

**Bedford Borough Safeguarding Children Board &  
Central Bedfordshire Safeguarding children Board**  
Working together to safeguard children



**BEDFORD BOROUGH  
CENTRAL BEDFORDSHIRE  
& LUTON  
CHILD DEATH OVERVIEW PROCESS  
ANNUAL REPORT  
2011-2012**

**Gerry Taylor**  
*Director of Public Health, Luton PCT*  
*Independent Chair*  
*Bedford Borough, Central Bedfordshire & Luton CDOP*

**Shirley Whiterod**  
*Manager*  
*Bedfordshire & Luton CDOP*

	<b>Page</b>
<b>Executive Summary</b>	3
<b>1. Introduction to Child Death Overview Process</b>	5
<b>2. Overview of Child Death Overview Process operation</b>	6
2.1 Numbers of deaths in Bedford Borough, Central Bedfordshire & Luton 2011-2012	
2.2 Meetings held & reviews conducted 2011-2012	
2.3 Organisation & resourcing of Child Death Overview Process	
<b>3. Role of Lead Nurse for Child Death Reviews in Luton</b>	8
<b>4. Rapid Response Information Sharing Meetings</b>	9
<b>5. Luton Cases reported &amp; reviewed 2011-2012</b>	10
5.1 Luton Neonatal deaths	
5.2 SUDI's	
5.3 Other unexpected deaths	
5.4 Expected deaths	
<b>6. Central Bedfordshire Cases reported &amp; reviewed 2011-2012</b>	13
6.1 Central Bedfordshire Neonatal deaths	
6.2 SUDI's	
6.3 Other unexpected deaths	
6.4 Expected deaths	
<b>7. Bedford Borough Cases reported &amp; reviewed 2011-2012</b>	15
7.1 Bedford Borough Neonatal deaths	
7.2 SUDI's	
7.3 Other unexpected deaths	
7.4 Expected deaths	
<b>8. Categories of Child Deaths reviewed</b>	17
<b>9. Modifiable factors noted in child deaths &amp; Public Health Actions</b>	17
<b>10. Actions taken as a result of CDOP reviews</b>	20
<b>11. Recommendations for 2012-2013</b>	20
<b>12. Appendix 1 Cases reported April 2011-March 2012</b>	23
<b>Appendix 2 Ethnicity of children</b>	24
<b>Appendix 3 Gender of children</b>	25
<b>Appendix 4 Summary of Child Death Data 2008-2012</b>	26

## **Executive Summary**

The Child Death Overview Process (CDOP) has been a statutory requirement since April 2008. (*Working Together to Safeguard Children 2006 & 2010*)

There is one CDOP across Bedford Borough, Central Bedfordshire and Luton based on the recommendation that there should be one CDOP for every 500,000 head of population. CDOP is accountable to the 3 Local Safeguarding Children Boards (LSCB) of Luton, Bedford Borough and Central Bedfordshire

Membership of CDOP is as Chapter 7 of *Working Together to Safeguard Children* and is managed on a day to day basis by a manager. This post is hosted on behalf of the 3 LSCB's by NHS Bedfordshire and Luton, and managed by the Designated Nurse for Safeguarding Children and Young People in Bedfordshire.

The CDOP panel is chaired by the Director of Public Health for Luton. The panel meet every 6 weeks and all child deaths up to the age of 18 are reviewed. Bedford Borough, Central Bedfordshire and Luton CDOP has robust terms of reference and objectives. which can be accessed on the Bedford Borough, Central Bedfordshire Safeguarding Children Board website. [www.bedfordshirelcb.org](http://www.bedfordshirelcb.org) or [www.lutonlscb.org](http://www.lutonlscb.org)

### **Panel membership**

In accordance with *Working Together to Safeguard Children (2010)* the panel is chaired by a Chair not directly involved in the provision of services to children and families in the area. Gerry Taylor, Director of Public Health for Luton was appointed and assumed Chairing responsibilities in March 2009.

The panel has an agreed, fixed, core multi agency senior membership from organisations across Bedford Borough, Central Bedfordshire & Luton.

- Gerry Taylor, Director of Public Health, Luton (Chair)
- Dr Salma Rehman, Lead Paediatrician in Bedfordshire
- Dr Catherine Kearney, Lead Paediatrician for Luton
- Dr Wendy Kuriyan Designated Doctor for Safeguarding for Bedfordshire
- Helena Hughes, Designated Nurse for Safeguarding for Bedfordshire
- Sue Steffens, Designated Nurse for Safeguarding for Luton
- Anita Wilson, Lead Nurse for Child Death Reviews Luton
- Sally Stocker, Business Manager, Bedford Borough, Central Bedfordshire Local Safeguarding Children Board
- Catherine Barrett, Business Manager, Luton Local Safeguarding Children Board

- Sue Ioannou, Central Bedfordshire Children's Services
- Caroline Brady, Bedford Borough Children's Services
- Keith Hill, Luton Children's Services
- Bernie White, Police Safeguarding Investigation Unit
- Graeme Tolliday, East of England Ambulance Service
- Shirley Whiterod, Manager Bedford Borough, Central Bedfordshire & Luton CDOP

The panel meeting will be deemed to be quorate if there is the following representation:

- A paediatrician
- Social care
- Police
- Designated nurse

### **Process**

If a child dies unexpectedly a rapid response/information meeting is held as soon as practicably possible after the death with all agencies and professionals who knew the child and family invited. The purpose of this meeting is to enquire into the circumstances of the death, to establish who will support the family and ensure there are no safeguarding concerns for other children in the family.

During the period 2011-2012, 8 meetings were held with 1 additional sub group meeting held with a neonatologist and senior nurses and midwives from the Luton & Dunstable and Bedford Hospital to review a cohort of neonatal deaths. In total the panel have reviewed and closed 57 cases in 2011-2012.

During 2011-2012 58 child deaths were reported to the Child Death Overview Panel. This is a decrease of 6% on the previous year. 32% of these cases have been reviewed and closed. This data is explored in the main body of the report.

Of the 57 cases reviewed and closed during 2011-2012 the panel identified modifiable factors in 45% of the cases reviewed and closed particularly in relation to babies born with congenital anomalies or metabolic disorders. A common feature in these deaths is consanguinity of parents, notably first cousins.

Other modifiable factors identified include unsafe sleeping practices for babies, parental smoking and clinical care.

## **1. Introduction to Child Death Overview Process**

Bedford Borough, Central Bedfordshire & Luton Child Death Overview Panel (CDOP) was convened in February 2008 in accordance with statutory guidance detailed in *Working Together to Safeguard Children (2006 & 2010)*. The child death review functions became compulsory from 1<sup>st</sup> April 2008. This panel is a sub committee of three Local Safeguarding Children's Boards in Bedford, Bedfordshire and Luton to which it is accountable to them and reports to them on a 6 monthly basis.

Based on population size recommended in *Working Together to Safeguard Children (2010)* there is one Child Death Overview Process for Bedford Borough, Central Bedfordshire and Luton for a population size of 500,000.

Through a comprehensive and multidisciplinary review of all child deaths, the Bedford Borough, Central Bedfordshire and Luton Child Death Overview Panel (CDOP) terms of reference are to understand how and why children in Bedford Borough, Central Bedfordshire and Luton die and use our findings to take action to prevent other deaths and improve the health and safety of our children in the area. Throughout this process the CDOP aims to ensure that families are treated with sensitivity and respect at all times and that cases are reviewed with an open mind.

### **1.1 Definition of child death categories:**

#### **Neonatal Death**

Death of a baby within the first 28 days of life

#### **Sudden Unexpected Death in Infancy (SUDI)**

Sudden death of an infant under the age of 1 year which was not anticipated by any professional in the 24 hours prior to the event which lead to the death

#### **Unexpected death**

A death which was not anticipated as a significant possibility for example 24 hours before the death

Or

Where there was a similarly unexpected collapse or incident leading or precipitating the events which led to the death

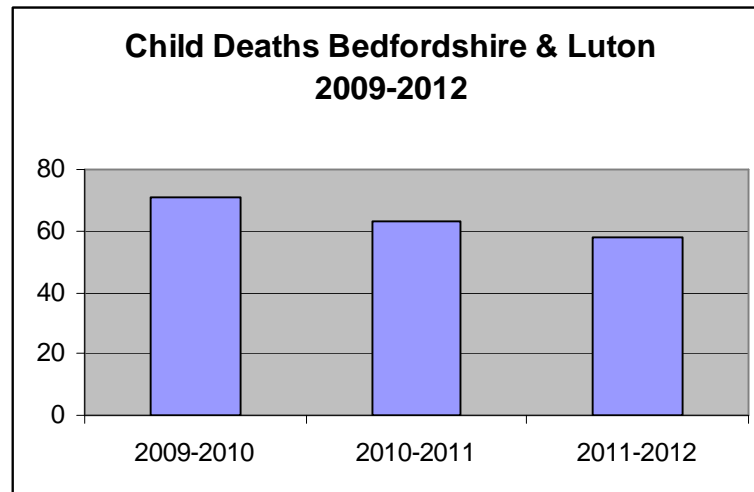
#### **Expected death**

Death of a child with a known life limiting condition

## **2. Overview of CDOP operation**

## 2.1 Number of deaths in Bedford Borough, Central Bedfordshire & Luton 2011-2012

During the period 1<sup>st</sup> April 2011 to 31<sup>st</sup> March 2012 a total of 58 child deaths were reported to the Bedford Borough, Central Bedfordshire and Luton Child Death Overview Panel. This is a reduction of just over 6% on the previous year. All of these children died in this reporting year.



Of these deaths

- 19 were children living in Bedford Borough,
- 17 were children living in Central Bedfordshire
- 22 were children living in Luton.

When reviewing the deaths, the panel is required to determine whether there were any modifiable factors that may have contributed to the death of the child and which by means of locally or nationally achievable interventions could be modified to reduce the risk of future deaths.

19 of these cases have been reviewed by the CDOP panel and closed. 4 cases were deemed by the panel to have modifiable factors.

## 2.2 Meetings held & reviews conducted 2011-2012

8 meetings were held during the 2011-2012. All were quorate with high levels of attendance by all panel members. One sub group meeting was held to discuss neonatal deaths. This meeting was held at Bedford Hospital with attendance from a neonatologist, senior neonatal nurses and midwives.

In total during 2011-2012, 57 cases have been reviewed and closed. 5.4% of these cases were babies or children who died during the period 2008-2009, 3.6% dying in the period 2009-2010, 61.8% died during the period 2010-2011 and 34.5% died during 2011-2012

Of the 57 cases reviewed, 25% of these deaths were reviewed at panel within 6 months of the child's death.

In total 83% of cases were reviewed within 1 year of the child's death. The cases which took longer than 12 months to come to the panel were due to internal investigations by other agencies and waiting for completion of coroners inquests.

46% of the 57 deaths reviewed were considered by the panel to have modifiable factors. The main identifiable factor was associated with babies/children dying from congenital anomalies or chromosomal defects which were considered by the panel to be as a possible consequence of consanguinity.

<b>Modifiable Factors</b>	<b>Number</b>
Consanguinity	9
Unsafe sleeping arrangements	6
Clinical Care	5
Smoking	3
Other	3

In 4 of the cases where unsafe sleeping arrangements were noted as a modifiable factor smoking was also identified

Data on all child deaths is reported annually to the Department for Education.

### **2.3 Organisation & resourcing of CDOP**

The day to day management of the CDOP process is undertaken by the CDOP manager. The manager is employed by NHS Bedfordshire and Luton, who host the post on behalf of partner organisations and is line managed by the Designated Nurse for Safeguarding Children and Young People in Bedfordshire.

Child deaths in Luton are reviewed by a lead paediatrician who is employed by Cambridge Community Services Trust (CCS) and child deaths in Bedford Borough and Central Bedfordshire are reviewed by a lead paediatrician who is employed by NHS Bedfordshire.

The CDOP process across Luton and Bedford Borough, Central Bedfordshire is currently funded by partner organisations from Central Government allocated monies:

- NHS Bedfordshire
- NHS Luton
- Luton Borough Council
- Central Bedfordshire Council
- Bedford Borough Council

Central Government funding for the CDOP process is no longer ring fenced and as a consequence funding for the continuation of CDOP has been reviewed by partner agencies and it is anticipated that there will be a reduction to the hours worked by the CDOP manager in the period 2012-2103.

### **3. Lead Nurse for Child Death Reviews (CDR): Luton**

This post is currently for Luton only. The Lead Nurse for CDR visits all families in Luton following the death of a child that meets the criteria for CDOP (unexpected & expected deaths). The main purposes of the role are to ensure families are informed of the child death review process, to offer bereavement support & to signpost families to local bereavement counselling services. Discussion on post mortem examinations and tissue retention occurs where relevant.

The role forms part of the rapid response to unexpected deaths and involves a home visit to obtain pertinent information and may involve observation of the scene of death. This knowledge is disseminated at the multi-agency professional's information sharing meetings.

The nurse is a permanent member of CDOP and presents information obtained from families. She notifies all families of the date of the CDOP meeting to give them an opportunity to contribute their views to the CDOP process. She then feeds back information about CDOP's findings to the family. This process of two way feedback enables a more in depth CDOP discussion and has highlighted issues that otherwise may not have been detected. For example, issues surrounding tissue retention, compliments and complaints. For families it provides additional information on their child's death and any potential lessons that have been learnt.

During 2011- 2012 the Lead Nurse CDR has posted an evaluation form to all families when the episode of care had ended. 21 forms were posted, 10 were received back (47.6%). The results were as follows;

- 100% (10/10) of families in this survey say they were informed about CDOP and given an opportunity to contribute to or receive feedback from the process. This demonstrates adherence to the statutory requirement outlined in 'Working Together to Safeguard Children' (2010)
- For 50% (5/10) of families the Lead Nurse for CDR was the only health professional to offer bereavement support. 40% (4/10) received support from their GP, 20% (2/10) from health visitors, 10% (1/10) from midwives & 10% (1/10) from the hospice. The Lead Nurse CDR supports families instead of the health visitor, unless the family were previously known to them
- 90% (9/10) of evaluation forms were completed by women.. Particularly in the case of expected deaths the initial visit is 1-2 weeks after the death & fathers have usually returned to work
- White British is the most represented ethnic group in this survey at 40% (4/10). The CDOP Annual report 2010-2011 states that 45% of child deaths in the same period were from Pakistani origin. Families are given the option of receiving an evaluation form in the language of their choice; however this has not been requested to date



- 90% (9/10) of families found home visits informative and they felt listened to
- 80% (8/10) are coping with their loss, however 20% (2/10) are only coping a little or not at all. The covering letter posted out with the evaluations invites families to make contact if they wish to have further support or for signposting to bereavement counselling services; to date no one has requested further support. The person who said they were not coping put their name on the form, they were contacted by telephone & additional support was offered, but declined

### **Recommendations**

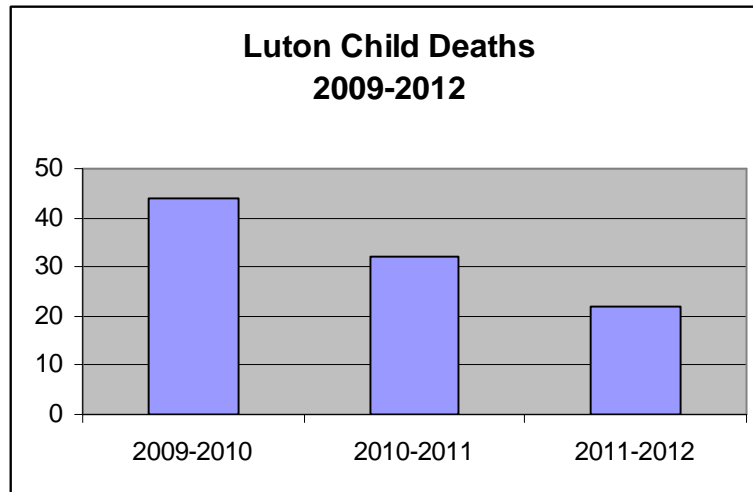
- Consider ways to further involve fathers in the child death review process
- Consider ways to increase ethnic minorities' participation in the evaluation process
- Start posting a leaflet with bereavement services contact details out with the evaluation form. This would ensure those whom are not coping have contact details for local services
- That a similar role is available to families in Bedford Borough and Central Bedfordshire. This will require funding

### **4. Rapid Response/Information Sharing Meetings**

A number of rapid response information sharing meetings were held in response to unexpected deaths. These meetings were held either on the day of the child death or within 48 hours. All such meetings are chaired by the Lead Paediatrician for the CDOP panel and are attended by all professionals who knew the child and family. This purpose of these meetings is to establish facts around the circumstances leading to the child's death, to take a decision on who will be supporting the family' offer bereavement support and discuss if there are any safeguarding concerns for other children in the family.

### **5. Luton Cases reported 2011-2012**

In total 22 Luton deaths were reported to the Child Death Overview Panel. This compares to 32 Luton deaths reported in 2010-2011 and 44 reported in 2009-2010



During the period April 2011 to March 2012 59% of the reported deaths were of children under the age of 1 year with 85% of these being neonatal deaths (deaths occurring within the 28 days of life).

The number of neonatal deaths reported is similar to the previous years numbers but there has been an 80% reduction in the number of children dying between 1 month and 1 year of age. Last year a large number of the deaths in this age range were due to babies born with congenital or chromosomal anomalies and complications of prematurity such as necrotising enterocolitis. The only 2 deaths in this age range this year were due Sudden Unexpected Deaths in Infancy.

There were 6 deaths in the age range 1year to 4 years.

### **Ethnicity**

#### **All Children**

In Luton 50% (11) deaths were from the British Pakistani community who are over represented in child mortality as only 18.5% of the community in Luton are of Pakistani origin.

The White British population of 0-19 year olds in Luton is around 52%, 22% of deaths reported were White British. The Eastern European population of Luton children 0-19 years is approximately 1.7% but 9% of deaths were from this community. The breakdown of the remaining deaths can be seen in Appendix 1

It was observed that 82% of the children who died during the period 2011-2012 were male. Not all of these deaths have been reviewed but on first analysis it would appear that 28 % of these male deaths may be attributable to genetic anomalies as a result of consanguinity, 11% of the deaths were Sudden Unexpected Deaths in Infancy. The unexplained infant death rate for boys is known to be 1.5 times the rate in girls. In Luton all the children that were in this category were boys .This will be investigated by Public Health in Luton

## **5.1 Luton Neonatal deaths**

During the period 1<sup>st</sup> April 2011 to 31<sup>st</sup> March 2012 a total of 11 neonatal deaths (deaths occurring during the first 28 days of life) were reported for babies whose parents live in Luton.

54% of these babies died within the first few hours of life either from complications of extreme prematurity or as a result of known congenital anomalies where parents had chosen to continue with the pregnancy.

The remaining 5 babies died aged between birth and 27 days due to complications of prematurity and congenital anomalies. 3 babies were delivered between 20 weeks and 22 weeks which are pre viable gestations but all were registered as live births due to presence of a heart rate after delivery.

3 of these cases have been reviewed and closed. 1 sub group meeting was held during 2011-2012 with a Consultant Neonatologist, senior nurses and midwives from the Luton and Dunstable Hospital and Bedford Hospital.

The meeting discussed work being undertaken by the Strategic Health Authority and local neonatal units to reduce the incidence of necrotising enterocolitis (NEC) which can affect babies born at an early gestation. There is a NEC care bundle and local policies. The care bundle is introduced for all babies being admitted to the neonatal unit.

## **5.2 SUDI's**

2 Sudden Unexpected Deaths in Infancy (SUDI) were reported. The babies that died were aged 3 months and 5 months. At the time of this report only one case has been reviewed and closed. Due to small numbers .it is not possible to comment further as this may identify the babies who died.

## **5.3 Other unexpected deaths (excluding SUDI's)**

There were 5 further unexpected deaths. To date only one of these cases has been reviewed and closed. The delay in reviewing these cases is due to ongoing hospital investigation, awaiting post mortem reports and coroners inquests.

The remaining 4 cases will be reviewed when the post mortem results are available.

## **.5.4 Expected deaths (excluding neonatal deaths)**

5 expected deaths were reported to the CDOP during 2011-2012.

3 of the children who died were aged between 1 and 4 years with the other 2 children aged 5-12 years. The children had metabolic disorders or malignancy. Consanguinity was noted as a modifiable factor in a small proportion of the cases

### **Luton Deaths reviewed during 2011-2012**

During the period April 2011 to March 2012 a total of 24 Luton deaths were reviewed and closed.

8% (2) of the deaths occurred in the period 2009-2010

67% (16) of the deaths occurred in the period 2010-2011

25% (6) of the deaths occurred in the period 2011-2012

In just over 58% (14) of the deaths reviewed modifiable factors were identified. These were factors associated with co sleeping, consanguinity and clinical care.

Of the 24 deaths reviewed 59% (14) were male with 41% (10) female.

42% (10) of the deaths were of British Pakistani ethnicity (compared to 12% of the population)

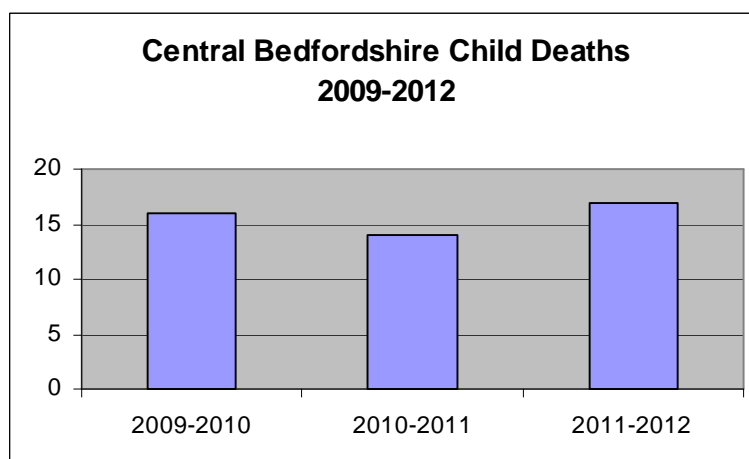
13% (3) of the deaths were of Black African ethnicity (compared to 5% of the population)

13% (3) of the deaths were of African Caribbean ethnicity (compared to 5% of the population with the remainder of the deaths White British or White Other.

17% (4) of the children lived in Dallow Ward. This ward has the highest level of deprivation in Luton and has a high proportion of Black Minority Ethnic residents. Dallow ward also has a lower life expectancy compared to other Luton wards

## **6. Central Bedfordshire Cases reported 2011-2012**

A total of 17 child deaths were reported from April 2011 to March 2012 for children living in Central Bedfordshire. This is an increase of 3 deaths from 2010-2011 but overall the number of deaths has remained fairly static.



65% (11) these deaths occurred in children under 1 year of age with over 90% (15) of these deaths being neonatal deaths (occurring in the 1<sup>st</sup> 28 days of life).

The remaining 6 deaths were reported in the ages 1 to 17 years.

4 of the deaths were classified as unexpected deaths- that is they were not anticipated in the 24 hours prior to the death

### **Ethnicity**

#### **All Children**

Approximately 93% of the population of Central Bedfordshire are White British but only 70% (12) of the children who died were White British with the remaining 30% (5) of children were from varying ethnic backgrounds.

### **6.1 Central Bedfordshire**

#### **Neonatal Deaths**

During the period 1<sup>st</sup> April 2011 to 31<sup>st</sup> March 2012 a total of 10 neonatal deaths were reported for babies whose parents reside in Central Bedfordshire.

Of these all 50% (5) died within the first few hours or days of life. 4 of these deaths were of babies born at pre viable gestations that had a heart rate present at birth and were registered as live births. A data set of information regarding the mothers past medical and obstetric history has been obtained. No modifiable factors have been identified.

The other deaths were due to complications of prematurity.

## **6.2 SUDI's**

As in the previous reporting year no SUDI's were reported in Central Bedfordshire.

## **6.3 Other unexpected deaths (excluding SUDI's)**

There were 4 unexpected deaths reported in Central Bedfordshire. 2 children died as a result of road traffic incidents but there were no common factors identified. One of the cases has been reviewed and closed and modifiable factors identified have been addressed at the location where the child died. The other 2 cases are yet to be reviewed.

## **6.4 Expected deaths (excluding neonatal deaths)**

There were 2 reported deaths of children with a life limiting conditions.

### **Central Bedfordshire Deaths reviewed during 2011-2012**

During the period April 2011 to March 2012 a total of 11 Central Bedfordshire deaths were reviewed and closed.

73% (8) of the deaths occurred in the period 2010-2011

27% (3) of the deaths occurred in the period 2011-2012

In just over 36% (4) of the deaths reviewed modifiable factors were identified. These were issues associated with co sleeping, maternal smoking and raised BMI

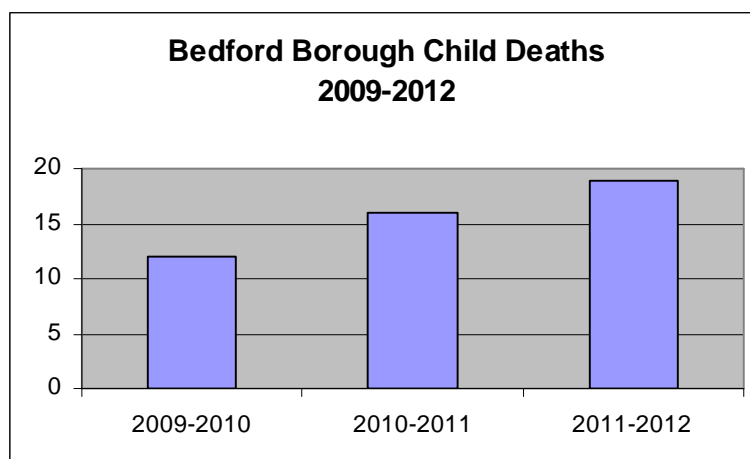
Over 81% (9) of the deaths reviewed were White British ethnicity

27% (3) of the deaths occurred in the Houghton Hall Ward of Central Bedfordshire. This ward is 3<sup>rd</sup> of the most deprived areas in Central Bedfordshire and parts of the ward are in the most deprived 50% in England.

## **7. Bedford Borough Cases reported 2011-2012**

In total 19 child deaths were reported to the panel for children who reside in Bedford Borough. This represents an increase of 3 from the previous reporting year.

An increase of 42% in the number of child deaths is noted since 2009-2010. Analysis of the data shows a rise in the number of neonatal deaths of 50% since 2010-2012 .and since 2009-2010 there have been deaths reported in the ages ranges 5-9years, 10-14 years and 15-17 years which did not occur in the year 2009-2010.



79% (15) of these deaths occurred in children under 1 year of age with 42% (6) of these deaths occurring in the early neonatal period. The remaining 4 deaths were reported in the age range 2 to 16 years.

Seven of the deaths were unexpected deaths i.e. the death was not anticipated within the previous 24 hours. One death occurred abroad and it has not been possible to collect a full data set of information on this child.

### **Ethnicity**

53% (10) of the children who died were White British ethnicity, 16% (3) were from other White ethnic groups with the other deaths reported in Black African, Black Caribbean and Pakistani ethnicities.

### **7.1 Bedford Neonatal deaths**

During the period 1<sup>st</sup> April 2011 to 31<sup>st</sup> March 2012 a total of 11 neonatal deaths were reported for babies whose parents reside in Bedford Borough. These babies died within the first month of life from complications of prematurity, congenital anomalies and as a consequence of complications in labour. Of the cases reviewed no modifiable factors were identified.

### **7.2 SUDI's & other unexpected deaths**

There were 7 unexpected deaths. 1 was a child who died abroad. 3 have been reviewed and closed. In one of the cases modifiable factors associated with emotional wellbeing were identified and have been the subject of a robust action plan which is being monitored by a local education establishment. The remaining deaths will be reviewed when inquests have been held.

### **7.3 Expected deaths (excluding neonatal deaths)**

2 expected deaths were reported of children with life limiting conditions.

#### **Bedford Borough Deaths reviewed 2011-2012**

During the period April 2011 to March 2012 a total of 22 Bedford Borough deaths were reviewed and closed.

5% (1) of the deaths occurred in the period 2008-2009

5% (1) of the deaths occurred in the period 2009-2010

45% (10) of the deaths occurred in the period 2010-2011

45% (10) of the deaths occurred in the period 2011-2012

In just over 36% (8) of the deaths reviewed modifiable factors were identified. These were issues associated with co sleeping, maternal smoking and emotional wellbeing

50%(11) of the deaths reviewed were White British ethnicity, 18% (3) being from White other ethnicity and 9% (2) Indian ethnicity. The remaining deaths were from a variety of other ethnicities.

23% (5) of the deaths occurred in the Harpur Ward of Bedford Borough with the remaining deaths occurring in different wards across the local authority. Harpur ward has pockets of deprivation including an area amongst the 10% most deprived in England although there are parts of the ward where deprivation is low. Harpur ward has the lowest life expectancy of all wards in Bedford Borough.

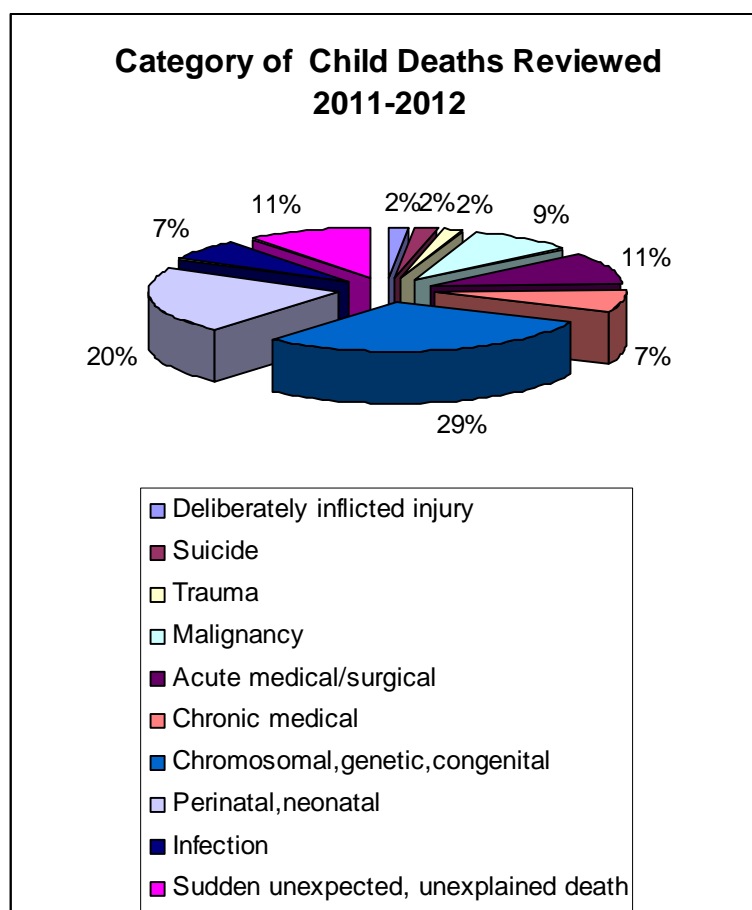
No common factors were identified in the review of these deaths; the children were from different ethnic backgrounds and died from varying unlinked conditions.

.



## 8. Categories of Child Deaths reviewed 2011-2012 for Bedford Borough, Central Bedfordshire and Luton

In total 57 child deaths were reviewed in the period 2011-2012. Below is a breakdown of categories into which each death was categorised. As will be noted 29% (17) of the children died as a result of chromosomal, genetic or congenital anomalies (the majority of these babies dying in the neonatal period) whilst 20% (11) of the deaths were attributable to a perinatal or neonatal event.



## 9. Modifiable factors noted in child deaths

### **Smoking, unsafe sleeping practices & consanguinity**

From reviews of child deaths undertaken smoking both in pregnancy and in the home was identified as a modifiable factor in a number of neonatal deaths. As a result of these findings the information has been provided to the public health teams in Bedfordshire and Luton to address as part of their tobacco control strategies. Midwives and health visitors continue to reinforce the message of safe sleeping practices to newly delivered mothers.

## **Smoking in Pregnancy and Secondhand Smoke**

Smoking during pregnancy leads to poorer health outcomes for the unborn child.

Smoking in pregnancy is both a cause and effect of health inequalities.

Smoking is a major threat to health across all groups and is the main contributor to the life expectancy gap between those who are least and most well off.

Babies born to smoking mothers are more likely to die during the first four weeks of life and stopping smoking at any stage during pregnancy brings proportional health benefits.

Maternal smoking is a potential cause of major morbidity and mortality to the foetus and new born baby.

- 32% increased risk of miscarriage (death before the 20th week of pregnancy)
- 26% increased risk of perinatal death (death between 20 weeks pregnancy and first week of life)
- Women who smoke are 1.5 to 2.5 times more likely to have low birth weight babies (intrauterine growth retardation)
- 27% increased risk of a preterm birth (birth before the 37<sup>th</sup> week of pregnancy).

Preterm birth is a major cause of infant mortality and can affect physical and mental development during childhood. (RCP Passive Smoking and Children report 2010).

### **Actions taken by Public Health in Luton**

NICE recommend all pregnant women are routinely monitored for carbon monoxide to monitor potential harm to the unborn baby. Since July 2011, NHS Luton have worked with the midwifery team at the Luton and Dunstable Foundation Trust Hospital and the Luton Stop Smoking Service to implement a smoking in pregnancy intervention. This includes routine carbon monoxide monitoring at the booking appointment with the midwife, automatic referral to the Stop Smoking Service for women who smoke, and monitoring of the pregnant woman's smoking status throughout pregnancy. This intervention has been fully implemented since December 2011, the next step is to ensure consistent and sustained messages are given to parents and pregnant women who smoke and/or stop smoking are monitored and followed throughout their pregnancy and beyond. A new smoking in pregnancy campaign will launch mid-2012 to raise awareness of the harms of tobacco.

### **Actions taken by Public Health in Bedford Borough, Central Bedfordshire**

The Public Health Smoking in Pregnancy lead works closely with maternity units to ensure maternity staff understand the importance of raising the issue of smoking and to ensure best recommended practice (as per NICE guidelines) is implemented.

NHS Bedfordshire's Stop Smoking Service Specialist Advisors, offer dedicated tailored clinics to pregnant women at maternity units, with clinics also available to pregnant women in the community at a range of different locations.

'Smoke free baby and me programme' supports pregnant women from referral up to 6 months post partum. This is delivered in partnership with Children Centres. The programme is an incentive based scheme to encourage ongoing cessation.

The Stop Smoking Service also maintain links with stop smoking services in Hertfordshire, as many Bedford Borough, Central Bedfordshire mothers deliver at Lister Hospital

Smokefree Homes and Cars is a national campaign that is being rolled out locally. In Bedford Borough, Central Bedfordshire it will include an online pledge system to 'keep homes and family cars smokefree'. This will be underpinned by a training programme for frontline staff that have contact with pregnant women and young families.

### **Obesity**

Maternal obesity can lead to significant medical issues, obese pregnant women who are at increased risk of many obstetric complications including still birth or pre term delivery.

While everyone is susceptible to obesity, levels are disproportionately higher in lower socio-demographic, socially disadvantaged groups and some ethnic groups.

There is a higher prevalence of obesity in pregnant women from the lowest socio-economic areas of Bedford Borough (Bedford Hospital NHS Trust midwifery records, 2011, IMD data 2010).

### **Actions taken by Public Health in Luton**

Work is underway to develop a clinical and patient referral pathway to enable early intervention for weight management issues from pre-conception through to 5 years. An essential part of this work is identifying those women who are carrying excess weight and are likely to put on excess weight during pregnancy. Activities include training for health professionals, brief intervention and referral to appropriate services.

**Actions taken by Public Health in Bedford Borough, Central Bedfordshire** A healthy weight in pregnancy programme has been locally developed and is presently running in Bedford Hospital and the local community. This work has been targeted to areas where there is the greatest potential to reduce health inequalities.

## **Consanguinity**

Evidence from the Child Death Overview Panel of child deaths reported in Luton between April 2009 and March 2012 attributes 20% of all deaths to genetic disorders as a result of autosomal recessive genetic risk as a result of consanguinity. All of the child deaths seen in this period were children born to British Pakistani families and the children died in early infancy.

A plan that brings together medical specialists, public health, community leaders and the community has been developed that aims to address genetic risk by working with specialists and the community to recognize how risk can be reduced effectively, raise awareness within high risk communities and support high risk families so they can make an informed decision regarding accessing genetic services to establish risk of giving birth to an affected child. The plan will be implemented in 2012/13.

The panel have deemed this as a modifiable factor and recommended that where parents are related genetic counselling is offered to these parents to ensure they are aware of the potential risks and can make informed decisions about future pregnancies.

## **10. Actions taken as a result of enquiries by CDOP 2011- 2012**

Where a review of a child's death has identified lessons learned or modifiable factors changes to practice have been effected by various organisations across Central Bedfordshire, Bedford Borough and Luton and these include:

- Clarification of pathways to ensure all Downs syndrome children receive flu vaccination
- Confirmation that DNA policies are in place at local hospitals particularly in relation to children attending dietetics
- Case flagged as Serious Incident by CDOP saw lessons learned put into practice and action plan monitored by NHS Luton
- Review of medicines management policy in Luton. Changes to prescribing practice implemented as a result of the review.
- Recommendation that emotional wellbeing is included as part of health screening at local independent school
- Continue to discuss issues of consanguinity in Luton with local communities

## **11. Recommendations for 2012/2013**

A review of the data for the period 2008/2011 (Appendix 2) demonstrated the need for continued focus on the public health issues raised above including genetic issues in relation to consanguinity, smoking and obesity in pregnancy and safe sleeping.

Data from 2010/11 suggest an overrepresentation of male deaths in Luton. This will be investigated.

Ofsted/CQC has recently undertaken joint inspections of Safeguarding and Looked After Childrens services in Bedford Borough, Central Bedfordshire and Luton. It was noted from all inspections that there was good engagement with partner agencies including the police and ambulance services. The inspections also noted the good links with the serious case review LSCB sub group. However it was noted that communication between the panel and some frontline staff in some areas was not sufficiently robust. The CDOP manager is now regularly attending the 2 day Bedford Borough, Central Bedfordshire LSCB Safeguarding Children training to explain the CDOP process and highlight emerging themes from the review of child deaths. In addition quarterly CDOP information sessions are now taking place with the lead paediatrician and police to ensure all frontline staff have awareness of their involvement with CDOP and that they are apprised of messages arising from child death reviews. Positive evaluation has been received on the sessions held to date. This will be rolled out to all partner agencies in Luton during 2012-2013.

It was highlighted by the inspectors that GP's were not sufficiently aware of the CDOP process. Action will be taken to raise the child death process with this group of health partners.

The inspection also highlighted that there was limited evaluation of the effectiveness of the local campaigns particularly with delivery of the safe sleeping message. In order to rectify this, an initial meeting was held with frontline staff to determine how to proceed with this issue. Staff felt that it was paramount that they were well educated about the themes/messages and how best to deliver them to women and their families. Work will continue with this initiative during the coming year.

Concerns have been raised by CDOP panel members that there is inequality of bereavement support in Bedford Borough, Central Bedfordshire as compared with Luton. The CDR nurse at the present time is employed by Cambridge Community Services (Luton Community Services) and only visits bereaved families in Luton. This issue has been raised with the Director of Quality and Nursing in NHS who has requested that a business case be written to consider the feasibility that the Child Death Review Nurse role be extended to cover Bedford Borough, and Central Bedfordshire

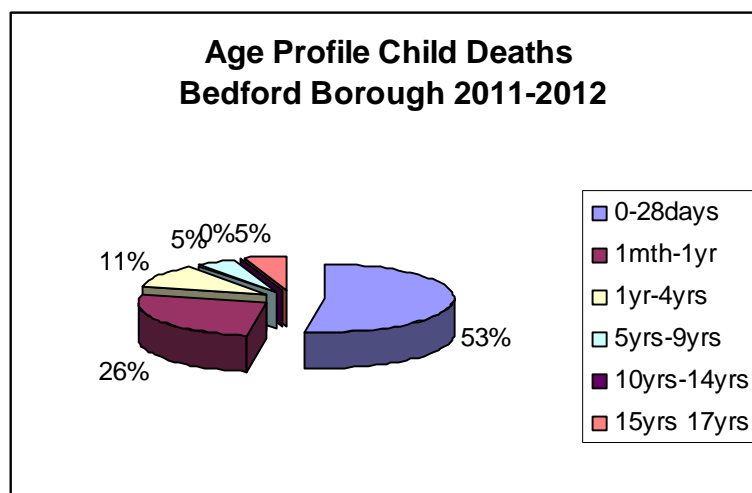
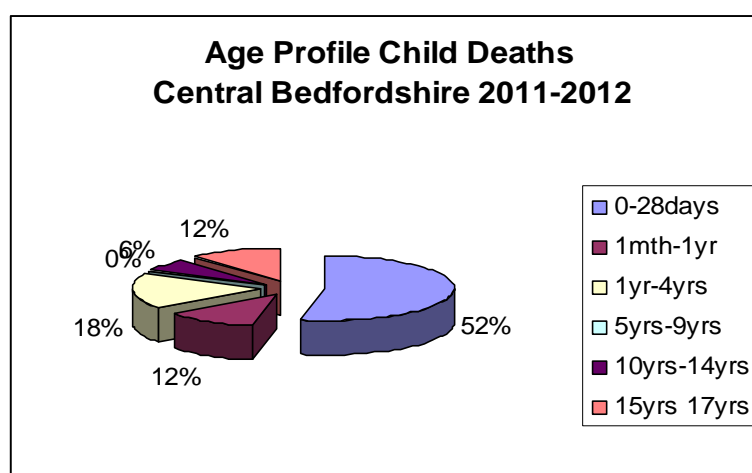
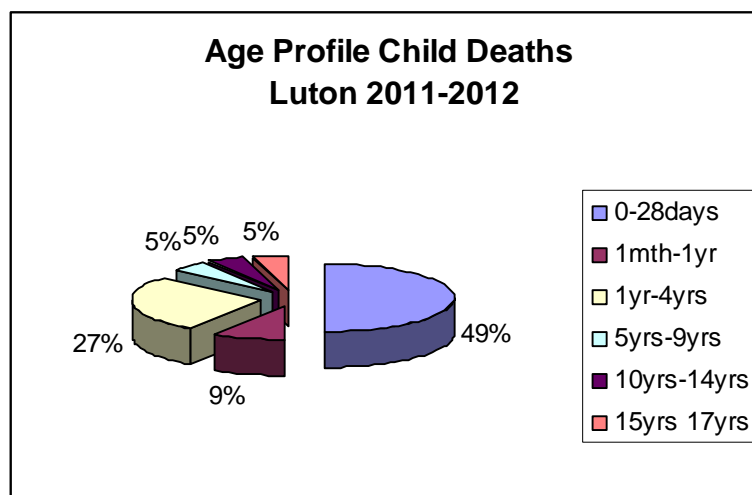
A review of CDOP in Bedford Borough, Central Bedfordshire and Luton has taken place. When the service became a statutory function in 2008, the CDOP manager was employed for 4 days per week. Since then processes have become embedded and streamlined. Furthermore there has been a small reduction in the number of child deaths reported. It is therefore proposed that from April 2012 the CDOP manager's hours will be reduced to 3 days per week.

During 2012-2013 CDOP will consider how the process will look and who the members of the panel will be once Clinical Commissioning Groups are established in April 2013

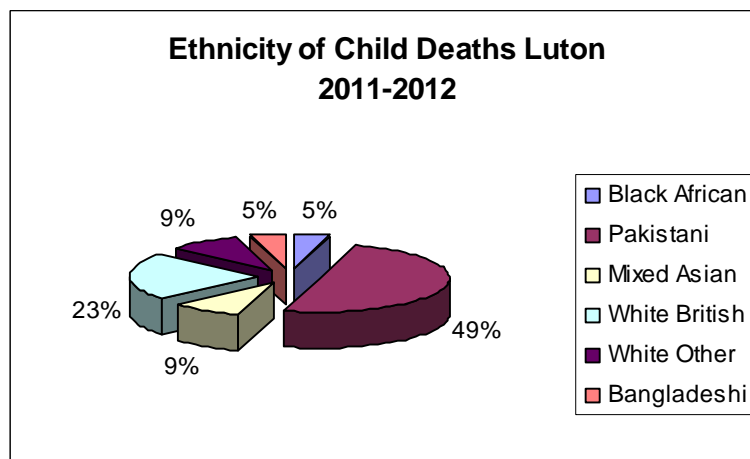
## Appendix 1

### Cases reported April 2011 – March 2012

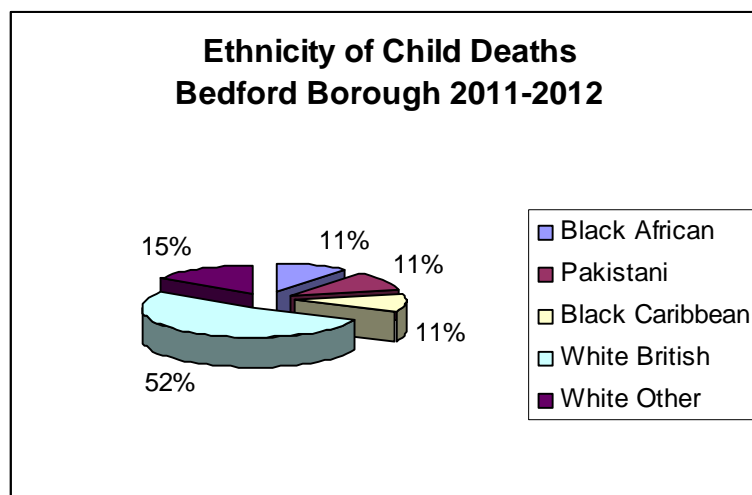
	Bedford Borough	Central Bedfordshire	Luton
<b>Cases Reported</b>	19	17	22
<b>Unexpected</b>	5	4	8
<b>Expected</b>	12	13	14



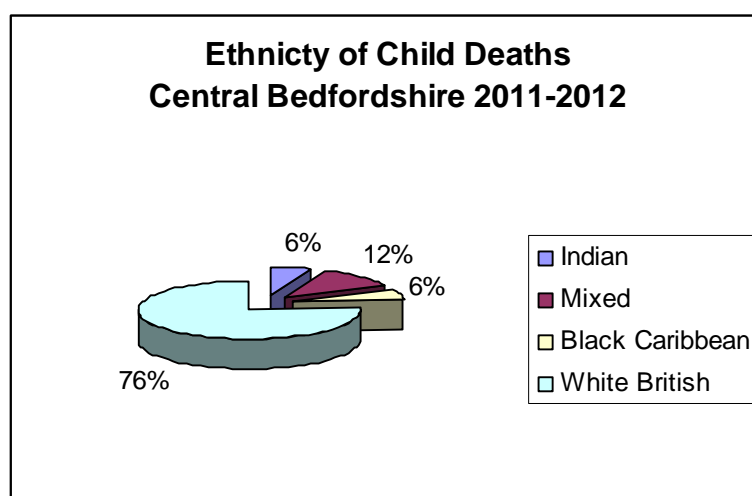
**Appendix 2**  
**Ethnicity of child deaths in Luton 2010-2011**



**Ethnicity of child deaths in Bedford Borough 2010-2011**



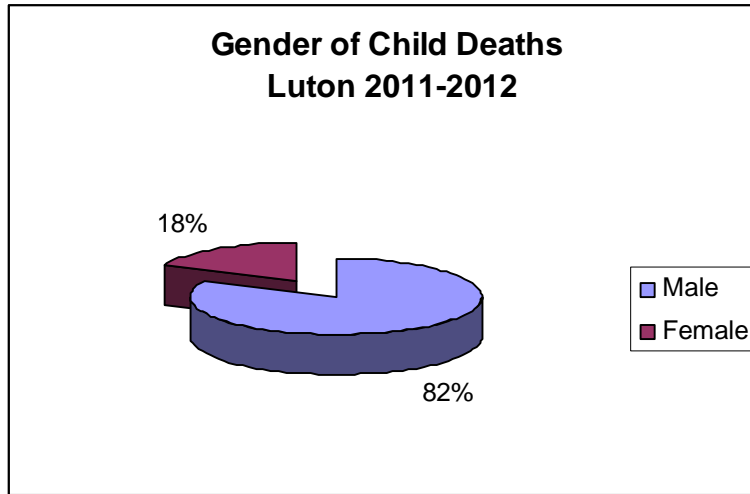
**Ethnicity of child deaths in Central Bedfordshire 2010-2011**



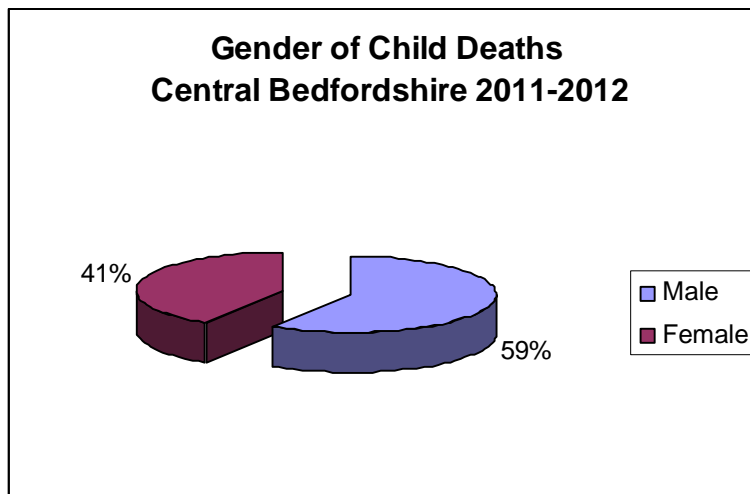
**Appendix 3**



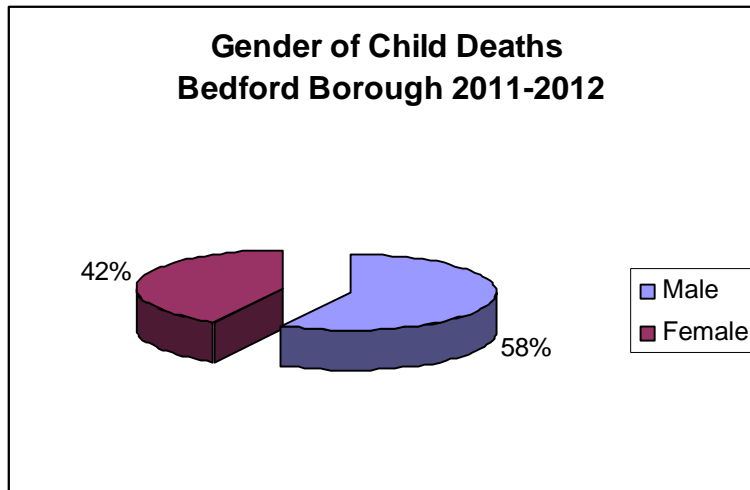
## Gender Child Deaths in Luton 2011-2012



## Gender Child Deaths in Central Bedfordshire 2011-2012



## Gender Child Deaths in Bedford Borough 2011-2012



## Appendix 4

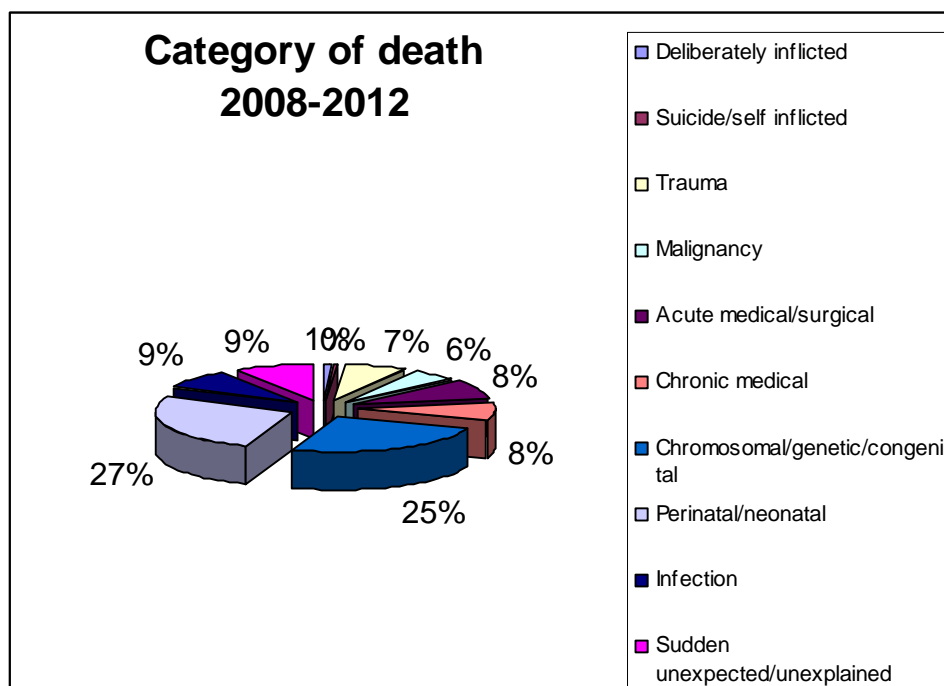
### Summary of Child Death Data 2011-2012

In the 4 year period April 2008 to March 2012 a total of 243 child deaths have been reported to the CDOP

Of these deaths 87% have been reviewed and closed

	2008-2009		2009-2010		2010-2011		2011-2012	
Child Deaths	Total deaths	Unexp	Total deaths	Unexp	Total deaths	Unexp	Total deaths	Unexp
Luton	20	7	44	13	34	12	22	7
Central Beds	16	6	18	6	14	7	17	4
Bedford Borough	14	5	11	0	16	4	19	8
	50		73		64		58	

### Category of death



Of the 212 cases reviewed and closed just over 25% of the deaths were categorised as deaths related to perinatal events such as complications of prematurity or of babies born at a pre viable gestation but who had a heart rate present for some time after delivery and were therefore registered as a live birth. A further 25% of the deaths were in the category genetic, chromosomal or congenital anomalies. In some of these cases the anomalies had been detected in the antenatal period but parents had opted to continue with the pregnancy despite knowing of the poor prognosis for their child. In many of these cases it was noted that the parents were in a consanguineous marriage and it is recognised that the incidence of chromosomal/genetic conditions is higher in these circumstances

20 (9.5%) of the deaths were recorded in the category sudden unexpected or unexplained death. The majority of these deaths were in babies under the age of 6 months and modifiable factors noted were as described previously, maternal/paternal

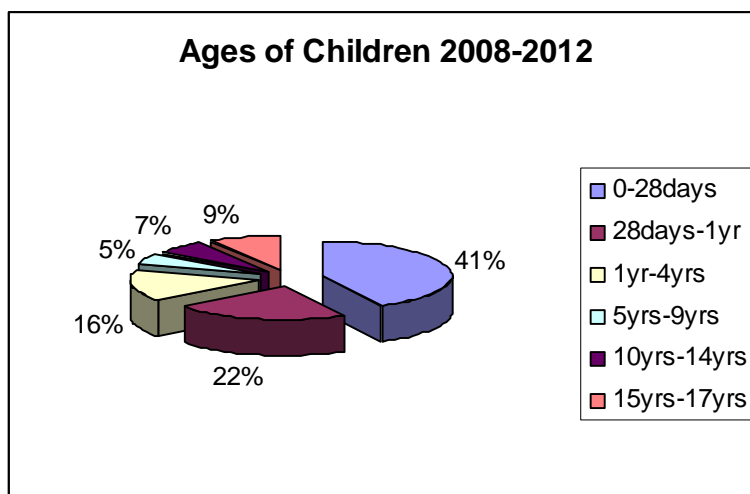
smoking, co sleeping or sleeping on a sofa, and drug and alcohol misuse. These emerging themes are highlighted in all CDOP information sessions and it is known that these issues are discussed with parents but it is recognised that more work is required to ensure parents and carers have received and understood the risks associated with unsafe sleeping practices and smoking and to identify barriers to parents changing behaviour

### **Modifiable Factors identified in the review of all child deaths 2008-2012**

<b>Modifiable Factor</b>	<b>Number of cases</b>
Smoking (maternal/parental)	16
Unsafe sleeping practices	12
Consanguinity	12
Clinical care	7
Raised maternal BMI	4
Other(factors associated with driving, prescribing practice, equipment)	11

### **Ages of children**

Of the 243 deaths reported in the period 2008-2012 over 60% (146) of the children who died were under 1 year of age with 41% (99) dying during the 1<sup>st</sup> month of life.



### **Ethnicity of children**

Almost 50% of the deaths reported were of White British children with the next largest group 21% (51) being from the Pakistani community.

### Ethnicity of Children 2008-2012

