



GUIDELINE

Follow-Up Program

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

Child Safe Organisation Statement of Commitment

CAHS commits to being a child safe organisation by applying the National Principles for Child Safe Organisations. This is a commitment to a strong culture supported by robust policies and procedures to reduce the likelihood of harm to children and young people.

This document should be read in conjunction with this [disclaimer](#)

Aim

To provide a structure 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 Neonatal Follow up program has as its primary function the audit of ever changing, increasingly complex and increasingly expensive neonatal intensive care. The nature of the very high risk infants seen also means that developmental problems and disabilities are frequently seen, and an important part of the program is to provide initial diagnosis, counselling and appropriate linkage to other community or hospital based services, with a view to implementing early intervention programs as soon as possible.

The program aims to foster research programs by actively encouraging research between interested groups.

The program operates at both KEMH and PCH. The program has entry criteria as there is limited capacity within the program. The focus of the follow up program is objective assessments at key ages.

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) – includes a few infants born <1500g who are above this gestational age.
- Hypoxic Ischaemic Encephalopathy requiring therapeutic hypothermia.
- Meningitis / Herpes Simplex Encephalitis and disseminated HSV infection.
- Neonatal seizures/ convulsions occurring for any reason.
- Neonatal Surgery involving opening a major body cavity, including:
 - Abdominal surgery e.g. Gastroschisis, Hirschsprung's disease
 - Cardiac surgery within the first three months excluding simple PDA ligation
 - Other Chest surgery e.g. Diaphragmatic Hernia, Oesophageal Atresia
 - CNS surgery
 - Other major surgery.
- Exchange Transfusion – now much more infrequent in recent years due to prenatal management of Rhesus disease.
- Nitric oxide >24hours.

Duration of Follow up:

Group A Followed to 5 years	<ul style="list-style-type: none"> • <28 weeks gestation
Group B Followed to 24 months	<ul style="list-style-type: none"> • 28 - 30 weeks gestation • Major surgery: gastroschisis, congenital diaphragmatic hernia, oesophageal atresia and cardiac surgery • HIE treated by therapeutic hypothermia
Group C Followed to 12 months	<ul style="list-style-type: none"> • 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

Infants living in the Perth metropolitan area

These infants will be seen by a doctor in the Paediatric Follow-Up Clinic (KEMH/PCH) at regular intervals, usually around the date they were due to be born, then at 4- and 8-months corrected age. Infants will be seen at the hospital where they received treatment. 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 (Griffiths III Test) is carried out at 12 months corrected age. This appointment will be posted to parents about 4 weeks prior to the appointment date. 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 a Bayley's assessment at 24 months at KEMH or PCH will be done. Subsequent assessments at 3 and 5 years of age are carried out at KEMH.

Prior to follow-up appointments, developmental questionnaires are posted to parents. These questionnaires, when completed, help to assess the infant's progress and monitor growth and behaviour. **Parents should bring the completed questionnaires with them when they attend the clinic.**

Questionnaires will also be forwarded to parents when the infant is 2 and 3 years corrected age. A self-addressed, reply **pre-paid envelope** will be provided for return. 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.

Infants living beyond the Metropolitan area/Country

Infants living beyond the metropolitan area/country where transport and distance are a problem, receive individualised follow-up with Rural Paediatrics Service/local General Practitioner (GP) and/or KEMH/PCH paediatricians after discussion with parents. If possible, we would encourage developmental assessment at 12 months corrected age to take place at KEMH/PCH. Subsequent annual appointments, if eligible, are also encouraged. 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.

A telehealth review will be offered depending on WA health guidelines in the face of pandemic restrictions or if parents prefer.

Physiotherapy play groups

Physiotherapy play groups are offered at KEMH for neonates admitted to the KEMH/PCH Neonatal Intensive Care Unit who were born at <32 weeks gestation or whose birthweight was <1500grams. Families that live within the metropolitan area will be notified via mail of the commencement of the group, usually around 3 months corrected age.

Follow up protocols:






With over 500 children entering the follow up program each year, it is necessary to be selective about the testing protocols and duration of follow up.

Table of Assessment and Questionnaire

Age	MED/Developmental	Cognitive	Language	Behaviour/Other
4m, 8m	Medical review	ASQ		
1yr	Griffiths-III/ medical review	ASQ		Health
2yr	Bayley-IV/ medical review	ASQ	Rescorla Screen	Health
3yr	Griffiths-III / medical review	ASQ		CBCL / Health
5yr	WPPSI-IV / medical review			Health/BRIEF
ASQ- Ages and Stages Questionnaire CBCL - Child Behaviour Checklist BRIEF – Behaviour Rating Inventory of Executive Function				

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. Other arrangements may well be available outside of the program.

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

Document Owner:	Neonatology		
Reviewer / Team:	Neonatology Coordinating Group		
Date First Issued:	August 2006	Last Reviewed:	25 th October 2022
Amendment Dates:		Next Review Date:	25 th October 2025
Approved by:	Neonatology Coordinating Group	Date:	25 th October 2022
Endorsed by:	Neonatology Coordinating Group	Date:	
Standards Applicable:	NSQHS Standards:      Child Safe Standards: 1, 10		

Printed or personally saved electronic copies of this document are considered uncontrolled



Healthy kids, healthy communities

Compassion Excellence Collaboration Accountability Equity Respect

Neonatology | Community Health | Mental Health | Perth Children's Hospital