NATIONAL PERINATAL EPIDEMIOLOGY CENTRE

# Perinatal Mortality in Ireland

Lay Summary 2020 Annual 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

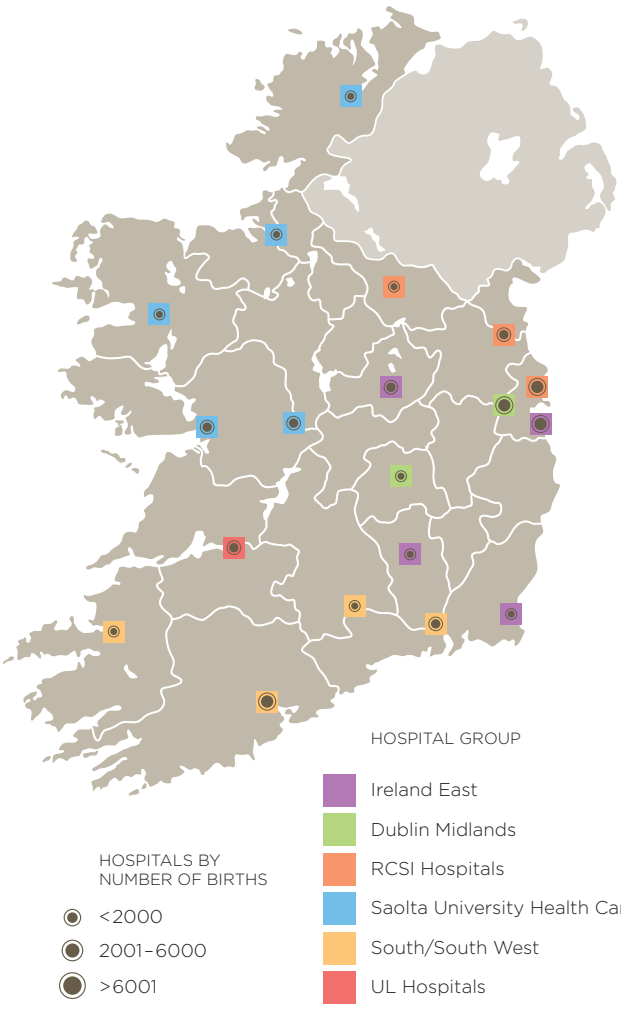
**Stillbirth:** a child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who shows no sign of life.[1]

**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**

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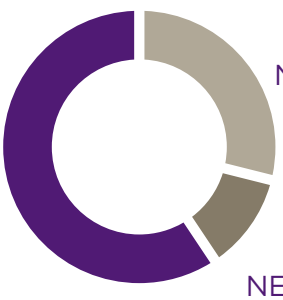
**2020**

**57,114**
BABIES BORN IN IRELAND



**240** STILL BIRTHS

**117** EARLY NEONATAL DEATHS

**35** LATE NEONATAL DEATHS

PERINATAL MORTALITY RATE

**6.25/1,000 births or 1-in-160 births**

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

# Deaths of babies in the Republic of Ireland in 2020

This is the ninth report of the national clinical audit on Perinatal Mortality in Ireland, using the NPEC data collection tool and classification system on cause of death. All 19 Irish maternity units reported anonymised data on 357 deaths arising from 57,114 births occurring in 2020, of at least 500g birthweight or at least 24 weeks gestation.

Stillbirths and early neonatal deaths accounted for 240 (67.2%) and 117 (32.8%) of the 357 deaths, respectively. There were a further 35 late neonatal deaths. The Perinatal Mortality Rate was 6.25 deaths per 1,000 births; corrected for Major Congenital Anomaly (MCA), the rate was 3.68 per 1,000 births; the stillbirth rate was 4.20 per 1,000 births; the early neonatal death rate was 2.06 per 1,000 live births.

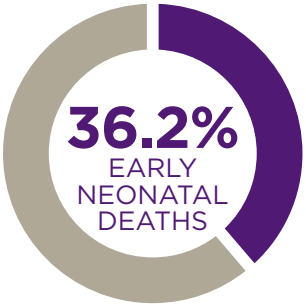
## Fetal growth in pregnancy

Low birthweight continues to be associated with perinatal death, particularly stillbirths, in 2020.

This highlights the importance of close monitoring for fetal growth during pregnancy.

### LOW BIRTHWEIGHT ASSOCIATED WITH PERINATAL DEATH IN 2020


34.7% OF ALL STILLBIRTHS CLASSIFIED AS SEVERELY SMALL FOR GESTATIONAL AGE




36.2% 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. Maternal age (greater than 40 years) and a high BMI were associated with a higher risk of perinatal mortality. Obese woman had twice the risk compared with women who gave birth during 2020 with a healthy BMI.

## Why do babies die?

**Major congenital anomaly was the most common cause of perinatal death in Ireland in 2020.**

The PMR rate was 3.68 per 1,000 births in 2020, when deaths due to major congenital abnormality were excluded.

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|---|---|---|
| **STILLBIRTH:** | Major congenital anomaly **32.9%** | Placental disease **30.4%** |
| **EARLY NEONATAL DEATHS:** | Major congenital anomaly **58.1%** | Respiratory disorders, most commonly related to prematurity **21.4%** |
| **LATE NEONATAL DEATHS:** | Major congenital anomaly **51.4%** | Infection & Neurological disorders **14.3%** |

## 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 (59.2 %) than in neonatal deaths (37.7%) in 2020. For the vast majority of the perinatal deaths where an autopsy was not performed, an autopsy was offered and presumably declined by parents (82.2% of the cases without autopsy).

It is encouraging to see that a high rate of placental histology examinations continues in 2020 98.3% in stillbirths and in 96.1% of neonatal deaths). As previously mentioned, placental disease was a leading cause of death in 30% of stillbirths. Within the report, placental disease have been classified in line with international recommendations and are presented under the following broad categories: Maternal vascular malperfusion, Fetal vascular malperfusion, Cord pathology, Cord pathology with distal disease, Delayed villous maturation, Chorioamnionitis, Villitis, Fetal Vasculitis and 'Other' placental pathology.

# Message from our public representative

This report on Perinatal Mortality from the NPEC is based on the 2020 data collected and reported on why our babies die from all nineteen maternity units in Ireland. Thankfully no unit perinatal mortality rate (PMR) has been identified as an outlier as defined by NOCA after unit rates were adjusted for major congenital anomaly and in-utreo transfers.

There were 57,114 births reported in Ireland for 2020 with a birthweight of ≥ 500g or a gestational age of ≥ 24 weeks gestation. Of this birth group, sadly there were 357 perinatal deaths that met this criteria, which is based on the legal definition for stillbirth in Ireland. However, I think it only fitting to give special mention to the babies who fall short of these criteria and the impact of their loss to their families. While their deaths are captured in the NPEC report, they have not been recognised by the state and their existence has not been recorded in any meaningful way before now. Thankfully, this is about to change with the forthcoming 'Certificate of Life' legislation being passed by Government. This new legislation is due to the great advocacy and relentless work by baby Stephen's parents, Caroline & Martin Smith. I believe we can all agree this recognition for families affected by the loss of these precious lives is vitality important and long overdue. This will enhance our national bereavement standards and support in Ireland's maternity services for all.

The purpose of this audit is to gather, measure and analyse the data on the incidence, prevalence and causation of why babies die during pregnancy and shortly after birth in Ireland. The aim is to identify any modifiable or contributing factors, to learn from them, so we can then implement preventative strategies where possible to help reduce re-occurrence of such deaths. We can compare our findings and standards against international best practices and look to see what other countries do differently, This is a good opportunity to learn from what has proven to work well internationally, and how we could develop and adapt similar screening policies and care bundles to achieve a similar reduction in perinatal deaths. For example, the positive results from screening policies and care bundles in the UK, New Zealand, Holland, USA and Canada. should be more than enough evidence to support the recommendations made here by the NPEC. These recommendations and those from numerous other investigative processes should be implemented as an urgent priority if we truly want to see a reduction in our perinatal mortality and morbidity rates. Especially now given that our mortality rates are on the rise again since 2018!

Similar to previous NPEC reports, we once again see similar trends on causations of why babies die. Three main factors assigned here are Major Congenital Anomaly (MCA), Placental Disease and respiratory disease in preterm births. Further, Small for Gestational Age (SGA), Multiple births and Maternal factors are associated risk factors for perinatal death.

The invited commentary from Dr Petch and Prof McAuliffe on maternal obesity highlights that Ireland has the second highest obesity rates in the European Union. Maternal obesity is associated with twice the risk of perinatal mortality and maternal morbidity compared with women in the healthy BMI range. The invited authors recommend improved education and an awareness campaign on obesity for women of childbearing age. Maybe starting an awareness campaign in secondary schools would be a good initiative. The authors also recommend that each healthcare professional should make each encounter with women count as an opportunity to address weight, nutrition and lifestyle to optimise her health.

With major congenital anomaly, there is not a lot that can be done to reduce the mortality rate for the majority of these babies sadly as they are most often life limiting conditions. But with the placental disease and small for gestational age cohorts for example, there is the absolute possibility that we could save a number of these precious lives with improved standardised antenatal screening, diagnosis and monitoring with timely interventions and appropriate treatments to hand. Hence the recommendation for '*care bundles*' and '*fetal growth monitoring* and *customised grow charts* and *training* on same is very much warranted' and proven to work by international best practices and audit results available and referenced in this report.

It is stated in a report on *Therapeutic Hypothermia (TH) Cooling of Neonates in Ireland 2019* (a joint NPEC, NWIHP collaboration[1]) that the placenta is

[1]Meaney S, McGinley J, Corcoran P, McKenna P, Filan P, Greene RA, Murphy J on behalf of Neonatal Therapeutic Hypothermia Working Group. Neonatal Therapeutic Hypothermia in Ireland, Annual Report 2019. Cork: National Perinatal Epidemiology Centre, 2021.

deemed to be the 'black box' of a pregnancy by perinatal pathologists. 'Put simply, the placental pathologies take place in the maternal plate, the fetal plate and the cord'. Most clinicians believe that 'pre-existing placental pathology' may compromise a baby's ability to withstand the stresses of labour, and in some cases directly cause harm to the brain and other organs. This is evident in the CTG review on intrapartum monitoring undertaken in the TH Cooling Reports, whereby three quarters of the CTG's were deemed pathological on a retrospective blinded review. This again supports the recommendation for standardisation of CTG monitoring, training and interpretation. We have a new national clinical practice guideline for CTG Monitoring implemented in 2021 and I sincerely hope it is standardised care practice now in all our maternity settings.

It is important to produce accurate timely reports with important learning from perinatal deaths to help effect changes in practice needed to save precious little lives. We need all this valuable information accessible to the NPEC sooner. The importance of the recommendation for *Funding for Protected Time* for staff tasked with the duty of collecting in each unit, has been repeated over a vast number of years. This must now be treated with the utmost priority and respect, if we are truly intent on our duty of care and equality of same for all staff and service users.

A delay in receiving timely coronial post-mortem results is another cause for some of the reporting delays. More significantly, these delays impact greatly on parents, families, their grieving process and the ability to move on from the bereavement. While we can all appreciate that a shortage in perinatal pathologists in Ireland attributed in part to this delay, this thankfully is being actively addressed now by the National Women & Infants Health Programme. However, feedback from families following their own advocacy, has identified as recently as 2022,that this delay was due to the lack of administrative support for a pathologist (leading to a delay in their report being typed). We cannot blame everything on the pandemic! Whilst Covid-19, no doubt has impacted vastly on all services and life in general, these same issues preceded and will continue to do so post pandemic if not actioned and governed appropriately and urgently. Maybe, an alternative would be the setting up of an independent, special perinatal coroner's court with an oversight governance structure in place including patient representation; a possible solution worthy of consideration?

While I do support and can see benefits on learning to be gained from a 'Confidential Review' recommended a few times now in the NPEC annual reports, many will no doubt ask; are we not just duplicating another form of investigation and why can't we get the more detailed information necessary to help ascertain the full clinical picture of events when a perinatal death occurs through additional questions on the NPEC PM Reporting form? What does this say about 'open disclosure' culture in our health services still? What are the obstacles in this regard?

A confidential review though potentially valuable, should never be used to replace other systems of investigation but certainly can run alongside them. For trust, integrity, responsibility, learning, accountability and open disclosure and policy and procedures in any service to be dutifully implemented and maintained, such investigations must remain accessible, independent, and offered to all patients when things go wrong, with suitably trained independent investigators and open disclosure at the helm.

Recent reports from the UK identified harrowing and numerous scandals coming to light from different hospital groups where great levels of distressing harm and loss of life were enabled to continue by non-disclosures cultures. Hopefully here in Ireland 2022, the time for great meaningful change is here, that we are learning and are all still in this together and want to achieve the same results;

***'saving precious lives, open disclosure, transparency and better safer services.'***

**Siobhan Whelan**
Patient representative,
NPEC Perinatal Mortality Group

# 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 finding.
- The establishment of a review 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 standardised review of specific cohorts, such as:
  - unexpected intrapartum related deaths
  - multiple pregnancies
  - term stillbirths and neonatal deaths (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.
  - 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.
- All health care professionals (obstetricians, GPs and midwives) should see every interaction with a woman as an opportunity to address weight, nutrition and lifestyle to optimize her health. This also supports the HSE Programme 'Making Every Contact Count' (MECC). Owner; All Healthcare staff.
- 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.

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

**National Perinatal Epidemiology Centre**
**Department of Obstetrics and Gynaecology,**
**5th Floor, Cork University Maternity Hospital,**
**Wilton, Cork**

**www.ucc.ie/en/npec/**
**npec@ucc.ie**
**+353 (0)21 420 5053**
**Follow us on twitter @NPEC_UCC**

NATIONAL PERINATAL EPIDEMIOLOGY CENTRE

NOCA National Office of Clinical Audit

HSE

UCC University College Cork, Ireland Coláiste na hOllscoile Corcaigh