

**LEEDS
SAFEGUARDING
CHILDREN BOARD**

**LEEDS CHILD DEATH
OVERVIEW PANEL**

**Report to Leeds Safeguarding
Children Board for the period
1st October 2009 to 31st
December 2010**

Foreword

The national requirement to review the death of every child under the age of 18 years was introduced from 1st April 2008. Over the past two and half years, this has been a learning process for all involved. But though the task has been demanding at times, it has also been hugely rewarding. Members of the Panel (both Neonatal and Older Children) have given their time generously to analyse and debate the sad circumstances and contributory factors in the deaths of Leeds children, and to draw out lessons and recommendations with the aim of preventing, where possible, the tragic loss of children's lives in the future.

The process for the investigation of sudden unexpected child deaths (SUDIC) has made an enormous contribution to work of the Child Death Overview Panel, providing a rich source of detailed information about the deaths of these children, and enabling the CDOP to hold informed discussions and make useful recommendations. The CDOP particularly extends it thanks to Dr John Roper, SUDIC Paediatrician for Leeds, who leads this process, and the Safeguarding Team who support him.

Finally, the CDOP process could not function without the input of many professionals across multiple agencies who give their time to complete the information proformas, and those who sit on the Panels and debate the issues and shape the recommendations, and the hard work of the administrative team at Enterprise House.

This report represents the culmination of the efforts and expertise committed by all these professionals. It summarises the work of the CDOP over the two and half years since its implementation, including statistical analysis of child deaths over this period, and a summary of recent recommendations and lessons, together with a progress report on the recommendations of the previous CDOP Annual Report 2008-9.

Dr Sharon Yellin

Chair of Leeds Child Death Overview Panel

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1. Introduction to the Leeds Child Death Overview Panel

1.1 Purpose

1.1.1 The Leeds Child Death Overview Panel (CDOP) was established from 1st April 2008 under guidance issued in Chapter 7 of Working Together to Safeguard Children 2006. The aim of the CDOP, (as required by the Local Safeguarding Children Boards Regulations 2006) is to undertake a comprehensive and multidisciplinary review of all deaths of children normally resident in Leeds aged under 18 years, in order to understand better how and why they die, and to use the findings to take action to prevent other deaths and improve the health, wellbeing and safety of children and young people.

1.1.2 The CDOP has specific functions, laid down in statutory guidance, including:

- Reviewing the available information on all deaths of children aged up to 18 years (including deaths of infants aged less than 28 days) to determine whether the death was preventable.
- Collecting and collating an agreed minimum data set on each child who has died.
- Meeting frequently to review and evaluate the routinely collected data on the deaths of all children, and thereby identifying lessons to be learnt or issues of concern.
- Monitoring the appropriateness of the response of professionals to an unexpected death of a child.
- Referring to the Chair of the LSCB any deaths where, on evaluating the available information, the Panel considers there may be grounds to undertake further enquiries, investigations or a Serious Case Review (SCR).
- Monitoring the support and assessment services offered to families of children who have died.
- Organising and monitoring the collection of data for the nationally agreed minimum data set.
- Identifying any public health issues and considering, with the Director of Public Health, how best to address these and their implications for both the provision of services and for training.

2. The Leeds CDOP Process

2.1 Under statutory national guidance contained in Chapter 7 of Working Together to Safeguarding Children, Leeds has both a Sudden Unexpected Death in Childhood (SUDIC) process, and a Child Death Overview Panel (CDOP) process. The two are separate processes, but are closely linked.

- 2.2 The SUDIC process involves early notification of the unexpected death of a child, and a prompt process of investigation, led by the SUDIC Paediatrician. This may involve discussion with clinicians at the hospital, Police, Social Care and others. Sometimes a visit to the place of death is undertaken. A meeting is held with professionals involved with the child, to learn lessons. A report into the circumstances of the child's death is produced, which is shared with the Coroner, and with the CDOP.
- 2.3 Notifications of child deaths may be made directly to the SUDIC Team, or to the CDOP Administrator at Enterprise House in Leeds. Some may be deaths of non-Leeds children, and these notifications are passed to other areas where the child was resident. Close communication between the SUDIC and CDOP Teams is essential to ensure full ascertainment. The Registrar of Births and Deaths now also has a duty to supply information to the Local Safeguarding Children Board (LSCB) regarding the death of any child under 18 years no later than 7 days from the date of registration (Children & Young Persons Act 2008). This has greatly improved ascertainment.
- 2.4 The CDOP Administrator issues and collates the standardised national Agency Report Forms, together with SUDIC reports, death certificates, post-mortem reports, inquest findings and other relevant reports of investigations if available. The collated papers are made available to Panel members prior to each meeting.
- 2.5 In Leeds, neonatal deaths (babies aged under 28 days), where the baby was never discharged from hospital, are considered by a Panel which includes Obstetricians, Neonatologists, and Midwives, from Leeds Teaching Hospitals NHS Trust (LTHT), to ensure appropriate expertise. The process of collating information about neonatal deaths is supported by the Centre for Maternal and Child Enquiries (CMACE) under a contract with the LSCB. Children aged over 28 days, and a few younger babies who died in the community, are considered by a Panel which includes representatives of various agencies (para 2.6).
- 2.6 The Leeds CDOP Panels are chaired a Consultant in Public Health Medicine from NHS Leeds, Dr Sharon Yellin. The following agencies contribute to Panel membership:
- Leeds Safeguarding Children Board
 - NHS Leeds Public Health
 - Designated Doctor for Safeguarding Children
 - Designated Doctor for Sudden Unexpected Childhood Death
 - Children and Young People's Social Care
 - Leeds Teaching Hospitals NHS Trust
 - Leeds Community Healthcare
 - Leeds Partnerships Foundation Trust
 - Youth Offending Service

- West Yorkshire Probation Service
- West Yorkshire Police
- Coroner's Office
- Education Leeds
- Early Years Service
- Martin House Children's Hospice

A full list of current Panel membership can be found at Appendix 1.

- 2.7 The CDOP considers the death of each child, and is required to complete a national proforma regarding its findings for each child. The proforma include factors relating to the child and family, and service provision; categorization of the cause of death; a judgment regarding preventability of the death; learning points and recommendations; immediate follow up actions for the family; and whether the case should be referred to the LSCB Chair for consideration of a Serious Case Review. In addition, during the past year, the Leeds CDOP has piloted a West Yorkshire form to collect specific information about preventable factors from a public health perspective.
- 2.8 There have been challenges in the running of the Panels over the past year, some of which are reflected in Panel minutes and recommendations. There have been delays in receiving completed Agency Report Forms from various agencies, and these issues have been addressed by direct liaison with those agencies at the time. Certain specialist reports, such as fire investigations and road traffic accident reports, have not been provided to the CDOP routinely, and again arrangements to obtain these for future have been made as each issue arose. By agreement with the Coroner, cases are not considered by the CDOP until the inquest is complete. There have also some pressures regarding administrative support in the Safeguarding Team. All these factors have contributed to a backlog of cases.
- 2.9 Panel meetings are scheduled to take place each month (either a Neonatal or Older Children Panel). This should be an appropriate frequency for meetings, based on the expected number of child deaths in Leeds (approx 80 per annum). However, owing to the factors outlined in Para 2.8, many Panel meetings have been cancelled during 2009-10, and this is reflected in the overall level of Panel activity (see Table 1).

3. Panel Activity

- 3.1 Since its implementation in April 2008 until end November 2010, the CDOP Panels have met on 14 occasions (7 Neonatal Panels, 7 Older Children Panels), and considered 70 child deaths.
- 3.2 Table 1 shows the number of notifications of deaths, and Panel activity in the corresponding year. A small number of cases (9) are still

outstanding from 2008-9, and these are likely to be cases awaiting the conclusion of Coronial processes.

- 3.3 There are a considerable number of outstanding cases for 2009-10 (52 outstanding cases). This has been raised in the context of the ongoing discussions about re-organisation of safeguarding functions to form an Integrated Safeguarding Unit in Leeds City Council, and it is expected that administrative support to the CDOP will be strengthened.

<u>Year</u>	<u>Notifications to CDOP Administrator</u>			<u>Number of cases reviewed by CDOP</u>			<u>Number of cases outstanding for CDOP review</u>		
	Neonatal	Older child	Total	Neonatal	Older child	Total	Neonatal	Older child	Total
2008-9	25	36	61	24	28	52	1	8	9
2009-10	28	42	70	10	8	18	18	34	52
2010 to end Dec	15	24	39	0	0	0			

4. Commentary on Neonatal Deaths reviewed by CDOP

- 4.1 The CDOP Neonatal Panel has reviewed a total of 34 neonatal deaths. In last year's CDOP Annual Report, 18 of these cases were described, though it was acknowledged that small numbers made it difficult to draw conclusions. The majority of the neonatal deaths reviewed since the last report occurred during the year 2008-9, and therefore the commentary presented in this section covers all neonatal deaths reviewed to date ie including neonatal deaths covered by the previous CDOP Annual Report. This will give a better overall understanding of the issues.
- 4.2 It is important to be aware that a small number of cases reviewed by the Neonatal Panel (5) related to babies aged over 28 days, but who had never been discharged from the hospital neonatal unit. This is appropriate, since the causes of death for babies who are never discharged from the hospital tend to be similar, often being linked to problems during the pregnancy and during delivery, and related to prematurity and low birthweight.
- 4.3 A small number of deaths reviewed by the CDOP Older Children Panel (3) related to children aged under 28 days but who died in the community. These cases could legitimately be considered by either Panel, since they may be similar to the babies who die on the neonatal unit, or there may be a range of contributory factors involving multiple

agencies. For administrative reasons, babies who die in the community are considered at the Older Children CDOP.

4.4 Most the deaths of babies considered by the CDOP Neonatal Death Overview Panel (32 deaths) were classified under one of the following categories:

- Category 7: Chromosomal, genetic and congenital anomalies (9)
- Category 8: Perinatal/neonatal event (23)

Two babies' deaths were assigned to Category 5: acute medical or surgical conditions. Both of these were among the babies who died in the community after discharge from the hospital.

4.5 As discussed in the previous CDOP Annual Report, known risk factors for stillbirth and neonatal death include¹:

- Extremes of maternal age (nationally, teenage mothers have the highest neonatal mortality rate)
- Non-White ethnicity
- Maternal social deprivation
- Maternal obesity

These factors have been considered specifically in the commentary that follows.

4.6 Of the 34 neonatal deaths considered in this report, age of mother was available for 28. Of these, only 2 were young mothers aged under 20 years old. 6 babies had mothers aged over 35 years.

4.7 Ethnicity was available for all cases considered. The data collection forms used by CMACE include both ethnicity of mother, and (on the supplementary CDOP form) ethnicity of the baby. In general, these are the same, and therefore they have not been analysed separately. The largest single ethnic group, unsurprisingly, is White British. However, as noted in the previous report, over a third of babies were of non-White origin, with a particularly high prominence of babies born to women of African origin, accounting for a quarter of neonatal deaths. Births to African women account for around 5% of Leeds births, so this group is clearly over-represented, although it is important to be aware that some of these were multiple births (so the actual number of women was fewer than 8).

¹ Reference: Perinatal Mortality 2007. CEMACH, June 2009.

Table 2		
<u>Ethnicity of babies who died aged under 28 days (neonatal deaths) and breakdown of ethnicity for all Leeds births</u>		
	Number (%) neonatal deaths considered by Panel	Percentage of Leeds births*
White British	20 (59%)	68%
African	8 (24%)	5%
Asian and Asian Mixed	5 (15%)	11%
White other	1 (3%)	5%
*Note: Data source is booking data returned to NHS Leeds for monitoring purposes during the period April-October 2010		

- 4.8 Consanguinity (the effect of parents being closely related to each other, frequently as a result of first cousin marriage) is known to be a risk factor for infant and later child deaths from genetic conditions. Cousin marriage is practiced widely in certain communities, notably those from parts of South Asia (Pakistan and Bangladesh), and parts of Africa and the Middle East. In the previous CDOP report, it was acknowledged that local data is not readily available concerning cousin marriage, and that staff may be reluctant to enquire about it, as it is perceived as a sensitive issue. Nonetheless, successful interventions may be available in the form of genetic testing and counseling for some conditions, and services to enhance uptake of such interventions have been developed in other parts of the country. It was therefore a recommendation of the previous CDOP Annual Report that efforts should be made to collect this information. Data were collected from hospital records by CMACE for all babies, indicating that, of the neonatal deaths, 2 babies were recorded as having related parents (first cousins). Deaths related to genetic conditions linked to cousin marriage may occur at older ages, or may manifest as illness during childhood, and this issue is therefore considered as a whole later in this report.
- 4.9 Maternal obesity is known to be associated with both neonatal and infant death. Body mass index (BMI) is a measure of obesity, and a BMI in excess of 30 is regarded as obese. BMI was recorded for just over two thirds of mothers (22), which is similar to the level of recording in last year's CDOP Annual Report. However, it is believed that BMI is routinely measured and recorded for all women, but the transfer of that information onto the CMACE forms is incomplete, and efforts are being made to improve this. Of those with a BMI available to the Panel, only 2 women had a BMI in excess of 30, and 3 further had BMIs between 25 and 30.
- 4.10 The neonatal data collection form, notably the supplementary CDOP form, includes information about smoking, drugs and alcohol use by parents, and domestic violence. However, the data suggest that only two women were actively smoking during the pregnancy, and none of the parents were using alcohol or drugs. There is one record of domestic violence. Given the known associations between these risk

factors and poor neonatal outcomes, it is surprising that this is not reflected at all by the local data. It is possible to speculate that these factors are not being noted in the hospital records from which the data are collected, or that women are not always open in admitting these behaviours. Whatever the reason, it seems probably that this is an artifact of the data collection rather than an accurate reflection of the prevalence of these risk factors.

- 4.11 Of the 34 neonatal deaths considered by the Panel, 25 were considered to have “no modifiable factors” (note: terminology in the national proformas has changed over this period). 9 deaths were identified as having potentially “modifiable factors”. Some of the issues debated by the Panel in relation to modifiable factors included: earlier diagnosis; variation in practice in respect of new or novel treatments or protocols which are not nationally standardised; variation in medical practice in other centres or countries which might increase risk, such as the number of embryos re-implanted during IVF; and population level public health interventions, such as improved awareness of genetic services.
- 4.12 A third of the babies (11) considered by the Panel were twins, relating to 10 pregnancies. Twin pregnancies are known to be higher risk of mid-trimester loss, prematurity and perinatal morbidity than singleton pregnancies.
- 4.13 The CDOP Neonatal Death Overview Panel did not refer any cases to the Chair of LSCB for consideration of a Serious Case Review.
- 4.14 The following learning points were identified by the Neonatal CDOP Panel:
- Improved completion of the CMACE form across maternity and neonatal services.
 - The need for early use of transcutaneous CO₂ monitoring in the most extreme preterm babies to reduce the risk of low carbon dioxide levels.

The following learning points were highlighted in the previous CDOP Annual Report:

- Improved communication between services
 - Improved multi-disciplinary antenatal management
 - Targeted teaching to improve antenatal diagnosis.
- 4.15 The Panel also highlighted issues arising from cases, some of which give rise to themes which may be the basis for future recommendations:
- Domestic violence and the importance of arranging protected time for women to speak alone with a professional.
 - Increased risk of genetic disorders in babies born to parents who are closely related, for example, first cousins.

- The role of the Panel in ensuring that Obstetric staff are made aware of later poor outcomes.
 - The fragmentation of care which can result from high mobility amongst certain ethnic groups.
 - Shared definitions of clinical terms.
 - The impact of late booking for maternity care.
- 4.16 In addition, the following issues were highlighted in last year's report:
- Limited availability of bereavement support services in the hospital.
 - Higher risk related to twin pregnancies.
 - Increasing numbers of people seeking in vitro fertilization (IVF) abroad, where practice is to transfer multiple embryos. The local unit is moving towards single embryo transfer.
 - Transfers between St James's and Leeds General Infirmary.
 - Lack of a breast milk bank in Leeds. Availability of breast milk from the Huddersfield bank may raise thresholds for use.

5. Recommendations from the CDOP Neonatal Death Overview Panel

- 5.1 The Panel has made the following recommendations:
- 5.2 **Recommendation 1:** Obstetricians and Neonatologists at LTHT should work together to clarify definitions of the PROM acronym and ensure common understanding and usage. (Completed)
- 5.3 **Recommendation 2:** Obstetricians at LTHT to audit two specific cases in order to review the risk assessment process and care plan. (Completed)
- 5.4 **Recommendation 3:** The Chair of CDOP should review the Panel processes in order to reduce the time taken between the death of the baby, and consideration at Panel. Ideally this should be reduced to 3 months. (Timescale: April 2011)
- 5.5 **Recommendation 4:** The Head of Midwifery at LTHT should ensure an audit is undertaken, to explore outcomes and satisfaction of BME women looked after by the team of BME midwives. (December 2011)
- 5.6 **Recommendation 5:** The Director of Public Health at NHS Leeds and Leeds City Council, and the Head of Midwifery at LTHT should ensure that programmes of work directed at reducing smoking by women during pregnancy are continued and outcomes are monitored. (Ongoing)

6. Progress towards implementation of recommendations made by the CDOP Neonatal Death Overview Panel in the CDOP Annual Report April 2008-November 2009

The Panel made the following recommendations in 2008-9:

- 6.1 The Consultant Obstetrician representatives on the Panel should ensure that a system is established for identifying women who have a pre-term delivery in order to offer a postnatal review and ensure early planning in the next pregnancy.

This action is complete.

- 6.2 The Chairs of CDOP will, through the CDOP Annual Report, highlight to the Executive Management Team of NHS Leeds the importance of centralisation of neonatal and obstetric services on the same site as children's services. (March 2010)

This issue is acknowledged by both LTHT providers and NHS Leeds commissioners, and is being given strategic consideration.

- 6.3 The Consultant Obstetrician representatives on the Panel should ensure that an audit is undertaken of the risk factors and outcomes in twin pregnancies across Leeds Teaching Hospitals NHS trust. (September 2010)

Audit is complete, and the findings have been presented within the Directorate. Specific changes to practice have been made with regard to mid-trimester screening for infection in African women with twin pregnancies, and consideration of cervical screening where appropriate.

- 6.4 The Consultant Obstetrician representatives on the Panel should ensure that a review of the care pathway for IVF pregnancies is undertaken. (March 2010)

Guidelines for assisted conception have been reviewed and re-written. Specific changes to practice have been made with regard to growth scans during pregnancy. An audit of the outcomes of IVF pregnancies is also being undertaken.

- 7. Commentary on Deaths of Older Children reviewed by CDOP**
- 7.1 The CDOP Panel has reviewed a total of 36 deaths of children aged over 28 days, of which the majority (28) occurred during 2008-9, and 8 occurred during 2009-10. Of the 36 deaths considered to date, 21 were reported in the previous annual report. The commentary presented in this section of the report relates to all 36 deaths, thus providing a better understanding of Leeds child deaths which took place largely in 2008-9.
- 7.2 The commentary in this section relates to all children who died aged over 28 days and up to 18 years. The majority, but not all, of these deaths were considered by the CDOP Older Children Panel. 5 of these cases were considered by CDOP Neonatal Panel because these babies were never discharged from the hospital neonatal unit.
- 7.3 The age distribution of the children considered by the CDOP Panel was:
- 14 children aged over 28 days and under 1 year
 - 5 children aged over 1 year and under 5 years
 - 3 children aged over 5 years and under 10 years
 - 7 children aged over 10 years and under 15 years
 - 7 children aged over 15 years and under 18 years
- 7.4 15 of the deaths were classified as “Sudden Unexpected Death in Childhood” (SUDIC) and were investigated under the SUDIC arrangements. Of these, 4 were babies aged under 1 year and 5 were older teenagers aged over 15 years. Among the older group of teenagers, 3 deaths were the result of road traffic injuries.
- 7.5 23 children who died were males, and 13 were females.
- 7.6 20 children were recorded as being of White British ethnicity, 8 as Asian (5 Pakistani, 1 Bangladeshi, and 3 Asian other) and 3 as African. The remaining 5 children were from a range of other ethnic backgrounds.
- 7.7 The CDOP Panel is required to consider the issue of “preventability” or “potential preventability” of the deaths, and this was reported in the previous annual report. However, this terminology was nationally contentious, and has been changed during 2009-10 to classify deaths as having “no modifiable factors” or “modifiable factors”. Of the 36 deaths of older children, 2 were classified as “preventable” (reported in the previous annual report). 8 were classified as “potentially preventable” and a further 3 as having “modifiable factors”. 18 were classified as “not preventable” and a further 3 as having “no modifiable factors”. There was not enough information available to assign a classification to 2 deaths.

- 7.8 The impact of cousin marriage as a risk factor for genetic conditions has been highlighted in paragraph 4.1.8. Among the older children, 2 deaths were related to genetic conditions and it was recorded that the parents were first cousins. Thus, overall, cousin marriage has been a contributory factor in 4 child deaths of the total 70 deaths considered by CDOP to date. These deaths have been classified as having “modifiable factors”.
- 7.9 Other aspects which were taken into account by the CDOP in assigning classifications of “potentially preventable” or “modifiable factors” included modifiable aspects of unintentional injuries (accidents) such as road traffic accidents, fire, falls and drowning where factors such as speeding, seat belts, alcohol, smoke detectors, or level of supervision could have influenced the outcome. The quality of care by agencies, at birth, throughout life or during the final events, was also considered.
- 7.10 Although the CDOP proformas have specific sections enquiring about use of alcohol and drugs, and about domestic violence, these issues have not been prominent. Only one child death proforma indicated parental use of drugs and alcohol, and one other indicated domestic violence although this was noted to be unrelated to the cause of death. It is unclear why these issues are not more prominent. It is possible that the issues are not recorded in the clinical notes which are used to complete the proformas for young babies, although this seems unlikely. For older children, issues around drugs, alcohol or domestic violence would potentially be known to several agencies, and should therefore appear. It is possible that, for young babies, the impact of these issues result in morbidity rather than death, which might account for the absence of these issues. For older children, it is possible that these issues may be more prominent among cases which have not yet reached the CDOP because they involve safeguarding issues, and are still within the Coronial processes.
- 7.11 The deaths of children considered by CDOP were classified under the following categories:
- Category 1: Deliberately inflicted injury, abuse or neglect (0)
 - Category 2: Suicide or deliberate self-inflicted harm (1)
 - Category 3: Trauma and other external factors (6)
 - Category 4: Malignancy (4)
 - Category 5: Acute medical or surgical condition (1)
 - Category 6: Chronic medical condition (4)
 - Category 7: Chromosomal, genetic and congenital anomalies (10)
 - Category 8: Perinatal/neonatal event (6)
 - Category 9: Infection (3)
 - Category 10: Sudden unexpected, unexplained death (1)
- 7.12 As in the previous annual report, no deaths have yet been assigned to Category 1: Deliberately inflicted injury, abuse or neglect. This probably

reflects that there are still outstanding cases even from the first full year of CDOP function (9 cases outstanding). These cases are likely to be those awaiting completion of the Coronial processes. An agreement has been reached with HM Coroner that the CDOP will not consider cases before the inquest is complete. Until CDOP has completed its consideration of all children who died in the calendar year 2008-9, a complete overview of the causes of death will not be possible.

- 7.13 The emerging pattern of deaths for Leeds reflects the nationally recognized causes of death among children aged over one year which include: unintended injury; malignancy; infection; and late deaths from congenital anomalies. The number of deaths is small, and patterns must therefore be interpreted with caution. However, Category 7 (Chromosomal, genetic and congenital anomalies) seems to be the predominant category. It is possible to speculate that this may be partly due to better survival of babies with complex condition owing to high quality obstetric and neonatal, and potentially some impact of cousin marriage on the prevalence of serious genetic conditions.
- 7.14 The CDOP did not refer any cases to the Chair of LSCB for consideration of a Serious Case Review.
- 7.15 The Panel identified a small number of learning points which, as appropriate, have been taken back to relevant agencies by their Panel representative. Some of these learning points related to Panel processes, and have been incorporated into way the CDOP operates. Some learning points have related to specific areas of clinical practice, and have been taken back for dissemination within the hospital.
- 7.16 The Panel also highlighted several issues arising from individual cases, which were recorded to be considered in the overall context of the Panel's findings. Some of the same issues arose in more than one case. Recommendations were framed in respect of some issues, whilst others were logged to be considered if themes emerge after consideration of a larger number of cases. The following issues were highlighted:
- The risks of smoking during pregnancy.
 - The risks of co-sleeping.
 - The value of "End of Life" plans.
 - Consanguinity (cousin marriage) as a risk factor for serious genetic conditions.
 - The role of speeding, drunkenness and reckless driving as a cause of child death.
 - The importance of universal early access to antenatal care.
 - The risks of acquiring Cytomegalovirus infection during early pregnancy, and action to raise awareness and reduce risk.
 - The excellent quality of care offered by Martin House Hospice and the Leeds Continuing Care Nursing Team.

- The impact of swine 'flu particularly on vulnerable children with complex needs.
- The need for adequate funding for children's hospices.
- The importance of functioning smoke detectors particularly in rented housing with young children.

In addition, the following issues were highlighted in the previous annual report:

- Lack of availability and timeliness of some key reports to inform the Panel.
- Limited availability of bereavement support services.
- Lack of information concerning consanguinity.
- Transfers between St James's and Leeds General Infirmary.
- Parental smoking.

8. Recommendations from the CDOP Older Children Death Overview Panel

8.1 The Panel has made the following recommendations:

Recommendation 6: The Director of Public Health at NHS Leeds and Leeds City Council should continue to progress work to reduce smoking during pregnancy and smoking by parents with young families. (March 2012)

Recommendation 7: The Director of Public Health at NHS Leeds and Leeds City Council should initiate social marketing work to ensure that co-sleeping messages are disseminated widely and appropriately to target populations. (March 2012)

Recommendation 8: The Director of Public Health at NHS Leeds and Leeds City Council should take forward work to raise awareness of the relationship between cousin marriage and genetic disorders, and ensure that appropriate genetic services are commissioned to respond to this need. (March 2012)

Recommendation 9: The relevant Clinical Leads at Leeds Community Healthcare, Leeds Teaching Hospitals NHS Trust and Martin House Hospice should put in place a common agreement (guideline?) regarding the arrangements for End of Life Plans for children. (September 2011)

Recommendation 10: The Director of Commissioning at NHS Leeds should ensure that the Children and Maternity Commissioning Team at NHS Leeds, and subsequently GP Consortia, are aware of the high quality service available to the children of Leeds from Martin House Hospice in the context of current funding arrangements. (May 2011)

Recommendation 11: The Chair of CDOP should write to Leeds Continuing Care Case Manager and the manager of Leeds Children's Continuing Care Nursing Team to commend the quality of care provided by these services. (Complete)

Recommendation 12: The Director of Public Health at NHS Leeds and Leeds City Council, in collaboration with the Health Protection Agency and Early Years Services at Leeds Local Authority, should ensure that materials to raise awareness of Cytomegalovirus and how to reduce risk of transmission, are developed and disseminated through Children's Centres. (Complete)

Recommendation 13: The Director of Children's Services, the Chair of LSCB and the Joint Director of Public Health at Leeds Local Authority and NHS Leeds should give consideration to strategic support for Smartrisk UK, which is an organization located in Leeds which draws upon the Canadian Smartrisk approach to reduce the risk of accidents among teenagers and young adults². (March 2012)

Recommendation 14: The Children's Centre Safeguarding Manager at Leeds City Council should liaise with West Yorkshire Fire Service to clarify the nature of existing services for checking fire safety and installing alarms in homes with young children, and to explore options for publicizing these services via Children's Centres. (September 2011)

9. Progress towards implementation of recommendations made by the CDOP Older Children Death Overview Panel in the CDOP Annual Report April 2008-November 2009

The Panel made the following recommendations in 2008-9:

- 9.1 The CDOP endorses the continued progression of work to reduce smoking in pregnancy and smoking by parents with young families. The Director of Public Health at NHS Leeds should ensure that co-sleeping messages continue to be disseminated as widely as possible through a range of agencies and professionals. (March 2011)

There is an ongoing programme of public health work to reduce smoking during pregnancy. Data collection regarding smoking during pregnancy has been improved, with ascertainment now over 95%. The latest data indicate that the current level of smoking during pregnancy in Leeds is 13%, which is better than the national target (15%). All Leeds midwives have received mandatory training, and referrals are made to the Leeds Smoking Cessation Service. Not all women take up the offer of an appointment, but for those who do, success rates in the Leeds service compare favourably with other parts of the country. Leeds has an active Smoke Free Homes programme, which promotes

² www.smartrisk.org.uk

the importance of parents keeping smoke away from children and outside the house.

Advice to all parents regarding smoking and co-sleeping is given by health visitors in accordance with the local clinical policy. This policy has been reviewed to ensure consistency of advice.

- 9.2 The Chairs of CDOP should keep under review the number and nature of road traffic accidents discussed by the Panel, with a view to considering appropriate recommendations. Possible recommendations may concern the fitting of “speed governors” to cars, or the recommendation of support for the SMARTRISK³ approach to unintentional injury prevention among young people. (Ongoing)

The CDOP has now considered 3 deaths of young people resulting from road traffic injuries. During 2009-10, the Director of Public Health at NHS Leeds was able to identify an amount of one-off funding (£18k) for Smartrisk UK. This funding was used to fund the HEROES show over a 2 week period in 8 targeted secondary schools, reaching around 600 pupils per school (4800 pupils total). The organization of the events was undertaken by Leeds Road Safety Unit. The HEROES show is an interactive sound and light show featuring an “injury survivor”, frequently a young adult with paralysis as a result of an accident. The injury survivor describes their own experience and answers questions from the audience. The sound and light show then highlights the key Smartrisk messages, including: Buckle Up; Get Trained; Wear the Gear; Drive Sober; Look First. In previous years, similar shows have taken place in Leeds funded by the Strategic Health Authority, and one-off funding by the Primary Care Trust. SHA funding has now ceased, and Smartrisk UK currently has no funding to enable it to deliver further interventions in Leeds.

- 9.3 The Chief Executive of LTHT should ensure that strategic plans in the city to develop a Paediatric Assessment Unit are progressed. (Completed)

This was in place at publication of CDOP Annual Report 2008-9.

- 9.4 The Chairs of CDOP should seek to clarify, through its data collection processes, the extent to which ethnicity and consanguinity are contributory factors in child deaths in Leeds. (Ongoing)

The quality of ethnicity and consanguinity information collected via the CDOP process is much improved, with almost 100% ascertainment of these fields in completed proformas. The CDOP will make a specific recommendation concerning consanguinity in the 2009-10 annual report.

³ www.smartrisk.org.uk

Appendix 1: Membership of the CDOP Panel

Representative	Agency	Job Title/ Role
Dr Sharon Yellin (Chair)	NHS Leeds	Consultant in Public Health Medicine
Older Children Death Overview Panel members:		
Dawn Wilkinson	Coroner's Office	Senior Coroner's Officer
Dr Chris Buller (co-optee)	Leeds Partnership Foundation Trust	Consultant Psychiatrist
Dr John Roper	NHS Leeds	SUDIC (Sudden Unexpected Death In Childhood) Paediatrician
Christina Fairhead	NHS Leeds	Deputy Designated Nurse
Jill Asbury	Leeds Teaching Hospitals Trust	Divisional Nurse Manager
Dr Chris Hobbs	LTHT	Designated Doctor and Consultant Paediatrician
Margaret Hainsworth	Early Years, Leeds City Council	Area Co-ordination Manager
Dr Mike Miller (co-optee)	Martin House Children's Hospice	Consultant in Paediatric Palliative Medicine
Bob Baird	Youth Offending Service	Operational Manager
Bridget Emery	Head of Housing Strategy and Solutions	Environment and Neighbourhoods
Carolyn Eyre	Team Manager Health and Safety	Education Leeds
Deborah Lightfoot	Social Care	Interim Head of Service for Safeguarding
Tanya Cockerill	West Yorkshire Probation	
Joanna Burton	West Yorkshire Police	
Bob Baird	Youth Offending Service	
Bryan Gocke	LSCB	LSCB Manager

Neonatal Death Overview Panel members:		
Dr Lawrence Miall	LTHT	Consultant Neonatologist
Dr Bryan Gill	LTHT	Consultant Neonatologist
Dr Kathryn Johnson	LTHT	Consultant Neonatologist
Ms Tracey Glanville	LTHT	Consultant Obstetrician
Ms Colette Sparey	LTHT	Consultant Obstetrician
Mr Nigel Simpson	LTHT	Consultant Obstetrician
Sue Deighton	LTHT	Matron Maternity Services
Heather Gwilliam	LTHT	Bereavement Support Midwife
Julie Scarfe	LTHT	Head of Midwifery
Dr John Roper	Leeds Community Healthcare	SUDIC Paediatrician

Appendix 2

Definitions

Stillbirth rate: The number of babies born after the 24th week of pregnancy who do not show any signs of life per 1000 total births (live and still births).

Perinatal mortality rate: The number of stillbirths plus the number of babies dying within the first week of life per 1000 total births (live and still births).

Low birth weight rate: The number of babies born weighing less than 2500g expressed as a percentage of total births (live and still births).

Infant mortality rate: The number of deaths of children aged under one year per 1000 live births.

Acronyms

BMI	Body Mass Index
CDOP	Child Death Overview Panel
CMACE	Centre for Maternal and Child Health Enquiries
IVF	In Vitro Fertilisation
LSCB	Leeds Safeguarding Children Board
LTHT	Leeds Teaching Hospitals NHS Trust
Neonatal DOP	Neonatal Death Overview Panel
NICU	Neonatal Intensive Care Unit
SCR	Serious Case Review
SUDIC	Sudden Unexpected Death in Childhood