FETAL ALCOHOL SPECTRUM DISORDER (FASD) Australian Paediatric Surveillance Unit If you have any questions about this form please contact the APSU (02) 9845 3005; SCHN-APSU@health.nsw.gov.au	*APSU Office Use Only*	
	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 2: 28.02.2017*	

REPORTING CLINICIAN'S DETAILS **1.** APSU Dr Code/Name: __ __ ___ __ /_____ **2**. Date questionnaire completed: __ _/__ __/__ __ __ __

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/hospital:_____

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 parents ☐ grandparent/s ☐ foster carer/s ☐ adoptive parent/s ☐ Other *(specify)*: _____

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

15a. If yes, specify: _____

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

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? _____

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):*_____

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 ($\leq 10^{th}$ 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 – FASD facial features

24. Were any of the following characteristic FASD 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 FASD 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

26a. Which palpebral fissure normative values used? _____

DIAGNOSTIC CRITERIA

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 < 6 years of age was there global developmental delay? ☐ Yes ☐ No ☐ DK

30a. If yes, what age was this diagnosed? _____ (years) _____ (months) ☐ DK

31. Was there evidence of clinically significant neurological CNS abnormality otherwise unexplained? ☐ No ☐ Yes ☐ DK

If yes: ☐ seizure disorder ☐ cerebral palsy ☐ visual impairment ☐ sensorineural hearing loss ☐ 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
☐ Motor skills		☐	☐	☐	☐
☐ Cognition		☐	☐	☐	☐
☐ Language		☐	☐	☐	☐
☐ Academic achievement		☐	☐	☐	☐
☐ Memory		☐	☐	☐	☐
☐ Attention		☐	☐	☐	☐
☐ Executive functioning, including impulse control and hyperactivity		☐	☐	☐	☐
☐ Affect regulation		☐	☐	☐	☐
☐ Adaptive behaviour, social skills or social communication		☐	☐	☐	☐

33. Has the child been diagnosed with ADHD? ☐ Yes ☐ No ☐ DK

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

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

DIAGNOSTIC CRITERIA – prenatal alcohol exposure and exposure to other substances

36. Was prenatal alcohol exposure: ☐ confirmed present ☐ unknown ***(please go to Q39)*** ☐ confirmed absent

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

37a. If the AUDIT-C was used, what was the score? _____

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

39. 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

40. 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

41. 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

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

43. 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 disorder: ☐ Yes ☐ No ☐ DK
(vii) Other *(specify):*_____

44. 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):*_____

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

46. 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

47. 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)*:_____

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

49. 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):*_____

50. Has the family been told 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 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. This study has been approved by a Human Research Ethics Committee properly constituted under NHMRC guidelines.

Evaluation Questions regarding the Australian Guide to the Diagnosis of FASD and FASD Education Modules

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Please answer all questions and click on SUBMIT when completed.

1. Are you aware of the Australian Guide to the Diagnosis of FASD? ☐ Yes ☐ No
   If yes, please answer the questions below, If No go to Q 6

2. Did you read the Guide? ☐ Yes ☐ No

3. Have you used the Guide in your clinical practice? ☐ Yes ☐ No

4. If you have read or have used the Guide please indicate your level of agreement with the following statements by placing an **X** under the most appropriate option on the scale Strongly Agree – Strongly Disagree:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Suggestions for improvement?
4a. I found the Guide useful						
4b.The content of the Guide was easy to understand						

5. How did you hear about the Australian Guide to the Diagnosis of FASD?

   ☐ APSU website
   ☐ APSU newsletter or mail-out
   ☐ Telethon Kids Institute Website
   ☐ A colleague
   ☐ Other, *Please Specify*: _____

FASD Education Modules

6. Are you aware of the FASD educational modules that accompany the Australian Guide to the Diagnosis of FASD? ☐ Yes ☐ No

If yes, please answer the questions below; ***If No*** there are no more questions

		I found this module useful (place an x under the most appropriate option below for each module					Suggestions for improvement?
	Did you complete this module?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	
Module 1. What is Fetal Alcohol Spectrum Disorder?	☐ Yes ☐ No						
Module 2: Alcohol use in pregnancy	☐ Yes ☐ No						
Module 3: Conducting a diagnostic assessment (includes 3 sub modules)	☐ Yes ☐ No						
Module 4: Referral and screening guidelines for FASD	☐ Yes ☐ No						
Module 5: Support and intervention after diagnosis	☐ Yes ☐ No						

Thank you for taking the time to complete this survey.
Your answers are important and will inform the future development of FASD Guidelines and educational modules.