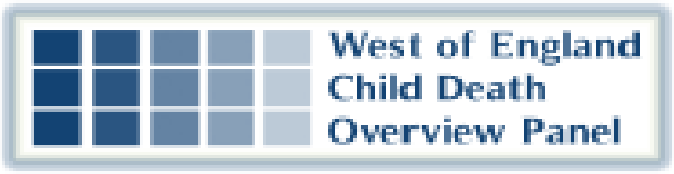

WEST OF ENGLAND

CHILD DEATH OVERVIEW PANEL

April 2020 – March 2021

ANNUAL REPORT

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Contents

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 and I am always impressed by the sensitivity with which the panel members approach each case discussion. We will always aim to keep the family and children at the centre of what we do.

Finally, I want to commend the hard work and dedication of the Panel members, and the support from Dr Mary Gainsborough, Designated Doctor for 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.

Matt Lenny

Director of Public Health for North Somerset
Chair of CDOP

3. Executive Summary

1. The processes to be followed when a child dies are currently outlined within Working Together to Safeguard Children 2018: Chapter 5 Child Death Review Processes and Child Death Review: Statutory and Operational Guidance 2018.

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

Data related to Child Death Notifications

2. 426 child deaths were notified to the West of England Child Death Enquiries Office between 1st April 2016 and 31st March 2021.
3. 16/426 (4%) of children were not residents of Bristol, North Somerset, South Gloucestershire or Bath and North East Somerset (BANES). The great majority of these children were receiving specialist medical care in Bristol Children's Hospital or St Michaels Hospital (NICU). This number has fallen from previous years, as has the total number of notifications.
4. Over the 5 year period, 83% died in hospitals, 8% in the parental home or in a relative's home, 4% in hospices and 5% in other locations.
5. Between 2016 and 2021, 68% of deaths occurred during the first year of life, 10% of deaths were of children ages 1-4, 7% age 5-9 and age 15-17, and 8% aged 10-18. Between 2016 and 2021, 39% of children had a post-mortem examination.

Data from cases reviewed by the Child Death Overview Panel

1. The West of England CDOP reviewed 264 cases in detail between 1st April 2016 and 31st March 2021.
2. There is an inevitable time-lag between notification of the child's death to discussion and two cases of children who died during the period of 2017-18 are outstanding. These are ongoing due to Police Investigations or deaths abroad. All other children who died before that date have been reviewed by CDOP. 95% of cases from 2018/19 have been reviewed, and 88% of cases from 2019/20.
3. The most common mode of death is following the active withholding, withdrawal or limitation of life-sustaining treatment, which occurred in 42% of cases.
4. CDOP identified 'modifiable factors' between 2016-2021 in 31% 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

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

Themes

2. Certain themes have emerged from reviewing children's deaths in the West of England this year including lower completion rate of new eCDOP Reporting Forms, maternal BMI, low temperature following preterm delivery, and acknowledgement of the effect on professionals when children in their care die.

3. **Achievements and Future Priorities**
   CDOP shifted fairly seamlessly to remote working with, and continues to be well-placed to capture some of the effects of COVID on children as well as operational changes to the delivery of the process. There was a pilot of 24/7 provision of paediatric palliative care and a Mortality oversight committee was established at the Children's Hospital. The CDOP chairing arrangements were renegotiated.

4. 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. 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[1]. 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 1st April 2019. For the data considered in this annual report (2015-2020), the previous version of Working Together to Safeguard Children (2015) was in place and governed the process for the children described in this report.

The overall purpose of the child death review process is to understand how and why children die, to put in place interventions to protect other children and to prevent future deaths. It is intended that these processes will:

- Document and accurately establish causation of death in each individual child.
- Identify patterns of death in a community so that preventable factors can be recognised and reduced.
- Contribute to improved multi-professional collection of medical, social and forensic evidence in the small proportion of deaths where there has been maltreatment or neglect.
- Ensure appropriate family and bereavement support is in place.
- Identify learning points for service provision, which relate to care of the child.

Working Together (2015) and the CDR Statutory Guidance (2018) outline two inter-related processes…a **'Joint Agency Response'** where a group of professionals came together for the purpose of evaluating the cause of death in an individual child, where the death of that child was not anticipated, and a **'Child Death Overview Panel**' (CDOP) that comes together to undertake an overview of *all* child deaths under the age of 18 years in a defined geographical area. These processes have been outlined in detail in previous annual reports.

In the area of the former county of Avon, four neighbouring LSCBs (Bristol, North Somerset, South Gloucestershire and Bath and North East Somerset) came together to form a single West of England (WoE) CDOP. The membership of the Panel (Appendix B) is arranged to ensure that there is the necessary level of expertise and experience, and that each of the four Local Authority areas is appropriately represented. During 2019/20, the WoE CDOP Chair has rotated from BANES to the North Somerset Director of Public Health. The Terms of Reference, Governance Arrangements,

[1] https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england

and Membership are summarised in documents available at www.bristol.gov.uk. The Child Mortality Analysis Unit at the University of Bristol administers all functions of the WoE CDOP.

The WoE CDOP reviews information on every child who has died whose post code of residence is within its geographical boundary. Some of these deaths may occur outside the West of England. The WoE CDOP additionally reviews the deaths of some non-resident children who may be under the care of a specialist paediatric medical or surgical team in Bristol.

A child's case is reviewed at the CDOP after it has been discussed at a local child death review meeting. Standard information on each child is collected on national 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 thirteenth Annual Report of the West of England CDOP. It was approved by the Panel on 14th July 2021. It will be a public document. Previous year's Annual Reports can be found online or requested from the Child Mortality Analysis Unit at University of Bristol.

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

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

Note: The UK Office for National Statistics advises that care should be taken with regard to publishing small numbers of events in person-related statistics. This is due to the need to preserve confidentiality as there may be a risk that individuals could be identified.

6.1 Summary Data (five-year dataset from 2016 – 2021)

This section summarises all deaths notified to the Child Mortality Analysis Unit, between April 1st 2016 and March 31st 2021, of children who have died in the West of England area or of a child residing in the West of England area who has died elsewhere. These data are drawn from the Notification database. This allows us to present information as a rolling total across the last five years. Data presented this way helps to "smooth out" the year on year variations that we expect if we are looking at rare events one year at a time.

6.2 Analysis of notifications by year (2016-2021)

During the period 2016-2021, year on year variation in notifications is to be expected and is demonstrated in Table 1. With relatively rare events such as child deaths, small variations each year can appear to represent a big difference.

The deaths notified over the 5-year period are reported by area of residence and by year in Table 1.

Table 1: Notifications by region of residence, 2016-2021

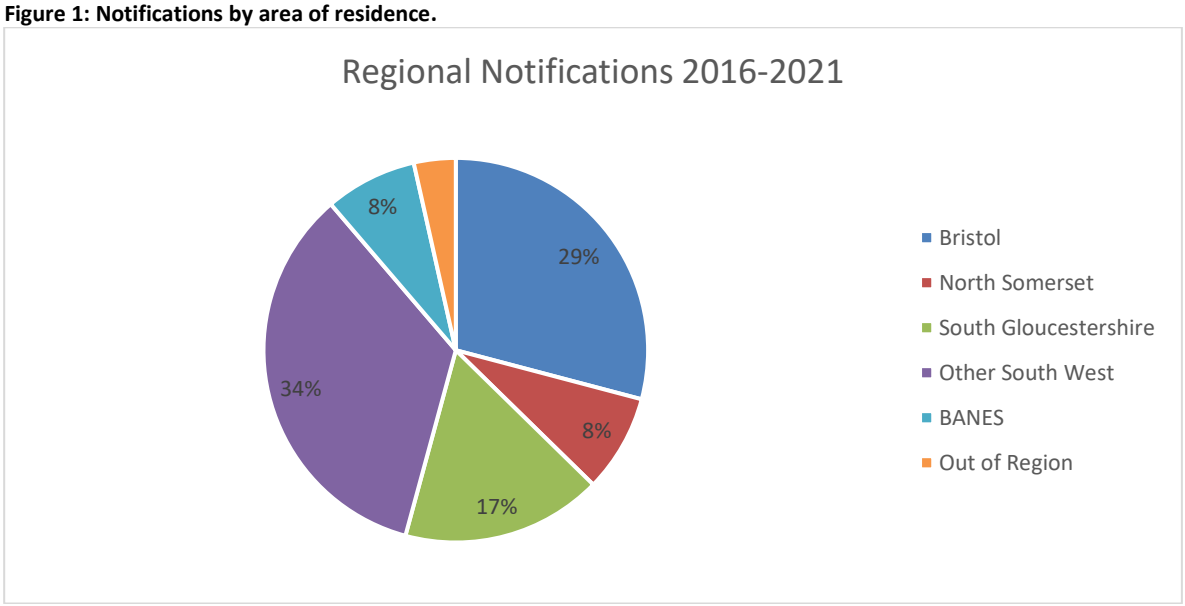
Region	**2016/17 Deaths**	**2017/18 Deaths**	**2018/19 Deaths**	**2019/20 Deaths**	**2020/2021 Deaths**
BANES	6	8	4	8	7
Bristol	28	34	18	23	21
North Somerset	9	6	8	4	7
South Gloucestershire	18	16	10	16	12
Other South West	40	37	51	19	11
Out of Region	1	2	4	8	6
Total WoE	***61***	***64***	***40***	***51***	***47***
Total	**102**	**103**	**95**	**79**	**64**

Figure 1 indicates that a proportion of notifications each year usually come from areas outside the West of England region (BANES, Bristol, North Somerset and South Gloucestershire), either within the South West region ('Other South West') this includes Wiltshire, Gloucestershire, Somerset, Swindon, Devon, and Cornwall, or outside the South West region ('Out of Region') this includes children visiting the area from other parts of the UK. This is because Bristol contains tertiary referral units for neonates and children and specialist services including cardiology, oncology and neurology.

The numbers of notifications for any one area of residence are so small that the most likely explanation for any pattern is random year-on-year variation. However, CDOP should always try to exclude contributory factors such as differences in coding practice or an increase in a particular category of death. During the last 5 years, postcode of residence has been used consistently and

there have been no significant changes in local authority boundaries. Additionally, analysis of category of death shows that there is no single category of death that appears to account for the patterns seen over the five-year period. It is therefore most unlikely that these variations in notifications within each area reflect any particular underlying cause and as such they should not be over-interpreted.

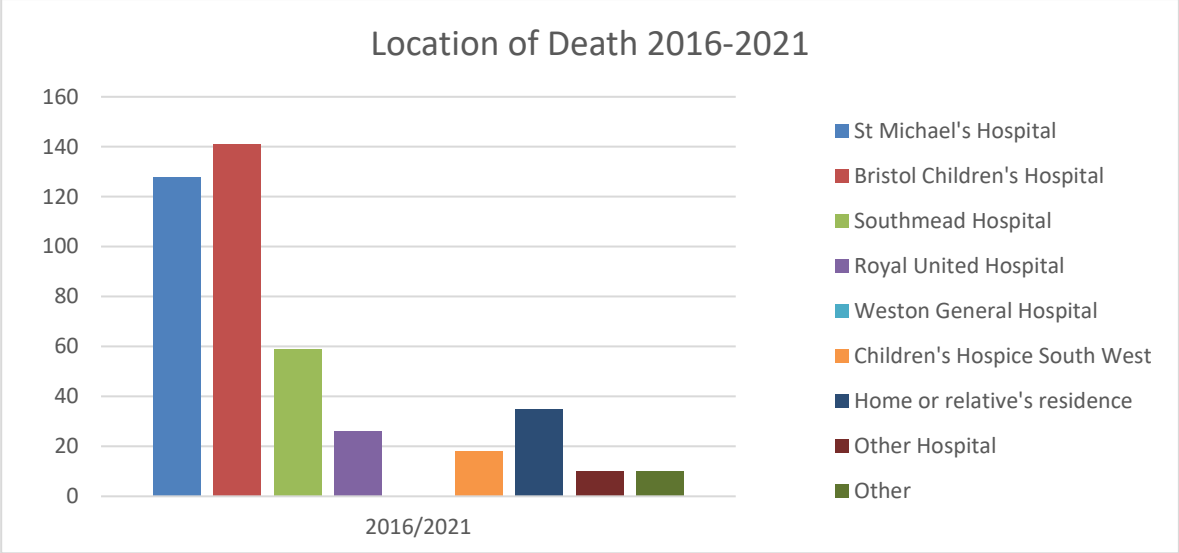
Figure 1: Notifications by area of residence.



6.3 Location of death (2016-2021)

This data records where the child actually died. Over the five-year period 33% (141/426) of all child deaths occurred at the Bristol Children's Hospital, 30% (128/426) at St. Michael's Hospital, 14% (59/426) at hospitals within North Bristol NHS Trust (Southmead Hospital), 8% (26/426) at Royal United Hospital Bath, less than 1% in Weston, 4% (18/426) died in a hospice, and 8% (35/426) died at home or at a relative's residence. Bristol contains tertiary referral units for patients with obstetric, neonatal and sub-speciality paediatrics. A large proportion of the deaths at the Bristol Children's Hospital, St Michael's Hospital and Southmead Hospital are of children who are resident outside of the West of England area, or outside the South West region, illustrating their importance as receiving hospitals for the sickest children who need access to specialist services (Figure 2).

Figure 2. Location of Death (Hospital) 2016-2020



The precise location of death for children dying within hospitals in the West of England region in 2016-2021, is shown below in Table 2.

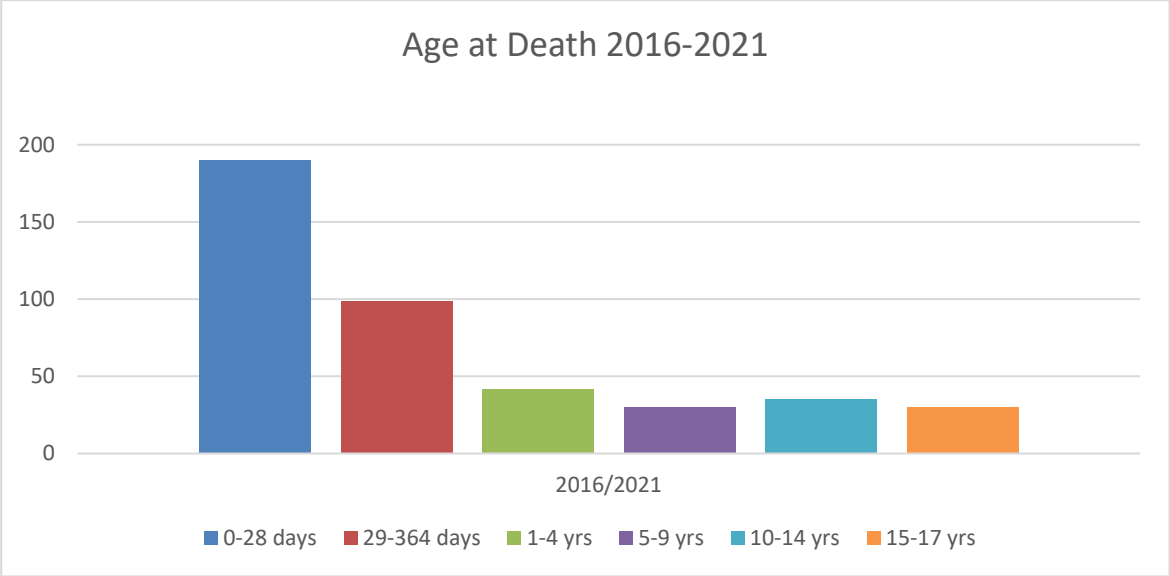
Table 2: Number of children dying in different locations within West of England hospitals

Hospital	Paediatric/Neonatal Intensive Care Units (PICU/NICU)	Emergency Department	Children's Wards/Theatres/Central Delivery Suite	Adult ICU
Bristol Children's Hospital, University Hospitals Bristol	PICU 83	15	31	2
Royal United Hospital, Bath	NICU 4	2	4	1
St Michael's Hospital, University Hospitals Bristol	NICU 96	0	3	0
North Bristol NHS Trust Hospitals	NICU 9	1	9	2
Weston General Hospital	0	0	3	0
Other Hospitals	1	0	0	0

6.4 Age at Death (2016-2021)

Using 5 year data, 190 notifications (45%) were received for babies dying in the neonatal period (0-28 days). A further 99 (23%) died in the first year of life. 42 (10%) between 1-4 years, 30 (7%) 5-9 years, 35 (8%) between 10-14 years and 30 (7%) between 15-17 years. It is worth noting that the age bands used below do not cover equal periods of childhood e.g. 10-14 years covers a five year period and 15-17 years covers a three year period.

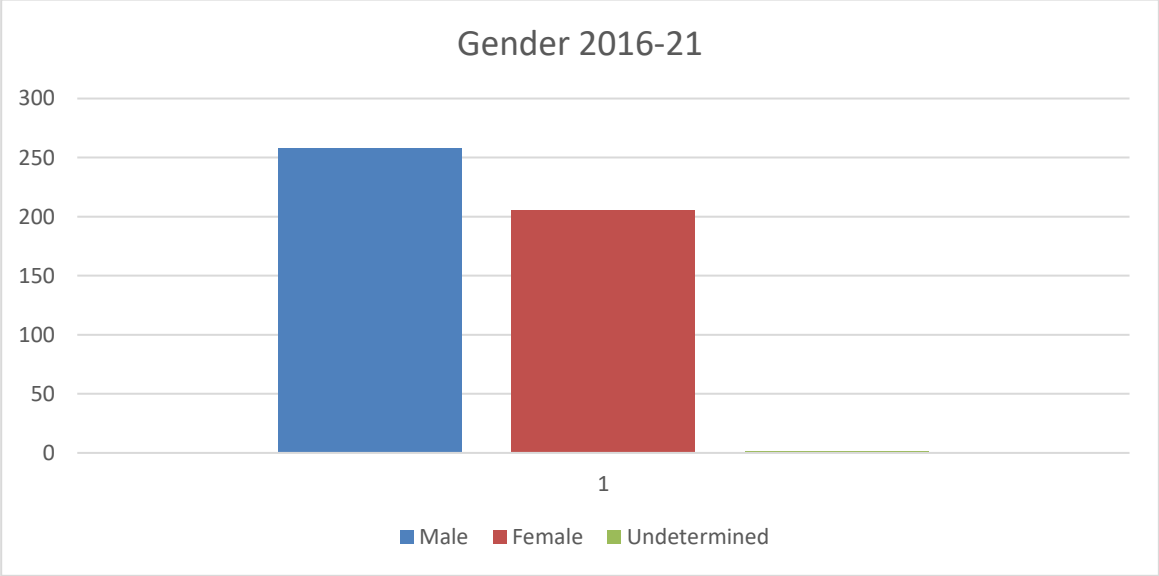
Figure 3: Notifications by age group, 2016-2021



6.5 Gender (2016-2021)

There have been more notifications of deaths in boys than girls (54% are boys).

Figure 4: Notifications by gender 2016-2021

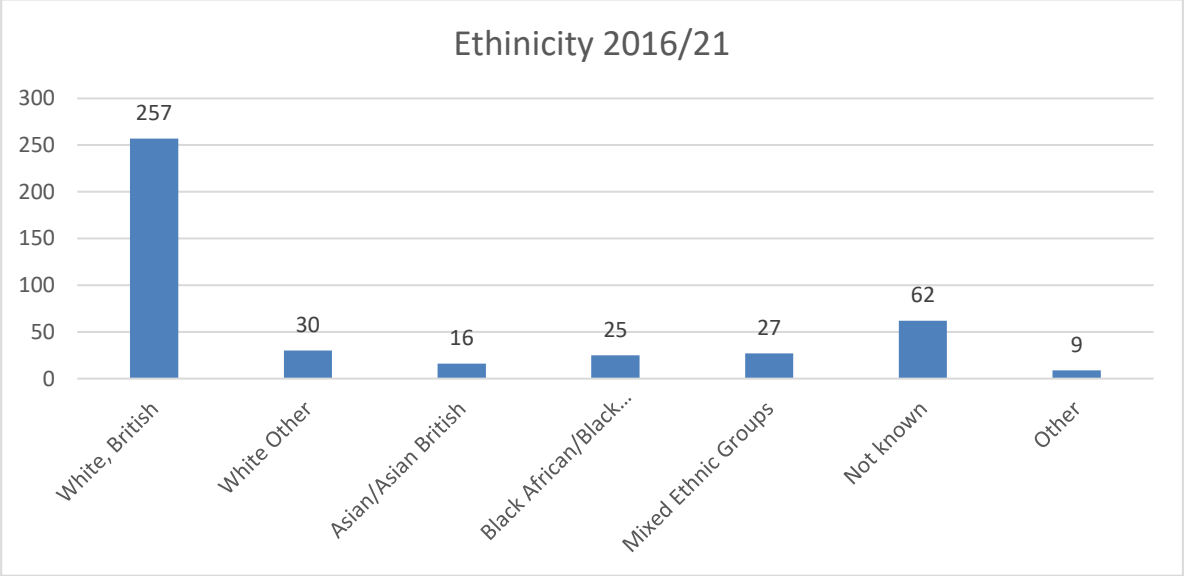


6.6 Ethnicity (2016-2021)

Figure 5 shows that 60% of notifications received by the Child Death Enquiries office between 2016 and 2021 were for children of White, British origin. 7% of notifications were for children of White, Other origin. This includes children of European ethnicity. The number of notifications for children whose ethnicity was recorded as Asian or Asian British was 4% and the number of notifications for children whose ethnicity was recorded as Black or Black British was 6%. In 15% of cases the ethnicity of the child was not known. No background population data was available to compare these figures to and therefore no conclusions can be drawn from this data.

The ethnic make-up of the different areas in the West of England region is diverse, making direct population comparison difficult.

Figure 5: Notifications by ethnic group, 2016-2021



6.7 Post mortem examinations (2016-2021)

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 164/426 deaths (48%). 195/426 (46%) cases did not have a post mortem. In 43/426 cases (10%) a post mortem was not applicable. In 24/426 (6%) it was not known if the child had a post-mortem examination at the point of notification of the death.

The national shortage of paediatric pathologists remains an issue with some recent improvements locally. Long delays in obtaining some post mortem reports continue to cause distress to families and delays in the child death review process. CDOP has documented this as a theme in previous annual reports and continues to work to highlight the effects of this issue.

6.8 Deaths requiring a Joint Agency Response (JAR) (2016-2021)

Since the inception of the child death review process there has been a requirement to perform further investigations for children who die where the cause is unknown. This was previously called a Rapid Response but the terminology has been changed following the publication of the Child Death Review Statutory and Operational Guidance in 2018 and it is now referred to as a Joint Agency Response (see Section 4 above). The full guidance for conducting a JAR can be found here

https://www.rcpath.org/uploads/assets/874ae50e-c754-4933-995a804e0ef728a4/Sudden-unexpected-death-in-infancy-and-childhood-2e.pdf

The criteria for triggering a JAR is as follows:
• is or could be due to external causes;
• is sudden and there is no immediately apparent cause (including sudden unexpected death in infancy/childhood (SUDI/C);
• occurs in custody, or where the child was detained under the Mental Health Act;
• where the initial circumstances raise any suspicions that the death may not have been natural; or
• in the case of a stillbirth where no healthcare professional was in attendance.

The full process for a Joint Agency Response is set out in the SUDI/C Guidelines.

Prior to 2018, these criteria were not used, and the definition for an Unexpected Death was the death of an infant or child, which was not anticipated as a significant possibility 24 hours before the death or, where there was a similarly unexpected collapse or incident leading to or precipitating the events that led to the death. This was counted if recognised to be an unexpected death and a multi-agency Rapid Response was carried out.

In the 5 years covered by this report, Table 4 below, shows the number of RRs or JARs that have taken place by year.

Table 4: Number of Rapid Responses / Joint Agency Responses

Year	Number of Rapid Responses or JARs
2016-2017	14
2017-2018	24
2018-2019	18
2019-2020	9
2020-2021	19
Total	**84**

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

7.1 Child Death Overview Panel Review Data (2016-2021)

This section summarises the Panel's review decisions for 2016-2021 and its actions for 2020-21. As explained previously, not all notifications received by the West of England Child Death Enquiry Office will be reviewed by the West of England CDOP. They will be reviewed by their local CDOP if it is deemed more appropriate.

There is an inevitable time-lag (4-12 months) between notification of a child's death and discussion at CDOP**.** There are various factors that contribute to this: the return of Reporting Forms from professionals, the completion of the final post-mortem report by the pathologist and receipt of the final report from the local child death review meeting. On occasion when the outcome of a Coroner's inquest is awaited, there may be a delay of over a year before a case might be brought before CDOP. The undertaking of a criminal investigation or a Serious Case

Review (now a Child Safeguarding Practice Review) will also affect when a case is discussed at Panel.

For these reasons, the population of children described in Section 6 *Summary Data* may partially overlap but is distinct from the population of children described in this section. This is illustrated in Table 5.

Table 5: The number of cases reviewed each year by year of death

	2016/17		2017/18		2018/19		2019/20		2020/21	
Total number of notifications	102		103		95		79		64	
Number of cases to be reviewed by WOE CDOP	61		64		40		34		47	
Years of Review	**Number reviewed**	**%**	**Number reviewed**	**%**	**Number reviewed**	**%**	**Number reviewed**	**%**	**Number Reviewed**	**%**
2015/16										
2016/17	8	13								
2017/18	36	59	5	8						
2018/19	13	21	33	52	4	10				
2019/20	4	7	15	25	24	60	**1**	**3**		
2020/21	**0**	**0**	**9**	**14**	**10**	**25**	**29**	**85**	**2**	**4**
Total	**61**	**100**	**62**	**99**	**38**	**95**	**30**	**88**	**2**	**4**

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

Two cases of children who died during the period of 2017-18 are outstanding. All other children who died before that date have been reviewed by CDOP. 95% of cases from 2018/19 have been reviewed.

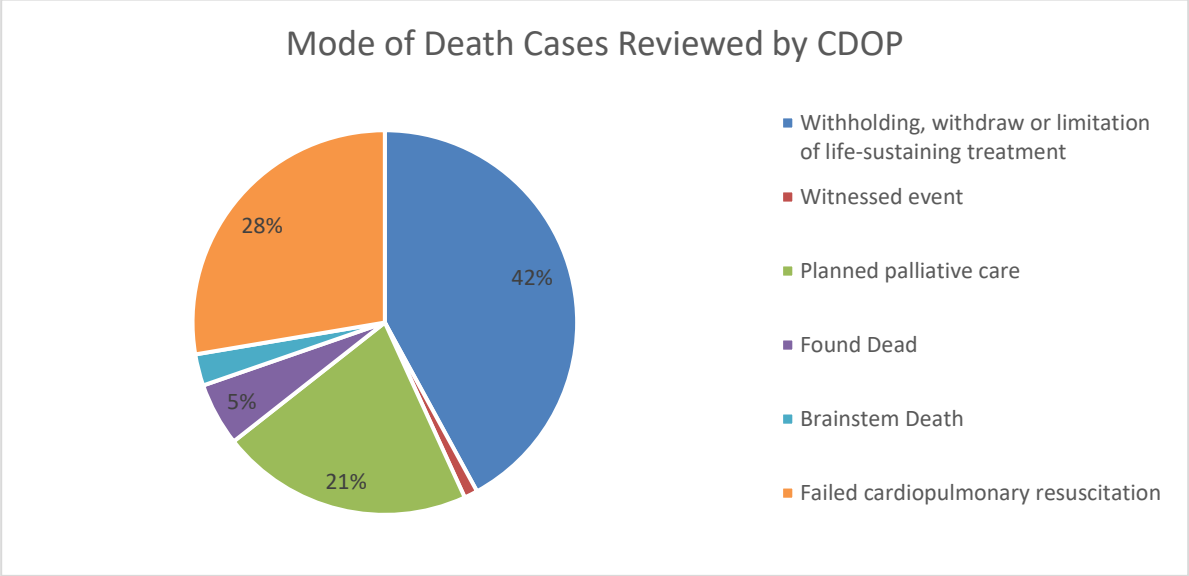
Sections 7.1 to 7.6.1 describe data relating to the 264 children reviewed by the West of England CDOP between 1st April 2016 and 31st March 2021. The data is drawn from eCDOP into which all information from Reporting Form, Analysis Form, the local child death review meeting and final CDOP review is entered.

7.2 Mode of death (2016-2021)

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 42% of the deaths reviewed by CDOP. In 28% of cases the child died following failed cardio-pulmonary resuscitation attempts although the child may have been critically ill on NICU or PICU prior to the final event. In 21% of cases the child died following planned palliative care and in 5% of cases the child was found dead. In 1% of cases the child's death was a witnessed event. This includes road traffic

collisions and other deaths by external causes. For a very small number of children (3%) the mode of death was brainstem death.

Figure 6: Mode of death of cases reviewed by CDOP between 1st April 2016 and 31st March 2021



7.2 Factors in the Social environment (2016-2021)

Table 5: Factors in the social environment (including parenting capacity recorded in cases reviewed by CDOP between 1st April 2016 and 31st March 2021

Factors in Social Environment	Yes	No	Not known
Smoking by a parent or carer / Smoking by Mum during pregnancy	82 (31%)	153 (57%)	31 (12%)
Alcohol or Substance Misuse by a parent or carer	45 (17%)	162 (61%)	57 (22%)
Domestic violence	48 (18%)	202 (77%)	14 (5%)
Emotional, Behavioural or Mental Health condition in a parent or carer	80 (30%)	140 (53%)	46 (17%)

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

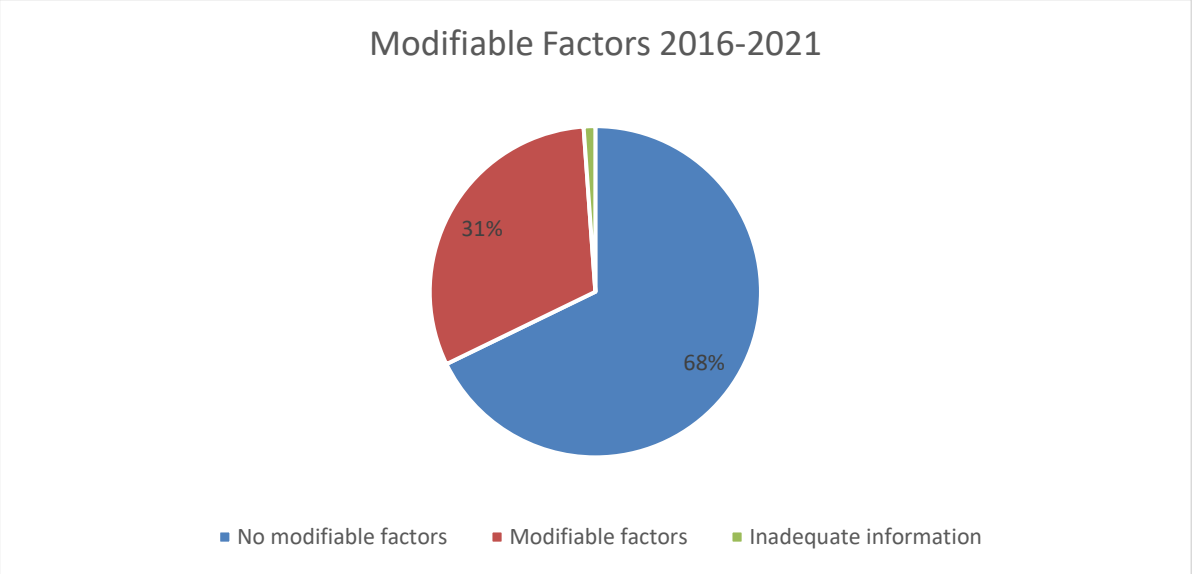
7.4 Modifiable Factors (2016-2021)

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 179 of the 264 cases (68%) reviewed by the West of England CDOP in the five year period no modifiable factors were identified. In 82/264 (31%) cases modifiable factors were identified. In

3/264 (1%) of cases there was not enough information available to determine if modifiable factors were present.

Figure 7: Modifiable Factors of cases reviewed by CDOP between 1st April 2016 and 31st March 2021



There seems to be a steadily increasing trend nationally in the percentage of child death reviews assessed as having modifiable factors from 24% in the year ending 31 March 2016 to 31% in the year ending 31 March 2020[2].

7.5 Family follow up (2016-2021)

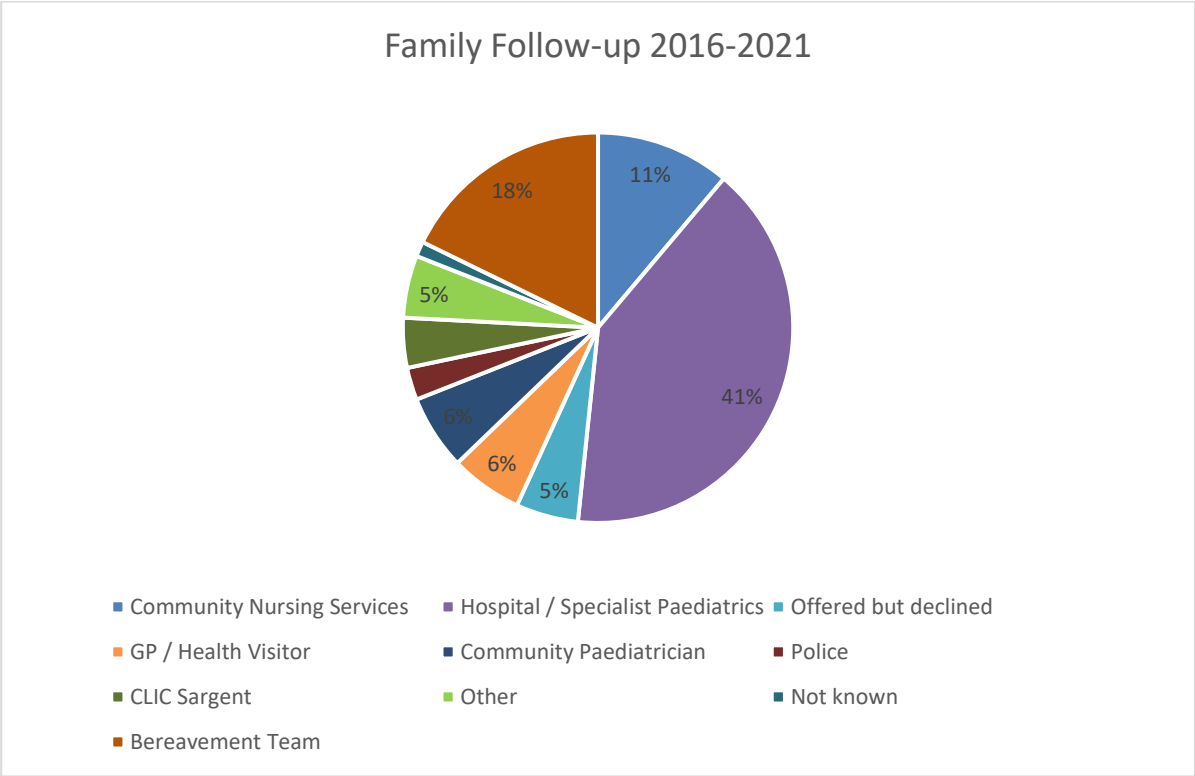
Active engagement with bereaved parents underpins the entire child death review process. Parental input into the child death review meeting should occur as a matter of course. Parents are invited to submit questions to the local child death review meeting, and feedback by the lead health professional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

Figure 7 shows the percentage of families offered follow up from each agency for cases reviewed by CDOP between 1st April 2016 and 31st March 2021. 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. 41% of families received follow-up from hospital or specialist paediatrics. This includes obstetrics, neonatology, cardiology and oncology. 8% of families received follow up from primary care (GP or health visitor) and a further 6% of families received follow up from a community paediatrician. The hospice or community nursing organisations such as CLIC Sargent, the Lifetime Service or Jessie May routinely offer follow-up to any family they work with and between these agencies they offered follow-up to 15% of families who had a child who died during this period. 5% of families were offered follow up but had declined the offer. In 1% of cases reviewed by CDOP the follow-up status of the family was unknown. In most cases this was because the family had moved out of the area following the death of the child. 3% of families were also offered support from the Police. Families are routinely given national and local information on charities offering bereavement support and a bereavement pathway has been developed within University Hospitals Bristol NHS Foundation Trust. This year represents the fifth year that data has been collected on the number of families

[2] https://digital.nhs.uk/data-and-information/publications/statistical/child-death-reviews/2019/content

being followed up by the Bristol Children's Hospital Bereavement Team and they have offered support to all families of children who have been seen at the Children's Hospital since the team was set up.

Figure 8: Agency providing follow up to families in cases reviewed by CDOP between 1st April 2016 and 31st March 2021



Child Death Overview Panel Activity (2020-2021)

7.6 Actions arising from CDR/CDOP review of individual cases (*details are not presented to maintain confidentiality of personal information)*

Effective governance procedures within organisations should ensure that significant factors are identified and managed through the local child death review meeting. The CDOP also reviewed many cases where good practice had been identified.

In order to ensure that issues identified at CDOP were rapidly disseminated through their constituent agencies, the Safeguarding Partners within the West of England area have CDOP matters as a standing agenda item at their meetings.

In certain cases, the CDOP sought assurance that a particular action arising from a child's death had been addressed. Table 6 summarises cases where issues were identified and followed up by the CDOP through the Chair or through individual agency leads. This table reflects a selection of CDOP actions for this year.

Table 6: Actions arising and outcomes 2020-2021

Case Description	Issue	CDOP Action	Response/ evidence	Recommended National Learning
Road Traffic Collision	Education for young people regarding road safety.	CDOP contacted Bristol City Council enquiring about local policies about road safety awareness raising in schools and colleges, in particular enquiring if there are means to reinforce learning throughout the age groups. CDOP is aware there are national campaigns such as those developed by BRAKE and the National Road Safety week, and would like to know if these are used and publicised in the local area. CDOP also requested information about the policy regarding 20mph zones, and how these speed restrictions are currently enforced.	Robust response about their policies to enforce 20mph speed limits and to provide relevant PHSE. They also have a number of school based safety initiatives underway including: - Show you care park elsewhere campaign. - Promotion of walking buses. - Safer routes to school strategy. - Primary schools piloting parking being moved further from the school entrance.	
Unexpected death of child with a life limiting condition	Services to support a child on home ventilation.	CDOP contacted the CCG following the death of this young person who had long term ventilation (LTV) in place, to support a Community Paediatric Respiratory Physiotherapy post. CDOP suggested the CCG use the NCEPOD report on LTV to review and benchmark the local provision against these national standards.	CCG have funded a pilot Community Respiratory Physiotherapy 6 month post which started in July 2020 and will be fully evaluated against the 5 key messages in the NCEPOD report.	
Unexpected death of child with LLC	Family expressed some discontent with bereavement contact from agencies.	CDOP have been involved checking that training and processes are in place to optimise initial contact with bereaved families.	Lifetime are in the process of finalising a Bereavement Standard Operating Procedure (SOP)	

			and this will then be shared with partner agencies.	
Child with long term complex disabilities	During a prolonged hospital stay, parent raised concern the child was missing the standard package of care which would have happened in the community. e.g. immunisations, orthopaedic review of hip stability, dental and eye checks, developmental stimulation & learning opportunities.	CDOP were informed by the hospital that all these are now in place although some require individual reminders.	Ongoing work with hospital. Disability team to ensure care crosses boundaries. e.g. Hospital passport	
Accidental drug toxicity	Non-attendance at CDR by social care representative.	A social care representative completed the CDOP Reporting form but unfortunately was not able to attend the Child Death Review meeting. This left some questions unanswered. CDOP underlined the importance of engagement with the CDR meetings, in particular those with direct social care issues or social adversity. While recognising the pressures on social workers' time, and the fact that an individual Social Worker may no longer be in post, CDOP would like to hear what process could be put in place to ensure a senior member of the team engages with the CDR meeting. This would allow questions about the case to be discussed adequately and shared opportunities for learning for the future. This is an example of	Local Authority acknowledged clear expectation for Social Worker to attend CDRs, although in this case as the young person hadn't had an allocated Social Worker it was not clear who could have usefully attended. CDOP reinforced the value of shared learning when all agencies meet.	

		the liaison CDOP undertakes when a particular agency struggles to engage in the CDR process.		
Accidental drug toxicity	Awareness of contextual safeguarding.	CDOP reviewed Social Care involvement and reasons for referrals being declined, and noted some of the concerns as possibly indicative of child exploitation.	Current increased awareness across agencies.	
Drowning/ Accidental death in the community	Education to young people and general public about water safety.	CDOP enquired about current water safety education for young people in the community and through schools and colleges, in particular the risks of alcohol use and water safety. CDOP also enquired about the provision and advice about appropriate buoyancy aids.	Detailed information was provided about current water safety awareness raising in school. A specific project has taken place regarding alcohol use in locations near to this location. A specific review followed this case and involved a wide range of agencies. The CDOP learning will also inform a consultation about water safety to involve local population and businesses.	
Metabolic disorder	Airway issue identified before birth enabled ENT surgeon to be present at delivery. However a duty ENT consultant is not on site and there is not always a Paediatric ENT surgeon available.	CDOP has raised this with the Trust and awaits a response.		

Metabolic disorder	Rapid exome sequencing (a specific form of genetic testing) resulted in this infant receiving a diagnosis during life.	CDOP commended the Genetics department for availability of exome sequencing which would not have been available 12 months earlier.		
Metabolic disorder	Child was transferred by an ad hoc neonatal transport team (i.e. professionals who happened to be available).	CDOP raised the question of a second Neonatal transport team with the Trust and awaits a response.		
Neonatal death	Non take up of bereavement support.	CDOP has worked with the bereavement team to ensure processes in place across departments to offer appropriate bereavement support, and to ensure primary care are informed when this has not been taken up by a family.		
Congenital cardiac disease	Lack of cardiology in reach to offsite NICU.	Although not thought to have affected the outcome, this child was not ever assessed directly by a cardiologist- scans were reviewed and advice given about the baby's care. CDOP flagged the lack of cardiology in reach to the Unit, which could potentially affect care in a future case.		
Child with long standing disability	Lack of clarity about decision making for a child in foster care where social care held parental responsibility.	CDOP asked social care partners to clarify contents of the 'Document of Expectation' in making clear who is responsible for what, including pre-empting a deterioration in health.	Responses provided by Local Authorities.	
Malignancy	Lack of 24/7 Community Paediatric Palliative care provision.	CDOP continue to log this issue One child died at home in line with parental preference, but availability of an out of hours service would have meant availability of advice for the parents, reducing the risk of needing to call an ambulance or		

		admit the child to hospital in the final days. Another child may have been enabled to die in the family's preferred place which was at home.		
Malignancy	Lack of Occupational therapy in hospital Oncology Team led to difficulties obtaining specialised equipment.	CDOP raised this with the hospital Patient Safety and Safeguarding Leads.	The lack of this specific service was acknowledged. A business case is in progress and this is on the divisional risk register.	
Malignancy	The health visitor was not aware the child had been admitted to PICU.	CDOP looked into the process for this.	Checklist on PICU includes to inform GP & Health Visitor when child admitted.	
Child with complex medical condition	Parents experienced poor continuity of care which undermined their confidence in the care of their child.	Discussion at the Child Death Review which raised that greater involvement of the speciality team alongside PICU may have prevented this. CDOP asked PICU for changes made in light of this.	PICU have addressed these concerns by sharing the experiences from this case during teaching and training sessions, and by making a commitment to try and identify a core nursing and medical team for complex & long stay patients to improve continuity of care.	
Malignancy	Report of stress placed on staff in providing medical care and supporting parents through a complex. episode of care, especially when a hospital investigation is	CDOP noted need for support for staff when a hospital investigation is conducted.		

	being carried out.			
Child with a life limiting condition	Transfer to hospice after extubation and death on PICU.	CDOP noted the recommendation for a checklist.	Reassurance provided that this is now in place.	
Cerebral palsy	Latest Wishes Document (Advance Care Plan) not available to GP.	CDOP noted that version control and electronic sharing between agencies remain a hurdle – the Paediatric Palliative care teams are looking at processes (see below)		
Child with a life limiting condition	Wishes Document (Advance Care Plan) not available at scene of collapse.	CDOP investigated this - there is an ongoing project about the best way to achieve this. The current option proposed is use of digital Summary of Care record for access for paramedics to the Advance Care Plan.		
Suicide	Young person took a taxi to a location well-known for suicides.	CDOP contacted Local Authority to request inclusion of awareness in safeguarding training for taxi drivers.	CDOP received replies from all 4 Local Authorities that this will be done.	
Death of baby following home delivery	Information to parents may not have included potential risks.	Free Birthing Guidelines at all Trusts were reviewed by CDOP, and suggestions made about changes to ensure families receive information about the risks.		
Neonatal death	Access to bereavement support.	CDOP looked into bereavement provision in NICU.	Bereavement midwife now in post. Also cross-city bid in progress for psychology support.	
Genetic diagnosis	Parents may not have been given sufficient detail about options in order to support their decision making.	CDOP have supported production and sharing of guidelines for this scenario, including detailed information about what would happen following birth of an affected infant.	Parallel planning and consideration of wording for Fetal Medicine Unit when providing prenatal counselling.	
Acute collapse	Difficulty for ambulance in locating house.	Ambulance service review took place. Assurance was sought for how services update systems re new housing developments.	Detailed response submitted – can take up to 2 years for GPS to be updated -	

			Computer Aided Dispatch is updated more frequently.	
Chromosomal abnormality	Parents agreed to organ donation, and this was put in train but then stood down at last minute when deemed not suitable as donor.	Checklist now in place in the hospital to ensure parental hopes are not raised inappropriately and resources wasted.		This case has been discussed nationally including with the National Paediatric Clinic al Lead for Organ Donation and Paediatric Organ Donation meeting. Checklist going through ratification for national use.
SUDI	Unsafe sleeping.	CDOP considered if it would be possible to ask about safe sleeping at 8 week GP check.	Response awaited.	
Child with genetic diagnosis	Child left the Emergency Department without being seen – Children Emergency Department triage of children with complex disabilities/ non-verbal.	CDOP identified that the family were phoned next morning by ED to check on child's well-being. CDOP (again) asked the Trust to identify a separate area in the Emergency Department for children with complex needs who may find it difficult to wait or be assessed within the standard waiting area and assessment cubicles.	ACHIEVED a soft space cubicle has been funded.	
Gastrointestinal event	Information provided to children with gastrostomies about possible malrotation/vol vulus.	Ongoing education for Doctors in Children Emergency Department about potential complications of gastrostomy/fundoplication CDOP checked what written information is given to families about the risks following gastrostomy insertion. Parent held/ electronic record could include alert to any specific conditions.		
SUDI	Low literacy	Need for all agencies to identify and take responsibility for sharing this with partner agencies to help anticipate parent's needs. All CDOP panel	Ongoing.	

		members took this back to their own organisations.		
Late onset Group B Strep sepsis	Lack of awareness of GBS swab results from previous pregnancies.	GBS swab results from previous pregnancies need to be available in current pregnancy but this is not always readily accessible. CDOP noted GP's need to be able to see Obstetric Guidelines to be aware of this.		
Antenatal diagnosis of baby with a genetic diagnosis	Good practice: This family were grateful to be offered the option to proceed with the pregnancy and a plan was in place for care following delivery to allow immediate stabilisation then withdrawal of active care in line with their wishes.	Parents gratitude was passed on to the Fetal Medicine Team, and good practice shared for future learning.		
SUDI	This and other babies had a fleece blanket and.	Concern was expressed about whether this may be linked to overheating	A review of literature regarding any known safety issues with fleece blankets showed no specific reports, but neither are they recommended, and some support groups actively discourage their use.	

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

In 2020/21 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:

- There is a need to level up **bereavement support** across settings, including community and NICU deaths, to ensure all families have access to the same high quality of guidance and practical and emotional support. Professionals, especially nominated key workers, need ready access to accurate guidance, and support in helping families engage in the Child Death Review process. This might include Standard Operating Procedures to cover actions following a death in the community, key working arrangements and enabling family's questions to be presented to the Child Death Review Meeting, standards for contact with a family after death. The BCH Paediatric Bereavement team now hold weekly catch-ups to improve joined up working between professional teams.
  Revised British Association of Perinatal Medicine ethical guidance 2020 regarding **resuscitation of extremely premature babies** – now includes those born at 22 weeks gestation and CDOP will monitor the effect on numbers of babies surviving beyond the delivery room.

- **Non-receipt of eCDOP forms** from certain professional teams. CDOP will keep track of this and offer 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.

- **Temperature loss following delivery** – the PERIPrem programme has now been adopted in the South West as regional QI – data reporting on all <33/40.

- **Raised maternal BMI** has been noted across a number of neonatal cases, and notably also features in the NCMD annual report as a Modifiable factor.

- A **parent held Electronic record** would support engagement with all services by providing easy access information summarizing a child's medical issues and care requirements.

- Uncertainty of **prognosis in antenatally diagnosed life limiting conditions** e.g., genetic diagnoses, potentially lethal abnormalities – requires ensuring accurate information and that parents are able to voice their concerns, support for decision-making within Fetal Medicine Unit and postnatal care settings.

- Acknowledging very challenging and **distressing sudden deaths** which have a huge effect on the professionals involved as well as, needless to say, the child's family.

- **Training** needs are ongoing for all frontline Joint Agency Response professionals.

- Further considerations of **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.

- There is a need for CDOP to respond to certain issues before the formal CDOP review (which can be 1-2 years later) – this year this has happened in regard to which professionals should be involved in a media appeals, and action to contact Test and Trace after a COVID result was given directly to a parent causing distress.

- **Care of the Next Infant (CONI) Programme** - this was successfully re-established in BNSSG in 2016 as a pilot using CDOP funds and is 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 programme.

8.0 Achievements

- Bristol Royal Hospital for Children have set up a hospital Mortality Oversight Committee attended by representatives of each specialty and led by a new Mortality Lead post holder. Integration with the wider CDR process is key and the CDOP Designated Doctor is in attendance as well as working on some specific issues between formal meetings.

- Following previous CDOP actions about lack of availability of 24/7 community paediatric palliative care, CDOP were pleased to note a 3 month pilot of 24/7 medical on-call in 2020 and eagerly await the learning from this.

- CDOP annual report 2019/2020 was provided to the Avon and Somerset Strategic Safeguarding Partners and as a virtual presentation to all partners in Nov 2020.

- CDOP Terms of Reference were updated and the rotation arrangements for CDOP Chairs was clarified so the Directors of Public Health will rotate on a biannual basis.

- **COVID related:**
    - West of England CDOP were involved in a national Multi-agency working group at the start of COVID to consider how Joint Agency Responses could continue safely and effectively and resulted in publication of interim JAR guidance.
    - Contingency planning across local partner agencies to agree best practice during lockdown.
    - There was a shift to conducting meetings remotely in order for CDRs and CDOP to proceed, which happened seamlessly, and this still continues with some advantages for attendance, but disadvantages in terms of team building.

- A successful and well-attended multi-agency training event on the Joint Agency Response was delivered virtually in Oct 2020 and remains available as a webinar on KBSP website.
- Sharing learning across CDOPs–
    - The WoE Designated Doctor took the lead in convening a meeting of other Designated Doctors across the South West Region.
    - The Designated Doctor identified a number of cases (death in Bristol but resident in another CDOP area) where a CDR could be scheduled in Bristol, CDOP either in WoE or in area of residence and then share learning with the other CDOP.
- Continuing to review and update local guidelines in light of Oct 2018 National Guidance.
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- Revised national Notification form to capture effects of COVID and lockdown on child deaths.

- CDR Chairing arrangements reviewed with the Designated Doctor chairing some of the more complex CDRs, while majority are chaired within departments.

- CDOP Strategic group reconvened to meet quarterly, chaired by CCG.

- Meeting with the Medical Examiner project lead to discuss opportunities for shared working and streamlining processes.

- Biannual Child Death peer review of Joint Agency Responses well-attended by Community Paediatricians, bereavement support, Police, Coroner, and pathologist, enabling closer working arrangements to be developed.

9.0 Future Priorities

- There continues to be a need for feedback from families about the experience of a Joint Agency Response.
- The Care of the Next Infant Programme needs a new source of funding following the CDOP-funded set-up within BNNSG.
- Securing appropriate professionals and time commitment to ensure CDOP has relevant expertise and representation, given competing demands on professionals' time.
- Anticipated introduction of the Medical Examiner service to include scrutiny of children's death from April 2022.
- Ensuring that deaths abroad receive the same scrutiny as those locally and that families can be supported throughout.

Appendix A - CDOP membership April 2020 to March 2021

Role	Core member	Organisation
Nominated Chair	Matt Lenny February 2021 - current (Mary Gainsborough chaired May 2020 – January 2021 due to DPH overcommitment during COVID response)	Director of Public Health, People and Communities Directorate, North Somerset Council
Designated Doctor for Childrens Deaths	Dr Mary Gainsborough	Sirona Care & health on behalf of CCGs
Consultant Neonatologist	Dr Ziju Elanjikal / Dr Claire Rose - April 2020	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- March 2020	Director of Children and Young People Services, Bath and North East Somerset Council
Designated Nurse for Safeguarding	Jackie Mathers to May 2020 Anne Fry from June 2020	BNSSG CCG BNSSG CCG
Designated Nurse for Safeguarding	Liz Plastow	BANES CCG
Professional Midwifery Advocate & Midwifery Matron	Julie Northrop	University Hospitals Bristol and Weston NHS Trust
Consultant Obstetrician	Dr Rachna Bahl – from January 2020	University Hospitals Bristol and Weston NHS Trust
General Practitioner	Dr Patrick Nearney / Dr Elaine Lunts	Bristol
Police	DCI Larisa Hunt / 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	Nick Sargant and 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	South Western Ambulance Service NHS Foundation Trust
Lay Representative	Julie Kembrey	Bereaved Parent & Trustee of Jessie May Trust