REPORT OF THE MALAYSIAN NATIONAL NEONATAL REGISTRY

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

EDITOR

Azanna Ahmad Kamar

WITH CONTRIBUTIONS FROM

- Ang Ee Lee
 Eric Ang Boon Kuang
- Boo Nem Yun
 Chee Seok Chiong
- Pauline Choo Poh Ling
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January 2023

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REPORT OF THE MALAYSIAN NATIONAL NEONATAL REGISTRY (MNNR) 2019

1. Organization of the MNNR

1.1 Objectives

The Malaysian National Neonatal Registry was set up in 2002 to study the outcomes 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 the 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 their care in the country.
- 2. To study the mortality and 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 the standard of care in various areas e.g. acceptable sepsis rate 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 monitors and directs the functions of MNNR and meets at least once a year.

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

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 the Perinatal Society of Malaysia & industrial sponsorship. .

2. Data Set 2.1 Registration criteria

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

- A. All babies admitted to a Neonatal Unit who have any of the following criteria:
 - 1. Gestation of <32 weeks i.e. up to 31 weeks + 6 days
 - 2. 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 (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 source data providers (SDPs) or sent to MNNR secretariat after a defined period for data entry.

2.3 Data Verification

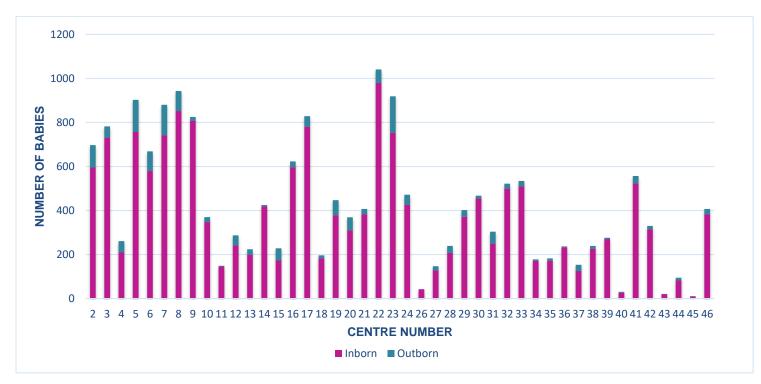
Missing or anomalous data was identified by manual check and then clarified with the respective centre. Further data verification was made on data entry onto the main database. Quantification of errors and the implementation of practices via website data entry to minimize errors are continually refined.

RESULTS

INTRODUCTION

- In 2019, the inclusion criteria for the MNNR registry included all babies (inborn and outborn babies) delivered at a
 gestation of below 32 weeks, or with a birth weight of between 500 grams to 1500 grams, or required respiratory
 support, or with hypoxic-ischaemic encephalopathy, confirmed sepsis; those with congenital heart disease, as
 well as, all neonatal deaths.
- The criteria for babies with confirmed sepsis, which was omitted in 2017, was re-instituted in 2018 and remained in the criteria for the 2019 data.
- A total of 44 hospitals participated in this study in 2019. Total livebirths in the participating hospitals were 331,055.
- A total of 10.8% of livebirths were delivered preterm at less than 37 completed weeks with 73.2% delivered at late preterm gestation between 34 to 36 completed weeks.
- A total of 18,319 babies met the study criteria, out of which 16,599 (90.6%) were inborn, while 1,720 (9.4%) were outborn babies as demonstrated in Table 1 and Figure 1 below.
- Of those who fulfilled the study criteria, 3,442 (18.8%) babies were born below 32 weeks of gestational age (Figure 2 and Table 2), and a total of 3,662 (19.9%) babies had birth weights of 1500g and below (Figure 3 and Table 3).

Figure 1



Number of babies according to place of centres

COMMENT: There was a total of 16599 (90.6%) inborn babies, and 1720 (9.4%) outborn babies in the MNNR.

Hospitals		Place of E		
		Inborn	Outborn	Total
2	n	595	102	697
Ζ	(%)	(85.4)	(14.6)	(100
3	n	731	51	782
3	(%)	(93.5)	(6.5)	(100
4	n	209	52	26
4	(%)	(80.1)	(19.9)	(100
5	n	757	146	90
5	(%)	(83.8)	(16.2)	(100
6	n	579	90	66
0	(%)	(86.5)	(13.5)	(100
7	n	742	138	80
1	(%)	(84.3)	(15.7)	(100
0	n	852	91	94
8	(%)	(90.3)	(9.7)	(100
0	n	808	17	82
9	(%)	(97.9)	(2.1)	(100
10	n	347	23	37
10	(%)	(93.8)	(6.2)	(100
4.4	n	145	4	14
11	(%)	(97.3)	(2.7)	(100
40	n	242	45	28
12	(%)	(84.3)	(15.7)	(100
40	n	199	25	22
13	(%)	(88.8)	(11.2)	(100
4.4	n	418	7	42
14	(%)	(98.4)	(1.6)	(100
45	n	173	55	22
15	(%)	(75.9)	(24.1)	(100
40	n	597	26	62
16	(%)	(95.8)	(4.2)	(100
47	n	781	48	82
17	(%)	(94.2)	(5.8)	(100

Table 1: Number of babies registered with the MNNR according to place of centres (Hospitals 2-17)

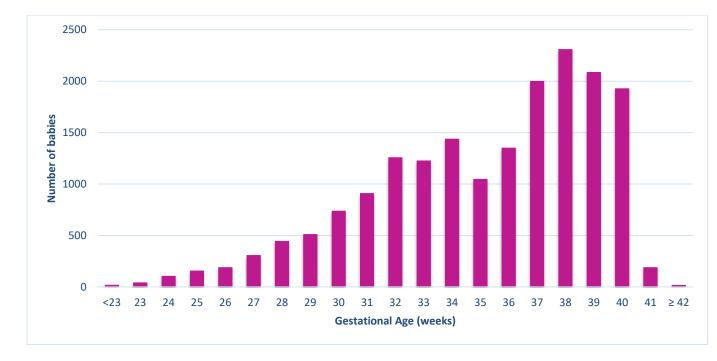
	itele	Place	of Birth	Tatal
Hosp		Inborn	Outborn	Total
10	n	183	13	196
18	(%)	(93.4)	(6.6)	(100)
10	n	378	69	447
19	(%)	(84.6)	(15.4)	(100)
20	n	309	60	369
20	(%)	(83.7)	(16.3)	(100)
01	n	383	24	407
21	(%)	(94.1)	(5.9)	(100)
00	n	979	62	1041
22	(%)	(94.0)	(6.0)	(100)
	n	753	166	919
23	(%)	(81.9)	(18.1)	(100)
0.1	n	426	46	472
24	(%)	(90.3)	(9.7)	(100)
	n	42	1	43
26	(%)	(97.7)	(2.3)	(100)
07	n	128	19	147
27	(%)	(87.1)	(12.9)	(100)
	n	207	32	239
28	(%)	(86.6)	(13.4)	(100)
	n	371	31	402
29	(%)	(92.3)	(7.7)	(100)
00	n	454	13	467
30	(%)	(97.2)	(2.8)	(100)
04	n	249	55	304
31	(%)	(81.9)	(18.1)	(100)
00	n	499	23	522
32	(%)	(95.6)	(4.4)	(100)
00	n	509	25	534
33	(%)	(95.3)	(4.7)	(100)
24	n	171	7	178
34	(%)	(96.1)	(3.9)	(100)
05	n	171	11	182
35	(%)	(94.0)	(6.0)	(100)

Table 1:	Number of babie	s reaistered with the	e MNNR according to	place of centres	(Hospitals 18-35)

l.l.e.e.	itala	Place of I	Birth	T ()
Hosp		Inborn Outborn		Total
36	n	233	4	23
30	(%)	(98.3)	(1.7)	(100
37	n	125	28	15
37	(%)	(81.7)	(18.3)	(100
20	n	227	12	23
38	(%)	(95.0)	(5.0)	(100
20	n	270	6	27
39	(%)	(97.8)	(2.2)	(100
40	n	27	3	3
40	(%)	(90.0)	(10.0)	(100
41	n	523	34	55
41	(%)	(93.9)	(6.1)	(100
42	n	314	16	33
42	(%)	(95.2)	(4.8)	(100
43	n	20	1	2
43	(%)	(95.2)	(4.8)	(100
44	n	82	12	9
44	(%)	(87.2)	(12.8)	(100
45	n	9	2	1
40	(%)	(81.8)	(18.2)	(100
46	n	382	25	40
40	(%)	(93.9)	(6.1)	(100
TOTAL	n	16599	1720	1831
IUTAL	(%)	(90.6)	(9.4)	(100

Table 1: Number of babies registered with the MNNR according to place of centres (Hospitals 36-46)

Figure 2

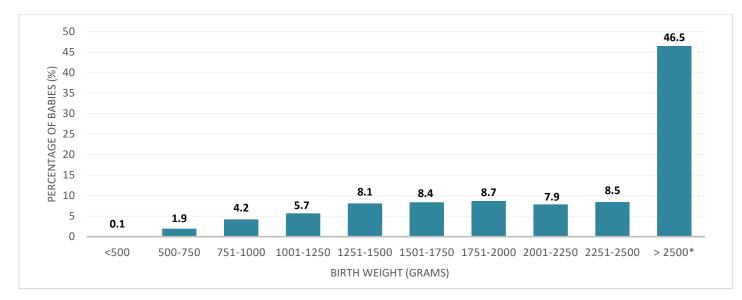


Frequency distribution of all babies in the MNNR according to gestational age

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



Percentage distribution of all babies in the MNNR according to birth weight categories



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

Gestational age in completed weeks at birth	Frequency (n)	Percent (%)
< 23	20	0.1
23	43	0.2
24	108	0.6
25	158	0.9
26	192	1.0
27	309	1.7
28	446	2.4
29	514	2.8
30	740	4.0
31	912	5.0
32	1260	6.9
33	1229	6.7
34	1440	7.9
35	1050	5.7
36	1353	7.4
37	2003	10.9
38	2312	12.6
39	2089	11.4
40	1931	10.5
41	191	1.0
≥ 42	19	0.1
Total included	18319	100
Total no. of babies with missing gestational age	0	
Total no. of babies	18319	

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

Table 3 : Frequency distribution of all babies in the MNNR according to birth weight categories

Birth weight (grams)	Frequency (n)	Percent (%)
<500	14	0.1
500-750	357	1.9
751-1000	774	4.2
1001-1250	1,039	5.7
1251-1500	1,478	8.1
1501-1750	1,548	8.4
1751-2000	1,591	8.7
2001-2250	1,445	7.9
2251-2500	1,553	8.5
> 2500mm	8,520	46.5
Total included	18319	100
Total no. of babies with missing birth weight	0	
Total no. of babies	18319	

MATERNAL INTERVENTIONS

- Antenatal corticosteroids for fetal lung maturation were provided to 79.54% of mothers of babies less than 32 weeks gestation. A high proportion of outborns did not receive antenatal corticosteroids with 82.6% of inborns compared to 46.2% of outborns less than 32 weeks gestation received this intervention. For the respective MNNR centres, the use of antenatal corticosteroids ranged between 35.1% to 100% for inborn babies, and, between none(0%) to 100% for outborn infants. (Figure 4a & 4b and Table 4)
- For the category of birth weight ≤1500 grams, antenatal corticosteroids were provided to 78.1% of mothers of babies in this category. 81.2% and 42.6% 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; 56.7% (1788 out of 3156 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, 83.06% (829 out of 998 babies) were wrapped with plastic at birth.

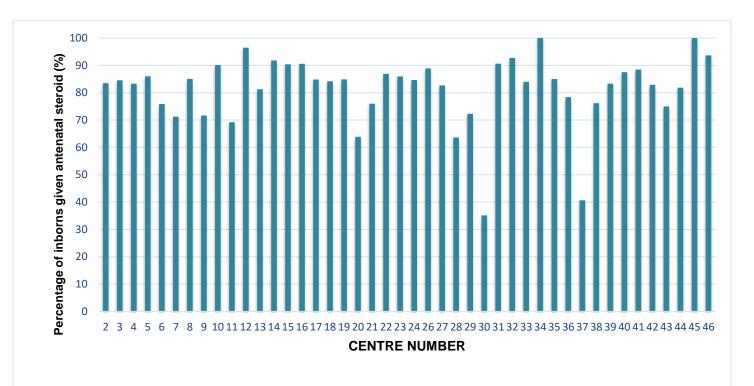
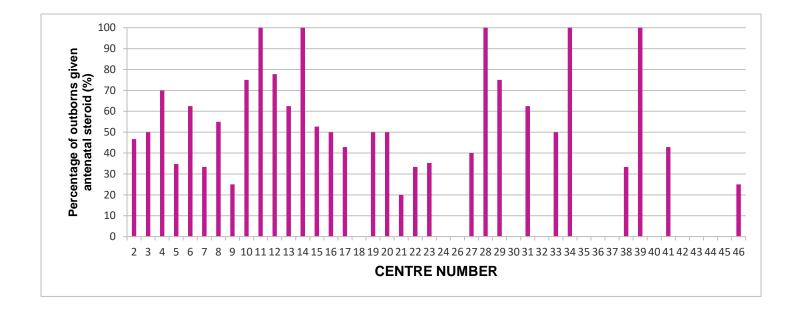


Figure 4a

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

Figure 4b



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

Table 4:Antenatal corticosteroids for all babies born at < 32 weeks gestational age according to centres</td>

	Inborn			Outborn		
Hospitals	Total no of babies		Given Antenatal Steroids			ntenatal oids
	n	Ν	%	n	Ν	%
	3,156	2,607	82.6	286	132	46.2
2	121	101	83.5	15	7	46.7
3	136	115	84.6	4	2	50.0
4	54	45	83.3	10	7	70.0
5	207	178	86.0	23	8	34.8
6	112	85	75.9	16	10	62.5
7	160	114	71.3	9	3	33.3
8	154	131	85.1	20	11	55.0

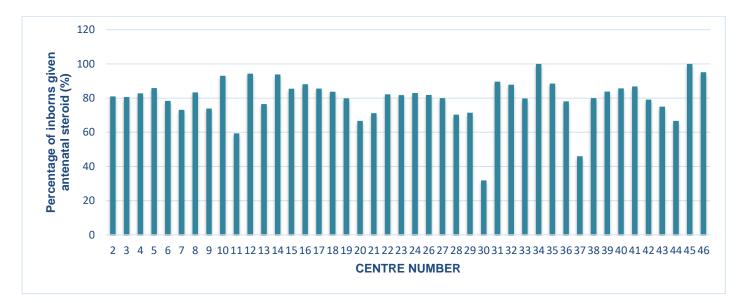
Table 4 (continued):Antenatal corticosteroids for all babies born at < 32 weeks gestational age according to centres</td>

		Inborn		Outborn		
Hospitals	Total no of babies			Total No of Babies		Antenatal roids
	n	N	%	n	N	%
9	127	91	71.7	8	2	25.0
10	81	73	90.1	4	3	75.0
11	39	27	69.2	2	2	100.0
12	57	55	96.5	9	7	77.8
13	48	39	81.3	8	5	62.5
14	73	67	91.8	1	1	100.0
15	52	47	90.4	19	10	52.6
16	106	96	90.6	8	4	50.0
17	79	67	84.8	7	3	42.9
18	38	32	84.2	2	0	0.0
19	106	90	84.9	12	6	50.0
20	36	23	63.9	6	3	50.0
21	50	38	76.0	5	1	20.0
22	107	93	86.9	6	2	33.3
23	121	104	86.0	17	6	35.3
24	137	116	84.7	7	0	0.0
26	9	8	88.9	0	0	0
27	52	43	82.7	5	2	40.0

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

		Inborn		Outborn		
Hospitals	Total no of babies	Given Antenatal Steroids		Total No Given An of Babies Stero		
	n	N	%	n	N	%
28	22	14	63.6	5	5	100.0
29	83	60	72.3	4	3	75.0
30	37	13	35.1	1	0	0.0
31	96	87	90.6	16	10	62.5
32	96	89	92.7	4	0	0.0
33	100	84	84.0	4	2	50.0
34	14	14	100.0	1	1	100.0
35	20	17	85.0	3	0	0.0
36	37	29	78.4	0	0	0
37	32	13	40.6	3	0	0.0
38	21	16	76.2	3	1	33.3
39	36	30	83.3	1	1	100.0
40	8	7	87.5	0	0	0
41	130	115	88.5	7	3	42.9
42	82	68	82.9	6	0	0.0
43	4	3	75.0	0	0	0.0
44	11	9	81.8	1	0	0.0
45	2	2	100.0	0	0	0
46	63	59	93.7	4	1	25.0

Figure 5a



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

Figure 5b

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

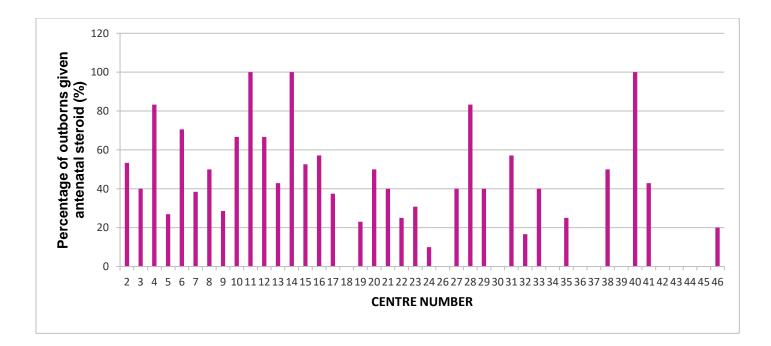


Table 5 : Antenatal corticosteroids for all babies born at ≤ 1500 grams birth weight according to centres

		Inborn		Outborn		
Hospitals	Total no of babies	Given A Ster		Total No of Babies		ntenatal oids
	n	Ν	%	n	Ν	n
	3,366	2,733	81.2	296	126	42.6
2	116	94	81.0	15	8	53.3
3	155	125	80.6	5	2	40.0
4	58	48	82.8	12	10	83.3
5	227	195	85.9	26	7	26.9
6	125	98	78.4	17	12	70.6
7	171	125	73.1	13	5	38.5
8	168	140	83.3	18	9	50.0
9	134	99	73.9	7	2	28.6
10	101	94	93.1	3	2	66.7
11	32	19	59.4	2	2	100.0
12	53	50	94.3	6	4	66.7
13	51	39	76.5	7	3	42.9
14	65	61	93.8	1	1	100.0
15	55	47	85.5	19	10	52.6
16	109	96	88.1	7	4	57.1
17	97	83	85.6	8	3	37.5
18	49	41	83.7	2	0	0.0
19	119	95	79.8	13	3	23.1

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

Hospitals		Inborn		Outborn		
	Total no of babies	Given Antenatal Steroids		Total No of Babies	Given Antenatal Steroids	
	n	Ν	%	n	N	%
20	36	24	66.7	6	3	50.0
21	52	37	71.2	5	2	40.0
22	124	102	82.3	8	2	25.0
23	137	112	81.8	13	4	30.8
24	129	107	82.9	10	1	10.0
26	11	9	81.8	0	0	0
27	50	40	80.0	5	2	40.0
28	27	19	70.4	6	5	83.3
29	77	55	71.4	5	2	40.0
30	44	14	31.8	1	0	0.0
31	106	95	89.6	14	8	57.1
32	99	87	87.9	6	1	16.7
33	109	87	79.8	5	2	40.0
34	23	23	100.0	1	0	0.0
35	26	23	88.5	4	1	25.0
36	32	25	78.1	1	0	0.0
37	37	17	45.9	3	0	0.0
38	20	16	80.0	2	1	50.0

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

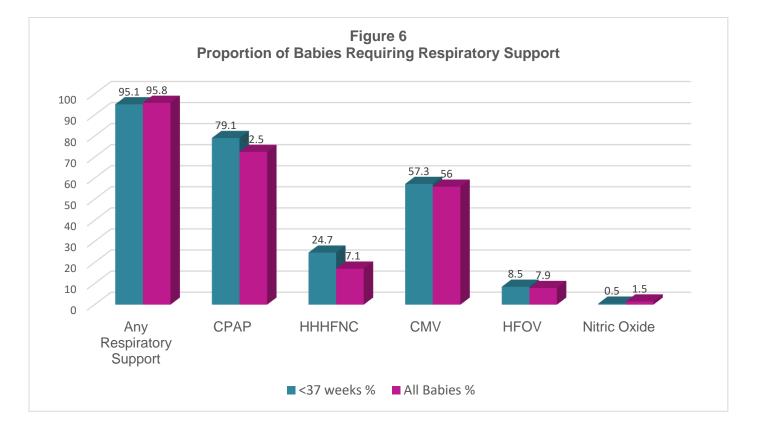
		Inborn		Outborn		
Hospitals	Total no of babies	Given Antenatal Steroids		Total No of Babies	Given Antenatal Steroids	
	n	N	%	n	Ν	%
39	37	31	83.8	0	0	0
40	7	6	85.7	1	1	100.0
41	129	112	86.8	7	3	42.9
42	91	72	79.1	6	0	0.0
43	4	3	75.0	0	0	0
44	9	6	66.7	1	0	0.0
45	3	3	100.0	0	0	0
46	62	59	95.2	5	1	20

RESPIRATORY SUPPORT AND SURFACTANT THERAPY

Overall, a total of 17,567 babies required respiratory support in the neonatal unit. Out of these, 10,268 babies required conventional ventilation, 1452 babies required high frequency ventilation (including jet ventilation), 13,297 babies required nasal CPAP (including bi-level CPAP) and 3,138 babies were given heated, humidified high-flow nasal cannula therapy (HHHFNC). A total of 235 babies were on HHHFNC as the only respiratory support modality.

Note: The numbers are not mutually exclusive, and a baby may receive multiple modes of respiratory support, unless otherwise stated.

 90.5% (3316 out of 3663) of babies with birth weight ≤1,500 grams; and 93.0% (3201 out of 3442) of babies born at less than 32 weeks gestation, required respiratory support.



Overall, regardless of gestational age, surfactant was administered to 4182 babies. 60.7% (2225 of 3663) of babies with birth weight ≤1,500 grams were given surfactant, where 43.9% of these were given within 1 hour of life. A total of 2350 of 3442 (68.3%) babies born below 32 weeks gestational age received surfactant, where 43.4% of these were given within 1 hour of life. A total of 1527 of 6341 (24.1%) babies born between 32-36 weeks gestation and 305 of 8556 (3.6%) term babies also received surfactant.

RESPIRATORY DISEASES AND CHRONIC LUNG DISEASE

Meconium Aspiration Syndrome

- A total of 1548 babies were diagnosed with meconium aspiration syndrome (MAS). 1381 of these were inborns, giving an incidence proportion of 4.17 per 1000 live births. Of these, the burden for respiratory support requirement remains high where the proportion for conventional and high-frequency ventilation in inborn babies ≥ 35 weeks gestation was 3.1/1000 live births.
- A total of 247 babies with MAS required high frequency ventilation, and 98 required inhaled nitric oxide.

• A total of 973 inborn babies and 140 outborn babies were ventilated for MAS. The mortality rate for inborn and outborn babies with MAS was 5.9% and 10.2% respectively, with an overall mortality rate of 6.4%.

Chronic Lung Disease

- 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-menstrual age, were 74.3% and 72.4% respectively for babies between 22-24 weeks gestational age; 67.7% and 54.4% for babies between 25-27 weeks gestational age; and 17.4% and 13.0% for babies between 28-31 weeks gestational age.
- A total of 569 babies remained oxygen dependent at 36 weeks post-menstrual age, with 514 survivors, where survival to discharge was at 80.0%, 91.6% and 92.8% for babies on oxygen born between 22-24 weeks, 25-27 weeks, and 28-31 weeks gestational age respectively. (Figure 7 and Table 6)
- The rates of chronic lung disease for babies with birth weight <1500g who survived to day 28 were 68.3% for babies with birth weight <750 g, 52.2% for babies with birth weight 750-999 g, 26.7% for babies with birth weight 1000-1249 g, and 8.9% 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 beyond 36 weeks post-menstrual age were 69.3% for babies with birth weight <750 g, 43.7% for babies with birth weight 750-999 g, 21.9% for babies with birth weight 1000-1249 g, and 9.5% for babies with birth weight 1250-1499 g.
- For babies born at ≥32 weeks gestation, the rates of chronic lung disease for babies who survived to day 56 were 42.9% for babies with birth weight <750 g, 9.7% for babies with birth weight 750-999 g, 4% for babies with birth weight 1000-1249 g, and 3.0% for babies with birth weight 1250-1499 g. (Figure 8 and Table 7)

Figure 7a

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

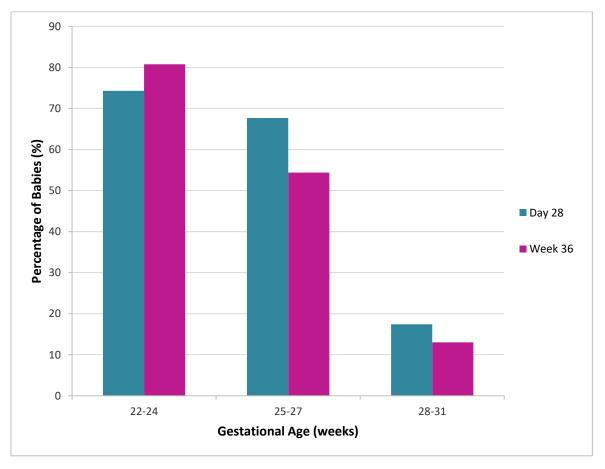


Table 7a :

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		120	35	26	29	21
22-24	%	3.9	29.2	74.3	24.2	80.8
25.27	n	579	390	264	375	204
25-27	%	18.8	67.4	67.7	64.8	54.4
28-31	n	2385	2227	388	2218	289
20-31	%	77.3	93.4	17.4	93.0	13.0
Total n included %		3084 100	2652 86.0	678 25.6	2619 84.9	514 19.6
Total babies		3084				

Figure 7b

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

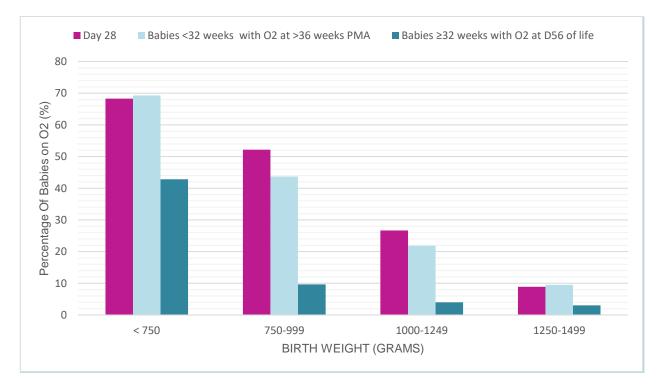


Table 7b: Incidence of oxygen dependency among admitted inborn babies with birth weight < 1500</th>grams

		Total no		Babies with	Babies <3	2 weeks	Babies	≥32 weeks
Birth Weight (grams)		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
< 750	n	286	123	84	101	70	7	3
	%	9.0	43.0	68.3	36.6	69.3	70.0	42.9
750-999	n	622	485	253	442	193	31	3
	%	19.7	78.0	52.2	75.2	43.7	91.1	9.7
1000 – 1249	n	975	893	238	708	155	176	7
	%	30.8	91.6	26.7	90.9	21.9	89.8	4.0
1250 - 1499	n	1281	1204	107	674	64	528	16
	%	40.5	94.0	8.9	94.9	9.5	92.5	3.0
Total	n	3164	2705	682	1925	482	742	29
Included	%	100	85.5	25.2	81.8	25.0	91.5	3.9
Total babie	S	3164						

CARDIOVASCULAR COMPLICATIONS

PATENT DUCTUS ARTERIOSUS

- Patent ductus arteriosus (PDA) was diagnosed in 1038 (33.7%) inborn babies with gestational age <32 weeks admitted to the NICUs. Among the 1038 babies, 20.3% and 46.4% were treated with indomethacin/ibuprofen and paracetamol, respectively. Only 4 (0.4%) babies diagnosed with PDA, underwent ligation. (Table 8)
- PDA was diagnosed in 1032 (32.6%) 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)

PERSISTENT PULMONARY HYPERTENSION OF THE NEWBORN (PPHN)

• A total of 864 babies were documented to have had persistent pulmonary hypertension of the newborn (PPHN) where 731 babies were of ≥35 weeks gestation. The overall mortality rate in babies with PPHN was 29.5%, 23.1% in those with no major congenital abnormality and 44.7% in those with major congenital abnormality. Inhaled nitric oxide was provided to 30.1% of babies with PPHN.

Table 8

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

	Total			Confirmed				Treatm	nent		
Gestation (weeks)	Gestation Inborn PDA I				Indomethacin/ Ibuprofen		Paracetamol		Ligation		
(weeks)	n	n	%	n	%	n %		n	%	n	%
22-24	120	35	29.2	34	97.1	15	42.9	15	42.9	0	0.0
25 - 27	579	321	55.4	312	97.2	105	32.7	172	53.6	3	0.9
28 -31	2385	682	28.6	658	96.5	91	13.3	295	43.3	1	0.1
Total	3084	1038	33.7	1004	96.7	211	20.3	482	46.4	4	0.4

Table 9

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

Birth	Total			Confi	irmed			Treatr	nent								
Weight (grams)	Inbor n	PD Diagn		Confirmed by ECHO								Indomethacin / Ibuprofen		Paracetam ol		Ligation	
	n	n	%	n	%	n	%	n	%	n	%						
< 750	286	106	37.1	103	97.2	31	29.2	49	46.2	3	2.8						
750 - 999	622	309	49.7	300	97.1	91	29.4	161	52.1	1	0.3						
1000- 1249	975	355	36.4	343	96.6	52	14.6	163	45.9	0	0.0						
1250 - 1499	1281	262	20.5	254	96.9	33	12.6	96	36.6	0	0.0						
Total	3164	1032	32.6	1000	96.9	207	20.1	469	45.4	4	0.4						

RETINOPATHY OF PREMATURITY

- For inborn babies born at gestational age <32 weeks and survived to 6 weeks of age, 2145 (81.5%) babies were screened for retinopathy of prematurity (ROP) before discharge. Among these babies, 1869 (87.1%) did not have ROP, 230 (10.7%) had ROP stage 1 or 2, 35 (1.6%) had ROP stage 3, and 8 (0.4%) had ROP stage 4 or 5. The incidence rates of severe ROP for the respective gestational ages were 20%, 7%, 0.7% in babies with gestational age of 22-24 weeks, 25-27 weeks and 28-31 weeks respectively. (Figure 10 and Table 10)
- For inborn babies born with birth weight <1500 g and survived to 6 weeks of age, 2190 (81.7%) were screened for ROP before discharge. Among these babies, 1918 (87.6%) did not have ROP, 226 (10.3%) had ROP stage 1 and 2, 36 (1.6%) had ROP stage 3, and 7 (0.3%) had ROP stage 4 or 5. The incidence rates of severe ROP (stage 3, 4 and 5) for the respective weight groups were 13.6%, 2.9%, 1.3%, and 0.6%, in babies with birth weights <750 g, 750-999 g, 1000-1249 g and 1250-1499 g, respectively. (Figure 11 and Table 11)
- A total of 38 babies underwent laser therapy and 1 baby had cryotherapy.

Figure 10

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

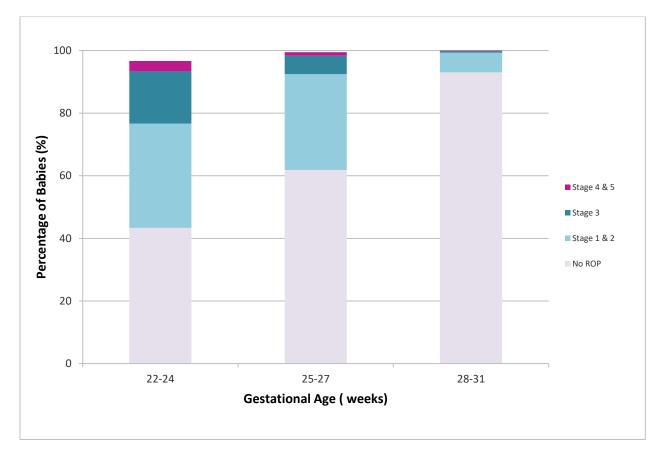


Table 10: Incidence of retinopathy of prematurity (ROP) in admitted inborn babies by gestational age categories

	Total number babies		No. of babies		Retinopathy of prematurity								Therapy	
Gestation al age at birth (weeks)	of admitted inborn babies	alive at 6 weeks	with examir	eye	No F	ROP		OP 1 or 2		OP Ige 3	Stag	OP e 4 or 5	Cryo	Laser
	n	n	n	%	n	%	n	%	n	%	n	%		
22-24	120	32	30	93.8	13	43.3	10	33.3	5	16.7	1	3.3	-	6
25-27	579	381	359	94.2	222	61.8	110	30.6	21	5.8	4	1.1	-	22
28-31	2385	2218	1756	79.2	1634	93.1	110	6.3	9	0.5	3	0.2	-	10
Total Included	3084	2631	2145	81.5	1869	87.1	230	10.7	35	1.6	8	0.4	-	38

Comment: Screening refers to those screened during the ward admission

Figure 11

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

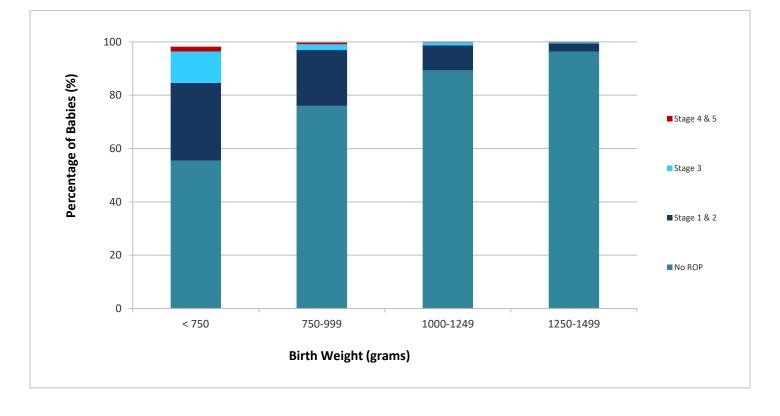


Table 11 :Incidence of retinopathy of prematurity (ROP) in admitted inborn babies by birth weight categories

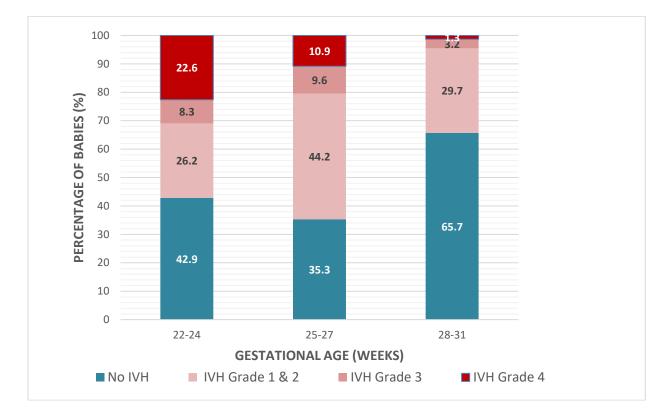
	Total						Retino	pathy o	of prem	aturity			The	rapy
Birth weight (grams)	no of admitte d inborn babies	No. of babies alive at 6 weeks	with	babies eye nation	Nol	ROP	Stage	OP e 1 or 2	R(Sta	-	RC Sta 4 o	ige	Cryo	Laser
	n	n	n	%	n	%	n	%	n	%	n	%		
< 750	286	115	110	95.7	61	55.5	32	29.1	13	11.8	2	1.8	-	13
750- 999	622	477	454	95.2	345	76.0	95	20.9	10	2.2	3	0.7	-	13
1000- 1249	975	886	788	88.9	704	89.3	74	9.4	9	1.1	1	0.1	-	7
1250- 1499	1281	1201	838	69.8	808	96.4	25	3.0	4	0.5	1	0.1	-	5
Total included	3164	2679	2190	81.7	1918	87.6	226	10.3	36	1.6	7	0.3	4	38

Comment: Screening refers to those screened during the ward admission

INTRAVENTRICULAR HAEMORRHAGE

- A total of 2963 (96.1%) inborn babies at gestational age <32 weeks underwent cranial ultrasound examination for intraventricular haemorrhage (IVH). Among these babies, 1761 (59.4%) did not have IVH, 957 (32.3%) had grade 1 or 2 IVH, 135 (4.6%) had grade 3 IVH, and 110 (3.7%) had grade 4 IVH. The incidence rates of severe IVH (grade 3 or 4) were 31.0%, 20.5%, and 4.6% in babies at gestational ages of 22-24 weeks, 25-27 weeks, and 28-31 weeks, respectively. (Figure 12 and Table 12)
- There were 3011 (95.2%) inborn babies with birth weight <1500 g who underwent cranial ultrasound examination. Among these babies, 1831 (60.8%) did not have IVH, 942 (31.3%) had grade 1 or 2, 126 (4.2%) had grade 3, and 112 (3.7%) had grade 4 IVH. The incidence rates of severe IVH (grade 3 or 4) were 24.6%, 14.7%, 7.4%, and 1.8% 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).
- A total of 11 babies <32 weeks required insertion of a ventricular shunt.

Figure 12

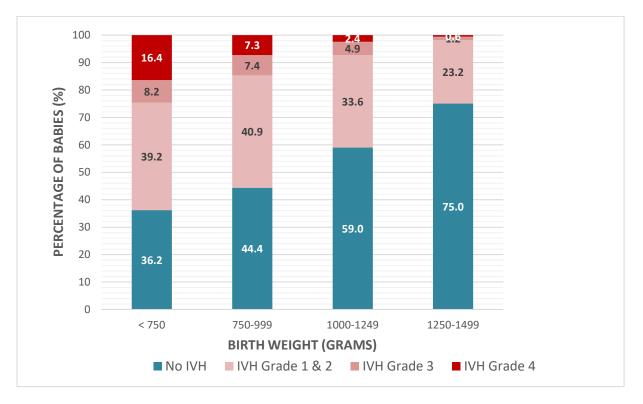


Incidence of intraventricular haemorrhage (IVH) in admitted inborn babies < 32 weeks gestational age

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

Gestational a (completed we		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	120	84	36	22	7	19
	%	3.9	70.0	42.9	26.2	8.3	22.6
	n	579	552	195	244	53	60
25-27	%	18.8	95.3	35.3	44.2	9.6	10.9
	n	2385	2327	1530	691	75	31
28-31	%	77.3	97.6	65.7	29.7	3.2	1.3
	Ν	3084	2963	1761	957	135	110
Total included	%	100	96.1	59.4	32.3	4.6	3.7
TOTAL BABIES	3084		<u>.</u>				

Figure 13



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

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

Birth weig (grams)	ht	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	286	232	84	91	19	38
	%	9.0	81.1	36.2	39.2	8.2	16.4
750-999	n	622	606	269	248	45	44
	%	19.7	97.4	44.4	40.9	7.4	7.3
1000-1249	n	975	951	561	320	47	23
	%	30.8	97.5	59.0	33.6	4.9	2.4
1250-1499	n	1281	1222	917	283	15	7
	%	40.5	95.4	75.0	23.2	1.2	0.6
Total included	n	3164	3011	1831	942	126	112
	%	100	95.2	60.8	31.3	4.2	3.7
Total babies	3164						

NECROTISING ENTEROCOLITIS

- 130 (4.2%) of the inborn babies with gestational age <32 weeks, developed necrotising enterocolitis (NEC) (Stage 2 and above modified Bell's criteria), where 30 (23.1%) of them required surgery. The incidence rates of NEC were 3.3%, 4.3%, and 4.2% for babies with gestational ages of 22-24 weeks, 25-27 weeks, and 28-31 weeks, respectively. (Figure 14 and Table 14)
- For inborn babies with birth weight <1500g, 135 (4.3%) developed NEC (Stage 2 and above modified Bell's criteria) and 30 (22.2%) required surgery. The incidence rates of NEC were 7.3%, 5.6%, 4.9%, and 2.4%, for babies with birth weights <750 g, 750-999 g, 1000-1249 g, and 1250-1499 g, respectively. (Figure 15 and Table 15)



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

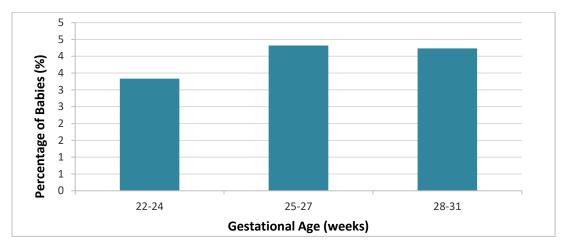
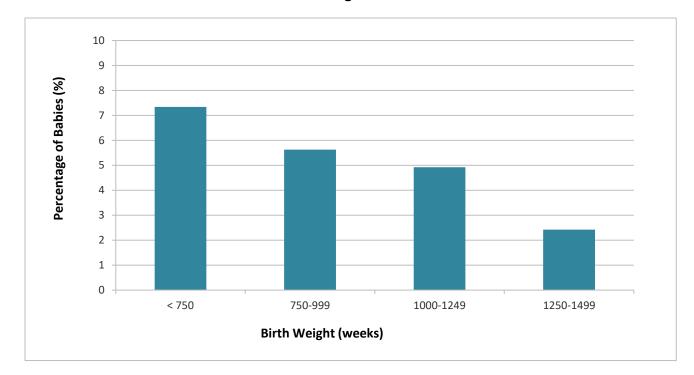


Table 14 : Incidence and treatment of necrotizing enterocolitis (NEC) in admitted inborn babies according to gestational age categories

Gestational age (weeks)	Total number of admitted inborn babies	Babies with NEC		With Surgical treatment			
	n	n	%	п	%		
22-24	120	4	3.3	0	0.0		
25-27	579	25	4.3	6	24.0		
28-31	2385	101	4.2	24	23.8		
Total Included	3084	130	4.2	30	23.1		
Total no. of missing (GA)	0						
Overall Total babies	3084						

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		
	п	n %		n	%		
< 750	286	21	7.3	3	14.3		
750-999	622	35	5.6	6	17.1		
1000-1249	975	48	4.9	13	27.1		
1250 – 1499	1281	31	2.4	8	25.8		
Total included	3164	135	4.3	30	22.2		
Total no. of missing (BW)	0						
Overall total babies	3164						

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 ages of <32 weeks, was 1.8%. The incidence rates were 1.7%, 3.6%, and 1.3% 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, 212 (7.6%) of inborn babies with gestational ages of <32 weeks who survived more than 3 days had one or more episodes. Among these babies, the incidence rates were higher among babies born at lower gestational ages, with rates of 26.1%, 16.3%, and 6.0% for babies at 22-24 weeks, 25-27 weeks, and 28-31 weeks, respectively. (Figure 17 and Table 17)
- 214 (7.5%) 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 19.6%, 10.6%, 8.6%, and, 3.6% for birth weight groups of <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

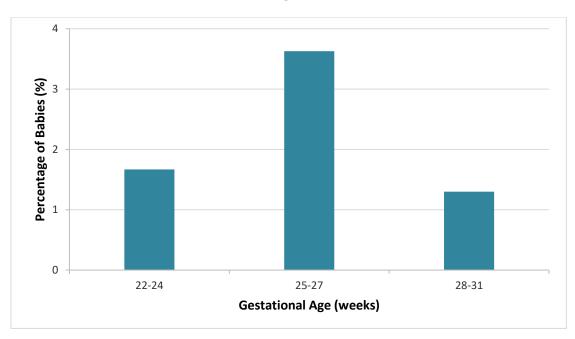


Table 16 :

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	No. of babies with early infection		
(completed weeks)	п	n	%	
22-24	120	2	1.7	
25-27	579	21	3.6	
28-31	2385	31	1.3	
Total included	3084	54	1.8	
Total no. of missing (GA)	0			
Total babies	3084			

Figure 17

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

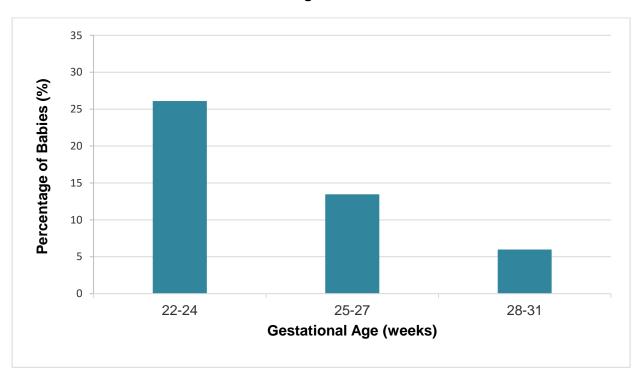


Table 17 :

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			
	п	п	n	%		
22-24	120	46	12	26.1		
25-27	579	468	63	13.5		
28-31	2385	2293	137	6.0		
Total included	3084	2807	212	7.6		
Total no. of missing (GA)	0					
Total Babies	3084					

Figure 18

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

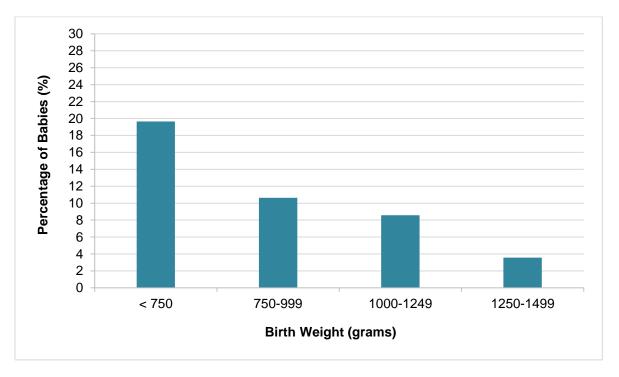


Table 18 :

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	least one	ies with at episode of et sepsis
	п	n	n	%
< 750	286	168	33	19.6
750-999	622	545	58	10.6
1000-1249	975	922	79	8.6
1250 - 1499	1281	1231	44	3.6
Total included	3164	2866	214	7.5
Total no. of missing (BW)	0			
Overall total babies	3164			

HYPOXIC ISCHAEMIC ENCEPHALOPATHY

- 799 babies, born at ≥35 weeks gestational age, were diagnosed with hypoxic-ischaemic encephalopathy (HIE), with 723 babies inborns and 76 babies outborns.
- Among babies with HIE, 514 (64.3%) had moderate to severe HIE; with 332 (41.6%) of babies diagnosed with moderate HIE and 182 (22.8%) of babies with severe HIE.
- A total of 564 (70.6%) babies with HIE underwent therapeutic hypothermia, where 53% used the cooling blanket, 41.6% documented use of gel packs and 5% used both.
- Ninety-three (11.6%) babies died. Mortality rates were 3.6% amongst those diagnosed with moderate HIE those versus 43.4% for those diagnosed with severe HIE.

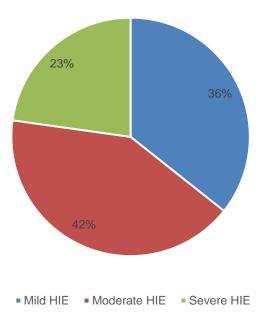


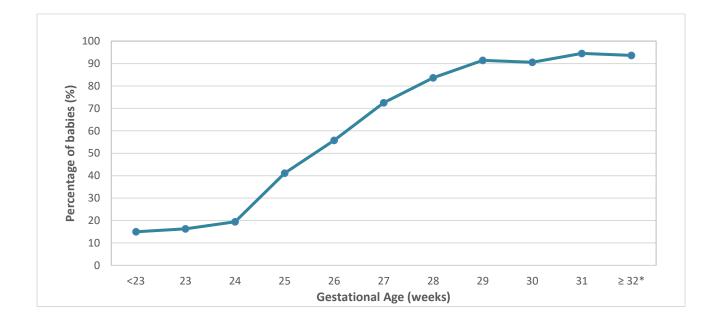
Figure 18: Severity of Hypoxic Ischaemic Encephalopathy (HIE) in Infants >/= 35 weeks

OVERALL NEONATAL SURVIVAL AND MORBIDITIES

- The survival rates of very preterm babies included in the MNNR according to gestational age were 19.4% for 24 weeks, 41.1% for 25 weeks, 55.7% for 26 weeks, 72.5% for 27 weeks, 83.6% for 28 weeks, 91.4% for 29 weeks, 90.5% for 30 weeks, and 94.5% for 31 weeks. (Figure 19 and Table 19)
- The survival rates of babies, according to birth weight categories, included in the MNNR were 14.3% for <500 grams, 30.8% for 500-750 grams, 72.0% for 751-1000 grams, 89.2% for 1001-1250 grams, 92.6% for 1251-1500 grams, 93.7% for 1501-1750 grams, 94.2% for 1751-2000 grams, 92.3% for 2001-2250 grams, 91.6% for 2251-2500 grams, and 94.6% for >2500 grams. For the birth weight category of >1500 grams, the calculated survival rate did not include all live births in that category (see inclusion criteria). (Figure 20 and Table 20)
- The proportion of admitted inborn survivors with significant major morbidities prior to discharge were analysed. The morbidities analysed were as below, where stage 3 and 4 intraventricular haemorrhage were additionally included into the count for significant major morbidities for this 2019 study.
 - 1) Patent ductus arteriosus (PDA) requiring surgical ligation
 - 2) Stage 3, 4 or 5 retinopathy of prematurity (ROP)
 - 3) Oxygen dependency at 36 weeks post-conceptional age
 - 4) Blood culture positive sepsis
 - 5) Stage 2 and above necrotizing enterocolitis (NEC) on modified Bell's criteria, and
 - 6) Stage 3 and 4 intraventricular haemorrhage
- None of the very preterm survivors less than 32 completed weeks had all the 6 significant morbidities.
- Among survivors at gestational ages of 22-24 weeks, 25.93% had 1 morbidity, 18.52% had 2 morbidities, 25.93% had 3 morbidities, 3.70% 4 morbidities, and none had 5 morbidities. 25.93% survivors did not have any of these morbidities.
- Among survivors born at gestational ages of between 25-27 weeks, 46.67% had 1 morbidity, 13.06% had 2 morbidities, 2.22% had 3 morbidities, 1.11% had 4 morbidities, and 0.28% had 5 morbidities. 36.67% infants born at gestational ages of between 25-27 weeks survived without significant morbidities.
- Among survivors born at gestational ages of between 28-31 weeks, 15.69% had 1 morbidity, 3.60% had 2 morbidities, 0.59% had 3 morbidities, 0.09% had 4 morbidities, and none had 5 morbidities. 80.03% infants born at gestational ages of between 28 31 weeks survived without significant morbidities. (Table 21a and Infographics).
- None of the very low birth weight babies <1500 grams had all the 6 significant morbidities.
- Among survivors with birth weight <750 g, 38.14% had 1 morbidity, 14.43% had 2 morbidities, 12.37% had 3 morbidities, 3.09% had 4 morbidities and none had 5 morbidities. 31.96% survivors with birth weight <750 grams had no significant morbidity.
- Among survivors with birth weight 750-999 g, 36.56% had 1 morbidity, 9.91% had 2 morbidities, 1.76% had 3 morbidities, 0.44% had 4 morbidities, and 0.22% had 5 morbidities. 51.10% babies with birth weights of between 750 to 999 grams survived without significant morbidities.
- Among survivors with birth weight 1000-1249 g, 21.31% had 1 morbidity, 5.73% had 2 morbidities, 0.80% had 3 morbidities, 0.23% had 4 morbidities and none had 5 morbidities. 71.94% did not have any of these morbidities.
- Among survivors with birth weight 1250-1499 g, 10.06% had 1 morbidity, 1.76% had 2 morbidities, 0.17% had 3 morbidities, none had 4 or more morbidities. 88.01% babies born between 1250 1499 grams survived without significant morbidity. (Table 21b and Infographics).

In conclusion, in the year 2019, 73.41% very preterm inborn babies <32 weeks, and 74.17% very low birth weight inborn babies <1500 grams, admitted to the neonatal intensive care units of the Malaysian National Neonatal Registry and survived to discharge, did not have significant morbidities.





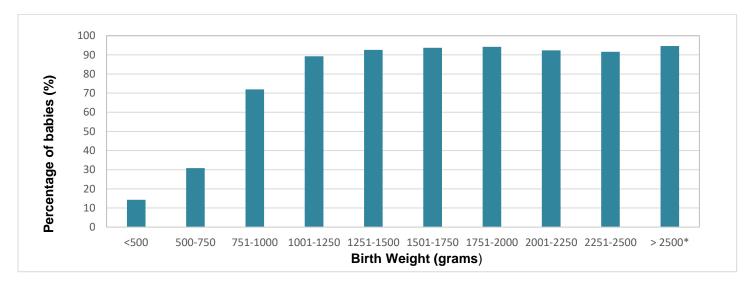
Survival to discharge of all live births admitted to MNNR hospitals according to gestational age

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 babies	Number of survivors	% survival
<23	20	3	15.0
23	43	7	16.3
24	108	21	19.4
25	158	65	41.1
26	192	107	55.7
27	309	224	72.5
28	446	373	83.6
29	514	470	91.4
30	740	670	90.5
31	912	862	94.5
≥32*	14877	13928	93.6
Total included	18319	16730	91.3
Total no. of missing (GA)	0		
Total babies	18319		

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	14	2	14.3
500-750	357	110	30.8
751-1000	774	557	72.0
1001-1250	1,039	927	89.2
1251-1500	1,478	1369	92.6
1501-1750	1,548	1450	93.7
1751-2000	1,591	1498	94.2
2001-2250	1,445	1334	92.3
2251-2500	1,553	1423	91.6
> 2500*	8,520	8060	94.6
Total included	18319	16730	91.3
Total no. of missing (BW)	0		
Total Babies	18319		

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

Gestationa at birtl	-	Total number of infants	Survived	No. with any one morbidities prior to discharge	No. with any two morbidities prior to discharge	No. with any three morbidities prior to discharge	No. with any four morbidities prior to discharge	No. with any five morbidities prior to discharge	No. without any of the five morbidities
(complet)		N,	n	n	n	n	n	n	n
weeks		%	%	%	%	%	%	%	%
22-24	n	120	27	7	5	7	1	0	7
	%	3.89	22.50	25.93	18.52	25.93	3.70	0.00	25.93
25-27	n	579	360	168	47	8	4	1	132
	%	18.77	62.18	46.67	13.06	2.22	1.11	0.28	36.67
28-31	n	2385	2193	344	79	13	2	0	1755
	%	77.33	91.95	15.69	3.60	0.59	0.09	0.00	80.03
Total babies <32 weeks included	N %	3084 100.00	2580 83.66	519 20.11	131 5.08	28 1.09	7 0.27	1 0.04	1894 73.41

Gestational age specific survival with significant morbidity(ies) in admitted inborn babies

Morbidities

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)

vi. Severe intraventricular haemorrhage (Grades 3 and 4)

Table 21b

Birth weight specific survival with significant morbidity(ies) in admitted inborn babies

Birth weight	Total number of infants	Survived	No. with any one morbidities prior to discharge	No. with any two morbidities prior to discharge	No. with any three morbidities prior to discharge	No. with any four morbidities prior to discharge	No. with any five morbidities prior to discharge	No. without any of the 6 morbidities
(grams)	n	n	n	n	n	n	n	n
	%	%	%	%	%	%	%	%
< 750	286	97	37	14	12	3	0	31
	9.04	33.92	38.14	14.43	12.37	3.09	0.00	31.96
750-999	622	454	166	45	8	2	1	232
	19.66	72.99	36.56	9.91	1.76	0.44	0.22	51.10
1000-1249	975	873	186	50	7	2	0	628
	30.82	89.54	21.31	5.73	0.80	0.23	0.00	71.94
1250-1499	1281	1193	120	21	2	0	0	1050
	40.49	93.13	10.06	1.76	0.17	0.00	0.00	88.01
Total babies <1500g included	3164 100.00	2617 82.71	509 19.45	130 4.97	29 1.11	7 0.27	1 0.04	1941 74.19

Morbidities

i. Patent ductus arteriosus (PDA) requiring surgical ligation

ii. Stage 3, 4 or 5 Retinopathy of prematurity (ROP) iii. Oxygen dependency at 36 weeks

v. Necrotizing enterocolitis (NEC) vi. Severe intraventricular haemorrhage (Grades 3 and 4)

iv. Confirmed sepsis

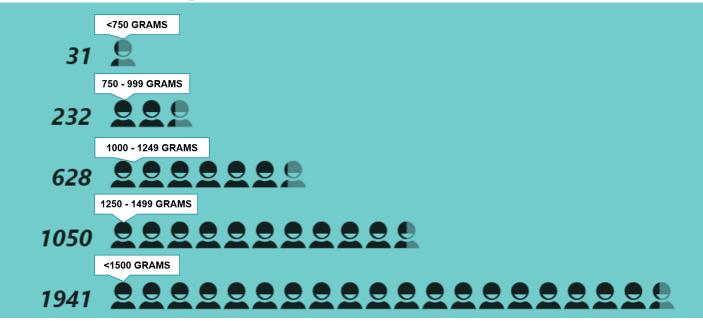
INFOGRAPHICS

SUMMARY OF MORBIDITIES IN BABIES BORN IN THE YEAR 2019

BABIES <32 WEEKS WITHOUT SIGNIFICANT MORBIDTITES



BABIES <1500 g WITHOUT SIGNIFICANT MORBIDTITES



APPENDICES

Appendix 1 Levels 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

Level II Neonatal Care (Specialty), Special care nursery: 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, tracheaoesophageal 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 pre-gestational) 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 <10th centile; AGA 10-90th centile; LGA >90th centile.
- 22. Gender: Indicate Male, Female or Ambiguous/Indeterminate.

23. Place of birth:

Inborn – born in the same hospital as the participating site. If born within the wards of 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
- 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 1st 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

Filled whenever there is neonatal death in accordance to the Modified Wigglesworth Classification of Perinatal 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</p>

Gestation \geq 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:
	 a. Presence of meconium stained amniotic fluid at birth 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. c. PaO₂ < 50 mmHg in room air, central cyanosis in room air or requirement for supplemental O₂ to maintain a PaO₂ > 50 mmHg 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. e. Absence of culture proven early onset bacterial sepsis or pneumonia (i.e. negative blood culture within 72 hours of birth).
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. Infection of the lungs acquired after admission to the
	ward.
Nosocomial pneumonia	Infection of the lungs acquired after discharge home
Community acquired pneumonia Transient Tachypnoea of Newborn	Benign disease of near-term, term or large premature infants with respiratory distress shortly after delivery resolving within 3 days.

L	
	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
Pulmonary Interstitial Emphysema	with a history of requiring increasing ventilatory support
Respiratory distress syndrome	Defined as: within the first 24 hours of life,
(RDS).	A. $PaO_2 < 50mmHg$ in room air, central cyanosis in room
	air, or a requirement for supplemental O ₂ to maintain a
	PaO₂ > 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	Receipt of continuous enriched oxygen concentration >
	21% by oxyhood, nasal cannula, nasal catheter,
Tick "yes" if the baby received	facemask or still requiring nCPAP or other forms of
continuous oxygen concentration > 21% for at least 28 continuous	respiratory support by Day 28 and 36 weeks or day 56.
days (note not "till 28 days of life").	'Continuous' means that the patient is receiving oxygen
Otherwise tick "no".	throughout the time period and not just in brief episodes
	as needed i.e. during feeds. 'Blow-by' oxygen dose not
For babies < 32 weeks – state if	counted unless it is the mode of oxygen administration
O ₂ / any form of CPAP or	used in a transport situation. Do not score oxygen given
ventilatory support required at 36 weeks corrected gestation.	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	echocardiography. In the absence of echo confirmation,
Hypertension (PPHN)	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.
	Failure of the heart to pump characterized by tachypnea,
b. Heart failure	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 ₂ 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) (Stage 2 and above) If 'yes' and managed surgically, tick 'Surgical Treatment' NEC present before admission to your centre? (applies to outborn babies)	 Definition for NEC stage 2 and above : Diagnosis at surgery or post mortem, or Radiological diagnosis, a clinical history plus pneumatosis intestinalis, or portal vein gas, Clinical diagnosis, a clinical history plus abdominal wall cellulitis and palpable abdominal mass. NEC according to Bell's criteria stage 2 or higher Stage 1: 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). Stage 2: 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). Stage 3: 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) 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 (e.g. threshold).	Criteria for screening for ROP are for babies with birth weight < or equal 1500 grams OR gestational < 32 weeks, as well as all preterm babies whose clinical course places them at increased risk for ROP as determined by the attending doctor. If an indirect ophthalmologic examination was performed at any time, enter the worst stage documented: No ROP : No Evidence of ROP Stage 1 : Demarcation Line Prethreshold ROP ("Prethresh") Threshold ROP ("Thresh")

If there is no explicit grade listed, then score according to the descriptions given by the ICROP. (e.g. threshold).	Stage 4 : Partial Retinal Detachment Stage 5 : Total retinal detachment
Tick 'Yes' if a retinal exam was done. State exact date of first screening and 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 No ROP)
State if laser, cryotherapy, intravitreal 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 worst grade before or on 28 days of life.	 Grade 1: Subependymal germinal matrix (GM) haemorrhage only Grade 2: IVH without ventricular dilation Grade 3: IVH with ventricular dilation Grade 4: IVH with parenchymal involvement
State if VP shunt/reservoir was inserted	Grade 4. IV H with parenchyman involvement
Tick 'No; if no IVH before or day 28 Tick 'Not Applicable' for term	
infant Tick "Ultrasound not done" if it was not done.	68

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 Date of removal (autocalculate)	 Central line defined as: (1) Umbilical catheters. (2) Percutaneously inserted central catheters. (3) Surgically placed Broviac catheter that terminates at or close to the heart or in one of the great vessels. Aorta, superior vena cava, brachiocephalic veins, internal jugular veins, subclavian veins, inferior vena cava, external iliac veins and common femoral veins are considered great vessels for this study.
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
Confirmed sepsis Tick 'Yes'if there is evidence of <u>confirmed</u> sepsis.	Confirmed sepsis Clinical evidence of sepsis plus blood culture-proven infection.
Tick 'Yes'if there is evidence of <u>confirmed</u> sepsis. Do not include presumed or clinical sepsis. State whether the onset of first confirmed sepsis was On or before	Clinical evidence of sepsis plus blood culture-proven
Tick 'Yes'if there is evidence of <u>confirmed</u> sepsis. Do not include presumed or clinical sepsis. State whether the onset of first	Clinical evidence of sepsis plus blood culture-proven infection. <u>For CONS:</u> 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
Tick 'Yes'if there is evidence of <u>confirmed</u> sepsis. Do not include presumed or clinical sepsis. State whether the onset of first confirmed sepsis was On or before 72 hours of life OR after 72 hours of life. State the organism cultured:	 Clinical evidence of sepsis plus blood culture-proven infection. 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 peripheral blood sample AND Signs of generalized infection (such as apnoea, temperature instability, feeding intolerance, worsening respiratory distress or

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	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. 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) Applies only to gestation ≥ 35 weeks	 HIE requires the presence of all 3 of the following criteria: 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: 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
	 Three or more supporting findings from the following list: Arterial cord pH<7.00 Apgar score at 5 minutes of 5 or less Evidence of multi-organ system dysfunction – dysfunction of one or more of the following systems within 72 hours of birth 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 Evidence of CT, MRI, technetium or ultrasound brain scan performed within 7 days of birth of diffuse or multifocal ischaemia or of cerebral oedema. 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
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	 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) b. 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)

 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 	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
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	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. Still	Births:
SECTION 1: DELIV	ERIES VERSUS E	BIRTH WEIGHT		
Birth Weight (grams)	No. of Still Births	No. of Live Births	No. Admitted to Neonatal Unit	No. who died in delivery room
< 500				
500				
501 - 600				
601 - 700				
701 - 800				
801 - 900		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 Neonatal Unit	No. who died in delivery room
<22		1		
22-24		2	7	
22-24				
26				
27				
28				2
29				
30				
31 32				0
33		<u>.</u>		- 15
34		2		
35				
36				
37-40				
> 40				
TOTAL				

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Mode of Delivery	No. of Still Births	No. of Live Births	No. Admitted to Neonatal Unit	No. who died in delivery room
SVD				
Breech				20
Forceps				
Ventouse				
LSCS Elective				
LSCS Emergency				
TOTAL :				

SECTION 4: BIRTHS VERSUS ETHNIC GROUP

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

1. Remarks:	
2. Name of Site Coordinator:	
3. Chop:	
4. Date:	

i. Bith census should be sent together with the tracking forms and the completed CRFs of discharges for the month by the end of the following month.

ii. Sample of tracking form are as follows

Appendix 4 Case Report Form (CRF)

MALAYSIAN NATIONAL NEONATAL REGISTRY (CRF 2019)						
Centre Name:		O New Case	MNNR No. (Office use): /			
		Readmission				
Date of Admission:	(dd/mm/yy)	 Transfer from another SDP Hospital or IJN: 	Centre:			
Admitted to neonatal ward: OYes-	Admitted to neonatal ward: OYes -> (Proceed to complete ALL sections in this CRF) ON No -> (Proceed to complete Section 1, 2 [without No.28], 4[No.47 only] and 5)					
Abandoned baby> (if this box						
Instruction: Where check boxes 📃	are provided, ticked (\checkmark) one	or more boxes. Where radio buttons 🔘	are provided, ticked (\/) one box only.			
SECTION 1 : PATIENT PA	RTICULARS & MATE	RNAL HISTORY				
*1. Name of mother:						
2. Name of baby (Optional): *3. RN of baby:						
*4a. Mother's I/C	MyKad:					
number:	Other ID document No:					
	Specify document Passp	ort Armed Force ID Driver's	S License Old IC Hospital RN			
	type (if others):	r's I/C Work Permit number Police I				
4b. Baby's MyKid number:						
*5a. Date of birth of baby: (dd/mm/yy)			: (24 hour format. Enter the best birth if the exact time unknown)			
*6. Ethnic group of Mother:	Malay Indian Chinese Orang Asli	 Bumiputra Sabah, specify: Bumiputra Sarawak, specify: 				
*7. Maternal age:						
*8. GPA: (current pregnancy before delivery of this child)	*Gravida:	*Parity:	*Abortion:			
*9. Maternal diabetes (including gestational diabetes):	O Yes	No	O Unknown			
*10. Maternal hypertension, chronic pregnancy included:	🔿 Yes	No No	O Unknown			
*11. Maternal Eclampsia:	O Yes	O No	Unknown			
*12. Maternal Chorioamnionitis:	O Yes	No O Unknown				
*13. Maternal Anaemia: (<11g/dL)	O Yes	O No O Unknown				
*14. Maternal abruption placenta:	O Yes	O No	O Unknown			
*15. Maternal bleeding placenta pra						
*16. Cord prolapse: *17. Other current illness:	Yes Yes If yes,s	o No	Unknown No			
		spoony				
SECTION 2 : BIRTH HIST						
*18. Antenatal steroid:	O Yes → O 1 dose	2 doses No	O Unknown			
*19. Antenatal magnesium sulphate:	O Yes	No	Unknown			
*20. Intrapartum antibiotic:	O Yes	No	O Unknown			
*21. Birth weight:	(gran	n)				
*22. Gestation:	(weeks)					
*23. Growth status:	SGA	AGA	OLGA			
*24. Gender:	 Male 	Female	Ambiguous / Indeterminate			
*25. Place of birth:	Inborn O Hor	me O Universit	ty hospital Others / specify			
	Outborn → O Priv O Gov Sper	Inborn Home University hospital Others / specify Outborn Health Clinic Enroute / during transport Unknown Private Hospital Maternity home with specialist Unknown Government hospital with specialist Alternative Birthing centre (ABC) Iternative Birthing centre (ABC) Outborn Operative Hospital with specialist Urban Or Rural				
*26. Multiplicity:	Singleton Twin	n Triplet Other, specify:	Specify birth order if not a singleton:			
*27. Final Mode of delivery:			Caesarean section Caesarean section Caesarean section Elective Emergency Caesarean section Emergency Emerg			
			Jnknown			

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SECTION 2 : BIR	гн нізто	RY (continue)								
*28. Apgar score at 1 mi 5 min (0-10)	n and	a) Score at 1 mi	n:			Unknown		e at 5 min: score even if the baby is		Unknown
		a) Oxygon:		Yes		_	intuba	tracheal tube vent:	Yes	No
29. Initial resuscitation: (applicable for inborn of		a) Oxygen:				No			-	
		b) Early CPAP : c) Bag and mas		Yes Yes		No No	e) Cardi	ac compression: aline:	Yes Yes	No No
		ventilation:		0			1,714101	unitot	0 100	0.10
*30. a) Plastic wrap at birth (for <1500 gm)				Yes Yes		No No				
 b) If yes : was baby wrapped without drying at birt c) Admission temperature: 			birth	Ves		-				
(mandatory if admitted to Neonatal ward)					(°C)		_			
SECTION 3: NEO	NATAL E	VENT								
*31. Respiratory support		🔘 Yes 🛶	a) CF CPA	PAP/bilevel						
If < 12 hours = state 0.5 da		🔘 No	CFA			centre:	ation of Ch	PAP/bilevel CPAP at yo	ur .	Day(s)
If > 12 to 24 hours = state 0.5 da				gh flow nasal nula (HFNC):	<u>ر</u>		AND 1192425			
If > 24 hours = state to neg			Can	nula (m NC).		→ i) Total dura	ation of HF	FNC at your centre:	·	Day (s)
days	a completed			onventional entilation:	<u>ا</u> ب					
Complete entry a) to e) for	each type o	F		entilation.		 i) Total dura ventilation 				Day (s)
respiratory support given			d) HF	JV/HFOV:	QY	es ONo				
						→ i) Total dura	ation of HF	FJV//HFOV at your cetr	e:	Day (s)
			e) Ni	tric Oxide:	0	res 🔘 N	0			
							tion of Ni	tric Oxide at your		
					I	centre:				Day (s)
*32. Surfactant:		O Yes •	→ [) < 1 hr		0 1	-2 hrs		> 2 hrs	
		🔘 No								
*33. Parenteral nutrition:		O Yes				1 🔘	No			
SECTION 4: PRO	BLEMS/	DIAGNOSE	s							
34. Respiratory:		um aspiration syn		Puln	nonarv I	naemorrhage		Congenital pneumon	ia 🔲 Comm	unity acquired
ou. Respiratory.		nt tachypnoea of				nterstitial emphy	sema	Nosocomial pneumo	pneun	noniá
*35. RDS:	O Yes			0						
*36. Pneumothorax:	O Yes _	Pneumoth	orax de	eveloped during		Sponta				1.100 /
+07. Ourselans and al	No No	on > 21% oxyger		uously for 28 da		ore?				i
*37. Supplemental oxygen and BPD:	b) If Yes			9787		U	Yes ns of respi	No ratory at 36 weeks	() Yes	s 💿 No
		(ii) for >= 32 we	eks GA	, baby still on o	xygen,	CPAP or other for	orms of res	piratory support at at day		
*38. CVS :	*37a. PPHN	L	s	<u></u> No		*38b. He	eart Failur	e: OYes	O No	
*39. PDA:	O Yes -			0.0	-	O Yes	0	No	0 1.0	114
	O No	b) Pharmaco	logica	closure		Yes	0	No	1851	
		c) Ligation:				→ If Ye	s then to c		n 📃 Ibuprofen [Paracetamol
	O Yes _					<u> </u>				
*40. NEC (stage 2 and above):		a) surgical u			to	aantra	0			
above).	No No	(for outborn	baby only	ore admission	to you	centre.	<u> </u>	Yes 🔘 No		
*41. ROP Retinal Exam Done	O Yes _	→	a) Dat	e of first scree	ning:					<u>ا</u> ۲
< 32 weeks OR ≤ 1500g	(If yes, wor	st stage of ROP):	b) Po	st conceptiona	l age at	1st screening:			tocalculate)	
- option 'Not Applicable' will be auto blocked										
> 32 weeks AND		c) No		No ROP OSta	age 1 (Prethresh OT	Thresh 🔘	Stage 4 OStage 5	-] APROP
>1500g: option 'Yes' & 'No' will be auto	option 'Yes' &			er Therapy:				Yes	No No	
blocked			-	otherapy: ectomy/AntiVE	GE			YesYes	 No No 	
			-	P present prior		ission?				
			(for	outborn baby o				O Yes	O No	
	🔘 No	\rightarrow	Appoi	ntment given:				O Yes		
	💿 Not Ap	plicable	cable					Date of appointment:	/	

SECTION 4: PROBLEMS/ DIAGNOSES (continue)

*42. IVH: < 37 weeks - option 'Not Applica- ble' will be auto blocked *43a. Central Venous Line (applies to the catheter in situ for the longest duration)	Yes If yes, worst grade: No Not applicable (term infant) Ultrasound not done i. O Yes ii. Date of insertion: Date of removal: Date of removal:	VP shunt/ reservoir i No / /	•	Grade 3 O Grade 4
43b. CLABSI	O Yes O I	No		
*44. Confirmed sepsis: (Blood culture positive only)	Yes Yes S 72 hours of life In Type of organism (can tick more than Group B Streptococcus MRSA CONS ≥ 72 hours of life In Type of organism (can tick more than Group B Streptococcus)	 Staphylococcus aureus Klebsiella Pseudomonas 	Acinetobacter Fungal Serratia Acinetobacter	ESBL organisms E. Coli Others, specify:
	MRSA	Klebsiella	Fungal	E. Coli
	CONS	Pseudomonas	Serratia	Others, specify:
*45. Neonatal meningitis:	O Yes	O No		
,	CSF Culture positive : Yes No			
	II) If Yes, type of organis		Acinetobacter Fungal Others , specify :	ESBL organisms
* 46. HIE :	a) HIE severity	🔵 None 🛛 🔘 Mild	I 🔘 M	oderate O Severe
(Only for ≥ 35 weeks GA)	b) Highest Thompson		0	0 1000
If None option chosen leave b,c and d blank	b) Highest Monipson Image: Color of the second			
	d) Seizures in HIE cases:	O Yes O No		
*47. Congenital anomalies:				
*47a. Major congenital anomalies		ypes of abnormalities (check al ot a recognized syndrome' or is		plies to all including 'known syndromes', ality'
Ves No Syndrome (known) Down Edward Patau Others, s (Refer to Not a recognized syndrome Isolated major abnormality		 Hydracephalus Hydrancephaly Holoprosencephaly Others (Refer to ICD Myelomeningocoele Anencephaly Encephalocoele Others (Refer to ICD 	2	 Skeletal dysplasia Respiratory CDH GIT Hydrops Renal Others , specify (Refer ICD10) : None of the above
		Please see (page 4)		

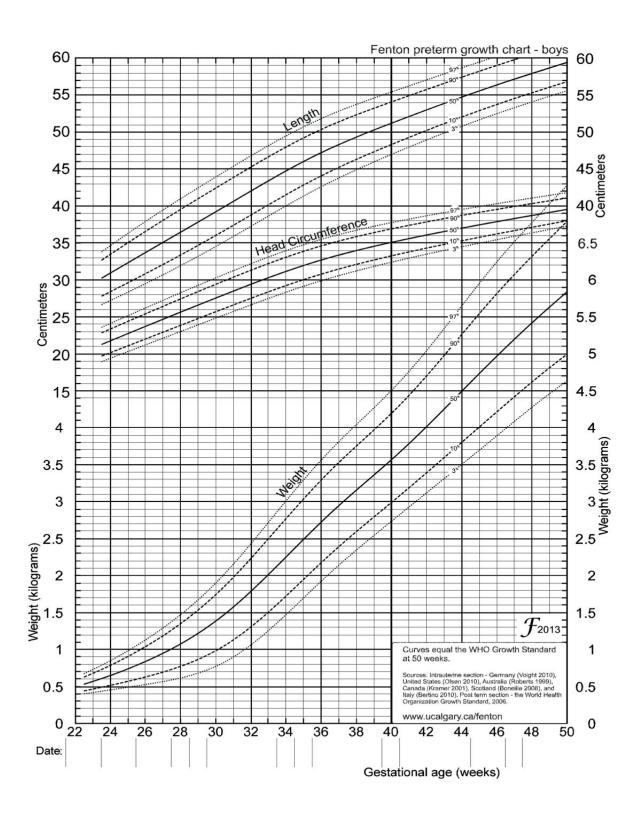
CVS Tick all present	BLEMS/ DIAGNOSES (continue) Duct dependent lesion TGA TOF or PA with VSD Pulmonary atresia (PA) with Intact ventricular septum Complex cyanotic heart with PA Critical PS Hypoplastic left heart syndrome Interrupted aortic arch Coarctation of aorta Critical AS Tricuspid atresia 	
	 Others, specify Non duct dependent lesion	
	Date of echo diagnosis : Date done: / auto calculate age (days) Intervention ● O Nil done ● Surgery Date done: / auto calculate age (days) ○ Catheterization ● Diet done: / auto calculate age (days) ○ Palliative ● For review later Date done:	
	Name of procedure:	

SECTION 5: OUTCOME

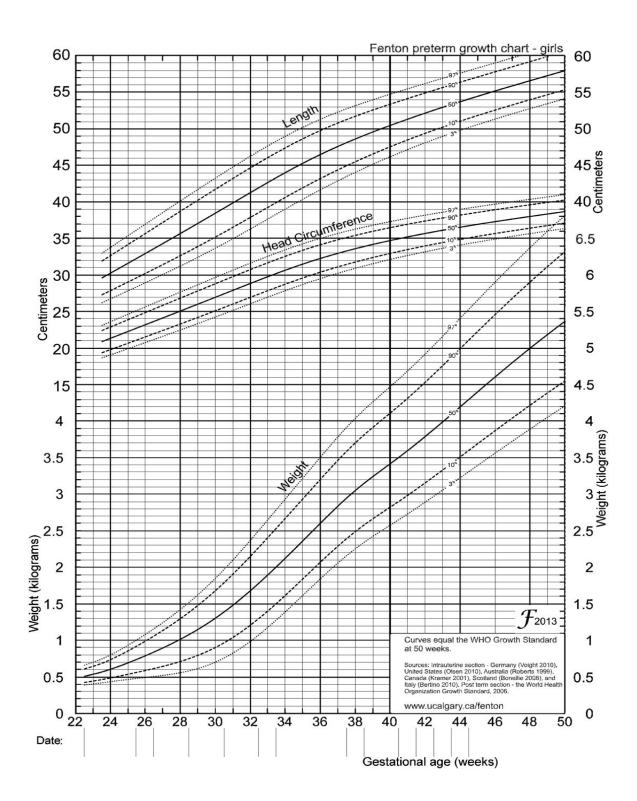
*48a. Date of discharge / transfer/ death: (dd/mm/yy)	/ / / 48b. Time of Death: (24 hour format) (mandatory for death cases) (enter the best estimated time of death if the exact time is unknown)
*49. Weight and growth status on discharge:	(grams)
b) Growth status:	SGA AGA CLGA
*50. Total duration of hospital stay (neonatal/ paeds care):	(in completed days) (auto calculate)
*51. Outcome:	
 Alive → Place discharged to: Home Social welfare ho Other wards with Still hospitalized Transfer to other 	n hospital as of 1st birthday
	b) Reason for transfer: O Growth/ stepdown care Acute medical/ O Lack of NICU bed diagnostic services O ther, specify: Chronic/ Palliative care Surgery
	 c) Post transfer disposition: (Please fill this section if place transferred is not part of the NNR Network) O Home Death O Transferred again to another hospital O Readmitted to your hospital O Still in ward
Dead Place of death:	Labour room/OT Neonatal unit Others, specify:
Name : Signatur	Date: (dd/mm/yy)

struction:						
For term babies please fill in according to the most p For preterm babies please fill in according to the mo						
Centre Name:		Office				
Name:	3. RN:	use: Centre:				
Nother's I/C Number: New IC:	Passport:					
nediate cause of death (Modified Wiggleswo	rth): Tick relevant button to read	h correct classification				
	NEONATAL DEATH	Note: LCM = Lethal Congenital Malform				
	(Is there any LCM?)					
LCM present		LCM absent				
		b) (ls gestation <37 weeks?)				
	1					
Lethal congenital malformation/defect, specify: Neural tube defects	Yes	No				
Anencephaly	 c) If preterm baby and LCM absent, was there an 	Gestation ≥37 weeks				
Encephalocoele	Aphyxial condition?	(Did the baby have an asphyxial condition				
Others,specify						
(Refer to ICD 10):	 Septicaemia PDA in failure 					
CVS	Pulmonary	· · · · · · · · · · · · · · · · · · ·				
Complex heart disease	hemorrhage	 d) Asphyxial condition absent (Did the baby die from infection?) 				
Acyanotic	Pneumonia					
CNS	PIE / BPD Pneumothorax					
Hydrancephaly	Extreme prematurity	e) If term and infection If term and infectio				
 Holoprosencephaly 	Acute intrapartum	present Are there any other				
Others, specify (Refer to ICD 10):	event Severe RDS	Group B streptococcal specific causes of death?)				
(Refer to ICD TO).	Others	Meningitis				
		 Congenital pneumonia Congenital Infection 				
Recognisable syndrome	1	Others, specify				
 Edward Patau 						
Others,specify						
(Refer to ICD 10):						
Not recognisable syndrome		f) Other specific causes of death: Unknov Cause Kernicterus/ severe neonatal				
Skeletal dysplasia		jaundice				
Respiratory (eg. lung hypoplasia)		Haemorrhagic disease of newborn/ Vitamin K deficiency				
GIT		 Intracranial bleed / SAH 				
Hydrops foetalis		Pneumothorax Rumanany homorphage				
Renal		 Pulmonary hemorrhage IEM 				
		MAS Surgical, specify:				
Others, specify:		 Others, specify: 				
		United, specify.				
		Culture, opcony.				
me : Sian	ature :	Date: (dd/mm/yy)				

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Appendix 5 Presentations

POSTER, ABSTRACT AND PAPER PRESENTIONS

- 1. Neoh, Siew Hong. Survival of VLBW neonates. Presented at the MNNR Online Seminar, December 2020
- 2. Boo, Nem Yun. *Hypoxic Ischaemic Encephalopathy (HIE) 2019.* Presented at the MNNR Online Seminar, December 2020
- 3. Chee, Seok Chiong. *Necrotising Enterocolitis (NEC) in VLBW neonates.* Presented at the MNNR Online Seminar, December 2020
- 4. Abdullah, Farah Inaz. *Meconium Aspiration Syndrome (MAS)*. Presented at the MNNR Online Seminar, December 2020
- 5. Wong, Ann Cheng. *Admission hypothermia in VLBW neonates*. Presented at the MNNR Online Seminar, December 2020
- 6. Choo, Pauline. Retinopathy of Prematurity. Presented at the MNNR Online Seminar, December 2020
- 7. Ang, Ee Loo. Intraventricular haemorrhage. Presented at the MNNR Online Seminar, December 2020
- 8. Ahmad Kamar, Azanna. *Respiratory Support and Bronchopulmonary Dysplasia (BPD) 2019.* Presented at the MNNR Online Seminar, December 2020
- 9. Ang, Eric Boon Kuang. *Central line associated blood stream infection*. Presented at the MNNR Online Seminar, December 2020