

Malaysian National Neonatal Registry

TRAINING MANUAL

1st January 2012

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INTRODUCTION

This registry aims to standardize 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 e.g. expected survival rate of infants ventilated for RDS.
6. To study in further detail the outcome of very low birth weight babies.
7. Stimulate and facilitate research on neonatal critical illness and its management.

METHODOLOGY

Inclusion criteria

- All babies admitted to a Neonatal Unit (NNU) who have any of the following criteria:
 1. Gestational age of <32 weeks ie up to 31 weeks + 6 days.
 2. Birth weight of 500-1500 gms
 3. Require respiratory support (i.e. ventilated or require CPAP).
 4. All infants with hypoxic ischaemic encephalopathy (HIE) (see Appendix 2) with or without requirement of ventilatory support.
- All neonatal deaths (i.e. newborn babies (<28days) who die in the Neonatal Unit delivery room [(includes OT, labour room) and other wards].

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.
3. Babies who are below 500g birth weight and below 22 weeks gestational age.

Data Collection Technique

The **Case Report Forms (CRF)** consists of 4 pages. The first page has two sections - Section 1: Patient Particulars & Maternal History, Section 2: Birth History, Section 3: Neonatal Event, Section 4: Problems/ Diagnoses, Section 5: Outcome, Intrauterine Growth Curves (Composite Male/Female) and for neonatal deaths, the Supplementary Form for the modified Wigglesworth's Classification of perinatal deaths. Fields that are marked with an asterisk are mandatory.

A first time admission to the NNU concerned will be considered as a **new case** (even if the baby 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 5 (Outcome) only information pertaining to the respective admission and for Section 4 only Diagnoses and Problems that are encountered or still being encountered during this said admission need to be entered in the data sheet.

Hard copy CRFs will be prepared. Where computer facilities are available at the participating site, data can be entered directly into the database software.

Completed CRFs should be sent to the MNNR secretariat after a defined period to assist data cleaning and analysis process i.e up to 1st birthday during hospitalization or still alive on 30th April the following year. (See enclosed monthly census and tracking of CRF forms).

Transfer out cases:

- Babies discharged / transferred out to *non-paediatric wards* in the same hospital will have one set of CRF completed until discharge – **maximum hospital stay for which CRF is kept is up to the 1st birthday.**
- A baby who is transferred between *neonatal and paediatric wards* under the same department will be considered same admission and the discharge CRF is to be completed after complete discharge from the hospital.
- **Cases that was transferred out / discharged to *other hospitals* will have two set of CRFs completed i.e one from referring hospital and another from referral hospital. The referring hospital must write ‘duplicate’ on top of the forms submitted to secretariat to notify that another form exists for that particular patient. The system will then merge up the two forms once they are identified as the same case.**

Readmission cases:

Readmission, or Transferred-in cases from Non-SDP NNU, of the same baby into the NICU e.g. from National Heart Institute (IJN) or home, will require the *readmission CRF* to be filled.

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

Malaysian National Neonatal Registry
C/o Clinical Research Centre (CRC)
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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 9.1)

MALAYSIAN NATIONAL NEONATAL REGISTRY (CRF 2012)

Centre Name: _____	<input type="radio"/> New Case <input type="radio"/> Readmission <input type="checkbox"/> Transfer from, if relevant : _____	MNNR No. (Office use): _____	
Date of Admission: _____ (dd/mm/yy)		Centre: _____	

Admitted to neonatal ward: Yes → (Proceed to complete all sections in this CRF) No → (Proceed to complete [Sections 1,2,4(No.47) and 5])

Abandoned baby → (if box is ticked, item # 1.4a, 6-16 not mandatory)

Instruction: Where check boxes are provided, check (✓) one or more boxes. Where radio buttons are provided (✓) one box only.

SECTION 1 : PATIENT PARTICULARS & MATERNAL HISTORY

*1. Name of mother	_____		
*2. Name of baby (Optional):	_____		
*3. RN of baby:	_____		
*4a. Mother's IC number:	Mycard: _____ - _____ - _____	Other ID document No: _____	
	Specify document type (if others): <input type="radio"/> Passport <input type="radio"/> Armed Force ID <input type="radio"/> Driver's License <input type="radio"/> Old IC <input type="radio"/> Hospital RN <input type="radio"/> Father's IC <input type="radio"/> Work Permit number <input type="radio"/> Police ID Card <input type="radio"/> Immigration permit <input type="radio"/> Other, specify: _____		
*4b. Baby's Mykid number:	_____ - _____ - _____		
*5a. Date of birth of baby: (dd/mm/yy)	____/____/____	*5b. Time of birth: (24- hour format) (enter the best estimated time of birth if the exact time unknown)	____:____
*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, specify country: _____		
*7. Maternal age:	____		
*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 included:	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		
*11. Maternal Eclampsia:	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		
*12. Maternal Choroamnionitis:	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		
*13. Maternal Anaemia:	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		
*14. Maternal abruption placenta:	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		
*15. Maternal Bleeding placenta praevia:	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		
*16. Cord prolapse:	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		

SECTION 2 : BIRTH HISTORY

*17. Antenatal steroids:	<input type="radio"/> Yes → <input type="radio"/> 1 dose <input type="radio"/> 2 doses <input type="radio"/> No <input type="radio"/> Unknown		
*18. Intrapartum antibiotic:	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown		
*19. Birth weight:	____ (grams)		
*20a. Gestation:	____ (weeks)	*20b. Gestational age based on: (if patient died)	<input type="radio"/> LMP <input type="radio"/> Ultrasound <input type="radio"/> Neonatal assessment <input type="radio"/> Unknown
*21. Growth status:	<input type="radio"/> SGA <input type="radio"/> AGA <input type="radio"/> LGA		
*22. Gender:	<input type="radio"/> Male <input type="radio"/> Female <input type="radio"/> Ambiguous/ Indeterminate		
*23. Place of birth:	<input type="radio"/> Inborn <input type="radio"/> Home <input type="radio"/> University hospital <input type="radio"/> Enroute/ During transport <input type="radio"/> Outborn → <input type="radio"/> Health Clinic <input type="radio"/> Private hospital <input type="radio"/> Others, specify: _____ <input type="radio"/> Private Hospital <input type="radio"/> Maternity home with specialist <input type="radio"/> Unknown <input type="radio"/> Government hospital with specialist <input type="radio"/> Maternity home without specialist <input type="radio"/> District <input type="radio"/> General <input type="radio"/> Alternative Birthing centre (ABC) <input type="radio"/> Government hospital without specialist <input type="radio"/> Urban <input type="radio"/> Rural		
*24. Multiplicity:	<input type="radio"/> Singleton <input type="radio"/> Twin <input type="radio"/> Triplet <input type="radio"/> Other, specify: _____		
*25. Final Mode of delivery:	<input type="radio"/> Vaginal delivery → <input type="radio"/> SVD <input type="radio"/> Breech <input type="radio"/> Caesarean section → <input type="radio"/> Elective <input type="radio"/> Emergency <input type="radio"/> Instrumental → <input type="checkbox"/> Vacuum <input type="checkbox"/> Forceps <input type="radio"/> Unknown Others, specify: _____		

SECTION 2 : BIRTH HISTORY (continue)

*26. Apgar score at 1 min and 5 min (1-10)	a) Score at 1 min:	<input type="text"/> <input type="checkbox"/> Unknown	b) Score at 5 min: (Please score even if the baby is intubated)	<input type="text"/> <input type="checkbox"/> Unknown
27. Initial resuscitation: (applicable for inborn only)	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		
*28. Admission temperature: (mandatory if admitted to Neonatal ward)	<input type="text"/> <input type="text"/> . <input type="text"/> (°C)			

SECTION 3: NEONATAL EVENT

*29. Respiratory support:	<input type="radio"/> Yes →	a) CPAP done?	<input type="radio"/> Yes <input type="radio"/> No
	<input type="radio"/> No		
		i) Early CPAP within 1 hour from birth:	<input type="radio"/> Yes <input type="radio"/> No
		ii) Total duration of CPAP at your centre:	<input type="text"/> <input type="text"/> day(s)
	b) Conventional ventilation:	<input type="radio"/> Yes <input type="radio"/> No	
		i) Total duration of Conventional ventilation at your centre:	<input type="text"/> <input type="text"/> day(s)
	c) HFJV/HFOV:	<input type="radio"/> Yes <input type="radio"/> No	
		i) Total duration of HFJV/HFOV at your centre:	<input type="text"/> <input type="text"/> day(s)
	d) Nitric Oxide:	<input type="radio"/> Yes <input type="radio"/> No	
		i) Total duration of Nitric Oxide at your centre:	<input type="text"/> <input type="text"/> day(s)
*30. Total number of days of ventilation support at your centre:	<input type="text"/> <input type="text"/> <input type="text"/> (auto calculate)		
*31. Surfactant:	<input type="radio"/> Yes →	<input type="radio"/> < 1 hr	<input type="radio"/> 1-2hrs
	<input type="radio"/> No	<input type="radio"/> >2 hrs	
*32. Parenteral nutrition:	<input type="radio"/> Yes	<input type="radio"/> No	

SECTION 4: PROBLEMS/ DIAGNOSES

33. 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	
*34. RDS:	<input type="radio"/> Yes <input type="radio"/> No		
*35. Pneumothorax:	<input type="radio"/> Yes →	Pneumothorax developed during: <input type="radio"/> CPAP <input type="radio"/> CMV <input type="radio"/> HFV	
	<input type="radio"/> No		
*36. Supplemental oxygen and BPD:	For babies <32 weeks-State 'yes' if O2 required for Day 28 AND if Oxygen or CPAP or ventilatory support required at 36 weeks corrected gestational age:		
	a) Day 28:	<input type="radio"/> Yes <input type="radio"/> No	b) 36 weeks corrected age: <input type="radio"/> Yes <input type="radio"/> No
	For babies ≥32 weeks-State 'yes' if O2 required at 28days AND if any oxygen or CPAP or ventilatory support required at ≥56 postnatal days:		
	a) Day 28:	<input type="radio"/> Yes <input type="radio"/> No	b) ≥ Day 56: <input type="radio"/> Yes <input type="radio"/> No
*37. Cardiovascular	PPHN:	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Unknown
*38. PDA:	<input type="radio"/> Yes →	a) ECHO done:	<input type="radio"/> Yes <input type="radio"/> No
	<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
*39. NEC (stage 2 and above):	<input type="radio"/> Yes →	A) surgical treatment:	<input type="radio"/> Yes <input type="radio"/> No
	<input type="radio"/> No	B) NEC present before admission to your centre: (for outborn only)	<input type="radio"/> Yes <input type="radio"/> No
*40. ROP Retinal Exam Done	<input type="radio"/> Yes →	a) Date of first screening/appointment:	<input type="text"/> / <input type="text"/> / <input type="text"/>
	<i>If yes, worst stage of ROP:</i>	b) Post conceptional age at 1st screening:	<input type="text"/> (auto calculate)
		c) <input type="radio"/> No ROP <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 <input type="checkbox"/> PLUS disease	
		d) Laser Therapy:	<input type="radio"/> Yes <input type="radio"/> No
		e) Cryotherapy:	<input type="radio"/> Yes <input type="radio"/> No
		f) Vitrectomy:	<input type="radio"/> Yes <input type="radio"/> No
		g) ROP present prior to admission? (for outborn baby only)	<input type="radio"/> Yes <input type="radio"/> No
	<input type="radio"/> No →	Appointment given:	<input type="radio"/> Yes <input type="radio"/> No
	<input type="radio"/> Not Applicable		

SECTION 4: PROBLEMS/ DIAGNOSES (continue)

*41. IVH: Yes *If yes, worst grade:* Grade 1 Grade 2 Grade 3 Grade 4
 No VP shunt/ reservoir insertion
 Not applicable (term infant)
 Ultrasound not done

*42. Central venousline: Yes No

*43. Seizures: Yes No

*44. Confirmed sepsis: Yes No
I) For first episode:
 On or before day of life After day 3 of life
II) Type of organism: (can tick more than one)
 Group B Streptococcus ESBL organisms Klebsiella Others, specify:
 MRSA Fungal Pseudomonas
 CONS Staphylococcus aureus Acinetobacter

*45. Neonatal meningitis: Yes No

*46. Hypoxic ischaemic encephalopathy (HIE): None Mild Moderate Severe

***47. Congenital anomalies:**

*47a. Major congenital anomalies: Yes No

Syndrome (known)
 Down Edward Patau
 Others, specify (Refer to ICD 10):
 Not a recognized syndrome
 Isolated major abnormality

*47b. Types of abnormalities (check all that are present. Applies to all including 'known syndromes', 'not a recognized syndrome' or 'isolated major abnormality')

<input type="checkbox"/> CVS →	<input type="radio"/> Cyanotic <input type="radio"/> Acyanotic	<input type="checkbox"/> Skeletal dysplasia
	<input type="checkbox"/> ECHO done	<input type="checkbox"/> Respiratory
<input type="checkbox"/> CNS →	<input type="radio"/> Hydrocephalus	<input type="checkbox"/> GIT
	<input type="radio"/> Hydrancephaly	<input type="checkbox"/> Hydrops
	<input type="radio"/> Holoprosencephaly	<input type="checkbox"/> Renal
	<input type="radio"/> Others (Refer to ICD 10):	<input type="checkbox"/> Cleft →
<input type="checkbox"/> Neural Tube Defect	<input type="checkbox"/> Spina bifida	<input type="radio"/> Lip <input type="radio"/> Palate <input type="radio"/> Lip and Palate
	<input type="checkbox"/> Anencephaly	<input type="checkbox"/> Others, specify (Refer to ICD10):
	<input type="checkbox"/> Encephalocele	<input type="checkbox"/> None of the above
	<input type="checkbox"/> Others (Refer to ICD 10):	

SECTION 5: OUTCOME

*48a. Date of discharge / transfer/ death: (dd/mm/yy) / / *48b. Time of Death: (24 hour format) (mandatory for death cases) (enter the best estimated time of death if the exact time is unknown)

*49. Weight and growth status on discharge: a) Weight: (grams)
b) Growth status: SGA AGA LGA

*50. Feeding at discharge / death: Never fed Human milk only Formula only No data/ Unknown

*51. Total duration of hospital stay (neonatal/ paed& care): (in completed days) (auto-calculate)

*52. Outcome:

Alive → **Place discharged to:**
 Home
 Social welfare home
 Other non Paeds ward
 Still hospitalized as 1st birthday
 Transfer to other hospitals →

a) Name of hospital:	<input type="text"/>
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"/> Other, specify: <input type="radio"/> Lack of NICU bed <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

Dead → **Place of death:**
 Labour room/OT Neonatal unit In transit Others, specify:

MALAYSIAN NATIONAL NEONATAL REGISTRY (CRF 2011)

Supplementary Form

Instruction:

- 1) For term babies please fill in according to the most pertinent underlying cause of death.
 2) For preterm babies please fill in according to the most immediate cause of death.

1. Centre Name:				Office use:	<input type="text"/>	<input type="text"/>
2. Name:		3. RN:		Centre:		
4. Mother's IC Number:	New IC:	Passport:				

Immediate cause of death (Modified Wigglesworth): Tick relevant buttons to reach correct classification

NEONATAL DEATH
(Is there any LCM?)

Note: LCM = Lethal Congenital Malformation

LCM present

a) Lethal congenital malformation/defect, specify:

Neural tube defects

- Anencephaly
- Encephalocele
- Others, specify:
- (Refer to ICD 10):

CVS

- Complex/ cyanotic heart disease
- Acyanotic

CNS

- Hydrocephalus
- Hydranencephaly
- Holoprosencephaly
- Others, specify:
- (Refer to ICD 10):

Recognisable syndrome

- Down
- Edward
- Patau
- Others, specify:
- (Refer to ICD 10):

Not recognisable syndrome

- Skeletal dysplasia
- Respiratory (eg. lung hypoplasia)
- GIT
- Hydrops foetalis
- Renal
- Others, specify:

LCM absent

b) (Is gestation <37 weeks?)

Yes

c) Gestation <37 weeks conditions associated with immaturity

- IVH
- Septicaemia
- PDA in failure
- Pulmonary hemorrhage
- NEC
- Pneumonia
- PIE / BPD
- Pneumothorax
- Extreme prematurity
- Asphyxia

No

Gestation ≥37 weeks (Did the baby have an asphyxial condition?)

d) Asphyxial condition absent (Did the baby die from infection?)

e) Infection present

- Group B streptococcal septicaemia
- Meningitis
- Congenital pneumonia
- Congenital Infection
- Others, specify:

Infection absent (Are there any other specific causes of death?)

f) Other specific causes:

- Kernicterus/ severe neonatal jaundice
- Haemorrhagic disease of newborn/ Vitamin K deficiency
- Intracranial bleed / SAH
- Pneumothorax
- Pulmonary hemorrhage
- IBM
- MAS
- Surgical, specify:
- Others, specify:

Unknown cause

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

DATA DEFINITION AND DATA STANDARDS

- a. **Centre Name:** Name of participating hospital.
- b. **Date of Admission (dd/mm/yy):** Date of first admission to the participating site.
- c. State Case Type, if it is a new case, a readmission and/or transfer in.

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

If the case was transferred out from your ward and then transferred back from another hospital (Hospital X), it is a readmission. Tick “Readmission” **and** “Transfer from”specify name of hospital.

Indicate whether the case was admitted to the neonatal ward

e.g. if the baby was born alive but died in labour room.

If case was admitted, complete all sections. If not admitted - proceed to sections 1, 2, 4 (No. 47) and 5

Indicate if the case was admitted to the neonatal ward as an abandoned baby

Abandoned babies, to state by ticking the box. Once this box is ticked, the IT system will allow items 1,4a,6-16 to be not mandatory entries and default entries will be inserted by the system as “not applicable”/ “data not entered”/“9999”.

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.
- 4a. **Mother’s identity card number:** MyKad number or Other ID document no. If “Other” please specify type of document.
- 4b. **Baby’s MyKid number:** add number if available
- 5a. **Date of Birth:** dd/mm/yyyy 5b. **Time of birth:** To state in 24 hour format (mandatory for death cases) Estimate time of birth if time not accurately known as in home delivery.
6. **Ethnic group of mother:** Malay / Chinese / Indian / Orang Asli / Bumiputra Sabah / Bumiputra Sarawak / Other Malaysian (e.g. Punjabi, Eurasian or Serani) /Non-citizen (specify country). 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) # to state number of ectopic pregnancies (Please note that ectopic pregnancy is also considered as an abortion). Multiple pregnancy considered as ONE para, e.g. Mother with second pregnancy with previous set of twins, it is considered as G:2,P:1,A:0.
9. **Maternal Diabetes:** State ‘yes’ or ‘no’ if mother had diabetes (regardless of whether it is gestational or pre-gestational). State ‘unknown’ if so.

10. **Maternal Hypertension:** State 'yes' or 'no' if mother had hypertension (regardless of whether chronic or pregnancy-induced). State 'unknown' if so.
11. **Maternal Eclampsia:** State 'yes' or 'no'. State 'unknown' if so.
12. **Maternal Chorioamnionitis:** State 'yes' or 'no' if mother had chorioamnionitis. State 'unknown' if so.
13. **Maternal Anaemia** – state Yes, No or Unknown. Mother's Hb level < 11 g/dL or noted to have anaemia of pregnancy by O&G
14. **Maternal abruptio placenta** – State 'yes' or 'no'.
15. **Maternal bleeding placenta praevia** - State 'yes' or 'no'.
16. **Cord prolapse** - State 'yes' or 'no'.

SECTION 2: Birth History

17. **Antenatal Steroid:** State 'yes' (regardless of number of doses or when it was given) or 'no' if this has not been given. If yes, state whether ONE or TWO doses given.. **State 'unknown' if so.**
18. **Intrapartum Antibiotics:**
State 'Yes' if systemic antibiotics (enteral or parenteral) were given to the mother in the 24 hours prior to delivery. **State 'unknown' if so.**
19. **Birth weight (g):** 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.
- 20a. **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. (Ultrasound date to be selected if done earlier than 25 weeks and 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. Preferably insert the exact gestation for term infants – i.e. ranging from 37-41 weeks
- 20b. **Gestational age based on:** LMP, Ultrasound, Neonatal assessment or unknown – mandatory to be filled if patient died. Choose only one – the option on which you based the baby's gestational age.
21. **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.
22. **Gender:** Indicate Male, Female or Ambiguous/Indeterminate.
23. **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 BBA- consider as outborn).

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 and not wards.

1. Home
2. Health clinic
3. Government hospital with specialist
 - a. District/General Hospital
4. Government hospital without specialist
5. University Hospital
6. Private hospital
7. Maternity home with specialist
8. Maternity home without specialist
9. Alternative birthing centre (ABC) – urban or rural.
10. Enroute/during transport
11. Others - - please specify
12. Unknown

24. **Multiplicity:** To indicate as singleton, twin, triplet or others i.e. quadruplets, etc.
25. **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. **Tick as “emergency” only if there is a reason for the Caesarian section that has an emergency indication, not whether it is listed as ‘semi-emergency’ or ‘emergency’ in the OT list.**
26. **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. Apgar score can be ‘0’ at 1 minute and 5 minutes.
27. **Initial resuscitation (for inborn babies only):** Tick “Yes for all intervention that apply at birth. Mandatory for inborn cases.
- 27a. **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.
- 27b. **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 resuscitation device was only used to administer CPAP (continuous positive airway pressure) and no positive pressure breaths were given.**
- 27c. **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”.
- 27d. **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.

27e. 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.

28. **Admission temperature** – Indicate the temperature on admission to one decimal point in degrees Celsius. Mandatory field only if patient admitted to any Neonatal Ward, i.e does not include babies who die in delivery room.

SECTION 3: Neonatal Event

29. **Respiratory support:**

29a. Tick “yes” if CPAP given.

i. Early CPAP within 1 hour from birth- State ‘yes’ or ‘no’.

CPAP – if the infant was given continuous positive airway pressure applied through the nose at any time after birth by CPAP e.g. by Neopuff.

ii. Total duration of CPAP (nCPAP/BiPAP/SiPAP) ; Days. State to next complete half day the number of days on CPAP i.e. < 12 hours is 0.5 day and >12 hours is rounded up to the next completed day e.g. 7 hours is filled in 0.5 day and 14 hours is filled as 1 day

29b. Conventional ventilation State ‘yes’ or ‘no’.

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.

i. Total duration of Conventional ventilation in Days at your centre. State to the next complete day for the number of days on conventional ventilation i.e. < 12 hours is 0.5 day and >12 hours is rounded up to the next completed day e.g. 7 hours is filled in 0.5 day and 14 hours is filled as 1 day

29c. High frequency ventilation (HFJ/HFOV) State ‘yes’ or ‘no’

i. Total duration of HFJ/HFOV in Days at your centre. State to the next complete half day for the number of days on HFJ/HFOV as stated similarly above in 29a

29d. Nitric oxide State ‘yes’ or ‘no’.

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

i. State total duration of Nitric oxide given to the nearest complete half day.

30. Total number of days on ventilation support at your centre: The number of days on conventional ventilation and high frequency ventilation. **Do not include days on “CPAP”.** (option to autocalculate)

31. **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.

32. **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 on first discharge

48a. **Date of discharge/transfer/death:** Enter the exact date.

48b. **Time of death:** Please use 24-hour format – this will be used to auto-calculate age at discharge. Mandatory item for death cases – give best estimate of time of death if exact time not known.

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

49a. Enter the exact weight in grams. For Weight on death – it is the last weight taken when the baby was alive.

49b. Indicate growth status as per Intrauterine Growth Curves (Composite Male/Female).

50. **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.

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

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

If Child Alive, state Place of discharged to: Home, Social welfare home, Other Non-Paeds Ward, 'Still hospitalized as of 1st birthday' or 'Transferred to other hospitals', or 'Still alive in the ward on 30/4/2013'

If transferred to other hospitals, specify the Name of Hospital transferred to.

If a case is **transferred to another hospital in the MNRR network**, complete the CRF up to current status and send photostat copy with the baby to assist the referral hospital in obtaining the patient particulars and birth history. The referring hospital still needs to key in the original form into the system. The referral centre would open and complete a new CRF and this will be **analysed together** with the CRF of the referring hospital.

Post transfer disposition. 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. **This includes ROP findings after discharge.**

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.

SUPPLEMENTARY FORM

To be filled whenever there is a neonatal death in accordance to the Modified Wigglesworth Classification of Perinatal Mortality:

To fill in only one cause of death under each classification.

Where “to specify” is required, to fill in “ICD code”

This is data additional to that collected in main CRF for neonatal deaths.

1. **Centre name:** State name of reporting hospital.
2. **Name:** State mother’s name.
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 new I/C number or passport whichever applicable.**

Patient name label can be used for section 1-4

Immediate Cause of death (Modified Wigglesworth):

(Adapted from *Garis panduan Penggunaan Format PNM1/97 (Pindaan 2000) bagi Melapor Kematian Perinatal, Jun 2000, Bahagian Pembangunan Kesihatan Keluarga, Kementerian Kesihatan Malaysia*).

a. Lethal Congenital Malformation (LCM)/ defect

Severe or lethal congenital malformation that contributed to the death. If Yes, tick specifically the cause of death.

b. Gestation < 37 w or ≥ 37 w.

c. Immaturity

This includes only livebirths less than 37 weeks gestation after excluding LCM. Tick the immediate secondary cause of death e.g. severe IVH, pulmonary haemorrhage

d. Asphyxial conditions

All term babies who die from birth asphyxia or meconium aspiration syndrome or PPHN.

e. Infection

This refers to term babies (> 37 weeks gestation) whose primary cause of death is an infection. Some examples include meningitis, group B streptococcal infection, intrauterine infections etc.

f. Other specific causes

Specify any other cause of death not included in the above classification. This includes kernicterus, haemorrhagic shock /inborn error of metabolism/pneumothorax/ pulmonary haemorrhage. Use ICD 10 code

g. Unknown

- Where cause of death is not known.

APPENDIX 1

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

Diagnosis	Definition
<p>33. 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>34. 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>35. 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 CPAP, Conventional ventilation or HFV.</p>
<p>36. Supplemental oxygen & BPD</p> <p>For babies < 32 weeks – State 'yes' if O₂ required for 28 days AND if oxygen or CPAP or ventilatory support required at 36 weeks corrected gestational age or discharge (=BPD yes)</p> <p>For babies ≥ 32 weeks, state 'yes' if O₂ required at 28 days AND if any oxygen or CPAP or ventilatory support required at 56 postnatal days or discharge (=BPD yes)</p>	<p>Receipt of continuous enriched oxygen concentration > 21% for at least 28 days or still requiring oxygen, CPAP or other forms of respiratory support at 36 weeks for babies < 32 weeks GA, or at day 56 for babies ≥ 32 weeks GA^{1,2}.</p> <p>'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 does 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>37. Cardiovascular</p> <p>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>

¹ Jobe, AH, Bancalari, E. Bronchopulmonary dysplasia. *Am J Respir Crit Care Med* 2001; 163:1723.

² Bancalari E, Claure N. Definitions and diagnostic criteria for BPD. *Seminars in Perinatology*. 2006;30:164-170

<p>38. 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>39. Necrotising enterocolitis (NEC) (Stage 2 and above)</p> <p>Tick 'yes' or 'no'</p> <p>If "Yes" and managed surgically tick 'Surgical Treatment'</p> <p>NEC present before admission to your centre?(applies to outborn babies):</p> <p>Tick "yes" or "no"</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>40. 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. State exact date of first screening and post conceptional age at screening. Specify only the worst stage. Also tick if PLUS disease present</p>	<p>If an indirect ophthalmologic examination was performed at any time, enter the worst stage documented:</p> <p>No ROP : 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>PLUS disease : dilated veins and tortuous arteries, papillary rigidity</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, if applicable.</p> <p>State date of appointment in the “date of first screening” section and postconceptional age will be autocalculated</p> <p>ROP present prior to admission? (applies to outborn babies) Tick ‘yes’ or ‘no’</p> <p>To trace back the outcome of ROP screening on first screening if done after discharge</p>	
<p>41. Intraventricular haemorrhage (IVH)</p> <p>Tick “Yes” if Intraventricular haemorrhage (IVH) is seen and enter 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</p>	<p>If Ultrasound of Brain done <u>on or before</u> 28 days of life, enter the worst grade:</p> <p>Grade 1 IVH Subependymal germinal matrix(GM) haemorrhage only Grade 2 IVH without ventricular dilatation Grade 3 IVH with ventricular dilatation Grade 4 IVH with parenchymal involvement</p>
<p>42. Central venous line</p>	<p>Presence of any of three types of catheters:</p> <ol style="list-style-type: none"> (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>NA – not applicable – no CVC line.</p>

<p>43. 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>44. Confirmed sepsis</p> <p>Tick ‘Yes’ if there is evidence of <u>confirmed</u> sepsis.</p> <p>Do not include presumed or clinical sepsis</p> <p>State whether the onset of first confirmed sepsis was On or before Day 3 of life or After day 3 of life.</p> <p>State the organism cultured:</p> <ol style="list-style-type: none"> 1 Group B streptococcus 2 MRSA 3 CONS (see definition) 4.ESBL organisms 5. Fungal (see definition) 6 Staphylococcus aureus 7 Klebsiella 8 Pseudomonas 9 Acinetobacter 10 Others, specify 	<p><i>Confirmed sepsis</i></p> <p>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>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><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 2. Signs of generalized infection (such as apnoea, temperature instability, feeding intolerance, worsening respiratory distress or haemodynamic instability) AND 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>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>45. 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>46. Hypoxic ischaemic encephalopathy (HIE)</p>	<p>HIE requires the presence of all 3 of the following criteria:</p> <ol style="list-style-type: none"> 1. Presence of a clinically recognized

Applies to any gestation so long the criteria fulfilled

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:

- 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

AND

2. Three or more supporting findings from the following list:

- a. Arterial cord pH < 7.00
- b. Apgar score at 5 minutes of 5 or less
- c. Evidence of multiorgan system dysfunction – dysfunction of one or more of the following systems within 72 hours of birth:
 - 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.

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

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.

f. Abnormal EEG: low amplitude and frequency, periodic, paroxysmal or isoelectric.

AND

3. The absence of an infectious cause, a congenital

HIE severity

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,

<p>pinching, shining a light or ringing of a bell:</p> <p>Tick “none” if there is no HIE</p> <p>Tick “Mild, Moderate, Severe ” according to the definition</p>	<p>malformation of the brain or an inborn error of metabolism, which could explain the encephalopathy.</p> <p><i>HIE severity</i></p> <p>a. Mild (normal or hyperalert) – infants in this category are alert or hyperalert with either a normal or exaggerated response to arousal.</p> <p>b. Moderate (lethargic or stupor) – infants in this category are arousable but have a diminished response to arousal maneuvers</p> <p>c. Severe (deep stupor or coma) – infants in this category are not arousable in response to arousal maneuvers</p>
<p>47a. 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>Proceed to 47b. (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>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 isolated findings such as ‘low-set ears’, sacral dimple or single transverse palmar crease”.</p>

READMISSION CRF

To be used for babies discharged well from any MNNR SDP hospital and then readmitted to same or another MNNR SDP hospital cohort within 44 weeks of corrected age.

The aim is to audit reasons for readmission when baby was supposedly well enough to be discharged.

Discharged from: specify name of hospital

Centre Name: Specify your hospital name as in MNNR

Date of admission: Date of this admission (dd/mm/yy)

Section 1: Patient particulars

1. **Name of mother:** Name as in hospital record.
2. **Name of baby:** Name as in hospital record
3. **RN of baby:** RN at participating hospital of last discharge.
- 4a. **Mother's identity card number:** MyKad number or Other ID document no. If "Other" please specify type of document.
- 4b. **Baby's MyKid number:** add number if available
5. **Date of Birth:** dd/mm/yyyy
6. **Birth weight:**(gms)
7. **Gestation at birth:** Best estimate of gestational age at birth given in full weeks
8. **Date of first discharge:** (dd/mm/yy) Date of discharge at the first admission after birth

Section 2: Particulars of this admission

9. **Age at readmission** (autocalculate from date of readmission and date of birth)
10. **Weight at this readmission:** _ _ _ _ (gms)
11. **Reason(s) for readmission** (tick all that apply) – apnoea, fever, URTI, LRTI, confirmed sepsis, poor weight gain, cyanosis due to sucking / swallowing coordination , jaundice, others
12. **Ventilated** - Yes/ No

Section 3: Outcome

13. **Date of this discharge/transfer/death:** Enter the exact date
14. **Total duration of hospital stay during this readmission** (in completed days): State to next complete day i.e. 10 days 6 hours is 11days. (autocalculate from date of this discharge and date of readmission)
15. **Outcome at readmission:** Alive / Dead



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

C e n s u s

2012

Malaysian National Neonatal Registry

D/A Hospital Selayang
 Lebuhraya selayang-Kepong
 68100 Batu Caves
 Selangor Darul Ehsan

Telephone: 603-61203233
 Ext: 4139/4181
 Fax: 603-61202761

i. Hospital:				
ii. Month:		iii. Year:		
iv. Total Births:		v. Live Births:		vi. Still Births:

SECTION 1: DELIVERIES VERSUS BIRTH WEIGHT

Birth Weight (grams)	No. of Still Births	No. of Live Births	No. Admitted to Neonatal Unit	No. who died in delivery room
< 500				
500				
501 - 600				
601 - 700				
701 - 800				
801 - 900				
901 - 999				
1000				
1001 - 1250				
1251 - 1499				
1500				
1501 - 2000				
2001 - 2500				
> 2500				
TOTAL				

SECTION 2: BIRTH VERSUS GESTATION WEEKS

Gestation (weeks)	No. of Still Births	No. of Live Births	No. Admitted to Neonatal Unit	No. who died in delivery room
<22				
22-24				
25				
26				
27				
28				
29				
30				
31				
32				
33				
34				
35				
36				
37-40				
> 40				
TOTAL				

SECTION 3: BIRTH VERSUS MODE OF DELIVERY

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

SECTION 4: BIRTHS VERSUS ETHNIC GROUP

Ethnic Group	No. of Still Births	No. of Live Births	No. Admitted to Neonatal Unit	No. who died in delivery room
Malay				
Chinese				
Indian				
Orang Asli				
Bumiputera Sabah specify ethnic group: _____				
Bumiputera Sarawak specify ethnic group: _____				
Foreigner				
Other Malaysian: _____				
TOTAL :				

1. Remarks:	
2. Name of Site Coordinator:	
3. Chops:	
4. Date:	<input type="text"/> <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/>

i. 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.

ii. Sample of tracking form are as follows



T r a c k i n g

F o r m s

Track 1

Tracking CRFs (eg Admissions in month of October 2012)

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: Ventilatory 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 one (1) month after the month admitted eg list of admissions from 1st to 31st October 2012 should be sent to NRU by the 30th November 2012 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 and 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 2012, just fill up this Track 2 forms as the cases are discharged.*

Track 3

CRFs of from Admissions from Previous year

(Form to be submitted in addition to Track 1 and Track 2 Forms. Completed CRFs should be submitted together).

Name	Hospital RN	Date admission	Criteria	Date discharged
GTH	12345	3 rd Dec 2011	VLBW	15 th Jan 2012
SMH	34562	7 th Nov 2011	VLBW	17 th Feb 2012
YIM	56432	2 nd Jul 2011	ELBW	20 th Apr 2012

Track 4

Cases of Admissions from previous year

2012 cases as of 31th Dec 2012. Form due to be submitted by 31st Jan 2013.

Cases reaching maximum hospital stay for which CRF was kept up to the 1st birthday. Form to be submitted in addition to Track 1 and 2 Forms for the month of Jan 2013. Completed CRFs should also be submitted together.

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
5. if any, Track 3 form of previous year's additional discharges

By the **end of January each year** the following should be submitted

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

Please duplicate and keep in your centre a set of all these forms and CRFs before sending them to Coordinating Centre to facilitate query and data cleaning.

Track 1

Centre Name:.....

Admissions in Month / Year

.....

Tracking CRFs

Name	Hospital RN	DOB	DOA	Criteria of inclusion	DOD	CRF attached	Comment

