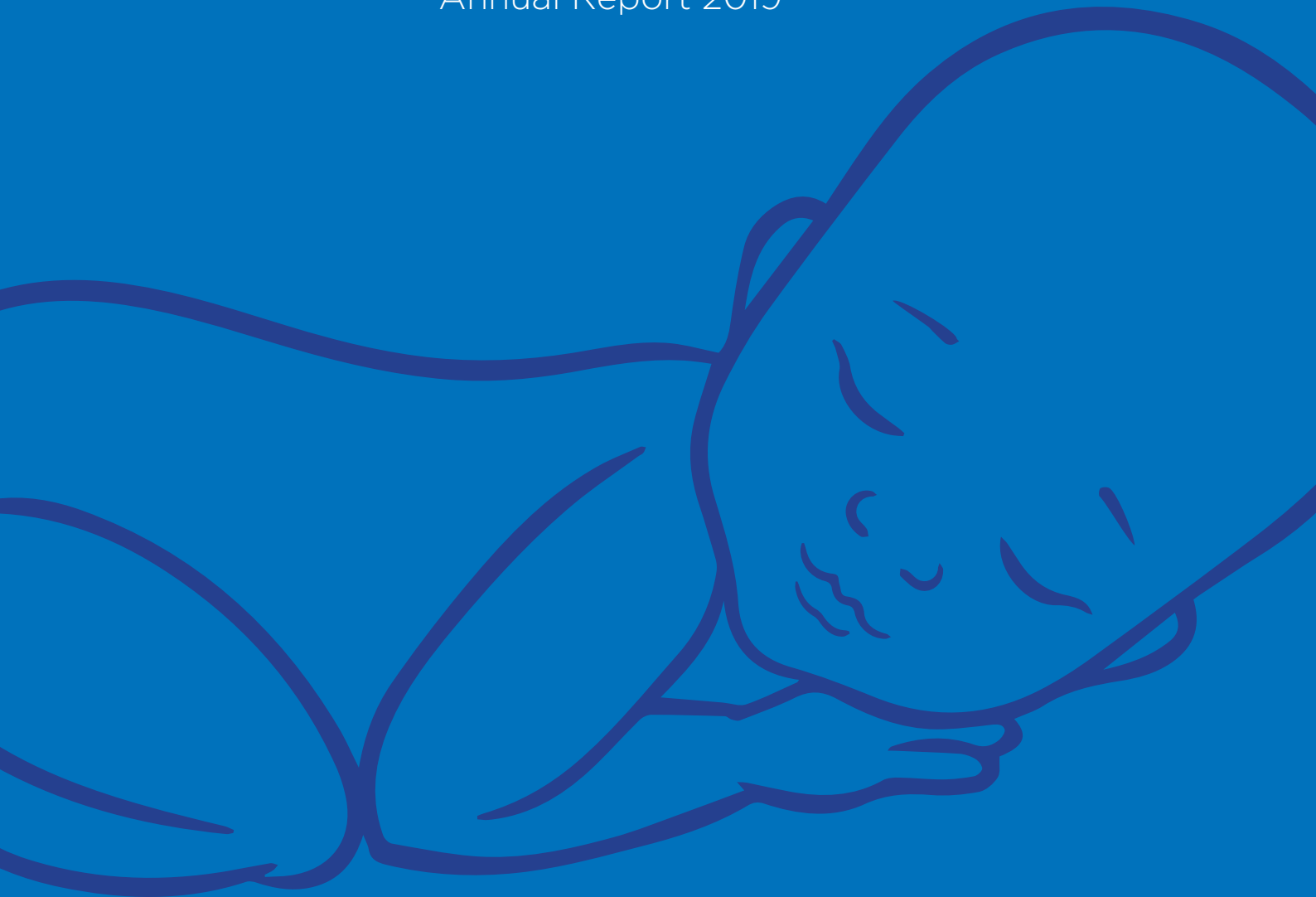


Very Low Birth Weight Infants in the Republic of Ireland

Annual Report 2019



NATIONAL PERINATAL
EPIDEMIOLOGY CENTRE



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Contents

List of Acronyms	2
List of Figures	2
List of Tables	3
Acknowledgements	4
Message from our public representative	5
The Impact to date of the Very Low Birth Weight Infant Audits	6
Executive Summary	7
Background	9
Governance	10
Methods	11
Data recording	11
Case Ascertainment	12
Statistical analysis	12
Definitions and terminology	13
Main findings	15
1. Overview	15
2. Infant Characteristics	16
3. Survival	17
4. Key Performance Indicators	20
Standard Mortality/Morbidity Ratios (SMRs for Key Performance Indicators)	20
Key Performance Indicators and Gestational Age	22
Time trends in relative risk	22
5. Survival according to Gestational Age Category and Location of Birth	24
Mortality and Delivery Room (DR) Deaths	33
In Summary	35
References	36
Appendices	
Appendix A: Endorsement by the National Office of Clinical Audit (NOCA)	37
Appendix B: VON unit leads and co-ordinators and contributors 2019	38
Appendix C: Vermont Oxford Network Data Collection Forms, 2019	39



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	Standard Mortality/Morbidity Ratios

List of Figures

- Figure I:** Member countries of the Vermont Oxford Network.
- Figure II:** 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.
- Figure III:** Flow of information and data management in the VON data collection process.
- Figure 6.1:** Comparison of mortality amongst ROI and VON infants, 2019.

List of Tables

Table 1.1: Number of cases reported to VON in 2015 – 2019 in Ireland, according to gestational age.

Table 1.2: Number of cases reported to VON in 2015 – 2019 in Ireland, according to birth weight.

Table 2.1: Infant characteristics in the Republic of Ireland and VON, 2019.

Table 3.1: Survival of ROI and VON infants, including those with congenital anomalies, 2019.

Table 3.2: Survival to discharge by gestational age breakdown for ROI infants, including those with congenital anomalies, 2015-2019.

Table 3.3: Survival to discharge by birth weight for ROI infants, including those with congenital anomalies, 2015-2019.

Table 3.4: Survival without specified morbidities of infants according to gestational age at birth of ROI infants reported to VON, 2015-2019.

Table 4.1: Risk Adjusted Standardised Mortality/Morbidity Ratios for Key Performance Indicators, Republic of Ireland, 2019.

Table 4.2: Rates of each Key Performance Indicator according to gestational age categories of VLBW infants born in the ROI, 2019.

Table 4.3: Standardised Mortality/Morbidity Ratios for Key Performance Indicators, Republic of Ireland, 2014-2019.

Table 5.1: Number of live births and stillbirths weighing greater than or equal to 500g in maternity centres in 2019.

Table 5.2: Survival of ROI Infants by category of neonatal centre, 2019, n=505.

Table 5.3: Number of infants born in each category of neonatal centre who were administrated resuscitation according to gestational age, 2019.

Table 5.4: Number of liveborn infants in ROI according to type of centre, number of infants born at 23-27 gestation weeks and number transferred within 48h of delivery, 2016-2019.

Table 5.5: Number of infants born in each category of neonatal centre, and number transferred within 48 hours, according to gestational age, 2019, n=505.

Table 5.6: Survival of ROI Infants born at 22 weeks (or less) gestation by category of neonatal centre, 2019, n=15.

Table 5.7: Survival of infants born at 22 weeks (or less) gestation, 2015-2019.

Table 5.8: Survival of ROI Infants born at 23 weeks gestation by category of neonatal centre, 2019, n=29.

Table 5.9: Survival of infants born at 23 weeks gestation, 2015-2019.

Table 5.10: Survival of ROI Infants born at 24-27 weeks of gestation by category of neonatal centre, 2019.

Table 5.11: Survival of ROI Infants born at 28-31 weeks gestation by category of neonatal centre, 2019, n=232.

Table 5.12: Survival of ROI Infants born at or greater than 32 weeks gestation by category of neonatal centre, 2019, n=65.

Table 6.1: Mortality amongst Republic of Ireland and VON infants, 2019.

Table 6.2: Percentage of mortalities in ROI 2015-2019.

Table 6.3: Deaths in the delivery room, by gestational age category and presence of major congenital anomaly, 2019.

Acknowledgements

Welcome to the sixth Very Low Birth Weight Infants (VLBW) 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 ≤ 1500 g and/or ≤ 29 weeks gestation in the Republic of Ireland for the calendar year 2019 and compares outcomes to the preceding five years.

Of note, in this year's report, is the reduction in the number of VLBW infants born in the Republic of Ireland in 2019. In total, 505 VLBW infants were born, a 19% reduction from a peak of 622 infants in 2015. The corresponding decrease in the number of livebirths in Ireland over the same time-period was 9% (from 65,536 birth in 2015 to 59,796 birth in 2019). This is the second year running that we have noticed a decrease in the number of VLBW infants born.

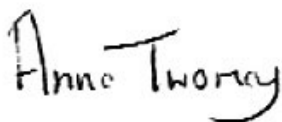
This year, we are delighted to have a public/patient representative from the INHA (Irish Neonatal Health Alliance) comment on our report prior to its publication. It is important that our families and the public are afforded such an opportunity. Such PPI (public and patient involvement) ensures that we continue to ask the right questions and in a way that the public can understand. We hope that this collaboration continues into the future.

We continue to make slow but steady progress on a national VLBW neurodevelopmental follow-up programme. 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 long-term neurodevelopmental outcomes. A Bayley Assessment of Infant Development at 2 years of age remains the gold standard in neonatology. The National Women and Infants' Health Programme have funded three 0.5 whole time equivalent (half-time) additional clinical psychology posts to carry out this important work. We hope to report on this new service in the coming years.

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. The membership of NICORE ROI is listed in Appendix B.

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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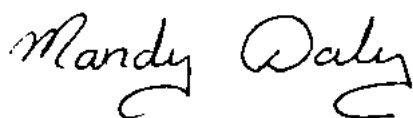


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Message from our public representative

Very Low Birth Weight can have far reaching consequences, not only for affected infants but also for their families, health systems and society. NPEC's VLBW Infant audit provides an invaluable opportunity to leverage national data to effect system changes that will improve outcomes.



Mandy C. Daly

Public/Patient Representative
VLBW infant audit
Director of Advocacy & Policy Making
Irish Neonatal Health Alliance (INHA)

The Impact to date of the Very Low Birth Weight Infant Audits

- Data has now been collected on almost 3,500 Very Low Birth Weight (VLBW) infants born in the ROI during the years 2014 to 2019. This is a remarkable achievement. Ireland remains one of very few countries worldwide that continues to review VLBW outcomes at a national level.
- Based on data provided by the VLBW Infant audits, the Clinical Programme in Neonatology, the Neonatal Clinical Advisory Group, the Faculty of Paediatrics, the Institute of Obstetrics and Gynaecology and The National Women and Infants' Health Programme published a consensus guideline in 2020 on the Perinatal Management of Extreme Preterm Birth at the Threshold of Viability. This document recommended a change in the threshold of foetal viability from 24+0 weeks to 23+0 weeks (once confounding clinical factors, the desires of the parents and the likely outcomes of both the mother and the infant have been duly considered). ⁽¹⁾ This national guideline is to be welcomed as it provides greater clarity and consistency to the perinatal and neonatal management of extremely preterm infants in this country. In 2019, 83% of infants born at 23 weeks were offered resuscitation in the Delivery Room (DR) as compared to 43% in 2014.
- The Model of Care for Neonatal Services⁽²⁾, published in 2015, recommended that infants born at <28 weeks gestation should ideally be delivered in a tertiary neonatal centre.

This recommendation was further supported by the findings of the 2018 NICORE Report on the Mortality Risk among Very Low Birth Weight Infants born in the Republic of Ireland 2014-2018.⁽³⁾ By combining three years of data from the VLBW audits, this latter report found that ROI infants born at 24-27 weeks gestation in a tertiary unit did not experience higher than expected mortality. However, ROI infants born in non-tertiary units had a 70% higher mortality risk, most of which arose from infants born in peripheral units. In 2019, 20% of infants born between 23 and 27 weeks of gestation were delivered outside tertiary neonatal centres and this percentage has remained unchanged since 2014. This fact needs to be highlighted at a national level and the reasons as to why infants of this gestational age are not being delivered in tertiary centres need to be examined and potential solutions considered.

- Serial audits have shown that ROI VLBW infants continue to have higher than expected (but not statistically significant) mortality rates when compared to VON infants. They also have higher than expected rates of pneumothorax. To look at possible reasons for these findings, NICORE plans to undertake a more detailed, in-depth analyses of six years of data, focusing specifically on mortality and pneumothorax. This will be published as a separate report later this year.

Executive Summary

- 1.** A total of 505 very low birth weight (VLBW) infants were born in the Republic of Ireland (ROI) in 2019. Of these, 13 infants had a birthweight >1500g but were \leq 29 weeks 6 days gestation. There has been a 19% decrease in the number of VLBW infants born in the ROI since 2015 compared to a 9% decrease in the birth rate.
- 2.** In all, 212 infants were born with a birth weight \leq 1000g and 148 infants were born with a gestational age \leq 26 weeks 6 days.
- 3.** The crude survival rate for ROI VLBW infants in 2019 was 82% (n=412). This rate of 82% lies outside the VON interquartile range (VON Median 88%; Q1=83%, Q3=92%) indicating that 75% of VON units report higher survival rate than ROI.
- 4.** Adjusting for the risk profile of the VLBW population, the risk of mortality was higher than expected in the VLBW ROI population in 2019 (SMR=1.21; 95% CI: 0.94, 1.47) but this was not statistically significant. This finding was consistent with previous years.
- 5.** 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 was also higher than expected in 2019 (SMR=1.14; CI 0.82, 1.47), but again, this finding was not statistically significant.
- 6.** There was no significant difference in the risk of death or morbidity for ROI infants compared to VON infants in 2019 (SMR=1.04, 95% CI: 0.90, 1.19).
- 7.** Again, adjusting for the risk profile of the VLBW population, the Key Performance Indicators in the neonatal care of VLBW infants born in the ROI in 2019, compared to VON infants showed that:
 - a. ROI infants had significantly higher rates of pneumothorax (SMR=1.97, 95% CI: 1.51, 2.44). This has been reported every year since the commencement of this audit in 2014. To better understand this elevated risk of pneumothorax amongst ROI infants, further in-depth analysis using data gathered over the past 6 years will be carried out and made available in a separate publication with specific focus on this issue.
 - b. ROI infants had significantly lower rates of retinopathy of prematurity (SMR=0.67, 95% CI: 0.47, 0.87) similar to previous years.
 - c. There were no significant differences in risk of the following outcomes for ROI infants compared to VON infants:
 - Late bacterial infection (SMR=0.95, 95% CI: 0.60, 1.30) as recorded in previous years;
 - Coagulase negative *Staphylococcus* infection (SMR=0.98, 95% CI: 0.53, 1.44), in line with previous years;
 - Nosocomial infection (SMR=1.01, 95% CI: 0.72, 1.31), similar to findings in previous years;
 - Intra-ventricular haemorrhage (SMR=0.90, 95% CI: 0.71, 1.10), in line with the past two years;
 - Necrotising enterocolitis (NEC) (SMR=1.05, 95% CI: 0.63, 1.47) in line with the past two years.

- 8.** In 2019, of the 505 infants born, 78% (n=392) were delivered in tertiary neonatal centres; 15% (n=76) were born in regional neonatal centres; and 7% (n=37) were born in peripheral centres.
- 9.** Of infants born between 23 and 27 weeks gestation (n=193), 155 (80%) were delivered in a tertiary neonatal centre, 21 (11%) were born in a regional neonatal centre and 17 (9%) were born in a peripheral centre, similar to the percentages reported in 2017 and 2018. The current Model of Care for Neonatal Services in Ireland recommends that infants born before 28 weeks should ideally be delivered at a tertiary neonatal centre.⁽²⁾
- 10.** Over the past four years, approximately 9% of all the infants who delivered at 23-27 weeks gestation were born in peripheral centres and 12% were born in regional centres. Since 2016, peripheral centres transferred out 84% (63/75) of these infants for ongoing care within 48 hours of birth and regional centres transferred out 20% (19/96).
- 11.** A total of 38 ROI infants died in the delivery room (8%). The VON median for DR deaths was 0% (Q1=0%, Q3=4%). The ROI rate for delivery room (DR) deaths lies outside the VON interquartile range.
- 12.** The ROI rate for major congenital anomaly (MCA) is 7%. This rate lies in the upper quartile with the VON Median being 4% (Q1=0%, Q3=7%), suggesting that ROI infants are more likely to be born with an MCA. Fourteen (37%) of the 38 infants who died in the DR had an MCA. Comparable data from VON are not available.
- 13.** 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.⁽³⁾ In 2019, 83% of infants born at 23 weeks gestation were offered resuscitation compared to 73% in 2015. Of 38 DR deaths, 21 (55%) were born at less than 24 weeks gestation and 15 (39%) were less than 23 weeks gestation.

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.

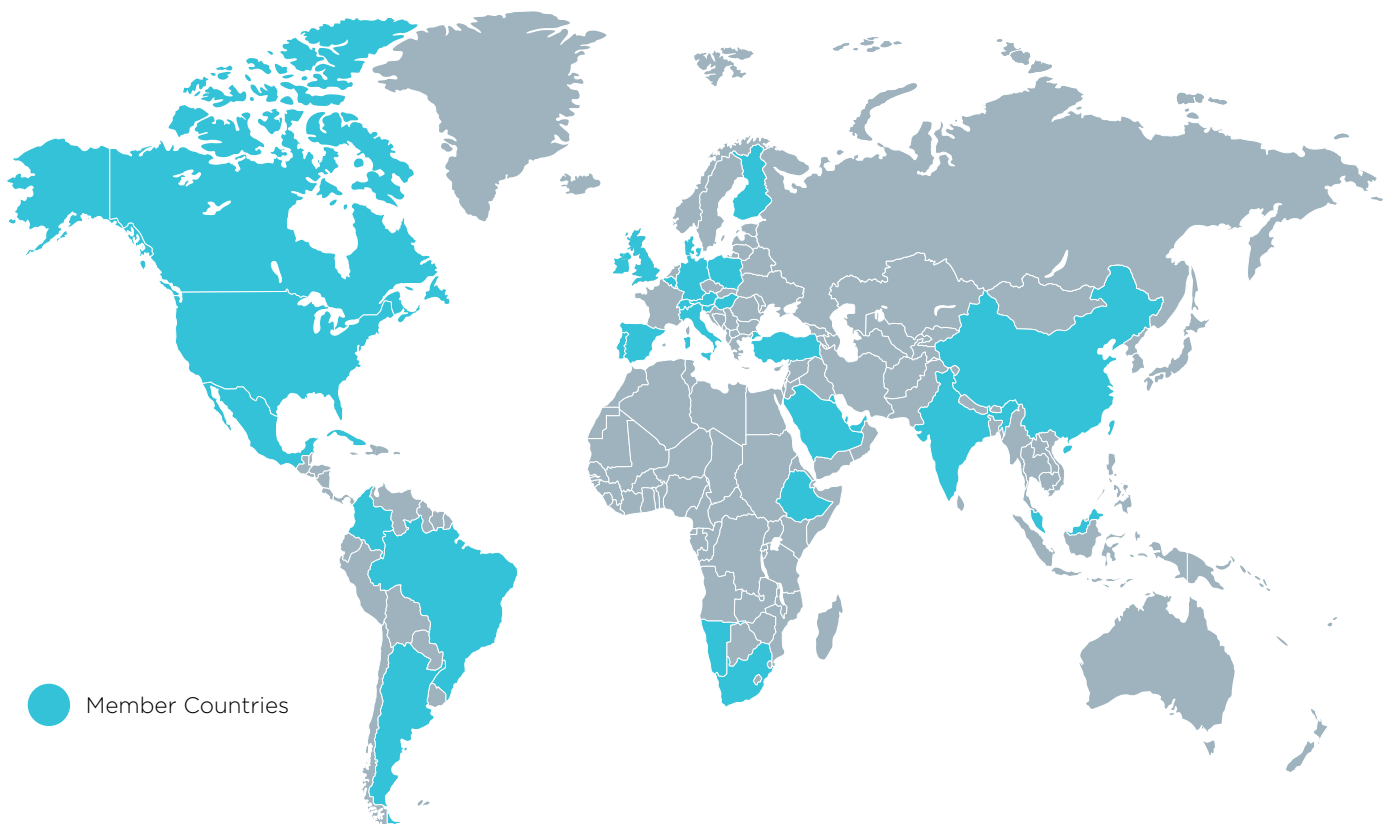


Figure 1: Member countries of the Vermont Oxford Network.

In the Republic of Ireland (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 (Neonatal Intensive Care Outcomes Research and Evaluation) group and the National Perinatal Epidemiology Centre (NPEC). In 2014, all 19 neonatal centres in the ROI submitted data to VON, marking the first year for which a national dataset is available. The first annual report on all very low birth weight (VLBW) infants born in the ROI was subsequently published for the year 2014. In 2018, one of the two tertiary paediatric centres in the country joined VON. The current report represents the sixth year, 2019, of a complete ROI dataset.

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 II 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.

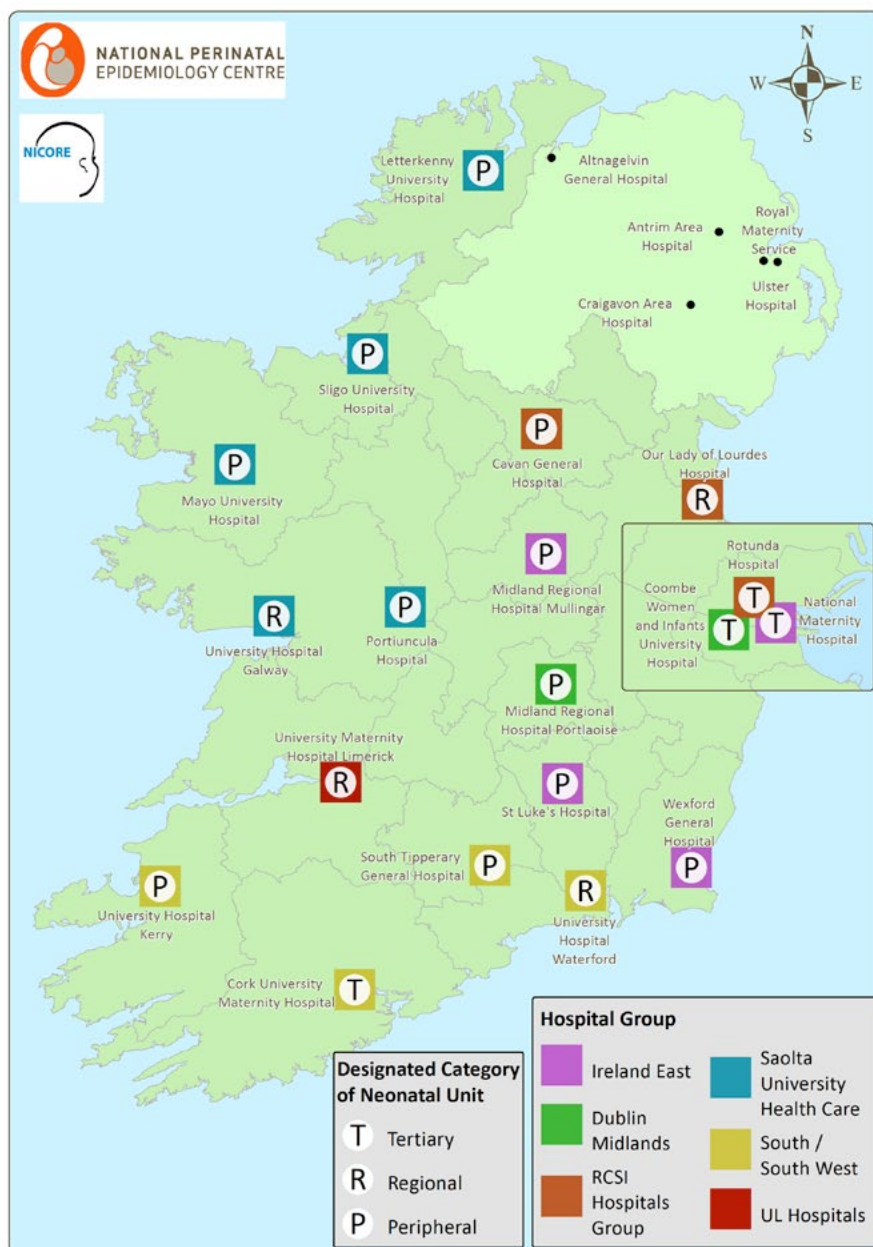


Figure II: Neonatal centres in the Republic of Ireland and Northern Ireland participating in the Vermont Oxford Network. ROI centres are classified according to category of Neonatal Units and the hospital group to which they are affiliated.

Methods

Data recording

In 2019, 19 neonatal centres and one tertiary paediatric centre participated in the VON's Very Low Birth Weight (VLBW) database. The following are the inclusion criteria for the data collected for VLBW infants:

Any infant whose birth weight is from 401 and 1500 grams OR whose gestational age is between 22 weeks 0 days and 29 weeks 6 days (inclusive) who is admitted to or dies in any location in your centre within 28 days of birth.

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

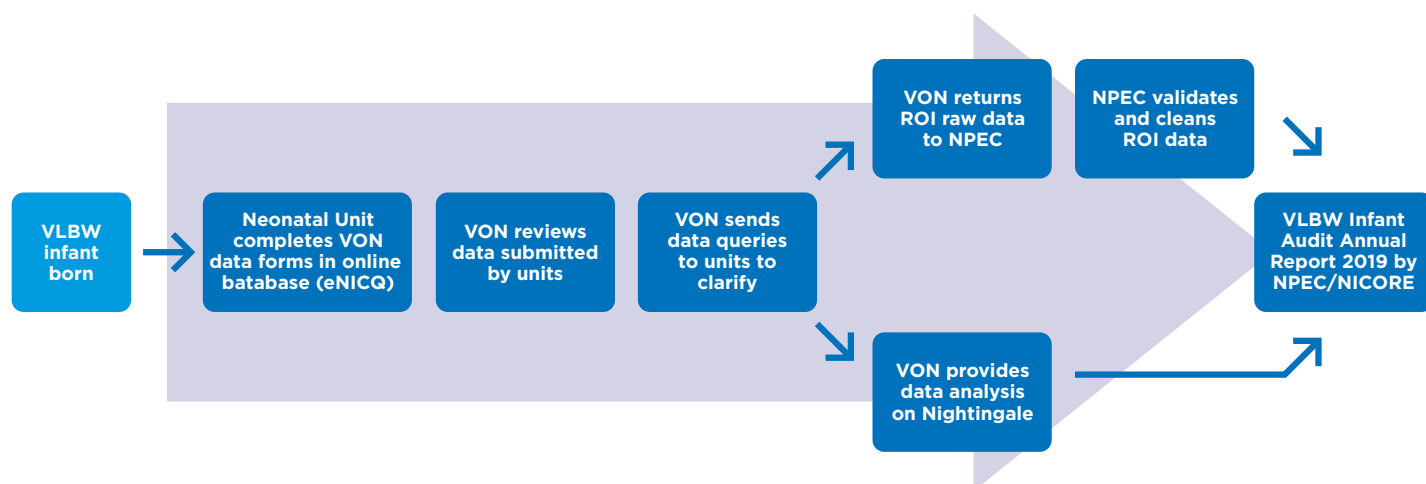


Figure III: Flow of information and data management in the VON data collection process.

On completion of all ROI submissions for 2019, VON forwarded a copy of the complete ROI dataset to the NPEC. The 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 online 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, if 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 2019 dataset from VON, NPEC undertakes a matching exercise to link data records associated with individual infants who are transferred (by matching the record of the unit in which the infant was born to the record of the unit to which the infant was transferred) in order to ensure that each infant is only counted once.

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

In previous reports, it was possible to compare the percentages of specific measures (e.g. KPIs, mortality etc.) for infants born in the ROI with the percentages reported for VON infants. Since 2018, VON no longer reports on the percentages for the whole network but reports the median percentage (the percentage at the median hospital in the network) and the interquartile range (i.e. the 1st and 3rd quartile percentages, Q1 and Q3). It is 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 will report a lower percentage than Q1 and 25% of the units will report a higher 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. While it is correct to present rates, even if based on rare outcomes and small numbers (as this is what the data shows), caution should be exercised when drawing conclusions 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 haemorrhage (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 data from '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 information in 'oxygen at discharge' from the hospital where infant was transferred from. Again, the latter is recorded as 'yes' for infants who were transferred and were on oxygen at the time of discharge from the transferring centre.

If the infant is discharged home before 34 weeks postmenstrual age 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 20.

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): Potentially blinding eye disorder that primarily affects premature infants. For the purpose of this report, ROP indicates whether the infant has stage 1, 2, 3, 4 or 5 of this condition.

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 505 VLBW infants were reported to VON in Ireland in 2019. Worldwide, 63,343 VLBW infants were reported to the VON Network in 2019.

Overall, there has been a 19% decrease in the number of very low birth weight infants recorded in Ireland since 2015 (Table 1.1). The corresponding decrease in the number of livebirths in Ireland over the same time period was of the order of 9% (from n=65,536 to n=59,796).⁽⁴⁾

Table 1.1 outlines the gestational age of VLBW infants reported in 2019. The highest proportion of infants were born in the 27-29 weeks gestation category (40%, n=202). A total of 44 (8%) infants were born with a gestation below 24 weeks and 37 (7%) infants were born with a gestation of more than 32 weeks. In total, 7% (37 out of 505) of VLBW infants born in 2019 had a major congenital anomaly (MCA).

Table 1.1: Number of cases reported to VON in 2015 – 2019 in Ireland, according to gestational age.

Gestational age	All cases					No. of cases with MCA				
	2015	2016	2017	2018	2019	2015	2016	2017	2018	2019
<24 weeks	48	48	38	44	44	0	3	1	1	3
24-26 weeks	114	134	125	138	104	11	12	12	10	8
27-29 weeks	235	217	240	198	202	14	20	19	16	12
30-32 weeks	170	152	172	126	118	10	15	11	10	10
>32 weeks	55	42	37	31	37	7	4	8	8	4
Total	622	593	612	537	505	42	54	51	45	37

Note: MCA=Major Congenital Anomaly. MCA was unknown for 2 infants in 2017.

Table 1.2 outlines the birthweights of VLBW infants born in 2019. A total of 26 infants (5%) weighed ≤ 500 g, of whom six were ≤ 401 g (the lowest birthweight recorded was 350g). The majority of infants (34%; n=171) were born with a birthweight >1250 g, 13 of whom had a birthweight >1500 g.

Table 1.2: Number of cases reported to VON in 2015 – 2019 in Ireland, according to birth weight.

Birth weight (g)	All cases					No. of cases with MCA				
	2015	2016	2017	2018	2019	2015	2016	2017	2018	2019
<501	23	21	23	24	26	0	1	2	0	4
501 – 750	100	104	93	97	89	5	14	8	8	5
751 – 1000	98	125	122	118	97	14	11	12	8	7
1001 – 1250	155	152	157	132	122	10	14	12	12	10
>1250	246	191	217	166	171	13	14	17	17	11
Total	622	593	612	537	505	42	54	51	45	37

Note: MCA=Major Congenital Anomaly; MCA was unknown for 2 infants in 2017.

2. Infant Characteristics

Table 2.1 outlines the characteristics of VLBW infants born in 2019.

In 2019, the rates for ROI Infants for multiple gestation, and major congenital anomaly were in the VON upper quartile. The proportion of maternal hypertension in ROI lies outside the VON interquartile range as shown in Table 2.1.

Table 2.1: Infant characteristics in the Republic of Ireland and VON, 2019.

Characteristic	Republic of Ireland			VON		
	Cases	N	%	Median %	Q1 %	Q3 %
Male	272	505	54	50	45	56
Prenatal Care	498	505	99	97	94	100
Chorioamnionitis	67	492	14	7	2	15
Maternal Hypertension	103	501	21	34	26	41
Antenatal Steroids	448	500	90	86	77	91
C-Section	352	505	70	75	67	82
Antenatal Magnesium Sulphate	366	499	73	63	44	75
Multiple Gestation	154	505	31	23	16	31
Major Congenital Anomaly (MCA)	37	505	7	4	0	7
Small for Gestational Age (SGA)	95	496	19	20	15	25

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 62,473 and 63,327.

3. Survival

In 2019, a total of 82% (n=412) of VLBW infants born in the ROI survived to discharge home or to their first birthday. The VON Median for 2019 was 88% (Q1 83%, Q3 92%). The ROI rate lies outside the interquartile range (Table 3.1).

In 2019, 56% 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 rate lies within the VON interquartile range (Table 3.1).

Table 3.1: Survival of ROI and VON infants, including those with congenital anomalies, 2019.

Measure	Year	Republic of Ireland			VON		
		Cases	N	%	Median %	Q1 %	Q2 %
Survival*	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
	2019	412	505	82	88	83	92
Survival without specified morbidities**	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
	2019	279	503	56	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 62,691 and 62,563 respectively.

* Defined as an infant who survives to discharge home or to first birthday.

** Defined as survival without any of the following morbidities of 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 gestational age and birthweight is reported in Tables 3.2 and 3.3 respectively for the years 2015 through to 2019.

Survival to discharge increases with advancing gestational age until 30 weeks gestation, above which there was a slight variation away from this pattern. This finding is consistent with previous years (Table 3.2). Survival at 23 weeks gestation was 34% (10 infants of a total of 29 infants).

Table 3.2: Survival to discharge by gestational age breakdown for ROI infants, including those with congenital anomalies, 2015-2019.

Number of survivors/Number of liveborn infants (%)					
Gestational Age	2015 (N=622)	2016 (N=593)	2017 (N=612)	2018 (N=530*)	2019 (N=505)
<22 weeks	0/2 (0%)	0/2 (0%)	0/6 (0%)	0/5 (0%)	0/2 (0%)
22 weeks	0/16 (0%)	0/19 (0%)	0/16 (0%)	0/12 (0%)	0/13 (0%)
23 weeks	9/30 (30%)	10/27 (37%)	7/15 (47%)	9/27 (33%)	10/29 (34%)
24 weeks	22/34 (65%)	25/45 (56%)	21/37 (56%)	20/39 (51%)	16/28 (57%)
25 weeks	33/43 (77%)	39/50 (78%)	27/50 (54%)	32*/41 (78%)	23/35 (66%)
26 weeks	30/37 (81%)	34/39 (87%)	31/39 (79%)	50*/54 (93%)	36/41 (88%)
27 weeks	40/46 (87%)	47/49 (96%)	60/69 (87%)	46*/52 (88%)	50/60 (83%)
28 weeks	82/90 (91%)	77/83 (93%)	83/88 (94%)	65*/69 (94%)	49/54 (91%)
29 weeks	94/99 (95%)	80/85 (94%)	74/83 (89%)	70/75 (93%)	84/88 (95%)
30 weeks	65/65 (100%)	62/66 (94%)	84/87 (97%)	51/53 (96%)	57/60 (95%)
31 weeks	64/68 (94%)	49/50 (98%)	52/54 (96%)	31/34 (91%)	28/30 (93%)
32 weeks	35/37 (95%)	34/36 (94%)	28/31 (90%)	36/39 (92%)	25/28 (89%)
>32 weeks	51/55 (93%)	39/42 (93%)	34/37 (92%)	25*/30 (83%)	34/37 (92%)
Total	525/622 (84%)	496/593 (84%)	501/612 (82%)	435/530 (82%)	412/505 (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.

Table 3.3: Survival to discharge by birth weight for ROI infants, including those with congenital anomalies, 2015-2019.

Number of survivors/Number of liveborn infants (%)					
Birth Weight	2015 (N=622)	2016 (N=593)	2017 (N=612)	2018 (N=530*)	2019 (N=505)
<501g	4/23 (17%)	6/21 (29%)	3/23 (13%)	2/23* (9%)	5/26 (19%)
501-600g	19/37 (51%)	12/33 (36%)	16/39 (41%)	19/32* (59%)	13/25 (52%)
601-700g	29/45 (64%)	32/51 (63%)	23/33 (70%)	24/42 (57%)	31/54 (57%)
701-800g	26/37 (70%)	35/49 (71%)	29/43 (67%)	27/39* (69%)	17/23 (74%)
801-900g	33/40 (83%)	40/47 (85%)	35/47 (74%)	37/44 (84%)	27/34 (79%)
901-1000g	34/39 (87%)	45/49 (92%)	48/53 (91%)	51/54 (94%)	44/50 (88%)
1001-1100g	54/59 (92%)	51/54 (94%)	55/64 (86%)	41/46 (89%)	35/38 (92%)
1101-1200g	58/64 (91%)	62/67 (93%)	60/64 (94%)	47/50 (94%)	54/61 (89%)
1201-1300g	63/67 (94%)	61/63 (97%)	65/69 (94%)	51/53* (96%)	46/47 (98%)
1301-1400g	84/87 (97%)	62/64 (97%)	74/80 (93%)	56/60 (93%)	56/60 (93%)
>1400g	121/124 (98%)	90/95 (95%)	93/97 (96%)	80/87 (92%)	84/87 (97%)
Total	525/622 (84%)	496/593 (84%)	501/612 (82%)	435/530 (82%)	412/505 (82%)

*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.

The proportion of infants who survived to discharge without specified morbidities since 2015 is outlined Table 3.4. This rate is seen to increase with advancing gestational age.

Table 3.4: Survival without specified morbidities¹ of infants according to gestational age at birth of ROI infants reported to VON, 2015-2019.

Number of survivors without morbidities ¹ / Number of liveborn infants (%)					
Gestational Age	2015 (N=622)	2016 (N=592*)	2017 (N= 605*)	2018 (N=527*)	2019 (N=503*)
≤ 22 weeks	0/18 (0%)	0/21 (0%)	0/22 (0%)	0/15 (0%)	0/15 (0%)
23 weeks	1/30 (3%)	2/27 (7%)	1/15 (7%)	0/27 (0%)	2/29 (7%)
24-27 weeks	40/160 (25%)	59/182 (32%)	57/190 (30%)	69/186 (37%)	56/162 (35%)
28-31 weeks	213/322 (66%)	202/284 (71%)	226/310 (73%)	158/230 (69%)	166/232 (72%)
≥32 weeks	83/92 (90%)	70/78 (90%)	59/68 (87%)	57/69 (83%)	55/65 (85%)
Total	337/622 (54%)	333/592* (56%)	343/605* (57%)	284/527* (54%)	279/503* (55%)

Note: Figures include infants with congenital anomalies.

¹Specified 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 1 infant born in 2016 at 24-27 weeks gestation;

Unknown for 7 infants born in 2017: 5 infants born at 24-27 weeks gestation and 2 infants born at 28-31 weeks;

Unknown for 8 infants born in 2018: 5 infants born at 24-27 weeks gestation, 2 infants born at 28-31 weeks and 1 born at >32 weeks.

Unknown for 2 infants born in 2019 at 24-27 weeks gestation.

4. Key Performance Indicators

VON reports on a number of Key Performance Indicators (KPIs). This allows the ROI to compare its outcomes to the Vermont Oxford Network. Such comparisons allow for the benchmarking of ROI performance and the identification of areas for improvement.

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 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 2019 is reported 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, VON uses multivariable logistic regression models for each KPI to quantify the risk of the outcome based on 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 are provided to NPEC to allow the calculation of SMRs for each KPI.

SMRs are calculated for ROI babies with birth weights between 501-1500g, and for whom complete data are available for the infant characteristics used in the regression models and for each of the KPIs analysed.

For each KPI, the coefficients are applied to the data of 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, is 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 is to be expected given the risk profile of the ROI infant population. SMRs greater than one indicate that more infants experience the outcome than expected given the risk profile of the ROI infants. SMRs less than one indicate that fewer cases are observed among ROI infants than expected.

A 95% confidence interval is calculated for each SMR so that inferences can be made about whether the SMR indicates if the difference between observed and expected is statistically significant. If the 95% confidence interval does not include the value of 1, it may be inferred that the difference between the numbers of observed and expected cases is statistically significant, i.e. there are more or fewer cases among the ROI infants than expected given the risk profile.

For each KPI, the absolute difference between the observed and expected number of cases 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 2019

For each key performance indicator, Table 4.1 displays the SMR, its 95% confidence interval, the difference between the observed and expected number of cases and the 95% confidence interval for this difference.

In 2019, ROI infants had significantly higher rates of pneumothorax (SMR 1.97; 95% CI: 1.51, 2.44) but significantly lower rates of retinopathy of prematurity (SMR 0.67; 95% CI: 0.47, 0.87).

Table 4.1: Risk-Adjusted Standardised Mortality/Morbidity Ratios for Key Performance Indicators, Republic of Ireland, 2019.

Outcome	O	E	SMR	(95% CI)	O-E	(95% CI)
Mortality	67	56	1.21	(0.94, 1.47)	11	(-3, 26)
Mortality excluding early death	42	37	1.14	(0.82, 1.47)	5	(-7, 17)
Death or Morbidity	192	184	1.04	(0.90, 1.19)	8	(-19, 34)
Chronic Lung Disease	79	80	0.99	(0.77, 1.21)	-1	(-18, 17)
Pneumothorax*	35	18	1.97	(1.51, 2.44)	17	(9, 26)
Late Bacterial Infection	30	32	0.95	(0.60, 1.30)	-2	(-13, 9)
Coagulase Negative Infection	18	18	0.98	(0.53, 1.44)	0	(-9, 8)
Nosocomial Infection	45	44	1.01	(0.72, 1.31)	1	(-12, 14)
Fungal Infection	2	3	0.58	(0, 1.64)	-1	(-5, 2)
Any Late Infection	47	46	1.02	(0.74, 1.31)	1	(-12, 14)
Intraventricular Haemorrhage	92	102	0.90	(0.71, 1.10)	-10	(-29, 10)
Severe Intraventricular Haemorrhage	26	30	0.86	(0.50, 1.21)	-4	(-15, 7)
Retinopathy of Prematurity	64	95	0.67	(0.47, 0.87)	-31	(-50, -12)
Severe Retinopathy of Prematurity*	11	16	0.68	(0.19, 1.17)	-5	(-13, 3)
Cystic Periventricular Leukomalacia	5	11	0.45	(0, 1.04)	-6	(-13, 0)
Necrotising Enterocolitis	23	22	1.05	(0.63, 1.47)	1	(-8, 10)

"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.

Key Performance Indicators and Gestational Age

Table 4.2 outlines the rates for each KPI according to gestational age. There was a statistically significant decrease in the occurrence of all KPIs with advancing gestational age, with the exception of three, namely pneumothorax, fungal infection and cystic periventricular leukomalacia.

Table 4.2: Rates for each Key Performance Indicator according to gestational age categories of VLBW infants born in the ROI, 2019.

Outcomes	24-27 weeks	28-31 weeks	≥32 weeks	Total
Mortality	39 (24%)	14 (6%)	6 (9%)	59 (13%)
Mortality excluding early death	27 (16%)	7 (3%)	2 (3%)	36 (8%)
Death or Morbidity	106 (65%)	66 (28%)	10 (15%)	182 (40%)
Chronic Lung Disease	49 (30%)	26 (11%)	4 (6%)	79 (17%)
Pneumothorax	15 (9%)	15 (6%)	2 (3%)	32 (7%)
Late Bacterial Infection	24 (15%)	7 (3%)	1 (2%)	32 (7%)
Coagulase Negative Infection	12 (7%)	7 (3%)	0 (0%)	19 (4%)
Nosocomial Infection	33 (20%)	14 (6%)	1 (2%)	48 (10%)
Fungal Infection	1 (1%)	0 (0%)	0 (0%)	1 (0%)
Any Late Infection	34 (21%)	14 (6%)	1 (2%)	49 (11%)
Intraventricular Haemorrhage	50 (30%)	30 (13%)	3 (5%)	83 (18%)
Severe Intraventricular Haemorrhage	16 (10%)	2 (1%)	0 (0%)	18 (4%)
Retinopathy of Prematurity	44 (27%)	14 (6%)	0 (0%)	58 (13%)
Severe Retinopathy of Prematurity	7 (4%)	2 (1%)	0 (0%)	9 (2%)
Cystic Periventricular Leukomalacia	5 (3%)	2 (1%)	0 (0%)	7 (2%)
Necrotising Enterocolitis	15 (9%)	6 (3%)	0 (0%)	21 (5%)

Note: Association between outcomes (KPIs) and gestational age was significant at P-value <0.05, except for pneumothorax, 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 since 2014. This allows us to see if the relative risk for any KPI has changed over time (Table 4.3).

There is evidence of improvement over time with respect to several KPIs. The SMR for Mortality was significantly higher in 2014 but this finding has not been replicated since. Statistically

significant increased risks for Death or Morbidity, Coagulase Negative Infection, Nosocomial Infection and Any Late Infection noted in 2014 and 2015 have not been observed since. NEC rates for the past three years remain similar to those for VON. For five of the past six years, statistically significant lower rates of retinopathy of prematurity have been reported. The rates for pneumothorax have remained significantly higher every year since 2014 with little improvement noted over time.^a

^aRates of pneumothorax in 2016 higher than VON but value not statistically significant.

Table 4.3: Standardised Mortality/Morbidity Ratios for Key Performance Indicators, ROI, 2014-2019

Outcomes	SMR (95% CI)					
	2014	2015	2016	2017	2018	2019
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)	1.21 (0.94, 1.47)
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)	1.14 (0.82, 1.47)
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)	1.04 (0.90, 1.19)
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)	0.99 (0.77, 1.21)
Pneumothorax	1.67 (1.25, 2.10)*	1.80 (1.37, 2.24)*	1.40 (0.98, 1.82)	1.69 (1.29, 2.10)*	1.56 (1.13, 1.98)*	1.97 (1.51, 2.44)*
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)	0.95 (0.60, 1.30)
Coagulase Negative Infection	1.84 (1.45, 2.23)*	1.60 (1.22, 1.99)*	1.13 (0.74, 1.52)	1.16 (0.80, 1.53)	1.20 (0.80, 1.61)	0.98 (0.53, 1.44)
Nosocomial Infection	1.30 (1.04, 1.57)*	1.43 (1.17, 1.69)*	1.17 (0.91, 1.43)	1.04 (0.80, 1.29)	0.97 (0.71, 1.24)	1.01 (0.72, 1.31)
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 (0.0, 1.17)	0.58 (0.0, 1.64)
Any Late Infection	1.26 (1.00, 1.52)*	1.44 (1.18, 1.70)*	1.13 (0.88, 1.39)	1.03 (0.78, 1.27)	0.96 (0.70, 1.22)	1.02 (0.74, 1.31)
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)	0.90 (0.71, 1.10)
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)	0.86 (0.50, 1.21)
Retinopathy of Prematurity	0.51 (0.33, 0.70)*	0.71 (0.53, 0.89)*	0.62 (0.45, 0.80)*	0.72 (0.54, 0.89)*	0.85 (0.67, 1.04)	0.67 (0.47, 0.87)*
Severe Retinopathy of Prematurity	0.83 (0.37, 1.29)	1.10 (0.66, 1.54)	0.54 (0.10, 0.97)	0.98 (0.55, 1.42)	0.39 (0.0, 0.83)*	0.68 (0.19, 1.17)
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)	0.45 (0.0, 1.04)
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)	1.05 (0.63, 1.47)

*indicates a statistically significant difference.

5. Survival according to Gestational Age Category and Location of Birth

There are 19 neonatal centres in the ROI that are affiliated with an Obstetric Service. These are classified as tertiary, regional or peripheral neonatal centres 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 deliver more than 7,000 infants per annum and all provide 24-hour consultant neonatology cover. The regional centres have dedicated neonatal intensive care

units (NICUs) but deliver less than 7,000 infants yearly and/or do not have 24-hour consultant neonatology cover. In 2019, one of these four centres delivered 4,000-5,000 infants, two centres delivered 2,000-3,000 infants and the fourth centre delivered fewer than 2,000 infants (Table 5.1). Peripheral centres do not have dedicated NICUs nor do they have dedicated consultant neonatology cover. They do have designated areas that care for newborn infants (i.e. Special Care Baby Units (SCBUs) who are under the care of general paediatricians. In 2019, all peripheral centres delivered fewer than 2,000 infants.

Table 5.1: Number of live births and stillbirths weighing greater than or equal to 500g in maternity centres in 2019.

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	2,000 - 3,000
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 hospitals.

All 505 VLBW infants in Ireland reported to VON in 2019 had complete data both on location of birth (i.e. tertiary, regional, peripheral) and survival.

In 2019, 392 infants (78%) were born in one of the four tertiary neonatal centres, 76 (15%) were born in one of the four regional neonatal centres and the remaining 37 infants (7%) were born in one of eleven peripheral centres (Table 5.2). This compares to 73% (n=393), 19% (n=101) and 8% (n=43) born in tertiary, regional and peripheral centres in 2018.⁽⁵⁾

Resuscitation in the delivery room is defined as the need for administration of positive pressure breaths either via a face mask and/or an endotracheal tube. Of the 353 infants who received resuscitation in the DR, 348 survived to admission to a NICU/SCBU but 5 infants died in the DR. Of these 348 admitted, 294 survived to discharge and 54 infants died (data not shown in table).

Table 5.2: Survival of ROI Infants by category of neonatal centre, 2019, n=505.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	392 (78%)	76 (15%)	37 (7%)	505
Received resuscitation in the delivery room	272/392 (69%)	52/76 (68%)	29/37 (78%)	353/505 (70%)
Admitted to a NICU/SCBU	363/392 (93%)	72/76 (95%)	32/37 (87%)	467/505 (93%)
Transferred to another neonatal centre within 48 hours of birth	4/392 (1%)	2/76 (1%)	21/37 (24%)	27/505 (5%)
Survived to discharge	317/392 (81%)	69/76 (91%)	26/37 (70%)	412/505 (82%)

Table 5.3 reports on the number of infants of each gestational age category who were born in tertiary, regional or peripheral centres and the number of these infants that were offered resuscitation at birth.

The 2018 report on mortality risk among VLBW infants between 2014-2016⁽³⁾, recommended that all infants born at 23 weeks gestation, presenting in a favourable condition, should be offered resuscitation. In 2019, 83% of infants born at 23 weeks gestation (n=24) were resuscitated at birth.

Table 5.3: Number of infants born in each category of neonatal centre who were administrated resuscitation according to gestational age, 2019.

Gestational Age	No. receiving resuscitation/ No. born (% of liveborn)			
	Tertiary Centres	Regional Centres	Peripheral Centres	Total
≤ 22 weeks	0/11 (0%)	1/3 (33%)	0/1 (0%)	1/15 (7%)
23 weeks	18/21 (86%)	1/2 (50%)	5/6 (83%)	24/29 (83%)
24-27 weeks	117/134 (87%)	18/19 (95%)	9/11 (82%)	144/164 (88%)
28-31 weeks	123/182 (68%)	25/35 (71%)	13/15 (87%)	161/232 (69%)
≥32 weeks	14/44 (32%)	7/17 (41%)	2/4 (50%)	23/65 (35%)
Total	272/392 (69%)	52/76 (68%)	29/37 (78%)	353/505 (70%)

Despite the guidance from the Model of Care for Neonatal Services⁽²⁾, published in 2015, that infants born <28 weeks should ideally be delivered in a tertiary neonatal centre, only 155 (80%) of infants born between 23 and 27 weeks gestation (n=193) in 2019 were delivered in a tertiary neonatal centre (Table 5.3). This figure has remained unchanged since 2017.⁽⁵⁾

A total of 21 (11%) infants delivered at <28 weeks were born in a regional neonatal centre and 17 (9%) were born in a peripheral centre in 2019.

Table 5.4: Number of liveborn infants in ROI according to category of neonatal centre, number of infants born at 23-27 gestation weeks and number transferred within 48h of delivery, 2016-2019.

Type of neonatal centre	2016	2017	2018	2019	Total
	n all liveborn infants				
Tertiary	421	439	392	392	1644
Regional	114	105	102	76	397
Peripheral	49	60	43	37	189
Total	593	612	537	505	2247
n (%) infants who were born 23-27 weeks gestation					
Tertiary	170 (82%)	158 (76%)	173 (79%)	155 (80%)	656 (79%)
Regional	27 (13%)	26 (13%)	22 (10%)	21 (11%)	96 (12%)
Peripheral	11 (5%)	24 (12%)	23 (11%)	17 (9%)	75 (9%)
Total	208 (100%)	208 (100%)	218 (100%)	193 (100%)	827 (100%)
n (%) infants born 23-27 weeks who were transferred within 48h					
Tertiary	9 (5%)	0 (0%)	11 (6%)	0 (0%)	20 (3%)
Regional	7 (26%)	6 (23%)	5 (23%)	1 (5%)	19 (20%)
Peripheral	11 (100%)	19 (79%)	20 (87%)	13 (76%)	63 (84%)
Total	27 (13%)	25 (12%)	36 (17%)	14 (7%)	102 (12%)

As outlined in Table 5.4, the number of infants born at 23-27 weeks in non-tertiary centres increased from 18% in 2016 to 24% in 2017 and has remained around 20%-21% in the years that followed. Over the past four years, approximately 9% of all the infants who delivered at 23-27 weeks gestation were born in peripheral centres and 12% were born in regional centres. Since 2016, peripheral centres transferred out 84% (63/75) of these infants for ongoing care within 48 hours of birth and regional centres transferred out 20% (19/96).

In 2019, admission to NICU/SCBU was recorded for 467 infants, of which 363 (93%) were born at tertiary centres, 72 (95%) at regional centres and 32 (87%) at peripheral centres (Table 5.2). Some of these infants were subsequently transferred out of their birth hospital to another neonatal and/or paediatric centre within 48 hours of birth. In all, 27 (5%) of the 505 infants were transferred within 48 hours and the majority of these infants (n=21; 77% of the total infants transferred) were born in peripheral centres (Table 5.5). Peripheral units generally only provide care for infants ≥ 32 weeks gestation while regional centres provide care for infants ≥ 28 weeks gestation.

Of the 33 infants born at <32weeks gestation in peripheral centres, 4 died in the DR (one infant at ≤ 22 weeks, one at 23 weeks, one at 24-27 weeks and one infant at 28-31 weeks; Tables 5.6, 5.8,

5.10, 5.11). A further 21 were transferred to another centre within 48 hours of birth (Table 5.2 and 5.5): 20 to a tertiary neonatal centre and one to a regional centre. The remaining 8 infants were managed in a peripheral centre and these infants were of the following gestations: 2 infants born at 24-27 weeks and 6 infants born at 28-31 weeks (data not included in tables).

Four infants born in regional centres at ≤ 23 weeks gestation died in the DR (Table 5.6 and 5.8). The remaining 72 infants born in regional centres, were all admitted to the NICU. Only 2 of these infants were transferred to another centre within 48 hours of life (one infant born at 24-27 weeks and an infant born at 28-31 weeks gestation). The rest were managed in the regional centre (1 infant born at 23 weeks gestation, 18 infants born at 24-27 weeks and 51 born at ≥ 28 weeks gestation).

All infants born in ROI in 2019, at ≤ 22 weeks of gestation died in the delivery room, and 23 (79%) infants born at 23 weeks survived to admission in NICU (Table 5.6 and 5.8).

Four infants born in a tertiary centre were transferred within 48 hours of birth, all of these infants were ≥ 28 wks gestation. Three infants were transferred to a paediatric hospital and one infant was transferred to another general hospital (not a neonatal centre) in Ireland.

Table 5.5: Number of infants born in each category of neonatal centre, and number transferred within 48 hours, according to gestational age, 2019, n=505.

No. transferred within 48 hours/ No. born (%)			
Gestational Age	Tertiary Centres	Regional Centres	Peripheral Centres
≤ 22 weeks	0/11 (0%)	0/3 (0%)	0/1 (0%)
23 weeks	0/21 (0%)	0/2 (0%)	5/6 (83%)
24-27 weeks	0/134 (0%)	1/19 (5%)	8/11 (82%)
28-31 weeks	2/182 (1%)	1/35 (3%)	8/15 (53%)
≥ 32 weeks	2/44 (5%)	0/17 (0%)	0/4 (0%)
Total	4/392 (1%)	2/76 (3%)	21/37 (62%)

Survival of Infants born at ≤ 22 weeks gestation according to category of neonatal centre

Table 5.6 outlines the survival of infants born at ≤ 22 weeks gestation in 2019. Only one of these infants was resuscitated in the DR but that infant did not survive to admission to the NICU. Two of these infants (born in tertiary centres) had an MCA.

Table 5.6: Survival of ROI Infants born at ≤ 22 weeks gestation by category of neonatal centre, 2019, n=15.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	11	3	1	15
Received resuscitation in the delivery room	0 (0%)	1 (33%)	0 (0%)	1 (7%)
Admitted to a NICU/SCBU	0 (0%)	0 (0%)	0 (0%)	0 (0%)
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%)

Table 5.7 outlines the trend in survival of ROI infants born at ≤ 22 weeks gestation for the past 5 years. There has been no reported survival at ≤ 22 weeks gestation since 2014, the first year of this annual report.

Table 5.7: Survival of infants born at 22 weeks (or less) gestation, 2015-2019.

	2015 n (%)	2016 n (%)	2017 n (%)	2018 n (%)	2019 n (%)
Liveborn infants	18	21	22	17	15
Received resuscitation in the delivery room	0	1 (5%)	2 (9%)	1 (6%)	1 (7%)
Admitted to a NICU/SCBU	0	1 (5%)	2 (9%)	1 (6%)	0 (0%)
Survived to discharge	0	0	0	0	0 (0%)

Survival of Infants born at 23 weeks (23+0 to 23+6) gestation according to category of neonatal centre

Table 5.8 outlines the survival of infants born at 23 weeks gestation in 2019. The majority of these delivered in tertiary centres (n=21, 72%). Twenty-four of these infants (83%) were resuscitated in the delivery room and all but one of these survived to admission to the NICU. There were six DR Deaths. Of note, of eight infants at this gestational age who were born outside a tertiary neonatal centre, six infants survived to admission to a NICU/SCBU. Of these six infants, 5 were subsequently transferred within 48 hours of birth to a tertiary neonatal centre.

The survival rate for infants born at 23 weeks gestation in the Republic of Ireland (as a percentage of the total number of liveborn infants) was 34%.

Table 5.8: Survival of ROI Infants born at 23 weeks gestation by category of neonatal centre, 2019, n=29.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	21	2	6	29
Received resuscitation in the delivery room	18 (86%)	1 (50%)	5 (83%)	24 (83%)
Admitted to a NICU/SCBU	17 (81%)	1 (50%)	5 (83%)	23 (79%)
Transferred to another neonatal centre within 48 hours of birth	0 (0%)	0 (0%)	5 (83%)	5/29 (17%)
Survived to discharge among liveborns	6/21 (29%)	1/2 (50%)	3/6 (50%)	10/29 (35%)
Survived to discharge among infants receiving resuscitation	6/18 (33%)	1/1 (100%)	3/5 (60%)	10/24 (42%)
Survived to discharge among infants admitted to NICU/SCBU	6/17 (35%)	1/1 (100%)	3/5 (60%)	10/23 (44%)

Table 5.9 outlines the trend in survival of ROI infants born at 23 weeks gestation for the past 5 years. There has been an increase in the number of infants offered resuscitation in the DR and the numbers surviving to admission to a NICU/SCBU. However, the overall survival to discharge home is relatively unchanged.

Table 5.9: Survival of infants born at 23 weeks gestation, 2015-2019.

	2015 n (%)	2016 n (%)	2017 n (%)	2018 n (%)	2019 n (%)
Liveborn infants	30	27	15	27	29
Received resuscitation in the delivery room	22 (73%)	20 (74%)	13 (87%)	24 (89%)	24 (83%)
Admitted to a NICU/SCBU	10 (33%)	20 (74%)	13 (87%)	22 (81%)	23 (79%)
Survived to discharge	9 (30%)	10 (37%)	7 (47%)	9 (33%)	10 (35%)

Survival of Infants born at 24 -27 weeks gestation according to category of neonatal centre

Table 5.10 outlines the survival of infants born at 24-27 weeks gestation in 2019. Overall, there were 164 infants born at 24-27 weeks gestation of whom 134 (82%) were born in tertiary neonatal centres, 19 (12%) in regional centres and 11 (7%) in peripheral centres. Of these 164 infants, 144 (88%) were offered resuscitation in the delivery room and all but one of these infants survived to admission to a NICU/SCBU. This infant was born in a tertiary centre at 26 weeks gestation and had an MCA. Of the 20 infants who did not receive resuscitation in the DR (17 infants born in tertiary centres, 1 infant in a regional and 2 infants in peripheral centres), eight infants died in the DR (7 in tertiary centres and 1 in a peripheral centre) and six of the infants had an associated MCA. The two additional infants who died in DR were born at 25 and 26 weeks of gestation. The remaining 12 infants (two infants born at 25 weeks, four at 26 weeks and six at 27 weeks) were admitted to the NICU/SCBU and subsequently survived to discharge. In total, there were 9 DR deaths of which 7 had an MCA.

With regards to the need for resuscitation with advancing gestational age, of the 27 liveborn infants born at 24 weeks, all of these infants

required resuscitation in the delivery room. Of those born at 25 weeks (n=32), two (6%) did not require resuscitation, at 26 weeks, the figure was 4/37 (11%) and at 27 weeks, the figure was 6/59 (10%).

Eleven of the 155 infants admitted to NICU (7% of those liveborn at 24-27 weeks gestation, N=164) were transferred from their hospital of birth within 48 hours of birth (Table 5.10). All of these infants were born in peripheral centres, with the exception of one infant born in a regional centre. All were transferred to tertiary neonatal centres within 48 hours of birth and three infants did not survive to discharge. Therefore, of the 11 infants who were born in peripheral centres at 24-27 weeks gestation, 10 were admitted to the NICU/SCBU and all these were transferred to another centre within 48 hours of birth. Of 19 who were born in a regional centre at 24-27 weeks gestation, 19 were admitted to the NICU and only 1 of these infants was transferred within 48 hours of birth.

In total, 125 (76%) infants born at 24-27 weeks gestation survived to discharge.

Table 5.10: Survival of ROI Infants born at 24-27 weeks of gestation by category of neonatal centre, 2019.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	134	19	11	164
Received resuscitation in the delivery room	117 (87%)	18 (95%)	9 (82%)	144 (88%)
Admitted to a NICU/SCBU	126 (94%)	19 (100%)	10 (91%)	155 (95%)
Transferred to another neonatal centre within 48 hours of birth	0/134 (0%)	1/19 (5%)	10/11 (91%)	11/164 (7%)
Survived to discharge among liveborns	101/134 (75%)	17/19 (90%)	7/11 (64%)	125/164 (76%)
Survived to discharge among infants receiving resuscitation	91/117 (78%)	16/18 (89%)	6/9 (67%)	113/144 (79%)
Survived to discharge among infants admitted to NICU/SCBU	101/126 (80%)	17/19 (90%)	7/10 (70%)	125/155 (81%)

Survival of Infants born at 28 -31 weeks gestation according to category of neonatal centre

Table 5.11 outlines the survival of infants born at 28-31 weeks gestation in 2019. Overall, there were 232 infants born at 28-31 weeks gestation of which 182 (78%) were born in tertiary neonatal centres, 35 (15%) in regional centres and 15 (7%) in peripheral centres. Of these 232 infants, 161 (69%) received resuscitation in the delivery room and all of these infants survived to admission to a NICU/SCBU. A total of 71 infants did not receive resuscitation in the delivery room and 67 survived to admission to an NICU/SCBU. Of these 4 DR deaths, 3 had an MCA.

Of the 228 infants born at this gestational age admitted to a NICU/SCBU, 11 (5% of the total 232 born) infants were subsequently transferred within 48 hours. Eight of the fourteen infants of

this gestational age who were born in peripheral centres and who survived to admission to NICU/SCBU, were transferred within 48 hours of birth. The remaining six infants were managed locally and were of the following gestational age: one infant 28 weeks, two infants 29 weeks, two infants 30 weeks and one infant 31 weeks gestation.

One infant of this gestational age group was transferred from a regional centre to a tertiary centre and two were transferred from a tertiary centre to a paediatric hospital.

A total of 218 (94%) infants born at 28-31 weeks gestation survived to discharge.

Table 5.11: Survival of ROI Infants born at 28-31 weeks gestation by category of neonatal centre, 2019, n=232.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	182	35	15	232
Received resuscitation in the delivery room	123 (68%)	25 (71%)	13 (87%)	161 (69%)
Admitted to a NICU/SCBU	179 (98%)	35 (100%)	14 (93%)	228 (98%)
Transferred to another neonatal centre within 48 hours of birth	2/182 (1%)	1/35 (3%)	8/15 (53%)	11/232 (5%)
Survived to discharge among liveborns	170/182 (93%)	35/35 (100%)	13/15 (87%)	218/232 (94%)
Survived to discharge among infants receiving resuscitation	114/123 (93%)	25/25 (100%)	12/13 (92%)	151/161 (94%)
Survived to discharge among infants admitted to NICU/SCBU	170/179 (95%)	35/35 (100%)	13/14(93%)	218/228 (96%)

Survival of Infants born at ≥ 32 weeks gestation according to category of neonatal centre

Table 5.12 outlines the survival of infants born at ≥ 32 weeks gestation in 2019. In total, there were 65 infants born at ≥ 32 weeks gestation in 2019. A total of 23 (35%) infants required resuscitation in the delivery room and all survived to admission to a NICU/SCBU. The other 42 infants born at ≥ 32 weeks gestation did not receive resuscitation in the delivery room. Four of these infants died in the delivery room and two of these infants had an MCA.

Two infants born in a tertiary centre were transferred within 48 hours of birth, one was transferred to paediatric hospital (this infant had an MCA) and another was transferred to a general hospital in ROI (not a neonatal centre). The survival rate for infants ≥ 32 weeks gestation was 91%.

Table 5.12: Survival of ROI Infants born at or greater than 32 weeks gestation by category of neonatal centre, 2019, n=65.

	Tertiary Centres n (%)	Regional Centres n (%)	Peripheral Centres n (%)	Total
Liveborn infants	44	17	4	65
Received resuscitation in the delivery room	14 (32%)	7 (41%)	2 (50%)	23 (35%)
Admitted to a NICU/SCBU	41 (93%)	17 (100%)	3 (75%)	61 (94%)
Transferred to another neonatal centre within 48 hours of birth	2/44 (5%)	0/17 (0%)	0/4 (0%)	2/65 (3%)
Survived to discharge among liveborns	40/44 (91%)	16/17 (94%)	3/4 (75%)	59/65 (91%)
Survived to discharge among infants receiving resuscitation	13/14 (93%)	6/7 (86%)	2/2 (100%)	21/23 (91%)
Survived to discharge among infants admitted to NICU/SCBU	40/41 (98%)	16/17 (94%)	3/3 (100%)	59/61 (97%)

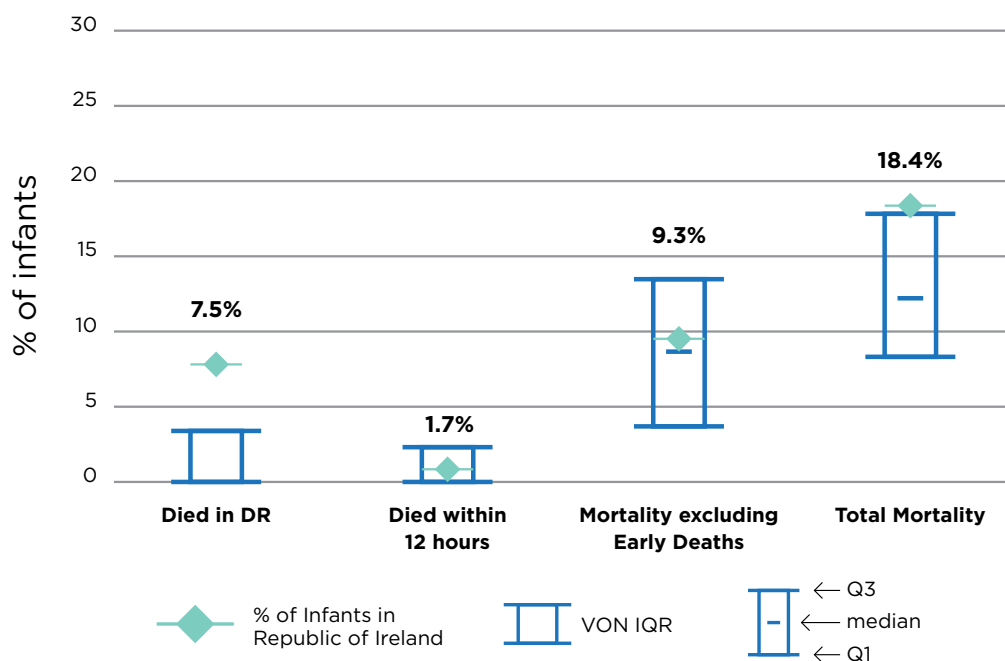
5.2. Mortality and Delivery Room (DR) Deaths

In 2019, 18% (n=93) of VLBW babies born in the ROI died (VON Median 13%; Q1=8%, Q3=18%). The timing of these deaths are outlined in Table 6.1 and Figure 6.1. A higher proportion of ROI infants died in the DR in 2019, when compared to VON. This is clearly shown in Figure 6.1 where the value for DR in ROI is markedly above the interquartile range recorded for VON.

Table 6.1: Mortality amongst Republic of Ireland and VON infants, 2019.

	Republic of Ireland			VON		
	Cases	N	%	Median %	Q1 %	Q3 %
Died in DR	38	505	8%	0%	0%	4%
Died within 12 Hours	8	505	2%	0%	0%	2%
Mortality Excl. Early Deaths	47	505	9%	9%	4%	14%
Total Mortality	93	505	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 59,373 and 62,948. 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.



Note: The blue box represents the interquartile range for units reporting to the VON. The blue internal marker indicates the median of units reporting to the VON. The VON reports the median % based on the units that submit data, as outlined in the methods section. 50% of units report a % lower than the median, 25% of units report a lower % than Q1 and 25% of units report a higher % than Q3.

Figure 6.1: Comparison of mortality amongst ROI and VON infants, 2019.

As highlighted in Table 6.2, the percentage of DR deaths has remained relatively constant in ROI in the past years, despite an increase in the number of infants of 23 weeks who are now offered resuscitation in the DR.

Table 6.2: Percentage of mortalities in ROI 2015-2019.

	2015	2016	2017	2018	2019
DR Deaths	7%	6%	6%	6%	8%
Deaths within 12 hours	2%	1%	1%	2%	2%
Mortality excluding Early Deaths (within 12h of birth)	7%	9%	11%	11%	9%
Total Mortality*	16%	16%	18%	18%	18%

*Percentage based on the total number of infants who were liveborn.

Deaths in the Delivery Room

In 2019, 8% (n=38) of ROI infants died in the DR (VON Median 0%; Q1=0%, Q3=4%), as shown in the above figure and tables 6.1 and 6.2. This figure is markedly above the VON interquartile range.

Of the 38 infants who died in the delivery room in 2019, 14 (37%) had a major congenital anomaly (Table 6.3). VLBW infants born in the ROI were

more likely to have an MCA when compared to VON (7% in ROI compared to the VON Median of 4% VON; Q1=0%, Q3=7%, see Table 2.1, page 16), nevertheless this was not statistically significant ($p>0.05$). A further 13 (34%) were less than 23 weeks gestation (one infant born at 21 weeks and 12 infants born at 22 weeks). These factors may have impacted on the higher delivery room death rate recorded in the ROI population.

Table 6.3: Deaths in the delivery room, by gestational age category and presence of major congenital anomaly, 2019.

Gestational Age Category	Major Congenital Anomaly		
	Absent	Present	Total
≤22 weeks	13	2	15
23 weeks	6	0	6
24-27 weeks	2	7	9
28-31 weeks	1	3	4
≥ 32 weeks	2	2	4
Total	24	14	38

In Summary

- In 2019, the overall survival rate of VLBW infants born in Ireland was 82% (412 infants of a total of 505). 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 (8%, n=38) when compared to VON (median 0%; Q1=0%, Q3=4%).
- The mortality risk in 2019 was consistent with the risk observed in the previous five years. It was 21% higher than expected after adjusting for the risk profile of the population (SMR=1.21; 95% CI 0.94, 1.47). The findings were similar when mortality excluding early deaths was considered (SMR=1.14; CI 0.82, 1.47). Neither of these findings were statistically significant.
- The risk of ROP among VLBW infants in ROI continues to be lower than expected, lower by a third in 2019 (SMR=0.67; CI 0.47, 0.87).
- ROI infants continue to show a higher than expected risk of pneumothorax (SMR=1.97; 95% CI 1.51, 2.44), a consistent finding since 2014. To better understand this elevated risk of pneumothorax amongst ROI infants, further in-depth analysis using data gathered over the past 6 years will be carried out and made available in a separate publication with a specific focus on this issue.
- A statistically significant decrease in most KPIs was observed with higher gestational ages. This denotes a lower risk of mortality, morbidity and specific outcomes (as measured by the KPIs) for infants born with higher gestational ages. Pneumothorax and cystic periventricular leukomalacia did not significantly decrease with advancing gestational ages.
- 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 83% in 2019) and this had been associated with an increase in the proportion of these infants who survive to discharge (from 19% in 2014, to 47% in 2017 and 35% in 2019).
- One in five of the VLBW infants born between 23-27 weeks of gestation (n=38 of 193, 20%) were not delivered in a tertiary neonatal centre in 2019. This proportion has remained virtually unchanged since 2014 despite Model of Care for Neonatal Services in Ireland recommending that infants born before 28 weeks of gestation ideally be delivered at a tertiary neonatal centre.

References

1. The Clinical Programme in Neonatology, The Neonatal Clinical Advisory Group, The Faculty of Paediatrics, The Institute of Obstetricians and Gynaecologists, The National Women and Infants Health Programme. Perinatal Management of Extreme Preterm Birth at the Threshold of Viability - A Framework for Practice. Dublin: Royal College of Physicians of Ireland; 2020.
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3. Corcoran P, Drummond L, Twomey A, Murphy BP, Greene RA oboNRoI. Mortality Risk Amongst Very Low Birth Weight Infants Born in the Republic of Ireland 2014-2016. Cork: National Perinatal Epidemiology Centre; 2018.
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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, Ireland.

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

30/07/2021

Dear Drs Twomey and Murphy,

I wish to acknowledge receipt of the Very Low Birth Weight Infants in the Republic of Ireland Annual Report 2019. Following the presentation to the NOCA Quality Assurance Committee on the 30th July, 2021 we are delighted to endorse this report.

On behalf of the NOCA Governance Board, I wish to congratulate you, your committee and healthcare professionals in participating maternity units on this report. This report clearly demonstrates how focussed high quality data used for national clinical audit facilitates clinical guidelines and ultimately improve the quality of care provided to patients. I welcome plans for further analyses of clinical outcomes- mortality and pneumothorax over six years. The inclusion of commentary from the public/patient representative from the Irish Neonatal Health Alliance is a welcome development and this ensures that this clinical audit has greater relevance for those directly affected.

Please accept this as formal endorsement from the NOCA Governance Board.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Brian Creedon', is written over a light grey horizontal line.

Dr Brian Creedon
Clinical Director
National Office of Clinical Audit

Appendix B: VON unit leads and co-ordinators and contributors 2019

Neonatal Unit	Leads	Co-ordinators
Cavan General Hospital	Dr Hamza Abdalla	Ms Evelyn McAdam
Coombe Women and Infants University Hospital	Dr John Kelleher	Ms Julie Sloan
Cork University Maternity Hospital	Dr Brendan Paul Murphy	
Kerry University Hospital	Dr Daniel Onyekwere	Ms Margaret Kelly
Letterkenny University Hospital	Dr Matthew Thomas	Ms Kate Greenough
Mayo University Hospital	Dr Hilary Stokes	
Midland Regional Hospital Mullingar	Dr Michael O'Grady	Ms Geraldine Kavanagh
Midland Regional Hospital Portlaoise	Dr Rizwan Gul	Ms Anne Blanche
National Maternity Hospital (NMH)	Dr Anne Twomey	Mr John Geoghegan
Our Lady of Lourdes, Drogheda	Dr Emma Gordon	Ms Claire Shannon
Portiuncula Hospital	Dr Paula Cahill	
Rotunda Hospital	Dr David Corcoran	Ms Kathy Conway
Sligo University Hospital	Dr Ghia Harrison	Ms Madeleine Munelly Ms Niamh McGarvey
South Tipperary General Hospital	Dr John Walsh	
St. Luke's Hospital, Kilkenny	Dr David Waldron	
University Maternity Hospital, Limerick	Dr Niazy Al-Assaf	Ms Elizabeth Reidy
University Hospital Galway	Dr Donough O'Donovan	
University Hospital Waterford	Dr Robert Kernan	Dr Shammaz Saeed
Wexford General Hospital	Dr Muhammad Azam	Dr Naeem Aziz Shori

Appendix C: Vermont Oxford Network Data Collection Forms, 2019

General Data Items - For Infants Born in 2019 at VLBW Centers



Center Number: _____ Patient ID Number: MRN: _____

VERMONT OXFORD NETWORK eNICQ PATIENT DATA BOOKLET FOR INFANTS BORN IN 2019

This booklet 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.

This booklet is designed for you to use to collect data that will later be entered by your center into eNICQ, the VON data submission tool.

Contents:
Page 1: Patient Identification Worksheet
Page 2-7: General Data Items For Infants Born in 2019 at VLBW Centers

PATIENT IDENTIFICATION WORKSHEET

Patient's Name: _____

Mother's Name: _____

Date of Birth: / /
 MM DD YYYY

Date of Admission: / /
 MM DD YYYY

Date of Day 28: / /
 MM DD YYYY

Date of Week 36: / /
 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

For Date of Day 28 use the *Day 28 Calculation Charts*:
<https://vtoxford.zendesk.com/hc/en-us/articles/360013115753-2019-Calculation-Charts-Date-of-Day-28>

For Date of Week 36 use the *Week 36 Calculator*:
<https://public.vtoxford.org/week-36-calculator/>

PLEASE DO NOT SUBMIT THIS WORKSHEET
Protected Health Care Information



General Data Items - For Infants Born in 2019 at VLBW Centers



Center Number: _____ Patient ID Number: MRN: _____

Patient ID number: _____ (this is the VON Network ID – it is auto-generated by eNICQ)	
Medical Record Number: _____	
Date of Birth: <u> </u> / <u> </u> / <u> </u> MM DD YYYY	
Died in Delivery Room: <input type="checkbox"/> Yes <input type="checkbox"/> No (If Yes, complete Delivery Room Death data booklet, not this booklet)	
Location of Birth: <input type="checkbox"/> Inborn <input type="checkbox"/> Outborn	
Patient's First Name: _____	
Patient's Last Name: _____	
Mother's First Name: _____	
Mother's Last Name: _____	
If Location of Birth is Outborn, Date of Admission: <u> </u> / <u> </u> / <u> </u> MM DD YYYY	
Birth Weight: _____ grams	
Gestational Age, Weeks: _____ Gestational Age, Days (0-6): _____	
If Location of Birth is Outborn, Transfer Code of Center from which Infant Transferred: _____ (List available at https://public.vtoxford.org/transfer-codes/)	
Head Circumference at Birth (in cm to nearest 10 th): <input type="text"/> <input type="text"/> <input type="text"/> .	
Maternal Ethnicity/Race (Answer both Ethnicity and Race):	
Ethnicity of Mother: <input type="checkbox"/> Hispanic <input type="checkbox"/> Not Hispanic	
Race of Mother: <input type="checkbox"/> Black or African American <input type="checkbox"/> White <input type="checkbox"/> Asian <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> Other	
Prenatal Care: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Antenatal Steroids: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Antenatal Magnesium Sulfate: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Chorioamnionitis: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Maternal Hypertension, Chronic or Pregnancy-Induced: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Maternal Diabetes: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Mode of Delivery: <input type="checkbox"/> Vaginal <input type="checkbox"/> Cesarean Section	
Sex of Infant: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown	
Multiple Gestation: <input type="checkbox"/> Yes <input type="checkbox"/> No If Yes, Number of Infants Delivered: _____	
Congenital Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Congenital Infection, Organism(s): _____ (If Congenital Infection is Yes, enter up to 3 Congenital Infection descriptions from Manual of Operations, Part 2 – Appendix E)	

General Data Items - For Infants Born in 2019 at VLBW Centers

Center Number: _____ Patient ID Number: MRN: _____

APGAR Scores:	1 minute _____	5 minutes _____
Initial Resuscitation:	Oxygen:	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Face Mask Vent:	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Laryngeal Mask Airway:	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Endotracheal Tube Vent:	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Epinephrine:	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Cardiac Compression:	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Nasal Vent:	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Nasal CPAP:	<input type="checkbox"/> Yes <input type="checkbox"/> No
Temperature Measured within the First Hour after Admission to <u>Your</u> NICU: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A		
If Yes, Temperature Within the First Hour after Admission to Your NICU: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>		
<small>(In degrees centigrade to nearest 10th)</small>		
Died within 12 Hours of Admission to Your NICU: <input type="checkbox"/> Yes <input type="checkbox"/> No		
Bacterial Sepsis and/or Meningitis on or before Day 3: <input type="checkbox"/> Yes <input type="checkbox"/> No		
Bacterial Sepsis and/or Meningitis on or before Day 3, Pathogen(s): _____		
<small>(If Bacterial Sepsis and/or Meningitis is Yes, enter up to 3 Bacterial Pathogen descriptions from Manual of Operations, Part 2 – Appendix B)</small>		
Oxygen on Day 28: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> 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: <input type="checkbox"/> Yes <input type="checkbox"/> No		
If Yes, Worst Grade of PIH (0-4): _____		
If PIH Grade 1-4, Where PIH First Occurred: <input type="checkbox"/> Your Hospital <input type="checkbox"/> Other Hospital		
Respiratory Support (at any time after leaving the delivery room/initial resuscitation area):		
Oxygen after Initial Resuscitation: <input type="checkbox"/> Yes <input type="checkbox"/> No		
Conventional Ventilation after Initial Resuscitation: <input type="checkbox"/> Yes <input type="checkbox"/> No		
High Frequency Ventilation after Initial Resuscitation: <input type="checkbox"/> Yes <input type="checkbox"/> No		
High Flow Nasal Cannula after Initial Resuscitation: <input type="checkbox"/> Yes <input type="checkbox"/> No		
Nasal Ventilation after Initial Resuscitation: <input type="checkbox"/> Yes <input type="checkbox"/> No		
Nasal CPAP after Initial Resuscitation: <input type="checkbox"/> Yes <input type="checkbox"/> No		
Nasal CPAP or Nasal Vent before or without ever having received ETT Vent: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A		
Surfactant during Initial Resuscitation: <input type="checkbox"/> Yes <input type="checkbox"/> No		
Surfactant at Any Time: <input type="checkbox"/> Yes <input type="checkbox"/> No <small>(Surfactant at Any Time must be Yes if Surfactant During Initial Resuscitation is Yes)</small>		
If Yes, Age at First Dose of Surfactant: Hours _____ Minutes (0-59) _____		
Inhaled Nitric Oxide: <input type="checkbox"/> Yes <input type="checkbox"/> No		
If Yes, Inhaled Nitric Oxide, Where Given: <input type="checkbox"/> Your Hospital <input type="checkbox"/> Other Hospital <input type="checkbox"/> Both		

General Data Items - For Infants Born in 2019 at VLBW Centers



Center Number: _____ Patient ID Number: MRN: _____

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 below)

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 below)

Other Surgery: Yes No
(If Yes, a Surgery Code, Location of Surgery, and an answer to Surgical Site Infection are required below)

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: _____	<input type="checkbox"/> Your Hospital	<input type="checkbox"/> Other Hospital	<input type="checkbox"/> Both	Surgical Site Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No
Surgery Code 2: _____	<input type="checkbox"/> Your Hospital	<input type="checkbox"/> Other Hospital	<input type="checkbox"/> Both	Surgical Site Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No
Surgery Code 3: _____	<input type="checkbox"/> Your Hospital	<input type="checkbox"/> Other Hospital	<input type="checkbox"/> Both	Surgical Site Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No
Surgery Code 4: _____	<input type="checkbox"/> Your Hospital	<input type="checkbox"/> Other Hospital	<input type="checkbox"/> Both	Surgical Site Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No
Surgery Code 5: _____	<input type="checkbox"/> Your Hospital	<input type="checkbox"/> Other Hospital	<input type="checkbox"/> Both	Surgical Site Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No
Surgery Code 6: _____	<input type="checkbox"/> Your Hospital	<input type="checkbox"/> Other Hospital	<input type="checkbox"/> Both	Surgical Site Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No
Surgery Code 7: _____	<input type="checkbox"/> Your Hospital	<input type="checkbox"/> Other Hospital	<input type="checkbox"/> Both	Surgical Site Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No
Surgery Code 8: _____	<input type="checkbox"/> Your Hospital	<input type="checkbox"/> Other Hospital	<input type="checkbox"/> Both	Surgical Site Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No
Surgery Code 9: _____	<input type="checkbox"/> Your Hospital	<input type="checkbox"/> Other Hospital	<input type="checkbox"/> Both	Surgical Site Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No
Surgery Code 10: _____	<input type="checkbox"/> Your Hospital	<input type="checkbox"/> Other Hospital	<input type="checkbox"/> Both	Surgical Site Infection: <input type="checkbox"/> Yes <input type="checkbox"/> No

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

General Data Items - For Infants Born in 2019 at VLBW Centers



Center Number: _____ Patient ID Number: MRN: _____

Respiratory Distress Syndrome:	<input type="checkbox"/> Yes <input type="checkbox"/> No
Pneumothorax:	<input type="checkbox"/> Yes <input type="checkbox"/> No
If Yes, Pneumothorax, Where Occurred:	<input type="checkbox"/> Your Hospital <input type="checkbox"/> Other Hospital <input type="checkbox"/> Both
Patent Ductus Arteriosus:	<input type="checkbox"/> Yes <input type="checkbox"/> No
Necrotizing Enterocolitis:	<input type="checkbox"/> Yes <input type="checkbox"/> No
If Yes, NEC, Where Occurred:	<input type="checkbox"/> Your Hospital <input type="checkbox"/> Other Hospital <input type="checkbox"/> Both
Focal Intestinal Perforation:	<input type="checkbox"/> Yes <input type="checkbox"/> No
If Yes, Focal Intestinal Perforation, Where Occurred:	<input type="checkbox"/> Your Hospital <input type="checkbox"/> Other Hospital <input type="checkbox"/> 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:	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
If Yes, Bacterial Sepsis and/or Meningitis after Day 3, Where Occurred:	<input type="checkbox"/> Your Hospital <input type="checkbox"/> Outside Your Hospital <input type="checkbox"/> Both
Bacterial Sepsis and/or Meningitis after Day 3, Pathogen(s): _____ (If Bacterial Sepsis and/or Meningitis is Yes, enter up to 3 Bacterial Pathogen descriptions from Manual of Operations, Part 2, Appendix B)	
Coagulase Negative Staph Infection after Day 3:	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
If Yes, Coagulase Negative Staphylococcal Infection after Day 3, Where Occurred:	<input type="checkbox"/> Your Hospital <input type="checkbox"/> Outside Your Hospital <input type="checkbox"/> Both
Fungal Infection after Day 3:	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Fungal Infection after Day 3, Where Occurred:	<input type="checkbox"/> Your Hospital <input type="checkbox"/> Outside Your Hospital <input type="checkbox"/> Both
Cystic Periventricular Leukomalacia:	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A (See Manual of Operations, Part 2 for N/A criteria)
ROP, Retinal Examination	<input type="checkbox"/> Yes <input type="checkbox"/> No
If Yes, Worst Stage of ROP (0-5):	_____
Congenital Anomaly:	<input type="checkbox"/> Yes <input type="checkbox"/> No
If Yes, enter up to 5 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, & 907:	

Is this infant still hospitalized at your center? <input type="checkbox"/> Yes <input type="checkbox"/> No	



General Data Items - For Infants Born in 2019 at VLBW Centers



Center Number: _____ Patient ID Number: MRN: _____

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

Date of Initial Disposition: ____ / ____ / ____ (Not required when Initial Disposition is *Still Hospitalized as of First Birthday*)
MM DD YYYY

Weight at Initial Disposition: _____ grams

Head Circumference at Initial Disposition (in cm to nearest 10th): . (For infants which have not transferred, infant record is now complete)

If an infant is transferred to another hospital, complete Data Items *Reason for Transfer, Transfer Code of Center to which Infant Transferred, Post Transfer Disposition, and the Data Items that follow your Post Transfer Disposition choice*. *Post Transfer Disposition* refers to the infant's disposition upon leaving the "transferred to" hospital.

If Transferred, Reason for Transfer: Growth/Discharge Planning Medical/Diagnostic Services
 Surgery ECMO Chronic Care Other

Transfer Code of Center to which Infant Transferred: _____
(List available at <https://public.vtoxford.org/transfer-codes/>)

Is This Infant Still Hospitalized at Another Center? Yes No

General Data Items - For Infants Born in 2019 at VLBW Centers



Center Number: _____ Patient ID Number: MRN: _____

Choose **one** of the five Post Transfer Disposition options below and complete the Data Item(s) that follow your choice

Post Transfer Disposition:

1. Home

Date of Final Discharge: ____/____/____ (infant record is now complete)

2. Died

Date of Final Discharge: ____/____/____ (infant record is now complete)
MM DD YYYY

3. Transferred Again to Another Hospital (2nd Transfer)

Ultimate Disposition:

Home

Date of Final Discharge: ____/____/____ (infant record is now complete)
MM DD YYYY

Died

Date of Final Discharge: ____/____/____ (infant record is now complete)
MM DD YYYY

Still Hospitalized as of First Birthday (infant record is now complete)

4. Readmitted to Any Location in Your Hospital

When infants are readmitted to your center, continue to update Data Items *Bacterial Sepsis and/or Meningitis* on or before Day 3 through *Nasal CPAP or Nasal Ventilation* before or without ever having received *ETT Ventilation* and Data Items *Surfactant at Any Time* through *Monitor at Discharge* based on all events at both hospitals until the date of Disposition after Readmission.

Disposition after Readmission:

Home

Weight at Disposition after Readmission: ____ grams

Date of Final Discharge: ____/____/____ (infant record is now complete)
MM DD YYYY

Died

Weight at Disposition after Readmission: ____ grams

Date of Final Discharge: ____/____/____ (infant record is now complete)
MM DD YYYY

Still Hospitalized as of First Birthday

Weight at Disposition after Readmission: ____ grams (infant record is now complete)

Transferred Again to Another Hospital

Weight at Disposition after Readmission: ____ grams

Ultimate Disposition:

Still Hospitalized as of First Birthday (infant record is now complete)

Home

Date of Final Discharge: ____/____/____ (infant record is now complete)
MM DD YYYY

Died

Date of Final Discharge: ____/____/____ (infant record is now complete)
MM DD YYYY

5. Still Hospitalized as of First Birthday (infant record is now complete)





**NATIONAL PERINATAL
EPIDEMIOLOGY CENTRE**

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