



BUCKINGHAMSHIRE CHILD DEATH OVERVIEW PANEL (CDOP)

12th ANNUAL REPORT

01/04/2019 – 31/03/2022

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Introduction and background:

This report is the 12th annual report by Buckinghamshire Child Death Overview Panel (CDOP) and focuses on the work of the panel between April 2019 and March 2022 inclusive. Changes in key personnel and the additional workload demands created for partners by the COVID-19 pandemic resulted in a significant backlog of cases during this period and prevented the production of routine annual reports. This report is intended to cover CDOP activity during this unusual period and reflects the way in which the Panel has worked to catch up with the backlog and return to business as usual in the post-pandemic phase. This report consists of the following sections:

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A. CHILD DEATH REVIEW PROCESS

The overall aim of the child death review processes is to understand why children die and to put in place interventions to help improve child safety and welfare and to prevent future avoidable deaths.

A key function of the Child Death Overview Panel (CDOP) is to identify if a child's death was preventable. Government guidance defines preventable child deaths *as those in which modifiable factors may have contributed to the death. These factors are defined as those which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths.*

There are two interrelated processes for reviewing child deaths as explained below.

1. Rapid Response by a group of key professionals who come together for the purpose of enquiring into and evaluating each unexpected death. Unexpected death in childhood is defined as 'the death of a child that was not anticipated as a significant possibility 24 hours before the death, or where there was a similarly unexpected collapse leading to or precipitating the events that led to the death'.
2. An overview of all deaths up to the age of 18 years (excluding both those babies that are stillborn and planned terminations of pregnancy carried out within the law) which happens at a later stage as part of a multidisciplinary panel discussion (CDOP). CDOP is a confidential review in which professionals from the services involved discuss cases and the circumstances leading to the death.

The purpose of a rapid response service is to ensure that the appropriate agencies are engaged and work together to:

- Respond quickly to the unexpected death of a child.
- Ensure support for the bereaved siblings, family members or members of staff who may be affected by the child's death.
- Identify and safeguard any other children in the household that are affected by the death.
- Make immediate enquiries into and evaluate the reasons for and circumstances of the death, in agreement with the coroner when required.
- Preserve evidence in case a criminal investigation is required.
- Enquire into and constructively review how each organisation discharged their responsibilities when a child has died unexpectedly and determine whether there are any lessons to be learnt.
- Collate information in a standard format when collecting information about child deaths
- Co-operate appropriately post-death, maintaining contact at regular intervals with family members and other professionals who have ongoing responsibilities to the family, to ensure that they are appropriately informed (unless such sharing of information would place other children at risk of harm or jeopardise police investigations)

- Consider media issues and the need to alert and liaise with the appropriate agencies
- Maintain public confidence

The rapid response begins at the point of death and ends when the final meeting has been convened and chaired by the designated paediatrician or equivalent. Any records of the meeting should be forwarded to the CDOP at the time of the review.

A1. CHANGES TO THE CHILD DEATH REVIEW PROCESS - OCT 2018

The Child Death Review Statutory and Operational Guidance for England was published in October 2018. The guidance is issued under section 16Q of the Children Act 2004 and it builds on the high-level principles for child death review set out in Chapter 5 of Working Together to Safeguard Children (2018).

The new guidance clarifies processes and sets out high-level principles for how professionals across all agencies involved in the child death review process should work together. This is for two main reasons:

- ✓ Firstly, and most importantly, to improve the experience of bereaved families, as well as professionals involved in caring for children, in the devastating and bewildering period after the death of a child.
- ✓ Secondly, to ensure that information from the child death review process is systematically captured in every case, to enable learning to prevent future deaths.

The Children Act 2004 requires Child Death Review (CDR) partners to make arrangements to carry out child death reviews. These arrangements should result in the establishment of a Child Death Overview Panel, or equivalent, to review the deaths of all children normally resident in the relevant local authority area, and if they consider it appropriate the deaths in that area of non-resident children. The review should then be carried out by a Child Death Overview Panel (CDOP), on behalf of CDR partners, and should be conducted in accordance with this guidance and that contained in Working Together to Safeguard Children (2018).

The new guidance specifies that:

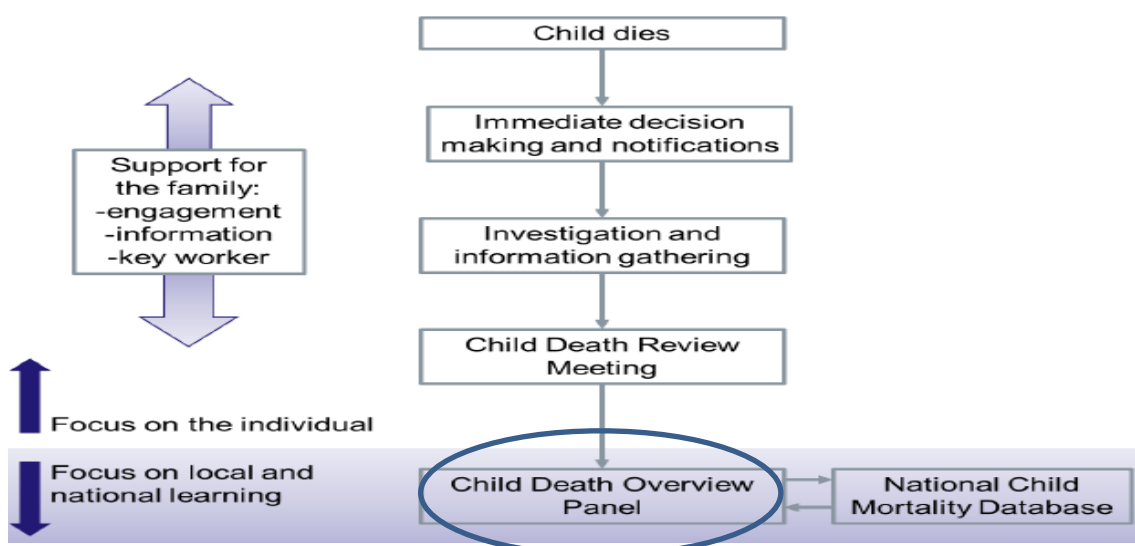
- CDR partner footprints should be locally agreed; they should be aligned to existing networks of NHS care and other children's services and should take account of agency and organisational boundaries. They should cover a child population such that they typically review at least 60 child deaths each year.
- Reviewing at least 60 deaths each year will better enable thematic learning in order to identify potential safeguarding or local health issues that could be modified in order to protect children from harm and, ultimately, save lives.

A.3 Child Death Overview Panel (CDOP) responsibilities:

The functions of CDOP include:

- to collect and collate information about each child death, seeking relevant information from professionals and, where appropriate, family members;
- to analyse the information obtained, including the report from the Child Death Review Meetings (CDRM), in order to confirm or clarify the cause of death, to determine any contributory factors, and to identify learning arising from the child death review process that may prevent future child deaths;
- to make recommendations to all relevant organisations where actions have been identified which may prevent future child deaths or promote the health, safety and wellbeing of children;
- to notify the Child Safeguarding Practice Review Panel and local Safeguarding Partners when it suspects that a child may have been abused or neglected;
- to notify the Medical Examiner and the doctor who certified the cause of death, if it identifies any errors or deficiencies in an individual child's registered cause of death (any correction to the child's cause of death would only be made following an application for a formal correction).
- to provide specified data to NHS Digital and then, once established, to the National Child Mortality Database;
- to produce an annual report for CDR partners on local patterns and trends in child deaths, any lessons learnt and actions taken, and the effectiveness of the wider child death review process; and
- to contribute to local, regional and national initiatives to improve learning from child death reviews, including, where appropriate, approved research carried out within the requirements of data protection.

Figure 1 below sets out the main stages of the child death review process



B. KEY FINDINGS

- Child mortality rates (including perinatal, neonatal and infant mortality) in Buckinghamshire are similar to the England average; however, as elsewhere, there is a large disparity between the most and least deprived populations in the county.
- In 2019-22 the panel reviewed and closed 68 cases in total (other cases were reviewed but carried over into 2022-23 in the event that more information needed to be sought in order to close them).
- The average time-lag to review and close cases during the COVID-19 pandemic was slower than best practice, due to the non-CDOP workload of panel members, a lack of consistent admin support and greater delays in obtaining information from partner organisations. Significant work has been undertaken in the post-pandemic period to improve processes and strengthen CDOP resilience while also catching-up with the backlog of cases.
- 23 cases (33.8%) were 0-27 days old at the time of death compared with 42% nationally (2018-19). A further 11 cases (16.2%) were aged between 28 and 364 days which is also lower than the national average of 19% in 2018-19.
- Overall, 34 cases (50%) were in children aged 0-1 year old which is below the national average of 62% (2018-19).
- 9 cases (13.2%) were in 1-4 year olds compared with 11% nationally (2018-19). 25 cases (36.8%) were in 5-17 year olds compared with 26% nationally (2018/19).
- 36 of the cases reviewed during this period (52.9%) were male and 32 (47.1%) were female, compared with the national average of 56% and 42% respectively (nationally in 2% of the cases the gender was unknown/not stated).
- The proportion of cases whose ethnicity was recorded as Asian or Asian British (22.1%) was higher than both the known representation within the Buckinghamshire population and the average Asian/Asian British proportion of national CDOP cases (approximately 15%).
- Perinatal/neonatal deaths were the most frequent category of death in Buckinghamshire (19 cases, 27.9%), jointly followed by malignancy and chromosomal/congenital abnormalities (with 12 cases, or 17.6% each).

- A range of lessons learned and remedial actions were identified and disseminated appropriately through the system during this period. The major themes of these recommendations were antenatal care, community paediatrics, clinical handovers/transfers, inpatient and end-of-life care.

C. BACKGROUND

Overall, the health and wellbeing of children in Buckinghamshire is generally better than the England average. The child mortality rate (1-17 years) for 2018-20 was 9.5 deaths per 100,000 population, compared to the national rate of 10.3. Similarly, the infant mortality rate (<1 year) in 2018-20 was 3.2 deaths per 100,000 population, compared to 3.5 for the South East and 3.9 for England as a whole.

More data and regional/national comparators can be found at the [Fingertips Local Authority Health Profiles website](#) (formerly managed by Public Health England, now the Office for Health Improvement & Disparities).

D. CDOP ACTIVITY 2019-22

D.1. CDOP Membership

The Child Death Overview Panel is drawn from the key organisations represented on the LSCP.

Core members of CDOP in 2019-22 include:

- The Designated nurse for safeguarding children and looked after children BOB ICB (Chair)
- Safeguarding nurse, Bucks Healthcare NHS Trust
- A Public Health Consultant [Deputy chair]
- A Consultant Paediatrician / Designated Doctor, Bucks Healthcare NHS Trust
- A Midwife, Bucks Healthcare NHS Trust
- An education representative
- A representative from Children's Social Care
- A representative from Thames Valley Police Child Abuse Investigation Unit
- A representative from the Coroner's Office
- The CDOP Coordinator
- Named GP safeguarding children BOB ICB

D.2. Number of child death cases reviewed and closed 2019-22

Between 1st April 2019 and 31st March 2022, CDOP reviewed and closed the cases of 68 deaths of children aged 0-17 who were normally resident in Buckinghamshire.

It is important to note that not all child deaths which occur each year will have their panel review completed by 31st March because it may take a number of months to gather sufficient information to fully review a child's death. This means that deaths that are notified in the last quarter of the year may not have their reviews completed in the same year and are therefore carried over to the next financial year. This lag effect was exacerbated by the pandemic, which further slowed the process of gathering and reviewing the necessary data.

D.3. Number of reviews and review time

68 cases were reviewed and closed by the CDOP panel between 2019/20 and 2021/22. A small number of outstanding cases from 2016/17 and 2017/18 were reviewed and closed in the first two financial years, with the large majority of cases reviewed in each subsequent year either having died in the current or previous financial year. See Table 1 below:

Table 1

| Year of death | 2019/2020 CDOP | 2020/2021 CDOP | 2021/2022 CDOP | Grand Total |
|----------------------|---------------------------|---------------------------|---------------------------|------------------------|
| 2016/2017 | 1 | 1 | | 2 |
| 2017/2018 | 3 | | | 3 |
| 2018/2019 | 15 | 3 | | 18 |
| 2019/2020 | 7 | 16 | 1 | 24 |
| 2020/2021 | | 13 | 8 | 21 |
| Grand Total | 26 | 33 | 9 | 68 |

During this period, the number of days that elapsed between death and CDOP review varied significantly. Only just over two-thirds of cases were reviewed between two months and one year after their death. A faster turnaround is clearly desirable, to ensure that lessons learned are embedded as soon as possible, so the Buckinghamshire CDOP has made it a priority to improve the speed with which cases are reviewed, where possible. It is noted that other statutory processes occasionally delay CDOP processes.

Table 2

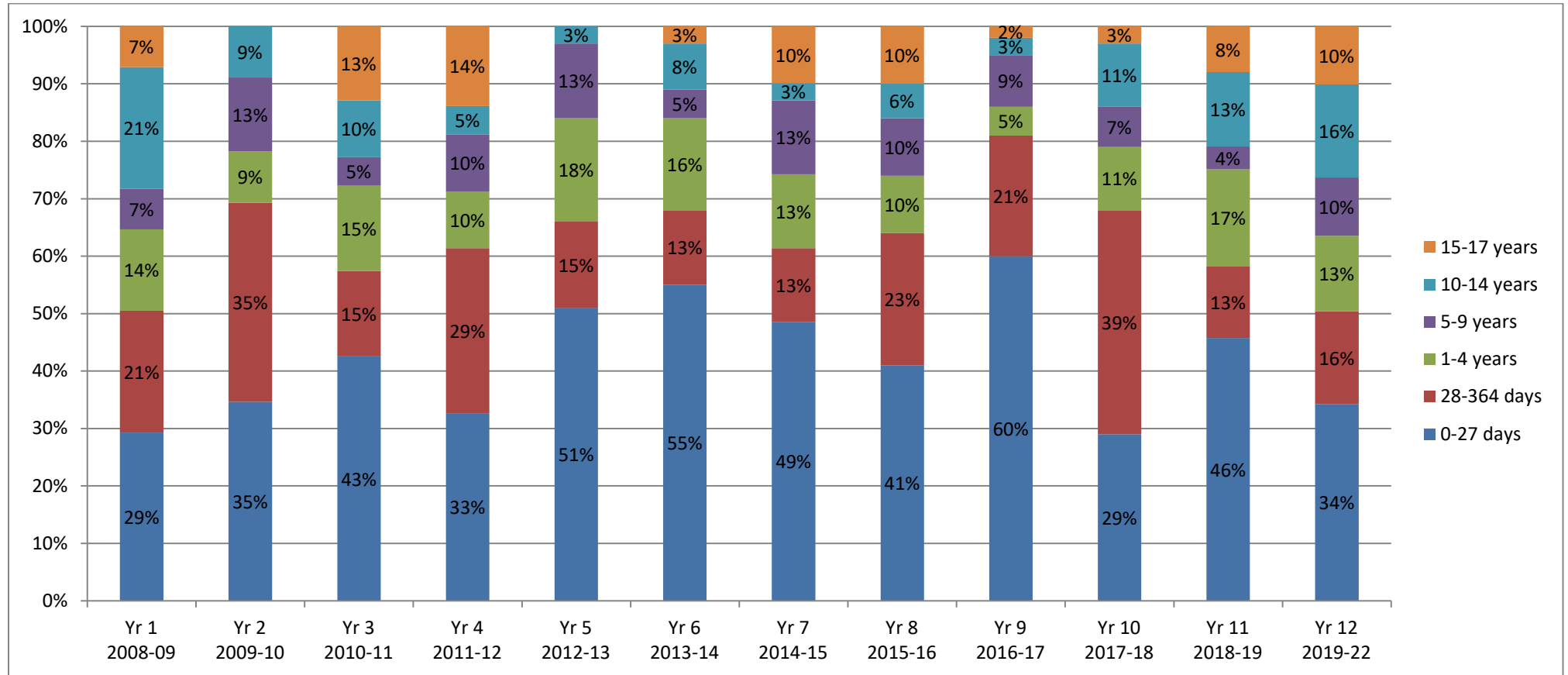
| Number of days between death and CDOP review | Cases | % of total |
|---|--------------|-------------------|
| 60-120 days | 9 | 13.2% |
| 121-240 days | 23 | 33.8% |
| 241-360 days | 16 | 23.5% |
| >361 days | 19 | 27.9% |
| Not recorded | 1 | 1.5% |

E. ANALYSIS OF CHILD DEATH REVIEWS & FINDINGS

E.1. Number of deaths reviewed by age group

Of the 68 cases reviewed and closed during the 2019/20 to 2021/22 financial years, 50% were under a year old. Of the remainder, approximately 24% were aged between 1-9 years, and 26% 10-17 years. Children aged 1 or older represented a larger proportion of CDOP cases during this period than has usually been the case in previous years, but due to small numbers it is difficult to identify any trend in particular age groups.

Figure 2 shows the trends in age of CDOP cases since 2008/09



E.2. Number of deaths reviewed by gender:

36 of the cases reviewed during this period (52.9%) were male and 32 (47.1%) were female. Nationally, boys' deaths have consistently accounted for over half of deaths reviewed since the year ending 31 March 2011.

E.3. Number of deaths by ethnicity

Information on ethnicity was not known/not stated in 10.3% of cases. The full breakdown is given in Table 3 below:

| Ethnicity | Number | % |
|---|---------------|----------|
| Asian or Asian British - Any other Asian background | 2 | 2.9% |
| Asian or Asian British - Indian | 4 | 5.9% |
| Asian or Asian British - Pakistani | 9 | 13.2% |
| Black or Black British - African | 1 | 1.5% |
| Mixed - White and Asian | 2 | 2.9% |
| Not known/not stated | 7 | 10.3% |
| White - Any other White background | 4 | 5.9% |
| White - British | 38 | 55.9% |
| White - Irish | 1 | 1.5% |

The 2011 Census recorded that 86.4% of the population of Buckinghamshire gave their ethnicity as "White", with "Asian/Asian British" accounting for 8.6% and "Black/African/Caribbean/Black British" 2.1%. Allowing for a small amount of demographic change over the intervening decade (and that the ethnic minority population share tends to be larger among younger age groups), it still seems likely that children of Asian heritage are over-represented in these data compared to their proportion of the population.

E.4. Category of deaths as determined by CDOP 2019-22

The Panel is required to classify the deaths into 10 categories and record the likely cause of death, the event which caused the death, the location of the death and whether any modifiable factors were identified. For each factor identified which could have plausibly been associated with a child's death (which can include chronic medical conditions, acute illnesses, injuries and social/family circumstances) the panel are asked to consider and score them accordingly:

- 0 (Information not available)
- 1 (No factors identified, or factors identified but are unlikely to have contributed to the death)
- 2 (Factors identified that may have contributed to vulnerability, ill health or death)

With regards to the category of death, our data show that perinatal/neonatal deaths¹ were the top category of death in Buckinghamshire (19 cases, 27.9%), jointly followed by malignancy and chromosomal/congenital abnormalities (with 12 cases, or 17.6% each). Table 5 below shows the category of deaths as determined by CDOP reviews.

Table 4: Category of deaths as determined by CDOP 2019-22

| Category of death | Total | National Benchmarking (2018/19) |
|---|------------|---------------------------------|
| Category 1: Deliberately inflicted injury, abuse or neglect | 0% (0) | 2% |
| Category 2: Suicide or deliberate self-inflicted harm | 4.4% (3) | 3% |
| Category 3: Trauma and other external factors | 2.9% (2) | 6% |
| Category 4: Malignancy | 17.6% (12) | 9% |
| Category 5: Acute medical or surgical condition | 8.8% (6) | 6% |
| Category 6: Chronic medical condition | 7.4% (5) | 4% |
| Category 7: Chromosomal, genetic and congenital anomalies | 17.6% (12) | 24% |
| Category 8: Perinatal/neonatal event | 27.9% (19) | 33% |
| Category 9: Infection | 10.3% (7) | 5% |
| Category 10: Sudden unexpected, unexplained death | 2.9% (2) | 7% |
| Total | 68 | 3,215 |

A detailed analysis of perinatal and neonatal mortality and deaths due to congenital abnormalities in Buckinghamshire was undertaken in 2017 which showed that child mortality rates and patterns of death in Buckinghamshire are consistent with the national picture and with research evidence.

Figure 3 overleaf shows the trend in category of deaths as determined by CDOP between 2008 and 2022.

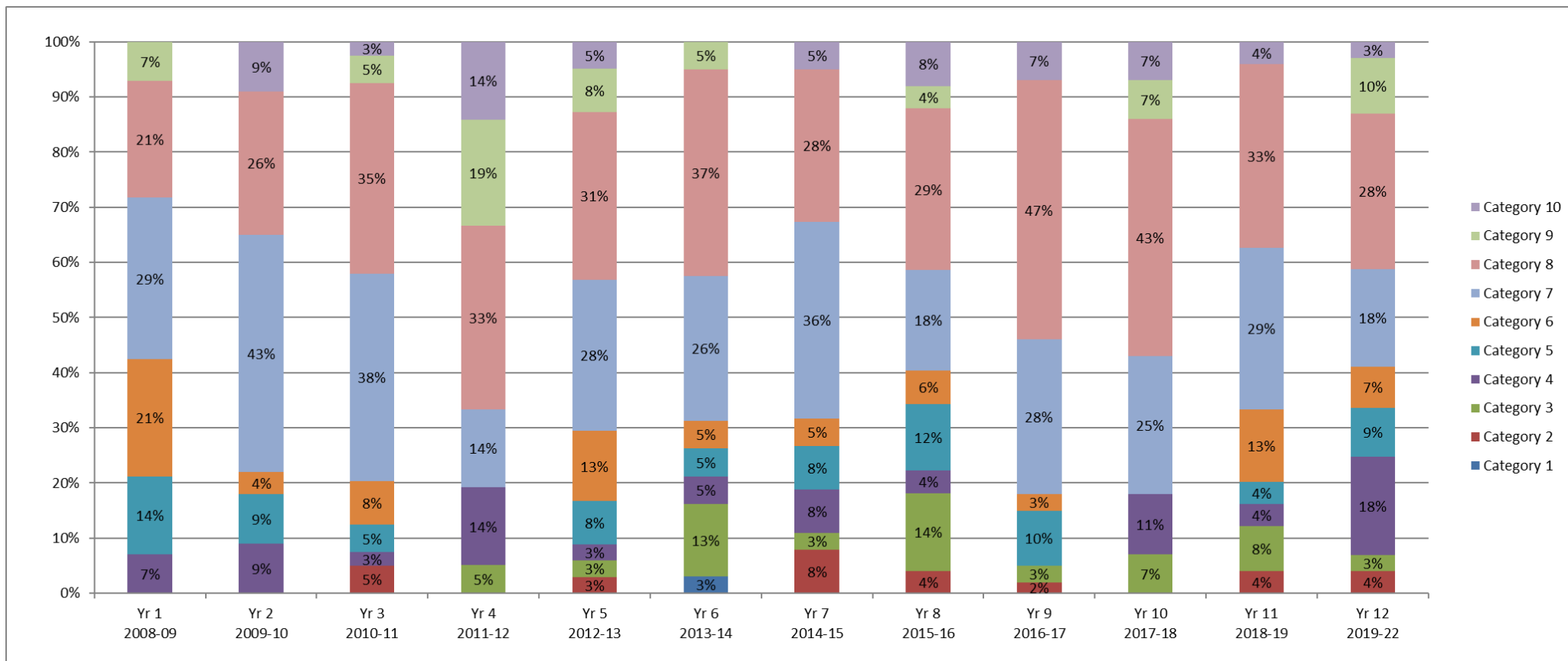
There is considerable variability in the proportions of the different categories of death year by year, which especially for the less common categories can be attributed to small numbers. There is a well-established pattern of over half of deaths being categorised as due to either “Chromosomal, genetic and congenital anomalies” or to a “Perinatal/neonatal event”.

¹ Perinatal mortality rate: the number of stillbirths and deaths in the first six postnatal days per 1,000 total births.

Neonatal mortality rate: the number of infants dying in the first 27 postnatal days per 1,000 live births

Post-neonatal mortality rate: the number of infants dying at 28 days and over but under one year per 1,000 live births

Figure 3: Trend in category of deaths as determined by CDOP 2008-22



| | |
|---|---|
| <p>Category 1: Deliberately inflicted injury, abuse or neglect</p> <p>Category 2: Suicide or deliberate self-inflicted harm</p> <p>Category 3: Trauma and other external factors</p> <p>Category 4: Malignancy</p> <p>Category 5: Acute medical or surgical condition</p> | <p>Category 6: Chronic medical condition</p> <p>Category 7: Chromosomal, genetic and congenital anomalies</p> <p>Category 8: Perinatal/neonatal event</p> <p>Category 9: Infection</p> <p>Category 10: Sudden unexpected, unexplained death</p> |
|---|---|

E.5. Place of death

The most common places of death for CDOP cases during this period were home or the Paediatric Intensive Care Unit (PICU, both 16.2%), closely followed by the neonatal unit (14.7%). The majority of deaths at home resulted from a choice made by the family as part of end-of-life care, although a small percentage also represent unexpected deaths.

| Place of death | Number of cases | % of total |
|---------------------------------------|-----------------|------------|
| Abroad | 1 | 1.5% |
| Home | 11 | 16.2% |
| Hospice | 2 | 2.9% |
| Hospital - ED | 6 | 8.8% |
| Hospital - Hospital ward | 3 | 4.4% |
| Hospital - Labour ward/delivery suite | 8 | 11.8% |
| Hospital - Midwifery unit | 1 | 1.5% |
| Hospital – Neonatal Unit | 10 | 14.7% |
| Hospital - PICU | 11 | 16.2% |
| Hospital - Theatre | 1 | 1.5% |
| Not known | 7 | 10.3% |
| Other residence (please specify) | 1 | 1.5% |
| Public place | 6 | 8.8% |

E.6. Modifiable and Contributory Factors

In 21 (30.9%) of cases there was no recorded pre-existing medical conditions. Possibly modifiable factors were identified in 12 cases (17.6%), including consanguinity (parents being blood relatives), smoking during pregnancy, the availability of harmful substances online and clinical issues such as delayed triage or fetal heart monitoring in maternity, and undetected growth restriction.

F. LEARNING POINTS AND RECOMMENDATIONS

Learning points and recommendations for health system improvement following CDOP review 01/04/2019 to 31/03/2022 were identified across a wide range of areas and throughout the life course. Recommendations were often drawn directly from serious incident (SI) reports or Root Cause Analyses, with additional points identified by the CDOP panel in many cases. It should be noted that not all learning points and recommendations were related to modifiable risk factors and may not have had an influence on the child death if amended – however, in most cases they would likely have resulted in improvements in quality of care.

Recommendations have been grouped around seven thematic areas: antenatal care, care in the community (social care/mental health/community paediatrics),

handover & transfer, inpatient care (routine and acute), management at the end of life, tissue donation and CDOP processes.

F.1. Antenatal care

Antenatal booking appointments were identified in several cases as missed opportunities to identify potential health challenges to mothers and unborn babies, including maternal smoking, domestic violence in the home and maternal mental health issues. Recommendations to address this included asking midwifery services to better utilise interpreter services and to continue to offer smoking cessation help to pregnant women. Other antenatal learning points included the need for improvement in the detection and monitoring of intrauterine growth restriction gestational diabetes and ensuring that women who have undergone LLETZ (large loop excision of the transformation zone) have rapid referral to assess the need for intervention to ensure a safe pregnancy. A range of perinatal learning points were also identified, including the need to transfer women in labour <27 weeks gestation to tertiary units wherever possible. In addition, one case identified a need to improve the quality of foetal monitoring, particularly during labour, to allow early escalation of foetal distress, and specific recommendations around the implementation of national RCOG guidance “Each baby counts” was made.

F.2. Care in the community

The interface between community paediatric and inpatient paediatric teams was highlighted as a key area of potential improvement in multiple cases. Key recurring issues were noted with knowledge sharing between the two teams and a lack of involvement of community paediatricians in acute admissions of community patients. Recommendations to address this included adding the community paediatric team email address to the inpatient paediatric handover for use when a community paediatric patient was admitted, and the upload of community paediatric letters to shared electronic notes systems.

Opportunities for learning by mental health services were also identified following the death by suicide of two adolescents. A key challenge in both cases was difficulties faced in the mental health assessment of children with autistic spectrum disorder (ASD). In one case a serious incident review recommended that standard training packages for CAMHs clinicians be updated to include a specific area on assessing risk in ASD. Other recommendations included the importance of providing comprehensive inductions for new staff and reducing the number of assessments expected from agency workers to ensure a manageable workload. Finally, CDOP also recommended online age restrictions for the purchase of toxic substances.

F.3. Handover & transfers

Points of transition between clinical teams were identified as areas of potential improvement in the quality of care. Clinical handovers were highlighted as an important point to discuss concerning or unwell patients. Several cases highlighted potential for improvements in care around transfers between clinical teams, including issues around who the senior responsible clinician was at any one time during transfers. This point was acknowledged and followed up by a transfer consultant following recommendations from CDOP. A more general point identified was that it can be inappropriate to transfer babies who are in extremely poor clinical condition.

F.4. Inpatient care

The most frequently highlighted issues were around the care of acutely unwell children. These included barriers to the timely recognition and correct management of unwell children, particularly regarding hospital triage processes and accurate antibiotic prescription and associated activities (e.g. taking timely blood cultures). In one case CDOP wrote a letter to an acute hospital trust expressing concerns about hospital capacity following a lack of long-term improvements in triage systems. Quality of clinical documentation was repeatedly recognised as an issue across multiple cases, and CDOP recommended that senior clinicians have clear oversight over discharge documentation.

F.5. End of life

End of life care was repeatedly highlighted as an area of good practice that provided a holistic and supportive service to families of children with likely terminal outcomes. Recommendations in this area were focussed on ensuring that children were made known to hospice services at an early stage of their illness, and that emergency departments were made continuously aware of children in the community under palliative care who did not have advanced care plans.

F.6. Tissue donation

Tissue donations were recognised as being of value to families, and CDOP recommended that healthcare professionals support the option of tissue donation in all cases of a child's death. Some problems were recognised with the current requirements for continual blood tests in deteriorating children to facilitate tissue donation, and in the adult-oriented consent form which contained questions that were not appropriate in the context of a child death.

F.7. CDOP processes

Several child deaths were not appropriately referred to CDOP in a timely way, and this was addressed through CDOP engagement with primary care, and in

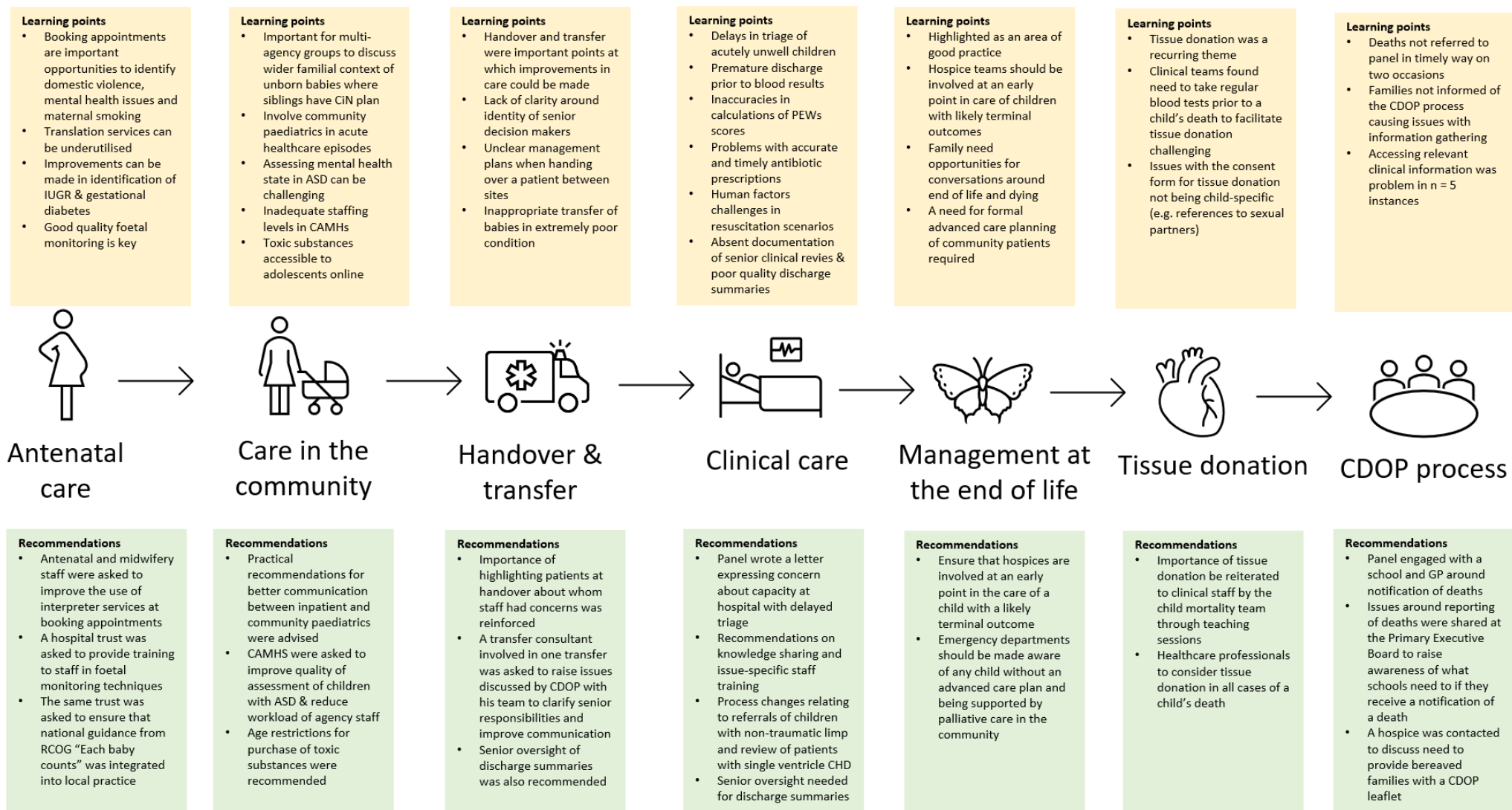
one instance a school to whom a death of a child whilst abroad was reported but not passed on to CDOP. Difficulties were also faced in accessing required information from frontline clinicians and hospital departments. Finally, an issue with families not being made aware of CDOP processes was addressed through engagement with a hospice and a reminder to distribute the NHS CDOP leaflet to bereaved families.

F.8. Conclusion

Over a three-year period CDOP made or supported 88 recommendations for healthcare service improvement based on 99 individual learning points. The breadth of these recommendations reflects the wide variety of services supporting children in the community. It is important to acknowledge that the CDOP process was significantly informed by the internal work of these organisations in quality checking and reviewing child mortality through root cause analysis and serious incident reviews. Future CDOP reviews may be enhanced by ensuring that healthcare professionals are aware of the need to report child deaths to CDOP and to provide information to help facilitate the learning process.

See overleaf for a summary infographic of CDOP learning points and recommendations during this period.

Figure 4: CDOP Learning points and Recommendations 2019-22 summary infographic



Appendix 1

Learning points and Recommendations in full (anonymised):

| Learning points | |
|--|--|
| Category | Learning point |
| Acute care | All children should have a PEWS score attributed to each set of observations |
| | All observations should be taken before PEWS score calculated |
| | Antibiotics should be given within an hour after prescription |
| | Blood cultures not taken prior to change in antibiotics |
| | Blood cultures should be taken prior to starting antibiotics |
| | Child discharged home before blood results were available to complete clinical assessment |
| | Delay in triage was a modifiable factor that led to death |
| | Deterioration of child might have been picked up earlier if had been admitted for further investigation of non-traumatic limp |
| | Difficulty accessing most appropriate healthcare for child prior to death |
| | Endotracheal tubes should be well secured to reduce chance of unplanned extubation |
| | Persistent tachycardia in infants should be recognised as an important sign of sepsis |
| | Single dose of amikacin required for cases with late onset sepsis particularly if have already received a recent course of antibiotics |
| | When recording blood pressure using an automated device observations consistently outside of normal limits should be re-measured using a manual sphygmomanometer |
| Clinical documentation | All face-to-face postnatal contacts and clinical care or advice given must be recorded in patient records |
| | Documentation by fetal medicine staff at re-booking required |
| | Not all senior discussions and clinical reviews clearly documented |
| | Nursing documentation completed by non-registered nurses must be countersigned by a registered nurse |
| | Poor quality of discharge summary |
| Upload letters for community paediatric patients to EDMS so that can be accessed by hospital paediatricians who do | |

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| | not know the patient |
| Clinical | Challenges in converting chronically unwell NG fed children to gastrostomy |
| | Challenges in converting unwell NG fed children to gastrostomy |
| | Collaboration between hospice and hospital led to good quality care |
| | Delay in swallow study was modifiable factor that may have contributed to death |
| | Difficulties faced accessing appropriate medications |
| | Medication being taken by case had not been monitored in accordance with NICE guidelines but did not feel this was contributory to death |
| | NIPE report should be completed in full and documented |
| | Opportunities to diagnose a rare cancer were missed |
| | Single ventricle CHD patients should also be on the Rapid access list organized by Attending A&E Consultant |
| | Single ventricle CHD patients should be reviewed by Paediatric Cardiac lead Clinician on a long-term basis as they may need rapid evaluation in the Emergency Department |
| Communication | Communication about deaths in other Trusts which are relevant to our area should be communicated more effectively |
| | Communication between clinical teams could have been improved |
| | Communication between clinical teams could have been improved |
| | Discharge letters should be copied to all acute providers involved in a child's management. |
| | Good communication between clinical teams |
| | Improved information sharing required from referring units |
| Community paediatrics | Mother spoke English as a second language and interpreter not used at every antenatal appointment |
| | Community paediatricians should be given regular updates when a paediatric patient who is well known to them is admitted to hospital |
| Community | Community paediatricians should be involved during acute admissions of community patients |
| | Good relationships between hospice and children's community nursing team were an important factor in ensuring good care |
| End of life | Benefits of early engagement with hospice highlighted |
| | Care of child towards end of life was "not as good" as professionals working with the family were reluctant to challenge |

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| | family |
| | Early involvement of hospice at home team would have given more conversations with family around end of life and dying |
| | Formal ACP discussion in the community could have improved clinical care |
| | Good communication about child's condition and treatment from hospice staff |
| | Parents kept updated on condition of child which allowed them to take appropriate decisions at end of her life |
| | Parents should be informed by clinical team as soon as a terminal outcome is recognised |
| | Support from hospice & hospice outreach nurses and community cancer nurse enabled case to stay at home for as long as she wanted |
| | Team that supported child towards end of her life worked well together and supported the family well |
| Handover & Transfer | Concerning or unwell patients should be highlighted and discussed at clinical handovers |
| | Issues with communication at points of transitions between teams, services or organisations |
| | Lack of clarity with handover between medical staff across two hospital sites regarding the differential diagnosis and subsequent plan for management of care |
| | Large numbers of people from different teams (prehospital & ED) can result in difficult and ineffective handovers |
| | No standard guidance exists for defining senior responsibility at each stage of infant transfer |
| | There should be clarity regarding the senior decision maker and responsible consultant at each stage of transfer of acutely unwell infant |
| | Transfer of babies in extremely poor condition is inappropriate |
| Human factors | All staff attending a resuscitation must be made aware the history of the patient and this should be clarified amongst the team |
| | Clinical team members should have confidence to challenge clinical decisions with specific reference to the management of babies born at threshold of viability |
| | Team members dealing with infant resuscitation should be aware of the correct pathway for infants at the threshold of viability |
| Mental health | Admission of mother of anxiety symptoms to hospital midwifery should have prompted a more informed and sympathetic response than is apparent from records |

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| | Agency workers given high caseloads to address wait time issue with consequence that staff member felt overwhelmed and post assessment administration was delayed |
| | Inadequate staffing levels in mental health trust potential factor in death |
| | There are unique challenges to assessing mood in children with ASD |
| Obstetrics | Guidance on fetal monitoring in the context of reduced fetal movements should be followed |
| | Carbon monoxide testing for mother not performed at booking despite NICE guidance |
| | Ensure placentas are sent for pathological examination including histology in line with national guidance |
| | Need to improve detection of IUGR and gestational diabetes |
| | No evidence that mother asked about domestic abuse at booking |
| | Rapid referral for women who have undergone LLETZ to assess need for cervical lengthening monitoring/cervical suture consideration |
| | Regional neonatal delivery network to review ECMO guidelines to include early referral for babies with severe myocardial dysfunction in addition to other recognised indication for neonatal ECMO |
| | Staff should be supported in understanding principles of intermittent auscultation and in providing a system where all fetal heart rates are recognised to enable an early escalation |
| | The guidance from RCOG "Each Baby Counts" report should be implemented into local guidance with regards recognition of the transition between first and second stage of labour and auscultation of the baby's heart rate |
| Where possible labouring women presenting <27 weeks gestation should be transferred to a tertiary unit for ongoing care | |
| Primary care | Family removed from their local GP practice and relocated to another from which GP was unable to do home visits |
| Process | As family not aware of CDOP processes GP unwilling to provide information without family's knowledge of information |
| | Difficulty in accessing information required for panel review from clinician |
| | Difficulty in accessing information required for panel review from hospital |
| | Family were not given leaflet explaining CDOP process |
| | Identify more efficient ways of contacting GP following patient deaths in order to invite them to key meetings - Oxford have a fast-track system for this purpose |
| | Inclusion of primary immunodeficiency on the DC was speculative |

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| | Issue raised that there was not sufficient information to determine if death was potentially preventable as it occurred abroad. |
| | Issue with reporting death to CDOP |
| | It is important that all teams involved in a child's care are informed when a child dies |
| | Lack of understanding from school and GP about CDOP processes and so death not referred to panel |
| | PICU and hospice documentation not received in a timely way by CDOP |
| Public Health | Panel discussed that some countries routinely vaccinate 2-year-olds against chicken pox |
| Smoking cessation | No stop smoking service available for family members of pregnant woman who smoke Please note: Smoking cessation support has since been extended to the family members of pregnant smokers |
| Smoking | Known issue with smoking in the home but not seen as a modifiable death |
| | Smoking cessation help for pregnant women needed Please note: Smoking cessation offer should be made to all eligible pregnant women (and documented) |
| | Smoking in family home was a potentially modifiable factor but child did not die of smoking related condition (e.g. chest infection) |
| | Smoking in the household was a modifiable factor |
| Social care | Child and family assessments should include relevant historical information and contributions from partner agencies & children & parents & carers to inform understanding of and response to safeguarding concerns. |
| | Clear support plan needed for parents with learning and social needs |
| | Insufficient curiosity of healthcare workers about the wider familial context into which the child was to be living |
| | Safeguarding used as a method of improving care in last weeks of life |
| | When siblings of an unborn baby are subject to a child in need plan it is important that there is an opportunity within the multi-agency CiN meetings to (i) discuss the impact of a new baby on the family circumstances (ii) include the UBB on the plan with specific reference to risks and vulnerabilities (iii) ensure there is a multi-agency agreement prior to closure of the plan |
| Tissue donation | Family had expressed wish for organ donation following her death but logistical issues (consent in advance & need for blood tests at intervals) |
| | Professionals should consider tissue donation in all cases of a child's death |

| Recommendations | |
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| Category | Recommendation |
| Acute care | Presentation made to radiology team on bone lesions following missed diagnosis of malignancy |
| | Team members dealing with infant resuscitation should be aware of the correct pathway for infants at the threshold of viability |
| Clinical documentation | Accurate and contemporaneous documentation of clinical decisions required |
| | Discharge letters should be copied to all acute providers involved in a child's management. |
| | Senior oversight and review of discharge summaries recommended |
| Clinical | Hypothermia focus board set up |
| | Letter written by panel highlighting concerns about capacity at hospital XXX |
| | Medical support worker recruited and trained |
| | Risk assessment processes need to be improved at local healthcare trust |
| | Single ventricle CHD patients should also be on the Rapid access list organized by Attending A&E Consultant |
| | Single ventricle CHD patients should be reviewed by Paediatric Cardiac lead Clinician on a long-term basis as they may need rapid evaluation in the Emergency Department |
| | Specific clinical learning points highlighted |
| | Specific learning point reminders shared in the governance newsletter |
| Standard SOP for gestational diabetes clinical required | |
| Communication | Communication about deaths in other Trusts which are relevant to us should be communicated more effectively |
| | Family followed up by clinical team |
| | Improve sharing of information for referring units |
| | Risk assessments should be shared with other agencies coming into contact with risk individuals |
| Community paediatrics | Community paediatricians should be involved during acute admissions of community patients |
| | Contact details to be shared between inpatient care and children's community paediatricians |
| | Community paediatricians should be given regular updates when a paediatric patient who is well known to them is admitted to hospital |

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| | Details of generic email for community paediatric patients to be added to inpatient handover list so community paediatrics can be informed when a paediatric patient well known to the community is admitted |
| | Upload letters for community paediatric patients to EDMS so that can be accessed by hospital paediatricians who do not know the patient |
| Education | Information sent out to schools via schools bulletin to support schools and parents in spotting signs of sepsis |
| | VCSEs (Papyrus & Samaritans) made aware of suicide of young person in school |
| | Following suicide of a child with ASD psychologists visited school to provide support for staff and students |
| End of life | Arrangement for bereavement counselling in place |
| | Emergency department to be made aware of any child without an advanced care plan and on palliative care in the community |
| | Introduce families to hospice care early if end of life care expected |
| | Involve hospice at earlier stage |
| | Raise profile of hospice |
| | Sibling to be provided with support through hospice |
| | Support from hospice outreach nurses and community cancer nurse enabled case to stay at home for as long as she wanted |
| | Work has been undertaken with hospice to ensure that the CDOP process is explained to parents, and they are given the NHS leaflet |
| Handover and Transfer | Transfer consultant discussed with team about clarifying senior responsibilities |
| Human factors | All staff attending a resuscitation must have the history of the patient and this should be clarified amongst the team |
| | Ensure that members of the clinical team have confidence to challenge clinical decisions with specific reference to the management of babies born at threshold of viability |
| Mental health | An operational lead and 2 service managers now in post and fully briefed |
| | CAMHS referral acceptance threshold lowered for young people affected by suicide in school community |
| | CAMHS service managers/head of service have met to discuss initial learning and engaged with operation leads to review current systems and processes |

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| | Number of assessments expected from agency workers reduced to ensure quality of assessments |
| | Parents & child to each be given opportunity to see assessing clinician alone |
| | Suicide prevention work |
| | The Head of CAMHS psychological therapies has redistributed documentation to managers re key areas that need to be covered in assessments |
| | Update training to ensure specific training in mental health assessments of those with ASD |
| Obstetrics | Trust to provide guidance on foetal monitoring in the context of reduced foetal movements should be followed |
| | Encourage antenatal & midwifery staff to improve the use of interpreter where required |
| | Ensure placentas are sent for pathological examination including histology in line with national guidance |
| | Ongoing work with community midwives to ensure routine questions asked about domestic violence at booking |
| | Regional neonatal delivery network to review ECMO guidelines to include early referral for babies with severe myocardial dysfunction in addition to other recognised indication for neonatal ECMO |
| | The trust to ensure guidance from RCOG "Each Baby Counts" report should be implemented into local guidance with regards recognition of the transition between first and second stage of labour and auscultation of the baby's heart rate |
| | Trust to support staff in understanding principles of intermittent auscultation and in providing a system where all fetal heart rates are recognised to enable an early escalation |
| Primary care | CCG bulletin has been used to advise/remind GPs that all children presenting with a limp and all children over the age of 10 need to be referred to XXX hospital and not XXX hospital |
| | GPs to be reminded that they should check that patients are being appropriately monitored (for what?) |
| Process | The XXXX to share the audit findings regarding the progress of implementing the actions identified by their internal investigation with the appropriate Safeguarding Children Partnership |
| | All partner agencies to be reminded about the decision-making process prior to closure of a CiN or CP plan |
| | Chase up post-mortem report and go through it with family |
| | Clear documentation required to ensure appropriate practitioners have oversight of care pathway |
| | Findings to be shared at the Buckinghamshire and Oxfordshire Clinical Leadership meeting for shared learning across the service and at the 3 respective operational and clinical governance meeting in the 3 CAMHS areas across Oxford Health. |

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| | Foetal medicine letters now uploaded to patient's files |
| | Learning points around notification of death discussed with GP and relevant schools |
| | Letter to be written to health providers to ensure where relevant babies are referred to local coroner |
| | Neighbouring area reviewed reporting procedures to improve them |
| | Panel asked that XXX contact the chair of the XXX CDOP to express concern about lack of adherence to guidance |
| | Require a robust and auditable trail for ultrasound referrals that is not dependent on patient's following up appointments |
| | Require improved communication between staff teams within same trust to ensure all teams involved in a child's care are informed when a child dies |
| | SI had addressed all the issues and case could be closed |
| | The Partnership to consider the use and effectiveness of existing tools to support professionals in the wider children's workforce to understand the impact of neglect on the lived experience of children. |
| | The local partnership to seek assurance that learning from this review is addressed in the new practice standards regarding unborn babies |
| | The local Partnership Independent Chair to write to the Independent Chair of the XXXX Safeguarding Children Partnership to ensure that lessons learnt in this review are shared |
| Public health | Continue to offer smoking cessation help to pregnant women |
| | Panel agreed to ask the CDOP network to see if any similar deaths (?chicken pox related) |
| Reflection | A practitioners' event was held to discuss the care this child received given her complex needs and copies of report from this event shared with panel |
| Regulatory | Age restrictions for the purchase of toxic substances online |
| Social | Child in need plan required |
| | Clear support plan needed for parents with learning and social needs |
| | XXX to work with neighbouring XXX housing authorities to develop a common cross-border understanding regarding the placement of vulnerable families in temporary accommodation |
| Tissue donation | Family had expressed wish for organ donation following her death but logistical issues (consent in advance & need for blood tests at intervals) |

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| | Importance of the consideration of tissue donation to be reiterated |
| | Importance of tissue donation to be reinforced through teaching sessions |
| | Same consent form for organ donation is used for everyone irrespective of age and it was felt that a more child specific form would be more appropriate without questions about sexual partners |
| Training | Copy of RCA report shared with x-ray reporter following missed malignancy |
| | Induction processes improved and monitored by operational leads |
| | Opportunity for newly recruited staff to shadow experienced clinicians when undertaking assessment is now in place |
| | Local Healthcare Trust to roll out the planned Unconscious Bias and Professional Curiosity training |
| | Local Healthcare Trust to strengthen the provision of supervision for health visitors to ensure that good quality regular supervision is offered |