COMMENCING December 2014

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

BACKGROUND

Fetal alcohol spectrum disorders (FASD) describes a range of adverse effects that may occur as a consequence of *in utero* exposure to alcohol, including fetal alcohol syndrome (FAS), partial FAS (PFAS), and neurodevelopmental disorders-alcohol exposed (ND-AE) (1). FASD are lifelong but potentially preventable conditions. Consequences of *in utero* exposure to alcohol include brain damage, growth failure, birth defects and problems with development, learning, behaviour and mental health. Children with FASD and their families require assistance from a range of health, community and education services (2).

An APSU study of FAS conducted from 2001-2004 showed that children with FAS were diagnosed late (mean 3 years of age) and presented with a wide range of medical, psychological and behavioural problems. About two-thirds were indigenous and two-thirds were in foster care (2). Subsequent surveys of paediatricians' knowledge, attitudes and practice demonstrated that paediatricians lacked confidence in FAS diagnosis and management and were unaware of the NHMRC (2001) guidelines on alcohol use in pregnancy. Only 20% routinely took a history about alcohol use in pregnancy (3, 4).

Since the initial APSU study there have been a number of important developments:

- National Health and Medical Research Council guidelines on alcohol use in pregnancy were updated in 2009 and advise that no alcohol is the safest option in pregnancy and in women planning a pregnancy (5)
- Publication of a monograph (Fetal Alcohol Spectrum Disorders in Australia: An update), an outcome of the Intergovernmental Committee on Drug Strategy Working Party on FASD (6)
- A Commonwealth House of Representatives Inquiry into FASD (7) and a Department of Health and Ageing response to the Inquiry, including a $9.3 million commitment to a national FASD Action plan (8).
- Funding the development of an Australian diagnostic instrument for FASD including diagnostic criteria in Australia (1).

The initial study included only FAS. The current study provides an opportunity to estimate the incidence of the full spectrum of FASD in Australia using the diagnostic categories and criteria (Table 1) outlined in the Australian diagnostic instrument for FASD, and to describe the characteristics of children with FASD.

STUDY OBJECTIVES

1. To estimate the incidence of FAS, partial FAS, and ND-AE in children <15 years over the study period.
2. To describe current diagnostic practice for FASD.
3. To describe the presenting features of FASD.
4. To describe the use of and gaps in health services for children with FASD.
5. To educate paediatricians on the APSU mailing list about the Australian criteria for FASD diagnoses.

CASE DEFINITION

Please report any child < 15 years of age newly diagnosed with any of the FASDs in the last month and who you have not previously reported to the APSU, and who fulfils the Australian FASD diagnostic criteria (see over).

TABLE 1: AUSTRALIAN FASD DIAGNOSTIC CATEGORIES AND CRITERIA

Diagnostic criteria	Diagnostic category		
	Fetal Alcohol Syndrome (FAS)	**Partial Fetal Alcohol Syndrome (PFAS)**	**Neurodevelopmental Disorder-Alcohol Exposed (ND-AE)**
Prenatal alcohol exposure	Confirmed or unknown	Confirmed	Confirmed
Facial anomalies	Simultaneous presence of all 3 of the following facial anomalies at any age: • short palpebral fissure length[1] (2 or more standard deviations below the mean) • smooth philtrum (Rank 4 or 5 on the UW Lip-Philtrum Guide[2]) • thin upper lip (Rank 4 or 5 on the UW Lip-Philtrum Guide[2])	Simultaneous presence of any 2 of the following facial anomalies at any age: • short palpebral fissure length[1] (2 or more standard deviations below the mean) • smooth philtrum (Rank 4 or 5 on the UW Lip-Philtrum Guide[2]) • thin upper lip (Rank 4 or 5 on the UW Lip-Philtrum Guide)[2]	No anomalies required[4]
Growth deficit	• Prenatal or postnatal growth deficit indicated by birth length or weight ≤ 10th percentile adjusted for gestational age, or postnatal height or weight ≤ 10th percentile[3]	• No deficit required[4]	No deficit required[4]
Central Nervous System (CNS) abnormality	**At least 1 of the following:** **Structural and/or neurological abnormalities** • clinically significant structural abnormality (e.g. head circumference ≤ 3rd percentile, abnormal brain structure), or neurological abnormality (seizure disorder or hard neurological signs); **AND/OR** **Functional abnormalities** • severe dysfunction (impairment in 3 or more domains of function (see below) at 2 or more standard deviations below the mean)[5] Domains of CNS function that may be affected in FASD : • Cognition (IQ or uneven cognitive profile) • Memory • Executive functioning and abstract reasoning • Communication **(**expressive/receptive language) • ADHD/abnormal sensory processing • Academic achievement • Adaptive behaviour/social skills/social communication • Global developmental delay at <5 years		

1. Appropriate reference charts should be used for assessing palpebral fissure length:
   a. Hall JG, Froster-Iskenius UG, Allanson JE, editors. *Handbook of normal physical measurements*. Oxford: Oxford University Press; 1989. pp. 149-50.
   b. Canadian Guidelines (http://www.cmaj.ca/content/172/5_suppl/S1.full.pdf+html)
2. University of Washington Lip-Philtrum Guides: http://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm
3. Appropriate reference charts for height, weight and head circumference should be used, and other causes of growth deficit and CNS abnormality excluded.

4. Not required for diagnosis but may be present.
5. Assessment of dysfunction based on evidence from standard validated assessments instruments interpreted by qualified professionals.

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References

1. Watkins RE, Elliott EJ, et al. Recommendations from a consensus development workshop on the diagnosis of fetal alcohol spectrum disorders in Australia. BMC Pediatrics 2013, 13:156
2. Elliott EJ, Payne J, Morris A, Haan E, Bower C. Fetal alcohol syndrome: a prospective national surveillance study. Archives of Disease in Childhood 2008; 93: 732-737.
3. Elliott EJ, Payne J, Haan E, Bower C. Diagnosis of fetal alcohol syndrome and alcohol use in pregnancy: a survey of paediatricians' knowledge, attitudes and practice. Journal of Paediatrics and Child Health 2006; 42: 698-703.
4. Payne JM, France KE, Henley N, D'Antoine HA, Bartu AE, Mutch RC, Elliott EJ, Bower C. Paediatricians' knowledge, attitudes and practice following provision of educational resources about prevention of prenatal alcohol exposure and fetal alcohol spectrum disorder. J Paediatr Child Health. 2011; 47; 704-710.
5. NHMRC. Australian Guidelines to Reduce Health Risks from Drinking Alcohol, Australian Government 2009; ISBN Online: 1864963808 http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/ds10-alcohol.pdf
6. Fetal Alcohol Spectrum Disorders in Australia: an Update. http://www.nationaldrugstrategy.gov.au/internet/drugstrategy/publishing.nsf/Content/mono-fasd-2012
7. FASD – the Hidden Harm http://www.aph.gov.au/parliamentary_business/committees/house_of_representatives committees?url=spla/fasd/report.htm
8. Department of Health and Ageing response to Inquiry. http://www.health.gov.au/