



CLINICAL PRACTICE GUIDELINE

Guideline coverage includes NICU KEMH, NICU PCH and NETS WA

Follow-Up Program

This document should be read in conjunction with the [Disclaimer](#)

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 eg Gastroschisis, Hirschsprungs disease
 - Cardiac surgery within the first three months excluding simple PDA ligation
 - Other Chest surgery eg Diaphragmatic Hernia, Oesophageal Atresia etc
 - 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"> • ≤ 27 week gestation and or <1001 grams BW
Group B Followed to 24 months	<ul style="list-style-type: none"> • 28 - 31 week gestation and or 1001-1501 grams BW • 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"> • Seizures/symptomatic hypoglycaemia • Meningitis/Encephalitis • Major Surgery - cranial, chest, open abdomen surgery (only gastroschisis, oesophageal atresia and CDH seen to 2 years) • Systemic Herpes simplex infections • Exchange transfusion • Nitric oxide greater than 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 the parents.

A developmental assessment (Griffiths 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 assessment at 24 months at KEMH or PCH will be done. Subsequent assessments at 3 and 5 years of age are in the process of transitioning to 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 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.

Physiotherapy play groups are offered at KEMH for neonates admitted to the KEMH/PCH Neonatal Intensive Care Unit who were born at less than 32 weeks gestation or whose birthweight was less than 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/ medical review	ASQ		Health
2yr	Bayley III/ medical review	ASQ	Rescorla Screen	Health
3yr	Griffiths/ medical review	ASQ		CBCL / Health
5yr	WPPSI – III / medical review			Health

ASQ- Ages and Stages Questionnaire; CBCL - Child Behaviour Checklist

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.

Related WNHS policies, procedures and guidelines

[Neonatal Follow-Up Data Request Form](#)

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