



Guideline for the 2-year Follow-up Assessment process under NorBOS (Northern Baby Outcome Survey)

September 2017

Due for review – September 2019

Northern Neonatal Network guideline

Guideline for the 2-year Follow-up Assessment process under NorBOS

Purpose

This guideline details the background to the Northern Baby Outcome Survey (NorBOS) project and its place in the Northern Neonatal Network strategy. It describes how to use the Badger database to record neuro-developmental outcomes needed for NorBOS, the same dataset needed for the National Neonatal Audit Project (NNAP) & CQUIN 2-year Outcomes question.

Summary

- Follow-up of babies requiring neonatal intensive care is essential in order to obtain robust outcomes data. This allows determination of the quality of the care and facilitates benchmarking.
- Obtaining robust outcomes data is a key part of the Northern Neonatal Network's work programme and has been designated as the Northern Baby Outcome Survey (NorBOS).
- Routine clinical follow up is already undertaken for the babies described below (primarily preterm infants and those with hypoxic brain injury). NorBOS aims to standardise the outcome data recorded across the network. CQUIN mandates that follow up is the responsibility of the discharging medical team however the Northern Neonatal Network feels there should be local flexibility in how assessments are carried out and by whom and does not aim to proscribe specific arrangements.
- Data should be entered 'real time' directly into Badgernet where possible.
- The Network will be responsible for compiling and publishing Outcomes Reports through appropriate collation of the anonymised data entered on to the Badgernet system.
- Badgernet entry will enable the appropriate data to be included in the National Neonatal Audit Project (NNAP) as 2-year Outcome Assessments now form a key part of their reporting and also any CQUINs negotiated with the commissioners, currently NHS England.

Background

For many years, the Northern region had the benefit of having amongst the most robust perinatal mortality data in the world through the work of the Regional Maternity Survey Office (RMSO). This resulted in detailed reports being published that gave a wealth of information about mortality rates and other key statistics relating to congenital abnormalities, twin and multiple pregnancies, diabetes in pregnancy and cerebral palsy. Some of this has been superseded by the new annual MBBRACE-UK Reports since the closure of the RMSO in early 2016. What has not yet been captured to any significant and standard definitions are similar data metrics relating to outcomes or “morbidity”, particularly in the cases of very premature and/or sick babies that have required admission to baby units. These have been ascertained within the context of specific research studies^{1,2} but no ongoing clinical mechanism exists. It has long been an ambition to address this and forms part of the Northern Neonatal Network strategy under the auspices of the “Northern Baby Outcome Survey” or NorBOS. This will eventually result in annual outcomes reports within local Network Annual Reports.

The aim is to record an agreed outcomes dataset entered onto the Badgernet system for each baby meeting the criterion for follow-up at 2-years of age. The system allows for a standardised developmental assessment, generally a Bayley 3 assessment in the Northern region, but the aim of NorBOS is to capture a more basic dataset. This more basic dataset can be completed by all paediatric staff (or appropriately trained health professionals) at 2 years of corrected age. There may in future be some flexibility in the follow up criteria, to reflect specific audits (for example the outcome of certain fetal anomalies) but the emphasis initially is to meet the basic requirements as detailed below.

The shift on emphasis to “outcomes” was a key element of the Government’s health policy plans. In the “Equity and excellence: Liberating the NHS” White paper³ it stated that “there will be a relentless focus on clinical outcomes”. It was also a focus of the Toolkit⁴, which stated that “Neonatal services should deliver the best quality care in order to achieve the highest quality outcomes for premature and sick newborn babies and their families.” (Page 15) and to;

“...monitor and report short- and long-term outcomes for children who meet the criteria for assessment within the unit/network, commencing with two-year outcomes.” (Toolkit, page 17, sect. 3.5f)

The National Neonatal Audit Project (NNAP) have included the 2-year follow-up assessment of babies less than 30 weeks as one of their key questions that will be published in their annual national reporting. This may in the future be “performance managed in line with their current policy and potentially identify low-compliance outliers - <http://www.rcpch.ac.uk/nnap>

The 2-year follow-up assessment also forms one of the nine NICE Quality Standards for Specialist Neonatal Care⁵. NorBOS is designed to meet these aims.

NorBOS Assessment criterion & outcomes dataset recording process

Criterion for assessment

Criterion 1

Gestational age < 30 weeks. This allows the NorBOS data to map onto and meet the NNAP & CQUIN inclusion criterion, as well as NICE Quality Standard 9.

Criterion 2

Infants treated with therapeutic hypothermia. At present these do not form part of the inclusion criterion for NNAP, CQUIN or NICE, but the Network is keen that these are recorded in NorBOS. This will under-represent for the diagnosis of Hypoxic ischaemic encephalopathy as not all are treated with therapeutic hypothermia but will capture most of those at risk of long term sequelae.

The Badgernet system can generate a list of babies that meet these 2 criterion (assuming data input is correct) and are due a follow-up assessment. Whilst this can be done “locally” and the guidance on how to do this is given below, the proposal is for the Network to generate “Assessment due” lists based on this prospectively on a quarterly basis to enable clinicians in each Unit to arrange for suitable appointments. The process for doing this and details of how the assessment data can be entered onto the system are described below.

Generating the list of babies that require follow up

The list can be generated in advance for the whole year if required and secretarial staff (for example) asked to ensure appointments are arranged as the 2-year age approaches for each baby. Responsibility for organising and performing the assessment rests with the consultant clinician responsible for ongoing care, even if the assessment itself is delegated to another individual. NorBOS aims to facilitate and capture the outcome data to inform Network activity, and not to fund or support the assessment visit *per se*.

1. Open BadgerNet front screen by clicking the installed icon. 
2. Click on the “Patient Lists” tab.
3. In the “specific groups” section, click on “Two year follow up due” report.
4. All babies that are due a follow up are displayed.
5. These are based on the hospital of final discharge home.
6. This list can be saved or printed by clicking on the down arrow icon on the top right.
7. You can also enter your own criteria by clicking on the “Refine this list” tab.

Note: Two year follow up assessments can be recorded in BadgerNet regardless of whether the assessment takes place at a different care provider to the original episode(s).

In addition to this the Network Data Manager will generate a list of “babies due” on a prospective basis in advance and email this to the Lead Clinician or other nominated link. It will then be the responsibility of the Lead/link to check this and arrange the appointment slots

Unit Leads/Links need to make their own checks via the Hospital DBS Trace mechanism to further verify and remove any deaths from the list. Ultimate responsibility for this lies with the Trust.

Local staff will ultimately need to check that any baby on the list identified as requiring follow-up has not since died. This can be checked by admin staff via NHS number and/or by contacting the Network Data Manager, who can check via the RMSO.

Assessment and data recording process

Local hospitals must determine how and by whom the assessments are performed, but the following suggestions may help data capture;

- Option 1: clinician enters the data directly onto Badger at the time of the assessment.
- Option 2: The clinician has a printed form (Appendix 1) that mirrors the data fields on Badger, fills this in at the time of assessment and then enters it on Badger at a later date For a full Bayley Scale of Infant Development (BSID) assessment both sides would be used. A pdf for this Form can be found at the Network website; www.nornet.org.uk
- Option 3: The assessment form is completed by the clinician at the time of the assessment but another colleague with Badger access and write permissions enters it on behalf of them. This may be an Administrative colleague such as a secretary, nurse or data clerk trained in how to do so.

The actual process involved in recording the data onto Badger whichever method is adopted locally is the same and involves the following steps;

1. Open the Badgernet front screen by clicking the installed icon .
2. Log on using your user name and password as above when you generated the patient list.
3. Click on ‘select the existing baby care episode...’ under the Patient Selection tab.
4. In the search window type either the NHS number or infant surname.
5. Select the infant you need and double click
6. In the ‘discharge’ window of the chart select ‘2 year follow up’
7. The assessment page will load and then you need to enter the data;
 - All assessors should work down it from “Neuromotor” down to “Growth” and then additionally fill out the fields for “auditory”, “vision” and “communication” according to your clinical findings.
 - Infants being assessed by a paediatrician should additionally have “neurological” diagnosis completed
 - Infants having a structured developmental assessment

(Bayley/Griffiths/SGS) should have this data input as well as the “developmental score” field completed.

8. Once ‘saved and closed’, click on the badger head in the top left of the screen to return to step 2 above.

Entering the assessment data onto Badger will automatically populate the fields required for NorBOS as well as the NNAP & for the CQUIN.

Brief summary:

- All babies under 30 weeks gestation or managed with therapeutic hypothermia require 2-year follow-up assessments
- Assessments have been mandated by CQUIN to be the responsibility of local clinicians in the unit discharging the infant home. In the majority of cases, this will be at the hospital of booking although a minority of babies might be offered follow up at one of the tertiary neonatal units according to their local policies.

The data required needs to be entered onto Badgernet but once done, this provides the data for NorBOS, NNAP & CQUIN. It also fulfils the NICE Standard and Toolkit requirement.

References

1. Wariyar U, Richmond S, Hey E. Pregnancy outcome at 24-31 weeks’ gestation: Neonatal survivors. *Arch. Dis. Child* 1998 May;64(5): 678-86
2. Tin W, Wariyar U, Hey E. Changing prognosis for babies of less than 28 week’s gestation in the north of England between 1983 and 1994. *Northern Neonatal Network. BMJ.* 1997;314:107-11
3. Department of Health (DH). *Equity and Excellence: Liberating the NHS.* 2010
4. Department of Health (DH). *Toolkit for High Quality Neonatal Services.* 2009
National Institute for Clinical Excellence (NICE). *Quality Standards for specialist neonatal care.* 2010

Appendix 1

TRPG/SEND/NNAP 2-YEAR CORRECTED AGE OUTCOME FORM

PLEASE DO NOT COMPLETE THIS FORM IF THE CHILD IS ACUTELY ILL

Name & Designation of person completing form _____

Hospital of Birth _____

Infant's name _____ Infant's NHS No _____

Date of Birth ____/____/____ Date of assessment ____/____/____

Gestation at birth (completed weeks) _____ Sex: Male / Female

Reason if child not assessed: Deceased post discharge / lost to follow up

Full Current Post Code _____ Date of death if applicable ____/____/____

Birth weight _____ Current hospital of follow up: _____

1. Neuromotor:	No	Yes	Don't Know
a. Does this child have any difficulty walking?			
b. Is this child's gait non-fluent or abnormal reducing mobility?			
c. Is this child unable to walk without assistance?			
d. Is this child unstable or needs to be supported when sitting?			
e. Is this child unable to sit?			
f. Does this child have any difficulty with the use of one hand?			
g. Does this child have difficulty with the use of both hands?			
h. Is this child unable to use hands (i.e. to feed)?			
2. Malformations:			
a. Does this child have a malformation identified at birth/ within the first 2yrs?			
b. Does this malformation impair daily activities despite assistance?			
3. Respiratory & CVS system:			
a. Does this child have limited exercise tolerance with or without treatment?			
b. Does child require supplemental oxygen or other respiratory support			
4. Gastro-intestinal Tract:			
a. Is this child on a special diet? If yes, what diet: _____			
b. Does this child have a stoma?			
c. Does this child require TPN, NG or PEG feeding?			
5. Renal:			
a. Does this child have renal impairment, no treatment?			
b. Is this child on dietary or drug treatment for renal impairment?			
c. Is this child having renal dialysis or awaiting renal transplant?			

6. Neurology:	No	Yes	Don't know
a. Has this child had a fit or seizure in the past 12 months?			
b. Is this child on any anticonvulsants?			
c. Has this child had more than 1 seizures a month despite treatment?			
d. Has this child ever had ventriculo-peritoneal shunt inserted?			
7. Growth: Give date of measurements if different from date of assessment _____			
Weight _____ kg Date _____			
Length _____ cm Date _____			
Head circumference _____ cm Date _____			
8. Development	No	Yes	Don't Know
a. Is the child's development between 3-6 months behind corrected age?			
b. Is the child's development between 6-12 months behind corrected age?			
c. Is the child's development more than 12 months behind corrected age?			
d. Will you be referring the child for a detailed neurodevelopmental assessment?			
e. If child had detailed neurodevelopmental assessment, provide name of the test: _____			
9. Neurosensory:			
a. Does this child have a hearing impairment?			
b. Does this child have hearing impairment corrected by aids?			
c. Does this child have hearing impairment not correctable with aids?			
d. Does this child have any visual problems (including squint)?			
e. Does this child have visual defect that is not fully correctable?			
f. Is this child blind or sees light only?			
10. Communication			
a. Does this child have any difficulty with communication?			
b. Does this child have difficulty with speech (<10 words/signs)?			
c. Does the child have <5 meaningful words, vocalisations or signs?			
d. Does this child have difficulty with understanding outside of familiar context?			
e. Is this child unable to understand words or signs?			
Special Questions:			
a. Is this child on at-risk register, fostered or adopted?			
b. Was this child difficult to test? If yes, circle appropriate below: (a) tired, (b) poor attention, (c) difficult to engage, (d) other			

Note: If answering 'yes' to questions 1a - 1h, 2b or 8e please classify/enter score on the reverse of this form

1) Does this child have Cerebral Palsy?

Yes	No
-----	----

If yes, please classify:

Spastic bilateral: 2 limb involvement	
Spastic bilateral: 3 limb involvement	
Spastic bilateral: 4 limb involvement	
Hemiplegia: Right sided	
Hemiplegia: left sided	
Dyskinetic/ dystonic/ choreo-athetoid	
Not classifiable	

2) Please give diagnosis: _____

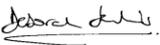
Bayley III (if performed) – please enter RAW scores	
Cognitive	
Receptive language	
Expressive language	
Fine Motor	
Gross motor	
Social emotional	
Adaptive behaviour (enter sum of scaled scores)	
Notes	

Griffiths (if performed) – please enter RAW scores	
A Locomotor	
B Personal and social	
C Hearing and Language	
D Eye and hand coordination	
E Performance	
F Practical reasoning	
Notes	

Schedule of Growing Skills (if performed) – please enter RAW scores	
Locomotor	
Manipulative	
Interactive Social	
Self-care social	
Hearing and Language	
Speech and Language	
Visual	
Notes	

This proforma was developed by the TRPG Outcome Group: it is used with their permission

Document Control

Document Ref. Number	NNNCGUIDE04
Title of document	Guideline for the 2-year Follow-up Assessment process under NorBOS
Original author's name	Martyn Boyd & Dr Nick Embleton
Author's job title	Northern Neonatal Network Manager Consultant Neonatologist, RVI (Newcastle)
Department/type	Network guideline
Document status	V 3.0
Based on	Revised guideline
Signed off by Board	11/01/12
Publication date	 D. Jenkins, Network Chair 11/01/12
Next review date	01/09/2019
Distribution	All Network Units & website

Consultation History

Version	Date	Consultation
V 1.0	November 2011	Nick Embleton Martin Ward-Platt
V 1.1	December 2011	Guideline Group
V 1.2	January 2012	Network Board
V 2.0	February 2015	Richard Hearn, Martyn Boyd, Martin Ward-Platt, Jenny Dixon, Mark Green
V 3.0	September 2017	Network Clinical & Educational Leads for revision