### Patient's Details

1. APSU Dr Code/Name: ____________________________
2. Date form completed: ___/___/______

#### Patient's Family Background

10. Ethnic background for both birth mother and father:
   - [ ] 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

#### Diagnostic Criteria – prenatal alcohol exposure

14. Was prenatal alcohol exposure:
   - [ ] Confirmed present
   - [ ] Unknown

15. What was the source of information about prenatal alcohol exposure?
   - [ ] 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
   - [ ] Never 2 (please go to Q18)
   - [ ] Monthly or less 1
   - [ ] 1 or 2 1
   - [ ] 3 or 4 1
   - [ ] Unknown
   - [ ] Never 3
   - [ ] Less than monthly 1

   **b.** How many standard drinks did the birth mother have on a typical day when she was drinking during this pregnancy?
   - [ ] Unknown
   - [ ] 5 or 6 2
   - [ ] 7 to 9 2
   - [ ] 10 or more 2

   **c.** How often did the birth mother have 5 or more standard drinks on one occasion during this pregnancy?
   - [ ] Unknown
   - [ ] Monthly 2
   - [ ] Weekly 3
   - [ ] Daily or almost daily 4

18. What was the total AUDIT-C score?
   (calculate by adding the corresponding subscripts in a, b and c)
   - [ ] No exposure 7
   - [ ] Confirmed exposure 1,4
   - [ ] Confirmed high-risk exposure 5

19. How many standard drinks did the birth mother have on one occasion during this pregnancy?
   - [ ] Unknown
   - [ ] 2-4 times a month 2
   - [ ] 2-3 times a week 3
   - [ ] 4 or more times a week 4

[ ] 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: ____________________________

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**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

*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*
### DIAGNOSTIC CRITERIA – neurodevelopmental domains

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

**20.** Which domains were assessed?

<table>
<thead>
<tr>
<th>Domains (tick all that apply)</th>
<th>Degree of impairment?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Brain structure/neurology</td>
<td>□ None  □ Severe</td>
</tr>
<tr>
<td>□ Motor skills</td>
<td>□ None  □ Some  □ Severe</td>
</tr>
<tr>
<td>□ Cognition</td>
<td>□ None  □ Some  □ Severe</td>
</tr>
<tr>
<td>□ Language</td>
<td>□ None  □ Some  □ Severe</td>
</tr>
<tr>
<td>□ Academic achievement</td>
<td>□ None  □ Some  □ Severe</td>
</tr>
<tr>
<td>□ Memory</td>
<td>□ None  □ Some  □ Severe</td>
</tr>
<tr>
<td>□ Attention</td>
<td>□ None  □ Some  □ Severe</td>
</tr>
<tr>
<td>□ Executive function, including impulse control and hyperactivity</td>
<td>□ None  □ Some  □ Severe</td>
</tr>
<tr>
<td>□ Adaptive regulation</td>
<td>□ None  □ Some  □ Severe</td>
</tr>
</tbody>
</table>

#### 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 (2SD 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)
- ☐ Direct measurement
- ☐ 2D photographic analysis
- ☐ Lip-Philtrum Guide (African American)
- ☐ 3D photographic analysis
- ☐ Not assessed (please go to Q32)

**28.** How were the sentinel facial features assessed? (tick all that apply)
- ☐ Stromland
- ☐ Clarren
- ☐ Iosub
- ☐ Hall
- ☐ Other (specify): ________________

**29.** What was the palpebral fissure length Z-score?
- ☐ Stromland
- ☐ Clarren
- ☐ Iosub
- ☐ Hall
- ☐ Other (specify): ________________

**30.** What was the philtrum rank (1-5)?
- ☐ Stromland
- ☐ Clarren
- ☐ Iosub
- ☐ Hall
- ☐ Other (specify): ________________

**31.** What was the lip rank (1-5)?
- ☐ Stromland
- ☐ Clarren
- ☐ Iosub
- ☐ Hall
- ☐ Other (specify): ________________

### 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:
   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 ≤ 3rd percentile for gestation  □ Yes □ No □ DK
(b) length ≤ 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 ≤ 3rd percentile for gestation  □ Yes □ No □ DK
(b) length/height ≤ 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 □ 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? □ General or developmental paediatrics □ Occupational therapy
□ Psychology □ Speech pathology
□ Physiotherapy □ Social work
□ Early childhood intervention □ Educational support
□ Child protection services □ NGOs
□ Other (specify): ________________________________________________________

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.