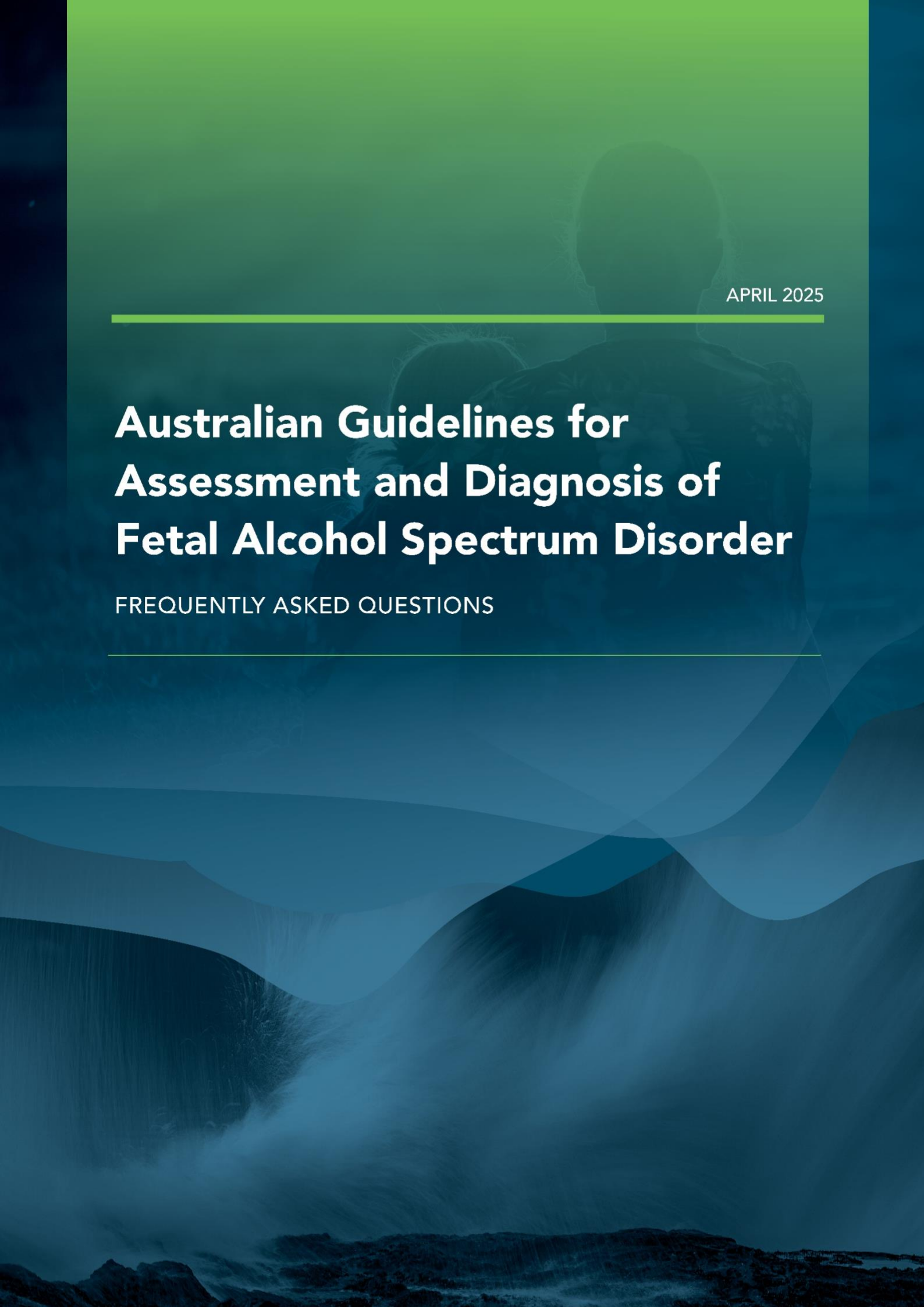

APRIL 2025

Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder

FREQUENTLY ASKED QUESTIONS

Frequently Asked Questions

Following the feedback gathered through the Public Consultation, the Guidelines Development Group has compiled a list of frequently asked questions (FAQs). Each FAQ includes direct links to further information and resources.

1. Is very specific information about the level of prenatal alcohol exposure mandatory for diagnosis of FASD?

No

While it is ideal to collect detailed information on the dose and timing of prenatal alcohol exposure (PAE), this level of specificity is not always attainable. The PAE standard drink levels outlined in the guidelines are provided to transparently reflect the findings of the evidence review. These levels are intended to support clinical decision-making but should not be viewed as mandatory requirements or as diagnostic cut-offs.

For more information see the full guidelines document sections:

→ Criterion A of the diagnostic criteria.
→ Additional information section 4.3.2 on Criterion A prenatal alcohol exposure.
→ Figure 9 – Visual to support the assessment of risk of FASD.
→ Chapter 6 – PAE assessment.
→ Good practice statements 1 to 11.
→ Implementation Considerations, Tools, and Tips 8 to 10.

2. Are the guidelines saying that a low level of alcohol is safe to consume during pregnancy?

No

These Guidelines are consistent with the Australian Guidelines to Reduce the Risks from Drinking Alcohol (2020), which state that **"no safe level of alcohol consumption during pregnancy has been identified."** The evidence review examining the diagnostic criteria strongly supports this position, highlighting the potential for adverse health effects at all levels of PAE.

Whilst PAE poses potential risks at any level, these guidelines specifically address the outcomes related to FASD. PAE is a risk factor for adverse physical and neurodevelopmental outcomes, potentially leading to a diagnosis of FASD. However, not every exposure results in neurodevelopmental impairments and/or adverse physical outcomes, and these features can also arise from a range of other genetic and environmental factors.

Health practitioners require evidence-based information to make informed clinical decisions regarding PAE risks, aiding in accurate diagnostic decision-making. The accurate diagnosis of FASD necessitates a different approach from public health messaging about PAE.

For more information see the full guidelines document sections:

→ Introduction section 1.2 Distinguishing public health messages on prenatal alcohol exposure from diagnostic requirements for FASD.
→ Additional information section 4.3.2 on Criterion A prenatal alcohol exposure.
→ Figure 9 – Visual to support the assessment of risk of FASD.
→ Chapter 6 – PAE assessment.
→ Good practice statements 1 to 11.
→ Implementation considerations, tools, and tips 8 to 10.

3. Why is the alternative terminology of neurodevelopmental disorder associated with prenatal alcohol exposure included in the guidelines?

There was a diversity of views and preferences regarding diagnostic terminology, and no clear consensus was reached. For consistency and clarity, the term FASD is used throughout the document. However, to be inclusive of different perspectives, alternative terminology is provided to support the choice of individuals and families.

Some individuals with living experience emphasised the importance of the term FASD to them, which influenced the decision to retain the terminology. However, this is not the experience of all individuals with living experience. Flexibility in terminology is important in clinical practice to accommodate those who do not identify with the term FASD. The Guidelines Development Group aimed to be respectful and inclusive of diverse views by offering these different options for individuals and families.

Practitioners are encouraged to engage in shared decision-making with individuals and families to determine the most appropriate terminology for their unique situation. This collaborative approach ensures that the language is respectful, inclusive, and aligns with the preferences and identities of those involved. This approach also aligns with the human-rights based approach of these guidelines.

For more information see the full guidelines document sections:

→ Chapter 1 Introduction section 1.3 Diagnostic Terminology
→ Chapter 3 Foundational Considerations
→ Chapter 4 Diagnostic criteria

4. Why are the guidelines not providing a list of recommended or example standardised tests?

The Guidelines Development Group considered including a list of standardised tests. However, feedback from the Advisory Groups highlighted several unintended adverse consequences from the previous list of example standardised tools in the 2016 Guide to Diagnosis of FASD. For example, these included inappropriate use of certain tools in certain population groups, such as First Nations Australians and some practitioners interpreting the Guide to mean that without access to the listed tools, they could not assess for FASD. These interpretations negatively impacted on the quality of assessments and service accessibility.

Additionally, standardised test versions quickly become outdated, affecting the applicability and usability of the guidelines. Assessment tools vary significantly in their availability across different settings and the ages of individuals attending for assessment. Furthermore, tests are validated only within certain populations and have limitations when used outside of these populations. It is impractical for the guidelines to cover all the available assessment tools for children of all ages, adolescents, and adults in sufficient detail to support practitioners in making informed decisions about test selection. As with all other conditions and areas of practice, it is the responsibility of practitioners to not act outside their area of expertise and seek clinical supervision when necessary.

Consequently, the Guidelines Development Group weighed up all the potential risks and benefits and decided against including a list of example tools.

Standardised tests are just one piece of information that practitioners can use, where appropriate, to inform diagnostic decision making. However, tests don't diagnose, clinicians do.

There are no standardised tests specifically designed to detect FASD. Practitioners must select tests based on a wide variety of factors and the guidelines recommend seeking clinical supervision if practitioners lack the appropriate knowledge to make these decisions.

The Guidelines Development Group also notes that not providing a list of standardised tests is aligned with other Australian Clinical Practice Guidelines. For example, the Autism Guidelines state:

- Practitioners should consider using, but not rely solely on, standardised assessment, to support clinical decision-making in relation to referral, Assessment of Functioning, Medical Evaluation, and Diagnostic Evaluation.
- Practitioners should know what concepts are being assessed by each tool, and the extent to which they will contribute information that is relevant to the purpose of the assessment.
- Be aware of the limitations of standardised assessments from a cultural perspective, including where they have not been developed, validated, and/or normed with a population relevant to the client, and therefore may be inaccurate, misleading, invalid, and/or otherwise inappropriate.

- Practitioners should not use standardised diagnostic tests solely, or as a substitute, for clinical decision making and diagnostic formulation that considers all relevant sources of evidence.

For more information see the full guidelines document sections:

→ Criterion B of the diagnostic criteria.
→ Additional information section 4.3.3.
→ Chapter 8: Holistic developmental, functional, and wellbeing assessment.
→ Chapter 9: Holistic profile, formulation, and strengths-based pathways.
→ Good Practice Statements 26, 28, 29 – 35.
→ Implementation Consideration, Tool and Tip 1, 3, 16 and 17.

5. What guidance is provided for practitioners regarding clinical cut-offs for interpreting standardised tests?

Diagnostic meaningfulness for clinical cut-offs requires evidence demonstrating significant differences in important life outcomes between individuals above and below those cut-offs. The extensive evidence reviewed as part the diagnostic criteria for FASD provided no technical, empirical, or statistical support for the clinical validity of specific percentiles or standard deviation cut-offs for diagnosis of FASD.

Until such evidence becomes available, the Guidelines Development Group recommends that the interpretation of test scores used to characterise impaired functioning is better informed by:

1. The practitioner exercising their clinical reasoning anchored in consensual expert guidance and/or best practices that apply to test interpretation in their specific professional field, and
2. An integrative analysis of the whole person profile, conducted by practitioners who exercise their professional expertise in synthesising relevant historical, cultural, medical and allied health, behavioural and other information into evidence-based clinical formulations.

A percentile range (2^{nd} – 8^{th} percentile) is provided to aid the interpretation of test scores. Scores within or below this range could be considered as being significantly below the normative level and may be indicative of impairment. However, practitioners need to consider their discipline specific and relevant other discipline and interprofessional guiding principles and exercise their informed professional judgement in the application of this in the FASD diagnostic process.

It is crucial to recognise that standardised tests are only one component of the diagnostic process. Practitioners must use their professional expertise to integrate any test results with a comprehensive understanding of the individual's context. The guidelines recommend that

practitioners seek clinical supervision if they lack the appropriate knowledge to make these decisions.

For more information see the main guidelines document sections:

→ Criterion B of the diagnostic criteria.
→ Additional information section 4.3.3 Criterion B: presence of pervasive neurodevelopmental impairments.
→ Chapter 8: Holistic developmental, functional, and wellbeing assessment.
→ Chapter 9: Holistic profile, formulation, and strengths-based pathways.
→ Good Practice Statements 26, 28, 29 – 35.
→ Implementation Consideration, Tool, and Tip 1, 3, 16, and 17.

6. Why is sensory processing not included as a neurodevelopmental domain?

The research team acknowledged to the concerns raised by parents, caregivers and practitioners about sensory processing challenges during the initial priority setting for the guideline review (Hayes et al., 2022). The research team thoroughly reviewed the available evidence in this area. However, the results did not provide strong enough evidence to establish an association between PAE and sensory processing issues. Consequently, these challenges could not be included in the diagnostic criteria at this time.

As new evidence emerges, the diagnostic criteria can be updated to reflect these findings. The guidelines recommend a broad assessment to identify any co-occurring conditions or issues, sensory processing challenges. This comprehensive assessment process ensures that all relevant factors are considered, providing a holistic understanding of the individual's needs.

For more information see:

→ The associated features section of the full guidelines document.
→ GRADE-based recommendation 11b – full guidelines document.
→ Technical Report - systematic review of the diagnostic criteria components.

7. Why is physical size (i.e., growth) now included in the diagnostic criteria?

While the previous Australian Guide was based on the Canadian Guidelines, which did not include physical size, there are discrepancies among international diagnostic criteria regarding the inclusion of physical size. To address these discrepancies, the evidence review aimed to understand the evidence for physical size was, along with other diagnostic features considered across all diagnostic criteria worldwide.

An extensive review of the evidence was conducted. In brief, this review found strong associations between PAE and physical size. The evidence review highlighted that physical size, particularly at birth, can be significantly impacted by PAE. Based on these findings, it is recommended that physical size be included in the diagnostic criteria for FASD. This inclusion aligns with the goal of providing a comprehensive and accurate diagnostic framework that reflects the latest research evidence.

For more information see:

→ GRADE-based recommendations 1 to 5 in the full guidelines document.
→ Physical specifiers section of the diagnostic criteria – full guidelines document.
→ Technical Report for the systematic review of the diagnostic criteria components.

8. Is it mandatory to have assessed for sentinel facial features to diagnose FASD?

No

The wording of Criterion A.2, stating that facial features "may be considered sufficient," reflects that the inclusion of facial features in Criterion A is not mandatory for diagnosis if deemed inappropriate after consultation with individuals and families.

Concerns have been raised about the lack of local norms and lip/philtrum guides for assessing people from diverse ethnic backgrounds in Australia, including Aboriginal and Torres Strait Islander peoples (e.g., Hayes et al., 2022). There is an urgent need for future research to develop local norms and tools relevant to the Australian context to improve the assessment of facial features.

It is crucial that practitioners do not assume whether individuals or families would or would not want facial features assessed, as there are diverse views on this ussie among First Nations Australians. The Cultural Advisory Group recommends that practitioners engage in shared decision-making with individuals and families attending for assessment. This approach involves providing information about the limitations of current facial features assessment methods available in Australia and respecting the preferences and perspectives of those being assessed.

For more information see the full guidelines document sections:

→ Criterion A of the diagnostic criteria.
→ Physical specifiers section of the diagnostic criteria.
→ Additional information section 4.3.6 Specifier: Sentinel facial features Physical specifiers section of the diagnostic criteria and specifically 4.3.6.4 assessment of facial features for individuals from culturally diverse backgrounds.
→ Good Practice Statement 12.

→ Implementation Consideration, Tool, Tip 2.

9. Do the guidelines apply to adults?

Yes

The guidelines take a lifespan approach and apply to individuals of all ages.

For more information see the full guidelines document sections:

→ Introduction section – overall objectives.

→ Relevant notes included in the diagnostic criteria to support application of the criteria for individuals of different age groups.

→ Additional information 4.3.3.3 – sub section 'assessment of infants and young children.'

→ Historical information about physical size or head circumference may not always be available for adolescents and adults and the structure of the diagnostic specifiers supports inclusion of this information where it is available but also provides opportunity for diagnosis without this information where it is not available.