East of England Neonatal ODN
(Hosted by Cambridge University Hospitals)

Clinical Guideline: Neurodevelopment Follow up

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Guidance specific to the care of neonatal patients.

Used by:

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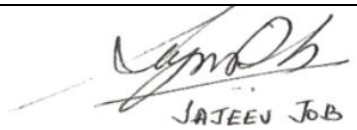
Clinical Lead Sajeev Job	

Ratified by ODN Board:

Date of meeting	

Audit Standards:

- There is an identified lead for follow up service
- All infants less than 30 weeks completing 2-year assessment Target 90% (as part of NNAP data)

- All infants with neonatal encephalopathy requiring therapeutic hypothermia completing 2-year assessment Target 90%
- All infants meeting the enhanced criteria for follow up Target 90% (information taken from Badgernet)

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DEVELOPMENTAL FOLLOW-UP POST NEONATAL DISCHARGE UNTIL 2 YEARS (CORRECTED) AGE

Importance of Developmental Follow-up

- Neurodevelopmental follow up is crucial to be able to continue optimal care and to achieve as close to the expected functioning on an age equivalent child.
- A standardised assessment minimises morbidity by early recognition of developmental issues and implementation of timely intervention.
- It is an important aspect for families for prognostication, understanding and planning for their child's needs.
- Outcome assessment is an important part of neonatal care: it provides basis for quality improvement studies, benchmarking, and monitoring population trends.

Scope of Guideline

The existing provision for developmental follow up following discharge from the neonatal unit varies greatly throughout the East of England (EoE) region. The purpose of this document is to set out a framework to support the delivery of the existing NICE guidelines (NG72, NG62 & CG128)[1-3], BAPM framework for Therapeutic hypothermia[4] , brain injury report commissioned by Department of Health[5 6] and British Association for Neurodevelopmental Developmental Follow up (BANNFU)[7] recommendations combined with a consensus of best practice derived from consultation with clinicians and families within the East of England region to:

- Ensure consistency in the delivery of neonatal developmental follow up across the East of England region.
- Improve collection of follow up data for National Neonatal Audit Programme (NNAP).
- Improve access to early intervention pathways and specialist care services.
- Provide guidance to support development of optimal follow-up pathways within each trust and throughout East of England neonatal ODN.

The guideline covers developmental follow up from the neonatal unit up to 2 years of age (or corrected age for preterm infants). Developmental care and intervention on the neonatal

unit is covered separately Developmental Care Toolkit found on the east of England ODN website.

NICE[1] also recommends follow up of infants born at less than 28 weeks' gestation to 4 years corrected age, this guideline does not include the 4 year assessment.

Introduction

Infants at high risk for perinatal brain injury are at increased risk of developmental disorders. Any insult or adversity during the process of neurodevelopment can lead to developmental difficulties including cognitive, motor, sensory, emotional, and behavioural challenges. The aim of early developmental intervention is to identify any challenges in these areas and provide a targeted early intervention plan to achieve the best possible outcome for every child.

Family Engagement

It is recognised that the engagement and involvement of the parents and carers is crucial because it can improve developmental outcomes for the child (ref NG72). Parents and carers should be empowered and involved in these assessments and decision making.

Prior to discharge from the neonatal unit, parents and carers should be given information about:

- The enhanced support and surveillance programme of their local area, what it is and why it is needed for their child.
- The process for arranging the follow up and a point of contact whom they could ask questions about their follow up or if they have any other concerns. Where possible this should be open access or patient initiated follow up.
- The routine postnatal care and the Healthy Child Programme.

Target Audience

All health professionals in East of England involved in follow up of neonates up to 2 years of age. All members of the neonatal team should be aware of their local follow-up pathway.

Criteria for Developmental Follow-up

In the UK, all infants will be followed through the universal screening and surveillance services delivered by the Healthy Child Programme and developmental concerns are escalated via the child's GP to community paediatric services. Ages and Stages Questionnaire (ASQ-3) at 9 months and 24-27 months of age are used initially and if there are any concerns raised, Strength and Difficulty Questionnaires are completed. The American Academy of Paediatrics (AAP) recommends developmental and behavioural screening at 9, 18 and 30 months of age[8] however this is not routine in the UK.

Enhanced developmental follow up and surveillance is often needed for certain groups of high-risk infants. National Institute of Healthcare and Excellence (NICE) NG72 guideline[1] discusses developmental follow up criteria for preterm infants, however there are other groups at high risk for brain injury who also need follow-up[5, 6]. BANNFU in their statement recommends that every baby discharged from a neonatal unit has the right to a purposeful comprehensive medical and developmental service that addresses their needs, from discharge for as long as they need[7].

Criteria for enhanced developmental surveillance [1-3 5-7]

For a visual flowchart, refer to Pathway for Infants requiring neonatal follow up in Appendix I.

1. Premature infants born less than 30 weeks of gestation
2. Moderate or severe neonatal encephalopathy (including Hypoxic ischaemic encephalopathy, bilirubin encephalopathy, metabolic encephalopathy)
3. Neonate requiring therapeutic hypothermia in the neonatal period
4. Neonate requiring Extra corporeal membrane oxygenation (ECMO)
5. Grade 3 or 4 intraventricular haemorrhage
6. Perinatal stroke
7. Cystic Periventricular leukomalacia (cPVL)
8. Any other brain lesion on neuroimaging likely to be associated with developmental problems or disorder
9. Neonatal meningitis and encephalitis, microbiologically confirmed

10. Developmental problem and disorder identified at a routine paediatrician or therapy appointment *
11. Any infant who does not meet the above criteria but suspected to be at high risk of developmental problems, should be referred for enhanced developmental surveillance. These may include (but not limited to)
    1. <32 weeks gestation, Birth weight <1.5 kg
    2. Neonatal sepsis, culture proven
    3. Congenital CMV
    4. Necrotising enterocolitis needing surgery
    5. Neonatal abstinence syndrome requiring opioid treatment
    6. Received postnatal steroids
    7. Clinical Judgement

* A group of problems that become apparent during child development and often occur together. They are characterised by impairments of personal, social, academic, or occupational functioning, ranging from very specific limitations to global impairments of social skills or cognition, as measured by parent or teacher reports and surveillance tools [1]

East of England ODN recommends: any baby who is born less than 32 weeks gestation and/or less than 1.5kg or fits the brain injury criteria should have an enhanced developmental surveillance.

Timing of Follow-up

All infants requiring enhanced developmental surveillance should be followed up to at least 2 years corrected age. NICE NG72[1] recommends follow-up of infants born at less than 28 weeks' gestation to 4 years corrected age.

All children who are having enhanced developmental surveillance should have at least:

➢ 2 face-to-face follow-up visits in the first year that focus on development, at around 3 and 9 months.

➢ A detailed face-to-face developmental assessment at 2 years (corrected age).

These three assessments are the **minimum** number of appointments that all children enrolled in the enhanced support and surveillance program should receive in the first 2 years of their life (corrected age).

Developmental support provided should be tailored to the family's preferences and needs and can include, telephone or video clinics, text messages and emails along with face-to-face consultation.

Who should follow up high-risk infants?

Each unit should identify a lead for the neurodevelopmental follow up service. They do not need to be the person doing every clinic, but they need to have specialist knowledge in neurodevelopmental follow-up (refer to MDT knowledge and expertise below). They should champion the NICE [1] and EoE follow-up regional guideline and support involvement of the MDT in service delivery. They are the link for communications including any significant local issues [1].

NICE[1] recommends that there should be a multidisciplinary team (MDT) approach and should be provided as an integral part of the neonatal service along with the local health services.
Professionals working in follow-up should have appropriate training: Certified and regular updates in accordance to the assessment tool used. Peer Review is recommended at least every 3 years.

The MDT for enhanced developmental surveillance should consist of the following [1]:

- Neonatologist or Paediatrician with an understanding of neonatal and family integrated care, psychological and physical impact of the neonatal journey on families and child development.
- At least one of the following Allied Health Professionals; Occupational Therapist, Physiotherapist and Speech and Language Therapist with an understanding of neonatal and family integrated care, psychological and physical impact of the neonatal journey on families and child development. AHP composition may vary from

service to service. It should be acknowledged there is some overlap between the professions but that each discipline brings their own specialist set of skills to the assessment. There are AHP staffing recommendations for follow up services available HERE (BAPM Service and Quality Standards 2022).

- Parents and carers.

The MDT delivering the enhanced developmental surveillance assessment should have specialist input and advice from the following:

- Community Nurse or Health Visitor
- Occupational Therapist
- Physiotherapist
- Speech and Language Therapist
- Paediatric Neurologist
- Dietitian

East of England ODN recommends: The 2-year developmental assessment should be a combined MDT assessment with a minimum of a neonatologist/paediatrician and one allied health professional.

Admin support role

Monitoring and arrangements of the follow up pathways require support from a named administrator to ensure smooth running of the MDT clinic.

- Telephone access for parents and carers.
- Appropriate booking of appointments (time sensitive).
- Knowledgeable of neonatal journey and follow up process.
- Ensure patients are aware of the appointment and to remind them prior to appointment.

Monitoring and checks at developmental assessments

Each assessment should include the following:

- Growth monitoring for corrected age (Centiles as per the appropriate growth chart). This should include head circumference, weight, and length/height as appropriate.
- Addressing parental concerns regarding health and developmental milestones.
- Systemic examination and developmental assessment of gross motor, fine motor, language, social skills, hearing and vision, emotional and behavioural problems, potential special educational needs, problems with inattention, impulsivity, or hyperactivity.
- Early intervention, developmental support, and advice (see below).
- Referrals as per local pathway if developmental concerns.
- As good standard and practice for any clinic, an interpreter or a language line should be used as deemed appropriate if the parents' first language is not English.

It is good practice to use General Movement Assessment from term to 3-5 months of age, which is emerging as a strong predictor of neurological integrity and association with cerebral palsy[9]. Identifying cerebral palsy at the earliest opportunity leads to improved outcomes for the child and their families.

At 2 years of age along with the above assessments **as a minimum**

- Parent Report of Children's Abilities – Revised (PARCA-R) should be used to identify if the child is at risk of global developmental delay, learning disability (intellectual disability) or language problems. PARCA- R has been translated in several languages, please check the website, or use an interpreter as deemed appropriate.
- If the PARCA-R is not suitable (for example, because of poor English language comprehension or the child being outside the validated age range of 23.15 to 27.15 months), use a suitable alternative parent questionnaire such as Ages and Stages Questionnaire.
- Gross Motor Function Classification System (GMFCS) score if cerebral palsy has been diagnosed.

- Ensuring that checks of vision and hearing have been carried out in line with national recommendations.

It is good practice to also complete standardised formal validated assessments such as Bayleys Scale of Infant Development or Griffiths Scale of Child Development.

Follow-up and assessment after 2 years (corrected age)

A comprehensive summary of the child's strengths and difficulties, including any developmental problems and disorders, should be provided to parents along with plans for interventions and educational support where needed and findings should be shared with community health professionals.

Parents are directed to appropriate resources (Appendix II) which will help support parents in monitoring the milestones and promoting development for their baby. They should be made aware of any open access appointments / self-initiated appointments available to them for any ongoing concerns.

After the developmental assessment at 2 years (corrected age): A plan will be made by the MDT whether ongoing referrals are required, or routine universal screening is recommended.

Referral to specialist services

There should be clear pathways for referral to ongoing specialist services if there are developmental concerns noted. For example, to Occupational Therapy, Physiotherapy, Speech & Language Therapy, Community Paediatrics, Audiology, Ophthalmology etc.
Note: Assessments up to 2 years of age are corrected for the gestational age while the 4-year assessments should be at chronological age.

Support for parents and health professionals

- Resources for parents available in Appendix II
- Top tips for health professionals of how to ensure appointment is family friendly can be found in Appendix III.
- Links to information regarding developmental assessment tools in appendix IV
- Parent information leaflets - in production.

Audit and quality improvement

- There is an identified lead for follow up service
- Peer review of practitioners and clinic has been completed (See Appendix V for Peer review questions).
- All infants less than 30 weeks completing 2 year assessment Target 90% (as part of NNAP data)
- All infants with neonatal encephalopathy requiring therapeutic hypothermia completing 2 year assessment Target 90%
- All infants meeting the enhanced criteria for follow up Target 90% (information taken from Badgernet)

References

1. National Institute for Health and Care Excellence (NICE). Developmental follow-up of children and young people born preterm NG72, 2017.

2. National Institute for Health and Care Excellence (NICE). Cerebral palsy in under 25s: assessment and management NG62, 2017.

3. National Institute for Health and Care Excellence (NICE). Austism spectrum disorder in under 19: recognition, referral and diagnosis, 2017.

4. British Association of Perinatal Medicine. Therapeutic Hypothermia for Neonatal Encephalopathy- BAPM framework for Practice, 2020.

5. Gale C, Jeyakumaran D, Ougham K, et al. Brain injury occurring during or soon after birth: annual incidence and rates of brain injuries to monitor progress against the national maternity ambition. 2016 and 2017 data: Imperial College London, NDAU, 2019.

6. Gale C, Jawad S, Uthaya S, et al. Brain injury occurring during or soon after birth: a report for the national maternity ambition commissioned by the Department of Health. In: Health Do, ed., 2017.

7. British Association of Neonatal Neurodevelopmental Follow up. [Available from: https://www.bapm.org/pages/146-bapm-special-interest-group-bannfu.]

8. Lipkin PH, Macias MM, Council On Children With Disabilities SOD, et al. Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening. *Pediatrics* 2020;145(1) doi: 10.1542/peds.2019-3449.

9. Kwong AKL, Fitzgerald TL, Doyle LW, et al. Predictive validity of spontaneous early infant movement for later cerebral palsy: a systematic review. *Dev Med Child Neurol* 2018;60(5):480-89. doi: 10.1111/dmcn.13697 .

Appendix I

PATHWAY FOR INFANTS REQUIRING NEONATAL FOLLOW UP

Enhanced

As a minimum

- <30 weeks
- Moderate/severe neonatal encephalopathy**
- Requiring therapeutic hypothermia
- Grade 3/4 Intraventricular haemorrhage
- Cystic periventricular leukomalacia
- Extra corporeal membrane oxygenation
- Perinatal stroke
- Neonatal meningitis, encephalitis confirmed
- Critical Congenital Heart Disease***
- Developmental problem or disorder on routine follow up****

Recommended (plus the minimum)

- <32 weeks, Bwt <1500g
- Neonatal sepsis, culture proven
- Congenital CMV
- Necrotising enterocolitis requiring surgery
- Neonatal abstinence syndrome requiring opioid t/t
- Postnatal steroids
- Clinical judgement*

Signposted to resources at discharge

As a minimum

- Face to face follow up - 3 month
- Face to face follow up – 9 month
- Detailed face to face MDT follow up – 24 months

Recommended (plus the minimum)

- General Movement Assessment at 3 months
- PARCA R and Bayleys Scale of Infant Development at 2 years of age

Tailored

- 30-31+6 weeks if not seen in enhanced group
- 32-33+6 weeks with no additional risk factors
- Mild Neonatal encephalopathy (not cooled)

Signposted to resources at discharge

Follow up in accordance to local protocol

Concerns escalated to community/paediatric services

Universal

All infants >34 weeks with no increased risk of developmental problems or disorders

Healthy Child Programme

Concerns escalated by GP to community/paediatric services

PLEASE NOTE:

* Clinical judgement: Consider providing enhanced developmental support for children who do not have the above risk factors but who are thought, using clinical judgement, to be at risk, taking in to account the presence and extent of risk factors

At all points in the professional pathway consider if referral to community paediatric developmental services is required

** Neonatal encephalopathy : including hypoxic ischaemic, metabolic, bilirubin encephalopathy

***Critical congenital heart disease
defined as any cardiac lesion from which infants die or require surgery or cardiac catheterisation within the first 28 days of life to prevent death or severe end-organ damage. (https://phescreening.blog.gov.uk/2021/07/09/nipe-heart-screening-pathway/)

****A group of problems that become apparent during child development and often occur together. They are characterised by impairments of personal, social, academic, or occupational functioning, ranging from very specific limitations to global impairments of social skills or cognition, as measured by parent or teacher reports and surveillance tools 1.

Terms used:

Enhanced Developmental support - Additional advice and interventions with skilled professionals for children and young people born preterm and their parents and carers. The aim is to support them after discharge from hospital, respond to their concerns, and reduce the impact of any developmental problems and disorders.

Enhanced Developmental surveillance - Active monitoring of a child's development, at set times and using specific tools, to detect developmental problems and disorders

Enhanced Pathway -

Tailored/targeted Pathway -

Universal Pathway - All babies will receive universal services in addition to any tailored/enhanced support or surveillance.

Neurodevelopmental follow up – this refers to the medical and developmental follow up assessments to identify developmental difficulties and provide targeted early intervention and achieve the best possible outcome for every child.

NNAP – National Neonatal Audit Programme - The audit assesses whether babies admitted to neonatal units in England, Scotland and Wales receive consistent high quality care and identify areas for quality improvement.

Appendix II – Suggested resources for Parents

Useful Resources	Link	
EI Smart – EiSMART is an evidence based framework to give high risk babies the best start in life. They span all aspects of a child's development: **S**ensory, **M**otor, **A**ttention and Regulation, and **R**elationships. Professionals and parents work **T**ogether to support premature and sick infants from birth (**E**arly **I**ntervention). The website has free to download resources for parents to promote early development.	https://eismart.co.uk/resources/	There are resources to use on the neonatal unit up until 3 years of age.
Milestone tracking App Pathways – A free tool to help empower parents to understand and encourage their baby's development to keep them on track or catch potentil delays early	https://pathways.org/	Useful from term age
Milestone tracking App CDC "*Learn the Signs. Act Early.*" program aims to improve early identification of developmental delays and disabilities, including autism, by facilitating parent-engaged developmental monitoring and promoting developmental screening so children and their families can get the early services and support they need.	https://www.cdc.gov/ncbddd/actearly/index.html	Useful from term age

Premature Infant Skills in Mathematics (PRISM) – Preterm birth information for education professionals. Useful for parents to give to their child's teacher when they start school Include a QR code link on your 2 year report.	https://www.nottingham.ac.uk/helm/dev/prism/index.html	Sign post to this information at the 2 year appointment.
What to expect from your child's follow up appointment (produced by vcreate in partnership with Neonatal and Paediatric Physiotherapy teams in NHS Scotland) A short animation video to give parents an idea about what to expect at the 2 year follow up appointment.	https://www.youtube.com/watch?v=KT3Ser2A81c	Include link on your appointment letter for the 2 year follow up clinic.
Utube video What to expect from your child's follow-up appointment.		Sign post to this QR code before follow-up appointment
The Smallest Things, is a registered charity promoting the good health of premature babies and their families.	the smallest things charity	Signpost this charity for family support for discharge
East of England Parent Portal	SCAN ME	Signpost this link for more information about the East of England For more resources and if they have an interest in sharing their story

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Appendix III- Support for health professionals

East of England Neonatal Operational Delivery Network

TOP TIPS FOR A SUCCESSFUL FOLLOW UP CLINIC

East of England Baby Brain Protection Group

INFORMATION PRIOR TO APPOINTMENT

To ensure families receive the following information in advance of their follow up appointments:

- What is the aim of the appointment, what it will involve, how long is it & who will be present
- Suggestions of how to prepare your child for it i.e who will be there and what activities they might be doing
- What to bring i.e a drink, a snack, a favourite toy, glasses, hearing aid etc
- Might be useful to bring videos on your phone of child moving, playing, talking etc
- Reassurance that it will be an opportunity to ask questions

ENVIRONMENT/CLINIC SET UP

Host the appointment in a child friendly room–or make it child friendly! Space, daylight and a set up that looks welcoming to a child e.g. appropriate toys, colourful things, mats on the floor. Create a welcoming, informal environment to make child and parent feel comfortable.

DURING THE APPOINTMENT

- Using a Family Integrated approach to the appointment
- Introduce everyone in the room
- Allow time at the end for parents to ask final questions and offer reassurance

2 YEAR FOLLOW UP

- Explain it is a supportive environment to see if the child needs further support and not a "test" they can pass or fail
- Explain it is fine to take a break at any point if the child needs.
- Encourage parents to share any concerns they have and ask questions at any point to allow time for the child to have a short break, snack, drink etc.

ADVICE FOLLOWING APPOINTMENT

- Ensure parents go away knowing where to seek further support by sign posting them to trusted and area specific information-a package of reassurance! Perhaps a QR code but also options for those that don't have the technology to access this
- If families are expecting further appointments or referrals let them know time frames for this and what to do if no referral / follow up letter comes i.e when and who to contact in this instance
- A contact number to ring and discuss with team report/ongoing referrals/diagnosis etc if have any questions after the appointment

Produced in collaboration with EoE PAG January 2024

Appendix IV

Links to webinars for different assessment tools and BANNFU page.
(please note: webinars are only accessible to BAPM members)

BAPM https://www.bapm.org/

BANNFU https://www.bapm.org/pages/146-bapm-special-interest-group-bannfu

Recorded Webinars (only accessible to BABPM members)

Newborn Behavioural Observations

https://www.bapm.org/resources/bannfu-webinar-newborn-behavioural-observations

Overview of PARCA-R
https://www.bapm.org/resources/bannfu-webinar-overview-of-parca-r

General Movement assessment Tool
https://www.bapm.org/resources/bannfu-webinar-general-movement-assessment-tool

Overview of the Bayley 4
https://www.bapm.org/resources/bannfu-webinar-overview-of-the-bayley-4

The INTER-NDA toolkit
https://www.bapm.org/resources/bannfu-webinar-neurological-examination-and-neurodevelopment-assessment-tools

The Griffiths III Developmental Assessment
https://www.bapm.org/resources/bannfu-webinar-griffiths-iii-developmental-assessment

The Evaluation of Preterm Imaging Study
https://www.bapm.org/resources/bannfu-webinar-the-evaluation-of-preterm-imaging-study-eprime

Appendix V Peer Review questions

1. Do you have a named lead for your Local Developmental Follow ups?
2. If yes, who is this person?
3. Do you run your clinics using a multi-professional approach?
4. Which professionals do you include as part of the clinic?
5. What Criteria / assessment pathway do you use for your follow-up clinics?
6. What are your NNAP data scores? (Recommended 90%)
7. If not achieving 90%, what action plan have you put into place to move towards the 90%.

Exceptional Circumstances Form

Form to be completed in the **exceptional** circumstances that the Trust is not able to follow ODN approved guidelines.

Details of person completing the form:	
Title:	Organisation:
First name:	Email contact address:
Surname:	Telephone contact number:
Title of document to be excepted from:	
Rationale why Trust is unable to adhere to the document:	
Signature of speciality Clinical Lead: Date:	Signature of Trust Nursing / Medical Director: Date:
Hard Copy Received by ODN (date and sign):	Date acknowledgement receipt sent out:

Please email form to: kelly.hart5@nhs.net requesting receipt.

Send hard signed copy to: Kelly Hart
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