AutismCRC

A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia

Administrative and Technical Report

Prof Andrew Whitehouse, Dr Kiah Evans, Prof Valsamma Eapen and A/Prof John Wray

October 2018

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ADMINISTRATIVE AND TECHNICAL REPORT

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Steering Committee

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Ms Jane Bollen (Australian Primary Health Care Nurses Association)

Ms Dianne Brookes (First Peoples Disability Network Australia)

Associate Professor Bob Davis (Royal Australian College of General Practitioners)

Jac den Houting (Autistic Self Advocacy Network of Australia and New Zealand)

Ms Helen Little (Australian Professional Teachers Association)

Mr Jon Martin (Australian Autism Alliance)

Dr Jo McCubbin (National Rural Health Alliance)

Ms Susanne Nelson, who replaced Ms Adele Suda (Occupational Therapy Australia)

Ms Nicole Rogerson (Autism Awareness)

Dr Jacqueline Small (The Royal Australasian College of Physicians – Paediatrics & Child Health Division)

Ms Robyn Stephen (Speech Pathology Australia)

Professor Julian Trollor and Professor Valsamma Eapen (Royal Australian and New Zealand College of Psychiatrists)

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The guideline was developed and is published by Autism CRC Ltd (www.autismcrc.com.au).

The authors and Autism CRC acknowledge the support of the National Disability Insurance Agency in the development of the Guideline, 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. Andrew Whitehouse, Valsamma Eapen, Margot Prior and John Wray received no personal financial or other remuneration for their involvement in this project.

The authors also acknowledge the support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centre Program. Staff and non-staff in kind were provided by Autism CRC participants.

ISBN: 978-0-9953736-2-4

Suggested citation: *Whitehouse AJO, Evans K, Eapen V, Wray J. A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia – Administrative and technical report. Cooperative Research Centre for Living with Autism, Brisbane, 2018.*

Associated documents

- National Guideline: Full Guideline (Register to access)
- National Guideline: Summary and Recommendations
- National Guideline: Evidence Tables
- National Guideline: Responses to Public Consultation Submissions

Contents

Acknowledgements

We would like to thank the many individuals with lived and/or professional experience of the ASD diagnostic process who volunteered their time to share their insights throughout the development of Australia's first national guideline for autism diagnosis.

We also acknowledge the contribution of the following people and organisations:

Steering Group: Dr Josephine Barbaro, Ms Jane Bollen, Ms Dianne Brookes, Associate Professor Bob Davis, Jac den Houting, Professor Valsamma Eapen, Ms Helen Little, Dr Janine Manjiviona, Mr Jon Martin, Dr Jo McCubbin, Ms Susanne Nelson, Ms Nicole Rogerson, Dr Jacqueline Small, Ms Robyn Stephen, Ms Adele Suda and Professor Julian Trollor.

Research assistance: Research assistance was provided by the Autism Research Team at Telethon Kids Institute, particularly Ms Angela Stojanoska, Ms Bahareh Afsharnejad, Ms Rebekka Jooste, Ms Sarah Pillar, Dr Diana Tan, Ms Joanna Granich, Ms Alexis Harun, Ms Brooke Peden, Ms Ciara Morrison, Ms Marisa Schonwolf, Ms Anna Schmid, Ms Isabella Atlas and Mr Adam Zeller.

We also acknowledge the contribution of two research students, Ms Emily D'Arcy and Mr Matthew De Broize, and their supervisors at Curtin University (Dr Marita Falkmer, Professor Torbjorn Falkmer and Associate Professor Sonya Girdler) and University of Queensland (Dr Anna Urbanowicz).

Methodological assistance: The rigour of the Guideline was enhanced through input of methodological experts at Telethon Kids Institute (Dr Jenny Downs, Professor Carol Bower, Professor Donna Cross and Ms Melanie Epstein), Curtin University (Dr Marita Falkmer and Associate Professor Sonya Girdler) and the University of Western Australia (Ms Karen Jones).

Further assistance: Support for the workshop consultations was provided by the Autism Association of WA, the Association of Independent Schools of Queensland, the University of New South Wales, and the Royal Children's Hospital in Melbourne. Kelly Somers provided assistance in copyediting the final documents.

We thank Dr Emma Goodall for providing the cover art for this document, titled *The Disconnect in the Infinity of Neurodiversity*. This artwork is described as:

> 'Hidden under the layers of the ¾ of an infinity symbol are a normal distribution curve, a brain and branches seeking connection from a brain/person to an anchor. The ¾ infinity symbol also more explicitly shows the variety within the spectrum but the gaps in knowledge and connections.'

This project was supported by funding from the National Disability Insurance Agency. The views of the funding body did not influence the Guideline.

1. Introduction

1.1 Background

In 2014, a review of autism spectrum disorder (ASD) diagnostic practices in Australia was jointly commissioned by the Cooperative Research Centre for Living with Autism (Autism CRC) and the Commonwealth Department of Social Services [1]. A key finding from this report was the considerable variability between states in diagnostic practices, including the quality and quantity of assessments administered, the professionals involved and the required experience of these professionals. The report concluded that this variability was highly likely to have contributed to uneven service provision across the states and confusion among clients undergoing diagnostic assessment.

The main recommendation of the report was:

> 'Adopting a minimum national standard for ASD diagnosis across Australia would improve diagnostic practices and consistency across the country, and ensure that future diagnostic assessments are in keeping with best practice Guidelines.'

In June 2016, the National Disability Insurance Agency (NDIA) of Australia commissioned the Autism CRC to develop Australia's first national Guideline for ASD diagnosis in Australia (hereafter, 'the Guideline') under the terms of a Collaboration Agreement between the two organisations. Autism CRC formed a Research Executive team to independently develop and publish the Guideline. The NDIA provided the funding for guideline development, publication and dissemination. This financial support covered salary costs for the project coordinator (Dr Kiah Evans) and several part-time research assistants, direct public consultation expenses and an honorarium to the Steering Committee members. Other members of the Research Executive (Professor Andrew Whitehouse, Professor Valsamma Eapen, Professor Margot Prior and Clinical Associate Professor John Wray) received no personal financial or other remuneration for their involvement in this project. Extensive in-kind support was provided by the Research Executive, research students, research supervisors, research assistants, methodological experts, consultative workshop hosts and the many individuals who participated in the research projects and feedback processes. The views of the NDIA have not influenced the content of the Guideline.

1.2 Objectives

The aim of this project was to develop a national guideline for ASD diagnosis in Australia. The objectives were to develop a guideline that:

(1) describes a rigorous framework for accurately determining whether an individual meets diagnostic criteria for ASD

(2) outlines a comprehensive approach to identifying 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.

1.3 Research Executive

Professor Andrew Whitehouse was appointed by the NDIA and Autism CRC as Chair of the Research Executive team. Dr Kiah Evans was subsequently employed as the Coordinator and Secretary of this team. Professor Valsamma Eapen, Professor Margot Prior and Clinical Associate Professor John Wray were engaged as clinical and research experts within the team. Collectively, this Research Executive team holds substantial and varied research, clinical and project experience relevant to the development of a guideline for ASD diagnosis (Table 1).

The Research Executive was a working committee created to conduct the background research (including the community consultation) and prepare documents for the development of the Guideline. The Research Executive existed for the duration of the project and met approximately bimonthly by teleconference, with additional communication via email and document review. In carrying out its duties, the Research Executive had authority to recommend and endorse preliminary and final models and recommendations relating to the diagnosis of ASD, as required to establish the Guideline.

The responsibilities of the Research Executive were to:

- ensure the development of the Guideline was consistent with best practice
- establish a Steering Committee
- ensure proper and timely communication with the Management and Steering committees
- establish, implement and monitor the project management process and documents
- conduct all research activities, including designing research methods/documents, reviewing literature, obtaining ethics approval, collecting data, analysing/interpreting data and summarising findings
- prepare the literature review report, research summary reports, various guideline versions and launch presentations
- prepare manuscripts describing the research findings and submit to peer-reviewed journals.

The Terms of Reference for the Research Executive (Appendix A) set out the declaration process for conflicts of interest (outcomes are described in Section 2.4), along with intellectual property, confidentiality and authorship requirements.

A Management Committee provided high-level oversight of the guideline development process. The Management Committee comprised representatives from the NDIA (Peter di Natris and Sarah Johnson) and Autism CRC (Andrew Davis) as well as the Research Executive Chair (Andrew Whitehouse) and Coordinator (Kiah Evans). The Management Committee met every 4-5 months (four occasions throughout the duration of the project), where the representatives from the NDIA and Autism CRC provided feedback to the project Chair and Coordinator on study progress. The Terms of Reference relating to the Management Committee are covered by a Collaborative Agreement between the NDIA and Autism CRC, and further information on the editorial independence of the Research Executive from the Management Committee is provided in Section 9.5 of this report.

Table 1. Members of the Research Executive

Name (role) **Discipline** **Institution** **Location**	**Expertise**
Professor Andrew Whitehouse (Chair) Speech Pathologist Telethon Kids Institute, the University of Western Australia and Autism CRC Western Australia	Professor Whitehouse is the Chief Research Officer of Autism CRC and Head of the Autism Research Team at Telethon Kids Institute. Professor Whitehouse originally trained and practised as a speech pathologist before becoming a full-time researcher. He has been directing the Autism Research Team at the Telethon Kids Institute since 2009, having arrived back in Western Australia from the University of Oxford, where he was the Scott Family Junior Research Fellow for Studies in Autism. Professor Whitehouse has been awarded competitive research funds from national and international funding bodies exceeding $40 million and he is currently funded by an NHMRC Senior Research Fellowship. He has over 150 publications (with approx. 5,000 citations), primarily on the topic of ASD.
Dr Kiah Evans (Coordinator) Occupational Therapist Telethon Kids Institute, Curtin University and Autism CRC Western Australia	Dr Evans is a Project Coordinator and Senior Research Officer in the Developmental Disorders Research Group at Telethon Kids Institute. Dr Evans has a Graduate Certificate in Research Commercialisation, including completion of a project management unit. She also has varied experience in research management and leading program implementation projects. Dr Evans has experience in a wide range of quantitative and qualitative research methods, gained through completion of a doctoral degree. She has undertaken research examining the experiences of individuals with ASD and their parents.
Professor Valsamma Eapen Psychiatrist University of New South Wales and Autism CRC New South Wales (NSW)	Professor Eapen is a child psychiatrist at The Delta Clinic, and is Professor and Chair of Infant, Child & Adolescent Psychiatry at the University of New South Wales. Professor Eapen has clinical expertise as a child psychiatrist assessing and treating children with autism spectrum disorder, along with research and teaching expertise in neurodevelopmental disorders (including ASD). Professor Eapen has successfully secured research funding of approximately $34 million in the past five years. She has 143 publications (with approximately 2,100 citations), many of which are on the topic of ASD.
Professor Margot Prior (Retired) University of Melbourne and LaTrobe University Victoria	Professor Prior holds positions with the University of Melbourne and with LaTrobe University. She has extensive research expertise in childhood learning and psychosocial problems, including a focus on autism and social inequalities in children's health and well-being. In addition, Professor Prior's past clinical work covering 45 years was with children and families from all walks of life and with a wide range of problems. She also worked with Aboriginal families and children on a voluntary basis for 12 years. She has over 300 publications (with approximately 5,200 citations).

Clinical Associate Professor John Wray Developmental Paediatrician Child Development Service (Health Department of WA) and University of Western Australia Western Australia	Clinical Associate Professor Wray is a developmental paediatrician and Senior Clinical Advisor at the Child Development Service of Western Australia, and is a developmental paediatrician at McCourt Street Paediatrics. Clinical Associate Professor Wray has clinical expertise assessing and treating children with autism spectrum disorder, along with expertise in research and establishing best practice standards for the diagnosis of ASD. He has over 20 publications (with approximately 250 citations), with the majority on the topic of ASD.

1.4 Research Questions

The Research Executive established a series of questions to direct the literature review, community consultation and guideline structure:

(1) What guiding principles should be followed when undertaking an assessment of ASD concerns?

(2) What activities are within the scope of an assessment of ASD concerns?

(3) What are the roles and responsibilities of members of the Assessment Team?

(4) What settings are appropriate for an assessment of ASD concerns?

(5) How should an assessment of ASD concerns be initiated?

(6) What process is required to accurately determine if the diagnostic criteria for ASD have been met or not? Specifically:

   a. Who should be involved in the Diagnostic Evaluation?
   b. Where should the Diagnostic Evaluation take place?
   c. What information should be collected during a Diagnostic Evaluation?
   d. How should information be collected during a Diagnostic Evaluation?
   e. How should information be used to reach a diagnostic decision?

(7) What process is required to holistically determine level of functioning and related support needs? Specifically:

   a. Who should be involved in the Assessment of Functioning?
   b. Where should the Assessment of Functioning take place?
   c. What information should be collected during an Assessment of Functioning?
   d. How should information be collected during an Assessment of Functioning?
   e. How should information be utilised to formulate recommendations to meet support needs?

(8) How should the findings of an assessment of ASD concerns be shared?

(9) How should an assessment of ASD concerns be tailored to meet the requirements of individuals from specific populations where the assessment of ASD concerns process is more complex? Specifically in relation to individuals of different:

   a. age
   b. intellectual and/or communication capacity
   c. gender
   d. cultural or language background
   e. regional or remote location
   f. medical complexity.

(10) What strategies can be put in place to ensure time and financial resources are utilised efficiently?

1.5 Research Process

Evidence was sought from a variety of sources, including literature reviews of scholarly articles and the collection of data from a series of community consultation projects (Figure 1). The methodologies used to collect and analyse this research evidence are described in detail in Chapters 3–8.

Approval was obtained from the Human Ethics Office at the University of Western Australia in December 2016 to undertake the Steering Committee and community consultation activities (RA/4/1/8709 and RA/4/1/8711). All participants were provided with a Participant Information Form and all provided informed consent.

The community consultation activities had a dynamic webpage that was hosted by Autism CRC: http://www.autismcrc.com.au/national-Guideline-autism-diagnosis-australia. Through this webpage community members could register their interest in participating in the consultation process and be updated about the guideline development progress. As of 16 July 2017, 1,098 people had registered their interest, predominantly parents of, and service providers to, individuals on the autism spectrum.

Along with these registrants being invited to participate in the consultation process, additional participants were recruited through the broader promotion of the community consultation activities through Autism CRC participant organisations, peak bodies, support groups, professional networks and broader media engagements (e.g. press releases, radio/television appearances and social media posts). The process involved recruitment efforts targeted at people on the autism spectrum, with flexible options to provide input, so as to increase the number of participants on the autism spectrum. Participants from an Aboriginal and/or Torres Strait Islander background were also intentionally sought. Participants were recruited for an eight-month period from late December 2016 until late August 2017.

Please note that identity-first language, such as ‘autistic children’, is often the preferred language of many people on the autism spectrum and their parents [1]. The Guideline uses the terminology of children/adults/individuals ‘on the autism spectrum’ to refer to people with a diagnosis of ASD. It is recognised that clinicians and the broader community may have their own terminology preferences, which they may use according to their own judgement.

Figure 1. Sources of research evidence used to develop the Guideline

1.6 Target Users

The primary target users of this Guideline are Australian clinicians who conduct clinical assessments that may result in an ASD diagnosis. This Guideline can be used by these clinicians to inform the process for completing an assessment of ASD concerns and making clinical decisions related to ASD diagnosis and support needs.

Secondary target users of this Guideline include the following groups:

- Australians who have behaviours that may be explained by an ASD diagnosis (and/or their caregivers) can use this Guideline to understand how to initiate, and what to expect from, an assessment of ASD concerns.
- Australian medical, allied health and education professionals and organisations who work with children or adults who are experiencing signs and symptoms that may be explained by an ASD diagnosis can use this Guideline to gain sufficient knowledge to initiate a referral for an assessment of ASD concerns.
- Australian medical, allied health and education professionals and organisations who work with individuals with an ASD diagnosis can use this Guideline to gain an understanding of what an assessment of ASD concerns involves to ensure recommendations are implemented and duplication of services is avoided.
- 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 conduct assessments of ASD concerns.
- Australian public and private funding bodies can use this Guideline to align resource allocation with the recommended assessment of ASD concerns process.

2. Steering Committee

2.1 Terms of Reference

A Terms of Reference document (Appendix B) was developed by the Research Executive and approved by the Management Committee, where the purpose of the Steering Committee was articulated as guiding the development of a national guideline for ASD diagnoses in Australia. The Steering Committee existed for the duration of the project and comprised up to twenty members from Australian national peak body organisations selected to represent stakeholders involved in ASD diagnosis. The Steering Committee was chaired by Professor Andrew Whitehouse.

The Terms of Reference specified that the Steering Committee would meet by teleconference at least three times during the one-year project duration and that members could nominate a proxy to attend a meeting on their behalf. The Steering Committee had the authority to recommend and provide feedback on recommendations relating to the diagnosis of ASD, as required to establish the Guideline. The Steering Committee did not have the authority to make decisions regarding recommendations for, or endorsement of, the published Guideline.

The responsibilities of the Steering Committee were to:

- provide feedback on the proposed process for developing the Guideline
- give input on documents and components to be included in the literature review
- nominate experts within their peak body to participate in the consultative phase of the project
- advise on the essential components to include in the Guideline
- provide feedback on draft versions of the Guideline.

The Terms of Reference for the Steering Committee set out the declaration process for conflicts of interest (described in Section 2.4), along with intellectual property, confidentiality and authorship requirements.

2.2 Recruitment

Following an initial scan of the international guidelines [e.g. 2, 3] and discussion among the Research Executive members, a list of the relevant stakeholder groups and associated national peak bodies was prepared. These stakeholder groups advocated for clients and/or professionals involved in the diagnosis and management of ASD.

A letter was sent via email to the president or chief executive officer of each national peak body, followed by a telephone call if a response was not received. This contact introduced the national guideline project and invited the organisation to nominate and provide contact details for a representative meeting the following criteria:

- a member of the organisation
- has substantial knowledge of the ASD diagnostic process
- committed to representing the collective perspective of members
- agrees to meet all conditions outlined in the Terms of Reference
- available to attend the scheduled teleconference meetings (meeting details provided).

All national peak bodies, with the exception of the Australian Association of Social Workers, accepted the invitation to nominate a representative.

On receiving contact details for the nominated representative, a letter was sent via email and post to the nominee. This letter introduced the national guideline project and contained the Terms of Reference and meeting details. The nominees were invited to provide a brief summary (approximately 100 words) outlining their expertise in the ASD diagnostic process and to complete the NHMRC Form for Disclosure of Interests (Guideline Development). Nominees were advised that this information

would be shared with other prospective members of the Steering Committee and possibly made publicly available online and in the published guideline documents.

A document was compiled with the expertise and declared interests of each prospective Steering Committee member (including Research Executive members). This document was shared among the nominees, with an invitation to update their own information or comment on information about other individuals. No concerns were expressed in relation to potential Steering Committee members and all members were officially appointed by the Chair during the second Steering Committee meeting.

Following the initial round of invitations, several gaps were identified within the Steering Committee composition. Two national peak bodies were subsequently invited to nominate a second representative with a specific skill set. The Royal Australian and New Zealand College of Psychiatrists was invited to nominate an adult psychiatrist and the Australian Psychological Society was invited to nominate a psychologist who had practice endorsement in clinical psychology. Furthermore, the Occupational Therapy Australia representative was replaced due to personal reasons. The same appointment process was followed for these new members. The Steering Committee comprised the Research Executive members (Chapter 1) and the members outlined in Table 2.

All Steering Committee members provided informed consented to take part in the overarching research project. National peak bodies were paid a total of $900 in compensation for providing a representative to sit on the Steering Committee, in recognition that Steering Committee members were required to spend time reviewing documents and attending teleconference meetings. National peak bodies were responsible for determining if this payment was subsequently distributed to the individual Steering Committee member or if the payment was retained by the national peak body.

Table 2. Client and professional representation on Steering Committee

Stakeholder group	National peak body	Representative	Location
Individuals on the autism spectrum	Autistic Self Advocacy Network of Australia and New Zealand	Jac den Houting	Qld
Individuals with an Aboriginal or Torres Strait Islander background	First Peoples Disability Network Australia	Ms Dianne Brookes	NSW
Individuals and service providers living in a rural or remote area	National Rural Health Alliance	Dr Jo McCubbin	Vic
ASD-specific service providers	Australian Autism Alliance	Mr Jon Martin	SA
General practitioners	Royal Australian College of General Practitioners	A/Prof Bob Davis	Vic
Occupational therapists	Occupational Therapy Australia	Ms Adele Suda* Ms Susanne Nelson	Qld Vic
Nurses	Australian Primary Health Care Nurses Association	Ms Jane Bollen	SA
Paediatricians	The Royal Australasian College of Physicians – Paediatrics & Child Health Division	Dr Jacqueline Small	NSW
Psychiatrists	Royal Australian and New Zealand College of Psychiatrists	Prof Julian Trollor Prof Valsamma Eapen	NSW NSW

Psychologists	Australian Psychological Society	Dr Josephine Barbaro Dr Janine Manjiviona	Vic Vic
Speech pathologists	Speech Pathology Australia	Ms Robyn Stephen	Vic
Teachers	Australian Professional Teachers Association	Ms Helen Little	Qld
** Ms Nelson replaced Ms Suda as the representative for Occupational Therapy Australia.*			

2.3 Expertise

The Steering Committee comprised individuals with a broad range of expertise gained from lived experience and/or professional involvement in clinical, research and policy settings (Table 3).

Table 3. Expertise of the Steering Committee members

Representative	Expertise
Jac den Houting	Jac den Houting is a psychologist and is very familiar with broad diagnostic processes for mental illness and neurodevelopmental conditions, including ASD. Regarding autism diagnosis specifically, she is knowledgeable of the current 'gold standard' for autism diagnosis, along with other screening tools which are often utilised in diagnostic assessments for autism. She is currently undertaking her PhD with Autism CRC on anxiety and academic achievement in students on the autism spectrum. In addition, Jac den Houting has personal experience of the diagnostic process from the perspective of a client, through her own autism diagnostic assessment at the age of 25 years. She has since established herself as a strong advocate for the autism community, with a special focus on mental health, girls'/women's sexuality, gender identity and the criminal justice system in the autism community.
Ms Dianne Brookes	Ms Brookes is an executive member of the First Peoples Disability Network Australia team. She is well versed in knowledge of the National Disability Insurance Scheme and how the scheme aims to support individuals to be the best they can be in their community. Personally, Ms Brookes is a mother of a young woman who lives within the spectrum.
Dr Jo McCubbin	Dr McCubbin is a regional paediatrician based in Gippsland, where she has lived and worked for nearly 25 years since completing training at the Sydney Children's Hospital. She has a son who is a speech pathology student, having enjoyed work experience with local allied health professionals. Her work is mainly with children and teenagers with developmental and behavioural issues. She regularly contributes to network meetings with allied health, mental health and school support teams in different East Gippsland towns.
Mr Jon Martin	Mr Martin was CEO of Autism SA for 11 years and has over 30 years of experience working with the autism community. Mr Martin is a registered psychologist and has conducted research and delivered clinical services, including diagnostic assessments. He recently established his own consulting business and private practice and is currently undertaking

	project work with the Australian Autism Alliance. Mr Martin was Chair of National Disability Services (NDS) State Committee for South Australia and a Director on the NDS Board. He was previously a Director/Chair of the Australian Advisory Board on Autism Spectrum Disorders. He participated in the successful bid team for the world's first Autism Co-operative Research Centre, was Convenor of the third Asia Pacific Autism Conference (APAC 13) and was National Project Manager for the Australian Autism Register Proposal in 2009.
Ms Nicole Rogerson	Ms Rogerson is the founding Director of Autism Awareness Australia. She volunteers her time as CEO and is one of the nation's leading advocates for the awareness and understanding of autism spectrum disorder. She has led many campaigns and events that have inspired, touched and educated Australians, including Light It Up Blue for World Autism Awareness Day, production of a short film 'What are you doing?' for school children, and three television community service announcements. Ms Rogerson is one of the most passionate voices on the challenges of autism in Australia, having hosted numerous seminars, advised the federal government, presented to the United Nations and through numerous media reports. She was also the former founder and Director of the Lizard Centre.
A/Prof Bob Davis	Adjunct Associate Professor Bob Davis was founding Director of the Centre for Developmental Disability Health Victoria from 1998 to 2013 and is its current Clinical Director. He sees adults with developmental disability, many of whom have undiagnosed ASD. He was founding president of the Australian Association of Developmental Disability Medicine, chaired the Disability Working Group for the RACGP curriculum and lobbied successfully for adoption of the Medicare item for the Health Assessment of People with Intellectual Disability. In 2014 Adjunct Associate Professor Davis was awarded the General Practitioner Award at the Victorian Minister for Health General Practice Awards. He is the current chair of the RACGP Disability Network.
Ms Adele Suda (retired)	Ms Suda is a senior occupational therapist and Lecturer at Southern Cross University. She has worked for over 22 years with children and their families that have a diagnosis of ASD. She is currently a PhD candidate with the University of Sydney studying family well-being for families that include an autistic child. Her clinical experience with autistic children has seen her involved in the diagnostic process at all levels including assessment, multidisciplinary team approach, intervention and outcomes. She has extensive experience in working within child/family-centred models of practice that is rigorous, evidence based and holistic.
Ms Susanne Nelson	Ms Nelson has 16 years of clinical experience (specifically in paediatrics and autism spectrum disorders) and 8 years as the Director of Susanne Nelson and Associates (SNAA). SNAA provides an occupational therapy outreach service in Melbourne for families whose children have been diagnosed or have suspected ASD. The SNAA therapists have close professional contacts within the ASD field and the team is often referred children in the early process of a diagnosis to support the assessment process. The SNAA therapists adopt a holistic and functional perspective when working closely with the children in their natural environments and

	case manage this early journey for the families, supporting them pre and post assessment/diagnosis. Ms Nelson is also a member of Occupational Therapy Australia, Autism Victoria and a facilitator of the Camberwell Mental Health Network for professionals (ASD specific group).
Ms Jane Bollen	Ms Bollen is a registered nurse and works in a general practice in Belair in the Adelaide Hills. Ms Bollen has recently completed 7 months working as a research surveyor for Macquarie University in the Caretrack Kids study, examining the appropriateness and safety of health care for children. Ms Bollen also works as a healthcare consultant for BMP Healthcare Consulting. In this role Ms Bollen works with nurses in general practice to help with care-planning as well as helping them understand their practice data to improve the health of the practice population. Ms Bollen's background of nursing and accounting plus a focus on systems and organisation has helped many general practices improve the use of personnel, the quality of care and the business outcomes. Ms Bollen is currently an active member of the APNA Board.
Dr Jacqueline Small	Dr Jacqueline Small MBBS MPH (Hons) FRACP is a developmental paediatrician who has worked in a multidisciplinary diagnostic and assessment team for nearly 20 years, Disability Specialist Unit (DSU), Sydney Children's Hospital Network. DSU provides services for children with a range of developmental disabilities, including ASD. She is also President, Australian Association Developmental Disability Medicine, Chair, Paediatric Policy and Advocacy Committee, RACP and Co-chair Access and Equity subcommittee, Agency of Clinical Innovation – Intellectual Disability Network. She is leading a project to evaluate the use of visuals in paediatric health care, an initiative that will benefit children on the autism spectrum.
Prof Julian Trollor	Professor Trollor is a neuropsychiatrist at the University of New South Wales, where he is the Chair of Intellectual Disability Mental Health and Head of the Department of Developmental Disability Neuropsychiatry within the School of Psychiatry. Professor Trollor has a special research interest in mental health of adults on the autism spectrum and leads the 'Australian Longitudinal Study of Adults with Autism Spectrum Conditions' project for Autism CRC. Professor Trollor is involved in diverse research and training programs in mental health and intellectual disability. He also works with government departments to improve capacity to deliver psychiatric services to people with an intellectual disability.
Prof Valsamma Eapen	Professor Eapen is currently a child psychiatrist at The Delta Clinic, along with being Professor and Chair of Infant, Child & Adolescent Psychiatry at the University of New South Wales. Professor Eapen has clinical expertise as a child psychiatrist assessing and treating children with autism spectrum disorder, along with research and teaching expertise in neurodevelopmental disorders (including ASD). Professor Eapen has successfully secured research funding of approximately $34 million in the past five years. She has 143 publications (with approximately 2,100 citations), many which are on the topic of autism spectrum disorder.

Dr Josephine Barbaro	Dr Barbaro is a Research Fellow at La Trobe University specialising in the early detection and diagnosis of autism. She conducted Australia's first study on the early detection and diagnosis of autism in 12–24 month old children in the Victorian Maternal and Child Health system between 2006 and 2010. In 2011, she co-established Australia's first Early Assessment Clinic for Autism at La Trobe University, working as both the lead researcher and clinician. She is a Project Leader in Autism CRC focusing on early detection, diagnosis and family well-being following a diagnosis. Over the last 10 years, she has assessed hundreds of children for autism between the ages of 11 and 48 months using gold-standard diagnostic and cognitive instruments (ADOS, ADI-R, Mullen), and has published widely on early detection and diagnosis. She is also completing a Master of Educational and Developmental Psychology at Monash University.
Dr Janine Manjiviona	Dr Manjiviona, a clinical psychologist, worked for the Royal Children's Hospital in Melbourne for nearly 20 years, and is presently in private practice. She specialises in assessment and diagnosis of autism spectrum disorder in infants, children, and adults. She is involved in treatment and management for individuals and families, and also deals with comorbid difficulties, and relationship difficulties within ASD. Dr Manjiviona completed her PhD in autism and provides lectures to the Autism Teaching Institute. Dr Manjiviona has published in the peer-reviewed literature and is well cited, including on neuropsychological profiles, sex differences and the female profile of ASD.
Ms Robyn Stephen	Ms Stephen is a clinical speech pathologist who has been practising for 36 years in a variety of fields. She started her own private practice in 1997, with a wide referral network for ASD assessment and intervention. Her company employs 12 staff and operates out of its own dedicated premises and in professional hospital-based suites. She has an honorary appointment at Royal Children's Hospital in Melbourne conducting ASD assessment in a multidisciplinary team and in parallel discipline assessments. Ms Stephen is Vice President of Speech Pathology Australia, currently serving her fifth year on the board, which has involved advocating at state and federal levels for services for autistic people. She has provided education in health and education sectors about diagnosis and treatment of ASD including study resources, workshops and lecturing positions.

2.4 Declared Interests

The declared interests of the Steering Committee members were recorded and shared among the group to determine if any were potentially competing interests that may affect the guideline development process. Given that the Steering Committee members were purposively recruited due to their expertise in relation to ASD diagnosis (Table 2), it is unsurprising that many members declared a range of relevant financial interests, professional activities and/or relationships related to the guideline development process. Following review by all members, none of these declared interests were deemed to cause a conflict that would bias the resulting Guideline. Each Steering Committee meeting commenced with an invitation for members to declare any new interests that arose during the project. The final declared interests are provided in Table 4.

Table 4. Declared interests of Steering Committee members (including Research Executive members)

Representative	Declared interests
Prof Andrew Whitehouse	Grants • Lead investigator on the National Disability Insurance Agency funded grant for this project – Developing National Standards for Autism Diagnosis (2016). Support for travel or accommodation • Some travel and accommodation support for this project. Meals/beverages • Some meal and beverage support for this project. Other roles • Director of a soon-to-be-established clinical service at the Telethon Kids Institute that may provide diagnostic services for children with neurodevelopmental disorders. This service will open in the first half of 2018. Other relevant financial interests • Co-author of the Communication Checklist – Adult (2009) and Communication Checklist – Self Report (2009) and in receipt of negligible royalties based on sales. Publications • TAYLOR L, BROWN P, EAPEN V, MIDFORD S, PAYNTER J, QUARMBY L, SMITH T, MAYBERY M, WILLIAMS K, WHITEHOUSE A. (2016). Autism spectrum disorder diagnosis in Australia: Are we meeting best practice standards? Cooperative Research Centre for Living with Autism and the Commonwealth Department of Social Services. • TAYLOR L, MAYBERY M, WILLIAMS K, PAYNTER J, EAPEN V, SMITH T, QUARMBY L, WHITEHOUSE A. (2016). Diagnostic evaluation for autism spectrum disorder: A survey of health professionals in Australia. BMJ Open, 6, 1-8. • WHITEHOUSE A. (2017). Rethinking the clinical pathway for autism spectrum disorders: Challenging the status quo. International Journal of Speech-Language Pathology, 19, 208-217. Speeches/lectures • WHITEHOUSE A. (2016). Very early identification and intervention in autism: Re-writing the rule book. Keynote Presentation at the Speech Pathology Australia National Conference, Perth, Australia. Other relationships/activities • Patron of ‘Kids are Kids’ (www.kidsarekids.org.au/) which is a service provider for children with developmental difficulties, including autism. Role is honorary and unpaid. • Member of the Western Australian Autism Diagnostician’s Forum.

Dr Kiah Evans	Employment • Employed by Telethon Kids Institute on a contract for the duration of the project, as the Project Coordinator to facilitate the development of a National Guideline for ASD Diagnosis in Australia. Payment is in the form of a salary and is not dependent on the content of the published Guideline. Support for travel or accommodation • Some travel and accommodation support for this project. Meals/beverages • Some meal and beverage support for this project.
Prof Valsamma Eapen	Publications • EAPEN V. (2016). Early identification of autism spectrum disorder: Do we need a paradigm shift? Australian and New Zealand Journal of Psychiatry, 50(8), 718-720. Speeches/lectures • EAPEN V. (2015). Early identification of autism. Presentation at the GAPIO Conference, Leicester, United Kingdom. Development of related documents • Watch Me Grow (https://www.watchmegrow.care/landing). Watch Me Grow helps track your child's progress & recommend opportunities to enhance early development. This programme is designed for children aged 6 months to 4 years and is supported by the University of New South Wales.
Prof Margot Prior	Support for travel or accommodation • Some travel and accommodation support for this project. Meals/beverages • Some meal and beverage support for this project. Development of related documents • PRIOR M, ROBERTS J. (2006, 2012). Guidelines for early intervention for autism spectrum disorder. Commonwealth Department of Social Services.
Clinical A/Prof John Wray	Employment • Conducts and supervises autism spectrum disorder diagnostic assessments within public and private practice. Grants • Named investigator on the National Disability Insurance Agency funded grant for this project – Developing National Standards for Autism Diagnosis (2016). Support for travel or accommodation • Some travel and accommodation support for this project. Meals/beverages • Some meal and beverage support for this project. Publications • GLASSON E, MACDERMOTT S, DIXON G, COOK H, CHAUVEL P, MALEY-BERG A, WRAY J. (2008). Management of assessments and diagnoses for children with autism

	spectrum disorders: The Western Australian model. Medical Journal of Australia, 188, 288-291. • WRAY J, CAMPBELL R, INAUGURAL BOARD OF WAADF, INC. (2005). The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder. The Western Australian Autism Diagnosticians' Forum, Inc. Speeches/lectures • Various invited lectures on the method of ASD assessment in WA. Development of related guidelines • Member of committee that developed WA ASD assessment Guidelines in 2005. Other experience • Consulted with regards to UWA Graduate Diploma in ASD assessment. Other relationships/activities • Member of the Western Australian Autism Diagnostician's Forum. • Member of NBPSA (professional group of paediatricians who assess and manage children with developmental difficulties).
Jac den Houting	Nothing declared.
Ms Dianne Brookes	Speeches/lectures • Conducted pre-planning workshops in ACT, NSW, SA, Victoria and WA in support of Aboriginal people living with disability and their carers to get ready for the transition to the NDIS through 'Living My Way'. Other roles • Participates with families when required for school engagement as an advocate for children on the spectrum. Other relationships/activities • First Peoples Disability Network has a memorandum of understanding with Positive Partnership, a program to improve the relationships of children on the spectrum and their carers with education. Also part of this process are Aspect, Autism Victoria, Autism QLD, Autism WA, Autism SA, Catholic Education, Combined Independent Schools and the Department of Education. • Member of the reference committee for Positive Partnership process and when required took part in the rollout of information sharing in communities. • Shared a personal story of growth on the 'Something about Kevin' animation and 'Jaki Story' tools used in the workshops.

Dr Jo McCubbin	Employment • I am self-employed but much of my work involves clients with autism or suspected. I am paid for seeing them. Support for travel or accommodation • MSOAP for outreach clinics which may include autistic children or multidisciplinary meetings regarding clients. Speeches/lectures • Parts of lectures to GPs, interns and medical students include reference to ASD. Expert testimony • Occasional in divorce cases / parenting disputes particularly, or child protection cases. Other relationships/activities • Fellow of The Royal Australasian College of Physicians • Australian Paediatric Society representative to the National Rural Health Alliance Council • Regularly participate in multidisciplinary diagnostic meetings. • Meet monthly with local school support and mental health services. • Quarterly Early Intervention Meetings with Allied Health staff in central and east Gippsland.
Mr Jon Martin	Development of related documents • Position papers for the Australian Advisory Board on Autism Spectrum Disorders. • Fact sheets for Autism SA. Other relationships/activities • Consultant for Australian Autism Alliance. • Consultant for Autism SA.
Ms Nicole Rogerson	Employment • Previous owner of the Lizard Children's Centre, but no longer associated with that organisation. Board membership • Board of Autism Awareness Australia. Consultancy fees/honorarium • Paid as a consultant for Lizard Centre and Disability Services Consulting during the last three years. Other relationships/activities • Volunteer CEO of Autism Awareness Australia, an organisation that has long advocated for the need for national diagnostic guidelines.
A/Prof Bob Davis	Other relationships/activities • Clinical director of the Centre for Developmental Disability Health Victoria. • Teaches Developmental Disability at Monash University.

	• Experience as a clinician will provide a background knowledge of the clinical implications and influence contribution.
Ms Adele Suda **(replaced)**	Speeches/lectures • Lecturer at Southern Cross University Other relationships/activities • Committee member of Autism Gold Coast. This is a support group for families that have an autistic child (not-for-profit organisation). • Member of the SARRAH NDIS Working Group. This is a group that examines allied health professionals' rural and remote services throughout Australia for NDIS participants. • OT Australia member
Ms Susanne Nelson	Employment • Director of Susanne Nelson and Associates. Manages nine OTs, together providing private occupational therapy services to over 150 families in the eastern suburbs of Melbourne (90% of clientele diagnosed with an ASD). Speeches/lectures • Provide professional development and staff meetings for teachers on an ongoing basis about autism spectrum disorders. • NELSON S. (2014). Exploring the impact of change during school transition for children with an Autism Spectrum Disorder. Presentation at the Victorian Autism Conference, Melbourne, Australia. Other relationships/activities • Facilitator of Camberwell Mental Health Network specifically supporting allied health professionals with increasing knowledge of ASD. • Member of Autism Victoria. • Mentor and supervisor to occupational therapists, supporting their development in the field of paediatrics, autism spectrum disorders and mental health.
Ms Jane Bollen	Employment • Employed as a Research Surveyor at Caretrack Kids (Macquarie University) from February to September 2016. Consultancy fees/honorarium • Husband, Dr Chris Bollen, engaged by Macquarie University for Caretrack Kids project (contract completed in July 2016). Support for travel or accommodation • Paid for when travelling for role with Caretrack Kids (Macquarie University). Meals/beverages • Paid for when travelling for role with Caretrack Kids (Macquarie University).

Dr Jacqueline Small	Speeches/lectures • General intellectual disability / developmental delay talks that include issues relevant to ASD diagnosis. Development of related documents • Involved in updating RACP position statement on the role of paediatricians in ASD. Other relationships / activities • RACP Chair – Paediatric Policy Committee.
Prof Julian Trollor	Employment • Better diagnostic tools will assist my clinical and research work. Consultancy fees/honorarium • Negligible fees received for several articles, lectures, webinars and reviews. • Paid as an Expert Opinion at the NSW Crown Solicitor's Office. Grants • Multiple NHMRC, ARC, CRC and other funding sources totalling $26+million. Publications • CASHIN A, BUCKLEY T, TROLLOR J, LENNOX N. (2016). Scoping review of what is known of the physical health of adults with autism spectrum disorder. Journal of Intellectual Disabilities, online first. • FOLEY K, TROLLOR J. (2015). Management of mental ill health in people with autism spectrum disorder. Australian Family Physician, 44, 784-790. • HWANG J, FOLEY K, TROLLOR J. (2016). Autism spectrum disorder. In N. Pachana (Ed.), Encyclopedia of Geropsychology (pp. 1-11). Singapore: Springer Singapore. Speeches/lectures • TROLLOR J, FOLEY K, HWANG J. (2015). Successful ageing for people with autism spectrum disorders. Presentation at ASPECT Practice Research Forum, Sydney, Australia. • TROLLOR J, FOLEY K, HWANG J. (2016). Giant steps. Presentation at Autism Research at 3DN, Sydney, Australia. • TROLLOR J, FOLEY K, HWANG J. (2015). Australian Longitudinal Study of Adults with Autism (ALSAA). Presentation at the Asia Pacific Autism Conference, Brisbane, Australia. • TROLLOR J, FOLEY K. (2014). Successful ageing for people with autism spectrum disorders. Presentation at the AADDM 2014 Conference, Brisbane, Australia. • TROLLOR J, FOLEY K. (2014). Longitudinal Study of Adults. Presentation at the Autism CRC Information Session, Sydney, Australia. • TROLLOR J. Autism and pervasive developmental disorders: Management issues. • D'ABRERA C, FRANKLIN C, O'BRIEN G, TROLLOR J. (2013). Psychiatric illness and behavioural disorders in adults with

	autism: Essential management skills for the psychiatrist, psychotropic medication use in adults with autistic disorder: Principles. Presentation at the Royal Australian and New Zealand College of Psychiatrists (RANZCP) Congress 'Achievements and Aspirations', Sydney, Australia. Development of related documents • Member of the RACP Committee for the draft Australian Guidelines on ADHD (2009) – these have some ASD relevant material. Other relationships and activities • Fellow, the Royal Australian and New Zealand College of Psychiatrists (RANZCP). • Member, Faculty of Psychiatry of Old Age, RANZCP. • Founder, Neuropsychiatry Section, RANZCP. • Co-Founder & Executive Member, Intellectual and Developmental Disability Special Interest Group, RANZCP. • Executive Committee Member, NSW Health Agency for Clinical Innovation, Intellectual Disability Health Network. • Member, Research and Development Committee, NSW Health Agency for Clinical Innovation, Intellectual Disability Health Network. • Executive Member, NSW Ministry of Health; Department of Family and Community Services, Joint Committee Intellectual Disability Mental Health. • NSW Ombudsman Panel of Expert Advisers. • Convenor of the RANZCP 2017 Congress, Member of the Scientific Program Committee. • Member, Health Education and Training Institute Higher Education Governing Council HETI. • Member, Joint Mental Health and Disability Committee, NSW Health and Ageing Disability and Home Care, NSW Government Family and Community Services. • Member, NSW Council for Intellectual Disability. • Member, Research Advisory Committee, NSW Mental Health Commission. • Vice President & Member, Australian Association of Developmental Disability Medicine.
Dr Josephine Barbaro	Employment • Autism CRC. 1 day p/w. Research on screening/family support following diagnosis. Consultancy fees/honorarium • Training professionals on early autism detection – directly invoiced to La Trobe University. Grants • Autism CRC/La Trobe University grants for ASD screening/diagnosis research. Support for travel or accommodation • When presenting on early ASD detection/diagnosis.

	Meals/beverages • When presenting on early ASD detection/diagnosis. Gifts or gratuities • Small token gifts following training/keynotes. Publications • BENT C, BARBARO J, DISSANAYAKE C. (in press). Change in autism diagnoses prior to and following the introduction of DSM-5. Journal of Autism and Developmental Disorders. • BARBARO J, DISSANAYAKE C. (2016). Diagnostic stability of autism spectrum disorder in toddlers prospectively identified in a community-based setting: Behavioural characteristics and predictors of change over time. Autism, online first. • DURKIN M, ELSABBAGH M, BARBARO J, GLADSTONE M, HAPPE F, HOEKSTRA R, LEE L, RATTAZZI A, STAPEL-WAX J, STONE W, TAGER-FLUSBERG H, THURM A, TOMLINSON M, SHIH A. (2015). Autism screening and diagnosis in low resource settings: Challenges and opportunities to enhance research and services worldwide. Autism Research. 8, 473-476. • BENT C, BARBARO J, DISSANAYAKE C. (2015). Mapping the diagnosis of autism in children under 7 years in Australia: 2010 – 2012. Medical Journal of Australia, 202, 317-320. • VIVANTI G, HUDRY K, TREMBATH D, BARBARO J, RICHDALE A, DISSANAYAKE C. (2013). Towards the DSM 5 criteria for autism: Clinical, cultural and research implications. Australian Psychologist, 48, 258-261. • BARBARO J, DISSANAYAKE C. (2009). Autism spectrum disorders in infancy and toddlerhood: A review of the evidence on early signs, early identification tools, and early diagnosis. Journal of Developmental and Behavioral Pediatrics, 30, 447-459. Speeches/lectures • BARBARO J. (2015). Presentation to the Autism CRC & Southern Cross University, Gold Coast, Australia. • BARBARO J. (2015). Presentation to the Northern Beaches Pediatric Network, Sydney, Australia. • BARBARO J. (2014). Presentation to the Early Childhood Intervention Services, Launceston, Australia. • BARBARO J. (2013). Invited keynote presentation at the Asia Pacific Autism Conference, Adelaide, Australia. • BARBARO J, RABBA S, DISSANAYAKE C. (2015). Invited keynote panel at the Asia Pacific Autism Conference, Brisbane, Australia. • BARBARO J, DISSANAYAKE C. (2015). Oral presentation at the Australasian Human Development Association (AHDA), Wellington, New Zealand. • BARBARO J. (2013). Presentation at the Women and Children's Health Centre, Tianjin, China. • BARBARO J, RICHDALE A. (2013). Presentation at the Women and Children's Health Centre, Tianjin, China.

	• BARBARO J. (2013). Presentation at an Amaze Autism Victoria Continuing Education event, Melbourne, Australia. Development of related documents • Early days workshops content development. • Parenting Research Centre materials on early detection and diagnostic process. Other relevant experience • Autism CRC Advisory Panel for Core Program 1 – Early detection / diagnosis / family support. Other relationships/activities • Employed and provide in-kind for Autism CRC. • Provisional Psychologist. • Student Member of Australian Psychological Society.
Dr Janine Manjiviona	Other relationships/activities • Clinical psychologist in private practice undertaking assessment of autistic infants, children and adults.
Ms Robyn Stephen	Ownership interests • Principal Robyn Stephen & Associates Speech Pathology. Speeches/lectures • Continuing Professional Development (CPD) for SPA 'Screening, Assessment and Differential Diagnosis of ASD: An Independent Study Resource' • Co-presented a workshop with Occupational Therapist on: Developmental Approach to the Treatment of Autism. • Lectured for 4 years (2012–2015) in ASD assessment and intervention at Melbourne University Masters of Speech Pathology. • Lectures to GPs, community & school nurses, teachers and parents. Expert testimony • Victorian Parliamentary Inquiry into Services for People with ASD. • Senate Inquiry into the prevalence of different types of speech, language and communication disorders and speech pathology services in Australia. Development of related documents • Governance of ASD clinical Guidelines at Speech Pathology Australia. Other relationships/activities • Vice President of Speech Pathology Australia. • Member of Speech Pathology Australia. • Member of the Victorian Independent Speech Pathologists Network.

2.5 Steering Committee Activities

The Research Executive met with the Steering Committee via teleconference on five occasions throughout the 20-month period in which the Guideline was developed. During these meetings, the Steering Committee provided critical feedback on the work generated to date and each member shared their stakeholder group's perspective on the assessment of ASD concerns process. The primary focus of each meeting was:

- Meeting One (October 2016): Provide input on the proposed methodology for literature reviews and community consultation.
- Meeting Two (February 2017): Provide feedback on the preliminary findings from the community consultation, input on the planned workshop format and support with participant recruitment.
- Meeting Three (May 2017): Provide feedback on the updated preliminary findings from the community consultation and input on the emerging assessment of ASD concerns model.
- Meeting Four (July 2017): Provide feedback on the draft recommendations for the Guideline.
- Meeting Five (December 2017): Receive update on the submissions received through the public consultation process and discuss the Guideline revision process.

In addition, the Steering Committee members facilitated additional input from other members of the national peak body they represented.

3. Literature Review

Advice was received from Ms Karen Jones (Librarian, University of Western Australia) during the planning phase of the scoping and systematic reviews.

3.1 Scoping Review

An initial scoping review was conducted to map the breadth and depth of the available evidence on the ASD diagnostic process within similar cultures. A scoping review is an appropriate approach to conducting a literature review when there is a need to rapidly map the breadth and depth of the available evidence on a topic, particularly for complex topics that have been comprehensively reviewed previously [4]. As is typical with scoping reviews, broad research questions were employed and an inclusive approach to information sources was utilised to ensure wide coverage of the topic. The scoping review utilised peer-reviewed journal articles, theses, published guidelines and grey literature. Evidence was then charted, collated and summarised under the following headings:

- international ASD diagnostic processes
- accuracy considerations
- acceptance considerations
- waitlist considerations.

3.2 Systematic Review of Diagnostic Guidelines

Three steps were utilised to identify ASD diagnostic guidelines published in the Anglosphere, including those occurring in both peer-reviewed journals and grey literature. The Anglosphere was defined as Australia, New Zealand, North America (Canada, United States) and British Isles (England, Ireland, Scotland, Wales).

(1) An internet Google search was conducted using the search terms “autism”, “diagnosis” and “[location]” for each included country. This search was repeated with the name of each individual state and territory for Australia, Canada and the United States. All potentially relevant links were explored in the attempt to locate guideline documents. This process involved searching through other pages within the website and following links to suggested external websites. Only websites and documents written in English were explored. This search strategy resulted in 28 relevant guideline-related documents and a further guideline was brought to the attention of the Research Executive during the community consultation process.

(2) A systematic database search was conducted of the scholarly literature (journal articles and postgraduate theses) published in English between 1 January 1997 and 23 October 2016. The included databases were CINAHL, Cochrane, Embase, Medline, Proquest, PubMed, Science Direct, Scopus and Web of Science. Search terms (title only) were: “autism” or “Asperger” or “pervasive developmental disorder” or “PDD” or “ASD” AND “guid*” or “protocol” or “parameter” or “process” or “consensus” or “best practice” or “standard” or “task force” or “procedure” or “agree” or “evidence” AND “diagnos*” or “identif*” or “evaluat*” or “asses*” or “recogni*”. Only articles that could be defined as a clinical guidance document were included, and all articles defined as research reports, literature reviews or editorial were excluded. This search strategy resulted in 178 articles and theses once duplicates were removed, with three guidelines remaining once the abstract and/or full text were reviewed. A further three guidelines published in journals were identified through other search mechanisms, such as reference lists, Google search results and suggestions from Steering Committee members. This resulted in a total of six guidelines published in journals. A further search conducted on 19 August 2017 (covering 2016 and 2017) did not reveal any new guidelines; however, a systematic review of guidelines was identified (Appendix C, [5]).

(3) Finally, an internet search for “autism” and “diagnosis” was conducted by reviewing websites for the largest public and private health insurance companies in the United States of America. These were: Aetna, Anthem Health Insurance, Centene Corporation, Cigna, Health Net, Humana, Kaiser Permanente, Magellan Health, Medicaid, Medicare, Molina Healthcare, Tricare, UnitedHealth

Group and WellCare Health Plans [6]. This approach led to the identification of seven guidelines that had not been identified previously.

This three-pronged search approach resulted in a total of 42 international ASD diagnostic guidelines or related documents providing guidelines. Information was extracted from 35 guidelines (insurance guidelines were excluded, as they summarised other guidelines [2, 3, 7–39]) using a matrix approach aligned with the research questions (Section 1.4). In addition, the quality of each guideline was evaluated by a single researcher using the AGREE II form [40]. A subset of 10 guidelines was evaluated further by a second researcher to determine if the quality score of each was at least 50 per cent and/or whether each was developed using a systematic literature review and input from a multidisciplinary team. The second researcher coded this subset of guidelines using NVivo software, where codes were informed by the content of the documents and the research questions. This second researcher also evaluated the quality of these guidelines using the AGREE II form. The rating scores from the two researchers were combined to form scaled scores for each of the six domains and the overall quality item (Table 5), according to the AGREE II manual [40].

Table 5. Quality ratings for evidence-based guidelines formed by a multidisciplinary team, using the AGREE II form (two raters)

Guideline [reference]	Scaled score (%)							
	D1	D2	D3	D4	D5	D6	Average	Overall quality
Canada [27]	64	78	48	83	19	38	65	58
England (Child) [3]	86	83	84	97	69	79	83	83
England (Adult) [2]	100	72	89	86	69	83	83	83
New Zealand [21]	64	83	69	89	35	42	64	58
Scotland [28]	92	69	67	86	50	33	66	75
USA (AAN) [25]	69	33	45	47	15	79	48	58
USA (AACAP) [24]	56	39	65	78	15	79	55	67
USA (Connecticut) [10]	61	67	9	19	29	33	37	42
USA (Missouri) [41]	67	67	3	67	25	50	46	33
USA (New York) [8]	72	31	46	53	29	54	47	50

D1 = Scope and Purpose; D2 = Stakeholder Involvement; D3 = Rigour of Development; D4 = Clarity of Presentation; D5 = Applicability; D6 = Editorial Independence.

3.3 Systematic Review on Diagnostic Accuracy

An existing systematic review of the diagnostic accuracy of ASD diagnostic instruments was published in 2013 [5]; a second systematic review on this topic is currently undergoing revisions with an international, peer-reviewed journal [42]; and a third systematic review on this topic is expected to be submitted for peer review in 2017 [43]. However, these systematic reviews do not address diagnostic accuracy in relation to the DSM-5, instead focusing on the DSM-III, DSM-IV, ICD-9 or ICD-10 diagnostic criteria (this consequently ensured that our systematic review would not report on the same studies). As Australian clinicians utilise the DSM-5 diagnostic criteria extensively, an inclusion criterion was defined for studies using a gold standard multidisciplinary DSM-5 diagnosis as the reference standard.

A systematic database search was conducted of the scholarly literature (journal articles and postgraduate research theses) published in English since the publication of the DSM-5 in January 2013 to 23 October 2016. Only studies reporting on diagnostic accuracy measures were included, and all articles reporting on other study designs, literature reviews or editorial were excluded. The search was restricted to studies with the full article available, but no limitations were set for age, gender, demographics or intelligence level of the sample. The included databases were CINAHL, Cochrane, Embase, Medline, Proquest, PubMed, Science Direct, Scopus and Web of Science. Search terms (title, abstract and keyword) were: "autism'' or "ASD" AND "sensitivity" or "specificity" or "diagnosis" or "diagnostic" or "diagnose" or "accura*" or "reliab*" AND "DSM-5". This search strategy resulted in 287 articles and theses once duplicates were removed. After the abstract and/or full text was reviewed for information about diagnostic accuracy, seven peer-reviewed journal articles remained. This included four diagnostic accuracy studies and one systematic review of diagnostic accuracy studies. A further one diagnostic accuracy study was suggested to the Research Executive and two systematic review protocols were identified through entering the search term "autism" into the Cochrane Library, resulting in a total of five diagnostic accuracy studies. A further search conducted on 19 August 2017 (covering 2016 and 2017) did not reveal any new diagnostic accuracy studies or systematic reviews.

Information was summarised from these articles using a data extraction form developed for this project (Appendix D) by one of two research assistants, following training from the Project Coordinator. In addition, the quality of research articles was evaluated by one of these research assistants using the QUADAS-2 form for diagnostic accuracy studies (Table 6, [44]). The systematic review article was reviewed using the AMSTAR and received a quality rating score of 55% [5, 45].

Table 6. Quality ratings for diagnostic accuracy studies, using the QUADAS-2 form

Instrument [reference]	**Risk of bias score**						
	Domain 1A	**Domain 1B**	**Domain 2A**	**Domain 2B**	**Domain 3A**	**Domain 3B**	**Domain 4A**
CARS2 [46]	Unclear	Low risk	High risk	Low risk	High risk	Low risk	Unclear
AMSE [47]	Unclear	Unclear	High risk	Low risk	Low risk	Low risk	Unclear
AMSE [48]	Low risk	Low risk	High risk	Low risk	Low risk	Low risk	Unclear
ADEC [49]	High risk	Low risk	Low risk	Low risk	Low risk	Low risk	High risk
NODA [50]	Unclear	Low risk	Low risk	Low risk	Low risk	Low risk	Unclear

Domain 1 = Patient Selection; Domain 2 = Index Test; Domain 3 = Reference Standard; Domain 4 = Flow and Timing; A = Risk of Bias; B = Concern in Applicability; CARS2 = Childhood Autism Rating Scale Second Edition; AMSE = Autism Mental Status Exam; ADEC = Autism Detection in Early Childhood; NODA = Naturalistic Observation Diagnostic Assessment.

3.4 Systematic Review on Diagnostic Experiences

Considerations that would have an impact on individuals on the autism spectrum, caregivers and practitioners accepting the outcome of assessments of ASD concerns were identified from studies reporting on the experiences and perceptions of these individuals and professionals. A systematic database search was conducted of the scholarly literature (journal articles and postgraduate theses) published in English between 1 January 2007 and 23 October 2016. The included databases were CINAHL, Cochrane, Embase, Medline, Proquest, PubMed, Science Direct, Scopus and Web of Science. Search terms (title, abstract and keyword) included: "autism" or "Asperger" or "pervasive developmental disorder" or "PDD" or "ASD" AND "diagnos*" or "assess" or "identif*" or "evaluat*" or "asses*" or "recogni*" AND "experience*" or "perce*" or "perspective" or "view". Only articles that could be defined as a research report (using any study design) were included, and all articles reporting on

literature reviews or editorial were excluded. The studies were only included if their sample was individuals on the autism spectrum, their families or practitioners delivering the autism diagnosis. Only studies with the full article were included, but no limitations were set for age, gender, demographics or intelligence level of the sample. Studies that investigated experiences post-diagnosis, the accuracy of diagnosis and assessment tools were excluded. Only studies that covered the experiences or perceptions of the sample during the diagnosis process were included. This search strategy resulted in 3,656 articles and theses once duplicates were removed, with 45 documents remaining once the abstract and/or full text were reviewed for relevance. A further search was conducted on 19 August 2017 (covering 2016 and 2017), resulting in 1,112 search results and a total of eight new articles for inclusion once the abstract and/or full text were reviewed for relevance. A further one experiential study was suggested to the Research Executive. This resulted in a total of 53 articles included in the review (Appendix C).

The data extraction form (Appendix D) was completed for each article by a postgraduate research student or research assistant, following training from the Project Coordinator. In addition, the quality of these articles was evaluated by one of the researchers using the 'Kmet forms' for quantitative and qualitative studies (Table 7, [45, 51]).

Table 7. Quality ratings for diagnostic experiences, using the Kmet forms

First author [reference]	Score		
	Kmet Quantitative	Kmet Qualitative	Kmet Average
Abbott, 2013 [52]		85	
Andersson, 2014 [53]	68		
Bargiela, 2016 [54]		80	
Barnett, 2014 [55]		100	
Bessette Gorlin, 2016 [56]		100	
Braiden, 2010 [57]		83	
Bressi, 2017 [58]		75	
Cane, 2015 [59]	95	95	95
Carlsson, 2016 [60]		85	
Chamak, 2011 [61]	59	70	65
Chiu, 2014 [62]	82		
Connolly, 2013 [63]		85	
Craig, 2015 [64]		100	
Crane, 2016 [65]	80		
Ducey, 2009 [66]		95	
Feliciano, 2008 [67]	82		
Greaves, 2014 [68]		90	
Hennel, 2016 [69]	73	60	67
Heredia-Alvarado, 2017 [70]		100	
Huws, 2008 [71]		75	
Jones, 2014 [72]	64		
Kalash, 2010 [73]		100	
Keenan, 2010 [74]	73	45	59
Lewis, 2016 [75]		85	
Lilley, 2011 [76]		90	
Mann, 2014 [77]		95	
Marco, 2010 [78]		60	
McCaffrey, 2011 [79]		75	

McMorris, 2013 [80]	64		
Mitchell, 2014 [81]		75	
Moh, 2012 [82]	64		
Molteni, 2014 [83]		80	
Murillo, 2016 [84]		60	
Navot, 2017 [85]		65	
Novoa, 2015 [86]		85	
Oswald, 2017 [87]	90	85	88
Powell, 2016 [88]	83	90	87
Punshon, 2009 [89]		85	
Rabbitte, 2017 [90]		65	
Ratto, 2013 [91]	86		
Rogers, 2016 [92]	89	75	82
Rose, 2011 [93]	64		
Rosqvist, 2012 [94]		60	
Russell, 2012 [95]		65	
Saggu, 2015 [96]	95		
Sansosti, 2012 [97]	82	55	69
Siklos, 2007 [98]	73		
Sweeney Gray, 2013 [99]	68	60	64
Tait, 2016 [100]	68	75	72
Thompson-Kroon, 2012 [101]		95	
Ward, 2016 [102]	68		
Zeiger, 2008 [103]	79		
Zuckerman, 2013 [104]		100	

3.5 Systematic Review of Diagnostic Time Factors

Factors influencing waitlist times for the completion of an ASD diagnostic assessment were identified from studies focused on temporal factors associated with the process. A systematic database search was conducted of the scholarly literature (journal articles and postgraduate theses) published in English between 1 January 2007 and 23 October 2016. The included databases were CINAHL, Cochrane, Embase, Medline, Proquest, PubMed, Science Direct, Scopus and Web of Science. Search terms (title, abstract and keyword) included: “autism” or “Asperger” or “pervasive developmental disorder” or “PDD” or “ASD” AND “diagnos*” or “assess” or “identif*” or “evaluat*” or “asses*” or “recogni*” AND “wait*” or “delay” or “time”. Research studies of any research design and literature reviews were included. Only articles that could be defined as a research report (using any study design) were included, and all articles reporting on literature reviews or editorial were excluded. Only studies with the full article were included, but no limitations were set for age, gender, demographics or intelligence level of the sample. Following the addition of previously identified resources, this search strategy resulted in 3,234 articles, theses and reports once duplicates were removed, with 26 documents remaining once the abstract and/or full text were reviewed for relevance. A further search was conducted on 19 August 2017 (covering 2016 and 2017), resulting in 1,183 search results and a total of two new articles for inclusion once the abstract and/or full text were reviewed for relevance. A further one study addressing time factors was suggested to the Research Executive. This resulted in a total of 29 articles included in the review (Appendix C).

The data extraction form (Appendix D) was completed for each article by a single research assistant, following training from the Project Coordinator. In addition, the quality of research articles was evaluated by one of the researchers using the ‘Kmet forms’ for quantitative and qualitative studies (Table 8, [51]).

Table 8. Quality ratings for diagnostic time factors, using the Kmet forms

First author [reference]	Score		
	Kmet Quantitative	Kmet Qualitative	Kmet Average
Adelman, 2011 **[105]**	82		
Austin, 2016 **[106]**	64		
Chamak, 2011 **[61]**	59	70	65
Connolly, 2013 **[63]**		85	
Crane, 2016 **[65]**	80		
Daniels, 2014 **[107]**	Not applicable		
Denman, 2016 **[108]**		90	
Ducey, 2009 **[66]**		95	
Fombonne, 2009 **[109]**		10	
Frenette, 2013 **[110]**	64		
Gordon-Lipkin, 2016 **[111]**	Not applicable		
Mann, 2014 **[77]**		95	
McClure, 2010 **[112]**	75		
McKenzie, 2015 **[113]**	78		
McKenzie, 2016 **[114]**	75		
McKenzie, 2016 **[115]**	55		
Miodovnik, 2015 **[116]**	85		
Oslejskova, 2007 **[117]**	59		
Randall, 2016 **[118]**	55		
Rose, 2011 **[93]**	64		
Rossi, 2012 **[119]**		75	
Rutherford, 2016 **[120]**		100	
Rutherford, 2016 **[121]**	73	85	79
Saggu, 2015 **[96]**	95		
Samms-Vaughan, 2009 **[122]**	77		

Siklos, 2007 **[98]**	73		
Taylor, 2016 **[123]**	75		
Ward, 2016 **[102]**	68		
Zuckerman, 2013 **[104]**		100	

4. Online Submissions

A web portal was created that enabled submissions to be made by an unlimited number of individuals from any stakeholder group, including clients, service providers and policymakers. The aim of this project was to provide an opportunity for a broader range of stakeholders to give input into the generation of the national Guideline. Advice was received from Professor Donna Cross (Head of Health Promotion and Education, Telethon Kids Institute) during the planning phase of the online submissions.

4.1 Participants

In total, 225 participants completed an online submission. Many participants had more than one interest in assessment of ASD concerns, including 20 adults on the autism spectrum, 83 caregivers / family members of individuals on the autism spectrum, 81 ASD diagnosticians and 58 other ASD service providers. The median age of participants was 41 years (range = 23–80), where most were females (n = 197, 88%). The vast majority identified as being Caucasian (n = 201, 89%), with four reporting to be from an Aboriginal and/or Torres Strait Islander background. All states and territories were represented.

4.2 Data Collection Procedure

The online submission portal was hosted by Autism CRC's website, on a webpage that was specific to this project. Participants reviewed the Participant Information Sheet and provided consent by proceeding with the submission. Participants completed a brief survey that established the type of stakeholder group they belonged to and their basic demographic characteristics. Participants were then requested to make a submission of up to 100 words in response to the question:

> 'From your perspective, what are the most important considerations to address when developing a national Guideline for the diagnosis of autism spectrum disorder in Australia?'

To assist participants, a range of voluntary prompts were provided:

- How should professionals communicate with individuals being assessed and their family members?
- Who should conduct assessments?
- Where should assessments take place?
- How should assessment information be collected?
- What topics should be covered in an assessment?
- How should diagnosis decisions be reached?
- How should the diagnosis be disclosed?

4.3 Data Analysis

The online submissions resulted in approximately 17,500 words of data, which were imported into NVivo software for coding. Two research assistants coded these data with codes that emerged from the submissions, with the research questions (Section 1.4) providing an overarching framework.

5. Workshops

A series of eight workshops were held in capital cities across Australia, with the aim of allowing key stakeholders to participate in small and large group discussions regarding the Guideline. In chronological order, workshops were conducted in Perth, Brisbane, Adelaide, Darwin, Melbourne, Hobart, Sydney and online (conducted via videoconference and surveys). Advice was received from Professor Donna Cross (Head of Health Promotion and Education, Telethon Kids Institute) and staff in her team (including Ms Melanie Epstein) during the planning phase of the workshops.

5.1 Participants

The workshops were open to adults on the autism spectrum, caregivers, ASD diagnosticians, clinical service providers and policymakers. A total of 265 participants attended, of which 20 (8%) were adults on the autism spectrum, 35 (13%) were caregivers / family members of individuals on the autism spectrum, 99 (38%) were diagnosticians and 165 (73%) other service providers. Many of the attendees fit more than one of these categories, and the aforementioned numbers relate to the category that attendees listed as their primary role. The median age of participants was 44 years (range = 17–72; though the age inclusion criteria was 18 years and older, one participant aged 17 attended to assist her mother with English language). All states and territories were represented at the workshops, with attendees from the Australian Capital Territory travelling to the Sydney workshop.

5.2 Data Collection Procedure

Each workshop commenced with a brief presentation from two representatives of the Research Executive (Andrew Whitehouse and Kiah Evans) to give attendees background information about the project as well as outlining one possible ASD diagnostic model. Participants were then requested to work in small groups to provide feedback on the aspects of this model that they liked and disliked, and to discuss a specific topic (assessment structure, assessment scope, potential impact, balancing competing priorities and equity for various populations). A scribe from each small group recorded the key discussion points by hand on A3 worksheets, which were collected by the Research Executive members at the conclusion of the workshop. In a session that followed, each participant was invited to write one statement on a stick-it note in response to the question ‘What are the most important considerations to address when developing the Guideline?’ Participants were encouraged to vote on their favourite responses during the tea break.

The eight workshops were conducted in four lots over a two-month period (10 March to 30 May 2017), allowing the Research Executive to update the proposed ASD diagnostic model in response to feedback. The specific wording of questions and prompts to elicit responses for each topic was modified slightly as the workshops progressed. The online workshop was adapted to allow interaction between participants located anywhere in Australia. This was achieved by using GoToWebinar, Zoom Meetings, Google Docs and RedCap surveys.

5.3 Data Analysis

The handwritten notes from participants, the primary source of data, were typed and compiled (resulting in approximately 13,000 words of data). These data were imported into NVivo software for coding by two research assistants, using codes that emerged from the written notes and underpinned by the research questions (Section 1.4).

6. Delphi Survey

A separate study sought to generate consensus recommendations for ASD diagnosis from medical, health and educational experts through a survey process that adopted the Delphi method. Advice was received from Professor Carol Bower (Senior Principal Research Fellow and Head of Alcohol & Pregnancy and FASD Research, Telethon Kids Institute) and Dr Jenny Downs (Co-Head of Child Disability, Telethon Kids Institute) during the planning phase of the Delphi survey.

6.1 Participants

Each Steering Committee member representing a national peak body for professionals was invited to nominate 10–20 experts in the assessment of ASD concerns field. This resulted in 118 professionals being invited to complete the Round 1 survey (Table 9). A total of 77 participants completed (n = 66) or partially completed (n = 11) the first round of the Delphi survey, with a wide variety of professional disciplines represented. The majority of participants were diagnosticians (n = 48) with other participants reporting their involvement in the clinical or educational management of children or adults on the autism spectrum as: initiating referrals for diagnostic assessments (n = 35); providing services to individuals (n = 50) or families (n = 40) after diagnosis; arranging government funding support (n = 13); and/or conducting research (n = 3). Some participants were involved in a number of these activities. The median period of participants' experience in the assessment process for ASD was 15 years (range = <1–40 years). Participants were primarily from Victoria (n = 22), New South Wales (n = 18) and Queensland (n = 18), with smaller representation from South Australia (n = 11), Western Australia (n = 5), Tasmania (n = 3) and the Northern Territory (n = 2). In total, 54 participants practised in a major city, while 32 practised in regional areas and 10 practised in remote parts of Australia (with some practising in multiple settings). Participants practised within public and private settings, including community, hospital and university environments. The participants worked with a wide age range of individuals on the autism spectrum, from babies to older adults. A total of 42 participants provided responses on the Round 2 survey.

Table 9. Delphi survey invitations and participants by professional background

Professional role	Invited	Round 1	Round 2
ASD service provider	6	4	2
General practitioner	3	3	2
Nurse	16	10	3
Occupational therapist	20	9	3
Paediatrician	17	14	8
Psychiatrist	16	9	5
Psychologist	23	14	9
Speech pathologist	14	12	9
Teacher	3	2	1
Total	118	77	42

6.2 Data Collection Procedure

The questions in Round 1 of the Delphi Survey were developed based on the scoping review (Section 3.1). Along with questions to clarify the participants' expertise in relation to assessments of ASD concerns, participants were asked whether each of a range of potential assessment components should be part of an assessment of ASD concerns, using a five-point scale: (1) strongly disagree, (2) disagree, (3) neither agree or disagree, (4) agree and (5) strongly agree. These quantitative ratings were used to help determine whether consensus had been reached on a given component (see Data Analysis). Along with free-text questions on the advantages and disadvantages of introducing a national guideline for ASD diagnosis, participants were able to make comments after each question, each section and at the end of the survey. The survey was piloted by six professionals with familiarity with the ASD diagnostic process (two occupational therapists, one clinical psychologist, one speech pathologist and one teacher). Participants were provided with instructions and a URL link to complete the survey online (administered with the assistance of RedCap software).

The questions in Round 2 of the Delphi Survey were developed on the basis of Round 1 results, with a focus on items where agreement had not been achieved. The questions were informed by the qualitative comments from Round 1 as well as findings that had emerged from the community consultation activities, which were being conducted in parallel. The same five-point scale and RedCap survey presentation was replicated in Round 2.

6.3 Data Analysis

Two criteria were used to determine if consensus had been achieved for a recommendation. Agreement was considered to exist if both criteria were met and partial agreement was achieved if only one of the two criteria was met:

- median ≥4 on the five-point scale and interquartile range (IQR) ≤1 for agreement that the recommendation should be included in the Guideline (or median ≤2 and IQR ≤1 for agreement that the recommendation should not be included in the Guideline)
- at least 70 per cent of participants giving a rating ≥4 for agreement that the recommendation should be included in the Guideline (or 70% at ≤2 for agreement that the recommendation should not be included in the Guideline).

Participants provided over 62,500 words of qualitative comments in the optional text boxes that followed each question. These data were imported into NVivo software and coded by two research assistants, using codes that emerged from the written notes and underpinned by the research questions (Section 1.4). These qualitative comments provided clarification and context

7. Viewpoint Survey

A further project, the Viewpoint survey, aimed to understand the relative importance of different aspects of an assessment of ASD concerns from the perspective of people with lived experience of ASD. Advice was received from Associate Professor Sonya Girdler (Director of Curtin Autism Research Group, Curtin University) and Dr Marita Falkmer (Research Associate, Curtin University) during the planning, data collection, analysis and interpretation phases of the Viewpoint survey.

7.1 Participants

A total of 12 adolescents or adults on the autism spectrum (12 years or older) and 26 caregivers of individuals on the autism spectrum of any age participated in the Viewpoint survey. The median age of participants was 42 years (range = 12–59) and most were females (n = 6 adolescents/adults on the autism spectrum; n = 23 caregivers). Most participants identified as Caucasian (n = 32), with two from an Aboriginal and/or Torres Strait Islander background. Approximately 75 per cent of the participants lived in a major city, with the remaining living in an inner or outer regional area. The median socioeconomic status (as represented by the Australian Bureau of Statistics' Index of Relative Socio-economic Advantage and Disadvantage) was the 6PthP decile (range = 1PstP – 10PthP decile). All states and territories except the Northern Territory were represented by survey participants.

7.2 Data Collection Procedure

This project employed a research methodology called a Q-sort [124]. The 66 statements in the Viewpoint survey were formulated from the scoping review. These statements were revised by three researchers experienced in both developing Viewpoint surveys and conducting research projects with adolescents and adults on the autism spectrum. The focus was on reducing the complexity of the statements and a Flesch-Kincaid Grade Level of 9.9 was achieved, which is consistent with being suitable for an adolescent population. The Viewpoint survey was piloted with two adults on the autism spectrum and two caregivers of individuals on the autism spectrum.

Participation in the Viewpoint survey involved three steps, each of which had detailed instructions for the participants:

(1) The first step required participants to sort 66 statements regarding the ASD diagnosis process into three broad categories: least important, neutral and most important.

(2) The second step required participants to place statements into a single position on a symmetrical sorting grid (Figure 2). Participants were asked to sort the 66 statements, all with the same lead-in phrase ('During the process of diagnosing autism, it is important to …'), from least important (–5) to most important (5). Participants were instructed to place only one statement in each grid square and, even if they felt all the statements were important, to sort them from least to most important.

(3) The third step required participants to complete a brief survey containing demographic, scale and open-ended questions. Demographic questions included age, postcode, gender, ethnicity and eligibility criteria. Scale questions asked participants to rate their ability to recall the diagnostic process, along with their satisfaction with the process and outcome of the diagnostic assessment (on a five-point Likert scale, where 1 represents very unsatisfied and 5 represents very satisfied). Open-ended questions allowed participants to give feedback and share any other information they thought relevant to the ASD diagnostic process.

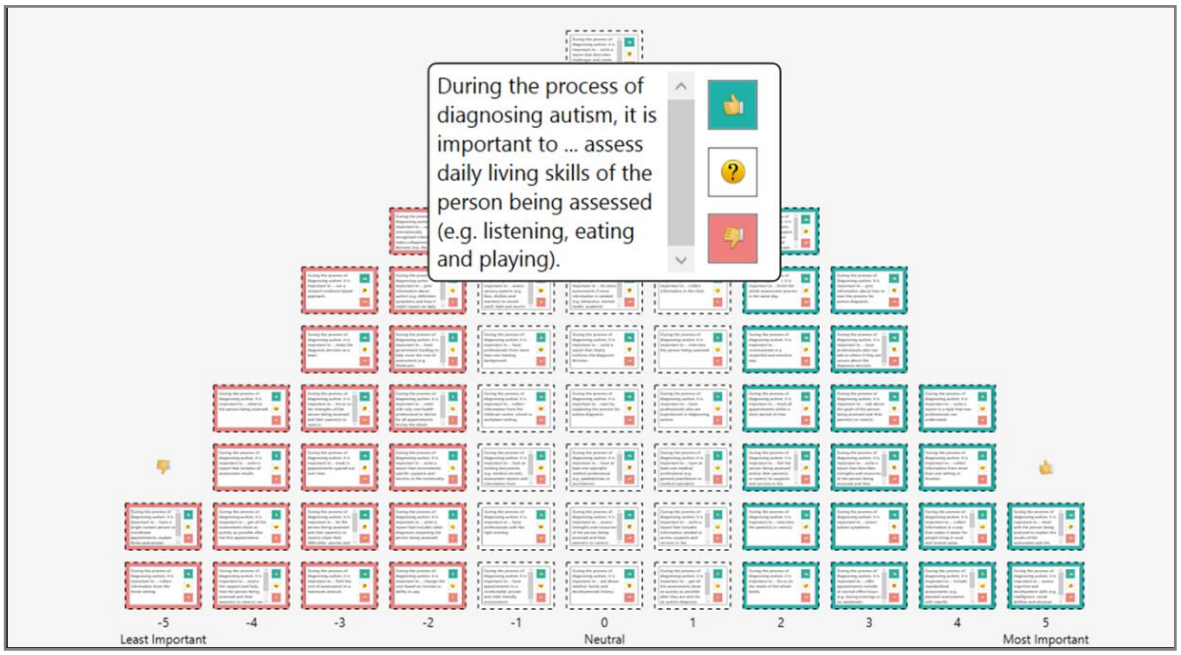

Figure 2. View of completed Q-sort grid on software

Participants were given the choice to complete the Q-sort either by using online Q-sort software [124], filling out a Microsoft Word document or cutting and pasting statements onto a printed Q-sort grid. The median survey completion time was 30 minutes (range = 10–210 minutes). A member of the research team entered data into the Q-sort software where required, so all results could be extracted together.

7.3 Data Analysis

After extraction from the online Q-sort software, the PQMethod software package was used to analyse the results according to the prescribed method [124]. Factors were extracted using centroid analysis and these preliminary results were assessed against a set of standard criteria (Kaiser–Guttman criterion, number of loading Q sorts, Humphrey's rule and scree test). This supported the retention of three factors, hence results were generated through by-person varimax rotation factor analysis. The three-factor varimax solution accounted for 42 per cent of the explained variance in the sample, with 36 of 38 Q-sorts loading significantly onto one of these factors. Factor arrays were created to define the three factors. The factor arrays were interpreted to formulate viewpoints by a group of five researchers familiar with Q-sort methodology research and the ASD diagnostic process.

8. Interviews

A range of interviews were conducted with adults on the autism spectrum with the aim of understanding the views of ASD diagnosis from adults with lived experience of ASD. Both research supervisors (Dr Kiah Evans and Postdoctoral Research Fellow Dr Anna Urbanowicz) were experienced in conducting qualitative interviews with adults on the autism spectrum, hence acted as methodological experts for this project.

8.1 Participants

A total of 14 adults on the autism spectrum participated in interviews, where this population was defined as: (1) adults with a confirmed ASD diagnosis (n = 12) or (2) adults who identify as autistic and who have not sought an ASD diagnosis (n = 2). The median age of participants was 46 years (range = 27–80) and eight participants were female. Most participants identified as Caucasian (n = 11), with none from an Aboriginal and/or Torres Strait Islander background. Nine of the participants lived in a major city, with the remaining living in an inner or outer regional area. The median socioeconomic status (as represented by the ABS IRSAD) was the 7PthP decile (range = 2PndP – 10PthP decile). Participants were from Victoria, Queensland, New South Wales and Tasmania.

8.2 Data Collection Procedure

Interviews were conducted using a semi-structured format devised by a research student, research supervisor (Dr Anna Urbanowicz) and the Research Executive Coordinator (Dr Kiah Evans). Feedback on the interview questions was obtained from two adults on the autism spectrum. Interview questions focused on three time periods: (1) the period before an ASD diagnosis or realisation that the participant was likely to have ASD; (2) the period during the diagnostic process; and (3) the period following the diagnosis/realisation. Interviews were conducted either face to face, in a telephone/video call or through written communication, according to the location and preference of the participant. Participants were provided with a copy of the questions in advance of the interview.

8.3 Data Analysis

All verbal interviews were audio recorded and transcribed, then thematically coded by the research student using NVivo software. Coding was checked and refined by the research supervisor. The relationship between codes was examined to form primary themes, with nested subthemes. Participant quotes were used to illustrate these themes and subthemes, and a summary of these findings was provided to participants, who in turn could give further feedback.

9. Recommendation Development

9.1 Formulating Recommendations

The recommendations included in the Guideline were formulated and refined using an extensive, iterative process over the duration of the project, where new evidence and feedback was continuously integrated with previously collected evidence. The following list outlines the steps that were taken during this process. While the list indicates a chronological sequence, there was some overlap in the steps:

(1) Preliminary recommendations were formulated on the basis of the initial scoping review.

(2) These were used to develop the statements for the Delphi and Viewpoint surveys.

(3) The data analysis process commenced as soon as participants started completing these surveys and online submissions.

(4) These early data were summarised in a report to the Steering Committee and were then used to refine the preliminary recommendations.

(5) These preliminary recommendations were presented to participants in the workshops, where small group discussions generated feedback. The preliminary recommendations were subsequently refined further in response to input from workshop participants, along with emerging evidence from the systematic reviews and other community consultation activities. A revised set of recommendations was presented at each of the four rounds of workshops.

(6) Data from the online submissions, workshops, Delphi survey and Viewpoint survey were summarised in a second report to the Steering Committee, who gave feedback on this report.

(7) Evidence from all literature review and community consultation activities was documented and reviewed in relation to the research questions, and a set of draft recommendations was prepared for the Steering Committee.

(8) These draft recommendations were further refined on the basis of feedback from the Steering Committee members (through a meeting and/or in writing), researchers involved in the systematic review and community consultation studies, and the Research Executive. These draft recommendations were included in the first draft of the Guideline, which was published and widely publicised for community feedback.

(9) The recommendations were then revised on the basis of written feedback obtained from a wide range of individuals and organisations representing relevant personal and professional experiences. This feedback, and the responses of the Executive Committee is provided in the accompanying document, Response to Public Consultation Submissions'. The revised draft of the Guideline (the 'second draft') was then presented to the Steering Committee members to obtain feedback from their national peak bodies.

(10) These recommendations were revised again following the written feedback from the national peak bodies represented on the Steering Committee, creating the third draft of the Guideline.

(11) The recommendations in the third draft of the Guideline were then reviewed by two international methodological experts. The recommendations were further refined based on the feedback received, leading to the recommendations that are present in the final Guideline document. (please refer to Section 10 of this document for further information).

The National Health and Medical Research Council (NHMRC) describes three types of recommendation that may be made in a guideline [125], with evidence levels drawn from the WHO's *General Guidelines for Methodologies on Research and Evaluation of Traditional Medicine* (defined in the note to Appendix C):

(1) **Evidence-based recommendations** are formulated based on high-quality evidence obtained from systematic reviews of randomised controlled trials (level I), randomised controlled trials (level II), pseudorandomised controlled trials (level III), comparative studies (level III) or case series that include post-test outcomes (level IV). These studies are identified through a systematic review of the evidence and graded according to the NHMRC-approved method. This grading system rates the evidence base (number, level and quality of studies), consistency, potential clinical impact,

generalisability to the target population and applicability in an Australian healthcare context. Given the paucity of high-quality evidence identified for this Guideline, it was not possible to form evidence-based recommendations.

(2) **Consensus-based recommendations** are formulated when a systematic review identifies an absence of high-quality evidence (level I–IV studies). The guideline developers instead use a consensus process to form these recommendations. As lower quality evidence and consultation findings were available to the guideline developers, this Guideline primarily presents consensus-based recommendations.

(3) **Practice points** are formulated when the topic is beyond the scope of the search strategy, and they are informed by expert opinion using a consensus process. As input was not sought on these topics during the consultative process, the future directions appearing at the conclusion of the Guideline are articulated as practice points.

9.2 Summarising Evidence for Recommendations

Evidence from the literature reviews and community consultation is summarised in an evidence table for each recommendation, with each of the sources of evidence assigned to a row (Figure 3). This allowed supporting evidence from community consultation activities and international guideline documents to be reviewed alongside published research evidence.

Evidence Table [Insert Number]. [Insert brief name]	
Recommendation	[Insert exact wording from Guideline document]
Category/grade	Consensus-based Recommendation, Grade [X]
Rationale	[Briefly describe reason(s) for recommendation and grade]
Evidence source	
Research literature	• [Include brief summary of relevant findings and reference details for each research study]
International guidelines	• [Include brief summary of relevant findings and reference details for each Guideline]
Online submissions	• [Include brief summary of relevant findings]
Workshops	• [Include brief summary of relevant findings]
Delphi survey	• [Include brief summary of relevant findings]
Viewpoint survey	• [Include brief summary of relevant findings]
Interviews	• [Include brief summary of relevant findings]
Feedback	• [Include brief summary of relevant findings]
References	[Insert full citation details for research studies / guidelines]

Figure 3. Template for evidence tables

9.3 Grading Evidence for Recommendations

The strength of each consensus-based recommendation was evaluated using a modified approach based on the NHMRC grading technique (Table 10, [125]). Due to a paucity of high-level evidence identified through the systematic literature review, this modified approach allowed supporting evidence from community consultation activities and international guideline documents to be reviewed along with the research evidence from peer-reviewed journals. The consensus-based rating was restricted to the NHMRC consistency criteria and breadth of evidence from multiple sources for several reasons: (1) it was deemed inappropriate to rate the evidence-base quality of our own research projects; (2) it was not possible to measure clinical impact for the included research designs; and (3) evidence was obtained only from similar cultures and applicable healthcare settings.

The Chair and Coordinator of the Research Executive independently rated each consensus-based recommendation on three descriptors, according to a set of descriptors developed for this project based on NHMRC terminology ([125], Table 10). The first descriptor was 'consistency', and a rating of 'fully', 'mostly', 'somewhat' or 'not' could be assigned. The second descriptor was 'evidence sources', and a rating of 'numerous', 'number', 'limited' or 'lacking' could be assigned. The third descriptor was 'support from experts', and a rating of 'excellent', 'good', 'satisfactory' or 'poor' could be assigned. These ratings were compared, with 91% agreement achieved on descriptor ratings. Discussion subsequently led to an agreed rating for each descriptor for all consensus-based recommendations, resulting in 100% agreement on overall consensus-based recommendation grades. The final consensus-based recommendation grade was the lowest descriptor rating for the item, where this ranged from 1 (highest) to 4 (lowest). Consensus-based recommendations were initially graded for the first draft of the Guideline, and the grading process was repeated prior to submitting the third draft for external review to ensure grades reflected new or revised recommendations following feedback processes.

Table 10. Evidence source descriptor and grades for consensus-based recommendations

Category	Evidence sources	Grade	
Consensus-based recommendation (CBR)	Scholarly literature that was systematically identified and critically appraised. Expert* opinion obtained through community consultation and/or a systematic review of consensus guideline documents, where a systematic review of published research studies revealed an absence of quality evidence.	1	Body of evidence is consistent across *numerous* evidence sources, and there is excellent support from experts for recommendation(s)
		2	Body of evidence is mostly consistent across a *number* of evidence sources, and there is good support from experts for recommendation(s) with few caveats
		3	Body of evidence is somewhat consistent but with some uncertainty or *limited* to a small number of evidence sources, and there is satisfactory support from experts for recommendation(s) with some caveats
		4	Body of evidence is inconsistent or *lacking* and there is poor support from experts for recommendation(s)

** An 'expert' is someone with expertise in the ASD diagnostic process gained through lived or professional experience.*

9.4 Risk Assessment

The potential risks and benefits of the recommendations included in the Guideline were considered for the Guideline as a whole, as the level of evidence available from the scholarly literature did not allow the magnitude of these impacts to be calculated for specific recommendations.

Overall, the risks associated with this Guideline were considered to be low. The Guideline is intended to formalise recommended clinical practices that will ensure clients receive a rigorous, accurate and efficient assessment of ASD concerns. The practices recommended are generally non-invasive, being primarily concerned with client interview and observation. While these non-invasive investigation methods are not without clinical risk, the Guideline stipulates the skills and experience required for members of an Assessment Team.

A key risk was that the formulation of a diagnostic guideline for a specific condition (ASD) might bias clinicians to incorrectly ascribe an ASD diagnosis to individuals where another diagnosis might be more appropriate. A mitigation strategy for this risk was the inclusion of a 'holistic approach' as an

overarching principle of the Guideline (Section 2.3 of the Guideline). This principle obliges diagnosticians to consider the full range of differential or co-occurring diagnoses (see Web Resources). Furthermore, the inclusion of an Assessment of Functioning as a critical part of the overall assessment of ASD concerns will ensure the assessment remains focused on the client's unique strengths and challenges, rather than matching individuals with diagnoses.

A range of ethical issues were considered throughout the development of the Guideline, including the impact of the recommendations on assessment costs and waiting lists as well as the acceptability of the process to disadvantaged groups. Certain features of the Guideline directly address these issues in access to an assessment of ASD concerns:

- The progressive stages of assessment allow flexibility in the process so that individuals do not undergo unnecessary clinical investigation if a diagnosis can be reached early in the assessment. This will have a positive impact on costs and the length of waiting lists.
- Chapter 13 ('Practice Points for Clinical, Research and Policy Settings') specifically recommends a review of the public funding available for neurodevelopmental assessments in light of the publication of this Guideline.
- Telehealth being considered an acceptable method for client interview and observation will enable more efficient diagnosis for individuals living in rural and remote regions.
- Chapter 12 ('Important Considerations') discusses critical concerns for specific population groups that are known to currently have poor access to ASD service provision, including clients who are adults, female, culturally and linguistically diverse (including Aboriginal people), and/or live in rural and regional communities.

9.5 Editorial Independence

A formal project agreement was in place between the National Disability Insurance Agency (project funding body) and Autism CRC. The project objective was articulated as:

> 'This project will involve a nationwide consultation to develop national minimal standards for ASD diagnosis in Australia. These standards will be formalised in a report including a set of national diagnostic guidelines to be presented to both the Autism CRC Board and the NDIA.'

The Management Committee, which included representatives from the NDIA (Peter di Natris and Sarah Johnson) and Autism CRC (Andrew Davis), was provided with a copy of the following documents during the guideline development process:

- ASD diagnosis guideline research summary: Steering Committee
- Autism spectrum disorder diagnostic process: an international scoping review
- Autism spectrum disorder diagnostic process: preliminary report 1 on research findings
- Autism spectrum disorder diagnostic process: preliminary report 2 on research findings
- Major considerations for the diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder (ASD) in Australia
- The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: a national guideline (draft version for community consultation)
- A guideline for the assessment and diagnosis of autism spectrum disorders in Australia: A minimum national standard (draft version for external review).

These documents were provided as evidence that the project was progressing according to the agreed milestones and that the agreed objective would be achieved. Feedback from the Management Committee on these documents was restricted to confirming that the project remained focused on the agreed objective and minor suggestions for terminology. The views of neither the NDIA nor Autism CRC have influenced the content of the final recommendations or Guideline.

10. Feedback and Revision

10.1 Guideline Versions

The feedback and revision process involved the development of several versions of the Guideline:

10.2 First Draft of the Guideline – Public Consultation

The first draft of the Guideline and online resources were made available for download on the Autism CRC website from 7 September until 19 October 2017. The Technical Report and Evidence Tables were available on request to any interested party, with an agreement that the information would be used purely to inform their submission as part of the public consultation process. It was decided not to place these documents directly on the Autism CRC website for download as the content will be submitted to peer-reviewed journals with a view to publication.

The Autism CRC webpage contained instructions for making a submission to provide feedback on the Guideline. Submissions could be made by any individual or organisation in the Australian community during this period. A six-week period was chosen (rather than the minimum required period of 30 days) to allow additional time for individuals and organisations to prepare submissions, given that the announcement was scheduled to coincide with an international conference (Asia Pacific Autism Conference 2017 in Sydney). Submissions could be made using the RedCap survey interface or by post or email to the Coordinator of the Research Executive at the Telethon Kids Institute address.

The following key stakeholders were notified about this consultation process via email on 7 September 2017:

- Steering Committee members
- chief executive officers (or equivalent) of the national peak bodies represented on the Steering Committee
- chief executive officers (or equivalent) of other peak bodies and key service providers with an interest in assessment of ASD concerns
- NHMRC Clinical Guidelines Department
- chief medical officers for the Commonwealth and each state and territory
- senior officials within education departments for the Commonwealth and each state and territory (including government, independent and Catholic systems).

In addition, the draft guideline release and public consultation process were advertised in the following ways on and following 7 September 2017:

- email to individuals who had expressed an interest in the ASD diagnostic guideline project
- media release
- media alert
- media interviews
- keynote presentation by Professor Andrew Whitehouse at the Asia Pacific Autism Conference in Sydney
- banner on the Autism CRC website home page.

10.3 Second Draft of the Guideline – Key Stakeholder Feedback

At the conclusion of the consultation period, over 150 written submissions had been received from a range of respondents, including state government departments, public and private clinical service organisations, client and advocacy groups, and individuals. These submissions were reviewed and discussed by the Research Executive, leading to decisions on amendments to be made to the structure and content of the Guideline. These amendments were integrated into a second draft of the Guideline and supporting documents.

A document was prepared to respond to the submissions (see accompanying Response to Public Consultation Submissions), containing a summary of the main amendments made to the draft Guideline and an extensive table outlining the Research Executive's response to each submission. These responses were either a:

- description of changes made to the Guideline or supporting documents
- rationale for not making changes in response to the submission
- statement that the submission was beyond the scope of the Guideline.

Steering Committee members were notified in December 2017 that the revised Guideline and response to submissions document would be emailed to them on 10 February 2018, with the expectation that they would work with other members of their national peak bodies to provide additional feedback on these documents during a four-week period concluding on 11 March 2018. In total, seven of the 13 national peak bodies represented on the Steering Committee provided written feedback through this process. A further two national peak bodies represented on the Steering Committee provided brief feedback after the conclusion of this period, and two additional national peak bodies with high relevance to the Guideline provided feedback. The Research Executive systematically addressed the feedback received from these national peak bodies when creating the third draft of the Guideline.

10.4 Third Draft of the Guideline – External Review

Along with the public consultation process, feedback was sought from numerous methodological and topic experts who were not involved in the guideline development process.

A Methodological Review Template [126] was completed in relation to the draft Guideline, where the location of information relevant to each requirement of the project was summarised by the Research Executive. The requirements covered: governance and stakeholder involvement; scope and purpose; evidence review; guideline recommendations; guideline structure and style; public consultation; and dissemination and implementation of the guideline. This template was submitted to NHMRC Clinical Guidelines in September 2017, along with the draft Guideline and supporting documents. The NHMRC appointed an independent methodological reviewer to provide feedback on the draft Guideline's compliance with NHMRC requirements. The independent methodological reviewer is an expert in guideline development, disability services and the ICF. This reviewer was selected by the NHMRC, had no involvement in the guideline development process and had no existing relationship with the Research Executive. The independent methodological reviewer provided written feedback in early November 2017, and additional verbal clarification was given during a teleconference attended by members of the Research Executive, NHMRC Clinical Guidelines Team and independent methodological reviewer later the same month. The Research Executive systematically addressed the feedback received from the independent methodological reviewer when creating the revised Guideline (Appendix E).

The revised Guideline and supporting documents were provided to two methodological experts with experience relevant to autism assessment and diagnosis to complete the AGREE II instrument [40] in early April 2018. The AGREE II form allows for feedback to be given using scores and comments regarding six domains of guideline development, along with an overall assessment of the Guideline. The domains are: scope and purpose; stakeholder involvement; rigour of development; clarity of presentation; applicability; and editorial independence. These reviewers were selected by the Research Executive on the basis of their expertise; neither reviewer had involvement with the guideline development process, nor did they have an existing relationship with the Research

Executive. The first methodological expert is an Australian researcher and neuroscientist with experience developing and implementing clinical practice guidelines for mental health conditions and cancer. The second methodological expert is a Canadian researcher and developmental paediatrician who has experience in systematically reviewing clinical guidance documents for neurodevelopmental disorders and has research interests in evaluating the impact and cost-effectiveness of new care models. The average overall scaled score from the two methodological experts was 95%, indicating that the Guideline has been developed to a high-quality standard (Appendix F). The Research Executive systematically addressed the feedback received from the methodological experts when creating the third draft of the Guideline (Appendix G).

The Research Executive nominated six Australian and international topic experts, with extensive knowledge and experience in autism assessment, diagnosis and/or guideline development. None of these experts were involved with the guideline development process, although at least one had a past co-authorship relationship with a member of the Research Executive. The NHMRC Clinical Guidelines Department provided the third draft of the Guideline and supporting documents to their choice of topic experts (some or all of whom may have been nominated by the Research Executive) who, in turn, advised the NHMRC Council as to whether the penultimate Guideline 'reflects the best available evidence and has considered the clinical implications appropriately' [127]. The Research Executive systematically addressed the feedback received from five topic experts before the NHMRC Council meeting (Appendix H).

10.5 Final Published Guideline – Endorsement

Along with seeking to obtain NHMRC approval for the Guideline, endorsement of the published Guideline will be sought from a range of key national peak bodies and government departments. An up-to-date list of organisations that endorse the Guideline will appear on the project webpage of the Autism CRC website. The following are some of the organisations that will be invited to endorse the published Guideline:

- Australian Autism Alliance
- Australian Clinical Psychology Association
- Australian Primary Health Care Nurses Association
- Australian Professional Teachers Association
- Australian Psychological Society
- Autism Awareness
- Autistic Self Advocacy Network of Australia and New Zealand
- Department of Education and Training
- First Peoples Disability Network Australia
- Independent Schools Council of Australia
- National Rural Health Alliance
- National Catholic Education Commission
- National Disability Insurance Agency
- Neurodevelopmental and Behavioural Paediatric Society of Australasia
- Occupational Therapy Australia
- Royal Australian and New Zealand College of Psychiatrists
- Royal Australian College of General Practitioners
- Royal Australasian College of Physicians
- Speech Pathology Australia.

11. Dissemination Plan

11.1 Guideline Dissemination and Implementation

A dedicated project webpage on the Autism CRC website (https://autismcrc.com.au/national-guideline) will make available the following resources for free download by members of the public:

- Guideline (PDF file)
- Guideline Summary and Recommendations (PDF file)
- Guideline Short Summary for the Community (PDF file)
- Administrative and Technical Report (PDF file)
- Evidence Tables (PDF file)
- Response to Public Consultation Submissions (PDF file)
- Web Resources (may be updated during implementation period), for example:
  - Referral Form (Word file)
  - Medical Evaluation Form (Word file)
  - Report Templates (Word files)
  - Case Studies (PDF file)
  - information about standardised assessment tools (web content with links to external resources).

The final published Guideline will be promoted through the following approaches:

- email to organisations that are invited to endorse the Guideline
- email to Steering Committee members and Autism CRC participants
- email to individuals and organisations who participated in the community consultation activities and/or provided a submission during the public consultation process
- email to individuals who expressed an interest in the ASD diagnostic guideline project through the Autism CRC website
- media release (and associated media interviews)
- banner on the Autism CRC website home page.

Data will be collected through the Guideline webpage, in particular web analytics of views and downloads as well as stakeholder type and email address requested at the time of download. This will help determine the extent to which the Guideline has been disseminated to clients and professionals.

In addition, manuscripts describing the findings of the systematic reviews and community consultation activities will be submitted to peer-reviewed journals, with a view to publishing articles as open access where possible. Links to the published articles will be added to the Guideline webpage.

A range of activities to assist implementation of the Guideline in local contexts are recommended as part of future dissemination and implementation projects, including the development of:

- fact sheets and explainer videos for clients, referrers and assessment professionals to obtain relevant information quickly
- checklists for professionals to self-evaluate readiness for implementing the Guideline and to self-audit adherence to recommendations
- instruction manuals for clients, referrers and assessment professionals that outline specific processes in greater detail
- online educational resources to allow clients, referrers and assessment professionals to access information in a convenient and flexible manner

- face-to-face educational programs to teach end-users how to use the Guideline.

The Research Executive acknowledges that the implementation of this Guideline may lead to a change in service delivery for some clinicians and organisations, but very little change for other clinicians and organisations. The extent of change will vary by sector and geographical location as well as individual clinician, depending on such factors as the years since they completed their clinical training. Throughout the Guideline development process, the Research Executive focused on designing a flexible and practical process. Although existing funding mechanisms were considered, these did not prevent the Research Executive from recommending innovative approaches to service delivery if these were supported by research evidence and/or expert opinion. Instead, the Research Executive has suggested advocating for change to funding systems. Potential existing facilitators and barriers that may have an impact on the implementation of Guideline recommendations were identified through the community consultation (in particular, the workshops and Delphi survey) and are described in Table 11.

Table 11. Potential facilitators and barriers to implementation of the Guideline

Potential facilitators	Potential barriers
A consensus among health professionals that a national guideline is an important step forward for the field A consensus among clients that a national guideline is an important step forward for the field An extensive, inclusive and public consultation process in the development of the Guideline A flexible assessment process outlined in the Guideline (see the bullet points under 'Risk Assessment', Section 9.4) which will facilitate its use in a broad range of settings and circumstances The availability of step-by-step instructions describing the Guideline that are freely available Information workshops where health professionals have the opportunity to ask questions	The financial cost to provide a comprehensive dissemination and implementation project The financial cost to change established clinical processes to meet the standards defined in the Guideline The time required to change established clinical processes to meet the standards defined in the Guideline Disagreements between professional groups about their role within an ASD diagnosis Medicare and private health insurers not covering the full cost of an assessment of ASD concerns, leading to increased 'out of pocket' expenses for some clients Wait times may increase where clinicians have to increase the amount of time spent on an assessment of ASD concerns to meet the Guideline requirements A paucity of diagnosticians in rural and remote communities who have the skills and experience required by the Guideline (though the Guideline incorporates elements, such as telehealth, that may actually increase access to diagnostic services compared to the status quo

11.2 Resource Implications

The potential resource implications of applying the recommendations have been considered throughout the guideline development process, particularly how to achieve cost-effectiveness for clients and government during the assessment of ASD concerns process. The following resource implications emerged from themes arising from the scholarly literature and community consultation data:

- The Guideline describes an assessment of ASD concerns process that may require more clinical time than is currently employed by some clinicians and organisations. These clinicians and organisations will be required to adjust their clinical processes accordingly.

- The Guideline describes levels of clinical skill and experience required by members of the Assessment Team. Some clinicians may need to acquire further skills and/or experience to meet these requirements.
- Current levels of Medicare and private health insurance rebates do not cover the full cost of the assessment described in the Guideline. The Guideline incorporates a flexible, staged system, which ensures that individuals do not undergo unnecessary clinical investigation if a diagnosis can be reached early in the assessment process. Adoption of the Guideline may increase 'out of pocket' expenses for some clients, where clinicians have had to increase the amount of time spent on an assessment of ASD concerns to meet the Guideline requirements. Yet the staged system may also decrease the out-of-pocket expenses of some clients if a diagnosis can be made with certainty earlier in the assessment of ASD concerns process.

11.3 Guideline Evaluation

Feedback may be sought from members of Assessment Teams who are early adopters of the Guideline recommendations, to determine if recommendations need to be modified or if additional recommendations should be included. This information may be used to refine the Guideline and supporting documents.

A preliminary evaluation of the Guideline is recommended in the future, to gauge in particular if it is perceived as acceptable to clients and feasible to administer by clinicians. Further funding opportunities will be explored for activities to evaluate the extent to which Guideline recommendations are adopted into routine practice, and the subsequent impact, including:

- measuring changes in knowledge about the Guideline recommendations among clients and professionals
- evaluating whether the Guideline provides a comprehensive assessment of the individual to help determine support needs
- measuring the psychometric properties of existing Assessment of Functioning tools in an Australian ASD population
- developing and validating an Assessment of Functioning tool based on the ICF Core Sets for ASD
- monitoring the proportion of Single Clinician Diagnostic Evaluations completed compared to those that progress to a Consensus Team Diagnostic Evaluation
- investigating the accuracy of Single Clinician Diagnostic Evaluations compared to those that progress to a Consensus Team Diagnostic Evaluation
- examining the impact of various diagnostic practices on diagnostic outcomes, including diagnostic decisions, costs and timeframes (e.g. wait time and assessment duration)
- auditing compliance with the Guideline's consensus-based recommendations in a variety of service settings
- ongoing measurements and audits of tangible indicators of the Guideline's dissemination, implementation and efficacy
- determining how the Guideline fits the requirements of health and education services in each state/territory of Australia for ASD diagnosis.

It is anticipated that these evaluations will help address the paucity of high-level empirical evidence identified in the scholarly literature reviews conducted as part of the development of this Guideline.

11.4 Guideline Revision

The project webpage on the Autism CRC website will contain a range of resources, such as information about standardised assessments, that can be easily updated as new evidence is published. The Research Executive recommends that a review, and possible revision, of the Guideline be completed approximately three years after publication (i.e. in mid-2021). It is anticipated that a revision will incorporate any improvements that were identified through the evaluation project, along with updates to reflect new relevant and significant scholarly publications or policy changes.

Appendix A – Research Executive Terms of Reference

Purpose

The ASD Diagnosis Guideline Research Executive ('the Committee') is a working committee of the Autism CRC Ltd (ACRC) created to conduct the background research and prepare the documents for the development of a national Guideline for autism spectrum disorder diagnoses in Australia (the 'Guideline'). The Committee will exist for the duration of the project.

Membership

The Committee comprises Professor Andrew Whitehouse (ACRC Program 1 Director), Clinical Associate Professor John Wray (Developmental Paediatrician and Senior Clinical Advisor of the Child Development Service, WA), the Project Coordinator and up to two external specialists. The secretary will be the Project Coordinator of the ASD Diagnosis Guideline project.

Appointment of Chair

The Chair of this Committee will be Professor Andrew Whitehouse (ACRC Program 1 Director).

Meetings

The Committee will meet as often as it agrees or as required. The Committee could expect to meet fortnightly or monthly by teleconference. The Committee will meet in person or by teleconference at the request of the Chair or at the request of two or more members of the Committee. A quorum will be a majority of the members present in person or by teleconference.

Delegated Authority

In carrying out its duties, the Committee has authority to recommend and endorse preliminary and final models and guidelines relating to the diagnosis of autism spectrum disorder, as required to establish the Guideline.

Responsibilities

The responsibilities of the Committee are as follows:

- ensure the development of the ASD Diagnosis Guideline is consistent with best practice
- establish a Steering Committee
- ensure proper and timely communication with the Management and Steering Committees
- establish, implement and monitor the project management process and documents
- conduct all research activities, including designing research methods/documents, literature review, obtaining ethics approval, data collection, data analysis/interpretation and summarising findings
- prepare literature review report, research summary reports, draft Guideline, final Guideline and launch presentation
- prepare manuscripts describing the research findings and submit to peer-reviewed journals.

Conflict of Interest

All Committee members are required to complete the Conflict of Interest form and return this to the secretary prior to the first Committee meeting. Members are also required to advise the Committee of any new conflicts of interest that arise during the project. The existence of a conflict of interest will not necessarily prevent a member from participating in the Committee. Committee members will discuss

any potential conflicts of interest during the meeting following disclosure, and determine any necessary management strategies. Details disclosed in the Conflict of Interest form will be publicly available in the Guideline and/or related documents. There are two general circumstances under which conflicts of interest may arise, and there may be others. Firstly, a member may have a financial conflict of interest if benefits or losses, either in money or in-kind, have occurred or may occur at a level that might reasonably be perceived to affect a person's judgement in relation to fair decisions about evidence and their participation in group decision-making. Secondly, a member may have a relationship conflict of interest if a strong position or prejudice or familial connection or other relationship held by a person could reasonably, or be perceived to, affect a person's judgement in relation to fair decisions about evidence and their participation in group decision-making, including making an effort to arrive at a consensus.

Intellectual Property

Each Committee member will make available to the project any Background Intellectual Property (that is pre-existing Intellectual Property created prior to or independently of the project) necessary to participate in the Committee. Upon its creation, all Project Intellectual Property (Intellectual Property developed in the course of developing the Guideline) will be owned by the Autism CRC. Intellectual Property includes all copyright (including rights in relation to phonograms and broadcasts), all rights in relation to inventions (including patents), plant varieties, trade marks (including service marks), designs, circuit layouts, all other rights resulting from intellectual activity in the industrial, scientific, literary or artistic fields and any right to have confidential information kept confidential, but does not include Moral Rights or rights of performers.

Confidentiality

Each member of the Committee will treat all Background Intellectual Property, Project Intellectual Property and Confidential Information owned by the other members or committees as confidential. Members will use Confidential Information only for the purposes of this project, and otherwise will keep confidential and not disclose any Confidential Information. The obligations of confidentiality imposed on a member will survive termination or completion of this project. Confidential Information means all information that is not in the public domain that is by its nature confidential or that has been designated as confidential by the disclosing party, and includes all trade secrets, know-how, financial information, other commercially or scientifically valuable information of whatever description and in whatever form (whether written, or oral, visible or invisible) and, except as required in relation to third-party participation in the project, the contents of this Terms of Reference and any project details.

Authorship

As per the Vancouver Protocol, authorship of the Guideline and any scholarly publications (the 'Publications') that are written during the process of developing the Guideline will not be automatically assigned to any members of the Committee. In accordance with the Vancouver Protocol, the contribution of members of the Committee will be acknowledged individually in the Guideline. Any Committee member who would like to become an author of Publications should notify the Committee secretary of their commitment to making a substantial contribution to the research and writing process involved in preparing Publications, as required by the Vancouver Protocol. Interested members should be aware that there is no remuneration associated with authorship of Publications. In accordance with the Vancouver Protocol, the contribution of non-author members of the Committee will be acknowledged individually or as a group in all Publications.

Performance and Review

This Terms of Reference document will be reviewed after the first three months of operation, and then on a quarterly basis, if required. A Committee performance review is to be undertaken three times per year by the ASD Diagnosis Guideline Management Committee. Additionally, the Committee will report to the Board at least twice per year on the activities of the ASD Diagnosis Guideline project, including:

- progress towards milestones, project deliverables and other achievements

- number of participants (individuals and peak bodies) who took part in research studies and consultation process
- total expenditure of funding and in-kind contributions
- number of co-authored publications or acknowledgements of the ASD Diagnosis Guideline project
- impact of the ASD Diagnosis Guideline project on the general field of ASD research and practice, in Australia and internationally.

Reporting

The Committee reports to the Autism CRC Ltd Board's appointees to the ASD Diagnosis Guideline Management Committee. The Terms of Reference relating to the Management Committee are covered by Collaborative Agreement between Autism CRC and the NDIA.

Appendix B – Steering Committee Terms of Reference

Purpose

The ASD Diagnosis Guideline Steering Committee ('the Committee') is a steering committee of the Autism CRC Ltd (ACRC) created to guide the development of a national Guideline for autism spectrum disorder diagnoses in Australia (the 'Guideline'). The Committee will exist for the duration of the project.

Membership

The Committee will consist of up to twenty (20) members, comprising the members of the ASD Diagnosis Guideline Research Executive and one nominee from Australian national peak body organisations (the 'Peak Body') that have been selected by the Research Executive to represent stakeholders involved in autism spectrum disorder diagnosis, including clients. The Chair of the Committee will invite the Leader of each Peak Body to nominate an individual that is a member of the Peak Body, has substantial knowledge of the ASD diagnosis process and is committed to representing the collective perspective of the Peak Body. The secretary will be the Project Coordinator of the ASD Diagnosis Guideline project.

Appointment of Chair

The Chair of this Committee will be Professor Andrew Whitehouse (Project Chief Investigator).

Meetings

The Committee will meet by teleconference at least three times during the one-year project duration. Additional meetings can be scheduled at the request of the Chair or at the request of a majority of the members of the Committee. Members of the Committee may nominate a proxy from the Peak Body they are representing to attend a meeting if the member is unable to attend. The proxy must also have substantial knowledge of the ASD diagnosis process, be committed to representing the collective perspective of the Peak Body and comply with this Terms of Reference. The Chair must be informed of the substitution at least one working day prior to the scheduled nominated meeting. The nominated proxy shall have all rights afforded to committee members at the attended meeting. A quorum will be a majority of the members, including proxy members, present by teleconference.

Delegated Authority

In carrying out its duties, the Committee has authority to recommend and provide feedback on Guidelines relating to the diagnosis of autism spectrum disorder, as required to establish the Guideline. The Committee does not have the authority to make decisions regarding guidelines or endorse the final Guideline.

Responsibilities

The responsibilities of the Committee are as follows:

- Provide feedback on the proposed process for developing the Guideline.
- Provide input on documents and components to be included in the literature review.
- Nominate experts within their Peak Body to participate in the consultative phase of the project.
- Provide advice on the most essential key components to include in the Guideline.
- Provide feedback on draft versions of the Guideline.

Conflict of Interest

All Committee members are required to complete the Conflict of Interest form and return this to the secretary prior to the first Committee meeting. Members are also required to advise the Committee of any new conflicts of interest that arise during the project. The existence of a conflict of interest will not necessarily prevent a member from participating in the Committee. Committee members will discuss any potential conflicts of interest during the meeting following disclosure, and determine any necessary management strategies. Details disclosed in the Conflict of Interest form will be publicly available in the Guideline and/or related documents. There are two general circumstances under which conflicts of interest may arise, and there may be others. Firstly, a member may have a financial conflict of interest if benefits or losses, either in money or in-kind, have occurred or may occur at a level that might reasonably be perceived to affect a person's judgement in relation to fair decisions about evidence and their participation in group decision-making. Secondly, a member may have a relationship conflict of interest if a strong position or prejudice or familial connection or other relationship held by a person could reasonably, or be perceived to, affect a person's judgement in relation to fair decisions about evidence and their participation in group decision-making including making an effort to arrive at a consensus.

Intellectual Property

Each Committee member will make available to the project any Background Intellectual Property (that is pre-existing Intellectual Property created prior to or independently of the project) necessary to participate in the Committee. Upon its creation, all Project Intellectual Property (Intellectual Property developed in the course of developing the Guideline) will be owned by the Autism CRC. Intellectual Property includes all copyright (including rights in relation to phonograms and broadcasts), all rights in relation to inventions (including patents), plant varieties, trade marks (including service marks), designs, circuit layouts, all other rights resulting from intellectual activity in the industrial, scientific, literary or artistic fields and any right to have confidential information kept confidential, but does not include Moral Rights or rights of performers.

Confidentiality

Each member of the Committee will treat all Background Intellectual Property, Project Intellectual Property and Confidential Information owned by the other members or committees as confidential. Members will use Confidential Information only for the purposes of this project, and otherwise will keep confidential and not disclose any Confidential Information. The obligations of confidentiality imposed on a member will survive termination or completion of this project. Confidential Information means all information that is not in the public domain that is by its nature confidential or that has been designated as confidential by the disclosing party, and includes all trade secrets, know-how, financial information, other commercially or scientifically valuable information of whatever description and in whatever form (whether written, or oral, visible or invisible) and, except as required in relation to third party participation in the project, the contents of this Terms of Reference and any project details.

Authorship

As per the Vancouver Protocol, authorship of the Guideline and any scholarly publications (the 'Publications') that are written during the process of developing the Guideline will not be automatically assigned to any members of the Committee. In accordance with the Vancouver Protocol, the contribution of members of the Committee will be acknowledged individually in the Guideline. Any Committee member who would like to become an author of Publications should notify the Committee secretary of their commitment to making a substantial contribution to the research and writing process involved in preparing Publications, as required by the Vancouver Protocol. Interested members should be aware that there is no remuneration associated with authorship of Publications. In accordance with the Vancouver Protocol, the contribution of non-author members of the Committee will be acknowledged individually or as a group in all Publications.

Performance and Review

This Terms of Reference document will be reviewed after the first three months of operation, and then on a quarterly basis, if required. A Committee performance review is to be undertaken once per year by the ASD Diagnosis Guideline Management Committee.

Reporting

The Committee reports to the Autism CRC Ltd Board's appointees to the ASD Diagnosis Guideline Management Committee.

Appendix C – Included Studies

First author, year [reference]	Level of evidence*	Design and key variables	Participants	Systematic review
Abbott, 2013 [52]	III	This is a descriptive study. The key variables measured were the parents' experiences of the structure, style and content of the feedback session they received that involved the disclosure of their child's diagnosis of ASD.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Adelman, 2011 [105]	III	This is a correlational/cross-sectional study design. The key variables measured looked at factors that may affect the age of diagnosis of ASD: ethnicity, various sibling factors, parent socioeconomic status and education, whether the child was first diagnosed with another disorder, the type of first symptoms to cause concern, whether the child was referred to early childhood intervention, and factors concerning the child's paediatrician action and the parents' relationship with the paediatrician.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum Professional who provides services to individuals on the autism spectrum or their carers/families	Time factors
Andersson, 2014 [53]	Ib	This is a comparative, descriptive, partly longitudinal study. The study aimed to evaluate parent and preschool teacher experiences, in regards to time of first concern about the child and about the diagnostic process at a specialised child neuropsychiatry clinic.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum Professional who refers individuals to diagnostic assessments for autism	Experience
Austin, 2016 [106]	III	This is a descriptive, cross-sectional study. A review of ASD diagnostic systems and assessment of their quality improvement of services to: decrease ASD diagnostic system complexity (where possible), decrease lengthy wait list for children aged 3–5 years, and improve access to ongoing ASD care clinics.	Professional who conducts diagnostic assessments for autism Professional who provides services to individuals on the autism spectrum or their carers/families ASD diagnostic and services clinics	Time factors

Bargiela, 2016 [54]	III	This is a qualitative study that additionally utilises quantitative data. The female autism phenotype and its impact on the under-recognition of autism spectrum conditions in girls and women is investigated.	Individual on the autism spectrum	Experience
Barnett, 2014 [55]	III	This is a qualitative study. The study explains how ASD diagnostic professionals deliver a diagnosis, identifying communication patterns, rules of symbol use, rules of meaning and action, strengths and weaknesses of the process, and individual and team goals.	Professional who conducts diagnostic assessments for autism	Experience
Bessette Gorlin, 2016 [56]	III	This is a qualitative study with a phenomenological approach. Families were asked to share their experiences of having a child with severe autism. Outcomes measured were: family perception of the mystery and complexity of severe autism; dealing with severe behaviour challenges; dealing with significant behaviour challenges; experiencing severe stress; living with severe isolation; and dependence on family and compassion for each other.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Braiden, 2010 [57]	III	This is a qualitative study relying on semi-structured interviews. This study looked at factors that were influential in the experiences of the parents during the process of their child being given a diagnosis of ASD. Key variables outlined were having the parents' initial concerns listened to; receiving their child's diagnosis in person; receiving written information and help in applying this information.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Bressi, 2017 [58]	III	This is a descriptive, mixed-methods study. The semi-structured interview design consisted of six primary questions targeting the parent and family journey for their child with autism; a comparison of how their child was doing currently to when they were diagnosed; who the primary caregiver was; any improvements in the child's	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience

		abilities and skills; if a genetic counsellor was seen; and any theories to the cause of the child's autism. The primary purpose of this study was to address issues for patients and families as well as provide information that would allow genetic counsellors to better aid the entire community of people with ASD.		
Cane, 2015 [59]	III	This is a descriptive study using narrative methodology. This study explored parental perceptions of the diagnostic process that their children underwent for ASD, particularly the reasons for a later diagnosis.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum Individual on the autism spectrum	Experience
Carlsson, 2016 [60]	III	This is a qualitative study relying on semi-structured interviews. Parents' lived experience of the neuropsychiatric diagnostic process was investigated and the key themes that emerged were: parents were seeking knowledge; parents were trusting and challenging the experts; and parents felt empowered and not alone.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Chamak, 2011 [61]	III	This is a survey of retrospective questionnaires that determined both qualitative and quantitative results. This survey focused on French parents' views of the diagnostic process relating to their child with ASD.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Time factors Experience
Chiu, 2014 [62]	III	This is a qualitative study comprising questionnaires and an interview. The study assessed the content and patterns of diagnosis-informed counselling for mothers of children with ASD and investigated the determinants for maternal satisfaction with this counselling.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Connolly, 2013 [63]	III	This is a qualitative, three-staged study involving a research phase, an intervention phase and an evaluation phase. The study involved a consultation with parents of children waiting for a diagnostic assessment for ASD. Parents reported benefits from the pilot	Carer of an individual who is currently, or considering, undergoing a diagnostic assessment for autism	Time factors Experience

		group through meeting professionals involved in assessment, being supported by other parents, and learning strategies to help their children.	Family member of an individual who is currently, or considering, undergoing a diagnostic assessment for autism	
Craig, 2015 [64]	III	This is a qualitative study with a phenomenological approach. Five themes were identified relating to parents' experiences of having an adolescent child on the autism spectrum. These were: seeking and receiving a diagnosis; the challenges of ASD; the impact of ASD on the family and family life; and coping with ASD.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Crane, 2016 [65]	III	This is a descriptive, cross-sectional survey. The survey questioned respondents about initial concerns they had regarding their child's development; the different professional groups seen during the diagnostic process; the time taken to get a formal diagnosis for the child; how the diagnosis was disclosed to them	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Time factors Experience
Daniels, 2014 [107]	Ia	This is a systematic review of the literature on early detection of ASD approached in primary care and other community settings in the USA.	Individual who is, or is considering, undergoing a diagnostic assessment for autism Carer of an individual who is, or is considering, undergoing a diagnostic assessment for autism Family member of an individual who is, or is considering, undergoing a diagnostic assessment for autism Professional who refers individuals to diagnostic assessments for autism	Time factors

Dawkins, 2016 [46]	III	This is a quantitative study assessing the diagnostic agreement of using the Childhood Autism Rating Scale: Second Edition (CARS2) with DSM-IV-TR criteria as opposed to using DSM-5 criteria to diagnose ASD.	Individual who is, or is considering, undergoing a diagnostic assessment for autism	Accuracy
Denman, 2016 [108]	III	This is a cross-sectional design. Variables were identified that determined how families made sense with each other while waiting for an ASD assessment. These were: an interactional pattern of interruptions impeding the progress of sense-making narratives; face saving to maintain positive identities and shared understanding; and difficulties in word finding within sense-making narratives.	Individual who is, or is considering, undergoing a diagnostic assessment for autism Carer of an individual who is, or is considering, undergoing a diagnostic assessment for autism Family member of an individual who is, or is considering, undergoing a diagnostic assessment for autism	Time factors
Ducey, 2009 [66]	III	A qualitative study describing the experiences of parents before and during their child's ASD diagnostic process, with the following themes emerging: confusion, reassurance and denial, realisation, and searching for answers.	Carer of an individual who is, or is considering, undergoing a diagnostic assessment for autism Family member of an individual who is, or is considering, undergoing a diagnostic assessment for autism Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Time factors Experience
Falkmer, 2013 [5]	III	A systematic review that analyses ASD diagnostic tools and assessments to determine their accuracy, validity, reliability and utility.	Professional who conducts diagnostic assessments for autism Individual on the autism spectrum	Accuracy

Feliciano, 2008 [67]	III	A descriptive study which aimed to understand how parents come to accept a diagnosis of chronic illness or disability in their child, and how this acceptance is related to a parent's engagement in play with their child, how the parent perceives the child's social deficits, and how the parent has addressed earlier relationship experiences.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Fombonne, 2009 [109]	III	This is a descriptive study which examined critical time points in the developmental trajectory of children eventually diagnosed with ASD.	Individual who is, or is considering, undergoing a diagnostic assessment for autism Carer of an individual who is, or is considering, undergoing a diagnostic assessment for autism Family member of an individual who is, or is considering, undergoing a diagnostic assessment for autism	Time factors
Frenette, 2013 [110]	III	This is a population-based cohort study examining the age at which children were diagnosed with ASD in Nova Scotia, Canada. Key variables were maternal age at delivery, rate of comorbidity with ADHD, and the county of residence.	Individual on the autism spectrum Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Time factors
Gordon-Lipkin, 2016 [111]	III	This literature review investigated how innovative clinical models address the factors that contribute to bottlenecks in the ASD diagnosis process. These factors were: time-consuming evaluations, cost of care, lack of providers, and lack of comfort of primary-care providers to diagnose autism.	Clinical autism centres in the USA Professional who refers individuals to diagnostic assessments for autism Professional who conducts diagnostic assessments for autism Professional who provides services to individuals on the	Time factors

			autism spectrum or their carers/families	
Greaves, 2014 [68]	III	This qualitative study documents the experiences of young adolescent men with Asperger syndrome. Key themes that emerged were: families' experiences obtaining the diagnosis; families' experiences of education following diagnosis; and the young men's experiences.	Individual on the autism spectrum Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Grodberg, 2014 [48]	III	This is an exploratory study. The sensitivity and specificity of scores produced by the Autism Mental Status Exam (AMSE) were tested using DSM-5 criteria in diagnosing ASD in a sample of high-risk, verbally fluent adults.	Individual who is, or is considering, undergoing a diagnostic	Accuracy
Grodberg, 2016 [47]	III	This is an exploratory study assessing the effectiveness of the AMSE in differentiating between patients who meet criteria for ASD using a gold-standard research diagnostic protocol and those who do not.	Individual who is, or is considering, undergoing a diagnostic assessment for autism	Accuracy
Hedley, 2015 [49]	III	This is a quantitative study assessing the diagnostic accuracy of the Autism Detection in Early Childhood (ADEC) screening tool.	Individual who is, or is considering, undergoing a diagnostic assessment for autism	Accuracy
Hennel, 2016 [69]	III	This is a survey producing both qualitative and quantitative results. Parent experiences regarding the ASD diagnosis of their child and preferences with paediatric practices were examined. Variables assessed were: diagnosis delivery and information given at diagnosis (written and spoken vs. neither); and parent-perceived importance and harms of information accessed post-diagnosis.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum Professional who conducts diagnostic assessments for autism	Experience
Heredia-Alvarado, 2017 [70]	III	A descriptive, transcendental study with a phenomenological approach, exploring the lived experiences of first-generation Latino mothers of children diagnosed with ASD. The variables assessed that affected the mothers' experiences were: resilience, stressors, coping	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience

		styles, social supports and systems, cultural factors, and access to services.		
Huws, 2008 [71]	III	In this qualitative study young people with high-functioning autism provided an account of their perceptions of autism and their diagnosis experiences. Themes that emerged were: disclosure delay; providing explanations; potential effects of labelling; disruptions and opportunities; and acceptance and avoidance.	Individual on the autism spectrum	Experience
Jones, 2014 [72]	III	This survey with quantitative results examined the overall levels of satisfaction with the diagnostic process of adults with high-functioning ASD. Predictive variables were: extent of delays, number of professionals seen, quality of information given at diagnosis, and levels of post-diagnostic support.	Individual on the autism spectrum	Experience
Kalash, 2012 [73]	III	This is a qualitative study with a phenomenological approach. The study addressed the experiences and perspectives parents had about their child's ASD diagnosis and treatment options.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Keenan, 2010 [74]	Ib	A cross-sectional study that explores the process and parents' experiences of gaining an ASD diagnosis for their child. The study confirmed that: diagnostic and planning processes are extremely stressful for parents; statutory diagnosis takes a long time; care and education plans do not include full parental participation; and reviews of plans do not consistently include intervention data.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum Professional who conducts diagnostic assessments for autism Professional who provides services to individuals on the autism spectrum or their carers/families	Experience
Lewis, 2016 [75]	III	This is a qualitative study. Adults who self-diagnosed having ASD completed an online open-ended survey about the experience of being self-diagnosed with ASD.	Individual on the autism spectrum	Experience
Lilley, 2011 [76]	III	In this qualitative study mothers were asked to recount their experiences regarding early	Carer of an individual on the autism spectrum	Experience

		intervention, treatment choices and the process of having their child with ASD diagnosed.	Family member of an individual on the autism spectrum	
Mann, 2014 [77]	III	This is a qualitative study examining the experiences of families of children with ASD to identify the barriers and facilitators to identification, diagnosis and treatment.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Time factors Experience
Marco, 2010 [78]	III	This is a qualitative study. This project set out to create guidelines for professionals who disclose diagnoses of ASD to parents with the aim of minimising emotional distress and maximising the potential for resolution. Variables measured were: alignment with current practice, importance of guidelines, proposed changes to guidelines, and ease of recommendation implementation.	Professional who conducts diagnostic assessments for autism	Experience
McCaffrey, 2011 [79]	III	This is a qualitative study with a phenomenological approach. Pre-diagnostic, diagnostic and post-diagnostic experiences of mothers of children with ASD were identified.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
McClure, 2010 [112]	III	This is a comparative analysis. Local teams were trained by a specialist ASD assessment team to reduce lengthy delays between ASD assessments. Correspondence between the diagnoses of the local teams and of the specialist team was analysed.	Professional who conducts diagnostic assessments for autism Individual on the autism spectrum	Time factors
McKenzie, 2015 [113]	III	This is a cross-sectional, case-note study with a retrospective approach. Main predictors of delays in ASD diagnosis were identified at the wait for the first appointment, assessment duration and total wait for the diagnosis. These factors were: the amount of relevant information available pre-assessment, the risk of ASD, and the number of contacts required for a diagnosis.	Individual on the autism spectrum	Time factors
McKenzie, 2016 [114]	III	This is a cross-sectional, case-note study with a retrospective approach examining the relationship between the	Professional who conducts diagnostic assessments for autism	Time factors

		variables of adherence to routine practice and of wait time for an ASD diagnosis as described in the Scottish Intercollegiate Guidelines Network.	Professional who provides services to individuals on the autism spectrum or their carers/families	
McKenzie, 2016 [115]	III	This is a cross-sectional, case-note study with a retrospective approach examining the relationship between the variables of routine practice recommendations and of wait time for an ASD diagnosis as described in the National Institute for Health and Care Excellence (NICE) 142 Guidelines.	Individual on the autism spectrum	Time factors
McMorris, 2013 [80]	III	This is a qualitative study relying on self-report questionnaire, measuring parental levels of satisfaction with their child's ASD diagnosis process.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Miodovnik, 2015 [116]	III	This is a cross-sectional survey investigating the relationship between the timing of ADHD diagnosis in children with ASD and the age at ASD diagnosis.	Individual on the autism spectrum	Time factors
Mitchell, 2014 [81]	III	This is a qualitative study measuring outcomes of: family members' coping abilities, the impact of ASD diagnosis on the sibling, and the impact of ASD diagnosis on marital relationships.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Moh, 2012 [82]	III	This population-based cohort study examines the duration of the diagnostic period, the number of professionals consulted, the relationship with the professional(s), and the perceived helpfulness of information provided in its impact on parental satisfaction and stress during the diagnostic process.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum Professional who conducts diagnostic assessments for autism Professional who provides services to individuals on the autism spectrum or their carers/families	Experience
Molteni, 2014 [83]	III	This is a multi-method case study. The aim of this study was to highlight the changes experienced by parents after the ASD diagnosis of their child.	Carer of an individual on the autism spectrum	Experience

		Outcomes measured were: warning signs of autism perceived by parents; the diagnosis delivery; and the changes in the family, in relationships and at work after the diagnosis.	Family member of an individual on the autism spectrum	
Murillo, 2016 [84]	III and IV	This is a case study. Cases of varying stakeholders were examined to demonstrate how the diagnostic process of ASD could be enhanced on a global level.	Individual on the autism spectrum Professional who refers individuals to diagnostic assessments for autism Professional who conducts diagnostic assessments for autism Professional who provides services to individuals on the autism spectrum or their carers/families	Experience
Navot, 2017 [85]	III	This is a qualitative study exploring the mother–child relationship and experiences of raising girls with ASD. Themes identified were scepticism and delayed diagnosis, disbelief from others, lack of information about girls with ASD, higher social demands in adolescence, puberty challenges around hygiene, disappointment about physical appearance, vulnerability in relationships and worries about future functioning.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Novoa, 2015 [86]	III	This is a qualitative study with a phenomenological approach, focusing on the experiences of immigrant Mexican families in the USA during the ASD diagnosis process of their child.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Oslejskova, 2007 [117]	III	This is a qualitative study with a retrospective approach. This study aimed to examine the delay between the recognition of the first symptoms by parents and a correct diagnosis of ASD. Variables investigated were: age of appearance of 'first signs', age at diagnosis and delay in diagnosis.	Individual on the autism spectrum Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Time factors
Oswald, 2017 [87]	III	This survey examined differences between diagnostic	Individual on the autism spectrum	Experience

		groups with respect to demographics, age of child at first parental concern about development, number and nature of first parental concerns, age at diagnosis, and health professionals' responses to parental concerns.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	
Penner, 2017 [128]	IV	This is a systematic review. The objective of this review was to assess the quality and content of professional association and government clinical guidelines for the diagnostic process of ASD.	Professional who conducts diagnostic assessments for autism Professional who provides services to individuals on the autism spectrum or their carers/families Government organisations and committees	Guideline
Powell, 2016 [88]	III	This is a descriptive study comprising qualitative and quantitative methods. This study analysed the experiences of adults with Asperger's syndrome diagnosis. The variables measured were: anxiety, depression, satisfaction with life, impact of diagnosis on life and impact on emotions.	Individual on the autism spectrum	Experience
Punshon, 2009 [89]	III	This is a qualitative study using a phenomenological approach, documenting experiences of adults given an ASD diagnosis. Key themes were aspects about life experience, service experience, beliefs about symptoms of Asperger's syndrome, identity, effects of diagnosis on beliefs, and effects of societal views.	Individual on the autism spectrum	Experience
Rabbitte, 2017 [90]	III	This is a qualitative study with a phenomenological approach. It aimed to identify, from parental experiences, the challenges that girls face, the benefits brought by the eventual diagnosis, and the appropriateness of the supports and services that girls were receiving.	Carer of an individual on the autism spectrum Family member of an individual on the autism spectrum	Experience
Randall, 2016 [118]	III	This is a descriptive study comprising quantitative methods investigating the consistency between current diagnostic practices and current diagnostic recommendations.	Professional who conducts diagnostic assessments for autism	Time factors

Ratto, 2013 [91]	III	This cross-sectional study examines how cultural factors affect various diagnostic processes. Variables included: age of ASD diagnosis, age of first parental concern, ASD knowledge, intervention, severity of symptoms, knowledge about development therapeutic service contact, and socioeconomic factors, such as educational attainment and income.	Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Experience
Reed, 2012 [129]	III	This is a literature review which highlights the widespread impact of an ASD diagnosis for a child in terms of the development of a treatment plan, and the impact on parental functioning.	Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Experience
Rogers, 2016 [92]	III	This is a cross-sectional study of both quantitative and qualitative methods. The study examined the professional perspective and experiences of the accessibility of services, the diagnostic process, post-diagnostic support, and improvement to patient pathways.	Professional who conducts diagnostic assessments for autism	Experience
Rose, 2011 [93]	III	This is a cross-sectional study with a quantitative method. Key variables were: parental stress; parental satisfaction; diagnostic processes, such as the number of professionals seen for diagnosis; ages of first concern, first diagnosis and current diagnosis; disclosure of diagnosis; length of diagnosis process; and information received.	Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Time factors Experience
Rosqvist, 2012 [94]	III	This is an observational, qualitative, case-series study which aimed to investigate the perceptions of receiving an Asperger's syndrome diagnosis and the process of 'coming out' as having this diagnosis.	Individual on the autism spectrum	Experience
Rossi, 2012 [119]	III	This qualitative study aimed to uncover the institutional understanding of an ASD diagnosis through in-depth interviews and content analysis.	Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Time factors
Russell, 2012 [95]	III	This qualitative study explored the function of an ASD diagnosis for parents and the effect the	Family member of an individual on the autism spectrum	Experience

		diagnosis has on parental perceptions of ASD.	Carer of an individual on the autism spectrum	
Rutherford, 2016 [120]	III	This is a sequential, mixed-methods study exploring ideas in waiting time reduction, and good adherence to clinical diagnostic guidelines and quality diagnostic processes.	Professional who conducts diagnostic assessments for autism	Time factors
Rutherford, 2016 [121]	III	This is a retrospective case-note analysis that explores the gender differences in ASD diagnosis though variables such as: the age of referral, ratio of diagnosis, duration of assessment, and diagnosis.	Individual on the autism spectrum Professional who conducts diagnostic assessments for autism Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Time factors
Saggu, 2015 [96]	III	This correlational study explores the relationship between the type of ASD diagnostic process (government funded or private) and parental satisfaction at different stages of the diagnostic process (before, during, after diagnosis).	Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Time factors Experience
Samms-Vaughan, 2009 [122]	III	This is a cross-sectional survey examining the age of maternal concern, the parental concerns, sources of referral, age of diagnosis, the diagnostic delay / wait time, geographical locations and socioeconomic status.	Individual on the autism spectrum Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum Professional who conducts diagnostic assessments for autism	Time factors
Sansosti, 2012 [97]	III	This study using a concurrent, embedded, mixed-methods approach aimed to explore perceptions of early intervention services, experiences of the diagnostic process, and variables which may affect the time of diagnosis.	Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Experience
Siklos, 2007 [98]	III	This is a descriptive study describing the parental experience of the ASD diagnostic process in terms of: age of first concerns, age of	Family member of an individual on the autism spectrum	Time factors Experience

		ASD diagnosis, professionals who diagnosed, and stress. It also examined the relationship between autistic features (communication, social and behaviour) and the diagnostic experience.	Carer of an individual on the autism spectrum	
Smith, 2017 [50]	III	This is a comparative study. The diagnostic accuracy of the Naturalistic Observation Diagnostic Assessment (NODA), a telehealth approach to ASD diagnosis that relies on parent-collected videos, is compared to an independently conducted in-person assessment.	Individual who is, or is considering, undergoing a diagnostic assessment for autism Family member of an individual who is, or is considering, undergoing a diagnostic assessment for autism Carer of an individual who is, or is considering, undergoing a diagnostic assessment for autism	Accuracy
Sweeney Gray, 2013 [99]	III	This is a cohort study comprising both qualitative and quantitative approaches. The study examines parental stress, parental experience 6 months after diagnosis, experience of diagnostic disclosure and family impact of disability.	Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Experience
Tait, 2016 [100]	III	This is a study comprising both qualitative and quantitative approaches which aimed to describe the parental experience of ASD diagnosis and examine variables related to family quality of life (emotional well-being, family interactions, physical and material well-being, and disability-related support).	Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Experience
Taylor, 2016 [123]	III	This quantitative study using a survey design was aimed at describing ASD diagnostic practices in Australia.	Professional who conducts diagnostic assessments for autism	Time factors
Thompson-Kroon, 2012 [101]	III	This is a qualitative study using a phenomenological method of inquiry. The aim was to explore the lived experience of parents of children with Asperger syndrome.	Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Experience

Ward, 2016 [102]	III	This is a descriptive, cross-sectional study that examined the assessment and diagnostic practices reported by Australian practitioners who routinely see children for ASD.	Professional who conducts diagnostic assessments for autism	Time factors Experience
Zeiger, 2008 [103]	III	This is a survey comparing results to data collected in previous surveys (of the topic). The project aimed to describe current general developmental and autism screening practices of paediatricians in the USA following the most recent practice guidelines published by the American Academy of Pediatrics (AAP) (in November 2007).	Professional who conducts diagnostic assessments for autism Professional who provides services to individuals on the autism spectrum or their carers/families	Experience
Zuckerman, 2013 [104]	III	This is a qualitative study which aimed to address the barriers to ASD diagnoses and understand the community and social context surrounding help-seeking behaviour.	Family member of an individual on the autism spectrum Carer of an individual on the autism spectrum	Time factors Experience

* *Levels of evidence based on the World Health Organization's* General Guidelines for Methodologies on Research and Evaluation of Traditional Medicine [130].

- *Ia – evidence obtained from meta-analysis or systematic review of randomised controlled trials*
- *Ib – evidence obtained from at least one randomised controlled trial*
- *IIa – evidence obtained from at least one well-designed controlled study without randomisation*
- *IIb – evidence obtained from at least one other type of well-designed quasi-experimental study*
- *III – evidence obtained from well-designed, non-experimental descriptive studies, such as qualitative studies, comparative studies, correlation studies and case control studies*
- *IV – evidence obtained from expert committee reports or opinions and/or clinical experience of respected authorities.*

Appendix D – Data Extraction Form

Review focus		
Reference		
Location		
Funding source		
Study design		
Level of evidence*		
Research aim		
Hypothesis		
Participants	*Type of stakeholder*	
	Target condition(s)	
	Inclusion criteria	
	Exclusion criteria	
	Recruitment setting	
	Recruitment strategy	
	Number	
	Age	
	Gender	
	Ethnicity	
	Socioeconomic status	
	Intellectual ability	
	Coexisting conditions	
	Other	

* Levels of evidence based on the World Health Organization's *General Guidelines for Methodologies on Research and Evaluation of Traditional Medicine* [130].

- Ia – evidence obtained from meta-analysis or systematic review of randomised controlled trials
- Ib – evidence obtained from at least one randomised controlled trial
- IIa – evidence obtained from at least one well-designed controlled study without randomisation
- IIb – evidence obtained from at least one other type of well-designed quasi-experimental study
- III – evidence obtained from well-designed, non-experimental descriptive studies, such as qualitative studies, comparative studies, correlation studies and case control studies
- IV – evidence obtained from expert committee reports or opinions and/or clinical experience of respected authorities.

Appendix E – Response to External Reviewer 1

NHMRC requirement	Mandatory requirement issue and suggested action	Response
B3 Scope and purpose: The intended end users of the guideline are clearly defined, and any relevant exceptions are identified.	Specifically list clinicians by discipline as well as secondary users (as per technical report). → Please list clinicians as requested.	Content from the Target Users section of the Administrative and Technical Report has been added to the Overview chapter of the Guideline.
C5 Evidence Review: The inclusion and exclusion criteria used to select studies for appraisal are described.	Clear and specific statements about inclusion and exclusion criteria, search limits are required and clarification about potential 'double ups' in the systematic reviews. → Please amend as requested.	Additional text was added to the methodology description of each systematic review to clarify inclusions and exclusions in relation to study design, as stated below (in order of suggested action):
Systematic Review of Diagnostic Guidelines	The first internet search inclusion criteria is not clear. The purpose of requirement is that for all scientific research, that being that it can be peer reviewed and the search strategy is reproducible and any gaps identified. Recognising it was a 'grey' literature search (e.g. guidelines despite them being a research project of themselves and scientifically peer reviewed !!), the issues in this first search are: – Was English language an inclusion criteria? – It is stated that English language countries included were Australia, each of the 8 states and territories (was each named in the search?) – Canada, United States, New Zealand, British Isles (which Ireland prefers to exclude itself from) and North America. It seems the Republic of Ireland was not included although this needs to be clarified and if not, the reasons why not. – It is recommended that each country/part of the UK or the terms used for the "British Isles' is explained to be clear. – The search engine needs to be stated (e.g. Google, Bing) as each internet browser uses a	• '… including those occurring in both peer-reviewed journals and grey literature.' • 'Only websites and documents written in English were explored.' • 'This search was repeated with the name of each individual state and territory for Australia, Canada and the United States.' • 'The Anglosphere was defined as Australia, New Zealand, North America (Canada, United States) and British Isles (England, Ireland, Scotland, Wales).' • 'An internet Google search was conducted using the search terms "autism", "diagnosis" and "[location]"… All potentially relevant links were explored in the attempt to locate guideline documents. This process involved searching through other pages within the website and following links to suggested external websites.'

	different one. - Or was Google Scholar used?	
	In the 2nd search using databases, the search string is specified but not the inclusion criteria (states journal articles, but not study type or if there was no limits on study – either way it needs to be stated). The method of "other search mechanisms' needs explanation.	• 'Only articles that could be defined as a clinical guidance document were included, and all articles defined as research reports, literature reviews or editorial were excluded.' • '… identified through other search mechanisms, such as reference lists, Google search results and suggestions from Steering Committee members.'
	The final internet search – the health insurance company websites need to be named.	• 'These were: Aetna, Anthem Health Insurance, Centene Corporation, Cigna, Health Net, Humana, Kaiser Permanente, Magellan Health, Medicaid, Medicare, Molina Healthcare, Tricare, UnitedHealth Group and WellCare Health Plans.'
	Typo on page 28 " a sub-set of seven ten guidelines' (is this meaning 17?).	• 'A subset of 10 guidelines was evaluated…'
Systematic Review on Diagnostic Accuracy	In the systematic review of diagnostic accuracy – inclusion criteria stated is 'studies using a gold standard multi-disciplinary DSM-5 diagnosis as reference standard". The search string includes AND DSM-5. No inclusion criteria are specified e.g. humans, study type, language, age etc. Was any of the 4 diagnostic accuracy studies included in the systematic review? in which case there is some double up. The phrase 'other search mechanisms is used again – the meaning of which needs explanation.	• 'Only studies reporting on diagnostic accuracy measures were included, and all articles reporting on other study designs, literature reviews or editorial were excluded. The search was restricted to studies with the full article available, but no limitations were set for age, gender, demographics or intelligence level of the sample.' • 'However, these systematic reviews do not address diagnostic accuracy in relation to the DSM-5, instead focusing on the DSM-III, DSM-IV, ICD-9 or ICD-10 diagnostic criteria (this consequently ensured that our systematic review would not report on the same studies).' • 'A further one diagnostic accuracy study was suggested to the Research Executive and two systematic review protocols were identified through entering the search term "autism" into the Cochrane Library.'
Systematic Review on Diagnostic Experiences	In the search for diagnostic experiences – the language limits are specified but again nothing	• 'Only articles that could be defined as a research report (using any study design) were included, and all articles

	about whether there was study type, humans, age range etc. Again 'other search mechanisms – please clarify what this refers to.	reporting on literature reviews or editorial were excluded. The studies were only included if their sample was individuals on the autism spectrum, their families or practitioners delivering the autism diagnosis. Only studies with the full article were included, but no limitations were set for age, gender, demographics or intelligence level of the sample. Studies that investigated experiences post-diagnosis, the accuracy of diagnosis and assessment tools were excluded. Only studies that covered the experiences or perceptions of the sample during the diagnosis process were included.' • 'A further one experiential study was suggested to the Research Executive.'
Systematic Review of Diagnostic Time Factors	The same issues arise with the search for diagnostic time factors (p.31) concerning limits.	• 'Research studies of any research design and literature reviews were included. Only articles that could be defined as a research report (using any study design) were included, and all articles reporting on literature reviews or editorial were excluded. Only studies with the full article were included, but no limitations were set for age, gender, demographics or intelligence level of the sample.' • 'A further one study addressing time factors was suggested to the Research Executive.'
D15 Guideline recommendations: The guideline and recommendations have been assessed by at least two reviewers, independent of the guideline development process, using the AGREE II instrument.	Two reviewers are required to complete an AGREE II an appraisal of the guideline. → Please ensure two AGREE assessments will be performed prior to submission to NHMRC.	This process was completed in April 2018 (see Feedback and Revision chapter of the Administrative and Technical Report).

NHMRC requirement	Desirable or future requirement issue and suggested action	Response
A4 Governance and stakeholder involvement: Consumers participate in the guideline development, and the processes employed to recruit, involve and support consumer participants are described.	Details of the capital cities and numbers of workshops conducted in each city. → Please name the cities concerned	The following was added to the introductory text for the Workshop chapter of the Administrative and Technical Report): • 'In chronological order, workshops were conducted in Perth, Brisbane, Adelaide, Darwin, Melbourne, Hobart, Sydney and online (conducted via videoconference and surveys).'
A7 Governance and stakeholder involvement: A list of organisations formally endorsing the guideline is provided.	Details of the organisations endorsing the guideline. → If you intend seeking the endorsement from organisations once the guideline is published please list these organisations.	The following was added to the Feedback and Revision chapter of the Administrative and Technical Report): • 'Along with seeking to obtain NHMRC approval for the Guideline, endorsement of the published Guideline will be sought from a range of key national peak bodies and government departments. An up-to-date list of organisations that endorse the Guideline will appear on the project webpage of the Autism CRC website. The following are some of the organisations that will be invited to endorse the published Guideline: [list of organisations].'
B4 Scope and purpose: The population to which the guideline recommendations will apply is defined (e.g. children, adolescents, adults or older adults) and population subgroups for which specific information is required are identified and described.	Explicitly describe the population to which the guideline applies in the beginning of the guideline – not only the title and section 12. → Please add these details as requested.	The following text was added to the Scope of the Guideline section of the Overview Chapter (italics indicates existing text): • '*This Guideline is intended to operate within the assessment processes applicable for* children, adolescents and adults presenting *with signs or symptoms of a broad range of neurodevelopmental conditions.*'
C1 Evidence Review: Clinical questions addressed by the guideline are stated in a structured and consistent format to define the boundaries of the topic, i.e. by specifying the relevant	The 'high' level clinical questions for the guideline to answer need to be placed in the guideline. They are available in the technical report. → Please add the details in the technical report to the guideline as requested.	The research questions have now been added to the Overview chapter of the Guideline.

population, intervention/s (e.g. treatment/s or diagnostic test/s), comparator/s and outcomes measured.		
C2 Evidence Review: Systematic searches for evidence are undertaken and the search strategy is documented, including the search terms and databases searched.	There is a phrase used 4 times in the systematic review descriptions "through other search mechanisms" but it is not articulated what these mechanisms are. Is this referring to the references lists of the retrieved articles? → Please explain and document as requested.	This has been addressed in Mandatory Requirement C5 above.
E3 Guideline structure and style: The guideline includes a brief (e.g. 1-page) plain English summary.	A 1-2 page summary for autistic people and their caregivers, written in plain English is recommended. The purpose is for consumers to know what the assessment might 'look like' and what they can do to empower themselves and engage in the process. It should be written with 'high level' information and general rather than listing the recommendations e.g. what the assessment should look like (e.g. occur in different settings, engagement of the person and their family, expertise of assessor, how they can check on the assessor's qualifications, etc.) → Please note these comments when planning and preparing the consumer version required under E3.	A two page layperson summary has been created and will be available on the dedicated project webpage on the Autism CRC website (https://autismcrc.com.au/national-guideline).
Section E Guideline structure and style: The layout of the Guideline is well designed with a table of contents and summary pages providing access to key information. The Guideline is written in plain English with a reading age appropriate to the specified target audience.	Section E Whilst the intent is for the guideline to use the framework of the ICF, there are inconsistencies in the developers apparent understanding of the ICF and biopsychosocial model and therefore the text and explanations. Those familiar with the ICF will see these in the guideline. Whilst fundamentally the overall approach is correct, the specifics need refinement. Whilst the intent is for the guideline to use the framework of the ICF, there are inconsistencies in the developers understanding of the ICF and biopsychosocial model and therefore the text and explanations. Those familiar with the ICF will see these in the guideline. Whilst	Modifications were added to the Guideline and associated documents to address concerns associated with ICF related terminology, as stated below (in order of suggested action): • 'domains of health' and 'domains of functioning' • Use of words function and functional removed in the context of activities and participation, for example through stating '… level of functioning…'. • Instructions on using the ICF to collect information have been removed from the Guideline, and will be provided in future Web Resources.

	fundamentally the overall approach is correct, the specifics need refinement. The concerns about the text and the apparent limits on the understanding on aspects of the biopsychosocial perspective of health (Articulated in the ICF) are: – The ICF refers to the DOMAINS of health (as per the one level category listed on page 50) and functioning within those domains. – The ICF does not use the word function or functional in reference to activities and participation. These terms are typically used in reference to the body in the medical model not the biopsychosocial model. Similarly the term 'functional status' is a medical model term. The term used in the ICF is 'functioning'. Functioning is defined in the ICF as 'Functioning is an umbrella term encompassing all body functions, activities and participation (p. 3 of the WHO 2001, publication). It recognises the interaction of the domains of health and the contextual factors (environmental and personal factors). Consequently 'functional status' relates to a static state in the body rather than functioning in a domain of health where the contextual factors are present (i.e. similar to the difference between capacity and performance). – The list on page 50 (learning and applying knowledge, general tasks and demands) are NOT the defined areas of activity (As stated) in the ICF they are domains of functioning. This has implications for the section in the guideline on scores for different activities or activity areas in the suggested profile of the 'functional assessment'. The critical perspective in the biopsychosocial model is the concepts of capacity and performance (also defined in the ICF). The purpose of the proposed assessment in the guideline is on performance	• The 'Functional and Support Needs Assessment' has been renamed as an 'Assessment of Functioning.' • The term 'character strengths' has been retained, as this has specific meaning in positive psychology. • The referenced tools included in the list of one level categories from the ICF were removed, as they have not all been mapped to the ICF domains.

	rather than capacity – and which is critical to an accurate picture of the person with autism and their functioning. – A more appropriate term would be 'Assessment of functioning and support needs' to align with the ICF framework and perspective. – In recommendation at the bottom of page 50 refers to "character strengths'. Is this referring to personal factors as in the ICF – if so then perhaps use the term personal factors (as in the ICF it includes factors such as diverse as age, habits, upbringing, coping styles, social background etc). If it is one aspect of the personal factors e.g. character style or individual assets or characteristics, personality strengths – it needs clear. – There are some concerns with the referenced tools included in the list of one level categories from the ICF and the text around these (see list and reference to tools). If each of these tools have not been mapped to the ICF domains, they should not be listed to infer that they directly relate to the domains of health as defined in the ICF. (Refer to Cieza et al (2005) ICF Linking rules). I am not aware as to whether all of the listed tools (referenced) have been formally linked to the domains of health. Of course some have, e.g. WHODAS, but I presume not others. If all of those listed have not been linked, then the references should be separated and a general paragraph about the assessment of the person's functioning (in domains of activity and participation) with a reference to the types of assessment which may be used – rather than linking them to specific domains. – It is strongly recommended that the text is revised and this section and recommendations related to 'functional	

	assessment and support needs' assessment be revised accordingly to better align with the biopsychosocial perspective (ICF). → Please refer to full review in footnote.	
NHMRC requirement	**More detail required and suggested action**	**Response**
A2 Governance and stakeholder involvement:	Developer may wish to provide further details in the technical report concerning the funding request to support implementation - clear who has submitted the funding request in the technical report. → Please consider including this information.	Clarification has been provided in the Dissemination Plan chapter in regards to the funding request: • 'A funding request is being considered by the National Disability Insurance Agency to undertake a range of activities to assist implementation of the Guideline in local contexts…'
A2.1 Governance and stakeholder involvement:	Amount of grant total to develop the guideline plus an estimate of in-kind costs. → Please consider giving more detail (if appropriate).	It was not deemed appropriate to reveal the exact grant total, nor was it possible to estimate the in-kind costs due to the extensive nature of the in-kind support beyond the Research Executive. Instead, the Background section in the Introduction Chapter of the Administrative and Technical Report was expanded to provide greater description of these two forms of support: • 'The NDIA provided the funding for guideline development, publication and dissemination. This financial support covered salary costs for the project coordinator (Dr Kiah Evans) and several part-time research assistants, direct public consultation expenses and an honorarium to the Steering Committee members. Other members of the Research Executive (Professor Andrew Whitehouse, Professor Valsamma Eapen, Professor Margot Prior and Clinical Associate Professor John Wray) received no personal financial or other remuneration for their involvement in this project. Extensive in-kind support was provided by the Research Executive, research students, research supervisors, research assistants, methodological experts, consultative workshop hosts

		and the many individuals who participated in the research projects and feedback processes. The views of the NDIA have not influenced the content of the Guideline.'
B5 Scope and purpose: Issues relevant to Aboriginal and Torres Strait Islander peoples (such as particular risks, treatment considerations or sociocultural considerations) are identified and described.	It is recommended that cultural sensitivity as a concept or term is woven into the text as well as the existing reference 'knowledge'. → If you agree, and if the evidence supports it, please consider inclusion of references to cultural sensitivity.	This sentence has been amended to include cultural sensitivity: • 'It is important that professionals maintain self-awareness about any lack of knowledge or sensitivity they may have about a particular culture.'
C1 Evidence Review: Clinical questions addressed by the guideline are stated in a structured and consistent format to define the boundaries of the topic, i.e. by specifying the relevant population, intervention/s (e.g. treatment/s or diagnostic test/s), comparator/s and outcomes measured.	The questions would benefit from being numbered in the guidance and technical report. → Please consider this request.	The research questions have now been formatted as a numbered list in both the Guideline and Administrative and Technical Report.
E2 Guideline structure and style: The guideline is easy to navigate and includes a table of contents.	The developers may wish to consider numbering the recommendations. In the context of the users, it will make discussion and training more difficult and complicated, if the recommendations are not numbered. → Please consider this request.	The consensus-based recommendations have now been numbered in the Guideline.
E7 Guideline structure and style: The document design and layout enables recommendations to be identified easily within the text.	It must be assumed that some users will print the document, and often in black and white rather than screen use only e.g. for training sessions on the use of the guideline. It is recommended that a different colour tone or shading is used instead of the current green. When printed out in black and white, the recommendations are too faint to read. When printed, the headings are easier to read as they	The font colour for the headings and consensus-based recommendations has been changed to a darker shade of green.

	are bold font, but these may require change also. → Please consider changing colour scheme as per this accessibility comment.	
E4.1 Guideline structure and style: A summary of recommendations is available as a separate document, and the guideline text states where to obtain this document.	A hyperlink in the resources section to the summary of the recommendations document. → Please consider this suggestion.	Hyperlinks will be added to the final documents when they are situated on the project webpage.
Section E Guideline structure and style: The layout of the Guideline is well designed with a table of contents and summary pages providing access to key information. The Guideline is written in plain English with a reading age appropriate to the specified target audience.	Each document (guideline, technical report and each of the resources) should have the hyperlink to the website and all the documents (e.g. at the bottom of the page). It is important that if someone has only one part of the package, that they know how to access all documents in the package. → Please consider this suggestion.	Hyperlinks will be added to the final documents when they are situated on the project webpage.

Appendix F – Scaled AGREE-II Scores

AGREE-II domain	Reviewer 1	Reviewer 2	Average
Domain 1. Scope and purpose	100.00	94.44	97.22
Domain 2. Stakeholder involvement	100.00	94.44	97.22
Domain 3. Rigour of development	97.92	91.67	94.79
Domain 4. Clarity of presentation	100.00	94.44	97.22
Domain 5. Applicability	87.50	75.00	81.25
Domain 6. Editorial independence	100.00	100.00	100.00
Overall guideline assessment	97.57	91.67	94.62

Appendix G – Response to External Reviewers 2 and 3

AGREE-II domain and item	Suggested action	Response
Domain 1. Scope and Purpose		
1. The overall objective(s) of the guideline is (are) specifically described.	The clearest and most concise description of the objectives come in section 3.6. There is some overlap in messaging with earlier paragraphs (3.1 - Purpose, 3.4 Scope of the Guideline). I do wonder whether the clarity of the objectives could be improved by having the stronger language closer to the beginning of the guideline, such as in the Purpose section.	The Scope of the Guideline section and research questions were moved to immediately following the Purpose section of the Overview chapter.
2. The health question(s) covered by the guideline is (are) specifically described.	Section 3.5 lists questions that were used to guide the literature review. These are clear and cover relevant topics within ASD diagnostic assessment. There is further detail provided in the Technical document.	Thank you for this feedback
3. The population (patients, public, etc.) to whom the guideline is meant to apply is specifically described.	ASD is well-described, along with diagnostic criteria. I also appreciated the clarity provided on the use of identity-first language. The guideline is clear that the recommendations are meant to apply to all cases of suspected ASD living in Australia.	Thank you for this feedback
Domain 2. Stakeholder Involvement 4. The guideline development group includes individuals from all relevant professional groups.	The representation and description of roles and expertise of guideline development members is a strength of this guideline. There is a high degree of detail about each member of the development group. A minor point: while service providers in general are represented, I did not specifically see behaviour therapists (no guidelines to date have, to my knowledge). This is an important perspective to consider, given that one of the main goals of the assessment is to inform treatment strategies.	In order to maximise the efficiency of the Steering Committee to a manageable size, it was decided at the commencement of the project to limit membership to disciplines involved in the assessment and diagnosis process, along with and the peak service provider body, Australian Autism Alliance. During the consultation period, we were vigilant in collecting the views of a wide range of behavioural analysts/therapists, and we solicited a formal submission of the draft Guideline from the Association for Behaviour Analysis Australia. The feedback of these stakeholders helped shape the

		final version of the Guideline we have submitted.
5. The views and preferences of the target population (patients, public, etc.) have been sought.	The steering committee included both autistic representation and parents of autistic people. Further, the guideline developers enacted an online submission process to allow the broader community of stakeholders the opportunity to influence the guideline. There were also workshops held across the country to obtain in-person feedback. Very thorough.	Thank you for this feedback
6. The target users of the guideline are clearly defined.	The statement in the main document is that the guideline is produced to support clinicians who undertake diagnostic assessments that may result in an ASD diagnosis. Section 1.6 of the technical report has a Target Users heading, and instead of clinicians uses the terminology of 'health professionals.' I am unclear as to whether these terms purposefully differ. The choice of wording is a bit vague, though I also understand the need to keep it broad to encompass all possible clinicians who may contribute to ASD diagnostic assessments. I wonder if a statement to that effect may be helpful to clarify, along with some examples. I.e. Many types of clinicians may be involved in the diagnostic process (physicians, psychologists, ...), and we intend for this guideline to be of use to all clinicians who play a role in the diagnostic assessment.	The term health professional has been changed to clinician.
Domain 3. Rigour of Development 7. Systematic methods were used to search for evidence.	Excellent detail is provided in the Technical Report.	Thank you for this feedback
8. The criteria for selecting the evidence are clearly described.	The search was broad and there were no stated limits with regard to study design. There are clear statements with regard to study population and outcomes. Including a grading for consensus statements is useful.	Additional text was added to the methodology description of each systematic review to clarify inclusions and exclusions in relation to study design, as stated below: • Systematic Review of Diagnostic Guidelines: 'Only articles that could be defined

		as a clinical guidance document were included, and all articles defined as research reports, literature reviews or editorial were excluded.' • Systematic Review on Diagnostic Accuracy: 'Only articles that could be defined as a diagnostic accuracy study were included, and all articles reporting on other study designs, literature reviews or editorial were excluded.' • Systematic Review on Diagnostic Experiences: 'Only articles that could be defined as a research report (using any study design) were included, and all articles reporting on literature reviews or editorial were excluded.' • Systematic Review of Diagnostic Time Factors: 'Only articles that could be defined as a research report (using any study design) were included, and all articles reporting on literature reviews or editorial were excluded.'
9. The strengths and limitations of the body of evidence are clearly described.	There is tension in this process, as identified by the authors in 3.5.4 Evidence Review, noting a paucity of high level published research evidence and a decision to instead focus on consensus-based recommendations. Recommendations are clearly identified as consensus-based, and the provided example of an evidence table is a generally clear and concise way to display this information, though a few words about the study design could be provided beyond just evidence level. It would be helpful for the authors to provide a description of the levels of evidence (I, II, III) in proximity of the tables (it is currently in the technical report). Section 4.4 states that the assessment should be evidence-based, and yet the authors have determined that there is lack of sufficient evidence to create evidence informed	Additional content has been added to Introduction chapter of the Evidence Tables document. This includes as section titled 'Grading Evidence for Recommendations', which includes the table from the full Guideline on consensus-based recommendation grades. In addition, there is a section titled 'How to Read the Evidence Tables', where an explanation of the content of each evidence table is provided. An addition was made to the introductory text for the evidence based principle recommendation: • 'Whilst it is recognised that high quality evidence is not currently available in relation to every aspect of the assessment of ASD concerns process, clinicians are encouraged to regularly update their awareness of emerging evidence and utilise

	recommendations, instead opting for consensus-based recommendations. Perhaps there could be a note to remind the reader of this in this section to ensure the messaging is consistent?	available high quality evidence.'
10. The methods for formulating the recommendations are clearly described.	A Delphi method was used. Experts in the field with geographical representation were invited to participate. They rated their endorsement of whether a component should be part of an ASD assessment on a 5 point Likert scale. A priori criteria were set for consensus. Qualitative comments were also collected and analyzed. A parallel Viewpoint survey captured the perspectives of autistic adults and caregivers. There is a transparent stepwise process documented in the Technical report.	Thank you for this feedback
11. The health benefits, side effects, and risks have been considered in formulating the recommendations.	In ASD diagnostic assessment, the competing forces are comprehensiveness (presumably linked to accuracy) and access/efficiency. From Section 3.6 in the main document: This 'minimum standard' Guideline has been developed with the aim of maintaining assessment rigour while also optimising access to clinical services for all Australians. There is a notation that while this is a Minimum Standard, additional elements may be necessary based on the individual client/patient. There is an included Important Considerations section. Repeated administration of the Assessment of Functioning is recommended, which is important given that the guideline takes a lifespan approach. There is also a note that when a client disagrees with a diagnostic decision, they have the right to seek a second opinion. There is a section on Risk Assessment in the Technical Report.	Thank you for this feedback
12. There is an explicit link between the recommendations and the supporting evidence.	The consensus-based recommendations have references to the relevant evidence tables. Where possible.	No response required

13. The guideline has been externally reviewed by experts prior to its publication.	Sections 10.4 and 10.5 detail this.	No response required
14. A procedure for updating the guideline is provided.	Section 11.4 states that the guideline will be reviewed, and possibly revised, three years after publication. Information from the evaluation project as well as new research will be incorporated. The methodology for revising the guideline is not provided (i.e. will a systematic review be completed to search for new evidence, is there a standing committee?). The section on page 73 could provide more detail. E.g. funding will be sought from key organisations. This way, the responsibility is shared with key organisations to ensure that the guideline is updated.	As funding has not yet been secured to update the Guideline, the terminology remains quite broad. However, the Guideline Updates practice point has been amended to include suggested methodology and funding sources (italics indicates existing text): • '…A suitable approach to updating the Guideline would involve re-forming a Research Executive and Steering Committee to update the systematic reviews (restricted to evidence published since the previous systematic reviews), and consider whether any of the recommendations require amending or updating. Relevant national peak bodies should be consulted during this process.'
Domain 4. Clarity of Presentation		
15. The recommendations are specific and unambiguous.	Figure 2 provides a clear, concise overview of the diagnostic process. There are clear recommendations re: the types of professionals that can be involved in the diagnostic assessment. The authors have done a commendable job in writing clear recommendations for a process that, by design, incorporates flexibility. The one recommendation I will flag is the one stating that ASD assessments follow an evidence-based approach. Due to the lack of evidence, this has to be a consensus-based recommendation, which creates some confusing messaging. The provided Evidence Table for this recommendation also highlights that there is not much evidence (and certainly not much high quality evidence) to support current diagnostic models. While I agree with the sentiment of this recommendation, I am wondering if the current evidence gaps	Please see response to item 9 (The strengths and limitations of the body of evidence are clearly described)

	should be a bit more clearly stated in the accompanying text.	
16. The different options for management of the condition or health issue are clearly presented.	Figure 2 shows the pathways for assessment. Importantly, the Comprehensive Needs Assessment is uncoupled from the Diagnostic Evaluation, allowing flexibility in when each is assessment is conducted. There are different assessment options depending on the case presentation, including different team composition.	Thank you for this feedback
15. The recommendations are specific and unambiguous.	Figure 2 provides a clear, concise overview of the diagnostic process. There are clear recommendations re: the types of professionals that can be involved in the diagnostic assessment. The authors have done a commendable job in writing clear recommendations for a process that, by design, incorporates flexibility. The one recommendation I will flag is the one stating that ASD assessments follow an evidence-based approach. Due to the lack of evidence, this has to be a consensus-based recommendation, which creates some confusing messaging. The provided Evidence Table for this recommendation also highlights that there is not much evidence (and certainly not much high quality evidence) to support current diagnostic models. While I agree with the sentiment of this recommendation, I am wondering if the current evidence gaps should be a bit more clearly stated in the accompanying text.	See response to item 9 (The strengths and limitations of the body of evidence are clearly described).
Domain 5. Applicability 18. The guideline describes facilitators and barriers to its application.	The technical report contains a table (Table 11) describing potential barriers and facilitators to implementation. An important consideration that is mentioned is that Medicare and private insurance do not cover the full cost of an ASD assessment. This list was developed through the community consultation and the Delphi survey. There is some	Additional text was added to the Guideline Dissemination and Implementation section of the Dissemination Plan chapter, in relation to the acknowledgement that the implementation of this Guideline may lead to a change in service delivery: • ‘Throughout the Guideline development process, the

	information on how this influenced some aspects of the guideline (i.e. rural populations and the use of telehealth), though it is not clear how the funding of the assessment itself influenced recommendations.	Research Executive focused on designing a flexible and practical process. Although existing funding mechanisms were considered, they did not prevent the Research Executive from recommending innovative approaches to service delivery if these were supported by research evidence and/or expert opinion. Instead, the Research Executive has suggested advocating for change to funding systems.'
19. The guideline provides advice and/or tools on how the recommendations can be put into practice.	There is a Dissemination plan provided. There will be some web resources, some of which sound quite practical, such as a report template. They have applied for funding to develop further materials, though these are not yet available. The Technical Report in Section 14.2 details a plan to submit the guideline to the Medicare Benefits Schedule Review Taskforce; however, the high likelihood of out-of-pocket costs for patients who require the full team assessment remains an important barrier to implementation.	A barrier was amended in the table in the Guideline Dissemination and Implementation section of the Dissemination Plan chapter (italics indicates existing text): • '*Medicare and private health insurers not covering the full cost of an assessment of ASD concerns*, leading to increased 'out of pocket' expenses for some clients'
20. The potential resource implications of applying the recommendations have been considered.	The Technical Report contains a section on Resource Implications (11.2). They note that some assessments may take longer than they currently do. In addition, some clinicians may need to take on additional training. Finally, the issue of coverage for these assessments is discussed here. The resource use is discussed in general terms without cost estimates provided. There are no costing studies or HTA's specifically for ASD diagnosis that have been published, to my knowledge. It may have been useful to see estimates here for what would be covered under Medicare and what families would pay out of pocket. The issue of wait times is discussed in the Risk Assessment in the technical report. The hypothesis of the authors is that this guideline will decrease wait times. I agree that this hypothesis sounds correct,	An additional barrier was added to the table in the Guideline Dissemination and Implementation section of the Dissemination Plan chapter: • 'Wait times may increase where clinicians have to increase the amount of time spent on an assessment of ASD concerns to meet the Guideline requirements' The Guideline Evaluation section of the Implementation Plan was reviewed, and already includes the suggestion: • 'examining the impact of various diagnostic practices on diagnostic outcomes, including … costs and timeframes'

	though there is a possibility that by implementing a minimum standard that diagnosis could become more restrictive (i.e. certain clinicians may opt not to obtain additional training). Given that the improvement in wait times is not a guarantee, I suggest adding an objective to the evaluation plan to measure impact on wait times. These were a bit difficult to find but one makes the assumption (based on the wording of recommendations) that have been considered.	The following text was added at the end of this point for further clarity: • '(e.g. wait time and assessment duration)'
21. The guideline presents monitoring and/or auditing criteria.	Section 11.3 of the Technical Report provides an Evaluation plan. They will seek out feedback from early adopters to refine the guideline, though no further details are reported. There is an approved application to conduct an evaluation of the guideline. Many of these questions are clear - measuring knowledge change, measuring proportion of single clinician evaluations compared to team evaluations, accuracy of single clinician evaluations. One audit criterion that is perhaps missing is the proportion of assessments carried out that meet the new minimum standard criteria. An additional consideration is the measuring the impact of the guideline on wait times.	The following was added as a research recommendation in the Guideline Evaluation section of the Implementation Plan: • 'auditing compliance with the Guideline's consensus-based recommendations in a variety of service settings'
Domain 6. Editorial Independence 22. The views of the funding body have not influenced the content of the guideline.	The guideline was developed with funding from the National Disability Insurance Agency. There is a statement that the organizations did not influence the guideline contents or recommendations.	No response required
23. Competing interests of guideline development group members have been recorded and addressed.	These are extensively documented.	Thank you for this feedback

Overall Guideline Assessment I would recommend this guideline for use:	This is a very comprehensive and well considered document. The structure and layout are easy to navigate and to find relevant information. In addition, the guiding principles and important considerations sections are useful as they reinforce the key messages.	Thank you for this feedback
Additional comments	I enjoyed reading your guideline and learned a lot! I especially liked the overview section including the guiding principles! The figures are also great. Just a minor note regarding figure 3: I noticed that sometimes a GP might be mentioned in the example (e.g. example 2) but I couldn't see a circle representing GPs in the diagram. I also had some difficulty finding indicators or a specific advice on how to monitor whether the recommendations are implemented. This is most likely in the supplementary documents (like the implementation plan).	Thank you for this feedback The references to GPs in figure 3 were when they acted as a 'referrer', a role that is not represented by a circle in the diagram. The following was added as a research recommendation in the Guideline Evaluation section of the Implementation Plan: • 'ongoing measurements and audits of tangible indicators of the Guideline's dissemination, implementation and efficacy'

Appendix H – Response to External Reviewers 4 to 8

	Reviewer comments	Suggested action	Response
Reviewer 4: (Australia)			
1	I congratulate the Guideline research executive committee chaired by Prof Andrew Whitehouse and coordinated by Dr Kiah Evans, the Steering Committee and all the research staff for their comprehensive, rigorous and inclusive approach to the development and production of this timely work with funding from the National Disability Insurance Agency.	Please note comment.	Thank you for this positive comment.
2	…I agree with the comment in the draft Guideline document that there is a "paucity of high level published research" to comprehensively inform a number of the research questions. However, the development of the Guideline used a process of grading consensus based recommendations supported by the best available evidence which is a process endorsed by the NH&MRC (page 6). I am of the opinion that as far as possible, the existing published evidence has been identified in order to inform the recommendations which reflect the best consensus possible at this time in Australia with respect to all the objectives and research questions except with some qualification regarding Objective 2 (and question 7) and Objective 4 (question 2 and 3).	Please note comment.	Thank you for these positive comments.
3	Objective 2 (question 7) This objective relates to the innovative and critical task of not only providing guidelines for the diagnosis of ASD, but developing guidelines for the comprehensive determination of the "level of functioning and related support needs". I applaud the Guideline for explicitly introducing this assessment requirement, given that there are few, if any, effective treatments for ASD but there is a range of evidence based supports and treatments for the potentially complex number of functional impairments and complications related to the symptoms of ASD and associated comorbidities, specifiers and socio-	Please review comment and respond.	Thank you for the positive comments in the first two paragraphs. These have all been noted. We also note that the reviewer is correct in writing that there is currently no published research that has used the ICF domains to develop a reliable and valid method for grading support needs. However, extensive research has been conducted to develop the ICF Core Sets for ASD (e.g. please see below reference), which provides a good conceptual framework for structuring the collection of information about functioning. Bölte S, Mahdi S, de Vries P, Granlund M, Robison JE, Shulman C, Swedo S, Tonge B, Wong V, Zwaigenbaum L, Segerer W, Selb M. The Gestalt of functioning in autism

	cultural contexts. The equitable and best delivery of services is therefore predicated by a comprehensive assessment of functioning. Assessment of functioning is also a guiding principle for the allocation of funds by government services such as the NDIS and other disability service agencies. I acknowledge that the NDIA, which funded the development of this Guideline, had no influence on the preparation of the Guideline. The DSM-5 and the ICD-10 provide clear criteria for the diagnosis of ASD including, for the DSM-5, a list of specifiers that are an essential part of the diagnosis. These specifiers such as cognitive ability and comorbid emotional and behavioural disorders are also likely to, through interaction with ASD symptoms and independently, adversely impact functioning. A DSM-5 ASD diagnosis also requires a severity rating (1, 2, 3) of support needs which relates specifically to each of the 2 groupings of ASD symptoms but not to any of the specifiers or comorbid conditions. The method for making these severity ratings is highly subjective and to date there are no reliable and valid evidence based methods for making these 2 severity ratings. The DSM-5 instructs users that these severity ratings are not to be used "to determine eligibility for and provision of services" (DSM-5, APA, 2013, p.51). Nevertheless, the NDIS states that ASD severity levels 2 or 3 are likely to be required for funding of individuals on the Autism Spectrum (Access to the NDIS Op Guideline-14. List A). The adoption of this Autism CRC Guideline should rectify this inappropriate use of the two DSM-5 ASD diagnosis severity ratings. The WHO International Classification of Functioning (ICF) is cited in the Guidelines as providing domains for "exploring" the level of support needs in domains of relevance to individuals on the Autism Spectrum. However, as yet, there is to my knowledge no published research that has used these domains to develop a reliable and valid method for grading support needs. What appears to be missing from the review of evidence is a critical review of the literature on "standardized assessment of development, social, communication, [behaviour and		spectrum disorder: Results of the international conference to develop final consensus International Classification of Functioning, Disability and Health core sets. Autism. 2018; early online: 1-19. The third paragraph raises the query about the absence of a critical review of standardised assessments of the full range of developmental and cognitive abilities. This work fell outside of the scope of this project,

	cognitive/educational] abilities" (7.2, p29) and economic-social-cultural context. Such a review could then act to inform the development of reliable and valid measures of functioning, with reference to the ICF domains and the diagnostic specifiers which would then provide "a benchmark ... for follow up assessments" (p29). Standardized assessments of functioning are referenced to the "web resources" at a number of places in the Guideline, but my reading of the web resources available online, or the technical report or evidence tables, do not provide a review of these assessments, their psychometric properties and how they might be used to guide clinicians in their considered assessment of the specific and overall functional strengths and weaknesses of an individual on the Autism Spectrum. It is highly likely and appropriate that service funding bodies will continue to require some form of comparative, valid and equitable assessment of functioning. If no clinical and evidence based assessment of functioning is available, then the unjustified recourse to the two DSM-5 autism symptoms severity scales will probably continue to be inappropriately used for the allocation of funding. In turn, clinicians who understandably wish to have their patients/clients receive the best available services, might be tempted to describe functional needs with a simplistic DSM-5 severity estimate at a level where support funding is likely.		and so this was not included in the final Guideline. (Please see Terms of Reference document). However, please note that the implementation plan (Section 11.1 of this document) includes the development of resources that will be on a website, hosted by the Autism CRC. These 'web resources' will provide further information on a range of elements related to this Guideline, such as the up-to-date evidence regarding standardised assessments, and will be updated as new evidence arises. These web resources will include a comprehensive description of each existing tool, including the psychometric properties, along with links to relevant systematic reviews (e.g. please see below reference). McConachie H, Parr JR, Glod M, et al. Systematic review of tools to measure outcomes for young children with autism spectrum disorder. Health Technology Assessment. 2015; No. 19.41. Available from: https://www.ncbi.nlm.nih.gov/books/NBK299302/ doi: 10.3310/hta19410
	The problem of developing a reliable and valid method of describing and quantifying functioning is an international challenge. The development of this Australian Guideline provides an opportunity to develop these much needed evidence based criteria for the assessment of functioning. I suggest that a solution to this issue might be that the Australian Guideline recommendations regarding assessment of functioning be regarded as interim guidelines until research is conducted on the development of the proposed model of assessment of functioning including field trials and research on its implementation. The funding of this research, perhaps by the NDIA and the NHMRC might be regarded as a priority		In the fourth paragraph, the reviewer notes that there is not currently a reliable and valid method of describing and quantifying an individual's level of functioning. Please note that the National Disability Insurance Agency (NDIA) has recently commissioned a research project to evaluate the reliability, validity and usability of a promising tool, the PEDI-CAT (ASD), as part of the broader 'implementation plan' for this Guideline. This project will also provide an understanding of the reliability, validity and usability of the Vineland Adaptive Behavior Scales Third Edition and an interview based on the ICF Core Sets for ASD. We argue against declaring 'interim recommendations' for two reasons. First, all recommendations have been defined as consensus-based (rather than evidence based) in recognition of the paucity of

	to ensure the feasibility and functionality of the Guideline implementation.		published evidence on the topic. Second, we have suggested that the recommendations made in the Guideline are reviewed regularly (Section 13.3). Through these reviews, all recommendations made in the Guideline could viewed as 'interim' until new evidence is generated that would necessitate a change in recommendation.
4	Objective 4 (question 2 & 3) In general the process of diagnostic assessment and the roles, responsibilities and clinical skills and training required by the clinicians are well based on existing evidence and the recommendations reflect the best of a consensus process. However, I have a concern relating to the objective of describing a "feasible process". To my knowledge, no other International Guideline or practice on the assessment of ASD, describes a process equivalent to the Australian Guideline, particularly the requirement to assess functioning. I know of no clinical service delivery or implementation science literature that provides even indicative evidence that the process described in the Guideline is "feasible ... across ... Australia including public and private settings" (1.2). The Guideline describe a number of potential barriers to feasibility and implementation for which there is no evidence that these will necessarily be overcome. Some of these barriers are: integration of some of the guidelines into the Medicare system; development of a reliable and valid system of assessing function; providing equity when the private system is likely to drive up fees and the resource limited public system is unable to cope with demand; the massive task of Universities and professional bodies to implement and provide accredited training and skills development in a workforce that is currently insufficient and inequitably distributed across the nation. Therefore, given the lack of evidence for feasibility, I am not convinced that there is sufficient consensus to describe the guideline process as clearly feasible even though the assessment process itself is relatively well evidence based. I would suggest that Objective 4 should be regarded as interim and be subject to a well-funded program of independent public health and implementation	Please review comment and respond.	The compromise between assessment rigour and feasibility is a challenge for any clinical guideline, and ASD diagnosis is no exception. The inclusion of an Assessment of Functioning in the Guideline was a clear and consistent theme in the evidence generated from the systematic reviews. The Australia-wide consultation process also led to a consensus view that this element of the is critical to achieving the ultimate aim of the assessment (i.e. the accurate assessment of an individual for an ASD diagnosis). It is important to highlight that each individual recommendation was based on consensus, and each of these met acceptable levels of consensus based on multiple evidence sources (see Evidence Tables). While feasibility was an important objective of the Guideline, the recommendations were also driven by Guiding Principles which emphasised the development of an evidence-based assessment process that cannot be substantially compromised by limitations in current practice (see Section 2.5). Whilst some of the barriers to implementation are beyond the control of the Guideline developers, care has been taken to ensure that recommendations on how clinicians 'obtain and maintain relevant training and expertise' are feasible and do not rely on capacity limitations of universities and professional bodies to deliver training. Clinicians can obtain the required competencies 'through peer observation, peer supervision and peer mentoring.' Clinicians will also be able to access a range of fact sheets, checklists, instruction manuals, online educational resources and face-to-face educational programs during the implementation phase (see section 11.1 of the Technical Report for more details). It is anticipated that most existing clinicians involved in the assessment of ASD concerns will already meet many, if not all, of the training and expertise requirements. Please also note that the Guideline includes Practice Points (Section 13) that highlight the importance of adequate levels of funding for neurodevelopmental assessments (Section 13.2), research into a functional assessment tool (Section 13.3) and

	science outcome research, for example funded by the NDIA and the NHMRC. The benefit of outcomes of this research would be much broader than relating only to those on the Autism Spectrum, but also to all those in Australia who have other neurodevelopmental disabilities.		revisions of this Guideline (Section 13.3). We have also added the following sentence to Section 13.2 (Practice Points): 'It will be important that an implementation process incorporates sufficient time for clinicians, professional bodies and health, education and disability systems to make adequate adjustments to accommodate the recommendations made in the Guideline.'
5	The Guideline directly considers potential risks and harms and also builds in processes which should obviate or prevent adverse outcomes. These processes have also been fully discussed and informed by a process of consultation with individuals on the Autism Spectrum, their families and support groups and peak bodies. For example, open communication is encouraged in the referral, assessment and feedback processes. The process of providing feedback and supporting individuals and families or carers through the process of assessment, diagnosis and management planning can be psychologically stressful and confusing unless comprehension ability, developmental level and socio-cultural context is taken into account. The Guideline well acknowledges that this necessary feedback process must be a matter for clinical judgement exercised within the processes described by the Guideline.	Please note comment.	Thank you for this positive comment.
6	I am not an economist or lawyer, therefore am not qualified to advise on economic and medicolegal risks. However, it seems to be likely that the costs will be considerable for training and accrediting the workforce necessary to deliver the assessment services consistent with the Guideline nationally. There are also potential cost implications in providing a face to face and telehealth consultation and assessment service for rural and remote communities. The integration of aspects of the Guideline into Medicare and NDIA funding procedures are also likely to incur costs.	Please review comment and respond.	As evidenced by the positive methodological and content reviews, this Guideline was generated through a high-quality and thorough research and consultation process. While there may be some cost implications in training clinicians to meet the Guideline recommendations, our research and consultation process indicates this is a necessary step to improve standards of ASD assessment in Australia. Peer learning approaches and free Web Resources (discussed in the response to Comment 4) will facilitate flexible, cost effective and timely upskilling for clinicians who do not already meet the training and expertise requirements. Whilst Medicare and NDIA funding procedures for face-to-face and telehealth assessments are beyond the control of the Guideline developers, the Research Executive will advocate for changes, as proposed in the Practice Points for Policymakers (Section 13.2).

7	There might also be some legal consequences. For example, because of funding, assessment service and workforce restrictions there is a risk that individuals with other neurodevelopmental disorders than ASD will be excluded from diagnostic and functional assessments that the clinicians described in the Guideline would be well able to undertake. This potential lack of equity might be grounds for legal action. The Guideline allows for flexibility of clinical practice but also specifies assessment and diagnostic requirements which, if not adequately undertaken, might lead to diagnostic error with potentially short and long term adverse outcomes for the individual on the Autism Spectrum.	Please review comment and respond.	While the current Guideline focuses on ASD, we have been careful to describe an assessment process that is applicable to the full breadth of neurodevelopmental conditions. The Guideline makes mention of this on several occasions. For example, the first two sentences of the Scope of the Guideline (Section 1.2) is: 'It is critical that an assessment of ASD concerns 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 signs or symptoms of a broad range of neurodevelopmental conditions.' Further sections also emphasise this point. For example, Section 1.8 ('an overarching diagnostic framework that could apply to the range of individuals that undergo neurodevelopmental disorder assessments'), as well in sections describing the skills and expertise required of clinicians (requirement of expertise for the assessment of the full breadth of neurodevelopmental disorders). We also highlight that the Guideline includes a Practice Point regarding a review of public funding for diagnostic evaluations (Section 13.2) for all neurodevelopmental conditions. For example, the Guideline states: 'It is important that there is a review of the public funding mechanisms for neurodevelopmental assessments (e.g. through Medicare and other mechanisms) and whether this is adequate to meet the assessment process described in the Guideline.' It is recognised that there is an inherent risk that if the recommendations are not followed, the result may be diagnostic error that leads to potential adverse outcomes. While this is a risk for all Guidelines, we feel that the implementation of Practice Points in relation to funding bodies endorsing the Guideline and developing accreditation and regulation programs will assist to reduce the risk of these adverse outcomes.
8	The development of this Guideline refers to all of the published international ASD assessment guidelines in the English speaking world. The Australian Guideline incorporates aspects of these other guidelines and to my knowledge does not conflict in any fundamental way	Please review comment and respond, if appropriate.	Thank you for these positive comments. No changes are suggested by the reviewer.

	with other guidelines. There are differences between the various guidelines that can be accounted for by differences in health, welfare and disability services between other countries and Australia. For example, the UK National Institute for Health and Care Excellence (NICE) have separate guidelines for the assessment of ASD in "Under 19's" (September 2011) and in "Adults" (June 2012). The draft Australian Guideline deals, in my opinion, effectively with the assessment of different age groups within the one Guideline. National ASD assessment practices can also differ between countries, influenced by different approaches to the delivery of public health and medical services. For example, in Sweden, there is a national public ASD assessment service which includes routine neuroimaging studies of children on the Autism Spectrum. They also have a system for national registration of neurodevelopmental disorders which incidentally has been recommended in the Australian Guideline. Consideration of the use of neuroimaging as part of the diagnostic process is mentioned in the draft Australian Guideline as being part of good medical practice rather than a requirement. This reinforces the recommendation of the Australian Guideline for a medical assessment to form a necessary part of the ASD diagnostic process. The assessment process in the NICE guidelines has a number of similarities to the draft Australian Guideline but there are justifiable differences in administration and assessment pathways due to the context of a national health and disability service structure in the UK compared to the public-private nature of health services, disability services funding and the challenges of provision of services to rural and remote communities in Australia.		
9	Although assessment of functioning is implied in other guidelines, usually within the necessary DSM-5 requirement to assess specifiers and socio-cultural factors as part of the diagnosis of ASD, I am not aware of any other guidelines that specifically include the requirement to assess function. This is a well justified	Please note comment.	Thank you for this positive comment.

	and, in my opinion, critical initiative of the draft Australian Guideline, even if the methods for reliably and validly conducting this assessment have still to be developed and researched.		
10	I highly commend the Draft Australian Guideline and consider that it is based on the best evidence and comprehensive consensus process possible including input from individuals on the Autism Spectrum and their families and carers. I do however consider that there are some aspects of the Guideline where evidence is lacking relating to the process of reliably and validly assessing function and the feasibility of a national implementation. As a consequence, I consider that these aspects should be seen as interim in order to allow research into their implementation.	Please note comment.	Thank you for this positive comment.
Reviewer 5 (International)			
11	…I applaud the effort and product.	Please note comment.	Thank you for this positive comment.
12	Assessment Process: 1. I found your assessment process very interesting, and spent a great deal of time thinking through it. I have several questions related to it that may guide further clarification in the guidelines: a. In our parlance, your Comprehensive Needs Assessment sounds like a comprehensive intake. These intakes are absolutely necessary, and can be extremely helpful in guiding triage to appropriate clinics – which will in turn aide in overall clinic flow and efficiency. However, these intakes can also become obstacles to access to care. i. How will you guard against false negatives with the Comprehensive Needs Assessment; that is, parents may not report symptoms accurately and you may miss those kids that really do have autism. ii. Per the above point, to guard against false negatives, wouldn't you also want	Please review comments and respond.	Thank you for this comment. We have addressed these comments in turn: i. The primary aim of Comprehensive Needs Assessment is not to triage clients (though, it may be used as this), but rather to understand the strengths, challenges and needs of the client that may inform future management. All members of the Assessment Team are required to have relevant training and expertise in the 'presentation of the signs and/or symptoms of ASD and other neurodevelopmental disorders across all developmental stages in which they practise' (please see Recommendation 10). The Comprehensive Needs Assessment includes collection of information about 'ASD-specific signs and/or symptoms' and 'other relevant signs and/or symptoms' (please see Recommendation 23) and direct observation of the individual being assessed (please see Recommendation 24). 'Administration of standardised and non-standardised assessments as required' has been added as a means for collecting information (see Recommendation 24). These inclusions would guard against the point raised by the reviewer. ii. As indicated in the response to (i) above, the Comprehensive Needs Assessment

	to recommend the use of an evidence-based screener to accompany this assessment? I would strongly suggest this, and the evidence supports this. Although population screeners have been criticized, many are gaining in psychometric strength and most guidelines strongly recommend their use.		involves information collection from a variety of sources (file review, interview, direct observation, and now the inclusion of standardised and non-standardised assessments as required) by an experienced clinician with expertise in ASD and other neurodevelopmental disorders. There is good evidence that this more comprehensive process is more accurate than relying on a parent-report screening questionnaire in guarding against false negatives (e.g. please see below references). Stone WL, Hoffman EL, Lewis SE, Ousley OY. Early recognition of autism: Parental reports vs clinical observation. Archives of Pediatrics & Adolescent Medicine. 1994;148(2):174-9.
			Stone WL, Hoffman EL, Lewis SE, Ousley OY. Early recognition of autism: Parental reports vs clinical observation. Archives of Pediatrics & Adolescent Medicine. 1994;148(2):174-9.
	iii. If so, which ones (SCQ, MCHAT-R/F)?		iii. The Guideline has included a suggestion that a developmental screening measure may be helpful for a primary healthcare provider to include in referrals to specialists for an ASD assessment (the step prior to the administration of a Comprehensive Needs Assessment). The 'implementation plan' for the Guideline includes the development of resources that will be on a website, hosted by the Autism CRC. These 'web resources' will provide further information on a range of elements related to this Guideline, including up-to-date evidence regarding developmental screening measures and ASD screening measures, and will be updated as new evidence arises. These web resources will include a comprehensive description of each existing tool, including the psychometric properties.
	iv. You note "may be helpful" in section 6.2, but I would state this more strongly.		iv. Please see our response to (ii) above. Furthermore, we would also highlight section 6.2 covers information collection by a primary healthcare provider, who may or may not have the necessary expertise to administer a standardised ASD screener. Hence, we feel that it is appropriate to retain the less restrictive phrasing 'it may be helpful' in this section. We felt it was more appropriate to include 'administration of standardised and non-standardised assessments as required' to the potential means of data collection in an Assessment of Functioning, where all clinicians have a prerequisite level of expertise in ASD

			(Recommendation 24, section 7.2). The detailed consultation and research process undertaken as part of the development of the guideline did not generate sufficient evidence or consensus to recommend the use of developmental screening measures in all cases. Similarly, we refer this reviewer to Comment 31 of this document, in which Reviewer 4 states the mixed evidence regarding developmental screeners. This evidence indicates that the working used in the Guideline corresponds to the latest evidence in this area.
13	2. With regard to the Consensus Team Diagnostic Evaluation: a. We attempted a similar conceptualization here with a "Tiered" approach. Tier 1 kids were the most severe in symptom presentation, and a single provider would suffice to diagnose these. Higher Tiers reflected more complex or subtle presentations, and thus a team approach was recommended. b. In reality, what has happened is that experienced clinicians make the majority of the diagnoses (your Single Clinician Diagnostic Evaluation), whereas the rest of the team is used primarily for assessing needs and recommendations for intervention. That is, the team is not necessarily better at making the diagnosis. c. Who would lead the Consensus Team? We found it very useful to create the concept of a "lead diagnostic clinician" to avoid any odd team dynamics that may occur.	Please note comment.	Thank you for these comments, which have been noted. Whilst consensus was not achieved in the Delphi survey that a 'lead clinician' should make the final diagnostic decision if agreement could not be reached by the Consensus Diagnosis Team, it is possible that a 'lead clinician' may have other functions. The Guideline currently states that 'it is the decision of the clinician who completed the Single Clinician Diagnostic Evaluation as to which professionals are invited to join the Consensus Diagnosis Team.' This implies a 'lead clinician' dynamic, however this is not explicitly stated (due to not reaching consensus on the Delphi survey).
14	Diagnostic Tools: I feel more strongly about this part. Having gone through your evidence tables, it seems to me that most stakeholders recommended the use of the ADOS or something similar. If so, your decision in your recommendation against endorsing its use more strongly may be one of practicality; that is, you may be thinking that many places can't afford the time or money or personnel to use this measure. In fact, that was the discussion we had here in when making our guideline.	Please review comments and respond.	Evidence Tables 43 and 53 were reviewed in relation to this reviewer comment, and the Guideline developers are confident that there is inconclusive evidence in relation to the mandatory use of ASD-specific assessments (including the ADOS) in ASD diagnostic evaluations. Our evidence for this is as follows: • These Evidence Tables have been updated to include more detailed findings from previously published systematic review findings, including a new paper released in February 2018 (e.g. please see below references). These systematic reviews revealed that there is inadequate or inconsistent

	If that is your reasoning, I would strongly encourage you to rethink this recommendation and state the need for an ADOS (or similar tool) more strongly. The recommendation for the use of a best-practice tool should be based on best patient care and help guide appropriate implementation however inconvenient or expensive that may be. A similar argument would not be valid for another disorder (e.g., "although this particular medical test is proven to be the 'gold standard' in helping to diagnose cancer, we do not strongly recommend its use because it is too expensive").		diagnostic accuracy evidence to support the use of any ASD-specific assessments (including ADOS) in relation to the previous DSM-IV diagnostic criteria, and very few studies included in the more recent paper refer to DSM-5 criteria. • The Evidence Tables were also updated with additional findings from the systematic review completed by the Guideline developers. The systematic database search revealed a very limited number of ASD specific diagnostic accuracy studies using a gold standard multidisciplinary DSM-5 diagnosis as the reference standard. The only two ASD-specific assessments that had an adequate evidence base (two or more studies) were the ADOS and AMSE. Despite the ADOS being considered 'gold standard' instruments, it did not consistently demonstrate the pre-specified level for 'adequate' diagnostic accuracy against the DSM-5 (at least 0.80 for both sensitivity and specificity). • Furthermore, as highlighted by Reviewer 3 (Comment 23), the empirical studies upon which most psychometric estimates of sensitivity and specificity for the ADOS tool were focused on the previous version of the ADOS-2 (the ADOS-G). • The Delphi survey with expert clinicians conducted as part of this project did not find that the mandatory administration of these instruments in an ASD diagnostic evaluation reached the predefined threshold of 'consensus'. We believe that the statement in the Guideline regarding the use of the ADOS tool – that it is a 'helpful complement to diagnostic formulation' but 'not to be used as a substitute for clinical judgement in diagnostic decision-making' – is in accordance with the evidence collated as part of the Guideline development process. We also note that other international guidelines have used similar statements regarding the use of these tools as those used in this Guideline (as mentioned by Reviewer 3 in Comment 23). To help clarify this point further, the Guideline includes a second mention of ASD-specific assessments in Section 10.2: 'If findings from a previously administered ASD-specific assessment (e.g., Autism Diagnostic Observation Schedule) are not

			available and current, then the administration of such a test at this stage may provide important information for the Consensus Diagnosis Team to consider. A variety of other assessments may also be appropriate.' Falkmer T, Anderson K, Falkmer M, Horlin C. Diagnostic procedures in autism spectrum disorder: A systematic review. European Child & Adolescent Psychiatry. 2013;22:329-340. Samtani A, Sterling-Levis K, Scholten RJPM, Woolfenden S, Hooft L, Williams K. Diagnostic tests for Autism Spectrum Disorders (ASD) in preschool children [Protocol]. Cochrane Database of Systematic Reviews. 2011;3. Wigham S, Rodgers J, Berney T, Le Couteur A, Ingham B, Parr JR. Psychometric properties of questionnaires and diagnostic measures for autism spectrum disorders in adults: A systematic review. Autism. 2018;Early online:1-19. Vllasaliu L, Jensen K, Hoss S, Landenberger M, Menze M, Schütz M, Ufniarz K, Kieser M, Freitag CM. Diagnostic instruments for autism spectrum disorder (ASD) [Protocol]. Cochrane Database of Systematic Reviews. 2016;1.
15	Section 6.2: I appreciate this recommendation and agree completely. However, I recommend wording it more strongly. What we have found, in the "real world," most paediatricians don't develop the expertise needed to accurately refer patients; thus, the reliance on a screening rule can help guard against missing children that may have ASD. The alternative would be to develop a system to better train paediatricians (or at least a select group) in the area of ASD.	Please review comment and respond.	Thank you for this comment. Please refer to our response to the identical query above in Comment 12 (iv).
16	Section 9.2: Most in the field, and most guidelines, note that the ADOS is the "gold-standard" tool to aide in clinical judgement. I understand the need for caution in recommending a single tool, but the way it is written does not recommend its use strongly enough in my opinion. Most centers of excellence use evidence-based measures, of which the ADOS is one of the most ubiquitous, important, and highly regarded. If you questioned whether your child had autism, you would likely bring them to a	Please review comment and respond.	Thank you for this comment. Please refer to our response to the query above in Comment 14.

	center that uses such a tool In fact, many centers (like ours) have to complete repeat evaluations on children for a question of autism when this tool was not used initially, as many agencies, funding sources, and parental confidence rely on this measure. I'm not suggesting that you do not include an appropriate cautionary statement in your guideline, but I would definitely encourage a stronger recommendation for the use of the ADOS or similar psychometrically sound and standardized tool. If not, you will likely regret it as it softens the guideline too much and its real-world impact will be diminished.		
17	Minor Issues: a. In the Foreword, you mention "…a best estimate clinical judgement based on the behavioural presentation of the individual [1-3]." Note that most practice parameters that I am familiar with recommend that the judgement is based on direct observation and interaction, and history (developmental and current) with regard to the individual. I realize that you note this later in the document, I just don't want others to think that your guideline is recommending their behavioral presentation alone without considering history based on this comment.	Please review comments and respond, if appropriate.	(a). We have changed this wording to: '…a best estimate clinical judgement based on the behavioural presentation of the individual in the context of their developmental and medical history' (p. ix)
	b. Also in the Foreword: Here in the US, we make special mention of the "diagnosis" being related to medical, whereas "eligibility" relates to disability and educational determinations. This tends to help reduce confusion on the parents' side, and thus reduces the tension that is often created in differing opinions base on different criteria. Again, I realize that you clarify this later in the document, but thought that it may need some clarification here as well.		(b). We have re-read the Foreword and are very confident that the terminology used is accurate to the Australian context. Based on this, we have made no changes related to this point.
	c. Section 1.4: Note that your definition of ASD reads more like a DSM-IV rather than a DSM-5 or ICD-11, which terms it social communication rather than parsing them out separately.		(c) We have adjusted the terminology to be more similar to DSM-5 wording. In particular, the definition is now amended to the following: 'ASD is the collective term for a group of neurodevelopmental disorders characterised by persistent deficits in social communication and social interaction, and by repetitive patterns of behaviour and restricted interests'. (p. 2).

	d. Section 1.6: Very good!! Excellent information that I don't often see in guidelines.		(d). Thank you for this positive comment. No changes are required in response to this comment.
	e. Table 2: In Australia, is there a difference between a paediatrician and a developmental paediatrician? There is a difference here in the US, with different training and expertise, which makes the developmental paediatrician much better equipped in this area.		(e). Yes, developmental paediatrics is a specialist paediatric discipline in Australia. The Guideline recognises this expertise through the statement regarding advanced training in 'community child health' (p. 18, 19, 38 and 43).
	f. Sections 2.1 – 2.6: I was just curious whether there was any priority given to how these areas were listed. Though all valid, I would give some thought into possibly listing these the highest priority first, to help manage the variability across all of your stakeholders (e.g., emphasize evidence-based first).		(f). The 'Evidence Based' principle has been moved to the first position.
	g. Table 4: We also have school psychologists who are also licensed and able to confer a diagnosis. Some of our best clinicians in ASD are school psychologists. Not sure if Australia has an equivalent.		(g). While the Australian educational systems do include School Psychologists, the qualifications, skills and experience of these professionals differs between Australia and the US. The high quality and thorough research and consultation process involved in the development of Guideline selected professions that were most applicable to the Australian context. Clinicians with a practice endorsement in educational/developmental psychology have been identified as eligible to be a Single Clinician, and they may be working in a school psychologist position.
	h. Section 5.3: Note that ECHO Autism is gaining a lot of momentum and may be a great alternative or adjunct to telehealth (https://thompsoncenter.missouri.edu/autism-training/echo-autism/). It is one way to approach training paediatricians in more rural areas and creating better access to care. Feel free to contact me if you want more information on this.		(h). Thank you for this comment, which we have noted for further exploration during the implementation phase.
	i. Section 7.2: I don't see any guidance with regard to collecting this type of information for non- or minimally verbal clients. Also, though the collection of information regarding character strengths is laudable, how these would translate into real world interventions, especially for the full range of ASD presentation, could be problematic.		(i). Clarification has been added to Section 7.2 that is hoped to make the description more relevant for minimally verbal clients. The statement 'by asking clients to identify…' has been changed to 'by asking individual being assessed for ASD and/or their caregivers to identify…'. The concept of strengths as a more holistic concept was captured by the addition of the sentence: 'In addition, open-ended questions and observations may be utilised to identify interests, resources and support systems.'

	j. Section 8: It would be helpful to mention that the medical evaluation is critical to establish a medical care team or professional as, whether ASD or not, there are likely symptoms that will need ongoing clinical care. That being said, placing this prior to the Single Clinician Diagnostic Evaluation seems to prioritize it – which I'm not sure is appropriate in most cases. That is, there are a great number of ASD diagnostic cases that need the diagnosis more urgently than the medical evaluation.		(j). Thank you for this comment, which we have noted. We have also added the sentence 'The Medical Evaluation may be helpful in identifying the need for specialist referrals, assessments and interventions as part of ongoing clinical care' to the introductory text under the Medical Evaluation 'Decision-making and Outcome' heading (Section 8.4).
	k. Table 8: I would not reference Pathological Demand Avoidance as it is not an actual diagnosis as of yet, and may confuse readers.		(k). The systematic reviews conducted as part of the development process identified that Pathological Demand Avoidance is a recognised set of symptomatology that often co-occurs with ASD. Please find below an addition recent reference that supports this point. The consultation process also provided overwhelming feedback endorsing this literature (please see document entitled, 'Responses to Public Consultation Submissions'). To further clarify this point, we have amended the wording of this section from: 'Pathological Demand Avoidance is a subtype of ASD that is recognised in the United Kingdom. It is typified by an avoidance of everyday demands and expectations to an extreme extent, and is driven by an anxiety-based need to be in control. Typical signs and/or symptoms include the resistance or avoidance of ordinary demands of life and the use of social strategies as part of the avoidance (e.g. distracting or giving excuses).' TO 'Pathological (or Extreme) Demand Avoidance are symptoms that can co-occur with ASD, and is recognised as a subtype of ASD in the United Kingdom. It is typified by an avoidance of everyday demands and expectations to an extreme extent, and is driven by an anxiety-based need to be in control. Typical signs and/or symptoms include the resistance or avoidance of ordinary demands of life and the use of social strategies as part of the avoidance (e.g. distracting or giving excuses).' Green J, Absoud M, Grahame V, Malik O, Simonoff E, Le Couteur A, et al. Pathological Demand Avoidance: symptoms but not a syndrome. The Lancet Child & Adolescent Health. 2018;2(6):455-64.

	l. Section 13.3: I'm not sure if I would state the last sentence under "Withdrawing a Diagnosis of ASD" so strongly. There is emerging evidence that these individuals continue to experience difficulties that may be associated with a historical diagnosis of autism. I would term this "behavioral criteria" rather than "diagnostic criteria," because many could still meet criteria for a diagnosis "by history." The philosophical camp here is that it is a genetic disorder that remains, though behavioral criteria may ameliorate, and there are continuing residual problems.		(l). We have reworded 'diagnostic criteria' as 'behavioural criteria' (p. 65).
Reviewer 6: (International)			
18	Thank you for inviting me to review this guideline which I find to be well constructed and comprehensively co-produced with those affected directly by the lived experience of autism spectrum disorder and the professionals charged with assessment responsibilities. Overall, my comments are very positive and I commend the authors. I would very much want to congratulate you on the production of this impressive body of work. Guidelines do need to be adopted, of course (McKenzie 2016), but I anticipate that your collaborative and ICF compliant approach will make your guideline meaningful, realistic and compelling for your target audience and therefore improve the outcomes for those affected by autism spectrum disorder and boost support for professionals seeking to ensure that they are expertly trained in this field of work.	Please note comment.	Thank you for this positive comment.
19	Annotations from guideline document: Pg 1. 1.1 Purpose. Second paragraph. This is a particularly helpful way of expressing the scope for tailoring complexity of assessment to the behavioural presentation of the individual. Pg 1. 1.2 Scope of the guideline. First paragraph. This is also a particularly helpful summary which is returned to in the document and emphasises that	Please note comments.	Thank you for these positive comments.

	professionals undertaking this work must have a good understanding of other neurodevelopmental disorders/conditions, both because of the potential for differential diagnosis but also because of their coexistence with autism spectrum disorder. Pg 4. 1.6 Provision of services based on as ASD Diagnosis. This is a particularly helpful strong point that individuals presenting with behavioural manifestations that may be arising from an autism spectrum disorder should not have to wait for a diagnostic term in order to have their needs met. Pg 5. Table 2. Steering Committee members The steering committee members appear very appropriate in their professional breadth and representation from those affected directly by autism spectrum disorder. Pg 32. Recommendation 26. This is very helpful so that clinicians can avoid direct observations at community locations if the information is furnished in alternative ways and this can improve efficiency and throughput and thus waiting times for diagnostic assessment (McKenzie K et al. The relation between practice that is consistent with NICE guideline 142 recommendations and waiting times within Autism Spectrum Disorder diagnostic service. Research in Autism Spectrum Disorders 2016 26: 10-15). References Rutherford M, Burns M, Gray L, Bremner L, Clegg S, Smith C, O'Hare A. Improving efficiency and quality of the Children's ASD diagnostic pathway: Lessons learned from practice. Journal of Autism and Developmental Disorders. 2017 Online first doi.org/10.1007/s10803-017-3415-7 McKenzie K, Forsyth K, O'Hare A, McClure I, Rutherford M, Murray A, Irvine L. Factors influencing waiting times for diagnosis of Autism Spectrum Disorder in children and adults.		

	Research in Developmental Disabilities. 2015; 45–46:300–306.		
20	The main areas of 'dissent' come down to terminology within the recommended process, illustrated in Figure 2, page 13, and a desire for some reassurance that some of the 'pragmatic' decisions taken particularly around single clinician diagnostic evaluation are not confounded. Pg 38. Recommendation 40. Whilst this is an excellent suggestion, it does make the term 'single clinician' a little confusing. Pg 27. Recommendation 19. 'assessment team' - it is unclear when the term 'assessment team' is employed on page 27 and 28 whether one is referring to all the different types of assessment, so including what is in essence described as a single clinician or whether this is only making reference to the consensus team diagnostic evaluation. I was reassured, in fact, that although the term 'single clinician diagnostic evaluation' is employed, it is recommended that the clinician is not in fact single but that there is significant input from another clinician eg from speech and language therapy so I suggest that maybe this title/designation could be rethought?	Please consider comments and respond.	The introductory text for the Single Clinician Diagnostic Evaluation has been adjusted to make this clearer: 'A Single Clinician Diagnostic Evaluation recognises that for clients whose clinical presentation is sufficiently clear, a diagnostic decision can be reliably made with high confidence by one suitably qualified and experienced clinician, when information is available from other experienced members of the Assessment Team and/or other professionals.' In addition, the wording of Recommendation 40 has been altered slightly to clarify that the 'input' is in the form of 'information': 'It is suggested that a Single Clinician Diagnostic Evaluation involve the collection of information from at least one other clinician from a different discipline or specialty to the Single Clinician, if information from at least one clinician from a different discipline has not yet been obtained (for example, from the Comprehensive Needs Assessment).' Recommendation 19: Assessment Team has been defined in Section 4.2, where it is stated: 'The Assessment Team comprises the clinicians who conduct the Comprehensive Needs Assessment and/or Diagnostic Evaluation.'
21	Pg 40. 9.4 Decision Making. Last paragraph. As discussed in my covering letter (below), should this escalate to the multidisciplinary team assessment? I also felt some concerns that with this single clinician level of assessment, if the outcome was at variance with the view of the individual/families/other informed parties eg education staff, then advise was that there should be an invitation to explore a second opinion. I wondered whether an escalation to the consensus team evaluation was preferable.	Please consider comment and respond.	We agree with this feedback, and is not inconsistent with the evidence through the systematic review and consultation process. We have now expanded a sentence in Section 9.4 from: 'Where a client disagrees with the diagnostic decision, they retain the right to seek a second opinion.' TO: 'Where a client disagrees with the diagnostic decision, they retain the right to seek a second opinion through another Single Clinician Diagnostic Evaluation or a Consensus Team Diagnostic Evaluation.'
22	I recognise in your assessment pathways, much of the approach that we	Please consider	Please refer to our response to Comment 21 in relation to assessment outcome disputes.

	have recently published (Rutherford 2018). It is certainly the case that there is no good quality evidence with respect to differences between a single clinician evaluation and a clinical multidisciplinary team, but in the former there would seem to be a requirement for safeguards, especially in assessment outcome disputes.	comment and respond.	Other safeguards include recommendations addressing the required qualifications, expertise and training for Single Clinicians, along with specific recommendations outlining the topics and means of for information collection, process for making diagnostic decisions and reporting assessment findings.
23	Pg 14. Figure 3. Examples of how the flexible assessment structure described in the Guideline may work in practice. Example 2. Is there a role for discussing escalating assessments to include the discretionary choice to undertake formal evaluation with instruments such as the ADI/ADOS? Pg 39. 9.2 Information Collection. Last paragraph. I have expanded on some reservations about the wording when making reference to the Autism Diagnostic Observation Schedule in my covering letter (below). I would want to make an additional point with respect to the Autism Diagnostic Observation Schedule which in recent years has moved from ADOS-G to ADOS-2 and most of the research which refers to specificities and sensitivities and has been discussed in the literature related to the former.	Please consider comment and respond.	Figure 3 - Example 2 now includes a mention of a formal evaluation instrument (ADOS-2) in Example 2.
	I felt that the guidelines discussion of the ADOS could be read as dismissive of the value of this direct observational technique, even though later in the guideline consideration of its use is recommended. Quoted sensitivity and specificity of the ADOS-G has confidence intervals that take in 80% which is respectable for an instrument that is not for screening and should never be treated as a stand-alone diagnostic tool. It should always be considered within the context of all the other contributions to diagnostic assessment.		The wording in this section has been strengthened to avoid appearing dismissive. It now states: 'The administration of ASD-specific assessments (e.g. Autism Diagnostic Observation Schedule) has been demonstrated to provide considerable assistance in making diagnostic formulations.' A more detailed response to the suggestion about the use of ASD-specific tools (e.g., ADOS) is provided in response to Comment 14.
	I wonder if the guideline could acknowledge a bit earlier how valuable it can be in setting up a situation to explore an individual's strengths and		The importance of setting up a situation in which to elicit an individual's strengths and difficulties in relation to ASD-specific behaviours is already included in the

	difficulties within social communication, reciprocal social interaction, imagination and behaviour? Both NICE and SIGN recognise that the use of the ADOS by clinicians is discretionary and should never supplant expert clinical assessment but I consider it is more valuable than is conveyed in your text. The widespread adoption of the ADOS in the research community similarly attests to its psychometric properties.		Guideline. Please refer to Section 9.2, where it is stated that the following can 'greatly assist the development of a comprehensive clinical picture of an individual': '…observation of the individual being assessed, where the clinician purposefully interacts with the individual in a manner that is likely to elicit behaviours consistent with ASD. A standardised observational tool may be used for this purpose, but is not required'. An addition sentence has been added to the introductory text of the Assessment of Functioning Information Collection heading (Section 7.2): 'The use of standardised assessments can also facilitate situations to explore an individual's strengths and difficulties with aspects such as social communication, reciprocal social interaction, imagination and behaviour.'
24	Pg 9. 2.1 Individual and Family Centred. I am unsure how the individual and/or family members are to be considered equal partners (in the process of assessing ASD) works in practice if the individual does not want to sanction involvement of the family members. There is discussion later in the document about the Australian stance for adults with incapacity and also discussion in another part of the document about the impact of adverse childhood experiences and how they can have overlapping features with ASD or coexist. Should there be cross-referencing to these later points in the document?	Please consider comment and respond.	Our reference to 'equal partners' (now Section 2.2) was intended to denote that individuals/family members are equal partners with the clinicians in the assessment. We have now clarified our wording, by amending this sentence: 'The individual and/or family members are to be considered equal partners in the process of assessing ASD, and their needs, priorities and resources remain critical considerations at each step.' TO 'The individual and/or family members are to be considered equal partners with clinicians in the process of assessing ASD, and their needs, priorities and resources remain critical considerations at each step.'
25	Pg 11. 2.6 Lifespan Perspective. ASD can be a disputed term amongst the autism community who prefer the term 'autism spectrum condition' to acknowledge that it is possible for someone affected by autism to function well and not to be disordered. Is there a place here for that recognition?	Please consider comment and respond.	Thank you for this comment. We have now added the following sentence at the end of the Foreword: 'The Guideline uses the term 'Autism Spectrum Disorder' or 'ASD', which reflects the terminology used in the international diagnostic manuals. However, the term 'Autism Spectrum Conditions' or 'ASC' is also widely used internationally, and can be used interchangeably with ASD.'
26	Pg 16. 4.2 Assessment Team. Recommendation 10. Dot point 2.	Please consider comment and respond	Thank you for this comment, and we have added this to Recommendation 10: 'presentation of the signs and/or symptoms of ASD and other neurodevelopmental disorders across all developmental stages in

	Those seeing adults should have a thorough understanding of the manifestations of ASD in childhood.	if appropriate.	which they practise, along with the manifestations of these symptoms during early development (which is relevant to diagnostic criteria).'
27	Pg 52. Table 9. Additional considerations for school-aged children (6-16 years). Sharing Findings. Does the guideline have accompanying material written specifically for children and young people, and parents and carers?	Please consider comment and respond.	A two-page 'lay summary' document has been created (and provided to the NHMRC) to provide high-level information to consumers about the recommended diagnostic process. This document is best suited to parents/caregivers and older individuals undergoing assessment (e.g. adolescents and adults) with higher intellectual and communication capacity. This document was created in close consultation with parents and carers of children with ASD. While the generation of a lay summary for children and young people was not within the scope of this project, we agree that this is an important endeavour. We will create a social story template and explainer video aimed at children and young people during the implementation phase.
28	Pg 54. 12.2 Intellectual and/or Communication Capacity. First paragraph. The '30% of individuals who receive a diagnosis of ASD have intellectual disability' comment is misleading as this only relates to children 8 years and under so that needs to be qualified.	Please consider comment and respond.	Thank you for this comment. We have now amended this sentence in section 12.2 to: 'Approximately 30 per cent of children 8 years and under who receive a diagnosis of ASD have intellectual disability.'
29	Pg 55. 12.2 Intellectual and/or Communication Capacity. Second paragraph. Would it be more accurate to say that when intellectual impairment operated as an inclusion ... 'was' an exclusion gives this a legitimacy whereas in fact it was more accurately described as being employed by services as it has always been recognised that intellectual disability can coexist with autism.	Please consider comment and respond.	Thank you for this comment. We believe that this sentence provided unnecessary confusion, and did not add a great deal of information to this section. For this reason, we have now omitted this sentence from the Guideline.
Reviewer 7: (International)			
30	This is very well done indeed.	Please note comment.	Thank you for this positive comment.
31	As you undoubtedly know there is now great controversy over screening (I see you avoid this issue largely) - the problem is the screeners are rather 'dirty' and in addition to getting lower (but not higher) functioning children with autism they pick up a lot of	Please consider comment and respond if appropriate.	Thank you for this comment. The issue of screening is outside of the scope of this diagnostic guideline. We have provided extended comment on the issue of screening in Comment 12. For the reasons in Comment 12, we have not made any change to the Guideline.

	developmental problems (i.e. effectively are level I not level 2 screeners – MCHAT is good example). We have conflicting recommendations in the US with AAP recommending universal screening for autism, while others recommend against, citing (among other things) danger of miss-diagnosis early on - don't know if you need to get into this or not! In the US one can use a rather generic label (developmental delay) until child is 6 or so. But something to think about.		
32	For what it is worth you have a LOT of recommendations – it will seem overwhelming maybe either combine OR label in some way to indicate that there are sometimes targeted at different groups!	Please consider comment and respond if appropriate.	The recommendations have been combined as much as possible to reduce the information load on readers. Critically, the Guideline has been through several rounds of public feedback, which has enabled us to determine the 'acceptability' of the document to clinicians. Through this process, we were able to identify and omit sections that were deemed unnecessary to achieving the objective of the Guideline. The penultimate draft of the Guideline was reviewed by the Steering Committee, who provided overwhelmingly positive feedback regarding the acceptability of the volume of information and content provided in the Guideline. The structure and style of the document have been designed to assist the reader to navigate to relevant sections of the Guideline (e.g. use of heading levels and fonts, interactive table of content, book marks). We also note that an abbreviated version of the Guideline has been created and submitted to the NHMRC ('Summary and Recommendations' document). Additional Web Resources will be created during the implementation phase to provide summaries of smaller sections of the Guideline targeted to specific audiences (e.g. fact sheets and explainer videos).
33	Pg 14. Figure 3. Examples of how the flexible assessment structure described in the Guideline may work in practice. It took me quite a while to sort this out. It is rather confusing	Please consider comment and respond.	Through the consultation process, we received extensive feedback from a wide range of peak bodies that Figure 3 was very helpful in describing the assessment process. For this reason, we have made no change to the figure.
34	Pg 26. 6.2 Information Collection. Second paragraph. I would amplify on this - when talking about infancy for older children it may be good to have parents look at baby books, home movies, or ask them to recall a special event like first birthday or	Please consider comment and respond.	Information regarding the use of baby books and home footage in the Diagnostic Evaluation is included in the Guideline in Section 9.2, which we believe is a most appropriate place for this detail. For this reason, no change has been made in response to this comment.

	first xmas - I would expand this section a bit		
35	Pg 51. Table 9. Additional considerations for school-aged children (6–16 years). Spoken language. ? where to put perseveration on a topic of interest - like in Asperger's	Please consider comment and respond.	This information is already included in the guideline (Section 12.1, Table 9, fourth dot point under 'Spoken Language'): 'Repetitive language, with frequent use of certain phrases or with content dominated by excessive information on topics of interest.' No change has been made to the Guideline.
36	Pg 57. 12.3 Gender. There is a paper about to come out in pediatrics on gender difference on mchat items in a VERY large sample of children in Norway -makes the point that girls and boys may have different features early on!		Thank you for this comment, which we have noted. We look forward to reviewing this paper in the near future.
Reviewer 8: (International)			
37	This is an excellent, well evidenced-based and comprehensive guideline for assessment and diagnosis of autism spectrum disorders (ASD) in Australia. I have few comments as it is a clear and first-class piece of work.	Please note comment.	Thank you for this positive comment.
38	Somewhere I would highlight that the 'clinical specifiers' in DSM-5 are important for 'clinical profiling' – which was also laid out in the UK NICE CG128 – which is often as relevant for thinking of an individual's needs and needs for support as the diagnosis of ASD itself. This is in the document (page 8) but is an essential part of any framework both for diagnostic teams but also for those commissioning services.	Please consider comment and respond.	Thank you for this comment. We have now highlighted the importance of the 'clinical specifiers' in DSM-5 earlier in the document. The introductory text to Diagnostic Criteria for ASD (Section 1.5), now includes three extra sentences: 'ASD is diagnosed when an individual displays a certain set of behaviours. There are two sets of diagnostic criteria commonly used throughout Australia and the world. The American Psychiatric Association publishes the Diagnostic and Statistical Manual of Mental Disorders (currently in its fifth edition – DSM-5), which uses the term 'Autism Spectrum Disorder' (Table 1). The DSM-5 requires clinicians to specify the severity of symptoms within the two domains and also if a range of conditions are co-occurring. This information can be helpful for clinical profiling to support both diagnostic decision making and identification of support needs. The World Health Organization publishes the International Classification of Diseases (currently in its 10th edition – ICD-10), which will adopt the term 'Autism Spectrum Disorder' in its 11th revision (ICD-11), due for release in 2018 (Table 1). It is

			expected that the ICD-11 will require clinicians to specify the presence and extent of intellectual and language impairment, along with the impact on numerous areas of functioning.'
39	I would emphasise in section 9.2 (page 38) that early (i.e. preschool) developmental history is critical to understand emergent ASD phenotype. This can be hard to acquire for some adults (reliant on parents) and in looked after (adopted/fostered) children but can be particularly important in differential diagnosis.	Please consider comment and respond.	This information is already strongly emphasised in the guideline in Section 9.2, with the third dot point: 'Developmental and educational history: how the individual has presented during their lifetime in terms of developmental milestones for intellectual, communication, social, and gross/fine motor and personal care skills as well as the presence of any developmental regression.' To further emphasise this point, we have now included the word 'early' prior to the phrase 'developmental milestones'.
40	Section 10.4 (page 46) in young children the notion of a 'working' (or even an 'uncertain') diagnosis can be useful with a reassessment and re-review once a period of time (e.g. 18 months or so depending on age and developmental level) has passed.	Please note comment.	We have noted this comment. The Research Executive deliberated over including a 'working' or 'provisional' diagnosis, however felt that this was too great a departure from current practice in Australia, and would require existing structures within health systems to ensure that individuals receiving such a diagnosis received the support they need. Currently, these are not in place in Australia. For this reason, we elected not to amend the Guideline in response to this comment.
41	Page 50 – Pathological demand avoidance in recognised by some groups (including the NAS) in the UK but is not recognised and used by the majority of clinical services.	Please note comment.	Please refer to item (k) in the response to Comment 17.

References

1. Taylor, L., Brown, P., Eapen, V., Harris, A., Maybery, M., Midford, S., … Whitehouse, A. (2016). *Autism spectrum disorder diagnosis in Australia: Are we meeting best practice standards?* Autism CRC: Brisbane.
2. National Collaborating Centre for Mental Health. (2012). *Autism: Recognition, referral, diagnosis and management of adults on the autism spectrum - National clinical guideline [142]*. London, England: National Institute for Health and Care Excellence.
3. National Collaborating Centre for Women's and Children's Health. (2011). *Autism spectrum disorder in under 19s: Recognition, referral and diagnosis - Clinical guideline [128]*. London, England: National Institute for Health and Care Excellence.
4. Arksey, H., & O'Malley, L. (2005). *Scoping studies: Towards a methodological framework*. International Journal of Social Research Methodology, *8*(1), 19–32. doi:10.1080/1364557032000119616
5. Falkmer, T., Anderson, K., Falkmer, M., & Horlin, C. (2013). *Diagnostic procedures in autism spectrum disorders: A systematic literature review*. European Child & Adolescent Psychiatry, *22*(6), 329–340.
6. Forbes. (n.d.). *America's Biggest Health Insurance Providers*. Retrieved from https://www.forbes.com/pictures/fefi45ejdih/the-biggest-health-insur/#742a219476ee
7. Juárez, P., Loring, L., Whitaker, T., Reed, C., Frank, K., Murphy, L., & Gassner, D. (2013). *Best practice guidelines: Children and adolescents with autism spectrum disorders*. Nashville, USA: Tennessee Department of Mental Health and Substance Abuse Services.
8. Bureau of Early Intervention. (2013). *Best practice protocol for early screening of young children for autism spectrum disorders (ASDs) by pediatric primary care providers*. Albany, USA: New York State Department of Health.
9. Perry, A., Condillac, R., & Freeman, N. (2002). *Best practices and practical strategies for assessment and diagnosis of autism*. Journal of Developmental Disabilities, *9*(2), 61–75.
10. University of Connecticut Center for Excellence in Developmental Disabilities. (2013). *Connecticut guidelines for a clinical diagnosis of autism spectrum disorder*. Mansfield, USA: University of Connecticut.
11. Silove, N., Blackmore, R., Warren, A., Gibbs, V., & Roberts, J. (2007). *A consensus approach for the paediatrician's role in the diagnosis and assessment of autism spectrum disorders in Australia*. Sydney, Australia: Paediatrics & Child Health Division, Royal Australasian College of Physicians.
12. Swingle, H., Anderson, S., Bailey, K., Becker, R., Dahle, K., Frame, D., … Wooster, D. (2014). *Diagnostic clinics standards of practice recommendations*. Montgomery, USA: The Alabama Interagency Autism Coordinating Council.
13. Amaze (Autism Victoria). (2009). *The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder*. Melbourne, Australia: Author.
14. Western Australian Autism Diagnostician's Forum Inc. (2005). *The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder*. Perth, Australia: Author.
15. Department of Health and Senior Services. (2010). *Early identification of autism spectrum disorders: Guidelines for healthcare professionals in New Jersey*. Trenton, USA: State of New Jersey.
16. Perry, A., & Condillac, R. (2003). *Evidence-based practices for children and adolescents with autism spectrum disorders: Review of the literature and practice guide*. Toronto, Canada: Children's Mental Health Ontario.
17. New Hampshire Task Force on Autism. (2003). *Assessment and interventions*. Concord, USA: Division of Developmental Services, Department of Health and Human Services, State of New Hampshire.
18. Bull, K. (2013). *A guide to identification, diagnosis and treatment of autism spectrum disorder in Victorian mental health services*. Melbourne, Australia: Mindful.
19. Johnson, C., & Myers, S. (2007). *Identification and evaluation of children with autism spectrum disorders*. Pediatrics, *120*(5), 1183–1215.
20. Abate, K., Apfel, C., Bolick, T., Bringolf, R., Bumbalo, J., Cashin, J., … Woodman, C. (2003). *The New Hampshire task force on autism: Part one - assessment and interventions*. Concord, USA: State of New Hampshire.
21. Ministries of Health and Education. (2016). *New Zealand autism spectrum disorder: Guideline*.

Wellington, New Zealand: Ministry of Health.
22. Bureau of Autism Services. (2011). *Pennsylvania autism needs assessment: A survey of individuals and families living with autism - Getting an autism diagnosis and follow-up care [Report 5]*. Harrisburg, USA: Pennsylvania Department of Public Welfare.
23. Barthélémy, C., Fuentes, J., Howlin, P., & van der Gaag, R. (n.d.). *Persons with autism spectrum disorder: Identification, understanding, intervention*. Brussels, Belgium: Autism Europe.
24. Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., & State, M. (2014). *Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder*. Journal of the American Academy of Child and Adolescent Psychiatry, *53*(2), 237–257. doi:10.1016/j.jaac.2013.10.013
25. Filipek, P., Accardo, P., Ashwal, S., Baranek, G., Cook Jr, E., Dawson, G., … Volkmar, F. (2000). *Practice parameter: Screening and diagnosis of autism. Report of the quality standards subcommittee of the American Academy of Neurology and the Child Neurology Society*. Neurology, *55*(4), 468–479.
26. Steiner, A., Goldsmith, T., Snow, A., & Chawarska, K. (2012). *Practitioner's guide to assessment of autism spectrum disorders in infants and toddlers*. Journal of Autism and Developmental Disorders, *42*(6), 1183–1196. Retrieved from http://ezproxy.library.uwa.edu.au/login?url=http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=emed14&AN=51702496 http://primo-direct-apac.hosted.exlibrisgroup.com/openurl/UWA/UWA_SERVICES_PAGE?sid=OVID:embase&id=pmid:22057879&id=doi:10.
27. Nachshen, J., Garcin, N., Moxness, K., Tremblay, Y., Hutchinson, P., Lachance, A., … Ruttle, P. (2008). *Screening, assessment, and diagnosis of autism spectrum disorders in young children: Canadian best practice guidelines*. Montreal, Canada: Mirium Foundation.
28. Scottish Intercollegiate Guidelines Network. (2016). *Assessment, diagnosis and interventions for autism spectrum disorders: A national clinical guideline [SIGN 145]*. Edinburgh, Scotland: Healthcare Improvement Scotland.
29. Incidence, O. C. for A. and L. (2010). *Service guidelines for individuals with autism spectrum disorder through the lifespan*. Columbus, USA: Authors.
30. Dua, V. (2003). *Standards and guidelines for the assessment and diagnosis of young children with autism spectrum disorder in British Columbia*. Victoria, Canada: The British Columbia Ministry of Health Planning.
31. California Department of Developmental Services. (2002). *Autistic spectrum disorders: Best practice guidelines for screening, diagnosis and assessment*. Sacramento, USA: Author.
32. Pennsylvania Autism Assessment and Diagnosis Expert Work Group. (2007). *Supporting quality diagnostic practices for persons with suspected autism spectrum disorder*. Harrisburg, USA: Pennsylvania Department of Public Welfare.
33. Autism Summit Team. (2014). *Tennessee autism plan: Stakeholder recommendations for a comprehensive coordinated system of care for children and youth with autism*. Nashville, USA: Authors.
34. Force, A. T. (2010). *Autism guidebook for Washington State: A resource for individuals, families, and professionals*. Olympia, USA: Washington State Department of Health.
35. Geschwind, D., & Cummings, J. (1998). *Autism screening and diagnostic evaluation: CAN consensus statement*. CNS Spectrums, *3*(3), 40–49.
36. Farmer, J., Kanne, S., Kilo, M., & Mantovani, J. (2010). *Autism spectrum disorders: Missouri best practice guidelines for screening, diagnosis, and assessment*. Jefferson City, USA: Thompson Foundation for Autism and the Division of Developmental Disabilities, Missouri Department of Mental Health.
37. Services, C. D. C. D. (2016). *Best practice guideline for the assessment & diagnosis of autism spectrum disorders*. Brisbane, Australia: Children's Health Queensland Hospital and Health Service.
38. Autism Spectrum Disorders Special Interest Group. (2010). *Best practice guidelines for the assessment and diagnosis of autistic spectrum disorders for children and adolescents (birth to 18 years)*. Dublin, Ireland: Psychological Society of Ireland.
39. McFadden, C., & Living, D. of D. A. and I. (2009). *Best practice guidelines for the diagnosis of pervasive developmental disorders*. Waterbury, USA: Agency of Human Services, State of Vermont.
40. Brouwers, M. C., Kho, M. E., Browman, G. P., Burgers, J. S., Cluzeau, F., Feder, G., … AGREE Next Steps Consortium. (2010). *AGREE II: Advancing guideline development,*

reporting and evaluation in health care. Canadian Medical Association Journal, *182*(18), E839-42. doi:10.1503/cmaj.090449
41. Missouri Autism Guidelines Initiative. (2010). *Autism spectrum disorders: Missouri best practice guidelines for screening, diagnosis, and assessment*. Jefferson City, USA: Thompson Foundation for Autism and the Division of Developmental Disabilities, Missouri Department of Mental Health.
42. Samtani, A., Sterling-Levis, K., Scholten, R. J., Woolfenden, S., Hooft, L., & Williams, K. (2011). *Diagnostic tests for Autism Spectrum Disorders (ASD) in preschool children*. Cochrane Database of Systematic Reviews. doi:10.1002/14651858.CD009044
43. Vllasaliu, L., Jensen, K., Hoss, S., Landenberger, M., Menze, M., Schütz, M., … Freitag, C. M. (2016). *Diagnostic instruments for autism spectrum disorder (ASD)*. Cochrane Database of Systematic Reviews. doi:10.1002/14651858.CD012036
44. Whiting, P. F. (2011). *QUADAS-2: A Revised Tool for the Quality Assessment of Diagnostic Accuracy Studies*. Annals of Internal Medicine, *155*(8), 529. doi:10.7326/0003-4819-155-8-201110180-00009
45. Shea, B. J., Grimshaw, J. M., Wells, G. A., Boers, M., Andersson, N., Hamel, C., … Bouter, L. M. (2007). *Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews*. BMC Medical Research Methodology, *7*(1), 10. doi:10.1186/1471-2288-7-10
46. Dawkins, T., Meyer, A., & Van Bourgondien, M. (2016). *The relationship between the Childhood Autism Rating Scale: Second Edition and clinical diagnosis utilizing the DSM-IV-TR and the DSM-5*. Journal of Autism and Developmental Disorders, *46*(10), 3361–3368.
47. Grodberg, D., Siper, P., Jamison, J., Buxbaum, J., & Kolevzon, A. (2016). *A simplified diagnostic observational assessment of autism spectrum disorder in early childhood*. Autism Research, *9*(4), 443–449.
48. Grodberg, D., Weinger, P., Halpern, D., Parides, M., Kolevzon, A., & Buxbaum, J. (2014). *The Autism Mental Status Exam: Sensitivity and specificity using DSM-5 criteria for autism spectrum disorder in verbally fluent adults*. Journal of Autism and Developmental Disorders, *44*(3), 609–614.
49. Hedley, D., Nevill, R., Monroy-Moreno, Y., Fields, N., Wilkins, J., Butter, E., & Mulick, J. (2015). *Efficacy of the ADEC in identifying autism spectrum disorder in clinically referred toddlers in the US*. Journal of Autism and Developmental Disorders, *45*(8), 2337–2348.
50. Smith, C., Rozga, A., Matthews, N., Oberleitner, R., Nazneen, N., & Abowd, G. (2017). *Investigating the accuracy of a novel telehealth diagnostic approach for autism spectrum disorder*. Psychological Assessment, *29*(3), 245.
51. Kmet, L., Lee, R., & Cook, L. (n.d.). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields*. Edmonton, Canada: Alberta Heritage Foundation for Medical Research.
52. Abbott, M., Bernard, P., & Forge, J. (2013). *Communicating a diagnosis of autism spectrum disorder: A qualitative study of parents' experiences*. Clinical Child Psychology and Psychiatry, *18*(3), 370–382.
53. Andersson, G., Miniscalco, C., & Gillberg, C. (2014). *Preschoolers assessed for autism: Parent and teacher experiences of the diagnostic process*. Research in Developmental Disabilities, *35*(12), 3392–3402.
54. Bargiela, S., Steward, R., & Mandy, W. (2016). *The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype*. Journal of Autism and Developmental Disorders, *46*(10), 3281–3294.
55. Barnett, N. (2014). *The process of diagnosis delivery of autism spectrum disorders [Doctoral thesis]*. University of New Mexico, Alburquerque, USA.
56. Bessette Gorlin, J., McAlpine, C., Garwick, A., & Wieling, E. (2016). *Severe childhood autism: The family lived experience*. Journal of Pediatric Nursing, *31*(6), 580–597.
57. Braiden, H., Bothwell, J., & Duffy, J. (2010). *Parents' experience of the diagnostic process for autistic spectrum disorders*. Child Care in Practice, *16*(4), 377–389.
58. Bressi, R. (2017). *Analysis of parental perspectives regarding the diagnostic process for their child with autism [Master's thesis]*. University of Oklahoma Health Sciences Center, Oklahoma City, USA.
59. Cane, F. (2015). *Late(r) diagnosis of ASC: Using parent narratives to understand the contextual factors associated with later diagnosis and its impact on children and families [Doctoral thesis]*. University of Birmingham, Birmingham, England.
60. Carlsson, E., Miniscalco, C., Kadesjö, B., & Laakso, K. (2016). *Negotiating knowledge:*

Parents' experience of the neuropsychiatric diagnostic process for children with autism. International Journal of Language & Communication Disorders, *51*(3), 328–338.
61. Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). *The autism diagnostic experiences of French parents*. Autism, *15*(1), 83–97.
62. Chiu, Y., Chou, M., Lee, J., Wong, C., Chou, W., Wu, Y., … Gau, S. (2014). *Determinants of maternal satisfaction with diagnosis disclosure of autism*. Journal of the Formosan Medical Association, *113*(8), 540–548.
63. Connolly, M., & Gersch, I. (2013). *A support group for parents of children on a waiting list for an assessment for autism spectrum disorder*. Educational Psychology in Practice, *29*(3), 293–308.
64. Craig, R. (2015). *"I don't know what's the Asperger's and what's me": An IPA exploration of young people and mothers' experiences of receiving and living with an autism spectrum condition diagnosis during adolescence [Doctoral thesis]*. University of Glasgow, Glasgow, Scotland.
65. Crane, L., Chester, J., Goddard, L., Henry, L., & Hill, E. (2016). *Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom*. Autism, *20*(2), 153–162.
66. Ducey, R. R. (2009). *Having a child diagnosed with autism: A phenomenological study of mothers' experiences [Doctoral thesis]*. University of Northern Colorado, Greeley, USA.
67. Feliciano, E. (2008). *Parental reactions to a diagnosis of autism: How resolution relates to engagement in the parent-child dyad [Doctoral thesis]*. Pace University , New York, USA.
68. Greaves, K. (2014). *Young men and their parents views on the impact of the diagnosis of Asperger Syndrome on their educational experiences [Doctoral thesis]*. University of East London, London, England.
69. Hennel, S., Coates, C., Symeonides, C., Gulenc, A., Smith, L., Price, A., & Hiscock, H. (2016). *Diagnosing autism: Contemporaneous surveys of parent needs and paediatric practice*. Journal of Paediatrics and Child Health, *52*(5), 506–511.
70. Heredia-Alvarado, K. (2017). *A mother's narrative: Experience as a Latino mother with a child diagnosed with autism spectrum disorder [Doctoral thesis]*. Alliant International University, San Diego, USA.
71. Huws, J., & Jones, R. (2008). *Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism*. Journal of Intellectual and Developmental Disability, *33*(2), 99–107.
72. Jones, L., Goddard, L., Hill, E., Henry, L., & Crane, L. (2014). *Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the United Kingdom*. Journal of Autism and Developmental Disorders, *44*(12), 3033–3044.
73. Kalash, L., & Olson, M. (2012). *Perspectives of parents who have a child diagnosed with an autism spectrum disorder*. Journal of the American Academy of Special Education Professionals, *93*, 121.
74. Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). *The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder*. Journal of Applied Research in Intellectual Disabilities, *23*(4), 390–397.
75. Lewis, L. (2016). *Realizing a diagnosis of autism spectrum disorder as an adult*. International Journal of Mental Health Nursing, *25*(4), 346–354.
76. Lilley, R. (2011). *Maternal intimacies: Talking about autism diagnosis*. Australian Feminist Studies, *26*(68), 207–224.
77. Mann, T. (2014). *"We didn't really know what was ahead of us." Family experiences with autism identification, diagnosis, and treatment in the policy context [Doctoral thesis]*. University of Delaware, Newark, USA.
78. Marco, P. (2010). *Disclosing a diagnosis of autism spectrum disorder to parents: Guidelines for professionals [Doctoral thesis]*. Massachusetts School of Professional Psychology, Newton, USA.
79. McCaffrey, E. (2011). *The maternal experience in the diagnosis of autism spectrum disorder [Clinical psychology thesis]*. Chestnut Hill College, Philadelphia, USA.
80. McMorris, C., Cox, E., Hudson, M., Liu, X., & Bebko, J. (2013). *The diagnostic process of children with autism spectrum disorder: Implications for early identification and intervention*. Journal on Developmental Disabilities, *19*(2).
81. Mitchell, C., & Holdt, N. (2014). *The search for a timely diagnosis: Parents' experiences of their child being diagnosed with an autistic spectrum disorder*. Journal of Child & Adolescent Mental Health, *26*(1), 49–62.
82. Moh, T., & Magiati, I. (2012). *Factors associated with parental stress and satisfaction during*

the process of diagnosis of children with autism spectrum disorders. Research in Autism Spectrum Disorders, *6*(1), 293–303.
83. Molteni, P., & Maggiolini, S. (2015). *Parents' perspectives towards the diagnosis of autism: An Italian case study research*. Journal of Child and Family Studies, *24*(4), 1088–1096.
84. Murillo, L., Shih, A., Rosanoff, M., Daniels, A., & Reagon, K. (2016). *The role of multi-stakeholder collaboration and community consensus building in improving identification and early diagnosis of autism in low-resource settings*. Australian Psychologist, *51*(4), 280–286.
85. Navot, N., Jorgenson, A., & Webb, S. (2017). *Maternal experience raising girls with autism spectrum disorder: A qualitative study*. Child: Care, Health and Development, *43*(4), 536–545.
86. Novoa, M. (2015). *Exploring the experiences of Mexican families with an autism spectrum diagnosis [Doctoral thesis]*. Alliant International University, San Diego, USA.
87. Oswald, D., Haworth, S., Mackenzie, B., & Willis, J. (2017). *Parental report of the diagnostic process and outcome: ASD compared with other developmental disabilities*. Focus on Autism and Other Developmental Disabilities, *32*(2), 152–160.
88. Powell, T., & Acker, L. (2016). *Adults' experience of an Asperger Syndrome diagnosis: Analysis of its emotional meaning and effect on participants' lives*. Focus on Autism and Other Developmental Disabilities, *31*(1), 72–80.
89. Punshon, C., Skirrow, P., & Murphy, G. (2009). *The not guilty verdict: Psychological reactions to a diagnosis of Asperger Syndrome in adulthood*. Autism, *13*(3), 265–283.
90. Rabbitte, K., Prendeville, P., & Kinsella, W. (2017). *Parents' experiences of the diagnostic process for girls with autism spectrum disorder in Ireland: An interpretative phenomenological analysis*. Educational and Child Psychology, *34*(2), 54–66.
91. Ratto, A. (2013). *The impact of cultural factors on the diagnostic process in autism: A comparison of Latina and European American mothers [Doctoral thesis]*. University of North Carolina at Chapel Hill, Chapel Hill, USA.
92. Rogers, C., Goddard, L., Hill, E., Henry, L., & Crane, L. (2016). *Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom*. Autism, *20*(7), 820–831.
93. Rose, A. (2011). *Parents' experiences of obtaining an autism spectrum disorder diagnosis [Doctoral thesis]*. University of Hartford, West Hartford, USA.
94. Rosqvist, H. (2012). *Normal for an Asperger: Notions of the meanings of diagnoses among adults with Asperger Syndrome*. Intellectual and Developmental Disabilities, *50*(2), 120–128.
95. Russell, G., & Norwich, B. (2012). *Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders*. Clinical Child Psychology and Psychiatry, *17*(2), 229–245.
96. Saggu, R. (2015). *Parental perceptions of the diagnostic process for autism spectrum disorder in British Columbia [Doctoral thesis]*. Walden University, Minneapolis, USA.
97. Sansosti, F., Lavik, K., & Sansosti, J. (2012). *Family experiences through the autism diagnostic process*. Focus on Autism and Other Developmental Disabilities, *27*(2), 81–92.
98. Siklos, S., & Kerns, K. (2007). *Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders*. Research in Developmental Disabilities, *28*(1), 9–22.
99. Sweeney Gray, J. (2013). *Parental experience of receiving an autism diagnosis and adjusting to the news [Doctoral thesis]*. Massachusetts School of Professional Psychology, Newton, USA.
100. Tait, K., Fung, F., Hu, A., Sweller, N., & Wang, W. (2016). *Understanding Hong Kong Chinese families' experiences of an autism / ASD diagnosis*. Journal of Autism and Developmental Disorders, *46*(4), 1164–1183.
101. Thompson-Kroon, J. (2012). *Defining reality: The parental experience of getting to a diagnosis of Asperger Syndrome [Doctoral thesis]*. Gannon University, Erie, USA.
102. Ward, S., Sullivan, K., & Gilmore, L. (2016). *Practitioner perceptions of the assessment and diagnosis of autism in Australia*. Australian Psychologist, *51*(4), 272–279.
103. Zeiger, V. (2008). *Screening for autism spectrum disorders: Pediatric practices eight years after publication of practice guidelines [Doctoral thesis]*. Indiana University of Pennsylvania, Indiana, USA.
104. Zuckerman, K., Sinche, B., Mejia, A., Cobian, M., Becker, T., & Nicolaidis, C. (2014). *Latino parents' perspectives on barriers to autism diagnosis*. Academic Pediatrics, *14*(3), 301–308.
105. Adelman, C. (2010). *Factors that influence age of identification of children with autism and pervasive developmental disorders not otherwise specified [Doctorial thesis]*. University of Houston, Houston, USA.

106. Austin, J., Manning-Courtney, P., Johnson, M., Weber, R., Johnson, H., Murray, D., … Murray, M. (2016). *Improving access to care at autism treatment centers: A system analysis approach*. Pediatrics, *137*(Supplement 2), S149–S157.
107. Daniels, A., Halladay, A., Shih, A., Elder, L., & Dawson, G. (2014). *Approaches to enhancing the early detection of autism spectrum disorders: A systematic review of the literature*. Journal of the American Academy of Child & Adolescent Psychiatry, *53*(2), 141–152.
108. Denman, K., Smart, C., Dallos, R., & Levett, P. (2016). *How families make sense of their child's behaviour when on an autism assessment and diagnosis waiting list*. Journal of Autism and Developmental Disorders, *46*(11), 3408–3423.
109. Fombonne, E. (2009). *A wrinkle in time: From early signs to a diagnosis of autism*. Journal of the American Academy of Child & Adolescent Psychiatry, *48*(5), 463–464.
110. Frenette, P., Dodds, L., MacPherson, K., Flowerdew, G., Hennen, B., & Bryson, S. (2013). *Factors affecting the age at diagnosis of autism spectrum disorders in Nova Scotia, Canada*. Autism, *17*(2), 184–195.
111. Gordon-Lipkin, E., Foster, J., & Peacock, G. (2016). *Whittling down the wait time: Exploring models to minimize the delay from initial concern to diagnosis and treatment of autism spectrum disorder*. Pediatric Clinics of North America, *63*(5), 851.
112. McClure, I., MacKay, T., Mamdani, H., & Mccaughey, R. (2010). *A comparison of a specialist autism spectrum disorder assessment team with local assessment teams*. Autism, *14*(6), 589–603.
113. McKenzie, K., Forsyth, K., O'Hare, A., McClure, I., Rutherford, M., Murray, A., & Irvine, L. (2015). *Factors influencing waiting times for diagnosis of autism spectrum disorder in children and adults*. Research in Developmental Disabilities, *45*, 300–306.
114. McKenzie, K., Forsyth, K., O'Hare, A., McClure, I., Rutherford, M., Murray, A., & Irvine, L. (2016). *The relationship between waiting times and 'adherence' to the Scottish Intercollegiate Guidelines Network 98 guideline in autism spectrum disorder diagnostic services in Scotland*. Autism, *20*(4), 395–401.
115. McKenzie, K., Rutherford, M., Forsyth, K., O'Hare, A., McClure, I., Murray, A., & Irvine, L. (2016). *The relation between practice that is consistent with NICE guideline 142 recommendations and waiting times within autism spectrum disorder diagnostic services*. Research in Autism Spectrum Disorders, *26*, 10–15.
116. Miodovnik, A., Harstad, E., Sideridis, G., & Huntington, N. (2015). *Timing of the diagnosis of attention-deficit/hyperactivity disorder and autism spectrum disorder*. Pediatrics, *136*(4), e830–e837.
117. Ošlejšková, H., Kontrová, I., Foralová, R., Dušek, L., & Némethová, D. (2007). *The course of diagnosis in autistic patients: the delay between recognition of the first symptoms by parents and correct diagnosis*. Neuroendocrinology Letters, *28*(6), 895–900.
118. Randall, M., Albein-Urios, N., Brignell, A., Gulenc, A., Hennel, S., Coates, C., … Silove, N. (2016). *Diagnosing autism: Australian paediatric research network surveys*. Journal of Paediatrics and Child Health, *52*(1), 11–17.
119. Rossi, N. (2012). *The production of autism diagnoses within an institutional network: Towards a theory of diagnosis [Doctoral thesis]*. Columbia University, New York, USA.
120. Rutherford, M., McKenzie, K., Forsyth, K., McCartney, D., O'Hare, A., McClure, I., & Irvine, L. (2016). *Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of autism spectrum disorder in adults and children*. Research in Autism Spectrum Disorders, *31*, 53–65.
121. Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., … Murray, A. (2016). *Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder*. Autism, *20*(5), 628–634.
122. Samms-Vaughan, M., & Franklyn-Banton, L. (2008). *The role of early childhood professionals in the early identification of autistic disorder*. International Journal of Early Years Education, *16*(1), 75–84.
123. Taylor, L., Eapen, V., Maybery, M., Midford, S., Paynter, J., Quarmby, L., … Whitehouse, A. (2016). *Diagnostic evaluation for autism spectrum disorder: A survey of health professionals in Australia*. BMJ Open, *6*(9), e012517–e012517.
124. Watts, S., & Stenner, P. (2012). *Doing Q methodological research: Theory, method and interpretation*. London, England: SAGE Publication Ltd.
125. National Health & Medical Research Council. (2009). *NHMRC additional levels of evidence and grades for recommendations for developers of guidelines*. Retrieved from http://www.nhmrc.gov.au/guidelines-publications/information-guideline-developers/2016-

nhmrc-standards-guidelines.
126. National Health & Medical Research Council. (n.d.). *NHMRC: Methodological review template (Using the 2011 NHMRC standard to assess clinical practice guidelines - For guideline developers)*. Retrieved from https://www.nhmrc.gov.au/guidelines-publications/information-guideline-developers/resources-guideline-developers
127. National Health & Medical Research Council. (2014). *Nomination of independent expert clinical reviewers for externally developed clinical practice guidelines*. Retrieved from https://www.nhmrc.gov.au/grants-funding/peer-review
128. Penner, M., Anagnostou, E., Andoni, L., & Ungar, W. (2017). *Systematic review of clinical guidance documents for autism spectrum disorder diagnostic assessment in select regions*. Autism, *Early Onli*, 1–11.
129. Reed, P., & Osborne, L. (2012). *Diagnostic practice and its impacts on parental health and child behaviour problems in autism spectrum disorders*. Archives of Disease in Childhood, *97*(10), 927–931.
130. World Health Organization. (n.d.). *World Health Organization's General Guidelines for Methodologies on Research and Evaluation of Traditional Medicine*. Retrieved from http://apps.who.int/medicinedocs/en/d/Jwhozip42e/13.1.html