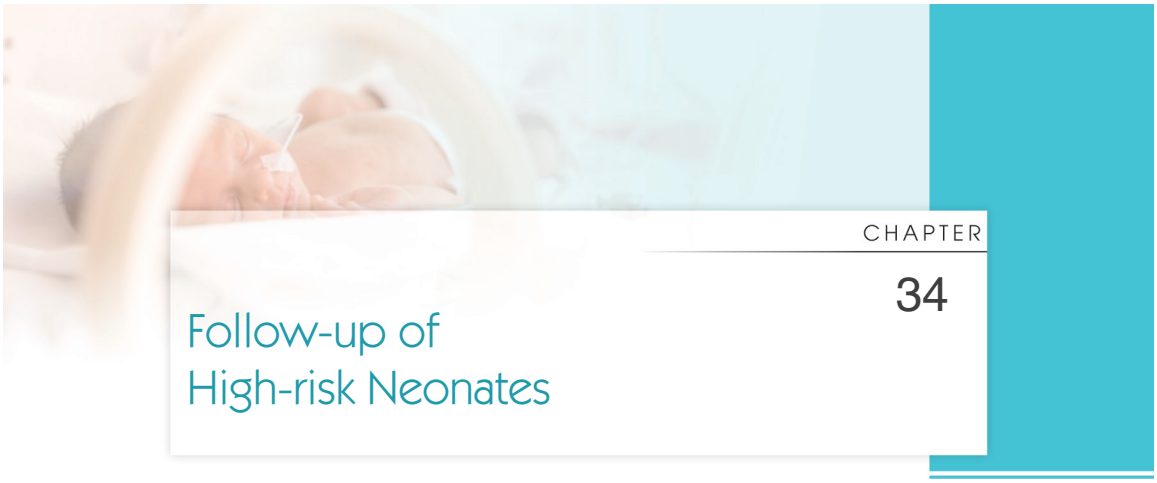

CHAPTER

34

Follow-up of High-risk Neonates

Improving perinatal-neonatal care has led to increased survival of newborns[1] at high risk of post-discharge morbidities, including growth failure, ongoing medical illnesses, neurosensory impairment, and developmental deficits.

What is the evidence?

A recent systematic review[2] has reported a high prevalence of long term neurodevelopmental sequelae after different intrauterine and neonatal insults,: sepsis 40.0%, meningitis 42.0%, HIE 31.0%, preterm birth 31.0%, jaundice 18.0%, tetanus 26.0%, CMV infection 41.0%.

Most common sequelae: Learning difficulties, cognition or developmental delay; cerebral palsy; hearing impairment and visual impairment.[3,4]

An appropriate and comprehensive follow-up program for high-risk infants will help detect and manage any morbidity associated with perinatal events early. It shall ensure intact survival, optimum growth, and optimal quality of life for these infants.

SETTING-UP–FOLLOW-UP CARE SERVICES

High-risk Clinic: Follow-up of high-risk infants should be done in a dedicated high-risk clinic (HRC). A detailed description is provided under "Procedure for follow-up."

High-risk Follow-up Team: High-risk infant follow-up requires a multidisciplinary approach and an experienced and dedicated team, including personnel from various specialties. Ideally, the team should comprise a neonatologist/pediatrician, a clinical psychologist and an early interventionist, a physiotherapist, an occupational therapist, a neurophysiologist and speech therapist, a nutritionist, and a medical social worker. An ophthalmologist and pediatric neurologist should also be a part of the team, available for ready referral.

The neonatologist/pediatrician is the nodal person of the team who provides and coordinates for holistic management of the high-

risk infant and counsels the family. The responsibilities include assessing the child on each visit, including growth and nutrition, managing ongoing morbidities, neurodevelopmental screening, and coordinating care with different specialists involved in managing the infant. Clinical psychologist performs formal developmental evaluation and manages behavioral and other domain-specific problems, while early interventionists work to enhance and facilitate the development of milestones in all domains of action; the physiotherapist is primarily responsible for the assessment and grading of muscle tone and power and plan appropriate training for an infant with tone abnormalities, prescription of appliances/casts and rehabilitation of infants with impairment/disability and the occupational therapist works to promote neuro-motor coordination and perceptual skills, fine motor functions, oro-motor coordination and training in activities of daily living like feeding, bathing, and dressing of children with special needs. Nutritionist can provide detailed complementary feeding advice and serves to manage infants with failure to thrive and those with special conditions (e.g. inborn errors of metabolism). The medical social worker is an essential interface between the follow-up care team and family, who helps to address parental expectations and social and socio-economic issues and coordinates for rehabilitation and integration of infants with impairment/disability. An ophthalmologist is required for treatment and follow-up of ROP and visual assessment and management of refractory errors, strabismus, etc. Neurologist aids in drug therapy and long-term management of neurological illnesses such as refractory seizures. Other specialists from pediatric genetics, pediatric surgery, pediatric cardiology, pediatric gastroenterology, hematology, etc. may be consulted as and when required.

As outlined above, all setups may not have a complete team of specialists. It is, therefore, essential that simple tools be available and the nodal person of the team have working knowledge of all the domains. Ideally, all the services should be provided under one roof as far as possible, and appropriate referrals should be sought as required. The days and timings of the different clinics and the appointment schedule should be marked on the patient's records, and multiple visits should be avoided.

WHO NEEDS FOLLOW-UP CARE?

A rigorous follow-up of all the neonates discharged from a particular health facility would neither be practical nor feasible. Therefore,

selecting a cohort of neonates at a higher risk of developing adverse outcomes is essential—'at-risk' or 'high-risk' infants are critical. Selection of high-risk infants should be based on the gestational age, birth weight, occurrence and severity of perinatal/neonatal illnesses, interventions received in the neonatal intensive care unit (NICU), presence of malformations, etc.

There are no standardized criteria for defining high-risk infants, even in tertiary care centers. Commonly used criteria have been outlined here (Table 34.1). These may be modified depending on the level of neonatal care provided by the unit and the mix of the neonatal population the unit caters to.

PREREQUISITES FOR FOLLOW-UP

Discharge planning. Discharge planning should ideally begin many days before discharge. This gives adequate time to the caretakers to ask questions and practice skills. The following criteria should be fulfilled before discharging a high-risk infant:

- Hemodynamically stable; able to maintain body temperature in an open crib.
- On full enteral feeds (either direct breastfeeding or by paladai/spoon).

Table 34.1: High-risk neonates who need follow-up care in a tertiarly care setting

1. Birth weight <1500 grams.
2. Gestation <32 weeks.
3. Infants with BW of 1500 g or more OR gestation 32 week or more AND a. Intrauterine growth <3rd centile. b. Meningitis. c. Received mechanical ventilation for 48 hours or more. d. Hypoxic ischemic encephalopathy stage 2 or higher. e. Major malformations. f. Inborn error of metabolism/chromosomal or genetic disorders/intrauterine infections. g. Symptomatic hypoglycemia. h. Symptomatic polycythemia. i. Retrovirus positive mother. j. Hyperbilirubinemia requiring exchange transfusion OR Rh isoimmunization/cholestasis. k. Abnormal neurological examination at discharge/seizures. l. Major morbidities such as chronic lung disease, IVH grade III or more (Papile's classification), and periventricular leucomalacia.

- Parents are confident enough to take care of the infant at home.
- Has crossed birth weight and showing a stable weight gain for at least three consecutive days; in case of very low birth weight infants, weight should be at least 1600 g before considering discharge.
- Not on any medications (except for vitamins and iron supplementation). Ideally, preterm infants on theophylline/caffeine therapy for apnea of prematurity should be off treatment for at least 5 days to ensure no recurrence.
- Received vaccination as per schedule (based on postnatal age).

These criteria can be individualized to meet the infant and family's needs.

Counseling before discharge: Counseling is essential in caring for these high-risk infants at home; regular counseling sessions should be done before discharge. Parents should be advised regarding the following:

- Temperature regulation—proper clothing, cap, socks, kangaroo mother care, etc.
- Feeding—The focus should be on exclusive breastfeeding. If required, other types and amounts of milk, method of administration, and nutritional supplementation, if any, should be advised as per the child's need.
- Prevention of infections—handwashing, avoidance of visitors, etc.
- Follow-up visits—where and when (refer to Table 34.2).
- Danger signs—recognition and where to report if symptoms are present.
- Vaccination—schedule, next visit, etc.
- Special needs—e.g. subsequent visits for ROP screening, USG/MRI brain, etc.

If possible, the family should be provided with the telephone number of the nursery/health care provider, e.g. the on-duty doctor, in case the family needs to consult for the infant's illness in an emergency or otherwise.

PROCEDURE FOR FOLLOW-UP

The family must be provided with a structured discharge summary, including the details of important events during the hospital stay, investigations and treatment received, and the schedule of follow-up visits. The venue and follow-up dates should be indicated on the discharge summary.

High-risk Clinic: A specified site should be earmarked for follow-up services. The venue, days, and timings of the clinic should be fixed. Prior appointments should be given, and ad-hoc visits should be discouraged. Registration procedures at the clinic should be simplified to avoid any undue delays.

Venue: Dedicated room(s) in the OPD premises should be designated for high-risk follow-up.

Days and Timing: One or more fixed days and times of the week should be allocated for the clinic.

Registration: The high-risk infant should be registered at the clinic on the first visit following hospital discharge. An OPD card for the same should be made.

Record Maintenance: A separate file for each high-risk infant should be made on the day of infant registration in the HRC. The HRC case file should have a uniform format and include the following information for each infant:

- Demographic and contact details of infants' family.
- Detailed diagnosis at discharge.
- Details of any intermittent morbidities/any critical investigations, e.g. cranial USG/MRI brain.
- Reports of hearing and vision (ROP) screening, as applicable.
- Nutritional details.
- Anthropometry (weight, head circumference, and length).
- Developmental screening chart.
- Neurological assessment proforma.
- Immunization details.
- Doctor's evaluation and note.

A copy of the discharge summary should be maintained in all these files for a ready referral. Essential details and advice should also be noted in the OPD card.

WHEN TO FOLLOW-UP

The follow-up schedule should be explained to the parents at discharge and should also be mentioned in the discharge summary (*see* below).

For follow-up visits, at-risk infants can be grouped under two major categories:

Table 34.2: Follow-up schedule for at-risk infants

Very preterm infants (<32 weeks or <1500 g)

- After 3–7 days of discharge to check if the infant has adjusted well in the home environment.
- Every 2 weeks until a body weight of 3 kg (6, 10 and 14 week immunization visits to be covered during these visits).
- At 3, 6, 9,12, 15 and 18 months of corrected age and then every 6 months until 8 years of age.
- More visits if required.

Infants with other conditions

- Two weeks after discharge
- At 6, 10, 14 weeks of age
- At 6, 9, 12, 15 and 18 months of corrected/postnatal age, as applicable and then every 6 months until 8 years of age
- More visits if required.

- Very preterm or very low birth weight (VLBW; <1500 g) infants and
- Infants with other conditions

The follow-up schedule for both these categories has been summarized in Table 34.2. This schedule represents a minimum number of visits for high-risk neonates. More frequent visits are recommended if the infant has ongoing issues or illness. Note that first contact of the infant with the health providers after discharge is essential and helps identify adjustment problems at home. Ideally, this contact should be achieved by the home visit, preferably within the first week of discharge.

Very low birth weight infants or those born at less than 32 weeks gestation (or bigger and sick infants) should be followed up for an eye check-up for retinopathy of prematurity till the postnatal age of 44 weeks (*see* chapter 35: ROP protocol).

Some neurological abnormalities identified in the first year of life are transient or improve, whereas findings in other children may worsen over time.[5] Standard follow-up for many multicenter networks is currently at 18–24 months corrected age. By 12 months, corrected age, the cognitive and language assessment can be done. By 18–24 months of corrected age, there is an improved prediction of early school-age performance.[6–8] Long-term follow-up is essential because minor neurological disabilities may not be detected early and become apparent only with increasing age.

Practice tip!

Corrected age: Age of the child since the expected date of delivery. The correction for gestational immaturity at birth should be done until 24 months age. All anthropometric parameters and developmental milestones are assessed according to corrected age to compensate for the prematurity. The initiation of complementary feeds is also according to corrected age.

Postnatal age: Age of the child since birth. Immunization is done according to postnatal age.

WHAT SHOULD BE DONE AT FOLLOW-UP?

Table 34.3 summarizes the follow-up plan.

1. **Assessment of feeding and dietary counseling:** Parents should be asked about the infants' diet and offered dietary counseling at each visit. Breastfeeding frequency and adequacy should be assessed. The amount, dilution, and feeding mode should be noted if supplemental feeding is given. It is a good idea to enquire about the source of milk as milk supplied by local vendors is often diluted (dilution has the same impact on the infant whether done by the family or the vendor!). It is also essential to record the duration of exclusive breastfeeding. If an infant is not gaining adequate weight on exclusive breastfeeding, take care of any illness or maternal problems which may interfere with feeding and milk output. Supplementation may be considered if poor weight gain persists despite all measures to improve breast milk output.

   We start complementary feeding at six months of corrected age. Initially, semisolids should be advised as per the local cultural practices. Spend adequate time explaining what and how to give. Giving too little or dilute complementary food, such as rice-water, dal-water, too much juice, etc. should be discouraged (Table 34.4).[9]

   Complementary foods (CF) should include a variety and adequate quantities of food groups (meat, poultry, fish, or eggs, as well as vitamin A-rich fruits and vegetables) daily. If not possible, use fortified foods and vitamin-mineral supplements to ensure adequate nutrient intake. As infants age, complementary foods should change from semisolid to solid, and the variety of foods should also increase. By eight months, infants should eat 'finger foods.' By 12 months of age, most children eat family food.

   Micronutrient supplementation: The LBW Feeding protocol may be referred to for the same.

Table 34.3: Follow-up plan for high-risk infants

Assessment	*Age in months*								
	1	2	3	6	9	12	15	18	24……..8 years
Assessment of feeding and dietary counseling	All visits								
Growth monitoring	All visits								
Immunization	As per schedule (based on postnatal age)								
Ongoing morbidities	All visits and as and when required								
Neurological examination			*	*	*	*	–	*	*
Developmental screening	All visits								
Formal developmental assessment			*	¶	¶	*	–	*	*
Hearing (BERA)			*	¶	¶	¶	–	¶	¶
Ophthalmic evaluation	ROP screening				*	¶	–	¶	¶
USG/MRI brain	As indicated								
¶ *If the previous test abnormal*									

Table 34.4: Amount and frequency of complementary foods		
Age	*Foods*	*Frequency*
6–8 months	Thick, soft porridge (khichri/dalia); add sugar and oil mixed with either milk or pounded ground nuts. Mixtures of mashed foods made of potatoes or millet or rice; mix with fish or beans or pounded groundnuts; add green vegetables	Breastfeeding plus 2–3 meals per day
9–11 months	–Do– Give nutritious snacks between meals, like eggs, bananas, or bread	Breastfeeding plus 3–4 meals/day plus one snack between meals
12–24 months	–Do– Family foods, chopped or mashed if necessary	3–4 meals/day plus two snacks between meals

2. **Growth monitoring:** Growth (including weight, head circumference, and length) should be monitored and plotted on an appropriate growth chart at each visit. The infant's growth pattern (slope of the curve) is compared with the standard curve; any deviation should be noted and appropriate remedial action taken. We use Fenton's charts (till 50 weeks postmenstrual age; PMA)[10] and WHO growth charts after that for growth monitoring of preterm neonates.[11]

   Anthropometry should be taken during follow-up visits. Weight and head circumference should be monitored at each visit and length three monthly. These should be marked on the gender-specific WHO-MGRS growth charts. The **Corrected age** of the child should be used while using these charts for preterm infants.

3. **Immunization:** Parents should be offered the option of additional vaccines such as hepatitis B, *Hemophilus influenz*a B, and MMR (where not in the routine immunization schedule) if they can afford them. Immunization should be ensured according to chronological age.

4. **Ongoing morbidity surveillance and management:** Ongoing morbidity and its management is one of the essential services a follow-up clinic is meant to provide. These may relate to prolonged jaundice, recurrent exacerbations of respiratory distress in a child with chronic lung disease, gastroesophageal reflux or other feeding difficulties or inadequate weight gain in

a preterm infant, anemia in an infant with Rh immunization, cardiac failure in an infant with congenital heart disease, diagnostic evaluation and intermittent illnesses in an infant born to HIV positive mother, etc. The details of any such intermittent morbidity/hospitalization should be systematically recorded in the high-risk file as well as the OPD card of the infant.

5. **Developmental follow-up:**[12] Early identification of infants who are at risk of developmental disability allows for appropriate parent counseling and for planning for the child's future. This counseling and planning should consider the uncertainty of standardized developmental screening tests that should be performed at 3, 6, 9, 18, and 24 months of corrected age. Regular screening is more helpful than a single screening to identify problems, especially in later-developing skills such as language. Screening does not help in making a diagnosis or designing a treatment plan but helps identify areas where a child's development differs from same-age norms.

   Early identification of developmental problems should lead to further developmental and medical evaluation, diagnosis, and treatment, including early developmental intervention. A pediatrician/neonatologist must be well-versed in the normal developmental milestones and be able to use the available screening tools effectively so that a formal developmental evaluation is required only for the most deserving cases.

   We currently use Trivandrum Developmental Screening Chart (TDSC) in our clinic. DDST-II is also used in some places, though it requires some training before it may be used. Table 34.5 lists the commonly available and used screening tests in India.

Practice tip!

Waiting until a child misses a major milestone such as walking or talking may delay the recognition of a problem that deprives the child benefits of early intervention.

Additional tools like VSMS, CBCL, and M-CHAT may be used beyond infancy (beginning at 18 months of age) for social, emotional, behavioral, and autism evaluation, respectively (Table 34.6).

A formal developmental assessment is done using DASII, which is the Indian adaptation of BSID-II and is considered to be the gold standard to date in Indian settings. It measures motor and mental domains using 230 items in children between 0–30 months

Table 34.5: Developmental screening tests commonly available in India

Test	*Domains assessed*	*Age range*	*No. of items*	*Psychometric properties*
Trivandrum Development Screening Test (TDSC)[13]	Gross motor, Fine motor, Vision/hearing, and personal/ social/language	0–2 years	17	Sensitivity 66.7%; Specificity 78.8%; validated against DDST
Denver Developmental Screening Test-II (DDST-II) or/ Denver-II	Gross motor, Language, Fine motor—adaptive, and personal-social. Also, a behavior rating scale	0–6 years	123	Sensitivity 83%; Specificity 43%[14]
Baroda Development Screening Test (BDST)[15]	Motor and mental	0–30 months	54	Sensitivity and specificity of 65–95%

Table 34.6: Other tools relevant to developmental evaluation early in life

Test	*Brief description*	*Age*
Screening tools		
Modified checklist of autism for toddlers (M-CHAT)	To identify children who may benefit from a more thorough developmental and autism evaluation	16–30 months
Vineland social maturity scale (VSMS)	Indian adaptation by Malins is available Assesses personal and social skills in the following areas: Self- help general, self-help eating, self-help dressing, self-direction, occupation, communication, locomotion, and socialization	0–15 years
Vineland adaptive behavior scale-II	It is a revision of the Vineland social maturity scale (VSMS) Assesses personal and social adaptive behavior skills in five domains- communication, daily living skills, socialization, motor skills, and maladaptive behavior (optional)	Birth–90 years

(*Contd.*)

Table 34.6: Other tools relevant to developmental evaluation early in life (*Contd.*)		
Test	*Brief description*	*Age*
Screening tools		
Child Behavior Checklist-Language development survey (CBCL-LDS $1^1/_2$)	Assesses different domains of behavior like emotionally reactive, anxious depressed, somatic complaints, withdrawn, sleep problems, attention problems, and aggressive behavior, along with language	1.6–5 years

of age. However, such tools are considered ideal to be periodically revalidated to account for secular trends. Also, since the arrival of BSID-III, which helps assess neurodevelopment in different domains (Cognitive, Language-receptive and expressive, fine and gross motor, socio-emotional, and adaptive behavior) till 42 months of age, it should be adapted and validated for use in India. Additional diagnostic tools for autism, intelligence, and specific learning disabilities may also be required as the child grows up (Table 34.7).

Table 34.7: Few diagnostic tools relevant to high-risk infants		
Test	*Brief description*	*Age*
Development Assessment Scale for Indian Infants (DASII)	• An Indian adaptation of Bayley-II, standardized on the Indian population. • Assesses two domains—Motor and mental. • Gives the developmental age of a child expressed as the percentile of normal. • Provides developmental quotients comparing the developmental and corrected age of the child.	Birth–30 months
Childhood Autism Rating Scale (CARS)	• Behavior rating scale. • Assessment on fifteen items—relationship to people, imitation, emotional response, use of body and object, adapt to change, visual and listening response, response to taste-smell-touch, presence of fear and nervousness, verbal and non-verbal communication, activity level, intellectual response, and general impression.	3–22 years

(*Contd.*)

Table 34.7: Few diagnostic tools relevant to high-risk infants (*Contd.*)

Test	*Brief description*	*Age*
Wechsler Preschool and Primary Scale of Intelligence-Third Edition (WPPSI-III)	• Test of Intelligence for younger children. • Provides verbal IQ, performance IQ, and full-scale IQ. • Comprises 14 subsets of three types: core, supplemental, or optional, which are - receptive vocabulary, block design, information, object assembly, picture naming, similarities, symbol search, vocabulary, word reasoning, coding, comprehension, picture completion, matrix reasoning, and picture concepts. • Children in the two years 6 months – 3 years 11 months age band are administered only the initial five subtests.	Divided into two age bands: 2 years 6 months to 3 years 11 months and 4–7 years 3 months
Malins Intelligence Scale for Indian Children (MISIC)	• An Indian adaptation of Wechsler's Intelligence Scale for Children. • Gives verbal and performance IQ. • Assess the following items: – *Verbal IQ*-Information, comprehension, arithmetic, similarities, vocabulary, digit span. – *Performance IQ*-Picture completion, picture arrangement, block design, object assembly, coding, and mazes. • Based on test scores, the intelligence grades are provided as extremely Low, borderline, low average, average, high average, superior and very superior.	6–15 years 11 months
NIMHANS Battery for specific learning disabilities	• The battery of tests for evaluating children suspected of having learning disabilities (dyslexia, dysgraphia, dyscalculia). • Consists of 2 levels for assessment of pre-academic skills for 5–7 years (includes evaluation of attention, auditory and visual discrimination, visual and auditory memory, speech and language, visual-motor, and writing and number skills) and academic skills at level 2 for age 8–12 years (which include attention, reading, spelling, perceptual-motor, visual-motor integration, memory, and arithmetic skills).	Two age bands: 5–7 years and 8–12 years

Also, if feasible, an objective assessment of the home environment shall be a good adjunct to any developmental evaluation of such children.

6. **Neurologic examination:** The main focus of neurological assessment during the high-risk follow-up visits is usually the evaluation of muscle tone besides vision and hearing. However, a complete neurological examination should be performed if indicated in a particular child. Amiel Tison's neurological assessment is currently the most widely used neurological examination tool during early follow-up of infants.

Evaluation of muscle tone is an integral part of the neurological examination. A waxing and waning pattern of neuromotor development from 28 weeks of gestation to the end of the first year of life was reported by Amiel-Tison. From 28 to 40 weeks gestation, muscle tone and motor function acquisition spread from the lower extremities towards the head (caudo-cephalic progression). After full term, the process is reversed so that relaxation and motor control proceed downwards for the next 12–18 months (cephalocaudal). So, the upper limbs begin to relax and acquire skills before the lower limbs. The axial tone follows a similar pattern. Head control appears first, followed by the ability to sit, stand and walk. Hypertonia or hypotonia should be examined by measuring the following angles: adductor angle, popliteal angle, ankle dorsiflexion, and scarf sign; any asymmetry between the extremities should also be recorded. Any history of seizures or involuntary movements should also be recorded.

The following angles should be measured to assess tone, as shown in Table 34.8:

The Hammersmith Neonatal Neurological Examination (HNNE) is a practical and easy-to-perform neonatal neurological examination that has 34 items assessing tone, motor patterns, observation of spontaneous movements, reflexes, visual and auditory attention, and behavior.[16] Each of the 34 items is

Table 34.8: Muscle tone norms (Amiel-Tison)

Age (mo)	*Adductor angle*	*Popliteal angle*	*Dorsiflexion angle*	*Scarf sign*
0–3	40–80°	80–100°	60–70°	The elbow does not cross the midline
4–6	70–110°	90–120°	60–70°	Elbow crosses midline
7–9	110–140°	110–160°	60–70°	The elbow goes beyond the axillary line
10–12	140–160°	150–170°	60–70°	–

assigned a score ("raw score"). Each row for a particular item is scored as 1,2,3,4,5 and if an item falls between two columns, it is given ½ score, e.g. 3.5. Individual optimality score is assigned for each item based on the raw score and the total optimality score is calculated by adding individual optimality score. The maximum possible score is 34. The presence of a suboptimal score does not mean that a neonate is abnormal. It just means that the neonate needs to be reassessed. The number of items falling outside the 90th centile is a better predictor of the severity of the outcome than global optimality. Preterm infants at term are more hyperexcitable and have less flexor tone in the limbs and less extensor tone in the neck in the sitting posture. They have a wider range in individual optimality scores than term. They generally have a wide range and lower scores and it may be difficult to define an optimality cutoff.

Cerebral palsy usually presents with definitely abnormal neurological examination with upper motor neuron signs with motor developmental delay. Hypertonia in lower limbs is defined as when either adductor angle is restricted to less than the age-specific norms as per Amiel–Tison or if there is scissoring or tight tendo-Achilles or restriction of ankle dorsiflexion on extension of knee. Hypertonia in upper limbs is defined as when the scarf sign does not cross the midline at one year corrected age. Hypertonia of the neck extensors can be inferred by an increased gap between the nape of the neck and examination table with the infant lying in the supine position. Truncal extensor hypertonia is present when the body tends to go into hyperextension or opisthotonus. Any tone abnormality requires a detailed evaluation and management by a trained physiotherapist.

The level of function in cerebral palsy should be categorized according to the Gross Motor Functional Classification System (GMFCS). Notably, even in children without cerebral palsy, the prevalence of motor impairment is 19% for moderate impairment and 40% for mild-moderate impairment.[17] With advances in neonatal intensive care, a new era of this no-CP "high-risk neonates" may be emerging. To identify these issues the first formal assessment is done at 3 months corrected age. As a single assessment is not sufficient, longitudinal follow-up is required up to at least two years.

During follow-up, at the end of 12 months, three major patterns can be identified:

a. Normal at all examinations,
b. Tone abnormalities and developmental delay suggests a definite brain injury, or
c. Abnormal development at 3, 6 months age and improving at 9 months and normal at 12 months age.

This third pattern of transient tone abnormalities has been described in preterm infants as neurological abnormalities which present early and disappear by 1 year of age. These infants have similar IQ compared to normal children but have significantly poor scores in cognitive function and are more likely to present as learning difficulties as they grow older.

7. **Hearing evaluation:** High-risk infants have a higher incidence of moderate to profound hearing loss (2.5–5% vs. 1% in normal infants). Since clinical screening is often unreliable, brainstem auditory evoked responses (BAER/BERA) should be performed on these infants before three months of postnatal age.

We do a screening BERA (*A*utomated *A*uditory *B*rainstem *R*esponse-AABR) initially in all cases before discharge.[18] Those who fail on the first screen are re-screened before discharge to minimize the false positivity rates.[19] Those failing on the second screen are referred for a diagnostic BERA in the Department of ENT.

- OAEs may be used at both steps in infants without risk factors, but for infants with risk factors, it is imperative to use an AABR for the initial screen so that neural hearing loss will not be missed.
- For premature infants (born at <34 weeks of gestation), hearing screening should ideally be done after they reach 34 weeks postmenstrual age as it has been shown to decrease false positive results.
- For readmissions in the first month of life for all infants at high risk (e.g. hyperbilirubinemia requiring exchange transfusion or meningitis), a repeat hearing screening is recommended before discharge.
- Any infant missing the initial screen should be instructed to return for a screen after six weeks, which may coincide with the immunization visit (to minimize fallouts).

However, even after a two-stage screening with an OAE pass followed by an AABR pass, permanent hearing loss has been significant.[20] Therefore, it is essential to continue hearing follow-ups.[21]

8. **Vision assessment:** Besides the check-up for retinopathy of prematurity which should start in the NICU and continue till 40–44 weeks postconceptional age or till the retinal vessels have matured (*refer to* Chapter 35: Retinopathy of Prematurity), the children should have an assessment for eye problems in the newborn period and then at all subsequent routine health supervision visits. The eye evaluation during follow-up should include the following:[22]

   Ocular history: Parents' observations are valuable and should be sought. Ask questions such as:

   a. Is the child able to see well?
   b. If the child holds objects close to her eyes while focusing?
   c. Do they find the child's eyes straight?
   d. Do the eyes seem to cross or seem hazy?
   e. Do eyes appear unusual?

   Vision assessment: The vision is evaluated by assessing the capability to fix and follow among children younger than three years or those not verbal yet. One should determine if an eye can fix and maintain it on an object and then be able to follow the object in different positions. If a child fails to do so, it indicates a significant visual impairment. The assessment should be performed with both eyes together and each eye separately. If there is a poor fixation and following binocularly after the age of 3 months, one should suspect a significant bilateral eye or brain abnormality. In such cases, a formal assessment is required. These examinations should only be done if the child is awake and alert, as disinterest or lack of cooperation may mimic a poor vision response.

   In addition, an external evaluation of the different eye structures, including lids, conjunctiva, sclera, cornea, and iris, should be performed, and ocular alignment should be checked. Strabismus can occur at any age, indicating serious orbital, intraocular, or intracranial disease. Examine pupils and red reflex to detect opacities in the visual axis, such as cataracts, corneal abnormality, or abnormalities in the posterior side of the eye, including retinal detachment. Examination of both eyes together permits the detection of potentially amblyopic conditions like asymmetric refractive errors or strabismus.

   Visual acuity should be formally assessed at nine months of age using the Cardiff or the Teller acuity cards. Rehabilitation

for visual impairment should be early so that the child gets appropriate stimulation. The child should be provided with glasses or corrective surgery as appropriate.

9. **Role of neuroimaging:**[23]

For very preterm neonates: Routine screening cranial ultrasound (CUS) is recommended for preterm neonates below 32 weeks gestation at the postnatal age of 7–14 days and between 36 and 40 weeks PMA. MRI brain detects more abnormalities than CUS; however, the current evidence does not support its routine use for neurodevelopmental prognosis.

Term infants with asphyxia: The conventional (T1, T2) and diffusion weighted (DWI) MRI scans can help in diagnosis (global hypoxia-ischemia, focal infarction), time of insult, and the outcome. The conventional MRI performed during the neonatal period carries a pooled sensitivity of 91% and specificity of 51% to detect abnormal neurological outcomes at ≥1 year.

Timing of scan: The prognostic utility of MRI has been shown from days 3–14. Late MRI (days 8–30) has higher sensitivity than early MRI (days 1 and 7) for prediction of outcome at age one year.

Term neonates with bilirubin encephalopathy: An MRI should be considered for infants with bilirubin encephalopathy. It should be done in the newborn period once the infant is clinically stable.

Early Enrichment

The evidence concerning the usefulness of early stimulation and intervention for high-risk neonates is limited to preterm and low birth-weight infants, mostly from developed countries.[24]

What is the evidence

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) developed to stimulate preterm infants at levels adapted to the child's degree of neurological maturity shows promising findings, primarily on cognitive and motor development, though the scientific evidence on the effects is limited.[25]

Early intervention programs (beginning in NICU and post hospital discharge) suggest positive influence on cognitive and motor development.[24, 25]

Early intervention programs from birth to nine years for children with physical disabilities result in positive outcomes for both children and families.[26]

A few measures that may help have been outlined below. These include tactile, kinesthetic, auditory, and visual components:

Birth–2 months	Place your infant's head and neck on the crook of your elbow and forearm while lifting or carrying her.
2–4 months	Help your infant to roll by placing her on either side and calling her name or making a sound with the rattle from behind encouraging her to turn.
4–6 months	Play different types of music for her to listen. Make her sit in front of the mirror and imitate the sounds that she makes. Roll a medium size ball gently in front of her for her to follow. Give her small light rattles to hold in each hand. Encourage her to sit by herself leaning on her arms and taking their support. Start an activity that she enjoys and then stop to see if she moves her body in the same manner to indicate her desire to continue the play.
6–8 months	Give her a spoon to bang on a steel plate, a small drum to bang her hand on, a rattle to shake, and paper to crumble and tear (please be there when she is playing with paper). Cover your face with a plain cloth, slowly remove it and say jha or thuki, and hug her. Repeat the activities a couple of times on yourself and then take her hand to pull off the cloth. Once she is familiar with the game cover her face and you pull off the cloth, clap, and show excitement. Call the child by one name only and encourage her to respond by smiling at her if she looks. Make her sit independently for 5–10 mins by putting her brightly colored and musical toys in front of her. If she loses balance, after some time help her to sit again by holding her by the hips lightly. Encourage crawling when she is on her tummy by placing her favorite toy in front of her just a little out of her reach so that she has to stretch her hands and push herself forward. Repeat the sounds of da da, ma ma, ga ga, ba ba that she makes. Pretend you understand them and answer back in your mother tongue with different intonations. Keep talking to her and naming all the family members who come to her, hold or play with her.

(*Contd.*)

(*Contd.*)

8–10 months	Put two blocks in each hand and encourage her to bang them together while looking at them. Encourage her to clap her hands. Hold her hand and help her to take out toys one by one from a tub filled with toys. Once she has learned to take out the toys, hold her hand and encourage her to drop the toys back into the tub one by one. When a family member leaves, ask her to wave bye bye. Take her in your lap and show her picture books with single, large, colorful pictures of everyday objects and animals. You name and point at the pictures.
10–12 months	Show her the functions of objects used in daily life, like glass for drinking, mobile for talking, comb for the hair. Encourage her to hold furniture and take some steps around it.
12–15 months	Take her hand and help her to point to a toy or any food item she wants. You say the name of the toy and encourage her to take out a sound resembling the name. Hold her lightly from the back and give her the confidence to take a few steps on her own.

HOW TO ENSURE A GOOD FOLLOW-UP RATE

A good follow-up rate may be ensured through the following:

The importance of follow-up should be routinely emphasized to the parents during the hospital stay. Elder members of the family, especially grandmothers should be involved in the process.

The permanent and present addresses of the families should be maintained, along with phone numbers. It shall be ideal if a person of follow-up team like the medical social worker can make an early visit to the infant's home, either at discharge or within 48–72 hours of discharge.

1. It is highly desirable that a permanent 24 × 7 helpline no. be provided to the family at discharge to contact in case of any problem. Regular contact with the parents with inquiry about the status of the child during follow-up shall be helpful.
2. An easily accessible, less time consuming, and hassle-free organizational flow of follow-up services, including the provision of comprehensive assessments under one roof shall encourage parents to come for regular follow-ups.

3. A person who serves as care coordinator and handles all appointments and services shall add to the quality of care experience of the families coming for follow-up.

Practice tip!

The most important determinant of if the family would come for follow-up is the availability of comprehensive and reliable clinical services that family can access easily in a dignified manner.

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