British Association of Perinatal Medicine

Neonatal Mortality Governance

A DRAFT BAPM Framework for Practice

August 2025

Contents

DRAFT

Executive summary

High-quality end-of-life care, and an open and transparent child death review process are of vital importance in providing understanding and closure for both families and staff as well as supporting shared system-wide learning. This framework complements existing national and statutory documents while providing more detailed operational guidance in areas where clinical interpretation is challenging.

The term Child Death Review Meeting (CDRM) is used throughout this document to describe the local health professionals review of the care of a baby that has died. Locally, different terminology is often used e.g. local Morbidity & Mortality meeting, Perinatal Mortality Review Tool (PMRT).

Recommendations for Neonatal Units

Care of baby and family

All units should

- have access to suitable bereavement facilities, and families should be given pragmatic options for where end of life care takes place.
- ensure all families have a named consultant and a named key worker (statutory in England) to provide a consistent point of contact regarding key decisions after death and for communication, engagement and support throughout all child death review processes.
- have guidance in place to facilitate rapid release of the baby's body on parental request.
- have guidance regarding neonatal organ and tissue donation and should review whether this was offered as part of the mortality review process.
- ensure postmortem examination is offered to families by a clinician who has received appropriate training (except where a coronial postmortem is mandated).

Child Death Review

All units should

- use bereavement checklists which are consistent with national and statutory guidance (**Appendix 2**).
- be familiar with national statutory/legal processes and child death review processes in their locality. Best Practice recommendations regarding completion of the medical certificate of cause of death are outlined in the Registering the death section, with specific case examples in **Appendix 3: Case Examples**.
- develop good working relationships and processes with His Majesty's Coroner/Procurator Fiscal (HMC/PF), to enable clear communication channels and information sharing to best support bereaved families. Families should be consulted on how they would like to receive information.
- use the Perinatal Mortality Review Tool (PMRT) to support the child death review meeting for all neonatal deaths in the first 28 days regardless of the location of death (may also be used for older babies who die in neonatal units).
- use a trauma informed approach to mortality review to enable families and staff to feel safe in raising concerns and identify learning (**Appendix 1: Supporting Families and Staff**).
- ensure the child death review meeting is conducted in accordance with national and statutory guidance, reviewing from pre-conception to bereavement and follow-up; to include appropriate internal and external peer review, the family's perspective and to provide answers to the family's questions.
- ensure sufficient protected time for bereavement care, leading and participating in mortality governance reviews (Staff considerations).

DRAFT

Recommendations for Neonatal Operational Delivery Networks

Neonatal ODNs should

- facilitate collation of contact details for clinicians in the network who are willing to undertake external review as well as working with other regions to support units to find external reviewers with similar expertise for complex cases where required e.g. neurosurgical, cardiac cases.
- review neonatal mortality data relevant to the ODN (Fig 1) and raise any concerns arising with the relevant neonatal/perinatal service, and with regional perinatal and commissioning organisations where appropriate.
- collate learning from individual Child Death Review Meetings (CDRMs) and Child Death Overview Panels (CDOPs)/National Child Mortality Database reports (or equivalent for devolved nations) to look for themes and facilitate shared learning across the ODN/perinatal system and more widely where appropriate.
- provide quality assurance around the CDRM process, including reviewing representation at CDRMs, appropriate family input and response to their questions, PMRT outcome gradings and learning outputs. Neonatal units should facilitate ODNs with the information required to facilitate this.

Recommendations for other bodies

Department of Health, Northern Ireland

- BAPM strongly supports the establishment of a formal child death review process in Northern Ireland which is an outlier in the UK in this respect.

National Medical Examiner: England and Wales

- To develop training resources to support all Medical Examiners (MEs) with understanding neonatal deaths and to consider initiatives to share insights and learning from the neonatal population as the ME system matures.

His Majesty's Coroner/Procurator Fiscal

- To develop good working relationships and processes with neonatal services to enable clear communication channels and information sharing to provide the best support for bereaved families.

Child Death Overview Panels (England only)

- 'Themed' neonatal CDOP meetings are strongly recommended, to ensure that maximum learning is derived through aggregate review of deaths. CDOPs are strongly encouraged to share learning with the neonatal ODN.

Child Death Review Programme (Wales only)

- Strengthening of information sharing between neonatal ODNs and Child Death Review Programme (CDRP).

DRAFT

Members of the Working Group

Eleri Adams (Chair)	BAPM President, Consultant Neonatologist, Oxford University Hospitals
Srinivas Annavarapu	Consultant Perinatal Pathologist, representing RCPath
Kate Laura Bannister	Lead Midwife for Quality, Safety and Risk, Singleton Hospital, Swansea
Stephen Brearey	Consultant Paediatrician, Countess of Chester Hospital
Katie Cullum	Lead Nurse, East of England Neonatal Network
Victoria Davies	HMC, Representing the medico legal committee of the Coroner’s Society of England and Wales
Lucy Deacon	ST6 Paediatric and Neonatal Medicine Trainee, Singleton Hospital, Swansea
Ngozi Edi-osagie	National Clinical Director for Neonatology, NHS England
Davy Evans	Consultant Clinical Psychologist, Birmingham Women's & Children's Hospital
Vikki Fradd	Consultant Neonatologist, Medical Examiner, Heartlands Hospital
James Fraser	Chair NCMD Professional Advisory Group, representing ACDRP
Janice Gibson	Consultant Obstetrician, Representing BMFMS
Kelly Gill	Yorkshire and Humber Neonatal ODN QI/Governance Lead Nurse
Richard Hearn	Consultant Neonatologist, Royal Victoria Infirmary
Zoe Hemsley	Regional Medical Examiner, England and Wales
Kathryn Johnson	Consultant Neonatologist, Mortality Lead, Leeds Teaching Hospitals
Nigel Kennea	Consultant Neonatologist, Medical Examiner, England and Wales
Adele Krusche	Researcher, National Perinatal Epidemiology Unit, Representing PMRT
Tracy Lawson	Consultant Neonatologist, Mortality Lead, Ashford & St. Peter's Hospitals
Louise Leven	Consultant Neonatologist, Royal Hospital for Children, Glasgow
Renton L'heureux	Consultant Neonatologist, London North West Healthcare NHS Trust
Ben Lobo	Regional Medical Examiner, England and Wales
Karen Luyt	Consultant Neonatologist, Programme Director, NCMD, representing NCMD
Sonia Macleod	Representing Sands Charity
Brad Manktelow	Professor of Medical Statistics, representing MBRRACE-UK
Tamas Marton	Consultant Perinatal Pathologist, representing RCPath
Kate Mulley	Director of Research, Education and Policy, Representing Sands Charity
Nicola Mundy	Lead for Learning from Child Deaths (public health), Surrey Heartlands ICB
Nicola Needham	Child Death Review Manager, Specialist Community Public Health Nurse
David Odd	Consultant Neonatologist, Epidemiologist, NCMD, representing NCMD
Sam Oddie	Consultant Neonatologist, Clinical Lead NNAP, representing NNAP
Hannah Shore	Consultant Neonatologist, Leeds Teaching Hospital, representing MNSI
Susan Smith	Maternity Neonatal Senior Independent Advocate, NHS Devon ICB
Lucy Smith	Professor of Perinatal Health, representing MBRRACE-UK
Timothy Taylor-Smith	Parent representative
Megan Tombling	Post Certificate of Completion of Training, Neonatal Clinical Fellow, Exeter
Alison Verner	Consultant Neonatologist, Craigavon Area Hospital, Northern Ireland

DRAFT

Acknowledgements
With thanks to Jessica Smith for supporting the working group meetings and Laura Fountain for the design.

Abbreviations

There are many abbreviations in use in national mortality governance documents. Please refer to the list below when reading this document.

Abbreviation	Full Name	Abbreviation	Full Name
ACDRP	Association of Child Death Review Professionals	**NICORE**	Neonatal Intensive Care Outcomes Research and Evaluation
BMFMS	British Maternal & Fetal Medicine Society	**NIMACH**	Northern Ireland Maternal and Child Health
CDOP	Child Death Overview Panel (England)	**NICU**	Neonatal Intensive Care Unit
CDR	Child Death Review	**NNA**	Neonatal Nursing Association
CDRM	Child Death Review Meeting	**NNAP**	National Neonatal Audit Programme
CDRP	Child Death Review Programme (Wales)	**NTG**	National Neonatal Transport Group
CGA	Corrected Gestational Age	**ODN**	Operational Delivery Network
CHIS	Child Health Information System	**ONS**	Office for National Statistics
GP	General Practitioner	**PAG**	Parent Advisory Group
HIE	Hypoxic Ischaemic Encephalopathy	**PF**	Procurator Fiscal (Scotland)
HIS	Healthcare Improvement Scotland	**PM**	Postmortem
HMC	His Majesty's Coroner	**PMRT**	Perinatal Mortality Review Tool
HTA	Human Tissue Authority	**PRUDiC**	Procedural Response to Unexpected Death in Childhood (Wales)
HV	Health Visitor	**PSIRF**	Patient Safety Incidence Response Framework (England)
ICB	Integrated Care Board	**QI**	Quality Improvement
JAR	Joint Agency Response	**RCPath**	Royal College of Pathologists
LMNS	Local Maternity and Neonatal System	**SAER**	Serious Adverse Event Reporting
LNU	Local Neonatal Unit	**SAI**	Serious Adverse Incident
M&M	Morbidity and Mortality	**SCU**	Special Care Unit
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries	**SNOD**	Specialist Nurse for Organ Donation
MCCD	Medical Certificate of Cause of Death	**SPEN**	Submit a Perinatal Event Notification
MDT	Multidisciplinary Team	**ST**	Specialty Trainee
ME	Medical Examiner	**SUDI**	Sudden Unexpected Death in Infancy
MNSI	Maternity and Newborn Safety Investigations	**SUDIC**	Sudden Unexpected Death in Infancy and Childhood
MNVP	Maternity and Neonatal Voices Partnership	**SUPC**	Sudden Unexpected Postnatal Collapse (first week of life)
MOSS	Maternity Outcomes Signal System	**TS**	Tissue Services
MW	Midwife	**VON**	Vermont Oxford Network
NCMD	National Child Mortality Database (England)	**WTE**	Whole Time Equivalent

DRAFT

Introduction

Deaths in the neonatal period (first 28 days of life) make up 52% of all child deaths under 16 years with nearly 2000 neonatal deaths in the UK each year[1,2]. 40% of all child deaths (0-17 years) in England occur in maternity and neonatal units[3]. Each of these events is a tragedy and it is of vital importance that the processes and procedures that occur following the death of a baby are conducted properly and sensitively, and that the subsequent review processes are thorough, open and transparent, providing an opportunity to shape understanding and psychological adjustment to loss for all those affected as well as opportunities for whole system learning. Throughout this document we aim to adopt a trauma-informed approach to reduce the psychological impact of neonatal death and mortality governance on parent(s), families and staff (**Appendix 1: Supporting Families and Staff**).

Aims and scope

Neonatal mortality governance processes are complex and are subject to statutory guidance, with differences across the UK (**Appendix 2: National and Statutory Guidance**). This framework is written in accordance with that guidance and aims to

- collate key aspects pertinent to neonatal practice,
- make recommendations for best practice, and
- provide more detailed operational guidance in areas where clinical interpretation is more challenging (**Appendix 3: Case Examples**)

It is aimed primarily at perinatal healthcare professionals but may also be helpful to His Majesty's Coroners (HMCs), Procurator Fiscals (PFs) and Medical Examiners (MEs). The focus is predominantly on babies who are born with signs of life and die whilst in the care of maternity and neonatal services, with limited information on miscarriages, stillbirths and paediatric deaths occurring outside of perinatal services.

We have provided a full list of abbreviations used in this document.

DRAFT

Development process

The scope and content of this document were determined by members of the working group, which contains wide representation across the various bodies involved in neonatal mortality governance. The content is consistent with national and statutory guidance available at the time of publication. Evidence is included from the literature where available. Where there is a lack of evidence/ national guidance, or where there is uncertainty or variation regarding the clinical interpretation of national guidance, an expert consensus from the working group has been developed.

Language

The British Association of Perinatal Medicine is committed to continuously fostering an inclusive environment and we acknowledge the effect language can have on individuals and populations. This framework uses the terms mother/birthing parent, parent(s) and families. We recognise that different terms may be preferred, and the meaning of these terms may be different to each of us. Please use a person's preferred pronouns and terminology.

Table 1: Timelines for End-of-Life Care and Child Death Review Processes

Timeline	Baby and Family Focused Actions	Staff Actions/Local Investigation	Statutory/National Safety Notifications
Prior to death where anticipated	• Parallel planning/treatment options/ comfort care • Making memories/ Family and Friends • Religious rites and consideration of urgent faith burial • Place of death: hospital/ hospice/ home • Discussion regarding organ donation (only include following SNOD/TS confirmation) • Diagnostic tests for SUPC if appropriate.	• Contact SNOD/TS re organ/tissue donation if eligible PRIOR to discussion with family • Documentation of palliative care/family wishes • Allocation of staff members to provide family support and may identify family keyworker/bereavement lead • Contact with neonatal transport service if transfer required. • Staff communication and wellbeing • Local safety incident report if applicable	• Early contact with ME (England/ Wales) +/- HMC/PF if uncertainty regarding MCCD <u>and</u> rapid release of the body is likely to be required for urgent faith burial.
Immediately after death	• Making memories/ Family and Friends • Religious rites and consideration of urgent faith burial • Post death care: location/ use of cold cots • Organ donation consent (only include following SNOD/TS confirmation) • Where death fulfils criteria for SUDI/PRUDiC/ SUPC explain next steps (referral HMC/PF/JAR or equivalent/ MDT/further tests).	• Contact SNOD/TS re organ/tissue donation if eligible PRIOR to discussion with family • Documentation of events leading up to death • Verify and document death in the notes • Documentation of discussions with family • Identify lead consultant and family key worker/bereavement lead • Staff communication and wellbeing	• Early contact with ME +/- HMC/PF if uncertainty regarding MCCD <u>and</u> rapid release of the body is required • In event of SUDI/PRUDiC/SUPC: contact designated individual to arrange JAR or equivalent, and refer to HMC/PF.
1-2 working days	• Discussion regarding death processes, MCCD and/or need for discussion with Coroner • Discuss PM (hospital and coronial) • Referral to bereavement services • Lactation care for mother	• Hot debrief (if required) • Complete Neonatal Bereavement Checklist • Complete bereavement +/- PM paperwork, and discharge summary (Lead consultant review) • Notify relevant health professionals and NHS information systems (e.g. GP/HV/MW/referring unit, CHIS) • Rapid review re any safety concerns - Local safety incident reporting (PSIRF/SAER/SAI or equivalent) if applicable	• Completion of MCCD following ME scrutiny (England/Wales) • If MCCD cannot be issued, referral to HMC/PF Notifications: • CDOP notification form (England), MBRRACE-UK (<48hrs England), Child death notification form (Wales) • MNSI if applicable (England).
First week	• Ongoing contact with family key worker/ bereavement lead • Registration of death (and birth if needed) • ME discussion with family (England) • Information regarding review timelines	• Cold debrief (if required) • Statements for investigations • Local safety incident report (PSIRF/SAER/SAI or equivalent) - Immediate Incident review completed/ duty of candour/ actions started (if applicable)	• JAR or equivalent MDT meeting is held (if applicable) • MBRRACE-UK reporting • CDOP reporting form completion (England)/ Child Death Notification Form (Wales)
1 week – 3 months (longer if PM/HMC/PF or MNSI)	• Input questions to local CDRM • Bereavement meeting if investigation findings are complete -this may take longer than 3 months	• Formal child death review meeting (CDRM) • CDOP Analysis and supplementary form completion • PSIRF/SAER or equivalent investigation findings/ reports	• HMC/PF process completed – may be >3 months • PMRT completion (pending MNSI/HMC/PF/PM findings) • CDOP review (England)/CDRP review Wales • CDR Core dataset (Scot)/NICOR (NI) completion • MBRRACE-UK surveillance data
>3 months	• Duty of candour and incident review finding meeting with the family (if applicable) • Bereavement meeting with post-mortem +/- histology/genetic/biochemistry results	• Regional Neonatal ODN Mortality Review • Local/regional review of themes in neonatal mortality	• Coronial inquest findings/ hospital postmortem findings • MNSI report with actions and learning • CDOP escalates alerts of national relevance to NCMD • CDRP (Wales) escalates alerts as appropriate • PMRT, MBRRACE-UK, NNAP, national reporting • NMCD (England), CDRP (Wales), HIS National Hub (Scot), NIMACH/NICORE (NI), national reporting

DRAFT

Care of baby and family

Please refer to Table 1 above for a timeline of actions to support families at the time of death.

Palliative care where death is anticipated

Most babies who die in maternity and neonatal units will have life-limiting or life-threatening conditions where death can be anticipated. Early identification of babies who fall into these categories allows important planning and support to be put in place. The BAPM Integrated Palliative Care framework provides more details on holistic support for families in these circumstances[4].

Family decisions around the time of death

A named consultant should be identified to coordinate care and discuss with parent(s) and families the practical arrangements that will be needed around the time of death. The following specific aspects should be considered:

- **Location of end-of-life care/care after death**
    - Where possible, families should be given options for where end of life care takes place, including hospice and home care as alternatives to hospital care where possible.
    - All units should have access to suitable bereavement facilities. See building note standards[5]. In smaller units, facilities may be shared with maternity services.
    - All units should have access to a cold cot or alternative cooling facilities, to facilitate parent(s)/ families to spend more extended periods of time with their deceased baby[6]. Most cold cots are portable and can also be used at home.
- **Religious rites**
    - Access to appropriate religious support should be provided (**Appendix 1: Supporting Families and Staff: Cultural and Spiritual Sensitivity**)
    - Consideration for whether urgent faith burial is required (see Rapid release of body)
- **Organ Donation**[7,8]

- Heart valves (tissue donation) can potentially occur from 32 weeks CGA in England and Wales (36 weeks CGA in Scotland). Heart valves cannot be donated in N Ireland.
- Solid organ donation can occur from 37 weeks CGA
- Organ/tissue donation should be considered at an early stage when considering end-of-life care
- Clinicians should aim to contact Specialist Nurse for Organ Donation (SNOD) and/or Tissue Services (TS) for advice BEFORE discussing with parent(s)

    - All units should have clear guidance regarding neonatal organ and tissue donation including how to contact their Regional Organ Donation Team and Tissue Donation Services.
    - Units should record information regarding contact with organ/tissue donation teams and reasons why SNOD teams were not approached for ALL neonatal deaths above the minimum gestation threshold. This information should be reviewed on a case-by-case basis in local CDRM meetings as well as audit of potential missed opportunities for discussion of organ/tissue donation with families.
- **Postmortem Examination**
    - All parent(s) should be offered a postmortem examination. In coronial cases there may be a mandated postmortem.

DRAFT

  - Families should have a named contact throughout the postmortem process from consent until the report is received (Eng and Wales)[9]
  - The clinician or specialist nurse leading this discussion should have received approved training in postmortem consent which meets HTA standards[10,11,12]. E-learning is available for everyone with a NHS email address[13]. Training in N. Ireland is run at hospital level.
  - Parent(s) should be made aware of the likely impact of postmortem on the timing of funeral arrangements and the likely timeframe for results of postmortem investigations to become available.

Lactation care

- Mothers/birthing parents should be supported by infant feeding teams to manage lactation. Options include milk donation (where appropriate) and lactation suppression[14,15,16].

Family Support and Communication

The death of a baby is a devastating experience for families, and it is vital that they are fully supported in a trauma informed, psychologically supportive and transparent manner through the mortality governance process. Key aspects of family support and communication are outlined below. More detailed information including support for more vulnerable groups and those requiring specialist support are included in **Appendix 1: Supporting Families and Staff**.

DRAFT

- Guidelines for effective communication with families at the time of death can be found in the Code of Practice for the diagnosis and confirmation of death[17].
- All families should have a named lead consultant and a named keyworker (statutory in Eng)[18] who can act as a consistent point of contact for families to facilitate support, communication and engagement in the process. There may be several reviews and families should be informed about the timelines; asked if they wish to contribute and receive regular updates.
- All families should be offered the opportunity to discuss the wording of the Medical Certificate of Cause of Death (MCCD) and ask any questions about their baby's care with the lead consultant and in England and Wales, separately, with the Medical Examiner.
- Involvement of families in the Child Death Review Meeting (CDRM) improves dialogue and continuity of care between parent(s) and providers and empowers parent(s) to maintain a purposeful role following the death of their baby. Families' views should be heard and questions answered at the CDRM. The extent of involvement should be agreed with the family and amended over time according to their wishes[19].
- Compassionate support and communication from the named consultant and keyworker should be maintained throughout His Majesty's Coroner/Procurator Fiscal (HMC/PF) or Maternity and Newborn Safety Investigations (MNSI) processes.
- Families should be consulted on how they would like to receive information, and this should be reviewed throughout the process.
- Where required, Maternity and Neonatal Independent Senior Advocates (England only) can be accessed through the local NHS ICB to provide independent support through investigations and complaints processes.
- Comprehensive information on bereavement care pathways after pregnancy or baby loss are available across the different countries of the UK[20,21,22].

Child Death Review

- England, Wales, and Scotland have established Child Death Review (CDR) programmes to safeguard children and learn from their deaths[18,23,24].
- A formal child death review programme is not currently in place in Northern Ireland and BAPM strongly supports its establishment.
- Further information on CDR programmes and other key national and statutory documents in use across the four nations are outlined in **Appendix 2: National and Statutory Guidance**.

Table 2: Child Death Review Processes and Reports

Coverage	CRD Process
Local	• Local CDRM • ME (Eng & Wales only) except when referral to HMC
Regional	• CDOP (England) • Regional Neonatal ODN Mortality Reviews • LMNS PMRT Review (England)
When Required	• HMC/PF investigation • Safety Investigations PSIRF/SAER/SAI or equivalent • MNSI* (England only) • SUDIC/SUDI/PRUDiC (including JAR or equivalent)
National Reports	• MBRRACE-UK Perinatal Surveillance Reports • MBRRACE-UK PMRT National Reports • NNAP (All except NI) • NCMD (England) • CDRP (Wales) • NICORE/NIMACH (NI) • HIS National Hub(Scotland)

Please refer to Abbreviations Table.
*Investigate term babies (37+ weeks) with no congenital anomalies born following onset of labour with one of following outcomes: a) intrapartum stillbirth, b) early neonatal death (0-6 days) or c) potential severe brain injury (required cooling or diagnosis mod/severe HIE)

- Neonatal CDR review processes shown in Table 2 begin shortly following death with timelines for notifications shown in Table 1.
- All units should be familiar with the child death review processes in place in their locality.
- All units should use bereavement checklists to ensure timely completion of all appropriate tasks, and these should be made available for review during the CDRM.

DRAFT

Immediate decisions

Verification of Life

- For babies who die shortly after birth it is important to establish whether there were signs of life. This, along with the gestational age, determines whether the death is a neonatal death, a miscarriage or a stillbirth. Legal requirements regarding certification of death and referral to HMC/PF differ depending on which country the death occurs in[25,26,27] (see **Appendix 2: National Guidance** and **Appendix 3: Case Examples 1-4**).
- Information and videos for family's and health professionals regarding determination of signs of life following spontaneous birth before 24+0 are available at MBRRACE-UK[28].

Verification of Death

- Confirmation of the diagnosis of death in most neonates will be following cardiorespiratory arrest. Occasionally, a diagnosis of death is made using neurological criteria[29].

Death Certification

- Following the death of a child, it is the statutory duty of a doctor who has attended in the last illness to write the MCCD. The MCCD may be issued if a doctor is able to identify a natural cause of death to the best of their 'knowledge and belief'. Absolute certainty is not required[30,31,32].

- Before writing the MCCD, the doctor should consider if the death requires reporting to His Majesty's Coroner (HMC) (Eng, Wales, NI) or the Procurator Fiscal (PF) (Scot) [33,34,35]. A conversation with the Medical Examiner (ME) (Eng/Wales only) as part of this process may aid decision making as to whether the MCCD can be written or not. When to refer to HMC/PF is discussed in more detail below; reporting requirements are shown in **Appendix 2: National and Statutory Guidance**.
- There are two versions of the MCCD for child deaths in England/Wales: a neonatal certificate (for deaths <28 days of life) and the standard certificate for older children. The MCCD for neonatal deaths reflects different aetiologies of death in this period and includes maternal factors. There is one MCCD for all deaths in Scotland/Northern Ireland (NI), and in NI it is electronically completed, with maternal complications leading to death being included in Part 1b if appropriate.
- The named consultant should oversee the discussions and writing of the death certificate and the information to be included should be shared with the family.
- The baby's name for registration of birth and death should be checked with the family to ensure the correct information is entered on the MCCD.
- In England and Wales, the proposed MCCD/case will then be scrutinised by a Medical Examiner (ME), with a discussion held between the ME and the attending physician if required. MEs also discuss the contents of the death certificate with the family. Once countersigned by the ME the death can be registered by the informant (usually the family).
- In Scotland, the completed MCCD is then sent directly to the registration office (not given to the family).
- Death Registration cannot occur before an MCCD is completed.
- Funeral arrangements can be started prior to death registration, but the funeral can only take place once the death has been registered or once HMC/PF has given permission – usually after a postmortem examination, but before an inquest has occurred.

The Medical Examiner (England and Wales only)

- Since September 2024, in England and Wales all deaths (that are not investigated by a Coroner) are scrutinised by Medical Examiners (MEs), and the MCCD agreed and signed off by the ME before it is sent to the Registrars of Births and Deaths[36,37].
- MEs review the clinical records and so rely on good contemporaneous documentation. MEs are independent doctors and provide oversight and safeguards for individuals and the public.
- Different areas of the country will have slightly differing processes in place for interacting with their local ME team. Neonatal teams should forge good relationships with their ME team and ensure all understand their roles.
- Few MEs will have clinical expertise in neonatal care. It is recommended that training resources are developed to support all MEs with understanding neonatal deaths and to consider initiatives to share insights and learning from the neonatal population as the ME system matures.
- An overview of the ME process is shown in **Appendix 2: National and Statutory Guidance**.

DRAFT

Role of the Medical Examiner

- Agree the proposed cause of death and the overall accuracy of the medical certificate of cause of death (MCCD) with the doctor completing it
- Discuss the cause of death with bereaved parent(s) (independent of those caring for the deceased) and establish if they have questions or concerns with care
- Act as a medical advice resource for the clinical teams and Coroner and ensure appropriate notification of death to the coroner
- Identify cases for further review under local mortality arrangements and contribute to other clinical governance processes including child death review.

Referral to His Majesty's Coroner (Eng, Wales, NI) or the Procurator Fiscal (Scot)

- The full criteria for referral to HMC/PF differ between England and Wales, Scotland and Northern Ireland[33,34,35] and are outlined in **Appendix 2: National and Statutory Guidance**; clinical teams need to be aware of their legal duties in this respect. General guidance regarding clinical interpretation of issues most pertinent to neonatal deaths are included below.
- If a live birth has been verified by a health professional other than a doctor (and/or midwife in Scotland) and the baby subsequently dies, a referral to HMC/PF referral is required. Referrals with regards to miscarriages and stillbirths differ across the UK. More details are included in **Appendix 3: Case Examples**: Table 1 and cases 1-4.
- Deaths that are unnatural, and those where the cause of death cannot be identified or explained, require referral to His Majesty's Coroner/Procurator Fiscal (HMC/PF). A death is potentially 'unnatural' and should be referred where there has been an act or omission in care which may have had a more than a minimal contribution to the death. This does not have to be an error in care and could, for example, be a recognised complication of necessary treatment. Referral in these cases should occur regardless of whether the cause of death is known and can be explained.
- Unexpected deaths are not a criterion for referral unless the death is felt to be unnatural, or there is no immediately apparent cause.
- On rare occasions, issues of care contributing to death might be identified sometime later (for example in PMRT or local governance reviews) in deaths initially considered 'natural'; in such cases HMC/PF should be informed although the MCCD may have already been written and the funeral taken place.
- Common clinical scenarios which can cause confusion or where clinical interpretation is variable are outlined in **Appendix 3: Case Examples**. Best practice recommendations are shown below and are based on clinical consensus.

DRAFT

Best practice recommendations for MCCD completion/ Referral HMC/PF

- Sensitively include relevant maternal diseases/conditions affecting the baby (<28-day MCCD)
- Be specific about conditions and congenital anomalies
- Where prematurity is a factor, always include the gestation in weeks.
- In babies over 24^{+0} weeks gestation, it is not usually appropriate to write the main cause of death "Extreme prematurity" without justifying it with further diagnoses or information.
- Hypoxic ischaemic encephalopathy should always be justified by its reason on a MCCD. There should be a very low threshold to refer such cases to HMC/PF.
- Where there is reasonable evidence to suggest infection, this can be included along with the source or "sepsis of unknown aetiology".
- Deaths which follow an operation necessitated by a natural illness need not be referred to HMC/PF unless the operation itself had a more than minimal contribution to the death
- Deaths should be referred to HMC/PF if an operative complication occurs and has a more than minimal contribution to death even if this is a recognised complication of the procedure.
- Clusters of deaths, or increased mortality rates or unexpected findings in individual case review need investigation. If any such investigations lead to concerns that previously unknown factors which require notification to HMC/PF may have contributed to the death in any individual case, then HMC/PF should be informed.

DRAFT

Communication with HMC/PF

- The named/lead consultant should support the family and liaise with HMC/PF team.
- When making the referral, it is important to inform the family of the reason for referral, that one cannot predetermine the level and timescale of HMC/PF's investigation, and that the investigation may include a post-mortem examination.
- Although the cases that require HMC/PF referral are defined by law, there is variation between Coroners in the mechanisms of referral, and their investigation processes.
- In all cases, referrals need to be timely and should provide accurate, detailed clinical information and contact information for the referrer and next-of-kin to best support HMC/PF in their investigation. It may also be appropriate to include the family's wishes with regards to postmortem whilst ensuring families are aware that the coroner will make a final decision on the need for postmortem examination.
- Neonatal units should develop good working relationships and processes with His Majesty's Coroner/Procurator Fiscal (HMC/PF, to enable clear communication channels and information sharing to best support bereaved families. This should include family consultation regarding how they would like to receive information. In England and Wales, the ME office will also have a close relationship with the coronial team and may be able to assist.

Sudden Unexpected Death

- Deaths meeting the criteria for sudden unexpected death (SUDIC/SUDI/PRUDiC/SUPC) are uncommon in neonatal units. Where these do occur, investigations and statutory procedures should follow national guidance[38,39,40,] (**Appendix 2: National and Statutory Guidance**). This includes a Joint Agency Response (JAR)/PRUDiC or equivalent) with precise arrangements for multi-agency involvement determined by the circumstances and place of the sudden collapse/death.

- Neonatal examples of when a JAR/PRUDiC or equivalent should be considered include:
    - baby born at home without medical professionals present and subsequently dies or was thought to be stillborn.
    - where the death is sudden with no immediate apparent medical cause.
    - where the initial circumstances of death raise any suspicion that the death may not have been natural.
- A JAR/PRUDiC should also be triggered if a baby is successfully resuscitated after any of the above events but is expected to die in the following days. In such circumstances the JAR should be considered at the point of presentation and not at the moment of death, since this enables an accurate history of events to be taken and, if necessary, a ‘scene of collapse’ visit to occur.
- If the attending neonatal consultant is uncertain about the need for a JAR/PRUDiC referral or equivalent, the case should be discussed with the designated doctor for child death, as part of the immediate decision-making processes.
- The BAPM Framework Sudden unexpected postnatal collapse (SUPC)[41] can also be used in specific circumstances (see below) but should not be used in isolation. The SUPC guidance aims to improve the likelihood of obtaining a diagnosis in babies who collapse soon after birth and there is often an opportunity to carry out investigations during the period of intensive care prior to death.

BAPM Sudden Unexpected Postnatal Collapse (SUPC) Framework Criteria

- Well at birth (Apgar 7+ at 5 minutes) and well enough to have routine postnatal care
- Term or near term (generally >35 weeks but may be applicable to less mature infants, particularly those nursed alongside their mothers whilst receiving postnatal care).
- Collapse within first 7 days following delivery, die or go on to require intensive care or develop encephalopathy.

DRAFT

Registering the death[42,43,44]

- Registration is the legal record of fact of death.
- The Registrar will issue the death certificate (Certificate of Registration of Death in Scot) and a certificate for the burial or cremation of the body (green form {Eng/Wal/Scot}, GR021 in NI), which is normally passed to the funeral director by the person making the arrangements; this document is necessary for the family to obtain the release of the body for funeral.
- If the birth has not been registered before the baby’s death, the team should inform the Registrars as both registration of birth and death would need to be done at the same time.
- The death must be registered within 5 days for Eng, Wales, NI (8 days in Scot).
- The registration of death in Eng/Wales/NI should be in the area/borough where the death occurred (telephone registration is available in NI if birth has been registered). Where birth and death are in different areas, registration of birth and death can occur in the area/borough where the death occurred. In Scotland, registration can be at any Scottish registration office.
- The person who registers the death is known as the ‘informant’. Either parent can register the death and if they are unable to do this another relative, or someone else present at the death, can register. In Scotland, only the mother can register the death if the parent(s) are not married.
- It is important to inform families that death registration will be delayed in cases investigated by HMC/PF.

Rapid Release

- Neonatal units should have guidance in place to facilitate rapid release of the baby's body on parental request e.g. urgent faith burial, taking the baby home or to a hospice.
- In families who wish for rapid release of the body, it is important to help manage expectations and recognise that where HMC/PF referral is necessary there may be delays.
- Where deaths are anticipated, discussions regarding organ donation, and with the ME +/- HMC/PF may be helpful in preparation, although for HMC/PF no formal decision can be made until the death has occurred.
- Neonatal units should ensure they know local arrangements for contacting the ME and HMC/PF out of hours. The chief coroner (England and Wales) has recommended that there should be an out-of-hours scheme in place across all coroner areas, to assist families[45]. However, HMC/PF services are local and out of hours provision varies.

Local Safety Reporting

- Any safety concerns or incidents associated with a neonatal death should be reported and investigated using the appropriate national patient safety incident reporting system (**Appendix 2: National and Statutory Guidance**) [46,47,48,49].
- The outcome of these investigations should be fed back to families by their named consultant.

Other Notifications

- GP, health visitor and community midwife (<24hrs/ next working day).
- NHS child public health and community-based healthcare records e.g. CHIS (Local Child Health Information System in England); Baby Box (Scot); notification to ensure clinic appointments, audiology screening, newborn screening and immunisations are not arranged.
- Other health care professionals involved in the baby's care in your hospital or other hospitals.
- **All Nations**
    - MBRRACE-UK[50] (< 48hrs/2 working days (Eng), no time limit for other UK nations)
        - for all deaths of liveborn babies, 20 weeks gestation or greater, who die up to 28 days after birth).
- **England only**
    - Statutory Child Death Overview Panel (CDOP) (<48hrs/ 2 working days)[18]
        - For all deaths of liveborn infants.
        - Notify via MBRRACE-UK CASCADE Process[51] if baby < 28 days old for joint MBRRACE-UK and CDOP/NCMD notification.
        - Babies >28 days – notify using CDOP notification form.
        - Notification should not be delayed where ME or HMC/PF are involved. Notify CDOP/NCMD with suspected cause of death, or state if unexplained.
        - The NCMD[52] utilises the notification data for real time surveillance and trend analysis, including quarterly ICB and ODN reports.
    - Maternity and Neonatal Safety Investigations (MNSI)[53](unspecified timing for notification)
        - for babies born 37+ weeks gestation with no congenital anomalies born following onset of labour who have an early neonatal death (<7 days) or intrapartum stillbirth.
        - Families should be informed about the referral and consent requested for MNSI to contact them.
        - An MNSI investigation should not prevent bereaved parent(s) from receiving

DRAFT

compassionate care and support from hospitals. Communication with families by the named consultant and key worker should continue.

  - A Single Notification Portal (Submit a Perinatal Event Notification -SPEN) will launch later in 2025 and facilitate a single notification for all the above notifications and NHS Resolution.

Child Death Review Meeting

Which babies should be reviewed?

- The review processes for deaths of live births should chiefly focus on babies who are born on or after 22+0 weeks gestation but should also include more immature babies if active resuscitation is undertaken.
- In England and Wales, the death review process (statutory in England)[18,24] includes all **live-born** babies where a death certificate has been issued. In practise, this will include babies born with signs of life below the limits of viability[54]. All these babies will require a CDOP referral, completion of analysis forms and any appropriate supplementary forms (Eng). Unattended stillbirths in the community also require referral to JAR and CDOP referral via obstetric/midwifery teams (Eng).
- In Scotland, the statutory death review process reviews all deaths of live-born children from 22 weeks (babies born with signs of life at <22 weeks are excluded)[23]. If the birth was not attended by a health professional, organisations may carry out initial enquiries to determine if the baby was born alive or not.

Child Death Review Meeting Process

The term Child Death Review Meeting (CDRM) is used to describe the local health professionals review of the care of a baby that has died. Locally, different terminology is often used including local morbidity and mortality (M&M) review, perinatal mortality review (PMR) and perinatal mortality review tool (PMRT).

Aims of Neonatal CDRM Review

- Identify the cause of each baby's death by robust and comprehensive review of each case and the quality of care provided.
- Identify contributory factors where issues are identified and assessing whether different care may have made a difference to the outcome (grading of care).
- Recognise good points in care as well as areas for improvement for shared learning
- Develop action plans to address the modifiable contributory factors identified and achieve organisational change and service improvements.
- Recognise a 'just culture' of accountability for individuals and organisations.
- Incorporate the parent(s)' perspective of care and address their questions and concerns.
- Provide parent(s) with a robust explanation of why their baby died (accepting that in some instances, despite full clinical investigations, it is not possible to determine this).
- Improve the care we provide for mothers, babies and families in the future.

- A trauma informed approach to mortality review processes should be used to enable families and staff to feel safe in raising concerns and identify learning (**Appendix 1: Supporting Families and Staff**).
- The child death review meeting (CDRM) in neonatal practice is predominantly conducted using the Perinatal Mortality Review Tool (PMRT) and for the purposes of the statutory Child Death Review (CDR) process qualifies as the local CDRM in England.

DRAFT

- Across the UK, the PMRT process should be used for all neonatal deaths in the first 28 days, regardless of where the patient dies, as it provides a standardised review.
- PMRT can also be used for babies who die in neonatal units after 28 days in neonatal units. The PMRT website[55] has a comprehensive list of guidelines, user manuals and training resources and online training.
- Information required to inform the CDRM review should be submitted promptly. Teams should have a process to expedite this to prevent unnecessary delays to the CDRM process.
- Where postnatal care has been more prolonged or complex, it may be helpful to have a CDRM focussed on postnatal events which then feeds into the PMRT.
- The review should proceed in a systematic fashion from pre-conception to bereavement and follow-up and be conducted in accordance with national and statutory guidance[18,23,24].
- Where the death is subject to external investigation (eg. HMC/PF, MNSI, PSIRF/ SAER/SAI or equivalent) the CDRM can be initiated before the results of these investigations are known to prevent delays in implementing any important learning (in N. Ireland the SAI investigator joins the CDRM). However, the CDRM should not be finalised until the results of external investigations have completed and been fed back to ensure comprehensive, joined up learning as timelines for these processes often differ.
- The PMRT should be completed at the CDRM. In England, the CDR draft analysis form also needs to be completed and submitted to the Child Death Overview Panel (CDOP) for final independent multi-agency review.
- After the review meeting parent(s) should be offered a meeting to discuss the findings and outcome of the review meeting.

Representation at the CDRM

- Where mothers and/or babies have been transferred, it is vital that there is good communication and sharing of information across organisations and all teams involved in the care should be represented including relevant speciality input (e.g. surgery, transport, ambulance services).
- The review should include both internal and external peer review of cases. Selecting the right external reviewer for the CDRM is crucial to ensure a thorough, unbiased examination. Ideally, the external reviewer should be a healthcare professional with significant expertise in perinatal and neonatal care and should be independent of the institution conducting the review.
- Neonatal ODNs should facilitate collation of contact details for clinicians in the network who are willing to undertake external review as well as working with other regions to support units to find external reviewers with similar expertise for complex cases where required e.g. neurosurgical, cardiac.
- Questions should be submitted by families via the key worker and/or lead consultant. The CDRM should ensure families views are included, and their questions answered. Parent engagement materials are included on the PMRT website[55].

Child Death Overview Panel (England only)

- Full details of roles and responsibilities of CDOP are outlined in statutory guidance[18].
- The CDOP aims to review cases to find modifiable factors within the care or service delivery of a death that could have a wider impact on learning from mortality. They will analyse the findings of the reports from the coroner, PMRT, MNSI and local PSIRF departments. CDOPs add data to national systems (NCMD) to learn from deaths and inform changes in practice.
- CDOPs can raise alerts of national relevance through the NCMD alert system, for escalation to NHS England.
- 'Themed' neonatal CDOP meetings are strongly recommended, to ensure that maximum learning is derived through aggregate review of deaths.

DRAFT

- Summaries of learning and modifiable contributory factors from CDOPs should feed into the neonatal ODNs for regional learning and to guide local and regional quality improvement strategies.

Child Death Review Programme (Wales only)

- Full details of the CDRP in Wales are contained in national guidance[24].
- All deaths are reviewed on a case-by-case basis with learning derived through aggregate thematic review of deaths.
- Strengthening of the information sharing between Neonatal ODN's and CDRP is recommended to ensure maximum learning is achieved.

DRAFT

Reporting, review and dissemination of learning

Reporting and review

- An overview of reporting outputs, data review requirements, dissemination of learning and assurance at local, regional and national level are shown in Figure 1 below.
- The core perinatal mortality governance team should consist of a neonatologist, neonatal nurse, midwife, obstetrician and where possible parent voice representation[56] e.g. MNVP (local) or PAG representative (regional)). Parent voice representatives should have access to psychological support when undertaking this work.
- Local and regional perinatal teams should review all relevant reporting outputs looking for recurring themes, developing and monitoring action plans, instigating further QI improvement work and benchmarking. Equality, diversity and inclusion should be a common thread throughout these reviews.
- Thought should be given to the strength of the action plan with systems-based solutions which eliminate human error developed wherever possible.
- Where possible, data collection for regional/national reporting and assurance purposes should be as aligned as possible –ongoing work is required to align the multiple systems currently in use.
- The regional ODN footprint provides a better platform for collating themes and shared learning. Regional level review should not repeat the local CDRM processes.
- The neonatal ODN should also promote a joined-up approach to review and shared learning in specialist areas e.g. surgery, cardiology.

Dissemination of learning

- Disseminating learning and actions from CDRM processes is essential for improving care.
- Barriers to sharing learning must be broken down as this is not in the best interest of babies and families. Systems need to work together to permit shared data outputs between key organisations involved in reviewing data (Fig 1).
- Learning from local CDRMs, patient safety investigations, and other local/regional reporting outputs should be shared across the local perinatal service, with other neonatal units, the neonatal ODN and regional maternity/perinatal systems and where appropriate with national organisations for dissemination (Fig 1).
- Keeping families informed about dissemination and implementation of actions is an important part of the grieving process and processes should be put in place to keep them informed.
- Mixed methods of communication should be used to disseminate learning e.g. huddles/handovers/newsletters/posters/message boards/emails/teaching sessions. A yearly audit of the methodology should be conducted to maintain assurance of message dissemination.
- Messages should be in a standardised format which allow staff to see the relevance of the learning to their clinical practice.

Assurance

- Review of benchmarking and outcome data against similar populations using reporting outputs (Fig 1) should be undertaken at local, regional and national level to ensure equity of outcomes for populations at high risk.
- Mortality data is complex with many external and potentially unmodifiable factors that impact on outcomes. Time should be spent to triangulate the different reports as they describe different aspects of the neonatal population. No one data source should be taken as “gospel”. Early warning signals should trigger further investigation to provide a deeper

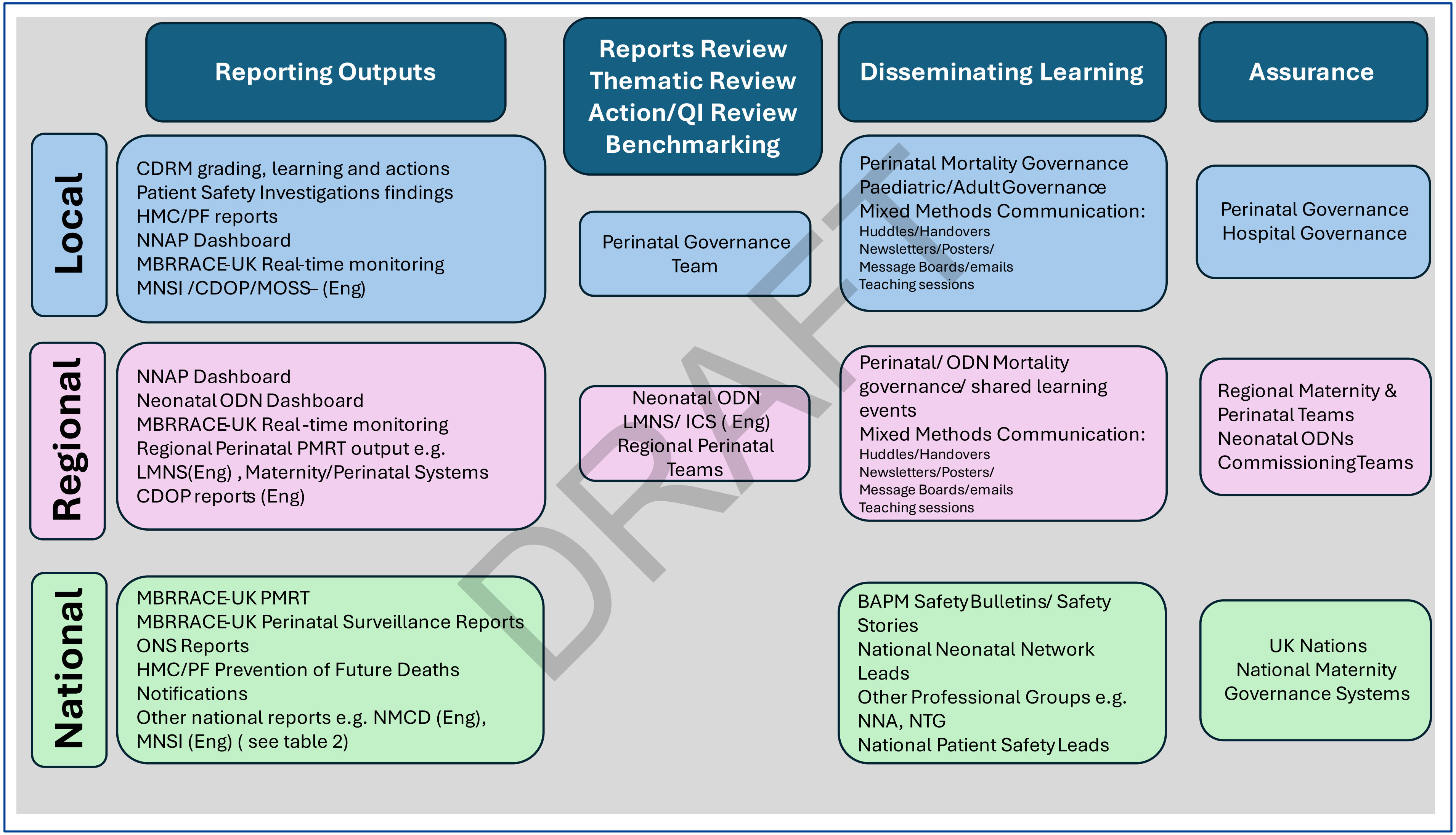
DRAFT

understanding.

- Neonatal ODNs should have a process in place for notifying neonatal/perinatal services about any concerns and for escalating concerns to regional perinatal and commissioning organisations where appropriate.
- Neonatal ODNs should provide quality assurance around the CDRM process, including reviewing representation at CDRMs, appropriate family input and response to their questions, PMRT outcome gradings and learning outputs. Neonatal units should provide ODNs with the information required to facilitate this.

DRAFT

Fig 1. Overview of Perinatal Mortality Governance Reporting, Review, Dissemination of learning and Assurance



	Reporting Outputs	Reports Review Thematic Review Action/QI Review Benchmarking	Disseminating Learning	Assurance
Local	CDRM grading, learning and actions Patient Safety Investigations findings HMC/PF reports NNAP Dashboard MBRRACE-UK Real-time monitoring MNSI /CDOP/MOSS– (Eng)	Perinatal Governance Team	Perinatal Mortality Governance Paediatric/Adult Governance Mixed Methods Communication: Huddles/Handovers Newsletters/Posters/ Message Boards/emails Teaching sessions	Perinatal Governance Hospital Governance
Regional	NNAP Dashboard Neonatal ODN Dashboard MBRRACE-UK Real-time monitoring Regional Perinatal PMRT output e.g. LMNS(Eng) , Maternity/Perinatal Systems CDOP reports (Eng)	Neonatal ODN LMNS/ ICS (Eng) Regional Perinatal Teams	Perinatal/ ODN Mortality governance/ shared learning events Mixed Methods Communication: Huddles/Handovers Newsletters/Posters/ Message Boards/emails Teaching sessions	Regional Maternity & Perinatal Teams Neonatal ODNs Commissioning Teams
National	MBRRACE-UK PMRT MBRRACE-UK Perinatal Surveillance Reports ONS Reports HMC/PF Prevention of Future Deaths Notifications Other national reports e.g. NMCD (Eng), MNSI (Eng) (see table 2)		BAPM Safety Bulletins/ Safety Stories National Neonatal Network Leads Other Professional Groups e.g. NNA, NTG National Patient Safety Leads	UK Nations National Maternity Governance Systems

DRAFT

DRAFT

Staff considerations

Staff support and training

- Staff must be trained appropriately to be able to deliver high quality end-of-life care; to provide good bereavement support and to be able to support the family to understand and contribute to mortality review processes.
- Staff and parent representatives e.g. MNVPs/PAGs must be aware of the psychological impact of this work on themselves and other staff and should receive appropriate training and support to mitigate psychological injury.
- A hot debrief[57,58] may be offered to affected staff members soon after the death or collapse of a baby (ideally within 24 hours) to share understanding, address immediate safety concerns, and provide support for staff.
- A cold debrief[59] focused on learning and/or wellbeing may also be offered sometime later.
- All staff likely to need to support hot or cold debriefs should be given specific training.
- Training for staff in understanding compassionate approaches to assurance and governance are strongly encouraged for all those involved in mortality governance review.
- More details on supporting staff, training requirements and resources are included in **Appendix 1: Supporting Families and Staff**.

Staffing to support bereavement care

- Bereavement and palliative care midwives and neonatal nurses are essential to support the bereavement process, provide expert bereavement support to families as well as ensuring the family voice is heard in the CDRM.

- BAPM staffing recommendations for bereavement support are included in full in the BAPM palliative care framework[4]. These include

    - 1xWTE band 7 midwife per 2500 deliveries.

    - 1xWTE band 7 minimum for NICUs.

    - 0.1-0.2 WTE band 7 for LNU/SCUs dependent on activity.

    - Consultant lead for palliative and bereavement care: 1-2PAs for NICUs, 0.1WTE per 1000 live births for LNUs/SCUs (minimum 0.2WTE).

Dedicated time to support mortality governance processes within neonatology

- Each unit should have a dedicated consultant and senior nurse for mortality governance with dedicated time to lead neonatal Child Death Reviews, thematic review, dissemination of learning and assurance processes.
- A recent neonatology consultant workforce survey highlighted insufficient time to lead child death review in job plans[60].
- For leadership of CDRM and thematic review and dissemination of learning BAPM recommends:
    - In NICUs: Medical Lead 1.5-2.5PAs, Nursing lead 0.15-0.25 WTE (depending on the size of the service).
    - in LNUs/SCUs: Medical Lead 0.5-1PAs, Nursing lead 0.05-0.1 WTE (depending on size of service).
    - Administrative support should also be provided.
- The above are requirements for the neonatal focus on mortality, separate to that required by maternity to support perinatal mortality governance.
- All networks should have allocated time for lead mortality governance roles for both medical

(minimum 1PA) and nursing (minimum 0.1WTE) staff to allow review of learning from neonatal network deaths, thematic review, network actions and QI and national benchmarking and assurance.

- All neonatal transport services should have allocated time for both medical and nursing staff to attend transport M&M review, as well as input to network and local CDRMs.
- Jobplans for all consultants should include appropriate time for:
    - Preparation of reports for CDRM and HMC/PF.
    - local CDRM meetings.
    - attendance at other hospital CDRM meetings in relation to care provided by your team; regional mortality governance and shared learning events, and CDOP panels.
- Jobplans should have for separate specific time allocated for external peer review at local and regional CDRM and CDOP panels.
- Where mortality governance activities are not appropriately remunerated, the time taken for these reviews should be recorded for local negotiation of job plans.

DRAFT

References

---

[1] Office for National Statistics. Child and Infant Mortality in England and Wales. [online]. ONS; 2022. ONS perinatal and child mortality

[2] Gallimore ID, Matthews RJ, Page GL, Smith LK, Fenton AC, Knight M, Smith PW, Redpath S, Manktelow BN, on behalf of the MBRRACE-UK Collaboration. MBRRACE-UK Perinatal Mortality Surveillance, UK Perinatal Deaths of Babies Born in 2022: State of the Nation Report. Leicester: The Infant Mortality and Morbidity Studies, Department of Population Health Sciences, University of Leicester. 2024 https://www.npeu.ox.ac.uk/mbrrace-uk/reports/perinatal-mortality-surveillance/perinatal-surveillance-2022

[3] National Child Mortality Database. Child Death Review Data Release: Year ending 31 March 2024. [online]. NCMD; 2024 Child death data release 2024 | National Child Mortality Database

[4] British Association of Perinatal Medicine. Recognising uncertainty: an integrated framework for palliative care in perinatal medicine. A BAPM Framework for practice. [online]. BAPM; 2024. https://www.bapm.org/resources/palliative-care-in-perinatal-medicine-framework

[5] Department of Health. Health Building Note 09-03:Neonatal units. https://www.england.nhs.uk/wp-content/uploads/2021/05/HBN_09-03_Final.pdf

[6] Hackett J, Heavey E, Beresford B. 'It was like an airbag, it cushioned the blow': A multi-site qualitative study of bereaved parent(s)' experiences of using cooling facilities. Palliative medicine. 2022; 36(2):365–74.

[7] NHS Blood and Transplant. Guidance for Neonatal Units when considering Organ and Tissue Donation as part of palliative and End-of-Life-Care. [online]. NHSBT; 2023. Infant Organ and Tissue Donation

[8] Scottish Government, Paediatric and Neonatal Organ and Tissue Donation. [online]. Govscot:document; 2018 Paediatric and Neonatal Organ and Tissue Donation Scotland

[9] NHS England. Perinatal post-mortam investigation of fetal and neonatal deaths (England and Wales). [online] 2024. NHS England » Perinatal post-mortem investigation of fetal and neonatal deaths (England and Wales)

[10] Human Tissue Authority. Codes of Practice and Standards. Code A: Guiding principles and the fundamental principle of consent. [online]. HTA; 2025. https://www.hta.gov.uk/guidance-professionals/codes-practice-standards-and-legislation/codes-practice

[11] Acts of Scottish Parliament. Human Tissue (Scotland) Act 2006. [online]. legislation.gov.uk; https://www.legislation.gov.uk/asp/2006/4/contents

[12] Osborn M, Cox P, Hargitai B, Marton T. G168 Guidelines on autopsy practice: Neonatal death. [online]. Royal College of Pathologists; 2019. G168 Guidelines on autopsy practice - Neonatal death For Publication.docx " .

[13] E-Learning for healthcare. Perinatal postmortem consent. [online]. NHS England. https://www.e-lfh.org.uk/programmes/perinatal-post-mortem-consent/

DRAFT

---

[14] Noble-Carr D, Carroll K, Copland S, Waldby C. Providing Lactation Care Following Stillbirth, Neonatal and Infant Death: Learning from Bereaved Parent(s). Breastfeed Med. 2023 Apr;18(4):254–64.

[15] British Association of Perinatal Medicine. Framework for Practice: Lactation and loss. Management of lactation following the death of a baby. [online]. BAPM; 2022. https://www.bapm.org/resources/lactation-and-loss-management-of-lactation-following-the-death-of-a-baby

[16] BAPM. The use of Donor Human Milk in Neonates Framework. A BAPM Framework for Practice. [online]. BAPM; 2023. BAPM Donor Milk FFP

[17] Academy of Medical Royal Colleges. A Code of Practice for the diagnosis and confirmation of death 2025 Update. [online]. AoMRC; 2025. AoMRC Diagnosis and Confirmation of Death

[18] HM Government. Child Death Review Statutory and Operational Guidance (England). [online]. Gov.uk; 2018. Child Death Review Guidance England

[19] Burden C, Bakhbakhi D, Heazell AE, Lynch M, Timlin L, Bevan C, et al. Parent(s)' Active Role and Engagement in The review of their Stillbirth/perinatal death 2 (PARENT(S) 2) study: a mixed-methods study of implementation. BMJ Open. 2021 Mar;11(3):e044563

[20] National Bereavement Care Pathway for pregnancy and baby loss, National Bereavement Care Pathway. [online]. NBCP; 2022. https://www.nbcpathway.org.uk/

[21] Welsh Government. End of life care and bereavement. [online]. Gov.wales; 2021. https://www.gov.wales/end-of-life-care

[22] National Bereavement Care Pathway for pregnancy and baby loss in Scotland, National Bereavement Care Pathway. [online]. NBCP ; 2022. https://www.nbcpscotland.org.uk/about-us/nbcp-in-scotland/

[23] Health Improvement Scotland, National Hub for Reviewing and Learning from the Deaths of Children and Young People. [online]. NHS Scotland; 2021. HIS National Guidance when a child or young person dies

[24] Public Health Wales. Child Death Review Programme. [online]. NHS Wales; 2009. Child Death Review - Public Health Wales

[25] Chief Coroner's Guidance No.45. Stillbirth, and Live Birth Following Termination of Pregnancy. [online]. Courts and Tribunals Judiciary; 2023. Chief Coroner's Guidance No.45

[26] Scottish Government. Maternity and neonatal (perinatal) adverse event review process: guidance. [online]. gov.scot; 2023.Scottish Mat Neo adverse event review process guidance

[27] Judiciary NI. In Her Majesty's Court of Appeal in Northern Ireland. Neutral Citation No. NICA 68 [online]. judiciaryni; 2013. NICA 68 2013 Landmark Decision

[28] MBRRACE-UK. Determination of signs of life following spontaneous birth before 24+0 weeks gestation where, following discussion with the parent(s), active survival-focused care is not appropriate [online]. MBRRACE-UK; 2020. MBRRACE-UK Signs fo LIfe Guidance

DRAFT

---

[29] Academy of Medical Royal Colleges: A Code of Practice for the diagnosis and confirmation of death 2025 Update. [online]. AoMRC; 2025. AoMRC Code of Practice Diagnosis of Death 2025

[30] Department of Health and Social Care. Guidance for medical practitioners completing medical certificates of cause of death in England and Wales. [online]. Gov.uk; 2025 Guidance for completion of MCCD Eng Wales

[31] NI Department of Health. Guidelines for Death Certification – Issuing MCCD using NIECR. [online]. ni.gov.uk; 2022. https://www.health-ni.gov.uk/publications/guidelines-death-certification-issuing-mccd-using-niecr

[32] Chief Medical Officer. Guidance for Doctors completing Medical Certificates of the cause of death (MCCD) and its quality assurance, [online]. National Records of Scotland; 2018. https://www.publications.scot.nhs.uk/files/cmo-2018-11.pdf

[33] Ministry of Justice. Guidance for registered medical practitioners on the Notification of Deaths Regulations. [online]. Gov.uk; 2024. Notification of Death Regulations

[34] NI Department of Health. Guidelines for Matters Relating to the Coroner. [online]. ni.gov.uk; 2018. https://www.health-ni.gov.uk/publications/guidelines-matters-relating-coroner

[35] Crown Office & Procurator Fiscal Service. Reporting deaths- information for medical practitioners. [online]. Gov.uk; 2019. https://www.copfs.gov.uk/publications/reporting-deaths/

[36] UK Statutory Instruments No 493. Medical Examiners (England) Regulations 2024. [online]. Legislation.gov.uk; 2024. Medical Examiner England Regulations

[37] Fletcher A. National Medical Examiner's Good Practice Series No. 6: Medical Examiners and child deaths [online]. RCPath; 2024. RCPath Good Practice Series ME and child death

[38] Royal College of Pathologists. Sudden and Unexpected death in Infancy and childhood. [online]. RCPath; 2016. RCPath SUDiC

[39] Public Health Wales. PRUDiC (Procedural Response to Unexpected Death in Childhood). [online]. NHS Wales; 2023. PRUDiC Guidelines

[40] Healthcare Improvement Scotland. SUDI Guidance and support documents. [online]. HIS; 2023. HIS SUDI Guidance

[41] British Association of Perinatal Medicine. Sudden and Unexpected Postnatal Collapse. A BAPM Framework for Reducing Risk, Investigation and Management. [online]. BAPM; 2022. BAPM SUPC Framework

[42] HM Government. Register a death. [online]. https://www.gov.uk/register-a-death

[43] NI Direct Government Services. [online]. https://www.nidirect.gov.uk/articles/registering-death-district-registrar

[44] National Records of Scotland. [online]. https://www.nrscotland.gov.uk/registration/registering-a-death/

DRAFT

---

[45] Chief Coroner. Guidance No. 28. Report of death to the coroner: decision making and expedited decisions. [online]. Judiciary.uk; 2018. Chief Coroner Guidance 28

[46] NHS England. Patient Safety Incident Response Framework. [online]. https://www.england.nhs.uk/patient-safety/patient-safety-insight/incident-response-framework/

[47] NHS Wales. National Policy on Patient Safety Incident Reporting. [online]. nhs.wales; 2023. https://du.nhs.wales/files/incidents/national-policy-on-patient-safety-incident-reporting-2-0-pdf/

[48] NI Department of Health. NIAIC adverse incident reporting – guidance and forms. [online]. HSCNI; 2023. NIAIC adverse incident reporting

[49] Healthcare Improvement Scotland. A national framework for reviewing and learning from adverse events in NHS Scotland: February 2025. HIS; 2025. HIS Reviewing and Learning from adverse events

[50] MBRRACE-UK. [online]. https://www.npeu.ox.ac.uk/mbrrace-uk

[51] MBRRACE-UK. Guidance: New process in England for notifying neonatal deaths to CDOPs. [online]. NPEU; 2025. MBRRACE-UK Cascade

[52] National Child Mortality Database. [online]. https://www.ncmd.info/

[53] Maternity and Neonatal Safety Investigations. [online]. https://www.mnsi.org.uk/

[54] British Association of Perinatal Medicine. Perinatal Management of Extreme Preterm Borth Before 27 weeks of Gestation [online]. BAPM; 2019. BAPM Extreme Preterm Birth Framework

[55] National Perinatal Epidemiology Unit. Perinatal Mortality Review Tool. Implementation Support [online]. PMRT Resources

[56] NHS Resolution. Maternity (and Perinatal) Incentive Scheme [online]. 2024 MIS-Year-6-guidance.pdf

[57] Paediatric Innovation Education and Research Network. Debrief tools after a difficult event. [online]. PIERnetwork; 2023. https://www.piernetwork.org/debrief.html

[58] Walker CA, McGregor L, Taylor C, Robinson S. STOP5: a hot debrief model for resuscitation cases in the emergency department. Clin Exp Emerg Med. 2020 Dec;7(4):259–66.

[59] Kolbe M, Schmutz S, Seelandt JC, Eppich WJ, Schmutz JB. Team debriefings in healthcare: aligning intention and impact. BMJ. 2021 Sep;374:n2042.

[60] British Association of Perinatal Medicine. Consultant working patterns. A BAPM report. [online]. BAPM; 2023. BAPM consultant working patterns

DRAFT

Appendix 1: Supporting families and staff

A compassionate, trauma-informed framework

The death of a baby is deeply painful and distressing for families. This distress is felt across the whole system by clinicians, teams and organisations. Additionally, in a clinical setting, the subject of mortality may be presented as failure, thereby placing neonatal death and mortality governance within a context of threat. The governance processes that follow a neonatal death provide an opportunity to shape understanding and psychological adjustment to loss for all those affected as well as providing opportunities for whole system learning.

To reduce the psychological impact of neonatal death and mortality governance on parents, families and staff, this framework assumes a trauma informed approach[1], by:

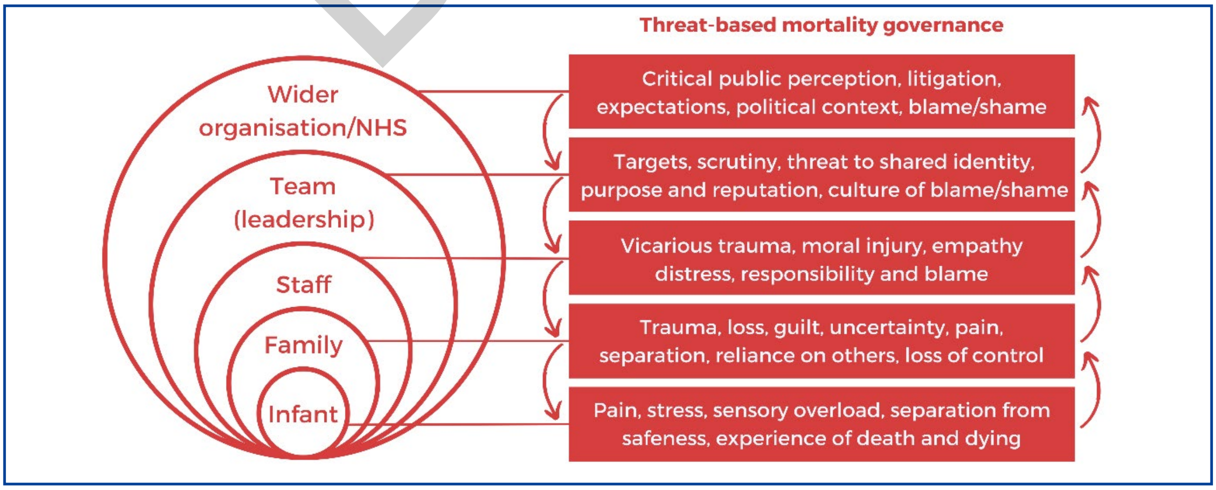
- **Realising** the potential for neonatal loss and related governance processes to be experienced by parents, families and staff as traumatic.
- Supporting staff to **recognise** when people (including themselves) are experiencing trauma in the context of perinatal loss. Outlining pathways for responding to trauma through additional support.
- **Responding** to signs of trauma with appropriate support and signposting.
- **Resisting** re-traumatising parents, families and staff in the way that mortality governance is approached (including how the mortality review process is navigated).

DRAFT

A key role for compassion

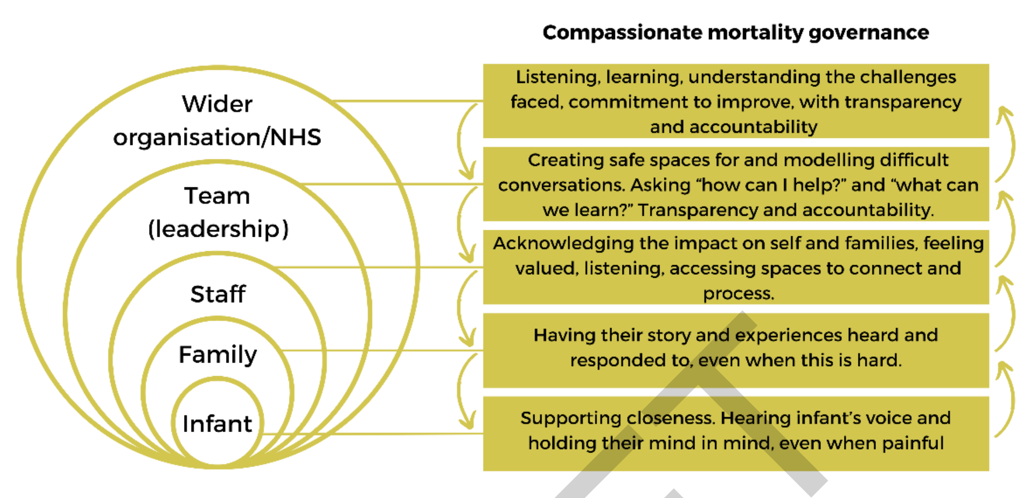
The context of distress and threat inherent in discussions of mortality may hinder learning. For example, fear of criticism and punishment may reduce trust and transparency or lead a team to seek to blame other parts of the baby's care for what happened. It is hard to learn or move forward through grief when faced with a context of threat. Figure A1 illustrates this threat-based approach to assurance processes in mortality review.

Figure A1. A threat-based model of governance, with threat being maintained through interactions between different parts of the system.



When mortality review at an organisational and local level can be approached with compassion, both learning and healing can begin. Compassion entails a sensitivity to the pain and suffering of self and others, with a commitment to relieving that suffering. In the context of mortality review, compassionate wisdom involves having courageous conversations about uncomfortable truths, whilst remaining connected as caring humans to find shared ways forward. Figure A2 illustrates this compassionate approach to assurance processes within mortality review, which is explored in depth by Evans and colleagues [2,3].

Figure A2. A compassionate model of mortality governance, with compassion filtering up and down through the system.



Compassionate mortality governance

Listening, learning, understanding the challenges faced, commitment to improve, with transparency and accountability

Creating safe spaces for and modelling difficult conversations. Asking "how can I help?" and "what can we learn?" Transparency and accountability.

Acknowledging the impact on self and families, feeling valued, listening, accessing spaces to connect and process.

Having their story and experiences heard and responded to, even when this is hard.

Supporting closeness. Hearing infant's voice and holding their mind in mind, even when painful

Universal Support for families and staff

Background

The death of a baby is a devastating experience for families, having far-reaching psychological consequences on parents and the wider family[4–7]. This leads to an increased risk of mental health difficulties in families, including depression, anxiety, post-traumatic stress disorder and suicidal ideation[8–11]. While the experience of parents (as most often the legal guardians of a baby) is of utmost importance in this framework, the needs of other family members (including siblings, grandparents and extended family members) should also be considered[12].

A detailed discussion of the comprehensive psychological, emotional, social, spiritual and practical support that families need in the period before and after a neonatal bereavement is beyond the scope of this framework. It should be noted that families do not experience the mortality governance process in isolation and so this framework should be read alongside other relevant guidance for high quality bereavement care such as the Neonatal Death Bereavement Care Pathway[13].

Staff who work with perinatal loss are at risk of burnout and, relative to their colleagues, elevated levels of post traumatic stress disorder, depression and psychosomatic symptoms[14]. This impact is greater for staff with lower perceived competence in the work, highlighting the need for adequate skills training (see below).

The skills and support required by staff involved in mortality governance processes go above and beyond bereavement care. Staff involved in perinatal mortality review, coroner's court and child death overview panel have continued contact with families through a time of increased and extended psychological vulnerability. This increases the chance of encountering situations that require coping skills to navigate moral distress, empathy distress fatigue and secondary traumatic stress. Staff who are well supported (with adequate skills training and wellbeing support) will provide better quality patient care, have greater satisfaction in work and lower sickness absence.

Below is a discussion of the universal support that is needed to support the wellbeing of families and staff through the mortality governance process. To create optimal conditions for system-learning

DRAFT

and psychological support within the mortality governance process, the following universal support is needed, to promote the principles of trauma informed care[1]:

- **A felt sense of safety:** Families and professionals feel that they are in a safe environment.
- **Trust & transparency** between families and professionals involved in mortality governance.
- **Collaboration & mutuality** in the relationships between families and professional teams.
- **Peer support** for families and staff.
- **Empowerment, voice and choice** for families within the requirements of statutory processes.
- Sensitivity to **cultural, historical and gender issues**.

Support for families

- **A felt sense of safety**

  Mortality governance processes are intended to reduce uncertainty and provide answers for both families and clinical teams, to better understand the causes and circumstances around a baby's death. Such answers can help parents to feel that their future perinatal care will be safer, or that they have contributed to safer perinatal care more broadly, bringing meaning to their grief and suffering. These processes can, however, expose family members to highly distressing information, and ultimately may not remove uncertainty completely.

  The emotional wellbeing of family members should be born in mind at all time points. This does not mean overly protecting families or avoiding distressing conversations but rather maintaining an open dialogue about what support they need to engage in mortality governance processes in a way that feels safe for them.

- **Trust and transparency**

  Even when governance addresses difficult or uncomfortable truths, it is crucial that communication with families prioritises transparency. Aside from duty of candour, transparency fosters trust, which promotes positive collaborative relationships – benefiting family and team.

  Emotionally attuned, compassionate communication with families is of paramount importance throughout the mortality governance process. 'Being heard' and 'recognised as a parent' are extremely important[15,16]. Insensitivity and poor communication have been highlighted as a factor that causes distress or feelings of helplessness in some cases [15,17]. Guidelines for effective communication can be found in the Code of Practice for the diagnosis and confirmation of death[12]. However, it should be noted that effective communication is a complex set of relational skills, and cannot be adequately conveyed in a written guideline.

  - All staff involved should have access to high quality specialist dialogical communication skills training, including opportunities for experiential, reflective learning with feedback[18].
  - Sands provides a range of specialist training workshops focusing on communication, for staff in clinician and non-clinical roles[19].

- **Peer support**

  Research and feedback from families repeatedly demonstrates the value of peer support from other families with lived experience following perinatal loss[20]. Families should be able

DRAFT

to access such peer support, and should be facilitated to do so. This can either be through large organisations such as Sands or local community-based groups. Hospitals teams should develop relationships with local peer support groups and maintain accessible information about how to access this support.

- **Collaboration and empowerment**

  Involvement of families in mortality governance improves dialogue and continuity of care between parents and providers[21] and supports parents to maintain a purposeful role following the death of their baby.

  - All families should have a named lead consultant and a named keyworker (this is a statutory requirement in England) who can act as a consistent point of contact for families to facilitate support, communication and engagement in the process, including involvement in PMRT/CDRM and CDOP meetings.
  - The Child Death Review Toolkit contains guidance to support professionals and services to ensure adequate support to families through the process[22].
  - Guidelines for effective communication with families can be found in the Code of Practice for the diagnosis and confirmation of death[12].
  - The level of involvement that families wish to have in the mortality governance process will vary and should be agreed, and continually reviewed, through discussion with the family[23].
  - All information required for the PMRT should be submitted promptly. Teams should have a process to expedite this to prevent unnecessary delays in the CDRM process.

DRAFT

Consensus from professionals and a parent collaborative group on the engagement of families in the perinatal mortality review process gave the following recommendations[24].

1. There should be a face-to-face explanation of the perinatal mortality review process, supported by a written information leaflet, prior to hospital discharge.
2. The form to obtain parental feedback should be completed in a face-to-face consultation at a private location of the parents' choice (if declined, option to receive feedback by telephone, e-mail or post should be offered).
3. The parents should be offered the opportunity to nominate a suitable advocate or bereavement-care midwife or nurse, who will complete the feedback form with the parents and attend the perinatal mortality review meeting.
4. All healthcare professionals involved in the case should be notified of the perinatal mortality review meeting in good time and attend where possible.
5. Staff involved in the case who cannot attend the perinatal mortality review meeting should, at the very least, submit their comments.
6. Responses to the parental feedback should be formally documented in the perinatal mortality review meeting.
7. If necessary, action plans should be made from the parental responses and monitored.
8. A plain-English summary should be produced for the parents following the perinatal mortality review meeting.
9. The feedback from the perinatal mortality review meeting should be discussed at the consultant follow-up meeting, supported by the plain-English summary.
10. The consultant follow-up meeting should take place as soon as possible after the perinatal mortality review meeting (approximately 2–4 weeks).
11. Parents should have the option to nominate a second member of staff (who could be the designated parents' advocate) to attend the follow-up meeting with the consultant.
12. If the parents decline to attend the consultant follow-up meeting, then the written plain-English summary should be offered to be sent to the parents instead.
13. There should be four different parental feedback forms (for stillbirth, neonatal death, coroner's case and termination for fetal abnormality).
14. The meeting should take place within approximately 12 weeks from the baby's death.

DRAFT

- **Cultural and spiritual sensitivity**

Care should be sensitive to the intersectional cultural, spiritual and individual identities and needs of families. Different families observe diverse important practices around the death of a baby, and cope with bereavement in different ways[25]. Specific guidance and information can be found in existing resource[26,27]. Online training is provided by The Lullaby Trust to aid in understanding the cultural context of grief[28].

It is paramount to ask all families what their particular preferences and needs are for all stages of the mortality governance process, and not to make assumptions that parents have specific wishes based on their cultural or religious backgrounds. This should be particularly born in mind when considering the timescale of the process, and the use of devices such as cool cots, as some communities have particular requirements regarding the timing of a baby's funeral.

Families may find that a process of memory making at or near the end of life aids the process of grief and loss[29]. Clinical staff should discuss this with families at an early stage to understand what meaningful memory making might involve for each family.

Chaplaincy within the hospital setting can be a helpful resource to facilitate families' preferences from an early stage, as well as community and religious or spiritual leaders from the family's own network.

To ensure accessibility of the whole mortality review process, all written materials should be available in a range of languages appropriate for the local population served.

DRAFT

Support for staff

- **A felt sense of safety**

When staff feel safe to ask for help, share struggles and name mistakes, the safety and quality of care improves as does the wellbeing of the staff team. Such psychological safety is crucial to consider when approaching learning events such as mortality review meetings, system or network-wide shared learning events.

Whilst accountability (taking ownership of actions and their consequences) is an important positive step for learning and development, blame (assigning fault and responsibility for a death) is unhelpful and reliably undermines psychological safety. Blaming leads to shame which inhibits learning. Blame is a common response when people acting from the psychological experience of threat seek to understand the causes of an incident. Psychological safety is a culture in which people feel able to name their mistakes or difficulties without fear of blame or judgement. Psychological safety does not ignore mistakes or difficulties. Rather it holds people accountable for their actions, but without resorting to blame and shame.

Psychological safety is fostered through cultures of openness, humility and compassion, where the intention is to ask "What help do we need?" rather than "Who is to blame?" There are well evidenced reasons why this is difficult and requires significant scaffolding across all layers of the system[2]. Practical steps towards compassionate, psychologically safe maternity and neonatal cultures are outlined by Evans and colleagues[3]. Psychological safety in a team is facilitated through other collective, connecting approaches such as reflective practice sessions and group supervision.

- **Trust and transparency**

Transparency of information sharing and communication both within and between teams is crucial, to foster trusting relationships. Trust and transparency contribute to a culture of accountability and learning, and provides the connected relationships that facilitate feelings of belongingness and wellbeing.

Debrief is one activity where transparent sharing of information can occur, in addition to other key meetings and forums such as mortality review meetings. Detailed consideration of debriefing practice is discussed below.

- **Peer support**

  Peer support should be facilitated both within and between teams. Peer support is about fostering a community with shared identity and relational safety – rather than simply providing a forum for shared learning. Debrief is one way to approach this. Other approaches include trained peer supporters within a staff group who can facilitate access to additional support. Neonatal Networks and local systems are well placed to facilitate peer support, especially between staff from different types of unit to promote transparency and broaden the community of support beyond the immediate team.

- **Collaboration and empowerment**

  Staff, regardless of their position or seniority, who have been involved in the care of a baby who dies should be empowered to have an active voice in the mortality governance processes that follow. This can follow the principles outlined in the Patient Safety Incident Response Framework (PSIRF (30)). Although not all neonatal deaths will be responded to formally using PSIRF, the underlying principle of compassionately involving all those impacted by the neonatal death (family members and staff) provides a helpful framework to guide support from staff.

  Other pathways of reporting can empower staff to contribute their voice to mortality governance, including Maternity and Neonatal Safety Champions, and Freedom to Speak Up Guardians. All trusts should ensure that such roles are in place, adequately resourced and easily accessible to all staff in the team. BAPM has produced guidance on ‘How to Raise a Concern’ for neonatal professionals[31] if such actions are required.

- **Cultural and spiritual sensitivity**

  Staff bring with them personal beliefs about death and dying – shaped by their culture, spirituality, gender and more – which impact on their experience of working with families who suffer a neonatal death. Care should be centred around the beliefs and experiences of families. This means that the intersection of the personal beliefs of family and staff can sometimes lead to significant moral distress for staff – where they are being asked to provide care that threatens or even violates their moral code. Staff should have the opportunity to reflect on their own intersectional identities and how this shapes their beliefs about the work that they are doing.

Targeted Support for families and staff

There are particular groups who may need targeted or particularly tailored support through mortality governance processes, to ensure they are able to access the universal information and support available. The information below is not exhaustive and providers should discuss any particular support needs with families individually.

Support for families

- **Parents with further needs**

  Autistic people may have specific ways of thinking about death and associated rituals. They might need additional support, in the way of adapted communication, to understand the

DRAFT

feelings and behaviour of other people, or to understand what has happened, and what might happen next in the process.

As with all families, the best way to support an autistic person is to get to know them, their strengths and their particular needs especially around adaptations to assist them in processing and communicating information. Additional information can be found on the autism.org website[32].

Adults with learning disabilities might have a reduced ability to understand new or complex information; struggle to learn new skills; and have difficulty coping independently. This group are at risk of exclusion from services due to a lack of adequate tailored support. The production of easy-read information resources; the use of advocacy services or other specialist professionals (such as learning disability nurses, social workers, psychiatrists, psychologists or speech and language therapists); and additional time and flexible arrangements to allow for processing of complicated information can help.

- **Children and young people**

  Although child siblings will not likely be directly involved in mortality governance processes, they may well have questions and needs arising from the information that is shared with their family. In some instances, young parents themselves may still be children. A list of resources available to support children, young people and those with special educational needs, in their understanding of bereavement can be found on the Child Bereavement UK website[33].

- **Families going through coronial proceedings**

  The particular stresses of a coroner's investigation cannot be underestimated. In fact, the counter-therapeutic impact for families of coronial investigations has been highlighted[34]. Families report valuing the presence of an advocate, either from within their existing network or from a professional organisation such as the Coroners Court Support Service[35].

DRAFT

Support for staff

There are particular groups who are more likely to experience a detrimental psychological impact of this work, by the nature of and proximity to their work. This includes staff who are directly involved in specific mortality governance processes, such as Child Death Review Keyworkers; bereavement midwives and nurses; staff involved in PMRT or CDOP, and any staff who are required to contribute to a coronial investigation. For these staff, restorative spaces such as clinical supervision, psychological case consultation and reflective practice groups can help mitigate the risks linked to the job. Professional Nurse Advocates are able to provide restorative clinical supervision, and specialist psychological professionals provide this range of interventions when integrated into the team.

Other processes such as Trauma Risk Management (TRiM) can be helpful to implement across provider trusts, and can be helpful to trigger following the death of a baby, to facilitate the recognition of those staff members who might benefit from additional support.

Specialist Support for families and staff

Support for families

For some families, particularly when there are already mental health difficulties or there is previous trauma present, the death of a baby can result in a deterioration in their mental health. To provide safe and inclusive mortality governance processes, providers should ensure:

- **Skills in screening for mental health difficulties**

Clinical staff working with families who have experienced bereavement, particularly during mortality governance processes, should be provided with training to recognise and identify signs of common mental health difficulties (see Support for staff section).

- **Signposting to services for the provision of mental health support**

  There is emerging evidence for psychological interventions to support the mental health of parents following perinatal loss[36] including cognitive behaviour therapy, and eye movement desensitisation and reprocessing[37]. Providers should have clear pathways of referral to local services such as local psychiatric support, NHS Talking Therapies, Maternal Mental Health Services, or their GP, to facilitate access to this support.

- **Psychological professionals integrated into the multidisciplinary team**

  The ability of staff teams to recognise and respond effectively to the psychological needs of families is significantly enhanced by the integration of psychological professionals into the multidisciplinary neonatal team[38]. Specialist neonatal psychological professionals can facilitate training, case consultation, reflective supervision to the team caring for families through mortality governance processes and also provide bereavement-focused psychological interventions where this is indicated.

Support for staff

When staff experience a deterioration in their mental health as a result of the emotional labour of their work with mortality, they should be able to access support from a range of sources. Above all, trusts should ensure that this support is easy to access, clear and responsive. The support should be multi-faceted to ensure that all staff needs can be addressed, including:

- Trust-wide psychological staff support services
- Employee assistance programs
- Occupational health services
- Practitioner Health
- Local external providers (e.g. NHS Talking Therapies)

Above all, it is of utmost importance that psychological professionals are integrated into the neonatal MDT. These specialists facilitate the recognition and signposting of mental health difficulties within the staff team related to the impact of working with death and dying, and can also offer focused interventions that are highly accessible.

DRAFT

Debriefing

Clinical teams should develop clear and consistent pathways of debriefing following the death of a baby. There are many different models and approaches to debriefing, with detailed protocols available at the Paediatric Innovation, Education and Research Network (PIER) website (39). Key to effective debriefing, is to approach with flexibility, addressing the clinical or emotional concerns of those present rather than being rigidly constrained by a protocol.

Common approaches to debriefing contrast “hot debrief” – carried out immediately after an incident, or within the same shift – and “cold debrief” – carried out in the days or weeks following an incident.

Hot debrief

The aim of a “hot debrief” is to ensure that any immediate safety concerns (both clinical and related to patient and staff wellbeing) are addressed in a timely manner. There may be specific questions that team members need to voice, answering which may prevent unhelpful patterns of rumination and catastrophic thinking for some. There are different published protocols for hot debrief, such as that available at the PIER website[39] or STOP5[40].

Cold debrief

"Cold debrief" is an umbrella term for multiple different types of conversation, which have different aims and intentions. The process and content of a cold debrief will differ according to the aim and intent. Therefore it is crucial to be clear about the intended aim before convening a cold debrief. The three primary types of debrief, identified by Kolbe and colleagues[41] are:

- **Debriefing to learn**.

Aim: This is a clinical governance-focused activity, with the intention of learning from what has happened. The aim is to identify areas of strong clinical practice and development needs within the team and its standard care processes.

Content: Details of the chronology and clinical scenario are examined from different angles. More detail about "debriefing to learn" can be found at PIER[39].

- **Debriefing to manage**.

Aim: This is a wellbeing-focused activity, with the intention of addressing the psychological needs of staff, to promote a culture of psychological safety, feelings of calm, self-efficacy, hope and connection[42]. The aim is to promote connection between members of the team and shared narratives.

> *Content:* Staff share stories of their emotional responses to the incident and their resonance with colleagues is explored.. Detailed guidelines for the facilitation of "debriefing to manage" (also known as "Post-Event Team Reflection) by specialist psychological professionals or other mental health professionals has been produced by the Association of Clinical Psychologists[43].

- **Debriefing to treat**.

Aim: This is an interventional activity, with the intention of undertaking group treatment for trauma-related psychological difficulties.

Content: **This is counter-indicated by the literature, can cause psychological harm and should not occur.**

DRAFT

Supporting skill development for staff

Staff need training that covers the range of competencies outlined below. Particularly for interpersonal and relational skills, initial training delivery should be followed by continued opportunities to embed learning through experiential and reflective practice (including simulation, video feedback guidance, reflective practice or supervision groups and psychological debrief[18]). Training for all staff should cover:

- High quality bereavement care, in line with guidance of the Neonatal Death Bereavement Care Pathway. National providers include:
  - https://training.sands.org.uk/
  - https://www.childbereavementuk.org/training
  - https://bereavementtraining.com/
- Support for families following loss of a baby in multiple pregnancy. Resources available at:
  - https://www.neonatalbutterflyproject.org/
- Recognition and signposting of mental health deterioration, for example:

    - https://mhfaengland.org/
- Cultural competence around death and dying. National providers include:
    - https://www.lullabytrust.org.uk/professionals/training/bereavement-training/
- Compassionate communication. For example:
    - https://training.sands.org.uk/
    - https://www.therelationalpractice.co.uk/
    - https://www.theneonatalpractice.co.uk/

Training for staff involved in specific processes should cover:

- Post-mortem consent taking. E-learning for this topic can be accessed:
    - https://www.e-lfh.org.uk/programmes/perinatal-post-mortem-consent/
- The role of the child death review keyworker
    - See https://www.ncmd.info/ for details
- Debrief. There are multiple models of debrief, for which training is available, including Post-Event Team Reflection; Critical Incident Stress Debriefing; Trauma Risk Management. National providers of these trainings include:
    - https://www.marchonstress.com/
    - https://www.tidaltraining.co.uk/
- Compassionate mind approaches to mortality governance and assurance processes. For example:
    - https://www.therelationalpractice.co.uk/

A range of learning resources are outlined in the Care After Death guidance (5th edition) produced by Hospice UK[44].

DRAFT

References

1. Substance Abuse and Mental Health Services Administration. SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. 2014.
2. Evans D, Butterworth R, Atkins E, Chilvers R, Marsh A, Barr K, et al. The anatomy of compassion: courage, connection and safeness in perinatal practice. Infant. 2023;19(3):88–92.
3. Evans D, Butterworth R, Atkins E, Barr K, Chilvers R, Cole S, et al. The anatomy of compassion part 2: nurturing compassionate cultures of maternity and neonatal care. Infant. 2023;19(6):213–8.
4. Bothou A, Bothou M, Tsikouras P, Iatrakis G, Anthoulaki X, Chalkidou A, et al. Consequences of perinatal mortality in parents' psychology and the role of health professionals in its management. Rev Clin Pharmacol Pharmacokinet Int Ed [Internet]. 2023 Oct;35(2):67–74. Available from: https://doi.org/10.5281/zenodo.10048497
5. Aydin R, Kabukcuoğlu K. Fathers' Experiences of Perinatal Loss: A Sample Meta-Synthesis Study. J Fam Issues [Internet]. 2021;42(9):2083–110. Available from:

https://doi.org/10.1177/0192513X20966002

6. Lockton J, Oxlad M, Due C. Grandfathers' Experiences of Grief and Support Following Pregnancy Loss or Neonatal Death of a Grandchild. Qual Health Res [Internet]. 2021;31(14):2715–29. Available from: https://doi.org/10.1177/10497323211041331

7. Kirui KM, Lister ON. Lived Experiences of Mothers Following a Perinatal Loss. Midwifery. 2021 Aug;99:103007.

8. Christiansen DM. Posttraumatic stress disorder in parents following infant death: A systematic review. Clin Psychol Rev. 2017 Feb;51:60–74.

9. Gausia K, Moran AC, Ali M, Ryder D, Fisher C, Koblinsky M. Psychological and social consequences among mothers suffering from perinatal loss: perspective from a low income country. BMC Public Health [Internet]. 2011;11(1):451. Available from: https://doi.org/10.1186/1471-2458-11-451

10. Herbert D, Young K, Pietrusińska M, MacBeth A. The mental health impact of perinatal loss: A systematic review and meta-analysis. J Affect Disord. 2022 Jan;297:118–29.

11. Bright A-M, Doody O, Tuohy T. Women with perinatal suicidal ideation-A scoping review of the biopsychosocial risk factors to inform health service provision and research. PLoS One. 2022;17(9):e0274862.

12. Academy of Medical Royal Colleges. A Code of Practice for the diagnosis and confirmation of death 2025 Update. 2025.

13. National Bereavement Care Pathway. Neonatal Death - Full Guidance Document. 2022.

14. Gandino G, Bernaudo A, Di Fini G, Vanni I, Veglia F. Healthcare professionals' experiences of perinatal loss: A systematic review. J Health Psychol. 2019 Jan;24(1):65–78.

15. Lundqvist A, Nilstun T, Dykes A-K. Both empowered and powerless: mothers' experiences of professional care when their newborn dies. Birth. 2002 Sep;29(3):192–9.

16. Redshaw M, Henderson J, Bevan C. "This is time we'll never get back": a qualitative study of mothers' experiences of care associated with neonatal death. BMJ Open. 2021 Sep;11(9):e050832.

17. Gold KJ, Dalton VK, Schwenk TL. Hospital care for parents after perinatal death. Obstet Gynecol. 2007 May;109(5):1156–66.

18. Rosenbaum ME, Silverman JD. Training for Effective Communication in Healthcare Settings. In: Martin L., DiMatteo R, editors. The Oxford Handbook of Health Communication, Behavior Change, and Treatment Adherence. Oxford: Oxford University Press; 2014.

19. Sands. https://training.sands.org.uk/bereavement-care/.

20. Zhuang S, Chen M, Ma X, Jiang J, Xiao G, Zhao Y, et al. The needs of women experiencing perinatal loss: A qualitative systematic review and meta-synthesis. Women Birth. 2023 Sep;36(5):409–20.

21. Burden C, Bakhbakhi D, Heazell AE, Lynch M, Timlin L, Bevan C, et al. Parents' Active Role and ENgagement in The review of their Stillbirth/perinatal death 2 (PARENTS 2) study: a mixed-methods study of implementation. BMJ Open. 2021 Mar;11(3):e044563.

22. National Child Mortality Database. https://www.ncmd.info/guidance/parents-cdr-toolkit/.

23. Bakhbakhi D, Siassakos D, Burden C, Jones F, Yoward F, Redshaw M, et al. Learning from deaths: Parents' Active Role and ENgagement in The review of their Stillbirth/perinatal death (the PARENTS 1 study). BMC Pregnancy Childbirth [Internet]. 2017;17(1):333. Available from:

DRAFT

https://doi.org/10.1186/s12884-017-1509-z

24. Bakhbakhi D, Siassakos D, Lynch M, Timlin L, Storey C, Heazell A, et al. PARENTS 2 study: consensus report for parental engagement in the perinatal mortality review process. Ultrasound Obstet Gynecol Off J Int Soc Ultrasound Obstet Gynecol. 2019 Aug;54(2):215–24.

25. Fernández-Basanta S, Coronado C, Movilla-Fernández M-J. Multicultural coping experiences of parents following perinatal loss: A meta-ethnographic synthesis. J Adv Nurs. 2020 Jan;76(1):9–21.

26. North West Neonatal Operational Delivery Network. https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2017/06/NWNODN-Religious-Practices-.pdf.

27. Child Bereavement UK. https://www.childbereavementuk.org/pages/faqs/category/faiths-beliefs-cultures-and-communities#.

28. Lullaby Trust. https://www.lullabytrust.org.uk/professionals/training/bereavement-training/.

29. Clarke T, Connolly M. Parent's Lived Experience of Memory Making With Their Child at or Near End of Life. Am J Hosp Palliat Care. 2022 Jul;39(7):798–805.

30. England N. Patient Safety Incident Response Framework [Internet]. Available from: https://www.england.nhs.uk/patient-safety/patient-safety-insight/incident-response-framework/

31. British Association of Perinatal Medicine. How to raise a concern [Internet]. Available from: https://www.bapm.org/resources/how-to-raise-a-concern

32. Autism.org. https://www.autism.org.uk/advice-and-guidance/topics/mental-health/bereavement/professionals.

33. Child Bereavement UK. https://www.childbereavementuk.org/FAQs/supporting-bereaved-children-and-young-people-with-sen.

34. Freckelton I. Minimising The Counter-Therapeutic Effects Of Coronial Investigations: In Search Of Balance. QUT Law Rev. 2016;16(3):4–29.

35. Coroners Court Support Service. https://coronerscourtssupportservice.org.uk/.

36. Shaohua L, Shorey S. Psychosocial interventions on psychological outcomes of parents with perinatal loss: A systematic review and meta-analysis. Int J Nurs Stud. 2021 May;117:103871.

37. National Institute for Health and Care Excellence. Antenatal and postnatal mental health: clinical management and service guidance [Internet]. 2020. Available from: https://www.nice.org.uk/guidance/cg192

38. Atkins E, Barr K, Butterworth R, Chilvers R, Cole S, Cordwell J, et al. Psychology Staffing on the Neonatal Unit: Recommendations for Psychological Provision [Internet]. 2022. Available from: https://hubble-live-assets.s3.amazonaws.com/bapm/redactor2_assets/files/1241/Psychology_Staffing_on_the_Neonatal_Unit.pdf

39. Paediatric Innovation Education and Research Network. https://www.piernetwork.org/debrief.html.

40. Walker CA, McGregor L, Taylor C, Robinson S. STOP5: a hot debrief model for resuscitation cases in the emergency department. Clin Exp Emerg Med. 2020 Dec;7(4):259–66.

41. Kolbe M, Schmutz S, Seelandt JC, Eppich WJ, Schmutz JB. Team debriefings in healthcare: aligning intention and impact. BMJ. 2021 Sep;374:n2042.

DRAFT

42. Archibald S-J, O'Curry S. Reflections on developing a protocol for pre and debriefs on a neonatal intensive care unit (NICU). J Neonatal Nurs [Internet]. 2020;26(4):192–6. Available from: https://www.sciencedirect.com/science/article/pii/S1355184120300156

43. Association of Clinical Psychologists. Group Psychological 'Debriefs': Practice guidance for post-event team reflection (PETR) following distressing events at work [Internet]. 2024. Available from: https://acpuk.org.uk/wp-content/uploads/2024/08/Group-Psychological-Debriefs.pdf

44. Hospice UK. Care After Death Guidelines [Internet]. Available from: https://www.hospiceuk.org/innovation-hub/clinical-care-support/care-after-death

DRAFT

Appendix 2: Mortality Governance National and Statutory Guidance

<table>
<tr><th></th><th>England</th><th>Wales</th><th>N. Ireland</th><th>Scotland</th></tr>
<tr><td>Child Death Review Guidance</td><td>Child Death Review Guidance England[1]</td><td>Child Death Review - Public Health Wales (nhs.wales)[2]</td><td>-</td><td>HIS National Guidance when a child or young person dies[3]</td></tr>
<tr><td rowspan="2">Bereavement Support</td><td rowspan="2">Bereavement Pathways (England)[4]</td><td rowspan="2">wales/end-of-life-care[5]</td><td>Bereavement Guidance[6]</td><td rowspan="2">Bereavement Care Pathways (Scotland)[7]</td></tr>
<tr><td>Bereavement network[8]</td></tr>
<tr><td>Registration of Deaths</td><td colspan="2">Death Registration[9]</td><td>Death Registration NI[10]</td><td>Death Registration Scot[11]</td></tr>
<tr><td>Reporting Deaths</td><td colspan="2">Notification of Death Regulations[12]</td><td>NI Matters relating to Coroner[13]</td><td>Referral to Procurator Fiscal[14]</td></tr>
<tr><td rowspan="2">Medical Death Certificate</td><td colspan="2" rowspan="2">MCCD Regulations[15]</td><td>MCCD Guidance[16]</td><td>MCCD Guidance Scotland[17]</td></tr>
<tr><td>Guidance surrounding death[18]</td><td>HIS DCRS key resources[19]</td></tr>
<tr><td rowspan="2">Medical Examiner</td><td>Medical Examiner England Regulations[20]</td><td rowspan="2">Medical Examiner Wales Regulations[21]</td><td rowspan="2"></td><td rowspan="2"></td></tr>
<tr><td>RCPath Good Practice Series ME and child death[22]</td></tr>
<tr><td rowspan="2">Unexpected Death</td><td>SUDIC Guidelines[23]</td><td>PRUDiC Guidelines[24]</td><td>SUDI Toolkit in draft: not currently available online</td><td>HIS SUDI Guidance[25]</td></tr>
<tr><td colspan="4">BAPM SUPC Framework[26]</td></tr>
<tr><td rowspan="2">Organ Donation</td><td colspan="3" rowspan="2">Infant Organ and Tissue Donation[27]</td><td>Infant Organ and Tissue Donation[27]</td></tr>
<tr><td>HIS Paediatric and Neonatal Organ and Tissue Donation[28]</td></tr>
<tr><td>Patient Incident Investigations</td><td>Patient Safety Incident Response Framework[29]</td><td>Patient Safety Incident Reporting[30]</td><td>NIAIC adverse incident reporting[31]</td><td>HIS Reviewing and Learning from adverse events[32]</td></tr>
</table>

DRAFT

UK requirements: verification of livebirths & deaths in babies[33,34,35]

<table>
<tr><th></th><th>England</th><th>Wales</th><th>Scotland</th><th>N. Ireland</th></tr>
<tr><td>Live birth (any gestation)</td><td colspan="4">MCCD must be issued. Where this is not possible referral to HMC/PF</td></tr>
<tr><td>Who can verify a live birth?</td><td>*Doctor</td><td>*Doctor</td><td>*Doctor or Attending Midwife</td><td>*Doctor</td></tr>
<tr><td>Who can verify death and issue an MCCD?</td><td colspan="4">*Doctor</td></tr>
<tr><td>**Live birth (any gestation), verification not done by doctor, baby subsequently dies</td><td colspan="2">Refer to HMC</td><td>Doctor can issue MCCD if attending midwife confirms live-birth. If no attending midwife refer to PF</td><td>Refer to HMC</td></tr>
<tr><td colspan="5"></td></tr>
<tr><td>Miscarriage (less than 24 weeks gestation)</td><td colspan="4">No legal certification or registration of death required</td></tr>
<tr><td>Who can verify a miscarriage?</td><td colspan="4">Doctor or Midwife</td></tr>
<tr><td>**Miscarriage, referral HMC/PF</td><td colspan="2">No referral to HMC (no jurisdiction for miscarriages)</td><td>No referral to PF unless potentially unnatural death</td><td>No referral to HMC (no jurisdiction for miscarriage)</td></tr>
<tr><td colspan="5"></td></tr>
<tr><td>Stillbirth (24 weeks gestation and over)</td><td colspan="4">Legal requirement to register death as stillbirth</td></tr>
<tr><td>Who can verify a stillbirth?</td><td colspan="4">Doctor or Midwife</td></tr>
<tr><td rowspan="2">**Stillbirth, referral HMC/PF</td><td colspan="4">Refer to HMC/PF if in doubt regarding live birth or stillbirth</td></tr>
<tr><td colspan="2">If stillbirth is established, HMC has no further jurisdiction for stillbirths</td><td>Refer to PF if unanticipated intrapartum stillbirth or potentially unnatural cause of death</td><td>Refer to HMC if capable of being born alive (potentially unnatural death)</td></tr>
</table>

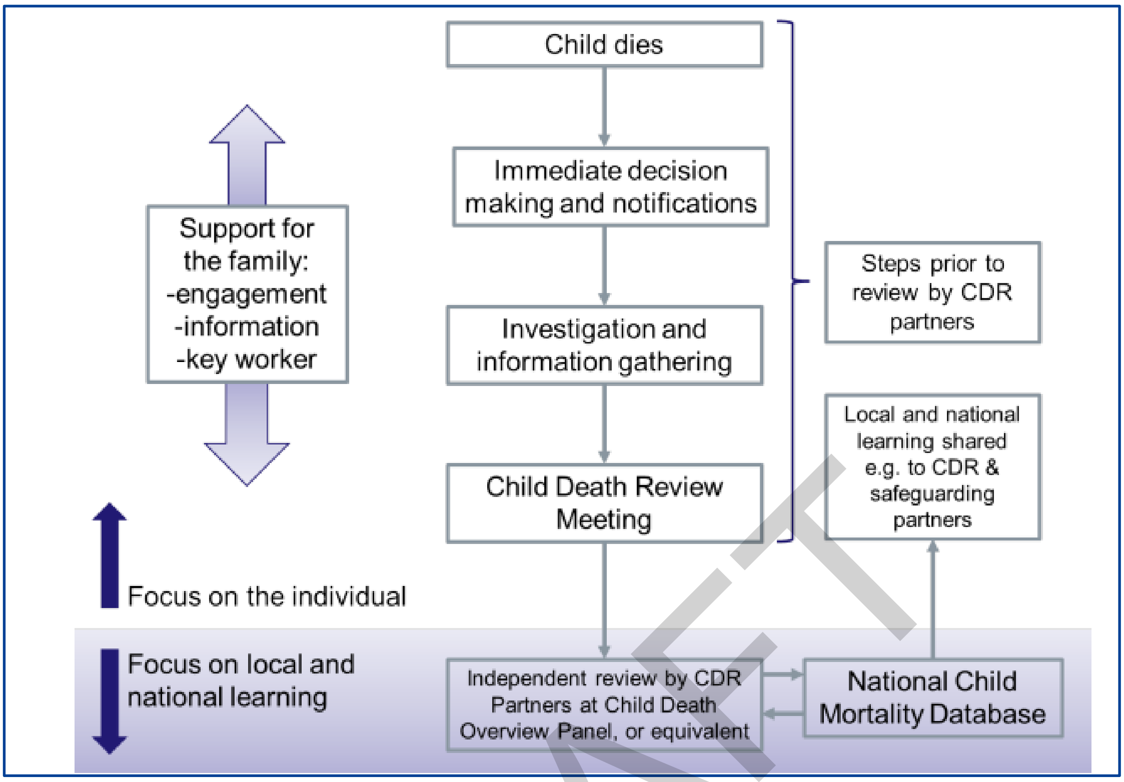
DRAFT

**Live-birth/death verification can be done by an Advanced Neonatal Nurse Practitioner (ANNP) or other trained personnel within health care settings, but they cannot issue the MCCD.*

***Please also see individual country HMC/PF referral requirements*

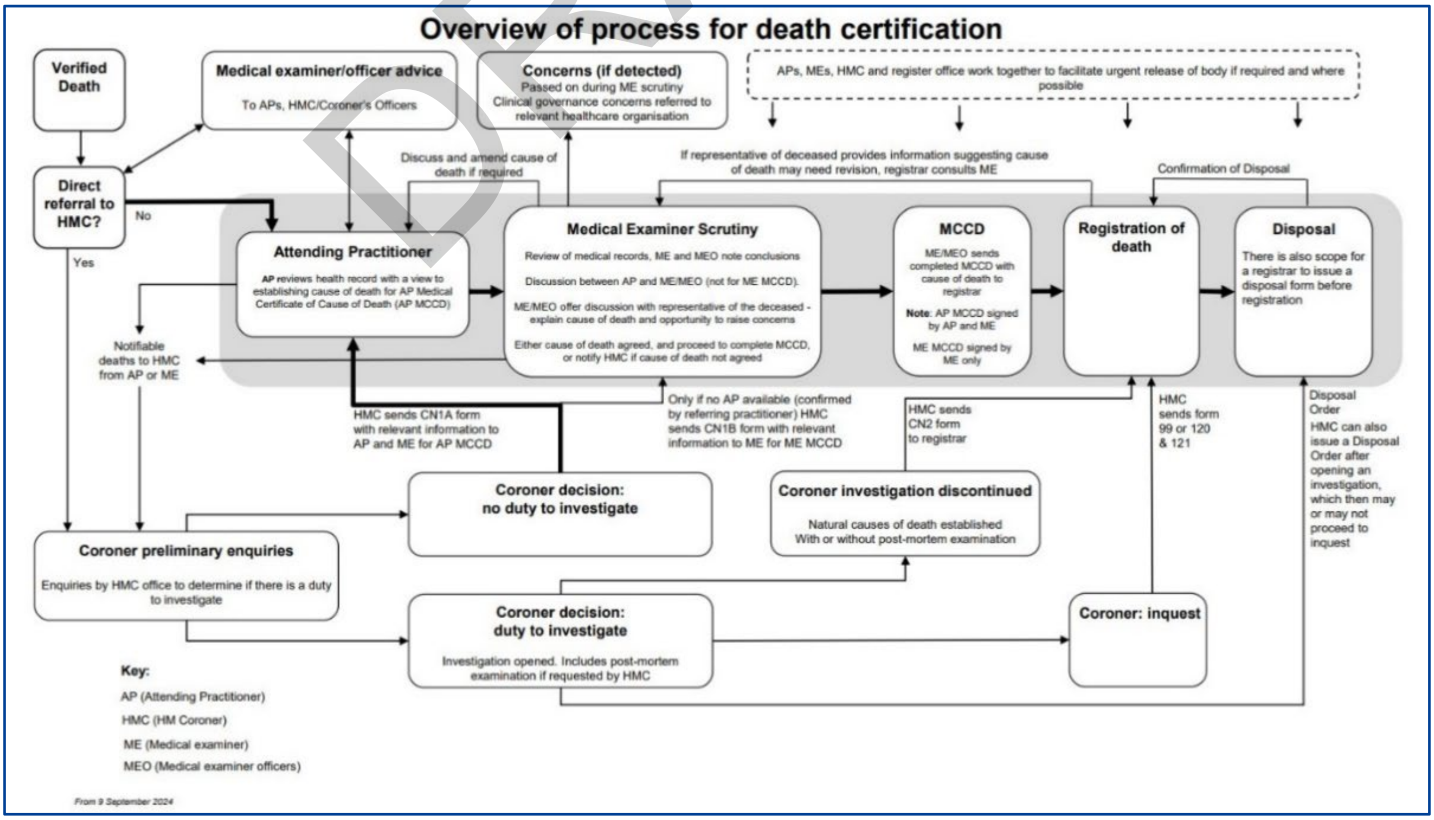
England

Child Death Review Overview[1]



DRAFT

Medical Examiner Process[20,22]



England and Wales

Circumstances Requiring Notification to HMC, England & Wales[12]

A baby's death should always be notified to the coroner where there is reasonable cause to suspect that the death was due to (i.e. more than minimally, negligibly, or trivially caused by or contributed to by) any of the following:

- poisoning including by an otherwise benign substance;
- exposure to, or contact with a toxic substance;
- use of a medicinal product, the use of a controlled drug or psychoactive substance;
- violence, trauma or injury;
- neglect, including self-neglect.
- the person undergoing any treatment or procedure of a medical or similar nature;

In addition, a person's death should always be notified to the coroner where:

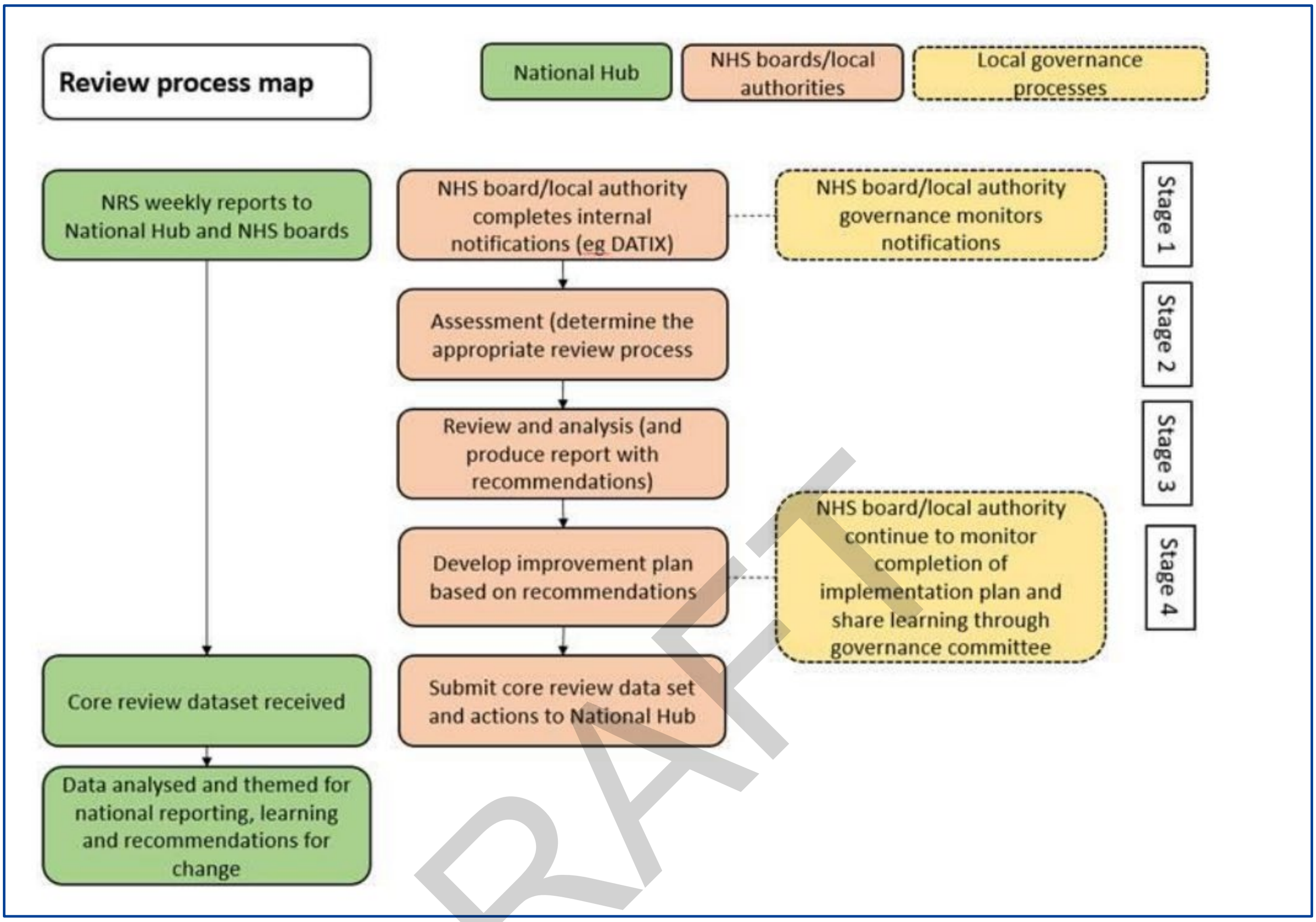
- the registered medical practitioner suspects that the person's death was unnatural, but does not fall within any of the above circumstances;
- the cause of death is unknown;
- the registered medical practitioner suspects that the person died while in custody or otherwise in state detention;
- there is no attending practitioner, or an attending practitioner is not available within a reasonable time to sign a MCCD in relation to the deceased person; or
- the identity of the deceased person is unknown.

Also see above table on UK requirements for verification of livebirths and deaths in babies.

DRAFT

Scotland

Reviewing and Learning from the Deaths of Children[3]



DRAFT

Circumstances Requiring Referral to Procurator Fiscal (Scotland)[14]

The following deaths must be reported to the Procurator Fiscal ('reportable deaths'):

Unnatural cause of death:
Any death which cannot be entirely attributed to natural causes (whether the primary cause or a contributing factor) including:

- Suspicious deaths – i.e. where homicide cannot be ruled out
- Drug related deaths - including deaths due to adverse drug reactions reportable under the Medicines and Healthcare Products Regulatory Agency (MHRA) (Yellow Card Scheme)
- Accidental deaths (including those resulting from falls)
- Deaths resulting from an accident in the course of employment
- Deaths of children from overlaying or suffocation
- Deaths where the circumstances indicate the possibility of suicide

Natural cause of death:
Deaths which may be due in whole or part to natural causes but occur in the following circumstances:

(a) Any death due to natural causes where the cause of death cannot be identified by a medical practitioner to the best of his or her knowledge and belief

(b) Deaths as a result of neglect/fault

Any death:

- which may be related to a suggestion of neglect (including self neglect) or exposure
- where there is an allegation or possibility of fault on the part of another person, body or organisation

(c) Deaths of children

Any death of a child:

- which is a sudden, unexpected and unexplained perinatal death
- where the body of a newborn is found
- where the death may be categorised as a Sudden Unexpected Death in Infancy (SUDI)
- which arises following a concealed pregnancy

Any death of a child or young person under the age of eighteen years who is 'looked after' by a local authority, including:

- a child whose name is on the Child Protection Register
- a child who is subject to a supervision requirement made by a Children's Hearing
- a child who is subject to an order, authorisation or warrant made by a Court or Children's Hearing (e.g. a child being accommodated by a local authority in foster care, kinship care, residential accommodation or secure accommodation)
- a child who is otherwise being accommodated by a local authority

(d) Deaths from notifiable industrial/infectious diseases

Any death:

- due to a notifiable industrial disease or disease acquired as a consequence of the deceased's occupation in terms of column 1 of Part 1 of Schedule 3 to the Reporting of Injuries, Diseases and Dangerous Occurrences Regulations 1995 (see http://www.legislation.gov.uk/uksi/1995/3163/schedule/3/made and Section 10 of this guidance)
- which poses an acute and serious risk to public health due to either a Notifiable Infectious Disease or Organism in terms of Schedule 1 of the Public Heath (Scotland) Act 2008 (see http://www.legislation.gov.uk/asp/2008/5/schedule/1) or any other infectious disease or syndrome,

(e) Deaths under medical or dental care (see full guidance for details)

Any death:

- the circumstances of which are the subject of concern to, or complaint by, the nearest relatives of the deceased about the medical treatment given to the deceased with a suggestion that the medical treatment may have contributed to the death of the patient.
- the circumstances of which might indicate fault or neglect on the part of medical staff or where medical staff have concerns regarding the circumstances of death
- the circumstances of which indicate that the failure of a piece of equipment may have caused or contributed to the death
- the circumstances of which are likely to be subject to an Adverse Event Review (as defined by Healthcare Improvement Scotland)
- where, at any time, a death certificate has been issued and a complaint is later received by a doctor or by the Health Board, which suggests that an act or omission by medical staff caused or contributed to the death
- caused by the withdrawal of life sustaining treatment or other medical treatment to a patient in a permanent vegetative state (whether with or without the authority of the Court of Session). (See Section 13 below)
- which occurs in circumstances raising issues of public safety.

Deaths while subject to compulsory treatment under mental health legislation and deaths in legal custody (see full guidance).

Also see above table on UK requirements for verification of livebirths and deaths in babies.

DRAFT

Northern Ireland

Circumstances Requiring Referral to HMC, N Ireland[13]

A death is reported to a Coroner in the following situations:

- a doctor did not treat the person during their last illness
- a doctor did not see or treat the person for the condition from which they died within 28 days of death
- the cause of death was sudden, violent or unnatural such as an accident, or suicide
- the cause of death was murder
- the cause of death was an industrial disease of the lungs such as asbestosis
- the death occurred in any other circumstances that may require investigation

A death in hospital should be reported if:

- there is a question of negligence or misadventure about the treatment of the person who died
- they died before a provisional diagnosis was made and the general practitioner is not willing to certify the cause
- the patient died as the result of the administration of an anaesthetic

A death should be reported to a Coroner by the police, when:

- a dead body is found
- death is unexpected or unexplained
- a death occurs in suspicious circumstances

Also see above table on UK requirements for verification of livebirths and deaths in babies.

DRAFT

References

[1] HM Government. Child Death Review Statutory and Operational Guidance (England). [online]. Gov.uk; 2018. Child Death Review Guidance England

[2] Public Health Wales. Child Death Review Programme. [online]. NHS Wales; 2009. Child Death Review - Public Health Wales.

[3] Health Improvement Scotland, National Hub for Reviewing and Learning from the Deaths of Children and Young People. [online]. NHS Scotland; 2021. HIS National Guidance when a child or young person dies

[4] National Bereavement Care Pathway for pregnancy and baby loss. National Bereavement Care Pathway. [online]. NBCP; 2022. https://www.nbcpathway.org.uk/

[5] Welsh Government. End of life care and bereavement. [online]. Gov.wales; 2021. https://www.gov.wales/end-of-life-care

[6] DHSSPS Northern Ireland. Regional Bereavement Guidance on evidence-based, holistic care of parents and their families after the experience of miscarriage, stillbirth or neonatal death. [online]. Northern Ireland Practice and Education Council; 2015. Bereavement Guidance N Ireland

[7] National Bereavement Care Pathway for pregnancy and baby loss in Scotland. National Bereavement Care Pathway. [online]. NBCP ; 2022. https://www.nbcpscotland.org.uk/about-us/nbcp-in-scotland/

[8] Northern Ireland Bereavement Network. [online]. Northern Ireland Bereavement Support

[9] HM Government. Register a death. [online]. https://www.gov.uk/register-a-death

[10] NI Direct Government Services. [online]. https://www.nidirect.gov.uk/articles/registering-death-district-registrar

[11] National Records of Scotland. [online]. https://www.nrscotland.gov.uk/registration/registering-a-death/

[12] Ministry of Justice. Guidance for registered medical practitioners on the Notification of Deaths Regulations. [online]. Gov.uk; 2024. Notification of Death Regulations

[13] NI Department of Health. Guidelines for Matters Relating to the Coroner. [online]. ni.gov.uk; 2018. https://www.health-ni.gov.uk/publications/guidelines-matters-relating-coroner

[14] Crown Office & Procurator Fiscal Service. Reporting deaths- information for medical practitioners. [online]. Gov.uk; 2019. https://www.copfs.gov.uk/publications/reporting-deaths/

[15] UK Statutory Instruments No 492. The Medical Certificate of Cause of Death Regulations 2024. [online]. Legislation.gov.uk; 2024. https://www.legislation.gov.uk/uksi/2024/492/contents/made

[16] NI Department of Health. Guidelines for Death Certification – Issuing MCCD using NIECR. [online]. ni.gov.uk; 2022. https://www.health-ni.gov.uk/publications/guidelines-death-certification-issuing-mccd-using-niecr

DRAFT

[17] Chief Medical Officer. Guidance for Doctors completing Medical Certificates of the cause of death (MCCD) and its quality assurance, [online]. National Records of Scotland; 2018. https://www.publications.scot.nhs.uk/files/cmo-2018-11.pdf

[18] NI Department of Health. Guidance surrounding Death. [online]. ni.gov.uk; 2019. https://www.health-ni.gov.uk/topics/guidance-surrounding-death

[19] Healthcare Improvement Scotland. DCRS Key Resources. [online]. HIS DCRS Key Resources

[20] UK Statutory Instruments No 493. Medical Examiners (England) Regulations 2024. [online]. Legislation.gov.uk; 2024. Medical Examiner England Regulations

[21] Wales Statutory Instruments No. 505 (W. 81). The Medical Examiners (Wales) Regulations 2024. [online]. Legislation.gov.uk; 2024. https://www.legislation.gov.uk/wsi/2024/505/made

[22] Fletcher A. National Medical Examiner's Good Practice Series No. 6: Medical Examiners and child deaths [online]. RCPath; 2024. RCPath Good Practice Series ME and child death

[23] Royal College of Pathologists. Sudden and Unexpected death in Infancy and childhood. [online]. RCPath; 2016. RCPath SUDiC

[24] Public Health Wales. PRUDiC (Procedural Response to Unexpected Death in Childhood). [online]. NHS Wales; 2023. PRUDiC Guidelines

[25] Healthcare Improvement Scotland. SUDI Guidance and support documents. [online]. HIS; 2023. HIS SUDI Guidance

[26] British Association of Perinatal Medicine. Sudden and Unexpected Postnatal Collapse. A BAPM Framework for Reducing Risk, Investigation and Management. [online]. BAPM; 2022. BAPM SUPC Framework

[27] NHS Blood and Transplant. Guidance for Neonatal Units when considering Organ and Tissue Donation as part of Palliative and End-of-Life-Care. [online]. NHSBT; 2023 Infant Organ and Tissue Donation

[28] Scottish Government. Paediatric and Neonatal Organ and Tissue Donation. [online]. gov.scot; 2018. HIS Paediatric and Neonatal Organ and Tissue Donation Scotland

[29] NHS England. Patient Safety Incident Response Framework. [online]. https://www.england.nhs.uk/patient-safety/patient-safety-insight/incident-response-framework/

[30] NHS Wales. National Policy on Patient Safety Incident Reporting. [online]. nhs.wales; 2023. https://du.nhs.wales/files/incidents/national-policy-on-patient-safety-incident-reporting-2-0-pdf/

[31] NI Department of Health. NIAIC adverse incident reporting – guidance and forms. [online]. HSCNI; 2023. NIAIC adverse incident reporting

[32] Healthcare Improvement Scotland. A national framework for reviewing and learning from adverse events in NHS Scotland: February 2025. HIS; 2025. HIS Reviewing and Learning from adverse events

[33] Chief Coroner's Guidance No.45. Stillbirth, and Live Birth Following Termination of Pregnancy.

DRAFT

[online]. Courts and Tribunals Judiciary; 2023. Chief Coroner's Guidance No.45

[34] Scottish Government. Maternity and neonatal (perinatal) adverse event review process: guidance. [online]. gov.scot; 2023.Scottish Mat Neo adverse event review process guidance

[35] Judiciary NI. In Her Majesty's Court of Appeal in Northern Ireland. Neutral Citation No. NICA 68 [online]. judiciaryni; 2013. NICA 68 2013 Landmark Decision

DRAFT

Appendix 3: Case examples

Case 1: Unattended birth below 22 weeks showing potential signs of life

A baby is delivered at home at 18 weeks gestation and mother and baby are brought to the hospital by ambulance. The parents report that their baby moved and gasped prior to the arrival of the ambulance. No signs of life were seen by the ambulance crew, and the baby has no signs of life when examined at the hospital.

Can the doctor issue a MCCD?

A MCCD cannot be issued as a doctor has not witnessed the baby showing signs of life.
It would be important to sensitively discuss with the family what movements they saw. Fleeting reflex activity including transient gasps, brief visible pulsation of the chest wall or brief twitches or involuntary muscle movement observed only in the first minute after birth do not constitute signs of life. In this case, the family thought their baby was breathing for several minutes and they could also see the heart beating through the chest wall.

The case should be referred to HMC/PF. This should be sensitively handled with families, and clinicians should work closely with HMC/PF to ensure a smooth process that does not cause delays and minimises distress to the parents.

Discussion Points

- In the UK, a baby born alive at any gestation who dies shortly after birth must legally be registered as a live birth and a neonatal death, and the parents issued with a neonatal death certificate
- Ensure thorough documentation of any signs of life witnessed by parents or other non-medical personnel present and how long these signs persisted for.
- If a baby is born showing signs of life, regardless of their gestational age, whenever possible, they should be assessed by a doctor (preferably an obstetric doctor with whom the family have had some contact) to confirm and document the live birth. Confirmation of death, and a death certificate can then be issued if the cause of death is known.
- Referral to HMC/PF for live-born infants who subsequently die differs between the 4 nations in UK depending on who has verified the live-birth (see Table 1)
- Information and videos for families and health professionals regarding determination of signs of life following spontaneous birth before 24+0 are available at MBRRACE-UK Signs of Life
- SUDIC/SUDI/PRUDiC processes would not normally be indicated in live births at or below the threshold of survival unless circumstances suggest an unnatural death. In cases where the gestation is unknown, these processes may be initiated but can be stood down if it is clear the baby is pre-viable and there are no other safeguarding concerns.
- In England, all livebirths need to be referred to CDOP.

DRAFT

**England/Wales <28 day MCCD nomenclature is used in these examples.*

Table 1: UK requirements for verification of livebirths and deaths in babies

	England	Wales	Scotland	N. Ireland
Live birth (any gestation)	MCCD must be issued. Where this is not possible referral to HMC/PF			
Who can verify a live birth?	*Doctor	*Doctor	*Doctor or Attending Midwife	*Doctor
Who can verify death and issue an MCCD?	*Doctor			
**Live birth (any gestation), verification not done by doctor, baby subsequently dies	Refer to HMC		Doctor can issue MCCD if attending midwife confirms live-birth. If no attending midwife refer to PF	Refer to HMC
Miscarriage (less than 24 weeks gestation)	No legal certification or registration of death required			
Who can verify a miscarriage?	Doctor or Midwife			
**Miscarriage, referral HMC/PF	No referral to HMC (no jurisdiction for miscarriages)		No referral to PF unless potentially unnatural death	No referral to HMC (no jurisdiction for miscarriage)
Stillbirth (24 weeks gestation and over)	Legal requirement to register death as stillbirth			
Who can verify a stillbirth?	Doctor or Midwife			
**Stillbirth, referral HMC/PF	Refer to HMC/PF if in doubt regarding live birth or stillbirth			
	If stillbirth is established, HMC has no further jurisdiction for stillbirths		Refer to PF if unanticipated intrapartum stillbirth or potentially unnatural cause of death	Refer to HMC if capable of being born alive (potentially unnatural death)

DRAFT

**Live-birth/death verification can be done by an Advanced Neonatal Nurse Practitioner (ANNP) or other trained personnel within health care settings, but they cannot issue the MCCD.*
*** Please see Appendix: National Guidance for a full list of referral criteria to HMC/PF across the UK*

**England/Wales <28 day MCCD nomenclature is used in these examples.*

Case 2: Attended Birth below 24 weeks gestation; not born alive

A baby is born in hospital at 22 weeks. There is brief visible pulsation of the chest wall for a few seconds after delivery, the baby takes 4 gasps with some twitching movements of the arms and legs which cease after 40 seconds. No spontaneous movement, heart rate, breathing or crying is seen after this.

Can the doctor issue a MCCD?

No, an MCCD cannot be issued as this baby was not born alive. Fleeting reflex activity including transient gasps, brief visible pulsation of the chest wall or brief twitches or involuntary muscle movement observed only in the first minute after birth does not warrant classification as signs of life. An unofficial "certificate of birth" or "certificate of pregnancy loss" can be issued from the hospital if this accords with parental wishes. Parents are also able to apply for a government sponsored Baby loss certificate in England and entry to the Memorial Book in Scotland. There is currently no official recognition for these losses in Wales and Northern Ireland.

Discussion Points

- For pregnancy or baby loss where the birth occurs before 24 weeks of pregnancy and there were no reported signs of life, there is no requirement or permission by law to officially certify the death or register the death as a stillbirth and an MCCD is not required.
- Referral to HMC/PF for miscarriages differs between the 4 nations in UK (see table 1)
- Information and videos for families and health professionals regarding determination of signs of life following spontaneous birth before 24+0 are available at MBRRACE-UK Signs of Life
- SUDIC/SUDI/PRUDiC processes do not apply to miscarriages. However, in cases where the gestation is unknown and the birth is unattended by the relevant health professional, these processes would be initiated as for an unattended stillbirth until gestation has been established.

DRAFT

Case 3: Unattended birth after 24 weeks; not born alive

A mother is alone and goes into labour at 33 weeks gestation. She calls her maternity unit, and they advise her to call an ambulance. When the ambulance arrives, the baby has recently been born, and the ambulance crew cannot detect any signs of life, with confirmation of these findings by a doctor on arrival at the hospital. Sensitive discussion with the mother following her admission to hospital indicate there were no signs of life after delivery. The circumstances surrounding the birth are not thought to be suspicious.

Can the doctor issue a MCCD?

A MCCD cannot be issued. A medical certificate of stillbirth can be issued, and the birth must legally be registered as a stillbirth. A JAR/PRUDiC referral or equivalent should take place.

Discussion Points

- It is a legal requirement that all babies born without signs of life from 24 weeks gestation onwards in the UK are registered as stillbirths
- A doctor or a midwife can issue a medical certificate of stillbirth.
- Where there is uncertainty regarding whether the baby was live-born or not, no MCCD should be issued, a referral to HMC/PF should take place and, in England, the case should be referred to CDOP. The CDOP process would not be continued if it is determined that a baby was stillborn.
- Investigation by HMC/PF for stillbirths differs between the 4 nations in the UK (see table 1)

**England/Wales <28 day MCCD nomenclature is used in these examples.*

- A hospital postmortem should be discussed with the mother/parents if HMC/PF postmortem is not required. Further information on investigations and management following stillbirth is included in RCOG Green top Guideline no.55. Care of Late Intrauterine fetal death and stillbirth
- A JAR/ PRUDiC referral or equivalent should take place where birth occurs without medical professionals being present, for a live-born baby who subsequently dies, or a stillborn baby born without medical professionals present.

Case 4: Attended Birth, 22 weeks, born alive Extreme Prematurity

A male baby is born at 22 weeks following spontaneous vaginal delivery. There has been good antenatal care and no known maternal factors. The parents and clinical team have agreed that intensive care is not in his best interests; he is live-born and receives comfort care/cuddles from his parents. He dies at 40 minutes of age on labour ward.

Can the doctor issue a MCCD?

A *MCCD can be written. The cause of this death was clear, and there were no unnatural features. The cause of death would be:

Main disease or condition	(a) Extreme prematurity – 22 weeks gestation

Discussion Points

- Include the gestational age in weeks on the death certificate
- Sensitively include relevant maternal diseases or conditions affecting the baby in discussion with the family
- When there is a livebirth following a termination of pregnancy, HMC/PF should be notified. More detailed information, including the different legal requirements across the UK in these circumstances are outlined in the RCOG position statement (RCOG Position Statement following Chief Coroner's Guidance no. 45)

DRAFT

Case 5: Unexplained Collapse

A male baby is born at 27 weeks gestation following spontaneous vaginal delivery. He has significant respiratory distress syndrome and is ventilated in 45% oxygen when he suddenly becomes hypoxic and bradycardic on day 5 and, despite full resuscitation, he does not survive.

Can the doctor issue a MCCD?

In this case the cause of the sudden deterioration is not clear. It would not be right to issue an MCCD and, if there was no further information, the case will need to be referred to HMC/PF. A discussion with the designated doctor (England only) regarding whether JAR/ PRUDiC or equivalent is indicated (see Sudden Unexpected Death in main framework document)

Discussion Points

- If there was evidence supporting the reason for collapse, for example pneumothorax, a MCCD could be written if no issues of care were thought to contribute to the death.
- It is not usually appropriate to write the main cause of death as (a) Extreme prematurity without justifying it with further diagnoses in babies over 24^{+0} weeks gestation.

Case 6: Hypoxic Ischaemic Encephalopathy

A female term baby has clear evidence of hypoxic ischaemic brain injury following a cord prolapse. She dies on day 6 following an MRI scan that confirms profound hypoxic ischaemic brain injury.

**England/Wales <28 day MCCD nomenclature is used in these examples.*

Can the doctor issue a MCCD?
An MCCD can be issued in this case (except in Northern Ireland – see below):

Main disease or condition	(a) Hypoxic Ischaemic Encephalopathy
Main maternity disease or condition	(c) Cord Prolapse.

Discussion Points

- Hypoxic ischaemic encephalopathy (HIE) should always be justified by its reason on an MCCD.
- Sometimes there is a clear and natural sentinel event that could not have been predicted and was well managed which would allow the death to be recorded as natural, but such events are not present in many cases.
- There should be a very low threshold to refer such cases to HMC/PF as not all information is available immediately following birth and issues of care that may have contributed are not known until a fuller investigation is undertaken. It is therefore important to provide as much information as possible in the HMC/PF referral.
- In Northern Ireland, all deaths from Hypoxic Ischaemic Encephalopathy must be reported to HMC.

Case 7: Death following possible Septicaemia

A 32-week gestation baby collapses on day 10 of life with low blood pressure and peripheral perfusion, a slightly elevated WBC and no rise in CRP. The infant sadly dies within 24 hours and blood culture results are not yet available.

Can the doctor issue a MCCD?
No. A slightly elevated white blood cell count alone is insufficient evidence of septicaemia and the case should be referred to HMC/PF. A JAR/ PRUDiC referral or equivalent should be initiated. If blood cultures subsequently grow a pathogenic organism consistent with the clinical picture, HMC/PF can be updated and may permit an MCCD to be written at this stage and the SUDIC/SUDI/PRUDiC process may be stood down.

Discussion Points

- Doctors should write the MCCD to their best knowledge and belief and so if they believe sepsis is the reason, they can write this but there needs to be more evidence than simply an unexplained collapse and minor changes in blood sepsis indicators.
- If sepsis is written on the MCCD, the source or “sepsis of unknown aetiology” should be included.
- In England, this case should be discussed with the ME; there may be an agreement to await blood culture before deciding on HMC/PF and JAR/SUDIC referrals.

Case 8: Death Following a Necessary Urgent Operation

A 26-week gestation baby develops sepsis and severe necrotising enterocolitis at 30 days of life. There have been no issues of care. The baby has a perforation identified on X ray and is taken for a laparotomy, which confirms total bowel involvement. With this information the team and family agree that this is not compatible with long-term survival and following discussion with the family, end of life care is supported.

Can the doctor issue a MCCD?
In this case the operation confirmed a devastating condition and did not contribute to death. It

**England/Wales <28 day MCCD nomenclature is used in these examples.*

DRAFT

would be reasonable for the doctor to write an MCCD:

Main disease or condition	(a) Necrotising enterocolitis,
Other diseases or conditions in infant	(b) Preterm 26 weeks gestation.

Discussion Points

- Deaths which follow an operation necessitated by a natural illness need not be reported unless the operation itself, or postoperative care, had a more than minimal contribution to the death.

Case 9: Death following a Recognised Complication of Treatment

A 24-week gestation baby dies following a brain haemorrhage which occurred after insertion of a ventriculo-peritoneal shunt for post-haemorrhagic hydrocephalus. Before the operation there were extensive conversations with family and formal consent, describing brain haemorrhage as a potential recognised serious complication of this procedure.

Can the doctor issue a MCCD?
No. This case requires referral to HMC/PF.

Discussion Points

- If a recognised complication of treatment has a more than minimal contribution to death the case needs referral to HMC/PF. Even the very best care can have complications.

New Findings discovered after an MCCD has been issued

- Clusters of deaths, or increased mortality rates or unexpected findings in individual case review need investigation.
- Such signals might be raised by neonatal unit members themselves, the medical examiner, regional organisations eg. neonatal ODN/ LMNS, the public or from national data sources.
- It is important that such investigations have clear terms of reference and families have the opportunity to contribute.
- If any such investigations lead to concerns that previously unknown factors which require notification to HMC/PF may have contributed to the death in any individual case, then HMC/PF should be informed.

DRAFT

**England/Wales <28 day MCCD nomenclature is used in these examples.*

BAPM

Leading Excellence in Perinatal Care

This document was produced by the British Association of Perinatal Medicine (BAPM).

BAPM ˋis a membership organisation that is here to support all those involved in perinatal care to optimise their skills and knowledge, deliver and share high-quality safe and innovative practice, undertake research, and speak out for babies and their families.

We are a professional association of neonatologists, paediatricians, obstetricians, nurses, midwives, trainees, network managers and other health professionals dedicated to shaping the delivery and improving the standard of perinatal care in the UK.

Our vision is for every baby and their family to receive the highest standard of perinatal care. Join us today.

www.bapm.org/join

British Association of Perinatal Medicine (BAPM)
is registered in England & Wales
under charity number 1199712 at
5-11 Theobalds Road, London, WC1X 8SH