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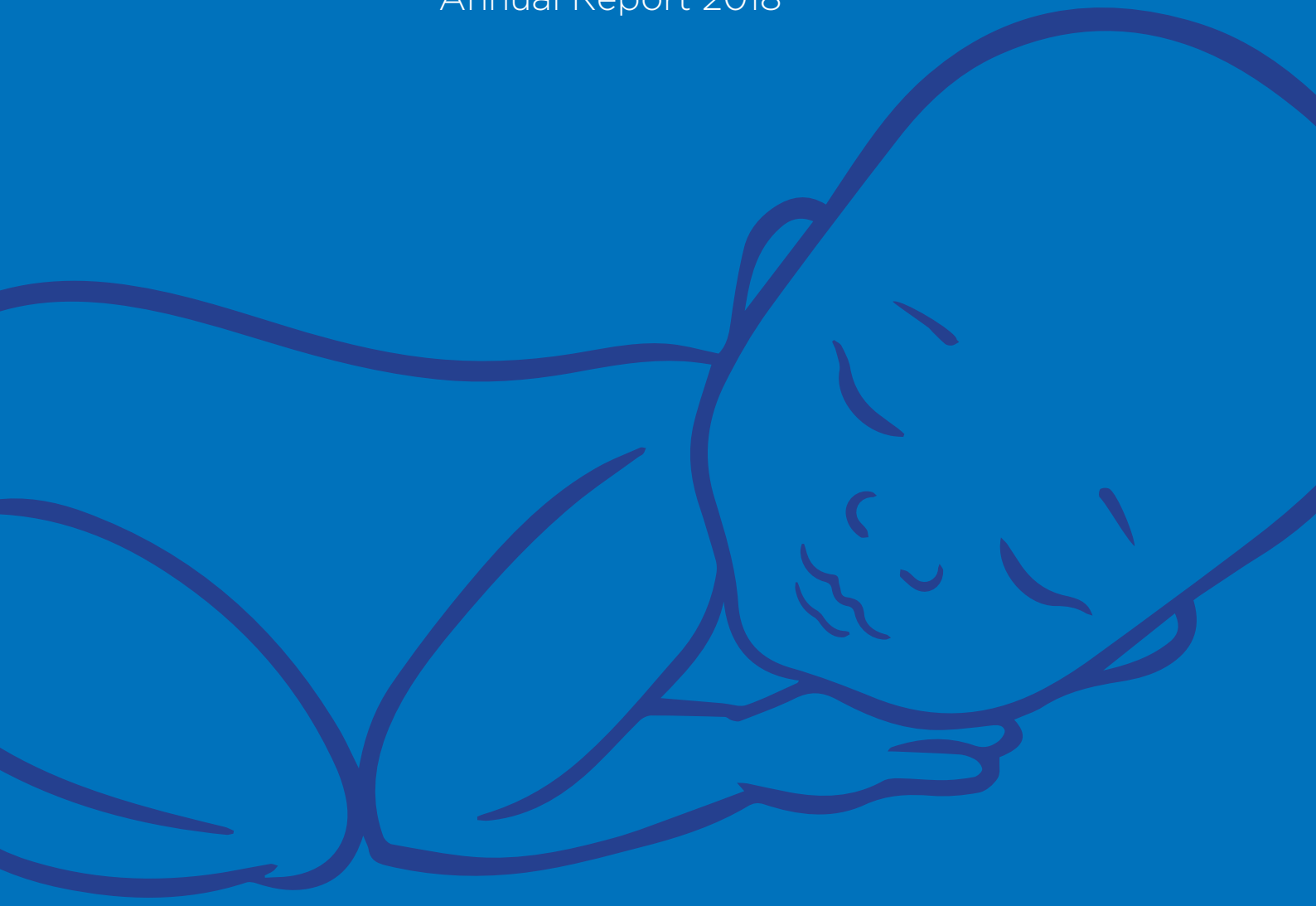
Very Low Birth Weight Infants in the Republic of Ireland

Annual Report 2018



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List of Acronyms

CLD	Chronic Lung Disease
HSE	Health Service Executive
KPI	Key Performance Indicator
MCA	Major Congenital Anomaly
NEC	Necrotising Enterocolitis
NICU	Neonatal Intensive Care Unit
NICORE	Neonatal Intensive Care Outcomes Research and Evaluation
NPEC	National Perinatal Epidemiology Centre
NOCA	National Office for Clinical Audit
PVL	Cystic Periventricular Leukomalacia
PIH	Periventricular-intraventricular haemorrhage
VLBW	Very Low Birth Weight
VON	Vermont Oxford Network
ROI	Republic of Ireland
RR	Relative Risk
ROP	Retinopathy of Prematurity
SCBU	Special Care Baby Unit
SMR	Severe Mortality Risk

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Acknowledgements

Welcome to the fifth 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 focuses on all babies born ≤1500g and/or ≤29 weeks gestation in the Republic of Ireland for the calendar year 2018 and compares outcomes to the preceding four years.

Data on every Very Low Birth Weight (VLBW) infant born in the ROI during the years 2014 to 2018 is now available: this is just under 3,000 infants and is a remarkable achievement, made all the more pertinent by the fact that we are one of very few countries reviewing outcomes of care of VLBW infants at a national level.

Of note, in this year's report is the reduction in the number of VLBW infants born in the Republic of Ireland in 2018. In total, 537 VLBW infants were born, a 14% reduction from a peak of 622 infants in 2015. This may be reflective of the reduction in the total number of liveborn infants in Ireland, the latter having decreased by 10% from 2014 to 2018 (from 67,285 birth in 2014 to 61,016 birth in 2018). This trend will be followed with interest in the coming years as it may have significant implications on how neonatology services are planned into the future. In 2018, the vast majority (89%) of infants born at 23 weeks were offered resuscitation in the Delivery Room (DR) – an increase from 43% for infants of the same gestational age born in 2014. Unfortunately, only 33% of these infants survived to discharge home. The Clinical Lead Programme in Neonatology, the Neonatal Clinical Advisory Group of the Faculty of Paediatrics, the Institute of Obstetrics and Gynaecology and The National Women and Infants' Programme are currently working on a Framework for Practice document on the "Perinatal Management of Extreme Preterm Birth at the Threshold of Viability". The publication of this document is eagerly awaited. The findings of our yearly reports, in addition to our 3 year report on the Mortality Risk among VLBW born between the Years 2014-2016 have been made available to all the above parties for their consideration.

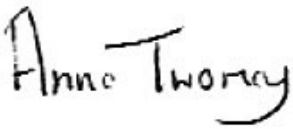
As mentioned in last year's report, the primary focus of the NICORE ROI group remains on obtaining detailed 2 year neurodevelopmental follow up on our VLBW infants. Families facing the imminent delivery of a very premature baby, particularly an infant born at the limits of viability, need accurate and up to date information not only on the chances of survival but also on the long term neurodevelopmental outcome. A Bayley Assessment of Infant Development at 2 years of age remains the gold standard in neonatology. Recent discussions among our NICORE member centres indicate that, in the vast majority of cases, even in the larger tertiary neonatal centres, neither the staff nor the financial resources are available to undertake this vital work. This is not just about accumulating good outcome data to expand our yearly report but what is even more critical is that these vulnerable infants, who are at high risk of long term neurodevelopmental problems, are diagnosed as early as possible and referred to community based Early Intervention Services as soon as possible. We submitted a business case to the Women and Infants' programme in 2019 and have been informed that some funding has been made available for this important work. We are awaiting more definitive information but we are strongly encouraged by this decision.

This report is based on data submitted by all 19 neonatal centres in the ROI. Another milestone for us in 2018 is that one of the two paediatric tertiary centres in the Republic of Ireland, namely CHI, Temple Street, has joined VON. This means that we are now in a position to gather even more important clinical outcome information on that subgroup of VLBW infants who require tertiary medical and surgical services that are only provided in paediatric centres.

This report would not be possible without the many neonatal nurses, paediatricians and administration staff who have supported the data collection process and we gratefully acknowledge the commitment of all those individuals. We thank the team at Vermont Oxford Network who continue to whole-heartedly support this initiative by working closely with the NPEC on data collection and statistical analysis. We thank the National Office of Clinical Audit (NOCA) for their continuing support to NPEC in ensuring that recommendations arising from national clinical audit are reviewed and actioned: this report, similar to previous reports, is endorsed by NOCA (Appendix A). We 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 on behalf of all 20 centres and for providing the logistical support required to oversee this project.

To our fellow members of the NICORE ROI group, we appreciate their support of this project from the onset. They have been instrumental in supporting our endeavour to expand our collection of data to include neurodevelopmental outcome. The membership of NICORE ROI is listed in Appendix B.

On a final note, this initiative of the ROI neonatal community to review its outcomes of care at both local and national levels demonstrates its commitment to improving outcomes for all VLBW infants in the ROI and their families. By continuing to assess the outcomes of care, learning from the data and working together, we have great potential to improve the outcomes of VLBW infants in Ireland.



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Executive Summary

1. A total of 537 very low birth weight (VLBW) infants were born in the Republic of Ireland (ROI) in 2018, of which 19 infants had a birthweight >1500g, all of these were ≤29 weeks 6 days gestation.

2. In all, 239 infants were born with a birth weight ≤1000g and 182 infants were born with a gestational age ≤26 weeks 6 days.

3. The crude survival rate for ROI VLBW infants in 2018 was 82% (n=435, survival information not available for seven infants). At least 75% of the VON units had higher survival than reported by the ROI for 2018 (VON Median 88%; Q1=83%, Q3=93%).

4. Adjusting for the risk profile of the VLBW population, the risk of mortality remains higher in the VLBW ROI population in 2018 (SMR=1.11; 95% CI: 0.87, 1.36) but this was not statistically significant. This finding is consistent with previous years.

5. Similarly, the risk of mortality excluding early deaths (deaths in the delivery room or deaths within 12 hours of admission to the NICU) in the VLBW ROI infants is also higher in 2018 (SMR=1.12; CI 0.83, 1.41), but again, this finding was not statistically significant.

6. There is no significant difference in the risk of death or morbidity for ROI infants compared to VON infants in 2018 (SMR=1.01, 95% CI: 0.88, 1.15). This is in line with 2017 but is in contrast to the two preceding years when ROI infants had significantly higher rates of death or morbidity.

7. Again, adjusting for the risk profile of the VLBW population, Key Performance Indicators in the neonatal care of VLBW infants born in the ROI in 2018 compared to VON infants showed that:

   - ROI infants had significantly higher rates of Pneumothorax (SMR=1.56, 95% CI: 1.13, 1.98). This has been reported each year since the commencement of this audit in 2014. In particular, ROI infants born at 28-31 weeks gestation have a risk of pneumothorax more than twice that expected (SMR=2.25; 95% CI: 1.95, 2.56). To better understand this elevated risk of pneumothorax amongst ROI infants, further in-depth analysis using data accumulated over multiple years will be carried out.

   - ROI infants had lower rates of retinopathy of prematurity (SMR=0.85, 95% CI: 0.67, 1.04) but this finding was not statistically significant as in previous years (2014-2017). However, in 2018, ROI infants had significantly lower rates of severe retinopathy of prematurity (SMR=0.39, 95% CI: 0.0, 0.83), it is the first year that we have reported such a finding.

- There were no significant differences in risk of the following outcomes for ROI infants compared to VON infants:
  - Late bacterial infection (SMR=0.88, 95% CI: 0.56, 1.20) as recorded in previous years;
  - Coagulase negative Staphylococcus infection (SMR=1.20, 95% CI: 0.80, 1.61), in line with previous years;
  - Nosocomial infection (SMR=0.97, 95% CI: 0.71, 1.24), similar to findings in previous years;
  - Intra-ventricular haemorrhage (SMR=0.99, 95% CI: 0.80, 1.17), in line with the past two years;
  - Necrotizing enterocolitis (NEC) (SMR=1.22, 95% CI: 0.83, 1.61). This is in contrast to the two preceding years when ROI infants had significantly higher rates of NEC.
- Of note, in 2014-2015, there was a higher-than-expected risk of coagulase negative infection, nosocomial infection and any late infection. This elevated risk has diminished over time so that currently the observed and expected number of cases are now similar. As multiple years of data are now available, it may be possible to investigate and better understand this improvement.

8. In 2018, of the 537 infants born, 73% (n=393) were born in tertiary neonatal centres; 19% (n=101) were born in regional neonatal centres; and 8% (n=43) were born in peripheral centre. Of those born outside tertiary centres, 30 of these were transferred within 48 hours of being born.

9. A total of 30 ROI infants died in the delivery room (6%). The VON median for delivery room deaths is 0% (Q1=0%, Q3=4.5%), hence, at least 75% of the VON units had a lower percentage of delivery room deaths than reported in ROI for 2018. Seven (23%) of these 30 ROI infants who died in delivery room had a major congenital anomaly and 21 (70%) were born at less than 24 weeks gestation.

10. Of all infants born between 23 and 27 weeks gestation (n=218), 174 (80%) were born in a tertiary neonatal centre, 21 (10%) were born in a regional neonatal centre and 23 (11%) were born in a peripheral centre. This compares to 167 (80%) of a total of 210 infants born at this gestation in tertiary centres in 2017 and 85% (n=178) in 2016. The current Model of Care for Neonatal Services in Ireland recommends that infants before 28 weeks should ideally be delivered at a tertiary neonatal centre.

11. In 2018, 72% of infants received active resuscitation at birth in the delivery room. The proportion was similar at 70% in 2017 and 75% in 2016. The 2018 report on mortality risk among VLBW infants between 2014-2016 recommended that resuscitation should be administered to all infants born at 23 weeks who present in a favourable condition. In 2018, 89% of infants born at 23 wks gestation were offered resuscitation compared to 42% in 2014.

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. More information on this Network can be found on their webpage: https://public.vtoxford.org/ . Established in 1988, the Network is today comprised of more than 1300 Neonatal Intensive Care Units around the world (Figure 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 had joined VON by 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. The first annual report on all VLBW infants born in the Republic of Ireland was subsequently published for the year 2014. The current report represents the fifth year, 2018, of a complete ROI dataset.

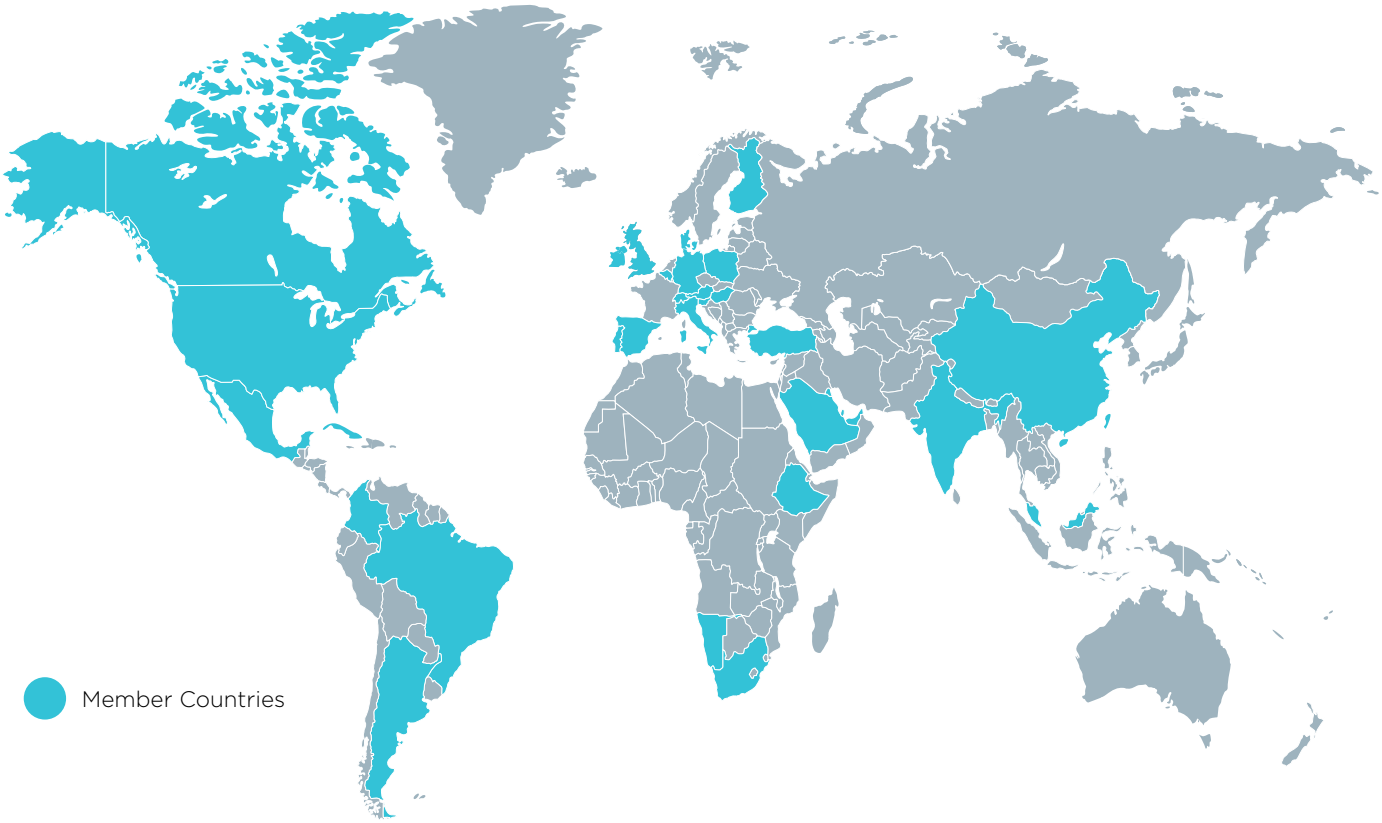

Figure 1: Member countries of the Vermont Oxford Network.

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 2 illustrates all units participating in VON in the island of Ireland according to the category of their Neonatal Units and the hospital group to which they are affiliated.

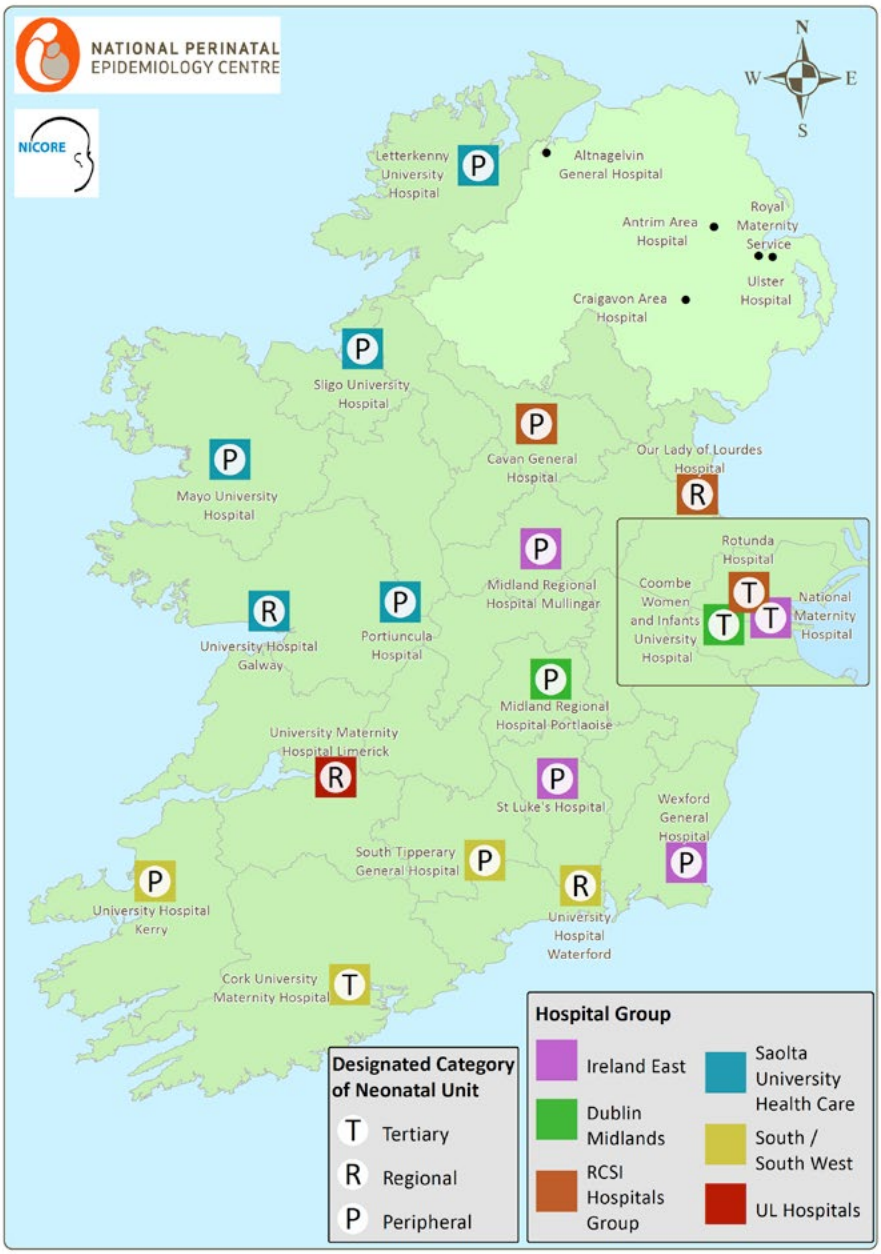

Figure 2: Neonatal centres in the Republic of Ireland and Northern Ireland participating in the Vermont Oxford Network. ROI centres are classified according to category of Neonatal Units and the hospital group to which they are affiliated.

Methods

Data recording

In 2018, 19 neonatal centres participated in the VON's Very Low Birth Weight (VLBW) database. The definition of eligibility for the VLBW database is:

Any infant who is born alive at a hospital 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 the hospital the infant receives care.

Anonymised data on VLBW infants born between 1st January and 31st December 2019 were submitted to VON's on-line database - eNICQ (Please see Appendix C for data collection forms). Figure 3 illustrates the flow of information involved.

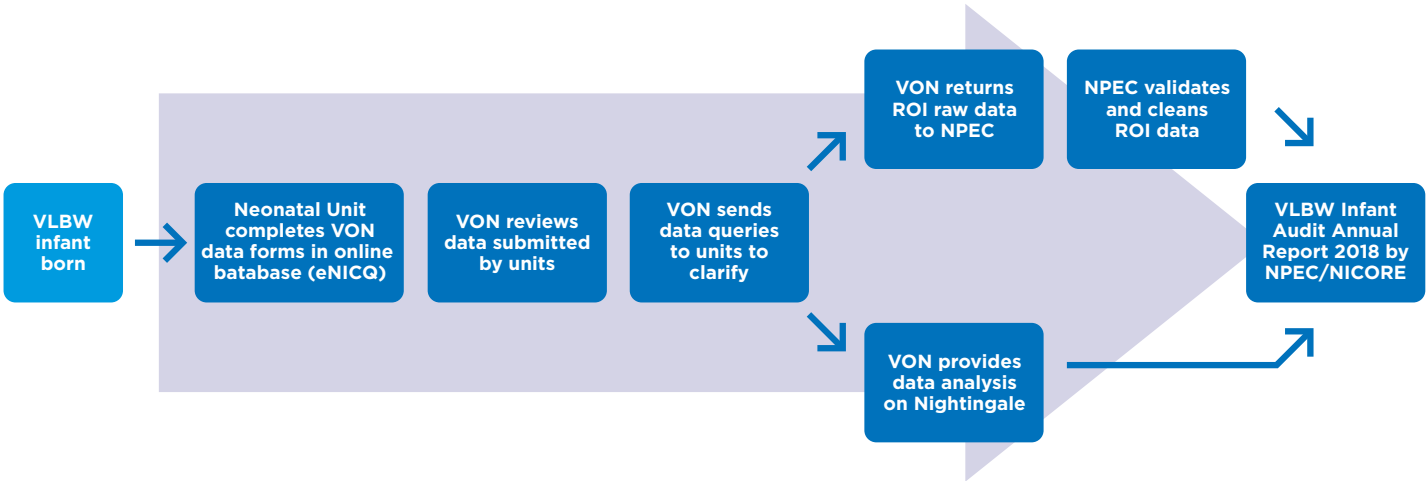

Figure 3: Flow of information and data management in the VON data collection process.

On completion of all ROI submissions for 2018, VON forwards a copy of the complete ROI dataset to the NPEC. The ROI data presented in this report are based on the ROI dataset. Throughout the report, ROI data are compared to VON data, comprising data from all centres across the Network. The Network data, referred to as VON data, are obtained from *Nightingale*, VON's on-line data reporting system.

Case Ascertainment

The VON database allows the capture of a data record from the birth centre of all VLBW infants. It also allows the capture of a record from the first centre to which an infant was transferred, where applicable. In cases of infants who were treated in more than two centres, the VON database does not capture a record from the second transfer centre, and thus these infants have two records only, one from the birth centre and the other from the first transfer centre. On receipt of the ROI 2018 dataset from VON, the NPEC undertook a matching exercise in order to link data records associated with individual infants who were transferred (matching the record of the unit where the infant was born with the record of the unit to where the infant was transferred) in order to ensure that each infant was counted only once.

Secondly, for the purpose of completion of data, in order to ensure that all infants which met the VLBW inclusion criteria in 2018 were captured in the dataset, the dataset was cross-checked with the NPEC's National Clinical Audit of Perinatal Mortality 2018 dataset. Early neonatal deaths, between 401g and 1500g or whose gestational age was between $22^{0/7}$ and $29^{6/7}$, even if never admitted to an NICU/SCBU, are eligible for reporting to VON. In cases of early neonatal deaths which met the VON criteria but were not captured in the VON dataset, the relevant neonatal centre was requested to complete and submit a record. The ROI dataset was subsequently updated.

Statistical analysis

Differences in proportions were assessed by the two-sample test of proportions. Pearson's chi-squared test (χ^2) was used to evaluate the association between outcomes and gestational age categories. Poisson regression was used to assess trend.

Reference to Very Low Birth Weight Infants in the Republic of Ireland Annual Report 2014 and 2015

Since publication of the 2014 and 2015 reports, the matching exercise described above was undertaken on the 2014 ROI dataset. This had the effect of reducing the number of VLBW infants born in the ROI in 2014 from 608, as described in the 2014 and 2015 reports, to 597. The current report utilises the most accurate values for 2014 ROI data and hence differs slightly from the values stated in the 2014 and 2015 reports. Values for 2015 data have not changed since publication of the 2015 report.

Comparing ROI Percentages with Medians reported by the VON

Although in previous reports it was possible to compare the percentages of specific measures (e.g. KPIs, mortality, among others) for infants born in the ROI with the percentages reported for VON infants, from 2018, VON no longer reports on the percentages for the whole network. Instead, VON reports the median percentage (the percentage at the median hospital in the network) along with the 1st and 3rd quartile percentages (Q1 and Q3) and it will be these values that are now presented in our tables. To interpret these values, 50% the units in VON will report a lower percentage than the median, 25% of the units report a lower percentage than Q1 and 75% of the units will report a lower percentage than Q3.

Reliability of conclusions based on small numbers

Population rates and percentages are subject to random variation. This variation may be substantial when the measure, such as a rate, has a small number of events in the numerator or denominator. Typically, rates based on large numbers provide stable estimates of the true, underlying rate. Conversely, rates based on small numbers may fluctuate dramatically from year to year, or differ considerably from one centre to another, even when differences are not meaningful. Meaningful analysis of differences in rates between geographic areas or over time requires that the random variation be quantified and that multiple years of data be incorporated. It is correct to present rates which are based on rare outcomes and small numbers as this is what the data shows, but conclusions cannot be drawn from rates and outcomes based on small numbers.

Definitions and terminology

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.

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).

Chronic Lung Disease (CLD): Based on an algorithm that was tested with hospital data and is more accurate than just oxygen dependency at 36 weeks 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: The same algorithm applied as above but only includes infants < 33 weeks gestation.

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.

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

Death or morbidity: Indicates if an infant died or was known to have one or more of the following key morbidities: severe intraventricular haemorrhage (IVH), chronic lung disease (CLD) in infants <33 weeks, necrotising enterocolitis (NEC), pneumothorax, any late infection or cystic periventricular leukomalacia (PVL).

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.

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

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 the hospital submitting the VON data.

Key Performance Indicators (KPIs): VON reports on a number of Key Performance Indicators (KPIs) which allow the ROI to compare its outcomes to VON as a whole. Further information on this is available on section 4 of the report (4. Key Performance Indicators) on page 19.

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

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.

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.

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

Outborn: Infant delivered outside the hospital submitting the VON data. Any infant requiring ambulance transfer is considered outborn.

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

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

Resuscitation: Defined, for the purposes of this report, as the administration of any positive pressure breaths via a face mask ventilation and/or via an endotracheal tube in the delivery room or in the initial resuscitation area.

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

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

Survival without Specified Morbidities: Indicates whether the infant survived with none of the following key morbidities: Severe IVH, CLD Infants <33 Weeks, NEC, Pneumothorax, Any Late Infection, or PVL.

Main findings

1. Overview

A total of 537 VLBW infants were reported to VON in Ireland in 2018, constituting infants born in all 19 maternity centres and their affiliated Neonatal Intensive Care Units (NICUs) in the Republic of Ireland (ROI). In 2018, data on infants transferred within 28 days of life to one of the two tertiary paediatric centres in the ROI were also reported to VON. Overall, 62,135 VLBW infants were reported to the VON Network in 2018.

Overall, there has been a 10% decrease in the number of very low birth weight infants recorded in Ireland in the past 5 years (Table 1.1). This is in line with the 10% reduction in the number of births in Ireland between 2014 and 2018 (from n=67,285 to n=61,016).[1]

As shown in table 1.1, outlining the gestational age of infants reported in 2018, the highest proportion of infants were born in the 27-29 weeks gestation (37%, n=198). A total of 44 (8%) infants were born with a gestation below 24 weeks and 31 (6%) infants were born with a gestation of more than 32 weeks. In total, 8% (45 out of 537) of VLBW infants born in 2018 had a major congenital anomaly (MCA) compared to the same proportions (8%) in 2017, 9% (54 out of 593) in 2016, 7% (42 out of 622) in 2015 and 9% (55 out of 597) in 2014.

Table 1.1: Number of cases reported to VON 2014 – 2018 in Ireland, according to gestational age.

Gestational age	All cases					No. of cases with MCA				
	2014	2015	2016	2017	2018	2014	2015	2016	2017	2018
<24 weeks	41	48	48	38	44	0	0	3	1	1
24-26 weeks	114	114	134	125	138	9	11	12	12	10
27-29 weeks	235	235	217	240	198	19	14	20	19	16
30-32 weeks	159	170	152	172	126	20	10	15	11	10
>32 weeks	48	55	42	37	31	7	7	4	8	8
Total	597	622	593	612	537	55	42	54	51	45

Note: MCA=Major Congenital Anomaly. MCA was unknown for 1 infant in 2014 and 2 infants in 2018.

In terms of birth weight, 24 infants (5%) weighed ≤500g (Table 1.2), of whom three were ≤401g (the lowest birthweight recorded was 350g). The majority of infants (31%; n=166) were born with a birthweight >1250g of which 19 infants had a birthweight >1500g. Data for the years 2014 to 2017 are also included in Table 1.2.

Table 1.2: Number of cases reported to VON in 2014 – 2018 in Ireland, according to birth weight.

Birth weight (g)	All cases					No. of cases with MCA				
	2014	2015	2016	2017	2018	2014	2015	2016	2017	2018
<501	26	23	21	23	24	1	0	1	2	0
501 – 750	85	100	104	93	97	3	5	14	8	8
751 – 1000	115	98	125	122	118	15	14	11	12	8
1001 – 1250	154	155	152	157	132	15	10	14	12	12
>1250	216	246	191	217	166	21	13	14	17	17
Total	596	622	593	612	537	55	42	54	51	45

Note: MCA=Major Congenital Anomaly; one infant in 2014 (Birthweight 501-750g) did not have a recorded birth weight. MCA was unknown for 1 infant in 2014 and 2 infants in 2018.

2. Infant Characteristics

In 2018, ROI and VON groups were relatively similar with respect to the proportion of infants who received prenatal care, antenatal steroids and who were born by C-Section (Table 2.1).

Differences between Ireland and the VON network were evident with respect to Maternal Chorioamnionitis, Antenatal Steroids, Antenatal Magnesium Sulphate, Multiple Gestation and Major Congenital Anomaly (MCA) (all of which were reported in a higher proportion of ROI infants compared to VON infants) and Maternal Hypertension (which was reported in a lower proportion of ROI infants).

Table 2.1: Infant characteristics in the Republic of Ireland and VON, 2018.

Characteristic	Republic of Ireland			VON		
	Cases	N	%	Median %	Q1 %	Q3 %
Male	283	537	53	51	46	56
Prenatal Care	518	535	97	97	94	100
Chorioamnionitis*	94	537	18	8	3	17
Maternal Hypertension	115	526	22	33	25	41
Antenatal Steroids	472	532	89	86	77	91
C-Section	391	537	73	73	67	80
Antenatal Magnesium Sulphate	366	531	69	62	43	75
Multiple Gestation	162	536	30	21	17	31
Major Congenital Anomaly (MCA)*	45	536	8	4	0	8
Small for Gestational Age (SGA)	115	535	22	24	19	31

Note: N represents the total number of very low birth weight babies (VLBW) in Ireland. For Ireland the % is based on the cases as the numerator and the total, N, as the denominator. For VON the total number of VLBW infants with information available on each characteristic reported ranged between 61,331 and 62,097. The VON reports the Median % based on the units that submit data, as outlined in the methods section. Half of the units report a % lower than the median, one quarter of the units report a % lower than Q1 and three quarters of the units report a % lower than Q3.

*At least 75% of all VON units had lower levels of chorioamnionitis & MCA than reported for ROI.

3. Survival

In 2018, a total of 82% (n=435) of VLBW infants born in the ROI survived to discharge home or first birthday. At least 75% of the VON units had higher survival than reported in ROI. (Table 3.1). Over the five-year period, 2014-2018, the range for the proportion surviving in Ireland was 82-84%. The median survival for VON over the same time period was 86-88%.

In 2018, 54% of infants survived without the specified morbidities of severe IVH, chronic lung disease in the group of infants with <33 weeks of gestation, NEC, pneumothorax, any late infection or cystic PVL. This figure is in line with previous years. While, this rate was lower than the VON Median of 61%, it was within the interquartile range of 51-71% (Table 3.1).

Table 3.1: Survival of ROI and VON infants, including those with congenital anomalies, 2018.

Measure	Year	Republic of Ireland			VON		
		Cases	N	%	Median %	Q1 %	Q2 %
Survival*	2014	492	600	82	87	82	91
	2015	525	622	84	87	82	92
	2016	496	593	84	87	83	92
	2017	501	611	82	86	83	92
	2018	435	530	82	88	83	93
Survival without specified morbidities**	2014	318	600	53	59	50	69
	2015	337	622	54	59	50	69
	2016	333	593	56	59	51	70
	2017	343	605	57	59	50	70
	2018	284	527	54	61	51	71

Note: N represents the total number of very low birth weight babies in ROI. For ROI the % is based on the cases as the numerator and the total, N, as the denominator. For VON the total number of VLBW infants with information on survival and survival without morbidities was 61,489 and 61, 294 respectively. The VON reports the Median % based on the units that submit data, as outlined in the methods section. Half of the units report a % lower than the median, one quarter of the units report a % lower than Q1 and three quarters report a % lower than Q3. At least 3 quarters of the VON units had higher survival than reported in ROI.

* 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 of VLBW infants by birth weight and gestational age is reported in Tables 3.2 and 3.3 respectively for the years 2014 through to 2018.

In line with previous years, there was a general trend of increased survival to discharge with increasing birth weight in 2018 (Table 3.2). In 2018, two infants born less than 501g survived (N=23, 9%).

Table 3.2: Survival to discharge by birth weight for ROI infants, including those with congenital anomalies, 2014-2018.

Number of survivors/Number of liveborn infants (%)					
Birth Weight	**2014 (N=596*)**	**2015 (N=622)**	**2016 (N=593)**	**2017 (N=612)**	**2018 (N=530*)**
<501g	2/26 (8%)	4/23 (17%)	6/21 (29%)	3/23 (13%)	2/23* (9%)
501-600g	9/32 (28%)	19/37 (51%)	12/33 (36%)	16/39 (41%)	19/32* (59%)
601-700g	24/36 (67%)	29/45 (64%)	32/51 (63%)	23/33 (70%)	24/42 (57%)
701-800g	27/37 (73%)	26/37 (70%)	35/49 (71%)	29/43 (67%)	27/39* (69%)
801-900g	29/37 (78%)	33/40 (83%)	40/47 (85%)	35/47 (74%)	37/44 (84%)
901-1000g	51/58 (88%)	34/39 (87%)	45/49 (92%)	48/53 (91%)	51/54 (94%)
1001-1100g	47/54 (87%)	54/59 (92%)	51/54 (94%)	55/64 (86%)	41/46 (89%)
1101-1200g	60/64 (94%)	58/64 (91%)	62/67 (93%)	60/64 (94%)	47/50 (94%)
1201-1300g	77/81 (95%)	63/67 (94%)	61/63 (97%)	65/69 (94%)	51/53* (96%)
1301-1400g	67/72 (93%)	84/87 (97%)	62/64 (97%)	74/80 (93%)	56/60 (93%)
>1400g	94/99 (95%)	121/124 (98%)	90/95 (95%)	93/97 (96%)	80/87 (92%)
Total	487/596* (82%)	525/622 (84%)	496/593 (84%)	501/612 (82%)	435/530 (82%)

*One infant in 2014 did not have a recorded birth weight and therefore the denominator was 596. *Seven infants in 2018 did not have information on survival to discharge: one infant <501g; one infant 501-600g; three infants 701-800g; two infants 1201-1300g. Hence the denominator is 530.

Survival to discharge increased with advancing gestational age in 2018 until 30 weeks gestation, above which there was a slight variation away from this pattern, consistent with previous years (Table 3.3). In 2018, all the infants born at >32 weeks and who did not survive, had an MCA.

At 23 weeks' gestation, nine infants (33% of 27 infants) survived to discharge in 2018, lower than the figure of 47% for 2017. The gradual increase in the percentage survival for this gestational age year on year since 2014 was not noted in 2018.

Table 3.3: Survival to discharge by gestational age breakdown for ROI infants, including those with congenital anomalies, 2014-2018.

Number of survivors/Number of liveborn infants (%)					
Gestational Age	**2014 (N=597)**	**2015 (N=622)**	**2016 (N=593)**	**2017 (N=612)**	**2018 (N=530*)**
<22 weeks	0/2 (0%)	0/2 (0%)	0/2 (0%)	0/6 (0%)	0/5 (0%)
22 weeks	0/18 (0%)	0/16 (0%)	0/19 (0%)	0/16 (0%)	0/12 (0%)
23 weeks	4/21 (19%)	9/30 (30%)	10/27 (37%)	7/15 (47%)	9/27 (33%)
24 weeks	18/36 (50%)	22/34 (65%)	25/45 (56%)	21/37 (56%)	20/39 (51%)
25 weeks	25/35 (71%)	33/43 (77%)	39/50 (78%)	27/50 (54%)	32*/41 (78%)
26 weeks	28/43 (65%)	30/37 (81%)	34/39 (87%)	31/39 (79%)	50*/54 (93%)
27 weeks	54/57 (95%)	40/46 (87%)	47/49 (96%)	60/69 (87%)	46*/52 (88%)
28 weeks	75/83 (90%)	82/90 (91%)	77/83 (93%)	83/88 (94%)	65*/69 (94%)
29 weeks	89/95 (94%)	94/99 (95%)	80/85 (94%)	74/83 (89%)	70/75 (93%)
30 weeks	68/71 (96%)	65/65 (100%)	62/66 (94%)	84/87 (97%)	51/53 (96%)
31 weeks	44/49 (90%)	64/68 (94%)	49/50 (98%)	52/54 (96%)	31/34 (91%)
32 weeks	36/39 (92%)	35/37 (95%)	34/36 (94%)	28/31 (90%)	36/39 (92%)
>32 weeks	46/48 (96%)	51/55 (93%)	39/42 (93%)	34/37 (92%)	25*/30 (83%)
Total	487/597 (82%)	525/622 (84%)	496/593 (84%)	501/612 (82%)	435/530 (82%)

*Seven infants in 2018 did not have information on survival to discharge: one infant born at 25 weeks; three infants born at 26 weeks; one infant born at 27 weeks; one infant born at 28 weeks and one infant born at 35 weeks. Hence the denominator is 530.

As shown in table 3.4, the proportion of infants surviving discharge without specified morbidities increased with advancing gestational ages. The percentage of infants surviving without specified morbidities has also marginally increased over the past four years, although a slight decrease was recorded for 2018. None of the infants born ≤ 23 weeks gestation survived without specified morbidities.

Table 3.4: Survival without specified morbidities[1] of infants according to gestational age at birth of ROI infants reported to VON, 2014-2018.

Number of survivors without morbidities[1]/ Number of liveborn infants (%)					
Gestational Age	**2014 (N=594*)**	**2015 (N=622)**	**2016 (N=592*)**	**2017 (N= 605*)**	**2018 (N=527*)**
≤ 22 weeks	0/20 (0%)	0/18 (0%)	0/21 (0%)	0/22 (0%)	0/15 (0%)
23 weeks	0/21 (0%)	1/30 (3%)	2/27 (7%)	1/15 (7%)	0/27 (0%)
24-27 weeks	45/169 (27%)	40/160 (25%)	59/182 (32%)	57/190 (30%)	69/186 (37%)
28-31 weeks	193/297 (65%)	213/322 (66%)	202/284 (71%)	226/310 (73%)	158/230 (69%)
≥32 weeks	73/87 (84%)	83/92 (90%)	70/78 (90%)	59/68 (87%)	57/69 (83%)
Total	311/594* (52%)	337/622 (54%)	333/592* (56%)	343/605* (57%)	284/527* (54%)

Note: Figures include infants with congenital anomalies.

[1]Specified Morbidities include severe IVH, chronic lung disease in infants <33 weeks gestation, NEC, pneumothorax, any late infection and/or cystic PVL.

*Data on survival without specified morbidities:

Unknown for 3 infants in 2014: 2 infants born at 24-27 weeks gestation and 1 infant born at 28-31 weeks;

Unknown for 1 infant born in 2016: infant born at 24-27 weeks gestation;

Unknown for 7 infant born in 2017: 5 infants born at 24-27 weeks gestation and 2 infants born at 28-31 weeks; Unknown for 7 infant born in 2018: 2 infants born at 22 weeks, 5 infants born at 24-27 weeks gestation, 2 infants born at 28-31 weeks and 1 born at >32 weeks.

4. 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. Pneumothorax
6. Late Bacterial Infection
7. Coagulase Negative Infection
8. Nosocomial Infection
9. Fungal Infection
10. Any Late Infection
11. Any Intraventricular Haemorrhage (IVH)
12. Severe IVH
13. ROP
14. Severe ROP
15. Cystic PVL
16. Necrotising Enterocolitis

For each KPI, the number and percentage of ROI infants that experienced the outcome in 2018 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 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.

SMRs for Key Performance indicators in 2018

Table 4.1 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.

Of all the KPIs measured, Pneumothorax recorded the highest SMR (1.56; CI 1.13, 1.98), as it did in 2017. Twelve more infants experienced this outcome in ROI than would have been expected considering their risk profile. The increased number of cases was greater, at 16 infants, in 2017. Additionally, the SMR data shows that ROI infants were less often than expected diagnosed with severe retinopathy of prematurity (SMR 0.39; CI 0, 0.83).

Table 4.1: Risk Adjusted Standardised Mortality/Morbidity Ratios for Key Performance Indicators, Republic of Ireland, 2018.

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Mortality	71	64	1.11	(0.87, 1.36)	7	(-8, 23)
Mortality excluding early death	52	46	1.12	(0.83, 1.41)	6	(-8, 19)
Death or Morbidity	216	214	1.01	(0.88, 1.15)	2	(-26, 31)
Chronic Lung Disease	95	98	0.97	(0.77, 1.17)	-3	(-22, 17)
Pneumothorax*	33	21	1.56	(1.13, 1.98)	12	(3, 21)
Late Bacterial Infection	34	39	0.88	(0.56, 1.20)	-5	(-17, 8)
Coagulase Negative Infection	28	23	1.20	(0.80, 1.61)	5	(-5, 14)
Nosocomial Infection	53	54	0.97	(0.71, 1.24)	-1	(-16, 13)
Fungal Infection	1	4	0.23	(0.00, 1.17)	-3	(-7, 1)
Any Late Infection	54	56	0.96	(0.70, 1.22)	-2	(-17, 12)
Intraventricular Haemorrhage	112	113	0.99	(0.80, 1.17)	-1	(-22, 19)
Severe Intraventricular Haemorrhage	32	35	0.90	(0.57, 1.23)	-3	(-15, 8)
Retinopathy of Prematurity	95	112	0.85	(0.67, 1.04)	-17	(-37, 4)
Severe Retinopathy of Prematurity*	8	20	0.39	(0.00, 0.83)	-12	(-21, -4)
Cystic Periventricular Leukomalacia	11	13	0.88	(0.32, 1.43)	-2	(-8, 5)
Necrotising Enterocolitis	31	25	1.22	(0.83, 1.61)	6	(-4, 16)

"O" refers to the number of observed cases with the outcome and "E" to 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.

*Indicates a statistically significant difference.

Mortality in infants with birth weights 501-1500g

Amongst ROI infants with birth weights 501-1500g, there were 71 deaths observed whereas the expected number based on the risk profile of the infants in the ROI population was 64 (Table 4.1). The SMR was 1.11 (95% CI: 0.87, 1.36). This SMR is consistent with that reported for previous years with SMR of 1.27, 1.15, 1.10 and 1.19 for 2014, 2015, 2016 and 2017, respectively (Table 4.3). In absolute numbers there were seven more deaths than expected in 2018 whereas the excess number in 2014-2017 was in the range 8-21 deaths.

The SMR for mortality was almost unchanged when calculated after excluding early deaths (SMR=1.12; 95% CI: 0.83, 1.41). There were 52 observed deaths and 46 expected deaths based on the risk profile of infants in the ROI (Table 4.1). Thus, there were six more observed deaths (excluding early deaths) than the number expected, a difference that was not statistically significant (95% CI -9, 19).

Death or Morbidity in infants with birth weights 501-1500g

The risk of the composite outcome of death or morbidity in 2018 showed no evidence of being higher or lower than expected (SMR=1.01; 95% CI: 0.88, 1.15). Amongst ROI infants with birth weights 501-1500g, there were 216 observed cases of death or morbidity, whereas the expected number based on the risk profile of the infants in the Irish population was 214 (Table 4.1). Thus, there were just two more cases of death or morbidity in the ROI than expected, a finding which was not statistically significant (95% CI: -26, 31).

CLD in infants with birth weights 501-1500g

There were 95 observed cases of CLD amongst ROI infants with birth weights 501-1500g whereas the expected number based on the risk profile of infants in the Irish population was similar at 98 (Table 4.1). The SMR was 0.97 (95% CI: 0.77, 1.17), reinforcing that the number of observed cases was in line with the expected number. In absolute numbers there were three fewer cases of CLD than expected, which not a statistically significant difference (95% CI: -22, 17).

Pneumothorax in infants with birth weights 501-1500g

There were 33 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 4.1). The SMR was 1.56 (95% CI: 1.13, 1.98), indicating that the number of observed cases was 56% higher than the expected number. In absolute numbers there were 12 more cases of pneumothorax (95% CI: 3, 21) than expected, a statistically significant difference, and similar to what was observed in 2017. To better understand the elevated risk of pneumothorax amongst ROI infants, further in-depth analysis using the data accumulated over multiple years will be carried out.

Infections: late bacterial infection, coagulase negative infection, nosocomial infection, fungal infection and any late infection.

Observed and expected risk were similar for the KPIs related to infection, as detailed in Table 4.1 and illustrated in Figure 4.1.

Amongst ROI infants with birth weights 501-1500g, there were 34 observed compared to 39 expected cases of late bacterial infection (SMR=0.88, 95% CI: 0.56, 1.20). There were 28 observed compared to 23 expected cases of coagulase negative infection (SMR=1.20, 95% CI: 0.80, 1.61). The observed and expected number of cases were almost identical for nosocomial infection (SMR=0.97, 95% CI: 0.71, 1.24) and any late infection (SMR=0.96; 95% CI: 0.70, 1.22).

Intraventricular Haemorrhage (IVH) and severe IVH in infants with birth weights 501-1500g

IVH was observed in 112 ROI infants weighing 501-1500g at birth, almost identical to the 113 cases expected based on the infants' risk profile (SMR=0.99, 95% CI: 0.80, 1.17; Table 4.1). In absolute numbers, there was one case fewer than expected, which was not statistically significant (95% CI: -22, 19).

For severe IVH, there were 32 observed cases compared to an expected number of 35 cases (SMR=0.90, 95% CI: 0.57, 1.23). This difference of three cases fewer than expected was not statistically significant (95% CI: -15, 8; Table 4.1).

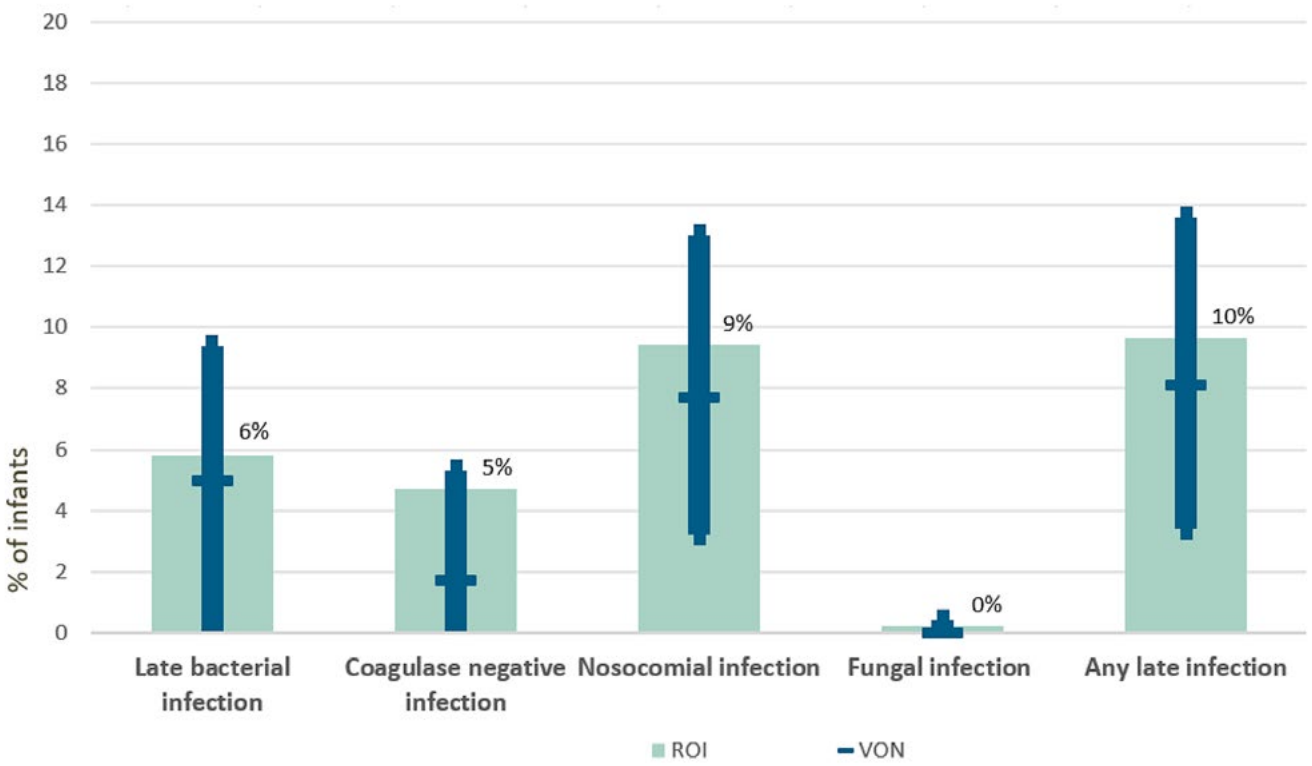

Figure 4.1: Comparison of infections in ROI and VON infants, 2018.

Note: Dark blue bar represents the interquartile range for units reporting to the VON. The dark blue horizontal marker indicates the median of units reporting to the VON.

ROP in infants with birth weights 501-1500g
Considering ROI infants born weighing 501-1500g for whom risk adjustment was performed, there were 95 observed cases of ROP compared to an expected number of 112 cases (Table 4.1). Thus, the observed number equated to 85% of the expected number, but this was not a statistically significant difference (SMR=0.85, 95% CI: 0.67, 1.04). In absolute numbers, there were 17 fewer cases of ROP than expected (95% CI: -37, 4).

The difference was more marked with regard to severe ROP. There were eight observed cases compared to an expected number of 20 cases based on the risk profile of infants in the ROI population. Thus, the observed number equated to less than half of the expected number, which was a statistically significant difference (SMR=0.39, 95% CI: 0, 0.83). In absolute terms, there were 12 fewer cases of severe ROP cases than expected (95% CI: -21, -4; Table 4.1).

Cystic PVL in infants with birth weights 501-1500g
Considering ROI infants with 501-1500g birth weights, there were 11 observed cases of cystic PVL whereas the number expected based on their risk profile was 13 (Table 4.1). Thus, the observed number was close to the expected (SMR=0.88, 95% CI: 0.32, 1.43). In absolute numbers the two fewer cases observed did not represent a statistically significant difference from the expected number (95% CI: -8, 5).

NEC in infants with birth weights 501-1500g
Amongst the ROI infants born weighing 501-1500g there were 31 observed cases of NEC and an expected number of 25 cases (SMR=1.22, 95% CI: 0.83, 1.61; Table 4.1). This was not a statistically significant difference (95% CI: -4, 16).

Key Performance Indicators and Gestational Age

The proportion and number of infants recording each of the KPIs measured according to their gestational age, for those born after 24 weeks of gestation, is outlined in table 4.2. A statistically significant decrease in all KPIs was observed with higher gestational ages, with the exception of fungal infection and cystic periventricular leukomalacia due to limited numbers. This denotes a lower percentage of mortality, morbidity and specific outcomes (as measured in the KPIs) in infants born with higher gestational ages.

Table 4.2: Distribution of each Key Performance Indicator according to gestational age categories of VLBW infants born in the ROI, 2018.

Outcomes	24-27 weeks	28-31 weeks	≥32 weeks	Total
Mortality	34 (19%)	10 (5%)	8 (12%)	52 (11%)
Mortality excluding early death	31 (17%)	7 (3%)	3 (4%)	41 (9%)
Death or Morbidity	112 (62%)	65 (31%)	12 (17%)	189 (41%)
Chronic Lung Disease	54 (29%)	26 (12%)	6 (9%)	86 (18%)
Pneumothorax	18 (10%)	13 (6%)	1 (2%)	32 (7%)
Late Bacterial Infection	19 (10%)	7 (3%)	1 (1%)	27 (6%)
Coagulase Negative Infection	17 (9%)	5 (2%)	0 (0%)	22 (5%)
Nosocomial Infection	33 (18%)	10 (5%)	1 (1%)	44 (9%)
Fungal Infection	1 (1%)	0 (0%)	0 (0%)	1 (0%)
Any Late Infection	34 (18%)	10 (5%)	1 (1%)	45 (10%)
Intraventricular Haemorrhage	70 (38%)	32 (15%)	4 (6%)	106 (23%)
Severe Intraventricular Haemorrhage	22 (12%)	7 (3%)	0 (0%)	29 (6%)
Retinopathy of Prematurity	68 (37%)	16 (8%)	5 (7%)	89 (19%)
Severe Retinopathy of Prematurity	8 (4%)	0 (0%)	0 (0%)	8 (2%)
Cystic Periventricular Leukomalacia	5 (3%)	6 (3%)	0 (0%)	11 (2%)
Necrotising Enterocolitis	20 (11%)	5 (2%)	1 (1%)	26 (6%)

Note: Association between outcomes (KPIs) and gestational age was significant at P-value <0.05, except for fungal infection and cystic periventricular leukomalacia.

Time trends in relative risk

SMRs for each KPI have been calculated for ROI infants with birth weights 501-1500g for four years, 2014 through to 2018. These SMRs enable an assessment of whether the risk of a KPI has changed over time. For each KPI, Table 4.3 displays the SMR and its 95% confidence interval for each year.

There is evidence of improvement with respect to several KPIs. In the first two years with national data, the observed risk of death or specified morbidity was 14-16% higher than expected, a statistically significant difference each year. The observed and expected risk were almost identical in each of the next three years.

A similar trend was observed between 2014-2015 and 2016-2018 for coagulase negative infection and nosocomial infection. The observed excess risk of coagulase negative infection was largely confined to 2014 and 2015 when 84% and 60% more cases than expected were observed. The excess risk of 13-20% reported during 2016-2018 was not statistically significant. Similarly, nosocomial infection was 30% and 43% more common than expected in 2014 and 2015, respectively (a statistically significant difference). The excess risk reduced to 17% in 2016 and reduced further in 2017 and 2018 and is no longer statistically significant.

Table 4.3: Standardised Mortality/Morbidity Ratios for Key Performance Indicators, Republic of Ireland, 2014-2018.

Outcome	2014		2015		2016		2017		2018	
	SMR	(95% CI)	SMR	(95% CI)	SMR	(95% CI)	SMR	(95% CI)	SMR	(95% CI)
Mortality	1.27	(1.03, 1.51)	1.15	(0.91, 1.39)	1.10	(0.87, 1.34)	1.19	(0.96, 1.42)	1.11	(0.87, 1.36)
Mortality excluding early death	1.23	(0.92, 1.54)	1.01	(0.70, 1.31)	1.12	(0.84, 1.41)	1.20	(0.93, 1.48)	1.12	(0.83, 1.41)
Death or Morbidity	1.14	(1.01, 1.27)	1.16	(1.03, 1.29)	1.02	(0.89, 1.15)	1.01	(0.89, 1.14)	1.01	(0.88, 1.15)
Chronic Lung Disease	1.08	(0.88, 1.28)	1.07	(0.87, 1.27)	0.95	(0.75, 1.15)	1.12	(0.93, 1.31)	0.97	(0.77, 1.17)
Pneumothorax	1.67	(1.25, 2.10)	1.80	(1.37, 2.24)	1.40	(0.98, 1.82)	1.69	(1.29, 2.1)	1.56	(1.13, 1.98)
Late Bacterial Infection	0.90	(0.58, 1.22)	0.97	(0.68, 1.26)	1.12	(0.81, 1.43)	0.89	(0.59, 1.18)	0.88	(0.56, 1.20)
Coagulase Negative Infection	1.84	(1.45, 2.23)	1.60	(1.22, 1.99)	1.13	(0.74, 1.52)	1.16	(0.8, 1.53)	1.20	(0.80, 1.61)
Nosocomial Infection	1.30	(1.04, 1.57)	1.43	(1.17, 1.69)	1.17	(0.91, 1.43)	1.04	(0.8, 1.29)	0.97	(0.71, 1.24)
Fungal Infection	0.55	(0.0, 1.57)	0.70	(0.0, 1.65)	0.25	(0.73, 1.24)	0.84	(0.06, 1.74)	0.23	(0, 1.17)
Any Late Infection	1.26	(1.00, 1.52)	1.44	(1.18, 1.7)	1.13	(0.88, 1.39)	1.03	(0.78, 1.27)	0.96	(0.70, 1.22)
Intraventricular Haemorrhage	1.07	(0.88, 1.26)	1.24	(1.05, 1.43)	1.06	(0.87, 1.24)	0.98	(0.81, 1.15)	0.99	(0.80, 1.17)
Severe Intraventricular Haemorrhage	1.22	(0.85, 1.58)	1.15	(0.80, 1.51)	1.32	(0.98, 1.67)	0.90	(0.59, 1.22)	0.90	(0.57, 1.23)
Retinopathy of Prematurity	0.51	(0.33, 0.70)	0.71	(0.53, 0.89)	0.62	(0.45, 0.8)	0.72	(0.54, 0.89)	0.85	(0.67, 1.04)
Severe Retinopathy of Prematurity	0.83	(0.37, 1.29)	1.10	(0.66, 1.54)	0.54	(0.1, 0.97)	0.98	(0.55, 1.42)	0.39	(0.00, 0.83)
Cystic Periventricular Leukomalacia	0.32	(0.0, 0.87)	1.26	(0.71, 1.82)	0.56	(0.0, 1.11)	0.66	(0.15, 1.16)	0.88	(0.32, 1.43)
Necrotising Enterocolitis	1.21	(0.84, 1.59)	1.47	(1.08, 1.86)	1.39	(1.01, 1.78)	1.22	(0.86, 1.59)	1.22	(0.83, 1.61)

5. Survival according to designated category of neonatal unit

There are 19 neonatal centres in the ROI that are affiliated with an Obstetric Service. These are classified as tertiary, regional or peripheral neonatal centre based on the number of births per annum in the affiliated obstetric centre and the level of neonatal consultant cover in the neonatal centre. There are four designated tertiary neonatal centres, four designated regional neonatal centres and eleven designated peripheral neonatal centres (Table 5.1). Each of the tertiary centres delivered more than 7,000 births per annum and all provide 24-hour consultant neonatology cover. The regional centres have dedicated neonatal intensive care units (NICUs) in their centres but deliver less than 7,000 infants yearly or do not have 24-hour consultant neonatology cover. In 2018, one of these four centres delivered between 4,000-5,000 births per annum; one centre delivered between 3,000-4,000 births per annum; one centre delivered between 2,000-3,000 births per annum and the fourth centre delivered less than 2,000 births per annum when births weighing 500g or more are counted (Table 5.1). Peripheral centres do not have dedicated NICUs nor do they have dedicated consultant neonatology cover but they do have designated areas for newborn infants namely Special Care Baby Units (SCBUs). In 2018, all peripheral centre delivered less than 2,000 births per annum.

Table 5.1: Number of live births and stillbirths weighing greater than or equal to 500g in maternity centres in 2018.

Hospital	Number of births
Designated Tertiary Neonatal Centres	
National Maternity Hospital	> 7,000
Coombe Women & Infants University Hospital	> 7,000
Rotunda Hospital	> 7,000
Cork University Maternity Hospital	> 7,000
Designated Regional Neonatal Centres	
University Maternity Hospital Limerick	4,000-5,000
Our Lady of Lourdes Hospital Drogheda	3,000-4,000
Galway University Hospital	2,000-3,000
University Hospital Waterford	< 2,000
Designated Peripheral Neonatal Centres	
Midland Regional Hospital Mullingar	< 2,000
Portiuncula Hospital Ballinasloe	< 2,000
Wexford General Hospital	< 2,000
Midland Regional Hospital Portlaoise	< 2,000
St Luke's Hospital Kilkenny	< 2,000
Cavan General Hospital	< 2,000
Mayo University Hospital	< 2,000
Letterkenny University Hospital	< 2,000
University Hospital Kerry	< 2,000
Sligo University Hospital	< 2,000
South Tipperary General Hospital	< 2,000

Source: Annual Clinical Reports of hospitals and hospital groups; and personal communication with individual.

All the 537 VLBW infants reported to VON in 2018, had birth location data suitable for analysis of survival outcome based on the designated category of neonatal centre in which they were born (i.e. tertiary, regional or peripheral).

In 2018, 393 infants (73%) were born in one of the four tertiary neonatal centres, 101 (19%) were born in one of the four regional neonatal centres and the remaining 43 infants (8%) were born in one of eleven peripheral centres (Table 5.2). This compares to 71% (n=112), 18% (n=112) and 11% (n=67) born in tertiary, regional and peripheral centres in 2017.[2]

Table 5.2 also shows that of all infants born between 23 and 27 weeks gestation (n=218), 174 (80%) were born in a tertiary neonatal centre, 21 (10%) were born in a regional neonatal centre and 23 (11%) were born in a peripheral centre in 2018. This compares to 167 (80%) in a total 210 infants born at this gestation in tertiary centres in 2017 and 85% (n=178) in 2016. The current Model of Care for Neonatal Services in Ireland recommends that infants born <28 weeks should ideally be delivered at a tertiary neonatal centre.[3]

Resuscitation in the delivery room (defined as the administration of positive pressure breaths via a face mask and/or an endotracheal tube) was provided to a total of 385 (72%) infants in 2018 (Table 5.2) compared to 68% of infants in 2017. Overall, 71% of those born in a tertiary centre, 72% of those born in a regional centre and 79% of those born in a peripheral centre were resuscitated in 2018 (Table 5.2). This compares to figures of 73%, 60% and 51% respectively for the previous year.[2]

Table 5.2: Survival of ROI Infants by category of neonatal centre, 2018, n=537.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	393 (73%)	101 (19%)	43 (8%)	537
Received resuscitation in the delivery room	278/393 (71%)	73/101 (72%)	34/43 (79%)	385/537 (72%)
Admitted to a NICU/SCBU	370/393 (94%)	97/101 (96%)	40/43 (93%)	507/537 (94%)
Transferred to another neonatal centre within 48 hours of birth	2/393 (1%)	5/101 (5%)	23/43 (54%)	30/537 (6%)
Survived to discharge	310/386* (80%)	88/101 (87%)	37/43 (86%)	435/530* (82%)

*No information available on the survival outcome of seven babies born in tertiary centres.

Of the 385 infants who received resuscitation in the delivery room, three died in the delivery room and 382 survived to admission to a NICU/SCBU (Figure 5.1). The gestational age category of infants resuscitated according to the category of neonatal centre where these infants were born, is shown in table 5.3. Of the 385 infants who received resuscitation, 314 (82%) survived to discharge (Figure 5.1). The remaining 71 (18%) infants died, three of whom died in the delivery room. Survival outcome was not known for seven infants.

The 2018 report on mortality risk among VLBW infants between 2014-2016, recommended that all infants born at 23 weeks gestation, if presenting in a favourable condition, should be offered resuscitation.[4] A total of 89% of infants born at 23 weeks gestation were resuscitated at birth compared to 87% in 2017 and 74% in 2016.

Table 5.3: Number of infants born in each category of neonatal centre who were administrated resuscitation according to gestational age, 2018.

Gestational Age	TERTIARY No. receiving resuscitation/ No. born (% of liveborn)	REGIONAL No. receiving resuscitation/ No. born (% of liveborn)	PERIPHERAL No. receiving resuscitation/ No. born (% of liveborn)	Total
≤ 22 weeks	1/14 (7%)	0/2 (0%)	0/1 (0%)	1/17 (6%)
23 weeks	22/24 (92%)	1/2 (50%)	1/1 (100%)	24/27 (89%)
24-27 weeks	134/150 (89%)	18/19 (95%)	19/22 (86%)	171/191 (90%)
28-31 weeks	102/152 (67%)	46/63 (73%)	13/17 (76%)	161/232 (69%)
≥32 weeks	19/53 (36%)	8/15 (53%)	1/2 (50%)	28/70 (40%)
Total	278/393 (71%)	73/101 (72%)	34/43 (79%)	385/537 (72%)

Admission to NICU/SCBU was recorded for 507 infants, of which 370 (94%) were born at tertiary centres, 97 (96%) at regional centres and 40 (93%) at peripheral centres (Table 5.2). These numbers included infants who were transferred out of the birth hospital and to another neonatal and/or paediatric centre within 48 hours of birth. A total of 30 (6%) of the 537 infants were transferred and the majority of these infants (n=23; 77% of the total infants transferred) were born in peripheral centres. The two infants born in a tertiary centre who were transferred out within 48 hours of birth were transferred to a paediatric hospital in Ireland. The five infants from regional centres and 20 infants from peripheral centres were all transferred out to tertiary neonatal centres. Three of the infants born in peripheral centres were transferred, within 48 hours of birth, to a regional centre.

Table 5.4 outlines the gestational age category of the infants born in each of the three categories of neonatal centres with reference to those infants who required transfer. As shown in the table, the majority of transfers from peripheral centres related to infants born between 24-27 and 28-31 weeks gestation whereas the two transfers that occurred from tertiary centres related to infants with a gestation birth between 28-31 weeks and ≥32 weeks.

Table 5.4: Number of infants born in each category of neonatal centre, and number transferred within 48 hours, according to gestational age, 2018, n=537.

Gestational Age	TERTIARY No. transferred within 48 hours/ No. born (%)	REGIONAL No. transferred within 48 hours/ No. born (%)	PERIPHERAL No. transferred within 48 hours/ No. born (%)
≤ 22 weeks	0/14 (0%)	0/2 (0%)	0/1 (0%)
23 weeks	0/24 (0%)	0/2 (0%)	0/1 (0%)
24-27 weeks	0/150 (0%)	3/19 (16%)	11/22 (50%)
28-31 weeks	1/152 (1%)	2/63 (3%)	12/17 (71%)
≥32 weeks	1/53 (2%)	0/15 (0%)	0/2 (0%)
Total	2/393 (1%)	5/101 (5%)	23/43 (53%)

The overall crude survival rate for ROI infants in 2018 was 82% (n=435/530): the highest rate of survival occurred in the regional centres at 87%, followed by the peripheral centres (86%) and the tertiary centres at 80% (Figure 5.1 and Table 5.2). In 2017, regional centres had a survival rate of 88%, and tertiary and peripheral centres had a rate of 81% and 79% respectively.[2]

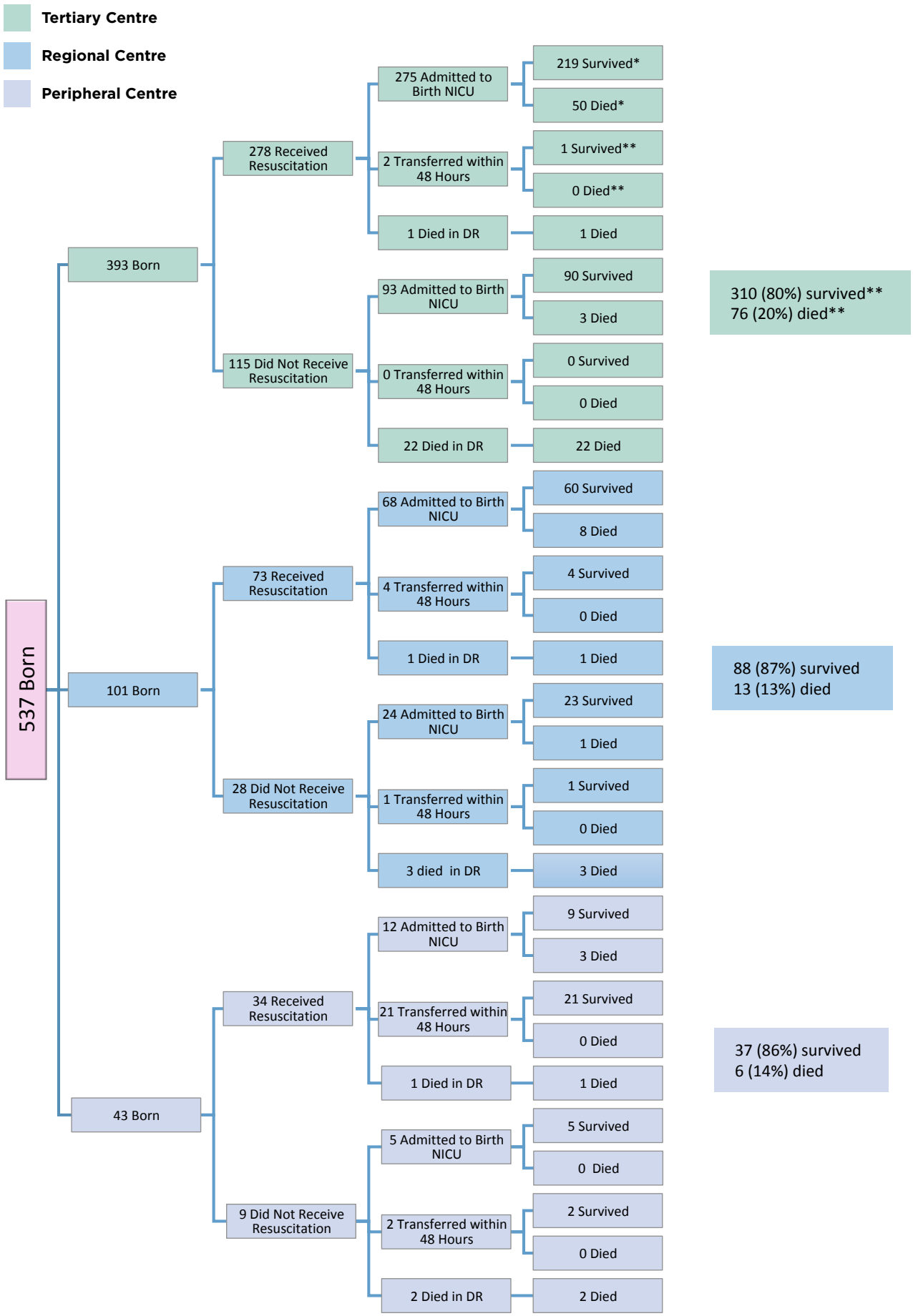

Figure 5.1: Flow chart illustrating survival outcomes of all VLBW infants born, according to designated category of neonatal centre, 2018, n=537. (Information not available on outcome of seven infants)

Survival of infants born at 22 and 23 weeks gestation according to category of neonatal centre

Overall, 44 infants were born <24 weeks gestation, of which 38 (86%) were born in tertiary neonatal centres, four (9%) in regional centres and the remaining two (5%) in one of the eleven peripheral centres.

Infants born at ≤ 22 weeks gestation in ROI
Of the 17 infants born at ≤ 22 weeks gestation in Ireland in 2018, 1 infant (6%) was born in a peripheral centre, 2 (12%) in regional centres and 14 (82%) infants were born in tertiary centres.

One infant born in a tertiary centre was resuscitated in the delivery room (Table 5.5), this infant was admitted to NICU although they did not survive to discharge.

The remaining 16 infants born at ≤ 22 weeks gestation died in the delivery room, none of these infants had an MCA.

Table 5.5: Survival of ROI Infants born at ≤ 22 weeks gestation by category of neonatal centre, 2018, n=17.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	14	2	1	17
Received resuscitation in the delivery room	1 (7%)	0 (0%)	0 (0%)	1 (6%)
Admitted to a NICU/SCBU	1 (7%)	0 (0%)	0 (0%)	1 (6%)
Transferred to another neonatal centre within 48 hours of birth	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Survived to discharge	0 (0%)	0 (0%)	0 (0%)	0 (0%)

Note: Percentage from the total liveborn infants in each category.

Table 5.6 outlines the trend in survival and provision of resuscitation to ROI infants born at ≤22 weeks gestation over the past 5 years. No infant born ≤22 weeks gestation survived to discharge since 2014, the inception of this report.

Table 5.6: Survival of infants born at ≤22 weeks gestation, 2014-2018.

	2014 n (%)	2015 n (%)	2016 n (%)	2017 n (%)	2018 n (%)
Liveborn infants	20	18	21	22	17
Received resuscitation in the delivery room	1 (5%)	0	1 (5%)	2 (9%)	1 (6%)
Admitted to a NICU/SCBU	0	0	1 (5%)	2 (9%)	1 (6%)
Survived to discharge	0	0	0	0	0

Infants born at 23 weeks gestation (23+0 to 23+6) in ROI
A total of 27 infants were born in 2018 in Ireland at 23 weeks gestation, the vast majority of these delivered in tertiary centres (n=24, 89%) (Table 5.7). Twenty-four of these infants (89%) were resuscitated in the delivery room, including 22 (92%) of the infants born in tertiary centres, one of the two infants born in a regional centre and one (the only) infant who was born in a peripheral centre. Of these infants who received resuscitation in the delivery room, only the 22 infants born in tertiary centres survived to admission to a NICU/SCBU.

Five of the 27 infants born at 23 weeks gestation died in the delivery room.

Of the 22 infants who survived to admission to a NICU/SCBU, none was transferred from their hospital of birth soon after they were born (Table 5.7).

In total, nine infants born at 23 weeks gestation in 2018 survived to discharge, all of these were born in tertiary centres (Table 5.7). The overall crude survival rate for infants of this gestational age was 33% (n=9/27).

Table 5.7: Survival of ROI Infants born at 23 weeks gestation by category of neonatal centre, 2018, n=27.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	24	2	1	27
Received resuscitation in the delivery room	22 (92%)	1 (50%)	1 (100%)	24 (89%)
Admitted to a NICU/SCBU	22 (92%)	0 (0%)	0 (0%)	22 (81%)
Transferred to another neonatal centre within 48 hours of birth	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Survived to discharge among liveborn babies	9/24 (38%)	0/2 (0%)	0/1 (0%)	9/27 (33%)
Survived to discharge among infants receiving resuscitation	9/22 (41%)	0/1 (0%)	0/1 (0%)	9/24 (33%)
Survived to discharge among infants admitted to NICU/SCBU	9/22 (41%)	0/0 (0%)	0/0 (0%)	9/22 (33%)

The figures in table 5.8 show an increase, over the past 4 years, in the proportion of infants born at 23 weeks gestation who were resuscitated in the delivery room and admitted to a NICU/SCBU. Despite this, in 2018, the number of infants born at this gestational age and who survived to discharge was lower.

Table 5.8: Survival of infants born at 23 weeks gestation, 2014-2018.

	2014 n (%)	2015 n (%)	2016 n (%)	2017 n (%)	2018 n (%)
Liveborn infants	21	30	27	15	27
Received resuscitation in the delivery room	9 (42%)	22 (73%)	20 (74%)	13 (87%)	24 (89%)
Admitted to a NICU/SCBU	5 (24%)	10 (33%)	20 (74%)	13 (87%)	22 (81%)
Survived to discharge	4 (19%)	9 (30%)	10 (37%)	7 (47%)	9 (33%)

Table 5.9 displays Standardised Mortality/Morbidity Ratios (SMR = Observed/Expected) for the main KPIs recorded for the infants born in ROI between 2014 and 2018, at 23 weeks of gestation. Necrotising Enterocolitis (NEC) was the only one of the KPIs analysed here with an observed number of cases in Ireland that was notably different than the expected number. Out of 80 infants for whom NEC was determined, there were 16 cases observed, almost twice the expected number of nine (SMR 1.78; CI 1.13, 2.43). This difference was statistically significant but it must be noted that the numbers involved are relatively small.

Table 5.9: Risk Adjusted Standardised Mortality/Morbidity Ratios for Key Performance Indicators within infants born with 23 weeks of gestation in ROI, 2014-2018.

Outcome	N	O	E	SMR	(95% CI)	O-E	(95% CI)
Mortality	120	81	68	1.19	(0.95, 1.42)	13	(-3, 29)
Death or Morbidity	120	116	111	1.04	(0.86, 1.23)	5	(-16, 26)
Chronic Lung Disease	36	32	29	1.10	(0.74, 1.47)	3	(-8, 14)
Pneumothorax	80	9	9	1.01	(0.36, 1.67)	0	(-6, 6)
Any Late Infection	70	27	27	1.00	(0.62, 1.37)	0	(-10, 10)
Severe Intraventricular Haemorrhage	75	23	26	0.90	(0.51, 1.29)	-3	(-12, 7)
Cystic Periventricular Leukomalacia	75	2	5	0.40	(0, 1.28)	-3	(-7, 1)
Necrotising Enterocolitis	80	16	9	1.78*	(1.13, 2.43)	7	(1, 13)

N specifies how many of the 120 infants had data on the KPI. Morbidities may not be recorded for infants who died, especially those who die soon after birth. O refers to the number of observed cases with the outcome and E to 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. *Indicates a statistically significant difference.

Mortality risk among the 120 infants born at 23 weeks of gestation was 1.19 times higher than expected in Ireland, however this was not a statistically significant difference.

Outcomes of infants born at 24-27 weeks gestation according to category of neonatal centre

The current Model of Care for Neonatal Services in Ireland recommends that infants born before reaching a gestational age of 28 weeks should ideally be delivered at one of the four tertiary neonatal centres.[3] Overall, there were 191 infants born at 24-27 weeks gestation of whom 150 (79%) were born in tertiary neonatal centres, 19 (10%) in regional centres and 22 (12%) in one of the peripheral centres (Table 5.10; Figure 5.2).

Of these 191 infants, 171 (90%) received resuscitation in the delivery room, including 134 (89%) of the infants born in tertiary centres, 18 (95%) of those born in regional centres and 19 (86%) of the infants born in peripheral centres (Table 5.10). One of the infants who were offered resuscitation in the delivery room died in the delivery room. This infant was born at 24wks gestation in a tertiary centre (Figure 5.2) with an infant born at 24 weeks gestation and was not diagnosed with an MCA.

Twenty infants did not receive resuscitation in the delivery room, 16 of these were born in tertiary centres, one in regional centres and three in peripheral centres. Three died in the delivery room (one case in a peripheral unit and two in tertiary centres) and two of these infants had an MCA. Of the 17 remaining cases, all of whom were admitted to a NICU/SCBU, 14 survived to discharge (Figure 5.2). The three infants who did not survive were born in tertiary units (n=2) and a regional centre (n=1) at 26, 27 and 24 weeks gestation (respectively) and one had an MCA.

In total, four (1%) infants born at 24-27 weeks gestation died in the delivery room, one of whom was resuscitated.

A total of 187 (98%) infants born at 24-27 weeks gestation survived to admission to a NICU/SCBU. Of these 187 infants, 170 (91%) received resuscitation in the delivery room but the remaining 17 infants did not require resuscitation in the delivery room. One of these infants was born at 24 weeks, six at 25 weeks, three at 26 weeks and the final seven at 27 weeks. Therefore, of 39 liveborn infants at 24 weeks, 1 infant (2.6%) did not require any resuscitation in the DR. At 25 weeks, the figures were 6/41 (14.6%), at 26 weeks, 3/54 (5.6%) and at 27 weeks, 7/52 (13.5%).

Fourteen of the 187 infants admitted to NICU (7% of those liveborn at 24-27 weeks gestation, n=191) were transferred from their hospital of birth within 48 hours of birth (Table 5.10). Eleven of these infants were born in peripheral centres, and three in a regional centre (Table 5.10, Figure 5.2). All were transferred to tertiary neonatal centres, except one who was transferred to a regional centre within 48 hours of birth and all infants survived to discharge.

In total, 148 (80%) infants born at 24-27 weeks gestation survived to discharge. The crude survival rate was 77% (n=116) for those born in tertiary centres, 74% (n=14) for those born in regional centres and 82% (n=18) for those born in peripheral centres (Table 5.10).

Table 5.10: Survival of ROI Infants born at 24-27 weeks of gestation by category of neonatal centre, 2018.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	150	19	22	191
Received resuscitation in the delivery room	134 (89%)	18 (95%)	19 (86%)	171 (90%)
Admitted to a NICU/SCBU	147 (98%)	19 (100%)	21 (95%)	187 (98%)
Transferred to another neonatal centre within 48 hours of birth	0/150 (0%)	3/19 (16%)	11/22 (50%)	14/191 (7%)
Survived to discharge among liveborns	116/145* (77%)	14/19 (74%)	18/22 (82%)	148/186* (80%)
Survived to discharge among infants receiving resuscitation	104/129* (81%)	14/18 (78%)	16/19 (84%)	134/166* (72%)
Survived to discharge among infants admitted to NICU/SCBU	116/142* (79%)	14/19 (74%)	21/21 (100%)	151/182* (81%)

*Survival outcome unknown for five infants. These infants were all born in a tertiary neonatal centre and required resuscitation at birth (none of them had an MCA).

The Standardised Mortality/Morbidity Ratios (SMR = Observed/Expected) for the main KPIs recorded for the infants born in ROI between 2014 and 2018, at 24-27 weeks of gestation are shown in Table 5.11. An excess risk that was statistically significant was observed with respect to four of the eight KPIs. Respectively, there were 22%, 33%, 24% and 72% greater risk in Ireland with respect to mortality (SMR=1.22; 95% CI: 1.07, 1.37), pneumothorax (SMR=1.33; 95% CI: 1.06, 1.59), any late infection (SMR=1.24; 95% CI: 1.09, 1.40) and necrotising enterocolitis (SMR=1.72; 95% CI: 1.49, 1.96).

Mortality data was available for 894 of the 900 infants born at 24-27 weeks of gestation between 2014 and 2018, of whom 213 died whereas the expected number was 175. Thus, an excess of 38 infants died, which was statistically significant (95% CI: 12, 64). The excess of 18 infants affected by pneumothorax, 40 infants with any late infection and 49 infants with NEC was also statistically significant.

Cystic periventricular leukomalacia, determined for 830 of the 900 infants, was rare but the observed risk was approximately half that expected (SMR=0.52; 95% CI: 0.18, 0.86). There were 17 diagnosed cases compared to an expected number of 33, a statistically significant difference.

Table 5.11: Risk Adjusted Standardised Mortality/Morbidity Ratios for Key Performance Indicators within infants born with 24-27 weeks of gestation in ROI, 2014-2018.

Outcome	N	O	E	SMR	(95% CI)	O-E	(95% CI)
Mortality	894	213	175	1.22*	(1.07, 1.37)	38	(12, 64)
Death or Morbidity	887	617	597	1.03	(0.95, 1.11)	20	(-28, 68)
Chronic Lung Disease	639	296	274	1.08	(0.96, 1.20)	22	(-11, 54)
Pneumothorax	869	74	56	1.33*	(1.06, 1.59)	18	(4, 33)
Any Late Infection	796	204	164	1.24*	(1.09, 1.40)	40	(15, 65)
Severe Intraventricular Haemorrhage	817	123	103	1.19*	(1.00, 1.38)	20	(0, 40)
Cystic Periventricular Leukomalacia	830	17	33	0.52*	(0.18, 0.86)	-16	(-27, -5)
Necrotising Enterocolitis	869	116	67	1.72*	(1.49, 1.96)	49	(33, 65)

N specifies how many of the 900 infants had data on the KPI. Morbidities may not be recorded for infants who died, especially those who die soon after birth. "O" refers to the number of observed cases with the outcome and E to 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.

*Indicates a statistically significant difference.

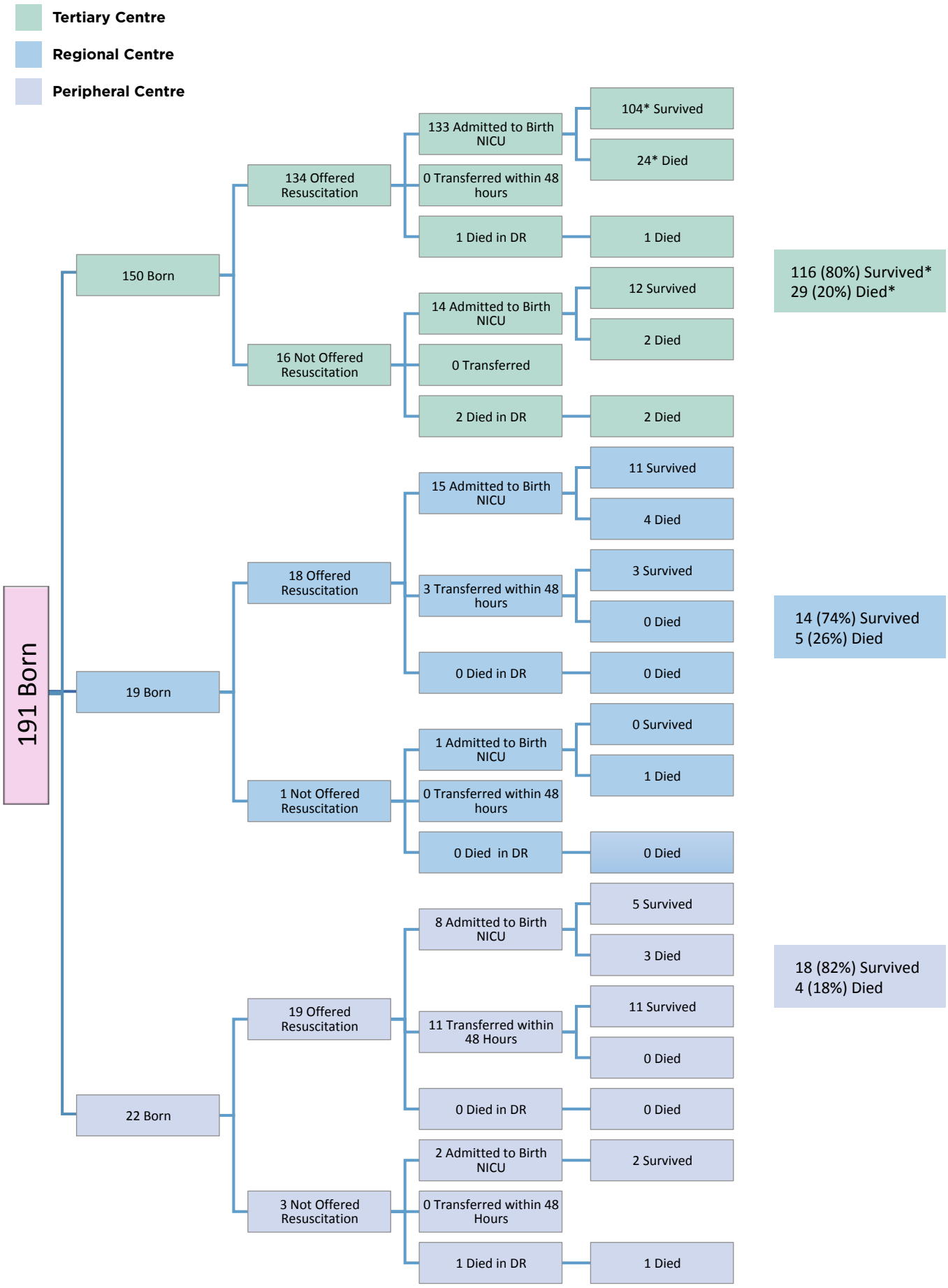

Figure 5.2: Flow chart illustrating survival outcomes of VLBW born at 24–27 weeks gestation according to designated category of neonatal centre, 2018, n=191. (Information not available on the outcome of 5 infants)

Outcomes of infants born at 28-31 weeks gestation according to category of neonatal centre

Overall, there were 232 infants born at 28-31 weeks gestation of which, 152 (6%) were born in tertiary neonatal centres, 63 (30%) in regional centres and 17 (10%) in peripheral centres (Table 5.12; Figure 5.3).

Of these 232 infants, 161 (69%) received resuscitation in the delivery room, which included 102 (67%) infants born in tertiary centres, 46 (73%) infants born in regional centres and 13 (76%) infants born in peripheral centres. All of these infants survived to admission to a NICU/SCBU, 17 of these infants had an MCA.

A total of 71 infants did not receive resuscitation in the delivery room (50 born in tertiary centres, 17 born in regional centres and 4 born in peripheral centres) (Figure 5.3). Three of these infants were transferred to other units within 48 hours of being born and the remaining 68 of these infants were subsequently admitted to a NICU/SCBU and all survived to discharge.

None of the infants born at 28-31 weeks gestation died in the delivery room (Table 5.11; Figure 5.3).

All the 232 infants born at 27-29 weeks gestation were admitted to a NICU/SCBU including 15 (7% of the total 232 born) infants who were subsequently transferred within 48 hours. Twelve of these where transferred from peripheral centres, two from a regional centre and one from a tertiary centre. All of the 15 infants who were transferred survived (Figure 5.3).

A total of 217 (94%) infants born at 27-29 weeks gestation survived to discharge (information on survival outcome not available for one infant): 141 (93%) of those born in tertiary centres, 59 (94%) of those born in regional centres and 17 (100%) of those born in peripheral centres (Table 5.12).

Table 5.12: Survival of ROI Infants born at 28-31 weeks gestation by category of neonatal centre, 2018, n=231.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	152	63	17	232
Received resuscitation in the delivery room	102 (67%)	46 (73%)	13 (76%)	161 (69%)
Admitted to a NICU/SCBU	152 (100%)	63 (100%)	17 (100%)	232 (100%)
Transferred to another neonatal centre within 48 hours of birth	1/152 (1%)	2/63 (3%)	12/17 (71%)	15/232 (6%)
Survived to discharge	141/151* (93%)	59/63 (94%)	17/17 (100%)	217/231* (94%)
Survived to discharge among infants receiving resuscitation	91/151* (60%)	42/63 (91%)	13/17 (100%)	146/160* (63%)
Survived to discharge among infants admitted to NICU/SCBU	151/151* (100%)	59/63 (94%)	17/17 (100%)	217/231* (94%)

*Survival outcome unknown for one infant, born in a tertiary neonatal centre, who required resuscitation, was not transferred within 48h of birth and had an MCA.

The Standardised Mortality/Morbidity Ratios (SMR = Observed/Expected) for the main KPIs recorded for the 1,446 infants born in ROI between 2014 and 2018 at 28-31 weeks of gestation are shown in Table 5.13. An excess risk that was statistically significant was observed with respect to two of the eight KPIs. There was 19% higher risk in Ireland with respect to death or specified morbidity (SMR=1.19; 95% CI: 1.09, 1.29). Risk of pneumothorax was more than twice that expected based on the profile of the infants (SMR=2.25; 95% CI: 1.95, 2.56).

Table 5.13: Risk Adjusted Standardised Mortality/Morbidity Ratios for Key Performance Indicators within infants born with 28-31 weeks of gestation in ROI, 2014-2018.

Outcome	N	O	E	SMR	(95% CI)	O-E	(95% CI)
Mortality	1398	83	69	1.21	(0.97, 1.45)	14	(-2, 31)
Death or Morbidity*	1441	449	378	1.19	(1.09, 1.29)	71	(33, 109)
Chronic Lung Disease	1331	173	169	1.02	(0.87, 1.17)	4	(-22, 29)
Pneumothorax*	1430	93	41	2.25	(1.95, 2.56)	52	(39, 64)
Any Late Infection	1380	109	99	1.11	(0.91, 1.3)	10	(-9, 30)
Severe Intraventricular Haemorrhage	1352	37	37	1.01	(0.69, 1.33)	0	(-12, 12)
Cystic Periventricular Leukomalacia	1394	28	26	1.10	(0.71, 1.49)	2	(-7, 12)
Necrotising Enterocolitis	1429	42	51	0.83	(0.55, 1.11)	-9	(-23, 5)

N specifies how many of the 1446 infants had data on the KPI. Morbidities may not be recorded for infants who died, especially those who die soon after birth. O refers to the number of observed cases with the outcome and E to the expected number with the outcome of ROI infants born at 28-31 weeks of gestation. 95% confidence intervals (CIs) are provided for the SMR and the difference in observed and expected cases.

*Indicates a statistically significant difference.

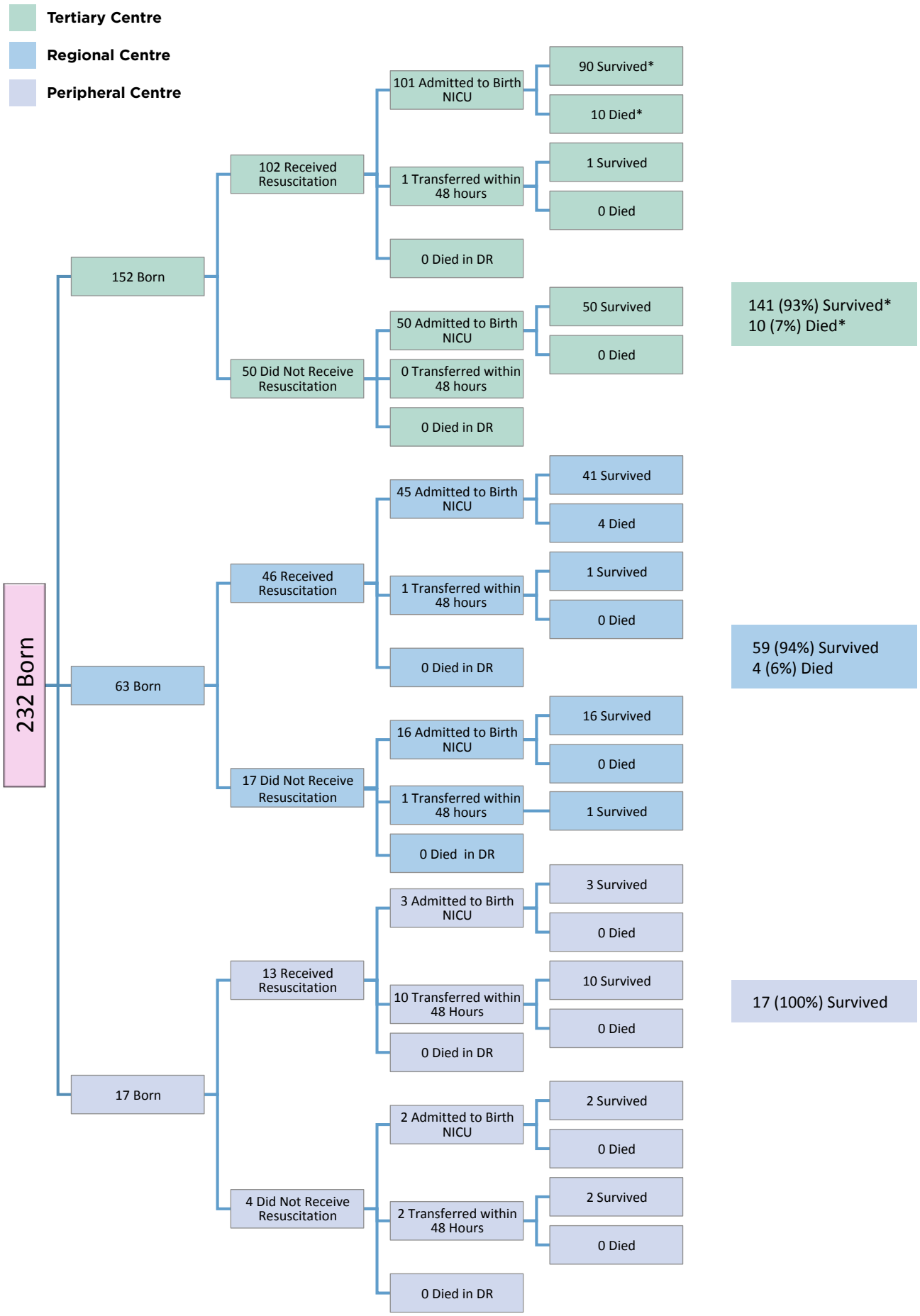

Figure 5.3: Flow chart illustrating survival outcomes of VLBW born at 28-31 weeks gestation according to designated category of neonatal centre, 2018, n=232.

Outcomes of infants born ≥32 weeks gestation according to category of neonatal centre

There were 70 infants born at ≥32 weeks gestation in 2018, 53 (75%) of these were born in tertiary neonatal centres, 15 (21%) in regional neonatal centres and 2 (3%) in one of the peripheral centres (Table 5.14).

A total of 28 (40%) infants required resuscitation in the delivery room, including 19 (36%) infants born in tertiary centres, 8 (53%) infants born in regional centres and 1 (50%) infant born in a peripheral centre. All survived to admission to a NICU/SCBU and two (infants born in tertiary units) died before discharge, (information on survival outcome not known for one infant). One baby, born in a tertiary centre was transferred to paediatric hospital within 48 hours of birth. This infant had a MCA.

Table 5.14: Survival of ROI Infants born at or greater than 32 weeks gestation by category of neonatal centre, 2018, n=70.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	53	15	2	70
Received resuscitation in the delivery room	19 (36%)	8 (53%)	1 (50%)	28 (40%)
Admitted to a NICU/SCBU	48 (91%)	15 (100%)	2 (100%)	65 (93%)
Transferred to another neonatal centre within 48 hours of birth	1/53 (0%)	0/15 (0%)	0/2 (0%)	1/70 (1%)
Survived to discharge	44/52* (85%)	15/15 (100%)	2/2 (100%)	61/69* (88%)
Survived to discharge among infants receiving resuscitation	16/18* (89%)	8/8 (100%)	1/1 (100%)	25/27* (36%)
Survived to discharge among infants admitted to NICU/SCBU	44/47* (94%)	15/15 (100%)	2/2 (100%)	61/64* (88%)

*Survival outcome unknown for one infant, born in a tertiary neonatal centre, who required resuscitation, was transferred within 48h of birth and had an MCA.

The other 42 infants born at ≥32 weeks gestation did not receive resuscitation in the delivery room (34 born in tertiary centres, 7 born in regional centres and 1 born in peripheral centres). Five of these infants died in the delivery room (all of them in tertiary centres) and all of these infants had an MCA. The remaining 37 infants who did not receive resuscitation were admitted to a NICU/SCBU and all but one survived to discharge. Two of these infants were born with MCA and only one survived to discharge.

Overall, 65 (93%) infants ≥32 weeks gestation were admitted to a NICU/SCBU. Survival outcome is not known for one baby (born in a tertiary centre). Of the remaining 64 infants, all but three infants survived to discharge. These three infants were born in tertiary centres. Two of the infants who died had an MCA (Table 5.14).

A total of 61 (88%) infants born at ≥32 weeks gestation survived to discharge (survival outcome unknown for one infant): 44 (85%) of those born in tertiary centres, 15 (100%) of those born in regional centres and 2 (100%) of those born in peripheral centres (Table 5.14).

The Standardised Mortality/Morbidity Ratios (SMR = Observed/Expected) for the main KPIs recorded for the 395 very low birth weight infants born in ROI between 2014 and 2018 at 32 or more weeks of gestation are shown in Table 5.15. No statistically significant differences were evident between the observed and expected number of cases for each of the eight KPIs.

Table 5.15: Risk Adjusted Standardised Mortality/Morbidity Ratios for Key Performance Indicators within infants born with 32 or more weeks of gestation in ROI, 2014-2018.

Outcome	N	O	E	SMR	(95% CI)	O-E	(95% CI)
Mortality	392	28	28	1.00	(0.63, 1.37)	0	(-10, 10)
Death or Morbidity	394	52	66	0.79	(0.55, 1.04)	-14	(-29, 2)
Chronic Lung Disease	370	20	27	0.73	(0.36, 1.11)	-7	(-18, 3)
Pneumothorax	379	2	5	0.36	(0, 1.20)	-3	(-8, 1)
Any Late Infection	374	9	13	0.70	(0.15, 1.25)	-4	(-11, 3)
Severe Intraventricular Haemorrhage	303	2	2	0.92	(0, 2.25)	0	(-3, 3)
Cystic Periventricular Leukomalacia	328	2	3	0.66	(0, 1.79)	-1	(-4, 2)
Necrotising Enterocolitis	378	5	7	0.76	(0, 1.53)	-2	(-7, 3)

N specifies how many of the 395 infants had data on the KPI. Morbidities may not be recorded for infants who died, especially those who die soon after birth. O refers to the number of observed cases with the outcome and E to the expected number with the outcome of ROI infants born at 32 or more weeks of gestation. 95% confidence intervals (CIs) are provided for the SMR and the difference in observed and expected cases.

*Indicates a statistically significant difference.

Summary survival outcomes of infants according to category of neonatal centre

Table 5.16 summarises the survival outcome of infants in the different gestational age categories according to birth location/category of neonatal centre. As rates are based on small numbers, particularly at the lower gestational ages, firm conclusions cannot be drawn from a single year of data.

Table 5.16: Survival rates for gestational age categories of VLBW infants born in the ROI according to category of neonatal centre, 2018 (N=530, survival outcome not known for seven infants).

Survival by Gestation Age Group	Tertiary Centres	Regional Centres	Peripheral Centres	ROI Total	VON		
					Median %	Q1	Q3
≤ 22 weeks	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0%	0%	18%
23 weeks	9 (38%)	0 (0%)	0 (0%)	9 (33%)	43%	0%	67%
24-26 weeks	83 (78%)	9 (64%)	10 (71%)	102 (76%)	79%	67%	91%
27-29 weeks	117 (91%)	40 (97%)	24 (100%)	181 (94%)	96%	90%	100%
30-32 weeks	82 (92%)	33 (100%)	3 (100%)	118 (83%)	100%	95%	100%
>32 weeks	310 (79%)	6 (100%)	0 (0%)	25 (83%)	100%	100%	100%
Total	310 (80%)	88 (87%)	37 (88%)	435 (82%)	88%	83%	93%

Note: N represents the total number of very low birth weight babies (VLBW) in Ireland. For Ireland the % is based on the cases as the numerator and the total, N, as the denominator. For VON the total number of VLBW infants with information available survival by gestational age was 61,484. The VON reports the Median % based on the units that submit data, as outlined in the methods section. Half of the units report a % lower than the median, one quarter of the units report a % lower than Q1 and three quarters of the units report a % lower than Q3.

6. Total Mortality and Mortality Excluding Early Death

In 2018, a total of 18% (n=95) of VLBW babies born in the ROI died (VON Median 13%; Q1=8%, Q3=18%). Among these ROI infants, 8% died either in the Delivery Room (6%, n=30) or within 12 hours of admission to the NICU (2%, n=8; Figure 6.1). After excluding early deaths, a further 11% (n=57) of ROI infants died after 12 hours of age (VON Median 8%; Q1=4%, Q3=13%). This pattern of mortality in both the ROI and in VON is similar to that observed in previous years.[2, 4, 5]

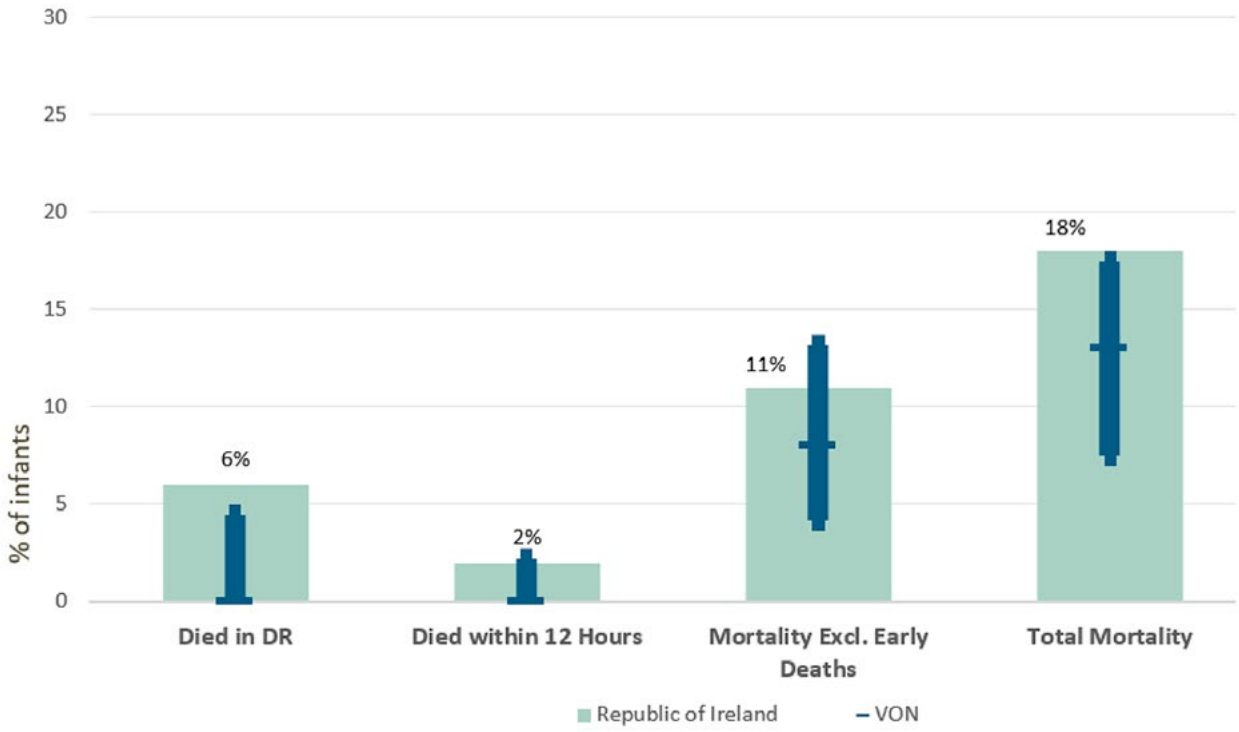

Figure 6.1: Comparison of mortality amongst ROI and VON infants, 2018.

Note: Dark blue bar represents the interquartile range for units reporting to the VON. The dark blue horizontal marker indicates the median of units reporting to the VON.

Table 6.1: Mortality amongst Republic of Ireland and VON infants, 2018.

	Republic of Ireland			VON		
	Cases	N	%	Median %	Q1	Q3
Died in DR	30	537	6%	0%	0%	5%
Died within 12 Hours	8	507	2%	0%	0%	2%
Mortality Excl. Early Deaths	57	530	11%	8%	4%	13%
Total Mortality	95	530	18%	13%	8%	18%

Note: N represents the total number of very low birth weight babies (VLBW) in Ireland. For Ireland the % is based on the cases as the numerator and the total, N, as the denominator. For VON the total number of VLBW infants with information available on each characteristic reported ranged between 58,807 and 62,135. The VON reports the Median % based on the units that submit data, as outlined in the methods section. Half of the units report a % lower than the median, one quarter of the units report a % lower than Q1 and three quarters of the units report a % lower than Q3.

Deaths in the Delivery Room in 2018

In 2018, 6% (n=30) ROI infants died in the DR (VON Median 0%; Q1=0%, Q3=5%). Hence, at least 75% of the VON units had a lower percentage of deaths in the Delivery room compared to ROI. The proportion of infants dying in the delivery room in 2018 in ROI was similar to that reported in the preceding years (6% in 2017 and 2016).

Of the 30 infants who died in the delivery room in 2018, 7 (23%) had a major congenital anomaly (Table 6.2). In total, 28 of 30 (93%) infants who died in the delivery room in the ROI in 2018 had either an MCA or were less than 24 weeks gestation. This is similar to the analogous proportions of 84% in 2017, 91% in 2016, 89% in 2015 and 86% in 2014.

As previously mentioned in section 2, (and Table 2.1, page 15), ROI infants were significantly more likely to be born with MCA compared to VON (8% in ROI compared to the VON Median 4% VON in 2018; Q1=0%, Q3=8%) and this factor is very likely to have impacted on the higher delivery room death rate seen in the ROI population.

A further 23 infants (77%), 21 (91%) of whom were born <24 weeks, died in the DR in 2018 and did not have an MCA. Of these 21 infants, 5 were born at 21 weeks, 11 at 22 weeks and five were 23 weeks gestation.

Table 6.2: Deaths in the delivery room, by gestational age category and presence of major congenital anomaly, 2018, n=30.

Gestational Age Category	Major Congenital Anomaly		Total
	Absent	Present	
< 24 weeks	21	0	21
24-26 weeks	2	1	3
27-29 weeks	0	1	1
30-32 weeks	0	2	2
> 32 weeks	0	3	3
Total	23	7	30

In Summary

- In 2018, the overall survival rate of VLBW infants born in Ireland was 82% (435 infants of a total of 530). These values, although equal to the previous year, represent a marginal decrease of 2% in the survival rates for ROI infants when compared to 2015 and 2016.

- Similar to previous years, a higher proportion of ROI infants died in the delivery room (6%, n=30) when compared to VON (median 0%; Q1=0%, Q3=4.5%).

- The mortality risk in 2018 was consistent with the risk observed in the previous three years. It was 11% higher than expected after adjusting for the risk profile of the population (SMR=1.11; CI 0.87, 1.36). The findings were similar when mortality excluding early deaths was considered (SMR=1.12; CI 0.83, 1.41).

- The risk of ROP among VLBW infants in ROI continues to be lower than expected, albeit by a smaller percentage in 2018 (SMR=0.85; CI 0.67, 1.04) compared to previous years but the risk of severe ROP was statistically significantly lower (SMR=0.39; CI 0.00, 0.83).

- ROI Infants continue to show a statistically higher rate of pneumothorax compared to VON (SMR=1.56; CI 1.13, 1.98), a consistent finding since 2014. Infants born at 28-31 weeks gestation were showed to have more than twice the expected risk of having a pneumothorax (SMR=2.25; 95% CI: 1.95, 2.56).

- A statistically significant decrease in all KPIs was observed with higher gestational ages. This denotes a lower percentage of mortality, morbidity and specific outcomes (as measured by the KPIs) for infants born with higher gestational ages.

- Since 2014, there has been a steady increase in the number of infants born at 23 weeks who are resuscitated in the delivery room (from 42% in 2014 to 89% in 2018) and this had been associated with an increase in the number of these infants who survive to discharge (from 19% in 2014, to 47% in 2017 and 33% in 2018).

- A total of 47 (20%) of ROI infants <28 weeks gestation were born outside tertiary neonatal centres in 2018, 14 of these infants were transferred within 48 hours of being born.

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NOCA National Office of Clinical Audit

The National Office of Clinical Audit (NOCA) was established in 2012 to create sustainable clinical audit programmes at a national level. NOCA enables those who manage and deliver healthcare to improve the quality of care through national clinical audit.

The NPEC aligns its audit governance structures to the NOCA audit governance standards for audit governance committees, monitoring and escalation of outliers and national reporting.

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

Dr Anne Twomey
Consultant Neonatologist
National Maternity Hospital
Holles Street, Dublin 2.

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

07 August, 2020

Re: Very Low Birth Weight Infants in the Republic of Ireland - Annual Report 2018

Dear Drs Twomey and Murphy,

We thank you for the presentation by Professor Richard Greene and Dr Paul Corcoran to the NOCA Governance Board on 25 June, 2020.

On behalf of the NOCA Governance Board, I wish to congratulate you, 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.

On behalf of the NOCA Governance Board, I am happy to endorse the Very Low Birth Weight Infants in the Republic of Ireland - Annual Report 2018.

Yours sincerely,

Dr Brian Creedon
Clinical Director
National Office of Clinical Audit Governance Board

c.c. Prof Richard Greene, National Perinatal Epidemiology Centre, CUMH, Cork

Appendix B: VON unit leads and co-ordinators and contributors 2018

Neonatal Unit	Leads	Co-ordinators
Cavan General Hospital	Dr Alan Finan	Ms Evelyn McAdam
Coombe Women and Infants University Hospital	Dr John Kelleher	Ms Julie Sloan
Cork University Maternity Hospital	Dr Brendan Paul Murphy	Dr Brendan Paul Murphy
Kerry General Hospital, Tralee	Dr Akhtar Khan	Ms Margaret Kelly
Letterkenny General Hospital	Dr Mathew Thomas	Ms Kate Greenough Ms Marion Doogan
Mayo General Hospital, Castlebar	Dr Hilary Stokes	Dr Hilary Stokes
Midland Regional Hospital, Mullingar	Dr Michael O'Grady	Ms Geraldine Kavanagh
Midland Regional Hospital, Portlaoise	Dr Anne Doolan	Dr Rizwan Gul Ms Anne Blanche
University Maternity Hospital, Limerick	Dr Niazy Al-Assaf	Ms Elizabeth Reidy
National Maternity Hospital, Dublin	Dr Anne Twomey	Mr John Geoghegan
Our Lady of Lourdes Hospital, Drogheda	Dr Emma Gordon	Claire Shannon
Portiuncula Hospital, Ballinasloe	Dr Paula Cahill	Dr Paula Cahill
Rotunda Hospital, Dublin	Dr David Corcoran	Ms Kathy Conway
Sligo General Hospital	Dr Hilary Greaney Dr Ghia Harrison	Ms Madeleine Munelly Ms Niamh McGarvey
South Tipperary General Hospital, Clonmel	Dr Justin Roche	Dr Justin Roche
St Luke's Hospital, Kilkenny	Dr David Waldron	Dr David Waldron
University Hospital Galway	Dr Donough O'Donovan	Dr Donough O'Donovan
Waterford Regional Hospital	Dr Animitra Das	Dr Shammaz Saeed
Wexford General Hospital	Dr Muhammad Azam	Dr Naeem Aziz Shori

Appendix C: Vermont Oxford Network Data Collection Forms, 2018

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

VERMONT OXFORD NETWORK
PATIENT DATA BOOKLET FOR INFANTS BORN IN 2018

This Worksheet contains protected health care information and must NOT be submitted to Vermont Oxford Network (VON). VON only accepts protected health care information in cases where members have both voluntarily elected to send this information to VON and have signed an appropriate Business Associate Agreement with VON.

Contents:

Page 1: Patient Identification Worksheet
Page 2: Length of Stay Calculation Worksheet
Page 3 - 6: General Data Items
Page 7: Transfer & Readmission Data Items (only infants who transfer to another hospital)
Page 8: Supplemental Data Items (Expanded Database only)

PATIENT IDENTIFICATION WORKSHEET

Patient's Name: _____

Mother's Name: _____

Patient's Medical Record Number: _____

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

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.

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

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.

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

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

PLEASE DO NOT SUBMIT THIS WORKSHEET
Protected Health Care Information

VON Vermont Oxford NETWORK

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

LENGTH OF STAY CALCULATION WORKSHEET FOR INFANTS BORN IN 2018

Protected Health Care Information. *DO NOT SUBMIT this Worksheet to Vermont Oxford Network.*
Use items *Date of Admission*, *Date of Initial Disposition*, and *Date of Transfer/Discharge Home/Death/First Birthday* from the Patient Identification Worksheet when completing this form.
Find day numbers corresponding to dates using the Day Number Chart for 2018-19 (www.vtoxford.org/downloads).

Part A. Initial Length Of Stay

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

Subtract Date of Admission to Your Hospital (Date of Admission): ____/____/____ **-** ☐☐☐ 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**

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 (Transferred/Home/Died/1st Birthday): ____/____/____ ☐☐☐ Day #

Subtract Date of Admission (Date of Admission): ____/____/____ **-** ☐☐☐ 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**

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 / 2018** ☐ 5 7 Day #

Subtract Date of Admission: **01 / 13 / 2018** **-** ☐ 1 3 Day #

☐ 4 4

Add 1: **+ 1**

INITIAL LENGTH OF STAY = ☐ 4 5 **Days**

Explanation: Date of 02/26/2018 is Day Number 57. Date of 01/13/2018 is Day Number 13. The day numbers for each date are found in the 2018-2019 Day Number Chart on the Network web site, **www.vtoxford.org/downloads**.

PLEASE DO NOT SUBMIT THIS WORKSHEET

Protected Health Care Information

Vermont Oxford NETWORK

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2

General Data Items - *For Infants Born in 2018*

VON Vermont Oxford NETWORK

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

Birth Weight: _____ grams

Gestational Age Weeks: _____ **Gestational Age Days (0-6):** _____

Died in Delivery Room: ☐ Yes ☐ No (***If Yes*, complete Delivery Room Death Data Items)**

Location of Birth: ☐ Inborn ☐ Outborn

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

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

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

Maternal Ethnicity/Race (Answer both Ethnicity and Race):

Ethnicity of Mother: ☐ Hispanic ☐ Not Hispanic

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

Prenatal Care: ☐ Yes ☐ No

Antenatal Steroids: ☐ Yes ☐ No

Antenatal Magnesium Sulfate: ☐ Yes ☐ No

Chorioamnionitis: ☐ Yes ☐ No

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

Maternal Diabetes ☐ Yes ☐ No

Mode of Delivery: ☐ Vaginal ☐ Cesarean Section

Sex of Infant: ☐ Male ☐ Female ☐ Unknown

Multiple Gestation: ☐ Yes ☐ No ***If Yes*, Number of Infants Delivered:** _____

Congenital Infection: ☐ Yes ☐ No

Congenital Infection, Organism(s): _____ _____ _____
(If *Congenital Infection* is *Yes*, enter up to three Congenital Infection codes from Manual of Operations, Part 2 – Appendix E)

APGAR Scores: **1 minute** _____ **5 minutes** _____

Initial Resuscitation:

Oxygen:	☐ Yes	☐ No
Face Mask Vent:	☐ Yes	☐ No
Laryngeal Mask Airway:	☐ Yes	☐ No
Endotracheal Tube Vent:	☐ Yes	☐ No
Epinephrine:	☐ Yes	☐ No
Cardiac Compression:	☐ Yes	☐ No
Nasal Vent:	☐ Yes	☐ No
Nasal CPAP:	☐ Yes	☐ No

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

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

Bacterial Sepsis and/or Meningitis on or before Day 3: ☐ Yes ☐ No

Bacterial Sepsis and/or Meningitis on or before Day 3, Pathogen(s): _____ _____ _____
(If *Bacterial Sepsis and/or Meningitis* is *Yes*, enter up to three Bacterial Pathogen codes from Manual of Operations, Part 2 – Appendix B)

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General Data Items - *For Infants Born in 2018*

VON Vermont Oxford NETWORK

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

Oxygen on Day 28: ☐ Yes ☐ No ☐ N/A (See Manual of Operations, Part 2 for N/A criteria)

Periventricular-Intraventricular Hemorrhage (PIH):
Cranial Imaging (US/CT/MRI) on or before Day 28: ☐ Yes ☐ No
If Yes, Worst Grade of PIH (0-4): _____
If PIH Grade 1-4, Where PIH First Occurred: ☐ Your Hospital ☐ Other Hospital

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

Respiratory Support (at any time after leaving the delivery room/initial resuscitation area):
Oxygen after Initial Resuscitation: ☐ Yes ☐ No
Conventional Ventilation after Initial Resuscitation: ☐ Yes ☐ No
High Frequency Ventilation after Initial Resuscitation: ☐ Yes ☐ No
High Flow Nasal Cannula after Initial Resuscitation: ☐ Yes ☐ No
Nasal Ventilation after Initial Resuscitation: ☐ Yes ☐ No

Nasal CPAP after Initial Resuscitation: ☐ Yes ☐ No
Nasal CPAP or Nasal Vent before or without ever having received ETT Vent: ☐ Yes ☐ No ☐ N/A

Surfactant during Initial Resuscitation: ☐ Yes ☐ No
Surfactant at Any Time: ☐ Yes ☐ No (*Surfactant an Any Time* must be *Yes* if *Surfactant During Initial Resuscitation* is *Yes*)
***If Yes*, Age at First Dose of Surfactant:** Hours _____ Minutes (0-59) _____

Inhaled Nitric Oxide: ☐ Yes ☐ No
***If Yes*, Inhaled Nitric Oxide, Where Given:** ☐ Your Hospital ☐ Other Hospital ☐ Both

Respiratory Support at 36 Weeks (See Manual of Operations, Part 2 for N/A criteria):
Oxygen at 36 Weeks: ☐ Yes ☐ No ☐ N/A
Conventional Ventilation at 36 Weeks: ☐ Yes ☐ No ☐ N/A
High Frequency Ventilation at 36 Weeks: ☐ Yes ☐ No ☐ N/A
High Flow Nasal Cannula at 36 Weeks: ☐ Yes ☐ No ☐ N/A
Nasal Ventilation at 36 Weeks: ☐ Yes ☐ No ☐ N/A
Nasal CPAP at 36 Weeks: ☐ Yes ☐ No ☐ N/A

Steroids for CLD: ☐ Yes ☐ No
***If Yes*, Steroids for CLD, Where Given:** ☐ Your Hospital ☐ Other Hospital ☐ Both

Indomethacin for Any Reason: ☐ Yes ☐ No

Ibuprofen for PDA: ☐ Yes ☐ No

Acetaminophen (Paracetamol) for PDA: ☐ Yes ☐ No

Probiotics: ☐ Yes ☐ No

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

Caffeine for Any Reason: ☐ Yes ☐ No

Intramuscular Vitamin A for Any Reason: ☐ Yes ☐ No

ROP Surgery: ☐ Yes ☐ No
***If Yes*, ROP Surgery, Where Done:** ☐ Your Hospital ☐ Other Hospital ☐ Both

Surgery or Interventional Catheterization for Closure of PDA: ☐ Yes ☐ No
(*If Yes*, a Surgery Code, Location of Surgery, and an answer to Surgical Site Infection are required at the top of the next page)

Surgery for NEC, Suspected NEC, or Bowel Perforation: ☐ Yes ☐ No
(*If Yes*, a Surgery Code, Location of Surgery, and an answer to Surgical Site Infection are required at the top of the next page)

Other Surgery: ☐ Yes ☐ No
(*If Yes*, a Surgery Code, Location of Surgery, and an answer to Surgical Site Infection are required at the top of the next page)

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General Data Items - *For Infants Born in 2018*

VON Vermont Oxford NETWORK

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

If *Yes* to *Surgery for Closure of PDA, Surgery for NEC*, or *Other Surgery*, enter up to 10 Surgery Codes, Locations of Surgery, and check Yes or No for Surgical Site Infection following Surgery at Your Hospital:
See Manual of Operations, Part 2 – Appendix D for Surgery Codes.
If *Surgery for NEC* is *Yes*, one or more of the following codes is required: S302, S303, S307, S308, S309, S333.
Indicate *Location of Surgery* for each surgery code.
If a surgical site infection is present, indicate "Yes" for the one surgical code that resulted in the surgical site infection.

Surgery Code 1: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	Surgical Site Infection:	☐ Yes ☐ No
Surgery Code 2: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	Surgical Site Infection:	☐ Yes ☐ No
Surgery Code 3: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	Surgical Site Infection:	☐ Yes ☐ No
Surgery Code 4: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	Surgical Site Infection:	☐ Yes ☐ No
Surgery Code 5: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	Surgical Site Infection:	☐ Yes ☐ No
Surgery Code 6: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	Surgical Site Infection:	☐ Yes ☐ No
Surgery Code 7: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	Surgical Site Infection:	☐ Yes ☐ No
Surgery Code 8: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	Surgical Site Infection:	☐ Yes ☐ No
Surgery Code 9: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	Surgical Site Infection:	☐ Yes ☐ No
Surgery Code 10: _____	☐ Your Hospital	☐ Other Hospital	☐ Both	Surgical Site Infection:	☐ Yes ☐ No

Include description for Surgery Codes S100,S200,S300,S400,S500,S600,S700,S800,S900,S1000, and S1001:

_____

Respiratory Distress Syndrome: ☐ Yes ☐ No

Pneumothorax: ☐ Yes ☐ No

***If Yes*, Pneumothorax, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

Patent Ductus Arteriosus: ☐ Yes ☐ No

Necrotizing Enterocolitis: ☐ Yes ☐ No

***If Yes*, NEC, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

Focal Intestinal Perforation: ☐ Yes ☐ No

***If Yes*, Focal Intestinal Perforation, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

Sepsis and/or Meningitis, Late (after day 3 of life) (See Manual of Operations, Part 2 for N/A criteria):

Bacterial Sepsis and/or Meningitis after Day 3: ☐ Yes ☐ No ☐ N/A

***If Yes*, Bacterial Sepsis and/or Meningitis after Day 3, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

Bacterial Sepsis and/or Meningitis after Day 3, Pathogen(s): _____ _____ _____
(If *Bacterial Sepsis and/or Meningitis* is *Yes*, enter up to three Bacterial Pathogen codes from Manual of Operations, Part 2 – Appendix B)

Coagulase Negative Staph Infection after Day 3: ☐ Yes ☐ No ☐ N/A

***If Yes*, Coagulase Negative Staphylococcal Infection after Day 3, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

Fungal Infection after Day 3: ☐ Yes ☐ No ☐ N/A

***If Yes*, Fungal Infection after Day 3, Where Occurred:** ☐ Your Hospital ☐ Other Hospital ☐ Both

Cystic Periventricular Leukomalacia: ☐ Yes ☐ No ☐ N/A (See Manual of Operations, Part 2 for N/A criteria)

ROP, Retinal Examination ☐ Yes ☐ No

***If Yes*, Worst Stage of ROP** (0-5): _____

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General Data Items - *For Infants Born in 2018*

Vermont Oxford NETWORK

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

Congenital Anomaly: ☐ Yes ☐ No

***If Yes*, enter up to five Congenital Anomaly Codes:** _____ _____ _____ _____ ____

See Manual of Operations, Part 2 – Appendix C for Congenital Anomaly Codes.

***If Yes*, as needed, include description(s) for Codes 100, 504, 601, 605, 901, 902, 903, 904, and 907:**

_____

_____

Enteral Feeding at Discharge:

- ☐ **None**
- ☐ **Human Milk Only**
- ☐ **Formula Only**
- ☐ **Human milk in combination with either fortifier or formula**

Oxygen, Respiratory Support, and Monitor at Discharge:

Oxygen at Discharge:	☐ Yes	☐ No
Conventional Ventilation at Discharge:	☐ Yes	☐ No
High Frequency Ventilation at Discharge:	☐ Yes	☐ No
High Flow Nasal Cannula at Discharge:	☐ Yes	☐ No
Nasal Ventilation at Discharge:	☐ Yes	☐ No
Nasal CPAP at Discharge:	☐ Yes	☐ No
Monitor at Discharge:	☐ Yes	☐ No

Initial Disposition (check only one):

- ☐ Home
- ☐ Died
- ☐ Transferred to another Hospital (When this Disposition is chosen, also complete Transfer & Readmission Data Items)
- ☐ Still Hospitalized as of First Birthday

Weight at Initial Disposition: _____ grams

Head Circumference at Initial Disposition (in cm to nearest 10th)**:** ☐☐.☐

Initial Length of Stay: _____ day(s) (Data Item *Initial Length of Stay* on Length of Stay Calculation Worksheet)

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6

Transfer & Readmission Data Items - *For Infants Born in 2018*

VON 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 Data Items *Reason for Transfer*, *Transfer Code of Center to which Infant Transferred*, and *Post Transfer Disposition* (below). Post Transfer Disposition refers to the infant's disposition upon leaving the "transferred to" hospital.

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

Transfer Code of Center to which Infant Transferred: _____ (List available at https://www.vtoxford.org/tools/transferlist.aspx)

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 Data Items *Disposition after Readmission* and *Weight at Disposition after Readmission* (below).

When infants are readmitted to your center, continue to update Items *Bacterial Sepsis and/or Meningitis on or before Day 3* through *PIH, Where First Occurred* and Items *Oxygen after Initial Resuscitation* through *Monitor at Discharge* 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 Data Items *ECMO at your Hospital*, *Hypothermic Therapy at Your Hospital*, *Cooling Method*, *Hypoxic-Ischemic Encephalopathy*, *HIE Severity*, and *Seizures* based on events that occur following transfer and readmission.

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.*

Weight at Disposition after Readmission: _____ grams

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

Answer *Ultimate Disposition* 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.

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 *Total Length of Stay* when the infant has been discharged Home, Died, or is Still Hospitalized as of First Birthday, whichever comes first.

Total Length of Stay: _____day(s) (Data Item *Total Length of Stay* on Length of Stay Calculation Worksheet)

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Supplemental Data Items - *For Infants Born in* 2018
(For Expanded Data Submitting Centers)

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

Treatments:

Duration of Assisted Ventilation:

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

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

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

Hypothermic Therapy at Your Hospital:

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

***If Yes*, Hypothermic Therapy Cooling Method**: ☐ Selective Head ☐ Whole Body ☐ Both

Diagnoses:

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

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

Meconium Aspiration Syndrome: ☐ Yes ☐ No

Tracheal Suction for Meconium Attempted during Initial Resuscitation: ☐ Yes ☐ No ☐ N/A

Seizures: ☐ Yes ☐ No ☐ N/A

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NATIONAL PERINATAL
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