



BUCKINGHAMSHIRE CHILD DEATH OVERVIEW PANEL (CDOP)

13th ANNUAL REPORT

01/04/2022 – 31/03/2023

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Introduction and background:

This report is the 13th annual report by Buckinghamshire Child Death Overview Panel (CDOP) and focuses on the work of the panel between April 2022 and March 2023 inclusive. The previous report covered a 3-year period during which CDOP activity was disrupted by the COVID-19 pandemic, and this report is intended to serve as a return to the usual practice of annual reports. The 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 any preventable factors that may have been implicated in the death of a child. 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.*

Recommendations and learning points generated by member organisations are collated and disseminated by the CDOP panel, and the responsibility to enact these service improvements rests with those member organisations.

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 those babies that are stillborn, late foetal loss without signs of life or 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 (National Health Service) 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.

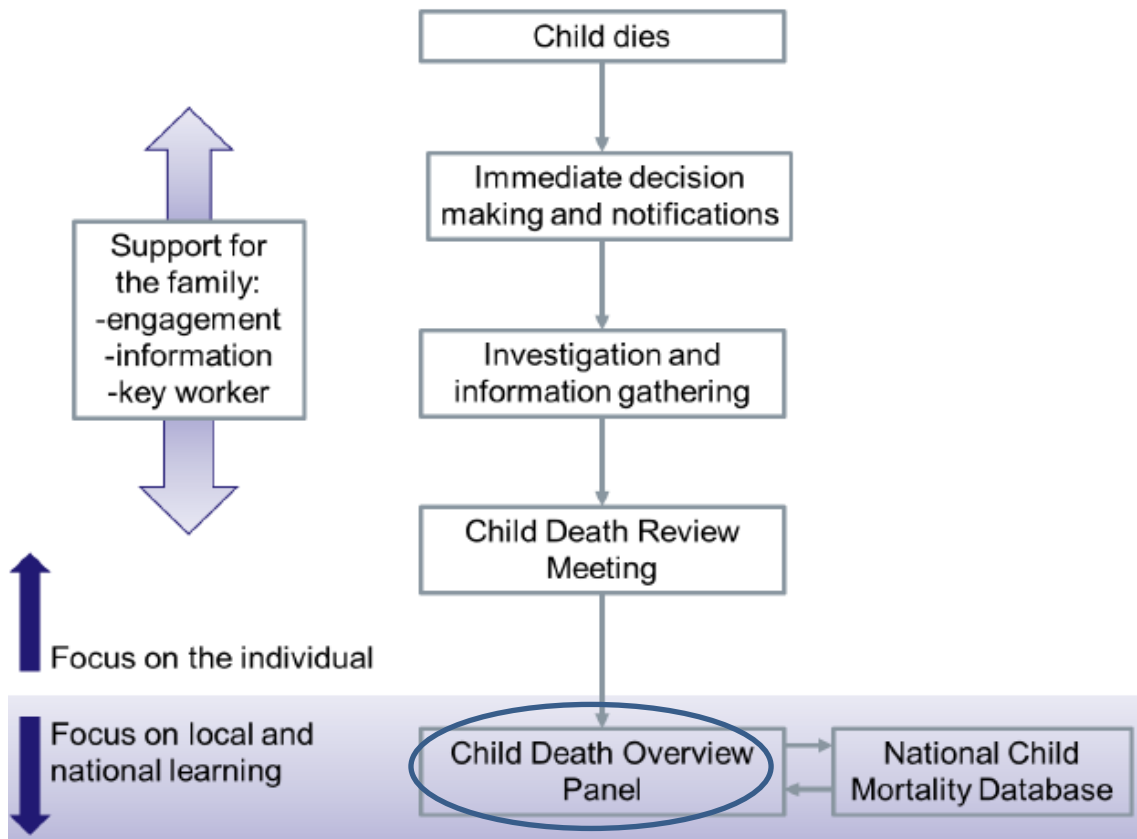
- Reviewing at least 60 deaths each year will better enable thematic learning in order to identify potential safeguarding or local health issues that could be modified in order to protect children from harm and, ultimately, save lives.

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 remain similar to or better than the England average; however, as elsewhere, there are large disparities between the most and least deprived populations in the county.
- In 2022/23 the panel reviewed and closed 61 cases in total. 80% of reviewed cases were of children who died between 2021 and 2023.
- Two thirds of cases were reviewed within a year of death. This is similar to the time taken to review cases presented in the last report (2019 – 2022).
- Of the 61 cases reviewed and closed during the 2022/23 year, 52% were under one year old. Of the remainder approximately 30% were aged between 1-9 years, and 18% 10-17 years. Children aged 1 or older represented a smaller proportion of CDOP cases during this period than in the 2019-22 period.
- 31/61 cases reviewed during this period (51%) were male. Nationally, boys' deaths have consistently accounted for over half of deaths reviewed since the year ending 31 March 2011.
- The proportion of cases where ethnicity was recorded as Asian/Asian British (34%) was higher than both the known representation of Asian/Asian British individuals within the Buckinghamshire population (12.4%) and the average Asian/Asian British proportion of national CDOP cases for 2022-23 (approximately 20%).
- Compared to children of white ethnicity, children of Asian, Black and Mixed ethnicity in this sample had significantly higher odds of death. This ranged from three and half times the odds of death in Asian or Asian British children (OR 3.6, 95% CI 2.0 to 6.5) to five times the odds of death in Black or Black British children (OR 5.2, 95% CI 2.0 to 13.6).
- Chromosomal, genetic or congenital anomaly deaths were the leading category of death in Buckinghamshire (21 cases or 34%), followed by perinatal/neonatal deaths (20 cases or 33%) and malignancy (9 cases or 15%).
- 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, clinical handovers/transfers, in-patient and end-of-life care.

C. BACKGROUND

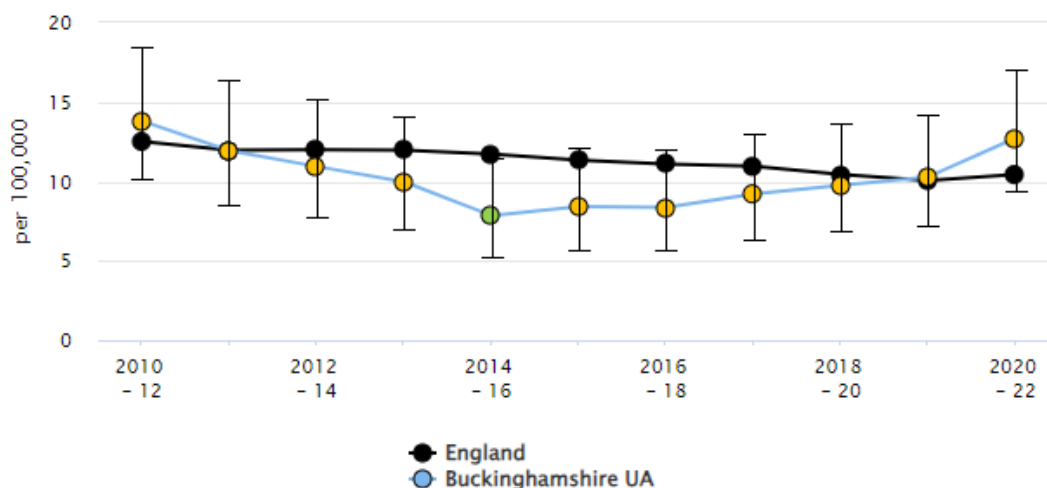
Overall, health and wellbeing indicators for children in Buckinghamshire are better than the England averages. One exception is the latest child mortality rate (1-17 years), which for 2020-22 was 12.7 deaths per 100,000 population, compared to the national rate of 10.4. Although the difference is not statistically significant, the Buckinghamshire rate shows a slight upwards trend which must be carefully monitored (see below).

Child mortality rate (1-17 years) New data

[Hide confidence intervals](#)

[Show 99.8% CI values](#)

Figure 1



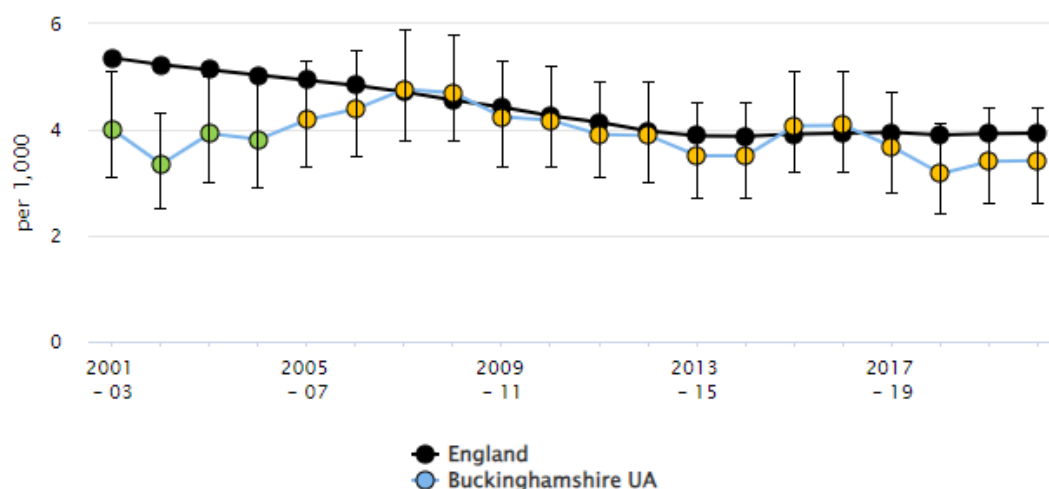
<https://fingertips.phe.org.uk/profile/child-health-profiles/data#page/4/gid/1938133228/pat/6/par/E12000008/ati/402/are/E06000060/iid/90801/age/177/sex/4/cat/-1/ctp/-1/yrr/3/cid/4/tbm/1/page-options/car-do-0>

The infant mortality rate (<1 year) in 2020-22 was 3.4 deaths per 1000 births, similar to 3.3 for the South East and lower than 3.9 for England as a whole (see overleaf).

Infant mortality rate New data

[Hide confidence intervals](#) [Show 99.8% CI values](#)

Figure 2



<https://fingertips.phe.org.uk/profile/child-health-profiles/data#page/4/gid/1938133228/pat/6/par/E12000008/ati/402/are/E06000060/iid/92196/age/2/sex/4/cat/-1/ctp/-1/yr/3/cid/4/tbm/1/page-options/car-do-0>

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 2022-23

D.1. CDOP Membership

The Child Death Overview Panel is drawn from the key organisations represented on the Local Safeguarding Children Partnership (LSCP).

Core members of CDOP in 2022-23 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 for Child Deaths, Bucks Healthcare NHS Trust
- A Midwife, Bucks Healthcare NHS Trust
- An education representative
- A representative from Buckinghamshire Children's Social Care
- A representative from Thames Valley Police Child Abuse Investigation Unit
- A representative from Buckinghamshire Coroner's Office

- CDOP Coordinator, Buckinghamshire Safeguarding Children's Partnership
- Named GP safeguarding children BOB ICB

Where illness or other commitments prevent the designated representative of a particular member organisation to attend, a deputy is requested to attend in their place. When there has been no representation from a member organisation for more than one meeting the matter is escalated within that organisation by the CDOP chair.

D.2. Number of child death cases reviewed and closed 2022-23

Between 1st April 2022 and 31st March 2023, CDOP reviewed and closed the cases of 61 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 as delays for coroners' investigations may mean that sufficient information to fully review a child's death will not be available to the panel for many months. Other statutory processes e.g. HSIB or LSCPR's may also impact the timeliness of a CDOP review. 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

61 cases were reviewed and closed by the CDOP panel between 1st April 2022 and 31st March 2023. See Table 1 below:

Table 1

Year of death	2022/2023 CDOP
2018/2019	1
2020/2021	11
2021/2022	28
2022/2023	21
Grand Total	61

During this period, the number of days that elapsed between death and CDOP review varied significantly. Two thirds of cases were reviewed within a year of death, with the remaining third over 12 months. This is similar to the time taken to review cases presented in the last report (2019 - 2022).

Table 2

Number of months between death and CDOP review	Cases	% of total
< 6 months	18	30%

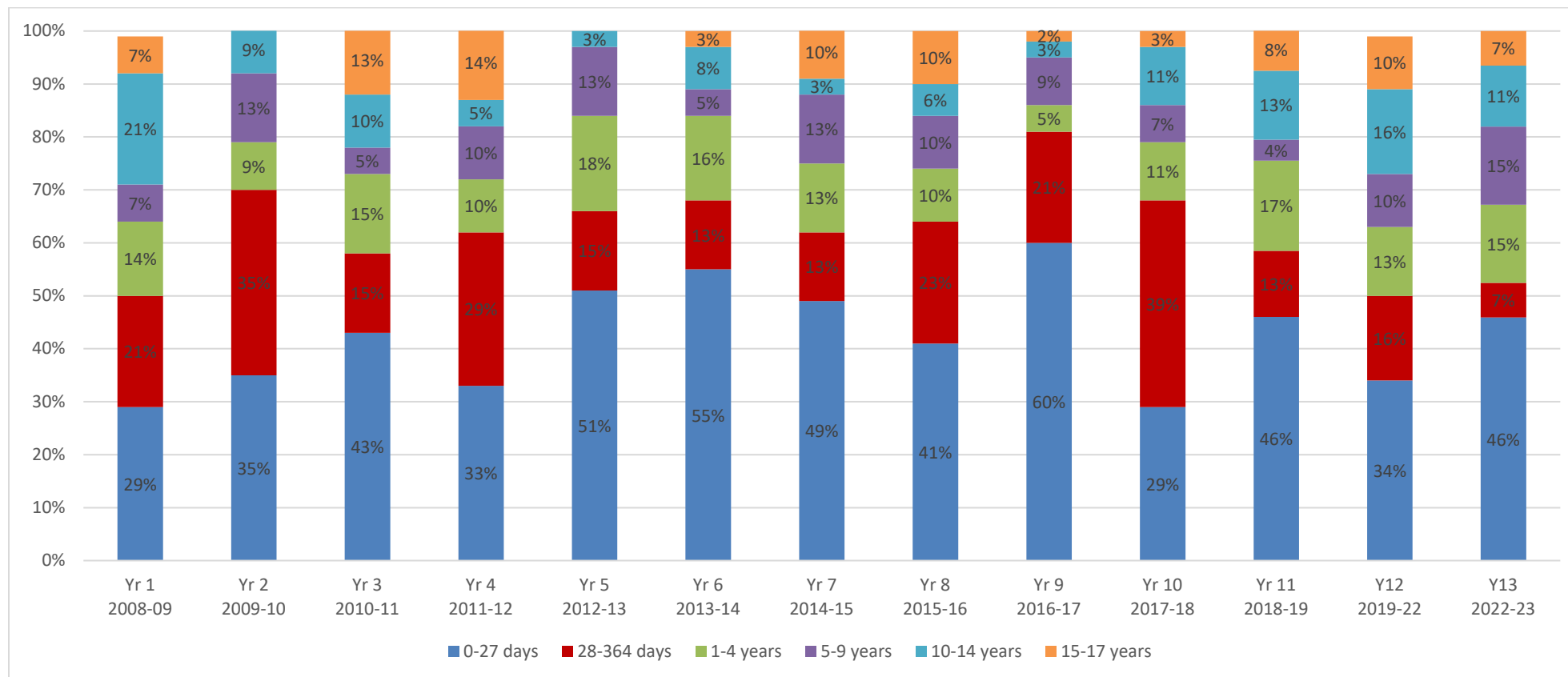
6 – 12 months	21	34%
>12 months	22	36%

E. ANALYSIS OF CHILD DEATH REVIEWS & FINDINGS

E.1. Number of deaths reviewed by age group

Of the 61 cases reviewed and closed during the 2022/23 financial years, 52% were under one year old. Of the remainder, approximately 30% were aged between 1-9 years, and 18% 10-17 years. Children aged 1 or older represented a smaller proportion of CDOP cases during this period than in the 2019-22 period.

Figure 3 shows the trends in age of CDOP cases since 2008/09



E.2. Number of deaths reviewed by gender:

31 of the cases reviewed during this period (51%) were male and 30 (49%) 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 available for all cases. The full breakdown is given in Table 3 below:

Ethnicity	Count	% of deaths	% of population <18 (Census 2021)
White	24	39%	70%
White - British	21	34%	
White - Any other White background	2	3%	
White - Gypsy or Irish traveller	1	2%	
Asian or Asian British	21	34%	17%
Asian or Asian British - Pakistani	14	23%	
Asian or Asian British - Indian	4	7%	
Asian or Asian British - Any other Asian background	3	5%	
Mixed	10	16%	7%
Mixed - White and Asian	6	10%	
Mixed - White and Black Caribbean	2	3%	
Mixed - Any other mixed background	2	3%	
Black or Black British	5	8%	3%
Black or Black British - African Caribbean	3	5%	
Black or Black British - Any other Black background	1	2%	
Other ethnic group - Any other ethnic group	1	2%	2%
Total	61	100%	

The 2021 Census¹ recorded that 79.9% of the population of Buckinghamshire gave their ethnicity as "White", with "Asian/Asian British" accounting for 12.4% and "Black/African/Caribbean/Black British" 2.6%. Despite children of Asian or Asian British ethnicity accounting for only 17% of the child population of Buckinghamshire², they represented 34% of child deaths.

Compared to the white population aged under 18, children from all large ethnic minority groups had significantly higher odds of death. This ranged from three and a half times the odds of death in Asian or Asian British children (OR 3.6, 95% CI 2.0 to 6.5) to five times the odds of death in Black or Black British children (OR 5.2, 95% CI 2.0 to 13.6). Children from Pakistani backgrounds had five

¹ [Ethnicity in Buckinghamshire - Bucks Data Exchange](#)

² Based on Census 2021

times the odds of death compared to white children (OR 5.0, 95% CI 2.6 to 9.6). By contrast, the odds of death in children from Indian backgrounds was not significantly higher than the odds of death in white children (OR 2.1, 95% CI 0.7 to 6.1). Children from Asian backgrounds accounted for 20% of deaths nationally 2022-23.

Although the CDOP panel cannot definitively account for these ethnicity-linked disparities in child mortality risk, there are a number of factors identified which are likely to play a role. [Deprivation](#) is known to be a significant risk factor for increased child mortality, and [national data](#) shows that the percentage of people from a Pakistani background living in low income households is more than double the national average (approximately the same for people of Black or Black British heritage), whereas the percentage for people from an Indian background is in line with the national average.

Some British-Asian communities also have a higher-than-average risk of life-limiting genetic/chromosomal disorders associated with consanguinity (cousin marriage), which tragically increases their representation in child death statistics. Many ethnic and/or cultural minority groups also have stronger prohibitions against medical terminations than is the national cultural norm. This increases their likelihood of being over-represented in child death statistics compared to other families when life-limiting disorders of any aetiology are diagnosed in utero (because terminated pregnancies are not included in the CDOP dataset).

E.4. Category of deaths as determined by CDOP 2022-23

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 chromosomal, genetic or congenital anomaly deaths was the leading category of death in Buckinghamshire (21 cases, 34%), followed by perinatal/neonatal deaths³ (20 cases, 33%) and malignancy (9 cases, 15% each). Table 4 below shows the category of deaths as determined by CDOP reviews.

³ 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

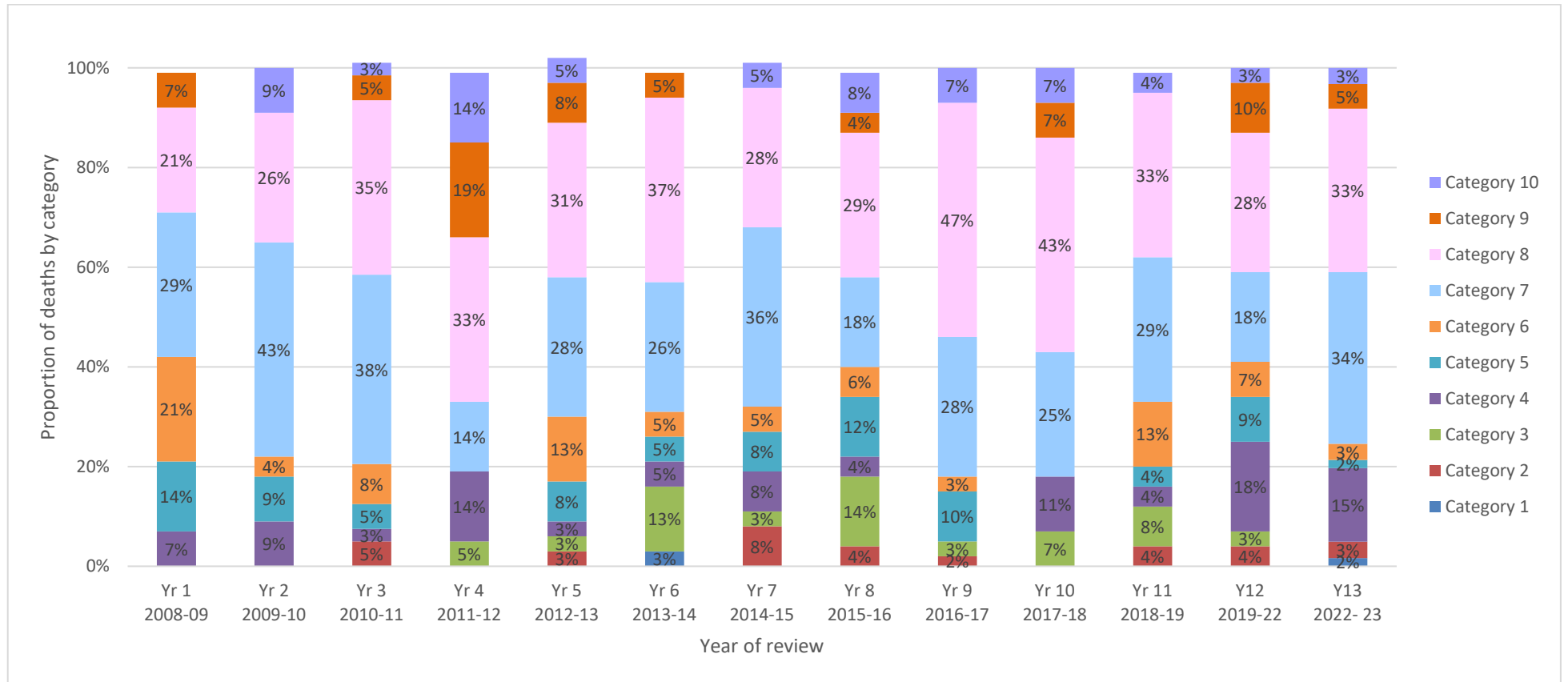
Table 4: Category of deaths as determined by CDOP 2022-23

Category of death	Total	National Benchmarking (2021)
Category 1: Deliberately inflicted injury, abuse or neglect	2% (1)	1%
Category 2: Suicide or deliberate self-inflicted harm	3% (2)	5%
Category 3: Trauma and other external factors	0% (0)	5%
Category 4: Malignancy	15% (9)	9%
Category 5: Acute medical or surgical condition	2% (1)	6%
Category 6: Chronic medical condition	3% (2)	5%
Category 7: Chromosomal, genetic and congenital anomalies	34% (21)	22%
Category 8: Perinatal/neonatal event	33% (20)	37%
Category 9: Infection	5% (3)	3%
Category 10: Sudden unexpected, unexplained death	3% (2)	7%
Total	61	2,735

Figure 4 overleaf shows the trend in category of deaths as determined by CDOP between 2008 and 2023.

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”.

Figure 4: Trend in category of deaths as determined by CDOP 2008-23⁴



<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>
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⁴ The totals in this chart do not always add up precisely to 100% due to some cases where more than one category of death was identified.

E.5. Place of death

The most common places of death for CDOP cases during this period were the neonatal intensive care unit (NICU, 28%), followed by the labour ward/delivery suite (16%) and home (15%).

Place of death	Number of cases	% of total
Abroad	2	3%
Home	9	15%
Hospice	5	8%
Hospital - AICU	1	2%
Hospital - ED	1	2%
Hospital - Hospital ward	6	10%
Hospital - Labour ward/delivery suite	10	16%
Hospital - Midwifery unit	1	2%
Hospital – NICU	17	28%
Hospital - PICU	6	10%
Hospital - Theatre	2	3%
Not known	1	2%

E.6. Modifiable and Contributory Factors

Possibly modifiable factors were identified in 9 cases (15%), compared to 39% of cases in England. Modifiable causes of death included smoking during pregnancy, maternal obesity, child not vaccinated and consanguinity.

E.7. Bereavement support

Although CDOP also reviews records on the after-care of bereaved families, the qualitative and subjective nature of bereavement support means that the majority of learning points that the panel has historically generated relating to it tend to focus on the more objective aspects of the process (such as tissue donation and the availability of hospital and hospice mortuary viewing rooms). The emotional and psychological support that frontline staff provide to grieving families is vitally important, and where the panel finds evidence of inadequate practice (or outstandingly good practice) in this area then we will feed this back via the relevant member organisation.

F. LEARNING POINTS AND RECOMMENDATIONS

Learning points and recommendations for health system improvement following CDOP review 01/04/2022 to 31/03/2023 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 therefore may not have changed the eventual outcome, but if amended still could have represented objective 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 as missed opportunities to collect information on maternal smoking, smoking in the wider family and domestic violence in the home. Where smoking was identified, either in the mother or wider family, there were cases where the relevant individuals were not appropriately offered referral to stop smoking services. A case was also highlighted where carbon monoxide screening was not completed. These points are similar to those raised in the last iteration of this report. These issues were planned to be addressed through discussions of NICE guidance around carbon monoxide testing with all staff by community matrons, and reminders to staff to document attempts to offer smoking cessation and to why the offer not taken up. In addition, new equipment for CO testing has been purchased in one area to increase staff compliance with processes.

Other issues were highlighted around the recognition and preparation for high-risk births. A recommendation was made that all women who are less than 27 weeks pregnant and report symptoms of possible labour should be examined by the members of the obstetric team with appropriate expertise. Another recommendation was identified around the need to involve the paediatric team at an early stage of pregnancy in women who are likely to deliver at less than 23 weeks' gestation. This learning was also planned to be addressed through case discussion at perinatal mortality and morbidity meetings and through relevant ward meetings.

Other practical learning points around obstetric management included in instances where C-section has been performed because of concerns around significant blood loss, requiring blood products to be ready and available for early transfusion. It was also identified in one case that if appropriate counselling had taken place pre-birth that active management might have more-appropriately not been offered for the child following the birth.

F.2. Care in the community

It was highlighted that social care assessments need to ensure that the views of all relevant caregivers are noted. In one case it was apparent that a father with a significant role in the care of the deceased child did not have his views sufficiently acknowledged. This was recommended to be addressed through

audit of work regarding fathers, and communications to be circulated highlighting the importance of engagement with this group.

In the case of a young person who died by suicide, it was identified that communication links with private therapists could have been improved. Communication between safeguarding teams and council social care teams was also noted to require improvement.

A recommendation around community paediatrics included a need to review processes around “Do Not Attempt Resuscitation” (DNAR) orders, and to ensure better communication between community paediatrics and education in cases where children not reviewed in scheduled clinics. There were also points noted around the difficulty experienced in communication between inpatient and community care when acute care is in one trust and community care is in another.

F.3. Handover & transfers

Several learning points under this theme were noted by CDOP. There were specific issues highlighted in a case where a baby with cardiac issues was discharged from a specialist tertiary centre back to the referring hospital via a third tertiary centre. This meant that normal information sharing around the management of a complex cardiac patient was not discussed with the referring hospital Paediatrician with Expertise in Cardiology by the specialist centre, and information was lost as a result. Whilst this discussion did not impact the outcome, this knowledge would have helped ensure staff at the receiving hospital were prepared for the higher likelihood of a poor outcome. This has been addressed through highlighting high-risk patients in daily safety huddles on ward round.

Human factor issues were also noted at the point of transfer. In one case, there were potential improvements identified in the handover of leadership on arrival of a Specialist Operations Response Team during the care of a critically ill child. It was noted that there were unclear processes for handover between rapid response assessment units and CAMHs, which needed to be reviewed to ensure clear processes were in place in both organisations.

A learning point was identified around repeated history-taking when children are transferred between different sites (hospice/hospital ward), and it was identified that this should be minimised to avoid distress and disruption for the family.

F.4. Inpatient care

Many learning points and recommendations were identified around inpatient clinical management to be addressed by secondary care. A key recommendation was made around the need to ensure that, where difficulties with peripheral IV access had been identified, alternative methods of access should be used at an earlier stage. In addition, it was noted that patients with

known difficulties with IV access in the community should have this noted on their symptom care plan.

Challenges were also experienced in one case during the removal of an umbilical arterial catheter (UAC). It was noted that there was potentially low awareness amongst staff of the risks associated with UAC removal and how to address associated blood loss. This resulted in a recommendation to increase staff awareness of the potential risks regarding removal of UACs and update guidelines and to produce a patient information leaflet on the topic. Similarly, there was learning identified around management of pneumothorax, with staff in one hospital reminded that needle thoracocentesis is a temporary emergency measure only, and that definitive management involves a chest drain. It was also recognised in one case that patient-specific factors such as lung compliance may result in different radiological presentations of pneumothorax.

Learning was also identified around ventilation. Recommendations were made on the prevention of accidental extubation through an internal quality improvement project at one trust. Additionally, it was highlighted that professionals responsible for initiating treatments such as non-invasive ventilation (NIV) should consider discussions at the outset around the reasons and parameters for stopping.

As in previous reviews there were learning points around appropriate prescribing. A learning point was identified that changing antibiotics in early onset sepsis to Cefotaxime and Amoxicillin may be appropriate for managing meningitis but does not provide good enough cover for other potential causes of early onset sepsis and that other antibiotics should be considered. Linked to antibiotic prescribing, there was a reminder made in one trust around the importance of taking blood cultures when changing antibiotics, and to ensure that new antibiotics are administered within one hour of the decision.

Whole-exome sequencing (WES) was noted in two cases as a potentially valuable clinical tool. One case mentioned that WES should be considered in cases with severe pneumothoraces to identify any possibly underlying lung pathology. In another, it was noted that parallel planning should be made for other investigations while waiting for the result of WES in case the process does not give a diagnosis.

A recommendation was made to re-discuss previously refused interventions with family when there is a change in their situation. Concerns were raised that children in the 16–18-year age bracket were occasionally being managed in adult services, despite being legally children. Finally, a recommendation was made to raise awareness around the use of the mobile extra-corporeal membrane oxygenation service for the retrieval of extremely sick children.

F.5. End of life

The planning for and recognition/understanding of end-of-life care was a particular area requiring improvement. Learning points included ensuring better communication between specialty and local teams when end of life planning, ensuring that DNARs were in place and that recognition of the dying child was made by acute teams. A recommendation was made to ensure that the cultural and spiritual wishes of parents were considered even if parents are not religious.

Access to hospices and appropriate place of death was identified in several cases as an issue. Process issues included delays in paperwork processing to allow release of a child to the hospice, and structural problems included the lack of bed availability at hospices. It was also highlighted that clinical teams should consider contacting hospices for advice on issues related to palliative care.

Pain and other symptom management at the end of life was identified as an issue in several cases. Specific learning needs were identified around anticipating needs for palliative medications such as diamorphine, as well as reviewing policies around IV morphine requiring administration by doctors. It was also noted that professionals responsible for putting together Advanced Care Plans should provide starting doses for syringe drivers as a guide for acute deterioration. Input from hospice teams into the palliative care of patients was recognised as being of value in two cases, with a suggestion in one case that Microsoft Teams could be used to facilitate joint reviews. There was also a suggestion highlighted that trainees must feel free to escalate end of life care concerns to the consultant body.

Finally, a range of recommendations were made around bereavement care. A key issue was identified with ensuring that staff were familiar with the use of cooling blankets, and that awareness was raised about the availability of cold cots. A recommendation was made around ensuring nurse verifiers were identified to prevent delays in the verification of death. Another point was identified that local teams and tertiary teams should communicate promptly after a child dies.

F.6. Tissue donation

There were few points raised around tissue donation. One case identified the need for note taking around tissue and organ donation discussions with parents. An action was identified to ensure that this was reviewed and incorporated into further teaching.

F.7. CDOP processes

CDOP process issues were highlighted related to ensuring that the appropriate professionals who were involved in the care of a child were invited to child death review meetings with sufficient notice. In addition, it was highlighted in one case that a clear key worker needed to be identified to avoid many separate contacts with families so as not to overwhelm parents. "Closing the loop"

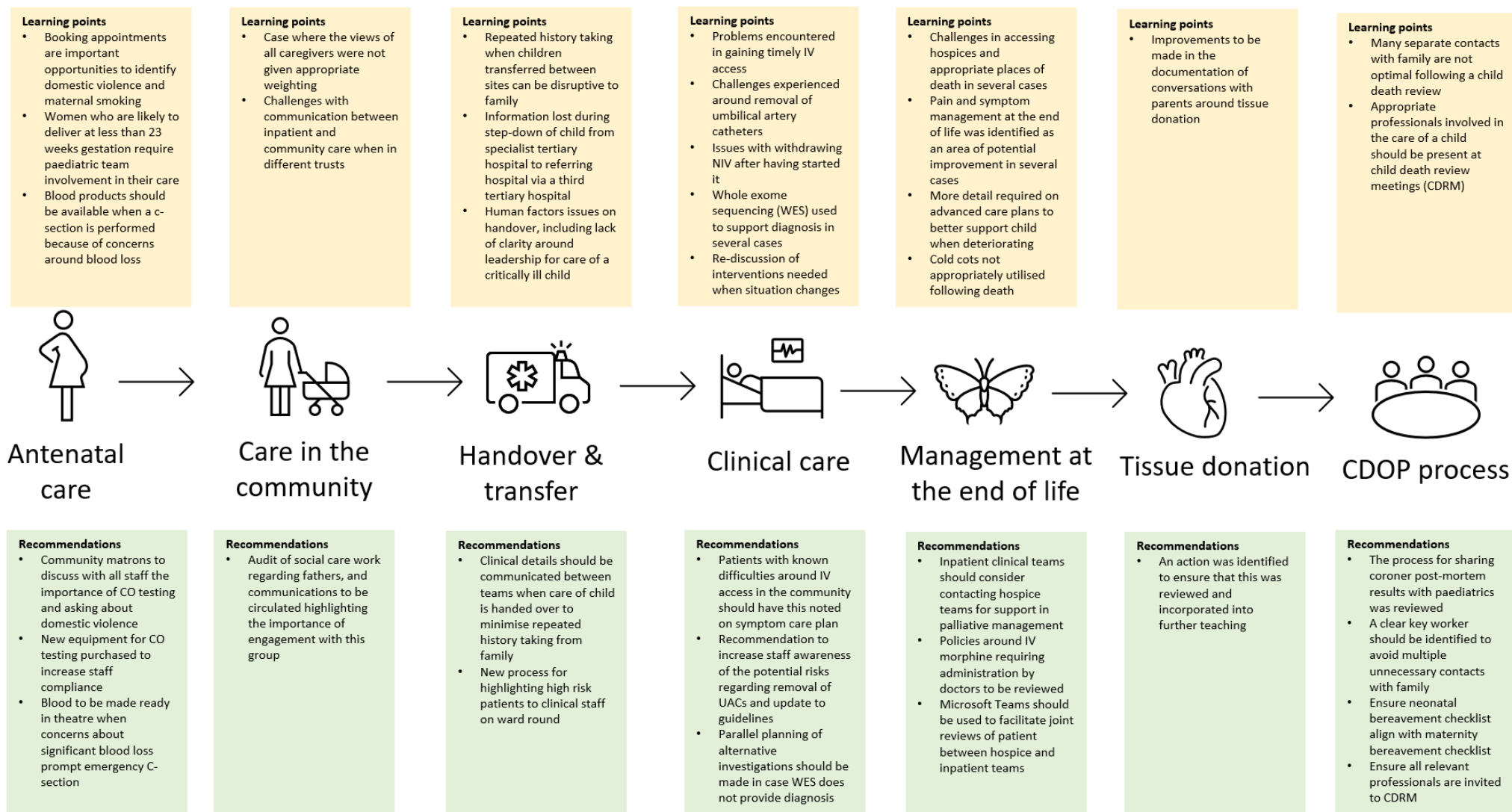
recommendations included ensuring that the process for sharing coroner post-mortem results with paediatrics was reviewed. It was also identified that a review was needed of policy on where children were brought to within the trust when death was declared prior to arrival at hospital.

F.8. Conclusion

During this period CDOP made or supported 75 recommendations for healthcare service improvement based on 77 individual learning points. The breadth of these recommendations reflects the wide variety of services supporting children in hospitals and 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 flag 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 5: CDOP Learning points and Recommendations 2022-23



Appendix 1

Learning points and Recommendations in full (anonymised):

Learning points	
Category	Learning point
Antenatal care (Smoking)	Important to offer smoking cessation services to the wider household of women attending antenatal appointments.
Antenatal care (Midwifery, Obstetrics and Paediatrics)	Cord gases should have been taken at delivery.
	Blood products should be prepared and ready for administration quickly after the recognition of the need for emergency c-section due to suspected blood loss.
	Midwives are crucial to bridging the support offer between community and hospital settings.
	Pregnant women must have access to accurate information to enable informed choice.
	Senior Obstetric involvement with the neonatal team is needed to address care that will be provided if labour and birth were to occur at gestations less than 23 weeks' gestation and tertiary centre referral is planned.
	Plans of care need to clearly identify actions to be taken both for the mother and baby if birth were to occur at less than 23 weeks' gestation whilst mother an inpatient in hospital (where this outcome is anticipated as a possibility).
	All women who are less than 27 weeks and report symptoms of possible labour should be examined by the appropriately skilled member of the obstetric team.
Care in the Community (Social care)	Ensure that all key caregivers are involved in developing care plans for children where appropriate.
Handover & transfer	The communication and handover process between Rapid Response Assessment Services and CAMHS should be reviewed to ensure clear processes in place.
	There can be loss of information when babies are transferred back from tertiary referral hospital to referring hospital via a third hospital.
	Involvement of the neonatal team in the antenatal period (prior to patient transfer to a tertiary centre) would allow the patient to gain a greater insight regarding care at less than 23 weeks' gestation.

Clinical	SORT should be involved early where cyanotic congenital heart disease is suspected.
	Radiological presentations of pneumothorax may differ where lung compliance is significantly reduced.
	Clinical learning point around correct ventilation of children with hypoxic ischaemic encephalopathy.
	Awareness of children in the 16–18-year age bracket being legally children but often managed in adult services. Learning point that paediatric input still required for these individuals.
	Remember to always take blood culture when changing antibiotics and always give antibiotics within one hour of the decision.
	Documenting and monitoring use of CADD-PCA is needed to ensure that there is enough volume in the PCA, especially once doses are increased.
	All aspects of an antenatal ultrasound report must be considered when risk assessing the clinical picture.
Clinical procedures	In acute situations, where peripheral IV access is difficult, earlier use of other methods of access should be considered and attempted.
	Specific clinical learning point.
	There is a sense of a lack of awareness of risk around removal of umbilical arterial catheters.
	Where IV access difficult, consideration should be made as to whether administration of IV medication could wait until existing lines can be accessed.
	Needle thoracocentesis for pneumothorax is not a definitive solution as pneumothoraces often re-accumulate following it. Use it only in emergency situations to stabilise/resuscitate baby or if there is a high chance that it will not re-accumulate.
	The first choice of drain is the pigtail drain. If they fail to clear the pneumothorax and a second drain is needed on the same side, this should be a straight one.
	Specific clinical learning point related to ventilation in the context of pneumothorax.
	Reflection on the relative ease of starting interventions such as NIV versus the difficulty of stopping.
Genetics	Consider parallel planning for other investigations while waiting for the result of whole-exome sequencing in case it does not give a diagnosis.
	Consider whole exome sequences in children with severe pneumothoraces to establish any possible underlying lung pathology.
Prescribing	Awareness that changing antibiotics in early onset sepsis to Cefotaxime and Amoxicillin may be helpful to

	treat meningitis but may not provide a good enough cover for some of the common bacteria causing early onset sepsis.
	Escalation of antibiotics in early onset sepsis is Meropenem and Vancomycin, but this combination should be used only in rare situations with life-threatening condition and after discussion with consultants.
	Clinical learning around furosemide-resistant renal failure.
Communication	Pre-birth counselling necessary if post-natal difficulties are expected.
	Clinical staff should be prepared to re-discuss previously refused interventions with family if/when the situation changes.
	It is important to communicate high risk patients within teams.
	Reminder to clinical teams that hospices are able to provide advice around palliative care.
	Access to ACP document needed on EPIC.
	Communication between local teams and tertiary teams should be prompt after a child dies, although parents may well reach out to well-known staff before professionals do.
	Important to maintain situational awareness during management of acutely unwell patients.
	Trainee should feel free to escalate end of life care concerns to the consultant body.
End of life & bereavement	Ensure that bereavement care for families is carried out in line with national guidance and that continuity of carer and information is provided wherever possible.
	Better communication with specialty and local teams is needed when end of life planning.
	Better plan is needed for identifying a key worker to liaise with family when death is anticipated.
	No area within Paediatric critical care to provide end of life care other than a cubicle.
	Learning around alternatives to syringe drivers by team, supported by BHT (Buckinghamshire Healthcare Trust) pharmacy.
	It is important to anticipate the need for end-of-life medications where possible to ensure they are available.
	One case highlighted the importance of palliative care and early access to respite care for children and families with complex medical diagnosis and life limiting conditions.
	Ensure staff familiar with cooling blanket.
	Consultants to make sure that they support trainees and nurses when managing babies at end-of-life care.

	Make sure that babies at the end of their life receive appropriate comfort care and pain management.
	Recognition of the dying child by acute teams could be improved.
	Management of acute pain in end-of-life care could be improved.
	Too much time required for paperwork to be processed to allow release of a particular patient to hospice.
	Temperature in cubicle not ideal after death, despite use of the cooling mattress.
	No available bed at Hospice in the time scale required highlights pressures on this valuable service.
	Important to always consider cultural/spiritual wishes of parents even if they are not religious.
	Handover of leadership is an important aspect in the handover and transfer of care of the acutely unwell patient
Tissue donation	Discussion of tissue and organ donation discussions with parents should be documented.
Process	At times follow-up with clinical teams not offered in timely way following death.
	Important to ensure that all key professionals who were involved in the care of a child are invited to CDRM's, allowing plenty of notice. If unable to attend, then their up-to-date involvement can be requested to contribute to the meeting.
	Identify a clear key worker at the JAR so that responses can be coordinated so as not to overwhelm parents in some situations.
	Difficulty experienced in accessing medical examiner for discussion.

Recommendations	
Category	Recommendation
Antenatal care (Smoking)	Community matron to discuss with all staff the importance of carbon monoxide testing for all mothers at booking.
	New equipment for CO monitoring purchased to increase staff compliance with CO monitoring policy.
	Reminder to staff to ensure that it is documented if smoking cessation is offered and, if not, why not.
	Ensure smoking cessation is offered at booking and all subsequent contacts during pregnancy.
	Wider members of a mother's family should be offered smoking cessation if they smoke.

Antenatal care (Midwifery, Obstetrics & Paediatrics)	Community matron to discuss with all staff the importance of discussing domestic abuse at booking.
	Management of care must incorporate action to be taken if a birth were to occur unexpectedly and prematurely with input from the wider multidisciplinary team.
	Discussion at Perinatal Mortality and Morbidity Meeting/Education Day to address when the Paediatric Team should be involved with planning care in the antenatal period.
	Discussion at Perinatal Mortality and Morbidity Meeting/Education Day to address appropriate staff messaging and when senior obstetric involvement is required in pregnancy.
	Discuss with antenatal midwifery team at ward meeting the need to ensure women are assessed by the appropriately trained staff member.
	Mother of case to be referred to preterm birth clinic in subsequent pregnancies.
	Referral to a local or regional preterm birth service is indicated with discussion of progesterone, serial cervical screening and cervical cerclage.
Care in the Community (Social care)	A review of social care records noted learning regarding engagement with fathers as the engagement appeared to focus on mother's views, despite father playing a significant role. This has been addressed by way of further audit work regarding fathers and learning events and communication going out highlighting the importance of engagement with fathers.
Handover & transfer	Minimise repeated history taking when child transferred between sites by having a handover at point of transfer between different sites.
Clinical	Policy on buccal medicine administration in the home to be formalised.
	Nurse verifier to prevent delays in verification of death.
	All aspects of an antenatal ultrasound report must be considered when risk assessing the clinical picture.
	Individual learning and reflection with regards to management of small for gestational age/fetal growth restriction and abnormal dopplers at different gestations.
	Education for all staff regarding supported decision making and informed consent.
	Advanced Care Plans to be uploaded to EPIC, specific actions for starting this process.
	Communication with care provider about the excellent level of support provided to a family.
	Tertiary hospital and local critical care nursing team to meet to improve knowledge of local support services for the tertiary team.

	Template to be available on EPR system to ensure all aspects of care addressed.
	Review of seniority of staff reviewing oncology patients when inpatients.
	Service to highlight that professionals responsible for initiating treatments such as NIV should consider discussion at the outset the reasons and parameters for considering stopping.
	A specific hospital HDU (High Dependency Unit) should consider how to ensure that the kit available for patients with NIV support in the community is accessed when admitted.
	To ensure that the contact details for Medical Examiner at a specific hospital are clear.
	Teams should work together to optimise coordinated care of anticipated case in anticipation of eventual deterioration based on lessons from death of relative.
	Create more awareness around the retrieval of extremely sick children through the use of mobile ECMO (Extra Corporeal Membrane Oxygenation) service. Colleagues within London and South-East region have initiated discussions.
Clinical procedures	In acute situations, where peripheral IV access is difficult, earlier use of other methods of access should be considered and attempted.
	A quality improvement project has made a number of recommendations to prevent accidental extubations.
	All staff have been emailed regarding vigilance when removing umbilical line.
	Guideline to be amended for removal of umbilical lines.
	Consider mentioning specifically on symptom care plans regarding IV access (for ambulance crews) and if IV medications can wait until hospital to avoid undue distress with a peripheral cannula.
Prescribing	Liaise with pharmacy about arranged for availability of medication on ward in case needed based on symptom management plan rather than needing each option prescribing.
End of life & bereavement	Bereavement care for families should be carried out in line with national guidance and continuity of care and information should be provided wherever possible.
	Plan to reach out to family again and ensure signposted to local support.
	Parents have been invited to a bereavement event at the Hospice.
	Bereavement meeting for family to be offered by doctor in 4-6 weeks' time following death.
	Doctor to liaise with Oxford to ensure family have been signposted to bereavement and find out what support has been offered via PICU.

	Paediatric critical care consultant to reach out to family for follow up.
	Training on the use of the cooling blanket to be organised on a specific hospital ward.
	Question to be raised with SORT team regarding transfer of children on vapotherm support to home at end of life to facilitate death at home.
	Suggestion to pharmacy to create working links with adult hospice pharmacist to provide peer support.
	Review of policy on IV morphine requiring administration by doctors.
	Education for professionals around symptom management at end of life.
	To highlight that professionals responsible for drawing up and reviewing ACPs should consider providing starting doses for syringe drivers as a guide for acute deterioration.
	During the early bereavement period the baby was not able to be cared for in a cold cot because the cold cot was already in use.
	Information to be shared with all staff that there is more than one cold cot available.
	EB team to liaise with Palliative care services in subsequent cases of EB (across country) to share plans/experience if required.
Process	Paediatric critical care (PCC) team to offer follow up appointment if desired for review of PCC care.
	CDRM minutes to be sent to other specified CDOP to enable CDOP analysis of case.
	Review process of coroner post-mortem results to ensure they are shared with Paediatricians.
	Review policy of where children are brought to within the Trust when death is declared prior to arrival.
	Highlight to team importance of allocating keyworker to families.
	To ensure that all key professionals who were involved in the care of case are invited to the CDRM.