

**WEST OF ENGLAND  
CHILD DEATH OVERVIEW PANEL  
April 2021 – March 2022  
ANNUAL REPORT**

**Dr Mary Gainsborough**  
**Consultant Community Paediatrician**  
**Child Death Review Team Designated Doctor for Child Deaths**

**Ann Farr**  
**University of Bristol**  
**University Hospitals Bristol NHS Foundation Trust**

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### **1. Acknowledgements**

We would like to acknowledge the hard work of all professionals involved in every step of the Child Death Review process, and those who sit on CDOP, who have made the content of this report possible.

**Mary Gainsborough and Ann Farr**

## 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 losing a child or 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, friends and community. During my time as Chair of the panel I have always been 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 Children's Deaths, and 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. It has been a real privilege to chair CDOP and support the important work it does to improve outcomes for children and young people in our area.

**Matt Lenny**

**Director of Public Health and Regulatory Services, North Somerset Council**

**Chair of CDOP**

## 3. Executive Summary

### Data related to Child Death Notifications

1. 51 child deaths were notified to the West of England Child Death Enquiries Office between 1<sup>st</sup> April 2021 and 31<sup>st</sup> March 2022.
2. Over the 12 month year period, 63% died in hospitals (NICU, PICU, ED and Hospital Wards/Delivery Suite), 15% at home or in a relative's home, 10% in hospices and 6% in other locations.
3. 20/51 notifications (39%) were received for babies dying in the neonatal period (0-28 days). A further 17 (33%) died in the first year of life, 8 (16%) of deaths were of children aged between 15-17. A further 3 (6%) were of children between 10-14 years.

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

1. The West of England CDOP reviewed 50 cases between 1<sup>st</sup> April 2021 and 31<sup>st</sup> March 2022.
2. There is an inevitable time-lag between notification of the child's death to CDOP review and 6 cases of children who died during the period of 2019-20 are still outstanding. There are 20 cases still to be reviewed

from 2020-2021. These are ongoing due to Police Investigations or deaths out of area or abroad. All other children who died before 2019 have been reviewed by CDOP.

3. The most common mode of death is following the active withholding, withdrawal or limitation of life-sustaining treatment, which occurred in 46% of cases.
4. CDOP identified 'modifiable factors' in 34% 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'.
5. 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**

CDOP has taken forward actions arising from individual cases which include contacting Local hospital Trusts, CCGs, SWAST and Local Authorities.

### **Themes**

Certain themes have emerged from reviewing children's deaths in the West of England this year including parental literacy, interpreting issues, unsafe sleep environments, and effect of the revised British Association of Perinatal Medicine ethical guidance on resuscitation of extremely preterm infants.

### **Achievements and Future Priorities**

Cases from other CDOPs have been reviewed where a child died in Bristol but resided elsewhere. A successful multi-agency JAR training event was delivered. A bereavement guide for GPs was written. The Designated Dr contributed to national research into the quality of JARs. CDOP continues to capture some of the effects of COVID lockdown on children.

## **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 which was continued by the alternative safeguarding arrangements from 2019. 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. 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. Child Death Review: Statutory and Operational Guidance<sup>1</sup> was published in October 2018 and applies to all the deaths reviewed in this year's 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.

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

Working Together (2018) 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.

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 in 2008. 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 2020/21, the WoE CDOP Chair was taken by North Somerset Director of Public Health. The Terms of Reference, Governance Arrangements and Membership are summarised in documents available from the Child Death office at the University of Bristol which 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, but this follows review by their local CDOP and these cases are no longer counted in the total of cases reviewed.

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 fourteenth Annual Report of the West of England CDOP. It was approved by the Panel on 13th July 2022. It is a public document. Previous year's Annual Reports can be found online or requested from the Child Death office at University of Bristol.

The Child Death office use the following sources to ensure optimal notification of child deaths:

- Weekly returns from the Local Registrar's Offices
- Regular checks on BadgerNet for missing cases
- Joint Agency Response phone calls and reports
- Closely working with the Child Health Information Service

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 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. eCDOP dataset is submitted to the National Child Mortality Database who produce data summaries on a quarterly basis and this report is based on the quarter 4 report from 2021/22.

Links to previous reports:

<https://bswccg.nhs.uk/for-clinicians/safeguarding/child-safeguarding/b-nes-locality/2251-final-revised-woe-cdop-annual-report-2020-2021-1-10-21/file>

[https://bristolsafeguarding.org/media/l14ptzog/woe\\_cdop\\_annual\\_report\\_2019-2020\\_final.pdf](https://bristolsafeguarding.org/media/l14ptzog/woe_cdop_annual_report_2019-2020_final.pdf)

**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 2021-22

This section summarises all deaths notified to the Child Death office, between April 1<sup>st</sup> 2019 and March 31<sup>st</sup> 2022, of children who are normally resident in the areas represented by the West of England CDOP. There were 51 notifications in this 12 month period. These data are drawn from the eCDOP Notification database.

### 6.1 Analysis of notifications by year (2019-2022)

For comparison, deaths notified over a 3 year period are reported by area of residence and by year in Table 1.

**Table 1: Notifications by region of residence, 2019-2022**

Region	2019/20Deaths	2020/2021Deaths	2021/2022 Deaths
BANES	8	7	12
Bristol	23	21	25
North Somerset	4	7	7
South Gloucestershire	16	12	7
<b>Total WoE</b>	<b>51</b>	<b>47</b>	<b>51</b>

A proportion of deaths occurring each year are of children residing in areas outside the West of England region (BANES, Bristol, North Somerset and South Gloucestershire), including children visiting the area from other parts of the UK. This is because Bristol has tertiary referral units for neonates and children and specialist services including cardiology, oncology and neurology. These cases are notified to their own area CDOPs and so it is no longer appropriate or possible to present these numbers as part of this report.

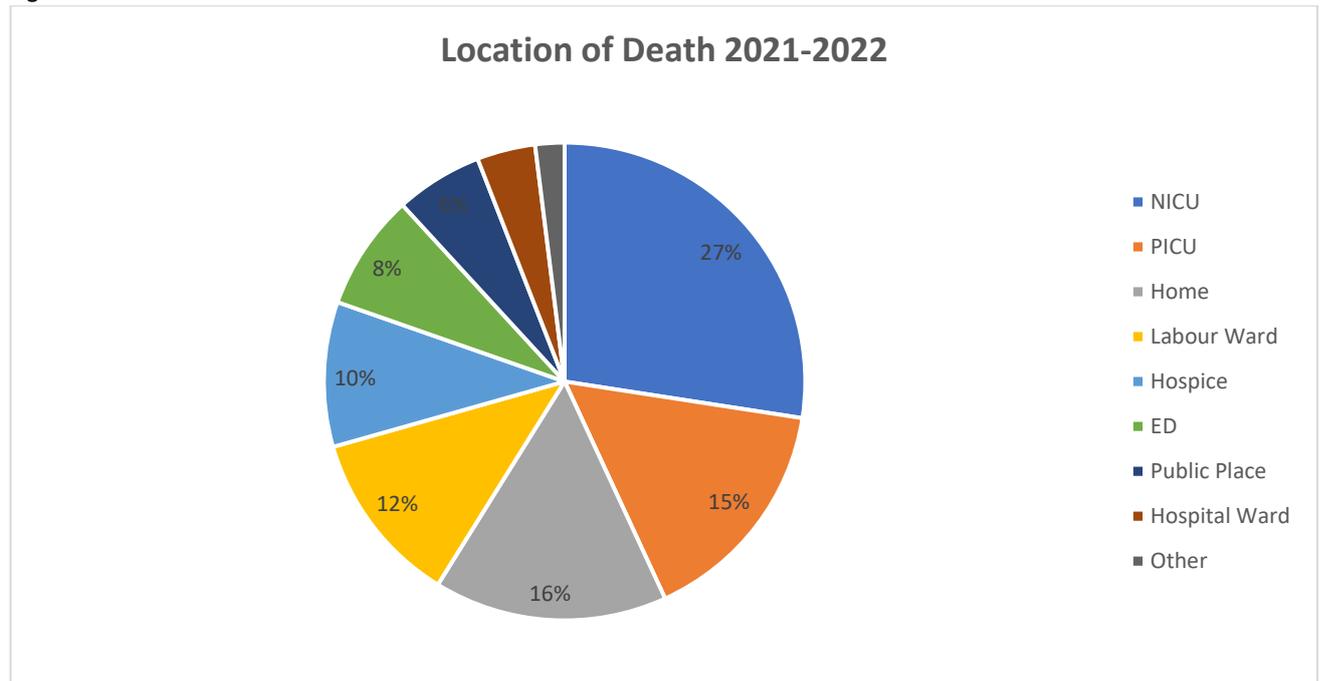
The numbers of notifications for any one area of residence are small so that the most likely explanation for any pattern is random year-on-year variation. However, CDOP should always try to exclude contributory factors such as differences in coding practice or an increase in a particular category of death.

It should be noted that UHBW produce an Annual Report on child deaths reviewed within the Bristol Royal Hospital for Children which includes children cared for from out of area, and this is available from the Child Death Review Coordinators at BRHC.

### 6.2 Location of death Notifications (2021-2022)

Over the 12 month period 27% (14/51) of all child deaths occurred in NICU, 16% (8/51) on PICU, 15% (8/51) at home, 12% (6/51) on a labour ward or delivery suite, 10% (5/51) in a hospice, 8% (4/51) the Emergency Department, and 6% (3/51) in a public place. <5% occurred on a hospital ward and <5% in other places. (Figure 1).

Figure 1. Location of Death Notifications 2021-2022



### 6.3 Age at Death (2021-2022)

20/51 notifications (39%) were received for babies dying in the neonatal period (0-27 days). A further 17 (33%) died in the first year of life, 8 (16%) of deaths were of children aged between 15-17. A further 3 (6%) were of children between 10-14 years. Comparison data for the 3 previous reporting years is shown below from NCMD data. A relative increase in deaths in the 28-364 day old age group is noted but as the final cause of death is not known at the point of notification this will need further scrutiny following full investigation and CDOP review. No specific cause can be identified to explain this at this point. Overall the number of deaths is similar year on year.

Figure 2:

## Death notifications by age group and year

Age group	2019-20	2020-21	2021-22
0 - 27 days	24	21	20
28 - 364 days	9	10	17
1 - 4 years	7	4	1
5 - 9 years	3	4	2
10 - 14 years	4	2	3
15 - 17 years	4	6	8
<b>Total</b>	<b>51</b>	<b>47</b>	<b>51</b>

#### 6.4 Gender (2021-2022)

There have been more notifications of deaths in boys than girls (61% are boys).

#### 6.5 Post mortem examinations in Deaths notified (2021-2022)

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 21/51 deaths notified during 2021-2022 (41%). 30/51 (59%) cases did not have a post mortem at the point of notification of the death.

#### 6.6 Deaths notified requiring a Joint Agency Response (JAR) (2021-2022)

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 in the Kennedy guidelines 2016

<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.

For the Notifications received during 2021-2022, there were 17 cases which required a Joint Agency Response, 34 which did not require a Joint Agency Response.

## 7. Child Death Overview Panel Review Data (2021-2022)

This section summarises the Panel's review decisions for 2021-2022 and its actions for 2021-22.

There is an inevitable time-lag (6-12 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 2.

**Table 2: The number of Completed CDOP reviews each year by year of death**

	2017/18		2018/19		2019/20		2020/21		2021/22	
<b>Total number of notifications</b>	103		95		79		64		51	
<b>Number of cases to be reviewed by WOE CDOP</b>	64		40		51		48		50	
<b>Years of Review</b>	<b>Number reviewed</b>	<b>%</b>	<b>Number reviewed</b>	<b>%</b>	<b>Number reviewed</b>	<b>%</b>	<b>Number reviewed</b>	<b>%</b>	<b>Number reviewed</b>	<b>%</b>
2017/18	5	8								
2018/19	33	52	4	10						
2019/20	15	25	24	60	1	3				
2020/21	9	14	10	25	27	53	2	4		
2021/22	2	1	2	5	17	33	26	54	3	6
<b>Total</b>	<b>64</b>	<b>100</b>	<b>40</b>	<b>100</b>	<b>45</b>	<b>88</b>	<b>28</b>	<b>58</b>	<b>3</b>	<b>6</b>

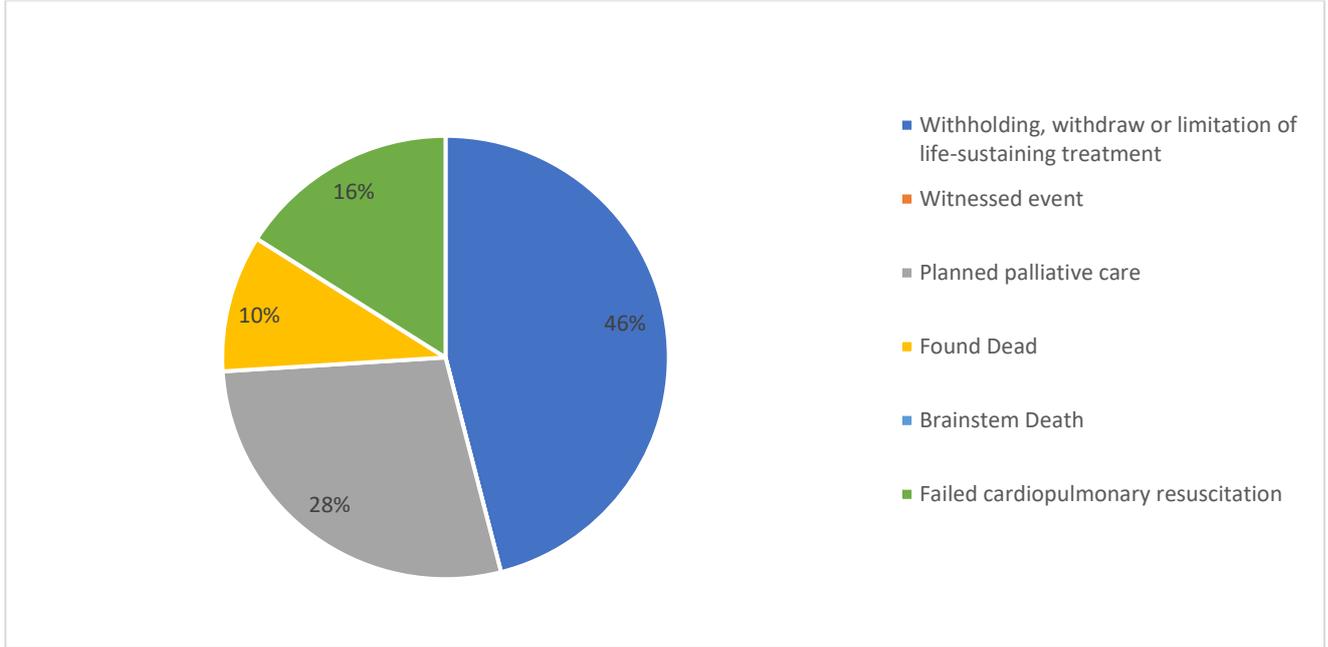
This includes all children resident within the West of England area at the time of their death and previously included selected specialist cases more appropriately discussed by the West of England CDOP e.g. those involving cardiac surgery.

Sections 7.1 to 7.6.1 describe data relating to the children reviewed by the West of England CDOP between 1<sup>st</sup> April 2021 and 31<sup>st</sup> March 2022. 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.

### 7.1 Mode of death (2021-2022)

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 46% of the deaths reviewed by CDOP. In 16% 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 28% of cases the child died following planned palliative care and in 10% of cases the child was found dead.

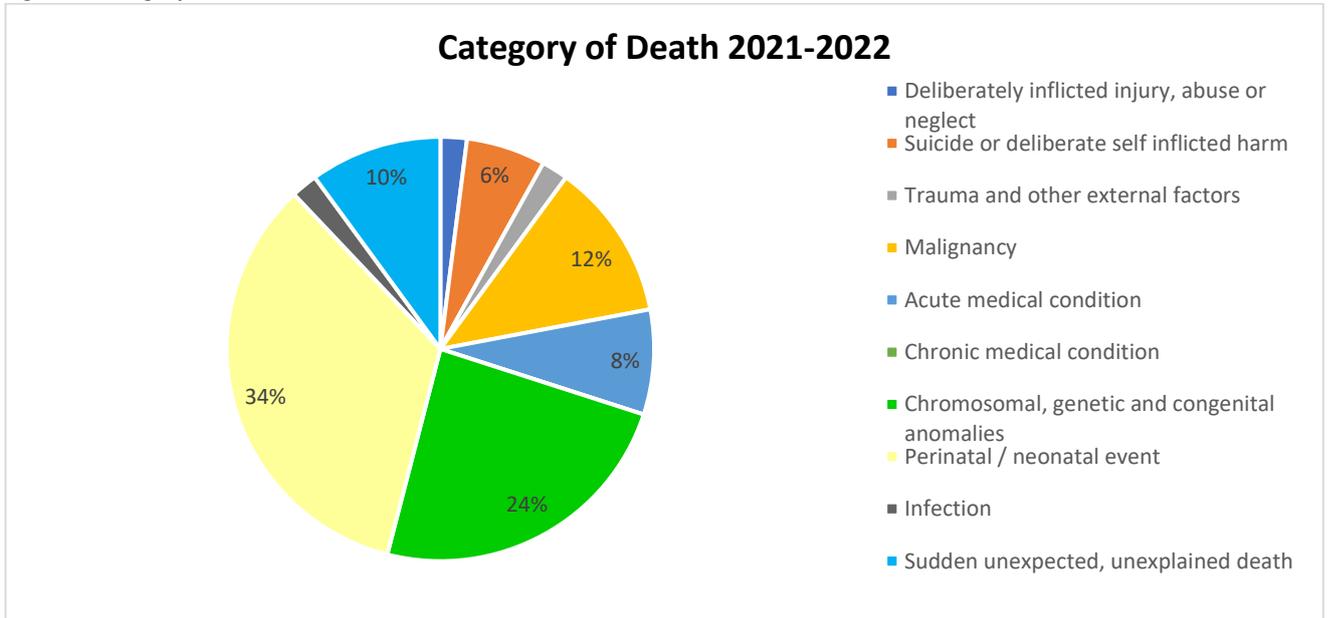
Figure 3: Mode of death of cases reviewed by CDOP between 1<sup>st</sup> April 2021 and 31<sup>st</sup> March 2022



### 7.2 Category of Death

The most frequent category of death is Perinatal and Neonatal deaths(34%) , followed by Chromosomal Genetic and Congenital Anomalies (24%). 10% of deaths remain unexplained after a full investigation. This distribution is similar to that seen in previous years.

Figure 4: Category of Death 2021-2022

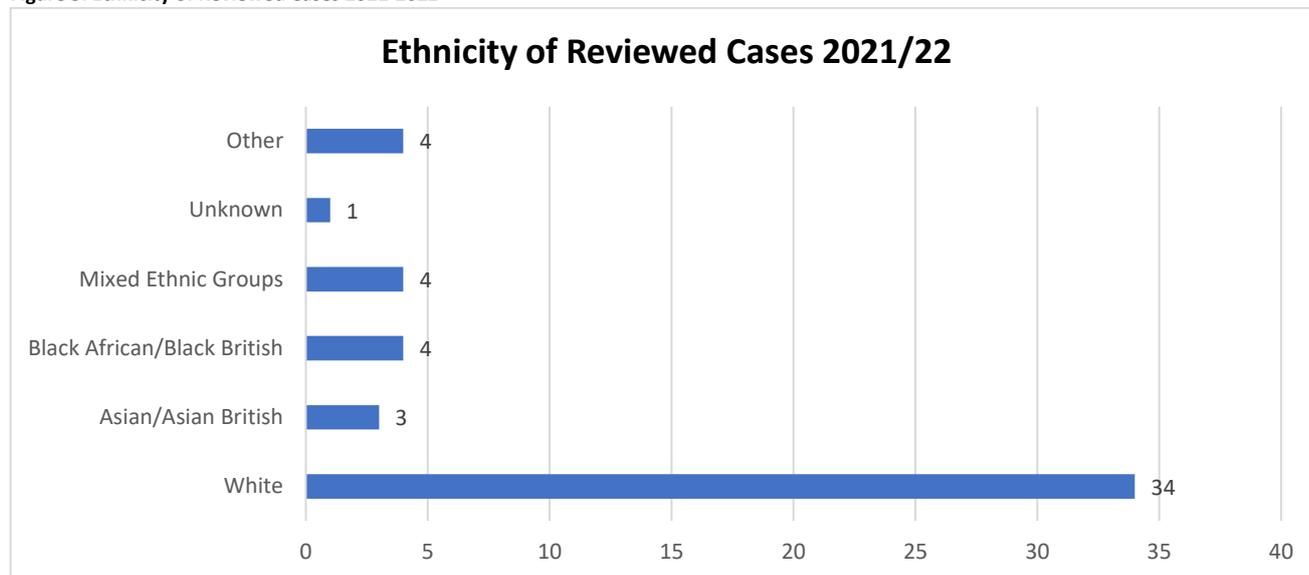


### 7.3 Ethnicity of cases reviewed.

Figure 5 shows that 68% of cases reviewed by CDOP between 2021 and 2022 were children of White British origin. The number of reviews for children whose ethnicity was recorded as mixed was 8%, Black or British was 8% and Asian or Asian British was 6% and the number of reviews for children whose ethnicity was recorded as Black or Black British was 8%. Other ethnicities were recorded as 8%. 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 5. Ethnicity of Reviewed Cases 2021-2022



#### 7.4 Factors in the Social environment (2021-2022)

Table 3: Factors in the social environment (including parenting capacity recorded in cases reviewed by CDOP between 1<sup>st</sup> April 2021 and 31<sup>st</sup> March 2022

Factors in Social Environment	Yes	No	Not known
Smoking by a parent or carer / Smoking by Mum during pregnancy	3 (6%)	7 (14%)	40 (80%)
Alcohol or Substance Misuse by a parent or carer	1 (2%)	12 (24%)	37 (74%)
Domestic violence	1 (2%)	12 (24%)	37 (74%)
Emotional, Behavioural or Mental Health condition in a parent or carer	8 (16%)	10 (20%)	32 (64%)

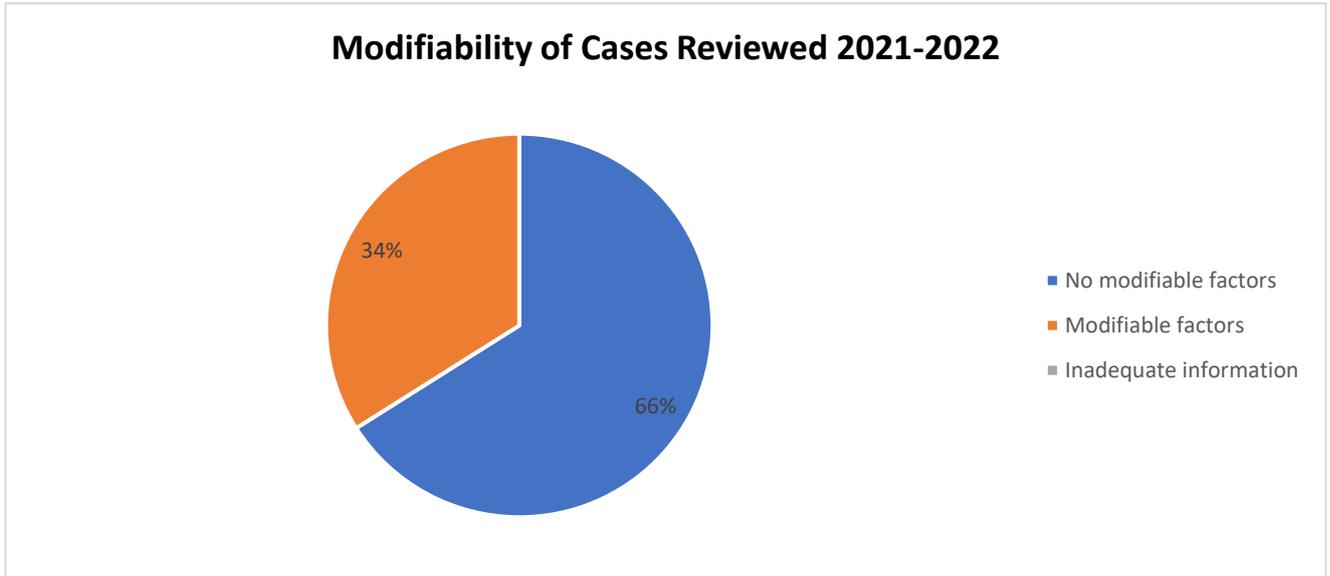
This data is collected in all cases, but less analysis is available at the local level from the new CDR forms. It is hoped this will come out from future NCMD national analysis. Overall these social factors are likely to be over represented in the families of children who die compared to the general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

#### 7.5 Modifiable Factors (2021-2022)

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 reviewed by the West of England CDOP in the twelve month period modifiable factors were identified in 34% of cases. Nationally 37% of child death reviews assessed as having modifiable factors in the same time period.

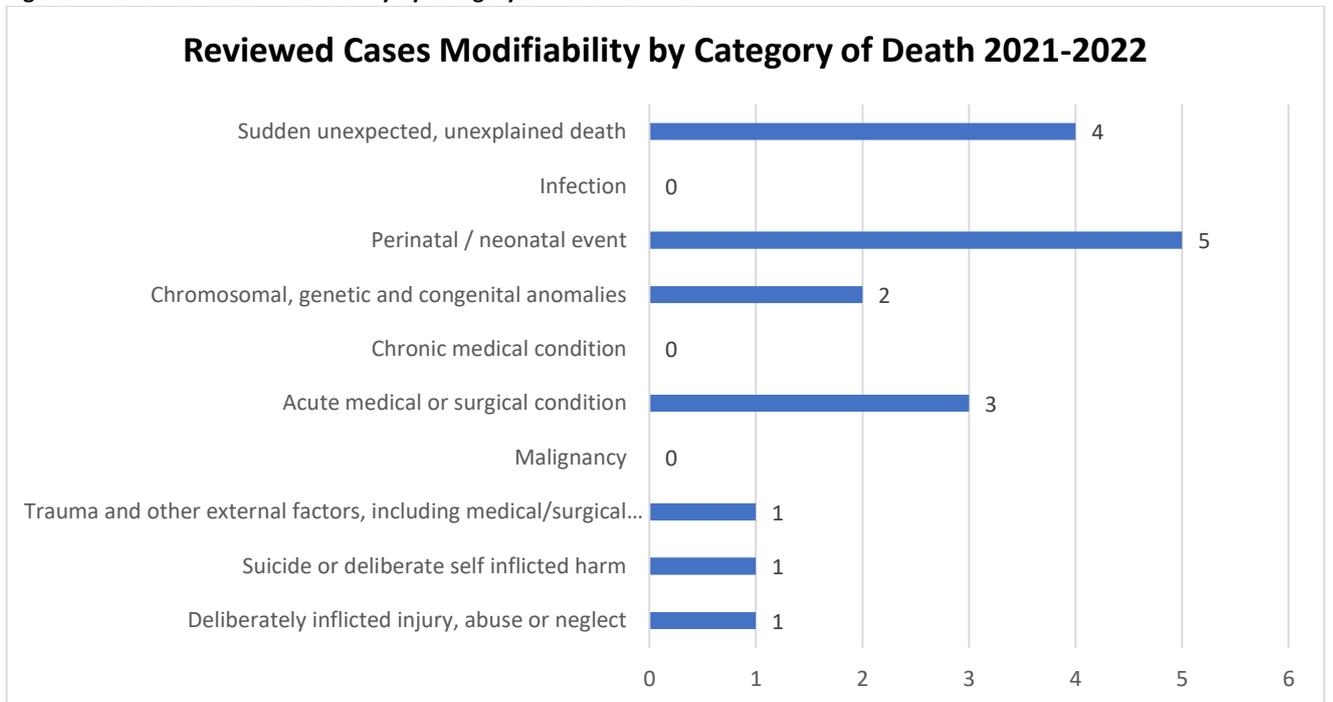
Figure 6: Modifiability of cases reviewed by CDOP between 1<sup>st</sup> April 2021 and 31<sup>st</sup> March 2022



### 7.6 Modifiability by Category of Death

This data show the most frequent category deemed to have Modifiable factors was Perinatal/Neonatal event, followed by Sudden unexpected, unexplained deaths, and then Acute medical or surgical conditions. The least common categories deemed to have modifiable factors were Malignancy and Infection (there were none categorised Chronic medical conditions in this time period). Note the categories are not even, see figure 6 above.

Figure 7: Reviewed Cases Modifiability by Category of Death 2021-2022



### 7.7 Family follow up (2021-2022)

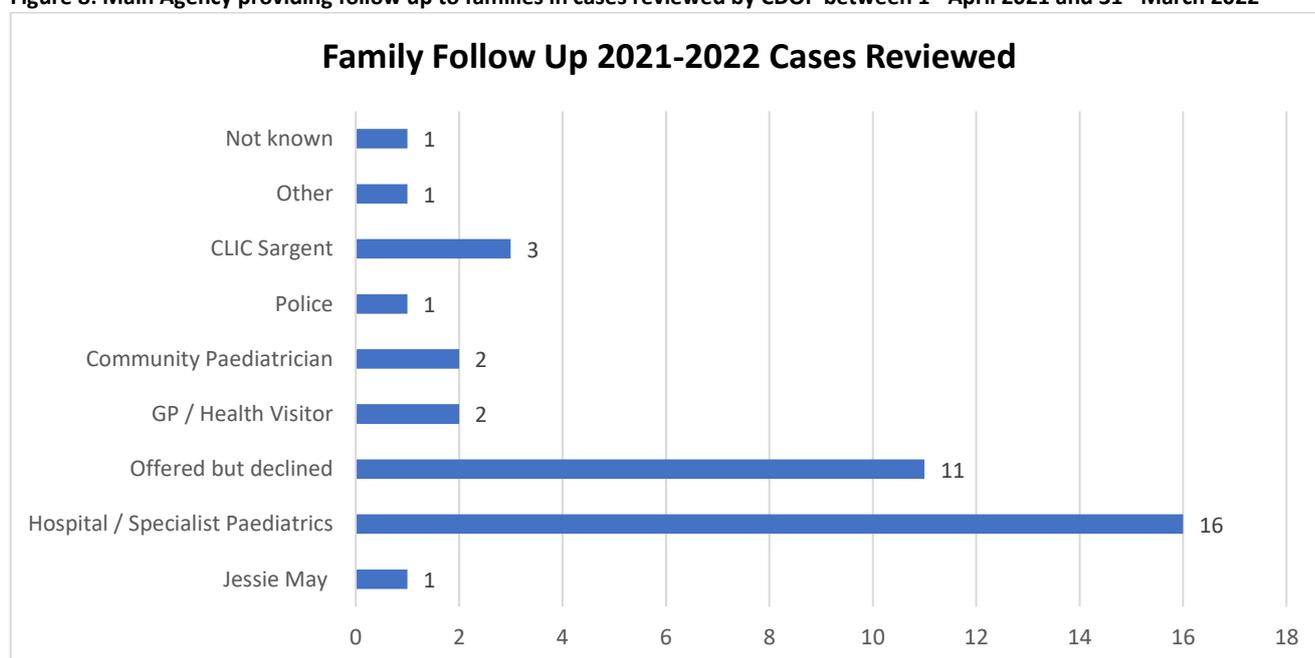
Active engagement with bereaved parents underpins the entire child death review process. Parental input into the child death review meeting should occur as a matter of course. Parents are invited to submit questions to

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 8 shows which was the main agency offering follow up for cases reviewed by CDOP between 1<sup>st</sup> April 2021 and 31<sup>st</sup> March 2022. However 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.

In addition, families are routinely given national and local information on charities offering bereavement support. A bereavement pathway has been developed within University Hospitals Bristol NHS Foundation Trust and the team have offered support to all families of children who have been seen at the Children's Hospital since the team was set up, and now extend this offer to the families of children and young people even when death is confirmed outside the hospital.

**Figure 8: Main Agency providing follow up to families in cases reviewed by CDOP between 1<sup>st</sup> April 2021 and 31<sup>st</sup> March 2022**



## Child Death Overview Panel Activity (2021-2022)

### 7.8 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 4 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 4

Case Description	Issue	CDOP Action	Response/evidence	Recommended National Learning
<b>Extreme prematurity</b>	Baby was delivered at home and was brought to the Children's Hospital	CDOP checked that a Standard Operating Procedure was in place and that the Ambulance Service knows to bring babies to Maternity Hospital/NICU in this circumstance	The most recent information was sent out in April 2021. There are local variations across areas served by SWAST Trust as some would require the baby be brought into the Emergency Department with a pre-alert notification given.	Further liaison with Oxford CDOP about same issue
<b>Extreme prematurity</b>	The baby was cold	CDOP checked if pre-hospital crews i.e. Doctors and advanced Paramedics have trans warmers for out of hospital births.	Frontline ambulances now carry trans-warmer baby mattresses which have been available to order since 01.02.21.	
<b>Sepsis in a premature infant</b>	Heavy growth of Pseudomonas which represented a significant risk for lungs in an extremely preterm baby	CDOP contacted NICU Infection Control Lead regarding additional hand hygiene measures e.g. 7 step washing, screen guidance, auditing of handwashing and hand gelling compliance	Interventions and strategies to further improve current infection rates ongoing. The unit infection rates are within an acceptable range looking at national and international benchmarking tools like Badger and VON (Vermont Oxford Network).	
<b>Extreme prematurity</b>	Lack of birth certification of babies born before 24 weeks gestation	A baby delivered before 24 weeks gestation who shows signs of life but subsequently dies within 28 days is registered as a neonatal death and the parents will receive a death certificate. A birth certificate is currently not issued for babies born before 24 weeks gestation who show signs of life.	NHS Trusts are encouraged to develop a system of hospital-based commemorative certification for babies that have not been classified as stillbirth.	

<b>Trisomy 18</b>	Home circumstances lacked suitability for care of a child with complex disability including home oxygen	Ask CCG about adequate arrangements for discharge of children with complex disabilities including opportunity to see the home before the child leaves hospital	Detailed response from NICU, still confirming process from Children's Hospital	
<b>SUDI</b>	Family members were used to interpret. The Mother was a child herself & didn't speak English; potentially vulnerable re trafficking & coercion	To seek reassurance from Trust about their policy and practice on use of interpreters.	Trust raised this issue through their Governance process	
<b>Metabolic disorder</b>	Delay in reporting of skeletal survey by radiology led to delay in post mortem	A skeletal survey is required following SUDIs before the main autopsy proceeds. Liaison with pathologist & clinical director for acute Trust to raise this issue.	Audit in progress of timelines across a number of similar cases. Shortage of Paediatric Radiologists nationally	
<b>Congenital heart disease</b>	Genetic testing was declined antenatally, and then delayed following delivery	Check process in place for genetic testing to be done as soon as possible following delivery.	NICU reassured CDOP that this process is in place. Guideline states "If antenatal genetic testing has been declined must have urgent genetic testing sent after birth to guide management plan."	
<b>Trisomy 18</b>	Lack of clarity about treatment options and reassurance for family that these were appropriately considered	CDOP requested information about the approach to care following diagnosis antenatally and postnatally.	Local Paediatricians and Fetal Medicine Unit have collaborated and written a protocol for ongoing care of babies/children with Trisomy 18.	This will be circulated to all neonatal units around the country
<b>SUDI</b>	Unsafe sleeping environment	GP rep to investigate if there is any capacity to include a question about the sleeping environment to the revised 8 week postnatal check template.	There is now a tick box on the BNSSG 8 week check template now to include this.	

<b>SUDI</b>	Use of fleece blankets	Paediatrician to undertake literature search into fleece blankets and safe sleeping advice.	Concern about the effect on temperature but no published evidence of risk yet. Continue to monitor cases where bedding may contribute to unsafe sleep environment. A poster will be submitted on this topic at the South West BACCH meeting	
<b>Severe Hypoxic ischaemic encephalopathy following placental abruption</b>	Check recommendations from HSIB report	CDOP sought assurance that the recommendations and actions from the HSIB report are completed and to check that the midwife was given access to support.	The Interim Head of Midwifery confirmed that the Midwife was given access to support and that the actions from the HSIB Report are complete.	
<b>Domestic drowning</b>	Domestic abuse may have contributed to the circumstances	Reassurance was sought that the recommendations from the Rapid Review Report have been completed by the Safeguarding Partnership.	The Practice Review Group agreed that the Domestic Abuse Partnership should conduct a case audit to gain further evidence and assurance around the application of this process and provide evidence of outcomes to the BCSSP. Recommendations from this rapid review have been addressed.	
<b>Death of child with a chronic medical illness while abroad</b>	It was unclear how prescribed medication was stored on a trip abroad.	Enquiries were made to establish how the Metabolic Team give information to families.	Patients with metabolic disorders that are at risk of acute decompensation have an acute management plan for home and hospital. If given enough notice for the travel abroad, a translated plan in the language of the country they visit if one exists is offered.	
<b>Malignancy</b>	Ambulance delays (x 2) to transfer from home to hospital or hospice as a 'non-urgent' transfer with a 4 hour	CDOP investigated the cause of the delay between home to hospital and hospice with the Ambulance Service.	The current situation is multi-factorial and not within the gift of the ambulance service, as a single agency to resolve. The barriers to responding to this sort of	

	window, as young person was not 'unconscious or needing lifesaving treatment'.		situation are ones of demand and capacity. There is an extended dialogue in progress with commissioners and partners at the moment.	
<b>Deliberately inflicted injury in young baby</b>	Mother presented as a late booking / concealed pregnancy in 2 <sup>nd</sup> trimester	CDOP to investigate if there is a late booking / concealed pregnancy policy for the Trust. There was not one at the time.	Development of a 'late booking' policy, practice tool or guidance for midwives, health visitors and doctors that highlights any potential vulnerabilities or safeguarding risks, including information sharing pathways and is included in mandatory training. Antenatal Care policy and SOP for women who present later in pregnancy was provided.	
<b>Death abroad</b>	Safety netting following discharge from hospital	CDOP challenged the speciality involved (in this case Neurology) about information provided to the parents about how to seek review and who to contact, in context of non-English speaking family	Further review of information provided and discharge in context of language/cultural differences	
<b>Sepsis</b>	Sepsis awareness in schools			CDOP noted the Coroner made a Prevention of Future Deaths ruling leading to the Outdoor Education Advisors Panel & UK Sepsis Trust producing new guidance & a video for World Sepsis Day Sep 2021
<b>Sepsis</b>	Good provision of support for pupils	CDOP noted good practice including involvement of the		

	following death of a peer	Samaritan's Step by Step programme		
<b>Asthma</b>	DNAs to hospital follow-up and poorly coordinated transition to adult services	Review of care at childrens and adult hospitals	Transition Respiratory Nurse now in place	
<b>Malignancy</b>	Recognising good practice of local hospital and hospice clinicians who enabled End of Life Care to take place at home	CDOP to commend the good practice of the local Hospital Oncology Clinicians and Hospice Team who enabled this child's End of Life Care to take place at home	Acknowledged receipt of the letter and will cascade to relevant staff	

### 7.8.1 Themes emerging from aggregate review of cases at CDOP during the year April 2020 – March 2021

In 2021/22 there were 3 Neonatal themed meetings. There were no other specific themed CDOP meetings.

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

Cardiotocograph interpretation: Competency assessments and updates, use of CTG stickers, identification of CTG champions

A working group was set up by CDOP to ensure GP systems follow best practice in supporting families when they have experienced a child death. This document is now live on Remedy:

<https://remedy.bnssgccg.nhs.uk/children-young-people/end-of-life-care-children/when-a-child-dies/>

Safe sleeping – CDOP continues to record examples of unsafe sleep environments and equipment, with a plan to discuss with Health Visiting leads to ensure all these areas are covered and reinforced in safe sleeping advice given to families.

Revised British Association of Perinatal Medicine ethical guidance regarding resuscitation of extremely premature babies [Perinatal Management of Extreme Preterm Birth Before 27 weeks of Gestation \(2019\) | British Association of Perinatal Medicine \(bapm.org\)](#) – now includes those born at 22 weeks gestation. CDOP have reviewed about 3 cases which are likely to relate to this guidance (and may not previously have been offered resuscitation). NICUs have to provide care for this group and CDOP discussions have raised the issue of no adjustment to service provision eg bed capacity or staffing. It is likely that nationally CDOPs will see an increase in these types of deaths.

Awareness of literacy issues in parents - all panel members raised the issue of literacy within their agencies and fed back to CDOP.

Interpreting for vulnerable children/parents - should not rely on family members, and CDOP has noted this also reduces opportunities to ask about sensitive topics such as domestic abuse and mental health.

Lack of 24/7 paediatric palliative care in the community was noted in a number of cases as a factor affecting the final place of care.

Non-receipt of eCDOP forms from certain professional teams. CDOP keeps track of this and offers support or training to teams that have serial non-responders, as well as escalating to their managers, as provision of information to CDOP is a statutory responsibility. CDOP has developed an escalation policy to approach this in a fair and consistent manner.

#### **Good practice:**

CDOP note many examples of good practice. Some of these are:

A school established and named an award after a young person.

In the end, after a long journey, a child had a beautiful & respectful death.

Kidney donation was achieved and the family received a grateful letter from the recipients.

A teacher who had to provide CPR was noted by emergency professionals as delivering this well & in line with life support training.

A working group was set up by CDOP to ensure GP systems follow best practice in supporting families when they have experienced a child death. This document is now live on Remedy:

<https://remedy.bnssgccc.nhs.uk/children-young-people/end-of-life-care-children/when-a-child-dies>

This is only BNSSG and not BaNES concerned that GPs in BaNES ? how is this learning shared, if through the designated Dr this should be highlighted. BaNES GPs would not be accessing REMEDY

#### **COVID related :**

Fortunately CDOP did not need to review any paediatric COVID deaths but continued to note issues relating to lockdown & COVID restrictions including:

Fear of COVID greatly affected a young person's school attendance

Referral of a baby to cardiology for a heart murmur was postponed due to COVID

COVID increased the isolation of mum during lockdown

A young person was more isolated due to COVID lockdown, and CAMHS follow-up arrangements were affected. It was noted that a family was sad not to be able to spend more time with their baby prior to death due to visiting restrictions.

Good phone review was noted and parental support during COVID.

#### **National Child Mortality Database**

WoE CDOP continue to contribute data to the NCMD. Data upload is audited and has reached 100% in the majority of areas.

NCMD annual and themed reports have been read & circulated by CDOP. Of the top 11 modifiable factors listed by NCMD, WoE CDOP have noted all these in one or more cases reviewed.

The latest published data from the National Child Mortality Database in England shows that 73% of deaths of children occur in hospital. The great majority of these deaths occur in tertiary paediatric and neonatal intensive care units. In terms of category of deaths, the percentage breakdown is as follows:

- 33% are due to perinatal or neonatal events, the vast majority of which are due to complications of premature delivery
- 24% are due to inherited chromosomal, genetic or congenital anomalies
- 8% are due to malignancy
- 11% are due to acute or chronic medical conditions including asthma, diabetes and epilepsy
- 5% are due to infection
- 18% are due to external causes (homicide, suicide, trauma and sudden unexplained deaths)
- around 4% are classified as 'sudden and unexpected'.

National Child Mortality Database. Child death review data release 2021. Available at:

[www.ncmd.info/publications/child-death-data-release-2021](http://www.ncmd.info/publications/child-death-data-release-2021)

## 8. Achievements

CDOP annual report 2020/21 was provided to the Avon and Somerset Strategic Safeguarding Partners and as a virtual presentation to all partners in Nov 2021.

Review of 2 cases from other regional CDOPs as 'Read only' demonstrating good practice to share learning across CDOPs.

A training day was run at Police HQ on 4<sup>th</sup> March 'Effective interagency working in the Joint Agency Response: An information and training day for multi-agency professionals involved at all stages of the Joint Agency Response to a Child Death' which was very well-received, and is available as online recordings.

The Designated Dr has contributed to a national research project looking at the quality of Joint Agency Responses following SUDIs. This has evolved into an 'Expert Group to Improve the Joint Agency Response to Unexpected Child Deaths'. National Child Death training videos are now being developed as an action from this group, including sections prepared and presented by the WoE Designated Dr. These will replace and update the former Warwick Child Death course.

Agreement to convene a JAR meeting (48-72hours) in all Joint Agency Response cases, with preparation of a standard agenda and logistic process to support these meetings.

A bereavement guide for GPs to support a family following the death of a child has been produced and now available on Remedy.

Further revision of the Where to Take a Child flowchart across agencies to aid appropriate decision making by police, ambulance staff and other professionals at the place of a sudden death in the community.

A local case contributed to raising the issue of eye examination following a SUDI and the subsequent revised statement from RCO/RCPCH to clarify the paediatrician's responsibilities. [Eye examination in Sudden Unexpected Death in Children \(SUDIC\) : Joint Statement | The Royal College of Ophthalmologists \(rcophth.ac.uk\)](#)

Meetings have continued to be convened remotely in order for CDRs and CDOP to proceed, and this still continues with some advantages for attendance, but disadvantages in terms of team building. However one of the biannual Child Death Peer Review meetings has been held in person, allowing much better peer support.

Review of Emotional and Well Being support available to frontline professionals - this no longer includes a specific local psychologist but there is a portfolio of support options which have been promoted, in particular to Community Paediatricians leading for the Joint Agency Responses.

## 9. Future Priorities

Sharing Annual Report more widely with CDR partners and other local organisations.

B&NES are moving to a nurse led JAR model from May 2022, and this will lead to some reflection on arrangements for JAR out of hours cover in BNSSG where this is still provided by Community Paediatricians.

Care of the Next Infant (CONI) Programme - this was successfully re-established in BNSSG in 2016 as a pilot using CDOP funds and was delivered by the North Bristol NHS Trust community neonatal midwives and neonatologists. However ongoing funding has still to be identified, and CDOP continues to be a supportive partner in this important program. [Care of Next Infant \(CONI\) - The Lullaby Trust](#)

Anticipated roll out of the Medical Examiner service to include scrutiny of children's deaths from later 2022 will need full integration with existing CDR processes, and consideration of the impact on bereaved families. <https://www.rcpath.org/profession/medical-examiners/good-practice-series.html> The Designated Dr is closely involved in local implementations.

## Appendix A - CDOP membership April 2021 to March 2022

<b>Role</b>	<b>Core member</b>	<b>Organisation</b>
Nominated Chair	Matt Lenny	Director of Public Health and Regulatory Services, North Somerset Council
Designated Doctor for Children's Deaths	Dr Mary Gainsborough	Sirona care & health on behalf of CCGs
Consultant Neonatologist	Dr Ziju Elanjikal / Dr Claire Rose	University Hospitals Bristol and Weston NHS Trust / North Bristol NHS Trust
Coroner's Officer	Debra Neil	Avon Coroner's Office
Children's Social Care	Mary Kearney-Knowles	Director of Children and Young People Services, Bath and North East Somerset Council
Designated Nurse for Safeguarding	Jackie Mathers Anne Fry	BANES CCG BNSSG CCG
Professional Midwifery Advocate & Midwifery Matron Midwifery Ward Manager	Julie Northrop  Sara Arnold	University Hospitals Bristol and Weston NHS Trust
Consultant Obstetrician	Dr Rachna Bahl	University Hospitals Bristol and Weston NHS Trust
General Practitioner	Dr Patrick Nearney / Dr Elaine Lunts	Bristol
Police	DI Kristina Windsor	Avon & Somerset Constabulary
Paediatric Palliative Care	Carl Joy	University Hospitals Bristol and Weston NHS Trust
Consultant Paediatric Intensivist	Dr Alvin Schadenberg	University Hospitals Bristol and Weston NHS Trust
Consultant in Paediatric Emergency Medicine	Dr Nick Sargant and Dr Bianca Cuellar	University Hospitals Bristol and Weston NHS Trust
Consultant Community Paediatrician / Designated Doctor for Safeguarding	Dr Fiona Finlay	BANES
Head of Safeguarding, Ambulance Service	Serena Mees/Simon Hester	South Western Ambulance Service NHS Foundation Trust
Lay Representative	Julie Kembrey	Bereaved Parent & Ambassador of Jessie May Trust

