

Malaysian National Neonatal Registry



TRAINING MANUAL

1st January 2009

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INTRODUCTION

This registry aims to standardise and formalize neonatal data collection to provide information that will help to identify the strengths and weaknesses of respective neonatal units in the country and to enable steps to be taken to improve on areas of deficiency.

OBJECTIVES OF THE NEONATAL REGISTRY

1. Determine the frequency and distribution of critically ill neonates in Malaysia. These are useful measures of the health burden arising of neonatal critical illness and its care in the country.
2. To study the mortality and some morbidity outcomes of babies admitted to NICU in participating hospitals.
3. To calculate the perinatal, neonatal, and stillbirth mortality rates of inborn babies.
4. To compare outcomes between various centres.
5. To develop indicators for standard of care in various areas eg. Expected survival rate of infants ventilated for RDS.
6. To study in further detail outcome of very low birth weight babies.
7. To study the frequency and distribution of babies with significant congenital anomalies in the country
8. Stimulate and facilitate research on neonatal critical illness and its management.

METHODOLOGY

Inclusion criteria

- All babies admitted to a Neonatal Unit who have any of the following criteria:
 1. Have a gestation of <32 weeks ie up to 31 weeks + 6 days.
 2. Have a birth weight of 1500 gms or below
 3. Are ventilated.
 4. All neonatal deaths (ie newborn babies (<28days) who die in the Neonatal Unit (NNU), delivery room [(includes OT, labour room) and other wards]
- All infants with major congenital anomaly/anomalies (see Appendix 2 definition No. 45)
- All infants with hypoxic ischaemic encephalopathy (see Appendix 2 definition No. 44)

Both inborn and outborn babies will be included

Exclusion criteria

1. Out born babies who expire before arrival will be excluded.
2. Babies who are admitted to the Neonatal Unit (NNU) at a corrected gestation of > 44/52 will not be considered a neonatal case and hence will be omitted from the study.

Data Collection Technique

The Case Report Forms (CRF) consists of 4 pages. The first page has two sections - Section 1 Patient Particulars & Maternal History and Section 2 Birth History. The second page has two sections: Section 3 Neonatal Event and Section 4 Problems/diagnoses. The third page consists of the continuation of Section 4 and Section 5 Outcome. The fourth page contain the Intrauterine Growth Curves (Composite Male/Female). Fields that are marked with an asterisk are mandatory.

Babies discharged /transferred out to non-paediatric wards in the same hospital or to other hospitals will have one set of CRFs completed until discharge. **Readmission of the same babies into the NNU will require a new set of CRFs.**

A baby who is transferred between neonatal and paediatric wards under the same department will be considered to be the same admission and the discharge CRF is to be completed after complete discharge from the hospital.

A first time admission to the NNU concerned will be considered as a **new case** (even if it has been previously admitted elsewhere) while a subsequent admission to the same NNU will be considered as a **readmission**. This will be accordingly indicated on the 1st sheet of the CRF. Section 2 (Birth History) will not be required again for a readmission while for Section 3 (Neonatal Event) only events occurring during the said admission need to be recorded.

For Section 4 (Outcome) only information pertaining to the respective admission and for Section 5 only Diagnoses and Problems that are encountered or still being encountered during this said admission need to be entered in the data sheet.

Neonates who are not admitted to the neonatal unit but fulfill the inclusion criteria e.g. stable Down syndrome etc. who are being nursed in the postnatal wards will require notification. Kindly fill up the information required in Sections 1, 2, 4 (no 45) and 5.

Hard copy CRFs will be prepared. Completed CRFs should be sent to the NRU after a defined period. (See enclosed monthly census and tracking of CRF forms).

When computer facilities are available at the participating site, data can be entered directly into the database software.

Confidentiality

Patient Data

All data are confidential. The data collection center requires the Hospital RN of the baby to facilitate communication between the data center and the participating Paediatricians should any data clarification be required.

Hospital Identification

A code will be given to each participating site. This code will only be known by the individual site and the data center. Hospital identification by code will not be disclosed in any report or publication. The code will be randomly assigned and all individual hospital data will be anonymous. Comparisons of hospital will only use codes and not the hospital names.

Secretariat

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C a s e R e p o r t F o r m

(V e r s i o n 6)

MALAYSIAN NATIONAL NEONATAL REGISTRY (CRF 09)

Centre Name: _____	<input type="radio"/> Stillbirth <input type="radio"/> Livebirth	MNNR No. (Office use): <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/>
Date of Admission: <input style="width: 20px;" type="text"/> / <input style="width: 20px;" type="text"/> / <input style="width: 20px;" type="text"/> (dd/mm/yy)	<input type="radio"/> New Case <input type="radio"/> Readmission <input type="radio"/> Transfer from, if relevant:	Centre: _____
Admitted to neonatal ward: <input type="radio"/> Yes → (Proceed to complete all sections in this CRF) <input type="radio"/> No → (Proceed to complete [Sections 1, 2, 4(No. 45) and 5])		
Instruction: Where check boxes <input type="checkbox"/> are provided, check (✓) one or more boxes. Where radio buttons <input type="radio"/> are provided, check (✓) one box only.		

SECTION 1 : PATIENT PARTICULARS & MATERNAL HISTORY

1. Name of mother: *	_____		
2. Name of baby (optional):	_____		
3. RN of baby: *	_____		
4. Mother's I/C number: *	MyKad: <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> - <input style="width: 20px;" type="text"/> - <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/>		
	Other ID document No: _____		
	Specify document type (if others): <input type="radio"/> Passport <input type="radio"/> Father's I/C <input type="radio"/> Armed Force ID <input type="radio"/> Work Permit number <input type="radio"/> Others		
5. Date of birth of baby: *	<input style="width: 20px;" type="text"/> / <input style="width: 20px;" type="text"/> / <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> (dd/mm/yyyy)		
6. Ethnic group of mother: *	<input type="radio"/> Malay <input type="radio"/> Indian <input type="radio"/> Bumiputra Sabah, specify: _____ <input type="radio"/> Other Malaysian		
	<input type="radio"/> Chinese <input type="radio"/> Orang Asli <input type="radio"/> Bumiputra Sarawak, specify: _____ <input type="radio"/> Non-citizen		
7. Maternal age: *	<input style="width: 20px;" type="text"/> (years)		
8. GPA: * (current pregnancy before delivery of this child)	Gravida: _____	Parity: _____	Abortion: _____
9. Maternal diabetes (including gestational diabetes): *	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Unknown
10. Maternal hypertension, chronic pregnancy induced: *	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Unknown
11. Maternal chorioamnionitis: *	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Unknown

SECTION 2 : BIRTH HISTORY

12. Antenatal steroid: *	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		
13. Intrapartum antibiotic: *	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		
14. Birth weight: *	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> (grams)		
15. Gestation: *	<input style="width: 20px;" type="text"/> (weeks)		
16. Growth status:	<input type="radio"/> SGA	<input type="radio"/> AGA	<input type="radio"/> LGA
17. Gender:	<input type="radio"/> Male	<input type="radio"/> Female	<input type="radio"/> Indeterminate
18. Place of birth: *	<input type="radio"/> Inborn	<input type="radio"/> University hospital <input type="radio"/> District hospital with specialist <input type="radio"/> General hospital <input type="radio"/> District hospital without specialist <input type="radio"/> Private hospital <input type="radio"/> Private maternity home	
	<input checked="" type="radio"/> Outborn →		
19. Multiplicity: *	<input type="radio"/> Singleton	<input type="radio"/> Twin	<input type="radio"/> Triplet <input type="radio"/> Others, specify: _____
20. Final mode of delivery: *	<input type="radio"/> Vaginal delivery →	<input type="radio"/> SVD <input type="radio"/> Ventouse <input type="radio"/> Forceps <input type="radio"/> Breech	
	<input type="radio"/> Caesarean section		
	<input type="radio"/> Unknown		
21. Apgar score at 1 min and 5 min (1-10): *	a) Score at 1 min: <input style="width: 20px;" type="text"/> <input type="checkbox"/> Unknown	b) Score at 5 min: (Please score even if the baby is intubated) <input style="width: 20px;" type="text"/> <input type="checkbox"/> Unknown	
	22. Initial resuscitation: *	a) Oxygen: <input type="radio"/> Yes <input type="radio"/> No	d) Cardiac compression: <input type="radio"/> Yes <input type="radio"/> No
	b) Bag-mask vent: <input type="radio"/> Yes <input type="radio"/> No	e) Adrenaline: <input type="radio"/> Yes <input type="radio"/> No	
	c) Endotracheal tube vent: <input type="radio"/> Yes <input type="radio"/> No		
23. Admission temperature: *	<input style="width: 20px;" type="text"/> (°C)		

SECTION 3 : NEONATAL EVENT

24. Respiratory support:	<input type="radio"/> Yes → <input type="checkbox"/> CPAP <input type="checkbox"/> Conventional ventilation <input type="checkbox"/> HFOV <input type="checkbox"/> Nitric oxide <input type="checkbox"/> Nasal CPAP before ETT ventilation: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> No
25. Total duration of ventilatory support: (Do not count the days on CPAP only)	<input type="text"/> <input type="text"/> <input type="text"/> (days)
26. Surfactant:	<input type="radio"/> Yes → <input type="radio"/> < 1 hr <input type="radio"/> 1- 2 hrs <input type="radio"/> > 2 hrs <input type="radio"/> No
27. Post natal steroid for CLD:	<input type="radio"/> Yes <input type="radio"/> No
28. Parenteral nutrition:	<input type="radio"/> Yes <input type="radio"/> No

SECTION 4 : PROBLEMS / DIAGNOSES

29. Respiratory :	<input type="checkbox"/> Meconium aspiration syndrome <input type="checkbox"/> Pulmonary haemorrhage <input type="checkbox"/> Pneumonia <input type="checkbox"/> Transient tachypnoea of newborn <input type="checkbox"/> Pulmonary interstitial emphysema <input type="checkbox"/> Unknown
30. RDS:	<input type="radio"/> Yes <input type="radio"/> No
31. Pneumothorax:	<input type="radio"/> Yes → <input type="checkbox"/> Pneumothorax developed during mechanical ventilation: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> No
32. Supplemental * oxygen at:	a) Day 28: <input type="radio"/> Yes <input type="radio"/> No b) 36 weeks corrected age : <input type="radio"/> Yes <input type="radio"/> No
33. Cardiovascular:	PPHN: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
34. PDA:	<input type="radio"/> Yes → a) ECHO done: <input type="radio"/> Yes <input type="radio"/> No b) Indomethacin/Ibuprofen: <input type="radio"/> Yes <input type="radio"/> No c) Ligation: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> No
35. NEC (Stage 2 and above):	<input type="radio"/> Yes → <input type="checkbox"/> Surgical treatment: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> No
36. ROP: Retinal * Exam Done:	<input type="radio"/> Yes (If yes, worst stage of ROP): → <input type="radio"/> Stage 0 <input type="radio"/> Stage 1 <input type="radio"/> Stage 2 <input type="radio"/> Stage 3 <input type="radio"/> Stage 4 <input type="radio"/> Stage 5 a) Laser therapy: <input type="radio"/> Yes <input type="radio"/> No b) Cryotherapy: <input type="radio"/> Yes <input type="radio"/> No c) Vitrectomy: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> No → <input type="checkbox"/> Appointment given: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not applicable
37. IVH:	<input type="radio"/> Yes If yes, worst grade : → <input type="radio"/> Grade 1 <input type="radio"/> Grade 2 <input type="radio"/> Grade 3 <input type="radio"/> Grade 4 <input type="checkbox"/> VP shunt / reservoir insertion <input type="radio"/> No <input type="radio"/> Not applicable (term infant) <input type="checkbox"/> Ultrasound not done
38. Central venous line:	<input type="radio"/> Yes <input type="radio"/> No
39. Catheter associated infection:	<input type="radio"/> Yes <input type="radio"/> No
40. Catheter associated ischaemic event:	<input type="radio"/> Yes → <input type="radio"/> Vasospasm <input type="radio"/> Gangrene <input type="radio"/> Organ dysfunction <input type="radio"/> No

SECTION 4 : PROBLEMS / DIAGNOSES (cont.)

41. Seizures:	<input type="radio"/> Yes	<input type="radio"/> No
42. Infection: (Clinical or Confirmed)	<input type="radio"/> Yes → <input type="radio"/> Clinical sepsis <input type="radio"/> No → <input type="radio"/> Confirmed sepsis	I) For first episode of confirmed sepsis: <input type="radio"/> On or before day 3 of life <input type="radio"/> After day 3 of life II) For confirmed sepsis: <input type="checkbox"/> Group B Streptococcus <input type="checkbox"/> Fungal <input type="checkbox"/> Acinetobacter <input type="checkbox"/> MRSA <input type="checkbox"/> Staphylococcus aureus <input type="checkbox"/> Others, specify: <input type="checkbox"/> CONS <input type="checkbox"/> Klebsiella <input type="checkbox"/> ESBL organisms <input type="checkbox"/> Pseudomonas
43. Neonatal meningitis:	<input type="radio"/> Yes	<input type="radio"/> No
44. HIE (≥ 36 weeks):	<input type="radio"/> None	<input type="radio"/> Mild <input type="radio"/> Moderate <input type="radio"/> Severe
45. Congenital anomalies:		
45a. Major congenital anomalies:		
<input type="radio"/> Yes → <input type="radio"/> No → (Proceed to No.46):		
<input type="checkbox"/> Syndrome (known) <input type="checkbox"/> Down <input type="checkbox"/> Edward <input type="checkbox"/> Patau <input type="checkbox"/> Others, specify (Please refer to ICD 10): <input type="checkbox"/> Not a recognised syndrome <input type="checkbox"/> Isolated major abnormality	<input type="checkbox"/> CVS → <input type="checkbox"/> Cyanotic <input type="checkbox"/> Acyanotic <input type="checkbox"/> ECHO done <input type="checkbox"/> CNS → <input type="checkbox"/> Hydrocephalus <input type="checkbox"/> Hydrancephaly <input type="checkbox"/> Holoprosencephaly <input type="checkbox"/> Others (Refer to ICD 10): <input type="checkbox"/> Neural Tube Defect → <input type="checkbox"/> Spina bifida <input type="checkbox"/> Anencephaly <input type="checkbox"/> Encephalocoele <input type="checkbox"/> Others (Refer to ICD 10):	<input type="checkbox"/> Skeletal dysplasia <input type="checkbox"/> Respiratory <input type="checkbox"/> GIT <input type="checkbox"/> Hydrops <input type="checkbox"/> Renal <input type="checkbox"/> Cleft → <input type="checkbox"/> Lip <input type="checkbox"/> Palate <input type="checkbox"/> Lip and palate <input type="checkbox"/> Others, specify <input type="checkbox"/> None of the above
46. Inborn Errors of Metabolism (IEM):	<input type="radio"/> Yes →	a) Clinical diagnosis? <input type="radio"/> Yes <input type="radio"/> No b) Confirmed diagnosis? <input type="radio"/> Yes, specify → <input type="radio"/> No
	<input type="radio"/> No	

SECTION 5 : OUTCOME

1. Date of discharge / transfer:	<input type="text"/> / <input type="text"/> / <input type="text"/> (dd/mm/yy)	
2. Weight and growth status on discharge / death:	2a) Weight:	<input type="text"/> (grams)
	2b) Growth status:	<input type="radio"/> SGA <input type="radio"/> AGA <input type="radio"/> LGA
3. Feeding at discharge / death:	<input type="radio"/> Never fed <input type="radio"/> Formula only <input type="radio"/> No data / Unknown <input type="radio"/> Human milk only <input type="radio"/> Human milk with formula	
4. Total duration of hospital stay (Neonatal / Paeds Care):	<input type="text"/> (in completed days)	
5. Outcome:		
<input type="radio"/> Alive →	Place discharged to: <input type="radio"/> Home <input type="radio"/> Social welfare home <input type="radio"/> Other non Paeds Ward <input type="radio"/> Still hospitalized as of 1st birthday <input type="radio"/> Transfer to other hospitals →	
	a) Name of hospital: b) Reason for transfer:	<input type="radio"/> Growth / Stepdown care <input type="radio"/> Acute medical / diagnostic services <input type="radio"/> Social/ Logistic reason <input type="radio"/> Lack of NICU bed <input type="radio"/> Others, specify: <input type="radio"/> Chronic/Palliative care <input type="radio"/> Surgery
	c) Post transfer disposition: (Please fill this section if place transferred is not part of the NNR Network) <input type="radio"/> Home <input type="radio"/> Transferred again to another hospital <input type="radio"/> Death <input type="radio"/> Readmitted to your hospital	
<input type="radio"/> Dead →	Died within 12 Hours of admission: <input type="radio"/> Yes <input type="radio"/> No	Place of death: <input type="radio"/> Labour room/OT <input type="radio"/> Neonatal unit <input type="radio"/> In transit <input type="radio"/> Others, specify:

Name : _____ Signature : _____ Date: / / (dd/mm/yy)

DATA DEFINITION AND DATA STANDARDS

Centre Name: Name of participating hospital

Date of Admission (dd/mm/yy): Date of first admission to the participating site

State if it is a Stillbirth or Livebirth

State if it is a new case, or a readmission.

If the case is transferred from another hospital and never admitted to your hospital, it is a new case, tick and specify “New case” and “Transfer from”. Please specify name of hospital.

Indicate whether the case was admitted to the neonatal ward

SECTION 1: Patient Particulars & Maternal History

1. **Name of mother:** Name as in hospital record
2. **Name of baby (optional):** Name as in hospital record, if relevant
3. **RN of baby:** RN at participating hospital. If the baby dies in Labour room and has no RN, then use the mother’s RN.
4. **Mother’s identity card number:** MyKad number or Other ID document no. Please specify type of document
5. **Date of Birth:** dd/mm/yyyy
6. **Ethnic group of mother:** Malay / Chinese / Indian / Orang Asli / Bumiputra Sabah / Bumiputra Sarawak / Non-citizen / Other Malaysian: If Bumiputra Sabah or Bumiputra Sarawak please specify the indigenous group.
7. **Maternal Age:** Age in completed years.
8. **GPA:** Gravida,, Parity, _Abortion (of current pregnancy **before** delivery of this child)
9. **State ‘yes’ or ‘no’ if mother had diabetes (regardless of whether it is gestational or pre-gestational). State ‘unknown’ if so**
10. **State ‘yes’ or ‘no’ if mother had hypertension (regardless of whether chronic or pregnancy-induced). State ‘unknown’ if so**
11. **State ‘yes’ or ‘no’ if mother had chorioamnionitis. State ‘unknown’ if so**

SECTION 2: Birth History

12. **Antenatal Steroid:** State ‘yes’ or ‘no’ if this has been given (regardless of number of doses or when it was given). **State ‘unknown’ if so**
13. **Intrapartum Antibiotics:** If systemic antibiotics were given to the mother in the 24 hours prior to delivery, record as ‘Yes’. This includes antibiotics given only enterally or parenterally, not topical antibiotics. **State ‘unknown’ if so**
14. **Birth weight (grams):** Weight in grams at birth hospital. If there are discrepant values, use the birth hospital value for out-born babies. If birth weight is unavailable, use the first weight taken up

to 24 hours of life. If birth weight is only listed as an estimate, record the estimate, but make a note on the CRF that this is an approximate birth weight.

15. **Gestation (weeks):** Best estimate of gestational age at birth given in full weeks. Preferences among estimates should be 1) obstetric estimate according to delivering obstetrician. (US date to be selected if done earlier than 25 weeks if there is a discrepancy with LMP dates. Otherwise use LMP dates. 2) new expanded Ballard scoring. If there is no definite estimate but baby is referred to as term baby, enter 40
16. **Growth status:** based on Intrauterine Growth Curves (Composite Male / Female) chart in page 4 of the CRF. SGA <10th centile; AGA 10-90th centile; LGA >90th centile
17. **Gender:** Indicate Male, Female or Indeterminate
18. **Place of birth:**

Inborn- born in the same hospital as the participating site. If born within the wards of the participating hospital to be considered as inborn (unless in the ambulance – born before arrival)

Outborn: Born in another place (includes BBA) and transferred after birth to the NNU of the participating site. Includes those born in the hospital compound.

1. University Hospital
2. General Hospital
3. Private Hospital
4. District Hospital with specialist
5. District Hospital without specialist
6. Private Maternity Home
7. Home
8. Others (e.g. in transit, please specify)

All big city government hospitals are considered as General hospitals and ticked as 2.
District hospitals with specialist pertain to availability of specialist post even if this post is not filled.

19. **Multiplicity:** To indicate as singleton, twin, triplet or others i.e. quadruplets, etc.
20. **Final Mode of delivery:** Tick as relevant. All caesarians are considered as such without differentiation into upper or lower segment. For breech presentation in Caesarian section, tick as Caesarean section only
21. **Apgar Score at 1 min and 5 min:** Enter the apgar score at 1 min and at 5 min as noted in the Labour and delivery record. Please score even if the baby was intubated by 5 minutes of life. Only tick ‘unknown’ if so, not because it was not scored once baby intubated.
22. **Initial resuscitation:** Tick “Yes for all intervention that apply
- 22a. **Oxygen:**
Tick “Yes” if the baby received any supplemental oxygen in the delivery room
Tick “No” if the baby did not receive supplemental oxygen in the delivery room.
- 22b. **Bag-mask vent :**
Tick “Yes” if the baby received any positive pressure breaths with a bag and face mask in the delivery room.
Tick “No” if the baby did not receive any positive pressure breaths with a bag and mask in the

delivery room. Tick “No” if a bag and face mask were only used to administer CPAP (continuous positive airway pressure) and no positive pressure breaths were given.

22c. Endotracheal tube ventilation:

Tick “Yes” if the baby received ventilation through an endotracheal tube in the delivery room

Tick “No” if the baby did not receive ventilation through an endotracheal tube in the delivery room.

If an endotracheal tube was placed only for suctioning, as for MAS, and assisted ventilation was not given through the tube, tick “No”

22d. Cardiac Compression:

Tick “Yes” if external cardiac massage was given in the delivery room

Tick “No” if external cardiac massage was not given in the delivery room

22e. Adrenaline:

Tick “Yes” if adrenaline was given in the delivery room via intravenous, intracardiac or intratracheal routes.

Tick “No” if adrenaline was not given in the delivery room via intravenous, intracardiac or intratracheal routes.

23. **Admission temperature** – Indicate the temperature on admission to one decimal point in degrees Celsius.

SECTION 3: Neonatal Event

24. **Respiratory support:** Tick “Yes” for all respiratory support given.

CPAP – if the infant was given continuous positive airway pressure (CPAP) applied through the nose at any time after leaving the delivery room. *Indicate whether CPAP was administered before endotracheal tube (ETT) ventilation.*

Conventional Ventilation – is intermittent positive pressure ventilation through an endotracheal tube with a conventional ventilator (IMV rate <240/min) at any time after leaving the delivery room

High frequency oscillatory ventilation as delivered by an oscillator.

High frequency oscillatory ventilation (IMV rate \geq 240/min) at any time after leaving the delivery room. High frequency oscillatory ventilation via nasal prongs is not considered HFOV

Nitric Oxide – nitric oxide delivered as a gas via a ventilator at any time after leaving the delivery room

25. **Total Duration of Ventilatory support:** State to next complete day i.e. < 24 hours is 1 day and 2 days 4 hours is 3 days, excluding days on “CPAP only”.

26. **Surfactant:** Indicate whether exogenous surfactant was given or not. If “Yes” indicate whether the infant received it at < 1hr, 1 to 2 hrs. or > 2hrs postnatal age.

27. **Post Natal Steroid for CLD:** Indicate given or not if systemic corticosteroids were used after birth to treat bronchopulmonary dysplasia or chronic lung disease (CLD). Steroids given for

other purposes e.g. hypotension and laryngeal oedema will not be included. Inhaled corticosteroids are not considered systemic corticosteroids and should be included.

28. **Parenteral Nutrition:** Nutrition given intravenously. Parenteral nutrition must include amino acids with or without fats, hence plain dextrose saline infusion is not parenteral nutrition.

SECTION 4: Problems / Diagnoses

Mandatory fields are included for some diagnoses /procedures that are very important in the care of VLBW and sick infants. Definitions of these conditions are as shown in Appendix 2. Other diagnoses or problems not given in the list can be referred to 'WHO 1992 ICD-10; Volume 1 document' and to be written in the space provided under 'Others'

There should not be too many NA (Not available) or 'Unknown' data

SECTION 5: Outcome

1. **Date of discharge:** Enter the exact date

2. **Weight (grams) and growth status on discharge/death:**

- 2a. Weight on Death is the last weight taken when the baby is alive. Enter the exact weight in grams
2b. Indicate growth status as per Intrauterine Growth Curves (Composite Male/Female)

3. **Feeding at Discharge/death:**

This applies to feeding received at the time of discharge:

Tick 'Never fed' if the infant did not receive any enteral feedings with either formula milk or human milk at discharge.

Tick 'Human milk only' if the infant was discharged receiving human milk as their only enteral feeding, either by being breast fed and/or by receiving expressed breast milk.

Tick 'Formula only' if the infant was discharged receiving formula milk as their only enteral feeding.

Tick 'Human milk with formula' if the infant was discharged receiving human milk and formula milk.

4. **Total Duration of hospital stay (Neonatal/Paed Care):** State to next complete day i.e. < 24 hours is 1 day and 10 days 6 hours is 11days.

5. **Outcome:** Alive or Dead – Alive at discharge or died before discharge.

If Child Alive, state Place of discharge to: Home, Social welfare home, Other Non-Paed Ward, 'Still hospitalised as of 1st birthday' or Transferred to other hospitals. If transferred to other hospitals, specify the name of hospital transferred to.

Post transfer disposition. If a case is transferred to another hospital in the NNR network, complete the CRF up to current status and send form with the baby. The referral centre would complete a new CRF and this will be analysed together with the CRF of the referring hospital.

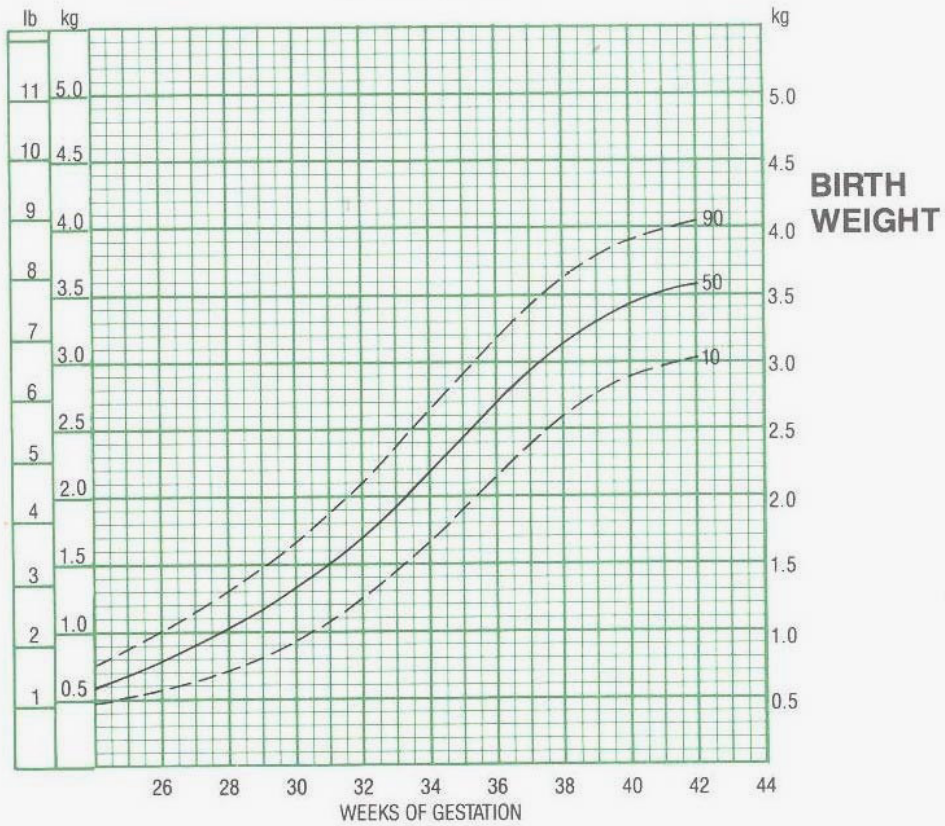
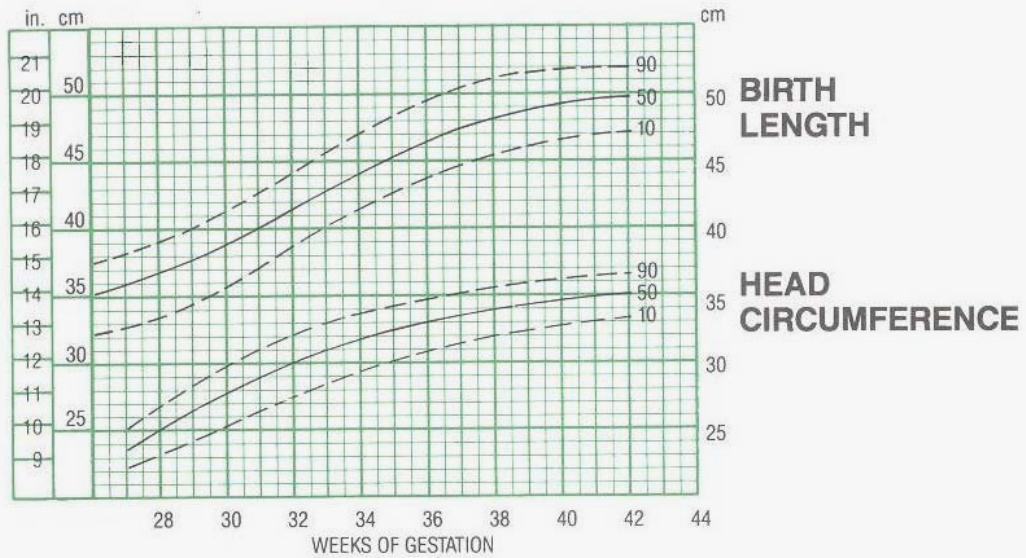
If the case is transferred to another hospital out of the NNR network the referring unit **must get the final 'outcome' of the baby** from the unit that the case was referred to.

If Child Died, tick 'Yes' or 'No' whether the infant died within 12 hours or less from the time of admission to the NICU.

Place of Death: Labour Room/OT, In Transit, Neonatal Unit and others, specify.

APPENDIX 1

INTRAUTERINE GROWTH CURVES (COMPOSITE MALE / FEMALE) (APPENDIX 2)



Data Source: W.H. Kitchen et al Revised intrauterine growth curves for an Australian hospital population. Aust. Paediatr. J. (1983) 19:157-161.

APPENDIX 2

Definitions of Certain Specified Diagnoses (In Section 4: Problems/Diagnosis)

Diagnosis	Definition
<p>29. Respiratory</p> <p>Meconium aspiration syndrome</p> <p>Pulmonary haemorrhage</p> <p>Pneumonia</p> <p>Transient Tachypnoea of Newborn</p> <p>Pulmonary interstitial emphysema</p>	<p>Tick “yes” if all 5 of the following criteria are satisfied:</p> <ol style="list-style-type: none"> 1. Presence of meconium stained amniotic fluid at birth 2. Respiratory distress with onset within 1 hour of birth. Respiratory distress will be defined as the presence of one of the following signs: tachypnoea, grunting, nasal flaring or intercostals retractions 3. A PaO₂<50mmHg in room air, central cyanosis in room air or a requirement for supplemental oxygen to maintain a PaO₂ >50mmHg 4. Abnormal CXR compatible with meconium aspiration: Findings may include coarse irregular or nodular pulmonary densities, areas of diminished aeration or consolidation alternating with areas of hyperinflation, or generalized hyperinflation 5. Absence of culture proven early onset bacterial sepsis or pneumonia (ie negative blood culture within 72 hours of birth) <p>Pulmonary haemorrhage originating in the perinatal period (as diagnosed clinically by pink or red frothy liquid draining from the mouth or arising from the trachea between the vocal cord or suctioned through the endotracheal tube. Diagnosis may also be made on autopsy finding of haemorrhage in the lungs)</p> <p>Infection of the lungs acquired prepartum, intrapartum, at birth or after birth. (Diagnosed with or without cultures). Diagnosis is made clinically and supported by CXR findings</p> <p>Benign disease of near-term, term or large premature infants with respiratory distress shortly after delivery resolving within 3 days.</p> <p>Dissection of air into the perivascular tissues of the lung from alveolar overdistention or overdistention of the smaller airways evident on CXR as linear or cast-like lucencies with a history of requiring increasing ventilatory support.</p>

<p>30. Respiratory distress syndrome (RDS). Tick 'yes' or 'no'</p>	<p>Respiratory Distress Syndrome (RDS) is defined as: A. PaO₂ <50 mmHg in room air, central cyanosis in room air, or a requirement for supplemental oxygen to maintain PaO₂ >50 mmHg AND B. A chest radiograph consistent with RDS (low lung volumes and reticulogranular appearance to lung fields, with or without air bronchograms).</p>
<p>31. Pneumothorax Tick 'yes' or 'no'</p>	<p>Presence of extrapleural air diagnosed by chest radiograph or needle aspiration (thoracocentesis).</p> <p>For infants who had thoracic surgery and a chest tube was placed at the time of surgery OR if free air was only present on a CXR taken immediately after thoracic surgery and was not treated with a chest tube, tick 'No'.</p> <p>For infants who had thoracic surgery and then later developed extrapleural air diagnosed by CXR or needle thoracocentesis, tick 'Yes'.</p> <p>Indicate whether pneumothorax developed during mechanical ventilation.</p>
<p>32. Supplemental oxygen State if required at Day 28 and 36 weeks corrected gestation</p>	<p>Receipt of continuous enriched oxygen concentration >0.21% by oxyhood, nasal cannula, nasal catheter, facemask or other forms of respiratory support. 'Continuous' means that the patient is receiving oxygen throughout the time period and not just in brief episodes as needed i.e. during feeds. 'Blow-by' oxygen dose not count unless it is the mode of oxygen administration used in a transport situation. Do not score oxygen given as part of a hyperoxia test.</p>
<p>33. Cardiovascular Persistent Pulmonary Hypertension (PPHN)</p>	<p>Failure of normal pulmonary vasculature relaxation at or shortly after birth, resulting in impedance to pulmonary blood flow which exceeds systemic vascular resistance, such that deoxygenated blood is shunted to the systemic circulation</p>
<p>34. Patent ductus arterious (PDA).</p>	<p>Clinical evidence of left to right PDA shunt documented by continuous murmur, hyperdynamic precordium, bounding pulses, wide pulse pressure, congestive heart failure, increased pulmonary vasculature or cardiomegaly by CXR, and/or increased oxygen requirement or ECHO evidence of PDA with documentation of left to right ductal shunting</p>

	<p>If ticked 'Yes', indicate whether ECHO was done and whether treatment (indomethacin/ibuprofen for >24 hours or ligation) was given or not.</p>
<p>35. Necrotising enterocolitis (NEC) (Stage 2 and above)</p> <p>Tick 'yes' or 'no'</p> <p>If "Yes" and managed surgically tick 'Surgical Rx'</p>	<p>NEC according to Bell's criteria stage 2 or higher</p> <p>Stage 1 : Suspect (History of perinatal stress, systemic signs of ill health ie temperature instability, lethargy, apnoea, GIT manifestations ie poor feeding, increased volume of gastric aspirate, vomiting, mild abdominal distension, fecal occult blood with no anal fissure)</p> <p>Stage 2 : Confirmed (Any of features of stage 1 plus persistent occult, or gastrointestinal bleeding, marked abdominal distension, abdominal radiograph; intestinal distension, bowel wall oedema, unchanging bowel loops, pneumatosis intestinalis, portal vein gas)</p> <p>Stage 3 : Advanced (Any of features of stages 1 or 2 plus: deterioration in vital signs, evidence of shock or severe sepsis, or marked gastrointestinal hemorrhage, or abdominal radiograph shows any of features of stage 2 plus pneumoperitoneum)</p>
<p>36. Retinopathy of prematurity (ROP) Maximum stage of ROP in left/right eye as defined by the International Committee on ROP (ICROP). Score according to the grade of ROP assigned on an eye exam done by an ophthalmologist.</p> <p>If there is no explicit grade listed, then score according to the descriptions given by the ICROP.</p> <p>Tick "Yes" if a Retinal exam is done and enter the worst stage.</p> <p>State if laser, cryotherapy or vitrectomy was done. If screening was not done, state "No" AND indicate whether an appointment for retinal examination was given.</p>	<p>If an indirect ophthalmologic examination was performed at any time, enter the worst stage documented</p> <p>Stage 0 : No Evidence of ROP Stage 1: Demarcation Line Stage 2: Ridge Stage 3: Ridge with Extraretinal Fibrovascular Proliferation Stage 4: Retinal Detachment Stage 5: Vitreous haemorrhage</p>
<p>37. Intraventricular haemorrhage (IVH)</p> <p>Tick "Yes" if Intraventricular haemorrhage (IVH) is seen and enter</p>	<p>If Ultrasound of Brain done <u>on or before</u> 28 days of life, enter the worst grade</p> <p>Grade 1 Subependymal germinal matrix(GM)</p>

<p>the worst grade before or on 28 days of life. State if VP shunt/reservoir insertion was done.</p> <p>Tick “No” if there was no IVH before or on day 28. Tick “Not applicable” for term infants Indicate if ultrasound was not done before or on 28 days.</p>	<p>haemorrhage only Grade 2 IVH without ventricular dilatation Grade 3 IVH with ventricular dilatation Grade 4 IVH with parenchymal involvement</p>
<p>38. Central venous line</p>	<p>Presence of any of three types of catheters:</p> <p>(1)Umbilical catheters (2)Percutaneously inserted central catheters (3)Surgically placed Broviac catheter that terminates at or close to the heart or in one of the great vessels. Aorta, superior vena cava, brachiocephalic veins, internal jugular veins, subclavian veins, inferior vena cava, external iliac veins and common femoral veins are considered great vessels for this study.</p> <p>NA – not applicable – no CVC line</p>
<p>39. Central Venous Catheter (CVC) associated infection</p>	<p>All 3 criteria to be present:</p> <ol style="list-style-type: none"> 1. A recognized pathogen isolated from one blood culture or a known skin pathogen isolated from two blood cultures (eg: coagulase negative staphylococcus sp.) 2. One or more clinical signs of infection such as fever, hypothermia, apnea and bradycardia. 3. A central venous catheter in place for at least 48 hours prior to the time the blood culture is drawn.
<p>40. Catheter associated ischaemic event:</p>	<p>Catheter related events leading to ischaemia which includes catheter occlusion and acute problems related to large vessel obstruction, including organ and limb dysfunction as well as embolic events. This ischaemia includes transient (eg. vasospasm) as well as permanent events. If yes, select ‘vasospasm’ (transient event) or ‘gangrene’ (permanent event) or others (organ dysfunction)</p>

<p>41. Seizures</p> <p>Tick 'yes' or 'no'</p>	<p>Clinical evidence of subtle seizures, or of focal or multifocal, clonic or tonic seizures, confirmed by 2 or more clinicians or diagnosed by EEG. Used synonymously with fits or convulsions</p>
<p>42. Infections</p> <p>Tick 'Yes' if there is evidence of clinical or confirmed sepsis.</p>	<p><i>Clinical sepsis</i> One of the following clinical signs or symptoms with no other recognised cause: Fever (>38°C), hypothermia (<37°C), apnoea, bradycardia <i>and all of the following:</i></p> <ol style="list-style-type: none"> a. Blood culture not done or no organism or antigen detected in blood b. No apparent infection at another site c. Physician institutes appropriate antimicrobial therapy for sepsis <p><i>Confirmed sepsis</i> Clinical evidence of sepsis plus culture-proven infection e.g.: positive blood, urine, or CSF culture or positive bacterial antigen test. Include congenital pneumonia if blood culture was positive.</p> <p>State whether the onset of first confirmed sepsis was Day 3 and below or after 3 days of birth.</p> <p>NOTE: The date of birth counts as day 1 regardless of the time of birth. For an infant born at 11:59 PM on September 1, day 3 will be September 3.</p> <p>Please state the organism cultured:</p> <ol style="list-style-type: none"> 1 Group B streptococcus 2 MRSA 3 CONS (see below) 4.ESBL organisms 5. Fungal (see below) 6 Staphylococcus aureus 7 Klebsiella 8 Pseudomonas 9 Acinetobacter 10 Others, specify <p><u>For CONS:</u> Place a tick if the infant has ALL 3 of the following:</p> <ol style="list-style-type: none"> 1. CONS is recovered from a blood culture obtained from either a central line, or a peripheral blood sample and/or is recovered from infant's CSF AND

	<p>2. Signs of generalized infection (such as apnoea, temperature instability, feeding intolerance, worsening respiratory distress or haemodynamic instability) AND</p> <p>3. Treatment with 5 or more days of IV antibiotics after the above cultures were obtained. If the patient died, was discharged, or transferred prior to completion of 5 days or more of IV antibiotics, this condition would still be met if the intention was to treat for 5 or more days</p> <p>Do not place a tick if any or all of the above are not true</p> <p><u>For FUNGAL infection:</u> Place a tick only if a fungus was recovered from a blood culture obtained from either a central line or peripheral blood sample after day 3 of life.</p>
<p>43. Neonatal meningitis</p>	<p>Signs of clinical sepsis and evidence of meningeal infection as shown in cerebrospinal fluid findings (i.e. cytology, biochemistry or microbiologic findings)</p>
<p>44. Hypoxic ischaemic encephalopathy (HIE)</p> <p>This item only applies to infants with a gestational age of 36 weeks and 0 days or more</p>	<p>HIE requires the presence of all 3 of the following criteria:</p> <p>1. Presence of a clinically recognized encephalopathy within 72 hours of birth. Encephalopathy is defined as the presence of 3 or more of the following findings within 72 hours after birth:</p> <ul style="list-style-type: none"> a. abnormal level of consciousness: hyperalertness, lethargy, stupor or coma b. abnormal muscle tone: hypertonia, hypotonia or flaccidity c. abnormal deep tendon reflexes: increased, depressed or absent d. seizures: subtle, multifocal or focal clonic e. abnormal Moro reflex: exaggerated, incomplete or absent f. abnormal suck: weak or absent g. abnormal respiratory pattern: periodic, ataxic or apnoeic h. oculomotor or papillary abnormalities: skew deviation, absent or reduced Doll's eye or fixed unreactive pupils <p style="text-align: center;">AND</p> <p>2. Three or more supporting findings from the following list:</p> <ul style="list-style-type: none"> a. arterial cord pH<7.00 b. Apgar score at 5 minutes of 5 or less c. evidence of multiorgan system dysfunction –

<p><i>HIE severity</i> If the infants diagnosed with HIE, record the worst stage observed during the first 7 days following birth based on the infant’s level of consciousness and response to arousal maneuvers such as persistent gentle shaking, pinching, shining a light or ringing of a bell:</p> <p>Tick “None, Mild, Moderate, Severe ” for infants of gestational age 36 weeks or more</p> <p>Tick “Not applicable” for infants below 36 weeks gestational age at birth</p>	<p>dysfunction of one or more of the following systems within 72 hours of birth:</p> <ul style="list-style-type: none"> i. renal: oliguria or acute renal failure ii. GI: necrotizing enterocolitis, hepatic dysfunction iii. haematologic: thrombocytopenia, disseminated intravascular coagulopathy iv. endocrine: hypoglycaemia, hyperglycaemia, hypercalcaemia, syndrome of inappropriate ADH secretion (SIADH) v. pulmonary: persistent pulmonary hypertension vi. cardiac: myocardial dysfunction, tricuspid insufficiency <p>d. evidence of foetal distress on antepartum monitoring: persistent late decelerations, reversal of end-diastolic flow on Doppler flow studies of the umbilical artery or a biophysical profile of 2 or less</p> <p>e. evidence of CT, MRI, technetium or ultrasound brain scan performed within 7 days of birth of diffuse or multifocal ischaemia or of cerebral oedema</p> <p>f. abnormal EEG: low amplitude and frequency, periodic, paroxysmal or isoelectric</p> <p style="text-align: center;">AND</p> <p>3. The absence of an infectious cause, a congenital malformation of the brain or an inborn error of metabolism, which could explain the encephalopathy.</p> <p><i>HIE severity</i></p> <ul style="list-style-type: none"> a. Mild (normal or hyperalert) – infants in this category are alert or hyperalert with either a normal or exaggerated response to arousal. b. Moderate (lethargic or stupor) – infants in this category are arousable but have a diminished response to arousal maneuvers c. Severe (deep stupor or coma) – infants in this category are not arousable in response to arousal maneuvers
<p>45a. Major Congenital Anomalies State ‘Yes’ or ‘No’. Tick “Yes” if any major congenital anomaly is present even if it is an isolated one (i.e. only one abnormality) If Yes, tick whether it is a ‘Known Syndrome’, ‘Not a Recognised Syndrome’ or ‘isolated major abnormality’ in 45a.</p> <p>If the syndrome is known, tick the specific syndromes or specify it.</p>	<p>A major congenital abnormality is defined as any abnormality of prenatal origin that if uncorrected or uncorrectable, significantly impairs normal physical or social function or reduce normal life expectancy</p> <p>Any abnormalities of prenatal origin that are present at birth, and do not have surgical, medical or cosmetic importance at the time of examination during the newborn period is a minor congenital abnormality and NOT included in this registry. Examples include</p>

<p>Proceed to 45b. (Type of Abnormalities) Tick all major abnormalities found for recognisable syndrome, non-recognisable ones or isolated major congenital abnormality - tick the abnormalities according to the list provided eg. in Down syndrome – tick all the congenital anomalies found in patient. Please specify if there are abnormalities not listed.</p>	<p>isolated findings such as ‘low-set ears’, sacral dimple or single transverse palmar crease”.</p>
<p>46. Inborn Errors of Metabolism (IEM)</p> <p>Tick “Yes” or “No”. If “yes”, tick either clinical diagnosis or confirmed diagnosis Specify the confirmed diagnosis if any</p>	<p>For clinical diagnosis, tick “yes” only if tandem spectrometry is not available to confirm diagnosis and there are signs such as encephalopathy not otherwise explained, hypoglycaemia, seizures, with or without associated family history or parental consanguineous marriage</p>



M o n t h l y B i r t h

C e n s u s

National Neonatal Registry

MONTHLY BIRTH CENSUS

Hospital :

Month : Year :

Total Births : Live Births:..... Stillbirths :

Deliveries Versus Birth Weight

Birth Weight (grams)	No. of Stillbirths	No. of Live Births	No. Admitted to Neonatal Unit	**No who died in delivery room
< 500				
500 – 600				
601 – 700				
701 – 800				
801 – 900				
901 – 1000				
1001 – 1250				
1251 – 1500				
1501 – 2000				
2001 – 2500				
>2500				
TOTAL				

** CRF to be filled for each case

Births Versus Mode of Delivery

Mode of Delivery	No. of Stillbirths	No. of Live Births	No. Admitted to Neonatal Unit	**No who died in delivery room
SVD				
Breech				
Forceps				
Ventouse				
LSCS Elective				
LSCS Emergency				
TOTAL				

** CRF to be filled for each case

Births Versus Ethnic Group

Ethnic Group	No. of Stillbirths	No. of Live Births	No. Admitted to Neonatal Unit	**No who died in delivery room
Malay				
Chinese				
Indian				
Orang Asli				
Bumiputra Sabah - specify ethnic group				
Bumiputra Sarawak - specify ethnic group				
Foreigner				
Other Malaysian				
TOTAL				

*** CRF to be filled for each case*

Remarks:.....

Name of Site Coordinator:.....

Chop:

Date:.....

- *Birth census should be sent together with the tracking forms and the completed CRFs of discharges for the month by the end of the following month.*
- *Samples of tracking forms are as follows.*



T r a c k i n g
A n d
M o n t h l y R e t u r n s
O f
C a s e R e p o r t
F o r m s

Track 1

Tracking CRFs (Admissions in month of October 2009)

Name	Hospital RN	Date of Birth	Date of admission	Criteria of inclusion	Date discharged	CRF status	Comment
THY		1 st October	1 st October	VS	20 th October	√	
NFR		2 nd October	2 nd October	LRD	2 nd October	√	
YHT		6 th October	6 th October	ELBW		Still in ward as of 31 st October	
THD		15 th October	15 th October	VS	26 th October	√	
ERT		20 th October	20 th October	VLBW	28 th October	Transfer red HKL (CRF sent with case)	
TEN		25 th October	26 th October	VS		Still in ward	
YTE		26 th October	26 th October	Died	28 th October	√	
REW		29 th October	29 th October	VP		Still in ward as of 31 st October	

Abbreviations:

√ : CRF completed and attached

Died: Died in NNU

ELBW: Extremely Low Birth Weight

LRD: Labour Room Death

VLBW: Very Low Birth Weight

VP: Very premature (<32 weeks)

VS: Venitlatory support

- **Please try to be as current as possible in registering cases in the study. Look at admissions in your neonatal ward and delivery suite and fill up this tracking form immediately every working day. Do remember to include cases that have been admitted on your off days, public holidays and weekends too.**
- The 'Tracking CRFs' list of admissions in a month should be sent to NRU within the following 1 month after the month admitted eg list of admissions from 1st to 31st October 2009 should be sent to NRU by the 30th November 2009 with the status of the CRF stated.
- The completed CRFs of patients on this list who are discharged between 1st October to 31st October should be submitted with this form to NRU

- Also patients admitted in the previous months and discharged between 1st to 31st October should also have their CRFs completed and sent together to the NRU by the 30th November.

An accompanying record (as below) of these cases should be filled and sent together.

Track 2

Crfs From Previous Months

Name	Hospital RN	Date admission	Criteria	Date discharged
GTH	12345	3 rd May	VLBW	15 th October
SMH	34562	7 th July	VLBW	17 th October
YIM	56432	2 nd September	ELBW	20 th October

Nurse coordinators or abstractors should refer to their 'Tracking CRFs' admission list of the earlier months and write under the Comment column 'CRF sent in November' for the respective case. *If there are no tracking forms of earlier admissions prior to 1st October 2009, just fill up this Track 2 form as the cases are discharged.*

Track 3

Preliminary Close-out report (in addition to Track 1 and Track 2 Forms for the month January 2010). CRF for case as of 28th January 2010 to be filled and sent by 28th February 2010 for purpose of calculating perinatal and neonatal mortality rates

Please look back at your earlier tracking admission forms for the previous months and select all those where status of CRFs is still not completed and sent as of 28th January 2010

Name	Hospital RN	Date of admission	Status of case	Comments
BGR	76854	1 st July 2009	Still in ward > 1 month	CRF incomplete (flagged by sending a photostat copy)
GHU	98765	3 rd January 2009	> 1 year	CRF completed and attached

** As the flagged cases get discharged even after the close-out date, complete the original CRF and send the CRFs at the end of the following month as in other cases.

Track 4

(Form to be submitted in addition to Track 1 and 2 Forms for the month of April 2011 by 31st May 2011)

Final close-out as of 30th April 2010 for purpose of Report Writing

Name	Hospital RN	Date of admission	Status of case	Comments
MHT	65743	5 th August 2009	Still in ward	CRF incomplete (flagged by sending a photostat copy)
YJU	67543	23 rd March 2008	> 1 year	CRF completed and attached

** As the flagged cases get discharged even after the close-out date , complete the original CRF and send the CRFs at the end of the following month as in other cases..

By the end of each month the following should be submitted

1. Birth census record of previous month
2. Track 1 form of previous month's admissions
3. Track 2 form of previous month's additional discharges
4. Completed CRFs of previous month's discharges

In addition to 1,2,3,4 for the month of February, following must be submitted

5. Track 3 form on close-out record
6. Completed and flagged CRFs as of 28th January

In addition to 1,2,3,4 for the month of May, the following must be submitted,

7. Track 4 form on close-out record
8. Completed or flagged CRFs as of 30th April

Please duplicate and keep in your centre a set of all these forms and CRFs before sending them to NRU.

