

## **Review of the BAPM dataset**

The current recommended BAPM neonatal dataset is now available on the website. There are 3 files – the dataset, the definitions of the data items and suggested outputs for the annual reports.

The principles on which this dataset has been developed are in the document. As this dataset is to be used to produce standard reports (either as paper annual reports or from pooled national data) it is vital that all the data items can be unambiguously defined. This has resulted in a number of data items being excluded, even though they may be thought by many to be important. It is clear that the work on this dataset is not complete and we need to have a mechanism to extend the work and try and develop agreed definitions for some of these 'missing' items.

The group would be interested to hear from BAPM members who want to comment on any of the content of the dataset. In particular we would be keen to know of members who feel they can help us develop robust definitions for any important item that has not been included at this stage.

# The BAPM Neonatal Dataset

## **Introduction**

A working party of the British Association of Perinatal Medicine produced the first BAPM Neonatal Dataset in 1997. This was used as a standard format for unit annual reports.

The Standards for Hospitals providing Neonatal Intensive Care and High Dependency published by BAPM in 2001 recommends that :

- each unit should use a data collection system to monitor workload and the results of practice. Appropriate audit assistance, IT and computer systems are essential if this is to be achieved;
- units should produce an annual report summarising their activity in a standardised form;
- all units providing neonatal care should be appraised against national criteria of service provision.

The last recommendation requires data to be pooled nationally. One of the recommendations in the 1997 report was for the BAPM to collect a few key items from computerised units with the aim of producing some pooled workload data.

Many units collect data but few have been producing annual reports using the format of the BAPM dataset. There are many examples where units have different definitions for data items, making comparisons impossible.

The lack of any centralised pooled data, whether as standardised annual reports or as a central pooled database, makes planning and monitoring of neonatal services difficult. With changes in service provision and the development of Managed Clinical Networks, there is an increasing need for good standardised data collection.

There is a need, therefore, to continue to support and develop an agreed BAPM neonatal dataset that can be used to produce standardised annual reports. At the same time it is important that, whatever dataset is used, the data items are capable of being pooled centrally.

At the AGM of the British Association of Perinatal Medicine in Reading in September 2002 it was agreed that a working party would be set up to review the BAPM dataset.

## **Members of the working party :**

Dr Andrew Lyon (chair)  
Professor Kate Costeloe  
Dr Ben Shaw  
Dr Neena Modi  
Dr James Moorcraft  
Dr Jag Ahluwalia  
Sue Broom – Neonatal Nurses Association

There have been discussions with Mr Victor Boston on behalf of the Paediatric Surgeons.

This working party acknowledges the tremendous work done in producing the first report in 1997. These new recommendations build on the experience gained from the use of the BAPM dataset.

### **Why define a minimum neonatal dataset ?**

The dataset is used to prepare standardised annual reports and the data items can also be pooled and used for a number of activities including :

- Description of population requiring treatment by a neonatal service
- Ascertainment of population based outcomes
- Internal audit
- Quantifying unit activity
- Clinical benchmarking
- Monitoring the performance of Trusts and Managed Clinical Networks against agreed standards and targets
- Linking outcomes with staffing and other resources
- Following temporal trends
- Provision of denominator data for perinatal statistics
- Linkage of perinatal variables with later outcomes
- Facilitation of epidemiological and other research

### **General principles**

During the development of the dataset there has been discussion with colleagues throughout the UK. It is clear that no single dataset will meet everyone's perceived data requirements. The aim of the working group was to produce a dataset dealing specifically with clinical activity and unit staffing which could be used for benchmarking and audit :

- Every data item must have an agreed, unambiguous definition (this is fundamental if any data item is to be used to compare any activity between units);
- the data items should be easy to collect;
- where there are clearly agreed standards, data items should be collected to audit unit activity against these standards;
- where possible, data should be consistent with that currently collected, and with other datasets;
- any outputs should be derived from raw data

### **Issues**

The 1997 dataset included a proposal that BAPM might coordinate the national collection and presentation of electronically submitted data. There remains a need for such a resource and in that respect the issues raised in the original report in 1997 still hold.

**Professional confidentiality:** The identity of each unit contributing to a pooled dataset must be confidential to BAPM and the unit itself. Professionals need to have confidence that information held by BAPM will not be "used" without their permission, or leak into the public domain. There is a great danger in publication of 'crude' league tables before there is a chance to explore the underlying reasons for any differences between units.

**Patient confidentiality:** The use of the data must comply with the Data Protection Act and Caldicott Principles. It is hoped that the baby's NHS number can be used to allow linkage of records from different units and subsequently with other datasets, e.g. child health surveillance.

**Incentive:** Units and/or networks providing information could reasonably expect to be given back information on their own activity compared to national figures and to data

from selected anonymised units with similar activity and resources. There should be a rapid way to access user defined reports.

**Cost:** The proposal will have a financial cost, both to neonatal units and to BAPM. There will be the need for adequate resources to ensure good data collection.

**Feasibility:** Although many units hold computerised patient based records, it is unlikely that comprehensive information could be obtained from all units. The datasets in this document would allow those units already capable of recording more information to ensure that this was consistent with that held by other units.

**Technical:** There is no single technical solution either to data collection at unit level or the format of the central database. Paper based systems may well remain an option for some units. It is important that any solution is able to change with future technological developments. Web based systems, using the NHS net, are likely to be the way forward. Any unit electronic database should be capable of allowing user defined changes to the datasets.

Any national project must produce a technical specification for data transfer which can be used by commercial software companies.

Although the purpose of this dataset is to help units to collect important information about neonatal care, it should be recognised that all the measures of outcome suggested in this document reflect the health of the population served. Conclusions about the quality of neonatal or obstetric care should not be drawn from simple comparisons between units. Even in the largest units, numbers are likely to be sufficiently small that inferences cannot be drawn from a single year's information.

**Copyright:** The dataset should be copyrighted by BAPM

### **The dataset**

The need for unambiguous definitions means that a number of data items cannot be included in a minimum dataset of pooled data, even though many may feel that they are important. Examples of these data items are included in a subset which, although not part of the minimum dataset, is included in this document to stimulate discussion. There will be units collecting these data items and we would welcome debate on how we may be able to standardise the definitions. In some cases there may be useful short term research that can be done to determine whether a specific data item can contribute to a minimum dataset.

It has not been possible to agree on the exact definition of 'an admission'. Do all units include babies who may only spend an hour or so on the unit? What about units that have a large Transitional Care ward where care is the responsibility of the midwifery service as well as the neonatal service? What about babies who die before admission? There are wide variations in the proportion of deliveries that get admitted to neonatal units in different hospitals and this depends on local policy. There is less variation with the preterm baby (probably below 35 weeks) as all of these will be admitted. Care must be taken in comparisons where number admitted is used as a denominator in calculations.

**All hospitals with a neonatal service must collect total numbers of livebirths (including those mothers transferred in utero) broken down by gestation and birthweight. Those babies dying on labour ward before admission must be documented.**

Many of the calculated rates of workload and outcome can then be determined using total number of livebirths as the denominator.

**Follow up:** The BAPM standards state that ‘each unit should have a defined protocol for neurodevelopmental follow up and close liaison with local child development teams’. It is recommended that this standard be achieved by all hospitals and the data linked to the minimum dataset.

**Data granularity:** A centralised pooled dataset is by its nature summary data, describing an individual baby’s episode of care in the neonatal unit. Units should collect raw data from which the summary information can be derived, either manually or by computer system. The advantages of this approach are:

- Derived data items, such as level of care, can be assigned consistently and objectively, rather than inconsistently as is the case at present;
- raw data will be available and derived data easily changed if definitions alter;
- cross validation will be easy;
- the raw data will provide the infrastructure to service a multiplicity of needs.

**This dataset is not intended to be restrictive. Individual units and networks will need to collect other data items to help in clinical care, or to answer their own specific questions. It is for them to agree on definitions for these data items, while at the same time ensuring on going support for the BAPM dataset.**

**The data items** (see appendix 1 for definitions)

#### **Inputs**

These are patient based and unit based data items. Some are collected at a single point in time (static data) and some at repeated intervals (daily items).

#### **Outputs**

These are either data items derived from the inputs (e.g. number of days at each level of care, total number of nurses involved in clinical care over a period of time) or suggested tables of summary data.

#### **Patient based data items**

##### **Static data items**

Name/code of Hospital\*  
Mother’s NHS number\*  
Postcode of mother’s residence at time of birth\*  
Planned place of delivery at booking\*  
Place of birth\*  
Baby’s NHS number\*  
Date of birth\*  
Time of birth\*  
Source of admission to the unit  
Date of admission  
Time of admission  
Birthweight\*  
Best estimate of gestational age at delivery\*  
Sex\*  
Number of fetuses\*  
Birth order\*

Antenatal steroids\*  
Date of discharge, transfer or death\*  
Time of death  
Discharge or transfer destination\*  
Whether postmortem performed\*  
Weight at discharge home  
Head circumference at discharge home  
Tube feeding at discharge home  
Oxygen at discharge home  
Surfactant therapy  
Chest drain for pulmonary air leak  
Date of first ROP screen  
Treatment for ROP  
Cerebral ultrasound (as per local policy)  
Hearing screening (as per local policy)  
Shunt surgery for hydrocephalus  
Surgery for PDA  
Surgery for NEC

Data items marked with \* should be collected for all livebirths that die before admission to the neonatal unit.

## Daily data items

It is recommended that all units gather these data items on a daily basis. They are all yes/no fields with the exception of the current weight :

- ET tube in situ
- Receiving nCPAP
- Surfactant given
- Receiving added oxygen therapy
- Current weight
- Full exchange transfusion done
- Partial (dilutional) exchange transfusion done
- Receiving peritoneal dialysis
- On treatment with an inotrope, pulmonary vasodilator or prostaglandin
- Receiving 1:1 nursing care
- Receiving parenteral nutrition (partial or total)
- On treatment for convulsions
- On treatment for neonatal abstinence syndrome
- Recurrent apnoea requiring frequent (more than 5 in 24 hours) interventions
- Intra arterial or central venous (including umbilical) line in situ

These daily data items can be used to derive the following **outputs** :

Days of respiratory support via an endotracheal tube  
Days of positive airways pressure (nCPAP)  
Date of final added oxygen  
Number of intensive care days  
Number of high dependency days  
Number of special care days  
Number of normal care days

Many units collect these data items as a one off exercise when the baby is discharged. Units should collect the daily raw data from which these outputs can be derived. It would also be possible to derive more of the static data items if the information is collected daily (e.g. surfactant, chest drain etc).

**Other outputs** – see appendix 2 for examples

## Unit based data items

### Static data items

These data items are collected annually

Number of WTE consultants with major involvement in neonatal care (6 or more sessions)  
Number of WTE ANNP/Nurse consultants in the unit.  
Senior nurse with managerial responsibility in post (yes/no)  
Nurse responsible for further education in post (yes/no)  
Family care team available (yes/no)  
Transport service available (yes/no)  
Number of support staff (includes senior nurse manager, ward manager, outreach nurses, family care team, quality nurses and research nurses)

Number Nursery nurses  
Physiotherapy, speech therapy, dieticians available (yes/no)  
Average (%WTE) annual sickness rate  
Percentage own staff (WTE) on maternity leave

### Daily data items

**Work is in currently in progress to develop and pilot a simple system of daily raw data collection that would inform ALL staffing queries - (i.e. in the same way that the daily raw clinical data collection informs a multiplicity of clinical queries). Precise definitions of these data items will also be developed.**

In the interim it is possible to collect a few daily data items that allow a unit to compare their staffing levels, on a day by day basis, against the current recommendations in the BAPM standards document. The use of bank/agency staff on a day by day basis can also be analysed. These data can be collected for each shift or at a fixed time point through the 24 hour period.

- Number nurses involved in clinical care (i.e. excludes managers or those whose primary role is educational) with a speciality qualification in neonatal care (excluding own staff on extra shifts and bank/agency)
- Number nurses (excluding students) involved in clinical care without speciality qualification in neonatal care (excluding own staff on extra shifts and bank/agency)
- Number students
- Number own staff doing extra shifts
- Number extra nurses requested from bank/agency
- Number extra nurses supplied from bank/agency
- Is there a resident SHO or ANNP whose sole responsibility is the neonatal unit (yes/no)
- Is there resident middle grade cover from a doctor or ANNP (yes/no)
- Does the middle grade have responsibility only for the neonatal unit (yes/no)
- Is there a consultant available during the day whose sole responsibility is the neonatal unit (yes/no)
- Is there a consultant on call out of hours whose sole responsibility is the neonatal unit (yes/no)

The daily items can then be used to derive **outputs** which can be used for comparison.

In any time period, the total number of nurses required, as recommended by the BAPM standards, is equal to :

$(\text{Sum of intensive care days}/1) + (\text{Sum of high dependency days}/2) + (\text{Sum of SC/NC days}/4) + 1$

If nursing numbers are collected a time points during the day and night, then it is possible to calculate the **outputs** :

Ratio of actual to recommended nurse numbers during day  
Ratio of actual to recommended nurse numbers during night

**Other outputs** - Work is in progress to determine the best ways of comparing unit staffing numbers. The annual static data items are outputs which can be compared across units.

**Other clinical data items, not included in minimum dataset**

This subset includes a number of data items for which the definitions cannot be agreed, but they represent clinically important predictors of outcome, or represent possible measures of quality of care. Many units already collect some of these data items and we are keen to stimulate a debate leading to a consensus view about their importance and, if appropriate, agreed definitions for inclusion in the dataset.

Some of the data items that need further consideration include :

**Temperature in admission**

There is evidence that this is closely related to outcome. It is also a good audit of care during resuscitation. Temperature on admission to the neonatal unit should be a data item we collect but some work needs to be done on agreeing how and when this should be collected. The group feel that this needs to be done urgently.

**CRIB**

CRIBII is relatively easy to collect and may give a means of standardising admissions by sickness severity.

**Grades of staff at resuscitation**

This may be important data when comparing outcomes between different units. Some work is needed to define exactly what constitutes being present at a resuscitation. For example, do you count the consultant who maybe arrives just as the baby is being transferred to the neonatal unit ?

**Other definitions of care categories**

The collection of daily 'raw data' allows comparisons of different systems for defining care levels. In a study of nursing workload Milligan et al showed that the Northern Region Care Categories gave similar results to the current BAPM levels of Care (Milligan DWA, Wooler L, Ward Platt MP et al. Early Human Development 2003;73:93-109)

**Cerebral ultrasound, periventricular haemorrhage, ventricular dilatation etc :**

There is no agreement on which babies should have a cerebral ultrasound scan and when these should be done. The dataset includes an item recording whether a baby had a scan done within the unit protocol. This will allow some comparison of protocols within different units.

There are wide variations in the views taken, in the expertise of the operator and the seniority of the reporter of the scans. There is no agreement on how scans should be reported. With this level of disagreement it is not possible to pool data from cerebral ultrasound scans. More work is needed on defining protocols and on linking agreed scan changes to outcome.

Information from longer term follow up may well be a much more sensitive marker of neurological outcome than changes on ultrasound in the neonatal period.

**Maximum grade of ROP in either eye :** It is uncertain if this gives more useful information than recording the number of babies treated for ROP.

**Neonatal encephalopathy** : Although there are definitions of the grades of encephalopathy (Sarnat), a great deal of subjectivity remains, particularly with Grade 2. This is an important subgroup of babies and they need to be recorded.

**Seizures** : In the absence of EEG evidence of seizure activity, there is no unambiguous definition of a seizure.

(Note : The current BAPM definitions of level of care place babies having seizures in high dependency. Although there is no unambiguous definition of seizures, and therefore this data item cannot be collected as part of any pooled data, it needs to be recorded as part of the daily data used to determine level of care. For this purpose it is whether there is a clinical decision to treat the baby for suspected fits).

**Infection** : This is of major concern in neonatology and it will be important to agree how we will define infection. Rates of infection with coagulase negative staphylococcus are important and work is needed to establish accepted definitions of infection which will allow collection and comparison of these data. Experience from other datasets, particularly Vermont-Oxford, needs to be considered.

**Blood transfusions** : Number of blood transfusions. There are no good guidelines on the use of blood products. Collection of this data item would allow a comparative audit of how blood products are being used.

**Ethnicity**: There is no agreement on how ethnicity should be defined. There will be specific needs of different areas and they need to collect ethnicity in a way that helps them deliver their specific service. With no agreed definitions ethnicity cannot be part of a minimum dataset used to pool data. The definitions used in the national census are shown in the appendix along with the categories implemented throughout the West Midlands.

**Congenital malformations** : This is important information to be included in an individual baby's record, but how this will be used in pooled data is uncertain. The accuracy of the diagnosis, extracted from routinely collected data, is open to debate.

**Follow up**: It is beyond the remit of this group at this time to advise on the content or timing of collection of a follow up dataset. However this work needs to be done. The report from the working group from National Perinatal Unit is likely to be the starting point. It is recommended that a group be formed to develop an easily used follow up dataset.

**Maternal breast milk at time of discharge**: It was thought that this would be an important audit measure and allow comparisons of successful breast feeding at time of discharge from neonatal units. Some work is needed to ensure this is a useful outcome measure and to define exactly which babies are included

**Ever entered into an ethical committee approved study** : With increasing problems around recruitment of babies into ethically approved studies, this data item may well be important in showing comparisons between units across UK.

## Appendix 1

### Item 1: Name of hospital

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby

**Definition:** The hospital location of the neonatal intensive care unit where the baby is admitted.

**Classification/coding:** A numerical code representing the hospital unit.

**Justification:** This allows data to be analysed by hospital delivering neonatal intensive care.

**Timing:** On admission

**Comment:** The coding of information assists in maintaining confidentiality.

### Item 2: Mother's NHS number

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby

**Definition:** Mother's unique NHS number

**Classification/coding:** NHS number format

**Justification:** This can be used for linking to information about the mother.

**Timing:** At the time of delivery

### Item 3: Postcode of mother's residence at time of birth

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby

**Definition:** Valid postcode at the time of booking. Where the first part of the postcode is 4 digits, leave no space before the second part of the postcode.

**Classification/coding:** Unspecified, 7 digit label.

**Justification:** This item can be used to derive the geographical distribution of babies; it will link to the corresponding enumeration district code to facilitate comparisons with ONS data; a deprivation score can be derived for the enumeration district.

**Timing:** At delivery.

### Item 4: Planned place of delivery at booking

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the

**Definition:** Type of place at which mother booked for her confinement. The first intended place of delivery by the health care professional in consultation with the woman.

**Classification/coding:**

1 = *this hospital*

2 = *another hospital*

3 = *home birth*

4 = *other*

5 = *No planned place of delivery – not booked*

9 = *unknown(information not available)*

**Definition:** Within any network this can be adjusted to include the codes of the hospitals within the network. This will allow more detailed analysis of where babies are booked and where they actually deliver. These data items can 'map' to the codes above for use in any national dataset.

**Justification:** Required to analyse pregnancy outcome according to the place of planned delivery.

**Timing:** At delivery

**Item 5: Place of birth**

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby

**Definition:** Actual place of baby's birth.

**Classification/coding:**

9 = *unknown* - information not available

1 = *this hospital*

2 = *another hospital*

3 = *home birth – planned home birth*

4 = *other, includes born before arrival* - born in an ambulance, home (not planned), in a car etc.

**Justification:** Place of birth is an important factor associated with outcome.

**Timing:** At delivery

**Item 6: Baby's NHS number**

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby

**Definition:** Baby's unique NHS number.

**Classification/coding:** NHS number format

**Justification:** This is the best unique identifier both for use at a local level, and for record linkage in babies receiving care in more than one unit and for follow up information.

**Timing:** At delivery.

**Item 7: Date of birth**

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby

**Definition:** Date of birth of the patient.

**Classification/coding:** DD / MM / YY

**Justification:** Required to derive patient age for analysis by age at admission or discharge as required.

**Timing:** At delivery

**Item 8: Time of birth**

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby

**Definition:** Time of birth of the patient (24 hour format).

**Classification/coding:** HH:MM

**Justification:** Required to derive accurate age at death.

**Timing:** At delivery

**Item 9: Source of admission to unit**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit.

**Definition:** Source of admission to the neonatal intensive care unit.

**Classification/coding:**

9 = *unknown*; information not available.

1 = *this hospital*, includes born before arrival

2 = *another hospital*

3 = *Home- planned home births and readmissions from home*

**Justification:** Outcome differences have been shown between inborn babies and outborn babies. Describes movement of a high risk group.

**Timing:** On admission

**Item 10: Date of admission**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate episode of care of the baby on the neonatal unit.

**Definition:** The date on which an inpatient commences an episode of care.

**Classification/coding:** DD / MM / YY

**Justification:** Required to identify period in which inpatient episode occurs and for derivation of length of stay. Assists in record linkage in babies transferred between units.

**Timing:** On admission

**Item 11: Time of admission**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate episode of care of the baby on the neonatal unit.

**Definition:** The date on which an inpatient commences an episode of care.

**Classification/coding:** HH:MM

**Justification:** Required to identify period in which inpatient episode occurs and for derivation of length of stay. Assists in record linkage in babies transferred between units.

**Timing:** On admission

**Item 12: Birthweight**

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** The first weight of the baby obtained after birth (record in grams), ideally within an hour of delivery.

**Classification/coding:** 4 digit numbered field representing birthweight in **grams**.

**Justification:** Birthweight is an important indicator of pregnancy outcome, a major risk factor for neonatal mortality and morbidity, and is required to analyse perinatal services for high risk babies.

**Timing:** At delivery

**Item 13: Best estimate of gestational age at delivery**

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** The best estimate of gestational age at the time of delivery in completed weeks. This will normally be based on the postmenstrual age, but may be modified on the basis of antenatal ultrasound scan. Where the gestational age at delivery is unknown, this is based on the postnatal estimate of maturity.

**Classification/coding:** 2 digit numbered field representing the number of completed weeks.

**Justification:** The gestational age is an important determinant of outcomes.

**Timing:** At delivery

**Item 14: Sex****Scope:** All livebirths**Level of enumeration:** Each separate care episode of the baby on the neonatal unit**Definition:** The sex of the baby.**Classification/coding:**1 = *male*2 = *female*3 = *ambiguous or indeterminate*9 = *unknown***Justification:** Required to analyse information by sex, an important outcome measure**Timing:** At delivery (in some circumstances it may be necessary to alter this field at some point after delivery, if sex is reassigned)**Item 15: Number of fetuses****Scope:** All livebirths**Level of enumeration:** Each separate care episode of the baby on the neonatal unit**Definition:** The total number of births resulting from this pregnancy**Classification/coding:**1 = *singleton*2 = *twins*3 = *triplets**etc*9 = *unknown***Guide for use:** The maximum number of fetuses **known** to be present at any time during this pregnancy. Includes early fetal loss if this has been documented.**Justification:** Multiple pregnancy increases the risk of complications during pregnancy, labour and birth and is associated with higher risk of perinatal morbidity and mortality. Birth order is required to analyse pregnancy outcome according to birth order and identify the individual baby resulting from a multiple birth pregnancy.**Timing:** At delivery (it is possible that this may need to be changed following further investigations – e.g. placental examination)**Item 16: Birth order****Scope:** All livebirths**Level of enumeration:** Each separate care episode of the baby on the neonatal unit**Definition:** The order of the baby in a multiple birth – the order in which they are delivered, regardless of the ‘numbering’ used before birth.**Classification/coding:** Single digit number representing the delivery order of baby**Justification:** Birth order is required to analyse pregnancy outcome according to birth order and identify the individual baby resulting from a multiple birth pregnancy.**Timing:** At delivery

**Item 17: Antenatal steroids**

**Scope:** All livebirths

**Level of enumeration:** First care episode of the baby

**Definition:** If any steroid (dexamethasone or betamethasone) administered before delivery with the intention of maturing the fetal lungs.

**Classification/coding:**

0 = *no steroids given*

1 = *at least one complete course of steroids given at some point before delivery (defined as per local policy)*

2 = *incomplete course of steroids given (defined as per local policy)*

9 = *unknown*

**Justification:** There are evidence based guidelines for use of antenatal steroids in preterm labour

**Timing:** At delivery

**Item 18: Date of discharge, transfer or death**

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** The date on which an inpatient completes an episode of care, either because of death, transfer to another ward or hospital, or because of discharge home.

**Classification/coding:** DD / MM / YY

**Justification:** Required to identify period in which inpatient episode occurs and for derivation of length of stay. Assists in record linkage in babies transferred between units.

**Timing:** On discharge or death

**Item 19: Time of death**

**Scope:** All babies dying

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** The time of death of the baby.

**Classification/coding:** HH:MM

**Justification:** Used to calculate days of survival, an important outcome.

**Timing:** At death

**Item 20: Discharge or transfer destination**

**Scope:** All livebirths

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** The destination of the baby at discharge from the neonatal unit at completion of an episode of care.

**Classification/coding:**

1 = *discharge home; baby discharged to care of mother or to substitute carer.*

2 = *transfer to another ward in the same hospital.*

3 = *transfer to another hospital for continuing care*

4 = *transfer to other hospital for specialist care*

5 = *died; before transfer elsewhere.*

9 = *unknown; information not available*

**Definition:** Within any network this can be adjusted to include the codes of the hospitals within the network. This will allow more detailed analysis of where babies are booked and where they actually deliver. These data items can 'map' to the codes above for use in any national dataset.

**Justification:** Required to assist in record linkage in babies transferred between units, or between wards in a hospital.

**Timing:** On transfer, discharge or death

**Item 21: Whether postmortem performed**

**Scope:** All babies dying

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Whether a postmortem was undertaken.

**Classification/coding:**

0 = *no postmortem performed*

1 = *full postmortem (including examination of the brain)*

2 = *other postmortem examination or investigations*

9 = *unknown*

**Justification:** Used to determine postmortem rates.

**Timing:** At death

**Item 22: Weight on discharge home**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Weight at time of discharge to home

**Classification/coding:** 4 digit number representing weight in grams

**Justification:** A marker of morbidity with resource implications

**Timing:** At discharge

**Item 23: Head circumference on discharge home**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Head circumference at time of discharge to home

**Classification/coding:** 3 digit number representing head circumference in cms

**Justification:** A marker of neurological problems and related to long term outcome

**Timing:** At discharge

**Item 24: Tube feeding on discharge home**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** On any tube feeding at time of discharge to home

**Classification/coding:**

0 = *not tube feeding on discharge*

1 = *having some or all feeds by nasogastric tub*

9 = *unknown*

**Justification:** Has resource implications and may be a marker of major morbidity

**Timing:** At discharge

**Item 25: Oxygen on discharge home**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** On supplementary oxygen at time of discharge to home

**Classification/coding:**

0 = *not on oxygen on discharge to home*

1 = *on added oxygen on discharge to home*

9 = *unknown*

**Justification:** Measure of significant chronic lung disease. Has resource implications for a unit

**Timing:** At discharge

**Item 26: Surfactant therapy**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** First care episode of the baby on the neonatal unit

**Definition:** If surfactant given at any time. Includes surfactant being given at delivery.

**Classification/coding:**

0 = *no surfactant given*

1 = *yes, at least one dose of surfactant given*

9 = *unknown*

**Justification:** There is good evidence base for the use of surfactant in respiratory distress syndrome

**Timing:** At discharge

**Item 27: Air leak requiring drainage**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** The presence of any form of pulmonary air leak receiving drainage (excluding diagnostic needling of chest, post thoracotomy, continuous drainage of an effusion).

**Classification/coding:**

0 = *no air leak receiving drainage present*

1 = *yes, air leak receiving drainage*

9 = *unknown*

**Justification:** Air leak is a major morbidity, associated with some treatments.

**Timing:** At discharge.

**Item 28: Date of first retinopathy of prematurity (ROP) examination**

**Scope:** All eligible babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** The examination of eyes for ROP was completed consistent with the national recommendations.

**Classification/coding:**

Date of first examination, dd/mm/yy

**Justification:** Allows estimation of adherence to local retinopathy surveillance policy.

**Timing:** At discharge.

**Item 29: Therapy for retinopathy of prematurity**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Any therapy used to treat retinopathy of prematurity

**Classification/coding:**

0 = *no therapy for ROP received*

1 = *yes; therapy given for ROP*

9 = *unknown*

**Justification:** Therapy for ROP is a secondary indicator of the severity of disease.

**Timing:** At discharge.

**Item 30: Cranial ultrasound screen according to defined local policy**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Whether a baby received cranial ultrasound screening according to the local policy

**Classification/coding:**

0 = *no, was not screened as per policy*

1 = *yes, cranial ultrasound screening performed*

2 = *not appropriate; local screening policy does not apply*

9 = *unknown*

**Justification:** Allows estimation of adherence to local ultrasound policy

**Timing:** At discharge

**Item 31: Hearing screening according to defined local policy**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Screening for hearing loss was completed consistent with the local policy.

**Classification/coding:**

0 = *no, examination was not completed*

1 = *yes, screened consistent with recommendations*

2 = *not appropriate; screening policy does not apply*

9 = *unknown*

**Justification:** Allows estimation of adherence to local hearing loss screening policy

**Timing:** At discharge

**Item 32: Surgical procedure as a result of post haemorrhagic hydrocephalus**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Insertion of a ventriculo-peritoneal shunt or an access device for CSF drainage, following post haemorrhagic hydrocephalus.

**Classification/coding:**

0 = *no device inserted*

1 = *yes, device inserted*

9 = *unknown*

**Justification:** Surgical intervention has a strong association with outcome

**Timing:** At discharge

**Item 33: Surgery to ligate a patent ductus arteriosus (PDA)**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Surgical treatment of the ductus arteriosus.

**Classification/coding:**

0 = *no surgery*

1 = *yes, surgery done*

9 = *unknown*

**Justification:** Has resource implications for neonatal service

**Timing:** At discharge

**Item 34: Surgery for necrotising enterocolitis (NEC)**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Surgical treatment where NEC suspected or confirmed. Includes placement of surgical drains as well as laparotomy.

**Classification/coding:**

0 = *no surgery*

1 = *yes, surgery done*

9 = *unknown*

**Justification:** Has resource implications for neonatal service

**Timing:** At discharge

**Item 35: Days where an endotracheal tube is in situ (for intermittent positive pressure or oscillatory ventilation or ET CPAP)**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal intensive care unit before discharge home.

**Definition:** Total number of days of ventilation via an endotracheal tube, at any rate and of any type. Any period of ventilation in 24 hours constitutes a day. The 24 hour period runs from midnight to midnight; however, units may use any other 24 hour period, e.g. 9am to 9am, as long as this remains consistent.

**Classification/coding:** 3 digit numbered field representing ventilation days.

**Justification:** Used to calculate the unit's experience of ventilation.

**Timing:** Ideally collected each day that the baby receives intensive care.

**Item 36: Days of nasal continuous positive airways pressure (nCPAP)**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit.

**Definition:** Total number of days of nCPAP and of nasopharyngeal ventilation. Any use of CPAP in 24 hours where ventilation has not been used constitutes a day. The 24 hour period runs from midnight to midnight; however, units may use any other 24 hour period, e.g. 9am to 9am, as long as this remains consistent.

**Classification/coding:** 3 digit numbered field representing CPAP days.

**Guide for use:** The highest level of assisted ventilation therapy that has been used in any 24 hour period is used.

**Justification:** Used to calculate the unit's experience of CPAP.

**Timing:** Ideally collected each day that the baby receives care.

**Item 37: Date of final added oxygen therapy**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Date supplemental oxygen (O<sub>2</sub>) finally ceased (according to local policy).

**Classification/coding:** DD / MM / YY

**Guide for use:** Any use of supplemental oxygen in any one 24 hour period constitutes a day. Any route of oxygen administration is used. If oxygen is ceased, and then the baby required more supplemental O<sub>2</sub> for the same illness, use final day of all the days that supplemental oxygen was used. However, do not include days of oxygen for subsequent illnesses such as oxygenation after surgery, RSV etc. If the baby never received supplemental oxygen leave blank. If the baby received only, say, 5 hours of oxygen on day one, use the date of birth. If the baby only received supplemental oxygen prior to this admission, enter date of final added oxygen therapy prior to this admission. If the baby received supplemental oxygen at discharge or transfer from the unit use the discharge date here.

**Justification:** Age last in supplemental oxygen is used to describe chronic lung disease, a major morbidity.

**Timing:** At transfer or discharge.

**Item 38: Number of intensive care days**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit.

**Definition:** Total number of days of intensive care (BAPM<sup>1</sup>, see page 13). Any period of intensive care in 24 hours constitutes a day. The 24 hour period runs from midnight to midnight; however, units may use any other 24 hour period, e.g. 9am to 9am, as long as this remains consistent.

**Classification/coding:** 3 digit numbered field representing number of intensive care days.

**Guide for use:** The highest level of care for any 24 hour period is used.

**Justification:** Used to estimate the intensive care experience of the unit.

**Timing:** Collected each day that the baby receives care and ideally derived from raw data.

**Item 39: Number of high dependency days**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Total number of days of high dependency (BAPM<sup>1</sup>, see page 14). Any period of high dependency in 24 hours where intensive care was not used constitutes a day. The 24 hour period runs from midnight to midnight; however, units may use any other 24 hour period, e.g. 9am to 9am, as long as this remains consistent.

**Classification/coding:** 3 digit numbered field representing number of high dependency days.

**Guide for use:** The highest level of care for any 24 hour period is used.

**Justification:** Used to estimate the high dependency experience of the unit.

**Timing:** Collected each day that the baby receives care and ideally derived from raw data.

**Item 40: Number of special care days**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Total number of days of special care (BAPM<sup>1</sup>, see page 14). Exclude any day when the baby has received intensive care or high dependency at any time in the 24 hour period. The 24 hour period runs from midnight to midnight; however, units may use any other 24 hour period, e.g. 9am to 9am, as long as this remains consistent.

**Classification/coding:** 3 digit numbered field representing number of special care days.

**Justification:** Used to estimate the special care experience of the unit.

**Timing:** Collected each day that the baby receives care and ideally derived from raw data.

**Item 41: Number of normal care days**

**Scope:** All babies admitted to a neonatal unit

**Level of enumeration:** Each separate care episode of the baby on the neonatal unit

**Definition:** Total number of days of normal care (BAPM, see page 14). Exclude any day when the baby has received intensive care at any time in the 24 hour period. The 24 hour period runs from midnight to midnight; however, units may use any other 24 hour period, e.g. 9am to 9am, as long as this remains consistent.

**Classification/coding:** 3 digit numbered field representing number of normal care days.

**Justification:** Used to estimate the normal care experience of the unit.

**Timing:** Collected each day that the baby receives care and ideally derived from raw data.

## Appendix 2

### Examples of unit report tables.

The BAPM neonatal dataset was first published to allow units to produce standardised annual reports. This revision has recommended some alterations to take into account changes in practice. Another aim has been to create a central dataset that can be collected electronically and used for national audit, benchmarking and quality improvement exercises.

The original report in 1997 included illustrative examples of annual report tables and these remain a very helpful guide to units preparing annual reports.

Examples of possible outputs from the dataset are outlined below. Differences between units will only rarely be easily explicable using the current dataset. It is much more likely that the comparisons will throw up further questions that need to be addressed before any differences can be explained.

### Description of unit workloads and outcomes

#### Proportion of babies admitted to neonatal unit

*This will define admission policy and allow comparisons across units*

- Total number of livebirths born in hospital (*includes babies born before arrival and those delivered after transfer in utero into the hospital*) (a)
- Total inborn babies admitted to neonatal unit (b)
- Percentage (b/a)
- Numbers of admissions by gestation and birthweight group
- Numbers of multiple births

*There remains the problem of defining an admission. Units may also want to record the percentage of livebirths that are admitted to transitional care, where this service exists. There will be slight differences as some units do not count babies who only spend a couple of hours or so on the unit.*

- Numbers of babies transferred in with reason for transfer
- Numbers of babies transferred out with reason for transfer

#### Activity

*Allows comparison of workloads across units*

- Number of intensive care days
- Number of high dependency days
- Number of special care days
- Number of normal care days
- Number of babies receiving intensive care at any stage of their admission
- Number of babies receiving high dependency at any stage of their admission
- Number of babies receiving special care but not intensive or high dependency care

## **Respiratory support provided**

*Allows comparison of workloads and also use of nCPAP vs ventilation. Compares numbers of babies with persistent oxygen requirements as well as policies for discharge home in oxygen.*

- Number of babies ventilated
- Number of babies receiving CPAP but no ventilation
- Number of days of ventilation
- Number of days of nCPAP
  
- Number of babies in oxygen at 36 weeks corrected age
- Number of babies in oxygen at term equivalent
- Number of babies discharged home in oxygen

For comparison these figures should be quoted as a percentage of all livebirths and broken down by gestation and birthweight group.

## **Outcome**

### **Mortality**

*All units should be able to collect all livebirths by gestation and birthweight. The total livebirths can be used as the denominator when looking at rates, not the number of admissions.*

- Number of livebirths and survival to 28 days by birthweight group
- Survival to discharge home by birthweight group
- Number of livebirths and survival to 28 days by gestation
- Survival to discharge home by gestation
- Number of deaths
- Number who had autopsy (*includes partial post mortem examination*)

### **Morbidity**

- Number of babies who had a PDA ligated
- Number of babies operated on for NEC
- Number of babies receiving surgical intervention following post haemorrhagic hydrocephalus
- Number chest drains for pulmonary air leak
- Number of babies receiving treatment for ROP

*The numbers will vary depending on local policies. This would be the same whatever definitions were used – there is wide variation in how people define PDA or NEC, for example. At best this information will show up differences in policy but may lead to further discussions, with a need for further data collection exercises to answer why any difference exist.*

*The collection of CRIBII data will allow some comparisons to be done taking disease severity into account. It may be possible at some point to agree on a definition of ethnicity and this can then be taken into account.*

*Once we have agreed on definitions then other important markers of morbidity, e.g. infection rates, need to be included.*

## **Screening**

### **Cerebral ultrasound**

Number of babies who should have been scanned under unit policy  
Number of babies who received a scan

### **Hearing screening**

Number of babies who should have been screened under unit policy  
Number of babies who had hearing screening

### **ROP**

Number of babies who should have been screened under unit policy  
Number of babies who were screened for ROP

### **Other**

- Number mothers given any antenatal steroids
- Number babies given surfactant

### **Staffing**

It is recommended that numbers of nurses are counted at two time periods during the 24 hours – one during the day and one at night.

It is also recommended that units collect daily information on number of babies in each level of care.

Over a year, the recommended number of nurses involved in direct patient care is :

- $(\text{Total intensive care days}/1) + (\text{Total high dependency days}/2) + (\text{Total special care and normal care days}/4) + 1$

For both day and night times the total number of nurse days is known allowing a calculation of the ratio of actual to recommended nurse numbers over the year.