

Local
Guideline

John Hunter
Children's Hospital
CHILDREN, YOUNG PEOPLE AND FAMILIES



Health
Hunter New England
Local Health District

Developmental Follow up of High Risk Neonates

Sites where Local Guideline applies	Neonatal Intensive Care and Special Care Nursery in JHCH
This Local Guideline applies to:	
1. Adults	No
2. Children up to 16 years	No
3. Neonates – less than 29 days	Yes
Target audience	Clinicians caring for infants in the NICU and SCN
Description	To provide information to clinicians about the procedure for babies to be followed up
National Standard	Standard 2 Partnering with consumers

[Go to Guideline](#)

Keywords	Discharge, neonate, follow up , developmental, JHCH, NICU
Document registration number	JHCH_NICU_06.08
Replaces existing document?	No

Related Legislation, Australian Standard, NSW Ministry of Health Policy Directive or Guideline, National Safety and Quality Health Service Standard (NSQHSS) and/or other, HNE Health Document, Professional Guideline, Code of Practice or Ethics:

- [HNELHD PD2013_043:PCP 31 Medication Safety in HNE Health](#)
- [NSW Health Policy Directive PD2017_013 Infection Prevention & Control Policy](#)

Local Guideline note	This document reflects what is currently regarded as safe and appropriate practice. The guideline section does not replace the need for the application of clinical judgment in respect to each individual patient but the procedure/s require mandatory compliance . If staff believe that the procedure/s should not apply in a particular clinical situation they must seek advice from their unit manager/delegate and document the variance in the patient's health record.
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PURPOSE AND RISKS

This local guideline has been developed to provide instruction to the health clinician and to ensure that the risks of harm to the high risk neonate associated with developmental follow up are prevented, identified and managed.

The risks are:

- Late diagnosis and treatment of negative effects of prematurity
- Incomplete immunisations
- Increased parental anxiety

The risks are minimised by:

- Clinicians having knowledge of process for referral for developmental follow up
- Communicating with parents the importance of developmental follow up
- Following the instructions set out in the clinical procedure

Risk Category: *Clinical Care & Patient Safety*

GLOSSARY

Acronym or Term	Definition
HINE	The Hammersmith Infant Neurological Examination
ROP	Retinopathy of Prematurity
CPA	Cerebral Palsy Alliance
CNC	Clinical Nurse Consultant
CPMD	Cerebral Palsy Movement Disorder Service
VLBW	Very low birth weight
NDIS	National Disability Insurance Scheme

GUIDELINE

This Guideline does not replace the need for the application of clinical judgment in respect to each individual patient.

Developmental Follow up of the High Risk Neonate

Advances in neonatal intensive care have improved survival rates of high-risk neonates. High risk infants discharged from neonatal intensive care units have a range of risk factors that may result in medical and developmental sequelae. Recent advances in neonatal care have greatly shortened the length of stay of many preterm infants in tertiary care centres with further monitoring done in an outpatient setting.

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The developing brain of the premature infant is extremely vulnerable to injury. The long term consequences of such injury include motor deficits commonly referred to as cerebral palsy as well as cognitive and behaviour problems. The risk for neurodevelopmental deficits increases with decreasing gestational age, resulting in relatively high risk of cerebral palsy, developmental delay, hearing and vision impairment and subnormal academic achievement among extremely premature infants. Cognitive deficits without major motor deficits are now the dominant neurodevelopmental sequelae. High prevalence, low severity dysfunction appears to be increasing. The abnormalities include learning disabilities, borderline to low-average intelligence quotient, attention-deficit hyperactivity disorder, specific neuropsychological deficit (e.g. visual motor integration, executive functioning) and behaviour problems (e.g. internalising problems, social difficulties). The changing nature of the impairments encountered may impact on the length of follow up that is required.

Follow up is critical to identify possible negative effect of being born prematurely as well as collecting outcome data.

The Growth and Developmental Follow-Up Clinic at John Hunter Hospital currently provides a service to at-risk infants (Northern Child Health Network Area) from birth to two years.

Follow up groups include:

GROUP 1

- < 29 weeks gestation
- < 1000 g at birth
- Hypoxic Ischaemic Encephalopathy (undergo therapeutic cooling)
- Major Surgery in the neonatal period

Specific follow up for this group includes:

Suggested timing of neonatal outpatient review:

- First Visit: 3 months corrected
- Second Visit: 6 months corrected
- Third Visit: 9 months corrected
- Forth Visit: 12 months corrected with Bayley Scales of Infant and Toddler Development (3rd edition)
- Fifth Visit: 18 months corrected
- Sixth Visit: 24 months corrected with Bayley Scales of Infant and Toddler Development (3rd edition)

3, 6 and 9 month visits can be shared with a pediatrician (either local or regional) with information forwarded to the Follow up CNC.

Ophthalmology review

- Prevalence of visual impairment increases with decreasing gestational age.
- Screening for retinopathy begins in the Neonatal Unit for infants < 30 weeks or < 1250g ([Refer to Retinopathy of Prematurity \(ROP\) - Screening for and Management of in NICU CPG.](#))
- It is suggested in infants < 30 weeks or < 1250g, even if they did not have retinopathy of prematurity, to have a repeat ophthalmology review at 9 to 12 months of age. There is well documented evidence of increased incidence of refractive errors, strabismus and cerebral vision impairment in children born prematurely, studies showing incidence as 17.6% to 51.5%.¹⁻⁵ A history of ROP is an additional risk factor. In one study, a near doubling of poor distance and near visual acuity, myopia and strabismus.⁶

Audiology review

- Prevalence of hearing impairment increases with decreasing gestational age.
- Other risk factors include: neonatal sepsis in babies born before 28 weeks, low birth weight, ototoxic medications and intensive care in excess of 7 days.⁷
- SWISH before discharge and a repeat hearing test is suggested around 10 -12 months corrected for those infants born < 30 weeks.

Assessments

- Precht General Movement Video prior to discharge with a follow up at 3 months corrected visit. Inpatients that meet criteria are identified by the multidisciplinary team and the follow up video documented on their 3 month corrected visit by physiotherapist. Absent Fidgety with abnormal imaging meets referral criteria, due to high risk of CP, to Cerebral Palsy Alliance (CPA) for Early Intervention.
- The Hammersmith Infant Neurological Examination (HINE): **Following the 3 month GM assessment, a conclusive categorisation of fidgety movements is not always possible and thus CP risk not determined at this point.** Best practice indicates the need for further review. These infants will be reviewed in a Thursday morning clinic (Korostenski clinic) held once a month by a multidisciplinary team using the HINE. The purpose of this clinic is to add value and prognostic information only. It would not change the primary neonatologist involved or alter the course of clinic follow up.

Eligible patients for review include those who have had an assessment of sporadic/intermittent fidgety at 12 weeks corrected. Parents will be given information regarding the HINE assessment. A repeat GM video and HINE assessment would be completed prior to 16 weeks corrected. It is anticipated that this further assessment will assist in determining risk category and therefore eligibility for services such as Cerebral palsy Alliance (CPA). The information from this review would be fed back to the treating Neonatologist and recommendations made.

- Formal developmental testing at 12 and 24 months corrected using the Bayley Scales of Infant and Toddler Development (3rd edition).

- < 27 weeks gestation: WIPPSI offered at 5 years of age (year before commencing school). Currently parents of eligible children are contacted by a Dr Korostenski, followed by direct contact with the psychologist who works off site to arrange appointment.

GROUP 2: Other groups that require follow up by Neonatologist and Pediatrician until a year of age:

- < 32 weeks and/or < 1500g
- 32 – 35 week gestation and IUGR
- Neonatal seizures/strokes
- Hypoxic ischaemic encephalopathy (not cooled)
- Neonatal bacterial sepsis/meningitis
- TORCH infections
- Symptomatic hypoglycemia
- Jaundice requiring exchange transfusion
- Major congenital anomaly
- History of Neonatal Abstinence Syndrome

**Group 3: Follow up by GP
> 32 weeks**

Areas reviewed in OPD setting:

- Nutrition and growth – screen for feeding and growth problem.
- Ongoing medical issues.
- Review **immunisation** status- offered and given.
- Assess for tone abnormalities and motor delays.
- Assess hearing status- Parents can arrange through **Australian Hearing Services**.
- Ensure that ophthalmological assessment is arranged as required.
- Screen for early language milestones and behavioral concerns, self-regulation and socialisation. Discuss with parents assessment options if needed. Self-referral to **Community Speech Pathology** by phoning the Referral and Information Centre on **(02) 49242590**.
- Care coordination to provide family support and help access community service that are required.
- Coordinate care with Early Intervention Services as needed.
- Be alert for family stress.
- Discuss smoking status of carers and if they are smokers, offer the 'Getting ready to quit' NSW Health factsheet which has details of the free quit kit and details to contact Quitline.
- Referrals for other services as needed (Neurology, Respiratory, Audiology, Gastroenterology & Nutrition, Orthopedics, Ophthalmology, Speech & Language, Physiotherapy, Occupational therapy, ENT specialists, Feeding Clinic, Rehabilitation services, Child Mental Health Service).

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- If a diagnosis of Cerebral Palsy is made or high risk of CP identified, a referral letter addressed to local CPA team is made. The physiotherapist involved in the neonatologist clinic will contact the CPA team as an initial referral. A referral to the Cerebral Palsy Movement Disorder Service (CPMD) should also be considered. This service provides a multidisciplinary, client-centred and comprehensive specialist assessment and review service for children and young people with cerebral palsy residing within the Children's Health Northern Network. The core service elements include the CPMD clinic, Cerebral Palsy Hip Surveillance Clinic and Botulinum Toxin Clinic.
- If a referral to the National Disability Insurance Scheme is appropriate, parents can be directed to the NDIS website which has detailed access requirements. Parents should then contact the **National Disability Insurance Agency (1800 800 110)** who confirm eligibility and forward the necessary paperwork by mail. The neonatologist/pediatrician will be required to fill in the medical section and provide additional supporting documentation.

APPENDIX: reference table

GROUP	F/U @ CGA 3, 6,9,12 months	F/U @ CGA 3,6,9,12,18,24 months	Ophthalmology	Audiology	Standardised Developmental Assessment @ CGA 12 and 24-36 months	Prechtl General Movements	WIPPSI
Group 1		√	√	√	√	√	√*
Group 2	√				√**	√**	

* < 27 weeks

** Refer to criteria lists

Prechtl General Movement criteria list

1. Prematurity (less than 30 weeks gestation)
2. Hypoxic Ischaemic Encephalopathy
3. Neurological Event: seizures, stroke, intraventricular haemorrhage grade 3 or 4
4. Post-surgical infants (general anaesthetic)
5. Prematurity (< 34 weeks) with one of the following:
 - Multiple birth with foetal loss of a co-twin
 - Growth restriction (SGA with birth weight < 3rd percentile)
 - Congenital Abnormality
 - Difficult neonatal course- referred for GM by neonatal team

Bayley Developmental Assessments criteria list on

1. Infants < 29 weeks gestation
2. VLBW neonates (<1000g)
3. Significant neurological issues (but not limited to):
 - a. Neonates with periventricular leukomalacia.
 - b. Seizures.
 - c. Meningitis.
 - d. Intraventricular Haemorrhage (grade 3 or 4).

- e. Hypoxic Ischaemic Encephalopathy.
- f. Neonates with strokes.
- g. Neonates with hydrocephalus requiring ventriculo-peritoneal shunts
4. Major surgical abnormalities including (but not limited to):
 - a. Congenital Diaphragmatic Hernia.
 - b. Tracheo-oesophageal fistula and oesophageal atresia.
 - c. Abdominal wall defects (e.g. gastroschisis and exomphalos).
 - d. Congenital cardiac lesions that underwent cardiac surgery (not followed up by Grace Centre for Newborn Care).
5. Infants identified as being developmentally at risk by Neonatologist.
6. Infants enrolled in developmental outcome studies.

Our team is made up of professionals who are experts in taking care of at-risk infants and involved in follow up.

They include:

- Neonatologists/Neonatal Fellows
- Physiotherapist
- Occupational Therapists
- Speech Pathologists
- Liaison Nurse Consultants
- Dietician
- Social Workers

Our Aims are:

- Promote the emotional and physical development of child and family.
- Provide parents with information about early childhood development.
- Increase knowledge of developmental outcomes through research.
- Improve the quality of care in the NICU.
- Share information with community partners.

Staff Preparation

It is mandatory for staff to follow relevant: “Five moments of hand hygiene”, infection control, moving safely/safe manual handling, documentation practices and to use HAIDET for patient/carer communication: Hand hygiene Acknowledge, Introduce, Duration, Explanation, Thank you or closing comment.

Implementation, monitoring compliance

1. Approved clinical guideline will be uploaded to the PPG and communication of updated ‘Developmental Follow up of High Risk Neonates’ clinical guideline to NICU staff will be via email and message on the HUB.
2. Incident investigations associated with this Guideline and Procedure will include a review of process.
3. The Guideline and Procedure will be amended in line with the recommendations.
4. The person or leadership team who has approved the Guideline and Procedure is responsible for ensuring timely and effective review of the Guideline and Procedure.
5. Evaluation will include a review of the most current evidence as well as a consideration of the experience of Neonatal staff at JHCH in the implementation of the Guideline and Procedure.

References

1. Hard AL, Hellstrom A. Ophthalmological follow-up at 2 years of age of all children previously screened for retinopathy of prematurity: is it worthwhile? *Acta Ophthalmol Scand.* 2006;84:631-635.
2. Holmstrom G, Larsson E. Long-term follow-up of visual functions in prematurely born children: a prospective population-based study up to 10 years of age. *J AAPOS.* 2008;12:157-162.
3. O’Connor AR, Stephenson T, Johnson A, et al. Long-term ophthalmic outcome of low birth weight children with and without retinopathy of prematurity. *Pediatrics.* 2002;109:12-18.
4. Page JM, Schneeweiss S, Whyte HEA, Harvey P. Ocular sequelae in premature infants. *Pediatrics.* 1993;92:787-790.
5. Tuppurainen K, Herrgard E, Martikainen A, Mantyjarvi M. Ocular findings in prematurely born children at 5 years of age. *Graefes Arch Clin Exp Ophthalmol.* 1993;231:261-266.
6. O’ Connor AR, Wilson CM, Fielder AR. Ophthalmological problems associated with preterm birth. *Eye.* 2007; 21, 1254-1260.
7. Bielecki I, Horbulewicz A, Wolan T. Risk Factors associated with hearing loss in infants: an analysis of 5282 referred neonates. 2011; 75(7) 925 – 30.

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