



Waltham Forest, East London and the City (WELC) Child Death Review System

Standard Operating Procedure September 2019



How to Notify the WELC CDR Hub team of a Child's Death

It is a statutory requirement to notify the Child Death Review Statutory Partners of all child deaths from birth up to their 18th birthday.

If you become aware of a the death of any child within the WELC footprint or of a child usually resident within the WELC footprint (who has died elsewhere), please notify the WELC Child Death Review (CDR) Hub team about a child death AS SOON AS POSSIBLE – using the electronic reporting system called eCDOP which can be accessed at: <https://www.welc.co.uk/WELC/xxx>

This link takes you straight to the 'Notification of Child Death' form. You do not need a user name or password to access this form. Please complete as much of the information requested as possible. Sections marked with a red Asterix are mandatory.

Once completed please press the submit button and you will see a message confirming that the form has been sent to the WELC CDR Hub Team. At this stage you also have the option to save a copy for your own records.

If you have any difficulties in using eCDOP to notify the CDR Hub Team, please contact the CDR Hub Team on xxx xxxxxx. You can also email them using one of the following:

- Yeba.Forbang@Hackney.gov.uk
- nicolaneedham@nhs.net (Newham)
- xxx.xxxx@nhs.net (Tower Hamlets)
- Bella.Lowen@walthamforest.gov.uk

Ownership and revision of this procedure

This *WELC Standard Operating Procedure* is owned by the WELC CDR Partners, who have responsibility for the WELC CDR System. It is prepared and published on their behalf by the WELC CDR Hub team. The procedure will be updated annually or as required by national/legislation changes, by the WELC CDR Hub team. The next revision date is 31 March 2020.

Proposals for additions or amendments to this edition should be directed to the WELC CDR Hub Team at xxxxxxxxxxxx, London xxxxx; or using the Hub team emails above.

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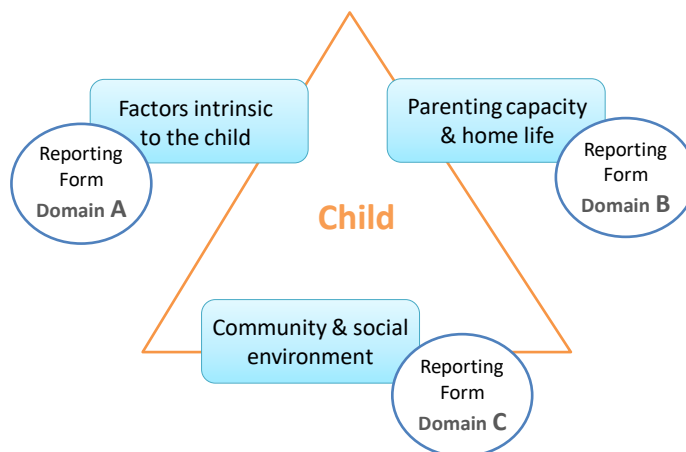
Quick guide to this procedure

This quick guide briefly describes the whole child death review (CDR) process. The primary objective for a child death review is to gather, analyse and learn from information which will help understanding of the circumstances (historical and recent) which led to the child's death.

The CDR process uses a Reporting Form to gather this information. The Form is designed to build a holistic picture of the child and any support which was or should have been available to him or her and his/her family, in the years, months, weeks and hours prior to the child's death (see the form in appendix 5).

The information is helpfully divided into: factors intrinsic to the child (Domain A); factors related to parenting capacity and home life (Domain B); factors relating to the community and social environment (Domain C); and finally, the accessibility and quality of services needed by the child and his or her family prior to the child's death (Domain D). Figure 1 illustrates the domains relating to the child.

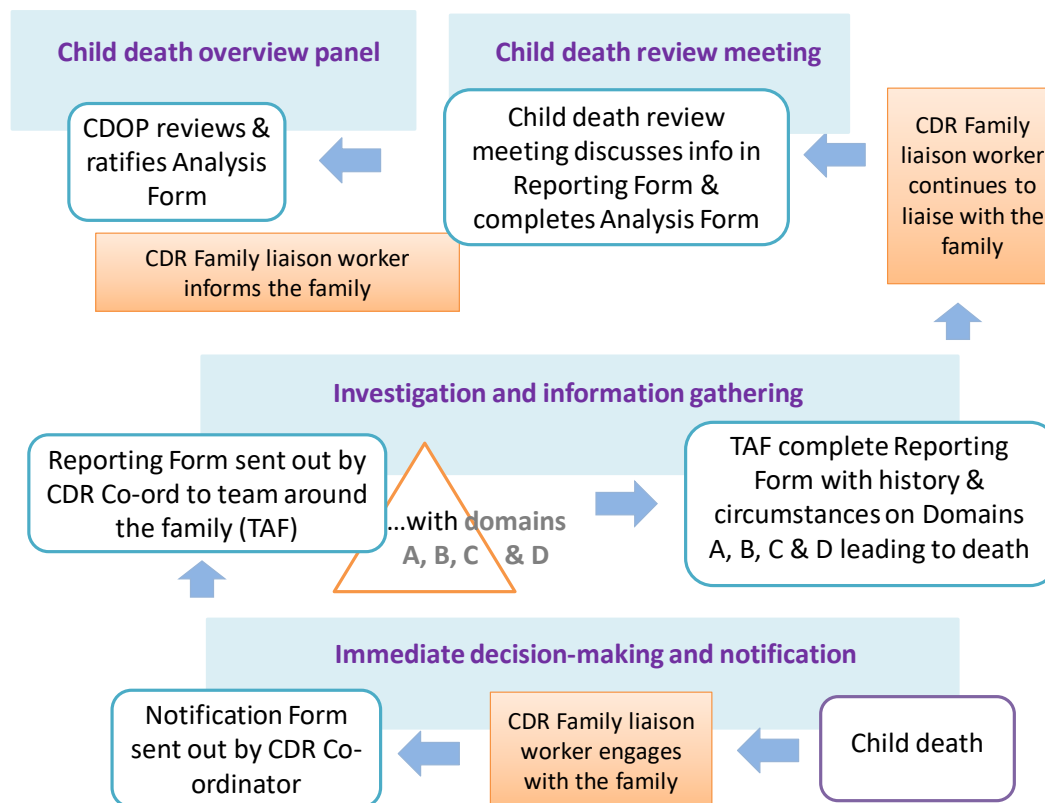
Figure 1



For child death reviews to be meaningful, the information must be gathered on all four domains with as few gaps as possible. This is in order to enable good quality learning for the best chance of preventing future child deaths

There are four main stages in the child death review process. These are illustrated in figure 2. and explored in detail in chapters 4-8.

Figure 2



The WELC CDR process is managed using eCDOP. This is illustrated in figure 4 and described in chapter 3, section 3 eCDOP

Chapter 1 describes the purpose and status of this procedure; and the anticipated audience. It identifies related guidance, sets out the principles underpinning the WELC CDR System and the procedure; and finally, defines commonly used terms.

Chapter 2 emphasises the primary importance throughout the whole child death review process of the family who have lost their child. Family Liaison support for them is critical. It also enables them help professionals understand the child's past and recent circumstances and experience of service support (as outlined in figure 1).

Chapter 3 provides an overview of the WELC CDR System structure and systems. It also describes the central role of the eCDOP IT system in helping CDR professionals manage the child death review process effectively and respectfully. Good use of eCDOP is critical for recording, storing, communicating and reporting information across the WELC CDR System and beyond.

Chapter 4 describes the immediate decisions to be taken after the death of a child, such as:

- How best to support the family – beginning with allocating a CDR Family liaison worker to keep them informed about the processes and outcomes and signpost them to sources of support

- Whether a medical certificate of cause of death (MCCD) can be issued, or whether a referral to the coroner is required; and
- Whether the death meets the criteria for a Joint agency response (JAR); a local Child safeguarding practice review (CSPR); and/or an NHS Serious incident investigation.

A number of notifications should be made (using the Notification Form); including, importantly, to the WELC CDR Hub Team.

Chapter 5 describes the investigation and information gathering (using the Reporting Form) – see figure 1, above. The chapter also summarises other investigations that may run in parallel to the CDR process:

- Coronial investigation
- Joint agency response (JAR) a local Child safeguarding practice review (CSPR)
- NHS Serious incident investigation.

Post-mortem examinations may be required in a number of cases.

Chapter 6 describes the child death review meeting (CDRM). It is multi-disciplinary and multi-agency discussion of the death of a child by the professionals who were directly involved in the care of that child during his or her life and those involved in the investigation into his or her death. The discussion is based on – and can contribute additional information to – the completed Reporting Form (figure 1). The output from the CDRM will be a completed draft Analysis Form.

The CDRMs should be flexible and appropriate to the circumstances of the child's death. It could take the form of a case discussion following a JAR; a hospital-based mortality meeting following the death of a child in a paediatric intensive care unit or a perinatal mortality review meeting in the case of a baby who dies in a neonatal unit.

Chapter 7 describes the case pathways which arise from the range of potential locations or circumstances in which a child may die. These include babies transferred between neonate units; in the community (as a result of illness or violence including suicide); in a mental health or adult healthcare setting; in state detention or police custody; and out of area or country.

Chapter 8 describes the statutory requirements and functions of the CDR partners; in particular the child death overview panel (CDOP). The CDOP should conduct an independent multi-agency scrutiny of deaths of children normally resident in the WELC footprint and, if appropriate and agreed between CDR partners, the deaths of children not normally resident in their area but who have died there. The discussion is based on the draft Analysis Forms which the CDOP ratifies as standardised outputs to enable thematic learning at national level.

Chapter 9 describes LeDeR reviews – which should be seamlessly integrated into the CDR process outlined in this procedure. These are reviews of the deaths of children aged 4-17 years, who had learning disabilities or who were very likely to have had learning disabilities, but had not yet had a formal assessment for this.

[Chapters 10](#) describes the supervision and training which should be in place to support staff in order that they can respond well to bereaved families and to the requirements of the child death review process.

[Chapter 11](#) sets out the arrangements for quality assurance which are in place so that the WELC CDR System can maintain a consistently high standard of review and learning – in respectful acknowledgement of the children who have died and their families.

WELC Standard Operating Procedure

1. Preface and introduction

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

These *WELC Child Death Review Procedures* are commissioned by the Statutory Child Death Review (CDR) Partners to underpin the WELC CDR System. The Partners to the WELC CDR System are the local authorities of Waltham Forest, East London (Hackney, Newham and Tower Hamlets) and City; together with the NHS Waltham Forest, Newham and Tower Hamlets; and Hackney clinical commissioning groups (CCGs). For information on CDR Partnerships see the Glossary; roles and responsibilities in section 1.5.

1.1 Purpose and status

1.1.1 Purpose of the procedures

These *WELC Child Death Review Procedures* set out key features of how individuals and organisations in the WELC footprint should work together to:

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

A child death review must be carried out regardless of the cause of death. The child death review process described in this procedure covers children defined in the Children Act 2004 as a person under 18 years of age; but excluding deaths in some circumstances – for exclusions see the Glossary; roles and responsibilities in section 1.5.

1.1.2 Status of this procedure

The statutory requirements of the CDR Partners are set out in sections 16M to 16P of the Children Act 2004. Chapter 9 of this procedure builds on the statutory requirements, taking in the Child Death Review guidance in chapter 5 of *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children* (July 2018).

Key elements of the requirements are that the CDR Partners must:

- a) Make arrangements to review all deaths of children normally resident in the local area (i.e. the WELC footprint) and, if they consider it appropriate, for any non-resident child who has died in their area;

- b) Make arrangements for the analysis of information from all deaths reviewed. The purpose of a review and/or analysis is to identify any matters relating to the death, or deaths, that are relevant to the welfare of children in the area or to public health and safety, and to consider whether action should be taken in relation to any matters identified;
- c) Inform a person or organisation where they find that that person or organisation needs to take action to avoid future child deaths. In addition, CDR partners may request information from a person or organisation for the purposes of enabling or assisting the review and/or analysis process – the person or organisation must comply with the request, and if they do not, the child death review partners may take legal action to seek enforcement; and
- d) Prepare and publish reports appropriately timed and informative on a) to c) above.

1.2 Who should read this procedure

Chief Executives of clinical commissioning groups (CCGs) and local authorities should ensure that all of their staff who are involved in a child death review read and follow them. The Procedures target audience includes other frontline staff (including unqualified staff and volunteers) and managers in all organisations in the event that:

- a) A child dies whilst in contact with them, receiving a service from them or on their premises; and /or
- b) They are being asked to contribute information about a child who has died;

so that they can respond to each child death appropriately. This includes people working within:

- Health services (across all sectors: acute, maternity, mental health, primary care and community);
- Children's social care services;
- Police, including British transport police, and royal military police;
- Coronial services;
- Education; and
- Public health.

1.3 Related guidance and procedures

These include:

- *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children* (July 2018) (*Working Together*) – statutory guidance covering the legislative requirements and expectations on multi-agency services to safeguard and promote the welfare of children.
- *Sudden unexpected death in infancy and childhood: multi-agency guidelines for care and investigation* (2016) (SUDI/C Guidelines) – statutory guidance covering the

statutory duties to investigate all sudden and unexpected deaths in infancy and childhood from a health perspective (Royal Colleges of Pathologists, and Paediatrics and Child Health)

- *National Guidance on Learning from Deaths. A Framework for NHS Trusts and NHS Foundation Trusts on Identifying, Reporting, Investigating and Learning from Deaths in Care* (2018) – a framework for NHS Trusts and Foundation Trusts on identifying, reporting, and learning from deaths; particularly the deaths of inpatients, people with learning disabilities, or serious mental health conditions. For the deaths of children Trusts should follow the child death review process set out in this guidance when reviewing the death of a child.
- *Guidance for the conduct of local reviews of the deaths of people with learning disabilities* (2017) – the Learning Disabilities Mortality Review (LeDeR) Programme has been set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England through local reviews of deaths of people with learning disabilities and improvement activity as appropriate. (Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England).
- *Learning from deaths: Guidance for NHS trusts on working with bereaved families and carers* (2018) – advice for acute, mental health and community Trusts (and services commissioned by NHS specialised commissioning) on how they should support, communicate and engage with families and carers following a death of someone in their care and focusses on engagement when a death is subject to an investigation.
- *When a Child Dies: child death review guide for parents and carers* (2018) – a guide for parents, families, and carers to help understand and navigate the child death review process,

1.4 Underpinning principles

The principles of the WELC CDR System, including in this procedure, are that:

- a) The contribution of the family is essential for informing each child death review and any consequent learning and improvement activity.
- b) Each child death review requires multi-disciplinary and multi-agency input to inform a holistic understanding of the child's life, giving equal weight to all sources of information.
- c) Development of a holistic understanding of the child includes review of the past, recent and final experiences and circumstances in his/her life.
- d) Reviews of deaths should lead to reflective learning and pro-active involvement in improving services and children's life-chances by all relevant local disciplines and agencies.
- e) This is a public health approach to child death review i.e. aiming to prevent future child deaths by reducing inequalities (as well as through improved service responses).

1.5 Links to Barking & Dagenham, Havering and Redbridge (BHR) CDR

Relatively frequently a death has been declared within the WELC footprint, for a child normally resident in BHR. The WELC CDR System should work closely with the BHR CDR system in order to align the cross-border CDR activity. This should be aimed at assisting the NHS provider trusts respond to child deaths and participate in child death reviews and investigations effectively and efficiently

2. Family Engagement and Bereavement Support

Reviewing the deaths of children is a statutory duty; every family has the right to have such reviews undertaken sensitively. Accordingly professionals have a duty to support and engage with families at all stages in the review of their child's death. Parents and carers should be informed about the review process, given the opportunity to contribute to investigations and meetings, and be informed of the outcomes from the post-mortem examination and/or other investigations, where relevant; and the CDRM.

2.1 The team around the family (TAF)

Within 24 hours of a child's death all bereaved families must be offered a CDR Family liaison worker and a Medical lead (either the doctor that the family had most involvement with while the child was alive/GP or the Designated doctor for child death/consultant paediatrician on-duty at the time of death); other professionals other professionals may also provide vital support to the family.

Where a death has been declared for a child not normally resident in the WELC footprint, the Designated doctor for child death/consultant paediatrician on-duty at the time of death should take the role of Medical lead, until the CDR Hub team can arrange the handover of the case, to the CDR team in the area where the child was normally resident (see also section 7.6 Out of area).

2.1.1 CDR Family liaison worker

This role is referred to in the national guidance as a 'Keyworker' role.

2.1.1.1 The CDR Family liaison worker performs a pivotal role as a single point of contact (SPOC) for the bereaved family. The CDR Family liaison worker is someone the family can turn to for information on the child death review process, who can signpost them to sources of support and advocate for them, and advocate for the family throughout the CDR process.

2.1.1.2 Deciding who the CDR Family liaison worker will be for a family is the responsibility of the WELC CDR System CDR Hub team. The CDR Hub team must liaise with the professionals attending the child's death to understand whether there is a practitioner who already has a relationship with the family, who the family would prefer to be their SPOC. In the absence of such a professional, the Family liaison worker in the CDR Hub team should offer to take on this role for the family. The organisation where the child was certified dead should help the CDR Hub team decide who should be the CDR Family liaison worker for the family.

2.1.1.3 Where a death has been declared for a child not normally resident in the WELC footprint, the WELC CDR Family liaison worker must commence the role of 'keyworker' for the bereaved family until the WELC CDR Hub team are able to hand over of the case, to the CDR team in the area where the child was normally resident (see also section 7.6 Out of area).

2.1.1.4 The CDR Family liaison worker role could be taken by a range of practitioners. For example:

- In the cases of children with long term conditions, the family may already be well known to a member of a specialty multi-disciplinary team such as a clinical nurse specialist, who could continue in a Family liaison worker role after the child has died.

- In the cases of children with acute conditions the child and family may not have been known to any health care practitioners before the child's admission to hospital. A Family liaison worker could be a member of the bereavement support team, a community health professional, a social worker or a voluntary and community sector practitioner.
- In criminal and coronial cases, the police family liaison and coroner's officer respectively provide support to the family in relation to all elements of those investigations. In such situations, the police family liaison and coroner's officer must keep the CDR Hub Team informed and request additional support for the family if required.

2.1.1.5 Regardless of professional background the practitioner undertaking the CDR keywork role should:

- Be a reliable and readily accessible point of contact for the family after the death;
- Help co-ordinate meetings between the family and professionals as required;
- Have oversight of the CDR process and be able to give this information to the family in a timely way throughout;
- Be able to provide information on the child death review process and the course of any investigations pertaining to the child;
- Liaise as required with the coroner's officer and police family liaison officer e.g. seeking advice about what information can be shared with the family in suspicious cases;
- Advocate for the parents/family, representing their 'voice' at professional meetings, ensuring that their questions are effectively addressed, and providing feedback to the family afterwards; and
- Consider with the family whether they (parents/cares and/or siblings) might need bereavement support and signpost to expert bereavement support if required; including making referrals to Mental health services.

2.1.1.6 If the practitioner undertaking CDR keywork role is not the CDR Family liaison worker, then the CDR Family liaison worker should have oversight and work in partnership with the professional who is providing keywork support to the family.

2.1.2 Medical lead

The Medical lead (either the doctor that the family had most involvement with while the child was alive/GP or the Designated doctor for child death/consultant paediatrician on-duty at the time of death) should liaise closely with the CDR Family liaison worker and arrange:

- Follow-up meetings at locations and times convenient to the family; and
- Clinical expertise (via other professionals if necessary) to be able to:
 - Answer questions relating to the medical, nursing or midwifery care of the child

- Explain the findings, where relevant, of the post-mortem examination and /or other investigations; and
- Report back the outcome from the CDRM.

Deciding who the Medical lead will be for a family must be decided jointly by the relevant NHS acute trust and the child's GP.

2.1.3 Other professionals

At the time of a child's death, other professionals may also provide vital support to the family. The CDR Hub Team should identify other professionals who can support the bereaved family. The organisations with whom the child had contact before his/her death have responsibility for assisting the CDR Hub team decide who is best to provide this support. This could include (but is not limited to) the GP, teacher or early years practitioner, clinical psychologist, social worker, family support worker, midwife, health visitor or school nurse, palliative care team, chaplaincy and pastoral support team; and/or a relevant voluntary and community organisation. The CDR Family liaison worker should help the family understand each professional's role so that that communication remains clear.

2.2 Support for bereaved families

The CDR Family liaison worker must contact the family within 24 hours of the child's death (other than if the death is on a weekend, when the contact must be made on the first working day after the weekend). The Family liaison worker must visit or meet with them (should they want to meet), within 5 working days of the child's death.

Where a death has been declared for a child not normally resident in the WELC footprint, the CDR Family liaison worker must commence the role of 'keyworker' for the bereaved family until the WELC CDR Hub team are able to hand over of the case, and the 'keywork' support, to the CDR team in the area where the child was normally resident (see also section 7.6 Out of area).

2.2.1 Information for families

The CDR Family liaison worker must ensure that as soon as possible after their child has died, all bereaved families are given the leaflet *When a Child Dies – A Guide for Parents and Carers*. The CDR Family liaison worker must offer to go through the leaflet with the family. This is because bereaved families are likely to be in state of extreme shock when their child has died. They may not be able to process or retain what they hear and read; it is usual that information needs to be repeated over time.

All staff in direct contact with bereaved families and carers should be familiar with the contents of the leaflet in order to ensure that bereaved families and carers receive the best support possible.

2.2.2 Practical assistance for families

When their child dies, bereaved families should:

- Have the opportunity to spend time with the child's body in a quiet and private environment. However, if there are any – even very slight – concerns about the death, a hospital staff member must maintain a discrete presence so that the parents/family should not be left alone with the child's body at any time.

See section 5.2.1 – concerns may include: that the death could have been due to external causes; was sudden with no immediate cause; there are suspicions that the death may not have been natural; or it was a stillbirth where no healthcare professional was in attendance);

- Have the opportunity to make memories including taking photographs, hand and foot prints and a lock of hair;
- If they so wish parents and carers should have a member of staff remaining with them to provide comfort and to ensure their basic needs are met;
- Be given the contact details of their CDR Family liaison worker and the identity of their Medical lead; be informed who will be contacting them and when they will be contacted after they leave the hospital or hospice; and what to do should they have any questions in the meantime;
- Know how to make arrangements to view their child's body;
- Be given information about the CDR process by the attending doctor/Designated doctor for child death;
- Be given information on death registration and the coronial process (if applicable);
- Understand why a post-mortem examination may be indicated and, if so, where it is taking place and when the results might be expected. In the event of a coroner's case this responsibility falls to the coroner's officer;
- Be supported to have an understanding of the child death review process and how they are able to contribute to it;
- Be given practical advice in respect to organising the child's funeral;
- Have the CDR Family liaison worker accompany them to meetings to provide practical and emotional support; and
- Be invited to consider whether they need expert bereavement support and supported to access it if required.

2.3 Planning prior to death

2.3.1 Parallel planning

Children with or without life-limiting conditions can 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.

The NHS provider trust responsible for the child should:

- Identify a 'team around the family' (TAF)
- Write an advance care plan; and
- Include in all plans any 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 management¹
- Core care pathway for children with life-limiting and life-threatening conditions²; and
- Perinatal pathway for babies with palliative care needs³.

2.4 An unplanned death (usually in an Emergency Department)

With a few exceptions, children who die unexpectedly in the community will be taken to an Emergency Department. For children who die or are certified dead in the Emergency Department there will usually be a Joint Agency response (JAR) (see chapter 5).

In such circumstances, the members of a TAF should be identified and the family should receive the information and practical assistance outlined in sections 2.1 and 2.2, above. The parents should normally be given the opportunity to hold and spend time with their child in a quiet designated area. However, where there are any – even very slight – concerns about the death, a hospital staff member must maintain a discrete presence so that the parents/family should not be left alone with the child's body at any time.

See section 5.2.1 – concerns may include: that the death could have been due to external causes; was sudden with no immediate cause; there are suspicions that the death may not have been natural; or it was a stillbirth where no healthcare professional was in attendance)

The doctor attending at the time of the death (this may or may not be the Medical lead or the Designated doctor for child death) must ensure that they liaise with the CDR Hub team to ensure appropriate care is provided to the family. The Hub team will act as SPOC for all deaths in WELC EDs. See appendix 1 for detailed guidance relating to support for the family in such situations (sourced from the SUDI/C Guidelines).

2.5 NHS Serious incident investigations and local Child safeguarding practice reviews

Concerns about service delivery may be raised by professionals or the family, in relation to any statutory services which were engaged with the family. The concerns can be raised before or during a child death review. If the concerns are about the NHS and another service (e.g. children's social care, the police), then a referral should be made to the Local Safeguarding Partnership (LSP) for consideration as to whether a CSPR should be initiated. If the concerns are about the NHS service, the NHS provider trust must also initiate an NHS Serious incident investigation (SI).

¹ National Institute for Clinical and Health Excellence, 2016 <https://www.nice.org.uk/guidance/ng61>

² Together for Short Lives, 2013

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

³ Together for Short Lives, 2017

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

Any professional can refer a case for a SI or a local Child safeguarding practice review (CSPR). Where a case meets the criteria for a local CSPR then the CDR process will be put on hold. Equally, should a CDR case identify concerns that require a local CSPR then all the information gathered for the CDR should be shared with the LSP and a decision made on the process to be followed. The CDR Hub should ensure that any independent lead for a SI or local CSPR (or serious case review (SCR)) is linked into the CDR process.

The decision to inform the family about the initiation of a local CSPR, must be taken by the LSP. For a LeDeR case, this should be with input from the LeDeR Local Area Contact (LLAC) and/or LeDeR steering group (see chapter 9 for LeDeR processes).

Where a SI, local CSPR or other investigation/review is initiated, NHS provider trusts must appoint a Case manager to support the CDR Family liaison worker in including contributions from the family appropriately (about the history and circumstances of the death and quality of care received) and ensuring that the family are supported appropriately.

2.6 Support for parents, carers and siblings

The CDR Family liaison worker has responsibility, working with the CDR Hub team if they are not part of the team, to ensure that the family is offered/signposted to bereavement support. In discussing whether a family may need or want bereavement support the CDR Family liaison worker must alert the family to the fact that siblings are known as the 'forgotten mourners' (Smith 1999)⁴ as their grief responses to bereavement are often overlooked.

Appendix 17 includes contact details for local and national charities who offer bereavement support for families. The CDR Family liaison worker should be able to direct families to the most appropriate support services.

⁴ Quoted in Holliday J. *A Review of Sibling Bereavement - Impact and Interventions*. Barnardo's; 2002, p7.

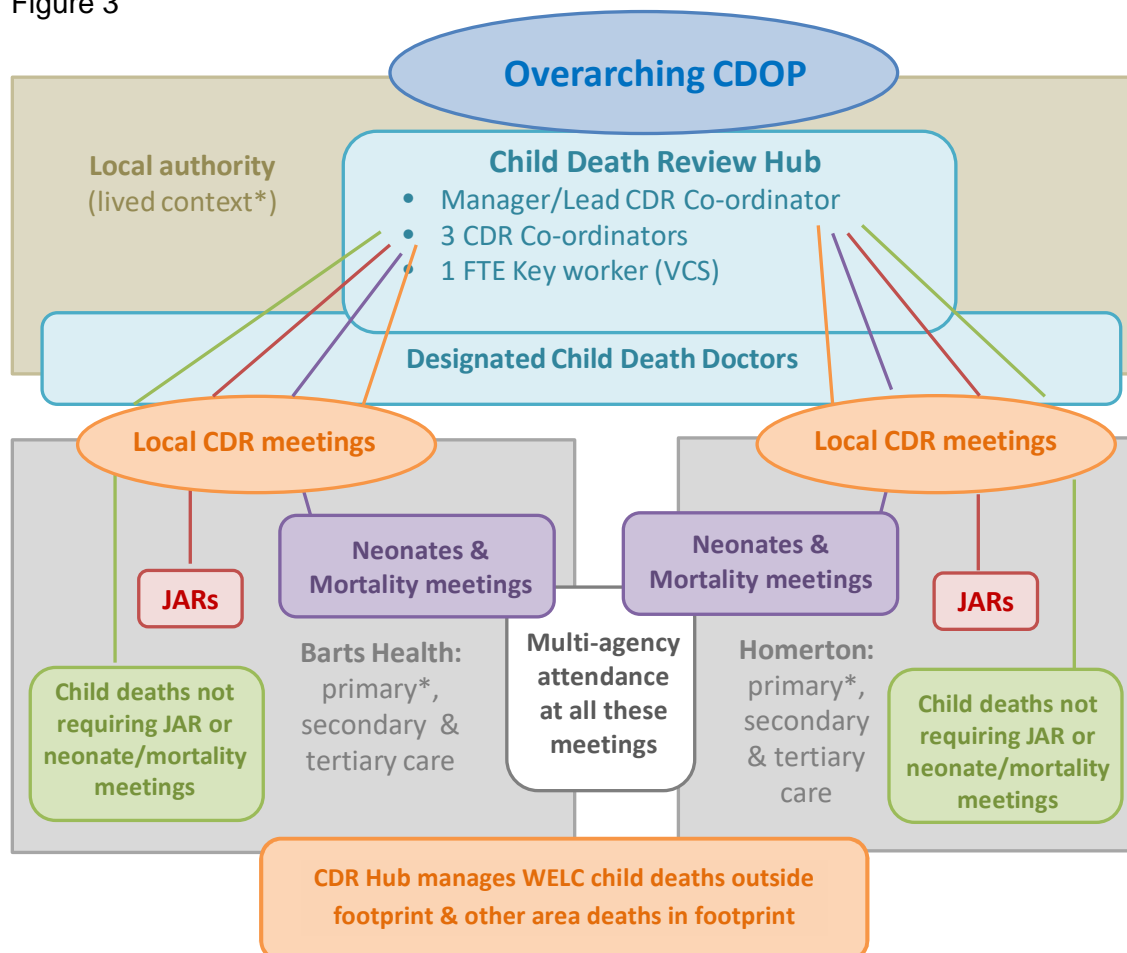
3. Structure and Systems; eCDOP

3.1 WELC CDR System structure

The WELC CDR System is a single CDR System across Waltham Forest, East London and the City (WELC) including the NHS CCGs and their NHS provider trusts (Barts Health and Homerton). The System links with multi-agency partner organisations such as the London Ambulance Service, the Metropolitan Police, the Coronial service, the Metropolitan Police, Children's services, the Mental Health trusts and voluntary and community sector organisations. It also links with national bodies such as the National Child Mortality database (NCMD), the Confidential Enquiry into Maternal Deaths (MBRRACE) and others.

The WELC CDR System is designed to support and enable local professionals to manage the child death review process in an efficient and respectful way. Figure 3 illustrates the WELC CDR System structure.

Figure 3



* Including health visitors, school nurses, GPs, Primary Care Networks; Early years settings, schools and other community groups & organisations.

The System structure recognises that the immediate response and review of child deaths is largely located within the NHS provider trusts (the grey areas in Figure 3) – both within and outside of the WELC footprint; and in primary, secondary and tertiary care settings. In general terms, this brings an important health focus (Domain A, in Figure 1). The System

locates the CDR Hub Team in a local authority in order to balance the focus on Domain A with contextual information (Domains B & C, in Figure 1) which is usually sourced from local authorities and other partners (the brown area in Figure 3).

Information for Domain D. will relate to a service.

3.1.1 The WELC CDOP

The multi-agency Overarching CDOP receives anonymised cases from the CDRMs to identify and embed thematic learning across the WELC footprint. The WELC CDOP is administered by the WELC CDR Hub team.

3.1.2 WELC CDR Hub team

The WELC CDR Hub is located in a local authority – to gather the contextual information relating to children’s home and community lives, complementing the information held by the NHS provider trusts about children’s intrinsic health and wellbeing. The WELC CDR Hub Coordinators maintain a network of contacts in the local authorities and local areas to access information about a child when needed.

3.1.3 WELC CDR Hub Family liaison worker

The WELC CDR Family liaison worker is seconded into the CDR Hub from a child bereavement voluntary sector organisation in line with Local Government Association⁵ and NHS England thinking⁶ that collaboration between the voluntary sector, local government and the NHS is crucial to improving care for people and communities. The CDR Family liaison worker is able to facilitate longer term bereavement support for families, as needed, within their own organisation.

3.2 eCDOP

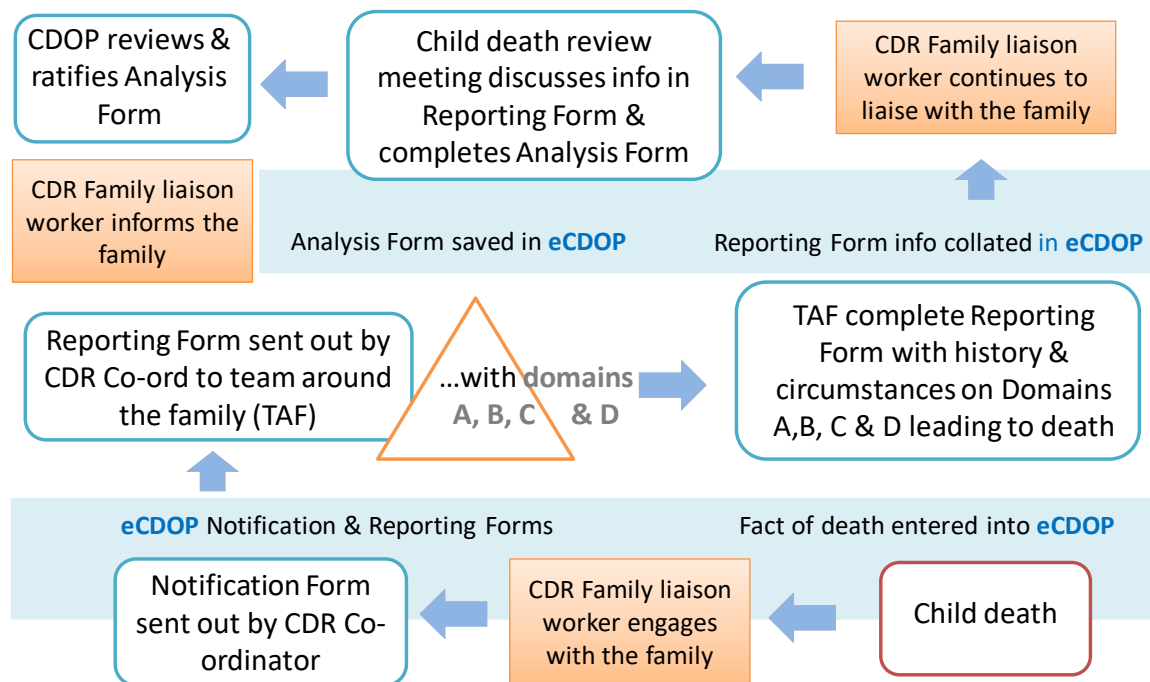
3.2.1 eCDOP’s contribution to the process

In line with national guidance, the WELC CDR System uses eCDOP as the core child death review process management, data storage and reporting, system. Figure 4 presents an overview of the CDR System process incorporating eCDOP.

⁵ <https://www.local.gov.uk/search/all/voluntary%2Bsector>

⁶ <https://www.england.nhs.uk/integratedcare/resources/voluntary-sector-partnerships/>

Figure 4



In summary, the role of eCDOP in the CDR process is as follows:

- Any professional or member of the public can notify the WELC CDR Hub Team of a child's death by going online at: <https://www.ecdop.co.uk/WELC/Live/public/>; completing the form and pressing the 'submit' tab.
- This information goes to the WELC CDR Hub Team, who can then start gathering information which will enable them, the Medical lead and the CDR Family liaison worker to support the family and begin the process of identifying others who might form the team around the family (TAF). For this the CDR Hub Co-ordinator uses the eCDOP database to search for relevant existing statutory professionals (e.g. health visiting and school nursing teams, schools safeguarding leads, GP practices, palliative care teams; the police, children's services and others). To this list must be added individuals who are relevant to the child but not members of statutory teams.
- The CDR Hub Team Co-ordinator sends out Notification of the fact that of the child's death to relevant professionals on the list.
- The CDR Hub Team Co-ordinator then uses the eCDOP to email a Reporting Form to the professionals on the list to gather the information in relation to the three domains (figure 3) in the Reporting Form which encompass a holistic picture of the child.

- e) The CDR Hub Team Co-ordinator receives back the completed Reporting Forms and uses eCDOP to combine them into one coherent Reporting Form, ready for presentation at the CDRM.
- f) At the CDRM additions can be made to the Reporting Form if new information comes to light. Also at the CDRM the CDR Hub Team Co-ordinator completes a draft Analysis Form directly into eCDOP; based on the analysis and judgements arising from the discussion.
- g) The Analysis Forms do not record the child's personal information; they are therefore in the correct anonymised format for presentation at the Child Death Overview Panel (CDOP). The CDR Hub Team Co-ordinator can then use eCDOP to email the draft Analysis Forms to the CDOP. At the CDOP the CDR Co-ordinator ratifies each case (making changes as they arise from the discussion at the CDOP).

For local learning to prevent child deaths, the CDR Hub Team can interrogate eCDOP and run reports, to understand patterns and anomalies across the WELC footprint and also for individual areas.

- h) Finally, the CDR Hub Team Co-ordinator can use eCDOP to email the ratified Analysis Forms directly into the National Child Mortality Database; to contribute to national learning.

3.2.2 eCDOP reach and flexibility

In terms of reach, eCDOP is being adopted by the vast majority of Child Death Review Partnerships across England. This assists both with managing the review of the death of a child within the WELC footprint when the child is resident elsewhere in the country; and with the review where a child usually resident within the WELC footprint has died elsewhere in the country.

In relation to flexibility, eCDOP is managed centrally by an organisation (QES) who have proved responsive to date about finessing the software to accommodate local need.

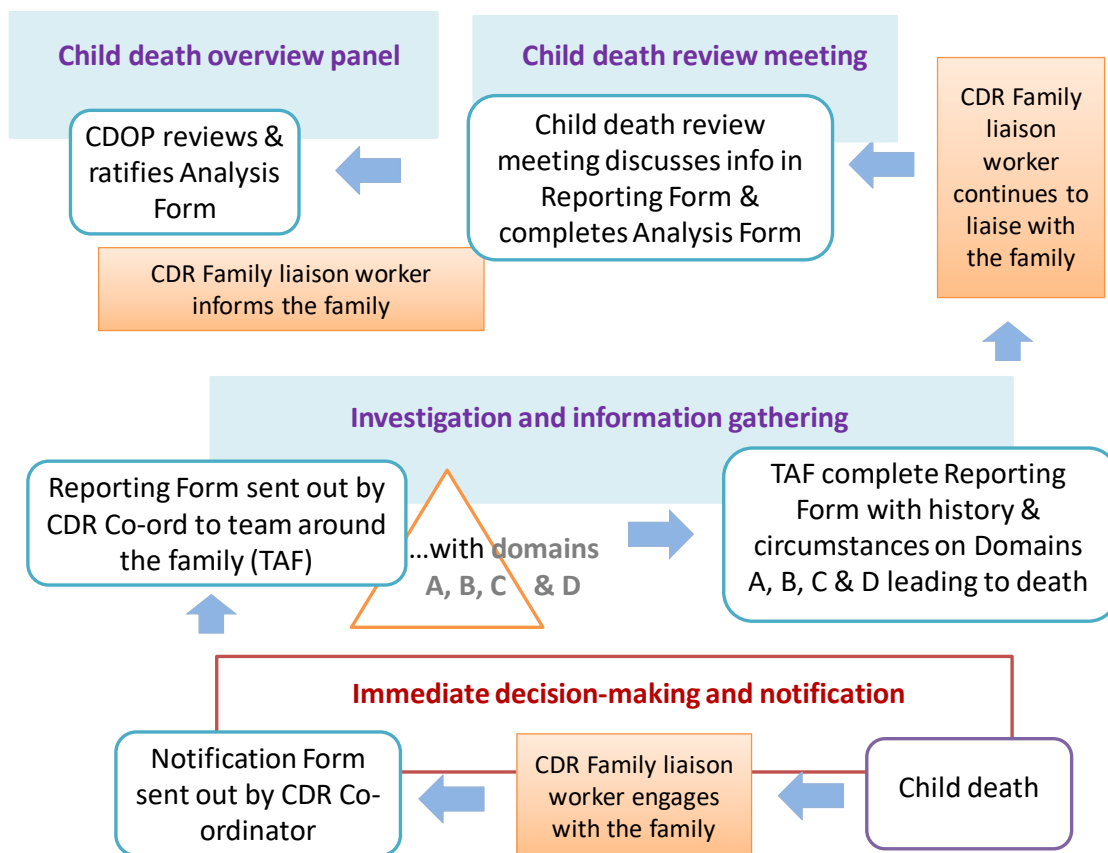
All feedback on eCDOP should be sent to the WELC CDR Hub Team who have responsibility for liaising with QES to continuously improve the efficiency which eCDOP brings to the WELC CDR System. The CDR Hub Team email for this is: CDRTeam-WELC@xxxxx.gov.uk

4. Immediate decisions and notifications

All children found collapsed or dead should be taken to the nearest Emergency Department with the facilities for paediatric resuscitation.

There are immediate decisions and notifications which professionals should make in the hours following the death of a child. This includes deciding whether a Medical Certificate of Cause of Death (MCCD) can be issued, or whether a referral to the coroner is necessary. Figure 5 locates the immediate decisions and notifications within the overall CDR process.

Figure 5



4.1 Immediate decision-making

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

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.

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

4.2 Professionals involved

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

- The consultant or GP attending the child at the end of his/her life (the attending doctor);
- The senior nurse, midwife, or health visitor attending the child at the end of his/her life;
- The Medical Examiner;
- Safeguarding children team or on call Named Nurse for Safeguarding Children
- Other professionals as appropriate; for example:
 - The on-call Designated doctor for child deaths, police investigator, and duty social worker in the context of a JAR (for details about the JAR process see chapter 5);
 - The coroner's officer in circumstances when a MCCD cannot be issued; and
 - Members of the hospital patient safety team when health service delivery issues are suspected or the safeguarding children lead in services other than Children's social care and the police e.g. education, leisure, faith (statutory, voluntary or private sector organisations).

4.3 Immediate decisions and timing

4.3.1 Within 1-2 hours if possible, the attending doctor, together with the other professionals identified in point 4.2.1 above, should:

- a) Identify the available facts about the circumstances of the child's death;
- b) 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 (see chapter 5; and appendix 2);
- c) Determine whether an MCCD can be issued, if not, consider whether the death should be referred to the coroner (see chapter 5);
- d) Determine whether any actions are necessary to ensure the health and safety in particular of other children. But also of other family or community members, healthcare patients and staff.

An initial strategy meeting/discussion should take place between the Medical lead, attending clinician (if different), the police investigator and the duty

social worker before the family leave the Emergency Department. This could trigger a JAR (see section 5.2 Joint agency response);

- e) Determine whether an issue relating to health (or other agency) care/service delivery has occurred or is suspected. This will inform whether the death should be referred to the coroner and/or a Serious incident (SI) investigation and/or a local Child safeguarding practice review (CSPR); and
- f) Identify how best to support the family (see section 2.2.2 Practical assistance for families).

4.3.2 In all deaths, the fact of the death and the outcome of the discussions should be:

- Recorded on the Immediate decision-making proforma (appendix 3).
- Communicated to the family

This should include explaining the involvement of the coroner and, where there are child protection concerns, must take into account the need for a co-ordinated plan of who talks to the family and when. The plan should be agreed between the police investigator and the Medical lead (see chapter 5).

- Recorded on the Notification Form in eCDOP, notifying the WELC CDR Hub team using the Notification Form accessed at: <https://www.welc.co.uk/WELC/xxx>. (There is a copy of the Notification Form in appendix 4).

The CDR Hub team will act as the single point of contact (SPOC) for all deaths that happen within WELC footprint. Where a death has been declared for a child not normally resident in the WELC footprint, the CDR Hub team must notify and arrange the handover of the case, to the CDR team in the area where the child was normally resident (see also section 7.6 Out of area).

The CDR Hub team will notify relevant services for the child and family e.g. General Practitioner, so that the GP is able to support the family; other professionals such as community midwives, health visitor, school nurse, hospital/community medical team; and eCDOP will automatically notify the local NHS England Child Health Information System (CHIS) in case there are other clinic appointments which must not be arranged for the child.

- Communicated to available bereavement/pastoral services. The CDR Hub team Family liaison worker will signpost the family for support.
- Communicated to the NHS Director on call.

4.4 Issuing an MCCD or referral to the coroner

- 4.4.1 At the death of a child, the attending doctor should first decide whether they are able to issue an MCCD in accordance with F66 guidance set out by the ONS and Home Office. Attention should then be given to how best to support the family and what information needs to be gathered to inform the CDRM.
- 4.4.2 There are two versions of the MCCD for child deaths: a neonatal certificate (up to 28 days) and the standard certificate. In deaths of children with complex conditions, the

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

4.4.3 If the attending doctor is unable to sign the MCCD, then they should refer the matter to the coroner. The Chief Coroner has issued guidance on which deaths should be reported to the coroner (see appendix 7). If there is any uncertainty over whether a referral is necessary, the attending doctor should contact the coroner's office to discuss.

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

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

4.5 The post-mortem examination

4.5.1 In deaths where a MCCD can be issued a hospital post-mortem examination (PM) may still provide important information as to why a child has died. If a coroner requires a post-mortem examination as part of his/her investigation parental consent is not required and parents cannot refuse the examination. However, if the coroner is not investigating the death, the parents have a right to request a hospital PM. The CDR Family liaison worker and clinical staff should explain the benefits of a PM to the family and what the process entails, so that they can make an informed decision on whether to request (consent to) one or not.

4.6 Other NHS notifications

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

- For neonatal deaths – the planned MBRRACE-UK/PMRT system; and
- The Lead Reporter at the hospital of birth in the case of perinatal deaths (22+0 week's gestation to 28 days after birth) to complete the national perinatal mortality surveillance data.

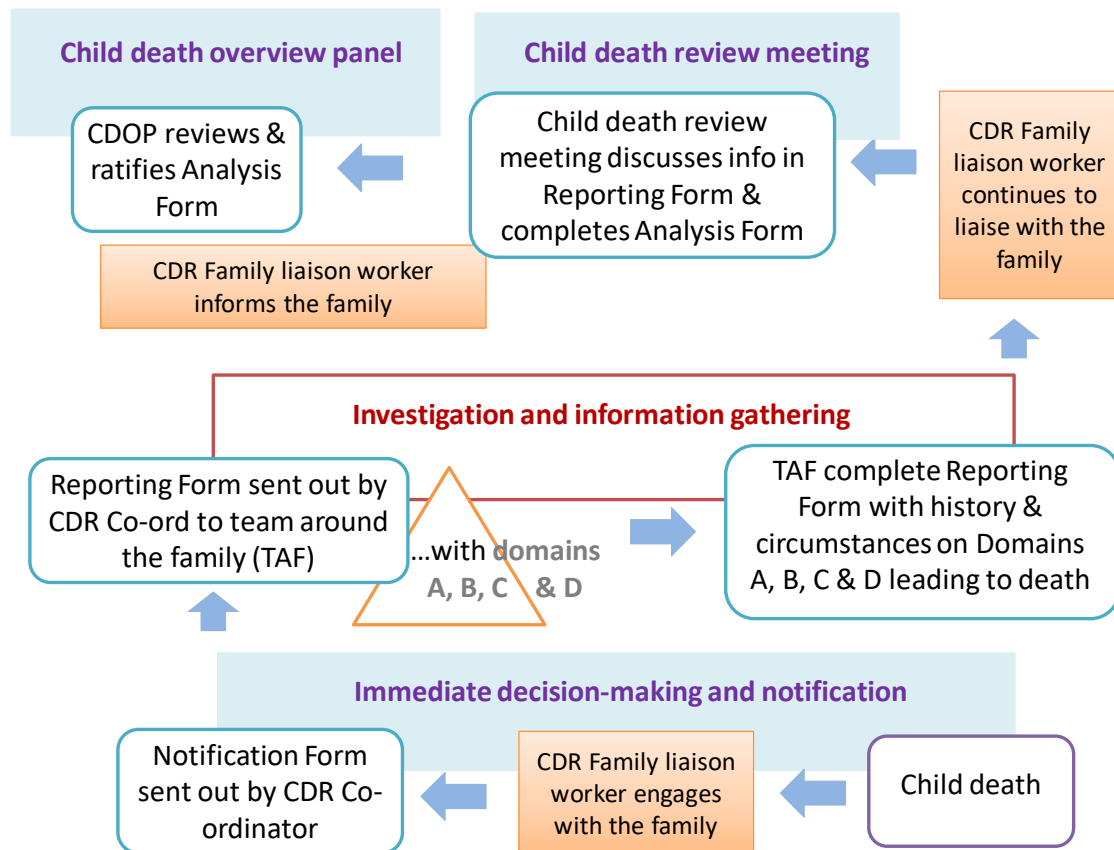
NHS and independent providers of inpatient mental health settings must notify the Care Quality Commission (CQC) or they can notify NHS England of the death of a patient through a local manager, or by reporting on the risk management system where information is uploaded to the national reporting and learning system.

Where a child was detained under the Mental Health Act 1883, the death must be reported to the CQC, to Ofsted and to the Local Safeguarding Partners.

5. Information gathering and investigation

After immediate decisions have been taken and notifications made in relation to a child death, essential information needs to be gathered on all child deaths. In addition, investigations may need to be initiated in some cases. Figure 6 locates the investigation and information gathering within the overall CDR process.

Figure 6



5.1 Gathering information

5.1.1 Essential information

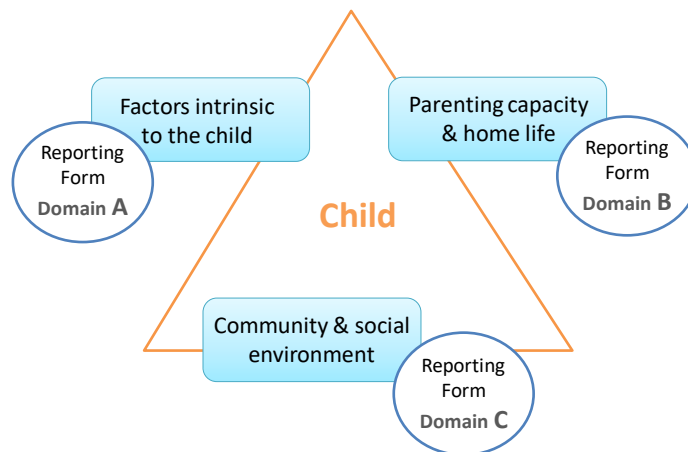
Essential information needs to be gathered to build an holistic picture of the child and any support which was or should have been available to him or her and his/her family, in the years, months, weeks and hours prior to the child's death. This information should be reported to CDOPs (or equivalent) via the CDR Reporting Form, or, for deaths of babies in neonatal units via the Perinatal Mortality Review Tool. The Reporting Form factors mirror those of the *Framework for the Assessment of Children in Need and their Families* (Department of Health et al, 2000); these are:

- Factors intrinsic to the child (Reporting Form Domain A) (appendix 4);

- Factors related to parenting capacity and home life (Reporting Form Domain B) (appendix 5); and
- Factors relating to the community and social environment (Reporting Form Domain C) (appendix 6).

This is illustrated in figure 8. The checklists in appendices 2 and 9 may be useful in considering and collecting the information.

Figure 8



The Reporting Form also prompts professionals to consider factors relating to services received or not by the child and his or her family prior to the child's death (Reporting Form Domain D) which could have contributed in some way to the child's death.

The CDR Hub team and the Designated doctor for child death are jointly responsible for gathering as much relevant information as possible from the Team around the Family (TAF); via the Reporting Form.

5.1.2 Investigations (triggered immediately or post-48 hours)

5.1.2.1 Investigations may be triggered immediately a child dies, in which case the gathering of information must be adapted in terms of detail and timely collection/sharing, to inform the investigation. The Coroner may be asked to investigate the cause of death and a Joint agency response (JAR) and or a serious incident (SI) investigation and/or a child safeguarding practice review (CSPR) may be triggered.

5.1.2.2 It is also not uncommon for an investigation to be triggered as a result of the process of multi-agency reviewing and sharing of information about a child that has come to light as a consequence of completing the Reporting Form i.e. in the days/weeks after the death. Concerns may arise as a consequence of practitioners being able to see patterns and links which could have influenced the child's death, in and between the factors which provide the holistic picture of the child's life.

5.1.2.3 Concerns about service failure are usually referred for consideration as a SI or a CSPR (see section 2.5 NHS Serious incident investigations and local Child safeguarding practice reviews). However, a JAR/strategy meeting should be

triggered where, for example, there is a suspicion that a professional deliberately harmed a child – because there may be a risk to other children.

- 5.1.2.4 If concerning information does come to light as the CDR process progresses, it should be documented and shared without delay with LA children's social care, the police, the coroner and the WELC CDR Hub.

5.2 Coronial investigation

The WELC footprint has two coroners. Anyone can refer a death to the coroner for investigation; a list of reasons for referral is set out in appendix 7.

- 5.2.1 In all deaths where a medical practitioner is unable to issue a MCCD, it is the responsibility of the coroner to determine the cause of death and to ensure all statutory requirements around registration are met.
- 5.2.2 Once referred and accepted, the coroner takes legal possession of the body and opens an investigation into the death. If there is a coronial investigation, it is the coroner who will order a post mortem examination, if necessary. Following this examination, the body of the child is usually promptly released back to their family for the death to be registered and funeral arrangements to be made. Release may however be later if organs have been taken for analysis, or if a second independent post-mortem examination is required.

Early release of the body and coroner out-of-hours services – the Chief Coroner has recommended that there should be an out-of-hours scheme in place across all coroner areas, to assist families. There will be a variety of reasons why a bereaved family may request early release of the body, including specific religious considerations. If the death is that of a young child, the family may ask for the body to be released as soon as possible to a dedicated room in the hospital. However, the coroner service is a local service, and out of hours provision varies. The Chief Coroner's guidance on decision making and expedited decisions can be found at: <https://www.judiciary.gov.uk/wp-content/uploads/2018/05/guidance-no-28-report-of-death-to-the-coroner-2010517.pdf>

- 5.2.3 The coroner may, as a result of preliminary inquiries, conclude that the death is from natural causes. In such cases the coroner may decide not to open a formal investigation (or hold an inquest), but may sign the case off to the local registrar as a natural cause of death. The coroner will use coronial Form 100 A (without a PM examination) or Form 100 B (with a PM examination).
- 5.2.4 If the coroner's duty to investigate a death is triggered he/she will open a formal investigation that will usually lead to an inquest. In cases where it can be argued that the State has not appropriately upheld a person's 'right to life', this remit may encompass the wider circumstances in which the death occurred. The coroner will examine the evidence and, commonly without a jury, record the answers to the questions listed on a public document called the Record of Inquest. The details of the coroner's findings are forwarded to the local registrar.
- 5.2.5 All agencies that have pertinent information (such as records of any internal or joint agency investigation and/or notes from the CDRM) are under a duty to disclose such information to the coroner in an un-redacted format and the coroner has common law and statutory powers to enforce such disclosure. However, individuals providing such

information may request that it is redacted before there is onward disclosure by the coroner to the Interested Persons⁷ (which includes the bereaved family) in the case.

5.2.6 The CDR Family liaison worker must inform the family 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.

5.3 Joint agency response

The information outlined here complements the *SUDI/C Guidelines* and the *London Child Protection procedures/Working Together to Safeguard Children* which should both be applied by all agencies involved in a Joint agency response (JAR).

5.3.1 A JAR should be triggered if the child's death:

- Is or could be due to external causes⁸;
- 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.

5.3.2 A JAR should also be triggered if such children are brought to hospital near death, are successfully resuscitated, but are expected to die in the following days. In such circumstances the JAR should be considered at the point of presentation and not at the moment of death, since this enables an accurate history of events to be taken and, if necessary, a 'scene of collapse' visit to occur.

5.3.4 The primary focus when initiating a JAR when a child has died must be the immediate protection of any other child/ren who may be at risk of serious harm or death. Where other such children are identified an agency with statutory child protection powers (the police, LA children's social care and the NSPCC) should act quickly to secure their immediate safety.

⁷ Part 1; Chapter 7; Sec. 47; Coroners and Justice Act 2009.

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

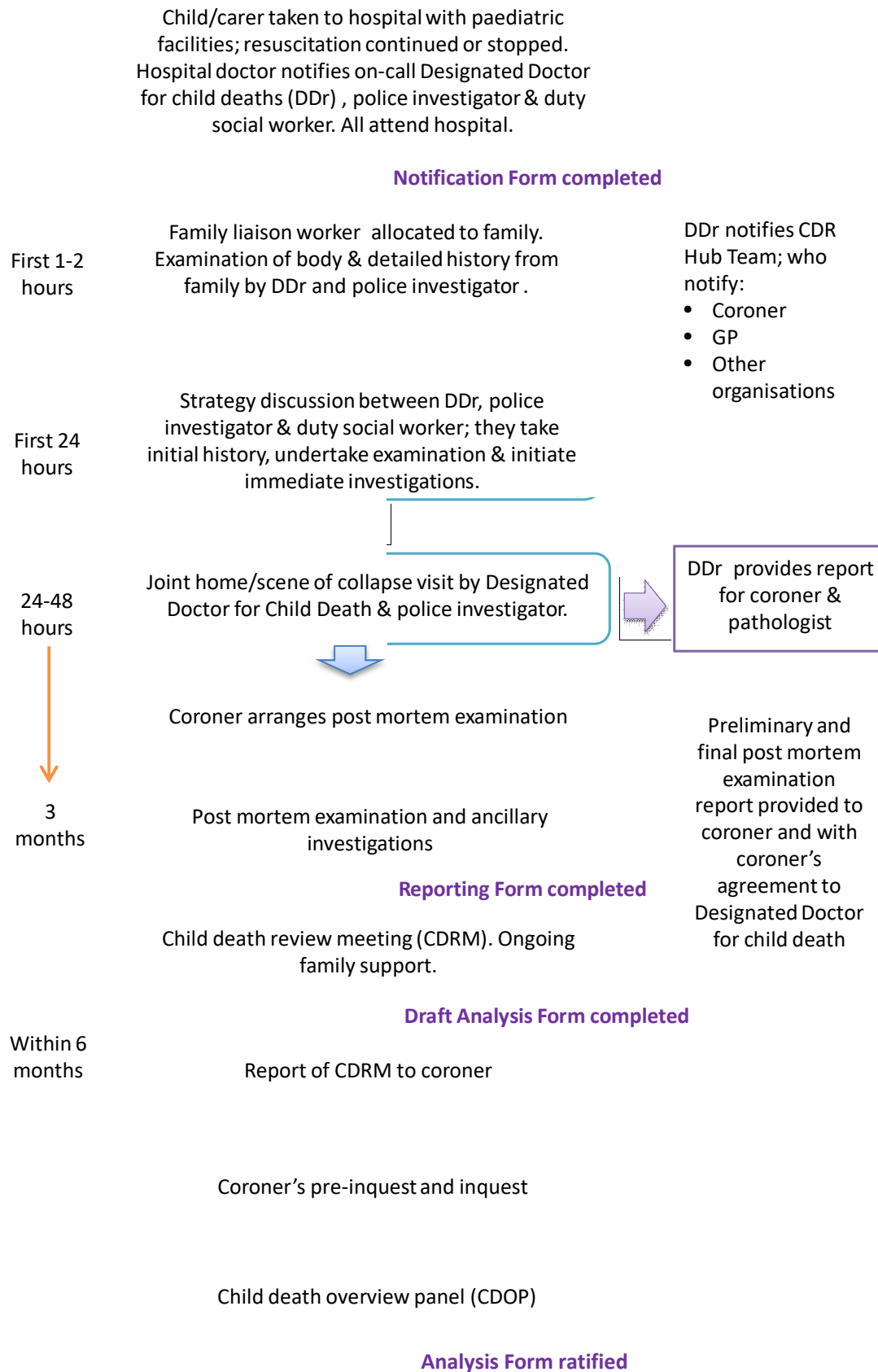
Consequently, in any of the circumstances in points 5.3.1 and 5.3.2, the on-call Designated doctor for child death, the relevant police investigator, and the duty social worker should be contacted immediately by the attending clinical team, to initiate a child protection (s47)⁹ strategy meeting/discussion and the JAR (See section 5.4 for information about the strategy meeting/discussion and the JAR).

- 5.3.5 Where a death has been declared for a child not normally resident in the WELC footprint, the CDR Hub team must take responsibility for arranging the JAR, until they are able to hand over of the case to the CDR team in the area where the child was normally resident (see also section 7.6 Out of area).
- 5.3.6 In addition to supporting the bereaved family and collecting information on the whole child (as in all child deaths), the JAR includes much more detailed careful:
- History-taking and examination of the child;
 - Preliminary medical and forensic investigations;
 - Immediate consideration of the circumstances and safety of the family, including siblings;
 - Assessment of the immediate environment and circumstances of the death; and
 - Post-mortem examination.

The sequence of procedures is set out in Figure 7.

⁹ Whenever there is reasonable cause to suspect that a child is suffering, or is likely to suffer, significant harm, there should be a strategy meeting / discussion under Decide whether an assessment under section 47 of the Children Act 1989 (s47) should be initiated. https://www.londoncp.co.uk/chapters/chi_prot_enq.html#strategy

Figure 7 Joint agency response



5.4 First 24 hours

5.4.1 Immediate response

5.4.1.1 As soon as possible after the attending doctor confirms death, a Medical lead should be assigned to the case (see section 2.1.2 Medical lead); and the following should be contacted:

- the coroner
- the relevant police investigator; and
- the duty social worker
- the CDR Hub team.

The Medical lead could be the doctor that the family had most involvement with while the child was alive/GP or the Designated doctor for child death on-duty at the time of death. The family must be offered a CDR Family liaison worker. The police may appoint a Family liaison officer over the few days after the death. In such a case the CDR Family liaison worker will work with the Family liaison officer rather than directly with the family (to minimise the number of professionals contacting the family).

5.4.1.2 Once death has been confirmed, the consultant paediatrician on call or the designated SUDI paediatrician should carefully and thoroughly examine the deceased child. The police investigator should be present while this happens. The deceased child should be re-examined where practicable to note any external marks that might not have been present on initial examination, particularly if trauma is being considered as a possible causative factor in the child's death. All injuries should be recorded immediately on a body map and again subsequently, and the police investigator should arrange a photographic record. Appropriate clinical investigations should be performed (see the *SUDI/C Guidelines*).

The Metropolitan Police Service (MPS) response to the death of a child varies according to the child's age and the whether the death is suspicious:

- The Safeguarding Hub responds to deaths where the child was under 2 years;
- The Borough police respond to deaths where the child was over 2 years; and
- The Serious and Organised crime (SOCA) teams respond to all suspicious deaths.

The police should begin an investigation on behalf of the coroner; in accordance with their Professional Practice guidance (*ACPO 2014: A Guide to Investigating Child Deaths, for comprehensive guidance*). The JAR should be adapted to take account of all forensic requirements.

5.4.1.3 The lead health professional (consultant paediatrician on call, Designated doctor for child death or specialist nurse) should take a detailed and careful history from the family. This should be carried out with the police investigator to avoid the need for repeated questioning. Where there are any suspicious circumstances surrounding

the child's death, it may be necessary for the police to interview separately the parents or carers. It is still important to obtain a full and careful medical history.

A co-ordinated plan of who talks to the family and when should be agreed between the police investigator and the Medical lead.

5.4.2 Strategy meeting

5.4.2.1 An initial child protection (s47)¹⁰ strategy meeting/discussion should take place between the Medical lead, attending clinician (if different), the police investigator and the duty social worker before the family leave the Emergency Department.

5.4.2.2 Deciding to convene a strategy meeting/discussion – if a child has died and the circumstances are suspicious, immediate consideration must be given to the risk of harm to any other child/ren. Responsibility for safeguarding another child or other children lies with the LA children's social care in the area where the child collapsed and/or died. The decision about how to safeguard the other children must be taken in a strategy meeting co-ordinated and chaired by a LA children's social care first line manager in that local authority area.

5.4.2.3 Timing of a strategy meeting/discussion – where there are concerns indicating a serious risk of harm to other child/ren (e.g. serious physical injury or serious neglect) the strategy meetings/discussions must take place the same day as the receipt by LA children's social care of the referral.

The strategy meeting should plan emergency action to protect the other child/ren. This could include:

- A parent taking action to remove an alleged abuser;
- An alleged abuser agreeing to leave the home;
- Child/ren not returning to the home (e.g. from school);
- The child being removed either on a voluntary basis or by obtaining an emergency protection order (EPO);
- Removal of the child/ren or prevention of removal from a place of safety under police powers of protection (PPO);
- Gaining entry to the household under police powers and to assess the situation.

5.4.2.4 Other attendees for a strategy meeting/discussion – in addition to the Medical lead, attending clinician (if different), the police investigator, the duty social worker; wherever possible attendees should include relevant other health professionals; and relevant other agencies which can inform thinking about the concerns about the child who has died and any other child//ren who may be at risk of harm.

Professionals participating in strategy meetings / discussions must have all their agency's information relating to the child to be able to contribute it to the meeting /

¹⁰ Whenever there is reasonable cause to suspect that a child is suffering, or is likely to suffer, significant harm, there should be a strategy meeting / discussion under Decide whether an assessment under section 47 of the Children Act 1989 (s47) should be initiated. https://www.londoncp.co.uk/chapters/chi_prot_enq.html#strategy

discussion, and must be sufficiently senior to make decisions on behalf of their agencies.

A professional may need to be included in the strategy meeting/discussion who was not involved with the child/ren or family, but who can contribute expertise relevant to the particular form of abuse or neglect in the case.

5.4.2.5 Topics for discussion in the strategy meeting/discussion – topics should include:

- 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;
- The history and circumstances of the death;
- Any immediate background information from health, police or social services; and
- Any concerns arising from these. In particular, consideration should be given to the safety and wellbeing of any other children in the household.

5.4.2.6 Sharing strategy meeting/discussion decisions – the chair of the strategy meeting/discussion is responsible for ensuring that the decisions and agreed actions are fully recorded using an appropriate form. All agencies attending should take notes of the actions agreed at the time of the meeting/discussion.

A copy of the record should be made available for all those, who had been invited, as soon as practicable by LA children's social care.

5.5 24-48 hours

5.5.1 Potential visit to the place where the child died

If the child collapsed and/or died in a non-hospital setting the strategy meeting/discussion should include consideration of a joint agency visit to the home/scene where the child died. The visit would be undertaken by the police investigator, the Designated Doctor for child death and the duty social worker.

The default position is that a visit should take place unless there are good reasons not to – and these should be recorded. As part of the visit, the police investigator should carry out an initial appraisal of the environment where the child collapsed and/or died. Further priorities are to ensure the safety of others, including other children in the home, and to maintain the integrity of the environment.

Following this visit, the Designated Doctor for child death and the police investigator should each prepare reports for the pathologist and coroner. These reports should be forwarded to the CDR Hub team; together with any report about the visit from the social worker.

5.5.2 Post mortem and further strategy meeting/discussions

The Coroner will arrange the post mortem examination and the preliminary and final post mortem examination reports will be provided to coroner and with coroner's agreement to Designated Doctor for child death.

Following the home/scene visit, and once the results of the post-mortem examination and other clinical investigations are known, a further strategy meeting/discussion should take place between the lead health professional, police investigator, children's social care (as appropriate) and the coroner's officer, to:

- Review any emerging information
- Discuss what is known about the cause of death and any contributory factors
- Determine what further investigations or enquiries are needed, and
- Confirm what information can be provided to the family, how and by whom.

5.5.3 Police specialisms

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.

5.6 Up to 3 months

Once the final post-mortem report has been released by the coroner, arrangements can be made for the child death review meeting. The child death review meeting should ideally take place before the inquest so as to inform the coroner's investigation. The CDOP or equivalent will normally take place after the conclusion of the inquest, taking account of the coroner's conclusions.

5.7 Co-ordination across investigations

- 5.7.1 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.
- 5.7.2 In deaths where there is more than one investigation, NHS trusts should appoint a Case manager to have oversight of procedures: ensuring that those involved are objective (e.g. through engaging the Patient Advice and Liaison Service), have an understanding of statutory requirements, follow appropriate timescales, ensure parents have an opportunity to contribute to the process and establish how they would like to receive feedback.
- 5.7.3 The Case manager must liaise closely with the CDR Family liaison worker who should co-ordinate all parallel investigations and communicate plans and progress appropriately to the family in order to avoid additional distress to bereaved parents.

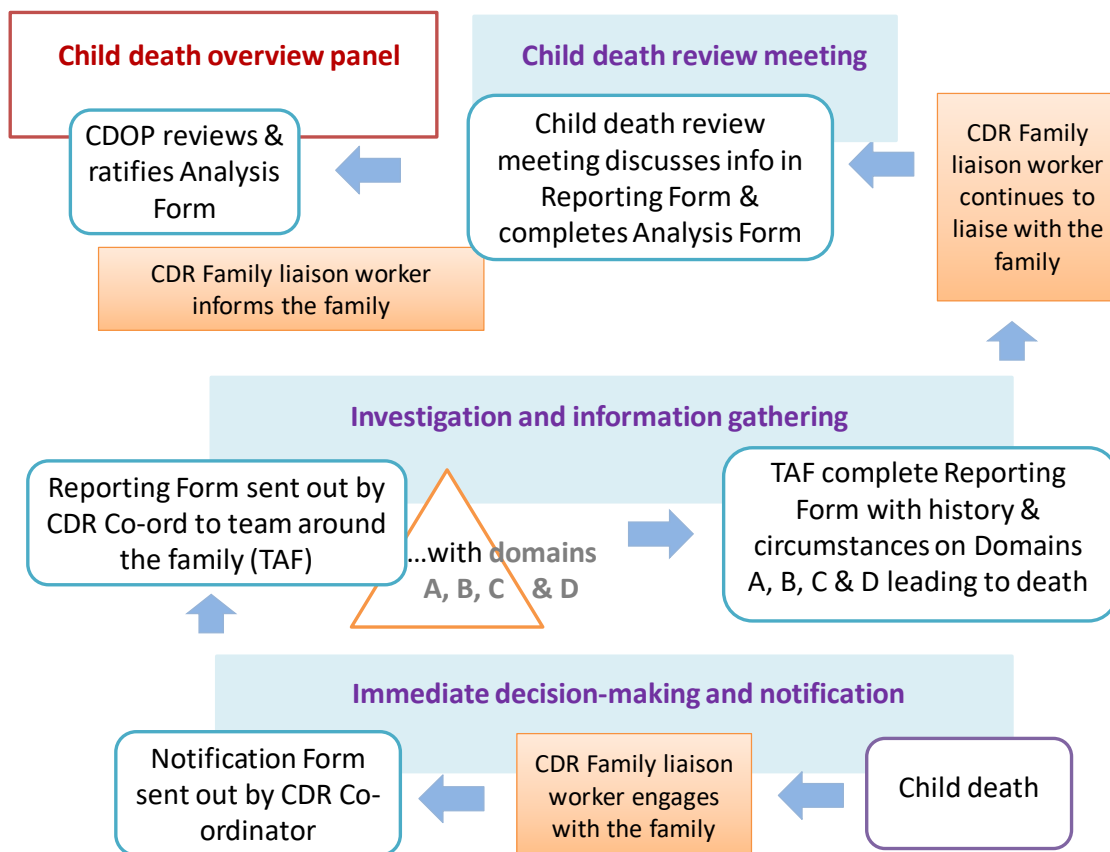
6. Child death review meeting (CDRM)

6.1 CDR Panels/meetings, JARs (Joint agency response), mortality and neonates meetings

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 review meeting should be flexible and proportionate, and focused on local learning.

It is important that all deaths are reviewed. However, in certain circumstances it may be appropriate for the review to be quite brief or for the meeting to discuss one child or several children. In every case, the Analysis Form should be drafted at the CDRM and then sent to the relevant CDOP. The CDRM stage in the CDR process is illustrated in figure 9.

Figure 9



6.1.1 The nature of this meeting will vary according to the circumstances of the child's death and the practitioners involved. For example, it could take the form of:

- CDR panels review a number of children at a time, with the practitioners relevant to each child attending for the child they were involved with. The CDR panels will need to be held at carefully chosen local venues.

The key benefits of managing child death review meetings in this way are that the:

- Local Area and Trust staff are able to see potential local themes (which would otherwise only be visible at footprint level by the Overarching CDOP)
- Hub Co-ordinator will be in a position to:
 - be able to support the Designated doctor for child deaths
 - support quality assurance at the CDR level
 - improve Area-Hub networking through face-to-face contact and counterbalance a tendency for centralised teams to become detached from practice on the ground
 - gather and retain the essence of the child's experience, which can easily be lost in the process of anonymisation for the CDOP.

The CDR panel/meeting will 'note', rather than review the deaths which are reviewed as JARs, mortality and neonates meetings (or similar case discussion).

- b) CDR meetings each review an individual child. These meetings, and the JARs, mortality and neonates meetings will be held in the location where the child died or received most treatment.

For example, 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 or school, 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.

- c) JARs are final case discussions following a Joint agency response
- d) Hospital-based mortality meetings (mortality meetings) are for the death of a child in a paediatric intensive care unit; or similar case discussion; and
- e) Perinatal mortality review group meetings (neonates meetings) are for a case of a baby who dies in a neonatal unit.

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>.

WELC areas are encouraged to convene joint mortality and neonates meetings where possible.

- 6.1.2 The WELC CDR Hub team, the Designated doctor for child death and the WELC provider trusts must together ensure that the factors related to parenting capacity and home life (Domain B); factors relating to the community and social environment (Domain C) are appropriately addressed in mortality and neonates meetings (see figure 8).

- 6.1.3 Where a death has been declared for a child not normally resident in the WELC footprint, the CDR Hub team will take responsibility for arranging the CDRM, until the they are able to hand over of the case to the CDR team in the area where the child was normally resident. The CDR Hub team and the organisation where the child died should work together to find a suitable location for the CDRM (see also section 7.6 Out of area).

6.2 CDRM aims

- 6.2.1 In all cases, the aims of the CDRM are to:

- Review the background history, treatment, and outcomes of investigations, to determine, as far as is possible, the likely cause of death;
- Ascertain contributory and modifiable factors across domains specific to the child, the social and physical environment, and service delivery;
- 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;
- 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;
- Ensure that CDOP and, where appropriate, the coroner is informed of the outcomes of any investigation into the child's death; and
- Review the support provided to staff involved in the care of the child. 4.2.2 Notes of the meeting should be taken to help with completion of the draft analysis form sent to CDOP.

- 6.2.2 NHS Trusts should note that, children's deaths (focused around an individual child) and matters of morbidity, should be considered separately. It is only through such a comprehensive approach that the contributory factors to death can be understood.

6.3 CDRM attendees

- 6.3.1 It is the responsibility of the WELC CDR Hub, together with the organisation responsible for the declaration of death to arrange the CDRM¹¹. The exception to this is when a Joint Agency Response has occurred, in which case responsibility defaults to the lead health professional. Where a death is declared

¹¹ In practice, a medical organisation, for example an NHS trust, General Practice surgery, or hospice would be the most appropriate place to hold the majority of child death review meetings, as most deaths will be declared in a hospital, or by a GP in the community.

- 6.3.2 Core members for the CDRM are the Designated doctor for child deaths and the CDR Coordinator, the health and social care staff (and staff in any other setting/service) directly involved in the events which led to the child's death.
- 6.3.3 Each child's death requires unique consideration and where possible, should engage professionals across the pathway of care. The following additional professionals *may* be invited, depending on their ability to contribute meaningfully to a discussion on the circumstances of the child's death:
- Pathologist, if a post-mortem examination has taken place, or placental histology has been reported in the case of a neonatal death;
 - Clinical GP lead for children from the area where the child was resident;
 - Other professional peers from relevant hospital departments and community services (e.g. mental health professionals, school nurses, health visitors);
 - Coroner's officer, if the case has been referred to the coroner;
 - Senior investigating police officer, if there is a JAR;
 - Early years and education professionals
 - Other professionals such as social workers, ambulance and fire service staff, criminal justice practitioners, local authority housing, environment or leisure services representatives and practitioners from voluntary organisations; and
 - Patient safety team if a SI investigation has taken place.
- 6.3.4 Wherever possible professionals who cannot attend should have the option of participating using skype or conference calling. In the event that a professional cannot participate in the discussion, they should submit a report to the meeting.

6.4 CDRM chairs

- 6.4.1 The CDRM should be chaired by a lead professional for the child death review process within the organisation where death was declared, or the lead health professional in a JAR. This person should have designated time assigned for this within their job plan.
- 6.4.2 If the lead professional also had overall clinical responsibility for the child, the role of chair should be delegated to another colleague to avoid any perceived conflict of interests. At the beginning of each meeting the Chair should inquire as to conflicts of interest among the attendees. In rare cases, it may be necessary to seek a chair external to the organisation; for example, when trust has broken down between the family and health care team in the organisation where death was declared. The Designated doctor for child deaths might advise in such circumstances.

6.5 Timing for CDRMs

- 6.5.1 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 meetings should be held in a timely and co-ordinated fashion. The WELC CDR Hub

team should co-ordinate the CDRMs together with the Designated doctor for child death and the relevant Medical lead.

Agencies must ensure that their staff participating in the review of a child death have the time allocated to ensure that they can attend meetings, so that the CDRMs are held in a timely and co-ordinated fashion.

- 6.5.2 The meeting should take place as soon as is practically possible, ideally within three months, although serious incident investigations and the length of time it takes to receive the final post-mortem report will often cause delay. In order to best capture the views of those directly involved, it may be beneficial to start the process as soon as possible, prior to the formal CDRM. The CDRM should occur before any coroner's inquest – it may be that two CDRs need to be convened, before and then again after completion of an inquest or a serious case review (SCR).
- 6.5.3 The CDRM may proceed in the context of a criminal investigation, or prosecution, *in consultation with* the senior investigating police officer. The meeting cannot take place if the criminal investigation is directed at professionals involved in the care of the child, when prior group discussion might prejudice testimony in court.

6.6 Family engagement in the CDRM

- 6.6.1 The CDRM is a meeting for professionals. In order to allow full candour among those attending, and so that any difficult issues relating to the care of the child can be discussed without fear of misunderstanding, parents should not attend this meeting.
- 6.6.2 Parents should be informed by their CDR Family liaison worker that the review at CDRM 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 about being excluded from a meeting about their child. They should be reassured that the CDRM's conclusion will be communicated to them.
- 6.6.3 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 via the CDR Family liaison worker or directly to a CDR Hub Coordinator.
- 6.6.4 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 CDRM's conclusions to the family. This would generally be the child's paediatrician, or in the case of a neonatal death, obstetrician and neonatologist. In a coroner's investigation, such liaison should take place in conjunction with the coroner's office, bearing in mind that the conclusion on the cause of death in such cases is the responsibility of the coroner at inquest.

7. Specific circumstances

7.1 Babies transferred between neonate units

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

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

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

7.2 Community (illness or violence incl. suicide)

Children who die in the community and whose deaths were not anticipated in the previous 24 hours, should be taken to an Emergency Department (ED) rather than a mortuary, and resuscitation should always be initiated unless clearly inappropriate. See the *UK Resuscitation Guidelines (2010)*.

As with children who die in hospital, their parent/s should be allocated a member of hospital staff to support them throughout the process.

A child should not be taken to ED in situations where:

- The circumstances of the death require the child's body to remain at the scene for forensic examination (police will be involved in these cases and decisions will be made after consideration by the police Senior Investigating Officer); or
- The death was expected in the context of the child's life limiting condition and they were receiving palliative care (the end of life care team must be involved in the decision on how to respond).

Where a child is not taken immediately to ED, the professional confirming the death should inform the coroner, the Designated doctor for child death and the CDR Hub team at the earliest opportunity. This death will be subject to local coronial guidelines if the doctor is unable to issue a Medical Certificate of the Cause of Death.

The CDR Hub team is responsible for ensuring that families of children who are not taken to hospital receive support from the CDR Family liaison worker (or police liaison officer) throughout the process.

7.2.1 Suicide

Suicide is defined as a death where the conclusion of suicide is given at inquest where the coroner (or jury) is satisfied that the deceased did an act knowing and intending that their death would result. A recent High Court ruling was that a conclusion of suicide, whether expressed as a narrative statement or in short-form, is required to be proved to the civil, and

not the criminal, standard of proof¹². This is a significant change to the previously understood position. It is likely that this case will be appealed to the Court of Appeal and therefore the legal position may be further clarified in due course.

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

- All deaths related to suspected suicide and self-harm should be referred to the coroner for investigation
- All deaths related to suspected suicide and self-harm will require a joint agency response
- The CDRM should include experts in mental health and key professionals involved in the child's life across education, social services and health; and
- Suspected child suicides should, where possible, be discussed at a themed specialist CDOP review with attendant mental health specialists.

7.3 Mental health settings

All deaths of children in inpatient mental health settings (general and secure) a JAR must be initiated (see chapter 5) – whether or not the child was being treated 'voluntarily' as informal inpatients or detained under the Mental Health Act 1983 (MHA).

In line with this, all child deaths in inpatient mental health settings 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.

Where a child was detained under the Mental Health Act 1983, the death must be reported to the CQC, to Ofsted and to the Local Safeguarding Partners. These deaths, along with the death of any child in custody or secure accommodation, may trigger a local or national Child safeguarding practice review.

7.4 Adult healthcare settings

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 subject to the child death review process exactly as outlined in this procedure.

7.5 State detention and custody

7.5.1 State detention

The coroner and Prisons and Probation Ombudsman (PPO) have primary responsibility for the investigation of the death 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).

¹² High Court has recently handed down a judgment (R (Maughan) v Senior Coroner for Oxfordshire [2018] EWHC 1955 (Admin))

The coroner's duty to investigate deaths in custody and state detention also includes patients detained under the Mental Health Act 1983.

While the CDR partners for the area where the child was normally resident are responsible for ensuring a review of the death takes place, it is the CDR team for the area where the most learning can be captured that would normally conduct the child death review.

7.5.2 Police custody

Deaths of children in police custody are not investigated by the Prisons and Probation Ombudsman (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.

7.5.3 Review of healthcare for the child

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.

7.5.4 Serious incident (SI) and Child safeguarding practice review (CSPR)

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 SI should be declared and the investigation managed according to the Serious Incident Framework. The NHS England commissioner should notify the NHS England central team via the Director of Health and Justice.

Usually the SI 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.

NHS providers should inform the CDR team 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 CDR team where the death occurs should receive the outcomes of those investigations and conduct a comprehensive review of the case. For a WELC child, the WELC CDR team must liaise with the other CDR team to contribute to the CDR and receive all the outcomes from the investigations and 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, the baby should be transferred to hospital. In both circumstances, should the baby then die in a neonatal unit, the standard CDR process should be followed.

7.6 Out of area

The CDR Hub team acts as the single point of contact (SPOC) for all deaths that happen within WELC footprint. There will be occasions when the death of a child is declared within the WELC footprint, but the child's normal place of residence was outside the WELC footprint. When this happens all staff should follow this WELC CDR procedure until CDR the Hub team can secure agreement for handover to the area where the child was normally resident.

The death should be notified to the CDR Hub team in the usual way and the Hub team must forward the notification to the CDR Coordinators for the area where the child was normally resident. If the WELC clinician issuing the MCCD has the contact details of the clinicians who attend the child in the area where the child normally lives, they should also notify them.

This means that where there is a decision to initiate a JAR, the CDR Hub team must take responsibility, together with the Medical lead and Designated doctor for child death, for convening and co-ordinating the JAR process. The JAR must be progressed (according to usual timelines) until agreement for handover can be secured with the area where the child was normally resident.

7.7 Out of country

The WELC CDR Hub team must make arrangements for the review of the death of a child normally resident in the area who dies overseas. The WELC CDR partners may learn about such a death from a variety of sources (e.g. Foreign and Commonwealth Office (FCO), media, coroner, public). If they do, they should notify the WELC CDR Hub team in the usual way.

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 coroner taking responsibility will usually be the coroner covering the area to which the child's body is brought for funeral arrangements. The duties of the coroner do not arise if the child is buried or cremated abroad.

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

When the death has taken place abroad, the WELC CDR Hub team should seek advice from the local senior coroner first; the WELC CDR Hub team may also need assistance from

agencies abroad, including police involved in the investigation of the death in question. The review will require careful coordination to ensure that relevant information from the FCO, international funeral directors, coroner, and local services (health, education, social services) informs the Reporting Form for the CDRM.

7.9.1 Foreign and Commonwealth Office

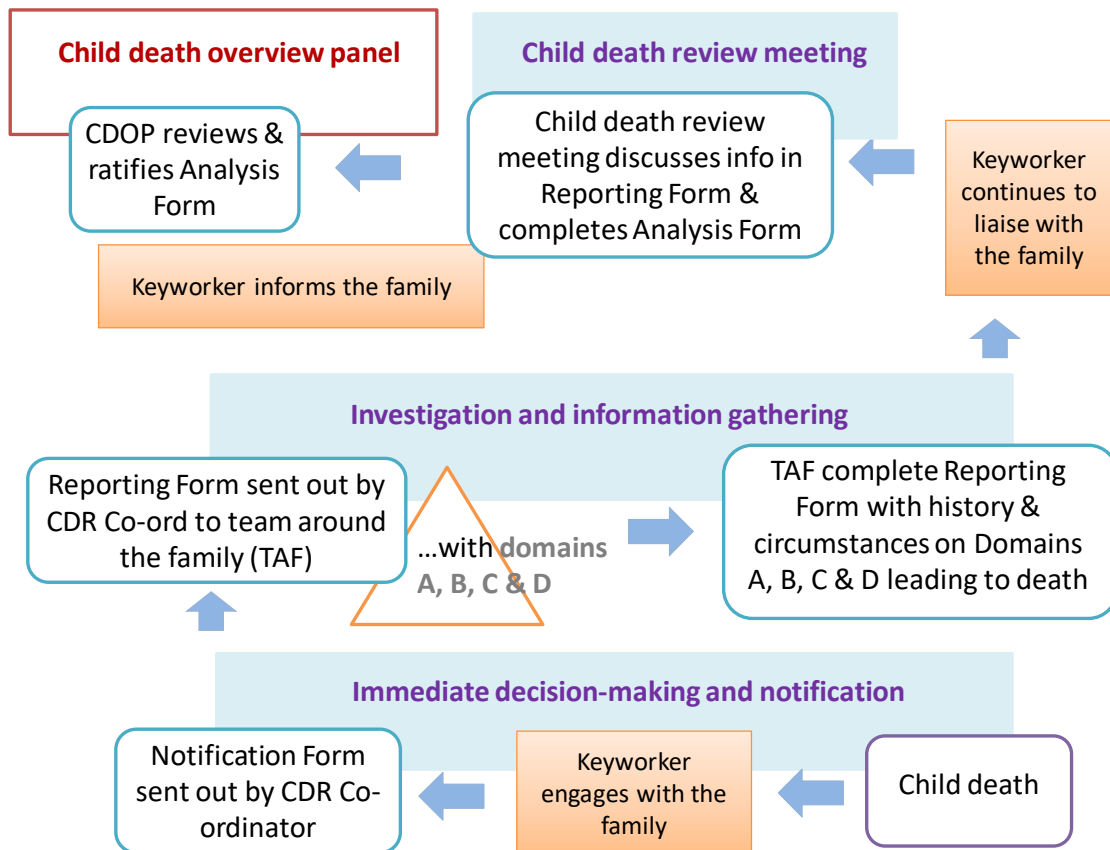
The FCO can provide support to British nationals in difficulties overseas and provides useful resources for what should happen in the event of a death overseas. In the event that a child who is a British national, dies abroad, the child's family should notify the local authorities and the UK Embassy, High Commission, or Consulate in the country where the child has died. The family can also contact the FCO directly. Diplomatic officials in these offices will, when notified of a death, advise relatives how to register the death (abroad and/or in the UK); advise on how to repatriate the body using local or international funeral directors, and give guidance relating to bereavement support. Their staff will also notify the coronial liaison officer at the FCO. The FCO collects routine information about each death such as name, date of birth, address, known cause of death, and the welfare of other siblings. It is customary practice for the FCO to also notify the relevant CDR partners and CDR team 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).

8. Child Death Overview Panel (CDOP)

The Children Act 2004 requires CDR partners to establish a Child death overview panel (CDOP), or equivalent, to review the deaths of all children normally resident in the relevant local authority area, and if they consider it appropriate the deaths in that area of non-resident children. The WELC CDOP acts on behalf of the WELC CDR partners. The CDOP stage in the child death review process is illustrated in figure 10.

Figure 10



In line with national guidance, the WELC CDOP will conduct an anonymised secondary review of each death where the identifying details of the child and treating professionals are redacted. This review will be informed by a standardised output from a CDRM – in the form of the draft Analysis Form.

The WELC CDOP Terms of reference can be requested from the CDR Hub team.

8.1 CDOP responsibilities

8.1.1 The functions of the WELC CDOP include to:

- Collect and collate information about each child death, seeking relevant information from professionals and, where appropriate, family members;

- Analyse the information obtained, including the report from the CDRM, in order to confirm or clarify the cause of death, to determine any contributory factors, and to identify learning arising from the child death review process that may prevent future child deaths;
- 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;
- Notify the Child Safeguarding Practice Review Panel and local Safeguarding Partners when it suspects that a child may have been abused or neglected;
- Notify the Medical Examiner (once introduced) and the doctor who certified the cause of death, if it identifies any errors or deficiencies in an individual child's registered cause of death. Any correction to the child's cause of death would only be made following an application for a formal correction;
- Provide specified data to NHS Digital and then, once established, to the National Child Mortality Database;
- Increase public awareness and advocate for the issues that affect the health and safety of children;
- Publish an annual report on local patterns and trends in child deaths, any lessons learnt and actions taken, and the effectiveness of the WELC CDR System; and
- 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.

8.2 Membership, chairing and timing

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

- Public health
- Designated doctor for child deaths (and a hospital clinician if the designated doctor is a community doctor or vice versa)
- Social services
- Police
- Education (early years, primary and secondary schooling)
- Safeguarding (Designated doctor or nurse)
- Clinical GP lead for children or Named GP for safeguarding
- Head of nursing and/or Head of midwifery
- Head of Community Health Services

- CDR Hub Coordinator
- Lay representation; and
- Additional professionals should be considered on a case-by-case basis, for example from: coroner's office, education, housing, council services, health and wellbeing board, ambulance services, or hospices.

In addition to the core membership, relevant experts should be invited as necessary to inform discussions.

- 8.2.3 The WELC CDOP will be chaired by someone independent of the key providers (NHS, social services and the police) in the WELC footprint. Panel members should be familiar with their responsibilities and ensure that they read all relevant material in advance of panel meetings. Conflicts of interest should be established at the outset of each meeting and panel members should not lead discussions if they are the named professional with responsibility for the care of the child.
- 8.2.4 Quoracy should usually demand attendance by lead professionals from health and the local authority. However, when a themed panel is discussing exclusively medical concerns (e.g. cardiac) the attendance of police and social care, beyond the core panel membership, might not be necessary. Where a themed panel is discussing social and environmental concerns (e.g. gang-related deaths) the attendance of medical staff beyond the core panel membership, might not be necessary. In such situations those agencies not present might review the cases being discussed, and their representative should bring to the panel's attention relevant issues, as required.
- 8.2.5 The WELC CDOP will meet on a monthly basis for ten months of the year, determined by the number and type of deaths to be reviewed across a year

8.3 CDOP administration

- 8.3.1 The WELC CDR Hub team will work closely with the chair of the panel and the Designated doctor for child deaths. The Designated doctor for child deaths and the CDR Hub manager have joint responsibility for the wider child death review process; advising the CDOP in relation to themed panels and presenting the cases at panel.
- 8.3.2 The WELC CDOP, acting on behalf of the CDR partners, may request any professional or organisation to provide relevant information to it, or to any other person or body, for the purposes of enabling or assisting the performance of the CDR partner's functions. Professionals and organisations must comply with such requests.
- 8.3.3 The WELC CDOP aims to review all children's deaths within six weeks of receiving the report from the CDRM or the result of the coroner's inquest. The exception to this might be when discussion of the case at a themed panel is planned.

8.4 Reviewing deaths of non-resident children

- 8.4.1 Legislation allows for CDR partners to make arrangements for the review of a death in their area of a child not normally resident there. A pragmatic approach should be taken to such deaths, entailing discussion between the CDR partners in the area where the child is normally resident and those in the area where the child died. In all cases, the CDR partners in the area where the child is normally resident is responsible for ensuring that a review *takes place* at CDOP level. Consideration should also be given to where the most learning can take place and this may

sometimes dictate that a different CDOP to the area where the child is normally resident leads the discussion.

- 8.4.2 For example: a child from area X drowns on holiday in area Y, and dies in a paediatric intensive care unit in area Z. While three CDR partners/CDOPs could be involved, the opportunities for most learning would likely be in Area Y, where the incident occurred, rather than the areas where the child was normally resident, or where they died^{13,14}. In such situations, it is important to avoid serial discussions about the same child by separate CDR partners¹⁵. CDR partners for the area where the child is normally resident should decide which area conducts the review and retains responsibility for ensuring the review has been carried out. The application of remote conferencing can facilitate a co-ordinated approach where experts are unable to attend in person, and/or the CDOP administrator where the child is resident wishes to participate in the meeting.

8.5 Themed panels

- 8.5.1 Some child deaths may be best reviewed at a themed meeting. A themed meeting is one where CDR partners arrange for a single CDOP, or neighbouring CDOPs, to collectively review child deaths from a particular cause or group of causes. Such arrangements allow appropriate professional experts to be present at the panel to inform discussions, and/or allow easier identification of themes when the number of deaths from a particular cause is small.
- 8.5.2 Examples of themed panels might be neonatal at a local level; and cardiac, cancer, SUDI/SUDC, suicide, and trauma at a regional level. The frequency of such panel meetings would be dictated by the number of deaths in each category. Themed panels will demand a customised approach and an experienced chair. Consideration might be given to experts attending from a neighbouring clinical network or region. Themed panels should occur within 12 months of the child's death. Designated doctors for child death should work together to decide which cases might best benefit from review at a themed panel.

8.6 Involvement of family or carers

- 8.6.1 Parents should be informed by their CDR Family liaison worker that the review at CDOP will happen, and the purpose of the meeting should be explained. Particular care and compassion is needed when informing parents about the meeting and its purpose, to avoid adding to parents' distress or giving the impression in error that the parents are being excluded from a meeting about their child. With this in mind, it should be made clear that the meeting discusses many cases, and that all identifiable information relating to an individual child, family or carers, and professionals involved is redacted. It should also be explained to parents that because of the anonymous nature of the CDOP review, it will not be possible to give them case specific feedback afterwards.

¹³ In practice, the majority of cases will occur in one or two geographical areas.

¹⁴ In all cases, the CDR partners for the area where the child is normally resident are responsible for ensuring that a child death review takes place.

¹⁵ It is possible that in some circumstances learning may be obtained in more than one area. These decisions can be decided between CDR Partners, with one area coordinating the discussion and the others contributing.

- 8.6.2 Parents should be assured that any information concerning their child's death which they believe might inform the meeting would be welcome and can be submitted via the CDR Family liaison worker or directly to the CDOP administrator.
- 8.6.3 CDOPs should assure themselves that the information provided to the panel provides evidence that the needs of the family, in terms of follow up and bereavement support, have been met.

8.7 National reporting

- 8.7.1 The WELC CDOP should record the outcome of their discussions on a final Analysis Form, and submit this to NHS Digital.
- 8.7.2 The WELC CDOP should submit copies of all completed forms associated with the CDR 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.

8.8 Local reporting and learning

- 8.8.1 The WELC CDOP must publish an annual report on the effectiveness and activity of the WELC CDR System:
- a) Effectiveness – more information about the effectiveness of the WELC System can be found in section 11.3 Monitoring, evaluation and improvement; and
 - b) Activity – at a minimum the report should include data on:
 - Cases
 - numbers and trends over time
 - cause of death
 - age, gender, ethnicity and location
 - investigations (SIs, CSPRs and others)
 - Service user complaints about the WELC CDR System (see section 11.5 Complaints)
 - Learning and how it was disseminated (awareness raising/training)
 - Progress on multi-agency improvements recommended in the previous year's report
 - Recommended multi-agency action for the coming year; to embed learning to prevent child deaths (changes to structure, systems and practice)
 - National and local strategic developments
 - Any new national legislation and guidance; and

- The CDOP workplan for the coming year.
- 8.8.2 The report must be written in plain English and published on the CDR partners' websites.
- 8.8.3 The WELC CDR Hub team are responsible for preparing the annual WELC CDR System report (and developing the CDOP work plan). Both the report and the workplan must be:
- Approved in draft by the CDOP;
 - Circulated for consultation to the WELC Partner LSPs; and
 - Approved in final form by the Newham LSP.
- 8.8.4 In addition to the annual report the WELC CDR Hub team should also produce borough level data for each area to identify and address any particularly localised learning; including where relevant for example complaints and local progress on embedding the learning.

9. Children with learning disabilities

In line with the Learning Disabilities Mortality Review (LeDeR) programme the deaths of the following children usually resident within the WELC footprint, must have a LeDeR review:

- Children who are aged 4-17 years; and
- Children with learning disabilities or who are very likely to have learning disabilities, but have not yet had a formal assessment for this

9.1 Definition of learning disabilities

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. 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.

This definition encompasses children and adults with a broad range of disabilities; IQ alone is not sufficient to identify this population. For example, it includes those with autism who also have learning disabilities but not those on a higher level of the autistic spectrum, such as some with Asperger's Syndrome, who may be of average or above average intelligence. The definition does not include those who only have a specific 'learning difficulty' (such as dyspraxia or dyslexia). The fact that a child has physical disabilities does not mean that they have learning disabilities.

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.

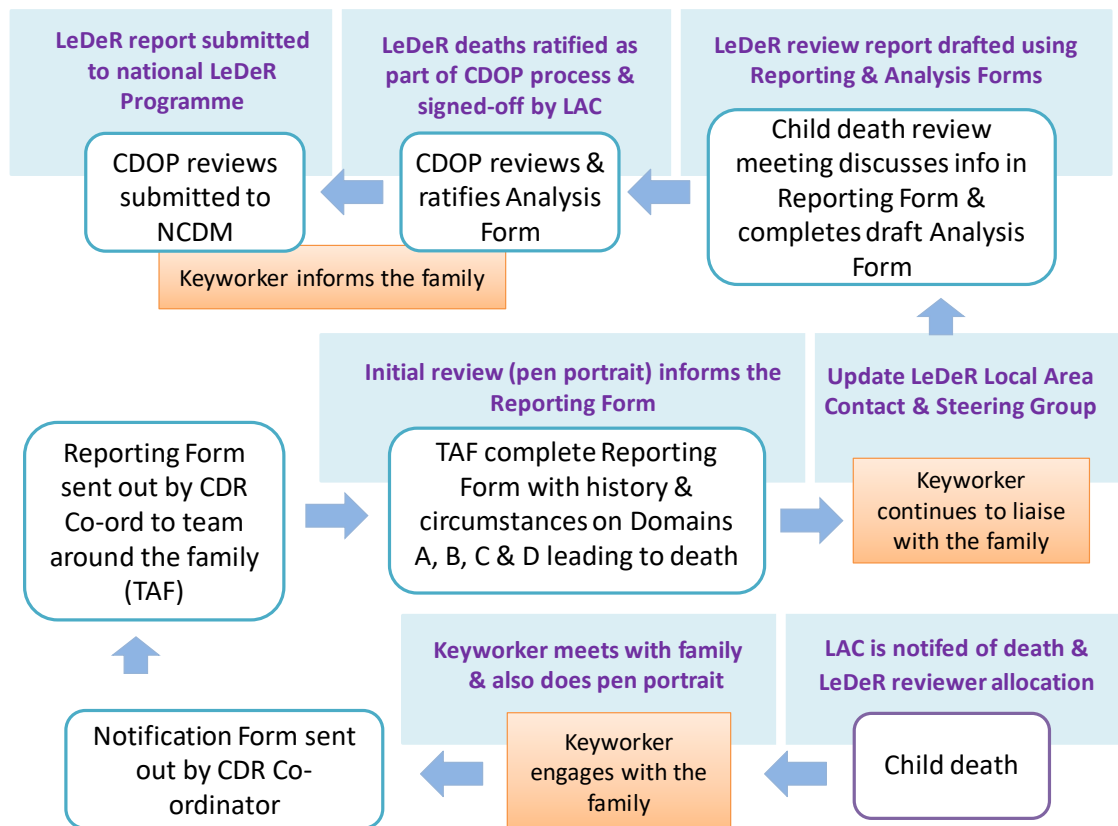
Further information about the definition of learning disabilities used in the LeDeR programme can be found at: <http://www.bristol.ac.uk/sps/leder/information-for-reviewers/briefing-papers/>.

9.2 CDR and LeDeR Review processes

9.2.1 Integration of the CDR and LeDeR Review processes

The CDR process is the primary review process for the deaths of children with learning disabilities. All the CDR Hub team staff will be trained LeDeR reviewers and will work to ensure that the LeDeR reviews are seamlessly integrated into the WELC CDR process. Accordingly professionals need to be confident and competent in integrating the LeDeR activities and focus into the CDR process. The integrated CDR and LeDeR processes are illustrated in figure 11.

Figure 11



9.2.2 LeDeR process

The LeDeR process involves:

- Notification 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, to the LeDeR Local area contact (LLAC); and also to the LeDeR programme at <http://www.bristol.ac.uk/sps/leder/notify-a-death/> or 0300 777 4774 – undertaken by the CDR Hub team Co-ordinators
- An initial review of each death in the form of a pen portrait and timeline of events from at least two sets of Health or Social Care records – undertaken by the CDR Hub team Family liaison worker and Coordinators (as trained LeDeR reviewers);
- Ongoing communication between the LLAC and the Hub team and the Hub team and the Designated doctor for child deaths and the TAF, to ensure that there is an appropriate focus on learning disability in the case;

This includes the need for expert clinical input on learning disabilities at appropriate points – pre-CDRM meetings, the Reporting Form, the CDRM, the CDOP and in relation to other investigations;

- d) Offering the child's family, or somebody who knew the child well, the opportunity to contribute information about the child's past and recent circumstances (as in the CDR process – Domains A,B & C in the Reporting Form);
- e) Offering the child's family the opportunity to contribute information about the service received by the child at the time of death and whether they feel the care was in any way contributory to the death (as in the CDR process – Domain D in the Reporting Form);
- f) The LLAC updating the LeDeR steering group;
- g) The LLAC signing-off all LeDeR cases and post-CDOP, submitting the Analysis Forms and any accompanying report to the national LeDeR programme; and
- h) The LeDeR steering group monitoring activity to implement the learning from LeDeR reviews to improve the care and treatment of children and adults with a learning disability in their area.

The LeDeR mortality review process is described on the LeDeR website (<http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/>).

9.2.3 Case management and the pen portrait

9.2.3.1 For LeDeR cases, the WELC CDR Hub Coordinator who is the allocated LeDeR reviewer for each individual case will manage that case throughout the CDR process. In addition to the responsibilities they have for all CDR cases, they will work closely with the medical team who attended the child in relation to his or her learning disability to:

- Produce a completed chronology;
- Summarise the key findings and recommendations of the review in the Reporting and Analysis Forms (which form the 'LeDeR report'); and
- Provide feedback on the findings to the family; where the findings are complex or clinical an expert from the child's medical team may need to be involved.

9.3.2.2 The Family liaison worker will develop a pen portrait of the family, using the Initial LeDeR review template in appendix 14. The pen portrait should inform the Reporting Form and be available for the CDRM.

9.2.4 Disability themed CDOP

It may be appropriate for the WELC CDOP to have a learning disability themed meeting at which common contributory factors leading to deaths, and frequently made learning points and recommendations, can be reviewed together through an equalities lens. One of the WELC LACs for the LeDeR programme should attend such meetings.

9.2.4 The LeDeR programme and NCMD

The LeDeR programme will work with the National Child Mortality Database (NCMD) team and NHS Digital, on behalf of the Department of Health and Social Care, to collate completed mortality reports relating to children with learning disabilities, and identify

common themes and patterns at regional and national levels. These will be reported back to CDR partners and CDOPs on an annual basis.

9.3 LeDeR and Serious incident investigations/local Child safeguarding practice reviews

As with other CDR cases, concerns about service delivery may be raised by professionals or the family before or during a CDR. See section 2.5 NHS Serious incident investigations and local Child safeguarding practice reviews above for more information on Serious incident investigations/local Child safeguarding practice reviews.

The decision to inform the family about the initiation of a local CSPR, will be taken by the Local Safeguarding Partnership, having taken into consideration input from the LLAC and/or LeDeR steering group.

10. Support for staff

Effective training and supervision can make a significant contribution to high standards of practice. The WELC CDR System relies on a core group of staff – the CDR Hub team, the Designated doctors for child death and the core CDOP membership (from the Police, the NHS, the Local authorities and the Voluntary and community sector). The CDR System also relies on staff from a range of agencies who are less frequently or infrequently involved. Individual agencies are responsible for ensuring that their staff are competent and confident in contributing to the CDR process.

10.1 Training

In proportion to the amount of engagement staff have in the CDR process, organisations are responsible for ensuring that their staff are competent to contribute effectively to the CDR process. They need to be able to work collaboratively with others within their own agency and across agency boundaries. This requires staff to be confident and competent in relation to:

- The WELC CDR processes (based on this procedure);
- Their own and their agency's role in the CDR process; and
- The roles of the staff and agencies they need to work collaboratively with.

This will be best achieved by a combination of single agency and inter-agency training. The latter benefits from promoting a common and shared understanding of the respective roles and responsibilities of different professionals and contributes to effective working relationships.

All awareness raising and training should include the WELC CDR System principles (see section 1.4 Underpinning principles), emphasising the value of the bereaved families' contributions and their need for sensitivity and support.

10.1.1 The CDR Hub team

In addition to the skills and experience which they bring to their positions, the CDR Hub team and the Designated doctors for child death should be trained in the WELC CDR process and the use of eCDOP. The CDR Hub team should all receive LeDeR Review training – to undertake submission of LeDeR required data as part of one aligned process under the CDR team. All the Hub team members should also receive training or refresher training in engaging with and supporting bereaved families – including professional liaison and an understanding of the experience of grief as a result of a child dying.

10.2 Supervision

The CDR Hub team should receive regular supervision to:

- Ensure competent and accountable performance/practice (soundly based and consistent with procedures);
- Engage the staff member with the organisation (important when a team is relatively autonomous);
- Enable continuing professional development (identifying training and development needs);

- Provide a supportive/restorative function recognising the emotional content of the work.

Core CDR staff and other staff relatively frequently involved in the CDR process, should have access to a supervisory support for:

- Managing workloads
- Sharing information;
- Seeking expert advice e.g. in relation to a case;
- Supporting service users;
- Maintaining quality standards e.g. audits of cases;
- Raising concerns/whistleblowing; and
- Professional development.

The CDR Hub team should receive supervision from the Public health department of the Local authority which hosts the team. In addition support for the team should include access for team members to a psychologist (reflecting the fact that their daily focus is reviewing deaths).

The NHS must provide both management and supervision for the designated doctors for child death. Line managers in health settings have a responsibility to support clinical staff in one of the forms of clinical supervision which best meets their clinical needs and allow protected time to attend.

11. Governance and quality assurance

This chapter sets out the arrangements for governance and quality assurance. Both are in place so that the WELC CDR System can maintain a consistently high standard of review and learning – in respectful acknowledgement of the children who have died and their families.

11.1 Local Safeguarding & CDR Partners

11.1.1 In line with the Children and Social Work Act 2017 Local authorities, Clinical Commissioning Groups and Police forces have Local Safeguarding Partnership (LSP) arrangements. This includes Child death overview panels (CDOP) as a distinct set of arrangements (rather than a subgroup of an LSP); with separate CDOP statutory guidance outside of the revised *Working Together* statutory guidance.

11.1.2 Only two of the three LSP partners have responsibility for reviewing child deaths – the local authority and a clinical commissioning group for an area, any part of which falls within the local authority area. These are the Local child death review partners (CDRP) who have a statutory responsibility to:

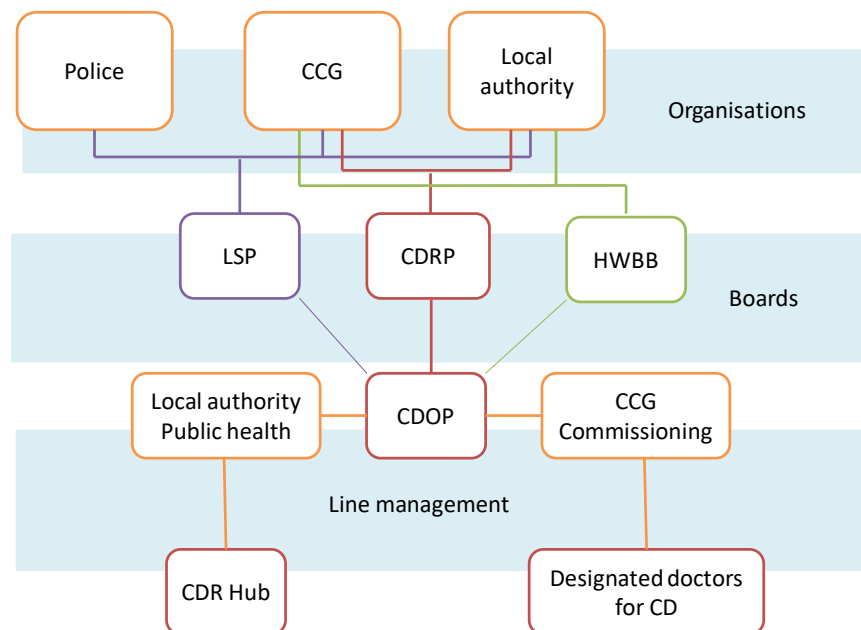
- Make arrangements to review all deaths of children normally resident in the local area and, if they consider it appropriate, for any non-resident child who has died in their area;
- Make arrangements for the analysis of information from all deaths reviewed; and
- Prepare and publish reports on what they have done and effectiveness of arrangements.

11.1.3 The Police are included when it is suspected or identified that abuse or neglect may have influenced the child's death. The case potentially then includes the need to investigate a crime and the case becomes a 'child safeguarding case' in parallel to being a 'child death case'. The CDR response is then a JAR.

11.1.4 The CDR process addresses predominantly public health matters. This fits with the functions of the Health and Wellbeing Board (HWBB) which is responsible for the joint activity required between the Local authority and the CCG to improve the health and wellbeing of the community they serve. The HWBB is the most appropriate place to address preventable factors which may influence the death of a child e.g. smoking, obesity, substance misuse, poor air quality, neighbourhoods not being conducive to child wellbeing. The themes and trends identified through the CDOP process should be placed within the context of the wider health and wellbeing data already considered at HWBB to inform local priorities and action, including joint commissioning.

11.1.4 The relationship between the local organisations, boards and line management for the WELC CDOP and CDR Hub team are illustrated in figure 12.

Figure 12



11.2 WELC governance

The WELC CDR partners have in place a Memorandum of Understanding (MOU) setting out the governance which supports the functioning of the WELC CDR System. Key points from the MOU include that:

- The CDR Hub team will be funded jointly and equally by the WELC Local authorities;
- The CDR Hub team will be hosted (employed and accommodated) by the London borough of Newham;
- The time contributed by the Designated doctors for child death will be commissioned by the WELC CCGs;
- The CDR Hub team will be supported with hot-desk space in the hospitals by the WELC NHS provider trusts;
- The WELC CDOP will be chaired on a rotating basis by the WELC Directors of Public Health;
- The WELC LSPs and CDRPs are jointly and equally responsible for ensuring that this procedure is correctly implemented; including embedding the learning from the child death reviews; and
- The London borough of Newham Public Health Directorate will provide regular information (as described in section 11.3 Monitoring, evaluation and improvement, below) to the other WELC CDR partners to enable all the CDRPs to be assured that the statutory CDR duty is being correctly discharged. This will take the form of

updates in quarterly CDRP meetings in the first year of the WELC CDR System (and less frequently thereafter).

11.3 Monitoring, evaluation and improvement

On behalf of the CDRP, the CCG and Local authority Public Health department (line managers for the CDR Hub team and the Designated Doctors for child death) are responsible for monitoring and evaluating the effectiveness of the WELC CDR System, including the CDOP. They also have responsibility for recommending improvements to the System and Panel.

A WELC CDR System monitoring and evaluation framework must be developed and implemented by the CDR Hub team. It should include tracking of activity at the four key stages of the CDR process e.g:

- Immediate decisions and notifications – did the right professionals participate in the decision-making; were the right professionals notified; quality of information shared; within 24-48 hours
- Investigation and information gathering – did the right professionals receive the Reporting Forms; how many were returned; with good quality information; within 7 or 14 days or longer
- Child death review meeting (CDRM/JAR/mortality or neonates) – was the draft Reporting Form completed before the CDRM; were the right professionals invited to the CDRM; did the right professionals attend; was it a meeting or a panel; was the draft Analysis Form completed; was the meeting timely
- Child death overview panel (CDOP) - draft Analysis Form completed before the CDOP; were the right professionals invited to the CDOP; did the right professionals attend (especially if the meeting was themed); was the meeting timely; and

In terms of family support – did the CDR Family liaison worker contact the family within 24 hours; did the CDR Family liaison worker meet with the family within 5 working days; how many families remained engaged; was good quality feedback received from the family (including LeDeR pen portraits); was the family kept informed according to their wishes.

See the Healthy London Partnership resource: *Gathering feedback from families and carers when a child or young person dies (2019) – a resource to help support professionals in their work with bereaved families and carers*; which includes the *Childhood Bereavement Experience Measure - Family and carer feedback questionnaire*.

eCDOP records many of these performance measures. Not all can be easily reported. Currently and for the foreseeable future the CDR Hub team may need to collect the information using Excel spreadsheets. What is already recorded on spreadsheets includes: a snapshot of what is outstanding on every case at any moment in time; whether Reporting Forms were returned and when; also CDOP member attendance. Spreadsheets are also currently used to record attendance at CDR awareness raising and training sessions delivered by the CDR Coordinators. The CDR Hub team should also use random case sampling to assess the quality and timeliness of the WELC CDR System.

The annual report which should be prepared and produced by the CDR Hub team will provide information, such as, numbers and types of death, the children's ages and circumstances and the outcomes from the reviews. As well as indicating what Public Health and other initiatives may be needed following from analysis of the deaths of the children in

the WELC footprint; the report should describe the results of the monitoring and evaluation of the WELC System. It should describe progress on improvements recommended in the previous year's report and contain recommendations for improving the System based on the current year's activity (see section 8.8 Local reporting and learning).

11.4 Multi-agency working and conflict resolution

The CDR process is a service provided by professionals to children and their families. The WELC CDR System relies on professionals from a range of agencies and disciplines working co-operatively to deliver on content and timescales. Concern or disagreement may arise over another professional's decisions, actions or lack of actions; including timeliness and quality of information given or received.

Professionals should attempt to resolve differences through discussion and/or meeting within a working week. All agencies are responsible for ensuring that their staff are competent and supported to escalate appropriately intra-agency and inter-agency concerns and disagreements if they are not able to resolve issues.

If the professionals are unable to resolve differences within the timescale, their disagreement must be addressed by more senior staff e.g. first line management.

These first line managers should seek advice from their agency's designated safeguarding children professional. If professional differences remain unresolved, the matter must be referred to the heads of service for each agency involved. In the unlikely event that the issue is not resolved by the steps described above and/or the discussions raise significant issues, the matter should be referred to the CDRP for resolution.

11.5 Complaints

In the WELC CDR System the bereaved family may want to make a complaint about the CDR process, this should be dealt with using the London borough of Newham complaints process. If the complaint relates to a single-agency process, incident or staff member from one of the organisations participating in the CDR process, then the complaint should be dealt with through that organisation's complaints process.

Staff participating in WELC child death reviews should welcome complaints as part of the quality assurance and improvement process for the WELC CDR System. Staff should take the approach outlined in *My expectations for raising concerns and complaints* (Local Government Ombudsman, Healthwatch England and the Parliamentary and Health Services Ombudsman, in response to the Francis Inquiry into the failings at Mid Staffordshire NHS Foundation Trust (2013))¹⁶. There are five stages:

- a) Considering a complaint – the service user knew they had a right to complain; was made aware of how to complain (when I first started to receive the service); understood that I could be supported to make a complaint and knew for certain that my care would not be compromised by making a complaint;
- b) Making a complaint – the service user felt that they could have raised concerns with any member of staff; was offered support to help make the complaint; was able to communicate concerns in the way that they wanted; knew that the concerns were taken seriously the first time they were raised; and was able to make a complaint at

¹⁶ *My expectations for raising concerns and complaints: a user-led vision for raising concerns and complaints*. Local Government Ombudsman, Healthwatch and the Parliamentary and Health Services Ombudsman. Available at: www.ombudsman.org.uk

a time that suited them;

- c) Staying informed – the service user always knew what was happening in their case; felt that responses were personal to them and the specific nature of their complaint; was offered the choice to keep the details anonymous and confidential; and felt that the staff handling my complaint were also empowered to resolve it;
- d) Receiving outcomes – the service user received a resolution in a time period that was relevant to my particular case and complaint; was told the outcome of my complaint in an appropriate manner, in an appropriate place, by an appropriate person; felt that the outcomes I received directly addressed my complaint; and felt that their views on the appropriate outcome had been taken into account; and
- e) Reflecting on the experience – the service user would complain again, if they needed to; felt that their complaint had been handled fairly; would happily advise and encourage others to make a complaint if they felt they needed to; understands how complaints help to improve services.

The CDR Family liaison worker should ensure that all bereaved families are aware of this approach as soon as possible and facilitate access to the complaints process in relation to the WELC CDR System and any of the participating organisations.

11.6 Whistle-blowing

Whistleblowing is a failsafe for staff who, acting in good faith, are fearful to/or have been unsuccessful in, representing to their immediate superiors/or have fears about, concerns within the organisation or multi-agency network such as:

- A failure to comply with a legal obligation
- A danger to the health and safety of an individual
- Deliberate concealment of information relating to the above.

The Public Interest Disclosure Act 1998 establishes a framework for responsible whistleblowing. The essence of a whistleblowing system is that staff should be able to by-pass their direct management line, as this may be the area about which their concerns arise. NHS England promotes whistleblowing as an important element of quality assurance and improvement. NHS England policy encourages all staff (and patients) to raise concerns with their organisation directly and at an early stage. See *NHS England's External Whistleblowing Policy (2017)* and the *Freedom to speak up: raising concerns (whistleblowing) policy for the NHS* April 2016.

All organisations party to this procedure should ensure that they have a robust, easily accessible whistleblowing process.

12. Information sharing

The information in this chapter summarises key points from Part B of the London Child Protection Procedures 2019: *Sharing and Processing Personal Information*

The statutory guidance in s10 of the Children Act 2004¹⁷ makes it clear that effective information sharing supports the duty to co-operate to improve the well-being of children. This includes information about adults and other children which may impact the child's safety or welfare.

12.1 The legal bases for sharing and processing personal information

Local authorities and partner agencies are advised to rely on 'legal obligation' and 'public task', as defined in the Data Protection Act 2018¹⁸, as the lawful basis to process any personal information required to establish whether there is a need to safeguard or promote the welfare of a child.

12.1.1 Legal obligation

The processing (collection, storage and sharing of personal data by organisations) of personal information (information that relates to an identified or identifiable individual) is necessary in order to comply with the law.

12.1.2 Public task

The processing of information is necessary in exercising official authority or carrying out a specific task in the public interest or for statutory functions; and the task or function has a clear basis in law.

12.1.3 The lawful basis

In the case [the public task] of processing information in order review child deaths (as part of safeguarding and promoting the welfare of children) the legal basis is:

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.

12.2 Responsibilities to families

Organisations must provide information about data processing through the publication of a data processing notice ("privacy notice"). In addition, professionals must meet the following requirements when sharing personal information:

- People have to be informed that their data will be recorded and shared and the purpose explained to them;

¹⁷ <https://www.legislation.gov.uk/ukpga/2004/31/section/10>

¹⁸ *The Data Protection Act 2018 incorporates the General Data Protection Regulations [GDPR] into British law.*

- The data processing needs to be proportionate to the purpose – that is safeguarding and promoting the welfare of children;
- The information must be accurate; and
- The data must be kept only as long as necessary.

The GDPR sets out seven key principles which should be applied when processing personal information. They can be seen at: <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/principles/>

12.3 Responsibilities about data

12.3.1 Professionals

Information must be shared in an appropriate manner. For professionals this means:

- Share the information which is necessary for the purpose for which it is being shared;
- Share the information with the person or people who need to know;
- Check that the information is accurate and up-to-date;
- Share it in a secure way;
- Establish with the recipient whether they intend to pass it on to other people, and
- Inform the person to whom the information relates, and, if different, any other person who provided the information, if professionals have not already done so and it is safe to do so.

12.3.1 Organisations

For organisations this means that:

- All agencies have arrangements in place that clearly set out the principles underpinning the processing of information and particularly for sharing information – both internally and with other appropriate agencies.
- That there is a shared understanding across agencies about what information should be processed, including when information can be shared, with whom and under what circumstances, and the dangers of not doing so.
- Where possible, develop common documentation, systems and a joint approach to multi-disciplinary and multi-agency information processing;
- There is confidence and trust with partners and families regarding the processing of personal information.
- Information processing leads to less repetition in the provision of personal information for children and their families
- Children and their parents are encouraged to see information sharing in a positive light, as something which makes it easier for them to receive the services they need.

- Good practice in processing information is understood and applied at an early stage as part of preventative work;
- Appropriate agency-specific guidance is produced to complement guidance issued by central government, and such guidance and appropriate training is made available to new staff as part of their induction and ongoing training;
- Guidance and training specifically covers the sharing of information between professions, organisations and agencies, as well as within them, and arrangements for training take into account the value of multi-agency as well as single agency training.

12.3.3 Support for staff

Local authorities and their partner agencies should ensure that all professionals in contact with children and their families:

- Understand what to record and when to share information if they believe that a child may be a child in need, including those children who have suffered, or are likely to suffer, significant harm
- Are aware of and understand this guidance and the legislative and statutory framework which underpins it.
- Know whether they are a data processor and/or a data controller and the responsibilities these roles entail including their legal duties to report data breaches.

Appendix 1. Family support in detail

Source: *Sudden unexpected death in infancy and childhood – The guidelines* (chapter 3 Family Support; pages 25-28)

- 3.1 Immediately upon their arrival at the hospital, the family should be allocated a member of staff to care for them, explain what is happening and provide them with facilities to contact friends, other family members and cultural or religious support. [C]
- 3.2 Where attempts are made at resuscitation, the member of staff allocated to the family should ensure that the family is kept fully informed during the course of the resuscitation and, subject to the approval of the medical staff involved, the family should be given the option to be present during the resuscitation. The allocated member of staff should stay with the family throughout this period to explain what is going on. [C]
- 3.3 It will normally be appropriate for the family to hold and spend time with their infant once death has been confirmed. This may happen in appropriate circumstances after discussion with the lead investigator, even if there are suspicions of possible abuse or neglect contributing to the infant's death, but there must be a discreet professional presence.²⁴⁻²⁷ [B]
- 3.4 Consideration should be given to the capacity of the family to engage in the processes unfolding around them. Particular consideration should be given to issues of language, health or mental capacity. Further considerations must also be given to the faith and culture of the infant and their family. [C]
- 3.5 Where English is not the family's first language, every attempt should be made to provide a translation/interpreting service, including out-of-hours provision, for example through Language Line. Family members, particularly children, should not act as interpreters for their parents. [C]
- 3.6 Responsibility for providing ongoing information and coordinating appropriate care and support for the family is shared between the lead health professional, police investigator and coroner's officer. There needs to be clear liaison between these three as to who will take responsibility for each aspect of care and support. [C]
- 3.7 The family should be told at an early stage that, because their infant's death was unexpected, the coroner will need to be informed and there will need to be a police investigation. This must be explained to the family in a sensitive way, emphasising that these are routine procedures that are followed in any unexpected infant death. [C]
- 3.8 The purpose and process of the joint agency response should be explained to the family, emphasising that all professionals are working together to try and help them understand why their infant has died and to support them. [C]
- 3.9 The family should be informed that, as part of this process, information will be shared with their primary care team, social services and other relevant professionals.² [S]
- 3.10 Unless the cause of death is immediately apparent, the family should be informed that the coroner is likely to order a post-mortem examination. The family should be informed about the post-mortem examination, including the likely venue and timing, any arrangements for moving their infant, and the likelihood that tissues will be retained during the post-mortem examination. This information should be provided in a sensitive and meaningful manner. [C]

- 3.11 The family should be made aware that it may take several weeks to secure the results of the post-mortem examination and for the coroner to come to a conclusion. Every effort should be made to keep the family informed at each stage of the process. The family should receive regular telephone calls from either the healthcare professional supporting the family or the coroner's office to let them know how matters are proceeding. The Lullaby Trust has told us that families greatly appreciate such calls, even if this is to tell them that a further delay is expected.^{24,25,27} [B]
- 3.12 Written information is important and valuable to the family, because much of the detail of what is discussed can be forgotten or lost in the immediate stress of their infant's death. It is important that the family are provided with relevant and up-to-date information, but are not overwhelmed by this. The Lullaby Trust produces a comprehensive leaflet, *When a Baby Dies Suddenly and Unexpectedly*,²⁸ which can be shared with families at the earliest opportunity. Details of local and national support organisations, and information about the post-mortem examination (NHS leaflet) and the child death review process by the local CDOP should also be provided to the family.
- Most families do seek immediate support from external agencies following the unexpected death of their infant, and their involvement with the family over a period of time needs to be factored in as part of the wider multi-agency response. [C]
- 3.13 The family should be clearly informed of the names and contact details of the lead professionals responsible for the joint agency response, including the lead health professional, police investigator and coroner's officer. If it becomes necessary to transfer responsibilities between professionals, the family should be informed of this and introduced to any new professionals involved. [C]
- 3.14 The family must be given clear details of whom to contact, both in working hours and out of hours, should they have any questions or concerns. [C]
- 3.15 Under the Police and Criminal Evidence Act 1984,²⁹ if the police investigator has suspicions that the death may be a crime, the law demands that the suspect's rights are protected and certain legal restrictions apply in terms of how they can be spoken to, and by whom. This is particularly relevant where the possible suspect is a family member. It should be noted that Section 66 of the Serious Crime Act 2015³⁰ amends Section 1(2)(b) of the 1933 Children & Young Persons Act,³¹ such that it is now an offence when a child dies through suffocation while sleeping with an adult, where the adult is under the influence of alcohol or 'prohibited drugs'. The definition of sleeping location has also been updated to include any furniture or surface – it is no longer restricted to 'beds'. [S]
- 3.16 As part of the explanation about the post-mortem examination given to the family, the lead health professional or coroner's officer should explain that tissue samples will be taken and that, following the coroner's investigation, the family can then determine the fate of the tissue according to the Human Tissue Act 2004.³² [S]
- 3.17 Since by definition the cause of death in SUDI is not known, it is important that all organs are examined carefully during the post-mortem examination. For this reason, the potential beneficial effects that organ donation may afford bereaved families are not available in the case of SUDI. If a family voluntarily raises this possibility, they should be sensitively informed that it is not an option in their infant's case.²² [S]
- 3.18 In situations where an infant has an unexpected cardiac arrest, is resuscitated and stabilised on an intensive care unit, but a decision is made subsequently to withdraw

care, there may be opportunities for organ donation if the cause of death is known. Each case should be considered in the context of the specific circumstances regarding organ and tissue donation, and the possibility should be discussed with the coroner and family at an early stage. [C]

- 3.19 Consideration should be given to any practical support needs the family might have, for example, support with suppressing breast milk production, housing or employment-related needs, and support with any anxiety-related symptoms such as sleep disturbance. Many of these issues will be best addressed through the primary care team, who should be kept informed of the process of the joint agency response at all stages. [C]

Appendix 2. Risk factors for suspicious child death

Extracted from A Guide to Investigating Child Deaths ACPO (2014)

Chapter 3. PRELIMINARY ASSESSMENT

Risk factors for suspicious child death (these are in priority of suspicion):

- History of violence to children;
- Inconsistent account;
- Mental health issues;
- Previous atypical hospital visits;
- History of alcohol abuse;
- Child over one year old;
- On child protection plan;
- Known to social services;
- History of drug abuse;
- History of domestic violence;
- Criminal record;
- Previous sibling dead.

The following features were found at autopsy to be significantly associated with suspicious deaths:

- Presence of features of the RADI (rotational acceleration deceleration impact injuries sometimes referred to as the triad which is subdural haemorrhages, brain swelling and retinal haemorrhages);
- Toxicological detection of drugs of abuse;
- Presence of fractures;
- Bruising at unusual sites, for example, torso;
- Post-mortem features indicating that the interval since death was significantly longer than stated by parents or carers.

In particular, suspicious child deaths were often associated with significant social issues for parents or carers, such as previous history of violence to children, mental health issues, alcohol and or drug abuse, or domestic abuse. Learning from serious case reviews into the deaths of children who die where abuse or neglect is a factor support these findings.

The data from the present study indicate that an inconsistent history of events provided by parents or carers is significantly more frequent in the suspicious death group and should therefore be regarded as one of the indicators of possible suspicious death. However, as with all the possible indicators they must be regarded as an indication or factor that merits further investigation. People react in different ways to death and may behave 'suspiciously' but after questioning, their rationale may provide an explanation which removes the suspicion and can negate an arrest (Wate and Marshall, 2009)¹⁹.

¹⁹ Wate R. & Marshall D. *Effective Investigation of Intra-familial Child Homicide and Suspicious Death*, Journal of Homicide and Major Incident Investigation, vol. 5, no. 2, Autumn 2009, pp. 17-38

Appendix 3. Immediate Decision-making Proforma

Child's name:				
Address:				
NHS 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, or sudden with no apparent cause, or in custody, or suspicious circumstances, or stillbirth with no healthcare professional in attendance)	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 or if death meets other criteria for referral to coroner, contact the coroner's office	Yes
3	Has a potential care or service delivery issue occurred?	Yes / No	If Yes contact the patient safety team	Yes
3a	In relation to 3: Has a Datix form been completed?	Yes / No / NA		
3b	In relation to 3: Have obligations under the Duty of Candour been fulfilled (family informed, offered apology, invited to submit questions)?	Yes / No / NA		
4	Are there any immediate actions necessary to ensure the health and safety of others, including family or community members, healthcare patients and staff?	Yes / No / NA	If Yes describe here:.....	
5	Describe the approach to supporting the family (CDR Family liaison worker , Medical lead):			

Appendix 4. Notification of Child Death Form

CDOP Identifier (Unique identifying number assigned by CDOP administrator)

.....

Notification of Child Death

Notification to be reported to CDOP administrator at:

Secure email:

Tel:

The information on these forms and the security for transferring it to the CDOP administrator should be clarified and agreed with your local Caldicott guardian.

Please remember it is a statutory requirement to notify CDOP of all child deaths from birth up to their 18th birthday. If there are a number of agencies involved, liaison should take place to agree which agency will submit the Notification. However, unless you know someone else has done so, please notify CDOP with as much information as possible,

Child's Details

Full Name of Child		
Any aliases		Male / Female
DOB / Age	/ / days/months/years	NHS No.
Address		
Postcode		
Name of school/nursery		

Other significant household and family members (parents, siblings, other relevant adults)

Name	DOB	Relationship	Address

Death details:

Date of death	/ /
Where was the child when they died? ²⁰	
Suspected cause of death	

Case Management:

Is there to be a Joint Agency Response?	Y / N / NK
Death discussed with the medical examiner?	Y / N / NK
Death to be investigated by Coroner?	Y / N / NK
Post-mortem examination?	Y / N / NK

²⁰ The place where the child is believed to have died regardless of where death was confirmed. Where a child is brought in dead from the community and no signs of life were recorded during the resuscitation, the place of death should be recorded as the community location; where a child is brought in to hospital following an event in the community and is successfully resuscitated, but resuscitation or other treatment is subsequently withdrawn, the place of death should be recorded as the location within the hospital where this occurs

Notification Details:

Please outline the circumstances leading to notification. Also include if any other review is being undertaken (e.g. internal agency review); and whether any immediate action is being taken as a result of this death.

Appendix 5. CDR Reporting Form

CDOP Identifier (Unique identifying number assigned by CDOP administrator)

.....

This form is used in the child death review process to gather information about each child's death. Its primary purpose is to enable CDOP to review all children's deaths in their area in order to understand patterns and factors contributing to children's deaths. Please complete those sections on which you hold information. If you do not have information for a particular item please tick NK (not known).

Information on this form will be shared with other professionals for the purposes of the child death review process. All professionals are entitled to share this information without contravening laws on data protection. All information gathered will be stored securely and statutory safeguards (s251) are in place to allow the legal transfer, storage, analysis of identifiable data

Identifying Details - to be removed for the purposes of anonymisation prior to discussion at the CDOP

Name		Date of birth	/	/
NHS No.		Date and time of death	/	/
		:	hrs (24hr)	
Postcode				

Reporting Details

Child's age at death (year/month/day)	/	/
Gender	Male Female Unknown Indeterminate	
Education/Occupation	Infant/young child, not yet in education Nursery School College Home schooled Not in education	

	Left education - Employed - Unemployed - Apprenticeship Not known
Was this death subject to a Joint Agency Response ²¹ ?	Yes No Indicated, but did not occur Not known
Was there a formal Serious Incident investigation or any other internal agency investigation?	Yes No Not known
Is this child's death subject to a Serious case review (child protection)/ local or national Child safeguarding practice review?	Yes No Not known
Is this child's death subject to any other statutory review?	Yes No Not known
Is this child's death subject to any criminal or police investigation?	Yes No Not known
If any of the above investigations apply, please provide details and if possible a copy of the report to the CDOP if it is available	

Summary of Case and Circumstances leading to the death

This section provides information on the nature and manner of the child's death.

Details of the Death

²¹ Joint Agency Response – a multiagency response involving police, social services, and health

Where was the child when they died? ²²	<p>Hospital</p> <ul style="list-style-type: none"> - Midwifery unit - Labour ward / delivery suite - NICU - PICU - AICU - ED - Hospital ward - Theatre <p>Hospice</p> <p>Home</p> <p>Other residence (please specify)</p> <p>Public place</p> <p>School</p> <p>Other (please specify)</p>
What is the cause of death as given on the Medical Certificate of Cause of Death (MCCD), or the coroner's conclusion as to the cause of death, if known?	<p>Cause of death (if known)</p> <p>Death currently being investigated by coroner, conclusion not known</p>
What was the mode of death?	<p>Planned palliative care</p> <p>Withholding, withdrawal, or limitation of life-sustaining treatment)</p> <p>Brainstem death</p> <p>Failed cardio-pulmonary resuscitation</p> <p>Found dead</p> <p>Not known</p>
Was this death discussed with the coroner?	<p>Yes, and the coroner carried out an investigation</p> <p>Yes, and the coroner agreed that the hospital should issue a MCCD</p> <p>No, and MCCD issued by medical team</p> <p>Not known</p>
Was a post-mortem examination carried out?	<p>Yes – coroner's PM</p> <p>Yes – hospital PM</p>

²² The place where the child is believed to have died regardless of where death was confirmed. Where a child is brought in dead from the community and no signs of life were recorded during the resuscitation, the place of death should be recorded as the community location; where a child is brought in to hospital following an event in the community and is successfully resuscitated, but resuscitation or other treatment is subsequently withdrawn, the place of death should be recorded as the location within the hospital where this occurs

	No
	Not known

Circumstances of Death:

Please provide a narrative account of the circumstances leading to the death. This should include a chronology of pertinent events in the background history and the events leading to the death. For hospital deaths this should include details of the health care provided and might include a copy of the death summary. If relevant please also provide information relating to the early family history; pregnancy and birth; infancy; pre-school; school years; and adolescence.

The CDOP is not expected to review original case files or other primary documents, unless specific circumstances deem this necessary.

Were any of the following events known to have occurred? (tick all that apply)	
Death in a neonatal unit (allows linkage to PMRT)	
Death of a child with a life-limiting condition	
Death of a child with an oncology condition	
SUDI/SUDIC	
Other external event (head trauma, vehicle collision, drowning, fire/burns, poisoning, other non-intentional injury)	
Recognised complication of a medical or surgical procedure	
Acute asthma	
Acute epilepsy	
Acute Metabolic / Diabetic Ketoacidosis	
Cardiac: Congenital and Acquired	

Other Chromosomal, Genetic or Congenital Anomaly (not including cardiac)	
Infection (after first week of life)	
Suicide or self-harm, including alcohol or substance abuse	
Violent or maltreatment-related death	

Domain A: Factors intrinsic to the child

This section provides information about the child and any known conditions intrinsic to the child that may have contributed to the death. For neonatal deaths, this includes factors relating to the pregnancy.

Birth weight (gm or lb and oz)	gm lb oz Small for gestational age? Y/N/NK	Gestational age at birth: completed weeks
For neonatal deaths, what was the mother's gravidity and parity?		Number of pregnancies (including this child) Number of births (including this child)
Did the child have any known pre-existing medical conditions (including any congenital anomalies) at the time of death? If yes, please provide details in the narrative section below		Yes No Not known
Did the child have a learning disability? ²³ If yes, please provide details in the narrative section below		Yes No Not applicable – too young (< 4yrs age) Not known
Did the child have any other developmental impairment or disability at the time of death? If yes, please provide details in the narrative section below		Yes No Not applicable – too young Not known
Did the child have any known pre-existing mental health conditions at the time of death? If yes, please provide details in the narrative section below		Yes No Not applicable

²³ In (impaired social functioning), which started in childhood with a lasting effect on development.

		Not known
<p>Did the child have any known drug or alcohol dependency issues?</p> <p>If yes, please provide details in the narrative section below</p>		<p>Yes</p> <p>No</p> <p>Not applicable</p> <p>Not known</p>
<p>Did the child have any known identity or social relationship issues? If yes, please provide details in the narrative section below</p>		<p>Yes</p> <p>No</p> <p>Not applicable</p> <p>Not known</p>
Ethnic group	White	<p>British</p> <p>Irish</p> <p>Any other White background</p>
	Mixed	<p>White and Black Caribbean</p> <p>White and Black African</p> <p>White and Asian</p> <p>Any other mixed background</p>
	Asian or Asian British	<p>Indian</p> <p>Pakistani</p> <p>Bangladeshi</p> <p>Any other Asian background</p>
	Black or Black British	<p>African</p> <p>Caribbean</p> <p>Any other Black background</p>
	Other ethnic group	<p>Chinese</p> <p>Any other ethnic group</p>

	Not known/ not stated
--	-----------------------

Factors intrinsic to the child (including the pregnancy):

Please provide (if necessary) narrative detail relating to the sections above and also consider other known health needs; factors influencing health; growth parameters development/educational issues; behavioural issues; social relationships; identity and independence; any identified factors in the child that may have contributed to the death. For neonatal deaths, include any relevant factors intrinsic to the pregnancy or mother's health

The CDOP is not expected to review original case files or other primary documents, unless specific circumstances deem this necessary.

Domain B: Factors in the Social Environment including parenting capacity

This section provides details of the child's social environment, in particular to understand factors in relation to the care of the child that may have had relevance to the child's death.

	Age	Gender	Relationship to child and/or family	Employment status/ Occupation	Living in primary household? ²⁴
Mother		F	Mother		Y / N / NK
Father		M	Father		Y / N / NK
Siblings (Please number and complete any information known; further siblings can be added below, please include step and half siblings)					
1					Y / N / NK
2					Y / N / NK
Other significant others (e.g. Mother's partner; significant carer. Please complete any					

²⁴ If the child is living in more than one household, for example where the parents have separated, the primary household is where the child spends most of his/her time; please provide any relevant details in the narrative section

<i>information known; further adults can be added below)</i>					
1					Y / N / NK
2					Y / N / NK
3					Y / N / NK

Further family information

(In relation to the primary household or other household where the child spends a significant amount of time)

Who was caring for the child at the onset of the illness or incident that led to their death?	Mother Father Other (please specify) The child/young person him/herself Hospital staff Hospice staff Not known
Were any significant family members known to have any physical health problems/disability? If so, please provide further details in the narrative section below	Mother Father Other significant adult Sibling Not known
Were any significant family members known to have any mental health problems/disability? If so, please provide further details in the narrative section below	Mother Father Other significant adult Sibling Not known

Are the child's parents known to be blood relatives?	Yes/No/Not known
Were any significant family members known to be smokers?	Mother Father Other significant adult Sibling Not known
Were any significant family members known to misuse alcohol?	Mother Father Other significant adult Sibling Not known
Were any significant family members known to misuse drugs?	Mother Father Other significant adult Sibling Not known
Was there any known domestic violence/abuse in the household?	Yes No Not known
Was the child known to children's social care prior to their death/the event leading to their death (tick all that apply)?	Yes, on a child protection plan Yes, as a looked after child Yes, as a child in need Yes, as an asylum seeker Yes, other (please specify) Previously known, but not an open case No Not known

Were there any concerns that child abuse or neglect may have contributed in any way to the child's death?	Yes No Not known
---	--------------------------------

Factors in the social environment including parenting capacity: Please provide (if necessary) narrative detail relating to the sections above. Please consider additional factors if relevant/known: family structure and functioning; provision of basic care (safety, emotional warmth; stimulation; guidance and boundaries; stability); engagement with health services (including antenatal care where relevant); employment and income; social integration and support; nursery/preschool or school environment. Include strengths as well as weaknesses.

The CDOP is not expected to review original case files or other primary documents, unless specific circumstances deem this necessary

Domain C: Factors in the Physical Environment

This section provides details of the physical environment in which the child was living or died, including any issues in relation to housing, the built environment, and environmental safety.

<p>Where was the child at the onset of the illness or incident that led to their death?</p>	<p>Hospital</p> <ul style="list-style-type: none"> - Midwifery unit - Labour ward / delivery suite - NICU - PICU - AICU - ED - Hospital ward - Theatre <p>Hospice</p> <p>Home</p> <p>Other residence (please specify)</p> <p>Public place</p> <p>School</p> <p>Other (please specify)</p>
<p>Factors in the physical environment:</p> <p>Please provide a description of any relevant factors known to you that have not been covered elsewhere. You might consider issues relating to the physical environment the child was in at the time of the event leading to death, or the mother during pregnancy, including: poor quality housing; overcrowding; environmental conditions; home or neighbourhood safety; as well as known hazards contributing to common childhood injuries (e.g. burns, falls, road traffic collisions)</p> <p>The CDOP is not expected to review original case files or other primary documents, unless specific circumstances deem this necessary</p>	

Domain D: Factors in Service Provision

This section provides a profile of services (required or provided) involved with the child and family, including services provided to the mother during pregnancy; the effectiveness of those services in supporting the child and family; and should identify any unmet needs or gaps in service provision. In completing this section please, if possible, consider factors across the pathway of care: pre-hospital/ primary care, emergency, transport, services, secondary and tertiary hospital care; end of life care

Please list key agencies and hospital services involved with this child and family	
Was this child in hospital as a planned admission? ²⁵	Yes No Newborn baby in hospital Not known
Was this child transferred from another hospital?	Yes No Not known
Was this child known to Mental Health Services (child and adolescent or adult mental health services)?	Yes No Not applicable Not known
In a child with a life-limiting condition is there evidence of appropriate parallel planning and engagement with palliative care?	Yes No Not known Not applicable
Were there any issues in identification of illness, assessment, investigation, or	Yes

²⁵ A **patient** admitted, usually as part of a planned sequence of clinical care, who has been given a date or approximate date at the time that the decision to admit was made.

<p>diagnosis?</p> <p>If so, please provide details in the narrative section below</p>	<p>No</p> <p>Not known</p>
<p>Were there any issues relating to treatment or healthcare management plan (tick all that apply)?</p> <p>If so, please provide details in the narrative section below</p>	<p>Medication, IV fluids/ anaesthesia?</p> <p>Infection management?</p> <p>Operation or invasive procedure</p> <p>Clinical monitoring</p> <p>Resuscitation</p> <p>Other</p>
<p>Were there any issues in communication and /or teamwork (either within or between agencies)</p> <p>If so, please provide details in the narrative section below</p>	<p>Yes</p> <p>No</p> <p>Not known</p>
<p>Were there organisational issues that may have contributed to the child's vulnerability, ill-health or death?</p> <p>If so, please provide details in the narrative section below</p>	<p>Yes</p> <p>No</p> <p>Not known</p>
<p>Were any patient safety incidents reported in this case?</p> <p>If so, please provide details in the narrative section below</p>	<p>Yes</p> <p>No</p> <p>Not known</p>
<p>Did the parents or carers express any concerns about the care offered to this child?</p> <p>If so, please provide relevant details in the narrative section below</p>	<p>Yes</p> <p>No</p> <p>Not known</p>

Factors in relation to service provision

Please provide (if necessary) narrative detail relating to the sections above for which you have answered yes. You might consider underlying staff factors, task factors, equipment, and work environment, education and training, and team factors

Also please provide any information known to you in relation to service provision that has not been covered elsewhere. Please describe positive as well as negative aspects of service delivery and give detail to examples of excellent care

Appendix 6. CDR Analysis Form

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

Factors intrinsic to the child 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

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 D - 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.	
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.	

Category	Name & description of category	Tick box below
3	Trauma and other external factors 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).	
4	Malignancy Solid tumours, leukaemias & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.	
5	Acute medical or surgical condition For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.	
6	Chronic medical condition 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.	
7	Chromosomal, genetic and congenital anomalies Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.	
8	Perinatal/neonatal event 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).	
9	Infection 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.	
10	Sudden unexpected, unexplained death Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).	

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

Issues and learning points

Actions

Appendix 7. Criteria for referral of deaths to coroner

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

Reasons for referral to the coroner are as follows:

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

Individual coroners may have their own reporting requirements.

Appendix 8. Routine suggested samples to be taken

Routine suggested samples to be taken immediately after SUDI/C; and to be considered in other circumstances where cause of death is unexplained.

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]

For 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

Source SUDI/C Guideline; page 37.

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]

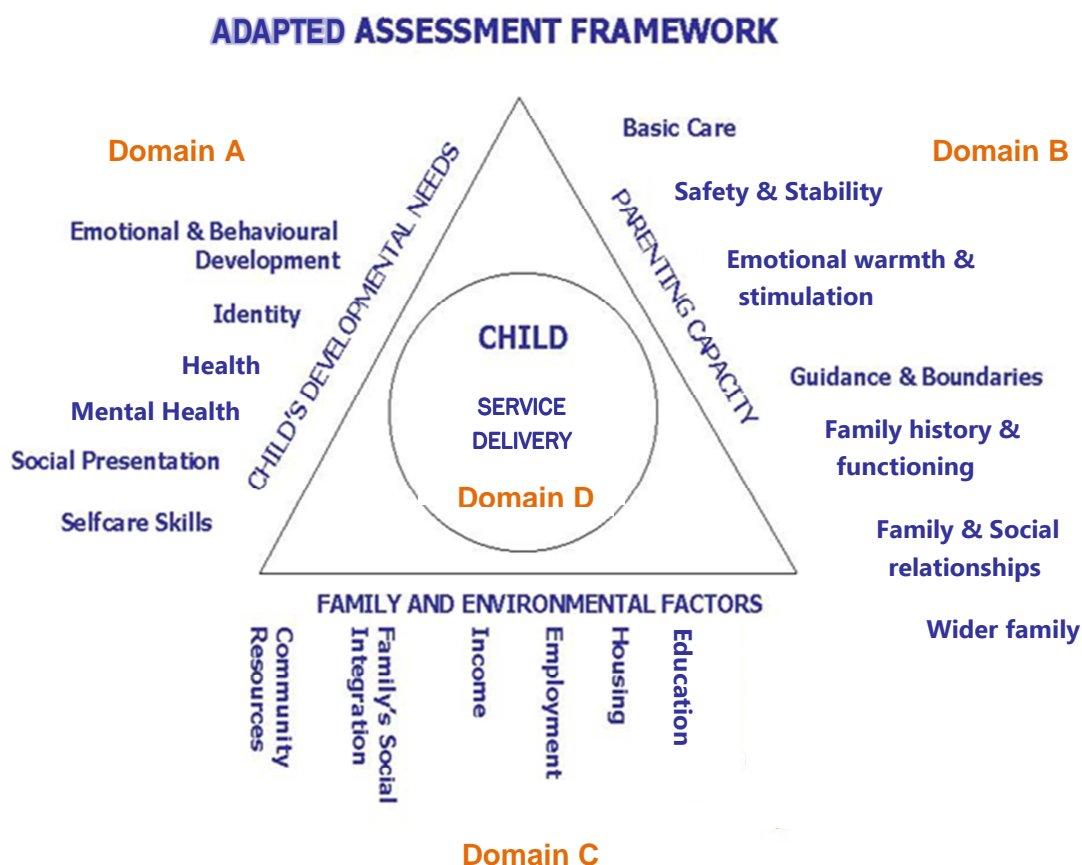
- Ensure the coroner has given permission to take samples.
- All samples taken must be documented and labelled to ensure there is an unbroken 'chain of evidence', using an appropriate 'chain of evidence' proforma.
- This may mean handing samples to a police officer directly, or having the laboratory 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.

Appendix 9. Home life and local environment checklist

An adapted version of the *Framework for the Assessment of Children in Need and their Families* (outlined at figure 13) provides a systematic basis for collecting and analysing information to support systematic reviewing of the factors which *could* have influenced a child's death.

The Framework offers the same four domains as the Reporting Form:

Figure 13



1. Factors intrinsic to the child (Domain A in the Reporting Form)

Factor	Explanation
Emotional and behavioural development	Concerns the appropriateness of response demonstrated in feelings and actions by a child, initially to parents and caregivers and, as the child grows older, to others beyond the family. Includes nature and quality of early attachments, characteristics of temperament, adaptation to change, response to stress and degree of appropriate self-control.
Identity	Concerns the child's growing sense of self as a separate and valued person. Includes the child's view of self and abilities, self-image and self-esteem, and having a positive sense of individuality. Race

Factor	Explanation
	religion, age, gender, sexuality and disability may all contribute to this. Feelings of belonging and acceptance by family, peer group and wider society, including other cultural groups.
Health	<p>Includes growth and development as well as physical and mental wellbeing. The impact of genetic factors and of any impairment need to be considered. Involves receiving appropriate health care when ill, an adequate and nutritious diet, exercise, immunisations where appropriate and developmental checks, dental and optical care and, for older children, appropriate advice and information on issues that have an impact on health, including sex education and substance misuse.</p> <ul style="list-style-type: none"> • Was the child in hospital as a planned admission?²⁶ • Was the child transferred from another hospital? • Was the child known to Mental Health Services
Social presentation	Concerns child's growing understanding of the way in which appearance, behaviour, and any impairment are perceived by the outside world and the impression being created. Includes appropriateness of dress for age, gender, culture and religion; cleanliness and personal hygiene; and availability of advice from parents or caregivers about presentation in different settings.
Selfcare skills	Concerns the acquisition by a child of practical, emotional and communication competencies required for increasing independence. Includes early practical skills of dressing and feeding, opportunities to gain confidence and practical skills to undertake activities away from the family and independent living skills as older children. Includes encouragement to acquire social problem solving approaches. Special attention should be given to the impact of a child's impairment and other vulnerabilities, and on social circumstances affecting these in the development of self-care skills.

2. Factors in the Social Environment including parenting capacity (Domain B in the Reporting Form)

Factor	Explanation
Basic care	Providing for the child's physical needs, and appropriate medical and dental care. Includes provision of food, drink, warmth, shelter, clean and appropriate clothing and adequate personal hygiene.

²⁶ A **patient** admitted, usually as part of a planned sequence of clinical care, who has been given a date or approximate date at the time that the decision to admit was made.

Factor	Explanation
Ensuring safety	<p>Ensuring the child is adequately protected from harm or danger. Includes protection from significant harm or danger, and from contact with unsafe adults/other children and from self-harm. Recognition of hazards and danger both in the home and elsewhere:</p> <ul style="list-style-type: none"> • Was there any known domestic violence/abuse in the household? • Were any significant family members known to be involved with violence outside of the home?
Stability	<p>Providing a sufficiently stable family environment to enable a child to develop and maintain a secure attachment to the primary caregiver/s in order to ensure optimal development. Includes: ensuring secure attachments are not disrupted, providing consistency of emotional warmth over time and responding in a similar manner to the same behaviour. Parental responses change and develop according to child's developmental progress. In addition, ensuring children keep in contact with important family members and significant others.</p>
Emotional warmth	<p>Ensuring the child's emotional needs are met giving the child a sense of being specially valued and a positive sense of own racial and cultural identity. Includes ensuring the child's requirements for secure, stable and affectionate relationships with significant adults, with appropriate sensitivity and responsiveness to the child's needs. Appropriate physical contact, comfort and cuddling sufficient to demonstrate warm regard, praise and encouragement.</p>
Stimulation	<p>Promoting child's learning and intellectual development through encouragement and cognitive stimulation and promoting social opportunities. Includes facilitating the child's cognitive development and potential through interaction, communication, talking and responding to the child's language and questions, encouraging and joining the child's play, and promoting educational opportunities. Enabling the child to experience success and ensuring school attendance or equivalent opportunity. Facilitating child to meet challenges of life.</p>
Guidance and boundaries	<p>Enabling the child to regulate their own emotions and behaviour. The key parental tasks are demonstrating and modelling appropriate behaviour and control of emotions and interactions with others, and guidance which involves setting boundaries, so that the child is able to develop an internal model of moral values and conscience, and social behaviour appropriate for the society within which they will grow up. The aim is to enable the child to grow into an autonomous adult, holding their own values, and able to demonstrate appropriate behaviour with others rather than having to be dependent on rules outside themselves. This includes not over protecting children from exploratory and learning experiences. Includes social problem solving, anger management, consideration for others, and effective discipline and shaping of behaviour.</p>
Family and social	<p>Development of empathy and the capacity to place self in someone</p>

Factor	Explanation
relationships	else's shoes. Includes a stable and affectionate relationship with parents or caregivers, good relationships with siblings, increasing importance of age appropriate friendships with peers and other significant persons in the child's life and response of family to these relationships.
Family history and functioning	<p>Family history includes both genetic and psycho-social factors. Family functioning is influenced by who is living in the household and how they are related to the child; significant changes in family / household composition; history of childhood experiences of parents; chronology of significant life events and their meaning to family members; nature of family functioning, including sibling relationships and its impact on the child; parental strengths and difficulties, including those of an absent parent; the relationship between separated parents.</p> <ul style="list-style-type: none"> • Who was caring for the child at the onset of the illness or incident that led to his or her death? • Are the child's carers birth parents? • Are the child's parents known to be blood relatives? • Are any significant family members known to: <ul style="list-style-type: none"> ◦ Have any physical health problems/disability? ◦ Have any mental health problems/disability? ◦ Be smokers? ◦ Misuse alcohol? ◦ Misuse drugs?
Wider family	Who are considered to be members of the wider family by the child and the parents? This includes related and non-related persons and absent wider family. What is their role and importance to the child and parents and in precisely what way?

4. Factors in the Physical Environment (Domain C in the Reporting Form)

Factor	Explanation
Education	Covers all areas of a child's cognitive development which begins from birth. Includes opportunities: for play and interaction with other children to have access to books; to acquire a range of skills and interests; to experience success and achievement. Involves an adult interested in educational activities, progress and achievements, who takes account of the child's starting point and any special educational needs.

Factor	Explanation
Housing	Does the accommodation have basic amenities and facilities appropriate to the age and development of the child and other resident members? Is the family living in poor quality housing? Is there overcrowding? Is the housing accessible and suitable to the needs of all family members? Includes the interior and exterior of the accommodation and immediate surroundings. Basic amenities include water, heating, sanitation, cooking facilities, sleeping arrangements and cleanliness, hygiene and safety and their impact on the child's upbringing.
Employment	Who is working in the household, their pattern of work and any changes? What impact does this have on the child? How is work or absence of work viewed by family members? How does it affect their relationship with the child? Includes children's experience of work and its impact on them.
Income	Income available over a sustained period of time. Is the family in receipt of all its benefit entitlements? Sufficiency of income to meet the family's needs. The way resources available to the family are used. Are there financial difficulties which affect the children?
Family's social integration	Exploration of the wider context of the local neighbourhood and community and its impact on the child and parents. Includes the degree of the family's integration or isolation, their peer groups, friendship and social networks and the importance attached to them. Is the neighbourhood clean and safe? Can young children play outside safely? Can older children go out safely?
Community resources	Describes all facilities and services in a neighbourhood, including universal services of primary health care, day care and schools, places of worship, public transport, shops, accessible green spaces and leisure activities. Includes availability, accessibility and standard of resources and impact on the family, including disabled members.

5. Services received (Domain D in the Reporting Form)

Please note which of the services below were involved with this child and family.

Is there any indication that the child and family received very good or very poor support (accessibility, timely response, appropriate intervention, ongoing support) from any of the following services historically or recently and/or [did the parents or carers express any concerns about the care offered to this child?](#)

Service	Involved	Very good/poor support. Family concerns
Health <u>Institution:</u> maternity, neonatal, Emergency Department, hospital,		

Service	Involved	Very good/poor support. Family concerns
mental health setting		
Health <u>Community:</u> GP, school nursing, health visiting, sexual health, CAMHS outpatient)		
Education Crèche, childminder, nursery, primary, secondary, home schooling, college, PRU, other		
Children's social care Early Help, Child in Need, Child Protection, Looked After Child, CSE, other		
Police		
YOS (incl. custody)		
Voluntary & Community services (incl. faith groups) Youth services, leisure & sport, domestic abuse, bereavement, counselling, addiction, parenting support		

Appendix 10. Specific cases e.g. suicide

In all cases for both CDRMs and the CDOP experts with insight on the characteristics of each case should contribute to the discussions and address a list of potential relevant areas in the child's life. Examples are given here of some specific cases and the relevant areas for discussion which might apply.

1. Suicide

- Specific risk factors should be considered, including:
 - family factors such as mental illness, alcohol or drug misuse, and domestic violence;
 - Abuse and neglect;
 - Bereavement and experience of suicide;
 - Bullying, including on-line bullying;
 - Suicide-related internet use, including searching for methods and posting suicidal messages;
 - Academic pressures, especially related to exams;
 - Social isolation, especially leading to withdrawal;
- Physical health conditions that may have social impact, and their treatment
- Alcohol and illicit drugs;
- Mental ill health, self-harm, and suicidal ideation;
- Issues relating to self-identity, including gender identity; or
- Exploitation, including child sexual exploitation, radicalisation, and gang-related exploitation.

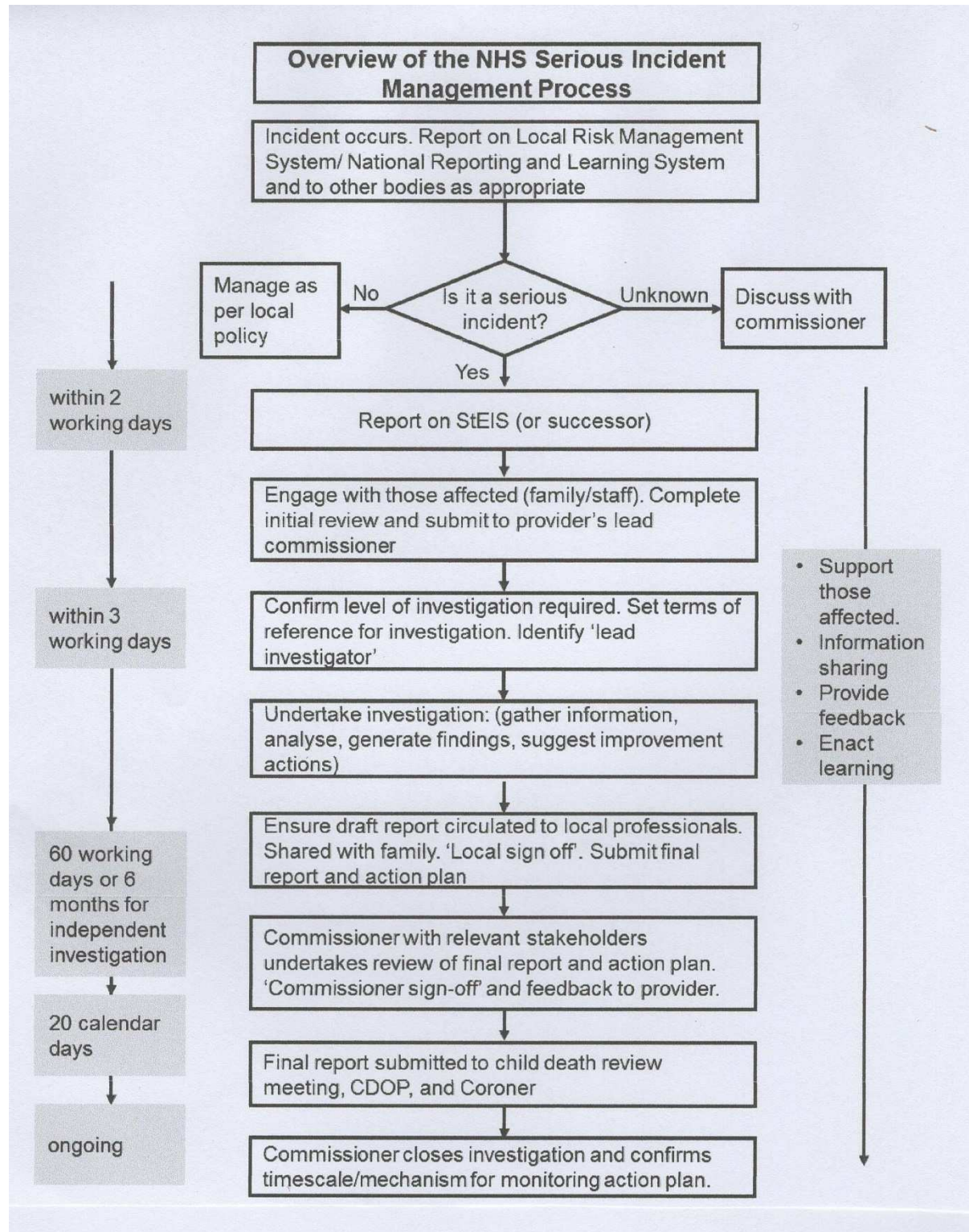
2. Asthma and allergy

For child deaths related to asthma and allergies, see the Healthy London Partnerships (HLP) CDOP Programme Asthma and Allergy Combined Checklists for CDOP and CDMR March 2018 Final

Appendix 11. NHS serious incident and Healthcare Safety Investigations

NHS serious incident investigations, when initiated, should inform the child death review process through providing a detailed analysis of patient safety incidents that may have contributed to the death by the way of a Reporting Form. The process is illustrated in figure 14.

Figure 14



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

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

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

- A local, provider-led concise Root Cause Analysis investigation (Level 1);
- A local, provider-led Comprehensive Root Cause Analysis Investigation (Level 2); or
- A fully independent, externally commissioned Root Cause Analysis Investigation (Level 3). 3.4.5 These have different time frames and processes attached to them. Level 1 and 2 investigations should take no more than 60 working days unless it is necessary to take longer. Level 3 independent investigations should take no more than 6 months unless it is necessary to take longer.

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.

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

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

[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. 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.

These investigations are intended to be conducted under the 'safe-space' principles for those reporting to investigations.

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

Appendix 12. Local Child safeguarding practice review

The purpose of Child safeguarding practice reviews is to identify improvements to be made to safeguard and promote the welfare of children.

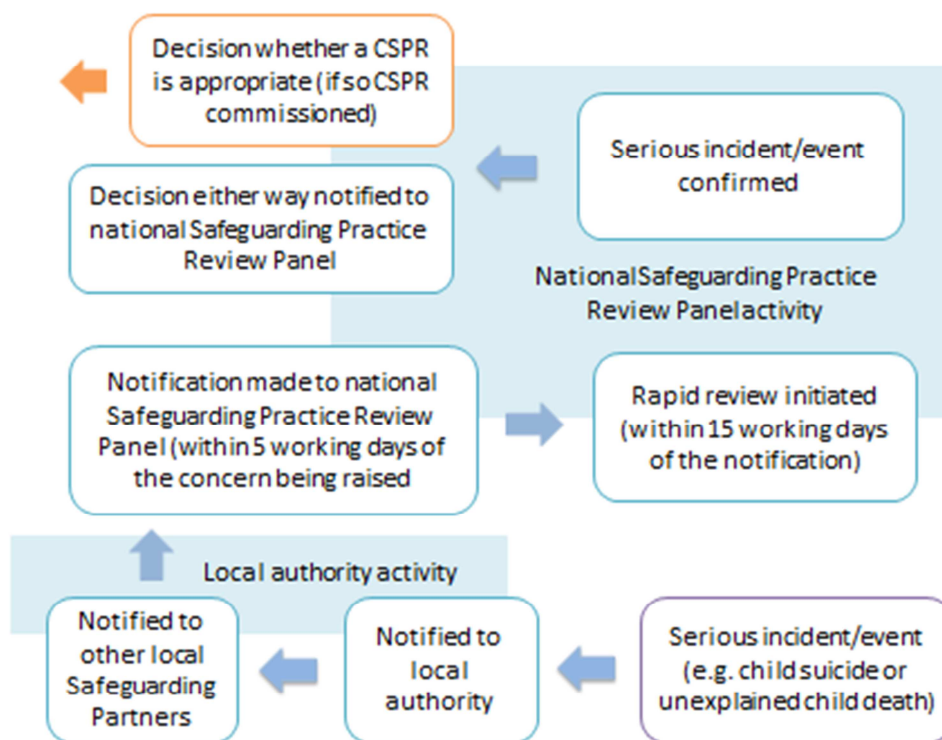
Safeguarding partners responsibilities

Safeguarding partners must make arrangements to:

- Identify serious child safeguarding cases which raise issues of importance in relation to the area; **and**
- Commission and oversee the review of those cases, where they consider it appropriate for a review to be undertaken.

When a serious incident becomes known to the local safeguarding partners, they must consider whether the case meets the criteria for a local review. The process for doing this is illustrated in figure 15.

Figure 15



Notifications

The local authority must notify any serious child safeguarding cases to the national Child Safeguarding Practice Review Panel²⁷ within five working days of becoming aware that a serious incident has occurred.

²⁷ Online notifications to the Panel will be shared with Ofsted (to inform its inspection and regulatory activity) and with DfE to enable it to carry out its functions.

The criteria for judging that an event is a serious child safeguarding incident is that

- Abuse or neglect of a child is known or suspected; and
- The child has died or been seriously harmed (Working Together (2018))²⁸.

Notifications must always be made if abuse or neglect is a cause of, or a contributory factor to, the serious incident, or where it is suspected. The exception to this is the local authority must notify the Secretary of State and Ofsted where a looked after child has died, whether or not abuse or neglect is known or suspected.

The local authority should also report the event to the other Safeguarding Partners in their area (and in other areas if appropriate²⁹) within five working days. The local authority must **also** notify the Secretary of State and Ofsted where a looked after child has died, whether or not abuse or neglect is known or suspected.

The duty to notify events to the national Panel rests with the local authority. Others who have functions relating to children³⁰ should inform the Safeguarding Partners of any incident which they think should be considered for a Child safeguarding practice review. The link to the Child Safeguarding Online Notification form for local authorities to notify incidents to the Panel is available from: [Report a serious child safeguarding incident page on Gov.uk](#)³¹.

Deciding to notify a child death incident

Where the family is known to Children's social care because of a recent incident or current concern about abuse and neglect, and where there has been for example, a suicide or unexplained death, it may well be prudent to notify the event as a serious incident. This is because it may be very unclear at this early stage the extent to which these broader social concerns are relevant to the serious incident.

The Rapid review process can then be used to examine critically the known facts at the time, and the extent to which there is a causal relationship between the abuse or neglect experienced and the incident under review.

Rapid reviews (safeguarding)

The safeguarding partners should undertake a Rapid review on all notified serious incidents; completing the Rapid review within 15 working days of the notification. The safeguarding partners should use the Rapid review to:

- Gather the facts about the case, as far as they can be readily established at the time;
- Discuss whether there is any immediate action needed to ensure children's safety and share any learning appropriately;
- Consider the potential for identifying improvements to safeguard and promote the welfare of children; and

²⁸ 16C(1) of the Children Act 2004 (as amended by the Children and Social Work Act 2017)

²⁹ If, for example, the event relates to a looked after child who has been placed out of area.

³⁰ This means any person or organisation with statutory or official duties or responsibilities relating to children.

³¹ This means any person or organisation with statutory or official duties or responsibilities relating to children.

- Decide what steps they should take next, including whether or not to undertake a child safeguarding practice review.

As soon as the Rapid review is complete, the safeguarding partners should send a copy to the Panel³². They should also share with the Panel their decision about whether a local child safeguarding practice review is appropriate, or whether they think the case may raise issues which are complex or of national importance such that a national review may be appropriate.

- A clear decision as to whether the criteria for a Serious case review (SCR) or local Child safeguarding practice review (CSPR) have been met and on what grounds, and if not, why not. Clear reasons are required;
- A recommendation on whether or not a national review would be considered necessary, and if so, why. Clear reasons are required;
- Any immediate learning already established and plans for dissemination;
- Potential for additional learning;
- If the decision is taken not to proceed with a local CSPR, a summary of why it is thought there is no further learning to be gained;
- Which agencies have been involved in the Rapid review, explaining any agency omission whose involvement would be usually expected;
- Who has been involved in the decision-making process; and,
- Relevant identifying details of the child and family.

The Rapid review should conclude with a decision about whether or not a local CSPR should be commissioned using the criteria set out in Working Together (2018).

Child safeguarding practice reviews (CSPRs)

Safeguarding partners must consider the criteria and guidance below when determining whether to carry out a local CSPR.

The criteria which the local safeguarding partners must take into account include whether the case³³:

- Highlights or may highlight improvements needed to safeguard and promote the welfare of children, including where those improvements have been previously identified;
- Highlights or may highlight recurrent themes in the safeguarding and promotion of the welfare of children;
- Highlights or may highlight concerns regarding two or more organisations or agencies working together effectively to safeguard and promote the welfare of children; and

³² The Panel may share this with DfE if requested, to enable DfE to carry out its functions.

³³ The Child Safeguarding Practice Review and Relevant Agency (England) Regulations 2018.

- Is one which the CSPR panel have considered and concluded a local review may be more appropriate.

Safeguarding partners should also have regard to the following circumstances:

- Where the safeguarding partners have cause for concern about the actions of a single agency;
- Where there has been no agency involvement and this gives the safeguarding partners cause for concern;
- Where more than one local authority, police area or clinical commissioning group is involved, including in cases where families have moved around; and
- Where the case may raise issues relating to safeguarding or promoting the welfare of children in institutional settings³⁴.

Meeting the criteria does not mean that safeguarding partners must automatically carry out a local CSPR. It is for them to determine whether a review is appropriate, taking into account that the overall purpose of a review is to identify improvements to practice. Issues might appear to be the same in some child safeguarding cases but reasons for actions and behaviours may be different and so there may be different learning to be gained from similar cases. Decisions on whether to undertake reviews should be made transparently and the rationale communicated appropriately, including to families.

As soon as the Rapid review is complete, the safeguarding partners should send a copy to the Panel³⁵. They should also share with the Panel their decision about whether a local child safeguarding practice review is appropriate, or whether they think the case may raise issues which are complex or of national importance such that a national review may be appropriate. They may also do this if, during the course of a local child safeguarding practice review, new information comes to light which suggests that a national review may be appropriate. As soon as they have determined that a local review will be carried out, they should inform the Panel, Ofsted and DfE, including the name of any reviewer they have commissioned.

³⁴ Includes children's homes (including secure children's homes) and other settings with residential provision for children; custodial settings where a child is held, including police custody, young offender institutions and secure training centres; and all settings where detention of a child takes place, including under the Mental Health Act 1983 or the Mental Capacity Act 2005.

³⁵ The Panel may share this with DfE if requested, to enable DfE to carry out its functions.

Appendix 13. WELC LeDeR Local area contacts

Waltham Forest CCG

Designated Lead: Safeguarding Adults
NHS Waltham Forest Clinical Commissioning Group
Kirkdale House
7 Kirkdale Road
LONDON E11 1HP

Newham CCG

Associate Director of Quality
NHS Newham CCG
4th Floor, Unex Tower
5 Station Street, London E15 1DA
0203 688 2147

Tower Hamlets CCG

Integrated Learning Disability Commissioner,
Integrated Commissioning, Tower Hamlets CCG & London Borough of Tower Hamlets
NHS Tower Hamlets Clinical Commissioning Group
2nd Floor Alderney Building
Mile End Hospital
Bancroft Road
London, E1 4DG

City & Hackney CCG

Head of Adult Safeguarding
City and Hackney CCG
St. Leonards Hospital
Nuttall Street
London N1 5LZ

Appendix 14. Initial LeDeR review template

How to carry out an Initial Review

Questions 1 – 35 below take information from the death notification. This information has been automatically posted into this document.

Please can you:

- ☐ Review the answers to Questions 1 – 35 whilst completing the Initial Review and then answer the remaining questions. Thank you.

Death notification information

1. Name of the person notifying the death
2. Role and agency of person notifying the death
3. How the reporter knew the person who has died
4. Reporter's contact details (if they are happy to be contacted), Telephone number, email address, postal address and postcode
5. Reporter's preferred method for contact
6. Reporter's comments about the death
7. Who else has been notified about the death? (Tick all that apply)
 - ☐ To the reporter's knowledge, no one else has been notified
 - ☐ Coroner
 - ☐ Safeguarding Board
 - ☐ Child Death Review
 - ☐ Police
 - ☐ Care Quality Commission
 - ☐ Anyone else
 - ☐ I don't know If anyone else has been notified about the death, please provide their contact details if you have them.

Details about the person who died

8. FIRST NAME of the person who died:
9. SURNAME of the person who died:
10. Was the person known by any other name? If so, what was it?

11. Date of BIRTH:
12. Date of DEATH;
13. Age at Death:
14. Gender:
15. How does the reporter believe the deceased person identified their ethnic group? (Tick One) ☐ White ☐ Mixed / Multiple ethnic groups ☐ Asian / Asian British ☐ Black / African / Caribbean / Black British ☐ I don't know ☐ Other: Click here to enter text.
16. Marital Status of the person who died ☐ Single ☐ Married / Partner ☐ Divorced / Separated ☐ Widowed ☐ I don't know ☐ Other: Click here to enter text.
17. In which area of England was the person registered with a GP? ☐ North: Yorkshire & the Humber ☐ North: Lancashire & Greater Manchester ☐ North: Cumbria & the North East ☐ North: Cheshire & Merseyside ☐ Midlands & East: North Midlands ☐ Midlands & East: Central Midlands ☐ Midlands & East: West Midlands ☐ Midlands & East: East Midlands ☐ South: South West ☐ South: South East ☐ South: Wessex ☐ South: South Central ☐ London Region ☐ Unknown
18. NHS Number:
19. Did they have any known conditions or health problems?
20. Usual address and postcode of the person who died
21. Did the person who died usually live alone?
22. Was the person who died in an out-of-area placement? If yes, please state which area was their 'home' area
23. Was the person subject to any restrictive legislation? ☐ None ☐ Deprivation of Liberty Safeguards (DoLS) ☐ Section of the Mental Health Act ☐ Detention in police custody/imprisonment ☐ Other: Click here to enter text. ☐ I don't know

If the person was subject to any restrictive legislation, please describe more fully (e.g. dates, reason for restriction)

Those who knew the person who died

24. Please can you provide the contact details of someone who knew the person well, which may or may not be yourself (e.g. address, email, telephone number)
25. How did they know the person who died
26. Name of person's GP and contact details of GP surgery (e.g. postal address, email, telephone number)

Details of the Death

27. What was the place of death ☐ Hospital ☐ Usual place of residence ☐ Hospice / palliative care unit ☐ Home of relative or friend ☐ Residential / nursing home that was not usual address ☐ I don't know ☐ Other

Please provide the name and address of the place where the person died:

28. What was the cause of death (as described on the Cause of Death Certificate 1a/1b/1c/2)
29. What did reporter think the cause of death was?
30. Will there be a post-mortem?
31. Will there be a Coroner's inquest? 32. Will there be any other investigation into the death? If YES please describe 33. Was the reporter surprised that this person died from this cause at this time? Give an explanation of response

Initial Review Of Death – additional questions

In preparation for the initial review of the person's death, please:

- ☐ Identify someone who knew the person well (e.g. close family member) and speak to them about the person themselves and the circumstances leading to their death. Ask them to help you complete a pen portrait of the person who has died, and a timeline of the circumstances leading to their death.
- ☐ Review at least one set of relevant case notes (e.g. hospital record, summary record from GP, social care record).
- ☐ Check and complete the information received at notification.

In order to upload case review notes from agencies, please contact the individuals involved and ask them to use the following link. When they click on this link they will be asked to identify themselves, and will then be able to upload files. These files will appear inside that case review process.

34. Optional space for you (the reviewer) to write any notes, comments or thoughts of your own about this review. You are welcome to delete these prior to submitting your completed review if you so wish.
35. Information provided at notification stage has been checked and completed. ☐ Please tick to confirm
36. Someone who knew this person well has provided information to the reviewer about the person themselves and the circumstances leading to their death. ☐ Yes ☐ No
37. Please explain who has provided information and in what capacity. If no one who knew the person well has provided information, please explain why.
38. Please describe what relevant case notes you have reviewed
39. Please confirm that at least one set of relevant case notes (e.g. summary GP record, hospital notes relating to most recent hospitalisation, social care records) has been reviewed. ☐ Please tick to confirm
40. Pen portrait of the individual

Pen portrait of the individual. Please include information about the person themselves, their health, the environment in which they were living, and a description of their service use. You

can find guidance about writing a pen portrait of an individual in the 'help' section on your LeDeR dashboard area.

41. Name of Local Authority/Health Commissioner

42. Was the person who died in regular contact with any of the following people?

- ☐ Their family / relative
- ☐ An attorney under a Lasting Power of Attorney direction
- ☐ A Deputy agreed / appointed by the Court of Protection
- ☐ An advocate
- ☐ Other:

Please add any further details:

43. Did the person who died usually receive statutory or voluntary sector support?

- ☐ Yes ☐ No If YES did they receive support:
 - ☐ Daytime only ☐ Day and night (waking night)
 - ☐ Day and night (sleeping night)

Please describe any services and supports that the person received

44. Did the person who died experience any of the following changes in service provision in the past year?

- ☐ Yes, change in service PROVISION (e.g. hours of support)
- ☐ Yes, change in service PROVIDER
- ☐ Yes, change in PLACE of provision
- ☐ No
- ☐ Not applicable as not in receipt of services

If YES can you provide details (e.g. number of changes, what changes were made, impact of changes)

45. Please provide a short summary of the circumstances leading to the person's death and then enter the key events in the timeline framework below. You can find guidance about completing the timeline in the 'help' section on your LeDeR dashboard area.

Timeline for circumstances leading to death

You can add rows by clicking into the last row of the table, going to 'Table Tools - Layout' and choosing the 'Insert Below' option from the 'Rows & Columns' section. Alternatively, click into the last row of the table, right click, select Insert – Insert Rows Below.

Date

Reported by / where evidence obtained from

Circumstances

46. Has anyone expressed any concern about this death? ☐ Yes ☐ Not to my knowledge

If yes, please add any comments about this here

47. If the person had Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) documentation, had this been fully and correctly completed with a clear and appropriate rationale for the decision not to resuscitate?

☐ Yes, and documentation was correctly completed

☐ Yes, but the documentation was NOT correctly completed

☐ No DNACPR order

Please add any comments about this here

8. Based on what you have found in conducting this review, would an assessment of mental capacity have been relevant for this person? ☐ Yes ☐ No

If yes, is there any indication that mental capacity has been considered? ☐ Yes ☐ No

Please add any comments about this here

49. From the evidence you have, do you think that the person was treated in a timely way without any delays in their care or treatment that adversely affected their health? ☐ Yes ☐ No

Please add any comments about this here

50. From the evidence you have, do you think that this death might be attributable to abuse or neglect in any setting? ☐ Yes ☐ No

Please add any comments about this here

51. From the evidence you have, do you think that the person experienced standards of care, including the coordination of their care, that might indicate organisational dysfunction, danger or inadequacy? ☐ Yes ☐ No

Please add any comments about this here

52. Do there appear to be any gaps in service provision that might have contributed in any way to the person's death? ☐ Yes ☐ No

Please add any comments about this here

53. To your knowledge, has the person ever been subject to safeguarding concerns, or is there a current Adult Protection Plan or Child Protection Plan in Place? ☐ Yes ☐ No

Please add any comments about this here

54. After reviewing this death, are you surprised that the person died from this cause at this time? ☐ Yes ☐ No

Please add any comments about this here

55. After reviewing this death, do you think that any further learning could be gained from a multiagency review of the death that would contribute to improving practice? ☐ Yes ☐ No Please add any comments about this here
56. From the information that you have, please grade your overall assessment of the care received by the person:

- ☐ 1. This was excellent care and met current best practice.
- ☐ 2. This was good care, which fell short of current best practice in only one minor area.
- ☐ 3. This was satisfactory care, falling short of current best practice in two or more minor areas, but no significant learning would result from a fuller review of the death.
- ☐ 4. Care fell short of current best practice in one or more significant areas, but this is not considered to have had the potential for adverse impact on the person and no significant learning would result from a fuller review of the death.
- ☐ 5. Care fell short of current best practice in one or more significant areas, although this is not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death.
- ☐ 6. Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.

Note: If you think that you have insufficient information and are unable to grade your overall assessment of the care received by the person, please seek further information until you can do so - for example, review further case notes or speak to those who knew the person well.

57. Please add any additional comments you might have in relation to this review (e.g. any examples of best practice that should be recognised; any particular difficulties you have had in completing this review). Additional Comments
58. Please add any comments that you might have about your experience of the LeDeR Review process or IT System. Comments

Next Action

59. Please review the options below and select one to decide your next action.
- 1. If you have answered any questions with an answer that is coloured red, a multiagency review of this death is recommended. ☐ Please tick box if this applies
 - 2. If this person meets the criteria for the current priority themed review deaths (the person was aged 18-24 (inclusive) when they died, or they came from a non-white ethnic background), a multiagency review of the death is required. ☐ Please tick box if this applies

3. If your initial assessment of this death suggests that NO multiagency review is required, but you think that such a review might be appropriate, (i.e. further learning could be gained from a multiagency review of the death that would contribute to improving practice), please do conduct a multi-agency review. ☐ Please tick box if this applies
4. If your initial assessment of this death suggests that NO multiagency review is required, and you consider that no further learning could be gained from a multiagency review of the death that would contribute to improving practice, please complete the Action Plan below and submit the Initial Review and Action Plan to your local area contact. ☐ Please tick box if this applies

YOUR NEXT ACTION:

Please now either START A MULTI-AGENCY REVIEW

Or

COMPLETE AN ACTION PLAN and submit the Initial Review and Action Plan to your local area contact.

Action plan

Please detail any actions that you recommend following this review of a person's death

Description of action

Date agreed

Date for review/ completion

Person responsible for action

Outcome/comments

Appendix 15. Roles and responsibilities of CDOP members

Chair

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

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

CDR Co-ordinator

The CDR Co-ordinator should, in conjunction with the Designated Doctor and CDOP Chair:

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

Designated doctor for child deaths

The designated doctor should:

- Be responsible for the child death review process;
- Advise on the appropriate response to a death in an adult ICU;

- Advise CDOP regarding necessary experts required to inform ordinary and themed panels;
- Advise CDOP in the identification of modifiable contributory factors;
- Liaise, as appropriate, with regional clinical networks to ensure that themed panels are properly co-ordinated;
- Assist CDOP in the development and implementation of appropriate preventative strategies to reduce the child deaths; and
- Prepare an annual report with the Chair summarising the activities of CDOP.

Nurse/Midwife

The CDOP nurse and/or midwife should:

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

Health professional (hospital/community)

The health professional shall:

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

Police

The Police representatives should:

- Provide, as appropriate, CDOP with information on the status of any criminal investigation;
- provide CDOP with expertise on law enforcement practices, including investigations, interviews and evidence collection;
- Assist CDOP to evaluate issues of public risk arising out of the review of individual deaths; and

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

Children's Social Care and Safeguarding

The Children's Social Care and Safeguarding representatives should:

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

Education Representative:

The Education representative should:

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

Lay Representative:

The Lay representative should:

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

Appendix 16. Suggested membership for themed panels

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

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

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

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
Police	

Appendix 17. Terminology; roles and responsibilities and acronyms

Terminology; roles and responsibilities

The term 'child death review process' refers to the entirety of the process described in this procedure; within the procedure the following definitions apply:

Case manager

A professional appointed by an NHS provider trust where there is more than one investigation, 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 CDR Family liaison worker, who acts as an ongoing single point of contact for families.

Child

The child death review process covers children; a child is defined in the Act as a person under 18 years of age. A child death review must be carried out for all children regardless of the cause of death. This includes the death of any live-born baby where a death certificate has been issued. In the event that the birth is not attended by a healthcare professional, child death review partners may carry out initial enquiries to determine whether or not the baby was born alive. If these enquiries determine that the baby was born alive the death must be reviewed.

For the avoidance of doubt, it does not include stillbirths, late foetal loss, or terminations of pregnancy (of any gestation) carried out within the law. Where stillbirth refers to a baby born without signs of life after 24 weeks gestation; and late foetal loss describes 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 Overview Panel (CDOP)

A multi-agency panel set up by CDR partners to review the deaths of all children normally resident in their area, and, if appropriate and agreed between CDR partners, the deaths in their area of non-resident children³⁶, in order to learn lessons and share any findings for the prevention of future deaths. The CDOP should be informed by a standardised report from the CDRM, and ensures independent, multi-agency scrutiny by senior professionals with *no named responsibility* for the child's care during life. In practice, CDOPs will conduct the independent multi-agency scrutiny on behalf of the local CDR partners responsible for ensuring that the review of deaths of all children normally resident in that area takes place.

Child Death Review Hub team

³⁶ In all cases, legal responsibility for ensuring that arrangements are made to review the death of a child lies with the CDR Partners where the child is normally resident; more information can be found in chapter 8.

The CDR Hub is the team of four CDR Co-ordinators and a CDR Family liaison worker who have responsibility for the day-to-day co-ordination of the WELC CDR System. The CDR Co-ordinators will support the Designated Doctors for child death. Their key functions include:

- Acting as the single point of contact (SPOC) for all deaths that happen within WELC footprint;
- Managing the flow of CDR information;
- Ensuring the family is informed, able to contribute and sign-posted to support;
- Arranging and/or supporting all CDR meetings, including providing a secretariat to the CDOP;
- Administering eCDOP to be optimally efficient;
- Building relationships to support effective multi-agency working;
- Ensuring that parallel investigations are managed well;
- Quality assuring the CDR process;

The CDR Co-ordinators will also be LeDeR reviewers.

Child Death Review (CDR) Partners

These are a local authority area, or more than one area, in England and any CCG for an area any part of which falls within the local authority/ies area (Section 16Q (and their responsibilities 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.)

Children's social care has lead responsibility for identifying as a 'serious incident' any deaths in which there are concerns that abuse and/or neglect were contributory factors to the death; including failure by supporting agencies (see below, the Medical Examiner has responsibility for highlighting health services failings). All serious incidents must be reported to the local safeguarding partnership (LSP).

Child Death Review Meeting (CDRM)

A multi-professional meeting where all matters relating to an individual child's death are discussed. The Child Death Review Meeting (CDRM) should be attended by professionals who were directly involved in the care of the child during his or her life, *and* any professionals involved in the investigation into his or her death.

A CDRM should be flexible and proportionate; can review the deaths of more than one child; and the practitioners involved, and should *not* be limited to medical staff.

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

Clinical Commissioning Groups (CCGs)

CCGs have responsibility for employing or have arrangements in place to secure the expertise of employing or have arrangements in place to secure the expertise of, consultant paediatricians in the role of Designated paediatrician or Doctor for child deaths (Health and Social Care Act 2012)

Coroner

The coroner has a duty to inform the Local Safeguarding Partners for the area in which the child died within three working days of the fact of an inquest or post-mortem; and has been granted powers to share information to inform a child death review and/or a CSPR (Child Safeguarding Practice Review) (Coroners Rules 1984 (as amended by the Coroners (Amendment) Rules 2008).

Designated doctor for child deaths

A senior paediatrician, appointed by the CDR partners, responsible for ensuring that relevant professionals are notified about a child's death; and for co-ordinating the health responses to child deaths. The Designated doctor for child deaths will take responsibility for ensuring that all health responses are implemented, and for ongoing liaison with the police and other agencies.

Where no out-of-hours rota for responding to child deaths exists in a locality, the role of lead health professional role should be taken by the senior attending paediatrician. This should then be handed over to the Designated doctor for child deaths at the earliest opportunity.

Family

The term 'family' is used in this procedure inter-changeably to refer to both the parents or primary carers for the child who has died; and also for the whole family i.e. including the child's siblings. There may be some occasions when it could also include extended family members. Professionals should use their judgement to as to when their focus should be limited to a parent or carer's needs and when to encourage them to include, rather than exclude, their remaining children – who are likely to benefit from appropriate information and support.

Forms: Notification, Reporting, Analysis

Three standard forms should be used in the child death review process:

- **Notification Form** for initial notification of a death to CDR partners
- **Reporting Form** for gathering information from agencies or professionals who have information relevant to the case. Composite Reporting forms should be completed by the relevant responsible officer prior to being shared with the relevant CDRM. Additional information may come to light at the CDRM, at which point the Reporting Form should be amended to take into account the new information. For certain child deaths, a supplementary Reporting Form should also be completed as required
- **Analysis Form** initially drafted at the CDRM and completed at CDOP for evaluating information and identifying lessons to be learned. The Analysis Form is the final output of the child death review process. From 2020 this information should be shared with the National Child Mortality Database (NCMD), when operational. Specified data to NHS Digital for the transitional period will be notified to Child Death Review Partners separately. The mechanism for collecting, and the content of, this data will evolve as the NCMD.

The forms can be found in appendix 2.

Inquest

An inquest is an official enquiry by a coroner into the cause of a sudden, unexplained or violent death of a person. The inquest aims to determine the identity of the person that died and how, when and where they came by their death.

Joint agency response

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

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

The full process for a Joint Agency Response is set out in the *SUDI/C Guidelines*.

CDR Family liaison worker

The CDR Family liaison worker performs a pivotal role as a single point of contact for the bereaved family. The CDR Family liaison worker is someone the family can turn to for information on the child death review process, who can signpost them to sources of support and advocate for them, and point of contact throughout the CDR process from beginning to end.

The CDR Family liaison worker in the CDR Hub team will be from a voluntary and community sector child bereavement organisation. S/he will be available for all families, however some families may prefer their Family liaison worker to be a practitioner they already had a relationship with (e.g. a social worker) or whom they feel is more appropriately placed (e.g. from a NHS bereavement team). The CDR Family liaison worker will also be trained as a LeDeR reviewer and will fulfil the requirements of the LeDeR process, such as, undertaking the pen portrait.

LeDeR Review Programme

The Learning Disabilities Mortality Review (LeDeR) Programme is a national programme which reviews all deaths for people with learning disabilities aged 4 years and above. The programme is funded by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP). The LeDeR programme sits within the National Quality Board (NQB) 'Learning from Deaths' guidance 2018.³⁷ The programme commenced in June 2015 and was extended nationally in April 2017 with the expectation that all deaths of people

³⁷ <https://www.england.nhs.uk/wp-content/uploads/2018/08/learning-from-deaths-working-with-families-v2.pdf>

with a learning disability would receive an initial review of the circumstances surrounding their deaths in order to:

- a) capture any learning from deaths to inform improved care, at local and national levels; and
- b) Improving the way health services engage with families and support them following a death.

LeDeR Project officer

The North East London area has a Project Officer to support in the completion of reviews, this role helps co-ordinate the LeDeR process across the region, providing administrative support to all reviewers, Local Area Contacts, as well as supporting interface with families and the different organisations. This role also supports reviewers to access any clinical advice as required. It is anticipated that the CDR process will manage all reviews within its remit, however advice can be accessed from the LeDeR Project officer.

LeDeR reviewer responsibilities

The LeDeR reviewer responsibilities will be undertaken by the staff in the WELC CDR Hub. The responsibilities include:

- Receiving notification of the death of a child with learning disabilities
- Visiting the family to build a pen portrait of the child who has died
- Communicating with the Local area contact on progress of the CDR
- Ensuring that learning disability-related issues are appropriately represented in the CDR Reporting and Analysis Forms; and
- Submitting the Analysis Form to the Local area contact and the LeDeR programme.

LeDeR steering group

Each area of England has a LeDeR steering group who are responsible for developing plans and monitoring activity to implement the learning from LeDeR reviews to improve the care and treatment of children and adults with a learning disability in their area.

LeDeR Local Area Contact (LLAC)

The LeDeR Local Area Contact is the link between the central LeDeR programme team, the Local LeDeR Steering Group and local LeDeR reviewers. The role of the Local Area Contact is to receive notifications of deaths of children with learning disabilities, to monitor allocation of cases to local LeDeR reviewers, and to quality assure the standard and timeliness of reviews. The LLAC receives and signs off completed review documents and action plans and works with the Local Steering Group to take appropriate action.

Local Child Safeguarding Practice Review (CSPR)

When a child dies, and abuse or neglect is known or suspected, the local safeguarding partnership (LSP) must consider undertaking a CSPR where it appears that improvements might be needed to safeguard and promote the welfare of children. This may include because there appear to have been failings in single or multi-agency working, or because

there was no agency involvement. In such a case the LSP must undertake a Rapid review to determine whether to carry out a local CSDR. They should inform the Panel, Ofsted and DfE.

Local Safeguarding & CDR Partners

For the purposes of making arrangements to work together to safeguard and promote the welfare of local children (including identifying and responding to their needs), the Local Safeguarding Partners (LSP) are the local authority; a clinical commissioning group for an area, any part of which falls within the local authority area; and the chief officer of police for a police area, any part of which falls within the local authority area.

For the purposes of making arrangements to review the deaths of children normally resident in the local area (and if they consider it appropriate, for those not normally resident in the area), the local Child Death Review Partners (CDRP) are the local authority; and a clinical commissioning group for an area, any part of which falls within the local authority area.

Medical Certificate of Cause of Death (MCCD)

The MCCD is 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 it is required; engage with the bereaved family to understand any concerns; and to ensure that possible clinical governance concerns have been highlighted.

There is a national system of Medical Examiners (introduced from April 2019) to provide independent medical scrutiny of all non-coronial deaths.

Medical lead

The Medical lead might either be the doctor that the family had most involvement with while the child was alive or the Designated Doctor for child death on-duty at the time of death. Deciding who the Medical lead will be for a family must be decided jointly by the relevant NHS acute trust and the child's GP.

Multi-agency partners

- Local authority services including – children's social care; adult social care; housing; environmental health and planning services; libraries; sport, culture, play and leisure; and education
- Other education establishments
- Social landlords
- The NHS and private and voluntary health services in London – Local Acute NHS provider trusts, NHS mental health Trusts; Health Visiting, School Nursing, Children's Continuing Care and the Primary Care services provided by General Practitioners (GP), Pharmacists, Dentists, and other allied health professionals and the voluntary and community sector.

- London Ambulance Service
- Metropolitan Police
- Children and Family Court Advisory and Support Service (CAFCASS)
- London probation service
- Courts
- Crown Prosecution Service
- The Prison Service and high security hospitals
- The secure estate for children
- The armed forces
- Immigration services
- The Refugee Council
- London Fire Brigade (London Fire and Emergency Planning Authority)
- Transport for London
- The private and voluntary sectors.

National Child Mortality Database (NCMD)

The National Child Mortality Database (NCMD) is the national mechanism for collecting a minimum dataset from the Child Death Overview Panel (CDOP) reviews of all child deaths in England. It is managed by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. Through the collection, analysis and public reporting of information from all child deaths across England the NCMD will drive improvement in the quality of health and social care for children in England to help reduce potentially avoidable deaths.

NHS Serious Incident

Serious Incidents in health care are adverse events where the consequences to patients, families and carers, staff or organisations are so significant or the potential for learning is so great, that a heightened level of response is justified. The NHS Serious Incident Framework describes the process and procedures to help ensure Serious Incidents are identified correctly, investigated thoroughly and, most importantly, learned from to prevent the likelihood of similar incidents happening again.

Peri-natal 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 <22+0 weeks gestation, where a death certificate has been issued. The PMRT is integrated with the national collection of perinatal mortality surveillance data.

Post-mortem examination

A detailed physical examination of the child after he or she has died. In most cases this will involve an examination by a specialist pathologist including opening of the body and head, collection of samples for ancillary investigations and microscopic examination of tissue samples. The results of all such investigations are usually required before a medical cause of death can be provided.

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.

Registrar General

The registrar general has the power to share child death information with the Secretary of State, including about children who die abroad (section 32 of the Children and Young Persons Act 2008).

Registrar of births and deaths

Are required by the Children & Young Persons Act 2008 to inform the LSP within 7 days of a death of child which they have registered or re-registered; or notify the LSP if they issue a Certificate of No Liability to Register in respect of what appears to be a child death.

Sudden infant death syndrome (SIDS)

The sudden and unexpected death of an infant under twelve months of age, with onset of the life threatening episode apparently occurring during normal sleep, which remains unexplained after a thorough investigation, including performance of a complete post-mortem examination and review of the circumstances of death and the clinical history. It is preferred as a registered cause of death to other equivalent terms such as 'unascertained' or 'undetermined'. Labelling a death as SIDS does not exclude the possibility that the child may have died of a natural or external cause that we have been unable to ascertain or prove conclusively³⁸.

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 death³⁹. 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 and unascertained deaths

An unexpected death is one in which the death follows so rapidly from the onset of symptoms that the cause of death could not be certified with confidence by a medical practitioner familiar with the patient. Although the World Health Organisation accepts a limit

³⁸ Krous et al. 2004. Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach. *Pediatrics* 114: 234-238

³⁹ Fleming, PJ et al (2000). *Sudden unexpected death in Infancy*. The CESDI SUDI Studies 1993-1996.

of 24 hours between the onset of symptoms and death, a much shorter time interval of within a few hours of apparently good health is preferred⁴⁰.

An unascertained death is a legal term often used by coroners, pathologists and others involved with death investigation, where following a complete investigation by a coroner, no specific cause of death (whether natural or external) has been found⁴¹. This will include those deaths meeting the internationally agreed definition for sudden infant death syndrome⁴² (SIDS), and those registered as unascertained.

WELC footprint

The WELC footprint comprises the London Boroughs of **W**altham Forest, Newham, Tower Hamlets and Hackney (**E**ast **L**ondon) and the **C**ity of London Corporation; including within them the four Clinical commissioning groups (CCGs) of Waltham Forest, Newham, Tower Hamlets, City and Hackney; and their NHS provider trusts, Barts Health and Homerton Hospital.

Acronyms

CCG – Clinical Commissioning Group

CDOP – Child death overview panel

CDR – Child Death Review

CDRM – Child death review meeting

DoLS – Deprivation of liberty safeguards

GP – General Practitioner

HSIB – Healthcare safety investigation branch

ICU – Intensive care unit

JAR – Joint agency response

LeDeR – Learning disabilities mortality review

MCCD – Medical certificate of cause of death

MBRRACE-UK – Mothers and babies: reducing risk through audits and confidential enquiries

MHA – Mental Health Act

NCISH – National confidential inquiry into suicide and homicide by people with mental illness

NCMD – National child mortality database

⁴⁰ Knight B. *Forensic pathology*, 2nd ed. London: Edward Arnold, 1996

⁴¹ ICD-10; Chapter XVIII; R00-99; World Health Organization 2016. From 2022 ICD-11 will replace ICD-10

⁴² ICD-10; Chapter XVIII; R95; World Health Organization 2016. From 2022 ICD-11 will replace ICD-10

NHS – National Health Service

NIV – Non-invasive ventilation

Ofsted – Office for standards in education, children's services and skills

ONS – Office for national statistics

PICU – Paediatric intensive care unit

PMRT – Perinatal mortality review tool

PPO - Prisons and Probation Ombudsman

RCP – Royal College of Physicians

SIDS – Sudden infant death syndrome

SJR – Structured judgement review

SMART – Specific, measurable, attainable, relevant, time-bound

SUDI – Sudden unexpected death in infancy

SUDC – Sudden unexpected death in childhood

SUDI/C Guidelines – Sudden death in infancy/childhood: multi-agency guidelines for care and investigation

WELC – Waltham Forest, East London (Hackney, Newham and Tower Hamlets) and the City

Appendix 18. Bereavement organisations

Support and resources for bereaved parents and families:

The Child Bereavement Trust Helpline:

0800 02 888 40 (office hours) www.childbereavement.org.uk

The Compassionate Friends

Dedicated to the support of bereaved parents, siblings and grandparents.

Helpline: 0345 123 2304 Office 0345 120 3785 (9.30 - 4.30 Mon to Fri) www.tcf.org.uk

Cruse (Bereavement Care)

Support and free counselling for bereaved people

Helpline: 0808 808 1677 www.cruse.org.uk

The Lullaby Trust

Bereavement support helpline following death of a baby or young toddler

Helpline: 0808 802 6868 (10.00am-5.00pm Mon-Fri, 6.00pm-10.00pm weekends)

www.lullabytrust.org.uk

Sands (Stillbirth and Neonatal Death Society)

Helpline: 020 7436 5881 www.uk-sands.org

Support for bereaved children and those supporting them

Child Bereavement Charity

Support and Information 0800 02 888 40 Monday to Friday, 9:00am - 17:00pm

www.childbereavementuk.org

Grief Encounter

Helpline 020 8371 8455 Monday to Thursday 9:00am -17:00pm

<http://www.griefencounter.org.uk/>

Winston's Wish

A national helpline offering support, information and guidance to all those caring for a child or young person who has been bereaved

Helpline: 08452 03 04 05

Monday to Friday 9:00am -17:00pm, also Wednesday 19:00-21.30pm

www.winstonswish.org.uk