## Pan Berkshire

# CDOP Annual Report

2020 / 2021











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## **Foreword**

Preventing deaths in children is an issue we take seriously in Berkshire. Our Child Death Overview Panel (CDOP) forms part of a national programme to examine all deaths in children. Our job is to look at the circumstances around the child and determine what can be learned, to prevent further deaths and better support families and communities affected by the death of a child. This important work has continued during the pandemic with the panels and meetings moving online.

There is a broad network of committed and inspirational professionals across Berkshire who contribute to this work and it is a pleasure to work alongside them. Their work is often unseen but crucial in improving services and support for children, their families and communities.

During 2019-20 we put new processes in place across our system to comply with the guidance. We have embedded eCDOP and our cases are included in the new National Child Mortality database. This is an important development as it will enable patterns to be seen across the country augmenting our learning and improving prevention. We have streamlined our panels to support better discussion and analysis and formed an executive group to drive improvement in our CDOP programme. In line with best practice, we run specialist panels to review neonatal deaths.

The report outlines the numbers and patterns of child deaths across our county. It also reports on our performance in reviewing the deaths and sharing the learning. Our numbers are small and therefore we see some fluctuation, but the overall trend is downward. We are completing reviews in a timely manner. COVID has been an additional procedural challenge and we have adapted our processes to continue this important work.

Meradin Peachey

Director of Public Health Berkshire West

Chair of Pan Berkshire Child Death Overview Panel

## **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

## Introduction

In 2008, Child Death Overview Panels were statutorily established in England under the aegis of Local Safeguarding Children Boards (LSCBs) with the responsibility of reviewing the deaths of all children (0 to <18 years) in their resident population.

In October 2018 new guidance from Government titled 'Child Death Review (CDR) Statutory and Operational Guidance' <a href="https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england">https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england</a> set out the key features of a good review process when a child dies, combining both statutory requirements and best practice. The Pan Berkshire CDOP assessed current processes against the new Guidance and put a plan in place to embed the necessary changes. Our formal response to the new Guidance was published on the CDOP website: <a href="New CDOP Arrangements">New CDOP Arrangements — June 2019</a>. The responsibility for CDOP is joint between CCGs and the LAs. CDOP reports to them through the safeguarding partnerships.

During 2020/21 in Berkshire 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. It was made up of representatives from across the county from a range of organisations, including health, social care, education and police. The CDOP also had representation from those with experience of supporting families of children and young people with life limiting conditions and those bereaved through a child's death. This is because experience and evidence tell us that what happens when a child is dying, or has died, can affect how families grieve and their future wellbeing.

Families will often want to know: Why did my child die? Was this death preventable? What lessons can be learnt? 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 as a result 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.

The purpose of the CDOP is to collect and analyse information about each child death in order to:

- Identify any changes that we can make or actions we can take that might help to prevent similar deaths in the future.
- Share learning with colleagues regionally and nationally so the findings will have wider impact.

This process is undertaken locally for all children who are normally resident in Berkshire and is started for any non-resident child that dies unexpectedly.

The aggregated findings from all child deaths should inform local strategic planning, including the local Joint Strategic Needs Assessments (JSNA)s, on how to best safeguard and promote the welfare of children in the area.

## The Pan Berkshire CDOP Process

Working Together to Safeguard Children 2018 sets out a CDOP process for all child deaths and a Sudden Unexpected Death in Childhood (SUDIC) process for when a child dies unexpectedly. The two are separate processes but are closely linked. All child deaths are to be notified to the Designated Person who is the CDOP Coordinator within the Safeguarding Partnership. Following notification, the CDOP Coordinator manages the information gathering and collation with all professionals who have been involved with the child or family prior to the child's death.

The SUDIC process involves early notification of the unexpected death of a child. A prompt process of investigation led by the Designated Paediatrician or Designated Healthcare Professional involves discussion with a range of Child Death Review partners<sup>1</sup>; a visit to the place of death, and a meeting between professionals involved with the child in order to gather information, learn lessons and ensure the family and others are supported. A report into the circumstances of the child's death is produced which is shared with the Coroner, and with the CDOP.

The CDOP panel\* (see below) meets quarterly and during this meeting reviews the death of every Berkshire resident child aged under 18 years to identify any themes, trends and learning. Under the new guidance the CDOP is required to finalise the "Analysis Form" (previously known as a Form C) completed by the Child Death Review meeting generally held 3 – 6 months after the death of the child in regard to its findings in relation to each child's death. The proforma collates information on;

- 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.

\*Membership of the Pan Berkshire CDOP includes:

- Strategic Director of Public Health CDOP Chair
- CDOP Coordinator
- Designated Paediatrician/Designated Health Professional East and West Berkshire
- Police Representative East and West Berkshire

<sup>&</sup>lt;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 CCG 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.

- Ambulance Service Representative
- Local Safeguarding Children Partnerships Business Managers where case relevant
- Children's Social Care Representative
- Bereavement Organisation Representative
- CCG (Clinical Commissioning Group) Representative East and West
- Berkshire Healthcare NHS Foundation Trust (BHFT) Representative
- Head of Midwifery East and West Berkshire
- Paediatrician with a special interest in neonatology East and West Berkshire
- Safeguarding Named Nurse, Frimley Health NHS Foundation Trust
- Hospice Representative
- CCN (Children's Community Nurse) Representative
- Health Visitor/School Nurse Representative
- Other professionals are invited to attend for specific cases or for professional development.

For 2021/2022 the CDOP Panel have agreed to a training placement on the panel for key workers to enable those involved in the pathway to understand the child death process better.

## **Our activity**

This section summarises data from all deaths notified to the Berkshire CDOP between 1<sup>st</sup> April 2020 and 31<sup>st</sup> March 2021. It includes all children who have died in the area and children residing in the area but who have died elsewhere. This data is drawn from the database of Notifications to CDOP (Form A from the National Data Set).

Throughout this report where numbers are <5 the data has been suppressed to prevent the identification of individuals.

The total number of deaths which occurred during April 2020 and March 2021 was 51. The number of neonatal deaths showed a slight increase and those for the older child (28 days – up to 18 years) a small decrease. Because of the low numbers involved, we would expect the year-on-year numbers to fluctuate somewhat, and the changes do not form a clear trend over recent years.

It has been reassuring to see that there have not been any deaths of Berkshire children from COVID-19. This is consistent with the national picture that children are less likely to get seriously ill from this disease.

Figure 1A: Number of deaths (neonates and older children) notified by year

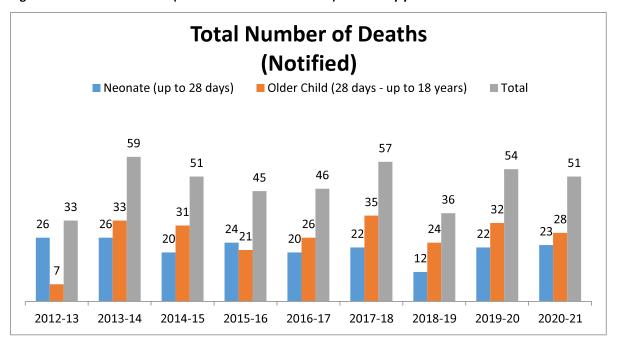
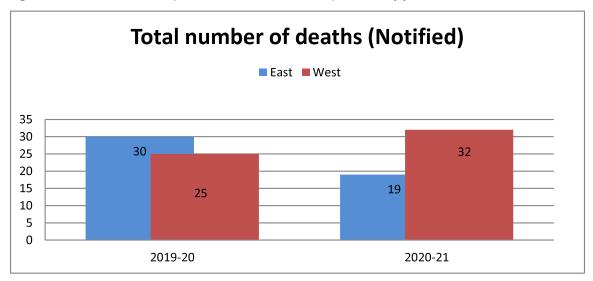


Figure 1B: Number of deaths (neonates and older children) notified by year/East and West Berkshire for 2019/2021



During 2020-21 there were 39 cases reviewed by the panel. The number of notifications and reviews differ as the cases reviewed include deaths notified in previous years but not reviewed until the current 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.

Both local and national timescales have been slower in 2020/2021. This appears to be because of delays within the coronial services during the pandemic, but this will be monitored over the next year. Also, the annual neonatal review which normally takes place in Q1 was cancelled due to lockdown and rescheduled for October/November so will be included in next year's figures.

Figure 2A: Number of Deaths reviewed per year by Berkshire CDOP

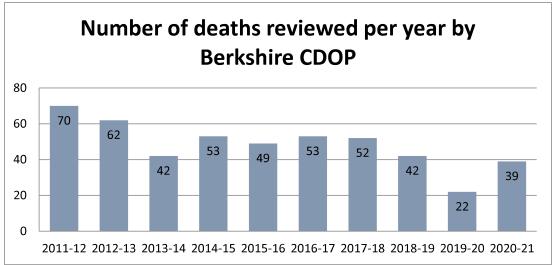
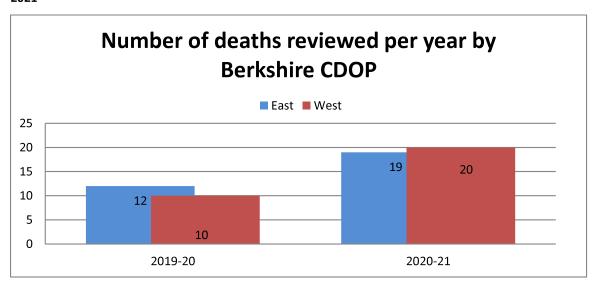


Figure 2B: Number of deaths (neonates and older children) reviewed by year/East and West Berkshire for 2019-2021



In 2020/21, of the 51 deaths that occurred, 39 deaths were reviewed within the year with 56 outstanding at April 2021.

Of the 39 cases that we reviewed during 2020/21:

- 10% were reviewed within 0-6 months of child death
- 41% were reviewed within 6-12 months of child death
- 49% were reviewed 12+ months of child death
- Median number of days between death and the CDOP meeting was on a par with the national figure as follows:
  - o Pan Berkshire CDOP: 364 days
  - o England: 333 days

## Our children

## Age

Across England & Wales, most child deaths occur in children aged under 1.

England & Wales data identifies that the next highest age group for deaths was for children aged 1-4 years. This is similarly reflected in the Berkshire data.

Locally, over the past ten years the pattern of age at time of death has fluctuated slightly. This is to be expected because of the low numbers involved. Over the past 5 years, as can be seen from figure 3, the proportion of deaths in the neonatal period (under 28 days) and older children has changed, with neonatal now accounting for a higher proportion which is back in line with the national picture.

Figure 3: Age at time of death 2016/17-20/21

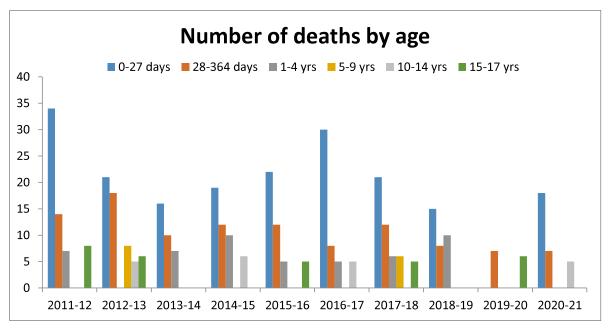
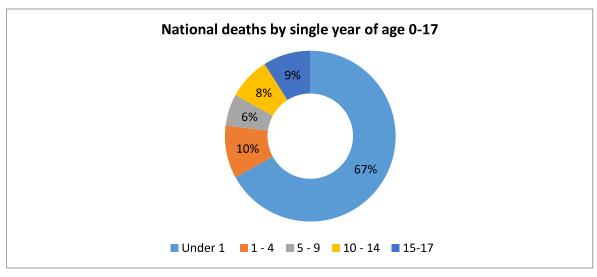


Figure 4: National deaths by single year of age 0-17



Source: ONS: Deaths by single year of age tables - UK 2019

## **Neonatal deaths – Special Review Panel**

In response to the balance of neonatal deaths among the overall numbers of child deaths reviewed, the Berkshire CDOP established a specialist panel in 2016/2017 to better enable the CDOP to consolidate learning.

The panel met for the fifth time in June 2021 to review all neonatal deaths in the period 01/01/2020 – 31/12/2020 and share the learning from this meeting. This meeting was originally scheduled for March 2021 but due to COVID-19 was rescheduled to later in the year. The panel planned to review >26 cases but reviewed 7 in the time allocated due to the more rigorous analysis demanded by recent changes to child death review guidance and the complexity of information gathering via eCDOP. The panel will reconvene in October and November 2021 to close the remaining cases. We plan to schedule 3 neonatal meetings per year from 2022 to determine best outcomes for the neonatal panel.

For the second time we were joined by colleagues from the John Radcliffe Hospital, Oxford and the Child Mortality Team from OUH (Oxford University Hospitals). It was very useful to have colleagues from Oxfordshire as many of our infants are treated at the John Radcliffe Hospital.

Not all the cases reviewed strictly met the criteria for Neonatal Death (a death in a child under 28 days old) but the process for reviewing neonatal deaths was felt to be appropriate as all of the care for our cases had been as inpatients on the neonatal units.

The Neonatal Panel consisted of the following CDOP members:

- Consultant Paediatrician FHFT (Frimley Health Foundation Trust) and Chair of the CDOP Neonatal Panel
- Head of Midwifery FHFT
- Director of Midwifery RBHFT (Royal Berkshire NHS Foundation Trust)
- Consultant Paediatrician RBHFT
- Consultant Community Paediatrician and Designated Doctor for Child Death (East Berkshire)
- Neonatal Consultant, OUH (Oxford University Hospitals)
- Consultant Paediatrician and Designated Doctor for Child Death (Oxfordshire)
- Members of the Child Mortality Team, OUH
- Pan Berkshire CDOP Co-ordinator

Clinical learning of these highly complex cases has been shared in detail with clinical staff. The panel noted the following points whilst carrying out their review:

- There was good antenatal planning with detailed plans for different possible outcomes when abnormalities were possible.
- A key worker was identified early on and involved throughout when needed. It was
  acknowledged however that allocating a key worker remains a challenge. This is reflected in
  feedback from CDOPs nationally.
- Excellent nursing care noted.
- Parents' views were listened to and involvement in all care choices.
- Good use of MDT (multi-disciplinary teams).

Further learning will be shared in next year's report when the remaining neonates are reviewed by the panel during 2021.

## Gender

Figure 7 shows the pattern of deaths for males and females. Over the last five years there have been more notifications of male deaths than female deaths. In 2020/2021: 67% were males and 33% females.

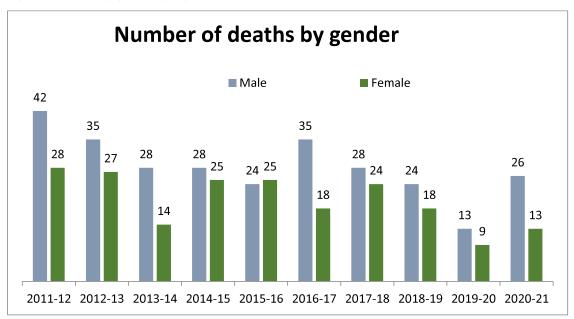


Figure 7: Deaths by gender, per year

## **Ethnicity**

The 2011 census, found Berkshire's general population to be 80.04% white with some Boroughs having more ethnic diversity than others, particularly Slough and Reading.

Figure 8 shows rates per 100,000 of the Berkshire population to compare ethnic groups. The white population group has lower rates than other ethnic groupings.

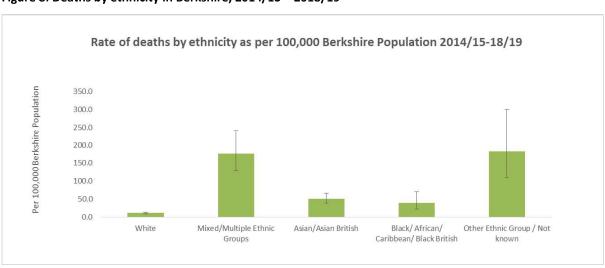
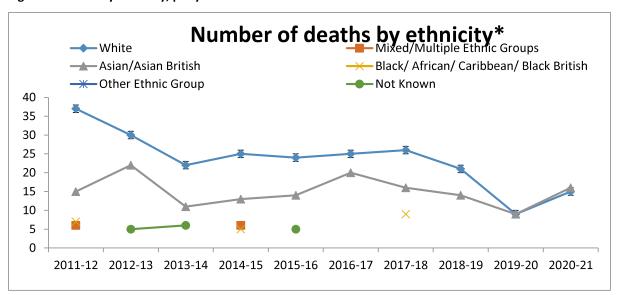


Figure 8: Deaths by ethnicity in Berkshire, 2014/15 – 2018/19

Figure 9: Deaths by ethnicity, per year



Although the numbers are small, cases of child death are proportionally higher in White and Asian/Asian British children. This pattern has been noted in previous CDOP annual reports and fits with the national picture.

## **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'.

Nationally the proportion of deaths which were assessed as having modifiable factors remains at 34% in 2020/2021. Locally in 2020/2021 of all cases reviewed 33% were considered to have modifiable factors including:

- Smoking in pregnancy
- Co-sleeping
- Animals
- Unsafe sleeping
- If road traffic rules and driving rules had been followed, a death could have been avoided
- The consideration of matching the car with the experience of the driver
- Investigations have identified that the barrier causing a fatal head injury was inadequately fixed
- Preventable death if child had been protected from possible gang crime
- Red flags for raised intracranial pressure (lethargy, sleeping a lot and vomiting) not recognised at school or first contact with ambulance service
- Communication/teamwork issue between DGH (District General Hospital) and tertiary centre time critical transfer pathway not followed. Local team knew the plan well and thus this did not cause a delay in transfer

• Tertiary centre organisational issue - knowledge of the time critical pathway for emergency transfers.

Some modifiable factors were relevant to more than one child death.

Each year, the panel takes a close look at deaths where modifiable factors occur, in order to learn lessons in the future.

Panel members are tasked with taking the learning from these cases and sharing it widely within their organisations in order that health and social care staff are aware of the risk factors when supporting and advising parents and carers.

## **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.

## **Summary of CDOP key findings during 2020-21**

- A Pan Berkshire/Thames Valley Suicide Audit 2015 2020 for 0-25-year-olds was carried out, led by NHS England. The CDOP Exec will review the report and learning will be shared within the CDRM (Child Death Review Meeting) community. The findings will contribute to a 'life course' renewed suicide prevention strategy and plan in Berkshire in 2022. There has been concern raised at a national level of an increase in the rate of suicides across all ages during the pandemic. This does not appear to be the case in Berkshire but the CDOP will continue to monitor the data for 2021/2022.
- A second Joint Themed Review was held during 2020/21 on SUDEP (Sudden Unexpected Death in Epilepsy) involving the CDOPs of Berkshire, Oxfordshire and Buckinghamshire. This has enabled the sharing of knowledge and learning across all systems. Further reviews are planned for 2021/2022.
- A local thematic review was carried out on the role of the key worker. It was agreed that a priority would be to develop a training course bespoke to key workers in child death in the Pan-Berkshire area. This should cover both the CDOP process, the key worker role and communication skills for bereaved families.
- An audit of compliance to the new child death review guidance of 2018 was carried out using eCDOP within Berkshire East. It revealed that CDOP were largely compliant with many areas of good practice identified. Similarly, there were areas of improvement, which will be followed up with a plan to re-audit in 2022. Berkshire West will carry out a similar audit to get the full picture.
- The notification process was strengthened with the release of updated guidance regarding anomaly notifications ie when the notification of a child death comes in via email, telephone or text and not eCDOP.
- The CDOP Database (in the form of a data extract) was transferred from Slough Borough Council (SBC) to Bracknell Forest Council by liaising with SBC IT and the Shared Team at Bracknell Forest.
- The move of the CDOP Coordinator (via TUPE) from Slough Borough Council to Bracknell Forest Council was successfully arranged in June 2021.
- CDOP has been working with the Frimley ICS (Integrated Care System) to work sensitively with local communities around consanguinity risks.

## Reflections on the work of CDOP

## **The Panel - Changes**

2020/2021 has continued to be challenging during the COVID-19 pandemic. Colleagues have worked hard to adapt our response and manage the impact on families and babies.

During the past year the panel has continued to maintain good operational performance against national standards whilst incorporating the changes to Child Death Review and despite difficult circumstances due to COVID-19. As a result of COVID-19 face-to-face CDOP meetings ceased in March 2020 and arrangements were swiftly made to hold the CDOP Exec and Case review meetings virtually via Teams. This arrangement for remote meeting continues. The CDOP has been well attended by relevant partners. Discussions are thorough and considered of high quality.

## **Challenges**

- An increase in the number of Joint Agency Responses held including 18 in Berkshire West making it the highest number since CDOP was established in 2008
- The complexity of cases and the number of Home Office Post Mortems
- The appointment of key workers with knowledge/capacity
- The appointment of a key worker for the unexpected medical death in a child <5 years old</li>
- Capacity with the RBHT (Royal Berkshire Foundation Trust) to case manage the volume unexpected child deaths
- COVID lockdown has meant delays in the coronial process and the availability of face-to-face bereavement support for parents/carers/siblings/families
- A Medical Examiner for <18 years is not yet in place</li>

Compliance with October 2018 – Child Death Review (CDR) Statutory and Operational Guidance has largely been achieved including:

- Child Death Review meetings are established
- Thematic reviews are established
- A JAR (Joint Agency Response) process for all unexpected child deaths in 2020/21 was triggered
- When a child dies: A guide for parents and carers is available
- Key workers have been appointed for all child deaths:

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 < 5 years	Health Visitor
Otherwise	Decided in JAR

#### **Staffing**

Succession planning is in place for the replacement of the Designated Professional for Berkshire West. From 1<sup>st</sup> April 2021 Dr K, Consultant Paediatrician, will be shadowing the Designated Professional taking on the title of Designated Doctor for Child Death from Autumn 2021 and taking over fully on 31<sup>st</sup> December 2021.

The CDOP plan to appoint a part-time administrator during 2021 to support the CDOP Coordinator.

## **Training**

Training entitled Saving Young Lives Child Death – Overview and learning sessions have been provided at all face-to-face full day RBFT Level 3 child safeguarding days.

A half day TEAMS multiagency training session was given to the BHFT Rapid Response nursing team to provide a joint home visit.

#### **eCDOP**

The embedment of eCDOP has continued at pace this year and awareness and knowledge of eCDOP is now well established within the CDR community. Training with partners continues, most recently with Primary Care colleagues. The CDOP Coordinator provides online support to users and attends eCDOP and NCMD (National Child Mortality Database) webinars to receive updates; share learning and network with the CDOP community.

#### LeDeR

The panel notified 3 cases to the LeDeR (Learning Disability Mortality Review) based at the University of Bristol. Cases will be reviewed locally within the LeDeR network and information shared with the CDOP when relevant.

#### Pan Berkshire CDOP Website

The Pan Berkshire CDOP Website is located here - https://www.berkshirewestccg.nhs.uk/cdop

#### Themed reviews

Two Joint Themed Reviews have been held with CDOP colleagues from Berkshire, Oxfordshire and Buckinghamshire on Haem-oncology and SUDEP. Local learning has been shared and applied across the wider system.

The panel shared learning via the CDOP newsletter on keeping children safe during lockdown and window and water safety for parents and carers: <u>document link here</u>

## Partnership working

Close partnership working continues with the Child Mortality Team at Oxford who provide case information for Berkshire children who die in Oxfordshire hospitals.

The CDOP Coordinator attends the eCDOP Regional User Group Webinar (South East) to network with other users and look for ways to enhance and improve the eCDOP system.

The CDOP South Network goes from strength to strength with 13 counties in the South now represented. It is a very successful and supportive networking forum for CDOP managers, coordinators and administrators that meets regularly. Berkshire held the most recent session in July and there was a presentation from Surrey around the role of the key worker.

## **Priorities for 2021/22**

- To work with partner agencies in Berkshire West ICP (Integrated Care Partnership) to develop
  a robust strategic approach plan to adolescent risk reduction and contextual safeguarding,
  including Reading Festival.
- To work with CDOP colleagues across Berkshire, Oxfordshire and Buckinghamshire ICS through a Safe Sleeping task and finish group. The project will include a 3-year audit of cases through collaboration with public health colleagues and the University of Reading to explore behavioural research.
- To work with the Lead Medical Examiner to explore the Medical Examiner model for <18
  years.</li>
- It is recognised that it is possible that the impact of the pandemic may be seen in the years to come and this will be closely monitored by CDOP.

Lorna Tunstall

Pan Berkshire CDOP Coordinator, September 2021



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