

DEVELOPMENTAL FOLLOW-UP OF CHILDREN BORN PRETERM

Based on NICE guideline NG72 Developmental follow-up of children and young people born preterm

INDICATIONS

- Gestation <30 weeks
- Grade 3 or 4 IVH, cystic PVL or other brain lesion likely to be associated with developmental disorders
- Grade 2 or 3 HIE
- Neonatal bacterial meningitis
- Neonatal herpes simplex infection
- Any other locally agreed criteria

IDENTIFICATION OF ELIGIBLE BABIES

- Responsibility of everyone admitting babies to use the correct coding to facilitate appropriate follow-up pathway
- Initial unit of booking is responsible for performing assessment
- NNU discharging baby to document unit responsible for follow-up in **BadgerNet** discharge summary
- NNU to use **BadgerNet** to confirm which babies are their responsibility for assessment.
 - if baby listed incorrectly contact follow-up lead in appropriate unit to ensure baby is seen by appropriate neonatal/community service

ASSESSMENTS

Timings

- Minimum of 2 face-to-face meetings that focus on development at corrected age of 3–5 months **and** by 12 months
- Detailed face-to-face assessment at aged 2 yr (corrected age) see below

Checks at each developmental visit

- Discuss any parental concerns regarding development
- Measure length, weight and head circumference
- Multidisciplinary review (see below) to check for signs and symptoms of developmental problems e.g.
 - cerebral palsy
 - global developmental delay and learning disability
 - autism spectrum disorder
 - visual impairment
 - hearing impairment
 - feeding problems
 - sleep problems, including sleep apnoea
 - speech, language and communication problems
 - motor problems
 - problems with inattention, impulsivity or hyperactivity
 - emotional and behavioural problems
 - executive function problems
 - potential special educational needs
- Possible early signs of cerebral palsy include:
 - delayed motor milestones, e.g. late sitting, crawling or walking
 - unusual (abnormal or absent) fidgety movements or other abnormalities of movement including asymmetry or paucity of movement
 - abnormalities of tone including hypo- or hypertonia
 - persisting feeding difficulties
- If problem suspected, refer child as per local pathway

- ensure child continues to be seen within developmental follow-up pathway

Assessment at 2 yr (corrected age)

- As a minimum, NICE advises all aspects listed above plus:
- use Parent Report of Children's Abilities – Revised (PARCA-R) to identify if child is at risk of global developmental delay, learning disability or language problem
- use Gross Motor Function Classification System (GMFCS) if cerebral palsy has been diagnosed
- ensure vision and hearing checks have been carried out in line with national recommendations
- National Neonatal Audit Programme (NNAP) analysis includes whether standardised assessment (Schedule of Growing, Bayley III or Griffiths) has been performed
- If Bayley III/IV assessment is used:
 - send parental questionnaire before assessment and request parents complete and bring to assessment
 - send copy of assessment outcome summary to GP, health visitor and parents. Complete 2 yr follow-up form in **BadgerNet**
- Children born ≥ 28 weeks:
 - if development is normal and no physical health issues, discharge
 - if continuing physical health problems, follow-up with general paediatrician or appropriate specialist
 - if neurodevelopmental problems identified, refer to relevant allied health professionals and community paediatrician

Assessment at 4 yr (uncorrected age)

- Indicated for children born < 28 weeks' gestation
- To include educational/clinical psychologist and paediatrician with expertise in neurodevelopment
- As a minimum, NICE recommends all the checks listed for every visit plus:
 - request parents complete Strengths and Difficulties Questionnaire (SDQ) and Ages and Stages Questionnaire (ASQ) 48-month questionnaire in advance and discuss results at appointment
 - review previous assessments and information from all other relevant sources
 - use standardised test to assess IQ e.g. Wechsler Preschool and Primary Scales of Intelligence (WPPSI)
 - GMFCS score if cerebral palsy diagnosed
 - ensure child has been offered orthoptic vision screening
- Provide a comprehensive summary, including a plan for any necessary intervention and support, in a format accessible to parents

Multidisciplinary team (MDT)

- MDT delivering enhanced developmental support and surveillance for children born preterm to include the following professionals:
 - neonatologist/paediatrician with understanding of neonatal care and child development
 - outreach nurse/nurse with expertise in development of babies born preterm
 - ≥ 1 of:
 - occupational therapist
 - physiotherapist
 - speech and language therapist
- In addition to the above, have access to:
 - paediatric neurologist
 - dietitian

RESOURCES

- Guideline summarised as flowchart – see **Supporting information**
- <https://www.nice.org.uk/guidance/ng72>
- <https://www.nice.org.uk/guidance/qs169>