Pan Berkshire CDOP Annual Report

2019/20

Berkshire West Safeguarding Children Partnership
Reading | West Berkshire | Wokingham

Bracknell Forest SAFEGUARDING BOARD

Royal Borough of Windsor & Maidenhead Safeguarding Partnership

Slough Safeguarding Partnership

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FOREWORD

Preventing deaths in children is an issue we take seriously in Berkshire. Our Child Death Overview Panel 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.

There is a broad network of committed and inspirational professionals across Berkshire who involved in this work and it is a pleasure to work alongside them. Their work is often unseen but absolutely 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.

Tessa Lindfield

Strategic Director of Public Health for Berkshire

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

November 2020 - Tessa Lindfield has now stepped down as Chair of Pan Berkshire CDOP and colleagues would like to thank her for all her hard work and wish her well for the future.

Introduction

In 2008, Child Death Overview Panels (CDOPs) 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' https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england 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: New CDOP Arrangements – June 2019

During 2019/20 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 (or Boards) 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 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 tells 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, (as required by the Local Safeguarding Children Boards Regulations 2006) 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[1]; 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 although this year there were 5 meetings and during this meeting reviews the death of every Berkshire resident child aged under 18 years in order 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
- Ambulance Service Representative
- Local Safeguarding Children Board Business Managers – where case relevant

[1] 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.

- Children's Social Care Representative
- Bereavement Organisation Representative
- CCG 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 Representative
- Health Visitor/School Nurse Representative

Other professionals are invited to attend for specific cases or for professional development.

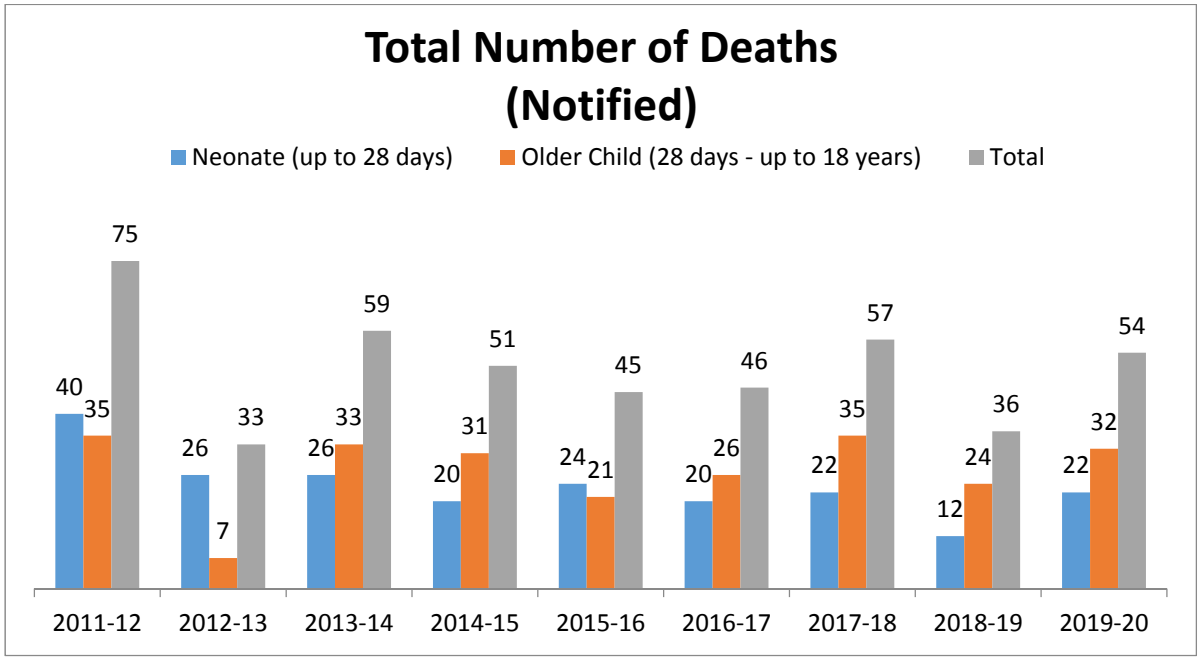
Our Activity

This section summarises data from all deaths notified to the Berkshire CDOP between 1st April 2019 and 31st March 2020. 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.

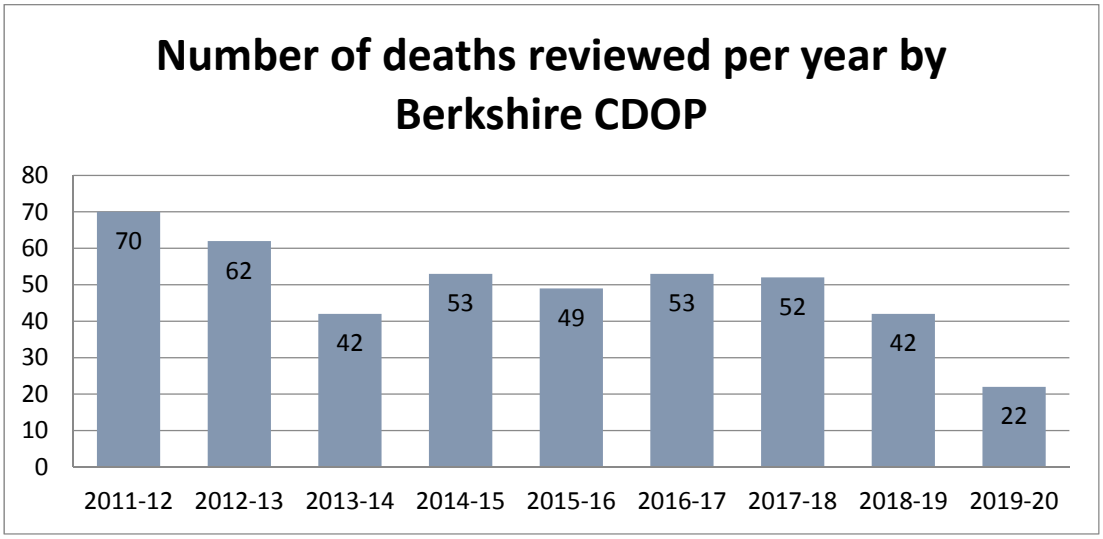
The total number of deaths which occurred during April 2019 and March 2020 was 54. The number of neonatal deaths and those for the older child (28 days – up to 18 years) all increased this year. Because of the low numbers involved, we would expect the year on year numbers to fluctuate somewhat and the changes do not form a clear trend over recent years.

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



During 2019-20 there were 22 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. However, this year the panel exceptionally reviewed a smaller number of cases than usual due to the effects of COVID-19. The annual neonatal review which normally takes place in Q1 was cancelled due to lockdown and rescheduled for June 2020 so will be included in next year's figures.

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



In 2019/20, of the 54 deaths that occurred, 22 deaths were reviewed within the year with 32 outstanding at April 2020.

Of the 22 cases that we reviewed during 2019/20:

- 45% were reviewed within 0-6 months of child death
- 45% were reviewed within 6-12 months of child death
- 9% were reviewed 12+ months of child death

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 eight 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[2]. In 2019-20 54% of actual deaths in year were in children under 1 year (and of reviewed deaths 43% were under 1 year). This is broadly consistent with the national figure (63%).

Figure 3: Age at time of death 2016/17-19/20

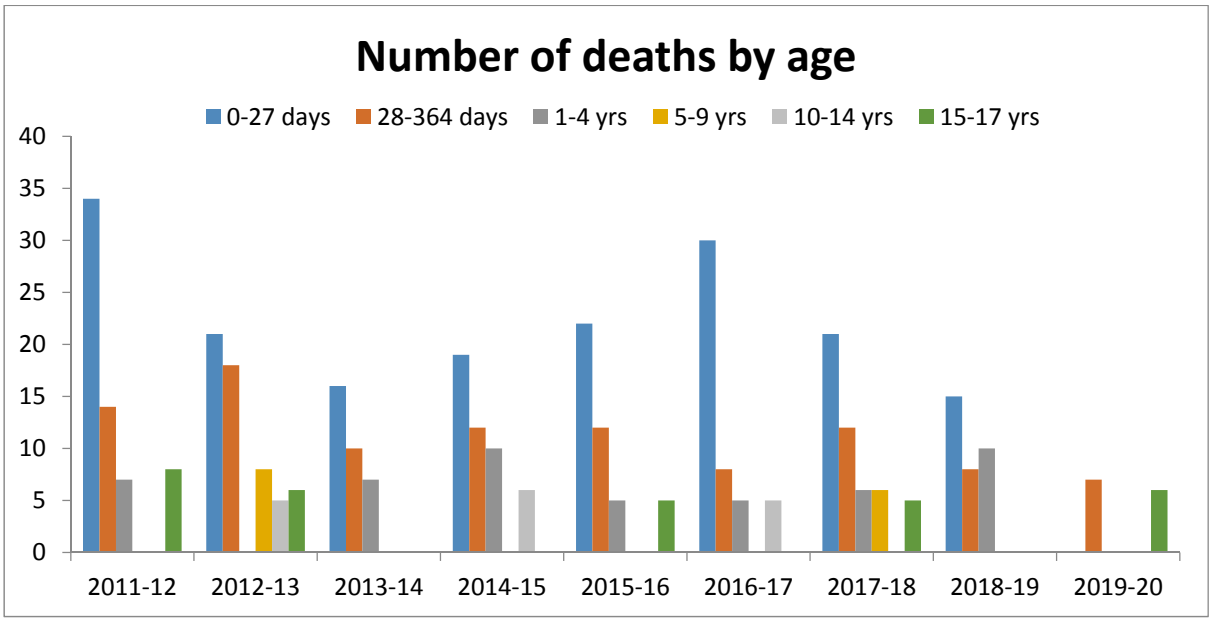
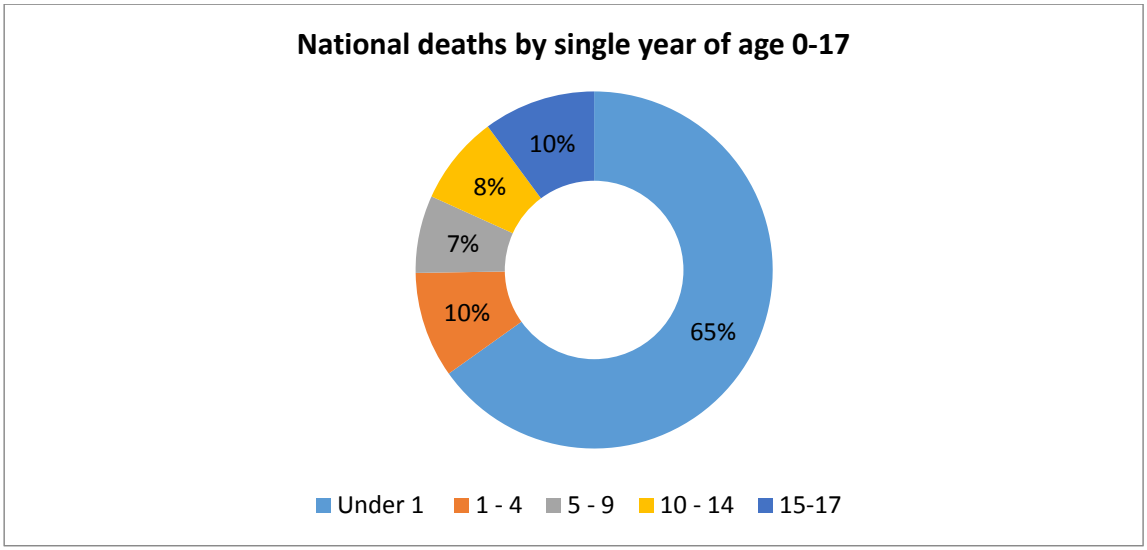


Figure 4: National deaths by single year of age 0-17

[2] The latest national data for the period 2014-16 states there are 2.74 per 1,000 deaths for neonatal mortality and 1.14 per 1,000 deaths for post-neonatal mortality. Source: PHE Child health mortality profile. https://fingertips.phe.org.uk/profile-group/child-health/profile/child-health-mortality



Source: *ONS: Deaths by single year of age, England and Wales 2017*

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 the possible learning.

The panel met for the fourth time in June 2020 to review all neonatal deaths in the period 01/01/2019 – 31/12/2019 and share the learning from this meeting. This meeting was originally scheduled for March 2020 but due to COVID-19 was rescheduled to later in the year.

For the first 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:

- Regular review of clinical practice in the management of necrotising colitis and consider atypical signs.
- Encouragement of breast feeding.
- Involving parents in the Forget-Me-Not study.
- Extensive reviews were undertaken with good clinical representation.
- Women with antenatal bleeding continue to be invited for obstetric review.

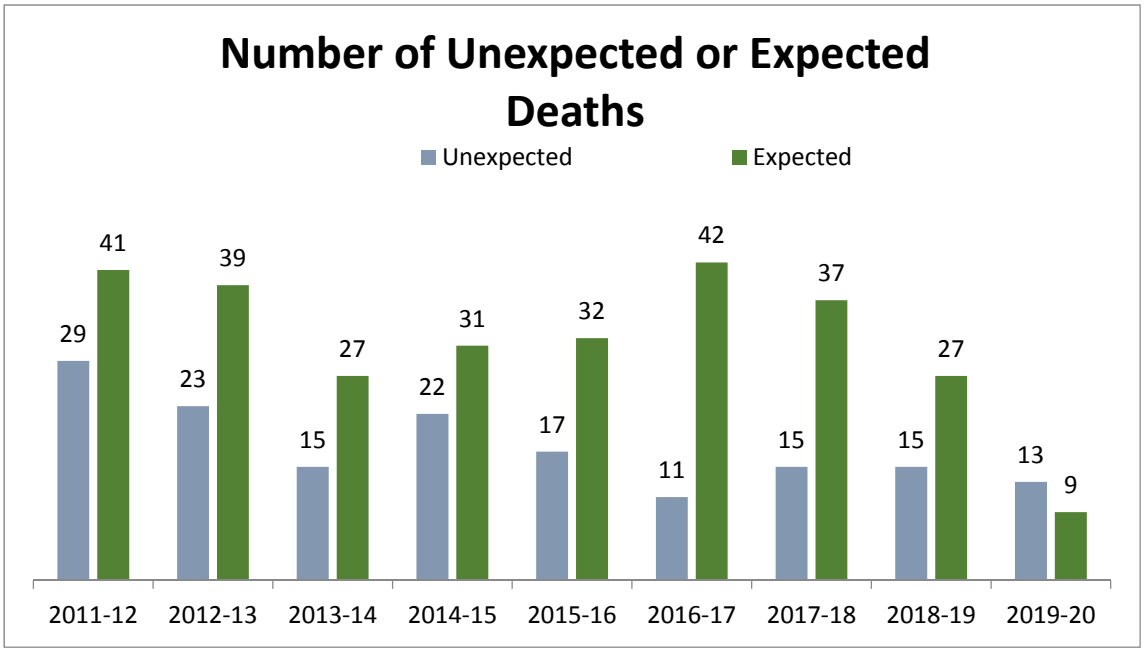
- There was good antenatal planning with detailed plans for different possible outcomes when abnormalities were possible.
- A Key Worker was identified early on and involved throughout when needed.
- Excellent nursing care noted.
- Parents' views were listened to and involvement in all care choices.
- Good use of MDT (multi-disciplinary teams).
- Continue to circulate antenatal letters widely in complex antenatal diagnoses to appropriate clinical staff involved in the care of the child and family.

Expected and Unexpected Deaths

An unexpected death is defined as 'the death of an infant or child which was not anticipated as a significant possibility for example, 24 hours before the death or where there was an unexpected collapse or incident leading to or precipitating the events which lead to the death.'

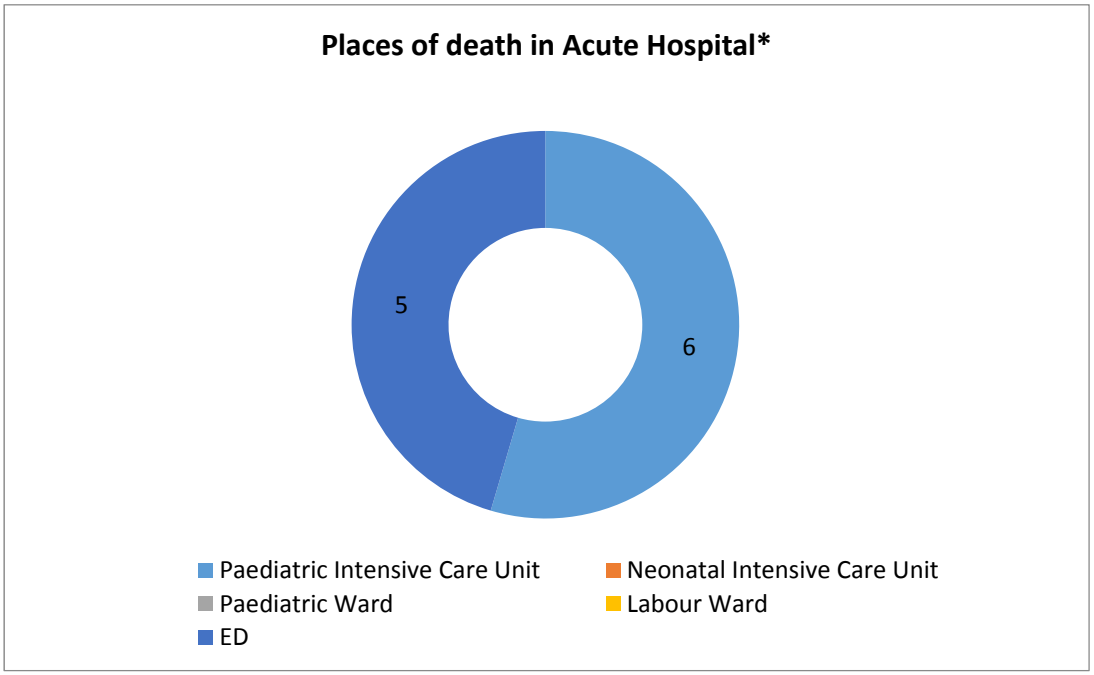
Looking at all the deaths in 0-18 years in 2019/2020 13 unexpected deaths were reviewed. 12 have documented joint agency reviews[3]. The remaining case was unexpected but explained and didn't meet the criteria for a Joint Agency Response (JAR). During the last eight years the proportion of unexpected deaths has fallen overall with the number dropping slightly this year. 68% of all deaths occur within the hospital setting. Figure 6 overleaf is a breakdown of location of death within a hospital setting.

Figure 5: Number of Unexpected or Expected Deaths, by Year



[3] Rapid Response Protocol here: http://www.westberkslscb.org.uk/professionals-volunteers/cdop/

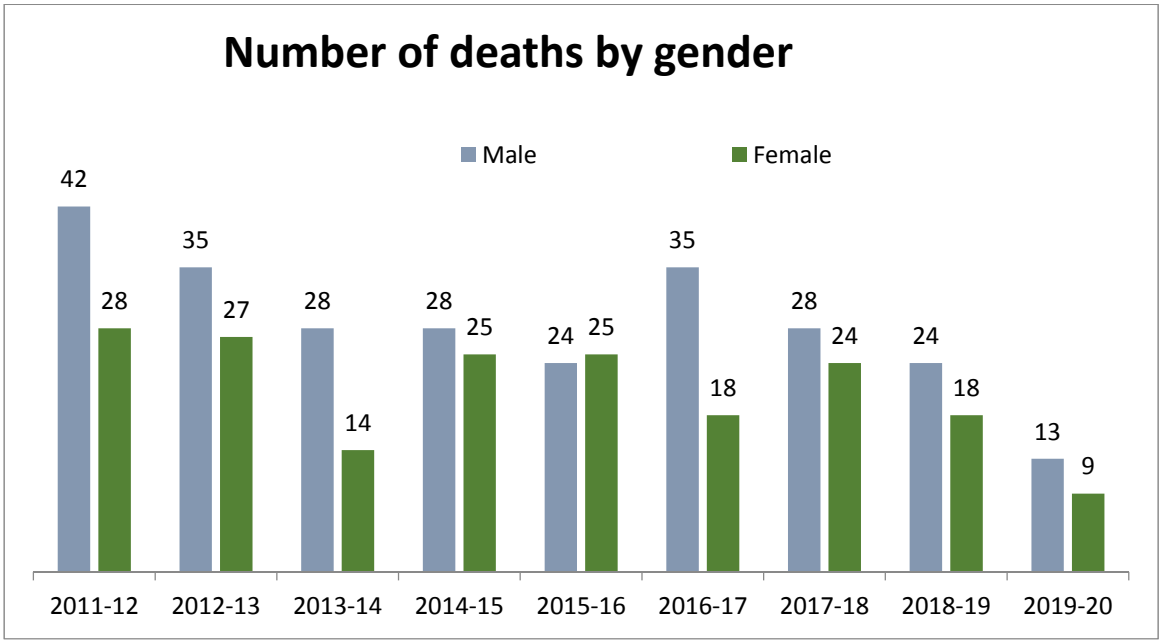
Figure 6: Places of death in Acute Hospital
***Numbers are suppressed in some categories because there are <5.**



Gender

Figure 7 shows the pattern of deaths for males and females. Over the last eight years there have been more notifications of male deaths than female deaths. In 2019/2020: 59% were males and 41% 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

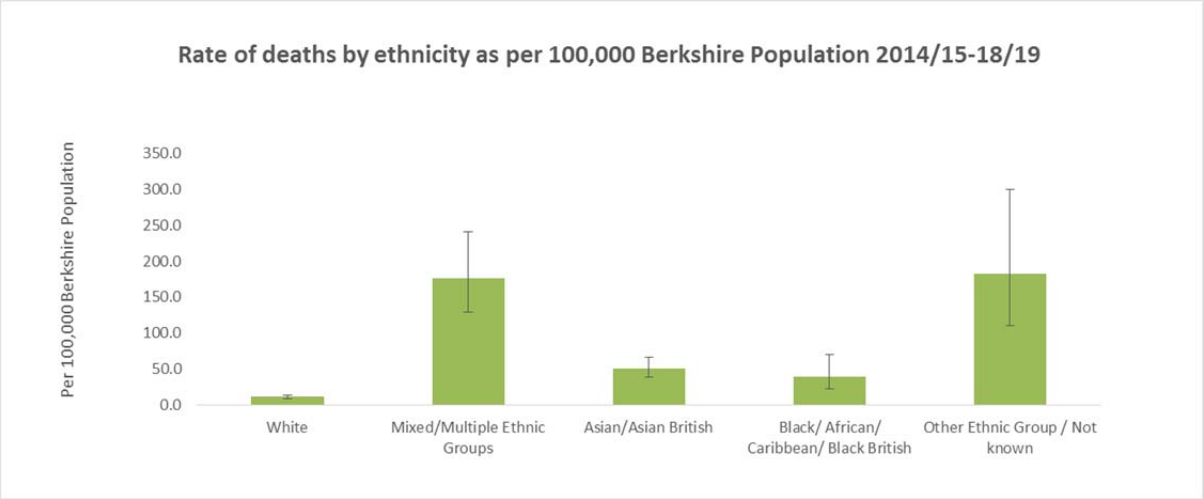
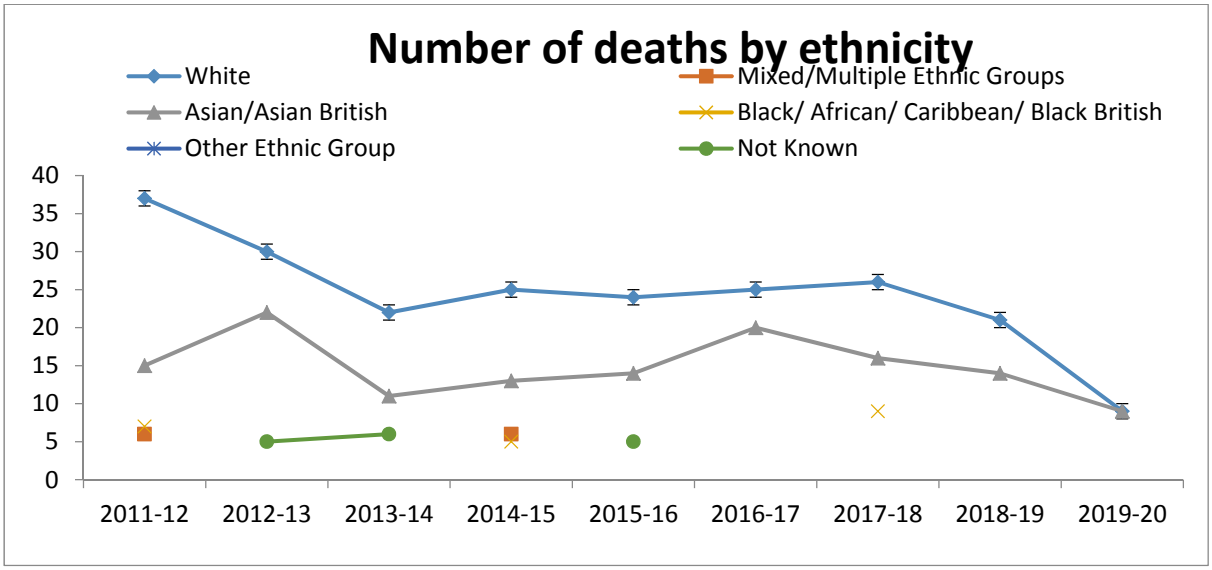


Figure 9: Deaths by ethnicity, per year



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 also 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 30% in 2019/2020. Locally in 2019/2020 of all cases reviewed 23% were considered to have modifiable factors including:

- Consanguinity
- Smoking in pregnancy
- Co-sleeping

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 2019-20

See Pages 10/11 for learning from the annual neonatal review

Specific areas for learning have been identified by the panel around:

- Learning about exam pressures in young people which may lead to self-harm.
- An opportunity to learn and review the pathway for children, and young people with VP shunts with the aim to develop an agency wide pathway improvement plan.
- Both West and East of Berkshire reported that implementation of the new Child Death Review arrangements is going well but key workers and case management are challenges.
- The need to continue to work sensitively with local communities around consanguinity risks.
- The need to reinforce the safe sleeping message for all contacts with babies/infants less than 1 year.
- Arrangements have now been made with the Coroner so that out-of-hours family viewing of a body will be made on a case by case basis. This applies to Berkshire hospitals. Contact with the coroner will be required in all cases as there are various factors that would inform the coroner's decision.
- There were issues with the transportation of a child's body following their death. After consideration by the panel it was agreed that that a child's body should be conveyed by ambulance with the full engagement of the family.

Reflections on the work of CDOP

The Panel - Changes

2019/2020 has been a year of two parts: pre-COVID and Q3 onwards 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. The CDOP has been well attended by relevant partners. Discussions are thorough and considered of high quality.

Campaigns

Lift the Baby

There have been several cases of infant death due to unsafe sleeping during the year and this remains an area of focus for the CDOP. The panel agreed that it was vital for all professionals to reinforce the safe sleeping message for all contacts with babies/infants less than 1 year and to continue to promote the Lift the Baby video. The video is aimed at promoting safer sleeping in younger babies.

www.liftthebaby.org.uk

Learning from Reading Festival 2019

A Reading multi-agency partnership group continued worked with Festival Republic, to further develop safety and safeguarding policy, practice and process. Updates were given to CDOP and the Berkshire West Safeguarding Partnership in the months leading up to 23 – 25 August 2019 and tested at a table top exercise and safeguarding partnership meeting. During the autumn/winter of 2019 we planned an engagement exercise with young people and their parents. The focus was on 'sex, bodies, consent and assault' and 'substances, alcohol, risk and choices' at events and risk reduction. A multiagency group of Royal Berkshire Hospitals NHS Foundation Trust, Festival Republic, It Happens, Brighter Futures for Children, youth services, schools and colleges in Reading, West Berkshire and Wokingham were part of this. Plans were well advanced to carry out a piece of qualitative research – questionnaires and workshops with schools and colleges across Berkshire West during April and May and a quantitative survey later in 2020. This was delayed due to Covid19.

Training

Training was delivered - particularly for on-call Detective Inspectors - in relation to the unexpected child death process by Health and the Police in the East and as part of a safeguarding disabled children day run by Health in the West.

The CDOP Coordinator attended an interactive learning event entitled Consanguineous Marriage & Genetic Risk at Sheffield University as consanguinity continues to be an area of focus for the CDOP. Learning was shared with the panel.

eCDOP

The embedment of eCDOP has continued at pace this year and awareness and knowledge of eCDOP is now much greater within the CDR community. Training with partners has continued to include sessions with GPs, RBH staff, health visitors, school nurses and the CCN team. 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 6 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 has relocated to the Berkshire West CCG - https://www.berkshirewestccg.nhs.uk/cdop

Themed Reviews

There was a Joint Themed Review held in March 2020 on Haematology Oncology involving the CDOPs of Berkshire, Oxfordshire and Buckinghamshire. Local learning has been shared and applied across the wider system. In particular there was sharing of information about specialist bereavement services available in the region. The consensus was it was an extremely successful event and would be a good idea to invite junior doctors to attend as part of their training.

An 11-year review of Neurodisability deaths (ND) in Berkshire was carried out by a local registrar and presented to BACD: *What can we do to improve end of life care for our Neurodisability population?*

The panel shared learning via the CDOP newsletter on safety around water; identifying and responding to suicide clusters and firework and bonfire safety.

Using data provided by SCAS (South Central Ambulance Service) the CDOP carried out a review of drownings and near drownings over 5 years within Berkshire.

Partnership Working

As a result of negotiation the newly created Child Mortality Team at Oxford have agreed to work closely with Pan Berkshire CDOP and 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.

Pan Berkshire CDOP organised the first local peer group session and CDOP reps from Buckinghamshire, Oxfordshire, Surrey, Sussex and Hampshire attended. This was held via teleconference and was a very successful networking forum; learning was shared with the group. As a result, more network meetings in this format have been planned.

Priorities for 2020/21

For 2020/2021 we will be carrying out thematic reviews on the following:

- A Pan Berkshire/Thames Valley Suicide Audit 2015 – 2020 for 0-25 year olds will be carried out led by NHS England. The findings will contribute to a 'life course' renewed suicide prevention strategy and plan in Berkshire in 2021, a second part of the audit will look at death in this age group as a result of self-harm involving substance abuse/alcohol.

- A second Joint Themed Review will be held during 2020/21 on SUDEP (Sudden Unexpected Death in Epilepsy) involving the CDOPs of Berkshire, Oxfordshire and Buckinghamshire.

- A local thematic review will be carried out on the role of the key worker.

- Review support responses to critical incidents involving children and young people to strengthen cross boundary working.

- Manage the transfer of the CDOP Database (in the form of a data extract) from Slough Borough Council to Bracknell Forest Council by liaising with SBC IT and the Shared Team at Bracknell Forest.

- Learning from unexpected deaths in infants, will be combined with learning from cases where infants have suffered significant harm and our response to 'Out of Routine: A review of sudden expected deaths in infancy (SUDI) in families where the children are considered at risk of significant harm.' July 2020 published on behalf of the National Safeguarding Practice Review Panel.

- Revisit our local response to safe sleeping in light of more active care giving by fathers.

- Consider how we will review the deaths of care leavers who are > 18 years so that lessons can be learnt and shared.

Lorna Tunstall

Pan Berkshire CDOP Coordinator, December 2020

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