REPORT OF THE MALAYSIAN NATIONAL NEONATAL REGISTRY 2016

A STUDY OF CRITICALLY ILL BABIES IN NEONATAL INTENSIVE CARE UNITS

EDITOR:

- Neoh Siew Hong

WITH CONTRIBUTIONS FROM:

- Boo Nem Yun
- Chee Seok Chiong
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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.

June 2019

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CONTENTS

Report of the Malaysian National Neonatal Registry (MNNR) 2016

1. Organization of the MNNR

1.1 Objectives

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

The Malaysian NNR aims:

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

1.2 Structure

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

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

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

1.3 Funding

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

2. Data Set

2.1 Participating Centres in 2016:

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. Hospital Tuanku Ja'afar, Seremban, Negeri Sembilan
42. Hospital Universiti Sains Malaysia, Kubang Kerian, Kelantan
43. 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 or high flow nasal cannula)
   4. Had hypoxic ischaemic encephalopathy (HIE) with or without requirement of ventilatory support.
   5. With confirmed sepsis i.e positive blood and/or 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

SUMMARY

The inclusion criteria for this study in 2016 were all preterm babies below 32 weeks gestational age, those of birth weight below or equal to 1500 g, all babies who required mechanical ventilation and/or nasal positive airway pressure (nCPAP) and/or high flow nasal canula (HFNC), all babies with hypoxic ischaemic encephalopathy (HIE), all babies with confirmed sepsis (positive blood and/or CSF culture) and all neonatal deaths (babies < 28 days old who died in Neonatal Unit, Obstetric Department and other wards). Both inborn and outborn babies were included.

Results:

- In 2016, there were 43 participating hospitals. There was a total of 302,539 livebirths in the 40 of the 43 participating centres that have submitted birth census.

- A total of 14638 babies who were in level III NICUs met the study criteria, 12858 (87.8%) were inborn whilst 1780 (12.2%) were outborn babies (Figure 1 & Table 1).

- There were 3413 babies (23.3%) below 32 weeks gestational age (Figure 2 and Table 2).

- Three thousand seven hundred and thirty eight babies (25.5%) were of birth weights of 1500 g and below (Figure 3 and Table 3).

- The survival rates of very preterm babies admitted to MNNR according to gestational age were 19.2% for 24 weeks, 36.6% for 25 weeks, 54.4% for 26 weeks, 72.2% for 27 weeks, 81.4% for 28 weeks, 87.8% for 29 weeks, 90.2% for 30 weeks and 92.5% for 31 weeks (Figure 4 and Table 4)

- The survival rates of babies admitted to MNNR according to birth weight category were 2.2% for $\leq$ 500 g, 57.9% for 501-1000 g, 89.2% for 1001-1500 g, 92.1% for 1501-2500 g and 92.4% for >2500 g. For the category > 1500 g birth weight, calculated survival rate does not include all live births in that category *(see inclusion criteria)* (Figure 5 and Table 5)

- In 2016, 74.5% of mothers who were less than 32 weeks gestation received antenatal steroids. It was given to mothers of 77.8% of inborn babies and 43.6% of outborn babies below 32 weeks gestation. There were marked differences in the use of antenatal steroids across centres for inborns who were less than 32 weeks gestation, varying from 50.0% to 96.3% (Table 6)

- Early nCPAP at initial resuscitation was given to 52.0% of inborn babies <32 weeks gestational age.

- Thirteen thousand seven hundred and ninety four babies (94.0% of the overall cohort) required respiratory support in NICU. Of these, 8247 (59.8%) were ventilated, 6731 had conventional ventilation, 290 had high frequency ventilation and 1226 had both conventional and high frequency ventilation. A total of 10,456 babies received nasal continuous positive airway pressure (nCPAP). nCPAP as the only mode of respiratory support was given to 5343 babies. Two thousand four hundred and eighty three babies were given heated humidified high flow nasal canula (HHHFNC) therapy.

- Eighty eight percent (3299/3751) of babies with birth weight of 1500 g and below required respiratory support, 26.3% (985/3751) had nCPAP as the only mode of respiratory support.

- Surfactant was given to a total of 3607 babies. Fifty four percent (2014/3751) of babies with birth weight of 1500 g and below were treated with surfactant for respiratory distress syndrome. Sixty one percent (2085/3423) of preterm babies below 32 weeks gestational age and 24% (1252/5234) between 32 and 36 weeks gestational age in the cohort had surfactant therapy.

- The rates of chronic lung disease for babies < 32 weeks who survived to Day 28 and 36 weeks post-conceptional age were 68.2% and 68.4% respectively for babies between 22-24 weeks gestational age, 58.1% and 54.1% respectively for babies between 25-27 weeks gestational age, and 16.0% and 16.9% respectively for babies between 28-31 weeks gestational age (Figure 8 and Table 8).

- The rates of chronic lung disease for babies with birth weight <1500g who survived to Day 28 and 36 weeks post-conceptional age were 68.4% and 54.7% respectively for babies with birth weight < 750 g, 45.3% and 37.8% respectively for babies with birth weight 750-999g, 19.1% and 16.0% respectively for babies with birth weight 1000-1249 g and, 8.1% and 3.7% respectively for babies with birth weight 1250-1499 g (Figure 9 and Table 9).

- Five hundred babies or 3.4% of the entire cohort had pneumothorax.

- The incidence rate for ventilated meconium aspiration syndrome (MAS) was 3.9 per 1000 live births. There were a total of 1203 inborn and 182 outborn babies ventilated for MAS. The overall mortality for babies ventilated for MAS was 7.4%. The mortality rates for inborn and outborn babies ventilated for MAS were 7.0% and 9.9% respectively.

- A total of 902 babies had persistent pulmonary hypertension of the newborn (PPHN) with an overall mortality rate of 30.4%. A total of 214 (23.7%) babies with PPHN received inhaled nitric oxide.

- Patent ductus arteriosus (PDA) was diagnosed in 877 (29.5%) inborn babies with gestational age <32 weeks admitted to the NICUs. Overall 35.9% and 0.9% of the 877 babies were treated with indomethacin/ibuprofen and PDA ligation respectively (Figure 10 and Table 10).

- Among the 1823 inborn babies with gestational age < 32 weeks who underwent ROP screening before discharge, 1572 (86.2%) did not have ROP, 203 (11.1%) had ROP Stage 1&2, 43(2.4%) had ROP stage 3 and 5 (0.3%) had ROP stage 4&5. The incidence rates of ROP Stage 3 in this cohort were 28.6%, 5.3% and 1.2% in babies with gestational age of 22-24 weeks, 25-27 weeks and 28-31 weeks respectively. Two of the babies with Stage 4 & 5 ROP were between 25-27 weeks geatational age and 3 were between 28-31 weeks. A total of 35 babies had laser therapy and 1 baby had cryotherapy (Figure 12 and Table 12).

- A total of 1945 (76.7%) inborn babies with birth weight <1500g were screened for ROP before discharge. One thousand six hundred and ninety two (87.0%) of those screened did not have ROP. Two hundred and nine (10.7%) had ROP Stage 1 & 2, 40 (2.1%) had ROP Stage 3 and 4 (0.2%) had ROP Stage 4&5. The incidence rates of ROP Stage 3 in this cohort were 12.5%, 4.1%, 1.5% and 0.1% in babies with birth weight <750g, 750-999g, 1000-1249g and 1250-1499g respectively. Two of the babies with Stage 4 & 5 ROP were <750g and 2 were between 1000-1249g. (Figure 13 and Table 13).

- Among the 2816 inborn babies with gestational age < 32 weeks who underwent cranial ultrasound examination, 1818 (64.6%) did not have intraventricular haemorrhage, 762 (27.1%) had Grade 1 or 2 intraventricular haemorrhage (IVH), 155 (5.5%) had Grade 3 IVH and 81 (2.9%) had Grade 4 IVH. The incidence rates of Grade 3 IVH were 14.3%, 15.4% and 2.4% in babies with gestational age of 22-24 weeks, 25-27 weeks and 28-31 weeks respectively. The incidence rates of Grade 4 IVH were 15.5%, 6.5% and 1.4% in babies with gestational age of 22-24 weeks, 25-27 weeks and 28-31 weeks respectively. (Figure 14 and Table 14).

- Two thousand nine hundred and eighteen (93.9%) of inborn babies with birth weight < 1500 g had cranial ultrasound examination. Among those screened, 65.8% did not have intraventricular haemorrhage (IVH). The incidence rates of Grade 3 IVH were 12.8%, 10.5%, 4.5% and 1.5% in babies with birth weight <750 g, 750-999 g, 1000-1249 g and 1250-1499 g respectively. The incidence rates of Grade 4 IVH were 9.4%, 5.9%, 2.4% and 0.2% in babies with birth weight <750 g, 750-999 g, 1000-1249 g and 1250-1499 g respectively (Figure 15 and Table 15).

- One hundred and fifty eight (5.3%) of the inborn babies with gestational age <32 weeks developed necrotizing enterocolitis (NEC), 19% of them required surgery. The incidence rates of NEC were 3.1%, 10.1% and 4.1% for babies with gestational age of 22-24 weeks, 25-27 weeks and 28-31 weeks respectively (Figure 16 and Table 16).

- The incidence rates of NEC among inborn babies by birth weight were 8.5%, 9.2%, 5.5% and 3.2% in the <750 g, 750-999 g, 1000-1249 g and 1250-1499 g categories respectively (Figure 17 and Table 17).

- The incidence of blood culture positive early onset sepsis among inborn babies with gestational age < 32 weeks was 1.6%. The incidence was highest (3.0%) in babies with gesational age 25-27 weeks (Figure 18 and Table 18).

- One hundred and sixty two (6.8%) of inborn babies with gestational age < 32 weeks who survived more than 3 days had one or more episodes of blood culture positive late onset sepsis. The late onset sepsis rates were 25%, 16.4% and 4.7% in the 22-24 weeks, 25-27 weeks and 28-31 weeks gestational age categories respectively (Figure 19 and Table 19).

- The incidence rates for blood culture postive late onset sepsis by birth weight categories were 17.3%, 12.8%, 7.9% and 2.9% for <750g, 750-999g, 1000-1249g and 1250-1499g respectively (Figure 20 an Table 20).

- The number of major morbidities (PDA requiring surgical ligation, stage 3/4/5 ROP, oxygen dependency at 36 weeks or discharge, confirmed sepsis, NEC) among survivors was analysed. Among survivors with gestational age of 22-24 weeks, 29.2% had 1 morbidity, 33.3% had 2 morbidities, 4.2% had 3 morbidities, 33.3% did not

have any of the 5 morbidities. Among survivors with gestational age of 25-27 weeks, 41.2% had 1 morbidity, 14.0% had 2 morbidities, 2.9% had 3 morbidities, 42.0% did not have any of the 5 morbidities. Among survivors with gestational age of 28-31 weeks, 12.9% had 1 morbidity, 2.2% had 2 morbidities, 0.3% had 3 morbidities, 0.1% had 4 morbidities, 84.6% did not have any of the 5 morbidities (Table 21a).

- Among survivors with birth weight < 750g, 35.4% had 1 morbidity, 26.7% had 2 morbidities, 5.1% had 3 morbidities, 1.0% had 4 morbidities, 36.4% did not have any of the 5 morbidities. Among survivors with birth weight 750-999g, 33.5% had 1 morbidity, 8.9% had 2 morbidities, 2.1% had 3 morbidities, 54.0% did not have any of the 5 morbidities. Among survivors with birth weight 1000-1249g, 18.6% had 1 morbidity, 2.9% had 2 morbidities, 0.4% had 3 morbidities, 77.3% did not have any of the 5 morbidities. Among survivors with birth weight 1250-1499g, 8.3% had 1 morbidity, 1.0% had 2 morbidities, 0.1% had 3 morbidities, 91.3% did not have any of the 5 morbidities. (Table 21b).

Study recommendations include collaboration with Obstetrics and Primary Healthcare staff:

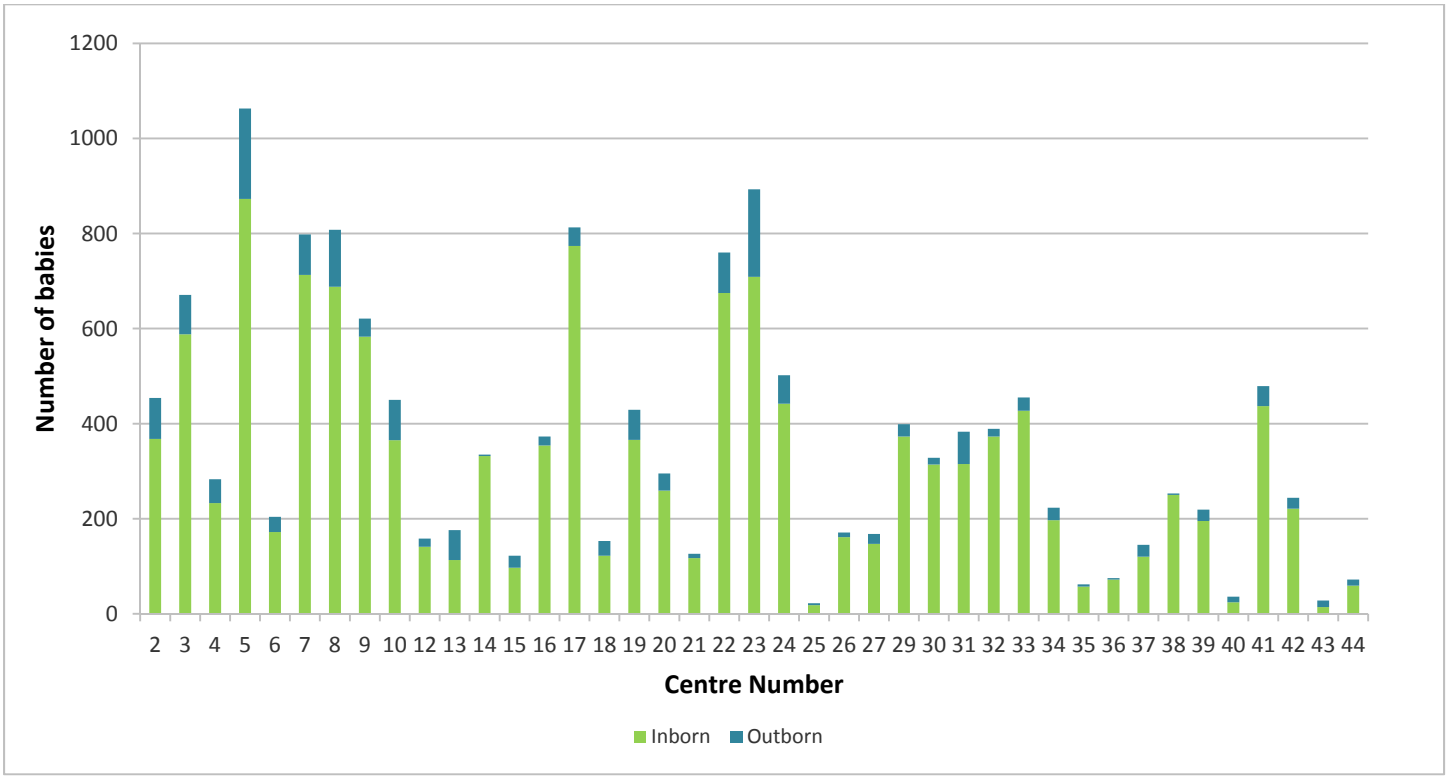
- To enhance the use of antenatal steroids and continue with in-utero transfer of high-risk pregnancies.
- To study factors contributing to preterm deliveres and implement measures to reduce such deliveries.
- To reduce the number of post term deliveries and to reduce the risk of thick meconium stained liquor.

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

Figure 1

Number of babies according to place of birth



COMMENT: There were 12858 inborn babies and 1780 outborn babies in the MNNR.

Table 1: Number of babies according to place of birth

Hospitals		Place of Birth		Total
		Inborn	Outborn	
2	n	368	86	454
	(%)	(81.1)	(18.9)	(100)
3	n	588	83	671
	(%)	(87.6)	(12.4)	(100)
4	n	233	50	283
	(%)	(82.3)	(17.7)	(100)
5	n	873	190	1063
	(%)	(82.1)	(17.9)	(100)
6	n	172	32	204
	(%)	(84.3)	(15.7)	(100)
7	n	713	85	798
	(%)	(89.3)	(10.7)	(100)
8	n	688	120	808
	(%)	(85.1)	(14.9)	(100)
9	n	583	38	621
	(%)	(93.9)	(6.1)	(100)
10	n	365	85	450
	(%)	(81.1)	(18.9)	(100)
12	n	141	17	158
	(%)	(89.2)	(10.8)	(100)
13	n	113	63	176
	(%)	(64.2)	(35.8)	(103)
14	n	332	3	335
	(%)	(99.1)	(0.9)	(100)
15	n	97	25	122
	(%)	(79.5)	(20.5)	(100)
16	n	354	19	373
	(%)	(94.9)	(5.1)	(100)
17	n	774	39	813
	(%)	(95.2)	(4.8)	(100)
18	n	122	31	153
	(%)	(79.7)	(20.3)	(100)

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

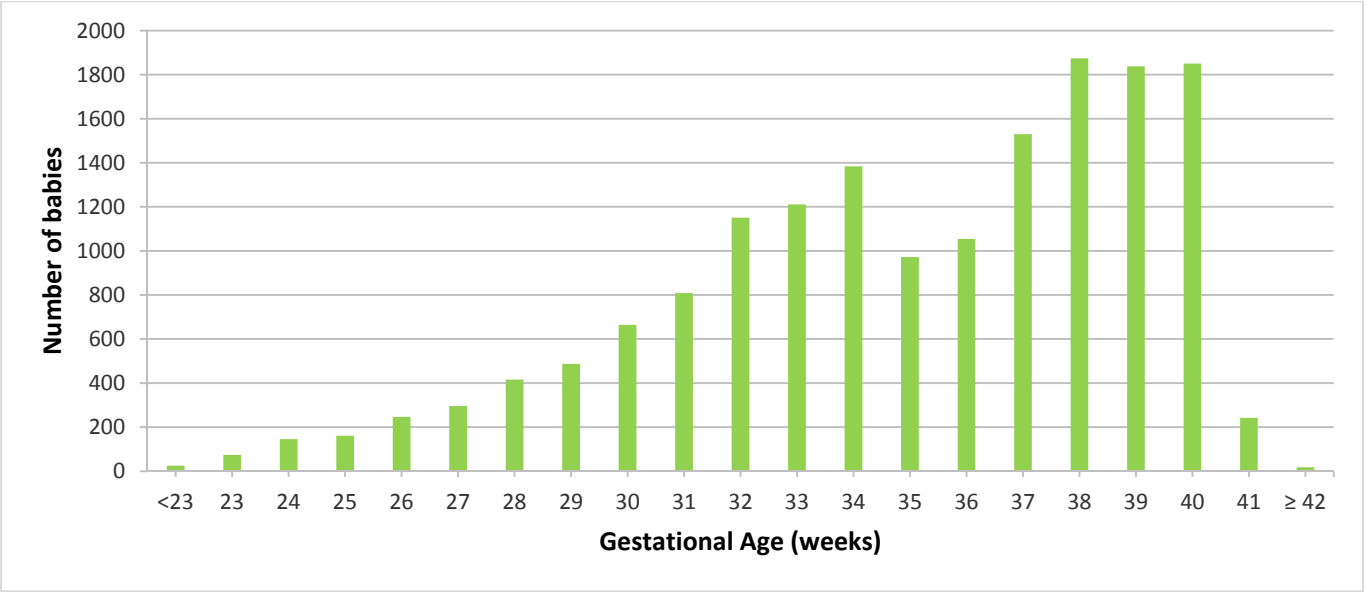
Hospitals		Place of Birth		Total
		Inborn	Outborn	
19	n	366	63	429
	(%)	(85.3)	(14.7)	(100)
20	n	259	36	295
	(%)	(87.8)	(12.2)	(100)
21	n	117	9	126
	(%)	(92.9)	(7.1)	(100)
22	n	675	85	760
	(%)	(88.8)	(11.2)	(100)
23	n	709	184	893
	(%)	(79.4)	(20.3)	(100)
24	n	442	60	502
	(%)	(88.0)	(12.0)	(100)
25	n	18	4	22
	(%)	(81.8)	(18.2)	(100)
26	n	161	10	171
	(%)	(94.2)	(5.8)	(100)
27	n	147	21	168
	(%)	(87.5)	(12.5)	(100)
29	n	373	26	399
	(%)	(93.5)	(6.5)	(100)
30	n	314	14	328
	(%)	(95.7)	(4.3)	(100)
31	n	315	68	383
	(%)	(82.2)	(17.8)	(100)
32	n	373	16	389
	(%)	(93.8)	(4.1)	(100)
33	n	427	28	455
	(%)	(96.6)	(6.2)	(100)
34	n	197	26	223
	(%)	(88.3)	(11.7)	(100)
35	n	57	5	62
	(%)	(91.9)	(8.1)	(100)
36	n	72	3	75
	(%)	(96.0)	(4.0)	(100)

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

Hospitals		Place of Birth		Total
		Inborn	Outborn	
37	n	120	25	145
	(%)	(82.8)	(17.2)	(100)
38	n	250	3	253
	(%)	(98.8)	(1.2)	(100)
39	n	195	24	219
	(%)	(89.0)	(11.0)	(100)
40	n	24	12	36
	(%)	(66.7)	(33.3)	(100)
41	n	437	42	479
	(%)	(91.2)	(8.8)	(100)
42	n	221	23	244
	(%)	(90.6)	(9.4)	(100)
43	n	14	14	28
	(%)	(50.0)	(50.0)	(100)
44	n	59	13	72
	(%)	(81.9)	(18.1)	(100)
TOTAL	**n**	**12858**	**1780**	**14638**
	(%)	**(87.8)**	**(12.2)**	**(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	37	0.3
23	51	0.3
24	99	0.7
25	164	1.1
26	248	1.7
27	309	2.1
28	484	3.3
29	482	3.3
30	704	4.8
31	835	5.7
32	1145	7.8
33	1092	7.5
34	1176	8.0
35	825	5.6
36	982	6.7
37	1170	8.0
38	1529	10.4
39	1506	10.3
40	1614	11.0
41	171	1.2
≥ 42	15	0.1
Total included	14638	100
Total no. of babies with missing gestational age	0	
Total no. of babies	14638	

Figure 3

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

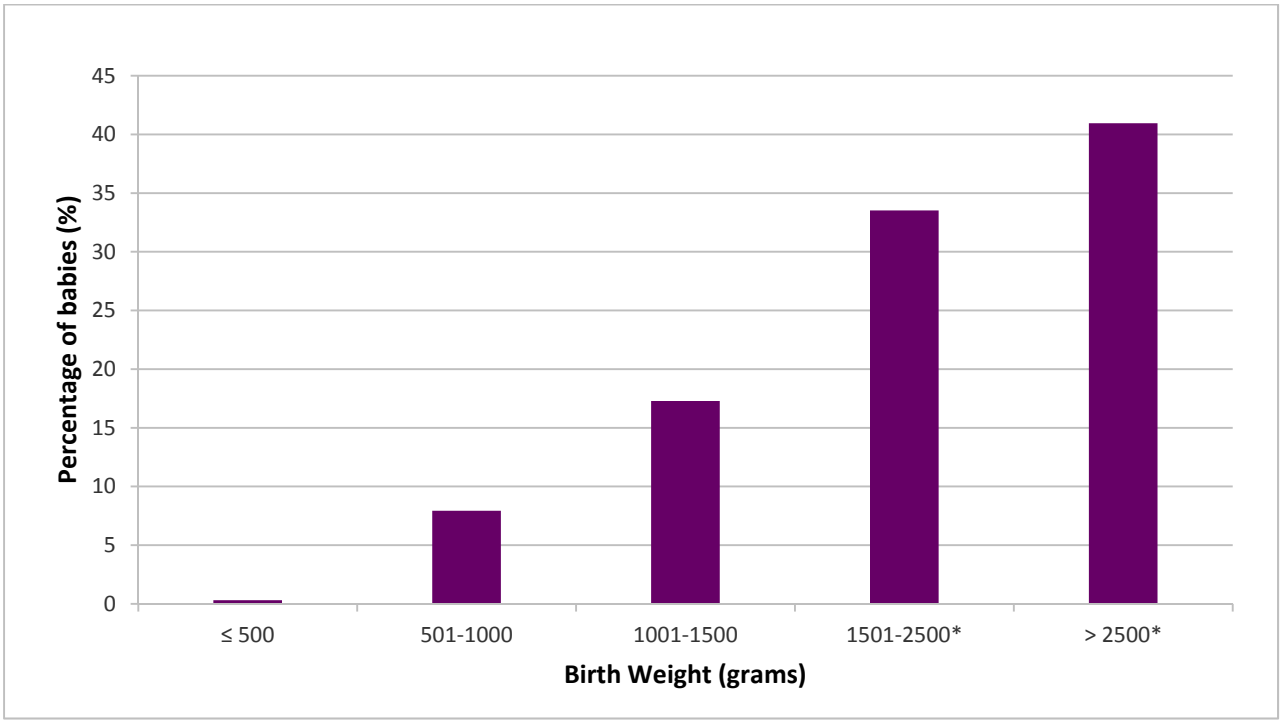


Table 3 :
Frequency distribution of all babies in MNNR according to birth weight (BW) categories

Birth weight (grams)	Frequency	Percent from total number of babies
≤ 500	46	0.3
501-1000	1161	7.9
1001-1500	2531	17.3
1501-2500*	4906	33.5
< 2500	5994	40.9
Total included	14638	100.0
Total no. of babies with missing birth weight	0	
Total no. of babies	14638	

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

Figure 4

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

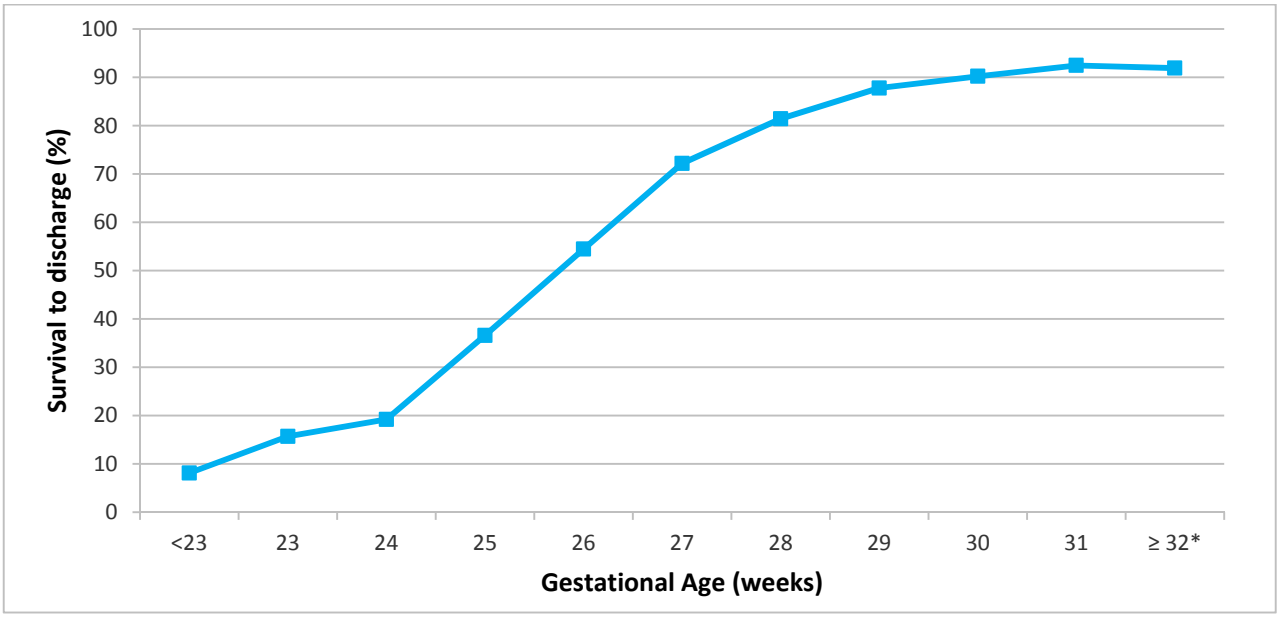


Table 4 :
Survival to discharge of all live births admitted to MNNR hospitals according to gestational age

Gestational age (completed weeks)	Total number of inborn & outborn babies	Number of survivors	% survival
<23	37	3	8.1
23	51	8	15.7
24	99	19	19.2
25	164	60	36.6
26	248	135	54.4
27	309	223	72.2
28	484	394	81.4
29	482	423	87.8
30	704	635	90.2
31	835	772	92.5
≥32*	11225	10314	91.9
Total included	14638	12986	88.7
Total no. of missing (GA)	0		
Total babies	14638		

*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

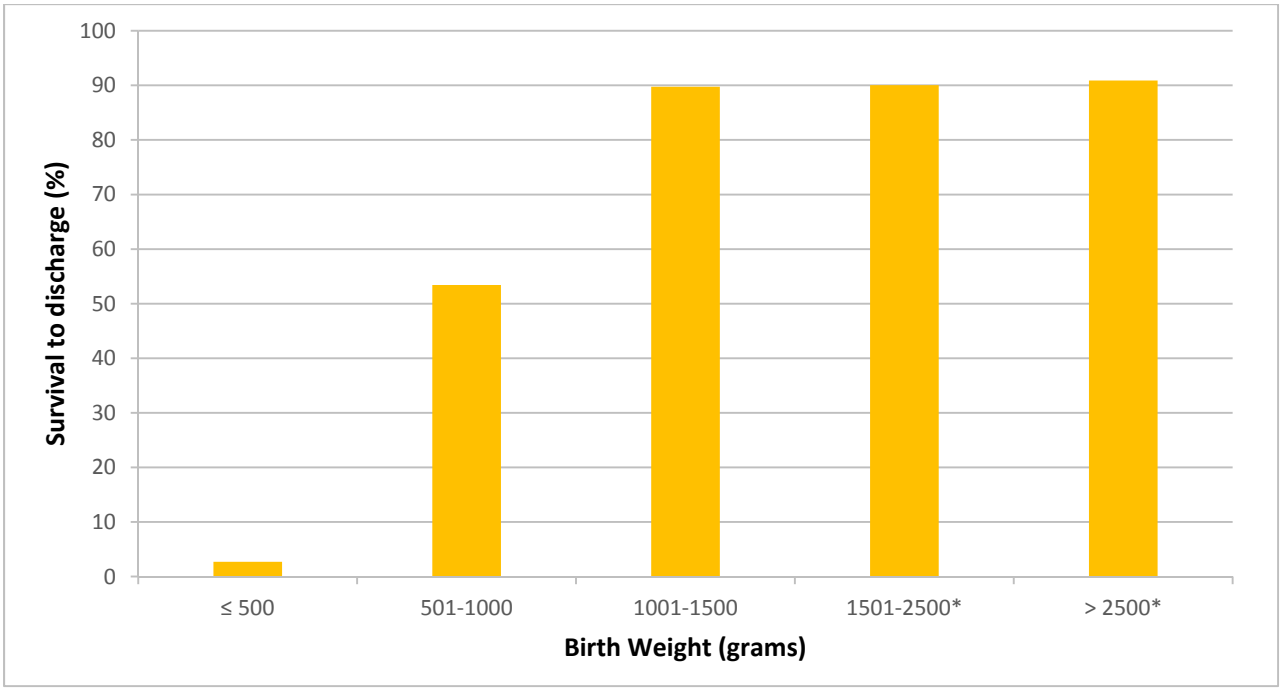


Table 5 :
Survival to discharge of all babies admitted to MNNR hospitals according to birth weight categories

Birth weight (grams)	Total number of inborn & outborn babies	Number of survivors	% survivors
≤500	46	1	2.2
501-1000	1161	672	57.9
1001-1500	2531	2258	89.2
1501-2500*	4906	4519	92.1
>2500*	5994	5536	92.4
Total included	14638	12986	88.7
Total no. of missing (BW)	0		
Overall Total babies	14638		

*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 age according to centres

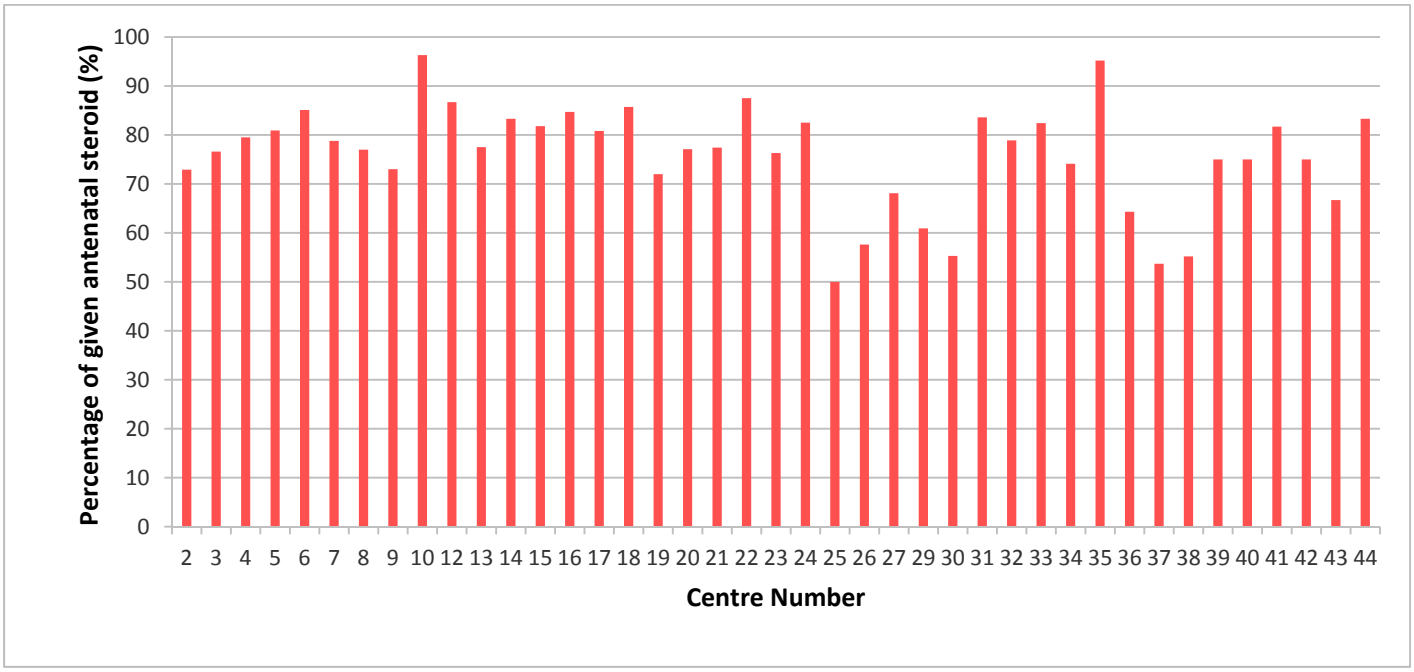


Figure 6b:

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

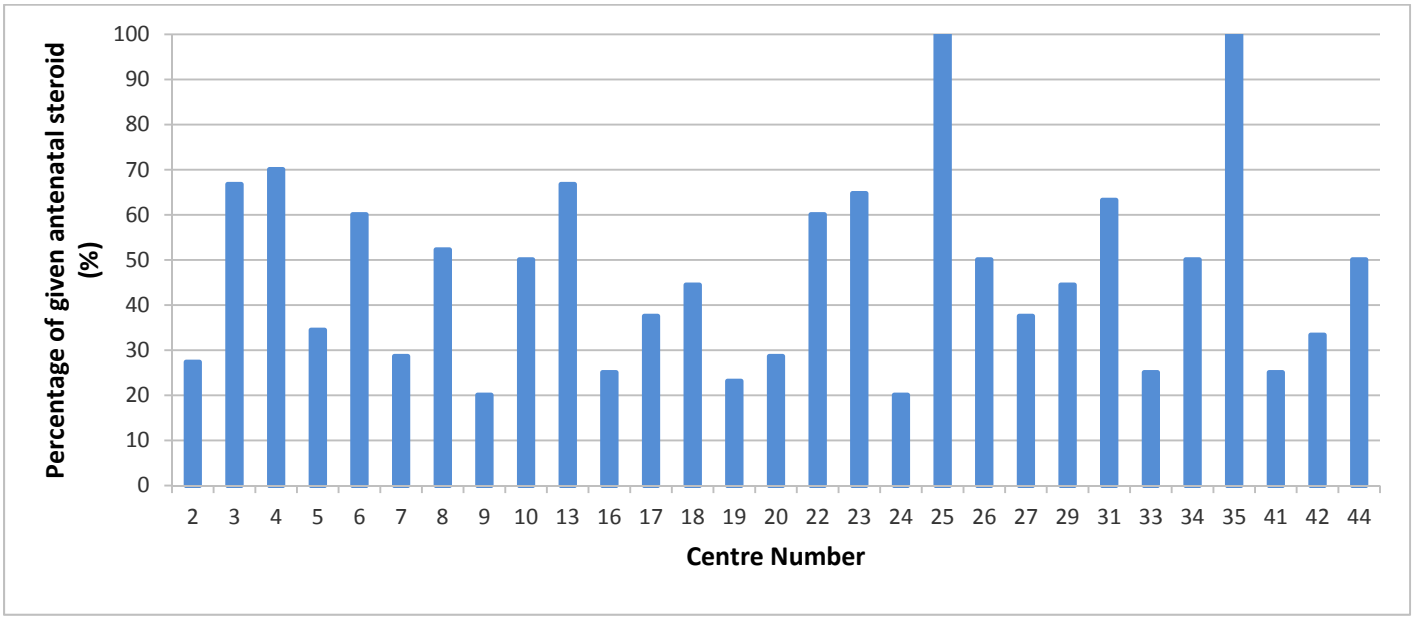


Table 6:
Antenatal corticosteroid for all babies born at < 32 weeks gestational age according to centres

Hospitals	Inborn			Outborn		
	Total number of babies	Given Antenatal Steroid		Total number of babies	Given Antenatal Steroid	
	n	*n*	%	*n*	*n*	%
Overall	3063	2383	77.8	330	144	43.6
2	59	43	72.9	11	3	27.3
3	175	134	76.6	15	10	66.7
4	44	35	79.5	10	7	70.0
5	220	35	80.9	32	11	34.4
6	47	40	85.1	5	3	60.0
7	208	164	78.8	14	4	28.6
8	161	124	77.0	23	12	52.2
9	111	81	73.0	5	1	20.0
10	54	52	96.3	14	7	50.0
12	45	39	86.7	2	0	0.0
13	40	31	77.5	15	10	66.7
14	60	50	83.3	0	0	0.0
15	33	27	81.8	0	0	0.0
16	124	105	84.7	8	2	25.0
17	120	97	80.8	8	3	37.5
18	35	30	85.7	9	4	44.4
19	100	72	72.0	13	3	23.1

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	70	54	77.1	7	2	28.6
21	31	24	77.4	3	0	0.0
22	104	91	87.5	20	12	60.0
23	160	122	76.3	17	11	64.7
24	177	146	82.5	25	5	20.0
25	4	2	50.0	2	2	100.0
26	33	19	57.6	2	1	50.0
27	47	32	68.1	8	3	37.5
29	115	70	60.9	9	4	44.4
30	38	21	55.3	1	0	0.0
31	122	102	83.6	19	12	63.2
32	90	71	78.9	1	0	0.0
33	91	75	82.4	4	1	25.0
34	27	20	74.1	4	2	50.0
35	21	20	95.2	1	1	100.0
36	28	18	64.3	1	0	0.0
37	41	22	53.7	3	0	0.0
38	29	16	55.2	1	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	44	33	75.0	2	0	0.0
40	4	3	75.0	1	0	0.0
41	104	85	81.7	12	3	25.0
42	44	33	75.0	3	1	33.3
43	3	2	66.7	0	0	0.0
44	12	10	83.3	8	4	50.0

Figure 7a

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

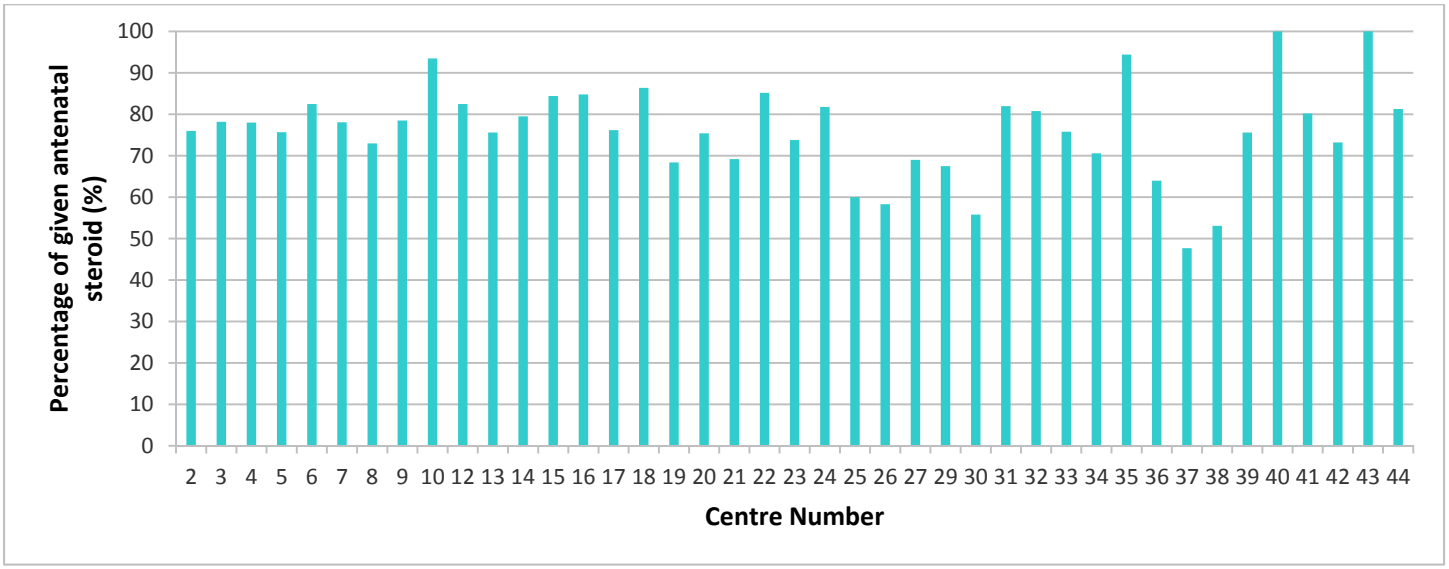


Figure 7b

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

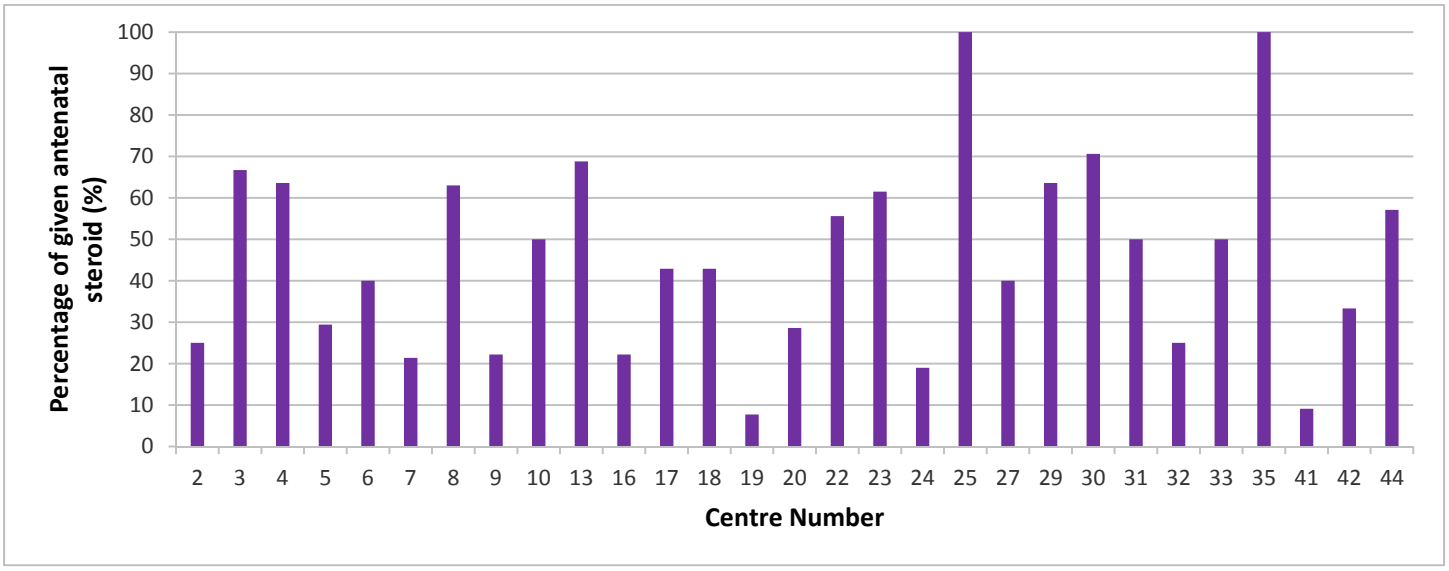


Table 7 :
Antenatal corticosteroid for all babies born at ≤ 1500 grams birth weight according to centres

Hospitals	Inborn			Outborn		
	Total number of babies	Given Antenatal Steroid		Total number of babies	Given Antenatal Steroid	
	n	*N*	%	*n*	*n*	%
Overall	3375	2583	76.5	363	152	41.9
2	75	57	76.0	12	3	25.0
3	188	147	78.2	15	10	66.7
4	59	46	78.0	11	7	63.6
5	263	199	75.7	34	10	29.4
6	57	47	82.5	5	2	40.0
7	224	175	78.1	14	3	21.4
8	189	138	73.0	27	17	63.0
9	135	106	78.5	9	2	22.2
10	77	72	93.5	20	10	50.0
12	40	33	82.5	2	0	0.0
13	45	34	75.6	16	11	68.8
14	78	62	79.5	0	0	0.0
15	32	27	84.4	1	0	0.0
16	125	106	84.8	9	2	22.2
17	126	96	76.2	7	3	42.9
18	44	38	86.4	7	3	42.9
19	98	67	68.4	13	1	7.7

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	69	52	75.4	7	2	28.6
21	39	27	69.2	3	0	0.0
22	108	92	85.2	18	10	55.6
23	168	124	73.8	26	16	61.5
24	170	139	81.8	21	4	19.0
25	5	3	60.0	1	1	100.0
26	48	28	58.3	0	0	0.0
27	58	40	69.0	10	4	40.0
29	114	77	67.5	11	7	63.6
30	43	24	55.8	17	12	70.6
31	128	105	82.0	2	1	50.0
32	104	84	80.8	4	1	25.0
33	91	69	75.8	6	3	50.0
34	34	24	70.6	0	0	0.0
35	18	17	94.4	1	1	100.0
36	25	16	64.0	1	0	0.0
37	44	21	47.7	7	0	0.0
38	32	17	53.1	2	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	45	34	75.6	2	0	0.0
40	3	3	100.0	1	0	0.0
41	116	93	80.2	11	1	9.1
42	41	30	73.2	3	1	33.3
43	1	1	100.0	0	0	0.0
44	16	13	81.3	7	4	57.1

Figure 8

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

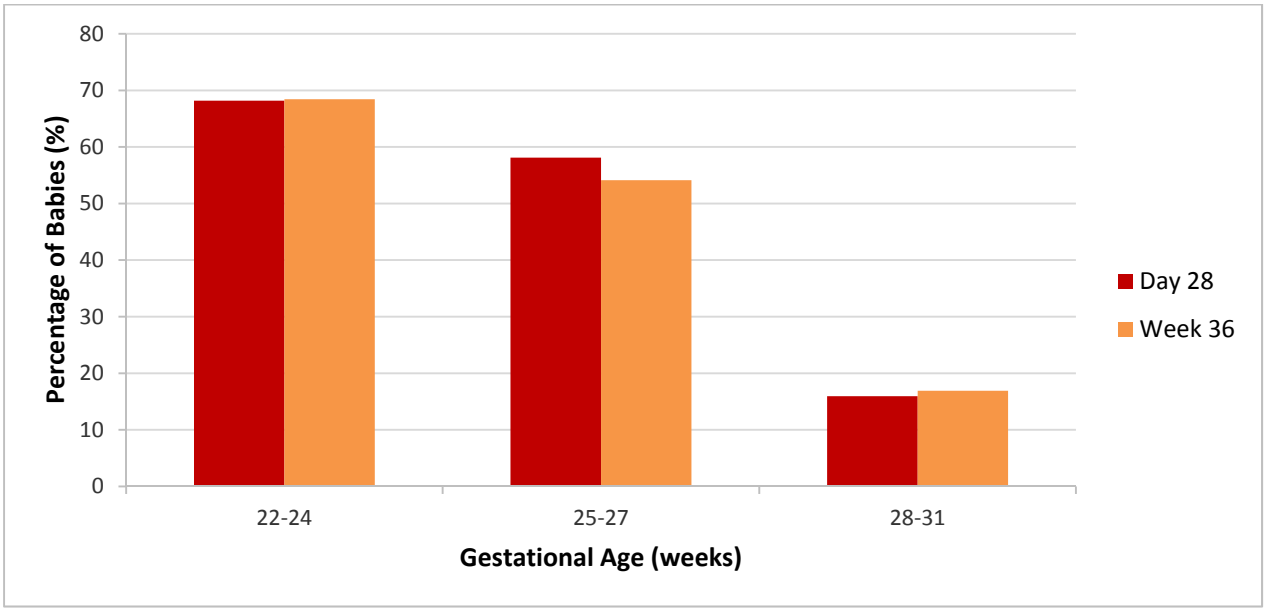


Table 8 :
Incidence of oxygen dependency among admitted inborn babies with gestational age < 32 weeks

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*	129	22	15	19	13
	%	4.3	17.1	68.2	14.7	68.4
25-27	*n*	626	370	215	292	158
	%	21.1	59.1	58.1	46.6	54.1
28-31	*n*	2217	1630	260	953	161
	%	74.6	73.5	16.0	43.0	16.9
Total included	*n*	2972	2022	490	1264	332
	%	100	68.0	24.2	42.5	26.3
Total no. of missing (GA)		0				
Total babies		2972				

Figure 9

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

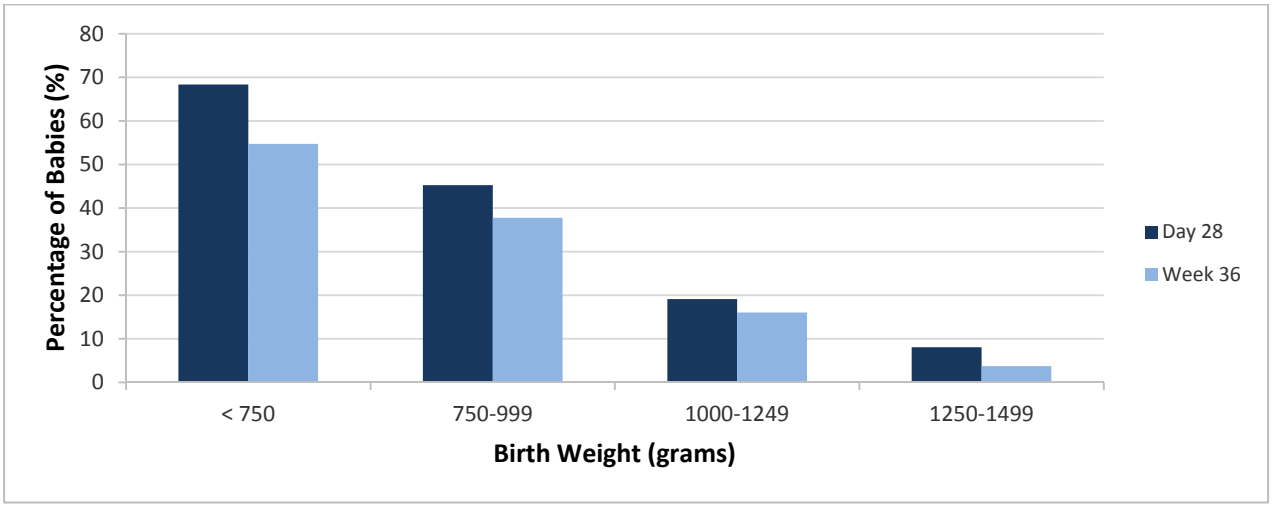


Table 9:
Incidence of oxygen dependency among admitted inborn babies with birth weight ≤ 1500 grams

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*	293	98	67	95	52
	%	9.4	33.4	68.4	32.4	54.7
750-999	*n*	639	433	196	389	147
	%	20.6	67.8	45.3	60.9	37.8
1000 – 1249	*n*	934	768	147	574	92
	%	30.1	82.2	19.1	61.5	16.0
1250 - 1499	*n*	1240	917	74	776	29
	%	39.9	74.0	8.1	62.6	3.7
Total Included	*n*	3106	2216	484	1834	320
	%	100	71.3	21.8	59.0	17.4
Total no. of missing (GA)		0				
Total babies		3106				

Table 10

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	129	4.3	129	100	22	17.1	22	100.0	12	54.5	0	0.0
25-27	626	21.1	626	100	313	50.0	289	92.3	123	39.3	6	1.9
28-31	2217	74.6	2217	100	542	24.4	523	96.5	175	32.3	2	0.4
Total included	2972	100	2972	100	877	29.5	834	95.1	310	35.3	8	0.9

Table 11
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*	%
< 750	293	9.4	293	100.0	74	25.3	70	94.6	30	40.5	2	2.7
750-999	639	20.6	639	100.0	279	43.7	268	96.1	101	36.2	3	1.1
1000-1249	934	30.1	934	100.0	308	33.0	298	96.8	107	34.7	4	1.3
1250-1499	1240	39.9	1240	100.0	224	18.1	216	96.4	63	28.1	0	0.0
Total included	3106	100	3106	100.0	885	28.5	852	96.3	301	34.0	9	1.0

Figure 12

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

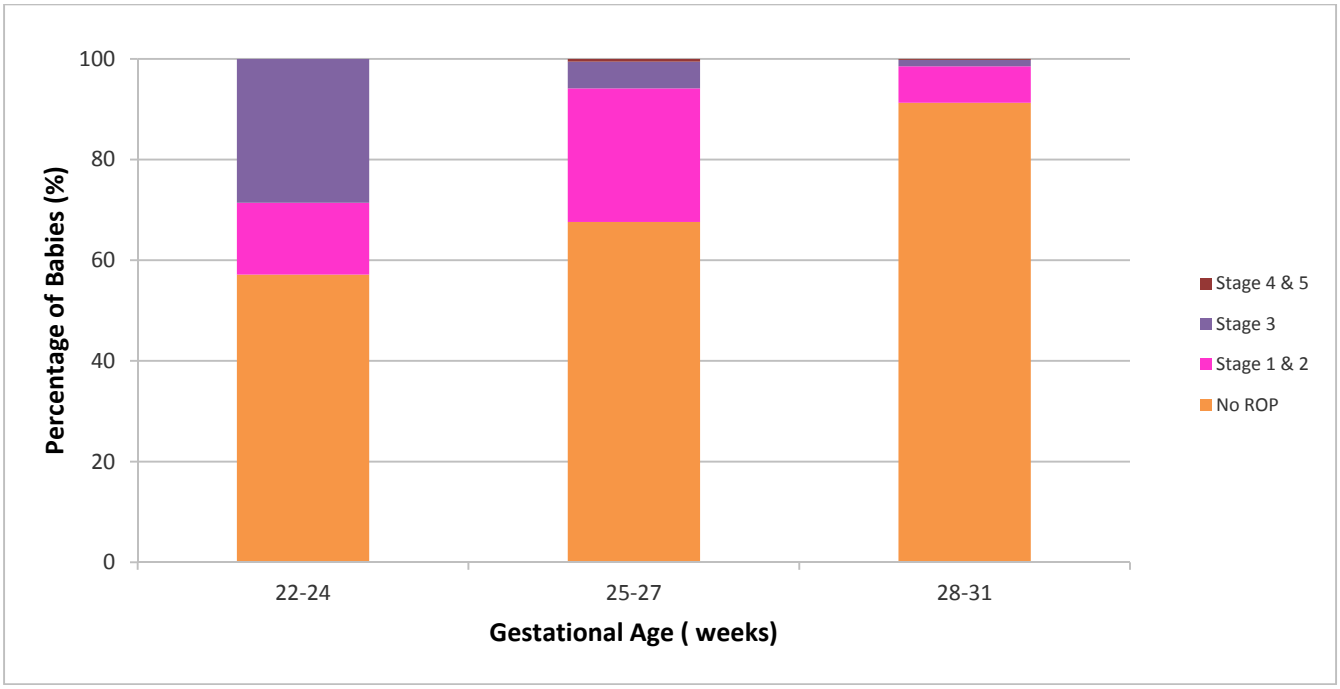


Table 12:
Incidence of retinopathy of prematurity (ROP) in admitted inborn babies in the MNNR by gestational age categories

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	129	25	21	84.0	12	57.1	3	14.3	6	28.6	0	0.0	0	6
25-27	626	397	358	90.2	242	67.6	95	26.5	19	5.3	2	0.6	0	16
28-31	2217	2019	1444	71.5	1318	91.3	105	7.3	18	1.2	3	0.2	1	13
Total Included	2972	2441	1823	74.7	1572	86.2	203	11.1	43	2.4	5	0.3	1	35

Comment: Screening refers to those screened during the ward admission

Figure 13

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

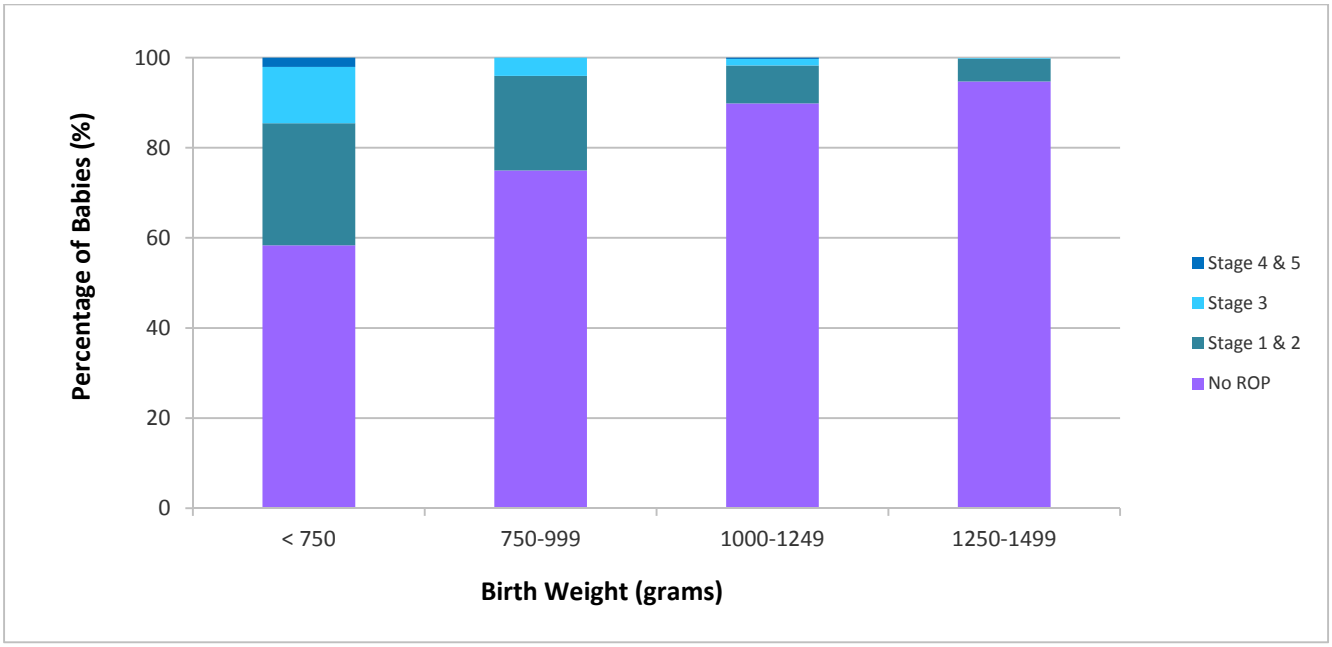


Table 13 :
Incidence of retinopathy of prematurity (ROP) in admitted inborn babies in the MNNR by birth weight categories

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	293	109	96	88.1	56	58.3	26	27.1	12	12.5	2	2.1	0	11
750-999	639	456	419	91.9	314	74.9	88	21.0	17	4.1	0	0.0	0	12
1000-1249	934	813	679	83.5	610	89.8	57	8.4	10	1.5	2	0.3	1	9
1250-1499	1240	1157	751	64.9	712	94.8	38	5.1	1	0.1	0	0.0	0	1
Total included	3106	2535	1945	76.7	1692	87.0	209	10.7	40	2.1	4	0.2	1	33

Comment: Screening refers to those screened during the ward admission

Figure 14

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

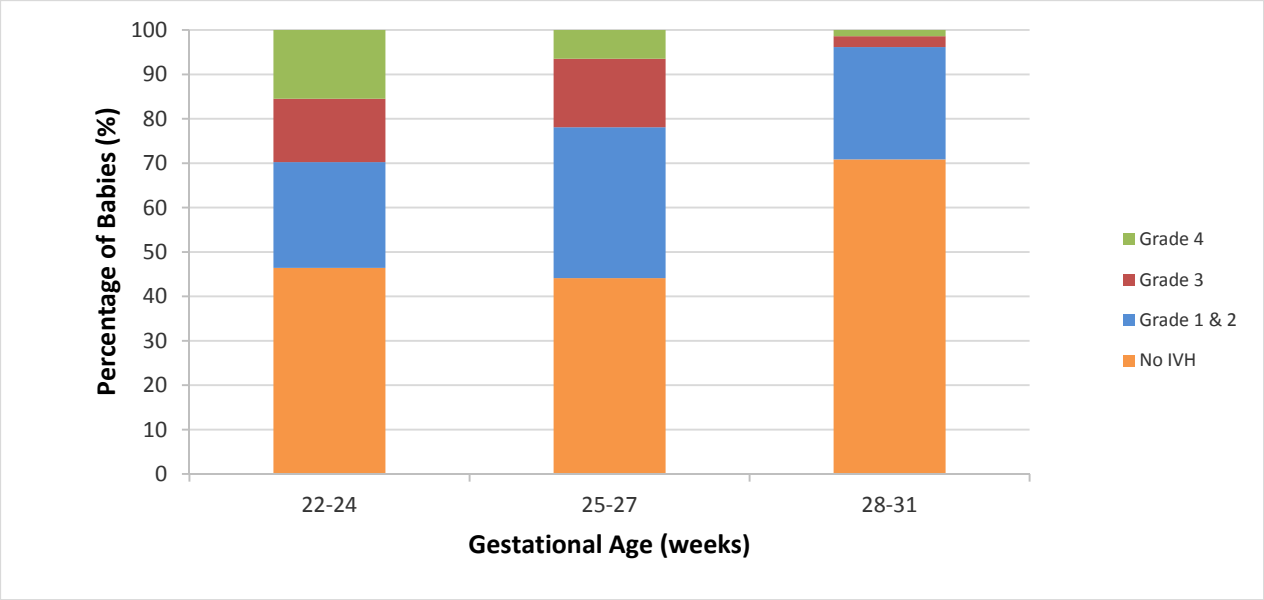


Table 14 :
Incidence of intraventricular haemorrhage (IVH) in admitted inborn babies < 32 weeks gestational age

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**	129	84	39	20	12	13
	%	4.3	65.1	46.4	23.8	14.3	15.5
25-27	**n**	626	589	260	200	91	38
	%	21.1	94.1	44.1	34.0	15.4	6.5
28-31	**n**	2217	2143	1519	542	52	30
	%	74.6	96.7	70.9	25.3	2.4	1.4
Total included	**n**	2972	2816	1818	762	155	81
	%	100	94.8	64.6	27.1	5.5	2.9
Total no. of missing (GA)	0						
Total babies	2972						

CUS – cranial ultrasound

Figure 15

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

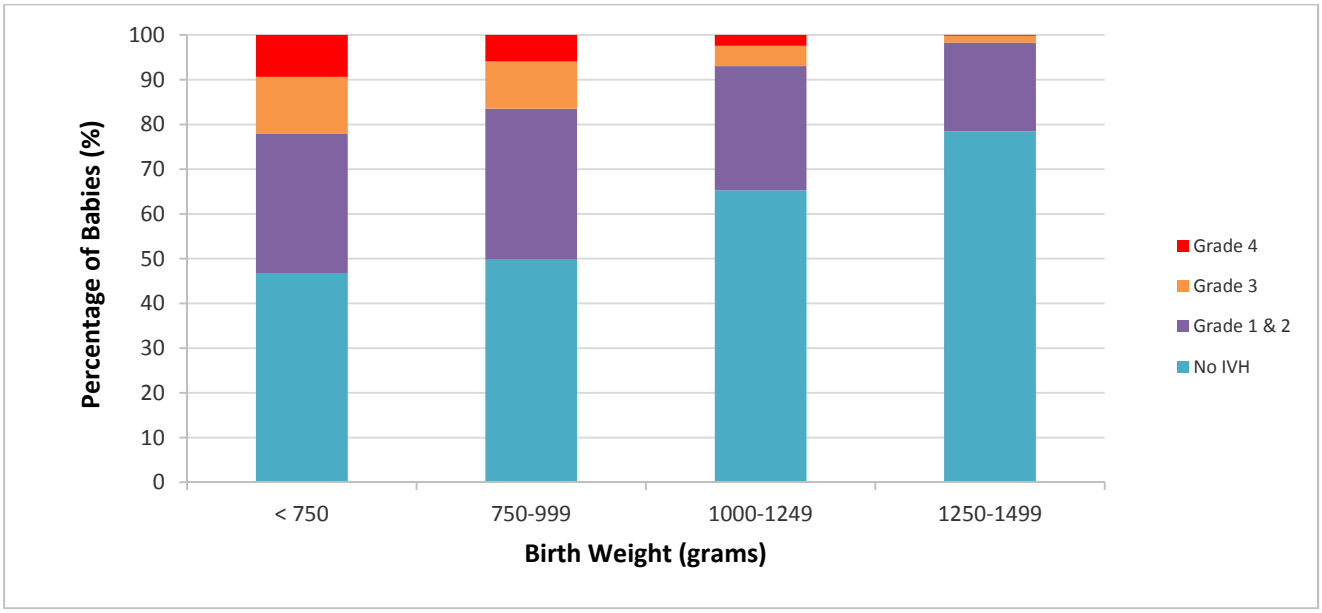


Table 15 :
Incidence of intraventricular haemorrhage (IVH) in admitted inborn babies < 1500 grams birth weight

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**	293	235	110	73	30	22
	%	9.4	80.2	46.8	31.1	12.8	9.4
750-999	**n**	639	607	302	205	64	36
	%	20.6	95.0	49.8	33.8	10.5	5.9
1000-1249	**n**	934	907	592	252	41	22
	%	30.1	97.1	65.3	27.8	4.5	2.4
1250-1499	**n**	1240	1169	917	232	18	2
	%	39.9	94.3	78.4	19.8	1.5	0.2
Total included	**n**	3106	2918	1921	762	153	82
	%	100	93.9	65.8	26.1	5.2	2.8
Total no. of missing (GA)	0						
Total babies	3106						

CUS – cranial untrasound

Figure 16

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

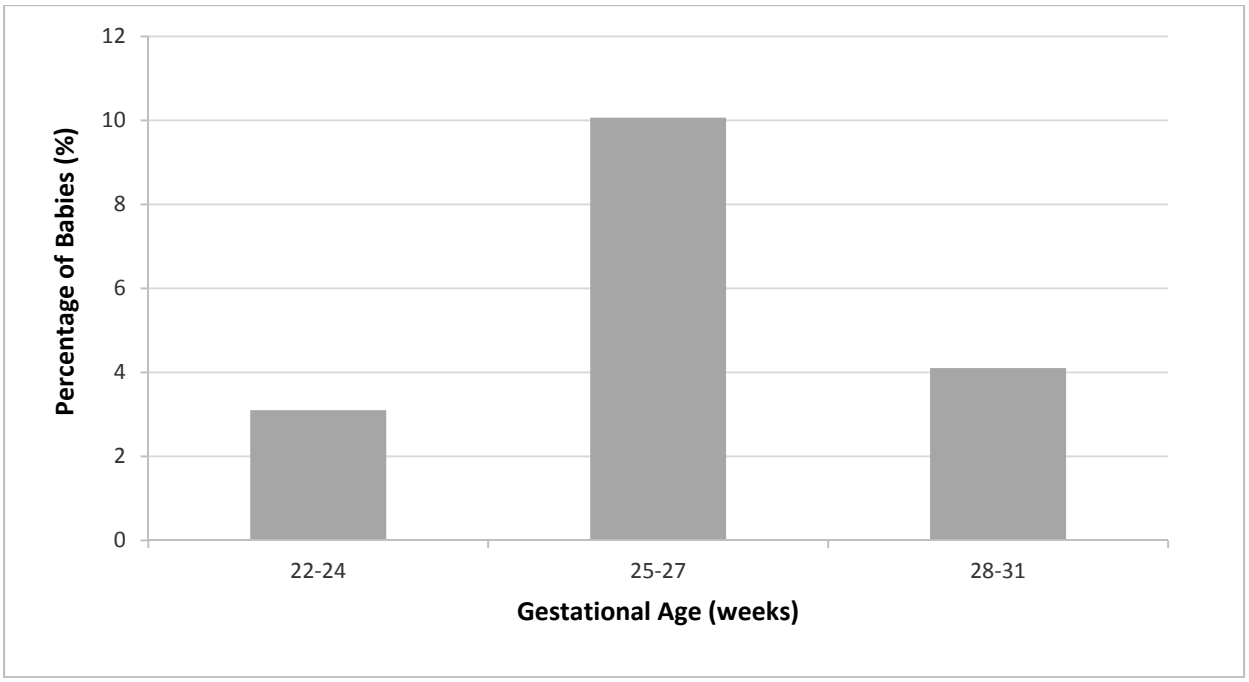


Table 16 :
Incidence and treatment of necrotizing enterocolitis (NEC) in admitted inborn babies according to gestational age categories

Gestational age (weeks)	Total number of admitted inborn babies	Babies with NEC		With Surgical treatment	
	n	*n*	*%*	*n*	*%*
22-24	129	4	3.1	1	25.0
25-27	626	63	10.1	13	20.6
28-31	2217	91	4.1	16	17.6
Total included	2972	158	5.3	30	19.0
Total no. of missing (GA)	0				
Overall Total babies	2972				

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

Figure 17

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

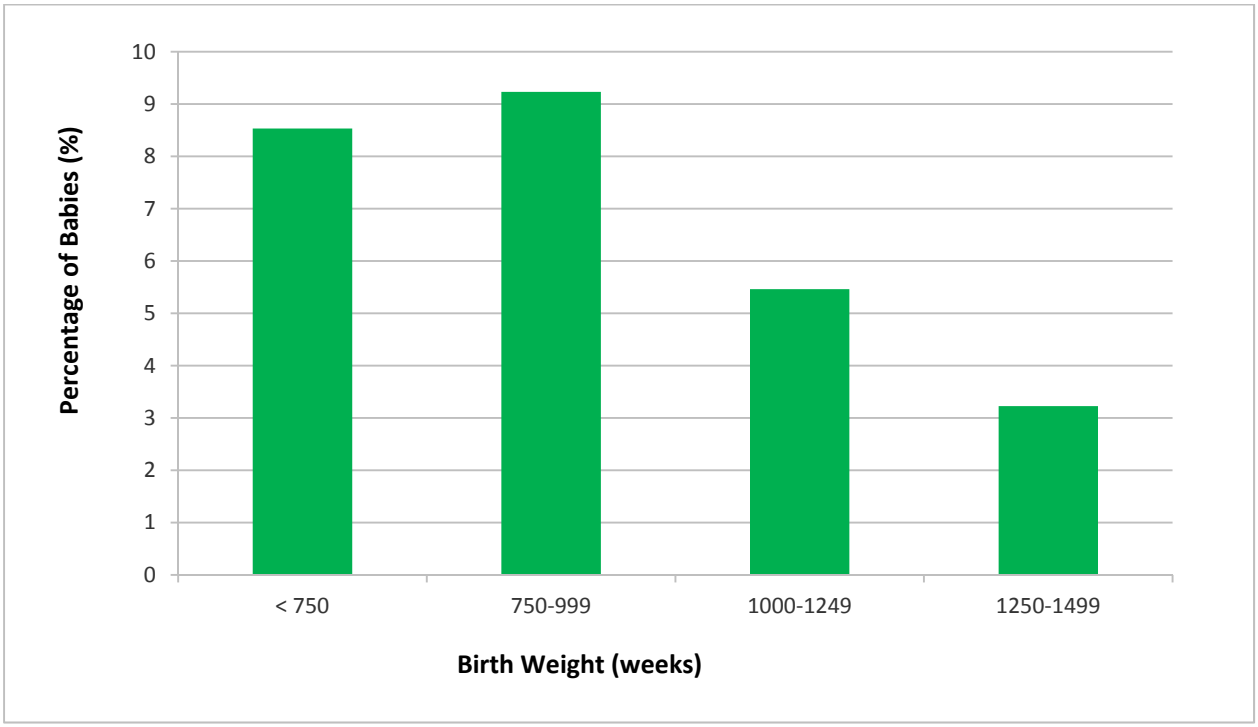


Table 17 :
Incidence and treatment of necrotizing enterocolitis (NEC) in admitted inborn babies according to birth weight categories

Birth weight (grams)	Total number admitted of inborn babies	Babies with NEC		With Surgical treatment	
	n	*n*	*%*	*n*	*%*
< 750	293	25	8.5	1	4.0
750-999	639	59	9.2	11	18.6
1000-1249	934	51	5.5	12	23.5
1250 - 1499	1240	40	3.2	7	17.5
Total included	3106	175	5.6	31	17.7
Total no. of missing (BW)	0				
Overall total babies	3106				

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

Figure 18

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

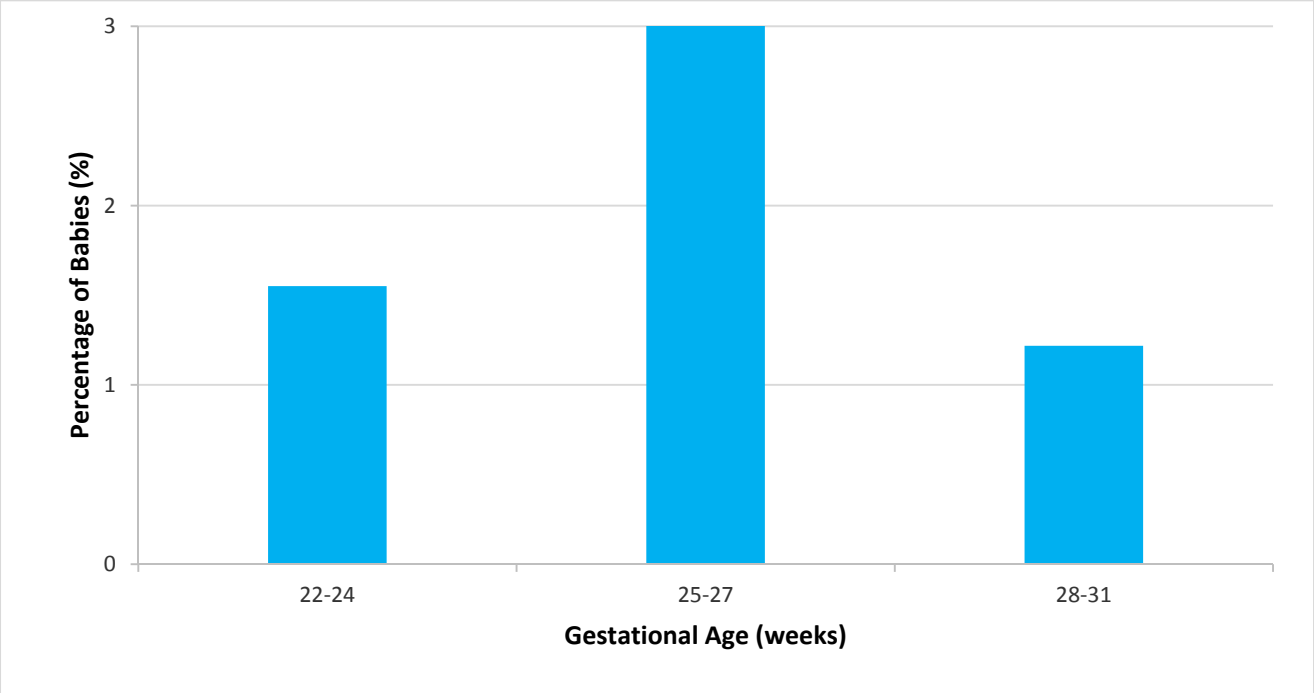


Table 18 :
Incidence of blood culture positive early onset sepsis in admitted inborn babies by gestational age categories

Gestational age at birth (completed weeks)	Total number of admitted inborn babies	No. of babies with early infection	
	n	*n*	%
22-24	129	2	1.6
25-27	626	19	3.0
28-31	2217	27	1.2
Total included	2972	48	1.6
Total no. of missing (GA)	0		
Total babies	2972		

Figure 19

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

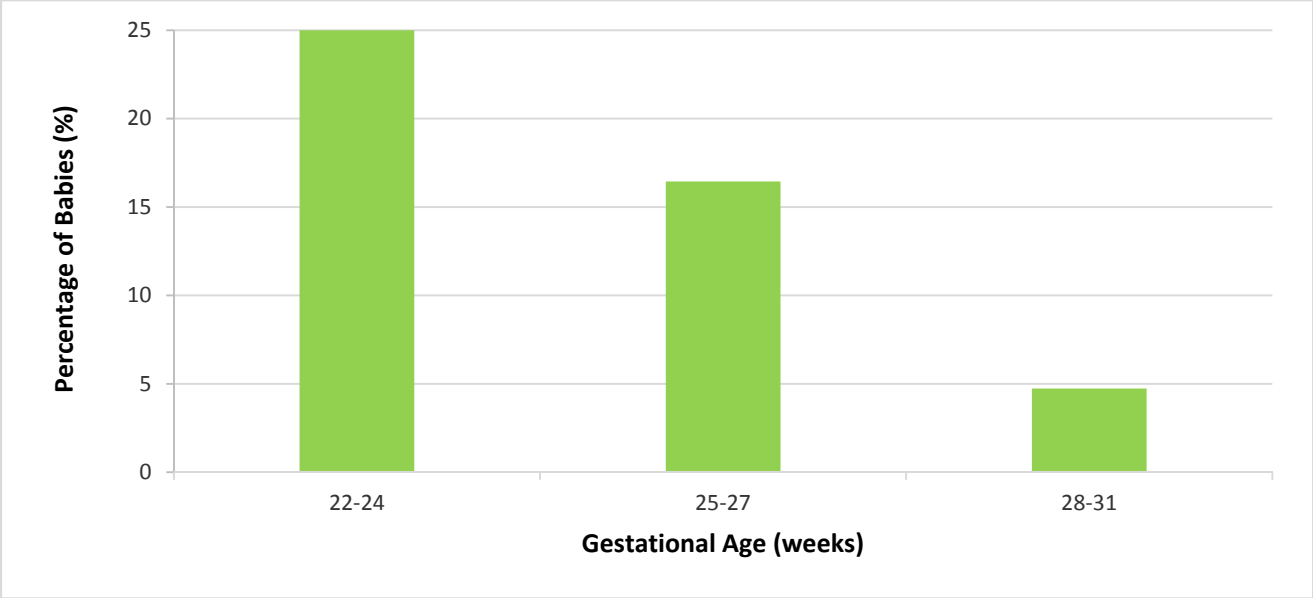


Table 19 :
Incidence of blood culture positive late onset sepsis in admitted inborn babies by gestational age categories

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	129	24	6	25.0
25-27	626	377	62	16.4
28-31	2217	1987	94	4.7
Total included	2972	2388	162	6.8
Total no. of missing (GA)	0			
Total babies	2972			

Figure 20

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

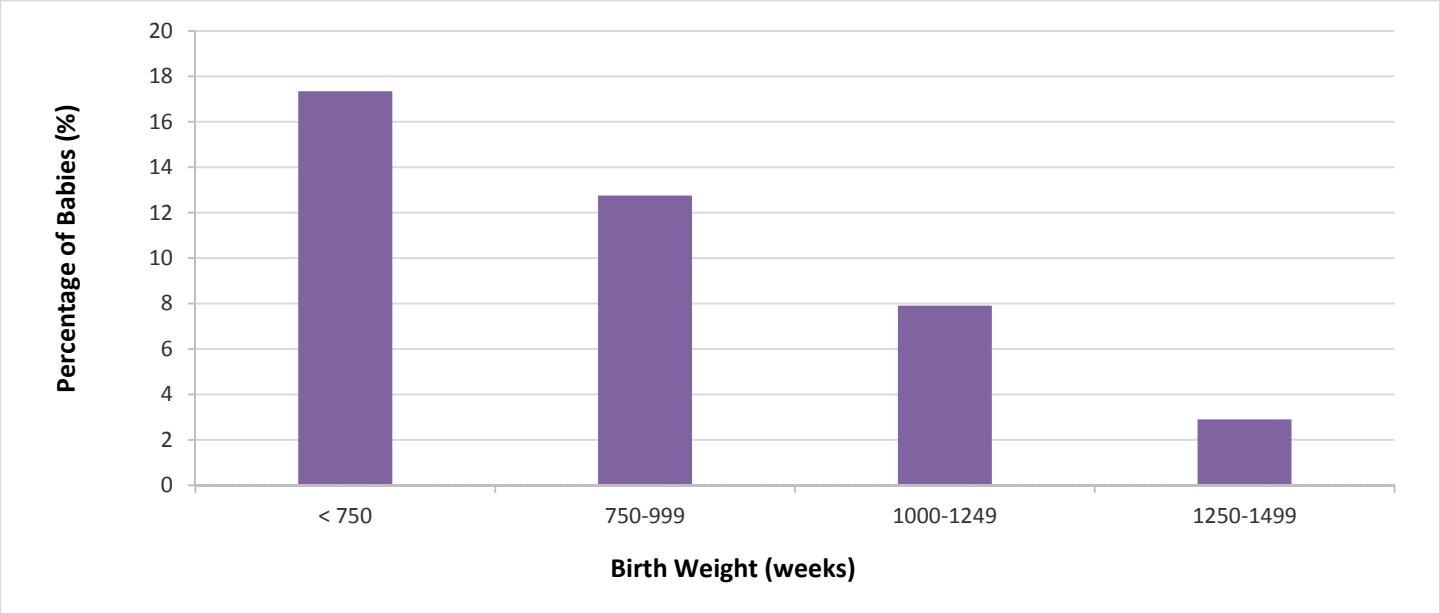


Table 20 :
Incidence of blood culture positive late onset sepsis in admitted inborn babies by birth weight categories

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	293	98	17	17.3
750-999	639	439	56	12.8
1000-1249	934	797	63	7.9
1250 - 1499	1240	1138	33	2.9
Total included	3106	2472	169	6.8
Total no. of missing (BW)	0			
Overall total babies	3106			

Table 21a

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

Gestational age at birth (weeks)		Total no. of admitt-ed inborn babies	Numb er Surviv ed	No. with any one 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	129	24	7	8	1	0	0	8
	%	4.3	18.6	29.2	33.3	4.2	0.0	0.0	33.3
25-27	n	626	379	156	53	11	0	0	159
	%	21.1	60.5	41.2	14.0	2.9	0.0	0.0	42.0
28-31	n	2217	1994	258	43	5	1	0	1687
	%	74.6	89.9	12.9	2.2	0.3	0.1	0.0	84.6
Total Included	n	2972	2397	421	104	17	1	0	1854
	%	100	80.7	17.6	4.3	0.7	0.0	0.0	77.3
Total no. of missing (GA)	-								
Total babies	2972								

i. PDA requiring surgical ligation
ii. Stage 3 / 4 or 5 ROP
iii. Oxygen dependency at 36 weeks or discharge
iv. Confirmed sepsis
v. NEC

Table 21b

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	293	99	35	22	5	1	0	36
	%	9.4	33.8	35.4	26.7	5.1	1.0	0.0	36.4
750 - 999	n	639	439	147	46	9	0	0	237
	%	20.6	68.7	33.5	8.9	2.1	0.0	0.0	54.0
1000 - 1249	n	934	800	149	30	3	0	0	618
	%	30.1	85.7	18.6	2.9	0.4	0.0	0.0	77.3
1250 - 1499	n	1240	1144	95	3	1	0	0	1045
	%	39.9	92.3	8.3	1.0	0.1	0.0	0.0	91.3
Total Included	n	3106	2482	426	101	18	0	0	1936
	%	100	79.9	17.2	3.8	0.7	0.0	0.0	78.0
Total no. of missing (GA)	-								
Total babies	3106								

i. PDA requiring surgical ligation

ii. Stage 3 / 4 or 5 ROP

iii. Oxygen dependency at 36 weeks or discharge

iv. Confirmed sepsis

v. NEC

APPENDICES

Appendix 1 Level of Neonatal Care

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

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

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

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 within 44 weeks postconceptional age.

'Previously admitted to another 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'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) CPAPA
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

29. ***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

30. ***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 – delivered as a gas via a ventilator at any time after leaving the delivery room.

31. ***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.

32. ***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.

33. ***Parenteral Nutrition***: Intravenous infusion of a nutrient solution consisting of a minimum of dextrose and protein but generally providing a complete nutrient infusion including electrolytes, calcium, phosphorus, zinc, trace elements, vitamins and fat. Nutrition given intravenously. Parenteral nutrition must include amino acids with or without fats, hence plain dextrose saline infusion 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

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

d. If term and no asphyxia conditions, was there Infection?
This refers to term babies (> 37 weeks gestation) whose primary cause of death is an infection. Some examples include meningitis, group B streptococcal infection, intrauterine infections etc.

e. If term and infection present, tick organism

f. If term and infection absent, are they any other specific causes of death?
Specify any other cause of death not included in the above classification. This includes kernicterus, haemorrhagic shock /inborn error of metabolism/pneumothorax/ pulmonary haemorrhage. Use ICD 10 code

g. Unknown
Where cause of death is not known.

Readmission CRF

To be used for babies discharged well from any MNNR SDP hospital and then readmitted to same or another MNNR SDP hospital cohort within 44 weeks of corrected age. The aim is to audit reasons for readmission when 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:*** (dd/mm/yy) Date of discharge 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 - If yes, fill in main CRF section 3&4

Section 5: Outcome

(Same as CRF Section 5 page 57) 47a - 51

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. 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 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).
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: within the first 24 hours of life, 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 after thoracic surgery and was not treated with a chest tube, tick **'No'**. For infants who had thoracic surgery and then later developed extra pleural air diagnosed by CXR or needle thoracocentesis, tick **'Yes'**. **Indicate whether pneumothorax developed during CPAP, Conventional ventilation or HFV.**
Supplemental oxygen & BPD Tick "yes" if the baby received continuous oxygen concentration > 21% for at least 28 continuous days (note not "till 28 days of life"). Otherwise tick "no". For babies < 32 weeks – state if O_2 / any form of CPAP or ventilatory support required at 36 weeks corrected gestation. For babies ≥ 32 weeks - state if O_2 / any form of CPAP or ventilatory support required at Day 56.	Receipt of continuous enriched oxygen concentration > 21% by oxyhood, nasal cannula, nasal catheter, facemask or still requiring nCPAP or other forms of respiratory support by Day 28 and 36 weeks or day 56. '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)	Definitive diagnosis of PPHN is made by echocardiography. In the absence of echo confirmation, pre and postductal pulse oxymetry difference of > 10% can be used. Preductal pulse oxymetry done on the right hand and post ductal

	pulse oxymetry done on lower limbs.
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 :*** 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	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

Committee on ROP (ICROP). Score according to the grade of ROP assigned on an eye exam done by an ophthalmologist (e.g. threshold). If there is no explicit grade listed, then score according to the descriptions given by the ICROP. (e.g. threshold). 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** 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	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") Stage 4 : Partial Retinal Detachment Stage 5 : Total retinal detachment PLUS disease : dilated veins and tortuous arteries, papillary rigidity (must also include stages other than No ROP)
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, 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

42. Central venous line 42a Central line - yes or no Date of insertion Date of removal (autocalculate) 42b. CLABSI	If more than one central line, use data of the central line with the longest duration 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. CLABSI defined as clinical sepsis with positive blood culture in patient with **ALL** 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 Tick 'Yes'if there is evidence of confirmed 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: • Group B streptococcus • MRSA • CONS (see definition) • Staphylococcus aureus • Klebsiella • Pseudomonas • Acinetobacter • Fungal (see definition) • Others, specify • ESBL organisms	***Confirmed sepsis*** 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 /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) **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** 2. Three or more supporting findings from the following list: a. Arterial cord pH<7.00 b. Apgar score at 5 minutes of 5 or less c. Evidence of multi-organ system dysfunction – dysfunction of one or more of the following systems within 72 hours of birth d. Evidence of foetal distress on antepartum monitoring: persistent late decelerations, reversal of end-diastolic flow on Doppler flow studies of the umbilical artery or a biophysical profile of 2 or less e. Evidence of CT, MRI, technetium or ultrasound brain scan performed within 7 days of birth of diffuse or multifocal ischaemia or of cerebral oedema. f. Abnormal EEG: low amplitude and frequency, periodic, paroxysmal or isoelectric. **AND** 3. The absence of an infectious cause, a congenital malformation of the brain or an inborn error of metabolism, which could explain the encephalopathy.

HIE severity If the infants diagnosed with HIE, record the worst stage observed during the first 7 days following birth based on the infant's level of consciousness and response to arousal maneuvers such as persistent gentle shaking, pinching, shining a light or ringing of a bell: Tick "none" if there is no HIE Tick '"Mild, Moderate, Severe " according to the definition 45a. Tick "none" if there is no HIE Tick '"Mild, Moderate, Severe " according to the definition 45b. Highest Thompson Score before 6 hours of life 45c. Cooling therapy 45d. Seizures in HIE cases	*HIE severity* a. Mild (normal or hyperalert) – infants in this category are alert or hyperalert with either a normal or exaggerated response to arousal. No seizures (Sarnat Stage 1) 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) 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
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". 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 :				

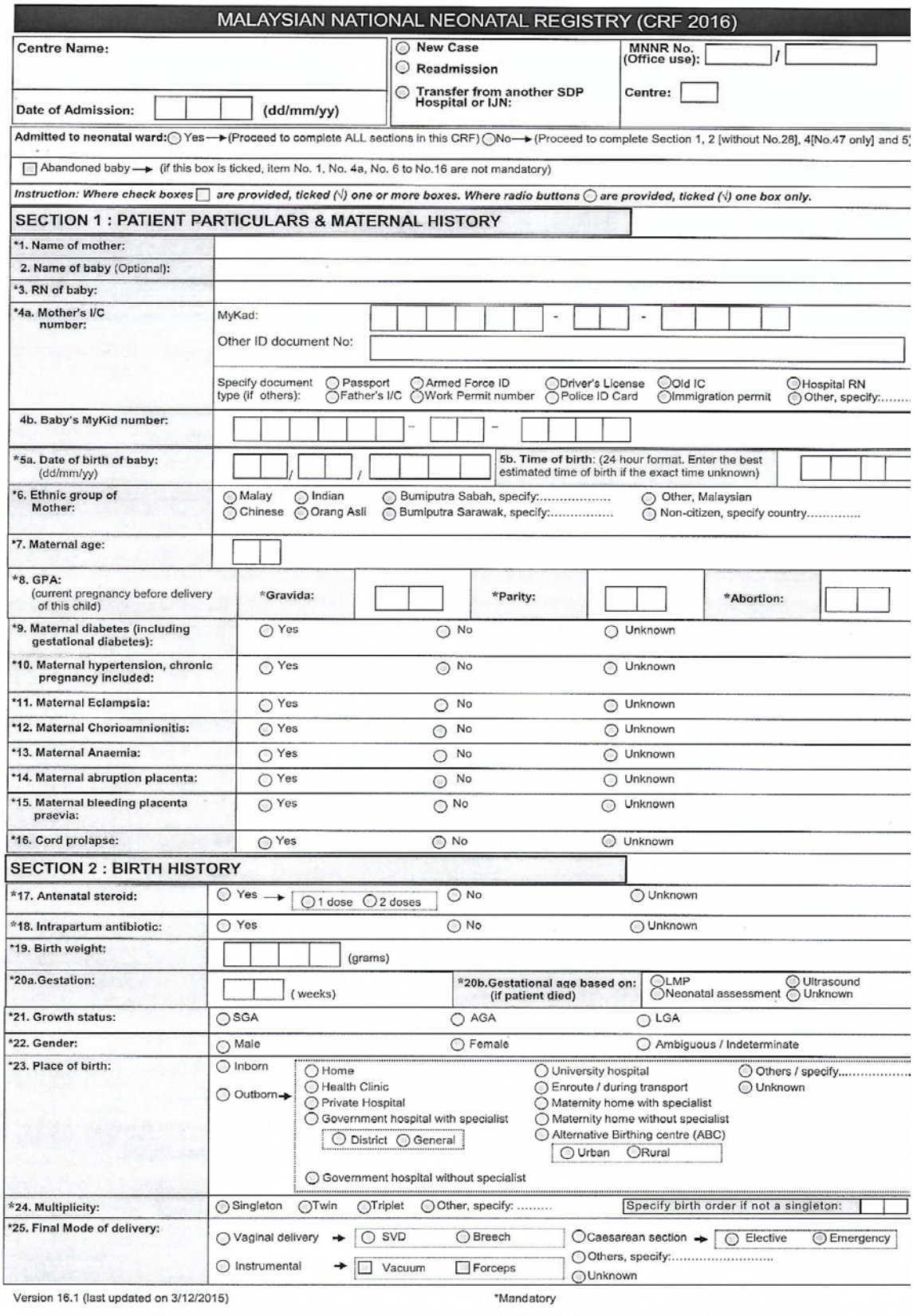
SECTION 4: BIRTHS VERSUS ETHNIC GROUP

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



MALAYSIAN NATIONAL NEONATAL REGISTRY (CRF 2016)

Centre Name:

Date of Admission: (dd/mm/yy)

New Case / Readmission / Transfer from another SDP Hospital or IJN:

MNNR No. (Office use): /

Centre:

Admitted to neonatal ward: Yes → (Proceed to complete ALL sections in this CRF) No → (Proceed to complete Section 1, 2 [without No.28], 4[No.47 only] and 5)

Abandoned baby → (if this box is ticked, item No. 1, No. 4a, No. 6 to No.16 are not mandatory)

Instruction: Where check boxes are provided, ticked (√) one or more boxes. Where radio buttons are provided, ticked (√) 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 / Private Hospital / Government hospital with specialist (District / General) / Government hospital without 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

Version 16.1 (last updated on 3/12/2015) *Mandatory

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) Early 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)	☐☐ . ☐ (°C)			

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	ii) Total duration of CPAP at your centre: ◯ Yes ◯ No ☐☐ . ☐ 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 ◯ No → ◯ < 1 hr ◯ 1-2 hrs > ◯ 2 hrs
*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. PPHN:	◯ Yes ◯ No ◯ Unknown
*38. PDA:	◯ Yes → a) ECHO done: ◯ Yes ◯ No; b) Indomethacin/Ibuprofen: ◯ Yes ◯ No; c) Ligation: ◯ Yes ◯ No ◯ No
*39. NEC (stage 2 and above):	◯ Yes → a) surgical treatment: ◯ Yes ◯ No; b) NEC present before admission to your centre: (for outborn baby only) ◯ Yes ◯ No ◯ No
*40. ROP Retinal Exam Done < 33 weeks OR ≤ 1500g - option 'Not Applicable' will be auto blocked > 32 weeks AND >1500g: option 'Yes' & 'No' will be auto blocked	◯ 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 ◯ Prethresh ◯ Thresh ◯ Stage 4 ◯ Stage 5 ☐ PLUS disease d) Laser Therapy: ◯ Yes ◯ No e) Cryotherapy: ◯ Yes ◯ No f) Vitrectomy/AntiVEGF: ◯ Yes ◯ No g) ROP present prior to admission? (for outborn baby only) ◯ Yes ◯ No ◯ No → Appointment given: ◯ Yes ◯ No; Date of appointment: ☐☐/☐☐/☐☐ ◯ Not Applicable

Version 16.1 (last updated on 3/12/2015) *Mandatory

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

***42a. Central Venous Line (applies to the catherer in situ for the longest duration)**

i. ◯ Yes ◯ No

ii. Date of insertion: ☐☐ / ☐☐ / ☐☐

Date of removal: ☐☐ / ☐☐ / ☐☐

42b. CLABSI

◯ Yes ◯ No

***43. Confirmed sepsis:**

(Blood culture positive only)

◯ Yes ◯ No

☐ ≤ 72 hours of life

II) **Type of organism** (can tick more than one)

☐ Group B Steptococcus ☐ 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: .....

***44. Neonatal meningitis:**

◯ Yes ◯ No

CSF Culture positive : ◯ Yes ◯ No

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

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

*** 45. HIE :**
(Only for ≥ 35 weeks GA)

a) HIE severity: ◯ None ◯ Mild ◯ Moderate ◯ Severe

b) Highest Thompson Score: ☐☐

c) Cooling therapy : ◯ Yes ◯ No

If yes ;then to choose
☐ Cooling blanket or cap
☐ Passive cooling plus or minus gel pack
☐ both

d) Seizures in HIE cases: ◯ Yes ◯ No

***45. Congenital anomalies:**

***46a. Major congenital anomalies :**

◯ Yes ◯ No

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

◯ Not a recognized syndrome

◯ Isolated major abnormality

***46b. 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 Bifida
◯ Anencephaly
◯ Encephalocoele
◯ Others (Refer to ICD 10):_____

☐ Skeletal dysplasia
☐ Respiratory
☐ GIT
☐ Hydrops
☐ Renal
☐ Cleft
◯ Lip ◯ Palate ◯ Lip and Palate
☐ Others, specify (Refer to ICD 10)
☐ 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. Total duration of hospital stay (neonatal/ peads care):	☐☐☐ (in completed days) (auto calculate)	

*51. Outcome:

◯ Alive →

Place discharged to:

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

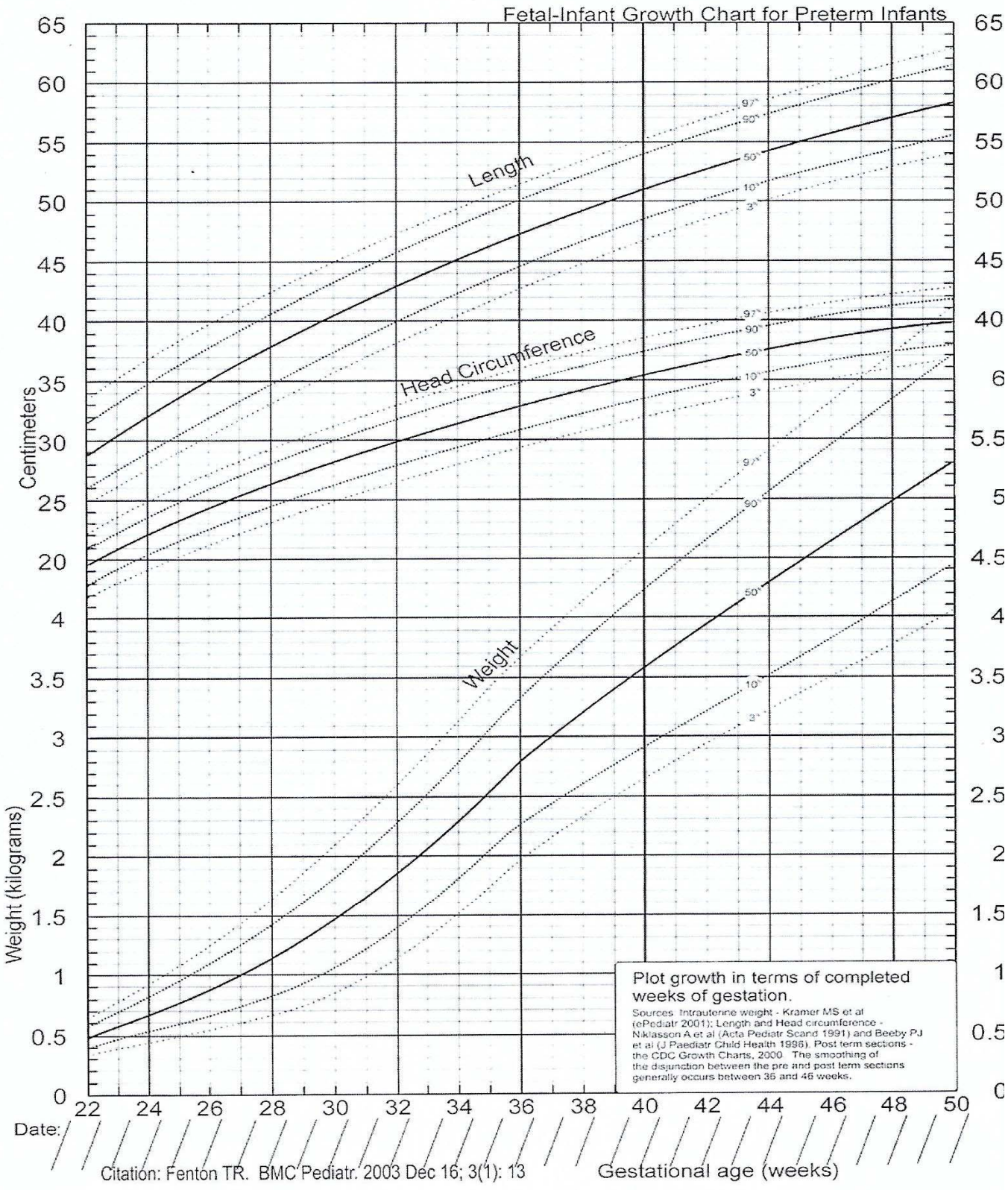
a) Name of hospital:	
b) Reason for transfer:	◯ Growth/ stepdown care ◯ Acute medical/ diagnostic services ◯ Social/ Logistic reason ◯ Lack of NICU bed ◯ Other, specify: ..... ◯ Chronic/ Palliative care ◯ Surgery
c) Post transfer disposition: (Please fill this section if place transferred is not part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

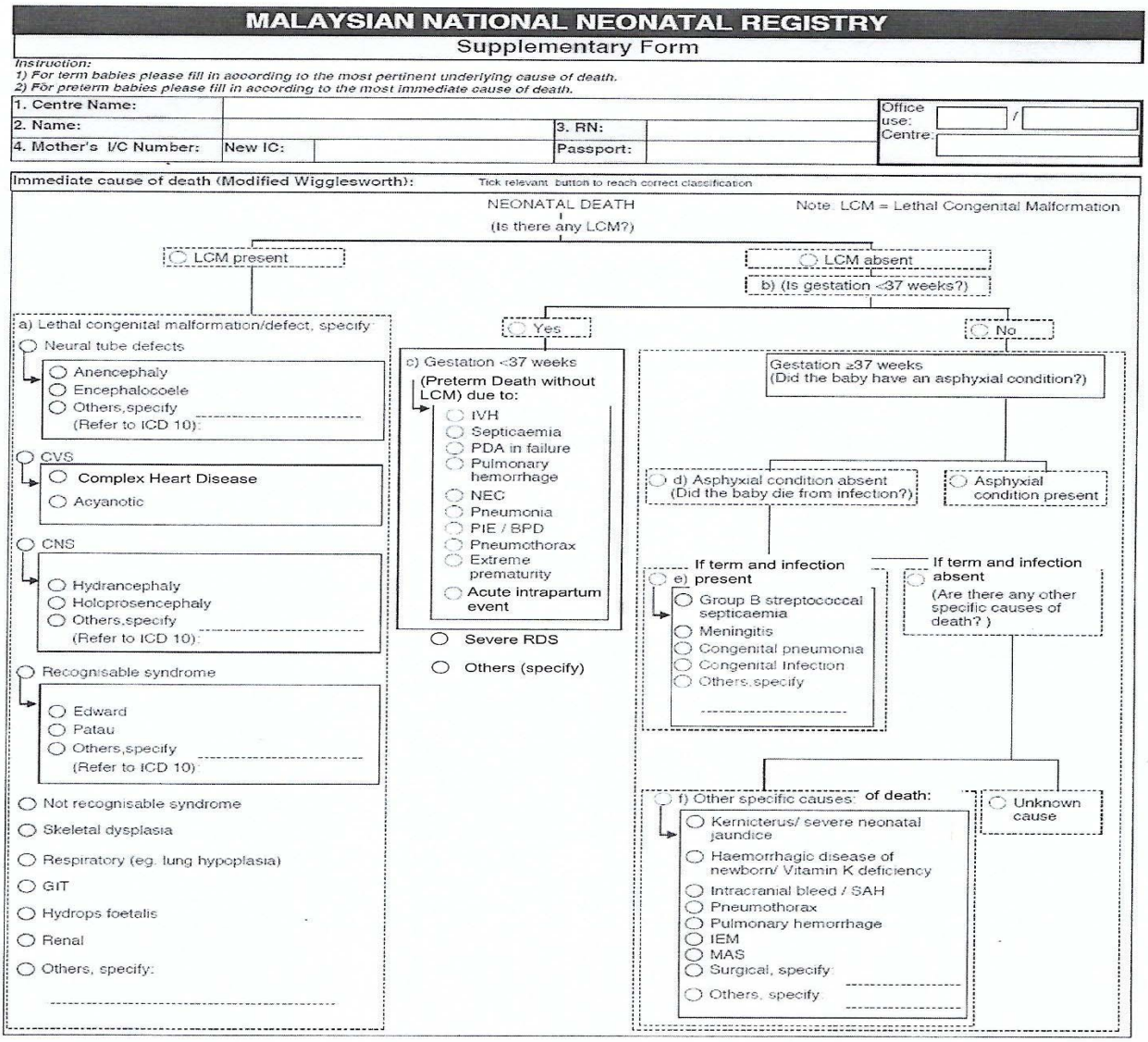
◯ Dead →

Place of death:

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

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


Fetal-Infant Growth Chart for Preterm Infants
Length
Head Circumference
Weight
97th
90th
50th
10th
3rd
Centimeters
Weight (kilograms)
Gestational age (weeks)
Date:
Plot growth in terms of completed weeks of gestation.
Sources: Intrauterine weight - Kramer MS et al (ePediatr 2001); Length and Head circumference - Niklasson A et al (Acta Pediatr Scand 1991) and Beeby PJ et al (J Paediatr Child Health 1996). Post term sections - the CDC Growth Charts, 2000. The smoothing of the disjunction between the pre and post term sections generally occurs between 35 and 46 weeks.
Citation: Fenton TR. BMC Pediatr. 2003 Dec 16; 3(1): 13



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?)

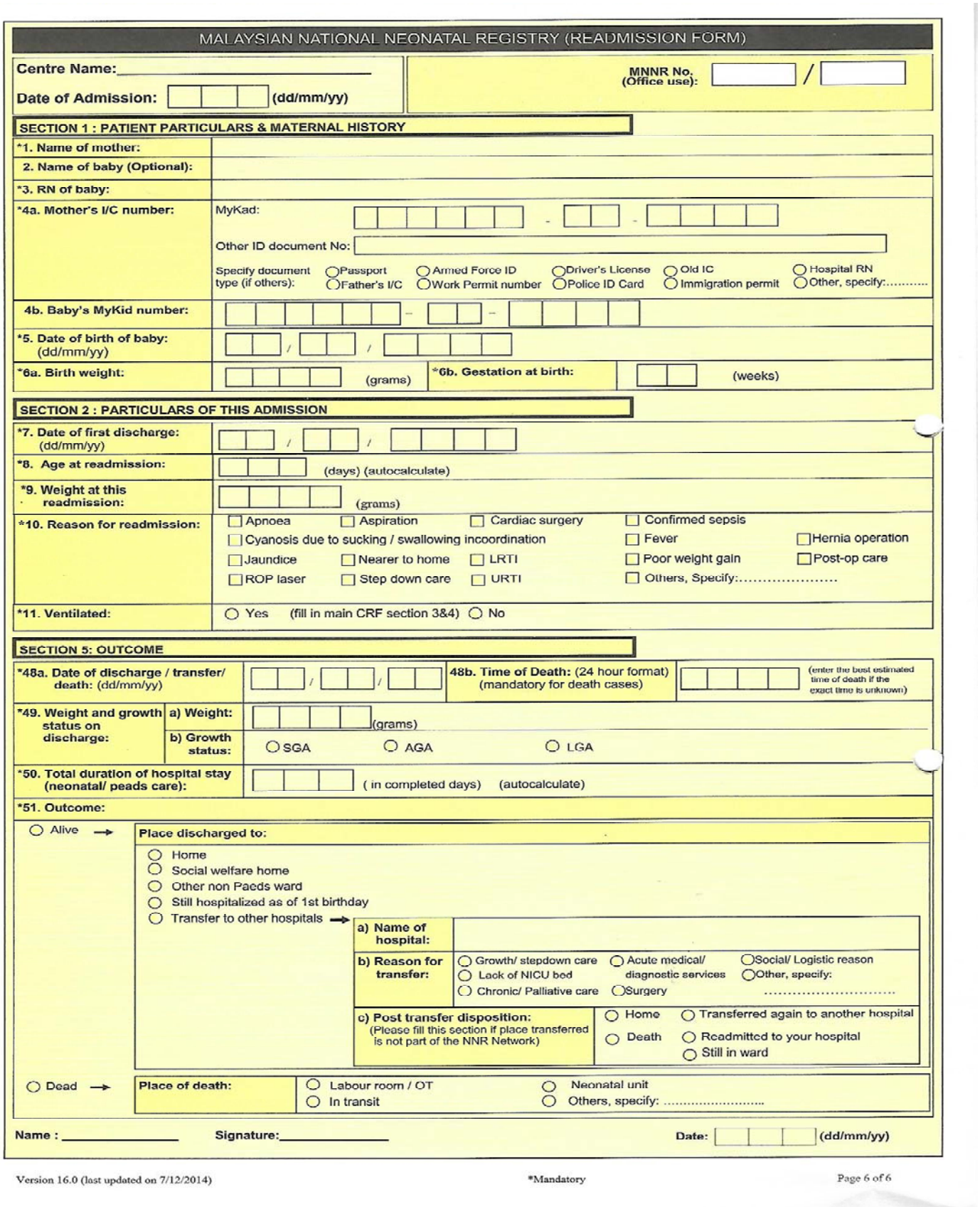
Note: LCM = Lethal Congenital Malformation

- ○ LCM present
  - a) Lethal congenital malformation/defect, specify:
    - ○ Neural tube defects
      - ○ Anencephaly
      - ○ Encephalocoele
      - ○ Others, specify ____ (Refer to ICD 10):
    - ○ CVS
      - ○ Complex Heart Disease
      - ○ Acyanotic
    - ○ CNS
      - ○ Hydrancephaly
      - ○ Holoprosencephaly
      - ○ Others, specify ____ (Refer to ICD 10):
    - ○ Recognisable syndrome
      - ○ 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 (Preterm Death without LCM) due to:
        - ○ IVH
        - ○ Septicaemia
        - ○ PDA in failure
        - ○ Pulmonary hemorrhage
        - ○ NEC
        - ○ Pneumonia
        - ○ PIE / BPD
        - ○ Pneumothorax
        - ○ Extreme prematurity
        - ○ Acute intrapartum event
      - ○ Severe RDS
      - ○ Others (specify)
    - ○ No
      - Gestation ≥37 weeks (Did the baby have an asphyxial condition?)
        - ○ d) Asphyxial condition absent (Did the baby die from infection?)
          - If term and infection
          - ○ e) present
            - ○ Group B streptococcal septicaemia
            - ○ Meningitis
            - ○ Congenital pneumonia
            - ○ Congenital Infection
            - ○ Others, specify ____
          - If term and infection absent
          - ○ (Are there any other specific causes of death?)
            - ○ f) Other specific causes of death:
              - ○ 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)

Version 15.1 (last updated on 27/11/2014) *Mandatory Page 5 of 6

Appendix 4b Readmission Form



MALAYSIAN NATIONAL NEONATAL REGISTRY (READMISSION FORM)

Centre Name:_____

Date of Admission: ☐☐☐ (dd/mm/yy)

MNNR No. (Office use): ☐☐☐☐ / ☐☐

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 ☐ Aspiration ☐ Cardiac surgery ☐ Confirmed sepsis
☐ Cyanosis due to sucking / swallowing incoordination ☐ Fever ☐ Hernia operation
☐ Jaundice ☐ Nearer to home ☐ LRTI ☐ Poor weight gain ☐ Post-op care
☐ ROP laser ☐ Step down care ☐ URTI ☐ Others, Specify:.....

*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. Total duration of hospital stay (neonatal/ peads care): ☐☐☐ (in completed days) (autocalculate)

*51. 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)

Version 16.0 (last updated on 7/12/2014) *Mandatory Page 6 of 6

Appendix 5 Presentations

POSTER, ABSTRACT AND PAPER PRESENTIONS

1. Neoh SH. *Survival of VLBW Babies in MNNR 2016.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

2. Boo NY. *NEC & Milk Hygiene.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

3. Boo NY. *Admission Hypothermia.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

4. Chee SC. *CLD & Early CPAP 2016.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

5. Ang EL. *Causes of Death in Pre-term Infants*. Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

6. Cheah IGS. *Benchmarking of the NICU Outcome.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

7. Wong AC. *Nosocomial Infection 2016.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

8. Pauline Choo. *Congenital Diaphragmatic Hernia*. Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

9. Fazila MK. *Retinopathy of Prematurity 2016*. Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

10. Ang EL. *IVH in Babies < 32 weeks GA*. Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

11. Neoh SH. *HIE.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017

12. Cheah IGS. *Outcome of VLBW Infants of Diabetic Mother/ Outcome of IDM Admitted to NNR.* Presented at the MNNR SDP Meeting, Selayang Hospital, Selangor, Malaysia, December 2017