Healthy London
Partnership

# Child Death Review Programme

## Programme Report

**September 2019**

Transforming London's health and care together

Supported by and delivering for London's NHS, London Councils, Public Health England and the Mayor of London

# FOREWORD

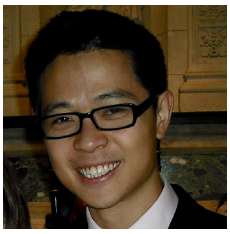
Each year approximately 700 children die across London. We know that for around a third of these children, aspects of their care could likely have been improved and that in some cases, deaths may have been prevented.  To ensure that we provide the highest quality of care for our children and young people, we must have effective systems in place to review the circumstances around their deaths. We must be transparent, open and honest about any deficiencies in care, and we must ensure that where improvements can be made, systems and processes are implemented to ensure that in the future, the highest quality of care is delivered. The introduction of new statutory requirements for the review of child death across England from September 2019; the establishment of a National Child Mortality Database; and the wider Learning from Deaths agenda, have been incredibly welcome developments which will go a long way towards ensuring that these aspirations are realised.

However, meeting the new statutory requirements has posed a considerable challenge to London, not least because they require significant additional and on-going resource at a time when front line systems are already heavily stretched. They have been set against a backdrop of historical under-resourcing of some London child death review systems, and without any additional national funding being made available.

When we first approached stakeholders across London to outline our intention to establish a pan-London programme to support this important area of work, it was because there was a tangible sense of frustration that such an important process was not given the support and attention it deserved. However, over the past three years, the profile of child death review has increased significantly and the learning from mortality reviews has enabled improvements across the system. The Healthy London Partnership Child Death Review Programme (formerly CDOP Programme) has been successful in bringing a wide range of disparate professionals from across the health and public sector arenas together and facilitating strong and effective networks, which has led to new partnership working. We have improved understanding, developed and rolled out a number of tools and resources to support greater standardisation of the process, and supported the development of the new child death review systems across London.

This report summarises the work and impact of the Programme between July 2016 and September 2019. We would like to thank the Programme Steering Group for providing their invaluable time and expertise, as well as stakeholders across London for embracing these new changes and for working so hard to make a success of them. We would also like to thank David McKinlay and his predecessor, Dan Devitt, for their dedication and hard work in managing the Programme. Finally, we would like to express our thanks to the Programme funders, NHS England (London Region), for prioritising this important area of work. Making sure that the system learns from the tragic deaths of London's children is the least that they and their families deserve. There is still much to do to ensure that can translate these lessons to ensure that we deliver the best care possible for London's children, but we are confident that our work has laid the foundations for London to achieve this moving forward.

*Tracy Parr, Director of Transformation, Healthy London Partnership*



*Dr Ronny Cheung, Clinical Director & Consultant Paediatrician*

*Dr Donal O'Sullivan, Clinical Advisor & former Chair Lewisham CDOP*

When conducted effectively, the child death review process, and resultant learning collected can contribute not only to a reduction in child mortality and improved health outcomes for our children, but also improvements to other services including policing and housing. When NHS England (London Region) first approached the Healthy London Partnership in 2015 to explore ways to improve the child death review process, there were 28 Child Death Overview Panels across London; wide variation in practice and data collection; limited partnership working; and a plethora of different systems and tools employed. Thematic learning was not routinely undertaken, limiting the potential identification of system improvements.

The programme has been successful in building awareness, bringing key partners together, and sharing best practice across London. Child Death Review has since taken on a national significance with statutory reforms now in effect. The programme team has positioned London well to meet the biggest system changes to these important processes in a decade. It is a great achievement that seven Child Death Review Partnerships have now come together to implement improved systems.

Reducing maternal and neonatal mortality is a key priority of the NHS Long Term Plan and NHS England has invested nationally in a world first National Child Mortality Database to disseminate learning and recommendations nationally. I am pleased to continue the partnership working with Healthy London Partnership over the coming months to continue to support these new partnerships deliver the best health outcomes for children and young people across the capital.

*Nicky Brownjohn, Head of Quality (South London) and Safeguarding (London Region), NHS England and NHS Improvement*

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# EXECUTIVE SUMMARY

Healthy London Partnership (HLP) works with partners across London to address issues within the healthcare system. Its Child Death Review Programme has sought to improve the quality of review of child deaths and support local authorities, clinical commissioning groups and hospitals comply with new statutory requirements. It is hoped that these changes will lead to a reduction in child mortality over the coming years.

**Approximately 5000 children across the UK and 700 in London die each year. Whilst the majority of deaths occur during infancy and are related to immaturity or congenital anomalies, a third of all child deaths are felt to be from causes considered avoidable[1].**

Until 2013, the UK's child mortality was in decline, however it has since stalled and the UK now compares less favourably to other similar European countries[2]. This contributed to a national *(Wood) review* of children's services in 2016 which recommended significant reforms including to the systems responsible for reviewing child deaths. These were taken forward as part of the *Children and Social Work Act (2017)*.

Local authorities and clinical commissioning groups were required to come together as new partnerships and: implement new processes; collect a standardised dataset; ensure multi-agency input; undertake thematic learning; and provide routine support to bereaved families.

Whilst supported by professionals, it was widely felt that these changes would be a challenge given that they place an additional and continuous resource burden on health services with stretched budgets without the prospect of further central funding.

An HLP workshops in 2015 identified wide scale variation in practice and funding across London's then 33 Child Death Overview Panels. It highlighted a number of challenges and areas for improvement which led to the establishment of the Child Death Review Programme in 2016. Funded by NHS England (London region), it has:

- Fostered a community of professionals
- Provided guidance and information
- Delivered events and workshops
- Facilitated pan-London networks
- Rolled out a standardised case management system, eCDOP
- Developed a range of tools and resources including *Gathering Feedback*, a tool to support the collection of feedback from bereaved families, and free-to-access eLearning (to be launched later in 2019)

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[1] *ONS: Avoidable mortality in the UK 2016*

[2] *International comparisons of health and wellbeing in early childhood, Cheung, R. Nuffield Trust*

Whilst child mortality rates across London have not significantly fallen during the programme term, there have been a number of successes for the programme:

- 7 new partnerships have replaced the previous 33 London CDOPs  improving the potential of local thematic learning
- Each partnership has submitted routine data to the new National Child Mortality Database from April 2019
- Each partnership published plans for how they will meet the new statutory requirements in July 2019

**MOVING FORWARD, LONDON'S 7 CHILD DEATH REVIEW PARTNERSHIPS SHOULD:**

1. Review their systems in early 2020 and share learning and best practice
2. Align their annual and thematic reporting cycles to inform public health campaigns
3. Provide training to all staff caring for bereaved families, including key workers
4. Ensure relevant staff undertake the HLP Child Death Review eLearning course once launched

**NHS ENGLAND (LONDON REGION)** should support London achieve the ambitions of the NHS Long Term Plan including a 50% reduction in stillbirth, maternal mortality, and neonatal mortality by 2025

**HEALTHY LONDON PARTNERSHIP** should manage a pan-London group to oversee the process and resultant learning, and continue to bring partners together, facilitate greater standardisation, and share learning and best practice at a regional level

# CHILD DEATH

## ‘IN 2016, 34% OF ALL DEATHS AMONGST CHILDREN AND YOUNG PEOPLE AGED 0 TO 19 YEARS IN THE UK, WERE FROM CAUSES CONSIDERED AVOIDABLE THROUGH GOOD QUALITY HEALTHCARE AND WIDER PUBLIC HEALTH INTERVENTIONS’[3].

5000 children die each year across the UK with approximately 700 within London. Most of these children die in hospital, predominantly in Neonatal Intensive Care or Paediatric Intensive Care Units. The causes or types of child death have not changed significantly in recent years.

**Approximately**

**60%**

**of all child deaths occur during infancy**

**and**

**70%**

**of those**

**occur during the neonatal period**

**Approximately**

**41%**

**of infant mortality occurs as a result of immaturity related conditions**

**and**

**33%**

**as a result of congenital anomalies**

**The remaining**

**26%**

**occur from a range of factors including, but not limited to, malignancy (cancer), sudden unexplained death, chronic or acute medical or surgical conditions, infection, and trauma[5].**

**Neonatal mortality is usually categorised as deaths occurring during the first four weeks of life**

**Infant mortality is usually categorised as deaths occurring within the first year of life[4]**

**Child mortality is usually categorised as deaths occurring between 1 and 18 years of age**

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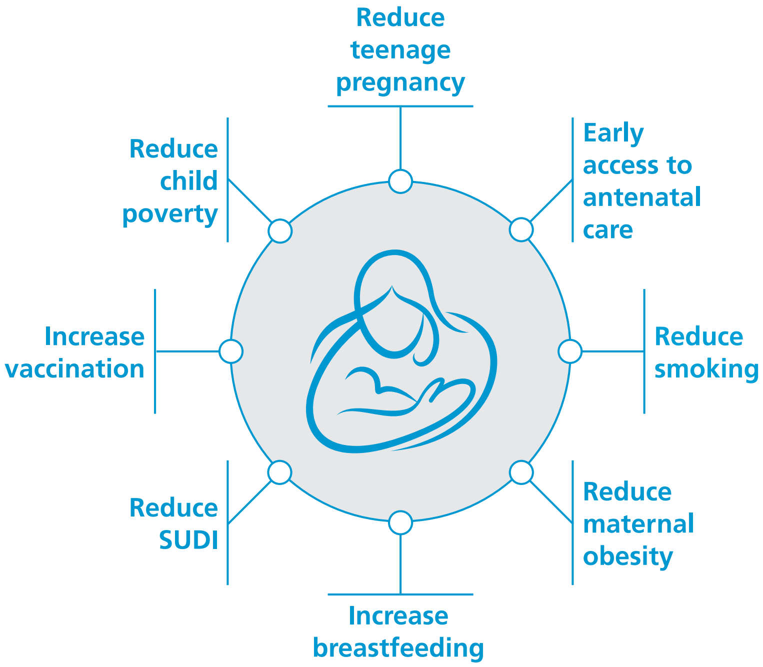
[3] *ONS: Avoidable mortality in the UK 2016. 1,674 deaths out of 4,995 deaths.*

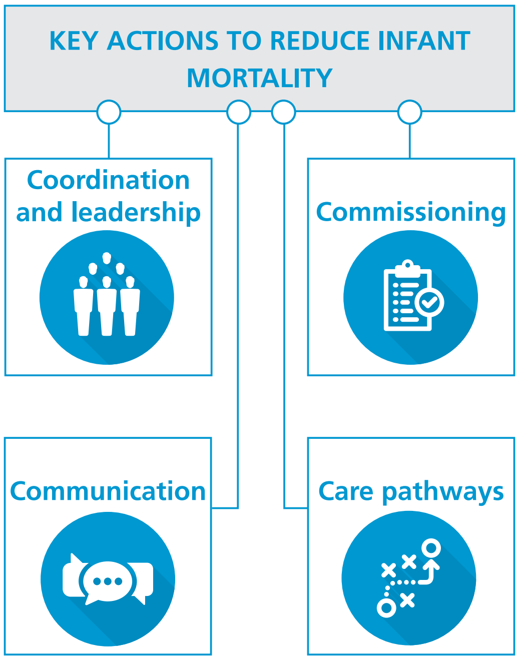
[4] *Public Health England Health profile for England 2018: health of children in the early years*

[5] *Public Health England Reducing infant mortality: A summary of the evidence, Marilena Korkodilos (2016)*

Social inequalities play a role in almost all leading causes of infant death where the risk increases with greater levels of maternal deprivation. There is an increased risk of preterm delivery in more deprived groups, often suboptimal maternal health in pregnancy (smoking, obesity, poor nutrition, substance abuse, teenage pregnancy) and reduced uptake of recommended practices such as breastfeeding and safe infant sleeping positions.

## WHAT NEEDS TO BE DONE TO REDUCE INFANT MORTALITY?





*Reference: Public Health England Reducing infant mortality: A summary of the evidence, Marilena Korkodilos (2016)*

Social inequalities also play a role in wider child death where environmental factors more common to deprived groups such as parental smoking, suboptimal care or understanding of healthcare needs, and suboptimal housing provision increase the risk factors for child death.

Medical causes accounted for 82% of all child deaths in England in 2015-16. However, only 16% of these deaths were understood to have modifiable risk factors. Of the 18% of deaths resulting from non-medical causes, 57% were understood to have had modifiable risk factors[6].

Mortality rates show considerable variation across the country which is likely to be due to a complex interaction between social disadvantage, ethnicity, parenting behaviours and healthcare quality and provision. Whilst reducing potential risk factors continues to form an important component of public health campaigns, there remains an onus on all healthcare systems to systematically review the care that they provide to learn from and improve any sub-optimal care identified. A process of Child Death Review has been established to support this purpose.

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[6] *Public Health England (2016) Reducing child mortality in London Marilena Korkodilos (2016)*

# CHILD DEATH REVIEW – A NATIONAL REQUIREMENT

## IN 2015, ROUGHLY ONE IN FOUR CHILD DEATH REVIEWS IN ENGLAND WAS IDENTIFIED BY LOCAL CHILD DEATH OVERVIEW PANELS AS HAVING A MODIFIABLE RISK FACTOR[7]

The *Children's Act* (2004) was introduced to improve the safety for children of all ages. Significantly it introduced new requirements on Local Authorities to conduct a review into the death of all children resident within their local area. Each review was designed to identify potentially modifiable factors around the care that was provided prior to the child's death, and to ensure that learning was routinely captured and used to improve services for children and their families.

Between 1990 and 2015, UK neonatal and under-five year old mortality fell from 4.5 to 2.7 and 9.3 to 4.5 deaths per 1000 of the population respectively. However, improvements in infant and neonatal mortality rates have stalled since 2013. Despite a decline in infant, neonatal and post-neonatal mortality, the UK has failed to keep pace with many comparable European countries. The UK's child mortality was decreasing but at a slower rate than many other countries within Europe[8].

A number of challenges faced the Child Death Review systems in England. Despite the majority (80%) of child deaths having a medical causation and only 4% of child deaths relating to safeguarding issues[9], the process fell under the remit of local authority safeguarding. This led to a disconnect between many hospitals and the bodies responsible for reviewing child deaths, as well as widespread variation in approach. Terminology around 'preventable' and 'avoidable' deaths hindered transparency and openness at a time when there was limited health care metrics within data-sets, evidence of effectiveness of the review systems, and no clear national leadership.

In 2016, the government tasked Alan Wood with conducting a review into the role and functions of Local Safeguarding Children Boards (LSCBs), the bodies established by local authorities to oversee the safeguarding of children. The *Wood Report* recommended fundamental reform to the LSCBs and the establishment of a 'new, more effective statutory framework that sets out the strategic multi-agency arrangements for child protection'. Specifically in relation to the child death review process, it recommended a shift in the responsibility from the Department for Education to the Department of Health and a number of changes to local Child Death Overview Panels (CDOPs), the panels established by LSCBs in 2008 to conduct the local child death reviews.

The Wood recommendations were accepted and implemented as part of *The Children and Social Work Act (2017)* which amended the governance framework for child death review. For the first time, responsibility would be instituted jointly to both local authorities and clinical commissioning groups as part of new 'Child Death Review (CDR) Partners'. The Act also mandated the submission of information requested by CDR Partners to support any review, thus enhancing the local levers for gaining multi-agency input into the process.

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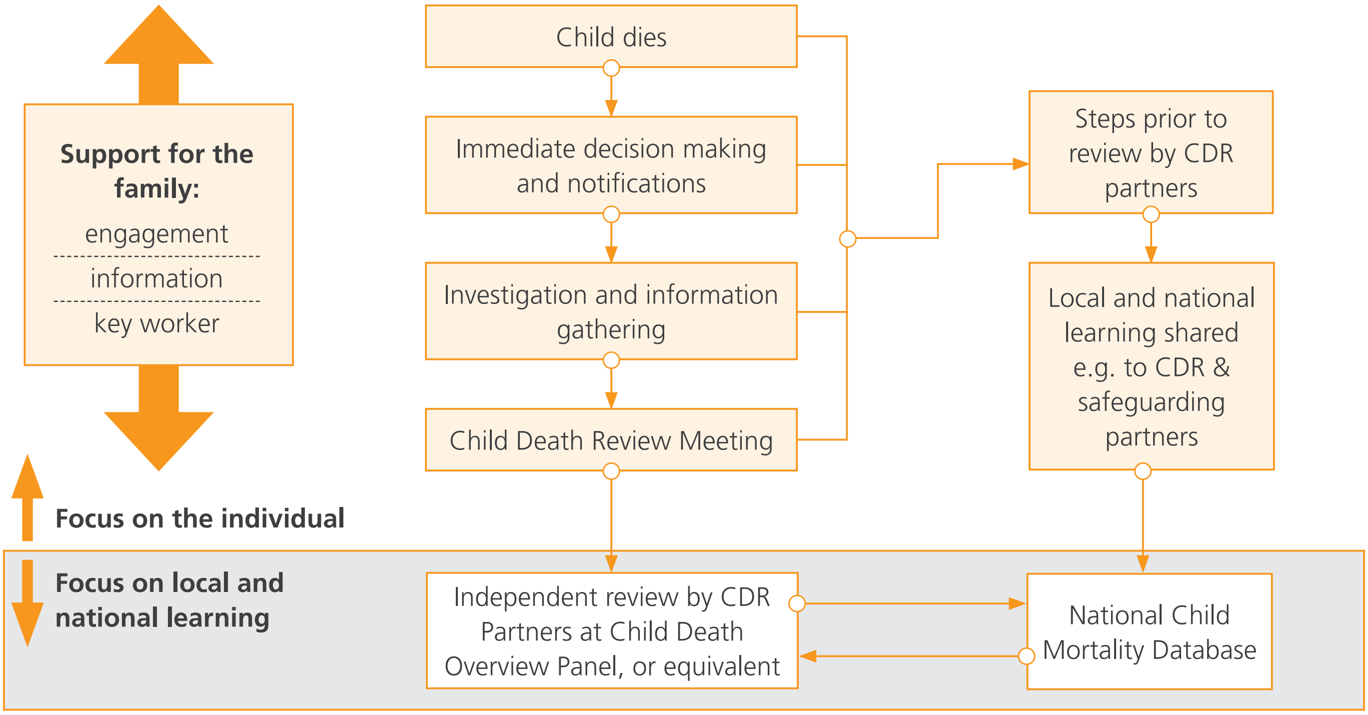
*7 Public Health England (2016) Reducing child mortality in London Marilena Korkodilos (2016)*
*8 International comparisons of health and wellbeing in early childhood, Cheung, R. Nuffield Trust (2018)*
*9 The Wood Report: Review of the role and functions of Local Safeguarding Children Boards (2016)*

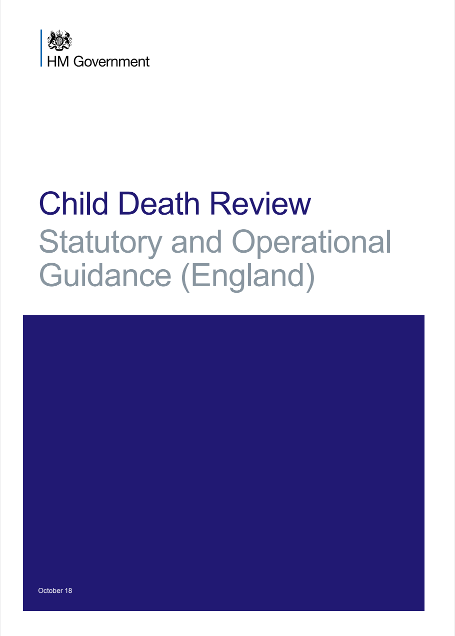
This new framework was complemented in July 2018 with the statutory *Working Together: transitional guidance* which confirmed that the changes to the local safeguarding and child death review arrangements should have begun by 29th June 2018 and must have been implemented by 29th September 2019. CDR Partners were required to publish their plans for meeting these new requirements by 29th June 2019.



*Reference: Summary of Child Death Review Process from* ***The Child Death Review Statutory and Operational Guidance (England)***

At the same time, further statutory guidance *Working Together to Safeguard Children* was published mandating that from September 2019, all CDR Partners would be required to:

- Cover a geographical and population 'footprint' area which would enable the review of a minimum 60 child deaths per year to enable thematic analysis
- Ensure that a 'Joint Agency Response' is established in the immediate aftermath of all deaths which meet certain criteria which can broadly be defined as 'unexpected'
- Continue to notify and liaise with safeguarding partners where abuse or neglect is known or suspected
- Use updated and standardised templates and datasets for the notification, reporting and analysis of all child deaths
- Ensure that local multi-agency CDR Meetings are conducted to review each child's death prior to an independent review by the CDOP
- Ensure that a senior paediatrician or 'designated doctor for child deaths' continues to lead on the co-ordination of responses and health input to the child death process within the new footprint
- Share data with the new National Child Mortality Database (NCMD) (from April 2019)
- Inform relevant persons or organisations of any action that they should take to improve the care and services that they deliver as a result of any review
- Publish reports on what changes had resulted from the child death review arrangements in their area, and how effective the arrangements had been in practice



HM Government

Child Death Review
Statutory and Operational
Guidance (England)

October 18

Working Together referenced a further set of statutory guidance in development which was subsequently published in October 2018: *The Child Death Review Statutory and Operational Guidance (England)*. This provided further clarity and detail on the process, including guidance on which professionals should fulfil the various roles. It also clarified a further requirement for CDR Partners to provide each bereaved family or carer with a 'Key Worker' to signpost them to other information, including bereavement support, and support them through the child death review process.

The reforms of the child death review processes complemented a wider *Learning from Deaths* agenda and national drivers for change. These included a revision of the *Serious Incident Framework (2015)* to support learning to prevent recurrence of harm, and an update to the *Sudden unexpected death in infancy and childhood guidelines (2016)*. The Care Quality Commission also published *Learning, candour, and accountability (2016)*, a report into the way NHS Trusts review and investigate the deaths of patients in England.

NHS England and NHS Improvement commissioned three national programmes to support the standardisation and review of deaths during this time, to complement other pre-existing programmes, (see *Related National Programmes*). In addition, NHS Improvement has begun to introduce a Medical Examiners system[10] to reform the death certification process, under the direction of Alan Fletcher, who became the first National Medical Examiner in 2019.

The reforms into the child death review process have been widely supported as ways of ensuring greater standardisation; strengthening multi-agency input; ensuring thematic learning takes place; and formalising structures to support bereaved families. However, they introduce significant changes during a time of substantial wider system change. They require additional resource on an on-going basis at a time when health services are already stretched and without any additional central funding. The introduction of these new reforms has therefore posed a considerable challenge to health systems across England including to London.

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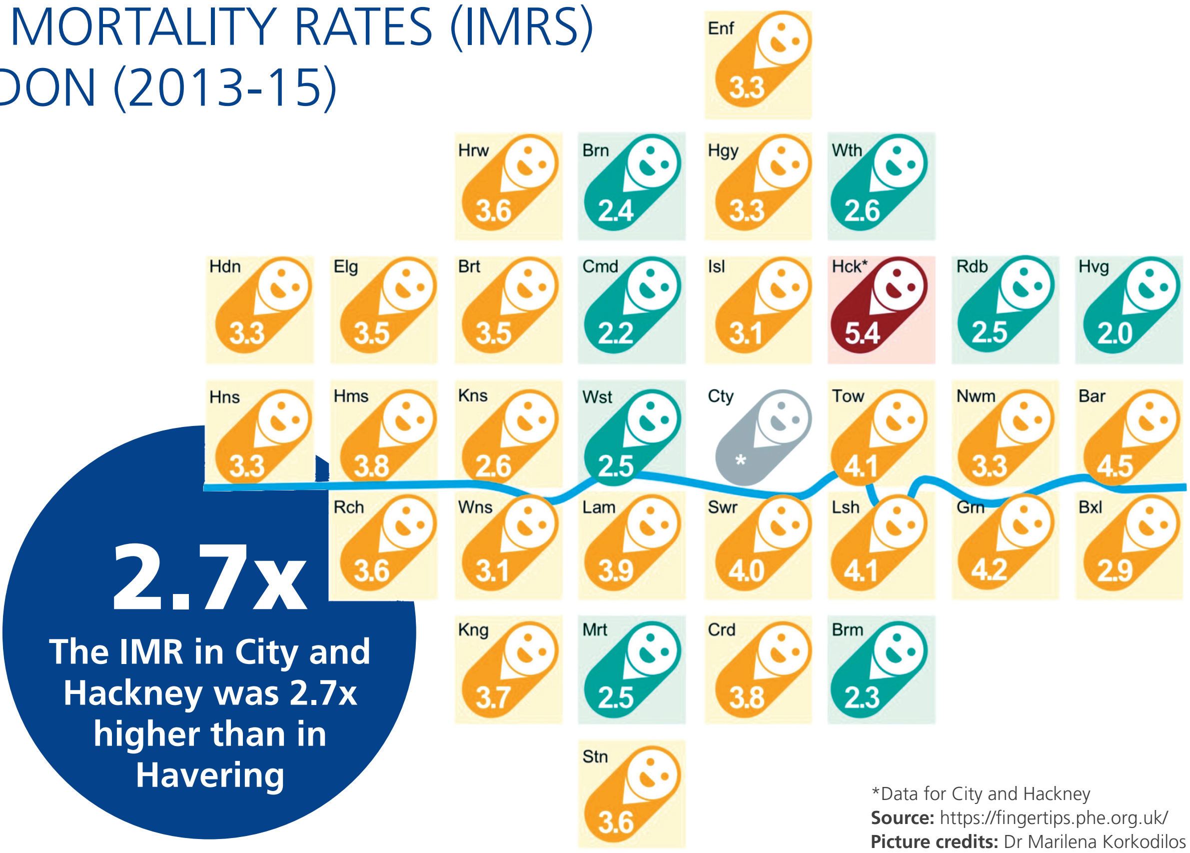
[10] *NHS Improvement: The national medical examiner system*

# CHILD DEATH IN LONDON AND THE HEALTHY LONDON PARTNERSHIP CHILD DEATH REVIEW PROGRAMME

**Approximately 700 children die in London each year. In 2015 infant and child mortality in London broadly aligned with that of the rest of the UK. Figures from 2011-13 outlined that 3.8 under one year of age and 12.2 aged one to 17 years per 100,000 died in London compared with an England average of 4.0 and 11.9 respectively. However, the widespread variation displayed across England was also evident within London. Between 2013-15 infant mortality rates in the City and Hackney region for instance, were 5.4 per 1000 live births, compared with Havering at 2.0[11].**

## INFANT MORTALITY RATES (IMRS) IN LONDON (2013-15)



**2.7x**
**The IMR in City and Hackney was 2.7x higher than in Havering**

*Data for City and Hackney
**Source:** https://fingertips.phe.org.uk/
**Picture credits:** Dr Marilena Korkodilos

By 2015, 30 London CDOPs had formed to review the deaths of children within their local footprint areas. These broadly aligned with London borough boundaries[12] and represented roughly a third of all CDOPs in England. A self-managed network of pan-London CDOP Chairs had established itself as a forum for discussing issues relating to child deaths and the review process, meeting twice each year.

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[11] *Public Health England Reducing infant mortality: A summary of the evidence, Marilena Korkodilos (2016)*

[12] *By 2015 the 30 London CDOPs had merged to create 28. The tri-borough CDOP of Westminster, Hammersmith & Fulham and Kensington & Chelsea, was formed along with the bi-borough CDOPs of Kingston and Richmond, and Southwark and Lambeth*

However, there was little regional benchmarked data that could be used to understand the outcomes of child death reviews at a London-population level. Annual mortality statistics were routinely collected and published by the Office of National Statistics (ONS) and the Department for Education had published annual reports since 2010 of data on child death reviews from every LSCB in England, however, these provided limited information on child death by region.

In 2015, Healthy London Partnership therefore led a project to explore the outputs of London's child death reviews, resulting in a detailed analysis and summary of the 30 London LSCB report submissions to the Department for Education for the period April 2014 to March 2015. This analysis outlined a number of variances between London when compared with the national average:

- **Higher %** of modifiable causes in 10-14 and 15-17 year olds
- **Higher %** of modifiable causes implicated in deaths of black children
- **Lower %** of modifiable causes in infants older than 1 month (post-neonatal mortality)
- **Higher %** of children who died in A&E and in hospital wards and a lower % who died at home
- **Higher %** of children who died of acute infections or acute medical or surgical problems, with a higher proportion of these deaths related to modifiable causes

To discuss these findings in more detail, Healthy London Partnership (HLP), the London CDOP Chairs, and other stakeholders across London held a joint workshop in September 2015 where considerable variation was highlighted in the governance and resourcing arrangements; volume of cases reviewed, inclusion and exclusion criteria applied, and the support offered to bereaved parents. A number of other themes and issues emerged:

- Variation in recording of cause of death especially in the neonatal population
- Issues in collation of data across boundaries and that is recorded differently
- Information sharing issues
- Lack of administrative support to pan London CDOP Chairs Network
- Different police and coroners' definitions
- Lack of shared learning
- A desire to establish a database for use by all CDOPs across London

It was evident that value could be added by in supporting the child death review systems at a London-regional level, maximise their potential impact by sharing best practice and reducing variation. In 2016 the Safeguarding team within the Nursing Directorate of NHS England (London Region) therefore agreed to fund an initial twelve month programme, led by the Healthy London Partnership (HLP), to work collaboratively with the London CDOPs and LSCBs, to achieve an overarching goal:

**1.** To support health systems in London to improve the quality of child death reviews to support a reduction in child mortality

Following the introduction of new statutory requirements, the programme term was extended until 2019 to incorporate a second goal:

**2.** To support health systems in London achieve compliance with the new statutory requirements by 29th September 2019

The programme was originally named the CDOP Programme, but was subsequently renamed the Child Death Review Programme. Led by Tracy Parr, HLP Director of Transformation for Children and Young People, and Dr Ronny Cheung, Consultant Paediatrician at the Evelina Children's Hospital, the programme was established in July 2016. Dr Donal O'Sullivan, a former Consultant in Public Health and Chair of the Lewisham CDOP, was appointed as clinical advisor.

A Programme Steering Group was established to supplement the Programme team with advice and guidance (see Appendix 2). The programme was overseen by the HLP Children and Young People's Programme Board which is currently co-chaired by Dr Vin Diwakar, Regional Medical Director & CCIO, NHS England / NHS Improvement (London Region) and Martin Wilkinson, Managing Director of Lewisham Clinical Commissioning Group.

# IMPROVING THE QUALITY OF CHILD DEATH REVIEWS ACROSS LONDON - SUPPORT FOR THE SYSTEM

## NETWORKS AND INFORMATION SHARING

The programme focussed on developing a community of child death review professionals across London which included all agencies that would be required to input into future child death reviews. In addition to engagement across the NHS, early focus was spent on developing networks that included wider public sector organisations, Education, the Metropolitan Police and London Ambulance services and established. In establishing itself as a conduit between the national team (NHS England) and stakeholders across London, by providing regular updates and information to the system, and in providing secretariat support to the London CDOP Chairs Network Group, the programme established itself as a single source of information and support for Child Death Reviews across London.

In July 2016 the programme hosted its first workshop to bring together colleagues from across London to understand the work of the National Network of Child Death Overview Panels, notably on their work on redefining data definitions. It also provided a forum for showcasing new ways of working including the eCDOP child death review case management system which had been developed in partnership with Kent Local Safeguarding Children's Board. This workshop was followed by a formal launch of the programme in September 2016 with an event aimed at CDOP Chairs, Designated Doctors, Lead Nurses for child death, and wider stakeholders. It provided an opportunity to discuss the recommendations of the Wood Report and the findings of the London Strategic Clinical Network survey, share best practice and consider potential cross-boundary working arrangements. Attended by 75 professionals across London, the discussions helped frame the future programme work plan. This would include five workshops for each of the London Sustainability Transformation Partnerships in June 2017 to support their mapping of child death review systems and processes.

## THEMED EVENTS

Feedback received from the early programme events outlined that the programme could add value by supporting the London system with best practice around the completion of thematic analysis of child deaths and the reporting of common and important causes of death in children across London. From September 2016 the programme ran a series of themed learning events based on a number of London's priority areas. These included local and strategic partnership approaches and prevention strategies to tackle these causes.

The events were attended by over 300 professionals across London and included:

December 2016 - **Understanding & Preventing Deaths Due to Suicide**

May 2017 - **Tackling Asthma Deaths**

May 2017 - **Understanding Neonatal deaths**

July 2017 - **Understanding Consanguinity related deaths**

February 2018 - **Understanding Youth Violence**

May 2018 - **Mass Mortality and Major Incidents**

# STANDARDISATION OF APPROACH – PROVISION OF ECDOP ELECTRONIC CASE MANAGEMENT SYSTEM

A key aspiration of the programme was to maximise efficiency and identify and reduce variation and improve CDOP operational practices and outcomes across London. In 2018 the programme facilitated the roll-out of free-access use of the **eCDOP** child death review electronic case management system for all London CDOPs. Developed by QES Ltd in collaboration with Kent Local Safeguarding Children Board it provided standardised processing and data collection and greater consistency, which had led to a reduction in the administrative burden of the Kent CDOP[13].

Following a review of the system functionality and discussions with Kent LSCB, the programme was successful in securing non-recurrent funding from NHS Digital for 12 months pan-London access from 1st April 2018. No London CDOP was mandated to use eCDOP, however the offer was provided to inform local decision making around which system could best support local requirements. The Programme led on the contractual and governance arrangements for the roll-out.

The timeliness of uptake by London CDOPs varied, and as such, not all child deaths that had occurred across London since April 2018 have been captured. However, by January 2019, 65 of the 93 CDOPs in England were actively using eCDOP. By April 2019, all 28 London CDOPs were actively using eCDOP. Whilst not all feedback received from London CDOPs has been positive, the majority (66%) of CDOPs have outlined that it has led to a reduction in the time to administer the process and (63%) that it has led to improvements in the child death review process. There have been a number of additional benefits of eCDOP to the London CDOPs:

- Supports the London Child Death Review system to undertake standardised, high quality child death reviews, in doing so reduce administrative burden and unwarranted variation
- Supports the system to meet the requirements of the new statutory requirements as outlined within the Act and *statutory and operational guidance*
- Enables the London system to meet strategic national objectives in regards to utilisation of digital technology, sharing data and learning from deaths
- Gains a greater understanding of the causes of child deaths across the London-region level by accessing valuable real time data with a view to improving systems and reducing future child deaths in London

However, by March 2019, local funding arrangements for the new CDR Partnerships had not been established and as a result, the London CDOPs were not in a position to continue funding eCDOP during 2019/20. HLP negotiated a £63,000 cost reduction for pan-London eCDOP provision with QES and successfully lobbied the public health commissioning team at NHS England (London Region) to provide an additional 12 months of non-recurrent funding for all London CDR Partners from 1st April 2019 – 31st March 2020. This provided an additional benefit in that it enabled all London CDOPs to meet their mandatory requirement to submit data to NCMD from 1st April 2019, which would otherwise have required a labour-intensive manual data entry process.

eCDOP is now starting to yield invaluable insights into the causes of child deaths across London.

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[13] *How Kent LSCB developed a national solution for recording child deaths, Children & Young People Now*

# DEVELOPMENT OF A PAN-LONDON DATASET

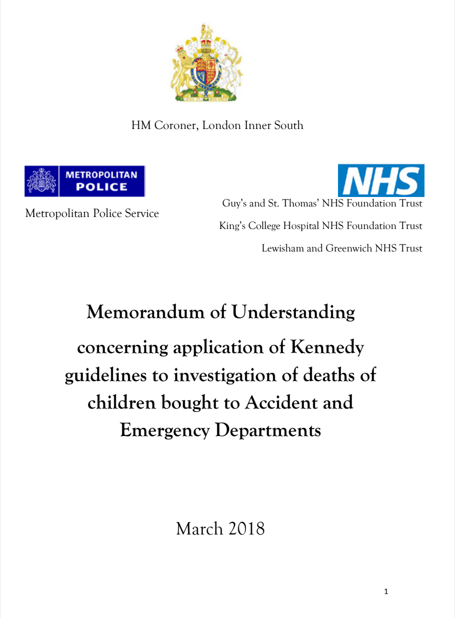
Another key aspiration of the programme was to enable collaboration between CDOPs to improve the epidemiological understanding of child death in London. As a result of the roll-out of eCDOP, for the first time, a complex and granular dataset is being collected at a London region level on child deaths. No other health population / region currently has access to such comprehensive and accurate data.

| Child deaths across London since 01.04.19 recorded in eCDOP (not complete capture during this period) | Data as of 31.08.19 |
|---|---|
| Cases notified (previously Form A) | 915 |
| Cases started (previously Form B) | 803 |
| Cases completed (previously Form C) | 255 |

The NCMD required CDOPs across England to submit data to it from 1st April 2019. The programme has worked to ensure that all data collected across London from 1st April 2018 has been uploaded. The potential utility of the pan-London data will increase over time in line with the number of completed child death reviews managed through eCDOP. The programme team has worked collaboratively with NCMD and is looking to facilitate the formation of pan-London regional reports from NCMD when they commence in early 2020.

Please see **Appendix 3** for statistics on child deaths in London recorded in eCDOP since April 2018.

# MEMORANDUM OF UNDERSTANDING WITH LONDON CORONER



HM Coroner, London Inner South

Metropolitan Police Service

Guy's and St. Thomas' NHS Foundation Trust
King's College Hospital NHS Foundation Trust
Lewisham and Greenwich NHS Trust

**Memorandum of Understanding**

**concerning application of Kennedy guidelines to investigation of deaths of children bought to Accident and Emergency Departments**

March 2018

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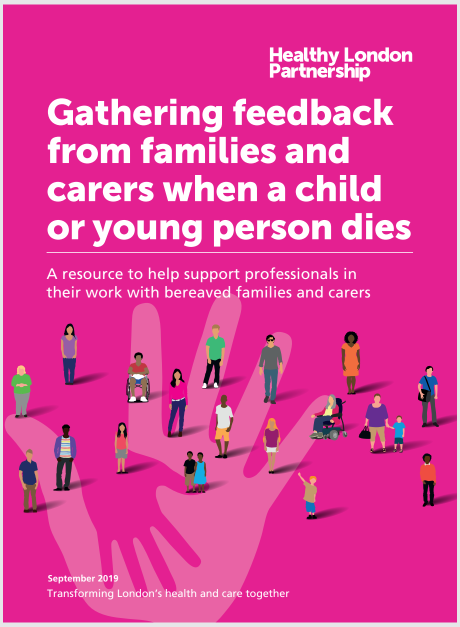
The programme team worked closely with HM Coroner for Inner South London, Dr Andrew Harris, and colleagues from health and police across South East London to agree a single pathway to guide health professionals in the aftermath of managing the unexpected death of a child. This resulted in a *memorandum of understanding* from the Coroner's officer pre-authorising certain processes after the death of a child; guidance for practitioners on statutory processes; and resources for bereavement support. While it carries legal weight only within the Inner South London jurisdiction of Coroner Harris, the programme team have encouraged other areas to work with their stakeholders (coroners, police, hospital and community trusts, and ambulance services) to use this as a template and develop and agree their own local versions in order to reduce the unnecessary variation in practice after a child's death.

This work builds on the South West London pathway which was agreed in 2018. We hope that other coronial jurisdictions will, if appropriate, agree local guidance along these lines.

# GATHERING FEEDBACK FROM FAMILIES AND CARERS WHEN A CHILD OR YOUNG PERSON DIES AND THE CHILDHOOD BEREAVEMENT EXPERIENCE MEASURE


Healthy London Partnership

**Gathering feedback from families and carers when a child or young person dies**

A resource to help support professionals in their work with bereaved families and carers

September 2019
Transforming London's health and care together

In September 2019, the programme team launched *Gathering feedback from families when a child or young person dies*, a resource outlining the key principles of good bereavement care. Based upon published literature and a survey of 382 families, it has been developed in collaboration with bereavement leads and families across England.

The resource provides guidance on how to collect feedback on the care of bereaved families and carers and the Childhood Bereavement Experience Measure, a suite of questions that can be used to develop personalised surveys of the care provided to bereaved families and carers.

NHS England has outlined its intent to publish this resource nationally through their Gateway process. It is hoped that it will increase the collection of feedback from bereaved families and lead to improvements in bereavement care and services across the Country

## ELEARNING

In Autumn 2019, the programme team plan to launch a free-to-access eLearning resource to provide knowledge and understanding of the child death review process, as well as best practice examples and taking inspiration and contributions from the Introduction to Child Death Review and Responding to Unexpected Child Deaths courses developed by Professor Peter Sidebotham and colleagues at Warwick University. The programme will cover both procedural knowledge and theoretical background on child death reviews, and is aimed at any professional across London that has a role or interest in, or will be required to contribute to, the child death review process.

Over the coming years, it is anticipated that this eLearning will inform the training and understanding of several hundred professionals across London, resulting in improved child death reviews and ultimately better care for children across London.

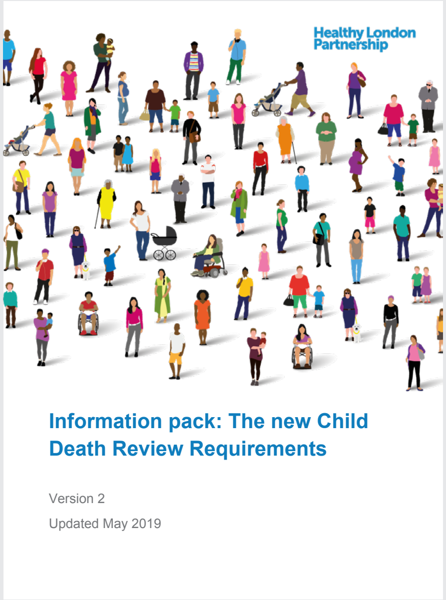
# SUPPORTING LONDON TO MEET THE NEW STATUTORY RESPONSIBILITIES

The *Children and Social Work Act 2017* outlined significant changes to the child death review systems from 29th September 2019. However, details of what these changes would entail and what the new systems would be required to deliver were only confirmed following the publication of *Working Together: transitional guidance* and *Working Together to Safeguard Children* in July 2019, and *The Child Death Review Statutory and Operational Guidance (England)* in October 2018.

Through its links with NHS England, and following the release of a consultation draft of the new statutory guidance, the programme team began a series of promotional activities and events to raise awareness, provide an outline of the primary changes, and share best practice examples and resources to support London CDOPs and wider system stakeholders. These included:

- An initial Understanding CDOP System Transformation Workshop in November 2017 for all professionals with an interest in child death review, attended by 57 attendees
- A number of local workshops to individual CDOPs and their stakeholders from February 2018
- A presentation to the March 2018 London CDOP Chairs Network meeting
- A pan-London transformation support workshop in April 2018 which was attended by over 50 child death review professionals across London
- A seminar on the new Child Death Review Processes in June 2018, attended by 37 paediatric clinical leads, designated children's safeguarding and quality leads and those responsible for local learning from mortality and morbidity review meetings within acute trusts

The programme team also presented an update on the work of the programme and the new requirements at national events including the NHS England Safeguarding Conference and National Network of Child death Overview Panel Chairs Annual Conference in May 2018. In June 2018, they developed and circulated a Toolkit for Acute, Community and Mental Health Trusts summarising the information from the recent presentations; the changes to the child death review process; the timetable for implementation and forthcoming publications; which also provided a suite of templates to support local resource mapping.

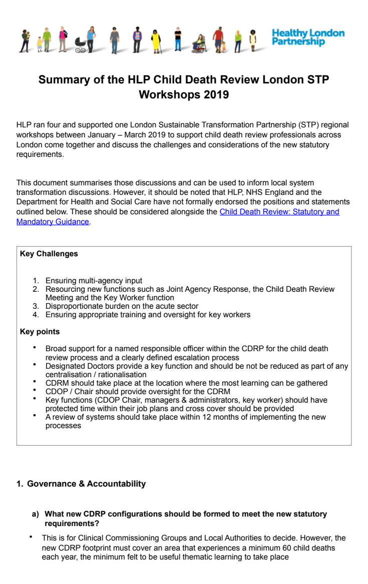


Healthy London Partnership

**Information pack: The new Child Death Review Requirements**

Version 2
Updated May 2019

Following the publication of The Child Death Review Statutory and Operational Guidance, the programme team published and circulated an information pack summarising the background and primary requirements of the new child death review systems. They presented to the London Joint Quality Committee and promoted the new changes through pan-London newsletters and bulletins. They also facilitated correspondence from Dr Vin Diwakar, Regional Medical Director NHS England (London Region), Professor Oliver Shanley OBE, Regional Chief Nurse (London Region), NHS England / NHS Improvement, and Iain Eaves, Director of Commissioning Operations, NHS England, to the Chairs of all London Clinical Commissioning Groups; Chief Executives of London Local Authorities, Trust Medical Directors, Directors of Nursing, Chairs of LSCBs and Directors of Public Health about the new Statutory Requirements for Child Death Review.



Healthy London Partnership

**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 programme team supported the agenda and facilitated discussion at the National Child Death Review Workshops held in London on 28th January 2019, led by Dr Jacqueline Cornish, National Clinical Director for Children and Young People, NHS England, and Dr James Fraser, Consultant in Paediatric Intensive Care and author of the statutory guidance.

The programme team also 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. These five workshops were attended by over 200 professionals across London. A summary of the discussions including the challenges and potential solutions from the London workshops was written up and circulated to the Steering Groups and wider child death review professionals across London.

As a result of the statutory requirement for each new CDR Partner to cover a minimum footprint of 60 child deaths each year, the programme team supported the formation of local steering groups and attended their early meetings to support them understand the new requirements and agree the new footprint areas.

Each CDR Partnership was required to publish a plan by 29th June 2019 of what system they intended to implement to meet the new statutory requirements by 29th September 2019. Following feedback from across London, the programme team lobbied and received from NHS England a non-mandatory template to support the development of local plans. They also distributed widely a range of resources and tools developed by NHS England to support the implementation and adoption of these new plans that were published on the Child Death Review section of the *Future NHS Collaboration platform website*. Ronny Cheung has spent considerable time between April – June 2019 advising and supporting acute trusts, developing and sharing draft job descriptions.

All 7 of the London CDR Partners met their statutory requirement of publishing a plan to implement new child death review systems by 29th June 2019

As a result of the information, guidance and support, the programme achieved its aim of supporting the London child death review 'system' understand, plan for, and implement new child death review systems and processes in response to the new statutory requirements, by September 2019.

# THE LONDON CHILD DEATH REVIEW SYSTEM - SEPTEMBER 2019

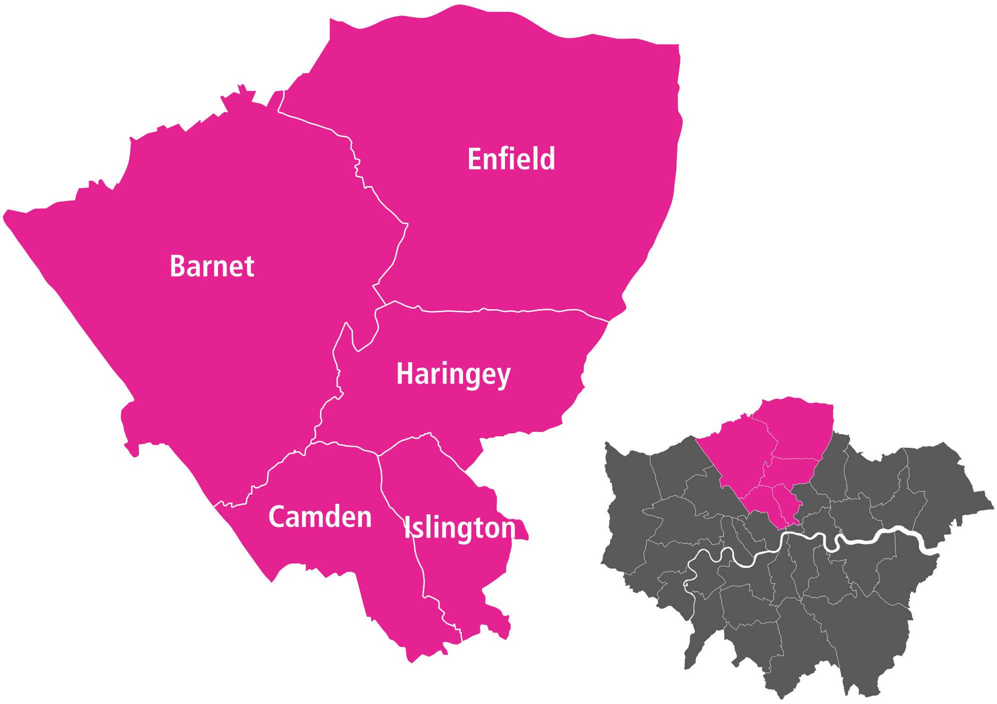
**Prior to September 2019, 28 Child Death Overview Panels existed across London which broadly aligned with borough boundaries. On average, each reviewed approximately 25 deaths per year. In response to the new statutory requirements, the London system has come together to form the seven new footprint areas listed below.**

See **Appendix 2** for further information on the London Child death Overview Panel contacts.

## NORTH CENTRAL LONDON

**10 CHILD DEATH REVIEW PARTNERS HAVE COME TOGETHER ACROSS NORTH CENTRAL LONDON:**

1. Barnet CCG
2. Camden CCG
3. Enfield CCG
4. Haringey CCG
5. Islington CCG
6. Barnet Council
7. Camden Council
8. Enfield Council
9. Haringey Council
10. Islington Council

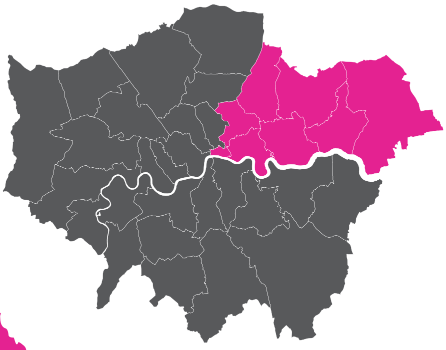


On average the NCL footprint experiences 80 child deaths annually.

The NCL plan for their child death review system is available at:
**www.haringeyccg.nhs.uk/about-us/north-central-london-child-death-review-arrangements.htm**

# NORTH EAST LONDON

Two separate CDR Partnerships have formed within North East London, one covering Barking, Dagenham, Havering & Redbridge (BHR) and the other covering Waltham Forest, East London & the City (WELC)



## BARKING, DAGENHAM, HAVERING & REDBRIDGE

### 6 CHILD DEATH REVIEW PARTNERS HAVE COME TOGETHER ACROSS BHR:

1. Barking & Dagenham CCG
2. Havering CCG
3. Redbridge CCG
4. Barking Council
5. Dagenham Council
6. Havering & Redbridge Council

On average the BHR footprint experiences 60 child deaths annually.

The BHR plan for their child death review system is available at: **www.havering.gov.uk/downloads/file/3236/barking_and_dagenham_havering_and_redbridge_child_death_review_system_plan**

## WALTHAM FOREST, EAST LONDON & THE CITY (WELC)

### 8 CHILD DEATH REVIEW PARTNERS HAVE COME TOGETHER ACROSS WELC:

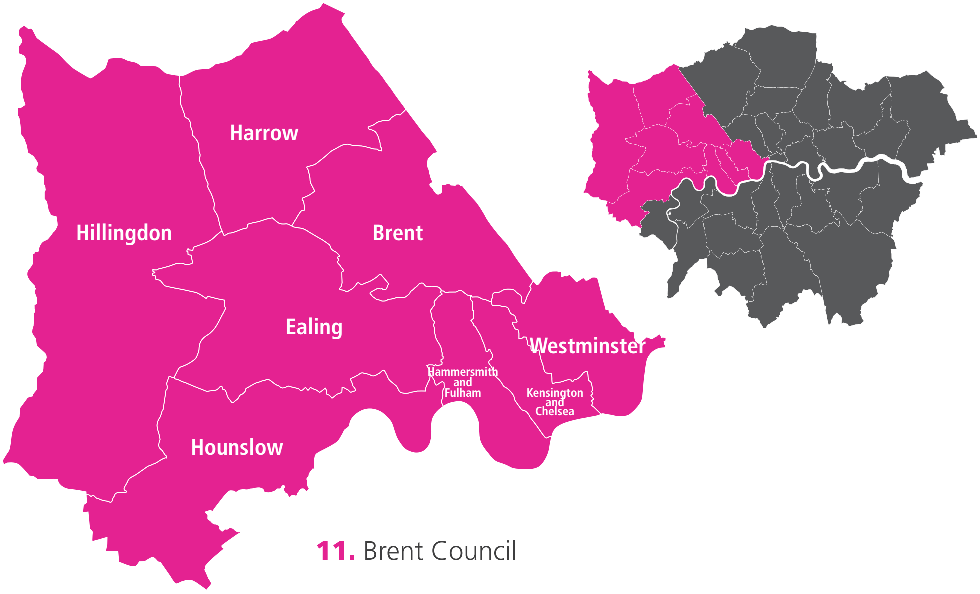
1. City & Hackney CCG
2. Newham CCG
3. Tower Hamlets CCG
4. Waltham Forest CCG
5. City & Hackney Council
6. Newham Council
7. Tower Hamlets Council
8. Waltham Forest Council

On average the WELC footprint experiences 60 child deaths annually.

The WELC plan for their child death review system is available at: **www.chscb.org.uk/wp-content/uploads/2019/06/WELC-CDR-System-Plan-270619-FINAL.pdf**

# NORTH WEST LONDON

## 14 CHILD DEATH REVIEW PARTNERS HAVE COME TOGETHER ACROSS NORTH WEST LONDON:



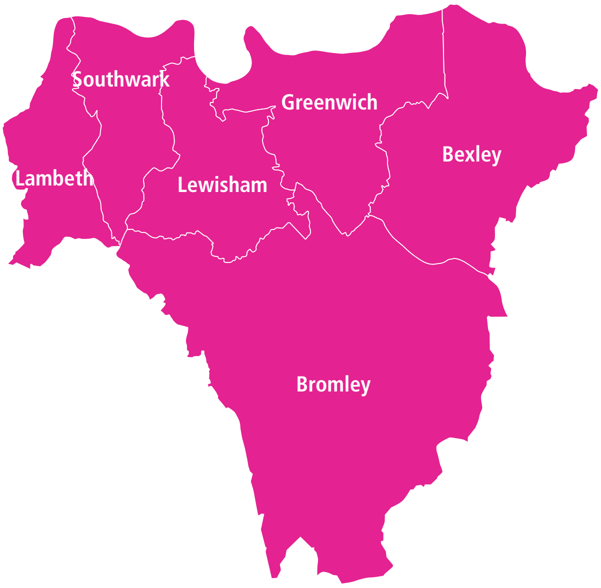
1. Brent CCG
2. Central London CCG
3. Ealing CCG
4. Hammersmith & Fulham CCG
5. Harrow CCG
6. Hillingdon CCG
7. Hounslow CCG
8. West London CCG
9. Hillingdon Council
10. Harrow Council
11. Brent Council
12. Royal Borough of Kensington & Chelsea Council
13. Westminster Council
14. Hounslow Council

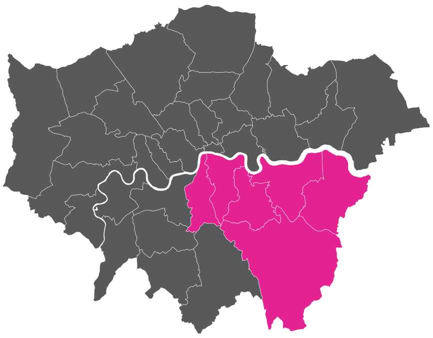
On average the NWL footprint experiences 154 child deaths annually. The responsible officer(s) within the footprint for child death are: Diane Jones, Chief Nurse, NHS Collaboration NWL CCGs.

The NWL plan for their child death review system is available at: **http://brentccg.nhs.uk/en/publications/doc_download/4629-nw-london-child-death-review-plans-statement-of-transition-june-2019**

# SOUTH EAST LONDON

Two separate CDR Partnerships have formed within South East London, one covering Bromley, Lambeth & Southwark and the other Bexley, Greenwich and Lewisham





## BROMLEY, LAMBETH & SOUTHWARK

### 6 CHILD DEATH REVIEW PARTNERS HAVE COME TOGETHER ACROSS BLS

1. Bromley CCG
2. Lambeth CCG
3. Southwark CCG
4. Bromley Council
5. Lambeth Council
6. Southwark Council

On average the BLS footprint experiences 70 child deaths annually.

The BLS plan for their child death review system is available at: **www.bromley.gov.uk/downloads/file/5039/bromley_child_death_review_plans**

## BEXLEY, GREENWICH & LEWISHAM

### 6 CHILD DEATH REVIEW PARTNERS HAVE COME TOGETHER ACROSS BGL:
### PARTNERS: 6 CDR PARTNERS INCLUDING 3 LAS AND 3 CCGS:

1. Bexley CCG
2. Greenwich CCG
3. Lewisham CCG
4. Bexley Council
5. Greenwich Council
6. Lewisham Council

On average the BGL footprint experiences 75 child deaths annually. A new Child Death Oversight Board comprising Directors of Public Health Lewisham, Bexley and Greenwich Managing Director, Lewisham CCG, Deputy Managing Director and Director of Quality, Greenwich and Bexley CCGs will oversee process in BGL.

The BGL plan for their child death review system is available at: **www.bexleyccg.nhs.uk/Downloads/Safeguarding%20children/Delivering%20the%20new%20child%20death%20review%20process%20across%20Bexley%20Lewisham%20Greenwich%20.pdf**

# SOUTH WEST LONDON

**12 CHILD DEATH REVIEW PARTNERS HAVE COME TOGETHER ACROSS SWL:**

1. Croydon CCG
2. Kingston CCG
3. Merton CCG
4. Richmond CCG
5. Sutton CCG
6. Wandsworth CCG
7. Croydon Council
8. Kingston Council
9. Merton Council
10. Richmond Council
11. Sutton Council
12. Wandsworth Council

On average the SWL footprint experiences 110 child deaths annually.

The SWL plan for their child death review system is available at: **www.croydonccg.nhs.uk/news-publications/news/Pages/Croydon-child-death-review---planned-new-arrangements.aspx**

# IMPACT

**During the programme term, London's neonatal, postneonatal and infant mortality rates have continued to score below the national average. Whilst the national child mortality rates have remained relatively static, there has been a minor reduction across London.**

**MORTALITY RATES**[14]

| Region | Perinatal | | | Neonatal | | | Postneonatal | | | Infant | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2016 | 2017 | 2018 | 2016 | 2017 | 2018 | 2016 | 2017 | 2018 | 2016 | 2017 | 2018 |
| **England** | 6.6 | 6.4 | 6.2 | 2.8 | 2.9 | 2.8 | 1.1 | 1.1 | 1.1 | 3.9 | 4.0 | 3.9 |
| **London** | 6.7 | 6.7 | 6.1 | 2.3 | 2.5 | 2.2 | 1.0 | 1.0 | 0.9 | 3.3 | 3.5 | 3.2 |

Whilst this is not as encouraging as we had hoped, it is not unexpected. The significant system reforms called for within the Wood Report, and enacted as part of The Children and Social Work Act, confirmed that there was no simple solution to reducing child mortality. The new systems that will come into effect by 29th September 2019, if operated effectively, will maximise the potential for learning to be identified and system improvements to be embedded. Effective review systems, whilst important, are only one part of the solution. We must continue to reduce potential risk factors where possible through education and public health campaigns.

However, the programme has been successful in many ways. Most significantly, it has supported the 32 CCGs, 32 local authorities, 28 London CDOPs, 37 acute and mental health trusts, and a range of other health and public sector organisations come together for the first time to form 7 new partnership areas. It has also supported these new partnerships develop new systems and publish outline plans summarising those systems as required.

At the time of writing it is too early to determine whether the systems that are being implemented will be fully compliant, or will function as effectively as is required. There is likely to be a period of refinement for all systems across England before the benefits can be fully realised. However, the programme team have confidence in those leading the new CDR Partnerships and believe that the systems and processes embedded will significantly improve the care of children across London over the coming years. It is hoped that these new partnerships may act as a blueprint for future system alignment within sustainability and transformation partnerships and integrated care systems.

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[14] *Perinatal deaths per 1,000 live births and stillbirths. Neonatal, postneonatal and infant deaths per 1,000 live births. ONS Death registrations summary tables - England and Wales: 2016 and 2017*

## OTHER IMPACTS OF THE PROGRAMME INCLUDE:

- **100% of the London CDR Partners met their statutory requirement** of publishing a plan to implement new child death review systems by the 29th June 2019 deadline
- **The roll-out of eCDOP across London resulted in the following being achieved:**
    - The implementation of a standardised case management system that 66% of London CDOPs who responded to an HLP survey reported had led to an overall reduction in the time taken to administer the child death review process and 63% reported had led to an overall improvement of the quality of child death reviews since it was implemented
    - 100% - all 28 London CDOPs met their requirement of submitting data on all child deaths to the NCMD since 1st April 2019 and without incurring any additional administration costs for this function
    - a £63,000 saving to London CCGs for pan-London access to eCDOP pan- for 2019/20
- Between December 2018 and August 2019, the *programme website* information, tools and resources were accessed over 1300 times with over 950 unique views. Whilst over 40% of these views were accessed within London, they were accessed by over 50 other cities and towns outside of London. On average visitors spent over two minutes reviewing the guidance and resources. This supports wider anecdotal feedback to the programme team that the information and guidance presented has been clear and helpful.

## THE PROGRAMME HAS ALSO BEEN SUCCESSFUL IN:

- Raising the profile of the review of the child death review process across London
- Acting as a conduit between the national team (NHS England) and stakeholders across London
- Engaging a multitude of agencies across London by supporting existing, and developing new networks of wider public sector organisations including Health, Public Health, Education, the Metropolitan Police, London Ambulance services, Coroners, charities and voluntary groups
- Provided a single source of information for Child Death Reviews for London

Given the scale of the changes that are being implemented, a formal review of the programme and resultant improvements to the London child death review system has not been conducted at this time. *Gathering feedback* was only launched in September 2019 and the Child Death Review eLearning programme is planned for release later in 2019. A review of these tools and the London system compliance with the new requirements will form part of the future work of the programme.

# KEY ACTIONS

**The Healthy London Partnership Child Death Review Programme Steering Group has developed a number of key actions broken down by relevant stakeholder groups, following consultation with child death review professionals across London:**

## THE SEVEN CHILD DEATH REVIEW PARTNERS ACROSS LONDON SHOULD:

1. **Review the regional child death review systems implemented during 2019** within six months to ensure that they both comply with the statutory requirements and provide high quality child death reviews for their constituent populations
2. **Come together at a London regional level** to share learning and best practice around how the child death review process, and care for children across London, can be enhanced
3. **Provide appropriate training to staff** caring for bereaved families, such as key workers
4. **Align their annual and thematic reporting format and cycles at a London-region level** to increase regional understanding of child death and inform any future regional public health campaigns
5. **Integrate Medical Examiners** (where appointed) into the child death review process
6. **Ensure that systems are in place to collect feedback** of the care for bereaved families and carers, see *Gathering feedback from families when a child or young person dies*
7. **Ensure that all staff involved in the child death review process have undertaken the Healthy London Partnership Child Death Review eLearning course** once published

## NHS ENGLAND (LONDON REGION)

8. **Support the Child Death Review Partnerships and health services across London** achieve the ambitions of the *NHS Long Term Plan (2019)* including a 50% reduction in stillbirth, maternal mortality, neonatal mortality and serious brain injury by 2025

## HEALTHY LONDON PARTNERSHIP

9. **Continue to work with Child Death Review Partnerships, health services and NHS England (London Region)** to promote awareness and understanding of child death review, facilitate greater standardisation and share learning and best practice at a regional level
10. **Manage a pan-London Group with oversight for child death review and learning across London,** engaging with relevant existing groups an networks

# FUTURE WORK

**NHS England (London Region) has agreed to extend funding for the Healthy London Partnership Child Death Review Programme for six months until March 2020. During this time, the programme will focus on the following areas:**

- **Manage a regional group to oversee the child death review process** and resultant learning at a London level, supporting engagement with existing inter-related regional networks
- **Facilitate the review of the systems implemented across London during 2019** to meet the statutory requirements, and share learning following the review
- **Continue to improve system understanding of the child death review process** and best practice through the publication and promotion of the HLP child death review eLearning programme and workshops. To review and enhance the programme following feedback
- **Continue to improve regional understanding of child deaths and system learning from child death reviews.** To align and developing pan-London regional reports to inform future public health campaigns across London

# GLOSSARY

| | |
|---|---|
| **Child Death Overview Panel (CDOP)** | An independent 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 children, in order to learn lessons and share any findings for the prevention of future deaths. A CDOP must take place following a CDRM |
| **Child Death Review Meeting (CDRM)** | A local multi-agency panel review meeting where all matters relating to an individual child's death are discussed. A CDRM must take place following the death of all children and prior to a CDOP meeting |
| **Child Death Review (CDR) Partner** | A partnership of the local authorities and clinical commissioning groups responsible for the child death review process for a specific geographic footprint area |
| **Designated doctor for child deaths** | A senior paediatrician, appointed by the CDR partners, who will take a lead in co-ordinating responses and health input to the child death review process, across a specified locality or region |
| **eCDOP** | The child death review electronic case management system developed by QES Ltd |
| **Joint Agency Response (JAR)** | A coordinated multi-agency response triggered by the lead health professional in the immediate aftermath of a child's death that has met certain specific criteria |
| **Key Worker** | A person who acts as a single point of contact for the bereaved family, who they can turn to for information on the child death review process, and who can signpost them to sources of support |
| **Lead health professional** | The person responsible for the CDR process and chairing the local CDR Meetings within an agency. Where a JAR is triggered, the lead health professional is the person responsible for coordinating the health response to that death. This person may be a doctor or senior nurse, with appropriate training and expertise |
| **Medical Examiner** | A medical practitioner whose responsibilities include ensuring: that the cause of death is accurately recorded by the attending practitioner; that timely and appropriate referral to the coroner occurs (where appropriate); and that possible clinical governance concerns are highlighted |
| **National Child Mortality Database (NCMD)** | A national programme responsible for the collection and maintenance of a comprehensive database of all child deaths across England, and the publication of thematic learning |
| **QES Ltd** | The commercial company that have developed the eCDOP child death review electronic case management system |

# RELATED NATIONAL PROGRAMMES

**There are a number of national mortality review programmes which mandate the local collection of data on deaths, including some child deaths. They have a remit for capturing learning and reporting on local and national themes and trends to inform local system improvements. Given the overlap of these programmes with the child death review processes, the potential exists for data entry duplication to occur. A brief summary of these programmes is incuded below.**

## NATIONAL CHILD MORTALITY DATABASE

*The National Child Mortality Database (NCMD)* aims to reduce premature mortality by analysing data on all deaths in all children in England, aged between birth and eighteen. Launched on 1st April 2019, it is the first comprehensive national database of child deaths anywhere in the world. All CDR Partners in England are required to submit data to NCMD. This has been simplified following the alignment of the child death review and NCMD datasets in April 2019. The eCDOP child death case management system automates the flow of data to NCMD. CDR Partners which do not use eCDOP will need to submit data though an NCMD Portal.w

NCMD is run by a collaboration which is led by the University of Bristol, and which includes the University of Oxford's National Perinatal Epidemiology Unit, UCL Partners and QES. It is commissioned by the Healthcare Quality Improvement Partnership and funded by NHS England.

## MBRRACE-UK

The Maternal, Newborn and Infant Outcome Review Programme, otherwise known as *Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK)*, investigates the deaths of women and their babies during pregnancy, or after childbirth, as well as cases where women and their babies have survived serious illness during pregnancy or after childbirth.

For those children whose deaths meet the MBRRACE-UK criteria, data should be provided to this programme. In such cases, both the standard child death review and the MBRRACE-UK process should be completed.

MBRRACE-UK is run by a collaboration led by the University of Oxford's National Perinatal Epidemiology Unit. It is commissioned by Healthcare Quality Improvement Partnership and funded by NHS England, NHS Wales, the Scottish Government, and the Department of Health for Northern Ireland.

## PERINATAL MORTALITY REPORTING TOOL

The *Perinatal Mortality Reporting Tool* programme aims to provide a standardised approach to perinatal mortality reviews across NHS maternity and neonatal units in England, Scotland and Wales.

Some children who die will meet the criteria of the Perinatal Mortality Reporting Tool. In such cases, data should be provided to this programme. During 2019 steps were taken to align the PMRT dataset with that of the NCMD. This should prevent data entry duplication in the future.

PMRT has been commissioned by the Healthcare Quality Improvement Partnership and funded by the Department of Health (England) and the Scottish and Welsh Governments.

### LEARNING DISABILITY MORTALITY REVIEW PROGRAMME (LEDER)

The *Learning Disability Mortality Review Programme (LeDeR)* aims to standardise the case record review of children and adults who have died with a learning disability. Many children who die with a learning disability (above 4 year of age) will meet the criteria for a LeDer review. In such cases, both the standard child death review and the LeDer review should be completed.

LeDer is run by the University of Bristol, commissioned by the Healthcare Quality Improvement Partnership and funded by NHS England. The University of Bristol has developed *eLearning* to support those performing LeDer reviews.

### National Mortality Case Record Review Programme

Until 2019, the *National Mortality Case Record Review Programme* was led by the Royal College of Physicians to introduce a standardised methodology for reviewing case records of adult patients who had died in acute general hospitals in England and Scotland. This methodology outlines the Structured Judgement Review (SJR) process. It is advised that children up until the age of 18 undergo the child death review process and not the SJR.

# BIBLIOGRAPHY AND FURTHER READING

Department of Education (2017) Child death reviews: year ending 31 March 2017. *https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/627206/SFR36_2017_Text.pdf*

Department for Education (2018) Working Together to Safeguard Children: Statutory guidance on inter-agency working to safeguard and promote the welfare of children from: *www.gov.uk/government/publications/working-together-to-safeguard-children--2*

Department for Education (2018) Working Together: Transitional guidance - Statutory guidance for Local Safeguarding Children Boards, local authorities, safeguarding partners, child death review partners, and the Child Safeguarding Practice Review Panel from *www.gov.uk/government/publications/working-together-to-safeguard-children--2*

Department of Health and Social Care: Child death overview panels: contacts *www.gov.uk/government/publications/child-death-overview-panels-contacts*

Department of Health and Social Care (2018-19) Child death reviews: forms for reporting child deaths – Forms to help child death overview panels (CDOPs) assess the causes of a child's death as part of the child death review process from *www.gov.uk/government/publications/child-death-reviews-forms-for-reporting-child-deaths*

Department of Health and Social Care & Department for Education (2018) Child Death Review Statutory and Operational Guidance (England) from *www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england*

Department for Health & Social Care (2019) National Child Mortality Database: transitional arrangements from: *www.gov.uk/government/publications/child-death-reviews-forms-for-reporting-child-deaths/national-child-mortality-database-transitional-arrangements*

Healthy London Partnership Child Death Review Programme: *www.healthylondon.org/our-work/children-young-people/child-death-review-programme/*

Healthy London Partnership (2019) Gathering feedback from families when a child or young person dies: *www.healthylondon.org/gathering-feedback-from-bereaved-families-and-carers/*

London Safeguarding Children Board: Local Child Death Contacts: *www.londonscb.gov.uk/local-child-death-contacts/*

National Network of Child Death Overview Panels (England and Wales): *www.nncdop.com/*

NHS England (2018) Learning from deaths: Guidance for NHS trusts on working with bereaved families and carers: *www.england.nhs.uk/publication/learning-from-deaths-guidance-for-nhs-trusts-on-working-with-bereaved-families-and-carers/*

NHS England (2018) Learning from deaths: Information for families following a bereavement: *www.england.nhs.uk/publication/learning-from-deaths-information-for-families/*

NHS England National guidance for NHS Trusts engaging with bereaved families: *www.england.nhs.uk/ourwork/part-rel/nqb/national-guidance-for-nhs-trusts-engaging-with-bereaved-families/*

NHS England (2018) When a child dies: A guide for parents and carers: *www.lullabytrust.org.uk/wp-content/uploads/parent-leaflet-child-death-review.pdf*

NHS Improvement The national medical examiner system: *https://improvement.nhs.uk/resources/establishing-medical-examiner-system-nhs/*

Nuffield Trust International comparisons of health and wellbeing in early childhood, Cheung, R. (2018): *www.nuffieldtrust.org.uk/research/international-comparisons-of-health-and-wellbeing-in-early-childhood*

Office for National Statistics: Avoidable mortality in the UK (2016): *www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/2016*

Public Health England (2015) Dr M Korkodilos, Reducing infant mortality in London: An evidence-based resource: *https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/431516/Reducing_infant_mortality_in_London_2015.pdf*

Public Health England (2016) Dr M Korkodilos, Reducing child mortality in London: *https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/551123/Reducing_child_deaths_in_London.pdf*

Public Health England (2016) Dr M Korkodilos, Reducing infant mortality: A summary of the evidence: *www.lullabytrust.org.uk/wp-content/uploads/Korkodilos_M_Reducing-infant-mortality-1.pdf*

Public Health England (2019) Pregnancy and early life: reducing stillbirth and infant death - A planning tool to examine factors that influence stillbirth and infant death at the population level, rather than in individual clinical care: *www.gov.uk/government/publications/pregnancy-and-early-life-reducing-stillbirth-and-infant-death*

The Royal College of Pathologists (2016) Sudden unexpected death in infancy and childhood: Multi-agency guidelines for care and investigation: *www.rcpath.org/uploads/assets/874ae50e-c754-4933-995a804e0ef728a4/sudden-unexpected-death-in-infancy-and-childhood-2e.pdf*

QES Ltd eCDOP online recording, casework and reporting software for child deaths: *www.qes-online.com/QESeCDOP*

The Children and Social Care Act (2017): *www.legislation.gov.uk/ukpga/2017/16/contents/enacted*

The Institute of Healthcare Management (2019) Bereavement: *A Practical Guide for NHS Managers: https://ihm.org.uk/wp-content/uploads/2019/07/Bereavement_A-guide-for-Managers.pdf*

# APPENDIX 1:

## HEALTHY LONDON PARTNERSHIP CHILD DEATH REVIEW PROGRAMME STEERING GROUP MEMBERSHIP

| NAME | ORGANISATION |
|---|---|
| **Ronny Cheung (Chair)** | Clinical Director, HLP Child Death Review Programme & Consultant Paediatrician, Evelina Children’s Hospital |
| **Arlene Boroda** | Consultant Paediatrician & Designated Doctor for Safeguarding Children and CDOP, Brent Clinical Commissioning Group |
| **Nicky Brown** | CYP Public Health Specialist & Senior Nurse, Public Health England |
| **Nicky Brownjohn** | Head of Quality (South London) and Safeguarding (London Region) NHS England and NHS Improvement (London) |
| **Charlotte Daman Willems** | Consultant Paediatrician, NHS Lewisham and Greenwich NHS Trust |
| **Georgios Eleftheriou** | HLP Acute Morbidity and Mortality Lead & Locum Paediatric Consultant, Barts Health NHS Trust |
| **David Elliman** | Former Consultant Paediatrician, Great Ormond Street Hospital |
| Seb Florent | Detective Chief Inspector, Metropolitan Police Service |
| **Marilena Korkodilos** | Deputy Director, Healthcare and Clinical Lead for Revalidation, Public Health England (London) |
| **Eugenia Lee** | Primary Care Clinical Lead, Healthy London Partnership & GP Commissioner, NHS Greenwich CCG |
| **Ian Lewis** | Local Authority Advisor, Healthy London Partnership |
| **David McKinlay** | Child Death Review Programme Manager, Healthy London Partnership |
| **Chris Miller** | Chair of the Local Safeguarding Children's Board, Harrow Council & London Region Director, Association of Independent LSCB Chairs |
| **Nicola Needham** | CDOP Co-ordinator, Department of Public Health, London Borough of Newham |

| NAME | ORGANISATION |
|---|---|
| **Sara Nelson** | Deputy Director of Transformation, Children and Young People's Programme, Healthy London Partnership |
| **Donal O'Sullivan** | Clinical Advisor, HLP Child Death Review Programme & former Consultant in Public Health and CDOP Chair, Lewisham |
| **Tracy Parr** | Director of Transformation, Children & Young People's Programme, Healthy London Partnership |
| **Jenny Selway** | Consultant in Public Health Medicine, London Borough of Bromley & Chair of London CDOP Chairs' Network |
| **Fiona Spargo-Mabbs** | Director and Operations Manager, The Daniel Spargo-Mabbs Foundation |
| **Gladys Xavier Redbridge** | Director of Public Health and Commissioning, London Borough of Redbridge |
| **Ann York** | Children and Young People's Programme Mental Health Clinical Lead, Healthy London Partnership & Consultant Child and Adolescent Psychiatrist, South West London & St George's Mental Health NHS Trust |

# APPENDIX 2:

## CONTACTS FOR LONDON CHILD DEATH REVIEW OVERVIEW PANELS

Contact information for those responsible for child death review across the London Child Death Review Partnerships (as of September 2019) is listed below. This information will change over time. Please therefore review the information listed on the *London Safeguarding Children Board website* and the *Department for Health and Social Care website*.

### NORTH EAST LONDON - BARKING, DAGENHAM, HAVERING & REDBRIDGE

PRIMARY CHILD DEATH REVIEW CONTACT / SPOC

**Barking & Dagenham:**
Liz Winnett: cdop.bdh@nhs.net
**Havering:**
Gloria Okewale: cdopadminhavering@nhs.net
**Redbridge:**
Jeanette Ford: nem-tr.CDOP@nhs.net

**TBC, CDOP Chair**
**Designated doctor for child deaths: TBC**

### NORTH EAST LONDON - WALTHAM FOREST, EAST LONDON & THE CITY (WELC)

PRIMARY CHILD DEATH REVIEW CONTACT / SPOC

**City & Hackney:**
Yeba Forbang: yeba.forbang@hackney.gov.uk
**Newham:**
Nicola Needham: cdopnewham@nhs.net
**Tower Hamlets:**
BHNT.TowerHamletsCDOP@nhs.net
**Waltham Forest:**
Bella Lowen: CDOP@walthamforest.gov.uk and wf.spoc@nhs.net

**CDOP Chair**
**City & Hackney:**
Sue Milner: sue.milner@hackney.gov.uk
**Newham:**
Jason Strelitz: Jason.Strelitz@newham.gov.uk
**Tower Hamlets:**
Katie Cole: Katie.Cole@towerhamlets.gov.uk
**Waltham Forest:**
Joe Mcdonnell: joe.mcdonnell@walthamforest.gov.uk

**DESIGNATED DOCTOR FOR CHILD DEATHS**
**City & Hackney:**
Carly Stephens: c.stephen@nhs.net
**Newham:**
Susan Liebeschietz: s.liebeschuetz@nhs.net
**Tower Hamlets:**
Tanja Sattherwaite: t.satterthwaite@nhs.net
**Waltham Forest:**
Christina Slocynska: christine.sloczynska@nhs.net

### NORTH WEST LONDON

PRIMARY CHILD DEATH REVIEW CONTACT / SPOC

**Brent:**
Arlene Boroda: arelene.boroda@nhs.net
**Ealing:**
Steve Bourne: steve.bourne@nhs.net
**Harrow:** haroccg.cdopharrow@nhs.net
**Hillingdon:**
Michelle Thomas: mthomas1@hillingdon.gov.uk
**Hounslow:**
Joanna Leader: Joanna.Leader@hounslow.gov.uk
**Tri-borough (Westminster, Kensington & Chelsea & Hammersmith & Fulham):**
Elaine Lee: CLCCG.tri-bCDOP@nhs.net

**CDOP Chair**
Diane Jones, Strategic CDOP Chair:
diane.jones11@nhs.net
**Brent & Harrow:**
Melanie Smith & Carole Furlong:
melanie.smith@brent.gov.uk &
carole.furling@harrow.gov.uk
**Ealing:**
Vaishnavee Madden: maddenV@ealing.gov.uk
**Hillingdon:**
Steve Hajioff bbakrania@hillingdon.gov.uk

**Hounslow:**
Via Joanna Leader
joanna.leader@hounslow.gov.uk
Tri-Borough: emma.biskupski@rbkc.gov.uk

### DESIGNATED DOCTORS FOR CHILD DEATH

**Brent:** Arlene Boroda: arelene.boroda@nhs.net
**Ealing:** Ronelle Naidoo: ronelle.naidoo@nhs.net
**Harrow:** Sue Sheldon: sue.sheldon1@nhs.net
**Hillingdon:** Jideofor Menakaya: jide.menakaya@nhs.net
**Hounslow:** Meenal Chaggar: meenal.chaggar@nhs.net
Tri-borough: Nelly Ninis: nelly.ninis@nhs.net

## NORTH CENTRAL LONDON - BARNET, CAMDEN, ENFIELD, HARINGEY AND ISLINGTON

PRIMARY CHILD DEATH REVIEW CONTACT / SPOC

**Haringey**:
Alison McIndoe: whh-tr.haringeycdop@nhs.net & whh-tr.SPOC@nhs.net
**Camden:**
Rizvana Ahmed and Sophie Kershaw:
rizvanaahmed@nhs.net
Sophie.kershaw@camden.gov.uk
**Islington:**
Miles Parmiter: m.parmiter@nhs.net & Whh-tr.SPOC@nhs.net
**Enfield:**
Lisa Tait & Jean Rogers: cdop@enfield.gov.uk & beh-tr.enfieldhealthsafeguarding@nhs.net
**Barnet**:
Terri Graham: barnet.cdop@barnet.gcsx.gov.uk

### CDOP Chair

**Haringey**:
Susan Otitis: susan.otitis@haringey.gov.uk
**Enfield:**
Duduzile Sher Arami: dudu.sher-arami@enfield.gov.uk
**Camden & Islington:**
Leonora Weil: leonora.weil@islington.gov.uk
**Barnet:**
Emma Waters: emma.waters@barnet.gov.uk

### DESIGNATED DOCTORS FOR CHILD DEATHS

**Haringey and Islington:**
Andrew Robins: andrew.robins@nhs.net
**Camden:**
Eleanor Day and Gita Croft: ellie.day@nhs.net & gitacroft@nhs.net
**Enfield:**
Piyusha Kapila & Austin Isaacs: piyusha.kapila@nhs.net & austin.isaacs@nhs.net
**Barnet:**
Paul de Keyser: paul.dekeyser@nhs.net

## SOUTH WEST LONDON

PRIMARY CHILD DEATH REVIEW CONTACT / SPOC

**Croydon**:
Lauren East: CDOPCroydon@croydon.gov.uk;
**Kingston & Richmond:**
Ellie Boorer: ellie.boorer@kingrichlscb.org.uk
amber.kahn@richmond.gcsx.gov.uk
lscb-support@kingrichlscb.org.uk
**Merton:**
Lorraine Beckford: MERCCG.spoc@nhs.net
**Sutton:**
Suzanne Whyton: esth.spoc-cdop.sutton@nhs.net
**Wandsworth:**
Kelly Slade & Stephanie Davern: wandsworth.cdop@nhs.net

### CDOP Chair

Rachel Flowers: rachel.flowers@croydon.gov.uk

### DESIGNATED DOCTORS FOR CHILD DEATHS

Rowan Heath (Until Jan 2020): rowan.heath@nhs.net

## SOUTH EAST LONDON – BROMLEY, LAMBETH & SOUTHWARK

PRIMARY CHILD DEATH REVIEW CONTACT / SPOC

**Neonatal deaths:**
Hazel Blackman: CDOP@bromley.gov.uk
**Non-neonatal deaths:**
Helen Turnage: CDOP@Southwark.gov.uk

**CDOP Chair**
**Neonatal deaths:**
Jenny Selway: Jenny.Selway@bromley.gov.uk
**Non-Neonatal deaths:**
Kirsten Watters: kirsten.watters@southwark.gov.uk

**DESIGNATED DOCTOR FOR CHILD DEATHS**
**Lambeth:**
Davina Mackenzie: gst-tr.childdeathreview@nhs.net and gst-tr.lambethscteam@nhs.net
**Southwark:**
Nikki Baatjes: gst-tr.childdeathswk@nhs.net and gst-tr.southwarkscteam@nhs.net

## SOUTH EAST LONDON – BEXLEY, GREENWICH & LEWISHAM

PRIMARY CHILD DEATH REVIEW CONTACT / SPOC

**Primary contact for Bexley, Greenwich & Lewisham:**
Helen Leahey helen.leahey@nhs.net
**Bexley:**
bscb@bexley.gov.uk
**Greenwich:**
Nikesh Parekh: nikesh.parekh@royalgreenwich.gov.uk
**Lewisham:**
lh.childdeath@nhs.net

**CDOP Chair**
Alternating CDOP Chairs:
**Bexley:**
Rebecca Nunn / Jill May: rebecca.Nunn@bexley.gov.uk jill.may@nhs.net
**Greenwich:**
Nikesh Parekh: nikeshparekh@nhs.net
**Lewisham:**
Pauline Cross: pauline.cross@lewisham.gov.uk

**DESIGNATED DOCTOR FOR CHILD DEATHS**
**Bexley:**
Thomas Jacob: bexleythomasjacob@nhs.net
**Greenwich:**
Grace Pereira: greenwichgrace.pereira@nhs.net
**Lewisham:**
Sarah Panjwani: sarahpanjwani@nhs.net

# APPENDIX 3:

## DATA ON CHILD DEATHS ACROSS LONDON RECORDED WITHIN ECDOP (APRIL 2018 - AUGUST 2019)

### LOCATION OF CHILD DEATHS BY CDOP FROM CHILD DEATH NOTIFICATIONS (FORMERLY FORM A) SUBMITTED TO ECDOP BETWEEN APRIL 2018 – AUGUST 2019

| LONDON CDOP | MALE | FEMALE | UNKNOWN |
|---|---|---|---|
| **Barking & Dagenham** | 17 | 14 | <5 |
| **Barnet** | 13 | 13 | <5 |
| **Bexley** | 16 | 7 | <5 |
| **Brent** | 10 | 16 | <5 |
| **Bromley** | 9 | 13 | <5 |
| **Camden** | <5 | <5 | <5 |
| **City & Hackney** | 18 | 17 | <5 |
| **Croydon** | 13 | 21 | <5 |
| **Ealing** | 8 | 16 | <5 |
| **Enfield** | <5 | 8 | <5 |
| **Greenwich** | 8 | 15 | <5 |
| **Haringey** | <5 | 11 | <5 |
| **Harrow** | 5 | <5 | <5 |
| **Havering** | 13 | 9 | <5 |
| **Hillingdon** | 11 | 10 | <5 |
| **Hounslow** | 19 | 12 | <5 |
| **Islington** | <5 | <5 | <5 |
| **Kingston & Richmond** | 40 | 33 | <5 |
| **Lewisham** | 17 | 15 | <5 |
| **Newham** | 47 | 28 | <5 |
| **Merton** | 5 | 8 | <5 |
| **Redbridge** | 27 | 19 | <5 |
| **Southwark & Lambeth** | 35 | 23 | <5 |
| **Sutton** | 14 | 9 | <5 |

| LONDON CDOP | MALE | FEMALE | UNKNOWN |
|---|---|---|---|
| **Tower Hamlets** | 31 | 24 | <5 |
| **Waltham Forest** | 35 | 23 | <5 |
| **Wandsworth** | 27 | 18 | <5 |
| **Westminster (Tri-borough)** | 40 | 23 | <5 |
| **TOTAL** | **487** | **410** | **18** |

*Figures taken from cases notified within eCDOP. This is not a complete capture of all cases notified across London during this period as not all CDOPs began using eCDOP at the same time.*

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### LOCATION OF CHILD DEATHS BY SETTING FROM CHILD DEATH NOTIFICATIONS (FORMERLY FORM A) SUBMITTED TO ECDOP BETWEEN APRIL 2018 – AUGUST 2019

| SETTING OF DEATH | NO |
|---|---|
| **Acute Hospital: Neonatal Unit** | 231 |
| **Home of normal residence** | 176 |
| **Acute Hospital: Other (including delivery suites, labour wards, transplant units etc)** | 139 |
| **Acute Hospital: Paediatric Intensive Care Unit** | 114 |
| **Acute Hospital: Paediatric Ward** | 70 |
| **Acute Hospital: Emergency Department** | 38 |
| **Public place (including roads, railways, parks, restaurants, beaches etc)** | 37 |
| **Abroad** | 35 |
| **Hospice** | 26 |
| **Other** | 21 |
| **Other private residence** | 17 |
| **Mental health inpatient unit** | <5 |
| **Not known** | <5 |
| **Residential care** | <5 |
| **School** | <5 |
| **TOTAL** | **915** |

*Figures taken from cases notified within eCDOP. This is not a complete capture of all cases notified across London during this period as not all CDOPs began using eCDOP at the same time.*

## CHILD DEATHS FROM COMPLETED CHILD DEATH REVIEWS CONDUCTED BETWEEN APRIL 2018 – AUGUST 2019 WITHIN ECDOP

| AGE | NO |
|---|---|
| 0 | 141 |
| 1 | 27 |
| 2 | 8 |
| 3 | 5 |
| 4 | 6 |
| 5 | 8 |
| 6 | 6 |
| 7 | <5 |
| 8 | <5 |
| 9 | <5 |
| 10 | 8 |
| 11 | <5 |
| 12 | 5 |
| 13 | 6 |
| 14 | <5 |
| 15 | 6 |
| 16 | 5 |
| 17 | 7 |
| 18 | <5 |
| **TOTAL** | **255** |

| CAUSE OF DEATH | NO |
|---|---|
| Perinatal / Neonatal event | 78 |
| Chromosomal, genetic and congenital anomalies | 77 |
| Malignancy | 33 |
| Sudden unexpected, unexplained death | 19 |
| Chronic medical condition | 15 |
| Infection | 12 |
| Acute medical or surgical condition | 11 |
| Trauma and other external factors | 5 |
| Suicide or other deliberate self-inflicted harm | <5 |
| Deliberately inflicted injury, abuse or neglect | <5 |
| **TOTAL** | **255** |

*Figures taken from cases completed within eCDOP. This is not a complete capture of all child death reviews completed across London during this period as not all CDOPs began using eCDOP at the same time.*

**Healthy London Partnership**
**www.healthylondon.org**
**September 2019**