GUIDELINE

Follow-Up Program

Scope (Staff):	Nursing and Medical Staff
Scope (Area):	NICU KEMH, NICU PCH, NETS WA

CAHS commits to being a child safe organisation by applying the National Principles for Child Safe Organisations.

Read the full statement here:
CAHS Child Safe Organisation Commitment Statement

This document should be read in conjunction with this disclaimer

Aim

To provide a structured approach to neonatal follow up services.

Risk

Risk to patients: Suboptimal clinical care, missed opportunities for detecting developmental delay or atypical neurodevelopment and missed referrals to early intervention thus compromising overall developmental trajectory.

Risk to institute: Suboptimal clinical care, significant gaps in data of preterm or high-risk infant outcomes thus jeopardising antenatal counselling or parental education.

Background

The core purpose of the program is to ensure early detection of developmental and medical concerns, enabling timely diagnosis, counselling, and linkage to appropriate community or hospital-based services. This supports the implementation of early intervention as soon as possible for high-risk infants.

Given the nature of the infants/ children seen, many of whom are at very high risk, developmental problems and disabilities are frequently identified. The program therefore plays a key role in providing initial diagnostic assessment, guiding families, and coordinating referrals.

The program also aims to foster research collaboration by actively encouraging partnerships between interested clinical and academic groups. The service operates across both KEMH and PCH, with defined entry criteria due to limited capacity. The focus of the follow-up program is on objective assessments at key developmental ages, ensuring consistent monitoring and high-quality longitudinal data.

Inclusion Criteria to the follow up program

The target populations currently admitted to the follow up program are those requiring Neonatal Intensive Care, as follows:

- Very Preterm births (VP <32w gestation)
- Hypoxic Ischaemic Encephalopathy (HIE) requiring therapeutic hypothermia.
- Meningitis / Herpes Simplex Virus (HSV) Encephalitis and disseminated HSV infection.
- Neonatal seizures
- Neonatal Surgery involving opening a major body cavity, including:
    - Abdominal surgery (e.g. Gastroschisis; Hirschsprung's disease, malrotation with volvulus)
    - Cardiac surgery within the first three months
    - Other Chest surgery e.g. Diaphragmatic Hernia, Oesophageal Atresia
    - CNS surgery
    - Other major surgery.
- Exchange Transfusion
- ECMO
- Miscellaneous: critically unwell medical patients discuss with FU co-ordinators (KEMH:0436595642, PCH: 0407 781 277) for eligibility e.g.: meconium aspiration, hydrops needing prolonged iNO (>24 hours) and/ inotropes

Infants who are ***not eligible*** for the follow up program cannot be entered into the program without prior discussion with the follow up team medical staff at the site. Routine growth and developmental monitoring maybe available through GP, paediatrician or child health nurse.

Table 1: Duration of Follow up

Group A Followed to 5 years	• <28 weeks gestation
Group B Followed to 24 months	• 28 – 29+6 weeks gestation • Major surgery: gastroschisis, congenital diaphragmatic hernia, oesophageal atresia and cardiac surgery • HIE treated by therapeutic hypothermia
Group C Followed to 12 months	• 30 – 31+6 weeks gestation • Seizures/symptomatic hypoglycaemia • Meningitis/Encephalitis/Systemic Herpes Simplex infections • Major Surgery - cranial, chest, open abdomen surgery (only gastroschisis, oesophageal atresia and CDH seen to 2 years • Exchange transfusion • Nitric oxide >24 hours, inotropes need • ECMO

Families living within the Perth metropolitan area

- These infants will be reviewed at the Paediatric Follow-Up Clinic (KEMH/PCH) at regular intervals by a multidisciplinary team (Nurse, Physiotherapist and Medical). Usually around the date they were due to be born (referred to as ‘term’), then at 4 and 8 months corrected age. Infants will be seen at the hospital where they received care (either PCH or KEMH). The follow-up coordinator will organise all appointments for the follow-up programme. Appointments for term, 4 and 8 months corrected age will be posted to the parents.

- A developmental assessment is carried out at 12 months corrected age. The appointment is organised via phone call and text to the family with an email sent out for confirmation. In addition, confirmatory phone call and SMS reminders are sent prior to the appointment to ensure attendance. Any queries regarding the appointment date can be made to the Neonatal Directorate at KEMH or PCH, depending on where the child is due to be seen.

- For those eligible, further standardised assessments are carried out at 24 months corrected age at KEMH or PCH. Subsequent assessments at 3 years corrected age and 5 years actual age are carried out only at KEMH (Table 2).

- Prior to follow-up appointments, developmental questionnaires (Table 2) are posted to parents. These questionnaires, when completed, help to assess the infant’s progress and monitor growth and behaviour.

- Questionnaires will also be forwarded to parents when the child is 2 and 3 years corrected age. A self-addressed, reply ***pre-paid envelope*** will be provided for return to the central KEMH/ PCH teams. These later questionnaires not only help to monitor progress but are valuable in building up an overall picture of how our “special graduates” fare in their early childhood years. By receiving this valuable information from parents, we are better informed to counsel future parents.

Families living outside the Metropolitan area

- Infants living outside metropolitan areas i.e. rural/country where transport and distance are a challenge, receive individualised follow-up with Rural Paediatrics Service/local General Practitioner (GP) and/or KEMH/PCH paediatricians after discussion with parents.

- Developmental assessment at 12 and 24 months should take place at the local hospital by the rural paediatric service or local GP (if this service is available). However, the 5 years school age assessment will be offered only at KEMH for eligible children.

- The Rural Paediatric Team and local doctor will receive a full summary of the infant's stay in the NICU so they will be fully informed of any problems that may need to be followed up.
- The Rural paediatric team will contact parents if their infant is due to be seen when they are visiting the area. The local child health nurse and GP will know when the team is due to the area. Developmental questionnaires will be forwarded as above.

Telehealth review

Where possible, infants and children will be seen face to face. Telehealth can be arranged as an alternative if required.

Physiotherapy Preterm Group

Physiotherapy preterm groups are offered at KEMH for neonates admitted to the KEMH/PCH Neonatal Intensive Care Unit who were born at <32 weeks gestation. Families that live within the metropolitan area will be notified via mail of the commencement of the group**,** usually around 3 months corrected age.

General movements assessment

Prechtl's general movements assessment plays a critical role in high-risk follow-up by enabling early identification of infants at risk of neurodevelopmental disorders, including cerebral palsy, through the evaluation of spontaneous movement patterns with high sensitivity and predictive validity. Refer to General Movement Video and Assessment Guideline.

Referrals/Follow up protocols

Referrals to appropriate intervention and other allied health services will be made depending on the assessment results as we do not offer therapy.

The administration of assessments, questionnaires and duration of follow-up is determined by the Follow-Up Program service based on the infants' requirements.

Table 2: Assessments and Questionnaires

Age (months)	**Medical/ Developmental**	**Questionnaires**	**Behaviour/Other**
*4m, 8m	Medical review	ASQ3	
*12m	Griffiths-III/ medical review	ASQ3	ASQ-SE2 /Health
*24m	Bayley-IV/ medical review	ASQ3	Health

*36m	Griffiths-III / medical review	ASQ3	CBCL / Health
5yr	WPPSI–IV / medical review		Health/BRIEF-P, SDQ
ASQ-TRAK for aboriginal families at 6,12,24 and 36 months ASQ- Ages and Stages Questionnaire ASQ-SE: Ages and Stages Questionnaire-Social Emotional CBCL - Child Behaviour Checklist BRIEF-P: Behaviour Rating Inventory of Executive Function-PreSchool version SDQ: Strengths and Difficulties Questionnaire ***corrected age**			

References

1. Boyd SM, et al. High-risk infant follow-up: where are we and where to from here? Pediatr Res. 2026 Jan;99(1):16-18.

2. Litt JS, Campbell DE. High-Risk Infant Follow-Up After NICU Discharge: Current Care Models and Future Considerations. Clin Perinatol. 2023 Mar;50(1):225-238.

3. Clifford D, et al; Newborn Brain Consortium. High-risk infant follow-up: current practice and factors determining eligibility. Pediatr Res. 2026 Jan;99(1):203-208.

4. Abell BR, et al. Implementing neurodevelopmental follow-up care for children with congenital heart disease: A scoping review with evidence mapping. Dev Med Child Neurol. 2024 Feb;66(2):161-175.

5. Abell B, et al. Neurodevelopmental follow-up care pathways and processes for children with congenital heart disease in Australia. Pediatr Res. 2025 Sep;98(3):966-975.

Related CAHS internal policies, procedures and guidelines

General Movement Video and Assessment Guideline

This document can be made available in alternative formats on request.

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