

**WEST OF ENGLAND**

**CHILD DEATH OVERVIEW PANEL**

**April 2018 – March 2019**

**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:

- Vicky Slep for co-authorship of the report.
- Dr May-Lin Lui, Community Paediatrics ST7 for providing data on crude death rates (2014-2019) for Section 6.1
- Dr Rachel Cox, Consultant Paediatric Oncologist and Dr Kim Blackwell, Community Paediatrics ST8 for help with the focus on Oncology deaths for Section 8

Mary Gainsborough

## 2. Foreword

In 2008, Child Death Overview Panels (CDOPs) were statutorily established in England under the aegis of Local Safeguarding Children Boards (LSCBs) with the responsibility of reviewing the deaths of all children aged 0 to 18 years in their resident population.

The West of England CDOP covers the four Unitary Authority areas of Bristol, North Somerset, South Gloucestershire and Bath & North East Somerset. It is made up of representatives from a range of organisations, including health, social care and the police. The CDOP also has representation from those with experience of supporting families bereaved through a child's death.

Every death of a child is a tragedy and the panel's task is to learn from the circumstances of every death to:

- Identify any changes which can be made that might help prevent further deaths
- Share the learning regionally and nationally, with other CDOPs and agencies involved in the process.
- Identify trends and target interventions to prevent further deaths

In doing this CDOP has had to consider implementation of the National Child Death Review Statutory and Operational Guidance 2018 which will strengthen processes and reduce variability between regional areas.

The review process is not about allocating blame but is about learning lessons to prevent deaths in the future.

Behind every child's death there is a grieving family and I am always impressed by the sensitivity with which the panel members approach each case discussion. It is crucial that we keep the family and children at the centre of what we do.

Finally, I want to commend the hard work and dedication of the Panel members, and the support from Dr Mary Gainsborough Designated Doctor for Child Deaths and Vicky Slep and her team in the Child Death Enquiry Office whose dedication enables an effective process and professional challenge within and across the spheres of expertise.



**Eifion Price**  
**Chair West of England CDOP**

### 3. Executive Summary

1. The processes to be followed when a child dies are currently outlined within Working Together to Safeguard Children 2018: Chapter 5 Child Death Review Processes<sup>1</sup>.
2. Crude death rates for the individual authorities across the West of England range from 2.07 to 3.46 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. 516 child deaths were notified to the West of England Child Death Enquiries Office between 1st April 2014 and 31<sup>st</sup> March 2019.
4. 220/516 (43%) 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, 81% died in hospitals, 9% in the parental home or in a relative's home, 6% in hospices and 2% in other locations.
6. Between 2014 and 2019, 67% of deaths occurred during the first year of life, 10% of deaths were of children ages 1-4, and rates then decrease in mid-childhood but are higher in ages 15-17 with 6% of deaths.
7. 74% of deaths notified in the last 5 years were children expected to die and 26% of deaths in children aged 0-17 years were unexpected; 33% remaining unexplained after a full investigation and the local case review meeting.
8. 33% of deaths were due to perinatal complications (mostly extreme prematurity), and 26% children had chromosomal, genetic or congenital conditions. Acquired natural causes account for 24% and external causes, encompassing deliberate injury, suicide and trauma, accounted for 8%.
9. Between 2014 and 2019, 42% of children had a post-mortem examination and of these 70% had a Coroner's post-mortem and the rest had a hospital post-mortem.

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

10. The West of England CDOP reviewed 312 cases in detail between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019. 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 2014/15 and 98% of those from 2015/16 have now been reviewed.
11. The most common mode of death is following the active withholding, withdrawal or limitation of life-sustaining treatment, which occurred in 37% of cases.
12. 15% of children reviewed have another disability. In 46% of those the disability was felt to have contributed to the ill-health, death or vulnerability in the child.
13. In 97% 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 1% 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 28%, related to parenting capacity in 10% and in service provision in 26%. Parental smoking was classed as contributory in 10% of deaths, emotional, behavioural or mental health issues in 3%, alcohol or substance abuse in 4%, housing issues in 3% and

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

domestic violence in 4%. It should be highlighted that positive parenting was noted in many cases.

15. CDOP identified 'modifiable factors' in 30%. 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
16. Family bereavement follow-up was documented in 98% of cases, with hospital or specialist paediatrics providing this in 39% of cases, primary care in 10% and hospice/community nursing in 17%. In 4% 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 the deaths of children from malignancy:**

Over the 5-year period, CDOP reviewed a total of 35 children who died from malignancy. A number of learning points regarding service improvement were identified, as well as good practice being highlighted.

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

17. 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.
18. Important issues highlighted by CDOP were disseminated through the constituent agencies and the chairs of the Local Safeguarding Children Boards.
19. Issues noted at CDOP led to specific actions in some case, for example:
  - Delay in the diagnosis of a brain tumour
  - Delay in transfer for surgical review as transport teams not available in a time critical situation
  - Delay in examination and transfer of mother to Central Delivery Suite in an out of region hospital
20. Actions arising from individual cases:
  - Poorer rate of uptake of influenza immunisation in pre-school age group
  - Where to take a child pathway developed across agencies following confusion about where to convey a 16yr old following death in the community
  - Information about Advanced Care Plans not easily available to ambulance crews led to project to simplify and streamline a new approach
  - Need to maintain awareness of need to review babies who have not passed meconium within 24hours of birth
  - Correspondence with Royal College of Pathologists about shortage of paediatric pathologists as delay in post-mortem reports causes additional distress to families

#### **21. Themes**

Certain themes have emerged from reviewing children's deaths in the West of England this year:

- Benefits of Family Nurse Partnership involvement in supporting first time mothers under 20 years old

- Difficulties accessing fathers with public health messages
- Rapid Response (now called Joint Agency Response) was not always triggered when appropriate
- Child Death process not always followed especially in adult settings for 16 – 17 year olds
- Co-sleeping in hazardous conditions
- Support for professionals when there are multiple reviews following high profile and traumatic deaths
- Managing “Did not Attend” (DNAs) and sharing knowledge of these between agencies
- Electronic prescribing to help reduce human error

## **22. Achievements and Future Priorities**

- For the second year a lecture format for presentation of the CDOP Annual Report to stakeholders was used. This was held in October 2018.
- eCDOP data management system has been introduced which will allow direct upload to the National Child Mortality Database and ensure the process is compliant with GDPR
- CDOP monitor death rates on a month by month basis in order to identify any emerging trends
- New national Statutory and Operational Guidance for Child Death Reviews was published in Oct 2018 and this has required a review of local processes, revised training to multi-agency professionals and renewed Commissioning arrangements.
- Themed CDOP reviews with links across the region for neonatal and cardiac deaths
- Annual multi-agency training has been revamped in line with the new Guidance

#### 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 2018: Chapter 5 Child Death Review Processes<sup>2</sup>. The process focuses on identifying 'modifiable factors' in the child's death. The new statutory guidance was published in July 2018 and must be followed for all deaths occurring after 1<sup>st</sup> April 2019. For the purposes of this annual report, the previous version of Working Together to Safeguard Children (2015) was in place and governed the process for the children described in this report.

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) outlined two inter-related processes...a '**Rapid Response**' where a group of professionals came together for the purpose of evaluating the cause of death in an individual child, where the death of that child was *unexpected*, and a '**Child Death Overview Panel**' (CDOP) that came 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 2018/19, the WoE CDOP Chair has rotated from Bristol to BANES 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 Mortality Analysis Unit 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

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



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 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 eleventh Annual Report of the West of England CDOP. It was approved by the Panel on 10<sup>th</sup> July 2019. It will be a public document. Previous year's Annual Reports can be found online or requested from the Child Mortality Analysis Unit at University of Bristol.

The report is produced using data collected by the Child Mortality Analysis Unit. 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 2014 – 2019)

This section summarises all deaths notified to the Child Mortality Analysis Unit, between April 1<sup>st</sup> 2014 and March 31<sup>st</sup> 2019, 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 2014-19.

**Table 1: Crude death rate per 10,000 children aged 0-17 (2014-2019)**

	Crude Rate per 10,000	Lower Limit	Upper Limit
BANES	1.9	1.3	2.7
Bristol	2.9	2.5	3.5
North Somerset	2.1	1.5	2.8
South Gloucestershire	2.4	1.9	3.1
West of England	2.6	2.3	2.9

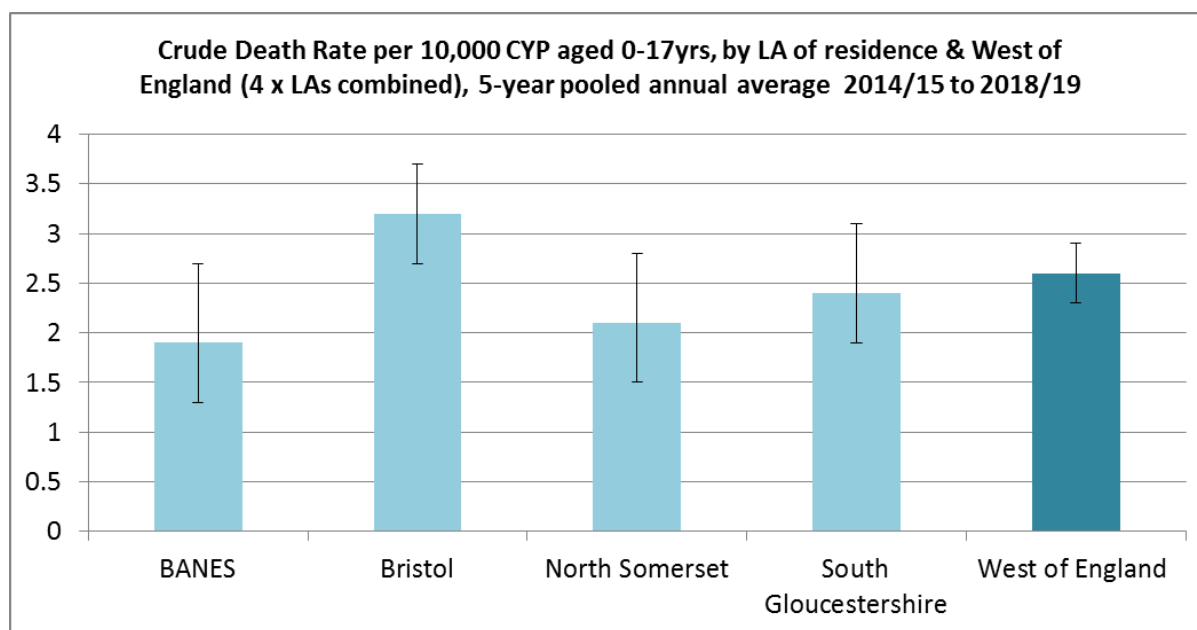
Notes: (1) 95% confidence intervals estimated using Byar's approximation

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

(2) Due to non-release of 2018 mid-year population estimates 2017 populations have been used as a proxy for 2018 figures

(3) The latest revised ONS population mid-year estimates have been used for mid-2014, mid-2015, mid-2016 and mid-2017

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



- No Local Authority /Local Safeguarding Children Board has a significantly different crude death rate compared to the West of England overall rate.
- Bristol, BANES, North Somerset and South Gloucestershire all have statistically similar crude death rates.

## 6.2 Analysis of notifications by year (2014-2019)

During the period 2014-2019, 516 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.

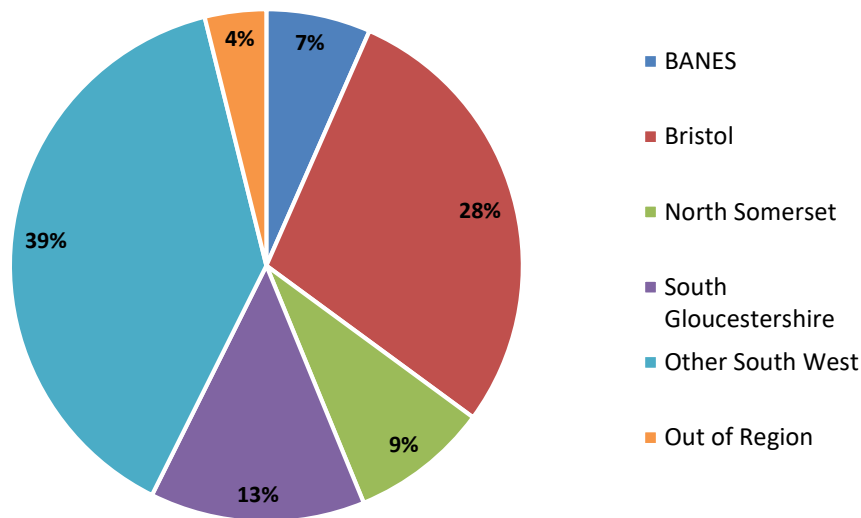
Table 2: Notifications by region of residence, 2014-2019

Region	2014/15 Deaths	2015/16 Deaths	2016/17 Deaths	2017/18 Deaths	2018/19 Deaths
BANES	8	8	6	8	4
Bristol	31	35	28	34	18
North Somerset	6	14	9	6	8
South Gloucestershire	12	13	18	16	10
Other South West	37	36	40	37	51
Out of Region	9	3	1	2	4
<b>Total</b>	<b>103</b>	<b>109</b>	<b>102</b>	<b>103</b>	<b>95</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 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, 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.

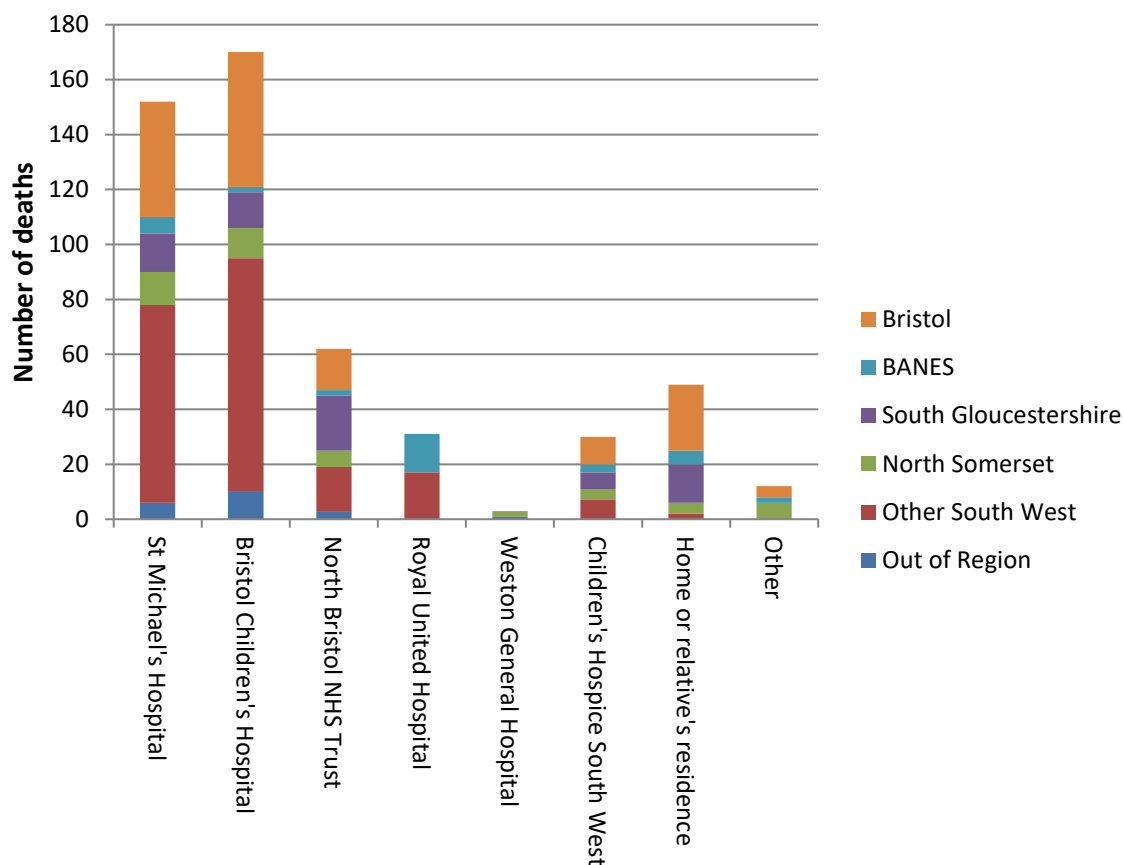
Figure 1: Notifications by area of residence, 2014-2019



### 6.3 Location of death (2014-2019)

This data records where the child actually died. Over the five-year period 32.9% (170/516) of all child deaths occurred at the Bristol Children's Hospital, 29.4% (152/516) at St. Michael's Hospital, 12% (62/516) at hospitals within North Bristol NHS Trust (Southmead and formerly Frenchay Hospitals), 5.8% (30/516) died in a hospice, and 9.4% (49/516) died at home or at a relative's residence. Of the children who died at home or at a relative's residence, 70.6% (36/51) were unexpected deaths and 29.4% (15/51) were expected deaths (See section 6.9 for further information on expected vs unexpected deaths). 7.9% (41/516) died in other hospitals and 2.3% (12/516) 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 of 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, 2014-2019



The precise location of death for children dying within hospitals in the West of England region in 2014-2019, is shown below in Table 3.

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

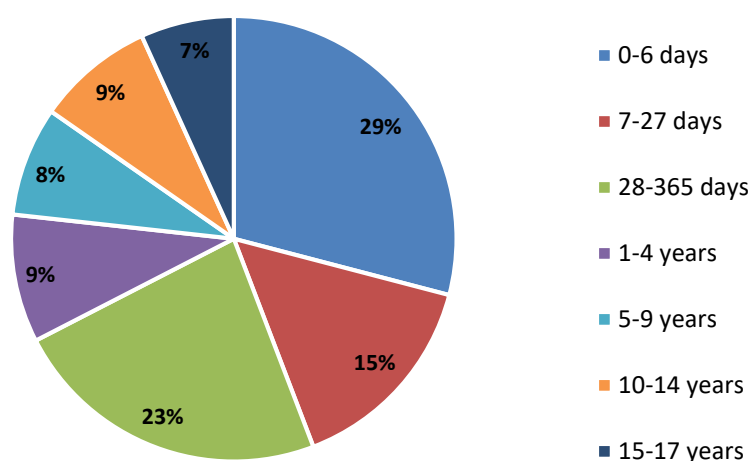
Hospital	Paediatric/Neonatal Intensive Care Units (PICU/NICU)	Emergency Department	Children's Wards/Theatres/Central Delivery Suite	Adult ICU
<b>Bristol Children's Hospital, University Hospitals Bristol</b>	118 (PICU)	29	23	n/a
<b>Royal United Hospital, Bath</b>	4 (NICU)	6	21	0
<b>St Michael's Hospital, University Hospitals Bristol</b>	138 (NICU)	n/a	14	n/a
<b>North Bristol NHS Trust Hospitals</b>	37 (NICU)	1	22	2

<b>Weston General Hospital</b>	n/a	2	1	0
<b>Other Hospitals</b>	3	1	0	3

#### 6.4 Age at Death (2014-2019)

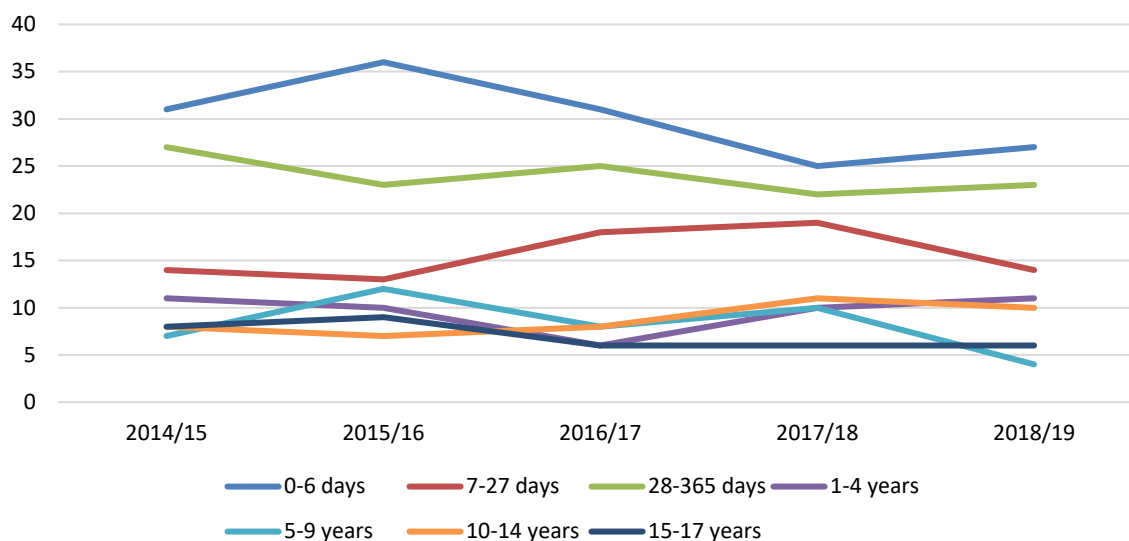
Using 5 year data, the greatest proportion of notifications (29%) were received for babies dying in the early neonatal period (less than seven days of life) (Figure 3). Considering the neonatal period as a whole (0-28 days) 44% of deaths occurred during this time. The first year of life is routinely 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 67% 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, 2014-2019



We can also look at the trends in deaths by age group over a five year period (2014-2019) in the line graph in Figure 4 below. This shows that the number of deaths in the 0-6 day age group, showed a consistent decrease between 2015/16 and 2017/18, followed by a slight increase this year. This year has seen a decrease in the numbers of deaths of 7-27 day olds and 5-9 year olds.

Figure 4: Line Graph to show the trends in notifications by age over an 8-year period (2010-2018):



### 6.5 Gender (2014-2019)

There have been more notifications of deaths in boys (56%) than girls (44%). This mirrors national data from the child death review process, with 56% of deaths reviewed occurring in boys nationally<sup>3</sup>. The data shows that boys are more likely to die from all causes.

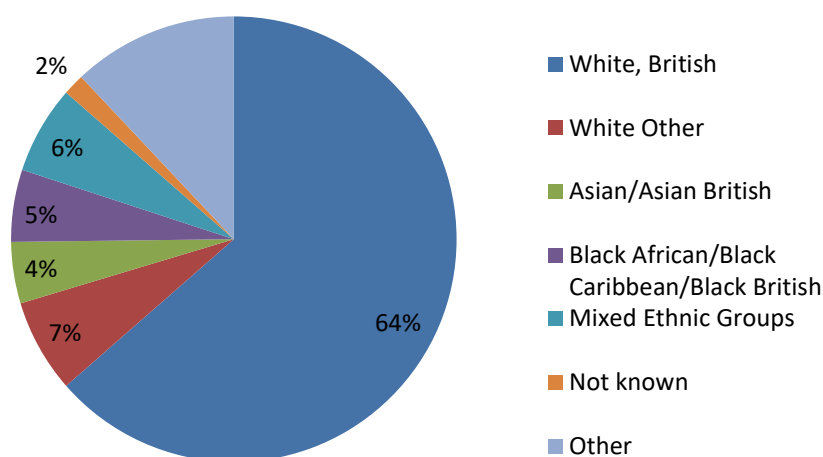
### 6.6 Ethnicity (2014-2019)

Figure 5 shows that 64% of notifications received by the Child Death Enquiries office between 2014 and 2019 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 4% and the number of notifications for children whose ethnicity was recorded as Black or Black British was 5%. In 2% of cases the ethnicity of the child was not known. 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, 2014-2019

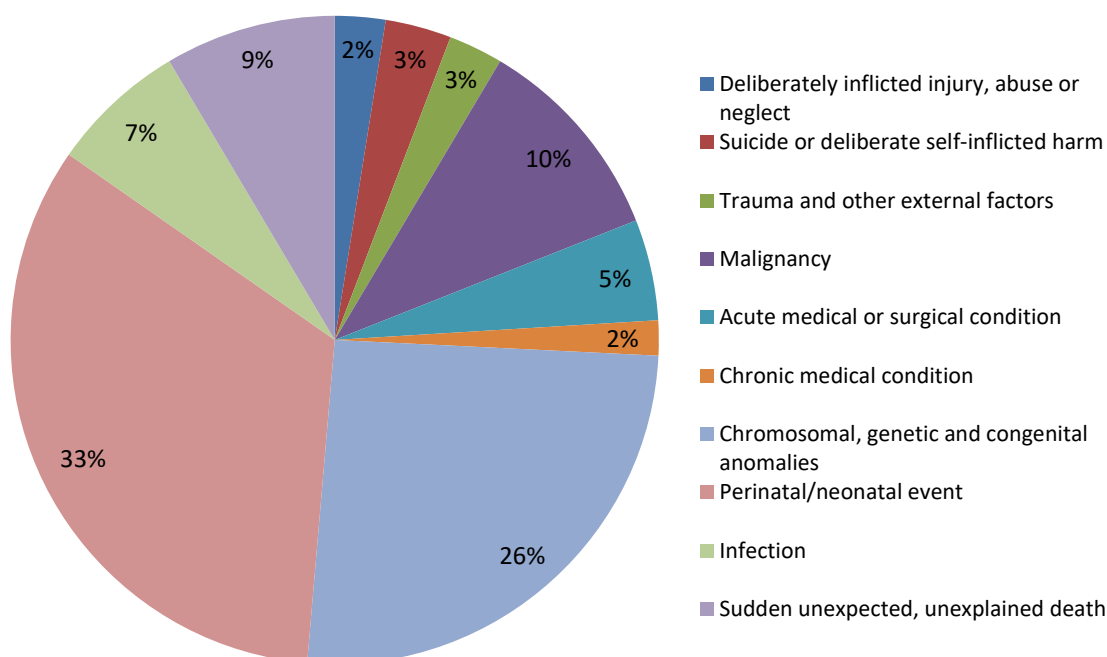
<sup>3</sup> Department for Education *Child Death Reviews: Year Ending 31 March 2017*, Department for Education, SFR 36/2017, 31<sup>st</sup> July 2017



### 6.7 Category of Death (2014-2019)

The CDOP is required to categorise each child death using a standard list of categories shown in Figure 6. During the five-year period, 33% of deaths were categorised as perinatal/neonatal events. The second most common cause was chromosomal, genetic or congenital abnormalities, with 26% of the deaths fitting into this category. Malignancy (10%), Sudden unexpected, unexplained deaths (9%), Infection (7%) and Acute medical or surgical condition (5%) comprise the next most common causes. Chronic medical conditions (2%), Trauma (3%), Suicide or self-inflicted injury (3%) 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, 2014-2019



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, chronic medical 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 2014 and 2019**

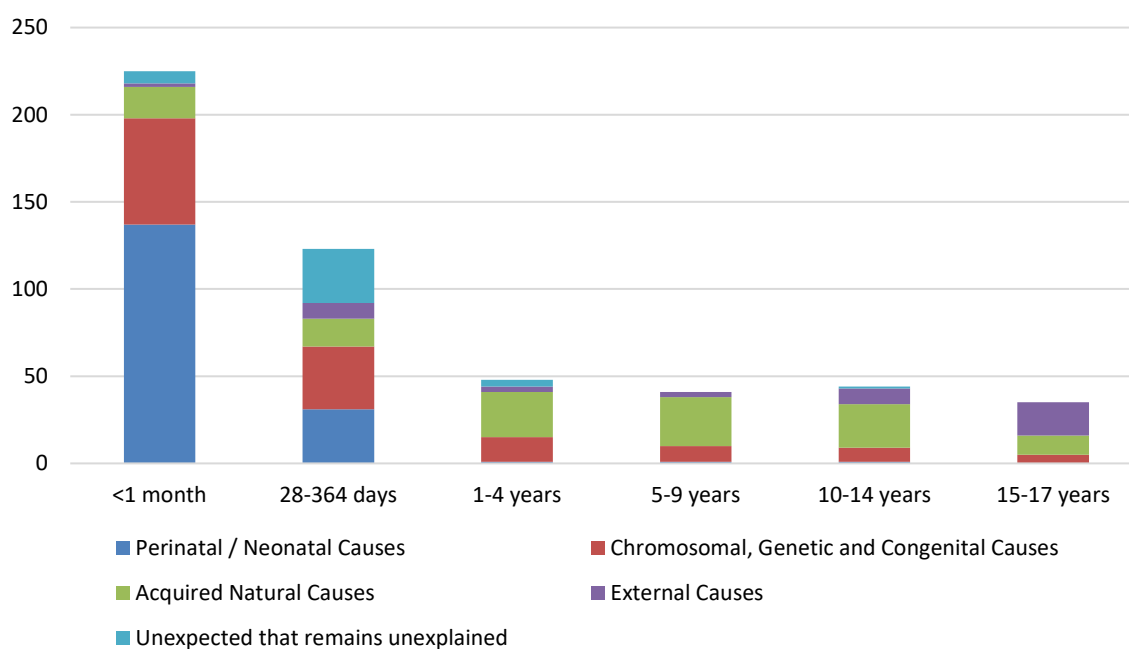
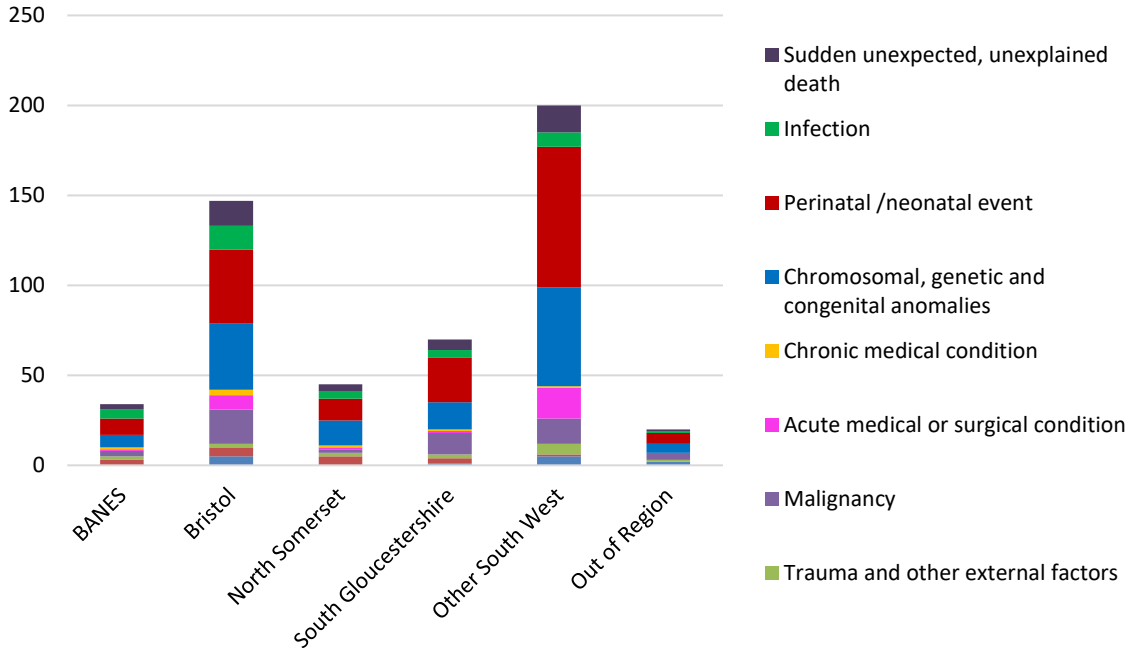


Figure 8 below shows the causes of childhood death for each of the LSCB areas within the WoE CDOP, together with those recorded for non-resident children who died within the West of England area.

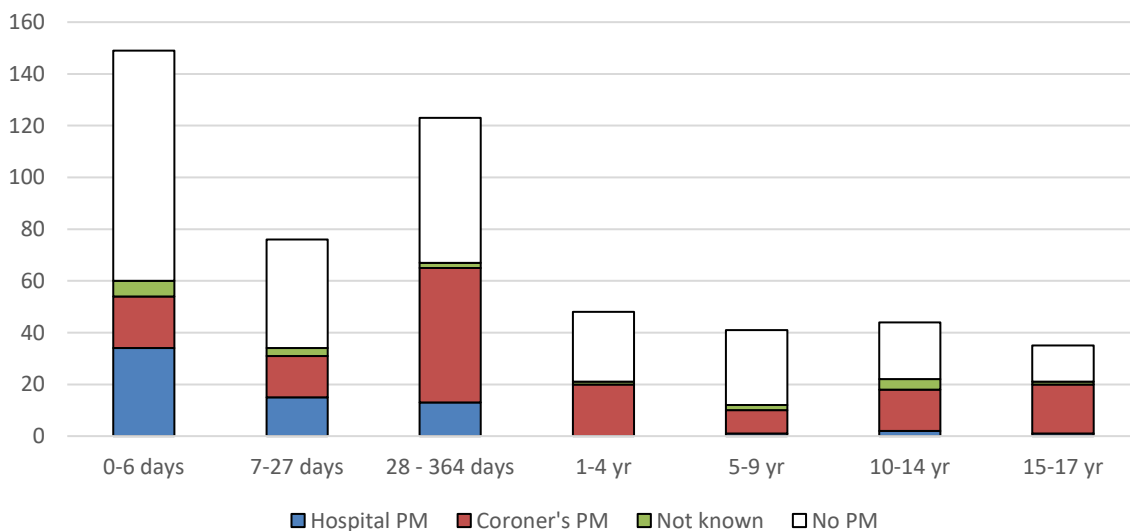
**Figure 8: Causes of childhood death by area of residence, 2014-2019**



### 6.8 Post mortem examinations (2014-2019)

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 152/516 deaths (29.5%) and a hospital post mortem occurred in 66/516 deaths (12.8%). 279/516 (54%) cases did not have a post mortem. In 19/516 (3.7%) it was not known if the child had a post-mortem examination at the point of notification of the death. Figure 8 below shows post mortems performed by age group. The national shortage of paediatric pathologist remains an issue in this area. Long delays in obtaining post mortem reports continue to cause distress to families and delays in the child death review process. CDOP has documented this as a theme in previous annual reports and continues to work to highlight the effects of this issue.

Figure 8: Post mortems performed by age, 2014-2019



### 6.9 Unexpected and Expected deaths (2014-2019)

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.

135/516 (26%) of deaths in children aged 0-17 years were unexpected. 44/135 (32.5%) 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 2014-2019**

Cause of death	% of total unexpected deaths
Sudden unexpected, unexplained death (including SIDS)	32
Trauma and other external factors (including road traffic accidents, drowning, deliberately inflicted harm and suicide)	31
Other (including chronic and acute medical conditions, malignancy and perinatal/neonatal event)	18
Infection	10
Chromosomal, genetic and congenital anomalies	9

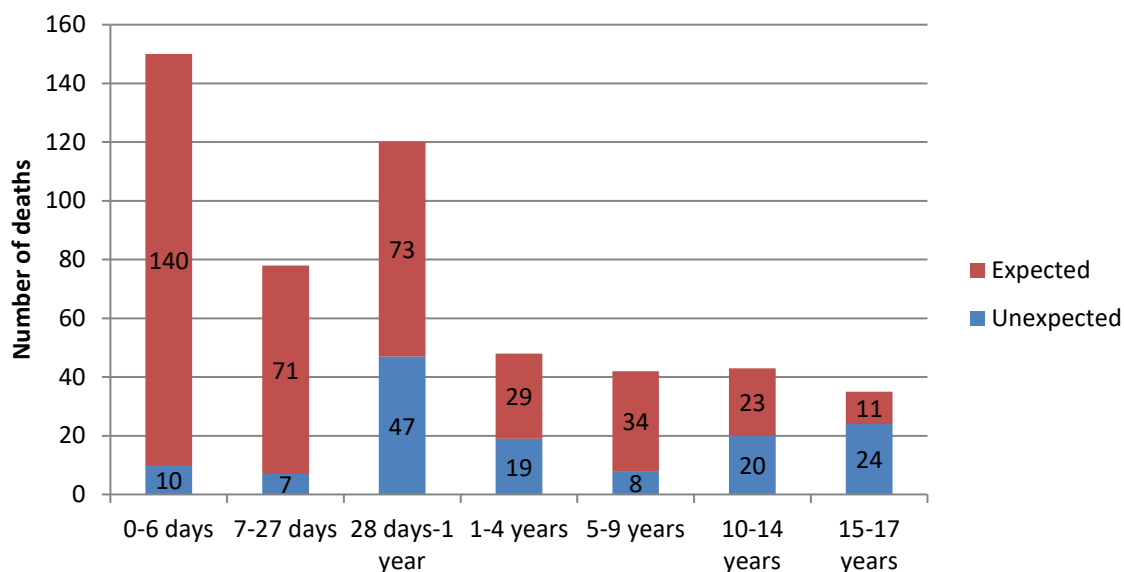
It is worth noting that children with chromosomal, genetic and congenital anomalies can die in an unexpected fashion many years after their birth.

Over the five year period there were 381 expected deaths notified to the Child Mortality Analysis Unit. Of these deaths 284/381 (74.5%) 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%) or chromosomal, genetic or congenital anomalies (31%). The main categories of the expected deaths can be broken down as follows:

**Table 5: Causes of expected deaths of children 2014-2019**

Cause of death	% of total expected deaths
Perinatal / neonatal event	45
Chromosomal, genetic and congenital anomalies	31
Malignancy	12.8
Infection	6
Chronic and acute medical conditions	5
Other	0.2

**Figure 9: Expected versus unexpected deaths by age group, 2014-2019**



## 7. Child Death Overview Panel Review Data (2014-2019)

These data are drawn from the CDOP database (see Section 5). They summarise the Panel's review decisions for 2014-2019 and its actions for 2018-19. 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 6.**

**Table 6: The number of cases reviewed each year by year of death**

	2014/15		2015/16		2016/17		2017/18		2018/19	
<b>Total number of notifications</b>	106		110		102		103		95	
<b>Number of cases to be reviewed by WOE CDOP</b>	60		71		61		64		40	
<b>Years of Review</b>	<b>Number reviewed</b>	<b>% reviewed</b>	<b>Number reviewed</b>	<b>% reviewed</b>	<b>Number reviewed</b>	<b>% reviewed</b>	<b>Number reviewed</b>	<b>% reviewed</b>	<b>Number reviewed</b>	<b>% reviewed</b>
2014/15	5	8								
2015/16	42	70	13	18						

2016/17	8	13	49	69	8	13				
2017/18	3	5	8	11	36	59	5	8		
2018/19	2	4	0	0	13	21	33	52	4	10
<b>Total</b>	<b>60</b>	<b>100</b>	<b>70</b>	<b>98</b>	<b>57</b>	<b>93</b>	<b>38</b>	<b>60</b>	<b>4</b>	<b>10</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

A single case of a child who died prior to 1<sup>st</sup> January 2017 is outstanding. All other children who died before that date have been reviewed by CDOP.

Sections 7.1 to 7.5 describe data relating to the 312 children reviewed by the West of England CDOP between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019. 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 (2014-2019)

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 312 children reviewed, 204/312 (65.3%) had no co-morbidities at all and 108/312 (34.6%) had at least one co-morbidity. Of the children with at least one co-morbidity 42/108 (39%) had a single co-morbidity and 66/108 (61%) had two or more co-morbidities.

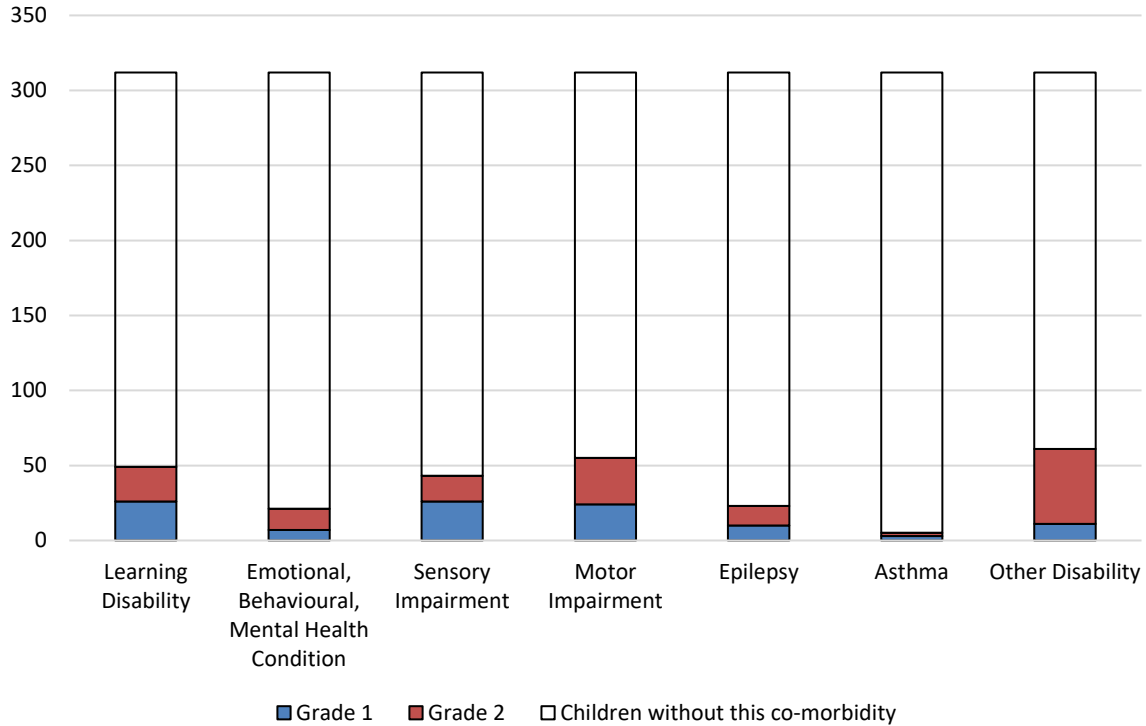
The CDOP grading system grades factors identified with a 1 if they are notable but not felt to have contributed to the ill-health or vulnerability of the child, with a 2 if they may have contributed to the ill-health, vulnerability or death of the child and with a 3 if they are felt to provide a complete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

Children with a motor impairment (10%) and children with a learning disability (7%) represent the most common co-morbidities thought to contribute to vulnerability.

Looking at factors graded as 2 (the red sections in the chart below), it can be seen that in 5% of cases reviewed the child suffered from a sensory impairment that was thought to have contributed to ill-health, vulnerability or death. In 4.4% of cases reviewed, the child suffered from an emotional, behavioural or mental health condition such as anxiety, which was graded as a 2. Epilepsy was also felt to have contributed to ill-health, vulnerability or death in 4% of cases.

16% of children reviewed had "other disability". An example of a co-morbidity included in this category 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.

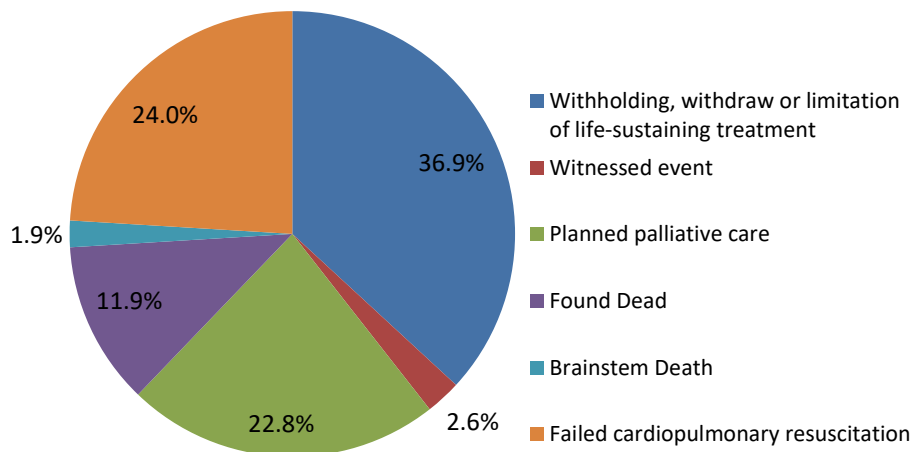
**Figure 10: Co-morbidities in children reviewed by CDOP between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019**



### 7.2 Mode of death (2014-2019)

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 37% of the deaths reviewed by CDOP. In 24% of cases the child died following failed cardio-pulmonary resuscitation attempts although the child may have been critically ill on NICU or PICU prior to the final event. In 23% of cases the child died following planned palliative care and in 12% of cases the child was found dead. In 3% of cases the child's death was a witnessed event. This includes road traffic collisions and other deaths by external causes. For a very small number of children (2%) the mode of death was brainstem death.

Figure 11: Mode of death of cases reviewed by CDOP between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019



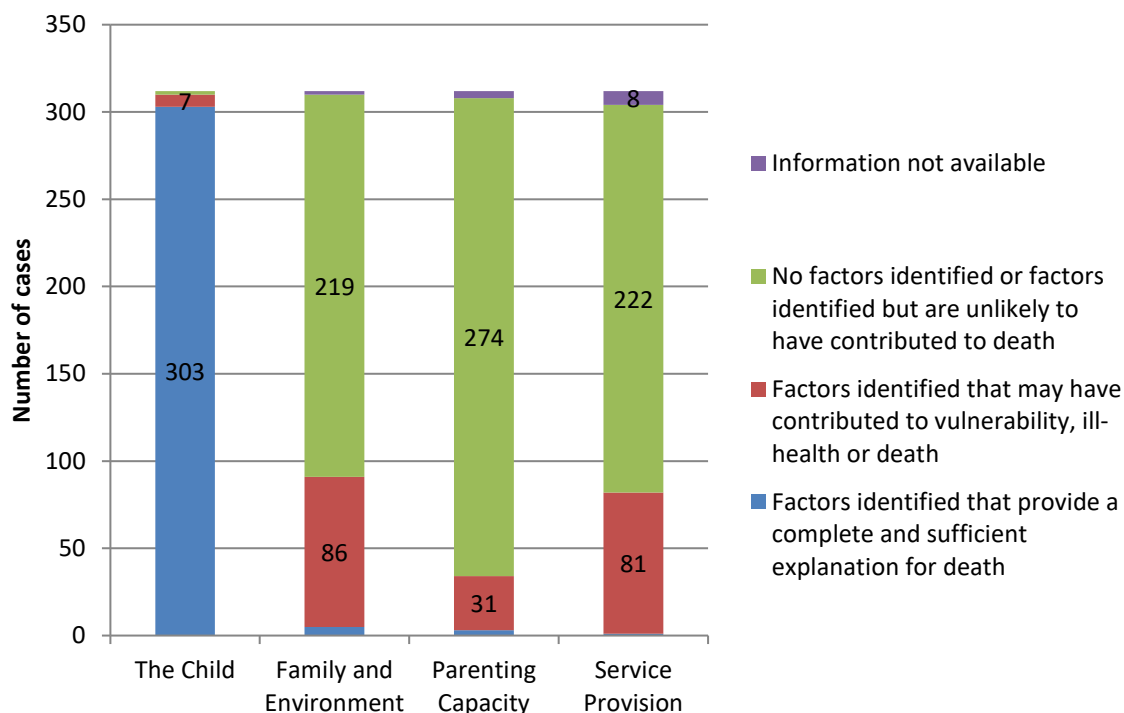
### 7.3 Summary factors identified as contributing to death (2014-2019)

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 97% of cases reviewed between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019, factors intrinsic to the child (i.e. the underlying medical or surgical problem) provided a complete explanation for the death. In 27.5% 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 5 cases, factors in the family and environment were thought to provide a complete explanation for the death. This includes deaths resulting from road traffic collisions. In 10% 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 three cases parenting capacity was thought to have provided a complete explanation for the death (i.e. safeguarding issue, child abuse or neglect). In 26% 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. In one case factors in service provision provided a complete explanation for the death. 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 2017-18 review year are:

- Delay in the diagnosis of a brain tumour
- Late notification of a vulnerable mother to the health visiting service
- Non-use of probiotics by neonatal unit due to a supply issue
- Delay in transfer for surgical review as transport teams not available in a time critical situation
- Delay in examination and transfer of mother to Central Delivery Suite in an out of region hospital
- Delay in commencement of CTG monitoring following transfer to Central Delivery Suite in an out of region hospital
- Lack of availability of beds at tertiary centre, leading to delay in transfer

**Figure 12: Contributory factors identified by CDOP in cases reviewed between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019**



### 7.3.1 Additional factors in the family and environment (2014-2019)

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 7. Of the 312 cases reviewed by CDOP between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019, parental smoking was noted to have contributed to the ill-health, vulnerability or death of the child in 10% of cases. Domestic violence was known to be present in 18% of cases, however this factor was thought to have contributed to the ill-health, vulnerability or death of the child in 4% of cases. An emotional, behavioural or mental health condition in a parent or carer was also identified as contributing to the ill-health, vulnerability or death of the child in 4% of deaths reviewed. Mental health issues include maternal or paternal depression, previous self-harm and previous suicide attempts. Alcohol or substance misuse by a parent or carer was thought to contribute to ill-health, vulnerability or death in 4% of cases and housing issues that contributed to the ill-health, vulnerability or death of a child were present in 3% of the deaths reviewed. These issues were usually overcrowding and/or a chaotic or extremely unclean environment.

**Table 7: Factors in the family and environment recorded in cases reviewed by CDOP between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019**

	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>	75	32	0	177	28	10.25%
<b>Alcohol or Substance Misuse by a parent or carer</b>	29	13	0	239	31	4.16%
<b>Domestic violence</b>	45	12	0	252	<5	3.84%
<b>Emotional, Behavioural or Mental Health condition in a parent or carer</b>	85	11	<5	186	29	3.80%
<b>Housing</b>	30	10	0	272	0	3.20%

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 (2014-2019)

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 8.

**Table 8: Factors in parenting capacity recorded in cases reviewed by CDOP between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019**

	<b>Grade 1</b>	<b>Grade 2</b>	<b>Grade 3</b>	<b>Factor not present</b>	<b>% of cases where factor considered to have contributed to ill-health, vulnerability or death of a child</b>
<b>Poor parenting / Supervision</b>	5	12	0	295	3.84%
<b>Child abuse / neglect</b>	5	10	<5	292	4.48%

Of the 312 cases reviewed between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019, CDOP concluded that poor parenting/supervision was a factor that had contributed to the ill-health, vulnerability or death of the child in 3.8% of cases. In 4.5% 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 Modifiable Factors (2014-2019)

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 212 of the 312 cases reviewed by the West of England CDOP in the five year period (68%) no modifiable factors were identified. In 94/312 (30%) cases modifiable factors were identified. In 6/312 (2%) 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 2016 to 31<sup>st</sup> March 2017 (the most recent data available) shows that nationally 27% of child deaths were found to have modifiable factors. This represents an increase from 24% for the previous two years. Panels across England have identified modifiable factors in between 22 and 32% of the child death reviews they completed<sup>4</sup>.

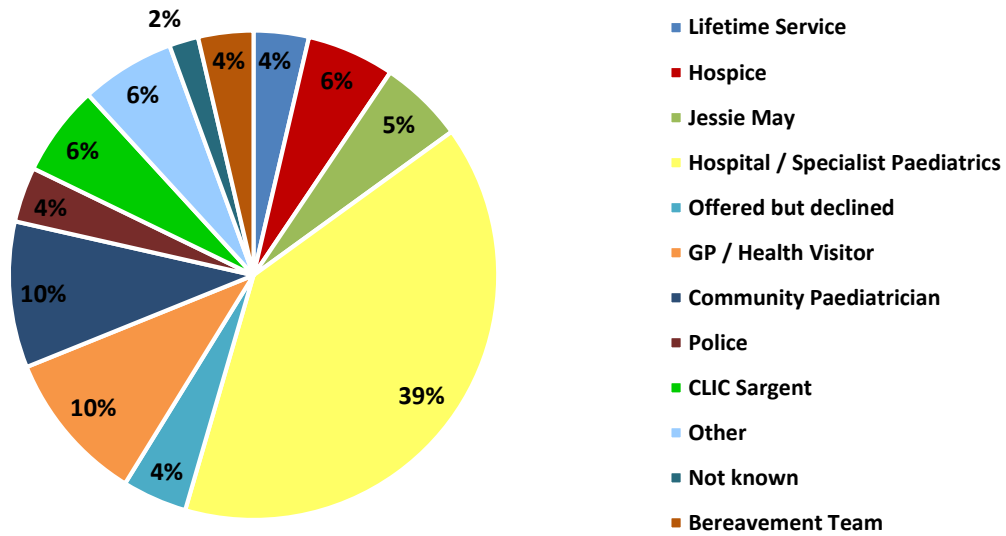
### 7.5 Family follow up (2014-2019)

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 2014 and 31<sup>st</sup> March 2019. 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. 39% of families received follow-up from hospital or specialist paediatrics. This includes obstetrics, neonatology, cardiology and oncology. 10% of families received follow up from primary care (GP or health visitor) and a further 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 21% of families during this period. 4% 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 University Hospitals Bristol NHS Foundation Trust. This year represents the second year that data has been collected on the number of families being followed up by the Bristol Children's Hospital Bereavement Team. 100% of children who died at Bristol Children's Hospital, or were taken there after death, received an offer of support from this team.

#### **Figure 13: Agency providing follow up to families in cases reviewed by CDOP between 1<sup>st</sup> April 2014 and 31<sup>st</sup> March 2019**

<sup>4</sup> Department for Education *Child Death Reviews: Year Ending 31 March 2017*, Department for Education, SFR 36/2017, 13<sup>th</sup> July 2017

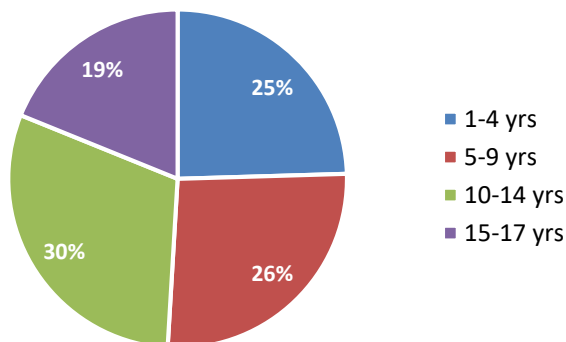


**8. Focus on the deaths of children with malignancy conditions (2014-2019)**

For the purposes of this section, the deaths included were all children who were determined by CDOP to have died from a condition categorised as malignancy. In paediatrics that includes children diagnosed with cancer (including malignant brain tumours and leukaemias) as well as related conditions managed by the Paediatric Haematology and Oncology teams – benign brain tumours, histiocytic disorders, marrow failure syndromes and other lymphoproliferative diseases. Classification of malignancy includes death due to the primary disorder or deaths due to conditions because of complications. Deaths unrelated to the malignancy i.e. road traffic accident are not included.

Over the 5-year period, 35 children were reported to have died from malignancy. Figure 14, below, shows the age of death of these children. 30% children were in the 10-14 year age group, with almost the same number of children in the 1-4 year and 5-9 year age groups. 19% were in the 15-17 year age group.

**Figure 14: Deaths from malignancy by age (2014-2019)**



Children had the following broad categories of malignancy:

Category of malignancy	Number of cases
Haematological	11
Central Nervous System (CNS)	12
Bone and soft tissue sarcoma	6
Relapsed Neuroblastoma	<5
Other	<5

3 children had second malignancies.

Cause of death was attributed to:

Cause of death	Number of cases
Relapsed or refractory cancer	24
Central Nervous System Causes (including bleed, infarction, dysfunction, leukoencephalopathy, acute obstructive hydrocephalus with brain stem compression)	5
Infection	<5
Multi-organ failure	<5
Pleuropulmonary fibroelastosis	<5

29 cases involved planned palliative care, 1 failed CPR, and 5 cases involved withdrawal or withholding of life sustaining treatment.

In 18 cases an end of life care plan was in place at the time the child died. In 4 cases there was no end of life care plan in place for reasons including rapid deterioration, discussions not formally recorded, and families not being ready or declined. 21 died in the family's location of choice. 4 of these cases were found at CDOP to have modifiable factors which may not have made a difference for that child but could potentially improve care in future cases. Factors identified include delay in the diagnosis due to factors such as an unusual presentation, non-registration of a child at a GP surgery, leading to late diagnosis of the malignancy.

Nationally, 230 children die of cancer each year<sup>5</sup> with brain and other CNS and intra-cranial tumours being the leading cause of death. Childhood cancer mortality has decreased by approximately 27% over the last 10 years<sup>6</sup> although cancer still continues to be the leading cause of death in children between the ages of 1-9 years in the UK. The data presented in this report is typical of the types of childhood cancer that lead to early death. Childhood leukaemia has a very favourable prognosis and all cases of death in this series were in relation to relapsed disease where prognosis for some is poor - in particular secondary Acute Myeloid Leukaemia (AML) which is known to be refractory to treatment with poor survival figures (approximately 25%).

Over half of the deaths in the CNS tumour group were in children with high grade brain tumours expected at diagnosis to have a poor outcome; the two relapsed brain tumours were also not expected to be cured. In the solid tumour group relapsed neuroblastoma accounted for the most

<sup>5</sup> Cancer Research UK data 2014-2016

<sup>6</sup> <https://www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers#heading-One>

deaths - this is a difficult tumour to treat with only 2/3 patients achieving 5 year survival, and in relapse prognosis is dismal.

Childhood cancer treatment requires multi-agent toxic therapies - surgery, chemotherapy and radiotherapy - and recorded cause of death for these children is a reminder that both the primary tumour and complications of the therapies used can lead to the death of the child by, for example, infection secondary to immunosuppression or cerebral infarction or brain stem compression secondary to brain tumour. Reducing death rates from childhood cancer therefore requires focus on development of new treatments for hard to cure cancers, strategies that reduce risk of secondary cancer and good supportive care. Other diagnoses for cause of death within this population such as fibroelastosis (lung scarring) and leukoencephalopathy (white matter degeneration of the brain) remind us that the long-term complications of childhood cancer treatment are widespread and can affect any organ system.

**The following areas of service delivery were noted for improvement:**

- Lack of home palliative nursing care (including lack of staff to appoint even if budget available)
- Late referrals for palliative/hospice care
- Late funding requests to commissioners
- Delays getting to settings
- Responding to families' ongoing requests for disease-modifying interventions at EOL
- Obtaining the right equipment (bed, stair lift, wheelchair)
- Difficulties for paramedics being able to access End of Life plan/knowing in advance child is EOL/Palliative
- Challenges around multiagency working and meaningful information sharing
- Need for urgent psychology e.g. for children who are aware they are dying and need support
- Finding the right palliative service for older teens
- Understanding cultural differences & English as second language
- Registering child death and certification difficulties

**Some examples of good practice were noted:**

- Services collaborating and sharing information and care
- Hospice responsive/early Paediatric Palliative care provided
- Good symptom control/peaceful death (directly mentioned in some– others implied)
- Hospital outreach to hospice
- Open involvement of child/young person with their care/prognosis
- Sibling support
- District nursing able to support 17yr old in community
- Suitable equipment & provided in a timely manner
- Personal health budget
- Being able to maintain education
- Flexible and supportive funeral directors

## **9. Child Death Overview Panel Activity (2018-2019)**

### **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 meeting. The CDOP also 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 9 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 9: Actions arising and outcomes**

<b>Case Description</b>	<b>Issue</b>	<b>CDOP Action</b>	<b>Response/evidence</b>	<b>Recommended National Learning</b>
Malignancy	The community team were unable to support the care of a specific chest drain due to lack of suitably trained community nursing support.	Wrote to Commissioners to highlight this case and questioned whether District Nurses could work alongside Paediatric community nurses in these cases, with appropriate adaptation of the adult guidelines for paediatric use in the future	Response from Divisional Director of Children's Services, Bristol Community Health suggesting these situations are rare but an approach to joint working could be considered - UHB Paediatric Palliative Care team have been asked to take this forward	Improvements needed to bring Palliative Care at home for children up to same standards as adults. (WoE Annual Report 2017/18 already quoted heavily in All Party Parliamentary working group report on Paediatric Palliative care 2018)
Infection	Pre-school children are not routinely invited for Influenza immunisation although they are eligible. There is a lower take up rate in this cohort as parents have to request immunisation from GP	Wrote to the Director of Public Health in area child resided highlighting the danger of influenza in young children	Response sets out robust and encouraging information about their extensive promotion of influenza immunisation for preschool children although still no universal invitation in this age group	Need for continued NHSE leadership on this issue - CDOP to write to Commissioning Lead for NHS England

Sudden, unexplained death of a teenager	Following death, there was confusion over where to take the child	To develop a pathway in conjunction with Police and the Ambulance Service to clearly identify where children should be conveyed following death	CDOP set up a working group including police, paediatrics, coroner and ambulance service (in particular considering where 16&17 year olds should be taken) to develop this pathway.	National Guidance does not always align with local service provision (e.g. 16 & 17 year olds not accepted in regional hospital following death so Child Death process not possible to follow in full for this age group)
Infection	After this child died there was inaccurate reporting of the cause of death by the newspaper and television media	Wrote to Public Health to find out what information was given and if this was potentially misleading	Public Health investigated and made several recommendations for future improvement	Issue of press reporting could be picked up via National Child Mortality Database in future
Malignancy	Lack of information available to ambulance crews regarding palliative care patients	Liaise with SWAST to consider more appropriate provision of information regarding patients with advance care plans	Working group involving CDOP Dr, Palliative care consultant and SWAST - a new pragmatic approach to be piloted involving better parent-held directive with simpler flag on SWAST system	This system could be published and shared nationally if successful
Acute surgical condition in a neonate	Delay in review of a baby following identification that the baby had not passed meconium in first 24hrs	Wrote to the Clinical Directors of all local trusts for reassurance that they are following NICE guidelines for babies who haven't opened their bowels by 24 hours of life and to ask how they ensure these guidelines are followed	Satisfactory responses received from local Trusts. Trust where this occurred have launched new educational materials to remind staff.	
Cardiac condition	Long delay in obtaining final post-mortem report causing distress to families	Wrote to the Royal College of Pathologists for an update on action being	Reply confirming there is still a shortage and many actions they are	

		taken to address the national shortage of paediatric pathologists	taking to recruit to the speciality	
Malignancy	This child was accepted for transfer to UK for treatment under the Vulnerable Child Refugee Programme - the poor prognosis for this child was not fully apparent until their arrival in the UK	Wrote to the Home Office regarding the Refugee Programme to enquire if clinician to clinician contact can be made mandatory prior to acceptance of a child through this scheme for treatment	Home Office stated that the decision was made locally by the CCG who stated they had all the information required and did not need clinician involvement at that stage. The CCG were informed of this issue.	This case raises the need for clinician involvement in acceptance of complex medical cases of through the VCRP.
Surviving twin following a SUDI	How to ensure a surviving twin is adequately protected	Check advice to SWAST and medical care providers	Presentation by CDOP Panel member to the European Paediatric Society on whether surviving twin should be admitted to hospital for assessment immediately. This practice adopted by SWAST.	
Neonatal death	Not clear if Hepatitis B vaccine offered to family members	Established that Public Health Guidance is that household contacts should be offered vaccination. Ascertain action taken from GP	Family were offered but did not take up vaccination. CDOP were satisfied there is a process in place to do this in line with Public Health England guidance.	

## 9.2 Themes emerging from aggregate review of cases at CDOP during the year April 2018 – March 2019

In 2018/19 there were three Neonatal themed meetings. There were no other specific themed CDOP meetings.

The following themes arose from review of 2 or more cases:



- Benefits of Family Nurse Partnership involvement in supporting first time mothers under 20 years old - CDOP noted a trial of Accelerated Design and Rapid Programme Testing (ADAPT) for mums over 20
- Difficulties ensuring public health prioritise targeting fathers - including provision of smoking cessation and safe-sleeping advice
- Rapid Response (now called Joint Agency Response) was not always triggered when appropriate – need to ensure this is considered and decision-making documented
- Serious Care Review – CDOP have made referrals to the SCR panel, but this should always be considered early and activated earlier in the process as soon as criteria may have been met
- Child Death process not always followed especially in adult settings where 16 – 17 year olds seen – poor engagement with Child Death Review meeting even when process is flagged – need for ongoing awareness raising of statutory nature of process
- Co-sleeping in hazardous conditions
- Support for professionals when there are multiple reviews following high profile and traumatic deaths
- Need to streamline and reduce duplication of processes
- Managing DNAs and sharing knowledge of these between agencies
- Electronic prescribing to help reduce human error

As always, much good practice was noted by CDOP including where professionals were proactive in enabling a child's voice to be heard in End of Life decision making

Child Death Peer Review Meetings for community paediatricians are facilitated by the Designated Doctor, to allow advice and shared learning from cases, as well as maintenance of a high standard of Child Death Processes.

## 10. Achievements and Future priorities

In 2018 the Annual Report was again presented in a lecture format as a single event for stakeholders which was well received and allowed high level discussion. The slide set and Annual report were provided to LSCBs.

The sepsis themed review from 2018 Annual Report was presented to the Bristol Children's Hospital Grand Round, as well as other audiences, with ensuing discussion.

The eCDOP data management system has been introduced, to allow direct upload to the National Child Mortality Database, reduce admin time and ensure our processes are compliant with GDPR. The shift to eCDOP and new national Notification, Reporting and Analysis forms has brought an administrative challenge but with longer term hopes of saving labour and improved standardisation.

The question was raised in CDOP of whether we would become aware of local rises in mortality similar to those identified in Chester or Shropshire recently. CDOP currently review death notifications on a month by month basis which should enable this. In particular, CDOP have noted the increased number of deaths of out of area children in our area, and the decrease in numbers of deaths of residents in Bristol and South Gloucestershire in the past year. CDOP spent time considering how these trends will be monitored with the transfer to the new eCDOP system of data collection.

Implementing the National CDR Statutory and Operational Guidance 2018 is an ongoing task. Commissioning arrangements and process pathways are being reviewed with partner organisations.

The annual multi-agency training has been revamped in line with the new Guidance, and all existing professionals invited for updates.

Themed reviews are set out in the new Guidance e.g. for neonatal, cardiac and suicide deaths. West of England CDOP already has these but has taken this as an opportunity to further strengthen networks. There is an option to expand CDOPs to cover a greater geographical area. WoE CDOP does not plan any change in this respect but is aware of the need to link to Sustainability and Transformation Plan areas / Operational Delivery Networks and have reciprocal arrangements with neighbouring areas when deaths involve regional specialist care or travel away from the place of residence.

WoE CDOP welcome the launch of the National Child Mortality Database hosted by the University of Bristol, and there is anticipation of much greater opportunity for national learning in future.

## Appendix A - CDOP membership April 2018 to March 2019

	<b>Core member</b>	<b>LSCB/Organisation</b>
Nominated Chair	Eifion Price	North Somerset
Public Health (to 31.08.18)	Bruce Laurence sharing with Rebecca Reynolds	BANES
Public Health (from 01.09.18)	Jo Williams sharing with Jo Copping	Bristol
Designated Doctor for Child Deaths	Mary Gainsborough	Sirona Healthcare
Coroner's Officer	Debra Neil	Bristol
Children's social care (until 31.08.18)	Jo Baker	North Somerset
Children's social care (from 01.09.18)	Catherine Boyce	South Gloucestershire
Head of Safeguarding BNSSG CCG	Jackie Mathers	BNSSG
Designated Lead Nurse Safeguarding BANES CCG	Liz Plastow	BANES
Midwifery	Julie Northrop	UHB NHS Trust
Consultant in Fetal Medicine and Obstetrics	Mark Denbow	UHB NHS Trust
Consultant in Neonatology	Steve Jones	RUH Bath NHS Foundation Trust
General Practice	Patrick Nearney / Elaine Lunts	Bristol
Police	Larisa Hunt	Avon & Somerset Constabulary
Paediatric Palliative Care	Francis Edwards	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
Head of Safeguarding; Ambulance Service	Simon Hester	South Western Ambulance Service NHS Foundation Trust

## Appendix B – UHB Financial Summary 2018/19

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 2018/19</b>			
<b>Description of Cost</b>		<b>Payment Due</b>	<b>£ Cost to UHB</b>
Designated Doctor	MPR	1.5 Additional PA's	£22,476
Paediatric Lead – Bristol Children's Hospital	BRCH	1 Additional PA	£11,683
Neonatology Lead - St Michael's	MPR	1 Additional PA	£9,326
Neonatology Lead - Southmead	MPR	0.5 Additional PA	£6,517
Community Paediatricians	RRT	320 hours Total	£25,346
GP and ED Consultant Costs	MPR	Attendance at some panels	£6,435
UOB Senior Manager	MPR	14 hours per week	£38,468
UOB Secretarial Support	MPR/PNM	3 days per week	£25,968
UOB Secretarial Support	PNM	2 days per week	£10,721
UOB Secretarial Support – Sirona Community Paediatricians	RRT		£3,001
Sirona Psychology support	RRT		£3,637
<b>Sub-total</b>			<b>£163,578</b>
Local authority funding UOB office			
• Manager	MPR		£5290
• Administrative support	MPR/RRT		£21,164
<b>Total Costs</b>			<b>£190,032</b>