Very Low Birth Weight Infants in the Republic of Ireland

NATIONAL PERINATAL EPIDEMIOLOGY CENTRE

NICORE Ireland

ANNUAL REPORT 2014

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Acknowledgements

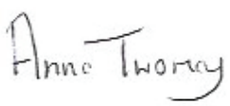
Welcome to the first Very Low Birth Weight Infants in the Republic of Ireland (ROI) Annual Report, produced by the Neonatal Intensive Care Outcomes Research and Evaluation (NICORE) ROI group and facilitated by the National Perinatal Epidemiology Centre (NPEC). This report is the first national report on all babies born ≤1500g and/or ≤29 wks gestation in the Republic of Ireland for a calendar year. Since 2003, nine neonatal centres in the ROI have participated in the Vermont Oxford Network (VON), the international network of health care professionals dedicated to improving the medical care of newborn infants and which is the entity which underpins this report. The remaining 10 ROI neonatal centres joined VON in 2013. Now, every neonatal centre in the country has signed up to VON and is submitting data on their very low birth weight (VLBW) infants. It is a credit to everybody involved and it is truly a great achievement.

Of note, this report is endorsed by the National Office of Clinical Audit (NOCA). Participation in NOCA ensures a process by which we can close the audit loop. This begins with bench marking clinical care with identified standards, such as those set by the National Clinical Programme in Neonatology and the Faculty of Paediatrics, and ends with implementing change for the improvement of patient safety and quality of care. The NOCA Governance Board endorsement of this report is included as Appendix A.

We wish to extend our sincere thanks to the NPEC, led by Professor Richard Greene, for its continued support of the ROI's participation in VON, specifically by financing the annual membership fee to the Network for all 19 centres, and also for providing the logistical support for this project. Similarly, we thank the team at VON which has whole-heartedly supported this initiative by processing and analyzing data and working closely with the team at the NPEC.

Measurement of the outcome of care is central to the development of safe and high quality health care services. Support from all Irish neonatal centres is instrumental in the success of this important national programme. On behalf of NICORE and the NPEC, we extend sincere thanks and appreciation to the many neonatal nurses, paediatricians and administration staff who have supported and contributed data to VON. In particular, we gratefully acknowledge the commitment of those who co-ordinate the collection of VON data at unit level.

Lastly, we would like to thank the NICORE ROI group (Appendix B) for their participation and support of this project from the onset, for their continuing intellectual input and for their vision of using national clinical audit data to improve neonatal services in the Republic of Ireland.



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Executive summary

1. A total of 608 very low birth weight infants (VLBW) were born in the Republic of Ireland (ROI) in 2014, of which two infants were <401g but ≥22 wks gestation and 16 infants were >1500g but ≤29 wks gestation.
2. In all, 228 infants were born with a birth weight ≤1000g and 158 infants were born with a gestational age ≤26 wks.
3. National survival figures for VLBW infants according to birth weight and gestational age categories are reported.
4. The Standardised Mortality Rate (SMR) for VLBW infants born in the ROI was 1.27 (95% CI: 1.03, 1.51). The number of observed cases of death was 1.27 times the expected number: this finding was statistically significant.

   5. Excluding early deaths (deaths in the Delivery Room or deaths within 12 hours of admission to the NICU), the standardised mortality rate was 1.23 (95% CI: 0.92, 1.54). The number of cases observed did not exceed the number of cases expected.
6. More VLBW infants in the ROI are born with a major congenital malformation than in the Vermont Oxford Network (VON) (9% vs 5%): this finding was statistically significant (p<0.001).
7. Survival for infants born at 23 weeks gestation in 2014 was 19%. More VLBW infants born at less than 24 weeks gestation in the ROI die in the Delivery Room than in VON (88% in the ROI vs 39% in VON): this finding was statistically significant (p<0.001). The availability of these data will be an invaluable resource to healthcare providers who counsel families that are about to deliver an infant at the "limits of viability". They help guide clinicians and families on decisions regarding transfer to a tertiary neonatal centre in anticipation of an imminent delivery.
8. Standardised Morbidity Rates for Key Performance Indicators in Neonatal Care of VLBW infants suggest that:
   - VLBW infants born in the ROI have significantly higher rates of pneumothorax. SMR for pneumothorax: 1.67 (95% CI: 1.25, 2.10).
   - VLBW infants born in the ROI have significantly higher rates of coagulase negative staphylococcus infection. SMR for coagulase negative infection: 1.84 (95% CI: 1.45, 2.23)
   - VLBW infants born in the ROI have significantly lower rates of retinopathy of prematurity. SMR for ROP: 0.51 (95% CI: 0.33, 0.70).
   - VLBW infants born in the ROI have significantly lower rates of cystic periventricular leukomalacia (PVL). SMR for PVL: 0.24 (95% CI: -0.31, 0.79).
9. Access to the raw anonymised data will allow a more in-depth analysis of this important national dataset year on year. Important questions that can now be addressed include but are not limited to an assessment of the best configuration of neonatal services in Ireland based on neonatal transfer data and outcomes of VLBW infants according to place of birth.

1. Background

The Vermont Oxford Network (VON) is a non-profit voluntary collaboration of health care professionals dedicated to improving the quality and safety of medical care for newborn infants and their families. Established in 1988, the Network is today comprised of nearly 1000 Neonatal Intensive Care Units around the world (Figure 1.1).

The Network maintains a database of information regarding the care and outcomes of high-risk newborn infants. The database provides unique, reliable and confidential data to participating units for use in quality management, process improvement, internal audit and peer review.

In the ROI, nine tertiary and regional neonatal centres joined VON in 2003, followed by the remaining 10 centres in 2013. This was on foot of a joint initiative between the NICORE group and the NPEC. In 2014, all 19 neonatal centres in the ROI submitted data to VON, signifying the first year for which a National dataset is available.

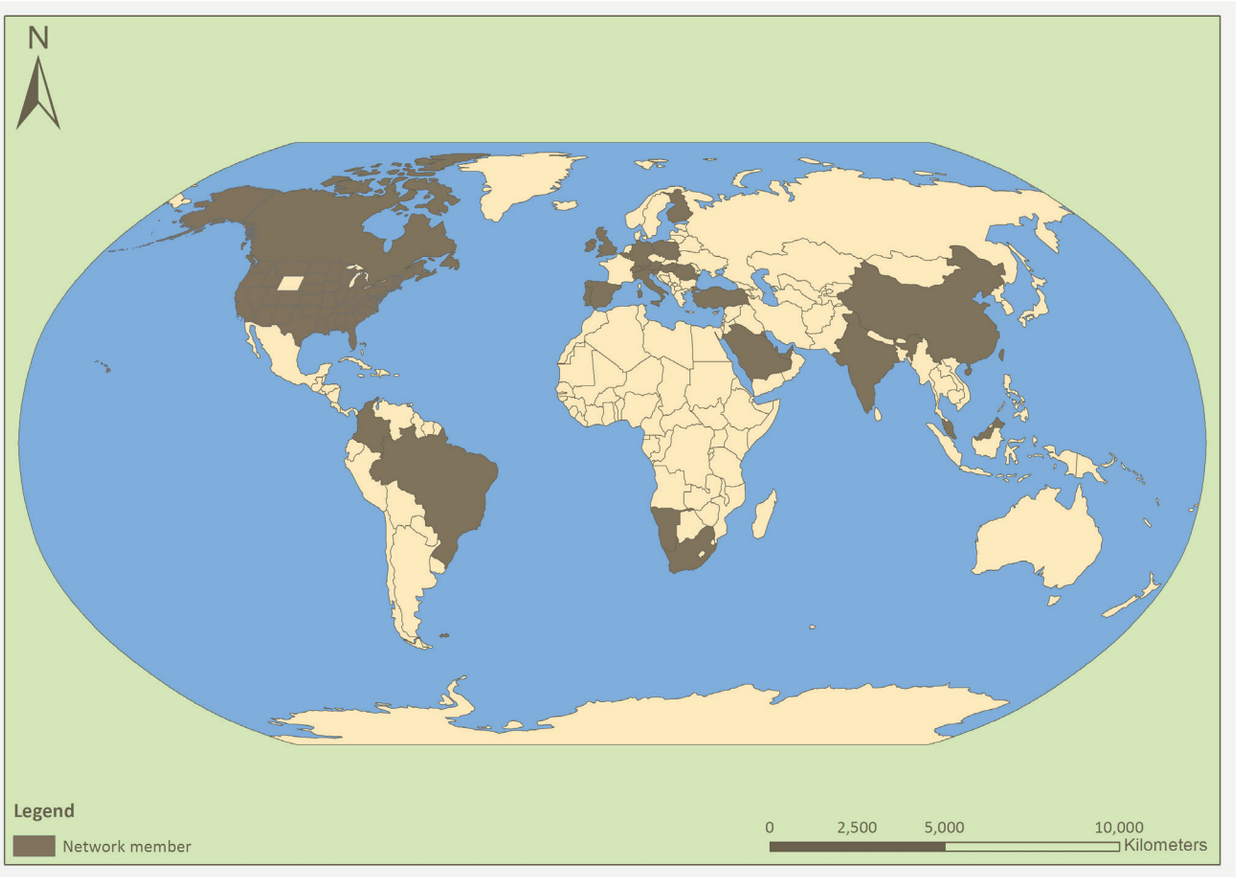

Figure 1.1: Member countries of the Vermont Oxford Network

Governance

For the ROI, data submitted to VON are controlled by NICORE (Neonatal Intensive Care Outcomes Research and Evaluation) ROI, a group of consultant neonatologists and paediatricians with formal representation from all 19 tertiary, regional and peripheral neonatal centres in the Republic. NICORE ROI is formally affiliated through a Memorandum of Understanding to the Faculty of Paediatrics, Royal College of Physicians of Ireland (RCPI). NICORE ROI is also formally affiliated to and functions in partnership with the National Perinatal Epidemiology Centre (NPEC) for the promotion and management of VON in the ROI.

NICORE ROI, incorporating all neonatal centres in the Republic, collaborates with the five neonatal centres in Northern Ireland (NI). This cross-border collaboration has been in existence since 2003 when only nine centres in the ROI were contributing data to VON. The collaborative group at that time was identified as NICORE Ireland. When all 19 centres in the ROI began submitting data to VON, the NICORE ROI group was created. Effectively, NICORE ROI is a subgroup of the parent group, NICORE Ireland. Figure 1.2 illustrates all units participating in VON in the island of Ireland.

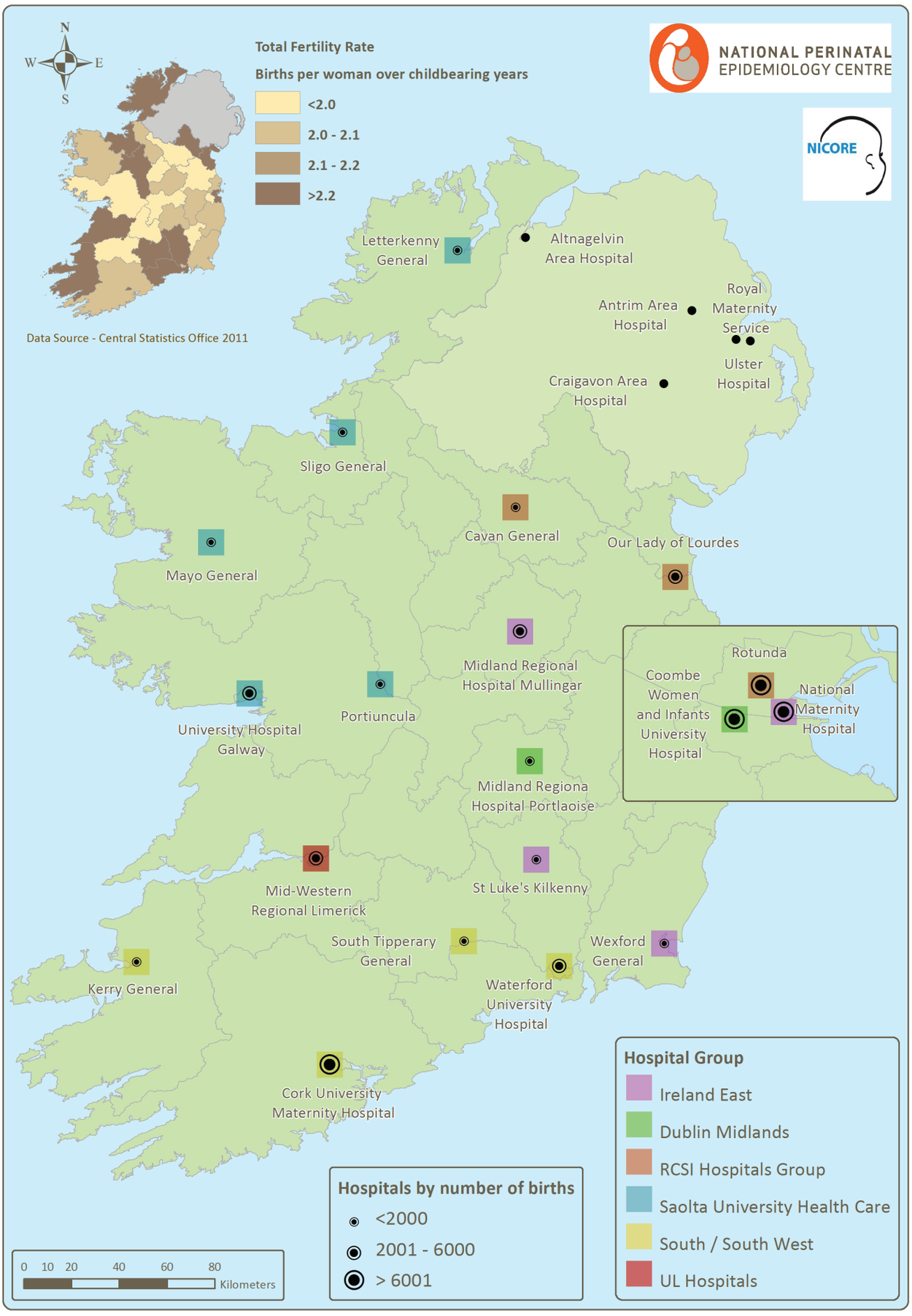

Figure 1.2: Neonatal centres in the Republic of Ireland and Northern Ireland participating in the Vermont Oxford Network. ROI centres are classified according to average annual number of births (in the associated obstetric centres).

2. Methods

Data recording

In 2014, 19 neonatal centres participated in the Vermont Oxford Network (VON)'s Very Low Birth Weight (VLBW) database. The definition of eligibility for the VLBW database is:

> Any infant who is born alive at your hospital and whose birth weight is between 401 and 1500 grams OR whose gestational age is between 22 weeks 0 days and 29 weeks 6 days (inclusive), regardless of where in your hospital the infant receives care

Anonymised data on VLBW infants born between 1st January and 31st December 2014 were submitted to VON's on-line database or alternatively by paper format to the NPEC (see Appendix C for data collection forms). Figure 2.1 illustrates the flow of information involved.

On completion of all ROI submissions for 2014, VON forwarded a copy of the complete ROI dataset to the NPEC. The data presented in this report are based on both the ROI dataset and data from "Nightingale", VON's on-line data reporting system. Throughout the report, ROI data is compared to VON data, comprising data from all centres across the Network.

Definitions and terminology

Birth weight: Weight from the Labour and Delivery record. If this is unavailable, weight on admission to the neonatal unit or lastly, the weight obtained on autopsy (if the infant expired within 24 hours of birth).

Gestational age: The best estimate of gestational age in weeks and days using the following hierarchy:

- obstetric measures based on last menstrual period, obstetrical parameters, and prenatal ultrasound as recorded in the maternal chart.
- neonatologist's estimate based on physical criteria, neurologic examination, combined physical and gestational ages exam (Ballard or Dubowitz), or examination of the lens.

Inborn: Infant delivered at your hospital.

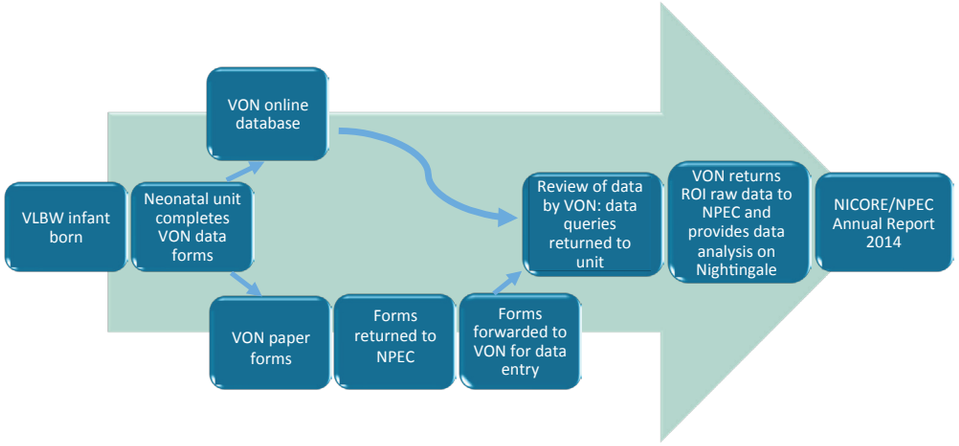

Figure 2.1: Flow of information in the VON data collection process.

Outborn: Infant delivered outside your hospital. Any infant requiring ambulance transfer is considered outborn.

Died in the delivery room: Death of a live born baby who was never admitted to the NICU, and died in the delivery room or at any other location in your hospital within 12 hours after birth.

Mortality: Indicates whether the infant died.

Mortality excluding early deaths: Death excluding those who died in the Delivery Room or within 12 hours of admission to the NICU.

Death or morbidity: Indicates if an infant died or was known to have one or more of the following key morbidities: severe IVH, CLD in infants <33 wks, NEC, pneumothorax, any late infection or PVL.

Chronic Lung Disease (CLD): Based on an algorithm that was tested with hospital data and is more accurate than just oxygen dependency at 36 wks gestational age. CLD is coded 'yes' if the infant is in your centre at 36 weeks postmenstrual age and 'oxygen at 36 weeks' is answered 'yes'. Infants are considered to 'be in your centre at 36 weeks' if they have not been discharged home on that date or if they have been transferred from your centre to another centre prior to the date of week 36 but have been readmitted to your centre before discharge home, death or first birthday or are not transferred a second time before 36 weeks.

If the infant is discharged home on or after 34 weeks postmenstrual age but before 36 weeks, then CLD is equal to the 'value of oxygen at discharge'. The latter is recorded as 'yes' for infants who went home and were on oxygen at the time of discharge. If the infant was transferred to another hospital on or after 34 weeks postmenstrual age but before the date of week 36, then CLD is equal to the 'value of oxygen at the time of discharge' from your institution. Again, the latter is recorded as 'yes' for infants who were transferred and were on oxygen at the time of discharge from your centre.

If the infant is discharged home before 34 weeks postmenstrual and is not on oxygen at the time of discharge, then CLD is coded as 'no'. If the infant is transferred before 34 weeks postmenstrual age and the infant is not on oxygen at discharge, then CLD is coded as 'no'. However, if the infant is discharged home or transferred to another hospital before 34 weeks postmenstrual age, and the infant is on oxygen at the time of discharge from our centre, then CLD is coded as 'unknown'.

Chronic Lung Disease (CLD) < 33 weeks gestation: Same algorithm applied as above but only includes infants < 33 weeks gestation.

Pneumothorax: Extra-pleural air diagnosed by chest radiograph or needle aspiration (thoracentesis).

Late Bacterial Infection: Bacterial pathogen recovered from blood and/or cerebrospinal fluid culture obtained after day 3 of life.

Coagulase Negative Infection: Coagulase negative staphylococcus recovered from a blood culture obtained from either a central line or a peripheral blood sample, and/or recovered from cerebrospinal fluid obtained by lumbar puncture, ventricular tap or ventricular drain after day 3 of life AND one or more signs of generalized infection AND treatment with 5 or more days of intravenous antibiotics.

Nosocomial Infection: Indicates whether the infant has either late bacterial infection and/or coagulase negative staphylococcal infection diagnosed after day 3 of life.

Fungal Infection: Fungus recovered from a blood culture obtained from either a central line or a peripheral blood sample after day 3 of life.

Any Late Infection: Indicates whether the infant has either any late bacterial infection, coagulase negative infection and/or fungal infection after day 3 of life.

Any Intraventricular Haemorrhage (IVH): Indicates whether the infant has a grade 1, 2, 3 or 4 periventricular-intraventricular hemorrhage (PIH) on or before day 28.

Severe Intraventricular Haemorrhage (IVH): Indicates whether the infant has a grade 3 or 4 periventricular-intraventricular hemorrhage (PIH) on or before day 28.

Retinopathy of Prematurity (ROP): Indicates whether the infant has stage 1, 2, 3, 4 or 5 ROP.

Severe Retinopathy of Prematurity (ROP): Indicates whether the infant has stage 3, 4 or 5 ROP.

Cystic Periventricular Leukomalacia (PVL): Evidence of cystic periventricular leukomalacia on a cranial ultrasound, CT, or MRI scan obtained at any time prior to discharge.

Necrotising Enterocolitis (NEC): NEC diagnosed at surgery, at post-mortem examination or "clinically and radiographically". To be diagnosed "clinically and radiographically", there has to be at least one of the following clinical signs present: bilious gastric aspirate or emesis; abdominal distension; occult or gross blood in stool AND at least one of the following radiographic findings present: pneumatosis intestinalis, hepato-biliary air, pneumoperitoneum.

Extreme Length of Stay (survivors only): Indicates whether the infant's total hospital stay is greater than the 90th percentile for the predicted value, based on a multivariable risk adjustment model.

3. Main findings

Overview

A total of 608 VLBW infants were reported to VON in 2014, constituting all 19 Neonatal Intensive Care Units (NICUs) in the Republic of Ireland. Data for two of these infants was not officially signed off by the submitting unit, but is however available on Nightingale, VON's data reporting system, with the result that these data are available for only some of the analyses to follow. In the case of a third infant's data, the birth weight variable had been omitted, therefore excluding this infant from all birth weight analyses.

Table 3.1 outlines the gestational age of infants reported in 2014: 41 infants were born <24 weeks gestation, 117 were between 24 and 26 weeks gestation, 240 between 27 and 29 weeks gestation, 161 between 30 and 32 weeks gestation, and 49 infants were >32 weeks gestation. With regards to birth weight, 26 infants weighed ≤501g, two of whom were ≤401g but ≥22 weeks gestation. A total of 86 infants had a birth weight in the 501-750g category, 116 in the 751-1000g category and 155 in the 1001-1250g category. Overall, 224 infants weighed more than 1250g, 16 of whom were ≥1500g but were ≤29 weeks gestation (Table 3.2).

A total of 60,909 VLBW infants were reported to the Network as a whole in 2014.

Table 3.1: Number of cases reported to VON in 2014, according to gestational age

Gestational age	All cases	No. of cases excluding congenital anomalies
< 24 weeks	41	40
24-26 weeks	117	108
27-29 weeks	240	220
30-32 weeks	161	142
> 32 weeks	49	42
Total	608	552

Table 3.2: Number of cases reported to VON in 2014, according to birth weight

Birth weight (g)	All cases	No. of cases excluding congenital anomalies
< 501	26	25
501 – 750	86	82
751 – 1000	116	101
1001 – 1250	155	140
> 1250	224	203
Total	607	551

One infant is excluded, as birth weight was unavailable

Infant Characteristics

Table 3.3 summarises the characteristics of ROI infants and compares them to those of all infants reported to VON in 2014. The majority of infants in both the ROI and VON received prenatal care, were administered antenatal steroids and were delivered by caesarean section. The proportion delivered by C-Section, administered antenatal magnesium sulphate and which were small for gestational age (SGA) was the same amongst ROI infants as amongst VON infants. There were marginal differences that reached statistical significance: a higher proportion of ROI infants were male, were exposed to chorioamnionitis and were in a multiple gestation, while maternal hypertension was less prevalent in the ROI cases. Prenatal care had been provided for virtually all ROI cases compared to 95% of the VON population; antenatal steroids were more often administered in ROI cases; and congenital malformation in ROI infants was more than twice as common; differences that were highly statistically significant.

Table 3.3: Infant characteristics in the Republic of Ireland and VON, 2014

Characteristic	Republic of Ireland			VON		
	Cases	N	%	N	%	P-value
Male	335	607	55	60,522	51	0.040
Prenatal Care	590	598	99	60,244	95	<0.001
Chorioamnionitis	96	591	16	59,511	13	0.020
Maternal Hypertension	152	599	25	60,066	30	0.014
Antenatal Steroids	516	596	87	60,127	80	<0.001
C-Section	418	605	70	60,508	71	0.303
Antenatal Magnesium Sulphate	304	593	51	58,890	52	0.720
Multiple Gestation	199	606	33	60,533	28	0.008
Congenital Malformation	54	605	9	60,490	5	<0.001
Small for Gestational Age (SGA)	152	607	25	60,409	24	0.551

Note: N represents all babies for whom the variable applies (the denominator).

Survival

In all, 82% (n=492) of VLBW infants born in the ROI survived compared to 86% (n=51,531) of VON infants, a difference which was statistically significant (Table 3.4). The denominator for the survival variable is all infants who survived to discharge home or first birthday (n=600). Eight infants did not have a valid value for this variable: these are all infants whose care was transferred to another hospital and who subsequently did not have their final disposition updated in the VON database.

The percentages of those who survived without specified morbidities, i.e. the key morbidities of severe IVH, chronic lung disease in infants < 33 weeks gestation, NEC, pneumothorax, any late infection or cystic PVL was 53% (n=318) in the ROI and 57% (n=33,983) in VON, a finding which was not statistically significant.

Table 3.4: Survival of ROI and Network infants reported to VON, including those with congenital anomalies, 2014.

Measure	Republic of Ireland			Network			
	Cases	N	%	Cases	N	%	P-value
Survival*	492	600	82%	51,531	60,200	86%	0.01
Survival without specified morbidities**	318	600	53%	33,983	60,148	57%	0.08

* Indicates whether the infant survived to discharge home or first birthday
**Denotes severe IVH, chronic lung disease in infants < 33 weeks gestation, NEC, pneumothorax, any late infection or cystic PVL.

Survival to discharge by gestational age and birth weight is reported in Tables 3.5 and 3.6 respectively.

Table 3.5: Gestational age breakdown and survival to discharge of ROI infants reported to VON, including those with congenital anomalies, 2014

Gestational Age	Number of Survivors to Discharge	Total Number of Liveborn Infants	Percentage
< 22 weeks	0	2	0%
22 weeks	0	18	0%
23 weeks	4	21	19%
24 weeks	16	34	47%
25 weeks	26	36	72%
26 weeks	28	43	65%
27 weeks	53	56	95%
28 weeks	75	83	90%
29 weeks	93	99	94%
30 weeks	69	72	96%
31 weeks	45	50	90%
32 weeks	36	38	95%
>32 weeks	47	49	96%
Total	492	601	82%

Table 3.6: Birth weight and survival to discharge of ROI infants reported to VON, including those with congenital anomalies, 2014 (N=600).

Birth Weight	Number of Survivors to Discharge	Total Number of Liveborn Infants	Percentage
<501g	2	26	8%
501-600g	8	31	26%
601-700g	24	36	67%
701-800g	25	35	71%
801-900g	29	37	78%
901-1000g	51	58	88%
1001-1100g	46	53	87%
1101-1200g	59	63	94%
1201-1300g	82	86	95%
1301-1400g	69	73	94%
>1400g	97	102	95%
Total	492	600	82%

Key Performance Indicators

VON reports on a number of Key Performance Indicators (KPIs). This allows the ROI to compare its outcomes to VON as a whole. It is important for benchmarking performance in the ROI in addition to identifying areas of strengths and areas where continuous improvements could/should be made.

The KPIs are listed below and relevant definitions are outlined above in the Definitions and Terminology section:

1. Mortality
2. Mortality Excluding Early Deaths
3. Death or Morbidity
4. CLD
5. CLD <33 weeks gestation
6. Pneumothorax
7. Late Bacterial Infection
8. Coagulase Negative Infection
9. Nosocomial Infection
10. Fungal Infection
11. Any Late Infection
12. Any IVH
13. Severe IVH
14. ROP
15. Severe ROP
16. Cystic PVL
17. Necrotising Enterocolitis
18. Extreme Length of Stay (survivors only)

For each KPI, the number and percentage of ROI infants that experienced the outcome in 2014 is reported and illustrated in the following charts alongside the equivalent figures for all infants recorded in the VON database. The reporting of the KPIs in numbers and percentages for ROI and VON infants is provided for descriptive purposes. Observed differences in KPIs may be related to the medical care provided but may also be due to differences between the ROI and VON infant populations. Robust comparison of KPIs between the ROI and VON requires that pertinent differences between the infant populations are taken into account. This is done through the calculation of standardised mortality/morbidity ratios (SMRs).

Standard Mortality/Morbidity Ratios (SMRs)

Based on all VON data for infants with birth weights 501-1500g, our VON colleagues use multivariable logistic regression models for each KPI to quantify the risk of the outcome associated with each of the following infant characteristics: gestational age, SGA, multiple gestation, Apgar score at 1 min, gender, vaginal birth, location (inborn or outborn) and birth defect severity. Coefficients from these regression models were provided to the NPEC for use in the calculation of SMRs for each KPI.

SMRs were calculated for ROI babies with birth weights 501-1500g and with complete data for the KPI in question and the infant characteristics used in the regression models. For each KPI, the coefficients were applied to the data of these eligible ROI infants to estimate the risk of the outcome for each infant. Summing these individual risk estimates gives the total number of infants that would be expected to experience the outcome, i.e. the expected number taking into account the risk profile of the ROI infants.

To obtain the SMR for each KPI, the number of eligible ROI infants that actually experienced the outcome, i.e. the observed number of cases, was divided by the expected number of cases (SMR = Observed/Expected).

SMR values equal or close to one indicate that there is little or no difference between the observed and expected number of infants that experienced the outcome, i.e. the number observed was to be expected given the risk profile of the ROI infant population. SMRs greater than one indicate that more infants experienced the outcome than expected given the risk profile of the ROI infants. SMRs less than one indicate that fewer cases were observed among ROI infants than expected.

A 95% confidence interval was calculated for each SMR in order to facilitate making inferences about whether the SMRs reported indicated if the difference between observed and expected was statistically significant. If the 95% confidence interval did not include the value one, it may be inferred that the difference between the numbers of observed and expected cases was statistically significant, i.e. there were more or fewer cases among the ROI infants than expected given their risk profile.

For each KPI, the absolute difference between the observed and expected number of cases is reported and the 95% confidence interval for this difference is also reported in order to provide statements in terms of the actual number of infants affected.

Table 3.7 displays Standardised Mortality/ Morbidity Ratios (SMR = Observed/Expected), the lower and upper bounds of its 95% confidence interval, the difference between the Observed and Expected number of cases and the lower and upper bound of the 95% confidence interval for this difference.

Table 3.7: Risk Adjusted Standardised Mortality/Morbidity Ratios for Key Performance Indicators, Republic of Ireland, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Mortality	86	68	1.27	(1.03, 1.51)	18	(2, 35)
Mortality excluding early death	50	41	1.23	(0.92, 1.54)	9	(-3, 22)
Death or Morbidity	260	228	1.14	(1.01, 1.27)	32	(3, 62)
Chronic Lung Disease*	104	96	1.08	(0.88, 1.28)	8	(-12, 27)
Pneumothorax	35	21	1.67	(1.25, 2.10)	14	(5, 23)
Late Bacterial Infection	34	49	0.69	(0.41, 0.97)	-15	(-29, -1)
Coagulase Negative Infection	46	25	1.84	(1.45, 2.23)	21	(11, 31)
Nosocomial Infection	71	55	1.30	(1.04, 1.57)	16	(2, 31)
Fungal Infection	2	4	0.55	(-0.48, 1.57)	-2	(-5, 2)
Any Late Infection	71	56	1.26	(1.00, 1.52)	15	(0, 29)
Intraventricular Haemorrhage	113	106	1.07	(0.88, 1.26)	7	(-13, 27)
Severe Intraventricular Haemorrhage	35	29	1.22	(0.85, 1.58)	6	(-4, 17)
Retinopathy of Prematurity	57	112	0.51	(0.33, 0.70)	-55	(-75, -34)
Severe Retinopathy of Prematurity	15	18	0.83	(0.37, 1.29)	-3	(-11, 5)
Cystic Periventricular Leukomalacia	3	13	0.24	(-0.31, 0.79)	-10	(-17, -3)
Necrotising Enterocolitis	33	27	1.21	(0.84, 1.59)	6	(-4, 16)

O is the number of observed cases with the outcome and E is the expected number with the outcome of ROI infants with birth weights 501-1500g. 95% confidence intervals (CIs) are provided for the SMR and the difference in observed and expected cases.
*The SMR for chronic lung disease (CLD) is provided: the SMR for CLD < 33 weeks is not provided.

KPI 1: Mortality and KPI 2: Mortality Excluding Early Death

In 2014, 18% of VLBW babies in the ROI infants died (n=109). This compares to 14% for all infants recorded in the VON database (n=8,649). Half of the ROI infants who died did so within the first 12 hours of life. After excluding such early deaths, the percentage who died was 9% for ROI infants (n=50) and 10% (n=5,653) for VON infants (Figure 3.1).

There were 86 deaths observed amongst ROI infants with birth weights 501-1500g whereas the expected number based on the risk profile of the infants in the Irish population was 68 (Table 3.8). The SMR was 1.27 (95% CI: 1.03, 1.51), indicating that the number of observed cases was 1.27 times the expected number. In absolute numbers there were 18 more deaths than expected. This was a statistically significant excess in mortality (95% CI: 2, 35).

Excluding early deaths, there were 50 observed deaths compared to an expected number of 41 (Table 3.8). Thus, the observed number equated to 1.23 times the expected number (SMR=1.23, 95% CI: 0.92, 1.54). In absolute numbers there were nine more cases of mortality excluding early death than expected but this difference was not statistically significant (95% CI:-3, 22).

A higher proportion of ROI infants died in the delivery room (8%, n=50) compared to VON (4%, n=2,193) (p<0.001). Seven of the 50 (14%) ROI infants who died in the delivery room had a major congenital malformation and a further 36 were born at less than 24 weeks gestation. In total, 43 of 50 infants who died in the delivery room in the ROI either had a major congenital malformation or were less than 24 weeks gestation.

Overall, there were 41 infants born less than 24 weeks gestation in the ROI, the majority of whom died in the delivery room (n=36, 88%).

This compares to 39% (1,592 of 4,051) of infants born less than 24 weeks gestation in the VON population. Again, this difference was statistically significant ($p<0.001$).

This is an area that NICORE ROI plans to explore in further detail for 2014 and future years. It will be possible to interrogate the raw data to determine whether these infants are being delivered in local, regional or tertiary maternity centres, whether they are being offered intensive care in the delivery room and whether intensive care when offered in the delivery room is successful or not. We may also be able to determine if there are specific factors that influence the decision as to whether intensive care is provided in the delivery room or not.

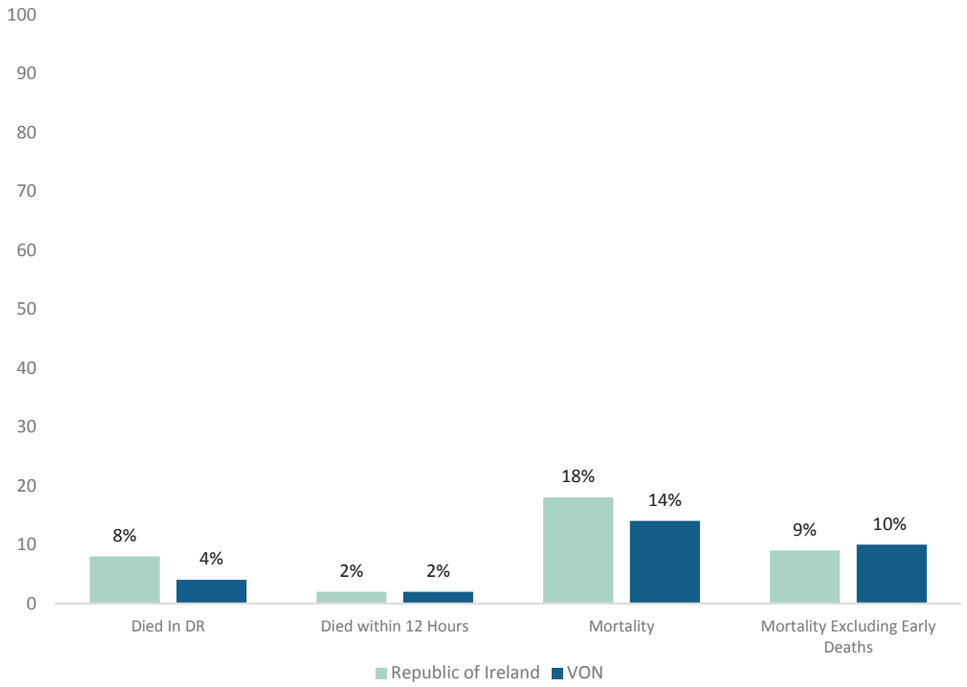

Figure 3.1: Distribution of mortality amongst ROI and VON infants, 2014.

Table 3.8: Risk Adjusted Standardised Mortality Ratios for Key Performance Indicators - KPI 1: mortality and KPI 2: mortality excluding early death, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Mortality	86	68	1.27	(1.03, 1.51)	18	(2, 35)
Mortality excluding early death	50	41	1.23	(0.92, 1.54)	9	(-3, 22)

O=observed, E=expected, SMR=standardised mortality ratio, CI=confidence interval

KPI 3: Death or Morbidity

In 2014, 47% of ROI infants (n=283) suffered death or morbidity. This compares to 44% of VON infants (n=26,224).

Figures 3.2 and 3.3 illustrate the change in the number of cases of death or morbidity across gestational age and birth weight categories respectively. As gestational age increases there was a clear statistically significant decrease in death or morbidity in ROI infants ($p<0.001$). Additionally, as birth weight increases there was a clear statistically significant decrease in death or morbidity in ROI infants ($p<0.001$).

There were 260 observed cases of death or morbidity amongst ROI infants with birth weights 501-1500g whereas the expected number based on the risk profile of the infants in the Irish population was 228 cases (Table 3.9). The SMR was 1.14 (95% CI: 1.01, 1.27), indicating that the number of observed cases was 1.14 times the expected number. In absolute numbers there were 32 more cases of death or morbidity in the ROI than expected. This was a statistically significant excess in death or morbidity (95% CI: 3, 62).

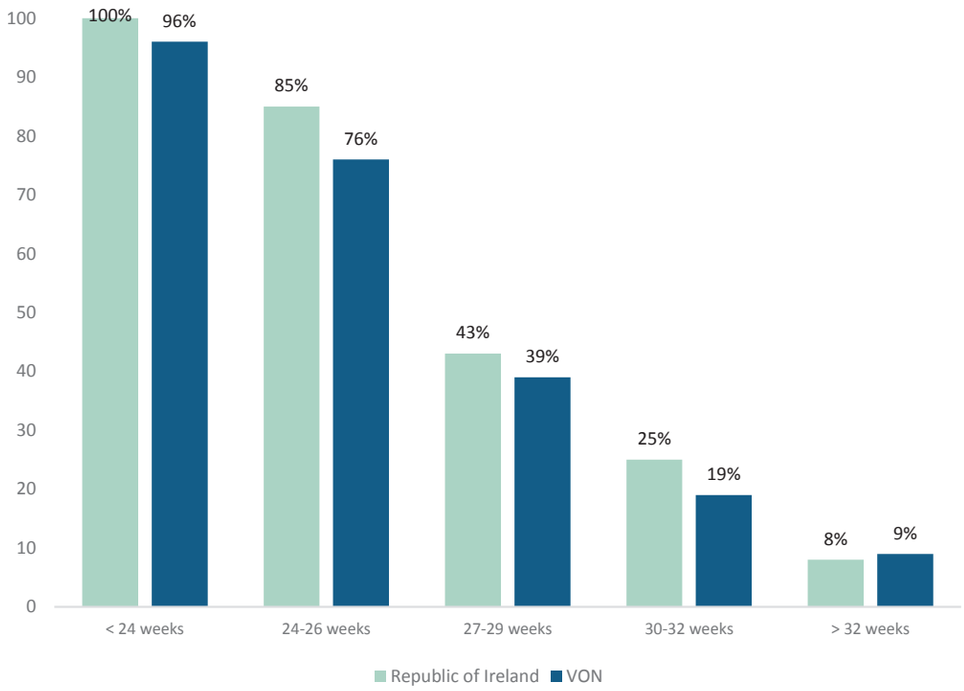

Figure 3.2: Distribution of death or morbidity amongst infants by gestational age, 2014

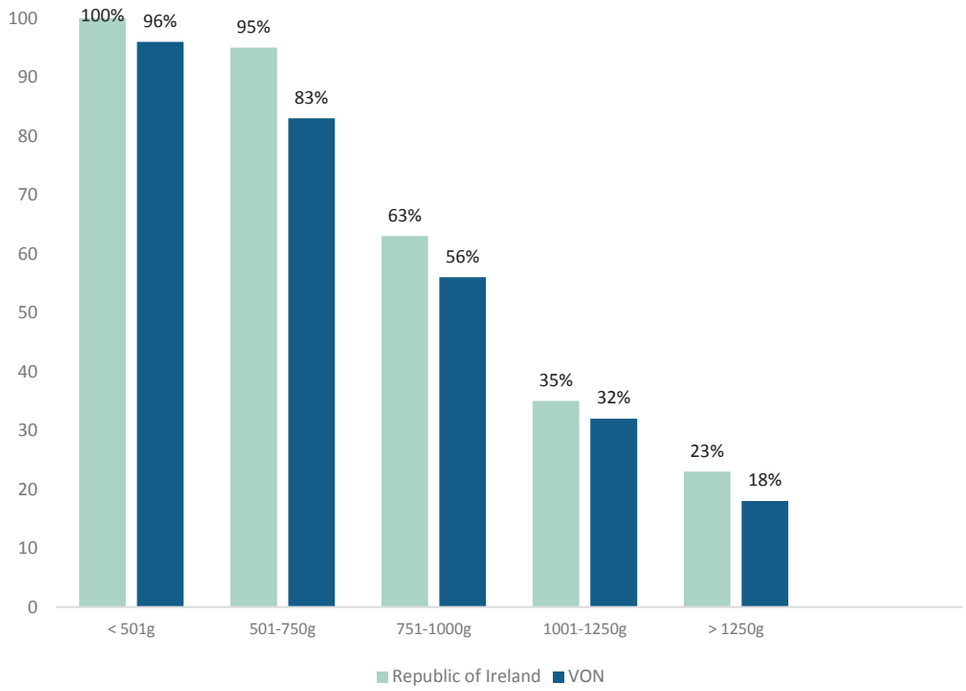

Figure 3.3: Distribution of death or morbidity amongst infants by birth weight, 2014

Table 3.9: Risk Adjusted Standardised Mortality Ratios for Key Performance Indicators - KPI 3: death or morbidity, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Death or Morbidity	260	228	1.14	(1.01, 1.27)	32	(3, 62)

O=observed, E=expected, SMR=standardised mortality ratio, CI=confidence interval

KPI 4: CLD and KPI 5: CLD < 33 weeks

In 2014, 22% of ROI infants (n=108) were classified as having CLD. This compares to 25% of VON infants (n=12,836). The proportion of CLD in infants <33 gestational weeks was 24% (n=107) in ROI infants and 27% (n=12,532) in VON infants.

Figures 3.4 and 3.5 illustrate the change in CLD cases across all gestational age and birth weight categories respectively. As gestational age increases there was a significant decrease in CLD cases in ROI infants (p<0.001). Likewise, as birth weight increases there was a significant decrease in CLD cases in ROI infants (p<0.001).

There were 104 observed cases of CLD amongst ROI infants with birth weights 501-1500g whereas the expected number based on the risk profile of the infants in the Irish population was 96 (Table 3.10). The SMR was 1.08 (95% CI: 0.88, 1.28), indicating that the number of observed cases was 1.08 times the expected number. In absolute numbers there were eight more cases of CLD than expected which was not statistically significant (95% CI:-12, 27).

SMR data for CLD < 33 weeks are not available.

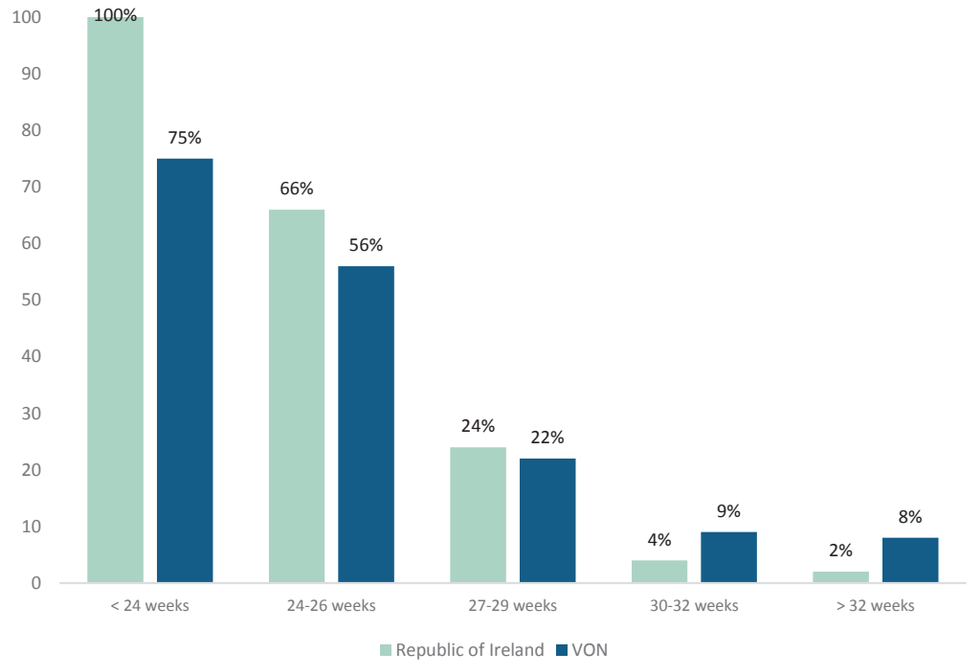

Figure 3.4: Distribution of chronic lung disease amongst infants by gestational age, 2014

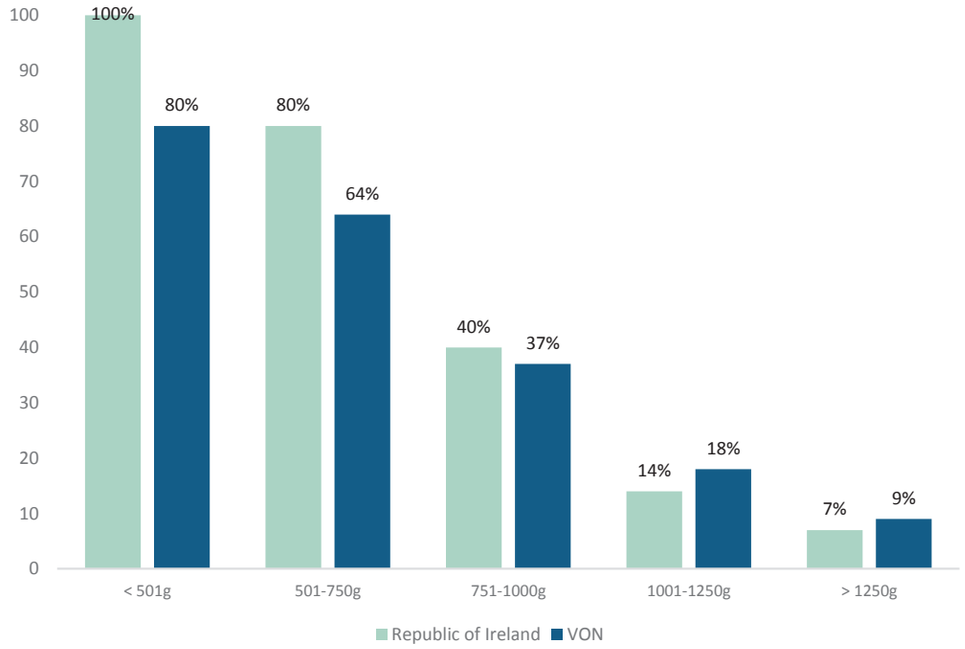

Figure 3.5: Distribution of chronic lung disease amongst infants by birth weight, 2014

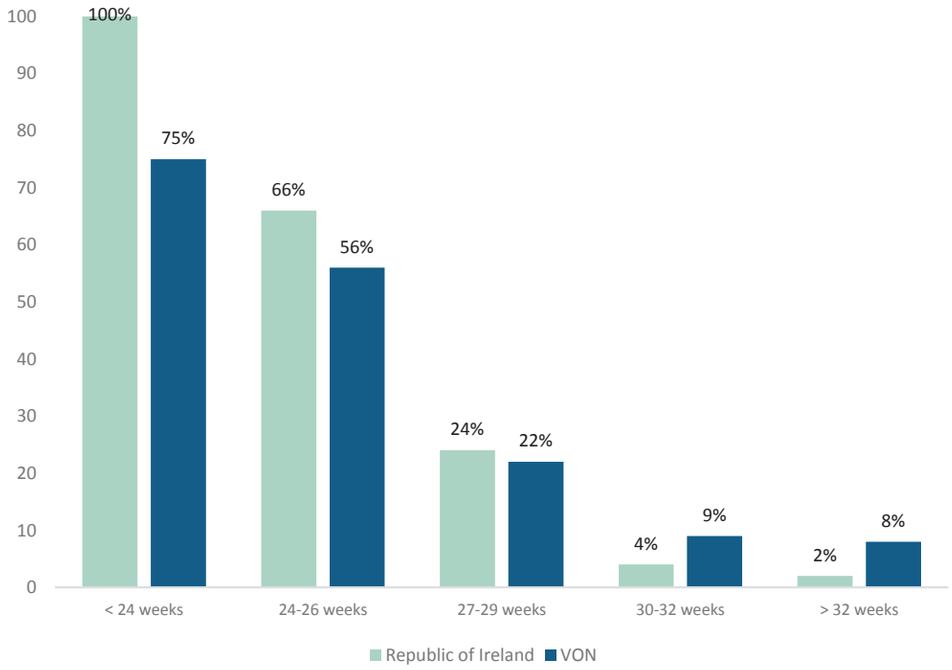

Figure 3.6: Distribution of chronic lung disease < 33 weeks amongst infants by gestational age, 2014

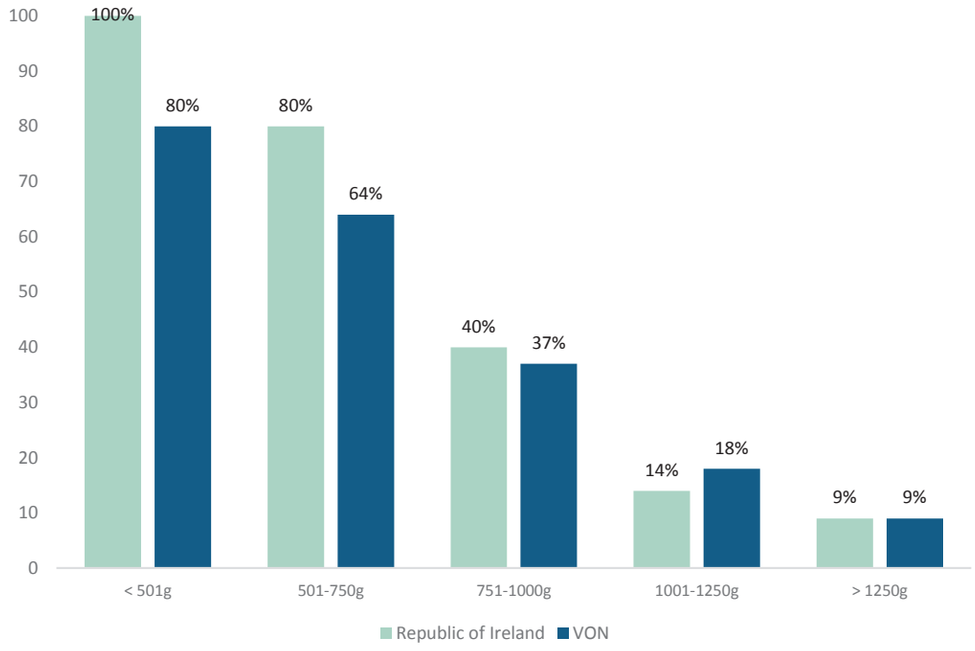

Figure 3.7: Distribution of chronic lung disease < 33 weeks amongst infants by birth weight, 2014

Table 3.10: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 4: chronic lung disease, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Chronic Lung Disease	104	96	1.08	(0.88, 1.28)	8	(-12, 27)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPI 6: Pneumothorax

In 2014, 6% of ROI infants (n=35) were classified as having pneumothorax. This compares to 4% of VON infants (n=2,565).

Figures 3.8 and 3.9 outline the proportion of pneumothorax in ROI and VON infants according to gestational age and birth weight categories respectively. In ROI infants, increasing gestational age was associated with a slight decrease in pneumothorax but this decrease was not statistically significant (p=0.492). Similarly, increasing birth weight was associated with a slight decrease in pneumothorax but this decrease was also not statistically significant (p=0.910). It must be noted that overall the number of pneumothorax cases seen across the gestational age and birth weight categories in ROI infants are quite small.

There were 35 observed cases of pneumothorax amongst ROI infants with birth weights 501-1500g whereas the expected number based on the risk profile of the infants in the Irish population was 21 (Table 3.11). The SMR was 1.67 (95% CI: 1.25, 2.1), indicating that the number of observed cases was 1.67 times the expected number. This was a statistically significant excess of 14 cases of pneumothorax (95% CI: 5, 23).

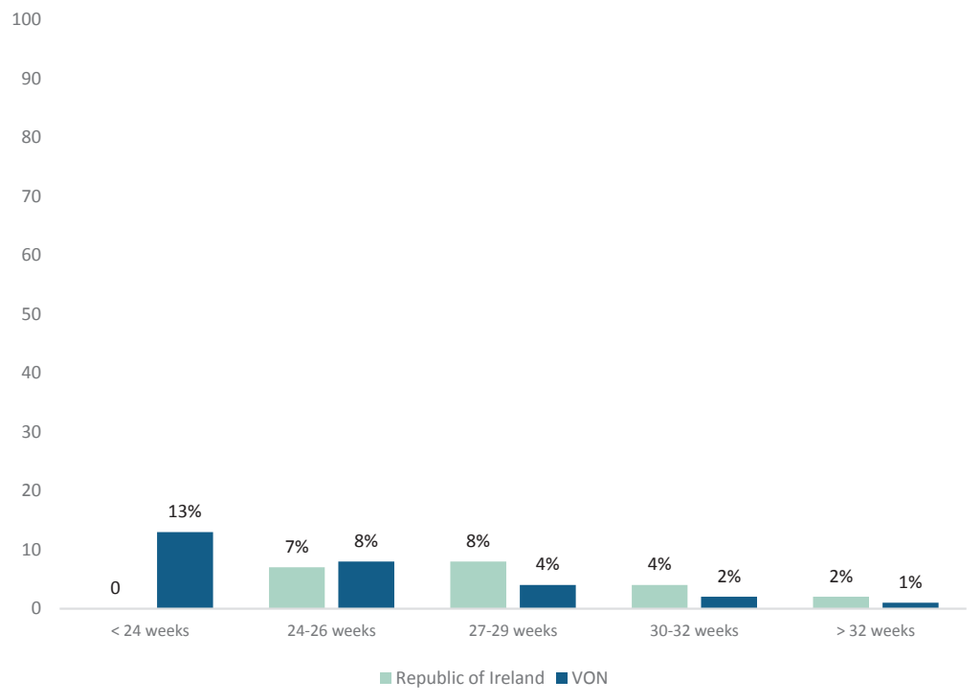

Figure 3.8: Distribution of pneumothorax amongst infants by gestational age, 2014

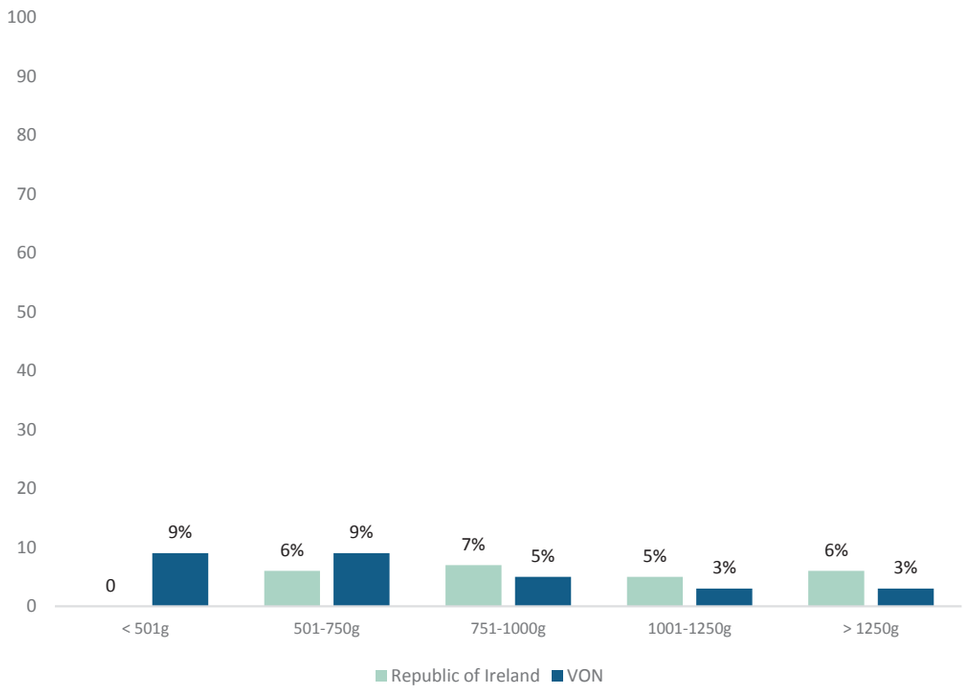

Figure 3.9: Distribution of pneumothorax amongst infants by birth weight, 2014

Table 3.11: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 6: pneumothorax, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Pneumothorax	35	21	1.67	(1.25, 2.10)	14	(5, 23)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPIs 7 – 11: Infections: late bacterial infection, coagulase negative infection, nosocomial infection, fungal infection and any late infection.

Figure 3.10 compares the proportion of infections in ROI and VON infants. For ROI infants, percentages of late bacterial infection compared favourably to the VON as a whole, but ROI infants had higher percentages of coagulase negative infection. Due to the higher proportion of coagulase negative infection in ROI infants, the percentages of nosocomial infection and any late infection were also higher in ROI infants.

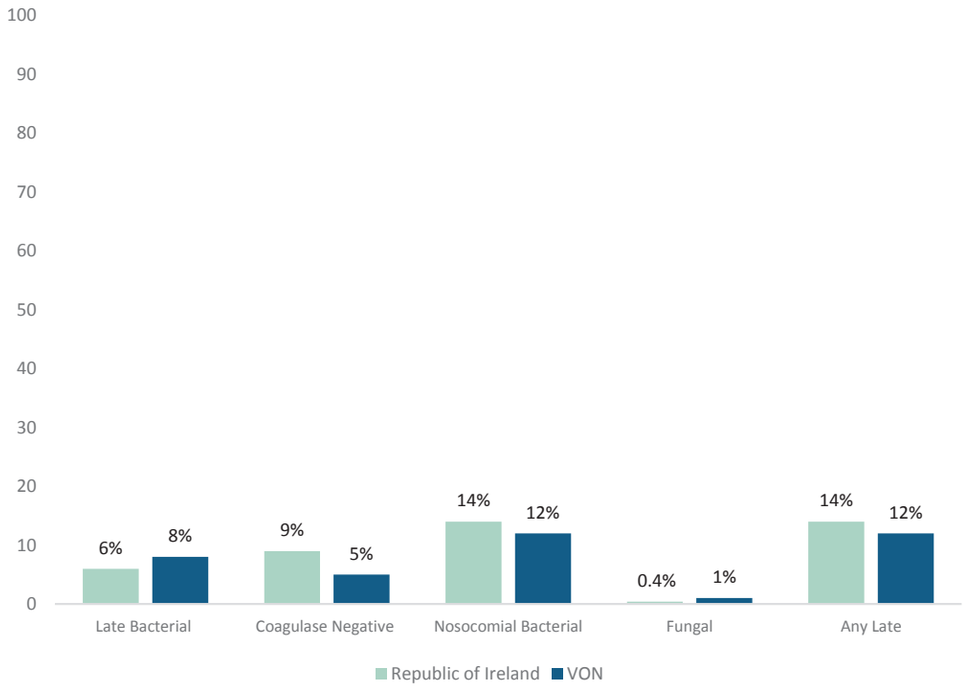

Figure 3.10: Distribution of infections in ROI and VON infants, 2014

KPI 7: Late Bacterial Infection

The proportion of late bacterial infection in ROI infants was 6% (n=34) compared to 8% (n=4,685) in all VON infants. Figures 3.11 and 3.12 illustrate the prevalence of late bacterial infection across all gestational age and birth weight categories respectively. As gestational age increases there was a statistically significant decrease in cases of late bacterial infection in ROI infants ($p<0.001$). Similarly, as birth weight increases there was a statistically significant decrease in cases of late bacterial infection in ROI infants ($p<0.001$).

Amongst ROI infant with birth weights 501-1500g, there were 34 observed cases of late bacterial infection compared to an expected number of 49 cases (Table 3.12). Thus, the observed number equated to 69% of the expected number (SMR=0.69, 95% CI: 0.41, 0.97). In absolute numbers there were 15 fewer cases of late bacterial infection than expected, which was statistically significant (95% CI: -29, -1).

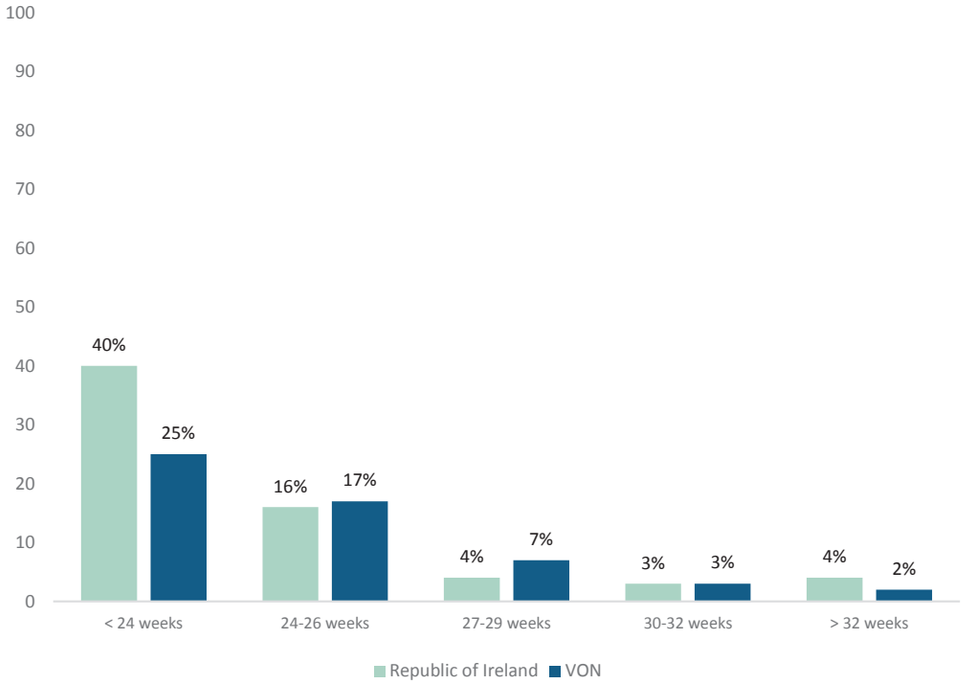

Figure 3.11: Distribution of late bacterial infection amongst infants by gestational age, 2014

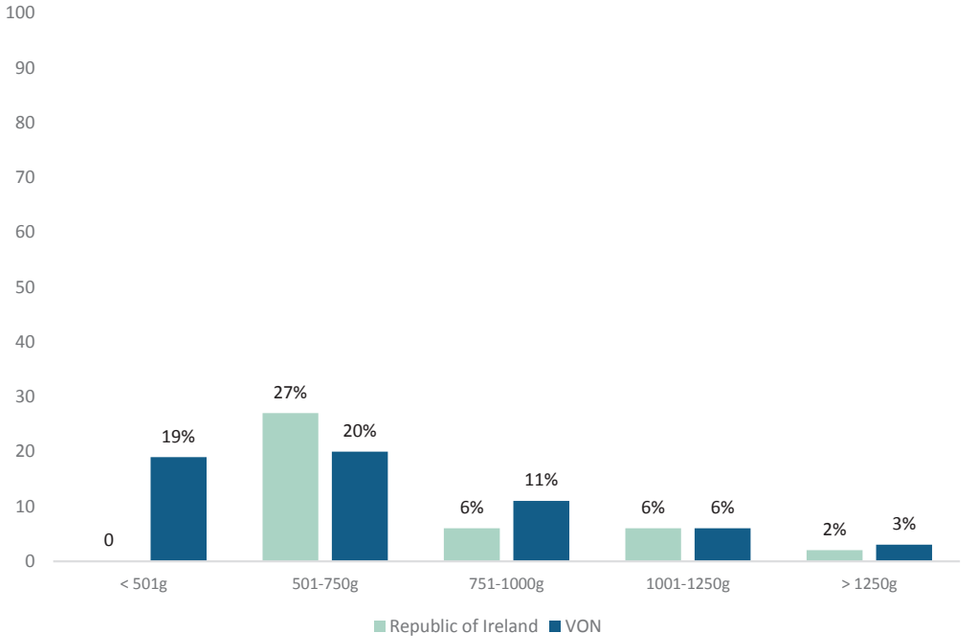

Figure 3.12: Distribution of late bacterial infection amongst infants by birth weight, 2014

Table 3.12: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 7: late bacterial infection, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Late Bacterial Infection	34	49	0.69	(0.41, 0.97)	-15	(-29, -1)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPI 8: Coagulase Negative Infection

Coagulase negative infection was observed in 9% (n=47) of ROI infants and 5% of VON infants (n=3,013). Figures 3.13 and 3.14 illustrate the change in cases of coagulase negative infection across all gestational age and birth weight categories respectively. In ROI infants, increasing gestational age was associated with a slight decrease in cases of coagulase negative infection but this decrease was not statistically significant (p=0.064). Increasing birth weight was however associated with a statistically significant decrease in cases of coagulase negative infection in ROI infants (p=0.013).

Adjusting for the risk profile of ROI infants born weighing 501-1500g, there were 46 observed cases of coagulase negative infection compared to an expected number of 25 cases (Table 3.13). Thus, the observed number was almost twice the expected number (SMR=1.84, 95% CI: 1.45, 2.23). In absolute numbers there were 21 more cases of coagulase negative infection than expected, which was a statistically significant excess (95% CI: 11, 31).

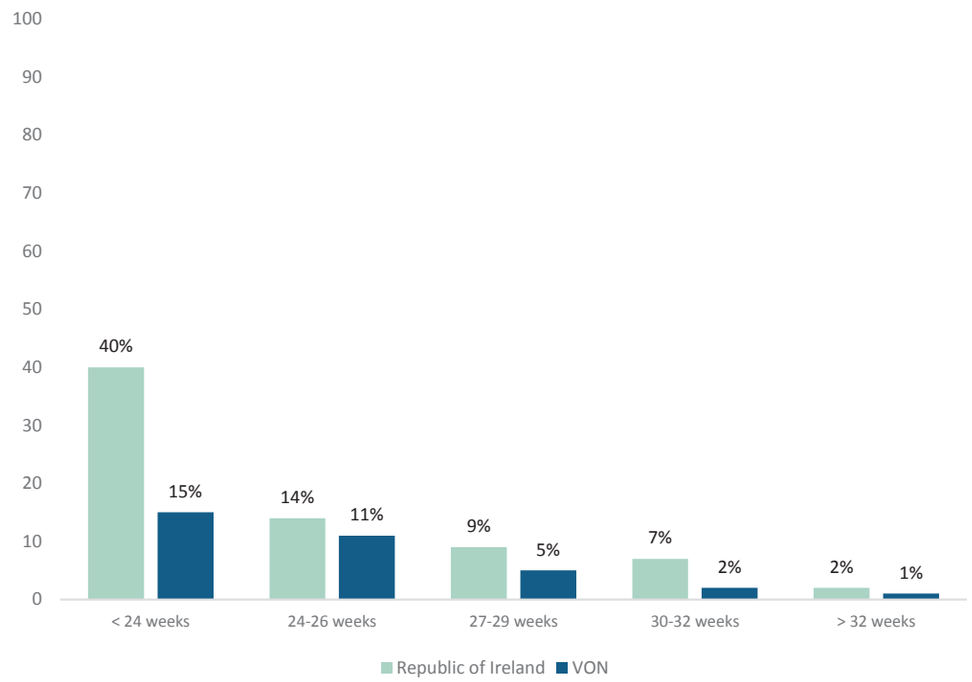

Figure 3.13: Distribution of coagulase negative infection amongst infants by gestational age, 2014

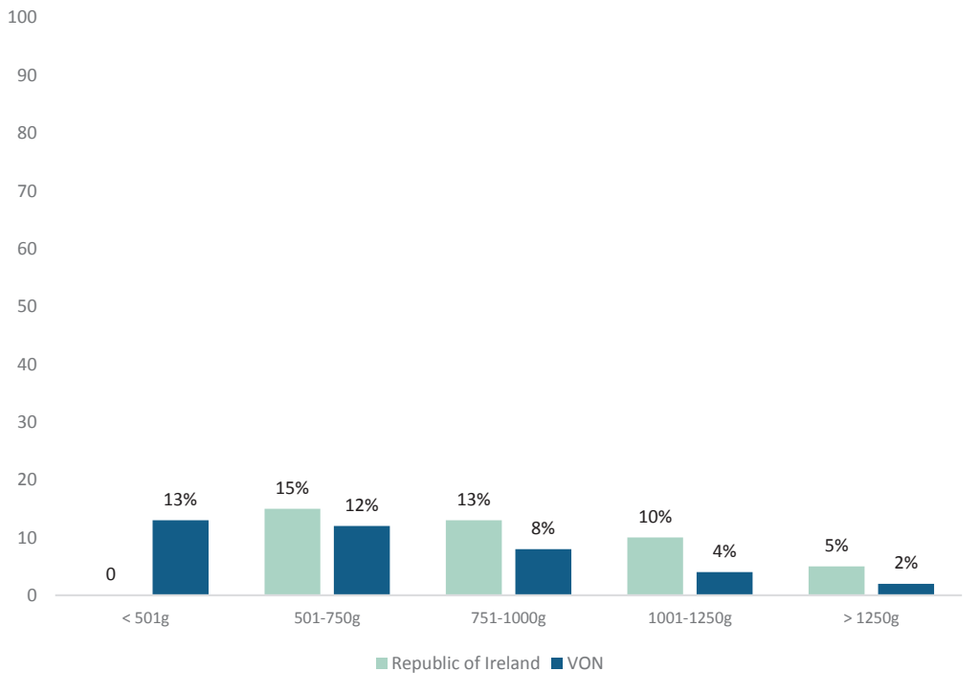

Figure 3.14: Distribution of coagulase negative infection amongst infants by birth weight, 2014

Table 3.13: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 8: coagulase negative infection, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Coagulase Negative Infection	46	25	1.84	(1.45, 2.23)	21	(11, 31)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPI 9: Nosocomial Infection

Nosocomial infection was reported in 14% (n=72) of the ROI infant population and 12% (n=6,636) of the VON population. Figures 3.15 and 3.16 illustrate the change in cases of nosocomial infection across all gestational age and birth weight categories respectively. As gestational age increases there was a statistically significant decrease in cases of nosocomial infection in ROI infants ($p<0.001$). Likewise, as birth weight increases there was a statistically significant decrease in cases of nosocomial infection in ROI infants ($p<0.001$).

There were 71 observed cases of nosocomial infection amongst ROI infants with birth weights 501-1500g whereas the expected number based on the risk profile of the infants was 55 cases (Table 3.14). Thus, there were 30% more cases observed than expected (SMR=1.30, 95% CI: 1.04, 1.57). In absolute numbers this equated to an excess of 16 cases, a statistically significant difference (95% CI: 2, 31).

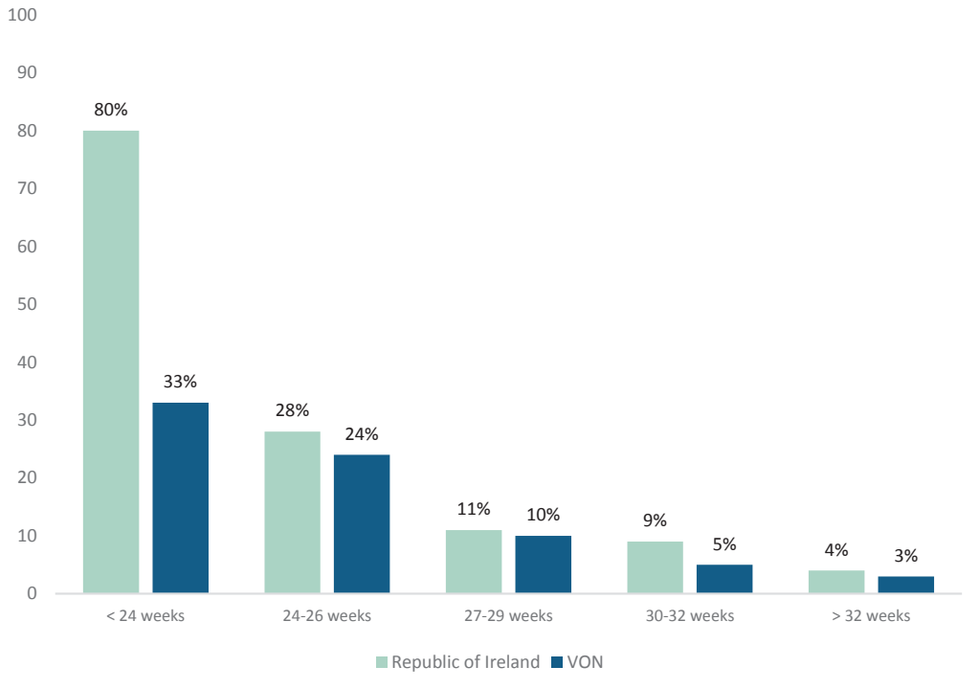

Figure 3.15: Distribution of nosocomial infection amongst infants by gestational age, 2014

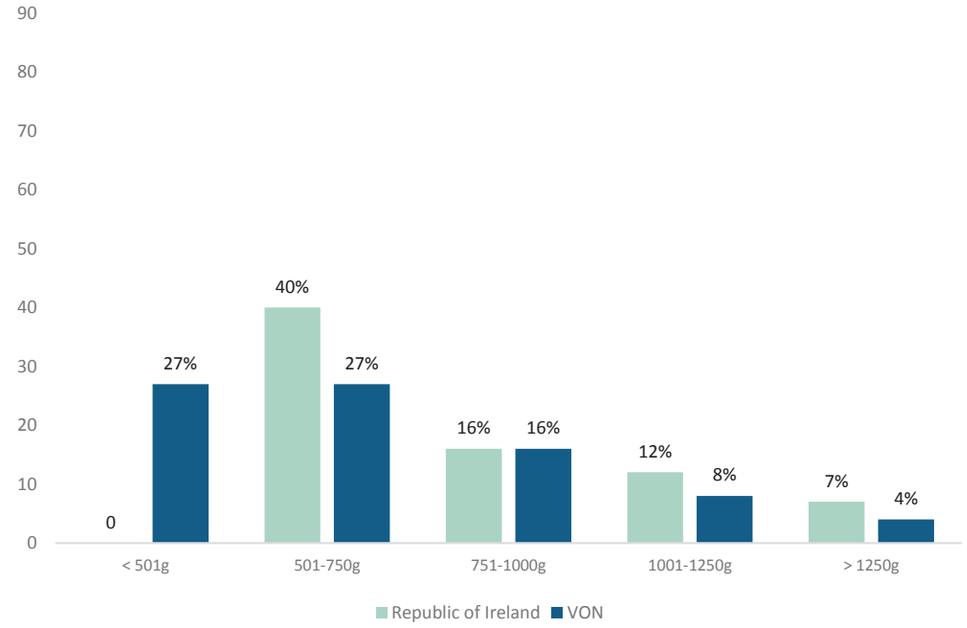

Figure 3.16: Distribution of nosocomial infection amongst infants by birth weight, 2014

Table 3.14: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 9: nosocomial infection, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Nosocomial Infection	71	55	1.30	(1.04, 1.57)	16	(2, 31)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPI 10: Fungal Infection

Two (0.4%) ROI infants experienced fungal infection in 2014, compared to 505 (0.9%) infants in the Network. Both ROI infants were in the 501-750g birth weight category and in the 24-26 week gestational age category. Graphs are not included.

The two observed cases of fungal infection were amongst the infants born weighing 501-1500g. Based on the risk profile of ROI infants, there was an expected number of four cases (Table 3.15). The two fewer cases of fungal infection than expected did not constitute a statistically significant reduction in fungal infection cases (95% CI: -5, 2).

Table 3.15: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 10: fungal infection, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Fungal Infection	2	4	0.55	(-0.48, 1.57)	-2	(-5, 2)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPI 11: Any Late Infection

Any late infection was reported for 14% of ROI infants (n=72) and 12% of VON infants (n=6,860). Figures 3.17 and Figure 3.18 illustrate the change in cases of any late infection across all gestational age and birth weight categories respectively. As gestational age increases there was a statistically significant decrease in cases of any late infection in ROI infants ($p<0.001$). Similarly, as birth weight increases there was a statistically significant decrease in cases of any late infection in ROI infants ($p<0.001$).

Considering ROI infants born weighing 501-1500g for whom risk adjustment was performed, there were 71 observed cases with any late infection compared to an expected number of 56 cases (Table 3.16). Thus, the observed number equated to 1.26 times the expected number (SMR=1.26, 95% CI: 1.00, 1.52) and the excess of 15 cases just reached statistical significance (95% CI: 0, 29).

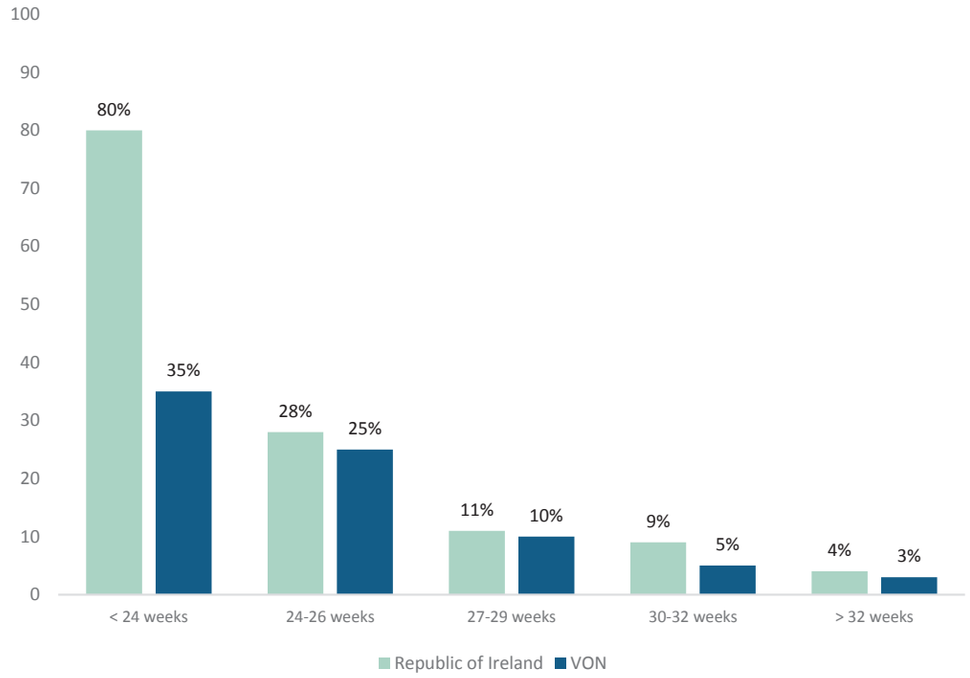

Figure 3.17: Distribution of any late infection amongst infants by gestational age, 2014

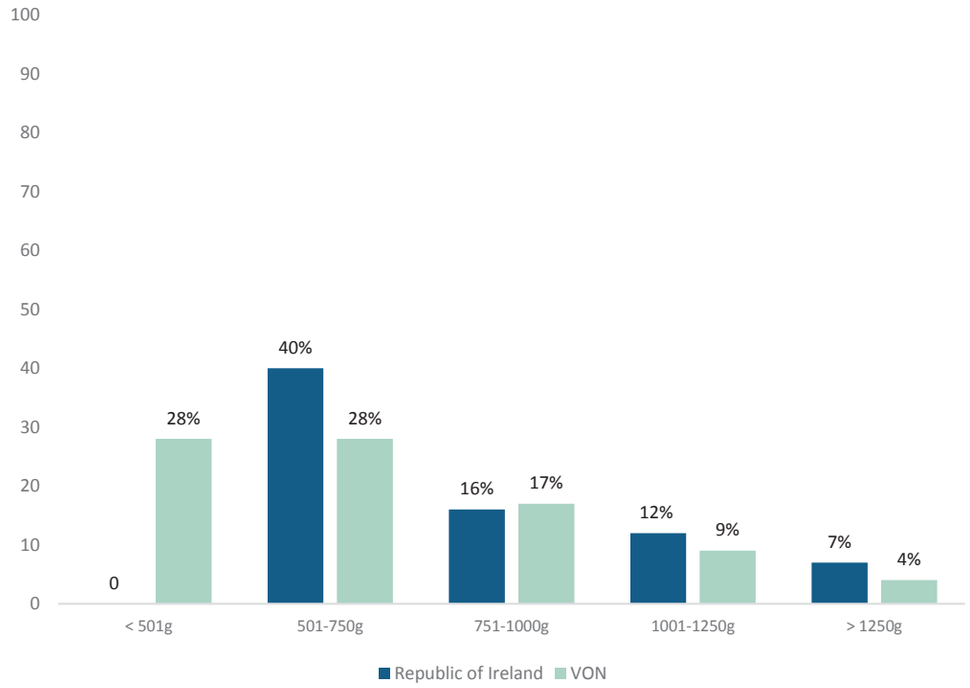

Figure 3.18: Distribution of any late Infection amongst infants by birth weight, 2014

Table 3.16: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 11: any late infection, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Any Late Infection	71	56	1.26	(1.00, 1.52)	15	(0, 29)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPI 12: Any IVH and KPI 13: Severe IVH

Overall, 23% (n=116) of ROI infants experienced IVH compared to 25% (n=13,040) of VON infants. Severe IVH was observed in 7% (n=35) and 8% (n=4,244) of ROI and VON infants respectively. Figures 3.19 and 3.20 illustrate the change in cases of IVH across all gestational age and birth weight categories respectively. As gestational age increases there was a statistically significant decrease in cases of IVH in ROI infants (p<0.001). Likewise, as birth weight increases there was a statistically significant decrease in cases of IVH in ROI infants (p<0.001).

Figures 3.21 and 3.22 illustrate the change in cases of severe IVH across all gestational age and birth weight categories respectively. As gestational age increases there was a statistically significant decrease in cases of severe IVH in ROI infants (p<0.001). Similarly, as birth weight increases there was a statistically significant decrease in cases of severe IVH (p<0.001).

IVH was observed in 113 ROI infants weighing 501-1500g at birth whereas the number of cases expected based on the infants' risk profile was 106 (Table 3.17). Thus, the observed number was only marginally higher than expected (SMR=1.07, 95% CI: 0.88, 1.26), by seven cases in absolute numbers, which was not a statistically significant difference (95% CI: -13, 27).

Similarly with severe IVH, there were 35 observed cases compared to an expected number of 29 cases, an excess of six cases which was not statistically significant (95% CI: -4, 17).

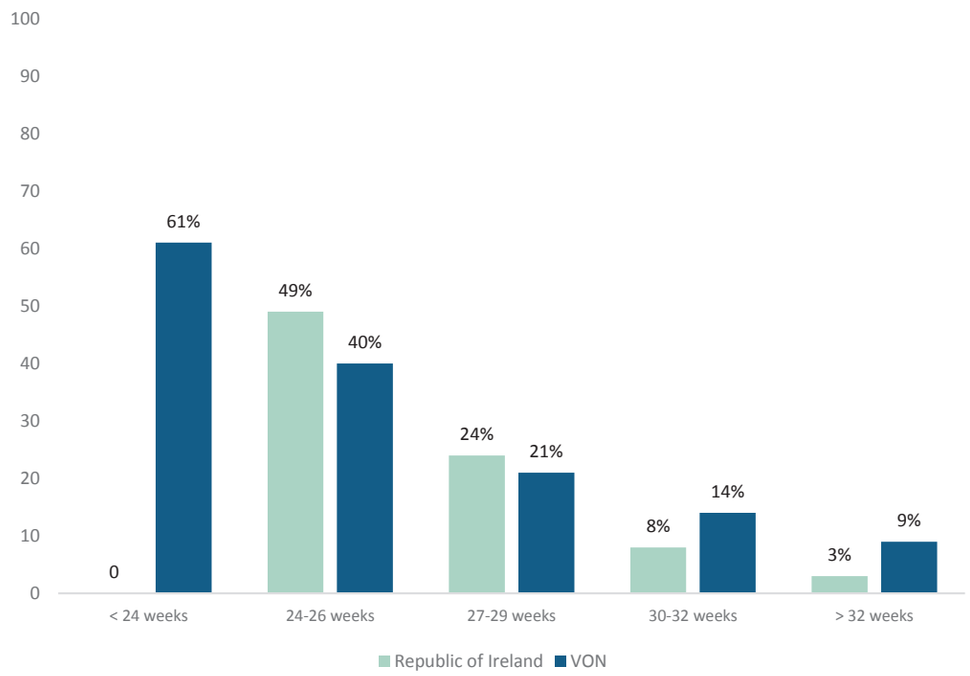

Figure 3.19: Distribution of any IVH amongst infants by gestational age, 2014

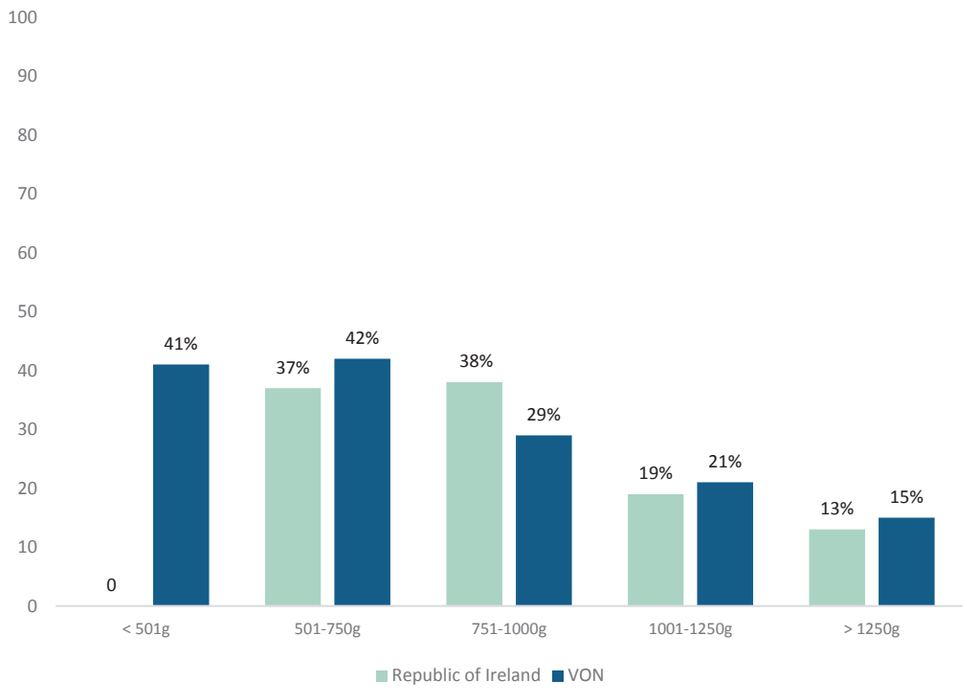

Figure 3.20: Distribution of any IVH amongst infants by birth weight, 2014

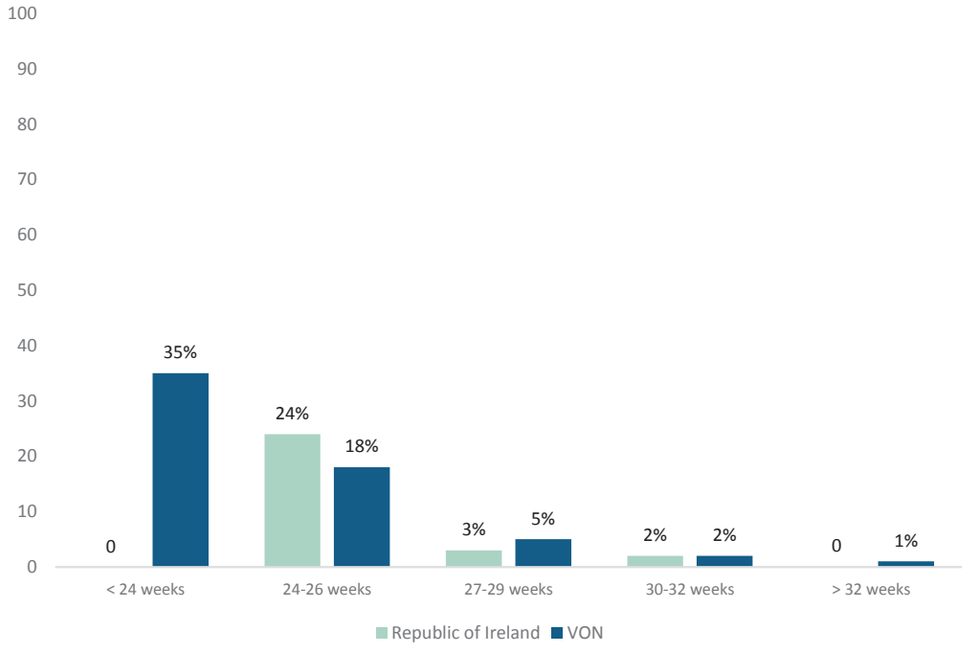

Figure 3.21: Distribution of severe IVH amongst infants by gestational age, 2014

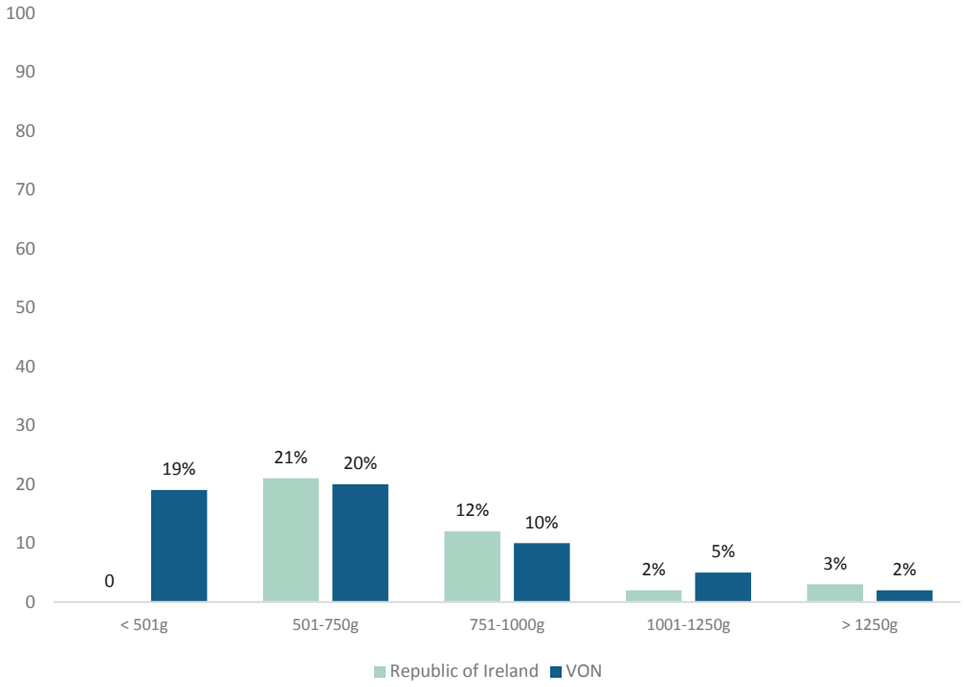

Figure 3.22: Distribution of severe IVH amongst infants by birth weight, 2014

Table 3.17: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 12: intraventricular haemorrhage and KPI 13: severe intraventricular haemorrhage, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Intraventricular Haemorrhage	113	106	1.07	(0.88, 1.26)	7	(-13, 27)
Severe Intraventricular Haemorrhage	35	29	1.22	(0.85, 1.58)	6	(-4, 17)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPI 14: ROP and KPI 15: Severe ROP

ROP was reported for approximately one in eight ROI infants (13%, n=58) whereas ROP affected one in three VON infants (32%, n=13,566). Severe ROP (stage 3 or greater) was reported for 3% of ROI infants (n=14) compared to 6% (n=2,713) of all VON infants. Figures 3.23 and 3.24 illustrate the change in cases of ROP across all gestational age and birth weight categories respectively. As gestational age increases there was a statistically significant decrease in cases of ROP in ROI infants ($p<0.001$). Likewise, as birth weight increases there was a statistically significant decrease in cases of ROP in ROI infants ($p<0.001$).

Figures 3.25 and 3.26 illustrate the change in cases of severe ROP across all gestational age and birth weight categories. As gestational age increases there was a statistically significant decrease in cases of severe ROP in ROI infants ($p=0.001$). Similarly, as birth weight increases there was a statistically significant decrease in cases of severe ROP in ROI infants ($p<0.001$). It must be noted that overall the number of cases of severe ROP seen across the gestational age and birth weight categories are quite small.

Considering ROI infants born weighing 501-1500g for whom risk adjustment was performed, there were 57 observed cases compared to an expected number of 112 cases (Table 3.18). Thus, the observed number equated to half the expected number (SMR=0.51, 95% CI: 0.33, 0.70). In absolute numbers there were 55 fewer cases of ROP than expected, which was a statistically significant reduction (95% CI: -75, -34).

With regard to severe ROP, there were 15 observed cases among these infants which was only marginally lower than the expected number of 18 cases (SMR=0.83, 95% CI: 0.37, 1.29). In absolute numbers the three fewer cases than expected was not statistically significant (95% CI: -11, 5).

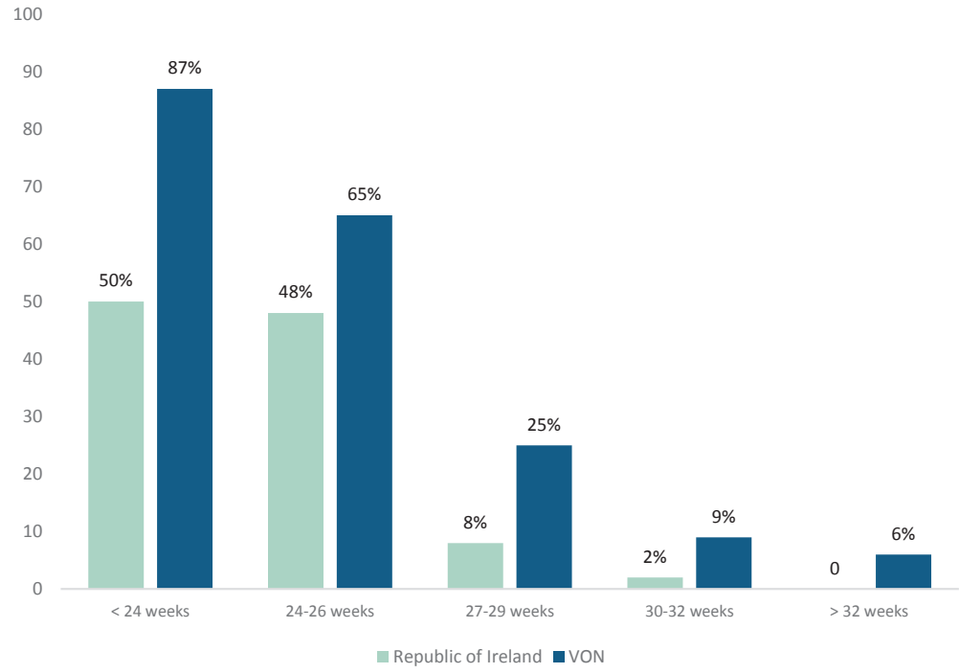

Figure 3.23: Distribution of ROP amongst infants by gestational age, 2014

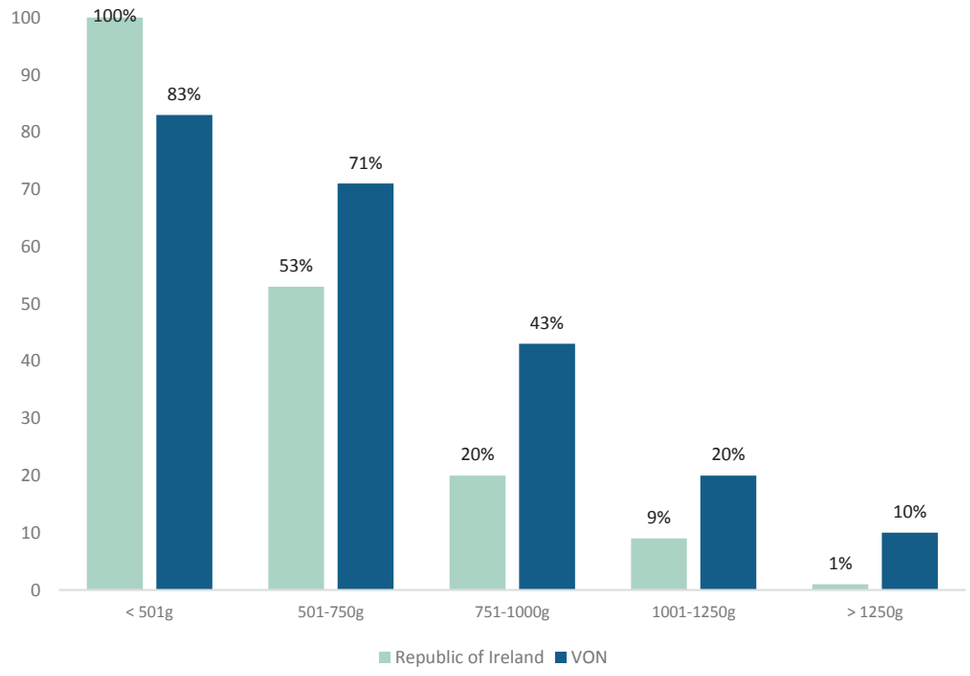

Figure 3.24: Distribution of ROP amongst infants by birth weight, 2014

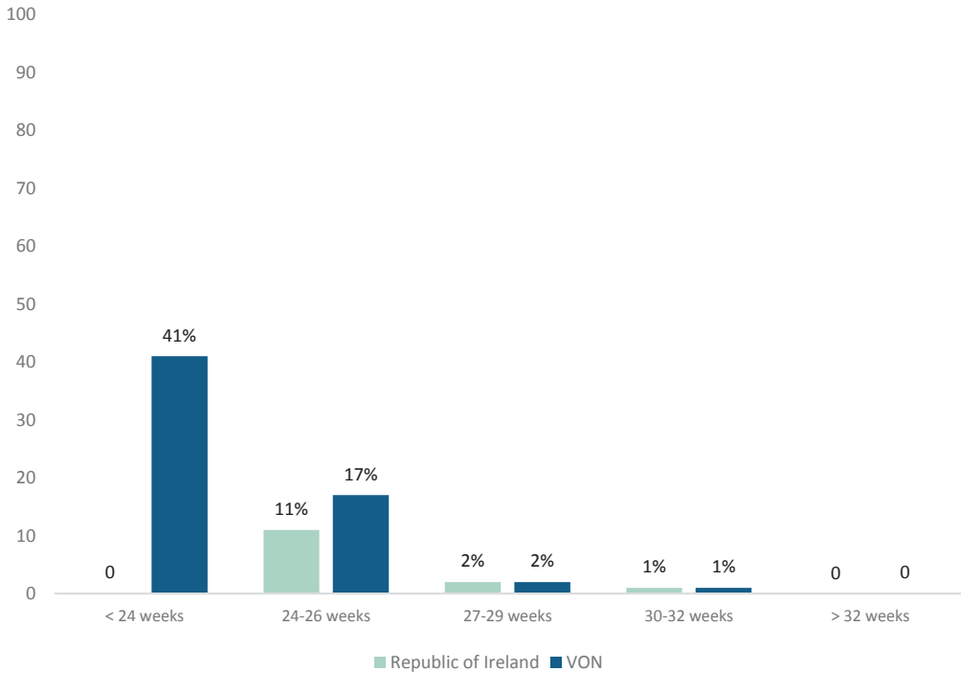

Figure 3.25: Distribution of severe ROP amongst infants by gestational age, 2014

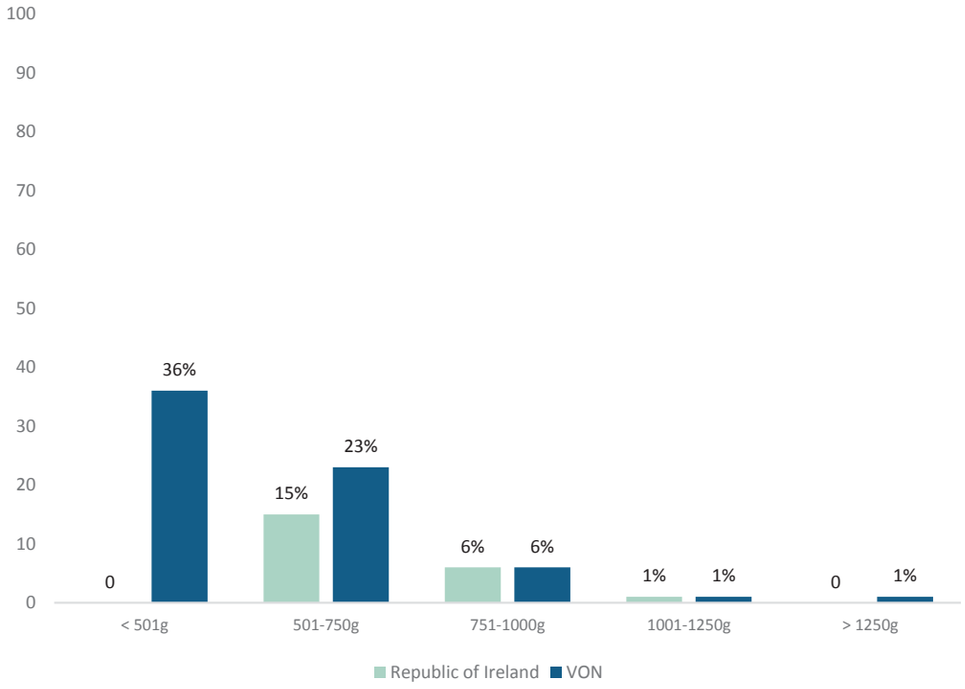

Figure 3.26: Distribution of severe ROP amongst infants by birth weight, 2014

Table 3.18: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 14: retinopathy of prematurity and KPI 15: severe retinopathy of prematurity, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Retinopathy of Prematurity	57	112	0.51	(0.33, 0.70)	-55	(-75, -34)
Severe Retinopathy of Prematurity	15	18	0.83	(0.37, 1.29)	-3	(-11, 5)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPI 16: Cystic PVL

Cystic PVL was reported in just 0.6% of ROI infants (n=3) compared to 2.8% (n=1,514) of VON infants. One ROI infant was in the 751-1000g birth weight category, one in the 1001-1250g category and another in the >1250g category, whilst two of the infants had a gestational age of 27-29 weeks and the other, a gestational age of 30-32 weeks. Graphs are not included.

Considering ROI infants with 501-1500g birth weights, there were three observed cases of cystic PVL whereas the number expected based on their risk profile was 13 (Table 3.19). Thus, the observed number equated to 24% of the expected number (SMR=0.24, 95% CI: -0.31, 0.79). In absolute numbers the ten fewer cases of cystic PVL represented a statistically significant reduction (95% CI: -17, -3).

Table 3.19: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 16: cystic periventricular leukomalacia, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Cystic Periventricular Leukomalacia	3	13	0.24	(-0.31, 0.79)	-10	(-17, -3)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPI 17: Necrotising Enterocolitis (NEC)

Similar proportions of NEC were observed in ROI and VON infants in 2014, at 6% (n=35) and 5% (n=3,168) respectively. Figures 3.27 and 3.28 illustrate the change in cases of NEC across all gestational age and birth weight categories. As gestational age increases there was a statistically significant decrease in cases of NEC in ROI infants ($p<0.001$). Likewise, as birth weight increases there was a statistically significant decrease in cases of NEC in ROI infants ($p<0.001$).

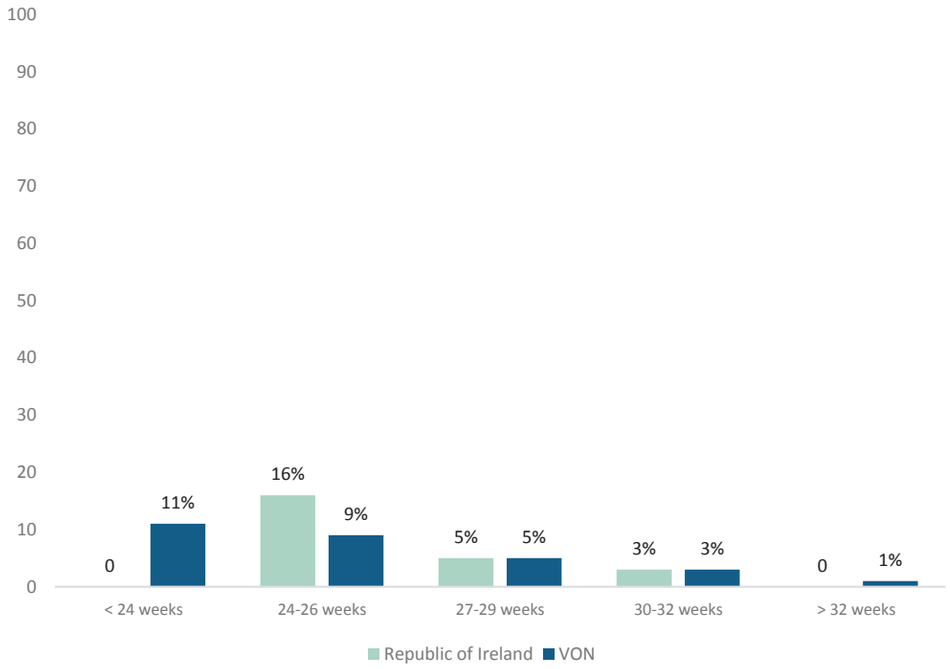

Figure 3.27: Distribution of necrotising enterocolitis amongst infants by gestational age, 2014

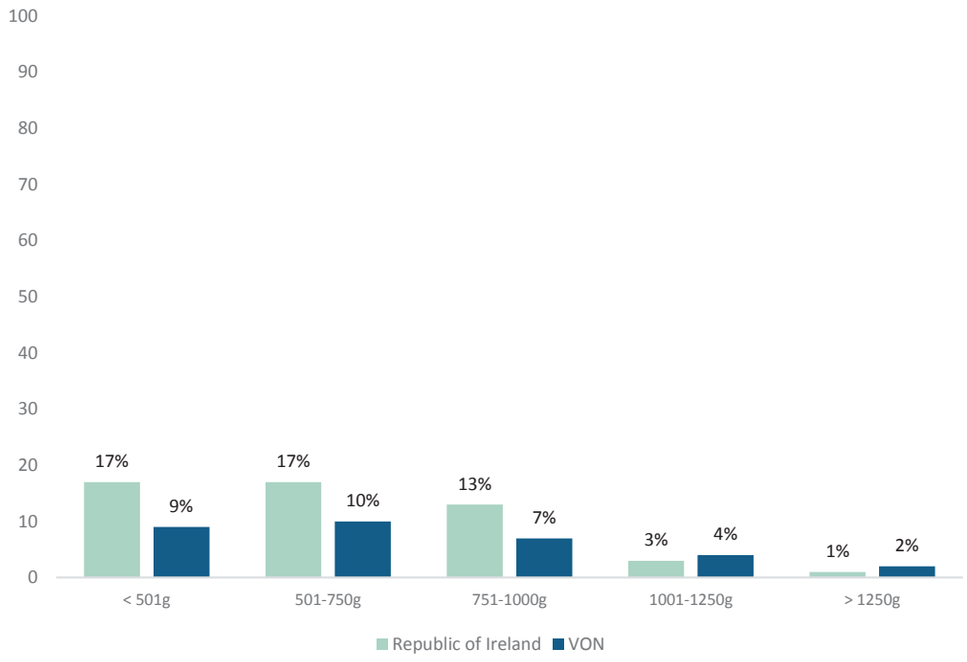

Figure 3.28: Distribution of necrotising enterocolitis amongst infants by birth weight, 2014.

Table 3.20: Risk Adjusted Standardised Morbidity Ratios for Key Performance Indicators - KPI 17: necrotising enterocolitis, ROI, 2014

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Necrotising Enterocolitis	33	27	1.21	(0.84, 1.59)	6	(-4, 16)

O=observed, E=expected, SMR=standardised morbidity ratio, CI=confidence interval

KPI 18: Extreme Length of Stay (Survivors only)

Similar levels of extreme LOS i.e. LOS greater than the 90th centile for the predicted value based on a multivariable risk adjustment model, were reported for ROI infants at 4% (n= 15) and for VON infants at 4% (n=2,254) in 2014. Figures 3.29 and 3.30 outline the percentages of extreme LOS according to gestational age and birth weight categories respectively.

SMR data for extreme LOS are not available.

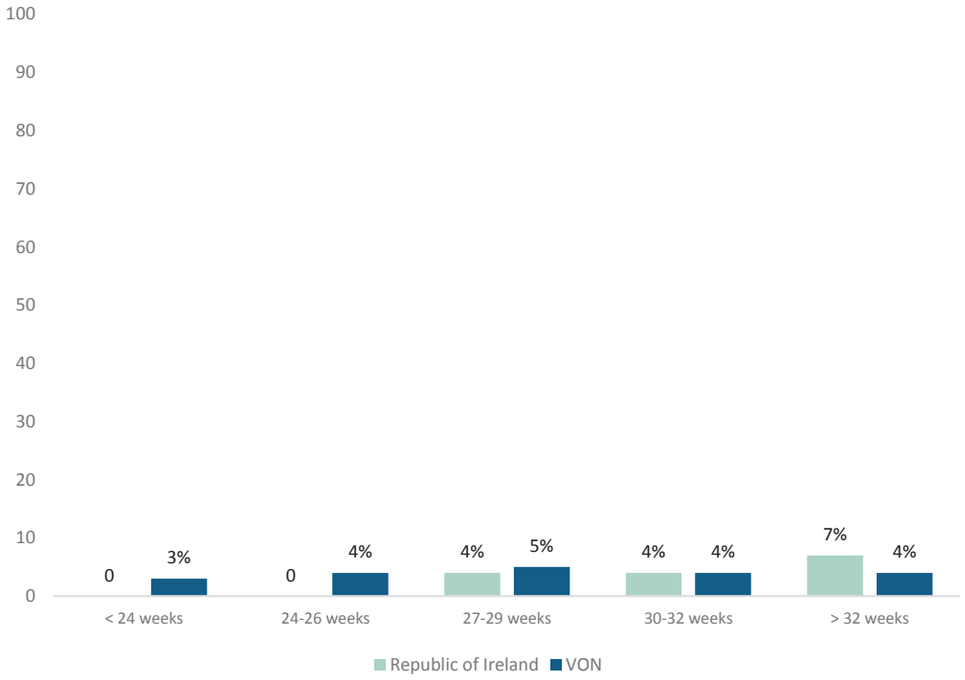

Figure 3.29: Distribution of extreme length of stay amongst surviving infants by gestational age, 2014.

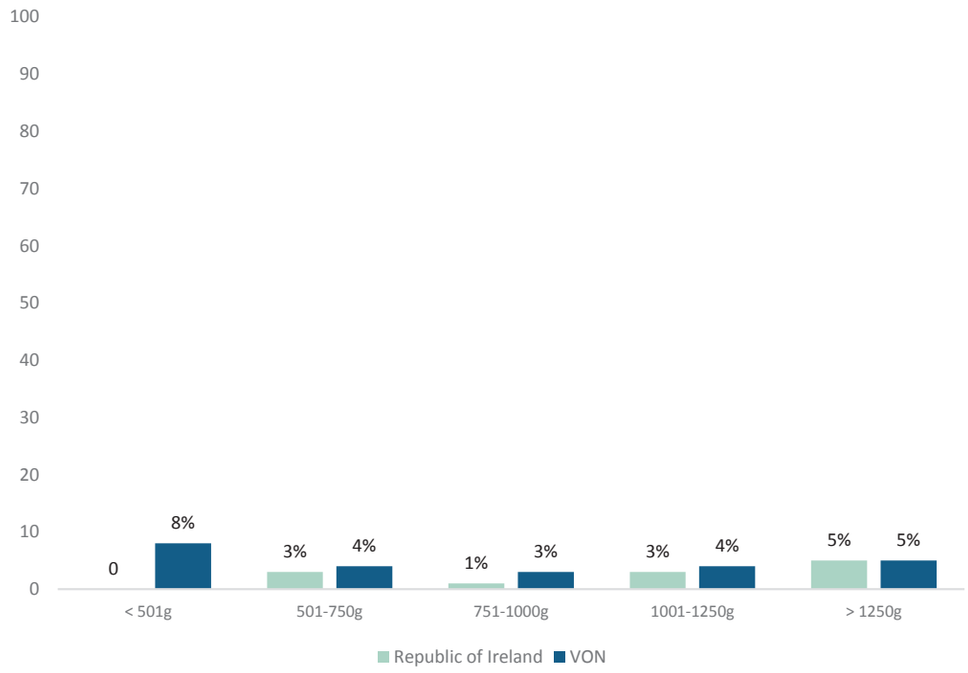

Figure 3.30: Distribution of extreme length of stay amongst surviving infants by birth weight, 2014.

Appendix A: Endorsement by the National Office of Clinical Audit (NOCA)

NOCA National Office of Clinical Audit

29th February 2016

Dr. Brendan Paul Murphy
Consultant Neonatologist
Cork University Maternity Hospital
Wilton
Cork

Very Low Birth Weight Infants in the Republic of Ireland - Annual Report 2014

Dear Dr Murphy,

On behalf of the NOCA Governance Board and our Executive Team, I wish to congratulate you, Dr Anne Twomey, the Neonatal Intensive Care Outcomes Research and Evaluation (NICORE) group and the National Perinatal Epidemiology Centre (NPEC) and all participating neonatal units for your combined efforts in initiating and supporting this valuable quality improvement initiative.

As you are aware, NOCA's core objective is to support the use of clinical audit to drive improvement for patients in Ireland. Improvement in care and outcomes can only be achieved by information gathered and monitored on how we deliver services. We certainly encourage your approach to follow up and provide feedback to individual hospitals on their own data. From this first national report you are in a position to inform future service delivery and support the bench marking of clinical care with identified standards, such as those set by the National Clinical Programme in Neonatology and the Faculty of Paediatrics. Over time this will allow real change through monitoring, education and the implementation of change to the betterment of future care for mothers and babies in Ireland.

Please accept this letter as formal endorsement of the first Very Low Birth Weight Infants in the Republic of Ireland - Annual Report 2014.

Yours sincerely,

Professor Sean Tierney
Chair
National Office of Clinical Audit

c.c. Dr. Anne Twomey, National Maternity Hospital, Holles Street, Dublin 2, Ireland
Prof Richard Greene, National Perinatal Epidemiology Centre, CUMH, Cork

National Office of Clinical Audit, 2nd Flr, Ardilaun House, 111 St Stephen's Green, Dublin 2 Tel: 4028577

Tús Áite do Shábháilteacht Othar
Patient Safety First

Appendix B: NICORE Group Members, 2014

Dr Muhammad Azam, *Consultant Paediatrician*, Wexford General Hospital

Dr Paula Cahill, *Consultant Paediatrician*, Portiuncula Hospital

Dr David Corcoran, *Consultant Neonatologist*, Rotunda Hospital

Dr Animitra Das, *Consultant Neonatologist*, University Hospital Waterford

Dr Alan Finan, *Consultant Paediatrician*, Cavan General Hospital

Dr Emma Gordon, *Consultant Neonatologist*, Our Lady of Lourdes Hospital

Dr Rizwan Gul, *Consultant Paediatrician*, Midland Regional Hospital Portlaoise

Dr Rizwan Khan, *Consultant Paediatrician*, Kerry General Hospital

Dr Imelda Lambert, *Consultant Paediatrician*, Midland Regional Hospital, Mullingar

Dr Jan Miletin, *Consultant Neonatologist*, Coombe Women & Infants University Hospital

Dr Brendan Paul Murphy, *Consultant Neonatologist*, Cork University Maternity Hospital

Dr Donough O'Donovan, *Consultant Neonatologist*, University Hospital Galway

Dr Justin Roche, *Consultant Paediatrician*, South Tipperary General Hospital

Dr Con Sreenan, *Consultant Paediatrician*, Limerick Regional Maternity Hospital

Dr Gay Fox, *Consultant Paediatrician*, Mayo General Hospital

Dr Mathew Thomas, *Consultant Paediatrician*, Letterkenny General Hospital

Dr Rohininath Tummaluru, *Consultant Paediatrician*, Sligo General Hospital

Dr Anne Twomey, *Consultant Neonatologist*, National Maternity Hospital

Dr David Waldron, *Consultant Paediatrician*, St. Luke's General Hospital

Appendix C: Vermont Oxford Network Data Collection Forms

Center Number:_____ **Network ID Number:** ☐☐☐☐☐

VERMONT OXFORD NETWORK
PATIENT DATA BOOKLET FOR INFANTS BORN IN 2014

The Patient Identification Worksheet contains personal patient identifiers and must NOT be submitted to the Vermont Oxford Network. The Vermont Oxford Network does not accept protected health care information.

Contents:

PATIENT IDENTIFICATION WORKSHEET

W1. Patient's Name: _____

W2. Mother's Name: _____

W3. Patient's Medical Record Number: _____

W4. Date of Birth: _____/_____/_____ (MM DD YYYY)

W5. Date of Admission: _____/_____/_____ (MM DD YYYY)
For inborn infants, the date of admission is the Date of Birth.
For outborn infants, the date of admission is the date the infant was admitted to your hospital.

W6. Date of Day 28: ____/____/____ (MM DD YYYY)

W7. Date of Week 36: ____/____/____ (MM DD YYYY)

Use the Calculation Charts for Date of Day 28 and Date of Week 36 for the infant's birth year.

W8. Date of Initial Disposition: _____/_____/_____ (MM DD YYYY)

W9. If Infant Transferred, Date Discharged Home, Died or First Birthday (if still hospitalized), whichever is soonest: _____/_____/_____ (MM DD YYYY)

DO NOT SUBMIT THIS WORKSHEET
Protected Health Care Information

Vermont Oxford NETWORK

Center Number:_____ **Network ID Number:** ☐☐☐☐☐

LENGTH OF STAY CALCULATION WORKSHEET FOR INFANTS BORN IN 2014

Protected Health Care Information. ***DO NOT SUBMIT this Worksheet to Vermont Oxford Network.***

Use items W5, W8 and W9 from the Patient Identification Worksheet when completing this form.

Find the day numbers corresponding to dates using the Day Number Chart for 2014-2015 (www.vtoxford.org).

Part A. Initial Length Of Stay

Enter Date of Initial Discharge, Transfer or Death (**W8**): ____/____/____ ☐☐☐ Day #

Subtract Date of Admission to Your Hospital (**W5**): ____/____/____ − ☐☐☐ Day #

For inborn infants, the date of admission is the Date of Birth.
For outborn infants, the date of admission is the date the infant was admitted to your hospital. ☐☐☐

Add 1: + 1

L1. INITIAL LENGTH OF STAY = ☐☐☐ **Days**

Note: the maximum value of Initial Length of Stay is 366 (or 367 if leap day must be added), because tracking ends on the infant's first birthday.

Part B. Total Length Of Stay

Only For Infants Transferred From Your Hospital to Another Hospital.

Enter Date of Final Discharge or Death (**W9**): ____/____/____ ☐☐☐ Day #

Subtract Date of Admission (**W5**): ____/____/____ − ☐☐☐ Day #

For inborn infants, the date of admission is the Date of Birth.
For outborn infants, the date of admission is the date the infant was admitted to your hospital. ☐☐☐

Add 1: + 1

L2. TOTAL LENGTH OF STAY = ☐☐☐ **Days**

Note: the maximum value of Total Length of Stay is 366 (or 367 if leap day must be added), because tracking ends on the infant's first birthday.

SAMPLE CALCULATION OF INITIAL LENGTH OF STAY

Enter Date of Initial Discharge, Transfer or Death: **02 / 26 / 2014** ☐57 **Day #**

Subtract Date of Admission: **01 / 13 / 2014** − ☐13 **Day #**

☐44

Add 1: _____ + 1

L1. INITIAL LENGTH OF STAY = _____ ☐45 **Days**

Explanation: Date of 02/26/2014 is Day Number 57. Date of 01/13/2014 is Day Number 13. The day numbers for each date are found in the 2014-2015 Day Number Chart on the Network web site, **www.vtoxford.org**.

PLEASE DO NOT SUBMIT THIS WORKSHEET

Protected Health Care Information

Vermont Oxford NETWORK

Center Number: _____ **Network ID Number:** ☐☐☐☐☐ **Year of Birth:** _____

1. Birth Weight: _____ grams

2. Gestational Age: **a) Weeks** _____ **b) Days (0-6)** _____

3. Died in Delivery Room: ☐ Yes ☐ No **(*If Yes*, Use Delivery Room Death Form.)**

4. a) Location of Birth: ☐ Inborn ☐ Outborn

b) If Outborn, Day of Admission to Your Center (Range: 1 to 28. Date of Birth is Day 1): _____

c) If Outborn, Transfer Code of Center from which Infant Transferred: _____
(List available at http://www.vtoxford.org/transfers)

5. Head Circumference at Birth (in cm to nearest 10th)**:** ☐☐.☐

6. Maternal Ethnicity/Race (Answer both a and b):

a) Ethnicity of Mother: ☐ Hispanic ☐ Not Hispanic

b) Race of Mother: ☐ Black or African American ☐ White ☐ Asian
☐ American Indian or Alaska Native ☐ Native Hawaiian or Other Pacific Islander
☐ Other

7. Prenatal Care: ☐ Yes ☐ No

8. Antenatal Steroids: ☐ Yes ☐ No

9. Antenatal Magnesium Sulfate: ☐ Yes ☐ No

10. Chorioamnionitis: ☐ Yes ☐ No

11. Maternal Hypertension, Chronic or Pregnancy-Induced: ☐ Yes ☐ No

12. Mode of Delivery: ☐ Vaginal ☐ Cesarean Section

13. Sex of Infant: ☐ Male ☐ Female

14. a) Multiple Gestation: ☐ Yes ☐ No **b) If Yes, Number of Infants Delivered:** _____

15. APGAR Scores: **a) 1 minute** _____ **b) 5 minutes** _____

16. Initial Resuscitation:

a) Oxygen:	☐ Yes	☐ No
b) Face Mask Vent:	☐ Yes	☐ No
c) Endotracheal Tube Vent:	☐ Yes	☐ No
d) Epinephrine:	☐ Yes	☐ No
e) Cardiac Compression:	☐ Yes	☐ No
f) Nasal CPAP	☐ Yes	☐ No

17. a) Temperature Measured within the First Hour after Admission to Your NICU:
☐ Yes ☐ No ☐ N/A

b) *If Yes*, Temperature Within the First Hour after Admission to Your NICU
(in degrees *centigrade* to nearest 10th)**:** ☐☐.☐

18. Bacterial Sepsis on or before Day 3: ☐ Yes ☐ No

19. Oxygen on Day 28: ☐ Yes ☐ No ☐ N/A (*See Manual for N/A criteria*)

20. Periventricular-Intraventricular Hemorrhage (PIH):

a) Cranial Imaging (US/CT/MRI) on or before Day 28: ☐ Yes ☐ No

b) *If Yes*, Worst Grade of PIH (0-4): _____

c) *If PIH Grade 1-4*, Where PIH First Occurred: ☐ Your Hospital ☐ Other Hospital ☐ N/A

21. Died Within 12 Hours of Admission to Your NICU: ☐ Yes ☐ No

DISCHARGE FORM - *For Infants Born in 2014* - PAGE 1

Vermont Oxford Network

Center Number: _____ **Network ID Number**: ☐☐☐☐☐ **Year of Birth:** _____

INTERVENTIONS

22. Respiratory Support (at any time after leaving the delivery room/initial resuscitation area):
- a) **Oxygen after Initial Resuscitation:** ☐ Yes ☐ No
- b) **Conventional Ventilation after Initial Resuscitation:** ☐ Yes ☐ No
- c) **High Frequency Ventilation after Initial Resuscitation:** ☐ Yes ☐ No
- d) **High Flow Nasal Cannula after Initial Resuscitation:** ☐ Yes ☐ No
- e) **Nasal IMV or Nasal SIMV after Initial Resuscitation:** ☐ Yes ☐ No

23. a) **Nasal CPAP after Initial Resuscitation:** ☐ Yes ☐ No
b) **NCPAP before or without ever having received ETT Vent:** ☐ Yes ☐ No ☐ N/A

24. a) **Surfactant during Initial Resuscitation:** ☐ Yes ☐ No
b) **Surfactant at Any Time:** ☐ Yes ☐ No (Item 24.b must be ***Yes*** if Item 24.a is ***Yes***)
***If Yes*, Age at First Dose:** c) Hours _____ d) Minutes (0-59) _____

25. a) **Inhaled Nitric Oxide:** ☐ Yes ☐ No
b) ***If Yes*, where given:** ☐ Your Hospital ☐ Other Hospital ☐ Both

26. Respiratory Support at 36 Weeks (See Manual for N/A criteria):
- a) **Oxygen at 36 Weeks:** ☐ Yes ☐ No ☐ N/A
- b) **Conventional Ventilation at 36 Weeks:** ☐ Yes ☐ No ☐ N/A
- c) **High Frequency Ventilation at 36 Weeks:** ☐ Yes ☐ No ☐ N/A
- d) **High Flow Nasal Cannula at 36 Weeks:** ☐ Yes ☐ No ☐ N/A
- e) **Nasal IMV or SIMV at 36 Weeks:** ☐ Yes ☐ No ☐ N/A
- f) **Nasal CPAP at 36 Weeks:** ☐ Yes ☐ No ☐ N/A

27. a) **Steroids for CLD:** ☐ Yes ☐No
b) ***If Yes*, Where Given:** ☐ Your Hospital ☐ Other Hospital ☐ Both

28. Indomethacin for Any Reason: ☐ Yes ☐ No

29. Ibuprofen for PDA: ☐ Yes ☐ No

30. Probiotics: ☐ Yes ☐ No

31. Treatment of ROP with Anti-VEGF Drug: ☐ Yes ☐ No

32. a) **ROP Surgery:** ☐ Yes ☐ No
b) ***If Yes*, Where Done:** ☐ Your Hospital ☐ Other Hospital ☐ Both

33. a) **PDA Ligation:** ☐ Yes ☐ No
b) ***If Yes*, Where Done:** ☐ Your Hospital ☐ Other Hospital ☐ Both

34. Surgery for NEC, Suspected NEC, or Bowel Perforation: ☐ Yes ☐ No (If ***Yes***, a Surgery Code is Required in item **36a**)

35. Other Surgery: ☐ Yes ☐ No (If ***Yes***, a Surgery Code is Required in item **36a**)

36a. If *Yes* to NEC Surgery or Other Surgery, Surgical Codes (See Appendix D): If NEC Surgery, one or more of the following codes is required: S302, S303, S307, S308, S309, S333. Indicate location of surgery for each surgery code.

Surgery Code 1: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	
Surgery Code 2: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	
Surgery Code 3: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	
Surgery Code 4: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	
Surgery Code 5: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	
Surgery Code 6: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	
Surgery Code 7: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	
Surgery Code 8: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	
Surgery Code 9: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	
Surgery Code 10: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	

36b. Include description for codes S100, S200, S300, S400, S500, S600, S700, S800, S900, S1000 & S1001:

_____

DISCHARGE FORM - *For Infants Born in 2014* - PAGE 2

Vermont Oxford NETWORK

Center Number: _____ **Network ID Number:** ☐☐☐☐☐ **Year of Birth:** _____

DIAGNOSES

37. Respiratory Distress Syndrome: ☐ Yes ☐ No

38. a) **Pneumothorax:** ☐ Yes ☐ No
b) ***If Yes*, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

39. Patent Ductus Arteriosus: ☐ Yes ☐ No

40. a) **Necrotizing Enterocolitis:** ☐ Yes ☐ No
b) ***If Yes*, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

41. a) **Focal Intestinal Perforation:** ☐ Yes ☐ No
b) ***If Yes*, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

Sepsis and/or Meningitis, Late (after day 3 of life): (See Manual for N/A criteria)

42. a) **Bacterial Pathogen:** ☐ Yes ☐ No ☐ N/A
b) ***If Yes*, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

43. a) **Coagulase Negative Staph:** ☐ Yes ☐ No ☐ N/A
b) ***If Yes*, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

44. a) **Fungal Infection:** ☐ Yes ☐ No ☐ N/A
b) ***If Yes*, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

45. Cystic Periventricular Leukomalacia: ☐ Yes ☐ No ☐ N/A (see Manual for N/A criteria)

46. ROP: a) **Retinal Exam Done:** ☐ Yes ☐ No
b) ***If Yes*, Worst Stage of ROP** (0-5)**:** _____

47. Major Birth Defect: ☐ Yes ☐ No
***If Yes*, enter codes:** _____ _____ _____ _____ _____
Include description for Codes 100, 504, 601, 605, 901, 902, 903, 904 & 907: _____
_____

DISCHARGE

48. Enteral Feeding at Discharge:
☐ None
☐ Human Milk Only
☐ Formula Only
☐ Human milk in combination with either fortifier or formula

49. Oxygen and Monitor at Discharge:
a) Oxygen at Discharge: ☐ Yes ☐ No
b) Monitor at Discharge: ☐ Yes ☐ No

50. Initial Disposition (check only one):
☐ Home
☐ Died
☐ Transferred to another Hospital (★ Complete Transfer and Readmission Form)
☐ Still Hospitalized as of First Birthday

51. Weight at Initial Disposition: _____ grams

52. Head Circumference at Initial Disposition (in cm to the nearest10th)**:** ☐☐.☐

53. Initial Length of Stay: _____ day(s) (Item L1 on Length of Stay Calculation Worksheet)

TRANSFER & READMISSION FORM - *For Infants Born in 2014*

Vermont Oxford Network

Center Number: _____ **Network ID Number:** ☐☐☐☐☐ Year of Birth: _____

Part A. Complete for ALL Transferred Infants

If an infant is transferred to another hospital, complete Items 54 - 56. Post Transfer Disposition (Item 56) refers to the infant's disposition upon leaving the "transferred to" hospital.

54. Reason for Transfer: (Check Only One)
☐ Growth/Discharge Planning ☐ Medical/Diagnostic Services
☐ Surgery ☐ ECMO ☐ Chronic Care ☐ Other

55. Transfer Code of Center to which Infant Transferred: _____ (List available at http://www.vtoxford.org/transfers)

56. Post Transfer Disposition (check only one):

☐ Home	*Skip Parts B and C. Complete Part D.*
☐ Transferred Again to Another Hospital (2nd Transfer)	*Skip Part B. Complete Parts C and D when data are available.*
☐ Died	*Skip Parts B and C. Complete Part D.*
☐ Readmitted to Any Location in Your Hospital	*Complete Parts B and D (and C if applicable) when data are available.*
☐ Still Hospitalized as of First Birthday	*Skip Parts B and C. Complete Part D.*

Part B. Complete ONLY for Readmitted Infants

If a patient is readmitted to your center after transferring once to another hospital without having been home, answer Items 57 - 58. When infants are readmitted to your center, continue to update Items 18 - 20 on the 28 Day Form, and Items 22 – 49 on the Discharge Form based on all events at both hospitals until the date of Disposition after Readmission. If your hospital participates in the Expanded Database and definition criteria are met, update Items S1.B, S1.C.1, S1.C.2, S2.A.1, S2.A.2 and S2.C based on events that occur following transfer and readmission.

57. Disposition after Readmission (check only one):

☐ Home	*Skip Part C. Complete Part D.*
☐ Died	*Skip Part C. Complete Part D.*
☐ Transferred Again to Another Hospital	*Complete Parts C and D when data are available.*
☐ Still Hospitalized as of First Birthday	*Skip Part C. Complete Part D.*

58. Weight at Disposition after Readmission: _____ grams

Part C. Complete ONLY for Infants Who Transferred More Than Once

Answer Item 59 if an infant transferred from your center to another hospital and was then either (1) transferred again to another hospital, or (2) readmitted to your center and then transferred again to another hospital.

59. Ultimate Disposition (check only one):

☐ Home	*Complete Part D.*
☐ Died	*Complete Part D.*
☐ Still Hospitalized as of First Birthday	*Complete Part D.*

Part D. Complete for ALL Transferred Infants

Complete Item 60 when the infant has been discharged Home, Died or is Still Hospitalized as of First Birthday, whichever comes first.

60. Total Length of Stay: _____day(s) (Item L2 on Length of Stay Calculation Worksheet)

Vermont Oxford NETWORK

SUPPLEMENTAL DATA FORM - *For Infants Born in* 2014

(For Expanded Database Centers)

Center Number: _____ **Network ID Number:** ☐☐☐☐☐ **Year of Birth:** _____

S1. Treatments:

A. 1. Duration of Assisted Ventilation:

☐ None ☐ <4 hours ☐ 4-24 hours ☐ > 24 hours ☐ N/A

2. If > 24 hours, Total Days of Assisted Ventilation: _____

B. ECMO at your Hospital: ☐ Yes ☐ No ☐ N/A

C. Hypothermic Therapy at Your Hospital:

1. Was Hypothermic Therapy Performed at Your Hospital: ☐ Yes ☐ No

2. If *Yes*, Cooling Method: ☐ Selective Head ☐ Whole Body ☐ Both

S2. Diagnoses:

A. 1. Hypoxic-Ischemic Encephalopathy: ☐ Yes ☐ No ☐ N/A

2. HIE Severity (check one): ☐ Mild ☐ Moderate ☐ Severe ☐ N/A

B. 1. Meconium Aspiration: ☐ Yes ☐ No

2. Tracheal Suction for Meconium Attempted in the DR:

☐ Yes ☐ No ☐ N/A

C. Seizures: ☐ Yes ☐ No ☐ N/A

Center Number: _____ **Network ID Number:** ☐☐☐☐☐

VERMONT OXFORD NETWORK
DELIVERY ROOM DEATH BOOKLET FOR INFANTS BORN IN 2014

Use the Delivery Room Death Booklet for eligible inborn infants who die in the delivery room or at any other location in your hospital within 12 hours of birth and prior to admission to the NICU.

The Delivery Room Death Patient Identification Worksheet contains personal patient identifiers and must NOT be submitted to the Vermont Oxford Network. The Vermont Oxford Network does not accept protected health care information.

Contents:

DELIVERY ROOM DEATH
PATIENT IDENTIFICATION WORKSHEET

W1. Patient's Name: _____

W2. Mother's Name: _____

W3. Patient's Medical Record Number: _____

W4. Date of Birth: _____/_____/_____
MM DD YYYY

PLEASE DO NOT SUBMIT THIS WORKSHEET
Protected Health Care Information

Vermont Oxford NETWORK

DELIVERY ROOM DEATH FORM – *For Infants Born in 2014*

Vermont Oxford Network

Center Number: _____ **Network ID Number:** ☐☐☐☐☐ **Year of Birth:** _____

1. Birth Weight: _____ grams

2. Gestational Age: **a)** Weeks _____ **b)** Days (0-6) _____

3. Died in Delivery Room: ☐ Yes ☐ No (***If NO***, **do not use this Form**)

4. a) Location of Birth: ☐ Inborn ☐ Outborn (***If OUTBORN***, **do not use this Form**)

b and c: Not Applicable

5. Head Circumference at Birth (in cm to the nearest 10th): ☐☐.☐

6. Maternal Ethnicity/Race: (answer both a and b)

a) Ethnicity of Mother: ☐ Hispanic ☐ Not Hispanic

b) Race of Mother: ☐ Black or African American ☐ White ☐ Asian
☐ American Indian or Alaska Native ☐ Native Hawaiian or Other Pacific Islander
☐ Other

7. Prenatal Care: ☐ Yes ☐ No

8. Antenatal Steroids: ☐ Yes ☐ No

9. Antenatal Magnesium Sulfate: ☐ Yes ☐ No

10. Chorioamnionitis: ☐ Yes ☐ No

11. Maternal Hypertension, Chronic or Pregnancy-Induced: ☐ Yes ☐ No

12. Mode of Delivery: ☐ Vaginal ☐ Cesarean Section

13. Sex of Infant: ☐ Male ☐ Female

14. a) Multiple Gestation: ☐ Yes ☐ No **b) *If Yes*, Number of Infants Delivered**: _____

15. APGAR Scores: **a)** 1 minute _____ **b)** 5 minutes _____

16. Initial Resuscitation:

a) Oxygen:	☐ Yes	☐ No
b) Facial Mask Vent:	☐ Yes	☐ No
c) Endotracheal Tube Vent:	☐ Yes	☐ No
d) Epinephrine:	☐ Yes	☐ No
e) Cardiac Compression:	☐ Yes	☐ No
f) Nasal CPAP:	☐ Yes	☐ No

17 – 23: Not Applicable

24. Surfactant Treatment:

a) Surfactant during Initial Resuscitation: ☐ Yes ☐ No

b) Surfactant at Any Time: ☐ Yes ☐ No (Part b must be answered "**Yes**" if Part a is "**Yes**")

***If Yes*, Age at First Dose:** **c)** hours _____ **d)** minutes (0-59) _____

25 – 46: Not Applicable

47. Major Birth Defect: ☐ Yes ☐ No ***If Yes*, enter codes** _____ _____ _____ _____ _____

Include description for Codes 100, 504, 601, 605, 901, 902, 903, 904 & 907: _____

_____

48 – 60: Not Applicable

If your center participates in the Expanded Database, answer Items S2. B.1 and S2. B.2 from the Supplemental Data Form. Items S1.A. to S1.C. and Items S2.A and S2.C are not applicable.

S2. B. 1. Meconium Aspiration: ☐ **Yes** ☐ **No**

B. 2. Tracheal Suction for Meconium Attempted in the DR: ☐ **Yes** ☐ **No** ☐ **N/A**

NATIONAL PERINATAL
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