

**WEST OF ENGLAND**

**CHILD DEATH OVERVIEW PANEL**

**April 2019 – March 2020**

**ANNUAL REPORT**

**Dr Mary Gainsborough**  
**Consultant Community Paediatrician**  
**Designated Doctor for Child Deaths**  
**University Hospitals Bristol NHS Foundation Trust**

**Ann Farr and Lara Cross**  
**Child Death Review Team**  
**University of Bristol**

## **Contents**

- 1. Acknowledgement**
  - 2. Foreword**
  - 3. Executive Summary**
  - 4. The Child Death Review Process**
  - 5. Production of annual report (processing and verification of data)**
  - 6. Summary Data (five-year dataset 2015 – 2020)**
  - 7. Child Death Overview Panel Review Data (2015-2020)**
  - 8. Future Priorities**
  - 9. Achievements**
- 
- I. Appendix A – CDOP Membership

## **1. Acknowledgement**

The compilation of this report has only been made possible with the help of the following individuals:

- Ann Farr and Lara Cross for co-authorship of the report.

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

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 the tragedy of a grieving family and I am always impressed by the sensitivity with which the panel members approach each case discussion. We will always aim to 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 the team in the Child Death Enquiry Office whose dedication makes sure that we focus our efforts on making things safer for children and families across our area.

Matt Lenny

Director of Public Health  
N Somerset

Chair of 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 and Child Death Review: Statutory and Operational Guidance 2018.

<https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england>

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

2. 488 child deaths were notified to the West of England Child Death Enquiries Office between 1st April 2015 and 31<sup>st</sup> March 2020.
3. 201/488 (42%) 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). This number has fallen from previous years, as has the total number of notifications.
4. Over the 5 year period, 84% died in hospitals, 8% in the parental home or in a relative's home, 5% in hospices and 2% in other locations.
5. Between 2015 and 2020, 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.
6. Between 2015 and 2020, 40% of children had a post-mortem examination.

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

7. The West of England CDOP reviewed 288 cases in detail between 1<sup>st</sup> April 2015 and 31<sup>st</sup> March 2020.
8. There is an inevitable time-lag between notification of the child's death to discussion and ten cases of children who died during the period of 2017-18 are outstanding. All other children who died before that date have been reviewed by CDOP. 60% of cases from 2018/19 have been reviewed.
9. The most common mode of death is following the active withholding, withdrawal or limitation of life-sustaining treatment, which occurred in 36% of cases.
10. CDOP identified 'modifiable factors' between 2015-2020 in 32% of cases. 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'.
11. Family bereavement follow-up was documented in nearly every case, but provided by a range of professionals depending on the type and location of the child's death.

#### **Service improvement**

12. CDOP has taken forward actions arising from individual cases which include contacting Local hospital Trust, CCGs, Road Traffic Police, SWAST, Coroner.

#### **Themes**

13. Certain themes have emerged from reviewing children's deaths in the West of England this year including lower completion rate of new eCDOP Reporting Forms, Education response to the death of a pupil and capturing the Voice of the Child.

#### 14. Achievements and Future Priorities

These included plans to improve sharing of learning across CDOPs, presentation of the annual report to the Avon & Somerset Strategic Safeguarding Partnership, and renewing chairing and contractual arrangements. COVID is likely to dominate the coming year's work, and CDOP is well-placed to capture some of the effects on children as well as resulting in operational changes to the delivery of the process.

## 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>1</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 data considered in this annual report (2015-2020), 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) and the CDR Statutory Guidance (2018) outline two inter-related processes...a '**Joint Agency 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 not anticipated, 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) came 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 of the four Local Authority areas is appropriately represented. During 2019/20, the WoE CDOP Chair has rotated from BANES to the North Somerset Director of Public Health. 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.

---

<sup>1</sup> <https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england>

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 Notification Forms and Reporting Forms during the child death review process. The Notification Form is a basic notification form that has essential identifying information on the child and key professionals. Reporting Forms 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. An Analysis Form 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 Reporting Forms & Analysis Form 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 Analysis Form for each child. The CDOP Chair records recurring themes relating to modifiable factors and takes responsibility for any actions arising from the case discussion

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

This is the twelfth Annual Report of the West of England CDOP. It was approved by the Panel on 24<sup>th</sup> July 2020. 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 CDOP is required to produce an annual report each year outlining the work of the panel and relevant learning from the cases reviewed to inform the priorities of the CDR Partners. The annual report is produced using data collected by the University of Bristol through the Child Death Enquiries Office. Information collected at the point of notification of death is entered onto the eCDOP case management tool. Information collected from statutory forms, CDRMs and CDOP reviews is populated onto eCDOP as the case progresses through the child death review process. The eventual CDOP multi-agency dataset is extremely comprehensive. The annual report includes five years of aggregate data to help reduce year on year variations associated with rare events such as a child death. This allows better identification of longer-term trends or key themes which may not have been as apparent within a single year of data.

- Weekly inquest returns from the Coroner's Office
- Weekly returns from the Local Registrar's Offices
- Post-mortem reports
- Regular checks on BADGERnet for missing cases.
- Joint Agency Response reports
- Root Cause Analysis documents.

**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.

## 6.1 Summary Data (five-year dataset from 2015 – 2020)

This section summarises all deaths notified to the Child Mortality Analysis Unit, between April 1<sup>st</sup> 2015 and March 31<sup>st</sup> 2020, 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.

## 6.2 Analysis of notifications by year (2015-2020)

During the period 2015-2020, 488 child deaths were notified. Year on year variation in notifications is to be expected and is demonstrated in Table 1. 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 1.

**Table 1: Notifications by region of residence, 2015-2020**

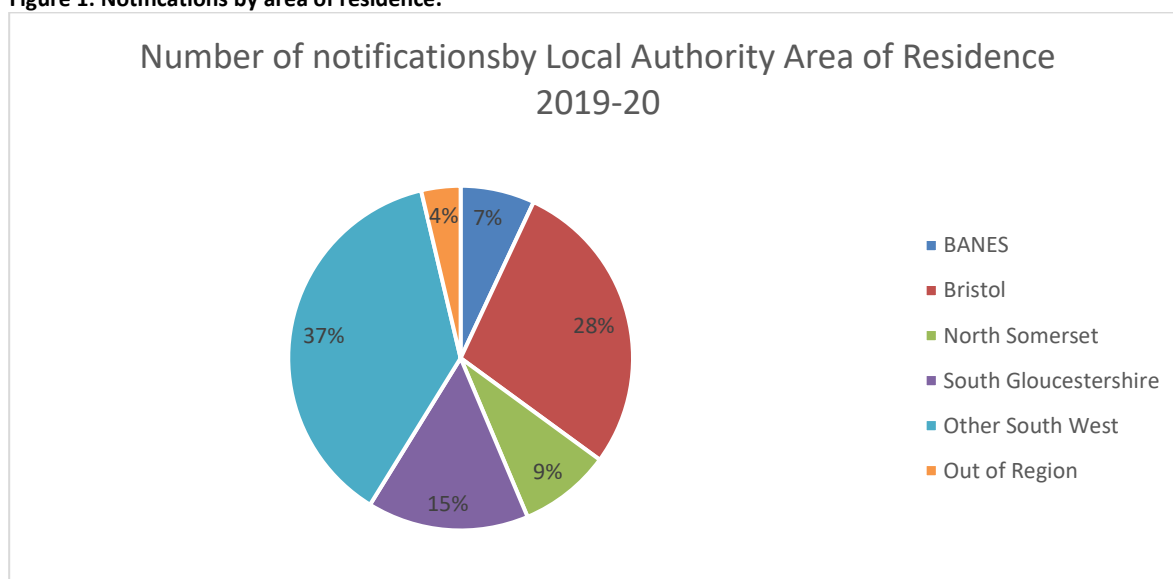
Region	2015/16 Deaths	2016/17 Deaths	2017/18 Deaths	2018/19 Deaths	2019/20 Deaths
BANES	8	6	8	4	8
Bristol	35	28	34	18	23
North Somerset	14	9	6	8	4
South Gloucestershire	13	18	16	10	16
Other South West	36	40	37	51	19
Out of Region	3	1	2	4	9
<b>Total WoE</b>	<b>70</b>	<b>61</b>	<b>64</b>	<b>40</b>	<b>51</b>
<b>Total</b>	<b>109</b>	<b>102</b>	<b>103</b>	<b>95</b>	<b>79</b>
<b>5 year Total</b>					<b>488</b>

Figure 1 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 each area reflect any particular underlying cause and as such they should not be over-interpreted.

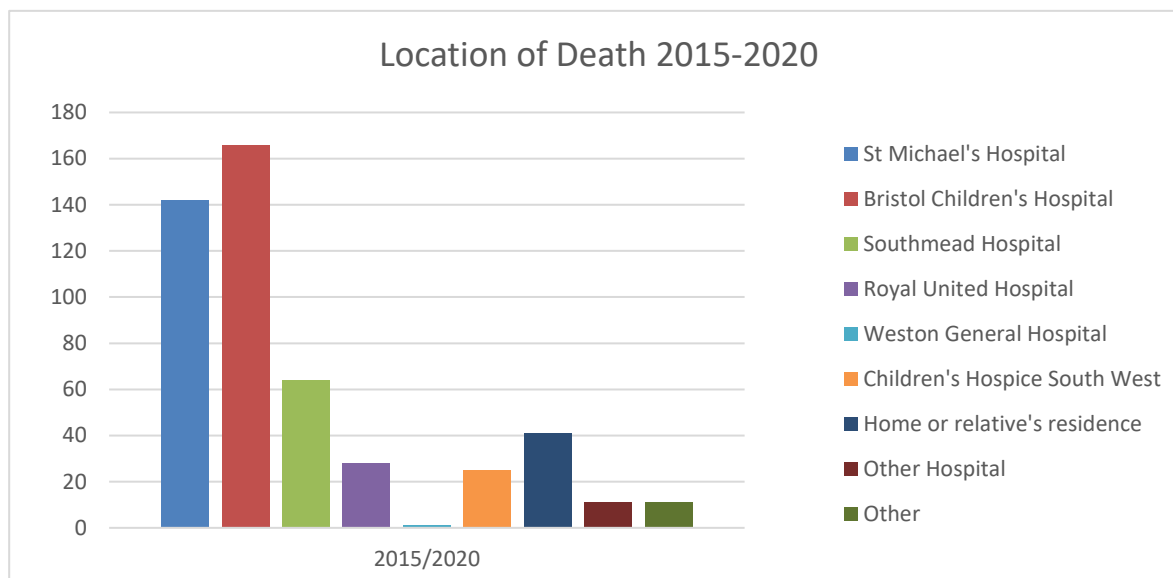
**Figure 1: Notifications by area of residence.**



### 6.3 Location of death (2015-2020)

This data records where the child actually died. Over the five-year period 34% (166/488) of all child deaths occurred at the Bristol Children's Hospital, 29% (142/488) at St. Michael's Hospital, 14% (64/488) at hospitals within North Bristol NHS Trust (Southmead Hospital), 5% (25/488) at Royal United Hospital Bath, less than 1% in Weston, 5% (25/488) died in a hospice, and 8% (41/488) died at home or at a relative's residence. 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, 2015-2020



The precise location of death for children dying within hospitals in the West of England region in 2015-2020, is shown below in Table 2.

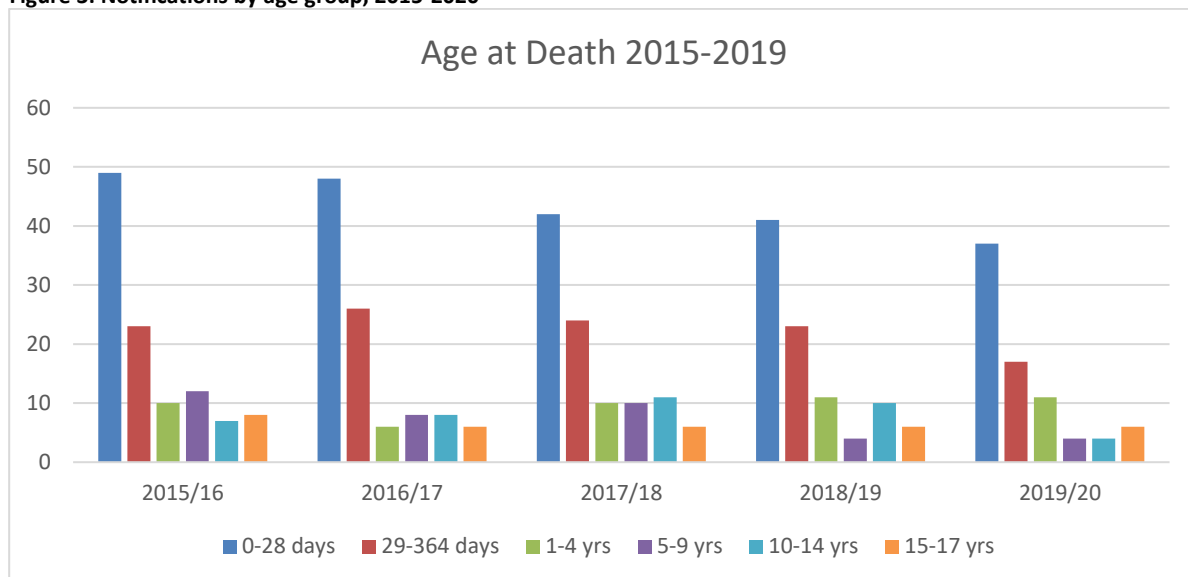
Table 2: Number of children dying in different locations within West of England hospitals

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>	(PICU) 151	3	2	4
<b>Royal United Hospital, Bath</b>	(NICU) 25	0	0	1
<b>St Michael's Hospital, University Hospitals Bristol</b>	(NICU) 139	0	1	0
<b>North Bristol NHS Trust Hospitals</b>	(NICU) 53	0	2	3
<b>Weston General Hospital</b>	1	0	0	0
<b>Other Hospitals</b>	0	0	0	0

### 6.4 Age at Death (2015-2020)

Using 5 year data, 217 notifications (44%) were received for babies dying in the neonatal period (0-28 days). A further 113 (23%) died in the first year of life. 48 (10%) between 1-4 years, 38 (8%) 5-9 years, 40 (8%) between 10-14 years and 32 (7%) between 15-17 years. 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, 2015-2020



### 6.5 Gender (2015-2020)

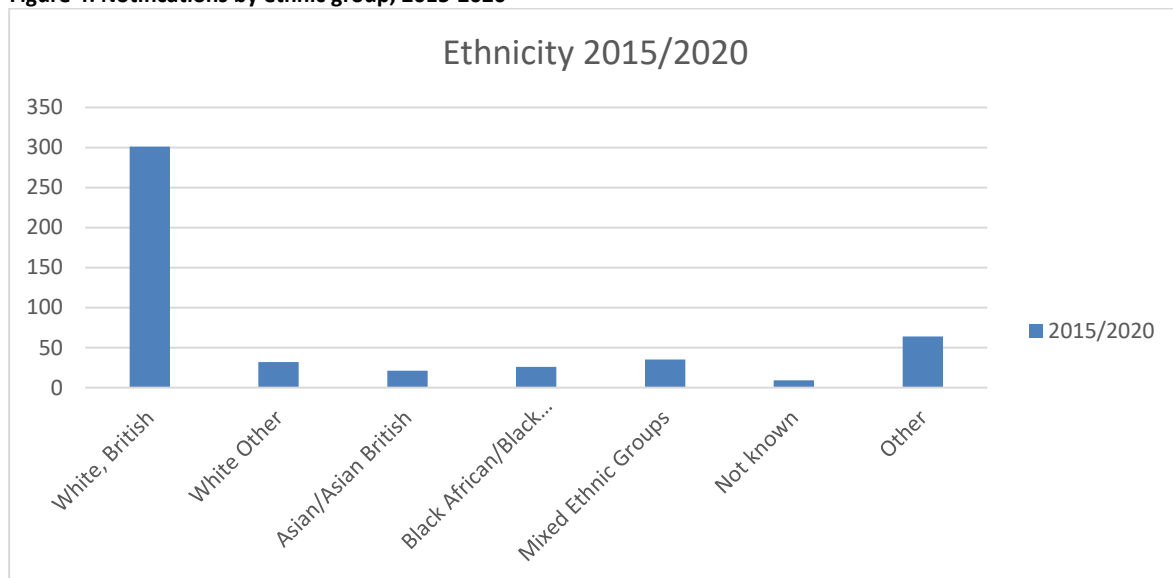
There have been more notifications of deaths in boys than girls (58% are boys).

### 6.6 Ethnicity (2015-2020)

Figure 4 shows that 62% of notifications received by the Child Death Enquiries office between 2015 and 2020 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 areas in the West of England region is diverse, making direct population comparison difficult.

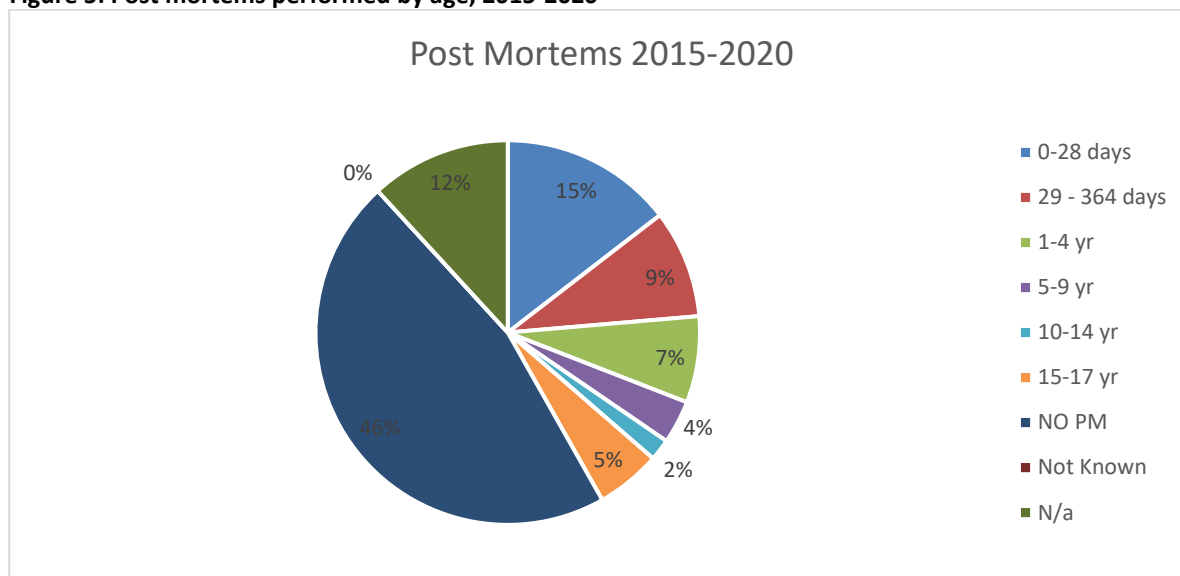
Figure 4: Notifications by ethnic group, 2015-2020



### 6.7 Post mortem examinations (2015-2020)

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. A post mortem occurred in 197/488 deaths (40%). 271/488 (55.5%) cases did not have a post mortem. In 20/488 (4%) it was not known if the child had a post-mortem examination at the point of notification of the death.

Figure 5 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 5: Post mortems performed by age, 2015-2020**

### 6.8 Deaths requiring a Joint Agency Response (JAR) (2015-2020)

Since the inception of the child death review process there has been a requirement to perform further investigations for children who die where the cause is unknown. This was previously called a Rapid Response but the terminology has been changed following the publication of the Child Death Review Statutory and Operational Guidance in 2018 and it is now referred to as a Joint Agency Response (see Section 4 above). The full guidance for conducting a JAR can be found here <https://www.rcpath.org/uploads/assets/874ae50e-c754-4933-995a804e0ef728a4/Sudden-unexpected-death-in-infancy-and-childhood-2e.pdf>

The criteria for triggering a JAR is as follows:

- is or could be due to external causes;
  - is sudden and there is no immediately apparent cause (including sudden unexpected death in infancy/childhood (SUDI/C));
  - occurs in custody, or where the child was detained under the Mental Health Act;
  - where the initial circumstances raise any suspicions that the death may not have been natural;
- or
- in the case of a stillbirth where no healthcare professional was in attendance. The full process for a Joint Agency Response is set out in the SUDI/C Guidelines.

Prior to 2018, these criteria were not used, and the definition for an Unexpected Death was 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. This was counted if recognised to be an unexpected death and a multi-agency Rapid Response was carried out.

In the 5 years covered by this report, Table 3 below, shows the number of RRs or JARs that have taken place by year.

**Table 3: Number of Rapid Responses / Joint Agency Responses**

Year	Number of Rapid Responses or Joint Agency responses.
2015-2016	26
2016-2017	14
2017-2018	24
2018-2019	18
2019-2020	9
TOTAL:	88

The main change in criteria for a JAR compared to a Rapid Response is that if a medical cause of death is known and there are no suspicious circumstances, the criteria would not be met. Although we do not have a record of how many cases would have met the previous definition for an unexpected death, and hence what the number of Rapid Responses would have been under the previous system, it is hypothesised that this change in criteria is the reason for the drop. However there is also a drop in the total number of deaths in the same period so it may also be that there were fewer unexpected deaths.

### **7.1 Child Death Overview Panel Review Data (2015-2020)**

This section summarises the Panel's review decisions for 2015-2020 and its actions for 2019-20. 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 Reporting Forms 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 (now a Child Safeguarding Practice Review) will also affect when a case is discussed at Panel.

**For these reasons, the population of children described in Section 6 *Summary Data* may partially overlap but is distinct from the population of children described in this section.** This is illustrated in Table 4.

Table 4: The number of cases reviewed each year by year of death

	2015/16		2016/17		2017/18		2018/19		2019/20	
Total number of notifications	110		102		103		95		79	
Number of cases to be reviewed by WOE CDOP	71		61		64		40		34	
Years of Review	Number reviewed	%	Number reviewed	%	Number reviewed	%	Number reviewed	%	Number reviewed	%
2015/16	13	18								
2016/17	49	69	8	13						
2017/18	8	11	36	59	5	8				
2018/19	0	0	13	21	33	52	4	10		
2019/20	1	2	4	7	16	25	24	60	1	3
<b>Total</b>	<b>71</b>	<b>100</b>	<b>61</b>	<b>100</b>	<b>54</b>	<b>85</b>	<b>28</b>	<b>70</b>	<b>1</b>	<b>3</b>

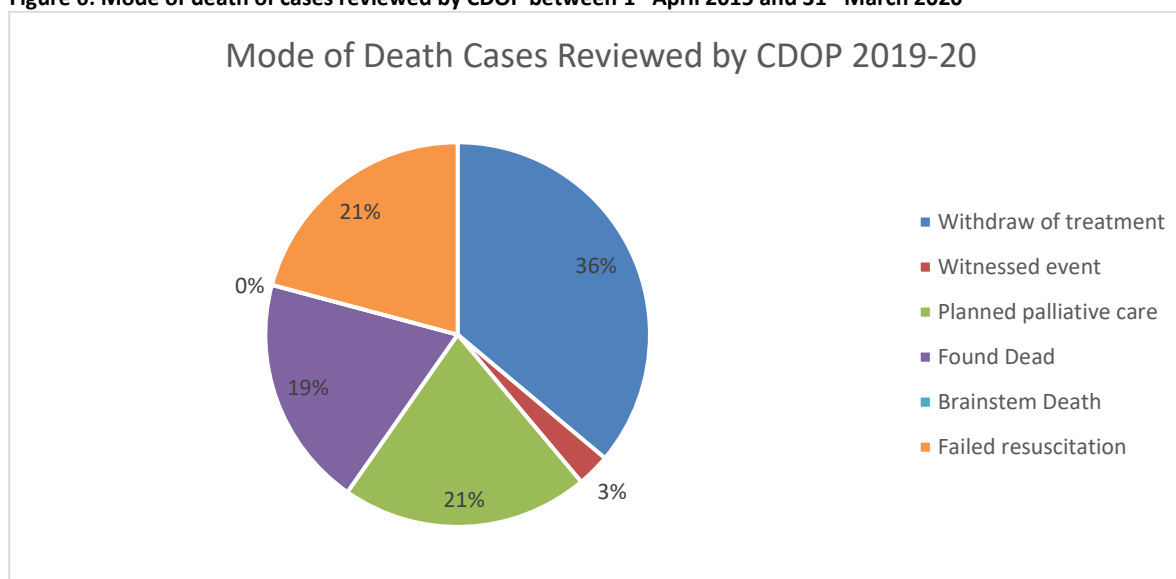
\*this includes all children resident within the West of England area at the time of their death and selected specialist cases more appropriately discussed by the West of England CDOP e.g. those involving cardiac surgery

Ten cases of children who died during the period of 2017-18 are outstanding. All other children who died before that date have been reviewed by CDOP.

Sections 7.1 to 7.6.1 describe data relating to the 288 children reviewed by the West of England CDOP between 1<sup>st</sup> April 2015 and 31<sup>st</sup> March 2020. The data is drawn from eCDOP into which all information from Reporting Form, Analysis Form, the local child death review meeting and final CDOP review is entered.

## 7.2 Mode of death (2015-2020)

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 36% of the deaths reviewed by CDOP. In 21% 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 21% of cases the child died following planned palliative care and in 19% 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 6: Mode of death of cases reviewed by CDOP between 1<sup>st</sup> April 2015 and 31<sup>st</sup> March 2020

### 7.3 Factors in the Social environment (2015-2020)

Table 5: Factors in the social environment (including parenting capacity recorded in cases reviewed by CDOP between 1<sup>st</sup> April 2015 and 31<sup>st</sup> March 2020

Factors in Social Environment	Yes	No	Not known
Smoking by a parent or carer / Smoking by Mum during pregnancy	95 (33%)	163 (57%)	30 (10%)
Alcohol or Substance Misuse by a parent or carer	37 (13%)	215 (75%)	36 (12%)
Domestic violence	54 (19%)	224 (78%)	10 (3%)
Emotional, Behavioural or Mental Health condition in a parent or carer	85 (30%)	176 (61%)	27 (9%)

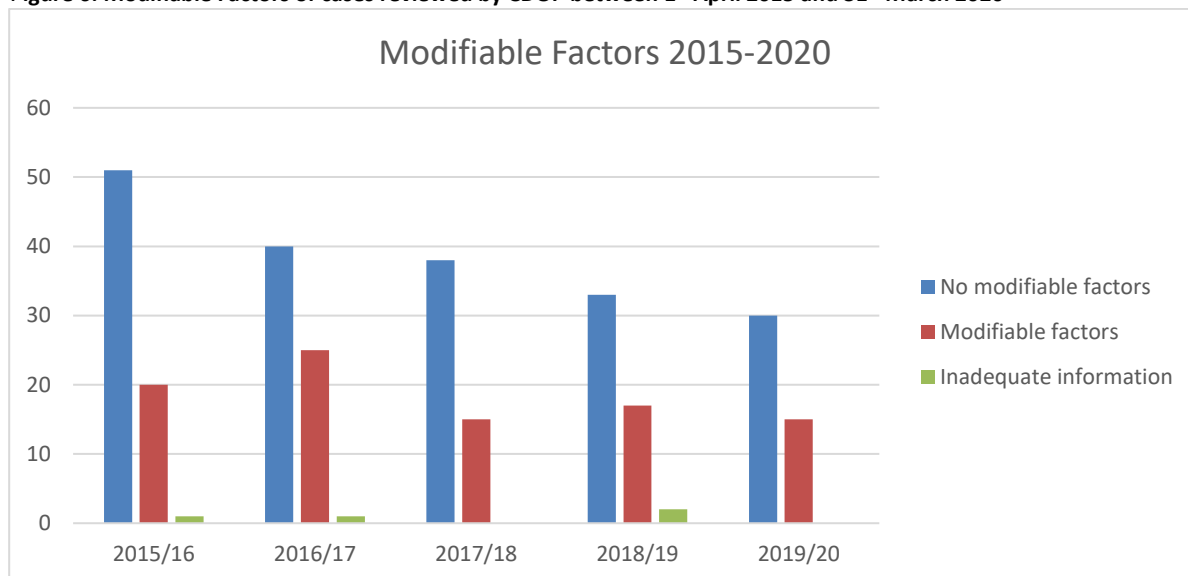
This data is collected in all cases, but less analysis is available at the local level from the new CDR forms. It is hoped this will come out from future NCMD national analysis. Overall these social factors are likely to be overrepresented in the families of children who die compared to the general population.

### 7.4 Modifiable Factors (2015-2020)

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 192 of the 288 cases (67%) reviewed by the West of England CDOP in the five year period no modifiable factors were identified. In 92/288 (32%) cases modifiable factors were identified. In 4/288 (1%) of cases there was not enough information available to determine if modifiable factors were present.



Figure 6: Modifiable Factors of cases reviewed by CDOP between 1<sup>st</sup> April 2015 and 31<sup>st</sup> March 2020

There seems to be a steadily increasing trend nationally in the percentage of child death reviews assessed having modifiable factors from 24% in the year ending 31 March 2015 to 30% in the year ending 31 March 2019<sup>2</sup>.

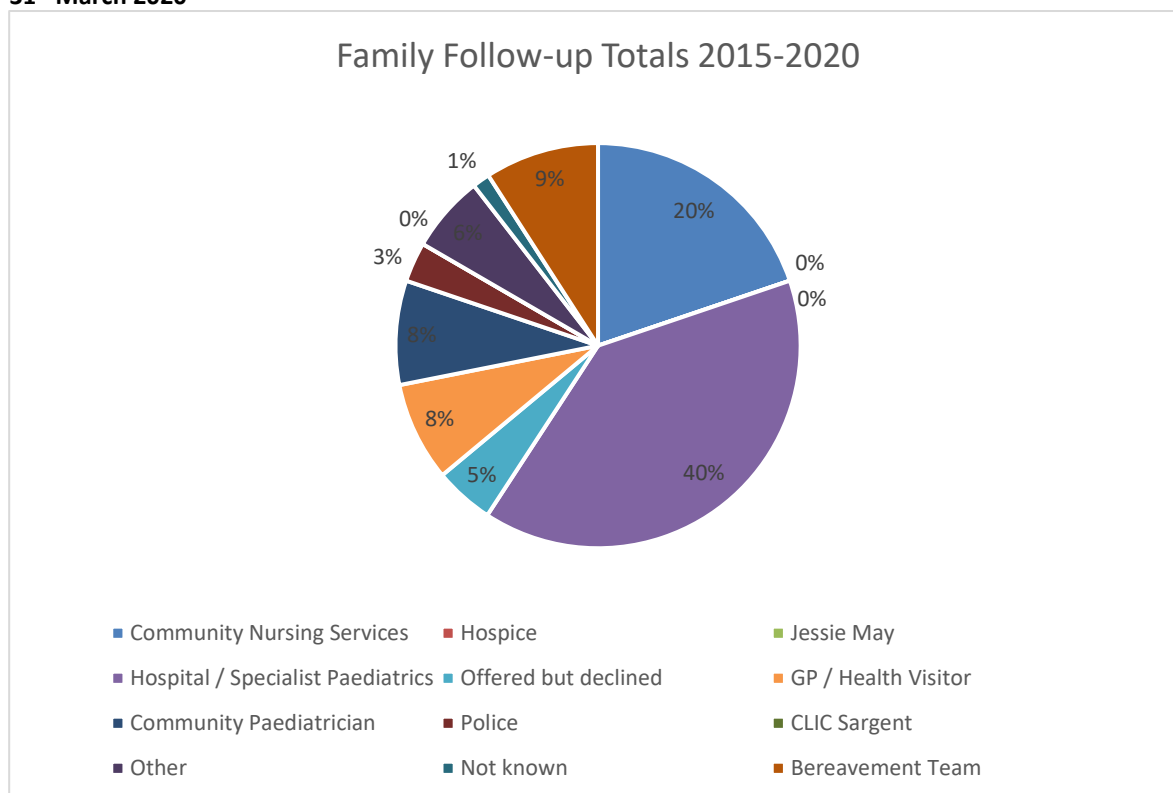
### 7.5 Family follow up (2015-2020)

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 7 shows the percentage of families offered follow up from each agency for cases reviewed by CDOP between 1<sup>st</sup> April 2015 and 31<sup>st</sup> March 2020. 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. 40% of families received follow-up from hospital or specialist paediatrics. This includes obstetrics, neonatology, cardiology and oncology. 8% of families received follow up from primary care (GP or health visitor) and a further 8% 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 20% of families who had a child who died during this period. 5% of families were offered follow up but had declined the offer. In 1% 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. 3% of families were also offered support from the Police. 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 third year that data has been collected on the number of families being followed up by the Bristol Children's Hospital Bereavement Team and they have offered support to all families of children who have been seen at the Children's Hospital since the team was set up.

<sup>2</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/child-death-reviews/2019/content>

**Figure 7: Agency providing follow up to families in cases reviewed by CDOP between 1<sup>st</sup> April 2015 and 31<sup>st</sup> March 2020**



### Child Death Overview Panel Activity (2019-2020)

#### 7.6 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 Safeguarding Partners within the West of England area have CDOP matters as a standing agenda item at their meetings.

In certain cases, the CDOP sought assurance that a particular action arising from a child's death had been addressed. Table 6 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 6: Actions arising and outcomes

Case Description	Issue	CDOP Action	Response/evidence	Recommended National Learning
<b>Sepsis</b>	NHS 111 may not be aware a child has died. CDOP were not receiving information about contact with NHS 111 prior to child's death.	NHS 111 (contract was held by Care UK at the time) need to be notified of deaths in order to contribute to the CDR process and for the purpose of their own learning	Since this case, the Child Death Office have set up a process to contact BrisDoc / NHS 111 (contract now held by Severnside Governance Integrated Urgent Care ) for every BNSSG death to see if the child/family have had contact with NHS 111 / OOH GP. If so, a Reporting Form is requested and BrisDoc are invited to the CDR meeting.	Is this happening in other areas? NHS 111 subcontracted to different companies in every area.
<b>SUDI</b>	Smoking and drug use in pregnancy	Enquire about a smoking cessation pilot in locality  Identify what drug treatment services are available to young pregnant women	Pilot presented to the FNP Board and findings shared  Young Person's Substance Misuse Treatment Service and ROADS	
<b>Neonatal death following premature delivery in a Teenage mother</b>	Age discrepancy with father	Ensure this is identified at points of contact with primary care, contraceptive and maternity services and any safeguarding actions raised	Update local GPs via newsletter Need to ensure midwifery services aware too	
<b>Malignancy</b>	Ascertaining pain may have been unreliable in a child with sensory impairment	Contact the pain management team to find out about the updated patient-controlled analgesia (PCA) devices since this case	Hospital now uses different PCA devices with a dual sensory alert (light and sound)	

<b>Metabolic disorder</b>	All carers may not have been aware that child needed prompt medical review in event of any health problems	Liaison with Metabolic team	Ensure this family aware of issue (for future children) and in general that written advice is provided to parents at diagnosis Education to families about 'what if' scenarios - Metabolic team do use leaflets, and now have a psychologist
<b>Congenital cardiac disease</b>	Collapse during an essential cardiac procedure	Ensure actions completed	Cardiac catheter guidelines have been updated and approved including formalisation of observation post-cardiac catheterization and new obs recording form in place
<b>Depression and suicide of young person</b>	SSRIs ( a type of anti-depressant medication) prescribed by GP after discussion with Child and Adolescent Mental Health (CAMHS) who offered an appointment in 2 weeks	CDOP identified that there is currently no specific policy regarding SSRI use in under 18s in the BNSSG area	No specific local policy but NICE guideline Depression in children and young people Sept 2005 (updated subsequent to this child's death in June 2019) states in <18s SSRIs should only be started in secondary care and reviewed within 1 week NICE guidance Depression in adults March 2020 states if <30yrs, GP should arrange review within 1 week and frequently thereafter until suicide risk no longer clinically important. However in practice there are anecdotal examples of GPs starting SSRIs in <18s after appropriate assessment and discussion with CAMHS SSRIs are Amber in

			BNSSG formulary (the decision to start the drug has to be made by a specialist but the first prescription can come from a GP and there isn't a formal shared care protocol)	
<b>Sepsis</b>	Recognition of illness by ambulance personnel	CDOP raised this with South West Ambulance Service Trust	Training updates on recognition of illness Family Liaison Officer appointed within ambulance service	
<b>Child with a life limiting condition who died at home</b>	Lack of knowledge about process for issuing a Medical Certificate of the Cause of Death Community nurse thought GP had to come and issue a Medical Certificate of the Cause of Death (MCCD) before child's body could be moved (only verification of death needed)	Encourage agency to draw up guidelines Raise same issue across other palliative care agencies to share learning	Guidance document now in place on the process to be followed by community nursing staff following a death in the community, although some issues need revising Awareness raising in team meetings Share learning across palliative care agencies	
<b>Suicide</b>	Emergency services had some difficulty finding location	Contact organisation concerned to discuss signage	This issue is already under consideration as part of a national review	This issue is already under consideration as part of a national review
<b>Suicide</b>	Whether public information measures have been considered to reduce this type of suicide	Contact organisation concerned regarding suicide prevention measures, including any local contributions such as posters created by local pupils	Comprehensive response about rationale for current measures and the need for a consistent national approach, and their current working relationship with Samaritans. This organisation has a Suicide Prevention Manager	Comprehensive response about rationale for current measures and the need for a consistent national approach, and their current working relationship with Samaritans.

				This organisation has a Suicide Prevention Manager
<b>Suicide</b>	Unclear what measures had been taken at location of death to reduce risk of suicide	Enquired about safety infrastructure	Comprehensive response about package of measures including infrastructure, monitoring and provision of personal support	
<b>Suicide</b>	Taxi transported young person to a well-known location at an unusual time of day	Suggested to local authority to add into safeguarding training for taxi drivers to question reasons for journey if concerns	Response awaited	
<b>Death following chronic illness</b>	Funeral director showed service 'above and beyond' standard offer	Letter to commend their good practice		
<b>Death following chronic illness</b>	Lack of information captured in eCDOP Reporting forms about child's voice	Request via NCMD for a question to be added to eCDOP Reporting form	Acknowledgment to add this with future update	Reporting form is in use nationally
<b>Neonatal death</b>	Death of a child following birth at home	Coroner asked about the inquest verdict which did not include reference to the setting	Response awaited	
<b>Neurological disorder</b>	Delay in diagnostic MRI brain scan	Write to hospital Trust to suggest vacant slots reserved for such cases	Response awaited	
<b>Death following chronic illness</b>	No Reporting forms completed (on eCDOP system) by Social Care and GP for this case which	Paper copies sent after CDOP meeting Consideration how to improve response rate to	Paper copies to be sent on occasions when continued difficulty obtaining online information (form now received from social	It is a statutory requirement for organisation to provide information to

	involved domestic and likely emotional abuse	new online forms	care) Further training offered by CDR personnel CDOP have developed an Escalation process for non-response	CDOP
<b>Neonatal death following home birth</b>	Support for professionals involved	CDOP enquired about this	Midwifery support in place through debriefs, and a monthly restorative session. This support is now delivered by Professional Midwifery Advocates (NHS role).	

### 7.6.1 Themes emerging from aggregate review of cases at CDOP during the year April 2019 – March 2020

In 2019/20 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:

- School response when a pupil has died – there is a need for standardized guidance to be available rapidly. CDOP raised whether a process for schools could be used to support those involved in suicides similar to Trauma Risk Management (TRiM) training used by police – in BANES there is a Critical Incident team set up for school Nurses and CAMHS to respond.
- Voice of the Child CDOP are routinely looking for evidence in content provided through agency Reporting forms of the child's view of their life, examples of their choice of activities/aspirations and their views about Advance Care planning where appropriate. Was the child helped to express their wishes and feelings?
- CDOP have been reviewing information provided to pregnant women in the event of a decision to have a home delivery or to free birth (disengage from antenatal care) to ensure this includes some indication of the potential risks attached.
- Drop in response rates to requests to complete eCDOP Reporting Form (formerly Form B) following introduction of eCDOP system despite this being a statutory requirement – CDOP has drawn up a local escalation process.
- New eCDOP Analysis form is cumbersome and CDOP is keeping under review the ability to capture a case summary, contributory factors, learning points & actions – feeding back to the company who design and maintain Ecdop.
- Attendance by Des Dr and CDR manager at newly formed Children's hospital Mortality Oversight Committee.

- Difficulty maintaining multi-agency representation on CDOP there have been multiple contacts with partner organisations to negotiate appropriate attendance this includes the Charing arrangements although this has now been taken on by the Directors of Public Health on a 2 year rotational basis.
- Retention of Kennedy samples – project work across agencies with agreement reached to store these for 2 years.
- CDOP continue to consider if another investigation e.g. Serious Incident, Root Cause Analysis, Serious Case Review should have been carried out, challenge partner agencies where appropriate, and confirm actions have been completed satisfactorily so that learning can benefit future cases.

## 8.0 Achievements

- The number of deaths notified within the West of England has decreased year on year. This reflects national data where deaths in 1-9year olds in England have dropped from 11.9 to 9.9 per 100000 since 2014 <https://stateofchildhealth.rcpch.ac.uk/> The Death rate in infants is unchanged at 3.9 per 1000 live births, and has barely changed in 10-19 year olds. However other national indicators have worsened, include children living in poverty, and in WoE we continue to note a high level of social factors.
- A successful and well-attended multi-agency training event on the Joint Agency Response was delivered at Police HQ in June 2019.
- Sharing learning across CDOPs–
  - WoE Des Dr took the lead in convening a meeting of other Des Drs across the SW region.
  - Des Dr identified a number of cases (death in Bristol but resident in another CD area) where CDR could be scheduled in Bristol, CDOP either in WoE or in area of residence and then share learning with the other CDOP.
- Continuing to review and update local guidelines in light of Oct 2018 National Guidance.
- CDR process arrangements were published on CCG websites by Sept 2019 in line with the national requirement.
- Agreement for chairing of CDOP to be by Directors of Public Health on 2 yearly rotation.
- CDR Chairing arrangements with Des Dr chairing some of the more complex CDRs, while majority are chaired within departments.
- Re-establishment of Lay Representation on CDOP.
- CDOP Strategic group reconvened to meet quarterly, chaired by CCG.
- Renegotiation of contract with CCGs.
- Presentation of 2018/19 Annual Report to Avon and Somerset Strategic Safeguarding Partnership – in future, request for CDOP reps from each LA to feedback in real-time, and for slide deck to be provided alongside online Annual Report publication.
- Meeting with Medical Examiner project lead to discuss opportunities for shared working and streamlining processes.
- Establishing clear Key worker for all deaths (in line with Oct 2018 Guidance).



- Biannual Child Death peer review of Joint Agency Responses well-attended by Community Paediatricians, bereavement support, police, coroner and pathologist, enabling closer working arrangements to be developed.
- Ongoing education to ensure all agencies aware of Joint Agency Response process.
- 'Where to take a child' policy regarding 16-17 yr olds when death confirmed in the community – policy has been shared with additional agencies including British Transport Police and also they have reminded officers about how to initiating a JAR.
- Review of Safe sleeping advice by a public health trainee on behalf of CDOP and presented to CDOP.

## 9.0 Future Priorities

- Changing leadership of the CDR partners in the Local authorities and CCGs – keeping new leads informed so they can provide support and advocacy.
- There have been personnel changes in the CDR office, requiring additional training and support from the existing small team to maintain the high standards and take forward new projects.
- Developing further multi-agency training models including through Simulation training.
- Supporting local roll out of the Medical Examiner role to community and paediatric deaths.
- Ensuring that deaths abroad receive the same scrutiny as those locally and that families can be supported throughout.
- Continued funding of the Care of the Next Infant programme through the CDR budget has not been approved by the CCG and alternative funding sources will be needed if this service is to continue to support parents with their next baby following a sudden infant death.
- The COVID crisis started just after the period covered by this Annual Report. However since April 2019 there has been:
  - Contribution to national working group chaired by the National Child Mortality Database to develop guidance for Joint Agency Responses during this period.
  - Revised local JAR guidance has been issued in light of the COVID restrictions.
  - Liaison with the Incident Control Centres.
  - CDOP meetings have been carried out remotely.
  - Revised national Notification form to capture effects of COVID and lockdown on child deaths.
  - Letter to all Trusts and partner agencies to support continuation of CDR process with appropriate adaptations despite the shutdown of some other non-essential services.

**Appendix A - CDOP membership April 2019 to March 2020**

<b>Role</b>	<b>Core member</b>	<b>Organisation</b>
Nominated Chair	Eiffon Price Matt Lenny	North Somerset Council
Public Health	Jo Williams and Jo Copping	Bristol City Council
Designated Doctor for Child Deaths	Mary Gainsborough	Sirona Care & health
Coroner's Officer	Debra Neil	Avon Coroner's Office
Children's social care	Catherine Boyce	South Gloucestershire Council
Designated Nurse for Safeguarding	Jackie Mathers	BNSSG
Designated Nurse for Safeguarding	Liz Plastow	BANES CCG
Professional Midwifery Advocate & Midwifery Matron	Julie Northrop	UHB NHS Trust
Consultant Obstetrician	Mark Denbow	UHB NHS Trust
Consultant Paediatrician & Neonatologist	Steve Jones	RUH Bath NHS Foundation Trust
General Practitioner	Patrick Nearney / Elaine Lunts	Bristol
Detective Chief Inspector	Larisa Hunt	Avon & Somerset Constabulary
Paediatric Palliative Care	Francis Edwards	UHB NHS Trust
Consultant Paediatric Intensivist	Meetings not attended during this period.	UHB NHS Trust
Consultant in Paediatric Emergency Medicine	Nick Sargent	UHB NHS Trust
Consultant Community Paediatrician	Fiona Finlay	BANES Safeguarding Children Board
Head of Safeguarding, Ambulance Service	Simon Hester	South Western Ambulance Service NHS Foundation Trust
Lay Representative	Julie Kembrey	Bereaved Parent & Trustee of Jessie May Trust