NATIONAL PERINATAL EPIDEMIOLOGY CENTRE

Perinatal Mortality in Ireland

Lay Summary 2018 & 2019 Biennial Report

National Perinatal Epidemiology Centre

The National Perinatal Epidemiology Centre works with the maternity services in Ireland. The NPEC are a team of midwives, researchers, administrators, clinicians and is directed by Professor Richard Greene. The NPEC produces annual reports on perinatal mortality in Ireland, maternal morbidity in Ireland, home births in Ireland and very low birth weight babies in Ireland. At local hospital level, the NPEC provides customised feedback to individual hospitals on how they compare against the national average. The NPEC is funded by the Health Service Executive (HSE) and is based at Cork University Maternity Hospital in the Department of Obstetrics and Gynaecology, University College Cork. *Every time a mother gives birth in Ireland, the important interventions, the good outcomes and the complications are recorded and analysed at a national specialist centre. Unusual trends are easily and quickly observed and most importantly acted on.* NPEC continues to build on its existing portfolio of audit and quality review.

What is clinical audit?

Clinical audit is a process that seeks to improve patient care and outcomes through the systematic review and evaluation of current practice against research based standards.

What is Epidemiology?

Epidemiology is the study (scientific, systematic, and data-driven) of the distribution (frequency, pattern) and determinants (causes, risk factors) of health-related states and events (not just diseases) in specified populations (neighbourhood, school, city, state, country, global).

Perinatal Mortality Clinical Audit

Since 2008, the NPEC has been auditing perinatal deaths occurring in the Republic of Ireland. Perinatal deaths include the death of a baby occurring during pregnancy (stillbirth) and the death of a baby occurring shortly after birth (neonatal death). The aim of this clinical audit is to identify quality improvement initiatives and make recommendations for the improvement of care for mothers and babies.

Definitions

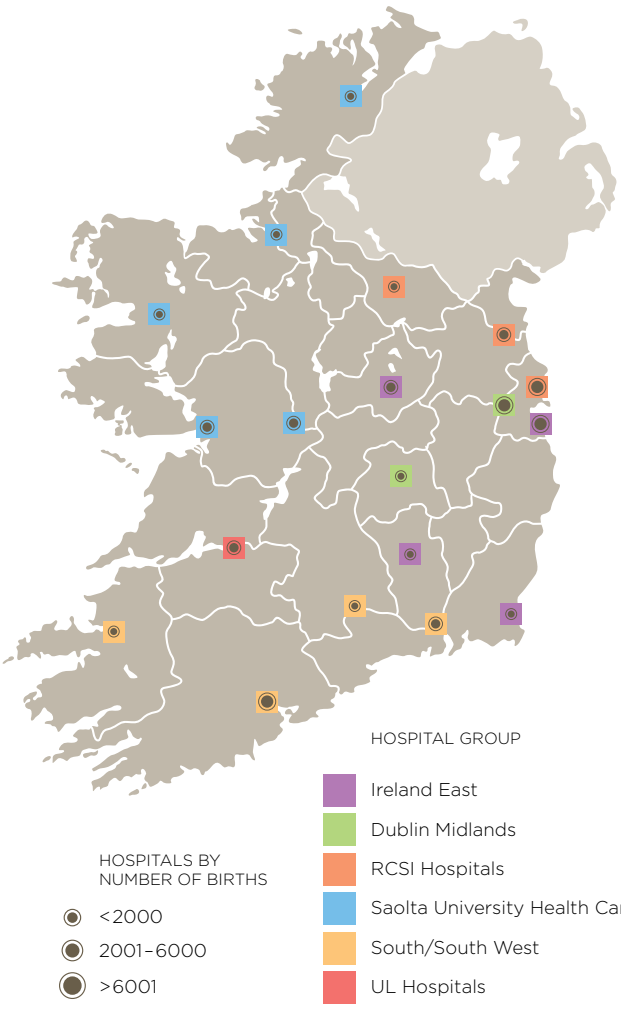
Stillbirth: a child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who shows no sign of life.[1]

Early neonatal death: Death of a live born baby occurring within 7 completed days of birth.

Late neonatal death: Death of a live born baby occurring after the 7th day and within 28 completed days of birth.

Perinatal mortality rate (PMR): Number of stillbirths and early neonatal deaths per 1,000 births (live births and stillbirths from 24 weeks gestation or weighing >500g).

Major congenital anomaly: Any genetic or structural defect arising at conception or during embryogenesis incompatible with life or potentially treatable but causing death.



[1]Stillbirth Registration Act, 1994. Available at: **www.irishstatutebook.ie/eli/1994/act/1/enacted/en/print**

2018

61,298 BABIES BORN IN IRELAND

108 EARLY NEONATAL DEATHS

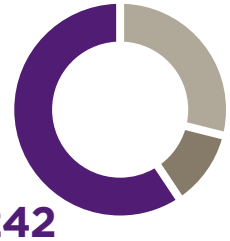
217 STILL BIRTHS

30 LATE NEONATAL DEATHS

PERINATAL MORTALITY RATE → **5.3/1,000 births or 1-in-189 births**

2019

59,574 BABIES BORN IN IRELAND



118 EARLY NEONATAL DEATHS

242 STILL BIRTHS

32 LATE NEONATAL DEATHS

PERINATAL MORTALITY RATE → **6.0/1,000 births or 1-in-166 births**

The overall perinatal mortality rate has remained unchanged for a number of years.

Deaths of babies in the Republic of Ireland in 2018 & 2019

This is the eight report of the national clinical audit on perinatal mortality in Ireland published by the National Perinatal Epidemiology Centre (NPEC).

In 2018 there were 325 perinatal deaths occurring during pregnancy or shortly after birth among 61,298 births with a birthweight of at least 500g or at least 24 weeks gestation at delivery.

In 2019, there were 360 perinatal deaths occurring during pregnancy or shortly after birth among 59,574 births meeting the same criteria.

In 2018, stillbirths and early-neonatal deaths accounted for 217 (66.8%) and 108 (33.2%) of the 325 perinatal deaths respectively. The Perinatal Mortality Rate (PMR) was 5.3 deaths per 1,000 births; corrected for Congenital Anomaly, the rate was 3.20 per 1,000 births or one in 313 births. There were a further 30 late neonatal deaths reported in 2018.

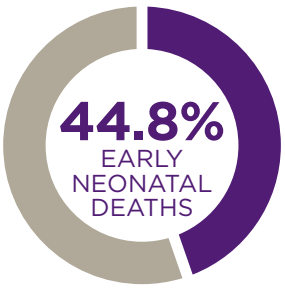
In 2019, stillbirths and early-neonatal deaths accounted for 242 (67.2%) and 118 (32.8%) of the 360 deaths, respectively. The PMR was 6.04 deaths per 1,000 births; corrected for Congenital Anomaly, the rate was 3.73 per 1,000 births (or one in 268 births). There were a further 32 late neonatal deaths reported in 2019.

Fetal growth in pregnancy

Low birthweight continues to be associated with perinatal death, particularly stillbirths, in 2018 and 2019. This highlights the importance of close monitoring for fetal growth during pregnancy.

LOW BIRTHWEIGHT ASSOCIATED WITH PERINATAL DEATH IN 2018 AND 2019

53.7% OF ALL STILLBIRTHS CLASSIFIED AS SEVERELY SMALL FOR GESTATIONAL AGE



44.8% OF EARLY NEONATAL DEATHS CLASSIFIED AS SEVERELY SMALL FOR GESTATIONAL AGE

Maternal characteristics

The report explores a number of maternal characteristics associated with perinatal loss. An association between maternal age/ increased BMI and perinatal mortality was identified. Compared to mothers aged between 25-29 years, women aged greater than 40 years had a higher rate of perinatal mortality (2018; 66% and 2019; 35% higher). Obese women had more than twice the risk of perinatal mortality compared to women who gave birth in 2019 with a healthy BMI.

Why do babies die?

Major congenital anomaly was the most common cause of perinatal death in Ireland in both 2018 and 2019.

The PMR rate was 3.2 and 3.7 per 1,000 births in 2018 and 2019 respectively, when deaths due to major congenital abnormality were excluded.

STILLBIRTH:	Major congenital anomaly (2018; 30.9% and 2019; 30.6%) Placental disease (2018; 26.3% and 2019; 30.2%)
EARLY NEONATAL DEATHS:	Major congenital anomaly (2018; 57.4% and 2019; 54.2%) Respiratory disorders, most commonly related to prematurity (2018; 23.1% and 2019; 23.7%).
LATE NEONATAL DEATHS:	Major congenital anomaly (2018; 40.0% and 2019; 37.5%) Respiratory disorders (2018; 10.0% and 2019; 18.8%)

Investigating perinatal deaths

Finding out why a baby dies is important not only to the bereaved family but is essential in learning lessons to help prevent such tragedies occurring in the future. An autopsy of the baby and a detailed examination of the placenta by a perinatal pathologist are both vital components in the thorough investigation of a perinatal death. Parental consent is required for an autopsy to be performed but is not needed for a placental examination.

Similar to previous reports, a post-mortem examination was performed more often in stillbirths (2018; 46.7% and 2019; 52.1%) than in neonatal deaths (2018; 32.0% and 2019; 43.1%) in both reporting years. For the majority of the perinatal deaths where an autopsy was not performed for the combined years 2018/2019, an autopsy was offered and presumably declined by parents (80.6% of the cases without autopsy).

It is encouraging to see that a high rate of placental histology examinations continues in 2018/2019 (99.1% in stillbirths and in 97.8% of neonatal deaths).

Message from our public representative

The World Health Organisation (WHO) has recommended that all countries access 'the burden of stillbirths and neonatal deaths' at national level and introduce strategies to reduce their perinatal mortality rates. Making Every Baby Count; Audit and review of stillbirths and neonatal deaths, WHO 2016 states that *''by counting the number of stillbirths and neonatal deaths, gathering information on where and why these deaths occurred and also by trying to understand the underlying contributing causes and avoidable factors, health-care providers, programme managers, administrators and policy-makers can help to prevent future deaths and grief for parents, and improve the quality of care provided throughout the health system.''*

To date, the NPEC, in partnership with all nineteen Irish maternity units, have done a great job in gathering the data required for national audit on Perinatal Mortality and other adverse perinatal outcomes (e.g. Neonatal Therapeutic Hypothermia). These two audits capture the incidence of perinatal mortality and morbidity nationally, identify causes and factors impacting on mortality and morbidity and also make a number of recommendations. Accountability for implementation of recommendations are now identified in this report. This will further enhance improvements in pregnancy screening, maternity care and perinatal outcomes. For the first time ever, this year's combined biennial report is naming the maternity units. This is a very positive step forward for transparency in Ireland and will be greatly welcomed by all.

As can be seen from the 'key findings' in the report, low birth weight (small for gestational age) is still a concerning factor, as is maternal age over 40 years and a high maternal BMI. Another concerning factor is that younger mum's in the Multiple pregnancy cohort have a higher risk of perinatal mortality compared to women over 40 years. We learned this from the detailed expert commentary on multiple pregnancies by Dr Muller, who suggested that this may be reflective of increased prenatal surveillance in older mothers owing to the higher anticipated risk profile. However, she also suggested that individual chart review is undertaken in multiple pregnancy deaths to further explore the reasons behind this trend. We should never assume one's risk stratification in any grouping but re-evaluate it at each point of care with the appropriate follow ups.

Autopsy uptakes varied around the country. The value of post mortem in any death is a very important learning tool as is placental and cord histology examination. In unexpected perinatal deaths, a coroner will rightly instruct that such examinations must be done. It is very hard to think of our babies undergoing such an examination process and it is very difficult to let them go. Through my work with other bereaved parents I have learned that even if the cause of death is assumed known at or before delivery, it is very important the choice is offered to all parents. It is not necessarily always the assumed visible factor that is the cause, sometimes other causes and factors are found which could greatly influence one's care in a future pregnancy and outcome. Answers from such examinations must be promptly delivered to all concerned!

Whilst we have seen an overall decline in our birth rates by about ten thousand since 2013, sadly we have not seen the same pattern of wanted decline in our mortality rates. We have plateaued in this area in recent years and yet other countries such as the UK, New Zealand and Holland have seen a welcome decline in their mortality rates by introducing different care bundles. So how do we address our perinatal mortality rates now in Ireland? The WHO states that perinatal losses *''associated with modifiable factors are preventable with high-quality, evidence-based interventions delivered before and during pregnancy, during labour and childbirth, and in the crucial hours and days after birth*". [2]A systematic review of the quality of care received, in a no-blame, interdisciplinary setting, with a view to improving the maternity care is advocated by the WHO. Recommendations in this NPEC report, for the establishment of an enquiry into unexpected intrapartum related deaths, multiple pregnancies and term stillbirths (in our otherwise healthy babies) to enhance lessons to improve care, is welcomed. If we are truly sincere in meeting our obligations to the WHO recommendations and our duty of care to all maternity service users, this should be an urgent priority for the maternity services.

Behind every number and percentage, no matter its significance in an overall picture of perinatal mortality, is a vulnerable woman, a precious little life lost and a family changed forever. While each family's journey is different, it is essential that care providers engage with them, to listen to and learn from their experience. This may identify modifiable factors that can inform future practice. Governance stakeholders and policy makers hold the power now to make changes to improve the maternity services. The evidence provided in successive NPEC audit reports and other investigative processes (e.g. Coronial Inquests/HSE external reviews) with recommendations to improve care, are there to inform them. The necessary actions should now be undertaken, with ring fenced funding, for safer better maternity services that meets international best practices.

Internationally, the WHO have acknowledged that ''it is time to make every baby count and prevent future tragedies, by learning from and effectively responding to preventable deaths''

Let's make sure each mother and baby really does count now in Ireland 2021.

Siobhan Whelan
Patient representative,
NPEC Perinatal Mortality Group

[2]Making every baby count; Audit and review of stillbirths and neonatal death. Geneva: World Health Organisation; 2016

Recommendations

Based on the findings of this and previous reports, the NPEC Perinatal Mortality Advisory Group makes the following recommendations:

- Robust clinical audit of perinatal outcomes in all maternity units in Ireland is vital for quality patient care. Funding should be provided to ensure protected time for clinical audit and implementation of its findings. Owner; the Health Service Executive (HSE).
- The establishment of an enquiry for stillbirth and neonatal deaths should be considered in order to enhance the lessons which may improve care. This could take the format of a standardized review of specific cohorts, such as:
  - unexpected intrapartum related deaths
  - multiple pregnancies
  - term stillbirths (in our otherwise healthy babies)

  These cohorts could be reviewed on a rolling basis. Owner; the National Women and Infants Health Programme (NWIHP) and the Institute of Obstetrics and Gynaecology (IOG) to progress.
- Standardised approach to improved antenatal detection of fetal growth restriction (FGR) with timely delivery is a preventative strategy to reduce perinatal mortality.
  - One option, as used previously and in other centres, is the generation of customized birth weight centile charts for every woman during pregnancy and concomitantly, staff should be trained in risk assessment, plotting of symphysial fundal height (SFH) and scan weight estimates in order to reduce stillbirths in Ireland. Owner; the NWIHP.
  - Based on feedback to the NPEC, other methodologies could be considered. A multidisciplinary working group should be developed to address a national standardised approach to the detection of FGR. A national approach should also evaluate the use of a standard growth curve across all Irish maternity units. Owner; the NWIHP and the IOG to progress.
- Consideration should be given to the establishment of a national working group to include Obstetricians, Neonatologists, Midwives and Allied Health Professionals whose remit is to look at the problem of preterm birth (PTB) in Ireland at a national level and how it is best addressed. Owner; the NWIHP.
- Further engagement with the Coroner Society of Ireland to explore the timeliness of autopsy reports reported to maternity units is warranted. Owner; the NWIHP to progress.
- Defining and auditing perinatal loss.

  (a) To allow for international comparison of stillbirths, a move towards collecting data on fetal deaths >22 weeks and <24 weeks should be considered in the audit of perinatal mortality in Ireland.

  (b) A national working group should be convened to review the definition of perinatal mortality in the Republic of Ireland (ROI). This working group should include the NWIHP, NPEC, the General Registers Office (GRO), the Institute of Obstetrics and Gynaecology, the National Clinical Programme for Paediatrics and Neonatology and the Department of Health. Owner; the NPEC to progress this.

Areas for potential research identified in the findings of this report.

- A public health education programme on perinatal deaths and modifiable risk factors should be developed.

Full report available at:
www.ucc.ie/en/npec/

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NOCA National Office of Clinical Audit

HSE

UCC University College Cork, Ireland Coláiste na hOllscoile Corcaigh