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Great Ormond Street Hospital for Children NHS Foundation Trust

Policy

Learning from Deaths Policy

Key Points
• Death in childhood is a rare event. Whenever a child dies, it is important to reflect and to learn if anything could be done differently in the future • This policy outlines how the Trust will review patient deaths, and share and act on learning. • This points within this policy are a statutory requirement, reflecting the Child Death Review: operational and statutory guidance (2018)

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1 Introduction

1.1 Death in childhood is a rare event. It is a devastating loss that profoundly affects bereaved parents as well as siblings, grandparents, extended family, friends and professionals who were involved in caring for the child in any capacity. Families experiencing such a tragedy should be met with empathy and compassion. They need clear and sensitive communication. They also need to understand what happened to their child and know that people will learn from what happened. The process of expertly reviewing all children's deaths is grounded in deep respect for the rights of children and their families, with the intention of preventing future child deaths where possible.

1.2 In March 2017, the National Quality Board published guidance, 'National Guidance on Learning from Deaths' to standardise the approach to reviewing and learning from deaths in the NHS.

1.3 'Following events in Mid Staffordshire, a review of 14 hospitals with the highest mortality noted that the focus on aggregate mortality rates was distracting Trust boards from the very practical steps that can be taken to reduce genuinely avoidable deaths in our hospitals'.

1.4 This is reinforced by the recent findings of the Care Quality Commission (CQC) report 'Learning, candour and accountability: A review of the way NHS trusts review and investigate the deaths of patients in England'. It found that learning from deaths was not being given sufficient priority in some organisations and consequently valuable opportunities for improvements were being missed.

1.5 In October 2018, HM Government released 'Child Death Review: Statutory and Operational Guidance (England)', a national statutory framework for the review of deaths of children.

1.6 The guidance sets out key features of a standardised mortality review process for children that combines best practice with statutory requirements that must be followed. This includes actions to be taken from the moment of the child's death, the local review by those who interacted with the child during life, any investigation into the death, and the completion of the review by the Child Death Overview Panel (CDOP) and Child Death Review (CDR) Partners (Children Act 2004). The aim of the document is to ensure outputs are standardised and of a uniform quality to enable thematic learning both locally and nationally to prevent future deaths.

1.7 Three standard outputs are to be used for the child death review process:

- The **Notification Form** for initial notification of CDR partners
- The **Reporting Form** for completion by those who have information relevant to the child, to be shared with the relevant CDOP.
- The **Analysis Form**, to be drafted at the Child Death Review meeting (CDR meeting) and completed by the CDOP.

1.8 The National Child Mortality Database (NCMD) was established in April 2019 and will become fully operational in 2020. The NCMD will be a central repository of the outputs of child death reviews in England. The database will enable detailed analysis of all data to

ensure that lessons are learned following a child's death, that learning is widely shared, and that actions are taken locally and nationally to reduce child mortality.

1.9 The National Guidance on Learning from Deaths and Child Death Review National Statutory and Operational Guidance requires Trusts to have a policy for reviewing and learning from deaths. This policy outlines the current and established processes for learning from deaths at Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH)

1.10 The GOSH Mortality Review Group (MRG) is a multidisciplinary group of senior clinicians that has conducted routine, independent structured case record reviews of all deaths that occur at GOSH since 2012. This updated policy defines the activities of the new Trust Child Death Review Group (CDR group), in line with national policy.

1.11 A Local Case Review (LCR) is undertaken by clinicians who were involved with the care of the child for all children who die at GOSH. This updated policy defines the role of the LCR and link with the new Trust CDR group, in line with national policy.

1.12 The Serious Incident Management Policy highlights the systematic investigation process that should be undertaken related to Serious Incidents (SI) at GOSH, in accordance with the NHS Improvement Serious Incident Framework. The purpose of the SI investigation is to understand and identify problems in service delivery or care that preceded adverse events, to understand how and why any problems occurred, and to identify what may need to change in service provision/care delivery to reduce the risk of similar events in the future.

1.13 The death of a child results in significant distress for families. Being open with parents and their families at all times including when something goes wrong is a key component of developing a safety culture; a culture where all incidents are reported, discussed, investigated and learned from. GOSH recognises that involvement in the care of a child who dies can result in significant distress for staff who have cared for that child. This policy highlights the support for families and staff that is available through Bereavement Services and must be read in conjunction with the Trust policy "Being Open and the Duty of Candour".

2 Scope

2.1 This policy applies to the following staff groups:

- All GOSH employed staff - where the individual is directly employed by GOSH either on a fixed term or permanent contract;
- Board Members – Member of the Trust Board. Specifically the Chair, Non-Executive Directors and Executive Directors
- Governors – Member of the Council of Governors
- Contractors – individuals on-site at GOSH, who are employed by an external contracting company including consultancy work;
- Agency staff – individuals on-site at GOSH who are employed via an agency on the NHS Agency Framework;
- Honorary contract holder – individuals engaged via a GOSH Honorary contract;
- Bank staff – individuals with a GOSH bank contract;

2.2 This policy does not apply to the following staff groups

- Students - students on placement at GOSH as part of their educational programme

- Work experience candidates – students who are gaining work experience at GOSH
- Foundation Year 1 & Foundation Year 2 Placements – those training to be doctors at Foundation Year 1 and 2 level, who wish to experience a Paediatric Hospital environment to help inform future career decisions
- Research Placements – those holding a research contract issued by the research and governance team or an Honorary contract if they are undertaking both Research and Clinical work

3 Aims and Objectives

3.1 To outline a clear and consistent approach to reviewing the death of a child who dies whilst receiving care as a GOSH patient. This includes any child who dies on Trust premises, and children who are receiving care at GOSH but who die elsewhere.

3.2 To ensure that learning from deaths of all GOSH patients is embedded into Trust practice.

3.3 To provide a framework so that GOSH is able to meet the current national and statutory requirements for learning from deaths in childhood.

3.4 To meet the requirement from the National Guidance on Learning from Deaths for all Trusts to have a policy on learning from deaths.

3.5 To clearly set out the requirements, roles and responsibilities for sharing information with CDOPs to facilitate awareness of the processes across GOSH and ensure clinical information is provided and communication is carried out within a timely manner.

3.6 This policy supports GOSH'S vision and strategy of achieving the best possible outcomes by providing the safest, most effective care by ensuring that there is a process in place to identify and act on any learning identified when a child dies whilst receiving care as a GOSH patient, and to any modifiable factors to prevent future child deaths.

4 Duties and Responsibilities

4.1 Chief Executive

Ultimate executive accountability for the quality of services at GOSH.

4.2 Medical Director

Executive Director responsible for mortality reviews at GOSH

- Provides the Trust Board with assurance regarding the GOSH Child Death Review process.
- Provides support and guidance to the CDR group Co-Chairs, as required.
- Takes action where concern is raised through mortality data and/or child death reviews

4.3 Non-Executive Directors

Oversight of progress with implementation of National Guidance on Learning from Deaths through review of reports to Trust Board.

4.4 Child Death Review Group

- The GOSH CDR group oversees the process of review for any child who dies whilst receiving care as a GOSH patient, either as an in-patient, or where the child dies

elsewhere. The purpose of this review is to provide a Trust-level overview of all deaths to identify themes/risks, and take action as appropriate to address those risks whether they are internally or externally facing. This may include suggestions for improvements in practice as well as changes to clinical care to prevent harm.

- The CDR group also functions to provide assurance that the child's pathway of care has been managed appropriately by the organisation, and where any issue or learning impacting on patient care is identified at a local or organisational level, this is fed back to the relevant leads for sharing or resolution as appropriate.
- The CDR group has responsibility for ensuring compliance with national reporting requirements, completion of the necessary outputs from the CDR process (Notification Form (formerly form A), Reporting Form (formerly form B), and Draft Analysis Form (formerly form C) for children reviewed at GOSH), in line with the National Guidance on Learning from Deaths and Child Death Review Statutory Guidance.
- The CDR group also coordinates information for relevant programmes e.g. national audits, CDOPS, Care Quality Commission and Dr Foster etc. where information on mortality across GOSH needs to be provided.
- The CDR group reports to the Patient Safety and Outcomes Committee (PSOC) quarterly, and through the Medical Director to the Trust Board.

4.5 Co-Chairs of the CDR group

The Co-Chairs are responsible for:

- Chairing the child death review meetings and ensuring that case discussions are completed in a timely manner. If the Chair had direct clinical responsibility for the child, the role of chair should be delegated to a colleague to avoid any conflict of interest. The Chair should ask members attending the CDR meetings to declare any conflicts of interest at the start of the meeting. Rarely, if trust has broken down between GOSH staff and the family, it may be necessary to appoint a chair who is external to the organisation.
- Ensuring actions from CDR meetings have been completed in a timely manner.
- Working with the Child Death Review Coordinator (CDR Coordinator) to ensure that CDR notifications, reports and analysis forms are sent to the relevant CDOPs in a timely manner.
- Working with the CDR Coordinator to coordinate responses by GOSH clinicians to requests for information from external bodies such as CDOPs, or other Trusts when a CDR meeting is to be held at another Trust.
- Working with the Clinical Audit Manager to compile quarterly reports and responding to requests for information from PSOC, Trust Board, Postgraduate Medical Education and the Quality and Safety Closing the Loop meeting, to include the number of deaths that occur in each quarter, the number of deaths reviewed, cases investigated as an SI, deaths in children with learning difficulties, and cases where modifiable factors and learning points were identified that could prevent future deaths.
- Providing input to the GOSH Annual Report.
- Ensuring that GOSH is meeting recommendations in line with statutory and national guidance on learning from deaths.

4.6 Chiefs of Service

- The Chiefs of Service are responsible for ensuring speciality teams within their Directorate have systems in place to complete the Medical Certificate of Cause of Death (MCCD) and to undertake a Local Case Review in a timely manner for all children who die at GOSH.
- Chiefs of Service for clinical areas are responsible for ensuring compliance with this policy and adherence of staff to the timescales set out.

4.7 Speciality Teams

- The medical and nursing teams looking after the child at the time of death must ensure the patient is cared for in accordance with the procedures described in the 'When a child dies' Clinical Guideline on the Hospital Intranet (also found in the 'When a child dies' purple box on all wards), and that the documentation in the 'When a child dies' tab in Epic has been completed.
- The medical and/or nursing team looking after the child at the time of death must notify Bereavement Services as soon as possible after the child dies to enable to CDR Coordinator to commence notification of the relevant CDOP and the Child Health Information System.
- The specialty team is responsible for conducting a Local Case Review within a local multidisciplinary mortality review meeting within 4 weeks of the death. Specialty teams are responsible for identifying and addressing any immediate issues relating to the delivery of patient care.
- The speciality team should identify members of the multidisciplinary team involved in the child's care leading up to death who should take part in the local case review meeting.
- Engage in statutory child death review processes outlined in this policy

4.8 The Responsible Consultant at the time of the child's death

- This may refer to the named Lead Consultant or the last attending consultant at the time of the child's death. The Lead Consultant is ultimately responsible for identifying the most appropriate consultant to ensure the statutory child death notification and reporting process has been completed.
- The Responsible Consultant is responsible for immediate decisions following the death of the child, including how best to support the family, whether a Medical Certificate of Cause of Death (MCCD) can be issued or whether the case should be referred to the Coroner, whether the death fits the criteria for Sudden Unexpected Death in Infancy/Childhood (SUDI/SUDC), and/or requires a Joint Agency Response involving the police and social services (see section 5 below for definitions).
- The Responsible Consultant must ensure that the clinical team caring for the child at the time of death has notified the Bereavement Team and the child's GP, and that other clinical teams involved are informed of the death.
- The Responsible Consultant is responsible for completing the MCCD so that the family can the register the death within five days (8 days in Scotland), or if an MCCD cannot be issued, for referring the death to the Coroner in accordance with government policy. The Responsible Consultant may delegate completion of the MCCD to an appropriate trainee, but must review the MCCD before it is released to the family.
- The Responsible Consultant is responsible for responding to any enquiries from the Medical Examiner. The Medical Examiner will be a new appointment, external to GOSH who will scrutinise all non-coronial deaths with the aim of improving the quality and accuracy of MCCDs and the national data on avoidable mortality. The Medical Examiner will also support families and provide them with an opportunity to raise concerns.
- The Responsible Consultant is responsible for completing the Child Death Reporting Form (formerly Form B), which must be submitted to the relevant CDOP panel within two weeks of the death. This process will be supported by the CDR Coordinator who will act as the single point of contact (SPOC) for the CDOPs. The CDR Coordinator will send a draft Reporting Form to the Responsible Consultant who must provide all required clinical information. The Responsible Consultant may delegate completion of the Reporting Form to an appropriate trainee, but they must have input into the

Reporting Form and include the outcome of discussions at the local case review meeting.

- The Responsible Consultant is responsible for ensuring a death discharge summary is written within four weeks of the child's death, in accordance with Trust policy.
- The Responsible Consultant must attend the GOSH CDR meeting or identify the most appropriate clinician to attend the CDR meeting. The GOSH CDR meeting will be held within 12 weeks of the child's death, following completion of all necessary investigations and reviews.

4.9 Clinical members of the Child Death Review group (CDR group)

The clinical members of the CDR group are responsible for

- Reviewing cases as agreed with the CDR Co-Chairs and the CDR Coordinator, reviewing the relevant Reporting Forms submitted for the CDR meeting, reviewing the case notes and drafting the initial analysis form to be discussed at the CDR meeting.
- Assisting with the peer review of cases.
- Implementing actions assigned to them and feedback issues/concerns to the specialty teams.

4.10 Child Death Review (CDR) Coordinator

The CDR Coordinator is a member of the Bereavement Services team, and provides administrative support for the CDR process to:

- Manage and maintain the Child Death Review Deaths and Review Schedule, updating the list of children receiving care from GOSH who have died in the hospital or elsewhere each month.
- Coordinate internal and external MDT attendance at the CDR meeting, gathering and submitting reports when required.
- Request copies of Datix, Bereavement, Palliative care and Legal Information, and MBRRACE-UK forms two weeks prior to the meeting.
- Produce meeting case summaries of key issues, learning points and actions from all case reviews discussed in each meeting; update the CDR analysis spreadsheet and Action Log after each meeting.
- Provide Governance support to the meeting, including data analysis and quarterly reporting to the Patient Safety and Outcomes Committee, Trust Board and Closing the Loop meeting.
- Provide administrative support for the CDR group, including compiling and distributing the agenda, maintaining the CDR Deaths and Review Schedule, and taking minutes.
- Act as the Single Point of Contact (SPOC) for CDOPs, facilitating information sharing between GOSH and CDOPs as relevant.
- Notify CDOPs of all child deaths by completion of the Notification Form (previously Form A) (see appendix 2)
- Liaise with the clinical teams to facilitate the completion of the Reporting Form (previously Form B) (see appendix 3)
- Liaise with the CDR co-chairs to facilitate the completion of the Analysis Form (previously Form C) following the internal CDR meeting (see appendix 4)
- Feedback learning from the CDOPs through the CDR group
- Liaise with clinical teams and the CDR group to complete and submit case information to the PMRT and MBRRACE-UK
- Liaise with the Key Worker and Bereavement Services throughout the process to ensure families have an opportunity to put their questions and concerns to the CDR group and are informed of outcomes of the CDR process. The CDR Coordinator will

report to the Bereavement Services Manager and will work closely with the CDR Co-Chairs.

4.11 The Bereavement Services Manager

The Bereavement Services Manager will:

- Act as a managerial lead for the CDR Coordinator.
- Provide clinical oversight and appropriate expertise to support the CDR Coordinator and the Key Worker roles.
- Ensure a Key Worker is identified as per the bereavement pathway who will act as a single point of contact for the bereaved family
- Liaise with the CDR Coordinator, the Key Worker and Medical Examiner to ensure that families have an opportunity to put their questions and concerns to the CDR group and are informed of outcomes of the CDR process.
- Act as a 'case manager' when there is more than one investigation to have oversight of procedures, to ensure that those involved are objective (e.g. through engaging the Patient Advice and Liaison Service), to have an understanding of statutory requirements and follow appropriate timescales, and to ensure parents have an opportunity to input into the process and establish how they would like to receive feedback.
- Carry out the Bereavement Measuring Tool Questionnaire of the end of life experience for families and carers at GOSH.

4.12 The Key Worker

- A nominated member of the Family Liaison Team for ICU deaths will act as a Key Worker for the family as the single named point of contact to provide bereavement support for the family, information on the processes following the death of their child and to signpost them to other sources of support.
- For non-ICU deaths, the Key Worker role will be fulfilled by a member of the care team who is the main link with the family at the time of death (e.g. CNS, Social Workers or other team member) for the first two weeks after death. They may need to hand over the role of Key Worker to Bereavement Services in the longer term, particularly in cases in which there is a Coroner's review.
- Members of the Family Liaison Team will provide cross cover for each other within their areas, and provide a contact person for families in the event of the absence of the named Key Worker. In the absence of a key worker the Bereavement Service will act as the Key worker in accordance with the bereavement care pathway

4.13 The designated lead for the Perinatal Mortality Review Tool Programme

- Ensure all deaths falling within the perinatal review criteria are reviewed and reported in line with the Perinatal Mortality Review Tool (PMRT) programme covering maternal and neonatal units in the NHS in England, Scotland and Wales.

4.14 The Palliative Care Administrative Team

- Provide links to palliative care notes and summaries for each case in advance of the CDR meetings.

4.15 Legal Team

- Provide the outcomes and reports from Coroner's inquests and police investigations (where applicable) for each case in advance of the meeting.

- Provide the outcomes and reports from Coroner's inquests and police investigations completed after the mortality review, where not available earlier. The CDR report will then be reviewed by the co-chairs with any new information taken into account

4.16 Clinical Nurse Specialist for Learning Disabilities.

- Submit death notifications as required to the Learning Disabilities Mortality Review (see section n 9 for further detail)

4.17 Child Death Overview Panel

- The responsibility for ensuring child death reviews are carried out is held by 'Child Death Review Partners,' who, in relation to a local area in England, are defined as the Local Authority for that area and any Clinical Commissioning Groups operating in the local authority area.
- Child Death Review Partners must make arrangements to review all deaths of children normally resident in the local area and, if they consider it appropriate, for any non-resident child who has died in their area.

The role of the CDOP is to:

- Collect and collate information about each child death, seeking relevant information from professionals and, where appropriate, family members;
- To analyse the information obtained, including the report from the CDR meeting, in order to confirm or clarify the cause of death, to determine any contributory factors, and to identify learning arising from the child death review process that may prevent future child deaths;
- To make recommendations to all relevant organisations where actions have been identified which may prevent future child deaths or promote the health, safety and wellbeing of children;
- To notify the Child Safeguarding Practice Review Panel and local Safeguarding Partners when the CDOP panel suspects that a child may have been abused or neglected;
- To notify the Medical Examiner (once introduced) and the doctor who certified the cause of death if the CDOP identifies any errors or deficiencies in an individual child's registered cause of death. Any correction to the child's cause of death would only be made following an application for a formal correction;
- To provide specified data to NHS Digital and then, once established, to the National Child Mortality Database;
- To produce an annual report for CDR partners on local patterns and trends in child deaths, any lessons learnt and actions taken, and the effectiveness of the wider child death review process; and
- To contribute to local, regional and national initiatives to improve learning from child death reviews, including, where appropriate, approved research carried out within the requirements of data protection.

5 Definitions

- CDR – Child Death Review
- CDR group - Child Death Review group
- CDOP – Child Death Overview Panel
- LCR – Local Case Review
- M&M - Mortality & Morbidity Meeting
- MBRRACE-UK – Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK

- JAR – Joint Agency Response
- PMRT – Perinatal Mortality Review Tool
- SUDI/SUDC - Sudden and unexpected death of infant/child
- SPOC - Single point of contact
- WACD - When a child dies

6 Process of Learning from Deaths at Great Ormond Street Hospital for Children NHS Foundation Trust

This policy outlines the Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) Trust-wide process for reviewing child deaths in line with the Child Death Review Statutory and Operational Guidance. This is through a case record review by clinicians who were involved with the care of the child, review of the care received around the time of death, and a multi-professional meeting where all matters relating to the child's death and the results of any investigations are discussed.

Specialty teams are responsible for conducting Local Case Reviews through the Local Case Review (LCR) (or Mortality & Morbidity (M&M) Meeting) process. The output of the LCR should be recorded using the standardised Trust pro forma, which must be shared with the CDR group and documented in the electronic patient record [location tbc].

Approximately 80% of GOSH inpatient deaths take place in ICU. All ICU deaths are reviewed at the weekly ICU M&M meeting, usually within a week of death.

6.1 The CDR group will:

- Review the care of all children who die as GOSH in-patients. In reviewing these deaths, the complete patient care pathway will be taken into account, not just the immediate period before death. If indicated, previous admissions will also be reviewed and taken into account.
- This process should also engage professionals across the pathway of care prior to admission to GOSH. The following professionals may be invited to contribute to the CDR meeting directly depending on their involvement in the case, or to contribute in writing by completion of a standard proforma or by teleconference:
    - Hospital or community healthcare staff or GP involved with the child at the end of his/her life, and those known to the family prior to this event;
    - Pathologist, if a post-mortem examination has taken place, or placental histology has been reported in the case of a neonatal death;
    - Other healthcare professionals from relevant hospital departments and community services;
    - Patient safety team if a serious incident investigation has taken place;
    - Coroner's officer, if the case has been referred to the Coroner;
    - Senior investigating police officer, if there is a Joint Agency Response; or
    - Other practitioners for example social work, ambulance and fire services, primary care clinicians, school nurse, head teacher, representatives from voluntary organisations.
- Review deaths on request e.g. by a CDOP, Palliative Care Team, Children's Acute Transport Service (CATS), or in response to mortality data.
- Review cases in response to requests from other organisations as part of their CDR processes to review the care provided to children who are GOSH patients but who were not in-patients at GOSH at time of death.
- Collaborate with others as requested to carry out reviews and investigations when a child has received care from several health and care providers.
- Within the scope described above, the CDR group will review deaths within 12 weeks of the date of death.

- Case record[1] reviews will be conducted using the complete set of patient notes, which are readily accessible to reviewers. At a minimum, the notes on Epic, hard copy notes (if in use), and any historical notes on CareVue and Electronic Document Management should be reviewed. The CDOP Reporting Forms, Datix incident reports, outcomes from coroner's inquests, bereavement and palliative care notes will also be provided in advance of the meeting.
- Post-mortem reports should be obtained from the Legal Team for review when available.
- Patient records should always be made available and prioritised for the CDR group, including standard proforma reports completed by the speciality team prior to the CDR review, to ensure the timely review of deaths within 12 weeks (as per national requirements) and support timely quarterly reporting.
- The output of the CDR meeting will be the draft CDR Analysis Form that will be forwarded to the CDOP team.
- Review the LCR documentation provided by the specialty team, and information gathered by different agencies involved in the child's pathway made available by the CDOP.
- Review the background history, treatment, and outcomes of investigations, to determine, as far as is possible, the likely cause of death; to ascertain contributory and modifiable factors across domains specific to the child, the social and physical environment, and service delivery.
- Drawing on the intelligence gathered, those present at the CDR meeting should then appraise all the relevant information in order to form an understanding of the circumstances of the child's death, identify any modifiable factors and lessons to be learnt, and any action that will be taken at a local level.
- Modifiable factors are defined as those, which by means of nationally or locally achievable interventions could be modified to reduce the risk of future child deaths.
- Ensure the relevant CDOP and, where appropriate, the Coroner is informed of the outcomes of the CDR meeting via the CDR Analysis Form.
- Where modifiable factors or other issues are identified, these must be fed back in an appropriate manner to the relevant clinical team and/or the Divisional Director(s) for action. The feedback mechanism will be determined based on the nature of the information to be shared, but could include a specialty case review meeting, email, Divisional Board meeting, 'Closing the Loop' Committee etc.
- Take into account any concerns raised by the family via the Key Worker, review the support provided to the family and to ensure that the family are provided with the outcomes and learning from the investigation and review.
- Identify any issues that require action at a Specialty, Divisional, Trust-wide, London, or National level, and take responsibility for liaising and/or engaging with relevant stakeholders to implement these actions.
- Where Trust-wide learning is identified, communicate this via the quarterly reports presented at PSOC and Trust Board for dissemination and action. Trust wide learning should also be shared via the Postgraduate Medical Education department and the Closing the Loop team.
- Where resolution requires Executive input or oversight, the CDR group should escalate issues to the Medical Director(s) or Senior Management Team as appropriate.

[1] A structured desktop review of a case record/note, carried out by clinicians, to determine whether there were any problems in the care provided to a patient. Case record review is undertaken routinely to learn and improve in the absence of any particular concerns about care. This is because it can help find problems where there is no initial suggestion anything has gone wrong. It can also be done where concerns exist, such as when bereaved families or staff raise concerns about care.

- Review relevant reports from, and/or provide data/analysis as appropriate to, national audits and other programmes reviewing child deaths.

This process has been summarised in Figure 1 below.

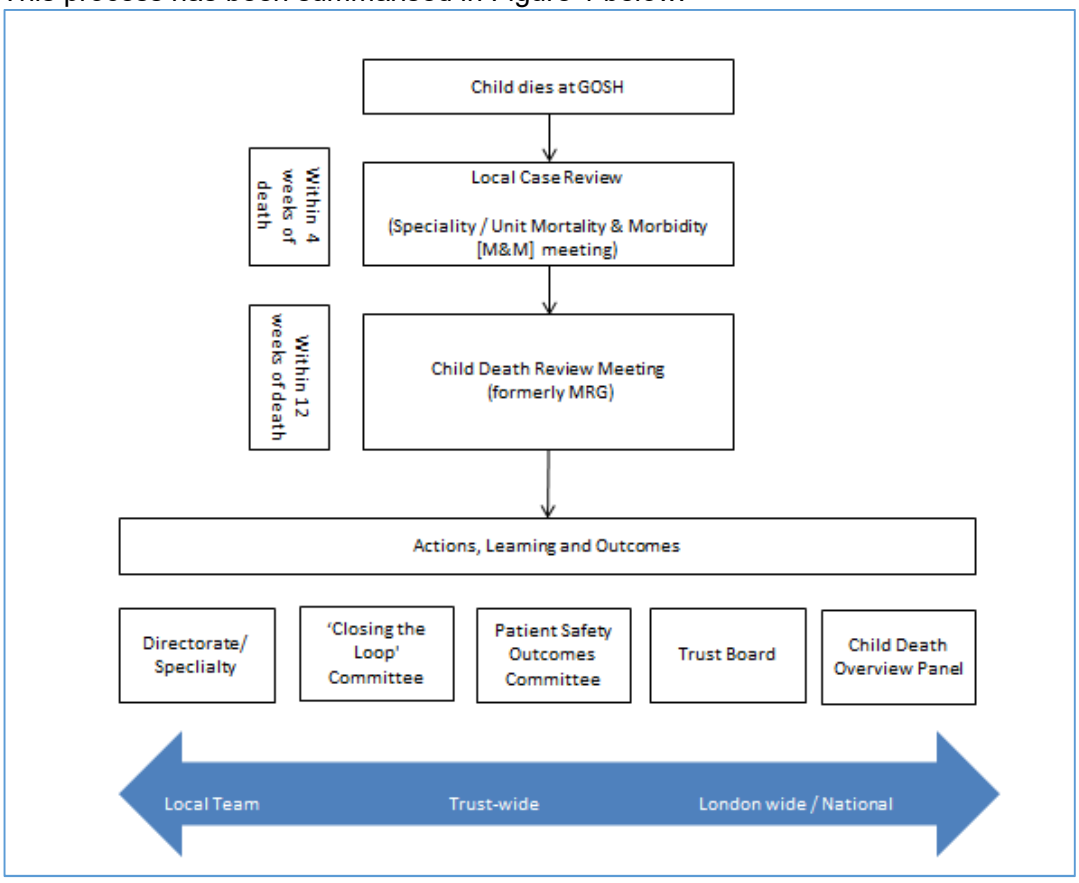


Figure 1. Process of learning from deaths at GOSH

7 Sudden unexpected deaths (SUD)

7.1 Unexpected death

A sudden unexpected death of an infant or child (SUDI/C) is defined (RCPath Royal college of Pathologists 2016) as all cases in which there is death (or collapse leading to death) of a child (less than 18 years old), which:

- Was not anticipated as a significant possibility 24 hours before the death; or
- Where there was a similarly unexpected collapse or incident leading to or precipitating the events which led to the death. This definition is especially relevant when there is a significant time delay between the collapse of the child and their eventual death.
- Unexpected deaths include those of children with existing medical conditions or disabilities (including those that are life limiting or threatening) whose death at the time that it occurred was not expected as a natural consequence
    - For sudden unexpected deaths, the Responsible Consultant and Designated Paediatrician for SUDI/C at the relevant CDOP should make a decision on whether or not a Joint Agency response is required based on their professional judgement, the information available to them at the time and liaison with the Coroner.

- The unexpected deaths of children with life-limiting conditions also fall within these procedures however professionals involved in managing these deaths should use their professional judgement in how they should be applied.

8 Joint Agency Response

- A Joint Agency Response should be triggered if a child's death:
    - Is or could be due to external causes;
    - Is sudden and there is no immediately apparent cause (including SUDI/C);
    - Occurs in custody, or where the child was detained under the Mental Health Act
    - Where the initial circumstances raise any suspicions that the death may not have been natural;
- In any of these circumstances, the Responsible Consultant (in this case, the on-call consultant), police investigator, and duty social worker should be contacted immediately so as to initiate the joint agency response.

8.1 Joint Agency Response Team

- A Joint Agency Response (JAR) team is a group of key professionals who come together for the purpose of enquiring into and evaluating the cause of death where the death of an individual child is unexpected. Consultants may be requested to attend JAR meetings and/or expedite their report for this purpose.
- The Designated Paediatrician at the local CDOP should be contacted immediately by the Responsible Consultant when the death is unexpected to enable doctor to doctor discussion for JAR. When there is a sudden unexpected death a JAR will be arranged by the local CDOP.
- The process for a Joint Agency Response is outlined in Appendix 5

9 The Learning Disabilities Mortality Review (LeDeR) Programme

9.1 The Learning Disabilities Mortality Review (LeDeR) Programme was commissioned in June 2015, by the Healthcare Quality Improvement Partnership (HQIP) and NHS England. The programme aims to make improvements to the lives of people with learning disabilities, identify any modifiable factors associated with a person's death and ensure learning is implemented. The roll out of the pilot phase was completed successfully in December 2017.

9.2 The 'National Guidance on Learning from Deaths' recognizes the LeDeR programme as an established methodology for reviewing of deaths of patients with learning disabilities, and requires that 'All deaths of people with learning disabilities aged four years and older are subject to review using LeDeR methodology'. The guidance recognises that Trusts may want to complete their own internal review, and recommends that providers notify LeDeR of the deaths of children with a learning disability (aged 4yrs+) utilising the LeDeR online notification form.

9.3 The Clinical Nurse Specialist for Learning Disabilities is responsible for submitting the LeDeR notification forms.

10 The Perinatal Mortality Review Tool (PMRT)

10.1 The Perinatal Mortality Review tool has been designed to ensure comprehensive and robust review of all perinatal deaths in a neonatal intensive care unit from 22+0 weeks

gestation until 28 days after birth, using a standardised nationally accepted tool. The tool follows the concept and principles established by a stakeholder group convened by the Department of Health and the stillbirth and neonatal death charity, Sands in 2012.

10.2 GOSH will review neonatal deaths in line with the child death review processes set out in this policy. In all cases, the review meeting will generate an Analysis Form, which will be sent to the local CDOP and could be used to inform the PMRT if necessary. The hospital of birth is responsible for completing the obstetric information for the PMRT.

10.3 GOSH will inform MBRRACE-UK with the details of infant's death

10.4 Where babies are transferred (either in utero or after birth) and receive care in more than one hospital, the care across all hospitals will be reviewed by the teams involved in the care at each hospital and;

10.5 If a baby was transferred between neonatal units, the neonatal unit where the baby died is responsible for leading the review, while ensuring that all units involved in the care (including care during pregnancy, labour and delivery) inform and preferably participate in a joint review meeting. The review will be carried out as a joint activity wherever possible, but if this is not possible then the perinatal mortality review group in the originating unit is responsible for reviewing the midwifery, obstetric and neonatal care provided in their unit before the baby was transferred.

10.6 The Trust/Health Board where the baby died is responsible for leading the review but all units involved in the care should be part of the review group to ensure that all aspects of the care are considered.

11 Support for families, carers, and staff

11.1 Bereavement support

The Bereavement services department operates across GOSH, offering advice and support to staff and parents in dealing with the 'when a child dies' process at the time of death and emotional support post death.

The Bereavement services department aims to be a point of contact for anyone working in GOSH, requiring support in caring for a dying child and after the death of a child. Bereavement services can be contacted on 020 7813 8551

11.2 End of Life Care group

The End of Life Care group meets regularly to develop core standards for issues around death and dying and to monitor implementation of an end of life care pathway.
It also seeks to enable staff who already have strong professional links with the children and families in their care to identify, address and support decision-making choices.

11.3 Child Death Helpline (CDH)

The Child Death Helpline is a National Freephone service run by GOSH and Alder Hey, for anyone affected by the death of a child of any age, in any circumstance, however long ago. It provides free confidential telephone advice and support that can be accessed by bereaved families.

12 Training requirements

12.1 The clinical reviewers of the CDR group will receive guidance from the co-chairs of the CDR group to ensure that reviews are undertaken appropriately using the specified review tool.

12.2 Detailed training on the when a child dies process is provided within the multidisciplinary 'When a child dies' simulation training, Palliative Care Foundation Course for nurses, medical training for ICU Doctors (ST6), and bespoke training for clinical areas delivered by Bereavement Services on request.

13 Communication and Consultation

13.1 This policy is based upon the terms of reference for the former Mortality Review Group, following consultation by the clinical membership of the MRG/CDR group.

13.2 The GOSH process for Learning from Deaths was outlined and shared as part of Trust-wide feedback for input into the December 2017 National consultation of 'Working Together to Safeguard Children'. This has been updated following the publication of the new Child Death Review: Statutory and Operational Guidance, published in September 2018.

13.3 The changes to practice in this policy have been agreed by a working group led by the Medical Director, and a communications plan has been developed as part of this work, through presentation at key meetings and committees.

14 Monitoring arrangements

Policy element to be monitored	Lead	Frequency	Reporting arrangements (Committee or group)
Assurance that all child deaths that occurred at GOSH have been reviewed within 12 weeks	Bereavement Services Manager	Monthly	Included in quarterly report to Patient Safety and Outcomes Committee
EOL experience questionnaire (bereavement measurement tool) sent to our bereaved families	Bereavement Services Manager	Annual	Patient Family Experience and Engagement Committee
Report produced summarising findings and learning points from all completed mortality reviews. Report includes following data: Total number of deaths at GOSH in each quarter Number of those deaths subject to case record review by the MRG Number of those deaths investigated under the serious incident framework and declared as serious incidents Number of deaths where a modifiable factor was identified at GOSH with an influence score of 2 Number of deaths where a modifiable factor was identified at GOSH with an influence score of 3 Number of deaths of people with learning disabilities Number of people with learning disabilities that have been reviewed Number of deaths of people with learning disabilities where a modifiable factor was identified at GOSH with an influence score of 2 or more	Co-chair of MRG	Quarterly	Patient Safety and Outcomes Committee
Assurance that all CDOPs are informed of child death within a timely manner	Bereavement Service Manager	6 monthly	Patient Family Experience and Engagement Committee
Executive summary of finding and learning points from all completed mortality reviews	Co-chair of MRG	Quarterly	Trust Board
Trust inpatient mortality rate	Quality Improvement Analyst	Monthly	Integrated Quality and Safety Report

15 Equality Impact Assessment

Title of Document:	Learning from Deaths policy
Completed By:	Isabeau Walker, CDRG Co-Chair
Date Completed:	June 2019
Summary of Stakeholder Feedback:	

Potential Equality Impacts and Issues Identified		
Protected Group	Potential Issues Identified	Actions to Mitigate / Opportunities to Promote
Age	Policy and process only applies to GOSH patients	GOSH will contribute to reviews held by other organisations where the care of the patient when at GOSH is relevant. This may result in review of patients aged over 21 years.
Disability (Including Learning Disability)	There are additional review requirements for children/young people with LD	This is a nationally mandated additional review requirement so outside the purview of GOSH to influence.
Gender Re-Assignment	None Identified	
Marriage or Civil Partnership	None Identified	
Pregnancy and Maternity	It is recognised that the CDR process requires reviews of neonatal and baby deaths, and the CDR group are sensitive to those members of the group who have a declared pregnancy or are returning to work following maternity leave	Members are given the option to refrain from participation
Race	None Identified	
Religion or Belief	None Identified	
Sex	None Identified	
Sexual Orientation	None Identified	

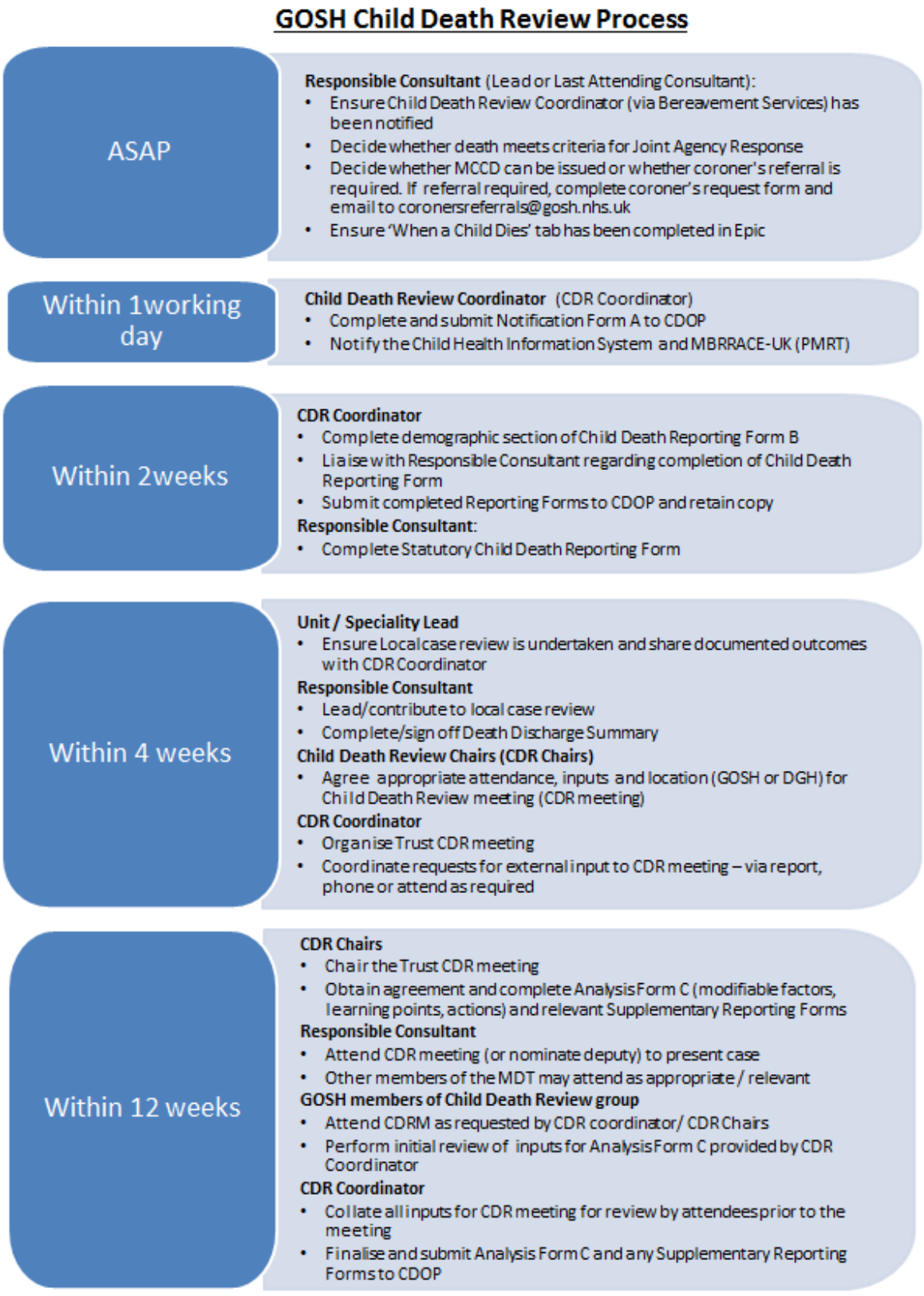
16 References and relevant statutory documents, guidelines

- Child Death Review Statutory and Operational Guidance (England) (2018) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/777955/Child_death_review_statutory_and_operational_guidance_England.pdf
- Guidance for Trusts and Health Boards Conducting Perinatal Mortality Reviews using the National Perinatal Mortality Review Tool (PMRT) https://www.npeu.ox.ac.uk/downloads/files/pmrt/3b_Guidance%20for%20using%20the%20PMRT%20July%202018%20v6.pdf
- National Quality Board (2017). National Guidance on Learning from Deaths https://www.england.nhs.uk/wp-content/uploads/2017/03/nqb-national-guidance-learning-from-deaths.pdf
- Care Quality Commission (2016). Learning, Candour and Accountability - A review of the way NHS trusts review and investigate the deaths of patients in England https://www.cqc.org.uk/sites/default/files/20161213-learning-candour-accountability-full-report.pdf
- Mazars (2015). Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015 https://www.england.nhs.uk/south/wpcontent/uploads/sites/6/2015/12/mazars-rep.pdf
- HM Government (2017 Consultation). Working Together to Safeguard Children: changes to statutory guidance (including Child Death Review Statutory guidance).

16.1 GOSH internal policies and guidelines

- Being Open and the Duty of Candour
- Serious Incident Management Policy
- Complaints policy
- Child Death Overview Information Sharing Policy
- When a child dies

17 Appendix 1: GOSH Child death Review Process Timeline



18 Appendix 2: CDOP Notification of Child Death Form

Notification to be reported to CDOP administrator at:
Secure email:
Tel:
The information on these forms and the security for transferring it to the CDOP administrator should be clarified and agreed with your local Caldicott guardian.
Please remember it is a statutory requirement to notify CDOP of all child deaths from birth up to their 18th birthday. If there are a number of agencies involved, liaison should take place to agree which agency will submit the Notification. However, unless you know someone else has done so, please notify CDOP with as much information as possible,

Child's Details

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

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

Name	DOB	Relationship	Address

Death details:

Date of death	/ /
Where was the child when they died? [2]	

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

Suspected cause of death	

Case Management:

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

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

Details of relevant agency contacts (please give as much information as you have easily available to you):

is subsequently withdrawn, the place of death should be recorded as the location within the hospital where this occurs

19 Agency	Name and contact details	√ Lead Professional (only one tick is required)
Community Paediatrician		
Local Paediatrician/ Neonatologist		
Tertiary Paediatrician/ Neonatologist		
Other local or tertiary specialists		
GP		
Midwife		
Health Visitor		
School Nurse		
Obstetrician		
Police – Collision Investigation Unit or Child Protection		
Children's Social Care		
Nursery/School College/Or Local Education Authority		
Others (list all agencies known to be involved)		

Referral details

Date of referral	/ /
Name of referrer	
Agency	
Address	
Tel Number	
Email	

20 Appendix 3: CDOP Child Death Review Reporting Form

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

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

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

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

Reporting Details

Child's age at death (year/month/day)	/ /
Gender	Male Female Unknown Indeterminate
Education/Occupation	Infant/young child, not yet in education Nursery School College Home schooled Not in education Left education - Employed - Unemployed - Apprenticeship Not known
Was this death subject to a Joint Agency Response[3]?	Yes No Indicated, but did not occur Not known
Was there a formal Serious Incident investigation or any other internal agency investigation?	Yes No Not known

[3] Joint Agency Response – a multiagency response involving police, social services, and health

Is this child's death subject to a Serious Case Review (child protection)/ local or national Child Safeguarding Practice Review?	Yes No Not known
Is this child's death subject to any other statutory review?	Yes No Not known
Is this child's death subject to any criminal or police investigation?	Yes No Not known
If any of the above investigations apply, please provide details and if possible a copy of the report to the CDOP if it is available	

Summary of Case and Circumstances leading to the death

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

Details of the Death	
Where was the child when they died? [4]	Hospital - Midwifery unit - Labour ward / delivery suite - NICU - PICU - AICU - ED - Hospital ward - Theatre Hospice Home Other residence (please specify) Public place School Other (please specify)
What is the cause of death as given on the Medical Certificate of Cause of Death (MCCD), or the coroner's conclusion as to the cause of death, if known?	Cause of death (if known) Death currently being investigated by coroner, conclusion not known

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

What was the mode of death?	Planned palliative care Withholding, withdrawal, or limitation of life-sustaining treatment) Brainstem death Failed cardio-pulmonary resuscitation Found dead Not known
Was this death discussed with the coroner?	Yes, and the coroner carried out an investigation Yes, and the coroner agreed that the hospital should issue a MCCD No, and MCCD issued by medical team Not known
Was a post-mortem examination carried out?	Yes – coroner's PM Yes – hospital PM No Not known

Circumstances of Death:

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

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

Were any of the following events known to have occurred? (tick all that apply)	
Death in a neonatal unit (allows linkage to PMRT)	
Death of a child with a life-limiting condition	
Death of a child with an oncology condition	
SUDI/SUDIC	
Other external event (head trauma, vehicle collision, drowning, fire/burns, poisoning, other non-intentional injury)	
Recognised complication of a medical or surgical procedure	
Acute asthma	
Acute epilepsy	
Acute Metabolic / Diabetic Ketoacidosis	
Cardiac: Congenital and Acquired	
Other Chromosomal, Genetic or Congenital Anomaly (not including cardiac)	
Infection (after first week of life)	
Suicide or self-harm, including alcohol or substance abuse	
Violent or maltreatment-related death	

Domain A: Factors intrinsic to the child

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

Birth weight (gm or lb and oz)	gm lb oz Small for gestational age? Y/N/NK	Gestational age at birth: completed weeks
For neonatal deaths, what was the mother's gravidity and parity?		Number of pregnancies (including this child) Number of births (including this child)
Did the child have any known pre-existing medical conditions (including any congenital anomalies) at the time of death? If yes, please provide details in the narrative section below		Yes No Not known
Did the child have a learning disability?[5] If yes, please provide details in the narrative section below		Yes No Not applicable – too young (< 4yrs age) Not known
Did the child have any other developmental impairment or disability at the time of death? If yes, please provide details in the narrative section below		Yes No Not applicable – too young Not known
Did the child have any known pre-existing mental health conditions at the time of death? If yes, please provide details in the narrative section below		Yes No Not applicable Not known
Did the child have any known drug or alcohol dependency issues? If yes, please provide details in the narrative section below		Yes No Not applicable Not known
Did the child have any known identity or social relationship issues? If yes, please provide details in the narrative section below		Yes No Not applicable Not known
Ethnic group	White	British Irish Any other White background
	Mixed	White and Black Caribbean White and Black African White and Asian Any other mixed background

[5] In children > 4 years of age, the LeDeR programme defines 'learning disabilities' as a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started in childhood with a lasting effect on development.

	Asian or Asian British	Indian Pakistani Bangladeshi Any other Asian background
	Black or Black British	African Caribbean Any other Black background
	Other ethnic group	Chinese Any other ethnic group
	Not known/ not stated	

Factors intrinsic to the child (including the pregnancy): Please provide (if necessary) narrative detail relating to the sections above and also consider other known health needs; factors influencing health; growth parameters development/educational issues; behavioural issues; social relationships; identity and independence; any identified factors in the child that may have contributed to the death. For neonatal deaths, include any relevant factors intrinsic to the pregnancy or mother's health The CDOP is not expected to review original case files or other primary documents, unless specific circumstances deem this necessary.

Domain B: Factors in the Social Environment including parenting capacity
This section provides details of the child's social environment, in particular to understand factors in relation to the care of the child that may have had relevance to the child's death.

	Age	Gender	Relationship to child and/or family	Employment status/ Occupation	Living in primary household? [6]
Mother		F	Mother		Y / N / NK
Father		M	Father		Y / N / NK
Siblings (Please number and complete any information known; further siblings can be added below, please include step and half siblings)					
1					Y / N / NK
2					Y / N / NK
Other significant others (e.g. Mother's partner; significant carer. Please complete any information known; further adults can be added below)					
1					Y / N / NK

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

2					Y / N / NK
3					Y / N / NK

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

Who was caring for the child at the onset of the illness or incident that led to their death?	Mother Father Other (please specify) The child/young person him/herself Hospital staff Hospice staff Not known
Were any significant family members known to have any physical health problems/disability? If so, please provide further details in the narrative section below	Mother Father Other significant adult Sibling Not known
Were any significant family members known to have any mental health problems/disability? If so, please provide further details in the narrative section below	Mother Father Other significant adult Sibling Not known
Are the child's parents known to be blood relatives?	Yes/No/Not known
Were any significant family members known to be smokers?	Mother Father Other significant adult Sibling Not known
Were any significant family members known to misuse alcohol?	Mother Father Other significant adult Sibling Not known
Were any significant family members known to misuse drugs?	Mother Father Other significant adult Sibling Not known
Was there any known domestic violence/abuse in the household?	Yes No Not known
Was the child known to children's social care prior to their death/the event leading to their death (tick all that apply)?	Yes, on a child protection plan Yes, as a looked after child Yes, as a child in need Yes, as an asylum seeker Yes, other (please specify) Previously known, but not an open case

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

Factors in the social environment including parenting capacity: Please provide (if necessary) narrative detail relating to the sections above. Please consider additional factors if relevant/known: family structure and functioning; provision of basic care (safety, emotional warmth; stimulation; guidance and boundaries; stability); engagement with health services (including antenatal care where relevant); employment and income; social integration and support; nursery/preschool or school environment. Include strengths as well as weaknesses. The CDOP is not expected to review original case files or other primary documents, unless specific circumstances deem this necessary

Domain C: Factors in the Physical Environment

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

Where was the child at the onset of the illness or incident that led to their death?	Hospital - Midwifery unit - Labour ward / delivery suite - NICU - PICU - AICU - ED - Hospital ward - Theatre Hospice Home Other residence (please specify) Public place School Other (please specify)

Factors in the physical environment: Please provide a description of any relevant factors known to you that have not been covered elsewhere. You might consider issues relating to the physical environment the child was in at the time of the event leading to death, or the mother during pregnancy, including: poor quality housing; overcrowding; environmental conditions; home or neighbourhood safety; as well as known hazards contributing to common childhood injuries (e.g. burns, falls, road traffic collisions) The CDOP is not expected to review original case files or other primary documents, unless specific circumstances deem this necessary

Domain D: Factors in Service Provision

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

Please list key agencies and hospital services involved with this child and family	
Was this child in hospital as a planned admission?[7]	Yes No Newborn baby in hospital Not known
Was this child transferred from another hospital?	Yes No Not known
Was this child known to Mental Health Services (child and adolescent or adult mental health services)?	Yes No Not applicable Not known
In a child with a life-limiting condition is there evidence of appropriate parallel planning and engagement with palliative care?	Yes No Not known Not applicable
Were there any issues in identification of illness, assessment, investigation, or diagnosis? If so, please provide details in the narrative section below	Yes No Not known
Were there any issues relating to treatment or healthcare management plan (tick all that apply)?	Medication, IV fluids/ anaesthesia? Infection management? Operation or invasive procedure Clinical monitoring

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

If so, please provide details in the narrative section below	Resuscitation Other
Were there any issues in communication and /or teamwork (either within or between agencies) If so, please provide details in the narrative section below	Yes No Not known
Were there organisational issues that may have contributed to the child's vulnerability, ill-health or death? If so, please provide details in the narrative section below	Yes No Not known
Were any patient safety incidents reported in this case? If so, please provide details in the narrative section below	Yes No Not known
Did the parents or carers express any concerns about the care offered to this child? If so, please provide relevant details in the narrative section below	Yes No Not known

Factors in relation to service provision Please provide (if necessary) narrative detail relating to the sections above for which you have answered yes. You might consider underlying staff factors, task factors, equipment, and work environment, education and training, and team factors Also please provide any information known to you in relation to service provision that has not been covered elsewhere. Please describe positive as well as negative aspects of service delivery and give detail to examples of excellent care

21 Appendix 4: CDOP Child Death Review Analysis Form

This analysis form should be read in conjunction with the collated reporting form, and the PMRT in babies who die on a neonatal unit, to provide relevant information on the child, the circumstances of their death, and factors identified in any of the relevant domains.

Using this form at the Child Death Review meeting
Information gathered from the different agencies should be made available to the Child Death Review meeting by CDOP. Drawing on the intelligence gathered, those present at the child death review meeting should then appraise all the relevant information in order to form an understanding of the circumstances of the child's death, identify any modifiable factors and lessons to be learnt, and any action that will be taken at a local level. The completed form from the Child Death Review meeting should then be submitted to the CDOP.

Using this form at the Child Death Overview Panel meeting
The completed form from the Child Death Review meeting, along with any additional information gained from other agency sources should be presented in anonymised form to the CDOP. Drawing on the intelligence gathered, those present at the CDOP should appraise the relevant information in order to affirm that the understanding of the circumstances of the child's death is correct, that appropriate modifiable factors and lessons have been identified, and decide upon any actions to be taken across agencies or networks of care

Child Death Review Meeting date: / /

CDOP Meeting date: / /

Individuals/ Departments/ agencies represented* at CDR meeting / CDOP:

* Including reports submitted by professionals and agencies unable to attend meeting in person

Additional agency reports provided for purposes of CDOP review

The review meeting should analyse any relevant factors that may have contributed to the child's death. In doing so you might take into account those issues that have been highlighted in the Reporting Form. For each of the four domains below, list the factor, and determine the level of influence (0-2):

0 - Information not available

1 - No factors identified, or factors identified but are unlikely to have contributed to the death

2 - Factors identified that may have contributed to vulnerability, ill health or death

This information should inform the learning of lessons at a local level.

Domain A: **Factors intrinsic to the child.** Please list factors in the child (and in neonatal deaths, in the pregnancy). Consider factors relating to the child's age, gender and ethnicity; any pre-existing medical conditions, developmental or behavioural issues or disability, and for neonatal deaths, the mother's health and wellbeing.	**Relevance (0-2)**	CDOP affirmation (0-2)

Domain B: **Factors in social environment including family and parenting capacity.** Please list factors in family structure and functioning and any wider family health issues; provision of basic care (safety, emotional warmth; stimulation; guidance and boundaries; stability); engagement with health services (including antenatal care where relevant); employment and income; social integration and support; nursery/preschool or school environment.	**Relevance (0-2)**	CDOP affirmation (0-2)
Please also describe positive aspects of social environment and give detail to examples of excellent care		

Domain C: **Factors in the physical environment**. Please list issues relating to the physical environment the child was in at the time of the event leading to death, and for neonatal deaths, the mother's environment during pregnancy. Include poor quality housing; overcrowding; environmental conditions; home or neighbourhood safety; as well as known hazards contributing to common childhood injuries (e.g. burns, falls, road traffic collisions)	**Relevance (0-2)**	CDOP affirmation (0-2)

Domain D: **Factors in Service Provision**. Please list any issues in relation to service provision or uptake. Include any issues relating to identification of illness, assessment, investigations and diagnosis; treatment or healthcare management; communication or teamwork within or between agencies; and organisational or systemic issues. Consider underlying staff factors, task factors, equipment, and work environment, education and training, and team factors.	**Relevance (0-2)**	CDOP affirmation (0-2)
Please also describe positive aspects of service delivery and give detail to examples of excellent care		

Consider whether the Review has identified one or more factors across any domain which may have contributed to the death of the child and which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future child deaths	CDR Review	CDOP affirmation
Modifiable factors identified – please list these below		
No Modifiable factors identified		
Inadequate information upon which to make a judgement. NB this category should be used very rarely indeed.		

List of modifiable factors identified		

In light of your consideration of the case categorise the likely cause of death using the following schema.

This classification is hierarchical. **All relevant categories should be ticked if more than one category could reasonably be applied**. The uppermost ticked category will be recorded as the primary category and others as secondary categories.

Category	Name & description of category	Tick box below	CDOP affirmation
1	**Deliberately inflicted injury, abuse or neglect** This includes suffocation, shaking injury, knifing, shooting, poisoning & other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death.		
2	**Suicide or deliberate self-inflicted harm** This includes hanging, shooting, self-poisoning with paracetamol, death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children.		
3	**Trauma and other external factors, including medical/surgical complications/error** This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. Also includes proven medical and surgical complications or errors as the primary cause of death. **Excludes** Deliberately inflected injury, abuse or neglect. (category 1).		
4	**Malignancy** Solid tumours, leukaemias & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.		
5	**Acute medical or surgical condition** For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.		
6	**Chronic medical condition** For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. **Includes** cerebral palsy with clear post-perinatal cause.		

7	**Chromosomal, genetic and congenital anomalies** Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease,cystic fibrosis, and other congenital anomalies including cardiac.		
8	**Perinatal/neonatal event** Death ultimately related to perinatal events, e.g. sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, necrotising enterocolitis, post-haemorrhagic hydrocephalus, irrespective of age at death. It **includes** cerebral palsy without evidence of cause, and **includes** congenital or early-onset bacterial infection (onset in the first postnatal week).		
9	**Infection** Any primary infection (i.e. not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc.		
10	**Sudden unexpected, unexplained death** Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. **Excludes** Sudden Unexpected Death in Epilepsy (category 5).		

Cause of death
In light of your review of this case, what is your opinion as to the likely cause/causes of death? Please indicate if this differs in any way from the registered cause of death or that assigned by the pathologist/coroner. Where possible, please express this in terms of the levels provided on the Medical Certificate of Cause of Death (MCCD) /neonatal MCCD.

Learning points and issues identified in the review:
List the learning points identified by the review group. A list of issues may include the absence of certain key persons from the discussion or the lack of key documents.

CDOP affirmation and reflection on learning points pertaining to wider agency, regional, and national bodies.

Actions Identify any local actions, the department or agency responsible, and the timeline to completion. This should include those interventions deemed achievable that determined contributory factor to be modifiable.
CDOP affirmation Identify any CDOP actions and/or recommendations at an agency, LSCB, regional or national level. This should include those interventions deemed achievable that determined contributory factor to be modifiable.

Summary of ongoing support needs and follow-up plans for the family and (where relevant) involved professionals

22 Appendix 5: Joint Agency Response Protocol