THAMES VALLEY & WESSEX NEONATAL OPERATIONAL DELIVERY NETWORK

Neonatal Death Guidance

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Related documents / References	Child Death Review Statutory Guidance HM Government October 2017 Sudden unexpected death in infancy and childhood: Multiagency guidelines for care and investigation. RCPCH 2nd Edition 2016
Implications of race, equality & other diversity duties for this document	This guideline must be implemented fairly and without prejudice whether on the grounds of race, gender, sexual orientation, or religion.

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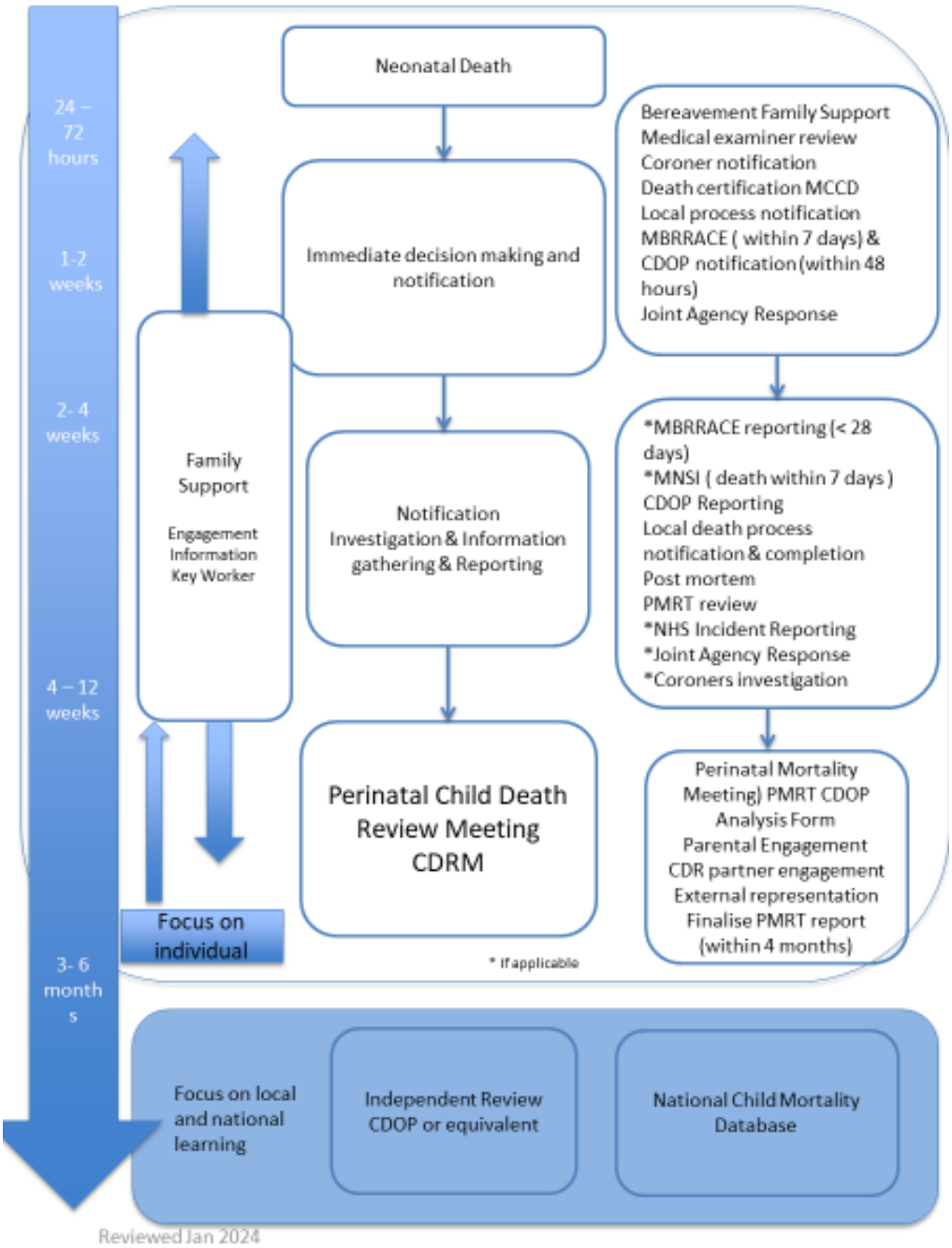
Neonatal Death Guidance

Contents

1.0 Executive Summary

For parents, the death of their baby is a devastating experience, and bereaved parents and families need to be supported with empathy and compassion. There are several statutory reporting processes and reviews which require sensitivity and understanding of the various requirements to ensure that parents and families are supported through their bereavement journey. It is important to ensure that their perspectives are considered in the review of their baby's death and that reports are shared with them. It is essential that the clinical team understand the care of a baby after death including bereavement care, the various child death reporting and review processes to support bereaved families and ensure completion of statutory requirements. Child Death Review Statutory and Operational Guidance (England) This guidance provides detailed information on the care of a baby after death and the notification and review processes that should be followed. For any patient safety processes, the governance for Patient Safety in Maternity and Neonatal Services provides clarity of these including the reporting requirements and timescales.

Overview Child Death Review: Neonatal Death Flow Chart



2.0 Scope and purpose of guidance

This guidance applies to all deaths on the neonatal units, any live born infant in the delivery room who dies prior to admission to the neonatal unit and all deaths of a neonate (within 28 days of birth).

For neonates that die within A&E and PICU this guidance outlines specific reporting for neonatal deaths (less than 28 days of birth), the Child Health bereavement guideline provides information for professionals in Child Health and specific information on Rapid Response processes.

There are particular reporting sections within this guidance that are applicable to non-viable live born infants including live born terminations of pregnancy.

This guidance can be used for neonatal deaths following transfer to a local hospice, home for palliative care or withdrawal of intensive care in the child's local hospital.

The aim of this guidance is to provide guidance to the clinical team following the death of a neonate and outlines the various reporting processes in these situations.

The guidance applies to all neonates who are born in neonatal units and maternity units covered by Thames Valley & Wessex Neonatal ODN. This includes the following hospitals:

Thames Valley		
Trust	Hospital	Designation
Oxford University Hospitals NHS Foundation Trust	- John Radcliffe Hospital, Oxford	NICU
Buckinghamshire Healthcare NHS Trust	- Stoke Mandeville Hospital, Aylesbury	LNU
Frimley Health NHS Foundation Trust	- Wexham Park Hospital, Slough	LNU
Milton Keynes University Hospital NHS Foundation Trust	- Milton Keynes General Hospital	LNU
Royal Berkshire NHS Foundation Trust	- Reading	LNU

Wessex		
Trust	Hospital	Designation
University Hospital Southampton NHS Foundation Trust	- Princess Anne Hospital	NICU
Portsmouth Hospitals University NHS Trust	- Queen Alexandra Hospital	NICU
Dorset County Hospital NHS Foundation Trust	- Dorset County Hospital, Dorchester	SCU
Hampshire Hospitals NHS Foundation Trust	- Basingstoke and North Hampshire Hospital	SCU (Temporary designation)
Hampshire Hospitals NHS Foundation Trust	- Royal Hampshire County Hospital, Winchester	SCU (Temporary designation)
Isle of Wight NHS Trust	- St Mary's Hospital	SCU
University Hospitals Dorset NHS Foundation Trust	- Poole Hospital	LNU
Salisbury NHS Foundation Trust	- Salisbury District Hospital	LNU
University Hospitals Sussex NHS Foundation Trust	- St Richard's Hospital, Chichester	SCU

3.0 Definitions

MBRRACE definitions:

Neonatal Death ND: Death of a live born baby within 28 days

Early Neonatal Death END: Death of a live born baby within 7 days of birth

Late Neonatal Death LND: Death of a live born baby after 7 days of birth and before 28 days

Perinatal death: A still birth or early neonatal death

Extended perinatal death: A still birth or neonatal death

Late fetal loss: a baby born between 22+0 and 23 +6 weeks gestation showing no signs of life at birth, or if unknown gestation > 400gms

Still birth: Born from 24 +0 with no signs of life or if unknown gestation > 400gms

MBRRACE definition live born baby: born at or greater than 20 weeks' gestation or birth weight 400 gms with signs of life

Abbreviations

CDRM	Child Death Review Meeting
CDOP	Child Death Overview Panel
CDR	Child Death Review
CDAD	Child Death & Deterioration Lead
EPR	Electronic patient record
NCMD	National Child Mortality Database
MBRRACE	Mothers and Babies: Reducing Risk through audits and Confidential enquiries across the UK
PMRT	Perinatal Mortality Review Tool
IM	Internal medical examiner
MES	Medical examiner service
MCCD	Medical Certificate of Cause of Death
MES	Medical examiner service
MEO	Medical examiner officer
HSSIB	Health Services Safety Investigation Body.
MNSI	Maternity & Neonatal Safety Investigations
SUDI /C	Sudden and Unexpected Death in Infancy and Childhood

4.0 Care before death

4.1 Neonatal death documentation

Commence the Neonatal Death paperwork applicable to your local setting and follow local polices and procedure for completion and dissemination.

These can be continued and should be accompany the baby when transferred to a local hospice for palliative care or post death, in line with local guidance.

4.2 Spiritual and religious support

Wherever it is possible, before death it is important to ascertain if the family have any specific thoughts about what religious or spiritual involvement they would like for their baby. All families should be asked about their wishes, individual practices, and requirements. An overview of the most common faith practices will be found on your local Chaplaincy guidance and Trust Web site. This will outline specific information for the main faiths encountered within your hospital setting.

The chaplaincy teams will offer a range of spiritual and religious support to all patients, families, and staff as appropriate. These services are available to everyone, whether or not they have a specific religious affiliation. A multi-faith team is available for this support. Whilst not every faith group is represented, contacts with many faith groups can be provided. Sometimes those contacts can come in to support a family, though this is by negotiation and cannot be guaranteed. A family may choose to invite a religious leader who is already known to them if time allows.

The chaplaincy services will operate a 24-hour Trust-wide on-call service for any urgent needs or referrals. Please refer to your local guidance on this. This will be found on your Trust website.

The death of a baby can inevitably raise bigger questions about life, death, meaning and hope and the chaplaincy team can offer support before and after death. The multi-faith team can provide a safe and supportive space to express and address some of these questions where appropriate. They recognize that each family's needs will be different and work with families at their pace. This support can be as simple as being present without any agenda, or it may involve a specific religious ritual or prayers.

The Chaplaincy and Spiritual Care Teams are also available to any staff member/s that are affected by the death of a child.

4.3 Hospital Baptism

If the death of a baby is anticipated, parents may request a baptism, blessing, or naming ceremony or staff may wish to suggest this to be considered. The appropriate duty chaplain or priest should be contacted via hospital switchboard Please use local Trust policy for this.

If it is not possible for one of the hospital chaplains or a priest to attend the ward in time to baptise the baby, it is possible for a member of staff to baptise the child using the emergency baptism procedure. However, the baby should only be baptised in this way if he/she is not likely to live long enough for a chaplain or priest to attend the ward.

When a baby is baptised by a member of staff on the ward the chaplain will help them in completing the hospital baptism register and a certificate, after the event. The chaplain will also offer pastoral care.

It is not usual for a baby to be baptised after death; however, a blessing can be considered after death and may be of pastoral benefit to the family. The chaplains may choose to exercise some flexibility in offering baptism after death and will certainly offer to pray with the family and bless the baby's body.

The Chaplaincy and Spiritual Care Service will offer the family suitable rituals appropriate to their faith and/or philosophy in a sensitive consultation with them at the time.

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4.4 Organ donation

The possibility of organ donation may be appropriate in some clinical situations and should always be considered by the healthcare professional caring for the child prior to death if appropriate. Currently this occurs infrequently for neonatal death so specialist advice should always be sought prior to presenting families with donation options. These discussions can begin antenatally in some circumstances.

There are currently no lower limits set on age or weight. Referral has been accepted from a 36-week gestation baby and organs have been transplanted from a 1.9 kg donor. Heart valves can be donated from 32 weeks' gestation and a lower limit of 2.5 kg.

Organ donation can be considered in the following situations. If these criteria are met the nursing or medical team should contact the organ donation team as soon as possible.

- There is a plan to withdraw life sustaining treatment and death is thought to be imminent.
- Brain Stem Death is suspected.

In a neonate between 37 weeks corrected gestational age and two months, criteria for brain stem testing must be met in accordance with '[The diagnosis of death by neurological criteria in infants less than two months old (RCPCH 2015)]'. Below this age, a child may not be brain stem death tested.

Donation of solid organs can occur under these circumstances. Tissue donation can potentially occur following any death.

In either of these situations, if there is a possibility that an infant may be eligible for organ donation, particularly if families have expressed an interest in donation, clinicians should contact and discuss with the local Specialist Organ donation team prior to withdrawal of life-sustaining treatment.

The healthcare professional that raises the subject of organ donation with the family should ideally be the Specialist Nurse Organ Donation, or have an existing relationship with the family, have experience in communicating with parents at the time of their child's death, have knowledge of organ and tissue donation and believe that donation may be a positive option for some families.

An approach to a family regarding donation opportunity should be carried out following an agreed plan and in conjunction with specialists in this area ensuring that families are given the full information they require to make an informed choice and that they are fully supported in their decision.

The Organ Donation Team can be contacted for advice and discussion. The team operates.
a 24 hour on call service and will provide advice to the clinical team and will come and discuss options with families where appropriate.

The contact details are as follows:
South Central **Organ Donation Services Team:**
Refer by regional pager 03000 20 30 40
(no response within 20 minutes then contact NHSBT Hub 01179 757580)

Children who die at home can still potentially donate tissues. Advice should be sought from the Specialist Nurse in Organ donation from either of the numbers listed above and discussed with the palliative care team prior to discussion with the family.

Further information on organ donation can be found South East Central Organ Donation Team.

5.0 Care after death

5.1 Confirmation of death and Death Certification

In some situations when a death may be anticipated i.e. planned withdrawal of intensive care, non-viable or lethal condition preparation for death processes can be considered prior to death.

In the unlikely event that a baby's parents are not present they must be informed immediately of the death. It is preferable to have a member of staff who the family know, present to communicate the news.

A key worker should be identified to link with and provide support to the families. Information on: When a baby dies should be provided to the family (Appendix F). The key worker should act as a single point of contact in relation to the child death review process. This would usually be an identified member/s of staff on the Neonatal Unit and a member of the Maternity Bereavement Team for deaths on labour ward.

5.2 Documentation

The date and time of the baby's death and the cause of death should be recorded in the patient record. This should be recorded in the relevant sections on the electronic patient record or paper notes and on the neonatal Badgernet discharge /death summary (or local equivalent).

It is important to ensure that the death is recorded on the electronic patient administration system CaMIS and all documentation completed, as part of the child death process should be uploaded to the electronic patient record Edocs/ or local system, on completion (or local equivalent).

If a baby dies following discharge to a hospice or at home, the death should be entered on the electronic system CaMIS or local system. This would be completed by the ward clerk or ward administrator.
The following professionals need to be notified that the baby has died as soon as possible.

- Appropriate clinical staff (Named Consultant Neonatologist, subspecialty clinicians, Obstetrician)
- General Practitioner
- Referring hospital Consultant (local hospital Paediatrician / Obstetrician)
- Family Support Team
- Mortuary staff
- Email NeonatalDeathNotifications specific for your Trust.

Notify when practical the following;

- Neonatal staff with offer of psychological support
- Religious representative if requested by the family
- Subspecialist teams/ Clinical Nurse Specialists where appropriate
- Health visitor
- Community nurse where appropriate
- Midwifery community coordinator if the child was a newborn or infant under 28 days old
- Social Care Team (if applicable)
- Hospital accommodation if appropriate

A discharge death summary should be completed as soon as possible after death and reviewed by the responsible named Consultant Neonatologist / Paediatrician or Consultant caring for the child at the time of the death. This should include the date and time of death and cause of death as written on the Medical Certificate of Cause of Death (MCCD). It should also include information about Coroner discussion/notification and parental decision and consent for a post-mortem.

For neonatal deaths on Labour ward when the baby has not been admitted to the neonatal unit, the neonatal outcome information should be completed on the maternity Badgernet EPR or local system discharge summary recording the outcome of a neonatal death. Labour ward neonatal deaths of babies who received neonatal care should also be recorded as a labour ward death on the neonatal Badgernet system/local system.

5.3 Post-mortem

Counselling should be provided to bereaved parents to help them to make informed decisions about a post-mortem. All parents should be offered a post-mortem regardless of the clinician's opinion of indication or need.

Discussions about post-mortem examination can begin prior to a baby's death if felt appropriate and consent may be sought at this stage, particularly if the family plan to leave hospital. A senior member of staff should sensitively discuss post-mortem examination so that families can make an informed choice.

A post-mortem may confirm the diagnosis and provide further information which may help parents to come to terms with their loss and may provide additional information important for future pregnancies.

A post-mortem requires informed consent, and parents should be provided with a SANDS parent post-mortem information leaflet: Understanding why your baby died. Parental consent is not required if a Coroners post-mortem is being undertaken.

The results of a post-mortem may take up to12 weeks and can take longer for specific examinations and if specific neuro pathological examination is required there may be some delay in a baby being ready for burial or cremation.

Where religious faith dictates the need for early burial or cremation it may be possible to return the body without nervous tissue which can be buried or cremated at a later date. It is important to discuss individual situations and expectations with the Pathologist.

If a post-mortem is being undertaken a Perinatal / Paediatric consent form & Perinatal/Paediatric Organ Retention form and Perinatal Pathology PM Request form should be completed as per local policies and procedures. Examples of these can be found in Appendix A. Post-mortem consent should be obtained by a trained healthcare professional.

For deaths on labour ward, the information on post-mortem is available from your local Bereavement Midwives

The results of a post-mortem should be provided to parents with explanation from an appropriate clinician, this would usually be the named Consultant responsible for the baby's care.

Further information on a Coroner's post-mortem is available. A guide to Coroner services for bereaved people The coroner office will provide parents with the result of a coroner's post-mortem. Permission from the Coroner's office is required to obtain a copy of the report to meet with the family to discuss the findings. This may not be provided until a Coroner's Inquest has been completed if an inquest is undertaken. This will need to be discussed with your local Coroner Office and a pathway established.

Consent needs to be obtained for all post-mortem samples using a PM consent form even if a complete PM is not being undertaken to comply with HTA regulations. This includes all samples including blood tests / samples for genetic testing.

https://www.hta.gov.uk/guidance-professionals/guidance-sector/post-mortem/consent-post-mortem-examination-and-tissue

Sands Guide for Sands Guide of consent takers : Seeking consent/authorisation for the post-mortem examination of a baby Post-Mortem consent takers. Appendix A consent forms.

5.4 Personal & Practical aspects following the death of a child/neonate.

Further information on the following important practical aspects following the death of a child / neonate is outlined in the Neonatal Palliative care guidance (Network Guideline) and Nursing Bereavement Guidance Care of a baby who has died and Guidance for parents taking their deceased baby home. This includes the following information on:

- Personal practical care after death: keepsakes, cold cots
- Offering choices and creating memories
- Special considerations for infection control
- Moving the child to the mortuary
- Moving the child: Home, hospice or to the funeral directors

5.5 Staff support

Support for staff affected by the death of a child should be provided and be available as required. There are various support services available within the neonatal services and the Trusts available to individuals and teams affected by the death of a child. These may include debrief support and access to a NNU Psychologist/ Counsellor, Trust Chaplaincy Service & TRiM Team**.**

Debrief sessions should be arranged if needed for all staff involved in the care of a baby who dies for those staff wishing to attend. Please locate your local service support and Trust guidance for debrief sessions and who facilitates them.

Support for staff should be considered again at key points likely to cause distress such as Coroner's hearings, interviews with outside agencies and following feedback of reports.

6.0 Decision Making and Death Notification

6.1 Joint Agency Response JAR

Most neonatal deaths that occur on the neonatal unit and labour ward are explained and expected and would not meet criteria for a Joint Agency Response JAR.
If a death meets the criteria for a JAR (Sudden and Unexpected Death in Infancy and Childhood: multiagency guidelines for care and investigation (2016).

This may be applicable to neonatal deaths (within 28 days) that are unexpected and unexplained i.e. neonates brought into A&E and later die on PICU /Child Health.

A Joint Agency Response should be triggered if a neonatal death:

- Is or could be due to external causes
- Is sudden and there is no immediately apparent cause (including SUDI/C)
- Occurs in custody, or where the child was detained under the Mental Health Act
- Where the initial circumstances raise any suspicions that the death may not have been natural
- Stillbirth where no healthcare professional was in attendance.

Further information on Joint Agency response processes within your Trust should be available.

Further information on the Rapid response procedure for deaths within Hampshire and the Isle of Wight are available on the Hampshire Safeguarding Children website. This includes information on samples to be collected following sudden unexpected deaths in infants.
https://hipsprocedures.org.uk/skyyth/safeguarding-partnerships-and-organisational-responsibilities/child-death-review-process/#s3839

Other counties will have local Rapid Repose Procedures in place. Please locate these and ensure staff on neonatal units are aware of them and how to access them.

A death in hospital within W&N Newborn would not normally trigger a JAR or Rapid Response process and should be discussed with the Senior Clinician and W&N Risk Management team.

6.2 Child Death Notification & Reporting

CDOP notification reporting has moved to the single notification portal via the MBRRACE system for babies who die up to the first 28 days of life. Cascade Integrated System

All other reporting for CDOP on the details of the baby (i.e. formerly From's B, D, and others relevant to the condition of the baby) are completed via the usual local CDOP e portal / reporting routes. The CDOP should contact the clinician for these.

Neonatal deaths that cannot be reported through this single notification system should be notified to ecdop via electronic submission using the HIPS ecdop portal or relevant CDOP portal for your Trust.

https://www.ecdop.co.uk/HIPS/Live/public

Completion of these forms is usually by the senior medical clinician responsible for baby's care at the time of death.

Notifications should be completed within (MBRRACE notification within 7 days completed within 1 month, PMRT started within 2 months, completed with 4 months, CDOP within 48hours).

The Child Death notification either via the single notification portal (via MBRRACE) or the via ecdop https://www.ecdop.co.uk/HIPS/Live/public and completion of electronic reporting/ Form B for neonatal labour ward deaths is usually the responsibility of the midwifery, obstetric teams. In cases where the neonatal team have been involved in the management or care of the baby born alive i.e. extreme prematurity or planned palliative care, notification and completion responsibility should be agreed by the clinical teams involved.

Child death review (CDOP notification, reporting and review) is not required for stillbirths (baby with no signs of life after 24 weeks) or late fetal losses (baby with no signs of life less than 24 weeks) where there are no signs of life at birth and live birth following planned termination of pregnancy.

6.3 Medical Certificate of Cause of Death MCCD

All deaths should be registered within 5 working days of the Registrar receiving the agreed MCCD. The cause of death for most children who die is understood and the MCCD should ideally be completed by the doctor who attends the child at the end of their life 'attending doctor' but may now be completed by any medical practitioner who has met the child in its lifetime. The attending doctor by completing the MCCD is the certifying doctor. This will enable the death to be registered. For complex neonatal deaths, the wording of MCDD should always be agreed with a Consultant and may be discussed within the team and need to be agreed by subspecialists involved in the care of the patient.

There are two types of MCCD both of which can apply to deaths on the neonatal unit and within the Trust.

- Neonatal death certificate deaths up to 28 days of life
- Standard certificate all deaths beyond 28 days

If a MCCD cannot be issued, i.e. cause of death is not known, the attending doctor should refer the case to the Coroner. If there are any doubts as to whether a case should be referred to the Coroner, the attending doctor should discuss with senior colleagues/ medical examiner and contact the Coroner's office to discuss the case. See criteria for Coroner referral.

All deaths should be discussed with the Internal Medical examiner by contacting the medical examiner service MES for independent scrutiny (Statutory requirement September 2024) National Medical Examiner Service NHS England prior to the MCCD being issued for registration of the death including deaths being reported to HM Coroner.

A proposed MCCD is discussed with the medical examiner service and completed by the attending doctor and signed by both attending medical practitioner and Medical Examiner before the Registrar can register the death. The Registrar receives confirmation that medical examiner review has occurred from the medical examiner service by email before the death can be registered.

The MCCD once finalised should be scanned and emailed to the registrar and Medical Examiner service. The MCCD is no longer given to the parents or family however the information on the MCCD should always be shared and explained to the parents by the clinical team. All parents should be given information on the registration of their child's death.

6.4 Internal Medical Examiner Review

Review of all deaths by the medical examiner service prior to registration of the death is a statutory requirement. The case should be discussed with the internal medical examiner prior to discussion with the coroner (if indicated) and prior to final completion of the medical death certificate. Local Arrangement for referral and discussion with the local ME should be followed. Please see local policies and procedures regarding this.

Internal medical examiner review can take place prior to the death of the child, pre-emptive review in cases when the child is at the end of life or expected to die and should take place prior to transfer to a hospice or home for end-of-life care. (See local procedure regarding this process)

On completion of the medical death certificate by the senior clinical team and medical examiner service the medical examiner service will inform the Registrar to enable completion of the death registration.

The completed MCCD should be scanned and emailed to the Medical Examiner team and the Registry office to enable the family to enable them to register the death of their baby within 5 working days of the Registrar receiving the MCCD. The Registry Office will contact the family regarding registration, once the MCCD have been received by them. (See local policy and procedures regarding this)

National Medical Examiners Good Practise Series No 6 : Child Death

6.5 MBRRACE PMRT Notification reporting

All neonatal deaths (within 28 days of life) of live born infants should have an MBRRACE notification (within seven days) and surveillance completed (within 1 month) via the online MBRRACE reporting system.
It is the responsibility of the organisation where the baby died to make the notification of the death and assign the case to the local Trust of the baby's birth for completion of maternal antenatal details of the record, and any outstanding birth details if born elsewhere.

There will be a few deaths within the Trust that occur outside of the Neonatal Unit and maternity service that will qualify for MBRRACE reporting (deaths within 28 days of life) and PMRT reporting (any death following neonatal care prior to discharge home). These deaths should be notified to neonatal death notifications within your local Trust. to ensure that the death notifications are undertaken. For deaths outside of the Neonatal Unit these are usually undertaken by the Child Health Risk Governance team with support from W&N and the neonatal team. It is the responsibility of the attending doctor of these neonatal deaths to notify the Neonatal Safety and Quality Matron or Neonatal Mortality Lead or equivalent and provide the following information: name, date of birth, date and time of death, cause of death as on MCDD, coroners notification and if a PM is being undertaken. Details of the named Consultant responsible for the care of the baby should be provided. All neonatal deaths (less than 28 days of life), deaths on a neonatal unit and deaths of a baby/child who received neonatal care and died prior to discharge from hospital require review of maternity, neonatal care using the PMRT Perinatal Mortality Review Tool

All parents should be informed that a review of their baby's death will take place and ensure that they have been asked if they have any views, questions or concerns for the review group and document this in the baby's medical notes.

A record of the MBRRACE reporting number should be recorded in the patient record for all neonatal deaths, a copy of MBRRACE form & PMRT report should be sent to CDOP administrator and the Neonatal Patient Safety Lead Nurse with the CDOP notification and reporting forms.

MBRRACE notifications for neonatal deaths on labour ward are usually completed by the midwifery MBRRACE lead. For cases with neonatal team involvement in the care of the baby prior to death this is a joint responsibility of the senior midwifery and neonatal clinical team. (see local policies and procedures regarding this).

Additional MBBRACE perinatal death reporting includes late fetal losses (22 – 23 weeks), stillbirths in addition to live born neonatal deaths within neonatal services and labour ward. These are completed by the midwifery MBBRACE lead and maternity bereavement team and are not subject to child death review processes.

6.6 Referral to Coroner

A coroner is an independent judicial office holder, appointed by a local council. Coroners usually have a legal background but will also be familiar with medical terminology.
Coroners investigate deaths that have been reported to them if it appears that:
• the death was violent or unnatural
• the cause of death is unknown,
• the person died in prison, police custody, or another type of state detention.
In these cases, Coroners must investigate to find out, for the benefit of bereaved people and for official records, who has died and how, when, and where they died.

For deaths within the neonatal unit, discussion with the local Coroner must take place if: (see local Coroner advice re local referrals – Appendix B).

- Any unexplained or unexpected death
- The likely cause is unknown so that the consultant cannot write a death certificate.
- The baby has not been seen by a doctor before death (for example extremes of viability i.e. 22/40 where a baby was thought to have signs of life at birth by the midwife but was not seen by a doctor prior to death).
- Complications of treatment or procedure including surgery that may have caused or contributed to the death
- A baby has died and there are major safeguarding concerns which may have contributed to the death (in which case a police rapid response is also required).
- The family have significant concerns about the medical care provided.
- Live births following termination of pregnancy (see section below)
- All hypoxic ischaemic encephalopathy neonatal deaths

The use of the terms “unexpected” and “expected” deaths have been used to guide referrals to the coroner but can lead to confusion amongst medical teams. In essence, an “expected” death refers to any baby with pre-existing significant medical condition(s) whereas a baby brought in from home having been found unresponsive constitutes an “unexpected” death.

Live birth following termination of pregnancy is sensitive issue. All deaths of live born infants following termination pregnancy including medical termination of pregnancy need to be notified to the Coroner. These should be dealt sensitively with the parents by the senior clinical team.

Information provided to the Coroner in writing via Coroners portal or equivalent should include the following i.e. “died from extreme prematurity after being born alive following termination of pregnancy under section 1 of Abortion Act 1967”. This should include a request to the coroner to consider an inquest in writing under Rule 23 (referring to paragraph 23 in Guidance 45) to avoid the family the stress of an in-person hearing.

Further information on Guidance for registered medical practitioners on the notifications of death regulations (Coroner Referral) March 2022 can be found here.
Chief Coroners Guidance No 45 : Stillbirth and live birth following termination of pregnancy Feb 2023
Chief Coroners Guidance No 29: Inquests in writing and rule 23 June 2022
RCOG Position statement following Chief Coroner Guidance no 45 December 2023

Following referral, a coroner may decide on one of the following:

- **No further investigation or action is required**: the attending doctor can issue MCCD. The coroner will issue a coronial Form CN1A to the referrer via email / portal and local registrar to support the cause of death by the Coroners Officer. This information including any changes to the MCCD and the final MCCD copy shared with the MES and the Registrar of Births and Deaths before a family can register their baby’s death. An appointment to register the death should not be made until there is confirmation that Form CN1A has been received by email/ portal. It is important to ensure that the MES, registrar have received a scanned copy of the Form CN1A and MCCD.

- **Case for investigation by the Coroner is accepted**: An MCCD cannot be issued. The Coroner will notify the cause of death to the Registrar following completion of the investigation and the family will be notified of the cause of death by the Coroner's Office.

The detailed clinical death summary of the patient sent to the Coroner and the medical examiner service as the referral clinical information and contact details for the parents. See Section 10 – Related Policies and Information Links for links to the TVW area Coroners.

Information to support parents where there a coroner's investigation and or coroner's post-mortem case can be given to parents to help them to understand the process. A guide to coroner services for bereaved people for bereaved people 2020.

6.7 Maternity and Newborn Safety Investigations MNSI notification

MNSI team investigate all incidents that fulfil Each Baby Counts EBC criteria which include eligible babies born at or above 37 weeks' gestation who fulfil the following criteria: Intrapartum stillbirths (babies alive during the onset of labour who are born with no signs of life), early neonatal deaths (babies who died within the first week of life 0-6 days) i.e. less than 7 days and severe brain injury diagnosed within the first seven days of life.

All early term neonatal deaths (died within the first week of life) with a gestation at birth at or greater than 37 weeks' gestation should be notified to MNSI by the Maternity Risk Team.

The Neonatal Unit are responsible for notifying the Maternity Risk team by the incident reporting system and emailing the Risk and Patient Safety Co-ordinator who will ensure /MBRRACE/PMRT and potentially MNSI (If the death occurs after 37 weeks' gestation and within 7 days of birth) notifications have been done. (see local policies and procedures regarding this)

The parents of babies who have died and are eligible for MNSI reporting should be notified of the external MNSI review process and provided with MNSI Family Information. The provision of MNSI information is a joint responsibility of the maternity obstetric teams and the clinical teams caring for the baby at the time of death. Permission from the family is required to provide their information to MNSI. Further information here: https://www.mnsi.org.uk/for-nhs/investigation-process-for-nhs/

For eligible babies who were not born in the receiving Trust i.e. ex-utero transfers or admitted from home, it is the responsibility of the clinical team caring for the baby at the time of the death to notify the local clinical team to make the MNSI notification.

6.8 Child Health Information System CHIS

The NHS England CHIS system provides a comprehensive local record of a child's public health and community-based healthcare. It is the responsibility of Neonatal Bereavement /Family Support Team to ensure that the Ward Clerk has updated the Trust Electronic patient administration system.

7.0 Investigation and review

7.1 Coroner's investigation

In circumstances where a death must be reported to the Coroner (Appendix B), a Medical Certificate of Cause of Death (MCCD) should not be issued to the family until the Coroner has agreed the cause of death. The Coroner has the following options:

- Following a telephone discussion with the medical team / email referral with clinical information i.e. Discharge summary (and others, if necessary, i.e. internal medical examiner /MES), the Coroner may conclude that the death is due to natural causes and no further action is required. The Coroner's office will issue a form to the Southampton Register Office (form CN1A) and the doctor should issue an MCCD to enable the family to register the death.
- Where a cause of death is unknown, or the Coroner decides that a post-mortem is required to clarify whether the death was natural or not, an MCCD should not be issued. At the conclusion of the post-mortem the Coroner will either:
    a. Conclude that the death was from natural causes. He will issue a form to the local Registry Officer (Form CN2 and the family will then be able to register the death. OR
    b. Decide that further investigations, including holding an Inquest, are required. At the conclusion of the Inquest, the Coroner will register the death, after which the family will be able to apply to their local Registry office for copies of the death certificate if required.

If a death has been referred and the case accepted, the Coroner takes legal possession of the body and opens and investigation into the death. If there is a coronial investigation, the Coroner will order a post-mortem examination (no parental consent is necessary). Following this examination the body will be released as soon as possible for the death to be registered and enable funeral arrangements to be made. Release of the body may be delayed if a second independent post-mortem examination is required or if organs have been taken for analysis.

If a Coroner investigates a death all agencies & providers that have pertinent information (such as hospital records, statements, and notes from CDRM) are under duty to disclose this information to the coroner.

Parents should be informed early on of the coroner's involvement, the need for and timings of a post-mortem examination; their right to be represented at the examination should they so wish and whether an investigation or inquest has been opened.

Once the Coroner has decided to undertake an investigation into the circumstances surrounding a death, the Coroner's office is the main point of contact with the family for matters relating to the coronial investigation and process.

The key worker should remain in contact with the family to continue to provide bereavement support and a follow up appointment with the named responsible Consultant and bereavement team should still be offered. It is likely that there will be additional investigation processes and reviews to the Coroner's Investigation i.e. local Trust review, NHS investigation, MNSI etc and it is important to maintain contact with the family and ensure bereavement support is being provided.

Information to support parents where there a coroner's investigation and or coroner's post-mortem case can be given to parents to help them to understand the process. A guide to coroner services for bereaved people for bereaved people

7.2 NHS Serious Incident Investigation

In deaths where there is more than one investigation, a Case manager should be appointed by the Trust to have oversight of the procedures, ensuring that those involved are objective, understand statutory requirements, follow appropriate timescales, ensure that parents have an opportunity to input into the process by the bereavement teams and establish how they would like to receive feedback.

The Case manager for neonatal deaths within W&NB is the Women & Newborn Maternity Risk Lead or Neonatal Patient Safety Lead Nurse as appropriate. The neonatal and maternity bereavement teams are the key workers and maintain support for families. (Refer to local arrangements re these)

7.3 Child Death Review Meeting (Neonatal M&M Meeting)

A child death review CDR meeting is multi professional meeting where all matters relating to an individual child's death are discussed and reviewed by health professionals directly involved in the care of that child during life. This should occur for all child deaths and should aim to have independent external representation at the CDRM.

All child death should be reviewed in a CDR meeting CDRM.

All deaths on the neonatal unit, including those transferred to hospice, other unit or home for palliative and end of life care should be reviewed in a Child Death Review meeting. This would be expected to be the neonatal CDR meeting / perinatal mortality review meeting.

Child deaths of babies or neonates that have been cared for on the neonatal unit should be reviewed jointly with the clinical teams involved in the care of that baby. The department leading the CDR meeting for review should be jointly agreed by the clinical teams and Child Death and Deterioration CDAD Lead.

Neonatal deaths of babies on labour ward where there was care provided by the neonatal team should be discussed at the neonatal CDR meeting.

Live born or pre viable neonates who are born alive and die on labour ward should be reviewed at the Perinatal Mortality Review Group meeting. Any case that fulfils PMRT criteria and completion, a copy of the completed PMRT should be submitted to CDOP along with any reports / minutes/ Analysis reporting form from the CDR meeting as evidence of local review of death.

The aims of the CDR meeting should include:

- To review the background history, treatment and outcome of investigations including post-mortems to determine the likely cause of death.
- To ascertain contributory and modifiable factors across domains specific to the child, the social and physical environment i.e. neonatal unit and service delivery.
- To describe any learning arising from the death and where appropriate to identify any actions that should be undertaken by any of the organisations & clinical teams involved in the care of the child prior to death.
- To review the support provided to the family and ensure that the family are provided with.
    - the outcome of any investigations into their child's death
    - An explanation of why their child died (this may not always be possible) and any learning from the review meeting.
- To ensure that CDOP and where appropriate, the coroner is informed of the outcomes of any investigation into the child's death
- To review the support provided to staff involved in the care of the child.

For all neonatal deaths (less than 28 days) and deaths on the neonatal unit, the neonatal CDR / perinatal mortality review group meeting should use the national Perinatal Mortality Review Tool PMRT for review of the case.

A case should be discussed as soon as possible ideally within 3 months, PMRT tool should be completed within 4 months. If there is an investigation report or PM report delay the case should be re-reviewed when this information is available
In addition to local multi professionals involved in the care of the baby, representative health care professionals from the local unit clinical teams i.e. Paediatricians, midwifery, obstetricians, and transport clinical teams should attend. There should be Risk, Safety, or governance representation. There should be external representation at the CDRM /PMRT reviews (Ockenden Report December 2020)

If key professionals are unable to attend from local units and a joint review is not possible, a report of local review of midwifery, obstetric and neonatal care can be provided. It is the responsibility of the originating unit to review these aspects.

A pathologist should attend if a post-mortem PM has taken place and a member of the patient safety team if a serious incident investigation has been undertaken.

The neonatal CDRM should be chaired by a lead professional, the Neonatal Mortality Lead or deputy. This should be delegated to another colleague if the lead professional also had overall professional responsibility for the child i.e. named Consultant.

Case presentation, clinical care review, lessons learnt should be part of this review meeting. Feedback from parents on the care of their baby should form part of this meeting. From this review meeting of a baby death the CDOP Analysis Form (Form C) should be completed and returned to CDOP administrator. The PMRT review tool generated report form can be submitted to CDOP as an Analysis Form C.

The neonatal CDR meeting is a professional meeting, parents should be informed of the meeting by the key worker and the family should have the opportunity to contribute information, parents' perspectives and any questions they may have. Information resource to support CDRM meetings, templates for communication with parents, information for parents can be found here https://www.ncmd.info/guidance/parents-cdr-toolkit/. Conclusions from the CDR meeting should be shared with the family usually by the named Consultant for the baby. This can be at the bereavement follow up meeting usually offered 6 -8 weeks following the death. (See local arrangements for this)

A record of the neonatal CDR meeting documentation and CDOP analysis form / PMRT tool report should be saved to the deceased babies' medical record. This should be uploaded to EDOCs/EDMS and it is the responsibility of the Case Manager to ensure that this is completed.

7.4 Perinatal Mortality Review Tool PMRT

This is a web-based tool with supports standardised, systematic perinatal review of care in perinatal deaths. This tool should be used for all stillbirths, live born neonatal deaths that occur in the delivery room, on the neonatal unit and deaths that occur following neonatal care for all babies who die prior to discharge from hospital.

The perinatal mortality review group should utilise the PMRT tool for review of clinical cases at the neonatal CDR meeting and Still Birth & Perinatal Review Group. Copies of the completed PMRT review should be sent to the CDOP panel HIPS CDOP hsiccg.hips.cdop@nhs.net

7.5 Parent Feedback and Family engagement

Parents should be supported and provided with information about what happens following the death of their child. This should be supplemented with the parent information leaflet 'When a child dies' (Appendix F).

Parents should be assigned a 'key worker 'who is a single point of contact in relation to the child death review process. A key worker should be assigned to the parents shortly after the death of their baby.

For neonatal deaths on the neonatal unit this should normally be a member of the Neonatal bereavement /Family Support team.

For neonatal deaths on labour ward this should be a member of the midwifery bereavement team, if there has been neonatal team involvement in a planned palliative care situation this would be agreed between the maternity & neonatal bereavement teams and clinicians involved. Parent information for labour ward deaths: Understanding why your baby has died.

Parents should have an opportunity to contribute information to the review processes including the CDRM's and have an opportunity to have any questions they may have answered. This would normally be through the bereavement and clinical teams involved with the parents and families.

Parents should receive bereavement support and signposted to local services and national organisations they might find helpful. (See section 11. Information Links).

Parents and families should be offered bereavement follow up by the clinical team responsible for the care of their baby within 6 – 8 weeks of the death of their baby. This may be undertaken jointly by multiprofessional teams if specialist teams were involved and may include the responsible obstetrician & midwife.

7.6 Child Death Overview Panel

The Child Death Overview panel CDOP reviews all deaths. Information should be provided to support this process by electronic reporting to ecdop. https://www.ecdop.co.uk/HIPS/Live/public
This includes the notification Form A & D, reporting Form B following the death of a child via ecdop. The analysis Form C or PMRT form should be provided following CDR meeting. All submissions should be made to the CDOP panel administrator as outlined in this guidance.

8.0 Death of a live born neonate on labour ward

All information to support staff following the death of a live born neonate on delivery suite will be available in the on all Labour wards**.** (Refer to local polices for this)

The key worker for a baby who dies on Labour ward is usually the Midwifery Bereavement team and can be notified by email.

The child death notification processes should be completed by the midwifery bereavement team and clinical obstetric team caring for the mother for expected deaths in live born babies i.e. pre viable miscarriages (less than 23 weeks) and terminations of pregnancy. It these situations the neonatal team would not normally be involved in the care of the live born baby unless active neonatal management has been agreed with the family.

For live born neonatal deaths on delivery suite of viable babies (after 23 weeks' gestation) where there has been involvement of the neonatal team either at delivery or in the antenatal period i.e. planned antenatal palliative care, the completion of child death review processes including notifications, MCCD and CDOP (after 24 weeks gestation), MBRRACE notification / PMRT reporting (22 completed weeks) should be agreed between the senior neonatal, midwifery and obstetric clinical teams.

These would usually be completed by the midwifery and obstetric teams with support from the neonatal clinicians subject to the level of involvement of the neonatal team after birth and before death. An exception example of an unsuccessful resuscitation or neonatal palliative care in with which the neonatal team were involved.

All live born babies at any gestation with signs of life at birth must be seen alive by a medical doctor in order to complete a medical certificate of cause of death MCCD. This would usually be a member of the obstetric medical team for expected deaths i.e. terminations or deaths following planned palliative care.

All statutory processes apply including internal medical examiner review for deaths on labour ward. See Coroners sections for notifications of live births following termination of pregnancy.
The applicable child death notification & review processes should be followed as outlined in this document. For deaths on the delivery suite these are outlined in Appendix D: Labour Ward Neonatal Death Flow Summary in the Neonatal Death overview flow chart.

The child death review CDOP process is not required for the following:

- Stillbirth: baby born without signs of life after 24 weeks gestation
- Late fetal loss: where a baby is born before 24 weeks of life with no signs of life.

- Terminations of pregnancy (of any gestation): if after planned termination of pregnancy the baby is born alive this is a neonatal death and child death review process and referral to the Coroner should take place.

A care record should be completed for neonatal deaths where neonatal care has been provided for babies that have not been admitted to the neonatal unit, a neonatal Badger net care record (death on labour ward section) or on equivalent system should be completed as the neonatal care record when the baby has received neonatal care and a copy sent to the GP, Obstetricians and clinical teams involved and uploaded to the medical record.

The neonatal outcome (including names of clinicians in attendance, care /resuscitation given, certified time of death and proposed cause of death) should be completed on the maternity Badgernet/or equivalent system, record by the clinical team involved and is finalised by the midwifery and obstetric teams.

9.0 Roles and Responsibilities

All staff who provide care for neonates have a responsibility to ensure that they are aware of this guideline and its contents. They should clearly document their rationale if they have not complied with the recommendations detailed in this guideline. It is the responsibility of department managers, consultants, team leaders and education leaders to ensure staff are aware of this guideline.

Neonatal Mortality Lead or equivalent has responsibility for implementation of child death review processes within the neonatal unit, ensuring reporting of neonatal deaths, Chairs monthly Child Death Review Meetings and annual reporting of neonatal deaths to Trust Board.

Neonatal Key worker has responsibility for the implementation of bereavement support and ensure parents are kept fully informed of the review process and its outcomes.
Key worker: is the named point of contact for parents following the death of their child. This could be the Neonatal Patient Safety Lead Nurse
Neonatal Patient Safety Lead Nurse: has responsibility for administration & coordination of the child death review processes within the Neonatal Unit and ensuring that all relevant documentation is uploaded on the patient record. (see local policies and procedures)

Consultant Neonatologist: is responsible for following the child death review operational policy for their patients and supporting medical staff in the implementation of this guidance.

Medical / ANNP staff are responsible for completion of the various aspects of this guidance and following the guidance on when a child dies: Guidance for Medical staff.

Nursing Staff are responsible for completion of the various aspects of this guidance and following the guidance on when a child dies: Guidance for nursing staff.

10.0 Related policies and information links

Network Guidance: Framework for Neonatal Palliative Care (Supportive and End of life Care)

Network Guidance on Spiritual Guidance

Consent for post-mortem examination and tissue retention under the Human Tissue Act 2004 | Human Tissue Authority

Sudden and Unexpected Postnatal Collapse | British Association of Perinatal Medicine

Sands Deciding about a post-mortem examination: Information for parents

Sands Guide For Consent Takers: Post-mortem examination of a baby

e learning for health perinatal post-mortem consent package

Mental health support | Bliss

Policies and guidance - ODT Clinical - NHS Blood and Transplant

Spiritual Care - Neonatal Network South East

CYPACP – Child & Young Persons Advance Care Plan

Ante-natal Advance Care Plan (with and without ReSPECT) – CYPACP

Cascade Integrated System

11.0 Information links

Stillbirth and Neonatal Death Charity Sands https://www.sands.org.uk/

Perinatal Mortality Review Tool PMRT https://www.npeu.ox.ac.uk/pmrt

Child Death Review: Statutory and Operational Guidance

https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england

Babies born premature or sick Bliss https://www.bliss.org.uk/

Hampshire Safeguarding Children Partnership https://hipsprocedures.org.uk/skyyth/safeguarding-partnerships-and-organisational-responsibilities/child-death-review-process/#s3839

A guide to Coroner services for bereaved people 2020

MNSI information for families

Child Bereavement UK Support for parents

When a child dies - A guide for parents and carers

12.0 TVW Coroner Contact Details

Hampshire and Isle of wight: HM Coroner's Service in Hampshire, Portsmouth, and Southampton | Hampshire County Council (hants.gov.uk)

Wiltshire: https://www.wiltshire.gov.uk/article/1029/Wiltshire-and-Swindon-coroner-s-service

Dorset: Dorset Coroners Service | BCP (bcpcouncil.gov.uk)

Oxfordshire: The Coroner's Service | Oxfordshire County Council

Buckinghamshire: The coroner service | Buckinghamshire Council

West Sussex: Coroner's Service - West Sussex County Council

Berkshire: Berkshire Coroners' Office - Reading Borough Council

Surrey: Surrey Coroner - Surrey County Council (surreycc.gov.uk)

13.0 Appendices

Appendix A – Example forms

Paediatric post-mortem consent form

Example document from University Hospital Southampton
Link to document here: https://neonatalnetworkssoutheast.nhs.uk/wp-content/uploads/2024/10/TVW-Neonatal-ODN-Death-SOP-v2-Appendix-A-Paediatric-post-mortem-consent-form-shared-by-UHS_v1.docx

Paediatric post-mortem consent form – Organ retention

Example document from University Hospital Southampton
Link to document here: https://neonatalnetworkssoutheast.nhs.uk/wp-content/uploads/2024/10/TVW-Neonatal-ODN-Death-SOP-v-2-Appendix-A-Paediatric-post-mortem-consent-form-organ-retention-shared-by-UHS_v1.docx

Perinatal Pathology post-mortem request form

Example document from University Hospital Southampton
Link to document here: https://neonatalnetworkssoutheast.nhs.uk/wp-content/uploads/2024/10/TVW-Neonatal-ODN-Death-SOP-v2-Appendix-A-Perinatal-pathology-post-mortem-request-form-shared-by-UHS_v1.docx

Appendix B – Criteria for Referral of deaths to the coroner

Link to document here: https://neonatalnetworkssoutheast.nhs.uk/wp-content/uploads/2024/10/TVW-Neonatal-ODN-Death-SOP-v2-Appendix-B-Criteria-for-referral-of-deaths-to-the-coroner.docx

Appendix C – Child death analysis form

Link to document here: https://neonatalnetworkssoutheast.nhs.uk/wp-content/uploads/2024/10/TVW-Neonatal-ODN-Death-SOP-v2-Appendix-C-Child-death-review-analysis-form.docx

Appendix D – Example documents

Perinatal death review meetings terms of reference

Link to document here: https://neonatalnetworkssoutheast.nhs.uk/wp-content/uploads/2024/10/TVW-Neonatal-ODN-Death-SOP-v2-Appendix-D-Example-perinatal-child-death-review-meeting-terms-of-reference.docx

Neonatal death communication check list

Example document from University Hospital Southampton's Neonatal Death SOP.
Link to document here: https://neonatalnetworkssoutheast.nhs.uk/wp-content/uploads/2024/10/TVW-Neonatal-ODN-Death-SOP-v2-Appendix-D-Example-neonatal-death-communication-medical-check-list-shared-by-UHS.docx

Neonatal death overview flow charts

Example document from University Hospital Southampton's Neonatal Death SOP.

Document includes:

- Reporting and referral
- Neonatal Internal Medical Examiner
- Labour Ward Neonatal Death Flow Summary

Link to document here: https://neonatalnetworkssoutheast.nhs.uk/wp-content/uploads/2024/10/TVW-Neonatal-ODN-Death-SOP-v2-Appendix-D-Example-neonatal-death-overview-flow-charts.pptx

Appendix E – Sands 'Deciding about a post-mortem examination information for parents'

Link to document here: Deciding about a post mortem LINKED.pdf

Appendix F – Lullaby Trust 'When a child dies. A guide for parents and carers'

Link to document here: When a child dies - A guide for parents and carers