Supplementary Information
S1: LEAP-CP Medical checklist: Part 1 and 2

Study ID: ☐☐☐ **Date:** ☐☐/☐☐/☐☐☐☐
Form completed by: **Interviewer initials:** ☐☐

Part 1: Perinatal data and Birth History – collected from Medical record

Infant details

Estimated date of delivery	
Date of birth	
Gestational age at birth (weeks.days)	
Maternal age at birth	
Gender	O Male O Female O Indeterminate
Multiple Births	O Singleton O Twin O Triplet O Surviving twin from multiple (eg singleton birth from triplet pregnancy, sibling died in utero or at birth)
Order of birth for multiples	
Birthweight (grams)	
Apgar at 1 minute	
Apgar at 5 minutes	
Resuscitation	O Nil (includes suction & O2 therapy) O Minor (bag and mask, CPAP or Hi-flow) O Major (intubation, CPR, adrenaline) O Resuscitation data not recorded

Infant complications

Respiratory (tick all that apply) Other respiratory issue please specify	O No (includes suppl O2 for <4 hrs) O Requiring ongoing ventilation or CPAP O Pneumothorax O Pneumonia O Other
Chronic lung disease (O2 and or ventilatory requirement at 36 weeks corrected age)	O Yes O No
Hypxoic Ischemic Encephalopathy (HIE)	O Yes O No
Sarnat stage or severity of HIE	O Stage 1 (mild) O Stage 2 (moderate) O Stage 3 (severe)
Received cooling	O Yes O No
Patent ductus arteriosus (PDA)	O No O Yes O Not documented
If yes to PDA, tick all that apply	O No treatment O Diuretics O Fluid restriction O Indomethacin/ibuprofen/paracetamol

	O Surgery
NEC	O No O Suspected (clinical signs, Xrays normal, nil by mouth &/antibiotics <5 days) O Definite (Xray changes, ≥5 days nil by mouth &/or triple antibiotics &/or surgery)
Seizures Aetiology if known	O Yes O No
Surgery	O Yes O No
Please specify what surgery (tick all that apply) Other surgery, please specify	O Bowel resection O Inguinal hernia repair O Tracheostomy O PDA ligation O Rickham's reservoir O VP shunt O other
Jaundice requiring exchange transfusion	O Yes O No
Major malformation or genetic syndrome Please specify	O Yes O No
Retinopathy of Prematurity (ROP)	O No O Yes, no intervention required O Yes, received laser therapy O Yes, received Avastin (brand name for Bevacizumab) O Not examined
Left eye: Max stage of ROP as recorded by ophthalmologist	
Right eye: Max stage of ROP as recorded by ophthalmologist	
Hearing Screen result Referred hearing result	O Pass O Referred for further examination O Not examined

Cranial and MRI findings Ultrasound findings (most severe reported)

IVH Maximum IVH grade Left Maximum IVH grade Right	O Yes O No
Cystic PVL	O Yes O No
Please specify any other abnormal neuroimaging findings	
Age at time of CUS/MRI	
Where was the CUS/MRI completed	

Discharge details

LOS in hospital (days) NICU SCN Transfered to other hospital	
Discharged home on Oxygen	O Yes O No
Was the infant receiving any tube feeding on discharge home?	O Yes O No

Developmental History

Complications since birth (please tick all that apply) Other, please specify	O CNS infection (eg meningitis/ encephalitis) O Head injury O Near drowning O Non-accidental injury O Tumour O CVA O Cerebral malformation O Other

Maternal details

Maternal age at delivery	
Mode of delivery	O Vaginal O Caesarean – in labour O Caesarean – not in labour O Not documented
Specify Caesarean section	O Elective O Emergency
Did the infant have foetal growth restriction?	O Yes O No
Did the mother have any of the following medical conditions during this pregnancy?	O None O Pre-eclampsia O Essential hypertension O Thrombophilia O Diabetes - specify O Epilepsy O Respiratory - specify O Renal disease - specify O Cardiac disease - specify O Pulmonary - specify O Red cell isoimmunisation O Autoimmune disease - specify O Psychiatric (diagnosed) - specify O Substance use - specify O Other
Diabetes (please specify)	O Gestational O Type 1 diabetes O Type 2 diabetes
Respiratory (please specify)	

Renal disease (please specify)	
Cardiac disease (please specify)	
Pulmonary (please specify)	
Autoimmune (please specify)	
Psychiatric (please specify)	
Substance use (please specify)	
Other (please specify)	
Antepartum haemorrhage (bleeding after 20 weeks gestation)? If Yes, specify at what gestation	O Yes O No
Did the mother receive corticosteroids (to enhance foetal lung maturation)?	O Yes O No O Not documented
Antenatal corticosteroids (number of completed courses; 2 doses = 1 course)	O None O Incomplete (1 dose only) O 1 course O 2 courses O 3 courses O Information not documented
Did the mother receive any intravenous magnesium sulphate	O No O Yes O Not documented
Duration of ruptured membranes	O N/A or no data available O <24 hours O ≥24 hours
Were antibiotics given?	O No O Yes O Not documented
Did any of the following intra &/or post-partum complications occur? Other, please specify	O None O Intra-partum fever (in mother) O Preterm labour O Meconium O Breech O Shoulder dystocia O Delayed cry (>5 minutes after birth) O Lethargy or seizures within 72 hours of birth O Cord around neck O Other
Antenatal care Number of visits	O Yes O No

Medications

During the last 6 months has your child had medications for…

1. Epilepsy	O Yes O No
A. Which medication	
Frequency (per day)	☐☐
Dosage (per day)	☐☐
Duration (length of treatment)	
Any adverse effects?	O Yes O No
B. Which medication	
Frequency (per day)	☐☐
Dosage (per day)	☐☐
Duration (length of treatment)	
Any adverse effects?	O Yes O No
C. Which medication	
Frequency (per day)	☐☐
Dosage (per day)	☐☐
Duration (length of treatment)	
Any adverse effects?	O Yes O No

2. Saliva control	O Yes O No
A. Which medication	
Frequency (per day)	☐☐
Dosage (per day)	☐☐
Duration (length of treatment)	
Any adverse effects?	O Yes O No
B. Which medication	
Frequency (per day)	☐☐
Dosage (per day)	☐☐
Duration (length of treatment)	
Any adverse effects?	O Yes O No

3. Other	O Yes O No
A. Which medication	
Frequency (per day)	☐☐
Dosage (per day)	☐☐
Duration (length of treatment)	
Any adverse effects?	O Yes O No
B. Which medication	
Frequency (per day)	☐☐
Dosage (per day)	☐☐
Duration (length of treatment)	
Any adverse effects?	O Yes O No

Co-morbidities

	Parent question (based on 10Q Screen)*	**Formal assessment**
Physical	Does your child have any serious delay in sitting, standing or walking? O Yes O No Does your child have difficulty walking or	

	using arms or does he/ she have weakness in the arms/ legs? O Yes O No	
Epilepsy/ infantile seizures (date of onset) and seizure type	Does your child sometimes have fits, become rigid, or lose consciousness? O Yes O No	Date of onset (from above): Type of seizure (from above): Defined by 2 unprovoked seizures excluding febrile or neonatal seizures O Generalised or partial O Generalised – sudden onset of seizures that compromises responsiveness and affects the whole body O Partial – seizures have focality therefore symptoms reflect onset in 1 part of the brain
Visual impairment	Compared with other children, does your child have difficulty seeing, either in the daytime or at night? O Yes O No	O No O Diagnosed impaired O Suspected impaired O Unsure
Hearing impairment	Does your child appear to have difficulty hearing? O Yes O No	O No O Diagnosed impaired O Suspected impaired O Unsure
Intellectual impairment	Does your child learn to do things like other children his/ her age? O Yes O No Compared with other children of his/ her age, does your child appear in any way mentally backward, dull or slow? O Yes O No	O No O Diagnosed impaired O Suspected impaired O Unsure
Communication impairment	When you tell your child to do something, does he/ she seem to understand what you are saying? O Yes O No Does your child speak at all? O Yes O No Can your child name at least one object? O Yes O No	O No O Diagnosed impaired O Suspected impaired O Unsure

*10 Question Screen is a standardised parent-reported measure. Please ask these questions verbatim.

Part 2: Socio-demographic information

Household Characteristics

Family pedigree (3 generations) * Note this is not completed if biological caregiver is not involved and information is not recorded in the infant's medical record.	Any evidence of illness in the family; any problems with development or intellect; presence of motor disorder, congenital deformity, decreased motor function over time, in-utero/death, disease; cousin marriage, sudden/ unexplained death				
Family structure	2 caregivers (nuclear)	Separated parents dual custody	Cared for by other intact family	Single caregiver	Other
Birth order (of blood siblings	First born	Second born	Third born	Fourth born	Other (specify)
Child lives with	Nuclear family	Extended family	Step family	Kinship care	Foster care
Family members in the house (number)				Adult men	
				Adult women	
				Children <18 years	
Other relatives living close by	Yes / no				
Who regularly provides care for the child (multiple times per week)? (select as many as apply, and provide their details) Other (specify):	**Relationship to child:** Age: Highest education: Occupation: Frequency of care:	**Relationship to child:** Age: Highest education: Occupation: Frequency of care:	**Relationship to child:** Age: Highest education: Occupation: Frequency of care:	**Relationship to child:** Age: Highest education: Occupation: Frequency of care:	**Relationship to child:** Age: Highest education: Occupation: Frequency of care
Does the infant's biological mother/ father identify as	Aboriginal	Torres Strait Islander			
Primary language(s) spoken at home	English only Some English No English Specify language(s):				
Where family traditionally from?					
Current postcode					
Distance to town (corner store)	☐☐☐ minutes (in car)				

Employment

Who are the main earners/ workers in the family?	Grandfather	Grandmother	Father	Uncle	Mother	Other
Main earners' occupation/s						
Main earner's employment	Fulltime/ secure	Part-time/ casual	Unemployed/ pension		Fly in fly out	
Does ill-health often prevent them from working?	Y		N		NA	

Alcohol use in early pregnancy (AUDIT-C)*

Question	Response
Was the pregnancy planned or unplanned?	O Planned O Unplanned O Unknown
At what gestation did the mother realise she was pregnant?	Weeks O Unknown
Did the birth mother drink alcohol before the pregnancy was confirmed?	O No O Yes O Unknown
Did the birth mother modify her drinking behaviour on confirmation of pregnancy?	O Yes O No O Unknown
During which trimesters was alcohol consumed, tick all that apply	O None O 1st O 2nd O 3rd O Unknown
1. How often did the birth mother have a drink containing alcohol during this pregnancy?	O Unknown O Never (skip Qn 2 & 3) O monthly or less O 2-4 times a month O 2-3 times a week O 4 or more times a week
2. How many standard drinks did the birth mother have on a typical day when she was drinking this pregnancy?	O Unknown O 1 or 2 O 3 or 4 O 5 or 6 O 7 to 9 O 10 or more
3. How often did the birth mother have 5 or more standard drinks on one occasion during this pregnancy?	O Unknown O Never O Less than monthly O Monthly O Weekly O Daily or almost daily

* Note this is not completed if biological caregiver is not involved and information is not recorded in the infant’s medical record.

S2: LEAP- CP (Learning through Everyday Activities with Parents) _ 12-Month Medical Assessment- Differential Diagnosis

Study ID: ☐☐☐ **Date:** ☐☐/☐☐/☐☐☐☐

Completed by:

Child's name		
Corrected Age at assessment		
Weight	kg /	percentile
Height	cm /	percentile
Head Circumference	cm /	percentile

Visual impairment (without correction, on both eyes)	Not assessed =0		Right (R=), Left (L=)
	Normal/No visual impairment =1		
	Squint =2		
	Impaired =3		
	Severely impaired (blind or no useful vision) =4		
Hearing impairment (before correction, on the better ear)	Not assessed =0		
	Normal =1		
	Impaired =2		
	Severely impaired (hearing loss > 70 dB) =3		
General Observation:	No abnormality =0	Abnormality=1	
Face	0	1	
dysmorphism	0	1	
general nutritional state	0	1	
Body proportions	0	1	
Muscle bulk	0	1	
symmetry	0	1	
tongue fasciculation	0	1	
excessive drooling	0	1	
other	0	1	
Gait:	Non ambulant = 0		**Comments:**
	Age appropriate = 1		
	Toe walking = 2		
	Asymmetrical gait = 3		

CEREBRAL PALSY

Motor type	**Primary**	**Secondary**
	Spastic =1	Spastic =1
	dyskinetic- dystonic =2	dyskinetic- dystonic =2
	dyskinetic- choreoathetotic =3	dyskinetic- choreoathetotic =3
	Hypotonic =4	Hypotonic =4
	Ataxic =5	Ataxic =5
Distribution	Bilateral =1 / unilateral =2	Bilateral =1 / unilateral =2
	No of limbs 1 / 2 / 3 / 4	No of limbs 1 / 2 / 3 / 4

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Neurological Signs:

Tone:	Left				Right			
Upper Limbs	Not tested = 0	Normal =1	Hypotonic =2	Hypertonic =3	Not tested = 0	Normal =1	Hypotonic =2	Hypertonic =3
Lower limbs	Not tested = 0	Normal =1	Hypotonic =2	Hypertonic =3	Not tested = 0	Normal =1	Hypotonic =2	Hypertonic =3

Tendon Reflexes:	Left	Right
Upper Limbs	Not tested =0 Present/Normal =1 Absent =2 Depressed =3 Brisk =4 Hyperreflexic/Very Brisk =5	Not tested =0 Present/Normal =1 Absent =2 Depressed =3 Brisk =4 Hyperreflexic/Very Brisk =5
Lower limbs	Not tested =0 Present/Normal =1 Absent =2 Depressed =3 Brisk =4 Hyperreflexic/Very Brisk =5	Not tested =0 Present/Normal =1 Absent =2 Depressed =3 Brisk =4 Hyperreflexic/Very Brisk =5

Clonus:						
Upper Limbs	Not tested = 0	Absent =1	Present =2	Not tested = 0	Absent =1	Present =2
Lower limbs	Not tested = 0	Absent =1	Present =2	Not tested = 0	Absent =1	Present =2

Plantar reflexes:							
Not tested = 0	Normal ↓ =1	No response =2	Abnormal ↑=3	Not tested = 0	Normal ↓ =1	No response =2	Abnormal ↑=3

Neurological Status	Normal = 0	Unspecified signs = 1	Abnormal (signs of CP) = 2

Cerebral palsy	No =0	High risk =1	Definitely =2	Unclear

Comments:

GMFCS level (0-2 years scale)	I =1 / II =2 / III =3 / IV= 4 / V= 5	
MACs level (1-4 year scale)	I =1 / II =2 / III =3 / IV= 4 / V= 5	
Upper limb/ Handedness	Right predominant =0 Left predominant =1 Bilateral =2	

FAS SYMPTOMOLOGY

Sentinel Facial Features

Assess for the 3 sentinel facial features of Fetal Alcohol Spectrum Disorder: short palpebral fissure length (2 SD or more below the mean), smooth philtrum (rank 4 or 5 on the Lip-Philtrum guide), and thin upper lip (rank 4 or 5 on the Lip-Philtrum guide).

Palpebral Fissure Length (PFL)

	Right PFL		Left PFL		Mean PFL	
Assessment method	mm	Z score (SD)	mm	Z score	mm	Z score*
☐direct measure ☐ photo analysis						
☐direct measure ☐ photo analysis						
PFL reference chart used: ☐ Stromland ☐ Clarren ☐ Other						

Philtrum

Assessment method	UW Lip-Philtrum Guide 5-point rank
☐direct measure ☐ photo analysis	
☐direct measure ☐ photo analysis	
☐direct measure ☐ photo analysis	

Upper lip

Assessment method	UW Lip-Philtrum Guide 5-point rank
☐direct measure ☐ photo analysis	
☐direct measure ☐ photo analysis	
☐direct measure ☐ photo analysis	

Lip-Philtrum Guide† used: ☐ Guide 1. Caucasian ☐ Guide 2. African American

Sentinel Facial Features Summary

Number of Sentinel Facial Features (PFL 2 SD or more below the mean, philtrum rank 4 or 5, upper lip rank 4 or 5): ☐ 0 ☐ 1 ☐ 2 ☐ 3

Functional Neurodevelopmental Domain Summaries

Assess evidence of significant CNS dysfunction due to underlying brain damage. Required evidence includes severe neurodevelopmental impairment (2 SD or more below the mean or < the 3rd percentile) in domains of brain function based on standardised psychometric assessment by a qualified professional.

1. **Neurological**

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Motor Skills impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

2. Motor skills

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Motor Skills impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

3. Cognition

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Cognition impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

4. Language
(Expressive and Receptive)

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Test/subtest name	Age/Date	Score	%ile/SD	Interpretation
Other information:				
Language impairment ☐ None ☐ Some ☐ Severe ☐ Not assessed				

5. Adaptive Behaviour, Social skills or Social Communication

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Adaptive behaviour, social skills, or social communication impairment ☐ None ☐ Some ☐ Severe ☐ Not assessed				

Neurodevelopmental Summary

Number of neurodevelopmental domains with evidence of severe impairment:

☐ None ☐ 1 ☐ 2 ☐ 3 or more(specify)

FAS	No =0	High risk of FAS =1	Definitely =2	Unclear

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ASD SYMPTOMOLOGY

Item	Score				
Visual Tracking	☐ 0	☐ 1	☐ 2		☐ 8
Disengagement of attentions	☐ 0	☐ 1	☐ 2		☐ 8
Orientation to name	☐ 0	☐ 1	☐ 2		☐ 8
Differential response to facial emotion	☐ 0	☐ 1	☐ 2		☐ 8
Anticipatory social response	☐ 0	☐ 1	☐ 2	☐ 3	☐ 8
Imitation	☐ 0	☐ 1	☐ 2		☐ 8
Social Babbing	☐ 0	☐ 1	☐ 2	☐ 3	☐ 8
Eye Contact	☐ 0		☐ 2		☐ 8
Reciprocal social smile	☐ 0	☐ 1	☐ 2	☐ 3	☐ 8
Coordination of eye gaze	☐ 0	☐ 1	☐ 2	☐ 3	☐ 8
Behavioural Reactivity	☐ 0	☐ 1	☐ 2	☐ 3	☐ 8
Social interest and shared affect	☐ 0	☐ 1	☐ 2	☐ 3	☐ 8
Transitions	☐ 0	☐ 1	☐ 2		☐ 8
Motor control	☐ 0	☐ 1	☐ 2		☐ 8
Atypical motor behaviour	☐ 0		☐ 2		☐ 8
Engagement of attention	☐ 0	☐ 1	☐ 2		☐ 8
Insistence on specific objects/activities	☐ 0	☐ 1	☐ 2		☐ 8
Sharing Interest	☐ 0	☐ 1	☐ 2		☐ 8
Total score					

ASD	No =0	High risk of ASD =1	Definitely =2	Unclear

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12-Month Medical Assessment- Blinded Differential Diagnosis

Study ID: ☐☐☐ **Date:** ☐☐/☐☐/☐☐☐☐
Completed by:

Cerebral palsy	No =0	High risk =1	Definitely =2	Unclear
Motor type	**Primary**		**Secondary**	
	Spastic =1		Spastic =1	
	dyskinetic- dystonic =2		dyskinetic- dystonic =2	
	dyskinetic- choreoathetotic =3		dyskinetic- choreoathetotic =3	
	Hypotonic =4		Hypotonic =4	
	Ataxic =5		Ataxic =5	
Distribution	Bilateral =1 / unilateral =2		Bilateral =1 / unilateral =2	
	No of limbs 1 / 2 / 3 / 4		No of limbs 1 / 2 / 3 / 4	
GMFCS level (0-2 years scale)	I =1 / II =2 / III =3 / IV= 4 / V= 5			
MACs level (1-4 year scale)	I =1 / II =2 / III =3 / IV= 4 / V= 5			
Comments				

FAS	No =0	High risk of FAS =1	Definitely =2	Unclear
Comments				

ASD	No =0	High risk of ASD =1	Definitely =2	Unclear
Comments				

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S3: LEAP – CP Medical and Allied Health Resource Form

Study ID: ☐☐☐ **Date:** ☐☐/☐☐/☐☐☐☐
Form completed by: **Interviewer initials:** ☐☐

Allied Health

During the last 6 months have you received treatment or advice from:

1. Physiotherapy	O Yes O No
Does it emphasise	O Motor learning O Equipment O Functional therapy O Stretching & positioning O Other: ____________________
How often	☐☐ Visits per 6 months
Format	O Individual O Group O Home program
Location	O Hospital O Community O Home O Private practice

2. Occupational therapy	O Yes O No
Does it emphasise	O Motor learning O Equipment O Functional therapy O Stretching & positioning O Other: ____________________
How often	☐☐ Visits per 6 months
Format	O Individual O Group O Home program
Location	O Hospital O Community O Home O Private practice

3. Speech therapy	O Yes O No
Does it emphasise	O Speech/ talking O Early communication skills (play) O Sign/ symbol O Mealtime O Other: ____________________
How often	☐☐ Visits per 6 months
Format	O Individual O Group O Home program
Location	O Hospital O Community O Home O Private practice

4. Other	O Yes O No
What does it emphasise?	
How often	☐☐ Visits per 6 months
Format	O Individual O Group O Home program
Location	O Hospital O Community O Home O Private practice

Medical

During the last fortnight, has your child been sick? O Yes ☐☐ (number of days) O No

During the 6 months, has your child had:

1. Admission to hospital	O Yes O No Number of admissions ☐
Visit 1	Reason: Treatment/ investigation: Length of stay ☐☐ days
Visit 2	Reason: Treatment/ investigation: Length of stay ☐☐ days
Visit 3	Reason: Treatment/ investigation: Length of stay ☐☐ days
Visit 4	Reason: Treatment/ investigation: Length of stay ☐☐ days

2. GP appointment	O Yes O No Number of appointments ☐
Visit 1	Reason: Treatment/ investigation:
Visit 2	Reason: Treatment/ investigation:
Visit 3	Reason: Treatment/ investigation:

1

Visit 4	Reason: Treatment/ investigation:

3. Paediatrician	O Yes O No Number of appointments ☐
Visit 1	Reason: Treatment/ investigation:
Visit 2	Reason: Treatment/ investigation:
Visit 3	Reason: Treatment/ investigation:
Visit 4	Reason: Treatment/ investigation:

4. Other specialist Who:	O Yes O No Number of appointments ☐
Visit 1	Reason: Treatment/ investigation:
Visit 2	Reason: Treatment/ investigation:
Visit 3	Reason: Treatment/ investigation:
Visit 4	Reason: Treatment/ investigation:

5. Other specialist Who:	O Yes O No Number of appointments ☐
Visit 1	Reason: Treatment/ investigation:
Visit 2	Reason: Treatment/ investigation:
Visit 3	Reason: Treatment/ investigation:
Visit 4	Reason: Treatment/ investigation:

6. Other specialist Who:	O Yes O No Number of appointments ☐
Visit 1	Reason: Treatment/ investigation:
Visit 2	Reason: Treatment/ investigation:
Visit 3	Reason: Treatment/ investigation:
Visit 4	Reason: Treatment/ investigation:

Equipment

Has your child been provided with any equipment:

- ☐ Supportive chair/ seating
- ☐ Walking aids
- ☐ standing frame
- ☐ Splints / orthoses
- ☐ Wheelchair

National Disability Insurance Scheme (NDIS) Funding

Does your child have an NDIS plan?	O Yes O No
Is the plan self managed?	O Yes O No
What are you able to use your funding for?	O Therapy (eg physiotherapy, OT) O Equipment (eg walking aid/ orthoses) O Consumables (eg feeding tubes)