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
- Gestation ≤31⁺⁶ weeks if any additional concerns (see Follow up of babies discharged from the neonatal unit guideline)
- Gestation >30 weeks and ≥1 of the following:
- 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

IDENTIFICATION OF ELIGIBLE BABIES

- 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 use standard network proforma to contact follow-up lead in appropriate unit (see network website https://www.networks.nhs.uk/nhs-networks/west-midlands-neonatal-operational-delivery/neonatal-guidelines/supporting-links-guidelines-book-2019-2021) to ensure baby is seen by appropriate NNU

ASSESSMENTS

Timings

- Two 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
- Check for signs and symptoms of developmental problems, such as
- cerebral palsy
- global developmental delay and learning disability
- autism spectrum disorder
- visual impairment or 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

The following is not yet available locally but we are in the process of trying to set this up.

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 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. Include copy of network booklet Explanation of assessment scores: Information for parents and carers (available at https://www.networks.nhs.uk/nhs-networks/west-midlands-neonatal-operational-delivery/neonatal-guidelines/supporting-links-guidelines-book-2019-2021) with parents' summary

Complete 2 yr follow-up form in BadgerNet

- Children born <30 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 professionals and community paediatrician

The following is not available locally and unikley to be in the foreseeable future: Assessment at 4 yr (uncorrected age)

- Indicated for children born <28 weeks' gestation
- 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 (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

RESOURCES

• http://pathways.nice.org.uk/pathways/developmental-follow-up-of-children-and-young-people-born-preterm