



HM Government

# Child Death Review

## Statutory and Operational Guidance (England)

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# Context

This guidance sets out key features of what a good child death review process should look like. This process combines best practice with statutory requirements that must be followed.

The purpose of setting out key features of a robust child death review process in one document is to ensure that the outputs from reviews are standardised as far as possible and of a uniform quality. This will enable effective thematic learning from reviews, *i.e.* a local review may be able to identify specific learning but trends analysis at a national level may identify modifiable factors that could be altered to prevent future deaths. This requires a degree of standardisation that this document aims to outline; however, clinical commissioning groups (CCGs) and local authorities (the **child death review partners**) are able to make arrangements for child death reviews as they see fit in order to meet the statutory requirements under the [Children Act 2004](#) (the Act).

The process set out in this document runs from the moment of a child's death to the completion of the review by the Child Death Overview Panel (CDOP) or any equivalent arrangements put in place by child death review partners. This includes the immediate actions that should be taken after a child's death; the local review of a child's death by those who interacted with the child during life, and with the investigation after the child's death; through to the final stage of the child death review process which is the statutory review arranged by child death review partners.

The process is designed to capture the expertise and thoughts of all individuals who have interacted with the case in order to identify changes that could save the lives of children.

## Table of Abbreviations

AHPs – Allied Health Professionals

CCG – Clinical Commissioning Group

CDOP – Child Death Overview Panel

CDR – Child Death Review

CDRM – Child Death Review Meeting

DoLS – Deprivation of Liberty Safeguards

ED – Emergency Department

GP – General Practitioner

HSIB – Healthcare Safety Investigation Branch

ICU – Intensive Care Unit

JAR – Joint Agency Response

LeDeR – Learning Disabilities Mortality Review

M&M – Mortality and Morbidity meeting

MCCD – Medical Certificate of Cause of Death

MBRRACE-UK – Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries

MHA – Mental Health Act

NCISH – National Confidential Inquiry into Suicide and Homicide by people with Mental illness

NCMD – National Child Mortality Database

NHS – National Health Service

NIV – Non-invasive ventilation

Ofsted – Office for Standards in Education, Children's Services and Skills

ONS – Office for National Statistics

PICU – Paediatric Intensive Care Unit

PMRT – Perinatal Mortality Review Tool

PPO - Prisons and Probation Ombudsman

RCP – Royal College of Physicians

SIDS – Sudden Infant Death Syndrome

SJR – Structured Judgement Review

SMART – Specific, Measurable, Attainable, Relevant, Time-bound

SUDI – Sudden Unexpected Death in Infancy

SUDC – Sudden Unexpected Death in Childhood

SUDI/C Guidelines – Sudden Death in Infancy/Childhood: multi-agency guidelines for care and investigation

## Terminology

Terminology around child death review can be confusing, and local usage varies. The term “child death review process” refers to the entirety of the process described in this guidance. Professionals have a duty to support and engage with this process. Throughout this document, the following definitions are used:

### Child

The child death review process covers children; a child is [defined in the Act](#) as a person under 18 years of age. A child death review must be carried out for all children regardless of the cause of death.

This includes the death of any live-born baby where a death certificate has been issued. In the event that the birth is not attended by a healthcare professional, child death review partners may carry out initial enquiries to determine whether or not the baby was born alive. If these enquiries determine that the baby was born alive the death must be reviewed.

*For the avoidance of doubt, it does not include stillbirths, late foetal loss, or terminations of pregnancy (of any gestation) carried out within the law.*

- Stillbirth: baby born without signs of life after 24 weeks gestation
- Late foetal loss: where a pregnancy ends without signs of life before 24 weeks gestation

Cases where there is a live birth after a planned termination of pregnancy carried out within the law are not subject to a child death review.

### Child Death Review Partners

“Child death review partners” (“CDR partners”) are defined in section 16Q of the Children Act 2004 and means, in relation to a local authority area in England, the local authority and any CCG for an area any part of which falls within the local authority area. CDR partners for two or more local authority areas in England may agree that their areas should be treated as a single area. The responsibilities of CDR partners regarding the child death review process are set out in sections 16M-Q of the Children Act 2004. CDR partners must also have regard to this guidance and Chapter 5 of *Working Together*. (Sections 16M-Q of the Children Act 2004 have been inserted by sections 24-28 of the Children and Social Work Act 2017.)

### Child Death Review Meeting

The stage of the review process that precedes the independent multi-agency panel arranged by CDR partners. This meeting should be a multi-professional meeting where all matters relating to an individual child’s death are discussed. The Child Death Review Meeting (CDRM) should be attended by professionals who were directly involved in the care of the child during his or her life, *and* any professionals involved in the investigation into his or her death. The nature of this meeting will vary according to the circumstances of the child’s death and the practitioners involved, and should *not* be limited to medical staff.



For example, the CDRM could take the form of a final case discussion following a Joint Agency Response, a perinatal mortality review group meeting in the case of a baby who dies in a neonatal unit, or a hospital-based mortality meeting following the death of a child on a paediatric intensive care unit. These meetings could, as a way of standardising practice nationally, be known as a Child Death Review Meeting.

*Outputs from CDRMs (draft Analysis Forms) should be shared with the group set up by CDR partners to conduct reviews, described in this guidance as a Child Death Overview Panel.*

### Child Death Overview Panel, or equivalent

A multi-agency panel set up by CDR partners to review the deaths of all children normally resident in their area, and, if appropriate and agreed between CDR partners, the deaths in their area of non-resident children<sup>1</sup>, in order to learn lessons and share any findings for the prevention of future deaths. This stage of the review process is described as a Child Death Overview Panel (CDOP) throughout this guidance.

The CDOP should be informed by a standardised report from the CDRM, and ensures independent, multi-agency scrutiny by senior professionals with *no named responsibility* for the child's care during life.

In practice, CDOPs will conduct the independent multi-agency scrutiny on behalf of the local CDR partners responsible for ensuring that the review of deaths of all children normally resident in that area takes place.

### Designated doctor for child deaths

A senior paediatrician, appointed by the CDR partners, who will take a lead in co-ordinating responses and health input to the child death review process, across a specified locality or region.

### Forms: Notification, Reporting, Analysis

[Three standard forms](#) should be used in the child death review process:

- Notification Form (previously “Form A”) for initial notification of a death to CDR partners;
- Reporting Form (previously “Form B”) for gathering information from agencies or professionals who have information relevant to the case. Reporting forms should be completed by the relevant responsible officer and shared with the relevant CDOP. For certain child deaths, a supplementary Reporting Form should also be completed as required; and
- Analysis Form (previously “Form C”) initially drafted at the CDRM and completed at CDOP for evaluating information and identifying lessons to be learned. The Analysis Form is the final output of the child death review process. From 2020 this information should be shared with the National

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<sup>1</sup> In all cases, legal responsibility for ensuring that arrangements are made to review the death of a child lies with the Child Death Review Partners where the child is normally resident; more information can be found in [chapter 5](#).

Child Mortality Database, when operational. Specified data to NHS Digital for the transitional period will be notified to Child Death Review Partners separately. The mechanism for collecting, and the content of, this data will evolve as the National Child Mortality Database becomes operational.

All forms and templates to be used for reporting child deaths can be found on [GOV.UK](https://www.gov.uk). These forms should continue to be used until the introduction of the National Child Mortality Database, in 2019.

## Joint Agency Response

A coordinated multi-agency response (on-call health professional, police investigator, duty social worker), should be triggered if a child's death:

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

The full process for a Joint Agency Response is set out in the [SUDI/C Guidelines](#).

## Key Worker

A person who acts as a single point of contact for the bereaved family, who they can turn to for information on the child death review process, and who can signpost them to sources of support. This person will usually be a healthcare professional. Core competencies for the key worker can be found at [Appendix 5](#).

## Lead health professional

When a Joint Agency Response is triggered, a lead health professional should be appointed, to coordinate the health response to that death. This person may be a doctor or senior nurse, with appropriate training and expertise. This person will ensure that all health responses are implemented, and be responsible for ongoing liaison with the police and other agencies. Where no out-of-hours health rota for a Joint Agency Response exists in a locality, the role of lead health professional should be taken by the senior attending paediatrician.

## Medical Certificate of Cause of Death (MCCD)

An official certificate that enables the deceased's family to register the death, provides a permanent legal record of the fact of death, and enables the family to arrange the funeral. It provides information on the relative contributions of different diseases to mortality.

## Medical Examiner

A medical practitioner appointed as medical examiner whose responsibility is to ensure: that the cause of death is accurately recorded by the attending practitioner

(doctor) on the MCCD; that timely and appropriate referral to the coroner has occurred where appropriate; engage with the bereaved to understand any concerns; and to ensure that possible clinical governance concerns have been highlighted.

*A national system of Medical Examiners will be introduced from April 2019 to provide independent medical scrutiny of all non-coronial deaths.*

### National Child Mortality Database

The National Child Mortality Database (NCMD) will be a repository of data relating to all children's deaths in England. Once operational it will enable more detailed analysis and interpretation of all data arising from the child death review process, to ensure that lessons are learned following a child's death that learning is widely shared, and that actions are taken, locally and nationally, to reduce child mortality.

Once operational, CDR partners should instruct their Child Death Overview Panel to submit copies of all completed forms associated with the child death review process and the analysis of information about the deaths reviewed (including but not limited to the Notification Form, the Reporting Form, Supplementary Reporting Forms and the Analysis Form) to the National Child Mortality Database. In the interim period, for child deaths prior to the NCMD becoming operational in April 2019, CDR partners should ensure that CDOPs return data (LSCB1 data) to NHS Digital, arrangements for this will be notified separately and detailed on the Child Death Review webpage.

### NHS Serious Incident

Serious Incidents in health care are adverse events where the consequences to patients, families and carers, staff or organisations are so significant or the potential for learning is so great, that a heightened level of response is justified. The [NHS Serious Incident Framework](#) describes the process and procedures to help ensure Serious Incidents are identified correctly, investigated thoroughly and, most importantly, learned from to prevent the likelihood of similar incidents happening again. The Serious Incident Investigation may take the form of a Root Cause Analysis (RCA) or other approved methodology (The Serious Incident Framework is under review and new guidance is expected to be issued next year).

### Perinatal Mortality Review Tool (PMRT)

The PMRT is a web-based tool that is designed to support a standardised review of care of perinatal deaths in neonatal units from 22<sup>+0</sup> weeks gestation to 28 days after birth. It is also available to support the review of post-neonatal deaths where the baby dies in a neonatal unit after 28 days but has never left hospital following birth. At clinicians' discretion it might also be used for the review of deaths of live-born infants <22<sup>+0</sup> weeks gestation, where a death certificate has been issued. The PMRT is integrated with the national collection of perinatal mortality surveillance data.

### Post-mortem examination

A detailed physical examination of the child after he or she has died. A coroner may *order* a post-mortem examination, that is, without the permission of the family. Any other post-mortem examination will only take place with the consent of the family.

## Sudden infant death syndrome (SIDS)

The sudden and unexpected death of an infant under twelve months of age, with onset of the lethal episode apparently occurring during normal sleep, which remains unexplained after a thorough investigation, including performance of a complete post-mortem examination and review of the circumstances of death and the clinical history. It is preferred as a registered cause of death to other equivalent terms such as 'unascertained' or 'undetermined'. Labelling a death as SIDS does not exclude the possibility that the child may have died of a natural or external cause that we have been unable to ascertain or prove conclusively.<sup>2</sup>

## SUDI/SUDC (sudden unexpected death in infancy/childhood)

A descriptive term used at the point of presentation for the death of an infant or child whose death was not anticipated as a significant possibility 24 hours before the death, or where there was a similarly unexpected collapse leading to or precipitating the events which led to the death<sup>3</sup>. At the conclusion of an investigation, they will divide into those for which we have a clear diagnosis (explained SUDI/SUDC) and those for which we do not have a diagnosis (SIDS up to 12 months of age, and sudden unexplained death in childhood for children over 12 months).

## Unexplained deaths

Where, following a complete investigation by a coroner, no specific cause of death (whether natural or external) has been found, a death may be considered unexplained<sup>4</sup>. This will include those deaths meeting the internationally agreed definition for sudden infant death syndrome<sup>5</sup> (SIDS), and those registered as unascertained.

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<sup>2</sup> Krous et al. 2004. Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach. *Pediatrics* 114: 234-238

<sup>3</sup> Fleming, PJ et al (2000). Sudden unexpected death in Infancy. The CESDI SUDI Studies 1993-1996.

<sup>4</sup> ICD-10; Chapter XVIII; R00-99; World Health Organization 2016. From 2022 ICD-11 will replace ICD-10

<sup>5</sup> ICD-10; Chapter XVIII; R95; World Health Organization 2016. From 2022 ICD-11 will replace ICD-10

# Introduction

The death of a child is a devastating loss that profoundly affects bereaved parents as well as siblings, grandparents, extended family, friends and professionals who were involved in caring for the child in any capacity. Families experiencing such a tragedy should be met with empathy and compassion. They need clear and sensitive communication. They also need to understand what happened to their child and know that people will learn from what happened. The process of expertly reviewing all children's deaths is grounded in deep respect for the rights of children and their families, with the intention of preventing future child deaths.

## What is the status of this guidance?

This guidance sets out key features of what a good child death review process should look like and should be followed by all organisations involved with the process of child death reviews in England in order to standardise practice nationally and enable thematic learning to prevent future deaths.

Chapter 5 of this guidance, as far as it relates to the functions conferred on CDR partners by sections 16M to 16P of the Children Act 2004, is statutory guidance issued under section 16Q of that Act and CDR partners must have regard to it.

It builds on the statutory requirements for child death review set out in Chapter 5 of *Working Together*.

## Who is this guidance for?

CDR partners must have regard to this guidance as far as it relates to the functions conferred on them by sections 16M to 16P of the Children Act 2004. Chief Executives of clinical commissioning groups (CCGs) and local authorities should ensure that all of their staff who are involved in a CDR read and follow it.

Senior leaders within organisations who commission or provide services for children, as well as relevant regulatory bodies, should also follow the procedures set out in this guidance.

All other professionals who care for children, or who have a role in the child death review process, should read and follow this guidance so that they can respond to each child death appropriately. This includes people working within:

- health services (across all sectors: acute, maternity, mental health, primary care and community);
- children's social care services;
- police, including British Transport Police, and Royal Military Police;
- coronial services;
- education; and
- public health.

## Purpose of this guidance

This guidance aims to set out the processes to be followed when responding to, investigating, and reviewing the death of any child, from any cause.

No guidance document could adequately do justice to the complexity that unfolds after the death of a child. This document attempts to clarify processes and set out high-level principles for how professionals across all agencies involved in the child death review process should work together. This is for two main reasons:

- 1). to improve the experience of bereaved families, as well as professionals, after the death of a child; and
- 2). to ensure that information from the child death review process is systematically captured to enable local learning and, through the planned National Child Mortality Database, to identify learning at the national level, and inform changes in policy and practice.

*How does this guidance fit with other relevant guidance documents?*

### ***Working Together to Safeguard Children (Working Together)***

[Working Together](#) is statutory guidance covering the legislative requirements and expectations on individual services to safeguard and promote the welfare of children. It also sets out a clear framework for the three local “child safeguarding partners” (the local authority; a clinical commissioning group for an area within a local authority area; and the chief officer of police for an area within the local authority area) to make arrangements to work together to safeguard and promote the welfare of local children including identifying and responding to their needs. Further, it sets out the legal responsibilities of CDR partners, and directs readers to this document for detailed guidance on the child death review process.

### ***Sudden unexpected death in infancy and childhood: multi-agency guidelines for care and investigation (SUDI/C Guidelines)***

Reference is often made within this document to the [Sudden and Unexpected Death in Infancy and Childhood: multiagency guidelines for care and investigation \(2016\)](#); the key operational guidance covering some of the statutory duties placed on some of the agencies involved in a Joint Agency Response. The SUDI/C Guidelines have been approved by the Royal College of Pathologists and Royal College of Paediatrics and Child Health, and endorsed by the National Police Chiefs Council and the Chief Coroner.

*This Child Death Review Statutory Guidance should be seen as complementary to the SUDI/C Guidelines and providing clarity when processes overlap.*

### ***National Guidance on Learning from Deaths***

This is a framework for NHS Trusts and Foundation Trusts on identifying, reporting, and learning from deaths; particularly the deaths of inpatients, people with learning disabilities, or serious mental health conditions. It requires trusts to collect and publish, on a quarterly basis, specified information on deaths of patients in their care. It also gives guidance to trusts on reviewing certain deaths for example, where learning will inform improvement work. Deaths of both adults and children should be

reported as set out in the [National Guidance on Learning from Deaths](#); however, **for the deaths of children Trusts should follow the child death review process set out in this guidance when reviewing the death of a child.**

***Guidance for NHS trusts on working with bereaved families and carers***

This [guidance](#) provides advice to acute, mental health and community Trusts (and services commissioned by NHS specialised commissioning) regarding expected practice on how to engage, and work effectively with bereaved families and carers following a death. It sends a clear message to Trusts that listening to bereaved families and carers and taking their experiences seriously should be integral to the way they are governed. It advises Trusts on how they should support, communicate and engage with families and carers following a death of someone in their care and focusses on engagement when a death is subject to an investigation. The guidance also acts as a vital source of information for families so they know what they can expect following the loss of their loved one.

*Specialist support and information for families who have lost a child is set out in additional guidance:*

***When a Child Dies: child death review guide for parents and carers***

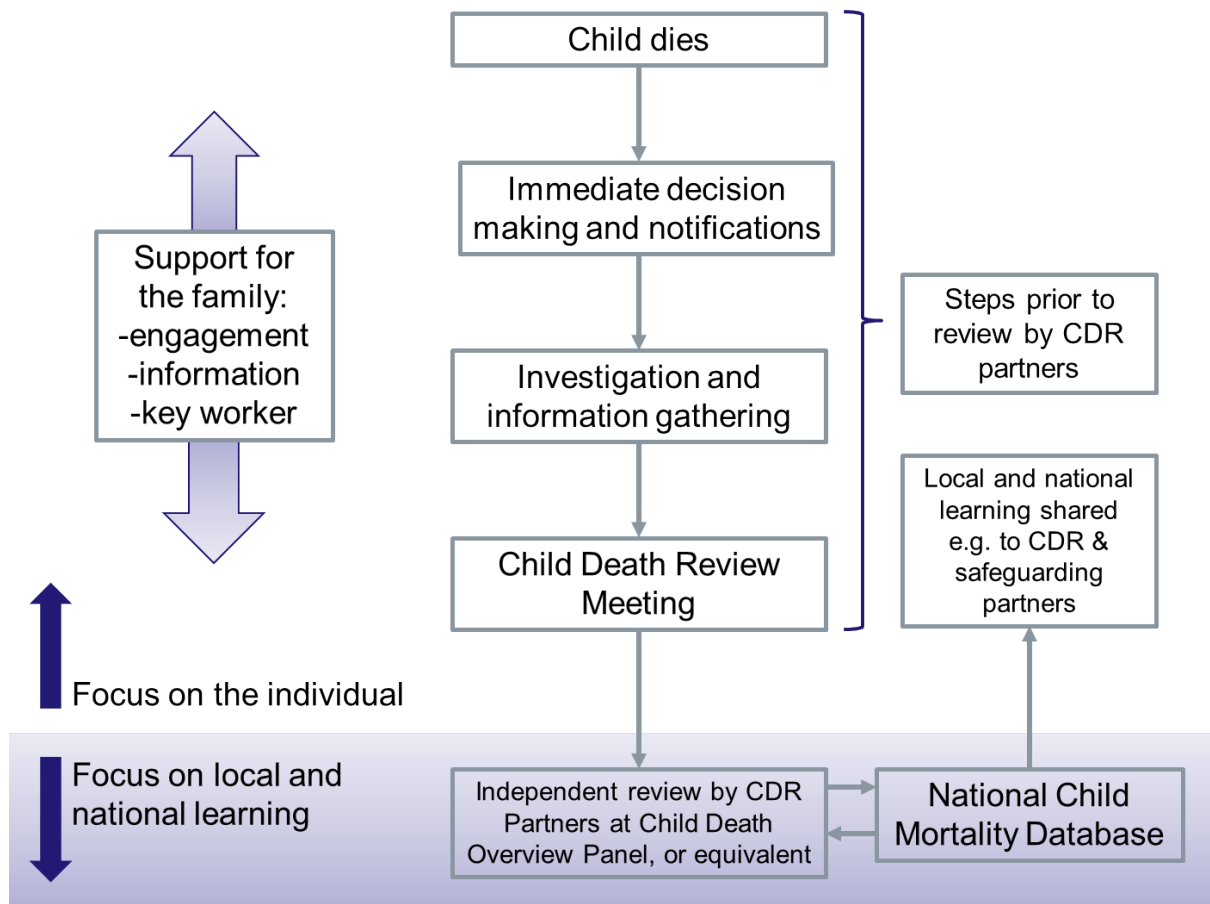
A guide for parents, families, and carers to help understand and navigate the child death review process, [When a Child Dies](#). This document should be offered, in a printed format, to *all* bereaved families and/or carers. Providers should be familiar with its contents in order to ensure that bereaved families and carers are offered the best possible support.

*Staff who cared for the child should also be offered appropriate support.*

# Chapter 1

## Overview

This chapter briefly describes the whole child death review process. The flow chart below (fig. 1) sets out the main stages of the child death review process. To help readers navigate the guidance, it appears at the start of chapters 2-6 with the relevant stage highlighted.



**Figure 1** Chart illustrating the full process of a child death review. This includes both the statutory responsibilities of CDR partners to review the deaths of children at an independent multi-agency panel (described here, and throughout, as review at CDOP or equivalent), and the processes that precede or follow this independent review. Further explanation is below.

Chapters 2-4 briefly describe procedures in the NHS that should follow a child's death. These procedures are illustrated in the flowchart as 'Immediate decision making and notification', 'Investigation and information gathering', and 'Child Death Review Meeting', which currently may be referred to by a number of different names including 'child death review meeting', 'hospital mortality review meeting', or 'final case discussion'.

The statutory responsibilities of CDR partners are set out in [Chapter 5](#) of this guidance. Whilst CDR partners are free to establish their own structure and process to review the deaths of children normally resident in their geographical area of responsibility based on local need, they should ensure that the processes align to the general principles set out in this guidance in order to enable local lessons to be reflected on at a national level.



In order to ensure that the entire child death review process is standardised nationally as far as possible, the general process of the review is described in detail through this guidance.

To illustrate how the process might unfold in different circumstances, four case examples are included at [Appendix 1](#).

## 1.1 Immediate decision making and notifications (Chapter 2)

*This section relates to the immediate actions to be taken after the death of a child, such as notification of death, or deciding whether other investigations are warranted. In practice, the majority of such discussions will happen in a clinical setting, but may require input from other agencies in certain cases.*

A number of decisions need to be made by professionals in the hours immediately following the death of a child. These include:

- how best to support the family;
- whether the death meets the criteria for a Joint Agency Response;
- whether a Medical Certificate of Cause of Death (MCCD) can be issued, or whether a referral to the coroner is required; and
- whether the death meets the criteria for an NHS serious incident investigation.

A number of notifications should also be made: to the child's GP and other professionals; to the Child Health Information System; and the relevant CDR partners and CDOP.

## 1.2 Investigation and information gathering (Chapter 3)

*This section is predominantly for those involved in the preliminary stages of the child death review process in the aftermath of a child's death. It also summarises other investigations that may run in parallel to the CDR process.*

After immediate decisions and notifications have been made, a number of investigations may then follow. These include:

- coronial investigation;
- Joint Agency Response;
- NHS Serious Incident Investigation.

Post-mortem examinations may be required in a number of cases. Which investigations are necessary will vary depending on the circumstances of the individual case. They may run in parallel, and timeframes will vary greatly from case to case.

## 1.3 Child death review meeting (Chapter 4)

*This section relates to the discussion of the death of a child by the professionals who were **directly involved** in the care of that child during his or her life and those professionals who were involved in the investigation into his or her death. The*

*outputs of this meeting will inform the statutory independent multi-agency panel arranged by CDR partners at CDOP or equivalent.*

Although investigations following the death of a child will vary, every child's death should be discussed at a child death review meeting. This is the multi-professional meeting attended by professionals directly involved in the care of that child during life and those involved in the investigation after death. The nature of this meeting will vary according to the circumstances of the child's death and the practitioners involved. It would, for example, take the form of a case discussion following a Joint Agency Response, a perinatal mortality review group meeting in the case of a baby who dies in a neonatal unit, or a hospital-based mortality meeting following the death of a child in a paediatric intensive care unit. It has common aims and principles in all cases.

## **1.4 Review of child deaths at a Child Death Overview Panel (CDOP) (Chapter 5)**

*This section describes some of the statutory requirements placed upon CDR partners, and the functions that they are expected to carry out. It outlines the function of an independent and multi-agency panel that should be established to scrutinise all aspects of a child's death, using evidence generated in the steps which precede this stage of the overall child death review process. This is known as a Child Death Overview Panel (CDOP) or equivalent.*

CDR partners are free to establish the specific structure to conduct this independent multi-agency scrutiny based on local need, using the information provided throughout the preceding steps of the review process. However, they should ensure that whatever structure they use should as far as possible ensure standardised output to enable thematic learning at national level. In all cases throughout this guidance, the body conducting the CDR partners review is identified as a CDOP.

In making arrangements to review child deaths, CDR partners should establish a structure and process to review all deaths of children normally resident in their area and, if appropriate and agreed between CDR partners, the deaths of children not normally resident in their area but who have died there.

## **1.5 Support for the family (Chapter 6)**

Supporting and engaging the family who have lost a child is of prime importance throughout the whole child death review process. Recognising the complexity of the process, and the different emotional responses that bereavement can bring, families should be given a single, named point of contact, *i.e.* the "key worker", for information on the processes following their child's death, and who can signpost them to sources of support.

# Chapter 2

## Immediate decision making and notifications

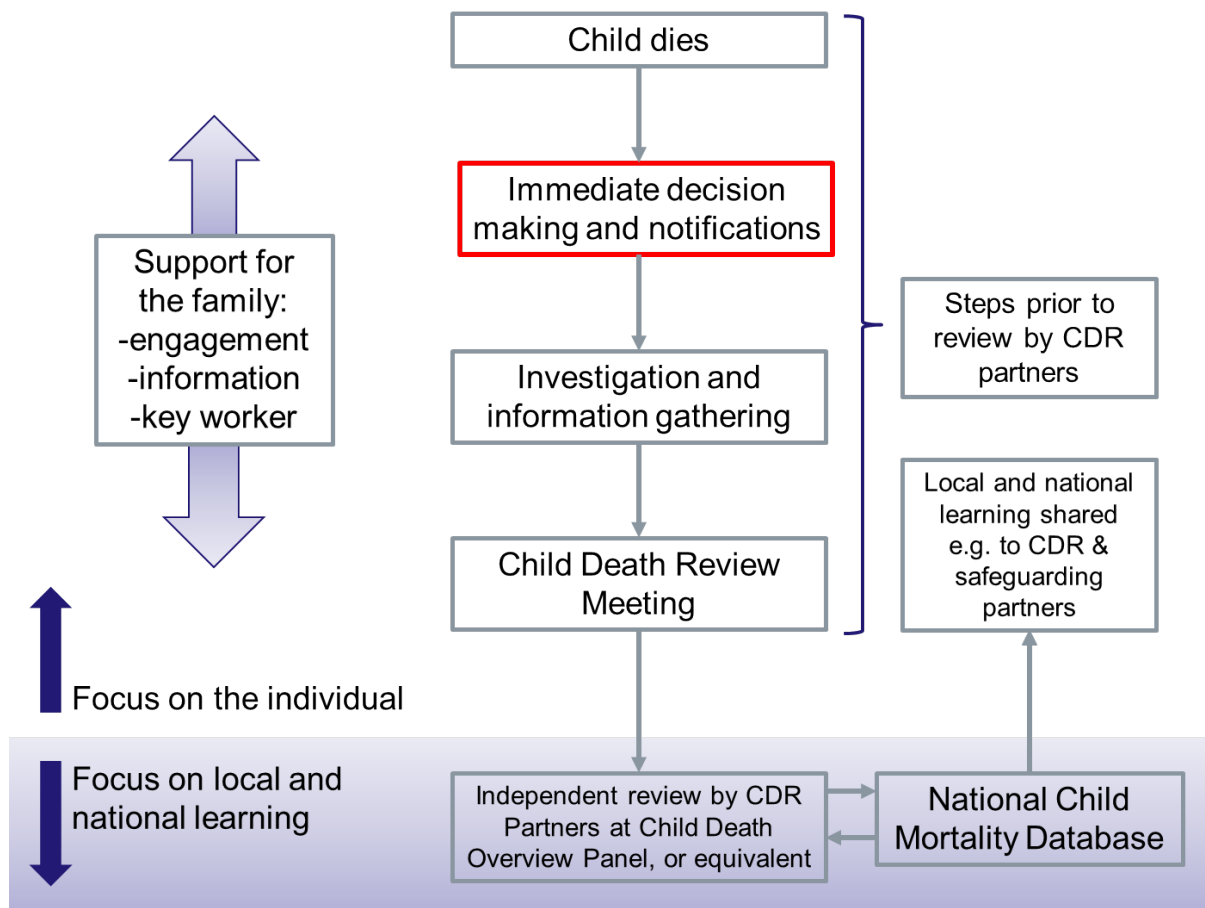


Figure 2: Chart indicating the general process to follow when a child dies – highlighting the immediate decision making and notifications stage of the review process (in this chart, CDOP is used to describe the review stage that CDR Partners are directly responsible for).

### 2.1 Introduction and principles

2.1.1 This chapter describes the immediate decisions that professionals should make in the hours following the death of any child. This includes deciding whether a MCCD can be issued, or whether a referral to the coroner is necessary.

2.1.2 The cause of death for most children who die is understood and the doctor who has attended the child at the end of their life (the “attending doctor”) will be able to issue a MCCD and the death will be able to be registered. Consideration should be given to how best to support the family, and to what information needs to be gathered to inform the CDRM.

2.1.3 However, if the death is from external causes, the circumstances are unclear, or safeguarding concerns or problems with care or service delivery are suspected, further investigations will be needed, to understand how the child has died.

2.1.4 In order to respond appropriately to each death, senior professionals attending the child at the end of his/her life should consult with each other in order to determine the correct course of action. This is relevant to all child deaths, wherever they occur.

## 2.2 Who should be involved

2.2.1 Necessary discussions may be face-to-face or by telephone and should engage the following professionals:

- The consultant or GP or other health professional attending the child at the end of his/her life;
- The senior nurse, midwife, or health visitor attending the child at the end of his/her life;
- The Medical Examiner, once the national system is introduced;
- Other professionals as appropriate; for example:
  - the on-call health professional, police investigator, and duty social worker in the context of a Joint Agency Response;
  - the coroner's officer in circumstances when a MCCD cannot be issued; and
  - a member of the hospital patient safety team when care or service delivery issues are suspected.

## 2.3 What immediate decisions are needed?

2.3.1 Within 1-2 hours if possible, senior professionals with responsibility for the child at the end of his/her life should:

- 1). identify the available facts about the circumstances of the child's death;
- 2). determine whether the death meets the criteria for a Joint Agency Response, and if so contact the on-call representatives for the police, children's social care and health so as to initiate the joint agency response. (see [Chapter 3.3](#));
- 3). determine whether an MCCD can be issued, if not, consider whether the death should be referred to the coroner. (see [Chapter 2.4](#) below);
- 4). determine whether an issue relating to health care or service delivery has occurred or is suspected and therefore whether the death should be referred to the coroner and/or a serious incident investigation;
- 5). identify how best to support the family; and
- 6). determine whether any actions are necessary to ensure the health and safety of others, including family or community members, healthcare patients and staff.

2.3.2 In all deaths, these discussions should be recorded on a relevant proforma (for an example see [Appendix 3](#)). The outcome of these discussions should also be fed back to the family.

## 2.4 Issuing an MCCD or referral to the coroner

2.4.1 At the death of a child, the attending doctor should first decide whether they are able to issue an MCCD in accordance with [F66 guidance](#) set out by the ONS and Home Office. Attention should then be given to how best to support the family and what information needs to be gathered to inform the CDRM.

2.4.2 There are two versions of the MCCD for child deaths: a neonatal certificate (up to 28 days) and the standard certificate. In deaths of children with complex

conditions, the correct wording of the MCCD should be discussed with the child's paediatric specialists.

2.4.3 If the attending doctor is unable to sign the MCCD, then they should refer the matter to the coroner. The Chief Coroner has issued guidance on which deaths should be reported to the coroner (see [Appendix 2](#)). If there is any uncertainty over whether a referral is necessary, the attending doctor should contact the coroner's office to discuss.

2.4.4 Following notification, a coroner may decide one of the following:

- That there is no need for further investigation – the attending doctor can then issue the MCCD without any coronial action;
- That the MCCD is agreed but that a coronial Form 100A or 100B (no further coroner investigation) will be provided to the local registrar to support the cause of death; or
- The case for investigation is accepted, in which case no MCCD is issued. At the conclusion of the investigation the coroner will notify the cause of death to the registrar.

## 2.5 The post mortem examination

2.5.1 In deaths where a MCCD can be issued a hospital post mortem examination (PM) may still provide important information as to why a child has died. It is the right of parents to request a hospital PM if this is their wish and the coroner is not investigating the death (the key worker and clinical staff should explain to those concerned the outcome of the request for a hospital post mortem). It is therefore good practice to inform the family of the benefits of a PM and what the process entails, so that they can make an informed decision regarding giving their consent for one to occur. If a coroner requires a post mortem examination as part of his/her investigation parental consent is not required and parents cannot refuse the examination.

## 2.6 Other NHS notifications

2.6.1 The attending health care team should also notify the following within 24 hours (or the next working day) of the child's death:

- **Child Health Information System (CHIS)**; the NHS England CHIS system provides a comprehensive local record of a child's public health and community based healthcare. Health care providers should notify their local CHIS to ensure that further clinic appointments are not arranged;
- **General Practitioner**; the attending health care team should inform the child's GP of the fact and circumstances of the death, so that the GP is able to support the family;
- **Other professionals, as appropriate**; community midwives, health visitor, school nurse, hospital/community medical team;
- **CDR partners, via the local CDOP administrator (or equivalent)**; through completion of a Notification Form and in future for neonatal deaths via the planned MBRRACE-UK/PMRT system. (The local CDR partners should coordinate with other CDR partners as required – see [Chapter 5.5](#) - on reviewing deaths of non-resident children for more information); and

- **Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries**<sup>6</sup> ([MBRRACE-UK](#)); Lead Reporter at the hospital of birth in the case of perinatal deaths (22<sup>+0</sup> week's gestation to 28 days after birth) to complete the national perinatal mortality surveillance data.

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<sup>6</sup> [MBRRACE](#) is a collaboration which delivers the Maternal, Newborn and Infant Clinical Outcome Review Programme:

# Chapter 3

## Investigating and information gathering

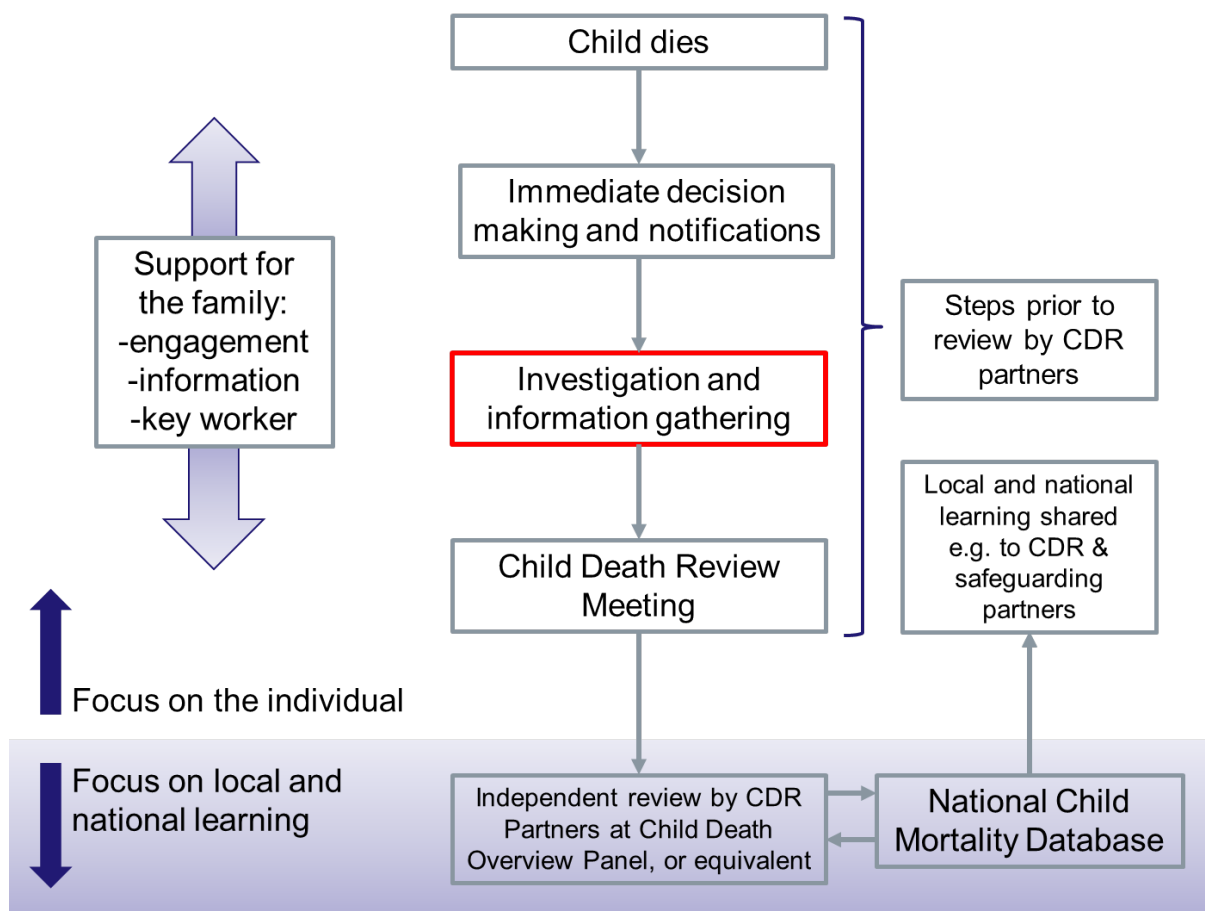


Figure 3 Chart indicating the general process to follow when a child dies – highlighting the investigating and information gathering stage of the review process (in this chart, CDOP is used to describe the review stage that CDR partners are directly responsible for).

### 3.1 Introduction and principles

3.1.1 After immediate decisions have been taken and notifications made, a number of investigations may then follow. They will vary depending on the circumstances of the case, and may run in parallel. Timescales will vary greatly from case to case. The learning from investigations will inform the CDRM and independent review by CDR partners at CDOP or equivalent. This chapter describes the main investigations that may take place.

3.1.2 Alongside this, essential information needs to be gathered for all child deaths. This includes demographic data, and information relating to the circumstances of death and background medical history. This information should be reported to CDOPs (or equivalent) via the Reporting Form, or, for deaths of babies in neonatal units via the Perinatal Mortality Review Tool.

### 3.2 Coronial Investigation

3.2.1 Anyone can refer a death to the coroner for investigation. See [Appendix 2](#) for guidance to doctors for a list of reasons for referral.

3.2.2 Once referred and accepted, the coroner takes legal possession of the body and opens an investigation into the death. If there is a coronial investigation, it is the coroner who will order a post-mortem examination, if necessary. Following this examination, the body of the child is usually promptly released back to their family for the death to be registered and funeral arrangements to be made. Release may however be later if organs have been taken for analysis, or if a second independent post-mortem examination is required.

### Early release of the body and coroner out-of-hours services

The Chief Coroner has recommended that there should be an out-of-hours scheme in place across all coroner areas, to assist families. There will be a variety of reasons why a bereaved family may request early release of the body, including specific religious considerations. If the death is that of a young child, the family may ask for the body to be released as soon as possible to a dedicated room in the hospital. However, the coroner service is a local service, and out of hours provision varies, often as a result of resources available. The Chief Coroner has recently issued related guidance on decision making and expedited decisions:

<https://www.judiciary.gov.uk/wp-content/uploads/2018/05/guidance-no-28-report-of-death-to-the-coroner-2010517.pdf>

3.2.3 Not all deaths reported to the coroner proceed to inquest (although most unexplained deaths of children do). The coroner may, as a result of preliminary inquiries, conclude that the death is from natural causes. In such cases the coroner may decide not to open a formal investigation (or hold an inquest), but may sign the case off to the local registrar as a natural cause of death. The coroner will use coronial Form 100 A (without a PM examination) or Form 100 B (with a PM examination).

3.2.4 If the coroner's duty to investigate a death is triggered he/she will open a formal investigation that will usually lead to an inquest. The inquest aims to determine the identity of the person that died and how, when and where they came by their death. In cases where it can be argued that the State has not appropriately upheld a person's 'right to life', this remit may encompass the wider circumstances in which the death occurred. The coroner will examine the evidence and, commonly without a jury, record the answers to the questions listed on a public document called the Record of Inquest. The details of the coroner's findings are forwarded to the local registrar.

3.2.5 All agencies that have pertinent information (such as records of any internal or joint agency investigation and/or notes from the CDRM) are under a duty to disclose such information to the coroner in an un-redacted format and the coroner has common law and statutory powers to enforce such disclosure. However, individuals providing such information may request that it is redacted before there is onward disclosure by the coroner to the Interested Persons<sup>7</sup> (which includes the bereaved family) in the case.

3.2.6 The family should be informed early on of the coroner's involvement; the need for and timing of a post-mortem examination; their right to be represented at the examination should they so wish; whether an investigation or inquest has been

<sup>7</sup> [Part 1; Chapter 7; Sec. 47; Coroners and Justice Act 2009.](#)



opened so that they may attend the inquest opening; and the dates of any investigation reviews, pre-inquest reviews and the inquest itself. Once the jurisdiction of the coroner is engaged, the coroner's officer is the main point of contact with the family for matters relating to the coronial process.

### 3.3 Joint Agency Response

The "[\*Sudden and Unexpected Death in Infancy and Childhood: multiagency guidelines for care and investigation \(2016\)\*](#)" give comprehensive advice and expectations of all agencies involved in a Joint Agency Response (JAR), and should be applied in full by all agencies. This Child Death Review Guidance should be seen as complementary to the SUDI/C Guidelines and does not replace them. All deceased children that meet the criteria for a JAR should be transferred to the nearest appropriate Emergency Department to enable the JAR to be triggered.

3.3.1 A Joint Agency Response should be triggered if a child's death:

- is or could be due to external causes<sup>8</sup>;
- is sudden and there is no immediately apparent cause (incl. SUDI/C);
- occurs in custody, or where the child was detained under the Mental Health Act;
- where the initial circumstances raise any suspicions that the death may not have been natural; or
- in the case of a stillbirth where no healthcare professional was in attendance.

3.3.2 In any of these circumstances, the on-call health professional, police investigator, and duty social worker should be contacted immediately so as to initiate the joint agency response.

3.3.3 A Joint Agency Response should also be triggered if such children are brought to hospital near death, are successfully resuscitated, but are expected to die in the following days. In such circumstances the Joint Agency Response 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. Appropriate clinical investigations should also be performed in these cases, as set out in Table 1 of the SUDI/C Guidelines (figure 4). Details of the recommended samples to be taken and the purposes for which they are intended are given on page 37 of the [\*SUDI/C Guidelines: Table 1. Routine suggested samples to be taken immediately after sudden unexpected deaths in infancy and childhood.\*](#)

3.3.4 Effective cross-agency working is key to the investigation of such deaths and to supporting the family, and requires all professionals to keep each other informed, to share relevant information between themselves, and to work collaboratively.

3.3.5 A lead health professional should be assigned. This person may be a doctor, senior nurse or health visitor with appropriate training and expertise. This person will ensure that all health responses are implemented, and be responsible for on-going liaison with the police and other agencies. Where no out-of-hours health rota for a

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<sup>8</sup> ICD-10 Chapter XX; World Health Organization 2016. From 2022 ICD-11 will supersede ICD-100.

Joint Agency Response exists in a locality, the role of lead health professional should be taken by the senior attending paediatrician.

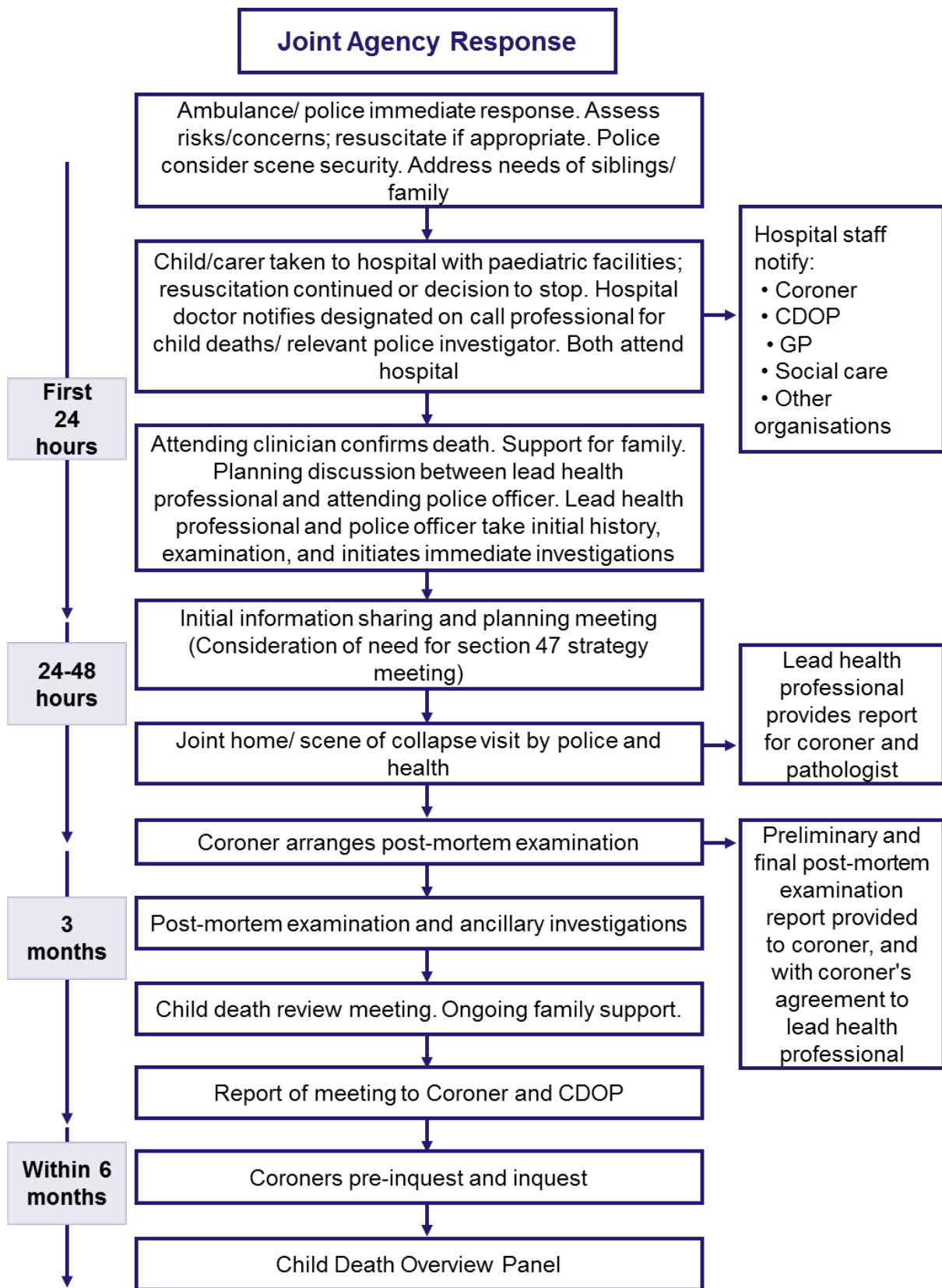


Figure 4: In this flow-chart, CDOP is used to represent the group established by CDR Partners that conducts the final stage of the child death review process.

3.3.6 The flow chart above (fig. 4) sets out the sequence of events that should unfold in a Joint Agency Response.

3.3.7 Local children's social care services should also be contacted and asked to check their records relating to the child, immediate family members, other members of the household and others with whom the child has lived.

3.3.8 Certain factors in the history or examination of the child may give rise to concerns about the circumstances of death. If such factors are identified, they should be documented and shared with the coroner and professionals in other key agencies. All injuries should be recorded and the lead police investigator should arrange a photographic record. Appropriate clinical investigations should be performed, as set out in Table 1 of the SUDI/C Guidelines. Details of the recommended samples to be taken and the purposes for which they are intended are given in Table 1 on page 37 of the [SUDI/C Guidelines](#).

3.3.9 An initial information-sharing and planning meeting should take place before the family leave the emergency department. This should include consideration of outstanding investigations, notification of agencies, arrangements for the post-mortem examination, and plans for a visit to the home or scene of collapse by those with appropriate forensic training. Following this visit, the lead health professional should prepare a report for the pathologist, coroner and the police investigator. This report should also be forwarded to the relevant CDOP administrator.

3.3.10 Once the results of the PM and other clinical investigations are known, a further multi-agency meeting should take place to review emerging findings. Once the final post mortem report has been released by the coroner, arrangements can be made for the child death review meeting. The child death review meeting should ideally take place before the inquest so as to inform the coroner's investigation. The CDOP or equivalent will normally take place after the conclusion of the inquest, taking account of the coroner's conclusions.

3.3.11 In circumstances where a child has died, and abuse or neglect is known or suspected, professionals at the initial information-sharing and planning meeting should notify the safeguarding partners whose responsibility it is to determine whether the case meets criteria for a child safeguarding practice review<sup>9</sup>.

3.3.12 There are some types of deaths which fall under the jurisdiction of a specific arm of the police force e.g. the Road Traffic Collision Unit or the British Transport Police. In such situations the Designated Doctor should ensure that there is a co-ordinated approach with other elements of the Joint Agency Response, and any report arising from their investigation informs the wider child death review process.

## 3.4 NHS serious incident investigation

3.4.1 NHS serious incident investigations, when initiated, should inform the child death review process through providing a detailed analysis of patient safety incidents that may have contributed to the death by the way of a Reporting Form. Serious incident investigations should occur when it is thought that a higher level of investigation (using Root Cause Analysis (RCA) or any future methodology endorsed

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<sup>9</sup> *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children* (2018); Chapter 4.

by the [Healthcare Safety Investigation Branch](#)) might help clarify understanding of the event and support subsequent improvements in safety.

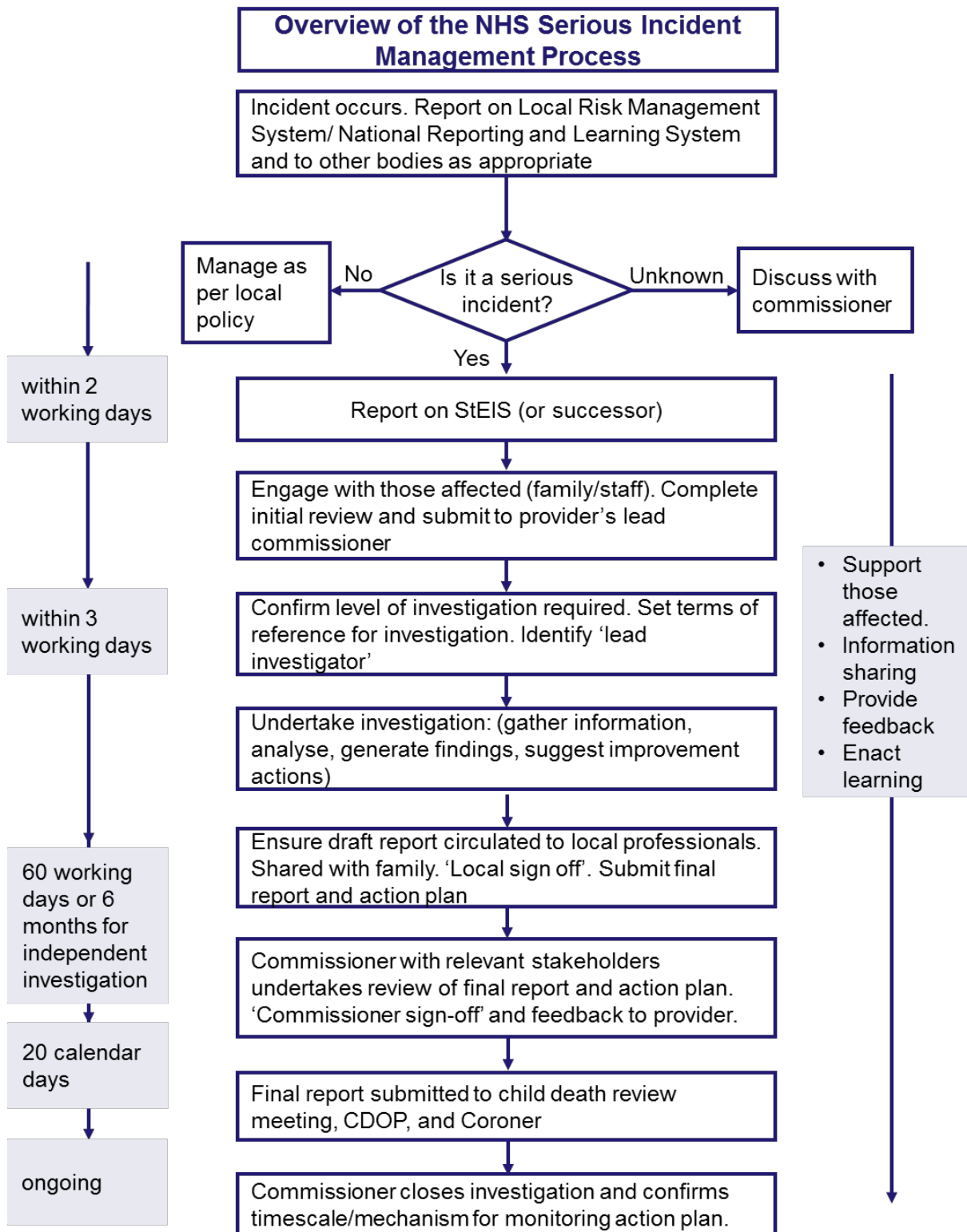


Figure 5: In this flow-chart, CDOP is used to represent the group established by CDR Partners that conducts the final stage of the child death review process.

3.4.2 Serious incident investigations are undertaken with the sole aim of learning about any problems in the delivery of healthcare services and in understanding the causes and contributory factors of those problems of which there may be several. Awareness that a serious incident may have occurred may come sometime after the

child's death. It is never too late to instigate a serious incident investigation. Serious incident investigations may occur in parallel to other investigations e.g. a Joint Agency Response. An outline of the serious incident investigation process is shown in figure 5.

3.4.3 NHS serious incident investigations are not conducted to hold organisations or individuals to account. They are designed to generate information that can be used to implement effective and sustainable changes to care provision, to reduce the risks of similar problems occurring in the future.

3.4.4 NHS trusts use the [Serious Incident Framework](#) to guide their investigation of serious incidents. Information about Serious Incidents should be submitted to the National Reporting and Learning System (NRLS) and Strategic Executive Information System (StEIS) or any systems that replace these. NHS trusts should review incident and rapid action forms and other available information to decide upon the appropriate level of investigation. There are three levels of investigation:

- a local, provider-led concise Root Cause Analysis investigation (Level 1);
- a local, provider-led Comprehensive Root Cause Analysis Investigation (Level 2); or
- a fully independent, externally commissioned Root Cause Analysis Investigation (Level 3).

3.4.5 These have different time frames and processes attached to them. Level 1 and 2 investigations should take no more than 60 working days unless it is necessary to take longer. Level 3 independent investigations should take no more than 6 months unless it is necessary to take longer.

3.4.6 Serious incident investigations should conclude with an investigation report that proposes effective and sustainable improvement activity that is designed to reduce the risk of similar incidents occurring. Actions proposed at the meeting should be written in "SMART" (Specific, Measurable, Attainable, Relevant, Time-bound) language and be agreed by individuals responsible for their completion. A generated action log should detail the responsible person and governance team, time-line, and evidence where actions are completed.

3.4.7 For early neonatal deaths of term babies (i.e. when the baby died within days 0-6, after at least 37<sup>+0</sup> weeks gestation) any NHS Serious Incident Investigation will be the responsibility of the Healthcare Safety Investigation Branch (HSIB).

3.4.8 Other organisations (e.g. police facilities, tier 4 mental health facilities) will have specific processes for investigation that should be followed in the event of a service delivery issue pertaining to that organisation. The involvement of multiple agencies may impact on timescales for a NHS serious incident investigation. The NHS Serious Incident Framework provides further guidance on coordinating serious incident investigations with other activity as well as how families/carers should be involved. It also provides links to the Root Cause Analysis methodology currently recommended for use in the NHS.

## 3.5 The Healthcare Safety Investigations Branch

3.5.1 Healthcare Safety Investigations Branch (HSIB) carries out independent investigations into safety concerns that occurred after 1 April 2017, within NHS funded care in England. Its objective is to be thorough, independent and impartial in

its approach without apportioning blame or liability. The HSIB accepts referrals from any source, and these can be made through the HSIB website. The investigations that are taken forward are chosen due to their potential to achieve system-wide learning and improvement, and ultimately to improve the care provided for patients. This is accomplished by working collaboratively with all involved in the incident, including patients and families, to establish cause and make recommendations that enable system-wide change.

**3.5.2** These investigations are intended to be conducted under the ‘safe-space’ principles for those reporting to investigations.

**3.5.3** Separately, HSIB investigate NHS Serious Incident Investigation cases of intrapartum stillbirth, early neonatal deaths and severe brain injuries from 37 weeks gestation. These investigations will continue to be characterised by a focus on learning and not attributing blame, and the involvement of the family is a key priority, but will not be covered by the safe space principles unlike the national investigations into broader safety concerns.

## **3.6 Co-ordination across investigations**

**3.6.1** It is vital that families do not become ‘lost’ in a myriad of parallel investigations following their child’s death. In addition to the investigations summarised above, families may raise complaints against one or more organisations, and cases may subsequently be referred to the relevant ombudsman. Effective co-ordination and good communication are vital to avoid additional distress to bereaved parents.

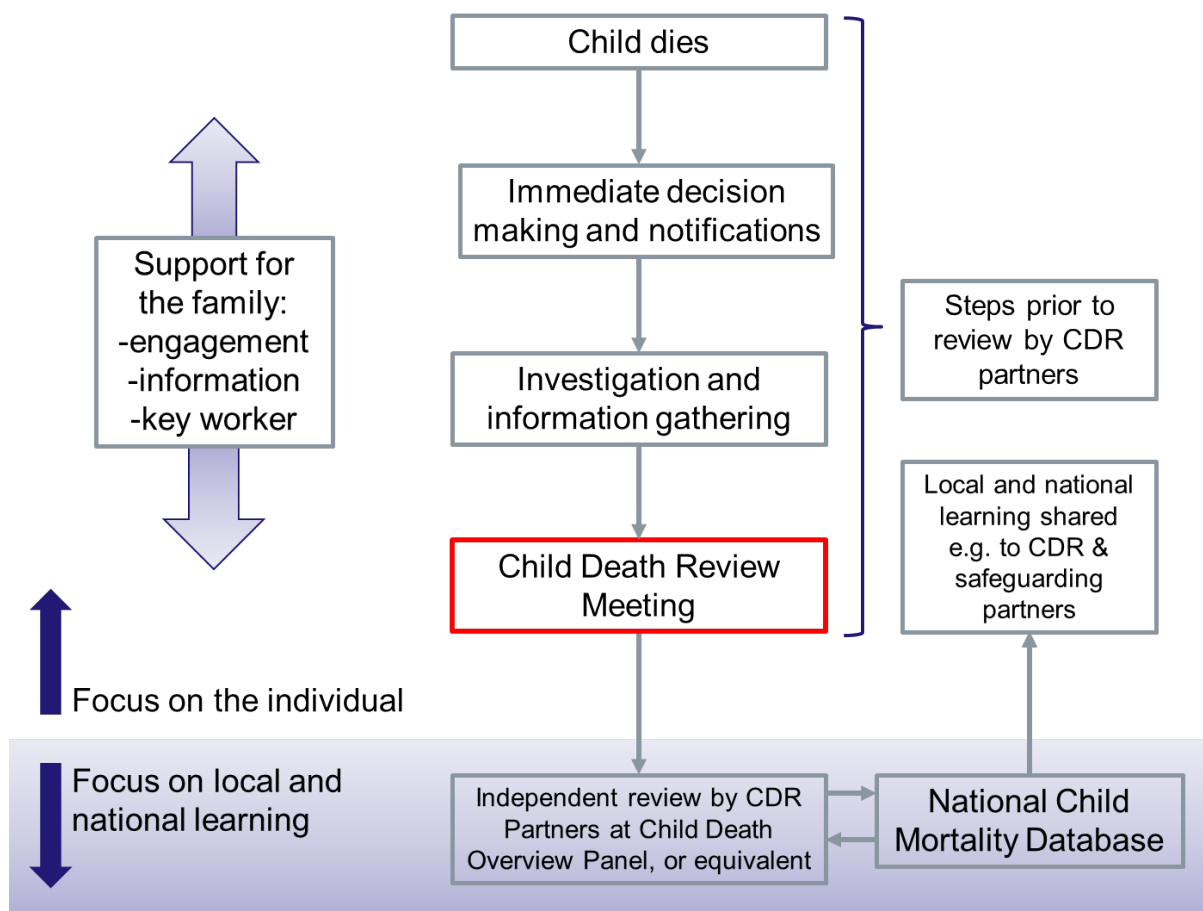
**3.6.2** A “key worker” should be assigned to every bereaved family, to act as a single point of contact in relation to the child death review process. The professional background to this role is less important than the expectations that come with the position (see [Chapter 7.2.1](#) for more information).

**3.6.3** In deaths where there is more than one investigation, NHS trusts should appoint a “case manager” to have oversight of procedures: ensuring that those involved are objective (e.g. through engaging the Patient Advice and Liaison Service), have an understanding of statutory requirements, follow appropriate timescales, ensure parents have an opportunity to input into the process and establish how they would like to receive feedback. This is distinct from the key worker, who acts as an ongoing single point of contact for families.

Please [see Appendix 1](#) for four case examples illustrating each stage of the child death review process.

# Chapter 4

## The child death review meeting



**Figure 6 Chart indicating the general process to follow when a child dies – highlighting the meeting of professionals where all matters relating to an individual child’s death are discussed by the professionals directly involved in the care of that child during life and those involved in the investigation after death. This meeting is referred to as the Child Death Review Meeting.**

### 4.1 Introduction and principles

4.1.1 The CDRM is a multi-professional meeting where all matters relating to an individual child’s death are discussed by the professionals directly involved in the care of that child during life and their investigation after death.

4.1.2 The nature of this meeting will vary according to the circumstances of the child’s death and the practitioners involved. For example, it could take the form of a final case discussion following a Joint Agency Response; a perinatal mortality review group meeting in the case of a baby who dies in a neonatal unit; a hospital-based mortality meeting following the death of a child in a paediatric intensive care unit; or similar case discussion.

4.1.3 The review meeting should be flexible and proportionate, and focused on local learning. It is important that all deaths are reviewed. However, in certain circumstances it may be appropriate for the review to be quite brief or for the meeting to discuss one child or several children. In every case, the Analysis Form should be drafted at the CDRM and then sent to the relevant CDOP.

4.1.4 For deaths in a neonatal intensive care unit, the review group meeting is supported by the use of the national Perinatal Mortality Review Tool (PMRT) and advice and support about the use of the tool is provided by the MBRRACE-UK/PMRT team: <https://www.npeu.ox.ac.uk/pmrt>.

### **The Perinatal Mortality Review Tool and the child death review process**

For deaths of babies in a midwifery unit, on delivery suite, and in a neonatal intensive care unit, the child death review meeting will often be known as a perinatal mortality review group meeting.

Perinatal mortality review groups should use the national PMRT, a web-based tool which supports standardised, systematic review of care in perinatal deaths.

If a baby was transferred between neonatal units, the neonatal unit where the baby died is responsible for leading the review (using the PMRT), while ensuring that all units involved in the care (including care during pregnancy, labour and delivery) inform and preferably participate in a joint review meeting. If it is not possible to carry out a joint review then the perinatal mortality review group in the originating unit is responsible for reviewing the midwifery, obstetric and neonatal care provided in their unit before the baby was transferred.

In all cases, the review meeting should generate an Analysis Form, which should be sent to the local CDOP.

## **4.2 Aims of the child death review meeting**

4.2.1 In all cases, the aims of the CDRM are:

- to review the background history, treatment, and outcomes of investigations, to determine, as far as is possible, the likely cause of death;
- to ascertain contributory and modifiable factors across domains specific to the child, the social and physical environment, and service delivery;
- to describe any learning arising from the death and, where appropriate, to identify any actions that should be taken by any of the organisations involved to improve the safety or welfare of children or the child death review process;
- to review the support provided to the family and to ensure that the family are provided with:
  - the outcomes of any investigation into their child's death;
  - a plain English explanation of why their child died (accepting that sometimes this is not possible even after investigations have been undertaken) and any learning from the review meeting;
- to ensure that CDOP and, where appropriate, the coroner is informed of the outcomes of any investigation into the child's death; and
- to review the support provided to staff involved in the care of the child.

4.2.2 Notes of the meeting should be taken to help with completion of the draft analysis form sent to CDOP.



### 4.3 Who should attend the child death review meeting?

4.3.1 It is the responsibility of the organisation responsible for the declaration of death to arrange the CDRM<sup>10</sup>. The exception to this is when a Joint Agency Response has occurred, in which case responsibility defaults to the lead health professional.

4.3.2 Each child's death requires unique consideration and where possible, should engage professionals across the pathway of care. The following professionals *may* be invited, depending on their ability to contribute meaningfully to a discussion on the circumstances of the child's death:

- hospital or community healthcare staff involved with the child at the end of his/her life, and those known to the family prior to this event;
- pathologist, if a post-mortem examination has taken place, or placental histology has been reported in the case of a neonatal death;
- other professional peers from relevant hospital departments and community services;
- patient safety team if a serious incident investigation has taken place;
- coroner's officer, if the case has been referred to the coroner;
- senior investigating police officer, if there is a Joint Agency Response; or
- other practitioners for example social work, ambulance and fire services, primary care clinicians, school nurse, head teacher, representatives from voluntary organisations.

4.3.3 NHS Trusts should note that, where practically possible, children's deaths should be discussed at an individualised meeting, and that matters of morbidity should be considered separately. It is only through such a comprehensive approach that the contributory factors to death can be understood. (See case examples at [Appendix 1](#) for further illustration).

4.3.4 If certain professionals are unable to attend, they might be invited to submit a report to the meeting.

### 4.4 Who should chair the meeting?

4.4.1 The CDRM should be chaired by a lead professional for the child death review process within the organisation where death was declared, or the lead health professional in a Joint Agency Response. This person should have designated time assigned for this within their job plan.

4.4.2 If the lead professional also had overall clinical responsibility for the child, the role of chair should be delegated to another colleague to avoid any perceived conflict of interests. At the beginning of each meeting the Chair should inquire as to conflicts of interest among the attendees. In rare cases, it may be necessary to seek a chair external to the organisation; for example, when trust has broken down between the

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<sup>10</sup> In practice, a medical organisation, for example an NHS trust, General Practice surgery, or hospice would be the most appropriate place to hold the majority of child death review meetings, as most deaths will be declared in a hospital, or by a GP in the community.<sup>11</sup> In practice, the majority of cases will occur in one or two geographical areas.

family and health care team in the organisation where death was declared. The designated doctor for child deaths might advise in such circumstances.

## 4.5 Where should the child death review meeting be held?

4.5.1 This comprehensive guidance pertains to all children's deaths. In general, children who die in hospital should be discussed within the department where the child died, and considered an integral part of wider clinical governance processes. Children who die in the community might be discussed at the local GP surgery, and children who die in a hospice discussed in that centre. However, the location of the meeting might also be informed by practical considerations relating to where the majority of the child's treatment took place.

4.5.2 For example, in the case of a child who has received many months' care at hospital A, and is then transferred in extremis for specialist treatment at hospital B, but dies within 24 hours; it might be sensible for the death to be primarily discussed at hospital A with input from the specialist team at hospital B. It is important that meetings relating to the same child are not duplicated in separate organisations (e.g. the local hospital and tertiary centre).

## 4.6 When should the meeting occur?

4.6.1 CDRMs require planning and co-ordination. Organisations should ensure that those responsible for reviewing child deaths have the proper resources to ensure that meetings are held in a timely and co-ordinated fashion. The meeting should take place once investigations (e.g. any NHS serious incident investigation or post-mortem examination) have concluded, and reports from key agencies and professionals unable to attend the meeting have been received. In some areas, the relevant CDOP office may be able to facilitate such co-ordination.

4.6.2 The meeting should take place as soon as is practically possible, ideally within three months, although serious incident investigations and the length of time it takes to receive the final post-mortem report will often cause delay. In order to best capture the views of those directly involved, it may be beneficial to start the process as soon as possible, prior to the formal CDRM. The CDRM should occur before any coroner's inquest, and before the CDOP meets.

4.6.3 The CDRM may proceed in the context of a criminal investigation, or prosecution, *in consultation with* the senior investigating police officer. The meeting cannot take place if the criminal investigation is directed at professionals involved in the care of the child, when prior group discussion might prejudice testimony in court.

## 4.7 Family engagement in the child death review meeting

4.7.1 The CDRM is a meeting for professionals. In order to allow full candour among those attending, and so that any difficult issues relating to the care of the child can be discussed without fear of misunderstanding, parents should not attend this meeting. However, parents should be informed of the meeting by their key worker and have an opportunity to contribute information and questions through their key worker or another professional.

4.7.2 At the meeting's conclusion, there should be a clear description of what follow-up meetings have already occurred with the parents, and who is responsible for reporting the meeting's conclusions to the family. This would generally be the child's paediatrician, or in the case of a neonatal death, obstetrician and neonatologist. In a coroner's investigation, such liaison should take place in conjunction with the

coroner's office, bearing in mind that the conclusion on the cause of death in such cases is the responsibility of the coroner at inquest.

Please see [Appendix 1](#) for four case examples illustrating each stage of the child death review process.

# Chapter 5

## The Child Death Overview Panel meeting

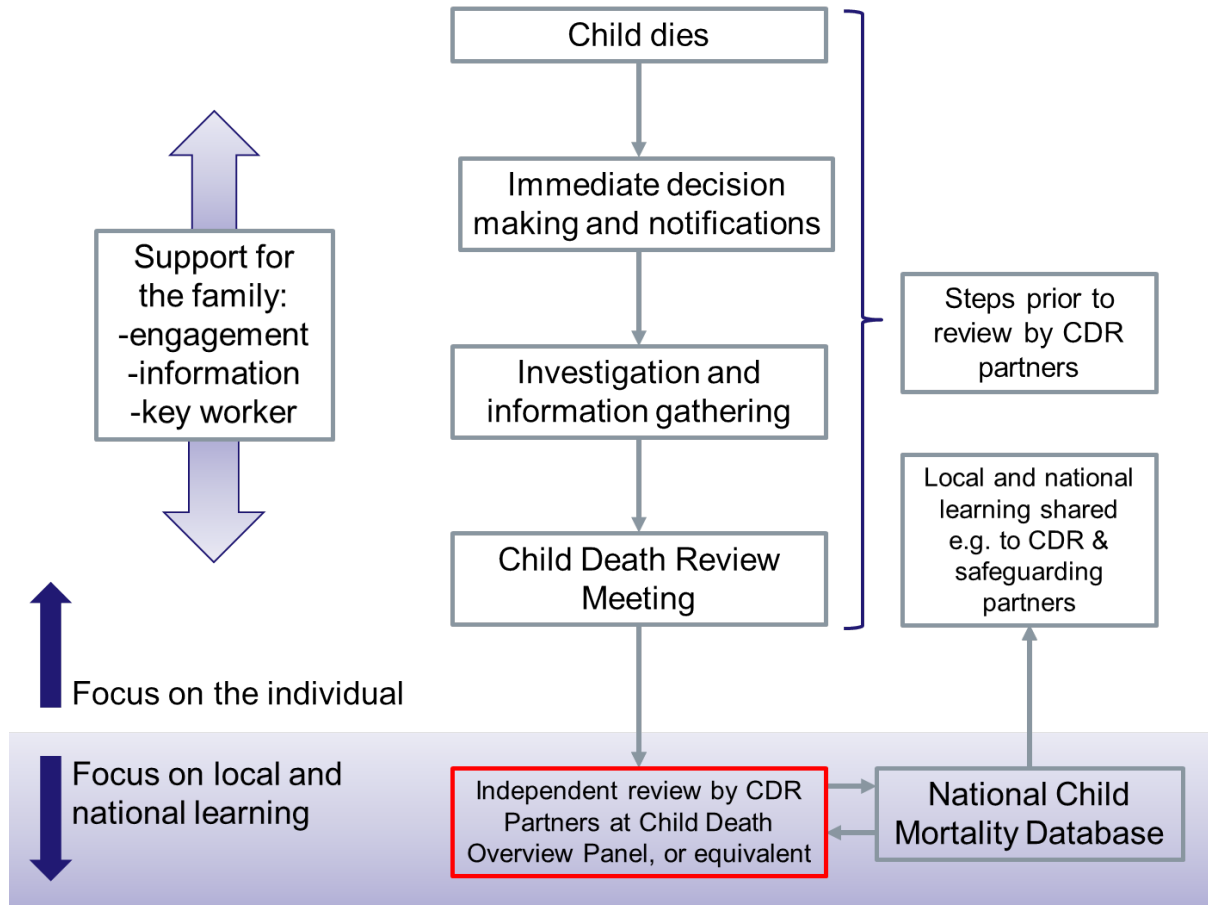


Figure 7 Chart indicating the general process to follow when a child dies – highlighting stage that child death review partners are directly responsible for, referred to as the Child Death Overview Panel.

As described above, CDR partners have a legal responsibility to ensure that the deaths of children normally resident in their area are reviewed. CDR partners can determine the structure that conducts the review at a local level, but should ensure that their local structure will enable learning at a national level – this will require a degree of standardisation to specific aspects of the review process. This chapter sets out guidance relating to the independent and final stage of the child death review process and CDR partners should have regard to the principles outlined in this chapter.

Chapters 2-4, 6 and 7 set out the procedures that should take place in advance of the independent scrutiny of a child's death at CDOP, or equivalent. For reviews to be effective and applicable nationally, CDR partners should ensure that the processes set out in chapters 2-4, 6 and 7 have been followed and that their local structures enable a CDOP review to be applicable to the national child mortality database.

## Statutory Requirements

When a child dies, in any circumstances, it is important for parents and families to understand what has happened and whether there are any lessons to be learned.

The responsibility for ensuring child death reviews are carried out is held by 'child death review partners,' who, in relation to a local authority area in England, are defined as the local authority for that area and any clinical commissioning groups operating in the local authority area.

Child death review partners must make arrangements to review all deaths of children normally resident in the local area and, if they consider it appropriate, for any non-resident child who has died in their area.

Child death review partners for two or more local authority areas may combine and agree that their areas be treated as a single area for the purpose of undertaking child death reviews.

Child death review partners must make arrangements for the analysis of information from all deaths reviewed.

The purpose of a review and/or analysis is to identify any matters relating to the death, or deaths, that are relevant to the welfare of children in the area or to public health and safety, and to consider whether action should be taken in relation to any matters identified. If child death review partners find action should be taken by a person or organisation, they must inform them. In addition, child death review partners:

- must, at such times as they consider appropriate, prepare and publish reports on:
  - what they have done as a result of the child death review arrangements in their area, and
  - how effective the arrangements have been in practice;
- may request information from a person or organisation for the purposes of enabling or assisting the review and/or analysis process - the person or organisation must comply with the request, and if they do not, the child death review partners may take legal action to seek enforcement
- may make payments directly towards expenditure incurred in connection with arrangements made for child death reviews or analysis of information about deaths reviewed, or by contributing to a fund out of which payments may be made; and may provide staff, goods, services, accommodation or other resources to any person for purposes connected with the child death review or analysis process.

### **5.1 Introduction and principles**

**5.1.1** The Children Act 2004 requires CDR partners to make arrangements to carry out child death reviews. These arrangements should result in the establishment of a Child Death Overview Panel (CDOP), or equivalent, to review the deaths of all children normally resident in the relevant local authority area, and if they consider it appropriate the deaths in that area of non-resident children. The review should then be carried out by a Child Death Overview Panel (CDOP), on behalf of CDR partners, and should be conducted in accordance with this guidance and *Working Together*.

**5.1.2** CDR partner footprints should be locally agreed; they should be aligned to existing networks of NHS care and other child services, and should take account of agency and organisational boundaries. They should cover a child population such

that they typically review at least 60 child deaths each year. Reviewing at least 60 deaths each year will better enable thematic learning in order to identify potential safeguarding or local health issues that could be modified in order to protect children from harm and, ultimately, save lives.

**5.1.3** Professionals in all agencies have a responsibility to notify the relevant CDOP of the death of any child of which they become aware, to share information for the purposes of reviewing the child's death, and to participate in local review arrangements when they have been involved with the child or family. CDOPs should conduct an anonymised secondary review of each death where the identifying details of the child and treating professionals are redacted. This review should be informed by a standardised output, the draft Analysis Form, from the CDRM.

## **5.2 Panel responsibilities**

**5.2.1** The functions of CDOP include:

- to collect and collate information about each child death, seeking relevant information from professionals and, where appropriate, family members;
- to analyse the information obtained, including the report from the CDRM, in order to confirm or clarify the cause of death, to determine any contributory factors, and to identify learning arising from the child death review process that may prevent future child deaths;
- to make recommendations to all relevant organisations where actions have been identified which may prevent future child deaths or promote the health, safety and wellbeing of children;
- to notify the Child Safeguarding Practice Review Panel and local Safeguarding Partners when it suspects that a child may have been abused or neglected;
- to notify the Medical Examiner (once introduced) and the doctor who certified the cause of death, if it identifies any errors or deficiencies in an individual child's registered cause of death. Any correction to the child's cause of death would only be made following an application for a formal correction;
- to provide specified data to NHS Digital and then, once established, to the National Child Mortality Database;
- to produce an annual report for CDR partners on local patterns and trends in child deaths, any lessons learnt and actions taken, and the effectiveness of the wider child death review process; and
- to contribute to local, regional and national initiatives to improve learning from child death reviews, including, where appropriate, approved research carried out within the requirements of data protection.

## **5.3 Panel Membership**

**5.3.1** The CDOP is a multi-professional panel whose core membership should include senior representatives from the following agencies or roles:

- public health;
- Designated Doctor for child deaths (and a hospital clinician if the Designated Doctor is a community doctor or vice versa);

- social services;
- police;
- safeguarding (designated doctor or nurse);
- primary care (GP or health visitor);
- nursing and/or midwifery;
- lay representation; and
- additional professionals should be considered on a case-by-case basis, for example from: coroner's office, education, housing, council services, health and wellbeing board, ambulance services, or hospices.

5.3.2 In addition to the core membership, relevant experts from health and other agencies should be invited as necessary to inform discussions.

5.3.3 The CDOP should be chaired by someone independent of the key providers (NHS, social services, and police) in the area. Panel members should be familiar with their responsibilities and ensure that they read all relevant material in advance of panel meetings (see [Appendix 6](#)). Conflicts of interest should be established at the outset of each meeting and panel members should not lead discussions if they are the named professional with responsibility for the care of the child.

5.3.4 Quoracy should usually demand attendance by lead professionals from health and the local authority. However, when a themed panel is discussing exclusively medical concerns (e.g. cardiac) the attendance of police and social care, beyond the core panel membership, might not be necessary (see [5.6](#) for more information on themed panels). In such situations those agencies not present might review the cases being discussed, and bring to the panel's attention relevant issues, as required. The CDOP should meet on a regular basis, determined by the number and type of deaths to be reviewed across a year.

## 5.4 CDOP administration

5.4.1 The CDOP administrator will work closely with the chair of the panel and the Designated Doctor for Child Deaths. The latter has responsibility for the wider child death review process and advising the CDOP in relation to themed panels. The CDOP administrative office should be notified according to local protocol whenever a child dies.

5.4.2 A CDOP, on behalf of CDR partners, may request any professional or organisation to provide relevant information to it, or to any other person or body, for the purposes of enabling or assisting the performance of the child death review partner's functions. Professionals and organisations must comply with such requests.

5.4.3 CDOPs should aim to review all children's deaths within six weeks of receiving the report from the CDRM or the result of the coroner's inquest. The exception to this might be when discussion of the case at a themed panel is planned. (See [5.6](#) below for more information on themed panels).

## 5.5 Reviewing deaths of non-resident children

5.5.1 Legislation allows for CDR partners to make arrangements for the review of a death in their area of a child not normally resident there. A pragmatic approach should be taken to such deaths, entailing discussion between the CDR partners in

the area where the child is normally resident and those in the area where the child died. In all cases, the CDR partners in the area where the child is normally resident is responsible for ensuring that a review *takes place* at CDOP level. Consideration should also be given to where the most learning can take place and this may sometimes dictate that a different CDOP to the area where the child is normally resident leads the discussion.

**5.5.2** For example: a child from area X drowns on holiday in area Y, and dies in a paediatric intensive care unit in area Z. While three CDR partners/CDOPs could be involved, the opportunities for most learning would likely be in Area Y, where the incident occurred, rather than the areas where the child was normally resident, or where they died.<sup>11,12</sup> In such situations, it is important to avoid serial discussions about the same child by separate CDR partners<sup>13</sup>. CDR partners for the area where the child is normally resident should decide which area conducts the review and retains responsibility for ensuring the review has been carried out. The application of remote conferencing can facilitate a co-ordinated approach where experts are unable to attend in person, and/or the CDOP administrator where the child is resident wishes to participate in the meeting.

## 5.6 Themed panels

**5.6.1** Some child deaths may be best reviewed at a themed meeting. A themed meeting is one where CDR partners arrange for a single CDOP, or neighbouring CDOPs, to collectively review child deaths from a particular cause or group of causes. Such arrangements allow appropriate professional experts to be present at the panel to inform discussions, and/or allow easier identification of themes when the number of deaths from a particular cause is small.

**5.6.2** Examples of themed panels might be neonatal at a local level; and cardiac, cancer, SUDI/SUDC, suicide, and trauma at a regional level. The frequency of such panel meetings would be dictated by the number of deaths in each category. Themed panels will demand a customised approach and an experienced chair. Consideration might be given to experts attending from a neighbouring clinical network or region. Themed panels should occur within 12 months of the child's death. Designated doctors for child death should work together to decide which cases might best benefit from review at a themed panel.

## 5.7 Involvement of family or carers

**5.7.1** Parents should be informed by their key worker that the review at CDOP will happen, and the purpose of the meeting should be explained. Particular care and compassion is needed when informing parents about the meeting and its purpose, to avoid adding to parents' distress or giving the impression in error that the parents are being excluded from a meeting about their child. With this in mind, it should be made clear that the meeting discusses many cases, and that all identifiable information relating to an individual child, family or carers, and professionals involved is redacted.

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<sup>11</sup> In practice, the majority of cases will occur in one or two geographical areas.

<sup>12</sup> In all cases, the CDR partners for the area where the child is normally resident are responsible for ensuring that a child death review takes place.

<sup>13</sup> It is possible that in some circumstances learning may be obtained in more than one area. These decisions can be decided between CDR Partners, with one area coordinating the discussion and the others contributing.



It should also be explained to parents that because of the anonymous nature of the CDOP review, it will not be possible to give them case specific feedback afterwards.

5.7.2 Parents should be assured that any information concerning their child's death which they believe might inform the meeting would be welcome and can be submitted to the CDOP administrator.

5.7.3 CDOPs should assure themselves that the information provided to the panel provides evidence that the needs of the family, in terms of follow up and bereavement support, have been met.

## **5.8 Local and national reporting**

5.8.1 CDR partners must at such intervals as they consider appropriate, prepare and publish a report on:

- a) what they have done as a result of the arrangements under this section; and
- b) how effective the arrangements have been in practice.

5.8.2 In addition to these statutory requirement CDR partners should aim to ensure that the report is written in plain English, and includes a summary of the key learning arising from the reviews, reports from themed panels, and actions that have been taken to prevent child deaths as a result of this learning.

5.8.3 CDOPs should record the outcome of their discussions on a final Analysis Form, and submit this to NHS Digital. Once it is operational, under instruction from the CDR partners CDOPs should submit copies of all completed forms associated with the child death review process and the analysis of information about the deaths reviewed (including but not limited to the Notification Form, the Reporting Form, Supplementary Reporting Forms and the Analysis Form) to the National Child Mortality Database.

Please see [Appendix 1](#) for four case examples illustrating each stage of the child death review process.

# Chapter 6

## Family Engagement and Bereavement Support

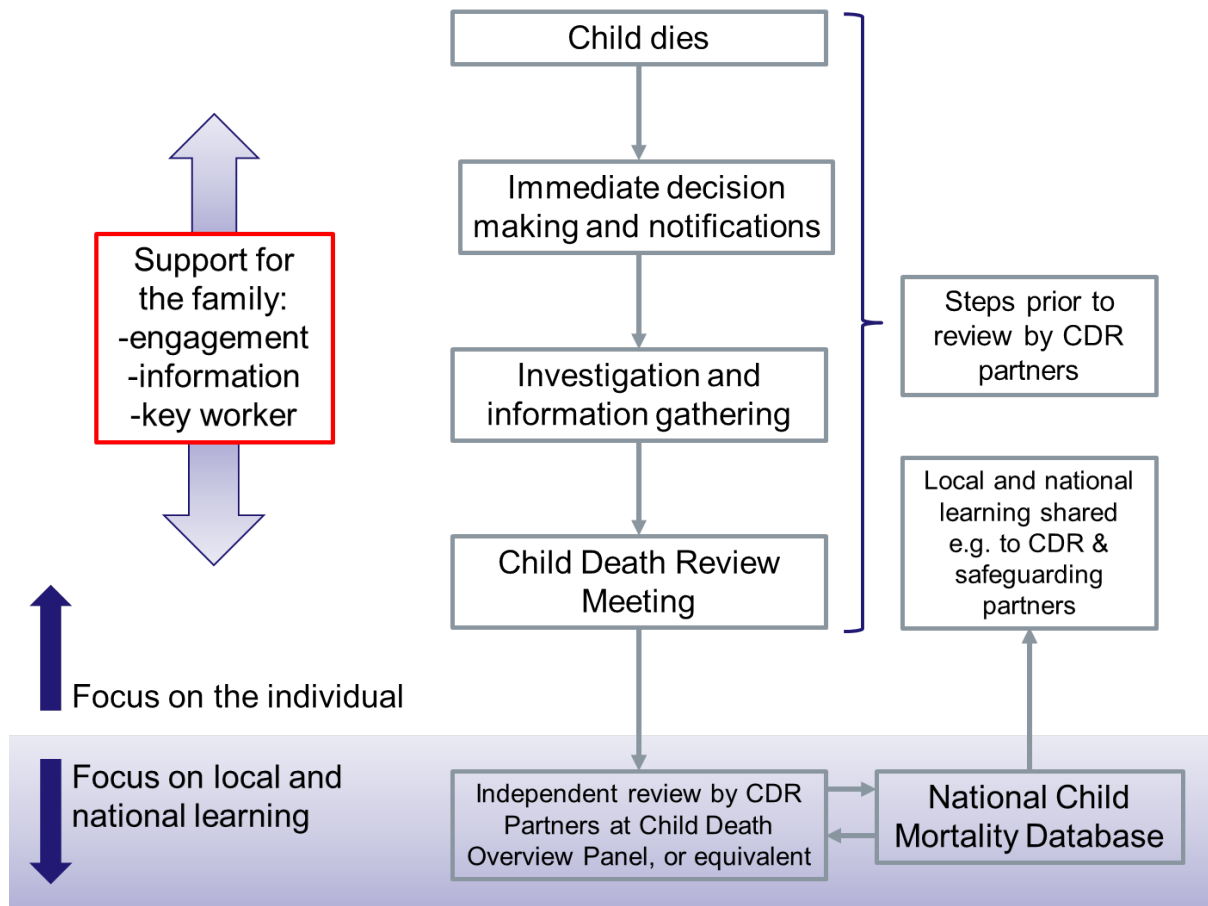


Figure 8 Chart indicating the general process to follow when a child dies – highlighting the support for the family throughout the entirety of the review process (in this chart, CDOP is used to describe the review stage that CDR partners are directly responsible for).

### 6.1 Introduction and principles

6.1.1 Every family has the right to have their child's death sensitively reviewed in order to, where possible, identify the cause of death and to ensure that lessons are learnt that may prevent further children's deaths. Professionals have a duty to support and engage with families at all stages in the review process. Parents and carers should be informed about the review process, and given the opportunity to contribute to investigations and meetings, and be informed of their outcomes.

6.1.2 This chapter describes the support that should be provided to all bereaved families and carers after the death of a child. [Appendix 7](#) includes contact details for national organisations offering bereavement support.

*All staff in all agencies and organisations have a duty to support bereaved parents and carers after their child's death and to show kindness and compassion. Where there have been issues with the quality of care provided, healthcare organisations have a duty of candour to explain what has happened, to apologise as appropriate, and to identify what lessons may be learnt to reduce the likelihood of the same*

*incident happening again. This provision should extend beyond the medical sector to any instances of error in the care of the child.*

*Whether the child's death is sudden or follows a long illness, the requirement for the following roles is universal:*

## **6.2 The team around the family**

### **6.2.1 A 'key worker'**

6.2.1.1 The processes that follow the death of a child are complex, in particular when multiple investigations are required (see [Chapter 3.6](#) on co-ordination across investigations). Recognising this, all bereaved families should be given a single, named point of contact to whom they can turn for information on the child death review process, and who can signpost them to sources of support.

6.2.1.2 It is the responsibility of the organisation where the child was certified dead to identify a key worker for the family. The role could be taken by a range of practitioners. For example:

- in the cases of children with long term conditions, the family may already be well known to a member of a specialty multi-disciplinary team such as a clinical nurse specialist, and this individual may be well placed to continue in a key worker role after the child has died; or
- in the cases of children with acute conditions (e.g. sepsis) the child and family may not have been known to any health care practitioners before the child's admission to hospital, and a key worker might instead be a member of the bereavement support team.

6.2.1.3 In criminal and coronial cases, the police family liaison and coroner's officer respectively provide vital support to the parents in relation to all elements of those investigations. In such situations, the key worker might play a supporting role in ensuring that the wider needs of the family are being met.

6.2.1.4 Regardless of professional background this person should:

- be a reliable and readily accessible point of contact for the family after the death;
  - help co-ordinate meetings between the family and professionals as required;
  - be able to provide information on the child death review process and the course of any investigations pertaining to the child;
  - liaise as required with the coroner's officer and police family liaison officer;
  - represent the 'voice' of the parents at professional meetings, ensure that their questions are effectively addressed, and to provide feedback to the family afterwards; and
  - signpost to expert bereavement support if required.
- A summary of responsibilities and competencies for the key worker role can be found at [Appendix 5](#).

### **6.2.2 A 'medical lead'**

6.2.2.1 An appropriate consultant neonatologist or paediatrician should also be identified after every child's death to support the family. This is distinct from the key

worker and might either be the doctor that the family had most involvement with while the child was alive or the designated professional on-duty at the time of death. This individual should liaise closely with the family's key worker and arrange:

- follow-up meetings at locations and times convenient to the family; and
- clinical expertise (via other professionals if necessary) to be able to i) answer questions relating to the medical, nursing or midwifery care of the child; ii) explain the findings, where relevant, of the post-mortem examination and /or other investigations and iii) report back the outcome from the CDRM.

### 6.2.3 Other professionals

6.2.3.1 At the time of a child's death, other professionals may also provide vital support to the family; these include (but are not limited to) the GP, clinical psychologist, social worker, family support worker, midwife, health visitor or school nurse, palliative care team, chaplaincy and pastoral support team.

6.2.3.2 In all cases, it is the duty of the key worker to ensure that there is clarity regarding each professional's role; that the family does not receive mixed messages; and that communication is clear.

## 6.3 What should bereaved families expect when their child has died?

6.3.1 It should be remembered that bereaved parents may be in state of extreme shock when their child has died. They may not be able to process or retain information and it is common that information needs to be repeated over time. The leaflet [When a Child Dies – A Guide for Parents and Carers](#) should be given to *all* bereaved families or carers.

6.3.2 *Providers should be familiar with its contents in order to ensure that bereaved families and carers receive the best support possible. Staff involved with the care of a child should also be offered appropriate support.*

6.3.3 When their child dies, bereaved parents or carers should:

- have the opportunity to spend time with the child's body in a quiet and private environment;
- have the opportunity to make memories including taking photographs, hand and foot prints and a lock of hair;
- (if the parents or carers wish) expect a member of staff to remain with them, to provide comfort, and to ensure their basic needs are met;
- be given the contact details of their key worker and the identity of their medical lead, be informed who will be contacting them and when they will be contacted after they leave the hospital or hospice (and what to do should they have any questions in the meantime);
- know how to make arrangements to view their child's body;
- be given information on death registration and the coronial process (if applicable);
- understand why a post-mortem examination may be indicated and, if so, where it is taking place, and when the results might be expected. In the event of a coroner's case this responsibility falls to the coroner's officer;

- be supported to have an understanding of the child death review process and how they are able to contribute to it;
- be given practical advice in respect to organising the child's funeral;
- have the key worker accompany them to meetings to provide practical and emotional support; and
- be able to access expert bereavement support if required (see below).

## 6.4 Planning prior to death with life-limiting conditions

6.4.1 Children with life-limiting conditions sometimes die following prolonged illnesses. In these situations, the best time to start supporting the family is while their child is still alive; 'parallel planning' is the term used to describe plans made for end of life while active treatment is still being pursued. It often involves a palliative care team. In parallel planning, consideration should be given to identifying a 'team around the family', writing an advance care plan, and giving thought to cultural and religious requirements. A child or family may choose to be cared for at home or in a hospice at the end of life. Parallel planning allows the clinical team to plan how best to move the child from the hospital (if appropriate) and to ensure that there are staff in place with the right skills to provide the appropriate level of care. Planning for death also allows discussions relating to organ and tissue donation to occur. For detailed guidance relating to the planning and management of end of life care in children with life-limiting conditions see:

- [end of life care for infants, children and young people with life-limiting conditions: planning and management](#)<sup>14</sup>;
- [core care pathway for children with life-limiting and life-threatening conditions](#)<sup>15</sup>; and
- [perinatal pathway for babies with palliative care needs](#)<sup>16</sup>.

## 6.5 When a child dies in the emergency department

6.5.1 When children die or are certified dead in the emergency department there will usually be a Joint Agency Response (see [Chapter 3.3](#) for more information). In such circumstances, the same expectations apply relating to identifying a 'team around the family'. Responsibility for ensuring that appropriate care is provided to the family falls to the organisation in which the child is certified dead. Detailed guidance relating to support for the family in such situations is provided in the SUDI/C Guidelines.

## 6.6 When a child dies and an NHS Serious Incident Investigation is instigated

6.6.1 On occasion, concerns about service delivery may be raised (by practitioners or the family) and the organisation will initiate an NHS serious incident investigation. Parents are often the expert in their child's condition and can provide vital insight into the circumstances of the death and quality of care received.

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<sup>14</sup> National Institute for Clinical and Health Excellence, 2016 <https://www.nice.org.uk/guidance/ng61>

<sup>15</sup> Together for Short Lives, 2013

[http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL\\_A\\_Core\\_Care\\_Pathway\\_ONLINE\\_.pdf](http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL_A_Core_Care_Pathway_ONLINE_.pdf)

<sup>16</sup> Together for Short Lives, 2017

[http://www.togetherforshortlives.org.uk/professionals/resources/11598\\_perinatal\\_pathway\\_for\\_babies\\_with\\_palliative\\_care\\_needs](http://www.togetherforshortlives.org.uk/professionals/resources/11598_perinatal_pathway_for_babies_with_palliative_care_needs)

6.6.2 In such cases, NHS trusts should appoint a “case manager”, who will support the key worker in having oversight of the various processes, tracking timelines, and ensuring commitments to the family are met. (See [Chapter 3.5](#) for more information on case managers).

## **6.7 Support for parents, families, and carers**

6.7.1 [Appendix 7](#) includes contact details for national charities who offer bereavement support for families. Local NHS services and CDOPs may also offer specific bereavement services. The key worker should be able direct families to the most appropriate support services.

# Chapter 7

## Specific situations

### 7.1 Deaths overseas of children normally resident in England

#### 7.1.1 Introduction and Principles

7.1.1.1 The CDR partners must make arrangements for the review of each death of a child normally resident in the area, including if they die overseas. They and CDR partners may learn about such a death from a variety of sources (e.g. Foreign and Commonwealth Office (FCO), media, coroner, public).

7.1.1.2 Because the duties of the coroner are engaged by the body of the deceased person lying within their area, these duties will only arise in respect of children who die abroad and whose bodies are returned to England. The duties of the coroner do not arise if the child is buried or cremated abroad. The coroner taking responsibility will usually be the coroner covering the area to which the child's body is brought for funeral arrangements.

7.1.1.3 The investigation of deaths that occur abroad by the coroner is often difficult due to problems securing evidence. The FCO usually assists by making contact with foreign authorities on behalf of the coroner, as the coroner has no power to summon evidence or witnesses outside England and Wales.

7.1.1.4 When the death has taken place abroad, the local CDR partners are advised to seek advice from the local senior coroner first; the CDR partners may also need assistance from agencies abroad, including police involved in the investigation of the death in question. Such reviews require careful coordination to ensure that relevant information from the FCO, international funeral directors, coroner, and local services (health, education, social services) is presented to the panel.

#### 7.1.2 Foreign and Commonwealth Office

7.1.2.1 The FCO can provide support to British nationals in difficulties overseas and provides [useful resources](#) for what should happen in the event of a death overseas. In the event that a child who is a British national, dies abroad, the child's family should notify the local authorities and the UK Embassy, High Commission, or Consulate in the country where the child has died. The family can also contact the FCO directly. Diplomatic officials in these offices will, when notified of a death, advise relatives how to register the death (abroad and/or in the UK); advise on how to repatriate the body using local or international funeral directors, and give guidance relating to bereavement support. Their staff will also notify the coronial liaison officer at the FCO. The FCO collects routine information about each death such as name, date of birth, address, known cause of death, and the welfare of other siblings. It is customary practice for the FCO to also notify the relevant CDR partners and CDOP where the child was normally resident, if a UK address is provided to them. The FCO will only be aware of a death if the family, local authorities or other interested party notifies them. The FCO can be contacted on [Coroner.LiaisonOfficer@fco.gov.uk](mailto:Coroner.LiaisonOfficer@fco.gov.uk), or in an emergency 0207 008 1500 (ask for Consular).

## 7.2 Children with learning disabilities

### 7.2.1 Introduction and principles

7.2.1.1 It is important to specifically recognise and record if a child or young person has learning disabilities, irrespective of any other diagnoses or syndromes that are recognised. This enables effective monitoring, auditing and evaluation of service provision; resource management and strategic planning; and assurance regarding equitable access to health services.

7.2.1.2 The Learning Disabilities Mortality Review (LeDeR) programme describes a review process for the deaths of people aged 4 years and over with learning disabilities in England<sup>17</sup>. Within the four NHS England regions, a LeDeR Regional Coordinator supports and provides a governance structure to local multi-agency Steering Groups to deliver the LeDeR mortality reviews. LeDeR recommends that CDOP Chairs are represented at the regional LeDeR Steering Group. The LeDeR programme team aims to support local areas to implement the LeDeR review process and to take forward the lessons learned from individual mortality reviews to make improvements to service provision. The LeDeR programme also collates and shares anonymised information from the review so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements.

### 7.2.2 Definition of learning disabilities

7.2.2.1 The LeDeR programme defines 'learning disabilities' to include the following:

- a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence), with
- a reduced ability to cope independently (impaired social functioning), which
- started in childhood with a lasting effect on development.

7.2.2.2 A child's ability to understand and use information and to cope independently should be interpreted in relation to other children of a similar age.

7.2.2.3 This definition encompasses children and adults with a broad range of disabilities; IQ alone is not sufficient to identify this population. For example, it includes those with autism who also have learning disabilities but not those on a higher level of the autistic spectrum, such as some with Asperger's Syndrome, who may be of average or above average intelligence. The definition does not include those who only have a specific 'learning difficulty' (such as dyspraxia or dyslexia). The fact that a child has physical disabilities does not mean that they have learning disabilities. Further information about the definition of learning disabilities used in the LeDeR programme can be found at: <http://www.bristol.ac.uk/sps/leder/information-for-reviewers/briefing-papers/>.

7.2.2.4 When it is obvious that a child has learning disabilities (e.g. because they have a specific syndrome that is associated with learning disabilities) this should be recorded even if a formal identification process for learning disabilities is yet to take place. In addition, even if a child has a specific condition associated with learning

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<sup>17</sup> Before the age of 4 years it can be difficult to ascertain if a child has learning disabilities, unless they have a specific syndrome always associated with learning disabilities. The LeDeR programme therefore starts reviewing deaths of people with learning disabilities from age 4 years onwards.



disabilities (e.g. Fragile X syndrome, Down's syndrome) they should still have their learning disabilities recorded as a separate and specific issue.

### **7.2.3 The interface between the child deaths review and the LeDeR mortality review process**

**7.2.3.1** The LeDeR mortality review process is described on the LeDeR website (<http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/>). The LeDeR programme adheres to key principles of communication, cooperation, and independence when liaising with other investigation or review processes. It is expected that the child death review process will be the primary review process for children with learning disability and that it will not be necessary for the LeDeR programme to review each case separately.

**7.2.3.2** When notified of the death of a child or young person aged 4-17 years who has learning disabilities, or is very likely to have learning disabilities but not yet had a formal assessment for this, the local CDR Partners should report that death to the LeDeR programme at <http://www.bristol.ac.uk/sps/leder/notify-a-death/> or 0300 777 4774. The person notifying the death to LeDeR should provide core information about the child and the relevant CDR partners. The CDR partners should then ensure that the LeDeR programme is represented at the meeting at which the death is reviewed. In addition, the Local Area Contact for the LeDeR programme and the CDOP or its equivalent chair should discuss the potential input from a LeDeR reviewer to offer expertise about learning disabilities (if appropriate) and to ensure the collection of core data for the LeDeR programme. Any completed notes and/or Analysis Form arising from the discussion should be submitted to the Local Area Contact for the LeDeR programme by the CDR partners. If the Local Area Contact is not known, contact the LeDeR team on 0300 777 4774.

**7.2.3.3** Some panels may find benefit in having additional 'learning disability themed meetings' at which common contributory factors leading to deaths, and frequently made learning points and recommendations, can be reviewed together through an equalities lens. The Regional Coordinator or Local Area Contact from the LeDeR programme should attend such meetings. The LeDeR programme, in liaison with the National Child Mortality Database team (once operational) and NHS Digital, on behalf of the Department of Health and Social Care, will collate completed mortality reports relating to children and young people with learning disabilities, and identify common themes and patterns at regional and national levels. These will be reported back to CDR partners and CDOPs on an annual basis.

## 7.3 Deaths of children in adult healthcare settings

### 7.3.1 Introduction and principles

7.3.1.1 A very small number of children (nearly always 16 and 17 year olds) die in adult intensive care units (ICUs), the deaths of these children are still subject to the child death review process.

7.3.1.2 The [Learning from Deaths](#) framework gives guidance to NHS trusts for reviewing adult inpatient deaths, and this should remain the primary approach for reviewing the *quality of care* for children who die in adult ICU. However, in all other respects, children who die in adult settings should have the same rigour of review as all other children who die. There should be close liaison with the designated doctor for child deaths from the outset, to ensure that this occurs.

### 7.3.2 Royal College of Physicians (RCP) National Mortality Case Record Review programme

7.3.2.1 *Learning from Deaths* requires NHS Trusts to review the deaths of patients in NHS care. For *adult* deaths, NHS providers are required to use a methodology for reviewing the *quality of care*, such as the Structured Judgment Review (SJR) approach advocated by the RCP [National Mortality Case Record Review Programme](#). This methodology has not been validated for use in relation to children. [More information on Learning from Deaths](#).

### 7.3.3 The approach to reviewing deaths of 16 and 17 year olds in adult ICU

7.3.3.1 The majority of hospital deaths in children and young people occur in regional paediatric and neonatal intensive care units. However, some age-admission policies across networks of care may stipulate that critically ill 16 and 17 year olds are cared for on an adult ICU. In order to avoid confusion for families and clinical staff, the general expectations arising from *Learning from Deaths* apply to children who die on adult ICUs, with the following essential caveats:

- There should be notification of the child health system, GP, and local CDR partners and CDOP office;
- The designated doctor for child deaths should be notified when a child dies in adult ICU. This individual can provide a central role in terms of:
  - advice regarding the need for a Joint Agency Response;
  - identifying whether the child is known to paediatric health professionals who should be represented at the adult mortality and morbidity (M&M) meeting; and
  - attending the adult M&M meeting and completing a standardised Analysis Form for the purposes of the relevant CDOP.
- The Structured Judgement Review approach, or other evidence based structured mortality review tool, should be used to review the quality of clinical care. This, the standardised CDR Analysis Form, and any other notes arising from the adult M&M meeting should be forwarded to the relevant CDOP. The designated doctor for child deaths should help co-ordinate this.

## **7.4 Suicide and self-harm**

### **7.4.1 Introduction and principles**

**7.4.1.1** Suicide is defined as a death where the conclusion of suicide is given at inquest where the coroner (or jury) is satisfied that the deceased did an act knowing and intending that their death would result. The High Court has recently handed down a judgment (*R(Maughan) v Senior Coroner for Oxfordshire [2018] EWHC 1955 (Admin)*) in which stated that its clear view was that a conclusion of suicide, whether expressed as a narrative statement or in short-form, is required to be proved to the civil, and not the criminal, standard of proof. This is a significant change to the previously understood position. It is likely that this case will be appealed to the Court of Appeal and therefore the legal position may be further clarified in due course.

### **7.4.2 National Confidential Inquiry into Suicide and Homicide by people with Mental illness (NCISH)**

**7.4.2.1** NCISH examined deaths of all children by suicide and published [annual reports](#) in 2016 and 2017. This review has now been suspended although further work may be undertaken using the same methodology in the future.

### **7.4.3 The approach to reviewing suicides in children**

**7.4.3.1** Child suicide should be reviewed in the same manner as other child deaths, with the following expectations:

- all deaths related to suspected suicide and self-harm should be referred to the coroner for investigation;
- all deaths related to suspected suicide and self-harm will require a Joint Agency Response;
- the CDRM should include experts in mental health and key professionals involved in the child's life across education, social services and health. Specific risk factors should be considered, including:
  - family factors such as mental illness, alcohol or drug misuse, and domestic violence;
  - abuse and neglect;
  - bereavement and experience of suicide;
  - bullying, including on-line bullying;
  - suicide-related internet use, including searching for methods and posting suicidal messages;
  - academic pressures, especially related to exams;
  - social isolation, especially leading to withdrawal;
  - physical health conditions that may have social impact, and their treatment
  - alcohol and illicit drugs;
  - mental ill health, self-harm, and suicidal ideation;
  - Issues relating to self-identity, including gender identity; or
  - exploitation, including child sexual exploitation, radicalisation, and gang-related exploitation.

7.4.3.2 Suspected child suicides should, where possible, be discussed at a themed specialist CDOP review with attendant mental health specialists.

## 7.5 Inpatient Mental Health settings

### 7.5.1 Introduction and principles

7.5.1.1 The principles set out in this section apply to all children in inpatient mental health settings whether they are treated 'voluntarily' as informal inpatients or detained under the Mental Health Act 1983 (MHA).

7.5.1.2 All deaths of children in inpatient mental health settings will trigger a Joint Agency Response (see [Chapter 3.2](#)).

7.5.1.3 All child deaths in an inpatient mental health setting (general and secure) should be reported to the coroner. If the death was not due to natural causes, the coroner is likely to open a formal investigation that may lead to an inquest.

7.5.1.4 When a child dies while detained under the MHA, there should also be a safeguarding practice review.

### 7.5.2 Child death review process

7.5.2.1 The professional confirming the death should inform the local designated doctor for child deaths at the same time as informing the coroner and the police. NHS and independent providers of inpatient mental health settings must notify the Care Quality Commission (CQC) or they can notify NHS England of the death of a patient through a local manager, or by reporting on the risk management system where information is uploaded to the national reporting and learning system. Where a child was detained under the Mental Health Act 1983, the death must be reported to the CQC.

7.5.2.2 Immediate decision making should take place as set out in [Chapter 2](#) of this guidance. Following necessary investigations (see [Chapter 3](#)), a CDRM should take place (see [Chapter 4](#)). The CDRM should involve the care coordinator for the community mental health team as well as other professionals from children and young people's mental health services. Other necessary attendees might be: GP, education/school representative, and social worker. This should be followed by a CDOP review (see [Chapter 5](#)).

### 7.5.3 Child Safeguarding Practice Reviews

7.5.3.1 When a child dies while detained under the Mental Health Act 1983 or while deprived of their liberty by the state, the death must be notified to Ofsted and the local safeguarding partners. These deaths, along with the death of any child in custody or secure accommodation, may trigger a local or national child safeguarding practice review.

### 7.5.4 Involvement and Support to Parents, Carers and Staff

7.5.4.1 As in any child death review process, there should be meaningful involvement of families (see [Chapter 6](#)). Effective co-ordination is vital when parallel investigations take place. A "key worker" should be assigned to every bereaved family to act as a single point of contact.

7.5.4.2 The inpatient manager might act as the case manager in providing progress updates on the separate investigations.

7.5.4.3 Bereavement support should be provided for families and consideration given to providing psychological support for staff involved in the care of the child.

## 7.6 Deaths in custody

### 7.6.1 Introduction and principles

**7.6.1.1** The primary responsibility for the investigation of the death of a child in custody lies with the coroner and Prisons and Probation Ombudsman (PPO). The coroner's duty to investigate deaths in custody and state detention also includes patients detained under the Mental Health Act 1983. The same processes also apply to the death of a child accommodated in a secure welfare placement<sup>18</sup>. While the CDR partners for the area where the child was normally resident are responsible for ensuring a review of the death at CDOP takes place, it is the CDOP for the area where the most learning can be captured that would normally conduct the CDOP review (as described in [Chapter 5.5](#)).

### 7.6.2 The Prisons and Probation Ombudsman

**7.6.2.1** The PPO investigates all deaths of children in prisons, secure children's homes, secure training centres, young offender institutions, immigration removal centres and approved premises (formerly known as probation hostels). This also generally includes children and young people temporarily absent from such establishments but still subject to detention (for example, where a young person is under escort or attending hospital). Deaths of children in police custody are not investigated by the PPO, but are instead investigated by the Independent Police Complaints Commission.

**7.6.2.2** Following a child death in custody, the police will begin an investigation and submit a report to the coroner. In tandem, the police may be involved in relation to investigating criminal matters related to the death, and not solely as the coroner's agent. The PPO will then further investigate the death to establish the circumstances surrounding the death and provide a written report with recommendations to the relevant organisations. The PPO investigation is separate to the coroner's inquest. However, a copy of the PPO report is sent to the coroner to assist their investigation. The PPO also publishes its investigation reports on its website after the inquest. HM Prison and Probation Service has its own internal guidance for staff following a death in custody which includes processes for providing support to family and carers.

### 7.6.3 The PPO and NHS England

**7.6.3.1** NHS England's Health and Justice commissioners are responsible for commissioning health services for children and young people in detained settings. When a child dies in custody the PPO will contact the lead within the local NHS England Health and Justice commissioning team, with details of the PPO Lead Investigator for the case, and will request the appointment of a [clinical reviewer](#). This will occur within one working day of the PPO being notified of the death. The aim of the clinical review is to examine the health services and treatment provided to the deceased individual while in custody, identify any areas of service delivery failure, identify any causes, contributory factors and learning opportunities, and make clear recommendations for the improvement of health service provision as appropriate.

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<sup>18</sup> The Children and Young People Secure Estate includes three types of residential placements for 10 to 17 year olds sentenced or remanded to custody. These are secure children's homes (SCHs), secure training centres and young offender institutions. SCHs may also provide care and accommodation for young people referred by local authorities for a secure welfare placement, in accordance with s.25 Children Act 1989, for the protection of themselves and/or others.

**7.6.3.2** The Children and Young People Secure Estate is a national resource, and children can be placed anywhere within the estate and may not be placed within their local area. Learning from child deaths in custody is important not just in terms of the health commissioner and secure setting, but also in terms of how placement decisions are made in the future.

## **7.6.4 Local NHS England response**

**7.6.4.1** Where it is suspected that problems with care or service delivery in relation to NHS-commissioned healthcare have contributed to or caused the death of a child in custody, a serious incident should be declared and an investigation managed according to the Serious Incident Framework. The NHS England commissioner should simultaneously notify the NHS England central team via the Director of Health and Justice.

**7.6.4.2** Usually the serious incident investigation will meet the needs of a clinical review for PPO purposes, so long as it is carried out by a clinician who is not involved in, or responsible for, the commissioning or provision of the healthcare service where the death occurred.

## **7.6.5 Deaths in custody and the child death review process**

**7.6.5.1** NHS providers should inform the CDOP where the child was normally resident of the death of any child in custody. Whilst it is acknowledged that such events will always be investigated by the PPO and the coroner, the CDOP where the death occurs should receive the outcomes of those investigations and conduct a comprehensive review of the case.

**7.6.5.2** Pregnant women in custody should be transferred to hospital for the delivery of their baby. If the baby delivers in the place of custody, that baby should be transferred to hospital. In both circumstances, should the baby then die in a neonatal unit, the standard child death review process should be followed.

# Appendices

## Appendix 1 – Case Examples

This section gives examples of how the child death review process might work in four scenarios.

### Case 1

A 15 month old child with complex congenital heart disease is admitted for elective cardiac surgery. The surgery is complicated by severe bleeding and low blood pressure. The child returns to the paediatric intensive care unit but dies from neurological complications several days later without recovering from anaesthesia.

#### Immediate decision making

A meeting is held with the child's cardiologist and a member of the patient safety team. The parents have raised concerns that they are not entirely clear what complications happened in the operating theatre.

The group agrees that the case meets the criteria for a referral to the coroner, and the coroner decides that a post-mortem examination should be carried out. They also decide that an NHS serious incident investigation is needed, to scrutinise events in the operating theatre. This will inform deliberations at the child death review meeting, as well as the coronial process.

#### Investigation and information gathering

The Coroner undertakes an investigation and a post mortem is carried out. The hospital patient safety team undertakes a serious incident investigation. A Reporting Form is completed by the hospital.

#### Involving and supporting the family

The family are assigned a key worker. They are informed of the planned serious incident investigation and given the details of the coroner's officer. A pre-serious incident investigation meeting with the family is arranged so that their concerns can be specifically documented. The wider child death review process is also explained.

#### The child death review meeting (hospital mortality meeting)

The post-mortem examination has been concluded and the coroner has given permission for its findings to be shared with professionals and the family. The serious incident investigation has also been concluded. The hospital mortality meeting is attended by the following professionals: patient safety team, local paediatrician, cardiac surgical team / perfusion, cardiology team, PICU team, nurses/AHPs and pathologist. Contributory factors and learning are discussed and a draft Analysis Form completed.

#### Involving and supporting the family

The family have already had two meetings organised by their key worker and attended by the patient safety team and their medical team. The results of the serious incident investigation and post-mortem examination have been fed back to them. They are



informed of the planned child death review meeting and have a few remaining questions not related to the serious incident investigation, which are discussed at the child death review meeting. At the meeting's conclusion, arrangements are made with the key worker, to offer to meet again with the parents.

### **The Child Death Overview Panel Meeting**

The CDOP was notified of the case at the time of death. The CDOP office has received the draft Analysis Form from the tertiary hospital, and the coroner's conclusion. The CDOP manager and designated doctor liaise with the cardiac network lead and agree that this child's death is best reviewed at a regional cardiac themed panel. In addition to the core CDOP membership, the following professionals attend: cardiac network lead, consultant cardiologist (different region), consultant surgeon (different region), paediatric pathologist and acute nursing representation.

### **Panel deliberations**

The panel reviews all the information provided to them and, in this case, agree with the conclusions of the child death review meeting, in relation to contributory factors and the learning arising from the case. The Panel chair writes to the Chief Executive of the hospital, seeking assurance that actions listed in the serious incident investigation have been completed. The designated doctor for child deaths writes a summary report of key issues arising from the themed meeting. Data are entered on the National Child Mortality Database once it is operational.

## **Case 2**

A three-month-old infant is put down to sleep by his mother in the middle of the day. When she checks on her child two hours later, she finds him cold and unresponsive in the cot. She calls 999. The child is rushed to the Emergency Department where sadly resuscitation is unsuccessful.

### **Immediate decision making**

The emergency department team quickly decide that the case meets the criteria for a Joint Agency Response and referral to the coroner. A quick background check reveals that the mother's other child is subject to a child protection plan. The team contacts the on-call health professional, police investigator, and duty social worker and requests they come into the hospital.

### **Investigation and information gathering**

The coroner undertakes an investigation and a post mortem is carried out. A Joint Agency Response is coordinated by the lead health professional and a Reporting Form is completed.

### **Involving and supporting the family**

The family are assigned a key worker. The child death review process is explained, the parents are informed of the planned Joint Agency Response, and given the details of the coroner's officer. They are informed of the need for further tests including a post-

mortem examination, and the rationale for a home visit is explained. The timing of this is then agreed.

### **The child death review meeting (final case discussion)**

The post-mortem examination has been concluded and the coroner has given permission for it to be shared with professionals and the family. The Joint Agency Response lead health professional organises the final case discussion, to occur at the local GP surgery. The following professionals attend: paramedics, police, social worker, GP, health visitor, pathologist, ED staff.

Contributory factors and learning are discussed and a draft Analysis Form completed.

### **Involving and supporting the family**

The family has already had several meetings with professionals and the results on the post-mortem examination has been fed back to them. At the child death review meeting's conclusion, arrangements are made to offer to meet again with the parents.

### **The Child Death Overview Panel meeting**

The CDOP was notified of the case at the time of death. The CDOP office has received the draft Analysis Form from the child death review meeting, and the coroner's verdict. A standard CDOP panel is attended by the coroner's officer and senior representatives from the health visiting team, social work and **police**.

### **Panel deliberations**

The panel reviews all the information provided to them and, in this case, take a different view from the local child death review meeting, in relation to the importance of the child's social environment. The Analysis Form is amended. Data are entered on the National Child Mortality Database once it is operational.

## **Case 3**

A baby girl is born at 24 weeks' gestation in poor condition, in a local hospital. She requires intubation and ventilation and is transferred to the tertiary Neonatal Intensive Care Unit for ongoing intensive care support. An early cranial ultrasound scan shows evidence of severe bilateral intraventricular haemorrhage with parenchymal infarction. She has severe respiratory distress syndrome and her clinical condition deteriorates after a massive pulmonary haemorrhage. After on-going discussions with her parents, a decision is made at three days of age to re-orientate care and she dies following extubation.

### **Immediate decision making**

A meeting is held with the neonatologists from both centres and the obstetrician from the local hospital. It appears that the mother presented acutely with reduced foetal movements, and was taken immediately for emergency caesarean section. There are no evident service delivery or social concerns. The case is discussed with the coroner, who feels a MCCD can be issued.

### **Investigation and information gathering**

The MBRRACE-UK lead reporter at the tertiary unit notifies the death to the MBRRACE-UK national perinatal mortality surveillance system and information about the pregnancy history and mother's care are entered in the PMRT by staff in the originating unit in preparation for the review meeting.

#### **Involving and supporting the family**

The parents are assigned a key worker from the neonatal bereavement team. They meet with the neonatologist to discuss the benefits of a post-mortem which they accept; the placenta has already been submitted for histology examination. The child death review process using the PMRT is explained to them and their perspectives of their care are sought to ensure that these are considered in the review process..

#### **The child death review meeting (hospital perinatal mortality review group meeting)**

The perinatal mortality review group meeting is arranged at the tertiary centre and is attended by the following professionals: neonatal transport team, midwifery service, NICU/obstetric team (tertiary hospital), bereavement team, neonatologist (local hospital), obstetrician (local hospital), midwifery team (local hospital), risk manager (local hospital) and pathologist. The GP is unable to attend but submits a report. The care provided to the mother during pregnancy, labour and delivery and the care provided for the baby following birth are discussed using the PMRT to support systematic discussion. Contributory factors and learning points are identified and a draft Analysis Form completed.

#### **Involving and supporting the family**

The parents have already met with their key worker and with the neonatologist where the outcome of the post-mortem and review of care is discussed. They also have a follow-up meeting with the obstetrician from the local hospital which provides them with the opportunity to ask further questions and planning for the care of a future pregnancy is also discussed.

#### **The Child Death Overview Panel meeting**

The CDOP was notified of the case at the time of death. The CDOP office has received the draft Analysis Form from the tertiary hospital. The CDOP manager and designated doctor liaise with the neonatal network lead and agree that this child's death is best reviewed at a neonatal themed panel. In addition to the core CDOP membership, the following professionals attend: neonatal network lead, obstetrician (different region), neonatologist (different region), midwife and pathologist.

#### **Panel deliberations**

The panel review all the information provided to them and agree with the conclusions of the perinatal mortality review group meeting. The panel chair writes to the hospital regarding this, and the designated doctor writes a summary report of key issues arising from the themed meeting. Data are entered on the National Child Mortality Database once it is operational.

## Case 4

A 17 year old boy with a progressive neuromuscular condition is admitted to a local hospital with respiratory failure. He has an advance care plan that stipulates that the family do not wish him to be intubated, or transferred to the regional Paediatric Intensive Care Unit. He is admitted to the adult intensive care unit where non-invasive ventilation (NIV) is commenced. After much deliberation a plan is made to transfer him to the local hospice where he is well known. There, NIV is withdrawn and he dies peacefully 36 hours later.

### Immediate decision making

The hospice doctor liaises with the boy's community paediatrician and neurologist. They agree an appropriate form of words for the MCCD.

### Involving and supporting the family

The family are assigned a key worker by the hospice. They stay for several days with their son in the hospice before he dies. The hospice helps them make arrangements for the funeral. The hospice has an open-access arrangement should the parents wish to come back and meet any of the professionals.

### Investigation and information gathering

No investigation is necessary. A Reporting Form is completed by the hospice team.

### The child death review meeting

It is agreed that the local hospice will organise the child death review meeting. This is attended by the following professionals: GP, community paediatrician, hospice team, local paediatrician, tertiary centre neurologist, palliative care team, ICU doctor. The meeting has reviewed all aspects of end of life management including the advanced care plan. Contributory factors and learning are discussed and a draft Analysis Form completed.

### Involving and supporting the family

The parents have met their key worker. The child's community paediatrician and a member of the hospice team offer to meet with the parents who, at this stage, do not feel that they want a meeting. The GP remains a point of contact should they change their minds.

### The Child Death Overview Panel Meeting

The CDOP was notified of the case at the time of death. The CDOP office has received the draft Analysis Form from the hospice. A standard CDOP panel is attended by senior representatives from the hospice / palliative care team

### Panel deliberations

The panel review all the information provided to them and, in this case, agree with the conclusions from the child death review meeting. Data are entered on the National Child Mortality Database once it is operational.

## Appendix 2 – Criteria for referral of deaths to coroner

Derived from 'Report of Death to the Coroner' form, issued with the [Chief Coroner's Guidance note 23, July 2016](#)

Reasons for referral to the coroner are as follows:

- the cause of death is unknown;
- the deceased was not seen by the certifying doctor either after death or within 14 days before death;
- the death was violent or suspicious;
- the death was unnatural;
- the death may be due to an accident (whenever it occurred);
- the death may be due to self-neglect or neglect by others;
- the death may be due to an industrial disease or related to the deceased's employment;
- the death may be due to an abortion;
- the death occurred during an operation or before recovery from the effects of an anaesthetic;
- the death may be a suicide;
- the death occurred during or shortly after detention in police or prison custody;
- the death occurred while the deceased was subject to compulsory detention under the Mental Health Act or a Deprivation of Liberty Safeguards authorisation (DoLS); or
- for any other concerning feature.

Individual coroners may have their own reporting requirements.

# Appendix 3 – Example; Immediate Decision Making proforma

<b>Child's name:</b>				
<b>Address:</b>				
<b>NHS number:</b>				
<b>Actions to be completed with 1-2 hours of death being declared</b>				
	<b>Decision?</b>	<i>Circle as appropriate</i>	<b>Action</b>	<i>Action completed?</i>
<b>1</b>	Does death meet criteria for a Joint Agency Response? (death due to external causes, or sudden with no apparent cause, or in custody, or suspicious circumstances, or stillbirth with no healthcare professional in attendance)	<b>Yes / No</b>	If Yes, contact on-call health professional, police, duty social worker and request they attend hospital	<b>Yes</b>
<b>2</b>	Can a MCCD be issued?	<b>Yes / No</b>	If No or if death meets other criteria for referral to coroner, contact the coroner's office	<b>Yes</b>
<b>3</b>	Has a potential care or service delivery issue occurred?	<b>Yes / No</b>	If Yes contact the patient safety team	<b>Yes</b>
<b>3a</b>	In relation to 3: Has a Datix form been completed?	<b>Yes / No / NA</b>		
<b>3b</b>	In relation to 3: Have obligations under the <a href="#">Duty of Candour</a> been fulfilled (family informed, offered apology, invited to submit questions)?	<b>Yes / No / NA</b>		
<b>4</b>	Are there any immediate actions necessary to ensure the health and safety of others, including family or community members, healthcare patients and staff?	<b>Yes / No / NA</b>	If Yes describe here:..... ..... ..... .....	
<b>5</b>	Describe the approach to supporting the family (key worker, end of life medical lead): ..... ..... .....			

<b>Name of person completing this form</b>	
<b>Job title</b>	
<b>Date</b>	

# Appendix 4 – Roles and responsibilities of CDOP members

## Chair

The Chair of the CDOP is responsible for ensuring that CDOP operates effectively and will:

- chair CDOP meetings effectively and ensure that all statutory requirements are met;
- with the CDOP management team and the Designated Doctor, take responsibility for co-ordinating meeting dates, panel agenda, the CDOP action plan, and the production of an annual report;
- ensure that new panel members, members invited to CDOP, and observers sign a Confidentiality Agreement;
- coordinate with a public health professional, if attending, in order to provide the CDOP with information about epidemiological and health surveillance data; and
- assist CDOP in evaluating patterns and trends in relation to child deaths and in implementing public health prevention initiatives and programmes;

## Manager or administrator

The CDOP manager or administrator should, in conjunction with the Designated Doctor and CDOP Chair:

- ensure the effective management of the notification, data collection and storage systems;
- ensure the effective running of ordinary and themed panel meetings;
- be the designated person to whom the child death notification and other data on each child death should be sent;
- allocate a unique identifier number to a deceased child following receipt of the Notification Form;
- seek to establish which agencies have been involved with the child or family either prior to or at the time of death and gain receipt of relevant information (Reporting Form);
- liaise with the Chair of the child death review meeting to receive that meeting's summary notes (draft Analysis Form); and
- record the CDOP's conclusions (final Analysis Form) and submit data to the Department of Health and Social Care and, once operational, to the National Child Mortality Database.

## Designated Doctor for Child Deaths

The designated doctor should:

- be responsible for the child death review process;

- advise on the appropriate response to a death in an adult ICU;
- advise CDOP regarding necessary experts required to inform ordinary and themed panels;
- advise CDOP in the identification of modifiable contributory factors;
- liaise, as appropriate, with regional clinical networks to ensure that themed panels are properly co-ordinated;
- assist CDOP in the development and implementation of appropriate preventative strategies to reduce the child deaths; and
- prepare an annual report with the Chair summarising the activities of CDOP.

## Nurse/Midwife

The CDOP nurse and/or midwife should:

- assist CDOP to evaluate health issues relating to the circumstances of the child's death;
- advise CDOP on nursing/midwifery practices that may have had a bearing on the child's health or well-being;
- assist CDOP in developing appropriate preventative strategies;
- liaise with other nursing and allied health professionals as appropriate;
- liaise with other midwifery and obstetric colleagues as appropriate; and
- assist CDOP in its evaluation of perinatal deaths (antenatal and perinatal care and support for the child and mother).

## Health professional (hospital/community)

The health professional shall:

- assist CDOP in interpreting medical information (including the post mortem examination findings and results of medical investigations) relating to the child's death; and
- advise CDOP on medical issues including child injuries and causes of child deaths, medical terminology, concepts and practices.

## Police

The Police representatives should:

- provide, as appropriate, CDOP with information on the status of any criminal investigation;
- provide CDOP with expertise on law enforcement practices, including investigations, interviews and evidence collection;
- assist CDOP to evaluate issues of public risk arising out of the review of individual deaths; and
- liaise with other Police departments, and the Crown Prosecution Service as necessary.



## Children's Social Care and Safeguarding

The Children's Social Care and Safeguarding representatives should:

- help CDOP to evaluate issues relating to the family and social environment and circumstances surrounding the death;
- assist CDOP in interpreting information about the social care needs of the child and family and any provision of social care services;
- identify cases that may require a further child protection investigation; and
- liaise with other local authority services.

## Education Representative:

The Education representative should:

- assist CDOP in interpreting information about the education needs and the education service provided for the deceased child and other children within the household; and
- assist CDOP in providing appropriate any strategies to prevent harm.

## Lay Representative:

The Lay representative should:

- provide additional expertise, for example, through previous professional involvement with children and families, experience of local context and services or involvement with a voluntary sector organisation; and
- be independent of statutory agencies.

# Appendix 5 – Support for the bereaved

## The key worker for bereaved families responsibilities and competencies

As set out in section [6.2.1](#) of this guidance, all bereaved families should be given a single, named point of contact, who can provide information on the child death review process, and who can signpost them to sources of support. In this guidance, this role is referred to as the “key worker”.

This role could be taken by a range of practitioners, for example a nurse or a member of a bereavement support team. The qualities and competencies of the individual are more important than their professional background.

Given shift patterns and annual leave, Trusts should ensure that the key worker is supported by a team who can step in to cover absences. Families should expect to be able to contact the key worker or a team member during normal working hours.

### Main Responsibilities

- Be a reliable and readily accessible point of contact for the family after the death;
- help co-ordinate meetings between the family and professionals as required.
- be able to provide information on the child death review process and the course of any investigations pertaining to the child, including liaising with the coroner’s officer and any police family liaison officer;
- represent the ‘voice’ of the parents at professional meetings, ensure that their questions are effectively addressed, and to provide feedback to the family afterwards; and
- signpost to expert bereavement support if required.

### Key competencies

- An empathic approach, and an ability and willingness to listen to, and be with, people in distress;
- strong communication and interpersonal skills in challenging and distressing situations;
- ability to maintain appropriate boundaries with families;
- sufficient experience and confidence to effectively represent the family at professional meetings; and
- ability to quickly develop a thorough understanding of child death review, in order to support the family through the process and answer any questions they may have.
- If the key worker is not already familiar with the child death review process, they should contact the local child death overview panel (CDOP) manager, or

local designated doctor for child death. Also see the leaflet [When a Child Dies – a Guide for Parents and Carers](#).

### **Support for the key worker**

1. *Time*. How much time will be needed for the role may vary greatly from case to case. It is important that all NHS organisations are flexible in enabling the key worker to support each individual family as required, over the weeks and months following the death of a child.
2. *Team support*. Families should expect to be able to contact the key worker or a team member during normal working hours. Given shift patterns and annual leave, Trusts should ensure that the key worker is part of a supportive team who can step in to cover absences.
3. *Individual support*. Working with bereavement can be stressful. The key worker and their line manager should agree a plan to ensure that they are appropriately supported in the role, including opportunities for debriefing and supervision.

## Appendix 6 – Suggested membership for themed panels

Themed CDOP panels should develop in line with local circumstances. The panels below are given as examples which areas may wish to consider.

<b>Neonatal panel:</b>	<b>Cardiac panel:</b>
Designated doctor	Designated doctor
CDOP manager	CDOP manager
Neonatal network lead (if neonatologist also need neonatal nurse and vice versa)	Cardiac network lead
Midwife	Cardiologist
Health visitor	Cardiac surgeon
Obstetrician	Cardiac liaison nurse
Pathologist	Pathologist
Transport team	Transport team
Lay representative	Lay representative

<b>SUDI/C panel:</b>	<b>Trauma panel:</b>
Designated doctor	Designated doctor
CDOP manager	CDOP manager
SUDI/C paediatrician	Trauma network lead
Midwife/Health visitor	Neurosurgeon/trauma surgeon
Police	Transport team
Social worker	Police
Pathologist	Social worker
Emergency Department representative	Emergency Department representative
Lay representative	Lay representative

<b>Suicide panel:</b>	<b>Learning disability panel:</b>
Designated doctor	Designated doctor
CDOP manager	CDOP manager
Lay representative	LeDeR reviewer
Child psychiatrist	Learning Disabilities Nurse
GP	Social worker/safeguarding
Social Worker	Relevant medical professional (e.g. neurologist, respiratory)
Education representative	Transitions lead
Youth justice representative	Lay representative
Police	

## Appendix 7 – Bereavement resources

### **Bereaved Parents Support Organisations Network (BPSON)**

Umbrella body for organisations supporting bereaved parents

[www.bpson.org.uk](http://www.bpson.org.uk)

[enquiries@bpson.org.uk](mailto:enquiries@bpson.org.uk)

### **Bereaved Parent Support, Care for the Family**

Peer support for bereaved parents including a telephone befriending service

[www.careforthefamily.org.uk/bps](http://www.careforthefamily.org.uk/bps)

[\*How can you help bereaved parents? BPS Handout resource\*](#)

029 2081 0800

### **Bliss**

Information and support for families of babies born premature or sick

[www.bliss.org.uk](http://www.bliss.org.uk)

0808 801 0322

[hello@bliss.org.uk](mailto:hello@bliss.org.uk)

### **Care for the Family**

Peer support for any parent whose son or daughter has died at any age, in any circumstance and at any stage in their journey of grieving.

[www.cff.org.uk/bps](http://www.cff.org.uk/bps)

029 2081 0800

[bps@cff.org.uk](mailto:bps@cff.org.uk)

### **Child Bereavement UK**

Training for professionals, support for families and a directory of local support services

[www.childbereavementuk.org](http://www.childbereavementuk.org)

0800 02 888 40

### **Child Death Helpline**

For anyone affected by the death of a child of any age from any cause.

[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

0800 282 986 or 0808 800 6019

### **The Compassionate Friends**

Peer support for bereaved parents and their families.

[www.tcf.org.uk](http://www.tcf.org.uk)

0845 123 2304

### **The Lullaby Trust**

Support for anyone affected by the sudden death of a baby or young child

[www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)

[support@lullabytrust.org.uk](mailto:support@lullabytrust.org.uk)

Bereavement support line: 0808 802 6868

## **Sands**

For anyone who has been affected by the death of a baby

<https://www.uk-sands.org/support>

Helpline: 0808 164 3332

## **Survivors of Bereavement by Suicide**

Support for people over 18 who have been bereaved by suicide.

<https://uksobs.org/>

0300 111 5065

## **TAMBA**

Support for anyone affected by the death of a multiple

[www.tamba.org.uk](http://www.tamba.org.uk)

0800 138 0509

[support-team@tamba.org.uk](mailto:support-team@tamba.org.uk)

## **Winston's Wish**

Supporting children and their families after the death of a parent or sibling.

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)

Tel: 08088 020 021

There are also a number of useful organisations who hold information about the many smaller, specialised and local organisations available for bereaved families. One may be able to find an organisation that focusses on a situation more specifically through one of these organisations:

### **The Childhood Bereavement Network**

[www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)

### **A Child of Mine**

[www.achildofmine.org.uk](http://www.achildofmine.org.uk)

### **At A Loss.org**

[www.ataloss.org](http://www.ataloss.org)

### **The Good Grief Trust**

[www.thegoodgrieftrust.org](http://www.thegoodgrieftrust.org)

*The local CDOP may also offer a bereavement advice or support service.*

