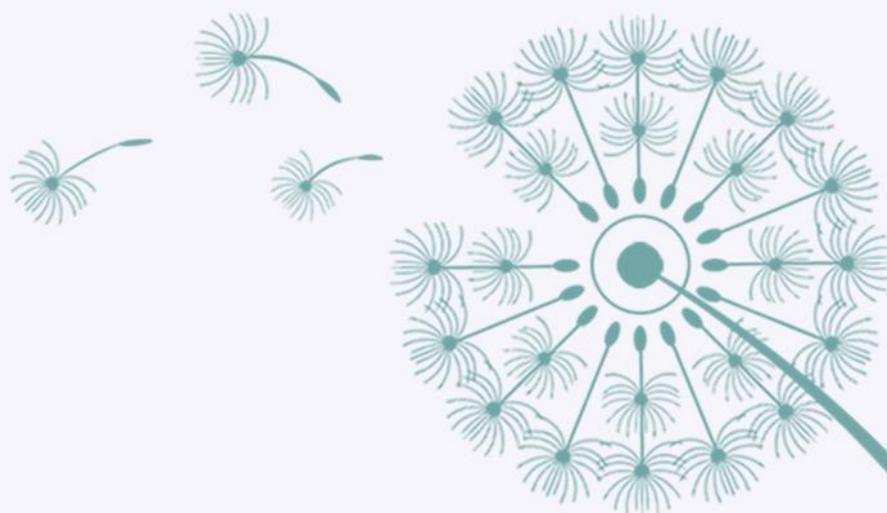


# Child Death Overview Panel (CDOP) Annual Report **2020-2021**



Child Death  
Overview Process

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Leicester, Leicestershire & Rutland

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## 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
DI	Detective Inspector
EMAS	East Midlands Ambulance Service
JAR	Joint Agency Response
LeDeR	Learning Disability Mortality Review
LLR	Leicester, Leicestershire & Rutland
LPT	Leicestershire Partnership NHS Trust
LRI	Leicester Royal Infirmary
LSCP	Local Safeguarding Children Partnership
NCMD	National Child Mortality Database
NNU	Neonatal Unit
SUDI/C	Sudden Unexplained Death in Infancy/Childhood
UHL	University Hospitals of Leicester NHS Trust

# Leicester, Leicestershire & Rutland Child Death Reviews 2020/21



## Introduction

This is the Annual Report for 2020/21 of the Leicester, Leicestershire, and Rutland (LLR) Child Death Overview Panel (LLR CDOP) and provides an overview of work and case reviews undertaken.

LLR CDOP has been in existence since 2009 and the number of child deaths has remained relatively constant over this time. Taking a 6-year snapshot across LLR allows for pooling of the datasets to allow for standardisation and correlation to demonstrate any relationship between child deaths and risk factors such as smoking, deprivation and ethnicity. It also allows benchmarking against England and highlights areas requiring further action to reduce child deaths.

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 three Clinical Commissioning Groups. Government advice is that CDOPs should cover populations of at least 500,000, reviewing at least 60 deaths per year, and it was for this reason that the three authorities of LLR came together from 1st April 2009.

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. However, detailed analysis and conclusions have been limited due to the fortunately small numbers reviewed on an annual basis. Pooling data together over this six-year period reduces random statistical error and therefore enables a more precise analysis.

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.

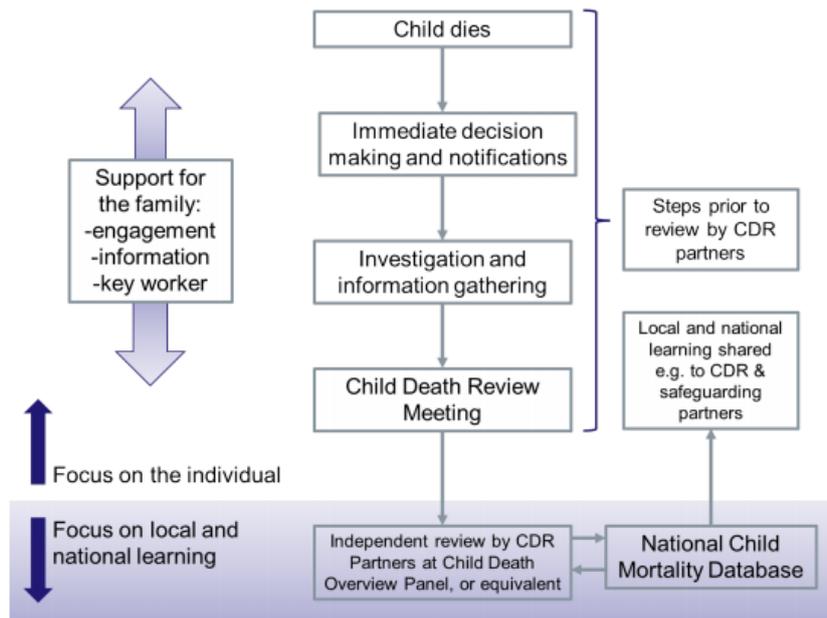


Figure 1: The Child Death Review process as set out in Working Together to Safeguard Children 2018, Chapter 5.

## Notes

As the numbers for Rutland are too small to analyse separately, Leicestershire County and Rutland data has been presented jointly; this is in accordance with the Office for National Statistics and the NHS Digital guidance relating to the publication of births and death statistics. This states that when a count is equal to or less than 5 (including zero), data must be suppressed. As such, data for Rutland cannot be reported separately.



## 1. Overview

The local Child Death Overview Panel covers Leicester, Leicestershire, and Rutland. During 2020-2021, five panels reviewing 64 cases were held. 32 of these cases related to Leicester City and 32 cases to Leicestershire and Rutland.

As a result of the panels that were held, the following areas are being progressed:

### 1.1 Suicide and self-harm in children & young people

A themed review of suicide in children and young people across LLR took place in July 2020 (second meeting Jan 2021), building on previous work including the 2017 themed review of children's suicides, 2018 multi-agency learning event, and 2019 conference, 'Learning from when Young People Take Their Lives.' 11 cases of death by suicide had been notified to the LLR CDOP Panel between January 2017 and July 2020 and were included in the review, noting that not all case reviews had been concluded. Following the review, the themed panel noted the most prevalent risk factors across the cases, including:

- Diagnosed or suspected neurodevelopmental disorders, particularly the prevalence of rigid thinking patterns and impulsivity.
- The impact of parental separation on children and young people.
- The impact of adverse experiences in childhood.
- Perceived pressure at school.
- Many of the young people had at some point expressed suicidal ideation.

Key recommendations were:

- Work with secondary schools (including private and faith schools), further education colleges, and home-schooled children to raise awareness of the services available to support pupils, parents and teaching staff.
- Work with frontline staff, teaching staff and commissioners to highlight the potential impact on mental health of parental separation, particularly for those children with other risk factors
- Examine the potential to target resilience programmes for children and young people with diagnosed or suspected neurodevelopmental conditions (Autism Spectrum Disorder and ADHD/ADD)
- Raise awareness of the detrimental impact of the pressure to succeed academically on mental health and wellbeing with both students and teaching staff.

- Work with commissioners to improve awareness of, and responses to young people with multiple adverse childhood experiences.

The report and recommendations have been shared with the LLR Suicide in Adults Prevention Group, and LLR CDOP will link in with the LLR All Age Mental Health Design Group and the LLR Children and Young People Design Group to share learning from cases on an ongoing basis.

## **1.2 Infant Mortality**

The LLR CDOP continued to support the delivery of the LLR Infant Mortality Strategy and Action Plan. This included attendance at Healthy Pregnancy and Babies Strategy Group meetings, presenting regular updates on CDOP to the group, and presenting our findings and recommendations. CDOP members have also participated in work around Consanguinity & Risk, and the ICON Project (reducing abusive head trauma – formerly known as ‘shaken baby syndrome’ triggered by crying).

CDOP have continued to work with partners through the Healthy Babies Strategy Group to share learning from SUDI cases in the development and delivery of safer sleep messaging, with particular consideration given to those from vulnerable families in light of local case learning, alongside the recommendations of the ‘Out of Routine’ report into sudden unexplained death in infancy (SUDI) in families where children are considered at risk of significant harm.

## **1.3 Learning Disability mortality reviews (LeDeR)**

The Learning Disabilities Mortality Review Programme (LeDeR) was launched in LLR in 2017, and throughout 2019-2020 CDOP continued to notify cases to LeDeR, and to carry out reviews on behalf of the LeDeR programme. For the period 1<sup>st</sup> October 2017 to 31<sup>st</sup> March 2020, 10% of LLR LeDeR referrals have been for children and young people with a learning disability.

During 2020-21, 8 LeDeR case reviews were completed; cases were clustered together within panels, with the LeDeR Local Area Contacts (LAC) invited to attend, to optimise thematic learning. Of the 8 cases, modifiable factors were identified in one; key learning themes included improving communication (3 cases) and improving complex care coordination (2 cases).

CDOP will continue to partner with LeDeR, and these themes and subsequent learning as identified by the LeDeR programme will be taken forward as part of ongoing work in 2021/2022.

## 1.4 Covid-19 pandemic

The Covid-19 pandemic has, and continues to impact on the way that CDOP has operated in several different ways:

- Guidance for the Joint Agency Response to child deaths during the Covid 19 pandemic was released and rapidly embedded as part of the LLR multiagency initial response to child deaths (including recommendations for reducing risk for families and practitioners, collating Covid swabs in all SUDIC cases, and guidance to ensure that the central aims of the response are maintained).
- There has been a rapid shift to virtual multiagency meetings at each stage of the Child Death Review process, which has been widely recognised as a positive change, and has increased practitioner involvement throughout the case review process.
- Whilst both the direct and indirect impact of Covid-19 on infants, children and young people remains to be seen in terms of medium and long-term impacts, engagement with the NCMD has enabled CDOP data to contribute to real-time monitoring of deaths not just from Covid-19, but from all causes including road traffic collisions, SUDI, and suicide on a national level, and LLR data contributed to the NCMD real-time surveillance of suicide in Children & Young People during the Covid 19 pandemic.

Of the cases reviewed during 2020-2021, only 2 completed reviews out of the 64 carried out involved deaths occurring during the Covid-19 pandemic. Covid-19 did not contribute either directly or indirectly to the vulnerability or death in either case. As cases are reviewed during 2021-22, the impact of the pandemic will continue to be assessed.

## 1.5 Other Key Learning from cases

As a result of the case reviews carried out and learning identified, since September 2020 LLR CDOP have implemented the 7-minute briefing format to disseminate learning on the following topics, which are distributed via panel members:

- Epilepsy Safety
- Community Defibrillators

## 2. National Learning – engagement with NCMD

The National Child Mortality Database (NCMD) is a 4-year programme commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England launched in April 2018. There is a statutory requirement for CDOPs

in England to collect this data and provide it to NCMD. The purpose of this is to learn from deaths, disseminate learning widely and ensure that actions are taken (locally and nationally) to reduce preventable child deaths in the future, with the publication of Annual Reports and additional thematic reports. As well as submitting local data to allow analysis at a national level, the NCMD portal also allows for same-day 'alerts' to be raised, should there be any cause for concern about any element in the environment or circumstances of death where action is required for urgent learning.

For 2020/2021 all case notifications were entered in real-time via the NCMD portal, and from September 2020 via the eCDOP platform, so that data is automatically uploaded to NCMD for all cases on a regular basis, at various points during the review process.

Data submitted from LLR CDOP was included in the 2021 NCMD Child Mortality and Social Deprivation Thematic Report; key findings included a clear association between the risk of death and level of deprivation. The report has been presented and discussed at the LLR CDOP Panel, the LLR Healthy Babies Strategy Group and LLR CYP Design Group.

### **3. LLR Child Death Review Service developments**

Following the publication of the LLR CDOP New Arrangements in 2019, work has continued to agree future funding arrangements and develop an all-inclusive SLA which will clarify service delivery and performance arrangements going forward. We anticipate new contracting arrangements to be agreed and in place by March 2022.

CDOP has continued to implement the new processes as set out in Child Death Review: Statutory and Operational Guidance, including ensuring a robust Joint Agency Response as appropriate and high-quality Child Death Review Meetings. Quarterly benchmarking against standards as set out in the guidance and agreed by the National Network of CDOPs (NNCDOP) has been ongoing; all areas are now at least partially implemented, and the majority fully implemented.

In May 2020, virtual Child Death Initial Meetings were implemented for all non-neonatal cases, to bring multiagency partners together within 24 hours (or next working day) of the notification to share information around the circumstances, identify any immediate actions needed, ensure the correct response is in place and ensure coordinated support for the family. Feedback from professionals involved has been overwhelmingly positive in terms of this meeting format being a valuable addition to the LLR Child Death Review process.

As per the recommendation from the 2019-20 Executive Summary, the cloud-based eCDOP system has been procured and rolled out. As of September 2020, all Notifications to LLR CDOP have been made via the eCDOP system, and it is now fully embedded for data collection via Reporting Forms, case and meeting management, enabling automatic submission of data to the National Child Mortality Database.

LLR CDOP has continued to be represented at the East Midlands Regional CDOP Network meetings, for the purpose of sharing learning and best practice.

## Key Findings: Completed reviews 2020/21



Of the 64 reviews completed by LLR CDOP between 01/04/2020 to 31/03/2021:

- Leicester City: 32 (50 %)
- Leicestershire County: 30 (47 %)
- Rutland: 2 (3%)

45% of all child death reviews for LLR were identified as having modifiable factors.

- Leicester City: 44%
- Leicestershire County 43%
- Rutland: 100%

### Top 3 causes of child deaths reviewed across LLR:

- 34% due to perinatal/neonatal events.
  - 43% of these were considered to have modifiable factors
- 27% due to chromosomal, genetic, or congenital anomalies.
  - 15% were considered modifiable
- 9% due to trauma or external factors.
  - 56% considered modifiable

Sudden unexpected, unexplained deaths (incorporating, but not limited to SIDS cases) accounted for 6% child deaths.

Of these, modifiable factors were identified in 73% of cases.

64% of all child deaths across LLR occurred within the first year of life.

# Key findings: Notifications 2020/21



## Case Notifications to LLR CDOP

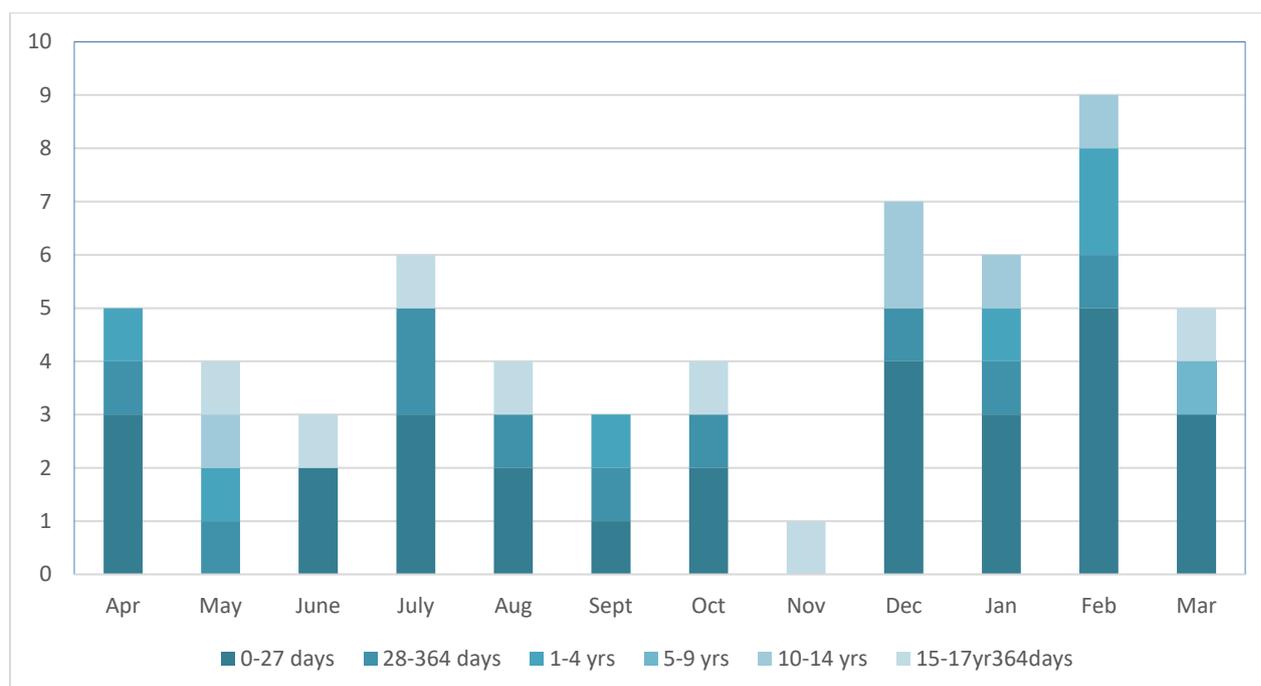
Working Together to Safeguard Children 2018 confirms that each LSCP has responsibility for the provision of a Designated Person to whom all child deaths are notified. Across LLR, this function is fulfilled by the Child Death Review (CDR) Manager, a position jointly funded by the Child Death Review Partners, together with the Designated Doctor for Child Death. Any professional who is aware of the death of a child or young person (excluding those babies who are stillborn or planned terminations that are within the law), where the child was normally resident in LLR must ensure that the CDR Manager is notified. The current procedures stipulate that a notification must be received within 24 hours (or the next working day). It is then the responsibility of the CDR Manager to co-ordinate the information collection and ensure liaison with families.

### 1. Death notifications by Local Authority

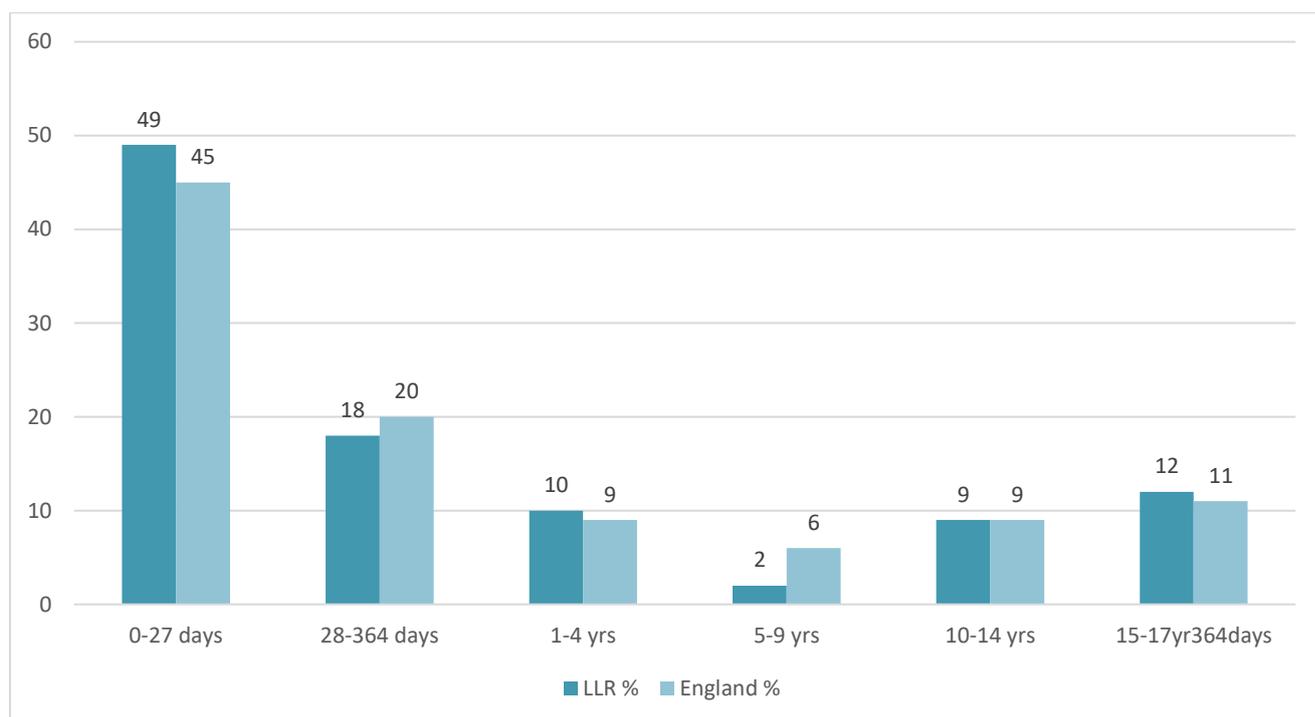
Of the 57 notifications to LLR CDOP between 01/04/2020 to 31/03/2021:

- Leicester City: 31 (54 %)
- Leicestershire County: 25 (44 %)
- Rutland: 1 (2%)

### 2. Death notifications by month



### 3. Death notifications by age group (%)



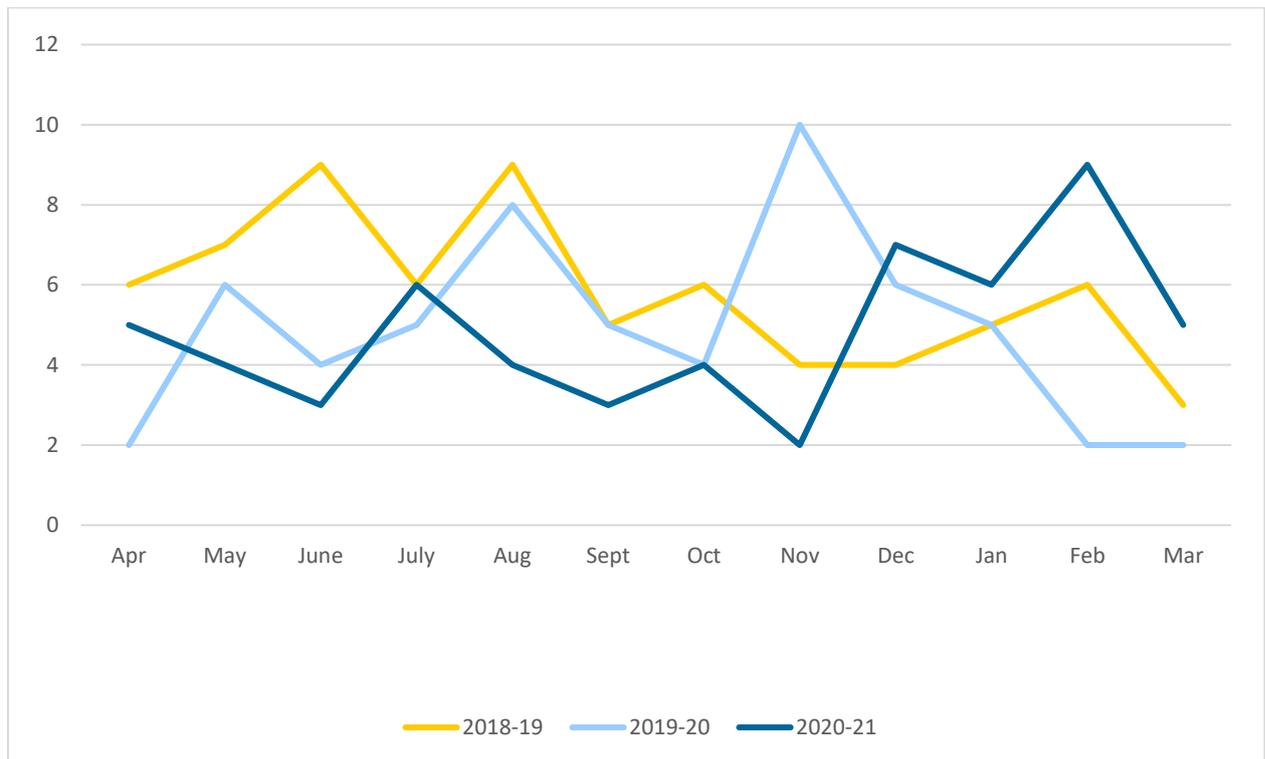
### 4. Death notifications by response category

The Joint Agency Response (JAR) is a coordinated multiagency response to child deaths occurring in specific circumstances, in line with the process set out in Sudden and Unexpected Death in Infancy and Childhood: Multiagency guidelines for care and investigation (2016). Working Together to Safeguard Children 2018 sets out the following criteria for cases requiring a Joint Agency Response, if the child’s death:

- Is or could be due to external causes.
- Is sudden and there is no immediately apparent cause (including sudden unexpected death in infancy/childhood).
- Occurs in custody, or where the child was detained under the Mental Health Act.
- Occurs where the initial circumstances raise any suspicions that the death may not have been natural.
- Occurs in the case of a stillbirth where no healthcare professional was in attendance.

Category	Cases	%
Non-JAR	12	21
JAR	19	33
Neonatal	26	46
<b>Total</b>	<b>57</b>	

## 5. Three-year trend in Notification numbers by month

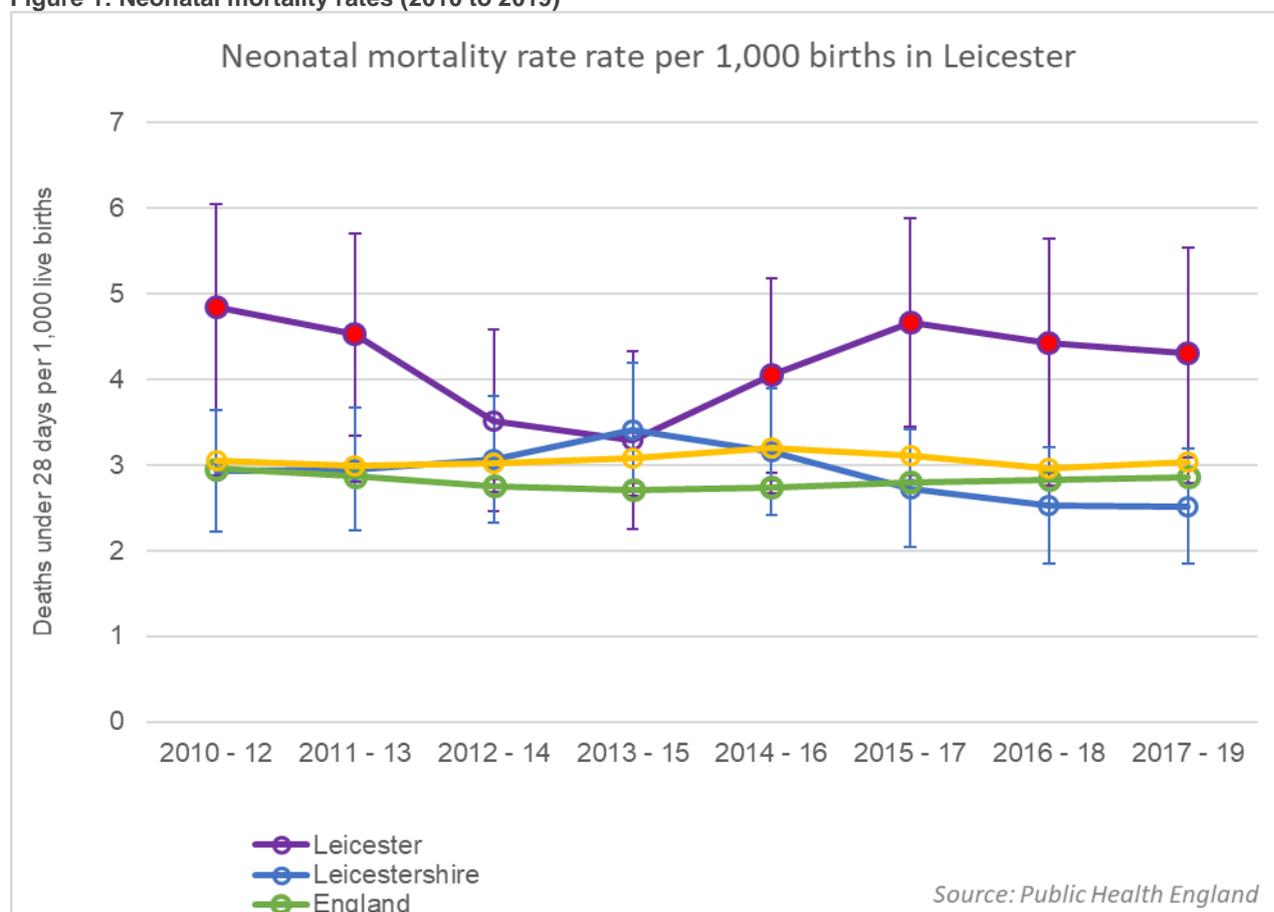




## Neonatal mortality rates

Neonatal mortality rate refers to deaths under 28 days per 1,000 live births (stillbirths are not included). Leicestershire's rates are similar to the East Midlands and England rates. Rutland's rates are not shown separately due to low numbers. Leicester's rate has consistently been significantly higher than East Midlands and England from 2004, improving in 2012-14, 2013-15 and rising to a significantly higher rate again from 2014-16 to 2017-19.

Figure 1: Neonatal mortality rates (2010 to 2019)



Data: Public Health England, Fingertips Child Health Profiles

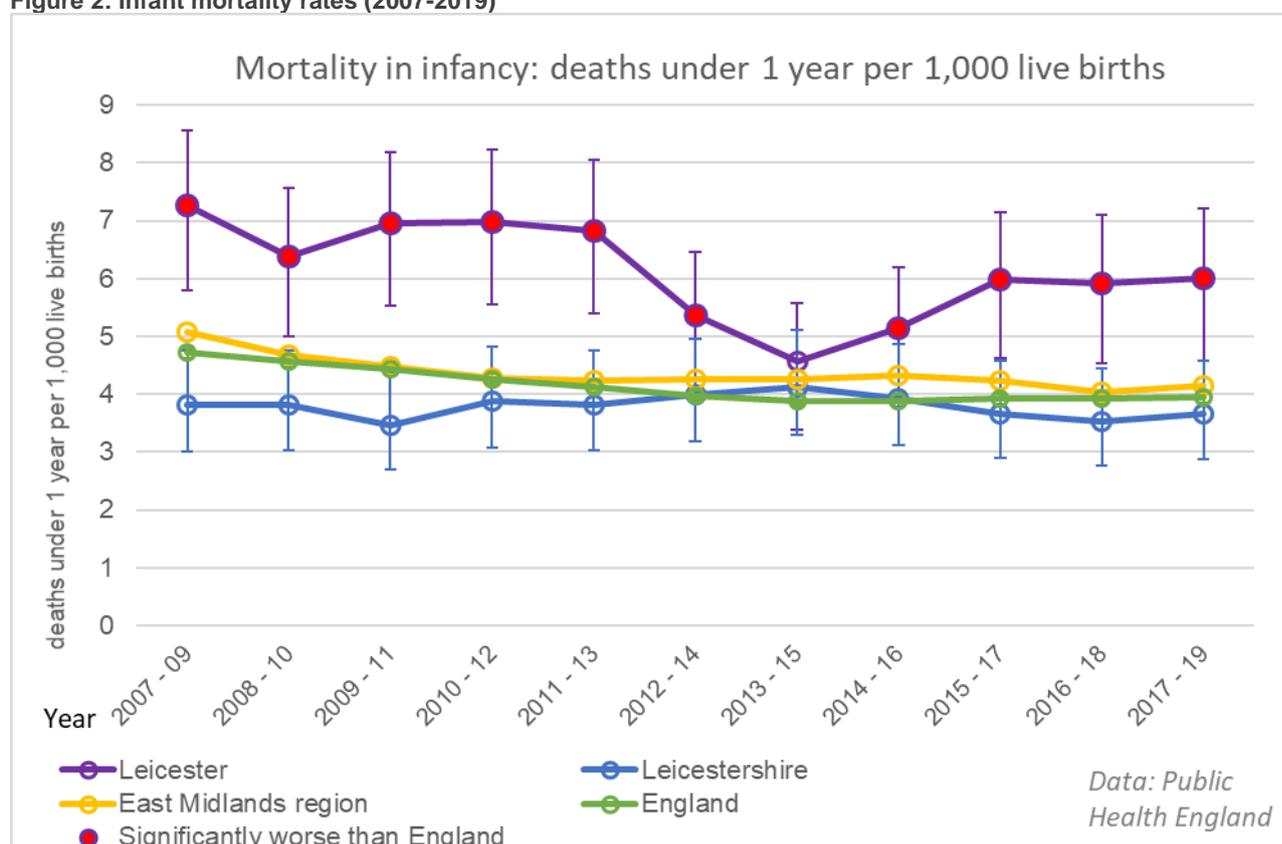
## Infant mortality rates

Infant mortality rate refers to deaths under one year per 1,000 live births (stillbirths are not included).

There were around 28 infant deaths per year in Leicester and 25 infant deaths in Leicestershire between 2017-2019. There were less than 3 infant deaths in Rutland over the same period.

Leicestershire has a similar rate (not significantly different) to the East Midlands and England rates, but Leicester has consistently been significantly higher since 2005, improving in 2013-2015 to a similar rate to England, and worsening again from 2014-16 to 2017-19.

Figure 2: Infant mortality rates (2007-2019)

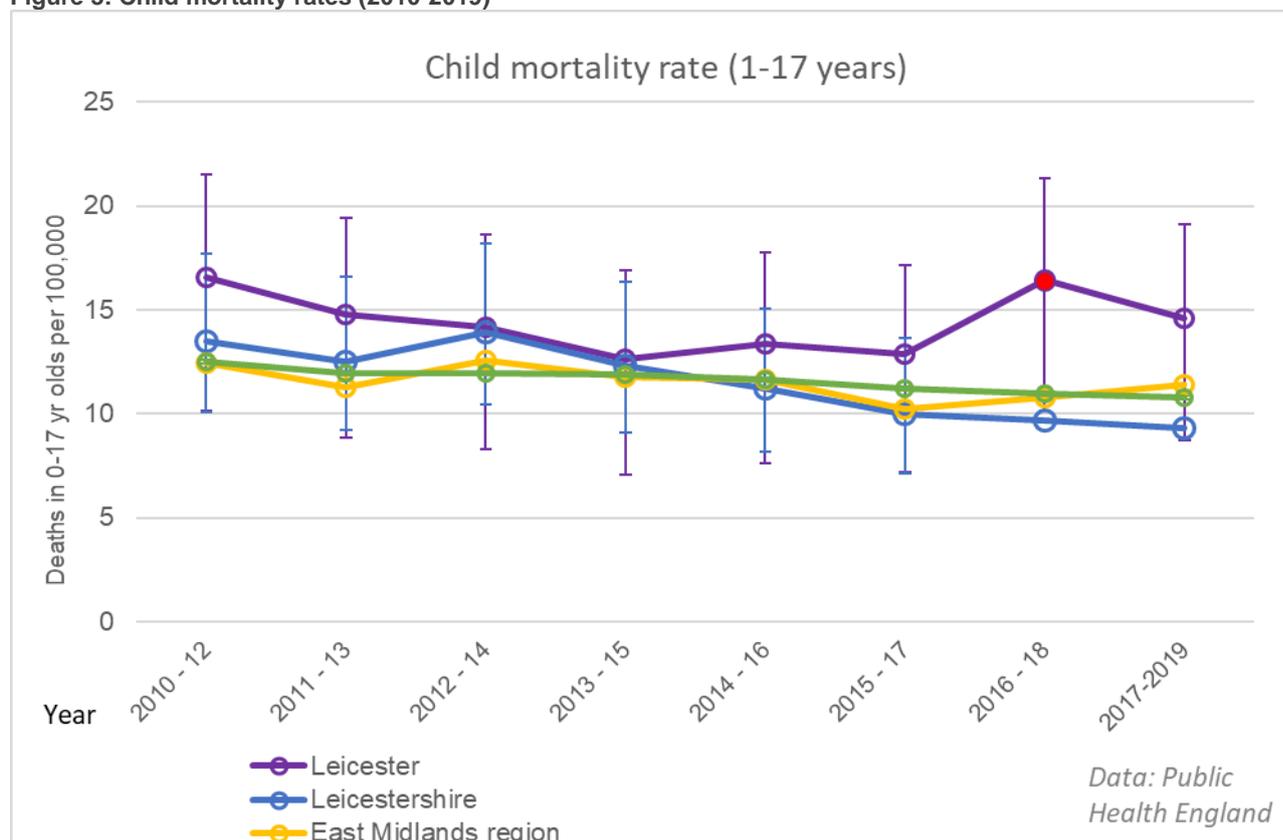


Data: Public Health England Child Health Profiles

## Child mortality rates (0-17 years)

The child mortality rate reported below refers to deaths in children aged 1 -17 years per 100,000 children (2010 to 2019). The rate for Leicestershire is similar (not significantly different) to the England rate. In Leicester, the rate is generally higher and significantly higher in 2016-18.

Figure 3: Child mortality rates (2010-2019)



Data: Public Health England Child Health profiles



## 1. Completed reviews: Overview

The CDOP panel does not review cases until all information is gathered and other processes have concluded such as criminal investigations and Child Safeguarding Practice Reviews; for cases where there will be a Coroner's inquest, the CDR Manager will liaise with the Coroner to agree case management. Therefore, the number of deaths reviewed during a year does not equate to the numbers of deaths notified in the same year, as a death may be reviewed many months after the death has occurred. Furthermore, reviews can take longer to complete if modifiable factors are identified.

The figure below shows the number of child death reviews completed between 2015/16 and 2020/21. Overall, 396 reviews were completed in this timeframe with 48% of reviews undertaken for children who were resident in Leicester City, 52% in Leicestershire and Rutland. Over the 6-year period there were 12 reviews completed in Rutland (3% of the LLR total).

### 1.1 Completed CDOP reviews by LSCP

Year	Number of review cases completed		
	Leicester	Leicestershire & Rutland	LLR Total
2015/2016	39	63	102
2016/2017	39	33	72
2017/2018	31	41	72
2018/2019	31	24	55
2019/2020	17	14	31
2020/2021	32	32	64
<b>Total</b>	<b>189</b>	<b>207</b>	<b>396</b>

The percentage of child death reviews completed in LLR within 12 months of the notification is variable year on year. The highest percentage was achieved in 2017/18 (86%) but is understandably lower in 2020/21 (22%).

Year	Number of review cases completed			% completed within 12 months
	Under 12 months from notification	Over 12 months from notification	Total	
2015/2016	41	61	102	40%
2016/2017	54	18	72	75%
2017/2018	62	10	72	86%
2018/2019	39	16	55	71%
2019/2020	15	16	31	48%
2020/2021	14	50	64	22%
<b>Grand Total</b>	<b>225</b>	<b>171</b>	<b>396</b>	<b>57%</b>

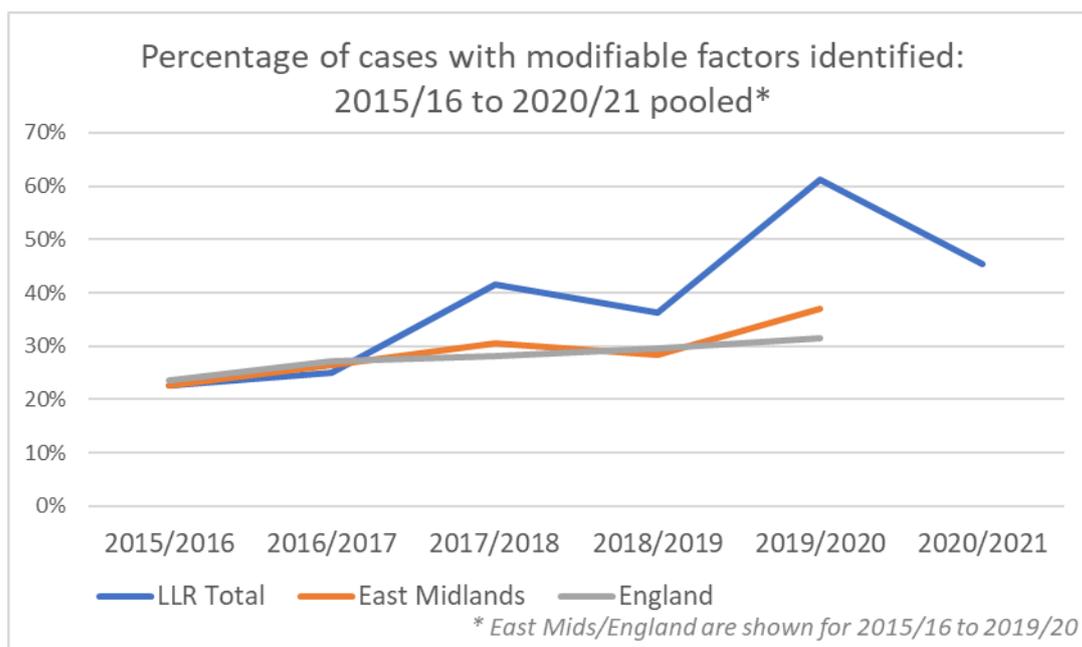
## 2. Modifiable factors

When reviewing each case, CDOP panels are asked to consider if there were any modifiable factors that may have contributed to the death. These factors are defined as those which “*The panel has identified one or more factors, in any domain, which may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths*” (Working Together to Safeguard Children 2015).

The figure below shows the trend in the percentage of cases with modifiable factors identified. East Midlands and England are both showing a gradual increase in modifiable factors over the period (East Midlands from 23% to 37% and England from 24% to 31%). There is more variation for LLR as the number of cases with modifiable factors identified each year is relatively low.

Latest data for England (2019/20) shows 30% of cases had modifiable factors identified.

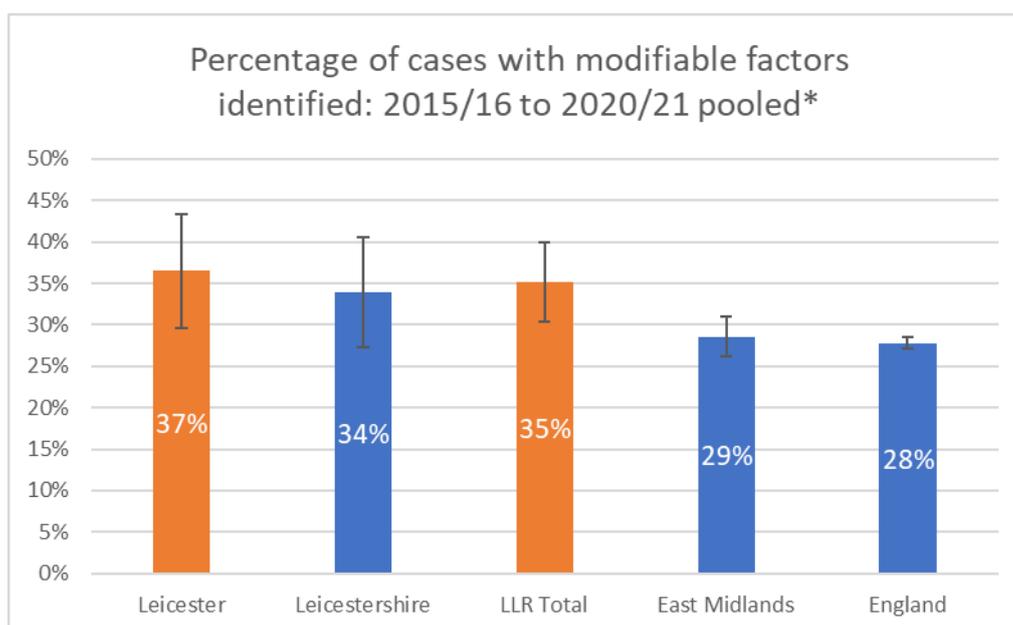
Figure 4: Percentage of cases reviewed with modifiable factors identified (2015/16 to 2020/21)



Looking at the pooled number of cases with modifiable factors for the 6-year period, Leicester City (37%) and LLR (35%) are significantly higher than England (28%)

Area	Percentage of cases with modifiable factors identified		
	Modifiable factors	All cases	% modifiable factors
Leicester	69	189	37%
Leicestershire and Rutland	70	207	34%
LLR Total	139	396	35%
East Midlands	380	1330	29%
England	4679	16823	28%

Figure 5: Percentage of cases reviewed with modifiable factors identified (2015/16 to 2020/21 pooled)

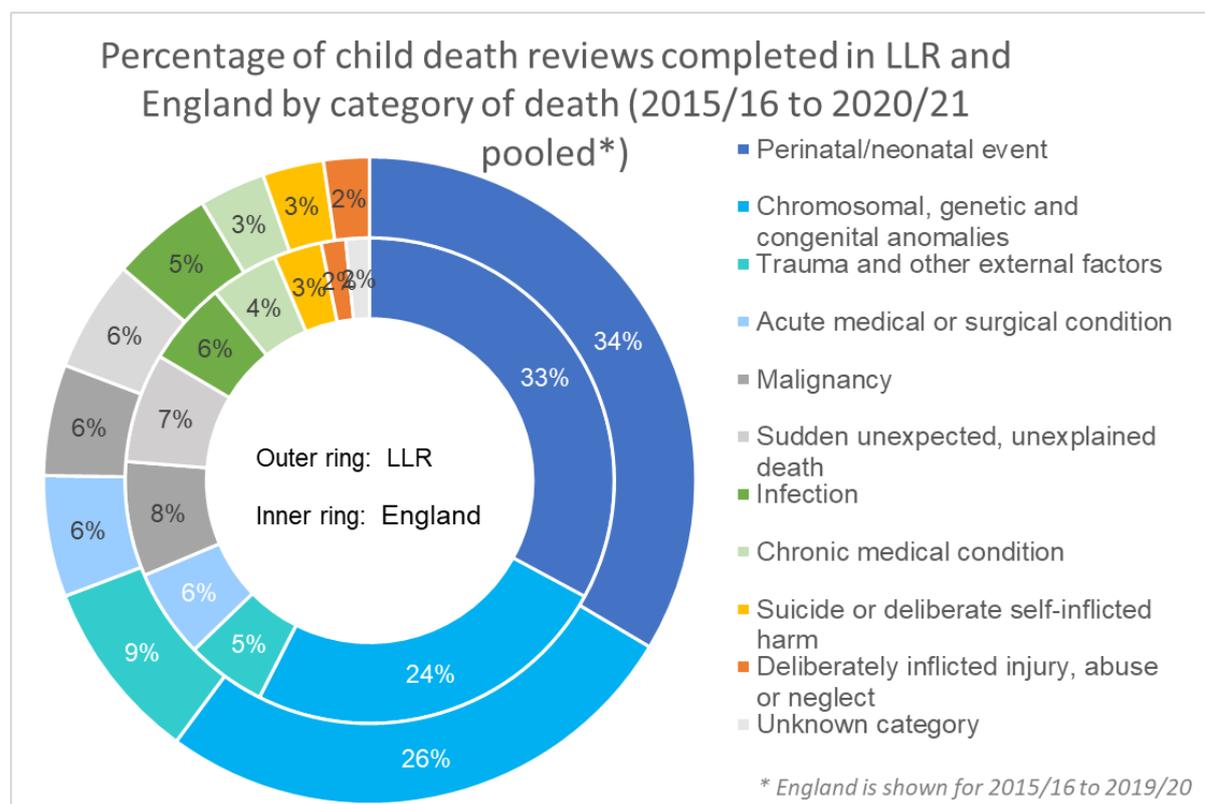


### 3. Categorisation and location of death

#### 3.1 Categorisation of death

CDOP categorises the likely cause of death using the national hierarchical format. Details of the ten categories are attached at Appendix A. When looking at causes of death of all cases reviewed by CDOP from 2015/16 to 2020/21, the highest proportion of deaths (34%) across LLR were from the perinatal/neonatal category. The next largest proportion of deaths (26%) was from the chromosomal/congenital category. Data for England - shows perinatal/neonatal category represents the largest proportion (33%) with chromosomal/congenital category being the next largest proportion (24%). The proportion of deaths due to a perinatal/neonatal event in LLR is not significantly different to the England rate.

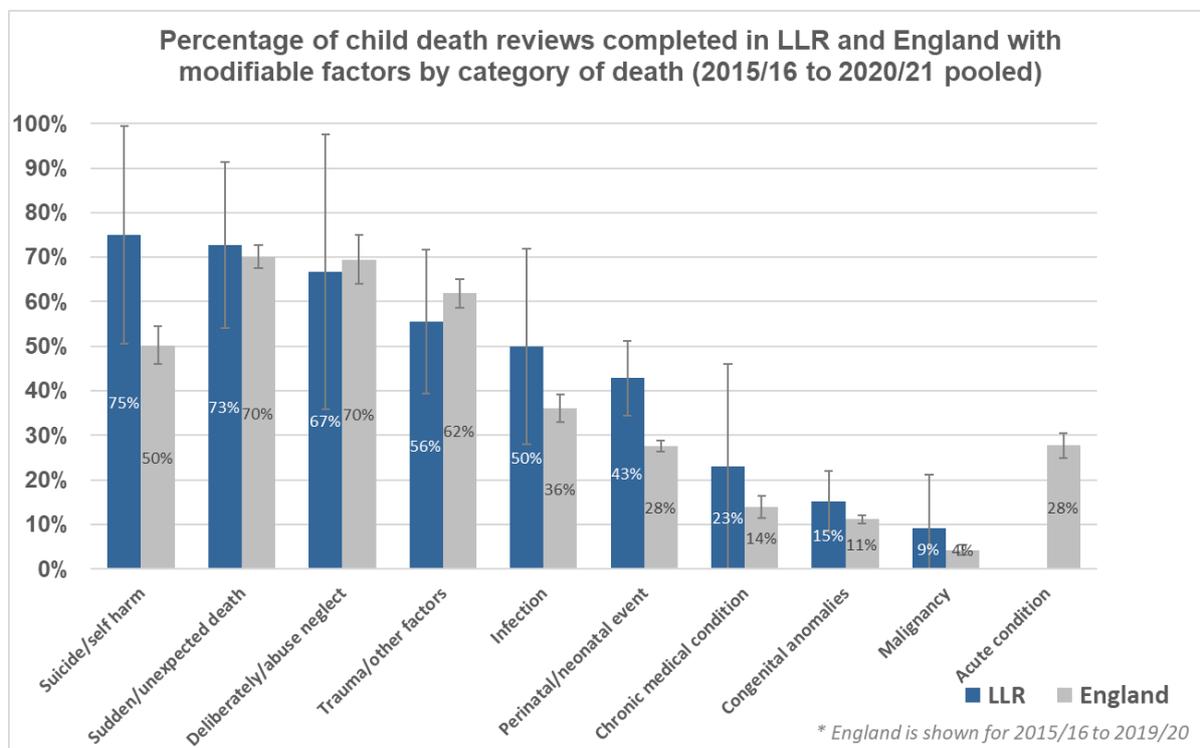
Figure 6: Percentage of child death reviews completed in LLR and England by category of death (2015/16 to 2020/21 pooled)



There are many different congenital anomalies and the cause of most is not known. Most infants born with a congenital anomaly will survive. In any single year infant deaths due to congenital anomalies are associated with over 150 different causes. Congenital anomalies accounts for about one third of the extra infant deaths experienced by the routine and manual socio-economic groups compared with the population as a whole. Of deaths due to genetic or congenital anomalies across LLR, only 15% were identified as modifiable (England 11%). Within perinatal or neonatal events, 43% were identified as modifiable (England 28%); this is significantly higher

than England. For child deaths in LLR due to trauma or external factors (9% which is significantly higher than England at 5%), 56% of such deaths in LLR and 62% in England identified as preventable. This is not significantly different.

Figure 7: Percentage of child death reviews completed in LLR by category of death (2015/16 to 2020/21 pooled)

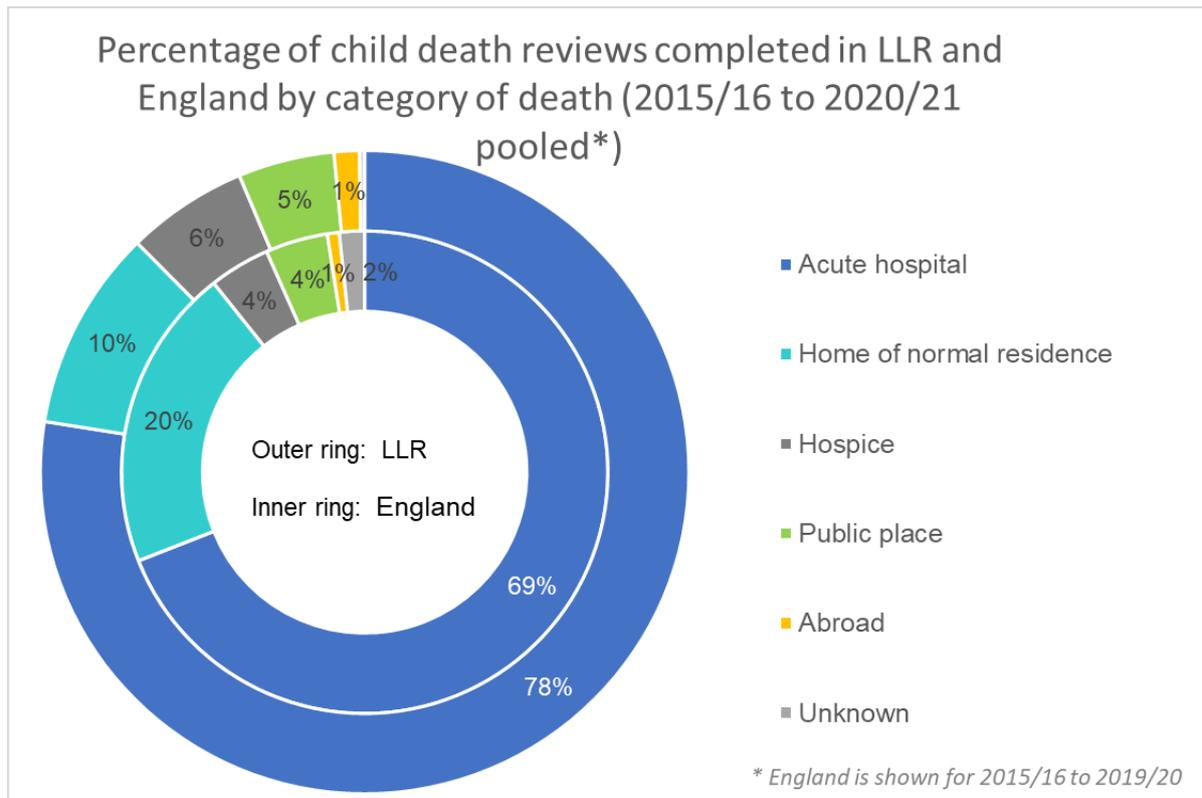


### 3.2 Location of death

This data records where the child actually died. The majority (78%) of child deaths in LLR occurred in acute hospitals, significantly higher than England (69%). A further 10% in LLR occurred in the child's home, significantly lower than England (20%). The remaining deaths took place in a hospice, public place or abroad.

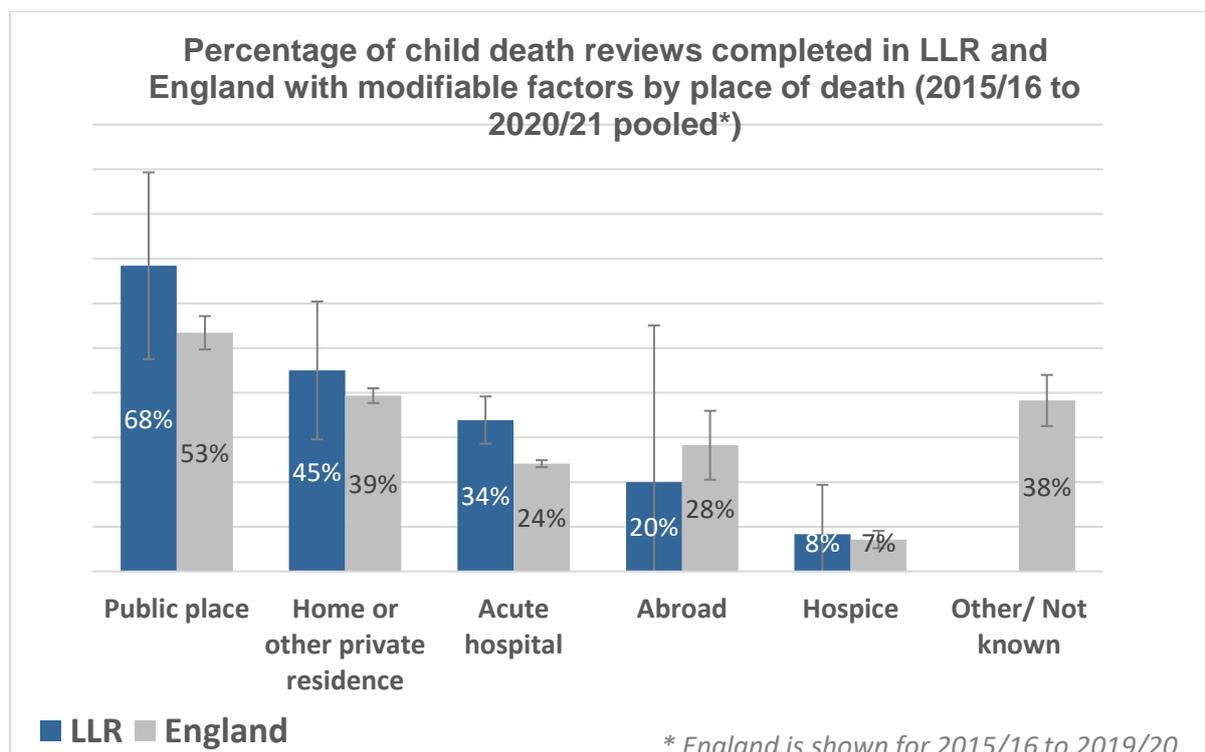
**Note:** with the implementation of new statutory Notification and Reporting Forms during 2020, 'Place of death' is now recorded as the last place the child was known to be alive and then found, as opposed to the location where life was declared extinct. Whereas for data from 2015 to 2019, the 'Place of death' may have been recorded as an acute hospital following unsuccessful resuscitation in the Emergency Department, as of 2020 this would be recorded as the place where the child was found prior to resuscitation being commenced. This may partially account for the difference between deaths occurring in LLR compared to England as a whole.

Figure 8: Percentage of child death reviews completed in LLR by location of death (2015/16 to 2020/21 pooled)



For deaths occurring in hospital, 34% in LLR were identified with modifiable factors which is significantly higher than England (24%). Similar proportions of modifiable factors were identified within LLR and England for deaths at home, in a public place, abroad or in a hospice.

Figure 9: Percentage of child death reviews completed in LLR with modifiable factors identified, by location of death (2015/16 to 2020/21 pooled)



## Sudden unexpected, unexplained deaths and Sudden Unexplained Deaths in Infancy (SUDI)

### 4.1 Sudden unexpected, unexplained deaths

In cases where, in spite of a full investigation and multiagency review the cause of death remains unclear (including all cases with a pathological diagnosis at post mortem of 'unascertained' or 'SIDS'), these are categorised as 'Sudden unexpected, unexplained deaths'.

Sudden unexpected death in infancy (SUDI) can be considered an umbrella term that captures all unexpected infant deaths., Investigations following death, including post-mortem examination and full history taking by a medical professional, may often lead to an explanation which falls into one of the following:

- Accidental death
- Non-accidental death
- Metabolic condition
- Congenital anomaly
- Unrecognised infection

For those deaths that remain unexplained following full investigation, the term Sudden Infant Death Syndrome (SIDS) applies, and the definition formulated by the American pathologist Beckwith in 1969 is still current: “*the sudden death of a baby that is unexpected by history and in whom a thorough necropsy examination fails to demonstrate an adequate cause of death*”. It is recognised as a category of natural death that carries no implication of blame for bereaved parents.

## 4.2 Sudden Unexpected Death in Infancy (SUDI)

In the period between 1st April 2015 and 31<sup>st</sup> March 2021, CDOP reviewed the deaths of 20 children (under 18 years) who were categorised as Sudden unexpected, unexplained deaths, 18 of which occurred in children aged under 1 year. Of these, 3 were in infants who died on a Neonatal Unit prior to discharge home.

Of the 15 cases involving infants under 1 year who died outside of a Neonatal Unit, the following data highlights some of the risk factors and characteristics of the cases reviewed:

### **SUDI Case characteristics:**

- In 12 (80%) cases the infant was bottle-fed.
- In 11 (73%) cases the infant was not a first-born.
- In 10 (67%) cases the infant had been born preterm.
- In 7 (47%) cases the infant lived in an area of deprivation (IMD decile 1 & 2).
- In 5 (33%) cases the infant had a birthweight below the second centile.
- Mean maternal age was 28.8 years (20-36yrs).
- Medical cause of death following post-mortem examination was given as ‘Unascertained’ in 12 (80%) cases and ‘SIDS’ in 3 (20%) cases.

### **SUDI Modifiable Factors:**

- 10 (67%) cases identified unsafe sleeping practices (including co-sleeping with additional risk factors) as a modifiable factor.
- 9 (60%) cases identified parental smoking as a modifiable factor.
- 13 (87%) cases identified one or more modifiable factor
- 10 (67%) cases identified more than one modifiable factor

## 5. Characteristics of child deaths

### 5.1 Gender

There have been significantly more reviews completed for deaths in boys (60%) than girls (39%) in LLR (1% unknown) from 2015/16 to 2020/21. This is similar to England. There is no single significant cause which results in a higher rate of male mortality.

### 5.2 Age of child at death

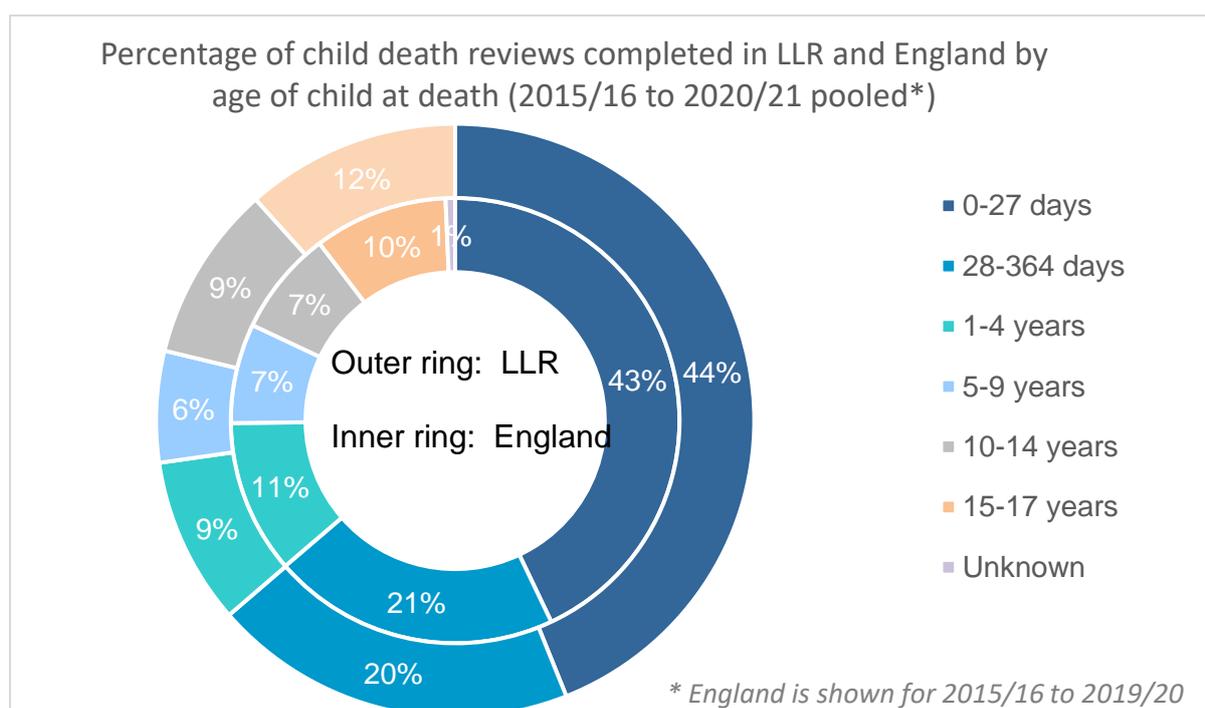
The first year of life is the riskiest period of childhood, with 65% of deaths in England occurring during this period. The first year of life is routinely categorised into three groups:

- deaths in the first week of life (early neonatal deaths)
- deaths between one week and one month of life (late neonatal deaths)
- deaths between one month and one year of life

The term 'infant death' refers to the death of any live born infant up to the age of one year. It is worth noting that the age bands used below do not cover equal periods of childhood e.g., 10-14 years covers a five-year period and 15-17 years covers a three year period.

Over the period 2015/16 to 2020/21, 44% child deaths in LLR were for infants under 28 days, a further 20% for infants aged 1-12 months and 9% aged between 1 and 4 years. These are not significantly different to England.

Figure 10: Child death reviews in LLR by age of child at death (2015/16 to 2020/21)

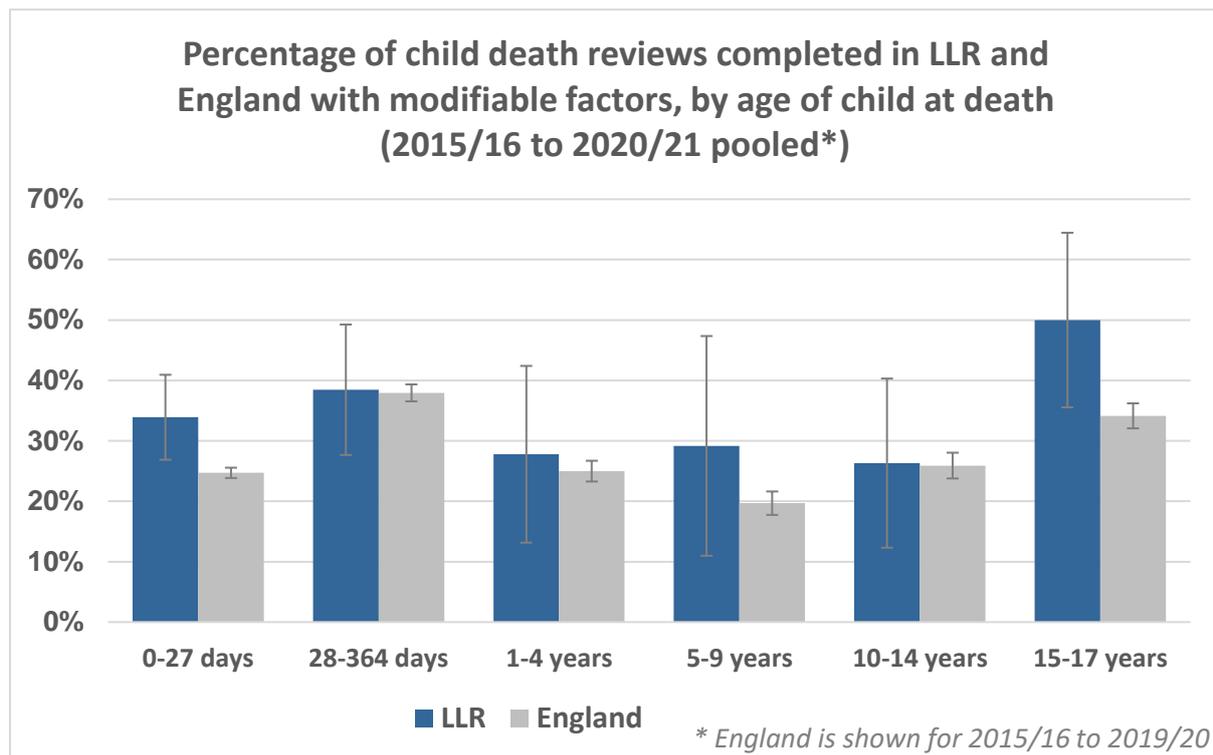


Factors which contribute to neonatal and infant deaths are generally recognised as poverty, infant nutrition, smoking in pregnancy, maternal and infant infections, obesity in mothers and early access to high quality, culturally sensitive maternity care.

Of the 174 cases of neonatal deaths (0-27 days), those in LLR with modifiable factors (34%) are significantly higher than England (25%).

The highest proportion of modifiable factors in LLR were identified in children aged between 15-17 years old (LLR 50%, 46 cases in total against 34% in England) although this is not significantly different. For deaths in children aged 0-27 days, 34% had modifiable factors identified, which is significantly higher than England (25%). In all other ages, the percentage of modifiable factors is not statistically different to England.

Figure 11: Percentage of child death reviews in LLR with modifiable factors identified, by age of child at death (2015/16 to 2020/21 pooled)



### 5.3 Completed CDOP reviews by age group

Some causes of death are more common within age groups.

Under 28 days:

- The highest proportion of child deaths is found in infants aged under 28 days (44% of all deaths). The most common causes of death are:
  - Perinatal/neonatal events (29%)
  - Chromosomal/congenital anomalies (12%)

28-364 days:

- 20% of all child deaths are between 28-364 days, with
  - 8% from chromosomal/congenital anomalies.
  - 4% from perinatal/neonatal events.
  - 4% from sudden/unexpected deaths.

1-14 years:

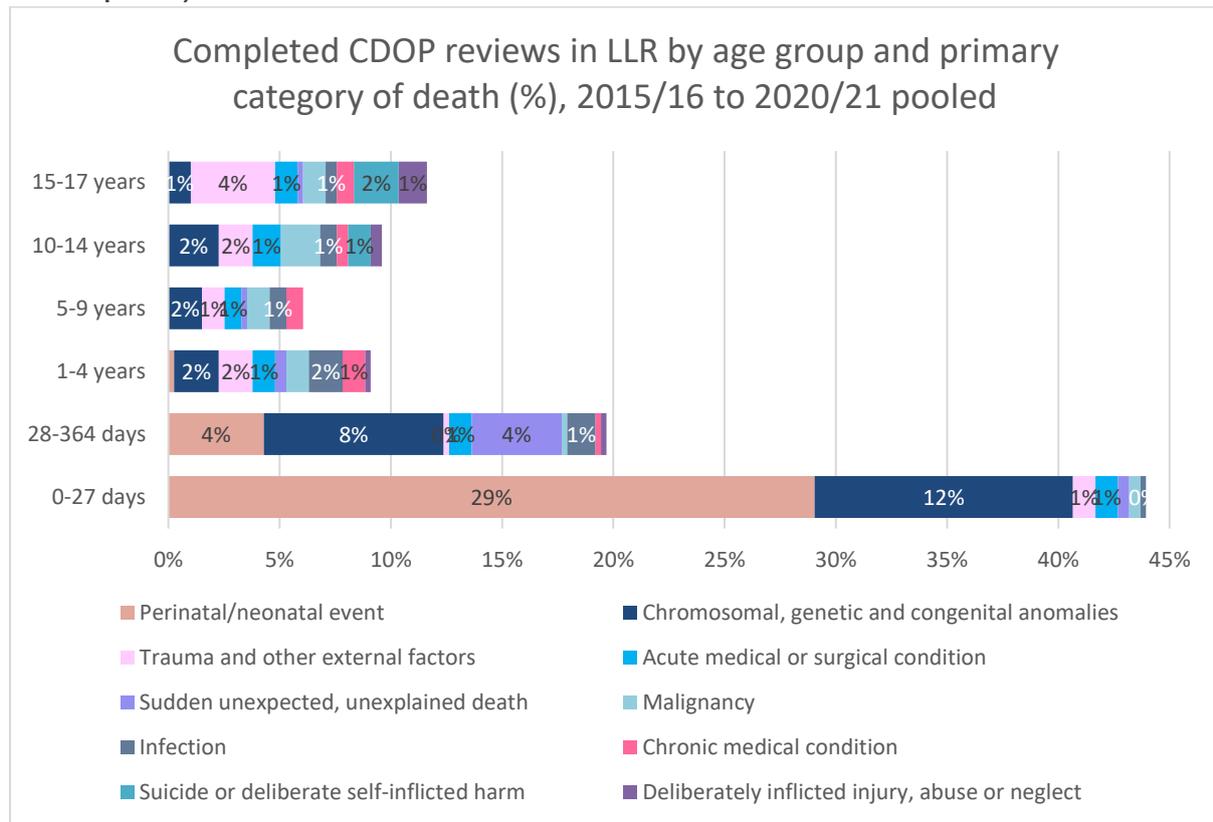
- 9% of child deaths are between 1-4 years, 6% between 5-9 years, 10% between 10-14 years and these are from a variety of causes

15-17 years:

- 12% of child deaths are in young people aged 15-17 years, with:
  - 4% caused by trauma or external factors.
  - 2% from suicide or deliberate self-harm as the highest causes.

The figure below shows the proportion of deaths by age group and cause of death.

**Figure 12: Completed CDOP reviews in LLR by age group and primary category of death (2015/16 to 2020/21 pooled)**



Of the cases where modifiable factors were identified (139/396 case), 42% were in infants under 28 days; 34% were due to perinatal/neonatal events and 6% chromosomal/congenital anomalies.

Infants aged 28-364 days, account for 22% of modifiable factors identified; 9% from sudden/unexplained death, 7% from perinatal/neonatal events, 3% chromosomal/congenital anomalies

For children 1-4 years, making up 7% of modifiable factors identified, 3% were identified from trauma/external factors, and the remainder from chromosomal /congenital anomalies, chronic medical conditions, infection, and sudden/unexplained death

Children aged 5-9 years represent 5% of modifiable factors identified from chromosomal/congenital anomalies, chronic medical conditions, infection, and trauma/external factors.

For children aged between 10-14 years making up 7% of modifiable factors; 4% were from trauma/external factors, and 2% from suicide/deliberate self-harm

Young people aged 15-17 years account for 17% of modifiable factors identified; 6% from trauma/external factors, 4% from suicide/deliberate self-harm, 4% from

deliberately inflicted injury/abuse/neglect and the remainder from infection, malignancy, and sudden unexplained death.

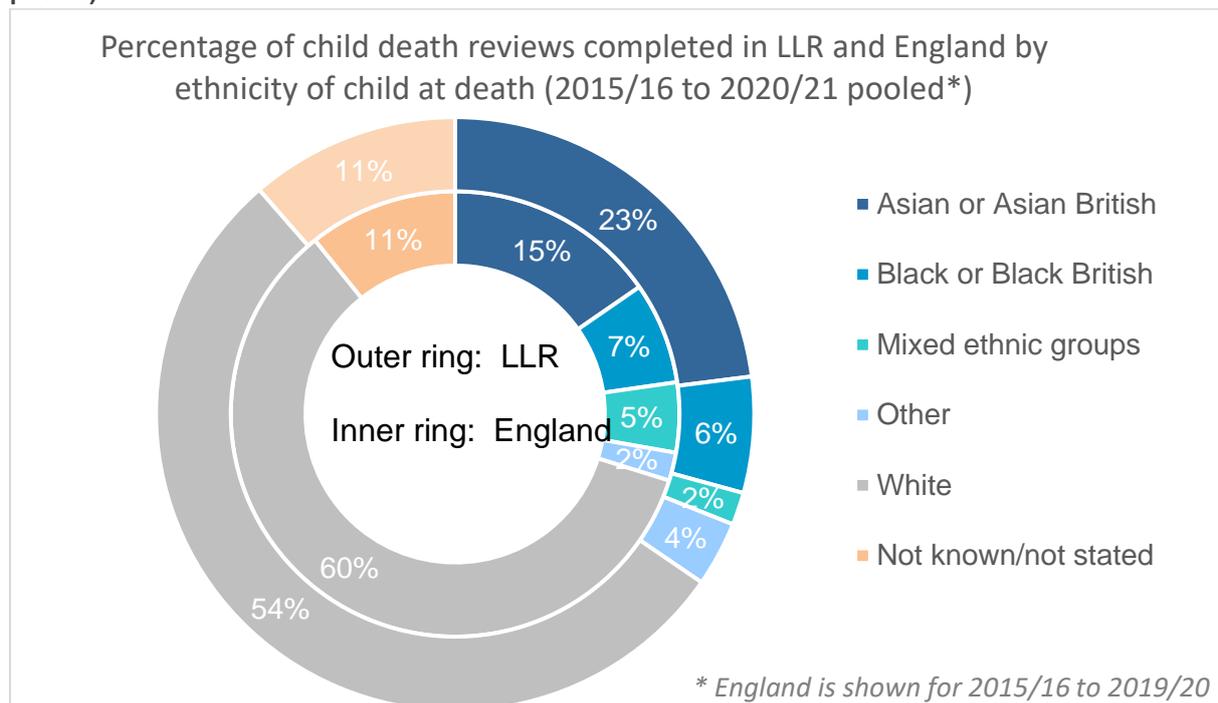
#### **5.4 Ethnicity**

In the early years of CDOP, data around ethnicity was not always collected in a robust manner. There has been significant improvement made in completion of ethnicity data over the years, however 11% of cases in LLR (11% nationally) still indicate unknown ethnicities. It should be pointed out that this is not a mandatory field for completion and some patients may not wish for their ethnicity to be recorded.

Approximately 41% of LLR's 0-17 population are of BME origin (GP registers for LLR residents: Leicester 68%, Leicestershire, and Rutland 21%). Leicester also has higher birth rates in most deprived areas with the highest concentration of BME population. Explanations for variations in infant mortality between ethnic groups are complex, involving the interplay of deprivation, physiological, behavioural, and cultural factors. More research is needed to identify the pathways that lead to higher risks of infant death among Black and other ethnic minority groups.

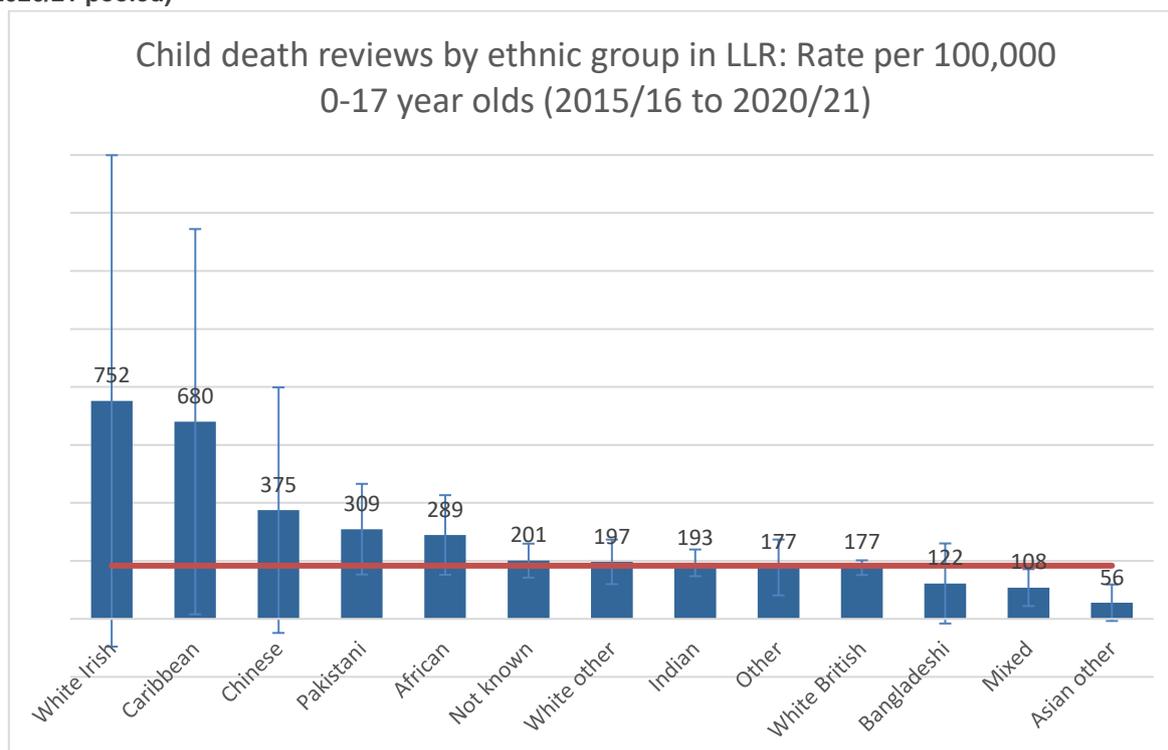
Nationally, 60% of all child deaths are of children from a White background, 56% in LLR. Asian children in LLR account for 23% of reviews, significantly higher than 15% nationally.

Figure 13: Percentage of child death reviews completed in LLR by ethnic group (2015/16 to 2020/21 pooled)



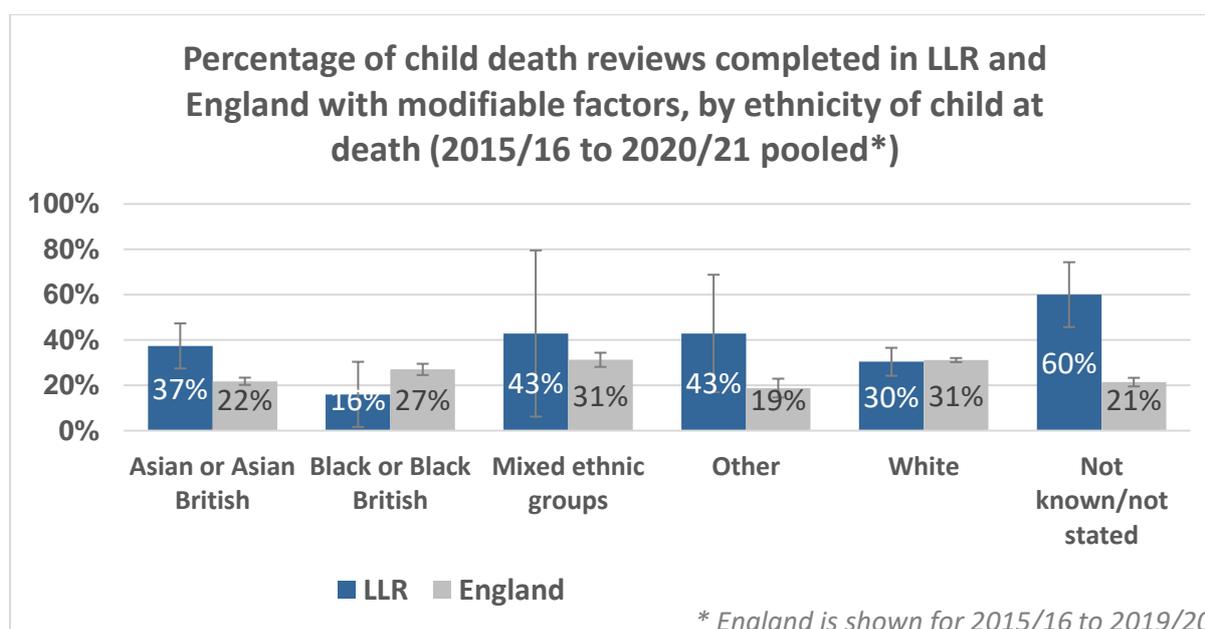
There are higher proportions of Asian, Black, and other minority ethnicity groups in LLR than England, such that a percentage of any ethnic group of the total number of deaths may not be representative of the population structure. The figure below shows a more detailed ethnic breakdown of child death reviews in LLR, shown as a rate per 100,000 0–17-year-olds within each ethnic group. The proportion of deaths within all ethnic groups are similar to the LLR rate per 100,000, with the exception of Asian other, noting there are only 3 cases in this group. Data for England is only available at the broad ethnic categories.

Figure 14: Child death reviews by ethnic group in LLR: Rate per 100,000 0–17-year-olds (2015/16 to 2020/21 pooled)



There are significantly higher levels of modifiable factors in Asian or Asian British ethnic groups in LLR (37%) compared with England (22%). The highest percentage of modifiable factors identified are seen in Unknown, Mixed, and other ethnic groups but numbers are relatively small in these groups and not significantly different to nationally.

Figure 15: Percentage of child death reviews completed in LLR with modifiable factors identified, by ethnic group (2015/16 to 2020/21 pooled)



# Recommendations



## 1. Update on previous recommendations for 2020/21

1. CDOP to procure eCDOP and roll out across LLR by September 2020 – recommendation completed.
2. CDOP to hold a themed Suicide Panel & publish a report with recommendations for partner agencies by end August 2020 – recommendation completed.
3. New commissioners to agree funding and new service level agreement for new service by end December 2020 – work ongoing with aim for completion by December 2021.
4. CDOP to continue to provide multiagency training to embed new processes and procedures – work going, multiagency training delivered.
5. CDOP to continue to work with all key stakeholders to progress work on Adverse Childhood Experiences – work ongoing.
6. CDOP to review and report on the direct and indirect impact of Covid 19 on mortality rates for children and young people – see Section 1 of this report, work ongoing.
7. CDOP to continue to support the LeDeR Programme and Healthy Babies Strategy & Action Plan and use CDOP data to inform future priorities – work ongoing.

## 2. Recommendations for 2021/22

1. CDOP to continue to work in line with agreed workstreams, with on-going thematic review to identify learning in key areas around suicide in children & young people, safer sleep, and Learning Disability mortality reviews.
2. CDOP to formalise agreed funding arrangements between Child Death Review Partners by December 2021.
3. CDOP to continue to delivery multiagency training incorporating all aspects of the Joint Agency Response.
4. CDOP to continue to work with all key stakeholders to progress work on the impact of Adverse Childhood Experiences, and provision of a Trauma-Informed approach.
5. CDOP to continue to review & report on the emerging impact (direct and indirect) of the Covid-19 pandemic for children and young people.
6. CDOP to work with the Healthy Babies Strategy Group using thematic learning from LLR SUDI & SIDS cases to enhance safer sleep messaging.

# 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	<b>Deliberately inflicted injury, abuse or neglect</b> 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	<b>Suicide or deliberate self-inflicted harm</b> 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	<b>Trauma and other external factors</b> This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. <b>Excludes</b> Deliberately inflicted injury, abuse or neglect (category 1).	
4	<b>Malignancy</b> 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	<b>Acute medical or surgical condition</b> For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.	
6	<b>Chronic medical condition</b> For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. <b>Includes</b> cerebral palsy with clear post-perinatal cause.	
7	<b>Chromosomal, genetic and congenital anomalies</b> Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.	
8	<b>Perinatal/neonatal event</b> 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 <b>includes</b> cerebral palsy without evidence of cause, and <b>includes</b> congenital or early-onset bacterial infection (onset in the first postnatal week).	
9	<b>Infection</b> 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	<b>Sudden unexpected, unexplained death</b> Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. <b>Excludes</b> Sudden Unexpected Death in Epilepsy (category 5).	

## Appendix B LLR Child Death Review Process Flowchart

