Leicester, Leicestershire and Rutland Child Death Reviews (2011/12 – 2016/17)

Annual Report 2016/17
Author
Rob Howard
Chair of LLR CDOP
Consultant in Public Health
Leicestershire County Council

Contributors
Helen Reeve
Senior Intelligence Manager (Public Health)

Lisa Hydes
Child Death Review Manager

Julie Isherwood
Project Support Officer Child Death Review

Acknowledgement to CDOP members:
Lucy Pathan, Lay Member
DI John Gray, Detective Inspector, Leicestershire Police CAIU
Dr. Sue Hughes, Designated Dr for Child Death (SUDIC Doctor), LPT
Dr. Rachel Rowlands, Children's Emergency Dept Consultant, UHL
Dr. Jeremy Tong, Consultant Intensivist, UHL
Steven Gauntley, Head of Safeguarding, Leicester City Council
Chris Nerini, Head of Safeguarding, Leicestershire County Council
Adrian Spanswick, Consultant Designated Nurse Safeguarding, CCG
Dr Jane Gill, Consultant Neonatologist, UHL NNU
Dr Elaine Boyle, Consultant Neonatologist, UHL NNU
Dr Penelope McParland, Consultant Obstetrician UHL NNU
Julie O'Boyle, Consultant in Public Health Leicester City Council
Dr Lina Gatsou, Consultant Child and Adolescent Psychiatrist Child Adolescent Mental Health Service
Russell Smalley, Safeguarding Lead East Midlands Ambulance Service
<table>
<thead>
<tr>
<th>Glossary Abbreviation</th>
<th>Explanation</th>
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<tr>
<td>CAIU</td>
<td>Child Abuse Investigation Unit</td>
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<td>CCG</td>
<td>Clinical Commissioning Group</td>
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<td>CDOP</td>
<td>Child Death Overview Panel</td>
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<td>CDR</td>
<td>Child Death Review Manager</td>
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<td>Detective Inspector</td>
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<td>LLR</td>
<td>Leicester, Leicestershire and Rutland</td>
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<td>LPT</td>
<td>Leicestershire Partnership Trust</td>
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<td>LRI</td>
<td>Leicester Royal Infirmary</td>
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<td>LSCB</td>
<td>Local Safeguarding Children’s Board</td>
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<td>NNU</td>
<td>Neonatal Unit</td>
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<td>SCR</td>
<td>Serious Case Review</td>
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<td>SILP</td>
<td>Serious Incident Learning Process</td>
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<td>SUDIC</td>
<td>Sudden Unexpected Death in Childhood</td>
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<tr>
<td>UHL</td>
<td>University Hospital of Leicester</td>
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Introduction

This is the Annual Report for 2016/17 of the Leicester, Leicestershire and Rutland (LLR) Child Death Overview Panel (LLR CDOP) and provides an analysis of data collation from 2011/12 to 2016/17. LLR CDOP has been in existence since 2009 and the number of child deaths has remained relatively constant over this time period. This report takes a 6 year snapshot across LLR to evaluate CDOP data in more detail. This 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 2015. It is the responsibility of Local Safeguarding Children Boards (LSCBs) to ensure that a review of every death of a child normally resident in their area is undertaken by a CDOP. Government advice is that CDOPs should cover populations of at least 500,000 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, in order 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.

Notes

Over the 6 year period from 2011/12 to 2016/17, there were 13 child death reviews carried out in Rutland. As the numbers for Rutland are too small to analyse further, Leicestershire County and Rutland data is presented jointly; this is in accordance with the Office for National Statistics and the Health and Social Care Information Centre 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.

Furthermore, due to data recording, there are only four indicators nationally that can be segregated and reported:

- Number of reviews completed within the year
- Number of reviews with modifiable factors
- Time taken to complete the reviews from date of child’s death
- Time taken to complete the reviews from date of child’s death by modifiable factors

Therefore, all other data indicators have to be reported for LLR as no further segregation can be undertaken.
The local CDOP covers Leicester, Leicestershire and Rutland and held nine panels reviewing 70 cases in 2016/17. Thirty-four of these cases related to Leicestershire and Rutland. As a result of the panels held the following areas are being progressed:

- A database is currently under development that will allow a more comprehensive analysis of the learning identified for cases and therefore serve to inform the work plan of CDOP.
- A campaign was undertaken to raise awareness (amongst the public and professionals) regarding the dangers associated with the ingestion of disc button batteries.
- CDOP worked with partners to develop a strategy for reducing infant mortality.
- CDOP presented at a conference during ‘Safer Sleep week’ to raise awareness amongst professionals regarding associated risk factors for sudden infant death syndrome and outline learning identified within CDOP.
- CDOP have supported awareness raising (among health, education and public forums) to raise awareness with regard to;
  - Spotting the signs of sepsis
  - Headsmart (early recognition of brain tumours)

Public health supported CDOP to undertake a piece of work to review cases where suicide or self-harm was categorised as the cause of death to ascertain if there are any additional areas of learning for organisations and identify any underlying themes. CDOP are also revisiting cases where consanguinity has been identified as a modifiable factor. Again, it is hoped that by undertaking further analysis additional learning may be identified that would help to inform future strategies.

During the year the Ofsted inspection for Leicestershire and Rutland noted; “The child death overview panel is highly effective. Careful analysis of findings over the longer term has enabled the panel to identify patterns that might otherwise be missed. It uses this intelligence well to raise awareness of safety risks for children, inform improvements and influence wider health and wellbeing priorities. This is a particularly strong element of the LSCB’s work.”

In addition CDOP received a nomination (within Leicestershire Partnership Trust) for an Excellence in Partnership Award, which recognised the work of CDOP as being ‘exemplary’.

The Child Death Review (CDR) Manager is engaging in national discussions regarding changes to CDOP following the Wood Review and Children and Social Work Act 2017. These discussions have highlighted that, as a whole, CDOPs could strengthen processes to ensure families form part of the review process. LLR CDOP had previously recognised and raised this as part of the work plan for 2017/18.

- An audit has been being undertaken by the CDR Manager to provide an overview of the ongoing contact families receive from the named nurses following the unexpected death of a child. This ongoing contact would allow families a greater opportunity to form part of the review process.
- From April 2017 onwards processes will be established for families of children where the death was felt to be expected to be offered the opportunity to participate within the CDOP process.
Key findings: 2011/12 to 2016/17

Of the 425 reviews completed by LLR CDOP
- Leicester City: 207 (49%)
- Leicestershire County: 204 (48%)
- Rutland: 14 (3%)

24% of all child death reviews for LLR were identified as having modifiable factors.
- Leicester City: 22%
- Leicestershire County and Rutland: 25%

24% of all child deaths reviewed across LLR were due to chromosomal, genetic or congenital anomalies. A separate breakdown for Leicester and Leicestershire County and Rutland (LCR) is not available as data was not segregated prior to 2013/14.

60% of all child deaths across LLR occurred within the first year of life.

Summary statistics across LLR

1. 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 were below national average, but not statistically significantly lower. Leicester’s rate has consistently been significantly higher than East Midlands and England from 2004, improving in 2012-14 and 2013-15 to a similar rate to England

Figure 1: Neonatal mortality rates (2004 to 2015)
2. Infant mortality rates

Infant mortality rate refers to deaths under one year per 1,000 live births (stillbirths are not included). Leicestershire and Rutland are both similar (not significantly different) to the East Midlands and England rates but the rate in Leicester has consistently been significantly higher since 2004, improving in 2013-2015 to a similar rate to England.

Figure 2: Infant mortality rates (2004 to 2015)

3. Child mortality rates (0-19 years)

The child mortality rate reported below refers to deaths in children aged 0 -17 years per 100,000 children (2006 to 2016). The aggregated rate for Leicestershire and Rutland is similar (not significantly different) to the England and Wales rate. In Leicester, the rate has been significantly higher since 2006, similar to England and Wales in 2014, and increasing slightly in 2015 and 2016 (due to a very low Infant Death Rate for Leicester City in 2014, probably due to random variation).
There are three key stages of documentation to support the child death review processes:

- Form A – notification record
- Form B – agency report form
  - A case summary to be compiled by professionals (form all agencies) who worked with the child/family
  - This acts as the "input data set" for CDOP
- Form C - analysis proforma. The form C details (an amalgamation) of all of the information provided by professionals on the B form. The C form then provides the "output" from CDOP

1. Notifications

Working Together to Safeguard Children (2015) confirms that each LSCB 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 three local authorities. 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 has to be received within 24 hours; in unexpected deaths this will usually occur at the same time the Coroner is informed. It is then the responsibility of the CDR Manager to co-ordinate the information collection and ensure liaison with families.
This section summarises all deaths notified to the LLR CDOP between 01 April 2011 and 31 March 2017. It includes all children who are normally resident in the area but who have died elsewhere. The data is collected from the database of notifications to CDOP (Form A from the national data set). During this period, 443 deaths of children and young people under the age of 18 years and normally resident in LLR were notified to CDOP. Year on year variation in notifications is to be expected and is demonstrated in the table below. Please note that the information below does not include those born at less than 23 weeks gestation.

Table 1: CDOP notifications (2011 to 2016) – please note that the notifications are listed in calendar year format in order to correspond with how data is received and recorded by LLR CDOP

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Leicester</td>
<td>45</td>
<td>43</td>
<td>39</td>
<td>23</td>
<td>28</td>
<td>35</td>
<td>213</td>
</tr>
<tr>
<td>Leicestershire</td>
<td>33</td>
<td>32</td>
<td>32</td>
<td>47</td>
<td>34</td>
<td>39</td>
<td>217</td>
</tr>
<tr>
<td>Rutland</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>13</td>
</tr>
<tr>
<td>LLR CDOP</td>
<td>80</td>
<td>78</td>
<td>73</td>
<td>74</td>
<td>64</td>
<td>74</td>
<td>443</td>
</tr>
</tbody>
</table>

The number of notifications for any one area of residence are so small that the most likely explanation for any pattern is random year-on-year variation. However, other contributory factors such as differences in coding practice or an increase in a particular category of death should also be considered. During the last 6 years, postcode of residence has been used consistently and there have been no significant changes in local authority boundaries. Additionally, analysis of category of death shows that there is no single category of death that appears to account for the patterns seen over the six-year period. It is therefore most unlikely that these variations in notifications within the LSCBs reflect any particular underlying cause and as such they should not be over-interpreted.

2. Reviews

The CDOP panel does not review cases until all information is gathered and other processes have concluded such as criminal investigations and serious case 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 2011/12 and 2016/17. Overall, 425 reviews were completed in this timeframe with 48% of reviews undertaken for children who were resident in Leicester City and 52% or reviews undertaken for children who were resident in Leicestershire and Rutland. The percentage of child death reviews completed in LLR within 12 months of the notification has improved since 2011/12 from 35% to 75% in 2016/17. The number of reviews undertaken from 2011/12 to 2016/17 is presented in the table below.

Table 2: CDOP reviews completed within timeframe (2011/12 to 2016/17)
3. 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 that over the 6 year period (2011/12 to 2016/17), there are no significant differences between the proportion of child deaths reviewed with modifiable factors when compared against East Midlands and England.

<table>
<thead>
<tr>
<th>Year</th>
<th>&lt; 12 months of notification</th>
<th>&gt; 12 months of notification</th>
<th>Total</th>
<th>% completed within 12</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011/12</td>
<td>27</td>
<td>50</td>
<td>77</td>
<td>35%</td>
</tr>
<tr>
<td>2012/13</td>
<td>17</td>
<td>36</td>
<td>53</td>
<td>32%</td>
</tr>
<tr>
<td>2013/14</td>
<td>24</td>
<td>22</td>
<td>46</td>
<td>52%</td>
</tr>
<tr>
<td>2014/15</td>
<td>25</td>
<td>50</td>
<td>75</td>
<td>33%</td>
</tr>
<tr>
<td>2015/16</td>
<td>41</td>
<td>61</td>
<td>102</td>
<td>40%</td>
</tr>
<tr>
<td>2016/17</td>
<td>54</td>
<td>18</td>
<td>72</td>
<td>75%</td>
</tr>
<tr>
<td>Total</td>
<td>188</td>
<td>237</td>
<td>425</td>
<td>44%</td>
</tr>
</tbody>
</table>

Figure 4: Percentage of child death reviews completed with modifiable factors (2011/12 to 2016/17)
4. Categorisation, events and location of death

4.1 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 2011/12 to 2016/17, the highest proportion of deaths (26%) across LLR were from the chromosomal/congenital category. The next largest proportion of deaths (28%) was from the perinatal/neonatal category. This is not the case when compared against England where perinatal/neonatal category represents the largest proportion (33%) with chromosomal/congenital category being the next largest proportion (26%). The proportion of deaths due to a perinatal/neonatal event in LLR is significantly lower than the England rate.

There are many different congenital anomalies and the cause of most is not known. The vast majority of 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 9% were identified as modifiable (England 8%). Within perinatal or neonatal events, 23% were identified as modifiable (England 20%). Neither is significantly different to the national rates. A further 10% of child deaths in LLR were due to trauma or external factors (England 6%) with 59% of such deaths in LLR and 55% in England identified as preventable. It has not been possible to segregate data for Leicester City and LR as it is not available in reports prior to 2013/14.

Figure 5: Percentage of child death reviews completed in LLR by category of death (2011/12 to 2016/17)
The categories with the highest proportion of deaths assessed as being due to modifiable factors in LLR in the same time period are:

- Sudden unexpected deaths
- Trauma or external causes
- Suicide or deliberate self-harm
- Deliberately inflicted injury, abuse or neglect
- Acute medical or surgical condition
- Infection

The proportion of modifiable factors for each category in LLR is not significantly different to England. As with other data indicators, it is not possible to segregate Leicester from LR prior to 2013/14.

**Figure 6: Causes of child death with top 6 modifiable factors (2011/12 to 2016/17)**

4.2 Events leading to death

Of the events leading to cause of death in children in LLR (2011/12 to 2016/17), 59% can be accounted for by neonatal deaths and known life limiting conditions.

- Neonatal death: 33% LLR, 41% England
- Known life limiting conditions: 26% LLR, 27% England

For these, modifiable factors were identified in LLR in 21% of neonatal deaths (18% in England) and 9% of known life-limiting conditions (8% in England).

The remaining causes of death include sudden unexpected death in infancy, road traffic accident/ collision, drowning, fire and burns, poisoning, other non-intentional injury/accident/trauma, substance misuse, apparent homicide and apparent suicide.
4.3 Location of death

This data records where the child actually died. The majority (73%) of child deaths occurred in acute hospitals with a further 17% in the child’s home. The remaining deaths took place in a hospice, public place, foster home, abroad or other private residence.

Figure 7: Percentage of child death reviews completed in LLR by place of death (2011/12 to 2016/17)

For deaths occurring in hospital, 19% in LLR were identified with modifiable factors. At the child’s home, 33% had modifiable factors. These are similar to national rates. The places of death with the highest percentage of modifiable factors in LLR are other private residences, public places and abroad, however numbers of deaths in these are very low.

Figure 8: Percentage of child death reviews with modifiable factors by place of death (2011/12 to 2016/17)
5. Expected vs Unexpected deaths

Deaths are currently grouped into expected and unexpected. Chapter 5 of Working Together to Safeguard Children 2015 defines an unexpected death of an infant or child (less than 18 years old) as a death which:

- was not anticipated as a significant possibility, for example 24 hours before the death; or
- where there was a similarly unexpected collapse or incident leading to or precipitating the events which led to the death

The local process for unexpected deaths is detailed in Appendix B.

Over the six year period, there were 268 expected deaths reviewed by CDOP. Of these deaths, 193 (72%) were children under 1 year of age. Of the expected deaths in children aged 0-17 years, 95 cases (35%) in children aged 0-17 years were categorised as due to chromosomal or congenital anomalies (35%), 110 cases (41%) were categorised as due to neonatal or perinatal events and 26 cases (10%) were due to malignancy.

For LLR overall, there were more expected deaths than unexpected (expected = 268, unexpected = 126). The majority of unexpected deaths across LLR were categorized as trauma and other external factors.

Table 3: Overview of expected and unexpected cases (2011/12 to 2016/17)

<table>
<thead>
<tr>
<th>CDOP cases reviewed</th>
<th>Expected No. of cases (% of all cases)</th>
<th>Unexpected No. of cases (% of all cases)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leicester City</td>
<td>138 (35%)</td>
<td>55 (14%)</td>
</tr>
<tr>
<td>Leicestershire County and Rutland</td>
<td>130 (33%)</td>
<td>71 (18%)</td>
</tr>
</tbody>
</table>

5.1 Sudden Unexpected Death in Infancy (SUDI) and Sudden Infant Deaths Syndrome (SIDS)

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.

In the period between 1st April 2011 and 31st March 2017, CDOP reviewed the deaths of 21 children who were categorised as SIDS, of which 16 were considered to have modifiable factors (76%).
5.2 Sudden Infant Deaths Syndrome (SIDS)
The following data highlights some of the risk factors and characteristics of the SIDS cases reviewed:

- In 9 (43%) cases, co-sleeping or an unsafe sleeping position was identified as a modifiable factor
- In 16 (76%) cases, one or both parents smoked (8 were co-sleeping with baby at time of death)
- In 13 (62%) cases, babies were not breastfed

6. Characteristics of child deaths

6.1 Age of child at death
The first year of life is the most risky period of childhood, with 55% 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 2011/12 to 2016/17, 42% child deaths in LLR were for infants under 28 days, a further 21% for infants aged 1-12 months and 12% aged between 1 and 4 years. These are not significantly different to England.

Figure 9: Child death reviews in LLR by age of child at death (2011/12 to 2016/17)
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 177 cases of neonatal deaths (0-27 days), 124 (70%) of these deaths were babies born prematurely.

No age group in LLR has a proportion of modifiable factors which is significantly different to England. The highest proportion of modifiable factors (31%: 15 cases in total) in LLR were identified in children aged between 1-4 years old. In children 1-11 months old, 26% were identified as modifiable.

Figure 10: Child death reviews with modifiable factors by age of child at death (2011/12 to 2016/17)

6.2 Gender
There have been more notifications of deaths in boys (57%) than girls (43%) in LLR (2011/12 to 2016/17) although it should be noted that this is not significantly higher, and the proportion of deaths identified as having modifiable factors is 25% for boys and 22% for girls. The national average in England over this six year period was 56% males, 43% females and 1% unknown. Nationally there is no single significant cause which results in a higher rate of male mortality.

6.3 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 10% of cases in LLR (9% 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 30% of LLR’s 0-17 population are of BME origin (Census 2011: Leicester 62%, Leicestershire and Rutland 13%). 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 in order to identify the pathways that lead to higher risks of infant death among Black and other ethnic minority groups.

Nationally, 61% of all child deaths are of children from a White background, 59% in LLR. Asian children in LLR account for 21% of reviews, significantly higher than 15% nationally. There are no significant differences in levels of modifiable factors across ethnic groups. Please note that a full breakdown of all ethnicity groupings in LLR can be seen in Appendix C – due to data reporting, it is not possible to compare the full breakdown of all ethnicity groupings with England. Figure 11 therefore shows ethnic groups in LLR that can be compared against England.

Figure 11: Percentage of child death reviews completed in LLR by ethnic group (2011/12 to 2016/17)

When analysing the rate per 100,000 of child death reviews by ethnicity groups, the rate of Pakistani children and children from other White backgrounds are significantly higher than the overall LLR average.
6.4 Other co-morbidities

When undertaking the review CDOPs review information on co-morbidities in children. These are underlying conditions which, while not considered to be the direct cause of death, are thought to have contributed to vulnerability in the child. In some cases, the children reviewed in this section may have more than one co-morbidity. The CDOP grading system is scored as follows:

- Grade 1: notable but not felt to have contributed to the ill-health or vulnerability of the child
- Grade 2: may have contributed to the ill-health, vulnerability or death of the child
- Grade 3: provide a complete and sufficient explanation of the death of the child

Of the 425 cases that were reviewed around 60% had a co-morbidity recorded:

Within this cohort, the most common co-morbidities thought to contribute to vulnerability were:

- Other chronic illness (53%)
- Motor impairment (20%)
- Diagnosed learning disability (14%)
- Epilepsy (5%)

An example of a co-morbidity included under ‘other’ would be an underlying genetic or congenital condition which is not known to be life-limiting but may impact on the child’s ongoing healthcare needs or irreversible but non-progressive conditions causing severe disability such as cerebral palsy.
6.5 Birthweight
Low birth weight is strongly associated with infant mortality and interventions to reduce low birth weight are central to giving every child the best start in life and reducing health inequalities across the life course. Low birth weight has many causes including smoking in pregnancy. It can also be caused by maternal stress during pregnancy. Low birth weight is more prevalent amongst the lower socio-economic classes and a key indicator of health inequalities. Nationally, mothers resident in the most deprived areas had a 2-fold increase in stillbirth and neonatal mortality rates. Reducing the incidence of low birth weight thus remains of high priority to public health.

Low birthweight rates in LLR are similar to England however Leicester City no longer has a significantly higher rate whilst Leicestershire County and Rutland has a significantly lower rate.

6.6 Additional factors in the family and environment
Social factors relating to mental health issues, drug abuse and other factors are routinely collected on the Form B dataset and summarised on the Form C dataset for review at the CDOP meetings.

Of the 425 cases reviewed by CDOP between 1st April 2011 and 31st March 2017, these additional factors were thought to have contributed to the ill–health, vulnerability or death of the child:

- parental smoking in 25 cases (6% of cases)
- domestic violence in 13 cases (3% of cases)

There is emerging data from CDOP and national research that maternal obesity is a significant risk factor both on an individual and population level, for neo-natal deaths. LLR CDOP is looking to capture this information and include relevant findings in future reports.

6.7 Additional factors in Parenting Capacity
Notable factors relating to parenting capacity are identified through the Form B and Form C data sets, and carefully reviewed at panel. Of the 362 cases reviewed between 1st April 2009 and 31st March 2015, CDOP concluded that poor parenting/supervision was a factor that had contributed to the ill-health, vulnerability or death of the child in 12 cases (3%).

7. Deprivation and child deaths

There is a strong evidence base which shows the strong association between deprivation and poor mortality outcomes: rates are lowest in the most advantaged families, highest in the most disadvantaged. This section of the report will look at mapping deprivation and child deaths reviewed between April 2011 and March 2017.

The figure below shows that there are higher mortality rates in 0-17 year olds living in areas of higher deprivation and lower mortality rates in areas of lower deprivation. Rates are generally higher in Leicester than in Leicestershire and Rutland.

Figure 13: Child deaths by deprivation quintile (2011/12 to 2016/17)
8. CDOP Challenges

8.1 Classification
Whilst reviewing the cases for this report, it was highlighted that there can be difficulty in ensuring consistency in how cases have been categorised, particularly in terms of the assessment of modifiable factors. This is due to some ambiguity in terms on how such factors can be interpreted and that there is also no national decision-making tool to support CDOP in this direction. However, it should be noted that standardisation at CDOP has improved in the last 18 months. Work is also underway with colleagues from across the region to review the possibility of ensuring a regional standardised approach.

8.2 Modifiable factors/identified learning
It is often the case that following review, no modifiable factors are identified; however this does not mean that there is no learning identified.

- In order to ensure all relevant learning is captured, CDOP will periodically undertake additional themed reviews, where all cases under a particular identified category will be revisited in order to ensure all available learning has been noted and is being progressed.
  - Suicide and deliberate self-harm cases are one such area that CDOP are currently undertaking additional work on.
8.3 Resources
CDOP acknowledges the work and commitment of all Panel members. However, although CDOP is a statutory function, it is recognised that for many Panel members their contribution to CDOP is in addition to their full time employment. This can place considerable pressures on members in terms of ensuring they have adequate time to prepare for Panel, attend the meetings, disseminate relevant learning and ensure any actions they are allotted are completed in a timely manner.

CDOP funding arrangements

The following table sets out the current funding of CDOP and the liability for future years in the event of there being no change in terms of hosting arrangements. It is important to note that the contributions are only to cover the cost of the salaries of the 2 staff employed by the CDOP. Their ‘additional’ costs (office accommodation, training, stationery, materials etc.) are all being met by the host agency (Leicestershire Partnership NHS Trust). The 2 members of staff are a full-time child death review manager and a full-time administrator.

Table 4: Contributions (per quarter) for CDOP

<table>
<thead>
<tr>
<th>Local Authority</th>
<th>Funding (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leicester City Council</td>
<td>10,748.40</td>
</tr>
<tr>
<td>Leicestershire County Council</td>
<td>10,748.40</td>
</tr>
<tr>
<td>Rutland County Council</td>
<td>895.20</td>
</tr>
</tbody>
</table>

Effectiveness of CDOP

It is difficult to quantify the specific impact of the CDOP process, or provide evidence where the work of the Panel has directly led to saving the lives of children across LLR. This is due to the protracted period of time under which any change in trends could be identified and the relatively low number of cases from which to provide an informed sample, which would be more tolerant to random fluctuations on a year by year basis.

Another aspect is that some issues, such as the dangers of disc button batteries or unsafe sleeping practices, are targeted at comparatively small audiences which change over time, meaning that certain CDOP actions need to feed into the continuous work streams of agencies rather than being one-off issues to be addressed.

While it is not possible to identify ‘hard’ evidence of the effectiveness of the CDOP at a local level, it is worthy of note that CDOP works closely with partners to ensure any learning is reflected in relevant policies and procedures and that where necessary training is undertaken in order to try and prevent future deaths occurring. It is through this mechanism that the CDOP can be seen to drive change and ensure the safety and welfare of children. The approach taken by CDOP has also been to develop a robust understanding of whether levels of modifiable risk factors identified in the case reviews are of concern; and secondly, to base recommendations on the best available evidence of what works to tackle these factors.
Recommendations


Recommendations from 2016

1. There is evidence of a disproportionate number of child deaths in the more deprived Quintiles. All partners should assess the work currently in place to target vulnerable groups and develop an action plan to identify how the number of deaths can be reduced.

2. It is a consistent feature both locally and nationally that children under the age of 1 account for the majority of child deaths. These deaths have common features which include low birth weight, prematurity and maternal smoking and associated issues of hypertension, diabetes and obesity and their links to poverty and infant nutrition. Given that year on year the percentage of deaths remains high, all partners should ensure that appropriate action plans are in place to address the areas identified.

3. A community engagement exercise should be commissioned to explore certain ethnic Groups’ views on consanguinity and access to universal and specialist services.

4. The proportion of child deaths aged 1-4 years is significantly higher than the national average: CDOP should undertake further analyses on this in order to inform partners' action plans.

5. The rate per 100,000 of child deaths for Pakistani children is significantly higher than the LLR average: CDOP should undertake further analyses on this in order to inform partners’ action plans.

6. CDOP should develop a tool to standardise decision making on categorisation of modifiable factors in all cases reviewed.

7. CDOP should provide assurance to the LSCBs on its action plan to improve the rate of completed reviews.

8. Further supplementary reports should be undertaken, pooling data as appropriate in order to look closely at trend, with this report providing a baseline.

Progress (on recommendations) made during 2016/17:

1. CDOP members have continued to work to promote actions that take a proportionate universalism approach – universal actions with a scale and intensity is proportionate to the level of disadvantage. There is however limited influence CDOP can have on national social, health and economic policy decision. However we have concerns that the continued pressure and reductions in funding for health and social care are felt most by the most vulnerable children and young people. We are also concerned that the national increase in inequality between local areas with the highest and lowest life expectancy at birth seen in recent years may begin to feed through to increasing infant and child death rates for our most deprived communities.

2. CDOP has contributed to the development of an LLR Infant Mortality Strategy and Action plan. This has ensured that priority is given to the modifiable factors identified in these reports, including smoking in pregnancy, childhood poverty, breast-feeding, smoke free homes, and safe sleeping.

3. An evidence review was undertaken to identify the associations between consanguinity and infant mortality, and work will continue to explore evidence based actions and educational programmes that address this in a culturally sensitive way as a risk factor.

4. Further analysis on the proportion of child deaths for 1 – 4 year olds showed that there was not a higher death rate for this age group compared to England. The
higher proportion could be attributed to lower death rates for other age groups across LLR.

5. Although no specific work was undertaken with Pakistani communities, CDOP has continued to analyse ethnicity and will undertake further work to examine the apparent high infant death rates for travelling families.

6. CDOP continue to develop our approach to both identifying and addressing modifiable risk factors for child deaths. We undertook a review of our Terms of Reference and membership to ensure the best representation from key stakeholders, and our approach was commended by the Ofsted Review of the Effectiveness of the Local Safeguarding Children Board in Leicestershire and Rutland as ‘highly effective’.

7. We now complete reviews in good time and do not have a backlog of cases caused by unnecessary delays.

8. We will continue to update this 6 year review.

CDOP Recommendations for 2017/18.

1. CDOP should continue to work with the LLR Infant Mortality Strategy Group to ensure all priorities and actions reflect the modifiable factors identified by CDOP Panels

2. Continue to support and promote work with partners that address key risk factors, including breast-feeding, childhood poverty, domestic violence, identification of sepsis, smoking in pregnancy and the home, safe sleeping, and maternal stress.

3. CDOP should complete the development of an electronic database that can be used in real time to investigate causes of deaths, factors that may have contributed to the vulnerability or deaths of children, and what actions might be taken at both national and local levels to prevent future deaths.

4. CDOP work with Public Health to undertake a Comprehensive Health Needs Assessment for Maternal Obesity across LLR.

5. CDOP should undertake further work to better understand and interpret the apparent high child death rate for travelling families.

6. CDOP should continue to audit child suicides and work with partners to identify those most at risk and to recommend commissioning of appropriate preventative services.

7. The CDOP Panel and LSCBs should undertake a review of the delivery of the Child Death Reviews, the resources allocated for the effective delivery of the CDOP function, and ensure that appropriate psychological support is put in place for the dedicated CDOP staff who undertake the reviews and support families throughout the most traumatic events imaginable in life.
## Appendix A

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.

<table>
<thead>
<tr>
<th>Category</th>
<th>Name &amp; description of category</th>
<th>Tick box below</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>Deliberately inflicted injury, abuse or neglect</strong>&lt;br&gt;This includes suffocation, shaking injury, knifing, shooting, poisoning &amp; other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death.</td>
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<tr>
<td>2</td>
<td><strong>Suicide or deliberate self-inflicted harm</strong>&lt;br&gt;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.</td>
<td></td>
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<tr>
<td>3</td>
<td><strong>Trauma and other external factors</strong>&lt;br&gt;This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis &amp; other extrinsic factors. <strong>Excludes</strong> Deliberately inflicted injury, abuse or neglect (category 1).</td>
<td></td>
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<tr>
<td>4</td>
<td><strong>Malignancy</strong>&lt;br&gt;Solid tumours, leukaemia’s &amp; lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.</td>
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<td>5</td>
<td><strong>Acute medical or surgical condition</strong>&lt;br&gt;For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.</td>
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<tr>
<td>6</td>
<td><strong>Chronic medical condition</strong>&lt;br&gt;For example, Crohn’s disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. <strong>Includes</strong> cerebral palsy with clear post-perinatal cause.</td>
<td></td>
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<tr>
<td>7</td>
<td><strong>Chromosomal, genetic and congenital anomalies</strong>&lt;br&gt;Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.</td>
<td></td>
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<td>8</td>
<td><strong>Perinatal/neonatal event</strong>&lt;br&gt;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 <strong>includes</strong> cerebral palsy without evidence of cause, and <strong>includes</strong> congenital or early-onset bacterial infection (onset in the first postnatal week).</td>
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<tr>
<td>9</td>
<td><strong>Infection</strong>&lt;br&gt;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 septicemia, pneumonia, meningitis, HIV infection etc.</td>
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<tr>
<td>10</td>
<td><strong>Sudden unexpected, unexplained death</strong>&lt;br&gt;Where the pathological diagnosis is either ‘SIDS’ or ‘unascertained’, at any age. <strong>Excludes</strong> Sudden Unexpected Death in Epilepsy (category 5).</td>
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</table>
Appendix B

LSCB SUDIC RESPONSE PROCEDURE FOR UNEXPECTED DEATHS

(Defined ‘as the death of a child not anticipated as a significant possibility 24 hours before the death, or where there was a similarly unexpected collapse leading to or precipitating the events that led to the death)

Child declared dead in Emergency Department (ED)

Child dies in ALTERNATIVE setting in or out of hospital & not taken to ED

Attending Dr to contact DI via Force Control Room.

Discussion will take place between attending Dr & DI to ascertain that:

• the child’s death is unexpected
• there are no suspicious circumstances

Where relevant, discussions will include the Coroner.

If death occurs Monday-Friday 9am-5pm, excluding Bank Holidays, the CDR Manager will then be notified. Outside of these hours, the CDR Manager is to be notified the next working day, The CDR manager will liaise with Designated Dr for Child Death

Contact details for CDR Manager: Tel 0116 295 8715, mobile 07876 034566.

Completion of CDOP Form A along with standard notification to be completed within 1 working day and forwarded to the CDOP Office via fax to: 0116 295 8712.

Home Visit: If a home visit is required (during office hours) the DI will contact the CDR Manager, discuss the circumstances of the child’s death and request a planned joint home visit.

Named Nurses are available between 9am – 5pm Monday to Friday excluding Bank Holidays. Outside these hours an urgent home visit may be undertaken by the Police as a single agency response.

The Named Nurse will be responsible for ensuring that the CDOP process has been explained to the parents, that parents are offered the opportunity to participate in the review and appropriate sources of support are identified

Phase 2 within 5 – 7 days: Professionals undertaking the home visit and other identified relevant practitioners will be contacted by the CDR Manager/SUDIC Dr. The aim of this discussion is to identify any key areas and agree an action plan to progress the case, including assessment of ongoing support to the family. The coroner will be kept informed of all necessary outcomes by the CDR Manager.

The CDR Manager will request information within 1-2 working days from identified relevant agencies to be completed and returned within 10 working days to the CDOP office.

Phase 3 within 20-26 weeks: Following receipt of post mortem results, a case discussion will be chaired by the SUDIC Dr. All relevant agencies will be requested to attend to share information, review the cause of death, ensure ongoing support to the family & identify any lessons learnt. A case summary including any recommendations will be completed ready for review by the CDOP Panel.

NB. Following receipt of a notification, the CDOP office will notify professionals and update systems as agreed.

Are the criteria met for a SCR?

No Further Action

No

Yes

Follow LSCB guidance
Appendix C

Please note that it is not possible to compare full ethnicity groups in LLR against England as full ethnicity data for England is not reported.

Percentage of child death reviews completed in LLR by ethnic group (2011/12 to 2016/17 pooled)