



HM Government

Child Death Review Statutory Guidance

October 2017

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Introduction

The death of a child is a devastating loss that profoundly affects bereaved parents as well as siblings, grandparents, extended family, friends and others who were involved in caring for the child. Families experiencing such a tragedy need to be met and supported with empathy and compassion. They need clear and sensitive communication. They also need to understand what happened to their child, and want to know that people will learn from what happened. The process of systematically and 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 statutory guidance applies to all organisations involved with the process of child death review, and should be complied with unless exceptional circumstances arise.

This guidance is issued under section 16Q of the Children Act 2004, as inserted by the Children and Social Work Act 2017, which states that the child death review partners for a local authority area in England must have regard to any guidance given by the Secretary of State for Health in connection with their functions under sections 16M-16P of the Act.

It builds on the high-level principles for child death review set out in Chapter 5 of *Working Together*.

Who is this guidance for?

This guidance should be read and followed by Chief Executives of clinical commissioning groups (CCGs) and local authorities, and by senior leaders within organisations who commission or provide services for children, as well as relevant regulatory bodies.

All 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, mental health, primary care and community)
- **children's social care services**
- **police**
- **coronial services**
- **education**
- **public health**

Purpose of this guidance

This guidance covers the deaths of all children, from any cause. (The charts below (figs 1&2) show the proportion of child deaths in 2016/17 by age, and 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:

- Firstly, and most importantly, to improve the experience of bereaved families, as well as professionals involved in caring for children, in the devastating and bewildering period after the death of a child.
- Secondly, to ensure that information from the child death review process is systematically captured in every case, to enable learning to prevent future deaths. To support this, NHS England is commissioning a National Child Mortality Database. In order for the Database to enable both local and national learning, and lead to changes in policy and practice, it is vital that good data is routinely captured.

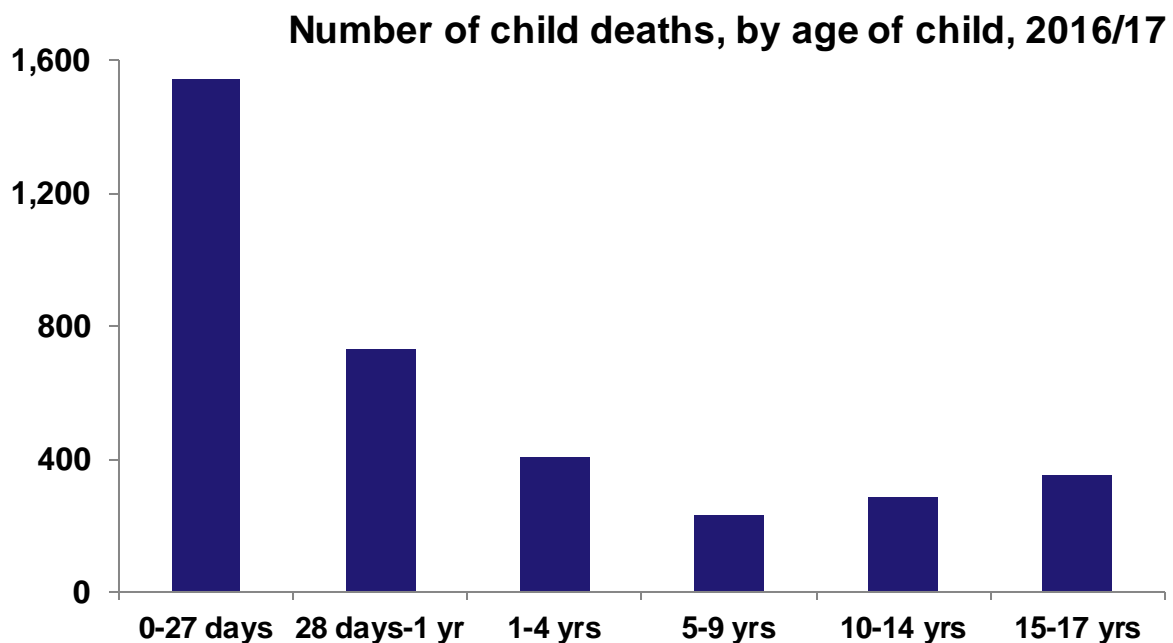


Figure 1

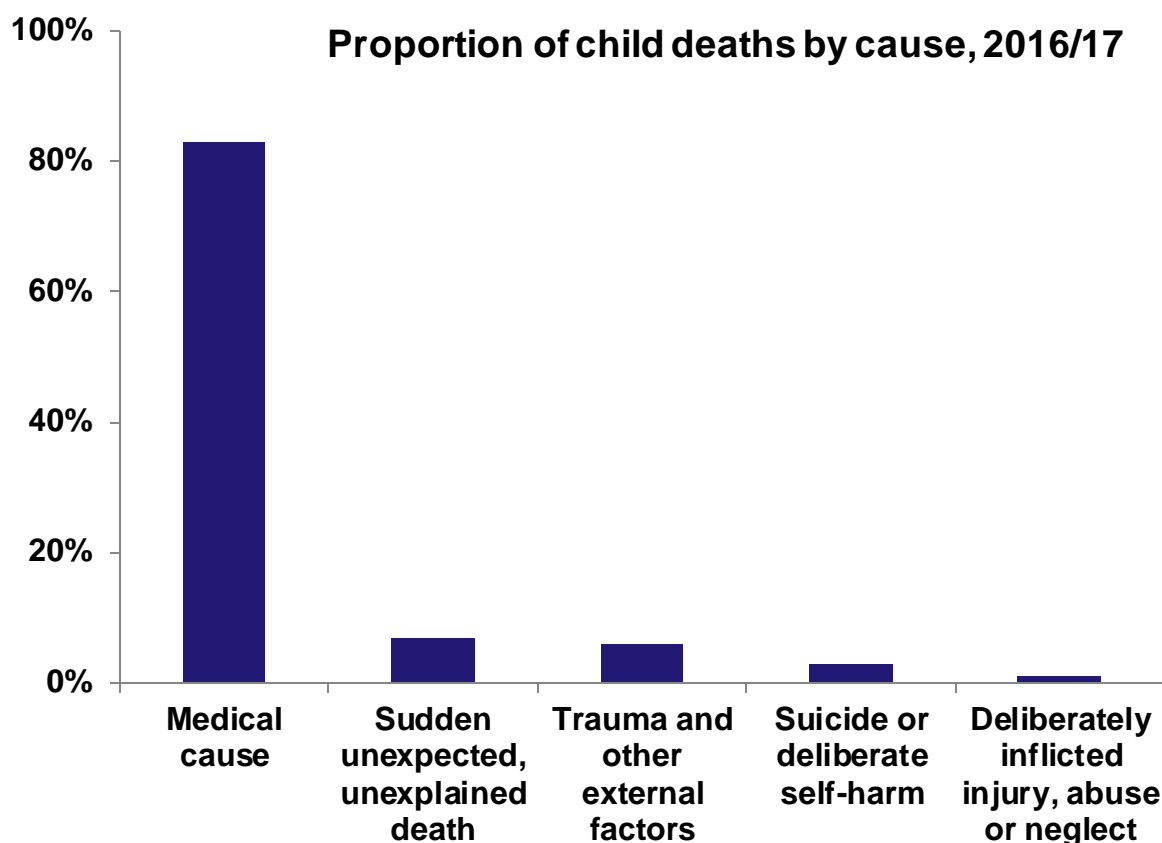


Figure 2

How does this guidance fit with other relevant guidance documents?

Working Together to Safeguard Children (Working together)¹

Working Together is statutory guidance covering the legislative requirements and expectations on individual services to safeguard and promote the welfare of children. It also covers the framework for the three local safeguarding partners (the local authority; a clinical commissioning group for an area within the local authority; and the chief officer of police for an area within the local authority area) to make arrangements to work together to identify and respond to the needs of local children. It includes a high-level chapter on the child death review process, which directs readers to this guidance. A consultation version of *Working Together 2018* can be found on the Department for Education section of gov.uk.

Sudden unexpected death in infancy and childhood: multi-agency guidelines for care and investigation (SUDI Guidelines).²

The SUDI Guidelines cover the statutory duties of professionals and agencies to investigate sudden and unexpected deaths in infancy and childhood. These deaths account for around 7% of all child deaths. This comprehensive guidance shows how the SUDI process fits into the overall process of child death review, and clarifies the circumstances in which a Joint Agency Response should be triggered.

¹ <https://www.gov.uk/government/publications/working-together-to-safeguard-children--2>

² <https://www.rcpath.org/resourceLibrary/sudden-unexpected-death-in-infancy-and-childhood-report.html>

Learning from Deaths³

This is a framework for NHS Trusts and Foundation Trusts on identifying, reporting, investigating and learning from deaths of inpatients. It requires trusts to collect and publish quarterly information on deaths in their care, reviews, investigations and resulting quality improvement. Deaths of both adults and children should be reported. However, different review processes apply for adults and children. For child death review, trusts should follow this statutory guidance.

Why is there a different approach to child death review, distinct from that for adults?

Child death review recognises the importance of learning and the needs of the family as paramount. The review of *adult* deaths focuses on identifying problems in the quality of care that was provided. Child death review includes this, but also has a wider scope, that seeks to understand why a particular child dies, of a particular cause, at a particular time. The causes of child death are complex and multifactorial, and the child death review process aims to understand these through an analysis of contributory factors across four areas: 1) factors intrinsic to the child; 2) the social environment; 3) the physical environment and 4) quality of care. Child death review also focuses on defining modifiable factors that might prevent future child deaths.

Guidance for families on child death review

Guidance specifically aimed at families, to help understand and navigate the child death review process will be developed during autumn 2017.

³ <https://www.england.nhs.uk/publication/national-guidance-on-learning-from-deaths/>

Terminology

Terminology around child death review can be confusing, and local usage varies. Throughout this document the following definitions are used.

Child

The child death review process covers infants, children and young people from birth until midnight the day before the young person's 18th birthday.

Child Death Overview Panel (CDOP)

A multi-agency panel set up by Child Death Review Partners to review the deaths of all children normally resident in that area, and also (if appropriate) the deaths in that area of non-resident children, in order to learn lessons for the prevention of future child deaths. It is attended by senior professionals across agencies *who have had no involvement in* the case under discussion. All identifying information relating to the child is redacted. CDOPs will usually operate at a sub-regional and/or regional level.

Child Death Review Meeting

The final 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. This meeting already occurs in different formats and is called a variety of names across hospital and community settings (for example: mortality and morbidity meeting, perinatal mortality meeting, local case discussion, and in the SUDI Guidelines the final case discussion).

Child Death Review Partners

Local authorities and clinical commissioning groups whose responsibilities are set out in sections 24-28 of the Children and Social Work Act 2017.

Child safeguarding practice review

A local or national review to identify any improvements that should be made by safeguarding partners or others to safeguard and promote the welfare of children, as set out in Chapter 4 of *Working Together 2018*

Designated doctor for child deaths

A senior paediatrician with responsibility for the child death review process in a specified locality or region.

Forms A, B and C

The standard forms used in the child death review process. Form A is for initial notification of death; Form Bs are for gathering information from agencies; Form C is for evaluating information and identifying lessons to be learned. All forms and templates to be used for reporting child deaths can be found here: [*placeholder for DH child death review web-page*]. These forms should continue to be used until the introduction of the National Child Death Database.

Joint Agency Response

A coordinated response involving police and health professionals, in circumstances when the death is due to external causes, is sudden and there is no immediately apparent cause (including SUDI), where the death occurs in custody or where the child was detained under the Mental Health Act or under a Deprivation of Liberty Safeguards authorisation. The framework for this Joint Agency Response is set out in the SUDI Guidelines.

Immediate decision making

The decisions that must be made by senior practitioners in the hours immediately following the death of a child.

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.

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 the designated doctor for child deaths, but more usually will be another professional, 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 disposal of the body. It provides information on the relative contributions of different diseases to mortality.

Medical Examiner

A national system of independent Medical Examiners is planned. Once introduced, the Medical Examiner will provide a system of effective medical scrutiny applicable to all deaths that do not require a coroner's post-mortem or inquest. The Medical Examiner is an independent senior doctor whose responsibility is to ensure: that the cause of death is accurately recorded on the MCCD; that timely and appropriate referral to the coroner has occurred; and that possible clinical governance concerns have been highlighted. They will have a mandated role to engage with bereaved families to understand any concerns that they may have.

National Child Mortality Database (NCMD)

The NCMD will be a repository of essential data relating to all children's deaths in England. Once operational, the NCMD will replace the current national data collection on child death reviews. It will be managed by a small team and will enable more detailed analysis and interpretation of data, to ensure that deaths are learned from, that learning is widely shared, and that actions are taken, locally and nationally, to reduce preventable child mortality.

Patient safety incident

Any unexpected or unanticipated event in healthcare that could have or did lead to harm to one or more patients.

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.

Qualified attending doctor

The doctor who attends the child at the end of his/her life.

Root Cause Analysis (RCA)

A systematic process whereby the factors that contributed to an incident are identified. As an investigation technique for patient safety incidents, it looks beyond the individuals concerned and seeks to understand the underlying causes and environmental context in which an incident happened.

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.⁴

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. The use of the term SIDS is an acknowledgement that we do not know why the child has died. 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

⁴ NHS Serious Incident Framework <https://improvement.nhs.uk/resources/serious-incident-framework/>

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.⁵

SUDI/C (sudden unexpected death in infancy/childhood)

A descriptive term used at the point of presentation for the death of an infant (up to 12 months of age) 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.⁶ During the course of an investigation into the cause of death, these deaths may be unexplained, pending further investigation. At the conclusion of an investigation, they will divide into those for which we have a clear diagnosis (explained SUDI/C) and those for which we do not have a diagnosis (SIDS). The term sudden unexpected death in childhood (SUDC) may be used for such deaths in children over the age of 12 months. Again, in such cases, it is a descriptive term rather than a diagnosis.

Unexplained deaths

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

⁵ Krous et al. 2004. Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach. *Pediatrics* 114: 234-238

⁶ Fleming, PJ et al (2000). Sudden unexpected death in Infancy. *The CESDI SUDI Studies 1993-1996*.

Chapter 1

Overview

This chapter briefly describes the whole child death review process. The flow chart below (fig. 3) 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.

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

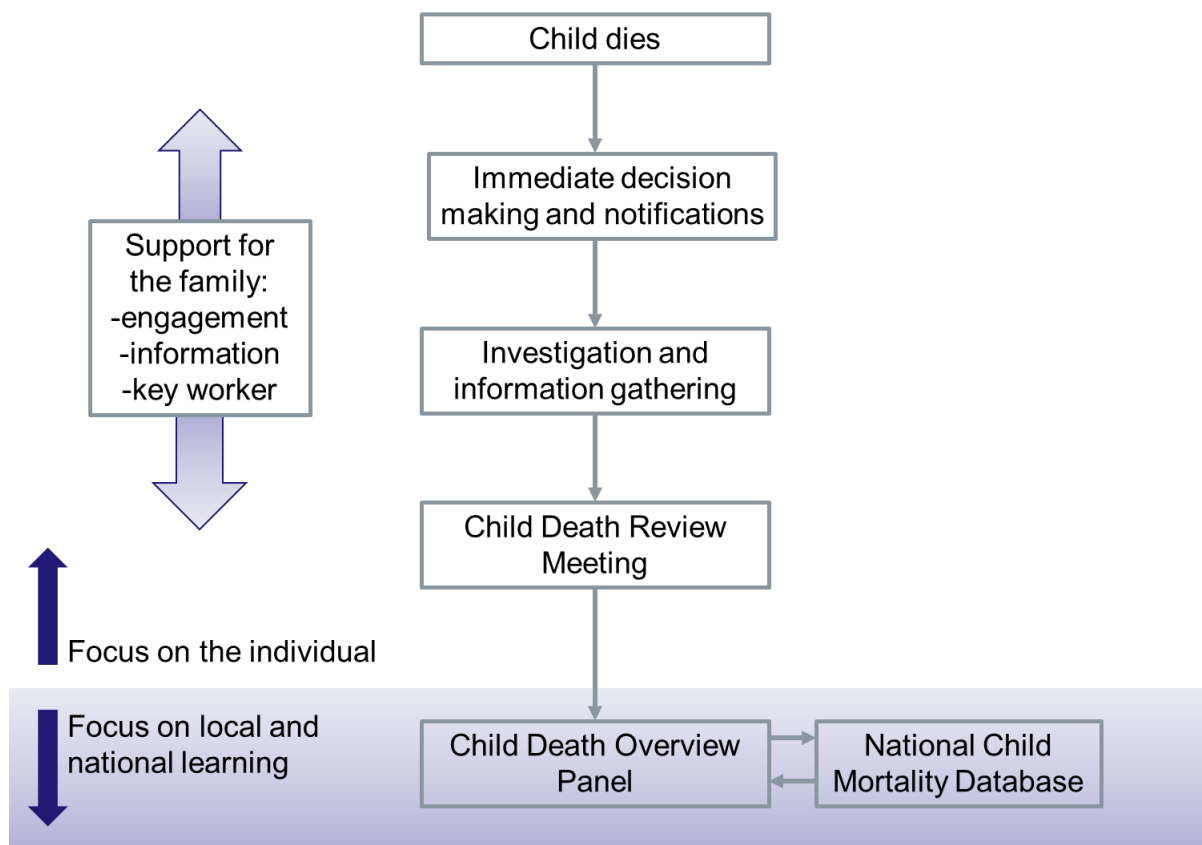


Figure 3

Immediate decision making and notifications (Chapter 2)

1.1.1 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;
- whether the death meets the criteria for a serious incident investigation.

1.1.2 A number of notifications must also be made, to the child's GP and other professionals, to the Child Health Information System, the relevant CDOP, and (once operational) the National Child Mortality Database.

Investigation and information gathering (Chapter 3)

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

- Coronial investigation
- Joint Agency Response
- Serious Incident Investigation

1.1.4 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.

Child death review meeting (Chapter 4)

1.1.5 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 final multi-professional meeting involving the individuals *who were directly involved* in the case. 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 final case discussion following a Joint Agency Response to a SUDI, or a hospital-based mortality meeting following a death on a neonatal unit. It has common aims and principles in all cases.

Child Death Overview Panel (CDOP) (Chapter 5)

1.1.6 This is a multi-agency panel for a defined area, whose role is to review the death of all children normally resident in that area, and also where appropriate the deaths of non-resident children, in order to learn lessons for the prevention of future child deaths. It provides independent scrutiny of each child's death from a multi-agency perspective. As such, it differs from the child death review meeting in two essential aspects: i) the information reviewed is made anonymous; and ii) the CDOP is made up of senior professionals *who have had no involvement* in the cases under discussion. CDOPs are required to report specified data on child death review to the Department of Health. Once operational, they will submit data directly to the National Child Mortality Database.

Support for the family (Chapter 6)

1.1.7 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 state of total shock that bereavement can bring, families should be given a single, named point of contact who they can turn to for information on the processes following their child's death, and who can signpost them to sources of support.

Specific situations (Chapter 7)

1.1.8 Chapter 7 provides guidance on expectations in a number of specific situations, including:

- Deaths of UK-resident children overseas

- Children and young people with learning disabilities
- Deaths of children and young people in adult healthcare settings such as adult intensive care units
- Suicide and self-harm
- Inpatient mental health settings
- Deaths in custody

Chapter 2

Immediate decision making and notifications

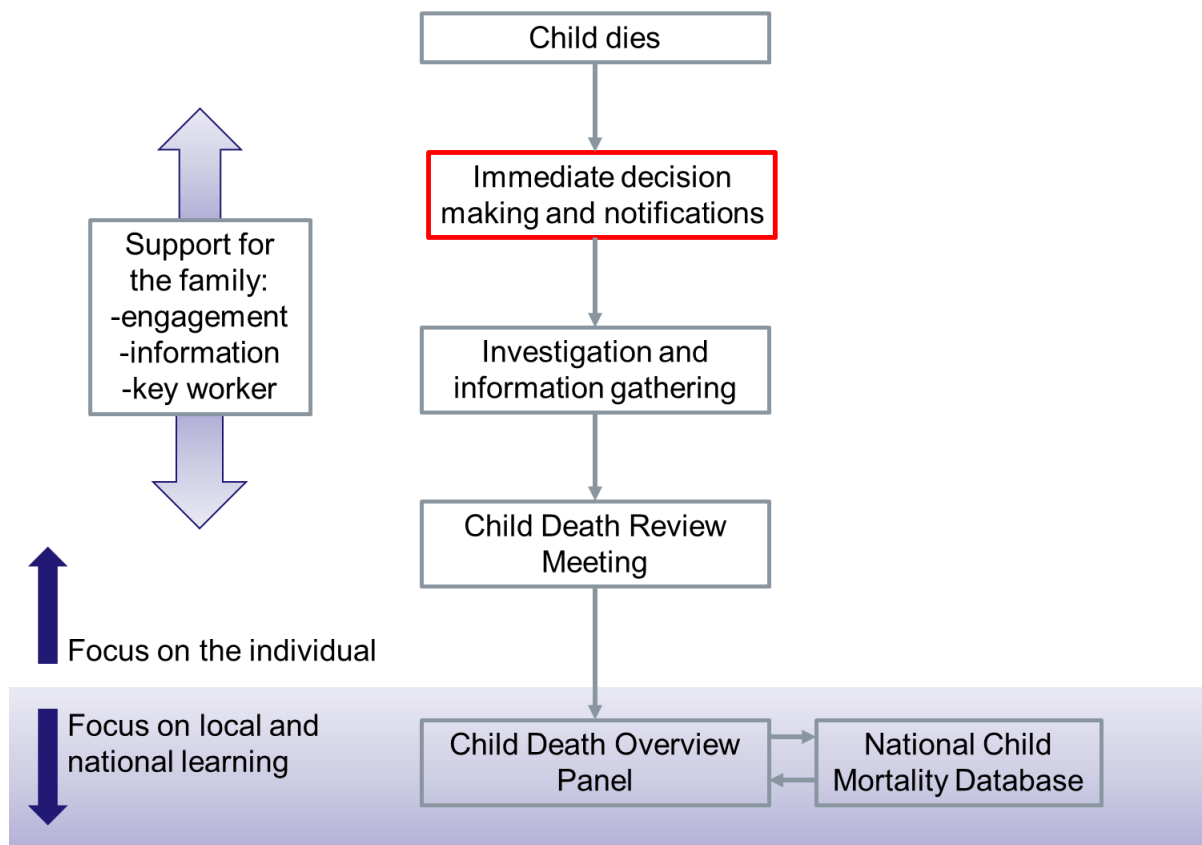


Figure 4

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 “qualified attending doctor”) will be able to issue a MCCD. Consideration should be given to how best to support the family, and to what information needs to be gathered to inform the child death review meeting.

2.1.3 However, when the circumstances of the death are unclear, or where safeguarding concerns or problems with care or service delivery are suspected, further investigations will be needed, to understand why 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 must consult with each other in order to determine the correct course of action. This is relevant to all child deaths, wherever they occur.

Who should be involved

2.1.5 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
- 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;
 - a member of the hospital patient safety team when care or service delivery issues are suspected.

2.1.6 Once the national system of independent Medical Examiners is introduced, it is expected that they will also be involved.

What immediate decisions are needed?

2.1.7 Within 1-2 hours if possible (and within 24 hours of the death being identified), 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 and ask them to attend the hospital (see [Chapter 3.3](#)).
- 3). Determine whether an MCCD can be issued; otherwise referral to the coroner is mandated (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 meets the criteria for a serious incident investigation; ensuring that, wherever possible, the views of the family and relevant staff members are taken into account.
- 5). Identify how best to support the family
- 6). Determine whether any actions are necessary to ensure the safety of other children

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

Issuing and MCCD or referral to the coroner

2.1.9 At the death of a child, the qualified attending doctor must first decide whether they are able to issue an MCCD in accordance with F66 guidance set out by the ONS and Home Office. If it is concluded that the cause of death is understood, and there are no significant concerns with the care provided to the

child who has died, an MCCD can be issued. Attention should then be given to how best to support the family and what information needs to be gathered to inform the child death review meeting. The latter may include consideration of a hospital post-mortem examination and/or other peri-mortem investigations. In the event of a post-mortem examination it is good practice for the lead health care professional to submit a summary report to the pathologist.

2.1.10 There are two versions of the MCCD relevant for child deaths: the standard version for children and a neonatal certificate for infants under the age of six weeks. The MCCD must be completed by the attending consultant or GP and be accurate, legible, and avoid abbreviations. In deaths of children with complex conditions, it is good practice to discuss the correct wording of the MCCD with the child's paediatric specialists to ensure that phraseology is accurate. The direct cause of death should be entered at 1a and diseases or conditions that directly led to the 1a entry should be entered beneath (at 1b and 1c) if applicable. Significant conditions that contributed to death but did not directly cause it should be entered in 2.⁷ In the neonatal certificate, the principles are the same, but all significant conditions are included in one section.

2.1.11 If the qualified attending doctor is unable to sign the MCCD, then they must refer the matter to the coroner. The Chief Coroner has issued guidance on which deaths should be reported to the coroner (see [Appendix 2](#)). The qualified attending doctor should notify a death to the coroner without delay. In most cases this can wait until the next working day, but any case where there is a potential forensic interest must be notified immediately. If there is any uncertainty over whether a referral is necessary, the qualified attending doctor should contact the coroner's office to discuss.

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

- That there is no need for further investigation and the qualified attending practitioner can issue the MCCD without any coronial action;
- That the MCCD is agreed and a coronial Form 100A is provided to the local registrar to support the cause of death;

2.1.13 The case for investigation is accepted, in which case no MCCD is required.

Other NHS notifications

2.1.14 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 (screening, immunisation, and other health improvement interventions) and their community based healthcare. When a child dies, health care providers should notify their local CHIS to ensure that further clinic appointments are not arranged.

⁷Guidance for doctors completing Medical Certificates of Cause of Death in England and Wales; ONS; 2010; https://www.gro.gov.uk/Images/medcert_July_2010.pdf

- **General Practitioner** When a child dies, 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. This is also an opportunity to inform the GP of the child death review process and request their support for the child death review meeting.
- **Other professionals as appropriate** Health visitor, school nurse, hospital/community medical team
- **The local CDOP administrator** through completion of a Form A. (The local CDOP will coordinate with other CDOPs as required – see [Chapter 5.5](#) on reviewing deaths of non-resident children for more information)
- **National Child Mortality Database**, once this is operational.

Chapter 3

Investigating and information gathering

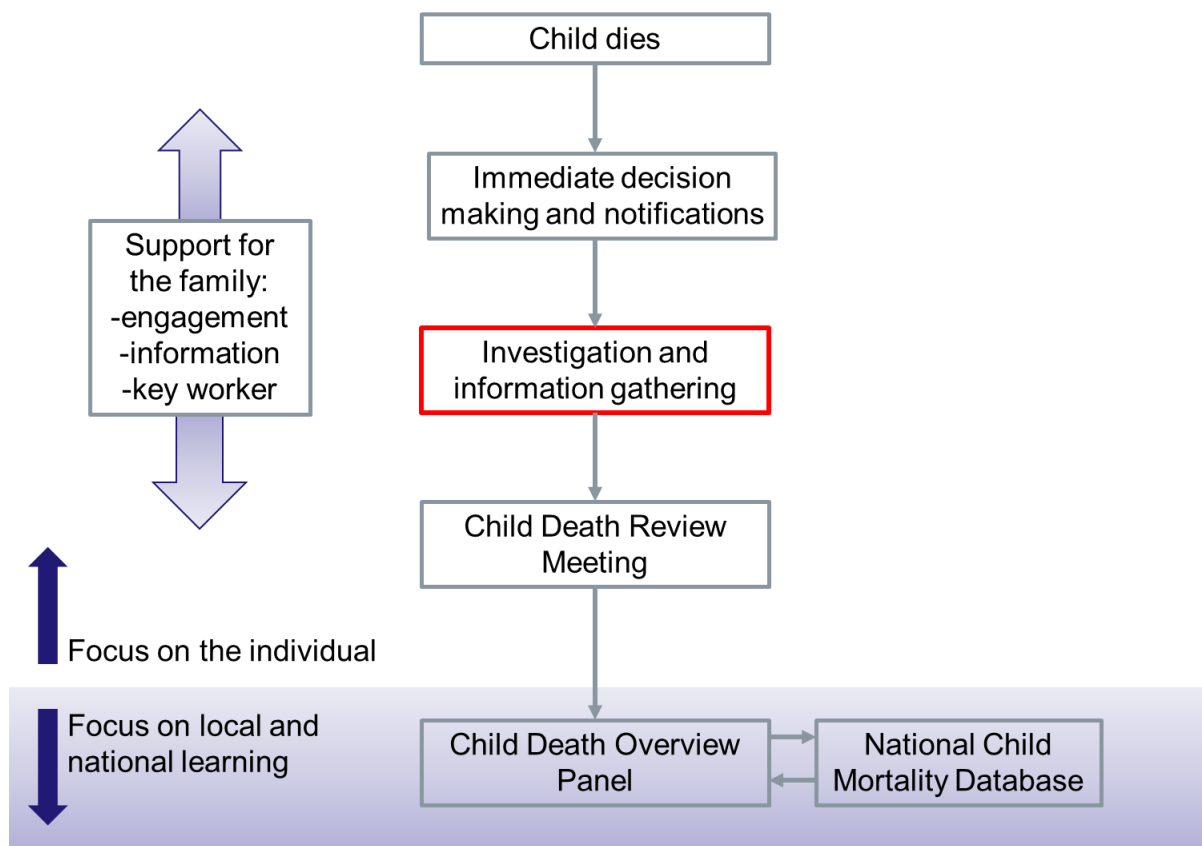


Figure 5

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. The timescales of investigations will vary greatly from case to case. The learning arising from investigations will inform the child death review meeting. This chapter describes the main investigations that may take place.

Coronial Investigation

3.1.2 Anyone can refer a death to the coroner for investigation. Most deaths are referred by doctors or police, but some are referred by registrars of births, deaths and marriages or family members. See [Appendix 2](#) for a list of referral criteria.

3.1.3 Once referred, 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. In suspicious deaths this will be in conjunction with the police. Following this examination the body of the child is usually promptly released back to their family for funeral arrangements to be made. Coroners will always try to release the body back to the family as quickly as possible. Release may however be delayed if organs have been

taken and the family wish for return of the organs before release, or if a second independent post-mortem examination is required.

3.1.4 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.⁸

3.1.5 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, the medical cause of death, and certain personal particulars that are required for registering the 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 circumstances in which the death occurred. The coroner will examine the evidence and, commonly without a jury (except where there are "right to life" issues), 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.

3.1.6 All agencies that have pertinent information (such as records of any internal or joint agency investigation and/or notes from the child death review meeting) 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 in the case.

3.1.7 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 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.

Joint Agency Response

3.1.8 When the death is due to external causes, is sudden and there is no immediately apparent cause (including SUDI), where the death occurs in custody, or where the child was detained under the Mental Health Act or while deprived of their liberty by the state, the attending doctor should ensure that the coroner and police are notified and there should be a Joint Agency Response to the death (as outlined in the SUDI Guidelines). If a Joint Agency Response is indicated, the on-call health professional, police investigator, and duty social worker should be contacted immediately and asked to attend the hospital.

3.1.9 A Joint Agency Response should also be triggered if such children are brought to hospital in a moribund state, are successfully resuscitated, but are expected to die in the following days. In such circumstances the Joint Agency

⁸ The coroner will use coronial Form 100 A (without a PM examination) or Form 100 B (with a PM examination)

Response should be initiated 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.

3.1.10 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.

3.1.11 A lead health professional should be assigned. This person may be the designated doctor for child deaths but more usually will be another professional (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 Joint Agency Response exists in a locality, the role of lead health professional should be taken by the senior attending paediatrician.

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

3.1.13 The flow chart below (fig. 6) sets out the sequence of events that should unfold in a Joint Agency Response.

3.1.14 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 (See [Appendix 4](#)).

3.1.15 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. 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. Once the results of the post-mortem examination 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 final child death review meeting.

3.1.16 In circumstances where a child has died, *and* abuse or neglect is a suspected factor in that death, *and* there is cause for concern as to the way in which agencies have worked together to safeguard the child, professionals at the initial sharing and planning meeting should determine if the case meets criteria for consideration of a child safeguarding practice review.

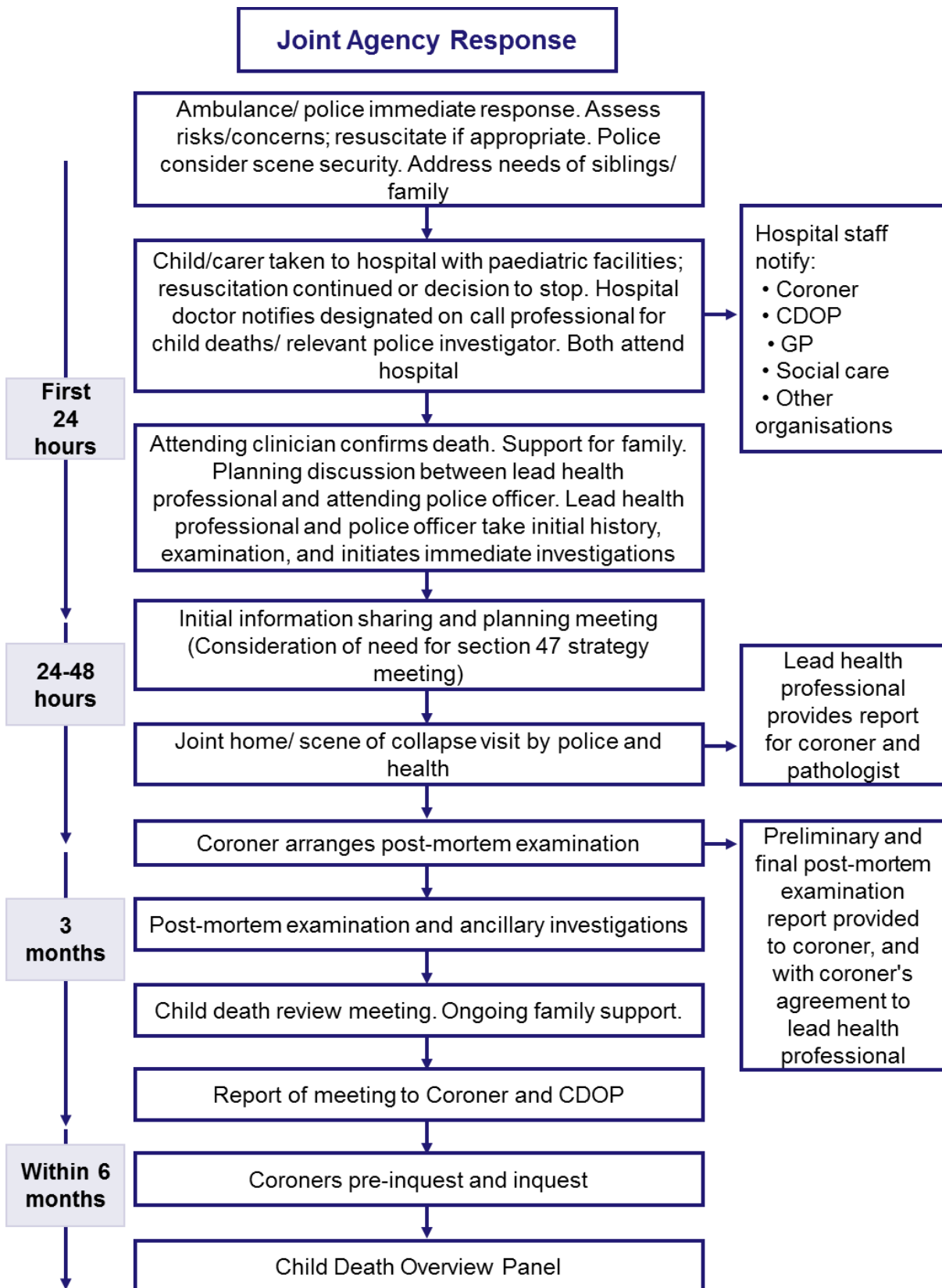


Figure 6

Serious incident investigation

3.1.17 Serious incident investigations are not designed to investigate the cause of death, but they inform the child death review process through providing a detailed analysis of patient safety incidents that may have contributed to the

death. 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 by the Healthcare Safety Investigation Branch) might help clarify understanding of the event and support subsequent improvements in safety. 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 some time 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 7.

3.1.18 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.

3.1.19 NHS trusts use the Serious Incident Framework⁹ 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).

3.1.20 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.

3.1.21 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.

⁹ NHS Serious Incident Framework <https://improvement.nhs.uk/resources/serious-incident-framework/>

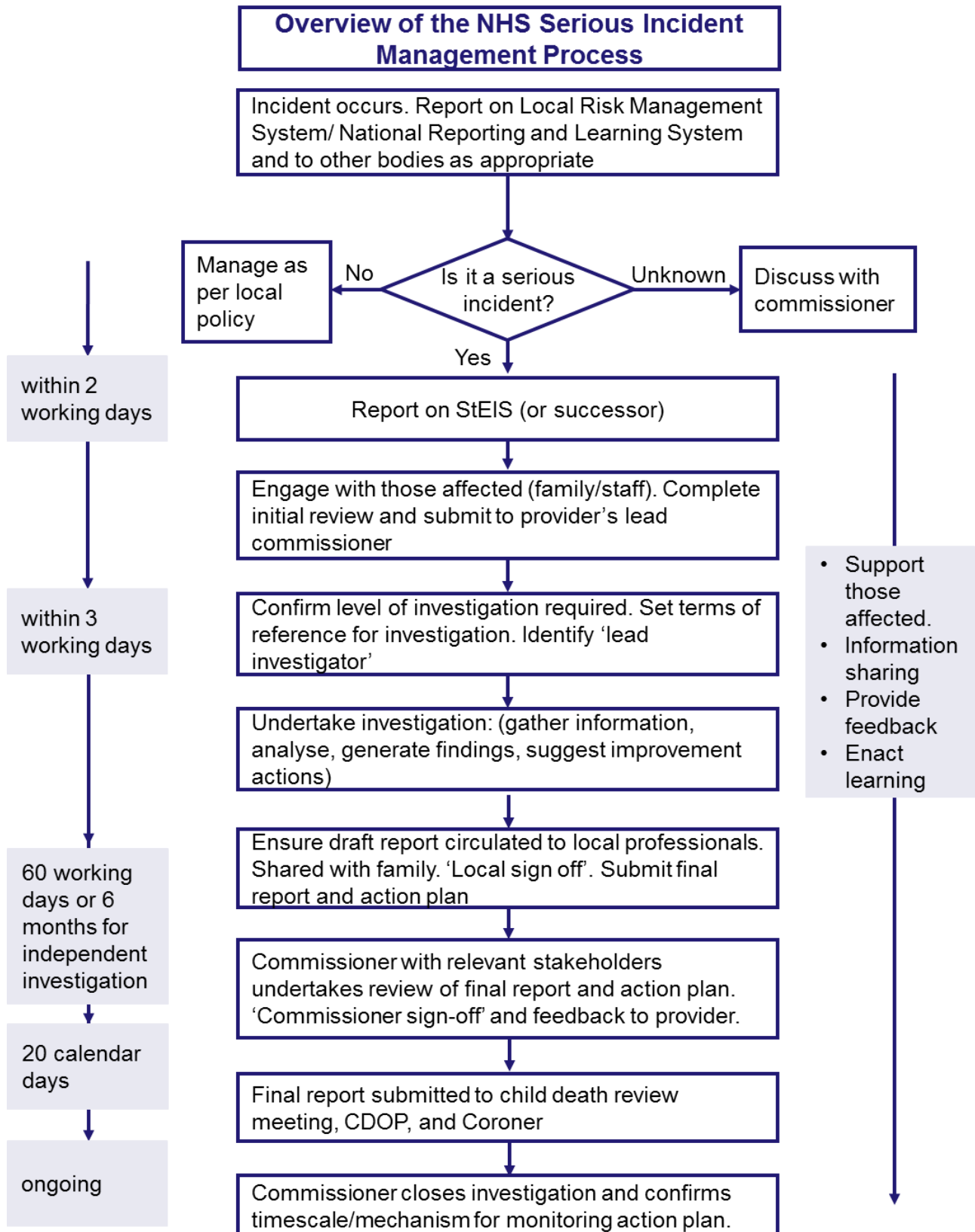


Figure 7

3.1.22 Different organisations (e.g. police facilities, tier 4 mental health facilities) will have specific processes for investigation that should be followed and the involvement of multiple agencies may impact on timescales for serious incident investigations. 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.

Co-ordination across investigations

3.1.23 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 a complaint about their child’s care through NHS Trust complaint policies and cases may subsequently be referred to the Parliamentary and Health Service Ombudsman. Effective co-ordination and good communication are vital to avoid additional distress to bereaved parents.

3.1.24 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).

3.1.25 In deaths where there are 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.

3.1.26 If a serious incident investigation runs alongside the child death review process, the case manager might be a member of the patient safety team providing an administrative function, tracking progress and monitoring deadlines, to ensure professionals provide information in line with commitments made to the family and organisational deadlines. If a complaint runs alongside the child death review process, the case manager might be an experienced general manager. If a complaint *and* a serious incident run alongside the child death review process, the case manager might still be an experienced general manager who should support the patient safety team in the serious incident investigation whilst also leading on the complaint response. In all situations, the case manager should work alongside the key worker who remains the main point of contact with the family. In complicated cases, an executive lead should be identified who should be kept apprised of issues arising and progress of different investigatory processes.

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

Chapter 4

The child death review meeting

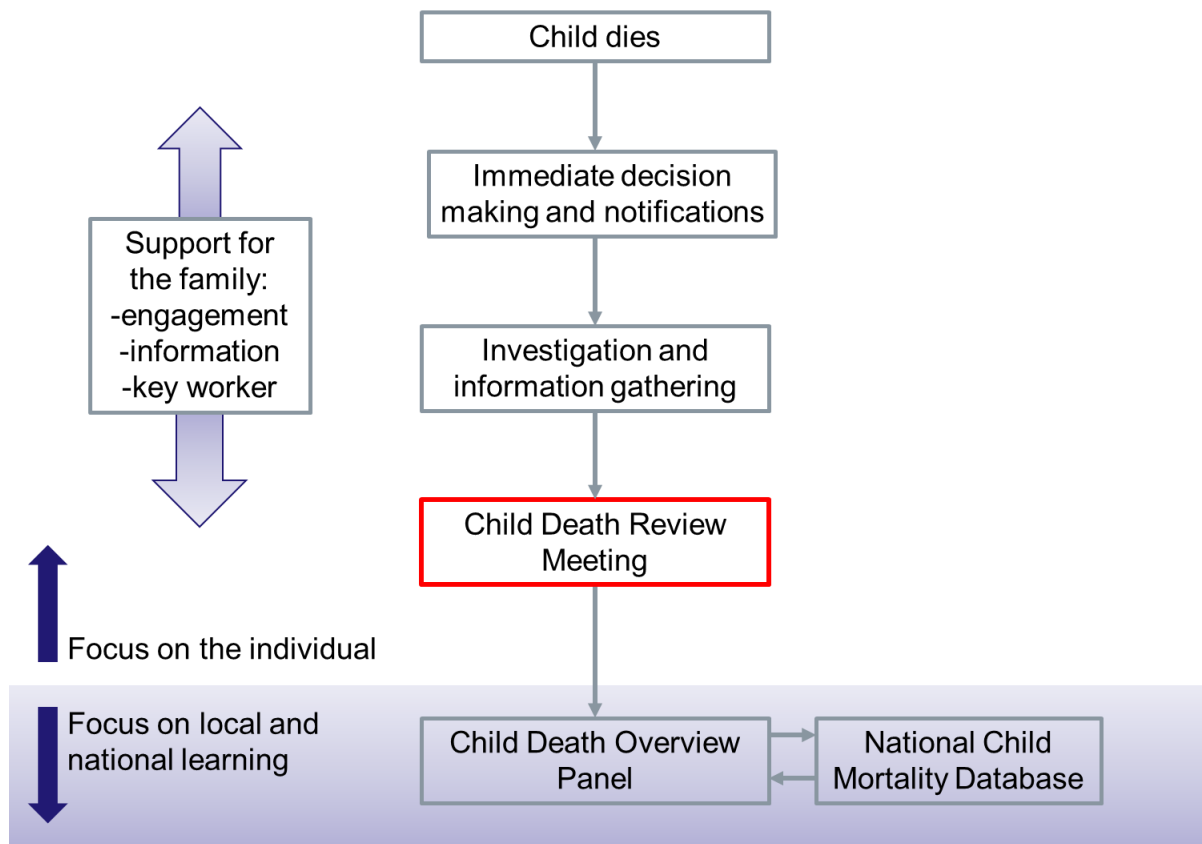


Figure 8

Introduction and principles

4.1.1 The child death review meeting is the final 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. This meeting already occurs in different formats and is called a variety of names across hospital and community settings (for example: mortality and morbidity meeting, perinatal mortality meeting, local case discussion, and in the SUDI Guidelines the final case discussion). In different settings the meeting might discuss one child or several children. The outcome of the child death review meeting (draft Form C) should be forwarded to the relevant CDOP.

Aims of the child death review meeting

4.1.2 In all cases, the aims of the child death review meeting are:

- To review the background history, all aspects of treatment, and the findings of investigations, to determine, as far as is possible, the likely cause of death;
- To ascertain, in a standardised fashion, contributory factors across domains specific to the child, the social and physical environment, and service delivery;
- To identify, in a standardised fashion, modifiable factors in any domain which may have contributed to the death of the child;

- To clearly describe any learning arising from the case and, where appropriate, to identify effective actions that may help prevent future child deaths and ensure such actions inform the governance processes of relevant organisations;
- To review the support provided to the family and the care needs relating to the safety and wellbeing of surviving or future children;
- To ensure that the family are informed of the outcomes of any investigation into their child's death and learning from the review meeting;
- To ensure that CDOP and, where appropriate, the coroner are informed of the outcomes of any investigation into the child's death and outcome of the review meeting (using Form C, see [Appendix 5](#));
- To ensure that relevant data are entered into the National Child Mortality Database, once it is operational;
- To review the support provided to staff working with the child and family.

Who should attend the child death review meeting?

4.1.3 It is the responsibility of the organisation where the child's death is declared to arrange the child death review meeting. Where a child has died at home, a Joint Agency Response would normally occur, and the lead health professional would be responsible for arranging this meeting.

4.1.4 Each child's death requires unique consideration and should engage professionals across the pathway of care. This approach utilises and strengthens networks across primary, secondary, and tertiary healthcare, statutory agencies, and the voluntary and private sector.

4.1.5 It is therefore recommended that, where practically possible, organisations discuss children's deaths at an individualised meeting, and that matters of morbidity¹⁰ are considered apart. 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).

4.1.6 The following professionals should be invited:

- 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
- Other professional peers from relevant hospital departments and community services to ensure objective review of treatment decisions
- 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 a Joint Agency Response has taken place

¹⁰ Morbidity in this context means poor outcomes related to disease and/or healthcare that do not result in death but still require scrutiny.

- Social worker, if there has been social work involvement
- Ambulance and fire services, if they have been involved
- Primary care representatives: GP, midwife or health visitor
- School nurse, or head teacher, for a school-aged child, if appropriate
- Voluntary or third sector organisations e.g. Barnardos, Teenage Cancer Trust, the Rainbow Trust, if appropriate

4.1.7 While videoconference and teleconference calls enable such an approach, certain professionals (such as the emergency services and representatives from primary care) may not be able to attend. If so, those professional groups should be asked to submit a report to the meeting (Form Bs could be used for this purpose).

Who should chair the meeting?

4.1.8 Where a Joint Agency Response has occurred, the meeting should be chaired by the lead health professional.

4.1.9 Where a Joint Agency Response has not occurred, the child death review meeting should be chaired by a nominated lead professional for the child death review process within the organisation where death was declared. This person should have designated time assigned for this within their job plan.

4.1.10 If the nominated lead also had overall clinical responsibility for the child, the role of chair should be deferred 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 family and health care team in the organisation where death was declared. The designated doctor for child deaths might advise in such circumstances.

Where should the child death review meeting be held?

4.1.11 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.

4.1.12 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). This can lead to silo thinking and creates confusion for the family.

When should the meeting occur?

4.1.13 Child death review meetings 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 preliminary investigations (Joint Agency Response, serious incident investigation, post-mortem examination) have been concluded, and reports from key agencies unable to attend the meeting have been received (via Form Bs). The relevant CDOP office could facilitate such co-ordination.

4.1.14 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. The child death review meeting should occur before the coroner's inquest, child safeguarding practice review and the CDOP review.

4.1.15 The child death review meeting can proceed in the context of a criminal investigation (e.g. non-accidental head injury), but not if that investigation is directed at professionals involved in the care of the child, when prior group discussion might prejudice testimony in court.

What should be discussed?

4.1.16 There should be a review of all matters relating to the death of the child.

4.1.17 When a Joint Agency Response has occurred, the lead health professional should present their report to the meeting. If a serious incident investigation has occurred, a member of the team who conducted the investigation should report its findings. A standardised agenda might read:

- Case presentation
- Findings from the post-mortem examination (or from the Joint Agency Response or serious incident investigation)
- Questions raised by the family
- Issues reflecting discussion
- Lessons learnt and agreed actions
- Conclusions regarding contributory and modifiable factors
- Family follow up
- Staff support

4.1.18 Notes of the meeting should be taken, that should inform the report to the CDOP (via Form C, see [Appendix 5](#)), the coroner and Child Safeguarding Practice Review Panel, if applicable. This is essential to inform their deliberation of the case. Actions reflecting learning should be written in SMART language and inform the governance programme of the relevant organisations. Once operational, data from the child death review meeting should also be entered directly into the National Child Mortality Database.

Family engagement in the child death review meeting

4.1.19 The child death review meeting 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.

4.1.20 It is expected that major problems related to service delivery will have been addressed prior to the meeting through discussions with the relevant medical or nursing staff, the joint agency team where involved, or through any serious incident investigation and/or complaints process. The child death review meeting provides an opportunity for outstanding issues to be discussed and for the team to gain assurance that the wider organisation has followed expected processes in regards to family engagement. Any discussions relating to family questions should be documented in the notes of the meeting.

4.1.21 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. In a coroner's investigation, such liaison should take place in conjunction with the coroner's office, bearing in mind that the final 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

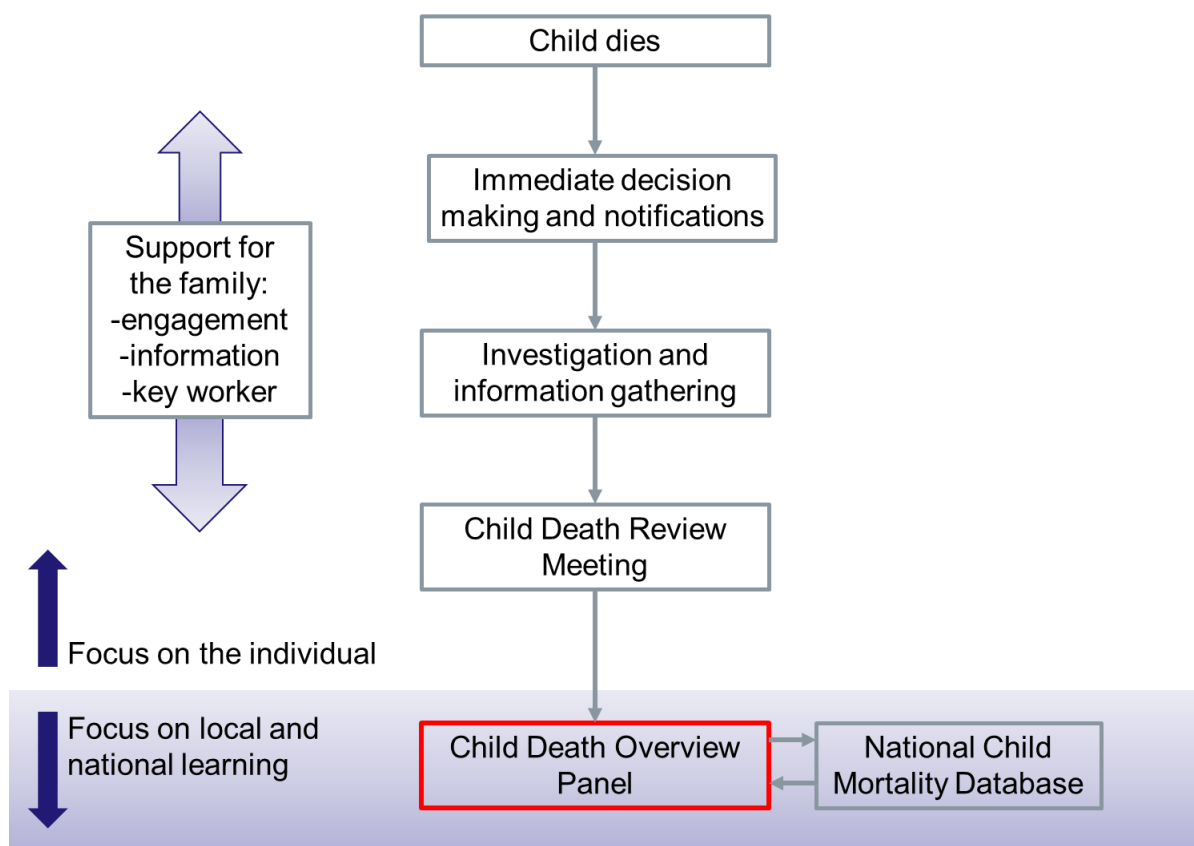


Figure 9

Introduction and principles

5.1.1 The Children and Social Work Act (2017) and *Working Together* set out expectations for Child Death Review Partners (Local Authorities and Clinical Commissioning Groups) to make arrangements for the review by a Child Death Overview Panel (CDOP) of 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.

5.1.2 This review includes the death of any newborn baby of any gestation who shows signs of life following birth, or where the birth was unattended; but does not include those (of any gestation) who are stillborn where there was medical attendance, or planned terminations of pregnancy carried out within the law.

5.1.3 CDR partner footprints should be locally defined, based on patient flows across existing networks of NHS care. CDR partner arrangements should typically cover a child population such that they review 80-120 child deaths each year.

5.1.4 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 the output (draft Form C, see [Appendix 5](#)) from the child death review meeting

5.1.5 As opposed to the child death review meeting, which is attended by those professionals (and their peers) who have looked after the child, the CDOP is attended by senior representatives across agencies who have had *no involvement* in individual cases being reviewed.

Panel responsibilities

5.1.6 The functions of CDOP include:

- to collect and collate information on each child death, seeking relevant information from professionals and, where appropriate, family members;
- to analyse the information obtained, including the report from the child death review meeting, 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 the Child Death Review Partners and other 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 identifies that a child was 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, for the purposes of improving death registration;
- to provide specified data to the Department of Health and then, once established, to the National Child Mortality Database;
- to produce an annual report for Child Death Review 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;
- 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.

Panel Membership

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

- Public health (often as Chair)
- Designated doctor for child deaths (*and a hospital clinician if the Designated Doctor is a community doctor or vice versa*)
- Health (Community/hospital)

- Social services
- Police
- Safeguarding (designated doctor or nurse)
- Primary care (GP or health visitor)
- Nursing and/or Midwifery
- CDOP (manager)
- Lay public /parent representation
- Additional professionals to be considered: coroner's officer, education, housing, council services, health and wellbeing board, ambulance services, hospice.

5.1.8 The CDOP should be chaired by someone independent of the key service providers in the area. In addition to this core membership relevant experts from health and other agencies should be co-opted as necessary to inform discussions. Panel members should be familiar with their responsibilities and ensure that they read all relevant material in advance of panel meetings ([Appendix 6](#)). Conflicts of interest should be established at the outset of each meeting and panel members should not lead discussions in cases where they have been directly involved in the care of the child.

5.1.9 Quoracy should demand attendance by lead professionals from health and the local authority. In "medical" themed panels (e.g. cardiac) the attendance of police and social care might not be necessary (see 5.7 below 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.

CDOP administration

5.1.10 The CDOP manager will work closely with the Chair of the panel and the Designated Doctor for Children's 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. A copy of the draft Form C report should be sought from the child death review meeting and be included with other documentation compiled for the CDOP meeting. A CDOP may request any professional or organisation to provide relevant information to enable or assist the purpose of reviewing each child's death. Professionals and organisations must comply with such requests. CDOPs should aim to review all children's deaths within six weeks of receiving the report from the child death review meeting 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 5.7 below for more information on themed panels).

Reviewing deaths of non-resident children

5.1.11 Legislation allows for CDR partners to review the deaths of non-resident children within the CDR partners' area of responsibility. A pragmatic approach

should be taken to such deaths, entailing discussion between the CDOP team in the area where the child is resident and that team in the area where the child died. The primary responsibility for panel discussion should lie with the CDOP where the child has died. However, consideration should also be given to where the most learning can take place.

5.1.12 For example: a child from area X drowns on holiday in area Y, and dies in a tertiary PICU in area Z. While three CDOPs could be involved, the opportunities for learning would most likely be in Area Y, where the incident occurred, rather than the areas where the child was resident, or where they died. In such situations, it is important to avoid serial discussions about the same child at separate CDOPs. The use of conference call and videoconference 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.

Themed panels

5.1.13 Some child deaths may be best reviewed at a themed meeting. A themed meeting is one where a single or neighbouring CDOPs co-operate 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 allow easier identification of themes when the number of deaths from a particular cause is small. Examples of themed panels might be neonatal at a local level; and cardiac, cancer, SUDI/C, suicide, and trauma at a regional level. The frequency of such panel meetings would be dictated by the number of deaths in each category and an anticipated ability for an expert panel to review up to 12 deaths at a half-day session. 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.

Involvement of parents and family

5.1.14 Parents should be informed by their key worker that the CDOP meeting 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 information relating to an individual child and treating professionals is made anonymous. It should also be explained to parents that because of the anonymous nature of the meeting, it will not be possible to give them feedback afterwards.

5.1.15 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.

5.1.16 CDOPs should assure themselves with each case 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. Lastly an annual CDOP

report should be written in plain English and placed in the public domain, summarising: the key learning arising from the child death review process, reports from themed panels, and actions that have been taken to prevent child deaths as a result of this learning.

National reporting

5.1.17 CDOPs should record the outcome of their discussions on a final Form C, and submit this to the Department of Health. This will be replaced by direct input to the National Child Mortality Database once it is operational.

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

Chapter 6

Family engagement and bereavement support

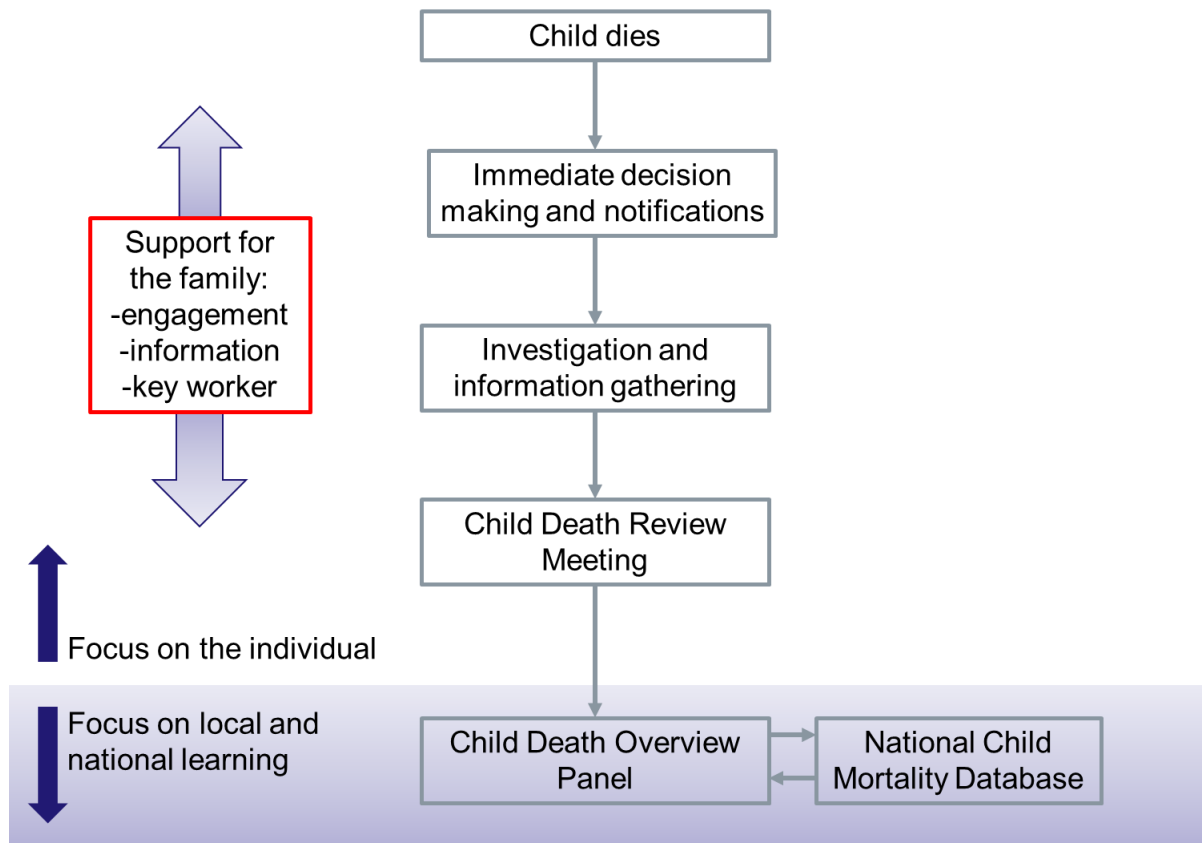


Figure 10

Introduction and principles

6.1.1 Every family has the right to have their child's death sensitively reviewed in order, where possible, to identify the cause of death and to learn lessons 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 should be informed about the review process, and given the opportunity to contribute to investigations and meetings, and be informed of their outcomes. Each family's needs are unique and much inherently good practice cannot be prescribed: namely effective communication, sensitivity, empathy, and compassion.

6.1.2 This chapter describes a core offer that should be provided to all families after the death of their child.

The team around the family

All staff have a duty to support bereaved parents after their child's death and to show kindness and compassion. When medical error has occurred, healthcare professionals have a duty to apologise, to explain what has happened, and to identify what lessons may be learnt to reduce the likelihood of the same thing happening again.

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

6.1.1 A 'key worker'

6.1.1.1 The processes that follow the death of a child are complex, in particular when multiple investigations are required (see [Chapter 3.5](#) on co-ordination across investigations). Recognising this, all bereaved families should be given a single, named point of contact, who they can turn to for information on the child death review process, and who can signpost them to sources of support.

6.1.1.2 Identifying a professional to act as the key worker is the responsibility of the organisation where the child was certified dead. The role could be taken by any of a range of professionals. For example, in 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. In many other situations (e.g. trauma, sepsis) the child and family will not have been known to any health care professionals before the child's admission to hospital, and a key worker might instead be a member of the bereavement support team.

6.1.1.3 Regardless of professional background this person should be able to perform the following roles:

- 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
- Represent the 'voice' of the parents at professional meetings, ensure that their questions are effectively addressed, and to provide feedback to the family afterwards
- Signpost to expert bereavement support if required.

6.1.2 A 'medical lead'

6.1.2.1 An appropriate consultant 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
- Clinical expertise (via other professionals if necessary) to be able to i) answer questions relating to the medical 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 child death review meeting

6.1.3 Other professionals

6.1.3.1 If there is a coronial investigation, the **coroner's officer** supports the parents and acts as a point of contact for the family in relation to all elements of the coronial process.

6.1.3.2 In criminal investigations, a **police family liaison officer** supports the parents and provides a point of contact for the family in relation to the police investigation.

6.1.3.3 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.

6.1.3.4 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.

What should bereaved families expect when their child has died?

6.1.3 It should be remembered that bereaved parents will 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. It is therefore helpful to provide easily-accessible written guidance (leaflet or web based) that explains the child death review process. If the family needs language or communication support, a translation service should be sought.

6.1.4 When their child dies, bereaved parents should:

- Have the opportunity to spend time with the child's body in a quiet and private environment
- 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 if it remains at the hospital or hospice
- Be given information on the 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
- Be able to access expert bereavement support if required (see below)

Planning prior to death with life-limiting conditions

6.1.5 Children with life-limiting conditions (e.g. cancer, complex neurological or genetic 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 management¹¹
- Core care pathway for children with life-limiting and life-threatening conditions¹²
- Perinatal pathway for babies with palliative care needs¹³

When a child dies in the emergency department

6.1.6 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 Guidelines.

When a child dies and an investigation is instigated

6.1.7 On occasion, concerns about service delivery may be raised (by practitioners or the family) and the organisation will initiate a serious incident investigation. Parents and family members should be respected as equal partners in any 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.

¹¹ National Institute for Clinical and Health Excellence, 2016 <https://www.nice.org.uk/guidance/ng61>

¹² Together for Short Lives, 2013

http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL_A_Core_Care_Pathway_ONLINE_.pdf

¹³ Together for Short Lives, 2017

http://www.togetherforshortlives.org.uk/professionals/resources/11598_perinatal_pathway_for_babies_with_palliative_care_needs

6.1.8 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).

Bereavement support and counselling

6.1.9 The death of a child is devastating to parents and wider families. Grief takes many forms and parents, siblings, grandparents and wider families can have a range of emotional, physical, cognitive and behavioural reactions.

6.1.10 The death of a child can overwhelm parents and families’ usual coping strategies and their social networks:

- the pain of grief and the intensity of feelings it brings can lead to parents feeling as if they are going mad, or that their feelings are wrong.
- families often report that their colleagues, friends, family and neighbours behave awkwardly around them, or express unhelpful views. This can include being expected to ‘get over it’, encouraging them to have another child, or to be grateful for their living children. Comments which are intended to be comforting but are experienced as unhelpful or insensitive can leave parents feeling even more isolated.
- different people express their grief in different ways¹⁴, and if families don’t expect this it can lead to misunderstandings or conflict.

6.1.11 Grief does not follow a specific pattern or timeframe. Families may have particularly intense reactions at times such as the birthday of the child who died, the anniversary of the death, Christmas and other religious or cultural times associated with family. Intense emotions may also arise at key moments during the investigation into the child’s death.

6.1.12 The child’s death often brings secondary losses to the family, such as changed relationships with each other. If the child had been ill for some time, the loss of the involvement of professionals who had been caring for them and their family can also be a significant change for families. Some families also experience financial hardship as allowances are withdrawn or reduced.

Support for parents and families

The Guide to Commissioning Bereavement Services in England sets out a 3-component model of support for people experiencing bereavement. Much of this support is provided by the voluntary sector. In the specific context of parents bereaved of a child, this would include:

6.1.4 Component 1: For all families

- A supportive response from their usual networks and from the professionals involved with them around their child’s death and afterwards
- Accessible and accurate information (online, paper and verbal) on

¹⁴ M Stroebe & H Schut; The dual process model of coming with bereavement: rationale and description; *Death Studies*; 1999; 23(3)

- the nature of grief following a child's death, (including issues such as explaining the death to siblings, going back to work, dealing with difficult dates)
- local and national support organisations

6.1.5 Component 2: For some families (those seeking support or at risk of developing complex needs)

- Assessment to establish appropriate level of support
- One-to-one, family and group opportunities for support, which might be from:
 - 2.1 Social support: self-help groups, faith groups, peer support, befriending and community groups
 - 2.2 Trained bereavement support workers

6.1.6 Component 3: Specialist interventions for a minority of families (those with complex needs or prolonged/complicated grief)

- Assessment to establish appropriate level of support
- One-to-one, family and group opportunities for specialist intervention, which might be from:
 - Specialist bereavement counsellors/practitioners (recognising that such roles within the NHS are limited)
 - Specialist mental health professionals for those with mental health problems which pre-date or are triggered by their bereavement.

6.1.6.1 The goals of organised bereavement support include

- describing normal grieving
- encouraging bereaved families to accept the loss by talking about it
- helping bereaved families to identify and express feelings related to the loss (for example, anger, guilt, anxiety, helplessness, and sadness)
- helping families to find a new relationship with their child who died, and a place for the child in the family's ongoing lives
- helping bereaved people to understand their methods of coping
- describing the differences in grieving among individuals
- providing support at important times, such as on birthdays and anniversaries
- helping families manage any secondary issues they are experiencing
- identifying coping problems bereaved people may have and making recommendations for professional grief therapy, if necessary.

Chapter 7

Specific situations

Deaths overseas of children normally resident in England

7.1.1 Principles

7.1.1.1 Any death overseas of a child normally resident in England requires comprehensive review. The default expectation is that all such deaths will be investigated by the coroner, and the primary responsibility for the child death review lies with the CDOP for the area where the child was normally resident. The Foreign and Commonwealth Office (FCO) is a vital source of information for professionals and families in such situations.

7.1.1.2 The principles of the process detailed in this guidance should be followed when a death occurs overseas, however implementation of the process may be affected by the availability of information from overseas authorities, and potential delays in obtaining that information.

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), 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 on 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 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, or in an emergency 0207 008 1500 (ask for Consular).

7.1.3 The approach to reviewing the deaths of children normally resident in England who die abroad

7.1.3.1 *The CDR review 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 CDOPs may learn about such a death from a variety of sources (e.g. FCO, media, coroner, public). All such deaths are subject to a coronial inquest. It is the coroner whose jurisdiction encompasses the port of entry of the child's body into the UK who has responsibility for reviewing the death. Responsibility for the primary review of such a death lies with the CDR partner area where the child was normally resident. Such reviews require careful coordination to ensure that all relevant information from the FCO, international funeral directors, coroner, and local services (health, education,

social services) is presented to the panel. The FCO's ability to assist a CDOP is limited to cases where the child was a British national.

Children and people with learning disabilities

7.1.4 Introduction and principles

It is important to specifically recognise and record that 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. Key reports in relation to children with learning disabilities are:

- The Independent Inquiry chaired by Sir Jonathan Michael in 2010¹⁵ which reported that ‘people with learning disabilities receive less effective care than they are entitled to receive’.
- Mencap’s ‘*Death by Indifference: 74 deaths and counting*’ (2012)¹⁶ which reported that the NHS failed children and adults with learning disabilities at a level of ‘institutional discrimination’.
- The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)¹⁷ which reported that seven of the fourteen deaths of young people aged 4-17 years reviewed could have received better care.¹⁸ Issues highlighted included:
 - delays in care pathways for investigation, diagnosis and treatment;
 - a lack of reasonable adjustments to help people and their families access health services; and
 - a lack of coordination of care across and between different disease pathways and service providers.

7.1.4.1 CIPOLD recommended the establishment of a National Learning Disability Mortality Review Body to learn from mortality reviews of people with learning disabilities and provide a driver to reduce inequalities in care for this population. The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

¹⁵ Michael J. (2008) Healthcare for all. http://webarchive.nationalarchives.gov.uk/20130105064756/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf

¹⁶ Mencap (2012) *Death by Indifference: 74 deaths and counting*. <https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf>

¹⁷ Heslop et al. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

¹⁸ Avoidable Mortality in England and Wales; ONS; 2012. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/2014-05-07>

7.1.5 The LeDeR programme

7.1.5.1 The LeDeR programme describes a review process for the deaths of people aged 4 years and over with learning disabilities in England.¹⁹ Within each NHS England region (North, Midlands & East, South and London) 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 the chairpersons of the respective locality CDOPs 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.

7.1.6 Definition of learning disabilities

7.1.6.1 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.

7.1.6.2 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.

7.1.6.3 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 also does not include those who have a 'learning difficulty' (such as dyspraxia or dyslexia) which is more broadly defined in education legislation. 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/>.

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

¹⁹ Before the age of 4 years it can be difficult to ascertain if a person 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.

7.1.7 The interface between the Child deaths review and the LeDeR mortality review process

7.1.7.1 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.

7.1.7.2 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 locality CDOP 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 regional CDOP. The administrator and chair of the CDOP should then ensure that the LeDeR programme is represented at the CDOP meeting at which the death is reviewed. In addition, the Local Area Contact for the LeDeR programme and the CDOP 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 Form C arising from the CDOP discussion should be submitted to the Local Area Contact for the LeDeR programme by the CDOP manager. If the Local Area Contact is not known, contact the LeDeR team on 0300 777 4774.

7.1.7.3 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 the Department of Health, 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 CDOPs on an annual basis.

Deaths of children in adult healthcare settings e.g. adult intensive care units (ICUs)

7.1.8 Introduction and principles

7.1.8.1 A very small number of children (nearly always 16 and 17 year olds) die in adult intensive care units (ICUs). The [Learning from Deaths](#) framework gives guidance to NHS trust 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.

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

7.1.9.1 *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](#).²⁰

7.1.9.2 There are two stages in the SJR method. The first stage involves trained reviewers scrutinising case records of a selected cohort of patients (e.g. patients undergoing elective procedures, patients not expected to die) to inform explicit judgements about the quality of care. If a reviewer judges overall care to be poor, or if concerns have been raised about a case, the case is referred to the hospital governance group. The governance group may investigate the death further, and may make an additional judgement concerning the potential avoidability of the patient's death. Finally, national guidance places expectations on Trust Boards to establish mortality surveillance groups under the oversight of executive and non-executive directors and to publish data on the number of inpatient deaths and the proportion judged to have been due to problems of care.

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

7.1.10.1 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:

- 1). There should be notification of the child health system, GP, and local CDOP office and the National Child Mortality Database (once operational);
- 2). 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:
 - a) advising regarding the need for a Joint Agency Response;

²⁰ More information on *Learning from Deaths* is available at <https://improvement.nhs.uk/resources/learning-deaths-nhs/>

- b) identifying whether the child is known to paediatric health professionals who should be represented at the adult mortality and morbidity (M&M) meeting;
 - c) attend the adult M&M meeting and complete a Form C for the purposes of reporting to the relevant CDOP.
- 3). The Structured Judgement Review approach or other evidence based structured mortality review tool should be used to review the quality of clinical care. This report, Form C, 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.

Suicide and self-harm

7.1.11 Introduction and principles

7.1.11.1 Suicide is defined as a death where the conclusion of suicide is given at inquest where the coroner (or jury) is satisfied beyond reasonable doubt that the deceased did an act knowing and intending that their death would result. The true rate of suicide is thought to be higher than that reported in national statistics and is one of the leading causes of death in young people. This child death review guidance provides an opportunity for enhanced suicide surveillance by the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (NCISH), the automatic engagement of mental health expertise at individual child death review and any themed CDOP meetings, and the collection of suicide-related intelligence at a national level.

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

7.1.12.1 The Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England commissions NCISH to deliver the Mental Health Clinical Outcome Review Programme. Since 2015, NCISH has examined deaths of all children by suicide based on data from the Office for National Statistics (ONS). Detailed information is currently received from a variety of sources, including: coroner inquest hearings, CDOP reviews, Serious Case Reviews, and the criminal justice system. Reports have been published in 2016 and 2017.

7.1.13 The approach to reviewing suicides in children

7.1.13.1 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 child death review meeting should be properly quorate and 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;
- The relevant CDOP should report to NCISH (ncish@nhs.net) all cases of child death that they believe might be due to suicide or self-harm, for as long as this national investigation of child suicide continues.
- Suspected child suicides should be discussed at a themed specialist CDOP review with attendant mental health specialists.

Inpatient Mental Health settings

7.1.14 Introduction and principles

7.1.14.1 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).

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

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

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

7.1.15 Child death review process

7.1.15.1 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 of the death of a service user, although NHS providers may discharge this duty by notifying NHS England through a local manager, or by reporting the death on the local risk management system where information is uploaded to the national reporting and learning system.

7.1.15.2 Immediate decision making should take place as set out in [Chapter 2](#) of this guidance. Following necessary investigations (see [Chapter 3](#)), a child death review meeting should take place (see [Chapter 4](#)). The child death review meeting should involve the care co-ordinator 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](#)).

7.1.16 Child safeguarding Practice Reviews

7.1.16.1 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 to the local safeguarding partners. These deaths, along with the death of any child in custody or secure accommodation, should trigger a local or national child safeguarding practice review. Child safeguarding practice reviews usually run in parallel to other investigations and often complete after the inquest and CDOP process has concluded.

7.1.17 Involvement and Support to Parents, Carers and Staff

7.1.17.1 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.

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

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

Deaths in custody

7.1.18 Introduction and principles

7.1.18.1 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 same processes also apply to the death of a child accommodated in a secure welfare placement.²¹ The CDOP for the area where the child dies is responsible for conducting a detailed secondary review.

7.1.19 The Prisons and Probation Ombudsman

7.1.19.1 The PPO investigates all child deaths of 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). The PPO does not investigate deaths in police custody or the deaths of children or young people detained in a hospital.

7.1.19.2 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.

7.1.20 The PPO and NHS England

7.1.20.1 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.²²

²¹ 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.

²² <http://www.ppo.gov.uk/app/uploads/2014/07/PPO-Clinical-Reviews-Part-2-Guidance-clinical-reviewers-September-2014.pdf>

7.1.21 Local NHS England response

7.1.21.1 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. It is the responsibility of the healthcare provider to inform the NHS England regional commissioner of all deaths of c NHS providers should inform the locality CDOP of all deaths of children 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, conduct a comprehensive review of the case and enter relevant data on the National Child Mortality Database once it is operational. Children in custody that meet the definition of a serious incident. The NHS England commissioner should simultaneously notify the NHS England central team via the Director of Health and Justice.

7.1.21.2 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.

7.1.22 Deaths in custody and the child death review process

7.1.22.1 NHS providers should inform the locality CDOP of all deaths of children 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, conduct a comprehensive review of the case and enter relevant data on the National Child Mortality Database once it is operational.

Chapter 8

The roles of specific agencies

Department for Education

The Department for Education is responsible for children's services and education, including higher and further education policy, apprenticeships and wider skills in England. The department is also home to the Government Equalities Office. The department works to provide children's services and education that ensure opportunity is equal for all, no matter what their background or family circumstances. Until 2017 it provided national oversight for the child death review process.

Department of Health

The Department of Health helps people to live better for longer. It leads, shapes and funds health and care in England, making sure people have the support, care and treatment they need, with the compassion, respect and dignity they deserve. In 2017, the Department of Health took on responsibility for national oversight for the child death review process.

Local authorities

Local authorities are responsible for providing a range of public services. This includes education, social care, roads and transport, economic development, housing and planning, environmental protection, waste management, cultural and leisure services.

Their responsibilities in relation to child death review are set out in the Children and Social Work Act 2017. Local authorities and CCGs, as Child Death Review Partners, are required to make arrangements for review of all deaths of children normally resident in the relevant local authority area, and if they consider it appropriate, deaths in that area of non-resident children.

Clinical Commissioning Groups (CCGs)

Clinical Commissioning Groups (CCGs) are clinically-led statutory NHS bodies, responsible for planning and commissioning health care services for their local area.

Their responsibilities in relation to child death review are set out in the Children and Social Work Act 2017. CCGs and local authorities, as Child Death Review Partners, are required to make arrangements for review of all deaths of children normally resident in the relevant local authority area, and if they consider it appropriate, deaths in that area of non-resident children.

Healthcare Safety Investigation Branch (HSIB)

The Healthcare Safety Investigation Branch (HSIB) is an organisation that carries out investigations within healthcare. 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.

Office of the Chief Coroner

The Chief Coroner is head of the coroner system, providing national leadership for coroners in England and Wales. Coroners are independent judicial office holders (like judges) who investigate certain deaths. When a coroner receives a report of a body within his/her geographical area the coroner will investigate any death which meets certain criteria (see Appendix 2).

Police

Police undertake a variety of activities, which relate to the prevention and detection of crime and the prosecution of offenders against the peace. The police are responsible for a range of services to protect and safeguard children in partnership with local authorities and CCGs. The police are the lead agency responsible for investigating the death of a child where concerns of a criminal or child protection nature are identified. The police are a key agency in a Joint Agency Response.

Public Health England

Public Health England (PHE) is an executive agency of the Department of Health which has operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner. PHE's mission is to protect and improve the nation's health and to address inequalities. PHE's Chief Nurse provides advice and expertise as the Government's professional advisor (Public Health Nursing), which in the context of children's health includes health visitors and school nurses.

Appendices

Appendix 1 – Case Examples

This section gives examples of how the child death review process might work in four well-recognised 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 tragically 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 a 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

The Coroner undertakes an investigation and a post mortem is carried out. The hospital patient safety team undertakes a serious incident investigation.

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 Form C 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 Form C from the tertiary hospital, and the coroner's verdict. 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 (CDOP chair, designated doctor, CDOP manager, lay representative), 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 review all the information provided to them and 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 Trust, seeking assurance that actions listed in the serious incident investigation have been completed. The designated doctor writes a summary report of key issues arising from the themed meeting. Data are entered on the National Child Mortality Database.

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 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 emergency department team contacts the on-call health professional, police investigator, and duty social worker and requests they come into the hospital.

Investigation

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

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 Form C 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 Form C 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 take a different view from the local child death review meeting, in relation to the importance of the child's social environment. The Form C is amended. Data are entered on the National Child Mortality Database.

Case 3

A baby girl is born at term in poor condition, in a local hospital. She requires intubation and ventilation and is transferred to the tertiary Neonatal Intensive Care Unit, for brain cooling for birth asphyxia. An MRI brain scan shows severe hypoxic ischaemic encephalopathy. After much discussion with the parents, a decision is made at four weeks of age to withdraw treatment.

Immediate decision making

A meeting is held with the neonatologists from both centres and 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

The family are offered a hospital post-mortem.

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. They feel that their baby has been through enough and decide against a post-mortem. The child death review process is explained to them and they are offered a further meeting in two weeks.

The child death review meeting (hospital perinatal mortality meeting)

The hospital perinatal mortality meeting is arranged to occur 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). The GP is unable to attend but submits a report. Contributory factors and learning are discussed and a draft Form C completed.

Involving and supporting the family

The parents have already met with their key worker and with the neonatologist. The parents tell the key worker that they would like to have a follow up meeting with the obstetrician from the local hospital. This is arranged.

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 Form C 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 (CDOP chair, designated doctor, CDOP Manager, lay representative), the following professionals attend: neonatal network lead, obstetrician (different region), neonatologist (different region), midwife.

Panel deliberations

The panel review all the information provided to them. This includes information provided by the GP and social worker that the child death review meeting had not sought out. Although they agree with child death review meeting's conclusions, they have concerns that that meeting was not sufficiently quorate to definitely understand the family's social background. 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.

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

No investigation is necessary

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. Contributory factors and learning are discussed and a draft Form C 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 Form C 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 agree with the conclusions from the child death review meeting. Data are entered on the National Child Mortality Database.

Appendix 2 – Criteria for referral of deaths to coroner

From the Chief Coroner's Guidance note 23, July 2016²³

Possible 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)
- for any other concerning feature

Individual coroners may have their own reporting requirements.

²³From the Chief Coroner's Guidance note 23, July 2016 <https://www.judiciary.gov.uk/wp-content/uploads/2016/07/guidance-no-23-report-of-death.pdf>

Appendix 3 – Example Immediate Decision Making proforma

Child's name:	
Address:	
NHS or hospital number:	

Actions to be completed with 1-2 hours of death being declared

	Decision?	<i>Circle as appropriate</i>	Action	<i>Action completed?</i>
1	Does death meet criteria for a Joint Agency Response? (death due to external causes, death sudden with no apparent cause (e.g. SUDI), death in custody or when child detained under MHA)	Yes / No	If Yes, contact on-call health professional, police, duty social worker and request they attend hospital	Yes
2	Can a MCCD be issued?	Yes / No	If No contact the coroner's office	Yes
3	Has a care or service delivery issue occurred?	Yes / No	If Yes contact the patient safety team	Yes
3a	In relation to 3: Are there any immediate actions necessary to ensure safety of other patients?	Yes / No / NA	If Yes describe here:.....	
3b	In relation to 3: Has a Datix form been completed?	Yes / No / NA		
3c	In relation to 3: Have obligations under the Duty of Candour been fulfilled?	Yes / No / NA		
4	Describe the approach to supporting the family (key worker, end of life medical lead):			

Name of person completing this form	
Job title	
Date	

Appendix 4 – Routine suggested samples for SUDI

Routine suggested samples to be taken immediately after sudden unexpected deaths in infancy (SUDI) and to be considered in other circumstances where cause of death unexplained

Sample	Send to	Handling	Test
Blood (serum) 1–2 ml	Clinical chemistry	Spin, store serum at –20°C	Toxicology if indicated*
Blood cultures – aerobic and anaerobic 1 ml	Microbiology**	If insufficient blood, aerobic only	Culture and sensitivity
Blood from Guthrie card	Clinical chemistry	Normal (fill in card; do not put into plastic bag)	Inherited metabolic diseases
Blood (lithium heparin) 1–2 ml	Cytogenetics	Normal – keep unseparated	Genetic testing (if indicated)
Cerebrospinal fluid (CSF)	Microbiology***	Normal	Microscopy, culture and sensitivity
Nasopharyngeal aspirate	Virology#	Normal	Nucleic acid amplification techniques**
Nasopharyngeal aspirate	Microbiology	Normal	Culture and sensitivity
Swabs from any identifiable lesions	Microbiology	Normal	Culture and sensitivity
Urine (if available)	Clinical chemistry	Spin, store supernatant at –20°C	Toxicology if indicated, inherited metabolic diseases

Notes - Such samples in most cases will fall under the jurisdiction of HM Coroner and hence communication with the coroner's officer is important. Before the infant is certified to have died and/or during the resuscitation period, various samples may have been collected. These samples should be clearly documented, the coroner's officer informed, the samples secured, and the results forwarded to the pathologist as soon as possible. It is important that a 'chain of evidence' is maintained underpinned by good documentation and labelling. The samples listed in this table should be taken in all SUDI cases. In unexplained deaths in older children, the appropriate clinical samples will be guided by the circumstances of the death and the clinical findings.

* Toxicology has a low yield in routine practice, and its use and coverage of substances varies according to coronial practice. Each case should be assessed individually.

** Appropriate interpretation of microbiological and virological results after SUDI remains difficult, with significant variation by group and individual.

*** If indicated based on clinical history or examination.

Samples must be sent to an appropriate virological laboratory.

1a Additional samples to be considered after discussion with consultant paediatrician

- Skin biopsy for fibroblast culture in all cases of suspected metabolic disease.
- Muscle biopsy if history is suggestive of mitochondrial disorder.
- In suspected carbon monoxide poisoning, blood sample for carboxyhaemoglobin.

1b Forensic considerations

- Ensure the coroner has given permission to take samples.
- All samples taken must be documented and labelled to ensure there is an unbroken 'chain of evidence', using an appropriate 'chain of evidence' proforma.
- This may mean handing samples to a police officer directly, or having the laboratory technician sign upon receiving them in the laboratory.
- Ensure that samples given to the police or coroner's officer are signed for.
- Record the sites from which all samples were taken

Appendix 5 – Revised Form C

Child’s age at death

Date of review

Gender

Cause of death as presently understood (include the cause of death given on the MCCD or as assigned by the pathologist/coroner)

Case Summary

Contributory Factors

The review meeting should analyse any relevant factors that may have contributed to the child’s death. For each of the four domains below, determine different levels of influence (0-3) for any identified factors:

- 0 - Information not available
- 1 - No factors identified or factors identified but are unlikely to have contributed to the death
- 2 - Factors identified that may have contributed to vulnerability, ill-health or death
- 3 - Factors identified that provide a complete and sufficient explanation for the death

This information should inform the learning of lessons at a local level.

Domain A - Child’s needs
<p>Factors intrinsic to the child</p> <p>Include any known health needs; factors influencing health; development/ educational issues; behavioural issues; social relationships; identity and independence; abuse of drugs or alcohol; note strengths and difficulties</p>
Please enter relevant information (Relevance 0-3)

--

Domain B – Social environment including family and parenting capacity	
Factors in the social environment Include family structure and functioning: provision of basic care; health care (including antenatal care where relevant); safety; any evidence of current or previous abuse or neglect; emotional warmth; stimulation; guidance and boundaries; stability; parental abuse of drugs or alcohol; wider family relationships; employment and income; social integration/ support; nursery/pre-school or school environment	
Please enter relevant information (Relevance 0-3)	

Domain C – physical environment	
Factors in the physical environment Include known hazards relating to the external environment in relation to common childhood injuries : burns, falls, road traffic accidents; issues relating to housing and home safety measures	
Please enter relevant information (Relevance 0-3)	

Domain - service provision	
Factors in relation to service provision Include any identified services (either required or provided); any gaps between child's or family member's needs and service provision; any issues in relation to service provision, access or uptake	
Please enter relevant information (Relevance 0-3)	

The Review meeting should categorise the likely/cause of death using the following schema.

This classification is hierarchical. All relevant categories should be ticked if more than one category could reasonably be applied. The highest marked will be recorded as the primary category and others as secondary categories

Category	Name & description of category	Tick box below
1	Deliberately inflicted injury, abuse or neglect This includes suffocation, shaking injury, knifing, shooting, poisoning & other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death.	<input type="checkbox"/>
2	Suicide or deliberate self-inflicted harm This includes hanging, shooting, self-poisoning with paracetamol, death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children.	<input type="checkbox"/>

3	<p>Trauma and other external factors</p> <p>This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. Excludes Deliberately inflicted injury, abuse or neglect. (category 1).</p>	<input type="checkbox"/>
4	<p>Malignancy</p> <p>Solid tumours, leukaemias & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.</p>	<input type="checkbox"/>
5	<p>Acute medical or surgical condition</p> <p>For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.</p>	<input type="checkbox"/>
6	<p>Chronic medical condition</p> <p>For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause.</p>	<input type="checkbox"/>
7	<p>Chromosomal, genetic and congenital anomalies</p> <p>Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.</p>	<input type="checkbox"/>
8	<p>Perinatal/neonatal event</p> <p>Death ultimately related to perinatal events, eg sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, post-haemorrhagic hydrocephalus, irrespective of age at death. It includes cerebral palsy without evidence of cause, and includes congenital or early-onset bacterial infection (onset in the first postnatal week).</p>	<input type="checkbox"/>
9	<p>Infection</p> <p>Any primary infection (i.e. not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc.</p>	<input type="checkbox"/>
10	<p>Sudden unexpected, unexplained death</p> <p>Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).</p>	<input type="checkbox"/>

Modifiable Factors

Consider whether any of the contributory factors identified might, by means of locally or nationally achievable interventions, be modified to reduce the risk of future child deaths

Modifiable factors identified	<input type="checkbox"/>
No modifiable factors identified	<input type="checkbox"/>
Inadequate information upon which to make a judgement. <i>NB this category should be used very rarely indeed.</i>	<input type="checkbox"/>

Issues and learning points

Actions

Follow up plans for the family

Appendix 6 – 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;
- If a public health professional will provide CDOP with information on epidemiological and health surveillance data;
- 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 will, 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 report (Form A);
- 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 (Form Bs);
- Liaise with the Chair of the child death review meeting to receive that meeting's summary notes (draft Form C);
- Record the CDOP's conclusions (final Form C) and submit data to the Department of Health. Once operational, submit data to the National Child Mortality Database.

Designated Doctor for Child Deaths

The designated doctor will:

- 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
- Prepare an annual report with the Chair summarising the activities of CDOP

Nurse/Midwife

The CDOP nurse and/or midwife will:

- 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
- 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 will:

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

Police

The Police representatives will:

- 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
- Liaise with other Police departments, and the Crown Prosecution Service as necessary

Safeguarding

The Children's Social Care and Safeguarding representatives will:

- 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
- Advise CDOP on children's rights and welfare, and on appropriate legislation and guidance relating to children
- Identify cases that may require a further child protection investigation
- Liaise with other local authority services

Education Representative:

The Education representative will:

- Assist CDOP in interpreting information about the education needs and the education service provided for the deceased child and other children within the household
- Assist CDOP in providing appropriate preventative strategies

Lay Representative:

The Lay representative will:

- Assist CDOP through providing an independent view;
- Represent the public and the family in interpreting and evaluating information

Appendix 7 – Suggested membership for themed panels

Neonatal panel:	Cardiac panel:
Designated doctor	Designated doctor
CDOP manager	CDOP manager
Neonatal network lead	Cardiac network lead
Midwife	Cardiologist
Health visitor	Cardiac surgeon
Obstetrician	Cardiac liaison nurse
Pathologist	Pathologist
Transport team	Transport team
Lay representative	Lay representative

SUDI panel:	Trauma panel:
Designated doctor	Designated doctor
CDOP manager	CDOP manager
SUDI 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

Suicide panel:	Learning disability panel:
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

Appendix 8 – Bereavement resources

Bereaved Parents Support Organisations Network (BPSON)

Umbrella body for organisations supporting bereaved parents

www.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

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

029 2081 0800

Child Bereavement UK

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

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

0800 282 986 or 0808 800 6019

The Compassionate Friends

Peer support for bereaved parents and their families.

www.tcf.org.uk

0845 123 2304

The Lullaby Trust

Emotional support for bereaved families, particularly around Sudden Infant Death Syndrome (SIDS)

www.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

Winston's Wish (siblings)

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

www.winstonswish.org.uk

Tel: 08088 020 021

