

Child Death Overview Panel (CDOP) Annual Report **2022-2023**



Child Death
Overview Process

Leicester, Leicestershire & Rutland

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Glossary of abbreviations used

CAIU	Child Abuse Investigation Unit
CDOP	Child Death Overview Panel
CDIM	Child Death Initial Meeting
CDRM	Child Death Review Meeting
CSPR	Child Safeguarding Practice Review
EMAS	East Midlands Ambulance Service
ICB	Integrated Care Board
JAR	<p>Joint Agency Response A coordinated multiagency response to a death occurring in any of the following circumstances:</p> <ul style="list-style-type: none"> - Death due to external causes - Death occurring in suspicious circumstances - Death that is sudden (not anticipated in preceding 24 hours) and for which no medical explanation is evident – a sudden unexpected death in infancy/childhood - Death of a child or young person detained under the mental health act or in custody - A stillbirth occurring without in the absence of a registered health professional.
LeDeR	Learning Disability Mortality Review
LLR	Leicester, Leicestershire & Rutland
LPT	Leicestershire Partnership NHS Trust
LRI	Leicester Royal Infirmary
LSCP	Local Safeguarding Children Partnership
MBRRACE-UK	Mothers & Babies: Reducing Risk through Audit & Confidential Enquiries across the UK
NCMD	National Child Mortality Database
NNU	Neonatal Unit
PMRT	Perinatal Mortality Review Tool
SUDI/C	<p>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.</p>
SIDS	<p>Sudden Infant Death Syndrome An unexpected death of an infant occurring during normal sleep, which remains unexplained after a thorough investigation and review of the circumstances.</p>
UHL	University Hospitals of Leicester NHS Trust



Introduction

The national process of reviewing child deaths was established in April 2008 and updated in Chapter 5 of Working Together to Safeguard Children 2018. It is the responsibility of the Child Death Review Partners to ensure that a review of every death of a child normally resident in their area is undertaken by a CDOP. Across LLR, the Child Death Review Partners are the three Local Authorities and the LLR Integrated Care Board.

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

The process for reviewing child deaths commences with Notification to the Child Death Review team and culminates in final scrutiny at the Child Death Overview Panel (please see fig 1). The Child Death Review process integrates with the Perinatal Mortality Review Programme and up until 1st July 2023 with the Learning Disability Mortality Review Programme (LeDeR). All data from LLR Child Death Reviews is submitted to the National Child Mortality Database (NCMD) for the purposes of data analysis and learning at a national level.

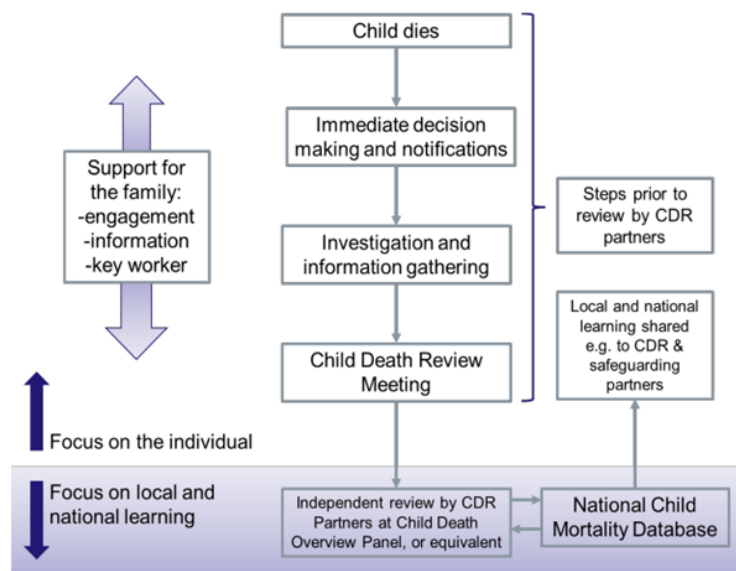


Figure 1: The Child Death Review process as set out in Working Together to Safeguard Children 2018, Chapter 5¹.



Our team: Child Death Review Practitioners

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

- Carrying out a joint home visit together with police, to gather further information around the circumstances of death. In addition, they will review the background history, identify support for the family, with signposting to specialist bereavement support where appropriate, supporting any other issues identified, preparing and submitting a report for HM Coroner (in line with guidance set out in Sudden Unexpected Death in Infancy & Childhood, 2016²).
- Acting as the named Key Worker for families ensuring that families are supported and engaged throughout the review process (in line with Statutory & Operational Guidance, 2018³), by:
 - Being a ready & accessible point of contact for the family.
 - Coordinating meetings as required.
 - Arranging & attending home visits with the Designated Doctor to discuss post-mortem report findings.
 - Providing information to the family on the Child Death Review process.
 - Liaising with Coroners Officer or Police Liaison Office.
 - Representing the voice of the family at professional meetings, ensuring their questions are effectively addressed and providing feedback to family afterwards.
 - Providing support to bereaved parents/carers, until specialist bereavement services commence.
 - Working with the wider multi- disciplinary network including Police, Social Care and Education amongst others.
- The CDRPs have also been involved with:
 - Delivering training about the Child Death Review process to other services including Bereavement specialist midwives, Diana Childrens Community Nursing team & Rainbows Hospice.
 - Scoping exercise looking at practice in another area, benchmarking and sharing local best practice with the other area.

Future plans for supporting families 2023/24:

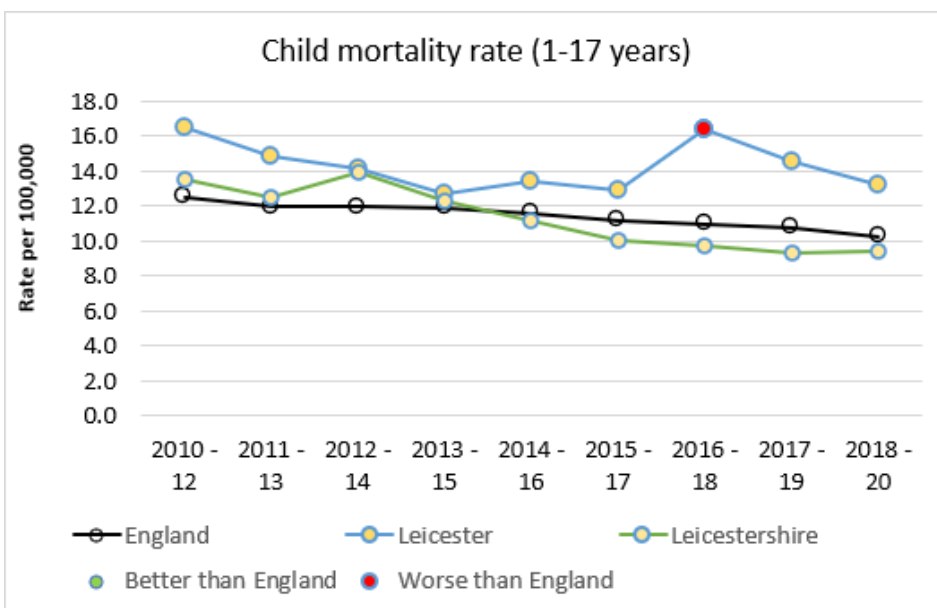
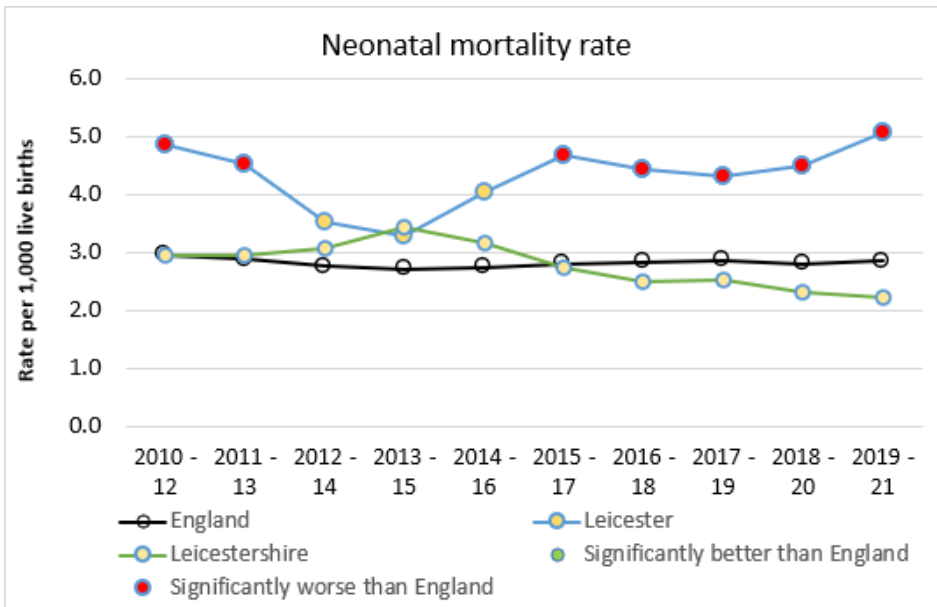
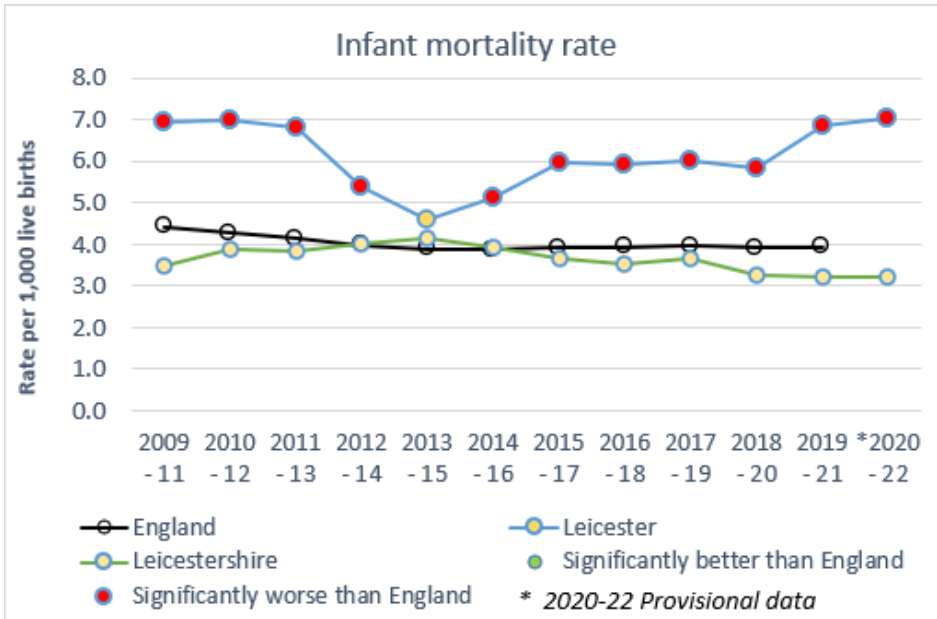
- Development of an online professionals and parent/carer information video.
- Development of feedback tool for parents/carers.
- Development of written information using ReachDeck for translation into other languages for parents/carers.

‘Thank you, I do appreciate your kindness and compassion, other than the GP, you’re the only professional that has really demonstrated how you understand the sheer magnitude of our loss and shown interest in helping us.’

‘CDRP was invited to attend the university to undertake a talk about her role as a Child Death Review Practitioner..... When CDRP discussed this role in the lecture, her passion for the role was evident and it inspired me to request a shadowing opportunity as part of my Alternative Practice.’

‘I have really enjoyed developing my knowledge and skills in this area, the work you do is amazing. Hope to work with you again in the future.’

LLR Summary statistics 2009 - 2021



Notifications 2022/23



Key information

LLR CDOP received 98 notifications of deaths of LLR residents under the age of 18 years (a continued increase from 2021/22).

Annual mean number of notifications over a 5-year period has risen from 67.6 (2017/18-2021/22) to 74.8 (2018/19-2022/23).

21 (21.4%) of cases met the criteria for a Joint Agency Response. Neonatal cases continue to make up the largest proportion of notifications received to CDOP (55% of the total; 37% of whom were babies born under 23 weeks gestation).

Leicester City: 56 cases (57%)

Leicestershire & Rutland: 42 cases (43%)

81% of children died in hospital.

9% died at home.

9% died in a hospice setting.

Table 1. Death notifications by Local Authority 2018/19 to 2022/23

	2018/19	2019/20	2020/21	2021/22	2022/23
Leicester City	36	24	30	48	56
Leics & Rutland	35	34	27	42	42
Total LLR	71	58	57	90	98

Chart 1. Notifications by category of response 2017/18 to 2022/23

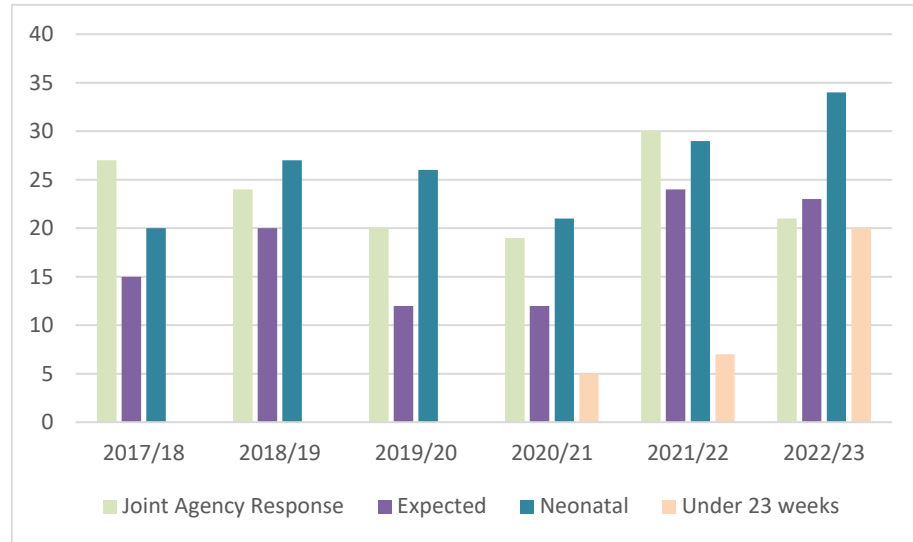


Chart 2. Notifications by place of death

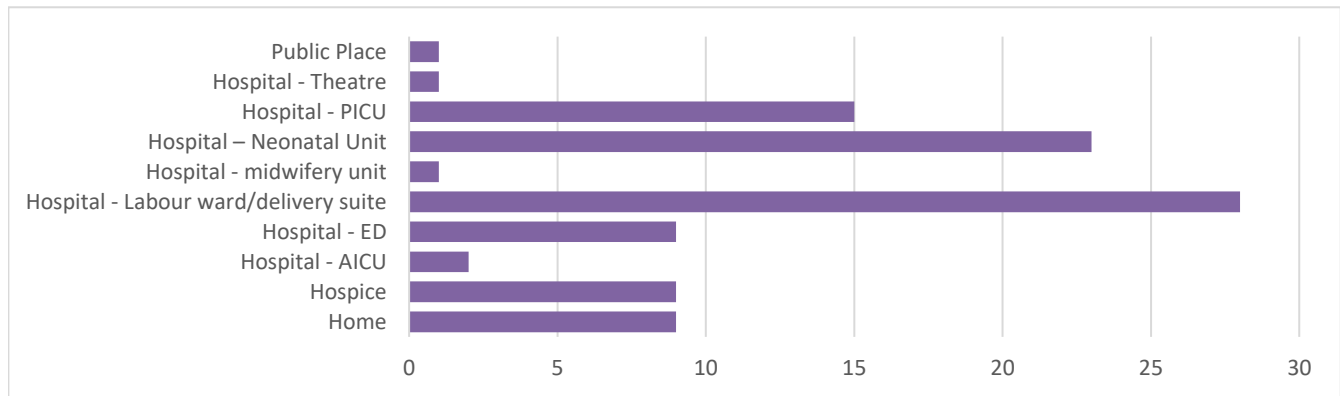


Chart 3. 3-year mean number of notifications by age group 2017 - 2023

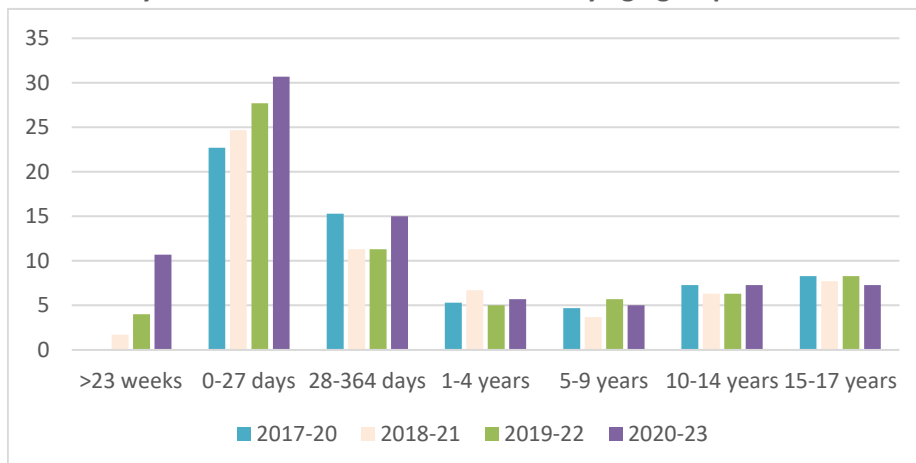
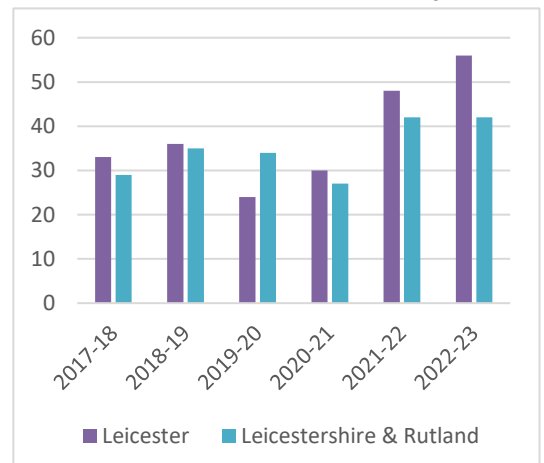


Chart 4. Number of notifications by LA



Completed reviews 2022/23



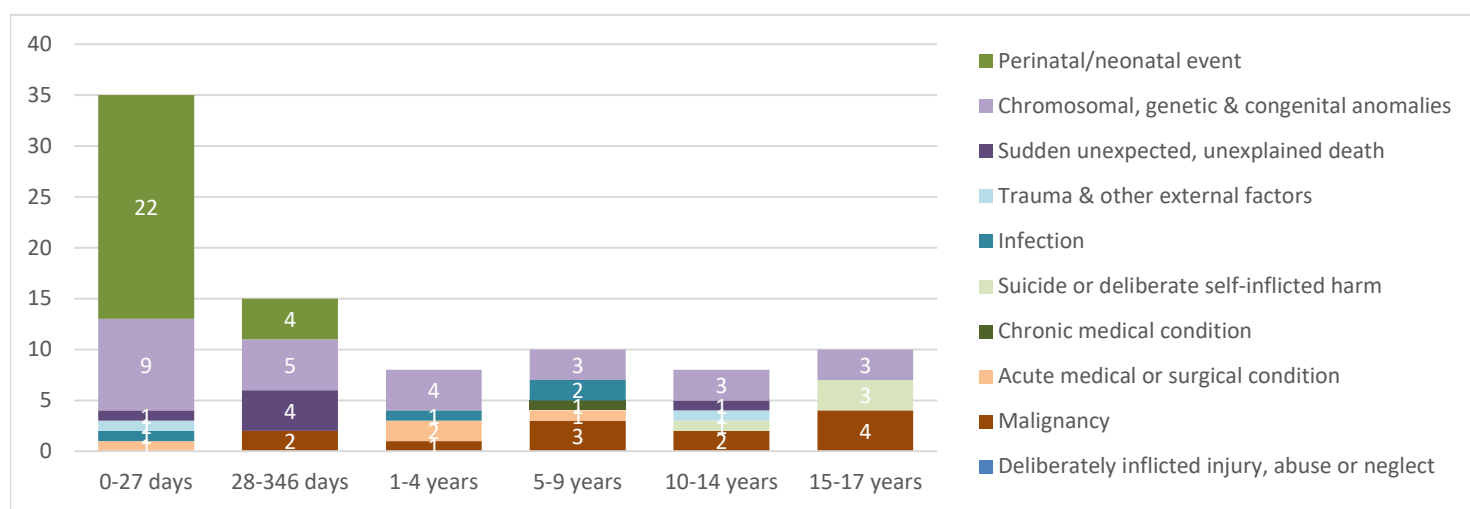
Table 2. Completed reviews by year 2018/19 – 2022/23

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

Table 3. Completed reviews by year of death 2022/23

Year of death	Cases
2018-19	1
2019-20	1
2020-21	12
2021-22	63
2022-23	9
Total	86

Chart 5. Completed CDOP reviews by age group & category of death 2022/23



- In 2022/23 LLR CDOP held 8 panels and completed the reviews for 86 cases.
- Cases are only brought to panel once all other investigations (including Inquests, Police investigations, Serious Incident Investigations and Child Safeguarding Practice Reviews) are concluded and reports available to CDOP, hence there is a time lag between the year of death and completion of the review.
- The top three most frequently recorded categories of death were:
 - Deaths due to a chromosomal, genetic, or congenital anomaly (31%)
 - Deaths due to a perinatal or neonatal event (30%)
 - Includes perinatal asphyxia, complications of prematurity/immaturity and perinatal infection.
 - Deaths due to malignancy (14%)
 - Sudden unexpected, unexplained deaths (7%)
 - Deaths occurring at any age, which, following a thorough investigation and post-mortem, no clear medical cause has been identified.
- Of the cases reviewed, (79%) of deaths occurred in hospital, 11% at home, and 9% in a hospice setting.

Table 4. Completed reviews by ethnic group & age of death 2022/23

Ethnic Group	Age of death						Total
	0-27 days	28-346 days	1-4 years	5-9 years	10-14 years	15-17 years	
White	19	7	6	7	5	8	52
Other	0	1	0	0	1	1	3
Mixed	1	2	1	1	1	0	6
Black or Black British	4	0	1	1	0	1	7
Asian or Asian British	11	5	0	1	1	0	18
Total	35	15	8	10	8	10	86

Modifiable factors 2022/23



Definition:

A modifiable factor is one which may have contributed to the death of the child, and which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of further deaths.

Working Together to Safeguard Children, 2018¹

Table 5: Cases where modifiable factors were identified by category of death 2022/23

Primary category of death (CDOP)	Completed reviews	Modifiable factors identified	Modifiable factors identified (%)
Deliberately inflicted injury, abuse or neglect	0	0	0
Suicide or deliberate self-inflicted harm	4	3	75
Trauma and other external factors	2	1	50
Malignancy	12	2	17
Acute medical or surgical condition	4	1	25
Chronic medical condition	1	0	0
Chromosomal, genetic or congenital anomaly	27	4	15
Perinatal/neonatal event	26	14	54
Infection	4	1	25
Sudden unexpected unexplained death	6	5	83
Total	86	31	36

- Modifiable factors were identified in 36 % of LLR cases (n=31) compared to 39% across England⁴.
- Across the 31 cases where modifiable factors were identified, 60 individual factors were recorded (mean 1.9 per case where MF found).
- Categorisation of factors was updated by the NCMD in November 2022, and used by Panel since that date (see Appendix B for updated classification). Cases with reviews completed prior to this date have been reviewed and assigned the updated classification for data analysis.
- Sub-domain analysis (see Appendix B) shows smoking (both in the household & during pregnancy) to be the most common modifiable factor (11 cases), followed by issues with diagnosis (5 cases) and issues with treatment, including delays (4 cases).

Parental smoking

- Most common modifiable factor nationally⁵.
- Babies exposed to cigarette smoke before birth are at increased risk of preterm birth, low birthweight and Sudden Infant Death Syndrome (SIDS).
- Children exposed to cigarette smoke are at higher risk of breathing problems.

Sleep environment

- Unsafe sleep arrangements and unsafe co-sleeping were identified as modifiable factors in 5 cases.
- As per NICE guidance⁵, families should be strongly advised not to share a sleep space with their baby if their baby was born preterm or low-birth weight, if they are smokers, have consumed drugs or alcohol, or are excessively tired.

Table 6: Most frequently recorded modifiable factors 2022/23

No of cases	Most frequently recorded modifiable factors by domain group:
12	Initiation of treatment/identification of illness
11	Risk factors in mother during pregnancy/delivery
9	Smoking/alcohol/substance misuse by a parent/carer
5	Sleep environment
4	Staffing/bed capacity/equipment
4	Following guidelines/pathway/policy
3	Communication with family
2	Smoking/alcohol/substance misuse by the child
2	Communication with or between agencies



A. Infant Mortality

Infant deaths in LLR: Key findings 2022/23

- Definition - Infant: liveborn (of any gestation) up to 364 days.
- Notifications received: 71 cases (72.4% of all case notifications).
- Reviews completed: 50 cases (58% of all completed reviews).
- Modifiable factors identified: 24 cases (48% of infant deaths reviewed).
- Most common modifiable factors:
 - Risk factors in mother during pregnancy/delivery (including smoking in pregnancy): 11 cases (22%)
 - Initiation of treatment/identification of illness: 9 cases (18%)
 - Smoking/alcohol/substance misuse by parent/carer: 8 cases (16%)
 - Sleep environment: 5 cases (10%)

Table 7. Age at death for deaths occurring under 1 year of age – notifications 2022/23

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

Chart 6. % of infant deaths reviewed by Index of Multiple Deprivation 2019/20 – 2022/23

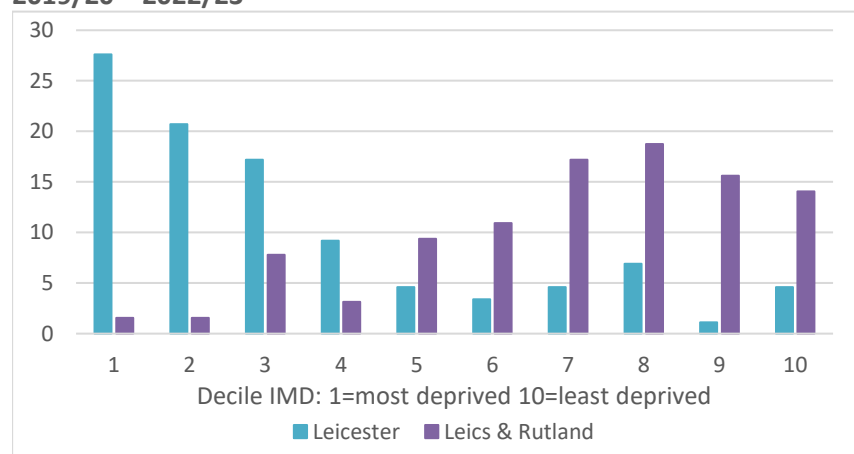


Chart 7. Infant mortality rate for Leicester City (deaths under 12 months per 1,000 live births)

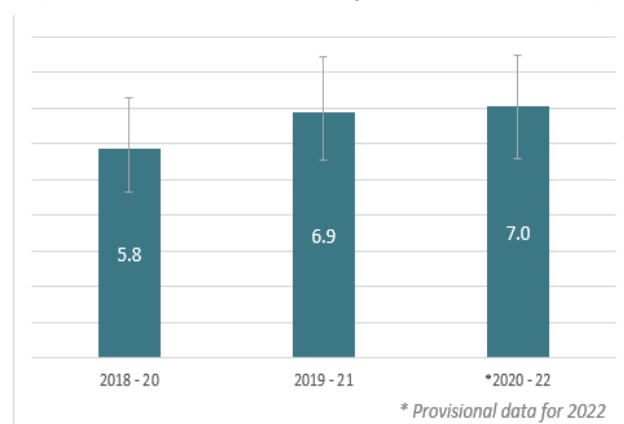


Table 7. Categories of death for children under 1 year – completed reviews 2022/23

Category of death	No of cases	Cases where modifiable factors identified	% of cases where modifiable factors identified
Perinatal/neonatal event	26	14	54
Chromosomal, genetic or congenital anomaly	14	2	14
Sudden unexpected, unexplained death	5	5	100
Malignancy	2	1	50
Acute medical or surgical condition	1	0	0
Infection	1	1	100
Trauma and other external factors	1	1	100
Total	50	24	



Sudden unexpected unexplained deaths of infants

In the period between 1st April 2017 and 31st March 2023, CDOP reviewed the deaths of 20 children who died under 1 year of age, and whose deaths were categorised by the panel as Sudden Unexpected Unexplained Deaths.

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

Table 8. LLR Sudden Unexpected Unexplained Deaths in Infancy –5-year pooled data 2015/16 to 2022/23

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

*Index of Multiple Deprivation Deciles 1&2: 1=most deprived 10=least deprived

NCMD Thematic Reports 2022/23

LLR CDOP submitted case data which was included in the National Child Mortality Database reports into **The Contribution of Newborn Health to Child Mortality** across England, published in July 2022, and into **Sudden and Unexpected Deaths in Infancy and Childhood**, published in December 2022. Key findings included:

- Children who received additional neonatal care after birth made up 83% of children who died before their 1st birthday, 38% of those dying between 1-4 years and 27% of deaths between 5-9 years⁶.
- Modifiable factors were found in 34% of deaths due to immaturity/prematurity, the most common of which were parental smoking & maternal obesity⁶.
- For sudden unexplained deaths in infancy, following a full investigation and review, causes were found in 48% of cases. There was a strong link with sleeping arrangements, and link with deprivation.
- For sudden unexplained deaths in 1–17-year-olds, of those cases which had completed reviews, causes were found in 84%⁷. Both explained and unexplained deaths in this group were associated with a history of convulsions.

Both reports are available in full on the NCMD website: www.ncmd.info



B. Learning Disability mortality reviews

LeDeR Scope & definition: Everyone with a learning disability aged four and above who dies and every adult (aged 18 and over) with a diagnosis of autism is eligible for a LeDeR review.

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 2021⁸




LLR CDOP & LLR LeDeR Joint Themed Review 2022/23

Deaths of all people with learning disabilities aged 4 years and over are reviewed as part of the LeDeR Programme, aiming to identify learning to reduce the increased mortality and morbidity rates seen for this cohort. During 2022-23, 10 case reviews were completed for children who had died, who met the criteria for notification to the LeDeR Programme. A review group was convened with representation from Public Health, Childrens Social Care, UHL, LPT, ICB and the LLR LeDeR Programme to look at these cases collectively, identify themes and learning, and to generate SMART actions.

Of the 10 cases:

- The most common category for cause of death:
 - Chromosomal, genetic, or congenital anomalies (60%)
 - Other categories included acute or chronic medical conditions, malignancy, and infection.
- Modifiable factors were identified in 2 cases.
- Positive aspects of service delivery were noted in 7 cases.
- Mean age at death was 8.3 years (4-17yrs)
- Of the two young people who were eligible for Annual Health Checks in primary care, neither were on the GP Learning Disability Register.

Children & Young People with a Learning Disability - key learning themes identified:

	<p>Children & young people being appropriately included on the GP Learning Disability Register at the earliest opportunity.</p> <ul style="list-style-type: none"> - Ensures appropriate adjustments are made within primary care, including offer of services tailored to children and young people with a Learning Disability (e.g. LD vaccination clinics). - Ensures once young person is 14 years, they are offered an Annual Health Check. - As well as optimising overall health, can provide support with transition from child to adult services. This is also an opportunity for the GP Practice to support the whole family including the needs of the parents.
	<p>Importance of communication with families.</p> <ul style="list-style-type: none"> - Complex care needs good coordination, families need to know who their lead professional is, effective transition to adult services for vulnerable young people is vital.
	<p>End of life care.</p> <ul style="list-style-type: none"> - Advanced Care Planning can be complex for children, young people, and their families, whether or not they have a Learning Disability, and it is important for services to communicate and work well together to provide timely and appropriate support.



C. Suicide & Self-Harm

In January 2023, the LLR CDOP Suicide & Self Harm Review group met to collectively review cases involving the deaths of children and young people in LLR due to suicide or self-inflicted harm (excluding deaths due to substance misuse). Findings and recommendations from the previous 2020 LLR CDOP Suicide & Self Harm Report were reviewed. The recommendations of the 2021 National Child Mortality Database thematic report⁹ were also reviewed and discussed in terms of relevance to local context and case learning.

Key findings:

- 13 cases were identified for inclusion - those cases included in the previous 2017-2020 review where the CDOP review remained open, and all new relevant notifications since.
- Contributory and modifiable factors (including presence of known risk factors for suicide), and case learning were reviewed, and common themes identified.
- 54% (7 cases) had 5 or more identified risk factors (comparable with 56% nationally⁹)
- The most prevalent contributory factors were:
 - Issues relating to school/education 54% (7 cases)
 - History of self-harm 46% (6 cases)
 - Parental separation or family discord 38% (5 cases)
 - Child/young person known to CAMHS 38% (5 cases)
 - Child/young person known to Childrens Social Care at any point 38% (5 cases)
 - Abuse or neglect, suspected or known 38% (5 cases)
- 7 cases occurred during March 2020 to August 2021; the impact of the Covid pandemic was noted as a contributory factor in 1 case and was not deemed to have contributed to the remaining 6 cases.

Summary of Recommendations

1. All frontline staff working with children should be supported to attend suicide prevention training.
2. All agencies should improve awareness of the impact of domestic abuse, parental physical and mental health needs, and conflict at home. This should include assessment of the needs of the child or young person where a parent or carer is open to adult mental health services.
3. Existing LLR Policies and guidance should be reviewed to ensure they emphasise the range of indicators identified (locally and nationally) to improve awareness of the possibility of child suicide.
4. All schools and colleges should have clear antibullying policies that include guidance on how to assess the risk of suicide for children and young people experiencing bullying.
5. When a child or young person is permanently excluded from school, relationships with universal services are at risk of fracturing; this should be considered when decisions are being made, should be identified as a potential risk factor for suicide, and multiagency engagement should be considered to discuss potential solutions.
6. The continued roll-out of children and young people's services across community settings should be supported.
7. To continue promotion of information and advice for parents/carers, primary care and community services about monitoring and support for children and young people, including access to local crisis helplines.
8. For continued work across LLR to ensure children and young people with neurodiversity can access appropriate, timely and informed support and resources around mental health & wellbeing.

D. Children with life-limiting conditions

What did we do?

Leicester, Leicestershire & Rutland CDOP held a themed panel to review nine cases involving children with life-limiting conditions who received planned end-of-life care, and died either at home, or in a hospice setting, between November 2021 and August 2022. Both positive aspects of care and areas of key learning were identified and shared with key stakeholders to inform both ongoing and future service provision for children with life-limiting conditions, and their families.

What did we learn?

Positive aspects of service delivery/examples of excellent care

- Well-coordinated & responsive multidisciplinary & multiagency support throughout care journey and at the end of life was noted in seven cases.
- Positive family feedback was recorded in three cases.
- Excellent examples of end-of-life care were noted in four cases, including supporting the young person to die in the place of their choosing, benefits of early engagement with parallel planning and end of life care, increased joint working across agencies which ensured the child received appropriate care and family were supported to be together.

Children with a life-limiting condition – key learning themes identified:





	<p>Availability of care - when local services (both in the community and in hospital) are not able to provide certain aspects of care, children and families have to travel, and in some circumstances spend less time at home, when receiving palliative care. As the result of local learning from one case, local service provision is now available for children and young people to receive highly specialist oncology treatment.</p>
	<p>Reconfiguration of service provision - children and young people receiving end-of-life care receive input from multiple teams; when one service changes their provision, even on a temporary basis, it can impact on the wider system and all services need to ensure high levels of communication, including during anticipatory care planning, so that the right care can continue to be accessed and provided in a timely way.</p>
	<p>Provision of specialist paediatric palliative medical care both in normal working hours and out-of-hours - Whilst hospice provision now has access to out-of-hours specialist medical advice, there is a lack of fully funded and commissioned specialist Paediatric Palliative Care medical input to support existing services both in the acute and community settings. There is a reliance on the goodwill of medical staff locally to work above and beyond what is currently commissioned to provide appropriate support to highly skilled nursing teams and ensure good quality end-of-life care to children, young people & their families.</p>
	<p>Ambulance transfers from home to hospice for end-of-life care – children and young people receiving end of life care who can no longer be safely managed at home, or who wish to transfer from home to a hospice setting in their final hours, are not currently prioritised for emergency ambulance transport. This risks inadequate symptom management whilst waiting, is potentially distressing for families and clinical staff involved, and impacts on family choices about location for end-of-life care.</p>



Table 9. Cases where learning identified by category of death, 2022/23

Category of death	Total no of cases	Cases where learning identified	% of cases where learning identified
Sudden unexpected, unexplained death	6	6	100
Chronic medical condition	1	1	100
Malignancy	12	10	83
Chromosomal, genetic or congenital anomaly	27	22	81
Infection	4	3	75
Suicide or deliberate self-inflicted harm	4	3	75
Perinatal/neonatal event	26	19	73
Acute medical or surgical condition	4	2	50
Trauma or other external factors	2	1	50
Deliberately inflicted injury, abuse or neglect	0	0	0
Total	86	67	

Key Learning Themes identified during Child Death Reviews 2022/23






	Children and young people with a Learning Disability should be on the GP Practice Learning Disability Register, to ensure that, from the age of 14 years, they are offered the opportunity for an Annual Health Check.
	Communication with families and coordination of care - it is vital that the voice of parents is heard whilst their child is receiving care; vital information informing care decisions can be missed, and distress amplified if families’ voices are not heard. Families need to know who is taking the lead on coordinating their child’s care, both in hospital and in the community.
	The Covid-19 pandemic impacted on children, young people & families’ experiences of care, choices around location for end-of-life and post-bereavement care.
	Safer Sleeping - unsafe sleep practices (including unsafe co-sleeping practices) continue to be a significant factor in sudden unexplained infant deaths; babies who die often have multiple vulnerability factors present.
	IT Integration issues – the lack of integrated IT systems, particularly when mitigating risks posed by services working at or beyond capacity, impacts on communication, information-sharing, and recognition of vulnerability factors for babies, children and young people.



Fig 1. Word cloud summarizing noted excellence in service provision.

Learning from excellence

Notably good or excellent aspects of service delivery are routinely considered during reviews and were recorded in 38 cases (44%).

- In 5 cases it was noted that parents had highlighted their positive experiences directly.
- Examples of excellent service provision across health, children’s social care, Early Help, third sector organisations and education were all seen.



1. Safer Sleeping

For the adoption & roll-out of the multiagency LLR Safer Sleeping Risk Assessment tool to support safer sleep conversations with all families, to reduce the risk of sudden deaths in infancy (particularly in relation to hazardous co-sleeping). Also, for the LLR Healthy Babies Strategy Group to prioritise actions over the next 1-to-2-year period on promoting safer sleep practices.

2. Digital solutions to improve communication

To continue to prioritise the development of integrated electronic records systems to support the appropriate sharing of information & communication between practitioners working with families, particularly to support the transition of families from maternity care to community services. Well-integrated systems would allow for better sharing of information and earlier identification of emerging vulnerabilities, allowing services to offer earlier intervention and support.

3. Infant mortality

Parental smoking and maternal obesity remain significant factors in infant deaths; smoking cessation programmes and work to ensure smoke-free homes need to remain priorities across LLR. We also recommend that the LLR Healthy Babies Strategy Group focus on this as a second priority for focused, intensive system-wide action.

4. Suicide & Self-harm

For all stakeholders to take forward the recommendations from the LLR CDOP Suicide & Self-harm themed report to inform strategies to support mental health and emotional wellbeing of children and young people across LLR.

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

For LLR CDOP to meet with the ICB Transformation Clinical Lead for Learning Disability to share the learning from the LLR CDOP Themed Review within 6 weeks of completion. Also, for LLR CDOP to continue to work collaboratively with the LeDeR team to carry out an annual thematic review of the deaths of children & young people with a Learning Disability, to identify and share learning themes & generate SMART actions based on thematic learning.

CDOP Work Plan for 2023/24

- CDOP Panels every 8 weeks, with additional themed Neonatal Panels.
- Ongoing participation in the phase 1 roll-out of MBRRACE/NCMD systems integration.
- Ongoing participation in East Midlands Regional CDOP Network.
- Delivery of multiagency training sessions including an in-person training day.
- Continued close working with the LLR LeDeR programme, with annual themed panels for children & young people with a Learning Disability and sharing of learning between LeDeR and CDOP.
- Ongoing development of the Key Worker role and resources to engage families in the Child Death Review process.



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5. National Institute for Health and Care Excellence (2021) Postnatal care. NICE guideline (NG194). Available at: <https://www.nice.org.uk/guidance/ng194/resources/postnatal-care-pdf-66142082148037>
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9. National Child Mortality Database. Suicide in Children and Young People, National Child Mortality Database Programme Thematic Report. Bristol: HQIP; 2021. 37. Available at: <https://www.ncmd.info/wp-content/uploads/2021/11/NCMD-Suicide-in-Children-and-Young-People-Report.pdf>



Appendix A. NCMD Cause of death categorisation.

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

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

Category	Name & description of category	Tick box below
1	Deliberately inflicted injury, abuse or neglect This includes suffocation, shaking injury, knifing, shooting, poisoning & other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death.	
2	Suicide or deliberate self-inflicted harm This includes hanging, shooting, self-poisoning with paracetamol, death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children.	
3	Trauma and other external factors This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. Excludes Deliberately inflicted injury, abuse or neglect (category 1).	
4	Malignancy Solid tumours, leukaemia's & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.	
5	Acute medical or surgical condition For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.	
6	Chronic medical condition For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause.	
7	Chromosomal, genetic and congenital anomalies Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.	
8	Perinatal/neonatal event Death ultimately related to perinatal events, e.g., sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, post-haemorrhagic hydrocephalus, irrespective of age at death. It includes cerebral palsy without evidence of cause and includes congenital or early-onset bacterial infection (onset in the first postnatal week).	
9	Infection Any primary infection (i.e., not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc.	
10	Sudden unexpected, unexplained death Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).	

Appendix B. Updated NCMD Contributory Factors – Nov 2022

Factors intrinsic to the child

Child health history/medical conditions	<p>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).</p>
Risk factors in mother during pregnancy/delivery	<p>Twin/multiple pregnancy. Assisted conception. High maternal BMI. Low maternal BMI. Smoking in pregnancy. Substance misuse in pregnancy. Alcohol misuse in pregnancy. Perinatal mental health condition. Maternal diabetes/gestational diabetes. Maternal age. Maternal infection. Late booking/concealed pregnancy. Other obstetric complications. Delivery complications.</p>
Child's developmental conditions/disabilities	<p>Learning disability. Sensory impairment. Motor impairment. Other developmental impairment or disability. Neurodevelopmental conditions.</p>
Emotional/behavioural factors	<p>Mental health condition. Risk-taking behaviour. Suicidal or self-harm ideation. Poor or non-compliance with medication. Sexual orientation/identity or gender identity issues. Loss of key relationships. Isolation from friends/family/support. Child was victim of bullying. Social media/internet use.</p>
Smoking/substance use/misuse by child	<p>Child consumed alcohol on day of death. Child consumed alcohol regularly/known to binge-drink. Child consumed drugs on day of death. Child was known to be a regular drug user. Child smoked tobacco/e-cigarettes.</p>
Other	

Family & Social Environment

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

Physical environment

Sleep environment	Unsafe sleeping arrangements. Co-sleeping.
Home safety/conditions	Overcrowded living conditions. Dirty, mouldy or property in poor repair. Unsafe appliances/environment. Attack by pets/animal. Living environment deprivation/homelessness.
Vehicle collision	Speeding vehicle/recklessness. Young child not appropriately restrained in car seat/booster seat. Child not using other appropriate safety equipment. Unsafe road conditions. Other factors.
Public safety	Absent/non-visible warning signs. Unsafe street furniture/public equipment. Availability of safety equipment. Accessible railway tracks/other infrastructure. Accessible water. Poor compliance with health & safety regulations. Other public safety factor.
Other	

Service Provision

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

Appendix C. LLR CDOP Annual Report All Data 2022-23

Notifications to LLR CDOP 2022-23

Number of deaths notified: 98

Notifications by LA:

- Leicester City 56
- Leicestershire 41
- Rutland 1

Is there to be a Joint Agency Response?

- Yes 21

- No 77

Table a1: Death notifications 2017/18 to 2022/23

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

Chart a1: Death notifications by type of response 2017/18 to 2022/23

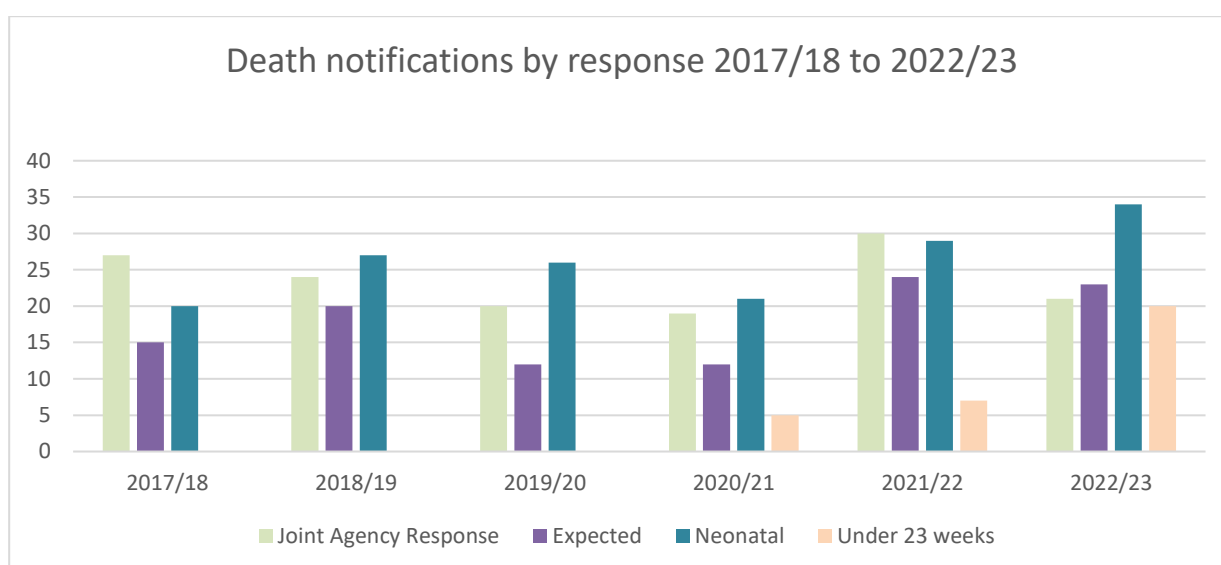


Chart a2: % of death notifications by response 2017/18 to 2022/23

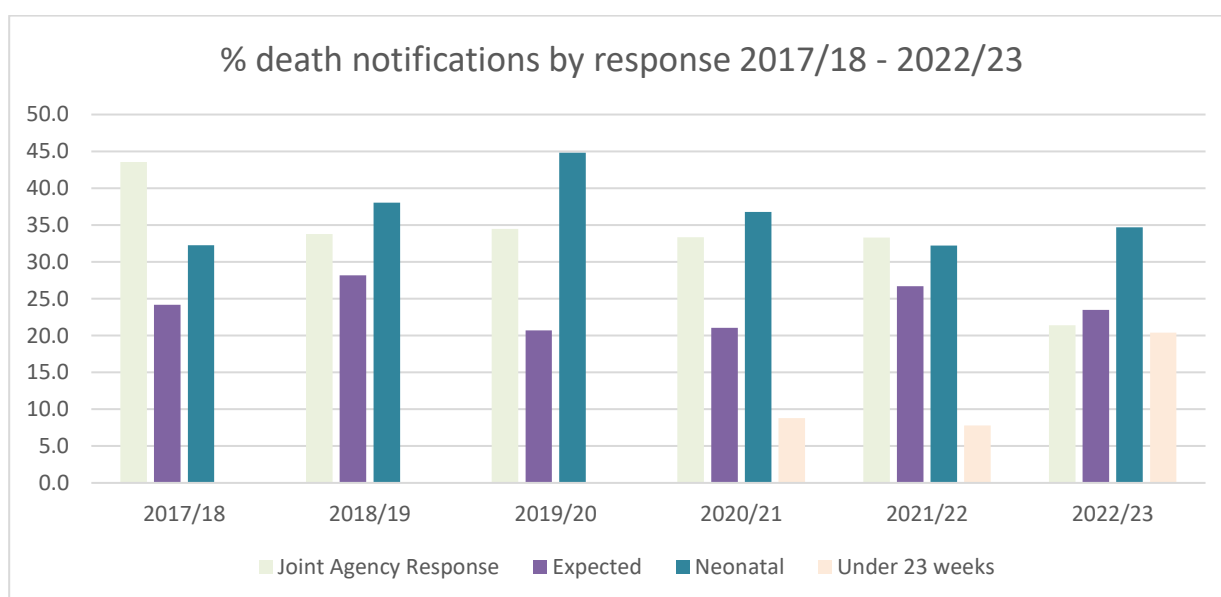


Chart a3: Number of death notifications by LA and year 2017/18 to 2022/23

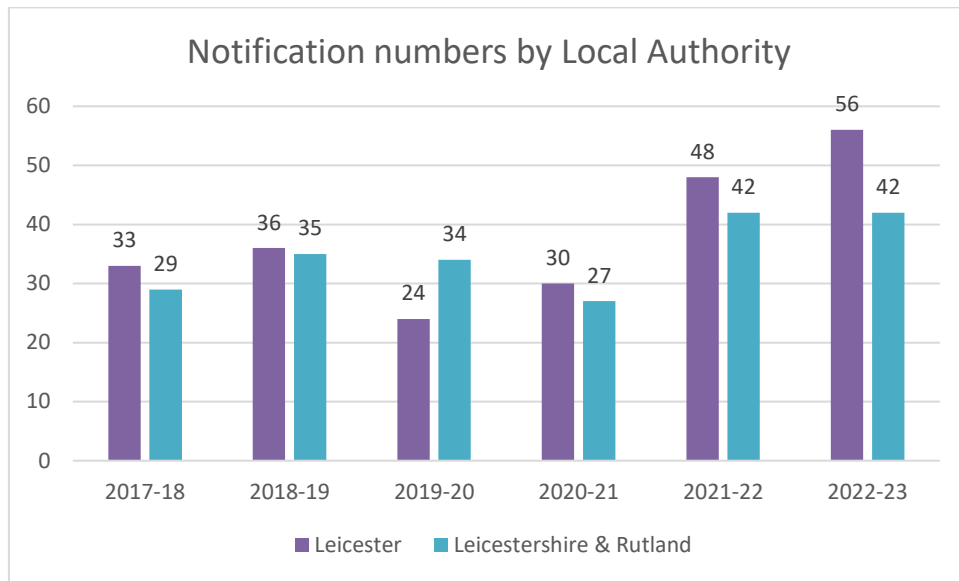


Chart a4: 3-year mean number of death notifications by age group & year 2017/18 to 2022/23

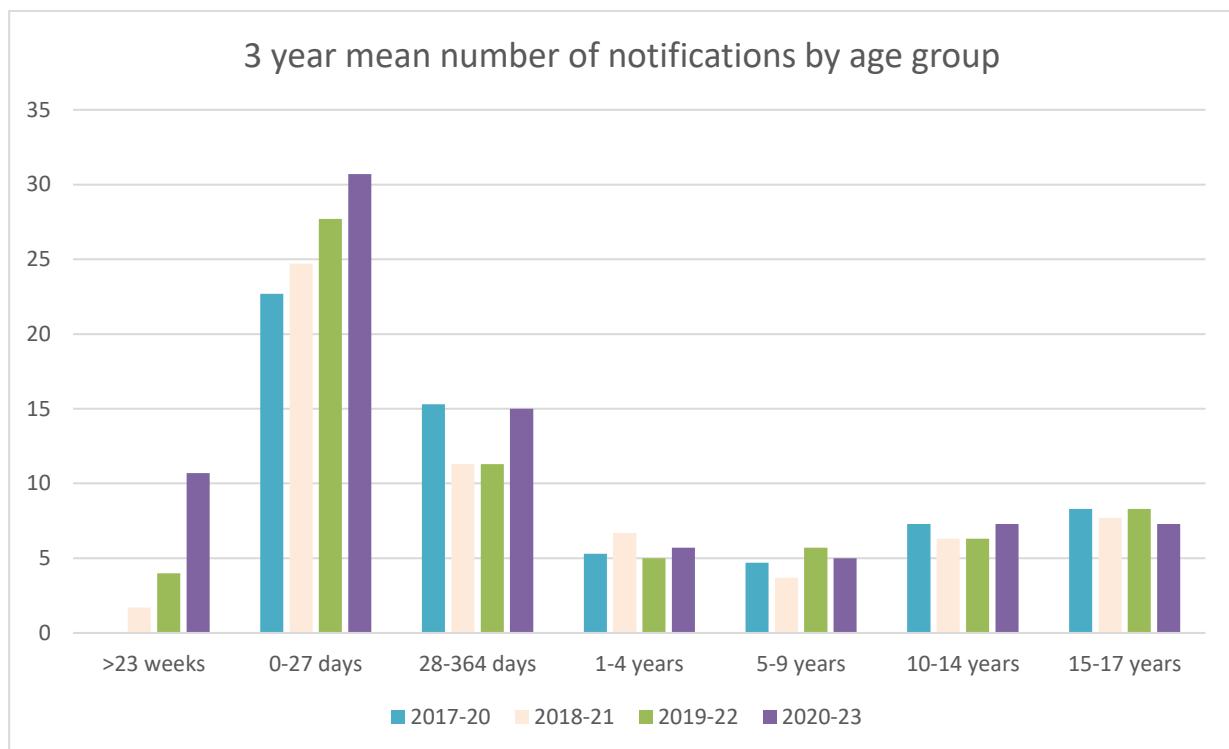


Chart a5: Death notifications by age & month of death 2022/23

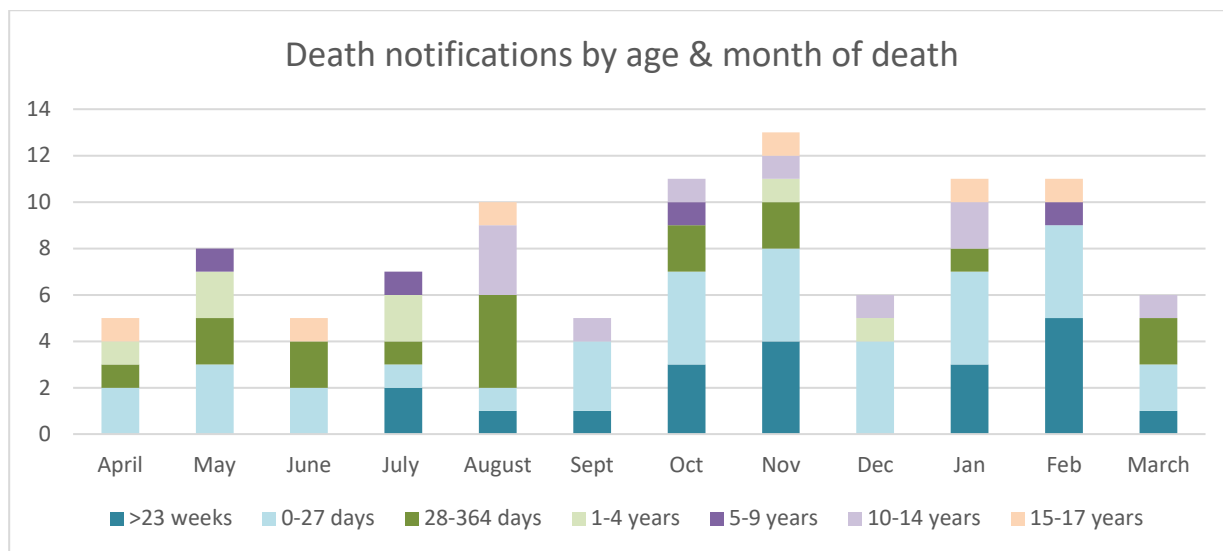
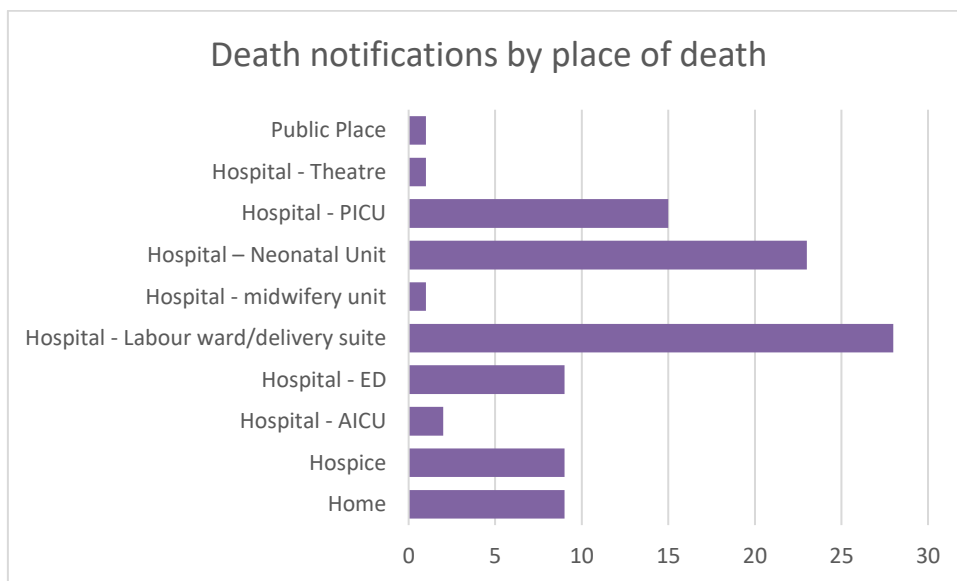


Chart a6: Death notifications by place of death 2022/23



Completed reviews 2022-2023 - Overview

Table a2: Completed CDOP reviews by year:

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

Table a3: Completed CDOP reviews by year of death 2022/23:

Year of death	Cases
2018-19	1
2019-20	1
2020-21	12
2021-22	63
2022-23	9
Total	86

Table a4: Completed CDOP reviews by primary category of death 2022/23

NCMD Category	LLR 2022/23		England 2019/20*
	N	%	%
Chromosomal, genetic or congenital anomaly	27	31	25
Perinatal/neonatal event	26	30	31
Malignancy	12	14	8
Sudden unexpected, unexplained death	6	7	8
Infection	4	5	6
Trauma and other external factors	2	2	4
Acute medical or surgical condition	4	5	6
Chronic medical condition	1	1	5
Suicide or deliberate self-inflicted harm	4	5	4
Deliberately inflicted injury, abuse or neglect	0	0	2
Total	86		

*Data from NCMD Second Annual Report published June 2021¹⁰

Table a5: Completed reviews by ethnic group & age group 2022/23

Ethnic Group	28-346		1-4 years	5-9 years	10-14 years	15-17 years	Total
	0-27 days	days					
White	19	7	6	7	5	8	52
Other	0	1	0	0	1	1	3
Mixed	1	2	1	1	1	0	6
Black or Black British	4	0	1	1	0	1	7
Asian or Asian British	11	5	0	1	1	0	18
Total	35	15	8	10	8	10	86

Chart a7: Completed CDOP reviews by age group 2022/23

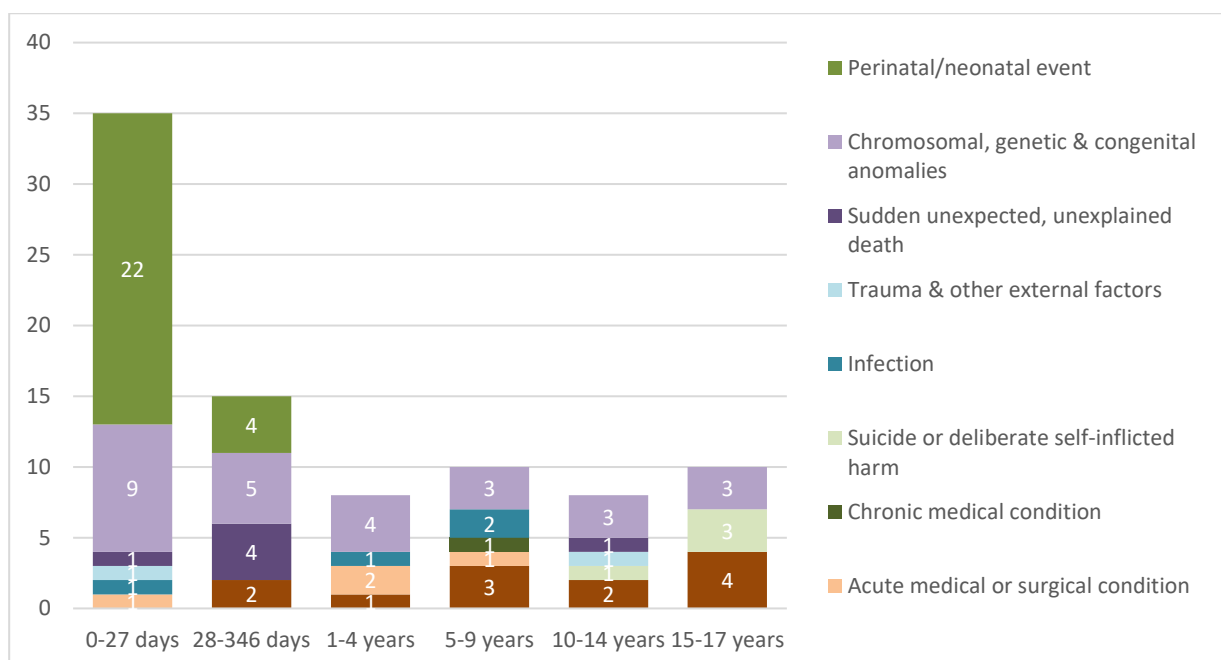


Table a6: Completed reviews by ethnic group & primary category of death 2022/23

	White	Other	Mixed	Black or Black British	Asian or Asian British	Total
Deliberately inflicted injury, abuse or neglect	0	0	0	0	0	0
Suicide or deliberate self-inflicted harm	4	0	0	0	0	4
Trauma and other external factors	2	0	0	0	0	2
Malignancy	7	1	0	2	2	12
Acute medical or surgical condition	2	0	1	1	0	4
Chronic medical condition	0	0	1	0	0	1
Chromosomal, genetic or congenital anomaly	17	2	2	2	4	27
Perinatal/neonatal event	13	0	1	2	10	26
Infection	3	0	0	0	1	4
Sudden unexpected, unexplained death	4	0	1	0	1	6
Total	52	3	6	7	18	86

Chart a8: Completed reviews by place of onset of illness/accident 2022/23

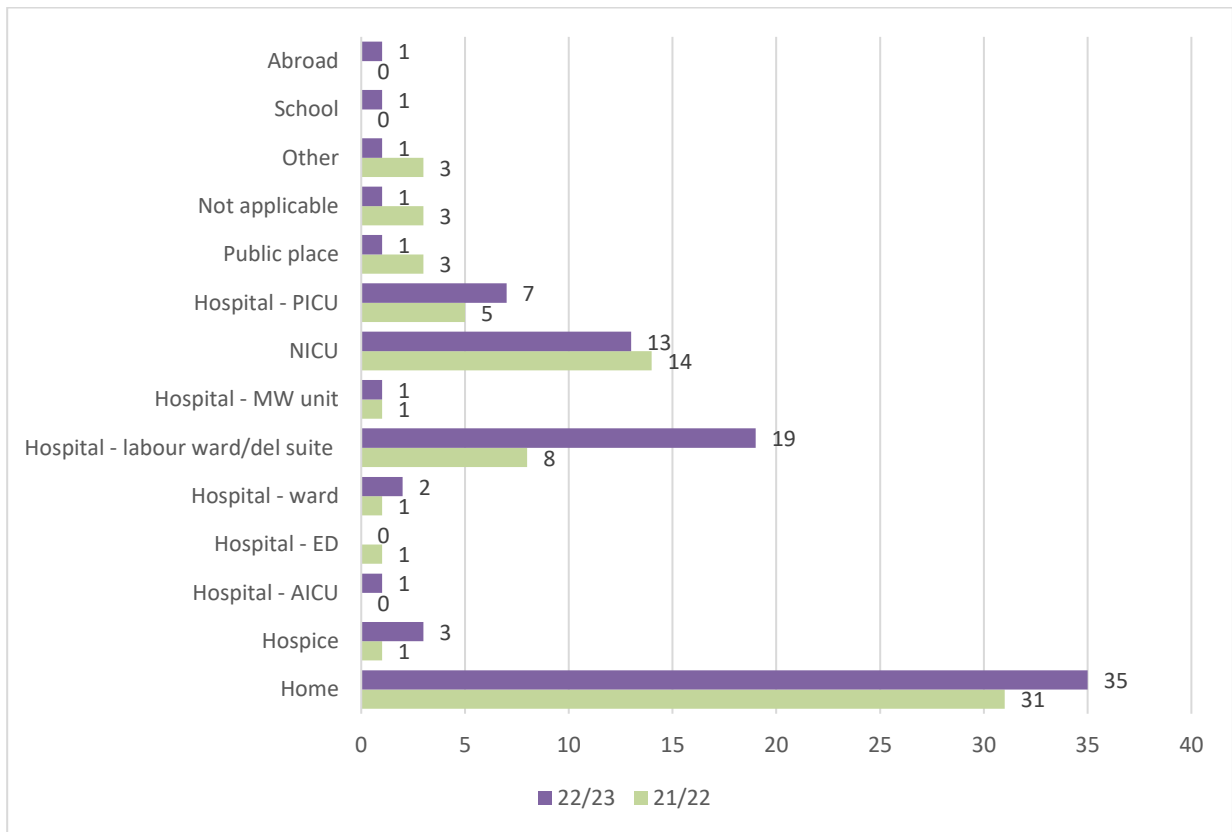
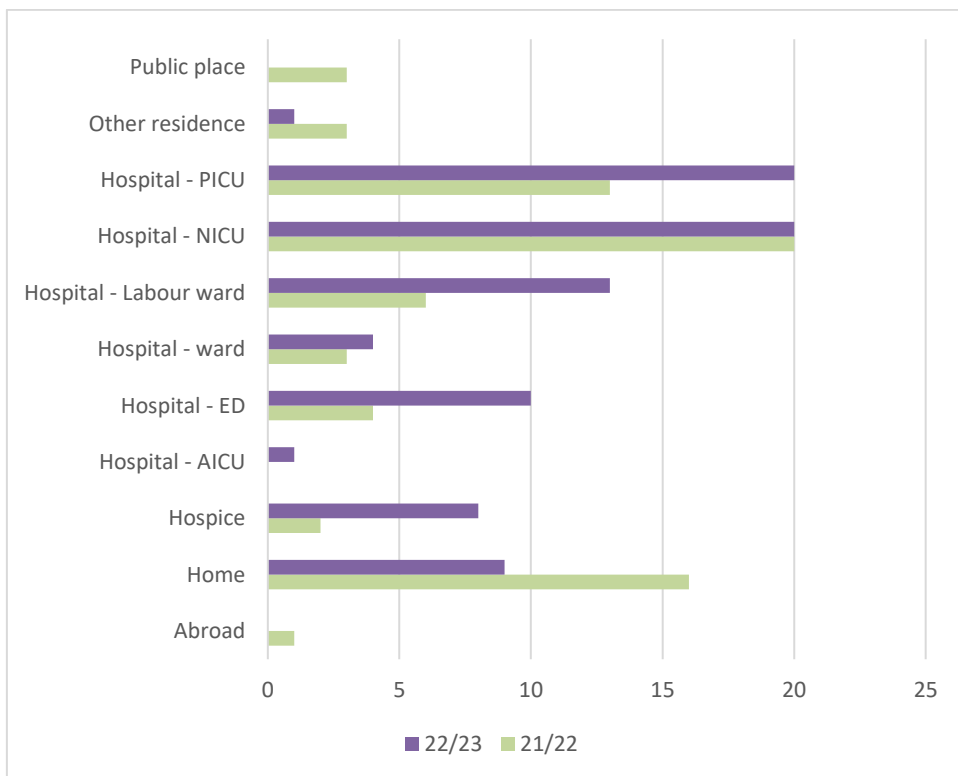


Chart a9: Completed CDOP reviews by place of death 2022/23



Completed Reviews – Modifiable Factors 2022/23

% of cases with modifiable factors (LLR CDOP): 36%

% of cases with modifiable factors (England): 39%⁴

Table a7: Cases where modifiable factors were identified by category of death 2022/23

Primary category of death (CDOP)	Completed reviews	Modifiable factors identified	% of cases where MF identified
Deliberately inflicted injury, abuse, or neglect	0	0	0
Suicide or deliberate self-inflicted harm	4	3	75%
Trauma and other external factors	2	1	50%
Malignancy	12	2	17%
Acute medical or surgical condition	4	1	25%
Chronic medical condition	1	0	0
Chromosomal, genetic, or congenital anomaly	27	4	15%
Perinatal/neonatal event	26	14	54%
Infection	4	1	25%
Sudden unexpected, unexplained death	6	5	83%
Total	86	31	36%

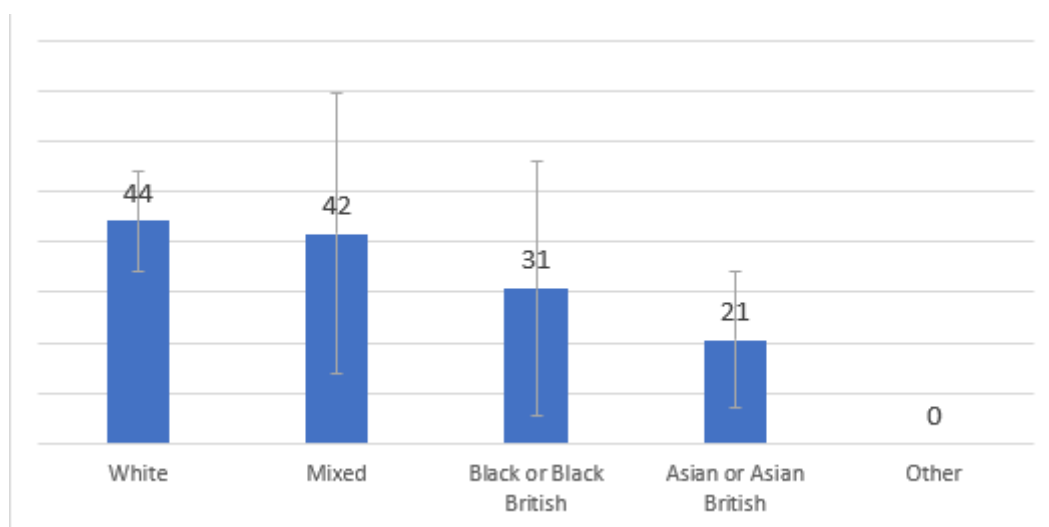
Table a8: Cases where modifiable factors were identified by age group 2022/23

Age group	Completed reviews	Cases where modifiable factors identified	Modifiable factors identified (%)
0-27 days	35	17	49
28-364 days	15	7	47
1-4 years	8	1	12
5-9 years	10	1	10
10-14 years	8	1	12
15-17 years	10	4	40
Total	86	31	36

Table a9: Cases where modifiable factors were identified by ethnic group 2022/23

Ethnic Group	Completed reviews	Cases where modifiable factors identified	Modifiable factors identified %
White	52	22	42
Unknown	0	0	0
Other	3	0	0
Mixed	6	2	33
Black or Black British	7	2	28
Asian or Asian British	18	5	28
Total	86	31	36

Chart a10: Percentage of child death reviews completed in LLR with modifiable factors, by ethnic group 2021/22 – 2022/23



Whilst the case numbers are very small, on pooling data from 2021/22 and 2022/23 together, there is no significant difference between rates at which modifiable factors have been identified between different ethnic groups.

Table a10: Cases where modifiable factors were identified by English Index of Multiple Deprivation (IMD) decile 2022/23

IMD decile	Completed reviews	Cases where modifiable factors identified	Modifiable factors identified %
1&2	21	8	38
3&4	21	11	52
5&6	13	3	23
7&8	17	5	29
9&10	14	4	29
Total	86	31	36

Across the 31 cases where modifiable factors were identified, 60 individual factors were recorded – between 1-6 per case (mean 1.9).

Note: NCMD reclassification of contributory & modifiable factors

Classification of factors was updated by the National Child Mortality Database in November 2022 & used at Panel since that date (see Appendix B for updated classification). This predominantly affects classification of factors relating to pregnancy or antenatal care (including antenatal smoking and maternal obesity), which are now recorded under Domain A: factors intrinsic to the child (as opposed to B: Factors relating to the family or social environment). Cases with reviews completed between April 22 and November 22 were classified at panel according to the previous classification, and have subsequently been reviewed and assigned classification according to the updated version to allow the following data analysis:

Table a11: Cases with modifiable factors recorded by domain (some cases had factors identified in multiple domains) 2022/23

Domain	Cases where modifiable factors were identified by LLR CDOP	% of cases where modifiable factors were identified by LLR CDOP
A: Factors intrinsic to the child	11	35
B: Factors relating to the family or social environment	11	35
C: Factors relating to the physical environment	5	16
D: Factors relating to service provision	15	48

Table a12: Most frequently recorded modifiable factors by domain 2022/23:

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

Table a13: Most frequently recorded modifiable factors by domain sub-group 2022/23:

No of cases 2022/23	Most frequently recorded modifiable factors by domain sub-group:
6	Parent/carer smoked tobacco/e-cigarettes in the household
5	Smoking in pregnancy
5	Issue in diagnosis
4	Issue with treatment, including delays
3	Unsafe sleeping arrangements
3	Guideline/policy/pathway available but not followed
3	Lack of recognition of deteriorating child/clinical symptoms/signs
3	Staffing capacity or inappropriate skill mix
2	Maternal age
2	Child consumed drugs on day of death
2	Parent/carer had consumed alcohol around the time of child's death
2	Co-sleeping
2	Poor communication between professionals & family
1	Child not fully immunised (regardless of reason)
1	Assisted conception
1	High maternal BMI
1	Substance misuse in pregnancy
1	Twin/multiple pregnancy
1	Maternal non-compliance with medication noted to be contributory
1	Child was not brought to appointment(s)/did not attend
1	Child was subject to neglect by adult
1	Complex home circumstances
1	Physical health condition in a parent/carer
1	Parent/carer had consumed drugs around the time of child's death
1	Equipment related issues
1	Information provided to parents was inappropriate
1	Other
1	Other - impact of C-19 guidance on reduced antenatal scan frequency
1	Poor communication/information sharing within an agency
1	Poor documentation/record keeping
1	Poor quality referral/assessment/review
60	Total number of factors identified

CDOP Theme: Infant Mortality

Cases notified to LLR CDOP in 2022/23 of deaths occurring under 1 year of age: 71 (72.4% of all notifications)

Table a14: Age at death for deaths occurring under 1 year of age 2022/23

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

Table a15: Categories of death for children under 1 year – completed reviews 2022/23

Category of death	No of cases	Cases where modifiable factors identified	% of cases where modifiable factors identified
Perinatal/neonatal event	26	14	54
Chromosomal, genetic or congenital anomaly	14	2	14
Sudden unexpected, unexplained death	5	5	100
Malignancy	2	1	50
Acute medical or surgical condition	1	0	0
Infection	1	1	100
Trauma and other external factors	1	1	100
Total	50	24	

Table a16: Modifiable factors were identified in 24 cases (48%) & noted in all 5 SUUD cases. Some cases had more than one modifiable factor noted

Most frequently recorded modifiable factors:	No of cases
Risk factors in mother during pregnancy/delivery	11
Initiation of treatment/identification of illness	9
Smoking/alcohol/substance misuse/use by parent/carer	8
Sleep environment	5
Following guidelines/pathway/policy	4
Communication with family	3
Staffing/bed capacity/equipment	3
D other	2
B other	1
Domestic or child abuse/neglect	1
Parent/carer's health	1
Communication between agencies	1

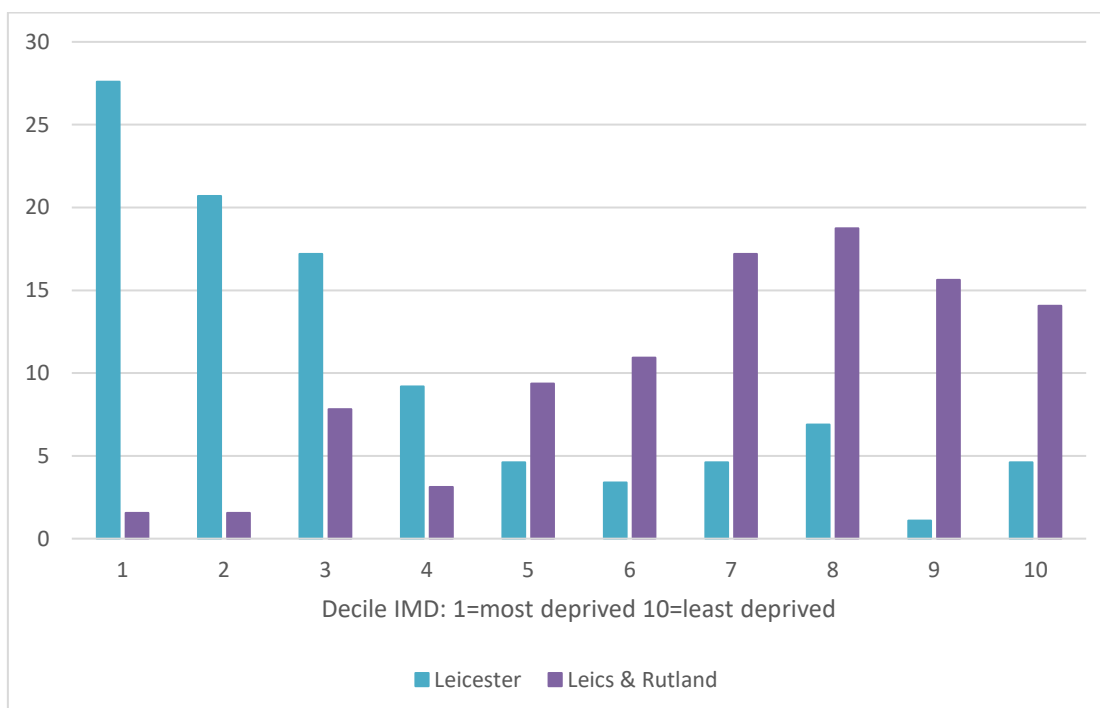
Table a17: Breakdown of modifiable factors by domain sub-category for three most frequently recorded domains

Risk factors in mother during pregnancy/delivery:	No of cases
Smoking in pregnancy	5
Maternal age	2
Assisted conception	1
High maternal BMI	1
Substance misuse in pregnancy	1
Twin/multiple pregnancy (in context of IVF pregnancy)	1
Total	11

Initiation of treatment/identification of illness	
Issue in diagnosis	4
Lack of recognition of deteriorating child/clinical symptoms/signs	3
Issue with treatment, including delays	2
Total	9

Smoking/alcohol/substance misuse/use by a parent/carer	
Parent/carer smoked tobacco/e-cigarettes in the household	5
Parent/carer had consumed alcohol around the time of the child's death	2
Parent/carer had consumed drugs around the time of the child's death	1
Total	8

Chart a11: % of infant deaths reviewed by Index of Multiple Deprivation 2019/20 to 2022/23



Sudden Unexpected Deaths in Infancy (SUDI)

In the period between 1st April 2017 and 31st March 2023, CDOP reviewed the deaths of 20 children who died under 1 year of age, and whose deaths were classified as Sudden Unexpected Unexplained Deaths. This will not include those children whose medical cause of death was deemed to be due to external causes associated with unsafe sleeping.

Table a18: SUUD Infant Case characteristics – 5-year pooled data 2015/16 to 2022/23

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

LLR CDOP Case Learning – completed reviews 2022/23

Learning identified? Yes 67/86 cases (78%)
No 19/86 cases (22%)

Table a19. Cases where learning identified by category of death, completed reviews 2022/23

Category of death	Total no of cases	Cases where learning identified	% of cases in category where learning identified
Sudden unexpected, unexplained death	6	6	100
Chronic medical condition	1	1	100
Malignancy	12	10	83
Chromosomal, genetic or congenital anomaly	27	22	81
Infection	4	3	75
Suicide or deliberate self-inflicted harm	4	3	75
Perinatal/neonatal event	26	19	73
Acute medical or surgical condition	4	2	50
Trauma or other external factors	2	1	50
Deliberately inflicted injury, abuse or neglect	0	0	0
Total	86	67	

Key learning themes identified:

1. Children with life-limiting conditions
 - a. Provision of specialist paediatric palliative care
 - b. Availability of care
 - c. Ambulance transfers into hospice from home
2. Children with a learning disability – all children and young people with a Learning Disability should be entered onto the GP Practice Learning Disability Register, and offered annual health checks.
3. Lack of integrated IT systems impacts on communication, information sharing and recognition of vulnerability factors for babies, children and young people.
4. Communication with families & coordination of care – it is vital that the voice of parents is heard whilst their child is receiving care; vital information informing care decisions can be missed, and distress amplified if families' voices are not heard.
5. Safer Sleeping – unsafe sleep practices (including unsafe co-sleeping practices) continue to be a significant factor in sudden unexplained infant deaths, and babies who die often have multiple vulnerability factors present.
6. Impact of Covid 19 – the Covid-19 pandemic impacted on children, young people & families' experiences of care, choices around end-of-life and post-bereavement care.

Learning Briefing developed to share case learning for cases reviewed 2022/23:

- Use of Seizure Monitors

Learning from excellence:

Notably good or excellent aspects of service delivery were recorded in 38 cases (44%).

- In 5 cases it was noted that parents had highlighted their positive experiences directly.
- Examples of excellent service provision across health, children’s social care, Early Help, third sector organisations and education were all seen.

Table a20: Cases where excellence in service provision identified, by category of death, completed reviews 2022/23

Category of death	Total no of cases	Cases where learning identified	% of cases in category where learning identified
Chronic medical condition	1	1	100
Infection	4	4	100
Malignancy	12	10	83
Chromosomal, genetic, or congenital anomaly	27	15	55
Suicide or deliberate self-inflicted harm	4	2	50
Sudden unexpected unexplained death	6	2	33
Acute medical or surgical condition	4	1	25
Perinatal or neonatal event	26	2	8
Trauma or other external factors	2	0	0
Deliberately inflicted injury, abuse, or neglect	0	0	0
Total	86	67	



Fig 1. Word cloud created using all information recorded about excellence in service provision.