

**WEST OF ENGLAND**

**CHILD DEATH OVERVIEW PANEL**

**April 2017 – March 2018**

**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 Sleaf for co-authorship of the report.
- Becky Reynolds (Consultant in Public Health, Bath & North East Somerset Council) for providing data on crude death rates (2013-2018) for Section 6.1
- Dr Karen Luyt, Dr Stefania Verganio and Dr Nicholas Sargant for helpful comments on section 7 'Focus on the deaths of children from infection'
- Dr Michelle Morgan for her comments on psychology support for the Paediatricians involved in this process.

Mary Gainsborough

## 2. Foreword

There is no footprint too small to leave an imprint on this world.

Whether a life is measured in minutes, months or years, the loss of a child is profoundly devastating. The professional care, kindness and dignity we afford to these children, their families and those close to them is at the heart of the Child Death Overview Panel's purpose and endeavour.

This is the tenth annual report of the West of England Child Death Overview Panel and it builds upon the body of knowledge that has been painstakingly gathered over those years. As Independent Chair I can attest to the thorough scrutiny every case receives and the candour and challenge with which Panel members pursue continuous improvement. Every opportunity is examined to reduce the likelihood of further child deaths.

It has been heartening that, in addition to seeking out modifiable factors, the Panel have identified a number of circumstances of exceptional care. These have been given formal recognition and, where appropriate, action taken to replicate initiatives.

The Panel looks carefully to ensure that the voice of the child or young person has been elicited and heard in determining, wherever appropriate and possible, the type of care they wish to receive. The care, respect and support shown to families is also carefully examined.

The work of the Panel is enhanced by the dataset of ten years it has collected (of which data from the last 5 years is presented in this report) and that provides sound evidence to direct us to emerging themes and issues. The expertise in this matter has contributed to University of Bristol making a successful bid to deliver the government contract for the National Child Mortality Database. This national initiative is internationally ground breaking and we are proud of our colleagues for their success in being chosen to deliver this work. The contract commenced 1 April 2018.

The information in this report will be of interest to professionals and local communities. Amongst the themes upon which we focus are,

- Death by infection or sepsis. This issue has received some increase in national public awareness and remains a significant proportion of the cases we examine. The findings in West of England are summarised below;
- Death by suicide. Recurring factors were recognised during themed CDOP meetings undertaken in May 2015 and January 2018. The Panel have further developed and added to this knowledge. There has been extremely valuable understanding gained and this is captured below. I am grateful that our recent themed meeting was supported by an invited expert in child suicide advising the Panel.

It is imperative that our findings, in addition to the many actions that we instigate, reach a wider audience who are able to make use of the learning achieved. Our report last year was presented in a lecture format for the first time and this proved a very engaging and

successful method of dissemination. It is important that the findings of the Panel are in the public domain, are widely understood and inform best practice.

The work of our Panel is underpinned by a small, highly skilled and hardworking team led by Vicky Sleep. Critical also to the leadership of the Panel is Dr. Mary Gainsborough Designated Doctor for Child Deaths. Our Panel members have worked diligently and offered professional challenge within and across their spheres of expertise. I am confident in reporting that it is a highly functioning scrutiny arrangement.

The national arrangements for Child Death Overview Panels are subject to legislative change. I am confident that West of England CDOP is well placed to make a successful transition to those new arrangements once revised guidance and requirements are enacted.

It has been my privilege to act as Independent Chair in this important work and I conclude my tenure in that role with great pride in the professionalism of my partners and colleagues. Whilst our work can never diminish the pain and loss of bereaved families; our most sincere and strenuous pursuit of continuous improvement is the very least they can expect from us.

SJ Lewis

Sally Lewis OBE

### 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 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. 532 child deaths were notified to the West of England Child Death Enquiries Office between 1st April 2013 and 31<sup>st</sup> March 2018.
4. Between 2013 and 2018, 216/532 (41%) 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 2013 and 2018, 69% 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. Deaths in 1-4 year olds showed a continued decrease over the 5 year period.
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; 35% remaining unexplained after a full investigation and the local case review meeting. 32% of deaths due to perinatal complications (mostly extreme prematurity), and 26% children with chromosomal, genetic or congenital conditions. Acquired natural causes account for 26% and external causes, encompassing deliberate injury, suicide and trauma, accounted for 7%.
8. Between 2013 and 2018, 45% 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 324 cases in detail between 1<sup>st</sup> April 2013 and 31<sup>st</sup> March 2018. 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 2013/14 and 2014/15 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 38% of cases.
11. 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.
12. In 97.8% 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.
13. Factors that may have contributed to the vulnerability, ill-health or death were identified in the family in 27%, related to parenting capacity in 9% and in service provision in 27%. Parental smoking was classed as contributory in 8.9% of deaths, emotional, behavioural or mental health issues in 3%, alcohol or substance abuse in 2.7%, housing issues in 1.8% and

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

domestic violence in 3.4%. It should be highlighted that positive parenting was noted in many cases.

14. 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
15. Family bereavement follow-up was documented in 98% of cases, with hospital or specialist paediatrics providing this in 43% of cases, primary care in 12% and hospice/community nursing in 14%. 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 the deaths of children from infection**

16. Over the 5-year period, a total of 51 children were reported to have died from specific infections. Many of these children were vulnerable because of prematurity or underlying complex medical problems, but around 1/3 were previously well children.
17. 29% 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.
18. Issues identified include some related to facilities, such a crowded Emergency department and lack of suitable resuscitation facilities at delivery, delay in considering rare infectious causes and delay in starting antibiotics.

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

19. 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.
20. Important issues highlighted by CDOP were disseminated through the constituent agencies and the chairs of the Local Safeguarding Children Boards.
21. Issues noted at CDOP led to specific actions in some cases:
  - Raising national mother and baby unit capacity with NHS England
  - Ensure local care standard for Spinal Muscular Atrophy type 1
  - Explore avenues for bystander support following a road traffic collision or other incident
  - Challenge Commissioners on out of hours provision for replacement of feeding tubes
  - Ensure pre-conception counselling to women with diabetes
  - Question British Transport Police about suicide reduction strategies

#### **Themes**

22. Certain themes have emerged from reviewing children's deaths in the West of England this year:
  - Review of suicides identified a number of themes
    - Role of Education in emotional support and safeguarding intervention
    - Potential for forthcoming changes to PHSE to improve reporting when young people have concerns about a peer
    - Press intrusion increasing distress

- Need for improved professional awareness of risk factors
- CDOP continues to review cases where a choice of place of End of Life care has been limited by the lack of availability of community based palliative care
- Challenges in the Child Death Review process for 16-17year olds, with small numbers across a number of 'adult' settings
- Inadequate or delayed communication about a child's death to involved professionals
- Lack of a commissioner Community Paediatric Respiratory Physiotherapy Service

#### **Achievements and Future Priorities**

##### 23. Achievements and Future Priorities

- New lecture format for presentation of CDOP Annual Report to stakeholders piloted in September 2017
- Agreements to coordinate with other review processes e.g. RCA, SCRs to avoid duplication
- University of Bristol have been awarded the contract for the National Child Mortality Database
- Anticipation of the new statutory National Guidance for Child Death processes which will require a review of local processes and revised training to multi-agency professionals



#### 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 2017/18, the WoE CDOP Chair has rotated from South Gloucestershire to Bristol LSCB. The Terms of Reference, Governance Arrangements, and Membership are summarised in documents available at [www.bristol.gov.uk](http://www.bristol.gov.uk). The Child Death Enquiries Office at the University of Bristol administers all functions of the WoE CDOP.

The WoE CDOP reviews information on every child who has died whose post code of residence is 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 tenth Annual Report of the West of England CDOP. It was approved by the Panel on Wednesday 11<sup>th</sup> July 2018 and will be presented to stakeholders including representatives from the 4 LSCBs on 5<sup>th</sup> October 2018. It will be a public document. Previous year's Annual Reports can be found online or requested from the Child Death Enquiries Office at University of Bristol.

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 2013 – 2018)

This section summarises all deaths notified to the Child Death Enquiry Office, between April 1<sup>st</sup> 2013 and March 31<sup>st</sup> 2018, 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 2013-18.

**Table 1: Crude death rate per 10,000 children aged 0-17 (2013-2018)**

	Crude Rate per 10,000	Lower Limit	Upper Limit
BANES	2.07	1.45	2.87
Bristol	3.46	2.94	4.04
North Somerset	2.30	1.70	3.03
South Gloucestershire	2.47	1.93	3.12
West of England	2.78	2.48	3.10

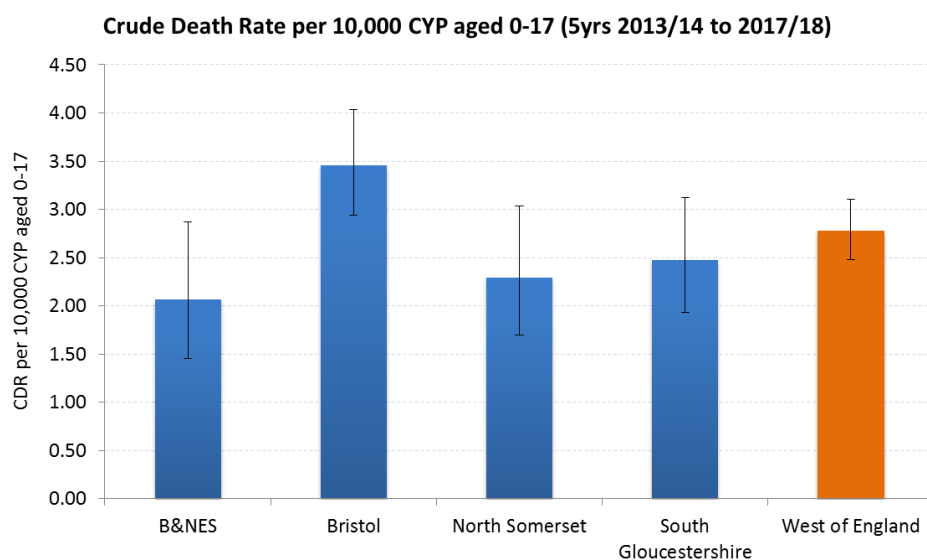
Notes: (1) 95% confidence intervals estimated using Byar's approximation

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

(2) Due to non-release of 2017 mid-year population estimates 2016 populations have been used as a proxy for 2017 figures

(3) The latest revised ONS population mid-year estimates have been used for mid-2013, mid-2014, mid-2015 and mid-2016

(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, North Somerset and South Gloucestershire all have statistically similar crude death rates.
- BANES, North Somerset and South Gloucestershire all have statistically similar crude death rates.
- Bristol has a significantly higher crude death rate compared to BANES.

## 6.2 Analysis of notifications by year (2013-2018)

During the period 2013-2018, 532 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.

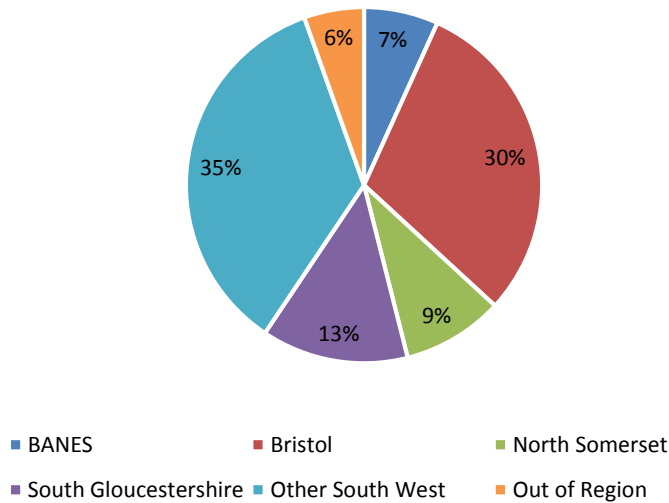
**Table 2: Notifications by region of residence, 2013-2018**

Region	2013/14 Deaths	2014/15 Deaths	2015/16 Deaths	2016/17 Deaths	2017/18 Deaths
BANES	6	8	8	6	8
Bristol	30	31	35	28	34
North Somerset	13	6	14	9	6
South Gloucestershire	12	12	13	18	16
Other South West	37	37	36	40	37
Out of Region	14	9	3	1	2
<b>Total</b>	<b>112</b>	<b>103</b>	<b>109</b>	<b>102</b>	<b>103</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.

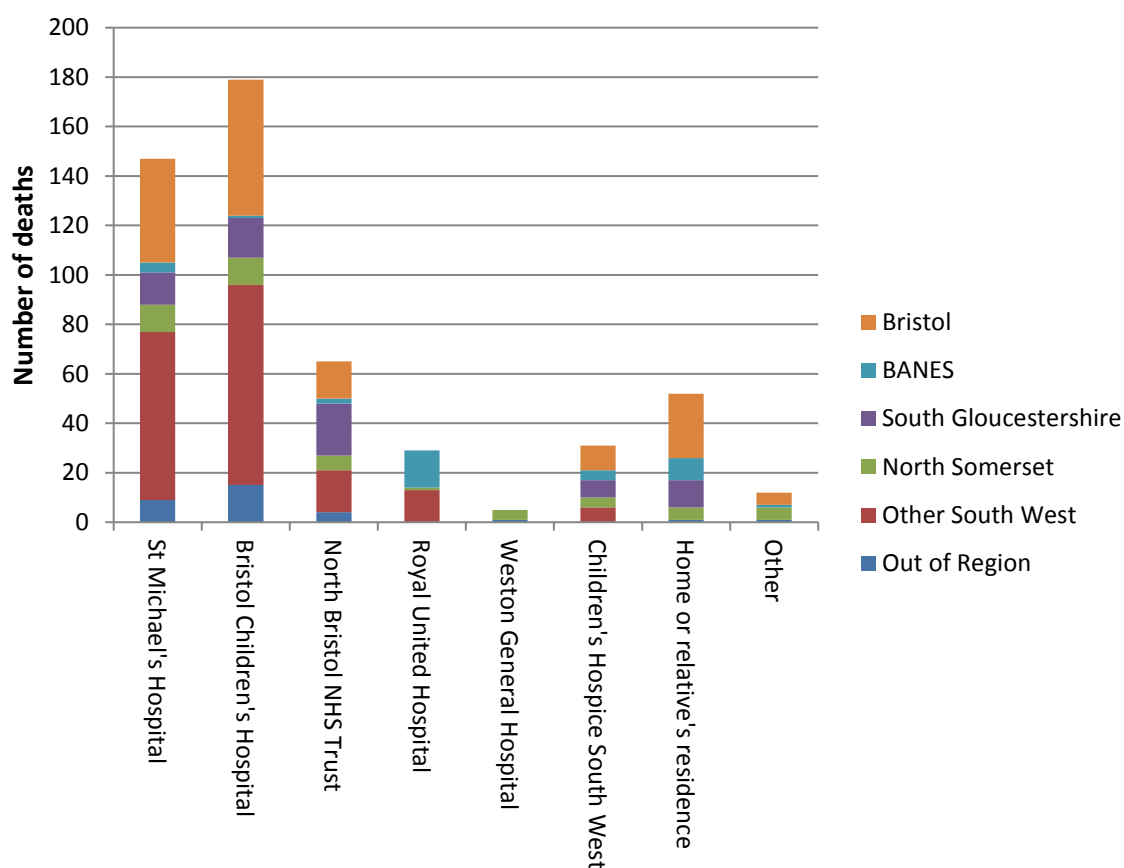
**Figure 1: Notifications by area of residence, 2013-2018**



### 6.3 Location of death (2013-2018)

This data records where the child actually died. Over the five-year period 33.6% (179/532) of all child deaths occurred at the Bristol Children's Hospital, 27.6% (147/532) at St. Michael's Hospital, 12.2% (65/532) at hospitals within North Bristol NHS Trust (Southmead and formerly Frenchay Hospitals), 5.8% (31/532) died in a hospice, and 9.9% (53/532) died at home or at a relative's residence. Of the children who died at home or at a relative's residence, 68% (36/53) were unexpected deaths and 32% (18/53) were expected deaths (See section 6.9 for further information on expected vs unexpected deaths). 8.6% (46/532) died in other hospitals and 2% (11/532) 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, 2013-2018



The precise location of death for children dying within hospitals in the West of England region in 2013-2018, is shown below in Table 3.

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

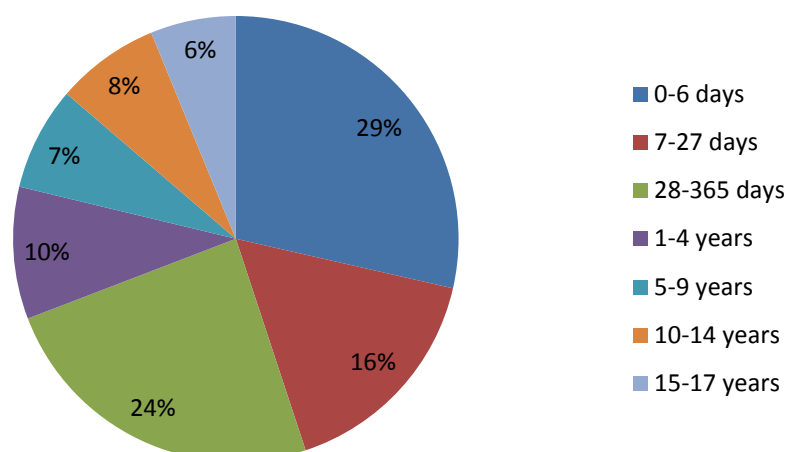
Hospital	Paediatric/Neonatal Intensive Care Units (PICU/NICU)	Emergency Department	Children's Wards/Theatres/Central Delivery Suite	Adult ICU
<b>Bristol Children's Hospital, University Hospitals Bristol</b>	125 (PICU)	31	24	n/a
<b>Royal United Hospital, Bath</b>	5 (NICU)	5	19	0
<b>St Michael's Hospital, University Hospitals Bristol</b>	131 (NICU)	n/a	16	n/a
<b>North Bristol NHS Trust Hospitals</b>	38 (NICU)	2	23	4

<b>Weston General Hospital</b>	n/a	4	1	n/a
<b>Other Hospitals</b>	6	1	1	1

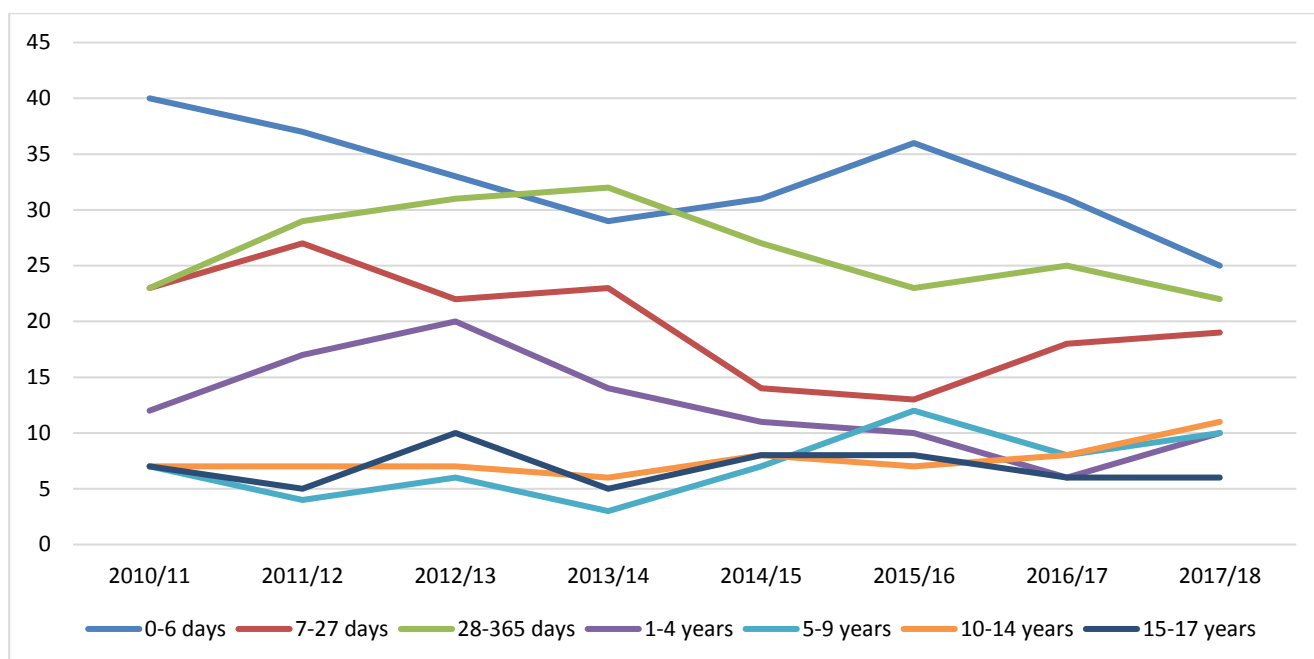
#### 6.4 Age at Death (2013-2018)

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 69% 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, 2013-2018



We can also look at the trends in deaths by age group over an eight year period (2010-2018) 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 for the first 4 years, followed by an increase in the following two years before a record low this year. This year has seen an increase in the numbers of deaths of 1-4 year olds, 5-9 year olds and 10-14 year olds.

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

### 6.5 Gender (2013-2018)

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 (2013-2018)

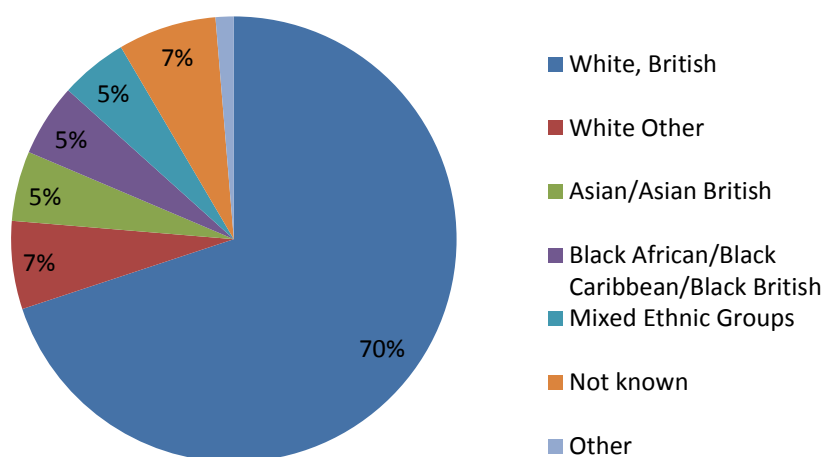
Figure 5 shows that 70% of notifications received by the Child Death Enquiries office between 2013 and 2018 were for children of White, British origin. 7% of notifications were for children of White, Other origin. This includes children of European ethnicity. The number of notifications for children whose ethnicity was recorded as Asian or Asian British was 5% and the number of notifications for children whose ethnicity was recorded as Black or Black British was 5%. In 7% 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, 2013-2018**

<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

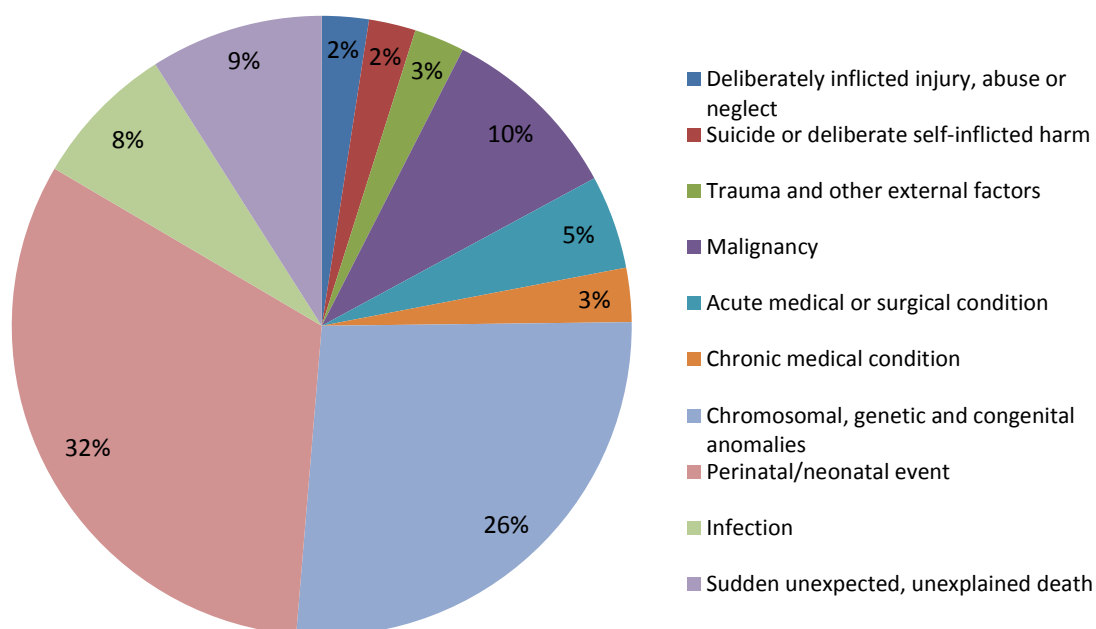




### 6.7 Category of Death (2013-2018)

The CDOP is required to categorise each child death using a standard list of categories shown in Figure 6. During the five-year period, 32% 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 (8%) and Acute medical or surgical condition (5%) 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, 2013-2018



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 2013 and 2018**

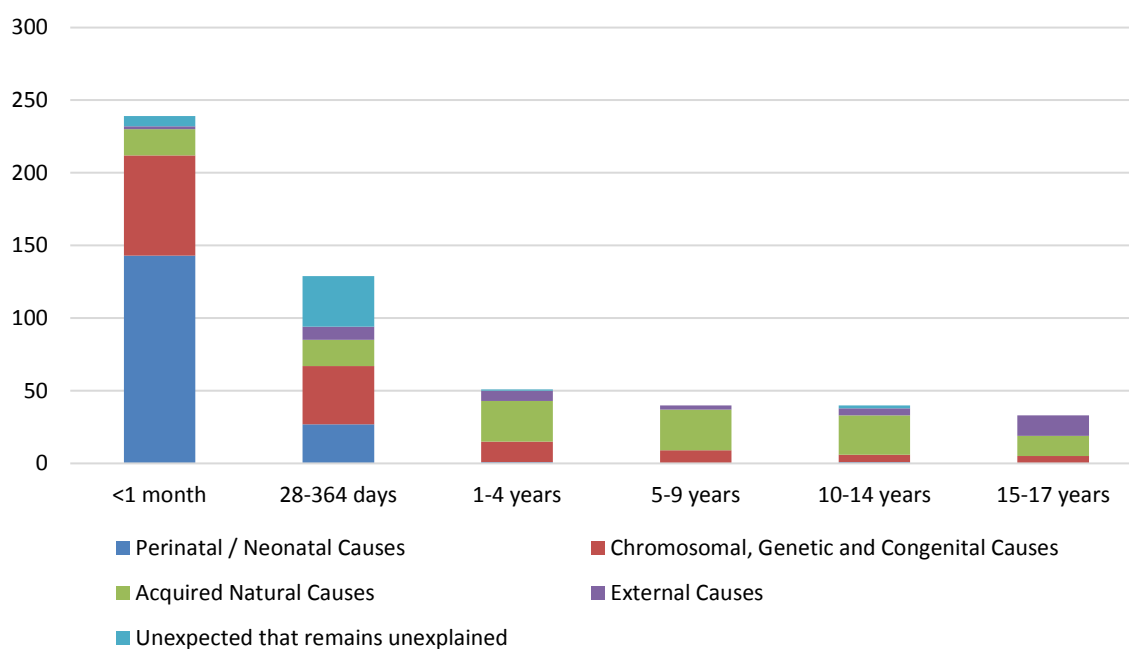
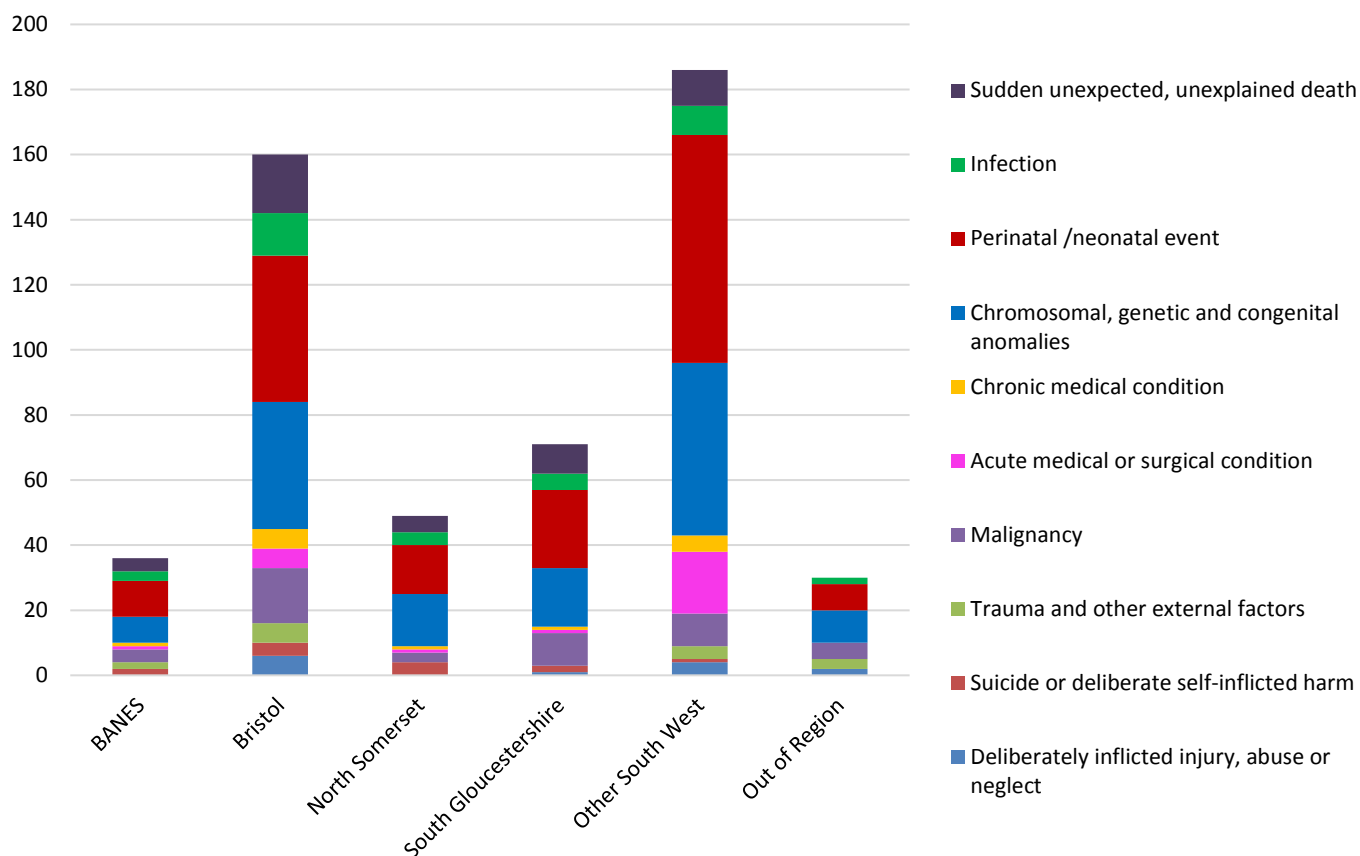


Figure 8 below shows the causes of childhood death for each of the LSCB areas within the WoE CDOP, together with those recorded for non-resident children who died within the West of England area.

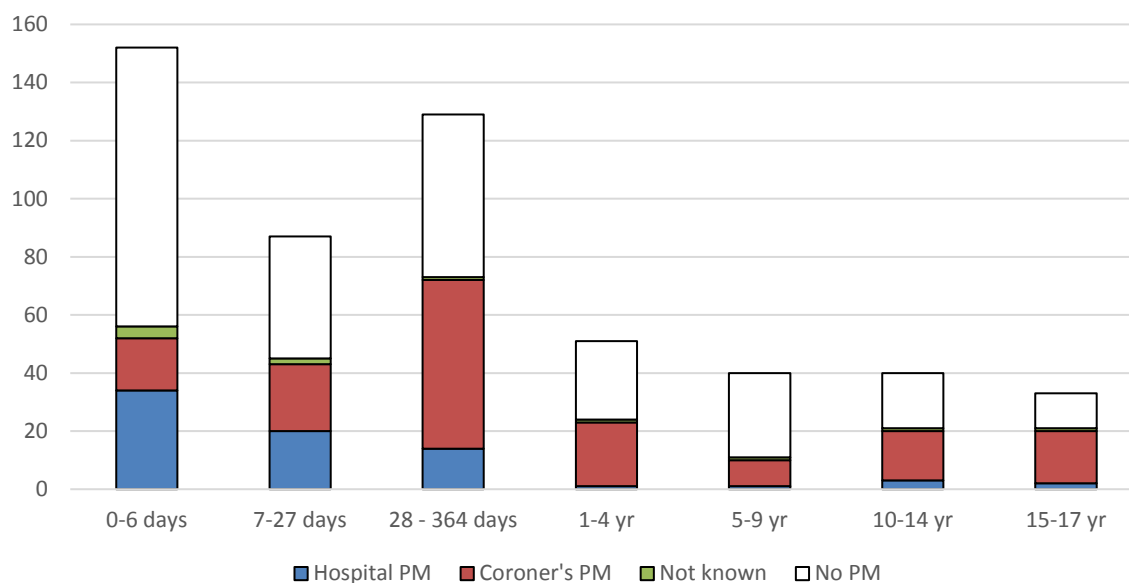
**Figure 8: Causes of childhood death by area of residence, 2013-2018**



### 6.8 Post mortem examinations (2013-2018)

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 165/532 deaths (31%) and a hospital post mortem occurred in 75/532 deaths (14%). 281/532 (53%) cases did not have a post mortem. In 11/532 (2%) it was not known if the child had a post-mortem examination at the point of notification of the death. 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. The national shortage of paediatric pathologist remains an issue in this area. Long delays in obtaining post mortem reports continues 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, 2013-2018**



### 6.9 Unexpected and Expected deaths (2013-2018)

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.

137/532 (26%) of deaths in children aged 0-17 years were unexpected. 48/137 (35%) 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 2013-2018**

Cause of death	% of total unexpected deaths
Sudden unexpected, unexplained death (including SIDS)	35
Trauma and other external factors (including road traffic accidents, drowning, deliberately inflicted harm and suicide)	29
Other (including chronic and acute medical conditions, malignancy and perinatal/neonatal event)	16
Infection	11
Chromosomal, genetic and congenital anomalies	9

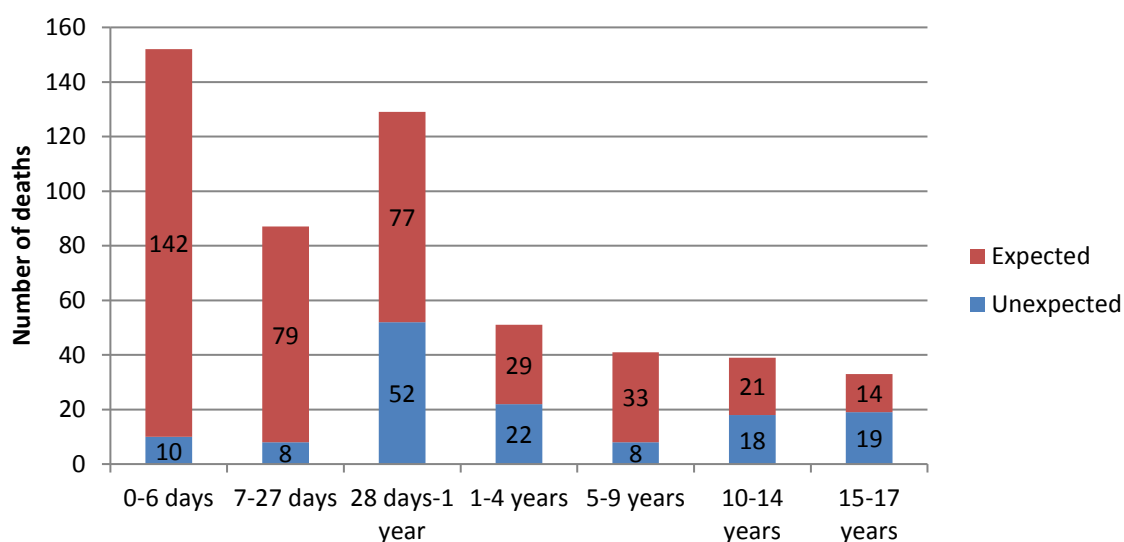
It is worth noting that children with chromosomal, genetic and congenital anomalies can die in an unexpected fashion many years after their birth.

Over the five year period there were 395 expected deaths notified to the Child Death Enquiries Office. Of these deaths 298/395 (75%) 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 (42%) or chromosomal, genetic or congenital anomalies (33%). The main categories of the expected deaths can be broken down as follows:

**Table 5: Causes of expected deaths of children 2013-2018**

Cause of death	% of total expected deaths
Perinatal / neonatal event	42
Chromosomal, genetic and congenital anomalies	33
Malignancy	12
Infection	6.5
Chronic and acute medical conditions	6.5

Figure 9: Expected versus unexpected deaths by age group, 2013-2018



## 7. Child Death Overview Panel Review Data (2013-2018)

These data are drawn from the CDOP database (see Section 5). They summarise the Panel's review decisions for 2013-2018 and its actions for 2017-18. 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

	2013/14	2014/15	2015/16	2016/17	2017/18
Total number of notifications	112	106	109	102	103

Number of cases to be reviewed by WOE CDOP	66		60		72		61		64	
	Number reviewed	% reviewed	Number reviewed	% reviewed	Number reviewed	% reviewed	Number reviewed	% reviewed	Number reviewed	% reviewed
2013/14	5	8								
2014/15	46	70	5	8						
2015/16	15	22	42	70	12	17				
2016/17	0	0	9	15	49	68	8	13		
2017/18	0	0	3	5	8	11	36	59	5	8
<b>Total</b>	<b>66</b>	<b>100</b>	<b>59</b>	<b>98</b>	<b>69</b>	<b>96</b>	<b>44</b>	<b>72</b>	<b>5</b>	<b>8</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 but four cases of children who died prior to 1<sup>st</sup> April 2016 have been reviewed by CDOP.

Sections 7.1 to 7.5 describe data relating to the 324 children reviewed by the West of England CDOP between 1<sup>st</sup> April 2013 and 31<sup>st</sup> March 2018. 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 (2013-2018)

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 324 children reviewed, 222/324 (68.5%) had no co-morbidities at all and 102/324 (31.5%) had at least one co-morbidity. Of the children with at least one co-morbidity 41/102 (40%) had a single co-morbidity and 61/102 (60%) 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.

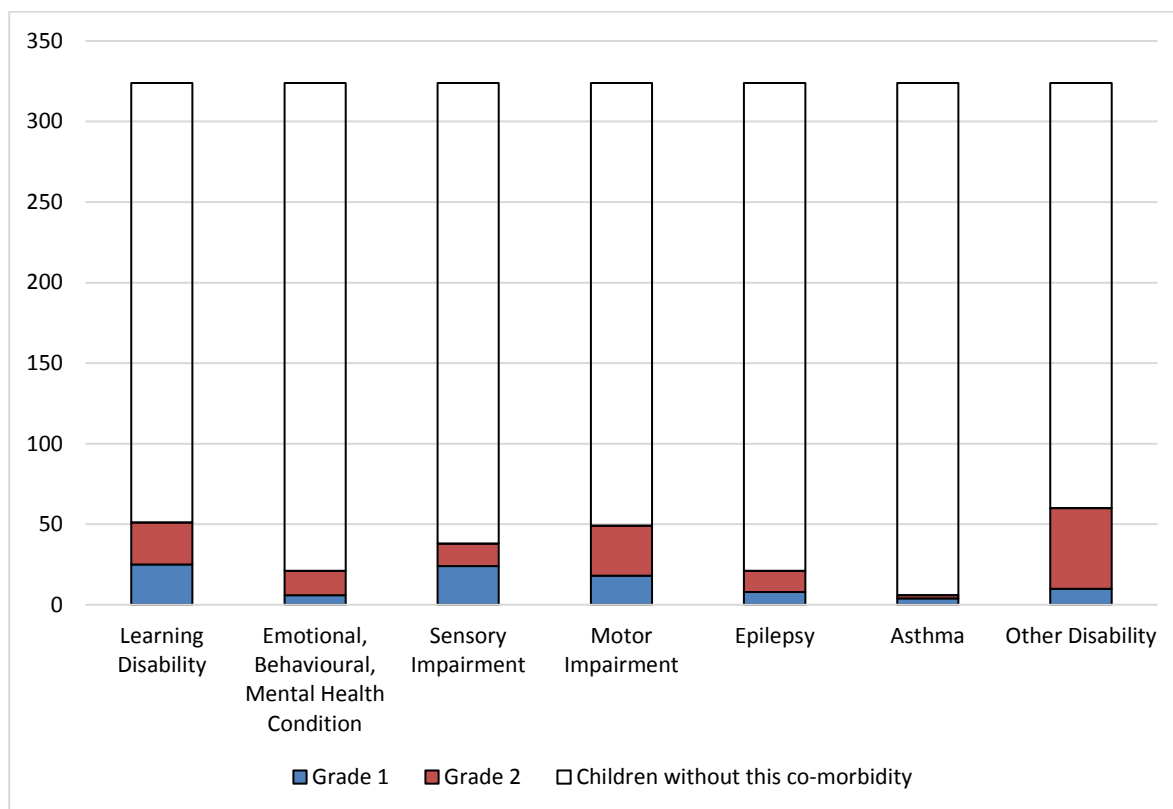
Children with a motor impairment (9%) and children with a learning disability (8%) represent the most common co-morbidities thought to contribute to vulnerability.

Looking at factors graded as 2 (the red sections in the chart below), it can be seen that in 4% of cases reviewed the child suffered from a sensory impairment that was thought to have contributed to ill-health, vulnerability or death. In 4.6% 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.

15% 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.

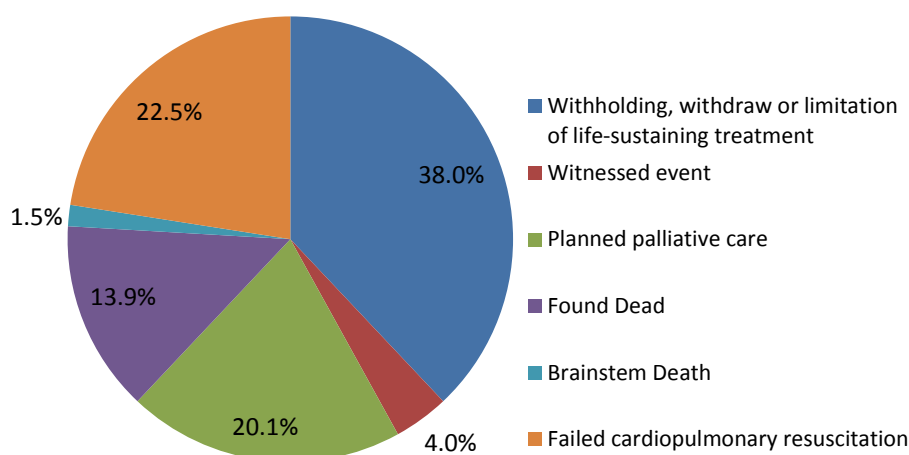
**Figure 10: Co-morbidities in children reviewed by CDOP between 1<sup>st</sup> April 2013 and 31<sup>st</sup> March 2018**



## 7.2 Mode of death (2013-2018)

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 38% of the deaths reviewed by CDOP. In 22.5% 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 20% of cases the child died following planned palliative care and in 14% of cases the child was found dead. In 4% 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 (1.5%) the mode of death was brainstem death.

**Figure 11: Mode of death of cases reviewed by CDOP between 1<sup>st</sup> April 2013 and 31<sup>st</sup> March 2018**



### 7.3 Summary factors identified as contributing to death (2013-2018)

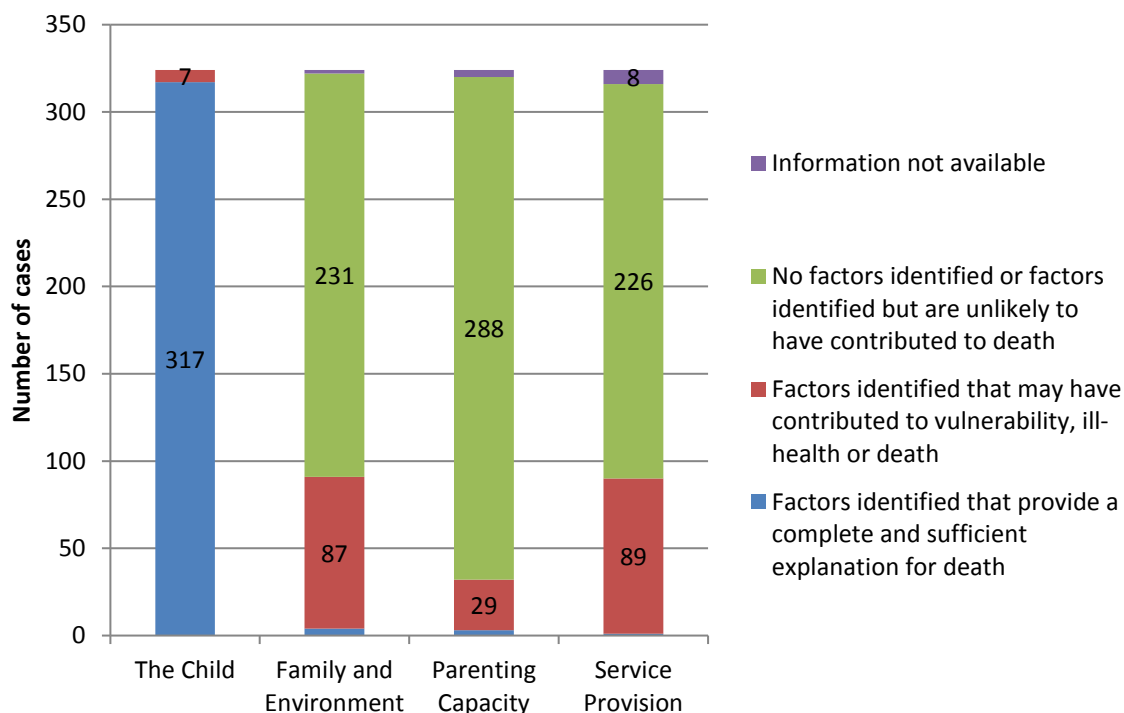
Form C of the national dataset requires the local child death review meeting to identify and 'grade' factors that have contributed to the child's death. The CDOP may amend this grading after full deliberation of the facts, to maintain consistency across cases.

Figure 12 shows that in 97.8% of cases reviewed between 1<sup>st</sup> April 2013 and 31<sup>st</sup> March 2018, factors intrinsic to the child (i.e. the underlying medical or surgical problem) provided a complete explanation for the death. In 26.8% 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 9% 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 27.4% 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:

- Vaccine for this infection not offered to this child's age group
- Delay in urine analysis for protein being undertaken in a pregnant woman
- Delay in discussion at specialist multi-disciplinary meeting
- Inconsistent advice on safety of drugs during breast-feeding
- Shortage of mother and baby unit beds
- Delayed in confirmation of diabetes in a pregnant woman in the context of a congenital anomaly that may be associated with diabetes

**Figure 12: Contributory factors identified by CDOP in cases reviewed between 1<sup>st</sup> April 2013 and 31<sup>st</sup> March 2018**





### 7.3.1 Additional factors in the family and environment (2013-2018)

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 324 cases reviewed by CDOP between 1<sup>st</sup> April 2013 and 31<sup>st</sup> March 2018, parental smoking was noted to have contributed to the ill-health, vulnerability or death of the child in 8.9% of cases. Domestic violence was known to be present in 17.2% of cases, however this factor was thought to have contributed to the ill-health, vulnerability or death of the child in 3.4% 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% 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 2.7% of cases and housing issues that contributed to the ill-health, vulnerability or death of a child were present in 1.8% 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 2013 and 31<sup>st</sup> March 2018**

	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>	87	29	0	193	15	8.9%
<b>Domestic violence</b>	45	11	0	263	<5	3.4%
<b>Emotional, Behavioural or Mental Health condition in a parent or carer</b>	86	9	<5	206	22	3.0%
<b>Alcohol or Substance Misuse by a parent or carer</b>	30	9	0	255	30	2.7%
<b>Housing</b>	32	6	0	286	0	1.8%

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 (2013-2018)

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 2013 and 31<sup>st</sup> March 2018**

	<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>	8	7	0	309	2.16%
<b>Child abuse / neglect</b>	<5	9	<5	307	3.70%

Of the 324 cases reviewed between 1<sup>st</sup> April 2013 and 31<sup>st</sup> March 2018, CDOP concluded that poor parenting/supervision was a factor that had contributed to the ill-health, vulnerability or death of the child in 2.2% of cases. In 3.7% 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 (2013-2018)

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 224 of the 324 cases reviewed by the West of England CDOP in the five year period (69%) no modifiable factors were identified. In 96/324 (30%) cases modifiable factors were identified. In 4/324 (1%) 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 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 (2013-2018)**

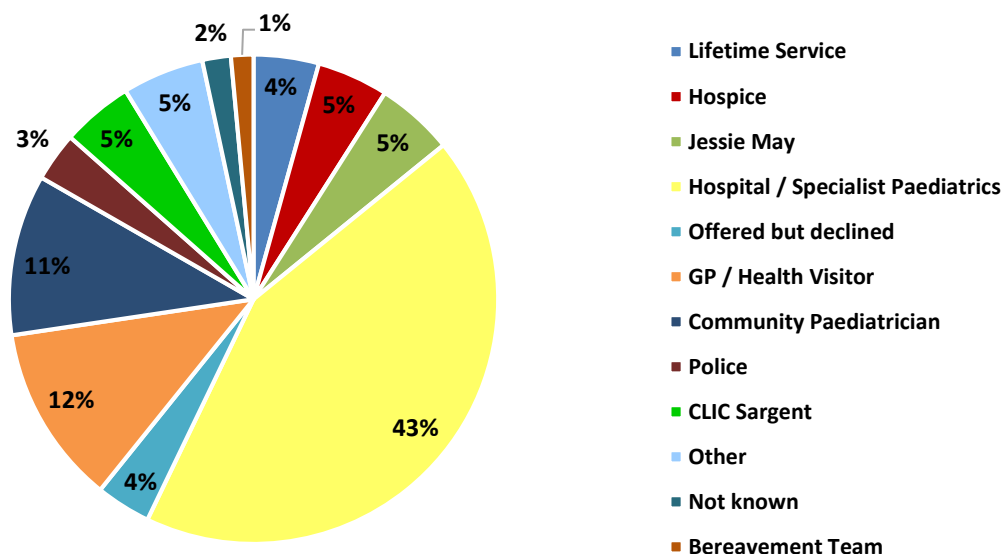
Active engagement with bereaved parents underpins the entire child death review process. Parental input into the child death review meeting should occur as a matter of course. Parents are invited to submit questions to the local child death review meeting, and feedback by the lead health professional 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 2013 and 31<sup>st</sup> March 2018. 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. 12% of families received follow up from primary care (GP or health visitor) and 11% 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. 4% of families were offered follow up but had declined the offer. 5% 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 in the last year. This year represents the first 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 2013 and 31<sup>st</sup> March 2018**

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<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 from infection (2013-2018)

For the purposes of this section, the deaths included were determined as follows:

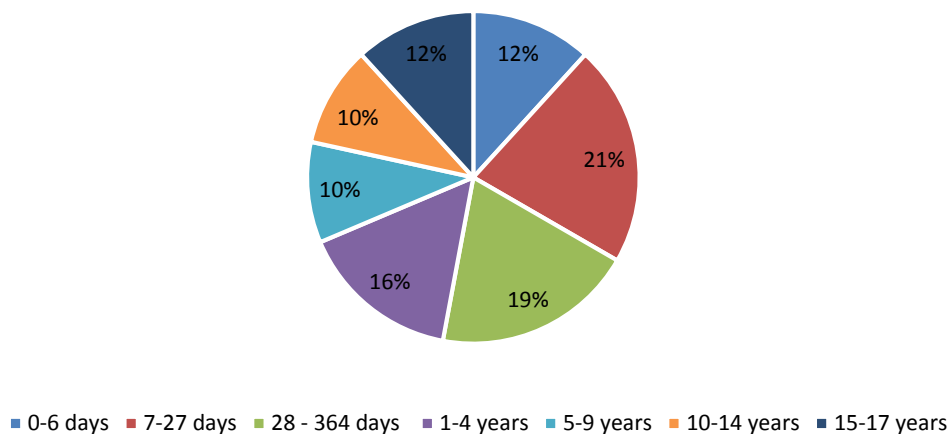
- all cases categorised as ‘infection’ by CDOP
- those cases in other categories where the narrative cause of death was infection or sepsis
- those cases where a specific infection was listed on the death certificate

Cases where the cause of death did not specify an organism were excluded e.g. ‘suspected sepsis’ or ‘bronchopneumonia’.

Over the 5-year period, a total of 51 children were reported to have died from specific infections. Many of these children were vulnerable because of prematurity or underlying complex medical problems, but around 1/3 were previously well children.

Figure 14, below, shows the age of children who died from infection.

**Figure 14: Deaths from infection by age (2013-2018)**



29% (15/51) 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. Issues identified include some related to facilities, such a crowded Emergency department and lack of suitable resuscitation facilities at delivery, delay considering rare infectious causes and delay starting antibiotics.

### **Neonatal infections**

There were 15 babies in the 1-27 day age group, but there were 3 in the 28-364 day age group who were extremely premature and are also included.

Gram negative sepsis (such as E Coli, Pseudomonas, Proteus and Klebsiella) stands out as a cause of death in premature babies, with 10 cases, the majority of whom had other complications at the time of death including necrotising enterocolitis, intraventricular haemorrhage, chronic lung disease. 3 of these were age 0-3 days at the time of death, which would be regarded as maternally acquired infection. Prevention involves recognition and treatment of maternal infection or chorioamnionitis before the time of delivery. The other 7 were >3 days old. For neonates admitted to the neonatal unit, these infections are hospital acquired with a high risk of mortality in vulnerable infants, sometimes they are due to bowel translocation (transfer of infection from carriage in the gut). Prevention can be improved with prophylactic probiotic treatment, lactoferrin and breast milk feeding. High standards of infection control and care also help prevent these late infections. Occasionally outbreaks are recognised with a specific source. One of these babies was infected with an antibiotic resistant organism and this is a threat for the future considering the lack of new available antibiotics.

Group B streptococcal (GBS) infection affected 4 babies. 2 of them were otherwise uncomplicated term infants. 3 of them died within the first week. Neither of the mothers of the full term babies showed risk factors for infection, so although selective screening is in place these mothers would have not been picked up. Widening GBS screening to all pregnant mothers and the development of a vaccine would be the next steps in reducing this infection, which also affects many more babies who survive, some of them with disabilities.

Congenital herpes infection caused 2 deaths, one following a normal term pregnancy and delivery. A high index of suspicion is needed in order to consider anti-viral agents, as well as awareness of risk factors and prophylactic treatment where possible.

Fungal coinfection was linked to the deaths of 2 premature infants with other complications. Anti-fungal prophylaxis in extremely premature babies or any baby on antibiotics could potentially prevent some of these deaths.

### **Vaccine preventable infections:**

There were no deaths from vaccine preventable infections affecting children who would have been immunised according to the standard immunisation schedule.

2 babies (1 with pneumococcal meningitis and 1 with pertussis) were too young to have been offered the relevant immunisation, although in one case maternal immunisation could have been effective. 1 child with an underlying genetic condition died of a chicken pox infection which is currently a non-scheduled immunisation although had been offered. 1 teenager and 1 younger child died from Group B meningococcal meningitis, this is a vaccine preventable disease, but it would not have been offered for these 2 cases as it has only been available in the vaccine schedule for younger children in the UK since 2015. Both had presented to medical attention with non-specific symptoms in the previous 24 hrs. One child with Group A streptococcal (GAS) infection

had coexisting influenza infection and it is recognised that mortality can be greater when these bacterial and viral infections coexist. This also raises concern about the take-up rates of seasonal flu immunisation in children. Another case of a rare complication of influenza in a pre-school child has been reviewed by CDOP more recently.

#### **Other bacterial infections in previously well children:**

There were 4 deaths from invasive Group A Streptococcal infection in this period and these were all in 1 – 6 year old children. 3 of these had either had a recent medical review or sought medical advice and one was already on antibiotics. This highlights the frequently non-specific nature of early Group A strep sepsis and the challenges clinicians face in identifying invasive Group A streptococcus infections from less serious illness.

There was 1 case of streptococcus pneumoniae sepsis in a previously well 10 year old. 1 death was due to Hib type B infection, but this was a non-vaccine preventable strain. There was a case of tuberculous (TB) meningitis diagnosed after a long course of fluctuating symptoms including vomiting. This non-specific presentation of meningeal TB is common although persistent vomiting should prompt clinicians to consider raised intracranial pressure and is an important presentation in a small number of children with brain tumours.

There was one case of E Coli sepsis in an infant following a series of respiratory illnesses, but who was otherwise well. One child had an antibiotic resistant organism associated with pneumonia. Many of these children sought medical attention before their final illness.

#### **Infections in children with chronic conditions**

7 children and young people with chronic medical conditions died unexpectedly from infection, including one Staphylococcal infection of an implanted device, one E Coli sepsis and pneumonia, one fungal sepsis and pneumonia, one systemic candida infection and one pseudomonas sepsis. 3 children with malignancies died with identified infections, including those with neutropenic sepsis. It was recognised that these children can present with non-specific signs of infection and a high index of suspicion is needed.

#### **Viral infections:**

2 cases of specific viruses (one with HHV6 and enterovirus and one with Coxsackie pneumonia) were associated with Sudden Unexpected Death in Infancy (SUDI) and categorised by CDOP as Infection. Other viruses were associated with severe illness in vulnerable children including post-cardiac surgery and prematurity.

#### **Recognition of illness:**

As indicated above, many children had been seen in the days or hours before their final collapse, and in the majority medical review was judged (by hospital Root Cause Analyses as well as CDOP) to have been satisfactory. In some cases, there was learning related to recognition of illness but in no case was this judged by CDOP to have been the full and sufficient cause of death. This is the area targeted by NICE sepsis guidance 2016 and other sepsis identification tools.

## **9. Child Death Overview Panel Activity (2017-2018)**

### **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>
Neonatal death	Shortage of mental health mother and baby unit beds	Write to NHS England to find out what plans there are for commissioning more beds in mental health mother and baby units	Response from NHSE confirmed additional beds are being commissioned on a sustainable basis in existing units, in particular in the South West, to increase national capacity by 49% by the end of 2018/19. To date £40m has been allocated to 20 areas to develop and expand capacity in specialist community perinatal mental health teams. This includes Bristol CCG.	Importance of inpatient mother and baby unit capacity as part of a comprehensive integrated care pathway
SMA Type 1	Lack of a local care standard for children with this genetic condition	Write to Hospital Trust to ask if a care standard has now been developed for children with this condition	Response received from Trust detailing a comprehensive care standard and management strategy for children with this condition in line with national standards but acknowledging forthcoming changes with new treatment options	Ensuring local care standards are regularly reviewed in the light of ongoing research and development
Injuries sustained in a	As this incident did not meet the	Find out what services are	British Red Cross has thousands of	Importance of agencies being

road traffic collision	criteria for major incident status, there was a lack of bystander support in the immediate aftermath. This led to ambulance crews providing emotional support to bystanders which caused a delay in those crews being re-operationalised	provided via the Red Cross to support bystanders in the aftermath of an incident that does not meet major incident status	emergency response volunteers across the UK that can provide practical and emotional support at a moment's notice including supporting statutory partners at a road traffic incident	aware of this service and able to access it
Child with a feeding tube	Some families of children with complex health needs experience a poor patient journey when they are required to attend the emergency department out of hours for NG or PEG tube changes. These are specialist procedures which are not delivered out of hours in the community due to commissioning restrictions and this results in families waiting a long time in A&E departments for their children to be seen as they cannot be prioritised above more urgent cases.	CDOP took steps to ensure consideration by Commissioners and relevant providers of provision of a suitable setting for children with complex health needs who require procedures out of hours e.g. replacement of nasogastric tubes		
Child born with congenital anomalies to a mother who had late recognition of diabetes	Delayed blood test at GP surgery to confirm diabetes in the context of a congenital anomaly that may be associated with diabetes	The GP rep conducted a practice audit on pre-conception counselling in women with diabetes (or at risk of diabetes)		



		resulting in a change of practice so this is flagged for all women of child-bearing age in these risk groups		
Suicide of a young person	Unclear what work is being done to reduce suicide by the British Transport Police	Contact the British Transport Police to ask about their public information campaign in relation to suicides	Very comprehensive response received highlighting the BTP Suicide Prevention Strategy "From Crisis to Care" and the "Small Talks Save Lives" Campaign	Awareness raising of the BTP suicide prevention strategy and public information campaigns in relation to suicide
Various cases	CDOP identified any potential Serious Incidents to check whether relevant processes were followed. In a number of cases CDOP made a submission to consider or reconsider a SCR before completion of the CDOP review. Following other processes, CDOP sought confirmation that recommendations had been carried out.			
Child at a special school	Good practice in bereavement support guidance in one special school was commended with a request for this to be shared with other schools			

## 9.2 Themes emerging from aggregate review of cases at CDOP during the year April 2017 – March 2018

### 1. Themes identified from review of deaths by suicide this year:

- During review of this group of deaths, it was recognised that the golden thread throughout all the cases was education and the importance of supporting children and young people in this setting. Questions were raised in each case relating to education.
- Press intrusion following inquests which is largely out of the Coroner's control but can add to families' distress.
- The expert in child suicide that attended this CDOP meeting highlighted that previous suicide in the family is associated with an increased incidence of suicide in children and young people.
- At the time of the previous suicide themed CDOP in May 2015, the PSHE programme was not statutory. All agreed in this meeting that PSHE was a vital part of school education particularly regarding child sexual exploitation, and they were reassured that Sex and Relationship Education is now to become statutory, although content has not yet been agreed nationally.
- Over the course of the last two suicide themed CDOP meetings, one issue that has been highlighted is that often the child's friends are more aware of their true feelings/intentions than family or professionals. This again highlighted the importance of emotional support in an educational setting and students feeling confident to signpost friends appropriately or disclose concerns to school staff.

### 2. Recognition of exceptional care being provided to families:

This year CDOP commended several teams on the outstanding care provided to a child, often in exceptional or challenging circumstances. These included examples of bespoke planning to meet highly individualised needs, ensuring time is made for parents to hold

their baby before emergency surgery and out of hospital resuscitation for children with complex medical issues.

**3. Choice of place of death for families with children on a palliative care pathway:**

CDOP has reviewed a large number of cases of children with palliative care needs where a wish to die at home has not been fulfilled because of lack of community-based professionals. CDOP note the recent extended working hours of Community nurses (now 8am-6pm)

**4. Challenges in reviewing the deaths of 16-17 year olds:**

- Following the Child Death Review (CDR) process for 16-17 year olds has been noted to be challenging as different processes are followed in adult settings, and staff are often less familiar with the CDR process. This can affect feedback to families as well as high quality data collection in this age group.
- The Rapid Response to unexpected deaths of 16-17 year olds has also been noted to be more challenging, as there may be a delay in notification of the multi-agency team and difficulty deciding which hospital setting is appropriate to take the young person to if investigations are needed before a post-mortem examination.
- This year the CDOP Manager, Paediatric Palliative Care Nurse and Specialist Child Abuse Police Officers provided 4 training sessions for police collision investigators on the Child Death Review Process. The sessions were very well received by those that attended and subsequent deaths due to road traffic collisions have followed the correct process.

**5. Inadequate communication about the news of a child's death to professionals:**

CDOP has reviewed a number of cases this year where either the GP or school have not been notified about a child's death through appropriate channels or not been informed promptly that a child has died. Cases reviewed this year have included examples of inadequate communication such as professionals finding out about a death from a family member or through social media, and professionals not being informed of the death for 5 days despite appropriate hospital protocols being in place.

**6. Lack of Commissioned Respiratory Physiotherapy Service in the community:**

Children with neuromuscular disorders and other complex medical conditions can have improved respiratory health with the availability of chest physio and support for interventions such as cough assist devices in the home setting. CDOP has reviewed a number of cases who may not have deteriorated or may have avoided hospital admission if this service was available.

## **10. Achievements and Future priorities**

In September 2017 the Annual Report was presented in a new format as a single event for the combined LSCBs and other stakeholders which was well received.

WoE CDOP welcomed some national representatives from NHS England who wished to observe given the high regard in which the WoE Panel is held nationally.

Shared pathways have been agreed with other processes such as Serious Case Reviews and the Learning Disability Mortality Review Programme (LeDeR) programme to ensure optimal collaborative working and reduce duplication of information collection

CDOP hears that following certain events or complications, learning is used within departments to train staff. However, the question is often posed of how this learning can best be extended to wider audiences, preserving anonymity while not reducing cases to mere 'statistics'.

The University of Bristol has been awarded the contract to build and host the new National Child Mortality Database, which will involve some of the existing CDOP team, and with the potential for improved national shared learning e.g. from rarer causes of death

CDOP took part in an interrater reliability exercise as part of working to better standardisation of data collection and grading of modifiability and contributory factors.

As a subgroup of the LSCBs, CDOP was subject to Ofsted inspections of BANES and N Somerset LSCBs this year, including scrutiny of the annual report data, minutes and interviews.

The CDOP team have provided training to multi-agency partners, which this year have included, Police Collision Investigators, Palliative Care Professionals undertaking a module at the University of the West of England, Paediatricians and Multi-agency Rapid Response Training. The necessary time and funds to do this need to be kept in balance and are likely to come under increasing pressure.

CDOP supports a Psychology service to provide clinical supervision to Consultant Paediatricians in BNSSG regarding cases of child death. The aim is to provide a safe space to facilitate processing of the emotional consequences of this challenging work and to build resilience in staff. The uptake of the service has been high with the majority of consultants making good use of the opportunity to reflect on their experience of the work.

In the coming year CDOP will need to implement the new National Guidance including potential reconfiguration of CDOPs to be a more uniform size. However, WoE CDOP is already reviewing the recommended number of 60-120 deaths per year.

## Appendix A - CDOP membership April 2017 to March 2018

	<b>Core member</b>	<b>LSCB/Organisation</b>
Nominated Chair	Sally Lewis	Bristol
Public Health (to 31.08.17)	Lynn Gibbons	South Gloucestershire
Public Health (from 01.09.17)	Bruce Laurence sharing with Rebecca Reynolds	BANES
Designated Doctor for Child Deaths	Mary Gainsborough	Sirona Healthcare
Coroner's Officer	Debra Neil	Bristol
Children's social care (until 31.08.17)	Fiona Tudge	Bristol
Children's social care (from 01.09.17)	Jo Baker	North Somerset
Head of safeguarding BNSSG CCG	Jackie Mathers	BNSSG
Midwifery	Julie Northrop	UHB NHS Trust
Consultant in Obstetrics	Dimitrios Siassakos	North Bristol NHS Trust
Consultant in Neonatology (to 11.10.17)	Paul Mannix	North Bristol NHS Trust
Consultant in Neonatology (from 12.10.17)	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 / 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
South Gloucestershire Safeguarding Children Board	Ali Sykes	South Gloucestershire

## Appendix B – UHB Financial Summary 2017/18

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 2017/18</b>			
<b>Description of Cost</b>		<b>Payment Due</b>	<b>£ Cost to UHB</b>
Designated Doctor	MPR	1.5 Additional PA's	£21,002
Paediatric Lead – Bristol Children's Hospital	BRCH	1 Additional PA	£12,404
Neonatology Lead - St Michael's	MPR	1 Additional PA	£10,908
Neonatology Lead - Southmead	MPR	0.5 Additional PA	£8,508
Community Paediatricians	RRT	320 hours Total	£22,272
GP and ED Consultant Costs	MPR	Attendance at some panels	£4,047
UOB Senior Manager	MPR	21 hours per week	£31,104
UOB Secretarial Support	MPR/PNM	3 days per week	£21,856
UOB Secretarial Support	PNM	2 days per week	£10,100
UOB Secretarial Support – Sirona Community Paediatricians	RRT		£2,525
Sirona Psychology support	RRT		£6,000
<b>Sub-total</b>			<b>£150,726</b>
Local authority funding UOB office			
• Manager	MPR		£5290
• Administrative support	MPR/RRT		£21,164
<b>Total Costs</b>			<b>£177,180</b>