (2021)	Within informing of a diagnosis, the families response, and positive and negative aspects of ASD seemed to be important aspects to several of the articles. Difficulties with services were identified to be a factor of the postdiagnosis experience for many of the articles. Communicating the diagnosis to the person and their family was described as timeconsuming and was a barrier to the decision to diagnose, as it meant a “whole separate visit” (Penner et al., 2017, p. 601) was needed in addition to the necessary visits during the assessment. Crane et al. (2018) identified that a balance was needed between raising awareness and sensitivity being used to inform parents of a possibility that their child may be displaying autistic traits. For example, one professional in Crane et al. (2018) identified that they sometimes had parents be told their child might have autism because they had “put their hands over their ears when they heard a loud noise” (Crane et al., 2018, p. 3766) and that in reality there are many reasons for this behavior not just autism. too little parental knowledge was a barrier to giving a diagnosis because it would mean additional time was needed to explain the diagnosis, while too much knowledge of the challenges a child with autism might face could indicate that the family would not accept a diagnosis if it was given. A lack of facts on ASD meant that some professionals felt they could not convey clear messages to parents about the diagnosis. Some professionals felt that communicating the diagnosis to the person and their family was a significant emotional burden.

		Multidisciplinary teams also allowed staff access to other professional opinions and expertise, when faced with uncertain cases. Multidisciplinary teams were thought to support parents' experience of the diagnostic process, as they allowed parents "time to talk" and gave clarity about the diagnostic process. Parents having some knowledge of ASD was thought to facilitate communication between the professional and the family. When informing the family of an ASD diagnosis, one study found that terminology is crucial, and some professionals suggested that they used the term "Asperger's" as they perceived the information available about Asperger's Syndrome to be less frightening than "autism" (Karim et al., 2014, p. 120). A professional in the Finke et al. (2010) study discussed that he would attempt to facilitate parents in their internet searching by telling them what they might see on the internet. Professionals depended on parents to disclose a diagnosis to the child, but would tell an adolescent of their diagnosis. The family response was a crucial experience for professionals, with Jacobs et al. (2018) identifying a dual effect where parents who had actively pursued an ASD diagnosis were relieved when they received the diagnosis, but not giving a diagnosis for these parents was seen as bad news. Additionally, some professionals acknowledged that parents viewed the practical use of the diagnostic label, such as an explanation for why their child might behave in a certain way, to be more important than it being an explanation of their child's condition. The most important implication of informing a diagnosis for the professionals from the Jacobs et al. (2018) study was the function of lifting the blame on parents for their child's behavior. The professionals in the Finke et al. (2010) study stated that a discussion around the worries of the causes of ASD, such as vaccines, was crucial to informing the family of a diagnosis. Additionally, the professionals perceived parental readiness to receive an ASD diagnosis as closely related to their understanding of ASD.

		In cases of diagnostic uncertainty, professionals would put the needs of the child and family first, such as giving a "false positive diagnosis" (Rogers et al., 2016, p. 827), due to diagnosis being a gateway for some services. Professionals in Rogers et al. (2016) recognized the need to communicate both the positive and negatives of the ASD diagnosis with both the person with autism and their family. Professionals stated they were often unable to offer support, even though they wanted to, and that they were put under "pressure" not to offer postdiagnostic support due to the demands that were already on them.
	Brown et al. (2021)	Some fathers described healthcare professionals not discussing the diagnosis and prognosis with them, with a need to provide information in language they could understand (Manor-Binyamini, 2019). Many fathers described feeling ignored by professionals in services, highlighting the view that there were more supports provided for mothers than fathers (Potter, 2017).

Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 5.1	Online survey

Community Survey

[Attachment: "Voice-to-text instructions.doc"]

Information Statement for the Research Project:

Update of the National Guideline for Assessment and Diagnosis of Autism in Australia: Community Consultation Online Survey

(GU ref no: 2022/780)

Part 1: Participation Information

What is this project about?

Autism CRC is leading the update of the National Guideline for Assessment and Diagnosis of Autism Spectrum Disorders in Australia. The Guideline, developed in 2018, will be undergoing a review and update based on recent research and consultation with members of the autistic and autism communities. The result will be a set of Recommendations and Good Practice Points to guide the practice of practitioners involved in assessment and/or diagnosis of autism in Australia.

Why are you being invited to participate?

We warmly invite all members of the autistic and autism communities who have an interest in assessment and diagnosis to share your views about the Guideline.

Who can participate in the research?

We would like to hear from the following people:

People on the autism spectrum (this includes children, young people, and people who communicate mainly in ways other than speech and/or writing). Parents, caregivers, and family members of individuals on the autism spectrum. Practitioners involved in assessment and/or diagnosis of autism across the lifespan. Other members of the autism community (e.g., informal support people, service providers, researchers). Where a person is under the age of 18 years, or is unable to provide informed consent, a parent or guardian will need to provide consent and support that person in accessing and/or completing the survey.

What will you be asked to do?

You will be asked to answer questions about assessment and diagnosis of autism. The questions are designed to help us work out what works well, what does not work well, and what practitioners can do to make it better. You will be asked to write your answers, but there will also be opportunities to upload artwork if preferred.

You can choose to give responses for some or all of these. We anticipate it will take between 10 and 60 minutes to complete, depending on how many questions you answer. You can return to the survey up to one week after you begin, provided the survey is still open. After one week, if the survey is still open, you would need to commence a new survey if you want to answer more questions.

Do I have to participate?

You can choose whether or not you participate. If you choose to complete the survey, we will take this as permission to use the information provided in updating the Guideline. 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 you begin the survey and decide that you would like to withdraw consent, there is a button at the end of the survey you can select to indicate that you no longer want the information you provided to be used in the project. If you change your mind after submitting the survey, your individual responses will still be analysed but rest assured you will not be identified due to the anonymous nature of data collection.

What are the benefits of participating?

We hope that it will be a positive experience for you, in helping to inform the Guideline. While you will not receive any direct benefits from participating in this research, the benefits of the research more broadly include an increase in knowledge and understanding regarding the most important factors relevant to assessment and diagnosis of autism.

Are there any potential risks?

We do not believe there are any direct risks associated with participation in this research. However, we understand that for some people thinking and talking about their experiences, can lead to a mixture of emotions, including sadness. If you, or anyone close to you, participates in this research and experiences any distress, we ask that you contact support services such as Lifeline on 13 11 14. More information on freely available mental health services can be found at https://www.healthdirect.gov.au/mental-health-helplines.

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 Dr Veronica Frewer, Griffith University Dr Rachelle Wicks, Griffith University Libby Groves, Griffith University Emma Hinze, 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 project 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 of the Guideline including a summary of the outcomes of this survey, 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 on the autism spectrum. The team has carefully selected the questions, considered how they are presented in the survey, and has made available different options for you and other people to share your thoughts. Only anonymous, summarised, and combined survey data will be used and reported.

Part 2: Ethical Information we must provide you.

What will be done with the data?

We will use the information you and others provide to help develop a set of draft recommendations for assessment and diagnosis of autism across the lifespan, and then share these with the community for feedback. We may also publish the findings in research journals and in professional (e.g., conferences) and community forums (e.g., seminars, via social media).

When we share the data, we will:

Present a summary of de-identified information about who participated (e.g., the variety of practitioners, broad geographical areas represented) in the Guideline and related documents. Present the themes that emerge from responses and use direct quotes from participants to help explain what the themes are about, in the Guideline and related documents. Any quotes will be presented de-identified, not using your real name. It is possible that if you read the findings or see them presented at a workshop or seminar that you might recognise your own quotes, but we will never attach real names to these quotes. We will make a copy of the de-identified information (i.e., themes and quotes) available in a public repository for people to review and possibly use in other research. No personally identifying information will be included. 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).

Consent to Participate

Consent Form for the Research Project:

Update of the National Guideline for Assessment and Diagnosis of Autism in Australia: Community Consultation Online Survey

(GU ref no: 2022/780)

Community Consultation: Online Survey

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

I understand that my participation in this research will involve completing a survey, which may take between 10-60 minutes to complete, depending on how many questions I decide to answer. I understand that any information I provide on behalf of myself or another person (i.e., a child, young person, or adult on the autism spectrum) will be used to inform the update of the National Guideline for Assessment and Diagnosis of Autism Spectrum Disorders in Australia. I understand that any written responses provided in this activity may be reproduced in the Guideline and related research activities (e.g., community presentations, research articles, online news and newsletters, social media), provided they contain no personally identifying information. I understand that my de-identified data may be included in a public repository for people to review and possibly use in other research. I have read the Information Statement, or someone has read it to me in a language that I understand. 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 am free to withdraw at any time during the project without question or consequence. 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 this research	○ No ○ Yes

Thank you again for your interest in this research.

As a reminder, you will have the opportunity to save your responses and return at a later time to complete this survey.

To assist us in our data analysis, we ask that you please finalise your responses within one week of starting the survey.

We will not analyse any additional responses provided in this particular form after this time.

If you need longer than one week to complete the survey, we ask that you start a new form after one week.

The survey will close at 5:00pm AEST on Monday the 5th of December, 2022

AutismCRC

Please note: In this survey we refer to autism, rather than Autism Spectrum Disorder. However, for clarity, where questions relate to diagnosis, we are referring to Autism Spectrum Disorder (ASD), as presented in The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR).

ABOUT ME

Please answer these questions to help us understand more about you, your experience and perspective.

Which of the following describes you? (select all that apply)	☐ I am an autistic person/person on the autism spectrum ☐ I am a parent, caregiver, or family member of an autistic person ☐ I am a practitioner involved in the assessment and/or diagnosis of autism ☐ I am a member of an organisation/body/group that has an interest in the assessment and/or diagnosis of autism ☐ Other (e.g., support person, researcher)
Please specify if you are:	○ Completing this survey on your own ○ Completing the survey with support
Please specify your relationship to the autistic person/person on the autism spectrum (e.g., parent, caregiver, grandparent, sibling)	______________________________

What is your profession (select all that apply)?	☐ Aboriginal and Torres Strait Islander Health Worker or Health Practitioner ☐ Aboriginal and Torres Strait Islander Health Advocate ☐ Accredited practising dietitian ☐ Audiologist ☐ Board Certified Behaviour Analyst ☐ Childcare worker ☐ Dentist ☐ Developmental educator ☐ Educator (early childhood) ☐ Educator (primary school) ☐ Educator (high school) ☐ Gastroenterologist ☐ General practitioner ☐ Geneticist ☐ Neurologist ☐ Nurse ☐ Nurse practitioner ☐ Occupational therapist ☐ Ophthalmologist ☐ Optometrist ☐ Paediatrician ☐ Physiotherapist ☐ Psychiatrist ☐ Psychologist ☐ Sleep and respiratory physician ☐ Social worker ☐ Speech pathologist ☐ Support worker ☐ Other
As you selected 'Other' for your profession, please specify	__________________________________
As you selected 'Other' to describe yourself, please specify	__________________________________
As you selected that you are a member of an organisation/body/group, please indicate which of the following apply:	○ I am completing this survey as an individual member of an organisation (i.e., the views are my own) ○ I am completing this survey as the nominated representative of the organisation (i.e., I am making a submission on behalf of the organisation as a whole)
What is your age?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)
Which state or territory of Australia do you currently reside in?	○ Australian Capital Territory ○ New South Wales ○ Northern Territory ○ Queensland ○ South Australia ○ Tasmania ○ Victoria ○ Western Australia ○ Do not currently reside in Australia

Which state(s) or territory(ies) of Australia does your organisation/body/group conduct services in?	☐ Australian Capital Territory ☐ New South Wales ☐ Northern Territory ☐ Queensland ☐ South Australia ☐ Tasmania ☐ Victoria ☐ Western Australia ☐ Does not currently service Australia
Do you identify as Aboriginal and/or Torres Strait Islander?	○ No ○ Yes, Aboriginal ○ Yes, Torres Strait Islander ○ Yes, both Aboriginal and Torres Strait Islander
Have you read or used the previously published 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (2018)?	○ Yes ○ No

Autistic people/people on the autism spectrum

You indicated that you are an autistic person/person on the autism spectrum, are you happy to tell us about your diagnosis?	○ Yes ○ No
Which of the following best describes your circumstances?	○ I have been given a formal diagnosis of autism (or a related diagnosis e.g., Asperger's, Pervasive Developmental Disorder) by one or more qualified health practitioners (e.g., paediatrician, clinical psychologist, psychiatrist) ○ I am currently being assessed for a possible diagnosis of autism ○ I self-identify as autistic, but have not been given a formal diagnosis by a qualified health professional
At what age did you receive a formal diagnosis? Please specify in years	________________________
What was your diagnosis (e.g., Autism Spectrum Disorder, Asperger's)?	________________________
At the time you were diagnosed, what level of support did you need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when I was diagnosed ○ It is the level I think was most appropriate at the time I was diagnosed
What level of support do you currently need to participate in everyday activities?	○ Level 1 - Requires support ○ Level 2 - Requires substantial support ○ Level 3 - Requires very substantial support ○ I am unsure ○ I would prefer not to say

Family members

You indicated that you are a parent, caregiver, or family member of an autistic person/person on the autism spectrum, are you happy to tell us more about your family member on the autism spectrum? We will ask you to focus on just one family member at a time.	○ Yes ○ No
What is your relation to this particular family member (e.g., parent, caregiver, sibling, grandparent)?	______________________________
Will this family member contribute to responses in the survey?	○ Yes ○ No
How old is your family member?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)
Has your family member received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your family member diagnosed (please round to the nearest year)?	______________________________
At the time your family member was diagnosed, what level of support did they need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when they were diagnosed ○ It is the level I think was appropriate at the time they were diagnosed
Do you wish to provide details for another family member on the autism spectrum?	○ No ○ Yes
What is your relation to this particular family member (e.g., parent, caregiver, sibling, grandparent)?	______________________________
Will this family member contribute to responses in the survey?	○ Yes ○ No
How old is your family member?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)
Has your family member received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes

At what age was your family member diagnosed (please round to the nearest year)?	________________________________
At the time your family member was diagnosed, what level of support did they need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when they were diagnosed ○ It is the level I think was appropriate at the time they were diagnosed
Do you wish to provide details for another family member on the autism spectrum?	○ No ○ Yes
What is your relation to this particular family member (e.g., parent, caregiver, sibling, grandparent)?	________________________________
Will this family member contribute to responses in the survey?	○ Yes ○ No
How old is your family member?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)
Has your family member received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your family member diagnosed (please round to the nearest year)?	________________________________
At the time your family member was diagnosed, what level of support did they need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when they were diagnosed ○ It is the level I think was appropriate at the time they were diagnosed
Do you wish to provide details for another family member on the autism spectrum?	○ No ○ Yes
What is your relation to this particular family member (e.g., parent, caregiver, sibling, grandparent)?	________________________________
Will this family member contribute to responses in the survey?	○ Yes ○ No

How old is your family member?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)
Has your family member received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your family member diagnosed (please round to the nearest year)?	__________________________________
At the time your family member was diagnosed, what level of support did they need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when they were diagnosed ○ It is the level I think was appropriate at the time they were diagnosed
Do you wish to provide details for another family member on the autism spectrum?	○ No ○ Yes
What is your relation to this particular family member (e.g., parent, caregiver, sibling, grandparent)?	__________________________________
Will this family member contribute to responses in the survey?	○ Yes ○ No
How old is your family member?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)
Has your family member received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ No ○ Yes
At what age was your family member diagnosed (please round to the nearest year)?	__________________________________
At the time your family member was diagnosed, what level of support did they need to participate in everyday activities?	○ Level 1 - Requires support ○ Level 2 - Requires substantial support ○ Level 3 - Requires very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when they were diagnosed ○ It is the level I think was appropriate at the time they were diagnosed

Practitioners

You indicated that you are a practitioner: are you happy to tell us more about your experience with assessment and/or diagnosis of autism?	○ Yes ○ No
How are you currently involved in assessment and/or diagnosis of autism? (select all that apply)	☐ I refer individuals with possible autism for assessment ☐ I conduct assessments that are relevant to considering an autism diagnosis ☐ I conduct assessments and diagnose autism ☐ I provide services to individuals once they have received an autism diagnosis ☐ Other
As you selected 'Other', please specify your current involvement in assessment/diagnosis of autism	______________________________
How many years of experience do you have in the assessment and/or diagnosis of autism? Please use the year you started and the year you finished/present time to calculate this. For example, if you started being involved in assessment and diagnosis in 2018, and are still involved currently (2022), you would answer 4 years even if there were some career breaks.	______________________________
Which of the following are you (or have you been) involved in, as part of your practice in the assessment and/or diagnosis of autism (select all that apply):	☐ Medical evaluation ☐ Assessment of functioning ☐ Single clinician diagnostic evaluation ☐ Consensus team diagnostic evaluation ☐ None of these
How many years of experience do you have working in clinical practice with individuals on the autism spectrum? Please use the year you started and the year you finished/present time to calculate this. For example, if you started working with individuals on the autism spectrum in 2018, and are still doing so currently (2022), you would answer 4 years even if there were some career breaks.	______________________________
Across your career to date, what age groups have you provided autism assessment and/or diagnostic services to?	☐ 0-12 years (children) ☐ 13-17 years (adolescents) ☐ 18-25 years (young adults) ☐ 26 years and older (adults) ☐ I do not provide assessment and/or diagnostic services to people on the autism spectrum
In which of the following service settings do you practice? (select all that apply)	☐ Private, including non-government organisations ☐ Government organisations (e.g., hospital and health services)

In which of the following settings do you currently provide assessment and/or diagnostic services? (select all that apply)	☐ Hospital (inpatient/outpatient) ☐ Community clinic (including private practice) ☐ University clinic (includes providing services as part of student training and research) ☐ Other
As you selected 'other' for the setting you currently provide assessment and/or diagnostic services within, please specify	__________________________________

Organisation/body/group

You indicated that you are responding as part of an organisation/body/group: are you happy to provide us with more details about your organisation/body/group?	○ Yes ○ No
What is the name of your organisation?	__________________________________
In under 30 words, please explain how your organisation is relevant to the assessment and/or diagnosis of autism across the lifespan.	____

SUMMARY OF QUESTIONS

This is a summary of the questions/sections in the survey, to help you work out which ones you might like to answer.

Section 1 This section invites you to share views and experiences of assessment and diagnosis (i.e., what is/was good, not good, and what you would change).

This section provides an opportunity to share your own experience and views and/or to help another person (e.g., your child or another family member) share their views.

Section 2 This section invites you to share your views on specific aspects of the assessment and diagnosis process (i.e., regarding principles that should be followed, referral, assessment of functioning, medical evaluation, diagnostic assessment, quality and safeguarding).

This section focuses on what practitioners can do to help improve the process of assessment and diagnosis for individuals and their families.

Section 3 Invites you to share your thoughts about the existing Guideline and the update.

This section focuses on what you would like to see changed or added to the Guideline, as well as your views on barries and enablers to the implementation of Recommendations in the Guideline.

SECTION 1: Sharing views and experiences of assessment and diagnosis

We would like to start by inviting you to share views and/or experiences regarding assessment and/or diagnosis of autism.

If you are a person on the autism spectrum, a family member, or someone else who has a personal experience of going through the process, we invite you to share your personal experience. If you are a practitioner or a member of an organisation that provides services, we invite you to share your observations based on professional experience. Some people may have both personal and professional experience, please share the information you feel is most relevant. If you are assisting someone else to complete the survey (e.g., you are asking your child for their views about assessment and diagnosis) you can also do that here. There is also an opportunity to upload an artwork as a way of sharing experiences and views. When helping someone else to share their views (i.e., your child/family member), we ask you to please:

Ensure that they are aware that they know that sharing their experience and views is their choice (i.e., it is voluntary) and that what they share will be provided to us, the research team. If they agree, please ask the following questions in a way that they will understand and be meaningful to them. If you are recording their response, please write down exactly what they say wherever possible.

Would you like to share your views and experience?	○ Yes ○ No

You can respond to the questions below by recording your responses in the feedback boxes or by producing a piece of art (e.g., a drawing, painting or other artwork) about your views and experiences of the assessment and/or diagnostic process and uploading it below.

What do you think is/was good about the assessment and/or diagnostic process? (word limit=150 words)	______________________
What do you think is/was bad about the assessment and/or diagnostic process? (word limit=150 words)	______________________
What do you think should be done better? (word limit=150 words)	______________________
If you are uploading a piece of artwork about your experience, please attach an image or file of the artwork here:	
Please tell us what the artwork is about and the messages that are shared through the artwork about assessment and/or diagnosis. (word limit = 200 words)	______________________

SECTION 2: Sharing your views about how specific aspects of assessment and diagnosis should occur

In this section, we ask for your feedback on how specific aspects of assessment and diagnosis should occur. We ask you to identify what practitioners should do to ensure specific aspects of assessment and diagnosis are timely, accurate and supportive to people on the autism spectrum and their families.

Would you like to answer one or more questions in this section?	○ Yes ○ No
What are the most important principles (e.g., evidence based, strengths focused) that practitioners should follow in the assessment and diagnosis of autism? (word limit = 150 words)	________________________________
What are the most important considerations for practitioners when making a referral for assessment and possible diagnosis of autism? (word limit = 150 words)	________________________________
What are the most important considerations for practitioners when conducting an assessment of functioning* that may lead to a diagnosis of autism? (word limit = 150 words)	________________________________ (*An assessment of functioning seeks to understand an individual's level of functioning and needs in order to support their full participation in society. It requires the collection of a range of information.)
What are the most important considerations for practitioners when conducting a medical evaluation* as part of a possible diagnosis of autism? (word limit = 150 words)	________________________________ (*The aim of the medical evaluation is to assess whether there are medical causes and/or associations with the behavioural presentation of an individual and to contribute to the identification of additional support needs.)
What are the most important considerations for practitioners when conducting a diagnostic assessment* as part of a possible diagnosis of autism? (word limit = 150 words)	________________________________ (*The diagnostic assessment seeks to answer the questions: (i) Does the individual meet criteria for a clinical diagnosis, such as ASD or other differential or co-occurring conditions? and (ii) if the individual does not meet criteria for a clinical diagnosis, are there other considerations that explain the presentation?)
What are the most important considerations for practitioners to ensure the safety and wellbeing of individuals during the assessment and diagnostic process? (word limit = 150 words)	________________________________

SECTION 3: Sharing your views about the existing Guideline and the update

Would you like to share your thoughts on the current version (i.e., the original 2018 version) of the Assessment and Diagnosis Guideline and/or the update process?	○ Yes ○ No
Do you have experience with the Guideline (e.g., you have used it, tried to use it, or accessed an assessment where it was used?)	○ Yes ○ No
Is there anything you would like to see changed or clarified in the Guideline, when it is updated?	○ Yes ○ No
Please state what you would like to see changed? (word limit = 150 words)	__________________________________
Are there any questions or issues about the assessment and diagnostic process that you feel were not addressed in the original Guideline, that you would like to see addressed in the updated Guideline?	○ Yes ○ No
Please list the questions/issues you would like to see addressed (word limit = 150 words)	__________________________________
If you haven't already identified these, what are the barriers to implementing the Recommendations in the existing guideline? (word limit = 150 words)	__________________________________
If you haven't already identified these, what are the enablers to implementing the Recommendations in the existing guideline? (word limit = 150 words)	__________________________________

Before you go

Are you happy for us to use the information you provided?	○ Yes ○ No

A note from the research team

Thank you very much for answering the questions. The information that you and others provide will directly inform the update of the Guideline.

The next step for the research team will be to analyse all of the information provided. The Guideline Development Group will then formulate updated Recommendations.

If you have not already done so, please register with 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 surveys like this. While we are not able to send a personal response to each person who completes it, please know that we genuinely value the information you have provided and will be reading every word.

We also acknowledge that if you are an autistic person, a parent, or other family member of a child on the autism spectrum, you will have shared in the survey insights from your own life, your experience, and your expertise. It is likely that you will have been asked to do this many times before, and we warmly thank you for being willing to do so again here, to help make the guideline the best it can be. We simply could not do this piece of important work, without your insights. Thank you.

We look forward to sharing updates, and the Guideline in due course, via Autism CRC's website.

Sincerely,

Rhylee Sulek, Kandice Varcin, Nicole Dargue, Hannah Waddington, Emma Hinze, Rachelle Wicks, Veronica Frewer, Libby Groves, Andrew Whitehouse, Emma Goodall, and David Trembath, on behalf of the Guideline Development Group.

Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 6.1	Demographics survey – focus group

Focus Group Demographics

Thank you for for registering to participate in one of the online focus groups that we are running as part of the update of the National Guideline for the assessment and diagnosis of autism in Australia.

We are interested to know a bit more about you so that we can present a de-identified summary in the updated Guideline of who participated in the focus groups (e.g., the variety of people, where they were from). Almost all of these questions are optional so that you can choose what information you would like to share about yourself.

While we do ask for your name and email address, this information will only be used for administrative purposes and will not be published in any format

If you have any questions, please contact the project team: ADGupdate@griffith.edu.au

This study is being conducted by the Guideline Development Group and is approved by the Griffith University Human Research Ethics Committee (GU Ref No: 2022/780).

First Name ________________________________

Surname ________________________________

Email you used to register for the focus groups ________________________________

Please indicate which perspective(s) you bring to the focus group: (select all that apply)

☐ I am an autistic person/person on the autism spectrum
☐ I am a parent, caregiver, or family member of a person on the autism spectrum
☐ I am a practitioner involved in the assessment and/or diagnosis of autism
☐ Other

As you selected that you are a practitioner, please indicate your profession	☐ Aboriginal and Torres Strait Islander Health Worker or Health Practitioner ☐ Aboriginal and Torres Strait Islander Health Advocate ☐ Accredited practising dietitian ☐ Audiologist ☐ Board Certified Behaviour Analyst ☐ Childcare worker ☐ Dentist ☐ Developmental educator ☐ Educator (early childhood) ☐ Educator (primary school) ☐ Educator (high school) ☐ Gastroenterologist ☐ General practitioner ☐ Geneticist ☐ Neurologist ☐ Nurse ☐ Nurse practitioner ☐ Occupational therapist ☐ Ophthalmologist ☐ Optometrist ☐ Paediatrician ☐ Physiotherapist ☐ Psychiatrist ☐ Psychologist ☐ Sleep and respiratory physician ☐ Social worker ☐ Speech pathologist ☐ Support worker ☐ Other
As you selected 'other' for your profession, please specify here:	__________________________________
As you selected 'Other' for the perspective that you bring to the focus groups, please specify:	__________________________________
With which gender do you identity?	○ Female ○ Male ○ Non-binary ○ Prefer not to say ○ Other
Which State or Territory of Australia do you currently reside in?	○ Australian Capital Territory ○ New South Wales ○ Northern Territory ○ Queensland ○ South Australia ○ Tasmania ○ Victoria ○ Western Australia ○ Outside of Australia
Do you identify as Aboriginal and/or Torres Strait Islander?	○ No ○ Yes, Aboriginal ○ Yes, Torres Strait Islander ○ Yes, both Aboriginal and Torres Strait Islander

Have you read or used the previously published 'National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (2018)?	○ Yes ○ No
What is your age?	○ 18-25 years ○ 26 years or older
You indicated that you are an 'Autistic person/person on the autism spectrum'. Are you happy to tell us about your diagnosis?	○ Yes ○ No
Which of the following best describes your circumstances?	○ I have been given a formal diagnosis of autism (or a related diagnosis e.g., Asperger's, Pervasive-Developmental Disorder) by one or more qualified health practitioners (e.g., paediatrician, clinical psychologist, psychiatrist) ○ I am currently being assessed for a possible diagnosis of autism ○ I self-identify as autistic/person on the autism spectrum, but have not been given a formal diagnosis by a health practitioner
At what age did you receive a formal diagnosis of autism?	__________________________________
What was your diagnosis (e.g., Autism Spectrum Disorder, Asperger's)?	__________________________________
At the time you were diagnosed, what level of support did you need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
What level of support do you currently need to participate in everyday activities?	○ Level 1 - Requires support ○ Level 2 - Requires substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
You indicated that you are a parent, caregiver, or family member of an autistic person/person on the autism spectrum: are you happy to tell us more about your family member on the autism spectrum? Please note: we will ask you to focus on just one family member at a time.	○ Yes ○ No
What is your relation to this particular family member? (e.g., parent, caregiver, sibling, grandparent)	__________________________________
What is the age of this particular family member?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)

Has your family member received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ Yes ○ No
At what age was your family member diagnosed?	__________________________________
At the time your family member was diagnosed, what level of support did they need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when they were diagnosed ○ It is the level I think was appropriate at the time they were diagnosed
Do you wish to provide details for another family member on the autism spectrum?	○ Yes ○ No
What is your relation to this particular family member? (e.g., parent, caregiver, sibling, grandparent)	__________________________________
What is the age of this particular family member?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)
Has your family member received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ Yes ○ No
At what age was your family member diagnosed?	__________________________________
At the time your family member was diagnosed, what level of support did they need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when they were diagnosed ○ It is the level I think was appropriate at the time they were diagnosed
Do you wish to provide details for another family member on the autism spectrum?	○ Yes ○ No
What is your relation to this particular family member? (e.g., parent, caregiver, sibling, grandparent)	__________________________________

What is the age of this particular family member?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)
Has your family member received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ Yes ○ No
At what age was your family member diagnosed?	________________________________
At the time your family member was diagnosed, what level of support did they need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when they were diagnosed ○ It is the level I think was appropriate at the time they were diagnosed
Do you wish to provide details for another family member on the autism spectrum?	○ Yes ○ No
What is your relation to this particular family member? (e.g., parent, caregiver, sibling, grandparent)	________________________________
What is the age of this particular family member?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)
Has your family member received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ Yes ○ No
At what age was your family member diagnosed?	________________________________
At the time your family member was diagnosed, what level of support did they need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when they were diagnosed ○ It is the level I think was appropriate at the time they were diagnosed
Do you wish to provide details for another family member on the autism spectrum?	○ Yes ○ No

What is your relation to this particular family member? (e.g., parent, caregiver, sibling, grandparent)	__________________________________
What is the age of this particular family member?	○ 0-12 years (child) ○ 13-17 years (adolescent) ○ 18-25 years (young adult) ○ 26 years or older (adult)
Has your family member received a formal diagnosis of autism (or a related condition e.g., Asperger's, Pervasive Developmental Disorder)?	○ Yes ○ No
At what age was your family member diagnosed?	__________________________________
At the time your family member was diagnosed, what level of support did they need to participate in everyday activities?	○ Level 1 - Required support ○ Level 2 - Required substantial support ○ Level 3 - Required very substantial support ○ I am unsure ○ I would prefer not to say
How did you decide on this level?	○ It was the level the practitioner assigned when they were diagnosed ○ It is the level I think was appropriate at the time they were diagnosed
You indicated that you are a practitioner: are you happy to tell us more about your experience with assessment and/or diagnosis of autism?	○ Yes ○ No
How are you currently involved in assessment and/or diagnosis of autism? (select all that apply)	☐ I refer individuals with possible autism for assessment ☐ I conduct assessments that are relevant to considering an autism diagnosis ☐ I conduct assessments and diagnose autism ☐ I provide services to individuals once they have received an autism diagnosis ☐ Other
As you selected 'Other' please specify how you are involved in assessment and/or diagnosis of autism?	____
How many years of experience do you have in the assessment and/or diagnosis of autism? Please use the year you started and the year you finished/present time to calculate this. For example, if you started being involved in assessment and/or diagnosis in 2018, and are still involved currently (2022), you would answer 4 years, even if there were some career breaks.	__________________________________
Which of the following are you (or have you been) involved in, as part of your practice in the assessment and/or diagnosis of autism (select all that apply)	☐ Medical evaluation ☐ Assessment of functioning ☐ Single clinician diagnostic evaluation ☐ Consensus team diagnostic evaluation ☐ None of these

How many years of experience do you have working in clinical practice with autistic people/people on the autism spectrum? Please use the year you started and the year you finished/present time to calculate this. For example, if you started working with individuals on the autism spectrum in 2018, and are still involved currently (2022), you would answer 4 years, even if there were some career breaks.	__________________________
Across your career to date, what age groups have you provided autism assessment and/or diagnostic services to?	☐ 0-12 years (children) ☐ 13-17 years (adolescents) ☐ 18-25 years (young adults) ☐ 26 years and older (adults) ☐ I do not provide assessment and diagnostic services to people on the autism spectrum
In which of the following service settings do you practice? (select all that apply)	☐ Private, including non-government organisations ☐ Government organisations (e.g., hospital and health services)
In which of the following settings do you currently provide assessment and/or diagnostic services? (select all that apply)	☐ Hospital (inpatient/outpatient) ☐ Community clinic (including private practice) ☐ University clinic (includes providing services as part of student training and research) ☐ None ☐ Other
As you selected 'Other', please specify the setting(s):	__________________________

Update of the National Guideline for the Assessment and Diagnosis of Autism in Australia

Appendix 6.2	Focus group PowerPoint presentation

Update of the National Guideline for Assessment and Diagnosis of Autism in Australia

Community Consultation: Focus Groups

AutismCRC

Acknowledgement of Country

Overview

- Housekeeping
- Guideline update
    - What?
    - Why?
    - Who is involved?
- Understanding and expectations for focus groups

This focus group is being recorded so that we can transcribe and analyse the information the group provides.

The recording ***will not*** be used for any other purpose.

We ***will not*** use anyone’s name or other identifying information when share the updated National Guideline.

AutismCRC

Housekeeping

- Introducing the facilitators
- Schedule
  - Introduction and house keeping (15 mins)
  - Focus questions (90 mins)
  - Summary and next steps (15 mins)
- Video/audio/chat options
- Tech Support
- Key ethical considerations (consent, privacy, seeking support)

Updating the National Guideline

What is happening?

We are completing a planned, periodic update of the National Guideline for Assessment and Diagnosis in Australia.

This will involve:

1. Reviewing the latest research evidence (published since 2018)
2. Community consultation involving online survey and focus groups
3. Public consultation on the updated Guideline (2023)

Updating the National Guideline

Why is it happening?

We need to ensure that the Guideline ***continues to be relevant*** to autistic people, their families, and practitioners who are involved in assessment and diagnosis.

We need to ensure that the Guideline continues to be ***evidence-based***, reflecting the best available evidence and community preferences and priorities, and as expected by the *National Health and Medical Research Council*.

AutismCRC

Updating the National Guideline

Who is involved:

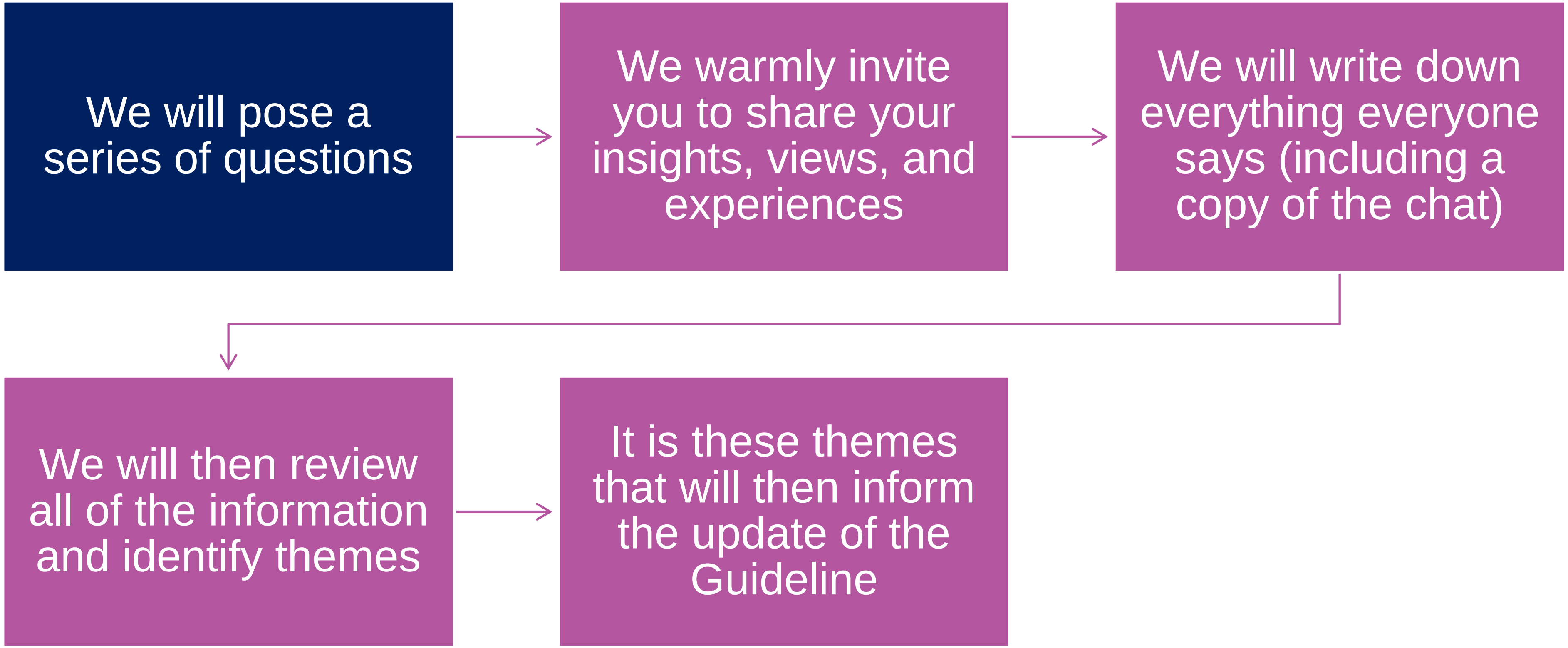
The Guideline Development Group leads the process.

A Reference Group representing peak bodies and organisations provides feedback.

All members of the autistic and autism communities are warmly invited and encouraged to contribute to the community consultation and public consultation.

AutismCRC

How will my involvement today help?



We will pose a series of questions

We warmly invite you to share your insights, views, and experiences

We will write down everything everyone says (including a copy of the chat)

We will then review all of the information and identify themes

It is these themes that will then inform the update of the Guideline

AutismCRC

How will my involvement today help?

We will pose a series of questions

We warmly invite you to share your insights, views, and experiences

We will write down everything everyone says (including a copy of the chat)

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AutismCRC

How will my involvement today help?

We will pose a series of questions

We warmly invite you to share your insights, views, and experiences

We will write down everything everyone says (including making a copy of the online chat)

We will then review all of the information and identify themes

It is these themes that will then inform the update of the Guideline

AutismCRC

How will my involvement today help?

We will pose a series of questions

We warmly invite you to share your insights, views, and experiences

We will write down everything everyone says (including a copy of the chat)

We will then review all of the information and identify themes

It is these themes that will then inform the update of the Guideline

AutismCRC

How will my involvement today help?

We will pose a series of questions

We warmly invite you to share your insights, views, and experiences

We will write down everything everyone says (including a copy of the chat)

We will then review all of the information and identify themes

It is these themes that will then inform the update of the Guideline

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What if I have questions about the Guideline?

Website:

https://www.autismcrc.com.au/access/national-guideline

Email:

guidelines@autismcrc.com.au

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Understanding and Expectations

You have volunteered your time because you want to make a difference

We are privileged to have people with diverse views and experiences joining

We want to ensure that everyone has the opportunity contribute and feels safe and supported

A positive and productive focus group

- As facilitators we will ensure:
  - On topic
  - On time
  - Everyone has a chance to share

- As facilitators, we are here to listen, not to comment or answer questions

- As participants, we ask that you please:
  - Stay on topic
  - Keep your comments relatively brief, so that more people have a chance to talk/share
  - Help us create a safe and supportive space, including respecting other people's views and experiences
  - Avoid naming specific people, practitioners, and service providers
  - Maintain the privacy of others during and following the group

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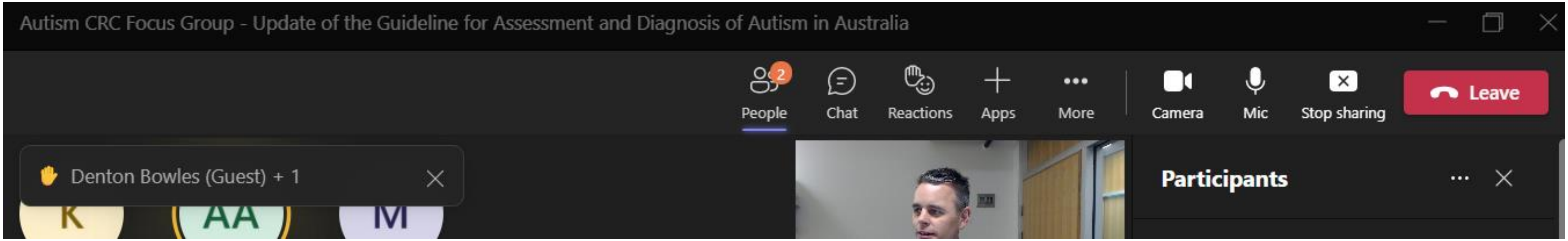
Autism CRC Focus Group - Update of the Guideline for Assessment and Diagnosis of Autism in Australia

Denton Bowles (Guest) + 1

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Please keep in mind…

This is a Guideline for practitioners.

This means we want to focus our discussion today on **what practitioners can do** to help ensure assessment and/or diagnosis is timely, accurate, and supportive.

There are many related issues, that are very important, but that are beyond the scope of the Guideline. These include:
- The cost of assessments, and how they should be funded.
- The need for more practitioners, including in regional and remote areas.
- The different roles of State and Federal Government departments and agencies (e.g., health, education, National Disability Insurance Agency)

We warmly encourage everyone to focus on the role of practitioners, to make the best use of the time available today.

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The questions we will ask

In your experience,

1. What is, or was, good about the way assessment and/or diagnosis happens in Australia?

2. What is, or was, bad about the way assessment and/or diagnosis happens in Australia?

3. What would like to see change in the way assessment and/or diagnosis happens in Australia?
    - Thinking to the future
        - What principles are important for the assessment and diagnosis process?
        - What can practitioners do to help ensure the safety and wellbeing of individuals and their families?

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In your experience,

What is, or was, good about the way assessment and/or diagnosis happens in Australia?

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In your experience,

What is, or was, bad about the way assessment and/or diagnosis happens in Australia?

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What would like to see change in the way assessment and/or diagnosis happens in Australia?

Thinking to the future:

- What principles are important for the assessment and diagnosis process?
- What can practitioners do to help ensure the safety and wellbeing of individuals and their families?

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Summary and Next Steps

- Reflections on discussion
- Next steps
- Acknowledgements

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