

## BACKGROUND

Fetal alcohol spectrum disorder (FASD) is a severe, pervasive neurodevelopmental disorder that occurs as a consequence of prenatal alcohol exposure. FASD is a lifelong but potentially preventable disorder. The effects of prenatal alcohol exposure include brain damage affecting development, learning, behaviour and mental health, and birth defects. Children with FASD and their families require assistance from a range of health, community and education services.

## UPDATE

This protocol has been modified to align with the release of a revised APSU FASD case report form. The links below to key FASD resources and the investigator list have also been updated. The diagnostic criteria, case definition, and study objectives remain essentially unchanged.

**Fetal Alcohol Spectrum Disorder (FASD)** continues to be used as a diagnostic term, with two sub-categories:

- FASD with 3 sentinel facial features; and
- FASD with less than 3 sentinel facial features.

## STUDY OBJECTIVES

1. To estimate the incidence of FASD in children less than 15 years over the study period.
2. To describe current diagnostic practice for FASD.
3. To describe the common features of FASD.
4. To describe the use of and gaps in health services for children with FASD.
5. To provide paediatricians on the APSU mailing list with the *Australian Guide to the Diagnosis of FASD* and to seek feedback on the Guide from paediatricians.

## CASE DEFINITION

Please report any child less than 15 years of age newly diagnosed with FASD meeting the Australian FASD Diagnostic Categories and criteria (please see over), whom you have seen within the last month and that you have not previously reported to the APSU. We anticipate that the case report form will take approximately 15 minutes to complete.

## RESOURCES

- The *Australian Guide to the Diagnosis of FASD* is available on-line and contains an **Assessment Form, a Summary Form and a Management Plan Form, which we encourage you to use.**  
<https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis/>
- Also on-line are **e-learning modules** to assist in making an assessment. These are free. A Certificate can be provided on successful completion of the modules, which can be used as evidence of continuing professional development.  
<https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis/eLearning-modules/>

The diagnosis criteria and categories are shown in Table 1.

**TABLE 1: Diagnostic criteria and categories for Fetal Alcohol Spectrum Disorder (FASD)**

<b>FETAL ALCOHOL SPECTRUM DISORDER</b>		
<b>Diagnostic criteria</b>	<b>Diagnostic categories</b>	
	<b>FASD with 3 Sentinel Facial Features</b>	<b>FASD with &lt; 3 Sentinel Facial Features</b>
<b>Prenatal alcohol exposure</b>	Confirmed or unknown <sup>#</sup>	Confirmed
<b>Neurodevelopmental domains</b> <ul style="list-style-type: none"> <li>- Brain structure/neurology</li> <li>- Motor skills</li> <li>- Cognition</li> <li>- Language</li> <li>- Academic achievement</li> <li>- Memory</li> <li>- Attention</li> <li>- Executive function, including impulse control and hyperactivity</li> <li>- Affect regulation</li> <li>- Adaptive behaviour, social skills or social communication</li> </ul>	Severe impairment* in at least 3 neurodevelopmental domains	Severe impairment* in at least 3 neurodevelopmental domains
<b>Sentinel facial features</b> <ul style="list-style-type: none"> <li>- Short palpebral fissure</li> <li>- Smooth philtrum</li> <li>- Thin upper lip</li> </ul>	Presence of 3 sentinel facial features	Presence of 0, 1, or 2 sentinel facial features

# A diagnosis of FASD with 3 sentinel facial features can be made if prenatal alcohol exposure is *unknown*, so long as the neurodevelopmental criteria are met as well as the three sentinel facial features.

\* Severe impairment is defined as either a global score or a major subdomain score on a standardised validated neurodevelopmental scale that is  $\leq 2$  SD below the mean or  $< 3^{\text{rd}}$  percentile.

REFERENCE:

Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report the Australian Government Department of Health: "Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder (FASD)".

**INVESTIGATOR CONTACT DETAILS (\*Principal Investigator and contact person)**

\*Dr Marcel Zimmet (NSW)  
 Professor Elizabeth Elliott (NSW)  
 Winthrop Research Professor Carol Bower (WA)  
 Dr Rochelle Watkins (WA)  
 Dr James Fitzpatrick (WA)  
 Dr Doug Shelton (QLD)  
 Dr Keith Edwards (NT)  
 Dr Amanda Wilkins (WA)  
 Dr Heidi Webster (QLD)  
 Dr Anne Morris (NSW)  
 Dr Melissa Cheung (NSW)  
 Tiffany Allen (NSW)