## REPORT OF THE MALAYSIAN NATIONAL NEONATAL REGISTRY



2018



## A STUDY OF CRITICALLY ILL BABIES IN NEONATAL INTENSIVE CARE UNITS

#### **EDITOR**

\* Eric Ang Boon Kuang

#### WITH CONTRIBUTIONS FROM:

- Boo Nem Yun
- \* Chee Seok Chiong
- \* Ang Ee Lee
- \* Pauline Choo Poh Ling
- \* Azanna Ahmad Kamar
- \* Farah Inaz
- \* Neoh Siew Hong
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#### Published by the:

Malaysian National Neonatal Registry (MNNR) Unit 2.4 (Suite 3), Level 2 Enterprise 3B, Technology Park Malaysia Lebuhraya Sungei Besi – Puchong Bukit Jalil 57000 Kuala Lumpur Malaysia

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August 2020

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#### **ACKNOWLEDGEMENTS**

The Malaysian National Neonatal Registry would like to express its sincere thanks and appreciation to all who have supported and contributed to this report.

We thank the following for their support:

- > The Ministry of Health, Malaysia.
- > Y.Bhg. Datuk Dr. Noor Hisham Abdullah, Director General of Health, Malaysia for his kind permission for publication
- > Dr. Goh Pik Pin, Director, Network of Clinical Research Centre
- Members of the MNNR Steering Committee for their contributions to the registry
- Our 43 source data providers from the government & private hospitals which comprise of doctors and nurses working in the NICUs
- Clinical Research Centre, Ministry of Health, Malaysia
- Ms. Thinisha a/p Mohan, Registry Manager, MNNR
- Pn. Ain Bt Hamdan, Assistant Registry Manager, MNNR
- Other sponsors and supporters from the professional bodies, industries and institutions as listed below:
  - Perinatal Society of Malaysia
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#### Report of the Malaysian National Neonatal Registry (MNNR) 2018

#### 1. Organization of the MNNR

#### 1.1 Objectives

The Malaysian National Neonatal Registry was set up in 2002 to study the outcome of sick babies admitted to Neonatal Intensive Care Units (NICUs) in the country. A minimum data set and a data collection system at a national level are important to monitor mortality and morbidity of babies admitted to NICUs.

#### The Malaysian NNR aims:

- 1. To determine the frequency and distribution of critically ill neonates in Malaysia. These are useful measures of the health burden of neonatal critical illnesses and its care in the country.
- 2. To study the mortality and some morbidity outcomes of babies admitted to NICUs in participating hospitals.
- 3. To calculate the perinatal, neonatal, and stillbirth mortality rates of inborn babies.
- 4. To compare the outcomes between various centres.
- 5. To develop indicators for standard of care in various areas e.g. acceptable septicaemic rates in NICUs.
- 6. To study, in further detail, the outcome of very low birth weight babies.
- 7. To stimulate and facilitate research on neonatal critical illness and its management.

#### 1.2 Structure

The MNNR consists of a Governance Board, Steering Committee and administrative staff. The Governance Board is to monitor and to direct the functions of MNNR and it meets at least once a year.

The Steering Committee consists of nine elected members. This committee is responsible for the general running and decision-making of the Registry and for approving the use of its data.

A Registry Manager assisted by a clinical research assistant heads the administrative staff at the Neonatal Registry Unit (NRU). Statistical support was provided by the CRC.

#### 1.3 Funding

Funding was provided via Perinatal Society of Malaysia & sponsors from industry.

#### 2. Data Set

#### 2.1 Registration criteria

The MNNR audit of critically ill babies admitted to Neonatal Units (NNUs) included

- A. All babies admitted to a Neonatal Unit who have any of the following criteria:
  - 1. Had a gestation of <32 weeks i.e. up to 31 weeks + 6 days
  - 2. Had a birth weight of 500-1500 g.
  - 3. Required respiratory support (ventilated or required CPAP or HFNC)
  - 4. Had hypoxic ischaemic encephalopathy (HIE) with or without requirement of ventilatory support.
  - 5. With confirmed sepsis i.e. positive blood cultures
  - 6. With congenital heart disease
- B. All neonatal deaths (i.e. newborn babies (<28days) who die in the NNU, delivery room i.e. operating theatre, labour room, and in other wards)
  - Both inborn and outborn babies were included.
  - Outborn babies who died before arrival were excluded. Babies who were admitted to the NNU at a corrected gestation of > 44/52 were not considered neonatal cases and hence were omitted from the study.

#### 2.2 Data Collection

The CRF consisted of four sheets (of forms).

- Babies discharged or transferred out to non-paediatric wards (e.g. paediatric surgical wards) in the same hospital
  or to other hospitals would have only one set of CRF completed and readmission of the same babies into the NNU
  would require a new set of CRF.
- A baby who was transferred between neonatal and paediatric wards under the same department was considered
  to be the same admission and the discharge CRF was completed after complete discharge from the hospital.
  Hardcopy CRFs were used and data from completed CRFs were entered via the MNNR website by the respective
  SDPs or sent to MNNR secretariat after a defined period for data entry.

#### 2.3 Data Verification

Missing or anomalous data was identified by manual check and then clarified with the respective centre. Further data verification was made on data entry onto the main database. Quantification of errors and the implementation of practices via website data entry to minimize errors are continually refined.

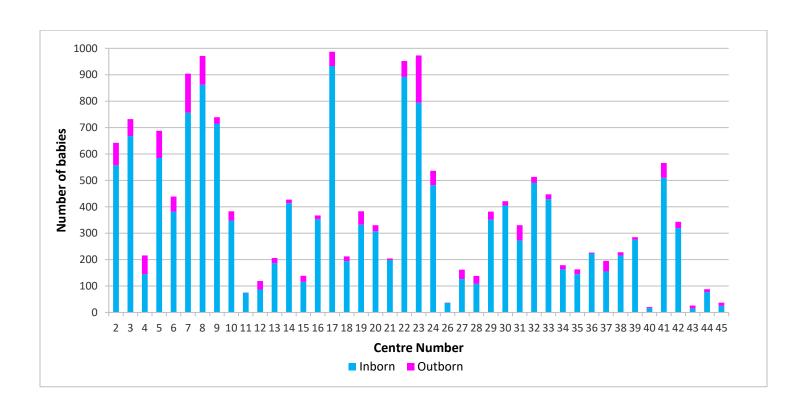
## RESULTS

#### **INTRODUCTION**

- In 2018, the inclusion criteria for this study included all babies (inborn and outborn babies) born at a gestation below 32 weeks; had birth weight of 500 grams to 1500 grams; required respiratory support; had hypoxic-ischaemic encephalopathy; had a confirmed sepsis; had congenital heart disease; and all neonatal deaths. The criteria of babies with confirmed sepsis, which was omitted in 2017, was re-institued in 2018.
- 43 hospitals participated in this study in 2018. Total livebirths in the participating hospitals were 322,999. A total of 16,411 babies met the study criteria, out of which 14,738 (89.8%) were inborn, while 1,673 (10.2%) were outborn babies. (Figure 1 and Table 1)
- There were 3,299 (20.1%) babies below 32 weeks gestational age. (Figure 2 and Table 2)
- There were 3,663 (22.3%) babies with birth weight of 1500g and below. (Figure 3 and Table 3)

Figure 1

Number of babies according to place of birth



COMMENT: There were 14738 inborn babies and 1673 outborn babies in the MNNR.

Table 1: Number of babies according to place of birth

Hoor	sitala	Place (	of Birth	Total
поѕр	oitals	Inborn	Outborn	Total
2	n	557	85	642
2	(%)	(86.8)	(13.2)	(100)
2	n	668	64	732
3	(%)	(91.3)	(8.7)	(100)
4	n	145	71	216
4	(%)	(67.1)	(32.9)	(100)
_	n	585	103	688
5	(%)	(85.0)	(15.0)	(100)
-	n	382	57	439
6	(%)	(87.0)	(13.0)	(100)
7	n	756	148	904
7	(%)	(83.6)	(16.4)	(100)
0	n	862	109	971
8	(%)	(88.8)	(11.2)	(100)
0	n	714	25	739
9	(%)	(96.6)	(3.4)	(100)
10	n	348	35	383
10	(%)	(90.9)	(9.1)	(100)
11	n	74	1	75
11	(%)	(98.7)	(1.3)	(100)
12	n	87	32	119
12	(%)	(73.1)	(26.9)	(100)
12	n	187	19	206
13	(%)	(90.8)	(9.2)	(100)
14	n	414	13	427
14	(%)	(97.0)	(3.0)	(100)
1.5	n	116	23	139
15	(%)	(83.5)	(16.5)	(100)
16	n	353	14	367
16	(%)	(96.2)	(3.8)	(100)
17	n	933	54	987
17	(%)	(94.5)	(5.5)	(100)

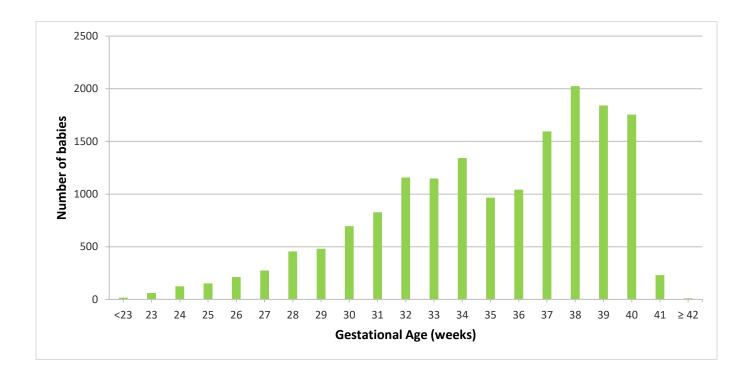
Table 1: Number of babies according to place of birth (continued)

llaa.	ماداد	Place o	of Birth	Tatal
Hosp	oitals	Inborn	Outborn	Total
18	n	194	18	212
10	(%)	(91.5)	(8.5)	(100)
10	n	332	51	383
19	(%)	(86.7)	(13.3)	(100)
20	n	307	23	330
20	(%)	(93.0)	(7.0)	(100)
21	n	198	6	204
21	(%)	(97.1)	(2.9)	(100)
22	n	892	60	952
22	(%)	(93.7)	(6.3)	(100)
22	n	794	179	973
23	(%)	(81.6)	(18.4)	(100)
2.4	n	482	54	536
24	(%)	(89.9)	(10.1)	(100)
2.6	n	36	1	37
26	(%)	(97.3)	(2.7)	(100)
27	n	126	36	162
27	(%)	(77.8)	(22.2)	(100)
20	n	109	29	138
28	(%)	(79.0)	(21.0)	(100)
20	n	351	31	382
29	(%)	(91.9)	(8.1)	(100)
20	n	405	16	421
30	(%)	(96.2)	(3.8)	(100)
21	n	273	57	330
31	(%)	(82.7)	(17.3)	(100)
22	n	490	23	513
32	(%)	(95.5)	(4.5)	(100)
22	n	429	18	447
33	(%)	(96.0)	(4.0)	(100)
2.4	n	163	16	179
34	(%)	(91.1)	(8.9)	(100)
25	n	145	18	163
35	(%)	(89.0)	(11.0)	(100)

Table 1: Number of babies according to place of birth (continued)

Hospitals		Place o	of Birth	Total
поѕр	iitais	Inborn Outborn		Total
36	n	223	4	227
30	(%)	(98.2)	(1.8)	(100)
37	n	155	40	195
37	(%)	(79.5)	(20.5)	(100)
38	n	216	12	228
36	(%)	(94.7)	(5.3)	(100)
39	n	275	10	285
33	(%)	(96.5)	(3.5)	(100)
40	n	16	4	20
40	(%)	(80.0)	(20.0)	(100)
41	n	510	56	566
41	(%)	(90.1)	(9.9)	(100)
42	n	319	24	343
42	(%)	(93.0)	(7.0)	(100)
43	n	15	11	26
43	(%)	(57.7)	(42.3)	(100)
44	n	77	11	88
44	(%)	(87.5)	(12.5)	(100)
45	n	25	12	37
43	(%)	(67.6)	(32.4)	(100)
TOTAL	n	14738	1673	16411
IOIAL	(%)	(89.8)	(10.2)	(100)

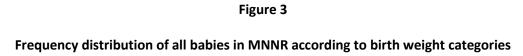
Figure 2 Frequency distribution of all babies in MNNR according to gestational age



COMMENT: For the categories  $\geq$  32 weeks, the case distribution does not include all livebirths in that respective gestational age group (See inclusion criteria).

Table 2 : Frequency distribution of all babies in MNNR according to gestational age

Gestational age in completed weeks at birth	Frequency (n)	Percent (%)
< 23	17	0.1
23	60	0.4
24	125	0.8
25	151	0.9
26	212	1.3
27	275	1.7
28	455	2.8
29	482	2.9
30	695	4.2
31	827	5.0
32	1157	7.1
33	1148	7.0
34	1342	8.2
35	966	5.9
36	1042	6.3
37	1595	9.7
38	2025	12.3
39	1841	11.2
40	1755	10.7
41	231	1.4
≥ 42	10	0.1
Total included	16411	100
Total no. of babies with missing gestational age	0	
Total no. of babies	16411	



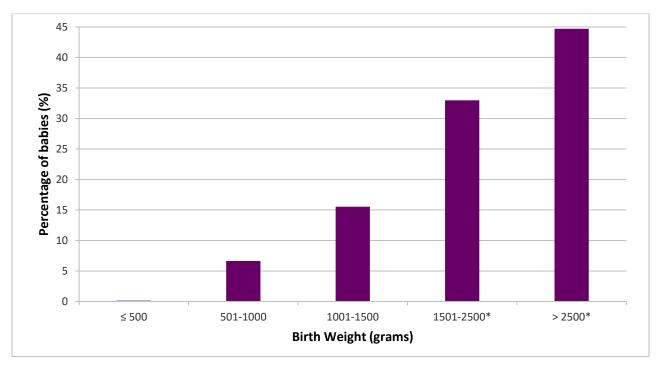


Table 3: Frequency distribution of all babies in MNNR according to birth weight (BW) categories

Birth weight (grams)	Frequency (n)	Percent (%)
≤ 500	22	0.1
501-1000	1,090	6.6
1001-1500	2,551	15.5
1501-2500*	5,413	33.0
> 2500	7,335	44.7
Total included	16,411	100
Total no. of babies with missing birth weight	0	
Total no. of babies	16411	

COMMENT: \* For the category > 1500 gram birth weight, calculated percentage does not include all live births in that category (see inclusion criteria).

#### **MATERNAL INTERVENTIONS**

- For babies born at less than 32 weeks gestation, antenatal corticosteroids were given to 75.4% of their mothers. 79.0% and 41.5% of mothers to babies in this category; who were born inborn and outborn respectively; received antenatal corticosteroids. For the respective MNNR centres, the use of antenatal corticosteroids ranges from 26.8% to 100% for inborn babies, and 0 to 100% for outborn babies. (Figure 4a & 4b and Table 4)
- For category of birth weight ≤1500 grams, antenatal corticosteroids were given to 75.2% of mothers of babies in this category. 78.8% and 38.2% of these mothers who had babies who were inborn and outborn respectively, received antenatal corticosteroids. (Figures 5a & 5b and Table 5)

#### INTERVENTIONS IN THE LABOUR ROOM

- Among inborn babies who were admitted to the neonatal unit, and who were below 32 weeks gestational age; 58.9% (1696 out of 2879 babies) were given early nasal CPAP at initial resuscitation in the labour room.
- For inborn babies with birth weight less than 1000 grams, who were admitted to the neonatal unit, 83.1% (728 out of 876 babies) were wrapped with plastic at birth.

Figure 4a

Antenatal corticosteroid for all inborn babies born at < 32 weeks gestational according to centres

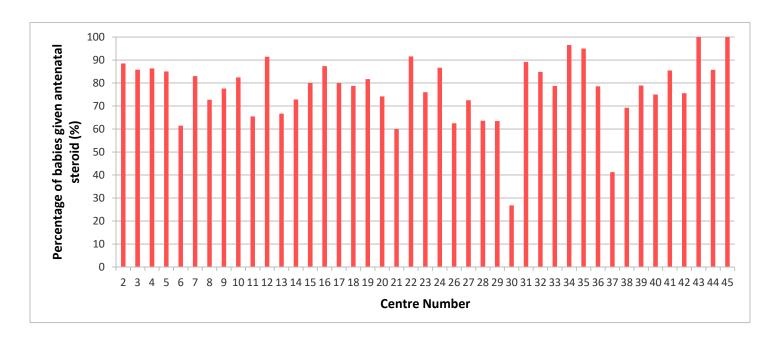


Figure 4b

Antenatal corticosteroid for all outborn babies born at < 32 weeks gestational according to centres

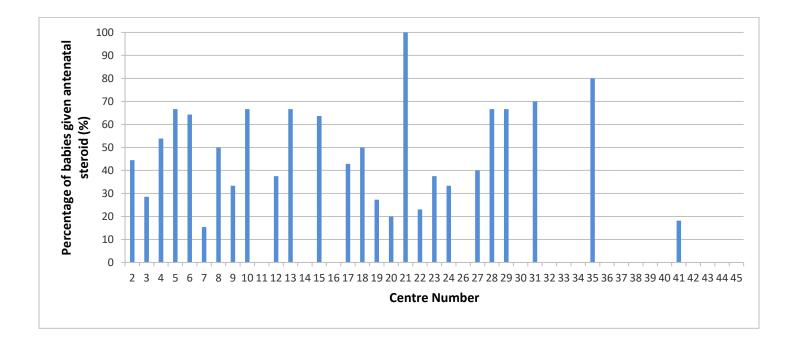


Table 4:
Antenatal corticosteroid for all babies born at < 32 weeks gestational age according to centre

		Inborn		Outborn		
Hospitals	Total no of babies	Given Antenat	tal Steroids	Total No of Babies	Given Anten	atal Steroids
	n	N	%	n	N	%
	2,986	2,359	79.0	313	130	41.5
2	122	108	88.5	18	8	44.4
3	127	109	85.8	14	4	28.6
4	44	38	86.4	13	7	53.8
5	154	131	85.1	15	10	66.7
6	83	51	61.4	14	9	64.3
7	194	161	83.0	13	2	15.4
8	154	112	72.7	24	12	50.0

Table 4 (continued):
Antenatal corticosteroid for all babies born at < 32 weeks gestational age according to centres

		Inborn			Outborn	
Hospitals	Total no of babies	Given Antenata	al Steroids	Total No of Babies	Given Antei	natal Steroids
	n	N	%	n	N	%
9	107	83	77.6	3	1	33.3
10	40	33	82.5	12	8	66.7
11	29	19	65.5	0	0	0
12	35	32	91.4	8	3	37.5
13	57	38	66.7	6	4	66.7
14	70	51	72.9	1	0	0.0
15	50	40	80.0	11	7	63.6
16	95	83	87.4	4	0	0.0
17	90	72	80.0	7	3	42.9
18	47	37	78.7	2	1	50.0
19	93	76	81.7	11	3	27.3
20	62	46	74.2	5	1	20.0
21	30	18	60.0	2	2	100.0
22	119	109	91.6	13	3	23.1
23	154	117	76.0	16	6	37.5
24	150	130	86.7	18	6	33.3
26	8	5	62.5	0	0	0
27	51	37	72.5	10	4	40.0

Table 4 (continued):
Antenatal corticosteroid for all babies born at < 32 weeks gestational age according to centres

		Inborn			Outborn	
Hospitals	Total no of babies	Given Antenata	al Steroids	Total No of Babies	Given Antei	natal Steroids
	n	N	%	n	N	%
28	11	7	63.6	3	2	66.7
29	93	59	63.4	6	4	66.7
30	41	11	26.8	2	0	0.0
31	92	82	89.1	20	14	70.0
32	99	84	84.8	2	0	0.0
33	94	74	78.7	1	0	0.0
34	29	28	96.6	3	0	0.0
35	20	19	95.0	5	4	80.0
36	28	22	78.6	1	0	0.0
37	46	19	41.3	7	0	0.0
38	13	9	69.2	1	0	0.0
39	19	15	78.9	0	0	0.0
40	4	3	75.0	1	0	0.0
41	117	100	85.5	11	2	18.2
42	90	68	75.6	5	0	0.0
43	1	1	100.0	1	0	0.0
44	14	12	85.7	4	0	0.0
45	10	10	100.0	0	0	0.0

Figure 5a

Antenatal corticosteroid for all inborn babies born at ≤ 1500g birth weight according to centres

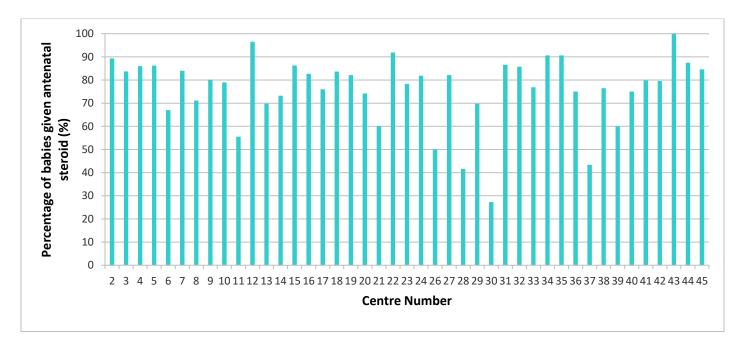


Figure 5b

Antenatal corticosteroid for all outborn babies born at ≤ 1500g birth weight according to centres

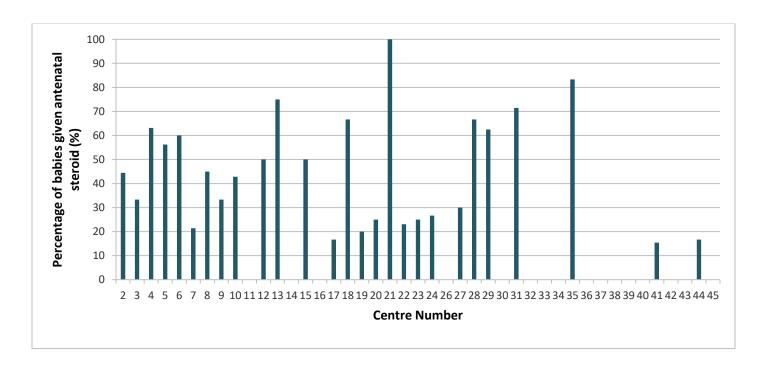


Table 5 : Antenatal corticosteroid for all babies born at ≤ 1500 grams birth weight according to centres

		Inborn			Outborn	
Hospitals	Total no of	IIIDOIII		Total No of	Outbolli	
	babies	Given Anten	atal Steroids	Babies	Given Anten	atal Steroids
	n	N	%	n	N	n
	3,338	2,629	78.8	325	124	38.2
2	122	109	89.3	18	8	44.4
3	154	129	83.8	12	4	33.3
4	43	37	86.0	19	12	63.2
5	167	144	86.2	16	9	56.3
6	106	71	67.0	15	9	60.0
7	206	173	84.0	14	3	21.4
8	163	116	71.2	20	9	45.0
9	131	105	80.2	3	1	33.3
10	57	45	78.9	14	6	42.9
11	27	15	55.6	0	0	0.0
12	29	28	96.6	6	3	50.0
13	63	44	69.8	4	3	75.0
14	71	52	73.2	1	0	0.0
15	51	44	86.3	10	5	50.0
16	104	86	82.7	3	0	0.0
17	125	95	76.0	6	1	16.7
18	49	41	83.7	3	2	66.7
19	101	83	82.2	15	3	20.0

Table 5 (continued):
Antenatal corticosteroid for all babies born at ≤ 1500 grams birth weight according to centres

		Inb	orn		Outborn	
Hospitals	Total no of babies	Given Anten		Total No of Babies	Given Anten	atal Steroids
	n	N	%	n	N	%
20	62	46	74.2	4	1	25.0
21	35	21	60.0	1	1	100.0
22	136	125	91.9	13	3	23.1
23	180	141	78.3	16	4	25.0
24	149	122	81.9	15	4	26.7
26	12	6	50.0	0	0	0.0
27	56	46	82.1	10	3	30.0
28	12	5	41.7	3	2	66.7
29	96	67	69.8	8	5	62.5
30	44	12	27.3	2	0	0.0
31	104	90	86.5	21	15	71.4
32	105	90	85.7	2	0	0.0
33	117	90	76.9	2	0	0.0
34	32	29	90.6	5	0	0.0
35	32	29	90.6	6	5	83.3
36	36	27	75.0	0	0	0.0
37	53	23	43.4	9	0	0.0
38	17	13	76.5	0	0	0.0

Table 5 (continued):

Antenatal corticosteroid for all babies born at ≤ 1500 grams birth weight according to centres

		Inb	orn	Outborn		
Hospitals	Total no of babies	Given Anten	atal Steroids	Total No of Babies	Given Anten	atal Steroids
	n	N	%	n	N	%
39	20	12	60.0	0	0	0.0
40	4	3	75.0	1	0	0.0
41	144	115	79.9	13	2	15.4
42	93	74	79.6	8	0	0.0
43	1	1	100.0	1	0	0.0
44	16	14	87.5	6	1	16.7
45	13	11	84.6	0	0	0.0

#### **RESPIRATORY SUPPORT AND SURFACTANT THERAPY**

- Total of 14,072 inborn babies required respiratory support in the neonatal unit. Out of these, 8,007 babies required conventional ventilation, 1104 babies required high frequency ventilation (including jet ventilation), 10,875 babies required nasal CPAP (including bi-level CPAP) and 2,423 babies were given heated, humidified high flow nasal cannula therapy (HHHFNC). (\*these numbers are not mutually exclusive, and a baby may receive multiple modes of respiratory support)
- 92.0% (2979 out of 3232) of babies with birth weight ≤1,500 grams; and 94.9% (2732 out of 2879) of babies born at less than 32 weeks gestation, required respiratory support.
- Surfactant was given to 3517 babies. 58.8% (1900 out of 3232) of babies with birth weight ≤1,500 grams were given surfactant, and 51% of these were given within 1 hour of life. 68.5% (1973 out of 2879) babies born below 32 weeks gestational age received surfactant, and 48.8% of these were given within 1 hour of life. There were 1283 babies born at 32-36 weeks gestation and 261 term babies, who also received surfactant.

#### RESPIRATORY DISEASES AND CHRONIC LUNG DISEASE

- For meconium aspiration syndrome (MAS), the rate for ventilation (conventional and high frequency ventilation) in inborn babies ≥ 35 weeks gestation was 2.8/1000 live births. A total of 909 inborn babies and 148 outborn babies were ventilated for MAS. The mortality rate for inborn and outborn babies ventilated for MAS was 9.9% and 9.5% respectively, with an overall mortality rate of 9.8%.
- The rates of chronic lung disease (oxygen dependency) for all inborn babies less than 32 weeks gestation surviving to day 28 of life and 36 weeks post-conceptional age, were 82.4% and 79.4% respectively for babies between 22-24 weeks gestational age; 58.8% and 43.7% for babies between 25-27 weeks gestational age; and 17.5% and 11.9% for babies between 28-31 weeks gestational age. For babies with oxygen dependency at 36 weeks post-conceptional age, survival to discharge were 92.6%, 94.8% and 95% for babies between 22-24 weeks, 25-27 weeks and 28-31 weeks gestational age respectively. (Figure 6 and Table 6)
- The rates of chronic lung disease for babies with birth weight <1500g who survived to day 28 were 76.6% for babies with birth weight <750 g, 49.4% for babies with birth weight 750-999 g, 23.6% for babies with birth weight 1000-1249 g, and 7.4% for babies with birth weight 1250-1499 g. Among these babies, for babies born at <32 weeks gestation, the rates of

chronic lung disease for babies who survived to 36 weeks post-conceptional age were 69.6% for babies with birth weight <750 g, 40.7% for babies with birth weight 750-999 g, 17.8% for babies with birth weight 1000-1249 g, and 7.3% for babies with birth weight 1250-1499 g. For babies born at  $\ge32$  weeks gestation, the rates of chronic lung disease for babies who survived to day 56 were 50% for babies with birth weight <750 g, 14.7% for babies with birth weight 750-999 g, 4% for babies with birth weight 1000-1249 g, and 1.1% for babies with birth weight 1250-1499 g. (Figure 7 and 1000-1249 g)

Figure 6

Incidence of oxygen dependency among admitted inborn babies with gestational age < 32 weeks

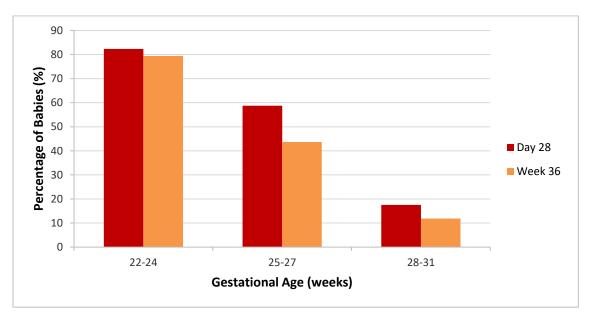
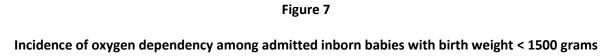


Table 6: Incidence of oxygen dependency among admitted inborn babies with gestational age < 32 weeks

Gestational age at birth (weeks)		Total no of admitted inborn babies	Babies alive at day 28	Babies with oxygen dependency at day 28 among survivors	Babies alive at 36 weeks postmenstrual age	Babies with oxygen dependency at 36 weeks among survivors
22-24	n	134	34	28	34	27
22-24	%	4.7	25.4	82.4	25.4	79.4
25-27	n	536	371	218	355	155
25-27	%	18.6	69.2	58.8	66.2	43.7
28-31	n	2208	2036	357	2023	241
20-31	%	76.7	92.2	17.5	91.6	11.9
Total included	n %	2878 100	2441 84.8	603 24.7	2412 83.8	423 17.5
Total babi	es	2878				



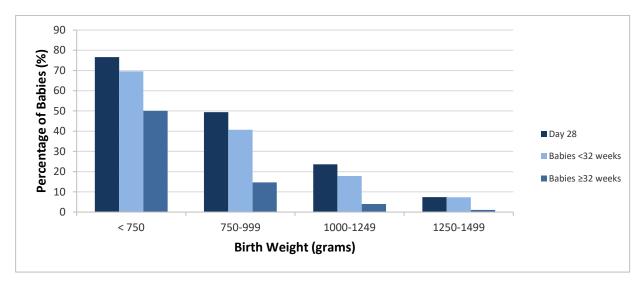


Table 7: Incidence of oxygen dependency among admitted inborn babies with birth weight < 1500 grams

Birth Weight (grams)				Babies with	Babies <32	2 weeks	Babies ≥32 weeks		
		Total no of admitted inborn babies	Babies alive at 28	oxygen dependency at day 28 among survivors	Babies alive at 36 weeks postmenstrual age	Babies with oxygen dependency at 36 weeks among survivors	Babies alive at day 56	Babies with oxygen dependency at day 56 among survivors	
	n	313	124	95	115	80	2	1	
< 750	%	10.0	39.6	76.6	37.1	69.6	66.7	50	
	n	563	435	215	388	158	34	5	
750-999	%	18.0	77.3	49.4	74.2	40.7	85.0	14.7	
	n	924	827	195	642	114	177	7	
1000 – 1249	%	29.5	89.5	23.6	90.4	17.8	82.7	4.0	
	n	1332	1256	93	699	51	552	6	
1250 - 1499	%	42.5	94.3	7.4	94.5	7.3	93.2	1.1	
Total	n	3132	2642	598	1844	403	765	19	
Included	%	100	84.4	22.6	80.8	21.9	90.1	2.5	
Total babies		3132							

#### **CARDIOVASCULAR COMPLICATIONS**

- Patent ductus arteriosus (PDA) was diagnosed in 934 (32.5%) inborn babies with gestational age <32 weeks admitted to the NICUs. Among the 934 babies, 22.5% and 42.4% were treated with indomethacin/ibuprofen and paracetamol, respectively.</li>
   1% of the babies diagnosed with PDA, underwent ligation. (Table 8)
- PDA was diagnosed in 948 (30.3%) inborn babies weighing <1500 g. Among them, 21% were treated with indomethacin/ibuprofen and 40%, paracetamol. 0.9% of the babies diagnosed with PDA, underwent ligation. (Table 9)
- A total of 615 babies ≥35 weeks gestation had persistent pulmonary hypertension of newborn (PPHN) with and overall mortality rate of 15.8%. Inhaled nitric oxide was given to 28% of babies with PPHN.

Table 8

Treatment of patent ductus arteriosus (PDA) in admitted inborn babies in the MNNR by gestational age categories

						Treatment					
Gestation Inborn		PDA Diagnosed		Confirmed by ECHO		Indomethacin/ Ibuprofen		Paracetamol		Ligation	
(weeks)	n	n	%	n	%	n	%	n	%	n	%
22-24	134	35	26.1	33	24.6	15	42.9	20	57.1	0	0.0
25 - 27	536	254	47.4	237	44.2	69	27.2	119	46.9	2	0.8
28 -31	2208	645	29.2	623	28.2	126	19.5	257	40.0	7	1.1
Total	2878	934	32.5	893	31.0	210	22.5	396	42.4	9	1.0

Table 9

Treatment of patent ductus arteriosus (PDA) in admitted inborn babies by birth weight categories

Birth						Treatment						
Weight (grams)	Total Inborn	PDA Diagnosed		Confirmed by ECHO		Indomethacin/ Ibuprofen		Paracetamol		Ligation		
	n	n	%	n	%	n	%	n	%	n	%	
< 750	313	97	31.0	90	28.8	32	33.0	46	47.4	1	1.0	
V 730	313	31	31.0	30	20.0	32	33.0	40	47.4		1.0	
750 - 999	563	248	44.1	242	43.0	64	25.8	112	45.2	4	1.6	
1000- 1249	924	306	33.1	287	31.1	57	18.6	134	43.8	1	0.3	
1250 - 1499	1332	297	22.3	287	21.6	46	15.5	87	29.3	3	1.0	
Total	3132	948	30.3	906	28.9	199	21.0	379	40.0	9	0.9	

#### RETINOPATHY OF PREMATURITY

- For inborn babies born at gestational age <32 weeks and survived to 6 weeks of age, 2007 babies were screened for retinopathy of prematurity (ROP) before discharge. Among these babies, 1746 (87%) did not have ROP, 218 (10.9%) had ROP stage 1 or 2, 41 (2%) had ROP stage 3, and 2 (0.1%) had ROP stage 4 or 5. The incidence rates of severe ROP (stage 3, 4 & 5) were 25%, 5.9%, 0.9% in babies with gestational age of 22-24 weeks, 25-27 weeks and 28-31 weeks respectively. A total of 32 babies had laser therapy and 1 baby had cryotherapy. (Figure 10 and Table 10)
- For inborn babies born with birth weight <1500 g and survived to 6 weeks of age, 2131 (81.5%) were screened for ROP before discharge. Among these babies, 1866 (87.6%) did not have ROP, 222 (10.4%) had stage ROP 1 or 2, 41 (1.9%) had ROP stage 3, and 2 (0.1%) had ROP stage 4 or 5. The incidence of severe ROP (stage 3, 4 and 5) were 9.6%, 4.5%, 1.4%, and 0.4%, in babies with birth weight <750 g, 750-999 g, 1000-1249 g and 1250-1499 g, respectively. A total of 32 babies underwent laser therapy and 1 baby had cryotherapy. (Figure 11 and Table 11)

Figure 10

Incidence of retinopathy of prematurity (ROP) in admitted inborn babies by gestational age categories

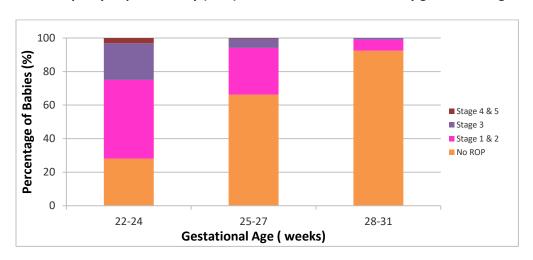


Table 10: Incidence of retinopathy of prematurity (ROP) in admitted inborn babies in the MNNR by gestational age categories

Gestatio	Total number	No. of	No	No. of Retinopathy of prematurity					The	rapy				
nal age at birth (weeks)	of admitted inborn babies	babies alive at 6 weeks	babies ey examin	/e	No I	ROP		OP e 1 or 2		OP ige 3	Stage	OP e 4 or	Cryo	Laser
	n	n	n	%	n	%	n	%	n	%	n	%		
22-24	134	34	32	94.1	9	28.1	15	46.9	7	21.9	1	3.1	-	6
25-27	536	360	338	93.9	224	66.3	94	27.8	19	5.6	1	0.3	1	16
28-31	2208	2024	1637	80.9	1513	92.4	109	6.7	15	0.9	1	0.0	1	10
Total Included	2878	2418	2007	83.0	1746	87.0	218	10.9	41	2.0	2	0.1	1	32

Comment: Screening refers to those screened during the ward admission

Incidence of retinopathy of prematurity (ROP) in admitted inborn babies by birth weight categories

Figure 11

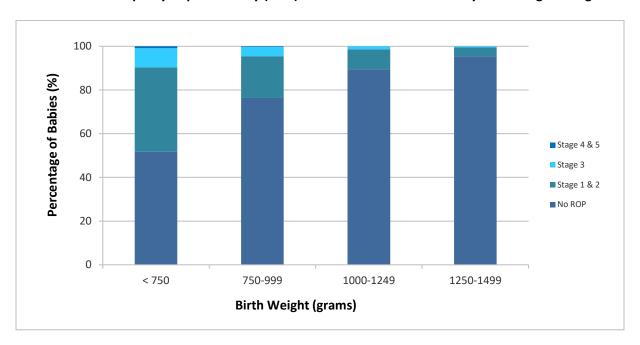


Table 11: Incidence of retinopathy of prematurity (ROP) in admitted inborn babies in the MNNR by birth weight categories

	Total no	No. of				Re	etinopa	athy of <sub>I</sub>	prema	turity			Therapy	
Birth weight (grams)	of admitte d inborn babies	babies alive at 6 weeks	No. of t with examin	eye	No R	ОР	Stag	OP e 1 or 2		OP ige 3	Sta	OP age or 5	Cryo	Laser
	n	n	n	%	n	%	n	%	n	%	n	%		
< 750	313	117	114	97.4	59	51.8	44	38.6	10	8.8	1	0.9	1	8
750-														
999	563	427	398	93.2	304	76.4	76	19.1	17	4.3	1	0.3	-	14
1000-														
1249	924	820	716	87.3	641	89.5	65	9.1	10	1.4	-	0.0	-	9
1250-														
1499	1332	1252	903	72.1	862	95.5	37	4.1	4	0.4	ı	0.0	-	1
Total						_								
included	3132	2616	2131	81.5	1866	87.6	222	10.4	41	1.9	2	0.1	1	32

Comment: Screening refers to those screened during the ward admission

#### INTRAVENTRICULAR HAEMORRHAGE

- There were 2727 inborn babies with gestational age <32 weeks who underwent cranial ultrasound examination for intraventricular haemorrhage (IVH). Among these babies, 1710 (62.7%) did not have IVH, 805 (29.5%) had grade 1 or 2 IVH, 115 (4.2%) had grade 3 IVH, and 97 (3.6%) had grade 4 IVH. The incidence rates of severe IVH (grade 3 or 4) were 27.4%, 18.5%, and 4.4% in babies with gestational age of 22-24 weeks, 25-27 weeks, and 28-31 weeks, respectively. 7 babies had ventriculo-peritoneal (VP) shunt inserted. (Figure 12 and Table 12)</p>
- There were 2937 inborn babies with birth weight <1500 g who underwent cranial ultrasound examination. Among these babies, 1888 (64.3%) did not have IVH, 840 (28.6%) had grade 1 or 2, 112 (3.8%) had grade 3, and 97 (3.3%) had grade 4 IVH. The incidence rates of severe IVH (grade 3 or 4) were 22.3%, 13.1%, 5.9%, and 2.4% in babies with birth weights <750 g, 750-999 g, 1000-1249 g, and 1250-1499 g, respectively. 6 babies had VP shunt inserted. (Figure 13 and Table 13)

Figure 12

Incidence of intraventricular haemorrhage (IVH) in admitted inborn babies < 32 weeks gestational age

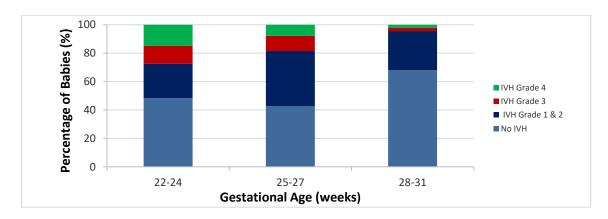
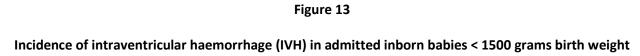


Table 12: Incidence of intraventricular haemorrhage (IVH) in admitted inborn babies < 32 weeks gestational age

Gestational age (completed weeks)		Total no. of admitted inborn babies	Babies with cranial US	NO IVH	IVH Grade 1 or Grade 2	IVH Grade 3	IVH Grade 4
22-24	N	134	95	46	23	12	14
	%	4.7	70.9	48.4	24.2	12.6	14.7
25-27	n	536	497	212	193	53	39
	%	18.6	92.7	42.7	38.8	10.7	7.8
28-31	N	2208	2135	1452	589	50	44
	%	76.7	96.7	68.0	27.6	2.3	2.1
Total included	N	2878	2727	1710	805	115	97
	%	100	94.8	62.7	29.5	4.2	3.6
Total babies	2878		20	- 11			3.0



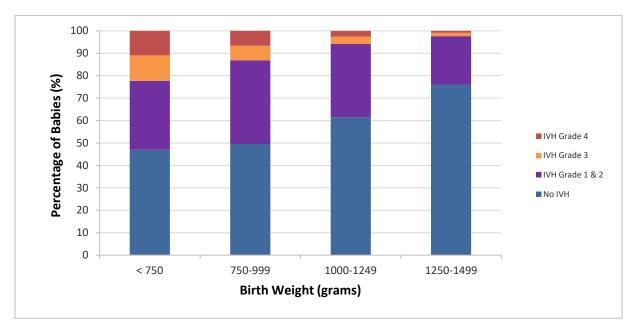


Table 13: Incidence of intraventricular haemorrhage (IVH) in admitted inborn babies <1500 grams birth weight

Birth weight (grams)		Total no. of admitted inborn babies	Babies with Cranial US	NO IVH	IVH Grade 1 or Grade 2	IVH Grade 3	IVH Grade 4
< 750	n	313	247	116	76	28	27
	%	10.0	79.8	47.0	30.8	11.3	10.9
750-999	n	563	541	268	202	35	36
	%	18.0	96.1	49.5	37.3	6.5	6.7
1000-1249	n	924	901	554	294	30	23
	%	29.5	97.5	61.5	32.6	3.3	2.6
1250-1499	n	1332	1248	950	268	19	11
	%	42.5	93.7	76.1	21.5	1.5	0.9
Total included	n	3132	2937	1888	840	112	97
	%	100	93.8	64.3	28.6	3.8	3.3
Total babies	3132						

#### **NECROTIZING ENTEROCOLITIS**

- 143 (5%) of the inborn babies with gestational age <32 weeks, developed necrotizing enterocolitis (NEC)(Stage 2 and above modified Bell's criteria) and 43 (30.1%) of them required surgery. The incidence rates of NEC were 2.2%, 8.8%, and 4.2% for babies with gestational age of 22-24 weeks, 25-27 weeks, and 28-31 weeks, respectively. (Figure 14 and Table 14)
- For inborn babies with birth weight <1500g, 146 (4.7%) developed NEC (Stage 2 and above modified Bell's criteria) and 38 (26%) required surgery. The incidence rates of NEC were 5.8%, 7.8%, 4.7%, and 3.1%, for babies with birth weights <750 g, 750-999 g, 1000-1249 g, and 1250-1499 g, respectively. (Figure 15 and Table 15)

Figure 14

Incidence of necrotizing enterocolitis (NEC) in admitted inborn babies according to gestational age categories

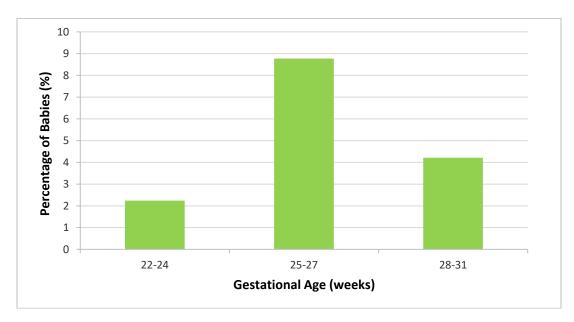


Table 14:
Incidence and treatment of necrotizing enterocolitis (NEC) in admitted inborn babies according to gestational age categories

Gestational age (weeks)	Total number of admitted inborn babies	Babies with NEC			With Surgical treatment		
	n	n	%	n	%		
22-24	134	3	2.2	0	0.0		
25-27	536	47	8.8	13	27.7		
28-31	2208	93	4.2	30	32.3		
Total Included	2878	143	5.0	43	30.1		
Total no. of missing (GA)	0						
Overall Total babies	2878						

Comment: NEC refers to those with at least Stage 2 modified Bell's criteria

Figure 15

Incidence of necrotizing enterocolitis (NEC) in admitted inborn babies according to birth weight categories

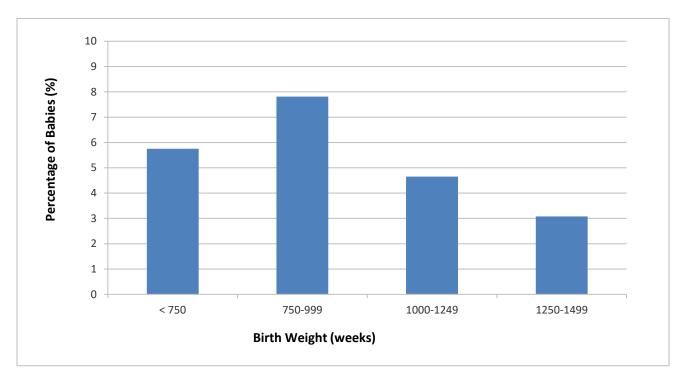


Table 15:
Incidence and treatment of necrotizing enterocolitis (NEC) in admitted inborn babies according to birth weight categories

Birth weight (grams)	Total number admitted of inborn babies	Babies with NEC		With Surgical treatment		
	n	n %		n	%	
< 750	313	18	5.8	4	22.2	
750-999	563	44	7.8	13	29.5	
1000-1249	924	43	4.7	8	18.6	
1250 – 1499	1332	41	3.1	13	31.7	
Total included	3132	146	4.7	38	26.0	
Total no. of missing (BW)	0					
Overall total babies	3132					

Comment: NEC refers to those with at least Stage 2 modified Bell's criteria

#### **NEONATAL SEPSIS**

- The incidence rate of early onset sepsis (blood culture positive) among babies with gestational age <32 weeks, was 1.9%. The incidence rates were 3.7%, 2.8%, and 1.5% in babies with gestational age 22-24 weeks, 25-27 weeks, and 28-31 weeks, respectively (Figure 16 and Table 16)
- In regards to blood culture positive, late onset sepsis, 208 (8%) of inborn babies with gestational age <32 weeks who survived more than 3 days had one or more episodes. Among these babies, the incidence rates were 26.8%, 16.9%, and 5.7% for babies with gestational age of 22-24 weeks, 25-27 weeks, and 28-31 weeks, respectively. (Figure 17 and Table 17)
- 215 (7.6%) of inborn babies with birth weights <1500 g who survived more than 3 days, had one or more episodes of blood culture positive, late onset sepsis. Among these babies, the incidence rates were 26.3%, 11.1%, 6.4% and 4.5% for birth weight groups <750 g, 750-999 g, 1000-1249 g, and 1250-1499 g, respectively. (Figure 18 and Table 18)

Figure 16

Incidence of blood culture positive early onset sepsis in admitted inborn babies by gestational age categories

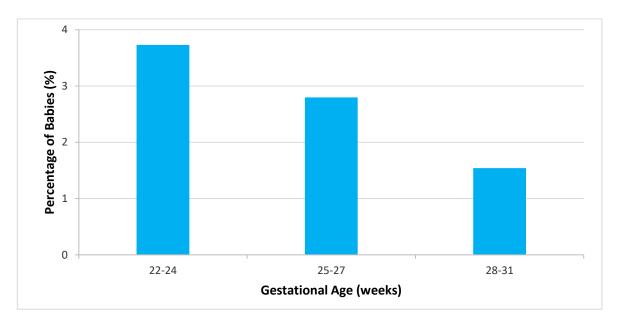


Table 16: Incidence of blood culture positive early onset sepsis in admitted inborn babies by gestational age categories

Gestational age at birth	Total number of admitted inborn babies		ies with early ection
(completed weeks)	n	n	
22-24	134	5	3.7
25-27	536	15	2.8
28-31	2208	34	1.5
Total included	2878	54	1.9
Total no. of missing (GA)	0		
Total babies	2878		

Figure 17

Incidence of blood culture positive late onset sepsis in admitted inborn babies by gestational age categories

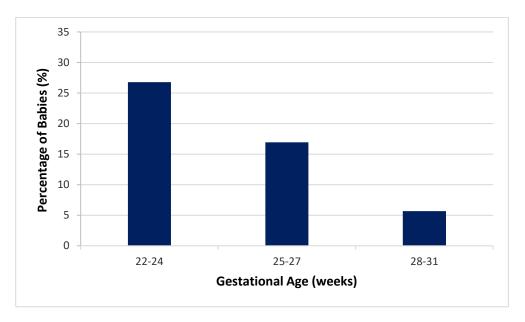


Table 17:
Incidence of blood culture positive late onset sepsis in admitted inborn babies by gestational age categories

Gestational age (weeks)	Total number of admitted inborn babies	No. of babies who survived beyond day 3 after birth	No. of babies with at least one episode of late onset sepsis		
	n	n	n	%	
22-24	134	56	15	26.8	
25-27	536	431	73	16.9	
28-31	2208	2112	120	5.7	
Total included	2878	2599	208	8.0	
Total no. of missing (GA)	0				
Total babies	2878				

Figure 18

Incidence of blood culture positive late onset sepsis in admitted inborn babies by birth weight categories

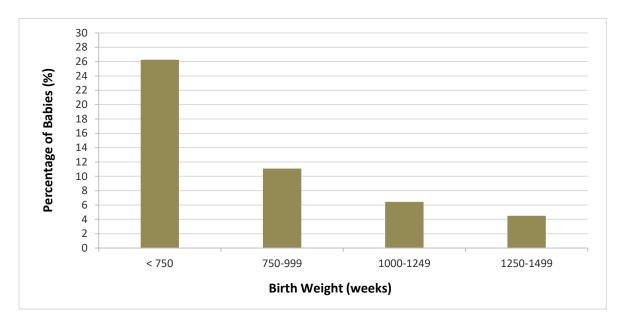


Table 18: Incidence of blood culture positive late onset sepsis in admitted inborn babies by birth weight categories

Birth weight (grams)	Total number of admitted inborn babies	No. of babies who survived beyond day 3 after birth	No. of babies with at least one episode of late onset sepsis		
	n	n	n	%	
< 750	313	179	47	26.3	
750-999	563	487	54	11.1	
1000-1249	924	869	56	6.4	
1250 - 1499	1332	1288	58	4.5	
Total included	3132	2823	215	7.6	
Total no. of missing (BW)	0				
Overall total babies	3132				

#### THERAPEUTIC HYPOTHERMIA

• 690 babies, born at ≥35 weeks gestational age, were diagnosed with hypoxic-ischaemic encephalopathy (HIE), with 618 babies who were inborn and 72 babies who were outborn. Among these babies, 462 had moderate to severe HIE; with 280 (88.6%) of babies diagnosed with moderate HIE and 106 (72.6%) of babies with severe HIE, underwent therapeutic hypothermia. Mortality rates for babies with moderate and severe HIE were 5.1% and 51.4% respectively.

#### **SURVIVAL AND MORBIDITIES**

- The survival rates of very preterm babies included in the MNNR according to gestational age were 20.8% for 24 weeks, 37.7% for 25 weeks, 59.4% for 26 weeks, 74.9% for 27 weeks, 82.6% for 28 weeks, 85.5% for 29 weeks, 92.7% for 30 weeks, and 93.6% for 31 weeks. (Figure 19 and Table 19)
- The survival rates of babies, according to birth weight categories, included in the MNNR were 18.2% for ≤500 grams, 57.2% for 501-1000 grams, 90.2% for 1001-1500 grams, 92.7% for 1501-2500 grams, and 94.0% for >2500 grams. For the category > 1500 grams birth weight, calculated survival rate did not include all live births in that category (see inclusion criteria). (Figure 20 and Table 20)
- The number of inborn survivors with 5 major morbidities prior to discharge were analysed; with the morbidities including:
  - o Patent ductus arteriosus (PDA) requiring surgical ligation
  - Stage 3, 4 or 5 retinopathy of prematurity (ROP)
  - Oxygen dependency at 36 weeks post-conceptional age
  - Blood culture positive sepsis
  - Stage 2 and above necrotizing enterocolitis (NEC) on modified Bell's criteria
- Among survivors with gestational age of 22-24 weeks, 31.3% had 1 morbidity, 34.4% had 2 morbidities, 15.6% had 3 morbidities, and none had more than 3 morbidities. 18.8% did not have any of these morbidities.
- Among survivors with gestational age of 25-27 weeks, 33.5% had 1 morbidity, 13.3% had 2 morbidities, 3.8% had 3 morbidities, 0.3% had 4 morbidities, and none had 5 morbidities. 49.1% did not have any of these morbidities.
- Among survivors with gestational age of 28-31 weeks, 15.3% had 1 morbidity, 2.4% had 2 morbidities, 0.4% had 3 morbidities, 0.1% had 4 morbidities, and none had 5 morbidities. 81.8% did not have any of these morbidities. (Table 21a)
- Among survivors with birth weight <750 g, 44.1% had 1 morbidity, 21.6% had 2 morbidities, 9% had 3 morbidities, 0.9% had 4 morbidities and none had 5 morbidities. 24.3% did not have any of these morbidities.
- Among survivors with birth weight 750-999 g, 30.6% had 1 morbidity, 11.4% had 2 morbidities, 2.4% had 3 morbidities, none had more than 3 morbidities. 55.6% did not have any of these morbidities.
- Among survivors with birth weight 1000-1249 g, 18.5% had 1 morbidity, 2.1% had 2 morbidities, 0.6% had 3 morbidities, 0.1% had 4 morbidities and none had 5 morbidities. 78.6% did not have any of these morbidities.
- Among survivors with birth weight 1250-1499 g, 8.3% had 1 morbidity, 1.2% had 2 morbidities, 0.2% had 3 morbidities, 0.1% had 4 morbidities and none had 5 morbidities. 90.1% did not have any of these morbidities. (Table 21b)

Figure 19

Survival to discharge of all live births admitted to MNNR hospitals according to gestational age

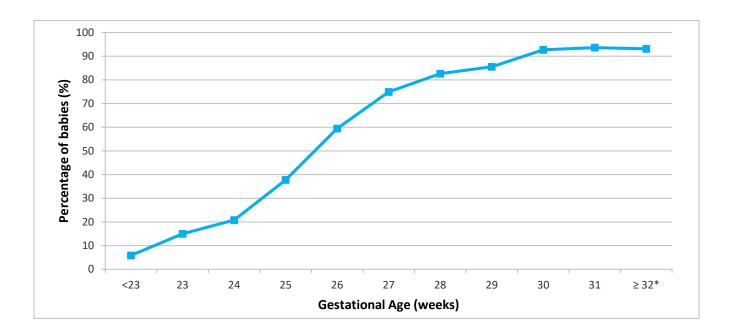


Table 19: Survival to discharge of all live births admitted to MNNR hospitals according to gestational age

Gestational age (completed weeks)	Total number of inborn & outborn		
Weeksy	babies	Number of survivors	% survival
<23	17	1	5.9
23	60	9	15.0
24	125	26	20.8
25	151	57	37.7
26	212	126	59.4
27	275	206	74.9
28	455	376	82.6
29	482	412	85.5
30	695	644	92.7
31	827	774	93.6
≥32*	13112	12208	93.1
Total included	16411	14839	90.4
Total no. of missing (GA)	0		
Total babies	16411		

COMMENT: \* For the category  $\geq$  32 weeks gestation, calculated survival rate does not include all live births in that category (see inclusion criteria).

Figure 20
Survival to discharge of all babies admitted to MNNR hospitals according to birth weight categories

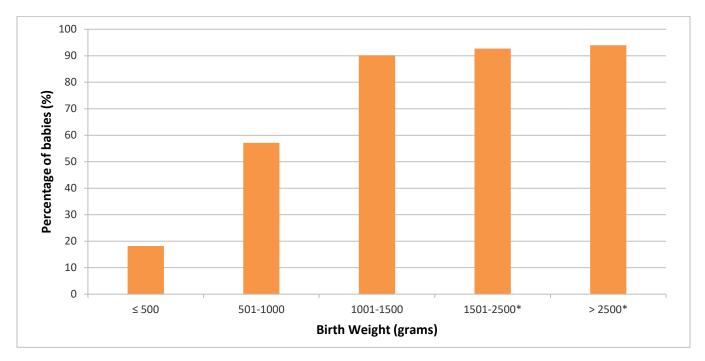


Table 20: Survival to discharge of all babies admitted to MNNR hospitals according to birth weight categories

Birth weight (grams)	Total number of inborn & outborn babies	Number of survivors	% survival
≤500	22	4	18.2
501-1000	1090	623	57.2
1001-1500	2551	2301	90.2
1501-2500*	5413	5019	92.7
>2500*	7335	6892	94.0
Total included	16411	14839	90.4
Total no. of missing (BW)	0		
Overall Total babies	16411		

COMMENT: \* For the category > 1500 gram birth weight, calculated survival rate does not include all live births in that category (see inclusion criteria).

Table 21a Gestational age specific mortality or significant morbidity in admitted inborn babies (five morbidities)

Gestational age at birth (weeks)		Total no. of admitt- ed inborn babies	Numb- er Surviv- ed	No. with any one morbidities prior to discharge among survivors	No. with any two morbidit- ies prior to discharge among survivors	No. with any three morbidit- ies prior to discharge among survivors	No. with any four morbidit- ies prior to discharge among survivors	No. with any five morbidit- ies prior to discharge among survivors	No. without any five morbidit- ies prior to discharge among survivors
22-24	n	134	32	10	11	5	0	0	6
	%	4.7	23.9	31.3	34.4	15.6	0.0	0.0	18.8
25-27	n	536	346	116	46	13	1	0	170
	%	18.6	64.6	33.5	13.3	3.8	0.3	0.0	49.1
28-31	n	2208	2003	306	48	9	2	0	1638
	%	76.7	90.7	15.3	2.4	0.4	0.1	0.0	81.8
Total	n	2878	2381	432	105	27	3	0	1814
Included	%	100	82.7	18.1	4.4	1.1	0.1	0.0	76.2
Total no. of missing (GA)	-								
Total babies	2070								

Total babies | 2878 |

i. Patent ductus arteriosus (PDA) requiring surgical ligation

ii. Stage 3, 4 or 5 Retinopathy of prematurity (ROP)

iii. Oxygen dependency at 36 weeks

iv. Confirmed sepsis

v. Necrotizing enterocolitis (NEC)

Table 21b

Birth weight specific mortality or significant morbidity in admitted inborn babies (five morbidities)

Birth weight (BW) (grams)		Total no. of admitt- ed inborn babies	Numb- er Surviv- ed	No. with any one morbidit- ies prior to discharge among survivors	No. with any two morbidit- ies prior to discharge among survivors	No. with any three morbidit- ies prior to discharge among survivors	No. with any four morbidit- ies prior to discharge among survivors	No. with any five morbidit- ies prior to discharge among survivors	No. without any five morbidit- ies prior to discharge among survivors
	n	313	111	49	24	10	1	0	27
< 750	%	10.0	35.5	44.1	21.6	9.0	0.9	0.0	24.3
750 - 999	n %	563 18.0	412 73.2	126 30.6	47 11.4	10 2.4	0 0.0	0 0.0	229 55.6
1000 - 1249	n %	924 29.5	809 87.6	150 18.5	17 2.1	5 0.6	1 0.1	0	636 78.6
1250 - 1499	n %	1332 42.5	1247 93.6	104 8.3	15 1.2	3 0.2	1 0.1	0 0.0	1124 90.1
Total Included	n %	3132 100	2579 82.3	429 16.6	103 4.0	28 1.1	3 0.1	0 0.0	2016 78.2
Total no. of missing (BW)	-								

Total babies 3132

i. Patent ductus arteriosus (PDA) requiring surgical ligationii. Stage 3, 4 or 5 Retinopathy of prematurity (ROP)

iii. Oxygen dependency at 36 weeks

iv. Confirmed sepsis

v. Necrotizing enterocolitis (NEC)

# **APPENDICES**

#### **Appendix 1 Level of Neonatal Care**

(Adapted from Committee on Foetus and Newborn, Levels of Neonatal Care, Paediatrics, Vol. 114 no. 5, November 2004, p.1345)

#### Level I Neonatal Care (Basic), well- newborn nursery: has the capability to:

- Provide neonatal resuscitation at every delivery
- Evaluate and provide postnatal care to healthy newborn infants
- Stabilise and provide care for infants born at 35 to 37 weeks gestation who remain physiologically stable
- Stabilise newborn infants who are ill and those born at <35 weeks gestation, until transfer to a hospital that can provide the appropriate level of neonatal care

<u>Level II Neonatal Care (Specialty)</u>, <u>Special care nursery:</u> Level II units are subdivided into two categories on the basis of their ability to provide assisted ventilation including continuous positive airway pressure

- **1.** Level II A has the capability to:
- Resuscitate and stabilise preterm and/or ill infants before transfer to a facility at which newborn intensive care is provided
- Provide care for infants born at >32 weeks gestation and weighing ≥1500 g (1) who have physiologic(al) immaturity such as apnoea of prematurity, inability to maintain body temperature, or inability to take oral feeding or (2) who are moderately ill with problems that are anticipated to resolve rapidly and are not anticipated to need subspecialty service on an urgent basis
- Provide Care for infants who are convalescing after intensive care
- 2. Level II B has the capabilities of a Level IIA nursery and the additional capability to provide mechanical ventilation for brief durations (<24 hours) or continuous positive airway pressure

#### Level III (Subspecialty) Neonatal Intensive Care Unit (NICU): Level III units subdivided into three categories:

- 1. Level III A NICU has the capability to
- Provide comprehensive care for infants born at >28 weeks gestation and weighing >1000 g
- Provide sustained life support limited to conventional mechanical ventilation
- Perform minor surgical procedures such as placement of central venous catheters or inguinal hernia repair
- 2. Level III B NICU has the capability to provide
- Comprehensive care for extremely low birth weight infants (≤1000 g and ≤28 weeks gestation)
- Advanced respiratory support such as high-frequency ventilation and inhaled nitric oxide
- Prompt and on-site access to a full range of paediatric medical subspecialties
- Advanced imaging, with interpretation on an urgent basis, including computed tomography, magnetic resonance imaging, and echocardiography Paediatric surgical specialists and paediatric anaesthesiologists on- site or at a closely related institution to perform major surgeries such as ligation of patent ductus arteriosus and repair of abdominal wall defects, necrotising enterocolitis with bowel perforation, trachea-oesophageal fistula and/or oesophageal atresia and myelomeningocele
- **3. Level III C NICU** has the capabilities of a Level III B NICU and which is located within an institution that has the capability to provide extracorporeal membrane oxygenation (ECMO) and surgical repair of complex congenital cardiac malformation that requires cardiopulmonary bypass.

#### **Appendix 2 Data Definitions**

#### **DATA DEFINITIONS AND CRITERIA**

Centre Name\*: Name of participating hospital

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

State if it is a new case, or a readmission and to specify the referring centre (Referral from :) if relevant.

#### **Case Status:**

'New case': First time admission to the NNU concerned will be considered as a new case.

'Readmission': Subsequent admission of the same baby to the same NNU within 44 weeks postconceptional age.

'Previously admitted to another SDP': Case transferred from SDP hospital to another SDP hospital for first time.

State if it is admitted to neonatal ward/ admitted to neonatal ward as an abandoned baby.

#### **SECTION 1: Patient Particulars**

- 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: Registration Number at participating hospital. If the baby dies in Labour room and has no RN, then use the mother's RN.
- 4. a) Mother's I/C Number: MyKad number or Other ID document no. If "Other" please specify type of document.b) Baby's MyKid number: add number if available
- 5. a) Date of Birth: dd/mm/yy b) Time of Birth: To state 24-hour format (mandatory for death cases) Estimate time of death if patient died at home and time accurately not known as in home delivery
- 6. Ethnic group: Malay / Chinese / Indian / Orang Asli / Bumiputra Sabah / Bumiputra Sarawak / Other Malaysian (e.g. Punjabi, Eurasian or Serani) / Non-citizen (specific country). If Bumiputra Sabah or Bumiputra Sarawak, please specify the indigenous group.
- 7. Maternal Age: Age in completed years.
- **8. GPA**: Gravida, Para, Abortion (of current pregnancy before delivery of this child). To state number of ectopic pregnancies (Ectopic pregnancy also considered as an abortion).
- 9. Maternal Diabetes: State 'yes' or 'no' if mother had diabetes (regardless of whether it is gestational or pregestational) State 'unknown' if so
- **10. Maternal Hypertension:** State 'yes' or 'no' if mother had hypertension (regardless of whether it is chronic or pregnancy induced) State 'unknown' if so

- 11. Maternal Chorioamnionitis: State 'yes' or 'no' if mother had chorioamnionitis. State 'unknown' if so.
- 12. Maternal Eclampsia: State 'yes' or 'no'. 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 steroids: Corticosteroids given antenatal via any route to the mother at a time likely to enhance fetal lung maturation. Excludes steroids given for other reasons. State 'yes' if this has been given (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: Antibiotic treatment is provided to the mother within the period mother is in labour, with the intent of preventing infection of the fetus. This includes the prophylactic use of parenteral penicillin or ampicillin. State 'Yes' if systematic antibiotics (enteral or parenteral) were given to mothers in the 24 hours prior to delivery. State 'unknown' if so
- **19.** *Birth weight (grams):* The weight of the baby immediately following delivery recorded in grams to the nearest gram and measured within the first hour of life.
- **20.** a) *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 selected if done earlier than 25 weeks and there is a discrepancy with the Last Menstrual Period (LMP) dates. Otherwise, use LMP dates.
  - 2) New expanded Ballard scoring. If there is no definite estimate but baby referred to as term baby, enter 40. Preferably insert the exact gestation for term infants i.e. ranging from 37-41 weeks
  - b) Gestational age based on: LMP, Ultrasound, Neonatal assessment or unknown mandatory if patient died.
- 21. Growth status: based on Intrauterine Growth Curves (Composite Male / Female) chart. SGA <10<sup>th</sup> centile; AGA 10-90<sup>th</sup> centile: LGA >90<sup>th</sup> 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 participating hospital also considered as inborn. (unless in ambulance – born before arrival BBA as outborn)

**Outborn** – Born in another place (includes BBA) and transferred after birth to NNU of the participating site. Includes those born in hospital compound but not wards.

- Home
- Health Clinic
- Government Hospital with specialist General/District
- Government Hospital without specialist
- University Hospital
- Private Hospital/maternity home<50 beds with/without specialist</li>
- Private Hospital/maternity home>50 beds
- Alternative Birthing Centre (ABC) Urban/Rural
- Enroute / During transport
- Others \_ \_(please specify)
- Unknown
- **24.** *Multiplicity*: To indicate as singleton, twins, triplets or others i.e. quadruplets, etc. If the baby is other than singleton, specify birth order 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.
- **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 sections, tick Caesarian only.
  - Tick as 'emergency' 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:** 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 and 5 min as noted in the labour and delivery record. Score even if baby was intubated by 5 minutes of life. Tick 'unknown' if so, not because it was not scored once baby intubated. Apgar score can be '0' at 1 minute & 5 minutes.
- 27. Initial Resuscitation (for inborn babies only): Tick 'Yes' for all intervention that apply at birth for inborn cases only
  - a) Oxygen
  - b) Early CPAP
  - c) Bag-mask ventilation
  - d) Endotracheal Tube Ventilation
  - e) Cardiac Compression
  - f) Adrenaline
- 28. a) Plastic wrap at birth: Yes /No (for < 1000 gm)
  - b) If yes: was baby wrapped without drying at birth: Yes /No

c) Admission Temperature: Indicate the first temperature (axillary) on admission to one decimal point in degree Celsius. Mandatory field for admission to Neonatal Ward. Does not include babies who die in delivery room.

#### **SECTION 3: Neonatal Events**

- **29. Respiratory support**: Tick 'Yes' if any respiratory support was given
  - a) CPAP Continuous Positive Airway Pressure.
  - b) High flow nasal cannula (HFNC)
  - c) Conventional Ventilation intermittent positive pressure ventilation through an endotracheal tube a conventional ventilator (IMV rate < 240/min) at any time after leaving the delivery room.
  - d) HFJV/ HFOV High frequency ventilation
  - e) Nitric oxide delivered as a gas via a ventilator at any time after leaving the delivery room.
- **30. Total number of days on ventilation support at your centre**: Total number of days on conventional ventilation and high frequency ventilation. Do not include days on CPAP of HFNC.
- **31. Surfactant**: A dose of any type of exogenous surfactant was used to treat the baby. Indicate whether exogenous surfactant given or not. If 'yes' indicate whether given at < 1 hour, 1 -2 hours or > 2 hours postnatal age.
- **32.** 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 in 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 (AFTER SECTION 5). 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'.

NA in the CRF means data is not applicable or not available. There should not be too many 'Not available' data

#### **SECTION 5: Outcome**

- 47a. Date of discharge/transfer/death: Enter the exact date
- **47b.** *Time of death:* State as 24-hour format used to auto calculate age at discharge. Mandatory for death cases give best-estimated time if of death if exact time not known.
- 48. 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 Intrauterine Growth Curves (Composite Male / Female)
- 49. Exclusive breastfeeding at discharge: Tick yes/no

- **50. 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.
- **51. Outcome**: Alive or Dead Alive at discharge or died before discharge.

If child alive, state Place of discharge to: Home, Other Non-Paeds Ward, Social Welfare home 'Still hospitalised as of  $1^{st}$  birthday' 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 will 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. 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

## <u>Filled whenever there is neonatal death in accordance to the Modified Wigglesworth Classification of Perinatal</u> Mortality:

An additional data to that collected in the 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:* whichever 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, Kementarian Kesihatan Malaysia)

#### a. 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 baby preterm?
- c. Gestation < 37 weeks (Preterm death without LCM) due to: 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, acute intrapartum event ("asphyxia"). Tick "extreme prematurity" in the subcategory only for babies less than 28 weeks only who died and no immediate secondary cause of death eg. as in palliative care

Gestation ≥ 37 weeks (did the baby had an was there an Asphyxial condition? All term babies who die from birth asphyxia or meconium aspiration syndrome or PPHN.

#### d. If term and no asphyxia conditions, 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.

- e. If term and infection present, tick organism
- f. If term and infection absent, are they any other specific causes of death?

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.

#### **DEFINITIONS OF CERTAIN SPECIFIED DIAGNOSES**

(Modified from ICD 10)

Diagnosis	Definition
Respiratory	
Meconium aspiration syndrome	Tick 'yes' if all 5 criteria are satisfied:
	<ul> <li>a. Presence of meconium stained amniotic fluid at birth</li> <li>b. Respiratory distress onset within 1 hour of birth. Respiratory distress defined as presence of one of the following signs: tachypnoea, grunting, nasal flaring, or intercostal retraction.</li> <li>c. PaO<sub>2</sub> &lt; 50 mmHg in room air, central cyanosis in room air or requirement for supplemental O<sub>2</sub> to maintain a PaO<sub>2</sub> &gt; 50 mmHg</li> <li>d. Abnormal CXR compatible with meconium aspiration: Findings may include coarse irregular or nodular pulmonary densities, areas of diminished aeration or consolidation alternating with area of hyperinflation, or generalized hyperinflation.</li> <li>e. Absence of culture proven early onset bacterial sepsis or pneumonia (i.e. negative blood culture within 72 hours of birth).</li> </ul>
Pulmonary haemorrhage	Originating in the perinatal period (as diagnosed clinically by pink or red frothy liquid draining from 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).
Congenital Pneumonia	Infection of the lungs acquired prepartum, intrapartum, at birth or after birth. (Diagnosed with / without cultures). Diagnosis made clinically and supported by CXR findings.
Nosocomial pneumonia	Infection of the lungs acquired after admission to the ward.
Community acquired pneumonia	Infection of the lungs acquired after discharge home

Transient Tachypnoea of Newborn	Benign disease of near-term, term or large premature infants with respiratory distress shortly after delivery resolving within 3 days.
Pulmonary Interstitial Emphysema	Dissection of air into the perivascular tissues of lung from alveolar overdistention or overdistention of smaller airways evident on CXR as linear or cast like lucencies with a history of requiring increasing ventilatory support
Respiratory distress syndrome (RDS).	Defined as: within the first 24 hours of life,  A. PaO <sub>2</sub> < 50mmHg in room air, central cyanosis in room air, or a requirement for supplemental O <sub>2</sub> to maintain a PaO <sub>2</sub> > 50mmHg  AND  B. A chest radiograph consistent with RDS (low lung volumes and reticulogranular appearance to lung fields, with or without air bronchograms)
Pneumothorax	Presence of extrapleural air diagnosed by chest radiograph or needle aspiration (thoracocentesis).  For infants who had thoracic surgery and a chest tube 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'.  For infants who had thoracic surgery and then later developed extra pleural air diagnosed by CXR or needle thoracocentesis, tick 'Yes'.  Indicate whether pneumothorax developed during CPAP, Conventional ventilation or HFV.
Supplemental oxygen & BPD  Tick "yes" if the baby received continuous oxygen concentration > 21% for at least 28 continuous days (note not "till 28 days of life"). Otherwise tick "no".	Receipt of continuous enriched oxygen concentration > 21% by oxyhood, nasal cannula, nasal catheter, facemask or still requiring nCPAP or other forms of respiratory support by Day 28 and 36 weeks or day 56.
For babies $<$ 32 weeks – state if $O_2$ / any form of CPAP or ventilatory support required at 36 weeks corrected gestation.	'Continuous' means that the patient is receiving oxygen throughout the time period and not just in brief episodes as needed i.e. during feeds. 'Blow-by' oxygen dose not counted unless it is the mode of oxygen administration used in a transport situation. Do not score oxygen given as part of a hyperoxia test.
For babies $\geq 32$ weeks - state if $O_2$ / any form of CPAP or ventilatory support required at Day 56.	

Cardiovascular	Definitive diagnosis of PPHN is made by
a. Persistent Pulmonary Hypertension (PPHN)	Definitive diagnosis of PPHN is made by echocardiography. In the absence of echo confirmation, pre and postductal pulse oxymetry difference of > 10% can be used. Preductal pulse oxymetry done on the right hand and post ductal pulse oxymetry done on lower limbs.
b. Heart failure	Failure of the heart to pump characterized by tachypnea, tachycardia, feeding difficulties, hepatic enlargement, and cardiomegaly.
Patent ductus arteriosus (PDA)	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 O <sub>2</sub> requirement or ECHO evidence of PDA with documentation of left to right ductal shunting.
	If ticked 'Yes', indicate whether ECHO was done and whether pharmacological closure (indomethacine/ibuprofen/paracetamol) or ligation was given or not.
Necrotising enterocolitis (NEC)	Definition for NEC stage 2 and above :
(Stage 2 and above)	<ol> <li>Diagnosis at surgery or post mortem, or</li> <li>Radiological diagnosis, a clinical history plus         <ul> <li>pneumatosis intestinalis, or</li> <li>portal vein gas,</li> </ul> </li> </ol>
If 'yes' and managed surgically, tick 'Surgical Treatment'	Clinical diagnosis, a clinical history plus     abdominal wall cellulitis and palpable abdominal     mass.
NEC present before admission to your centre? (applies to outborn babies)	NEC according to Bell's criteria stage 2 or higher
	<b>Stage 1:</b> Suspect (History of perinatal stress, systemic signs of ill health i.e. temperature instability, lethargy, apnoea, GIT manifestations i.e. poor feeding, increased volume of gastric aspirate, vomiting, mild abdominal distension, faecal occult blood with no anal fissure).
	<b>Stage 2:</b> Confirmed (Any 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).
	<b>Stage 3:</b> Advanced (Any features of stages 1 or 2 plus: deterioration in vital signs, evidence of shock or severe sepsis, or marked gastrointestinal

haemorrhage, or abdominal radiograph shows any features of stage 2 plus pneumoperitoneum). Retinopathy of prematurity (ROP) Criteria for screening for ROP are for babies with birth weight < or equal 1500 grams OR gestational < 32 Maximum stage of ROP in left/right eve weeks, as well as all preterm babies whose clinical as defined by the International course places them at increased risk for ROP as Committee on ROP (ICROP). determined by the attending doctor. Score according to the grade of ROP If an indirect ophthalmologic examination was assigned on an eye exam done by an performed at any time, enter the worst stage documented: ophthalmologist (e.g. threshold). If there is no explicit grade listed, then No ROP: No Evidence of ROP score according to the descriptions given Stage 1: Demarcation Line by the ICROP. (e.g. threshold). Prethreshold ROP ("Prethresh") Threshold ROP ("Thresh") Tick 'Yes' if a retinal exam was done. Stage 4: Partial Retinal Detachment State exact date of first screening and Stage 5: Total retinal detachment post conceptional age at screening. Specify only the worst stage. Also tick if **PLUS disease present** PLUS disease: dilated veins and tortuous arteries, papillary rigidity (must also include stages other than State if laser, cryotherapy, intravitreal No ROP) anti VEGF or vitrectomy was done. If screening was not done, state 'No' and indicates whether an appointment for retinal examination was given, if applicable. State "date of appointment" or "date of first screening" section and postconceptional age will be autocalculated ROP present prior to admission? (applies to outborn babies) To trace back the outcome of ROP screening on first screening if done after Tick "Not applicable" if does not fulfill criteria Intraventricular haemorrhage (IVH) If ultrasound of brain done, enter the worst grade: Tick 'Yes' if IVH is seen and enter the **Grade 1:** Subependymal germinal matrix (GM) worst grade before or on 28 days of life. haemorrhage only **Grade 2:** IVH without ventricular dilation State if VP shunt/reservoir was inserted Grade 3: IVH with ventricular dilation

Tick 'No; if no IVH before or day 28 Tick 'Not Applicable' for term infant Tick "Ultrasound not done" if it was not done.	Grade 4: IVH with parenchymal involvement					
Central venous line	If more than one central line, use data of the central line with the longest duration					
a. Central line - yes or no						
Date of insertion	Central line defined as:					
Date of removal (autocalculate)	<ol> <li>(1) Umbilical catheters.</li> <li>(2) Percutaneously inserted central catheters.</li> <li>(3) Surgically placed Broviac catheter that terminates at or close to the heart or in one of the great vessels.</li> <li>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.</li> </ol>					
b. CLABSI	CLABSI defined as clinical sepsis with positive blood culture in patient with <u>ALL</u> of the following: 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 cultures of the same organism from different sites if the organism is a common skin organism (to differentiate from skin contaminant)					
Confirmed sepsis	Confirmed sepsis					
Tick 'Yes'if there is evidence of confirmed sepsis.	Clinical evidence of sepsis plus blood culture-proven infection.					
Do not include presumed or clinical sepsis.	For CONS:  Place a tick if the infant has ALL 3 of the following:  1. CONS is recovered from a blood culture obtained from either a central line, or a					
State whether the onset of first confirmed sepsis was On or before 72 hours of life OR after 72 hours of life.	peripheral blood sample AND					
State the organism cultured:	<ol><li>Signs of generalized infection (such as apnoea, temperature instability, feeding</li></ol>					
State the organism cultured:  • Group B streptococcus	intolerance, worsening respiratory distress					
MRSA	or haemodynamic instability) AND					
CONS (see definition)						
<ul><li>Staphylococcus aureus</li><li>Klebsiella</li></ul>	<ol> <li>Treatment with 5 or more days of IV antibiotics after the above cultures were obtained. If the patient died, was</li> </ol>					

<ul> <li>Pseudomonas</li> <li>Acinetobacter</li> <li>Fungal (see definition)</li> <li>Others, specify</li> <li>ESBL organisms</li> </ul>	discharged, or transferred prior to completion of 5 days or more of IV antibiotics, this condition would still be met if the intention were to treat for 5 or more days.  Do not place a tick if any or all of the above are not true.  For FUNGAL infection: 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.
Neonatal meningitis  Tick 'yes' (if CSF biochem or cytology suggestive even if CSF C&S is negative) or 'no'  If yes, State if CSF Culture positive - Yes / No  State the organism cultured:  • Group B streptococcus  • MRSA  • CONS (see definition)  • Staphylococcus aureus  • Klebsiella  • Pseudomonas  • Acinetobacter  • Fungal (see definition)  • Others, specify  • ESBL organisms	Signs of clinical sepsis and evidence of meningeal infection as shown in cerebrospinal fluid findings (i.e. cytology, biochemistry or microbiologic findings).
Hypoxic ischaemic encephalopathy (HIE)	HIE requires the presence of all 3 of the following criteria:
Applies only to gestation ≥ 35 weeks	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:

- 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 multi-organ system dysfunction dysfunction of one or more of the following systems within 72 hours of birth
  - 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 malformation of the brain or an inborn error of metabolism, which could explain the encephalopathy.

#### 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, pinching, shining a light or ringing of a bell:

Tick "none" if there is no HIE

Tick "Mild, Moderate, Severe" according to the definition

45a. Tick "none" if there is no HIE Tick "Mild, Moderate, Severe" according to the definition

45b. Highest Thompson Score before 6 hours of life

45c. Cooling therapy

45d. Seizures in HIE cases

Major Congenital Abnormalities

Tick 'Yes' if major congenital anomaly is present even if it is an isolated one (i.e. only one abnormality)

If Yes, state:

- 1. 'Known Syndrome',
- 2. 'Not a Recognised Syndrome'
- 3. 'Isolated major abnormality'

If the syndrome is known, tick the specify syndromes or specify it.

Types of Abnormalities:

Tick all major abnormalities found for recognisable syndrome, non-recognisable ones or isolated major congenital abnormality

HIE severity

- a. Mild (normal or hyperalert) infants in this category are alert or hyperalert with either a normal or exaggerated response to arousal.
   No seizures (Sarnat Stage 1)
- Moderate (lethargic or stupor) infants in this category are arousable but have a diminished response to arousal maneuvers. Such babies frequently have seizures (Sarnat Stage 2)
- c. Severe (deep stupor or coma) infants in this category are not arousable in response to arousal maneuvers. (Sarnat Stage 3)

Insert highest score

Yes/ No if yes , completed 72 hours yes no If yes : cooling blanket or cap / passive cooling plus or minus gel pack / both

Yes / No

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

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".

For congenital heart disease,
Type Operation yes or no
Age of operation \_\_\_\_\_ (days)

### **Appendix 3 Census Forms**

Tel/Fax: 03-89964505

#### Malaysian National Neonatal Registry

Unit 2.4 (Suite 3), Enterprise 3B, Technology Park Malaysia, Lebuhraya Puchong -Sg. Besi 57000 Bukit Jalil, Kuala Lumpur

i. Hospital:				
ii. Month:			iii. Year:	
iv. Total Births:		/. Live Births:	vi. Sti	II Births:
SECTION 1: DELIV	ERIES VERSUS E	BIRTH WEIGHT		
Birth Weight	No. of Still Births	No. of Live Births	No. Admitted to Neonata	No. who died in delivery
(grams)			Unit	room
< 500				
500				
501 - 600				
601 - 700				
701 - 800				
801 - 900		3		
901 - 999				
1000				
1001 - 1250				
1251 - 1499				
1500				
1501 - 2000				
2001 - 2500				
> 2500				
TOTAL				
SECTION 2: BIRTH	VERSUS GESTA	TION WEEKS		
Gestation (weeks)	No. of Still Births	No. of Live Births	No. Admitted to Neonata Unit	al No. who died in delivery room
<22			1	
22-24				
25				
26				
27				
28 29	F			
30				
31				
32				
33				
34				
35				
36				
37-40				
> 40 TOTAL				
IVIAL		1		The state of the s

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SECTION 3: BIRT	TH VERSUS MOD	E 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: BIRT	THS VERSUS ETH	INIC 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							
Burniputera Sabah specify ethnic group:							
Bumiputera Sarawak specify ethnic group:							
Foreigner							
Other Malaysian:							
TOTAL:							
1. Remarks:							
2. Name of Site Coordinator:							
3. Chop:							
4. Date:		ı.					

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month.

ii. Sample of tracking form are as follows

## **Appendix 4 Case Report Form (CRF)**

MA	LAY:	SIA	N NATI	ONAL NE	ATANO	L REG	ISTRY	(CRF	2018)		
Centre Name:	Centre Name:					ther SDP		NNR No. [fice use): [		'	
Date of Admission: (dd/mm/yy)				Hospit	al or IJN:	uner obi			_		
Admitted to neonatal ward:   Yes -	→(Proc	ceed to	o complete ALI	L sections in this C	RF)   No —	➤ (Proceed t	to complete	e Section 1,2	2 [without No.	28], 4[No.	47 only] and 5)
■ Abandoned baby → (if this box	is ticked	d, iten	n No. 1, No. 4a	a, No. 6 to No. 16 a	re not manda	tory)					
Instruction: Where check boxes	are pro	ovided	d, ticked (√) o	ne or more boxes	. Where radio	buttons (	are prov	ided, ticked	(√) one box	only.	
SECTION 1 : PATIENT PA	RTIC	ULA	RS & MA	TERNAL HIS	TORY						
*1. Name of mother:						-					
2. Name of baby (Optional):											
*3. RN of baby:											
*4a. Mother's I/C number:	MyKad	d:				] - [					
	Other	ID do	cument No:								
	Specify type (if				d Force ID Permit numbe		r's License		ation permit	Other	ital RN r, specify:
4b. Baby's MyKid number:	7,-	1	1 1 1		П.Г	1 1		<u> </u>		0	, -,,
	-							-			
*5a. Date of birth of baby: (dd/mm/yy)				/	estim	ime of birth ated time of	birth if the	exaxt time u	inknown)		
*6. Ethnic group of Mother:	O Ma	lalay hinese	<ul><li>○ Indian</li><li>○ Orang A</li></ul>		Sabah, speci Sarawak, spe			Other, Ma	llaysian en, specify co	untry	
*7. Maternal age:	Ļ		]								
*8. GPA: (current pregnancy before delivery of this child)	,	*Gra	avida:		*Parit	y:			*Abortion	: [	
*9. Maternal diabetes (including gestational diabetes):		( )	Yes	•	◯ No						
*10. Maternal hypertension, chronic pregnancy included:	D	( ) \			○ No ○ Unknown						
*11. Maternal Eclampsia:		<u> </u>									
*12. Maternal Chorioamnionitis:		( ) \									
*13. Maternal Anaemia: ( <11g/dL)		( )			○ No ○ Unknown						
*14. Maternal abruption placenta:		() \	Yes	0	⊚ No ⊝ U			nown			
*15. Maternal bleeding placenta praevia:		() Y	Yes		○ No			nown			
*16. Cord prolapse:		() \	Yes	0	○ No			nown			
SECTION 2 : BIRTH HIST	ORY										
*17. Antenatal Steroid:	O Ye	s —	► 01 dose	©2 doses	● No		<u> </u>	Unknown			
*18. Intrapartum antibiotic:	○ Ye	s			● No		0	Unknown			
*19. Birth weight:			(gr	rams)							
*20a.Gestation:			(weeks)		*20b. Gestat	tional age ba	ased on:	<ul><li>LMP</li><li>Ballard</li></ul>	Score	<ul><li>Ultra</li><li>Unkr</li></ul>	
*21. Growth status:	( ) SG	<u>.                                    </u>		-				LGA			
*22. Gender:	● Ma	ale			Female			Ambiguou	ıs / Indetermir	nate	
*23. Place of birth:	○ Inb	born	Home				sity hospita			ers / spec	ify
	⊚ Ou	utborn	Gover	e Hospital Inment hospital wit District	spital Maternity home with special Maternity home without specialist Alternative District Position and the special Maternity home without special Maternity home without special Maternative District Position and the special Maternative Position and M			vith specialis vithout speci ng centre (Al	alist	nown	
*24. Multiplicity:	⊚ Sir	ngleto	n 🔘 Twin	Triplet Of	her, specify: .		Spe	ecify birth	order if not a	asingleto	on:
*25. Final Mode of delivery:	○ Va		delivery →	SVD SVD	○ Breech Forceps	····	Others, sp	n section →	● Electiv	/e	Emergency
					Vacadini Unknown						

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SE	CTION 2 : BIRT	гн ніѕто	ORY (	(continu	ue)											
*26.	Apgar score at 1 mii 5 min (0-10)	n and	a) Sco	ore at 1 mi	in:			Unknown		re at 5 m ase score is intuba	e even if	the				Unknown
	Initial resuscitation: applicable for inborn of		a) Oxy	ygen:		O Yes	(	) No	d) Endo	otrachea	al tube v	rent:	○ Ye	es		⊚ No
ļ '	applicable for inborn c	illy)	b) Ear	rly CPAP :		O Yes	(	No No	e) Card	liac com	pressio	n:	○ Ye	es		⊚ No
			c) Bag ven	g and mas ntilation	k	O Yes	(	€ No	f) Adre	naline:				es		○ No
*28.	a) Plastic wrap at I	oirth (for < 1	1000 gn	n)		O Yes	(	) No								
	b) If yes : was bab	y wrapped v	without	drying at	birth	O Yes	(	) No								
	c) Admission temp (mandatory if adr	perature	onatal w	/ard)				(°C)								
SF	CTION 3 : NEO															
				_												1:
*29.	Respiratory support	:	1	Yes →	a) CI	PAP done?	9 Y	es No i) Total durati	on of C	DAD at v	our can	tro:	T .	_		
lf <	12 hours = state 0.5 da	ays	C	No				i) Total durati	011 01 01	Alaty	our cer	itie.			· L	Day (s)
lf > '	12 to 24 hours = state	1 day				igh flow nasal	( Y	es								
If > 2	24 hours = state to nex	kt completed			Ca	annula (HFNC):		i) Total durati	on of H	FNC at	your ce	ntre			. [	Day (s)
ı i	nplete entry a) to d) for	each tyne o	ıf			onventional	⊚ Y	es No								
	iratory support given	odon typo o			V	entilation:		i) Total durati			onal				. [	Day (s)
					d) H	FJV/HFOV:	( Y									
							L	i) Total durati	ion of HF	FJV//HF	OV at y	our			. [	Day (s)
					e) Ni	itric Oxide:	( Y	es								
							i) Total duration of Nitric Oxide at yo centre:			our			٠ [	Day (s)		
*30.	Total number of days	on														
V	entilation support at	your centre	:		<u>ш</u>	(autoc	alculate	)								
*31.	Surfactant:			<ul><li>Yes</li><li>No</li></ul>	→ (	) < 1 hr		<u></u> 1	-2 hr				(	) > 2 hr		
*32.	Parenteral nutrition:			Yes	⊚ No											
SE	CTION 4: PROI	BLEMS/I	DIAG	NOSES	;											
33.	Respiratory:	Meconi Transie		iration syn		_		aemorrhage nterstitial emphys	sema		_	al pneumo			munity imonia	acquired
*34.	RDS:	O Yes				<b>O</b>	No									
*35.	Pneumothorax:	O Yes _	•			developed di		○ Spontan	eous	<u> </u>	CPAP	(	) CMV		(i)	HFV
*36.	Supplemental	a) Is baby	on > 2			uously for 28 day		ore?	Yes	<b>()</b>	No					
	oxygen and BPD:	b) If Yes	- 17		eks GA, baby still on oxygen, CPAP or other forms of respiratory at 36 weeks									Yes	⊚ No	
					veeks GA, baby still on oxygen, CPAP or other forms of res									( No		
_	cvs:	*37a. PPHI	N :	○ Ye		○ No		*37b. Hea			○ Y	es		● No		
*38.	PDA:	● Yes ■	<b>→</b>		lO done	e: logical closure		Yes Yes	O No							
		⊚ No						If Yes the	n to choo	ose	Indor	nethacin	■ Ibu	profen	■ Pa	racetamol
				c) Liga	ition:		1 (	) Yes	⊚ No	)						
*39.	NEC (stage 2 and above):	O Yes	<b>→</b>			eatment:	!			Yes		⊚ N				
	,	⊚ No		(for	outborn	nt before admis baby only)	ssion to	your centre:		O Yes		⊚ N	lo			
*40.	ROP Retinal Exam Done	Yes ■	<b>—</b>		a) Date	e of first screen	ning:					/ 🔲	/			
	weeks OR ≤ 1500g	(If yes, wor	st stage	of ROP):	b) Pos	st conceptional	age at	Ist screening:				(autoca	lculate)			
	tion 'Not Applicable' be auto blocked					c) No ROP Stage 1 Prethresh Three				sh (	Stage	4 🔘 🤄	Stage 5	■ P	LUS di	sease
≥ 32 weeks AND >1500g:					er Therapy:				⊚ Y			) No				
option 'Yes' & 'No' will be auto blocked					otherapy:	0.5			● Y			) No				
					ectomy/AntiVE		colon?		⊚ Y			) No				
						P present prior outborn baby or		ssion?								
		○ No -	<b>—</b>		Appoi	ntment given:				⊚ Y	es	0	) No			
○ Not Applicable				[						Date of appointment: / / /				/		

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SECTION 4: PROBLEM	IS/DIAGNOSES (continue)
*41. IVH: < 37 weeks - option 'Not Applicable' will be auto blocked	<ul> <li>○ Yes If yes, worst grade:</li> <li>○ No</li> <li>○ Not applicable (term infant)</li> <li>○ Ultrasound not done</li> <li>○ Grade 1</li> <li>○ Grade 2</li> <li>○ Grade 3</li> <li>○ Grade 4</li> <li>○ WP shunt/ reservoir insertion</li> </ul>
*42a. Central Venous Line (applies to the catheter in situ for the longest duration)	i. Yes No ii. Date of insertion: / / / / Date of removal: / / / / Date of central line (autocalculate) :days
*42. CLABSI:	
*43. Confirmed sepsis:	
(Blood culture positive only)	☐ ≤ 72 hours of life  II) Type of organism: (can tick more than one)
	☐ Group B Streptococcus ☐ Staphylococcus aureus ☐ Acinetobacter ☐ ESBL organisms
	■ MRSA ■ Klebsiella ■ Fungal ■ E.Coli
	CONS Pseudomonas Serratia Others, specify:
	II) Type of organism: (can tick more than one)
	☐ Group B Streptococcus ☐ Staphylococcus aureus ☐ Acinetobacter ☐ ESBL organisms
	■ MRSA ■ Klebsiella ■ Fungal ■ E.Coli
	CONS Serratia Others, specify:
*44. Neonatal meningitis:	⊚ Yes
	CSF Culture positive : Yes No
	II) If Yes, type of organism: (can tick more than one)
	Group B Streptococcus Staphylococcus aureus Acinetobacter ESBL organisms
	■ MRSA ■ Klebsiella ■ Fungal ■ E.Coli
	CONS Others, specify:
*45. HIE: (Only for ≥ 35 weeks GA)	
(Only for 2 33 weeks GA)	a) HIE severity
	c) Cooling therapy:
	○ Yes ○ No
	If Yes; then to choose
	Cooling blanket or cap  Passive cooling ± gel pack
	■ Both
	d) Seizures in HIE cases :   Yes  No
*46. Congenital anomalies:	
*46a. Major congenital anomalie	ss: *46b. Types of abnormalities (check all that are present. Applies to all including 'known syndromes', 'not a recognized syndrome' or 'isolated major abnormality')
○ Yes ○ No	
Syndrome (known) Down	☐ CNS → ☐ Hydrocephalus ☐ Skeletal dysplasia ☐ Respiratory
Patau	● Holoprosencephaly ■ CDH
Others,	Hydrops
(Refer to	Neural Neural Renai
	Tube Officer (Note to 155 16).
	○ Encephalocoele ○ Others (Refer to ICD 10):
Not a recognized syndrome	
Isolated major abnormality	□ CVS → Please see (page 4)
-	

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SECTION 4: P	ROBLEMS/DIA	GNOSES (	continue)							
46b. CVS	<ul> <li>Duct dependent</li> <li>Severe congeni (needs early int</li> <li>Other significan</li> </ul>	tal heart ervention)	TOF or PA with VSD Pulmonary atresia (PA) with Intact ventricular septum Complex eyapontic heart with PA Critical PS Hypoplastic left heart syndrome Interrupted aortic arch Coarctation of aorta Critical AS  TAPVD ention)  TOF or PA with VSD Hypoplastic left was the part with PA Critical PS TAPVD Coherts  TAPVD Others							
	Date of echo dia	agnosis : Date o		specify						
	Intervention —	Surgery Catheteri		e:/ auto ca e:/ auto ca						
SECTION 5: C	UTCOME									
*47a. Date of dischadeath: (dd/mm			/	47b. Time of Death: (24 hours) (mandatory for death			(enter the best estimated time of death if the exact time is unknown)			
*48. Weight and gro status on disch		(grams)								
	b) Growth status:	⊚ SGA		○ LGA	A					
49. Exclusive brea at discharge  ( Tick yes if > 72 hou		O Yes	○ Yes ○ No							
*50. Total duration (neonatal/ pead			( in completed day	ys) (auto calculate)						
*51. Outcome:										
⊙ Alive →	Place discharged to Home Social welfare h Other wards wit Still hospitalize Transfer to othe	ome hin hospital d as of 1st birthd	a) Name of hospital: b) Reason for transfer:	Growth/ stepdown care Lack of NICU bed	Acute med diagnostic		il/ Logistic reason			
			c) Post transfer dis (Please fill this se not part of the N	ection if place transferred is	Death	Transferred again to Readmitted to your Still in ward				
○ Dead →	Place of death:		abour room/OT n transit		Neonatal unit	t ify:				
Name :	Signat	ture:			Dat	e:	(dd/mm/yy)			

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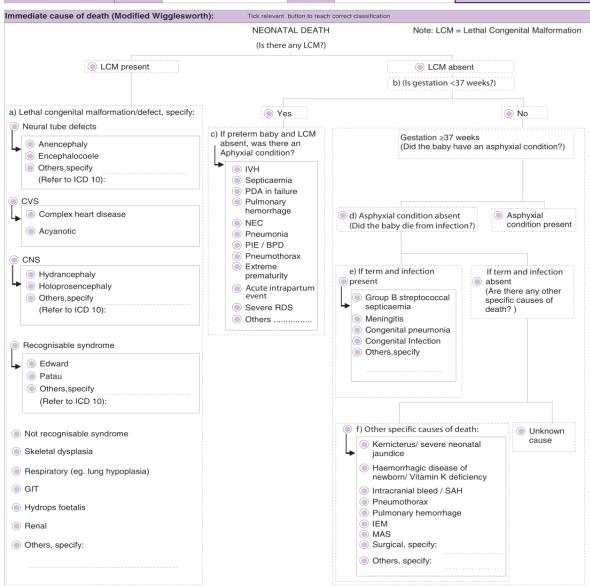
#### MALAYSIAN NATIONAL NEONATAL REGISTRY

#### **Supplementary Form**

Instruction:

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

2) For preterm bables please fill in according to the most immediate cause of death.									
1. Centre Name:				Office	/				
2. Name:		3. RN:		use: Centre:					
4. Mother's I/C Number:	New IC:	Passport:							

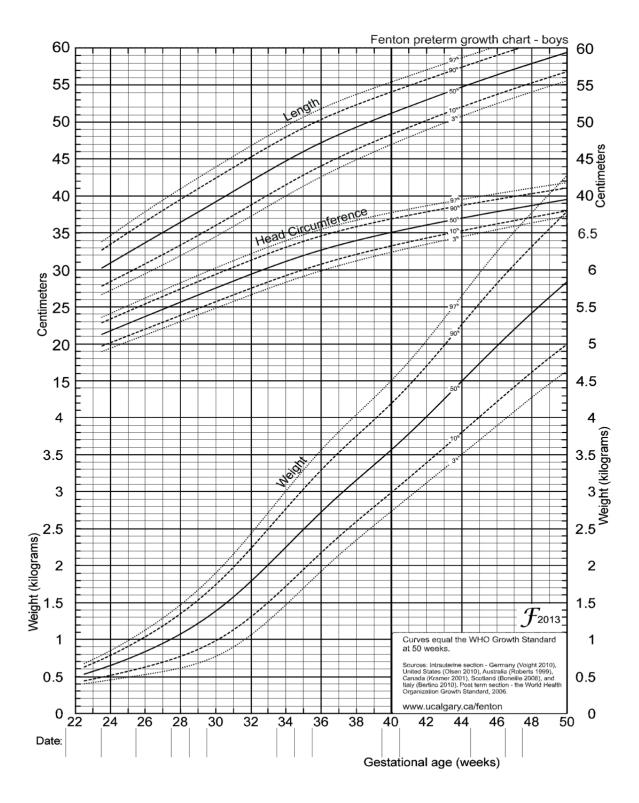


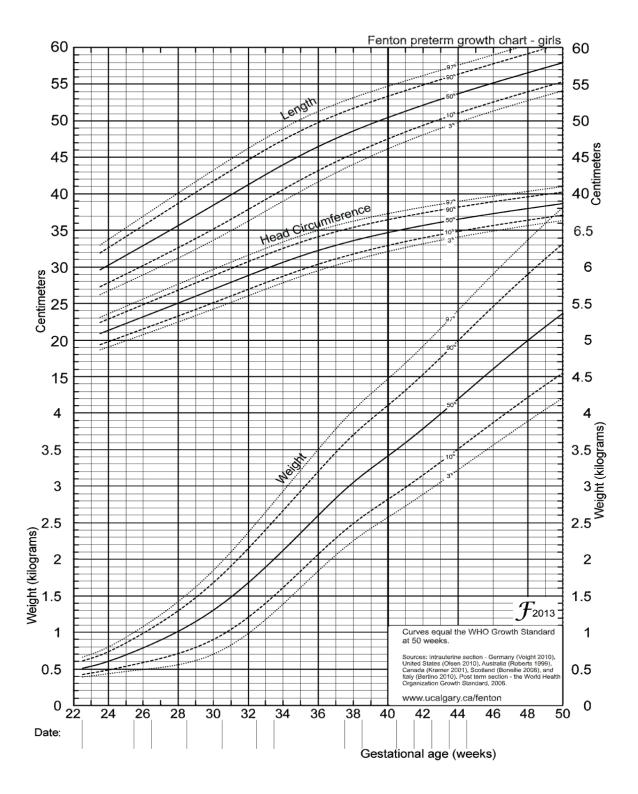
Name :	Signature :	Date:		(dd/mm/yy)

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#### **Appendix 5 Presentations**

#### POSTER, ABSTRACT AND PAPER PRESENTIONS

- 1. Neoh SH. *Survival of VLBW neonates*. Presented at the MNNR SDP Meeting, Auditorium Hospital Wanita & Kanak-kanak Kuala Lumpur, Malaysia, November 2019
- 2. Boo NY. *HIE 2018.* Presented at the MNNR SDP Meeting, Auditorium Hospital Wanita & Kanak-kanak Kuala Lumpur, Malaysia, November 2019
- 3. Chee SC. *NEC in VLBW neonates*. Presented at the MNNR SDP Meeting, Auditorium Hospital Wanita & Kanak-kanak Kuala Lumpur, Malaysia, November 2019
- 4. Farah Inaz. *Cardiac Anomalies*. Presented at the MNNR SDP Meeting, Auditorium Hospital Wanita & Kanak-kanak Kuala Lumpur, Malaysia, November 2019
- 5. Wong AC. *Admission hypothermia in VLBW neonates*. Presented at the MNNR SDP Meeting, Auditorium Hospital Wanita & Kanak-kanak Kuala Lumpur, Malaysia, November 2019
- 6. Pauline Choo. *Retinopathy of Prematurity*. Presented at the MNNR SDP Meeting, Auditorium Hospital Wanita & Kanak-kanak Kuala Lumpur, Malaysia, November 2019
- 7. Ang EL. *Intraventricular haemorrhage*. Presented at the MNNR SDP Meeting, Auditorium Hospital Wanita & Kanak-kanak Kuala Lumpur, Malaysia, November 2019
- 8. Azanna AH. *BPD 2018*. Presented at the MNNR SDP Meeting, Auditorium Hospital Wanita & Kanak-kanak Kuala Lumpur, Malaysia, November 2019
- 9. Eric Ang BK. *Central line associated blood stream infection.* Presented at the MNNR SDP Meeting, Auditorium Hospital Wanita & Kanak-kanak Kuala Lumpur, Malaysia, November 2019