

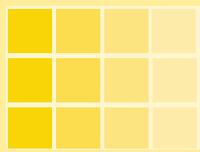
WEST  
OF  
ENGLAND AND  
CHILD  
DEATH  
OVERVIEW  
PANEL

ANNUAL  
REPORT

APRIL

2013  
TO

MARCH  
2014



West of England  
Child Death  
Overview Panel





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## I. Acknowledgement

The compilation of this report has only been made possible with the help of the following individuals: Julie Mytton (Consultant in Child Public Health, Bristol City Council) for providing data on crude death rates (2010-2014) for Section 6.1 and Vicky Slep for co-authorship of the report.

**Mary Gainsborough**

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## 2. Forward

As the outgoing Chair of the West of England Child Death Overview Panel I am very pleased to introduce the sixth Annual Report of the Panel. This report highlights the main themes and findings from 2013/14 and will be presented to the Local Safeguarding Children Boards for their consideration when preparing their annual reports. During this period, the Panel has maintained the effective collaborative arrangements for reviewing child deaths within the Local Safeguarding Children Board areas in the West of England (Bath & North East Somerset, Bristol, North Somerset and South Gloucestershire). This Annual Report offers an important source of data and information that local agencies should take account of to improve the quality of services and shape the future safety and wellbeing of children and young people.

The West of England CDOP has benefitted from valuable local and national expertise as it has conducted detailed overviews of child deaths, which have occurred in the area. The Panel has been proactive in pursuing modifiable factors, including at Ministerial level where the potential for improving policy, practice and learning for the future exists. Local Safeguarding Children Boards responsible for the Panel have been advised of learning arising from review as well as specific action required.

The West of England CDOP continues to demonstrate an excellent example of effective partnership working across local authority, NHS and the voluntary sector. This doesn't happen by chance and I would like to thank colleagues who have contributed to the detailed work of the panel and the Local Safeguarding Children Boards for their continued support.

I particularly wish to thank Vicky Slep and her team in the Child Death Enquiry Office for their efficient and proactive administration of the Child Death Review process; Professor Peter Fleming for the valuable national perspective he has provided and Dr Mary Gainsborough for her role as Designated Doctor.

The West of England Child Death Overview Panel will continue to work towards identifying and addressing issues of preventable deaths for children and young people across the West of England in the year ahead.



*Tony Melville*

*Chair of the West of England Child Death Overview Panel (April 2013 to March 2014)*

Independent Chair of Bristol Safeguarding Children Board



### 3. Executive summary

1. The processes to be followed when a child dies are currently outlined within Working Together to Safeguard Children 2013: Chapter 5 Child Death Review Processes<sup>1</sup>.
2. Crude death rate in the West of England was significantly lower than that for England and Wales as a whole.

#### Data related to Child Death Notifications

3. 483 child deaths were notified to the West of England Child Death Enquiries Office between 1<sup>st</sup> April 2010 and 31<sup>st</sup> March 2014.
4. Between 2010 and 2014, 46% of children were not residents of Bristol, North Somerset, South Gloucestershire or Bath and NE Somerset. The great majority of these children were receiving specialist medical care in Bristol Children's Hospital or St Michaels Hospital (NICU).
5. Over the 4 year period, 37.3% died in NICUs, 24.8% died in PICU or adult ICUs, 7.7% in Emergency Departments, 11% in other hospital wards/theatres/central delivery suites, 8.4% in the home, 4.5% in hospices and 12.6% in other locations.
6. Between 2010 and 2014, 71% of deaths occurred during the first year of life, 13.1% of deaths were of children ages 1-4, and rates then decrease in mid-childhood but are higher in ages 15-17 with 5.7% of deaths.
7. 76.7% of deaths notified in the last 4 years were children expected to die with 35.5% of deaths due to perinatal complications (mostly extreme prematurity), and 28.9% children with chromosomal, genetic or congenital conditions. Acquired natural causes account for 19% and

external causes, encompassing deliberate injury, suicide and trauma, accounted for 8.4%. 23.3% of deaths in children aged 0-17 years were unexpected with 8.3% remaining unexplained after a full investigation and the local case review meeting.

8. Between 2010 and 2014 there was a Coroner's post mortem in 31.4% and a hospital post mortem in 14.2% of cases.

#### Data from cases reviewed by the Child Death Overview Panel

9. The West of England CDOP reviewed 280 cases in detail between 1<sup>st</sup> April 2010 and 31<sup>st</sup> March 2014. There is an inevitable time-lag between notification of the child's death to discussion at CDOP but 100% of the cases requiring review from 2010/11 have now been reviewed and 78% from 2011/12.
10. 22.7% of deaths reviewed were unexpected and 21% of these were due to trauma or other external causes, 14% due to chromosomal genetic or congenital anomalies, 10% due to infection and the rest remained unexplained (includes SIDS).
11. The most common mode of death is following the active withholding, withdrawal or limitation of life-sustaining treatment, which occurred in 47.1% of cases.
12. 10% had co-morbidities recorded as contributory, of which learning disabilities, motor impairment and emotional/behavioural difficulties were the most common.
13. In 95% of cases, factors intrinsic to the child (i.e. the underlying medical or surgical problem)

<sup>1</sup> HM Government Department for Education (June 2013)

provided a complete and sufficient explanation for the death. In 1% factors in service provision provided a complete and sufficient explanation for the death, and in one case issues with parenting capacity provided a complete explanation.

14. Factors that may have contributed to the vulnerability, ill-health or death were identified in the family in 25%, related to parenting capacity in 18% and in service provision in 26%. Parenting capacity issues include poor parenting/supervision and/or child abuse/neglect and poor engagement with services. Parental smoking was classed as contributory in 7% of deaths, parental mental health, alcohol or substance abuse in 5%, housing issues in 4% and domestic violence in 4%. It should be highlighted that positive parenting was noted in many cases.
15. CDOP identified 'modifiable factors' in 36%. 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'. Current national data shows this is higher than the national average and the average from the South West. This is due to the open scrutiny with which this panel seeks opportunities to learn from every case reviewed and the fact that factors considered to be modifiable may not be considered modifiable by other panels
16. Family bereavement follow-up was documented in over 85% of cases, with paediatrics/specialists

services providing this in 52.3%, primary care in 20.3% and hospice/community nursing in 13.5%. In 5.7% the offer of follow-up had been declined or was yet to be taken up, and no information was available in 8.2% including whether families had accessed national or local non-statutory bereavement support, information about which is routinely provided through the child death review process

### **Focus on Sudden Unexpected Death in Infancy**

17. CDOP reviewed the deaths of 20 children categorised as Sudden Infant Death Syndrome.
18. Smoking was noted in 75% of households.
19. Co-sleeping at the time of death was found in 65%, 77% of whom had additional risk factors such as smoking, substance abuse or sleeping environment.
20. 45% were sleeping in an adult bed at the time of death, 20% on a sofa and 25% in a crib or cot.
21. 68% infants were placed supine for their last sleep, with 10.5% placed prone and 10.5% on their side.

### **Service improvement issues**

22. Some service improvement actions were taken as a direct result of discussion at the local child death review meeting and in some cases good practice was commended.
23. Important issues highlighted by CDOP were disseminated through the constituent agencies and the chairs of the Local Safeguarding Children Boards.
24. Issues noted at CDOP led to specific actions in some cases:



- Certain deaths from trauma and injury have led to direct liaison with agencies such as Avonsafe and the Canal and Rivers Trust regarding improved safety advice to parents.
  - Safeguarding training for health professionals has been revised to ensure consideration of any children in the care of adult patients, whose illness or treatment may affect their ability to provide appropriate care.
  - SIDS deaths have highlighted the lack of a formal Care of the Next Infant programme in this area, and commissioners have been made aware of this.
  - Good practice by a GP providing medical leadership for a package of home-based palliative care led to further discussion with commissioners in recognising that coordinated medical advice is not always available in this situation.
  - In some hospital deaths CDOP has noted the absence of or lower than expected quality of a Root Cause Analysis or other enquiry, and CDOP always liaises closely to ensure any actions are completed.
  - Delay in detecting pulmonary hypertension in a child with Down syndrome led to a case for a local screening programme being raised with commissioners in line with RCPCH guidelines.
25. Certain themes have emerged from reviewing children's deaths in the West of England this year:
- Safe sleeping advice – CDOP has reviewed written and verbal advice given to parents and is supporting research into factors influencing parental decision making about sleeping arrangements. To ensure a national approach to this important issue, local data is being contributed to the NICE review of co-sleeping,
  - Child Death Review process – training for partner agencies to ensure submission of appropriate information and convening of robust Child Death Review meetings
  - Family follow-up – CDOP continue to fund a Bereavement Nurse based in UH Bristol and have arranged training from the Lullaby Trust for professionals involved in the rapid response team
  - Voice of parents – some cases reviewed have drawn attention to less than optimal communication with parents during their child's illness and CDOP has supported processes to address this. Efforts are made to ensure effective parental involvement in the Child Death process, in particular ensuring parental questions and concerns are addressed.



## 4. The Child Death Review Process

Since April 1st 2008, Local Safeguarding Children Boards (LSCBs) in England have had a statutory responsibility for child death review processes. The relevant legislation is enshrined within the Children Act 2004, and applies to all young people under the age of 18 years. The processes to be followed when a child dies are currently outlined within Working Together to Safeguard Children 2013: Chapter 5 Child Death Review Processes<sup>2</sup>. The process focuses on identifying ‘modifiable factors’ in the child’s death.

The overall purpose of the child death review process is to understand how and why children die, to put in place interventions to protect other children and to prevent future deaths. It is intended that these processes will:

- Document and accurately establish causation of death in each individual child
- Identify patterns of death in a community so that preventable factors can be recognised and reduced
- Contribute to improved multi-professional collection of medical, social and forensic evidence in the small proportion of deaths where there has been maltreatment or neglect
- Ensure appropriate family and bereavement support is in place
- Identify learning points for service provision, which relate to care of the child

Working Together (2013) outlines two inter-related processes...a ‘**Rapid Response**’ where a group of professionals come together for the purpose of evaluating the cause of death in an individual child, where the death of that child is unexpected, and a ‘**Child Death Overview Panel**’ (CDOP) that comes together to undertake an overview of all child deaths under the age of 18 years in a defined geographical area. These processes have been outlined in detail in previous annual reports.

In the area of the former county of Avon, four neighbouring Local Safeguarding Children Boards (LSCBs) (Bristol, North Somerset, South Gloucestershire and Bath and North East Somerset) have come together to form a single West of England (WoE) Child Death Overview Panel (CDOP). The membership of the Panel (Appendix B) is arranged to ensure that there is the necessary level of expertise and experience, and that each LSCB is appropriately represented. During 2013/14, the WoE CDOP Chair has rotated from South Gloucestershire to Bristol LSCB. The Terms of Reference, Governance Arrangements, and Membership are summarised in documents available at [www.bristol.gov.uk](http://www.bristol.gov.uk). The Child Death Enquiries Office at the University of Bristol administers all functions of the WoE CDOP.

The WoE CDOP reviews information on every child who has died whose post code of residence is

<sup>2</sup> HM Government Department for Education (June 2013)

within its geographical boundary. Some of these deaths may occur outside the West of England. The WoE CDOP additionally reviews the deaths of non-resident children who may be under the care of a specialist paediatric medical or surgical team in Bristol.

A child's case is reviewed at the CDOP after it has been discussed at a local child death review meeting. Standard information on each child is collected on national Forms A and B during the child death review process. Form A is a basic notification form that has essential identifying information on the child and key professionals. Form Bs are completed by all agencies involved in the care of a child, and capture basic clinical and social data on the child and background information relating to the family. Additional Forms B2 –B12 capture specific data relating to the type of death (sudden infant death, life-limiting condition etc). Form B13 has information relating to post mortem findings. Form C is completed at the local Child Death Review meeting and aims to identify modifiable factors relating to the child's death, as well as highlight learning that arises from each case. All patient information is made anonymous. A detailed compilation of all data on Forms B & C on each child is presented to the CDOP as an anonymous case record. At CDOP meetings each case is reviewed and the Panel deliberates on the decisions reached at the local Child Death Review

meeting. The panel will agree any additions or amendments on a final Form C for each child. The CDOP Chair records recurring themes relating to modifiable factors.



## ● ● 5. Production of annual report (processing and verification of data)

This is the sixth Annual Report of the West of England CDOP. It was approved by the Panel on 9th July 2014 and will be presented to each of the four constituent LSCBs and will be a public document. Last year's Annual Report (2012/2013) can be found at:

<http://www.northsomersetlscb.org.uk/child-death-overview-panel.htm>

<http://www.bristol.gov.uk/page/children-and-young-people/bscb-protocols-multi-agency-action>

The report is produced using data collected by the Child Death Enquiries office. They enter Form A information on all children who die in the West of England region onto a **Notification database**. Information collected from Form Bs and both the local child death review and CDOP Form C (including a case summary) is entered into a separate **CDOP database**. The eventual CDOP

multiagency dataset on each child is extremely comprehensive. The dataset is verified through the following means:

- Weekly inquest returns from the Coroner's Office
- Information downloads from the I.T. departments at University Hospitals Bristol NHS Foundation Trust, and North Bristol NHS Trust
- Print outs from the Child Health System
- Office for National Statistics downloads from the General Registrars Office\*
- Post mortem reports
- Reports from BADGER
- Monthly reports from UH Bristol Trust Data Analysts

\* The returns from the GRO do not capture coroners' cases that have not yet proceeded to Inquest. Thus data presented through the child death review process is more complete and up to date than national statistics.



## 6. Summary Data (four year average from 2010 – 2014)

This section summarises all deaths notified to the Child Death Enquiry Office, between April 1st 2010 and March 31st 2014, of children who have died in the West of England area or of a child residing in the West of England area who has died elsewhere. These data are drawn from the Notification database. This allows us to present information as a rolling average across the last four years. Data presented as an average helps to “smooth out” the year on year variations that we expect if we are looking at rare events one year at a time.

### 6.1 Crude Death Rates

Table 1 shows the crude death rate per 10,000 children aged 0-17 years for the period 2010-14. The death rates for children resident in the LSCB areas of Bristol, BANES, South Gloucestershire and North Somerset appear to be quite different however all of their confidence intervals overlap. This means that any difference between areas could be due to chance and not a real difference in rates.

**Table 1** *Crude death rates by area, 2010/11 - 2013/14, four year average*

Region	Crude Rate per 10k	Lower Limit	Upper Limit
BANES	2.15	1.44	3.08
Bristol	3.58	2.98	4.26
North Somerset	3.24	2.43	4.22
South Gloucestershire	2.50	1.89	3.24
West of England	3.02	2.67	3.40

**Note: (1) 95% confidence intervals estimated using Byar’s approximation**

**(2) Due to non-release of 2013 mid-year population estimates, 2012 populations have been used as a proxy for 2013 figures.**

## 6.2 Analysis of notifications by year, 2010-2014

**Table 2** *Notifications by region of residence, 2010-2014*

Region	2010/11 Deaths	2011/12 Deaths	2012/13 Deaths	2013/14 Deaths
BANES	9	8	6	6
Bristol	23	30	40	33
North Somerset	16	16	10	12
South Gloucestershire	19	11	15	12
Other South West	43	50	40	37
Out of Region	10	14	12	11
Total	120	129	123	111

During the period 2010-2014, 483 child deaths were notified. Year on year variation in notifications is to be expected, and is demonstrated in Table 2. With relatively rare events such as child deaths, small variations each year can appear to represent a big difference.

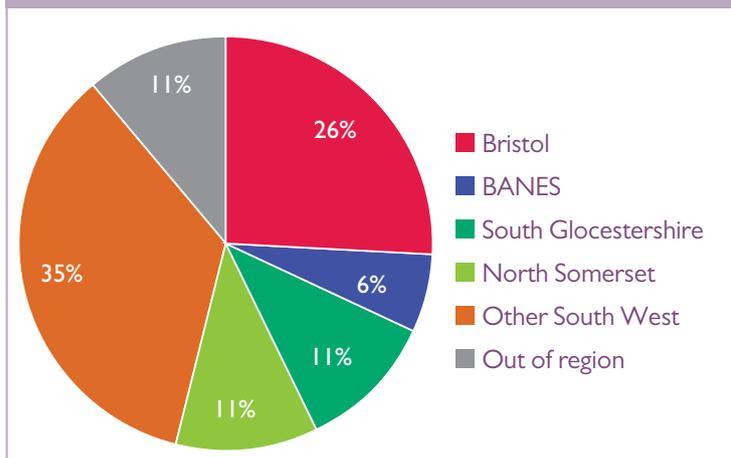
The deaths notified over the 4 year period are reported by area of residence and by year in Table 2.

Table 2 indicates that a large proportion of notifications each year come from areas outside the West of England region (BANES, Bristol, North Somerset and South Gloucestershire), either within the South West region ('Other South West') this includes Wiltshire, Gloucestershire, Somerset, Swindon, Devon, Dorset and Cornwall, or outside the South West region ('Out of Region') this includes South Wales and children visiting the area from other parts of the UK. This is because Bristol contains tertiary referral units

for neonates and children and specialist services including cardiology, oncology and neurology.

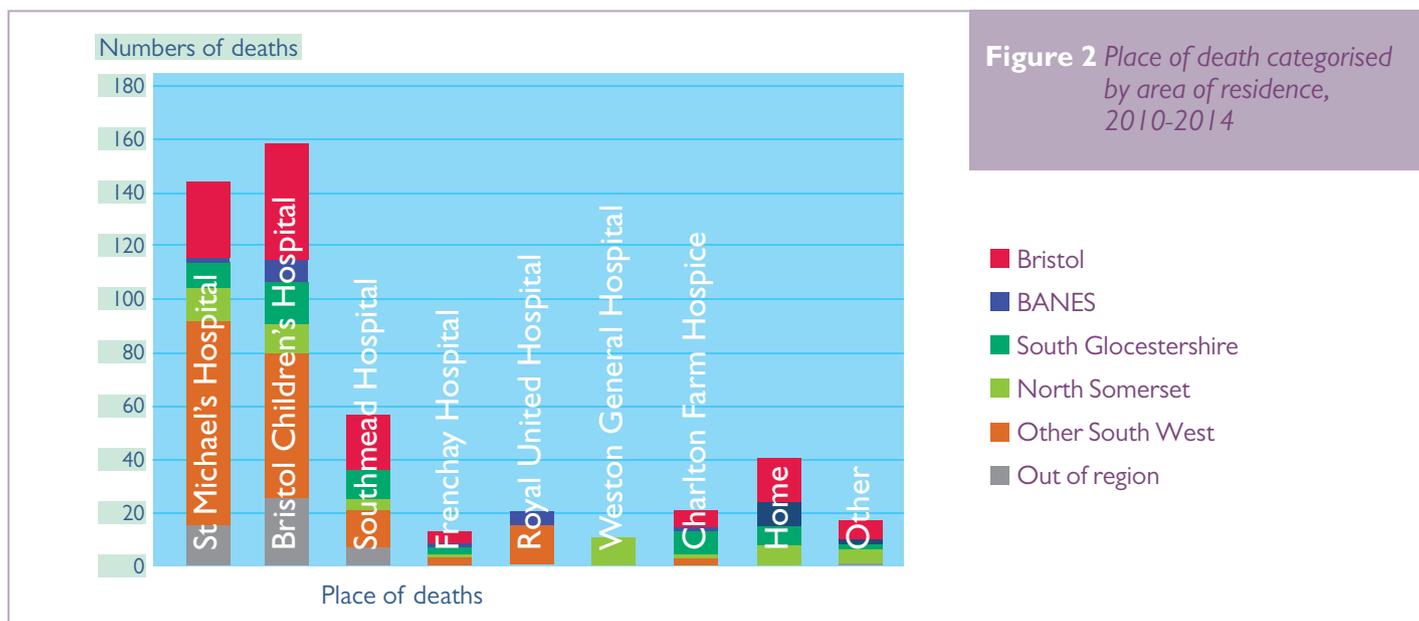
The numbers of notifications for any one area of residence are so small that the most likely explanation for any pattern is random year-on-year variation. However one should always try and exclude contributory factors such as differences in coding practice or an increase in a particular category of death. During the last 4 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 four-year period. It is therefore most unlikely that these variations in notifications within LSCBs reflect any particular underlying cause and as such they should not be over-interpreted.

**Figure 1** Notifications by area of residence, four year average, 2010-2014



### 6.3 Location of death

This data records where the child actually died. Over the four-year period (144/483) 29.8% of all child deaths occurred at St. Michael's Hospital, (158/483) 32.7% at the Bristol Children's Hospital, and (57/483) 11.8% at Southmead Hospital, (22/483) 4.5% died in a hospice, and (41/483) 8.4% died at home. Of the children who died at home, 65% (27/41) were unexpected deaths and 34% (14/41) were expected deaths (See section 6.9 for further information on expected vs unexpected deaths). (61/483) 12.6% died in other locations. Bristol contains tertiary referral units for patients with obstetric, neonatal and childhood illness. A large proportion of the deaths at the Bristol Children's Hospital, St Michael's Hospital and Southmead Hospital are in children who are resident outside of the West of England area, or outside the South West region, illustrating their importance as receiving hospitals for the sickest children who need access to specialist services (Figure 2). The categorisation of "Other" below, includes deaths that occur in public places, deaths abroad and deaths of West of England residents in other specialist hospitals out of the West of England region.



The precise location of death for children dying within hospitals in the West of England region in 2010-2014, is shown below in Table 3.

**Table 3** Number of children dying in different locations within West of England hospitals

Hospital	Paediatric/Neonatal Intensive Care Units (PICU/NICU)	Emergency Department	Children's Wards/Theatres/Central Delivery Suite	Adult ICU
Bristol Children's Hospital, University Hospitals Bristol	120 (PICU)	22	17	n/a
Royal United Hospital, Bath	3 (NICU)	8	10	0
St Michael's Hospital, University Hospitals Bristol	132 (NICU)	n/a	12	n/a
Southmead Hospital, North Bristol NHS Trust	45 (NICU)	n/a	12	0
Weston General Hospital	n/a	7	3	0
Frenchay Hospital, North Bristol NHS Trust	n/a	5	2	4

## 6.4 Age at Death

Using averaged 4 year data, the greatest proportion of notifications (27.9%) was received for babies dying in the early neonatal period (less than seven days of life) (Figure 3). Considering the neonatal period as a whole (0-28 days) 47.6% of deaths occurred during this time. Figure 3 shows that the first year of life is the most risky period of childhood, with 71% of deaths 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) and 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.

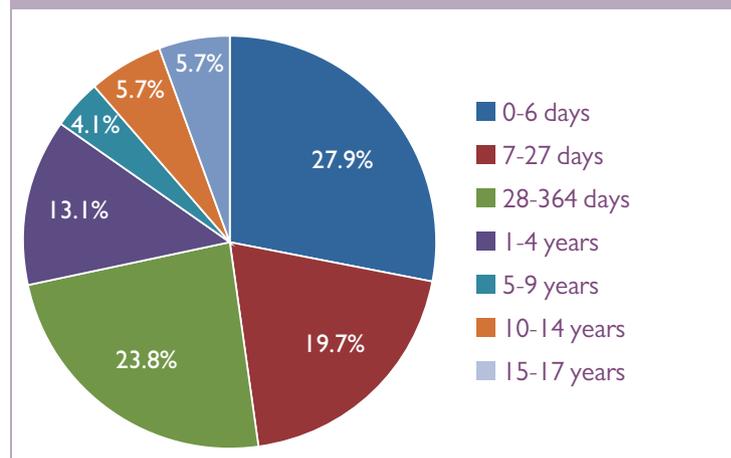
## 6.5 Gender

There have been more notifications of deaths in boys (57.7%) than girls (41.8%). This mirrors national data from the child death review process, with 57% of deaths reviewed occurring in boys nationally<sup>3</sup>. The data shows that boys are more likely to die from all causes.

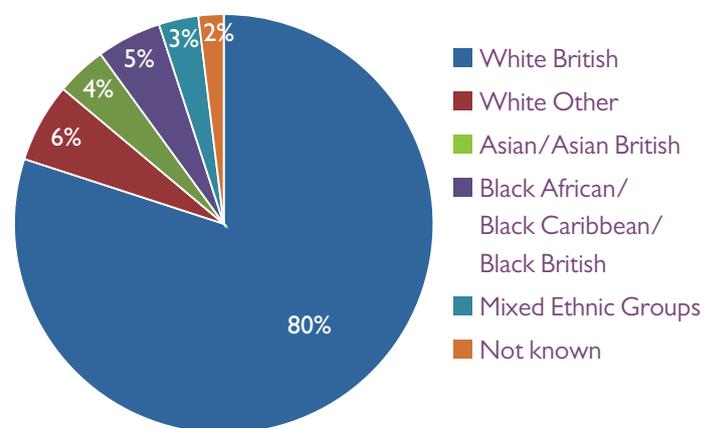
## 6.6 Ethnicity

There has been significant improvement made in completion of ethnicity data since 2011. For 2013-2014 we had completed ethnicity data for 96% of notifications.

**Figure 3** Notifications by age group  
(four year average) 2010-2014



**Figure 4** Notifications by ethnic group,  
2012-2014



<sup>3</sup> Department for Education Child Death Reviews:

Year Ending 31 March 2013, Department for Education, SFR/26/2013, 18th July 2013

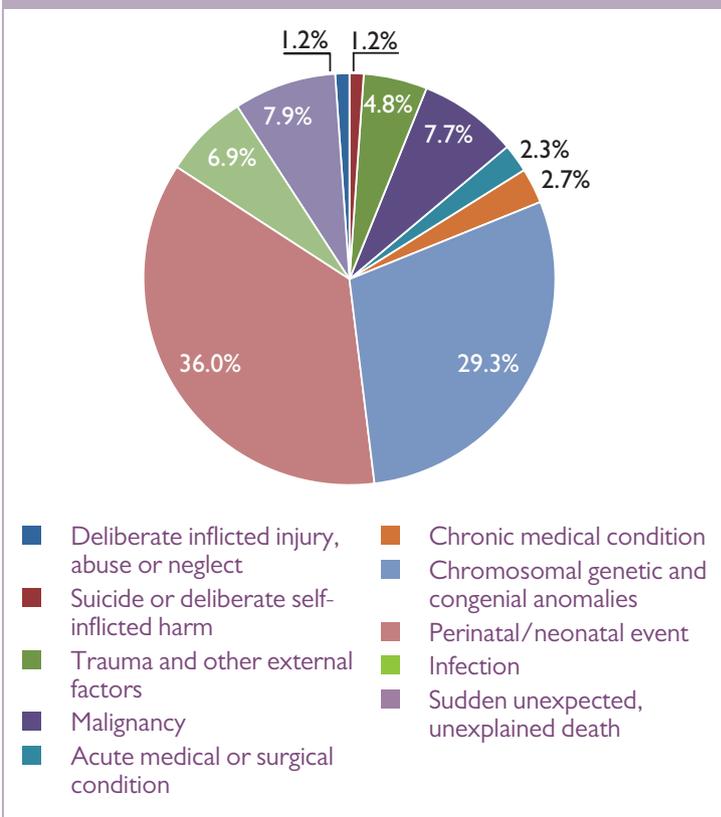
Figure 4 shows that 80% of notifications received by the Child Death Enquiries office between 2010-14 were for children of White, British origin. 6% of notifications were for children of White, Other origin. This includes children of European ethnicity. The number of notifications for children whose ethnicity was recorded as Black or Black British was 5% and the number of notifications for children whose ethnicity was recorded as Asian or Asian, British was 4%.

### 6.7 Category of Death

The Child Death Overview Panel is required to categorise each child death using a standard list of categories shown in Figure 5. During the four-year period, 36% of deaths were categorised as perinatal/neonatal events. The second most common cause was chromosomal, genetic or congenital abnormalities, with 29.3% of the deaths fitting into this category. Sudden unexpected, unexplained deaths (7.9%), malignancy (7.7%), infection (6.9%) and trauma (4.8%) comprise the next most common causes. Chronic medical conditions (2.7%), acute medical or surgical conditions (2.3%) deliberate harm by others (1.2%) or self (1.2%) are less common. Figure 5 shows the breakdown of childhood deaths for each category.

The same data can be grouped into categories as seen in Figure 6 where it is seen that perinatal/neonatal remains the largest category for

Figure 5 Notifications by category of death, 2010-2014

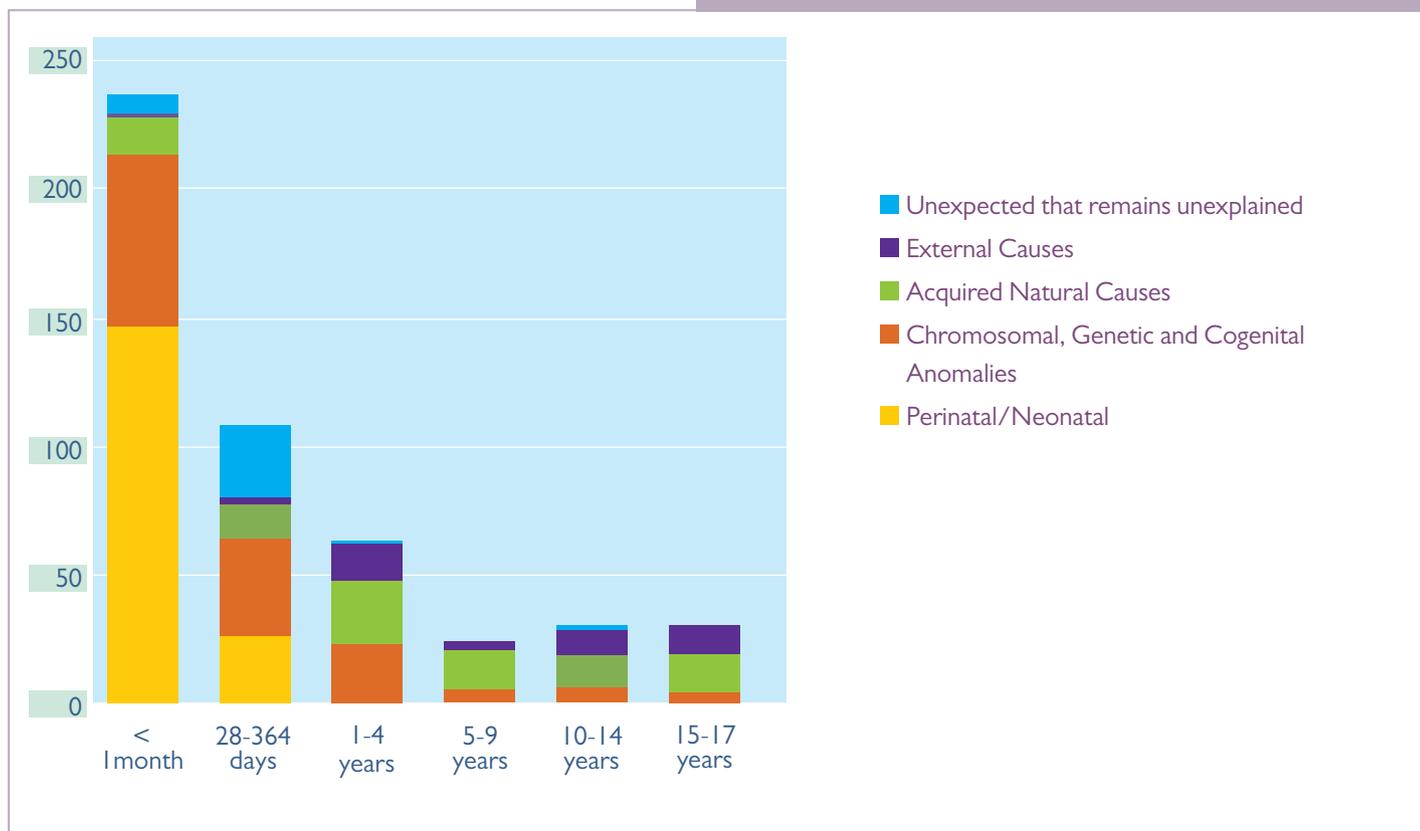


Note: The UK Office for National Statistics advises that care should be taken with regard to publishing small numbers of events in person-related statistics. This is due to the need to preserve confidentiality as there may be a risk that individuals could be identified.

<1 month olds, followed by chromosomal, genetic and congenital causes. ‘Acquired natural causes’ groups together malignancy, acute medical or surgical conditions and infection. ‘External causes’ groups deliberately inflicted injury, suicide, trauma and other external factors. It can be seen that in early childhood, 1-4 years, acquired natural causes and chromosomal,

genetic and congenital conditions predominate, but by later teenage years, ages 15-17, external causes are almost as frequent as acquired natural causes as cause of death.

**Figure 6** Causes of childhood death in cases notified between 2010 and 2014



## 6.8 Post mortem examinations

Post mortem examinations make an important contribution to explaining how a child dies and may be ordered by the Coroner or offered by the attending clinician when the circumstances surrounding the death remain unclear. Over the last four years detailed data was collected relating to the post mortem process. A Coroner's post mortem occurred in 152/483 deaths (31.4%) and a hospital post mortem occurred in

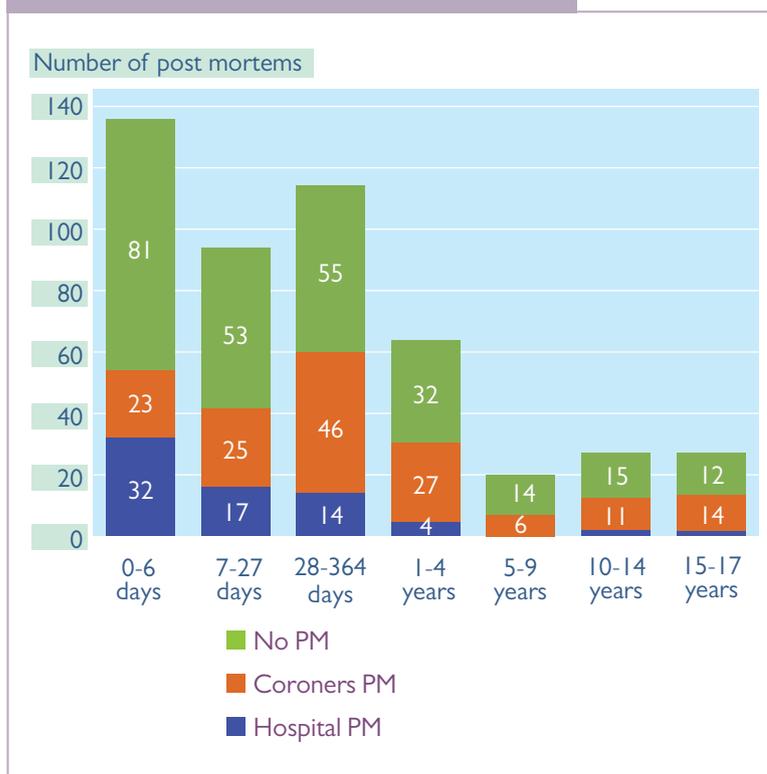
69/483 deaths (14.2%). 262/483 (54.2%) cases did not have a post mortem compared with 56.4% in the period 2010-2013. There was no hospital post mortems carried out in children over 5 years of age. Figure 7 below shows post mortems performed by age group.

## 6.9 Unexpected and Expected deaths

An unexpected death is defined as the death of an infant or 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. They are defined in the Notification database as deaths that were unexpected and triggered a rapid response. There has been one occasion where a rapid response should have happened but did not. This was due to the hospital of death being unfamiliar with the child death review protocols as they are primarily an adult facility. This issue has been addressed, and staff in this facility are now aware of the appropriate protocols.

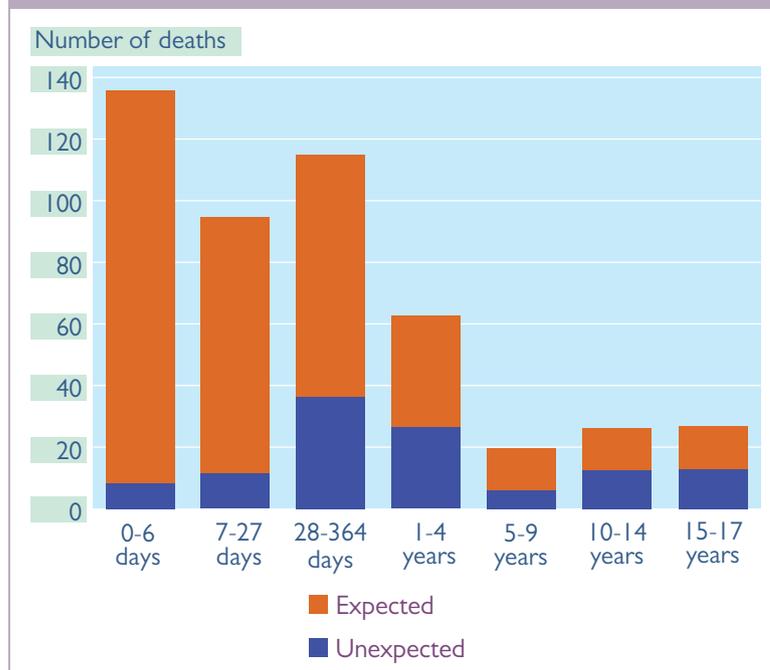
110/483 (22.7%) of deaths in children aged 0-17 years were unexpected. 34.5% of those unexpected deaths remained unexpected and unexplained after a full investigation and the local case review meeting. The main categories of these unexpected deaths can be broken down as follows:

**Figure 7** Post mortems performed by age (four year average) 2010-2014



**Table 4** *Causes of unexpected deaths of children 2010-2014*

Cause of death	% of total unexpected deaths
Sudden unexpected, unexplained death (including SIDS)	34.5
Trauma and other external factors (including road traffic accidents, drowning, deliberately inflicted harm and suicide)	32
Chromosomal, genetic and congenital anomalies	13.5
Infection	10
Other (including chronic and acute medical conditions)	10

**Figure 8** *Expected versus unexpected deaths by age group, 2010-2014*

It is worth noting that children with chromosomal, genetic and congenital anomalies often die in an unexpected fashion many years after their birth.

Over the four year period there were 373 expected deaths notified to the Child Death Enquiries Office. Of these deaths 292/373 (78%) were children under 1 year of age. The vast majority of expected deaths in children aged 0-17 years were categorised as due to perinatal/neonatal events (45.8%) or chromosomal, genetic or congenital anomalies (33.2%). 9.6% were due to malignancy.



## 7. Child Death Overview Panel Review Data

These data are drawn from the CDOP database (see Section 5). They summarise the Panel's review decisions for 2010-2014 and its actions for 2013-14. As explained previously, not all notifications received by the West of England Child Death Enquiry Office will be reviewed by the West of England CDOP. They will be reviewed by their local CDOP if it is deemed more appropriate.

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 local child death review 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.

**For these reasons the population of children described in Section 6 Summary Data (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).** This is illustrated in Table 5.

**Table 5** *The number of cases reviewed each year by year of death*

	2010/11		2011/12		2012/13		2012/14	
Total number of notification	120		129		123		111	
Number of cases to be reviewed by WOE CDOP*	72		79		81		69	
Years of review	Number reviewed	% of no. to be reviewed	Number reviewed	% of no. to be reviewed	Number reviewed	% of no. to be reviewed	Number reviewed	% of no. to be reviewed
2010/11	18	25						
2011/12	40	56	10	10				
2012/13	14	19	54	68	14	17		
2013/14	0	0	14	17	45	56	5	7
<b>Total</b>	<b>72</b>	<b>100</b>	<b>78</b>	<b>99</b>	<b>59</b>	<b>73</b>	<b>5</b>	<b>7</b>

\* this includes all children resident within the West of England area at the time of their death and selected specialist cases more appropriately discussed by the West of England CDOP e.g. those involving cardiac surgery

All cases of children who died prior to 1st April 2011 have been reviewed by CDOP.

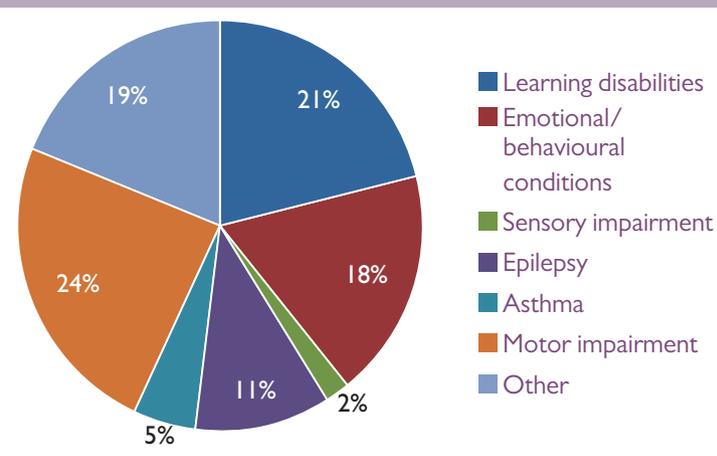
Sections 7.1 to 7.5 describe data relating to the 280 children reviewed by the West of England CDOP between 1st April 2010 and 31st March 2014. The data is drawn from the CDOP database into which all information from Form B, C, the local child death review meeting and final CDOP review is entered.

### 7.1 Other co-morbidities

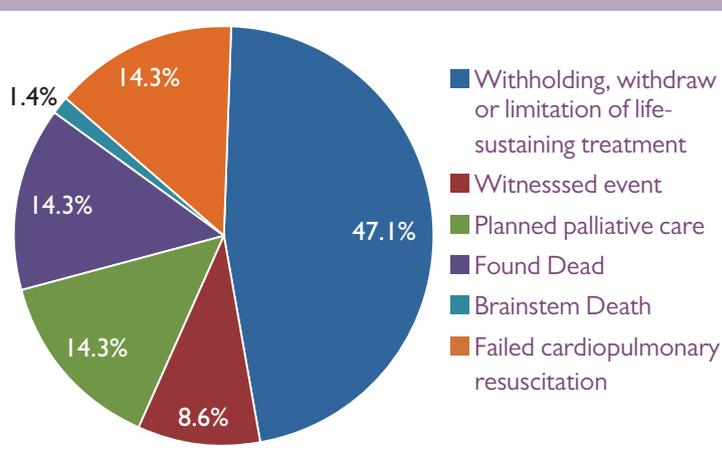
CDOP reviews information on co-morbidities in children who die. These are underlying conditions which, while not considered to be the direct cause of death, are thought to have contributed to vulnerability in the child. In some cases, the children reviewed in this section may have more than one co-morbidity. Of the 280 children reviewed, 152/280 (54%) had no co-morbidities at all and 128/280 (46%) had any co-morbidity.

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 9 details the figures for children who have at least one co-morbidity graded as a 2 or higher when reviewed by CDOP. In 66/128 (52%) of children with a co-morbidity CDOP graded the co-morbidity as a 1 as it had not

**Figure 9** Co-morbidities in children reviewed by CDOP and graded as 2 or higher (2010-2014)



**Figure 10** Mode of death of cases reviewed by CDOP (2010-2014)



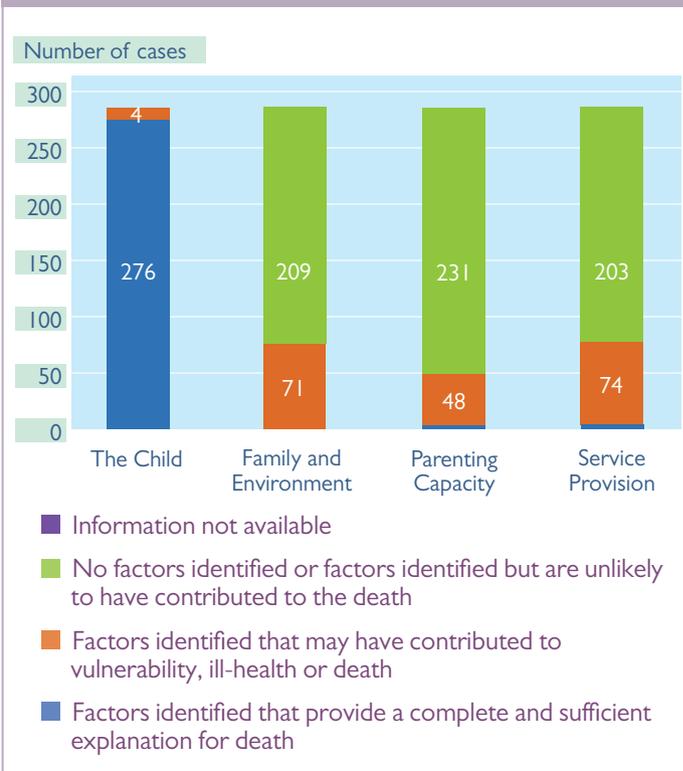
contributed to the ill-health or vulnerability of the child. The remaining 62 children had at least one co-morbidity graded as a 2 or higher. The data represented in Figure 9 relates to this cohort of children.

Within this cohort, children with a motor impairment 15/62 (24%) and children with a diagnosed learning disability 13/62 (21%) represent the most common co-morbidities thought to contribute to vulnerability. In 11/62 (18%) of cases reviewed, children suffered from an emotional or behavioural condition such as ADHD. Epilepsy was present in 7/62 (11%). 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.

## 7.2 Mode of death

The most common manner in which children died was following active withdrawal of life sustaining treatment most commonly in an intensive care situation (this decision is always made following careful consideration with the parents and carers). In 14.3% of cases the child was found dead, and in the same percentage of cases the child died following planned palliative care or failed cardio-pulmonary resuscitation. In 8.6% of cases a witnessed event was the mode of death. This includes road traffic collisions and other deaths by external causes.

**Figure 11** Contributory factors identified by CDOP (2010-2014)



## 7.3 Summary factors identified as contributing to death

Form C of the national dataset requires the local child death review meeting to identify and ‘grade’ factors that have contributed to the child’s death. The CDOP may amend this grading after full deliberation of the facts, to maintain consistency across cases, and this occurred in 77% of the 280 cases reviewed in the four year period.

Figure 11 shows that in 98.5% of cases reviewed between 1st April 2010 and 31st March 2014, factors intrinsic to the child (i.e. the underlying

medical or surgical problem) provided a complete explanation for the death. In 25% of cases, factors in the family and environment were identified that may have contributed to the vulnerability, ill health or death of the child, for example domestic violence or drug using parents. In 18% of cases factors in the parenting capacity were identified that may have contributed to the vulnerability, ill health or death of the child, for example poor parental supervision and in one case parenting capacity was thought to have provided a complete explanation for the death. In 26% of cases factors related to service delivery were identified that may have contributed to the vulnerability, ill health or death of the child. These included lack of timely senior medical review; lack of timely specialist medical review and delay in recognition of clinical deterioration. In 1% of cases factors related to service provision provided a complete explanation for the death of the child.

### 7.3.1 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, summarised on the Form C dataset at the local child death review meeting, and carefully reviewed at Panel. These are shown in Table 6. Of the 280 cases reviewed by CDOP between 1st April 2010 and 31st March 2014, parental smoking was noted to have contributed to the ill-health, vulnerability or death of the child in 7% of cases. Mental health issues in one or both parents were thought to have contributed to the ill-health, vulnerability or death of the child in 5% of cases. Mental health issues include maternal or paternal depression, previous self-harm and previous suicide attempts. Alcohol or substance misuse by one or both parents was also thought to have contributed to the ill-health, vulnerability or death of the child in 5% of cases. Housing issues were felt to be a significant factor

**Table 6** Factors in the family and environment recorded in cases reviewed by CDOP between 1st April 2010 and 31st March 2014

	Grade 1	Grade 2	Grade 3	Factor not present	% of cases where where factor considered to be significant
Emotional, Behavioural or Mental Health Condition in a parent or carer	40	14	0	226	5
Alcohol or Substance misuse by a parent or carer	15	15	0	250	5
Smoking by a parent or carer / Smoking by Mum during pregnancy	34	20	0	226	7
Housing	12	11	0	257	4
Domestic Violence	21	11	0	248	4

in 4% of the deaths reviewed. These issues were usually overcrowding and/or a chaotic or extremely unclean environment. Domestic violence was also thought to have contributed to ill-health, vulnerability or death in 4% of cases reviewed.

### ■ ■ 7.3.2 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. These are shown in Table 7.

Of the 280 cases reviewed between 1st April 2010 and 31st March 2014, CDOP concluded that poor parenting/supervision was a factor that had contributed to the ill-health, vulnerability or death of the child in 7% of cases. In 4% child abuse or neglect was judged to have contributed to the ill-health, vulnerability or death of the child. In a further 7% of cases reviewed, CDOP identified other factors which may have contributed to the ill-health, vulnerability or death of the child. These include poor parental engagement with antenatal services, missed appointments with specialist services e.g. cardiology and concealment of

pregnancy. CDOP also noted examples of positive parenting during review of cases.

### ■ ■ 7.4 Preventability – Modifiable Factors

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'. 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. The West of England CDOP has also regarded bed-sharing with parents known to be smokers to be a modifiable factor in cases of Sudden Infant Death Syndrome (SIDS).

In 179 of the 280 cases reviewed by the West of England CDOP in the four year period (64%) no modifiable factors were identified. In 101/280 (36%) cases modifiable factors were identified. Data from the Department for Education for the period 1st April 2012 to 31st March 2013 shows that nationally 21% of child deaths were found to be modifiable. However panels in the South West identified the highest proportion of modifiable

**Table 7** Factors in parenting capacity recorded in cases reviewed by CDOP between 1st April 2010 and 31st March 2014

	Grade 1	Grade 2	Grade 3	Factor not present	% of total where factor considered to be significant
Poor parenting/supervision	7	20	0	253	7
Child abuse/neglect	2	9	3	266	4
Other	25	19	0	236	7

factors in the child death reviews they completed (29%)<sup>4</sup>. This is due to the open scrutiny with which this panel seeks opportunities to learn from every case reviewed and the fact that factors considered to be modifiable may not be considered modifiable by other panels

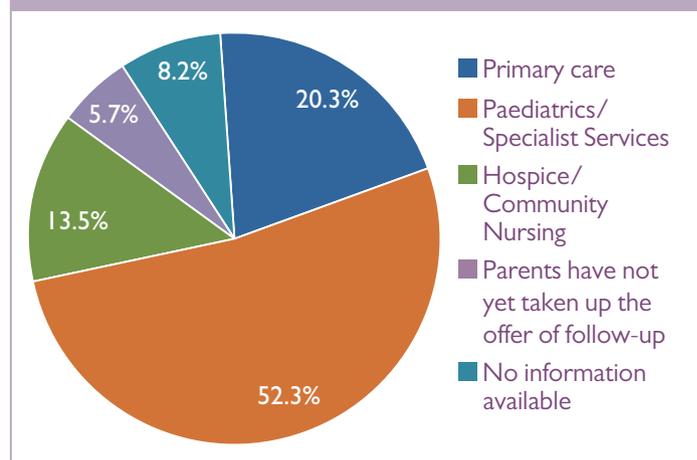
## ■ ■ 7.5 Family follow up

Active engagement with bereaved parents underpins the entire child death review process. Parental input into the child death review meeting should occur as a matter of course. Parents are invited to submit questions to the local child death review meeting, and feedback by the lead health professional on all aspects of this meeting is then given at a follow-up appointment with the family. Figure 12 shows the agency offering follow up to the families of children whose cases were reviewed by CDOP between 1st April 2010 and 31st March 2014. 52.3% of families received follow-up from paediatrics or specialist services. This includes obstetrics, neonatology, cardiology and oncology. 20.3% of families received follow up from primary care (GP or health visitor) and 13.5% of families received follow up from a hospice or community nursing organisation such as CLIC Sargent, the Lifetime Service or Jessie May. 5.7% of families were offered follow up but declined. In 8.2% of cases reviewed by CDOP the follow-up status of the family was unknown. In most cases this was because the family had moved out of the area following the death of the child. Families are routinely given

national and local information on charities offering bereavement support.

Despite the data recorded above, there is anecdotal evidence that families are not as fully informed of the child death review process as they should be, and that practice varies across hospitals and the community. It is noted that formal bereavement counselling is not within the remit of the national child death review process. However a bereavement nurse is funded as part of the service, primarily working with families on PICU at the Bristol Children's Hospital; some other hospitals have similar posts.

**Figure 12** Agency providing follow up to families in cases reviewed by CDOP between 1st April 2010 and 31st March 2014



<sup>4</sup> Department for Education Child Death Reviews: Year Ending 31 March 2013, Department for Education, SFR 26/2013, 18th July 2013

## 8. Focus on Sudden Unexpected Deaths in Infancy (SUDI)

### Definition of SUDI and SIDS:

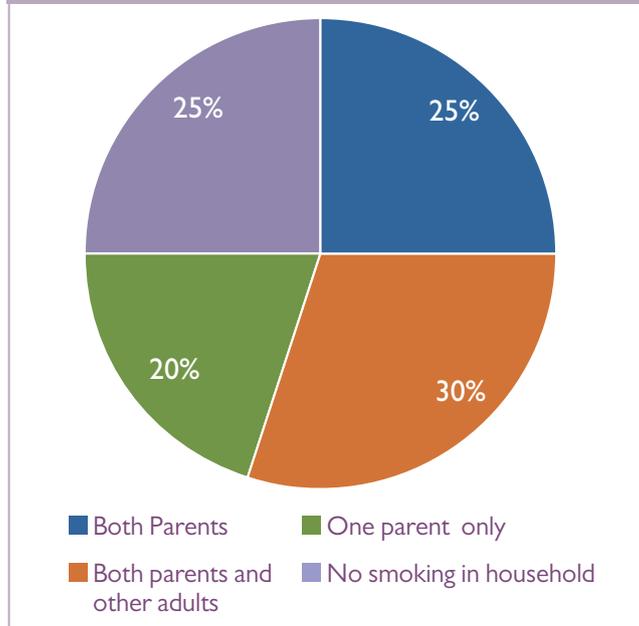
Sudden unexpected death in infancy (SUDI) can be considered an umbrella term that captures all unexpected infant deaths. Investigations following death, including post-mortem examination and full history taking by a medical professional, can often lead to an explanation which falls into one of the following:

- 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<sup>5</sup>.

In the period between 1st April 2010 and 31st March 2014 CDOP reviewed the deaths of 20 children who were categorised as SIDS.

Figure 13 Smoking Status of Households with a SIDS death



### Smoking

Several studies have shown that parents who smoke put the infant at increased risk of a SIDS death both in terms of prenatal and postnatal exposure. Figure 13 below shows the smoking status of households with a SIDS death in the above period. It shows that smoking rates are high (smoking occurs in three-quarters of households) and similar to the high rates observed amongst SIDS families in the 2003-6 case-control study in the South West of England<sup>6</sup>.

<sup>5</sup> Fleming, P., Blair, P., Bacon, C. and Berry, J. Sudden Unexpected Death in Infancy (2000)

<sup>6</sup> Blair Sidebotham et al. Hazardous co-sleeping environments and risk factors amenable to change: case-control study of SIDS in South West England. BMJ (2009)

## ■ ■ Co-sleeping

Since the UK ‘Back to Sleep’ Intervention campaign in the early 1990’s subsequent observational SIDS studies have shown a proportional increase in co-sleeping SIDS deaths (from 20% to 50%) although this seems to be related to a faster decline in solitary deaths occurring in a cot than an increase in the number of co-sleeping SIDS<sup>6</sup> deaths. No smoking in household. Specific hazards within the co-sleeping environment have been identified including an increased risk when infants co-sleep with smokers, next to adults who consume alcohol or sleep-inducing drugs and when co-sleeping occurs on a sofa<sup>7</sup>.

In our series 13/20 (65%) involve co-sleeping and for 10 out of 13 babies that were co-sleeping, there were additional risk factors, for example smoking in the household (9/13) alcohol/ substance use by the parent or carer the night the child died (2/13), the location of the baby within the co-sleeping environment (e.g. between parents)(1/13) co-sleeping with multiple individuals (parents and another sibling) (6/13) or the baby not put down to sleep in a supine position (4/13). Of the remaining 3/13, two were co-sleeping with both parents (the position of the child in the sleeping space was not known) and 1 with only one parent.

<sup>7</sup> Blair PS, Sidebotham P et al. Major changes in the epidemiology of Sudden Infant Death Syndrome: a 20 year population based study of all unexpected deaths in infancy. *Lancet* (2006.)

## ■ ■ Sleeping position

Rapid response professionals responding to the unexpected death of an infant routinely obtain information from the parents on the sleeping space of the child for their final sleep and the position the child was put down in and subsequently found in.

Table 8 below shows the sleeping space of the child for their final sleep. It shows that for almost half of children who die of SIDS (45%) an adult bed with another person is the final sleeping space.

In one case the sleeping position of the child was not known when put down or found, however in respect of the other 19 cases 68% of children were put down to sleep in the supine position, 10.5% of children were put down to sleep in the prone position and 10.5% on their side. When found 42% of children were in the supine position, with 21% found in the prone position and 26% were on their side. This is comparable with findings in the 2003-6 case-control study in the South West of England<sup>8</sup>.

**Table 8** *Sleeping space of the child for their final sleep*

Sleeping Space	Number of children
Adult bed with another person(s)	9
Cot, Crib, Carry Cot or Moses basket	5
Sofa	4
Other e.g. on the floor	<5

<sup>8</sup> Blair Sidebotham et al. Hazardous co-sleeping environments and risk factors amenable to change: case-control study of SIDS in South West England. *BMJ* (2009)

## ■ ■ Avon Clinico-pathological Classification <sup>9</sup>

This classification system is used in the West of England region to inform the participants in local child death review meetings for SUDI deaths, of the agreed significance to attach to various factors in the history, scene examination, post mortem findings or special investigations. In general the factors can be divided into:

- 1. Notable Factors** - features that are not normal, or which may possibly contribute in some way to an increased vulnerability of the baby or family, but are not linked in any obvious way to the pathway by which an infant may have become ill or died – e.g. minor malformations, preterm birth, being a twin or triplet.
- 2. Possibly or probable contributory factors** - features that possibly (IIA) or probably (IIB) contributed to significant illness or death in the infant, but which are not, in their own right identifiable as a sufficient or complete cause of the infant's death. – e.g. evidence of significant illness at the time of death; significant alcohol consumption by a bed-sharing adult; dangerous sleep environment. Factors in this category are those that have been shown to be consistently associated with an increased risk of SUDI, and for which a possible contribution to the causal pathway may be implicated.

- 3. Causal factors** - Features which, on their own, constitute a complete and sufficient “cause” of death, or which are likely (on balance of probability) on their own to have led directly to death in a large proportion of infants with this factor. – e.g. Overwhelming infection or major cardiac abnormality

CDOP reviews this classification at panel meetings and in the cases in this period the following classifications were agreed:

**Table 9** *Avon Clinico-Pathological Classifications*

Avon Clinico-Pathological Classification	Number of children
I: Notable Factors	2
IIA: Possible Contributory Factors	3
IIB: Probable Contributory Factors	8
III: Causal Factors	0

There were 7 cases in which no Avon Clinico-Pathological Classification was recorded.

<sup>9</sup> Blair PS, Byard RW, Fleming PJ. Sudden unexpected death in infancy (SUDI): suggested classification and applications to facilitate research activity. *Forensic Sci Med Pathol*. 2012 Sep;8(3):312-5.)



## 9. Child Death Overview Panel Activity

### 9.1 Actions arising from CDR/CDOP review of individual cases (*details are not presented to maintain confidentiality of personal information*)

**Effective governance procedures within organisations should ensure that significant factors are identified and managed through the local child death review process. The CDOP reviewed many cases where good practice had been identified.**

In order to ensure that issues identified at CDOP were rapidly disseminated through their constituent agencies, the Chairs of each Local Safeguarding Children Board within the West of England were sent the abridged minutes of each monthly meeting, and have CDOP matters as a standing agenda item at their Board meetings.

In certain cases, the CDOP sought assurance that a particular action arising from a child's death had been addressed. Table 10 summarises cases where issues were identified and followed up by the CDOP through the Chair or through individual agency leads.

**Table 10** *Actions arising and outcomes*

Case Description	Issue	CDOP Action	Response/evidence	Recommended National Learning
Deaths occurring as the result of trauma / unintentional injury	Availability of safety advice for parents	To contact local agencies regarding current advice to parents	Information received from AvonSafe confirming details of their current work plan and draft strategy. CDOP commented on this draft document.  Information received from the Canal and River Trust via the Coroner, regarding safety advice and their ongoing education programme	Recognition of the different ways in which different age groups of children interact with the environment
SUDI	Issue of changes to parental medications which have potential side effects impacting their ability to care for a child	To ensure adequate training of professionals in adult services to be aware of these issues when their patients have children in their care	Response received from named nurses confirming this issue is included in their safeguarding mandatory training updates.	Importance of training for professionals in adult services regarding the effects of medication on patients with children in their care.

**Table 10** *Actions arising and outcomes*

Case Description	Issue	CDOP Action	Response/evidence	Recommended National Learning
Sepsis	Primary care raised the issue of lack of clear information on safeguarding status of the child.	Contact LSCB Chair regarding the diverse systems for sharing child protection information in primary care	Response received from LSCB confirming they were aware of this issue and would continue to discuss ways of addressing it through their audit processes.	Uniform practice across GP surgeries to interpret and flag up information from social care
Meningococcal Meningitis	GP surgery, hospital ED and OOH service were not offered advice or prophylaxis by the HPA resulting in anxiety of staff	Although prophylaxis was not deemed to be necessary in this case CDOP wrote to the HPA highlighting this issue and asking for advice on how this service may be improved in the future	Response received agreeing to disseminate a general reminder to all acute trust teams the HPA works with to deliver advice and prophylaxis. Also to support training on health protection response to meningococcal disease to staff	Availability of advice about prophylaxis to all staff that come into contact with a child with meningococcal disease. Ongoing training of primary care in recognition of the sick child
Pulmonary Hypertension in children with Downs Syndrome	Lack of local screening for this condition	Liaison with respiratory paediatrics to develop a case for screening locally	Commissioners aware this is not provided locally	There are already RCPCH guidelines about this but evidence base is poor and further research is in progress
Malignancy	Good Practice: The child's GP agreed to be the Lead Professional for the end of life period and reflected on this experience in his submission to the CDR process	To write to the GP to commend him on his care and explain how helpful his submission was in reviewing the child's death	This practice was drawn to the attention of commissioners with recognition that individual GP practices do not always have capacity to provide this level of service	Continued development of multi-agency end of life care packages for children

**Table 10** *Actions arising and outcomes*

Case Description	Issue	CDOP Action	Response/evidence	Recommended National Learning
SUDI	Lack of funding for a formal Care of the Next Infant (CONI) scheme in the area. This scheme provides additional support to parents in the following pregnancy	To contact commissioners and the Clinical Lead at the local Trust to re-establish this service	Working Group in progress to re-establish this service	90% of community trusts in England, Wales and Northern Ireland currently use The Lullaby Trust CONI programme
Various deaths in hospital	There have been a few cases with a poor quality or absence of RCA provided to CDOP where deemed necessary	Write to relevant hospital trust to question quality/ existence of report	Alternative internal enquiries have taken place and CDOP has been satisfied that the relevant issues have been addressed	Importance of internal reviews within hospital trusts
Deaths of children receiving palliative care	Themed review of these cases by CDOP highlighted issues of medicine prescribing and administration, medical leadership, key working, end of life care at home, advanced care and parallel planning	CDOP to raise issues highlighted with Commissioners and relevant service providers	Comprehensive response received from Commissioners addressing each issue in turn and confirming current action including launch of a new informatics system to improve the quality of delivery of drugs at the end of life phase, implementation of a spot purchase model to support end of life care at home and recruitment of a palliative care consultant	Importance of CDOP process in highlighting these issues in cases where death may not have been modifiable, but lessons in provision of care have been identified

## ■ ■ 9.2 Themes emerging from aggregate review of cases at CDOP during the year April 2013 – March 2014

### ■ ■ Safe-sleeping advice

CDOP has reviewed safer sleeping leaflets and verbal information given to new parents and concluded that these messages are accurately represented. However parents do not always adhere to this advice. Research is ongoing into the factors influencing decisions about sleeping arrangements. Rather than changing local parent education strategies WOE CDOP have contributed this data to the current NICE review of co-sleeping which will make national recommendations

### ■ ■ Continuing training for professionals involved in the child death review process

This year has seen the development of some additional guidance for rapid response professionals and other agencies with responsibility for chairing local child death review meetings. This was identified as a local need due to the wide range of professionals who adopt the chairing role in this region and was designed to help to bring more consistency in the way in which these meetings are arranged and carried out. The new guidance is now available to any professionals involved in the CDR process and has been useful in ensuring the correct professionals are present to ensure a robust child death review discussion.

In addition the Designated Doctor for Children's Deaths in the West of England has met with

several specialist groups including paediatric cardiologists, paediatric emergency department consultants, community paediatricians and palliative care agencies. These meetings have been designed to further embed the CDR process within local agencies and to identify and address any issues specific to those agencies. For example increasing understanding of how the Form B contributes to the CDR discussions and case summary.

### ■ ■ Family follow-up

Follow-up for a family that have lost a child is an important part of the information reviewed by CDOP. Follow-up can be provided by many different agencies and can take many forms. Good follow-up includes giving the family an opportunity to meet with relevant professionals to answer questions about their child's death, discussions around the post-mortem and Coronial process (where relevant), including discussing post mortem results and signposting them to counselling/bereavement services.

UH Bristol Trust employs a bereavement nurse, funded through the CDR process, who is responsible for ensuring that families receive appropriate follow-up, should they wish to, after the death of their child. In addition to this post the CDE Office has arranged two training sessions by the Lullaby Trust on communicating with bereaved parents for a wide range of professionals and office staff who may have contact with family members. Feedback from these training sessions has been overwhelmingly positive and those who have attended have



reported that they have used the skills developed in these sessions since undertaking the training. CDOP has also recognised the differing needs of parents from a range of religious and cultural backgrounds and the need to support these families in the bereavement process. For example, the Children of Jannah is a charity that provides support to grieving Muslim families and education and training for professionals providing follow-up to them. Their information is now available through hospitals and community professionals to be passed onto Muslim families in this region.

#### ■ ■ The voice of the parents:

The voice of the parents/care givers and wider family members is vital during a child's care. CDOP has reviewed some cases in the last year where parents have found it difficult to be fully heard or informed and this has led to poor communication /integration of parents into the process of treatment for their child. CDOP has supported ongoing discussions to improve this within the local hospital trusts and other settings. Parents input after their child's death is integral to the CDR process and opportunities are provided to all parents to enable this. The most appropriate professional in contact with the family, including the CDE office in some cases, ensures that the questions and comments of parents are presented at the local child death review meeting

and fully addressed if this has not happened at an earlier stage. Parents have an opportunity to meet again with professionals following the meeting . The questions and comments of parents are also provided in the papers reviewed at CDOP.



## 10. Future priorities and challenges

The joint RCPCH, NCB and BACAPH report ‘Why Children Die 2014’<sup>10</sup> highlights again that the UK falls behind many other developed countries in child mortality, and in particular draws attention to social inequality and preventable deaths. CDOP will remain committed to highlighting learning from case examples in the West of England, as well as cumulative data, and through the LSCBs and other partner agencies, ensuring policies address these themes.

This year the report contains a theme on Sudden Unexpected Death in Infancy. Associated smoking and co-sleeping are two areas CDOP is committed to highlighting with appropriate parental advice and support. Some of the cases reviewed have highlighted the absence of a formalised Care of the Next Infant programme in Bristol, to support families in the next pregnancy. CDOP is active in emphasising the importance of this and working with clinicians and commissioners to find solutions.

CDOP notes the high quality of local Child Death Review meetings conducted in the West of England and continues to appreciate the time and expertise many professionals contribute to this. Supporting families and helping to answer their questions is integral to the CDR process. Training provided on chairing CDRs this year has emphasised this. Some of the cases reviewed are inevitably high profile, and efficient working relationships with other agencies is necessary, as well as maintaining the independence of the CDR process.

West of England CDOP processes and database received highly positive comments in a national report. The outcome of this was for the Healthcare Quality Improvement Programme to put out an invitation to tender for development of a national CDOP information system and database (as part of the Child Health Clinical Outcome Review Programme). We are pleased to note progress with this important issue to maximise potential of the data we collect, as part of a national dataset and learning.

We supply regular updates to Commissioners as well as annual presentations to the LSCBs. As local and partner agencies become more aware of the dataset arising from the CDR process, CDOP receive a large number of requests for data for service provision, audit and research purposes. This output demonstrates the potential for high quality data collection, but requires resourcing. There have been some changes within the admin team to support this, but future funding will need to be allocated if the current level of output continues. However CDOP wishes to prioritise this work, alongside actions prompted by individual cases, as a means of contributing to a wider understanding of the causes of child mortality.

<sup>10</sup> Kurinczuk, J. and Knight, M. (2013) Child Death Reviews Improving the Use of Evidence, Research Report, Department for Education, October 2013

## ●● Appendix A – West of England Rapid Response Audit

The Child Death Enquiries office at the University of Bristol audits the rapid response process on all unexpected deaths. Questions 1 to 11 are completed at the point of notification. Questions 12 to 20 are completed after the local case review meeting. Between 1st April 2013 and 31st March 2014 there were 16 deaths which required a

rapid response. Questions 1 to 11 have been completed for all of these deaths and questions 12 to 20 have been completed to date for 9 of them. For the other 7 cases we are waiting for the local case review meeting to be held, which is where the second part of the rapid response audit questionnaire will be completed.

Audit question		Response			
1	Time to notification of child's death	Within 12 hours <b>94% (15/16)</b>	Within 24 hours <b>6% (1/16)</b>	Longer	
2	Were appropriate investigations carried out?	Yes <b>100% (16/16)</b>		No	
3	Were the parents offered bereavement care and support?	Yes <b>100% (16/16)</b>		No	
4	Were the parents offered information about the post mortem?	Yes <b>100% (16/16)</b>		No	
5	Were the parents offered information about the rapid response process?	Yes <b>81% (13/16)</b>		No <b>19% (3/16)</b>	
6	Were the parents given contact numbers?	Yes <b>88% (14/16)</b>		No <b>12% (2/16)</b>	
7	Was an early multi-agency information sharing meeting held?	Yes <b>88% (14/16)</b>		No <b>12% (2/16)</b>	
8	When did this meeting occur?	< 4 hours <b>43% (6/14)</b>	< 24 hours <b>50% (7/14)</b>	24-28 hour <b>7% (1/14)</b>	Later
9	Did a joint agency home visit take place?	Yes <b>88% (14/16)</b>		No <b>6% (1/16)</b>	
10	Was a post mortem carried out?	Yes <b>100% (16/16)</b>		No	
					Single agency visit <b>6% (1/16)</b>

Audit question	Response			
11 When was the rapid response report received by the pathologist	Before PM performed <b>81% (13/16)</b>	After PM performed <b>12% (2/16)</b>	No report was written <b>6% (1/17)</b>	
12 Was there a final local case review meeting?	Yes <b>100% (9/9)</b>		No	
13 When did this meeting occur?	If PM < 4 weeks of PM report	If PM > 4 weeks of PM report <b>100% (9/9)</b>	If no PM < 4 months of child death	If no PM > 4 weeks of child death
14 If there was an inquest, did the LCR precede or follow the inquest	Precede <b>67% (6/9)</b>		Follow <b>22% (2/9)</b>	No Inquest <b>10% (1/9)</b>
15 Was a final report written to the coroner?	Yes <b>100% (9/9)</b>		No	
16 When was this report sent?	Within 2 weeks of LCR <b>89% (8/9)</b>	2-4 weeks <b>10% (1/9)</b>	1-2 months	Longer
17 Have all the Form Bs been received by the CDOP office?	Yes <b>100% (9/9)</b>		No	
18 When were Form Bs received?	Within 3 months <b>100% (9/9)</b>	3-4 months	4-5 months	Longer
19 Were the family informed of the outcome of the final LCR meeting?	Yes – meeting <b>45% (4/9)</b>	Yes – letter <b>33% (3/9)</b>	Yes – phone <b>22% (2/9)</b>	No
20 When were the family informed	Within 4 months of the death: <b>10% (1/9)</b>		Longer <b>89% (8/9)</b>	

## ●● Appendix B - CDOP membership April 2013 to March 2014

	Core member	LSCB/Organisation
Nominated Chair	Jimmy Doyle/Tony Melville	Bristol
Consultant in Public Health	Mark Pietroni	South Gloucestershire
Designated Doctor for Child Deaths	Mary Gainsborough	North Bristol NHS Trust
Coroner's Officer	Debra Neil	Bristol
Children's social care (until 01.09.13)	Catherine Boyce	Bristol
Children's social care (from 01.09.13)	Sadie Hall	North Somerset
Designated nurse for safeguarding children (until 01.09.13)	Sophia Swatton	BANES
Designated nurse for safeguarding children (from 01.09.13)	Lisa Harvey	South Gloucestershire
Midwifery	Julie Northrop / Esther Hatfield	UHB NHS Trust
Obstetrics	Sherif Abdel-Fattah	North Bristol NHS Trust
Neonatology	Paul Mannix	North Bristol NHS Trust
General Practice	Matt Hoghton	North Somerset
Police (until 01.09.13)	Leanne Pook	Avon & Somerset
Police (from 01.09.13)	Simon Crisp	Avon & Somerset
Bereavement Services	Claire Storey	SANDS
Acute Nursing	Ann Miller	UHB NHS Trust
Acute Paediatrician	Margrid Schindler / Nick Sargant	UHB NHS Trust
Ambulance Service	Ali Mann	SWAST

## Appendix C – UHB Financial Summary 2013/14

MPR = Multi-professional Review

BRCH – Bristol Royal Hospital for Children

RRT = Rapid Response team

PNM – Perinatal Mortality Meeting St Michael’s Hospital

### Child Death Review Costs for 2013/14

Description of Cost		Payment Due	£ Cost to UHB
Designated Doctor	MPR	1.5 Additional PA's	£15,800
Paediatric Lead – Bristol Children’s Hospital	BRCH	1 Additional PA	£11,312
Neonatology Lead - St Michael’s	MPR	1 Additional PA	£11,196
Neonatology Lead - Southmead	MPR	0.5 Additional PA	£7,562
Community Paediatricians	RRT	320 hours Total	£18,560
GP and ED Consultant Costs	MPR	Attendance at some panels	£4,457
Bereavement Nurse	BRCH		£19,612
UOB Senior Manager	MPR	21 hours per week	£30,796
UOB Secretarial Support	MPR/PNM	3 days per week	£21,640
Additional admin support to CDE Office	MPR	3 months	£655
UOB Secretarial Support	PNM	2 days per week	£9,808
UOB Secretarial Support – NBT Community Paediatricians	RRT		£2,500
NBT Psychology support	RRT		£3,100
<b>Sub-total</b>			<b>£156,998</b>
Local authority funding UOB office			
• Manager	MPR		£4982
• Administrative support	MPR/RRT		£20,333
<b>Total Costs</b>			<b>£182,313</b>





