

FETAL ALCOHOL SPECTRUM DISORDER (FASD)

APSU Office Use Only

Australian Paediatric Surveillance Unit

If you have any questions about this form, please contact the APSU (02) 9845 3005
or email SCHN-APSU@health.nsw.gov.au

Study ID #:

Month/Year Report:

Instructions: Please answer each question by ticking the appropriate box or writing your response in the space provided. DK=Don't Know; NA = Not Applicable

Version 5.1: 22.08.2022

REPORTING CLINICIAN'S DETAILS

1. APSU Dr Code/Name: _____ / _____

2. Date form completed: ___ / ___ / _____

PATIENT'S DETAILS

3. First 2 letters of first name: _____

4. First 2 letters of surname: _____

5. Date of birth: _____ / _____ / _____

_____ / _____ / _____

6. Sex:

 Male Female

7. Postcode of family: _____

8. Date of diagnosis: _____ / _____ / _____

_____ / _____ / _____

9. Did you make the FASD diagnosis?

 Yes (*please go to Q10*)

No – If this patient is primarily cared for by another physician who you believe could provide additional details, please write their name below and return this form to the APSU. If no other report is received for the child, we will contact you for further information.

Physician's name: _____

Clinic/Hospital: _____

PATIENT'S FAMILY BACKGROUND10. Ethnic background for both birth mother and father
(tick all that apply): Caucasian Asian Aboriginal Torres Strait Islander African Pacific Islander DK Other (*specify*): _____

11. Who is the child's primary carer?

 Biological parent/s Grandparent/s Foster carer/s Adoptive parent/s Other (*specify*): _____

12. Have any of the child's siblings been diagnosed with FASD?

 Yes No NA – no siblings DK

12a. If yes, specify who: _____

13. Have either of the child's birth parents been diagnosed with FASD?

 Yes No DK

13a. If yes, specify who: _____

DIAGNOSTIC CRITERIA – prenatal alcohol exposure

14. Was prenatal alcohol exposure:

 Confirmed present Unknown

15. What was the source of information about prenatal alcohol exposure? (tick all that apply)

 Birth mother Direct witness Official records (e.g. medical, legal, child protection) Other (*specify*): _____

16. In your judgement, what is the reliability of the information about alcohol exposure?

 High Low Unknown

17. Please complete the following AUDIT-C questions:

(a) How often did the birth mother have a drink containing alcohol during this pregnancy?

 Unknown Never₀ (*please go to Q18*) Monthly or less₁ 2-4 times a month₂ 2-3 times a week₃ 4 or more times a week₄

(b) How many standard drinks did the birth mother have on a typical day when she was drinking during this pregnancy?

 Unknown 1 or 2₀ 3 or 4₁ 5 or 6₂ 7 to 9₃ 10 or more₄

(c) How often did the birth mother have 5 or more standard drinks on one occasion during this pregnancy?

 Unknown Never₀ Less than monthly₁ Monthly₂ Weekly₃ Daily or almost daily₄

18. What was the total AUDIT-C score? (Enter "N/A" if not available) (calculate by adding the corresponding subscripts in a, b and c)

18a. What was the AUDIT-C category of risk? (according to the total score range in subscripts)

 No exposure₀ Confirmed exposure₁₋₄ Confirmed high-risk exposure₅₊ Not available

DIAGNOSTIC CRITERIA – neurodevelopmental domains

19. Was there severe impairment in 3 or more neurodevelopmental domains? Yes No DK

20. Which domains were assessed?

Domains (tick all that apply)	Degree of impairment?		
<input type="checkbox"/> Brain structure/neurology	<input type="checkbox"/> None	<input type="checkbox"/> Severe	
<input type="checkbox"/> Motor skills	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe
<input type="checkbox"/> Cognition	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe
<input type="checkbox"/> Language	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe
<input type="checkbox"/> Academic achievement	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe
<input type="checkbox"/> Memory	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe
<input type="checkbox"/> Attention	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe
<input type="checkbox"/> Executive function, including impulse control and hyperactivity	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe
<input type="checkbox"/> Affect regulation	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe
<input type="checkbox"/> Adaptive behaviour, social skills or social communication	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe
<input type="checkbox"/> Not assessed			
<input type="checkbox"/> Not known			

Brain structure/neurology domain

21. Was the child’s head circumference ≤ 3rd percentile at any time? Yes No DK

21a. If yes, specify age when recorded: _____

22. Which of the following tests have been performed? None Brain MRI Brain CT EEG DK

23. Was a structural brain or EEG abnormality detected? Yes No DK

23a. If yes, specify abnormality: _____

24. Was there evidence of a neurological condition otherwise unexplained? Yes No DK

24a. If yes, specify condition: Seizure disorder Cerebral palsy Hearing impairment Visual impairment Other (specify): _____

25. If the child is < 6 years of age, was there global developmental delay? Yes No DK

25a. If yes, specify age of this diagnosis: _____ years _____ months DK

DIAGNOSTIC CRITERIA – sentinel facial features

26. What was the total number of sentinel FASD facial features? None 1 2 3 DK

27. Which sentinel facial features were abnormal? (tick all that apply)
 Short palpebral fissure length (2 SD or more below the mean)
 Smooth philtrum (philtrum rank 4 or 5 on Lip-Philtrum Guide)
 Thin upper lip (lip rank 4 or 5 on Lip-Philtrum Guide)

28. How were the sentinel facial features assessed? (tick all that apply)
 Direct measurement Lip-Philtrum Guide (Caucasian)
 2D photographic analysis Lip-Philtrum Guide (African American)
 3D photographic analysis Not assessed (please go to Q32)

29. What was the palpebral fissure length Z-score? _____ DK

29a. Which palpebral fissure charts were used?
 Stromland Clarren Iosub Hall
 Other (specify): _____

30. What was the philtrum rank (1-5)? _____ DK

31. What was the lip rank (1-5)? _____ DK

FASD DIAGNOSIS

32. What is the child's FASD diagnosis?

- FASD with 3 sentinel facial features
- FASD with *less than* 3 sentinel facial features
- At risk of FASD Incomplete assessment
- Other (*specify*): _____

PRENATAL FACTORS

33. Was there prenatal exposure to the following substances?

- (a) Nicotine Yes No DK
- (b) Cannabis Yes No DK
- (c) Opioids Yes No DK
- (d) Amphetamines Yes No DK
- (e) Cocaine Yes No DK
- (f) Phenytoin or valproate Yes No DK
- (g) Prescription medication: Yes No DK

If yes, *specify* medication/s: _____

(h) Other (*specify*): _____

34. Was there prenatal exposure to pregnancy complications (e.g. infection, diabetes, hypertension)?

- Yes No DK

34a. If yes, *specify* exposure: _____

35. Was there prenatal growth impairment with:

- (a) weight \leq 3rd percentile for gestation Yes No DK
- (b) length \leq 3rd percentile for gestation Yes No DK

POSTNATAL FACTORS

36. Was there postnatal exposure to the following?

- (a) Early-life trauma Yes No DK
- (b) CNS infections (e.g. meningitis) Yes No DK
- (c) Significant head injury Yes No DK
- (d) Other (*specify*): _____

37. Was there postnatal growth impairment with:

- (a) weight \leq 3rd percentile for gestation Yes No DK
- (b) length/height \leq 3rd percentile for gestation Yes No DK

38. Has the child ever been in out-of-home care?

- Yes No DK

38a. If yes, *specify* time the child has been in out-of-home care: _____ months DK

CONCURRENT DIAGNOSES

39. Does the child have any of the following conditions?

- (a) Attention-deficit hyperactivity disorder Yes No DK Type/Details: _____
- (b) Trauma/stress-related/attachment disorders Yes No DK Type/Details: _____
- (c) Autism spectrum disorder Yes No DK Type/Details: _____
- (d) Intellectual disabilities Yes No DK Type/Details: _____
- (e) Communication disorders Yes No DK Type/Details: _____
- (f) Specific learning disorders Yes No DK Type/Details: _____
- (g) Motor disorders Yes No DK Type/Details: _____
- (h) Anxiety disorders Yes No DK Type/Details: _____
- (i) Mood disorders Yes No DK Type/Details: _____
- (j) Disruptive/impulse control/conduct disorders Yes No DK Type/Details: _____
- (k) Sleep disorders Yes No DK Type/Details: _____
- (l) Other (*specify*): _____

40. Does the child have any *major* congenital anomalies (e.g. heart, lung, kidney)?

- Yes No DK

40a. If yes, *specify* anomalies: _____

41. Does the child have any *minor* congenital anomalies (e.g. clinodactyly, epicanthic folds, midface hypoplasia)?

- Yes No DK

41a. If yes, *specify* anomalies: _____

OTHER INVESTIGATIONS

42. Has the child had a chromosomal microarray analysis? Yes No DK

42a. If yes, *specify* results: Normal DK

CNV of known significance CNV of unknown significance
Deletion details: _____ Duplication details: _____

43. Has the child had Fragile X testing?

Yes No DK

43a. If yes, *specify* results:

Normal Abnormal DK

Details: _____

44. Has the child had whole exome sequencing?

Yes No DK

44a. If yes, *specify* results:

45. Has the child had any other relevant abnormal results (e.g. ferritin, CK, urine metabolic screen, lead)?

Yes No DK

45a. If yes, *specify* tests and results:

MANAGEMENT

46. Which services have been or are currently being accessed by the child?

- | | |
|---|---|
| <input type="checkbox"/> General or developmental paediatrics | <input type="checkbox"/> Occupational therapy |
| <input type="checkbox"/> Psychology | <input type="checkbox"/> Speech pathology |
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Social work |
| <input type="checkbox"/> Early childhood intervention | <input type="checkbox"/> Educational support |
| <input type="checkbox"/> Child protection services | <input type="checkbox"/> NGOs |
| <input type="checkbox"/> Other (<i>specify</i>): | |

47. Does the child receive NDIS funding?

Yes No DK

48. Has the family been informed about the National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD)?

Yes No DK

Thank you for your help with this research project.

Please return this questionnaire to the APSU via email to SCHN-APSU@health.nsw.gov.au or fax to 02 9845 3082

or mail to Australian Paediatric Surveillance Unit, Kids Research, Locked Bag 4001, Westmead NSW 2145 – even if you don't complete all items

The APSU is affiliated with the Royal Australasian College of Physicians (Paediatrics and Child Health Division) and the Faculty of Medicine and Health, the University of Sydney.

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This study has been approved by a Human Research Ethics Committee properly constituted under NHMRC guidelines.