

Gloucestershire Child Death Overview Panel (CDOP)

Annual Report for Child Death Reviews Gloucestershire Safeguarding Children Board (GSCB)

1st April 2018 – 31st March 2019

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1. Introduction

We are fortunate that a child death is a rare event in our society, however, each death represents a tragedy for the family and the purpose of the Child Death Review process (CDR) is to identify potentially modifiable factors¹ which may prevent future deaths from occurring. The CDR process is also able to identify local and regional trends to inform the work of Commissioners, Providers and other relevant organisations. For example, in the case of children with life-limiting conditions, the CDR process is able to consider whether these children were in receipt of appropriate care during their life and had access to appropriate support services at the end of life. Where the CDR process identifies learning, this is fed back to the relevant agencies by the Child Death Overview Panel on behalf of the Local Safeguarding Children Board (LSCB) in Gloucestershire.

At the beginning of the CDR process in 2008, the Gloucestershire Child Death Overview Panel (CDOP) was established in line with guidance set out in *Working Together to Safeguard Children*. This CDOP continues to review the deaths of all children resident in this area. Some of these deaths may occur outside of the region and these are also reviewed by this panel.

2. Background to the Child Death Review Process

Chapter 5 of "Working Together to Safeguard Children" (2018) outlines the processes to be followed when a child dies. In addition to this, new statutory and operational guidance was published in October 2018 and must be followed for all deaths occurring after 1st April 2019. For the purposes of this annual report, the previous version of Working Together to Safeguard Children (2015) was in place and governed the process for the children described in this report.

Under Working Together (2015) statutory national guidance, LSCBs were required to establish a procedure to respond rapidly in the event of an unexpected death of any child under 18 years of age. In Gloucestershire a joint police, social care and health rota is staffed during office hours (Monday to Friday 9am to 5pm) to provide this response. Outside of these hours an initial safeguarding discussion occurs at the time of death between police, social care, health and the Coroner's Officer. On the next working day, a formal initial case discussion (rapid response) is undertaken. This involves statutory agencies and all professionals involved with the child. LSCBs are also required to ensure there is a Child Death Overview Panel (CDOP) process. The two are separate processes but are closely linked. The Rapid Response process ensures early notification of the unexpected death of a child and a prompt process of investigation. The CDOP process ensures that every child's death is comprehensively reviewed, and lessons learnt so that action can be taken to prevent future deaths where possible.

3. The Child Death Review Process

A child's death is reviewed by CDOP after a range of standard information has been collected using statutory forms and the case has been discussed by professionals involved in the child's life at a final case discussion (FCD) meeting. Following the FCD meeting, a detailed compilation of data from the statutory forms (Form Bs) and outcomes of the FCD meeting (Form C) is produced and anonymised by the Child Death Enquiries Office at the University of Bristol for presentation to CDOP. CDOP reviews each case with the aim of identifying modifiable factors and highlights any learning identified. The CDOP panel aims to identify those factors in the course of a child's life, and leading to the child's death, which might have directly led to the child's death or increased their vulnerability, and which might have been amenable to modification. It also makes recommendations which may prevent similar deaths occurring in the future. However, it may also make recommendations related

¹ A modifiable death is defined as one where there are factors which may have contributed to the death which, by means of nationally or locally achievable interventions, could be modified to reduce the risks of future child deaths.

to service improvement, where changes in practice could lead to improved experiences for children and young people at the end of life or during the course of their treatment.

4. Production of this report

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 LSCBs. This annual report has been 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 a **Notification Database**. Information collected from statutory forms, final case discussion meetings and CDOP reviews is entered onto a separate **CDOP Database**. The eventual CDOP multi-agency dataset is extremely comprehensive. The annual report includes five years of 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.

5. Notifications of child deaths

5.1 Summary Data (2014 – 2019)

This section summarises all the deaths notified to the Child Death Enquiries Office between 1st April 2014 and 31st March 2019, of children resident in the Gloucestershire area. This data is drawn from the notification database.

5.2 Analysis of notifications by year (2014-2019)

During the period 2014-2019, 154 child deaths were notified. Year on year variation in notifications is to be expected (as shown in Table 1) and with rare events such as a child death, small variations can appear to represent a big difference. However, because the number of notifications for one area of residence are so small the most likely explanation for any patterns is random year-on year variation.

	Number of child deaths notified								
	2014-2015	2015-2016	2016-2017	2017-2018	2018-2019	Total			
Gloucestershire	45	19	36	31	23	154			

Table 1: Numbers of deaths notified by year 2014 to 2019 in Gloucestershire

5.3 Duration of reviews

There is an inevitable time-lag (4-12 months) between notification of a child's death and discussion at CDOP. There are various factors that contribute to this: the return of Form Bs from professionals, the completion of the final post mortem report by the pathologist and receipt of the final report from the FCD meeting. On occasion when the outcome of a Coroner's inquest is awaited, there may be a delay of over a year before a case might be brought before CDOP. The undertaking of a criminal investigation or a Serious Case Review will also affect when a case is discussed at Panel. See Appendix A for a full breakdown of duration of reviews by year.

5.4 Age at death

Using five year data, the greatest proportion of notifications (41%) were received for babies dying in the neonatal period (under one month of age), especially in the first week after birth (31%). This

figure increases to 66% when all deaths under one year are included, this is the same as is observed nationally².

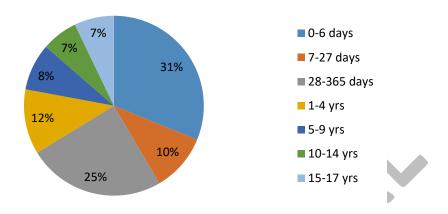
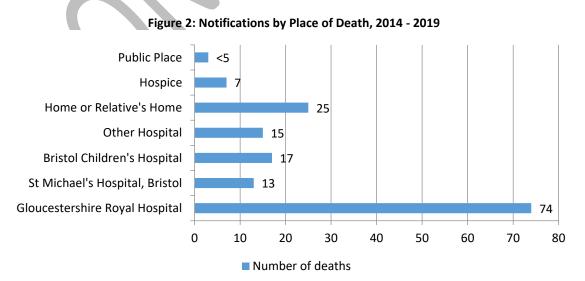


Figure 1: Notifications by Age, 2014 - 2019

5.5 Location of death – where child was confirmed deceased

This data records where the child actually died. Many children resident in Gloucestershire may be transferred to tertiary hospitals in other regions for treatment. A number of these children go on to die in those locations as can be seen in Figure 2 below. The figures in this section represent the total number of deaths at each location during the five year period. A total of 119 deaths (77%) occurred in a hospital setting. 5% of deaths occurred in a hospice, this is slightly higher than nationally where 4% of children die in a hospice. 2% of the deaths were in public places, which is lower than the national figure of 4%³.

Children resident in Gloucestershire are treated in many different hospitals. This reflects the wide geographical area covered by Gloucestershire and the number of counties in which residents receive healthcare services including Bristol, Oxfordshire, Swindon and Birmingham and their willingness to contribute to the process. This can present particular issues for Gloucestershire CDOP for the timely and complete collation of information for the review of children's deaths due to the wide range of organisations that must be engaged.



² Department for Education *Child Death Reviews: Year Ending 31 March 2017*, Department for Education, SFR 36/2017, 31st July 2017

³ Department for Education. Child Death Reviews – Year Ending March 2016

In Gloucestershire, policy recommends that all collapsed children are brought into hospital. In total 25 (16%) children died at home or at a relative's home in the five year period. This can include both expected deaths where a child has received palliative care support at home and unexpected deaths that happened within the home setting. 31% (17/55) of unexpected deaths were confirmed deceased within the home setting.

5.6 Gender

There have been more notifications of deaths in boys than in girls as can be seen in the table below. In total 52% of deaths were male and 48% were female. This is in line with national trends for childhood deaths which also show slightly higher proportions of deaths registered in England were for male children⁴.

Table 2: Numbers of deaths notified betweer	1 st April 2014 and 21 st March 2010	hy gondor
Table 2. Numbers of deaths notified between	TI April 2014 and 51 Warch 2015	, ny genuer

	Male	Female	
Gloucestershire	80	74	
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5.7 Ethnicity

Figure 3 shows that the majority of deaths for Gloucestershire are children of White British ethnic origin. The 2011 Census showed Gloucestershire's residents to be 91.6% White British, 3.1% White Other, 2.2% Asian, 0.9% Black, 1.5% Mixed and 0.2% Other. Though Figure 3 shows that ethnicity was unknown in 8% of cases, there may be over-representation of children from Mixed Ethnic and White Other groups. With increasing migration from East European countries into the county from 2004, the White Other population in the county more than doubled between 2001 and 2011.

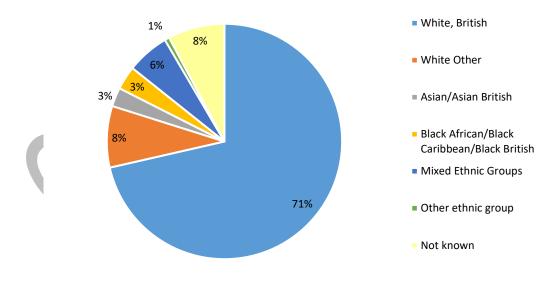


Figure 3: Notifications by Ethnic Groups, 2014 - 2019

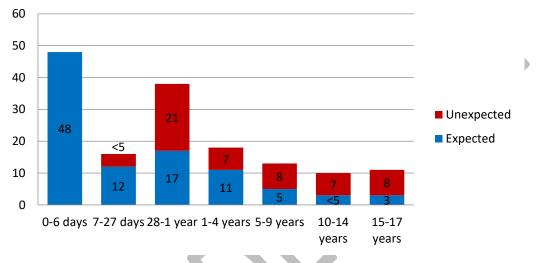
5.8 Unexpected and Expected Deaths

An unexpected death is defined as the death of a 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. During the five year period 55 deaths

⁴ Department for Education *Child Death Reviews: Year Ending 31 March 2017*, Department for Education, SFR 36/2017, 31st July 2017

(36%) were unexpected. The remaining 99 were expected deaths of children with known illnesses or life-limiting conditions.

Figure 4 presents data on expected versus unexpected deaths for 2014-19 by age group. This data show that the highest numbers of unexpected deaths occur in the 28-364 day age group, whilst the vast majority of deaths within the first month of life were expected. Within the 28-364 day age group, the expected deaths would usually be a baby that dies following complications of a premature delivery or of a known chromosomal, genetic or congenital anomaly and the unexpected deaths would include sudden unexpected deaths in infancy and infection.





6. Child Death Overview Panel Review Data

This data is drawn from the CDOP database. It summarises the panel's review decisions for 2014-2019 and its learning for 2018-2019. There is an inevitable time lag between the notification of a child's death and the discussion at CDOP. There are various factors that contribute to this including return of statutory paperwork by professionals, receipt of the final post mortem report and receipt of the report from the Form C. The Gloucestershire CDOP took the decision in 2009 to wait for the inquest verdict in child deaths that involve the Coroner. In these cases, there may be a delay of over a year before a case might be brought for review by CDOP. The undertaking of a criminal investigation or a Serious Case Review can also affect when a case is discussed at panel. In addition, certain children who have been under the care of specialist regional paediatric teams (e.g. cardiology) will be reviewed at a specialist themed CDOP for the region before coming to Gloucestershire CDOP for final review, to ensure that the relevant expertise is present when identifying learning from these cases.

For these reasons the population of children described in the notifications section (drawn from the Notification Database) may partially overlap but is distinct from the population of children described in this section (drawn from the CDOP Database).

The Gloucestershire CDOP has reviewed 172 deaths between 1st April 2014 and 31st March 2019. Of the 154 deaths notified between 1st April 2014 and 31st March 2019, there are currently 38 that have not yet been reviewed by CDOP. All but 3 children who died before 1st April 2017 have been reviewed by CDOP. See Appendix A for a full breakdown.

During the 2018/19 child death review year the Gloucestershire CDOP panel reviewed a total of 17 deaths.

	2014-15	2015-16	2016-17	2017-18	2018-19	Totals			
Gloucestershire	34	55	38	28	17	172			

Table 3: Number of child deaths reviewed by CDOP, 2014 - 2019

6.1 Categorisation of death for cases reviewed by CDOP

As part of the Child Death Review process, each death reviewed by the panel is categorised by the most likely cause of death based on a set of pre-defined categories. The categorisation of deaths for cases reviewed by the panel over the five year period is shown in Figure 5 below. This shows that the most common categorisation is perinatal/neonatal event (35%) followed by chromosomal, genetic and congenital anomalies (20%). The other categories are much less common.

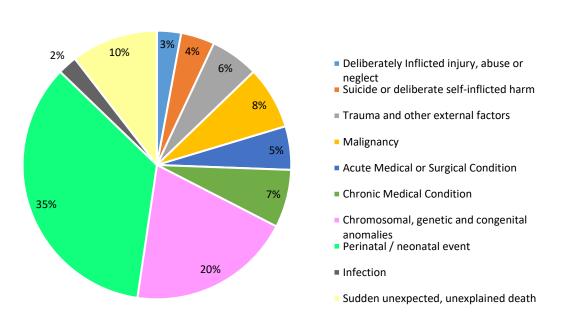
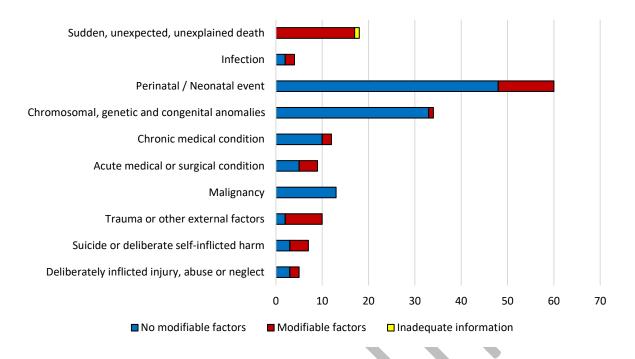
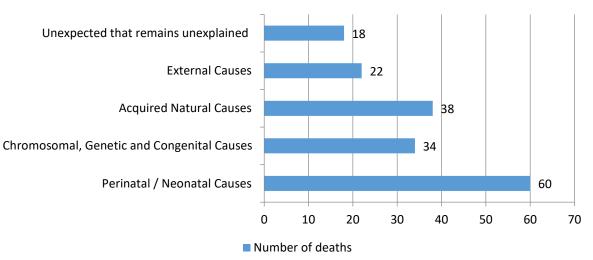


Figure 5: Categorisation of Deaths for Children Reviewed by CDOP, 2014 - 2019

Figure 6, below, shows the proportion of deaths within each category that were considered to have modifiable factors following review by CDOP. This shows that the categories that represent unexpected deaths, e.g. suicide or deliberate self-inflicted harm, trauma and other external factors and sudden, unexpected, unexplained death, have the highest proportion of modifiable factors associated with them. This is as expected and is in line with the national picture. Perinatal or neonatal event, malignancy and chromosomal, genetic and congenital anomalies have the lowest proportion of modifiable factors associated with them, this is also in line with the national picture.



The same data can be grouped into the categories below. This shows that perinatal/neonatal causes remain the largest category, followed by 'Acquired Natural Causes', which groups together malignancy, acute medical or surgical conditions, chronic medical conditions and infection. 'External Causes' groups together deliberately inflicted injury, suicide, trauma and other external factors. The smallest group are those unexpected deaths that remain unexplained following a full investigation and final case discussion meeting.





6.2 Co-morbidities

As well as categorising the cause of death CDOP considers information on co-morbidities in children who die. These are underlying conditions which, while not considered to be the direct cause of death, are thought to have potentially contributed to vulnerability in the child, for example by making treatment more complex or contributing additional challenges to a child living a full and active life. It should be noted however that the existence of a co-morbidity does not necessarily have an impact on the circumstances that led to a child's death.

The CDOP grading system grades factors identified with a 1 if they are notable but not felt to have contributed to the ill-health or vulnerability of the child, with a 2 if they may have contributed to the ill-health, vulnerability or death of the child and with a 3 if they are felt to provide a complete and sufficient explanation of the death of the child.

Figure 8 shows that 109 children (63%) reviewed by CDOP had no co-morbidities at all. Of the remaining children reviewed, 20 (12%), had just one co-morbidity and 43 (25%) had more than one co-morbidity. The chart below reflects the number of children reviewed that had each particular co-morbidity and how significant the panel felt that co-morbidity was, using the grading system described above.

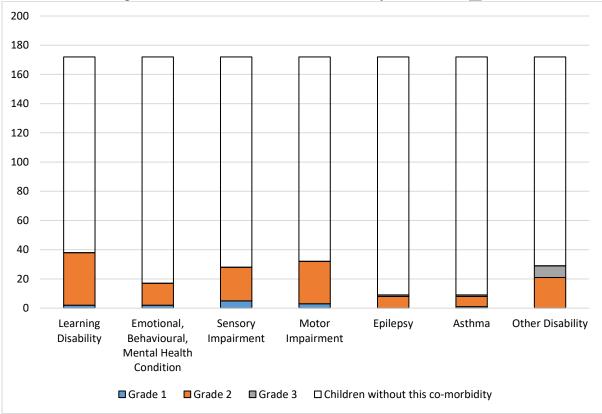




Figure 8 shows that the co-morbidities found to have a significant impact on vulnerability are learning disability, motor impairment, sensory impairment, emotional, behavioural and mental health conditions and other disability. An example of "other disability" would be a child with an underlying chromosomal disorder or a genetic syndrome. Children with a learning disability represent the most common co-morbidity. 38 children had a diagnosed learning disability, and this was considered to be a significant factor in all but 2 cases. Motor impairment is the second most common with 32 children in that cohort. Learning disability and motor impairment are also identified as the most common comorbidities in children reviewed by CDOP panels across the South West.

6.3 Mode of death of cases reviewed by CDOP

As can be seen from the pie chart in Figure 9 below, the most common manner of death for Gloucestershire children is withholding, withdrawing or limitation of life-sustaining treatment (41%). This decision is always made following careful consideration with the child's parents and carers. This is followed by those children who died following planned palliative care (20%) and children who died

following failed cardio-pulmonary resuscitation (18%). Children who were found dead in 16% of cases reviewed.

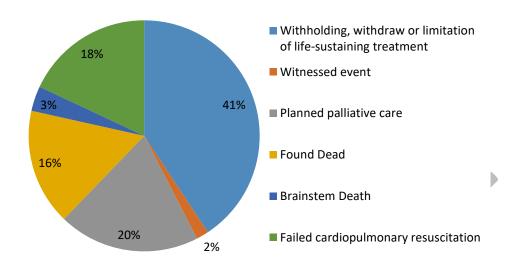


Figure 9: Modes of Death of Cases Reviewed by CDOP, 2014 - 2019

6.4 Factors identified as having contributed to death

Form C of the national dataset requires CDOP to identify and 'grade' factors that have contributed to the child's death (see description of grading system in Section 6.2 of this report).

In 97% of deaths reviewed factors in the child (i.e. the underlying medical or surgical condition) provided a complete and sufficient explanation of the death.

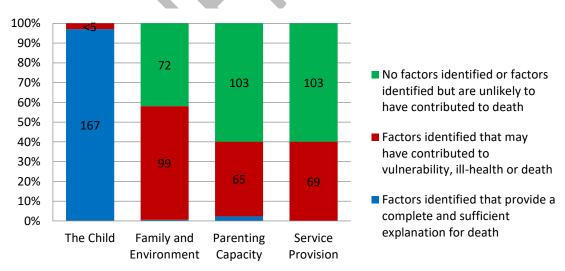


Figure 10: Contributory Factors in Cases Reviewed by CDOP, 2014 - 2019

In 57% of children, factors in the family and environment were identified that may have contributed to the vulnerability, ill health or death of the child. These would be factors such as drug or alcohol use by a parent or carer, smoking during pregnancy or a physical or mental health condition in a parent or carer.

In 40% of children factors in the parenting capacity were identified that may have contributed to the vulnerability, ill-health or death of the child. This includes parents who are unable to prioritise the needs of their child e.g. not seeking medical attention appropriately, poor engagement by parents with professionals and lack of attendance at obstetric appointments during pregnancy.

In 40% of children reviewed, factors related to service delivery were identified that may have contributed to the vulnerability, ill-health or death of the child. These included poor communication between agencies, delay in transfer of the child or access to appropriate treatment, no access to translation services for non-English speaking families (particularly in the acute situation) and difficulties accessing appropriate housing for vulnerable families.

In any case where factors are identified at the final case discussion meeting or at CDOP that may have contributed to vulnerability, ill-health or death, the context is carefully reviewed, and appropriate actions logged on the Child Death Review Team Work Plan or CDOP action log to be followed up.

All unexpected child deaths are discussed at the Serious Case Review (SCR) Sub-Group to facilitate joined up working between the two processes. If at anytime throughout the Child Death Review it is identified that the case should be considered for a Serious Case Review a Case for Consideration will be presented to the SCR Sub Group.

6.5 Additional social factors in the family and environment

The presence or absence of social factors in the family and environment such as mental health issues and drug abuse are routinely collected on the Form B dataset from professionals who have contact with the families. These are summarised on the Form C dataset at the final case discussion meeting and carefully reviewed by CDOP. They are shown in the Table 4 below. Please note that these factors are not necessarily considered to be modifiable in every case and may not have been directly contributory to the child's death, rather this data reflects the presence or absence of a social factor within the family or environment.

Factor	Grade 1	Grade 2	Grade 3	Factor known not to be present	Not known if factor present	% of cases where factor considered to be
				present	Prosent	significant
Emotional, behavioural,	33	47	0	87	5	27.3%
mental health condition						
in a parent or carer						
Alcohol or substance	11	27	0	125	9	15.7%
misuse by a parent or						
carer						
Smoking by a parent or	28	50	0	86	8	29.0%
carer / Smoking by Mum						
during pregnancy						
Housing	9	32	0	131	0	18.6%
Domestic violence	7	38	<5	123	<5	22.6%

Table 4: Factors in the family and environment recorded in cases reviewed by CDOP of children resident in Gloucestershire 2014-2019

Table 4 above shows significant factors to include smoking in a parent/carer, emotional, behavioural or mental health condition in a parent/carer and alcohol/substance abuse in a parent/carer. Domestic violence is also a significant factor in 22.6% of cases.

6.6 Modifiable Factors – Reducing the Risk of Future Deaths

The focus of the Child Death Review process is to assess modifiable factors in each child's death. 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". Panels can identify modifiable factors in the child's direct care by any agency, including parents, latent, organisational, systemic or other indirect failure(s) within one or more agency. Therefore, a death identified as having modifiable factors may not necessarily be due to a failure of the Local Authority or other agencies to safeguard the child's welfare. 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.

For cases reviewed by CDOP during the five year period, modifiable factors were identified in 30% of cases. In the majority of cases, (119/172) no modifiable factors were identified. In the case of one child reviewed during the period there was inadequate information on which to make a judgment. This is slightly higher than the national figure, where 27% of deaths were categorised as having modifiable factors⁵. This represents an increase from 24% for the previous two years. Panels across England have identified modifiable factors in between 22 and 32% of the child death reviews they complete.

7. Summary statistics, Key Themes, Recommendations and Actions taken

7.1 Summary Statistics

- The majority of child deaths are expected deaths accounting for 64% of child deaths in the five-year period.
- 41% of child deaths occurred in the perinatal or neonatal period and 66% occurred within the first year of life.
- The most common category of death in Gloucestershire is perinatal or neonatal event (35%). This is in line with the national picture.
- Deaths from external causes, which includes deliberately inflicted abuse or neglect, trauma and external factors or self- inflicted harm and suicide are rare. They account for 13% of deaths (equivalent to <5 child deaths in 2018-19).
- In the majority of deaths reviewed no modifiable factors were identified. However modifiable factors were identified in 30% of cases reviewed by the panel during the five-year period. Nationally this figure is 27%.

7.2 Key Themes and Actions Taken

At each stage of the child death review, potential learning to improve the delivery of services in the future, is identified. Below are some of the areas of work which have been undertaken.

⁵ Department for Education *Child Death Reviews: Year Ending 31 March 2017*, Department for Education, SFR 36/2017, 31st July 2017

Gloucestershire Hospitals NHSFT

The Child Death Review Team wish to express our thanks for all the work Sister Barbara Hall undertook on behalf of the team in Gloucestershire Hospitals NHSFT. Barbara was our link in the Emergency Department who ensured due process was followed for our unexpected deaths (as per the Kennedy recommendations). She also provided and headed a bereavement service for the families over many years.

We are pleased to inform that Sister Clare Morris is continuing the good work. Clare was initially involved with an infant death in the Emergency Department (ED) and subsequently, recognising the benefits of the service Barbara offered, has taken the lead for this role. Clare has worked with the charity 4LOUIS to fund memento boxes in the ED, new white clothing for dressing the babies and a Moses basket for use within ED. She is also continuing to train other nurses in due process and is supporting the bereaved families.

Following liaison post child death reviews, further work has been undertaken in GHNHSFT in relation to PEWS scoring, the role of probiotics in the neonatal period for premature babies and correct age-specific resuscitation equipment is available in areas of the Hospital children access regularly etc.

End of Life Care and Support for the Families post death

The Child Death Review Team have worked with the Paediatric Palliative Care Team to highlight learning demonstrated from our reviews to ensure this is cascaded to health professionals and for the Palliative Care Professionals to have an understanding of the child death process so they can discuss it with families.

Through this work, we have raised the following issues:

- The need to clarify causation of death with pathologist/core medical team prior to issuing the death certificate
- The need to engage early with GPs for children needing palliative care at home and to offer access to specialist Palliative Care Doctors for support in prescribing medication
- The need for the family to be introduced to the services of the hospice early to ensure better support from time of diagnosis
- For children who have been referred to the hospice, the access to the cold bedroom, hospice family flat and support in arranging funerals post the child's death. In addition, the hospice provides a holistic bereavement service adapted to the need of each family member. This service has been critical for many families at a very difficult time and currently is not commissioned, hence, in the current economical clime may be withdrawn.
- The need for clinical psychology support from the time of diagnosis.

Emergency Transfer of Children to Tertiary Centres

In children who are medically critically ill, the timeliness of hospital transfer to Tertiary Centres can be crucial. Currently there is only one transfer team funded in the South West and this can present difficulties when more than one child needs transfer at the same time.

<u>Asthma</u>

Gloucestershire has had three teenage deaths from asthma in the past 10 years. Lack of awareness of potential consequences of asthma, limited insight into severity of symptoms, poor compliance of medication and attendance at appointments have all been highlighted. Working with the Gloucestershire Respiratory Paediatricians, our aim is to try and identify 'red risk' factors and work with schools to help facilitate better understanding of asthma and its potential implications. We hope to have a Gloucestershire Health and Schools launch in the Autumn.

<u>Schools</u>

The collapse of a child in school is a tragedy with potential wide implications for other school children, staff etc. *The Gloucestershire Support for Schools who Experience a Child Death Pack* continues to be used widely and is amended to reflect any new learning.

This year the school's policy for 999 has been amended and additional support is provided to Heads by other Heads who have already been through the process.

Self-Harm and Aerosol Abuse

CDOP has recognised and shared the continuing need to raise awareness for professionals of how to detect self-harm in children and young people. It also became aware of increasing aerosol and gas cannister abuse. Information was shared with Community Support Groups who then targeted Schools and local Youth Clubs to raise awareness of possible risks.

Poor Communication

Sadly, at times this problem continues to be raised whether this relates to difficulties between Primary and Secondary Care, Secondary and Tertiary Care or multi-agency working. When this problem is identified, the Child Death Review Team will feedback to the Professionals who have been involved with the child and family to help improve communication for other families in similar positions. In addition, the new Well Child Nurse post will help facilitate better communication between Secondary and Tertiary care.

Supporting Bystanders Who Help When a Child Collapses:

This year we have undertaken work with the SWAS paramedics and Police who attend the scene of a child's collapse to try and identify any by-standers/neighbours who might have been involved with the collapse. The Child Death Review Team aim to provide an opportunity for support or de-brief acknowledging the traumatic event these people will have witnessed.

Appendix A: Duration of CDOP Reviews by Year (2010-2019)

	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19
Total number of notifications	36	30	43	26	45	19	36	31	23
Total number of cases reviewed	24	34	33	34	34	55	38	28	17
Years of Review	Number reviewed								
2008/09	14	3	3	0					
2009/10	9	16	4	1	1	1			
2010/11	1	15	16	4	0	0			
2011/12		0	10	15	5	0			
2012/13			0	14	25	4			
2013/14				0	3	23			
2014/15					0	27	17	0	1
2015/16						0	17	2	0
2016/17							4	17	10
2017/18								9	6
2018/19									0

• NB: All but 3 children who died before 1st April 2017 have been reviewed by CDOP (this is due to ongoing investigations/Serious Case Reviews/DHR)

• NB: The above details the number of cases awaiting review by CDOP, all cases except those of children who died in the last 6 months have already undergone a final case discussion meeting