# Child Death Review Guidance Implementation: FAQs

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#### Background

In Spring 2019, NHS England organised a series of regional events and webinars to support transitions to the Department of Health and Social Care's new statutory guidance for Child Death Review, published on 15<sup>th</sup> October 2018. The events and webinars were aimed at bringing together decision makers for allocating resource, commissioning services, and leading processes relating to child death reviews in their areas. Child Death Review Partners have until September 2019 to revise child death overview panel (CDOP) arrangements to ensure the requirements of the guidance are met which aim to link the child death or mortality review that occurs in the acute hospital setting with the regional process and the National Child Mortality Database.

This document lays out common themes, questions and answers which emerged from these events and webinars, in order to help Child Death Review partners to transition to the new guidance's requirements.

#### 1. Transitions to the new Child Death Review Guidance

#### 1.1. Child Death Review (CDR) and Child Death Overview Panel (CDOP) meetings

#### Question: Who should attend the Child Death Review Meeting?

**Answer**: [See CDR Statutory and Operational Guidance, Section 4.3] "This meeting should be a multi-professional meeting where all matters relating to an individual child's death are discussed. The Child Death Review Meeting (CDRM) should be attended by professionals who were directly involved in the care of the child during his or her life and the mother's pregnancy (where relevant and possible), and any professionals involved in the investigation into his or her death." In hospitals, the CDRM may be called a child mortality or perinatal mortality meeting. This is not necessarily a new meeting and may already be happening in many settings.

#### Question: Who should chair the Child Death Review Meeting?

**Answer**: [See CDR Statutory and Operational Guidance, Section 4.4] The child death review meeting (CDRM) should be chaired by a lead professional for the child death review process within the organisation where death was declared. In hospitals this may be a senior professional in the team caring for the child. If this 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. It is good practice at the beginning of each meeting for the Chair to 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.

Question: Who should follow up with the family?

Answer: Chapter 6 of the CDR Guidance sets out expectations for a 'team around the family'. All professionals have a duty to support bereaved parents after their child's death and to show kindness and compassion. Where there have been issues with the quality of care provided, healthcare organisations have a legal Duty of Candour to explain what has happened. Section 6.2 and 6.3 in Chapter 6 sets out expectations for the role of a key worker and medical lead. While the former has an important liaison role, it is the medical lead that is the essential professional responsible for answering any questions about the cause of death or results of any tests including a post mortem. This might either be the doctor that the family had most involvement with while the child was alive or the designated professional on-duty at the time of death. This individual should liaise closely with the family's key worker and arrange follow-up meetings at locations and times convenient to the family.

It is accepted that other professionals may also provide vital support to the family; these include (but are not limited to) the GP, clinical psychologist, social worker, family support worker, midwife, health visitor or school nurse, palliative care team, chaplaincy and pastoral support team. In all cases, it is the duty of the key worker to ensure that there is clarity regarding each professional's role; that the family does not received mixed messages; and that communication is clear. The key worker is there to provide help, support, throughout the process.

## Question: Will processes for inputting information for Child Death Review Meetings be digitised?

**Answer**: The Chair of the CDRM is responsible for completing the draft analysis form and submitting it to their local CDOP office. This can be done on paper forms but wherever possible, this should be completed electronically and emailed to their CDOP office. Some CDOPs have an online case management system called e-CDOP for entering information collected by the Analysis form. Contact your local CDOP office to find out if they are using this tool and if so, how it can be accessed.

Question: Child Death Review colleagues have found it difficult to ensure that CDR meetings take place in a timely fashion with sufficient and relevant information to the case, and with adequate clinical representation. What can be done to overcome this and ensure it is a meaningful meeting?

**Answer**: The CDR Guidance emphasises that these meetings should be flexible and proportionate. It makes sense that they occur once all investigations are completed. The post mortem (PM) report is key although we know that in many areas there is a delay in receiving this. For this reason, some hospitals have decided to have a very early and then host a later meeting when the PM report is completed. From experience, if the family is kept well informed throughout, a delay of a few months does not matter if it results in a properly constituted meeting that allows the family's concerns and questions to be addressed.

In Section 4.3 of the CDR Guidance, we advocate that professionals 'across the pathway of care' are invited. It is worth reflecting who the 'key players' are in the child's care. The

meeting may still be able to go ahead with the 3 or 4 core professionals thought to be essential to understanding the case. That said, it is acknowledged that many paediatricians and other professionals are very busy but their inability to attend a meeting should not necessarily delay its happening. In these situations, those professionals could be asked to submit a short report. In many areas, the local CDOP facilitates this. Alternatively, teleconference calls allow professionals to join the meeting and this also is happening in many parts of the country. A record should be kept of when a professional was invited to submit a report to the meeting; their report should be used to help complete the draft Analysis Form. It should be noted on the Analysis Form when a report was not provided.

## Question: How can it be ensured that multi-agency CDOP meetings do not have an overly medical approach and sufficiently focus on wider, contextual factors as they are supposed to?

**Answer**: The essential functions of the CDOP as laid out in Section 5.2 of the CDR Guidance have not changed. The Reporting and Analysis forms still set out contributory factors in domains intrinsic to the child, family and social environment, physical environment, and service delivery. Appendix 4 of the CDR Guidance sets out the roles and expectations of CDOP members.

That said, the new CDR Guidance emphasises that the role and purpose of the CDOP meeting is not to review the individual care received by one child. This has already been done at the CDR meeting. CDOPs should be looking at themes and patterns that emerge from a number of reviews. These may be related to service provision or they may be societal or community factors that are amenable to change.

## Question: How to ensure that learning emerging from Child Death Review meetings will be acted upon?

**Answer**: Learning may occur at a local, regional or national level. At the Child Death Review meeting, all matters relating to an individual child's death are discussed by professionals involved with the case. As such, it forms an essential pillar of that organisation's governance process. Section 4.2 of the CDR Guidance is clear in stating that the aim of the CDR meeting is to "...describe any learning arising from the death and, where appropriate, to identify any actions that should be taken...to improve the safety or welfare of children". Hospital trusts have a responsibility to act on any learning arising from the review of deaths of children within their organisation.

Section 5.2 of the CDR Guidance is clear in stating the aims of the CDOP meeting are to "...make recommendations to all relevant organisations where actions have been identified which may prevent future chid deaths or promote the health, safety and wellbeing of children". CDOPs, on behalf of CDR partners, have a responsibility to inform relevant persons and organisations if they find action should be taken, and to identify initiatives to address modifiable factors arising from themed or other reviews. The Terms of Reference for the CDOP should include details of the routes for dissemination of learning, as well as an Action Log that captures evidential completion of actions. The CDOP Annual Report should clearly record what learning and initiatives have come via the CDOP review.

Both the CDR and CDOP meetings have a responsibility to process data for analysis. This is facilitated and fulfilled through the National Child Mortality Database, which will enable wider learning from all child deaths. It is this that will help identify key priorities for government policy and national research.

Question: Are Child Death Review colleagues expected to start to use the new reporting form on 1<sup>st</sup> April, or when they move to the new Child Death Review arrangements in September 2019?

**Answer**: The new Reporting Form should be used for deaths occurring after September 2018. However, recognising that CDR Partners have until September 2019 to implement their new arrangements, only a few of the fields on the forms will be mandatory for the National Child Mortality Database (NCMD) before September and these are largely the fields that are required for completion of the 2019/20 statistical return to NHS Digital. From 1st October 2019, more of the fields will become mandatory to help improve the quality and completeness of the data collection process.

Question: Will the Reporting form be completed by more than one agency involved in the child's death, or is the trust where the child died responsible for collating that information from other relevant agencies onto one form? If the former, what role will the CDOPs play in collating reporting forms from other agencies and sharing these with the Trust reviewing the death to feed into that review?

**Answer**: The CDOP administrator should send out the relevant Reporting form to all agencies who had contact with the child during their life, or after their death. We are aware the many Trusts have systems in place to collate information from all health professionals into one reporting form and this is acceptable for the health input to the process. However, separate reporting forms should still be sent to non-health agencies such as education, social care and the police (where relevant). CDOP administrators also have a vital role in supporting the Chairs of local CDR meetings through ensuring that they then receive any relevant completed 'agency' reporting forms to assist their discussions. This is especially important when those agencies are not represented in person.

To prevent instances where a request for information was not fulfilled, CDOPs should ensure that colleagues are aware of their statutory responsibilities to fulfil requests for information.

#### **1.2.** Job descriptions

Question: Are there job descriptions available for the following roles: Designated Doctor, key worker, CDOP manager?

**Answer**: In short, the Designated Doctor has oversight of the child death review process, the key worker is responsible for liaising with the family with regards to the child death review process, and the CDOP manager is responsible for administering the CDOP process. More detailed descriptions of these roles according to the guidance is as follows:

The Designated Doctor should be a senior paediatrician who has the following responsibilities:

- be responsible for the child death review process;
- advise on the appropriate response to a death in an adult ICU;
- advise the CDOP regarding necessary experts required to inform ordinary and themed panels;
- advise the CDOP in the identification of modifiable contributory factors:
- liaise, as appropriate, with regional clinical networks to ensure that themed panels are properly coordinated;
- assist the CDOP in the development and implementation of appropriate preventative strategies to reduce the child deaths;
- prepare an annual report with the Chair summarising the activities of the CDOP.
- Should be notified of each child death and sent relevant information.

The key worker is a single, named point of contact to whom families can turn for information on the child death review process, and who can signpost them to sources of support. The role can be taken by a range of practitioners, identified by the organisation in which the child was certified dead. In the cases of children with long term conditions, the family may already be well known to a member of a specialty multi-disciplinary team such as a clinical nurse specialist, and this individual may be well placed to continue in a key worker role after the child has died. In cases of children with acute conditions (e.g. sepsis) the child and family may not have been known to any health care practitioners before the child's admission to hospital, and a key worker might instead be a member of the bereavement support team.

Finally, while the role of the CDOP manager or administrator is for local determination by the child death review partners, his/her duties would generally be as follows:

- 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 National Child Mortality Database

Question: How can Designated Doctors improve the flow of information for CDOP meetings? For example, are regional networks (e.g. regional network for trauma)

#### aware of the new child death review guidance, and aware of information needed?

Answer: The NHSE team have presented the CDR Statutory Guidance to the national paediatric trauma network meeting. It is planned to disseminate national network contacts via the NCMD team. That said, it is the responsibility of each Designated Doctor to form functional relationships with the key stakeholders in their regions. This includes the clinical leads for the relevant operational delivery networks (neonatal, cardiac, trauma, PIC, etc). Intelligent 'flow of information' will only come about through relationships being established, and leadership around instigating themed meetings that interface in coordinated fashion with the above-mentioned Operational Delivery Networks.

Question: Has anyone considered an independent chair, whether this is preferable (i.e. not a public health professional) for the CDOP, and if so, has a job description been developed?

**Answer**: The CDR Guidance does not preclude it. The guidance does state that the Chair should not have been directly involved in the care of the child. The Review is intended to be independent scrutiny by professionals who had no responsibility for the child during their life. There may be a cost associated with having an independent chair and it is for local consideration whether this is something that is wanted.

### Question: Are the roles of the SUDIC doctor and the Designated Doctor for Child Deaths the same?

Answer: We are aware that in some parts of the country there is confusion about this. The 2016 'Sudden Unexpected Death in Infancy and Childhood: Multiagency Guidelines' described two roles: the Designated Paediatrician for Unexpected Deaths, and the Lead Health Professional. The former was a senior paediatrician with a duty to coordinate responses to unexpected deaths. The latter was an appropriate health professional who coordinated the response to an individual unexpected child's death. In many parts of the country, this latter role has 'morphed' into being called the 'SUDI' paediatrician or 'SUDI' nurse. However, it has become clear during our road shows that there is great variation. In some parts of the country, the role defaults to the Designated Paediatrician for Unexpected Deaths, and in other parts where no out of hours rota exists, the senior attending paediatrician will perform this work.

The new CDR Guidance no longer refers to designated paediatrician for unexpected deaths but instead to Designated Doctor for children's deaths. Importantly, this individual is not meant to be involved in 'front line' investigation but instead, have an overview of processes and appropriately advise CDOPs in relation to their responsibilities.

Multiagency investigations (the Joint Agency Response - JAR) occur in a small proportion of child deaths, and areas across the country already have processes in place for this. Importantly though, the new CDR Guidance is clear in which specific types of death a JAR should occur. The term 'unexpected' is no longer recognised as a generic 'trigger' for these responses; other than in the specific situation when the death is sudden and there is no apparent cause (which includes sudden unexpected deaths in infancy (SUDI)/childhood (SUD(C))

Question: Can the lead health professional in a trust who has initial information about the case, such as a SUDIC, now be any clinician, rather than the Designated Doctor for unexpected deaths?

**Answer:** See the answer above. The Designated Doctor role is completely different from the 'lead health professional' role. Different areas of the country have different systems (and names) for providing the health care cover provided to a JAR rota (SUDI nurse, SUDI doctor, lead health professional). There is no directive that stipulates that either the Designated Doctor role or the lead health professional role should be a hospital or community clinician as long as they bring the right competencies to the post.

#### 1.3. Medical Examiners

Question: Will Medical Examiners be extending their role to examine child death certificates?

Answer: The medical examiner role involves providing scrutiny to all non-coronial deaths

#### **1.4.** Themed meetings

Question: The new Statutory and Operational guidance recommends Child Death Overview Panels (CDOP) to conduct themed meetings, with operational and commissioning insight, such as a CDOP wide themed meeting for trauma-related deaths. However, many small CDOPs do not oversee enough child deaths to be able to coordinate themed meetings. What can they do about this?

**Answer**: The CDR Guidance requires CDOPs to merge such that they cover a geographical footprint large enough to aim to review over 60 deaths per year. This approach will enable thematic learning, and would allow for CDOPs to hold themed reviews, e.g. for neonatal deaths, which will help to save resources and ensure the maximum learning can be identified. For other types of themed meetings (e.g. suicide), some CDOPs may wish to consider having discussions with their neighbouring CDOPs to explore how these may be facilitated.

#### **1.5.** Hospice deaths

Question: Is a Child Death Review conducted in a hospice if the child is transferred to receive end of life care?

Answer: Section 4.5 of the CDR Guidance states that the Child Death Review meeting should be held in the location where the majority of the child's treatment took place. For example, if a child was transferred in their final 24 hours of life to a hospice, having spent much of the end of their life on a Paediatric Intensive Care Unit, it is likely that the hospital will be the most appropriate place to hold the CDRM. However, if they have spent many years accessing the hospice for respite care and then spend their final weeks there, it may be more sensible for the hospice to organise the CDRM. Good communication between professional agencies is essential to ensure that an appropriate decision is made about where to hold the meeting.

#### **1.6.** Avoiding duplication

Question: What is the role of existing operational networks in reviewing child deaths?

**Answer:** NHS England and NHS Improvement is still developing arrangements for emerging operational delivery networks. It may include a need for reviewing a variety of outcomes such as child mortality. That said, the statutory responsibilities of CDOPs to review deaths, as well as the clear operational expectations described in the national CDR Guidance towards 'themed' meetings, should take primacy. Designated Doctors should liaise with operational network leads to ensure that review of child deaths are coordinated.

Question: How can CDOPs avoid duplication?

**Answer:** See above for approach to avoid duplication of discussion in relation to ODNs and CDOP. The other potential for duplication is in relation to a child resident in the area of one CDOP who dies in the area of another. The Act (section 16M (2) of the Children Act 2004) gives licence for the CDR Partners (this can be the local CDOP) where the child died to be the primary CDOP that discusses the case. This is a common scenario and there is often good reason for this approach to be taken.

In order to avoid duplication in such situations, it might be that the CDOP where the child dies conducts the primary review, collating all the information from the CDR meeting and completing the Analysis form. They would then forward this 'completed' review to the CDOP of the child's residence for the record. The respective Designated Doctors in such situations have a key role in deciding upon the most appropriate course of action.

#### **1.7.** Coroner's post mortem reports

Question: The Coroner's <u>post mortem report</u> is often crucial for the Child Death Review meeting to be able to take place, and can bring a lot of information relevant for the review. However, there are often delays in receiving results of a post mortem. What can be done about this?

**Answer:** We are aware of the national shortage of paediatric pathologists and the delays that can be experienced in receipt of the final post mortem report. The Royal College of Pathologists is also aware of the shortage of paediatric pathologists and is working to address this problem. Where a Coroner's post mortem examination has taken place, the Child Death Review meeting should be conducted after the final PM report has been received. There is little value in holding a meeting and taking the time of professionals when it is not known why the child died. Once the PM report is received and the Child Death Review meeting has taken place, the draft Analysis form should be provided to the Coroner. Once the inquest has occurred, the CDOP discussion can then take place.

Question: The Chief Coroner has little authority over coroner's arrangements locally which can lead to regional variation in coronial practice. This means coroner's reports may not include sufficient information for a CDOP meeting to take place, making it hard to have a standardised review process. There are often delays with receiving the post mortem report. Criminal investigations also come before health reviews, possibly creating further delays. What is being done about this?

**Answer:** There was a hope that the standardisation of the medical examiner function would have an effect on standardising coronial practice. It is more important that all information is available for the review than that the review takes place within a certain timeframe.

#### **1.8.** Parental involvement

Question: What responsibility will CDOPs have to manage and meet queries parents may have about the care their child received?

**Answer:** Section 5.7 of the CDR Guidance describes how CDOPs should engage with bereaved families. Parents should primarily address any concerns they have about their child's care to the relevant organisation or agency, supported by their assigned key worker. These concerns should also be picked up and addressed at the local child death review meeting, with feedback provided to the family by their key worker.

CDOPs do not have a direct responsibility to manage parental queries. Cases discussed at CDOP should not contain identifying information relating to the child or professionals. CDOPs should, on request from appropriate CDR partner, produce an annual report summarising the learning and actions they have taken in relation to the deaths they have reviewed. This should be explained to the family by their assigned Key Worker.

Question: Can parents be informed about modifiable factors discussed at the child death review meeting? It is possible parents may not see modifiable factors as an opportunity to learn, but an opportunity to blame?

**Answer**: Section 4.7 of the CDR Guidance describes how CDR meetings should engage with bereaved parents, particularly though their assigned key worker. Parents should be offered the opportunity to contribute their questions and comments in advance of the CDR meeting and the new Guidance requires professionals to offer the family an opportunity to meet for feedback following this meeting. They should be provided with a written output from the discussion if they would like it. This should include discussion of modifiable factors where they have been identified, together with a description of what has been learned and what will be done to address these factors going forward.

#### 1.9. Funding

Question: The CDR Guidance does not mention funding which opens risk of stretched LAs and CCGs using the changes to reduce expenditure on CDOPs and to 'pass the buck' - are there any plans for advice or guidance on funding arrangements?

Answer: Section 16O of the Children Act 2004 states that CDR partners for a local authority area in England may make payments towards expenditure incurred in connection with CDRs (by making payments directly or by contributing to a fund out of which payments may be made). CDR Partners may also provide staff, goods, services, accommodation or other resources for purposes connected with CDR arrangements. This will be a local decision, as agreed by the child death review partners, so for CCG's this will involve funding within existing allocations.

Question: Due to the large remit of the Designated Doctor role, which could even get larger due to the merging of some CDOP territories, some Designated Doctors are finding it difficult to sufficiently review all cases. What can be done about this?

**Answer:** The Designated Doctor is not expected to review all deaths. Their primary responsibility is to oversee the CDR process. In many parts of the country the work of the Designated Doctor (if they reviewed all deaths in the past) may actually reduce. Appendix 4 of the CDR Guidance lists the specific duties of the Designated Doctor as follows:

- be responsible for the Child Death Review process;
- advise on the appropriate response to a death in an adult ICU;
- advise the CDOP regarding necessary experts required to inform ordinary and themed panels;
- advise the CDOP in the identification of modifiable contributory factors:
- liaise, as appropriate, with regional clinical networks to ensure that themed panels are properly coordinated;
- assist the 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, as requested by appropriate CDR partner.

## Question Is there any funding associated with supporting training and awareness raising at the local level for the new CDR guidance's requirements?

**Answer**: There is no specific funding being made available for local education. However, a number of regional events and webinars have taken place to support the implementation of the CDR Guidance and details of this can be found on the Safeguarding shared online platform

#### **1.10.** Other questions

Question: Will the NHS England and NHS Improvement publication for parents be printed and made available for partners to distribute?

**Answer:** Commissioners should be reminded of the statutory responsibility of care providers to keep parents informed about this process and the costs associated. An editable version is available on the NHS England website so trusts can use this to print

leaflets with their specific key worker details etc. The CDR Guidance makes clear reference that the child's next of kin should receive a physical copy of the guide, with the details of their assigned key worker.

Question: In what cases is a Joint Agency Response triggered at presentation? Is a Joint Agency Response required for sepsis deaths, and suspected non-accidental injury?

**Answer:** The criteria for the Joint Agency Response (JAR) to be triggered is set out in the CDR Guidance in Section 3.3. The JAR should be triggered if the death:

- is or could be due to external causes;
- is sudden and there is no immediately apparent cause (inc. 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; (e.g. suspected non-accidental injury) or
- in the case of a stillbirth where no healthcare professional was in attendance.

It should NOT be triggered in deaths due to presumed sepsis or other 'medical' causes of mortality.

#### 2. National Child Mortality Database

Question: Will the National Child Mortality Database collect information on social deprivation?

**Answer:** Yes.

Question: Will the National Child Mortality Database data be available for local providers to download and inform local discussion?

**Answer:** It is hoped this data will be provided data eventually, although at present this function is not available (as at June 2019). The NCMD team are working on developing a policy for accessing the data and will advise when this is in place.

Question: Will there be a national consideration of modifiable factors for certain types of deaths, for the sake of consistency in national output data?

**Answer:** Yes. One of the main aims of the NCMD is to look at trends within modifiable factors across England. Collation of data will also enable us to identify issues of consistency and take these forward to the relevant organisations for action.

Question: Is the National Child Mortality Data exempt from FOIs?

**Answer:** No. There is no national exemption from FOIs for the NCMD. However, we would consider any FOI case that come into the team and respond on an individual basis assuming it met the criteria for disclosure.

Question: Is there a care pathway dataset?

**Answer:** Yes. This is available online with the other supplementary reporting forms. It can be accessed <u>here</u>.

Question: Should the care pathway dataset be completed at the CDR meeting?

**Answer:** It can be completed at the CDR meeting or it can be sent out with a reporting form to be completed by the relevant agency(s).

Question: Will CDOPs be able to access the National Child Mortality Database to create a data report for its annual report processes?

**Answer:** CDOPs will be able to view all the cases they have submitted to the NCMD and download their data directly.

#### 3. Perinatal Mortality

Question: Is there an expectation for a Child Death Review Meeting to take place for babies who have very brief signs, life prior to age, of viability (e.g. 21 weeks)?

**Answer:** The NHS England & NHS Improvement team took expert advice on the lower gestational age limit that should apply. It was concluded that a gestational limit was not helpful since a) gestational age is not always known and b) resuscitation practice varies in tertiary centres. It was also concluded that 'signs of life' were a subjective assessment and, as such, would not enable a standardised approach to a national data record.

Therefore, it was decided that the CDR process should capture the death of any live-born baby where a <u>death certificate</u> has been issued. A death certificate can only be issued where a healthcare professional has previously issued a birth certificate. The latter requires a judgement to be made by the senior attending health care professional present at the birth. 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, the CDR process does not include stillbirths, late foetal loss, or terminations of pregnancy (of any gestation) carried out within the law.

The PMRT is designed to be used for babies of 22 weeks gestation to 28 days after birth who die in a neonatal unit. It may also be used in babies who die after 28 days in a

neonatal unit. If a baby is transferred between neonatal units it is the responsibility of the unit where the baby died to lead the review.

Question: When does MBRRACE (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries) need to be notified of an infant death?

**Answer:** For all perinatal deaths (22+0 week's gestation to 28 days after birth), the Lead MBRRACE-UK reporter at the hospital of birth should be informed in order to complete the national perinatal mortality surveillance data.

Question: Is a Joint Agency Response required for stillbirths with no health professional in attendance, and are these events discussed at CDOP level or elsewhere?

**Answer:** See above. In these rare cases where a baby is born at home, unattended by a health professional and the death is reported as a stillbirth, a Joint Agency Response should take place to ascertain whether or not the child was born alive. This is so professionals can be assured that this is a genuine stillbirth and not a covert homicide (i.e. where the baby has been born alive and unlawfully killed). If, following investigation, professionals are assured it was a genuine stillbirth, there is no requirement for a CDR meeting or a CDOP meeting to take place. However, if this cannot be established, the normal Child Death Review process applies and should be followed.

Question: Is there a child death review for neonatal deaths if the baby took a breath and wasn't a planned termination?

**Answer:** See above.

Question: If the PMRT has been completed and there is a Child Death Review Meeting, is there an expectation that the new Analysis form draft has been completed?

**Answer:** Yes, the PMRT is in the process of being updated to reflect the questions asked on the Analysis form (as at May 2019). However, in the interim period, both the PMRT and the Analysis form should be completed. We are aware that this represents some duplication of effort by professionals and are working hard to overcome this by aligning the two processes.

Question: Does the PMRT need to be completed in babies who die outside neonatal units (e.g. on PICU)?

**Answer**: No. Section 4.1.4 in the CDR Guidance explains the relationship between the PMRT and the CDR process. For perinatal deaths in a <u>midwifery unit</u>, on <u>delivery suite</u>, <u>and in a neonatal intensive care unit</u>, as well as post-neonatal deaths where a baby dies in a neonatal unit after 28 days but has never left hospital after birth, the perinatal mortality

review meeting should use the national PMRT (a web-based tool which supports standardised, systematic review of care in perinatal deaths) in addition to the CDR Reporting and Analysis form (see above regarding intention to align processes). 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 <u>originating</u> unit is responsible for reviewing the midwifery, obstetric and neonatal care provided in their unit before the baby was transferred.