REPORT OF THE MALAYSIAN NATIONAL NEONATAL REGISTRY

A Study of Critically Ill Babies in Neonatal Intensive Care Units

2014

EDITOR:

- Fazila Mohamed Kutty
- Pauline Choo Poh Ling
- Ang Ee Lee

WITH CONTRIBUTIONS FROM:

- Boo Nem Yun
- Irene Cheah Guat Sim
- Chee Seok Chiong
- Neoh Siew Hong
- Wong Ann Cheng

Perinatal Society of Malaysia

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Important information

Disclaimer

There is a potential that data for previous years printed in this report are different from what were printed in previous reports. This is because analysis for this report is based on latest dataset in the web which may have been updated by SDP.

January 2018

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CONTENTS

SUMMARY

The inclusion criteria for this study in 2014 were all preterm babies below 32 weeks gestational age, those of birth weight below or equal to 1500 g, all cases with hypoxic ischaemic encephalopathy, all babies with confirmed sepsis, all babies who were ventilated and all neonatal deaths. In 2014, there was a total of 309127 livebirths and 2204 stillbirths in the 41 participating centres. A total of 12723 babies, who were in level III NICUs, met the study criteria, 11115 were inborn whilst 1608 were outborn. There were 3333 preterm babies below 32 weeks gestational age, and 3716 babies were of birth weights of 1500 g and below. (Table 1, 2, 3)

Results:

- In 2014, 78% of mothers of inborn babies were less than 32 weeks' gestation received antenatal steroids, with 64% received a complete course. There were marked differences in the use of antenatal steroids across centres, varying from 50-100% of preterm babies below 32 weeks gestational age (GA)

- The use of antenatal steroids in mothers of outborn babies below 32 weeks gestation was only 34% (Table 17,18).

- Continuous positive airway pressure as a mode of respiratory support was used 8859 babies, including term babies. In inborn babies less than 32 weeks gestation, 45% received CPAP support in the delivery. In those inborn preterm babies of more than or equal to 32 weeks gestation, early CPAP in delivery room was given to 43% of babies.

- 11908 babies (93% of the overall cohort) required some form of respiratory support. Of these, 7558 (63%) received ventilatory support and the rest CPAP support only. Total of 1572 (54%) babies less than 1500g birth weight that survive till discharge were ventilated. The ventilation days are longer from mean of 5.5 days to 16.5 days as the weight category decreases.

- Seventy-six percent of babies (2791 babies) less than or equal to 1500 grams birth weight (total of 3630 babies) had Respiratory Distress Syndrome. Sixty eight percent of them treated with surfactant and 93% of the babies required ventilatory support.

- The rates of chronic lung disease (CLD)(the requirement for oxygen supplementation) for babies between 501- 750g BW at Day 28 and 36 weeks post conceptional age were 59% and 46 % respectively.

- CLD for babies 751-1000 g BW at Day 28 and 36 weeks post-conceptional age were 42% and 32% respectively.

- The CLD rates for babies 1001-1250g were 13% and 9% at Day 28 and 36 weeks post-conceptional age respectively and the rates for babies 1251- 1500g were 8% and 6% at Day 28 and 36 weeks post-conceptional age respectively.

- One hundred and twenty seven (2%) of the babies on respiratory support had developed pneumothorax

- The incidence rate for meconium aspiration syndrome (MAS) was 3.3 per 1000 live births, with ventilation rate of 87%. The overall mortality for babies ventilated for MAS was 9.2%.

- In babies above 35 weeks gestation, a total of 569 babies (8.8%) develop Persistent Pulmonary Hypertension (PPHN), out of which 22% of them received inhaled nitric oxide.

- In babies above 35 weeks gestation, 857 babies (13%) had HIE, with the highest percentage, 48%, in the moderate HIE category that will benefit from early cooling therapy. A large proportion of these babies were inborn (over 85%). Incidence of HIE was 2.7 per 1000 live births

- Among the inborn babies <1500 g who underwent cranial ultrasound examination, 232 (8%) had Grade 3 or 4 of IVH (table 10, 11).

- Among the 969 inborn babies with gestational age < 32 weeks who underwent ROP screening before discharge, 55 babies (3%) had ROP stage 3, 2 babies (0.1%) had ROP stage 4 and above. (table 19,20)

- In babies less than 32 weeks gestation, 752 babies (26%) developed PDA with 282 of them (38%) required ibuprofen/indomethacin and 11(1.5%) required surgical ligation. (table 6,7,8,9)

- One hundred and fifteen (3.6%) of the inborn VLBW babies developed necrotizing enterocolitis (NEC). Twenty eight percent of these babies required surgery. (Table 15, 16)

- In babies below 32 weeks gestation 59 babies (2%) had early onset sepsis and 147 babies (6.3%) had late onset sepsis (table 12,13,14)

- In babies below 1500g birth weight, 64% received total parenteral nutrition

- For babies less than 32 weeks gestation that survive till discharge, the median length of hospital stay is 36 days (interquartile range of 13 – 58 days). (Sheet 4, 27a)

- The average survival rate of babies of birth weight between 500-1001 gm was 55% and that for babies between 1001-1500 gm birth weights was 88.8%. (Table 4,5)

Study recommendations include collaboration with Obstetrics and Primary Healthcare staff:

- To enhance the use of antenatal steroids and continue with in-utero transfer of high-risk pregnancies.
- To reduce the number of post term deliveries and to reduce the risk of thick meconium stained liquor.
- To review preventable causes of HIE.
- To enhance antenatal detection of congenital abnormalities and to provide counselling to parents.

And in the NICUs:

- To continue to promote the use of nasal continuous positive airway pressure as early as possible after birth to reduce the need for mechanical ventilation for the spontaneously breathing preterm babies.
- To reduce the risk of pneumothorax.
- To enhance infection control in the NICUs.
- To increase availability of nitric oxide in state hospitals to reduce mortality from PPHN.
- To increase ROP screening before or soon after discharge

Report of the Malaysian National Neonatal Registry (MNNR) 2014

1. Organization of the MNNR

1.1 Objectives

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

The Malaysian NNR aims:

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

1.2 Structure

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

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

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

1.3 Funding

Funding was provided via Clinical Research Centre (CRC) of Ministry of Health, Malaysia, the Perinatal Society of Malaysia & sponsors from industry.

2. Data Set

2.1 Participating Centres in 2014:

1. Hospital Ampang
2. Hospital Batu Pahat, Johor
3. Hospital Bintulu, Sarawak
4. Hospital Raja Permaisuri Bainun, Ipoh, Perak
5. Hospital Kajang, Selangor
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41. Pusat Perubatan Universiti Malaya, Kuala Lumpur

Centre numbers allocated to centers were different from the numbers above.

2.2 Registration criteria

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

A. All babies admitted to a Neonatal Unit who have any of the following criteria:
   1. Had a gestation of <32 weeks i.e. up to 31 weeks + 6 days
   2. Had a birth weight of 1500 g and below.
   3. Required respiratory support (ventilated or required CPAP)
   4. Had hypoxic ischaemic encephalopathy (HIE) with or without requirement of ventilatory support.
   5. With confirmed sepsis i.e positive blood cultures and CSF cultures

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.

2.3 Data Collection

The CRF consisted of four sheets (of forms).

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

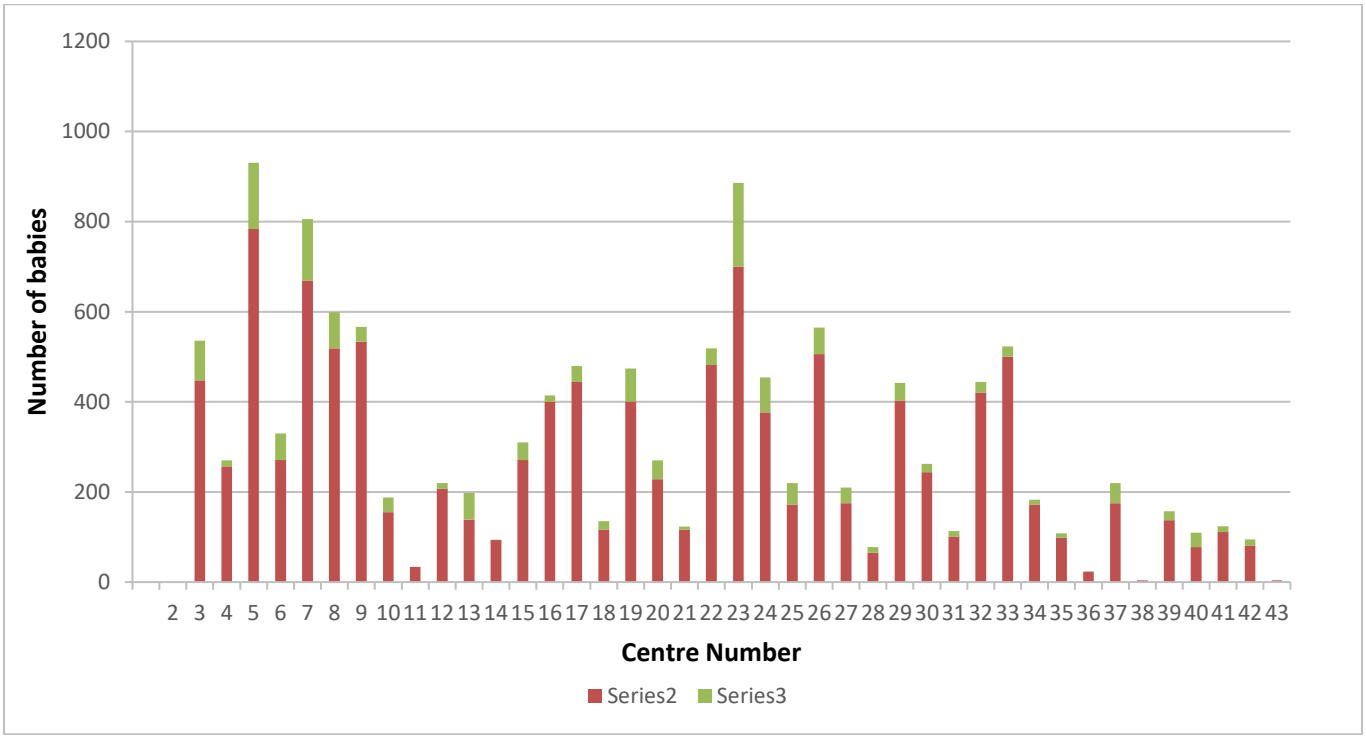
2.4 Data Verification

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

Figure 1

Number of babies according to place of birth



COMMENT: There were 11111 inborn babies and 1608 outborn babies in the MNNR.

Table 1: Number of babies according to place of birth

Hospitals		Place of Birth		Total
		Inborn	Outborn	
2	n	0	0	0
	(%)	(0)	(0)	(0)
3	n	448	88	536
	(%)	(83.6)	(16.4)	(100)
4	n	257	13	270
	(%)	(95.2)	(4.8)	(100)
5	n	784	147	931
	(%)	(84.2)	(15.8)	(100)
6	n	271	59	330
	(%)	(82.1)	(17.9)	(100)
7	n	669	137	806
	(%)	(83.0)	(17.0)	(100)
8	n	519	80	599
	(%)	(86.6)	(13.4)	(100)
9	n	534	32	566
	(%)	(94.3)	(5.7)	(100)
10	n	155	33	188
	(%)	(82.4)	(17.6)	(100)
11	n	34	0	34
	(%)	(100.0)	(0.0)	(100)
12	n	207	13	220
	(%)	(94.1)	(5.9)	(100)
13	n	139	59	198
	(%)	(75.4)	(29.8)	(105)
14	n	93	1	94
	(%)	(98.9)	(1.1)	(100)
15	n	271	39	310
	(%)	(87.4)	(12.6)	(100)
16	n	400	14	414
	(%)	(96.6)	(3.4)	(100)
17	n	444	36	480
	(%)	(92.5)	(7.5)	(100)
18	n	116	19	135
	(%)	(85.9)	(14.1)	(100)

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

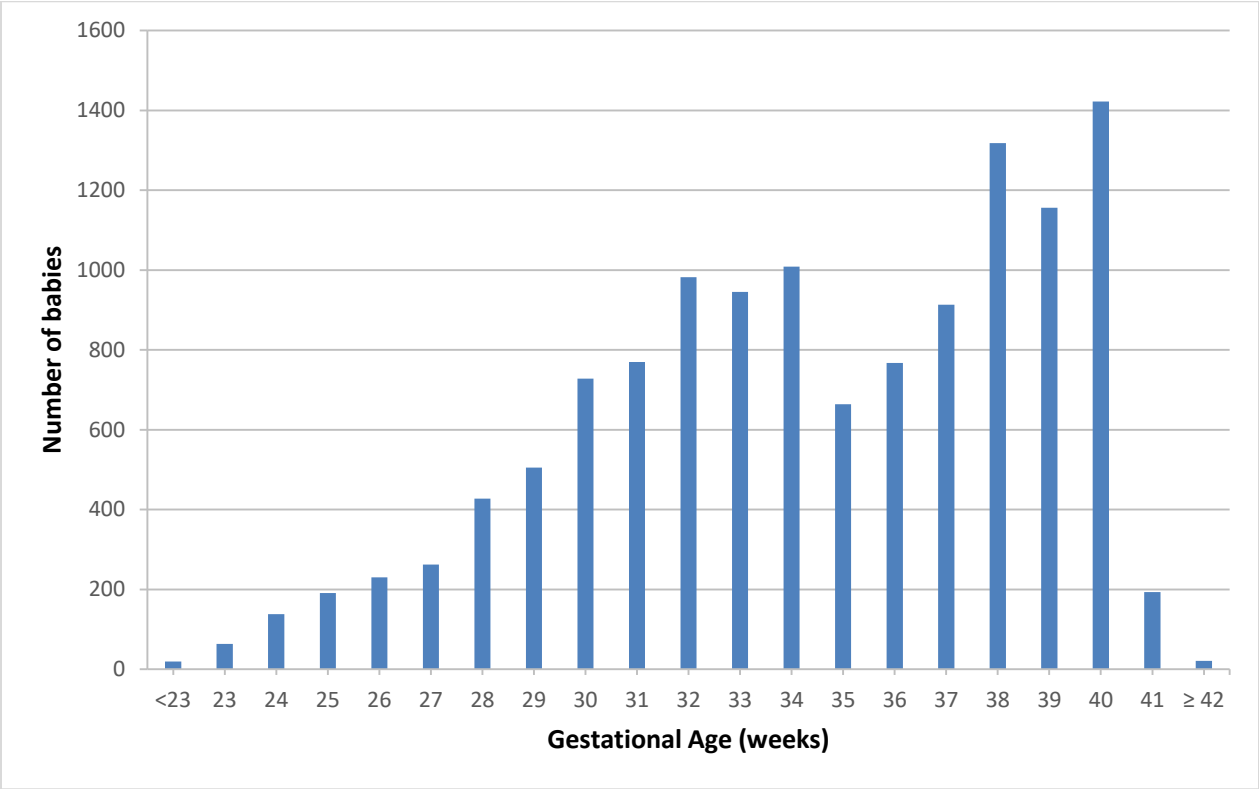
Hospitals		Place of Birth		Total
		Inborn	Outborn	
19	n	401	73	474
	(%)	(84.6)	(15.4)	(100)
20	n	228	42	270
	(%)	(84.4)	(15.6)	(100)
21	n	116	7	123
	(%)	(94.3)	(5.7)	(100)
22	n	482	37	519
	(%)	(92.9)	(7.1)	(100)
23	n	700	186	886
	(%)	(79.0)	(21.0)	(100)
24	n	377	77	454
	(%)	(83)	(17.0)	(100)
25	n	172	48	220
	(%)	(78.2)	(21.8)	(100)
26	n	506	59	565
	(%)	(89.6)	(10.4)	(100)
27	n	175	35	210
	(%)	(83.3)	(16.7)	(100)
28	n	65	13	78
	(%)	(83.3)	(16.7)	(100)
29	n	403	39	442
	(%)	(91.2)	(8.8)	(100)
30	n	244	18	262
	(%)	(93.1)	(6.9)	(100)
31	n	101	12	113
	(%)	(89.4)	(10.6)	(100)
32	n	421	23	444
	(%)	(94.8)	(5.2)	(100)
33	n	500	23	523
	(%)	(95.6)	(4.4)	(100)
34	n	172	11	183
	(%)	(94.0)	(6.0)	(100)
35	n	98	10	108
	(%)	(90.7)	(9.3)	(100)

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

Hospitals		Place of Birth		Total
		Inborn	Outborn	
36	n	23	1	24
	(%)	(95.8)	(4.2)	(100)
37	n	175	45	220
	(%)	(79.5)	(20.5)	(100)
38	n	4	0	4
	(%)	(100)	(0)	(100)
39	n	137	20	157
	(%)	(87.3)	(12.7)	(100)
40	n	78	32	110
	(%)	(70.9)	(29.1)	(100)
41	n	111	13	124
	(%)	(89.5)	(10.5)	(100)
42	n	81	14	95
	(%)	(85.3)	(14.7)	(100)
Total	n	11111	1608	12719
	(%)	(87.4)	(12.6)	(100)

Figure 2

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



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

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

Gestational age in completed weeks at birth	Frequency	Percent
< 23	19	0.1
23	63	0.5
24	138	1.1
25	191	1.5
26	230	1.8
27	262	2.1
28	427	3.4
29	505	4.1
30	728	5.7
31	770	6.1
32	982	7.7
33	945	7.4
34	1009	7.9
35	664	5.2
36	767	6.0
37	913	7.2
38	1318	10.4
39	1156	9.1
40	1422	11.2
41	193	1.5
≥ 42	21	0.2
Total included	12723	100
Total no. of babies with missing gestational age	0	
Total no. of babies	12723	

Figure 3

Frequency distribution of all babies in MNNR according to birth weight categories

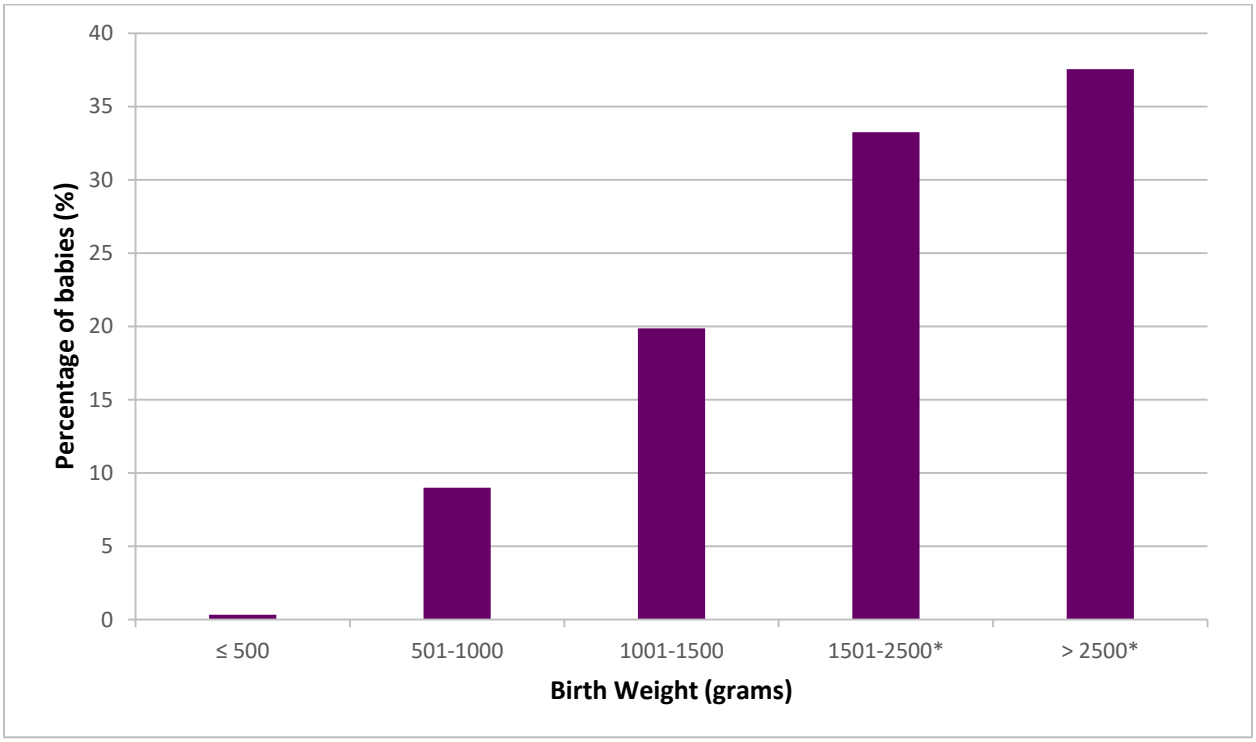


Table 3 :
Frequency distribution of all babies in MNNR according to birth weight (BW) categories

Birth weight (grams)	Frequency	Percent from total number of babies
≤ 500	43	0.3
501-1000	1145	9.0
1001-1500	2528	19.9
1501-2500*	4231	33.3
< 2500	4776	37.5
Total included	12723	100
Total no. of babies with missing birth weight	0	
Total no. of babies	12723	

Figure 4

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

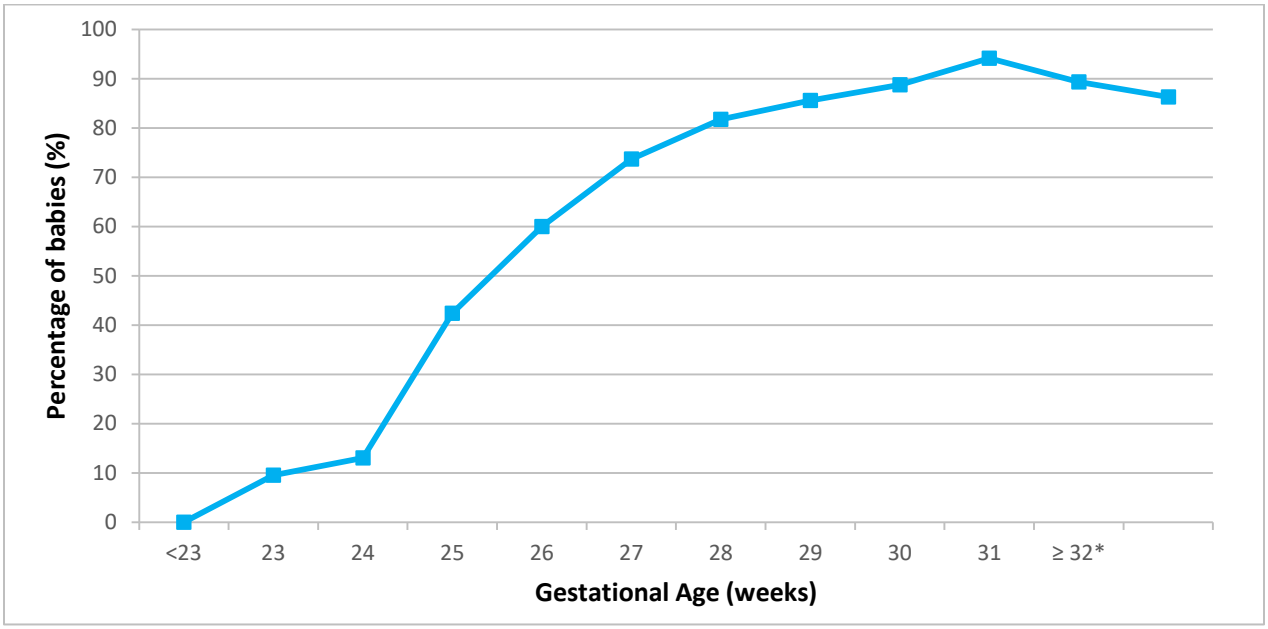


Table 4 :
Survival to discharge of all live births admitted to MNNR hospitals according to gestational age

Gestational age (completed weeks)	Total number of inborn & outborn babies	Number of survivors	% survival
<23	19	0	0.0
23	63	6	9.5
24	138	18	13.0
25	191	81	42.4
26	230	138	60.0
27	262	193	73.7
28	427	349	81.7
29	505	432	85.5
30	728	646	88.7
31	770	725	94.2
≥32*	9390	8392	89.4
Total included	12723	10980	86.3
Total no. of missing (GA)	0		
Total babies	12723		

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

Figure 5

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

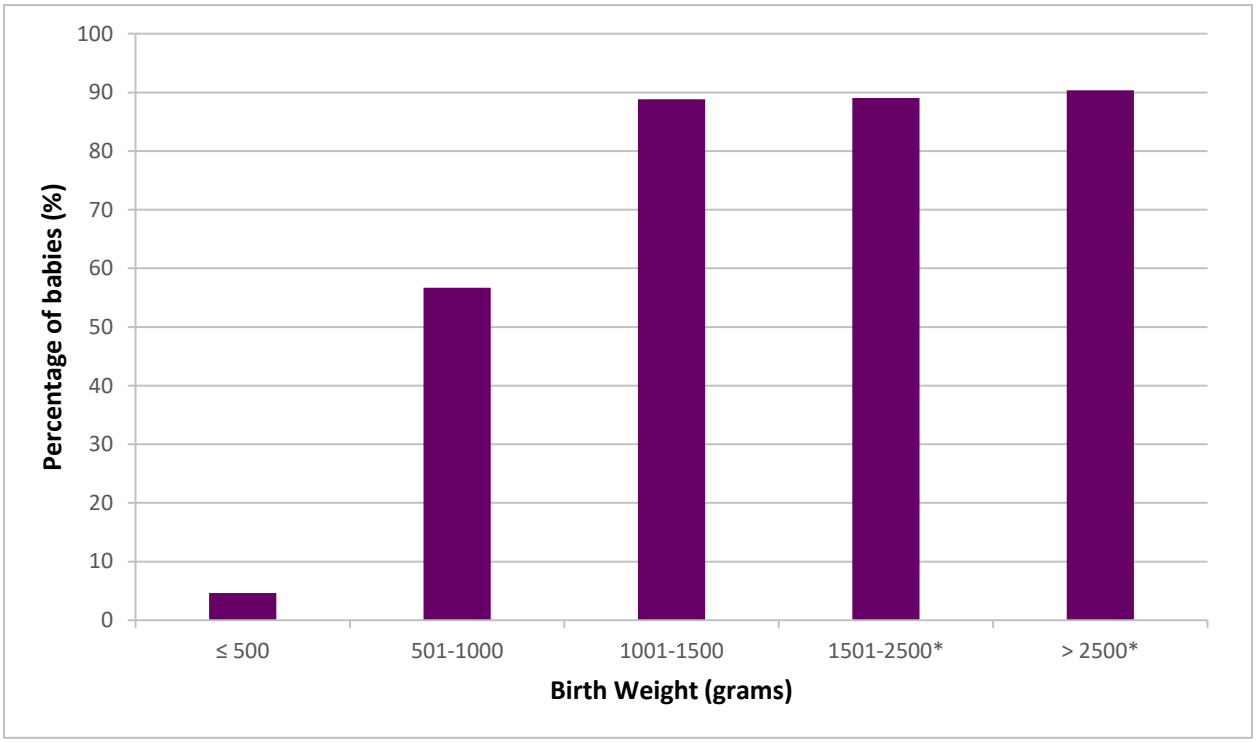


Table 5 :
Survival to discharge of all babies admitted to MNNR hospitals according to birth weight categories

Birth weight (grams)	Total number of inborn &outborn babies	Number of survivors	% survivors
≤500	43	2	4.7
501-1000	114	649	56.7
1001-1500	2528	2245	88.8
1501-2500*	4231	3768	89.1
>2500*	4776	4316	90.4
Total included	12723	10980	86.3
Total no. of missing (BW)	0		
Overall Total babies	12723		

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

Figure 6a

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

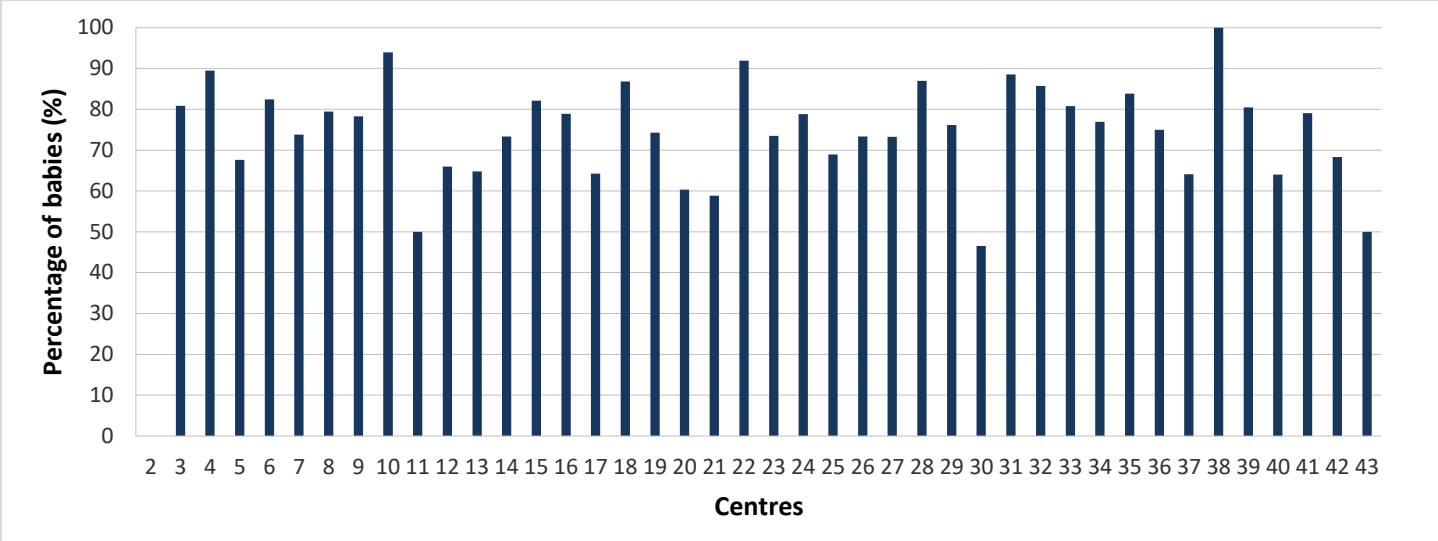


Figure 6b

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

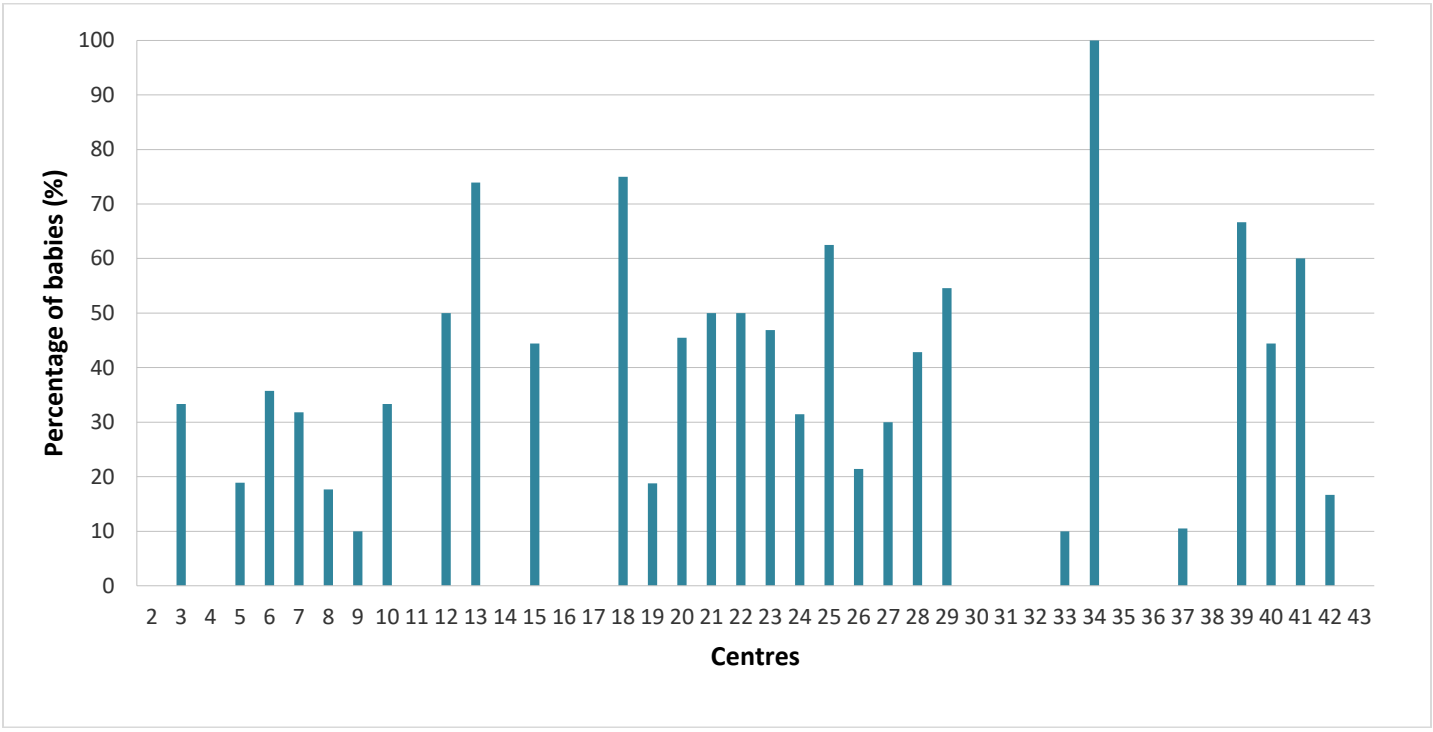


Table 6:
Antenatal corticosteroid for all babies born at < 32 weeks gestational age according to centres

Hospitals	Inborn			Outborn		
	Total number of babies	Given Antenatal Steroid		Total number of babies	Given Antenatal Steroid	
	n	*N*	%	*n*	*n*	%
Overall	2983	2294	76.9	350	120	34.3
2	0	0	0.0	0	0	0.0
3	157	135	86.0	12	5	41.7
4	29	24	82.8	0	0	0.0
5	220	156	70.9	34	7	20.6
6	69	54	78.3	10	4	40.0
7	182	134	70.9	16	6	37.5
8	151	125	82.8	15	2	13.3
9	114	88	77.2	6	1	16.7
10	29	27	93.1	10	4	40.0
11	6	4	66.7	0	0	0.0
12	50	38	76.0	4	2	50.0
13	56	41	73.2	24	17	70.8
14	26	14	53.8	0	0	0.0
15	84	72	85.7	4	1	25.0
16	121	98	81.0	2	0	0.0
17	110	75	68.2	4	1	25.0
18	52	44	84.6	2	1	50.0
19	117	87	74.4	18	2	11.1

Table 6 (continued):

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

Hospitals	Inborn			Outborn		
	Total number of babies	Given Antenatal Steroid		Total number of babies	Given Antenatal Steroid	
	n	*N*	%	*n*	*n*	%
20	52	33	63.5	13	6	46.2
21	30	18	60.0	2	1	50.0
22	100	96	96.0	7	3	42.9
23	162	123	75.5	32	17	53.1
24	162	130	80.2	26	7	26.9
25	49	37	75.5	6	5	83.3
26	141	102	72.3	15	5	33.3
27	59	40	67.8	8	2	25.0
28	19	16	84.2	6	1	16.7
29	93	73	78.5	12	7	58.3
30	36	18	50.0	2	0	0.0
31	32	26	81.3	1	0	0.0
32	99	84	84.8	5	0	0.0
33	90	71	78.9	7	1	14.3
34	32	24	75.0	2	1	50.0
35	31	26	83.9	2	1	50.0
36	11	7	63.6	1	1	100.0
37	63	44	69.8	18	1	5.6
38	2	0	0.0	0	0	0.0

Table 6 (continued):

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

Hospitals	Inborn			Outborn		
	Total number of babies	Given Antenatal Steroid		Total number of babies	Given Antenatal Steroid	
	n	*N*	%	*n*	*N*	%
39	35	28	80.0	2	1	50.0
40	22	14	63.6	8	4	50.0
41	38	29	76.3	5	3	60.0
42	52	39	75.0	9	0	0.0

Figure 7a

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

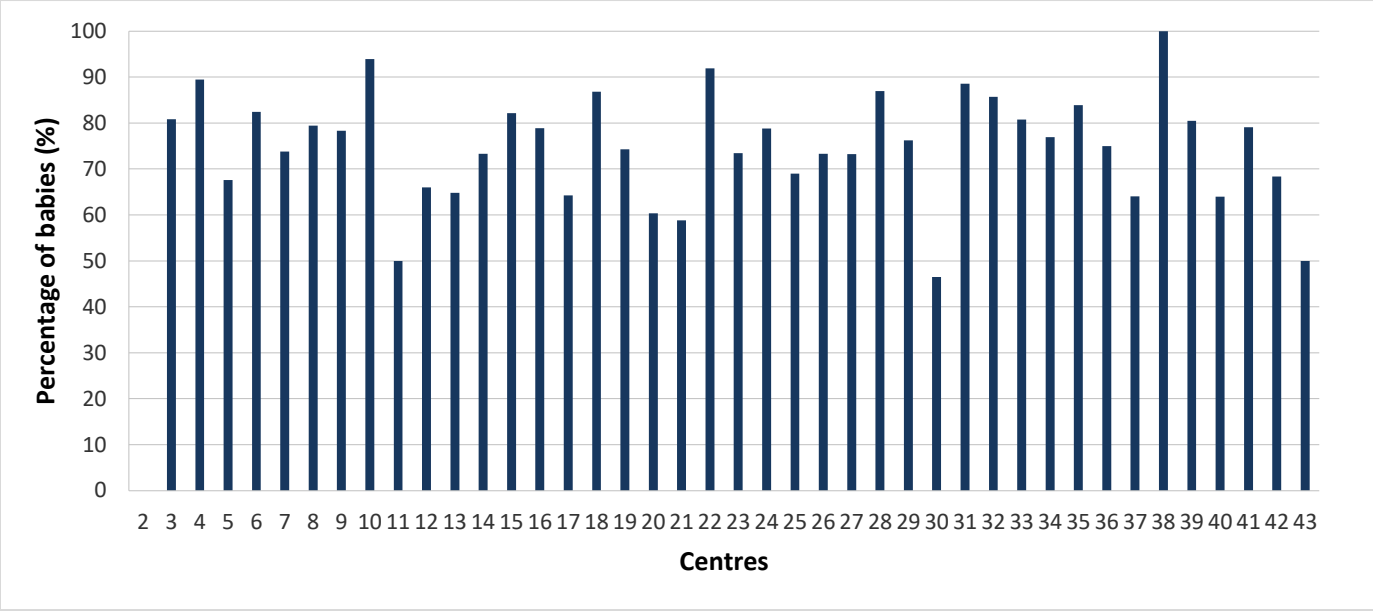


Figure 7b

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

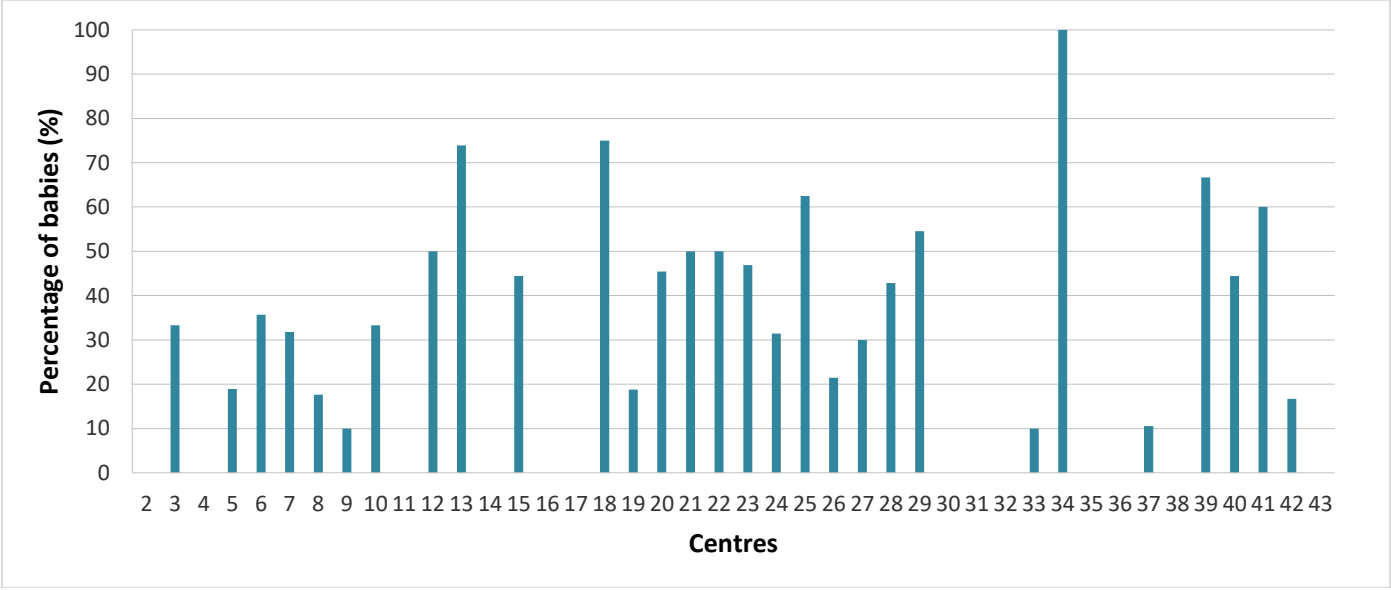


Table 7 :
Antenatal corticosteroid for all babies born at ≤ 1500 grams birth weight according to centres

Hospitals	Inborn			Outborn		
	Total number of babies	Given Antenatal Steroid		Total number of babies	Given Antenatal Steroid	
	n	*N*	%	*n*	*n*	%
Overall	3319	2517	75.8	395	144	36.5
2	0	0	0.0	0	0	0.0
3	188	152	80.9	12	4	33.3
4	38	34	89.5	1	0	0.0
5	219	148	67.6	37	7	18.9
6	74	61	82.4	14	5	35.7
7	210	155	73.8	22	7	31.8
8	185	147	79.5	17	3	17.6
9	129	101	78.3	10	1	10.0
10	33	31	93.9	9	3	33.3
11	8	4	50.0	0	0	0.0
12	47	31	66.0	4	2	50.0
13	54	35	64.8	23	17	73.9
14	30	22	73.3	0	0	0.0
15	84	69	82.1	9	4	44.4
16	142	112	78.9	4	0	0.0
17	109	70	64.2	4	0	0.0
18	53	46	86.8	4	3	75.0
19	132	98	74.2	16	3	18.8

Table 7 (continued):

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

Hospitals	Inborn			Outborn		
	Total number of babies	Given Antenatal Steroid		Total number of babies	Given Antenatal Steroid	
	n	*N*	%	*n*	*n*	%
20	58	35	60.3	11	5	45.5
21	34	20	58.8	2	1	500
22	123	113	91.9	10	5	50.0
23	162	119	73.5	32	15	46.9
24	165	130	78.8	35	11	31.4
25	58	40	69.0	8	5	62.5
26	165	121	73.3	14	3	21.4
27	71	52	73.3	10	3	30.0
28	23	20	87.0	7	3	42.9
29	105	80	76.2	11	6	54.5
30	43	20	46.5	3	0	0.0
31	35	31	88.6	1	0	0.0
32	126	108	85.7	5	0	0.0
33	104	84	80.8	10	1	10.0
34	39	30	76.9	1	1	100.0
35	31	26	83.9	1	0	0.0
36	8	6	75.0	0	0	0.0
37	64	41	64.1	19	2	10.5
38	1	1	100.0	0	0	0.0

Table 7 (continued):
Antenatal corticosteroid for all babies born at ≤ 1500 grams birth weight according to centres

Hospitals	Inborn			Outborn		
	Total number of babies	Given Antenatal Steroid		Total number of babies	Given Antenatal Steroid	
	n	*N*	%	*n*	*N*	%
39	41	33	80.5	3	2	66.7
40	25	16	64.0	9	4	44.4
41	43	34	79.1	5	3	60.0
42	60	41	68.3	12	2	16.7

Figure 8

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

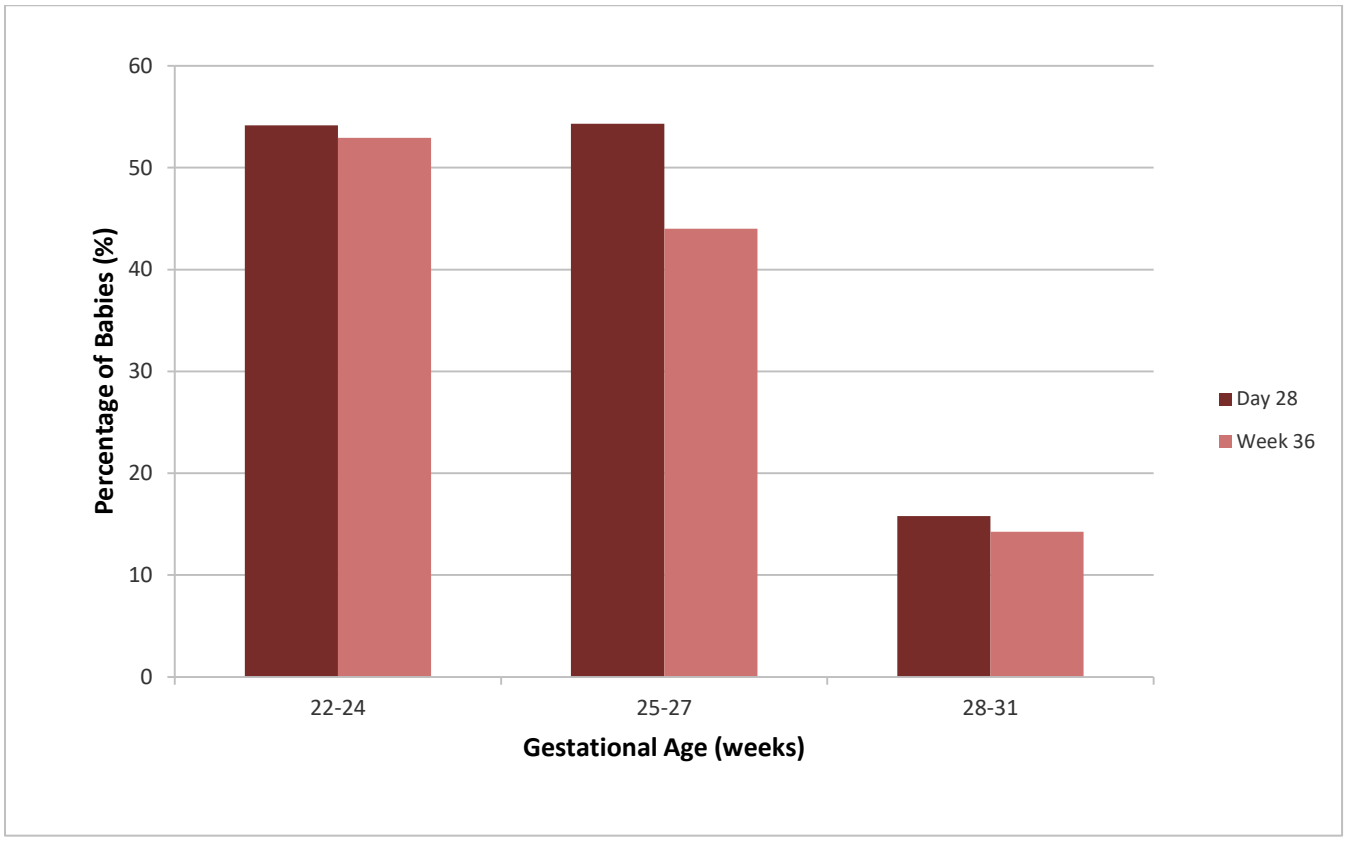


Table 8 :
Incidence of oxygen dependency among admitted inborn babies with gestational age < 32 weeks

Gestational age at birth (weeks)		Total no of admitted inborn babies	Babies alive at day 28	Babies with oxygen dependency beyond day 28 among survivors	Babies alive at 36 weeks postmenstrual age	Babies with oxygen dependency beyond 36 weeks among survivors
22-24	*n*	159	18	12	16	10
	%	5.5	11.3	66.7	10.1	62.5
25-27	*n*	584	358	187	262	120
	%	20.1	61.3	52.2	44.9	45.8
28-31	*n*	2159	1563	241	947	143
	%	74.4	72.4	15.4	43.9	15.1
Total included	*n*	2902	1939	440	1225	273
	%	100	66.8	22.7	42.2	22.3
Total no. of missing (GA)		0				
Total babies		2902				

Figure 9

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

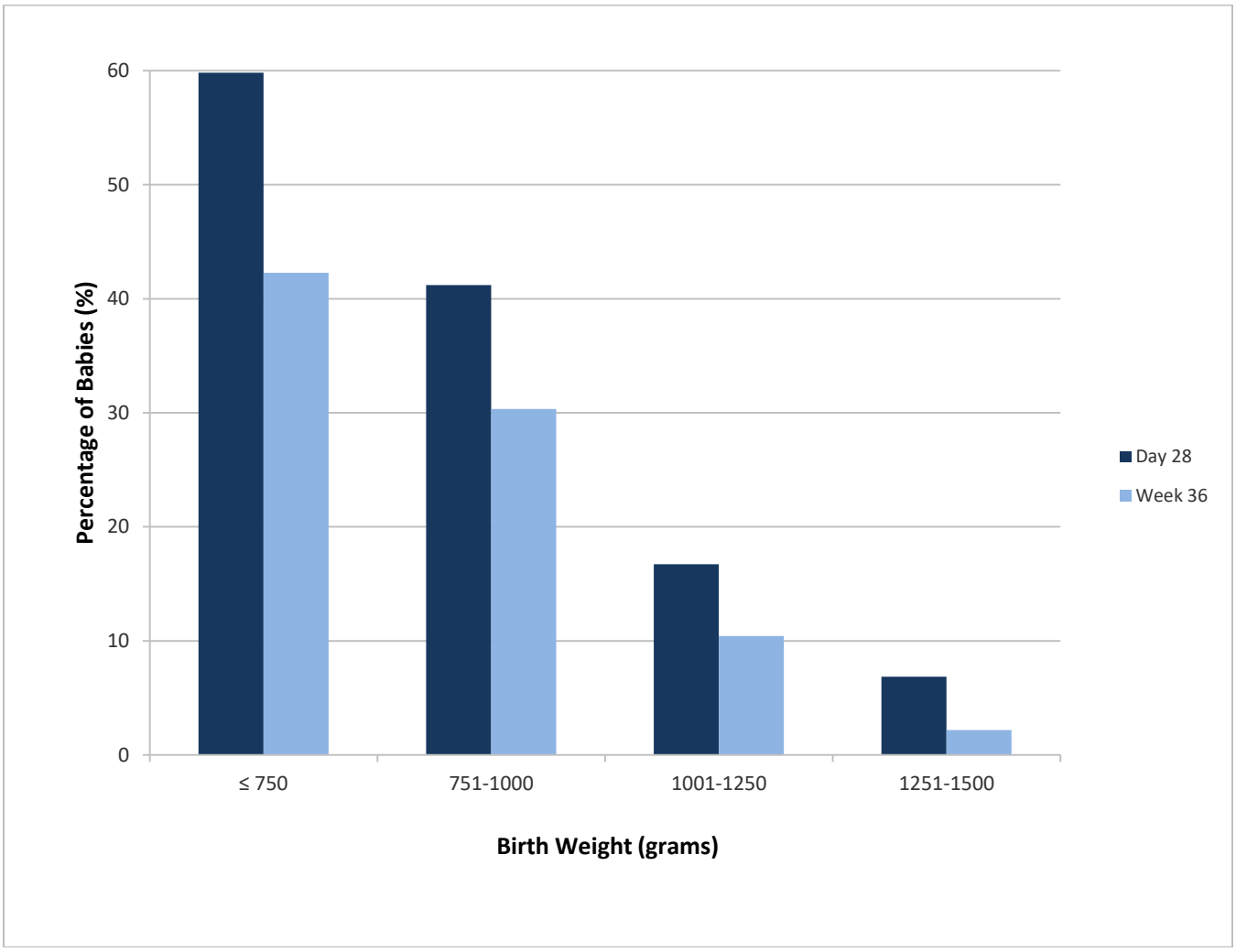


Table 9:
Incidence of oxygen dependency among admitted inborn babies with birth weight ≤ 1500 grams

Birth Weight (grams)		Total no of admitted inborn babies	Babies alive at 28	Babies with oxygen dependency beyond day 28 among survivors	Babies alive at 36 weeks postmenstrual age	Babies with oxygen dependency beyond 36 weeks among survivors
≤ 750	*n*	375	108	63	95	46
	%	11.0	30.3	58.3	26.6	48.4
751-1000	*n*	639	465	195	342	125
	%	19.7	72.8	41.9	53.5	36.5
1001 - 1250	*n*	933	760	108	561	54
	%	28.8	81.5	14.2	60.1	9.6
1251 - 1500	*n*	1310	922	74	759	25
	%	40.4	70.4	8.0	57.9	3.3
Total Included	*n*	3239	2255	440	1757	250
	%	100	69.9	19.5	54.2	14.2
Total no. of missing (GA)		0				
Total babies		3239				

Figure 10

Incidence of patent ductus arteriosus (PDA) among all admitted inborn babies in the MNNR by gestational age

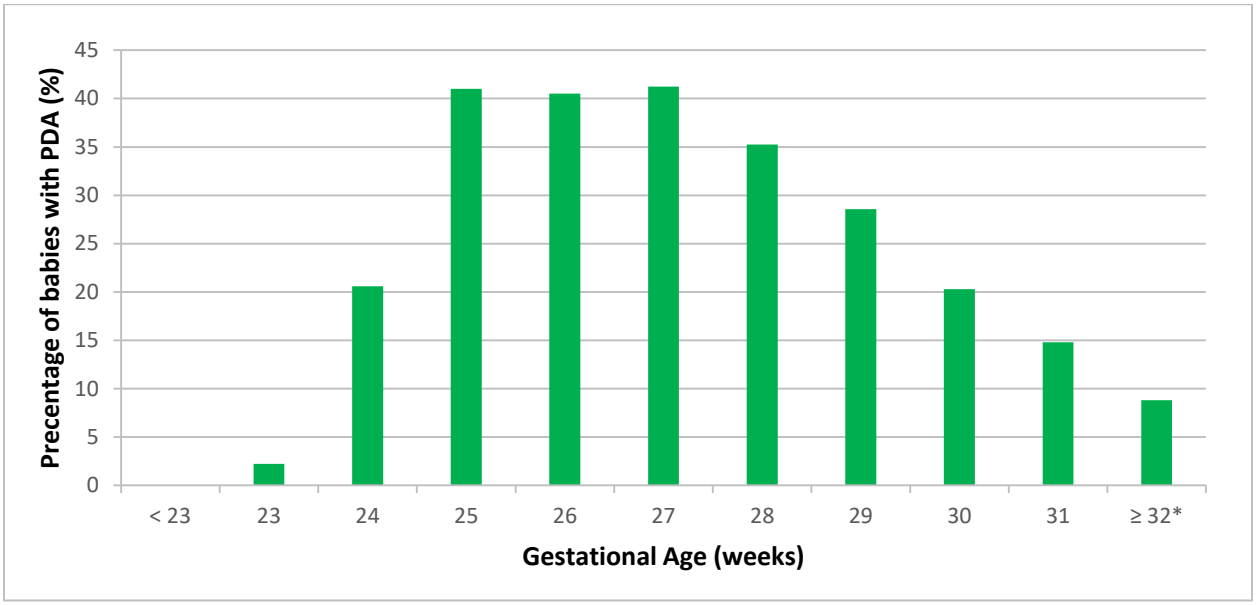


Table 10 :
Treatment of patent ductus arteriosus (PDA) in admitted inborn babies in the MNNR by gestational age

Gestational age (completed weeks)	Total number of admitted inborn babies		PDA		Confirmed by ECHO		Indomethacin/ Ibuprofen		Ligation	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
<23	12	0.1	0	0.0	0	0.0	0	0.0	0	0.0
23	45	0.4	1	2.2	1	100.0	0	0.0	0	0.0
24	102	0.9	21	20.6	18	85.7	8	38.1	1	4.8
25	161	1.5	66	41.0	56	84.8	25	37.9	1	1.5
26	195	1.8	79	40.5	69	87.3	25	31.6	1	1.3
27	228	2.1	94	41.2	87	92.6	44	46.8	3	3.2
28	363	3.3	128	35.3	118	92.2	56	43.8	3	2.3
29	448	4.1	128	28.6	121	94.5	48	37.5	1	0.8
30	645	5.9	131	20.3	125	95.4	50	38.2	1	0.8
31	703	6.4	104	14.8	96	92.3	26	25.0	0	0.0
≥32*	8081	73.6	711	8.8	683	96.1	77	10.8	16	2.3
Total included	10983	100	1463	13.3	1374	93.9	359	24.5	27	1.8
Total no. of missing (GA)	0									
Overall Total babies	10983									

*COMMENT: *For the category ≥ 32 weeks gestation, calculated percentage does not include all livebirths in the hospital that do not fit inclusion criteria.*

Figure 11

Prevelance of patent ductus arteriosus (PDA) in admitted inborn babies in the MNNR by birth weight categories

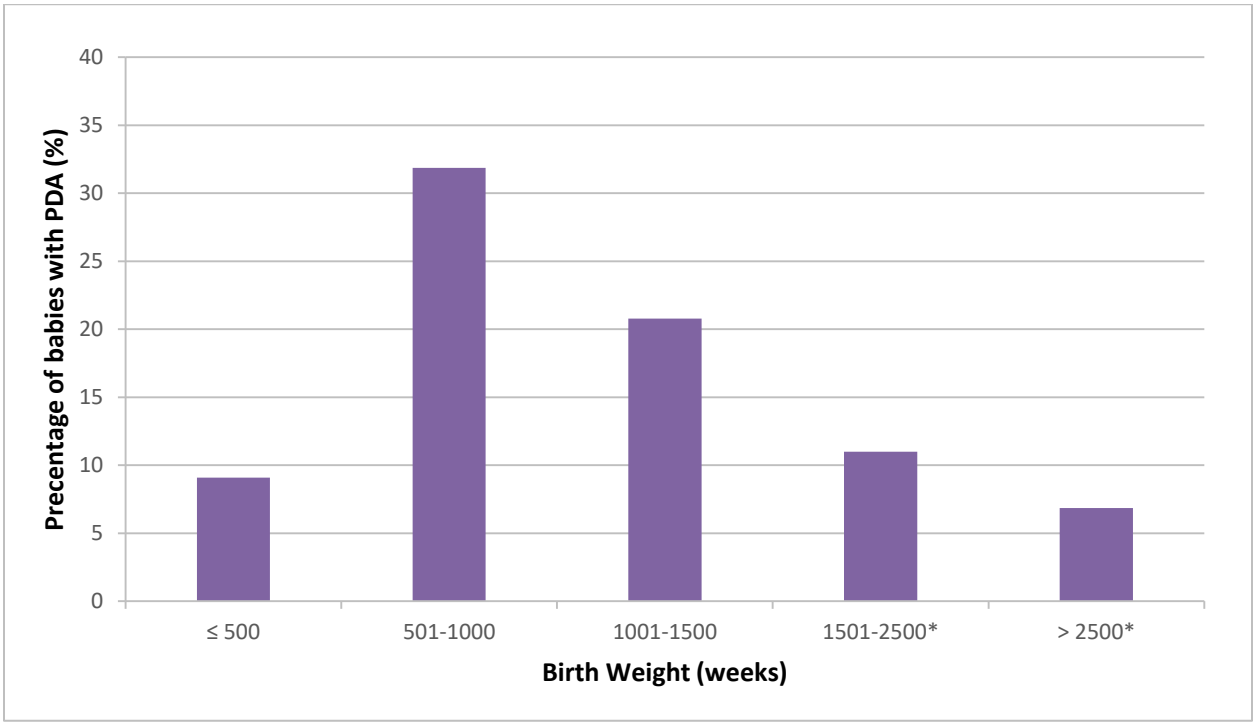


Table 11 :
Treatment of patent ductus arteriosus (PDA) in admitted inborn babies in the MNNR by birth weight categories

Birth weight (grams)	Total number of admitted inborn babies		PDA		Confirmed by ECHO		Indomethacin/ Ibuprofen		Ligation	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
≤500	33	0.3	3	9.1	2	0.0	0	0.0	0	0.0
501-1000	963	8.8	307	31.9	277	90.2	119	8.8	8	2.6
1001-1500	2243	20.4	466	20.8	433	92.9	162	34.8	5	1.1
1501-2500*	3776	34.4	415	11.0	394	94.9	74	17.8	9	2.2
≥2500*	3968	36.1	272	6.9	268	98.5	4	1.5	5	1.8
Total included	10983	100	1463	13.3	1374	93.9	359	24.5	27	1.8
Total no. of missing (BW)	0									
Total babies	10983									

Table 12
Treatment of patent ductus arteriosus (PDA) in admitted inborn babies in the MNNR by gestational age categories

Gestational age at birth (weeks)	Total no. of admitted inborn babies		No. of babies with data available on PDA diagnosis		No. of babies with diagnosed PDA		Confirmed by ECHO		Treatment			
									Indo-methacin/ Ibuprofen		Ligation	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
22-24	159	5.5	159	100.0	22	13.8	19	86.4	8	36.4	1	4.5
25-27	584	20.1	584	100.0	239	40.9	212	88.7	94	39.3	5	2.1
28-31	2159	74.4	2159	100.0	491	22.7	460	93.7	180	36.7	5	1.0
Total included	2902	100.0	2902	100.0	752	25.9	691	91.9	282	37.5	11	1.5

Table 13
Treatment of patent ductus arteriosus (PDA) in admitted inborn babies by birth weight categories

Birth weight (grams)	Total number of admitted inborn babies		No. of babies with data available on PDA diagnosis		No. of babies with diagnosed PDA		Confirmed by ECHO		Treatment			
									Indo-methacin/ Ibuprofen		Ligation	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
Less than 750	357	11.0	357	100.0	77	21.6	6	85.7	23	29.9	3	3.9
751-1000	639	19.7	639	100.0	233	36.5	213	91.4	96	41.2	5	2.1
1001-1250	933	28.8	933	100.0	252	27.0	235	93.3	96	38.1	3	1.2
1251-1500	1310	40.4	1310	100.0	214	16.3	198	92.5	66	30.8	2	0.9
Total included	3239	100	3239	100.0	776	24.0	712	91.8	281	36.2	13	1.7

Figure 14

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

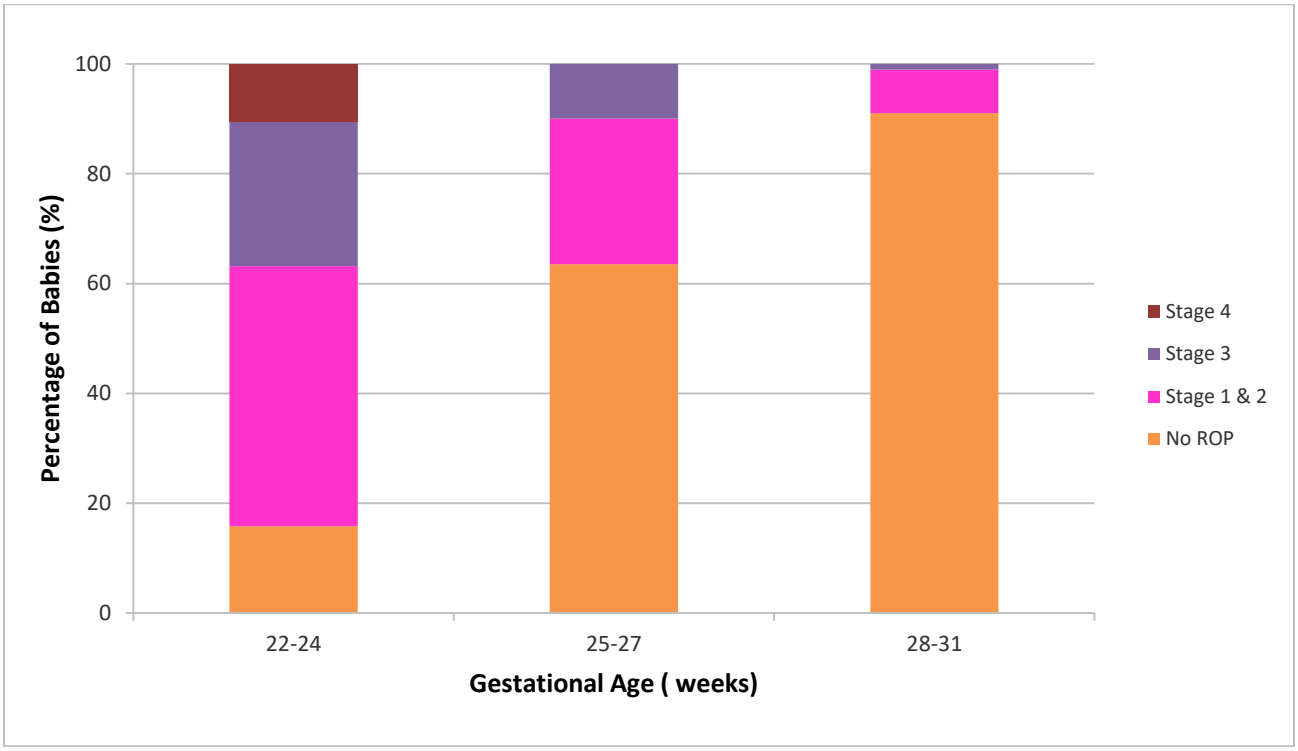


Table 14 :
Incidence of retinopathy of prematurity (ROP) in admitted inborn babies in the MNNR by gestational age categories

Gestational age at birth (weeks)	Total number of admitted inborn babies	No. of babies alive at 6 weeks	No. of babies with eye examination		Retinopathy of prematurity								Therapy	
					No ROP		ROP Stage 1 & 2		ROP Stage 3		ROP Stage 4 & 5		Cryo	Laser
	n	*n*	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%		
22-24	159	27	19	70.4	3	15.8	9	47.4	5	26.3	2	10.5	0	3
25-27	584	388	351	90.5	223	63.5	93	26.5	35	10.0	0	0.0	0	26
28-31	2159	1969	1446	73.4	1316	91.0	115	8.0	15	1.0	0	0.0	1	9
Total Included	2902	2384	1816	76.2	1542	84.9	217	11.9	55	3.0	2	0.1	1	38

Comment: Screening refers to those screened during the ward admission

Figure 15

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

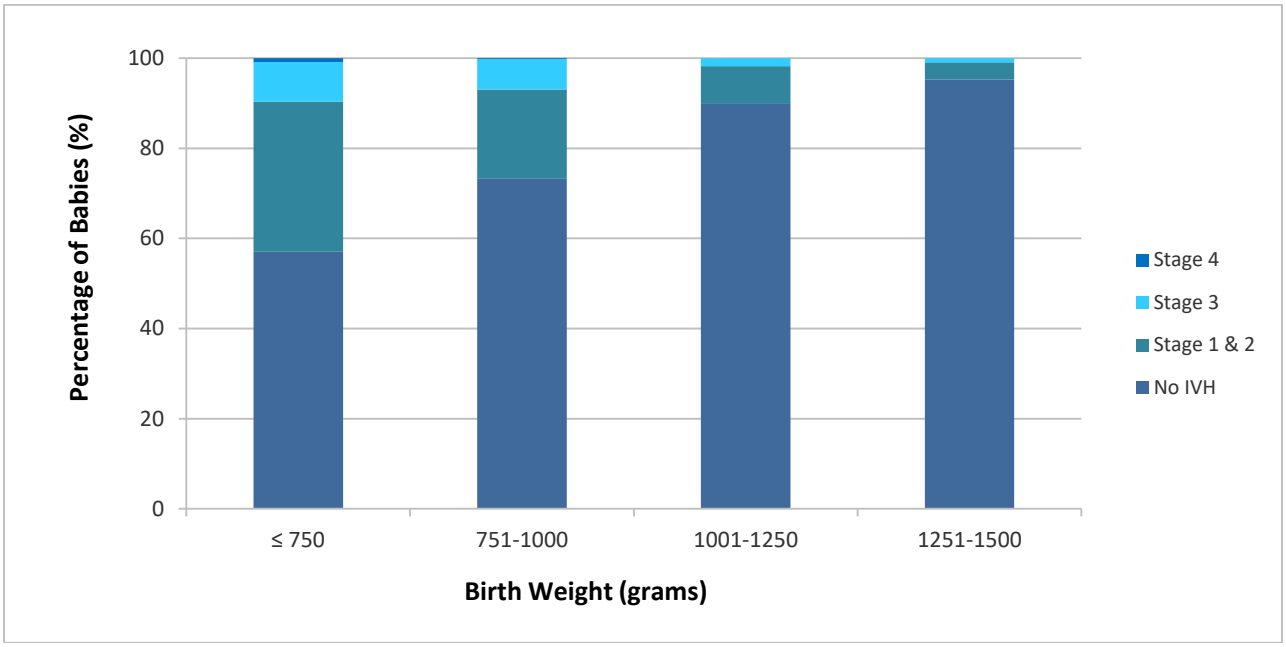


Table 15 :
Incidence of retinopathy of prematurity (ROP) in admitted inborn babies in the MNNR by birth weight categories

Birth weight (grams)	Total no of admitted inborn babies	No. of babies alive at 6 weeks	No. of babies with eye examination		Retinopathy of prematurity								Therapy	
					No ROP		ROP Stage 1 & 2		ROP Stage 3		ROP Stage 4 & 5		Cryo	Laser
	n	*n*	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%		
≤ 750	357	130	114	87.7	65	57.0	38	33.3	10	8.8	1	0.9	0	10
751-1000	639	494	459	92.9	336	73.2	91	19.8	31	6.8	1	0.2	0	20
1001-1250	933	819	690	84.2	620	89.9	58	8.4	12	1.7	0	0.0	0	10
1251-1500	1310	1208	784	64.9	747	95.3	30	3.8	7	0.9	0	0.0	1	1
Total included	3239	2651	2047	77.2	1768	86.4	217	10.6	60	2.9	2	0.1	1	41

Comment: Screening refers to those screened during the ward admission

Figure 16

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

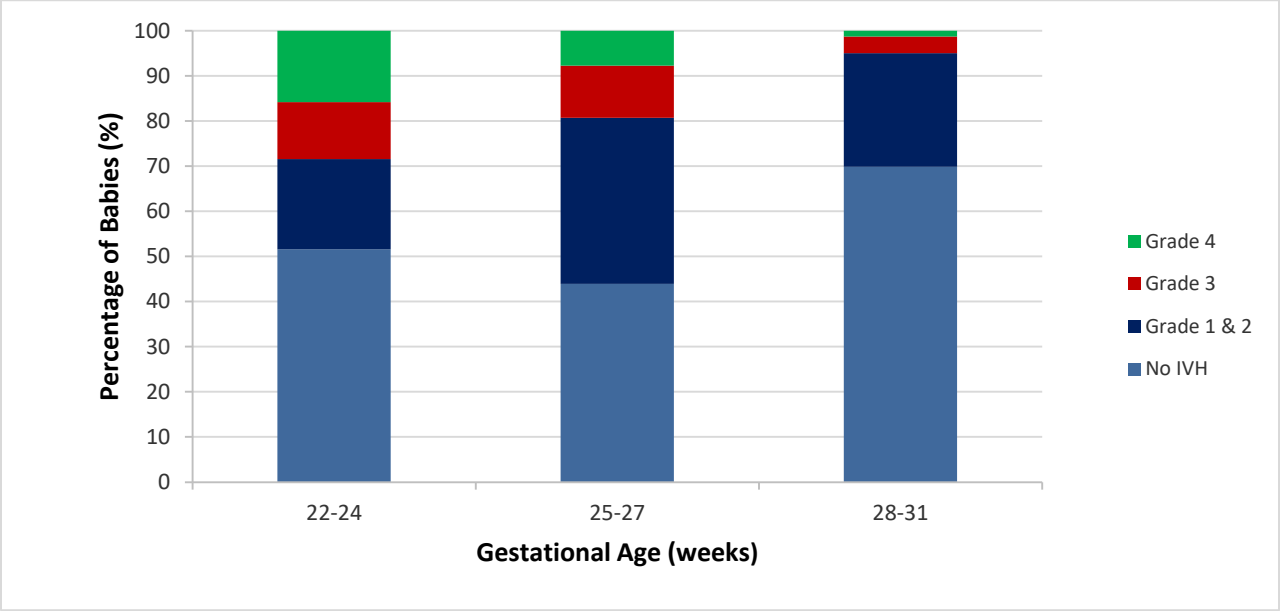


Table 16 :
Incidence of intraventricular haemorrhage (IVH) in admitted inborn babies < 32 weeks gestational age

Gestational age (completed weeks)		Total no. of admitted inborn babies	Babies with CUS	NO IVH	IVH Grade 1 & Grade 2	IVH Grade 3	IVH Grade 4
22-24	n	15	95	49	19	12	15
	%	5.5	59.7	51.6	20.0	12.6	15.8
25-27	n	584	528	232	194	61	41
	%	20.1	90.4	43.9	36.7	11.6	7.8
28-31	n	2159	1980	1384	497	73	26
	%	74.4	91.7	69.9	25.1	3.7	1.3
Total included	n	2902	2603	1665	710	146	82
	%	100.0	89.7	64.0	27.3	5.6	3.2
Total no. of missing (GA)		0					
Total babies		2902					

CUS – cranial untrasound

Figure 17

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

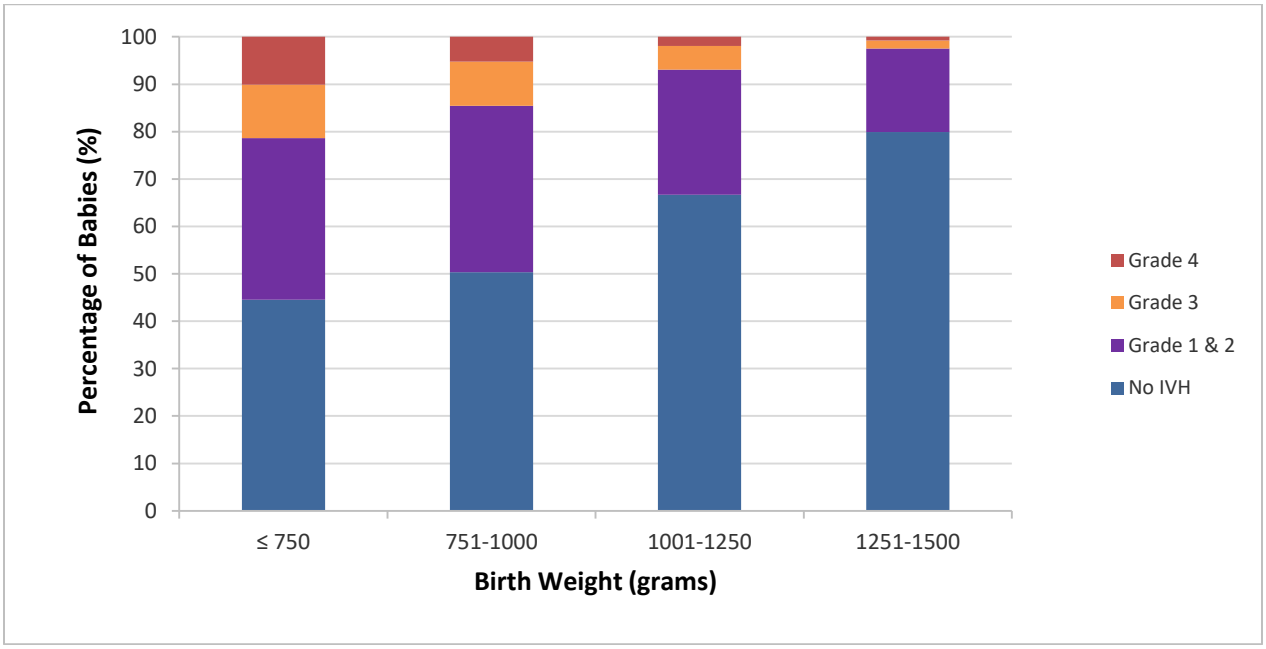


Table 17 :
Incidence of intraventricular haemorrhage (IVH) in admitted inborn babies ≤ 1500 grams birth weight

Birth weight (grams)		Total no. of admitted inborn babies	Babies with CUS	NO IVH	IVH Grade 1 & Grade 2	IVH Grade 3	IVH Grade 4
≤ 750	**n**	357	267	119	91	30	27
	%	11.0	74.8	44.6	34.1	112	10.1
751-1000	**n**	639	590	297	207	55	31
	%	19.7	92.3	50.3	35.1	9.3	5.3
1001-1250	**n**	933	867	578	229	43	17
	%	28.8	92.9	66.7	26.4	5.0	2.0
1251-1500	**n**	1310	1171	936	206	20	9
	%	40.4	89.4	79.9	17.6	1.7	0.8
Total included	**n**	3239	2895	1930	733	148	84
	%	100	89.4	66.7	253	5.1	2.9
Total no. of missing (GA)	0						
Total babies	3239						

Figure 18

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

Table 18 :
Incidence and treatment of necrotizing enterocolitis (NEC) in admitted inborn babies according to gestational age categories

Gestational age (weeks)	Total number of admitted inborn babies	Babies with NEC		With Surgical treatment	
	n	*n*	*%*	*n*	*%*
22-24	159	6	3.8	0	0.0
25-27	584	41	7.0	14	34.1
28-31	2159	62	2.9	18	29.0
Total included	2902	109	3.8	32	29.4
Total no. of missing (GA)	0				
Overall Total babies	2902				

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

Figure 19

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

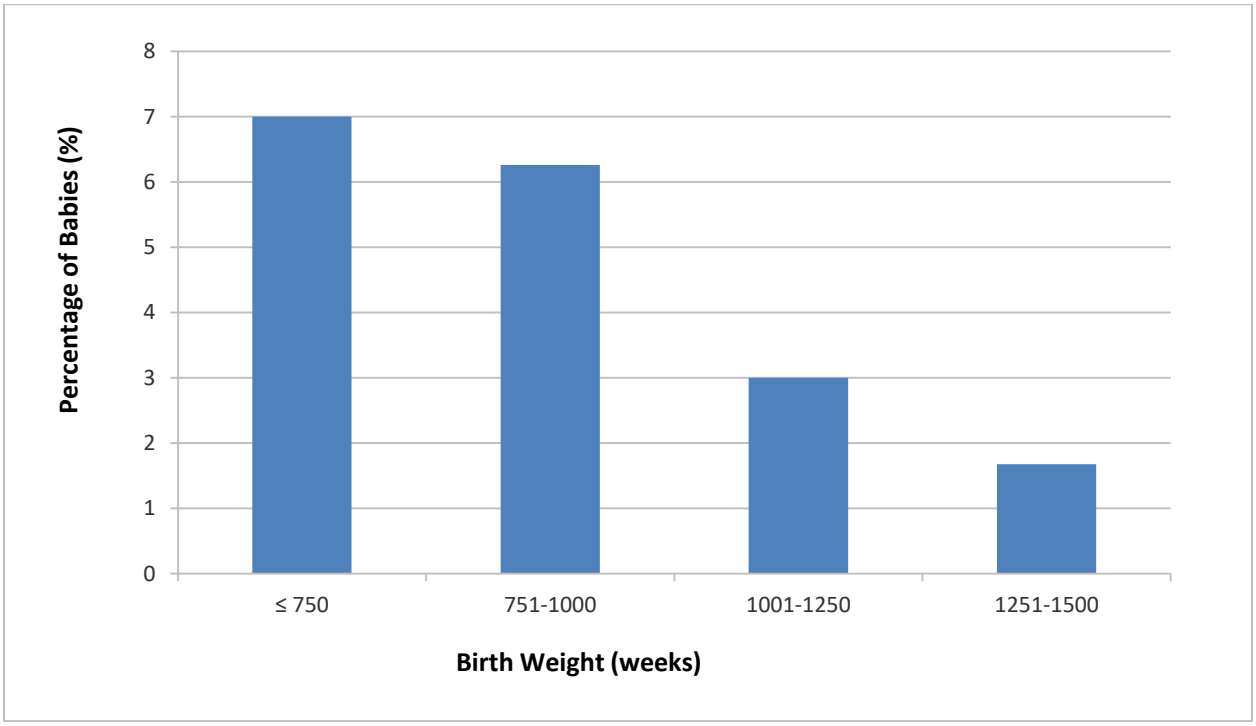


Table 19 :
Incidence and treatment of necrotizing enterocolitis (NEC) in admitted inborn babies according to birth weight categories

Birth weight (grams)	Total number admitted of inborn babies	Babies with NEC		With Surgical treatment	
	n	*n*	*%*	*n*	*%*
≤ 750	357	25	7.0	7	28.0
751-1000	639	40	6.3	11	27.5
1001-1250	933	28	3.0	10	35.7
1251 - 1500	1310	22	1.7	5	22.7
Total included	3239	115	3.6	33	28.7
Total no. of missing (BW)	0				
Overall total babies	3239				

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

Figure 20
Incidence of blood culture positive early onset sepsis in admitted inborn babies by gestational age categories

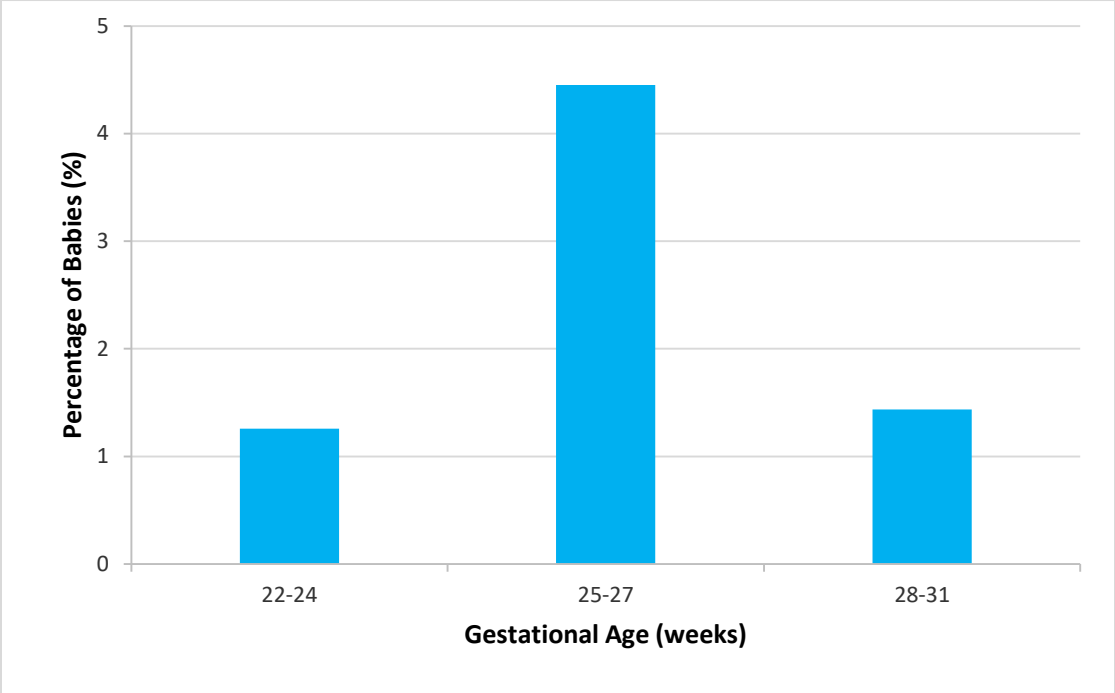


Table 20 :
Incidence of blood culture positive early onset sepsis in admitted inborn babies by gestational age categories

Gestational age at birth (completed weeks)	Total number of admitted inborn babies	No. of babies with early infection	
	n	*n*	%
22-24	159	2	1.3
25-27	584	26	4.5
28-31	2159	31	1.4
Total included	2902	59	2.0
Total no. of missing (GA)	0		
Total babies	2902		

Figure 21

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

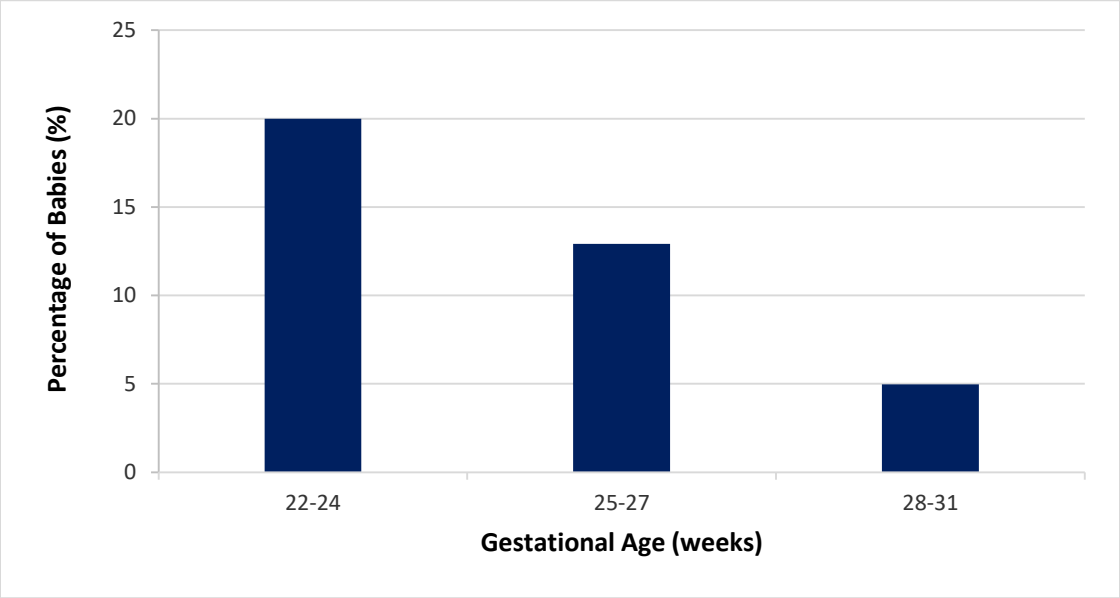


Table 21 :
Incidence of blood culture positive late onset sepsis in admitted inborn babies by gestational age categories

Gestational age (weeks)	Total number of admitted inborn babies	No. of babies who survived beyond day 3 after birth	No. of babies with at least one episode of late onset sepsis	
	n	*n*	n	%
22 – 24	159	20	4	20.0
25 – 27	584	364	47	12.9
28 – 31	2159	1932	96	5.0
Total included	2902	2316	147	6.3
Total no. of missing (GA)	0			
Total babies	2902			

Figure 22

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

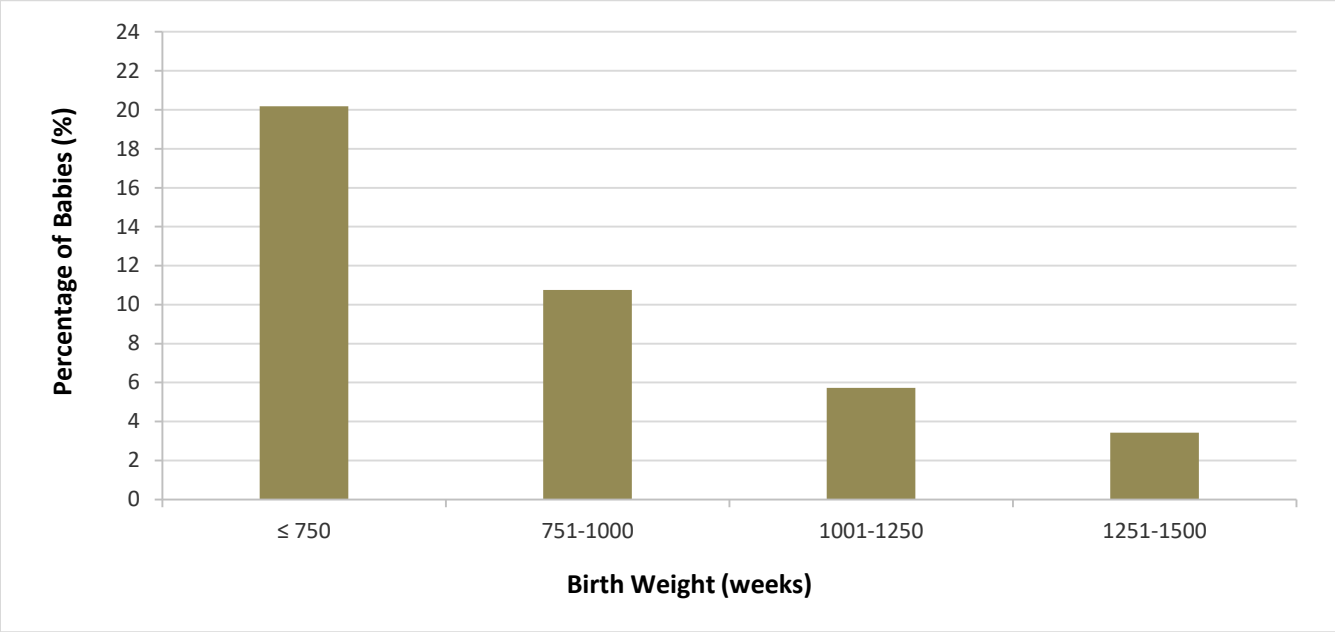


Table 22 :
Incidence of blood culture positive late onset sepsis in admitted inborn babies by birth weight categories

Birth weight (grams)	Total number of admitted inborn babies	No. of babies who survived beyond day 3 after birth	No. of babies with at least one episode of late onset sepsis	
	n	*n*	n	%
≤ 750	357	109	22	20.2
751-1000	639	474	51	10.8
1001-1250	933	802	46	5.7
1251-1500	1310	1196	41	3.4
Total included	3239	2581	160	6.2
Total no. of missing (BW)	0			
Overall total babies	3239			

Table 23a

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

Gestational age at birth (weeks)		Total no. of admitt-ed inborn babies	Numb er Surviv ed	No. with any one morbiditi es prior to discharge among survivors	No. with any two morbiditi es prior to discharge among survivors	No. with any three morbiditi es prior to discharge among survivors	No. with any four morbiditi es prior to discharge among survivors	No. with any five morbiditi es prior to discharge among survivors	No. without any five morbiditi es prior to discharge among survivors
22-24	n	159	21	5	6	1	0	0	9
	%	5.5	13.2	23.8	28.6	4.8	0.0	0.0	42.9
25-27	n	584	370	111	38	18	0	0	203
	%	20.1	63.4	30.0	10.3	4.9	0.0	0.0	54.9
28-31	n	2159	1942	238	43	3	0	0	1658
	%	74.4	89.9	12.3	2.2	0.2	0.0	0.0	85.4
Total Included	n	2902	2333	354	87	22	0	0	1870
	%	100	80.4	15.2	3.7	0.9	0.0	0.0	80.2
Total no. of missing (GA)	-								
Total babies	2902								

i. PDA requiring surgical ligation
ii. Stage 3 or 4 ROP
iii. Oxygen dependency at 36 weeks or discharge
iv. Confirmed sepsis
v. NEC

Table 23b

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

Gestational age at birth (weeks)		Total no. of admitt-ed inborn babies	Numb er Surviv ed	No. with any one morbiditi es prior to discharge among survivors	No. with any two morbiditi es prior to discharge among survivors	No. with any three morbiditi es prior to discharge among survivors	No. with any four morbiditi es prior to discharge among survivors	No. with any five morbiditi es prior to discharge among survivors	No. without any five morbiditi es prior to discharge among survivors
≤ 750	n	357	113	29	21	16	1	0	19
	%	11.0	31.7	25.7	18.6	14.2	0.9	0.0	16.8
751- 1000	n	639	479	135	41	9	1	0	293
	%	19.7	75.0	28.2	8.6	1.9	0.2	0.0	61.2
1001 - 1250	n	933	808	102	20	3	0	0	683
	%	28.8	86.6	12.6	2.5	0.4	0.0	0.0	84.5
1251 - 1500	n	1310	1199	92	13	0	0	0	1094
	%	40.4	91.5	7.7	1.1	0.0	0.0	0.0	91.2
Total Included	n	3239	2599	358	95	28	2	0	2089
	%	100	80.2	13.8	3.7	1.1	0.1	0.0	80.4
Total no. of missing (GA)	-								
Total babies	3239								

APPENDICES

Appendix 1 Level of Neonatal Care

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

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

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

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:

3. ***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

4. ***Level III B NICU*** has the capability to provide
   - Comprehensive care for extremely low birth weight infants (≤1000 g and ≤28 weeks gestation)
   - Advanced respiratory support such as high-frequency ventilation and inhaled nitric oxide
   - Prompt and on-site access to a full range of paediatric medical subspecialties
   - Advanced imaging, with interpretation on an urgent basis, including computed tomography, magnetic resonance imaging, and echocardiography Paediatric surgical specialists and paediatric anaesthesiologists on- site or at a closely related institution to perform major surgeries such as ligation of patent ductus arteriosus and repair of abdominal wall defects, necrotising enterocolitis with bowel perforation, trachea-oesophageal fistula and/or oesophageal atresia and myelomeningocele

5. ***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 will be considered as a readmission.

'Previous admission from anothr SDP': Case transferred from SDP hospital to another SDP hospital for first time.

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 MyKid number: add 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/ 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) ***Gestional 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. 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: 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) CPAP
c) Bag-mask vent
d) Endotracheal Tube Ventilation
e) Cardiac Compression
f) Adrenaline

28. 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. Early CPAP – given during initial stabilization at birth

b) 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.

c) HFJ/ HFOV – High frequency ventilation

d) Nitric oxide – gas delivered 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.

31. SurfactantA 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

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

48b. 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.

49. 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)

50. Feeding at discharge/death: Refers to feeding received at the time of discharge

'Never Fed' – if infants did not received any enteral feeding at discharge either formula milk or human milk.

'Human milk only' – if infants was discharge receiving human milk either by breast-fed and/or expressed breast milk.

'Formula only' – if infants was discharge receiving formula milk at discharge

'Human milk with formula' –if infants was discharge receiving received both human milk and formula milk at discharge.

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

52. 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. **This includes ROP findings after discharge.**

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

Place of Death: Labour Room/OT, In Transit Neonatal Unit 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. **Gestation***
< 37 or ≥ 37 weeks

*c. **Immaturity***
This includes only livebirths < 37 weeks gestation after excluding LCM. Tick immediate secondary cause of death e.g. severe IVH, pulmonary haemorrhage

*d. **Asphyxial conditions***
All term babies who died from birth asphyxia or meconium aspiration syndrome or PPHN

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

*f. **Other specific causes***
Specify any course of death not included in the above classification. This includes kernicterus, haemorrhagic shock/inborn error of metabolism/pneumothorax/pulmonary haemorrhage.

*g. **Unknown***
Where cause of death is not known.

Readmission CRF

To be used for MNNR babies who were discharged well to home or social welfare home from any MNNR SDP hospital and then readmitted to same or another MNNR SDP hospital cohort - only for those still within gestation of 44 weeks postmenstrual age. The aim is to audit reasons for readmission when bay was supposedly well enough to be discharged.

Discharge from: specify name of hospital

Centre Name: hospital name as in MNNR

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

Section 1: Patient particulars

1. ***Name of mother***: Name as in hospital record
2. ***Name of baby (optional)***: Name as in hospital record.
3. ***RN of baby****:* RN at participating hospital of last discharge.
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 if available
5. ***Date of Birth****:* dd/mm/yy
6. ***a) Birth weight:*** (grams)
   b) Gestation at birth**:** best estimate of gestational age given at full weeks

Section 2: Particulars of this admission

7. ***Date of first discharge:*** discharge date at the first admission after birth
8. ***Age at this readmission:*** auto-calculate from date of readmission & date of birth
9. ***Weight at this readmission:*** (grams)
10. ***Reason(s) for readmission:*** apnoea/fever/URTI/LRTI/confirmed sepsis/poor weight gain/cyanosis due to sucking/ swallowing coordination/jaundice/others; specify
11. ***Ventilated*** – Yes/No

Section 5: Outcome (Same as Section 5 page 16)

48b. ***Time of death*** (24 hour format): Mandatory for death cases

49. ***Weight (grams) and growth status on discharge/death:***
a) Weight: Enter the exact weight in grams.
b) Growth Status: Indicate growth status as per Intrauterine Growth Curves (Composite Male/Female)

50. ***Feeding at discharge/death:*** Tick 'Never fed', 'Human milk only', 'Formula only' or 'Human milk with formula' upon feeding received at the time of discharge:

51. ***Total duration of hospital stay during this readmission*** (in completed days): State to next complete day i.e. 10 days 6 hours is 11days. (auto calculate from date of this discharge and date of readmission)

52. ***Outcome at readmission:*** Alive / Dead

DEFINITIONS OF CERTAIN SPECIFIED DIAGNOSES
(Modified from ICD 10)

Diagnosis	Definition
Respiratory	
Meconium aspiration syndrome	Tick 'yes' if all 5 criteria are satisfied: Presence of meconium stained amniotic fluid at birth a. Respiratory distress onset within 1 hour of birth. Respiratory distress defined as presence of one of the following signs: tachypnoea, grunting, nasal flaring, or intercostals retraction. b. PaO_2 < 50 mmHg in room air, central cyanosis in room air or requirement for supplemental O_2 to maintain a PaO_2 > 50 mmHg c. 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. d. 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 made on autopsy finding of haemorrhage in the lungs).
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.
Transient Tachypnoea of Newborn	Benign disease of near-term, term or large premature infants with respiratory distress shortly after delivery resolving within 3 days.

Pulmonary Interstitial Emphysema	Dissection of air into the perivascular tissues of lung from alveolar overdistention or overdistention of smaller airways evident on CXR as linear or cast like lucencies with a history of requiring increasing ventilatory support.
Respiratory distress syndrome (RDS).	Defined as: A. PaO_2 < 50mmHg in room air, central cyanosis in room air, or a requirement for supplemental O_2 to maintain a PaO_2 > 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 afther thoracic surgery and wat 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 For babies < 32 weeks – state if O_2 / any form of CPAP or ventilatory support required at Day 28 and 36 weeks corrected gestation For babies ≥ 32 weeks - state if O_2 / any form of CPAP or ventilatory support required at Day 28 and ≥ 56 postnatal days	Tick "yes" if the baby received continuous oxygen concentration > 21% for at least 28 continuous days (note not "till 28 days of life"). Otherwise tick "no". 'Continuous' means that the patient is receiving oxygen throughout the time period and not just in brief episodes as needed i.e. during feeds. 'Blow-by' oxygen dose not counted unless it is the mode of oxygen administration used in a transport situation. Do not score oxygen given as part of a hyperoxia test.

Cardiovascular Persistent Pulmonary Hypertension (PPHN)	Failure of normal pulmonary vasculature relaxation at or shortly after birth, resulting in impedance to pulmonary blood flow, which exceeds systemic vascular resistance, such that deoxygenated blood shunted to the systemic circulation.
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 treatment (indomethacine/ibuprofen for > 24 hours 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 :*** 1 Diagnosis at surgery or post mortem, or 2 **Radiological diagnosis, a clinical history plus** • pneumatosis intestinalis, or • portal vein gas, 3 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. If there is no explicit grade listed, then score according to the descriptions given by the ICROP. 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**. Include if PLUS disease present** State if laser, cryotherapy or vitrectomy was done. If screening was not done, state 'No' and indicates whether an appointment for retinal examination was given. 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	If an indirect ophthalmologic examination was performed at any time, enter the worst stage documented: **Stage 0:** No Evidence of ROP **Stage 1**: Demarcation Line **Stage 2**: Ridge **Stage 3**: Ridge with Extraretinal Fibrovascular Proliferation **Stage 4**: Retinal Detachment

Intraventricular haemorrhage (IVH) Tick 'Yes' if IVH is seen and enter the worst grade before or on 28 days of life. State if VP shunt/reservoir was inserted Tick 'No; if no IVH before or day 28 Tick 'Not Applicable' for term infant Tick "Ultrasound not done" if it was not done.	If ultrasound of brain done on or before 28 days of life, enter the worst grade **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
Seizures	Clinical evidence of subtle seizures, or of focal / multifocal, clonic or tonic seizures, confirmed by 2 or more clinicians or diagnosed by EEG. Used synonymously with fits or convulsions.
Central Venous Line	Presence of any of three types of catheters: 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. Those great vessels considered are: ○ Aorta ○ Superior vena kava ○ Brachiocephalic veins ○ Internal jugular veins ○ Subclavian veins ○ Inferior vena kava ○ External iliac veins ○ Common femoral veins NA – not applicable: no CVC line
Confirmed sepsis Tick 'Yes'if there is evidence of confirmed sepsis. Do not include presumed or clinical sepsis.	***Confirmed sepsis*** Clinical evidence of sepsis plus culture-proven infection e.g. positive blood, urine, or CSF culture or positive bacterial antigen test. Includes congenital pneumonia if blood culture was positive.

State whether the onset of first confirmed sepsis was On or before Day 3 of life OR after Day 3 of life. State the organism cultured: • Group B streptococcus • MRSA • CONS • ESBL • Fungal • Staphylococcus aureus • Klebsiella • Pseudomonas • Acinetobacter • Others, specify	***Confirmed sepsis*** 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 peripheral blood sample and /or recovered from infants CSF AND 2. Signs of generalized infection (such as apnoea, temperature instability, feeding intolerance, worsening respiratory distress or haemodynamic instability) AND 3. Treatment with 5 or more days of IV antibiotics after the above cultures were obtained. If the patient died, was discharged, or transferred prior to completion of 5 days or more of IV antibiotics, this condition would still be met if the intention were to treat for 5 or more days. Do not place a tick if any or all of the above are not true. <u>For FUNGAL infection</u>: Place a tick only if a fungus recovered from a blood culture obtained from either a central line or peripheral blood sample after day 3 of life.
Neonatal meningitis Tick 'yes' (if CSF biochem or cytology suggestive even if CSF C&S is negative) or 'no' If yes, State if CSF Culture positive **- Yes / No** State the organism cultured: • Group B streptococcus • MRSA • CONS (see definition) • Staphylococcus aureus • Klebsiella • Pseudomonas • Acinetobacter • Fungal (see definition) • Others, specify • ESBL organisms	Signs of clinical sepsis and evidence of meningeal infection as shown in cerebrospinal fluid findings (i.e. cytology, biochemistry or microbiologic findings).

Hypoxic ischaemic encephalopathy (HIE) **Applied to <u>any gestation</u> so long the criteria fulfilled.**	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** 2. Three or more supporting findings from the following list: a. Arterial cord pH<7.00 b. Apgar score at 5 minutes of 5 or less c. Evidence of multi-organ system dysfunction – dysfunction of one or more of the following systems within 72 hours of birth: i. Renal: Oliguria or acute renal failure. ii. GI: necrotizing enterocolitis, hepatic dysfunction iii. Haematologic: thrombocytopaenia, disseminated intravascular coagulopathy. iv. Endocrine: hypoglycaemia, hyperglycaemia, hypercalcaemia, syndrome of inappropriate ADH secretion (SIADH). v. Pulmonary: persistent pulmonary hypertension vi. Cardiac: myocardial dysfunction, tricuspid insufficiency.

HIE severity If the infants diagnosed with HIE, record the worst stage observed during the first 7 days following birth based on the infant's level of consciousness and response to arousal maneuvers such as persistent gentle shaking, pinching, shining a light or ringing of a bell: Tick "none" if there is no HIE Tick '"Mild, Moderate, Severe " according to the definition	d. Evidence of foetal distress on antepartum monitoring: persistent late decelerations, reversal of end-diastolic flow on Doppler flow studies of the umbilical artery or a biophysical profile of 2 or less e. Evidence of CT, MRI, technetium or ultrasound brain scan performed within 7 days of birth of diffuse or multifocal ischaemia or of cerebral oedema. f. Abnormal EEG: low amplitude and frequency, periodic, paroxysmal or isoelectric. **AND** 3. The absence of an infectious cause, a congenital malformation of the brain or an inborn error of metabolism, which could explain the encephalopathy. *HIE severity* a. Mild (normal or hyperalert) – infants in this category are alert or hyperalert with either a normal or exaggerated response to arousal. b. Moderate (lethargic or stupor) – infants in this category are arousable but have a diminished response to arousal maneuvers c. Severe (deep stupor or coma) – infants in this category are not arousable in response to arousal maneuvers
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 Recognized Syndrome' 3. 'Isolated major abnormality' If the syndrome is known, tick the specify syndromes or specify it.	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".

Types of Abnormalities: **Tick all major abnormalities found for recognisable syndrome, non-recognisable ones or isolated major congenital abnormality** E.g. in Down Syndrome, Tick all the congenital anomalies found in patient. Please specify if there are abnormalities not listed.	

Malaysian National Neonatal Registry

2-7, Medical Academies of Malaysia
210 Jln Tun Razak
50400 Kuala Lumpur

Telephone: 016– 270 4505
03- 4023 4505
Fax 03- 4023 4505

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

SECTION 1: DELIVERIES VERSUS BIRTH WEIGHT

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

SECTION 2: BIRTH VERSUS GESTATION WEEKS

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

SECTION 3: BIRTH VERSUS MODE OF DELIVERY

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

SECTION 4: BIRTHS VERSUS ETHNIC GROUP

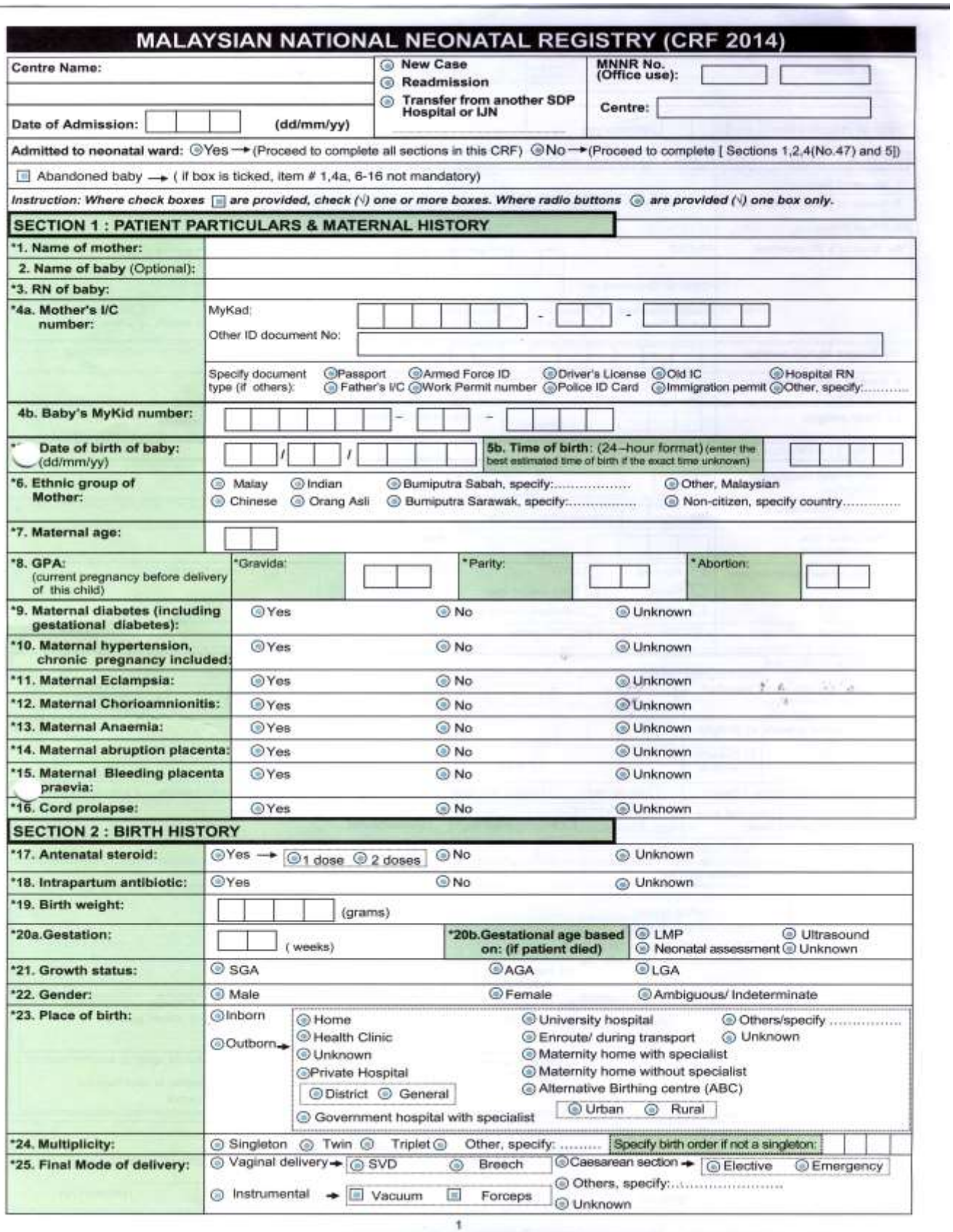
Ethnic Group	No. of Still Births	No. of Live Births	No. Admitted to Neonatal Unit	No. who died in delivery room
Malay				
Chinese				
Indian				
Orang Asli				
Bumiputera Sabah specify ethnic group _____				
Bumiputera Sarawak specify ethnic group _____				
Foreigner				
Other Malaysian _____				
TOTAL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

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

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

ii Sample of tracking form are as follows

Appendix 4 Case Report Form (CRF)



MALAYSIAN NATIONAL NEONATAL REGISTRY (CRF 2014)

Centre Name:	◎ New Case ◎ Readmission ◎ Transfer from another SDP Hospital or IJN	**MNNR No. (Office use):**
Date of Admission: (dd/mm/yy)		**Centre:**

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

☐ Abandoned baby → (if box is ticked, item # 1,4a, 6-16 not mandatory)

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

SECTION 1 : PATIENT PARTICULARS & MATERNAL HISTORY

*1. Name of mother:	
2. Name of baby (Optional):	
*3. RN of baby:	
*4a. Mother's I/C number:	MyKad: - - Other ID document No: Specify document type (if others): ◎Passport ◎Armed Force ID ◎Driver's License ◎Old IC ◎Hospital RN ◎Father's I/C ◎Work Permit number ◎Police ID Card ◎Immigration permit ◎Other, specify:.....
4b. Baby's MyKid number:	- -
*5a. Date of birth of baby: (dd/mm/yy)	/ / **5b. Time of birth:** (24–hour format) (enter the best estimated time of birth if the exact time unknown)
*6. Ethnic group of Mother:	◎ Malay ◎ Indian ◎ Bumiputra Sabah, specify:..... ◎ Other, Malaysian ◎ Chinese ◎ Orang Asli ◎ Bumiputra Sarawak, specify:..... ◎ Non-citizen, specify country.....
*7. Maternal age:	
*8. GPA: (current pregnancy before delivery of this child)	*Gravida: *Parity: *Abortion:
*9. Maternal diabetes (including gestational diabetes):	◎Yes ◎ No ◎ Unknown
*10. Maternal hypertension, chronic pregnancy included:	◎Yes ◎ No ◎ Unknown
*11. Maternal Eclampsia:	◎Yes ◎ No ◎ Unknown
*12. Maternal Chorioamnionitis:	◎Yes ◎ No ◎ Unknown
*13. Maternal Anaemia:	◎Yes ◎ No ◎ Unknown
*14. Maternal abruption placenta:	◎Yes ◎ No ◎ Unknown
*15. Maternal Bleeding placenta praevia:	◎Yes ◎ No ◎ Unknown
*16. Cord prolapse:	◎Yes ◎ No ◎ Unknown

SECTION 2 : BIRTH HISTORY

*17. Antenatal steroid:	◎Yes → ◎1 dose ◎ 2 doses ◎ No ◎ Unknown
*18. Intrapartum antibiotic:	◎Yes ◎ No ◎ Unknown
*19. Birth weight:	(grams)
*20a.Gestation:	(weeks) ***20b.Gestational age based on: (if patient died)** ◎ LMP ◎ Ultrasound ◎ Neonatal assessment ◎ Unknown
*21. Growth status:	◎ SGA ◎AGA ◎LGA
*22. Gender:	◎ Male ◎Female ◎Ambiguous/ Indeterminate
*23. Place of birth:	◎Inborn ◎Outborn → ◎ Home, ◎ Health Clinic, ◎ Unknown, ◎Private Hospital, ◎ District ◎ General, ◎ Government hospital with specialist, ◎ University hospital, ◎ Enroute/ during transport, ◎ Maternity home with specialist, ◎ Maternity home without specialist, ◎ Alternative Birthing centre (ABC), ◎ Urban ◎ Rural, ◎Others/specify ....., ◎ Unknown
*24. Multiplicity:	◎ Singleton ◎ Twin ◎ Triplet ◎ Other, specify: ..... Specify birth order if not a singleton:
*25. Final Mode of delivery:	◎ Vaginal delivery → ◎ SVD ◎ Breech ◎ Instrumental → ☐ Vacuum ☐ Forceps ◎Caesarean section → ◎ Elective ◎ Emergency ◎ Others, specify:..... ◎ Unknown

1

SECTION 2 : BIRTH HISTORY (continue)

*26. Apgar score at 1 min and 5 min (0-10)	a) Score at 1 min:	☐ Unknown	b) Score at 5 min: (Please score even if the baby is intubated)	☐ Unknown
27. Initial resuscitation: (applicable for inborn only)	a) Oxygen:	○ Yes ○ No	d) Endotracheal tube vent:	○ Yes ○ No
	b) CPAP :	○ Yes ○ No	e) Cardiac compression:	○ Yes ○ No
	c) Bag and mask ventilation:	○ Yes ○ No	f) Adrenaline:	○ Yes ○ No
*28. Admission temperature: (mandatory if admitted to Neonatal ward)	☐☐ . ☐ (ºC)			

SECTION 3: NEONATAL EVENT

*29. Respiratory support:

If < 12 hours = state 0.5 days

If > 12 to 24 hours = state 1 day

If > 24 hours = state to next completed days

Complete entry a) to d) for each type of respiratory support given

○ Yes →
○ No

a) CPAP done?	○ Yes ○ No	
	→ i) Early CPAP within 1 hour from birth:	○ Yes ○ No
	ii) Total duration of CPAP at your centre:	☐ . ☐ Day (s)
b) Conventional ventilation:	○ Yes ○ No	
	→ i) Total duration of Conventional ventilation at your centre:	☐ . ☐ Day (s)
c) HFJV/HFOV:	○ Yes ○ No	
	→ i) Total duration of HFJV//HFOV at your centre:	☐ . ☐ Day (s)
d) Nitric Oxide:	○ Yes ○ No	
	→ i) Total duration of Nitric Oxide at your centre:	☐ . ☐ Day (s)

*30.Total number of days on ventilation support at your centre:	☐☐☐ . ☐ (autocalculate)
*31. Surfactant:	○ Yes → ○ < 1 hr ○ 1-2 hrs ○ > 2 hrs ; ○ No
*32. Parenteral nutrition:	○ Yes ○ No

SECTION 4: PROBLEMS/ DIAGNOSES

33. Respiratory: ☐ Meconium aspiration syndrome ☐ Pulmonary haemorrhage ☐ Pneumonia ☐ Transient tachypnoea of newborn ☐ Pulmonary interstitial emphysema

*34. RDS: ○ Yes ○ No

*35. Pneumothorax: ○ Yes → Pneumothorax developed during: ○ Spontaneous ○ CPAP ○ CMV ○ HFV ; ○ No

*36. Supplemental oxygen and BPD:

a) Is baby on > 21% oxygen continuously for 28 days or more? ○ Yes ○ No

b) If Yes

(i) for < 32 weeks GA, baby still on oxygen / CPAP / ventilator support at 36 weeks corrected age?	○ Yes ○ No
(ii) for >= 32 weeks GA, baby still on oxygen / CPAP / ventilator support at day 56 of life?	○ Yes ○ No

*37. Cardiovascular PPHN: ○ Yes ○ No ○ Unknown

*38. PDA: ○ Yes → ; ○ No

a) ECHO done:	○ Yes ○ No
b) Indomethacin/Ibuprofen:	○ Yes ○ No
c) Ligation:	○ Yes ○ No

*39. NEC (stage 2 and above): ○ Yes → ; ○ No

a) surgical treatment:	○ Yes ○ No
b) NEC present before admission to your centre: (for outborn baby only)	○ Yes ○ No

*40. ROP Retinal Exam Done

○ Yes (If yes, worst stage of ROP):

a) Date of first screening:	☐☐ / ☐☐ / ☐☐
b) Post conceptional age at 1st screening:	☐☐ (autocalculate)
c) ○ No ROP ○ Stage 1 ○ Stage 2 ○ Stage 3 ○ Stage 4 ○ Stage 5 ☐ PLUS disease	
d) Laser Therapy:	○ Yes ○ No
e) Cryotherapy:	○ Yes ○ No
f) Vitrectomy:	○ Yes ○ No
g) ROP present prior to admission? (for outborn baby only)	○ Yes ○ No

○ No → Appointment given: ○ Yes ○ No ; Date of appointment ☐☐ / ☐☐ / ☐☐

○ Not Applicable

SECTION 4: PROBLEMS/ DIAGNOSES (continue)

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

***42. Seizures :** ○ Yes ○ No

***43. Central venous line:** ○ Yes ○ No

***44. Confirmed sepsis:** ○ Yes ○ No

(Blood culture positive only)

☐ ≤ 72 hours of life **II) Type of organism:** (can tick more than one)

☐ Group B Streptococcus ☐ Staphylococcus aureus ☐ Acinetobacter ☐ ESBL organisms
☐ MRSA ☐ Klebsiella ☐ Fungal ☐ E.Coli
☐ CONS ☐ Pseudomonas ☐ Others, specify: .....

☐ > 72 hours of life **II) Type of organism:** (can tick more than one)

☐ Group B Streptococcus ☐ Staphylococcus aureus ☐ Acinetobacter ☐ ESBL organisms
☐ MRSA ☐ Klebsiella ☐ Fungal ☐ E.Coli
☐ CONS ☐ Pseudomonas ☐ Others, specify: .....

***45. Neonatal meningitis:**

○ Yes
○ No

CSF Culture positive : ○ Yes ○ No

If Yes, type of organism: (can tick more than one)

☐ Group B Streptococcus ☐ Staphylococcus aureus ☐ Acinetobacter ☐ ESBL organisms
☐ MRSA ☐ Klebsiella ☐ Fungal ☐ E.Coli
☐ CONS ☐ Pseudomonas ☐ Others, specify: .....

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

***47. Congenital anomalies:**

***47a. Major congenital anomalies:** ○ Yes ○ No

○ Syndrome (known)
- ☐ Down
- ☐ Edward
- ☐ Patau
- ☐ Others, specify (Refer to ICD 10):

○ Not a recognized syndrome

○ Isolated major abnormality

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

☐ CVS → ○ Cyanotic ○ Acyanotic; ☐ ECHO done

☐ CNS →
- ○ Hydrocephalus
- ○ Hydrancephaly
- ○ Holoprosencephaly
- ○ Others (Refer to ICD 10):_____

☐ Neural Tube Defect →
- ○ Spina bifina
- ○ Anencephaly
- ○ Encephalocoele
- ○ Others (Refer to ICD 10):_____

☐ Skeletal dysplasia
☐ Respiratory
☐ GIT
☐ Hydrops
☐ Renal
☐ Cleft → ○ Lip ○ Palate ○ Lip and Palate
☐ Others, specify (Refer to ICD10):
☐ None of the above

SECTION 5: OUTCOME

*48a. Date of discharge / transfer/ death:(dd/mm/yy)	☐☐ / ☐☐ / ☐☐	48b. Time of Death: (24 hour format) (mandatory for death cases) ☐☐☐☐ (enter the best estimated time of death if the exact time is unknown)
*49. Weight and growth status on discharge: a) Weight:	☐☐☐☐ (grams)	
b) Growth status:	○ SGA ○ AGA ○ LGA	
*50. Feeding at discharge / death:	○ Never fed ○ Human milk only ○ Formula only ○ Human milk with Formula	
*51. Total duration of hospital stay (neonatal/ peads care):	☐☐☐ (in completed days) (autocalculate)	

*52. Outcome:

○ Alive →

Place discharged to:

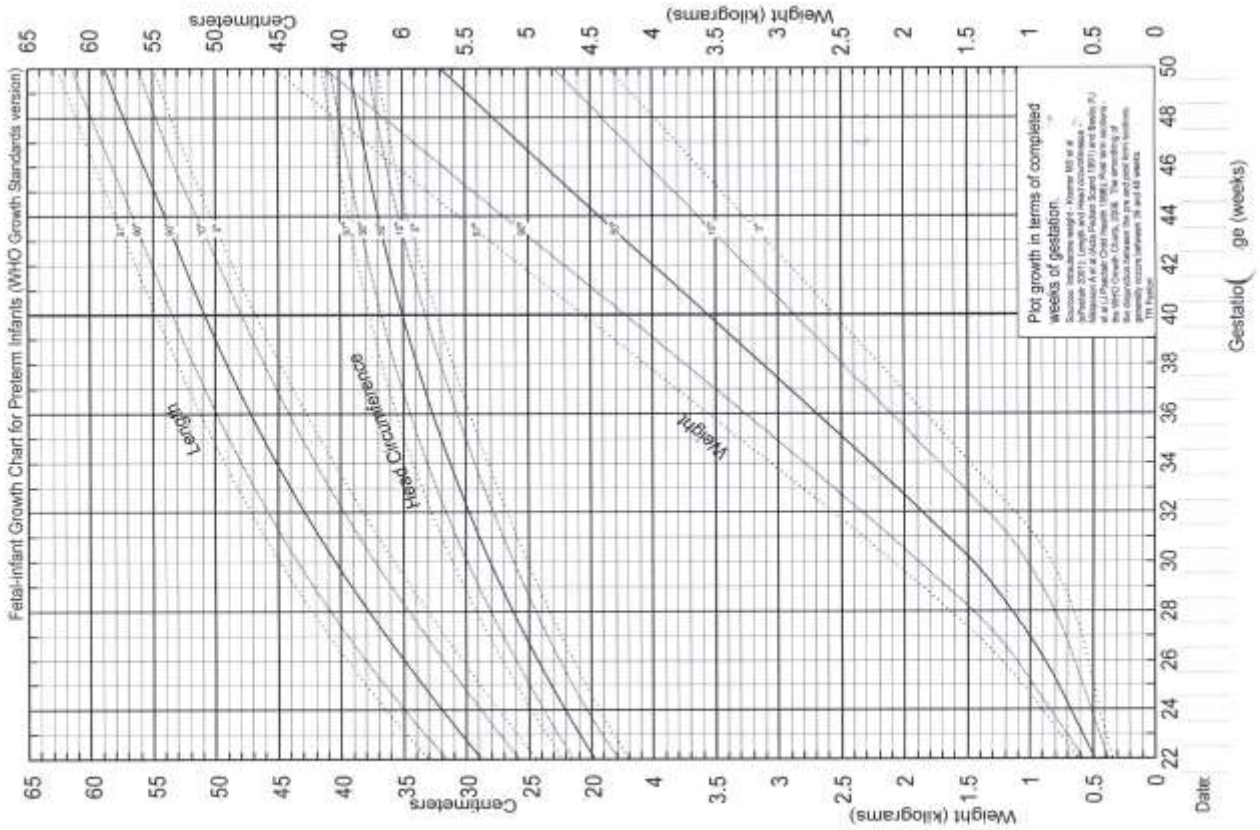
- ○ Home
- ○ Social welfare home
- ○ Other non Paeds ward
- ○ Still hospitalized as of 1st birthday
- ○ Transfer to other hospitals →

a) Name of hospital:	
b) Reason for transfer:	○ Growth/ stepdown care ○ Acute medical/ diagnostic services ○ Social/ Logistic reason ○ Lack of NICU bed ○ Chronic/ Palliative care ○ Surgery ○ Other, specify: .....
c) Post transfer disposition: (Please fill this section if place transferred is not part of the NNR Network)	○ Home ○ Death ○ Transferred again to another hospital ○ Readmitted to your hospital ○ Still in ward

○ Dead →

Place of death: ○ Labour room/OT ○ In transit ○ Neonatal unit ○ Others, specify: .....

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



Appendix 4a Supplementary Form (Death cases)

MALAYSIAN NATIONAL NEONATAL REGISTRY

Supplementary Form

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

1. Centre Name:			Office use: / Centre:
2. Name:		**3. RN:**	
4. Mother's I/C Number:	**New IC:**	**Passport:**	

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

NEONATAL DEATH
(Is there any LCM?)

Note: LCM = Lethal Congenital Malformation

- ○ LCM present
  - a) Lethal congenital malformation/defect, specify:
    - ○ Neural tube defects
      - ○ Anencephaly
      - ○ Encephalocoele
      - ○ Others,specify (Refer to ICD 10):
    - ○ CVS
      - ○ Complex/ cyanotic heart disease
      - ○ Acyanotic
    - ○ CNS
      - ○ Hydrocephalus
      - ○ Hydrancephaly
      - ○ Holoprosencephaly
      - ○ Others,specify (Refer to ICD 10):
    - ○ Recognisable syndrome
      - ○ Down
      - ○ Edward
      - ○ Patau
      - ○ Others,specify (Refer to ICD 10):
    - ○ Not recognisable syndrome
    - ○ Skeletal dysplasia
    - ○ Respiratory (eg. lung hypoplasia)
    - ○ GIT
    - ○ Hydrops foetalis
    - ○ Renal
    - ○ Others, specify:
- ○ LCM absent
  - b) (Is gestation <37 weeks?)
    - ○ Yes
      - c) Gestation <37 weeks conditions associated with immaturity
        - ○ IVH
        - ○ Septicaemia
        - ○ PDA in failure
        - ○ Pulmonary hemorrhage
        - ○ NEC
        - ○ Pneumonia
        - ○ PIE / BPD
        - ○ Pneumothorax
        - ○ Extreme prematurity
        - ○ Asphyxia
    - ○ No
      - Gestation ≥37 weeks (Did the baby have an asphyxial condition?)
        - ○ d) Asphyxial condition absent (Did the baby die from infection?)
          - ○ e) Infection present
            - ○ Group B streptococcal septicaemia
            - ○ Meningitis
            - ○ Congenital pneumonia
            - ○ Congenital Infection
            - ○ Others,specify
          - ○ Infection absent (Are there any other specific causes of death?)
            - ○ f) Other specific causes:
              - ○ Kernicterus/ severe neonatal jaundice
              - ○ Haemorrhagic disease of newborn/ Vitamin K deficiency
              - ○ Intracranial bleed / SAH
              - ○ Pneumothorax
              - ○ Pulmonary hemorrhage
              - ○ IEM
              - ○ MAS
              - ○ Surgical, specify:
              - ○ Others, specify:
            - ○ Unknown cause
        - ○ Asphyxial condition present

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

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MALAYSIAN NATIONAL NEONATAL REGISTRY (READMISSION FORM)

Centre Name: _____

Date of Admission: ☐☐☐ (dd/mm/yy)

MNNR No. (Office use): ☐☐☐☐ / ☐☐☐☐

Centre: ☐☐☐☐

SECTION 1 : PATIENT PARTICULARS & MATERNAL HISTORY

*1. Name of mother:	
2. Name of baby (Optional):	
*3. RN of baby:	
*4a. Mother's I/C number:	MyKad: ☐☐☐☐☐☐ - ☐☐ - ☐☐☐☐ Other ID document No: ☐☐☐☐☐☐☐☐☐☐☐☐ Specify document type (if others): ◯Passport ◯Armed Force ID ◯Driver's License ◯Old IC ◯Hospital RN ◯Father's I/C ◯Work Permit number ◯Police ID Card ◯Immigration permit ◯Other, specify:.....
4b. Baby's MyKid number:	☐☐☐☐☐☐ - ☐☐ - ☐☐☐☐
*5. Date of birth of baby: (dd/mm/yy)	☐☐ / ☐☐ / ☐☐☐☐
*6a. Birth weight:	☐☐☐☐ (grams) *6b. Gestation at birth: ☐☐ (weeks)

SECTION 2 : PARTICULARS OF THIS ADMISSION

*7. Date of first discharge: (dd/mm/yy)	☐☐ / ☐☐ / ☐☐☐☐
*8. Age at readmission:	☐☐☐ (days) (autocalculate)
*9. Weight at this readmission:	☐☐☐☐ (grams)
*10. Reason for readmission:	☐ Apnoea ☐ LRTI ☐ Confirmed sepsis ☐ Others, Specify:..... ☐ Fever ☐ Poor weight gain ☐ Jaundice ☐ URTI ☐ Cyanosis due to sucking / swallowing incoordination
*11. Ventilated:	◯ Yes → (fill in main CRF section 3&4) ◯ No

SECTION 5: OUTCOME

*48a. Date of discharge / transfer/ death: (dd/mm/yy)	☐☐ / ☐☐ / ☐☐	48b. Time of Death: (24 hour format) (mandatory for death cases) ☐☐☐☐ (enter the best estimated time of death if the exact time is unknown)
*49. Weight and growth status on discharge:	a) Weight: ☐☐☐☐ (grams)	
	b) Growth status: ◯ SGA ◯ AGA ◯ LGA	
*50. Feeding at discharge / death:	◯ Never fed ◯ Human milk only ◯ Formula only ◯ Human milk with formula ◯ No data / Unki	
*51. Total duration of hospital stay (neonatal/ peads care):	☐☐☐ (in completed days) (autocalculate)	

*52. Outcome:

◯ Alive →

Place discharged to:

- ◯ Home
- ◯ Social welfare home
- ◯ Other non Paeds ward
- ◯ Still hospitalized as of 1st birthday
- ◯ Transfer to other hospitals →

a) Name of hospital:	
b) Reason for transfer:	◯ Growth/ stepdown care ◯ Acute medical/ diagnostic services ◯ Social/ Logistic reason ◯ Lack of NICU bed ◯ Other, specify: ..... ◯ Chronic/ Palliative care ◯ Surgery
c) Post transfer disposition: (Please fill this section if place transferred is not part of the NNR Network)	◯ Home ◯ Transferred again to another hospital ◯ Death ◯ Readmitted to your hospital ◯ Still in ward

◯ Dead →

Place of death: ◯ Labour room / OT ◯ Neonatal unit ◯ In transit ◯ Others, specify: .....

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

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Appendix 5 Presentations

POSTER, ABSTRACT AND PAPER PRESENTIONS

1. Neoh SH. *COD in preterm infants 2014.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, 2015

2. Neoh SH. *Survival of babies in MNNR.*Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, 2015

3. Boo NY.*Impact of early CPAP therapy on outcome of VLBW.*Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, 2015

4. Chee SC. *CLD 2014.*Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, 2015

5. Lee JKF.*Morbidity in ELBW.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, 2015

6. Cheah IGS. *ROP Screening.*Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, 2015

7. Cheong HK. *Preterm babies 32 -34 weeks in Ipoh Hospital.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, 2015