FETAL ALCOHOL SPECTRUM DISORDERS (FASD)
Australian Paediatric Surveillance Unit
Please contact the APSU (02) 98453005 or apsu@chw.edu.au if you have any questions about this form.

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

REPORTING CLINICIANS DETAILS

1. APSU Dr Code/Name: ☐☐☐☐/_____ **2.** Month/Year of Report: ☐☐/☐☐☐☐

PATIENT 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. Racial Background (select all that apply): ☐ Aboriginal ☐ Caucasian ☐ Pacific Islander ☐ Torres Strait Islander ☐ African ☐ Asian ☐ DK ☐Other *(specify):* _____ _____

10. Did you make the FASD diagnosis? ☐ Yes (***please go to Q11***) ☐ 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 this child we will contact you for further information. Physician's Name:_____ Clinic:_____

BIOLOGICAL MOTHER'S DETAILS

11. Mother's age at the time of child's birth: ☐☐ (years) **or** ☐ DK

12. Mother's country of birth: ☐ Australia ☐Other *(specify):*_____ **13.** Mother's racial background: ☐ Caucasian ☐ Aboriginal ☐ Pacific Islander ☐ Torres Strait Islander ☐ African ☐ Asian ☐DK ☐ Other *(specify):*_____

PATIENT'S FAMILY CHARACTERISTICS

14. Who is the child's primary carer? ☐ biological parent/s ☐ grandparent/s ☐ foster carer/s ☐ adoptive parent/s ☐ Other *(specify):* _____

15. Has the child ever been or is currently under the care of community or child protection services? ☐ Yes ☐ No ☐ DK

16. Have any of the child's siblings been diagnosed with FASD? ☐ No ☐ No Siblings ☐ Yes *(specify):*_____ ☐ DK

FASD DIAGNOSIS

17. Who first suspected this child may have a FASD? ☐ I did ☐ parent/caregiver ☐ teacher ☐GP ☐ Other *(specify):*_____

18. What is the child's FASD diagnosis? ☐ Fetal Alcohol Syndrome ☐Partial Fetal Alcohol Syndrome ☐ Neurodevelopmental Disorder-Alcohol-Exposed ☐Other FASD *(specify):* _____

19. Was the diagnosis made by: ☐ paediatrician or other medical practitioner in a multidisciplinary or interdisciplinary team
☐ paediatrician or other medical practitioner, based on reports from one or more health professionals
☐ paediatrician or other medical practitioner, on their own
☐ Other *(specify):*_____

20. Did the diagnostic process include assessments by any of the following health professionals?
☐ clinical geneticist ☐ psychologist/neuropsychologist ☐ occupational therapist ☐ speech pathologist
☐ physiotherapist ☐ child/adolscent psychiatrist ☐ Other *(specify):*_____

DIAGNOSTIC CRITERIA - GROWTH

21. Please specify the measurements at birth: **(i)** Gestational age: ____(Wks) ☐ DK **(ii)** Head Circumference: ____(cm) ___(%ile) ☐ DK
(iii) Birth Weight: _____ (kg) ____ (%ile) ☐ DK **(iv)** Birth Length: _____ (cm) ___(%ile) ☐ DK

22. Has the child had unexplained deficit in height or weight (≤10th percentile) at any time after birth? ☐ Yes ☐ No ☐ DK

If Yes, please specify: Age ☐☐ (years) ☐☐ (months) Weight:_____(kg) _____(%ile) ☐DK Height:_____(kg) _____ (%ile) ☐ DK

23. Which growth charts were used? ☐CDC Growth Charts ☐WHO Child Growth Standards ☐None ☐DK ☐Other:_____

DIAGNOSTIC CRITERIA – FAS facial features

24. Were any of the following characteristic FAS facial features identified?

(i) short palpebral fissures (2 SD or more below the mean)	☐ Yes	☐ No	☐ DK	☐ not assessed
(ii) smooth philtrum (philtrum rank 4 or 5 on Lip-Philtrum Guide UW guidelines)	☐ Yes	☐ No	☐ DK	☐ not assessed
(iii) thin upper lip (lip rank 4 or 5 on Lip-Philtrum Guide UW guidelines)	☐ Yes	☐ No	☐ DK	☐ not assessed

25. How were the characteristic FAS facial features assessed *(tick all that apply)*? ☐ visual examination for facial phenotype (gestalt method) ☐ direct measurement palpebral fissure (ruler) ☐ ranking lip-philtrum guide ☐ facial photographic analysis ☐ not assessed

26. Which University of Washington Lip-Philtrum Guide was used? ☐ Caucasian ☐ African American ☐ None

DIAGNOSTIC CRITERIA – structural or functional CNS abnormalities

27. Was the child's head circumference ≤3rd percentile at any time? **i)** ☐ No ☐ DK ☐ Yes **ii)** Age when first noted?_____

28. Was CNS imaging performed? ☐ No ☐ Yes; ***If yes, which tests*** (eg. CT, MRI, PET)_____

29. Was a clinically significant structural CNS abnormality detected? ☐ No ☐ Yes *(specify):* _____

30. If child is < 5 years of age was there global developmental delay? ☐ Yes ☐ No ☐ DK

31. Was there evidence of clinically significant neurological CNS abnormality? ☐ No ☐ Yes; **If yes:** ☐ seizure disorder

☐ hard neurological signs, e.g. abnormal reflexes, altered muscle tone *(specify):*_____

☐ soft neurological signs; If yes: ☐ Gross and/or fine motor functioning ☐ articulation/motor speech
☐ Other *(specify):*_____

32. Was CNS function assessed? ☐ Yes ***(Complete table below)*** ☐ No ***(please go to Q33)***

Which domains were assessed ***(please tick all that apply)***	**Impairement Yes/No/DK**	**How were impairments Assessed?** ***(please tick all that apply)***			
		Caregiver report	Clinical evaluation /observation	Standardised, validated or psychometric testing	Specify other test used
☐ Cognition (IQ or uneven cognitive profile)		☐	☐	☐	☐
☐ Memory		☐	☐	☐	☐
☐ Executive functioning and abstract reasoning		☐	☐	☐	☐
☐ Communication (expressive/receptive language)		☐	☐	☐	☐
☐ ADHD		☐	☐	☐	☐
☐ Academic achievement		☐	☐	☐	☐
☐ Adaptive behaviour/ social skills/ social communication		☐	☐	☐	☐

33. Does the child have a hearing impairment? ☐ No ☐ DK ☐ Not tested ☐ Yes *(specify)*:_____

34. Does the child have a vision impairment? ☐ No ☐ DK ☐ Not tested ☐ Yes *(specify)*:_____

DIAGNOSTIC CRITERIA – prenatal alcohol exposure and exposure to other substances

35. Was prenatal alcohol exposure: ☐ confirmed present ☐ unknown ***(please go to Q40)*** ☐ confirmed absent

36. Was a standard tool used to assess prenatal alcohol exposure: ☐ No ☐ Yes; ***specify which tool (e.g. AUDIT-C):***_____

37. What was the main source of information about prenatal alcohol exposure? ☐ biological mother ☐ direct witness
☐ offical records (e.g. medical, legal) ☐ Other *(specify)*: _____

38. At any time during pregnancy, was alcohol consumption reported at the following levels:
(i) 7 or more standard drinks per week: ☐ Yes ☐ No ☐ DK **(ii)** 5 or more standard drinks on any occasion: ☐ Yes ☐ No ☐ DK

39. Does the biological mother have a history of: **(i)** alcohol use disorder (including dependency): ☐ Yes ☐ No ☐ DK
(ii) alcohol-related health problems/injury: ☐ Yes ☐ No ☐ DK

40. Was there prenatal exposure to other substances? **(i)** Cigarettes: ☐ Yes ☐ No ☐ DK **(ii)** Marijuana: ☐ Yes ☐ No ☐ DK
(iii) Heroin: ☐ Yes ☐ No ☐ DK **(iv)** Amphetamines: ☐ Yes ☐ No ☐ DK **(v)** Cocaine: ☐ Yes ☐ No ☐ DK
(vi) Phenytoin or Valproate: ☐ Yes (s*pecify):*_____ ☐ No ☐DK **(vii)** Other(s*pecify):*_____

OTHER CONDITIONS

41. Does the child have any other congenital anomalies? ☐No ☐ DK ☐ Yes *(specify):*_____

42. Does the child have any behavioural/psychiatric conditions?
(i) Conduct disorder: ☐ Yes ☐ No ☐DK **(ii)** Anxiety: ☐ Yes ☐ No ☐DK **(iii)** Oppositional defiant disorder ☐ Yes ☐ No ☐ DK
(iv) Intermittent Explosive Disoder: ☐yes ☐no ☐DK **(v)** Depression: ☐ Yes ☐ No ☐ DK **(vi)** Sleeping disoder: ☐ Yes ☐ No ☐ DK
(vii) Other *(specify):*_____

43. Does the child have any of the following dysmorphisms?
(i) clinodactyly ☐ Yes ☐ No ☐ DK **(ii)** camptodactyly ☐ Yes ☐ No ☐DK
(iii)'railroad-track' ear (helix crus horizontal) ☐ Yes ☐ No ☐ DK **(iv)** epicanthic folds ☐ Yes ☐ No ☐ DK
(v)'hockey stick' palmar creases ☐ Yes ☐ No ☐ DK **(vi)** Other*(specify):* _____

44. Has the child had: Chromosomal microarray analysis; ☐ No ☐ DK ☐ Yes; ***Results***:_____
Karyotype testing: ☐ No ☐ DK ☐ Yes; ***Results:***_____

45. Have the following conditions been excluded: **(i)** fragile X syndrome ☐ Yes ☐ No ☐DK **(ii)** fetal anticonvulsant syndromes (Dilantin/Valproate) ☐ Yes ☐ No ☐DK **(iii)** chromosome microdeletions syndromes (e.g. Williams syndrome) ☐ Yes ☐ No ☐ DK

MANAGEMENT

46. Which services are currently being accessed by this child?
☐ general or developmental paediatrics ☐ occupational therapy ☐ psychology ☐ speech pathology
☐ physiotherapy ☐ early childhood intervention ☐ educational support ☐ social work
☐ child protection services ☐ Other *(specify)*:_____

47. Are these services adequate to manage this child's needs? ☐ Yes ☐ DK ☐ No
If No, (specify):_____

48. Has information on this child's FASD diagnosis been provided to any third parties (e.g. other health professionals, teacher, lawyer, community services)? ☐ No ☐ DK ☐ Yes *(specify):*_____

49. Has the family been told about the National Organisation for Fetal Alcohol Spectrum Disorders? ☐ Yes ☐ No ☐ DK

Thank you for your help with this research project. Please return this questionnaire to the APSU in the reply-paid envelope or fax to 02 9845 3082. Australian Paediatric Surveillance Unit, Kids Research Institute, Locked Bag 4001, Westmead NSW 2145. This study is supported by a grant from the Australian department of Health and Ageing, Chronic Disease Service Improvement Fund. *This study has been approved by a Human Research Ethics Committee properly constituted under NHMRC guidelines.*