Gloucestershire Child Death Overview Panel (CDOP)

Annual Report for Child Death Reviews
Gloucestershire Safeguarding Children Board (GSCB)

1st April 2015 – 31st March 2016

Vicky Sleap
Child Death Review Process Manager

This report is provided to professionals working in the field of safeguarding children. As such, if this report is further distributed, it should only be forwarded to persons that it is appropriate to do so, given the nature of its contents.

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1. Introduction

We are fortunate that a child death is a rare event in our society, however, each death represents a tragedy for the family and the purpose of the Child Death Review process (CDR) is to identify potentially modifiable factors[1] which may prevent future deaths from occurring. The CDR process is also able to identify local and regional trends to inform the work of Commissioners, Providers and other relevant organisations. For example in the case of children with life-limiting conditions, the CDR process is able to consider whether these children were in receipt of appropriate care during their life and had access to appropriate support services at the end of life. Where the CDR process identifies learning this is fed back to the relevant agencies by the Child Death Overview Panel on behalf of the Local Safeguarding Children Board (LSCB) in Gloucestershire.

At the beginning of the CDR process in 2008, the Gloucestershire Child Death Overview Panel (CDOP) was established in line with guidance set out in *Working Together to Safeguard Children*. This CDOP continues to review the deaths of all children resident in this area. Some of these deaths may occur outside of the region and these are also reviewed by this panel.

2. Background to the Child Death Review Process

Chapter 5 of "Working Together to Safeguard Children" (2015) provides the framework for processes to review all child deaths. Under statutory national guidance, LSCBs are required to establish a procedure to respond rapidly in the event of an unexpected death of any child under 18 years of age. In Gloucestershire a joint police, social care and health rota is staffed during office hours (Monday to Friday 9am to 5pm) to provide this response. Outside of these hours an initial safeguarding discussion occurs at the time of death between police, social care, health and the Coroner's Officer. On the next working day, a formal initial case discussion (rapid response) is undertaken. This involves statutory agencies and all professionals involved with the child. LSCBs are also required to ensure there is a Child Death Overview Panel (CDOP) process. The two are separate processes, but are closely linked. The Rapid Response process ensures early notification of the unexpected death of a child and a prompt process of investigation. The CDOP process ensures that every child's death is comprehensively reviewed and lessons learnt so that action can be taken to prevent future deaths where possible.

3. The Child Death Review Process

A child's death is reviewed by CDOP after a range of standard information has been collected using statutory forms and the case has been discussed by professionals involved in the child's life at a final case discussion (FCD) meeting. Following the FCD meeting, a detailed compilation of data from the statutory forms (Form Bs) and outcomes of the FCD meeting (Form C) is produced and anonymised by the Child Death Enquiries Office at the University of Bristol for presentation to CDOP. CDOP reviews each case with the aim of identifying modifiable factors and highlights any learning identified. The CDOP panel aims to identify those factors in the course of a child's life, and leading to the child's death, which might have directly led to the child's death or increased their vulnerability, and which might have been amenable to modification. It also makes recommendations which may prevent similar deaths occurring in the future. However it may also make recommendations related to service improvement, where changes in practice could lead to improved experiences for children and young people at the end of life or during the course of their treatment.

[1] A modifiable death is defined as one where there are factors which may have contributed to the death which, by means of nationally or locally achievable interventions, could be modified to reduce the risks of future child deaths.

4. Production of this report

The CDOP is required to produce an annual report each year outlining the work of the panel and relevant learning from the cases reviewed to inform the priorities of the LSCBs. This annual report has been produced using data collected by the University of Bristol through the Child Death Enquiries Office. Information collected at the point of notification of death is entered onto a **Notification Database**. Information collected from statutory forms, final case discussion meetings and CDOP reviews is entered onto a separate **CDOP Database**. The eventual CDOP multi-agency dataset is extremely comprehensive. This year the annual report includes five years of data to help reduce year on year variations associated with rare events such as a child death. This allows better identification of longer term trends or key themes which may not have been as apparent within a single year of data.

5. Notifications of child deaths

5.1 Summary Data (2011 – 2016)

This section summarises all the deaths notified to the Child Death Enquiries Office between 1st April 2011 and 31st March 2016, of children resident in the Gloucestershire area. This data is drawn from the notification database.

5.2 Analysis of notifications by year (2011-2016)

During the period 2011-2016, 166 child deaths were notified. Year on year variation in notifications is to be expected (as shown in Table 1) and with rare events such as a child death, small variations can appear to represent a big difference. However because the number of notifications for one area of residence are so small the most likely explanation for any patterns is random year-on year variation.

Table 1: Numbers of deaths notified by year 2011 to 2016 in Gloucestershire

	Number of child deaths notified					
	2011-2012	2012-2013	2013-2014	2014-2015	2015-16	Totals
Gloucestershire	31	44	26	46	19	166

5.3 Duration of reviews

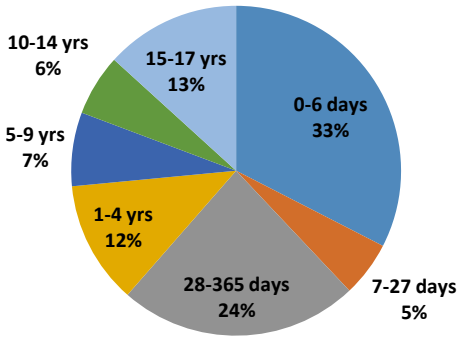
There is an inevitable time-lag (4-12 months) between notification of a child's death and discussion at CDOP**.** There are various factors that contribute to this: the return of Form Bs from professionals, the completion of the final post mortem report by the pathologist and receipt of the final report from the FCD meeting. On occasion when the outcome of a Coroner's inquest is awaited, there may be a delay of over a year before a case might be brought before CDOP. The undertaking of a criminal investigation or a Serious Case Review will also affect when a case is discussed at Panel. See Appendix A for a full breakdown of duration of reviews by year.

5.4 Age at death

Using five year data, the greatest proportion of notifications (38%) were received for babies dying in the neonatal period (under one month of age), especially in the first week after birth (33%). This figure increases to 62% when all deaths under one year are included, similar to 64% observed nationally[2].

[2] Department for Education. Child Death Reviews – Year Ending March 2015. https://www.gov.uk/government/collections/statistics-child-death-reviews

Figure 1: Notifications by Age, 2011 - 2016

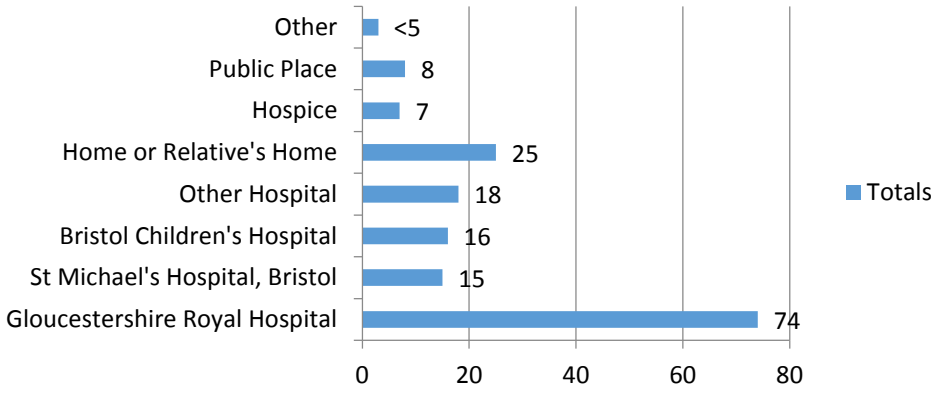


5.5 Location of death

This data records where the child actually died. Many children resident in Gloucestershire may be transferred to tertiary hospitals in other regions for treatment. A number of these children go on to die in those locations as can be seen in Figure 2 below. The figures in this section represent the total number of deaths at each location during the five year period. A total of 123 deaths (74%) occurred in a hospital setting. This is slightly higher than the national figure of 67%. About 4% of deaths occurred in a hospice, this is the same nationally. 4.8% of the deaths were in public places, which is in line with national figure of 4%[3].

Children resident in Gloucestershire are treated in many different hospitals. This reflects the wide geographical area covered by Gloucestershire and the number of counties in which residents receive healthcare services including Bristol, Oxfordshire, Swindon and Birmingham and their willingness to contribute to the process. This can present particular issues for Gloucestershire for the timely and complete collation of information for the review of children's deaths due to the wide range of organisations that must be engaged.

Figure 2: Notifications by Place of Death, 2011 - 2016



[3] Department for Education. Child Death Reviews – Year Ending March 2015

The most common location of death is in hospital, where 123 children died (74%). In total 25 (15%) children died at home or at a relative's home in the five year period. This can include both expected deaths where a child has received palliative care support at home and unexpected deaths that happened within the home setting. 23% (14/60) of unexpected deaths happened within the home setting.

5.6 Gender

There have been more notifications of deaths in boys than in girls as can be seen in the table below. In total 56.6% of deaths were male and 43.4% were female. This is in line with national trends for childhood deaths which also show slightly higher proportions of deaths registered in England were for male children[4].

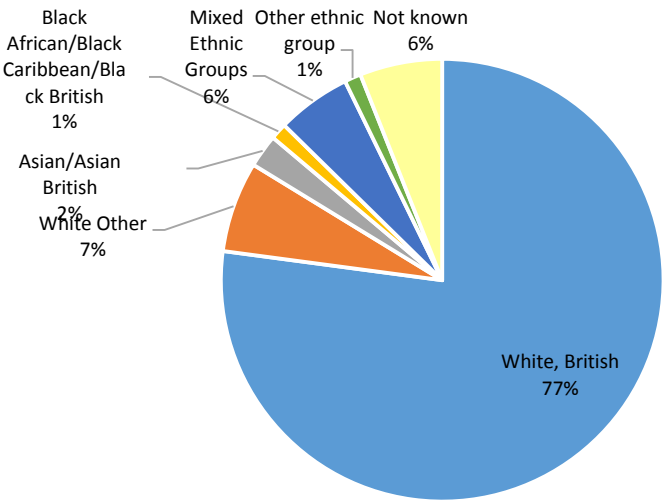
Table 2: Numbers of deaths notified between 1st April 2011 and 31st March 2016 by gender

	Male	Female
Gloucestershire	94	72

5.7 Ethnicity

Figure 3 shows that the majority of deaths for Gloucestershire are children of White British ethnic origin. The 2011 Census showed Gloucestershire's residents to be 91.6% White British, 3.1% White Other, 2.2% Asian, 0.9% Black, 1.5% Mixed and 0.2% Other. Though Figure 3 shows that ethnicity was unknown in 6% of cases, there may be over-representation of children from Mixed Ethnic and White Other groups. With increasing migration from East European countries into the county from 2004, the White Other population in the county more than doubled between 2001 and 2011.

Figure 3: Notifications by Ethnic Groups, 2011 - 2016



5.8 Unexpected and Expected Deaths

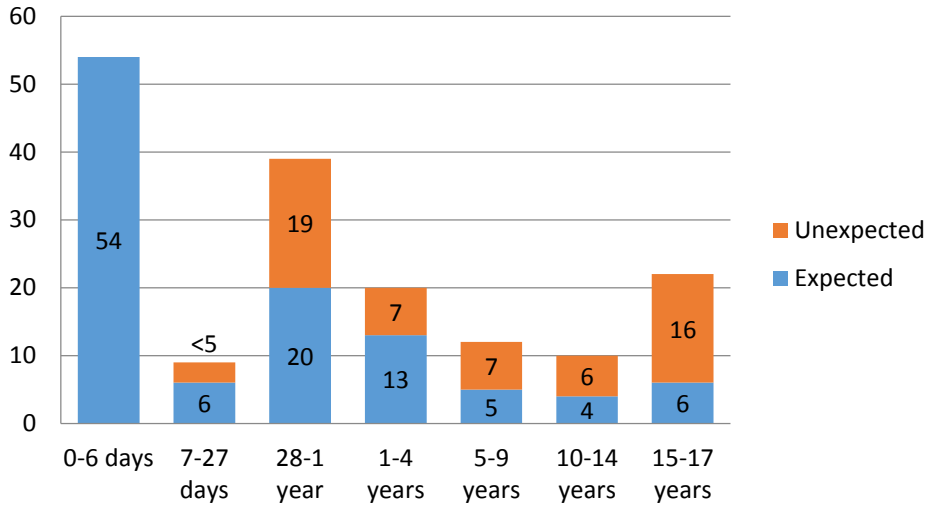
An unexpected death is defined as the death of a child which was not anticipated as a significant possibility 24 hours before the death or, where there was a similarly unexpected collapse or incident leading to or precipitating the events that led to the death. During the five year period 58 deaths

[4] Department for Education, Statistical Release - Child Death Reviews: Year ending March 2015

(34.9%) were unexpected. The remaining 108 were expected deaths of children with known illnesses or life-limiting conditions.

Figure 4 presents data on expected versus unexpected deaths for 2011-16 by age group. This data show that the highest numbers of unexpected deaths occur in the 28-364 day and the 15-17 year age groups, whilst all deaths within the first week of life were expected. Between 28 days and one year of age, expected and unexpected deaths were of equal proportions. Within this age group, the expected deaths would usually be a baby that dies following complications of a premature delivery or of a known chromosomal, genetic or congenital anomaly and the unexpected deaths would include sudden unexpected deaths in infancy and infection.

Figure 4: Expected vs. Unexpected Deaths by Age, 2011 - 2016



6. Child Death Overview Panel Review Data

This data is drawn from the CDOP database. It summarises the panel's review decisions for 2011-2016 and its learning for 2015-2016. There is an inevitable time lag between the notification of a child's death and the discussion at CDOP. There are various factors that contribute to this including return of statutory paperwork by professionals, receipt of the final post mortem report and receipt of the report from the final case discussion meeting. The Gloucestershire CDOP took the decision in 2009 to wait for the inquest verdict in child deaths that involve the Coroner. In these cases there may be a delay of over a year before a case might be brought for review by CDOP. The undertaking of a criminal investigation or a Serious Case Review can also affect when a case is discussed at panel. In addition, certain children who have been under the care of specialist regional paediatric teams (e.g. cardiology) will be reviewed at a specialist themed CDOP for the region before coming to Gloucestershire CDOP for final review, to ensure that the relevant expertise is present when identifying learning from these cases.

For these reasons the population of children described in the notifications section (drawn from the Notification Database) may partially overlap but is distinct from the population of children described in this section (drawn from the CDOP Database).

The Gloucestershire CDOP has reviewed 190 deaths between 1st April 2011 and 31st March 2016. Of the 166 deaths notified between 1st April 2011 and 31st March 2016, there are currently 37 that have not yet been reviewed by CDOP. The deaths of all children who died before 1st April 2014 have now

been reviewed and 60% of the deaths of children who died between 1st April 2014 and 31st March 2015 have also been reviewed. This has been a major achievement of the CDOP this year and has been achieved through the arrangement of two additional panel meetings in 2015/16. See Appendix A for a full breakdown.

During the 2015/16 child death review year the Gloucestershire CDOP panel reviewed a total of 55 deaths. This is a significant increase on previous years where the average has been 34 as can be seen from the table below. This was due to CDOP meeting on an additional two occasions to help clear a backlog of cases.

Table 3: Number of child deaths reviewed by CDOP, 2011 - 2016

	2011-12	2012-13	2013-14	2014-15	2015-16	Totals
Gloucestershire	34	33	34	34	55	190

6.1 Categorisation of death for cases reviewed by CDOP

As part of the Child Death Review process, each death reviewed by the panel is categorised by the most likely cause of death based on a set of pre-defined categories. The categorisation of deaths for cases reviewed by the panel over the five year period is shown in Figure 5 below. This shows that the most common categorisation is perinatal / neonatal event (41%) followed by chromosomal, genetic and congenital anomalies (18%). The other categories are much less common.

Figure 5: Categorisation of Deaths for Children Reviewed by CDOP, 2011 - 2016

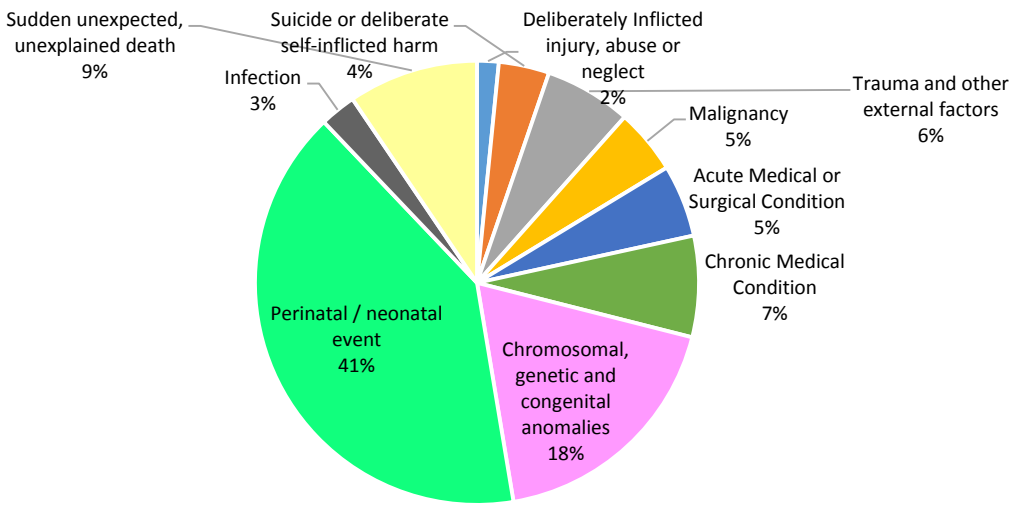
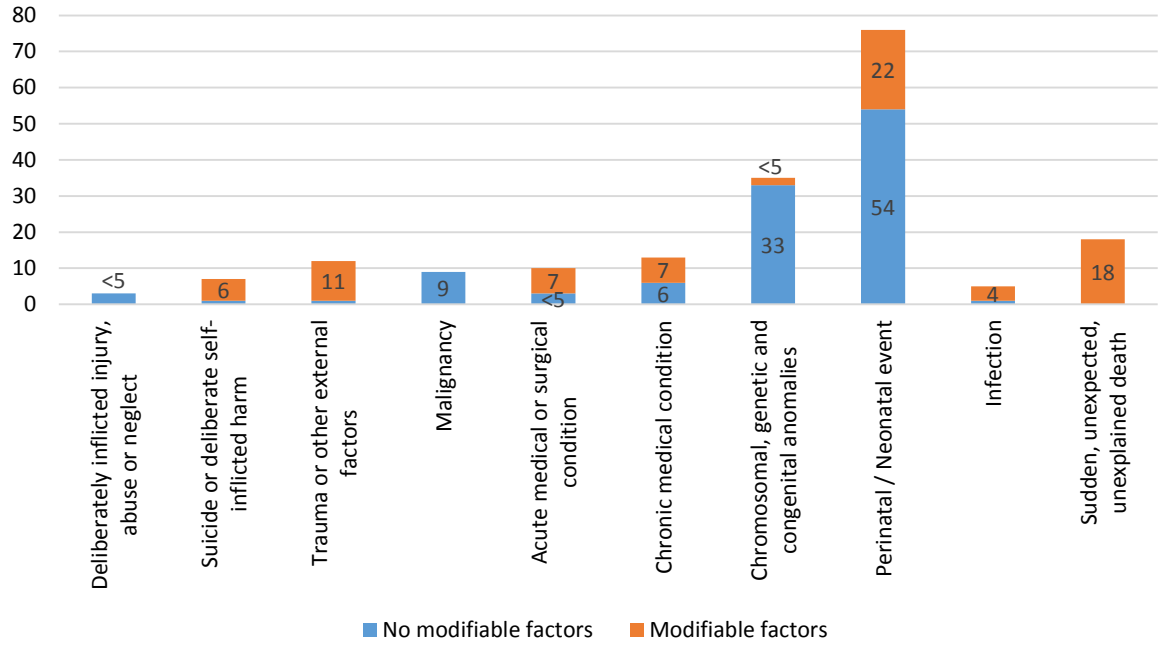


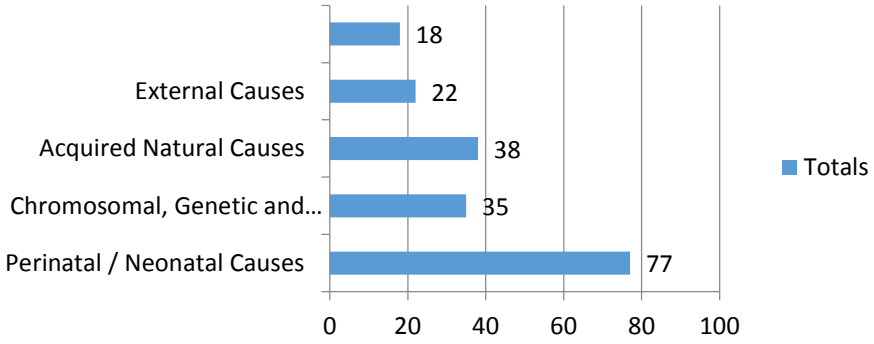
Figure 6, below, shows the proportion of deaths within each category that were considered to have modifiable factors following review by CDOP. This shows that the categories that represent unexpected deaths, e.g. suicide or deliberate self-inflicted harm, trauma and other external factors and sudden, unexpected, unexplained death, have the highest proportion of modifiable factors associated with them. This is as expected and is in line with the national picture. Perinatal or neonatal event, malignancy and chromosomal, genetic and congenital anomalies have the lowest proportion of modifiable factors associated with them, this is also in line with the national picture.

Figure 6: Modifiable factors by category of death, 2011-2016



The same data can be grouped into the categories below. This shows that perinatal/neonatal causes remain the largest category, followed by 'Acquired natural causes', which groups together malignancy, acute medical or surgical conditions, chronic medical conditions and infection. 'External causes' groups together deliberately inflicted injury, suicide, trauma and other external factors. The smallest group are those unexpected deaths that remain unexplained following a full investigation and final case discussion meeting.

Figure 7: Causes of Death of Cases Reviewed by CDOP, 2011 - 2016



6.2 Co-morbidities

As well as categorising the cause of death CDOP considers information on co-morbidities in children who die. These are underlying conditions which, while not considered to be the direct cause of death, are thought to have potentially contributed to vulnerability in the child, for example by making treatment more complex or contributing additional challenges to a child living a full and active life. It should be noted however that the existence of a co-morbidity does not necessarily have an impact on the circumstances that led to a child's death.

The CDOP grading system grades factors identified with a 1 if they are notable but not felt to have contributed to the ill-health or vulnerability of the child, with a 2 if they may have contributed to the ill-health, vulnerability or death of the child and with a 3 if they are felt to provide a complete and sufficient explanation of the death of the child.

Figure 8 shows that 132 children (69.5%) reviewed by CDOP had no co-morbidities at all. Of the remaining children reviewed 23 (12%) had just one co-morbidity and 35 (18.4%) had more than one co-morbidity. The chart reflects the number of children reviewed that had each particular co-morbidity and how significant the panel felt that co-morbidity was, using the grading system described above.

Figure 8: Co-morbidities of Children Reviewed by CDOP, 2011 - 2016

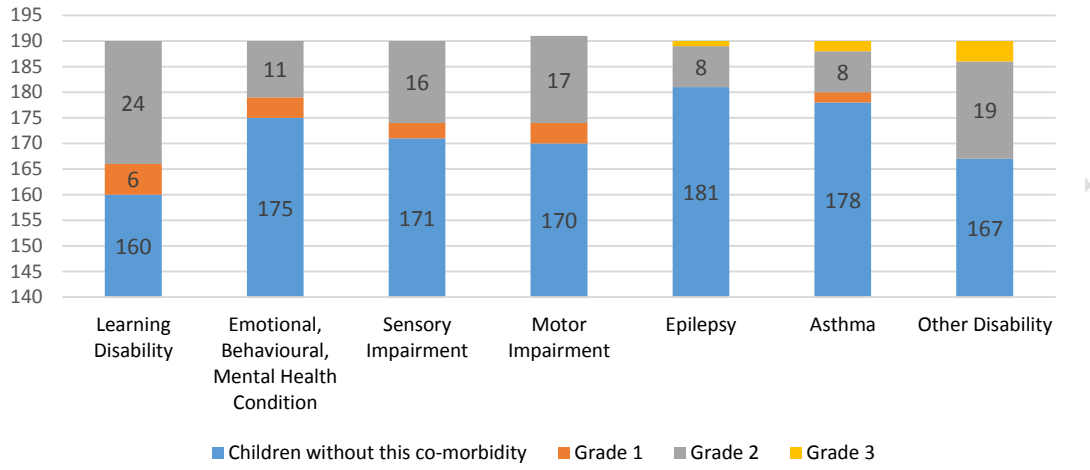


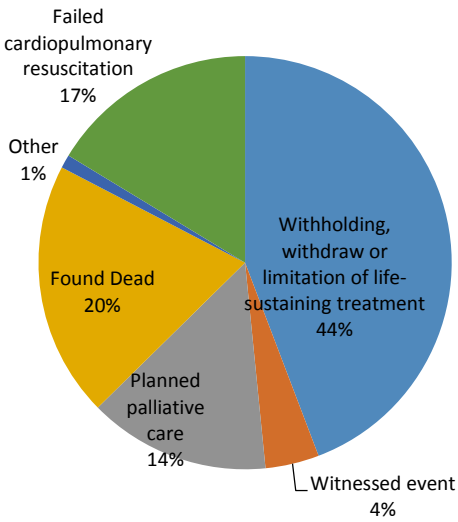
Figure 8 shows that the co-morbidities found to have a significant impact on vulnerability are learning disability, motor impairment, emotional, behavioural and mental health conditions and other disability. An example of "other disability" would be a child with an underlying chromosomal disorder or a genetic syndrome. Children with a learning disability represent the most common co-morbidity. 30 children had a diagnosed learning disability and this was considered to be a significant factor in all but 6 cases. Other disability is the second most common with 23 children in that cohort. Learning disability and motor impairment are also identified as the most common comorbidities in children reviewed by CDOP panels across the South West.

6.3 Mode of death of cases reviewed by CDOP

As can be seen from the pie chart in Figure 9 below, the most common manner of death for Gloucestershire children is withholding, withdrawing or limitation of life-sustaining treatment. This decision is always made following careful consideration with the child's parents and carers. This is followed by those children who were found dead (20%) and then those children who died following failed cardio-pulmonary resuscitation (17%) and following planned palliative care (14%).

Of the children who died following withdrawal of treatment 77/84 (91.6%) were expected deaths, similarly of the children who died following planned palliative care 25/27 (92.6%) were expected deaths. This reflects the national picture. Of the children who were found dead, the vast majority, 37/38 (97.4%) were unexpected deaths and of those who died following failed cardio-pulmonary resuscitation, 55% were unexpected. This is similar to other CDOPs in the South West and nationally.

Figure 9: Modes of Death of Cases Reviewed by CDOP, 2011 - 2016

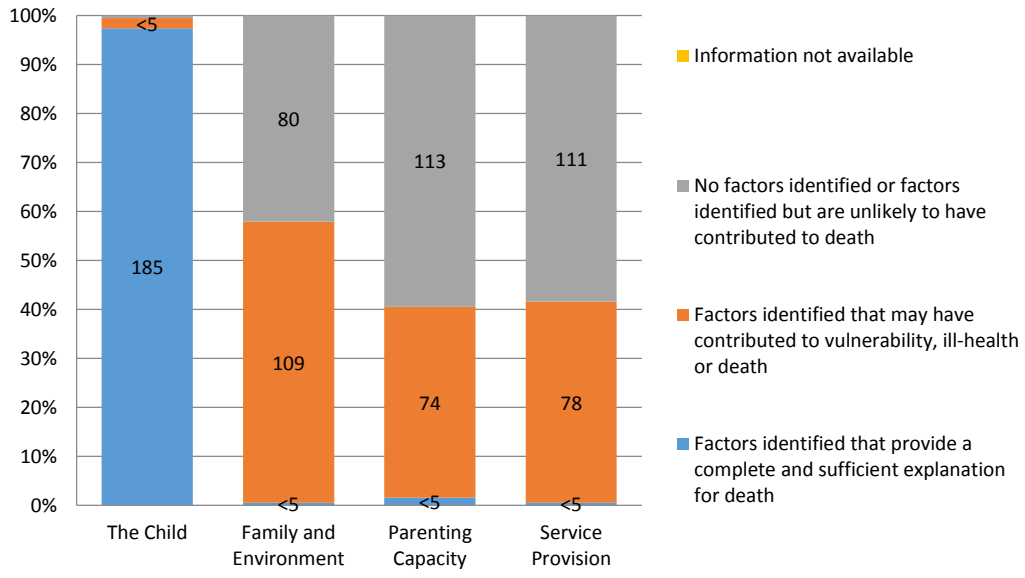


6.4 Factors identified as having contributed to death

Form C of the national dataset requires that the professionals present at the final case discussion meeting identify and 'grade' factors that have contributed to the child's death. CDOP may make additions or amendments to the information recorded on Form C at the final case discussion meeting after full deliberation of the facts. CDOP amended some information in 89% of child deaths reviewed over the five year period. This is consistent with the level of amendments made by other CDOPs in the South West.

In 97.4% of deaths reviewed factors in the child (i.e. the underlying medical or surgical condition) provided a complete and sufficient explanation of the death.

Figure 10: Contributory Factors in Cases Reviewed by CDOP, 2011 - 2016



In 58% of children, factors in the family and environment were identified that may have contributed to the vulnerability, ill health or death of the child. These would be factors such as drug or alcohol use by a parent or carer, smoking during pregnancy or a physical or mental health condition in a parent or carer.

In 40.5% of children factors in the parenting capacity were identified that may have contributed to the vulnerability, ill-health or death of the child. This includes parents who are unable to prioritise the needs of their child e.g. not seeking medical attention appropriately, poor engagement by parents with professionals and lack of attendance at obstetric appointments during pregnancy.

In 41.6% of children reviewed, factors related to service delivery were identified that may have contributed to the vulnerability, ill-health or death of the child. These included poor communication between agencies, delay in transfer of the child or access to appropriate treatment, no access to translation services for non-English speaking families (particularly in the acute situation) and difficulties accessing appropriate housing for vulnerable families.

In any case where factors are identified at the final case discussion or at CDOP that may have contributed to vulnerability, ill-health or death, the context is carefully reviewed and appropriate actions logged on the Rapid Response Nurse Work Plan or CDOP action log to be followed up.

6.5 Additional social factors in the family and environment

The presence or absence of social factors in the family and environment such as mental health issues and drug abuse are routinely collected on the Form B dataset from professionals who have contact with the families. These are summarised on the Form C dataset at the final case discussion meeting and carefully reviewed by CDOP. They are shown in the Table 4 below. Please note that these factors are not necessarily considered to be modifiable in every case and may not have been directly contributory to the child's death, rather this data reflects the presence or absence of a social factor within the family or environment.

Table 4: Factors in the family and environment recorded in cases reviewed by CDOP of children resident in Gloucestershire

Factor	Grade 1	Grade 2	Grade 3	Factor known not to be present	Not known if factor present	% of cases where factor considered to be significant
Emotional, behavioural, mental health condition in a parent or carer	24	41	0	115	10	21.5%
Alcohol or substance misuse by a parent or carer	9	27	0	140	14	14.2%
Smoking by a parent or carer / Smoking by Mum during pregnancy	34	48	0	97	11	25.2%
Housing	9	19	0	162	0	10%
Domestic violence	11	27	0	147	5	14.2%

Table 4 above shows significant factors to include smoking in a parent/carer, emotional, behavioural or mental health condition in a parent/carer and alcohol/substance abuse in a parent/carer. Domestic violence is also a significant factor in 14% of cases.

6.6 Modifiable Factors – Reducing the Risk of Future Deaths

The focus of the Child Death Review process is to assess modifiable factors in each child's death. Modifiable factors are defined as "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". Panels can identify modifiable factors in the child's direct care by any agency, including parents, latent, organisational, systemic or other indirect failure(s) within one or more agency. Therefore a death identified as having modifiable factors may not necessarily be due to a failure of the Local Authority or other agencies to safeguard the child's welfare. An example of a modifiable factor might be a death resulting from a vaccine preventable infection where the vaccine had not been given to the child.

For cases reviewed by CDOP during the five year period, modifiable factors were identified in 40.5% of cases. In the majority of cases, (111/190) no modifiable factors were identified. In the case of two children reviewed during the period there was inadequate information on which to make a judgment.

In 2015/16 33% of cases reviewed identified modifiable factors associated with a child's death. The proportion of deaths where modifiable factors have been identified have generally been higher than the national average (Table 5). South West CDOPs as a whole record a higher level of modifiable factors than anywhere else in the country and this is felt to be due to the high level of scrutiny to which these cases are subject during both the local and CDOP reviews. In addition, around 35% of the overall deaths of children in Gloucestershire are unexpected and these would be the deaths that might be expected to identify modifiable factors. A closer review of the data has not shown any particular themes or patterns of death in Gloucestershire children, either in terms of age at death or cause of death.

Table 5: Percentage of cases where sufficient information was available and modifiable factors were identified, by year of review

	2011/12	2012/13	2013/14	2014/15	2015/16
Gloucestershire	50%	48.5%	35.3%	41.2%	33%
England	20%	21%	22%	24%	-

7. Lessons Learnt, Actions Taken and Recommendations as a Result of the Gloucestershire CDOP in 2015/16

7.1 Lessons Learnt

- The majority of child deaths are expected deaths accounting for 63.2% of child deaths in the past year.
- This year 37% of child deaths occurred in the perinatal or neonatal period and 52.6% occurred within the first year of life.
- The most common cause of death in Gloucestershire this year was perinatal or neonatal event (31.5%). This is in line with the national picture.
- Deaths from external causes, which includes trauma from external factors or self- inflicted harm and suicide are rare. This year they accounted for 10% of deaths (equivalent to 2 child deaths in 2015-16).

- In the majority of deaths reviewed no modifiable factors are identified. However modifiable factors were identified in 32.7% of cases reviewed by the panel in 2015/16. Nationally this figure remains at around 24%.
- At county level, a decision has been taken to stop NG feeding of children overnight due to possible risk of aspiration. This learning was circulated nationally through the CDOP Managers email network
- Importance of giving broad spectrum antibiotics following premature rupture of membranes
- Placental histology is helpful in confirming chorioamnionitis
- During the review of the deaths of children abroad it was highlighted that when a person dies abroad, unless their body is returned to the UK, the Coroner is not informed and there is no requirement to register the death within the UK. The panel, including our colleagues in the police, felt very strongly that this represents a loophole within the law which prevents appropriate investigation of a death if the child's body is not returned to the UK. CDOP has written to the Children's Commissioner regarding this issue.
- Importance of basic life support education for parents and the need to re-educate about prop feeding
- Good communication between agencies is essential, particularly when parents are separated
- Importance of good cross border communication and information sharing
- In end of life provision of care for child it is fundamental all involved understand each person's role and what they will provide at end of life.
- When engaging with families agencies should be more inclusive of dads
- Professionals experience difficulties in the management of patients who don't engage with services and defining what is neglect when not engaging
- National shortage of paediatric pathologists leads to extended timescales for post-mortem reports causing distress to families

7.2 Actions Taken

- Co-sleeping was one of the themes in county wide safety week in June 2014. This has also been reinforced by literature given to parents at birth and continues to be maintained.
- This year CDOP identified a poor rate of return of Form Bs by social care. Following investigation into the reasons for this, a new process has been set up to ensure senior professionals are aware when requests are made. This has significantly improved the quality and quantity of Form Bs from this agency
- CDOP wrote to the GSCB Chair regarding the importance of Education Welfare Officers (EWOs)
- A letter was sent to the Children's Commissioner for England highlighting that when a child dies abroad, unless their body is returned to the UK, the Coroner is not informed and there is no requirement to register the death within the UK. The panel felt that this represents a loophole within the law which prevents appropriate investigation of a death if the child's body is not returned to the UK.
- Designated Doctor for Children's Deaths has held several teaching sessions with professionals to disseminate learning identified to relevant agencies
- A new process is in place for what happens after death if the family want their child's body to go to the hospice. Hospital action cards have been updated accordingly.

7.3 Recommendations:

- CDOP remains concerned about the theme of difficulties in accessing appropriate translation services in the acute setting and is in discussion with the GSCB regarding this issue

- CDOP recommends the development of a local strategy for children who die out of county, to help sign post families to professionals who may be able to support them when their child dies.
- This year, Gloucestershire CDOP plans to explore in more detail the deaths with modifiable factors to identify any themed learning, as well as exploring potential vulnerability from the presence of Learning Disability as a co morbidity

Appendix A: Duration of CDOP reviews by year

	2008/09		2009/10		2010/11		2011/12		2012/13		2013/14		2014/15		2015/16	
Total number of notifications	43		33		36		30		43		26		45		19	
Total number of cases reviewed	6		17		24		34		33		34		34		55	
Years of Review	**Number reviewed**	**% reviewed**	**Number reviewed**	**% reviewed**	**Number reviewed**	**% reviewed**	**Number reviewed**	**% reviewed**	**Number reviewed**	**% reviewed**	**Number reviewed**	**% reviewed**	**Number reviewed**	**% reviewed**	**Number reviewed**	**% reviewed**
2008/09	6	14%	16	37%	14	33%	3	7%	3	7%	0					
2009/10			1	3%	9	27%	16	49%	4	12%	1	3%	1	3%	1	3%
2010/11					1	3%	15	42%	16	44%	4	11%	0	0	0	0
2011/12							0	0	10	33%	15	50%	5	17%	0	0
2012/13									0	0	14	33%	25	58%	4	9%
2013/14											0	0	3	12%	23	88%
2014/15													0	0	27	60%
2015/16															0	0

- NB: All deaths of children who died before 1st April 2014 have now been reviewed by CDOP
- NB: 60% of the deaths of children who died between 1st April 2014 and 31st March 2015 have also been reviewed.
- NB: The above details the number of cases awaiting review by CDOP, all cases except those of children who died in the last 6 months have already undergone a final case discussion meeting