Summary of the HLP Child Death Review London STP Workshops 2019

HLP ran four and supported one London Sustainable Transformation Partnership (STP) regional workshops between January – March 2019 to support child death review professionals across London come together and discuss the challenges and considerations of the new statutory requirements.

This document summarises those discussions and can be used to inform local system transformation discussions. However, it should be noted that HLP, NHS England and the Department for Health and Social Care have not formally endorsed the positions and statements outlined below. These should be considered alongside the Child Death Review: Statutory and Mandatory Guidance.

Key Challenges

1. Ensuring multi-agency input
2. Resourcing new functions such as Joint Agency Response, the Child Death Review Meeting and the Key Worker function
3. Disproportionate burden on the acute sector
4. Ensuring appropriate training and oversight for key workers

Key points

- Broad support for a named responsible officer within the CDRP for the child death review process and a clearly defined escalation process
- Designated Doctors provide a key function and should be not be reduced as part of any centralisation / rationalisation
- CDRM should take place at the location where the most learning can be gathered
- CDOP / Chair should provide oversight for the CDRM
- Key functions (CDOP Chair, managers & administrators, key worker) should have protected time within their job plans and cross cover should be provided
- A review of systems should take place within 12 months of implementing the new processes

1. Governance & Accountability

a) What new CDRP configurations should be formed to meet the new statutory requirements?

- This is for Clinical Commissioning Groups and Local Authorities to decide. However, the new CDRP footprint must cover an area that experiences a minimum 60 child deaths each year, the minimum felt to be useful thematic learning to take place

- The proposed London CDRPs (as of April 2019) are listed within the information pack on the HLP Child Death Review Programme webpages.

b) Where should ultimate responsibility for the child death review process sit?

- Responsibility rests jointly with the Clinical Commissioning Groups and Local Authorities within the CDRP footprint
- London stakeholders felt that one of the primary challenges would be in ensuring multi-agency input and engagement into the process. As a result, London stakeholders broadly supported having a named responsible officer for child death / review within each STP region. This could be a senior officer from the STP. Alternatively there could be a nominal lead for child death review within each CCG and LA, such as the NHS officer for Quality on a CCG Board
- It was widely felt that the new requirements in effect placed a disproportionate burden upon the acute sector, given that the majority of deaths occur or are declared within this setting. It was therefore felt that trust Medical Directors and Directors of Nursing should have a close understanding of the new requirements
- Acute professionals outlined a significant risk that non-acute agencies within the CDRP footprint may fail to co-own the new process or view it as their responsibility and therefore fail to adequately engage with it

c) What new resource is available to support the new child death review functions?

- The new functions place an extra / additional resource burden on existing local systems. However, no new central resource is being made available by NHS England across England
- Local transformation steering groups have undertaken mapping exercises to understand what dedicated resource is currently allocated across their CDRP footprint areas to support the child death review functions. Whilst some staff may currently support child death review in a full-time capacity (such as some CDOP managers / administrators), in many cases, the functions account for only a small proportion of time for a number of different professionals across the footprint
- A number of local CDRPs have developed business cases for additional resource for these new functions to ensure that their CDRP will be compliant with the new statutory requirements from 29th September 2019. It was widely felt that conversations regarding resource should include representation CCGs, LAs and Acute trusts
- There was a difference of opinion as to whether any additional costs should be split equally between each CCG and LA within a footprint area, or based upon the child population, or proportion of child deaths
- London stakeholders noted that as the CDRP footprints formed, opportunities existed for centralisation and rationalisation of resources. Whilst in some cases this could lead to efficiency savings, it was widely felt that it should not lead to a reduction of Designated Doctors for Child Death across a footprint area given the vital role they provide

d) Will existing job roles need to change?

- Potentially. This will depend largely upon decisions taken by each local CDRP
- If functions are centralised into a single team within the CDRP, there may be a requirement for staff to relocate to a different employer and / or location. In such cases, TUPE may need to apply and each CDRP should explore this with their local human resources teams

- London stakeholders broadly supported the inclusion of defined functions, such as the CDOP Chair, CDRM Chair and the key worker, within relevant job plans with protected time made available

e) Where there is a dispute, for instance where there is failure to secure routine multi-agency input into the process, or enact system changes in response to identified learning, what should the escalation process be within the CDRP?

- London stakeholders broadly supported a clear outlined escalation process within each CDRP that should be used when issues cannot be resolved locally. This should complement existing local structures. This could include the head of maternity/midwifery or the deputy chief nurse as a first stage. If resolution cannot be found then this could be escalated further to the Director of Nursing and / or the Medical Director before finally to any accountable officer for the CDRP or STP

f) How should links between the CDRP and new local safeguarding arrangements be ensured?

- Whilst the child death review process is separate to safeguarding, it was felt by London stakeholders that links to safeguarding structures, specifically following the dissolution of LSCBs, should be maintained. It was suggested that links to any strategic safeguarding meetings / local safeguarding partnerships should be developed

g) How should data sharing be managed within the new footprint?

- A legal basis for the collection and sharing of data for the child death review process is established within The Children Act 2004. As such, there is no barrier to sharing such data within the wider CDRP footprint
- However, data protection and data security principles would still apply. Local CDRPs should explore a framework that covers the sharing of data to the relevant agencies across the footprint for this purpose. For instance, this could take the form of a Data Sharing Framework / Agreement. Caldicott guardian support should be gained for this data sharing
- eCDOP includes functionality to anonymise data submitted by CDRMs to their overarching CDOP (except in cases where non redacted / de-identified documents had been uploaded into the system). CDRMs should be encouraged to anonymise data (where possible) before it is submitted to the overarching CDOP

h) How should any electronic case management system to support the child death review process (such as eCDOP[1]) be funded beyond March 2020?

- Details of how any case management system will be funded should be included within the CDRP plans to meet the new requirements that need to be published by 29th June 2019
- Where a CDRP plans to use an electronic case management system to support the child death review process, the recurrent costs should be included within any business case or local request for funding. For 2019/20, QES have outlined that the costs for a single CDRP using eCDOP to review 60-90 or 91-120 child deaths annually would be £9,813 and £12,927 (excluding VAT) respectively. For costs beyond March 2020, CDRPs should contact QES Ltd directly

i) How should each CDRP ensure that learning identified is translated into system improvements?

[1] *There is no mandatory requirement for London CDRPs to use any specific case management system, such as eCDOP*

- Learning should be recorded and communicated to relevant agencies across the CDRP. The relevant quality meetings within the STP (at both CCG and LA level) should be identified and learning fed into these at regular intervals
- London stakeholders understood that information provision alone would not change clinical practice. Therefore, it was suggested that a range of training, newsletters, events and other activities be organised to ensure that learning and system changes were embedded locally. Reports should be routinely tabled to appropriate boards

j) How should the CDRP ensure that the child death review process, and specifically the CDOP, operates effectively?

- Each CDRP is responsible for ensuring that the local review of child deaths and implementation of local learning is completed to a high standard
- Where a named lead for child death is identified either within the STP or each CCG or LA, this individual(s) will hold responsibility for the process
- It was suggested that there may be value in having a named 'champion' for child death review within each of the various agencies within the CDRP (acute, mental health, social care, community, police, ambulance etc) and a communications lead for child death review
- It was widely felt that the systems implemented by 29th September 2019, would require review and potentially some refinement. It was suggested that such a review should take place between 6-12 months following their introduction

2. The Joint Agency response

As outlined on page 23 of the statutory and operational guidance, and Working Together to Safeguard Children, along with the process set out in Sudden and Unexpected Death in Infancy and Childhood: multiagency guidelines for care and investigation, a JAR should be triggered if a child's death:

1. Is or could be due to external causes
2. Is sudden and there is no immediately apparent cause
3. Occurs in custody or where the child was detained under the mental health act
4. Where the initial circumstances raise suspicions that the death may not have been natural
5. In the case of a stillbirth where there was no healthcare professional in attendance

a) How should a Joint Agency Response be convened?

- If was suggested that the JAR, whilst different to existing Rapid Response meetings, could be managed in a similar way. Where Rapid Response meetings currently function well, London stakeholders felt that they should not be reinvented but rather tweaked to accommodate the additional functions required of the JAR
- A lead health professional should liaise with police, social care, education and other agencies, potentially by phone. This could be the senior attending paediatrician. They should convene a meeting to determine what information needs to be collected, who needs to be contacted, and what investigations need to be triggered.
- It was felt that in many cases it would be appropriate for JAR meetings to be undertaken virtually

b) Is it practical for 'an initial information-sharing and planning meeting to take place before the family leave the emergency department' as is outlined on page 24 of the statutory and operational guidance?

- London stakeholders felt this requirement would be a significant challenge to the acute sector. However, they felt that whilst still ambitious, it may be possible to schedule a virtual meeting / telephone discussion within this timeframe

c) Should the JAR function be supported out of hours?

- This will be a decision for each CDRP. It was understood that out-of-hours JAR support was likely to provide a significant challenge for many local teams. However, some London stakeholders felt that an initial planning meeting, led by the relevant healthcare professional (such as a senior paediatrician), could take place out-of-hours. Otherwise, it should be held on the next working day

d) How should the JAR run?

- There must be cross-agency involvement. Information should be received from all relevant professionals involved in the child's care prior to their death
- It was felt that there would be value to those administering JARs, CDRMs and CDOPS, as well as the key workers, in having access to a map of all relevant organisations and agencies within the footprint, and lead contact for child death within each

e) Who should Chair the JAR

- JAR meetings, virtual or otherwise, should be chaired by the lead health professional

f) Who should provide administrative support?

- As many child deaths are confirmed within hospital, it was felt that the acute sector would be required to provide this function for at least the deaths that occurred in their setting, if not the wider CDRP
- It may be possible for the team that currently provides support for the CDOP to also support this function

g) Who should attend Joint Agency Response meetings?

- All relevant professionals involved in the care of a child prior to their death should input into the JAR. However, they may not all be required to attend a physical meeting as this may occur virtually. This will be dependent upon the individual circumstances
- It was suggested that representatives from any Multi Agency Safeguarding Hub (MASH) should join JAR meetings

3. The Child Death Review Meeting (CDRM)

As outlined on pages 28-32 of the statutory and operational guidance, a CDRM is a new requirement that is different to existing Morbidity & Mortality (M&M) meetings. It should occur for every child's death, have multi-agency representation and / or input and should have a focus on local learning. The administration and functioning of the CDRM was considered to be a significant challenge by the London stakeholders

a) Who should Chair the CDRM?

- The statutory guidance states that 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 if a Joint Agency Response has taken place. This person should have designated time assigned for this within their job plan

- London stakeholders felt that it was important that the CDRM Chairs had experience of chairing meetings

b) Who should provide administrative support to the CDRM?

- This will need to be considered by each CDRP. Where the administration of the child death review function is centralised within the CDRP, the team that administers the existing CDOP functions may be able to support these meeting
- Cross cover should be factored in to ensure that these important meetings take place during staff leave or absences

c) When should the CDRMs take place?

- Every child's death should be reviewed at a local CDRM
- London stakeholders felt that CDRMs should take place at the earliest opportunity once the majority (if not all) of the information on a child's death had been gathered
- In certain circumstances, such as where a coronial investigation was taking place, it may be appropriate to hold the CDRM once the majority of the information on the child's death had been collected, rather than wait, for instance, for the final coroner's report. In such circumstances, it may be appropriate to hold an additional CDRM to review a specific child's death once the coroner's report had been issued. Similarly, in circumstances where professionals involved in the care of a child prior to their death are unable to join the CDRM, it may be appropriate to discuss that child's death at a second CDRM where specific attendance would be provided. The CDRM Chair is responsible for this determination

d) Who should attend the CDRM?

- The relevant professionals involved in the care of a child prior to their death should input into that child's CDRM. They should attend where practically possible, or dial in by telephone. In some circumstances written input alone may be acceptable
- London stakeholders identified a risk that CDRMs could become predominantly medical in focus and not have true multi-agency input as is required. The CDRM Chair should ensure that appropriate input is gathered from the various agencies involved, and escalate this as an issue in circumstances where it is not provided
- London stakeholders broadly felt that the CDRM should have an appropriate balance of attendees from the agencies within the footprint and not disproportionately favour one agency
- In instances where a child had been transferred from one trust to another, the balance in attendees from both trusts should be carefully considered to support an impartial review
- Whilst CDRMs could be scheduled in an ad-hoc way, many London stakeholders felt that there could be greater efficiency in pre-scheduling CDRM meetings for the year, such as on a monthly basis, where potentially 5-10 cases could be discussed. Specific cases would then need to be added to the agenda, and relevant professionals invited, once the relevant information had been gathered on individual deaths. If this model was adopted, a core membership would be required for the CDRM and other professionals would need to be invited depending upon the cases tabled for discussion
- Many stakeholders across London felt that the time spent on each case and the level of detail provided to CDRMs should be proportionate depending upon the case – some cases would require more time to be spent on the review than others

e) Where should the CDRM take place?

- This would depend largely upon where the administration for the CDRM was based. If it had been centralised then it may take place in a routine location. However, if it was to rotate across the footprint, some felt that tertiary centres may require additional resource
- It was noted that not all NHS rooms provide teleconferencing facilities. It was felt that rooms with teleconference facilities should be prioritised for this function

f) If a child dies outside an acute hospital (for instance in a mental health/community trust, in custody or state detention, or in a school) who should lead the CDRM?

- The guidance outlines that responsibility for the CDRM should rest with the organisation of the lead health professional who declares the child's death
- However, London stakeholders were in broad agreement that certain organisations (such as Mental Health Trusts) may not be best placed to deliver a high quality child death review given the low numbers of child deaths they may experience each year
- Some stakeholders favoured the acute sector taking responsibility for all CDRMs within their CDRP. It was noted that this would increase the resource requirement on the acute sector

g) Where a child has been transferred from one region to another, should the CDRM always take place where the child died, as is outlined within the guidance?

- London stakeholders were broadly supportive that the CDRM should take place where the most learning was likely to be identified. In such circumstances, they supported a pragmatic discussion between the lead healthcare professionals from the two regions
- In the event that these local professionals fail to agree on the most suitable region for the CDRM, an agreed escalation process should be followed

h) How should multi-agency input be ensured?

- It was widely felt that there would be a significant challenge in gathering input from all agencies (where relevant) into the CDRM. Where input is not provided, the agreed escalation process should be followed
- It was suggested that there could be value in a responsible officer being identified and empowered by the CDRP to ensure that representation and/or input is gained

i) Who should provide oversight of the process?

- The CDOP and the CDOP Chair should provide oversight of the CDRM process. Learning and quality improvements should be fed both upwards from CDRMs into CDOPs, as well as to local professionals within the CDRP

4. The Child Death Overview Panel

As outlined on pages 33-38 of the statutory and operational guidance, CDOPs should take place take place and review all child deaths within a CDRP and should undertake themed reviews.

a) How often should the CDOP meet?

- Given the numbers of deaths within the new footprints, London stakeholders felt that these would likely need to meet monthly or bi-monthly. However CDRPs which only

review the minimum 60 deaths each year may be able to run less frequently. This would vary depending upon the number of deaths within the region annually

b) Who should Chair the meetings?

- London stakeholders felt that it was important that the CDOP Chairs had experience in chairing meetings and did not rotate too frequently in order that continuity could be maintained and oversight of the embedding of any local learning monitored
- It was suggested that there could be value in having a co-Chair or Deputy-Chair. There was also a suggestion that there could be value in having two Chairs, one of which could review all neonatal deaths and another to review the remainder
- It was felt that there would be value in having an independent CDOP Chair. This role could be fulfilled by a Designated Doctor or even a clinician from outside the footprint if a reciprocal arrangement could be agreed

c) Who should sit on the CDOP?

- London stakeholders felt that there should be an appropriate balance between CCG and LA representation on the CDOP. Where a CDRP has a number of similar roles, such as a number of Directors of Public Health, these professionals could rotate onto the CDOP
- Consideration should be given to the size of the membership as too large a group could provide difficult to manage and / or remain quorate
- London stakeholders broadly supported having a core membership with others joining as required. Pages 35-36 of the statutory guidance outlines which agencies should provide the core membership
- It was suggested that invited members (depending upon the theme being reviewed) could include: widwives, oncologists, coroners, obstetricians, representatives from CAHMS, Housing, Hospices, Council services, Health and Wellbeing Boards, and Coronial services. It was felt that professionals conducting other mortality reviews such as the Learning Disability Mortality Review should be engaged.

d) How should the CDOP undertake effective thematic learning?

- Some London stakeholders felt that CDRPs should develop criteria for how they would run themed meetings. For instance, they may decide to have recurring themed meetings around neonatal deaths given the volume, but could review other themes once a specific number of cases had been reviewed (such as suicide, cardiac, oncology, trauma, SUDI)
- It was felt that it was important for specific agency attendance to be prioritised at specific thematic meetings. For instance it may be appropriate for police and ambulance services to attend any thematic review of traumatic death
- It was felt that learning should be fed both upwards from CDOPs into board structures, as well as to professionals within the CDRP

5. Development of the new ‘key worker’ role

As outlined on page 40 of the statutory and operational guidance, the key worker role is not designed to be a stand-alone role but one which:

1. acts to signpost families to bereavement support
2. acts as a first point of contact for the family

3. supports (and represents) the family with information at various stages of the child death review process, specifically during any investigations (coronial, serious incident etc)

The key worker role is not expected to provide bereavement support, however, the role may be filled by a professional who provides bereavement support as part of their other functions. It was felt that there may be value in the key worker supporting families in their understanding of any post-mortem reports.

a) Which agencies / roles have responsibility for providing the key worker function

- There is no restriction on which agencies, roles or staff grade/band can fulfil this function. It will be for the local CDRP to determine whether all agencies within the footprint contribute towards this (police, hospital, community and mental health trusts, social care, ambulance services, general practice etc). Whilst the statutory guidance outlines that the key worker would usually be a healthcare professional, it also states that their qualities and competencies are of greater importance than their professional background
- The key worker role should be filled by someone that the bereaved family feel comfortable with and who has received training. It may be appropriate for the key worker to be drawn from the agency from which the family is likely to have the most contact / touch points with
- London stakeholders felt that it was important that any professionals taking on the Key worker role had appropriate personality traits including empathy and resilience
- It was suggested that key workers should have access to local psychology teams
- Accommodation should be made to provide an alternate key worker if either the family or key worker feel that this would be appropriate
- Similar to the CDRM, there should be a pragmatic discussion about which CDRM will provide the key worker in instances where a child dies in a different region to where they lived

b) What are the resource implications for the geographical footprint?

- London stakeholders identified significant challenges with financing, resourcing and training key workers to fulfil these functions
- It was noted that in certain circumstances, such as where a coronial investigation was required, the child death review process could take in excess of 18 months. The potential therefore existed for Key workers to support a large number of families at any given time
- The resource implications for the CDRP would depend on the number of child deaths within the CDRP. Some CDRPs outlined that they intended to have a number of full time key workers to fulfil this function. Where there are existing teams (such as bereavement support or palliative care teams) with capacity to take some of this function on, it may be possible to spread this work out over a wider number of professionals. In such cases, it was suggested that there may be value in having a small number of central leads within the CDRP who could provide advice and guidance to any wider network of key workers
- Several London steering groups had outlined that they would request additional resource to meet this requirement. One local Steering Group member outlined that they had been successful in securing some funding from the Mental Health Investment Fund to support this function
- If stand-alone key workers are appointed, there must be appropriate cross-cover built in during times of absences

c) Should the key worker function be provided solely during core business hours or should there be an on-call rota for weekends and evenings?

- Many London stakeholders felt that there would be significant challenge in providing this function out-of hours. However, some felt that there would be value in providing a limited service at weekends

d) Should the same key worker support the bereaved family throughout the review of their child's death

- In an ideal circumstance, a single professional would act as a key worker to a bereaved family throughout the review of their child's death. However, as this process can in some circumstances take over 18 months, it may not be possible to have a single professional fulfil this role for the entire period
- In some circumstances a key worker may be appointed to a family in the immediate aftermath of their child's death and this function may then be transferred to a different key worker (e.g when a child dies outside the region where they lived)
- An alternative key worker should be made available to bereaved families when their primary key worker is on leave

e) Who should hold responsibility for this service?

- CDRPs hold overall responsibility for this function. However, there should be appropriate oversight of the key workers which could be fulfilled by an existing team such as bereavement support team
- Where the key worker function is managed by a central team, that team should identify, select and allocate an appropriate key worker and ensure that the support that this function is provided to a consistent and high standard across the CDRP
- In circumstances where the key workers within a CDRP are not managed by a single team, it may be appropriate for a team, such as the team that provides the administrative functions for the CDOP, to co-ordinate the key worker function

f) What training should be provided for the key workers and who should be responsible for this training?

- London stakeholders felt strongly that appropriate training should be provided to key workers given their proximity to the bereaved family and the potential for them to unintentionally cause further distress. This would help develop a standardised service. No known training for this role is understood to exist
- It was widely felt that key workers should have defined clinical supervision

g) Should job plans need to be updated to reflect this requirement?

- It was felt that the key worker role should be reflected within the job plans of those individuals performing the function. It was also felt that there would be value in a standard job description for key workers being developed

Further information about the Healthy London Partnership Child Death Review Programme is available at https://www.healthylondon.org/our-work/children-young-people/child-death-review-programme/.