

**WEST OF ENGLAND**

**CHILD DEATH OVERVIEW PANEL**

**April 2016 – March 2017**

**ANNUAL REPORT**

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## **1. Acknowledgement**

The compilation of this report has only been made possible with the help of the following individuals: Lynn Gibbons (Consultant in Public Health, South Gloucestershire Council) for providing data on crude death rates (2012-2017) for Section 6.1 and Vicky Slep for co-authorship of the report.

Mary Gainsborough

## 2. Foreword

I am very proud to report upon the work that has underpinned the production of this, the ninth Annual Report of the West of England Child Death Overview Panel. In addition to summarising the work and findings of the Panel for the period 2016/2017 we are pleased to present this important information within the context of a growing body of evidence created by the five year West of England CDOP dataset.

Our findings contribute to national statistical evidence and learning. I am pleased to attest to the quality of the information upon which our data, the analysis and key findings within this report is based. Every case has been subject to the most detailed scrutiny and professionals have consistently demonstrated candour and rigour in seeking to identify opportunities for modifications that may reduce the risk of future child deaths. In addition, the Panel is constantly alert to examples of exceptional practice that can be captured and shared.

Themes for our learning are presented within this report and the Panel has been scrupulous in pursuing all actions that have potential to improve future circumstances for our children and families. Where appropriate we have engaged constructively with individuals or bodies well placed to effect the required changes.

The main themes which have emerged in 2016/2017 have built, where appropriate, upon previous findings and are,

- Issues associated with Group A Streptococcal sepsis;
- Area based inequalities of healthcare provision;
- Potential for improvements to 24/7 End of Life care for children;
- Co-ordination of care for children with the most complex medical conditions and disabilities
- Lack of Care of the Next Infant Scheme.

These themes are described within this report and actions taken by the Board are summarised.

West of England CDOP benefits from the support of an experienced and committed staff within the Child Death Enquiry Office. The team is exceptionally led by Vicky Sleaf. In addition, Dr Mary Gainsborough Designated Doctor for Child Deaths has been a consistent and highly valued figure in the work undertaken. The active participation and skills of Board members and their level of scrutiny and determination to achieve continuous improvement has been of the highest quality. As a consequence of these features I am pleased to advise that this report sets out the findings of a hard-working and highly functioning Board which it is my privilege to chair.

Sally Lewis OBE



Chair of West of England CDOP  
Independent Chair 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 2015: Chapter 5 Child Death Review Processes<sup>1</sup>.
2. Crude death rates for the individual authorities across the West of England range from 1.98 to 3.70 per 10,000 children aged under 18. There is some variation between authorities with Bristol having the highest rate. This is likely to be due to multiple reasons e.g. social, economic and cultural.

#### **Data related to Child Death Notifications:**

3. 557 child deaths were notified to the West of England Child Death Enquiries Office between 1st April 2012 and 31<sup>st</sup> March 2017.
4. Between 2012 and 2017, 261/557 (47%) of children were not residents of Bristol, North Somerset, South Gloucestershire or Bath and North East Somerset (BANES). The great majority of these children were receiving specialist medical care in Bristol Children's Hospital or St Michaels Hospital (NICU).
5. Over the 5 year period, 82% died in hospitals, 10% in the parental home or in a relative's home, 6% in hospices and 2% in other locations.
6. Between 2012 and 2017, 70% of deaths occurred during the first year of life, 11% of deaths were of children ages 1-4, and rates then decrease in mid-childhood but are higher in ages 15-17 with 7% of deaths. Deaths in 1-4 year olds showed a continued decrease over the 5 year period.
7. 76% of deaths notified in the last 5 years were children expected to die and 24% of deaths in children aged 0-17 years were unexpected; 30% remaining unexplained after a full investigation and the local case review meeting. 34% of deaths due to perinatal complications (mostly extreme prematurity), and 28% children with chromosomal, genetic or congenital conditions. Acquired natural causes account for 21% and external causes, encompassing deliberate injury, suicide and trauma, accounted for 9%.
8. Between 2012 and 2017, 44% of children had a post-mortem examination and of these 69% had a Coroner's post mortem and the rest had a hospital post mortem.

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

9. The West of England CDOP reviewed 356 cases in detail between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017. 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 2012/13 and 2013/14 have now been reviewed.
10. The most common mode of death is following the active withholding, withdrawal or limitation of life-sustaining treatment, which occurred in 41% of cases.
11. 16% of children reviewed have another disability. In 76% of those the disability was felt to have contributed to the ill-health, death or vulnerability in the child
12. In 98.3% of cases, factors intrinsic to the child (i.e. the underlying medical or surgical problem) 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.
13. Factors that may have contributed to the vulnerability, ill-health or death were identified in the family in 29%, related to parenting capacity in 11% and in service provision in 28%. Parental smoking was classed as contributory in 8.4% of deaths, emotional, behavioural or mental health issues in 3.6% alcohol or substance abuse in 3.9%, housing issues in 2.8%

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

and domestic violence in 3.6%. It should be highlighted that positive parenting was noted in many cases.

14. CDOP identified 'modifiable factors' in 32%. 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 may be 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
15. Family bereavement follow-up was documented in 95% of cases, with hospital or specialist paediatrics providing this in 43% of cases, primary care in 14% and hospice/community nursing in 19%. In 3% the offer of follow-up had been declined, and no information was available in 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 deaths of children with life-limiting conditions**

16. Between 1st April 2012 and 31<sup>st</sup> March 2017, deaths of children with life limiting conditions (LLC) accounted for 21% of child deaths.
17. In 71.6% an end of life (EOL) plan was in place when the child died. 73% died in the family's location of choice. Most died from natural progression of the underlying disease. 50% had a named EOL care coordinator. In the last 3 years 33/52 (63.5%) had a symptom management plan in place.

#### **Service improvement issues:**

18. Some service improvement actions were taken as a direct result of discussion at the local child death review meeting and in some cases exceptional practice was commended.
19. Important issues highlighted by CDOP were disseminated through the constituent agencies and the chairs of the Local Safeguarding Children Boards.
20. Issues noted at CDOP led to specific actions in some cases:
  - Exploring how to ensure safe sleeping advice is given to fathers as well as mothers
  - Improved information sharing when a Serious Case Review is being carried out
  - Improving the availability of specialist reports when children are seen in other health settings
  - Ensuring discussion with social care in cases of concealed pregnancy
  - Explore whether road design processes take into account proximity of cyclists
  - Explore remit of NHS 111 in providing resuscitation advice

#### **Themes**

21. Certain themes have emerged from reviewing children's deaths in the West of England this year:
  - A number of deaths from Group A streptococcal infection were noted and although not necessarily modifiable individually these are important for Public Health strategy and future research opportunities
  - The Panel has been aware of some inequalities of health provision across the areas within Wets of England, and this year noted cases illustrating a difference in provision of pre-hospital care and in staff experience in managing paediatric resuscitation situations.
  - Choice of place of End of Life care is sometimes limited by the lack of availability of community based palliative care

- Coordination of hospital care for those with complex medical needs
- There has been no formal support for parents in the next pregnancy after a sudden unexpected death in infancy although CDOP have now been able to support a pilot Care of the Next Infant programme

### **Achievements and Future Priorities**

#### 22. Achievements and Future Priorities

- RCPCH State of Child Health 2017 report draws attention to higher child mortality rates in the UK compared to similar European countries, and sets out a strategy in response to this.
- The Children and Social Work Act 2017 paves the way for changes to the Child Death and CDOP processes, and Bristol continues to be seen nationally as an example of good practice.
- Maintaining the quality of local Child Death Review meetings, and engagement of professionals in the process. CDOP has a role in ensuring families questions are addressed and that appropriate bereavement support is offered
- Sharing data with partner agencies through presentations and reports and in some cases, data requests.

#### 4. The Child Death Review Process

Since April 1<sup>st</sup> 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 2015: 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 (2015) 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 LSCBs (Bristol, North Somerset, South Gloucestershire and Bath and North East Somerset) have come together to form a single West of England (WoE) 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 2016/17, the WoE CDOP Chair has rotated from North Somerset to South Gloucestershire 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 within its geographical boundary. Some of these deaths may occur outside the West of England. The WoE CDOP additionally reviews the deaths of some 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 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

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

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 ninth Annual Report of the West of England CDOP. It was approved by the Panel on 12<sup>th</sup> July 2017 and will be presented to stakeholders including representatives from the 4 LSCBs on 28<sup>th</sup> September 2017. It will be a public document. Previous year's Annual Reports can be found online.

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 Registrar's 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.**

**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.

## 6. Summary Data (five-year dataset from 2012 – 2017)

This section summarises all deaths notified to the Child Death Enquiry Office, between April 1<sup>st</sup> 2012 and March 31<sup>st</sup> 2017, 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 total across the last five years. Data presented this way 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 below shows the crude death rate per 10,000 children resident in the West of England area aged 0-17 years for the period 2012-17.

**Table 1: Crude death rate per 10,000 children aged 0-17 (2012-2017)**

	Crude Rate per 10,000	Lower Limit	Upper Limit
BANES	1.98	1.37	2.76
Bristol	3.70	3.16	4.30
North Somerset	2.50	1.87	3.27
South Gloucestershire	2.45	1.91	3.09
West of England	2.89	2.59	3.22

Notes: (1) 95% confidence intervals estimated using Byar's approximation

(<http://www.apho.org.uk/resource/view.aspx?RID=48457>)

(2) Due to non-release of 2016 mid-year population estimates 2015 populations have been used as a proxy for 2016 figures

(3) Figure for count of deaths taken from WOE annual report data provided by Child Death Enquiries Office

The crude death rates and corresponding confidence intervals overlap for BANES, North Somerset and South Gloucestershire indicating there is unlikely to be a significant difference between these areas. The rate and confidence interval for Bristol is higher than BANES and South Gloucestershire, but similar to North Somerset. The reasons behind the higher crude death rate in Bristol compared to some of the other localities is likely to be multi-factorial.

## 6.2 Analysis of notifications by year, 2012-2017

During the period 2012-2017, 557 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 5 year period are reported by area of residence and by year in Table 2.

**Table 2: Notifications by region of residence, 2012-2017**

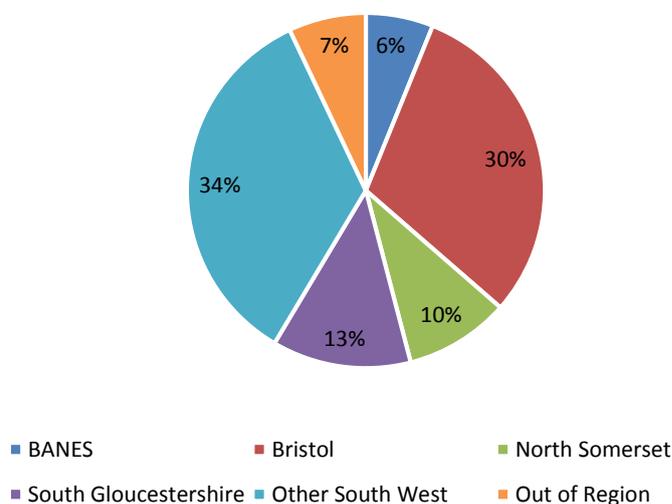
Region	2012/13 Deaths	2013/14 Deaths	2014/15 Deaths	2015/16 Deaths	2016/17 Deaths
BANES	6	6	8	8	6
Bristol	43	30	31	35	28
North Somerset	10	13	6	14	9
South Gloucestershire	15	12	12	13	18
Other South West	43	37	37	36	40

Out of Region	12	14	9	3	1
<b>Total</b>	<b>129</b>	<b>112</b>	<b>103</b>	<b>109</b>	<b>102</b>

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, 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. From 2015 CDOP discontinued collecting data and reviewing deaths on children resident in South Wales who died in a Bristol hospital.

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, CDOP should always try to exclude contributory factors such as differences in coding practice or an increase in a particular category of death. During the last 5 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 five-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, 2012-2017**

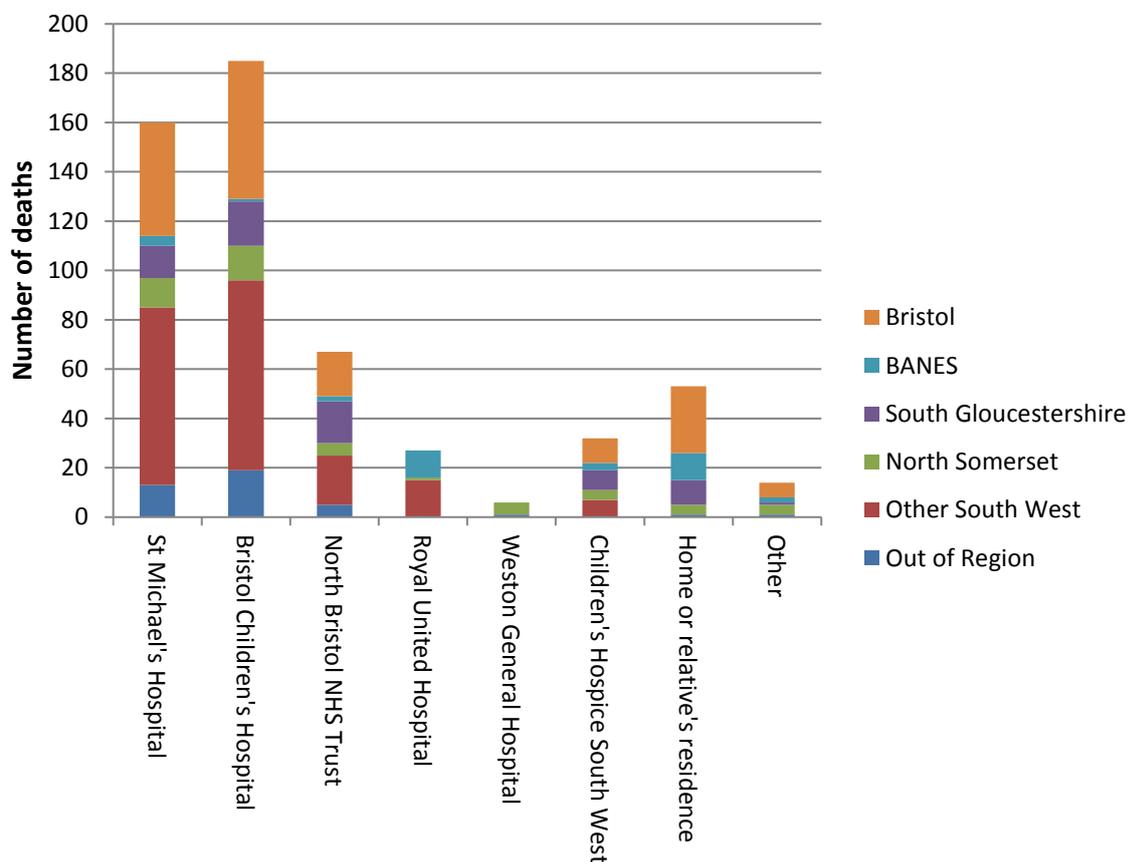


### 6.3 Location of death

This data records where the child actually died. Over the five-year period (185/557) 33% of all child deaths occurred at the Bristol Children's Hospital, (160/557) 29% at St. Michael's Hospital, (67/557) 12% at hospitals within North Bristol NHS Trust (Southmead and formerly Frenchay Hospitals), (32/557) 6% died in a hospice, and (55/557) 10% died at home or at a relative's residence. Of the children who died at home or at a relative's residence, 69% (38/55) were unexpected deaths and 31% (17/55) were expected deaths (See section 6.9 for further information on expected vs unexpected deaths). (46/557) 8% died in other hospitals and (12/557) 2% died in other locations. This includes deaths abroad and deaths in public places e.g. road traffic

collisions. Bristol contains tertiary referral units for patients with obstetric, neonatal and sub-speciality paediatrics. 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).

Figure 2: Place of death categorised by area of residence, 2012-2017



The precise location of death for children dying within hospitals in the West of England region in 2012-2017, is shown below in Table 3.

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

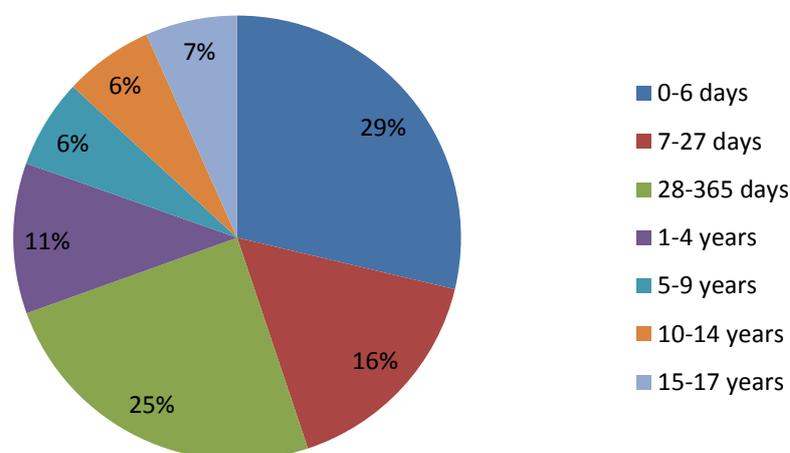
Hospital	Paediatric/Neonatal Intensive Care Units (PICU/NICU)	Emergency Department	Children's Wards/Theatres/Central Delivery Suite	Adult ICU
Bristol Children's Hospital, University Hospitals Bristol	132 (PICU)	28	26	n/a
Royal United Hospital, Bath	7 (NICU)	4	16	0
St Michael's Hospital,	143 (NICU)	n/a	17	n/a

<b>University Hospitals Bristol</b>				
<b>North Bristol NHS Trust Hospitals</b>	38 (NICU)	3	24	4
<b>Weston General Hospital</b>	n/a	5	1	n/a
<b>Other Hospitals</b>	5	2	2	1

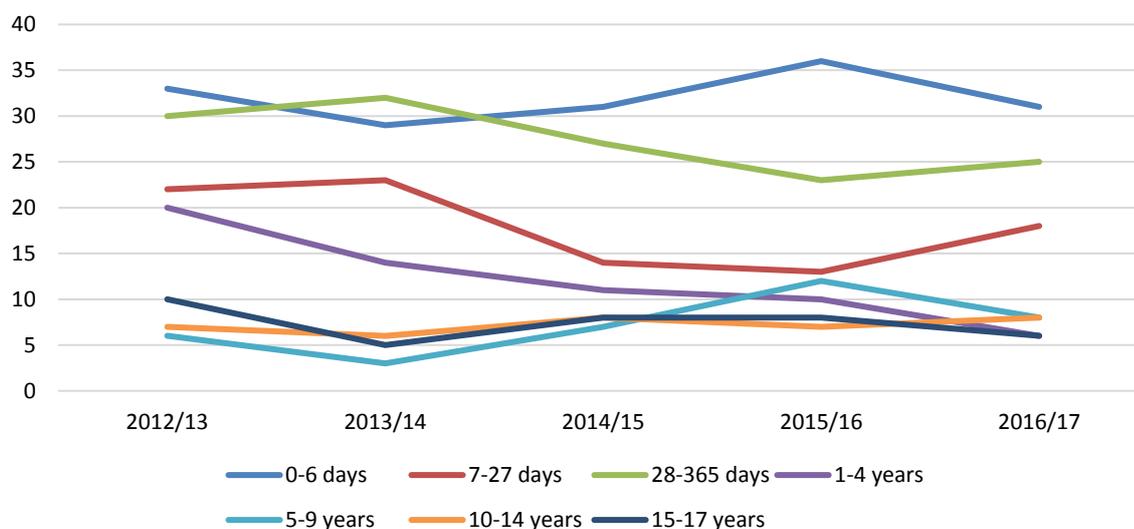
#### 6.4 Age at Death

Using 5 year data, the greatest proportion of notifications (29%) were 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) 45% of deaths occurred during this time. 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. Figure 3 shows that the first year of life is the riskiest period of childhood, with 70% of deaths occurring during this period. 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.

Figure 3: Notifications by age group, 2012-2017



We can also look at the trends in deaths by age group over the five year period in the line graph in Figure 4 below. This shows that the number of deaths in the 7-27 day age group, which had shown a consistent decrease over the last 3 years has seen an increase this year, whereas the 0-6 day age group which had seen an increase over the last 3 years has decreased this year. A continuing decrease in the numbers of deaths of 1-4 year olds is observed. This has been a year on year drop from 20 deaths in 2012-13 to 6 deaths this year.

**Figure 4: Line Graph to show the trends in notifications by age over the 5 year period:**

### 6.5 Gender

There have been more notifications of deaths in boys (55%) than girls (45%). 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.

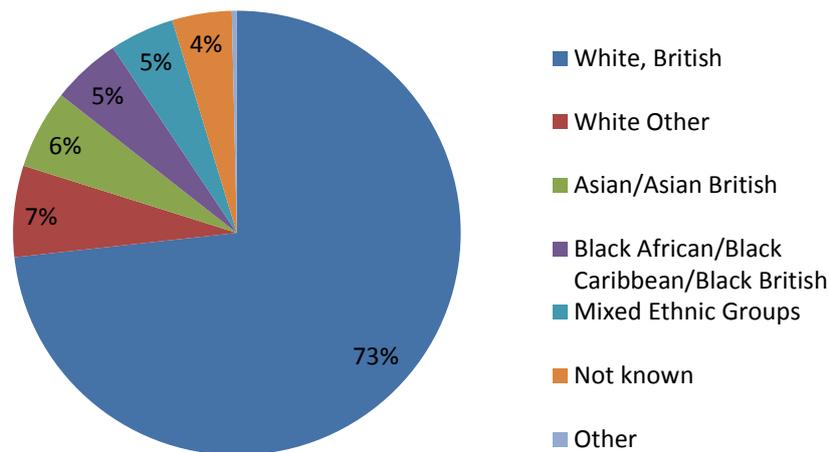
### 6.6 Ethnicity

Figure 5 shows that 73% of notifications received by the Child Death Enquiries office between 2012 and 2017 were for children of White, British origin. 7% 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 Asian or Asian British was 6% and the number of notifications for children whose ethnicity was recorded as Black or Black British was 5%. No background population data was available to compare these figures to and therefore no conclusions can be drawn from this data.

The ethnic make-up of the different LSCB areas in West of England is diverse, making direct population comparison difficult.

**Figure 5: Notifications by ethnic group, 2012-2017**

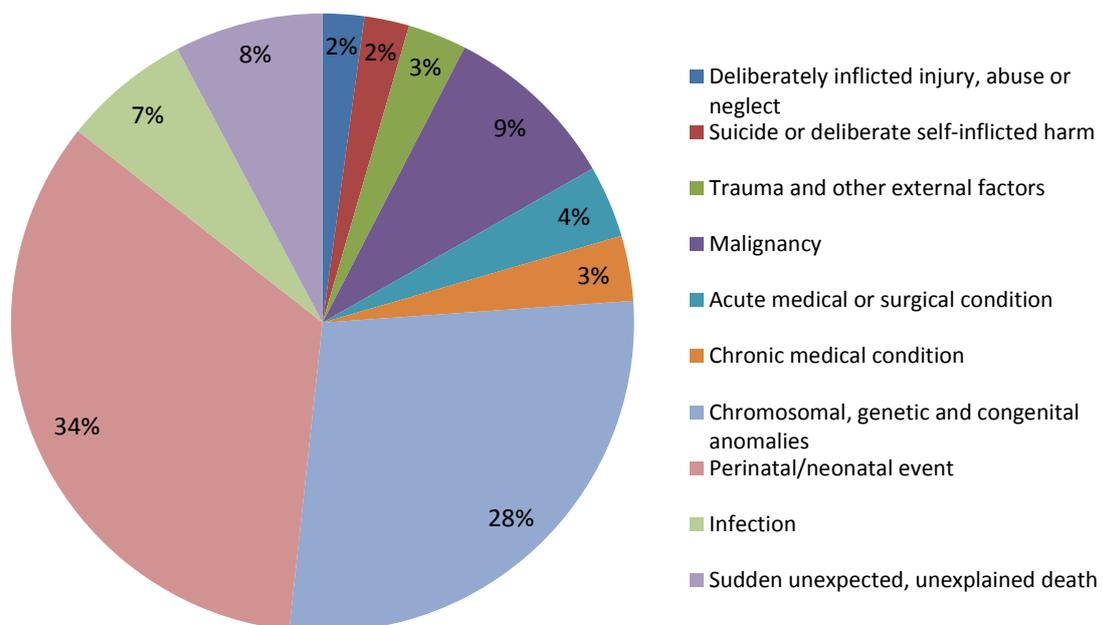
<sup>3</sup> Department for Education *Child Death Reviews: Year Ending 31 March 2013*, Department for Education, SFR 26/2013, 18<sup>th</sup> July 2012



### 6.7 Category of Death

The CDOP is required to categorise each child death using a standard list of categories shown in Figure 6. During the five-year period, 34% of deaths were categorised as perinatal/neonatal events. The second most common cause was chromosomal, genetic or congenital abnormalities, with 28% of the deaths fitting into this category. Malignancy (9%), Sudden unexpected, unexplained deaths (8%), Infection (7%) and Acute medical or surgical condition (4%) comprise the next most common causes. Chronic medical conditions (3%), Trauma (3%) Suicide or self-inflicted injury (2%) and Deliberate harm by others (2%) are less common. Figure 6 shows the breakdown of childhood deaths for each category.

Figure 6: Notifications by category of death over the 5 year period, 2012-2017



The same data can be grouped into categories as seen in Figure 7 where it is seen that perinatal/neonatal remains the largest category for <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 7: Causes of childhood death in cases notified between 2012 and 2017**

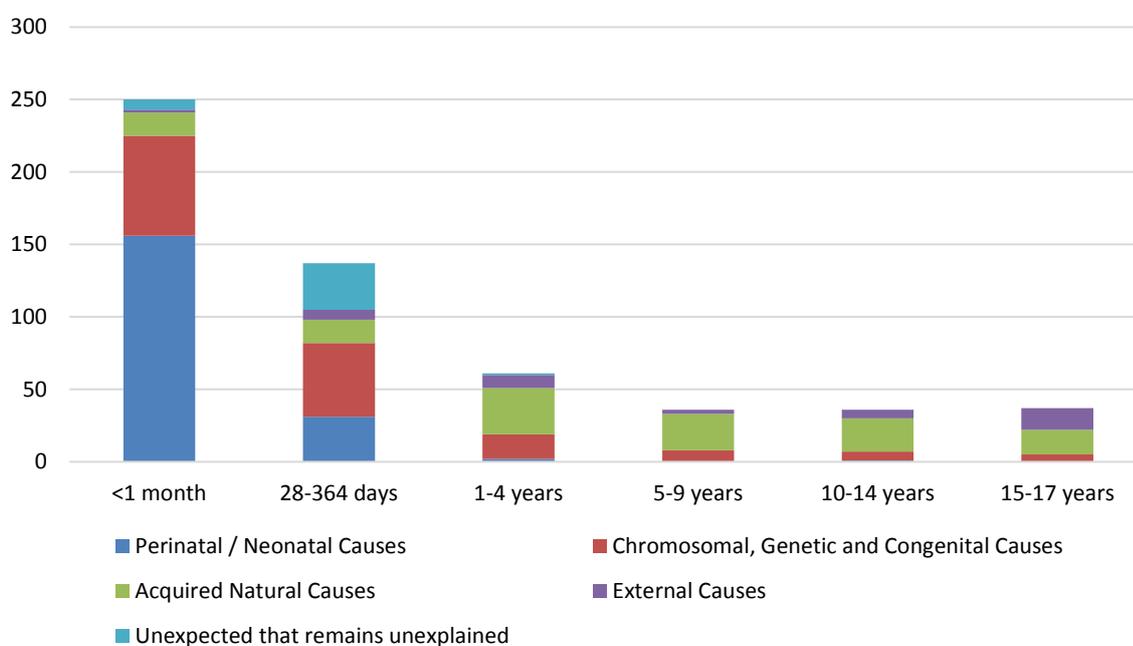
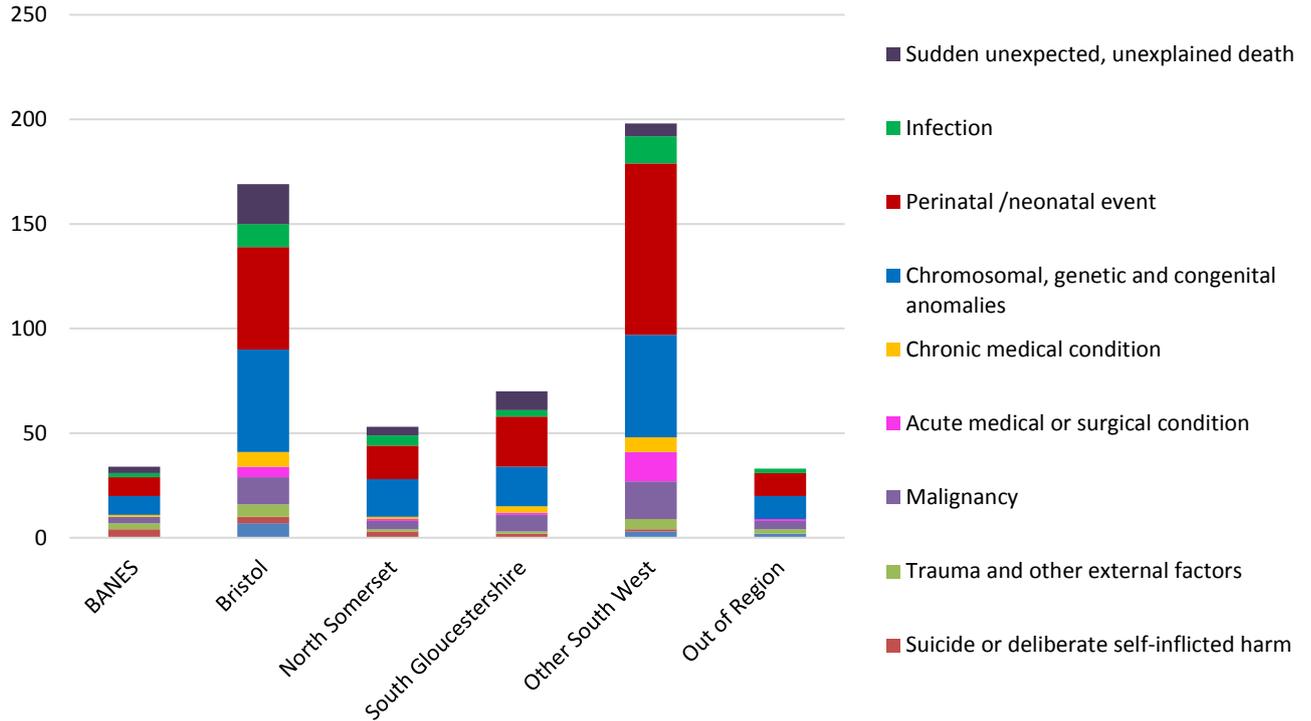


Figure 8 below shows the causes of childhood death for each of the LSCB areas within the WoE CDOP, together with those recorded for non-resident children who died within the West of England area.

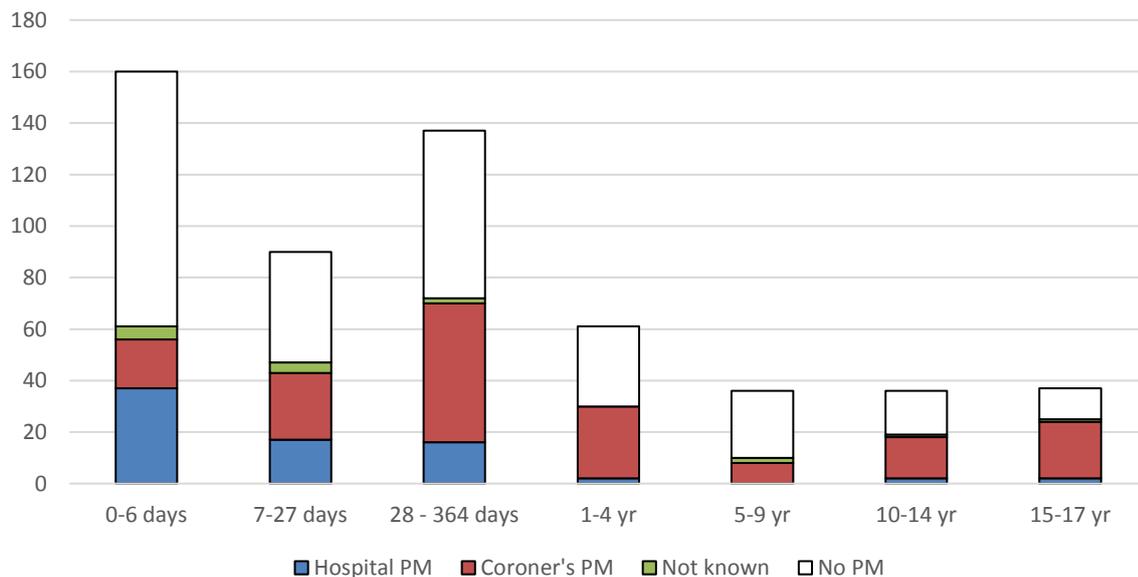
**Figure 8: Causes of childhood death by area of residence, 2012-2017**



### 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. Detailed data is collected relating to the post mortem process. A Coroner’s post mortem occurred in 173/557 deaths (31%) and a hospital post mortem occurred in 76/557 deaths (14%). 293/557 (53%) cases did not have a post mortem. In 15/557 (2%) it was not known if the child had a post-mortem examination. There were no hospital post mortems carried out in children in the 5-9 year age group. Figure 8 below shows post mortems performed by age group.

**Figure 8: Post mortems performed by age, 2012-2017**



## 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.

134/557 (24%) of deaths in children aged 0-17 years were unexpected. 44/134 (33%) of those unexpected deaths remained unexpected and unexplained after a full investigation and the local child death review meeting. The main categories of these unexpected deaths can be broken down as follows:

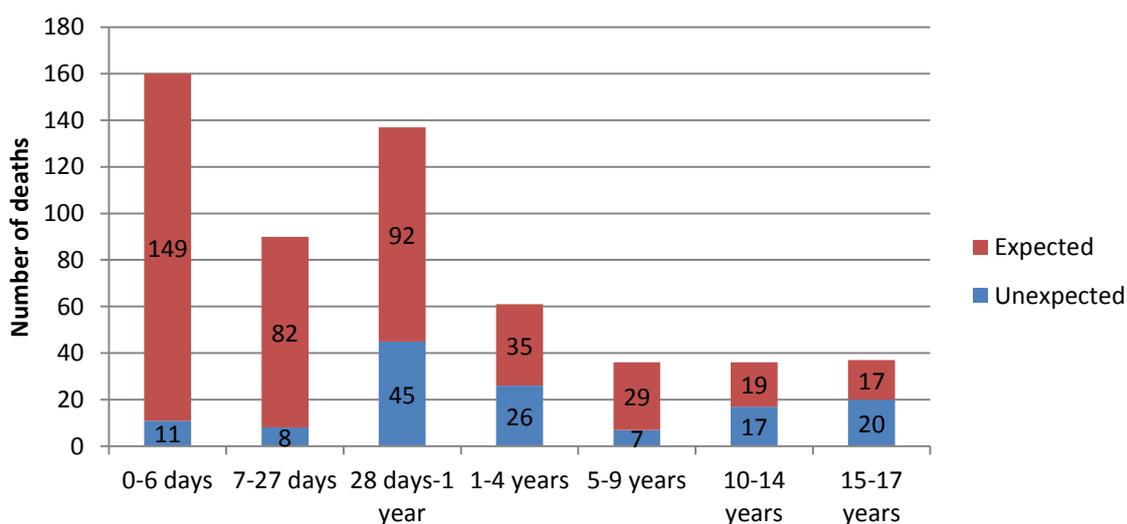
**Table 4: Causes of unexpected deaths of children 2012-2017**

Cause of death	% of total unexpected deaths
Sudden unexpected, unexplained death (including SIDS)	33
Trauma and other external factors (including road traffic accidents, drowning, deliberately inflicted harm and suicide)	32
Other (including chronic and acute medical conditions)	16
Chromosomal, genetic and congenital anomalies	10
Infection	9

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

Over the five year period there were 423 expected deaths notified to the Child Death Enquiries Office. Of these deaths 323/423 (76%) 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 (43%) or chromosomal, genetic or congenital anomalies (33%). 11% were due to malignancy.

**Figure 9: Expected versus unexpected deaths by age group, 2012-2017**



## 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 2012-2017 and its actions for 2016-17. 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**

	2012/13		2013/14		2014/15		2015/16		2015/16	
<b>Total number of notifications</b>	128		112		106		109		109	
<b>Number of cases to be reviewed by WOE CDOP</b>	82		66		60		72		72	
<b>Years of Review</b>	<b>Number reviewed</b>	<b>% reviewed</b>								
2012/13	15	18								
2013/14	45	55	5	8						
2014/15	20	25	46	70	5	8				
2015/16	2	2	15	22	42	70	12	17		
2016/17	0	0	0	0	9	15	49	68	8	13
<b>Total</b>	<b>82</b>	<b>100</b>	<b>66</b>	<b>100</b>	<b>56</b>	<b>93</b>	<b>61</b>	<b>85</b>	<b>8</b>	<b>13</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 1<sup>st</sup> April 2014 have been reviewed by CDOP.

Sections 7.1 to 7.5 describe data relating to the 356 children reviewed by the West of England CDOP between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017. 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 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 356 children reviewed, 247/356 (69%) had no co-morbidities at all and

109/356 (31%) had at least one co-morbidity. 42/109 (38.5%) of children with a co-morbidity had a single co-morbidity and 67/109 (61.5%) had two or more co-morbidities.

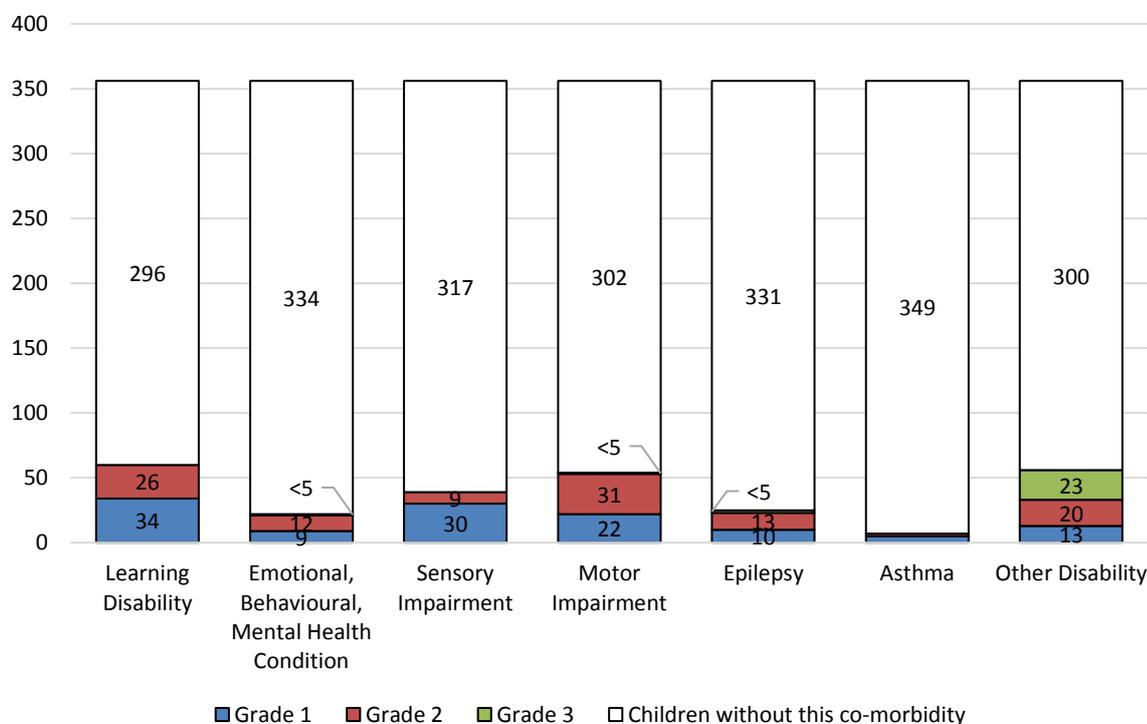
The CDOP grading system grades factors identified with a 1 if they are notable but not felt to have contributed to the ill-health or vulnerability of the child, with a 2 if they may have contributed to the ill-health, vulnerability or death of the child and with a 3 if they are felt to provide a complete and sufficient explanation of the death of the child. Figure 10 details the figures for children who have at least one co-morbidity graded as a 2 or higher when reviewed by CDOP.

Looking at factors graded as 2 or higher (the red and green sections in the chart below), we can see that children with a motor impairment 32/356 (9%) and children with a learning disability 26/356 (7%) represent the most common co-morbidities thought to contribute to vulnerability.

Looking at factors graded as 2 or higher, it can be seen that 9/356 (2.5%) of cases reviewed the child suffered from a sensory impairment that was thought to have contributed to ill-health, vulnerability or death. In 13/356 (3.7%) of cases reviewed, the child suffered from an emotional, behavioural or mental health condition such as anxiety, which was graded as a 2 or higher. Epilepsy was graded as 2 or higher in 15/356 cases (4.2%).

56/356 (16%) of children reviewed had another disability. 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. Of those 56 children, the disability was felt to have contributed to ill-health or vulnerability in 43/56 (76%) of cases.

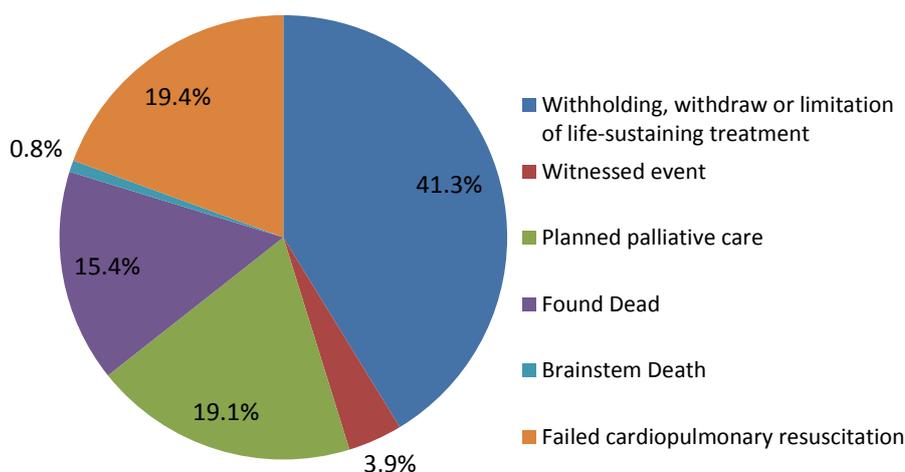
Figure 10: Co-morbidities in children reviewed by CDOP between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017



## 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). This occurred in almost half of the deaths reviewed by CDOP. In 15.4% of cases the child was found dead and in 19.1% of cases the child died following planned palliative care. In 19.4% of cases the child died following failed cardio-resuscitation attempts although the child may have been critically ill on NICU or PICU prior to the final event. In 3.9% of cases the child's death was a witnessed event. This includes road traffic collisions and other deaths by external causes.

Figure 11: Mode of death of cases reviewed by CDOP between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017

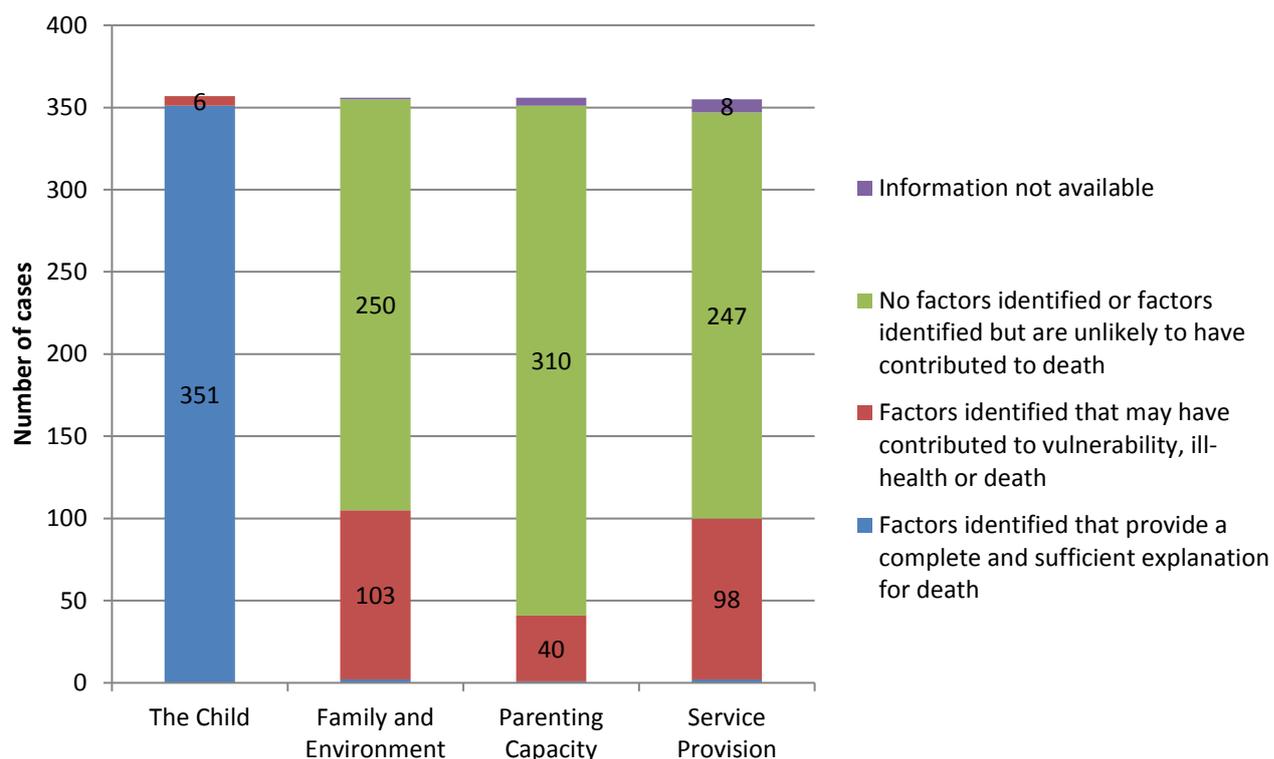


## 7.3 Summary factors identified as contributing to death

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.

Figure 12 shows that in 98.3% of cases reviewed between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017, factors intrinsic to the child (i.e. the underlying medical or surgical problem) provided a complete explanation for the death. In 29% 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 use by parents. In 11% 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 (i.e. safeguarding issue, child abuse or neglect). In 27.5% of cases factors related to service delivery in an agency were identified that may have contributed to the vulnerability, ill health or death of the child. CDOP examines service delivery by all agencies e.g. social care, health education and in all LSCB areas. Examples of service delivery issues highlighted in the 2016-17 review year are

- Lack of continuity of community paediatric review
- No availability of paediatric community nurses to cover out of hours' end of life care
- Poor thermal management of premature infants
- Lack of capacity of NICU cots
- Lack of provision of home respiratory physiotherapy support.

Figure 12: Contributory factors identified by CDOP in cases reviewed between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017

### 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 5. Of the 356 cases reviewed by CDOP between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017, parental smoking was noted to have contributed to the ill-health, vulnerability or death of the child in 8.4% of cases. Alcohol or substance misuse in a parent or carer was thought to have contributed to the ill-health, vulnerability or death of the child in 3.9% of cases. An emotional, behavioural or mental health condition in a parent or carer was identified as contributing to the ill-health, vulnerability or death of the child in 3.6% of deaths reviewed. Mental health issues include maternal or paternal depression, previous self-harm and previous suicide attempts. Housing issues were felt to have contributed to the ill-health, vulnerability or death of a child in 2.8% of the deaths reviewed. These issues were usually overcrowding and/or a chaotic or extremely unclean environment. Domestic violence was present in 17.4% of cases reviewed, however it was thought to have contributed to ill-health, vulnerability or death in 3.6% of cases reviewed.

Table 6: Factors in the family and environment recorded in cases reviewed by CDOP between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017

	Grade 1	Grade 2	Grade 3	Factor not present	Not known if factor present	% of cases where factor considered to have contributed to ill-health, vulnerability

						or death of the child
<b>Smoking by a parent or carer / Smoking by Mum during pregnancy</b>	96	30	0	212	18	8.4
<b>Alcohol or Substance Misuse by a parent or carer</b>	30	14	0	281	31	3.9
<b>Emotional, Behavioural or Mental Health condition in a parent or carer</b>	93	13	0	228	22	3.6
<b>Domestic violence</b>	49	13	0	288	6	3.6
<b>Housing</b>	34	10	0	312	0	2.8

NB: 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.

### 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.

**Table 7: Factors in parenting capacity recorded in cases reviewed by CDOP between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017**

	Grade 1	Grade 2	Grade 3	Factor not present	% of cases where factor considered to have contributed to ill-health, vulnerability or death of a child
<b>Poor parenting / Supervision</b>	10	12	0	334	3.3
<b>Child abuse / neglect</b>	5	12	<5	337	3.9

Of the 356 cases reviewed between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017, CDOP concluded that poor parenting/supervision was a factor that had contributed to the ill-health, vulnerability or death of the child in 3.3% of cases. In 3.9% child abuse or neglect was judged to have contributed to the ill-health, vulnerability or death of the child. CDOP also noted examples of positive parenting during review of cases. This table highlights that in the majority of child deaths there are no safeguarding concerns.

### 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 237 of the 356 cases reviewed by the West of England CDOP in the five year period (66.5%) no modifiable factors were identified. In 114/356 (32%) cases modifiable factors were identified. In 5/356 (1.5%) of cases there was not enough information available to determine if modifiable factors were present. An example of a case in which CDOP may not be able to determine modifiable factors would be the death of a child abroad. In these cases, it can be difficult to obtain sufficiently detailed information from agencies in the country of death to make a decision.

Data from the Department for Education for the period 1<sup>st</sup> April 2015 to 31<sup>st</sup> March 2016 shows that nationally 24% of child deaths were found to have modifiable factors. However, panels in the South West have identified modifiable factors in 28% of the child death reviews they completed and panels in the East of England identified modifiable factors in 30% of the child death reviews they completed<sup>4</sup>.

### 7.5 Family follow up

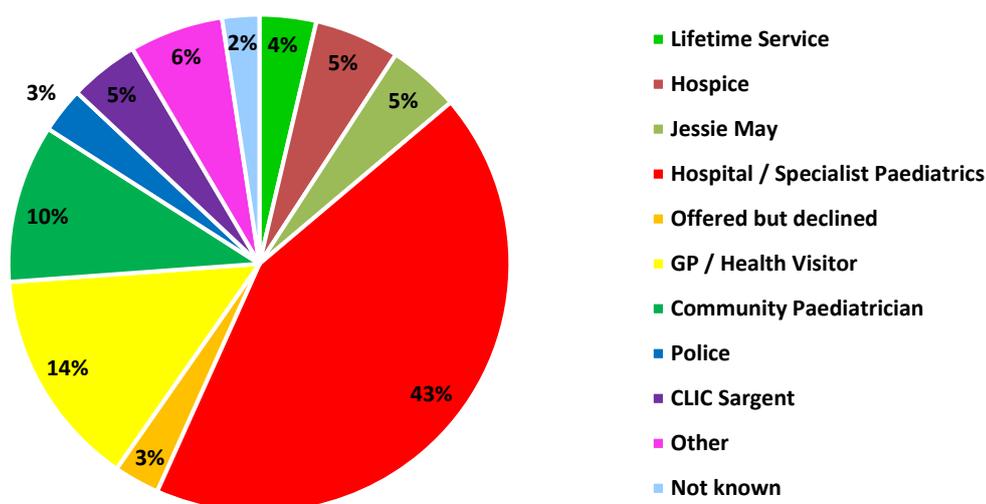
Active engagement with bereaved parents underpins the entire child death review process. Parental input into the child death review meeting should occur as a matter of course. Parents are invited to submit questions to the local child death review meeting, and feedback by the lead health professional on all aspects of this meeting is then given at a follow-up appointment with the family. Families may access follow-up from more than one professional agency.

Figure 13 shows the percentage of families offered follow up from each agency for cases reviewed by CDOP between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017. Families may have been offered follow-up by more than one agency following their child's death. The offer of follow-up remains open to families; however, some families may choose not to take-up this offer for months or sometimes years depending on their specific need. 43% of families received follow-up from hospital or specialist paediatrics. This includes obstetrics, neonatology, cardiology and oncology. 14% of families received follow up from primary care (GP or health visitor) and 10% of families received follow up from a community paediatrician. The hospice or community nursing organisations such as CLIC Sargent, the Lifetime Service or Jessie May routinely offer follow-up to any family they work with and between these agencies they offered follow-up to 19% of families during this period. 3% of families were offered follow up but had declined the offer. 6% of families were offered follow-up from another agency, for example, social care or a mental health worker. In 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 and a bereavement pathway has been developed within UHB in the last year.

**Figure 13: Agency providing follow up to families in cases reviewed by CDOP between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017**

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<sup>4</sup> Department for Education *Child Death Reviews: Year Ending 31 March 2016*, Department for Education, SFR 24/2016, 14<sup>th</sup> July 2016



## 8. Focus on the deaths of children with life-limiting conditions

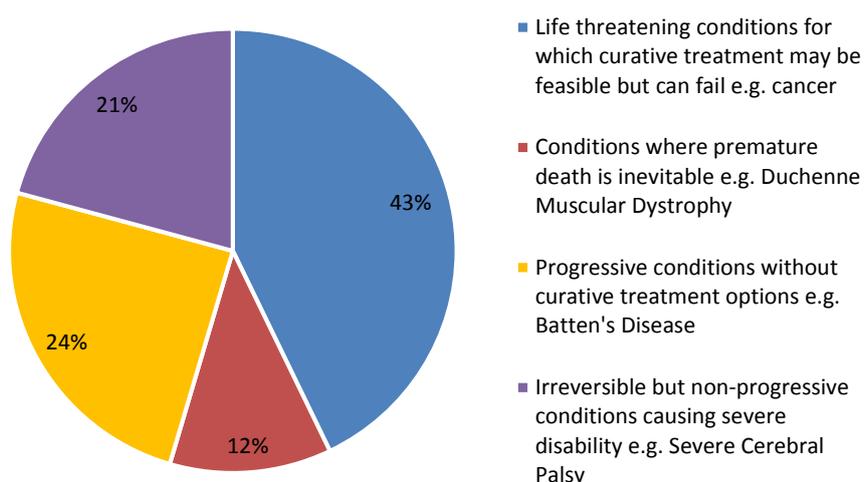
The data in this section relates to the 77 children who have died and who have had a Form B3 completed in relation to their death. Form B3 comprises an additional set of detailed questions relating to end of life care provision for children who conditions that are known to be life-limiting.

In the cases reviewed by CDOP between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017, deaths of children with life-limiting conditions accounted for 21% of the total number of child deaths. The categorisation of death for children with life-limiting conditions is as follows:

- Chromosomal, genetic and congenital anomalies (52%)
- Malignancy (35%)
- Chronic medical condition (8%)
- Perinatal / Neonatal event (4%)
- Acute Medical or Surgical Condition (1%)

Form B3 uses the Together for Short Lives four categories of life-limiting and life-threatening conditions ([www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)) to categorise the condition from which the child died. Figure 14 provides details of these categories, and the number of children reviewed by CDOP during the five year period who fell into each category.

**Figure 14: Main diagnosis of children with life-limiting conditions reviewed by CDOP between 1<sup>st</sup> April 2012 and 31<sup>st</sup> March 2017**



These data show that the most common diagnosis is children with life-threatening conditions for which curative treatment may be feasible, but can fail (43%). The second most common diagnosis is progressive conditions without curative treatment options (24%), closely followed by children with irreversible but non-progressive conditions causing severe disability (21%). The final group is conditions where premature death is inevitable, 12% of children with life-limiting conditions fell into this category.

### 8.1 End of Life Care Plans

End of life care plans are an important part of the management of children with life-limiting conditions. They give the family an opportunity to discuss their wishes and are a helpful tool for all the professionals involved with the family. Together for Short Lives has developed a Core Care Pathway for Children with Life-limiting and Life-threatening Conditions (3rd edition May 2013), and within this Standard 5 states that 'Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this'. End of Life plans give the family an opportunity to discuss and record their preferences for care their child receives when their condition deteriorates. The 'Child and Family Wishes' document developed in Bristol is one example of an advance care plan:

[http://www.togetherforshortlives.org.uk/professionals/external\\_resources/p2](http://www.togetherforshortlives.org.uk/professionals/external_resources/p2)

Advanced care plans may include preferences for treatment in the event of acute deterioration, place of care, withdrawal of treatment, resuscitation status, organ donation, and where the child's body should be taken after death. They may also document special wishes for life expressed by the young person or family such as trips, events or memory boxes.

In 55/77 (71%) of cases of children with life-limiting conditions reviewed by CDOP in the five year period an end of life care plan was in place at the time the child died. In 22/77 (29%) of cases there was no end of life care plan in place. Of these 22 children, in 6 cases (27%) the family was not ready to discuss an end of life care plan and in a further 8 cases (36%) a discussion took place and the family chose not to complete an end of life care plan. In the remaining 8 cases where there was no end of life care plan in place the main reason was due to the rapid deterioration of the child which did not allow time for discussions with the family to take place.

### 8.2 Location of death

One of the things discussed with parents when talking about end of life care for their child is the location in which the family wishes the child to die. All the options are presented to the family to help them to make a decision which provides them with the best experience possible in the circumstances. In response to the issue of lack of funding for 24 hour paediatric palliative care nursing staff raised in the 2012-13 CDOP annual report, CDOP contributed to the setting up by BNSSG Commissioners of a spot purchasing system in the West of England region to provide additional funding for paediatric palliative care nursing staff at short notice during the end of life phase and the data recorded here has been collected since the implementation of that system.

CDOP routinely reviews whether the child died in the location of choice when reviewing the deaths of children with life-limiting conditions. In 54/77 (70%) of cases the child did die in the family's location of choice. Of this group, 24 families chose for their child to die at a hospice, 14 at home, 12 in hospital and 4 in another place of their choosing.

In 12/77 (16%) of cases the child did not die in the family's location of choice. Of this group 7 families wanted their child to die at home, 4 at the hospice and 1 in hospital. In 11/77 (14%) of cases the location of choice for the family was not known and therefore it was not known if the child died where the family wished. In most cases the reason this information is unknown is due to the absence of an end of life care plan.

### **8.3 End of Life Care Co-ordinators and End of Life Medical Leads**

For the last three years CDOP has collected information on whether the child had an end of life care co-ordinator and an end of life medical lead at the time of their final illness and death. For the 55 children reviewed by CDOP in that period (1<sup>st</sup> April 2014 to 31<sup>st</sup> March 2017), 26 (47%) had a named EOL care co-ordinator and 30 (55%) had a named EOL medical lead. In 12 cases (22%) it was not known if an EOL medical lead was in place at the time of death and in 15 cases (27%) it was not known if an EOL care co-ordinator was in place at the time of death. The intention is that these professionals are identified on the Advanced Care Plan and can take a lead in organising the logistics of EOL care when the need arises.

### **8.4 Symptom Management Plans**

Symptom management planning for children's palliative care is a skilled task. An effective plan may take time to prepare, but the potential impact is considerable. The plan can reassure parents that potential symptoms have been anticipated and their child should not suffer unduly and professionals can be equally reassured that they have one agreed plan to follow across settings. In the 55 cases reviewed by CDOP over the last three years 34 children (62%) had a symptom management plan in place at the end of their life. 3/55 (5%) did not have a symptom management plan in place and for 18 children (32%) it was not known if a plan was in place.

### **8.5 Prescribing and Drug Delivery Issues**

In several cases CDOP noted specific issues in this area which can be summarised as follows:

- Challenging symptom control
  - Higher doses required than usually recommended eg phenobarbitone
  - Use of medications at EOL against usual advice (as a last resort)
  - Use of infrequently used medications requiring specialist advice at short notice
  - Complex opioid rotation
  - Dose adjustments and increased monitoring on account of underlying disease eg hepatic, renal
  - Combination of physical and psychosocial/spiritual distress requiring a highly individualised approach

- Difficulty dispensing very small doses of Oramorph and Midazolam using standard strength medications available in the community. Both medications are available as a special preparation from hospital pharmacies but with a short shelf-life
- Route of administration
  - Change required e.g. when unable to swallow
  - Strong patient preference taken into account
- Inadequate community support for use of subcutaneous infusion pump at home (nursing and equipment availability)

### 8.6 Parallel Planning from Intensive Care Settings

There are a small number of babies and children who have been transferred from intensive care settings to the hospice or home to allow withdrawal of ventilation and other life sustaining interventions in a place of the families choice. To enable this to happen, a complex package of care may be required involving hospital staff, the transport teams and palliative care teams, as well as full involvement of the family. This is one example of parallel planning, where alternative choices are presented to a family, sometimes even when curative treatments are also being pursued.

In reviewing a number of other deaths of children in hospital in this period, it is possible to identify whether this type of package of care could have been offered in the time available from recognition of EOL to the child's death.

From a sample of 32 neonatal cases reviewed, 21 died quickly without any obvious opportunity to plan EOL care, 9 died within a few hours of EOL being recognised which would have made transfer to another setting very challenging, and 2 babies had a EOL phase which was clearly recognised and may have allowed transfer out. This happened in 1 out of 2 cases, and was a moving and highly valued experience for the parents of the baby concerned. The small number of babies where this would have been possible suggests staff should be proactive about raising this as a possibility without fear of overwhelming the services involved.

## 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 LSCB within the West of England area 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 8 summarises cases where issues were identified and followed up by the CDOP through the Chair or through individual agency leads. This table reflects a selection of CDOP actions for this year.

**Table 8: Actions arising and outcomes**

<b>Case Description</b>	<b>Issue</b>	<b>CDOP Action</b>	<b>Response/evidence</b>	<b>Recommended National Learning</b>
SUDI	Safe sleeping messages not being given to fathers as well as mothers	Find out what mechanisms are in place for safety advice to be given to every caregiver of a child	Highlighted issue to Public Health England	Pending
Three cases	Highlighted the challenges of information sharing between the SCR and CDOP processes	Write a protocol to be shared with the 4 LSCBs to detail how and when information should be exchanged between the two processes	Draft protocol completed	
Acute infection on top of underlying medical complication in a child with Down Syndrome	Weight measurements not plotted on appropriate growth chart and faltering growth not recognised	Availability of specialist clinic letters when child seen in CED and Community clinics	Added to local protocol	Poster presentation at national meeting
Hypoxic ischaemic encephalopathy	Unclear if LSCB unborn baby policies include concealed pregnancies	Check if all 4 LSCB unborn baby policies include requirement to discuss with social care if baby is born following a concealed pregnancy	Copies of 3 of the 4 policies received confirming this requirement is met. Letter sent to 4 <sup>th</sup> LSCB recommending revision of their unborn baby protocol to include this	N/A
Injuries sustained in a road traffic collision	Unclear if current road design processes consider proximity of cycle paths to roads at the point of construction	Highlight learning from this case to Heads of Planning at 3 other local authorities following action taken by local authority in area of residence	Comprehensive responses received from all 3 local authorities confirming industry guidance on road design is followed and a Safe Systems Approach is in use in some areas. The responses also gave detail on their road	Recognition of the increase in the number of cyclists on the road in recent years which may have an impact on the number of collisions involving cyclists.

			safety and education programmes.	
Sudden collapse of an infant at home	Unclear what is detailed in CARE UKs contract for the NHS 111 service regarding giving advice on CPR	Contact CARE UK to enquire what is in the service specification relating to resuscitation advice	Response provided by Senior Contract Manager at Commissioning Support confirming contract includes provision of CPR instructions until further support arrives	N/A
Severe Hypoxic Ischaemic Encephalopathy with multi-organ failure	Unclear what guidance is in place at the local maternity unit when a woman reports reduced fetal movements	Write to the local birthing centre to investigate what guidance is in place	Current guideline on Management of Reduced Fetal Movements was provided	N/A

## 9.2 Themes emerging from aggregate review of cases at CDOP during the year April 2016 – March 2017

### Group A Strep Infection:

CDOP has reviewed 4 cases in the last two years where the cause of death has been Group A Streptococcal sepsis. The panel has scrutinised these cases in detail and challenged local protocols when appropriate and will continue to contribute to national guidance regarding detection of sepsis.

**Inequalities of healthcare provision:** This year, CDOP wrote to the Children’s Health Commissioner responsible for one of the LSCB areas as the panel felt that they had identified a theme of inequalities of healthcare provision across the West of England area despite the best efforts of professionals on the front line providing services. Two areas where this issue was highlighted are:

- The level of specialist paediatric pre-hospital critical care available in one part of the region varies by time of day; there are also regional variations in services provided and CDOP felt this may have affected the care available in one case reviewed.
- In rare cases, the local district general hospital provides services via its emergency department to children in extremis, where transfer to a specialist paediatric hospital would not be possible. CDOP was informed that this means that the Emergency Department staff at the local hospital may lack in confidence and familiarity in dealing with these scenarios. CDOP was aware that the local hospital staff receive Advanced Paediatric Life Support (APLS) training and appropriate refreshers, however without regular patient contact the panel felt this may result in a level of de-skilling. The importance of this issue was sharply illustrated by one of the cases discussed at CDOP.

A response was received from the Children’s Health Commissioner confirming that provision of paediatric services from the local hospital is currently under review including looking at ways to improve the availability of paediatric clinical expertise and paediatric upskilling of staff.

**24/7 End of Life care for children:**

This year has seen a number of children die as the result of life-limiting conditions. It was recognised by CDOP that there is a shortage of paediatric palliative care trained clinicians in the community. This has an impact on the level of support and care that families receive as there is no weekend or out of hours service provision. This is despite the agreed availability of funding to “spot purchase” a package of end of life care for a child. Families can choose to be at the hospital or the hospice but they do not have a full choice of place of care at the time of their child’s death.

CDOP prepared a report entitled “End of Life Care at Home” at the request of commissioners to help with scoping the need for this service and informing possible models that could be considered

**Co-ordination of care for children with the most complex medical conditions and disabilities:**

CDOP reviewed a number of cases where children had accessed care from a number of different services within the local hospital trust to meet their complex health needs. During review of these cases it was highlighted that there can be difficulties co-ordinating care for these children and in one case the family of the child performed this role. CDOP recognised the important role that parents can play in co-ordinating such matters but felt this was not an appropriate measure to be relied upon

**Lack of Care of the Next Infant Scheme:**

This has continued to come to light through case reviews following Sudden Infant Death Syndrome and other SUDIs. This year CDOP has supported the training for Community Neonatal Nurses to provide this programme, and coordinated the input required from other professionals including Neonatologists, Health Visitors and the Childrens Emergency Department.

**10. Achievements and Future priorities**

The Royal College of Paediatrics and Child Health published its State of Child Health report 2017<sup>5</sup>. The UK ranks 15 out of 19 Western European countries on infant mortality and has one of the highest death rates for children and young people in Western Europe. Each UK government is challenged to develop a child health and wellbeing strategy as well as adopting a ‘child health in all policies’ approach. There are a number of specific recommendations for the England government regarding reducing the number of child deaths. These include funding health visiting and home safety equipment schemes which educate and equip parents and carers to keep their children safe, with a focus on water safety, blind cord safety and safe sleeping. Road safety features with a suggested introduction of graduated driving licences for novice drivers and 20mph speed limits in built-up areas. The report also recommends development of integrated health and care statistics. In fact, West of England CDOP has been an active player in addressing several of these issues locally and nationally, none more so than the National Child Mortality Database. The Healthcare Quality Improvement Partnership tendered for this in early 2017 and University of Bristol is part of a collaborative bid.

Working Together guidance is being revised to complement legislative change with the upcoming Children and Social Work Act 2017. Working Together will continue to set out principles of the child death review process but will also signpost to more detailed guidance which will clarify arrangements and improved standardisation across areas. WoE CDOP team are contributing in this process at a high level through consultation meetings and drafting guidance. The process as it is

<sup>5</sup> Royal College of Paediatrics and Child Health 2017 <http://www.rcpch.ac.uk/state-of-child-health/report-in-a-glance>

run in WoE continues to be held in high esteem nationally. Under the new Act, responsibility for the CDR process is likely to pass from LSCBs to CCGs. There is likely to be a requirement for a child death review meeting in every case which we already carry out in WoE. With some changes to CDOP configuration, regionalisation is anticipated, and once again our CDOP has been asked to contribute options to this revision.

One task of the Designated Doctor is maintaining and improving quality of Child Death Review meetings. This is done through ongoing training and service development. All partner agencies need to be involved in this, and this year has seen specific training to hospice and sub-speciality paediatric teams, and multi-agency training on the rapid response process. It is important to ensure CDOP processes dovetail with hospital processes where possible and active liaison continues regarding this. Similarly, a sensible approach to storing and sharing data is needed.

Feedback and presentation of data to the four LSCBs has been done on an annual basis through presentations at the Boards as well as sharing this annual report. In 2016, a small number of specific cases were presented to enable a more thorough understanding of the Child Death process and provide examples of how CDOP tries to affect change and generalise learning from specific deaths.

CDOP has taken the lead in development of written info for parents on the different processes which may follow a child's death. CDOP has also contributed to the new Bereavement pathway at the local Trust.

We are lucky to have such a stable and dedicated team in the Child Death Enquiries Office who, together with our partner agencies, enable this significant body of data and learning to be brought together and presented in this report. There is a responsibility to families to optimise learning from child deaths, but the framework and the changes ahead hopefully provide an ongoing opportunity to do this to the best of everyone's ability.

## Appendix A - CDOP membership April 2016 to March 2017

	<b>Core member</b>	<b>LSCB/Organisation</b>
Nominated Chair	Sally Lewis	Bristol
Consultant in Public Health (to 31.08.16)	Jon Roberts	North Somerset
Consultant in Public Health (from 01.09.16)	Lynn Gibbons	South Gloucestershire
Designated Doctor for Child Deaths	Mary Gainsborough	Sirona Healthcare
Coroner's Officer	Debra Neil	Bristol
Children's social care (until 31.08.16)	Sally Churchyard	BANES
Children's social care (from 01.09.16)	Fiona Tudge	Bristol
Designated nurse for safeguarding children (until 31.08.16)	Jackie Mathers	Bristol
Designated nurse for safeguarding children (from 01.09.16)	Lisa Harvey	South Gloucestershire
Midwifery	Julie Northrop	UHB NHS Trust
Consultant in Obstetrics	Dimitrios Siassakos	North Bristol NHS Trust
Consultant in Neonatology	Paul Mannix	North Bristol NHS Trust
Consultant in Fetal Medicine	Mark Denbow / Tim Overton	UHB NHS Trust
General Practice	Patrick Nearney / Sarah Woodward / Elaine Lunts	Bristol
Police	Ed Yaxley / Louise Boyce	Avon & Somerset Constabulary
Paediatric Palliative Care	Francis Edwards / Charlotte Mellor	UHB NHS Trust
Consultant Paediatric Intensivist	Margrid Schindler	UHB NHS Trust
Consultant in Paediatric Emergency Medicine	Nick Sargant	UHB NHS Trust
Consultant Community Paediatrician	Fiona Finlay	BANES
Safeguarding Named Professional; Ambulance Service	Simon Hester	South Western Ambulance Service NHS Foundation Trust

## Appendix B – UHB Financial Summary 2016/17

MPR = Multi-professional Review

BRCH – Bristol Royal Hospital for Children

RRT = Rapid Response team

PNM – Perinatal Mortality Meeting St Michael's Hospital

<b>Child Death Review Costs for 2016/17</b>			
<b>Description of Cost</b>		<b>Payment Due</b>	<b>£ Cost to UHB</b>
Designated Doctor	MPR	1.5 Additional PA's	£16,500
Paediatric Lead – Bristol Children's Hospital	BRCH	1 Additional PA	£11,527
Neonatology Lead - St Michael's	MPR	1 Additional PA	£10,794
Neonatology Lead - Southmead	MPR	0.5 Additional PA	£6,078
Community Paediatricians	RRT	320 hours Total	£18,560
GP and ED Consultant Costs	MPR	Attendance at some panels	£5,007
UOB Senior Manager	MPR	21 hours per week	£30,991
UOB Secretarial Support	MPR/PNM	3 days per week	£21,640
Additional admin support to CDE Office	MPR	3 months	£19,600
UOB Secretarial Support	PNM	2 days per week	£10,533
UOB Secretarial Support – NBT Community Paediatricians	RRT		£2,500
NBT Psychology support	RRT		£5,000
<b>Sub-total</b>			<b>£158,730</b>
Local authority funding UOB office			
• Manager	MPR		£5238
• Administrative support	MPR/RRT		£20,954
<b>Total Costs</b>			<b>£184,922</b>