2022 - 2023



Last updated: May 2024



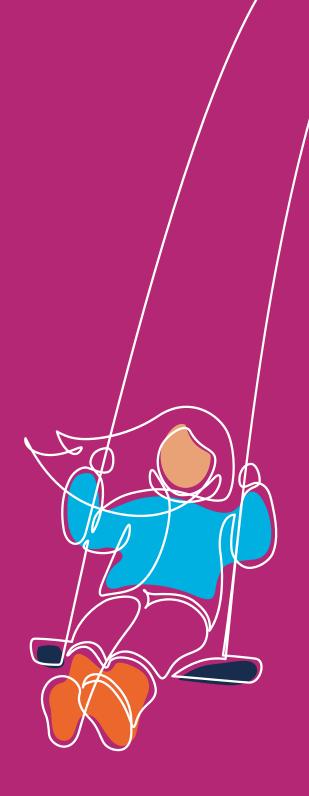






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#### **Foreword**

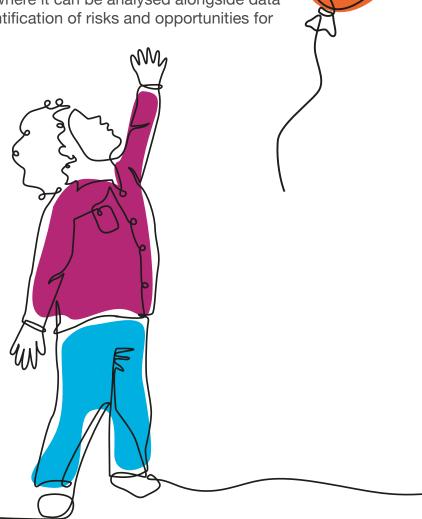
The death of a child is a rare but tragic event. We have more and more technologies and medicines available to us to keep children well and prevent harm to them and fewer children are dying than in the past. However, there are still around 50 to 60 deaths in Berkshire families each year and each of these are reviewed using the nationally mandated Child Death Review (CDR) processes.

The results of these reviews are carefully examined by our Pan Berkshire Child Death Overview Panel (CDOP), formed of experts in the field of child health and care. The idea is to look at the circumstances surrounding each case to see what we can learn to prevent a future death and to improve the support given to the child, their family, and carers both during the child's life and after their death. The information that we gather is used for actions locally and nationally.

Thankfully our numbers are, on the whole, relatively low. We feed our data into the National Child Mortality Database (NCMD) where it can be analysed alongside data from around the country, enabling early identification of risks and opportunities for prevention.

The whole point of CDOP is identifying where we can do things better, to learn and identify opportunities to improve. It is about avoiding complacency, always looking to prevent harm and act where we can improve.

This 2022/23 Annual Report demonstrated that our CDOP process has shown itself to be reliable and resilient. We altered our ways of working during the pandemic to keep on task. We have caught up with our backlog of cases post pandemic and introduced focused thematic reviews where we have particular learning to find.



2022 - 2023

The report highlights shifts in patterns of deaths across Berkshire and compares with regional and national trends. We noted a rise in the numbers of deaths in Slough and rises in infant mortality in West Berkshire which are explored in the report. The performance data shows that we consistently review our cases in a timely fashion and act on opportunities for improvement.

This year we responded to a series of drownings, working closely with our local Water Safety Partnership to promote and disseminate resources to help children, particularly teenagers, stay safe in the water. We have also been successful in attracting additional resources to Wexham Park Hospital to boost genetic services. We have not been complacent around ongoing causes of death - continuing our work on SUDIC and the further developing our baby campaign to minimise harm from co-sleeping.

We have a committed group of professionals across the county working on minimising child deaths and supporting families who are affected. We remain committed to learning and improving.

#### Tessa Lindfield MSc FFPH

Director of Public Health Berkshire East

#### **Acknowledgements**

Thank you to the team who wrote and produced this report, in particular

- Lorna Tunstall, Pan Berkshire CDOP Coordinator
- April Oughton, Public Health Information Analyst
- Sam Claridge, Public Health Recovery Programme Manager



#### The purpose of this report

CDOP publishes a report each year. The purpose is to describe the nature of child deaths locally, drawing out any patterns or anomalies. Also, to summarise the learning identified by CDOP and the actions resulting from that learning, and finally to recommend improvements for CDOP to take forward.

The analysis is based on the child deaths that were reported and reviewed by the panel between 1 April 2022 and 31 March 2023. Fortunately, the number of child deaths is small and therefore some of the data cannot be shared to ensure compliance with data protection guidance; specifically, statistics representing fewer than five cases are not published. As a result, it is not possible to draw significant conclusions from a single year's data. For comparison, child death data is collated over a number of years to show trends across time.





#### Introduction

Families will often want to know:

Why did my child die?
Was this death preventable?
What lessons can be learnt to avoid future deaths?

In some circumstances, the wider public may have similar questions. The Pan Berkshire CDOP seeks answers to these questions to prevent future child deaths and improve care and support to children and their families.

Child deaths may result from previously recognised or unrecognised medical conditions or because of unintentional incidents or (rarely) deliberate acts. A significant proportion of sudden unexpected deaths in infancy (SUDI) remain unexplained. Understanding that the death of an infant or child, whatever its cause, is a tragedy for the family and for all involved, the Pan Berkshire CDOP strives to make enquiries that keep an appropriate balance between forensic, medical, and social care requirements and supporting the family at a difficult time.

Since 1 April 2008, there has been a legal requirement across England that Child Death Overview Panels conduct a review for all child deaths (including live-born babies of any gestation) up to the age of <18 years. Under the Children Act 2004, as amended in the Children and Social Work Act 2017, it is the statutory responsibility of the Child Death Review Partners to make arrangements to review all deaths of children normally resident in the local area and, if they consider it appropriate, for those not normally resident in the area. These reviews should be carried out through a Child Death Overview Panel.

Reviews are not indicated for:

- stillbirths (a baby born without signs of life after 24 weeks gestation)
- late foetal loss (where a pregnancy ends before 24 weeks gestation)
- terminations of pregnancy (of any gestation) carried out within the law, even if signs of life were present.

Neonatal deaths should be reviewed at a themed neonatal panel for infants of 21 weeks gestation with signs of life as determined medically using the <a href="MBRRACE guidelines.">MBRRACE guidelines.</a>

2022 - 2023

The CDR partners for Berkshire are the local authorities and Integrated Care Boards (ICBs) for the area, namely:

- Bracknell Forest Council
- Reading Borough Council
- Royal Borough of Windsor & Maidenhead
- Slough Borough Council
- West Berkshire Council
- Wokingham Borough Council
- BOB (Berkshire West, Oxfordshire and Buckinghamshire) ICB
- Frimley ICB

In Berkshire during 2022/23 the CDOP was a subgroup of the Berkshire West Safeguarding Partnership (Reading, West Berkshire and Wokingham in collaboration) and the individual Safeguarding Partnerships of Bracknell Forest, Slough and Windsor & Maidenhead.

The panel has a broad membership with county wide representation from local authorities, the NHS the police and the education sector. Importantly our CDOP includes those with experience of supporting families of children and young people with life limiting conditions and those bereaved through a child's death. As a collective we seek to learn what happened and how it happened in the time leading up to and surrounding the death. This is because what happens when a child is dying, or has died, affects how families grieve and their future wellbeing.

#### **Key functions of the CDOP:**

- To collect, collate and analyse the information obtained about each child death in order to confirm or clarify the cause of death, to determine any contributory factors, to determine whether the death was modifiable, 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 produce an annual report for Child Death Review 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
- 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.

#### **CDOP Membership:**

Strategic Director of Public Health Berkshire East (Chair main panel)

**CDOP Coordinator** 

**CDOP Administrator** 

NHS designated Doctors for child deaths

Designated Nurses for Safeguarding (Vice Chair main panel)

Thames Valley Police, Child Abuse Investigation Unit (CAIU) (not for neonatal cases unless appropriate)

Head of Operations SCAS for Oxfordshire and Berkshire West (not for neonatal cases unless appropriate)

Children's Social Care Representatives

Clinical Director Children, Young People and Families, BHFT

Safeguarding Partners Representatives

Hospice care representatives Alexander Devine, Helen & Douglas House and any other as appropriate

Daisy's Dream Bereavement Charity

The neonatal panel has a specialist membership including a Neonatologist, Midwife and Obstetrician.



# The Pan Berkshire child death review process

Building on Working Together to Safeguard Children, the child death review guidance sets out a process for all child deaths alongside a separate but closely linked Sudden Unexpected Death in Childhood (SUDIC) process for when a child dies unexpectedly. All child deaths are notified via the eCDOP platform.

Following notification, the CDOP team gathers information from professionals who have been involved with the child or family prior to the child's death. The SUDIC process involves early notification a child death. A prompt process of investigation led by the Designated Paediatrician or Designated Healthcare Professional involves discussions with Child Death Review partners¹; a visit to the place of death, and a meeting between the professionals involved with the child, to gather information, identify learning and ensure the family and others are supported. The findings are written up in a which is shared with the Coroner and the CDOP.

The CDOP meets quarterly to review the death of every Berkshire resident child to identify themes, trends and learning. CDOP finalises the "Analysis Form" (previously known as a Form C) initially compiled during a Child Death Review meeting held three to six months after the death. The information gathered includes:

- the child and family, and service provision;
- identification of the key worker;
- categorisation of the cause of death;
- a judgment regarding whether there were modifiable factors;
- learning points and recommendations;
- immediate follow up actions for work with the family;
- whether to refer the case to the Safeguarding Partnership for consideration of a Serious Case Review.

<sup>1</sup> Child death review partners ("CDR partners") are defined in section 16Q of the Children Act 2004 and means, in relation to a local authority area in England, the local authority and any ICB for an area any part of which falls within the local authority area. CDR partners for two or more local authority areas in England may agree that their areas should be treated as a single area.

2022 - 2023

#### **National Child Mortality Database (NCMD)**

The NCMD was set up in April 2019 to enable more detailed strategic analysis and interpretation of the data arising from the complete Child Death Review process across England. CDOPs are required to submit copies of their data collected and analysis via eCDOP to the NCMD who will ensure that learning from the reviews of child deaths is widely shared, locally and nationally with the aim of saving lives. With the establishment of the NCMD, the quality of local CDOP data collection has seen improvements compared to previous years. Consistent and enhanced local data has allowed the NCMD to conduct national analysis and produce a variety of reports and analyses, which are available at: <a href="https://www.ncmd.info">www.ncmd.info</a>.

#### Learning Disabilities Mortality Review (LeDeR) Programme

The LeDeR Programme reviews deaths to identify areas of learning, opportunities to improve, and examples of excellent practice. Deaths of children aged four to 17 (inclusive) are reviewed through the Child Death Review process. CDOP and LeDeR work closely together in Berkshire with the CDOP notifying the LeDeR Local Area who routinely contributes their expertise to the CDOP review. Of the 55 child deaths notified in 2022-2023 there were six children who were known to have a learning disability (aged four plus). This number has remained stable with six cases in 2021-2022, less than five in 2020-2021 and seven in 2019-2020.

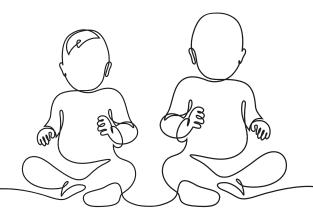


#### Children and young people in Berkshire

over **10,000** 

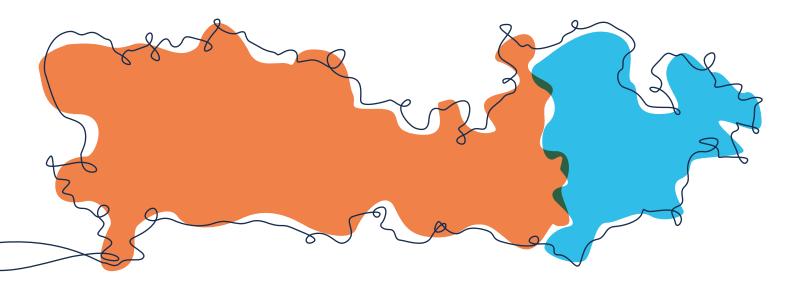
babies are born each year to Berkshire residents. (Office for National Statistics 2023).

The 2021 Census indicated that nearly 23 per cent of the Berkshire population are children and young people aged under 18 years (218,034 in 2021).



of the population of Berkshire East (comprising the local authorities of Bracknell Forest, Windsor and Maidenhead and Slough) are aged under 18. The proportion of younger residents in Slough's population is nearly 28 per cent, which is significantly higher than the rest of Berkshire East. Bracknell Forest and Windsor and Maidenhead both have approximately 22 per cent of their population aged under 18.

of the population of Berkshire West (comprising the local authorities of Reading, West Berkshire and Wokingham) are aged under 18. The proportion of younger residents in Wokingham's population is over 23 per cent, which is significantly higher than the rest of Berkshire West. Reading and West Berkshire have 21 per cent and 22 per cent of their population aged under 18, respectively.

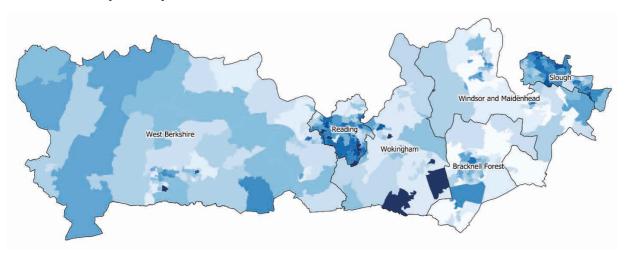


Sources: Nomis: Official Census and Labour Market Statistics
Births in England and Wales: Office for National Statistics

#### **Deprivation**

Berkshire is a largely affluent county with significant pockets of deprivation and a mix of urban and rural communities. The map in Figure 1 illustrates these pockets of deprivation across the six local authorities that make up Berkshire. The darker the colouring, the higher the level of deprivation. Deprivation is not restricted to the town centres and spans into more rural areas.

Figure 1: Berkshire index of multiple deprivation 2019 at a lower super output area



© This map has been produced using the Ministry of Housing, Communities and Local Government (2019) English Indices of Deprivation 2019 and Crown copyright and database rights 2023 Ordnance Survey AC0000814058.

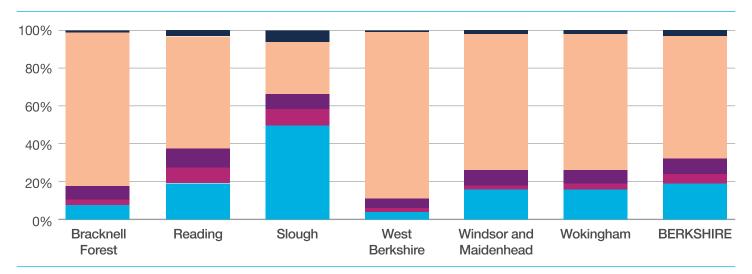
Source: Ministry of Housing, Communities & Local Government (2019); **English indices of deprivation 2019** 

#### **Ethnicity**

The 2021 census showed that 65 per cent of Berkshire's residents aged 0 to 24 identified as a white ethnic group (Office for National Statistics 2023). The ethnicity of the population varies considerably between local authorities with Slough and Reading being more diverse than other areas. Figure 2 and Table 1 provide a breakdown of ethnic groups for the 0 to 24 age group for each Berkshire local authority. Data has been presented for the 0 to 24 age group, as this is the most appropriate available age-band for this analysis.

2022 - 2023

Figure 2: Proportion of Berkshire local authority population aged 0 to 24 by ethnic group



Source: Office for National Statistics (2023); RM032 - Ethnic Group by sex by age

■ Asian/Asian British ■ White ■ Other ethnic group ■ Mixed or multiple ■ Black/Black British

Table 1: Proportion of Berkshire local authority population aged 0-24 by ethnic group

Area	Asian/Asian British	Black/Black British	Mixed or multiple	White	Other ethnic group
Bracknell Forest	8%	3%	7%	82%	1%
Reading	19%	8%	10%	59%	3%
Slough	50%	9%	8%	28%	6%
West Berkshire	4%	1%	5%	88%	1%
Windsor and Maidenhead	16%	2%	8%	73%	2%
Wokingham	16%	3%	7%	72%	2%
Berkshire	20%	5%	8%	65%	3%

Source: Office for National Statistics (2023); RM032 - Ethnic Group by sex by age

#### Child deaths and reviews in Berkshire

#### **Overall notifications**

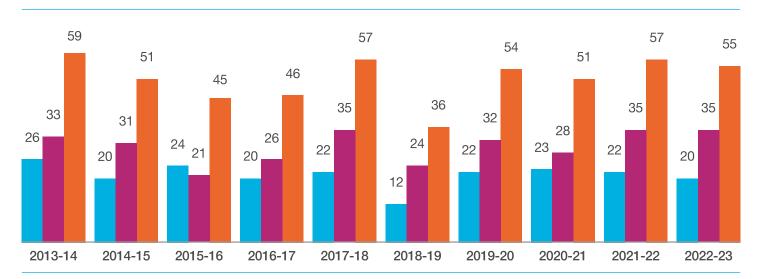
This section summarises data from all deaths notified to Pan Berkshire CDOP between 1 April 2022 and 31 March 2023. It includes both children who have died in Berkshire and children residing in the area who have died elsewhere. This data is drawn from the database of Notifications to eCDOP (Form A from NCMD). Numbers lower than five are suppressed to prevent the identification of individuals. As low numbers are involved, year-on-year fluctuation is expected.

There were 55 child deaths (0 – 17 years) reported between April 2022 and March 2023, which is similar to previous years in Berkshire. Nationally there were 3,743 child deaths in England, at a rate of 31.8 deaths per 100,000 children. This is higher than the regional rate of 23.5 per 100,000. The number of deaths nationally increased by eight per cent on the previous year and was the highest number of deaths in a year since the NCMD started data collection in 2019 (NCMD 2023).

Comparison of the CDOP data with the Primary Care Mortality Data set revealed an improving situation regarding completeness of CDOP notifications. In previous years a discrepancy had been noted where children who died in the first day of life had not been notified to CDOP. CDOP staff had been assisting services in improving notifications and in 2022-23 only one case had not been notified.

Looking at Berkshire as a whole, the number and distribution of deaths across age groups have been broadly stable over recent years with no significant increases or decreases, as seen in Figure 3. Further detail on patterns within Berkshire are provided later in the report.

Figure 3: Number of deaths for people aged under 18 years in Berkshire by year of notification.



Source: Pan Berkshire Child Death Review databases (restricted)

#### **Completed reviews**

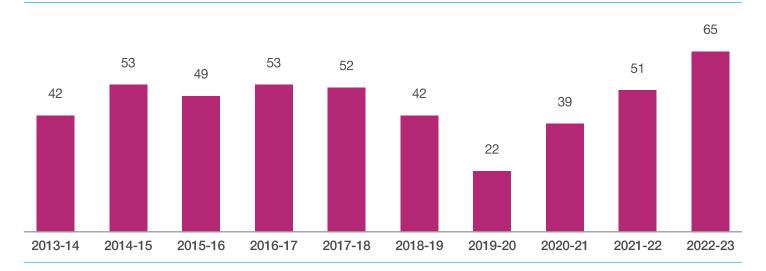
During 2022-23, 65 cases were reviewed by the panel. This is an increase on the previous year. The number of notifications and reviews differ for each year as the cases reviewed include deaths notified in previous years but not reviewed until the next year. This anomaly occurs because of the time taken to review the circumstances of each death following notification, which can be significant in the event of an inquest or criminal proceedings.

There was a notable decrease in reviews completed during the pandemic and an increase in the last two years, as we have eliminated our backlog from this period. Review numbers are balanced between Berkshire East and Berkshire West, as shown in figure 5.

Neonate
(up to 28 days)
Older Child
(28 days up to
18 years)

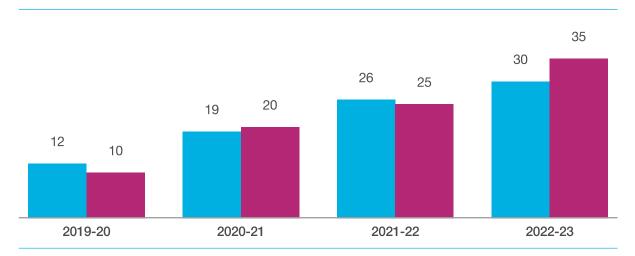
Total

Figure 4: Number of deaths reviewed per year by the Pan Berkshire CDOP



Source: Pan Berkshire Child Death Review databases (restricted)

Figure 5: Number of deaths reviewed per year by Berkshire East and Berkshire West geographies



Source: Pan Berkshire Child Death Review databases (restricted)

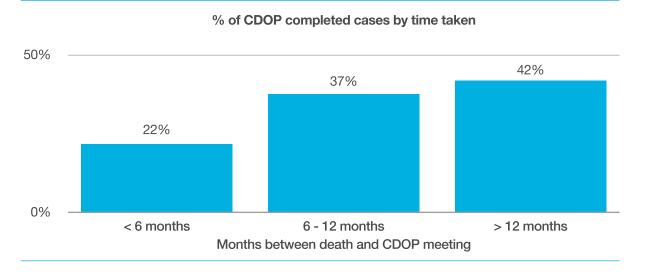
We aim to complete reviews in a timely fashion to enable identification of themes and patterns and prompt implementation of any learning. In 2022-23, 38 of the 55 deaths reported were reviewed within the year. As of April 2023, 62 reviews were outstanding, including those cases awaiting review from pre 2022-23.

Figure 6 indicates the time between the death and the CDOP review. The median number of days between death and review by CDOP is 338 days. This compares similarly with the national average (335 days) and is an improvement on our 2021-22 performance (404 days).

East
West

Figure 6: Interval between date of death and CDOP meeting

	CDOP	England
Median number of days between death and CDOP meeting	338	335



Source: NCMD Monitoring Report Pan Berks CDOP 31/10/2023

The number of reviews completed for each local authority reflect the geographical variations in the numbers of deaths. Slough has the highest number of cases outstanding across Berkshire to be reviewed, but in turn, are also the Berkshire local authority with the highest number of child deaths.

# Patterns of child deaths in Berkshire place of residence

There are variations in the numbers and rates of child deaths between local authorities across Berkshire. Numbers are small across the local authorities, so three-year periods have been used to calculate the mortality rates per local authority to avoid identification of cases. This is shown in Table 2.

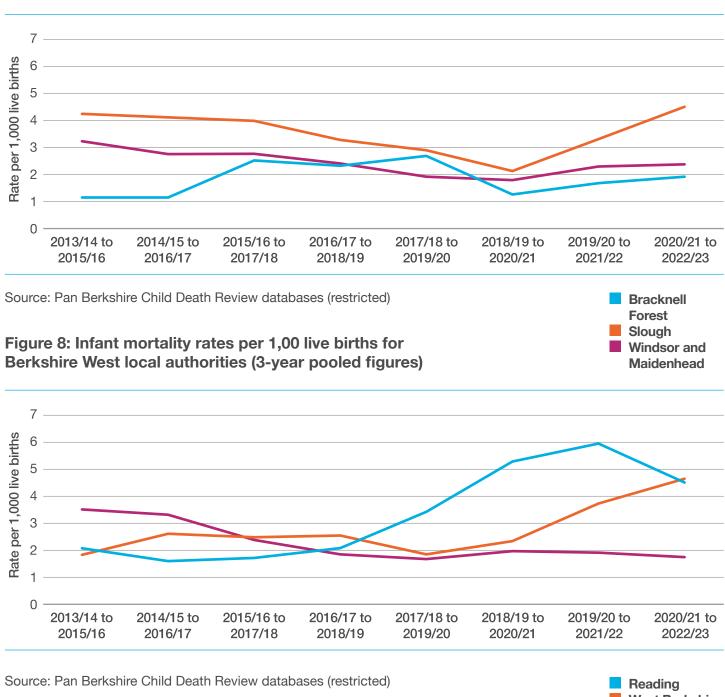
Table 2: Rates of infant and child mortality in Berkshire local authorities in 2020-21 to 2022-23

Area	Neonatal mortality rate per 1,000 live births (deaths under 28 days)	Post-neonatal mortality rate per 1,000 live births (deaths from 28 days to 1 year)	Infant mortality rate per 1,000 live births (deaths under 1 year)	Child mortality rate per 100,000 poulation (deaths aged 1 to 17 years)
Bracknell Forest	1.4	0.5	1.9	7.5
Reading	3.7	0.8	4.5	8.7
Slough	2.4	2.1	4.5	13.7
West Berkshire	2.4	2.2	4.7	9.0
Windsor and Maidenhead	1.2	1.2	2.3	7.1
Wokingham	1.2	0.6	1.7	5.1
Berkshire	2.2	1.3	3.4	8.6

Source: Pan Berkshire Child Death Review databases (restricted)

Figures 7 and 8 show the infant mortality rates in Berkshire local authorities since 2013-14. Data from the latest three-year period (2020-21 to 2022-23) does indicate an increase in infant mortality rates for both Slough and West Berkshire, when compared to the previous three-year period (2017-18 to 2019-20). Reading's infant mortality rates have reduced from a peak of 6.0 per 1,000 live births in 2019-20 to 2021-22. Child mortality rates have not changed significantly across any of the Berkshire local authorities in recent years.

Figure 7: Infant mortality rates per 1,00 live births for Berkshire East local authorities (3-year pooled figures)



#### Age of death

Across England & Wales, most child deaths occur in children aged under one followed by children aged one to four years. In 2022-23, infant (children under one year) deaths increased by four per cent on the previous year and deaths of children aged between one and 17 years increased by 16 per cent (NCMD 2023).

In Berkshire, most deaths occur in children aged under one year. However, this can vary on a year-to-year basis due to small numbers.

Figure 9 shows that the highest proportion of deaths from 2019-20 to 2022-23 were consistently in the neonatal period (aged under 28 days), followed by the perinatal period (aged 28 days to one year).

41 per cent of child deaths were neonatal deaths in England 2022-23, comparable to what we are seeing in Berkshire (NCMD 2023).

100% 18%\* 13% 80%-13% 16% 11% 18%\* 60% 24% 28% 29% 20% 40% 46% 39% 20% 36% 36% 0% 2019-20 2020-21 2021-22 2022-23

Figure 9: Proportion of deaths by age-group in Berkshire

\*data rounded to nearest five to avoid identifying through differencing. Figures do not show a full 100 per cent for each year, as data has been suppressed for some age groups due to small numbers.

Source: Pan Berkshire Child Death Review databases (restricted)

#### Age at death by local authority

Due to small numbers, data for age at time of death by local authority uses data between 2019-20 and 2022-23. Consistently across all six local authorities in Berkshire, neonatal deaths see the highest proportion of deaths by age group. In Reading, over half (55 per cent) of all deaths were for this age group during this time-period. Slough had equal numbers of deaths in both the neonatal and perinatal period, with nearly a third of all deaths in each of these age groups (31 per cent).



#### **Reviewing neonatal deaths**

In line with best practice, the Berkshire CDOP established a specialist panel in 2016-17 to consolidate learning from deaths in the first 28 days of life.

During 2022-23 the neonatal panel met three times with cases reviewed by location of death: Royal Berkshire Hospital, Reading; John Radcliffe Hospital, Oxford and, Frimley plus out of area of all cases. Over 30 cases were reviewed.

In Berkshire, cases whose entire care had been delivered in patient neonatal units are included, even if death occurs after 28 days. Inclusion of these cases in a focussed panel is felt to be the most appropriate way to identify learning.

#### **Clinical learning**

Clinical learning from these highly complex cases is routinely shared in detail with clinical staff. The Neonatal Panel noted the following points whilst carrying out their reviews in 2022-23:

- There was good antenatal planning with detailed options in place for different potential outcomes
- A key worker was identified early on and involved throughout when needed.
   In common with other CDOPs, allocating key workers remains challenging
- Examples of excellent nursing care were identified
- Parents' views were listened to and they were involved in care choices
- Excellence in practice by bereavement midwifery and neonatal lead nurses in supporting bereaved families was noted
- Good use of multi-disciplinary teams



- There are multiple reviews of neonatal deaths by the neonatal/maternity teams, including perinatal mortality and morbidity (M&M) reviews, use of the Perinatal Mortality Review Tool, the Thames Valley and Wessex neonatal network, out of area M&Ms and transport M&Ms. HSIB<sup>2</sup> investigations, serious case reviews internally and with external reviewers are also held
- The impact of the <u>Ockenden review</u> (2022) has been significant on maternity and neonatal care across the UK and locally. A local working group has been formed with a focus on safety and cases with evidence of pro-active neonatal intervention and on safety
- The opportunity to donate organs is not always offered to all families
- As the result of a sudden unexpected postnatal collapse, an internal review
  was carried out at Royal Berkshire Hospital to look at similar cases. As a
  result, MDT training was carried out with midwifery and neonatology staff to
  reinforce "eyes on the baby" and to improve parental awareness of positioning
  during skin to skin contact in line with recent guidance issued by the British
  Association of Perinatal Medicine (2022)
- A need for post operative single ventricle babies to stay on the high risk feeding protocol until fully established on enteral feeds was identified.
   A review of local high risk feeding protocols was recommended to ensure they were clearly written and fully understood.

Following an HSIB investigation into a neonatal death, the following recommendations were made:

- That staff are supported to use personalised growth charts, in line with local guidance, to augment their decision-making processes
- That telephone triage services have access to a mother's antenatal history when assessing her risks, in order that she may receive correct and timely advice
- That the telephone triage service uses a triage risk assessment tool to enable full consideration of mother and baby's clinical status to flag those who require immediate attention.

Modifiable factors noted by the neonatal panel for action included:

- Stopping smoking during pregnancy
- Substance use by parents whilst caring for the child
- High maternal weight
- Challenges with access to services
- Domestic violence
- Poor communication and information sharing
- Limited social support for mothers

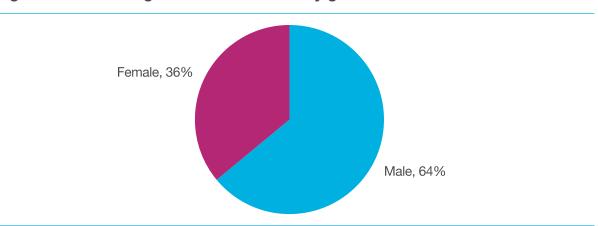
<sup>2</sup> The Healthcare Safety Investigation Branch (HSIB) is the independent national investigator for patient safety in England

#### Gender

Over the last five years there have been more male deaths than female deaths in Berkshire, in line with the national picture. Figure 10 shows that nearly two-thirds of deaths in Berkshire were for males in 2022-23. Figure 11 shows the minimal change in the number and proportion of deaths by gender since 2019-20.

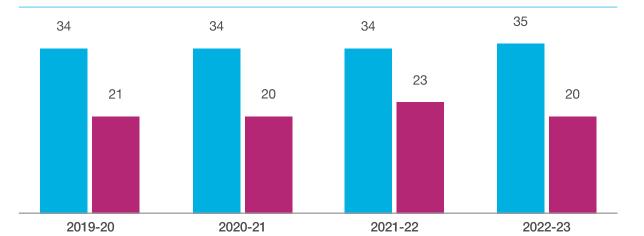
From 2019-20 to 2022-23, Slough was the only Berkshire local authority where the number of deaths in female children was higher than males. This differs from the national and Berkshire picture.

Figure 10: Percentage of notified deaths by gender 2022-23 in Berkshire



Source: Pan Berkshire Child Death Review databases (restricted)

Figure 11: Notified deaths by gender per year in Berkshire Pan Berkshire 2019-20 to 2022-23



Year of notification

Source: Pan Berkshire Child Death Review databases (restricted)

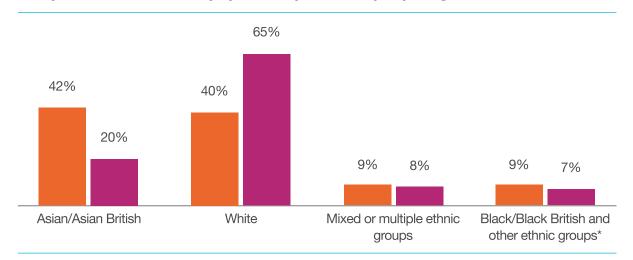
Female
Male

#### **Ethnicity**

Nationally, higher rates of child deaths are seen in Asian and Black ethnic groups and this pattern is also seen across the South East region (NCMD 2023).

Figure 12 shows that Berkshire children from an Asian or Asian British ethnic group were over-represented in the proportion of child deaths in 2022-23. Children from white ethnic backgrounds were under-represented in the proportion of deaths. As previously shown in this report (at Figure 2 and Table 1), Slough's population is more diverse than other areas of Berkshire, with half of the younger population identifying as Asian or Asian British. In all other Berkshire local authorities, young people from a white ethnic group make-up the majority of the 0 to 24 population.

Figure 12: Proportion of child deaths (aged under 18 years) by ethnicity, compared to Berkshire's population profile for people aged under 24



\*Black/Black British and other ethnic groups have been combined in this graph, as the number of children who died from these ethnic groups was too small to analyse.

Source: Child deaths by ethnicity - Pan Berkshire Child Death Review databases (restricted); Population profile - Office for National Statistics (2023); RM032 - Ethnic Group by sex by age

- Child deaths where ethnicity is recorded
- Census 2021 for people aged 0 to 24

#### **Deprivation**

Figure 13 shows the proportion of infant and child deaths that occurred in Berkshire and the South Region by deprivation decile (NCMD 2023; Regional Report - South East). This indicates that there is an over-representation of deaths in more deprived areas, when compared to the deprivation profiles of Berkshire and the South East.

Figure 13: Proportion of deaths by IMD quintile (2019-20 to 2022-23), compared to proportion of Lower Super Output Areas (LSOAs) by IMD quintile



Source: National Child Mortality Database (2023); Regional Report: South East Data up to 31 March 2023 and Ministry of Housing, Communities & Local Government (2019); English indices of deprivation 2019.

1 (Most deprived)
2
3
4
5 (Least deprived)



#### Patterns: modifiable factors

Modifiable factors are defined as 'those, where, if actions could be taken through national or local interventions, the risk of future child deaths could be reduced'. The Child Death Review process determines whether there were any modifiable factors which may have contributed to the death. These are factors which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths.

Each year, the panel takes a close look at deaths where modifiable factors occur, in order to learn and implement change. Nationally the proportion of deaths which were assessed as having modifiable factors was 39 per cent in 2022-2023 in comparison to 20 per cent in Berkshire (NCMD 2023).

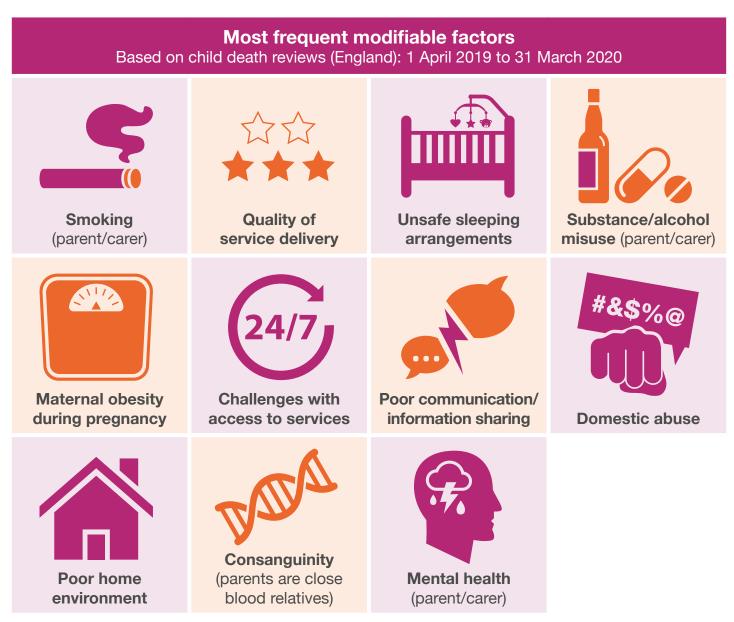
In the reviews that occurred in 2022-23 in Berkshire, there were 16 deaths (20 per cent) deemed to have modifiable factors, of which nine (60 per cent) were in the neonatal (under 28 days) age group. Regional partner CDOPs tended to have higher proportions of cases with modifiable factors.

There is an upward trend of deaths with identified modifiable factors locally and nationally. Locally the following factors are noted, some of which were relevant to more than one child death:

- Domestic violence
- Unsafe co-sleeping
- Exposure to tobacco smoke
- Alcohol or drug use by carer
- Presence of animals
- Unsafe sleeping arrangements
- Treatment plan issues
- Suboptimal communication and information sharing

Panel members are tasked with taking the learning from these cases and sharing it widely within their organisations to improve knowledge and change practice. Figure 14 shows the most frequent modifiable factors as identified by NCMD at a national level.

Figure 14: Most frequent modifiable factors nationally, identified by NCMD

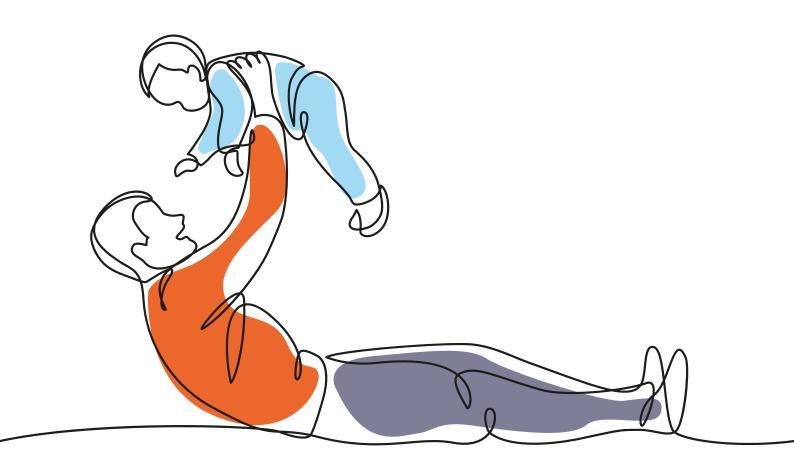


Source: National Child Mortality Database (2021) Second Annual Report

#### **Categorisation of cases**

During the CDOP meeting, the panel members categorise a child's death according to nationally defined categories which are determined by the Department of Health. The numbers in each category are collated for learning within the CDOP. This process is subject to the scrutiny of the Safeguarding Partnerships and Independent Chairs.

Of the 55 deaths reviewed in 2022-23 across Berkshire, just under a quarter of all deaths reviewed were categorised against 'Chromosomal, genetic or congenital anomaly', equating to 13 reviews. This was followed by nine deaths (16 per cent) categorised as 'Chronic medical condition'. Of the 55, 11 (20 per cent) did not have a category associated to the review.



#### **Achievements from 2022-23**

#### Safe sleeping

Following CDOP review it was noted that in 80 per cent of cases where unsafe sleeping was seen, alcohol and/or drug use by parents was also noted.

#### **Evidence**

The Who's in Charge campaign continues following the work by NHS Frimley ICS on improving awareness on the risks of unsafe sleeping.

The campaign, led by Frimley ICB, uses the resources produced by Birmingham Healthcare Trust/Safeguarding Board alongside local assets to support a media campaign, that are hosted on Frimley Healthier Together platform along with signposting to other local and national support services such as 0-19 public health nursing, Lullaby Trust, alcohol services.

The aim is to raise the awareness of the increased risk when using alcohol on how parents follow safe sleep practice for babies and young children. Asking parents and care givers to "Think, Plan and Share" safe sleep for their children.

The first phase of the campaign was launched on 15 August 2022. A communication plan and a resource tool kit was widely disseminated for supporting agencies and services to endorse and share through their own communication processes, as well as giving practitioners resources to start conversations with parents about infant sleep.



2022 - 2023



#### **Early Evaluation, Reach and Impact:**

Social Media reach - data taken 45 days post- launch of the campaign looking just at the reach across the Frimley ICB platforms showed it was seen by 11.3k people, the content displayed 13,000 times. It was mainly viewed across the UK, but we also had locations recorded for the Netherlands, US, Ireland, Finland and Japan.

Feedback received following the launch:

- Frimley Health Foundation Trust (FHFT) Midwifery Services were using the resources antenatally and with new parents, aiding difficult conversations.
- Achieving for Children 0-19 Services are using the videos in the antenatal and postnatal course with good feedback from practitioners and parents.
- Thames Valley Police (TVP) are using the videos in their induction training for new staff in the Child Abuse Investigation Team.
- Police colleagues reported that the campaign had raised their awareness and were able to advise parents where they had noted risks.
- GP surgeries have shared the campaign on their webpages with a link to Frimley Healthier Together.

Phase Two was launched on 5 December 2022, and broadened the campaign to include the safety of children during parties, playdates and other social engagements where adults are drinking alcohol. This was timed to release in the lead up to Christmas when alcohol consumption increases.







#### Close relative parents project

Slough successfully bid for funding as part of the Frimley ICS to become a High Need Area in the NHSE Culturally Competent Genetic Services project. This is to provide education and access to genetic screening and support for parents when planning a family.

#### **Evidence**

NHS England (NHSE) has developed a national strategy on genetic risk and close relative parents. Slough is one of ten identified High Need Areas (HNAs) that will receive funding to support the implementation of the project. The project is comprised of four strands:

Strand 1 raise genetic literacy at community level	Strand 2 educate and equip healthcare professionals
	nt genetic services
Strand 3 improve access to genomics services for underserved groups	Strand 4 continuously improve with national support

The funding agreed for Frimley ICS for Slough HNA in 2023-24 will cover the following:

Close Relative Marriage Midwife – 0.4WTE, Bank 6 including on costs and HCA allowance (fringe) – from July 2023

Genetic literacy programme at community level

Start-up costs

- Close Relative Marriage Midwife this post will be responsible for having empowering conversations with families, early identification and referrals to support services and acting as a champion for the service.
- Developing methods to increase genetic literacy and awareness in the community and measuring improvement using a baseline survey approach.
- Providing in-person training to both clinical and non-clinical staff and equip our workforce with tools to engage in sensitive conversations with families in a culturally competent manner.

2022 - 2023

Additionally, NHSE will provide funding directly to Oxford Centre for Genomic Medicine to support a Genomic Associate – this postholder will be responsible for liaising with Slough families, preparing them for appointments and offering support.

A multi-disciplinary Steering Group has been established and will oversee project development and ensure all stakeholders are involved in the process. Membership includes Frimley Local Maternity & Neonatal System (LMNS), FHFT Screening Team, Public Health, Pan Berkshire CDOP, Paediatrics, Obstetrics & Gynaecology, Voluntary and Community Sector organisations, Special Educational Needs and Disability (SEND) Lead and the Maternity and Neonatal Voices Partnership (MNVP). The group meets monthly and will work to develop a high-quality referrals process and ensure services are delivered in a culturally competent manner.



2022 - 2023

#### **Reading Festival**

Following the death of a young person at Reading Festival several years ago, a Reading multi-agency partnership group was formed to work with the organisers Festival Republic, to further develop safety and safeguarding policy, practice and processes. The work of this group continues.

#### **Evidence**

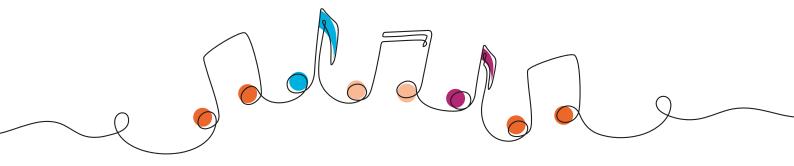
- Reading Festival 2022 Safeguarding young people and adults safeguarding, welfare and risk reduction
  - A multiagency 'Senior managers on call' information sheet
  - A 2022 updated RBH child safeguarding flow chart
  - A Safeguarding and Welfare sub-group reviewed and updated the 2021 arrangements

#### New for 2022:

- British Transport Police Reading Station
  - Plain clothes officers specifically on the lookout for 'predatory' behaviour
  - Display stand in the northern entrance area of the station throughout the festival period advertising their safe space and safeguarding operation
  - Allocated two rooms in Vastern House, to be their safe space. The area includes a dedicated toilet / shower facility
  - GWR / Network Rail briefed all those working throughout the festival
  - Reading Street Pastors worked closely with BTP, at station as well as on the festival site



- Allegations against staff and contractors as people in position of Trust -Safeguarding Policy reviewed and strengthened
- Safe Hubs five safe hubs staffed 24/7 (in addition to the Welfare Tent run by TLC Welfare and Street Pastors, the Samaritans, the Salvation Army).
   Communication and information sharing between and with safe hubs staff reviewed and improved.
- Sexual Assault pathway reviewed in partnership with TVP sexual assault cabin (quiet confidential space) established next to the Welfare Tent
- **Sexual harassment** reviewed and strengthened the culture around not tolerating sexual harassment. Festival Republic has worked with campaigns such as 'Violence Against Women and Girls' (VAWG), 'Enough', and 'Ask for Angela' which will be included in security, bar and staff briefings and handbooks; Home Office VAWG Campaign promoted on big screens. Safe Gigs for Women On-site.
- Spiking Festival Republic worked with NHS <u>www.antispiking.org</u>; security
  will be seeking out potential spiking drugs on the gates; Central Fusion will be
  providing stop tops at high risk/high volume bars (e.g. cocktail bars); ongoing
  social media campaign alongside Violence Against Women and Girls; exploring
  post spiking test kits being available to TLC
- Mental Health BFfC worked with Festival Republic and TLC to provide targeted information for 16 – 21 year olds. Postcard A5, one side how to seek urgent help, onsite contacts and Berkshire EDS contact details, the other more specialist services accessed online and posters. Aim is to encourage helpseeking behaviours for young people that might be struggling at the festival
- Berkshire West Schools survey and workshops Reading Festival (paid for by Festival Republic) took place during June and July 2021, arranged through Berkshire West Safeguarding Children Partnership. Data analysed July and August 2022 through working in partnership with UoR. Key messages shared by analyst Beth Harvey at the 2022 Table Top Exercise – presentation shared.
- Safeguarding, welfare services and personal safety messaging sent to all festival goers could be seen on the Reading Festival website #lookoutforeachother.



2022 - 2023

#### **Drowning**

There were several deaths due to drowning during 2022. The Berkshire Water Safety Partnership took action to share and promote water safety resources.

#### **Evidence**

The aim of the Water Safety Partnership is to work to improve the safety of persons from water risks in Berkshire with the intention to reduce accidental drowning deaths of people who live, work and visit the county.

The partnership is preparing the sharing of resources around water safety to be distributed in good time before the summer via the <u>Water Safety Partnership - PPP</u> website.



#### Serious youth violence

#### A Thematic Child Safeguarding Practice Review:

Services provided to young people and their families in relation to serious youth violence, was carried out. This was an important piece of work carried out via the Berkshire West Safeguarding Children Partnership after a fatal stabbing in 2019 and other stabbing injuries.

This has now been published:

- Executive summary
- Learning & recommendations
- Overview report



#### Reflections on the work of CDOP

#### **CDOP Panel**

2022-2023 has continued to be challenging and colleagues have worked hard to adapt our response during the pandemic and manage the impact on children and families.

During the past year the panel has maintained good operational performance against national standards. As a result of pandemic, face-to-face CDOP meetings ceased in March 2020 and arrangements were swiftly made to hold the CDOP Exec and Case review meetings met virtually. This arrangement for remote meeting continues. The CDOP panel meets four times a year and aims to review eight -10 cases per meeting. The CDOP Exec meet three times a year to drive the CDOP process. All meetings are well attended by relevant partners. Panel members are experts in their field and encouraged to offer constructive challenge. Discussions are detailed and thorough and considered of high quality. However, due to staff changes within Public Health, consistency of chairing has been challenging.



2022 - 2023



#### Challenges

- A significant proportion of deaths in Slough are classified as Chromosomal, genetic and congenital anomalies. An area of priority for 2023-24 will be around genetic screening and support for parents when planning a family because of this trend.
- A cluster of children from our area died due to drowning in 2022-23 reflecting our access to rivers and pools. The CDOP will continue to advocate improved water safety messaging around the dangers of entering water and what to do if you get into difficulties during 2023-24.
- Panel members note that they are seeing an increase in the complexity of the cases reviewed by CDOP.
- Cases remain open due to a continued delay in the coronial process including post-mortems (PM) being carried out and inquests being held. If toxicology forms part of the PM enquiry, this can mean additional delay with a wait of nine months to over a year. This is distressing to families and requires prolonged support from the key worker.
- Home Office PMs and specialist opinions such as skeletal pathologist opinions have taken up to two years or more.
- CDOP is hosted by the East Berkshire Public Health Hub. The backlog of cases waiting to be reviewed has been put on the Hub risk register and this situation will be closely monitored over the next year while processes are put in place to catch up.
- Information gathering has been hampered at times by safeguarding and clinical teams' capacity pressures.
- The time for each case to be reviewed has increased due to an increase of information required and the number of different types of reviews to be held.
- The appointment of key workers with the requisite knowledge and capacity to dedicate to the role has proved challenging especially in the five to 17 year olds when there is no professional looking after them before the death.
- The number of child deaths remains static despite many interventions and an increase in the numbers with modifiable factors. The challenge remains in choosing local actions that have potential to reduce numbers whilst supporting national actions.
- Capacity for CDOP support within the Public Health Hub has been challenging with fluid chairing arrangements and limited capacity to support epidemiological analysis.

2022 - 2023

Compliance with October 2018 – <u>Child Death Review (CDR) Statutory and Operational Guidance</u> continues including:

- Child Death Review meetings well established
- Separate Child Death Review meetings for difficult and complicated deaths and our processes are now well established
- Thematic reviews well established
- A JAR (Joint Agency Response) process for all unexpected child deaths in 2022-23 was triggered
- When a child dies: A guide for parents and carers is available
- Peer review in Pan Berkshire CDOP panel well established
- BHFT Rapid Response nursing team service who provide joint home visits with TVP – well embedded and working well
- Close team working with CAIU/Children's services/Safeguarding team/Health Visiting team – well established
- Appropriate key workers have been appointed for all child deaths well established

Context	Keyworker
Home Office Post Mortem/RTI	TVP Family Liaison Officer
Neonatal < 28 days	Bereavement Midwife
CYP (Children & Young People) with life limiting illness, already known to service	Children's Community Nurse
Child or sibling under five years	Health Visitor
Otherwise	Decided in JAR

2022 - 2023

#### **Education and Training**

The CDOP team attended the National Network of CDOPs conference in Liverpool in April 2022 and the Association of Child Death Review Professionals conference in Birmingham in November 2022. They took part in training sessions and networked with colleagues involved in child death review.

The CDOP Coordinator gave a presentation on CDOP to Health Visitors, School Nurses and the Police at an Autumn Solutions4Health Level 3 Safeguarding Training Day.

The CDOP team continue to support colleagues in the CDOP process and give 1:1 training on eCDOP to a variety of users.

Royal Berkshire Foundation Trust (RBFT) Training - Saving Young Lives Child Death talks – Overview and Learning sessions provided at all face-to-face full level 3 child safeguarding days.

It is hoped that training events and our conference can resume next year.

#### Pan Berkshire CDOP Website

The Pan Berkshire CDOP Webpages are now located here.

#### **Themed Reviews**

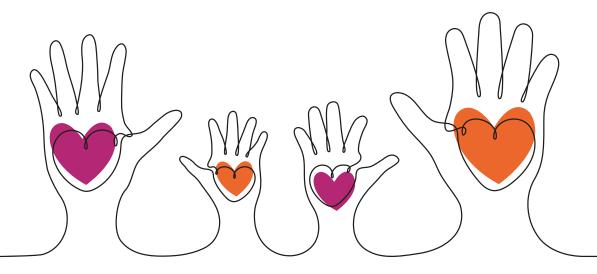
One Joint Themed Review has been held with CDOP colleagues from Berkshire, Oxfordshire and Buckinghamshire on Supporting Families Bereaved By Sudden Infant and Child Death. Local learning has been shared and applied across the wider system.



#### **Priorities for 2023-24**

- To continue to embed the Culturally Competent Genetic Services programme within Slough.
- To link in with the Water Safety Partnership to have a robust messaging campaign. This will be shared across multiple media in Q2 2023 in recognition of the increased risk with warmer weather starting earlier and in good time before the school holidays.
- To complete the accreditation of the ICON
  Babies Cry, You Can Cope! Campaign
  throughout Berkshire. The campaign aims to
  help parents and carers cope with a crying
  baby. This is achieved by sharing simple
  messages and avenues of support for parents
  and carers. The bones of ICON are already
  in place in maternity, neonatal and Health
  Visiting services and online ICON training has
  been introduced into Primary Care. To achieve
  full accreditation there will be the formalising
  of the five touchpoints (already being used)
  that are part of the programme.
- To work with Reading Football Club and refresh the safe sleeping campaign "Lift the Baby".
- For Pan Berkshire CDOP to host the next BOB thematic review on drowning following the tragic death of four Berkshire residents in summer 2022.

- To raise the profile of the Child Death Review Process by delivering multiagency training across the system.
- To ensure learning from child death is shared widely and is regularly reviewed for progress.
- Audit the effectiveness of dissemination of learning and impact on service provision.
- Continue to escalate issues where agencies are not providing timely information.
- To provide more learning and dissemination events.
- To develop further good links with existing maternity and neonatal networks to improve outcomes.
- The key worker role to be strengthened across Pan Berkshire with a (rescheduled) key worker training day to be held on 4 September 2023.
- To continue to embed the Medical Examiner model for under 18 years throughout the Berkshire footprint.
- To develop robust and sustainable support for CDOP analysis and chairing supported by a Memorandum of Understanding (MOU) between the six Local Authorities.





# Appendix one Glossary

# Glossary

Acronym	Explanation
BHFT	Berkshire Healthcare NHS Foundation Trust
вов	Berkshire West, Oxfordshire and Buckinghamshire
CAIU	Child Abuse Investigation Unit
CDOP	Child Death Overview Panel
CDR	Child Death Review
CDRM	Child Death Review Meeting
CSPR	Child Safeguarding Practice Review
GDPR	General Data Protection Regulation
FHFT	Frimley Health Foundation Trust
HSIB	Healthcare Safety Investigation Branch
ICB	Integrated Care Board
JAR	Joint Agency Response
LeDeR	Learning Disabilities Mortality Review Programme
MDT	Multi-Disciplinary Team
NCMD	National Child Mortality Database
ONS	Office for National Statistics
PMRT	Perinatal Mortality Review Tool
RBHFT	Royal Berkshire NHS Foundation Trust
SIDS	Sudden Infant Death Syndrome
SUDIC	Sudden Unexpected Death in Childhood

## **Categories of death**

Category		Tick box below	CDOP affirmation
1	Deliberately inflicted injury, abuse or neglect  This includes suffocation, shaking injury, knifing, shooting, poisoning & other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death.		
2	Suicide or deliberate self-inflicted harm  This includes hanging, shooting, self-poisoning with paracetamol, death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children.		
2 (i)	Please choose from the sub-categories below:     Suicide (where the panel feels the intention of the child was to take their own life)		
2 (ii)	<ul> <li>Self-inflicted harm leading to death (where it is unclear if the child's intention was to take their own life)</li> </ul>		
2 (iii)	<ul> <li>Death as the result of substance misuse (excluding deaths as a result of a deliberate overdose)</li> </ul>		
3	Trauma and other external factors, including medical/surgical complications/error  This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in preschool children, anaphylaxis & other extrinsic factors. Also includes proven medical and surgical complications or errors as the primary cause of death. Excludes Deliberately inflicted injury, abuse or neglect (category 1).		
4	Malignancy Solid tumours, leukaemias & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.		
5	Acute medical or surgical condition  For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.		

Category		Tick box below	CDOP affirmation
6	Chronic medical condition  For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause		
7	Chromosomal, genetic and congenital anomalies  Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.		
8	Perinatal/neonatal event  Death ultimately related to perinatal events, e.g. sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, necrotising enterocolitis, post-haemorrhagic hydrocephalus, irrespective of age at death. It includes cerebral palsy without evidence of cause, and includes congenital or early-onset bacterial infection (onset in the first postnatal week).  Please choose from the sub-categories below:		
8 (i)	Immaturity/Prematurity related		
8 (ii)	Perinatal Asphyxia (HIE and/or multi-organ failure)		
8 (iii)	Perinatally acquired infection		
8 (iv)	Other (please specify)		
9	Infection  Any primary infection (i.e. not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc.		
10	Sudden unexpected, unexplained death  Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).		



For further information, please write to:

Pan Berkshire Child Death Overview Panel
Bracknell Forest Council
Time Square
Market Street
Bracknell
RG12 1JD

Or email: panberkshire.cdop@bracknell-forest.gov.uk







