

Malaysian National Neonatal Registry

TRAINING MANUAL 2026

1st January 2026

CONTENTS

INTRODUCTION3
OBJECTIVES OF THE NEONATAL REGISTRY3
METHODOLOGY3
DATA COLLECTION TECHNIQUE4
CONFIDENTIALITY5
CASE REPORT FORM7
DATA DEFINITION AND DATA STANDARDS8
SECTION 1: Patient Particulars & Maternal History9
SECTION 2: Birth History10
SECTION 3: Neonatal Event12
SECTION 4: Problems / Diagnoses12
SECTION 5: Outcome on discharge22
Supplementary Form23
MONTHLY BIRTH CENSUS24
TRACKING FORM2

INTRODUCTION

The Malaysian National Neonatal Registry (MNNR) 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 from 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

1. All babies admitted to a Neonatal Unit (NNU) who have any of the following criteria:
 - **Gestational age of <32 weeks** ie up to 31 weeks + 6 days.
 - Birth weight of **500-1500 grams**.
 - Require **respiratory support** (i.e. ventilated or require Continuous positive airway pressure (CPAP) or high flow nasal cannula (HFNC)).
 - All infants with hypoxic **ischaemic encephalopathy (HIE)** (see Appendix 2) with or without requirement of ventilatory support.
 - All babies with **confirmed sepsis** i.e positive blood cultures or CSF cultures.
 - All babies admitted with **congenital heart disease**.
 - All babies with **Neural tube defect**.
2. **All neonatal deaths** (i.e. newborn babies (<28days) who die in the Neonatal Unit delivery room [(includes OT, labour room) and other wards].
3. 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 weeks** 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 7 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.

Additional pages are the **Supplementary Form** for the modified Wigglesworth's Classification of perinatal deaths and Intrauterine Growth Curves (Composite Male/Female). Fields that are marked with an asterisk are mandatory.

The top section of the CRF for "New case", "Readmission" and "Previously admitted to another SDP hospital" is to enable tracking the patient from one hospital to another so as to merge the data. Please refer to the following page for the list of SDP hospitals.

A first-time admission to the NNU concerned will be considered as a **new case** (if the baby has never been previously admitted to any Source Data Provider (SDP) hospital within the MNRR network) while a subsequent admission of the same baby to the same NNU will be considered as a **readmission to registry**. If the baby has previously been admitted to another SDP hospital or transferred from another hospital or IJN, the admission will be considered as "**Previously admitted to another SDP**". This will be accordingly indicated on the 1st sheet of the CRF.

Section 2 (Birth History) will not be required again for a readmission or previous admission if already previously filled in, while for Section 3 (Neonatal Event) only events occurring during the said admission need to be recorded. For Section 4, enter only Diagnoses and Problems that are encountered or still being encountered during this current admission, and for Section 5 (Outcome) only information pertaining to the current admission need to be entered in the data sheet for the current admission.

If the patient is still hospitalized up to 1st birthday or on 30th April the following year, the CRF should be closed. (See enclosed monthly census and tracking of CRF forms).

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

Tracking forms should be sent to the MNRR secretariat after 2 months to assist data cleaning. CRF's with data already entered in the database should be kept by the respective hospitals.

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 were transferred out / discharged to other hospitals or readmitted will have more than one set of CRFs completed. Each SDP hospital must write 'duplicate' on top of the forms to note that another form exists for that particular patient. **Before data entry, search for the patient in the database if it is a readmission or previous admission**. In the database, the two admissions will be merged during analysis once they are identified as the same case. The different admissions can be viewed on the individual hospital website.

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 pediatricians 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.

SDP Directory

Selangor

1. Ampang Hospital
2. Kajang Hospital
3. Selayang Hospital
4. Serdang Hospital
5. Sungai Buloh Hospital
6. Tengku Ampuan Rahimah Hospital, Klang
7. Shah Alam Hospital
8. University Putra Malaysia Teaching Hospital
9. Cyberjaya Hospital

Johor

1. Sultanah Nora Ismail Hospital, Batu Pahat
2. Sultanah Aminah Hospital, Johor Bahru
3. Sultanah Fatimah Specialist Hospital, Muar
4. Kluang Hospital
5. Segamat Hospital
6. Sultan Ismail Hospital
7. KPJ Putri Hospital

Perak

1. Raja Permaisuri Bainun Hospital
2. Seri Manjung Hospital
3. Taiping Hospital
4. Teluk Intan Hospital
5. Slim River Hospital

Sabah

1. Sabah Women and Children Hospital (Likas)
2. Keningau Hospital
3. Duchess of Kent Hospital, Sandakan
4. Lahad Datu Hospital
5. Tawau Hospital

Sarawak

1. Miri General Hospital
2. Sarawak General Hospital, Kuching
3. Sibu Hospital
4. Bintulu Hospital

Melaka

1. Melaka Hospital

Kuala Lumpur

1. Tunku Azizah Hospital, Kuala Lumpur
2. Pusat Perubatan Univeriti Malaya (PPUM)
3. Gleneagles Hospital, Kuala Lumpur
4. Pantai Hospital, Kuala Lumpur

Pulau Pinang

1. Pulau Pinang Hospital
2. Seberang Jaya Hospital

Putrajaya

1. Putrajaya Hospital

Kelantan

1. Raja Perempuan Zainab II Hospital, Kota Bharu
2. Kuala Krai Hospital
3. Tanah Merah Hospital

Kedah

1. Sultan Abdul Halim Hospital, Sungai Petani
2. Sultanah Bahiyah Hospital, Alor Setar
3. Kulim Hospital
4. Sultanah Maliha Hospital, Langkawi
5. Baling Hospital

Pahang

1. Sultan Haji Ahmad Shah Hospital, Temerloh
2. Tengku Ampuan Afzan Hospital, Kuantan
3. Kuala Lipis Hospital

Terengganu

1. Sultanah Nur Zahirah Hospital, Kuala Terengganu

Perlis

1. Tuanku Fauziah Hospital, Kangar

Negeri Sembilan

1. Tuanku Ja'afar Hospital, Seremban
2. Tuanku Ampuan Najihah Hospital, Kuala Pilah
3. Port Dickson Hospital

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CASE REPORT FORM

2026

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 or 'previously admitted to another SDP hospital'. SDP hospital is a source data provider hospital (list of current SDP hospitals in Appendix).

New case - if the baby has never been previously admitted to any SDP hospital within the MNNR network or admitted directly to your Neonatal Unit (NNU) after birth. If the case is transferred from another non-SDP hospital and never previously admitted to any other SDP hospital, it is also a new case. Example:

1. inborn preterm 31 weeks baby, or
2. baby born in private hospital and then transferred to your hospital
3. inborn baby who did not fulfill MNNR criteria, discharged home and then admitted at 4 days old to your hospital for ventilation.

Readmission - the baby previously admitted to your hospital only, example:

1. inborn ex preterm who fulfills MNNR criteria who has been discharged and then readmitted from home to NICU within 44 weeks postconceptional age (PCA).
2. inborn baby with congenital heart disease who was ventilated in your NNU, transferred to IJN and then back to your NNU.

Transfer from another SDP Hospital or IJN - If the patient has been admitted after passing through another SDP hospital e.g. from your NNU to HKL for surgery and then readmitted to your NNU – this is considered a “previous admission from another SDP hospital” for HKL data entry, and “readmission”- for your NNU – so that the system can pick up that there is another CRF for merging from another SDP hospital. Tick and specify name of other SDP hospital. If a patient was already discharged home from another SDP hospital and admitted to your hospital within 44 weeks gestational age – include as “Previous admission to another SDP 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. **a) Mother's identity card number:** MyKad number or Other ID document number. If "Other" please specify type of document.
b) Baby's MyKid number: add number if available
4. **a) Date of Birth:** dd/mm/yyyy
b) 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.
5. **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.
6. **Maternal Age:** Age in completed years.
7. **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).
8. **Maternal Diabetes:** State 'yes' or 'no' if mother had diabetes (regardless of whether it is gestational or pre-gestational).
9. **Maternal Hypertension:** State 'yes' or 'no' if mother had hypertension (regardless of whether chronic or pregnancy- induced). Include pre-eclampsia in this category. State 'unknown' if so.
10. **Maternal Eclampsia:** State 'yes' or 'no'. State 'unknown' if so.
11. **Maternal Chorioamnionitis:** State 'yes' or 'no' if mother had chorioamnionitis. State 'unknown' if so.
12. **Maternal Anaemia:** State Yes, No or Unknown. Mother's Hb level < 11 g/dL or noted to have anaemia of pregnancy by O&G.
13. **Maternal abruptio placenta:** State 'yes' or 'no'.
14. **Maternal bleeding placenta praevia:** State 'yes' or 'no'.
15. **Cord prolapse:** State 'yes' or 'no'.
16. **Maternal obesity:** BMI > 30 at booking weight during 1st trimester. State 'yes' or 'no'.
17. **Other current maternal illness:** State 'yes' or 'no'. Examples of other current illness are SLE, renal disease, cancer, epilepsy, cardiovascular disease, mental disorder, etc.

SECTION 2: Birth History

18. **Antenatal Steroid: Definition:** Corticosteroids given antenatally via any route to the mother at a time likely to enhance fetal lung maturation. Excludes steroids given for other reasons. State 'yes' (regardless of number of doses or when it was given) or 'no' if this has not been given. If yes, state whether 'complete' (if intended doses were all given) or 'incomplete' (if intended doses according to centre were not given). **State 'unknown' if so.**
19. **Antenatal magnesium sulphate: Definition:** Antenatal magnesium sulphate given to mother.
20. **Intrapartum Antibiotics: Definition:** Antibiotic treatment is provided to the mother within the period mother is in labour, with the intent of preventing infection of the fetus. This include the prophylactic use of parenteral penicillin or ampicillin. State 'Yes' if systemic antibiotics (enteral or parenteral) were given to the mother from the onset of labour. **State 'unknown' if so.**
21. **Birth weight (g):** The weight of the baby immediately following delivery recorded in grams to the nearest gram and measured within the first hour of life.
22. **Gestation (weeks):** Best estimate of gestational age at birth given in full weeks. Preferences among estimates should be:
 - i. 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.)
 - ii. 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
 - iii. LMP, Ultrasound, Ballard score or unknown. Choose only one – the option on which you based the baby's gestational age.
23. **Growth status:** based on Fenton preterm growth chart (for boys and girls) on page 6 and 7 of the CRF. SGA <10th centile; AGA 10-90th centile; LGA >90th centile).
24. **Gender:** Indicate Male, Female or Ambiguous/Indeterminate.
25. **Place of Birth:**
 - i. **Inborn-** born in the same hospital as the participating site. If born within the wards of the participating hospital to be considered as inborn
 - ii. **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.
 - Home
 - Health clinic
 - Government hospital with specialist
 - Government hospital without specialist
 - University Hospital
 - Private hospital
 - Maternity home with specialist
 - Maternity home without specialist
 - Alternative birthing centre (ABC) – urban or rural.
 - Enroute/during transport (including delivery in ambulance within own hospital grounds)
 - Others - - please specify
 - Unknown

26. **Multiplicity:** To indicate as singleton, twin, triplet or others i.e. quadruplets, etc. Fill in the birth order if the baby is other than singleton, e.g. if baby is twin 1 – fill in “01”. For triplet three, fill “03”. This together with mother’s IC no. will act as unique identifier.

27. **a) 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.**

b) Delayed cord clamping: Tick ‘yes’ if delayed cord clamping is done.

28. **Apgar Score at 1 min and 5 min:** A numerical score of the condition of newborn at 1 min and 5 min after birth based on heart rate, colour, respiratory effort, muscle tone and reflex irritability. Enter the Apgar score at 1 min & 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 truly so and not because it was not scored once baby intubated. Apgar score can be ‘0’ at 1 minute and 5 minutes.

29. **a) Active resuscitation:** Tick ‘Yes’ if baby is actively resuscitated at birth. Tick ‘No’ if palliative care is instituted.

b) Initial resuscitation (for inborn babies only): Tick ‘Yes’ for all intervention that applies at birth. **(Mandatory for inborn cases)**

a) **Oxygen:**

Tick “Yes” if the baby received any supplemental oxygen with $FiO_2 >21\%$ in the delivery room, regardless of whether the baby had invasive or non-invasive respiratory support. Tick “No” if the baby did not receive supplemental oxygen in the delivery room.

b) **Early CPAP:**

Tick “Yes” if the baby received any CPAP immediately after birth, within 15 minutes. Tick “No” if the baby did not receive any CPAP in the delivery room

c) **Bag and mask ventilation:**

Tick “Yes” if the baby received any positive pressure breaths with a mask in the delivery room through a bag and mask or T-piece resuscitator.

Tick “No” if the baby did not receive any positive pressure breaths 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.**

d) **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 meconium aspiration syndrome, and assisted ventilation was not given through the tube, tick “No”.

e) **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.

f) **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.

30. **a) Plastic wrap at birth without drying (only for neonates < 1500grams):** Tick ‘Yes’ if baby wrapped with plastic wrap at birth.

b) Admission temperature – Indicate the first temperature (axillary) on admission to one decimal point in degree 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

31. **Respiratory support:**

- a) **nCPAP (Nasal Continuous Positive Airway Pressure)** – CPAP mode given in the ward
- b) **Bilevel CPAP**
- c) **HFNC (High Flow Nasal Cannula)**
- d) **NIPPV (Nasal Intermittent Positive Pressure Ventilation)**
- e) **Conventional ventilation** - intermittent positive pressure ventilation through an endotracheal tube with a conventional ventilator (IMV rate <240/min) at any time after leaving the delivery room.
- f) **High Frequency Ventilation (HFJV/HFOV)**
- g) **Inhaled nitric oxide** - nitric oxide delivered as a gas via a ventilator at any time after leaving the delivery room.

Total duration of respiratory support mode in days.

- If the baby was not put on the mode of respiratory support, to state ‘0’.
- State to next complete half day the number of days on the ventilation support i.e. < 12 hours is 0.5 day and > 12 hours is rounded up to the next completed day eg. 7 hours is filled in 0.5 day and 14 hours is filled as 1 day.
- If duration is more than 1 day, round up to next complete day eg. duration of 2 days and 6 hours be rounded to 3 days.

32. **Surfactant:** A dose of any type of exogenous surfactant was used to treat this baby. 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.

33. **Parenteral Nutrition:** Intravenous infusion of a nutrient solution consisting of a minimum of dextrose and protein but generally providing a complete nutrient infusion including electrolytes, calcium, phosphorus, zinc, trace elements, vitamins and fat. 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 below. 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’.

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

<p>34. Respiratory Meconium aspiration syndrome</p>	<p>Tick "yes" if all 5 of the following criteria are satisfied: Presence of meconium stained amniotic fluid at birth.</p> <ul style="list-style-type: none"> i. 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. ii. A PaO₂<50mmHg in room air, central cyanosis in room air or a requirement for supplemental oxygen to maintain a PaO₂ >50mmHg. iii. Abnormal CXR compatible with meconium iv. aspiration: Findings may include coarse irregular or nodular pulmonary densities, areas of diminished aeration or consolidation alternating with areas of hyperinflation, or generalized hyperinflation. v. Absence of culture proven early onset bacterial sepsis or pneumonia (ie negative blood culture within 72 hours of birth).
<p>Pulmonary haemorrhage</p>	<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>Congenital Pneumonia</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>Nosocomial pneumonia</p>	<p>Infection of the lungs acquired after admission to the ward.</p>
<p>Community acquired pneumonia</p>	<p>Infection of the lungs acquired after discharge home.</p>

	<p>Grades:</p> <p>a) Grade 1:</p> <ul style="list-style-type: none"> - Nasal cannula (NC) < 1L/min, FiO₂ 22-70% - NC 1-< 3L/min, FiO₂ 22-29% - CPAP, NIPPV or NC ≥ 3L/min, FiO₂ 21% <p>b) Grade 2:</p> <ul style="list-style-type: none"> - NC < 1L/min, FiO₂ ≥70% - NC 1-< 3 L/min, FiO₂ ≥30% - CPAP, NIPPV or NC ≥ 3L/min, FiO₂ 22-29% - Mechanical ventilation, FiO₂ 21% <p>c) Grade 3:</p> <ul style="list-style-type: none"> - CPAP, NIPPV or NC ≥ 3L/min, FiO₂ ≥30% - Mechanical ventilation, FiO₂ >21%
<p>Cardiovascular</p> <p>38a. Persistent pulmonary hypertension (PPHN)</p> <p>38b. Heart failure</p>	<p>Definitive diagnosis of PPHN is made by echocardiography. In the absence of echo confirmation, pre and postductal pulse oximetry difference of > 10% can be used. Preductal pulse oximetry done on the right hand and post ductal pulse oximetry done on lower limbs.</p> <p>Failure of the heart to pump characterized by tachypnea, tachycardia, feeding difficulties, hepatic enlargement, and cardiomegaly.</p>
<p>39. Patent ductus arteriosus (PDA)</p> <p>Only applies for pre term < 37 weeks GA only</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 pharmacological closure (indomethacin / ibuprofen / paracetamol) was given. Indicate if intervention is done to close PDA (no/ligation/device closure).</p>
<p>40. Necrotizing 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>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</p>

	<p>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>41. Retinopathy of prematurity (ROP)</p> <p>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 (eg threshold).</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 is present.</p> <p>State if laser, cryotherapy, intravitreal VEGF 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” or “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 on first screening if done after discharge.</p> <p>Tick ‘Not Applicable’ if does not fulfill criteria</p>	<p>Criteria for screening for ROP are for babies with birth weight ≤ 1750 grams OR gestational < 34 weeks, as well as all preterm babies whose clinical course places them at increased risk for ROP as determined by the attending doctor.</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 Prethresh : Prethreshold ROP Thresh. : Threshold ROP Stage 4 : Partial Retinal Detachment Stage 5 : Total retinal detachment AROP : Aggressive Retinopathy of Prematurity</p> <p>PLUS disease: dilated veins and tortuous arteries, papillary rigidity (must also include stages other than No ROP)</p>

<p>42a. Intraventricular haemorrhage (IVH)</p> <p>If ultrasound done: 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 for post-haemorrhagic hydrocephalus.</p> <p>Tick "No" if there was no IVH before or on day 28.</p> <p>Tick "Not applicable" for term infants</p> <p>Tick "Ultrasound not done" if it was not done</p> <p>42b. Cystic Periventricular Leukomalacia</p>	<p>If Ultrasound of Brain done enter the worst grade:</p> <p>Grade1 IVH : Sub-ependymal 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>State 'Yes or 'No'</p>
<p>43a. Central venous/arterial line</p> <p>Central line - yes or no</p> <p>If "Yes", to state the total central catheter days. Central catheter days refer to the total number of calendar days during which any central catheter is present during the admission. A central catheter day is counted as one per patient per day, regardless of the number or type of central catheters in place. If more than one central catheter is present on the same day, it is still counted as one catheter day. A day is counted if the central line is present at any time during that calendar day.</p> <p>Eg. Day 1: UVC in place – 1 catheter day Day 2: UVC and PICC in place – still 1 catheter day</p> <p>43b. CLABSI</p>	<p>Central line defined as:</p> <ol style="list-style-type: none"> (1) Umbilical catheters (2) Percutaneously inserted central catheters (PICC) (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>CLABSI defined as clinical sepsis with positive blood culture in patient with <u>ALL</u> the following:</p> <ol style="list-style-type: none"> a. central line in place for at least 48 hours, or within 48 hours after removal. b. no other apparent source of infection c. two positive culture of the same organism from different sites if the organism is a common skin organism (to differentiate from skin contaminant)

<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 72 hours of life OR after 72 hours of life.</p> <p>State the organism cultured: <i>Acinetobacter sp.</i> <i>Candida sp.</i> Coagulase-negative <i>Staphylococcus</i> (CONS) <i>Escherichia coli</i> <i>Enterobacter sp</i> <i>Klebsiella pneumoniae</i> <i>Pseudomonas aeruginosa</i> <i>Staphylococcus aureus</i> Others, specify</p> <p>If antibiotic resistance is present in organism cultured, to tick?</p> <ul style="list-style-type: none"> • Carbapenem-resistant (CRE) • Extended Spectrum Beta-Lactamase (ESBL) • Methicillin-resistant (MRSA, MRCONS) • Multidrug-resistant organism (MDRO/MRO) • Vancomycin-resistant (VRE) • Others, specify <p>Can tick more than one option</p>	<p>Confirmed sepsis</p> <p>Clinical evidence of sepsis plus blood culture-proven infection.</p> <p>For skin commensals, eg CONS: Place a tick if the infant has the following:</p> <ol style="list-style-type: none"> 1. CONS/other skin commensals is recovered from a blood culture obtained from either a central line, or a peripheral blood sample and /or recovered from infants CSF AND 2. Signs of generalized infection (such as apnoea, temperature instability, feeding intolerance, worsening respiratory distress or haemodynamic instability) AND 3. Presence of abnormal septic markers, eg high or low total white count, raised CRP or procalcitonin. <p>Do not place a tick if any or all of the above are not true.</p> <p><u>For FUNGAL infection:</u></p> <p>Place a tick only if a fungus 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>Tick 'yes' (if CSF biochemistry or cytology suggestive even if CSF C&S is negative) or 'no'</p> <p>If yes, State if CSF Culture positive - Yes / No</p> <p>State the organism cultured: <i>Acinetobacter sp.</i> <i>Candida sp.</i> Coagulase-negative <i>Staphylococcus</i> (CONS) <i>Escherichia coli</i> <i>Enterobacter sp</i> <i>Klebsiella pneumoniae</i> <i>Pseudomonas aeruginosa</i> <i>Staphylococcus aureus</i> Others, specify</p> <p>If antibiotic resistance is present in organism cultured, to tick?</p> <ul style="list-style-type: none"> • Carbapenem-resistant (CRE) 	<p>Signs of clinical sepsis and evidence of meningeal infection as shown in cerebrospinal fluid findings (i.e. cytology, biochemistry or microbiologic findings)</p>

<ul style="list-style-type: none"> • Extended Spectrum Beta-Lactamase (ESBL) • Methicillin-resistant (MRSA, MRCONS) • Multidrug-resistant organism (MDRO/MRO) • Vancomycin-resistant (VRE) • Others, specify <p>Can tick more than one option</p>	
<p>46. Hypoxic ischaemic encephalopathy (HIE)</p> <p>Applies only to gestation \geq 35 weeks</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 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: <ol 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>AND</p> <ol style="list-style-type: none"> 2. Three or more supporting findings from the following list: <ol style="list-style-type: none"> a. 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 b. Arterial cord pH c. Apgar score at 5 minutes of 5 or less d. Evidence of multi-organ system dysfunction within 72 hours of birth 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. g. abnormal aEEG: discontinuous, burst suppression, low voltage, iso-electric.

<p>46a. HIE severity</p> <p>If the infants diagnosed with HIE, record the worst stage observed during the first 7 days following birth based on the assessment for neonatal encephalopathy using the modified Sarnat and Sarnat staging, in the following areas:</p> <ul style="list-style-type: none"> i) level of consciousness ii) activity iii) neuromuscular control iv) complex reflexes v) autonomic nervous system vi) seizures. <p>Tick “none” if there is no HIE Tick “Mild, Moderate, Severe” according to the definition</p>	<p>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>HIE severity</p> <ul style="list-style-type: none"> a. Mild – hyperalert with normal activity; normal muscle tone, mild distal flexion and overactive tendon reflexes; weak suck, strong Moro’s reflex; dilated pupils, tachycardia with regular breathing; and no seizures. b. Moderate – lethargic with decreased activity; mild hypo/hypertonia, strong distal flexion, overactive tendon reflexes; weak/absent suck, weak/incomplete Moro’s reflex; constricted pupils, bradycardia with periodic breathing; and common to have seizures. c. Severe – coma with absent activity; flaccid/rigid tone, intermittent decerebration, decreased/absent tendon reflexes; absent suck and Moro’s reflex; variable pupillary reflex (unequal, poor light reflex, fixed, dilated), variable heart rate, apnoea; seizures are uncommon (excluding decerebration).
<p>46b. Cooling therapy</p>	<p>State ‘Yes/No’</p> <p>If ‘Yes’, - please state age started cooling (in hours of life)</p> <p>- please tick the type of cooling therapy method.</p> <p>If ‘No’ – tick reason for not starting cooling therapy; either ‘not indicated’, eg mild HIE or ‘contraindicated’ if cooling therapy is indicated but cannot be started eg due to coagulopathy or hypoxemia</p>
<p>46c. Seizures in HIE cases</p>	<p>State ‘Yes/No’</p>
<p>47. Congenital Anomalies</p> <p>47a. Major Congenital Anomalies</p> <p>Tick ‘Yes’ if major congenital anomaly is present even if it is an isolated one (i.e. only one abnormality)</p> <p>If Yes, state:</p> <ol style="list-style-type: none"> 1. ‘Known Syndrome’ 2. ‘Not a Recognised Syndrome’ 3. ‘Isolated major abnormality’ 	<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</p>

<p>If the syndrome is known, tick the specified syndromes or specify it.</p> <p>Proceed to 47b & 47c. Types of Abnormalities: Tick all major abnormalities found for recognisable syndrome, non-recognisable ones or isolated major congenital abnormality. If there are no abnormalities, tick 'None of the above' in 47b.</p> <p>E.g. in Down Syndrome, tick all the congenital anomalies found in patient. Please specify if there are abnormalities not listed.</p> <p>For CVS: congenital heart disease, state:</p> <ul style="list-style-type: none"> • Type - duct dependent lesion/ non duct dependent lesion • ECHO Done – date done (days) • Invasive procedure – date done for surgery & catheterization (days) 	<p>such as 'low-set ears', sacral dimple or single transverse palmar crease".</p> <p>For PDA under non duct dependent lesion – only applies for term babies (≥37 weeks GA only)</p>
<p>48. Palliative Care</p>	<p>State 'Yes' if baby had initial active resuscitation and redirection of care to palliative care after new findings/clinical course. Otherwise state 'No'.</p>

SECTION 5: OUTCOME ON DISCHARGE

49a. **Date of discharge/transfer/death:** Enter the exact date

49b. **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-estimated time if of death if exact time not known.

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

a) Weight in grams. For weight on death is the last weight taken when the baby was alive

b) Indicate growth status as per Fenton preterm growth chart (for boys and girls)

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 11 days.

52. **Home oxygen therapy** – State if baby discharged home with oxygen. Also Includes non-invasive ventilation e.g. CPAP/HFNC

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

If child alive, state Place of discharge to after leaving Neonatal Unit: Home, Social welfare home, Other Non-Paediatrics Ward, 'Still hospitalised as of 1st birthday/close out date on the following year' or 'Transferred to other hospitals'. If transferred to other hospitals, specify the name of hospital transferred to.

If a case is transferred to another hospital in the MNNR network, complete the CRF up to current status and send photocopy of the form with the baby to assist the referral hospital in obtaining the patient particulars and birth history. The referring hospital still need to key in the original form into the system. The referral centre should open and complete a new CRF but Section 1 & Section 2 need not to be filled again if this has already been keyed in by referring centre. 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. Click "still in the ward" if patient is still hospitalized in the non-NNR hospital at close out. **ROP findings after discharge can also be updated in the ROP section.**

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 or others, specify

SUPPLEMENTARY FORM

Filled whenever there is 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 hospitals
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, use mother’s RN.
4. **Mother’s new IC number or passport:** which ever applicable

Immediate Cause of Death (Modified Wigglesworth):

(Adapted from Garis panduan Penggunaan Format PNM 1/97 (Pindaan 2000) bagi Melapor Kematian Perinatal, Jun 2000, Bahagian Pembangunan Kesihatan Keluarga, Kementerian Kesihatan Malaysia)

a. *Is there Lethal Congenital Malformation (LCM)/defect?*

Severe or lethal malformation that contribute to death. If ‘Yes’, tick specifically the cause of death.

b. *If no LCM, is Gestation < 37 weeks?*

c. - *Gestation < 37 weeks: Preterm death without LCM*

This includes only livebirths < 37 weeks gestation after excluding LCM. Tick immediate secondary cause of death e.g. severe IVH, pulmonary haemorrhage, acute intrapartum event. Tick “extreme prematurity’ in the subcategory only for babies < 28 weeks only who died and no immediate secondary cause of death e.g. as in palliative care.

- *Gestation ≥ 37 weeks: Preterm death without LCM, was there an Asphyxial condition?*

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

d. *Asphyxial conditions absent, was there 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. *If term and infection present, tick organism.*

h. *If term and infection absent, other specific cause of death*

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

j. *Unknown* - Where cause of death is not known.



MONTHLY BIRTH CENSUS 2026

Please click on the link:

https://macr.org.my/enr/pdf/Census_2020.pdf



TRACKING FORM

Track 1

Tracking CRFs (e.g. Admissions in month of October 2020)

Name	Hospital RN	Date of Birth	Date of admission	Inclusion Criteria
THY		1/10	1/10	
VS NFR		2/10	2/10	
LRD		6/10	6/10	
ELBW		15/10	15/10	
VS		20/10	20/10	Died
ERT		26/10	26/10	VP

Abbreviations:

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 the admission in your neonatal ward and delivery suite and fill up new admission that fulfill the criteria into this tracking form immediately every working day. Do remember to include cases that has been admitted on your off days/public holidays and weekends too.

To include all types (New/Transfer/Readmission) into this tracking form.

The monthly tracking list of admission should be sent to the secretariat by the date of 7th of the following month. E.g. list of admission from 1st – 31st October should be sent by 7th November with the status of the CRF stated.

The completed list of babies on this list who are discharged between 1st – 31st October should be updated on the MNNR website as soon as possible.

