NATIONAL PERINATAL EPIDEMIOLOGY CENTRE

REFERENCE MANUAL

For completion of

Perinatal Death Notification Forms 2022

If you have any queries regarding the Perinatal Death Notification Form, please contact us at the National Perinatal Epidemiology Centre

Tel: (0)21 420 5042
E-mail: npec@ucc.ie

Please return all completed forms to:

Ms E. Manning, Project Manager Perinatal Mortality Audit
National Perinatal Epidemiology Centre
Department of Obstetrics and Gynaecology
5th Floor
Cork University Maternity Hospital
Wilton
Cork
Queries: +353 (0) 21 4205042

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Reportable perinatal deaths

The National Perinatal Epidemiology Centre (NPEC) kindly requests that units submit completed perinatal death notification forms on the following perinatal deaths:

Stillbirths

All stillbirths when:

(i) the baby was delivered in the reporting maternity unit;

(ii) the reporting unit was the intended place of delivery but the baby was born before arrival;

(iii) the mother had not booked to deliver in any maternity unit but presented to the unit after unattended delivery in the community.

Neonatal deaths

(i) The death of any live born infant delivered in your unit occurring within 28 completed days of birth. This includes babies who were transferred and died in another unit (e.g. tertiary maternity unit, paediatric hospital or at home).

(ii) All neonatal deaths occurring in your unit, regardless of place of delivery.

Please note that the above request will not result in duplication of reporting on neonatal deaths nationally, or an increase of perinatal mortality rates in individual units, but is necessary to ensure complete case ascertainment.

Calculating Perinatal Mortality Rates (PMR) for individual units

Perinatal deaths are included in a maternity unit's PMR if:

(i) the baby was delivered in the maternity unit

(ii) the unit was the intended place of delivery but the baby was born before arrival

The overall PMR is based on the number of stillbirths and neonatal deaths per 1,000 births (live births and stillbirths from 24 weeks gestation or weighing >500g). For consistency with the Irish Healthcare Pricing Office reporting of perinatal statistics, we also report the PMR using the criterion of birthweight >500g.

Neonatal deaths occurring in babies with a birthweight < 500g and delivered before 24 weeks are not included in the PMR. However, the collation of data on these perinatal events by the NPEC provides vital information surrounding adverse pregnancy outcomes in all registered live births.

Definitions

Stillbirth: Baby delivered without signs of life from 24 weeks gestation or with a birthweight ≥500g.[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.

Live birth: Live birth refers to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life - e.g. beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles - whether or not the umbilical cord has been cut or the placenta is attached. Each product of such a birth is considered live born.[2]

Booking: Some data sought by the NPEC relate to the time of booking. Booking in this regard relates to the mother's first antenatal visit at the maternity unit.

Parity: The number of completed pregnancies, whether live birth or stillbirth, of at least 24 weeks gestation or with a birthweight ≥500g. The NPEC refer to parity prior to the pregnancy that resulted in a perinatal loss.

In utero transfer: The care of the mother was transferred, with the fetus in utero, to the care of another maternity unit where the baby delivered.

Genetic analysis: The study of the fetal chromosomes using varying techniques in the antenatal or post natal period. Sampling techniques include: Amniotic fluid analyses, Chorionic Villus Sampling (CVS), Percutaneous umbilical blood sampling (PUBS), Fetal tissue/organ sampling and Extra-fetal tissue analysis, such as placental or umbilical cord biopsy .

Guidance for completion of the notification form

- **Please complete the notification form using the information available on the maternity case notes, the post mortem report and the placental histology report.**
- 'Not known' codes should be used as sparingly as possible.
- Please complete all dates in the format DD/MM/YY; and all times using the 24hr clock e.g. 17.45.

[1] Stillbirths Registration Act, 1994.
[2] World Health Organisation. Available at: http://www.who.int/healthinfo/statistics/indmaternalmortality/en/

Guidance for completion of specific questions within sections

Most questions are self-explanatory but the following notes give guidance to specific questions within sections of the notification form.

Section 1: contains questions on maternal characteristics**.**

Q 1.7, Q 1.8 and Q 1.9: Maternal weight, height and body mass index (BMI) must be completed to enable the NPEC to calculate customised birth weight centiles for infants.

Section 4: contains questions on clinical and hospital details related to the pregnancy.

Q 4.1 Final Estimated Date of Delivery (EDD): please use the final date agreed in the clinical notes based on best estimate EDD (from ultrasound scan or date of last menstrual period based on a 40 week gestation).
Q 4.5 Intended place at delivery at booking: Place in this regard relates to the maternity unit where the mother intended to deliver at her first antenatal visit.
Q 4.7 (b) Gestation at time of in-utero transfer: This refers to the gestation of the pregnancy at the time when the hospital where the delivery took place, received care of the mother.

Section 6:

Q 6.6: 'Was this a termination of pregnancy?'
Termination of Pregnancy (TOP) refers to all cases where the pregnancy is medically ended, with the expected outcome of fetal or early neonatal death, in either of the following events:
(a) In the interest of the maternal health
(b) Fatal fetal malformation

Please record the indication for TOP in **Section 12 Q 12.1.**

Q 6.7: 'Was a local hospital review of this case undertaken?'
Hospital review includes in depth case review, review by risk management and clinical case presentation at multidisciplinary meetings.

Section 8: refers to stillbirths only

Q 8.1 Refers to the date when a diagnosis of perinatal death was made.
Q 8.2 Was the baby alive at onset of care in labour? Responses to this question identifies whether the death of the baby occurred during labour under the care of a health professional.

Section 9: refers to neonatal deaths only.

Q 9.1 Was spontaneous respiratory activity absent or ineffective at 5 minutes? If a baby is receiving any artificial ventilation at 5 minutes, the assumption is absent/ineffective activity: a 0 Apgar score indicates absent activity.
Q 9.3 Was the baby offered active resuscitation in the delivery room? Active resuscitation includes BMV, PPV, intubation, cardiac massage.

Q 9.7 Place of neonatal death. This question refers to where the baby actually died, e.g. 'ICU, 'at home' or 'in transit'. Babies are deemed to have died 'at home' if there are no signs of life documented in the home even if resuscitation is attempted. A baby is deemed to have died 'in transit' if signs of life are documented prior to transfer but the baby was either declared dead on arrival to the hospital or showed no subsequent signs of life in the hospital, despite attempted resuscitation..

Sections 11, 12 and 13: Cause of Death and Associated Factors, Stillbirths and Neonatal Deaths

The main cause of death and conditions/ events associated with the perinatal death are identified in sections 11, 12 and 13.

- The post-mortem and or placental histology report should be referred to when completing sections 11, 12 and 13. In the absence of a post-mortem and / or placental histology report, please refer to the death certificate.
- For completion of sections 11, 12 and 13 (cause of death and associated factors), please refer to Table 1 and Table 2 for guidance on definitions and associated subcategories.
- For completion of Question 11.1.8 'Specific Placental Conditions', please refer to Table 3.

Cause of death, Stillbirths:

Please complete Section 11 and 12.

Section 11: Please **TICK ALL** the maternal or fetal conditions that were present during pregnancy or were associated with the death. Table 1 (page 8) outlines definitions of terms.

Q 11.1.8 Specific Placental Conditions. Guidance notes on reporting placental histology results are available in Table 3 (page 10). An alternative to completing this question is to submit an anonymised copy of the placental histology report to the NPEC.

Section 12: Q 12.1. Please specify the condition, indicated in Section 11, that was the MAIN condition or sentinel event causing or associated with the death. "Non-MAIN" conditions are best described as the "Other clinically relevant maternal or fetal conditions / factors that were associated with but not necessarily causing the death".

Cause of death, Neonatal Deaths:

Please complete sections 11, 12 and 13.

Please note that completion of all sections is important and not a duplication of data points.

- Section 11 and 12 allows for classification of maternal and fetal factors associated with the death.
- Section 13 allows for classification of 'specific neonatal conditions' associated with the death.

Section 11: Please TICK ALL the maternal or fetal conditions that were present during pregnancy or were associated with the death. Table 1 (page 8) outlines definitions of terms.

Q 11.1.8: Specific Placental Conditions

- Guidance notes on reporting placental histology results are available in Table 3 (page 10). An alternative to completing this question is to submit an anonymised copy of the placental histology report to the NPEC.

Section 12: **Q 12.1.**

Please specify the condition, indicated in Section 11, that was the MAIN condition or sentinel event causing or associated with the death. "Non-MAIN" conditions are best described as the "Other clinically relevant maternal or fetal conditions / factors that were associated with but not necessarily causing the death".

Section 13. Q 13.1.

Please TICK ALL the neonatal conditions causing and associated with the death.

Q 13.2. Which condition, indicated in Section 13.1 as being present, was the MAIN condition causing or associated with the death. "Non-MAIN" conditions are best described as the "Other clinically relevant neonatal conditions / factors that were associated with but not necessarily causing the death"

SECTION 11: STILLBIRTHS AND NEONATAL DEATHS

Table 1 Definitions and associated subcategories in Section 11 that will help you choose the relevant maternal and fetal conditions causing and associated with perinatal death.

DEFINITION OF TERMS	Subcategory
MAJOR CONGENITAL ANOMALY Any genetic or structural defect **arising at conception or during embryogenesis** incompatible with life or potentially treatable but causing death	Central nervous system Cardiovascular system Respiratory system Gastro-intestinal system Musculo-skeletal anomalies Multiple anomalies Chromosomal disorders Metabolic diseases Urinary tract Other
HYPERTENSIVE DISORDERS OF PREGNANCY	Pregnancy induced hypertension Pre-eclampsia HELLP syndrome Eclampsia
ANTEPARTUM OR INTRAPARTUM HAEMORRHAGE After 20 w gestation, whether revealed or not. If associated with PET, APH will be a secondary diagnosis. Ignore minor degrees of haemorrhage (e.g. 'shows', cervical polyps etc). Recurrent bleeding of uncertain origin followed by preterm labour should not be ignored.	Praevia Abruption Uncertain
MECHANICAL. Any death attributed to uterine rupture, deaths from birth trauma or intrapartum asphyxia associated with problems in labour such as cord compression, malpresentation, shoulder dystocia etc. Antepartum deaths associated with cord entanglement in the absence of strong circumstantial evidence that cord compression caused death should be classified as having no associated factor.	**Cord Compression** Prolapsecord Cord around neck Other cord entanglement or knot **Uterine Rupture** Before labour During labour **Mal-presentation** Breech / Transverse Face / Compound Other **Shoulder dystocia**
MATERNAL DISORDER. Specify hypertensive disease present before pregnancy or any other maternal disease or condition sufficient to jeopardise the baby such as diabetes, cardiac disease etc. Infection is classified separately.	Pre-existing hypertensive disease Diabetes Other endocrine conditions Thrombophilias Obstetric cholestasis Drug misuse Uterine anomalies Connective tissue disorders / Other
INFECTION. Confirmed by microbiology / placental histology. Specify maternal infections sufficient to have compromised the baby which may be associated with congenital infection of the baby. Trans-placental transmission may have occurred such as CMV, toxoplasmosis etc. Specify only those ascending infections that are a significant factor in death. Chorioamnionitis sufficient to cause preterm birth may be specified for some neonates but evidence of fetal infection may be required as an explanation of stillbirth.	**Maternal infection** Bacterial / Viral diseases Syphilis /Group B Streptoccus Protozoal Other **Ascending infection** Chorioamnionitis Other

SPECIFIC FETAL CONDTIONS. Document only those specific conditions **arising in the fetal period.**	Twin-twin transfusion Feto-maternal haemorrhage Non-immune hydrops Iso-immunisation Other
SPECIFIC PLACENTAL CONDITIONS. Specific placental conditions sufficient to cause death or be associated with fetal compromise such as IUGR. Cord problems associated with compression will normally be classified under 'Mechanical'. **Please refer to guidance notes prior to completing this section (Page 10). Alternatively, an anonymised placental histology report can be attached to the Perinatal Mortality Notification form.**	Chorioamnionitis Fetal vasculitis Maternal vascular malperfusion Fetal vascular malperfusion Cord pathology Delayed Villous Maturation defect Villitis Other
INTRA-UTERINE GROWTH RESTRICTION DIAGNOSIS MADE. IUGR may be suspected antenatally by abdominal circumference (AC) less than the centile threshold used to define IUGR locally, or decreased AC growth velocity, +/- oligohydramnios.	Suspected antenatally Observed at delivery Observed at post mortem
ASSOCIATED OBSTETRIC FACTORS. Factors recorded as Other Associated Obstetric Factors will be important clinical or pathological features of the pregnancy or baby but may not be an explanation of the death; they will often be secondary to other maternal or fetal conditions. Birth trauma and/or Intrapartum asphyxia should normally be classified primarily by the underlying cause (e.g Mechanical). Birth Trauma and/or other antenatal/intra-partum factors can be recorded here either as a secondary factor or when there is no underlying explanation.	**Birth Trauma** Intracranial haemorrhage Birth injury to scalp Fracture Other **Intrapartum fetal blood sample <7.25** **Other** Polyhydramnios Oligohydramnios Premature rupture of membranes Spontaneous premature labour Other
NO ANTECEDENT OR ASSOCIATED OBSTETRIC FACTORS. Deaths with no explanation or significant associated factor.	
UNCLASSIFIED. Cases where little or nothing is known about pregnancy or delivery and which cannot be fitted into any of the above categories**.** **Use as sparingly as possible**.	

PLACENTAL PATHOLOGY

Table 2 Guidance notes for completion of question 11.1.8: Placental pathology

CATEGORY OF PLACENTAL PATHOLOGY	GUIDANCE NOTES
NO ABNORMAL HISTOLOGY REPORTED	No abnormal pathology reported.
CHORIOAMNIONITIS	Please specify if the finding of chorioamnionitis was reported as mild, moderate or severe.
FETAL VASCULITIS	Please specify if the finding of fetal vasculitis was arterial, venous or in both vessels.
MATERNAL VASCULAR MALPERFUSION (UTEROPLACENTAL INSUFFICIENCY)	Refers to the spectrum of findings related to shallow implantation of the placenta, often found in conjunction with PET and IUGR. Please specify the conditions associated with this finding: **Distal villous hypoplasia** is an early/severe form of maternal vascular malperfusion and is often accompanied by absent or reduced end-diastolic flow. This usually occurs at less than 32 weeks gestation. **Accelerated villous maturation, ischaemic villous crowding and placental infarction** are other findings associated with maternal vascular malperfusion. **These conditions are listed in increasing order of severity in question 11.1.8, please tick the most severe finding**. **Retroplacental haemorrhage** frequently occurs with a background of maternal vascular malperfusion, but may occur in isolation with no other identified placental disease. **Placental hypoplasia:** the placenta may be small in cases of maternal vascular malperfusion. While no standards for Ireland currently exist, placental weight <350g at term is taken to be the 10th centile and warrants use of the term hypoplasia. The finding of a small histologically normal placenta should be reported here.
FETAL VASCULAR MALPERFUSION	Refers to thrombosis or the effect thereof in the fetal circulation. It may be difficult to distinguish arterial from venous vessels, and pathology may be present in both. The findings of fetal vascular malperfusion are listed in order of severity: patchy hypofusion, scattered avascular villi and fetal thrombotic vasculopathy. Please tick the most severe finding
CORD PATHOLOGY	Cord pathology may exist by itself, or may be accompanied by evidence of other disease. Abnormal cord insertion (marginal/velamentous) may be seen in cases of shallow implantation. **Cord hypercoiling** A diagnosis of cord hypercoiling should be supported by measurement of an umbilical coiling index (number of coils/length of the cord in cm) of 0.3 or more. Cord stricture should be sought in these cases. Where delayed placental maturation is accompanied by a hypercoiled cord, it suggests that the latter may have caused the former. Other effects of impaired fetal flow include multiple non-occlusive thrombi in chorionic plate or fetal stem vessels.
DELAYED VILLOUS MATURATION DEFECT	Villous maturation defect is a term used synonymously with distal villous immaturity.
VILLITIS	The term is used to mean villitis of unknown aetiology, and assumes that the reporting pathologist has excluded infection where appropriate.
OTHER	Please specify any other pathological findings reported by the pathologist e.g. maternal floor infarction.

Placentas may have more than one pathologic finding.
If placental disease was the main condition associated with the perinatal death, please specify in Section 12: Q 12.1, which placental pathological finding was most likely to have caused the pregnancy loss.

Please note that an alternative to completing question 11.1.8 is to submit an anonymised copy of the placental histology report to the NPEC.

SECTION 13: NEONATAL DEATH ONLY

Table 3 Definitions and associated subcategories in Section 13 that will help you choose the relevant neonatal conditions causing and associated with death

DEFINITION OF TERMS	Subcategory
MAJOR CONGENITAL ANOMALY Any genetic or structural defect arising at **conception or during embryogenesis** incompatible with life or potentially treatable but causing death.	Central nervous system Cardiovascular system Respiratory system Gastro-intestinal system Musculo-skeletal system Multiple anomalies Chromosomal disorders Metabolic disorders Urinary tract Other
PRE-VIABLE Babies (less than 22 weeks) who are non-viable at birth because of gestation but who show signs of life.	
RESPIRATORY DISORDERS Severe pulmonary immaturity will encompass those babies where structural lung immaturity is so gross as to mean ventilatory support is unsustainable at the outset. Surfactant Deficient Lung Disease may include babies with clinical or pathological evidence of hyaline membrane disease. Please note that neonatal deaths previously attributed to prematurity, would most often be captured under the subcategory of 'severe pulmonary immaturity'.	Severe pulmonary immaturity Surfactant deficiency lung disease Pulmonary hypoplasia Meconium aspiration syndrome Primary persistent pulmonary hypertension Chronic lung disease / BPD Other (includes pulmonary haemorrhage)
GASTRO-INTESTINAL DISEASE Many babies with NEC will have associated sepsis which may be given as a secondary cause.	Necrotising enterocolitis (NEC) Other
NEUROLOGICAL DISORDER HIE includes those babies with severe hypoxic-ischaemic brain injury before birth. If possible, please specify if HIE was primarily of intrapartum or antepartum origin. Specify periventricular leukomalacia only if this is a significant factor in the infant death. Birth Trauma will usually be classified here.	Hypoxic-ischaemic encephalopathy (HIE) Intraventricular/Periventricular haemorrhage Other
INFECTION Where possible specify the location of infection and whether due to bacteria, virus, fungus or other specific organism. If infection was the main cause of death please specify whether infection is congenital (i.e. acquired ante or intrapartum acquired) or neonatal in origin.	Generalised (sepsis) Pneumonia Meningitis Other
INJURY / TRAUMA Post natal trauma only including iatrogenic injury. 'Birth Trauma' will usually be classified under neurological disorder e.g. HIE; the obstetric classification identifying the timing of the injury.	
OTHER SPECIFIC CAUSES Death due to **specific fetal and neonatal conditions** such as isoimmunisation or unexplained hydrops. Neonatal conditions will include aspiration, unexplained pulmonary haemorrhage.	Malignancies/Tumours Specific conditions

SUDDEN UNEXPECTED DEATHS. SIDS should conform to the accepted definition. Unascertained are those unexpected deaths that are not explained despite a full investigation including autopsy, but do not conform to the accepted definition of SIDS.	Sudden Infant Death Syndrome (SIDS) Infant deaths – cause unascertained
UNCLASSIFIED. Cases where little or nothing is known about the pregnancy or delivery and which cannot be fitted into any of the above categories**.** **Please use this category as sparingly as possible.**	