

WEST OF ENGLAND CHILD DEATH OVERVIEW PANEL April 2022 – March 2023 ANNUAL REPORT

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Appendix A – CDOP Membership

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.

In particular we acknowledge the contribution of Sarah Phillips, Senior Public Health Intelligence Specialist South Gloucestershire Council, who has provided analytical support and background demographics.

Mary Gainsborough and Ann Farr

Foreword

The West of England Child Death Overview Panel is a multi-professional panel that 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 which impacts of family, friends and community. 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
- Identify learning and service improvements that will ensure that families are well supported

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

All CDOP Members have a responsibility for sharing learning from panel discussions.

Local and national mechanisms are in place to report data in to the National Child Mortality Database which means that learning is widely shared and that actions are taken, locally and nationally, to reduce the number of children who die and improve the care and support for those who do and their families and communities.

As you read this report I ask that you to consider the data and learning within it and how this is relevant to your work and that of your organisation, share this learning and identify any changes which can be made that might help prevent further deaths, as well as improvements that will ensure that children receive excellent care and families are well supported.

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.

In my first year as Chair of the panel I have been impressed by the sensitivity with which the panel members approach each case discussion and 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. We will always aim to keep the family and children at the centre of what we do.

Sarah Weld Director of Public Health, South Gloucestershire Chair of CDOP

Executive Summary

This report provides an overview of all deaths notified to the Child Death office between April 1st 2022 and March 31st 2023 of children who are normally resident in the areas represented by the West of England CDOP and those cases reviewed by the Child Death Overview Panel over the same period.

Data related to Child Death Notifications

- 59 child deaths were notified to the West of England Child Death Enquiries Office between 1st April 2022 and 31st March 2023. This is more than reported in any of the preceding 3 years (2019-20 51; 2020-21 47; 2021-22 51).
- Over the 12 month period, 66% died in hospitals (NICU, PICU, ED and Hospital Wards/Delivery Suite/Labour ward), 20% at home or in a relative's home, public place or other locations and 14% in hospices.
- 24 notifications (41%) were received for babies dying in the neonatal period (0-28 days). A further 10 (17%) died in the first year of life, 7 deaths (12%) were children aged between 1-4 years old, 5 (8%) were aged 5-9 years old, 9 (15%) were children between 10-14 years and 4 (7%) of deaths were of children aged between 15-17.
- Regarding ethnicity, there was a higher mortality rate in those who were registered as 'other ethnicity' compared to the rate of all-child mortality rate and compared to white children.
- Mortality rate by local area relative deprivation quartile did not show a relationship with greater deprivation.
- 18 (31%) cases triggered a Joint Agency Response.

Data from cases reviewed by the Child Death Overview Panel

- The West of England CDOP reviewed 44 cases between 1st April 2022 and 31st March 2023.
- There is an inevitable time-lag between notification of the child's death to CDOP review and 1 case of a child who died during the period of 2019-20 is still outstanding. There are 34 cases still to be reviewed from 2020-2021, 20 cases from 2021-22 and 56 from 2022-23. These are ongoing due to Police Investigations or deaths out of area or abroad. All other children who died before 2020 have been reviewed by CDOP.
- The most common Category of death was perinatal or neonatal event which occurred in 34% of cases.
- The most common Mode of Death was withholding, withdraw or limitation of life sustaining treatment which occurred in 39% of deaths reviewed.
- Mental health of a parent is mentioned in 46% or reviewed cases and smoking in 36%.
- CDOP identified 'modifiable factors' in 30% 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'.
- Family bereavement follow-up was documented in every case, but was offered or provided by a range of professionals depending on the type and location of the child's death.
- Due to the small numbers there is only weak evidence of any differences in mortality by different ethnic groups, however it does appear that in those cases reviewed there were disproportionally more deaths amongst black, mixed and other ethnicities compared to their respective population, and proportionally fewer deaths amongst white and Asian compared to the population.

Service improvement

CDOP has taken forward actions arising from individual cases which include contacting local Hospital Trusts, ICB's and Local Authorities. Specific actions relate to learning from managing chronic health conditions for Children in Care and during transition to adult services, Suicide prevention, access to Advance Care Plans for

emergency services, support for schools following the death of a pupil, early recognition of congenital anomalies, and the effect of un-booked pregnancies.

Themes

Certain themes have emerged from reviewing children's deaths in the West of England this year including interpreting issues including for pregnant women whose first language is not English and their families, unsafe sleep environments, and the ongoing impact of COVID on children and young people.

Achievements and Future Priorities

These include renewed working arrangements with the new ICBs, the role out of the Medical Examiner Service to the paediatric age group, and teaching and training contributions at a national level.

1. Background

1.1 The Child Death Review Process

Since April 1st 2008, Local Safeguarding Children Boards (LSCBs) in England have had a statutory responsibility for child death review processes which was continued by the alternative local safeguarding arrangements implemented 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 Processes¹. The process focuses on identifying 'modifiable factors' in the child's death.. Child Death Review: Statutory and Operational Guidance² 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.

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 the cause is not fully understood, and a 'Child Death Overview Panel' (CDOP) that comes together to undertake an overview of <u>all</u> 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 A) 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 2022/23, the WoE CDOP Chair was taken by the South Gloucestershire 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 by WoE CDOP.

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

¹ Chapter 5: Child death reviews (workingtogetheronline.co.uk)

² https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidanceengland

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.

All CDOP Members have a responsibility for sharing learning from panel discussions. Data and learning gathered through the CDR process also feeds in to the National Child Mortality Database (NCMD)³ which records comprehensive data, standardised across a whole country (England), on the circumstances of children's deaths. The purpose of collating information nationally is to ensure that deaths are learned from, that learning is widely shared and that actions are taken, locally and nationally, to reduce the number of children who die.

1.2 Production of annual report (processing and verification of data)

This is the fifteenth Annual Report of the West of England CDOP. It was approved by the Panel 20th July 2023. It is a public document. Previous Annual Reports can be found online:

<u>WoE Annual Report 2021-2022</u> (right click and open hyperlink) or request 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
- Close 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 2022/23.

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.

³ About the NCMD - National Child Mortality Database

2. Summary Death Notification Data 2022/23

This section summarises all deaths notified to the Child Death office between April 1st 2022 and March 31st 2023 of children who are normally resident in the areas represented by the West of England CDOP.

A proportion of deaths occurring each year in the West of England area 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 then notified to their own area CDOPs.

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

There were 59 notifications in the last 12 month period. This is more than reported in any of the preceding 3 years (2019-20 51; 2020-21 47; 2021-22 51). These data are drawn from the eCDOP Notification database.

Figure 1: Notifications by LSCB 2022-23

LSCB name	Cases
Bath & North East Somerset	4
Bristol City	31
North Somerset	10
South Gloucestershire	14
Total	59

Data from the NCMD indicates that nationally, following a significant reduction in child deaths during the first year of the pandemic (2020-21), mortality returned to close to pre-pandemic levels in the following year (2021-22). However, fewer children died overall in the full three-year period, with a net reduction of 4% in child mortality. The greatest reductions in deaths were among children under 10 years of age, and those living in rural areas⁴.

Figure 2: West of England Notifications by year 2019-20 to 2022-23



⁴ Child Mortality in England During the Covid-19 Pandemic (ncmd.info)

2.1 Analysis of notifications by Area of Residence

Crude mortality rate by area of residence (2022/23 deaths and 2021 populations) with 95% confidence intervals 60 50 Crude rate per 100,000 40 30 20

Figure 3: Notifications by area of residence

BANES

11.18

10 0

crude rate

There is no evidence of a significant difference in mortality rates between West of England areas of residence. There is weak evidence of a lower rate in BaNES but caution should be applied as these rates are informed by small numbers.

North Somerset

23.34

Bristol

33.74

South

Gloucestershire

23.65

WoE Total

25.68

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.

2.2 Location of death

Over the 12 month period, 66% died in hospitals (NICU, PICU, ED and Hospital Wards/Delivery Suite/Labour ward), 20% at home or in a relative's home, public place or other locations and 14% in hospices.

Figure 4. Location of Death

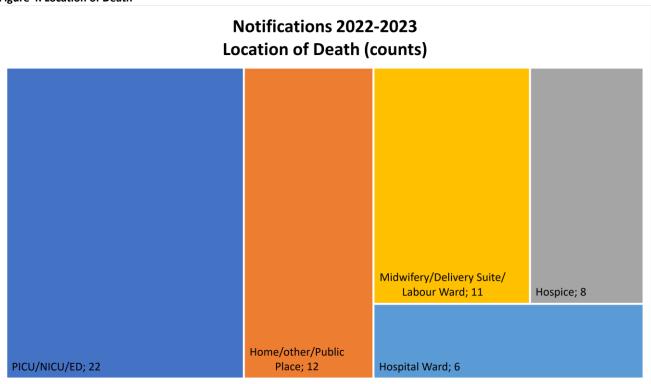
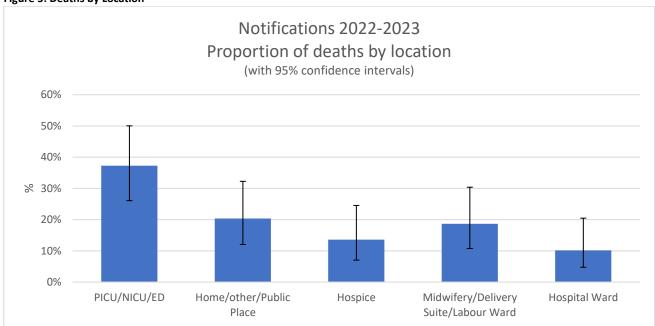


Figure 5: Deaths by Location



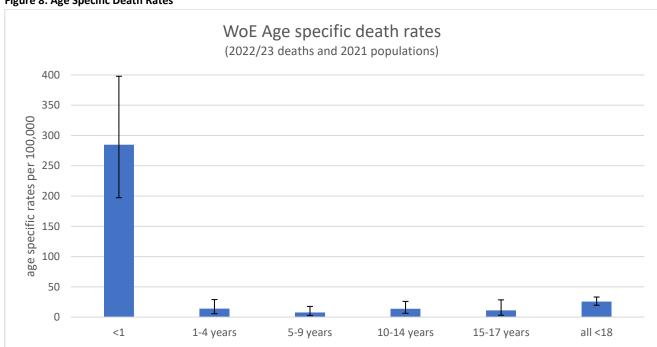
2.3 Age at Death of notifications

In 2022-23 24/59 notifications (41%) were received for babies dying in the neonatal period (0-27 days). A further 10 (17%) died in the first year of life, 7 of deaths (12%) were children aged between 1-4 years old, 5 (8%) were aged 5-9 years old, 9 (15%) were of children between 10-14 years and 4 (7%) of deaths were of children aged between 15-17.

Figure 7: notifications of death by age and year (NCMD)

	2019-2020	2020-2021	2021-2022	2022-2023
0-27 days	24	21	20	24
28 days - 364 days	9	10	17	10
1 - 4 years	7	4	1	7
5 - 9 years	3	4	2	5
10 - 14 years	4	2	3	9
15 - 17 years	4	6	8	4
TOTAL	51	47	51	59

Figure 8: Age Specific Death Rates



WoE Age specific death rates in 1-17 year olds (2022/23 deaths and 2021 populations) 35 age specific rates per 100,000 30 25 20 15 10 5 0 1-4 years 5-9 years 10-14 years 15-17 years all <18

Figure 9: WoE Age Specific Death Rates in 1-17 year olds

There is strong evidence of a higher rate of deaths in children aged under one compared to all other age groups. Amongst children aged over 1, there is no evidence of any differences between age group. However, there is strong evidence of a lower rate amongst 5-9s compared to all under 18s.

Figure 10 Crude rate of death notifications by year and age (using ONS 2018 based population projections)

		<u> </u>		
Age	2019/20	2020/21	2021/22	2022/23
<1 years	252.5	233.4	276.0	251.9
1-4 years	13.3	7.6	1.9	13.4
5-9 years	4.3	5.8	2.9	7.4
10-14 years	6.2	3.0	4.4	13.0
15-17 years	11.6	16.9	21.7	10.5
All <18	21.8	19.8	21.3	24.5

Whilst there have been some variations in the crude rate of death notifications in 10-14s and 15-17 year olds over the last 4 years, due to the small numbers these differences are not statistically significant.

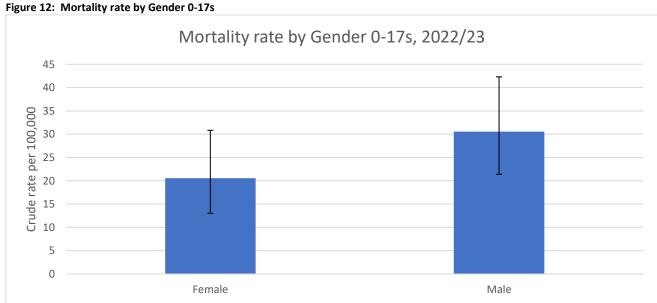
Crude rate of death notifications by age and year of notification, 1-17 year olds, WoE, 2019-2022 45.0 40.0 crude rate per 100,000 35.0 30.0 25.0 20.0 15.0 10.0 5.0 01 - 042020/21 ■ 2021/22 2019/20 2022/23

Figure 11: Crude Rate of Death Notifications 2019-2023

Comparison data for the 3 previous reporting years is shown below from NCMD data in Table 1.

2.4 Gender of notifications

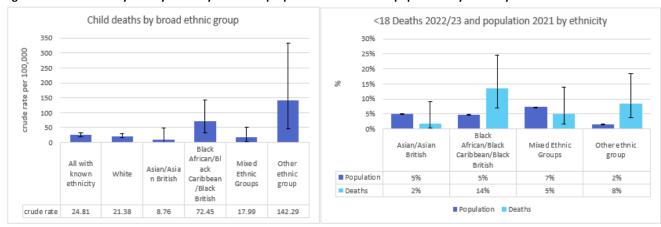
61% of notifications of deaths were of boys and 49% of girls.



There is only weak evidence of a difference by gender at the 0-17 crude level. Stronger evidence may be obtained by pooling multiple years' worth of data.

2.5 Ethnicity of notifications

Figure 13 & 14 Mortality rate by ethnicity 0-17s and proportion of deaths and population by ethnicity



Amongst cases notified, there is strong evidence of a higher mortality rate in those whose are registered as 'other ethnicity' compared to the rate of all-child mortality rate and compared to white children.

Numbers of deaths in the West of England area are too small to be able to explore this in great deal. It should be noted that there is national evidence that babies from the Black ethnic group have the highest rates of stillbirths and infant deaths, with babies from the Asian ethnic group consistently the second highest⁵.

2.6 Area Deprivation (Indices of Multiple Deprivation) of notifications

Figure 15: Notifications Mortality rate by local area relative deprivation Crude rate of deaths notified by local (within LA) deprivation quintile (IMD 2019, 2020 LSOA populations) 70.00 Srude rate per 100,000 60.00 50.00 40.00 30.00 20.00 10.00 0.00 DQ 1 - most DQ 5 - least DQ2 DQ3 DQ4 deprived deprived crude rate 20.11 23.14 35.69 25.77 19.96

There was no obvious pattern associated with local area relative deprivation. There was some weak evidence of death rates being higher in the median deprivation group (DQ 3).

This pattern observed for death notifications and reviews by IMD quintiles is unexpected. There have been known inequalities by deprivation at a national level for neonatal, post neonatal and child mortality between 2010 and 2020 ⁶. Local Primary Care Mortality Data (PCMD) for Bristol, North Somerset and South

⁵ Births and infant mortality by ethnicity in England and Wales - Office for National Statistics (ons.gov.uk)

⁶ Child and Maternal Health - Data - OHID (phe.org.uk)

Gloucestershire (BNSSG)⁷ also shows a similar pattern with deprivation up to 2021, but deaths occurring in 2022 in BNSSG show a similar pattern to the WoE CDOP data. The small numbers of deaths means these local patterns could be a result of chance, and deaths broken down by deprivation will need to be monitored in future reports.

2.7 Post mortem examinations in Deaths notified

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 7/59 deaths notified during 2022-2023 (12%). 30/51 (88%) cases did not have a post mortem at the point of notification of the death.

2.8 Deaths notified requiring a Joint Agency Response (JAR)

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 was 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 2016⁸

A Joint Agency Response should be triggered if a child's death⁹:

- 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
- in the case of a stillbirth where no healthcare professional was in attendance

A JAR is also required when a child collapses unexpectedly, is resuscitated and admitted to hospital but expected to die shortly.

For the Notifications received during 2022-2023, there were 18 (31%) cases which required a Joint Agency Response, 41 did not have a Joint Agency Response.

3. Child Death Overview Panel Review Data 2022-23

This section summarises characteristics of the children reviewed at CDOP and the Panel's review decisions actions for 2022-23. The West of England CDOP reviewed 44 cases between 1st April 2022 and 31st March 2023. 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 Child Safeguarding Practice Review will also affect when a case is discussed at Panel.

⁷ data accessed by Local Authority Public Health team for ICB footprint

⁸ Sudden-unexpected-death-in-infancy-and-childhood-2e.pdf (rcpath.org)

⁹ Child Death Review Statutory and Operational Guidance (England) (publishing.service.gov.uk)

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. During the year 2022-23 CDOP reviewed 44 cases. This is illustrated in Table 2.

Figure 16: The number of Completed CDOP reviews each year by year of death

	2018/	19	2019/2	0	2020/2	1	2021/2	2	2022/2	3
Total										
number of										
notifications	40		51		48		51		59	
Number of										
cases to be										
reviewed by										
WOE CDOP	40		51		48		50		59	
Years of	Number		Number		Number		Number		Number	
Review	reviewed	%	reviewed	%	reviewed	%	reviewed	%	reviewed	%
2018/19	4	10								
2019/20	24	60	1	3						
2020/21	10	25	27	53	2	4				
2021/22	2	5	17	33	26	54	3	6		
2022/23	0	0	3	9	11	23	27	54	3	5
Total	40	100	48	94	39	81	30	60	3	5

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 1st April 2022 and 31st March 2023. 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.

3.1 Mode of death

The most common manner in which children died was following active withholding, withdrawal or limitation 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 39% of the deaths reviewed by CDOP. In 29% of cases the child died following planned palliative care and 25% after failed cardio-pulmonary resuscitation attempts although the child may have been critically ill on NICU or PICU prior to the final event. In 7% of cases the child was found dead.

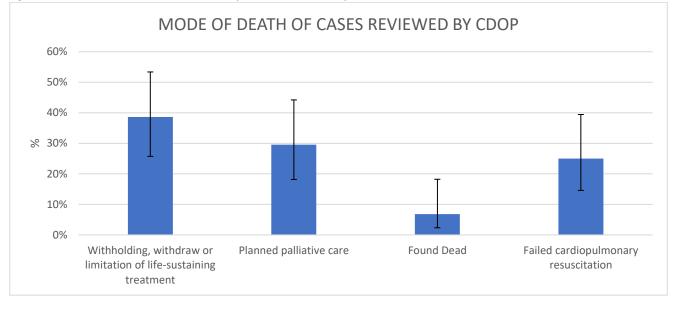
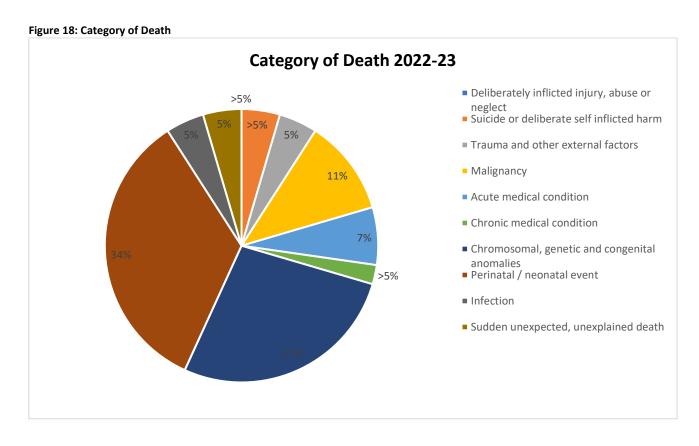


Figure 17: Mode of death of cases reviewed by CDOP between 1st April 2022 and 31st March 2023

3.2 Category of Death

The most frequent category of death in cases reviewed is Perinatal and Neonatal deaths (34%), followed by Chromosomal Genetic and Congenital Anomalies (27%). 11% of deaths were due to malignancy, 5% were due to Sudden or unexplained deaths, 5% Trauma and other external factors, 5% were as a result of an acute medical condition. Less than 5% were as a result of a Chronic medical condition or suicide deliberate or self inflicted harm.



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3.3 Ethnicity of cases reviewed

Figure 13 shows that 68% of cases reviewed by CDOP between 2022 and 2023 were children of White British origin. The number of reviews for children whose ethnicity was recorded as Mixed was 9%, as was those described as White, other. Black African, Black Caribbean or Black British was 7%. Other ethnicities were recorded as <5%.

The 2021 census indicates that amongst the WoE area, 81% of 0-17s are white (British & other), 5% are of Asian descent, 4.8% are of black African or Caribbean decent, 7.3% are of mixed ethnicity, and 1.5% are from another ethnic group. Due to the small numbers there is only weak evidence of any differences by ethnicity, however it does appear that there are disproportionally more deaths amongst black, mixed and other ethnicities compared to their respective population, and proportionally fewer deaths amongst white and Asian compared to the population.

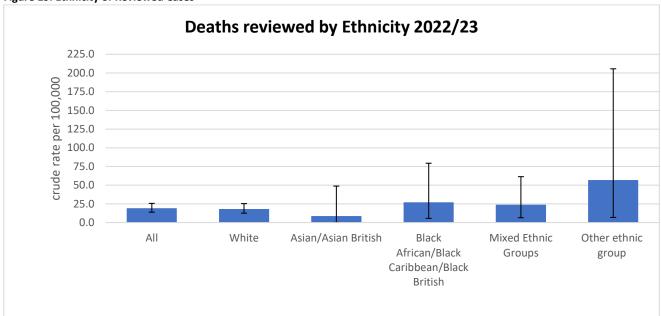
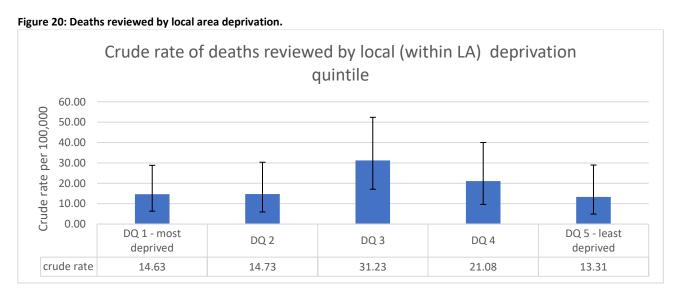


Figure 19. Ethnicity of Reviewed Cases

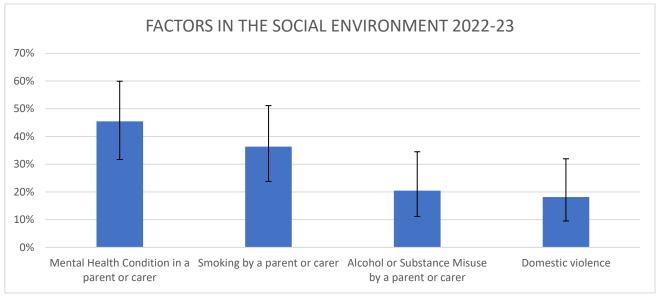
3.4 Local area deprivation of cases reviewed

Figure 14 shows that there was weak evidence of a higher rate of cases reviewed in the median deprivation quintile (DQ 3), but no overall pattern associated with local area deprivation.



3.5 Factors in the Social Environment

Figure 21: Factors in the social environment (including parenting capacity recorded in cases reviewed by CDOP between 1st April 2022 and 31st March 2023



A mental health condition in a parent or carer is mentioned in 46% of all reviews.

For context, nationally the estimated prevalence of common mental disorders in the population aged 16 and over is $16.9\%^{10}$.

It is estimated that between 26% and 42% of mothers in England will experience some sort of perinatal mental health condition (OHID), there are no estimates for the mental health of fathers.

Smoking of a parent is mentioned in 36% of reviews. Nationally smoking in adults is estimated to be around 15% 11 .

For context, the South West rate of mothers smoking at time of delivery is around 10%. There is no equivalent figure for father or partner smoking or smoking in a child's home more generally.

3.6 Modifiable Factors

Modifiable factors are defined as one or more factors, in any domain, which may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths'. An example of a modifiable factor might be a death resulting from a vaccine preventable infection where the vaccine had not been given to the child. The West of England CDOP has also regarded bed-sharing with parents known to be smokers to be a modifiable factor in cases of Sudden Infant Death Syndrome (SIDS).

Of cases reviewed by the West of England CDOP in this twelve-month period 2022-23 modifiable factors were identified in 30% of cases. Nationally 39% of child deaths were assessed as having modifiable factors in the same time period.

¹⁰ Common Mental Health Disorders - OHID (phe.org.uk)

¹¹ Public health profiles - OHID (phe.org.uk)

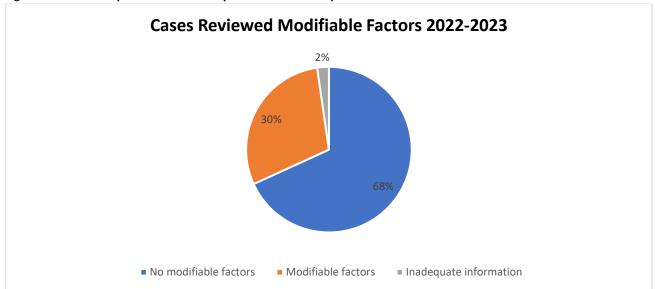


Figure 22: Modifiability of cases reviewed by CDOP between 1st April 2022 and 31st March 2023

3.7 Modifiability by Category of Death

Sudden unexpected, unexplained deaths reviewed by CDOP ((n=2), and 100% of deaths in the Deliberately inflicted injury, abuse or neglect category (n=2). 40% of cases reviewed in the Perinatal/Neonatal category of death had modifiable factors identified (n=6)). The least common categories deemed to have modifiable factors were Chromosomal, and congenital genetic abnormalities, Acute Medical or Surgical Condition and Suicide and Deliberate or Self Inflicted Harm.

Figure 23: NCMD Reviewed Cases Modifiability by Category of Death 2022-2023

Primary Category of Death	Completed Reviews	Cases where modifiable factors identified	Modifiable Factors Identified (%)
Trauma and other external factors, including medical/surgical complications/error	2	0	0%
Suicide or deliberate self-inflicted harm	2	2	100%
Sudden unexpected, unexplained death	2	2	100%
Perinatal/neonatal event	15	6	40%
Malignancy	5	0	0%
Infection	2	0	0%
Deliberately inflicted injury, abuse or neglect	0	0	0%
Chronic medical condition	1	0	0%
Chromosomal, genetic and congenital anomalies	12	2	17%
Acute medical or surgical condition	3	1	33%
Totals:	44	13	30%

3.8 Family follow up

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

Figure 24 shows which was the main agency that offered follow-up for cases reviewed by CDOP between 1st April 2022 and 31st March 2023. 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 & counselling.

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. Case reviews undertaken by CDOP in 2022-23 have provided evidence that families are consistently offered this support and it is welcomed by many.

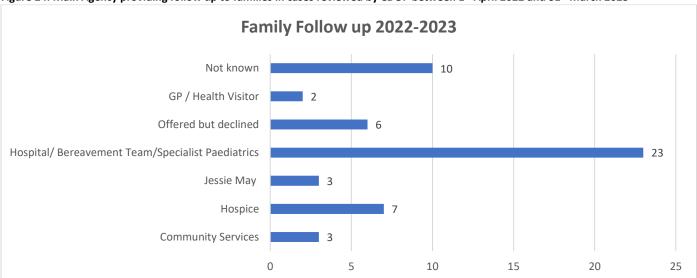


Figure 24: Main Agency providing follow up to families in cases reviewed by CDOP between 1st April 2022 and 31st March 2023

4. Child Death Overview Panel Activity

4.1 Actions arising from CDR/CDOP review of individual cases

The key purpose of a robust child death review process is to enable effective learning from individual deaths and also trends and thematic reviews.

All CDOP Members have a responsibility for sharing learning from panel discussions.

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. Figure 25 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. Details have been redacted to maintain confidentiality of personal information.

Figure 25

Case Description	Issue	CDOP Action	Response/evidence	Recommended National Learning
Asthma	Poor awareness of health issues across agencies.	Service Manager for the Bristol First Assessment Service to draft a health checklist to circulate to CAMHS, YOT and other relevant agencies across non-acute health provision. Checklist to also be shared across BNSSG and BANES.	Young Person's Health Questionnaire now launched – "All About My Health", can be used with young people in particular those in care or supported living.	None
Asthma	Concern about delivery of and engagement with asthma care, in particular following hospital attendances.	Mortality Governance Lead to facilitate the review of this death with Respiratory Governance within BRHC and BRI. Facilitate meeting with ICB Asthma leads to optimise learning from this case.	ICB Asthma leads reviewing local policies and contributing to national developments including management of nonengagement.	Local ICB leads contributing to national policy development.
Child with congenital anomaly and status epilepticus	Lack of access to EEG reporting out of hours.	Contacted Neurophysiology about availability of EEG and interpretation out of hours.	Neurophysiology committed to review the feedback received from paediatric neurology, PICU and other children's hospitals that have been approached. This data will then be used to help inform decisions in relation to EEG service provision going forward.	None
Suicide	Hospital Emergency dept not always most suitable location following a traumatic death.	CDOP raised lack of access to Bereavement support 24/7 and questioned if access to Coroner's mortuary would help some families.	Visit to Coroners mortuary by Police Representative and Des Dr and discussion about support that could be offered there – at this time, premises not suitable for supporting a bereaved family out of hours.	None

Case Description	Issue	CDOP Action	Response/evidence	Recommended National Learning
Suicide	Ease of access to location of suicide.	Contact Highways agency about accessibility of road bridges & height of barriers.	Detailed information received from Highways Agency about their risk management approach to height of barriers parapets, and suicide deterrent. Comprehensive response detailing legal requirements and rationale for current signage & barriers height.	None
Trisomy 18	Lack of knowledge about ongoing health issues for those babies surviving longer than expected.	Explore with local Paediatricians existing practice & guidelines.	Consultant Paediatrician along with bereaved parents have created a guideline for the care and management of children with Trisomy 18, particularly as more children are surviving for longer than expected with this condition.	The poster will be presented at the RCPCH Conference.
Likely neurogenetic condition	Not clear if father's GP informed of child's death.	Request this is added to hospital checklists following a Child death to check and inform father's GP so appropriate bereavement support can be offered.	Some complexities due to fathers not always having parental responsibility etc, but to remind teams to consider father's needs.	None
Suicide	Duty police attended home to discuss issue of young person sending inappropriate sexual images.	CDOP raised this with police to ensure appropriately trained personnel make contact with families after a multi-agency discussion.	There is now training in place to all teams about appropriate management of sexually harmful behaviour.	None

Case Description	Issue	CDOP Action	Response/evidence	Recommended National Learning
Genetic syndrome	Advance Care Plan documents were not available to ambulance before/on arrival at home.	Ongoing discussions with SWAST about best way to make ambulance crew aware of resus status – likely move to using Respect form for children and young people will make documents more familiar & quicker to read.	Current advice is need to keep updated paper copy of ACP with child at all times.	None
Suicide	Unclear what support is offered to Schools following a serious incident or child death.	Identify what support for school pupils and staff following the death of pupil.	Bristol LA are developing "good practice guidance" on responding to Critical Incidents involving reps from educational settings. There is an existing standardised offer of Educational Psychology Response divided into 3 levels of support according to the nature, size and severity of an event. The new guidance document will be shared with the other Local Authorities in WoE when complete. In B&NES there is a critical incident policy. CDOP to invite Educational Psychologists to CDRs.	None
Extreme prematurity 19/40	Gynae nurse not aware that Doctor needs to confirm signs of life in order to write MCCD.	CDOP explored protocol and training.	Trust have put a Training package in place for guidance around recognition of signs of life at the extremes of prematurity.	
Prematurity & fetal hypoxia	CTG not classified adequately	Check actions of RCA carried out from Patient Safety team.	Received	There is a national programme for

Case Description	Issue	CDOP Action	Response/evidence	Recommended National Learning
	Loss of situational awareness - use of Ultrasound rather than CTG.			CTG interpretation and new package for classifying fetal wellbeing in labour.
Congenital malformation	Delay in recognition of congenital anomaly.	CDOP to identify what measures in place to prevent this happening again.	Share training materials on NIPE and this specific issue shared with other Trusts and is ongoing for future staff.	None
Prematurity & Hypoxia	Pregnancy not booked.	Strategies to aid booking with midwife when English is a second language - in particular through GP services.	Ongoing.	None
Liver disease	Failure of Out of Area tertiary centre to provide information or engage with CDR process.	Write to Chief Executive of tertiary centre.		None
Malignancy	GP made a referral via 2 week wait pathway.	To ensure that current NICE guidance on urgent 48 hour suspected malignancy referrals rather than the 2 week wait referral is updated on both the BNSSG and BANES GP referral pathway systems.	Ongoing	None
SUDI (near miss OOH cardiac arrest)	Unsafe sleep environment.	cdot have previously engaged with primary care to add a 'safe sleeping' prompt to 8 week check template for GPs. CDOP has worked with HV leads to ensure up to date information about potential hazards is included in safe sleeping pathways for advice given by HVs. CDOP to keep these groups aware of potential hazards including co-sleeping after smoking/alcohol, fleece blankets, adult duvets, pillow	NCMD webinar on safe sleep – to promote in WoE area NCMD thematic report on SUDI launched Dec 22 and publicised to WoE partners.	NCMD thematic report on SUDI includes all CDOP data including data from WoE.

Case Description	Issue	CDOP Action	Response/evidence	Recommended National Learning
		etc and monitor cases where these have been noted.		

4.2. Themes emerging from aggregate review of cases at CDOP during the year April 2022 – March 2023

In 2022/23 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:

- Bereavement support at St Michael's improved following appointment of a Bereavement midwife and NICU nurse.
- Good memory making e.g. baby supported to visit home during final hospice stay.
- Interpreter issues were again noted where an interpreter was not always used for important information gathering conversations or decision making with parent(s).
- Safe sleeping further cases noted where fleece blankets were in use CDOP have liaised with HV leads about promoting safe sleeping from current best evidence
- Disability Living Allowance CDOP recognised that all benefits will stop immediately for families as soon
 as the child dies which will be an added stress on top of grief and bereavement, especially if this is their
 sole source of financial income. A bereaved parent has recently taken a paper to Parliament to try and
 extend benefit payments for families following a child death.

COVID impact:

• COVID restrictions negatively impacted on family experience during patient stay in hospital in regards to visiting possibilities. COVID lockdowns negatively affected the dynamic of a family as all children were socially vulnerable but unable to go to school (while parent shielding) leaving them without the support of their usual social networks. CDOP acknowledged the detrimental effects of COVID restrictions on young people being unable to access special schools and related therapies especially postural management equipment & hydrotherapy for a sustained period of time.

5. Achievements

Meeting with new Integrated Care Board leads for BNSSG and for B&NES to brief them about local arrangements for fulfilling statutory requirements in delivering CDR process and to reestablish the CDR partners strategic meeting on a quarterly basis.

Reviewing contract arrangements including subcontracting of Child Death office function to University of Bristol.

Engagement with the newly formed Association of CDR Professionals - including annual conference in Nov 2022 attended by Designated Doctor, CD office team and Police - allowed learning from other areas and sharing good practice; Designated Doctor is SW rep for ACDRP.

Designated Doctor and Police representative contributed video teaching to new NCMD online teaching resource on the Joint Agency Response.

Ongoing working with specialty teams to brief members about the CDR process and how to contribute most effectively, including Oncology and PICU teams.

Contribution lecture to the Multi-disciplinary Approach to the pilot national Paediatric End of Life care Education (MAPLE) course hosted at UHBW.

6. Future Priorities

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

Working with local Medical Examiners to develop & embed processes for scrutinizing all paediatric deaths before date of statutory ME service from April 2024.

Work with ICB in reviewing delivery of health contribution to Joint Agency Responses in parallel to changes to Community Paediatric safeguarding on call availability.

Lack of Care of the Next Infant programme in BNNSG following end of successful pilot funded by CDOP.

Appendix A - CDOP membership April 2022 to March 2023

Role	Core member	Organisation
Nominated Chair	Sara Blackmore until July 2022 Sarah Weld from August 2022	Director of Public Health, South Gloucestershire. Director of Public Health South Gloucestershire.
Designated Doctor for Children's Deaths	Dr Mary Gainsborough	Sirona Care & health on behalf of ICBs
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 Becky Lewis Before March 2023	Director of Children's Services and Education/DCS, Bath and North East Somerset Council
Designated Nurse for Safeguarding Children	Jackie Mathers	Bath & North East Somerset Locality of NHS Bath & North East Somerset, Swindon and Wiltshire Clinical Commissioning Group (BSW CCG)
	Anne Fry until July 22 Karen Hickey from Sept 22	NHS Bristol, North Somerset and South Gloucestershire ICB
Professional Midwifery Advocate & Midwifery Matron	Julie Northrop	University Hospitals Bristol and Weston NHS Trust
Midwifery Ward Manager	Sara Arnold	Midwifery Ward Manager, 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 & Dr Caroline Furnell	Bath & North East Somerset Locality of NHS Bath & North East Somerset BANES
Head of Safeguarding, Ambulance Service	Serena Mees/Simon Hester/ Chris Rogers	South Western Ambulance Service NHS Foundation Trust
Lay Representative	Julie Kembrey	Bereaved Parent & Trustee of Jessie May Trust