Child Death Overview Panel (CDOP) Annual Report **2021-2022**

Child Death Overview Process

Leicester, Leicestershire & Rutland

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Contents

Glossary of abbreviations used

CAIU	Child Abuse Investigation Unit
CCG	Clinical Commissioning Group
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
JAR	**Joint Agency Response** A coordinated multiagency response to a death occurring in any of the following circumstances: - Death due to external causes - Death occurring in suspicious circumstances - Death that is sudden (not anticipated in preceding 24 hours) and for which no medical explanation is evident – a sudden unexpected death in infancy/childhood - Death of a child or young person detained under the mental health act or in custody - A stillbirth occurring without in the absence of a registered health professional.
LeDeR	Learning Disability Mortality Review
LLR	Leicester, Leicestershire & Rutland
LPT	Leicestershire Partnership NHS Trust
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	**Sudden Unexplained Death in Infancy/Childhood** Descriptive term, used at presentation - the death of an infant/child which was not reasonably expected to occur 24 hours previously, and in whom no pre-existing medical cause of death is apparent. Following detailed investigation, a cause of death may be found.
SIDS	**Sudden Infant Death Syndrome** An unexpected death of an infant occurring during normal sleep, which remains unexplained after a thorough investigation and review of the circumstances.
UHL	University Hospitals of Leicester NHS Trust

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 Clinical Commissioning Groups.

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 the Learning Disability Mortality Review Programme (LeDeR). All data from LLR Child Death Reviews is submitted to the National Child Mortality Database (NCMD) for the purposes of data analysis and learning at a national level.

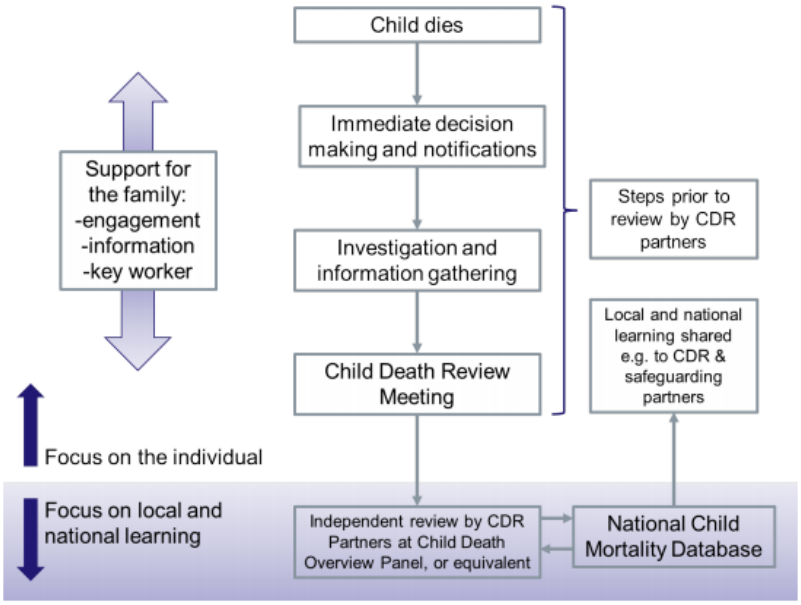


Figure 1: The Child Death Review process as set out in Working Together to Safeguard Children 2018, Chapter 5[1].

Our team: Child Death Review 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). In November 2020 LLR CDOP appointed a 0.4 WTE equivalent in order to support the current 0.6 WTE post. The CDRP role is an essential aspect to the service to ensure statutory requirements are met, and families are adequately supported, through:

- Carrying out a joint home visit together with police, to gather further information around the circumstances of death. In addition, they will review the background history, identify support for the family, with signposting to specialist bereavement support where appropriate, supporting any other issues identified, preparing and submitting a report for HM Coroner (in line with guidance set out in Sudden Unexpected Death in Infancy & Childhood, 2016[2]).
- Acting as the named Key Worker for families ensuring that families are supported and engaged throughout the review process (in line with Statutory & Operational Guidance, 2018[3]), by:
    - Being a ready & accessible point of contact for the family
    - Coordinating meetings as required
    - Arranging & attending home visits with the Designated Doctor to discuss post-mortem report findings
    - Providing information to the family on the Child Death Review process
    - Liaising with Coroners Officer or Police Liaison Office
    - Representing the voice of the family at professional meetings, ensuring their questions are effectively addressed and providing feedback to family afterwards,
    - Signposting to specialist bereavement support if required.
    - Identifying any additional support needs (e.g. around housing, liaison with siblings schools, liaison with GP)

Examples of Child Death Review Practitioner work undertaken with families during 2021/22:

- Carrying out 23 Joint Agency Response home visits along with the police
- Referral to Specialist Bereavement Support
- Liaison with hospital to locate a lost item belonging to child
- Home visits with Designated Doctor to discuss post-mortem results
- Liaison with agencies to ensure equipment sensitively removed from home
- Meeting to discuss the hospital response to parents' questions with support of interpreter
- Liaison with specialist bereavement support for nursery staff
- Referral for funding towards funeral costs
- Providing telephone support to families
- Liaison with Educational Psychology for sibling support

'The team have been abundantly supportive in all aspects of our professional interactions – from the facilitation of meetings and panels to operational support and information sharing around live incidents. The team consistently strived to support joint visits in a timely and flexible way. Equally, where there have been areas for multi-agency development the team have always worked with us to find a way to make improvements in the best interests of the families and the children who sadly no longer have a voice'.

'Leicester, Leicestershire and Rutland CDOP have worked closely with [our agency] over the many years. This relationship is of course based on statutory reporting process; however it is much more than that. Frequently the bereaved families we are working with talk of the value of being able to speak to CDOP about the care of their child and the sensitivity of these interactions. As a team we have valued the advice from CDOP who have supported us around our own policy and the challenges around the death of a child. Our experience of the service is responsive, professional but importantly for our bereaved families, compassionate.'

Above: Feedback from two of our LLR multiagency partners

LLR CDOP Family Support Audit 2021-22

In order to benchmark the service offered by LLR CDOP, an audit was undertaken to review the support offered to families.

What did we learn?

- Documentation of actions required strengthening
- Stronger liaison required with key workers (who were not from CDOP) in order to ensure actions were identified and followed up

What did we do?

- Paperwork reviewed and amended to capture all information needed to demonstrate compliance with statutory guidance including a pre and post visit checklist
- CDRP pathway developed
- CDRP either keyworker or joint keyworker for all cases
- LeDeR proforma developed

Future plans: Family Feedback & enhancing family involvement in the LLR Child Death Review process

Obtaining feedback from a family is not undertaken widely by CDOPs around the Country and therefore teams need to look at alternatives to ensure they gather the voices of families. There are plans within the coming year to liaise with Rainbows, Bodie Hodges and the Diana Team to look at how we progress this with a potential to establish more regular meetings to collect feedback on a more formal basis with the aim of further developing the service and better meeting family's needs.

The team are also looking to ensure CDOP is accessible for all for families who may choose not to engage initially or have struggled to understand the role of CDOP. Options for development include:

- Plans for CDOP to have space on the BHF website where CDOP is explained using Avatars
- A local Easy read CDOP leaflet is also in development following securing funds from LLR project Launch Fund.

Notifications 2021/22

Key information

LLR CDOP received 90 notifications of deaths of LLR residents under the age of 18 years (substantially more than the previous two years). Nationally overall child mortality appeared to fall from April to December 2020 [4], which may in part explain this. Mean number of notifications per year (67.6) over the past 5 years remains similar to previous years.

30 (33%) of cases met the criteria for a Joint Agency Response. Neonatal cases continue to make up the largest proportion of notifications received to CDOP (32%).

Leicester City: 48 cases (53%)
Leicestershire & Rutland: 42 cases (47%)

82% of children died in hospital.
11% died at home.
4% died in a hospice setting.

Table 1: Death notifications by Local Authority 2017/18 to 2021/22

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

Chart 1. Notifications by category of response 2017/18 to 2021/22

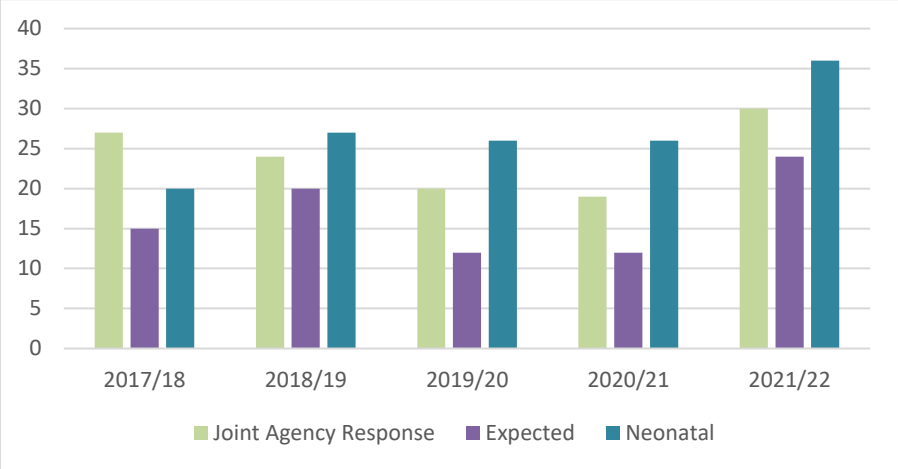


Chart 2. Notifications by place of death

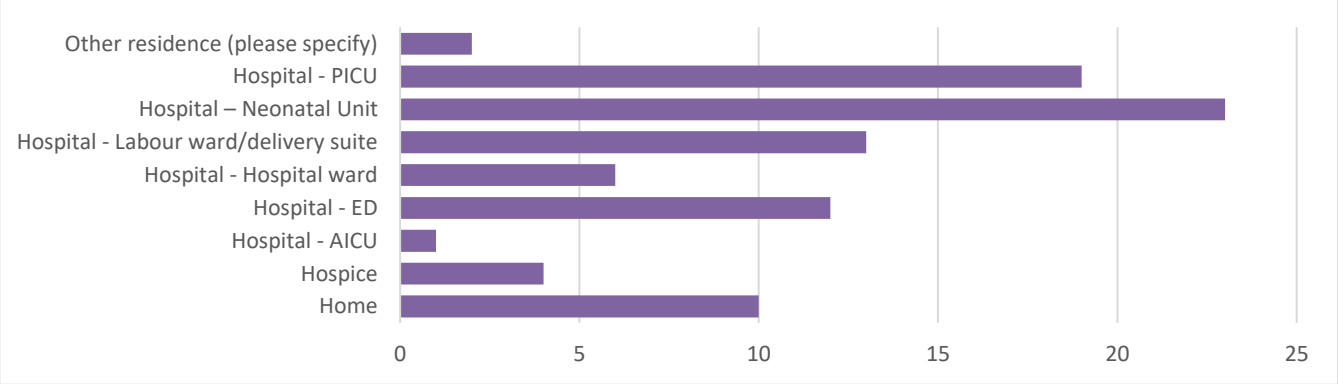


Chart 3. Notifications by age group & year

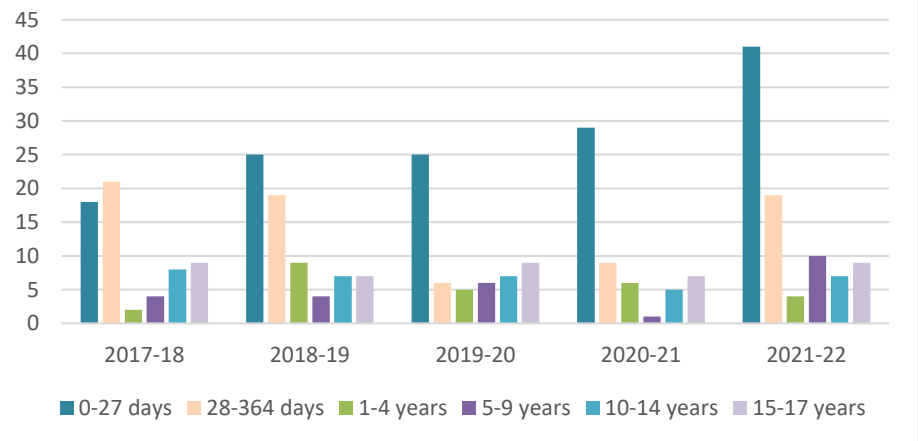
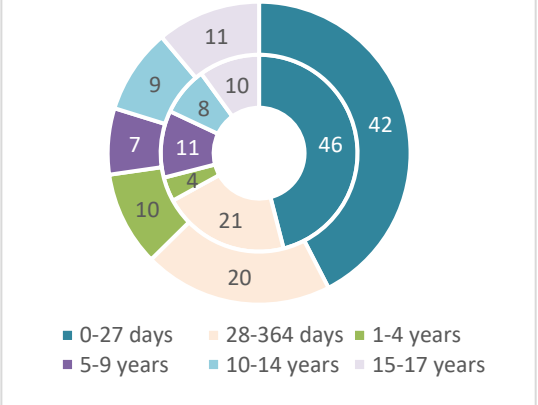


Chart 4. % of notifications by age group Inner ring LLR, Outer ring England



Completed reviews 2021/22

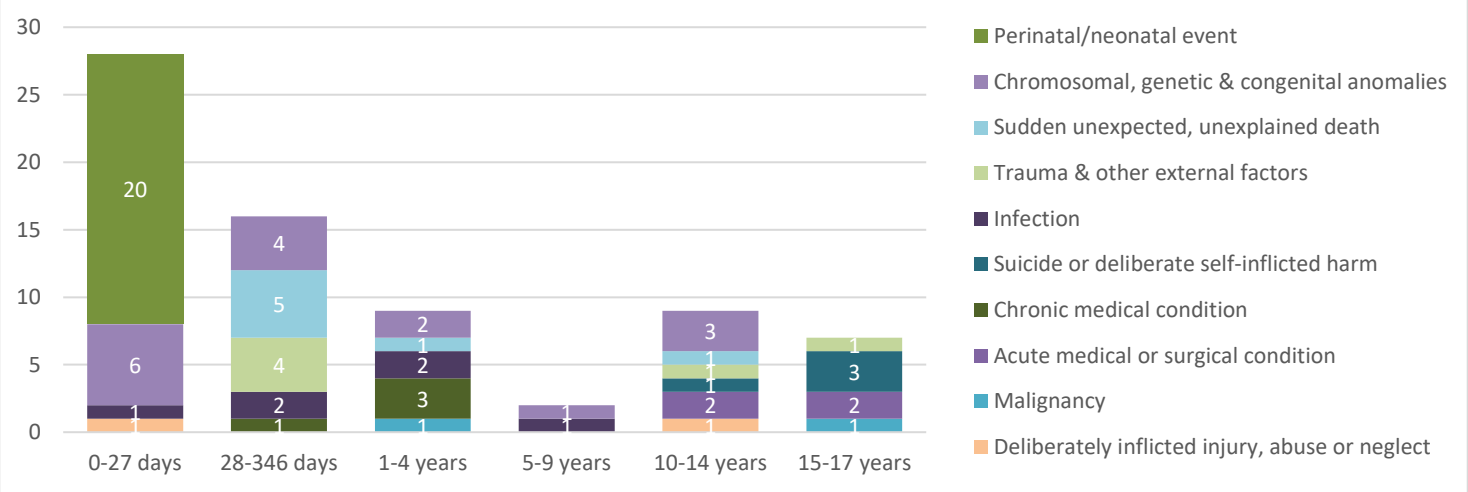
Table 2. Completed reviews by year

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

Table 3. Completed reviews by year of death 2021/22

Year of death	Cases
2017-18	2
2018-19	4
2019-20	22
2020-21	40
2021-22	3
Total	**71**

Chart 5. Completed CDOP reviews by age group & category of death 2021/22



- In 2021/22 LLR CDOP held 6 panels and reviewed 71 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 perinatal/neonatal event (28.2%)
        - Includes perinatal asphyxia, complications of prematurity/immaturity and perinatal infection.
    - Deaths due to a chromosomal, genetic, or congenital anomaly (22.5%)
    - Sudden unexpected, unexplained deaths (10%)
        - Deaths occurring at any age, which, following a thorough investigation and post-mortem, no clear medical cause has been identified.
- Of the cases reviewed, most children (64.8%) died in hospital, with 22.5% dying at home, 4.2% in a public place, and 2.8% in a hospice setting.

Table 4. Completed reviews by ethnic group & primary category of death 2021/22

Ethnic Group	0-27 days	28-346 days	1-4 years	5-9 years	10-14 years	15-17 years	**Total**
White	11	14	5	2	3	6	**41**
Other	1	0	1	0	0	0	**2**
Mixed	4	1	0	0	0	1	**6**
Black or Black British	4	0	1	0	1	0	**6**
Asian or Asian British	8	1	2	0	5	0	**16**
Total	**28**	**16**	**9**	**2**	**9**	**7**	**71**

Modifiable factors 2021/22

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, 2018[1]

Table 5: Cases where modifiable factors were identified by category of death 2021/22

Primary category of death (CDOP)	Completed reviews	Modifiable factors identified	Modifiable factors identified (%)
Deliberately inflicted injury, abuse or neglect	2	2	100
Sudden unexpected, unexplained death	7	6	86
Trauma and other external factors	6	4	67
Infection	6	3	50
Suicide or deliberate self-inflicted harm	4	2	50
Perinatal/neonatal event	20	6	30
Acute medical or surgical condition	4	1	25
Chromosomal, genetic or congenital anomaly	16	2	13
Chronic medical condition	4	0	0
Malignancy	2	0	0
Total	**71**	**26**	**37**

- Modifiable factors were identified in 37 % of cases (n=26).
- Across the 26 cases where modifiable factors were identified, 60 individual factors were recorded (mean 2.3, range 1-6 per case).

Table 6: Most frequently recorded modifiable factors 2021/22

No of cases	Most frequently recorded modifiable factors:
9	Parental smoking
6	Maternal obesity
6	Service provision - education
5	Unsafe sleeping practices
4	Service provision - communication
4	Service provision - local/national commissioning
2	Safeguarding
1	Public safety
1	Vehicle/transport related
1	Service provision - human factors
1	Child physical condition
1	Child mental health condition

Parental smoking

- Most common modifiable factor nationally[5].
- 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.

Maternal obesity

- 5th most common modifiable factor nationally[5].
- Challenges with identification of fetal anomalies on antenatal scans.
- Increased risk of gestational diabetes which can lead to adverse pregnancy outcomes.

A. Infant Mortality

Infant deaths reviewed 2021/22

Infant: liveborn (of any gestation) to 12 months of age

- Infant Mortality Rates for Leicester City remain significantly higher than for England (see Appendix B)
- 44 cases reviewed, 36% with modifiable factors
- Most frequently noted modifiable factors:
  - Parental smoking
  - Maternal obesity

Table 7. Infant deaths: completed reviews by ethnic group

Ethnic Group	0-27 days	28-346 days	Total
White	11	14	25
Other	1	0	1
Mixed	4	1	5
Black/Black British	4	0	4
Asian/Asian British	8	1	9
Total	28	16	44

Table 8. Categories of death for children under 1 year – completed reviews

Category of death	No of cases	No of cases where modifiable factors identified	% of cases where modifiable factors identified
Perinatal/neonatal event	20	6	30
Chromosomal, genetic or congenital anomaly	10	1	10
Sudden unexpected, unexplained death	5	5	100
Trauma or other external factors	4	2	50
Infection	3	1	33
Deliberately inflicted injury, abuse or neglect	1	1	100
Chronic medical condition	1	0	0
Total	44	16	

Sudden unexpected unexplained deaths of infants

In the period between 1st April 2016 and 31st March 2022, CDOP reviewed the deaths of 15 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 9. Sudden Unexpected Unexplained Deaths - Infant case characteristics – 5 year review

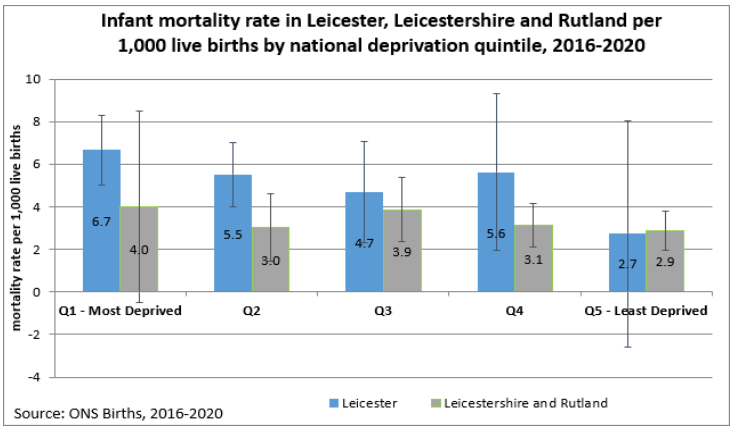
	2015/16 to 2020/21 (n=15)		2016/17 to 2021/22 (n=15)	
	N	%	N	%
Bottle fed	12	80 %	11	73 %
First born	4	27 %	6	40 %
Preterm	10	67 %	9	60 %
IMD 1&2	7	47 %	6	40 %
Birthweight <2.5kg	9	60 %	9	60 %
Mean maternal age	28.8 (20-36)		28.73 (20-36)	
Medical cause of death:				
'Unascertained'	12	80 %	11	73 %
'SIDS'	3	20 %	4	27 %
Modifiable Factors				
Unsafe sleeping	10	67 %	9	60 %
Parental smoking	9	60 %	9	60 %
One or more MF	13	87 %	13	87 %

B. Deprivation & Child Mortality

LLR CDOP submitted case data which was included in the National Child Mortality Database report into Child Mortality & Social Deprivation[6] published in May 2021, looking at the relationship between deprivation and child deaths for cases that occurred during or were reviewed by CDOPs between 1st April 2019 & 31st March 2020.

The full report is available here: https://www.ncmd.info/publications/child-mortality-social-deprivation/

Chart 6. Infant Mortality Rate in LLR by deprivation quintile 2016-2020



Key findings [6]:

1. Clear association between risk of death and deprivation across all categories except malignancy.
2. Relative 10% increase in risk of death between each decile of increasing deprivation.
3. **More than 1 in 5 deaths might be avoided if children living in the most deprived areas had the same mortality risk as those living in the least deprived.**
4. Increased proportion of deaths with modifiable contributory factors with increasing deprivation.
5. 1 in 12 child deaths reviewed in 2019/20 identified 1 or more factors related to deprivation.

C. Suicide & Self-harm

In October 2021, the National Child Mortality Database published their thematic report into Suicide in Children & Young People [7], looking at deaths that occurred or were reviewed by a CDOP between 1st April 2019 & 31st March 2020.

The full report is available here: https://www.ncmd.info/publications/child-suicide-report/

Key findings [7]:

- Services should be aware that child suicide is not limited to certain groups; rates of suicide were similar across all areas, and regions in England including urban and rural environments, and across deprived and affluent neighbourhoods
- 62% had suffered a **significant personal loss** in their life prior to their death (including bereavement and living losses e.g. loss of friends and routine due to moving home, school or other close relationship breakdown).
- Over 1/3 had **never been in contact with mental health services**.
- 16% had a confirmed **neurodevelopmental condition** at the time of their death – this appears higher than the general population.
- Almost a quarter had experienced **bullying either face to face or cyberbullying**, the majority reporting bullying in schools.

D. Learning Disability Mortality Reviews (LeDeR)

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 of 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 Reviews

Deaths of all people with learning disabilities aged 4 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 cohort. In addition to the standard Child Death Review process, a 'pen portrait' of the child or young person is completed with the family, and since September 2020, areas of best practice are identified, and quality of care provided is graded.

Over the past two years (2020-21 & 2021-22), 16 LeDeR case reviews were completed.

Of these 16 cases:

- The top three most common categories for causes of death were:
  - Chromosomal, genetic or congenital anomalies
  - Acute medical condition
  - Chronic medical condition
- Modifiable factors were identified in 3 cases.
- Areas of best practice were identified in 4 cases.
- LeDeR Care Grading was completed in 13 cases:
  - Good or excellent care was noted in 9 cases
  - Satisfactory care was noted in 2 cases
  - Care fell far short of expected good practice in 2 cases.

Key learning themes identified during reviews

	Communication is key - Good communication was the most frequently cited issue in good or excellent care. - Poor communication was the most frequently noted issue in terms of issues with care, including those raised by families.
	Care Coordination/transition - 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.
	Access to services at the right time - Both in terms of physical accessibility and availability, ensuring equity of access for children and young people to the services they need.

Table 10. Cases where learning identified by category of death, 2021/22

Category of death	Total no of cases	Cases where learning identified	% of cases where learning identified
Sudden unexpected, unexplained death	7	7	100
Trauma or other external factors	6	6	100
Infection	6	6	100
Deliberately inflicted injury, abuse or neglect	2	2	100
Acute medical or surgical condition	4	3	75
Suicide or deliberate self-inflicted harm	4	3	75
Chromosomal, genetic or congenital anomaly	16	10	62.5
Perinatal/neonatal event	20	10	50
Chronic medical condition	4	2	50
Malignancy	2	1	50
Total	**71**	**50**	

Key Learning Themes identified during Child Death Reviews

	Lack of integrated IT systems impacts on communication, information-sharing and recognition of vulnerability.
	Early recognition of emerging vulnerabilities is vital, to inform an appropriate response with support, advice and information to mitigate risks to the health of babies and children.
	Importance of timely communication and information-sharing within and between agencies.
	Safer Sleeping ○ Sleep positioners can be marketed as reducing risk, when they are not recommended. ○ Impact on family sleep choices when unexpectedly out-of-routine. ○ Importance of involving partners in safer sleep conversations. ○ Importance of documenting safer sleep conversations with families. ○ Baby illness as a factor in parental decision-making around co-sleeping.
	Impact of Covid 19 pandemic: ○ Reduced service capacity impacted on ability of practitioners to spend time with families and hear their voice. ○ Reduced face-to-face contact with families & visibility of the home environment was a limitation to assessments. ○ Online only services may not be acceptable or accessible to children & young people. ○ Increased social isolation compounding existing challenges faced by children, young people & families, particularly those already experiencing isolation.

Resources developed to share case learning 2021/22:

- 7 Minute Briefing: Private Fostering
- 7 Minute Briefing: Guidance when asked for informal medical advice – for health professionals
- Rapid Read: Management of blood-stained diarrhoea – for health professionals

1. **Safer Sleeping**
   To develop a multiagency approach, based on the 'prevent and protect' practice model for reducing the risk of SUDI described by the Child Safeguarding Practice Review Panel[9] in 2020. This includes the development of guidance for all practitioners around safer sleep messaging (including with partners and families) embedded within systems & processes that support effective multiagency practice across the continuum of risk.

2. **Digital solutions to improve communication**
   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**
   For the LLR Healthy Babies Strategy Group to use this report to refresh their strategy and action plan to address the social determinants of infant mortality, including parental smoking, maternal obesity and the impact of socio-economic deprivation.

4. **Suicide & Self-harm**
   For LLR CDOP to work with stakeholders to carry out a thematic report into deaths due to suicide and self-inflicted harm in children and young people, and to share the report & recommendations to inform strategies to support mental health and emotional wellbeing of children and young people across LLR.

5. **LeDeR Reviews**
   For LLR CDOP to work collaboratively with the LLR LeDeR Programme to commence annual thematic reviews of cases, and to work together to generate clear SMART actions based on the learning themes that have been identified to support improvements in care quality, effectiveness and accessibility for children and young people with a learning disability across LLR.

CDOP Work Plan for 2022/23

- CDOP Panels every 8 weeks, with additional themed Neonatal Panels.
- 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.
- Thematic panel and report into Suicide & Self-harm in children & young people across LLR.
- Implementation of the latest LeDeR grading system, plan for annual thematic review and report into deaths of children & young people with a learning disability across LLR.
- Ongoing development of the Key Worker role and audit of support for families.
- Ongoing work to improve the dissemination of learning from CDOP reviews.

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8. Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021. London: NHS England & NHS Improvement; 2021. 62. Available at https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf

9. The Child Safeguarding Practice Review Panel. Out of Routine: A review of sudden unexpected death in Infancy (SUDI) in families where children are considered at risk of significant harm. London: Department for Education; 2020. 56.

Appendices

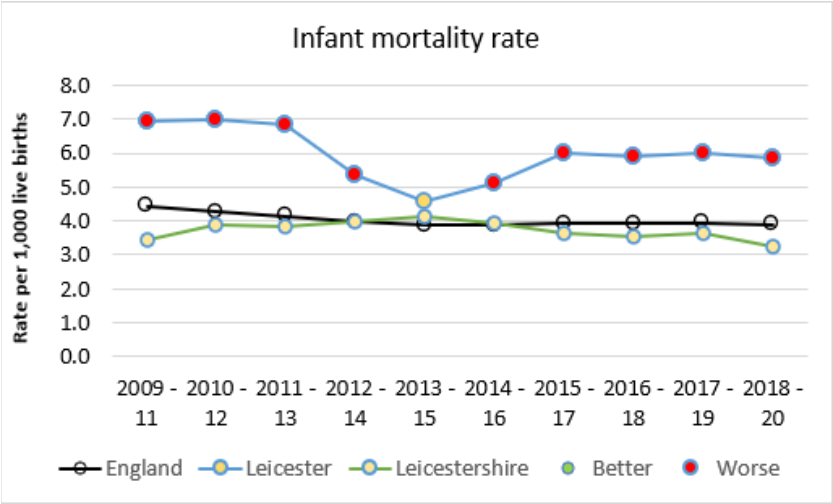
Appendix A. Cause of death categorisation

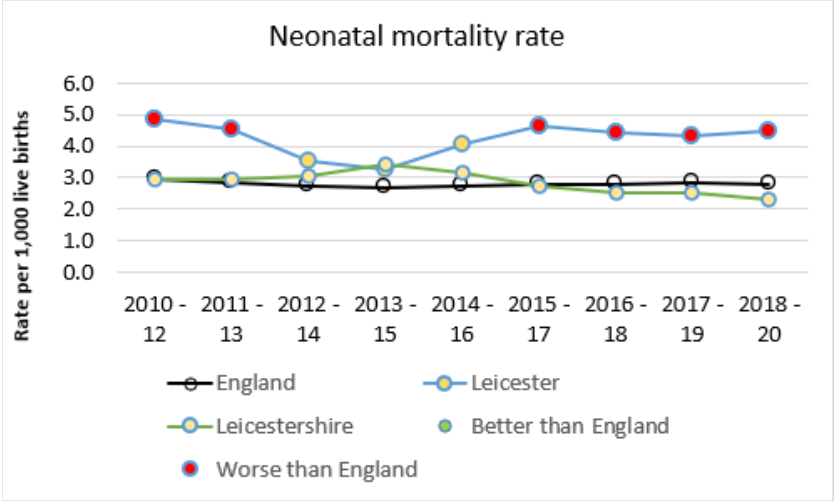
The CDOP should categorise the likely cause of death using the following schema.

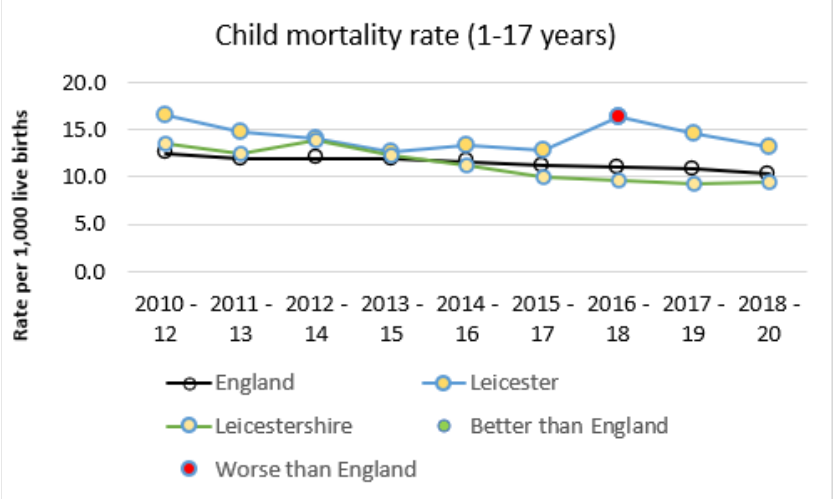
This classification is hierarchical: where more than one category could reasonably be applied, the highest up the list should be marked.

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

Appendix B. LLR Summary Mortality Rate Trends 2009-2020







Appendix C. LLR CDOP Annual Report All Data 2021-22

Notifications to LLR CDOP 2021-22

Number of deaths notified: 90

Notifications by LA:

- Leicester City 48
- Leicestershire 40
- Rutland 2

Is there to be a Joint Agency Response?
- Yes 30
- No 60

Table a1: Death notifications 2017/18 to 2021/22

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

Chart a1: Death notifications by type of response 2017/18 to 2021/22

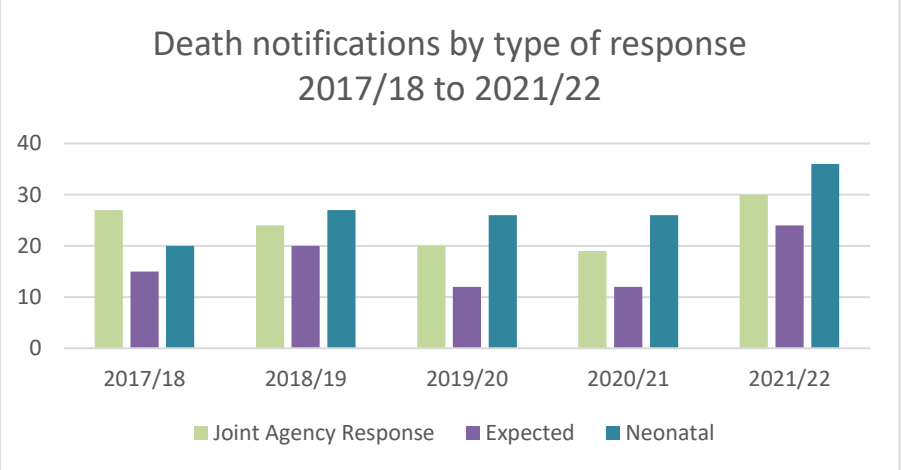


Chart a2: % of death notifications by LA and year 2017/18 to 2021/22

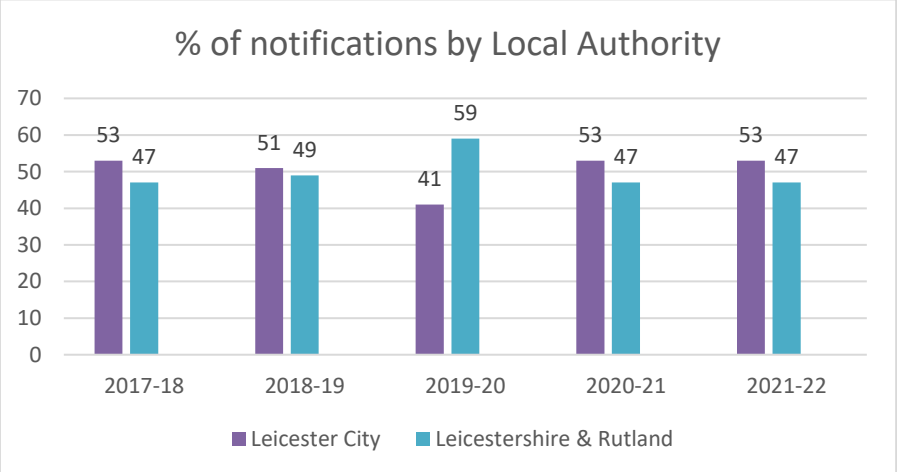


Chart a3: Death notifications by age group and year 2017/18 to 2020/21

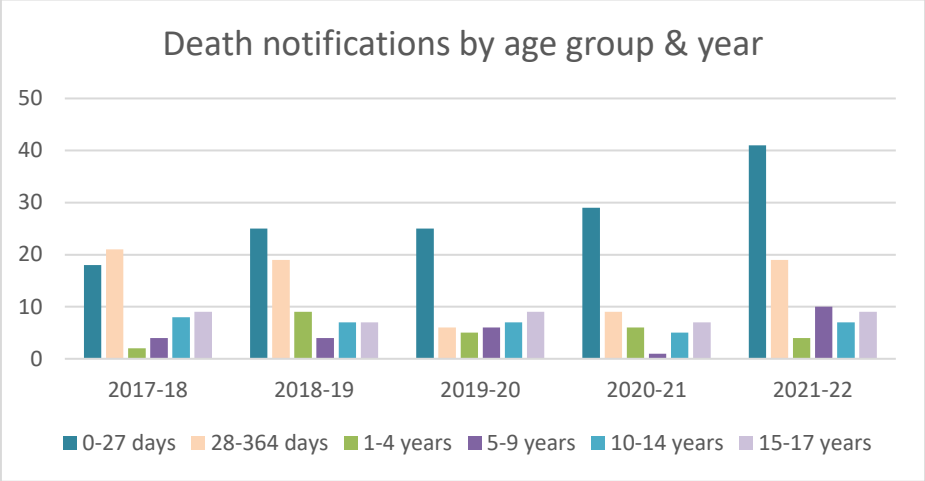


Chart a4: Death notifications by age & month of death 2021/22

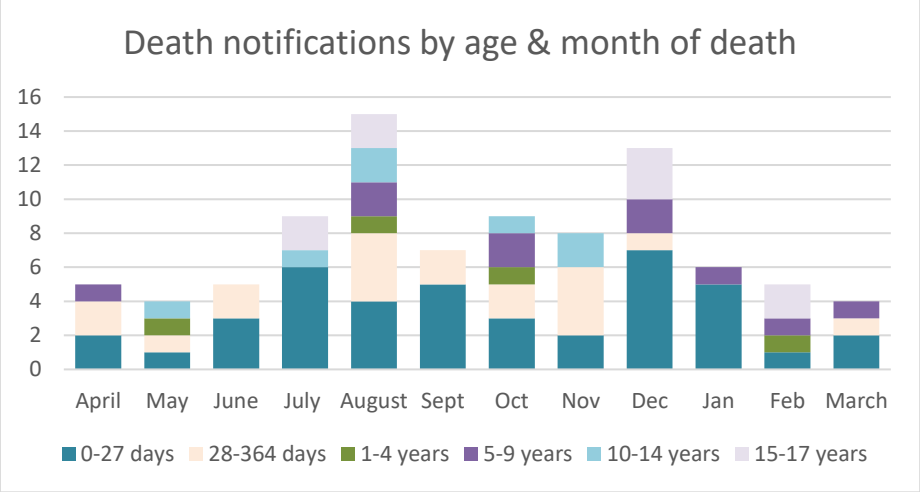


Chart a5: Death notifications by age group 2021/22

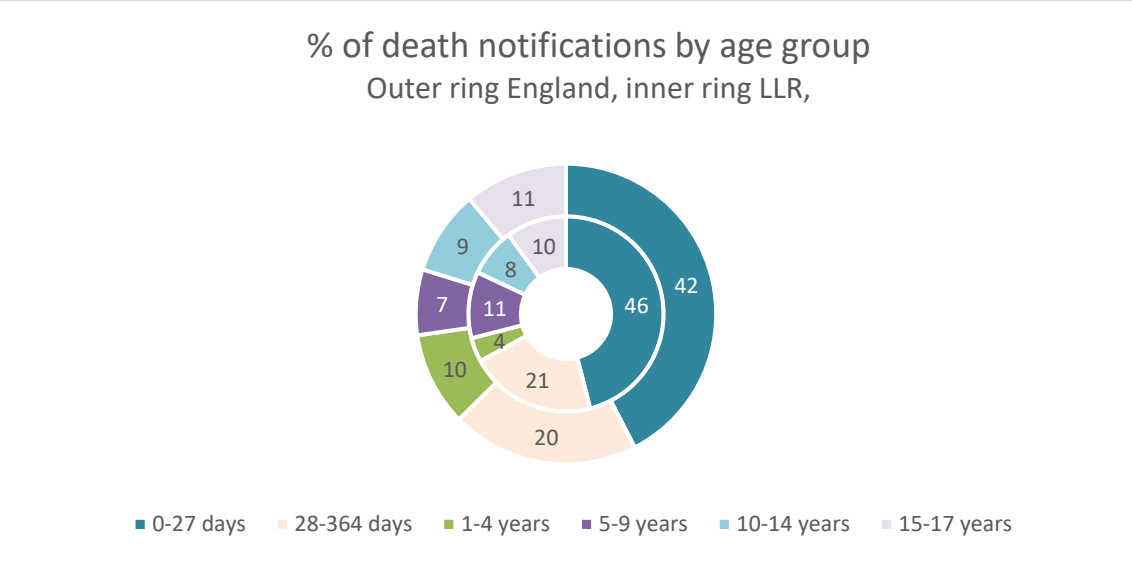
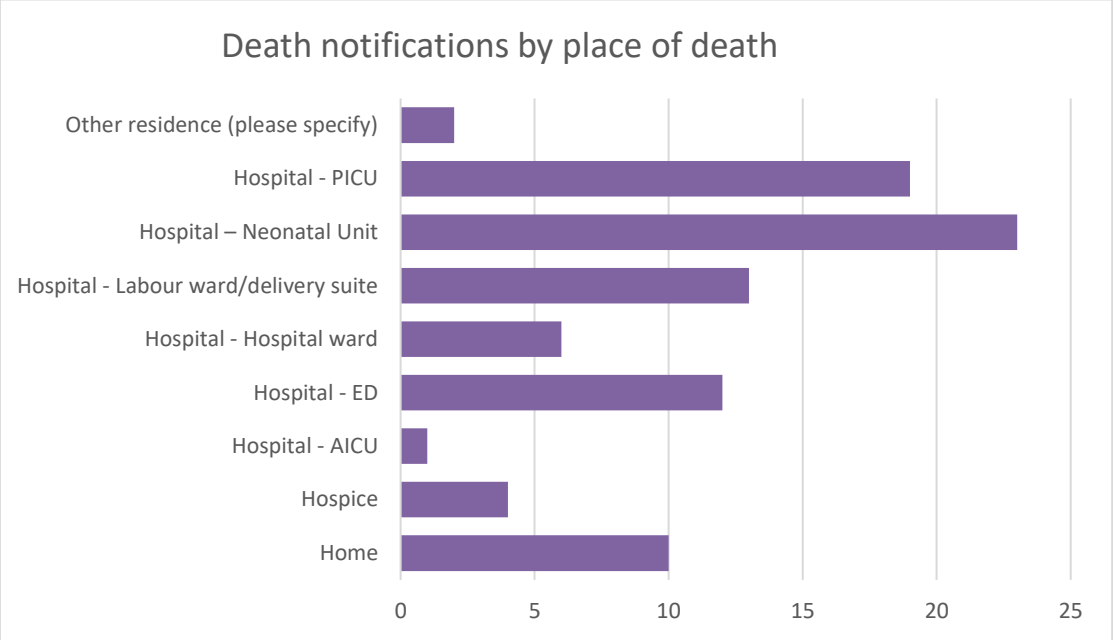


Chart a6: Death notifications by place of death 2021/22



Completed reviews 2021-2022 - Overview

Table a2: Completed CDOP reviews by year:

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

Table a3: Completed CDOP reviews by year of death 2021/22:

Year of death	Cases
2017-18	2
2018-19	4
2019-20	22
2020-21	40
2021-22	3
Total	71

Table a4: Completed CDOP reviews by primary category of death 2021/22

NCMD Category	N	%
Perinatal/neonatal event	20	28.2
Chromosomal, genetic or congenital anomaly	16	22.5
Sudden unexpected, unexplained death	7	10
Infection	6	8.5
Trauma and other external factors	6	8.4
Acute medical or surgical condition	4	5.6
Chronic medical condition	4	5.6
Suicide or deliberate self-inflicted harm	4	5.6
Deliberately inflicted injury, abuse or neglect	2	2.8
Malignancy	2	2.8

Table a5: Completed reviews by ethnic group & age group 2021/22

Ethnic Group	0-27 days	28-346 days	1-4 years	5-9 years	10-14 years	15-17 years	Total
White	11	14	5	2	3	6	41
Unknown	0	0	0	0	0	0	0
Other	1	0	1	0	0	0	2
Mixed	4	1	0	0	0	1	6
Black or Black British	4	0	1	0	1	0	6
Asian or Asian British	8	1	2	0	5	0	16
Total	28	16	9	2	9	7	71

Chart a7: Completed CDOP reviews by age group 2021/22

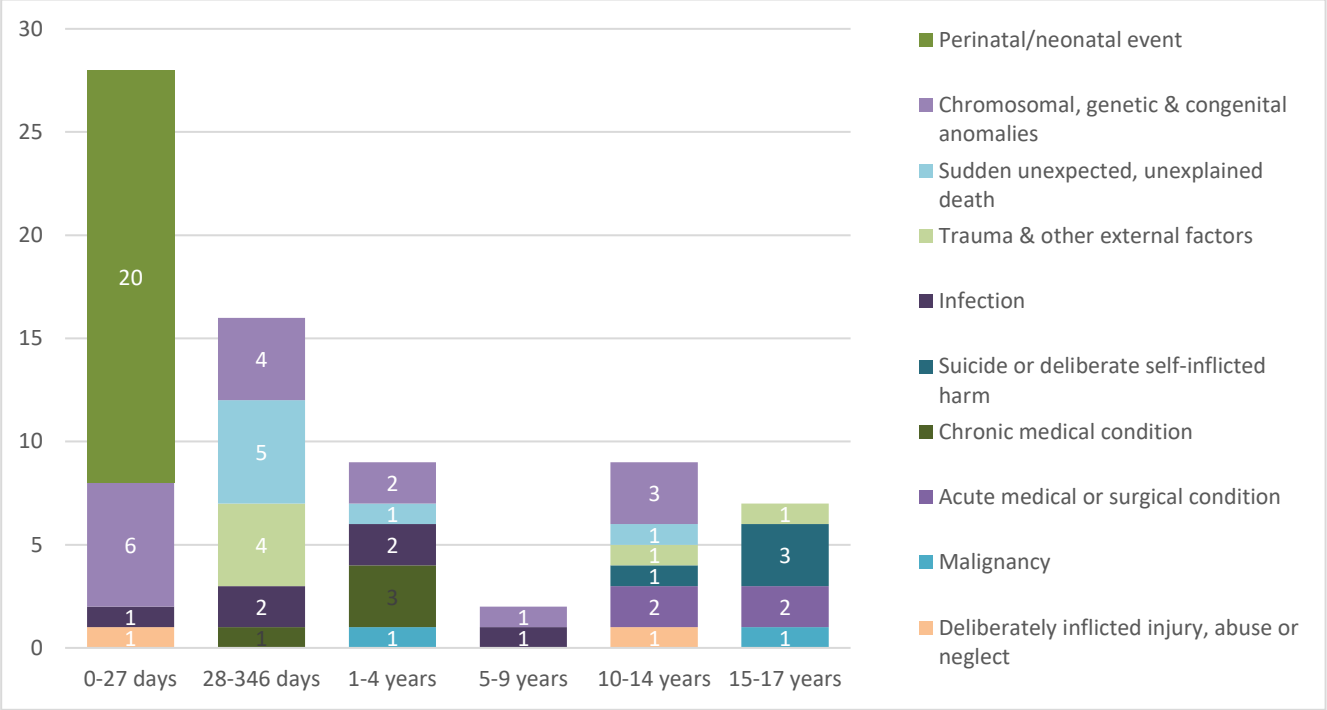


Table a6: Completed reviews by ethnic group & primary category of death 2021/22

	White	Other	Mixed	Black or Black British	Asian or Asian British	Total
Deliberately inflicted injury, abuse or neglect	2	0	0	0	0	2
Suicide or deliberate self-inflicted harm	2	0	1	0	1	4
Trauma and other external factors	5	0	0	0	1	6
Malignancy	1	0	0	1	0	2
Acute medical or surgical condition	2	0	0	1	1	4
Chronic medical condition	3	1	0	0	0	4
Chromosomal, genetic or congenital anomaly	6	0	2	1	7	16
Perinatal/neonatal event	8	1	2	3	6	20
Infection	6	0	0	0	0	0
Sudden unexpected, unexplained death	6	0	1	0	0	7
Total	**41**	**2**	**6**	**6**	**16**	**71**

Chart a8: Completed reviews by place of onset of illness/accident 2021/22

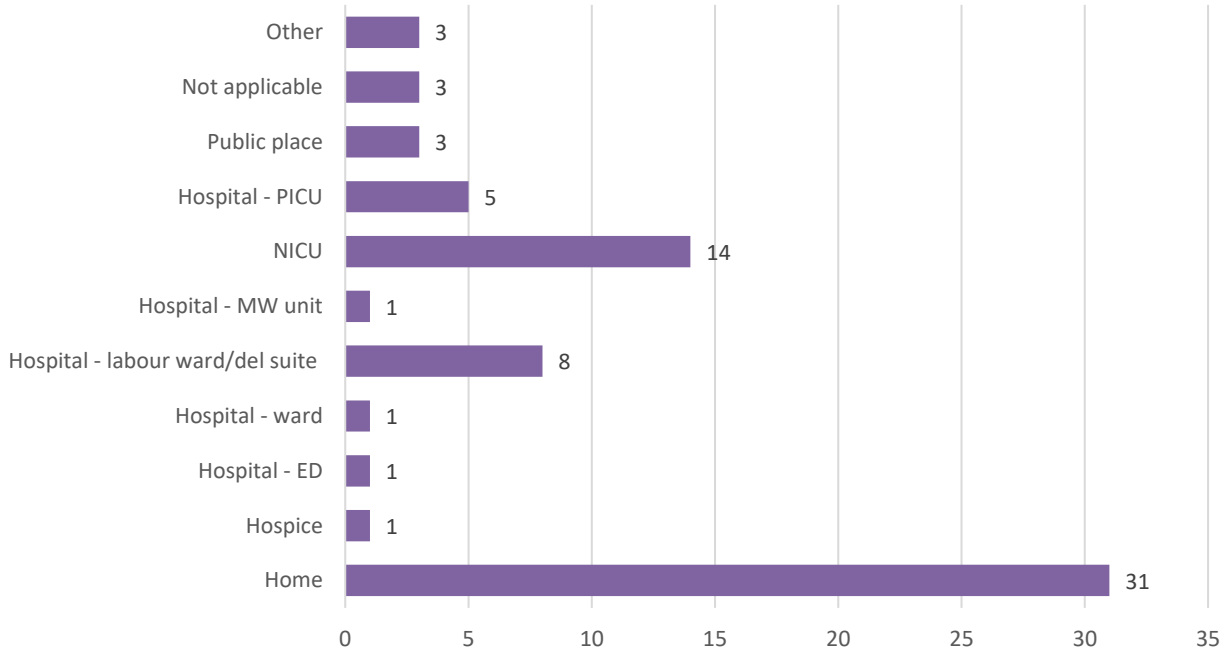
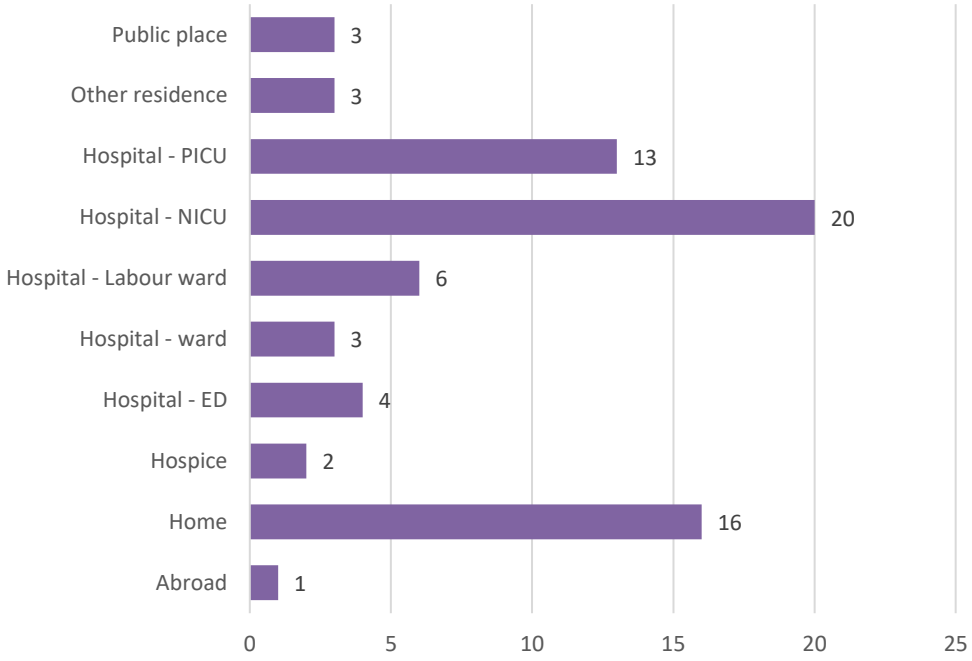


Chart a9: Completed CDOP reviews by place of death 2021/22



Completed Reviews – Modifiable Factors

% of cases with modifiable factors (CDOP): 37%
% of cases with modifiable factors (England): 37%

Table a7: Cases where modifiable factors were identified by category of death 2021/22

Primary category of death (CDOP)	Completed reviews	Modifiable factors identified	Modifiable factors identified (%)
Deliberately inflicted injury, abuse or neglect	2	2	100
Sudden unexpected, unexplained death	7	6	86
Trauma and other external factors	6	4	67
Infection	6	3	50
Suicide or deliberate self-inflicted harm	4	2	50
Perinatal/neonatal event	20	6	30
Acute medical or surgical condition	4	1	25
Chromosomal, genetic or congenital anomaly	16	2	13
Chronic medical condition	4	0	0
Malignancy	2	0	0
Total	**71**	**26**	**37**

Table a8: Cases where modifiable factors were identified by age group 2021/22

Age group	Completed reviews	Cases where modifiable factors identified	Modifiable factors identified (%)
0-27 days	28	8	29
28-364 days	16	8	50
1-4 years	9	2	22
5-9 years	2	0	0
10-14 years	9	4	44
15-17 years	7	4	57
Total	**71**	**26**	**37**

Table a9: Cases where modifiable factors were identified by ethnic group 2021/22

Ethnic Group	Completed reviews	Cases where modifiable factors identified	Modifiable factors identified %
White	41	19	46
Unknown	0	0	0
Other	2	0	0
Mixed	6	3	50
Black or Black British	6	2	33
Asian or Asian British	16	2	13
Total	**71**	**26**	**37**

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

IMD decile	Completed reviews	Cases where modifiable factors identified	Modifiable factors identified %
1	10	5	50
2	9	2	22
3	6	3	50
4	4	0	0
5	7	2	29
6	6	2	33
7	7	3	43
8	12	5	42
9	5	3	60
10	5	1	20
Total	**71**	**26**	**37**

Across the 26 cases where modifiable factors were identified, 6o individual factors were recorded – between 1-6 per case (mean 2.3)

Table a11: Cases with modifiable factors recorded by domain (some cases had factors identified in multiple domains) 2021/22

Domain	Cases where modifiable factors were identified by LLR CDOP	% of cases where modifiable factors were identified by LLR CDOP	% of cases where modifiable factors were identified England (2019/20)*
A: Factors intrinsic to the child	2	7	11
B: Factors relating to the family or social environment	16	62	61
C: Factors relating to the physical environment	7	27	27
D: Factors relating to service provision	11	42	35

***Data taken from NCMD 2nd Annual Report 2019/2020**

Table a12: Most frequently recorded modifiable factors 2021/22:

No of cases	Most frequently recorded modifiable factors:
9	Parental smoking
6	Maternal obesity
6	Service provision - education
5	Unsafe sleeping practices
4	Service provision - communication
4	Service provision - local/national commissioning
2	Safeguarding
1	Public safety
1	Vehicle/transport related
1	Service provision - human factors
1	Child physical condition
1	Child mental health condition

CDOP Theme: Infant Mortality

Cases reviewed 2021-22 of deaths occurring under the age of 1 year: 44

Table a13: Categories of death for children under 1 year – completed reviews

Category of death	No of cases	Cases where modifiable factors identified	% of cases where modifiable factors identified
Perinatal/neonatal event	20	6	30
Chromosomal, genetic or congenital anomaly	10	1	10
Sudden unexpected, unexplained death	5	5	100
Trauma or other external factors	4	2	50
Infection	3	1	33
Deliberately inflicted injury, abuse or neglect	1	1	100
Chronic medical condition	1	0	0
Total	44	16	

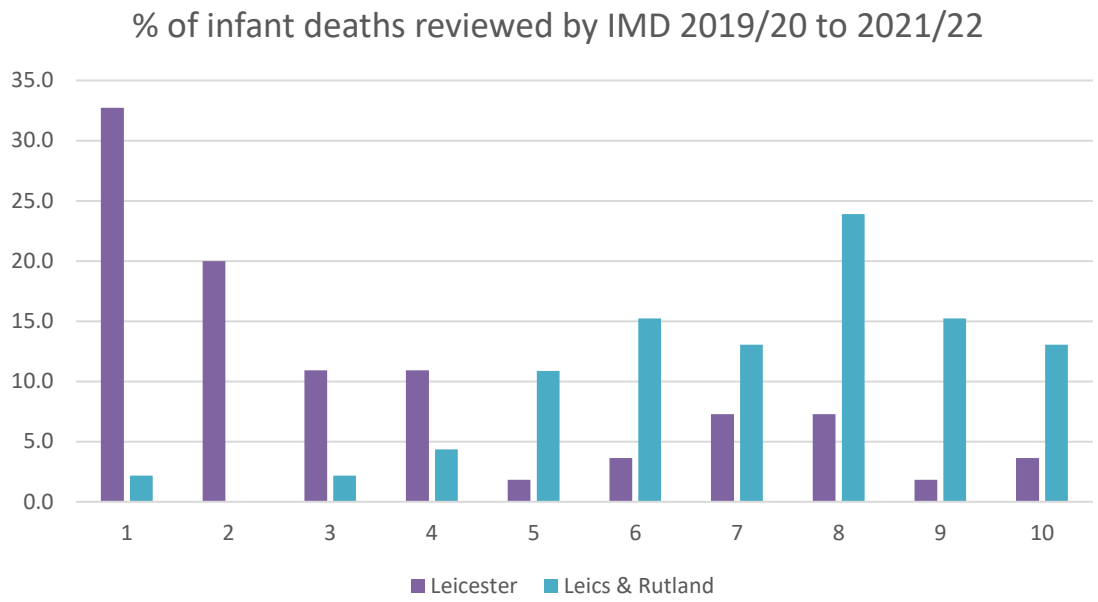
Table a14: Modifiable factors were identified in 16 cases (36%) & noted in all 5 SUUD cases. Some cases had more than one factor noted

Most frequently recorded modifiable factors:	No of cases
Parental smoking	8
Maternal obesity	6
Unsafe sleeping practices	5
Service provision issues	4
Maternal behavioural - other	2
Safeguarding-related issues	1
Maternal drug/alcohol misuse	1
Maternal health issues	1
Distance to travel to access specialist services	1

Table a15: Infant mortality & deprivation

Deprivation decile	Deaths reviewed 2019/20 to 2021/22 Leicester	Leics & Rutland	LLR	% of deaths Leicester	Leics & Rutland	LLR
D1	18	1	19	**32.7%**	**2.2%**	**18.8%**
D2	11	0	11	**20.0%**	**0**	**10.9%**
D3	6	1	7	**10.9%**	**2.2%**	**6.9%**
D4	6	2	8	**10.9%**	**4.4%**	**7.9%**
D5	1	5	6	**1.8%**	**10.9%**	**5.9%**
D6	2	7	9	**3.6%**	**15.2%**	**8.9%**
D7	4	6	10	**7.3%**	**13.0%**	**9.9%**
D8	4	11	15	**7.3%**	**23.9%**	**14.9%**
D9	1	7	8	**1.8%**	**15.2%**	**7.9%**
D10	2	6	8	**3.6%**	**13.0%**	**7.9%**
Total	55	46	101	**100.0%**	**100.0%**	**100.0%**

Chart a10: % of infant deaths reviewed by Index of Multiple Deprivation 2019/20 to 2021/22



Sudden Unexpected Deaths in Infancy (SUDI)

In the period between 1st April 2016 and 31st March 2022, CDOP reviewed the deaths of 15 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 a16: SUUD Infant Case characteristics – 2015/16 to 2020/21 compared with 2016/17 to 2020/21

	2015/16 to 2020/21 (n=15)		2016/17 to 2021/22 (n=15)	
	N	%	N	%
Bottle fed	12	80 %	11	73 %
First born	4	27 %	6	40 %
Preterm	10	67 %	9	60 %
IMD 1&2	7	47 %	6	40 %
Birthweight <2.5kg	9	60 %	9	60 %
Mean maternal age	28.8 (20-36)		28.73 (20-36)	
Medical cause of death:				
'Unascertained'	12	80 %	11	73 %
'SIDS'	3	20 %	4	27 %
Modifiable Factors				
Unsafe sleeping	10	67 %	9	60 %
Parental smoking	9	60 %	9	60 %
One or more MF	13	87 %	13	87 %
More than one MF	10	67 %	11	73 %

CDOP Theme: LeDeR cases

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 of 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]

In addition to the Child Death Review process, information is gathered in the form of a 'pen portrait' of the child or young person, and since September 2020, areas of best practice are identified, and the quality of care provided is graded.

Modifiable factors were identified in 3 of the 16 LeDeR cases reviewed.

Table a17: Number of LeDeR cases reviewed by LLR CDOP

	2020-21	2021-22	Total
Number of cases reviewed	8	8	16

Table a18: Categories of death of LeDeR Cases

Category of death	No of cases
Chromosomal, genetic or congenital anomaly	7
Acute medical condition	4
Chronic medical condition	3
Deliberately inflicted injury, abuse or neglect	1
Infection	1
Total	16

Table a19: LeDeR care grading – completed in 13/16 cases:

Grade of care	No of cases
1. This was excellent care and met current best practice.	2
2. This was good care, which fell short of current best practice in only one minor area.	7
3. This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing.	2
4. Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.	0
5. Care fell short of current best practice in one of more significant areas, although this is not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death.	0
6. Care fell far short of expected good practice and this contributed to the cause of death.	2
Total	13

Areas of best practice were identified in 4 of these 13 cases

Top 3 learning themes from the 16 cases reviewed:

1. **Communication**
   Of the 4 cases where best practice was identified, good or excellent communication between agencies was noted, including between hospital and community teams, around areas such as end of life care and complex decision making. The role of virtual platforms in enhancing this during the Covid-19 pandemic was also noted.

   Issues with poor communication, either between different teams of professionals or between professionals and families were noted the most frequently.

2. **Issues of care coordination/transition**
   Importance of good care coordination, of families being aware of who the lead professionals were, and of effective transition of care from children's to adult services were highlighted.

3. **Access to services at the right time**
   Both in terms of physical accessibility and availability, ensuring equity of access for children and young people to the services they need.

As part of the work plan for the coming year, CDOP will work collaboratively with colleagues' from LeDeR to develop SMART actions (utilising the new grading system that LeDeR has adopted). In addition, in order to support the identification of themes, CDOP will hold an annual themed panel, which will be supported by a themed analysis report.

CDOP Theme: Suicide/Self-harm

The National Child Mortality Database published their thematic report into Suicide in Children & Young People, looking at deaths that occurred or were reviewed by a CDOP between 1st April 2019 & 31st March 2020.

https://www.ncmd.info/publications/child-suicide-report/

Key findings:

- Services should be aware that child suicide is not limited to certain groups; rates of suicide were similar across all areas, and regions in England including urban and rural environments, and across deprived and affluent neighbourhoods
- 62% of CYP had suffered a significant personal loss in their life prior to their death (including bereavement, and living losses such as loss of friends and routine due to moving home, school or other close relationship breakdown)
- Over 1/3 of CYP had never been in contact with mental health services
- 16% of CYP had a confirmed neurodevelopmental condition at the time of their death – this appears higher than the general population
- Almost a quarter of CYP reviewed had experienced bullying either face to face or cyberbullying, the majority reporting bullying in schools.

CDOP Theme: Deprivation

The National Child Mortality Database published their thematic report into Child Mortality & Social Deprivation, looking at deaths that occurred or were reviewed by a CDOP between 1st April 2019 & 31st March 2020.

https://www.ncmd.info/publications/child-mortality-social-deprivation/

Key findings:

- Clear association between risk of death and deprivation across all categories except malignancy
- Relative 10% increase in risk of death between each decile of increasing deprivation
- >1 in 5 deaths might be avoided if children living in the most deprived areas had the same mortality risk as those living in the least deprived
- Increased proportion of deaths with modifiable contributory factors with increasing deprivation
- 1 in 12 child deaths reviewed in 2019/20 identified 1 or more factors related to deprivation

Recommendation:

Use of the data in this report to develop & monitor the impact of future strategies to reduce social deprivation and inequalities

Action by:

Policy makers, Public Health Services, service Planners and Commissioners at a local & national level.

LLR CDOP Case Learning – completed reviews 2021/22

Learning identified? Yes 50/71 cases (70.4%)
No 21/71 cases (29.6%)

Table a20. Cases where learning identified by category of death

Category of death	Total no of cases	Cases where learning identified	% of cases where learning identified
Sudden unexpected, unexplained death	7	7	100
Trauma or other external factors	6	6	100
Infection	6	6	100
Deliberately inflicted injury, abuse or neglect	2	2	100
Acute medical or surgical condition	4	3	75
Suicide or deliberate self-inflicted harm	4	3	75
Chromosomal, genetic or congenital anomaly	16	10	62.5
Perinatal/neonatal event	20	10	50
Chronic medical condition	4	2	50
Malignancy	2	1	50
Total	**71**	**50**	

Key learning themes identified:

1. Lack of integrated IT systems impacts on communication, information sharing and recognition of vulnerability factors for babies, children and young people.
2. Safer Sleeping
    - Unknown risks posed by sleep positioners – not recommended for use, but often perceived by families & professionals as enhancing safety rather than increasing risk
    - Impact on family sleep choices when unexpectedly out-of-routine,
    - Importance of involving partners in safer sleep conversations,
    - Importance of documenting safer sleep conversations with families,
    - Baby illness as a factor in parental decision-making around co-sleeping
3. Importance of early recognition of emerging vulnerabilities, to inform an appropriate response with support, advice and information to mitigate risks to the health of babies and children.
4. Importance of timely communication and information-sharing within and between agencies
5. Impact of Covid 19
    - Reduced service capacity impacted on ability of practitioners to spend time with families and hear their voice,
    - Reduced face to face contact with families & visibility of the home environment was a limitation to assessments
    - For some children, young people & families, face to face work may be more accessible and acceptable than online or virtual options
    - Increased social isolation compounding existing challenges faced by children, young people & families, particularly those already experiencing isolation.

7 Minute Briefings developed to share case learning for cases reviewed 2021/22:

- Private Fostering
- Informal Medical Advice – for health professionals

Rapid Read for health professionals on Blood-stained diarrhoea