Leicester, Leicestershire & Rutland Child Death Overview Panel (CDOP) Annual Report 2024-2025

Child Death Overview Panel

Leicester, Leicestershire & Rutland

Authors

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LLR Child Death Review Service
Sue Stephenson, Child Death Review Nurse
Jo Lane, Child Death Review Nurse
Kerry Wale, Child Death Review Nurse
Melvinna West, Child Death Overview Panel Administrator

A tribute to our colleague and friend, Kerry Wale
Kerry worked as a Child Death Review Nurse (having previously been a Health Visitor) since 2023 and was a key part of our small team, until her sudden death in 2025. She worked closely with families and professionals from many different backgrounds and agencies. She was a passionate advocate for bereaved families, a highly respected colleague, and is remembered with much fondness.

Contents

Glossary of abbreviations used

CAIU	Child Abuse Investigation Unit
CDOP	Child Death Overview Panel
CDIM	Child Death Initial Meeting
CDRM	Child Death Review Meeting
CSPR	Child Safeguarding Practice Review
EMAS	East Midlands Ambulance Service
ICB	Integrated Care Board
IMD	**Index of Multiple Deprivation** Official measure of relative deprivation for small areas (population 1500) in England. IMD 1 refers to an area which is in the 10% most deprived small areas in the country, IMD 10 an area in the 10% least deprived.
JAR	**Joint Agency Response** A coordinated multiagency response to a death occurring in any of the following circumstances: - Death due to external causes - Death occurring in suspicious circumstances. - Death that is sudden (not anticipated in preceding 24 hours) and for which no medical explanation is evident – a sudden unexpected death in infancy/childhood. - Death of a child or young person detained under the mental health act or in custody. - A stillbirth occurring without in the absence of a registered health professional.
LeDeR	Learning Disability Mortality Review
LLR	Leicester, Leicestershire & Rutland
LPT	Leicestershire Partnership NHS Trust
MBRRACE-UK	Mothers & Babies: Reducing Risk through Audit & Confidential Enquiries across the UK
MNSI	Maternity & Neonatal Safety Investigation
NCMD	National Child Mortality Database
NNU	Neonatal Unit
PMRT	Perinatal Mortality Review Tool
SUDI/C	**Sudden Unexplained Death in Infancy/Childhood** Descriptive term, used at presentation - the death of an infant/child which was not reasonably expected to occur 24 hours previously, and in whom no pre-existing medical cause of death is apparent. Following detailed investigation, a cause of death may be found.
SIDS	**Sudden Infant Death Syndrome** An unexpected death of an infant occurring during normal sleep, which remains unexplained after a thorough investigation and review of the circumstances.
UHL	University Hospitals of Leicester NHS Trust

LLR CDOP 2024/2025

1 LLR Genetic Pathway for unexplained child deaths launched

4 Presentations & briefings for Safer Sleeping Risk Assessment

64 Attendees at Joint Agency Response training (↑9)

92 notifications received (↑10)

19 Joint Agency Responses undertaken (↓8)

33 Child Death Initial Meetings held (↓16)

8 Child Death Overview Panels held (↓2)

81 Case reviews completed (↓8)

424 Contributory factors identified (↑11)

119 Modifiable factors identified (↑16)

49 Cases where CDOP raised actions (↑5)

1 National Alert raised to NCMD (↓1)

Top 6 contributory factors that could be modified to reduce future child deaths in our area

Smoking in pregnancy

Unhealthy weight in pregnancy

Household exposure to cigarette smoke

Poor communication between agencies

Guidelines or policies not being followed

Missed signs of deterioration

Introduction

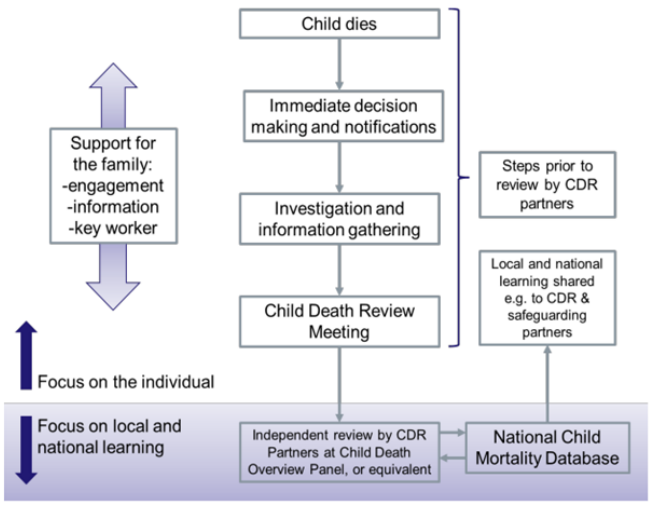
The national process of reviewing child deaths was established in April 2008 and updated in Chapter 6 of Working Together to Safeguard Children 2023. It is the responsibility of the Child Death Review Partners to ensure that a review of every death of a child normally resident in their area is undertaken by a CDOP. Across LLR, the Child Death Review Partners are the three Local Authorities and the LLR Integrated Care Board.

The overall purpose of the LLR CDOP is to undertake a comprehensive and multi-agency review of all child deaths, to better understand how and why children across LLR die, with a view to detecting trends and/or specific areas which would benefit from further consideration[1,2]. The LLR CDOP has been gathering data since 2009 and been producing annual reports which summarise the data collected in each year.

The process for reviewing child deaths commences with Notification to the Child Death Review team and culminates in final scrutiny at the Child Death Overview Panel (please see fig 1). The Child Death Review process integrates with the Perinatal Mortality Review Programme and shares learning by collaborative working with the Learning Disability Mortality Review Programme (LeDeR). All data from LLR Child Death Reviews is submitted to the National Child Mortality Database (NCMD) for the purposes of data analysis and learning at a national level.

Hearing the experiences of families is an important part of the Child Death Review process, particularly in learning about what went well, and what needs to be improved in terms of care and service provision. All families will have contact either via the Perinatal Mortality Review process, their Key Worker or Child Death Review Nurse, to ensure they are offered support, and the opportunity to ask questions about their child's care. Families are also offered the opportunity to have feedback after their child's review meeting. Whether or not families have been asked for feedback is noted in every case, as are any questions or feedback raised, along with the assurance that their questions and any concerns have been sensitively dealt with and addressed.

Figure 1: The Child Death Review process as set out in Working Together to Safeguard Children 2018, Chapter 5[3].



Family Support: Child Death Review Nurse update

- The Child Death Review Nurses continued joint home visits with police under the Joint Agency Response, providing support for families, acting as Child Death Review Key Workers, and representing families' voices at professional meetings.
- Building on their involvement in the Birmingham University study which led to the development of the *NCMD Key Worker Toolkit*, the team have worked on the implementation of the Toolkit across LLR.
- The team developed a local information booklet for families with clear signposting to local support services, complementing the national 'When a child dies' booklet.

Genetics pathway development

- In 2023, the R441 Whole Genome Sequencing (WGS) gene panel became available for unexplained child deaths (those where a medical cause of death could not be found following post-mortem examination).
- Working with HM Coroner, the local Clinical Genetics service, and Paediatric staff from UHL, a local pathway has been developed for integrating WGS into the Joint Agency Response.
- As one of the first areas in England to have a pathway in place, the LLR pathway has been shared nationally at the Association of Child Death Review Professionals National Conference 2024. Learning from the pathway development was also included in the 'SIDS Masterclass' at the Royal College of Paediatrics & Child Health Annual Conference 2025.
- We are immensely grateful for feedback from families which has enabled us to further improve and develop the pathway, ensuring rapid access to testing, and better communication and coordination of care.

Training delivery

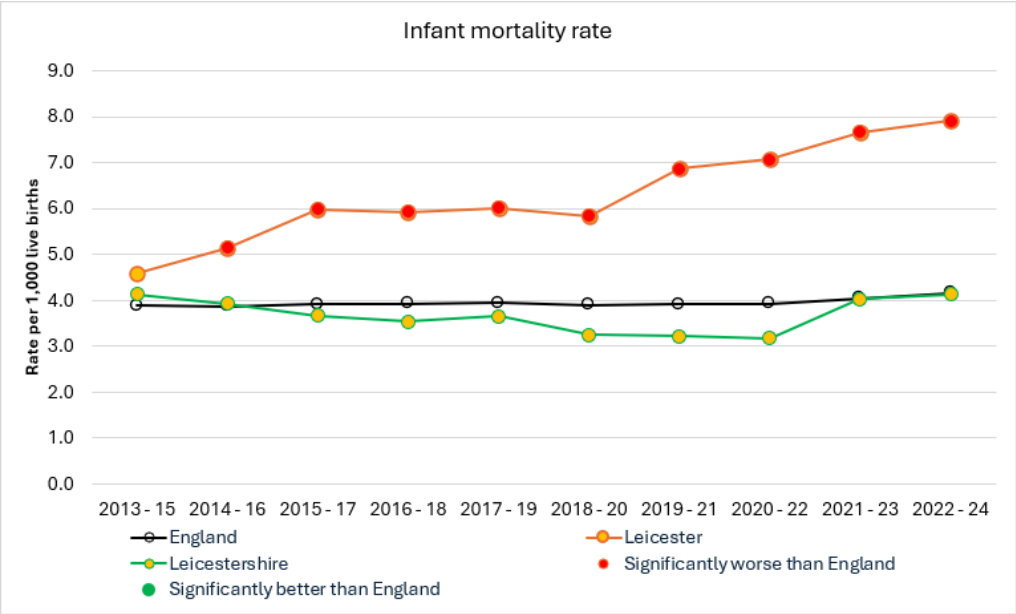
- The LLR Child Death Review service deliver local Joint Agency Response training for health professionals and police.
- In 2024/25 both face-to-face and online training were offered for the first time since the pandemic; 64 professionals attended, 100% of feedback respondents said they would recommend the course to colleagues.
- Annual training will now continue in both formats.

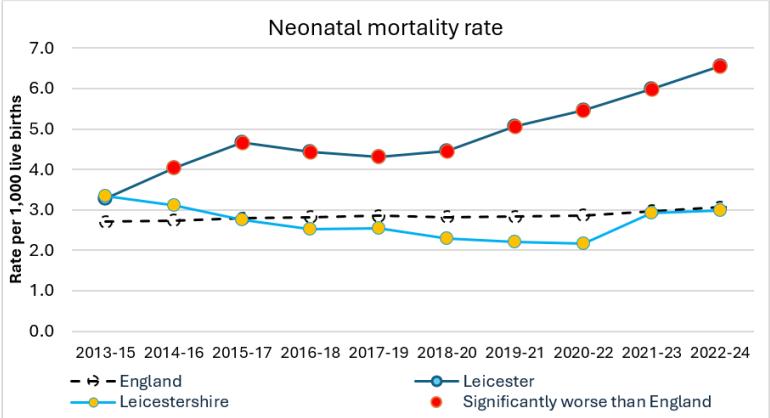
Gathering information for reviews

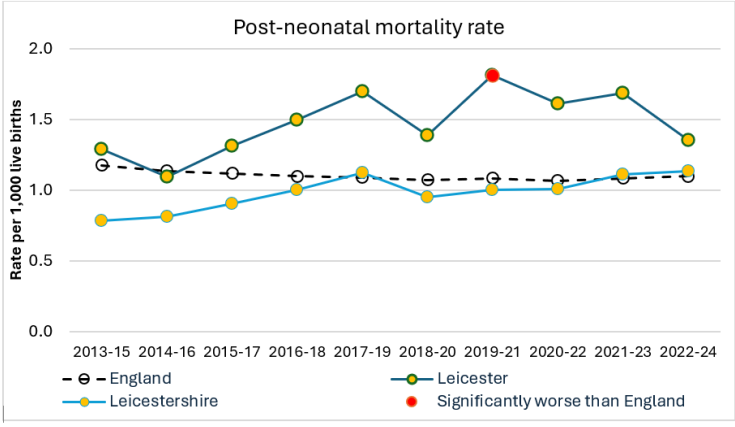
- Each child death review requires comprehensive data collection via statutory Reporting Forms, completed by front-line professionals, covering information about the child, family, social and physical environments, and the services provided. Additional reports and any governance reviews are also collated. During 2024/25 updates to information gathered included:
    - GPs completing Reporting Forms for all neonatal cases.
    - Collecting information from smoking cessation services on engagement after referral.
- LLR CDOP (together with maternity & neonatal staff at UHL) participated in Phase 1 of the integrated MBRRACE-NCMD system roll-out to streamline neonatal notification and reviews.

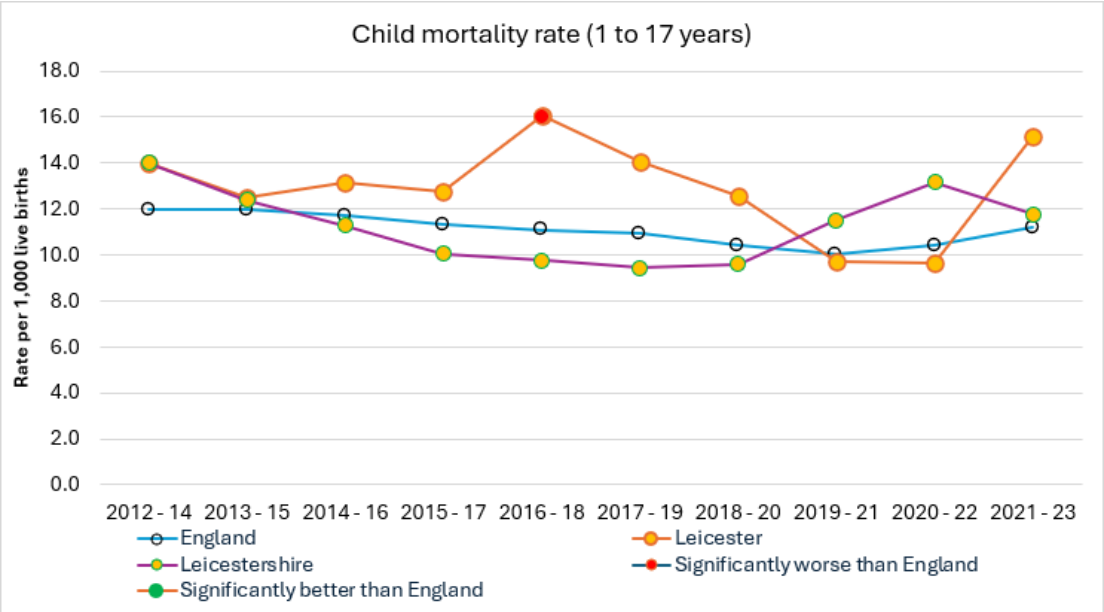
Notification & Child Death Initial Meeting Audit

- A three-month audit of cases notified to LLR CDOP assessed compliance with Child Death Review Statutory & Operational Guidance.
- Whilst some aspects of the Joint Agency Response require refinement, it is well-recognised that there are limitations to the current Kennedy Guidance, with a need for a more situation-specific guidance, which remains proportionate to the individual case context. An update to the 2016 Kennedy Guidance remains awaited.
- Areas of good practice included universal Key Worker allocation, timely notifications, and good multiagency representation at Child Death Initial Meetings, including primary care and community services.
- Actions have been taken to improve post-mortem sampling in the Emergency Department, enhance support and information for Initial Meeting attendees, and clarify how family feedback is shared with other agencies.









Data: https://fingertips.phe.org/profile/child-health-profiles

LLR CDOP Notifications 2024/25

Key information: Notifications

LLR CDOP received 92 notifications of deaths of LLR residents under the age of 18 years (an increase from 2023/24).

27 (29%) of cases met the criteria for a Joint Agency Response. 'Neonatal' response cases (babies who die after birth but before discharge from hospital) continue to make up the largest proportion of notifications received (55% of the total; 37% of whom were babies born under 23 weeks gestation). CDOP has only reviewed deaths of babies under 23 weeks since 2020, however these children have always been included in ONS data (p8). This cohort of babies contribute to the increasing trend seen in the infant mortality & neonatal mortality rates.

Local Authority:
Leicester City: 48 cases (52%)
Leicestershire & Rutland: 44 cases (48%)

Place of death:
77% of children died in hospital.
- 56% in Neonatal Unit/Delivery Suite
- 9% in Paediatric Intensive Care

20% of children died at home.
1% of children died in a hospice setting.
1% of children died abroad.

Chart 1. Death notifications by LA of residence 2017/18 to 2024/25

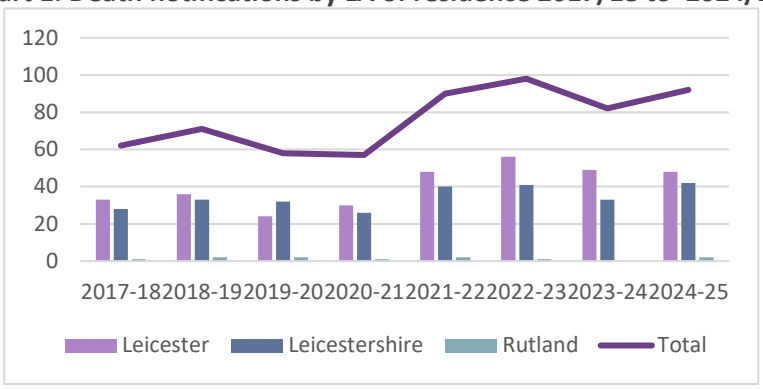


Chart 2. 5-year mean notifications by age group 2017/18 – 2024/25

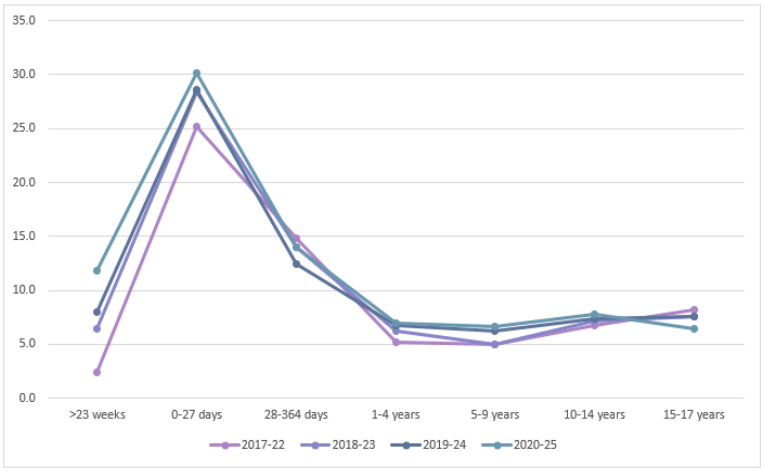


Chart 3. Notifications by category of response 2017/18 to 2024/25

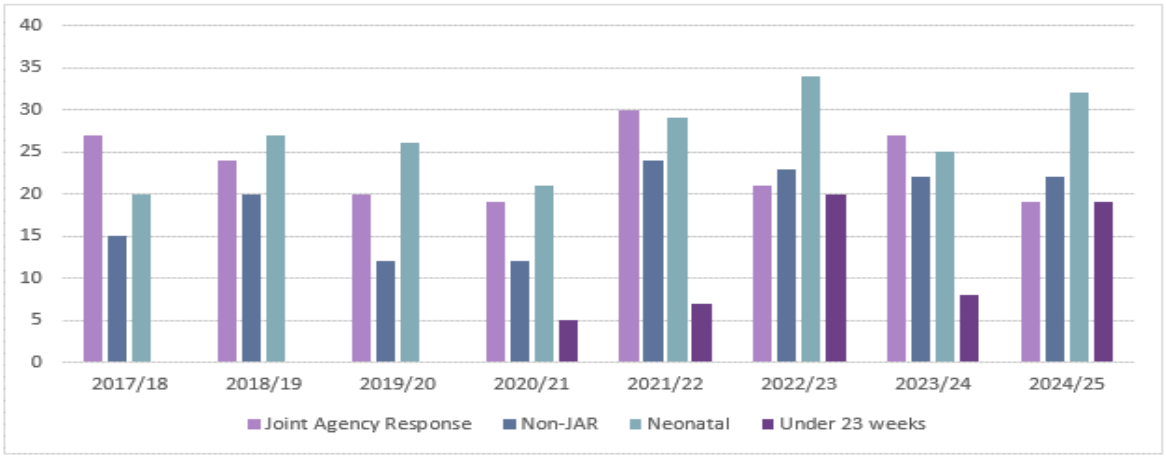


Table 1. Notifications by age & ethnicity 2024/25

Ethnic Group	0-27 days	28-346 days	1-4 years	5-9 years	10-14 years	15-17 years	Total
White	21	5	2	4	7	1	**40**
Other	2	1	0	0	0	0	**3**
Mixed	5	1	1	0	1	0	**8**
Black or Black British	2	1	0	0	1	0	**4**
Asian or Asian British	22	6	3	4	0	2	**37**
Total	52	14	6	8	9	3	**92**

Table 2. Completed reviews by year 2020/21 – 2024/25

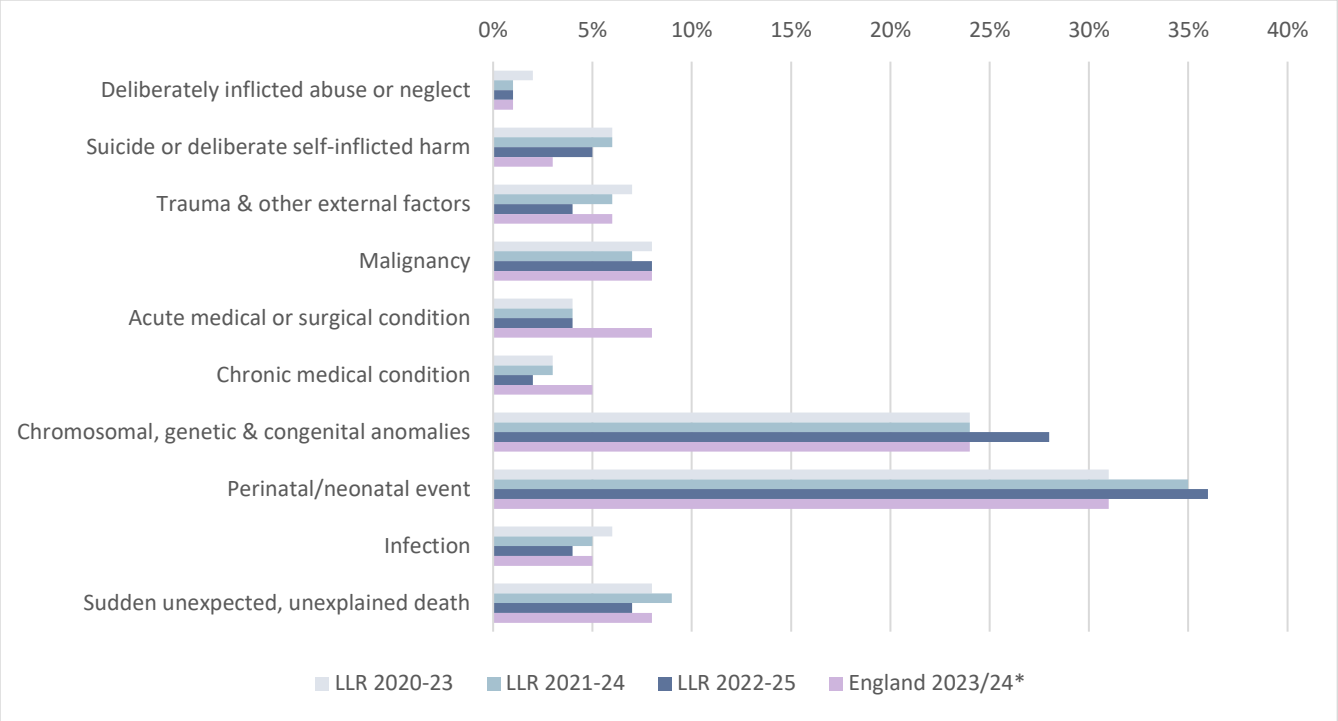
	2020/21	2021/22	2022/23	2023/24	2024/25
Leicester City	32	35	45	53	46
Leicestershire & Rutland	32	36	41	36	35
Total LLR	**64**	**71**	**86**	**89**	**81**

Table 3. Completed reviews by year of death 2024/25

Year of death	Cases
2017-18	1
2021-22	4
2021-22	24
2022-23	47
2023-24	5
Total	**81**

Chart 4. Category of death for completed reviews – 3 year merged data 2020 – 2025

*Data from NCMD Data Release Child Death Reviews Data: year ending 31 March 2024, published November 2024



Key information: Completed reviews

- Cases are only brought to panel once all other investigations (including Inquests, Police investigations, Serious Incident Investigations and Child Safeguarding Practice Reviews) are concluded and reports available to CDOP, hence there is a time lag between the year of death and completion of the review.
- In 2024/25 LLR CDOP held 8 panels and completed reviews for 81 cases.
- CDOPs are asked to categorise each case by cause of death (see Appendix A). In 2024/25 in LLR, the percentage of deaths due to congenital anomalies equalled perinatal/neonatal events as the most frequently recorded category of death.
    - Deaths due to a perinatal or neonatal event (33% in LLR vs 35% in England*).
        - Includes complications of prematurity/immaturity, perinatal asphyxia and perinatal infection.
    - Deaths due to a chromosomal, genetic, or congenital anomaly (33% in LLR vs 24% in England*).
    - Sudden unexpected, unexplained deaths (6% in LLR vs 4% in England*).
        - Deaths occurring at any age, which, following a thorough investigation and post-mortem, no clear medical cause has been identified.
    - Deaths due to malignancy (6% in LLR vs 9% in England*).
    - Deaths due to infection (5% in LLR vs 4% in England*).
    - Deaths due to acute medical or surgical condition (5% in LLR vs 6% in England*).

Local learning: Contributory Factors

Contributory factors: definition

A factor is deemed to be 'contributory' if it was known to be present and may have contributed to the vulnerability or death of the child. Had that factor been absent, it would have created the prospect of a different outcome.

Contributory factors are classified by Domain, then by Group, and finally by Sub-group to provide both a thematic overview, and a more in-depth, nuanced analysis of those features known to be present which may have shaped the outcome in each case. For a full list of Contributory Factor Domains, Groups & Subgroups, please see Appendix B.

Table 4. Domain A: Factors intrinsic to the child 2024/25

Noted in 80 cases (99%).

Factor by group	No of cases	% of cases
Child health history/medical condition	77	95
Risk factor in mother during pregnancy	32	40
Child's developmental condition/disability	11	14
Emotional/behavioural factors	3	4
Other	2	2
Smoking/alcohol/substance use/misuse by child	2	2

Table 5. Domain B: Factors in the family/social environment 2024/25

Noted in 31 cases (39%).

Factor by group	No of cases	% of cases
Parent/carer's health	12	15
Cultural factors	10	12
Smoking/alcohol/substance misuse/use by parent/carer	10	12
Challenges for parents with access to services	9	11
Household functioning, parenting/supervision	8	10
Domestic or child abuse/neglect	7	9
Social Care	3	4
Poverty & deprivation	2	2
Other	1	1
School/peer groups	1	1

Table 6. Domain C: Factors in the physical environment 2024/25

Noted in 5 cases (6%).

Factor by group	No of cases	% of cases
Sleep environment	4	5
Home safety/conditions	1	1
Public Safety	1	1
Vehicle collision	0	0

Table 7. Domain D: Factors in service provision 2023/24

Noted in 24 cases (30%).

Factor by group	No of cases	% of cases
Following guidelines/pathway/policy	13	16
Initiation of treatment/identification of illness	8	10
Communication within or between agencies	6	7
Access to appropriate services	5	6
Communication with family	5	6
Staffing/bed capacity/equipment	5	6
Other	1	1

Key information: Contributory Factors

- Domains, Groups and Subgroup categories are determined nationally by the National Child Mortality Database, to enable standardised case analysis across England.
- In 99 % of cases, factors intrinsic to the child were identified as contributing to vulnerability or death.
  - Sole domain in which factors were identified for deaths due to malignancy and infection.
- In 39% of cases, factors in the family or social environment contributed to vulnerability or death.
  - Noted in 100% of deaths due to deliberately inflicted injury, abuse or neglect and suicide/self - inflicted harm, 50% of deaths due to trauma, chronic or acute medical conditions, 41% of deaths due to genetic or congenital anomalies, 40% of sudden unexpected unexplained deaths & 37% of deaths due to perinatal or neonatal events.
- In 6% of cases, factors in the physical environment contributed to vulnerability or death.
  - Noted in 80% of sudden unexpected unexplained deaths, and 4% of deaths due to perinatal or neonatal events.
- In 30% of cases, factors in service provision contributed to vulnerability or death.
  - Noted in 100% of deaths due to suicide/self-inflicted harm, that were sudden unexpected unexplained, 41% of deaths due to neonatal or perinatal events & 22% of deaths due to congenital or genetic anomalies.

Local learning: Modifiable Factors

Modifiable factors: definition

A factor is deemed to be 'modifiable' if it may have contributed to the vulnerability or death of a child (i.e., has been identified as a Contributory Factor), and through means of a locally or nationally achievable intervention, could be modified to reduce the risk of future deaths.

Table 8. Number of cases where modifiable factors identified by category of death 2024/25

	Completed reviews	Modifiable factors identified	% of cases where MF identified
Deliberately inflicted injury, abuse, or neglect	2	1	50
Suicide or deliberate self-inflicted harm	3	3	100
Trauma and other external factors	2	1	50
Malignancy	5	0	0
Acute medical or surgical condition	4	2	50
Chronic medical condition	2	1	50
Chromosomal, genetic, or congenital anomaly	27	10	37
Perinatal/neonatal event	27	14	52
Infection	4	1	25
Sudden unexpected, unexplained death	5	4	80
Overall	**81**		**46**

Key information: Modifiable factors

- Modifiable factors were identified in 46% of LLR cases (n=37) compared to 43% across England[4].
- Across the 37 cases where modifiable factors were identified, 119 individual factors were recorded (1-11 per case).
    - 49% of these cases were in children who died in the first 28 days of life.
- Modifiable factors were found in 60% of cases for those living in the most deprived areas (IMD 1&2) compared to 25% for those in the least deprived areas (IMD 9&10).
- The top six modifiable factors identified in 2024/25 (by sub-group) were:
    - Smoking in pregnancy.
        - Leads to adverse pregnancy outcomes including placental abruption, prematurity and low birth weight.
        - Exposure to nicotine during pregnancy increases SIDS risk, through affecting development of the parts of the nervous system which enable the body to respond to changes in oxygen and carbon dioxide levels[5].
    - High maternal Body Mass Index.
        - Healthy pre-pregnancy weight reduces the risk of pregnancy complications including gestational diabetes & pre-eclampsia, and the risk of congenital malformations[6].
    - Household smoking/e-cigarette use by parent/carer.
    - Poor communication/information-sharing between agencies.
    - Guidelines/policy/pathways not being followed.
    - Failure to recognise signs of deterioration in a child.
- Sleep environment was the 7th most frequently recorded modifiable factor in 2024/25, having been 4th in 22/23 and 5th in 23/24.

Table 9: Most frequently recorded modifiable factors by Domain Group 2024/25

Most frequently recorded modifiable factors by domain Group:	No of cases 23/24	No of cases 24/25
Risk factors in mother during pregnancy/ delivery	14	14
Following guidelines/pathway/policy	7	13
Smoking/alcohol/substance misuse/use by a parent/carer	8	9
Initiation of treatment/identification of illness	5	7
Communication within/between agencies	3	6
Staffing/bed capacity/equipment	4	5

Local learning: Service provision factors

Key information: Modifiable factors in Service Provision

25% of completed case reviews in 2024/25 were found to have modifiable factors in Service Provision. In 80% of these cases, learning and actions had already been identified via internal or external governance reviews, Prevention of Future Death Report, Child Safeguarding Practice Review or Rapid Reviews. In 20% of cases learning was identified for the first time in the Child Death Review Meeting (15%) or at Panel (5%).

In England in the 21st century, the death of any child is a high-harm, but low-frequency event. Safety systems exist within all agencies to identify and stratify risk, with the aim of reducing chances of harm, but cannot prevent every adverse event.

Models such as SIEPS, FRAM and Accimap are used in healthcare to analyse incidents (system failures), mapping the interplay of technical and human factors. Child Death Review identifies factors which may have contributed to a child's vulnerability, ill-health or death, incorporating learning from incident analysis and the family perspective. This leads to a broader consideration of factors at play, including around interagency working, where different organisational systems may intersect.

Nathan et al[7] describe a model for risk assessment to reduce such high-harm, low-frequency events, which describes the recognition and response to risk as fundamentally embedded in interpersonal interaction. This in turn takes place in the context of wider organisational and system pressures and processes. Mapping out modifiable factors in service provision using this model, reveals some common, cross-cutting themes which are relevant to all agencies, contexts and categories of death.

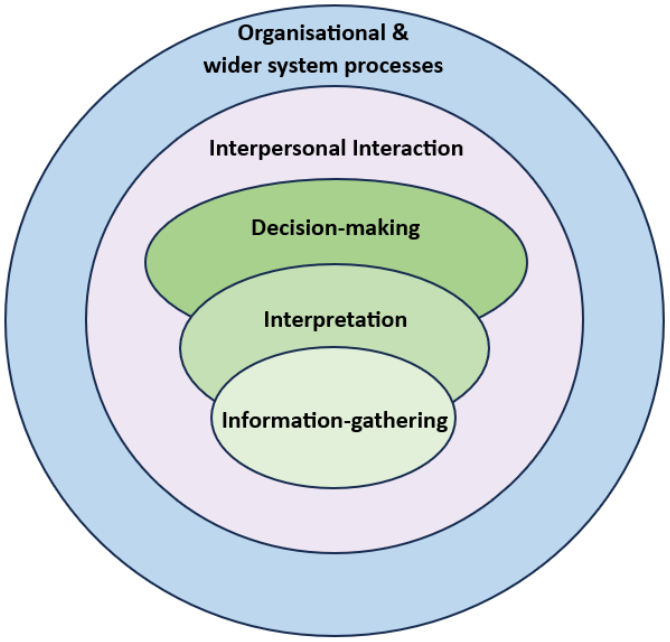


Fig 2. Risk assessment framework for reducing high-harm low-frequency events, adapted from Nathan et al[7] .

1. **Recognising risks: Information-gathering, interpretation & decision-making**
   - **A. Subject-matter expertise**
     - Knowledge & experience, supported by risk identification tools, are necessary to accurately identify and interpret risk factors in context.
     - Practitioners need easy access to senior or expert support, advice and review, and the ability to escalate concerns quickly. This includes access to senior oversight and support for less experienced staff to deliver high-quality care.
     - Practitioners need to be able to easily escalate when demand (acuity) threatens to exceed capacity for safe care.

- **Issues with initiation of treatment or identification of illness** were seen in 7 cases, including:
  - In diagnosis (2 cases)
  - With availability of information (1 case)
  - With treatment, including delays (1 case)
  - Lack of recognition of a deteriorating child (6 cases)
    - Recognising & interpreting abnormal clinical observations and investigations (4 cases)
    - Recognising vulnerability and risk in young people with neurodiversity, emotional distress & high-risk behaviours (1 case)
- **Equipment related issues** were noted in 2 cases.
- **Issues impacting on the quality of referral, assessment or review** were seen in 5 cases, including:
  - Referrals for smoking cessation
  - Assessment of risk for neonatal sepsis
  - Assessment of risk for preterm labour
  - Inclusion of fathers in multiagency assessment

B. Clear evidence-based guidance, policies and pathways are essential to support information-gathering, interpretation & decision-making.

Issues with guidelines, pathway or policy were seen in 9 cases, including:

- Pathways/guidance available but not followed (6 cases)
  - Out-of-hospital resuscitation of newborns
  - Antenatal referrals for smoking cessation or toxicology screening
  - Mental health support pathways
- Pathways/guidance unclear or unavailable (4 cases)
  - Recognition of risk in children with a Learning Disability
  - Guidance about stepping down observations.
  - Unclear referral pathways.

C. Information-sharing to build, revisit & revise emerging pictures of risk.

- Practitioners need time, resources, and access to information, so that they can communicate, share, and build an up-to-date picture of cumulative and emerging risks.
- Timely sharing of the right information with the right agency is essential.
- Clear, consistent language, free of intra-agency jargon, supports situational awareness between agencies, and enables safe decision-making.

Issues in communication within or between agencies were seen in 6 cases:

- Between clinical teams:
  - Obstetric & neonatal teams
  - Referring location & critical care transport teams
  - Handover between day & night shifts
  - Referring team and investigation team
- Between hospital and Social Care
  - Complex discharge-planning following prolonged hospitalisation.
- Between school, family, and primary care
  - Mental health and emotional wellbeing concerns.
- Between NHS & private care providers delivering mental health services.
- Between health and Social Care services supporting families after the birth of a new baby.

2. The role of interpersonal interactions

Risk assessment relies on experience, clear pathways, and inter-agency communication. However, all risk assessment (information-gathering, interpretation & decision-making) occurs in, and is shaped by, interactions between a practitioner and the child or family. Children, young people & their families are critical partners in this process, and the quality of this interaction is critical in recognising & responding to risk.

Communication with families was noted as modifiable in 4 cases.

- Interpreters need to be available & appropriate – different dialects within a language can add an additional barrier and lead to misunderstanding.
- An empathetic, collaborative approach fosters shared understanding and better outcomes. When parents raise concerns about their child, or about their care, it is safety-critical that these concerns are heard and addressed.

3. **Organisational and wider system processes.**

Risk assessment and interpersonal interaction occur within broader organisational and system processes and pressures. To mitigate identified risks, resources must be available to children, families & practitioners. From our case reviews, this would include:

- Provision of Mental Health Support Teams in all schools.
- Organisational level processes for Care Planning & risk assessment.
- Organisational level support for practitioners to develop their expertise (skills, knowledge and experience).
- Clear and frictionless pathways for referrals into services.

Issues with staffing capacity or inappropriate skill mix impacting on situational awareness and quality of assessment – were seen in 3 cases.

Issues with access to appropriate services were seen in 2 cases.

4. **Addressing inequalities**

It is now well-established that child mortality rates are directly proportional to deprivation for all categories of death apart from malignancy. Those from black and minority ethnic backgrounds are also known to have poorer outcomes, separate to the contribution of deprivation, as are those with a Learning Disability. In line with NCMD Thematic Report recommendations, from individual practitioners through to system-level working, all agencies need to consider how diversity & difference may alter how risk factors appear, intersect and impact on children, young people, and families, including:

- Those with English as an additional language.
- Those with neurodiversity or sensory impairment.
- Those with a Learning Disability.
- Those from Black & Minority Ethnic Groups.
- Those who have previously experienced trauma and loss.
- Those experiencing economic deprivation.

Table 10: Panel Actions undertaken in cases where modifiable factors in service provision identified.

Action undertaken	Number of cases
Seek assurance that previously identified actions completed	12
Escalation of response/actions:	4
To HM Coroner	1
To provider trust	1
To commissioners (ICB)	1
To National Child Mortality Database	1
Sharing of information/learning	3
Clarification of information provided	5
All previously identified actions completed, no additional Panel actions required	2

Figure 3. Word cloud created using Analysis Form free-text data recording family questions or concerns about care and responses provided.

Key information – learning from what went well.

Notably good or excellent aspects of service delivery were recorded in 49 cases (60% of cases, compared with 22% for 2023/24). Using locally derived themes, good or excellent aspects of care were seen in:

- Advanced care planning (9 cases, 8 of which related to antenatal advanced care planning)
- Communication & teamwork between agencies (9 cases)
    - Including across hospital specialties, different hospitals, primary care, hospice, community healthcare teams and children's social care.
- End of life care planning & delivery (8 cases)
- Bereavement midwifery care (5 cases)
- Aspects of clinical care, including clinical investigations (5 cases)
- Antenatal & perinatal care delivery (3 cases)
- Communication & information-sharing within an agency (3 cases)
- Use of the GP Learning Disability Register & Annual LD Health Check (2 cases)
- Communication with family (1 case)
- Organ donation (1 case)
- Pastoral support provided by school (1 case)
- Delivery of safer sleeping advice (1 case)

Figure 4. Word cloud created using Analysis form free-text data recording positive aspects of service delivery and examples of excellent care for all cases with completed reviews 2024/25.

Table 11: Cases where excellence in service provision identified, by category of death for completed reviews 2024/25

Category of death	Cases where positive aspects identified
Chromosomal, genetic, or congenital anomaly	21
Perinatal or neonatal event	16
Malignancy	2
Chronic medical condition	2
Infection	0
Suicide or deliberate self-inflicted harm	1
Sudden unexpected unexplained death	2
Trauma or other external factors	2
Acute medical or surgical condition	2
Deliberately inflicted injury, abuse, or neglect	1
Total	**49**

Theme: Infant Mortality

Key information: Infant deaths in LLR

Definition - Infant: liveborn child (of any gestation), up to 364 days of age.

- Notifications received: 66 cases (72% of all case notifications) – marked increase from 55% in 2023-24.
- Births at previable gestation: 18 cases (27% of all infant case notifications).
- Reviews completed: 55 cases (68% of all completed reviews).
- Modifiable factors identified in 25 cases (45% of infant deaths reviewed).
- Most common modifiable factors by Domain Group (as percentage of infant cases reviewed):
  - Risk factors in mother during pregnancy/delivery (including smoking in pregnancy): 14 cases (25%)
  - Not following guidelines, pathways or policies: 9 cases (16%)
  - Smoking/vaping/alcohol/substance misuse/use by parent/carer: 4 cases (7%)
  - Sleep environment: 4 cases (7%)
  - Issues with staffing/bed capacity/equipment: 4 cases (7%)
  - Issues with initiation of treatment or identification of illness: 4 cases (7%)

Table 12. Age at death for notifications of deaths occurring under 1 year of age 2024/25

	No of cases			
Age at death	**21/22**	**22/23**	**23/24**	**24/25**
Born under 23 weeks gestation & died <1 day	7	20	8	18
0-27 days	34	34	26	34
28-364 days	19	17	11	14
Total	**60**	**71**	**45**	**66**

Chart 5. Percentage of infant deaths reviewed by Index of Multiple Deprivation 2022/23 – 2024/25

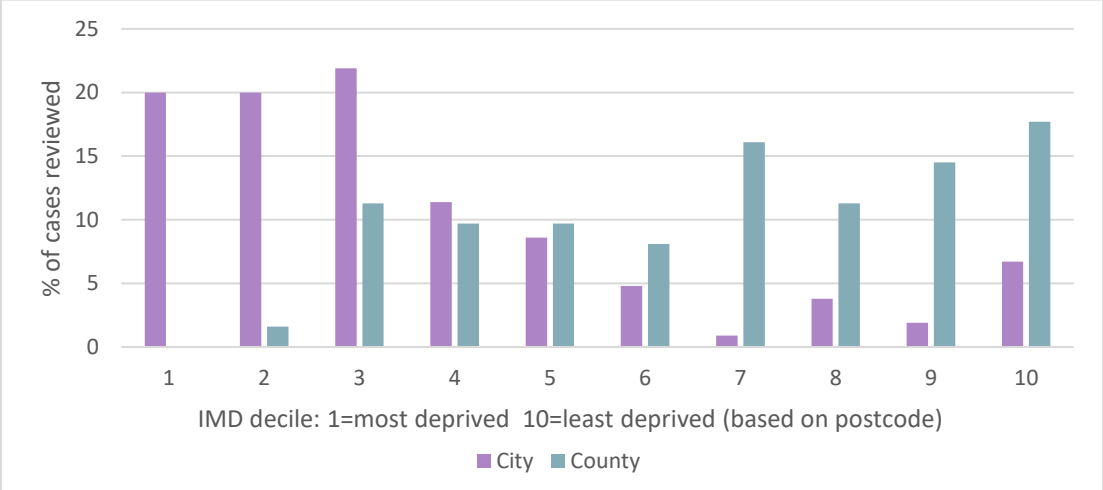


Table 13. Categories of death for children under 1 year – completed reviews 2024/25

	% of cases under 1 yr of age			% of cases under 1 yr of age where modifiable factors identified by category		
Category of death	**22/23**	**23/24**	**24/25**	**22/23**	**23/24**	**24/25**
Perinatal/neonatal event	52%	64%	49%	54%	35%	52%
Chromosomal, genetic or congenital anomaly	28%	18%	38%	14%	0	29%
Sudden unexpected, unexplained death	10%	11%	7%	100%	71%	100%
Infection	2%	2%	2%	100%	100%	0
Malignancy	4%	2%	2%	50%	0	0
Deliberately inflicted injury, abuse or neglect	0	0	2%	0	0	100%
Trauma or other external factors	2%	2%	0	100%	100%	0
Acute medical condition	2%	2%	0	0	0	0
Chronic medical condition	0	2%	0	0	0	0

Theme: Sudden unexplained infant deaths

Key information: Sudden unexpected unexplained deaths of infants

In the period between 1st April 2018 and 31st March 2024, CDOP reviewed the deaths of 26 children who died under 1 year of age, and whose deaths were categorised by the panel as Sudden Unexpected Unexplained Deaths.

This categorisation is based on the medical cause of death at post-mortem and review of the circumstances of death & will include all deaths attributed to Sudden Infant Death Syndrome (SIDS) or with an 'unascertained' medical cause (where it was not possible to determine the most likely medical cause of death), but not those as a result of external causes such as overlay or mechanical airways obstruction.

- 62% of infants who died suddenly & unexpectedly over the past 5 years were bottle-fed.
    - Breast-feeding is known to reduce the risk of SIDS, and this is likely to be through a variety of physiological mechanisms which may be protective for babies. It is important that safer sleeping messages are accessible to all caregivers, regardless of feeding methods.
- Half of babies were not first-born infants, highlighting the importance of reiterating safer sleeping advice to families with each baby that is born.
- 35% of babies were born premature.
    - The proportion of babies born preterm and dying suddenly & without explanation has fallen from around two thirds in 2015-16 to 2020/21, however this group is still over-represented. There is an association between maternal smoking and prematurity, and both these factors increase the risk of SIDS.
- Unsafe sleeping practices were identified in 56% of cases – this has remained relatively unchanged over time.
- Parental smoking was noted in around three quarters of cases.
- Over two thirds of cases had multiple modifiable factors, highlighting both the many vulnerabilities that are often present, and the need to consider safer sleeping alongside support for wider contextual issues in reducing risk.

Table 14. LLR Sudden Unexpected Unexplained Deaths in Infancy –5-year pooled data 2016/17 to 2024/25

	2016/17 to 2021/22 (n=15)		2017/18 to 2022/23 (n=20)		2018/19 to 2023/24 (n=24)		2019/20 to 2024/25 (n=26)	
	N	%	N	%	N	%	N	%
Bottle fed	11	73%	15	75%	16	67%	16	62%
First born	6	40%	8	40%	12	50%	13	50%
Preterm	9	60%	10	50%	9	38%	9	35%
IMD 1&2	6	40%	7	35%	7	29%	7	27%
Birthweight <2.5kg	9	60%	10	50%	9	38%	10	38%
Mean maternal age	28.73 yrs (20-36 yrs)		27.4 yrs (20-36 yrs)		25.7 yrs (17-36 yrs)		27.1yrs (17-36yrs)	
Known to Social Care	8	53%	10	50%	10	42%	10	38%
Housing issues	6	40%	7	35%	9	38%	8	31%
Domestic Abuse	7	47%	8	40%	7	29%	6	23%
Parental drugs/alcohol	5	33%	7	35%	7	29%	7	27%
Medical cause of death:								
'Unascertained'	11	73%	16	80%	20	83%	21	81%
'SIDS'	4	27%	4	20%	4	17%	4	15%
Other (inc 'SUDI')	0	0	0	0	0	0	2	8%
Modifiable Factors								
Unsafe sleeping	9	60%	12	60%	15	63%	17	56%
Parental smoking	9	60%	14	70%	18	75%	19	73%
One or more MF	13	87%	18	90%	20	83%	22	85%
More than one MF	11	73%	15	75%	17	71%	17	65%

Theme: Deaths of children with a Learning Disability

Definition:
Individuals with a learning disability are those who have:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- A significantly reduced ability to cope independently (impaired adaptive or social functioning), and
- Which is apparent before adulthood is reached and has a lasting effect on development.

Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) Policy 2021[8]

LLR CDOP LeDeR Themed Review

Deaths of all people with learning disabilities aged 18 years and over are reviewed via the LeDeR Programme, to identify learning and reduce the increased mortality and morbidity seen for this population. Since the cessation of child reviews by LeDeR in 2023, in LLR close collaboration continues between LeDeR and Child Death Reviews, via an annual thematic review. During 2024-25, 6 case reviews were completed for children with a Learning Disability who had died. The review group (including representation from Public Health, Childrens Social Care, UHL, LPT, ICB and the LeDeR Programme) looked at these cases collectively, identifying themes, learning, and actions.

Update on actions from 2023/24 Review:

1. **For the use of hospital passports to be fully embedded across LLR for children, young people & adults with a Learning Disability.**
   Hospital Passports are being promoted within UHL Childrens Hospital; it is recognised that a broader 'Care Passport' single document recognised by all care providers would be beneficial.
2. **For LLR CDOP to meet with the ICB Pharmacy team to share learning & review mechanisms for supporting families to access timely prescriptions.**
   A meeting took place with the ICB Head of Pharmacy, who shared processes already in place to support vulnerable patients with accessing prescriptions, with plan to share the learning further via Medication Safety Leads training, and review of the LLR Prescribing Guidance.
3. **For LLR CDOP to share with LLR LeDeR the resources & advice about how to gather mortality review information for deaths which occur overseas.**
   Resources developed through the Association of Child Death Review Professionals were shared to the LLR LeDeR team.
4. **For ongoing work to ensure all children & young people with a Learning Disability are on the GP Practice Learning Disability Register and offered annual health checks from 14 years.**
   Quality Improvement work, led by the Learning Disability Primary Care Liaison Nurse team, is ongoing, and numbers of children and young people on the GP LD Registers is rising. To address barriers around diagnosis, Paediatricians can now use the 'On the Learning Disability Register' read code within SystmOne electronic records.

Case characteristics of the 6 cases with reviews completed in 2024/25

- The most common category for cause of death was Chromosomal, genetic, or congenital anomalies (67%). Other categories included chronic medical condition and trauma/other external factors.
- Modifiable factors were identified in 5 cases.
- Positive aspects of service delivery were noted in 5 cases (see Fig 4).
- Median age at death was 12 years (9-17 years)
- 83% were on the GP Practice Learning Disability Register (compared to 80% in 2023/24 and none of the 10 cases in 2022/23).

Fig 5. Word cloud: What did good care look like?

Table 15. Key learning themes identified during the 2024/25 LD Thematic Review

	Children & young people with a Learning Disability and their families often describe challenges with navigating and accessing health and care systems, often having to repeat their stories. Care Passports can provide a single summary of a child's health and care needs, and reasonable adjustments to enable them to access the care and support they require.
	When Children & young people with a Learning Disability are included on the GP Practice Learning Disability Register, this enables reasonable adjustments to be provided, and delivers enhanced support for their long-term health & wellbeing, and for their family.
	Children & young people with a Learning Disability are vulnerable to the impact of second-hand cigarette smoke inhalation, which can exacerbate existing health issues.
	Aspiration pneumonia is a significant cause of ill-health and death for children, young people & adults with a Learning Disability; identification of those at risk and appropriate management can reduce the impact of aspiration pneumonia on long-term health & outcomes.
	For those with a life-limiting condition, children, young people & their families benefit significantly from timely and clear advanced care planning, including being offered choice around their preferred place of death, and information about practical considerations, before and after bereavement.
	Having an allocated lead medical consultant enables delivery of high-quality coordinated care across different teams and agencies, even in highly medically and socially complex cases. In line with national guidance & the recommendations of the Francis Report, every child and young person with complex healthcare needs should have an allocated lead medical consultant.

Recommendations & actions for 2025/26

7. For collaboration between UHL, LPT & the ICB LDA Collaborative to develop an LLR-wide Care Passport for children & young people with a Learning Disability.

8. For continuation of the ongoing work across LLR, led by the Learning Disability Primary Care Liaison Nurse team, to identify children & young people with a Learning Disability, to ensure they are included on the GP Practice Learning Disability Register, and for all agencies to promote participation in the Annual Learning Disability Health Check for young people (aged 14yrs onwards) and their families, as a key part of transition to adulthood.

9. For Public Health in Leicester City & Leicestershire to explore expanding smoking cessation in-reach services to parents and carers of children and young people with a Learning Disability.

10. For the LDA Collaborative to evaluate whether the Aspiration Pneumonia tool used for adults with a Learning Disability would be clinically appropriate for use in the paediatric population across LLR.

11. For paediatric services across UHL and LPT to continue to ensure that all children and young people with a life-limiting condition are considered for a Children & Young People's Advanced Care Plan (CYPACP), that discussions around advanced care planning with families are informed, timely, sensitive and clear, and that (wherever possible) the wishes of children, young people & their families are accommodated in end-of-life care planning.

12. In line with the recommendations of the NCMD Report Learning from deaths: Children with a learning disability and autistic children aged 4-17yrs (based on the Francis Report findings & Paediatric Critical Care Society 2021 Standards), paediatric services across LPT & UHL to ensure that every child & young person with a Learning Disability & medical complexity has an allocated lead medical consultant.

Key information: National Child Mortality Database

In line with statutory guidance, all data collected by every CDOP across England is submitted to the National Child Mortality Database (NCMD). This is the only such database in the world, collecting a unique standardised dataset about every child who dies (including the facts of the case & case analysis), regardless of the circumstances of their death. As such, it is a very powerful tool to identify themes and trends which may be contributing to child mortality in England.

The NCMD are commissioned by NHS England to publish two thematic reports each year, looking at specific themes and making recommendations for action to national & local bodies (both commissioners and providers) to improve quality of care, address safety issues, share learning and reduce child mortality.

All NCMD Thematic Reports are published and available online: www.ncmd.info/publications/

NCMD Report: Learning from Deaths: Children with a learning disability & autistic children aged 4-17 years [9]

Key points:

- 818 deaths occurring between April 2019 – March 2022, with completed reviews by November 2023.
- 669 deaths of a child with a learning disability, 77 deaths of autistic children, 87 deaths of autistic children with a learning disability.
- Children with a learning disability made up 31% of total number of deaths of children aged 4-17yrs.
- Autistic children made up 3% of the total number of deaths of children aged 4-17yrs.
- Recommendations included:
    - Provision of reasonable adjustments, with use of digital flags in electronic records.
    - Ensuring recognition that children with a learning disability are at higher risk of death from infection – guidance and training needed to support this.
    - Ensure autistic children and young people or those with learning disability who have multiple co-morbidities or complex health care needs, have a named lead healthcare professional.
    - Ensuring timely access to appropriate support for those waiting for an autism assessment.
    - Ensuring 'was not brought' policies recognise and meet the needs of the complex lives of children with a learning disability, autistic children, and their families, and that they support effective attendance with suitable safeguarding and escalation in place where needed.

NCMD Programme Thematic Report: Child Deaths due to Asthma or Anaphylaxis, Dec 2024 [10]

Key points:

- 54 child deaths due to asthma, and 19 due to anaphylaxis, between April 2019 – March 2023.
- Death rate from asthma 4 times higher for children from most deprived areas.
- 15-17 year olds were the age group with the highest death rate due to asthma and anaphylaxis.
- 87% had 3 or more reliever inhalers dispensed in the year before death.
- 65% had attended an emergency department or had an emergency admission in the year before death.
- 87% of cardiac arrests due to asthma occurred outside of hospital.
- Recommendations included:
    - Recognising asthma as an important and significant public health issue.
    - Ensuring a government plan to reduce air pollution levels to meet the World Health Organisation guidelines.
    - Adoption of the 'Asthma Friendly Homes' initiative to tackle mould, damp and reducing household smoking.

LLR CDOP Actions 2024/25

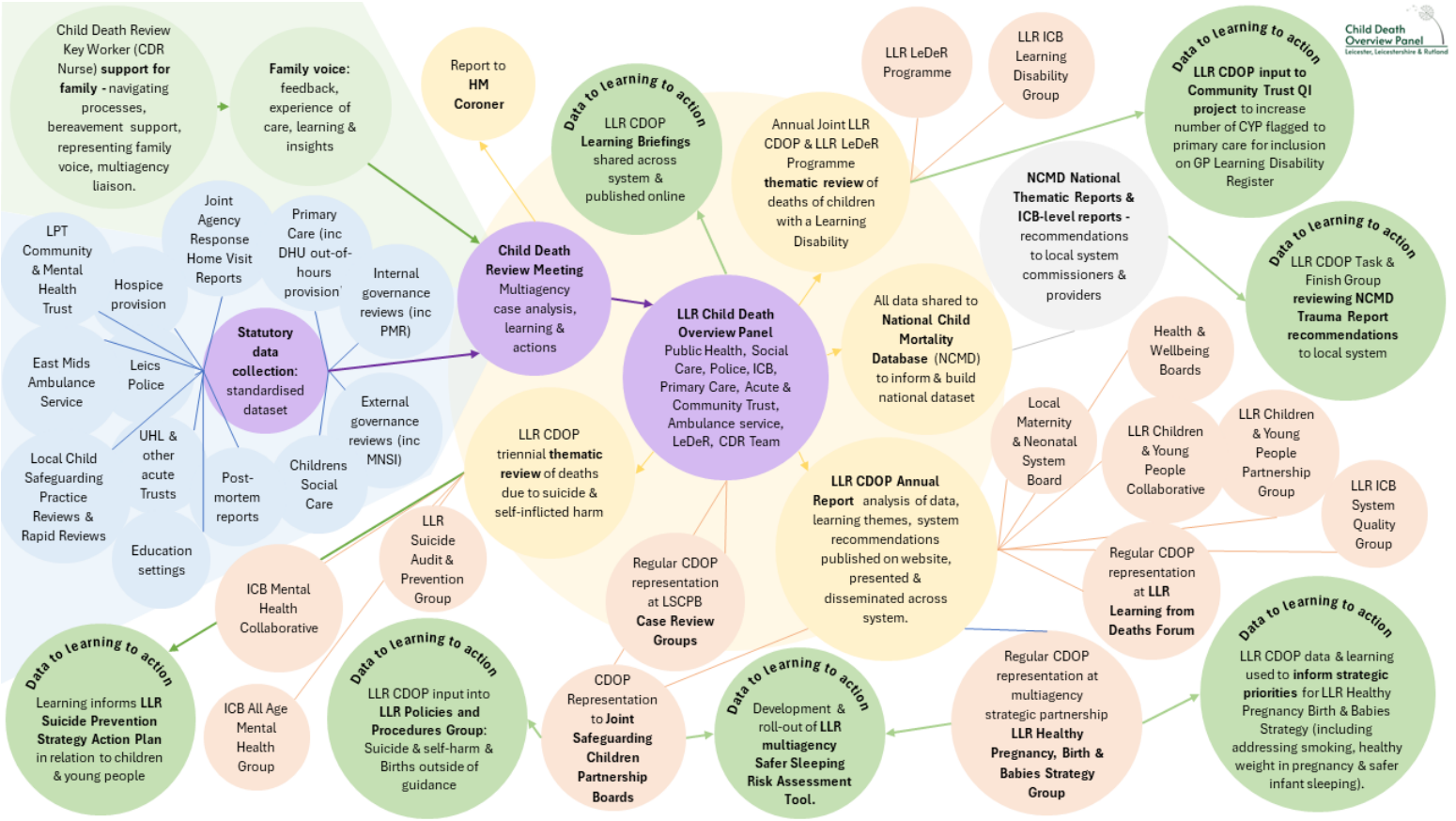
Key information: CDOP Actions 2024/25

- The role of LLR CDOP is to review and analyse information about the death of any child normally resident in our area.
- Where it is considered that it would be appropriate for a person to take action, there is a statutory duty (as set out in the Children Act 2004) to inform that person.
- Out of 81 completed case reviews, actions were raised in relation to 49 cases.
- In the 32 cases where no additional CDOP actions were raised, this includes all cases where actions had been raised and completed prior to the case coming to panel.
- 'Data to learning to action': LLR CDOP has engaged widely across the system, using the data gathered to inform learning, and sharing this to shape actions taken to reduce child mortality and enhance the welfare of children, young people and their families across Leicester, Leicestershire & Rutland. Examples of this are shown in Fig 6 (also see Appendix A).

Table 16. Cases where actions undertaken by LLR CDOP in 2024/25

Action undertaken	Number of cases
Clarification of information	16
Escalation of response (including via NCMD Alert)	5
Sharing of information/learning - includes with: ○ Bereaved family ○ Another locality Child Death Overview Panel ○ Primary care ○ Healthy Together team ○ Midwifery service	6
Seeking assurance	32
Other	4
No Panel actions identified	32

Fig 6. LLR CDOP System map to illustrate the process of data collection, learning, collaboration and action.



1 Infant Mortality in LLR

- For all agencies in LLR to promote and protect breastfeeding for all families as a golden thread running throughout all other work, as this is a key means of both reducing risk of sudden unexplained infant deaths and improving short and long-term health outcomes for women & children.
- For all agencies in LLR to continue to promote and audit the use of the LLR Safer Sleeping Risk Assessment Tool.
- For commissioners & providers to increase resources to tackle rates of smoking in pregnancy and to increase the number of smoke-free homes in LLR.
- For an increase in work to promote healthy weight both pre-pregnancy and in pregnancy, linking with the Leicester City Whole Systems Approach to Healthy Weight and NHS #Readyforpregnancy campaign.

2 Service Provision

- For agencies to fully explore, as part of internal governance reviews, the barriers or drivers behind decision-making when guidance or policy is not followed by front-line practitioners.
- For all staff working within health (primary and secondary care, physical and mental health, perinatal and paediatric services) to be able to assess and recognise risk (within expected levels of competence), and to respond appropriately, with all staff being empowered to escalate any concerns as soon as they arise.
- For a restorative culture of openness and learning throughout all agencies, which welcomes the voices and experiences of children, families, and front-line staff as an opportunity for learning, and fully considers the wider contextual, human and system factors which may have contributed to outcomes.

3 Learning from excellence: End-of-life care

- For sharing of best practice in end-of-life care, so that all senior clinical staff caring for infants, children and young people are aware of what good care, good communication, and advanced care planning looks like.
- For both UHL and LPT to ensure appropriate training is delivered to medical staff to support timely conversations, delivery of high-quality child-centred advanced care planning, (including robust anticipatory care planning and parallel planning), and family awareness of post-bereavement care & processes.

4 Children & Young People with a Learning Disability

- For a multiagency approach to develop, promote & embed the use of ‘Care Passports’ for children and young people with a Learning Disability.
- For health services across LLR to ensure all children & young people with a Learning Disability are identified for inclusion on the GP Practice Learning Disability Register to support optimisation of health outcomes.
- For all children and young people with a Learning Disability & medical complexity to have an allocated lead medical consultant.

5 Healthy lungs for babies, children, young people & their families

- For increasing promotion of smoke-free homes across Leicester City, Leicestershire & Rutland.
- For ongoing work to ensure accessible smoking cessation services are offered to households as part of standard antenatal care.
- For ongoing work to address childhood exposure to poor outdoor air quality through work including transport plans, promotion of active travel, and anti-idling campaigns outside schools.
- For the development of smoking cessation in-reach services via Paediatric Respiratory Clinics, ensuring particularly that those children and young people with both a Learning Disability and complex respiratory needs, are afforded the opportunity to live in a smoke-free home.
- For consideration by the ICB, Public Health and Housing across LLR, of adopting the ‘Asthma-friendly homes’ initiative, as recommended in the NCMD Asthma Report, to tackle mould, damp and household smoke exposure.

1. Oversight of the 2024/25 Annual Report recommendations as a standing item on the Panel Agenda, and development of an Action Plan with allocated leads for progression of the recommendations.

2. Regular Child Death Overview Panels every 6-8 weeks, with additional themed Neonatal Panels.

3. LLR CDOP triennial thematic review of deaths due to suicide & self-inflicted harm, with development and publication of an LLR Joint Agency Response Pathway following a suspected suicide of a child or young person.

4. Multiagency stakeholder review of the NCMD Deaths due to Traumatic Incidents report recommendations, to establish whether additional actions are indicated within LLR.

5. Ongoing participation in East Midlands Regional CDOP Network.

6. Delivery of Joint Agency Response multiagency training sessions, including an in-person training day, and development of an online e-learning offer.

7. Continued close working with the LLR LeDeR programme, with annual themed panels for children & young people with a Learning Disability and sharing of learning between LeDeR and CDOP.

8. Engagement with LLR Learning from Deaths Forum to share learning themes with the wider system.

9. Sharing of learning via the LLR CDOP Annual Report across the Integrated Care System.

10. Ongoing implementation of the NCMD Key Worker Toolkit, in close collaboration with agencies supporting bereaved families, to ensure equity of access to bereavement support and to the opportunity for families to participate in the Child Death Review process.

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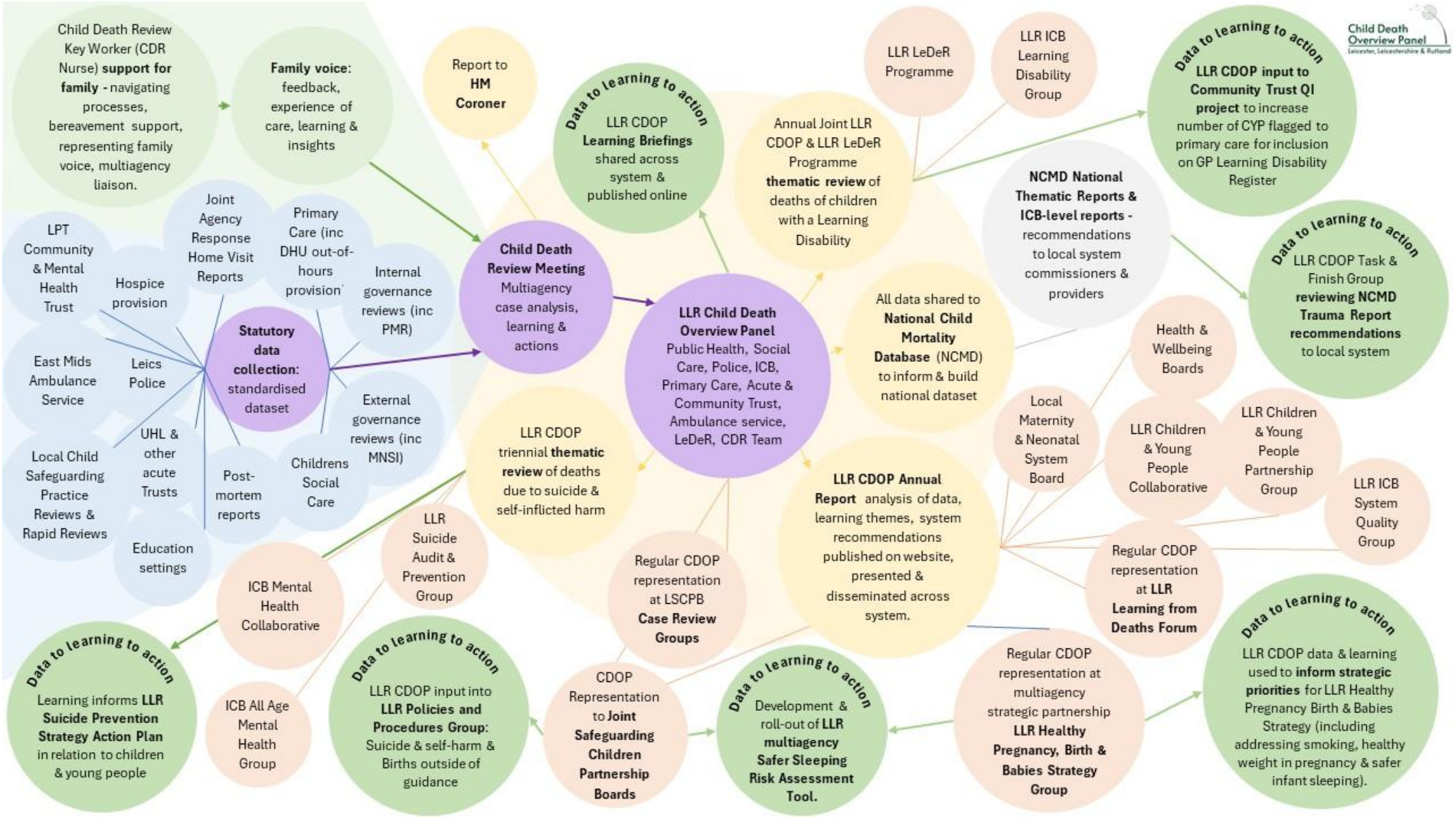
Appendix A. LLR CDOP System Map 2026.



Key:

- Data source: professionals
- Data source: families
- Child death review process.
- Regular CDOP data & learning outputs.
- System-level groups and multiagency partnerships.
- Example of translating CDR data into learning, & then into action.

Appendix B. NCMD Cause of death categorisation.

The CDOP should categorise the likely cause of death using the following schema.

This classification is hierarchical: where more than one category could reasonably be applied, the highest up the list should be marked.

Category	Name & description of category	Tick box below
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** This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. **Excludes** Deliberately inflected injury, abuse or neglect (category 1).	
4	**Malignancy** Solid tumours, leukaemia's & 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, 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).	

Appendix C. Updated NCMD Contributory Factors – Oct 2024

Domain A. Factors intrinsic to the child

Domain Group	Domain Sub-group
Child health history/medical conditions	Prematurity. Low birth weight. Bottle-fed. Breast-fed. Acute/sudden onset illness. Chronic health condition. Malignancy/cancer Congenital/genetic/chromosomal condition. Child not fully immunised (regardless of reason).
Risk factors in mother during pregnancy/ delivery	Twin/multiple pregnancy. Assisted conception. High maternal BMI. Low maternal BMI. Smoking cigarettes/tobacco in pregnancy. E-cigarette use (including vaping devices) in pregnancy. Substance misuse in pregnancy. Alcohol misuse in pregnancy. Perinatal mental health condition. Maternal diabetes/gestational diabetes. Maternal age. Maternal infection. Late booking/concealed pregnancy. Other obstetric complications. Delivery complications.
Child's developmental conditions/disabilities	Learning disability. Sensory impairment. Motor impairment. Other developmental impairment or disability. Neurodevelopmental conditions.
Emotional/behavioural factors	Mental health condition. Behaviour that put the child at risk. Suicidal or self-harm ideation. Poor or non-compliance with medication. Sexual orientation or gender identity issues. Loss of key relationships. Isolation from friends/family/support. Child was victim of bullying. Social media/internet use.
Smoking/vaping/alcohol/substance use/misuse by the child	Child consumed alcohol on day of death. Child consumed alcohol regularly/known to binge-drink. Child consumed drugs on day of death. Child was known to be a regular drug user. Child smoked tobacco/ used e-cigarettes (including vaping devices).
Other	

Domain B. Family & Social Environment

Domain Group	Domain Sub-group
Smoking/vaping/alcohol/substance misuse/use by a parent/carer	Parent/carer had consumed alcohol around the time of child's death. Parent/carer known for alcohol misuse. Parent/carer had consumed drugs around the time of child's death. Parent/carer known for substance misuse. Parent/carer smoked cigarettes/tobacco in the household. Parent/carer used e-cigarettes (including vaping devices).
Challenges for parents with access to services	Parental non-engagement with any service. Child was not brought to appointment(s)/did not attend. Evidence of disguised compliance by parents in any service. Delay in seeking/failure to seek medical support.
Domestic or child abuse/neglect	Child was subject to physical abuse by an adult. Child was subject to sexual abuse by an adult. Child was subject to emotional abuse by an adult. Child was subject to neglect by an adult. Other known domestic violence/abuse in the household.
Household functioning, parenting/supervision	Complex home circumstances. Lack of appropriate supervision.
Poverty & deprivation	Income deprivation. Employment deprivation/unemployment. Health deprivation & disability. Barriers to services.
Social Care	Child on child protection plan at time of death. Child on Child in need plan at time of death. Child was a looked after child at time of death. Child was previously known, but not an open case. Child was a refugee/asylum seeker. Parent/carer was a care leaver.
Cultural factors	English not parents' first language. Parents are/were asylum seekers/refugees. Close relative marriage (consanguineous).
Parent/Carer's health	Physical health condition in parent/carer. Mental health condition in parent/carer. Disability in parent/carer. Learning disability in parent/carer.
School/peer groups	Exclusion/suspension from school. Truancy/poor attendance record. Gang/knife crime. Drug use in peer group.
Other	

Domain C. Physical environment

Domain Group	Domain Sub-group
Sleep environment	Unsafe sleeping arrangements. Co-sleeping. (*Co-sleeping alone does not constitute an unsafe sleep environment. IT is only a risk when combined with other factors e.g. smoking or drug/alcohol use.)*
Home safety/conditions	Overcrowded living conditions. Dirty, mouldy or property in poor repair. Unsafe appliances/environment. Attack by pets/animal. Living environment deprivation/homelessness.
Vehicle collision	Speeding vehicle/recklessness. Young child not appropriately restrained in car seat/booster seat. Chid not using other appropriate safety equipment. Unsafe road conditions.
Public safety	Absent/non-visible warning signs. Unsafe street furniture/public equipment. Availability of safety equipment. Accessible railway tracks/other infrastructure. Accessible water. Poor compliance with health & safety regulations.
Other	

Domain D. Service Provision

Domain Group	Domain Sub-group
Initiation of treatment/identification of illness	Issue in diagnosis. Issue with availability of information. Issue with treatment, including delays. Lack of recognition of deteriorating child/clinical symptoms/signs. Lack of escalation for senior review.
Following guidelines/pathway/policy	Guideline/policy/pathway available but not followed. Guideline/policy pathway unclear or unavailable No referral/assessment/review undertaken. Poor quality referral/assessment/review. Delayed referral/assessment/review.
Access to appropriate services	Issue with or lack of transfer of child. Child not born in appropriate setting. Service uncommissioned/unfunded/unavailable. Availability/accessibility of medication. Transition between paediatric and adult services.
Staffing/bed capacity/equipment	Staffing capacity or inappropriate skill mix. Bed/cot capacity. Equipment related issues.
Communication within or between agencies	Poor communication/information sharing within an agency. Poor communication/information-sharing between agencies. Poor documentation/record keeping.
Communication with family	Poor communication between professionals and family. Poor information sharing with family. Information provided to parents was inappropriate. Lack of interpreter availability/use/suitability.
Other	