



Child Death Overview Panels Programme

Annual Report 2016/17

November 2017

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

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Foreword

In 2014, 675 children and young people died in London. The death of a child is a devastating event to parents, carers, siblings and those around them. Each death represented a huge individual loss, affecting on families' carers, siblings and communities. Child Death Overview Panels (CDOPs) oversee the investigation of each death within each local authority. The-CDOP programme was established within Healthy London Partnership (HLP) to determine how a population-based approach to examining deaths of children can enable wider learning to be adopted across the system in order to prevent future deaths. In addition, the programme was set up to explore how we can better engage with and support those impacted by the death of a child.

This report outlines both the challenges faced and the work we have undertaken to respond to these. It outlines our efforts to ensure that the London CDOPs are well placed to meet future challenges and underlines the way we will seek to support the professionals engaged in this work.

Importantly, this report seeks to capture the commitment of those involved in the London CDOP system. Their role in ensuring that we learn what we can from each death and use this learning and the resources we have to do everything possible to prevent further deaths makes them a core component of the health and care system.

Finally, we would like to express our sincere and heartfelt appreciation to Dan Devitt, HLP Programme Manager for CDOP who has worked tirelessly on this project to ensure it achieves its aims and delivers effective outputs. Without his enthusiastic approach we would not have been able to make the extensive progress described in this report.



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Executive Summary

Child Death Overview Panels (CDOP) review child deaths, identify “modifiable factors” & share lessons learned to help prevent “avoidable” deaths. Despite significant reductions in child deaths over past 30 years too many children are still dying unnecessarily.

Key statistics for Child Deaths in London from Public Health England and the Office for National Statistics (ONS 2014 – England & Wales) ¹

- **675 CYP** aged 0-19 years died in London in 2014, **1 in 3 child deaths were avoidable**
 - **Infant mortality 3.8 deaths per 1000 live births**
 - **Child mortality 12.2 deaths per 100,000 aged 1 to 17**

Issues: It is not currently possible to routinely and rapidly elicit the common reasons why children in London die, or share/ and analyse either data or lessons learned to prevent avoidable deaths in a timely manner. London CDOPs have the following characteristics:

- I. Are not at the right scale or structure to allow population level analysis
- II. Have significant variations in resources, structures, procedures & offer/outputs
- III. Have cumbersome, time- & resource-intensive processes and limited ability to share or analyse data

Current Governance Structure and Stakeholders: Legislative responsibility currently lies with the Department for Education (DfE) - New legislation published May 2017 will have significant impacts on safeguarding and the-CDOP system in London.

- London has 28 (and soon 29) of the 90 CDOPs in England
- London CDOP Chairs group meets twice yearly to discuss issues - there is also a voluntary National Network for CDOPs (NNCDOP)

Healthy London Partnership Programme objectives: programme launched in September 2016 to deliver a collaborative response to system changes and issues faced, and deliver reduction of the numbers of avoidable child deaths in London.

Priority agendas include **asthma deaths, deaths due to suicide, sudden unexpected deaths in infancy and childhood, neonatal deaths, and bereavement.** A calendar of events and support programme for 2017/18 is currently being finalised.

Healthy London Partnership Programme outputs

1. Systems and Structures

- **London CDOP Survey:** An online survey was conducted among London CDOPS to gain an understanding of the current system, and highlighted variations in process, workforce, terminology and definitions used across the region. This has informed both our subsequent work as well as providing data, and a template for a similar national survey, to the NHS England Child Death Review programme.
- **Pathway process mapping:** We have been developing a supportive, networked approach to London CDOPs, including development of minimum standard operating procedures (SOPs) and minimum data set. We conducted pathway mapping workshops across all 5 regions in London in order to better understand existing processes and structures and identify opportunities for future collaboration to improve-CDOP services. Possible efficiencies were also identified as the system moves towards a networked approach covering a larger geographical footprint.

¹ See <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2015-07-15>

- **Support for London CDOP Chairs Group:** Healthy London Partnership has provided secretariat support for the duration of the programme to support and ensure close alignment of the Healthy London Partnership programme with the London CDOP chairs' group.

2. Pan-London learning and outputs on specific themes

In the first year, we have concentrated on strengthening a culture of collaboration and shared learning among CDOPs in London through a series of themed conferences, workshops and seminar. These have been aimed at sharing best practice and learning in the London system as well as external expertise on specific topics including asthma deaths, prevention of suicides, bereavement, sudden unexpected deaths and deaths in the neonatal period.

3. A number of topic-specific resources have been developed:

- **CDOP checklists and user guides:** Checklist methodology has been utilised to help London CDOP develop a high quality standardised approach to case review focussing on three key themes: **asthma, neonatal deaths and deaths due to suicide**. Each required specialist input and a standardised approach to contextual and clinical care factors not previously available on a routine basis to London CDOPs. Accompanying user guides explain usage and minimum data sets for the checklists.
- **Suicide prevention:** In conjunction with Healthy London Partnership's mental health team, we have created a practical, accessible and free resource collating evidence-based prevention approaches available for use across all age ranges. These are being incorporated into the mayor's Thrive London social movement for mental health. The resource will be available online.
- **Bereavement Support:** This resource collates evidence and London-wide available services relating to the care of bereaved families. This facilitates CDOPs and all those involved with children who die in providing sensitive and timely support to bereaved families. The resource will be available online.

4. An online best practice platform hosted within the HLP website, to support sharing of best practice, network orientated delivery and online resources

5. E-CDOP business support: Support for CDOPs to acquire an electronic CDOP case management system (E-CDOP) locally, based on the Kent e-CDOP system. A draft case for change and fully costed business case is available

SECTION 1

Child Death Overview Panels – National and Regional Perspectives

Established in law in the 2008 Children's Act CDOPs occupy a unique position in the statutory framework and work across NHS, Local authority and Public Health systems to provide standardised mortality reviews following the death of CYP. Arising from a safeguarding response to Dame Carol Black's Shipman Enquiry² they established a systematic review of deaths for CYP that had not previously existed.

Nationally there are 90 CDOPs, with 28 in London alone. Some areas in London have their own CDOP coterminous with borough or CCG footprints, with others sharing functions across a wider area. Local Safeguarding Children's boards (LSCBs) usually have a key role in the day to day management of CDOPs and provide a multi-agency body through which Local Authority and NHS resources and personnel associated with LSCB functions (including CDOP) can be pooled.

Looking at both expected and unexpected deaths, they are charged with the key role of determining if any modifiable factors can be identified leading to the death, sharing lessons learned, and making recommendations to the wider health and care system to prevent, wherever possible, further deaths.

Challenges and New Legislation

The Children and Social Work Bill 2017, taking its cue from the 2016 Wood Review of Local Safeguarding significantly alters the delivery and structures associated with safeguarding in the English system. The Children and Social Work Act 2017 and the NHSE national child death review programme bring about significant changes to CDOPs

In response to the Wood Review of Local Safeguarding (2015³) new legislation was drafted and received Royal Assent in May 2017⁴. This put into force the five "Wood recommendations":

- The move of responsibility reporting and data flow from the Department for Education (DfE) to the Department of Health (DH) to match this.
- The creation of a national database into which CDOP data would be sent – The National CDOP Programme launched its procurement for this in early 2017 via the Healthcare Quality Improvement Partnership⁵
- A review of CDOP structures and size to ensure a catchment population of around 500,000 to enable meaningful population level analysis of trends.
- A national standard for investigations and links into the new Health Safety Investigation Branch
- A call for DH to consider the fit of CDOPs and role with regard to local system leaders such as Health and Wellbeing Boards and Joint Strategic Needs Assessments

The Children and Social Work Act 2017 (CSWA17) radically changes the safeguarding landscape in England. Draft guidance "sets out what is expected of organisations, individually and jointly, to safeguard and promote the welfare of children"⁶. Key changes include:

• **Replacement of Local Safeguarding Children Boards** with new flexible local arrangements led by three safeguarding partners (LA/ Police and NHS)

²² http://webarchive.nationalarchives.gov.uk/20130124073453/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4137276.pdf

³ <https://www.gov.uk/government/publications/wood-review-of-local-safeguarding-children-boards>

⁴ See <https://www.legislation.gov.uk/ukpga/2017/16/contents>

⁵ See Appendix C NCMD below

⁶ <https://consult.education.gov.uk/child-protection-safeguarding-and-family-law/working-together-to-safeguard-children-revisions-t/>

- **Replacement of Serious Case Reviews (SCRs)** with a requirement to identify and arrange for **local review of serious child safeguarding cases**
- **Establishment of a National Child Safeguarding Practice Review Panel** to commission and publish reviews of serious child safeguarding cases of national importance
- **Establishment of joint responsibility for child death reviews (CDRs)** on wider geographical footprint and new functions for review of child deaths/bereavement support

Consultation “Working Together” Child Death Reviews

The section specific to CDOPs reasserts central consideration of prevention of child deaths and emphasises identification of modifiable factors to assist this.

- 1 **Removal of the term “preventability”** and focus shift to modifiable factors
- 2 **Removal of the distinction between expected and unexpected deaths** and shift to proportionate appropriate review of all deaths
- 3 **Larger footprint of the-CDOP** with enabling legislation to allow two or more areas to deliver CDR functions together arrangements to be locally agreed
- 4 Development of a **new “key worker” role** to act as a single point of contact with the bereaved for information on the child death review process, able to signpost to sources of support. ⁷
- 5 **Child Death Review Meetings (CDRM)** every child’s death is to be reviewed at a CDRM to ensure local learning involving practitioners directly involved in the child’s care. Joint Agency Response or hospital based mortality and morbidity meeting prior to being discussed anonymously by the-CDOP.
- 6 CDOP administrators to work closely with CDR partners
- 7 Revised Form C
- 8 CDRMs to routinely send a report to the-CDOP to help inform review
- 9 Additional requirements to address a number of **“complex” circumstances**
10. **Themed review meetings:** Some types of deaths (e.g. suicides) requiring specialist input and either of very low or high could be conducted these sessions in wider footprints.
- 11 **Transitional arrangements:**
A transitional version of Working Together Guidance for Local Safeguarding Children Boards, applicable during the transition period, will underpin transition to the new system.

HLP has been successful in a funding application to NHS England safeguarding team to continue the work of the programme to July 2018. It will focus on supporting London CDOPs to meet the challenges and system changes outlined above.

⁷ See section Chapter 6.5.1 of the Child Death Review Statutory guidance ibid

SECTION 2

About Healthy London Partnership

Healthy London Partnership formed in April 2015. It has been working across health and social care, with the Greater London Authority, Public Health England, NHS England, London's councils, clinical commissioning groups, and Health Education England. We have united to amplify the efforts of a growing community of people and organisations that believe it is possible to achieve a healthier, more liveable global city by 2020.

The NHS cannot achieve this goal alone and is working with partner organisations to ensure improvements are made through the London Health Board and the London Health and Care Devolution Programme. Partners involved include 32 Clinical Commissioning Groups, NHS England (London), Public Health England, London Councils, Health Education England, the Greater London Authority and the Mayor of London.

Healthy London Partnership CDOP Programme

London will shortly have 29 CDOPs (nearly a third of the English system total). Whilst the intention is that information coming out of CDOPs is aggregated to enable trends to be noted and acted upon; in reality there are a number of issues which prevent this taking place. At a London Child Death Overview Panel (CDOP) chairs' meeting in September 2015 a number of themes and issues emerged:

- Variation in recording and collection of data relating to child deaths across London CDOPs
- Variations in practice and procedures, resources and available personnel
- Issues in collation of data across boundaries
- Lack of dedicated administrative support to pan London CDOP work
- Variation in police, coroners' and health professional definitions of factors relevant to child death
- Insufficient sharing of learning and recommendations derived by individual CDOPs

There was overwhelming support to try to overcome these issues, to improve communication and learning across London CDOPs in order to strengthen their impact and, ultimately reduce child deaths.

The Healthy London Partnership CDOP programme was established in July 2016 and formally launched in September 2016, under the auspices of the Healthy London Partnership Children and Young People's team in collaboration with the CDOPs linking in to local safeguarding structures across London. A project team was established to take this work forward:

- **Head of Children and Young People's Programme, Healthy London Partnership:** Tracy Parr
- **Clinical Director:** Dr Ronny Cheung (Consultant Paediatrician, Evelina Children's Hospital)
- **CDOP Advisor:** Dr Donal O'Sullivan (Consultant in Public Health and previous Chair of Lewisham CDOP)
- **Programme Manager:** Daniel Devitt

The programme team worked to the guidance of an expert steering group, including subject matter experts from the CDOP system, Metropolitan Police, local authorities and Public Health England. The group has provided focussed steer and constructive challenge and ensured clear accountability underpinning its work. (Appendix B Steering Group Terms of Reference)

Healthy London Partnership Programme Objectives

The following seven programme objectives were established and formally launched in September 2016.

Identify and prevent common/important causes of death

1. Enable collaboration between CDOPs to improve epidemiological understanding of child deaths
2. Facilitate the analysis and reporting of common and/or important causes of death in children
3. Facilitate the identification and delivery of London-wide measures to tackle these causes

Improve services

1. Identify and reduce variation in CDOP operational practices and outcomes across London
2. Improve-CDOP processes to maximise efficiency, resource use and outcomes, including opportunities for regional or sub-regional collaborations and networks
3. Enable sharing of best practice between CDOPs across London
4. Coordinate the input of London CDOPs to the National Review of Child Death Processes, and facilitate changes resulting from national policy and guidance.

Stakeholder engagement

The HLP team liaised with the National CDOP Programme, NHSE safeguarding team, London Coroners, London Ambulance Service, and other vital stakeholders to ensure that the London CDOP system and external partners were fully aware of developments and programme outputs. The national CDOP programme team has throughout requested input from the HLP team to support the development of national policy and statutory guidance.

Monthly bulletins were circulated to key stakeholders updating the London system on programme activities and presentations delivered to a variety of strategic partners

- CDOP Chairs, designated Doctors, CDOP Co-ordinators and administrators
- Directors of Children's Services, LSCB Chairs, local authority & NHS children's commissioners, STP Strategic Leads
- Children's commissioning Leads
- CCG GP children's leads
- Local and regional public health leads
- Acute and community paediatricians
- Safeguarding leads, networks and operatives
- Public Health England
- Health Education England
- HLP CYP Mental Health and Wellbeing Implementation Group
- London CAMHS and adult mental health services
- Area Metropolitan Police Service SO17 child abuse investigation teams
- London Ambulance Service NHS Trust representatives
- HM Coroner Service representatives
- Third sector partners including The Lullaby Trust, SANDS, BLISS, PAPYRUS, SAMARITANS, SLOW, CLASP Charity

The voice of the bereaved has been represented through third sector partners, especially the Lullaby Trust, Sands and Papyrus and the inclusion of a bereaved parent on the steering group.

Presentations on different aspects of the programme have included

- North East London CDOP co-ordinators' network
- London Safeguarding Children's Board
- HLP CYP Transformation Board
- HLP CYP Mental Health and Wellbeing Implementation Group
- Bexley Integrated Children's Commissioning Board
- Barking and Dagenham, Havering and Redbridge LSCB planning meeting

SECTION 3

Review of Year One Progress

1. Systems and Structures

A. London CDOP Survey: An online survey was conducted among London CDOPs July to December 2016 to gain an understanding of the current system. This highlighted variations in process, workforce, terminology and definitions used across the region. This has informed both our subsequent work as well as providing data, and a template for a similar national survey, to the NHS England Child Death Review programme. London CDOPs were encouraged to share examples of best practice and invited to participate in the planned programme launch in September 2016.

There will shortly be 29 CDOPs in London. They are all delivering the same function in very different ways and with varying resources, protocols and practices.

The survey exposed significant variations across the London system including:

- Numbers of deaths varied between 94 to 254 per CDOP
- Significant variation on how many reviewed - one cited “perfunctory” reviews of all deaths
- 3763 Deaths reported in total with 3110 reviewed
- 16 Asthma deaths reported from 11 CDOPs (others could not confirm/had access to data)
- Inclusions and exclusions including threshold for premature baby mortality
- Variable offer of meetings to bereaved parents
- Variable staffing and WTE, organisational mix, hosting, governance, funding and systems
- Local protocols – 17 Working Together Chapter 5/ LSCB only - 4 had additional Standard Operating Procedures
- IT systems – heavy reliance on Excel spread sheets (21) and Access (2)
- Variable access to Child Health Information System records
- Web resources - most had some content available via LSCB web resources
- Variable scale and publication of reports
- Methods for sharing learning outputs with local system varied

In addition to the survey the programme received a significant number of face to face and telephone call contacts raising the following issues and suggestions:

- Wood review impacts on staffing and size
- Lack of training available for staff new to CDOP
- Explicit guidance on how best to conduct specific parts of role – i.e. Rapid response or early meeting and issue of terminology between CDOPS
- Familiarity with the 2015 SUDI Guidance
- Lack of shared London standards
- Potential to work across London i.e. Transport for London/Metropolitan Police Service/Coronial Jurisdictions/LAS and Recognition of Extinction of Life issues/SUDI teams

B. Pathway process mapping: Throughout the programme HLP have been seeking to understand and capture the nuances and innovations, best practice and resources that have been developed to meet the day to day requirements of CDOP operations. The work stream had two key aims:

1 “Reading the System”: To engage with all 27/28 London CDOPs and encourage them to collaborate at STP footprint level and raise awareness of the challenges faced and suggest opportunities for enhancing their work.

2 “Strengthening the system” To identify current commissioning arrangements and the need to

ensure commitment from commissioners and CDOP providers towards an evolved response to strengthen the London system in light of the Wood review and legislation.

As part of this work, we conducted pathway mapping workshops across all 5 regions in London in order to better understand existing processes and structures, identify opportunities for future collaboration to improve services and possible efficiencies. The workshops generated a systems map of the London CDOPs, identifying areas of alignment and opportunities with wider system stakeholders. This will be used to support the next year of the programme and generate an outline standard operating policy and minimum standards and definitions for London CDOPs.

C: Support for London CDOP Chairs' Group: The programme has provided secretariat support for the six-monthly meetings of the London CDOP chairs to facilitate closer working relationships with London CDOPs. This is chaired by Dr Jenny Selway, Consultant in Public Health LB Bromley. These network meeting support the sharing of issues and best practice responses for London CDOPs and has supported the London system since 2008. The-CDOP Chairs' network is a key method of engagement and system reach for the programme.

2. Pan-London learning and outputs on specific themes

In the first year, we concentrated on strengthening a culture of collaboration and shared learning among CDOPs in London. This was through a series of themed workshops and seminars, aimed at sharing best practice and learning in the London system. In addition, external expertise was brought in on specific topics including asthma and neonatal deaths, sudden unexpected deaths, prevention of suicides and bereavement. A chronology of the events is listed below

- September 2015: system engagement event with London CDOP Chairs
- July 2015: wider CDOP system engagement event
- September 2015: launch event with a focus on asthma and the Wood Recommendations
- December 2016: suicide prevention
- March 2017: SUDI/SUDC
- April 2017: London sector process mapping workshops
- May 2017: Asthma deaths Workshop
- May 2017: Neonatal deaths Workshop
- June 2017: Bereavement workshop
- July 2017: Consanguinity workshop
- September 2017: Working with coroners

3. Collation of topic specific resources

Many of the resources and outputs outlined here have come about as a direct result of ideas and discussion arising from the workshops listed above. All resources, briefings, workshop slide decks and outputs will be available via the www.healthylondon.org website by December 2017.

HLP CDOP Programme Resources

Resource Overview	Status/Next Steps
A web based best practice/evidence platform	HLP have recent changed web provider and a web resource is under development.
E-CDOP Outline business case, and presentations	All products are being refreshed in light of national guidance. Business case assists local CDOPs identify potential take up of E-CDOP system to support integrated approach to data sharing and networking
Children and Social Work Act Briefing	Shared with the system in two formats – executive briefing and long form detailed assessment from May 2017

Suicide Prevention Resource	Draft shared with the London system and feedback received July to September 2017. Resource is being remodelled in conjunction with THRIVE London suicide prevention work stream
Bereavement Resource	Draft shared with the London system and feedback received July to September 2017.
Checklists and User Guides support CDOPs approach to reviewing deaths with a “manualised” approach that can be duplicated across regional CDOPs to ensure a standardised and high quality review. Variants have been developed to support review of asthma deaths, SUDI, neonatal deaths and deaths due to suicide.	Drafted, shared for consultation, refined and currently being finalised prior to publication in November 2017
Minimum Data Sets	Through the HLP CDOP workshops we have generated several indicative minimum data sets including • Suicide • SUDI • Neonatal deaths • Asthma deaths
CYP Bereavement Experience Measure At the bereavement workshop in June 2017, the NHSE Bereavement Experience Measure (NHSE BEM) was presented. A bereavement experience tool is needed to capture the insights and experiences of the bereaved for a broader range of bereaved parents, siblings and community. The project aims to create a CYP BEM tool that captures experiences of those affected by the death of a child or young people not currently addressed by the NHSE BEM.	The project team has assembled and commenced the development of a wider age range suitable bereavement experience tool.
Coronial Memorandum of Understanding (MOU) - sample taking	Work is continuing to approach individual coronial jurisdictions to get sign up to MOUs covering sample-taking principles.
London Ambulance Service and Coronial MOU on conveyance Opportunity to refresh the pan-London agreement covering issues of conveyance of deceased CYP	Work is proceeding on a draft refresh of the LAS protocol with the aim of sharing this with the HLP Steering Group and Coroners in London in late 2017.

CDOP Checklists and User Guides

The checklists seek to support CDOPs’ approach to priority themes with a “manualised” approach that can be shared across London to ensure a standardised high quality review is delivered for those deaths which present particular challenges for review.

Checklists suggest a series of prompts for enquiry and ask the panel undertaking the review to capture what pertinent information they have access to and what additional input they will require. They allow a degree of flexibility of response but ultimately seek to support CDOPs to select the information that they will need to deliver high quality reviews

Supported by a comprehensive user guide, providing a wealth of additional resources, guidance and materials, checklists are a tool to focus attention on the data that will really make a difference to the quality and depth of the review.

CASE REVIEW Suspected Deaths Due to Allergy or Asthma MULTI AGENCY WORKING ARRANGEMENTS & INTELLIGENCE – DRAFT 1.4				
Multi Agency Linkages and Data Feeds: Have you got the information/inputs you need to review this case? TICK ALL THAT APPLY TO THE CASE YOU ARE REVIEWING				
LAS	☐	Acute Trust	☐	
		School/College/Training Provider	☐	
MPS	☐	Social Care	☐	
		Safeguarding	☐	
Pathologist	☐	Family/Friends	☐	
		Community Nursing (SN/HV/CCNT)	☐	
Community Paediatrics	☐	CAMHS	☐	
		Coroner	☐	
Other Do you have access to/input from BTS/SIGN/NRAD expertise				
Yes . ☐ No. ☐				
Suspected Deaths due to Allergy or Asthma: REVIEW CHECKLIST Core data to collect and assess in your review of the case				
Core Demographic Information: DO YOU HAVE THE FOLLOWING CORE DATA? Yes No Partial Not relevant				
Name:	YES	NO	Partial relevant	Not relevant
Age:	☐	☐	☐	☐
DOB:	☐	☐	☐	☐
DOD:	☐	☐	☐	☐
Withdrawal of care:	☐	☐	☐	☐
NHS No:	☐	☐	☐	☐
Age at Time of Death	☐	☐	☐	☐
Sex M/F	☐	☐	☐	☐
Sexual Orientation– Hetero/LGBT/Unknown	☐	☐	☐	☐
Post Code of Residence	☐	☐	☐	☐
Religion	☐	☐	☐	☐
Ethnicity	☐	☐	☐	☐
Any Siblings?	☐	☐	☐	☐
GP record and input from responsible clinician	☐	☐	☐	☐
Secondary Care record and input from responsible clinician	☐	☐	☐	☐
Tertiary Care record and input from responsible clinician	☐	☐	☐	☐
PICU record and input from responsible clinician	☐	☐	☐	☐
Pathologist report and input	☐	☐	☐	☐
Coroner report and input	☐	☐	☐	☐
Education/Training status				
Name of School, College, Training Provider, Employer	☐	☐	☐	☐
Type of School, College, training Provider, Employer	☐	☐	☐	☐
Post Code of School, College, training Provider, Employer	☐	☐	☐	☐
Year Group	☐	☐	☐	☐
Were there any issues with attainment?	☐	☐	☐	☐
Were there any issues with attendance?	☐	☐	☐	☐

Fig 1 Draft checklist for review of deaths due to asthma or allergic reaction

Suicide Prevention Resources

Prevention of suicide is a moral imperative and a national priority. CDOPs are uniquely positioned to help drive the prevention of suicide agenda through their potential for delivering in depth analysis and supporting high quality “postvention” support.

From the publication of the 2012 National Suicide Prevention Strategy the NHS has been a partner agency responsible for delivering substantial aspects of the cross governmental agenda. London Councils as leads for education and safeguarding been similarly charged with delivering this agenda. The strategy aims to reduce the suicide rate in the general population in England and provide better support for those bereaved or affected by suicide. The strategy has six key areas for action to support delivery of these objectives:

- 1** Reduce the risk of suicide in key high-risk groups
- 2** Tailor approaches to improve mental health in specific groups
- 3** Reduce access to the means of suicide
- 4** Provide better information and support to those bereaved or affected by suicide
- 5** Support the media in delivering sensitive approaches to suicide and suicidal behaviour

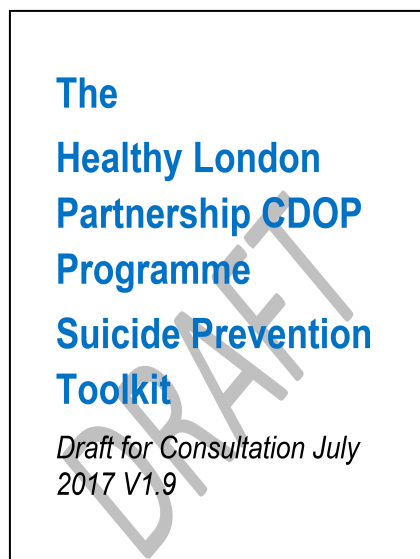


Fig 3 Draft Suicide Prevention Resource

Evidence suggests that if we target resources and focus activity at the school-aged population we can help prevent deaths by suicide. Similar evidence suggests that those affected by bereavement due to suicide benefit significantly from “postvention” support.

The HLP CDOP Programme has developed an evidence based resource, drawing upon examples of good practice from the UK and overseas for use in the education sector. This has been informed and driven by the experience of CDOPs. It identifies the key areas where “up-stream” preventative actions have the potential to prevent suicides, develop or promote positive mental health and wellbeing or resilience. It also describes effective postvention or bereavement support. The resource is comprised of two parts; an introduction to suicide prevention and prevention through the promotion of better mental health wellbeing and resilience. Key themes within the resource include:

- 1 Deaths due to suicide are not inevitable
- 2 Suicide is not a normal response to either normal or abnormal experiences and is amenable to intervention
- 3 You cannot make it worse by talking about it
- 4 You do not need to be a clinician to have a role in helping

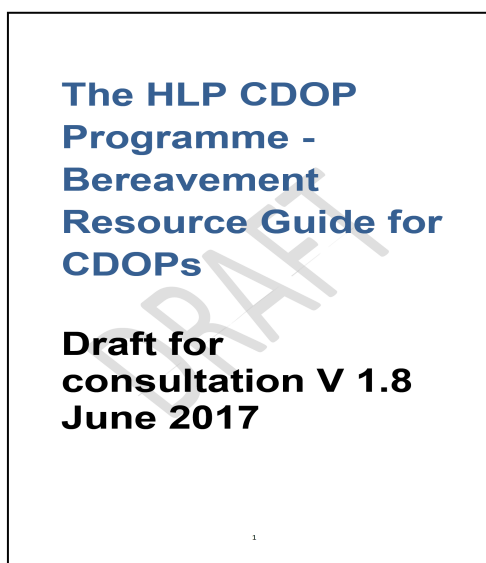
At the request of the THRIVE London work stream the resource is being refreshed in light of the July 2017 Manchester report on Suicide of Children and Young People⁸.

Bereavement Resource Guide

The death of a child is a catastrophic event for a parent or carer and other family members. Effective bereavement support is critical for this population. CDOPs do not in themselves *provide* bereavement support, except in their sensitive and supportive role throughout the review process and their interaction with the bereaved. They do however have a clear role in

⁸ http://research.bmh.manchester.ac.uk/cmhs/research/centreforsuicideprevention/nci/reports/cyp_2017_report.pdf

signposting the bereaved to support and ensuring that local system is well placed to ensure the bereaved receive the care support and clarity they need.



This need has been emphasised in the new statutory guidance and the feedback from London CDOPs to the Healthy London Partnership programme over the last year of activity. For this reason, a bereavement resource was produced. Drawing from national and local practice it is an attempt to encourage and guide a shared delivery of high quality information and support for those who have been bereaved. It is divided into three sections:

Part One is aimed at supporting CDOP processes including:

- information on how CDOPs can include families in the review process
- communication of findings with families
- checklists
- standardised letter
- feedback summary
- recommendations on supporting families around receiving the post mortem report and best practice pathway shared by Lewisham CDOP

Part Two focuses on how local CDOPs can ensure that their areas are providing a high-quality bereavement service and links to both standards and experience measures.

Part Three focuses on resources and information that London CDOPs can use or signpost the bereaved towards.

The guide is undergoing minor redrafting to ensure fit with the new expectations for CDOPs with regards to bereavement flowing from the new statutory guidance.⁹

Children and Young People's Bereavement Experience Measure (CYP-BEM)

At a workshop in June 2017 focused on strengthening bereavement support offers and working towards a minimum standard offer for CDOPs, the recently launched NHSE Bereavement Experience Measure (NHSE BEM) was presented. There was recognition of

⁹ https://consult.education.gov.uk/child-protection-safeguarding-and-family-law/working-together-to-safeguard-children-revisions-t/supporting_documents/Child_death_review_stat_guidance.pdf

the need to develop a broader bereavement experience tool to capture the insights and experiences of a wider range of the bereaved. A task and finish group to expand on the work of the existing BEM and outline existing resources and identify and new requirements for a CYP Bereavement Experience Measure (CYP-BEM) has been assembled and is working on developing the new resource.

The group will seek to facilitate the sharing of the CYP BEM across London in support of the development of a London minimum standard. It will work closely with the national programme to ensure alignment of approach. The group is proposing to deliver the CYP BEM and supporting guidance in Spring 2018.

Table 1 Outline of Age ranges and classes of deaths to be addressed by the CYP BEM

Indicative age ranges:	Indicative death agenda classes
• Early years deaths age 1 to 5 • Childhood deaths age 5 to 12 • Teenage deaths age 13 to 18	• <i>Expected deaths - palliative care, withdrawal of care specialisms</i> • <i>Unexpected deaths – accident, homicide, suicide, major incident, medical emergencies</i>

Working with London Coroners

From early 2017 the Programme has been engaging with the eight coronial jurisdictions in London to understand and realise potential system wide-issues and reach agreements and aligned approaches across London.

The work has centred on developing a London Memorandum of Understanding (MOU) that will deliver an exemplar model of integrated working between agencies. This will entail agreement of standard principles and procedures to ensure effective working relationships between stakeholders (bereaved parent carers and siblings, London coroners, CDOPs, blue light services, pathology/mortuary/etc.)

The work stream has the following key objectives

- To agree an overarching MOU to deliver minimum standards, expectations timescales and resources
- To develop shared understanding of roles, responsibilities and legislative duties of all partners
- Bereavement support and information sharing to ensure that bereaved receive relevant information
- Sample taking agreement on minimum standards in line with Royal College of Pathology recommendations
- Agreement on transportation of bodies of the deceased
- Effective information flows across coronial and CDOP processes

We are in the process of engaging with coroners and other key stakeholders to deliver the outputs in 2018

e-CDOP business case

The e-CDOP system was designed in collaboration with Kent's LSCB to support the collating and reporting processes around child deaths. It is a commercial case management system allowing multi agency working within a 'cloud based' shared working environment allowing for

rapid and secure sharing of multi-agency information

It allows multiple partners to access and supply requested information; timely collection, collation and presentation of information that is important to identify trends, share recommendations and deliver system level improvements. It also enables reporting of how many cases are being managed and at what stage each one has progressed to.

Many London CDOPs are interested in the system. In order to support them, the programme has worked closely with the Kent CDOP to develop a draft business case aimed at supporting take up of a network orientated approach to CDOP operations.

Online Best Practice Platform

Work is underway to create an area within www.healthylondon.org to support sharing of best practice, network orientated delivery and online resources. Materials will be hosted from workshops including slide decks, contact lists, best practice examples, evidence base and programme outputs. This will be available online by the end of 2017.

London Chairs' Secretariat Support

In addition to the HLP Programme has provided secretariat support for the on-going six-monthly meetings of the London CDOP chairs to facilitate closer working relationships with London CDOPs chaired by Dr Jenny Selway, Consultant in Public Health LB Bromley.

SECTION 4

Year Two Programme 2017/18

HLP has been successful in a funding application to NHS England safeguarding team to continue the work of the programme for another year to build upon the work in 2016/17. Year two will focus on supporting London CDOPs to meet a number of challenges and system changes.

New Legislation and Challenges: The Children and Social Work Act 2017 and the NHSE national child death review programme will bring about significant changes to CDOPs. The work of the Programme in 2017/18 will focus primarily on facilitating the transition of London CDOPs to the proposed new system.

2017/18 Programme Priorities: During Year 1 of the Programme we have concentrated efforts on joint learning and improving existing practices and processes – such as through the themed workshops, topic-specific review checklists, work with coronial processes and the national programme. The change in legislation as well as the NHSE national child death review programme will require change in how CDOPs are organised, and the work they do. This is extensively documented earlier in this report. The work of the HLP CDOP programme in 2017/18 will focus primarily on facilitating the transition of London CDOPs to the proposed new system.

Year Two Work Plan 2017/18

1 On-going themed learning and sharing events and resources: Continued focus on improving CDOP processes, learning locally and London-wide, supporting sectors who are

already exploring opportunities for cross-sectoral working, including collaboration with coronial services; violent/knife related crime & child deaths, major incident, mass mortality. The initial event has been scheduled for November 2017.

2 Supporting the transition to the new child death review processes: Work in the first year of the programme to support the London system understand and meet the challenges of the new legislative landscape and NHSE programme will continue alongside engagement stakeholders in the new child death review systems (including LSCBs, Directors of Children's Services, CCG and STP leads for children's healthcare)

3 Collaboration with coronial services to reduce variation in practices relating to unexpected child death across London, and create standards for supportive and sensitive communications with bereaved families

4 Sector-based reviews: We will explore and facilitate sector-wide themed reviews on a voluntary or trial basis as a precursor to full integration of processes. Potential themed review processes include neonatal deaths or deaths due to suicide.

5 Synthesis and dissemination of child death review recommendations across London: We will continue and complete a project to collate and thematically analyse all recommendations emanating from London CDOPs in 2015-16, aiming to highlight common themes, and facilitate the coordination of London-wide responses.

6 Child death data collection and analysis: We will continue to advise and collaborate with NHSE child death review programme and the team who successfully fulfil the HQIP tender to develop the National Child Death Database, to ensure that the mechanism of data collection (both retrospective and prospective), analysis and dissemination align with the needs of CDOPs in London.

7 Bereavement Experience Measure tool: We will continue collaboration with NHS England to create a Bereavement Experience Measure that captures the experiences of those affected by the death of a child or young people, building on existing Maternity-related measures.

8 Public Health England Child and Maternal Health Intelligence Network retrospective national analysis of child deaths: We will provide regional support and coordination for London's contribution to PHE's collation and analysis of national data on child death reviews from 2013-2015.

HLP are currently finalising a full programme of support for London CDOPs and have begun to develop a series of workshops to address the identified priorities.

SECTION 5

Appendices

Appendix A Steering Group Terms of Reference and Membership

HLP Children and Young People's Child Death Overview Panel Programme Steering Group

Terms of Reference

Child Death Overview Panels (CDOPs)

Healthy London Partnership (HLP) was established in 2015 to bring about large scale transformation on behalf of London's 32 CCGs and NHS England (London). One of the thirteen programmes is themed around the needs of children and young people (CYP). As part of this programme, work has already been undertaken around how to best utilise the wealth of information obtained through the Child Death Overview Panel (CDOP) process from different areas. A formal programme running to September 2017 has now been established around this and is being launched at a major stakeholder event on the 22nd of September 2016.

Introduction

From 2004 CDOPs have been charged with the vitally important role of investigating the circumstances and contexts for the death of a child. Nationally there are 98 CDOPs, with circa 30 in London alone. Some areas in London have their own CDOP coterminous with borough or CCG footprints, with others sharing functions across a wider area.

Looking at both expected and unexpected deaths they are charged with the key role of determining if any modifiable factors can be identified leading to the death and sharing lessons learned and making recommendations to the wider health and care system to prevent, wherever possible further deaths.

Purpose

The HLP CDOP Steering Group will act as the driving force for supporting improvement and system development for London's CDOPs. It will provide strategic leadership, oversight, expertise and guidance for the-CDOP Programme. It will ensure there is effective support to Strategic Planning Groups and CCGs the development of London CDOPs. The responsibilities of the group include:

- Overseeing the delivery of the programme objectives and benefits
- Acting as ambassadors and leader for CDOP across the system
- Overseeing and agreeing the outputs from the HLP CDOP Steering Group
- Agreement and scrutiny of metrics for successful outcomes and deliverable
- Ensuring linkage for the work to HLP Children and Young People programmes
- Understanding and supporting the delivery of support for the London CDOPs
- Report on progress to the both HLP and wider stakeholders

- Work with commissioners to help develop system levers to support delivery of a high quality CDOP offer for London

Scope and deliverables

The HLP CDOP Implementation Group is responsible for providing strategic leadership to the CDOP transformation programme in London.

Membership

HLP Programme Team: HLP has appointed a CDOP programme team to support this work:

Dr Ronny Cheung: Clinical Director CDOP Programme, Consultant Paediatrician, Evelina London Children's Hospital

Dr Donal O'Sullivan: CDOP advisor, Public Health Consultant, formerly Chair of Lewisham CDOP

Tracy Parr: Head of HLP Children and Young People's Programme

Dan Devitt: CDOP Programme Manager

Members

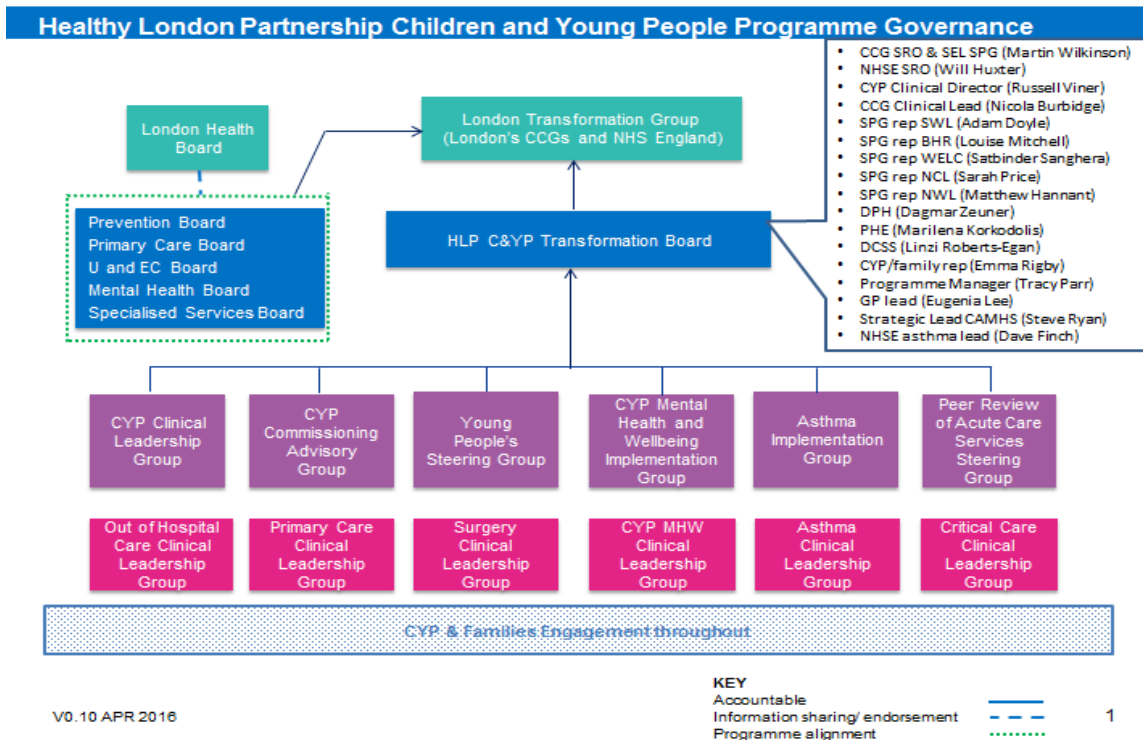
Wider membership has been sought from a range of London system stakeholders (see appendix B). The Chair may approach representatives directly to enable membership to reflect the skills, backgrounds and expertise required for its work. Delegation of attendance is not permitted.

CYP/carers representatives will be supported to work with this group as required

Name	Role	Organisation/CDOP area (LB)
Dr Ronny Cheung	Clinical Director HLP CDOP Programme	GSTT/HLP
Dr Donal O'Sullivan	CDOP Advisor HLP CDOP Programme	HLP
Tracy Parr	Head of CYP Programme	HLP
Chris Miller	LSCB Chair and London Region Director for Association of Independent Chairs of LSCBs	LSCB Barnet & Association of Independent Chairs of LSCBs
Gladys Xavier	Deputy Director of Public Health/Head of Integrated Strategy and Commissioning	LB Redbridge
Dawn Cox	Public Health Principal	LB Croydon – left in 2017

Name	Role	Organisation/CDOP area (LB)
Dr David Elliman	Consultant Paediatrician	GOSH /LB Haringey
Dr Arlene Boroda	Designated Doctor	LB Brent
Dr Charlotte Daman Williams	Consultant Paediatrician	LB Lewisham
Diane Jones	Director of Integrated Governance	Greenwich/ Brent CCG
Andy Cox	Detective Superintendent Lead for tackling Child Abuse (CAIT) SCO17	Met Police Service
Dr Richard Iles (as required)	HLP Clinical Lead HLP CYP Asthma Programme	GSTT/HLP
Dan Devitt	HLP CDOP Programme Manager	HLP
Rachel Cook (As required tbc)	Bereavement Service manager & Joint National Child Death Helpline Manager	GOSH
Fiona Spargo Mabbs	Parent/Sibling Representation	Daniel Spargo Mabbs Foundation
Marilena Korkodilos /Nicky Brown TBC	Public Health Expertise	PHE
Nicola Needham	Community Nursing expertise/CDOP Coordinator	London Borough of Newham
	Third sector Input as required Lullaby SANDS SLOW CB UK	

Appendix B HLP CYP Programme Governance Structure July 2016



Appendix C National Child Mortality Database

The Healthcare Quality Improvement Partnership is currently procuring the NCMD on behalf of the NHS.¹⁰ The objectives of the NCDM tender are:

1. To create a national database whose minimum dataset should include appropriate data from the existing DfE forms (A, B and C), but additionally contain relevant metrics relating to:

- categories of death with a high proportion of modifiable factors;
- categories of deaths where the UK is a relative 'outlier' compared with other countries;
- service delivery issues across the patient pathway;
- essential socio-economic and demographic data.

2. To provide local data management solutions to enable-CDOPs to share identifiable data with the national database and local child death review meetings and other front line professionals to share identifiable data with CDOPs

3. To enable the national database to receive, hold, and process identifiable quantitative and qualitative data from CDOPs and other sources.

4. To enable-CDOPS and local child death review meetings to have access to pre-specified reports of their own data, as well as the ability to request ad-hoc reports that describe aggregated data for the purposes of comparison with statistical neighbours.

5. To provide a range of useful outputs, both at a local and national level, which facilitate learning in preventing child deaths (such as a national report, interactive comparative tables, bulletins, themed reports/studies) and to also allow the sharing of good practice.

6. To inform health care, public health, and social care policy as it applies to children.

¹⁰ See <https://www.hqip.org.uk/national-programmes/a-z-of-clinical-outcome-review-programmes/the-child-death-review-database/>

7. To validate and support enhancement of other national data sets when requested (e.g. Office for National Statistics).
8. To enable calculation of mortality rates and condition-specific mortality trends over time.
9. To better understand, through facilitating temporary in-depth data collection, the burden of deaths arising from a particular cause.
10. To identify clusters of deaths.
11. To identify newly emerging causes of death and to issue relevant alerts.
12. To identify potential new risk factors for specific causes of death.
13. To facilitate (on instruction from HQIP and any other relevant data controllers, and according to compliance with the relevant legal frameworks) additional interrogation and analysis of pseudonymised or non-identifiable data through allowing transparent access to individuals and organisations with legitimate requests such as researchers.
14. To provide a focus for national leadership (priority setting, data definition standardisation, influence of relevant national agencies to ensure learning is translated to actions).