Northern Lincolnshire Child Death Review (CDR) Process and Child Death Overview Panel (CDOP) Guidance

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The statutory child death review partners are the clinical commissioning groups and the local authorities for North and North East Lincolnshire.

However, it is acknowledged that there are several wider partners involved in the full child death review process. The support these agencies/organisations provide is both valued and appreciated by the statutory partners.

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1. Introduction

The death of a child is a devastating loss that profoundly affects bereaved parents as well as siblings, grandparents, extended family, friends and professionals who were involved in caring for the child in any capacity. Enquiries should keep the appropriate balance between forensic and medical requirements and the supporting the family at a difficult time. Professionals supporting parents and family members should assure them that the objective of the child death review process is not to allocate blame but to learn lessons. Families should always be treated with sensitivity, discretion and respect, and professionals should approach their enquiries with an open mind.

The process of expertly reviewing all children's deaths is grounded in deep respect for the rights of children and their families, with the intention where possible, of preventing future child deaths.

1.1 Who is this guidance for?

This guidance is applicable in the circumstances of a death for any child who resides or passes away in Northern Lincolnshire. The geographical footprint for the Northern Lincolnshire Child Death Review arrangements is the North Lincolnshire, and North East Lincolnshire local authority areas. This footprint corresponds with that of North Lincolnshire and North East Lincolnshire Clinical Commissioning Groups' (CCG) footprint.

The Northern Lincolnshire Child Death Review (CDR) partners (Clinical Commissioning Groups (CCG's) and the local authority) are responsible for ensuring that this statutory framework is implemented. Senior leaders within organisations who commission or provide services for children, as well as relevant regulatory bodies, should also follow the procedures set out in this guidance.

All other professionals who care for children, or who have a role in the child death review process, must read and follow this statutory guidance so that they can respond to each child death appropriately. This includes, but is not limited to, people working within:

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

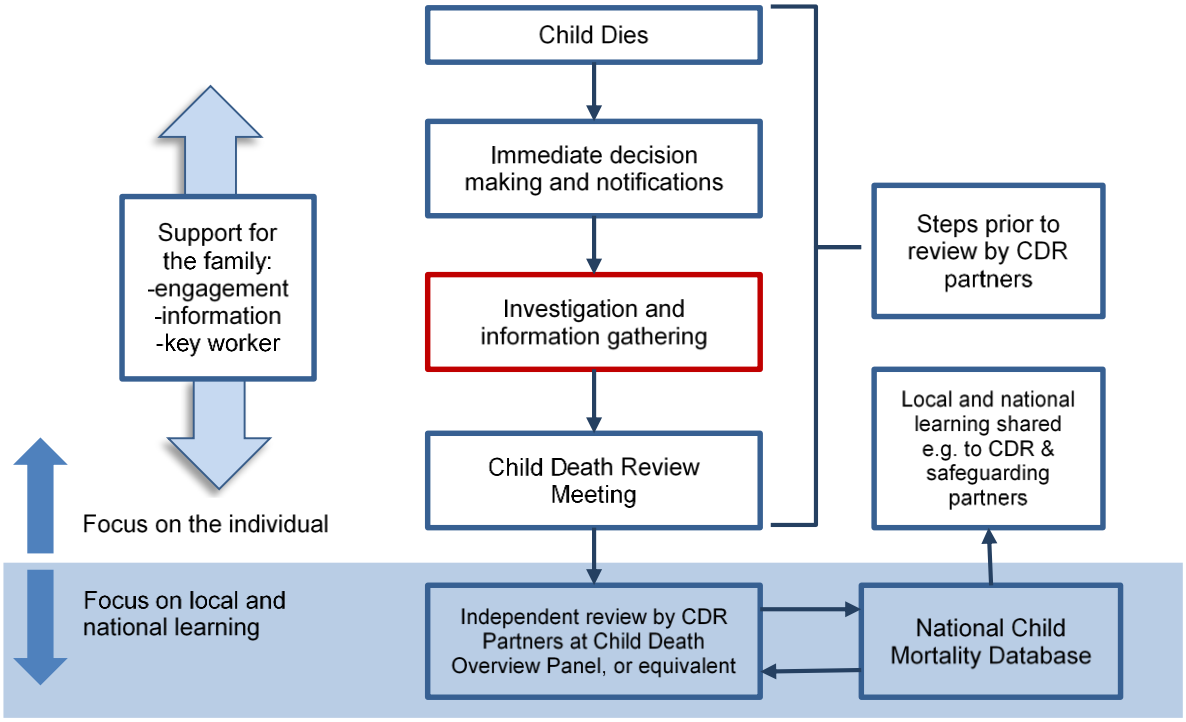
1.2 How does this guidance fit with other relevant guidance documents?

This guidance fits with the following relevant guidance:

- Child Death Review – Statutory and operational Guidance (England) (2018)
- Working Together to Safeguard Children (Working Together) (2018)
- Sudden and Unexpected Death in Infancy and Childhood: multiagency guidelines for care and investigation (2016)
- National Guidance on Learning from Deaths (2017)
- Information for families following a bereavement (2018)
- Learning from Deaths: Guidance for NHS trusts on working with bereaved families and carers (2018)
- When a Child Dies: A guide for parents and carers (2018)

2. The CDR Process Outline

This is an overview of the process as sourced from the Child Death Review Statutory and Operational Guidance (England) 2018



A more detailed process overview for Northern Lincolnshire can be found in appendix A

3. Immediate Decision making and notifications

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

3.1 Who should be involved?

Necessary discussions via any medium 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 (JAR)
    - the coroner's officer in circumstances when a Medical Certificate of Cause of Death (MCCD) cannot be issued.
    - Child Death Review Manager for Northern Lincolnshire
    - a member of the hospital patient safety team when care or service delivery issues are suspected.
    - SUDIC Nurse for NLaG information to be shared with the appropriate agencies.

3.2 What immediate decisions are needed?

Senior professionals attending the child at the end of his/her life should consult with each other to determine the correct course of action. This is relevant to all child deaths, wherever they occur.

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

- Identify the available facts about the circumstances of the child's death.
- Determine whether the death meets the criteria for a JAR, and if so, contact the on-call representatives for the police, children's social care and health to initiate the JAR. However, if the death is from external causes, the circumstances are unclear, or safeguarding concerns or problems with care or service delivery are suspected, further investigations will be needed, to understand how the child has died.
- Determine whether a MCCD can be issued, if not, consider whether the death should be referred to the coroner. The cause of death for most children who die is understood and the doctor who has attended the child at the end of their life (the "attending doctor") will be able to issue a MCCD and the death will be able to be registered. Consideration should be given to how best to support the family, and to what information needs to be gathered to inform the Child Death Review Meeting (CDRM).
- Determine whether an issue relating to health care or service delivery has occurred or is suspected and therefore whether the death should be referred to the coroner and/or a serious incident investigation.
- Identify how best to support the family and consider who would be the most appropriate key worker. For details of the key worker role see pages 18-19.
- Determine whether any actions are necessary to ensure the health and safety of others, including family or community members, healthcare patients and staff.

3.3 Issuing a MCCD or referral to the coroner

At the death of a child, the attending doctor should first decide whether they are able to issue a MCCD in accordance with Guidance for doctors completing Medical Certificate of Cause of Death in England and Wales set out by the Office for National Statistics and Home Office. Attention should then be given to what information needs to be gathered to inform the CDRM.

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

3.4 The Post-Mortem

In deaths where a MCCD can be issued a hospital post-mortem examination (PM) may still provide important information as to why a child has died. It is the right of parents to request a hospital PM if this is their wish and the coroner is not investigating the death (the key worker and clinical staff should explain to those concerned the outcome of the request for a hospital post mortem).

3.5 Other Notification

The attending senior nurse and doctor will ensure the notification to those relevant as listed below within 24 hours (or the next working day) of the child's death:

- Child Health Information System (CHIS); Health care providers should notify their local CHIS to ensure that further clinic appointments are not arranged.
- General Practitioner: the attending health care team should inform the child's GP of the fact and circumstances of the death, so that the GP is able to support the family.
- Other professionals, as appropriate; community midwives, health visitor, school nurse, hospital/community medical team.
- CDR administrator and manager:
    - For every child death a notification form needs to be submitted to trigger the CDR process. The notification form is the initial submission of information relating to a child death. These can be completed by any individual when accessing the eCDOP webpage and they are to be completed for all child deaths.
    - Depending on where the child is normally resident, the notification form is to be sent to the relevant CDOP; For anticipated deaths, the notification will go to the locality for where the child is resident. For unanticipated deaths, the notification will go to where the child died.
    - Once the notification form is received, the CDR administrator is to share details of the death with all relevant agencies. This includes the GP, Integrated family services, Family Hubs, safeguarding services, social care services, named nurses and Humberside Police Protecting Vulnerable Persons team.

The CDR manager or administrator is required to liaise with the local CDR manager from where the child is resident to ensure all information relating to the child is fully contributed to the CDR process.

4. Investigating and Information Gathering

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

4.1 Forms

The forms for CDOP are:

- A. Notification form
- B. Reporting Form with inclusion of supplementary forms, where appropriate
- C. Analysis Form

A Reporting form is distributed, along with the relevant supplementary forms, by the CDR administrator with use of eCDOP, to gather information relating to the death and welfare of the child prior to the death occuring. These forms are also used as a basis for considering whether further action is to be taken in relation to matters identified.

Reporting Form should be sent to:

- GP
- PVP Humberside Police
- Children's Safeguarding (This would be dependent on where the death occurs)
- Educational Provision (if appropriate)
- Social worker
- Named Midwife
- Ambulance Trust (Dependent on death)
- Children's Public Health Named Nurse

Other professionals will require the distribution of Reporting forms, and this is to be decided on a case-by-case basis. Further distribution would be informed by the Lead Health Professionals or through receipt of Reporting form if other service involvement is identified.

It is a statutory requirement for these forms to be completed within 6 weeks or at your earliest opportunity.

4.2 Coronial Investigation

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

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

5. Action by professionals when the death of the child is unanticipated

5.1 The criteria for deaths to be considered for a Joint Agency Response (JAR).

The "Sudden and Unexpected Death in Infancy and Childhood: multiagency guidelines for care and investigation (2016)" gives comprehensive advice and expectations of all agencies involved in a JAR, and should be applied in full by all agencies. This Child Death Review Guidance should be seen as complementary to the SUDI/C Guidelines and does not replace them.

If the child dies suddenly or unexpectedly at home or in the community, the child should normally be taken to Accident and Emergency rather than the mortuary, unless it is deemed inappropriate to take the child to A&E. In some cases when a child dies at home or in the community, the police may decide that it is not appropriate to immediately move the child's body, for example because forensic examinations are needed.

If a child has died at home or in the community, the lead investigator and senior health care professional should decide whether there should be a visit to the place where the child has died, ideally within 24 hours and who should attend. This should almost always take place for cases of sudden infant death.

A JAR should be triggered if a child's death:

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

The on-call health professional should contact the police investigator and duty social worker to discuss the initiation of a JAR. If a JAR is to be initiated, it is to be held as soon as practicable.
A JAR can be triggered at any point in the CDR process.

A JAR can be triggered if such children are brought to hospital near death, are successfully resuscitated, but are expected to die in the following days. In such circumstances the JAR should be considered at the point of presentation and not at the time of death, since this enables an accurate history of events to be taken and, if necessary, a 'scene of collapse' visit to occur. Appropriate clinical investigations should also be performed in these cases, as set out in Table 1 of the SUDI/C Guidelines, Appendix B.

A lead health professional should be assigned to the case as per NLaG's SUDIC policy. This person may be a doctor, senior nurse or health visitor with appropriate training and expertise. This person will ensure that all health responses are implemented and be responsible for on-going liaison with the police and other agencies. Where no out-of-hours health rota for a JAR exists in a locality, the role of lead health professional should be taken by the senior attending paediatrician.

Certain factors in the history or examination of the child may give rise to concerns about the circumstances of death. If such factors are identified, they should be documented and shared with the coroner and professionals in other key agencies. All injuries should be recorded, and the lead

police investigator should arrange a photographic record. Appropriate clinical investigations should be performed, as set out in Table 1 of the SUDI/C Guidelines.

5.2 Initial information and sharing and planning meeting as part of a JAR

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

An initial information-sharing discussion should take place before the family leave the hospital. This should include consideration of:

- outstanding investigations
- notification of agencies
- arrangements for the post-mortem examination
- plans for a visit to the home or scene of collapse by those with appropriate forensic training.

Following this visit, the medical lead health professional should prepare a report for the pathologist, coroner and the police investigator. This report should also be forwarded to the relevant CDR administrator to be uploaded on the eCDOP system.

The nurse lead health professional will liaise with the CDR administrator to assist in arranging a JAR meeting. This is a multi-agency meeting to review emerging findings. once the PM and other clinical investigations are known to review emerging findings. This meeting will be chaired by a senior representative from NLaG. Attendance will consist of professionals who were involved with the child/family during the child's life and immediately around the time of death and should include a representative of children's social services. The CDR administrator would make arrangements to attend and minute these meetings.

Once the final post-mortem (PM) report has been released by the coroner and any serious incident reports or Health Care Safety Investigations Branch (HSIB) are completed then the nurse lead health professional will make arrangements for the CDRM which are to be minuted by the CDR administrator. The CDRM should ideally take place before the inquest to inform the coroner's investigation. The CDOP or equivalent will normally take place after the conclusion of the inquest, taking account of the coroner's conclusions.

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

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

5.3 NHS Serious Incident Investigations

Serious incident investigations are undertaken with the sole aim of learning about any problems in the delivery of healthcare services and in understanding the causes and contributory factors of those problems of which there may be several. Awareness that a serious incident may have occurred may come sometime after the child's death. It is never too late to instigate a serious incident investigation. Serious incident investigations may occur in parallel to other investigations e.g., a JAR.

Serious incident investigations are NHS processes and will be managed in accordance with provider and CCG arrangement.

There is an expectation that the SI leads, and family liaison worker would have an interface with the nurse lead health professional to ensure connectivity between the two processes.

Once assured by the commissioner, the provider shares the serious incident investigation findings with the CDR Manager. SI identification numbers are to be shared with the CDR administrator in the relevant locality. As part of the CDRM there is an expectation that the author or representation of the provider contributes to the CDRM.

Further details on this framework can be found on the NHS-E site.

5.4 The Healthcare Safety Investigations Branch

Healthcare Safety Investigations Branch (HSIB) carries out independent investigations into safety concerns that occurred after 1 April 2017, within NHS funded care in England. Its objective is to be thorough, independent and impartial in its approach without apportioning blame or liability. The HSIB accepts referrals from any source, and these can be made through the HSIB website

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

5.5 Co-ordination Across Investigations

It is vital that families do not become 'lost' in a myriad of parallel investigations following their child's death. In addition to the investigations summarised above, families may raise complaints against one or more organisations, and cases may subsequently be referred to the relevant ombudsman. The CDR Manager should have an oversight on all the relevant information regarding all parallel investigations. Effective co-ordination and good communication are vital to avoid additional distress to bereaved parents.

In deaths where there is more than one investigation a "case manager" will be identified. They will have oversight of procedures: ensuring that those involved are objective, understand 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.

6. The Child Death Review Meeting (CDRM)

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

The nature of this meeting will vary according to the circumstances of the child's death and the practitioners involved. This happens after every child death and could take the form of:

- a final case discussion following a JAR.
- a perinatal mortality review group meeting in the case of a baby who dies in the neonatal period; [1]
- a hospital-based mortality meeting following the death of a child in a paediatric intensive care unit.
- a similar case discussion

6.1 Aims of the CDRM

In all cases, the aims of the CDRM are:

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

6.2 Who should chair the meeting?

The CDRM should be chaired by a senior representative from within NLaG. Where this is not possible, the organisation where the death was declared are to nominate an appropriate chair for the child death review process. This person should have designated time assigned for this within their job plan and be competent in undertaking this duty.

If the medical lead health professional also had overall clinical responsibility for the child, the role of chair should be delegated to another colleague to avoid any perceived conflict of interests.

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

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.

It is the responsibility of the organisation responsible for the declaration of death to arrange the CDRM and ensure that an appropriate chair is in place.

6.3 Who should attend the child death review meeting?

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

- Hospital or community healthcare staff involved with the child at the end of his/her life, and those known to the family prior to this event.
- Pathologist, if a post-mortem examination has taken place, or placental histology has been reported in the case of a neonatal death.
- Other professional peers from relevant hospital departments and community services.
- Patient safety team if a serious incident investigation has taken place.
- Coroner's officer if the case has been referred to the coroner.
- The Key Worker.
- CDR Manager for the relevant area.
- Senior investigating police officer if there is a JAR.
- Other practitioners for example social work, ambulance and fire services, primary care clinicians, school nurse, educational representative, Hospice, representatives from voluntary organisations.

If a JAR has already taken place, if required, the same representatives should be invited to the CDRM.

NHS Trusts should note that, where practically possible, children's deaths should be discussed at an individualised meeting, and that matters of morbidity should be considered separately.

If certain professionals are unable to attend, they will be required to submit a report to the meeting.

6.4 Where should the CDRM be held?

The CDRM should take place in a confidential space, using the appropriate technology, or face to face as required for full contribution by the membership.

6.5 When should the meeting occur?

The meeting should take place once investigations (e.g., any NHS serious incident investigation or post-mortem examination) have concluded, and reports from key agencies and professionals unable to attend the meeting have been received.

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 CDRM should occur before any coroner's inquest, and before the CDOP meets.

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

6.6 Family engagement in the child death review meeting

Parents should not attend this meeting to allow full candour among those attending.

Therefore, it is the responsibility of the Key Worker to inform the parents of the meeting and to capture any questions and concerns they would like the meeting to consider. The key worker will contribute this information and questions on their behalf. Feedback from the CDRM to the family will be considered at the meeting and may require further clarification from a Paediatrician/ Obstetrician/neonatologist as required dependant on case. This will be done in a timely manner following the meeting to keep the family as informed as possible.

In a coroner's investigation, such liaison should take place in conjunction with the coroner's office, bearing in mind that the conclusion on the cause of death in such cases is the responsibility of the coroner at inquest.

The full role of the key worker can be found on pages 18-19 of this guidance.

6.7 The Next Steps

Notes of the meeting should be taken to help with completion of the draft analysis form taken to CDOP which should ideally take place within 6 weeks. The CDR administrator will minute the meeting and upload any relevant materials to eCDOP.

7. The Child Death Overview Panel

7.1 Panel Responsibilities

The functions of CDOP include:

- to analyse the information obtained, including the report from the CDRM (Draft analysis form, previously Form C), to confirm or clarify the cause of death, to determine any contributory factors, and to identify learning arising from the CDR process that may prevent future child deaths.
- to consider the following questions:
    - What was the service provision for the child in life and immediately around their passing?
    - What support was provided to the child in life and immediately around their passing?
    - Were there any identified social issues that were relevant to the child's death?
    - What support was provided to the family?
- to make recommendations to all relevant organisations where actions have been identified which may prevent future child deaths or promote the health, safety and wellbeing of children.
- to seek assurance from partner organisations that actions identified in all completed statutory investigations (e.g., HSIB, SI) have been implemented.
- to ensure the Child Safeguarding Practice Review Panel and local Safeguarding Partners have been notified when child abuse (including neglect) is suspected.
- to notify the doctor who certified the cause of death, if it identifies any errors or discrepancy in an individual child's registered cause of death. Any correction to the child's cause of death would only be made following an application for a formal correction.
- to provide specified data to the National Child Mortality Database.
- to produce an annual report for CDR partners on local patterns and trends in child deaths, any lessons learnt, and actions taken, and the effectiveness of the wider child death review process; and
- to contribute to local, regional and national initiatives to improve learning from child death reviews, including, where appropriate, approved research carried out within the requirements of data protection.

7.2 Panel Membership

The Northern Lincolnshire CDR partners have identified the following as members of the Child Death Overview Panel

Required member	Job title	Organisation
Chair	Director of Public Health	North and North East Lincolnshire Council
Vice Chair	Public Health Consultant	North or North East Lincolnshire Council
Child Death Review Manager		North and North East Lincolnshire Council
Child Death Review Administrator(s)		North Lincolnshire Council and North East Lincolnshire CCG
Designated Doctor for Child Deaths		Northern Lincolnshire and Goole Hospitals
Designated Doctor or Nurse for Safeguarding Children	Designated Nurse	North East Lincolnshire CCG
	Designated Nurse	North Lincolnshire CCG
Senior Nurse and/or Midwife	Head of Midwifery	Northern Lincolnshire and Goole Hospitals

Primary care representative	Named GP	North East Lincolnshire CCG
	Named GP	North Lincolnshire CCG
Police	DCI	Humberside Police
Children's Social Care	Service Manager	North Lincolnshire Council
	Service Manager	North East Lincolnshire Council
Education services	Head of Access and Inclusion	North Lincolnshire Council
	Principal Educational Psychologist	North Lincolnshire Council
	Head of Young People Support	North East Lincolnshire Council
Lay Representative		Also Lay Member for NLCCG Governing Body
Hospice	Director of Clinical Services	St Andrew's Hospice

Other professionals will be included in the membership of the CDOP on a case-by-case basis, or to inform specific discussions.

For more detail on roles and responsibilities of CDOP members please see Appendix 4 (page 60 – 62) of the Child Death Review – Statutory and operational Guidance (England) (2018)

See Appendix G: Useful Documents for the CDOP TOR.

7.3 Reviewing deaths of non-resident children

Legislation allows for CDR partners to make arrangements for the review of a death in their area of a child not normally resident there. In all cases, the CDR partners in the area where the child is normally resident is responsible for ensuring that a review takes place at CDOP level. Consideration should also be given to where the most learning can take place, and this may sometimes dictate that a different CDOP to the area where the child is normally resident leads the discussion.

Any learning arising from the CDR process of a non-resident child will be shared with the child death review manager of the area of which the child is resident. Northern Lincolnshire CDR partners would expect a recipient arrangement.

7.4 Themed Panels

Some child deaths may be further reviewed post CDOP at a themed meeting. The arrangements in Northern Lincolnshire underpinned by a Letter of Understanding is for East Riding CDOP, Hull CDOP and North Yorkshire and York CDOP with Northern Lincolnshire CDOP to collectively review child deaths from a particular cause or group of causes.

7.5 Involvement of families and carers

Parents and or carers will not attend CDOP neither will the Key worker. Parents should be informed by their key worker that the review at CDOP will happen, and the purpose of the meeting should be explained. Care and compassion are 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. It should be made clear that the meeting discusses many cases, and that all identifiable information relating to an individual child, family or carers, and professionals involved is redacted. Although, it should also be explained to parents the anonymous nature of the CDOP review means it will not be possible to give them case specific feedback, agreed feedback will be provided to the families by the keyworker.

Should cases be challenged by the CDOP panel for further questioning, any further feedback to families must be agreed by the CDOP panel and delivered by the designated doctor for child deaths, to the families.

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.

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

8. Family Engagement and Bereavement Support

8.1 Introduction

Professionals have a duty to support and engage with families at all stages in the review process. Parents and carers should be informed about the review process and given the opportunity to contribute to investigations and meetings and be informed of their outcomes.

All staff in all agencies and organisations have a duty to support bereaved parents and carers after their child's death and to show kindness and compassion. Where there have been issues with the quality of care provided, healthcare organisations have a duty of candour to explain what has happened, to apologise as appropriate, and to identify what lessons may be learnt to reduce the likelihood of the same incident happening again. This provision should extend beyond the medical sector to any instances of error in the care of the child.

8.2 The team around the family

8.2.1 Key Worker

The statutory processes that follow the death of a child are complex, particularly when multiple investigations are required. Recognising this, all bereaved families should be given a single, named point of contact to whom they can turn for information on the CDR, and who can signpost them to sources of support. This will be the key worker.

Once a notification of a death has been received the CDR Manager will review the child's records to determine who might be best placed to support the family. This may be the professional who has had the most contact with the family. If the child died in the community and had little continuity of contact with professionals, it may be more appropriate for the SUDIC nurse to carry out this role.

The CDR Manager is responsible for:

- Identifying the most appropriate professional to act as key worker
- Liaising with the most appropriate professional to ensure they understand the role of a key worker
- Informing the CDR administrator of the key workers name for eCDOP purposes
- Seeking outcomes from investigations and updating the key worker accordingly
- Acting as a point of contact for the key worker when required.

It is the duty of the key worker to ensure the family receive clear, consistent information. The Key worker will have an intermediate role between the family and all professionals involved in the CDR process to ensure that advice and information relayed is not conflicting. The key worker must be linked into the CDR process via the CDR administrator/manager and/or the nurse lead health professional.

Key worker responsibilities include:

- Being a reliable and readily accessible point of contact for the family after the death
- Facilitating the co-ordination of meetings between the family and professionals as required

- Providing information, updates and outcomes on the child death review and investigations carried out
- Liaising with the CDR administrator to provide a brief, written overview of the visit details and any feedback for eCDOP purposes
- Signpost to bereavement support if required
- Conducting a first visit to the family within 7 days after the death of the child. If a JAR is required, a visit should take place 48 hours after this meeting for an update to be provided.
- Between the final child death review meeting and the CDOP the key worker should seek feedback from the family regarding how the process has been for them and what could be improved.

8.2.2 A medical lead health professional

Following discussion with the family, should the need arrive, a consultant neonatologist or paediatrician should be identified after a 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 CDR administrator/manager and/or nurse lead health professional to arrange:

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

8.2.3 Other professionals

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.

8.3 What should bereaved families expect when their child dies?

Providers, e.g., all practitioners and services, should ensure that bereaved families and carers receive the best support possible. Staff involved with the care of a child should also be offered appropriate support and this should be considered based on the details of the case.

When their child dies, bereaved parents or carers should:

- be given the contact details of their key worker and/or the identity of their medical lead health professional
- be given the appropriate literature including When a Child Dies: A guide for parents and carers (2018)
- 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).

- be supported by the Key worker to understand the child death review process and how they can contribute to it

9. Specific situations

9.1 Children with learning disabilities

For the CDR, children with Learning disabilities aged 4-17 years are within the scope of the LeDeR process.

The child death review process will be the primary review process for children with learning disability and it will not be necessary for the LeDeR programme to review each case separately.

For more information on the LeDeR process please visit the NHS England Website.

9.2 Suicide

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 JAR.

The CDRM should include experts in mental health and key professionals involved in the child's life across education, social services and health.

9.3 Further Information

Please see the appendixes for information on deaths to be reviewed in circumstances of:

- Deaths overseas of children normally resident in England (Appendix C)
- Deaths of children in adult healthcare settings (Appendix D)
- Inpatient Mental Health settings (Appendix E)
- Deaths in custody (Appendix F)

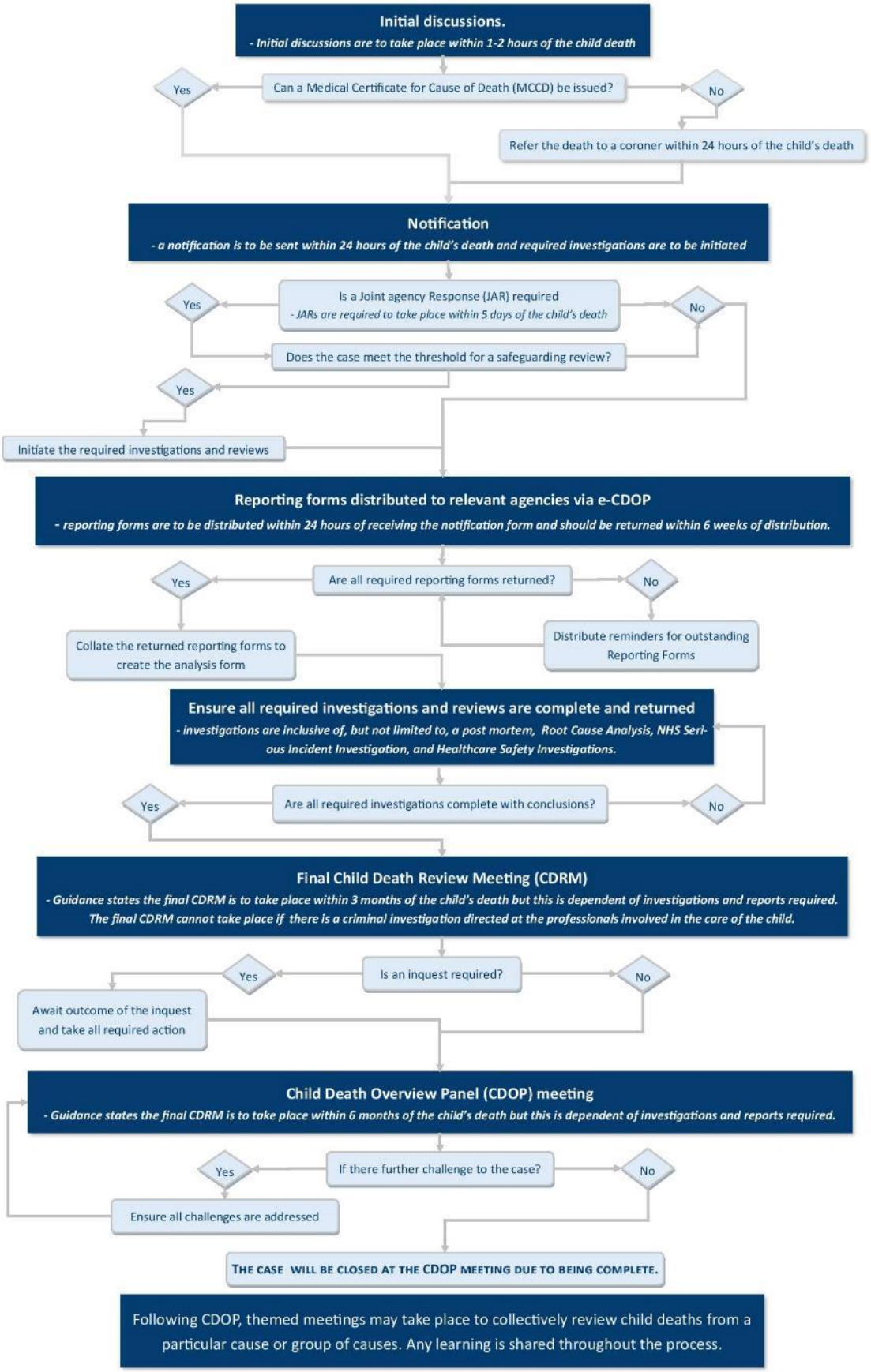
10. Glossary

Word or Phrase	Definition
Attending Doctor	The attending doctor is the individual who attends the death of the child and issues an MCCD or referral to the coroner. The attending doctor may be a GP, attending paediatrician or medical lead.
Child	The child death review process covers children; a child is defined in the Act as a person under 18 years of age. A child death review must be carried out for all children regardless of the cause of death. This includes the death of any live-born baby where a death certificate has been issued. If the birth is not attended by a healthcare professional, child death review partners may carry out initial enquiries to determine whether or not the baby was born alive. If these enquiries determine that the baby was born alive the death must be reviewed. For the avoidance of doubt, it does not include stillbirths, late foetal loss, or terminations of pregnancy (of any gestation) carried out within the law. • Stillbirth: baby born without signs of life after 24 weeks gestation • Late foetal loss: where a pregnancy ends without signs of life before 24 weeks gestation Cases where there is a live birth after a planned termination of pregnancy carried out within the law are not subject to a child death review.
Child Death Review Partners	"Child death review partners" ("CDR partners") are defined in section 16Q of the Children Act 2004 and means, in relation to a local authority area in England, the local authority and any CCG for an area any part of which falls within the local authority area. CDR partners for two or more local authority areas in England may agree that their areas should be treated as a single area. The responsibilities of CDR partners regarding the child death review process are set out in sections 16M-Q of the Children Act 2004. CDR partners must also have regard to this guidance and Chapter 5 of Working Together. (Sections 16M-Q of the Children Act 2004 have been inserted by sections 24-28 of the Children and Social Work Act 2017.)
Coroner	A Coroner is a judicial officer who makes inquiries into all sudden, unexpected or unnatural deaths.
Embrace	Embrace is a highly specialist, round-the-clock transport service for critically ill infants and children in Yorkshire and the Humber who require care in another hospital in the region or further afield.
Healthcare Safety Investigation Branch (HSIB)	Healthcare Safety Investigations Branch (HSIB) carries out independent investigations into safety concerns that occurred after 1 April 2017, within NHS funded care in England. Its objective is to be thorough, independent and impartial in Child Death Review. 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.
Inquest	The coroner's inquiry to confirm who has died, when and where, and to decide if a cause of death can be established.
Learning Disabilities Mortality Review (LeDeR)	The Learning Disabilities Mortality Review (LeDeR) programme describes a review process for the deaths of people aged 4 years and over with learning disabilities in England. 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
Medical Certificate of Cause of Death (MCCD)	An official certificate that enables the deceased's family to register the death, provides a permanent legal record of the fact of death, and enables the family to arrange the funeral. It provides information on the relative contributions of different diseases to mortality
Medical Examiner	A medical practitioner appointed as medical examiner whose responsibility is to ensure that the cause of death is accurately recorded by the attending practitioner (doctor) on the MCCD; that timely and appropriate referral to the coroner has occurred where appropriate; engage with the bereaved to understand any concerns; and to ensure that possible clinical governance concerns have been highlighted.
National Child Mortality Database (NCMD)	The National Child Mortality Database (NCMD) will be a repository of data relating to all children's deaths in England. Once operational it will enable more detailed analysis and interpretation of all data arising from the child death review process, to ensure that lessons are learned following a child's death that learning is widely shared, and that actions are taken, locally and nationally, to reduce child mortality. Once operational, CDR partners should instruct their Child Death Overview Panel to submit copies of all completed forms associated with the child death review process and the analysis of information about the deaths reviewed (including but not limited to the Notification Form, the Reporting Form, Supplementary Reporting Forms and the Analysis Form) to the National Child Mortality Database. In the interim period, for child deaths prior to the NCMD becoming operational in April 2019, CDR partners should ensure that CDOPs return data (LSCB1 data) to NHS Digital, arrangements for this will be notified separately and detailed on the Child Death Review webpage.
Perinatal Mortality Review Tool (PMRT)	The PMRT is a web-based tool that is designed to support a standardised review of care of perinatal deaths in neonatal units from 22+0 weeks gestation to 28 days after birth. It is also available to support the review of post-neonatal deaths where the baby dies in a neonatal unit after 28 days but has never left hospital following birth. At clinicians' discretion it might also be used for the review of deaths of live-born infants
Stillbirth	A stillbirth is a baby born without signs of life after 24 weeks gestation
SUDI/SUDC (sudden unexpected death in infancy/childhood)	A descriptive term used at the point of presentation for the death of an infant or child whose death was not anticipated as a significant possibility 24 hours before the death, or where there was a similarly unexpected collapse leading to or precipitating the events which led to the death3. At the conclusion of an investigation, they will divide into those for which we have a clear diagnosis (explained SUDI/SUDC) and those for which we do not have a diagnosis (SIDS up to 12 months of age, and sudden unexplained death in childhood for children over 12 months).
Unexplained deaths	Where, following a complete investigation by a coroner, no specific cause of death (whether natural or external) has been found, a death may be considered unexplained4. This will include those deaths meeting the

	internationally agreed definition for sudden infant death syndrome5 (SIDS), and those registered as unascertained

11. Appendix A: Child Death Review Process Flowchart



12. Appendix B: Table 1 of the SUDI/C Guidelines

Table 1. Routine suggested samples to be taken immediately after sudden unexpected deaths in infancy and childhood

Note that such samples in most cases will fall under the jurisdiction of HM Coroner, and hence communication with the coroner's office 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. The samples listed in this table should be taken in all SUDI cases.[34,35,39] [B]

In unexpected deaths in older children, the appropriate clinical samples will be guided by the circumstances of the death and the clinical findings. [C]

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

* 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. [C]

** Appropriate interpretation of microbiological and virological results after SUDI remains difficult, with significant variation by group and individual.[40] [B]

*** If indicated based on clinical history or examination. [C]

\# Samples must be sent to an appropriate virological laboratory. [C]

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

- 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 [C]

- 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.

13. Appendix C: Deaths overseas of children normally resident in England

13.1 Introduction and Principles

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

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

13.2 Investigations

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

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

13.3 Foreign and Commonwealth Office (FCO)

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. If a child who is a British national, dies abroad, the child's family should notify the local authorities and the UK Embassy, High Commission, or Consulate in the country where the child has died. The family can also contact the FCO directly.

Diplomatic officials in these offices will, when notified of a death, advise relatives how to register the death (abroad and/or in the UK); advise on how to repatriate the body using local or international funeral directors, and give guidance relating to bereavement support. Their staff will also notify the coronial liaison officer at the FCO.

The FCO collects routine information about each death such as name, date of birth, address, known cause of death, and the welfare of other siblings. It is customary practice for the FCO to also notify the relevant CDR partners and CDOP where the child was normally resident if a UK address is provided to them. The FCO will only be aware of a death if the family, local authorities or other interested party notifies them. The FCO can be contacted on Coroner.LiaisonOfficer@fco.gov.uk, or in an emergency 0207 008 1500 (ask for Consular).

14. Appendix D: Deaths of children in adult healthcare setting

14.1 Introduction and principles

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

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

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

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

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

Most 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. To avoid confusion for families and clinical staff, the general expectations arising from Learning from Deaths apply to children who die on adult ICUs, with the following essential caveats:

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

15. Appendix E: Inpatient Mental Health Settings

15.1 Introduction and Principles

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).

All deaths of children in inpatient mental health settings will trigger a JAR.

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

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

15.2 Child Death Review Process

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

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

15.3 Child Safeguarding Practice Reviews

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

15.4 Involvement and Support to Parents, Carers and Staff

As in any child death review process, there should be meaningful involvement of families. 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.

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

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

16. Appendix F: Deaths in Custody

16.1 Introduction and Principles

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

16.2 The Prisons and Probation Ombudsman

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

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.

16.3 The PPO and NHS England

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.

The Children and Young People Secure Estate is a national resource, and children can be placed anywhere within the estate and may not be placed within their local area. Learning from child deaths

in custody is important not just in terms of the health commissioner and secure setting, but also in terms of how placement decisions are made in the future.

16.4 Local NHS England response

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

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.

16.5 Deaths in Custody and the Child Death Review Process

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

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