Child Death Overview Panel (CDOP) Annual Report

2023-2024

Child Death Overview Process

Leicester, Leicestershire & Rutland

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Glossary of abbreviations used

<table>
<tr><td>CAIU</td><td>Child Abuse Investigation Unit</td></tr>
<tr><td>CDOP</td><td>Child Death Overview Panel</td></tr>
<tr><td>CDIM</td><td>Child Death Initial Meeting</td></tr>
<tr><td>CDRM</td><td>Child Death Review Meeting</td></tr>
<tr><td>CSPR</td><td>Child Safeguarding Practice Review</td></tr>
<tr><td>EMAS</td><td>East Midlands Ambulance Service</td></tr>
<tr><td>ICB</td><td>Integrated Care Board</td></tr>
<tr><td>JAR</td><td>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.</td></tr>
<tr><td>LeDeR</td><td>Learning Disability Mortality Review</td></tr>
<tr><td>LLR</td><td>Leicester, Leicestershire & Rutland</td></tr>
<tr><td>LPT</td><td>Leicestershire Partnership NHS Trust</td></tr>
<tr><td>LRI</td><td>Leicester Royal Infirmary</td></tr>
<tr><td>LSCP</td><td>Local Safeguarding Children Partnership</td></tr>
<tr><td>MBRRACE-UK</td><td>Mothers & Babies: Reducing Risk through Audit & Confidential Enquiries across the UK</td></tr>
<tr><td>NCMD</td><td>National Child Mortality Database</td></tr>
<tr><td>NNU</td><td>Neonatal Unit</td></tr>
<tr><td>PMRT</td><td>Perinatal Mortality Review Tool</td></tr>
<tr><td>SUDI/C</td><td>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.</td></tr>
<tr><td>SIDS</td><td>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.</td></tr>
<tr><td>UHL</td><td>University Hospitals of Leicester NHS Trust</td></tr>
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LLR CDOP 2023/2024

82 notifications received

27 Joint Agency Responses undertaken

49 Child Death Initial Meetings held

10 Child Death Overview Panels held

89 Case reviews completed

413 Contributory factors identified

103 Modifiable factors identified

1 LLR Safer Sleeping Risk Assessment launched

7 Presentations & briefings for Safer Sleeping Risk Assessment

55 Attendees at Joint Agency Response training

44 Cases where CDOP raised actions

2 National Alerts raised to NCMD

Top 5 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

Unsafe infant sleeping

Guidelines or policies not being followed

See Appendix C Table a18.

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. 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.

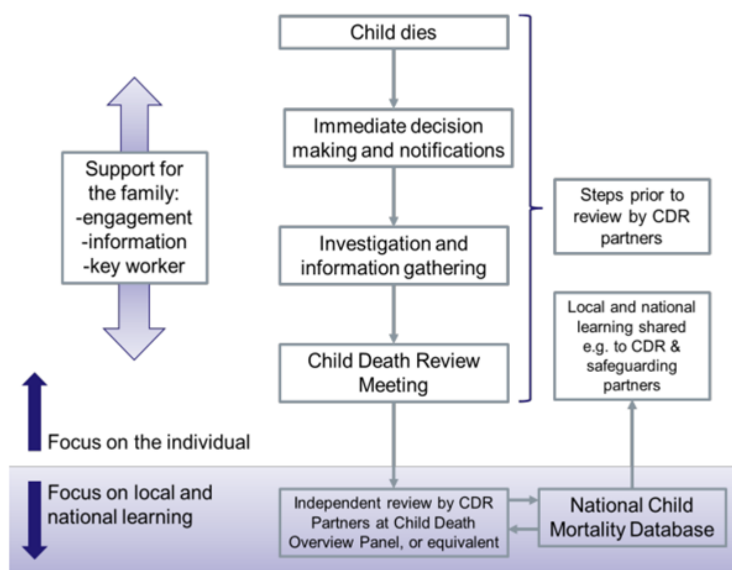


Figure 1: The Child Death Review process as set out in Working Together to Safeguard Children 2018, Chapter 5[1].

Our team: Child Death Review Nurses

The role of supporting the families and undertaking Joint Agency Response visits with the police sits within the remit of the Child Death Review Nurse role (CDRN). This role is an essential aspect to the service carried out by Band 7 nursing staff, ensuring statutory requirements are met and families are adequately supported, through:

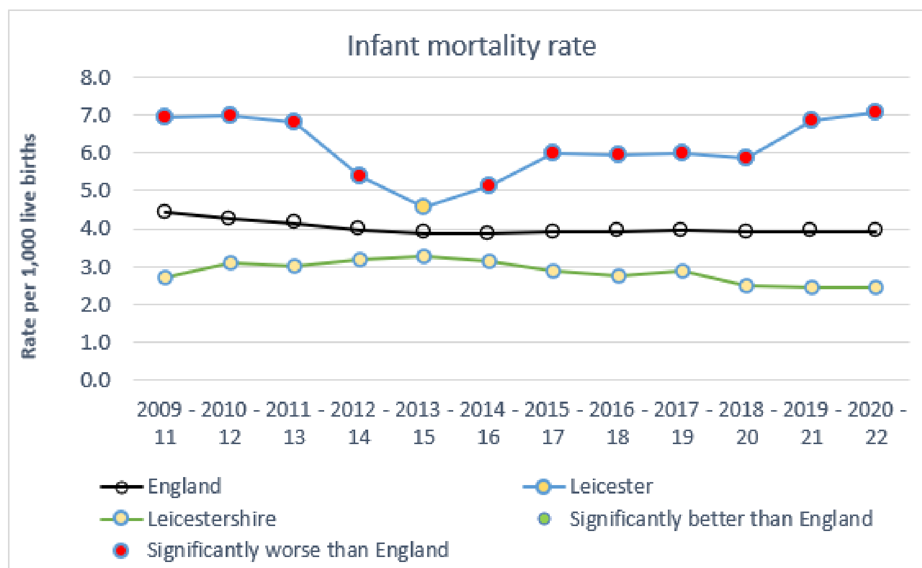
- Carrying out a joint home visit together with police, to gather further information around the circumstances of death. In addition, they will review the background history, identify support for the family, with signposting to specialist bereavement support where appropriate, supporting any other issues identified, preparing, and submitting a report for HM Coroner (in line with guidance set out in Sudden Unexpected Death in Infancy & Childhood, 2016[2]).
- Acting as the named Key Worker for families ensuring that families are supported and engaged throughout the review process (in line with Statutory & Operational Guidance, 2018[3]), by:
  - Being a ready & accessible point of contact for the family.
  - Coordinating meetings as required.
  - Arranging & attending home visits with the Designated Doctor to discuss post-mortem report findings.
  - Providing information to the family on the Child Death Review process.
  - Liaising with Coroners Officer or Police Liaison Office.
  - Representing the voice of the family at professional meetings, ensuring their questions are effectively addressed and providing feedback to family afterwards.
  - Providing support to bereaved parents/carers, until specialist bereavement services commence.
  - Working with the wider multi- disciplinary network including Police, Social Care and Education amongst others.
- In 2023/24 our team of CDRNs has grown through a secondment which has enabled further development of the service, Child Death response, and support for families including:
  - More frequent support calls and visits to families as required.
  - Liaison with a wide range of agencies to support families including the Police, Social Care, Coroner's Officers, schools, and Bereavement support charities.
  - More frequent liaison with GP Practices to ensure families have access to emotional and mental health support were required.
  - Obtaining feedback from families to include in the Child Death Review process and feeding back the outcome of review meetings.
  - Building on existing links with services including Hospice and local Bereavement Support charities to increase accessibility for families to participate in the review process.
  - Development of information resources for families about the local Child Death Review process.
  - Participation in a research study led by the University of Birmingham on 'Improving Parental Engagement in Child Death Review'.

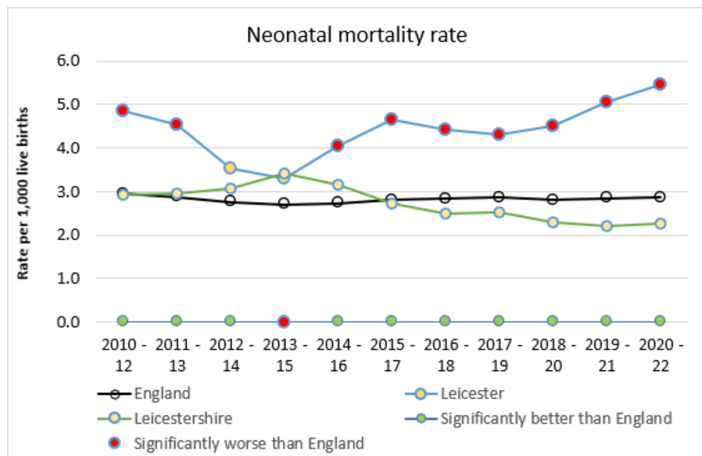
'I just wanted to write to you as the Senior Investigating Officer to say a big thank you for the support your team have provided to my team and the family over the past couple of months. Kerry and Sue have been working tirelessly with the family. I am really grateful for their help. Your team are amazing people and do great work every day and I just wanted to say it's very much appreciated.'

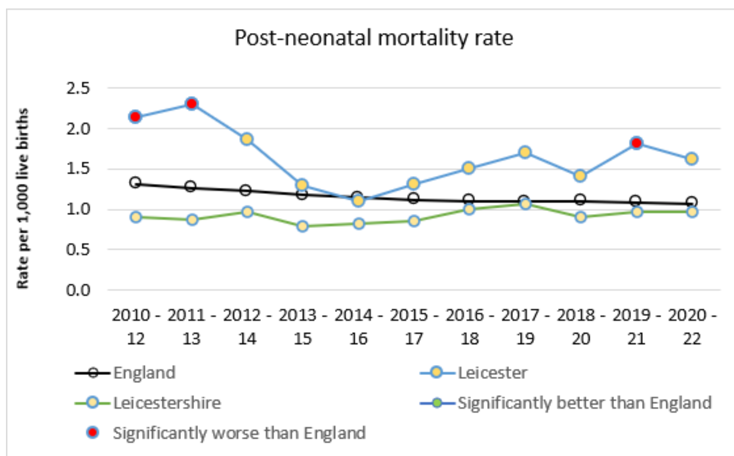
'Without your support and kindness I would not have been able to get through this.'

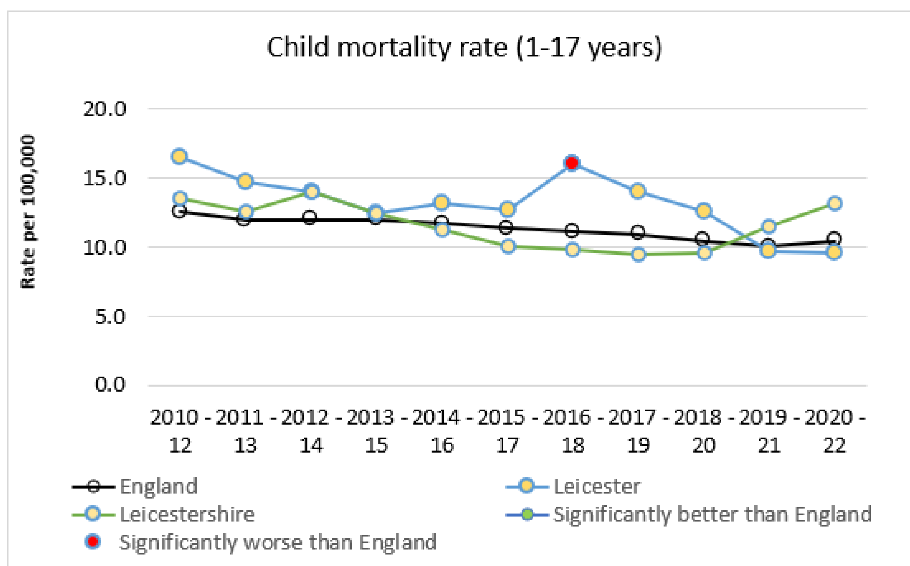
Above: Examples of feedback received from multiagency partner & family.

LLR Summary statistics 2009 - 2022









LLR CDOP Notifications 2023/24

Key information: Notifications

LLR CDOP received 82 notifications of deaths of LLR residents under the age of 18 years (a slight decrease from 2022/23).

27 (30%) 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 (37% of the total; 24% of whom were babies born under 23 weeks gestation).

Leicester City: 49 cases (60%)
Leicestershire & Rutland: 33 cases (40%)

78% of children died in hospital.

- 28% in a Neonatal Unit
- 20% in Paediatric Intensive Care
- 12% in an Emergency Department

13% of children died at home.

Table 1. Death notifications by Local Authority 2018/19 to 2023/24

	2019/20	2020/21	2021/22	2022/23	2023/24
Leicester City	24	30	48	56	49
Leics & Rutland	34	27	42	42	33
Total LLR	**58**	**57**	**90**	**98**	**82**

Chart 1. Notifications by category of response 2017/18 to 2023/24

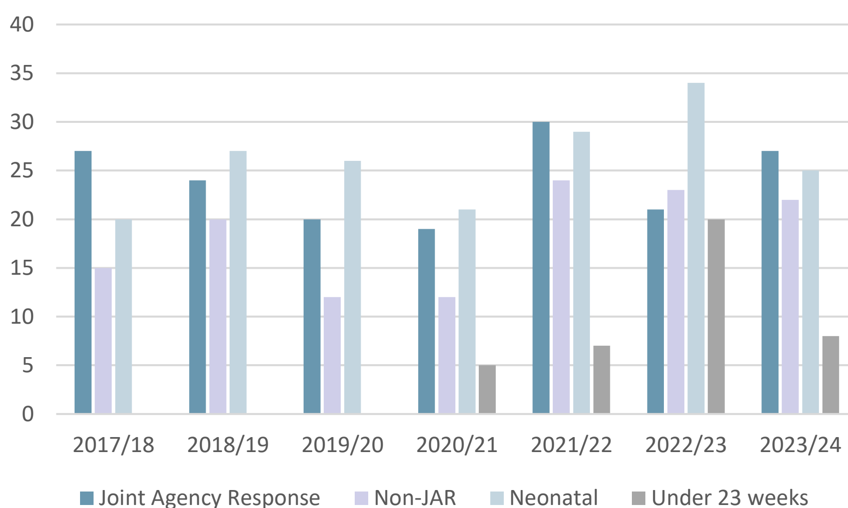


Table 2. Notifications by age & ethnicity 2023/24

Ethnic Group	0-27 days	28-346 days	1-4 years	5-9 years	10-14 years	15-17 years	Total
White	16	6	5	4	3	4	**38**
Other	1	0	0	2	0	0	**3**
Mixed	2	2	1	0	0	1	**6**
Black or Black British	2	2	2	2	2	0	**10**
Asian or Asian British	13	1	4	2	3	2	**25**
Total	**34**	**11**	**12**	**10**	**8**	**7**	**82**

Chart 2. 5-year mean notifications by age group 2017/18 – 2023/24

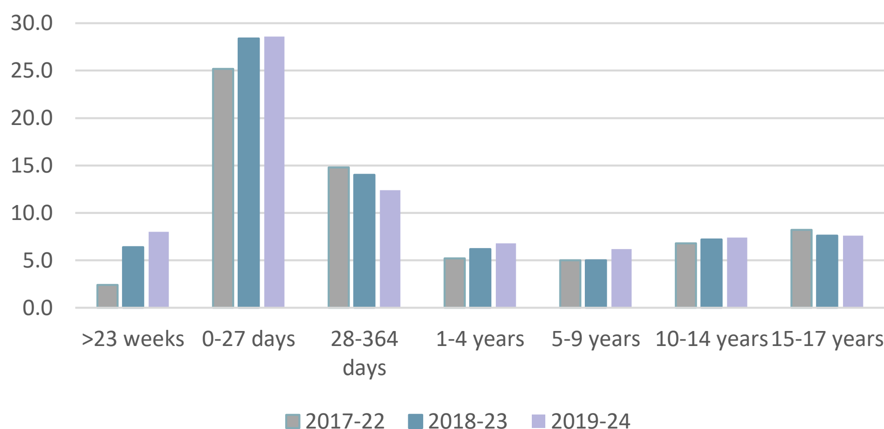
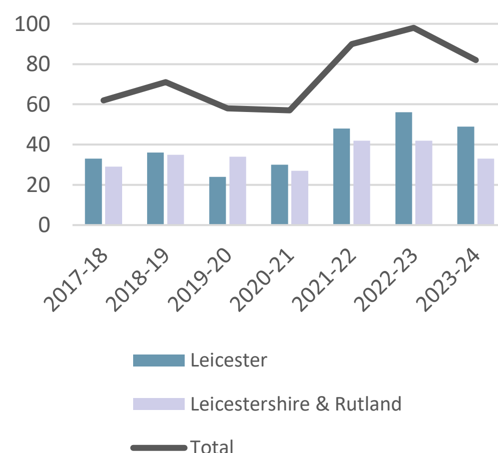


Chart 3. Number of notifications by LA



LLR CDOP Completed reviews 2023/24

Table 3. Completed reviews by year 2019/20 – 2023/24

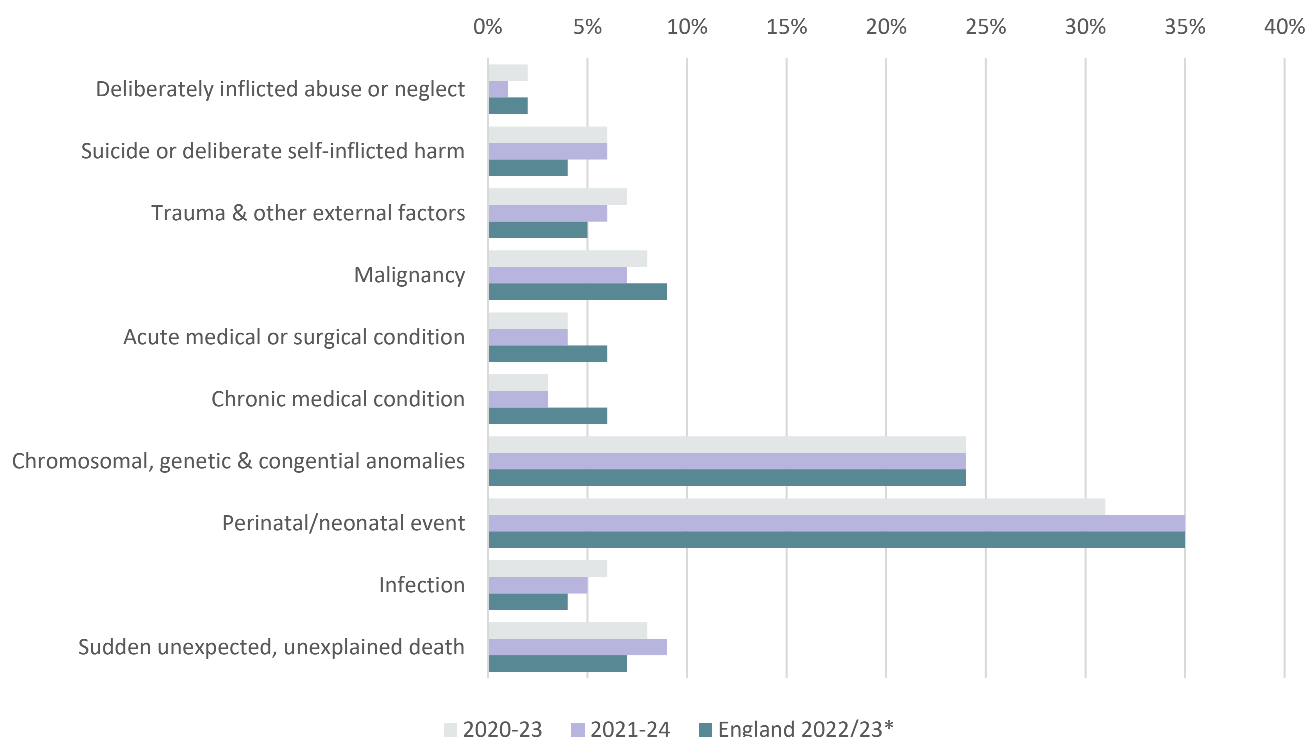
	2019/20	2020/21	2021/22	2022/23	2023/24
Leicester City	17	32	35	45	53
Leicestershire & Rutland	14	32	36	41	36
Total LLR	**31**	**64**	**71**	**86**	**89**

Table 4. Completed reviews by year of death 2023/24

Year of death	Cases
2019-20	1
2020-21	2
2021-22	17
2022-23	59
2023-24	10
Total	**89**

Chart 4. Category of death – 3 year merged data 2020 – 2024

*Data from NCMD Data Release Child Death Reviews Data: year ending 31 March 2023, published November 2023



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 2023/24 LLR CDOP held 10 panels and completed reviews for 89 cases.
- CDOPs are asked to categorise each case by cause of death (see Appendix A). In 2023/24 the most frequently recorded categories of death were:
    - Deaths due to a perinatal or neonatal event (45%)
        - Includes perinatal asphyxia, complications of prematurity/immaturity and perinatal infection.
    - Deaths due to a chromosomal, genetic, or congenital anomaly (19%)
    - Sudden unexpected, unexplained deaths (9%)
        - Deaths occurring at any age, which, following a thorough investigation and post-mortem, no clear medical cause has been identified.
    - Deaths due to suicide/self-inflicted harm (7%)
    - Deaths due to trauma/other external factors (7%)

Contributory factors - What did we learn about factors that contribute to child deaths in LLR?

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.

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 5. Domain A: Factors intrinsic to the child 2023/24

Noted in 85 cases (96%).

Factor by group	No of cases	% of cases
Child health history/medical condition	77	86
Risk factor in mother during pregnancy	46	52
Child's developmental condition/disability	12	13
Emotional/behavioural factors	7	8
Other	6	7
Smoking/alcohol/substance use/misuse by child	1	1

Table 6. Domain B: Factors in the family/social environment 2023/24

Noted in 33 cases (37%).

Factor by group	No of cases	% of cases
Parent/carer's health	15	17
Household functioning, parenting/supervision	10	11
Smoking/alcohol/substance misuse/use by parent/carer	8	9
Challenges for parents with access to services	6	7
Domestic or child abuse/neglect	6	7
Cultural factors	5	6
Other	3	3
School/peer groups	2	2
Social Care	1	1

Table 7. Domain C: Factors in the physical environment 2023/24

Noted in 9 cases (10%).

Factor by group	No of cases	% of cases
Sleep environment	4	4
Home safety/conditions	3	3
Vehicle collision	2	2
Public Safety	1	1

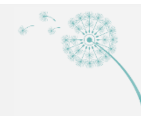
Table 8. Domain D: Factors in service provision 2023/24

Noted in 14 cases (16%).

Factor by group	No of cases	% of cases
Following guidelines/pathway/policy	8	9
Initiation of treatment/identification of illness	5	6
Staffing/bed capacity/equipment	4	4
Other	3	3
Access to appropriate services	2	2
Communication with family	2	2
Communication within or between agencies	2	2
Following guidelines/pathway/policy	8	9
Initiation of treatment/identification of illness	5	6

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 96 % of cases, factors intrinsic to the child were identified as contributing to vulnerability or death.
    - Sole domain identified in deaths due to malignancy, acute & chronic medical conditions & infection.
- In 37% of cases, factors in the family or social environment contributed to vulnerability or death.
    - Noted in 100% of deaths due to suicide/self - inflicted harm, 67% deaths due to trauma, 67% of sudden unexpected unexplained deaths & 23% of deaths due to perinatal or neonatal events.
- In 10% of cases, factors in the physical environment contributed to vulnerability or death.
    - Noted in 67% of deaths due to trauma & 44% of sudden unexpected unexplained deaths.
- In 16 % of cases, factors in service provision contributed to vulnerability or death.
    - Noted in 44% of deaths that were sudden unexpected unexplained, 35% of deaths due to congenital or genetic anomalies, & 15% of deaths due to neonatal or perinatal events.



Modifiable factors - What factors that contributed to child deaths in LLR are modifiable?

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 9. Number of cases where modifiable factors identified by category of death 2023/24

	Completed reviews	Modifiable factors identified	% of cases where MF identified
Deliberately inflicted injury, abuse, or neglect	0	0	0
Suicide or deliberate self-inflicted harm	6	6	100%
Trauma and other external factors	6	5	83%
Malignancy	4	0	0
Acute medical or surgical condition	2	0	0
Chronic medical condition	3	1	33%
Chromosomal, genetic, or congenital anomaly	17	2	12%
Perinatal/neonatal event	40	14	35%
Infection	3	3	100%
Sudden unexpected, unexplained death	8	6	75%
Overall	**89**	**37**	**41%**

Key information: Modifiable factors

- Modifiable factors were identified in 41 % of LLR cases (n=37) compared to 43% across England[4].
- Across the 37 cases where modifiable factors were identified, 103 individual factors were recorded (1-10 per case).
- The same top six factors by Domain Group were seen in 2023/24 as the previous year (see Table 10 below).
- Sub-domain analysis (see Appendix B) shows the top five modifiable factors identified in reviews completed in 2023/24 were:
    - Smoking in pregnancy.
    - High maternal Body Mass Index (BMI - above 35 kg/m^2).
    - Household smoking/e-cigarette use by parent/carer.
    - Unsafe Sleeping arrangements.
    - Guidelines/policy/pathways not being followed.

Table 10: Most frequently recorded modifiable factors by Domain Group 2023/24

Most frequently recorded modifiable factors by domain Group:	No of cases 23/23	No of cases 23/24
Risk factors in mother during pregnancy/ delivery	11	14
Smoking/alcohol/substance misuse/use by a parent/carer	9	8
Following guidelines/pathway/policy	4	7
Initiation of treatment/identification of illness	12	5
Sleep environment	5	5
Staffing/bed capacity/equipment	4	4

Smoking in pregnancy

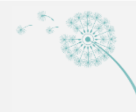
- Known link to adverse pregnancy outcomes including placental abruption, prematurity and low birth weight.
- Exposure to nicotine during pregnancy affects development of the parts of the nervous system which enables the ability of the body to respond to changes in oxygen and carbon dioxide levels[5].

High maternal BMI

- Healthy pre-pregnancy weight reduces the risk of pregnancy complications including gestational diabetes & pre-eclampsia, and the risk of congenital malformations[6].

Sleep environment

- Unsafe sleep arrangements and unsafe co-sleeping were identified as modifiable factors in 5 cases.
- As per NICE guidance[7], families should be strongly advised not to share a sleep space with their baby if their baby was born preterm or low-birth weight, if they are smokers, have consumed drugs or alcohol, or are excessively tired.



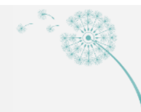
Learning from bereaved families
Hearing the experiences of families is an important part of the Child Death Review process, particularly in learning about what went well, and what needs to be improved in terms of care and service provision. All families will have contact either via the Perinatal Mortality 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. 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.

Learning from case reviews: additional learning themes

In addition to learning from identification of contributory or modifiable factors, the CDOP are asked to:

1. Identify and record additional learning from cases. This is in free text form; data is entered into an excel spreadsheet and can then be categorised according to common themes.
2. Identify and record any areas of notable good practice or excellence in relation to service provision.

Theme	Learning
Safer infant sleeping	Importance of a safe sleep environment, clarity of language with families, influence of intergenerational sleeping practices, and role of alcohol and cannabis use as factors which increase risk.
Palliative care	Lack provision for specialist Paediatric Palliative Medicine in the East Midlands leads to difficulties in handing over care when children move into our area and no equivalent local provision is available. Timely & appropriate consideration of advanced & parallel care planning supports high quality care provision.
Suicide & self-harm	Social isolation, issues around sexuality, early life experiences and previous trauma may all impact on resilience. Key to ensure signposting of support that is available outside of a school setting & accessible during school holidays.
Trauma	Key to teach children about water safety & risks of open water, as well as teaching swimming skills. Risks of mobile devices as a source of distraction for drivers.
Maternity care	Accurate identification of risk factors for pre-term birth enables planning, counselling & optimisation of care, ensuring wherever possible that babies are born in the appropriate setting for their care needs.



Learning from case reviews: learning from excellence

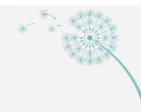
Notably good or excellent aspects of service delivery are considered, and were recorded in 20 cases (22%), across the range of categories of cause of death.

- In 4 cases it was noted that parents had highlighted their positive experiences and feedback directly.
- Examples of excellent practice were seen across health, Children's Social Care, Early Help, third sector organisations and schools.

This data is currently collected via free text boxes. The word cloud below illustrates the key themes:

Table 11: Cases where excellence in service provision identified, by category of death, completed reviews 2023/24

Category of death	Cases where positive aspects identified
Chromosomal, genetic, or congenital anomaly	8
Perinatal or neonatal event	3
Malignancy	3
Chronic medical condition	2
Infection	1
Suicide or deliberate self-inflicted harm	1
Sudden unexpected unexplained death	1
Trauma or other external factors	1
Acute medical or surgical condition	0
Deliberately inflicted injury, abuse, or neglect	0
Total	**20**



A. Infant Mortality

Infant deaths in LLR: Key information

- Definition - Infant: liveborn child (of any gestation), up to 364 days of age.
- Notifications received: 45 cases (55% of all case notifications) – marked decrease from 2022/23.
- Reviews completed: 62 cases (70% of all completed reviews).
- Modifiable factors identified: 21 cases (34% 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 (23%)
  - Smoking/alcohol/substance misuse by parent/carer: 6 cases (10%)
  - Following guidelines/pathway/policy: 5 cases (8%)
  - Sleep environment: 4 cases (6%)

Table 12. Age at death for notifications of deaths occurring under 1 year of age 2021/22 – 2023/24

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

Chart 5. Percentage of infant deaths reviewed by Index of Multiple Deprivation 2019/20 – 2023/24

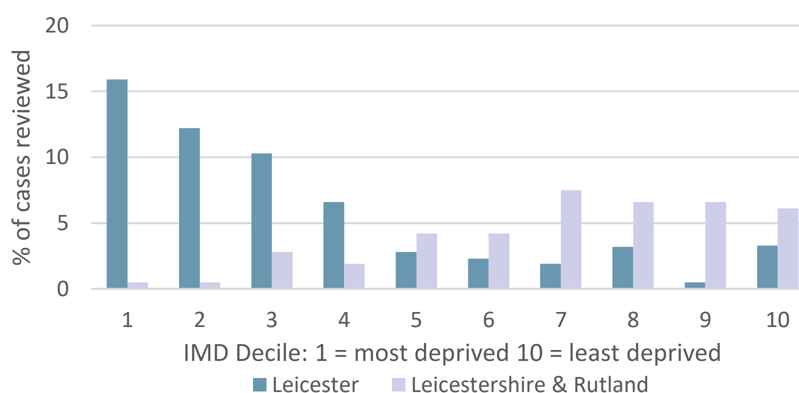


Table 13. Categories of death for children under 1 year – completed reviews 2022/23

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

Sudden unexpected unexplained deaths of infants

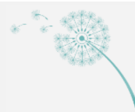
In the period between 1st April 2018 and 31st March 2024, CDOP reviewed the deaths of 24 children who died under 1 year of age, and whose deaths were categorised by the panel as Sudden Unexpected Unexplained Deaths.
This categorisation is based on the medical cause of death at post- mortem and review of the circumstances of death & will include all deaths due to '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.

Table 14. LLR Sudden Unexpected Unexplained Deaths in Infancy –5-year pooled data 2015/16 to 2023/24

	2015/16 to 2020/21 (n=15)		2016/17 to 2021/22 (n=15)		2017/18 to 2022/23 (n=20)		2018/19 to 2023/24 (n=24)	
	N	%	N	%	N	%	N	%
Bottle fed	12	80 %	11	73 %	15	75%	16	67%
First born	4	27 %	6	40 %	8	40%	12	50%
Preterm	10	67 %	9	60 %	10	50%	9	38%
IMD 1&2	7	47 %	6	40 %	7	35%	7	29%
Birthweight <2.5kg	9	60 %	9	60 %	10	50%	9	38%
Mean maternal age	28.8 yrs (20-36 yrs)		28.73 yrs (20-36 yrs)		27.4 yrs (20-36 yrs)		25.7 yrs (17-36 yrs)	
Known to Social Care	7	47%	8	53%	10	50%	10	42%
Housing issues	7	47%	6	40%	7	35%	9	38%
Domestic Abuse	5	33%	7	47%	8	40%	7	29%
Parental drugs/alcohol	4	27%	5	33%	7	35%	7	29%
Medical cause of death:								
'Unascertained'	12	80 %	11	73 %	16	80%	20	83%
'SIDS'	3	20 %	4	27 %	4	20%	4	17%
Modifiable Factors								
Unsafe sleeping	10	67 %	9	60 %	12	60%	15	63%
Parental smoking	9	60 %	9	60 %	14	70%	18	75%
One or more MF	13	87 %	13	87 %	18	90%	20	83%
More than one MF	10	67 %	11	73 %	15	75%	17	71%

Key information: Infants who died suddenly & unexpectedly & whose death remains unexplained after full investigation:

- Two thirds 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.
- 38% 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 63% of cases – this has remained relatively unchanged over time.
- Parental smoking was noted in three quarters of cases.
- 71% 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.



B. 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 as part of LeDeR Programme, aiming to identify learning to reduce the increased mortality and morbidity rates seen for this population. In 2023, LeDeR stopped reviewing the deaths of children with a learning disability under 18 years of age due to duplication between LeDeR & CDOP. In LLR, it was agreed that we continue to work closely together, and this is now achieved through an annual themed review. During 2023-24, 5 case reviews were completed for children with a Learning Disability who had died. A review group was convened with representation from Public Health, Childrens Social Care, UHL, LPT, ICB and the LeDeR Programme to look at these cases collectively, identify themes and learning, and to generate actions.

Of the 5 cases:
- The most common category for cause of death was:
    - Chromosomal, genetic, or congenital anomalies (60%) – identical to 2022/23 review.
    - Other categories included acute or chronic medical conditions and trauma/other external factors.
- Modifiable factors were identified in 2 cases.
- Positive aspects of service delivery were noted in 1 case.
- Mean age at death was 12.4 years (11-14 yrs)
- 80% were on the GP Practice Learning Disability Register (compared to none of the 10 cases in 2022/23).

Children & Young People with a Learning Disability - key learning themes identified for 2023/24:

	Communication. - Reasonable adjustments in communication (including use of interpreters) should be made by all agencies. - Hearing the voice of families, which is key to providing safe and effective patient care for children and young people with learning disabilities. Language barriers, diagnostic overshadowing and professional assumptions can all inhibit this.
	Prescriptions - Where possible, systems should be put in place to support families of children with complex needs to access repeat prescriptions in a timely way.
	Advanced Care Planning. - When done well, this ensures high quality support and allows family wishes to be followed. - Hospital Passports are a valuable tool for children and young people with a learning disability, to ensure they are appropriately supported in all healthcare settings.
	Challenges of reviewing deaths when children die abroad. - Guidance is available on how to obtain information for child death reviews. - Advice for child travellers is also available and should be shared with families considering travelling overseas

Recommendations to providers caring for children and young people with a Learning Disability:

1. **Hospital passports to support communication and planning.**

Going into hospital can be a worrying time for children and young people with a learning disability, and for their families. This can be further heightened around the time young people are transitioning from paediatric to adult services. Hospital passports are one way to help prepare for a hospital admission, and to ensure that services know what reasonable adjustments are required. They can also be used to support transition from paediatric to adult services.

- Services should be aware of Hospital Passport templates that they can share with families of children and young people. The use of Hospital Passports for children, young people and adults with a Learning Disability or Autism should be routinely embedded in all healthcare settings.
- Within UHL, all people with a Learning Disability should be 'flagged' on record systems, to ensure that they are known, and reasonable adjustments can be provided.
- Those aged 18yrs or more can also be supported by the Learning Disability Acute Liaison Nurse Team within the hospital setting.

2. **Prescriptions for children with complex medical needs**

Children and young people with complex neurodisability may be on a significant number of medications; some prescribed medication may have specific requirements in terms of manufacturing, order and preparation time and availability. Mechanisms should be in place to support families wherever possible with ordering repeat prescriptions in a timely way, particularly in relation to critical medication where delays in obtaining repeat prescriptions may lead to an increase in symptoms such as seizures.

3. **Mortality reviews for when children, young people and adults die abroad**

The death of a child, young person or adult abroad can present very significant challenges for families in terms of accessing care and support, and for gathering of information around the circumstances of death.
Services should ensure that if families are planning to travel abroad with children who have complex health needs, that they are signposted to information and guidance, and know how to access medical support whilst travelling.

Actions:

- For the use of hospital passports to be fully embedded across LLR for children, young people and adults with a Learning Disability.
- For LLR CDOP to meet within the ICB Pharmacy team to share learning and review mechanisms for supporting families to access timely repeat prescriptions.
- For LLR CDOP to share with LLR LeDeR the resources and advice about how to gather mortality review information for deaths which occur overseas.
- For ongoing work to ensure all children and young people with a Learning Disability are on the GP Practice Learning Disability Register and offered annual health checks from 14 years.

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

NCMD Report: Infection related deaths of children & Young people in England, Dec 2023 [9]

Key points:

- 1507 infection related deaths between April 2019 – March 2022 – 15% of all child deaths during that period.
- In 37%, infection was the full & sufficient explanation for the death.
- Risk of death from infection varies with age, children under 1 year more at risk than any other age group.
- Risk varied by ethnicity – Asian/Asian British or black/black British ethnic group at higher risk.
- Chance of dying twice as high in most deprived neighbourhoods compared to least deprived neighbourhoods.
- 90% of children had an underlying health condition, 68% a life-limiting conditions.
- 67% of children dying with infection had a learning disability (pneumonia in 75% of cases).
- 36% of reviews recorded issues related to service provision as a contributory factor; in half of these cases service provision was identified as a modifiable factor.
- Recommendations included:
    - Ensuring coherent & aligned guidelines on infections and administering treatment across services providing early care to children.
    - Ensuring recognition of children at higher risk of death from infection (due to learning disability, ethnicity, children of parents who smoke, children with underlying health conditions, those known to Childrens Social Care) is included in guidance and training for healthcare professionals.
    - Ensuring parental concerns about their baby or child's health are listened to and acted on, with timely escalation for senior review (in line with NICE guideline NG194).
    - Ensuring children are supported to receive all vaccinations they are entitled to, with reasonable adjustments made to ensure equity of access.

NCMD Report: Deaths of children & young people due to traumatic incidents, July 2023 [10]

Key points:

- 644 deaths between April 2019 – March 22, 6% occurred abroad.
- 211 deaths due to vehicle collision
- 160 deaths due to violence/maltreatment – those under 1 year of age had risk of death 5 times greater than the average.
- 84 deaths due to drowning, 45% in children under 5 years
- Of completed reviews, 42% of children were known to Social Care at the time of their death.
- Factors contributing to vulnerability were noted as presence of a Learning Disability in 8% and a neurodevelopmental condition (Autism or ADHD) in 11%.
- Key recommendations include training around managing traumatic injury, effective violence reduction strategies, the importance of supervision when bathing at home, equitable access to swimming lessons, water safety messaging in the springtime and improved open-water safety knowledge for all children & young people.

Fig 1 & Fig 2: NCMD Infographics summarising learning from deaths due to vehicle collisions & drownings, used with permission.

211
There were 211 child deaths due to vehicle collisions between April 2019 and March 2022

NCMD
National Child Mortality Database

20
20 of these deaths occurred while the child was abroad

15-17
15-17 year olds were the age group with the highest death rate from vehicle collisions

2x
2x as many boys died in vehicle collisions as girls

2x
The risk of dying in a vehicle collision was 2x higher for children from the most deprived areas than from the least deprived

The most common type of collision for 15-17 year olds was in a car or van

In car or van
Other
Pedestrian

The most common type of collision for 10-14 year olds was as a pedestrian

Children can die in vehicle collisions as pedestrians, or passengers, or drivers.

20%
In 20% of all reviews appropriate safety equipment had not been used

33%
In 33% of all reviews risk-taking behaviour on the part of the driver, such as speeding or drug use, was identified

Recommendations

Improve support for witnesses to vehicle collisions and other traumatic events

Ensure all primary school children receive road safety education

27% of all reviews identified a vehicle that was speeding or reckless driving

Road design was identified as a common theme in child deaths by vehicle collision

84
There were 84 child deaths due to drowning between April 2019 and March 2022

NCMD
National Child Mortality Database

40
20
0
2019/20
2020/21
2021/22
Drowning deaths increased over the 3 year period

3.5x
The risk of drowning was 3.5x higher for children of Black ethnicity than White

3x
3x as many boys drowned as girls

2x
The risk of drowning was 2x higher for children from more deprived areas than from less deprived

The most common place of drowning for under 5s was in the bath

<5
5-14
15-17

The most common place of drowning for 15-17 year olds was inland water

The children most at risk were those aged under 5 and between 15-17 years

83%
83% of all drownings reviewed occurred when the child was not supervised by an adult

Drownings of this type increased during the period

Recommendations

Make safe bathing techniques a public health focus

Address inequalities in access to swimming and water safety tuition

Invest in water safety education programmes for children and young people

Disseminate water safety advice earlier in the year, starting in Spring

53%
53% of the 8-17 year olds whose deaths were reviewed were thought to be able to swim

54% of all drownings were between June and August; the number between March and May increased during the period

LLR CDOP Actions 2023/24

Key information:

LLR CDOP has a statutory duty to raise actions where needed following case reviews.

- Out of 89 completed case reviews, actions were raised in relation to 44 cases.
- In the 45 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 (including for example, a case where escalation to the Regulator had taken place shortly following notification).
- LLR CDOP produces learning briefings to share case learning, & in 2023/24 this included:
    - 7 Minute Briefing on Signs of steroid abuse
    - 7 Minute Briefing on Eczema & steroid cream use

Table 15. Cases where actions undertaken by LLR CDOP in 2023/24

Action undertaken	Number of cases
Clarification of information	16
Escalation of response (including via NCMD Alert)	3
Sharing of information/learning	10
Seeking assurance	26
Other	3
No Panel actions identified	45

Actions taken on recommendations from 2022/2023

1. Safer Infant Sleeping in LLR

Members of LLR CDOP have been involved in the development & roll-out of the LLR Multiagency Safer Sleeping Risk Assessment tool, which was formally launched in November 2023, with a number of stakeholder briefing events held online, as well as presentations to a wide range of groups of practitioners. Work is ongoing to gather feedback around the tool.

2. Digital solutions to improve communication

Learning from LLR CDOP reviews has been shared with the ICB Digital Innovation & Transformation Team to help inform development of IT systems within health & maternity services.

3. Infant mortality

LLR CDOP representatives attend the LLR Healthy Pregnancy, Birth & Babies Strategy Group, and learning & recommendations from the Annual Report 2022/23 were shared with the Group to help inform future priorities and strategy around reducing infant mortality.

4. Suicide & self-harm in children & young people

Recommendations & learning from the LLR CDOP themed review were shared with stakeholders and informed the review and update of LLR Safeguarding Practice Guidance around suicide & self-harm.

5. Deaths of children & young people with a Learning Disability

LLR CDOP representative met with the ICB Clinical lead for Learning Disability to share the learning from the themed review, with ongoing Quality Improvement work to increase the numbers of eligible children and young people on GP Practice Learning Disability Registers.

LLR CDOP Recommendations 2024/25

1 **Safer Infant Sleeping in LLR**

- For all agencies in LLR to promote and audit the use of the LLR Safer Sleeping Risk Assessment Tool.
- For LLR CDOP to support review of feedback from users, update, and relaunch of the Tool in 2025, to promote curious & effective conversations with families around infant sleeping, and to identify and tackle barriers that families face to following the guidance.
- For all agencies in LLR to continue to promote breastfeeding to all families as a key means of reducing risk of sudden unexplained infant deaths and improving health outcomes for women & children.

2 **IT Systems within LLR**

- For all agencies within health & Social Care to engage with and adopt the LLR Summary Care Record for maternity care, children, young peoples & family services, to ensure safe sharing of relevant information to optimise health outcomes, and support early recognition of, and effective response to, emerging vulnerabilities.

3 **Infant Mortality**

- For the LLR Healthy Pregnancy, Birth & Babies Strategy Group to include smoking cessation and healthy weight in pregnancy as key strategic priorities.
- 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.

4 **Children & Young People with a Learning Disability**

- For health services across LLR to promote & embed the use of 'Patient Passports' (or 'Hospital 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 included on their GP Practice Learning Disability Register to support optimisation of health outcomes.
- For LLR CDOP to meet within the ICB Pharmacy team to share learning and review mechanisms for supporting families to access timely repeat prescriptions.
- For LLR CDOP to share learning with the LLR LeDeR team about routes to access information when an individual has died overseas, to facilitate high quality mortality reviews and identify learning.

5 **Deaths of children & young people due to trauma**

- For LLR CDOP to bring together a Task & Finish Group to review the NCMD Trauma Report recommendations, and whether any additional actions are indicated within LLR.

CDOP Work Plan for 2025/26

- CDOP Panels every 6-8 weeks, with additional themed Neonatal Panels.
- Implementation of a referral pathway for genetic testing following sudden unexpected unexplained deaths in infants & children.
- Ongoing engagement in the development of MBRRACE/NCMD data systems integration.
- Ongoing participation in East Midlands Regional CDOP Network.
- Delivery of Joint Agency Response multiagency training sessions including an in-person training day.
- 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.
- Engagement with LLR Learning from Deaths Forum to share learning themes with the wider system.
- Sharing of learning via the LLR CDOP Annual Report across the Integrated Care System.

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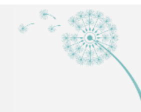

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Appendix A. NCMD Cause of death categorisation.

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 B. Updated NCMD Contributory Factors – Nov 2022

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 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. Risk-taking behaviour. Suicidal or self-harm ideation. Poor or non-compliance with medication. Sexual orientation/identity or gender identity issues. Loss of key relationships. Isolation from friends/family/support. Child was victim of bullying. Social media/internet use.
Smoking/substance use/misuse by 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/e-cigarettes.
Other	

Domain B. Family & Social Environment

Domain Group	Domain Sub-group
Smoking/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 tobacco/e-cigarettes in the household.
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 adult. Child was subject to sexual abuse by adult. Child was subject to emotional abuse by adult. Child was subject to neglect by 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. Other social factors.
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 school/peer group related factor.
Other	

Domain C. Physical environment

Domain Group	Domain Sub-group
Sleep environment	Unsafe sleeping arrangements. Co-sleeping.
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. Other factors.
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 public safety factor.
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 agencies. 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	

Appendix C. LLR CDOP Annual Report All Data 2023-24

Notifications to LLR CDOP 2023-24

Number of deaths notified: 82

Notifications by LA:

- Leicester City 49
- Leicestershire 33
- Rutland 0

Is there to be a Joint Agency Response?

- Yes 27
- No 55

Table a1. Death notifications 2017/18 to 2023/24

	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24
Leicester City	33	36	24	30	48	56	49
Leics & Rutland	29	35	34	27	42	42	33
Total LLR	**62**	**71**	**58**	**57**	**90**	**98**	**82**

Chart a1. Death notifications by LA of residence 2017/18 to 2023/24

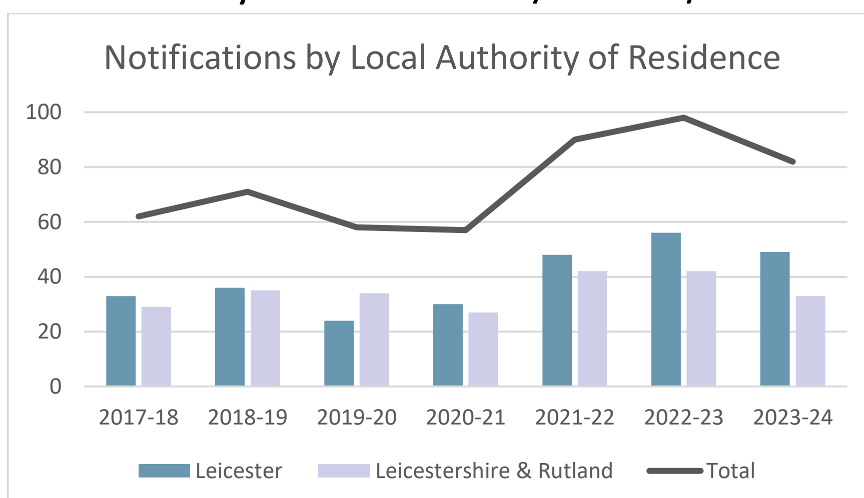


Chart a2. Death notifications by response type 2017/18 to 2023/24

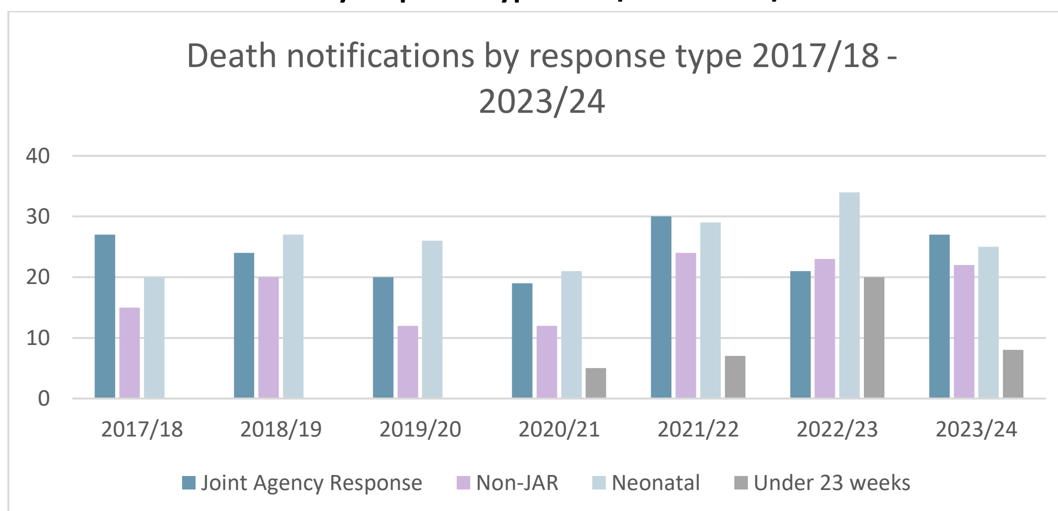


Chart a3. % of death notifications by response type 2017/18 to 2023/24

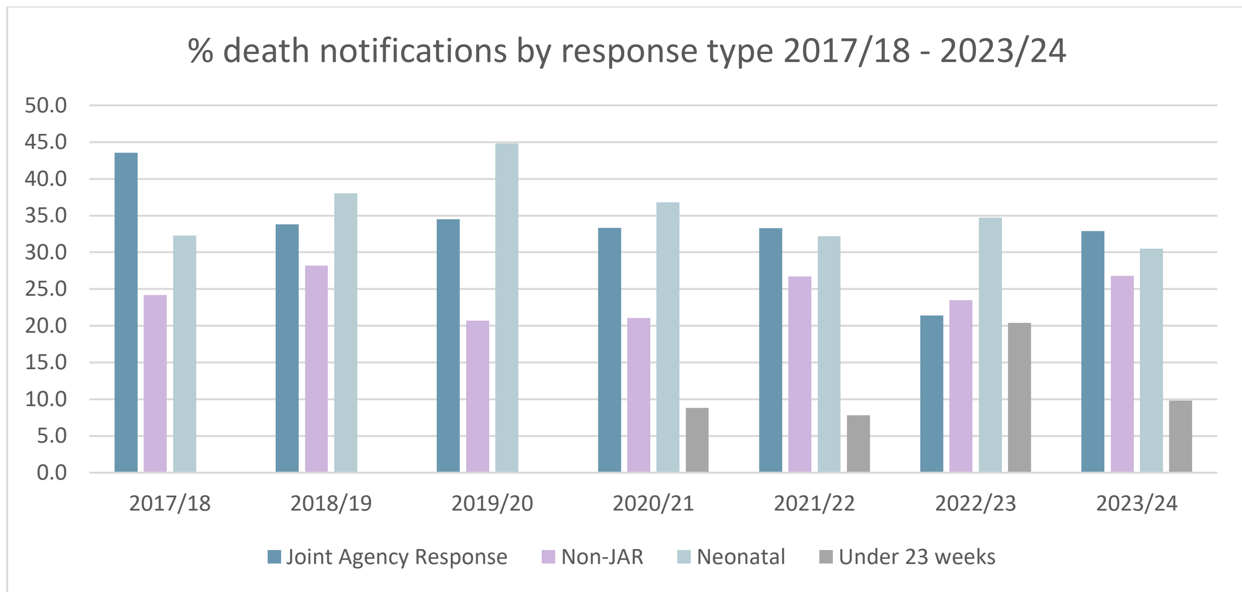


Chart a4. Number of notifications received of deaths of LLR residents <18 years by fiscal quarter 2019/20-2023/24

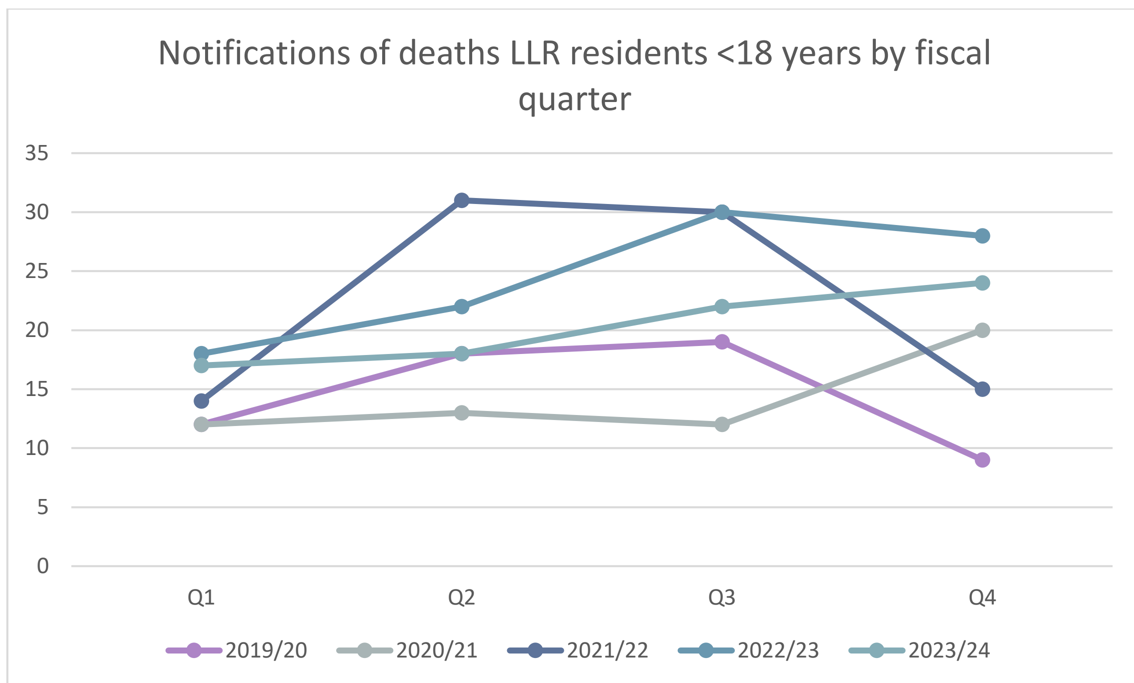


Chart a5. Total notification numbers (including deaths of out-of-area residents) to LLR CDOP by fiscal quarter 2019/20-2023/24

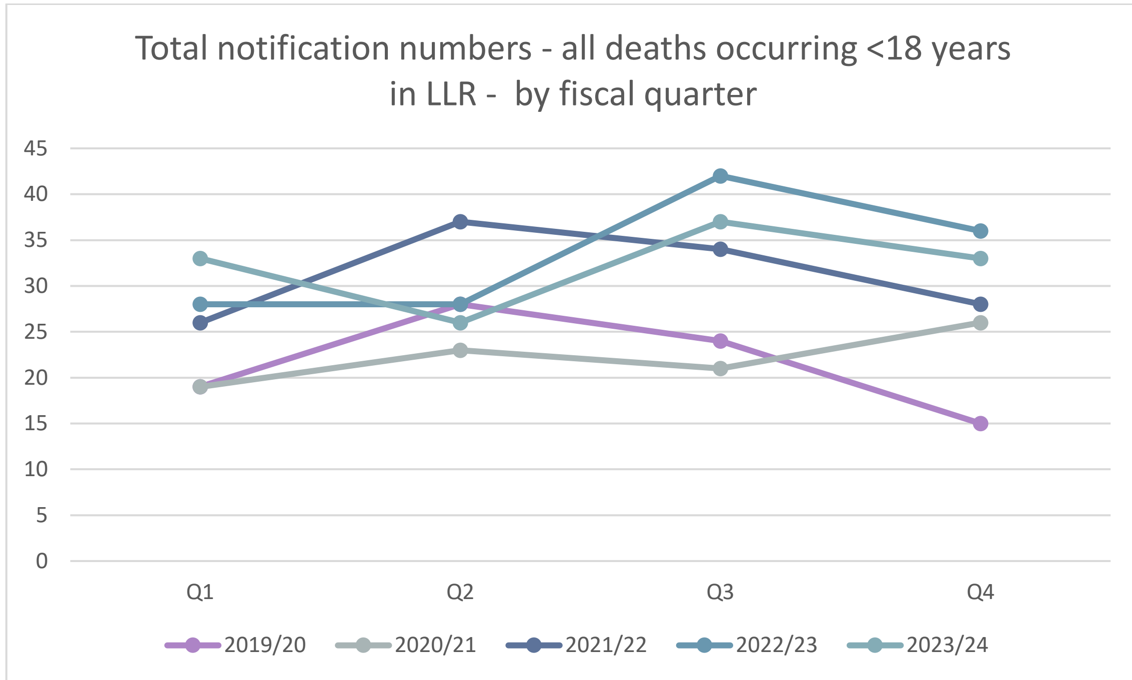


Chart a6. 5-year mean number of death notifications by age group and year 2017/18 to 2023/24

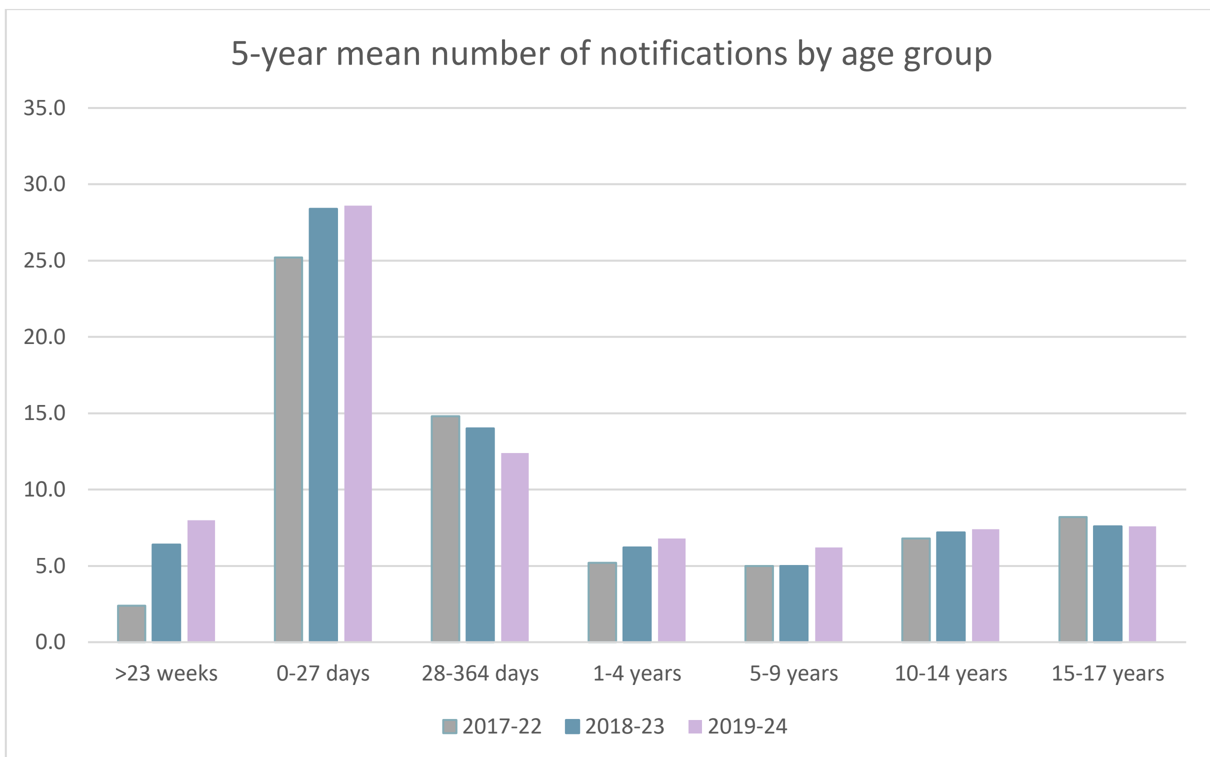
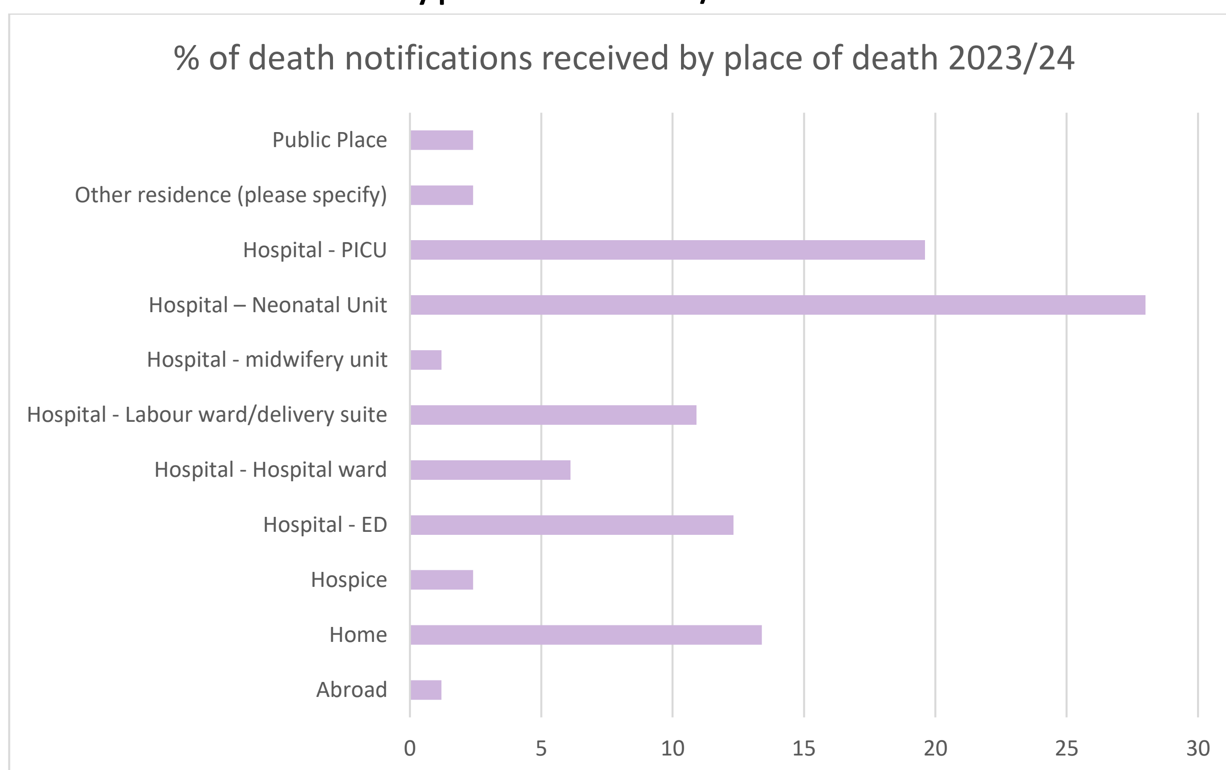


Table a2. Death notifications by age & ethnicity 2023/24

Ethnic Group	0-27 days	28-346 days	1-4 years	5-9 years	10-14 years	15-17 years	**Total**
White	16	6	5	4	3	4	**38**
Other	1	0	0	2	0	0	**3**
Mixed	2	2	1	0	0	1	**6**
Black or Black British	2	2	2	2	2	0	**10**
Asian or Asian British	13	1	4	2	3	2	**25**
Total	34	11	12	10	8	7	**82**

Chart a7. Death notifications by place of death 2023/24



Location of death (place where child/young person declared deceased) 2023/24:

78% of deaths occurred in hospital setting (51% in maternity setting, 25% PICU, 16% ED, 8% hospital wards)

16% of deaths occurred at home/other place of residence

2% of deaths occurred in a hospice setting.

2% of deaths occurred in a public place.

1% of deaths occurred abroad.

Completed reviews 2023-2024 - Overview

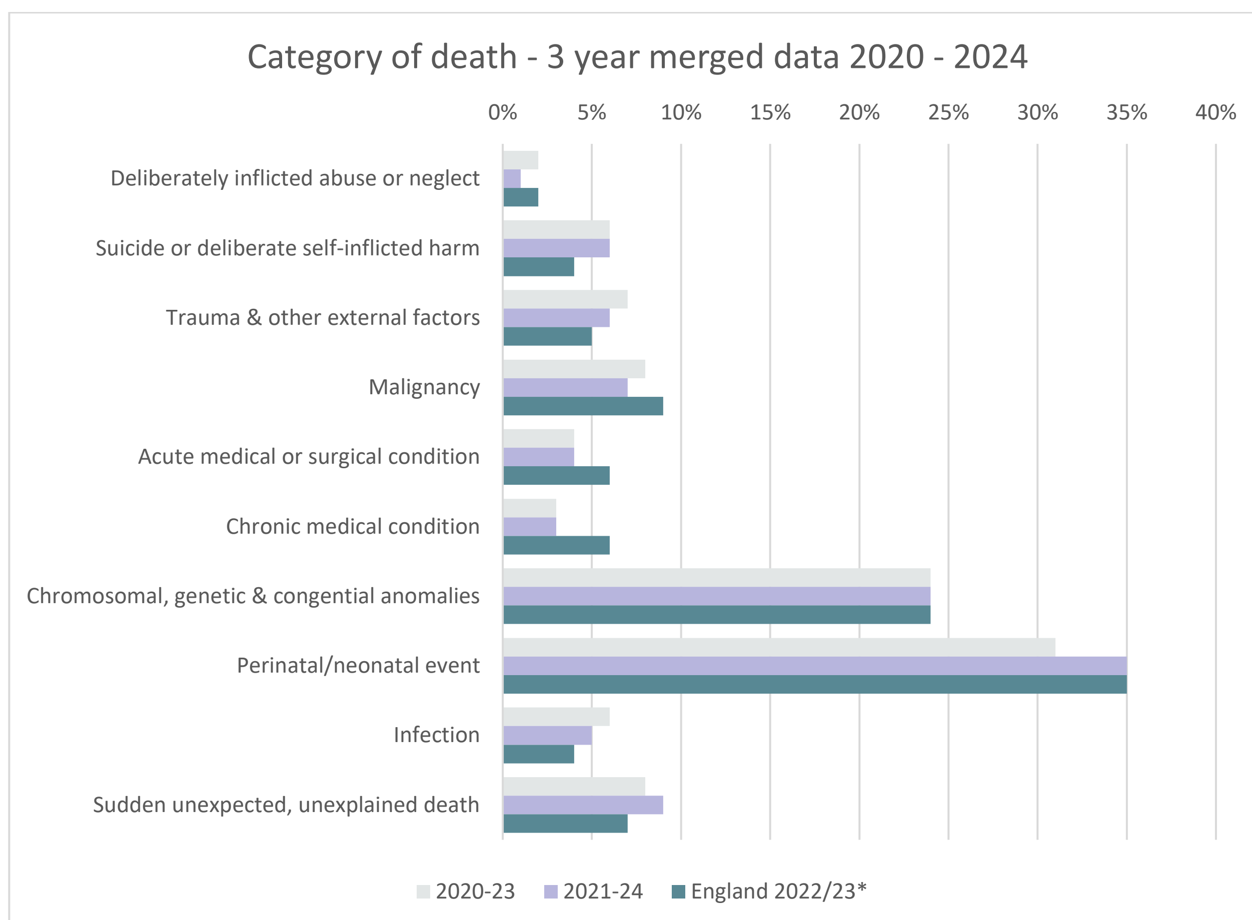
Table a3. Completed CDOP reviews by year: 89

	2017/18	2018/29	2019/20	2020/21	2021/22	2022/23	2023/24
Leicester City	31	31	17	32	35	45	53
Leicestershire & Rutland	41	24	14	32	36	41	36
Total LLR	**72**	**55**	**31**	**64**	**71**	**86**	**89**

Table a4. Completed CDOP reviews by year of death 2023/24:

Year of death	Cases
2019-20	1
2020-21	2
2021-22	17
2022-23	59
2023-24	10
Total	**89**

Chart a8. Completed CDOP reviews by primary category of death - 3 year merged data 2020 - 2024



*Data from NCMD Data Release Child Death Reviews Data: year ending 31 March 2023, published November 2023

Chart a9. Completed CDOP reviews by age group & category of death 2023/24

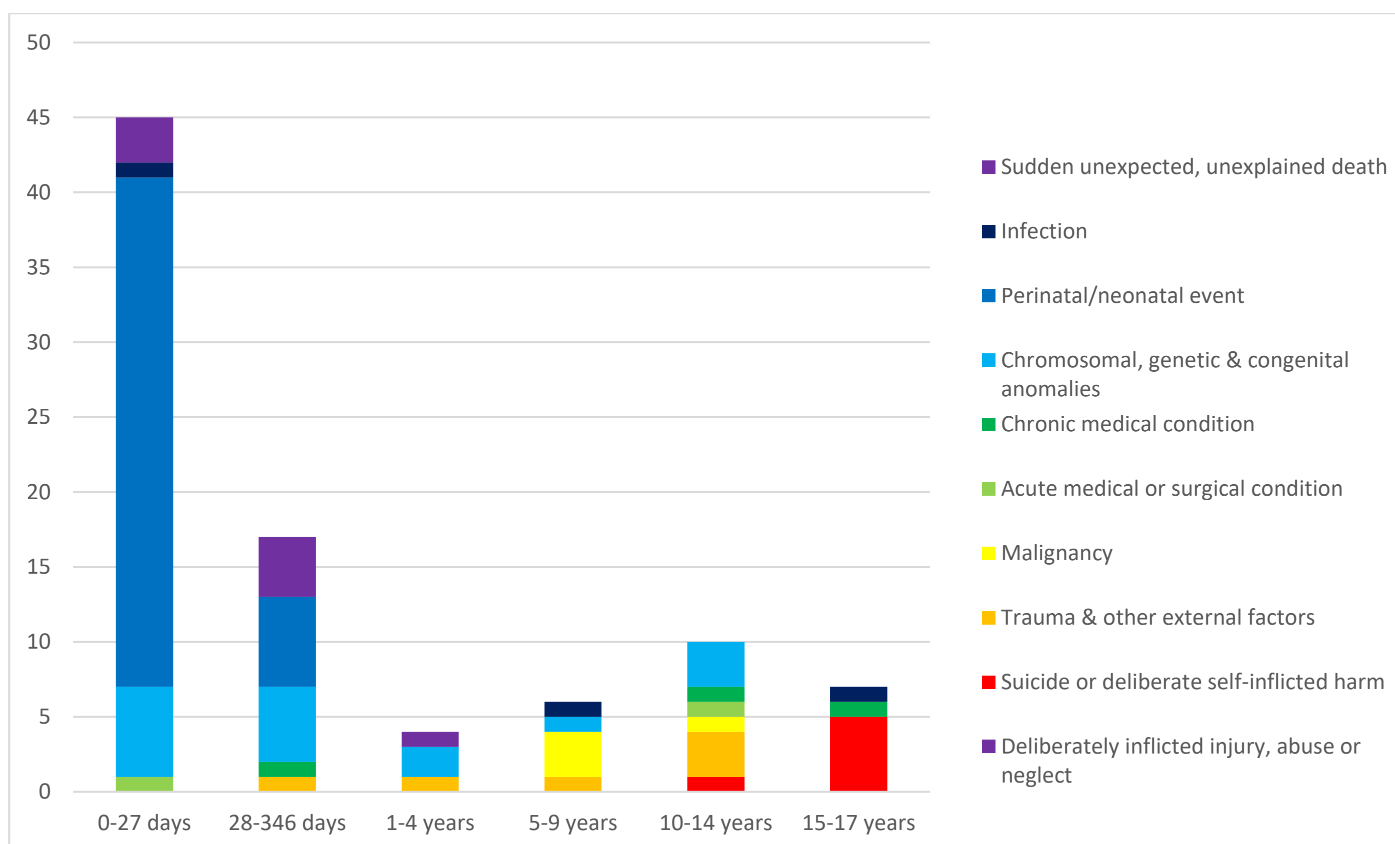


Table a5. Completed reviews by ethnic group & age group 2023/24

Ethnic Group	0-27 days	28-346 days	1-4 years	5-9 years	10-14 years	15-17 years	**Total**
White	17	9	1	3	5	4	**39**
Other	2	0	1	0	0	0	**3**
Mixed	3	1	1	1	1	0	**7**
Black or Black British	5	2	0	1	1	1	**10**
Asian or Asian British	18	5	1	1	3	2	**30**
Total	45	17	4	6	10	17	**89**

Table a6. Completed reviews by ethnic group & primary category of death 2023/24

	White	Other	Mixed	Black or Black British	Asian or Asian British	Total
Deliberately inflicted injury, abuse or neglect	0	0	0	0	0	0
Suicide or deliberate self-inflicted harm	3	0	0	0	3	6
Trauma and other external factors	4	0	0	0	2	6
Malignancy	3	0	1	0	0	4
Acute medical or surgical condition	0	0	1	0	1	2
Chronic medical condition	2	0	0	1	0	3
Chromosomal, genetic or congenital anomaly	5	2	0	2	8	17
Perinatal/neonatal event	16	1	3	5	15	40
Infection	1	0	0	2	0	3
Sudden unexpected, unexplained death	5	0	2	0	1	8
Total	**39**	**3**	**7**	**10**	**30**	**89**

Completed Reviews 2023/24 – Learning: 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.

The National Child Mortality Database uses lists & categories of contributory factors which are set and used nationally. 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 NCMD Contributory Factor Domains, Groups & Subgroups, please see Appendix B

% of cases reviewed in 2023/24 with contributory factors identified: 98%

Table a7. Contributory factors identified by Domain

Across the 89 cases with completed reviews, 413 separate contributory factors were identified.

Domain	Number of cases where CF identified	% of cases where CF identified
Factors intrinsic to the child	85	96%
Factors in the family & social environment	33	37%
Factors in the physical environment	9	10%
Factors in Service Provision	14	16%

Table a8. Contributory factors intrinsic to the child (Domain A) by group

Contributory factors intrinsic to the child were noted in 85 cases; a total of 295 factors were identified.

Factors by group	Number of cases where CF identified	% of cases where CF identified
Child health history/medical conditions	77	86
Risk factors in mother during pregnancy/delivery	46	52
Child's developmental conditions/disabilities	12	13
Emotional/behavioural factors	7	8
Other	6	7
Smoking/alcohol/substance use/misuse by the child	1	1

Table a9. Contributory Factors in the family & social environment (Domain B) by group

Contributory factors in the family and social environment were noted in 33 cases; a total of 67 factors identified.

Factors by group	Number of cases where CF identified	% of cases where CF identified
Parent/carer's health	15	17
Household functioning, parenting/supervision	10	11
Smoking/alcohol/substance misuse/use by parent/carer	8	9
Challenges for parents with access to services	6	7
Domestic or child abuse/neglect	6	7
Cultural factors	5	6
Other	3	3
School/peer groups	2	2
Social Care	1	1

Table a10. Contributory factors in the physical environment (Domain C) by group

Contributory factors in the physical environment were noted in 9 cases; a total of 15 factors were identified.

Factors by group	Number of cases where CF identified	% of cases where CF identified
Sleep environment	4	4
Home safety/conditions	3	3
Vehicle collision	2	2
Public Safety	1	1

Table a11. Domain D: Contributory factors in Service Provision (Domain D) by group

Contributory factors in service provision were noted in 14 cases; a total of 36 factors were identified.

Factors by group	Number of cases where CF identified	% of cases where CF identified
Following guidelines/pathway/policy	8	9
Initiation of treatment/identification of illness	5	6
Staffing/bed capacity/equipment	4	4
Other	3	3
Access to appropriate services	2	2
Communication with family	2	2
Communication within or between agencies	2	2

Completed Reviews – Learning: Modifiable Factors

Definition: A contributory factor is deemed to be modifiable if it may be altered by means of a locally or nationally achievable intervention.

In line with the statutory remit to review child deaths with regards to preventing future child deaths, in addition to identifying Contributory Factors (CF), the CDOP has to consider whether each contributory factor is also a 'modifiable factor' (MF), based on the definition above.

% of cases with modifiable factors (CDOP 2023/24): 42% % of cases with modifiable factors (England): [39%]

Across the 37 cases where modifiable factors were identified, 103 individual factors were recorded – between 1-10 per case (mean 2.8).

Table a12. Number of cases where modifiable factors were identified by category of death 2023/24

Primary category of death (CDOP)	Completed reviews	Modifiable factors identified	% of cases where MF identified
Deliberately inflicted injury, abuse or neglect	0	0	0
Suicide or deliberate self-inflicted harm	6	6	100%
Trauma and other external factors	6	5	83%
Malignancy	4	0	0
Acute medical or surgical condition	2	0	0
Chronic medical condition	3	1	33%
Chromosomal, genetic or congenital anomaly	17	2	12%
Perinatal/neonatal event	40	14	35%
Infection	3	3	100%
Sudden unexpected, unexplained death	8	6	75%
Overall	**89**	**37**	**41%**

Table a13. Cases where modifiable factors were identified by age group 2023/24

Age group	Completed reviews	Cases where modifiable factors identified	% of cases where MF identified
0-27 days	45	13	29%
28-364 days	17	8	47%
1-4 years	4	3	75%
5-9 years	6	2	33%
10-14 years	10	5	50%
15-17 years	7	6	86%
Total	**89**	**37**	**42%**

Table a14. Cases where modifiable factors were identified by ethnic group 2023/24

Ethnic Group	Completed reviews	Cases where modifiable factors identified	% of cases where MF identified
White	39	18	46%
Unknown	0	0	0
Other	3	1	33%
Mixed	7	2	29%
Black or Black British	10	5	50%
Asian or Asian British	30	11	37%
Total	**86**	**37**	**42%**

Table a15. Cases where modifiable factors were identified by English Index of Multiple Deprivation (IMD) decile

IMD decile	Completed reviews	Cases where modifiable factors identified	% of cases where MF identified
1&2	25	13	52%
3&4	20	7	35%
5&6	14	4	29%
7&8	14	7	50%
9&10	16	6	38%
Total	**89**	**37**	**42%**

Table a16. All cases with modifiable factors recorded by Domain (some cases had factors identified in multiple domains) 2021/22 – 2023/24

Domain	Cases with modifiable factors identified by LLR CDOP			% of cases with modifiable factors identified by LLR CDOP, by domain		
	2021/22	2022/23	2023/24	2021/22	2022/23	2023/24
A: Factors intrinsic to the child	2	11	22	7%	35%	59%
B: Factors relating to the family or social environment	16	11	12	62%	35%	32%
C: Factors relating to the physical environment	7	5	9	27%	16%	24%
D: Factors relating to service provision	11	15	13	42%	48%	30%

Note data in this table reflects some of the changes in categorisation between 2021/22 and 2022/23, where factors relating to the pregnancy (including smoking during pregnancy & maternal obesity) are now recorded under Domain A: Factors intrinsic to the child (as opposed to Factors relating to the family or social environment). National comparator data is not yet available for the new categorisation.

Table a17. Most frequently recorded modifiable factors by Domain Group 2023/24:

Most frequently recorded modifiable factors by domain group:	No of cases 2022/23	No of cases 2023/24
Risk factors in mother during pregnancy/ delivery	11	14
Smoking/alcohol/substance misuse/use by a parent/carer	9	8
Following guidelines/pathway/policy	4	7
Initiation of treatment/identification of illness	12	5
Sleep environment	5	5
Staffing/bed capacity/equipment	4	4
Communication within or between agencies	2	3
Child health history/medical conditions	1	3
Household functioning, parenting/supervision	1	3
Challenges for parents with access to services	1	3
Emotional/behavioural factors in child	0	3
Home safety conditions	0	3
D Other	2	2
Communication with family	3	2
Domestic or child abuse/neglect	1	2
Vehicle collision	0	2
Access to appropriate services	0	2
Smoking/alcohol/substance use/misuse by the child	3	1
Public Safety	0	1
A other	0	1
B other	1	0
Parent/carer’s health	1	0
Total number of modifiable factors identified by domain group	**60**	**74**

Table a18. Most frequently recorded modifiable factors by Domain Sub-group 2023/24:

Most frequently recorded modifiable factors by domain sub-group:	No of cases 2022/23	No of cases 2023/24
Smoking in pregnancy	5	9
High maternal BMI	1	7
Parent/carer smoked tobacco/e-cigarettes in the household	6	7
Unsafe sleeping arrangements	3	5
Guideline/policy/pathway available but not followed	3	5
Poor quality referral/assessment/review	1	4
Bottle-fed	-	4
Issue with treatment, including delays	4	3
Child not fully immunised (regardless of reason)	1	3
Co-sleeping	2	3
Service uncommissioned/unfunded	-	3
Poor communication/information sharing between agencies	-	3
Lack of recognition of deteriorating child/clinical symptoms/signs	3	3
Assisted conception	1	2
Delay in seeking/failure to seek medical support	-	2
Lack of appropriate supervision	-	2
Parent/carer known for alcohol use	-	2
Unsafe appliances/environment	-	2
Other factors - C	-	2
Guideline/policy/pathway unclear or unavailable	-	2
Other factors - D	2	2
Staffing capacity or inappropriate skill mix	3	2
Chronic health condition	-	1
Acute/sudden onset illness	-	1
Mental health condition	-	1
Suicidal or self-harm ideation	-	1
Child was victim of bullying	-	1
Social media/internet use	-	1
Risk-taking behaviour	-	1
Substance misuse in pregnancy	1	1
Child known to be a regular drug user	-	1
Child was not brought to appointment(s)/did not attend	1	1
Child was subject to neglect by adult	1	1
Other known domestic violence/abuse	-	1
Complex home circumstances	1	1
Parent/carer had consumed alcohol around the time of child's death	2	1
Parent/carer known for substance misuse	-	1
Overcrowded living conditions	-	1
Accessible water (open water)	-	1
Speeding vehicle/recklessness	-	1
Lack of interpreter availability/use/suitability	-	1
Poor communication between professionals & family	2	1
Poor information sharing with family	-	1
Issue in diagnosis	5	1

Lack of escalation for senior review	-	1
Bed/cot capacity	-	1
Equipment related issues	1	1
Maternal age	2	-
Child consumed drugs on day of death	2	-
Twin/multiple pregnancy	1	-
Maternal non-compliance with medication	1	-
Physical health condition in parent/carer	1	-
Parent/carer had consumed drugs around time of child's death	1	-
Information provided to parents was inappropriate	1	-
Poor communication/information sharing within an agency	1	-
Poor documentation/record keeping	1	-
Total number modifiable factors identified, by domain sub-group	**60**	**103**

Contributory & Modifiable factors by category of death – completed reviews 2023/24

Table a19. Deaths due to suicide or deliberate self-harm- contributory factors by domain

6 cases reviewed during 2023/24 were categorised as deaths due to suicide or deliberate self-inflicted harm. A total of 56 factors were identified across all 6 cases. 23 factors were identified as modifiable across 5 cases.

Factors by domain	Number of cases where CF identified	% of cases where CF identified	Number of cases where MF identified	% of cases where MF identified
Factors intrinsic to child	6	100%	3	50%
Factors in family & social environment	6	100%	2	33%
Factors in physical environment	1	17%	1	17%
Factors in service provision	2	33%	2	33%

Table a20. Deaths due to trauma and other external causes – contributory factors by domain

6 cases reviewed during 2023/24 were categorised as deaths due to trauma and other external causes. A total of 23 factors were identified across all 6 cases. 9 factors were identified as modifiable across 5 cases.

Factors by domain	Number of cases where CF identified	% of cases where CF identified	Number of cases where MF identified	% of cases where MF identified
Factors intrinsic to child	4	67%	2	33%
Factors in family & social environment	4	67%	2	33%
Factors in physical environment	4	67%	4	67%
Factors in service provision	0	-	-	-

Table a21. Deaths due to malignancy – contributory factors by domain

4 cases reviewed during 2023/24 were categorised as deaths due to malignancy. A total of 9 factors were identified across all 4 cases. No modifiable factors were identified.

Factors by domain	Number of cases where CF identified	% of cases where CF identified	Number of cases where MF identified	% of cases where MF identified
Factors intrinsic to child	4	100%	0	-
Factors in family & social environment	0	-	-	-
Factors in physical environment	0	-	-	-
Factors in service provision	0	-	-	-

Table a22. Deaths due to acute medical conditions

2 cases reviewed during 2023/24 were categorised as deaths due to acute medical conditions. A total of 5 factors were identified across both cases. No modifiable factors were identified.

Factors by domain	Number of cases where CF identified	% of cases where CF identified	Number of cases where MF identified	% of cases where MF identified
Factors intrinsic to child	2	100%	0	-
Factors in family & social environment	0	-	-	-
Factors in physical environment	0	-	-	-
Factors in service provision	0	-	-	-

Table a23. Deaths due to chronic medical conditions

3 cases reviewed during 2023/24 were categorised as deaths due to chronic medical conditions. A total of 12 factors were identified across all three cases. 1 factor was identified as modifiable.

Factors by domain	Number of cases where CF identified	% of cases where CF identified	Number of cases where MF identified	% of cases where MF identified
Factors intrinsic to child	3	100%	1	50%
Factors in family & social environment	0	-	-	-
Factors in physical environment	0	-	-	-
Factors in service provision	0	-	-	-

Table a24. Deaths due to chromosomal, congenital or genetic anomalies

17 cases reviewed during 2023/24 were categorised as deaths due to chromosomal, congenital or genetic anomalies. A total of 65 factors were identified across all 17 cases. 5 factors were identified as modifiable across 2 cases.

Factors by domain	Number of cases where CF identified	% of cases where CF identified	Number of cases where MF identified	% of cases where MF identified
Factors intrinsic to child	17	100%	0	-
Factors in family & social environment	7	41%	1	6%
Factors in physical environment	0	-	-	-
Factors in service provision	6	35%	1	6%

Table a25. Deaths due to perinatal or neonatal events

40 cases reviewed during 2023/24 were categorised as deaths due to perinatal or neonatal events. A total of 176 factors were identified across all 40 cases. 23 factors were identified as modifiable across 14 cases.

Factors by domain	Number of cases where CF identified	% of cases where CF identified	Number of cases where MF identified	% of cases where MF identified
Factors intrinsic to child	40	100%	9	23%
Factors in family & social environment	9	23%	1	3%
Factors in physical environment	0	-	-	-
Factors in service provision	6	15%	6	15%

Table a26. Deaths due to infection

3 cases reviewed during 2023/24 were categorised as deaths due to infection. A total of 9 factors were identified across all 3 cases. 3 factors were identified as modifiable across 3 cases.

Factors by domain	Number of cases where CF identified	% of cases where CF identified	Number of cases where MF identified	% of cases where MF identified
Factors intrinsic to child	3	100%	3	100%
Factors in family & social environment	0	-	-	-
Factors in physical environment	0	-	-	-
Factors in service provision	0	-	-	-

Table a27. Deaths that were sudden, unexpected, and unexplained

9 cases reviewed during 2023/24 were categorised as deaths which were ultimately sudden, unexpected & unexplained. A total of 58 factors were identified across 6 cases. 39 factors were identified as modifiable across 6 cases.

Factors by domain	Number of cases where CF identified	% of cases where CF identified	Number of cases where MF identified	% of cases where MF identified
Factors intrinsic to child	6	67%	5	56%
Factors in family & social environment	6	67%	5	56%
Factors in physical environment	4	44%	4	44%
Factors in service provision	4	44%	4	44%

CDOP Learning Theme: Infant Mortality

Cases notified in 2023-24 of deaths occurring under 1 year of age: 45 (55% of all notifications)

Table a28. Age at death for notifications of deaths occurring under 1 year of age 2023/24

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

Completed reviews 2023/24

62 cases with completed reviews in 2023/24 were for children dying under 1 year of age (70% of all completed case reviews for 2023/24) compared with 50 cases in 2022/23 (58% of all completed case reviews for 2022/23).

34% of cases with completed reviews in 2023/24 for children dying under 1 year of age had modifiable factors identified, compared to 48% in 2022/23. Some cases had more than one factor noted.

Table a29. Categories of death for children under 1 year – completed reviews 2023/24

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

Table a30. Most frequently recorded modifiable factors by Domain Group for infant deaths with completed reviews 2023/24

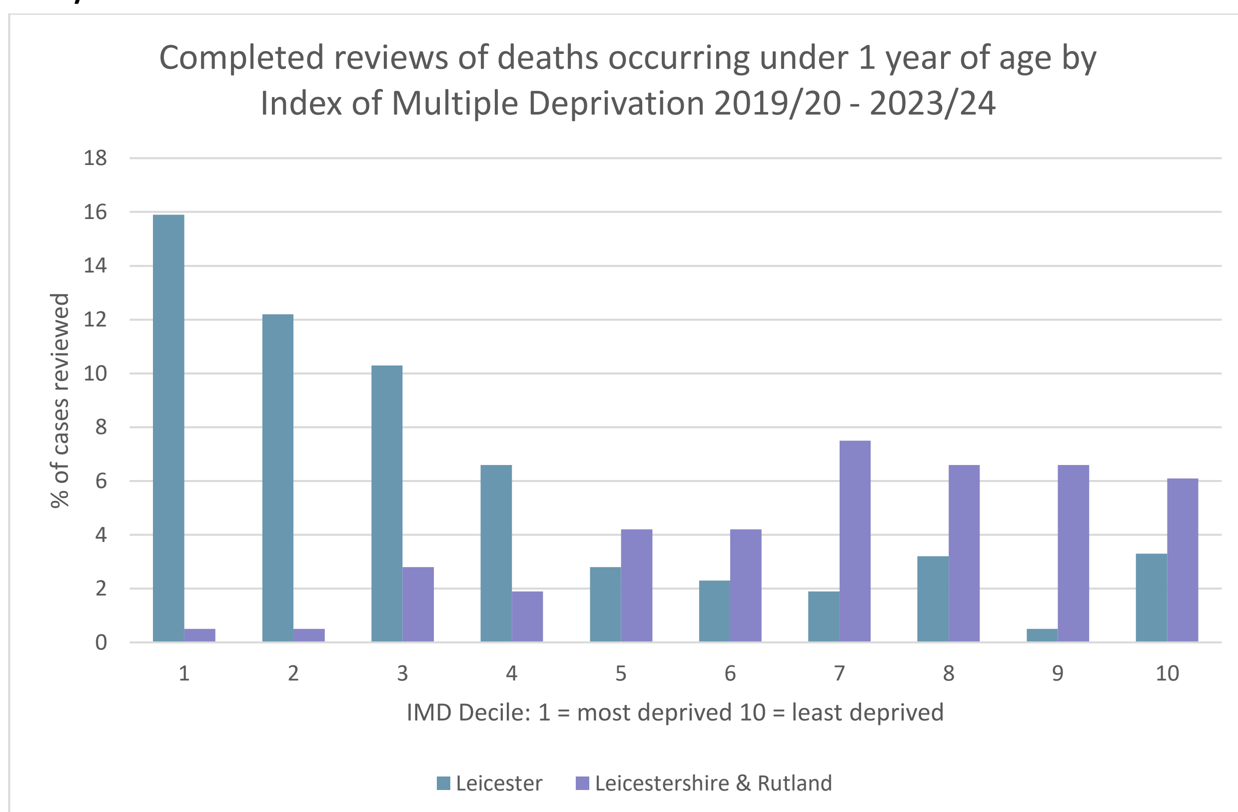
60 separate Modifiable Factors were identified across 21 cases (mean 2.9 factors per case, ranging from 1 to 11 factors identified); some cases had multiple modifiable factors identified within one domain or domain group.

Most frequently recorded modifiable factors by Domain Group:	No of cases 22/23	No of cases 23/24
Risk factors in mother during pregnancy/ delivery	11	14
Smoking/alcohol/substance misuse/use by a parent/carer	8	6
Following guidelines/pathway/policy	4	5
Sleep environment	5	4
Child health history/medical conditions	0	4
Initiation of treatment/identification of illness	9	2
Staffing/bed capacity/equipment	3	2
Communication within or between agencies	1	2
Household functioning	0	2
D Other	2	1
Domestic or child abuse/neglect	1	1
Challenges for parents with access to services	0	1
Home safety/conditions	0	1
Access to appropriate services	0	1
B Other	1	0
Parent/carer's health	1	0
Communication with family	3	0
Total number of cases with factors identified by domain group	**49**	**46**

Table a31. Modifiable factors by Domain Sub-category for three most frequently recorded Domain Groups for infant deaths with completed reviews 2023/24

Risk factors in mother during pregnancy/ delivery:	
Smoking in pregnancy	9
High maternal BMI	7
Assisted conception	2
Substance misuse in pregnancy	1
Smoking/alcohol/substance misuse/use by a parent/carer:	
Parent/carer smoked tobacco/e-cigarettes in the household	6
Parent/carer had consumed alcohol around the time of child's death	1
Parent/carer known for alcohol misuse	1
Parent/carer known for substance misuse	1
Following guidelines/pathway/policy	
Guideline/policy/pathway available but not followed	4
Guideline/policy/pathway unclear or unavailable	1
Sleep environment	
Unsafe sleeping arrangements	5
Co-sleeping (all unsafe/high-risk)	3

Chart a10. % of infant deaths reviewed by Index of Multiple Deprivation 2019/20 to 2023/24



Sudden Unexpected Unexplained Deaths (SUUD) occurring in infants under 1 year

In the period between 1st April 2018 and 31st March 2024, CDOP reviewed the deaths of 24 children who died under 1 year of age, and whose deaths were classified as Sudden Unexpected Unexplained Deaths. This will not include those children whose medical cause of death was deemed to be due to external causes associated with unsafe sleeping.

Table a32. SUUD Infant Case characteristics – 5-year pooled data 2015/16 to 2023/24

	2015/16 to 2020/21 (n=15)		**2016/17 to 2021/22 (n=15)**		**2017/18 to 2022/23 (n=20)**		**2018/19 to 2023/24 (n=24)**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Bottle fed	12	80 %	11	73 %	15	75%	16	67%
First born	4	27 %	6	40 %	8	40%	12	50%
Preterm	10	67 %	9	60 %	10	50%	9	38%
IMD 1&2	7	47 %	6	40 %	7	35%	7	29%
Birthweight <2.5kg	9	60 %	9	60 %	10	50%	9	38%
Mean maternal age	28.8 yrs (20-36 yrs)		28.73 yrs (20-36 yrs)		27.4 yrs (20-36 yrs)		25.7 yrs (17-36 yrs)	
Known to Social Care	7	47%	8	53%	10	50%	10	42%
Housing issues	7	47%	6	40%	7	35%	9	38%
Domestic Abuse	5	33%	7	47%	8	40%	7	29%
Parental drugs/alcohol	4	27%	5	33%	7	35%	7	29%
Medical cause of death:								
‘Unascertained’	12	80 %	11	73 %	16	80%	20	83%
‘SIDS’	3	20 %	4	27 %	4	20%	4	17%
Modifiable Factors								
Unsafe sleeping	10	67 %	9	60 %	12	60%	15	63%
Parental smoking	9	60 %	9	60 %	14	70%	18	75%
One or more MF	13	87 %	13	87 %	18	90%	20	83%
More than one MF	10	67 %	11	73 %	15	75%	17	71%

LLR CDOP Additional Case Learning – completed reviews 2023/24

In addition to learning from identification of contributory and modifiable factors, the CDOP are asked to:

1. Identify and record additional learning from cases. This is in free text form; data is entered into an excel spreadsheet and can then be categorised according to common themes.
2. Identify and record any areas of notable good practice or excellence in relation to service provision.

Learning is shared through a number of routes, and LLR CDOP use 7-minute briefings as a tool to share & disseminate learning points across the system.

Additional learning identified?	Yes 54/89 cases (61%) No 35/89 cases (39%)

Key additional learning themes identified:

1. **Safer Infant Sleeping**
   Importance of seeing sleep environment, clarity of language with families, intergenerational sleeping practices & how to challenge – potential source of conflicting advice for families & may be barrier to following safer sleep guidance, alcohol & cannabis use as risk factors – how to talk to families about this/mitigate risks.
2. **Children with life-limiting conditions**
   Lack of Paediatric Palliative Medicine Consultant in East Midlands **–** explicit communication pathways with cross border cases where different model of service provision used, timely & appropriate consideration of advanced care planning, good communication & advanced planning supports excellent provision of End of Life care regardless of place of death**.**
3. **Suicide & Self-harm in children & young people**
   Potential for hidden difficulties in relation to sexuality - social isolation, early life experiences & previous trauma impacting on resilience - importance of seeking the voice of the child/young person - ensuring support available not just through school term-time, but throughout the academic year (signposting to support during school holidays).
4. **Deaths due to trauma**
   Importance of teaching water safety & risks of open water, as well as teaching children to swim, mobile devices as distraction to drivers.
5. **Assessment/referral in maternity care**
   Accurate identification of risk factors for pre-term births facilitates planning & counselling, optimisation of care through anticipatory management, & ensures babies wherever possible are born in the appropriate setting for their care needs.

Learning from excellence:

Notably good or excellent aspects of service delivery were recorded in 20 cases (22%).

- In 4 cases it was noted that parents had highlighted their positive experiences and feedback directly.
- Examples of excellent service provision across health, children's social care, Early Help, third sector organisations and education were all noted.

Table a33. Cases where excellence in service provision identified, by category of death, completed reviews 2023/24

Category of death	Cases where positive aspects identified
Chromosomal, genetic, or congenital anomaly	8
Perinatal or neonatal event	3
Malignancy	3
Chronic medical condition	2
Infection	1
Suicide or deliberate self-inflicted harm	1
Sudden unexpected unexplained death	1
Trauma or other external factors	1
Acute medical or surgical condition	0
Deliberately inflicted injury, abuse, or neglect	0
Total	**20**

Fig a1. 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 2023/24.

Child Death Overview Panel Actions – completed reviews 2023/24

LLR CDOP has a statutory duty to raise actions following case reviews. Out of 89 completed case reviews, actions were raised in relation to 44 cases. In the 45 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 (including for example, a case where escalation to the Regulator had taken place shortly following notification).

Table a34. Actions taken by LLR CDOP following completion of case review 2023/24

Action undertaken	Number of cases
Clarification of information	16
Escalation of response (including via NCMD Alert)	3
Sharing of information/learning (includes with primary care, ICB, schools, family, clinical teams, Road Safety Partnership & Suicide Audit Prevention Group)	10
Seeking assurance	26
Other	3
No Panel actions identified	45

Learning Briefings developed to share case learning for cases reviewed 2023/24:

- Signs of Aerosol Abuse – 7-minute briefing
  https://lrsb.org.uk/uploads/7-minute-briefing-aerosol-abuse.pdf?v=1723200363

- Eczema & steroid cream use – 7-minute briefing
  https://lrsb.org.uk/uploads/7-minute-briefing-eczema-steroid-creams.pdf?v=1723200400