Pan Berkshire

# CDOP Annual Report

2016/17

Windsor and Maidenhead
LOCAL SAFEGUARDING
CHILDREN BOARD

Reading Local
Safeguarding
Children Board

# Introduction

> *There is no tragedy in life like the death of a child.*
>
> *Things never get back to the way they were.*

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 Berkshire the CDOP is a subgroup of the six Unitary Authority Local Safeguarding Children Boards. It is made up of representatives from across the county from a range of organisations, including health, social care and police. The CDOP also has representation from those with experience of supporting families 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 face life with this sorrow always present.

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 Berkshire CDOP has a professional interest in seeking answers to these questions with the intention of trying to prevent future child deaths. In undertaking this work it also reflects on how better to understand and support bereaved 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 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 Assessment (JSNA), on how to best safeguard and promote the welfare of children in the area.

Every CDOP should prepare an annual report of relevant information for the LSCB. This information should in turn inform the LSCB Annual Report. This is the 2016/17 report of the Berkshire CDOP panel. The report reflects the continued commitment of its members to ensuring that we review with rigour and care each individual tragedy and support the system in identifying key learning and opportunities to develop our responses.

**Rachael Wardell**
*(Corporate Director – Communities, West Berkshire Council)*
*Acting Chair of Berkshire Child Death Overview Panel*

# Berkshire CDOP Process

Working Together to Safeguard Children 2015 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 closely linked. All child deaths are to be notified to the Designated Person within the LSCB. The Designated Person is the CDOP Coordinator. Following notification the CDOP Coordinator manages the information gathering and collation with all professionals who have been involved with the child or family prior 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 involving discussion with a range of partners, 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 meets quarterly and during this meeting reviews the death of every Berkshire resident child aged under 18 years and is required to complete a national proforma regarding its findings in respect each child's death. The proforma includes factors relating to:

- the child and family, and service provision;
- categorization 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 LSCB Chair for consideration of a Serious Case Review.

**Membership of the Berkshire CDOP includes:**

- Director of Public Health - CDOP Chair
- CDOP Coordinator
- Designated Paediatrician/Designated Health Professional – East and West Berkshire
- Public Health Representative
- Police Representative – East and West Berkshire
- Ambulance Service Representative
- Local Safeguarding Children Board Business Managers – where case relevant
- Children's Social Care Representative
- Bereavement Organisation Representative
- CCG Representative – East and West
- Berkshire Healthcare NHS Foundation Trust 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
- Named Midwife for Safeguarding, Frimley Health NHS Foundation Trust

Other professionals are invited to attend for specific cases or for professional development. The work of CDOPs is aggregated nationally in a Statistical Release by the Department for Education. The latest such release was published for the year ending March 2017[1] .

# Our Activity

This section summarises all deaths notified to the Berkshire CDOP between April 1st 2011 and 31st March 2017. 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).

The total number of deaths which occurred during April 2016 and March 2017 was 46. Since 2011-12, whilst there have been some random fluctuations in numbers of deaths, there is a downward trend overall in the total number of deaths notified.

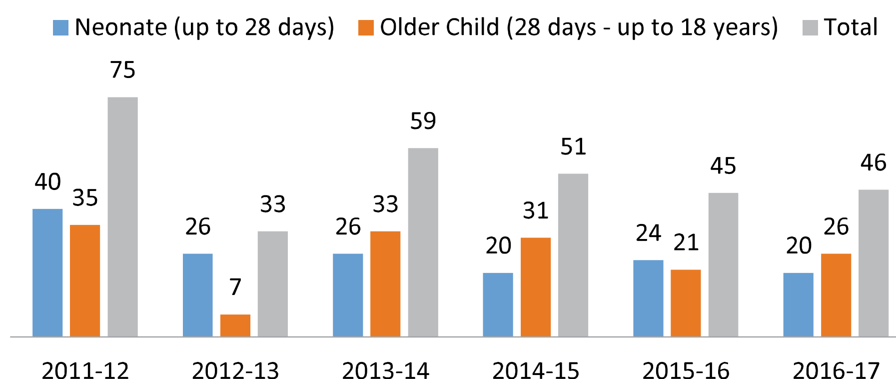


*Figure 1: Number of deaths (neonates and older children) notified by year*

During 2016-17 there were 53 cases reviewed by the panel. The numbers differ as the cases reviewed include deaths notified in previous years but not reviewed until the current year. This slight 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.

[1] *www.gov.uk/government/statistics/child-death-reviews-year-ending-31-march-2017*

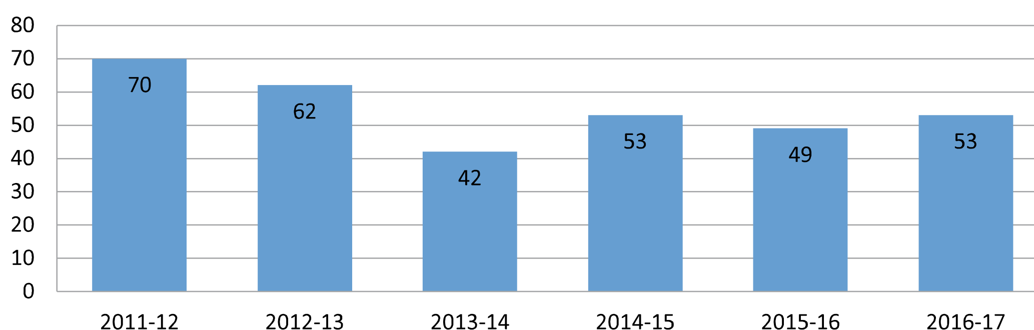


*Figure 2 – Number of deaths reviewed, by year.*

In 2016/17 of the 46 deaths that occurred, 39 deaths were reviewed within the year with 7 outstanding at April 2017.

Of the cases that we reviewed during 2016/17:

- Reviewed cases - 53 deaths
- 34 (64%) were reviewed within 0-6 months of child death
- 15 (28%) were reviewed within 6-12 months of child death
- 4 (8%) were reviewed 12+ months of child death

Nationally 76% of cases are reviewed within 12 months: locally this year we achieved closure on 92% of cases within 12 months.

In cases where modifiable factors were identified (see later for definition) we would expect the process to be longer, indeed this is seen nationally. However locally we managed to achieve a similar timescale to those cases without identified factors.

- Reviewed deaths with modifiable factors: 7
- 5 (71%) were reviewed within 0-6 months of child death
- 2 (29%) were reviewed within 6-12 months of child death

We reported in last year's Annual Report 2015/2016 that there were three outstanding cases not yet reviewed. All these case remained outstanding as at end March 2017.

# Our Children

## Age

Nationally the information shows that most children's' deaths occur in children aged under one.

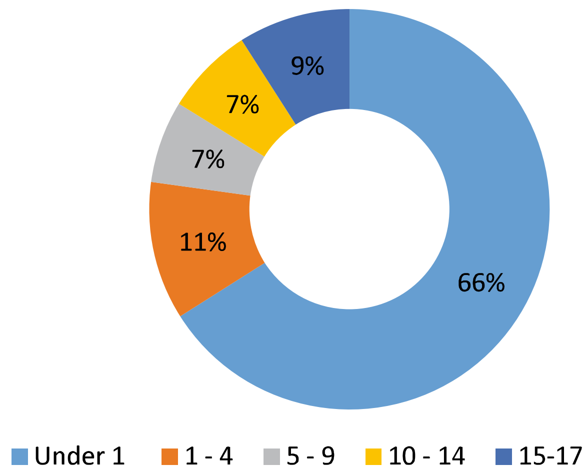


*Figure 3: National deaths by single year of age*

National data identifies that the next highest age group for mortality was for children aged 1-4 years. This is similarly reflected in the Berkshire data. This may be due to the influence of congenital abnormalities as a major underlying factor that will be discussed later.

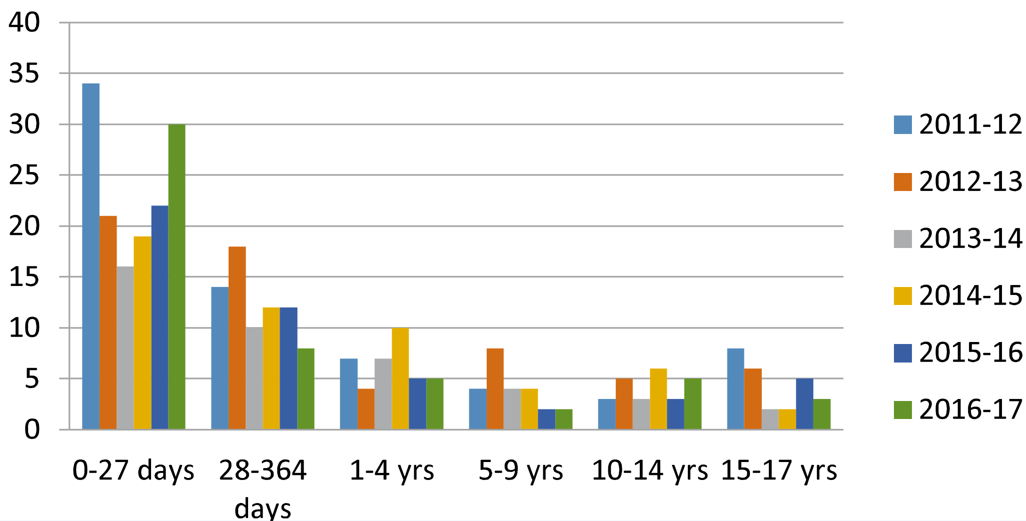


*Figure 4: Age at time of death 2011 – 2017*

Locally over the past six years the pattern of age at time of death has fluctuated slightly. In the past year, as can be seen from figure 4, 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 2016-17 68.8% of actual deaths in year were in children under 1 year (and of reviewed deaths 69.4% were under 1 year) which is broadly consistent with the national figure (66%).

## Neonatal Deaths – Special Review Panel

In response to the high proportion of neonatal deaths among the overall numbers of child deaths reviewed, the Berkshire CDOP established a specialist panel to better enable the CDOP to consolidate the possible learning.

The panel consisted of CDOP members Dr Peter de Halpert (RBFT), Gill Valentine (RBFT) and Dr Rekha Sanghavi (FHFT), supported by Lorna Tunstall (CDOP). Of the 20 deaths reviewed by the panel (which included three deaths at 22 weeks gestation, a gestational age not usually considered by the CDOP), ten (seven, plus the three deaths at 22 weeks) were found to be caused by perinatal factors and ten caused by chromosomal/genetic factors. Only one of the deaths caused by perinatal factors occurred at term; all the other deaths occurred at a gestational age of pre-30 weeks. By contrast all but one of the deaths caused by chromosomal/genetic factors occurred at or after term.

**This review identified the following learning points:**

- There are challenges for parents in identifying and receiving appropriate bereavement support when an infant's care has transferred between two or more hospitals.
- In 2 cases of preterm labour, mothers were seen with signs and symptoms of a UTI a few days prior to spontaneous labour. Neither case was treated. While this may not have been causative, it is recognised that infection can trigger preterm labour. It is recommended to treat clinical UTIs in pregnancy.
- There was concern that not all cases have been notified to CDOP. The CDOP coordinator will contact local trusts to double check.
- The majority of the chromosomal/genetic factor cases were ante-natally diagnosed, and parents elected to continue with the pregnancy after counselling. The deaths were, in these cases, "expected" deaths.
- 3 of the 10 chromosomal/genetic factor cases were associated with consanguinity.
- There appears to be a cluster of chromosomal/genetic factor deaths with Potters syndrome. However there is no association with modifiable factors that can be made. It is considered likely that this is a statistical blip. The CDOP will seek to clarify this through the use of longitudinal data.
- Midwifery representation from Frimley Health will be sought for the neonatal subgroup.
- The clinical neonatal group unanimously felt that 22/40 gestation babies should not be included in the analysis as all national and network guidance states that these babies should not be resuscitated (unless there are exceptional circumstances). As such they have been separated out for the purpose of this report.

[2] *The latest data for this (2013-15) states there are 2.71 per 1,000 deaths for neonatal mortality and 1.18 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*

## 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.'

In the past year, 11 cases where there were unexpected deaths were reviewed. All have documented rapid response reviews [3]. During the last six years the proportion of unexpected deaths continues to show a downward trend, with the lowest number of unexpected deaths this year. Over 90% of all deaths now occur within the hospital setting.

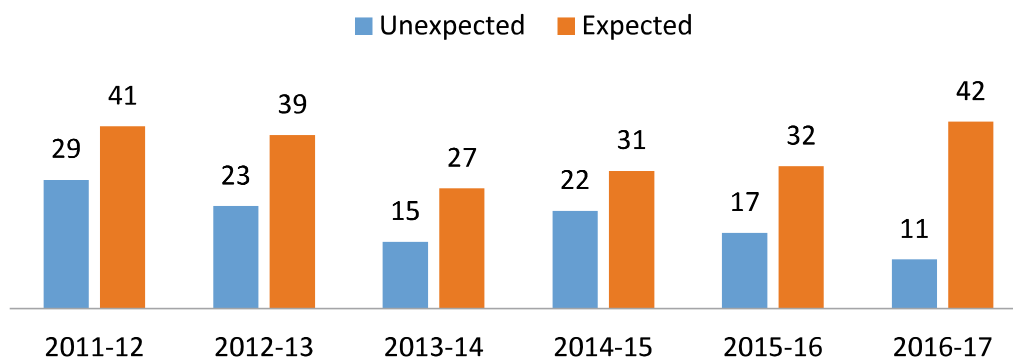


*Figure 5: Number of Unexpected or Expected Deaths, by Year.*

In addition, the CDOP undertook a special review of the circumstances of a serious road traffic accident on the A34 which had resulted in both child and adult fatalities.

## Gender

Over the last six years there have been more notifications of male deaths (58%) than females (42%). An apparent narrowing of this gap between 2014 and 2016 has been thrown into reverse by this year's data. However, caution should be taken in interpreting this due to the small numbers. The percentage of child deaths for males over the past 5 years is broadly consistent with national data published by the Department for Education in its Statistical Release of Child Death Reviews. In 2016/2017 56% were males and 44% were females.

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

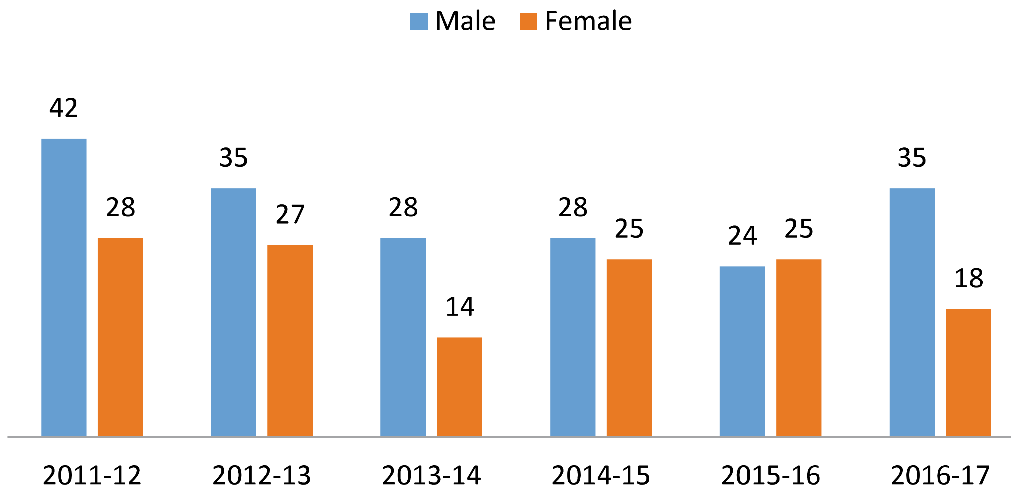


*Figure 6: Deaths by gender, per year.*

## Ethnicity

Over the past six years the largest numbers of child deaths have occurred in the white British population, with the next largest number occurring in the Asian/Asian British population. However, children who are of ethnicity other than White British appear to be over-represented among child deaths compared with their prevalence in the general population as measured in the 2011 census, which found Berkshire's general population to be 80.04% white.

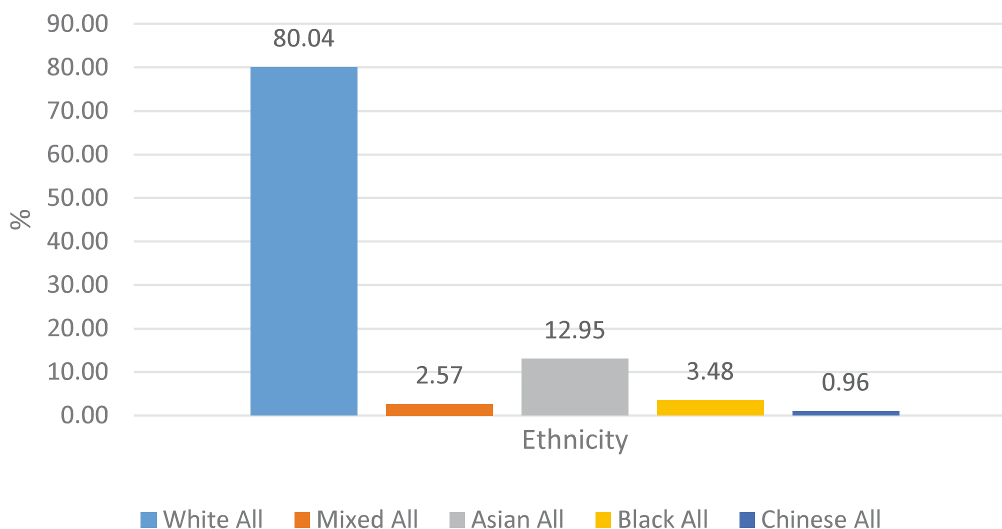


*Figure 7: Census ethnicity data for Berkshire*

Some of the prevalence of chromosomal / genetic causes of death is known to be linked to consanguinity, which is itself more of a feature within certain ethnic groups than in others. The CDOP is working sensitively with local communities to share information about the risks of consanguinity in relation to chromosomal abnormalities so that parents and communities can be better informed.

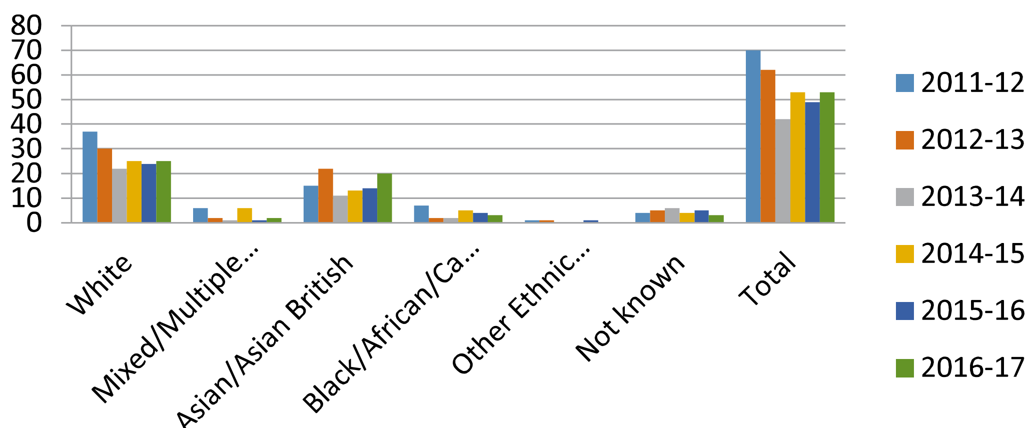


*Figure 8: Deaths by ethnicity, per year.*

## 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 has remained unchanged at 27 per cent in the most recent year. Locally in 2016 – 2017 of the cases reviewed there were 7 cases that had modifiable factors (11%). The modifiable factors were as follows:

- Co-sleeping with an infant
- Alcohol consumption
- Consanguinity
- Untreated UTI in mother before delivery
- Missed opportunity in healthcare

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

## 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 for Education. Detailed in the table below are the categories of child deaths that have been agreed as at the end of March 2015.

| Category | 2011-12 | 2012-13 | 2013-14 | 2014-15 | 2015-16 | 2016-17 |
|---|---|---|---|---|---|---|
| **Category 1** Deliberately inflicted injury, abuse or neglect | 0 | 0 | 1 | 1 | 0 | 0 |
| **Category 2** Suicide or deliberate | 0 | 2 | 0 | 0 | 0 | 1 |
| **Category 3** Trauma and other external | 7 | 4 | 2 | 2 | 5 | 0 |
| **Category 4** Malignancy | 1 | 6 | 4 | 5 | 2 | 3 |
| **Category 5** Acute medical or surgical condition | 5 | 2 | 1 | 3 | 2 | 0 |
| **Category 6** Chronic medical condition | 2 | 1 | 5 | 1 | 4 | 1 |
| **Category 7** Chromosomal, genetic | 14 | 24 | 10 | 21 | 17 | 29 |
| **Category 8** Perinatal/Neonatal Event | 26 | 20 | 16 | 11 | 15 | 15 |
| **Category 9** Infection | 5 | 3 | 2 | 7 | 2 | 3 |
| **Category 10** SUDI | 10 | 0 | 1 | 2 | 2 | 1 |

*Figure 9: Deaths by Category*

# Summary of CDOP key findings during 2016-17

Neonatal cases (<28 days) are numerically the largest sub-group group of all deaths in 0-19 years. Most deaths are due to congenital anomalies and/or perinatal medical problems, particularly complications of prematurity and low birth weight. It was agreed that a themed overview approach to neonatal deaths would be extremely valuable to CDOP and an operational neonatal review group was formed. The group met for the first time in March 2017 and reviewed all neonatal cases between 01/01/2016 and 31/12/2016 with a focus on categories, modifiable factors, trends and further actions. The findings were fed back to the CDOP panel with the focus on themes and trends rather than individual cases and were well received. (See Neonatal Deaths – Special Review Panel, above).

Learning from some of the other deaths reviewed led to procedural changes for health services (particularly hospitals or ambulance services). These were:

- A consultant and anaesthetist should always be called for a second opinion following a sudden deterioration.
- A member of staff should be appointed to take notes e.g. junior nurse, A & E nurse or junior doctor to ensure case documentation is accurate.
- All second presentations at A&E should have a senior review
- A review of the Sepsis triage tool and a collaboration of practice over the county.
- Training for health care professionals should include recognition of shockable heart rhythms and defibrillation.

**Other learning included:**

- A recommendation that if a general pathologist carries out a post mortem on an adolescent in circumstances of a medical death they should consider seeking the opinion of a paediatric pathologist.
- Complete agreement with the police advice to never use a mobile phone while driving.

# Reflections on the work of CDOP

During the past year the panel has continued to maintain good operational performance against national standards. The CDOP is well attended by relevant partners. Discussions are good quality and improvements have been made to documentation to facilitate categorisation of deaths, identification of modifiable factors and recording of recommendations, which are circulated via a regular CDOP Newsletter and to LSCBs for their attention and action.

In response to the issue raised in last year's report that new members found it took too long to settle in, the new induction pack has been issued and is available to all new (and existing) panel members.

Following a training needs analysis Berkshire CDOP agreed to organise a child safeguarding training event to promote knowledge and understanding of the CDOP processes within Berkshire. A multi-agency training day entitled "Saving Children's Lives" was held on 1 March 2017 in Bracknell Forest with 90+ people attending. The day included a series of talks by Professor Peter Sidebotham, Associate Professor of Child Health from Warwick Medical School. This was followed by break out groups with practical sessions. This counted as a full day CPD training course and Level 3 Child Protection training. The event received very positive evaluation by delegates. The delegates were asked to give feedback about future training needs and themes and scenario papers to support learning in relation to voice of the child and disguised compliance were circulated as a result. This successful event will now be held regularly.

The CDOP developed a new website to support frontline practitioners, parents and the public: **www.westberkslscb.org.uk/professionals-volunteers/cdop/**

# Priorities for 2017/18

The 2ND annual multi-agency CDOP training day will take place on Wednesday 07/03/2018 at Easthampstead Park Conference Centre, Wokingham. We are looking forward to another very interesting and informative conference to include a selection of talks including Professor Peter Fleming, interactive group sessions and a chance to network with fellow professionals.

The CDOP will continue to build on our successful work to date in supporting a reduction in mortality from SUDI and accidents. We will look to reduce risk factors for preterm and low birth weight deaths and to continue our work with families and communities to reduce risk of congenital / genetic abnormality.

For 2017/2018 we will be carrying out thematic reviews on the following:

- Sepsis management/effectiveness of paediatric early warning and sepsis tools
- Knife crime (because nationally there is a rise)
- Children with life limiting conditions and deteriorating neurological conditions – now the largest group we review other than neonatal
- Better community understanding of Safe Sleeping
- Home educated children, as they can become invisible.