Leicester, Leicestershire & Rutland Child Death Overview Panel (CDOP) Annual Report 2025-2026

Child Death Overview Panel

Leicester, Leicestershire & Rutland

'The death of a child is a devastating loss that profoundly affects bereaved parents as well as siblings, grandparents, extended family, friends, and professionals who were involved in caring for the child in any capacity. Families experiencing such a tragedy should be met with empathy and compassion. They need clear and sensitive communication. They also need to understand what happened to their child and know that people will learn from what happened. The process of expertly reviewing all children's deaths is grounded in deep respect for the rights of children and their families, with the intention of preventing future child deaths.' [1]

The Leicester, Leicestershire & Rutland Child Death Overview Panel have a statutory duty to review every child death. We also acknowledge that this report represents the individual stories and lives of many children and their families. We are grateful to families, and the professionals who work with them, for sharing their stories and information with us.

We also recognise that the content of this report may be distressing for some readers. Child Bereavement UK is a national organisation that can provide support to anyone affected by the death of a child or young person:

Child Bereavement UK: **childbereavementuk.org** / 0800 02 888 40

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LLR Child Death Review Service
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Sue Stephenson, Child Death Review Nurse
Jo Lane, Child Death Review Nurse
Cristina Young, Child Death Review Nurse
Melvinna West, Child Death Review Service 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 May 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.

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Glossary of abbreviations

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 in the 10% most deprived small areas in the country, IMD 10 an area in the 10% least deprived.
ISMR	Initial Service Management Review
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 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
PSIRF	The NHS Patient Safety Incident Response Framework
SEIPS	Systems Engineering Initiative for Patient Safety A framework for improving quality and safety in healthcare, that looks at how people, equipment, tasks and processes all interact together as part of a system within a particular environment and organisation.
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 a child under 1 year of age, which remains unexplained after a thorough case investigation, including autopsy, examination of the death scene and review of the clinical history.
SUDC	Sudden Unexplained Death in Childhood An unexpected death of a child between 1-18 years that remains unexplained.
UHL	University Hospitals of Leicester NHS Trust

Leicester, Leicestershire & Rutland Child Death Overview Panel 2025/26

Notifications

66 Notifications received for children usually resident in our area. ↓ Down from 92 in 2024/25.

62% Under 1 year

77% In hospital

29% Joint Agency Response

Reviews completed

115 Highest annual number yet. Median 410 days to complete reviews (↓national average). 10 Panels held.

Causes of deaths

54% Perinatal or neonatal events

27% Congenital, chromosomal or genetic anomalies

8% Malignancies

48% Modifiable factors identified

32% Excellent care noted

Top opportunities to reduce risk

Healthy weight in pregnancy • Smoke-free homes • Reduce antenatal smoking • Reduce risks in assisted conception • Follow guidance and policies

LLR CDOP priorities for 2026/27

- Infant mortality
- Suicide prevention
- Family support
- Complex care needs
- Safer infant sleeping

Every review represents a child, a family, and an opportunity to learn. Through partnership working across Leicester, Leicestershire & Rutland, the child death review process seeks to support families, improve services, reduce inequalities and prevent future child deaths.

For more information, see: https://lrsb.org.uk/child-death-overview-panel-cdop

Introduction

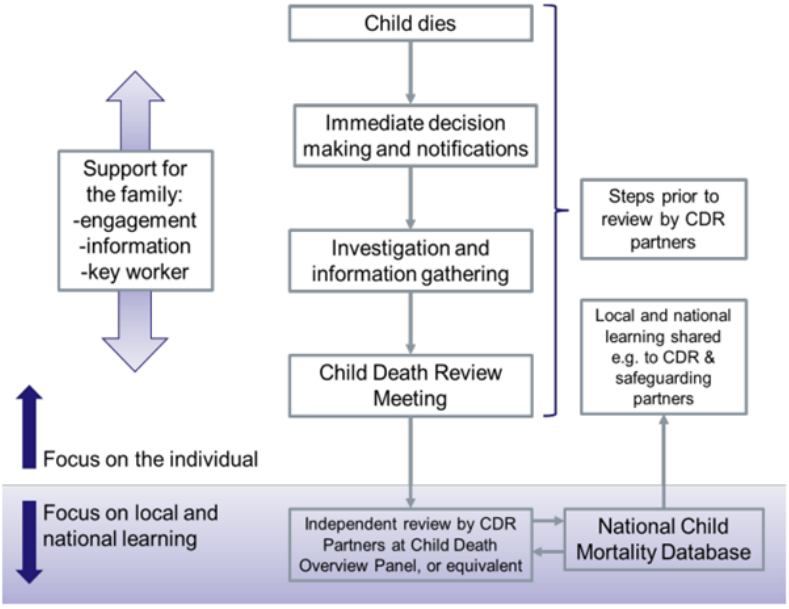
The national process of reviewing child deaths was established in April 2008 and updated in Chapter 6 of Working Together to Safeguard Children 2026. It is the responsibility of the Child Death Review Partners to ensure that a review of every death of a child normally resident in their area is undertaken by a Child Death Overview Panel (CDOP)[2]. Across Leicester, Leicestershire and Rutland (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. 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 (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 as their Key Worker, and representing families' voices at professional meetings.
- Building on 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, particularly focusing on enabling family participation, including providing and receiving feedback as an integral part of the review process for their child.
- Following a period of significantly reduced capacity after bereavement, after successful recruitment, the nursing team are back to full capacity, with Cristina joining the service in January 2026.

Training delivery

- The LLR Child Death Review service organised and ran well-received local Joint Agency Response training for health professionals and police both online and in-person, along with a bespoke session for UHL midwifery & nursing forum.

Progress with case review numbers and review duration

- Having a reduced number of notifications during 2025/26 has allowed the team and panel to complete an unprecedented number of case reviews (115).
- The median time for case completion (410 days) was consistently below the average for England (435 days) throughout 2025/26 for the first time. Whilst there are external factors which impact on review timeframes, this represents considerable and sustained improvement from a nadir of 556 days median time for case completion in LLR in 2021/22 (compared to 335 days for England at that point).

CDOP key workstreams

- LLR CDOP has continued work aligned to 4 key workstreams:
    - Addressing Infant Mortality
        - Collaborative working with key stakeholders to share data and learning from CDOP reviews of infant deaths, to help inform system priorities in addressing high infant mortality rates particularly in Leicester City, including identifying the potential contribution of risks associated with overseas IVF practices.
    - Deaths due to suicide & self-inflicted harm
        - A thematic review was completed, with input from a wide range of stakeholders, learning shared and recommendations fed into the Action Plan for the LLR Suicide Prevention Strategy children and young people's strand (see p20). The **LLR Joint Agency Response pathway for suspected suicide** was agreed, finalised and published.
    - Deaths of children and young people with a learning disability
        - Regular annual thematic review completed (see p19), and representation from LeDeR for every panel case discussion of the death of a child or young person with a Learning Disability).
    - Safer infant sleeping
        - Online session promoting safer infant sleeping & the LLR Safer Sleeping Risk Assessment Toolkit during Baby Fortnight 2025 and Safer Sleep week 2026.

Sharing case learning

- The CDOP produced and disseminated STAR briefings (Situation/Takeaway/Actions/Resources) & STAR case learning on topics arising from case reviews. All briefings are available on the **CDOP webpages**:
    - Lithium-ion battery risks/Booking for antenatal care (for primary care)/Management of a floppy infant (for primary care).
- During 2025/26, CDOP has commenced sharing of relevant case learning with the LLR Drug & alcohol related deaths review panel (DARDRP), covering topics around alcohol misuse and mental health difficulties and aerosol misuse.

CDOP representation across the system, partnerships & region

- In addition to the above, LLR CDOP continues to be represented at:
    - The Joint Safeguarding Children Partnership Boards and Case Review Groups.
    - The LLR Healthy Pregnancy, Birth & Babies Strategy Group.
    - The LLR Learning from Deaths Forum.
    - East Midlands Regional CDOP Network, National CDR Nurses network & regional Designated Doctor group.
    - The Association of Child Death Review Professionals (ACDRP) at Working Group & Executive Committee level.

Chart 1. Rate of infant (under 1 year) deaths of babies per 1000 live births by year

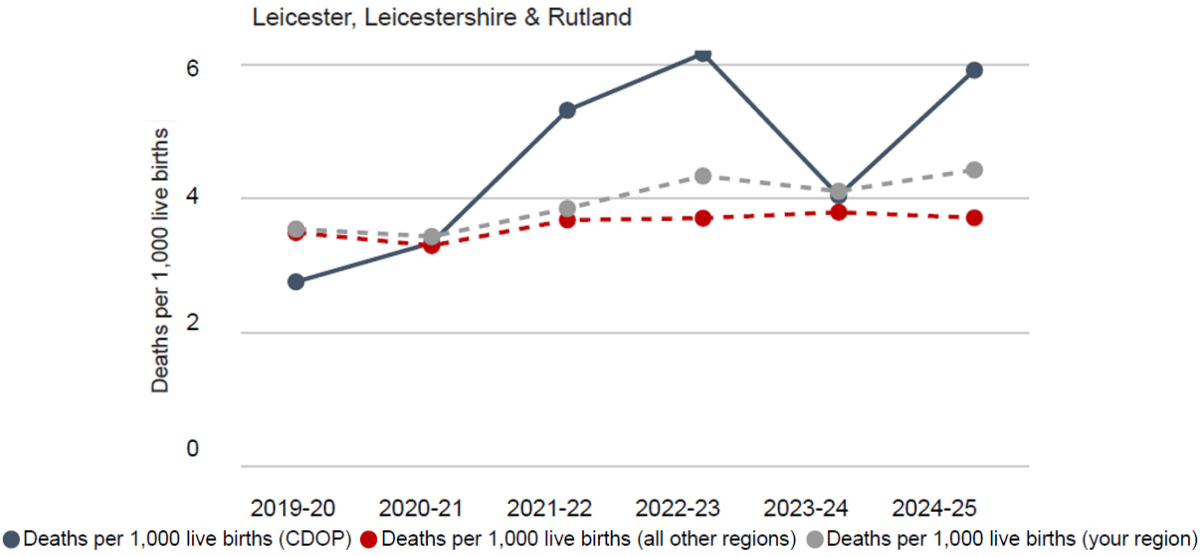


Chart 2. Rate of neonatal (aged under 28 days) deaths per 1000 livebirths by year

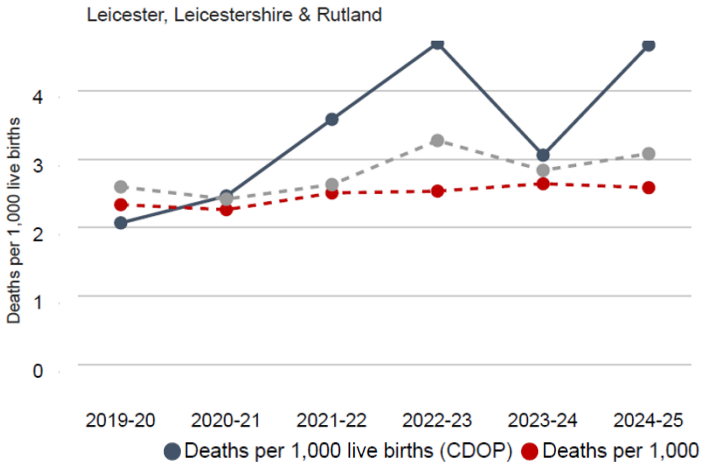
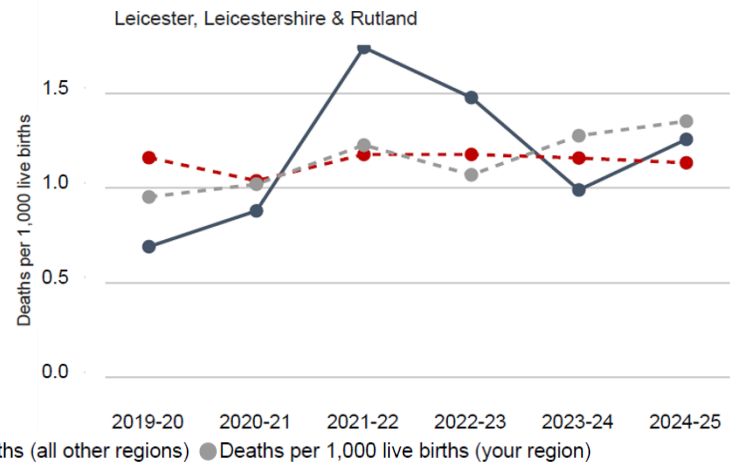
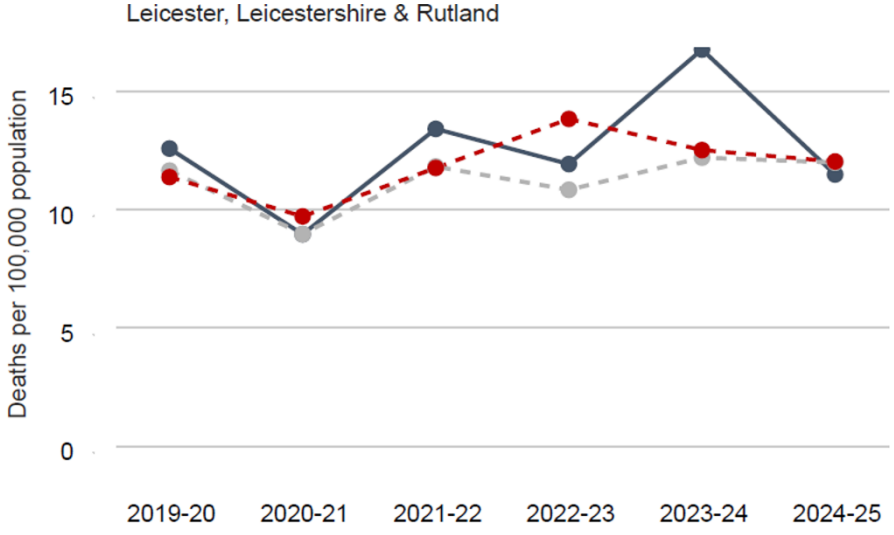


Chart 3. Rate of deaths of babies aged 28-364 days per 1000 live births by year



Deaths per 1,000 live births (CDOP) Deaths per 1,000 live births (all other regions) Deaths per 1,000 live births (your region)

Chart 4. Rate of deaths per 100 000 population of children aged 1-17 years, by year



Deaths per 100,000 population (CDOP) Deaths per 100,000 population (your region) Deaths per 100,000 population (all other regions)

LLR CDOP Notifications 2025/26

Key information: Notifications

LLR CDOP received 66 notifications of deaths of LLR residents under the age of 18 years (a decrease from 92 in 2024/25), the mean number being 85.6 notifications each year for the past 5 years.

Local Authority:

- Leicester City: 34 cases (52%)
- Leicestershire & Rutland: 32 cases (48%)

0-17yr population (ONS 2025 estimates):

- Leicester City: 86 600
- Leicestershire & Rutland: 154 700

19 (29%) of cases met the criteria for a Joint Agency Response. 'Perinatal' cases (babies who die after birth but before discharge from hospital, excluding stillbirths) continue to make up the largest proportion of notifications received (56% of the total)

- 32% of perinatal cases were babies born before 23 weeks gestation.
- This proportion has increased over time since 2017.

Location of death:

77% of deaths occurred in hospital.

- 52% in Neonatal Unit/Delivery Suite
- 12% in Paediatric Intensive Care

14% of deaths occurred at the child's home (both expected and unexpected).

6% of deaths occurred in a hospice setting.

Ethnicity:

LLR mortality rates by ethnicity largely mirror those seen nationally (NCMD data). Even when deprivation is controlled for, ethnicity is associated with mortality[5].

Infant deaths (per 1000 infants)

- Asian/Asian British 6.5 (6.0 for England)
- Black/Black British 9.2 (7.9 for England)
- White 3.4 (2.9 for England)

Child deaths – 1-17yrs (per 100 000 population)

- Asian/Asian British 12.1 (16.6 for England)
- Black/Black British 21.4 (16.3 for England)
- White 10.6 (10.4 for England)

Deprivation is closely linked to child Mortality[6]. The LLR infant mortality rate for those living in the most deprived areas is 7.7 per 1000 infants, compared to 3.1 per 1000 for those in the least deprived, both of which are higher than comparable figures for England. Child mortality rates for LLR show a similar trend, with 13.0 deaths per 100 000 population in the most deprived areas and 8.3 per 100 000 population in the least deprived (based on NCMD data).

Chart 5. Death notifications by LA of residence 2017/18 to 2025/26

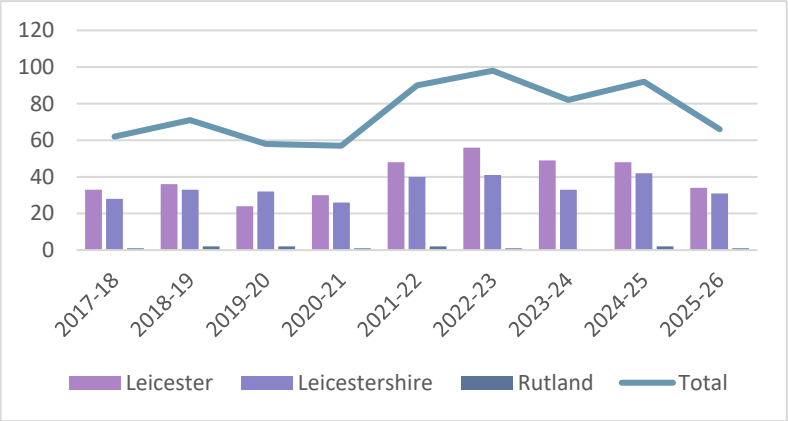


Chart 6. 5-year mean notifications by age group 2017/18 to 2025/26

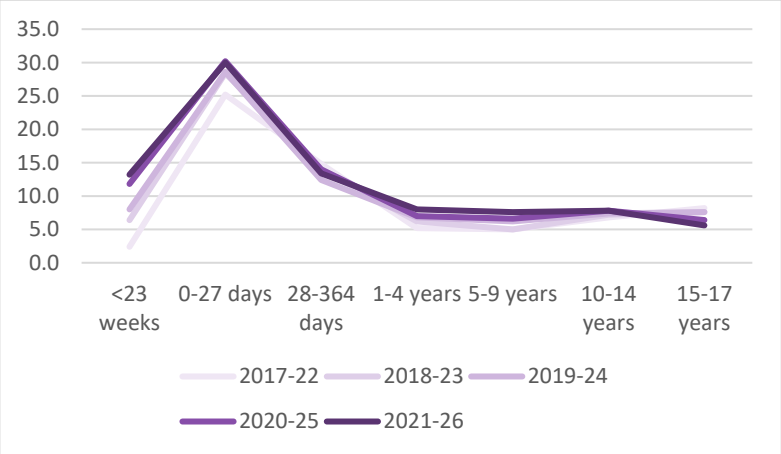


Table 1. Notifications by age & ethnicity 2025/26

Ethnic Group	0-364 days	1-9 years	10-17 years	Total
Asian or Asian British	15	8	3	**26**
Black or Black British	3	2	0	**5**
Mixed	6	0	0	**6**
Other	3	0	0	**3**
White	14	7	5	**26**
Total	**41**	**17**	**8**	**66**

Chart 7. Notifications by category of response 2017/18 to 2025/26

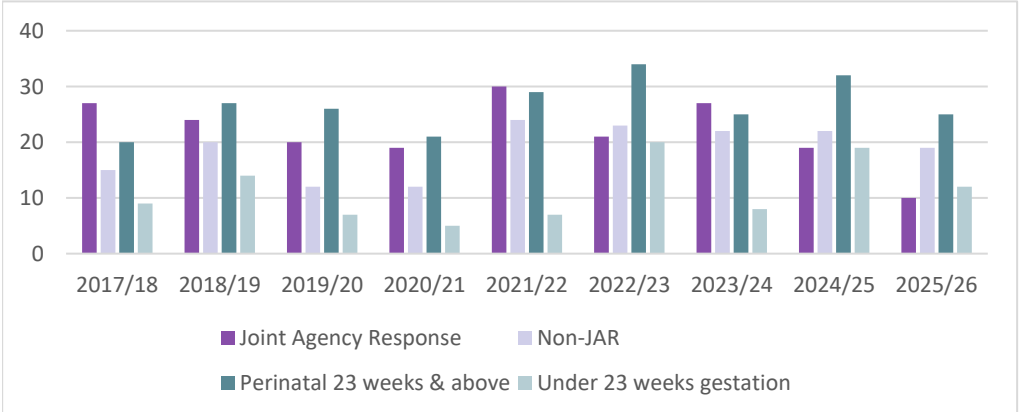


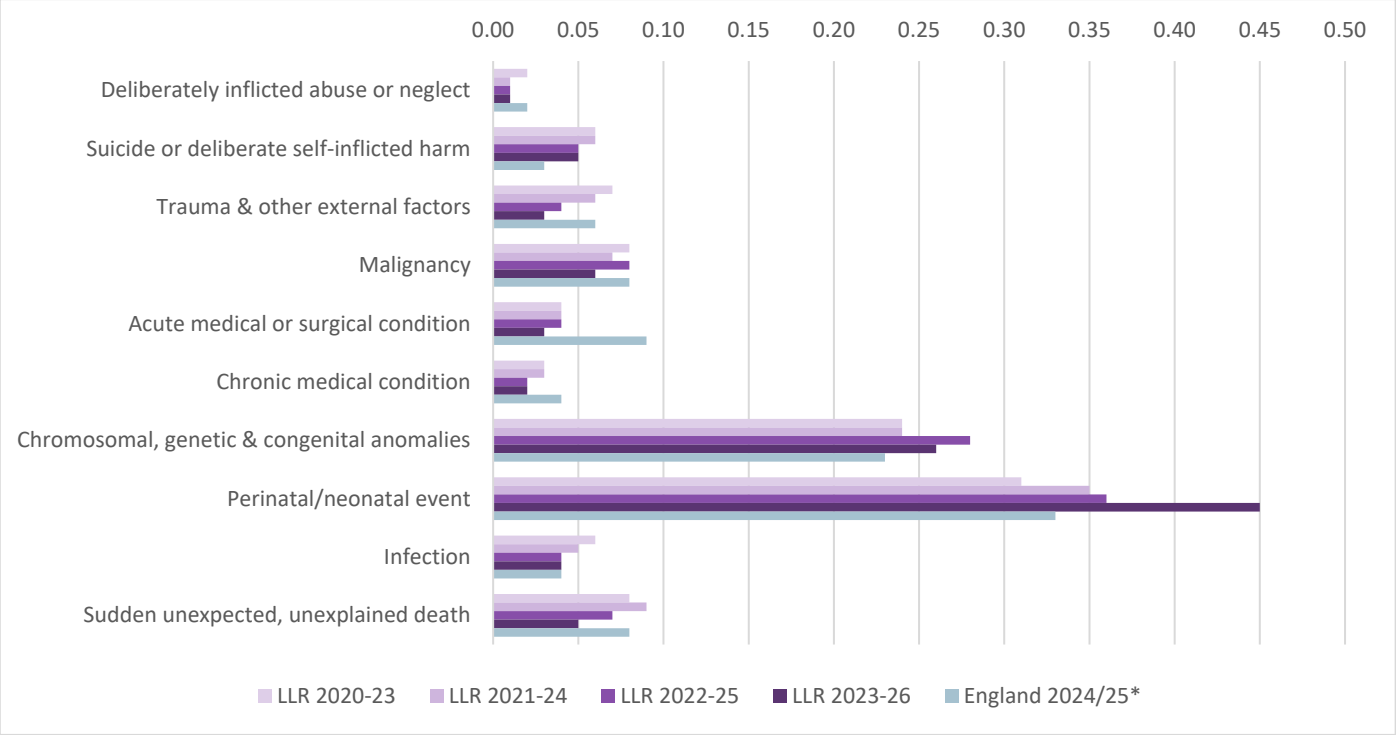
Table 2. Completed reviews by year 2020/21 – 2025/26

	2021/22	2022/23	2023/24	2024/25	2025/26
Leicester City	35	45	53	46	64
Leicestershire & Rutland	36	41	36	35	51
Total LLR	**71**	**86**	**89**	**81**	**115**

Table 3. Completed reviews by year of death 2025/26

Year of death	Cases
2021-22	1
2022-23	4
2023-24	21
2024-25	78
2025-26	11
Total	**115**

Chart 8. Category of death for completed reviews – 3 year merged data 2020 – 2025



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, hence there is a time lag between the year of death and completion of the review.
- In 2025/26 LLR CDOP held 10 panels and completed reviews for 115 cases.
- CDOPs are asked to categorise each case by cause of death (see Appendix A). In 2025/26 in LLR, for completed reviews, the most frequently recorded categories of death were:
    - Deaths due to a perinatal or neonatal events (54% in LLR vs 33% in England*).
        - Includes complications of prematurity/immaturity, perinatal asphyxia and perinatal infection.
        - The increased percentage in LLR is due in large part to a high number of Neonatal-themed panels that were held, driven by a previous backlog in processing and sharing case information.
    - Deaths due to a chromosomal, genetic, or congenital anomaly (27% in LLR vs 31% in England*).
    - Deaths due to malignancy (8% in LLR vs 8% in England*).
    - In the completed reviews cohort, for the first time since 2020, there were no deaths that were classified as Sudden unexpected, unexplained deaths.

*Data from NCMD Data Release Child Death Reviews Data: year ending 31 March 2025, published November 2025

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 C.

Table 4. Domain A: Factors intrinsic to the child 2025/26

Noted in 113 cases (98%).

Factor by group	No of cases	% of cases
Child health history/medical condition	107	93%
Risk factor in mother during pregnancy/delivery	68	59%
Child's developmental condition/disability	8	7%
Emotional/behavioural factors	4	3%
Other	2	2%
Smoking/alcohol/substance use/misuse by child	2	2%

Table 5. Domain B: Factors in the family/social environment 2025/26

Noted in 35 cases (30%).

Factor by group	No of cases	% of cases
Parent/carer's health	16	14%
Smoking/alcohol/substance misuse/use by parent/carer	13	11%
Challenges for parents with access to services	8	7%
Domestic or child abuse/neglect	8	7%
Cultural factors	6	5%
Household functioning, parenting/supervision	4	3%
Poverty & deprivation	4	3%
Social Care	3	3%
Other	1	1%
School/peer groups	1	1%

Table 6. Domain C: Factors in the physical environment 2025/26

Noted in 1 case (1%).

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

Table 7. Domain D: Factors in service provision 2025/26

Noted in 21 cases (18%).

Factor by group	No of cases	% of cases
Initiation of treatment/identification of illness	10	9%
Following guidelines/pathway/policy	7	6%
Communication within or between agencies	4	3%
Communication with family	3	3%
Staffing/bed capacity/equipment	3	3%
Access to appropriate services	2	2%

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.
- Year-on-year normal variation in types of cases reviewed will have an impact on contributory factors captured within that year, so it is important to consider trends over time as well as single-year results.
- Contributory factors were found in every case that was reviewed during 2025/26. Across the 115 cases, 544 separate factors were identified.

- Factors relating to the child were found in 98% of cases.
    - Risk factors in the mother during pregnancy or delivery were seen in 59% of cases (an increase from 40% in 2024/25 and 52% in 2023/24).

- Factors in the social or family environment were noted in 30% of cases.
    - Factors relating to parent or carer's health were seen in 14% of cases, and smoking, alcohol, substance misuse or use by a parent or carer was seen in 11% - both similar to previous years.

- Factors in the physical environment were seen in 1% of cases.
    - For the first time since at least 2015-16, no cases reviewed had contributory factors relating to the sleeping environment.

- Factors in service provision were noted in 18% of cases.
    - This is a decrease from 2024/25, where factors in service provision were noted in 30% of cases.
    - Issues relating to initiation of treatment or identifying illness were noted most frequently (9% of cases, similar to previous years).
    - Following guidelines, pathways or policy was noted in 6% of cases, compared with 16% in 2024/25.

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 2025/26

	Completed reviews	Modifiable factors identified	% of cases where MF identified
Deliberately inflicted injury, abuse, or neglect	1	1	100%
Suicide or deliberate self-inflicted harm	4	4	100%
Trauma and other external factors	1	1	100%
Malignancy	9	0	0
Acute medical or surgical condition	3	1	33%
Chronic medical condition	1	0	0
Chromosomal, genetic, or congenital anomaly	31	6	19%
Perinatal/neonatal event	62	41	66%
Infection	3	1	33%
Sudden unexpected, unexplained death	0	0	0
Overall	**115**	**55**	**48%**

Key information: Modifiable factors

- Modifiable factors were identified in 48% of LLR cases (n=55), the same percentage of cases with modifiable factors for England as a whole in 2025/26. This also serves as a good indicator that LLR CDOP are working in line with other Panels across the country in defining and identifying modifiability.
- The top modifiable factors identified in 2025/26 (by sub-group) were:
  - High maternal Body Mass Index
    - Seen in 20.1% of cases across all ages, and 27% of cases occurring under 1 year of age.
    - ONS data indicates obesity in early pregnancy is seen in 28.3% of women in Leicestershire & 26.3% of women in Leicester City (2023/24 – latest data available).
    - Healthy pre-pregnancy weight reduces the risk of pregnancy complications including gestational diabetes & pre-eclampsia, and the risk of congenital malformations[7].
  - Household smoking/e-cigarette use by parent/carer (10.4% of cases).
    - Household exposure to cigarette smoke is well-established to increase the risk of poor child health outcomes, including SIDS, lower respiratory tract infections (chest infections) and asthma[8].
  - Assisted conception (8.7% of cases) & twin/multiple pregnancy (6.1% of cases).
    - All cases involved assisted conception practice which was carried out outside of the UK, outside of best practice guidance (adhered to within the UK under the auspices of the HFEA), involving either mothers with significant risk factors for adverse outcomes, return of multiple embryos, or both (see p16).
  - Smoking in pregnancy was only noted in 4.3% of cases, a year-on-year decrease since 2023/24.
  - No cases with reviews completed during 2025/26 had modifiable factors relating to infant sleeping.

Table 9: Most frequently recorded modifiable factors by Domain Group 2025/26

	2023/24 N (%)	2024/25 N (%)	25/26 N (%)
Total number of cases reviewed	**89**	**81**	**115**
Risk factors in mother during pregnancy/ delivery	14 (12.8%)	14 (17.3%)	36 (31.3%)
Smoking/alcohol/substance misuse/use by a parent/carer	8 (8.9%)	9 (11.1%)	13 (11.3%)
Initiation of treatment/identification of illness	5 (5.6%)	7 (8.6%)	8 (6.9%)
Following guidelines/pathway/policy	7 (7.9%)	13 (16.0%)	7 (6.1%)
Challenges for parents with access to services	3 (3.4%)	1 (1.2%)	5 (4.3%)
Domestic or child abuse/neglect	2 (2.2%)	3 (3.7%)	5 (4.3%)

Key information – learning from what went well.

Learning from good practice, and recognition of excellence in care, is just as important as learning from when care could, or should, be improved. As a standard part of every case analysis, consideration is given to what went well. Notably good or excellent aspects of service delivery were recorded in 37 (32%) of cases, compared with 60% for 2024/25 and 22% for 2023/24).

Using locally derived themes, good or excellent aspects of care were seen in:

- Palliative care (8 cases, including anticipatory care planning, end-of-life care, and family communication)
- Compassionate care following bereavement (3 cases involving Police, Health Visiting and bereavement midwifery care)
- Continuity of care (2 cases, both involving the Diana Childrens Community Nursing Service)
- Multidisciplinary or multiagency working (4 cases, including CAMHS, Social Care, Paediatric Services and Police)
- High quality clinical care (7 cases, including Paediatric Oncology, Obstetric & neonatal care, EMAS, and community nursing input.
- Delivery of emergency care (3 cases, including EMAS and the UHL Home Birth midwifery team)
- Family communication (5 cases, including obstetrics, neonatal services and paediatric oncology)
- Family & SEN support through school (2 cases)
- Inclusion of children & young people with a Learning Disability on the GP LD Register (3 cases)
- Successful organ donation (1 case)
- Sharing of learning through education/training (1 case)

Figure 2. 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 2025/26.

Table 10: Cases where excellence in service provision identified, by category of death for completed reviews 2025/26

Category of death	Cases where positive aspects identified
Chromosomal, genetic, or congenital anomaly	13
Perinatal or neonatal event	12
Malignancy	7
Chronic medical condition	1
Infection	1
Suicide or deliberate self-inflicted harm	2
Sudden unexpected unexplained death	0
Trauma or other external factors	1
Acute medical or surgical condition	0
Deliberately inflicted injury, abuse, or neglect	0
Total	**37**

Theme: Infant Mortality

Key information: Infant deaths in LLR

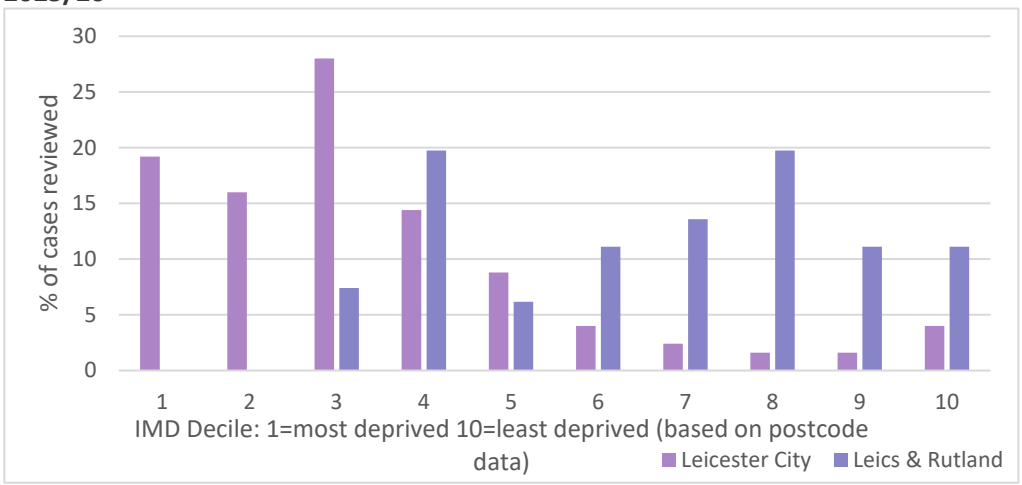
Definition - Infant: liveborn child (of any gestation), up to 364 days of age.

- Between 2022-2024, the infant mortality rate for Leicester City was the second highest in England (7.9 per 1000 live births for Leicester, compared with 4.2 per 1000 live births for England, and 4.1 per 1000 live births for Leicestershire)[9].
- Notifications received in 2025/26: 41 cases (62% of all case notifications) – a decrease from 66 cases (72% of all notifications) in 2024/25.
- Deaths following births at previable gestation (<23 weeks): 12 cases (29% of all infant case notifications).
- Reviews completed in 2025/26: 89 cases (77% of all completed reviews).
- Categories of infant deaths (underlying cause of death) for completed reviews 2025/26:
  - Perinatal/neonatal event: 67%
  - Chromosomal, genetic or congenital anomalies: 19%
  - Malignancy: 1%
- Many factors contributing to infant deaths are related to risk factors for, and consequences of, premature birth.

Table 11. Age at death for notifications of deaths occurring under 1 year of age 2025/26

Age at death	No of cases				
	21/22	22/23	23/24	24/25	25/26
Born under 23 weeks gestation	7 (12%)	20 (28%)	8 (18%)	18 (27%)	12 (29%)
0-27 days	34 (57%)	34 (48%)	26 (58%)	34 (52%)	23 (56%)
28-364 days	19 (32%)	17 (24%)	11 (24%)	14 (24%)	6 (15%)
Total	**60**	**71**	**45**	**66**	**41**

Chart 9. Percentage of infant deaths reviewed by Index of Multiple Deprivation 2022/23 to 2025/26



Deprivation & infant mortality

- There are well-established links between deprivation and infant mortality[6].
- Infant mortality reflects the underlying general health of a population.
- 53.5% of the population of Leicester live in the most deprived quintile (poorest 20% of areas in England), compared to 2.4% of the population of Leicestershire.

Table 12. Most frequently recorded contributory factors by domain sub-category 2025/26

	2024/25 N=55		2025/26 N=89	
Contributory factor by domain sub-category	**N**	**%**	**N**	**%**
Prematurity	27	49.1%	64	71.9%
Congenital/genetic/chromosomal condition	23	41.8%	39	43.8%
Other obstetric complications	15	27.3%	33	37.1%
- Preterm prelabour rupture of membranes	7	12.7%	13	14%
Acute/sudden onset illness in the child	21	38.2%	30	33.7%
Maternal infection (including chorioamnionitis)	10	18.2%	25	28.1%
High maternal BMI	7	12.7%	24	27.0%
Twin/multiple pregnancy	5	9.1%	21	23.5%
Assisted conception	-	-	16	18.0%
Chronic health condition in the child	8	14.5%	12	13.5%

Theme: Infant Mortality

Key information: Modifiable factors in infant deaths

- Modifiable factors identified in 47 cases (52% 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): 36 cases (40%)
  - Smoking/vaping/alcohol/substance misuse/use by parent/carer: 10 cases (11%)
  - Issues with initiation of treatment or identification of illness: 6 cases (7%)
- High maternal Body Mass Index
  - Healthy pre-pregnancy weight reduces the risk of significant pregnancy complications which impact on both mother and baby, including gestational diabetes & pre-eclampsia, and the risk of congenital malformations for the baby[7].
- Household exposure to cigarette smoke
  - Antenatal exposure to second-hand smoke increases the risk of the same complications as smoking (including prematurity, low birth weight and SIDS[8]).
  - Infants exposed to second-hand smoke have increased risks of poor respiratory health and infection; in a car, exposure to second-hand smoke can reach hazardous levels even with windows open, hence the change in the law in 2015 to ban smoking in a private vehicle if a young person (under 18yrs) is present.

Table 13. Most frequently recorded modifiable factors by domain sub-category

Year of review	23/24	24/25	25/26
Total number of infant death cases reviewed	62	55	89
High maternal BMI at booking	7 (11%)	7 (13%)	24 (27%)
Parent/carer smoked tobacco/e-cigarettes in the household	6 (10%)	4 (7%)	10 (11%)
Assisted conception	2 (3%)	-	10 (11%)
Twin/multiple pregnancy	-	-	7 (8%)
Smoking cigarettes/tobacco in pregnancy	9 (14%)	7 (13%)	5 (6%)
Issue in treatment, including delays	1 (2%)	1 (2%)	4 (5%)
Co-sleeping (unsafe/high risk)	3 (5%)	4 (7%)	-
Unsafe sleeping arrangements	5 (8%)	2 (4%)	-

Key information: Infant deaths, assisted conception, multiple pregnancies and risk.

- Assisted conception was identified as a modifiable factor in 11% of infant death reviews completed in 2025/26.
- Twin/multiple pregnancies were identified as modifiable in 8% of cases; these were exclusively cases where IVF (in-vitro fertilisation) had been performed overseas and multiple embryos had been returned, resulting in a multiple pregnancy.
- When multiple embryos are returned, this typically results in a dichorionic, diamniotic (DCDA) pregnancy – each baby has its own placenta and amniotic sac, and the babies are non-identical.
- 'Multiple (twin, triplet or more) pregnancy is the single biggest avoidable risk of IVF' [10].
  - Increased risk of maternal complications including pre-eclampsia, pregnancy-induced hypertension and gestational diabetes.
  - Significantly increased risk of premature birth (being born before 37 weeks).
  - Prematurity is a significant underlying cause of infant mortality, and for those born extremely preterm who survive, there is an increased risk of long-term significant health and developmental challenges.
- Assisted conception in the UK is regulated by the Human Fertilisation & Embryology Authority; the 'One at a Time' campaign has significantly reduced the numbers of multiple pregnancies resulting from assisted conception within the UK.
- Double embryo transfer continues to be widely practised globally, along with offering treatment that may be more affordable and more available to those who would not be eligible for treatment on the NHS in the UK.
- In the 300 infant deaths reviewed by LLR CDOP between 2021 – 2026, assisted conception taking place overseas was deemed contributory in 20 cases, and modifiable in 15 cases.
  - More babies who died having been conceived through assisted conception abroad were twins or multiples (73% vs 36%) and were born earlier (59% vs 36% born before 24 weeks).
  - India was the most frequently identified location for overseas IVF (68% of cases).

Theme: Sudden unexplained infant deaths

Key information: Sudden unexpected unexplained deaths of infants

In the period between 1st April 2020 and 31st March 2026, 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 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 with an identified external cause such as overlay or mechanical airways obstruction.

- 71% 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.
- Over half of babies were not first-born infants, consistent with the wider evidence-base, and highlighting the importance of reiterating safer sleeping advice to families with each baby that is born.
- 33% of babies were born premature (before 37 weeks completed gestation).
    - 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 71% 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.
- With the implementation of whole genome sequencing following unexplained child deaths, the hope is that more families will find out why their child died, and it is anticipated that the number of ultimately unexplained deaths will fall.
- Evidence-based & individualised safer infant sleeping advice remains key to reducing risks, protecting vulnerable infants from both sudden infant death syndrome (SIDS) and from accidental suffocation during sleep.

Table 14. LLR Sudden Unexpected Unexplained Deaths in Infancy –5-year pooled data 2017/18 to 2025/26

	2017/18 - 22/23 (n=20)		2018/19 - 23/24 (n=24)		2019/20 - 24/25 (n=26)		2020/21-25/26 (n=24)	
	N	%	N	%	N	%	N	%
Breast fed	5	25%	8	33%	10	38%	7	29%
First born	8	40%	12	50%	13	50%	11	46%
Preterm	10	50%	9	38%	9	35%	8	33%
IMD 1&2	7	35%	7	29%	7	27%	6	25%
Birthweight <2.5kg	10	50%	9	38%	10	38%	9	38%
Mean maternal age	27.4 yrs (20-36 yrs)		25.7 yrs (17-36 yrs)		27.1 yrs (17-36yrs)		27.1 yrs (17-36yrs)	
Known to Social Care	10	50%	10	42%	10	38%	9	38%
Housing issues	7	35%	9	38%	8	31%	7	29%
Domestic Abuse	8	40%	7	29%	6	23%	6	25%
Parental drugs/alcohol	7	35%	7	29%	7	27%	7	29%
'Unascertained'	16	80%	20	83%	21	81%	19	79%
'SIDS'	4	20%	4	17%	4	15%	3	13%
Other (inc 'SUDI')	0	0	0	0	2	8%	2	8%
Modifiable factors								
Unsafe sleeping	12	60%	15	63%	17	56%	15	63%
Parental smoking	14	70%	18	75%	19	73%	17	71%
One or more MF	18	90%	20	83%	22	85%	20	83%
More than one MF	15	75%	17	71%	17	65%	16	67%

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[11]

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 2025-26, 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. The full report from the LLR CDOP 2025/26 LD thematic review (including updates on 2024/25 recommendations) is in Appendix D – a summary of key findings and themes is presented below:

Progress on action to address 2024/25 recommendations:

- Quality improvement work led by LD Primary Care Liaison Nurses has successfully introduced IT system changes, making it easier for staff to flag those with a learning disability to primary care, and add them to the LD Register.
- Links made between the Step Right Out smoking cessation campaign and Paediatric Respiratory team.
- An NIHR funding bid to support evaluation of an aspiration risk assessment tool for adults and children.
- Training delivery on end-of-life care and palliative care for paediatric clinicians across LLR
- Introduction of the Children with Medical Complexity team within UHL to provide oversight and coordination of MDT care and discharge planning for children with complex medical needs.

Case characteristics of the 6 cases with reviews completed in 2025/26

- As 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 perinatal/neonatal events (where death is due to long-term complications of events occurring in the perinatal period).
- No modifiable factors were identified in any of the cases.
- Positive aspects of service delivery were noted in 5 cases (see Fig 4).
- Median age at death was 11 years (5-17 years)
- 100% of the children & young people were on the GP Practice Learning Disability Register. This is a continued improvement seen over previous years, and testament to the work of the Learning Disability Primary Care Liaison team who have been instrumental in driving positive change through quality improvement work, education, and training across primary and secondary care.
    - In 2024/25, 83% of cases were on the GP Practice Learning Disability Register, compared to 80% in 2023/24 and none of the 10 cases in 2022/23.

Fig 3. Word cloud: What did good care look like?

Fig 4. Word cloud: Family voices – feedback given.

Table 15. Key learning themes identified during the 2025/26 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. Healthcare 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.
	All children whose cases were reviewed during 2025-26 were appropriately on the GP Learning Disability Register. This is a significant improvement from 2022/23 where none were. The Learning Disability Primary Care Liaison team have been instrumental in driving forwards quality improvement work, education, and training for both primary and secondary care, to ensure that every opportunity is taken to optimise the long-term health outcomes for both children and adults with a learning disability.
	Excellent collaborative working between EMAS, Leicestershire Police, Coroners and Acute/Emergency Paediatrics meant that in two cases, the Joint Agency Response was appropriately commenced, but was then able to be rapidly stepped down as more information became available. Children & their families were able to then access the local hospice bereavement suite, for ongoing care.
	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.
	Due to a national workforce shortage of specialist paediatric pathologists, there are delays in post-mortems being undertaken, which can increase the distress to families, particularly if it impacts on cultural mourning practices. Whilst the issue has been raised at a national level, locally the Child Bereavement Specialist Nurse and Child Death Review Nurses (in conjunction with the Coroners Offices) ensure that families are support and kept regularly updated.

Recommendations & actions for 2026/27

1. For the CDOP Chair to write to the Chair of the LDA Collaborative, recommending the development of 'Healthcare passports' for children & young people with a Learning Disability.

2. 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.

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

4. 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.

5. For LLR CDOP to routinely collect information from primary care about participation in Annual Health Checks, as part of the review of deaths of children & young people with a Learning Disability, and to include this information in future thematic reviews.

Theme: Deaths due to suicide or self-inflicted harm

Background:
The death of any child or young person from suicide or self-inflicted harm is a tragedy firstly for them, but also their family, their community and professionals who knew them. These remain a relatively rare event, and so, to help us understand and learn more about how to prevent deaths, LLR CDOP has a longstanding practice of thematic reviews of deaths of children & young people due to suicide or self-inflicted harm. Each case is reviewed by the CDOP, recognising each child or young person's individual and unique circumstance. As set out in statutory guidance, reviewing and analysing information from a larger number of cases grouped together (collated over several years) can also help to identify themes and trends. This can then help to develop informed recommendations and actions that can be taken, to prevent future deaths.

LLR CDOP Suicide & self-inflicted harm thematic review

The review group consisted of members of the CDOP together with colleagues from Public Health, Leicestershire Police, the LLR Suicide & Audit Prevention Group, ICB, Leicestershire Partnership NHS Trust (including representation from CAMHS clinicians and managers), University Hospitals of Leicester NHS Trust, and education (including the Educational Psychology services) and Social Care.

Thematic review elements

- Review of progress on recommendations made following 2023 report.
- Presentation of the current multiagency child death response process following a death due to suspected suicide or self-inflicted harm, and current bereavement and postvention support in place.
- Finalisation & publication of the agreed LLR-wide **Joint Agency Response to suspected suicide pathway**.
- Review of 5-year dataset and case analyses for all cases notified and reviewed by LLR CDOP of deaths due to suicide/self-inflicted harm (or suspected as such at the point of notification); deaths due to substance use/misuse were excluded from this review.
- Drawing up of new recommendations and Action Plan, for review every 6 months, overseen by the LLR Mental Health Collaborative.

Case characteristics of the 17 cases with reviews completed between Jan 2020 – Dec 2024

- 50% had had current or previous involvement with Social Care.
- 35% had contact with primary care in the preceding 6 months.
- 28% were known previously to CAMHS.
- Most frequently identified contributory factors:
    - Complexities in household functioning (59%)
    - Risk-taking behaviours (including self-harming or previous suicidal behaviours) (53%)
    - Loss of key relationships (53%)
- Most frequently identified modifiable factors:
    - Emotional or behavioural factors in the child (including risky behaviour, social media & internet use, bullying) (35%)
    - Smoking, vaping, alcohol or substance misuse by a parent or carer (23%)
    - Problems in communication within or between agencies (23%)

Recommendations:

- Suicide prevention training for all.
- 'Think family' to help identify those with additional vulnerabilities.
- Bullying & mental health/emotional wellbeing – joining up policies for schools.
- Ensuring access to support if excluded from school, attending alternative provision or electively home-educated.
- Ensuring awareness of the support that is available outside of school term-time.
- For a tailored approach to suicide prevention in children and young people.
- Going beyond signposting: supporting access to the right care and support at the right time.
- Better communication between agencies.
- Supporting parents and carers when a child or young person has emotional distress and mental health difficulties.
- Empowering children and young people to speak up & access support.

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 briefings and thematic reports are published and available online: **https://www.ncmd.info/**

NCMD Programme Thematic Report: Children with life-limiting conditions and palliative and end-of-life care needs, July 2025 [12]

Key points:

- 54% of child deaths occurring between April 2019 – March 2022 were of children who had a life-limiting condition (LLC).
- 58% of deaths of children with a LLC were in those under 1 year of age.
- 77% of children with a LLC died in hospital.
- The review identified needs for improvement in:
    - Appropriate parallel planning & timely engagement with palliative care.
    - Documented and accessible advanced care plans.
    - Appropriateness, timeliness and availability of prescribed medications
    - Leading & coordination of care by a named medical specialist
    - Commissioning & funding of palliative care services
    - Bereavement support and allocation of a key worker for every family.

NCMD Programme Thematic Report: understanding consanguinity-related child deaths, Feb 2026 [13]

Key points:

- Consanguinity (close-relative marriage) is a risk factor for children being born with a genetic disorder, amongst others.
- Across England, 7% of children who died between April 2019 – March 2023 were born to parents who are consanguineous.
- 440 children out of 2602 who died from congenital, chromosomal or genetic conditions during this time period were born to consanguineous parents, and 23% had a history of the condition in at least one family member.
- Key learning themes identified included:
    - Support for families in making informed choices about pregnancy, clinical care and future family planning.
    - Accessibility of information in multiple languages & consistent interpreter use.
    - Appropriate genetic testing offered in a timely, appropriate, sensitive and culturally competent way.
    - Importance of referral to further genetic counselling following the death of a child with sensitivity to emotional, religious and cultural needs.

LLR CDOP Actions 2025/26

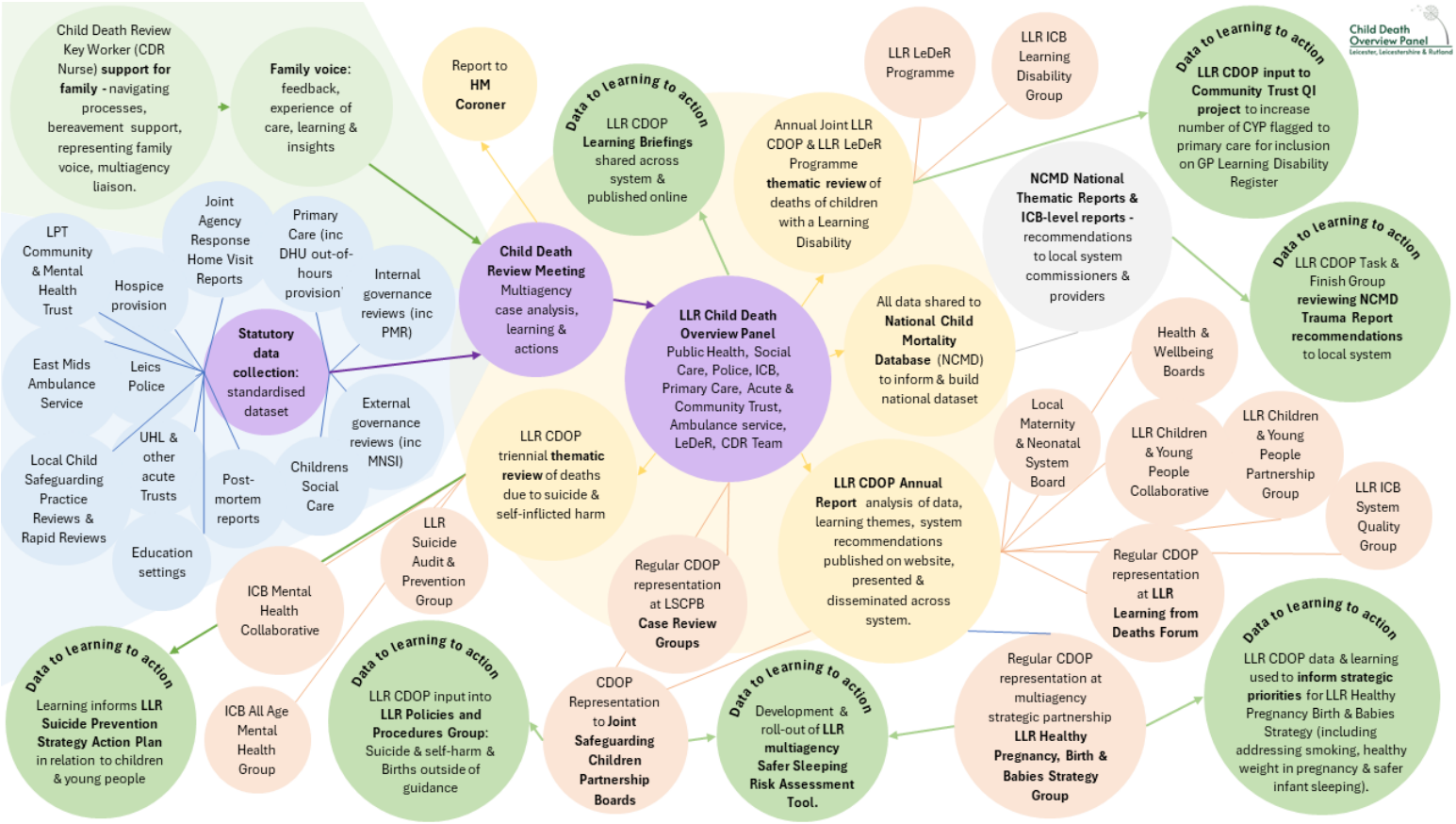
Key information: CDOP Actions 2024/25

- LLR CDOP has a statutory duty to raise actions following case reviews.
- Out of 115 completed case reviews, actions were raised in relation to 70 cases.
- In the 45 cases where no additional CDOP actions were raised, this includes all cases where actions had been raised and assurance of completion of those actions was given prior to the case coming to panel. LLR CDOP has a robust approach to raising and ensuring actions are addressed, with a detailed action log, and escalation process embedded into the panel Terms of Reference.
- The increase in cases where information and case learning was shared (from 6 in 2024/25 to 22 in 2025/26) demonstrates an ongoing commitment to using data from Child Death Reviews and an increase in the strength of partnerships across the system.
- Learning briefings ('**STAR Briefings**') were disseminated to share learning about access to maternity care, primary care management of the floppy infant, and risks of lithium-ion batteries (including those in rechargeable vape devices).

Table 16. Cases where actions undertaken by LLR CDOP in 2025/26

Action undertaken	Number of cases
Clarification of information	18
Escalation of response (including via NCMD Alert)	4
Sharing of information/learning ○ (includes with clinical teams in hospital and community, Social Care, LLR Drug & Alcohol related deaths review panel, ICB, primary care, Public Health, Police, Housing departments)	22
Seeking assurance	47
Other	5
No Panel actions identified	45

Fig 5. LLR CDOP System map showing the process of data collection, learning, collaboration and action (See Appendix A).



1. Infant Mortality in LLR

- Within Leicester City:
  - As part of the Long-Term Plan Tobacco Dependency funding Maternity CURE provides support for any birthing person who sees a midwife to access smoking cessation support. Through the service people are also linked to the national maternity incentive scheme. Community and hospital-based midwives can make referrals to the service, and information on smoking in pregnancy and how to give very brief advice is included within the mandatory training days that midwifery teams attend. The service and pathways into the service are well established.
  - The Step Right Out campaign aims to support Leicester residents to pledge to maintain a smoke free home and car. **Step Right Out – Live Well Leicester**.
  - Very brief advice content is currently being developed to embed within midwives and midwifery team mandatory training days. Conversations had during the initial engagement with midwives will support development of a longer package that will equip midwives with conversations about healthy lifestyles and weight. Leicestershire Nutrition and Dietetics Service are developing this training and aim to bring in people with lived experience. LiveWell Mums Walks are to be expanded in 2026 to other locations outside of Abbey Park. The LiveWell service has also started accepting pregnant women with long term conditions and has actively supported some through the healthy lifestyle service. Wider actions that have been identified during the maternal weight health needs assessment development in 2025/26 are to be progressed due to staffing capacity.
- Within Leicestershire & Rutland:
  - In Leicestershire, QuitReady has strengthened its specialist support for pregnant smokers, including expanded treatment options and delivery of the national pregnancy incentive scheme, with up to £400 available for achieving quit milestones. Support is provided throughout pregnancy and up to three months postnatally and extends to smoking household members, alongside promotion of smokefree homes to reduce baby's exposure to second-hand smoke.
- Across LLR:
  - Sessions covering safer infant sleeping & use of the Safer Sleeping Risk Assessment tool were delivered as part of 'Baby Fortnight' and Safer Sleep Week 2026.
  - In view of high infant mortality rates, a significant amount of work is ongoing across LLR. This has included insight work, gathering intelligence from key stakeholders around potential drivers and solutions, which has allowed key themes to be identified, and an Action Plan to be drawn up. Progress on priority actions will be led by a Steering Group, with local and regional oversight and support from OHID and NHSE.

2. Service Provision – learning from incidents: understanding decision-making and assessing risks through a restorative culture of learning.

- Within UHL:
  - The PSIRF framework is utilised to ensure learning is identified, barriers to guidance/policy compliance are explored and actions implemented to support sharing and embedding of learning. Tools such as SBAR, learning boards and briefs are used to communicate good practice and enhance compliance.
  - Easily accessible risk assessments, policy and guidance support all staff to assess and recognise risk with clear escalation processes in place. Training and education are mandatory for risk assessment, identification and management.
  - The PSIRF framework supports a transparent just culture of learning. Families are provided with opportunities to share their experiences, contributing towards investigation reports, feedback and opportunities to meet face-to-face/virtually with clinicians. In addition, frontline staff contribute to quality and safety discussion and are invited to tabletop reviews to ensure they have a voice.

- Within LPT, across the Family, Young People & Childrens, Learning Disability and Autism (FYPCLDA) directorate:
    - Governance and learning processes are strengthened by using SEIPS reviews, round table discussions and learning boards to identify the human, environmental and system barriers that influence practitioner decision-making when guidance is not followed, ensuring this analysis directly informs service improvement.
    - Staff are supported to assess and recognise risk through routine completion of risk assessments, a clear and well-embedded escalation policy, refreshed training and clinical supervision, with ISMRs completed consistently and learning shared widely across teams to reinforce early, confident escalation.
    - A restorative culture of openness and learning continues to be embedded through reflective practice, duty-of-candour contact with families, timely responses through the complaints process, and routine feedback from children, young people and families via mechanisms such as the Friends and Family Test, ensuring their voices and experiences shape understanding of contextual factors and contribute meaningfully to continuous improvement across services.

3. Learning from excellence: End-of-life care

- Regular training is in place for clinicians within LPT to support discussion and development of CYP Advanced Care Plans/Respect forms with families, and training has been delivered to clinicians within UHL as part of a thematic palliative care learning event.
- Close collaborative working continues between hospice, acute and community services with regular meetings to discuss those children with complex care needs who are approaching the end of life.

4. Children & Young People with a Learning Disability

- Advocating for the development of ‘Care Passports’ for children and young people with a Learning Disability has been incorporated into the 2025/26 LD review recommendations.
- A large amount of work has been undertaken, led by the Learning Disability primary care liaison team, to ensure that more children & young people with a Learning Disability are identified for inclusion on the GP Practice Learning Disability Register to support optimisation of health outcomes. This was reflected in the findings from the 2025/26 LD thematic review.
- Children and young people with medical complexity now come under the remit of a specialist team within UHL to ensure there is leadership and oversight of care and discharge-planning.

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

- Within Leicester City:
    - Maternity CURE supports pregnant women throughout their pregnancy journey. Pregnant women are booked/seen by a community midwife and their smoking status is recorded. For smokers very brief advice is offered and they are referred to tobacco dependency support services via email. A CO reading is taken at each antenatal appointment. Every time a patient makes a high CO reading, they are re-referred to stop smoking services. When a patient is admitted smoking status is established and a referral is made to in-house tobacco dependency advisors who visit at the bedside and re-establish and records smoking status. Nicotine replacement therapy is provided, and very brief advice is offered. Conversations about smoking should be carried out at every booking appointment.

  - Step Right Out campaign information is shared with Health Visiting and Midwifery teams via the maternity CURE team. Staff have received information on the campaign via team meetings.
  - From 2023-2024, the Leicester Energy Action (LEA) programme linked Leicester City Council with National Energy Action (NEA), a national charity, to tackle fuel poverty in Leicester. Despite conclusion of the commissioned project, other forms of support remain available and are planned for Winter 2026. This includes warm spaces, pre-tenancy energy management training, city centre comms for advice and support, increasing referrals via referrer refresh (for front line professionals and community organisations), Health and Energy Action Today (HEAT) stations at food aid projects, GP visits, and the Energy Hub (a physical location in City Centre being developed by the LCC Energy Efficiency Team). Funding has also been awarded to reintroduce education sessions in schools and front-line team training.
- Within Leicestershire & Rutland:
  - QuitReady has strengthened its specialist support for pregnant smokers, including expanded treatment options and delivery of the national pregnancy incentive scheme, with up to £400 available for achieving quit milestones. Support is provided throughout pregnancy and up to three months postnatally and extends to smoking household members, alongside promotion of smokefree homes to reduce baby's exposure to second-hand smoke.
  - Public Health works closely with Highways and Transport colleagues to promote sustainable and active travel, helping to reduce traffic-related air pollution around schools and communities. This includes supporting initiatives that encourage walking, wheeling and cycling, with a particular focus on areas and schools experiencing poorer health outcomes, such as higher levels of childhood obesity, poor air quality and deprivation.
  - Public Health also works closely with Planning colleagues to ensure that health and the wider determinants of health are considered early in the development process. This includes promoting the use of Health Impact Assessments for major developments, helping to identify opportunities to improve health and minimise potential negative impacts on local communities.
- Across LLR:
  - Development of smoking cessation in-reach services via Paediatric Respiratory Clinics is still being explored by both City & County teams.

1. **Infant Mortality in LLR**
   - For all agencies across LLR to continue to promote and audit the use of the LLR Safer Sleeping Risk Assessment Tool, and support consistent, evidence-based conversations with families, to help them make informed choices around infant sleeping.
   - For CDOP to continue to gather, analyse and share data around infant mortality across LLR to help inform ongoing work to reduce infant mortality rates, particularly in Leicester City.
   - For CDOP to receive updates from the LLR Infant Mortality Steering Group on progress with identifying system-level collaborative solutions to address some of the wider determinants of health and vulnerability, alongside existing workstreams to address healthy weight in pregnancy and smoke-free households across LLR.

2. **Awareness of the risk of multiple pregnancies when accessing assisted conception outside of the UK**
   - For LLR CDOP to continue to work together with the ICB, Public Health and with the members of the Overseas IVF Task & Finish Group, to share data and learning, and inform next steps to be taken to understand more around drivers for those seeking assisted conception abroad.
   - For LLR CDOP to continue to work with the Association of Child Death Review Professionals Public Health Subgroup and the National Child Mortality Database, sharing local learning, and collaborating to identify wider themes and trends linking infant mortality with assisted conception practices.

3. **Palliative & End-of-life care**
   - For commissioners to address the gaps in paediatric palliative medical expertise across LLR, facilitating access to expert care and advice, and improving transition and handover of medical care for children seen in tertiary centres outside of LLR.
   - Straightforward and timely access to Continuing Health Care assessments and provision of support.
   - Recognition of the cumulative impact of multiple moderate-level care needs across multiple physical domains, on those caring for children and young people should be incorporated into assessment thresholds.
   - Recognition that physical health & support needs may change rapidly during unstable phases of disease progression, with high quality anticipatory care and planning, and services that have the capacity to re-assess and respond rapidly, ensuring needs are met.

4. **Children & Young People with a Learning Disability**
   - For the development and implementation across the system of 'Healthcare passports' for children & young people with a Learning Disability, which follows them through all healthcare settings, not just in hospital.
   - For the Learning Disability Primary Care Liaison Nurse team to continue work to support GP Practices in identifying children and young people with a learning disability, and in providing high-quality annual health checks.
   - For an ongoing focus on smoking cessation in-reach services via Paediatric Respiratory Clinics to promote smoke-free homes and optimise health outcomes for those with complex medical needs and learning disability.
   - For paediatric services across UHL & LPT to ensure that discussions with children, young people and their families about advanced care planning are informed, timely, sensitive and clear, and that, wherever possible, family wishes are accommodated, both as part of anticipatory care, and post-bereavement care.
   - For LLR CDOP to routinely request information about participation in Learning Disability Annual Health Checks, when reviewing the deaths of young people (14yrs or over) with a learning disability.

5. **Suicide & self-inflicted harm**
   - For work to continue to deliver on the recommendations and Action Plan following the thematic review, with six-monthly meetings of the stakeholder group to review progress, and updates provided to the LLR Mental Health Collaborative.

1. **Annual report recommendations:**
   Oversight of the 2025/26 Annual Report recommendations as a standing item on the Panel Agenda, with regular updates from allocated leads for progression of the recommendations.

2. **Reviews & Panel meetings:**
   Regular Child Death Overview Panels every 6-8 weeks, including themed Neonatal Panels, with ongoing work to ensure case reviews are completed in a timely way.

3. **Changes to ICBs:**
   Close working with counterparts in Northamptonshire to optimise opportunities for sharing best practice and learning, and for the intelligence gathered as part of Child Death Review to be shared regularly with the new clustered LLR & Northamptonshire Integrated Care Boards, to help inform strategic commissioning, and to provide assurance to the ICBs in their role as statutory Child Death Review partners.

4. **Ongoing work focused on the 4 Key Workstreams:**
   - Addressing Infant Mortality
     - Ongoing collaborative working with key stakeholders to share data and learning from CDOP reviews of infant deaths, to help inform system priorities, with ongoing participation in the LLR Infant Mortality Steering Group, and work addressing risks and harms associated with overseas IVF.
   - Deaths due to suicide & self-inflicted harm:
     - Ongoing work with key stakeholders to take forwards the recommendations of the Suicide & Self-harm report, with six-monthly reviews of the action plan and reporting on progress to the LLR Mental Health Collaborative.
     - Collaboration with the Suicide Audit & Prevention Group in using the recommendations and action plan to inform the Children & Young People's strand of the LLR Suicide Prevention Strategy.
   - Deaths of children and young people with a learning disability:
     - Ongoing work with the LLR LeDeR programme, representation from LeDeR as co-opted members of CDOP, and annual themed panels for children & young people with a Learning Disability.
   - Safer infant sleeping:
     - Ongoing delivery, promotion, evaluation & updating of the LLR Safer Sleeping Risk Assessment Toolkit and engagement in the annual Lullaby Trust Safer Sleep Week.

5. **Sharing learning & practice across the system & wider networks:**
   - Sharing learning via the LLR CDOP Annual Report across the Integrated Care System
   - Delivery of Joint Agency Response multiagency training sessions, through an annual in-person training day, and through our online e-learning offer.
   - Development and implementation of a quarterly 'CDOP Bulletin'.
   - Engagement with the LLR Learning from Deaths forum to share learning themes with the wider system.
   - Ongoing participation in East Midlands Regional CDOP Network, with LLR taking a lead role in chairing and administering network meetings.

6. **Family support:**
   - 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.
   - Audit of practice in communicating and supporting families, along with use of the toolkit.

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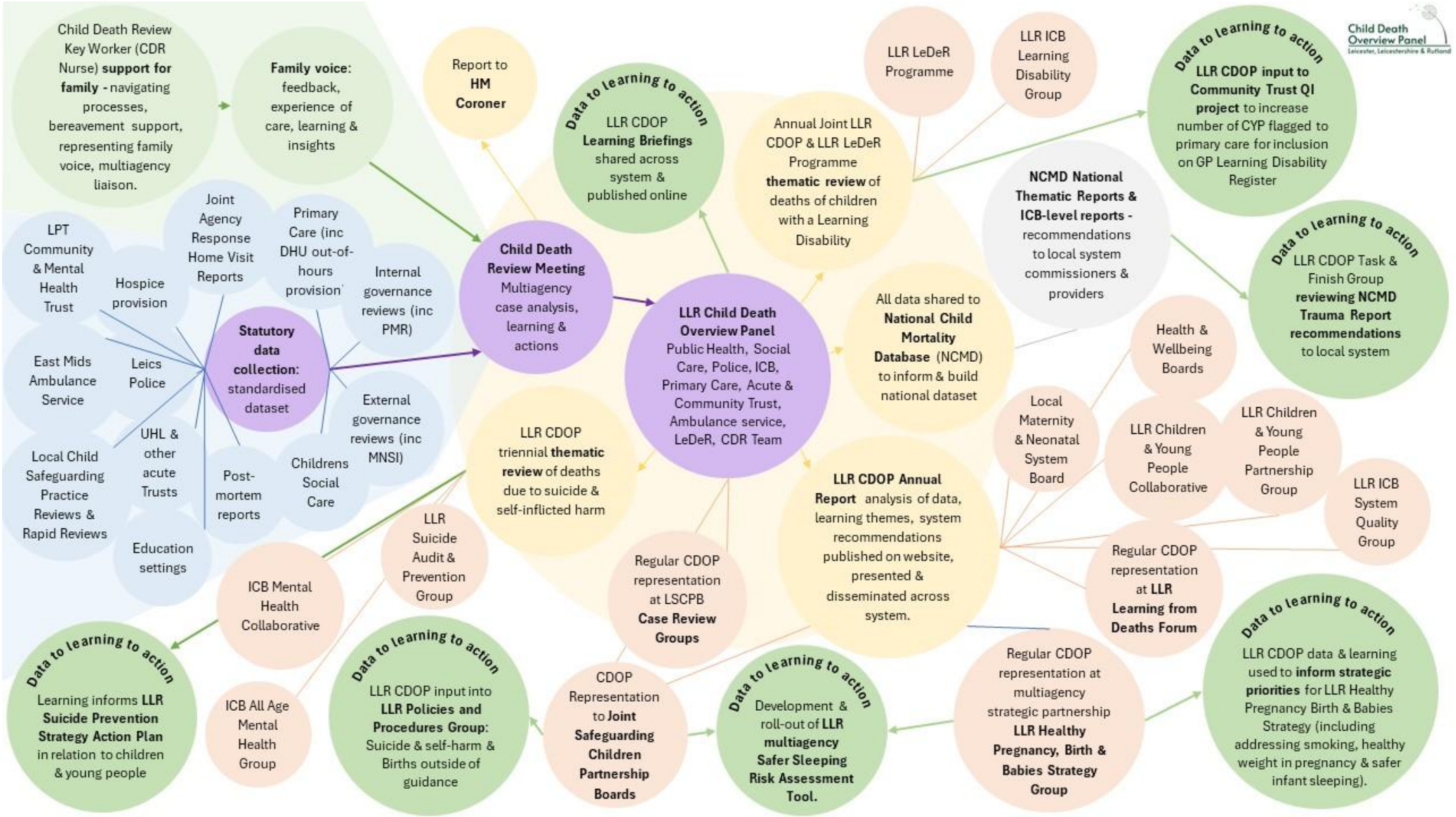
Appendix A. LLR CDOP System Map 2026.



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	

Appendix D

Learning Disability Child Death Reviews

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 collaborate, by carrying out a joint annual themed review. During 2025-26, 6 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.

Update on actions from 2024/25 Review:

1. **Collaboration between UHL, LPT & the ICB LDA Collaborative to develop an LLR-wide Care Passport for children & young people with a Learning Disability.**
   An LLR-wide Hospital Passport is in place currently; a 'Healthcare Passport' that can be used in any care setting would reduce the need for families to repeat information, and support joined-up care, ensuring reasonable adjustments can be made in all healthcare settings that a child or young person may access.

2. **Ongoing work across LLR (led by the Learning Disability Primary Care Liaison Nurse team), to ensure children & young people with a Learning Disability 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.**
   A Quality Improvement project within LPT led by the Primary Care LD Liaison Nurses has led to successful IT system changes, to make it much easier for children & young people with a Learning Disability to be flagged to primary care.

3. **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.**
   Links have been shared between the Step Right Out campaign, and the Paediatric Respiratory Team.

4. **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.**
   This has been incorporated into a larger piece of work, with a bid for NIHR funding to evaluate its use in children as well as adults.

5. **Paediatric services across UHL and LPT to continue to ensure that all children and young people with a life-limiting condition are offered a Children & Young People's Advanced Care Plan (CYPACP), with informed, timely, sensitive, and clear discussions, and that (wherever possible) wishes of children, young people & families are accommodated.**
   Training has been delivered in both LPT & UHL settings, however, there remains no commissioned specialist Paediatric Palliative Medicine input within the East Midlands.

6. **For paediatric services across LPT & UHL to ensure that every child & young person with a Learning Disability & medical complexity has an allocated lead medical consultant.**
   The Children with Medical Complexity team within UHL now provides oversight & supports coordinated MDT care and discharge planning for this cohort of children and young people. The NCMD have updated data collection forms to ask about Medical Leads in every case, enabling monitoring of this locally.

Case characteristics of the 6 cases with reviews completed in 2025/26:

- The most common category for cause of death was:
  - Chromosomal, genetic, or congenital anomalies (67%).
  - Other categories included chronic medical condition and perinatal/neonatal events.
- No modifiable factors were identified.
- Positive aspects of service delivery were noted in 5 cases.
- Median age at death was 11 years (5-17 years)
- 100% were on the GP Practice Learning Disability Register (compared to 83% in 2024/25, 80% in 2023/24 and none of the 10 cases in 2022/23).

Table a1. Key learning themes identified during the 2025-26 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. Healthcare 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.

All children whose cases were reviewed during 2025-26 were appropriately on the GP Learning Disability Register. This is a significant improvement from 2022/23 where none were. The Learning Disability Primary Care Liaison team have been instrumental in driving forwards quality improvement work, education, and training for both primary and secondary care, to ensure that every opportunity is taken to optimise the long-term health outcomes for both children and adults with a learning disability.

Excellent collaborative working between EMAS, Leicestershire Police, Coroners and Acute/Emergency Paediatrics meant that in two cases, the Joint Agency Response was appropriately commenced, but was then able to be rapidly stepped down as more information became available. Children & their families were able to then access the local hospice bereavement suite, for ongoing care.

For those with a life-limiting condition, children, young people & their families benefit significantly from timely, clear and sensitive advanced care planning, including being offered choice around their preferred place of death, and information about practical considerations, before and after bereavement. Discussions around advanced care planning can be complex, and family wishes should be accommodated wherever possible, whilst recognising the needs of the child remain paramount.

Due to a national workforce shortage of specialist paediatric pathologists, there are delays in post-mortems being undertaken, which can increase the distress to families, particularly if it impacts on cultural mourning practices. Whilst the issue has been raised at a national level, locally the Child Bereavement Specialist Nurse and Child Death Review Nurses (in conjunction with the Coroners Offices) ensure that families are support and kept regularly updated.

Fig a1. (Right) Word cloud: Learning from excellence – what good care looked like for completed reviews

Fig a2. (Left) Family voices – family feedback received as part of review for 2025/26

Ongoing recommendations & actions:

1. For CDOP Chair to write to the Chair of the LDA Collaborative, recommending the development of 'Healthcare passports' for children & young people with a Learning Disability.

2. 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.

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

4. 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.

5. For LLR CDOP to routinely collect information from primary care about participation in Annual Health Checks, as part of the review of deaths of children & young people with a Learning Disability, and to include this information in future thematic reviews.

Appendix E: Suicide & Self-inflicted harm report recommendations

Recommendation 1: Suicide prevention training for all.

As per the NCMD national thematic report, for all frontline staff working with children & young people to be supported to attend suicide prevention training:

- We recommend that the LLR Suicide Audit & Prevention Group continue to work to summarise what training currently available, identify gaps in provision for suicide prevention training and assess what is required to fill those gaps.
- We recommend that Leicestershire Partnership NHS Trust consider the purchase and delivery of the STORM Skills Training package for Children & Young People (or equivalent), for frontline staff working in LPT, in addition to the current Adult Training package.

Recommendation 2: 'Think family' to help identify those with additional vulnerabilities.

As per the NCMD national thematic report, for all agencies to improve their awareness of the impact of domestic abuse, parental physical and mental health needs and conflict at home. In addition, where a parent or carer is open to adult mental health services, existing processes should include systematic risk assessment of the needs of the child or young person (including thoughts of suicide) by all partner agencies, to ensure they receive appropriate support:

- We recommend to Health & Social Care across LLR, that with the roll-out of Family hubs & move to the Family Help model of Social Care, that the 'think family' approach includes recognition of the impact of parental mental health needs, parental emotional distress, and complex home circumstances, on both the immediate and the long-term wellbeing of children & young people.

Recommendation 3: Bullying & suicide risk.

As per the NCMD national thematic report, all schools and colleges should have clear anti-bullying policies that include guidance on how to assess the risk of suicide for children and young people experiencing bullying, and when and under what circumstances multiagency meetings will be called to discuss individual children/young people.

- We recommend all schools across LLR (including private schools) to include links/references to guidance on assessing the risk of suicide for children & young people experiencing bullying within their behaviour/anti-bullying policies.
- We recommend that Local Authority Anti-bullying leads in Education carry out an audit of school anti-bullying policies, including guidance on assessing risk of suicide for those who have experienced bullying.

Recommendation 4: Access to support when excluded from school.

When a child or young person is permanently excluded from school or college, any relationships with universal services are at risk of becoming fractured. This should be considered when decisions are being made for a young person's future and should be identified as a potential risk factor for suicide. If a school or college is considering excluding someone there should be multiagency engagement to discuss other potential solutions.

- We recommend that Local Authority Education Inclusion Services ensure the provision of signposting to universal health (physical & mental health) services to those who are attending Alternative Provision settings across LLR.

Recommendation 5: Access to support when electively home educated.

As per the NCMD national thematic report, for the continued roll-out of children and young people's mental health services across community settings to be supported, covering the spectrum of prevention, early intervention, and specialist treatment.

- We recommend that, via Local Authority Inclusion Services across LLR, families of children & young people who are Electively Home Educated are provided with clear and up-to-date information for how to access Tier1/Tier 2 level mental health support for their child or young person.

Recommendation 6: Access to support outside of term-time.
For many children and young people, their educational setting provides them with routine, structure, familiarity, and access to trusted adults outside of their immediate family network. During school holidays and school closure periods (including when transitioning from one school setting to the next), the absence of this may mean that children and young people are isolated and at increased risk.

- We recommend that all education settings across LLR (including private and alternative provision settings) continue to ensure children, young people & families are aware of where they can access support outside of school term-time, particularly for those without a trusted adult outside of their school community.
- We recommend that commissioners support the expansion of provision including 'Community Chill-out zones' and MHST workshop provision across the summer holiday periods (including the period of transition between the end of Year 11 and post-16 settings).

Recommendation 7: A tailored approach for preventing suicide in children & young people.
It was recognised that the findings of this current review highlight the differences in typical characteristics in children compared to adults who die by suicide.

- We recommend that SAPG undertake a similar audit of 5 years data from the LLR adult cohort, to compare characteristics, and use this to inform a more nuanced approach to suicide prevention in those under 18 years.

Recommendation 8: Beyond signposting: supporting access to the right care & support at the right time.
Signposting is not enough for some children, young people & families, and can be perceived as minimising difficulties. Supporting professionals to feel confident in the role of a 'trusted adult' for a child or young person, empowering the wider workforce with skills & confidence to take on that role, is vital to ensure children, young people & families can access the support that is available.

- We recommend all agencies identify & promote training available for adults to increase confidence in talking with children & young people about their mental health.
- We recommend all agencies ensure they can provide children & young people with the support to make self-referrals with them and navigate the system alongside them.
- We recommend increased awareness within the Voluntary, Community & Social Enterprise Sector of how to identify & support vulnerable at-risk children & young people who access their services, using existing resources including the LLR Safeguarding Childrens Partnership guidance.

Recommendation 9: Better communication between services.
Sharing information between parents, schools, health providers and social care can be key in recognising risk, identifying potentially harmful non-engagement, and optimising provision of support. High quality decision-making and provision of best quality care requires all agencies to work together to share information appropriately. Professional supervision within agencies is essential as part of this, as is a clear knowledge of escalation processes. It is key to use a common language across agencies when talking about emotional distress, reactive distress, intent, risk, and mental health conditions.

- We recommend all agencies are aware of, promote and engage with the LLR Safeguarding Children's Partnership Guidance for professionals around self-harming and suicidal behaviours, to recognise and respond appropriately when a child or young person is at risk of significant harm.
- LLR Practice Guidance: Supporting Children and Young People who self-harm and or have suicidal thoughts.

Recommendation 10. Supporting parents and carers of children & young people with emotional distress and mental health difficulties.
Support & resources are key for all families in recognising the emotional needs of their child or young person and understanding their child's behaviour as a means of communication. Support is also needed for parents and carers to understand, locate & navigate the support resources and options available for their child or young person, if they experience emotional distress or mental health difficulties.

- We recommend the ICB All-age Mental Health Group to continue work to map out the current support and information available to parents & carers, to identify where the gaps are currently.

Appendix E: Suicide & Self-inflicted harm report recommendations

Recommendation 11: Empowering children and young people to speak up & access support.
Work to design materials or training for young people should be co-designed by young people. Young people and their peer groups are often trusted confidants for each other and have unique insights and awareness of areas of difficulty, challenge and risk. For some children and young people, their online world is their main source of information and support. Young people need to be empowered to know how to speak up and advocate for themselves and each other.

- We recommend the Suicide Audit & Prevention Group consider expanding resources and training for Mental-Health Friendly Places to those spaces accessed and used by children & young people & provision of spaces where these are not currently available.
- We recommend the Suicide Audit & Prevention Group consider how resources can be co-produced with children and young people, and how this can be utilised to improve the offer for children and young people within the LLR 'Start a Conversation' website.