Australian Paediatric Surveillance Unit
STUDY PROTOCOL
Fetal Alcohol Spectrum Disorder (FASD)
UPDATE

BACKGROUND

Fetal alcohol spectrum disorder (FASD) is a severe, pervasive neurodevelopmental disorder that occurs as a consequence of prenatal alcohol exposure. FASD is lifelong but potentially preventable. 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 slightly modified to align with the release of the ***Australian Guide to the Diagnosis of FASD*** (Bower, C & Elliott, E.J., 2016), in which the terminology and criteria for diagnosis of FASD have been revised. E-learning modules have been developed to assist clinicians with using the guidelines.

Available at: http://www.apsu.org.au/home/australian-fasd-diagnostic-guidelines/

We also invite you to provide feedback on the new resources (see evaluation survey)

Note that Fetal Alcohol Spectrum Disorder (FASD) is now used as a diagnostic term, with two sub-categories:

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

The study objectives remain essentially unchanged.

STUDY OBJECTIVES

1. To estimate of the incidence of FASD in children <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 < 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.

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.**
http://alcoholpregnancy.telethonkids.org.au/australian-fasd-diagnostic-instrument/australian-guide-to-the-diagnosis-of-fasd/

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.
http://alcoholpregnancy.telethonkids.org.au/australian-fasd-diagnostic-instrument/e-learning-modules/

The Diagnosis criteria and categories shown in Table 1.

Table 1 Diagnostic criteria and categories for Fetal Alcohol Spectrum Disorder (FASD)

FETAL ALCOHOL SPECTRUM DISORDER		
Diagnostic criteria	**Diagnostic categories**	
	FASD with 3 Sentinel Facial Features	FASD with < 3 Sentinel Facial Features
Prenatal alcohol exposure	Confirmed or unknown#	Confirmed
Neurodevelopmental domains - Brain structure/Neurology - Motor skills - Cognition - Language - Academic Achievement - Memory - Attention - Executive Function, including impulse control and hyperactivity - Affect Regulation - Adaptive Behaviour, Social Skills or Social Communication	Severe impairment* in at least 3 neurodevelopmental domains	Severe impairment* in at least 3 neurodevelopmental domains
Sentinel facial features - Short palpebral fissure - Smooth philtrum - Thin upper lip	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 ≤ 2 SD below the mean or < 3rd percentile.

REFERENCE:
Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to 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)
A/Professor Yvonne Zurynski (NSW)
Dr Rochelle Watkins (WA)
Dr James Fitzpatrick (WA)
Dr Doug Shelton (QLD)
Dr Keith Edwards (NT)
Dr Amanda Wilkins (WA)
Dr Heidi Webster (QLD)
Ms Amy Phu (NSW)
Dr Marie Deverell (NSW)
Dr Natalie Phillips (NSW)