

## Follow up After Discharge - NICU - Neonatal Full Clinical Guideline - Royal Derby Only

Reference no.: NIC GI 24

### 1. Introduction

To provide a consistent approach to follow up of infants where risk factors for adverse neurodevelopment have been identified during admission in the Neonatal intensive Care Unit (NICU).

### 2. Aim and Purpose

To enable continuity of care, appropriate surveillance and, where necessary, early support for infants and their families following discharge from NICU

### 3. Main body of Guidelines

#### Scope

This guidance is intended for the use of the paediatric team at the Derbyshire Children's Hospital

#### Background

Advances in neonatal care have resulted in improved survival and outcomes not only in infants born prematurely but also in term infants with serious illness. However adverse health and neurodevelopmental outcomes are more frequent in those who have required neonatal intensive care.<sup>[1]</sup> It is important that babies who received specialist neonatal care have 'their health and social care plans coordinated to help ensure a safe and effective transition from hospital to community care'.

This guideline is to help identify those infants who at discharge from NICU have increased risk factors for adverse outcomes and outline an approach to help achieve this transition. It is recognised that individualised plans will need to be developed to meet specific needs as they arise and be responsive to an evolving picture.

#### At risk infants

Infants with higher risk of a worse neurodevelopmental outcome require enhanced follow up and a screening assessment at 2 years corrected gestational age in the neonatal neurodevelopmental follow up clinic. Aim of the enhanced follow up assessment is for early detection of any neurodevelopmental disorders and early intervention by the multidisciplinary team to reduce impact of adverse outcomes. This can be in addition to or instead of the planned 2 year follow up as is felt most

appropriate by the named consultant. All babies seen at 2 years corrected gestational age should have a neurodevelopmental assessment documented on the BadgerNet 2 year follow up form to ensure completeness of our NNAP 2 year follow up data.

Children are eligible for enhanced developmental assessment by the multidisciplinary team at 2 years (corrected gestational age) if they are identified to have additional risk factors.

#### At risk infants:

- Premature (<30 weeks) and/or low birthweight (<1000g)
- Neonatal encephalopathy (moderate or severe including those who have had active cooling)
- Confirmed neonatal meningitis
- Herpes simplex encephalitis
- Abnormal brain lesion on neuroimaging; for example PVL, IVH (grade III-IV)
- Neonatal stroke

Infants who do not fit this criteria but are suspected of being at increased risk at consultant discretion (for example significant resuscitation during neonatal period) may warrant enhanced developmental assessment Please discuss with the enhanced neurodevelopmental assessment team (Victoria Davies or Helen Carter)

At risk babies are identified by the enhanced neurodevelopmental assessment team and there is no need to refer to into this clinic.

For at risk infants that meet the criteria for an enhanced follow up, an invitation will be offered to attend for a multidisciplinary clinic whereby a standardised neurological developmental assessment is performed (Bayleys III/IV) at 2 years corrected gestational age. This comprises a parent questionnaire and a clinical assessment.

Patients that miss this clinic appointment are not routinely offered a repeat clinic appointment into the enhanced neurodevelopmental assessment clinic at present.

#### **Timing of Out Patient Reviews**

During the first 2 years of life, there is benefit for family and patient in receiving continuity from the named neonatal consultant who will lead and coordinate the required care. This will form the basis for ongoing surveillance for the majority of infants. Individualised plans are the responsibility of the named consultant. A suggested schedule using corrected gestational age is as follows:

- 6 weeks
- 6months
- 12 months
- 18 months
- 24 months

Addressing specific medical needs may require more frequent visit schedule.

Families that warrant neonatal follow up should have this explained to them at point of discharge from the neonatal unit. This should be clear in the badger discharge letter given to families prior to discharge. The 'Neonatal Follow-Up (NNFU) and your baby' leaflet<sup>[2]</sup> is a useful resource to give parents explaining the purposes of this follow up. (Appendix 1)

Any parental concerns should be discussed regarding development. It may also be helpful to signpost parents to the EiSMART website<sup>[3]</sup> for useful developmental play leaflets. This excellent resource is available for different developmental ages and in different languages.

The following may prompt a referral to Community Paediatric team at Ronnie MacKeith centre:

- inability to sit independently by age 9 months (CGA), or
- hand function asymmetry before 18 months(CGA), or
- inability to take weight through the plantar surface (heel and forefoot) of the feet by 9 months (CGA)
- if there are any significant concerns regarding development for corrected gestational age

There will also be infants where follow up is required that need early specific support or MDT input. Examples include:

- Chromosomal abnormalities
- Congenital infections
- Syndromes
- Specific neurological conditions

### **Multidisciplinary Team (MDT)**

Where specific MDT is already in place at discharge from NICU or is required in early infancy e.g. by 6 months CGA, referrals can be made to the Ronnie MacKeith centre. Please discuss with Dr Griffin, particularly when there are indicators of abnormal tone that may require specific early intervention. Ensure that physiotherapy support is in place and/or follow up arrangements have been made. Please discuss with NICU physiotherapist or the team based in Ronnie MacKeith Centre.

### **Transition**

At 2 years CGA the health status and ongoing health needs can often, but not always, be defined. This should be recorded in the Badger system or on a paper record (see appendix 2)

Many infants can be discharged to primary care team at this point. Please send details of health status and relevant clinic letter to the Health Visitor and copy to the Community Paediatrician.

Some infants will have a specific diagnosis or diagnoses that, although no longer needing hospital based care, will require ongoing support and coordination of services in the community e.g. community physiotherapy, educational support. This should be communicated with the Community Paediatric team and details of the neonatal course and anticipated needs made clear. This may include for example support for CP and coordination of therapy service or emerging concerns in learning domains that require formal developmental assessment, a specific communication or developmental disorder.

There may be health needs that require ongoing hospital care. Where a shared care approach is needed this should be communicated with the Community paediatric services. This may be best be arranged through the Ronnie Mackeith centre for the preschool children and a referral will be considered and allocated appropriately.

### **Infants NOT in the above 'risk' Group.**

For infants outside the group identified at 'risk', many will not require hospital based follow up after discharge. Their routine surveillance and check ups can be with the GP or Health Visitor. Often the admission has been for special care only and/or short (typically <48hrs) with discharge to the Post Natal Ward prior to going home. Typical examples (but not an exhaustive list) include:

- mild RDS/TTN that did not require respiratory support other than supplemental oxygen
- the 'cold baby' who required simple thermal care
- asymptomatic hypoglycaemia with normal glucose requirements
- feeding difficulty that resolved quickly.

Infants who do not meet the criteria for follow up to 2 years of age may require outpatient follow up but need a shorter period of surveillance. Examples include the term or near term with moderate RDS or required non-invasive support or IPPV. Follow up in the 'Registrar' clinic should be considered.

Please check with a senior or the named consultant if unsure whether hospital follow up is indicated.

## **4. References**

[1] Developmental follow-up of children and young people born preterm NICE guideline August

[2] [www.eismart.co.uk](http://www.eismart.co.uk)

## 5. Documentation Controls

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# BANNFU

British Association for Neonatal  
Neurodevelopmental Follow-Up

## 6. Appendices

### Appendix 1 – Neonatal follow up parental leaflet

#### Neonatal Follow-Up (NNFU) and your baby



[www.bapm.org/bannfu](http://www.bapm.org/bannfu)



# BANNFU

British Association for Neonatal  
Neurodevelopmental Follow-Up

## What is Neonatal Follow-Up (NNFU)?

Your baby is a patient on a Neonatal Unit (NNU), so they must have been unwell. We understand this will have been a very difficult time for you and your family.

The most common reason for a baby to be admitted is prematurity (birth before 37 weeks of pregnancy); other babies may have had a difficult birth, or had infections, feeding difficulties or jaundice; or been born with concerns about their internal organs such as the heart or gut, or had another medical concern that needed intensive care.

Your baby's conditions, or treatment for these conditions, may affect their ongoing health or development. So we would like to offer them follow-up after discharge.

The Neonatal Follow-Up (NNFU) programme consists of experienced health care professionals seeing your child at intervals after discharge. They can give information and advice about treatment that is tailored to each baby's needs.

## Why do we need NNFU?

The NNFU programme monitors your child's progress and gives expert medical and/or developmental advice according to each child's needs. The professionals you see can make sure other experts are involved if and when necessary. We know it is important to intervene early when problems arise – this gives the best results.

Beyond this, the professionals can provide helpful advice on everyday matters which require special solutions because your baby was unwell. Families find this very reassuring and supportive.

There is variation in the way the follow up is provided. Some services offer clinics where several families are seen together, other hospitals prefer a one-to-one approach. At your appointment you may see several different members of the multidisciplinary team where several professionals with different specialisms will meet with your family at the same appointment.

There are usually several families attending clinic in the same session, so you have the opportunity to meet old friends from the NNU, or to discuss shared concerns about your children, or just to establish new friendships.

[www.bapm.org/bannfu](http://www.bapm.org/bannfu)



# BANNFU

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Neurodevelopmental Follow-Up

## What happens in the NNFU clinic?

Somebody will chat with you about your child's abilities and problems, going over the whole range of daily living, including sleeping, eating, toileting, medical needs, mobility, speech, and so on. You may be asked to complete a questionnaire about this before coming to the clinic.

The child will be examined, including measurements of their growth; and especially looking at their movements and developmental achievements.

Sometimes, with your permission, the infant's spontaneous movements are video-recorded so that we can look back at them after the clinic, with our colleagues if needed.

At various age points there will be assessments of the infant's development, using a play-based assessment. Usually both you and your child will enjoy these sessions as they are fun for the child and interesting for parents.

If there are specific concerns there may be tests of hearing, social interaction, and vision.

For older children, there may be a more detailed test of thinking skills.

## Who are the staff in the clinic?

This will vary from clinic to clinic, but generally there will be several types of professionals. There may be nurses, who might be based in the Neonatal Unit or NNU discharge support team.

There will be paediatricians, who might be based in the NNU or specialising in Community Paediatrics.

There may be occupational therapists, physiotherapists or speech and language therapists. Some clinics may also have a psychologist.

Receptionists and administrators will ensure the smooth running of the clinic.

Several professionals may be responsible for the co-ordination of the NNFU programme, including the paediatricians.





# BANNFU

British Association for Neonatal  
Neurodevelopmental Follow-Up

## **When will my child be seen?**

It is likely that this will be at set ages and intervals, often around 3 months, 6 months, 1 year and 2 years (all adjusted for prematurity if relevant). Some clinics have extra visits or different timings and may see your child whenever you are concerned. In some cases there may be a further visit around 4 years.

## **Where will the clinic be?**

Many of the NNFU clinics are in the hospital your baby was discharged home from, or occasionally the hospital where the baby was looked after when most unwell. Some take place in community clinics serving your local area.

## **What about the paperwork?**

Before your child is first discharged home, you should be told where and on what date and time your child's follow-up appointment will be.

At each appointment, the team should make a plan of when the next appointment should be. If they can't tell you the exact date/time there and then, they should send this on. If you haven't heard by about a month before the next appointment is due, contact them to find out.

If your child needs a referral for a medical opinion or to start therapy, the team should tell you how soon you should hear about it and how to contact the department if you do not.

You should receive a written report about your child's assessment after each visit. If you do not, contact the clinic to tell them. If there is something in the letter that you are unclear about or disagree with, contact whoever prepared the letter through the details given in the letter.



# BANNFU

British Association for Neonatal  
Neurodevelopmental Follow-Up

## Do I have to take my child to NNFU appointments?

We know that it can be difficult to fit additional appointments into a busy family schedule but we still recommend attending even if it seems like your child is completely fine. Subtle signs that the professionals can spot may lead them to make early referrals to achieve the best outcome for your child. On the other hand, if your child already has many different appointments to deal with a variety of problems, speak to the clinic to see if the NNFU appointments can be combined with another visit.

If you miss an appointment, inform the clinic as soon as possible or let us know in advance if you can't attend and we will do our best to give you a new appointment. Our priority is for you and your child's health and wellbeing to give them the best start in life.

## About BANNFU

The British Association for Neonatal Neurodevelopmental Follow-up (BANNFU) is a Special Interest Group of The British Association of Perinatal Medicine (BAPM). BANNFU is a multidisciplinary group which exists to improve the long term outcomes of all babies that have had neonatal care by disseminating best practice and improving care.

This leaflet may be downloaded, printed out, photocopied and distributed free of charge, as long as BANNFU and BAPM are properly credited.

Cover image by Markus Spiske on Unsplash.

[www.bapm.org/bannfu](http://www.bapm.org/bannfu)

**Appendix 2****Classifying Health Status at 2 years**

This form is based on the *Report of a BAPM/RCPCH Working Group: Classification of health status at 2 years as a perinatal outcome*. It should be completed at 2 years corrected age. A copy should be retained in the medical records and a copy forwarded to the health visitor and Community Paediatrician

Name of Examiner	<input type="text"/>
Date of Assessment	<input type="text"/>
Place of Assessment	<input type="text"/>
<b>Identifiers</b>	
Child's NHS/Hosp Number	<input type="text"/>
Child's Name	<input type="text"/>
Child's Sex	<input type="text"/>
Child's Date of Birth	<input type="text"/>
Gestational Age at birth	<input type="text"/> weeks
Age at assessment	<input type="text"/> months
Age corrected for prematurity	<input type="text"/> months
Main language spoken at home	<input type="text"/>

## Developmental Assessment

Assessment complete?

yes

no

If not, please describe reasons in Notes, below

### Developmental assessment results

Name of test applied

Score

Test score achieved (DQ or standardised score)

Subscales scores if appropriate (please label)	Subscale	Score
		—
		—
		—
		—

*Notes: If unable to carry out formal or screening assessment, please record reasons and your estimate of developmental level below*

Please tick one box below

- Normal development (DQ > 85 or < 3 mo delay)
- Mild delay (DQ 70-84 or 3-6mo delay)
- Moderate delay (DQ 55-69 or 6-12mo delay)
- Severe delay (DQ < 55 or > 12mo delay)

Assessed	Estimated
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
	Unknown <input type="checkbox"/>

### Clinical Assessment and Cerebral Palsy

Please tick one

		<b>NO CEREBRAL PALSY</b>	<input type="checkbox"/>
<b>Classification of Cerebral Palsy (SCPE classification)</b>			
Spastic bilateral	2 limb involvement		<input type="checkbox"/>
	3 limb involvement		<input type="checkbox"/>
	4 limb involvement		<input type="checkbox"/>
Hemiplegia	Right sided		<input type="checkbox"/>
	Left sided		<input type="checkbox"/>
Dyskinetic	Dystonic		<input type="checkbox"/>
	Choreoathetoid		<input type="checkbox"/>
	Ataxic		<input type="checkbox"/>
Non-classifiable (comment below please)			<input type="checkbox"/>

What do you think is the cause of this child's motor impairment (if present)?

### Ventricular shunt

Is there a ventricular shunt present?  yes  no

### Seizures

In the past 12 months has the child had a fit or seizure?  yes  no

If yes, when was the last seizure?

Within the – last 24hrs=1; last 48hrs=2; last weeks=3; last months=4; last 6 mos=5; last year=6

Is the child receiving anticonvulsant medication?  yes  no

### Other neurological problems

Please describe any other neurological problems

## Functional Disability - MOTOR

### Gross Motor Function Classification Scale for Cerebral Palsy (GMFCS)

Record the level of *gross motor ability* you have observed

Record 0 if the child does not have cerebral palsy

- Level 1** Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device
- Level 2** Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture
- Level 3** Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs
- Level 4** Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone
- Level 5** Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll

*Note:*

*Distinction between Level I and Level II: Compared with children in Level I, children in Level II have limitations in the ease of performing movement transitions; walking outdoors and in the community; the need for assistive mobility devices when beginning to walk; quality of movement; and the ability to perform gross motor skills such as running and jumping.*

*Distinction between level II and level III: Differences are seen in the degree of achievement of functional mobility. Children in Level III need assistive mobility devices and frequently orthoses to walk, while children in Level II do not require or are unlikely to require assistive mobility devices after age 4.*



## Functional Disability – SENSORY and COMMUNICATION

### Problem with vision or eye defect

Is there a visual or eye defect of any type present?  yes  no  
 Does the child wear spectacles?  yes  no  
 Is there a squint present?  yes  no

#### Usual vision (with spectacles if worn)

Please tick one

Normal or near normal

Reduced vision but not blind as below

Blind: No useful vision - sees light only or no vision

### Problem with Hearing

Is there a hearing impairment of any type present?  yes  no  
 Does the child normally wear hearing aids?  yes  no

#### Usual Hearing (with aids if worn)

Please tick one

Normal or near normal

Hearing loss corrected with aids (usually moderate 40-70dBHL)

Some hearing but loss not corrected by aids (usually severe 70-90dBHL)

No useful hearing even with aids (profound >90dBHL)

### Problem with Speech or Language

*\*exclude isolated articulation defects*

Are there communication difficulties of any type present?  yes  no

#### If yes – how does the child usually communicate?

Please tick one

Speech

Speech + other formal systematised methods (e.g. signing)

Formal systematised methods only

Not communicating by speech or other method

#### Comprehension Is the child able to understand a simple command

(such as "give me the ...")

In an unfamiliar situation?  yes  no

Only in a cued situation?  yes  no

#### Expressive language

Please tick one

>5 words or signs

fewer than 5 words or signs

No meaningful words or signs

Comments (including level of hearing impairment if known)

## FUNCTIONAL DISABILITY – SOMATIC PROBLEMS

Please rate the following areas of somatic function:

### Respiratory

- No concerns (may be on medication)*
- Limited exercise tolerance*
- Requires continued respiratory support or oxygen*

Please tick one

  
  

### Renal Function

- No concerns*
- Renal impairment requiring treatment or special diet*
- Requires dialysis or awaiting organ transplant*

Please tick one

  
  

### GI Function

- No concerns*
- On special diet or has stoma*
- Requires TPN, NG or PEG feeding*

Please tick one

  
  

### GROWTH

Weight  kg

Height  cm

Head circumference  cm

Office use

sd

sd

sd

Please describe any other disability not covered above, explaining how it affects daily life

**Thank you for completing this assessment**