

Why Children Die: A Pilot Study 2006



May 2008

England (South West, North East & West Midlands),
Wales and Northern Ireland

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CEMACH Mission Statement

Our aim is to improve the health of mothers, babies and children by carrying out confidential enquiries on a nationwide basis and by widely disseminating our findings and recommendations.



Contents

Acknowledgements.....	vi
Glossary and abbreviations	viii
Foreword	x
Preface	xi
1. Introduction	1
2. Key Findings and Recommendations	3
3. Methodology <i>Gale Pearson</i>	8
Commentary: The Working Group’s perspective <i>Moira Stewart</i>	
4. Consultation with children <i>Gale Pearson</i>	15
5. Analysis of the deaths <i>Martin Ward-Platt, Naufil Alam, Gale Pearson</i>	17
Commentary: A Pathologist’s perspective <i>Marian Malone</i>	
6. Primary Care <i>Anthony Harnden and Richard Mayon-White</i>	37
7. Description of the cases that went to Panel <i>Gale Pearson</i>	47
Commentary: A Public Health perspective <i>Shona Golightly and Jean Chapple</i>	
8. Avoidable factors <i>Gale Pearson and Anthony Harnden</i>	54
Commentary: From the Royal College of Emergency Medicine <i>Ian Maconochie and Ffion Davies</i>	
Commentary: A Hospital Care perspective <i>James Fraser</i>	
Commentary: From the Royal College of Paediatrics and Child Health <i>Sue Hobbins and Andrew Boon</i>	
9. Further Interpretation of Panel findings <i>Gale Pearson</i>	68
Commentary: A Coroner’s perspective <i>Aidan Keith Cotter</i>	
10. Examples of good practice <i>Gale Pearson and Anthony Harnden</i>	75
Commentary: From the Health Care Commission <i>Maddie Blackburn</i>	
Commentary: Perspective of a children’s advocate <i>Peter Fleming</i>	

11. CEMACH Child Death Review and “Working Together”
Richard Congdon, Anne Aukett, Fiona Reynolds and Dawn Roberts **82**

Commentary: The local authority perspective *Sarah Webb*

Commentary: The Police perspective *Richard Henson*

References **95**

List of Figures, Tables & Boxes **97**

Appendices **99**

A CEMACH Advisory groups and contributors

B CEMACH Child Death Review core dataset

C CEMACH Child Death Review panel proforma

D Guidance for doctors certifying cause of death

E Analysis of CEMACH & LSCB Child Death Reviews



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Glossary and abbreviations

Antepartum	Before birth
ANZPICS	Australia and New Zealand Paediatric Intensive Care Society
Ataxic	A lack of coordination that is characteristic of particular types of problem
CAMHS	Child and Adolescent Mental Health Services
CDOP	Child Death Overview Panel: A group with a standing membership set up by a Local Safeguarding Children Board (or Boards) to review the child deaths and amongst other things look for patterns or trends in the local data.
CEMACH	Confidential Enquiry into Maternal and Child Health
Congenital	A condition present from birth
Coning	Herniation (see below) of the brain stem into the spinal cord
DCSF	Department for Children Schools and Families (formerly part of the Department for Education and Skills)
Denominator	The lower part of a fraction. The part which is required in order to determine a rate or proportion from a number of cases
DfES	Department for Education and Skills
Empyema	A condition where pus accumulates between the lung and the chest wall
Fisher's Exact Test	A statistical test for comparing small proportions
Genetic	A condition or characteristic acquired by biological inheritance
GP	General Practitioner
Haemophilus influenzae	A germ that can cause (amongst other things) respiratory infections and meningitis
Haemoptysis	Coughing up blood
Herniation	Protrusion from one body compartment to another
Hyaline membrane disease	A lung disease that particularly affects premature babies
Intrapartum	During birth
Intraventricular Haemorrhage	A pattern of bleeding into the brain seen in premature babies
JCVI	Joint Committee on Vaccination and Immunisation
Limitation	Of treatment – where (usually by agreement) certain treatments are precluded
LHB	Local Health Boards (Wales)
LSCB	Local Safeguarding Children Board – the group that will review child deaths and respond rapidly to unexpected deaths under the Children Act 2004 as described in “Working Together to Safeguard Children” (HM Government 2006)

Meningococcaemia	Presence in the blood of one of the bacteria that can cause meningitis (N.meningitidis)
Morbidity	A pattern of symptoms or disability arising from a disease. As opposed to mortality which is the resulting pattern of death.
NACECH	National Advisory Committee for Confidential Enquiries in Child Health
Neonatal	From birth to before 28 completed days of life
NICE	National Institute of Clinical Excellence now renamed the National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
NISRA	Northern Ireland Statistics and Research Agency
NPSA	National Patient Safety Agency
NSF	National Service Framework
ONS	Office for National Statistics
Palliative	Relieving symptoms without effecting a cure
PCT	Primary Care Trust. PCTs commission local health care.
Peak Flow	A measure of ability to rapidly exhale that is decreased in asthma
Perinatal	Around the time of birth
Pertussis	Whooping cough
PIAG	Patient Information Advisory Group
Poisson Distribution	A discrete probability distribution in statistics that expresses the probability of a number of events occurring in a fixed period of time
Primigravida	A lady in her first pregnancy
PVL	Panton-Valentine Leukocidin a toxin that can be produced by a rare (but virulent) form of the Staphylococcus aureus bacterium
Quintile	Where a group is divided into fifths. A quintile contains one fifth of the population.
RTA	Road Traffic Accident
SUDEP	Sudden Unexpected Death in Epilepsy
SUDI	Sudden Unexpected Death in Infancy
Vignette	A literary sketch or illustration
Withdrawal	Of treatment – where (usually by agreement and where the consequences are known) a treatment is deliberately stopped

Foreword

The Confidential Enquiry into Maternal and Child Health (CEMACH) has demonstrated that it is feasible to identify avoidable factors in child deaths. There are few subjects as important as the care and protection of children and I welcome this valuable contribution to improving healthcare for children.

I am delighted that children were involved in the inception of the study and that some of the key findings were in areas of importance to them.

This study comes at the same time that Local Safeguarding Children Boards take up their mandate to review all deaths and investigate unexpected deaths. Hopes are high that the Children Act 2004, the Safeguarding Vulnerable Groups Act 2006 and the revision of "Working Together to Safeguard Children" 2006 will effectively promote the welfare of children and protect them from harm. Structures now exist to ensure that local and national learning are enhanced and embedded in the function of child care processes.

This CEMACH project is a pilot study designed to test the feasibility of national confidential enquiry work in this field. So what does it contribute?

Despite many positive examples of good care, this study found avoidable factors in children's deaths in a variety of situations. Healthcare professionals need to be trained in the recognition of serious illness in children. There are lessons here for every adult who cares for children whether professionally or socially, with an emphasis on the need for effective communication between existing agencies.

Confidential enquiry methodology is a powerful audit tool in healthcare. This study provokes serious reflection on the specialist nature of child healthcare, and how to provide it.

The most important conclusion relates to the feasibility of confidential enquiry work in children. I would encourage CEMACH to pursue this work and to audit the implementation of the recommendations.

Lord Naren Patel
Chairman – The National Patient Safety Agency

Preface

We are delighted to publish this pilot study, which establishes the feasibility of collecting comprehensive data on child deaths in England, Wales and Northern Ireland.

We have demonstrated not only that relevant data can be collected using established CEMACH networks but also that confidential enquiry methodology can be effectively used to determine whether the deaths of children could have been avoided.

This is an important study, the first of its kind. It is vital that the work is continued through the Local Safeguarding Children Boards so that important lessons can be learned to improve healthcare for children and young people in the United Kingdom.

We appreciate the dedication and support of the many clinicians and health professionals who made this study possible.

Deirdre Kelly
Chair
National Advisory Committee for
the Child Health Enquiry

Michael Weindling
Chair
CEMACH



1. Introduction

This is the first report of a national confidential enquiry specifically focussed on child deaths. Confidential enquiries have already contributed to major improvements in obstetrics, neonatal, and perioperative care in the United Kingdom (UK). However they are time consuming and require extensive collaboration between various professional groups as well as the attention of a dedicated full-time research team. Hence, when planning a confidential enquiry in a new patient group, it is pertinent to investigate both feasibility and utility at its outset. The aim of this new enquiry was to evaluate the feasibility of using this methodology to reduce the number of child deaths and make a significant contribution to child health in the UK.

The basic functions of a confidential enquiry are:

- To develop and maintain a register of the cases under scrutiny
- To subject cases in the register (or a specific sample of them) to review by a panel of experts with a focus on identifying avoidable factors where there have been adverse outcomes.

Subsequent recommendations are then derived from both the analysis of the register and the conclusions of the expert review panels. This report presents the findings of a feasibility study “The Child Death Review” in which confidential enquiry methodology was applied to child deaths (28 days to 17 years 364 days) occurring in three regions of England, all of Wales and Northern Ireland in the calendar year 2006.

A surveillance programme was mounted in order to determine where and when deaths occurred. A comprehensive core dataset (Appendix B) was developed and then collected on all deaths. A sample, designed to have an even spread across age groups and the geographical areas involved, was then subjected to more detailed enquiry. This involved scrutiny of the available records by a multidisciplinary panel in each case.

1.1 Background to the Enquiry

In 2003 the Confidential Enquiry into Maternal and Child Health (CEMACH) was formed through a merger of the Confidential Enquiries into Maternal Deaths (CEMD) and the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI). The newly formed CEMACH was required to extend its programme into the area of child health and to consider morbidity as well as mortality in terms of outcome in its reviews.

A formal consultation exercise was undertaken by an advisory committee (National Advisory Committee for Enquiries in Child Health, NACECH) to consider which topics were relevant. Of the 45 candidate subjects, a feasibility study for a confidential enquiry in child death was ranked highest. Parent bodies and organisations representing children were consulted about the protocol for this Child Death Review. In particular, considerable weight was placed upon a consultation exercise involving children, which is summarised in Chapter 4.

Local Safeguarding Children Boards (LSCBs) in England were established as the result of the Children Act 2004¹. Their terms of reference and modus operandi are fully explained in “Working Together to Safeguard Children” produced by HM Government in April 2006². LSCBs have a responsibility to review all child deaths and respond rapidly to unexpected deaths. The latter is defined as a death “which was not anticipated as a significant possibility 24 hours before the death or where there was a similarly unexpected collapse leading to or precipitating the events which led to the death”. From 1st April 2008 LSCBs also have a statutory responsibility to use the aggregated findings from all child deaths, collected according to a nationally agreed data set, to inform local strategic planning on how best to safeguard and promote the welfare of children in their area (paragraph 7.7, “Working Together”). “Working Together” was published during the data collection phase of the CEMACH Child Death Review and refers to the core dataset of the CEMACH Child Death Review in relation to the derivation of a nationally agreed minimum data set relating to child death.

1.2 The place of the Child Death Review within the Child Health Enquiry at CEMACH

The aim of this pilot study was to assess the feasibility of using the confidential enquiry approach to investigate children's deaths in the UK. It was anticipated that the study would also make a useful contribution to the health and safety of children. Wherever possible CEMACH has also sought to support and advise LSCBs through the production of interim reports relating to the progress of the study. Nevertheless this CEMACH project was not a 'pilot' for the processes to be implemented by LSCBs, particularly because it did not include review of neonatal deaths which are covered by the existing perinatal enquiry at CEMACH.

The objectives of the CEMACH Child Death Review were:

1. To identify all child deaths aged 28 days to 17 years 364 days in the selected regions during the calendar year 2006
2. To collect a "core" dataset on all those deaths
3. To conduct a detailed review, through multidisciplinary panel enquiry, of a subset of the deaths with a focus on identifying avoidable factors
4. To inform the feasibility of conducting national confidential enquiry work into child deaths.

In addition to the information provided at registration, a child death review should help understand child deaths, the social and environmental context, underlying medical conditions, and the complexity of contributing factors.

CEMACH currently has a national core dataset and surveillance programme on the 40% of all child deaths that occur in the neonatal period (<28 completed days of age). This study did not collect data on this group to avoid duplication. For further information see www.cemach.org.uk.



2. Key Findings and Recommendations

This was a pilot study to determine whether confidential enquiry methodology could be used to identify avoidable factors in child deaths and to indicate potential areas for further study. This report is based upon the analysis of two datasets: the quantitative analysis of the core dataset (957 deaths) and the qualitative analysis of 126 of the deaths evaluated by 41 multidisciplinary panels.

Key Finding 1: The feasibility of confidential enquiries in children

The study detected child deaths in expected numbers (2.47/10,000 children). The local CEMACH networks detected deaths more quickly than the process of registration. Data capture was comprehensive and the quality of data was good.

The primary purpose of a confidential enquiry is to review deaths and other adverse outcomes, seeking to identify avoidable factors and to derive lessons for wider policy and practice. Since this was a pilot study we did not use matched case controls and cannot reliably extrapolate, from the sample of cases reviewed in additional detail, to the provision of care for children throughout the UK. Nevertheless, using this methodology, we identified factors in a proportion of deaths which might have been avoided. These factors were not detected from the dataset that we collected on all deaths, nor were they discernible from the entries on the death certificate. Multidisciplinary panel review identified areas of concern in which deaths might have been avoided in 31 out of 119 cases where there was sufficient information to make such a determination.

Recommendations:

- ***Future development of confidential enquiries in children***

CEMACH should prepare a strategy for the future development of the national confidential enquiry for child health in liaison with the National Patient Safety Agency, the Department of Health, the Department for Children, Schools and Families and other relevant bodies.

Key Finding 2: Good practice

The CEMACH enquiry panels found many examples of high quality care and examples where, even with outstanding care, the child died.

Key Finding 3: The recognition of serious illness in children

- a) We found occasional examples amongst the 126 cases analysed in detail, in which health care practitioners both in primary care and in hospital had difficulty in recognising serious illness in children. Aspects of this included failure to meet standards set by the NSF for Children, Young people and Maternity services (2004) and highlighted by the Health Care Commission in their report "Improving Services for Children in Hospital" (2007). They include: care in a non-paediatric unit, failure to take sufficient care with history or examination, inadequate observation, failure to anticipate or recognise complications or follow published guidance. These errors were made by individuals with little or no training in paediatrics or where there was little paediatric supervision. Panels were particularly concerned when they identified situations where parents appeared to accept the reassurance of initial consultations despite their continued concerns.
- b) Aspects of this report raise concerns about the mental health of the children in the populations studied. The children consulted in preparation for the study raised substance abuse and suicide as important issues. The majority of children who died following suicide or substance abuse were not in contact with mental health services. We encountered situations where failure to follow published NICE guidelines (e.g. in respect of children who self harm) had adverse consequences.

Best practice in this respect includes:

- All health care professionals who treat sick children should have appropriate training and supervision such that their key skills and competencies can be demonstrated, standards maintained and performance assured.
- All healthcare institutions need to ensure that staff are aware and implement national guidelines. All clinicians especially those in primary care and Accident and Emergency departments should, as a matter of course, encourage and empower parents and carers to seek further advice if a child's condition fails to improve or deteriorates after medical advice has been provided.

Recommendations:

- ***For paediatric care in hospital we recommend a standardised and rational monitoring system with imbedded early identification systems for children developing critical illness – an early warning score.***
- ***Efforts should be made to improve the detection of children with mental health problems.***



Key Finding 4: Missed appointments and poor coordination of care

In the 126 cases reviewed by panels, there were situations where failure to follow up patients who did not attend for their appointments was associated with later death.

The practice outlined in the National Service Framework for Children 2004 states that Children or young people failing to attend clinic appointments "... may trigger concern, given that they are reliant on their parent or carer to take them to the appointment. Failure to attend can be an indicator of a family's vulnerability, potentially placing the child's welfare in jeopardy." Whilst there may be policies in which adults are not sent repeat appointments, this will rarely be appropriate practice with children.

Recommendation:

- ***Health Services, including primary care and Child and Adolescent Mental Health Services (CAMHS) should proactively follow up children who do not attend their appointments.***

Key Finding 5: Response to the recognition of life limiting illness

32% of all children who died had developmental delay, impairment or disability and a further 45% of deaths occurred in individuals with existing illnesses or complex needs. 73% of these deaths occurred in hospital, 19% at home and only 2.6% in hospices. The low proportion of hospice deaths suggests that there is an opportunity to improve practice when potentially life limiting illness is recognised.

Recommendation:

- ***Planning for future terminal care should consider where best to deliver care, at home or in a hospice.***

Key Finding 6: The need for further epidemiological review of child deaths

- a. The use of a core dataset for all the deaths included in the CEMACH study enabled the enquiry to identify a number of epidemiological and public health issues relevant to children. This is despite the fact that the CEMACH study was relatively small. We are confident that if the study was continued and broadened to include a wider range of issues, it would have great value for informing future health and social care policy for children.

As an example, the analysis of the data on all the deaths identified issues concerning the ethnicity of children who died. The overall mortality rates for children of Pakistani and Black African origin were significantly in excess of the rate seen in white children. Death was also more common amongst the more socially or economically deprived and this may explain some of the ethnic differences. Although numbers were small it appeared that there were also ethnic differences in the children who were victims of homicide. Five out of twelve cases occurred in non-white ethnic groups which is disproportionate to the overall ethnic distribution of the deaths. We also found regional differences in the mortality rates of older children (highest in the North East and Northern Ireland).

- b. We also note that some 40% of all child deaths occur during the neonatal period (0-28 days). CEMACH already maintains a neonatal mortality surveillance system with reports at national, Strategic Health Authority (SHA) and Neonatal Network and provider level. To avoid duplication this system could be extended cost-effectively to encompass Local Safeguarding Children Boards (LSCBs) and Primary Care Trusts (PCTs).
- c. Half of the deaths, which panels considered might have been avoided would not have been identified as “unexpected” under the “Working Together” definition. We concluded that scrutiny by a multidisciplinary panel review is required to confidently detect the presence of preventable factors.

Recommendations:

- **Ongoing national epidemiological analysis of child mortality**

A mechanism should be developed for ensuring ongoing national epidemiological analysis of all child deaths using the common data set of child deaths referred to in “Working Together”, with an annual report drawing out information relevant for public health and national policy on children. There would need to be periodic review and update of the national core dataset for child deaths.

- **Neonatal mortality surveillance**

Given the considerable expertise of CEMACH in the development of datasets and databases and in ensuring accurate and comprehensive data collection for neonatal deaths, there needs to be further consideration of its role and how it might support LSCBs in carrying out their functions in respect of neonatal mortality under “Working Together”.

- **Extended scope of case review**

For LSCBs to be as successful as they could be in identifying preventable factors, as many child deaths as possible should be reviewed using an in-depth approach such as multi-disciplinary assessment including full access by appropriate experts to relevant clinical notes and documentation from other agencies. This supports the statutory requirement in the Children Act 2004 that all child deaths should be reviewed and LSCBs should use the aggregated review findings to inform local strategic planning on how best safeguard and promote the welfare of the children in their area.

Key Finding 7: The complexity of child death

A high proportion (77%) of deaths occurred in individuals with existing illnesses or complex needs. We found that the information on the death certificate was sometimes incorrect (inaccurate or insufficient in 33 out of 95 certificate entries reviewed by panel). Despite the facility to highlight that “information may be available later” on a medical certificate of the cause of death, it would be important to be able to highlight to the Coroner when avoidable factors had been identified. It is likely that the implementation and outcomes of “Working Together” will be more successful if panels work closely with the coronial service.

Recommendation:

- **Improving death certificate information**

We recommend that extensive communication takes place between Coroners and local safeguarding children boards, particularly when there is cause to reconsider the information entered onto a death certificate or if avoidable factors have been identified.

Key Finding 8: The role of primary care

We found examples of both high quality and substandard primary care in five broad thematic areas: immunisation, diagnosis, chronic disease management, palliative care and at risk teenagers. Timely immunisation, accurate diagnosis of acute illness, continuity of care and regular review of children with chronic disease, availability in palliative care and recognition of at risk teenagers would improve the care of children in general practice.

Recommendation:

- **Maintenance of paediatric skills in general practice**

Primary care professionals must ensure that they maintain their skills in the recognition of serious illness in children. They should also ensure that children are immunised in a timely, safe and efficient manner and grasp opportunities for prevention in all age groups.

3. Methodology

Gale Pearson

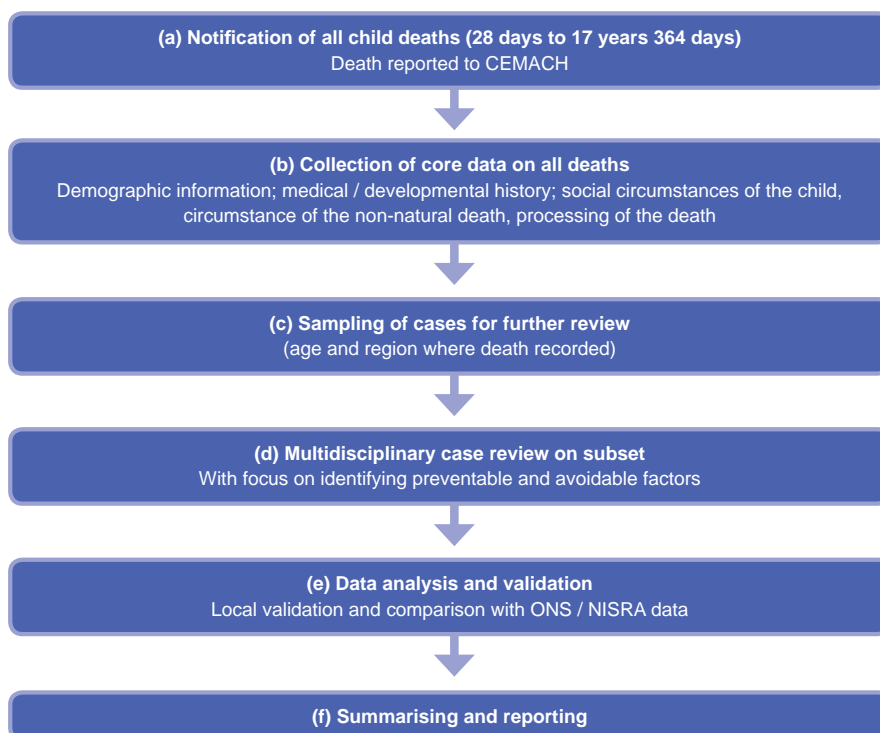
3.1 The method of case ascertainment and data acquisition

The regions that participated in the child death review were the South West, North East and West Midlands of England, Wales and Northern Ireland. CEMACH's regional structure is largely coterminous with Government Office regions except in the North East region where the North East is combined with North Cumbria. Also the regional manager for the North West manages CEMACH activity in the West Midlands. Local networks were established in each region in order to gather data. Regional CEMACH managers had to establish new clinical contacts and other local contacts including Coroners, police (including youth offending teams and prisons), other emergency services, health and safety executives, social workers and general practitioners. Local CEMACH staff also searched through local newspapers and other media sources in attempts to ensure comprehensive case ascertainment.

The study itself included all deaths of children aged between 28 days and 17 years and 364 days, occurring from midnight December 31st 2005 to midnight on 31st December 2006. When a death was discovered, basic descriptive details (the "Notification dataset") were recorded. Regional contacts were then used to complete a more comprehensive Core dataset, which was adapted from that used in the Arizona Child Fatality Review⁷. Its content is covered in the first interim report <http://www.cemach.org.uk/Publications/Child-Health.aspx>. Some licence was provided for regional variation in how the dataset was completed. For example in the South West region a small group of local clinicians discussed the case with the regional manager and completed the core dataset together at a "local case conference".

Figure 3.1

Summary of CEMACH Child Death Review pilot study design



An inclusive approach to data collection was adopted. Data were collected on all children dying in the CEMACH region (wherever they were resident) and upon all detected deaths of children resident in the CEMACH region wherever they died. These data were entered onto the database regionally and analysed centrally.

3.2 Selection of cases for panel review

The cases for panel review were selected at the stage of notification and were spread across age groups and geographical regions. Age was stratified in bands: 28 to 364 days, 1 to 4 years, 5 to 14 years and 15 to 17 years 364 days. The rationale was to separate school age children from pre-school children, and to distinguish the 15 to 17 year old children who have different patterns of mortality compared with younger children. When a case was selected the local team gathered the records using a checklist (which included copies of original medical, social and educational records relating to the deceased's life as well as the incident leading to death) and anonymised them. They were then sent to CEMACH central office from where they were distributed for discussion at a confidential enquiry panel in another region involved in the study. Since this was a pilot study, case controls were not sought for any of the deaths.

3.3 Composition of multidisciplinary panels

Multidisciplinary panels were convened by the regional CEMACH manager and chaired by the regional clinical lead (a volunteer who also shared responsibility for local liaison between CEMACH and LSCBs). The core panel members were:

- an acute (hospital based) paediatrician,
- a community paediatrician (if the acute paediatrician does not cover community),
- a pathologist (with paediatric expertise),
- a general practitioner,
- a nursing representative,
- two non-medical representatives.

It was also considered desirable to include a representative of a Local Area Child Protection Committee / LSCB amongst or in addition to these individuals. Further additional experts were recruited to the panel to suit the nature of the case. Likely additions being:

- For children less than a year of age, a health visitor and a neonatologist.
- For children aged 1-9 years, a health visitor or school nurse.
- For children aged 10-17 years, a school nurse.
- A relevant medical specialist such as a surgeon, intensive care specialist, or other sub-speciality medical representative such as a paediatric cardiologist or paediatric neurologist.
- A specialist paediatric nurse, community nurse or other sub-speciality nursing representative.
- A Child & Adolescent Mental Health Service (CAMHS) representative.
- A representative of children's social care services, paramedic, radiographer or representative of the police.

In addition, the Clinical Director of the Child Health Enquiry attended as many panels as possible (functioning as an observer). The principal researcher of the primary care review also attended panels across regions.

3.4 Conduct of the multidisciplinary panels

Each panel sitting (half day session) considered three to four cases having had copies of the anonymised records to review in advance. The regional manager, who convened a panel, nominated individuals within it to present a summary of each case to the meeting in order to initiate discussion. Following a discussion of the case, a standardised reporting tool (Appendix C) was used to describe the case, capture factors that could have contributed to the death, and to score the strength of this contribution. The rationale for using this tool was that it was likely to reduce the variation between panels in their approach. In order to support the chosen style of reporting (using vignettes), several "Free text" fields were incorporated including one for a description of the case and chosen examples of "Good practice". All entries on the proforma were agreed by consensus during the meeting.

Finally, the panel had to categorise the most avoidable factor they had identified as contributing to the death, using a pre-specified format described below. It was the responsibility of the panel chair to ensure that the members contributed evenly and freely and that the report reflected the balanced views of all members. The data on the panel reporting proforma were entered locally and analysed centrally.

3.5 Data analysis

The database for the core dataset was closed for analysis on the 31 May 2007. Panel reviews continued and were completed by 31 October 2007. Subsequent data checking included a cross reference against Office for National Statistics (ONS) / Northern Ireland Statistics and Research Agency (NISRA) death registration data to assess the level of case ascertainment. Cases reviewed by panels were not compared to controls and a largely qualitative approach was chosen to present the results.

3.6 The consideration of avoidable factors

In medical literature relating to “avoidable death”, authors frequently study registration data and try to distinguish deaths due to diseases (or processes amenable to medical care / technology) from those mainly responsive to health or public safety policy. In the analysis of the core dataset, at some level all “non-natural” deaths could be considered to contain avoidable factors but that does not imply that anything could necessarily have been done to prevent them at the time, since this would require prior knowledge of impending events.

Panels had the opportunity to consider “avoidability” in much more detail than is possible from the core dataset alone and were wary of using “top down” approaches to avoidability such as that described above. The working group also preferred not to assume that any particular medical condition could be designated as “avoidable” per se. Each case history was considered in context, in order to assess its severity and the likely impact of interventions. To this end, each of the factors involved in each death was considered individually in preference to the death itself. Hence the concept of “avoidability” was deconstructed and a standardised tool derived in advance to both classify and record the opinion of the panels. Each case was given a single classification based upon the hierarchical consideration of all factors involved in the death. Where multiple factors were present the most avoidable would be scored irrespective of its position in an apparent chain of causation or its proximity to the time of death. The definitions used in the panel reporting tool were as follows:



1) Avoidable

- a) Where there were identifiable failures in the child's direct care by any agency, including parents, with direct responsibility for the child
- b) Where there were latent, organisational or other indirect failure(s) within one or more agency, including parents, with direct or indirect responsibility for the child
- c) Where there was a failure of design, dilapidation of barriers, or inadequate maintenance by agencies with responsibility for public safety (e.g. rail maintenance leading to Hatfield rail disaster).

2) Potentially avoidable

- a) At a higher level than the agencies with direct or indirect responsibility for the child (e.g. political violence, war, terrorism, crime, and if the child is the victim of homicide)
- b) Where no agency, including parents, was involved directly or indirectly with the child
- c) Where intrinsic factors (e.g. an acquired disease with a known high mortality such as meningococcaemia) were the principal factors leading to the death
- d) Where there were potentially modifiable factors extrinsic to the child
- e) Where the causal pathway leading to the death could reasonably be traced back to antepartum or intrapartum obstetric events.

3) Unavoidable

- a) Death caused by unmodifiable factors extrinsic to the child (e.g. lightning strike, earthquake)
- b) Death due to undiagnosed, asymptomatic conditions presenting with a lethal event (e.g. hypertrophic obstructive cardiomyopathy)
- c) Planned palliation for unpreventable, incurable disease or anomaly (e.g. Leigh's disease).

In interpreting the panel conclusions as reported using this system, it would be wrong to assume that correction of the most avoidable factor would, on its own, or in other similar cases, have necessarily prevented the death although the likelihood increases with avoidable factors of higher grades.

In advance of the study, the working group tried to ensure that constructive conclusions were drawn from multidisciplinary panels. An example of the behaviour of panels in drawing such conclusions can be gained by comparing two deaths of pedestrians hit by motor vehicles. In each case, at the appropriate point in the database, the road hazards were graded as "directly and overwhelmingly important factors" in the children's deaths. However in terms of avoidability they were distinguished from each other. The "hit and run" case where the child died at the scene and where no information was available about the vehicle or the driver, was graded as 2d ("potentially modifiable factors extrinsic to the child"). The other case, where the driver of a large vehicle had not seen the child but where investigation by the Health and Safety Executive had led to the issue of an enforcement notice was graded 1c ("... inadequate maintenance by agencies with responsibility...").

3.7 Cause for concern reporting

An internal CEMACH policy was derived in advance to cover the consequences of a case being so severe that reviewers might feel obliged to take further action as a consequence of analysing the case. The policy required discussion of the case with the Clinical Director and Chief Executive of the enquiry. It was agreed that the Clinical Director would clarify if an appropriate investigation had taken place and if not to contact the medical director of the trust involved, initially by telephone followed by a letter documenting that such information had been imparted.

In order to follow this policy, the director of the child death review evaluated cases reported to contain avoidable factors graded 1a, to establish whether local review had occurred. In cases where the data implied it had not, the notes were recalled to clarify whether any local review or a Coroner's inquest had taken place.

3.8 Vignettes

Short case studies ('vignettes') of a number of the deaths have been included in this report. Vignettes are an important way of showing how and why improvements in practice need to be made. Each vignette does however describe a personal tragedy for a child and their family. We aim to reconcile the need to learn from these deaths with the right to privacy of the families involved by providing information on an anonymous basis and by altering details where appropriate. We also destroy all documentation collected for the enquiry prior to publication of the report.



Invited commentary: The Working Group's perspective

Moira Stewart

The CEMACH Child Death Review was a feasibility study. Although the panels were necessarily constrained in several areas (see below) and therefore in the conclusions that can be drawn, the project has demonstrated that detailed examination of all available information by multidisciplinary teams, can identify factors contributing to child deaths, over and above that derived from routinely collected data and registration of deaths. It has also shown that, in some cases, incorrect information has been recorded, with implications for guidelines issued on delivery of care in the future. However such an enquiry is costly, time consuming and resource dependent and it is unlikely that it is sustainable and generalisable without identified funding. In order to justify these costs, the conclusions and recommendations must have the potential to improve the care given to children by professionals and carers and lead to avoidance of some childhood deaths.

There are limitations to the CEMACH study. The enquiry is retrospective and relies on documentation that no matter how complete, cannot reproduce events as they occurred. This is especially the case when there has been rapid or unexpected deterioration and record keeping has necessarily been after the terminal event. The panel also had access to information after death, which might not, or could not have been available at the time of presentation for healthcare. In particular, bacteriology results, post mortem findings, detailed social history, were often provided to panels but not available prior to death. In most cases there was little information on organisational structures within various hospital units including staffing levels within hospital and community, local guidelines and for some children, even when information was presumed to exist, it was not always available to the panels.

The conclusions drawn on "avoidability" were in part subjective although reached after detailed debate and discussion and did represent the consensus view of the panel. Panels examined different cases and although an external observer "sat in" on one or two panels in each of the five pilot sites, it cannot be presumed or asserted that all panels would have reached the same conclusion.

One key factor which came up over and over again was around "communication" – transfer of information between professionals, and from professionals to carers and vice versa. "Communication" and "teamwork" have been recurrent themes in key reports such as 'Kennedy' and the "Victoria Climbié Inquiry" but appear to be still limited by lack of a unique identifier, inadequate technological support to facilitate transfer of information and by human factors such as shared language and assessment protocols. In some cases, it was impossible to determine whether failure to act appropriately and/or in a timely manner were due to poor assessment, including failure to recognise the seriousness of the child's condition, or that there was inadequate interpretation of appropriate information by the recipient.

There were examples of good team-working such as common medical and nursing notes. However, there were also cases where there appeared to be lack of confidence on the part of parents and/or other professionals to challenge the decisions made by medical staff. The possible reasons are beyond the scope of the enquiry but crucial to the debate on future professional roles, shared working practices and training at undergraduate level.

Each child is an individual, every child death is unique, even when the cause of death is common and therefore direct comparison is impossible. The enquiry covered a wide range of child deaths – from infancy to late childhood – so that common themes are limited by numbers in various age groups and diagnostic categories. Cases were not matched with children with similar conditions who survived, although the inclusion of "specialists" on panels served to provide information on current evidence based practice.

Mortality rates at all ages during childhood have decreased enormously over the past century and parents no longer expect to lose a child. One consequence is that it is increasingly difficult for parents to accept and cope with the death of a child – even when death is inevitable and predicted. Almost half the children whose deaths were reviewed by panel had a chronic or congenital disease, some of which are associated with shortened life expectancy. The identification of “good practice” within palliative care, management of terminal events and communication after the child’s death, should be recognised as important outcomes from the enquiry and form part of the recommendations. In other cases, such as asthma, which is a common chronic disease of childhood and generally considered treatable, the review serves as a reminder that there remains a significant associated mortality and that symptom management, rather than cure, is the aim of treatment.

Despite improved recognition and treatment of acutely ill children there will continue to be deaths in infancy and childhood – and the future, almost certainly, will throw up new challenges in terms of “superbugs”, environmental hazards, societal changes etc. The largest single cause of death in children dying of an acute physical illness was infection, highlighting the continued vulnerability at the lower end of the age spectrum to a wide range of infectious agents. Despite comprehensive and expanding immunisation programmes, antibiotic availability, training in resuscitation and life support, significant number of children still die from infectious diseases each year, and infection control, antibiotic prescribing and vigilance remain key priorities in planning and delivering health care to children.

The identification of extrinsic factors – especially in the case of road traffic accidents points to the need for an advocacy role for professionals and parents in seeking mandatory safeguarding actions and activities. Similarly, the identification of extrinsic factors relating to the role of carers either in protecting children from harm, or in engaging with professionals in prevention and management of health problems – highlights the need for government targets that take into account the dependence of children on their parents or carers in availing of services.

Professionals who care for children – of whom a small number will die – have two main responsibilities – paramount is to provide the best possible care for each child. There is the additional requirement to be cognisant of the needs and wishes of families and of the implications of morbidity and mortality for carers and for the wider society. Drawing attention to the avoidability of childhood deaths has the potential to add to the distress of families unless it is matched with recommendations, which can impact to prevent such deaths in the future. If lessons can be learned and acted on following detailed examination of each child death, the time and effort are well spent.



4. Consultation with children

Gale Pearson

NACECH and the Patient Information Advisory Group (PIAG) both indicated that CEMACH should consult with children regarding the ethical issues and sensitivities surrounding the collection of information on child health, especially the deaths of young people aged between 14 to 18 years. Hence, in collaboration with the National Children's Bureau, two consultation sessions with a total of 24 young people aged between 14 and 20 years of age from St. Marylebone School and Barnet FE College, were conducted early in the review. The full results of these consultation sessions are available at <http://www.cemach.org.uk/Programmes/Child/Child-Death-Review.aspx>. The participants were asked to advise on health topics of significance to them, how cases subject to review could be managed and what type of questions they would ask to get a truer picture of the events that took place.

The young people consulted were selected from those with an interest in health and social care. 75% of the group were under 18, the gender mix was 18 female and 6 male and there was a broad ethnic mix. Ground rules ensured that all participants felt comfortable discussing and sharing information within the group – a key aspect being an explanation of confidentiality and confirmation that the participants were aware of the support available to them in relation to their participation.

A "Thought shower" process (later revisited after the session) revealed what the participants saw as "Child Health". In this way, the young people were able to provide feedback on their experience of the day as well as suggesting priorities for future study. These included; Mental Health, Drugs (Smoking and Drinking), Child Protection and Abuse, Sexual Health / Contraception and Eating Disorders.

In the most significant session of each day, two groups of 12 young people, each working with three facilitators, reviewed three cases taken from the emerging review.

- Case study A looked at a young woman who had been raped and who had then committed suicide,
- Case study B concerned a death associated with substance abuse and
- Case study C was a report on a young person who had been killed in a car accident.

The participants asked many practical questions and directed the researchers on what should be further investigated to obtain a clearer idea of how the young people had died. Some of these questions involved looking in more depth into their recent health history but also asking for more information from witnesses and friends and relatives about the deceased's prior emotional and physical state.

The group asked why they had not been aware of CEMACH's work in this field and requested that the results of the Child Death Review be publicised widely. They considered there to be a need for such studies to inform the public but also felt that just reading about the cases would itself educate people and reduce the likelihood of similar events occurring in the future. After reviewing the cases the young people felt that they needed a greater awareness of danger in their lives, particularly with regards to substance abuse and traffic accidents. The group gave very practical lessons that occurred to them during the case studies and recommended that if CEMACH were to follow their advice and share case studies on a wider scale to promote safer outcomes for children and young people, then it would be important to avoid using too much detail for fear that the individuals could be identified.

The children understood that the bereaved families would still be grieving, so that the revelation or publication of details such as the relevance of substance abuse or whether suicide was implicated, might add to the pain they were experiencing. They were vocal about the manner in which the results should be reported, stating that each case should be treated "individually" and not just as "another case". This, they felt, would demonstrate sensitivity on the part of the investigators that would aid both the process and the response generated by the report.

It is clear that having found out about it, these young people valued the work of CEMACH and saw the Child Death Review as an important project, which would have an educational impact on children's lives and a preventative impact on child death. They expressed sincere appreciation for the opportunity to participate in the formative stages of the work and were keen to encourage CEMACH to solicit further child involvement in the future. The consultation with children was therefore a rewarding process for CEMACH and an important validation and endorsement of the child death review both in design and the chosen method of reporting.

CEMACH and The National Children's Bureau have produced a version of this main 'Why Children Die' report suitable for children and young people. This report is available to download from the CEMACH website.



5. Analysis of the deaths

Martin Ward-Platt, Naufil Alam and Gale Pearson

Notable findings

- 77% of the children had previous history of a medical condition, or some sort of developmental delay / impairment / disability.
- 66% of deaths were certified in hospital, only 2% occurred in hospices.
- We detected higher rates of child suicide than previously reported. Only a quarter of these cases were known to have mental health problems prior to death.
- We found significant regional variation in the death rates of 15 to 17 year olds.
- The differences in child death included:
 - The overall death rates for children from families of Pakistani and Black African origin children were significantly in excess of the rate seen in white children.
 - Higher rates of congenital malformation were seen in children from families of Pakistani origin.
 - Although child homicide was rare, in a disproportionate number of cases the victim came from a non-white ethnic group.
- Death was more common amongst those in deprived circumstances.

5.1 Introduction

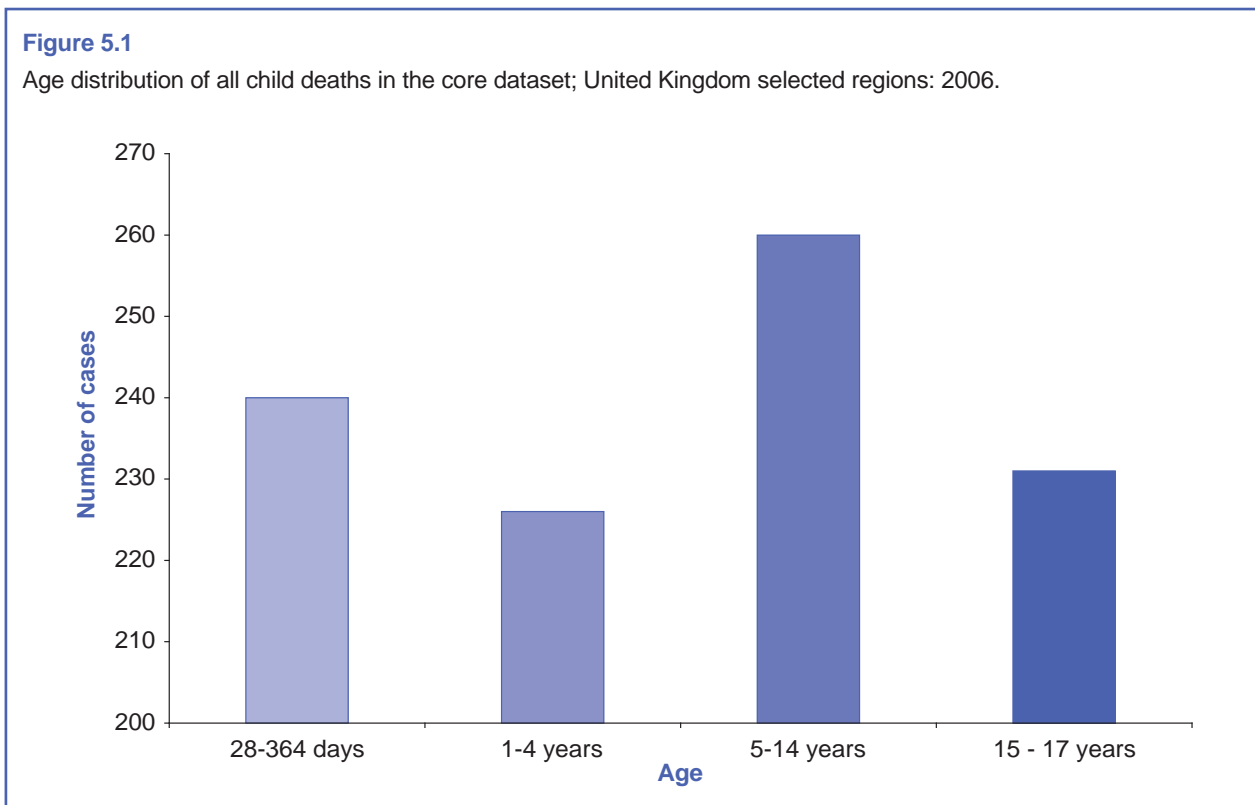
The dataset used for this chapter could eventually provide significant additional epidemiological data to that available from accumulated registration data. However the dataset was not designed to detect avoidable factors or unexpected deaths. This required experienced expert review of the sort that was only performed at panel enquiries and in the primary care project within this study. Furthermore, before presenting our analysis of this pilot, some issues that influence the interpretation of our analysis need to be discussed.

First, the data are confined to deaths from 28 days to 17 years and 364 days of age. This limitation was chosen because the factors contributing to neonatal deaths are covered by a separate confidential enquiry programme. Leaving out these deaths somewhat limits the overall picture of child death. The number of child deaths aged 0 to 27 days (neonatal deaths) in the five regions of the CEMACH pilot during 2006 was 732: this represents just over two-fifths of all child deaths in the CEMACH pilot areas for 2006. The deaths which occurred between birth and 28 days post-partum are reported in the CEMACH publication “Perinatal Mortality 2006” (www.cemach.org.uk/Publications).

The “cause of death” as used in this analysis relates to the medical certificate of the cause of death and does not take account of the conclusions of confidential enquiry panels because not all cases went to panel. As well as having the opportunity to revise the cause of death, panels could also reconsider the location of each death and distinguish it from the place where certification occurred. Since, when death occurs outside hospital, certification may still occur in an Accident and Emergency department. The tendency to bring patients to hospital rather than the Coroner’s mortuary is much greater in children’s deaths as compared to adults.

Finally, even though the project succeeded in covering a third of the UK child population, the contributing regions (which did not include Scotland or any part of the South East of England) cannot be assumed to be representative of the UK as a whole.

The deaths were distributed within the age stratifications as shown in Figure 5.1.



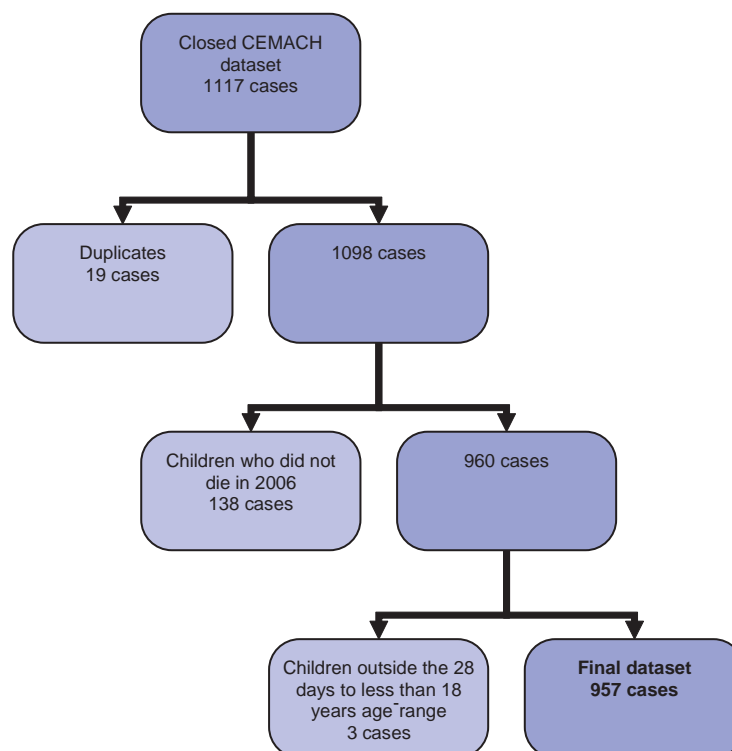
Cause of death was classified using the Australia and New Zealand Paediatric Intensive Care (ANZPIC) registry coding system⁸. This is a pragmatic coding system which, like the International Classification of Diseases (tenth revision), is based on body systems. The apparent utility of a system designed for intensive care admissions does not necessarily transfer to “cause of death” across a population. This is especially true where some children die without pre-existing disease and without admission to hospital. One of the problems encountered in the analysis of child death is in grouping the cases by principal diagnosis where, whichever system is used, one inevitably ends up with a large group of miscellaneous cases.

5.2 Data processing

Figure 5.2 shows how the final core dataset of 957 cases was derived. The estimated total child population (under 18 years) of the participating regions for 2006 was 3,868,617. Although this denominator included babies up to the age of a month that were not part of our numerator, the error that this introduced was less than 1%, which should be seen in the context of the errors intrinsic in estimating the child population in the first place. Nevertheless, attempts were made to take into account any discrepancy arising from the extra 28 days in the ONS denominator on calculation of the rates.

Figure 5.2

How the final core dataset of 957 cases was derived.



5.3 Validation of case ascertainment

Epidemiological information, based upon coded registration data (death certificates), suggested that approximately 3050 children between the ages of 28 days and 17 years and 364 days, die in England, Wales and Northern Ireland each year⁹ and that the study regions accounted for about a third of this number. We detected deaths in the numbers anticipated and performed a limited cross validation with data from the Office for National Statistics and the Northern Ireland Statistics and Research Agency for 2006. National statistics might be anticipated to be more likely than CEMACH to detect deaths outside the regions involved in the study but might also be more vulnerable to missing cases where registration was delayed. An important category of such cases were those undergoing Coroners' review. Case matching indicated a high degree of case ascertainment.

5.4 Calculation of rates

Estimates of the mid-year population for England and Wales were obtained from ONS and NISRA. Data pertaining to the regions included in this investigation were extracted using the standard Government Office regions. The boundaries of these regions are similar to those of the CEMACH regions except for the North East region of England which includes the North East and North Cumbria. These denominator data were processed to extract the number of children under 18 years of age. This was possible because the denominator data were provided by single year of age. The problem of excluding children less than 28 days was circumvented using data collected by CEMACH from its perinatal surveillance programme. Death rates were calculated per 10,000 population in a given age group. Ninety-five percent confidence intervals for the rates were calculated under the assumption of a Poisson distribution.

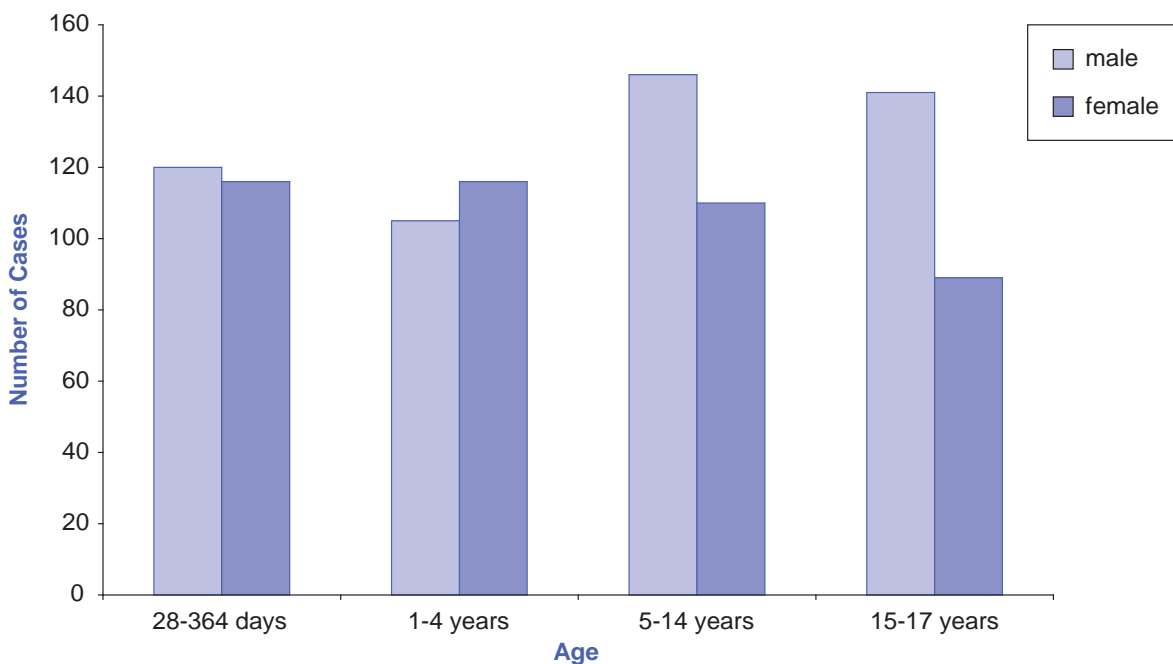
5.5 Characteristics of the core data

5.5.1 Gender and age

The cases available for our analysis consisted of 512 males and 431 females (in 14 cases, gender was unknown however these cases were not excluded from the subsequent analysis). The overall age breakdown for the deaths is shown in the Figure 5.3. There is little discrepancy between boys and girls in the younger age groups, but a clear tendency for higher numbers of deaths in boys than girls among school-age children and adolescents.

Figure 5.3

Age and gender distribution of all children in the core CEMACH dataset; United Kingdom selected regions: 2006.



5.5.2 Death rates

There was little regional variation in death rates overall (Figure 5.4a), but among 15 to 17 year old children there were significantly higher rates in North East England and Northern Ireland compared with the West Midlands (Figure 5.4b).

5. Analysis of the deaths

Table 5.1

Estimated death rate per 10,000 live children by region; children aged 28 days to 17 years 364 days; United Kingdom selected regions: 2006.

Region	Number of deaths	Estimated mid year population aged 28 days - 17 years and 364 days*	Rate per 10, 000 children [95% confidence interval]
North East England	154	536, 150	2.87 [2.45, 3.36]
South West England	228	1, 057, 538	2.16 [1.89, 2.45]
West Midlands England	301	1, 205, 119	2.50 [2.23, 2.80]
Wales	163	640, 235	2.55 [2.18, 2.97]
Northern Ireland	111	432, 806	2.56 [2.13, 3.09]
TOTAL	957	3, 871, 848	2.47 [2.32, 2.63]

* Data provided by the Office for National Statistics (ONS)

Figure 5.4a

Child death rate per 10,000 live children: children aged 28 days to up to 17 years 364 days; United Kingdom selected regions: 2006.

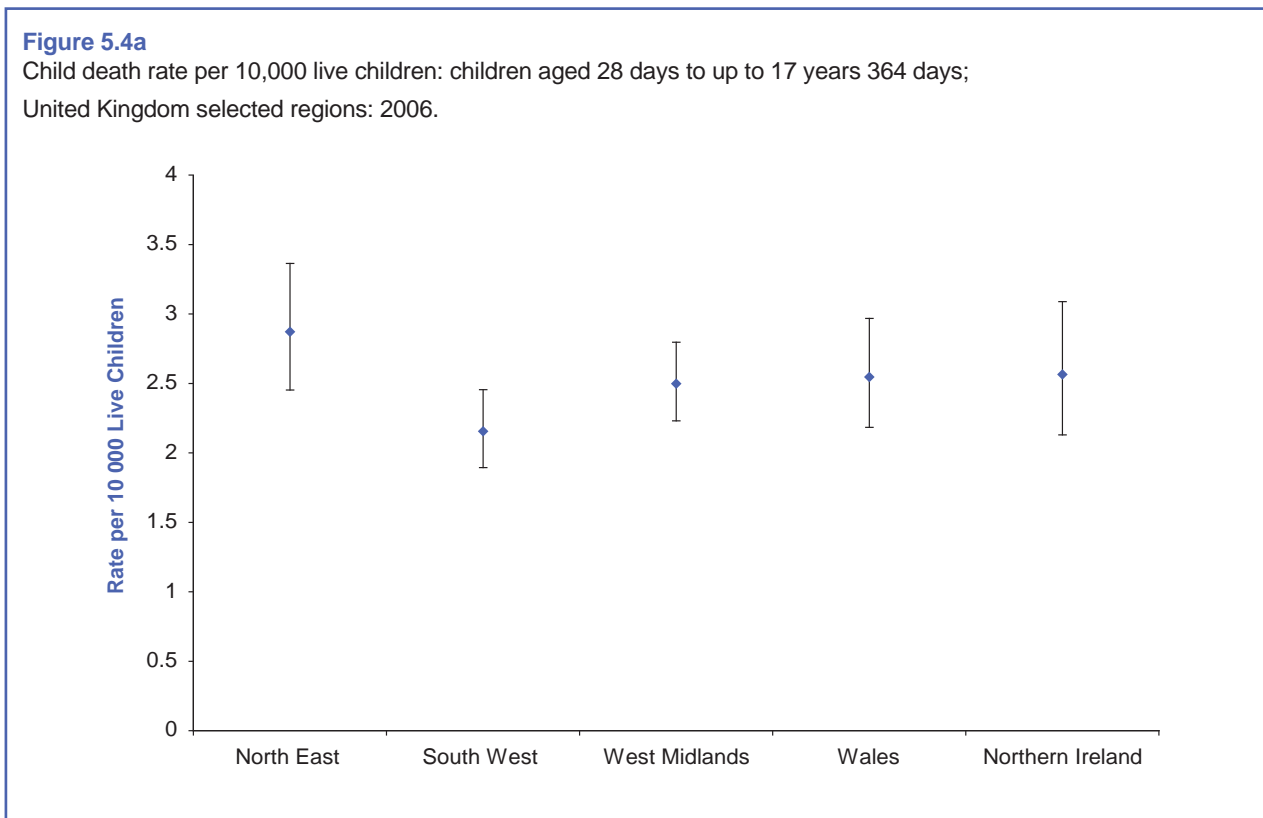
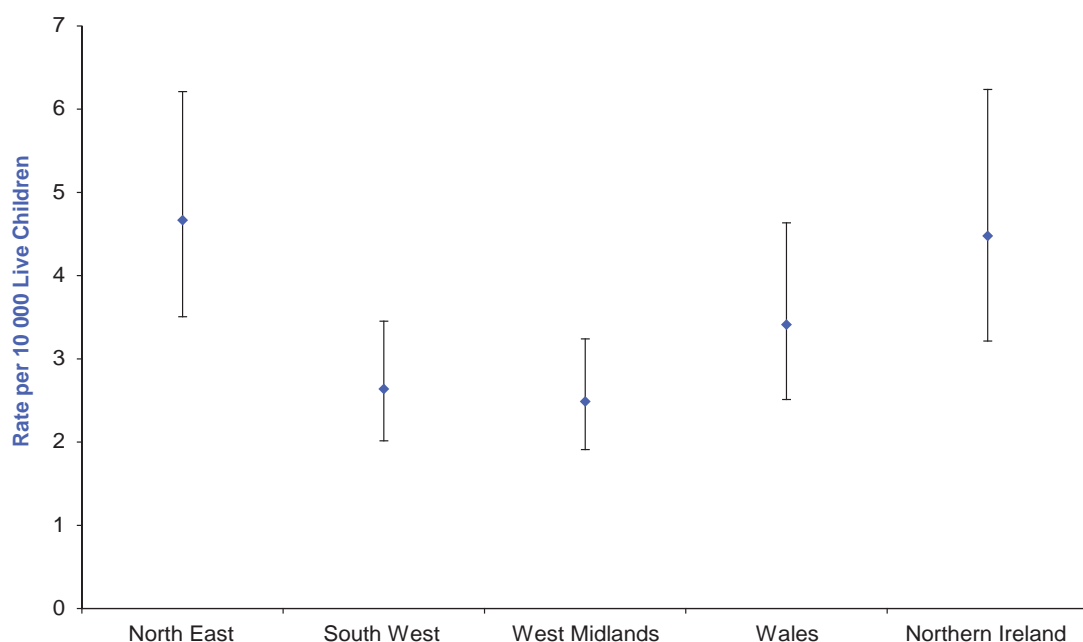


Figure 5.4b

Child death rate per 10,000 live children: children aged 15 to 17 years 364 days; United Kingdom selected regions: 2006.



5.5.3 Location of deaths

Sixty-six percent of deaths were certified in hospital, 2% in hospices and the remaining 32% were in the community (18% of the total were at home). Using all available data sources, the location of death within hospital was determined for 565 (89%) of the hospital deaths. These were broken down as illustrated in Table 5.2:

Table 5.2
Location of deaths in hospital

Location	Number (Percentage)
Paediatric Intensive Care Unit	188 (33)
Accident & Emergency department	152 (27)
Children's Ward	103 (18)
Neonatal Intensive Care Unit	57 (10)
Adult Intensive Care Unit	39 (7)
Operating Theatres	21 (4)
Adult Ward	5 (1)
TOTAL	565 (100)

5. Analysis of the deaths

More detail can be derived from these figures using other explanatory variables in the dataset. For example 32 of the paediatric intensive care deaths were after limitation of treatment and 85 after active withdrawal of support. This implies that treatment failure is recognised in 62% of paediatric intensive care deaths even if futility cannot be determined or acted on at the outset of intensive care admission.

The “Accident and Emergency” category included 78 children classified as dead on arrival. 60 of the remaining 74 died during attempted resuscitation. This prompted further interrogation of the location of death. Using CEMACH definitions where the site of the incident / collapse was recorded and using data from the core dataset (not from panels) 129/645 (20%) of death locations could be reconsidered as “community” and five changed from community to hospital. The location where incidents / collapses occurred that ultimately lead to deaths certified in hospital, are illustrated in Table 5.3.

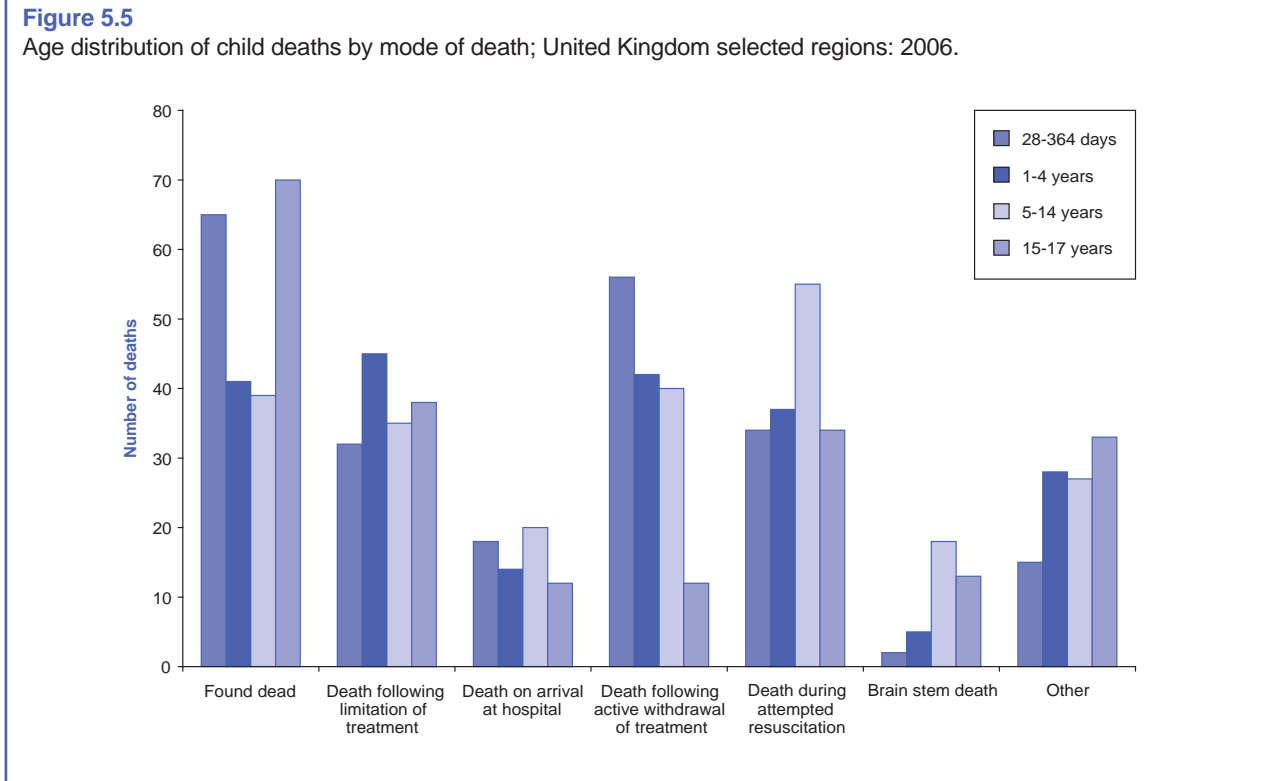
Table 5.3
Cases which were reclassified from a hospital location to a community location

New Location	Number
Home	80
Public place	25
Other (Residence)	13
Transit	7
Hospice	2
School	1
Residential	1
TOTAL	129

These data will be of interest when considering where the most effective preventative measures could be applied for any avoidable factors.

5.5.4 Mode of death

Figure 5.5 charts the numbers of children in each age category according to the Mode of Death: the manner in which the child died. The diagnosis of brain stem death requires a particular set of formal clinical tests and is used to identify potential organ donors. It is an uncommon mode of death in paediatrics but relatively more frequent in the older children.

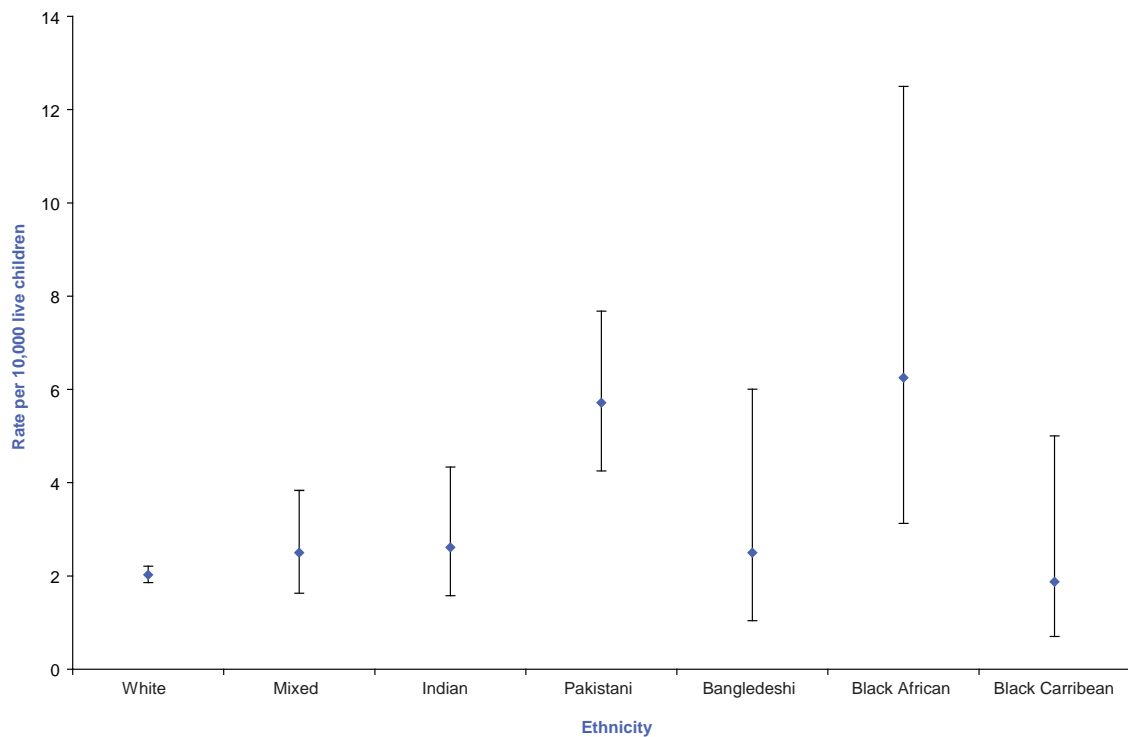


5.5.5 Ethnicity

The numbers of children who died from ethnic minority groups were very small outside England and overwhelmingly the absolute numbers of children dying from non-natural causes in this study were white. However concentrating on the three English regions and calculating death rates per 10,000 population using ONS data as denominators we were able to calculate rates of death by ethnic group. Figure 5.6 shows the death rates for all causes of death. Although the numbers of ethnic minority children dying were small in themselves (hence the wide confidence intervals), the overall rates for children from families of Pakistani and Black African origin were significantly in excess of the rate seen in white children. Fifteen of the 46 deaths (33%) in children from families of Pakistani origin were listed as having a congenital condition, either at death or in the previous history. These families in general have a higher rate of malformations than other groups, possibly due to rates of parental consanguinity, which is likely to contribute to their higher death rates.

Figure 5.6

Child death rate per 10,000 live children by ethnic group; selected England regions: 2006.



When we analysed other causes of death by ethnicity we found that although homicide was a rare cause of death overall (12 cases), five of these occurred in non-white ethnic groups, which is disproportionate to the overall ethnic distribution of the deaths.

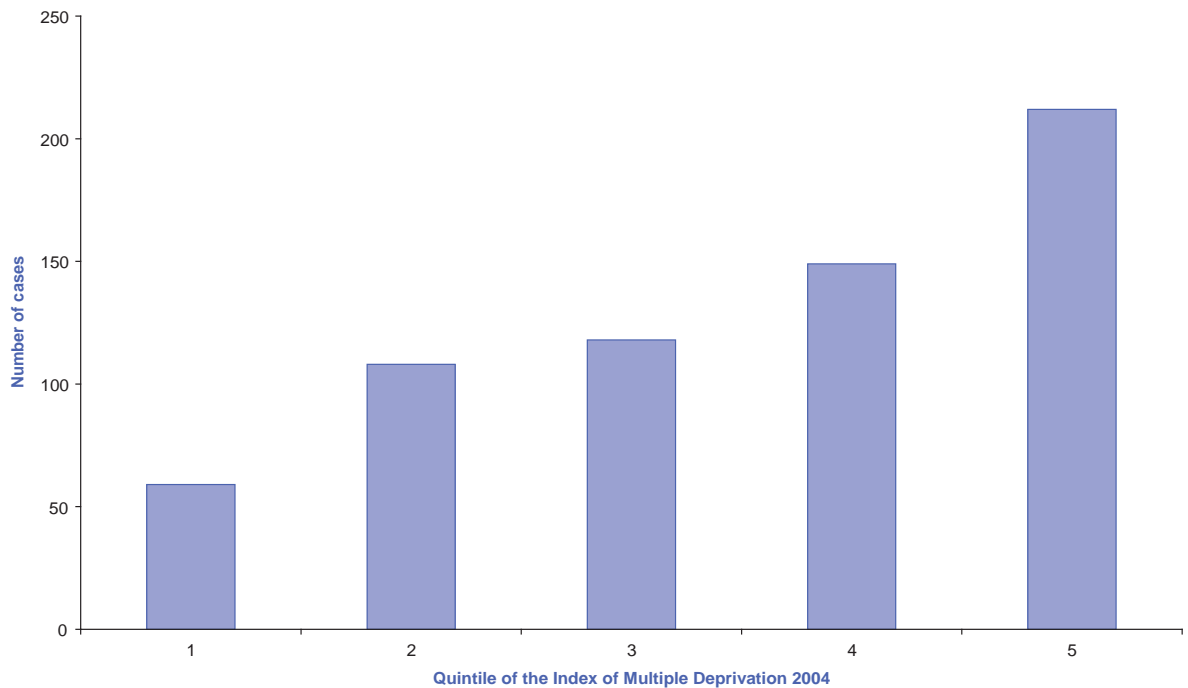
5.5.6 Deprivation

For methodological reasons we could not control the ethnicity data for differences related to deprivation. However we were able to present the deaths in the English regions grouped by the quintiles of deprivation using data provided by the Office for National Statistics (ONS) and the Office of the Deputy Prime Minister (2004). This measure encompasses seven domains; income, employment, health deprivation and disability, education skills and training, barriers to housing and services and, crime and living environment. The quintile of deprivation is derived from the postcode.

As in other groups, child death is more common amongst those in more deprived circumstances (higher quintiles). These data are displayed in Figure 5.7.

Figure 5.7

Number of cases by deprivation quintile (based on postcode residence); selected England regions: 2006.



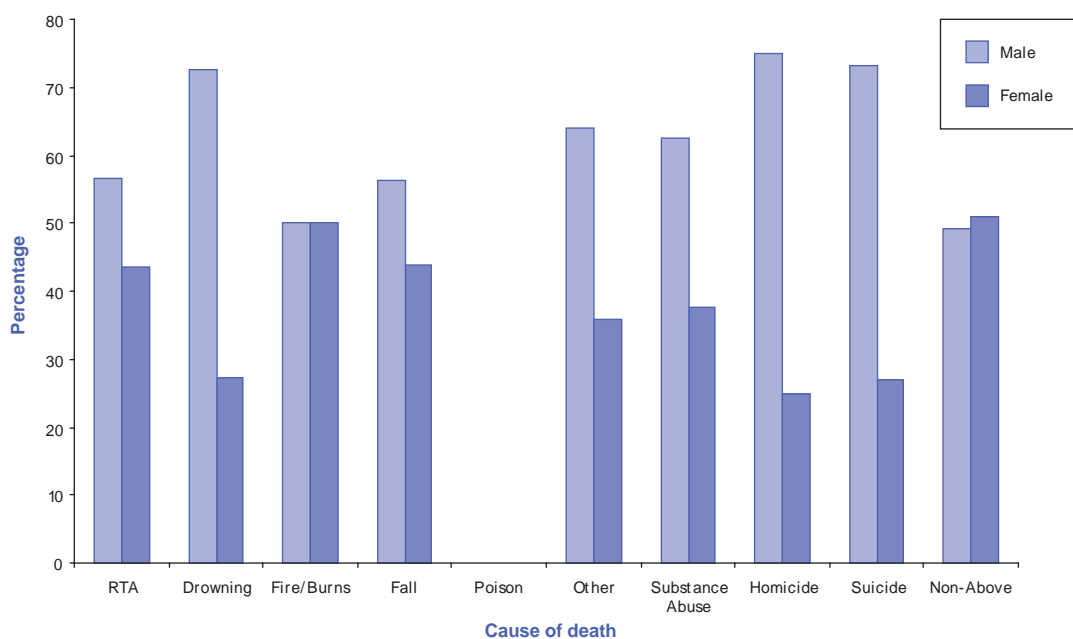
5.6 Non-natural causes of death

There were 229 cases of non-natural death which are listed in Table 5.4. The dominant category was deaths in road traffic accidents.

Figure 5.8 demonstrates that boys also accounted for much higher proportions than girls for deaths by drowning, homicide, suicide and substance abuse.

Figure 5.8

Percentage gender distribution of non-natural deaths; United Kingdom selected regions: 2006.



5. Analysis of the deaths

Table 5.4

Causes of non-natural deaths: Children aged 28 days - 17 years and 364 days:
United Kingdom selected regions: 2006

Cause	Number of deaths	(Percentage)
Road traffic accident	108	(47)
Suicide	26	(11)
Other	25	(11)
Drowning	22	(10)
Falls	16	(7)
Fire	12	(5)
Homicide	12	(5)
Substance Abuse	8	(3)
Poisoning	0	(0)
TOTAL	229	(100)

5.6.1 Road traffic accident

Boys outnumbered girls for deaths in road traffic accidents with the greatest disparity in the older age groups. Furthermore, in the older age group, deaths as pedestrians became less common than those as driver / passenger and the accidents tended to occur in the evening.

Figure 5.9

Age distribution of children who died from Road Traffic Accidents (RTA); United Kingdom selected regions: 2006.

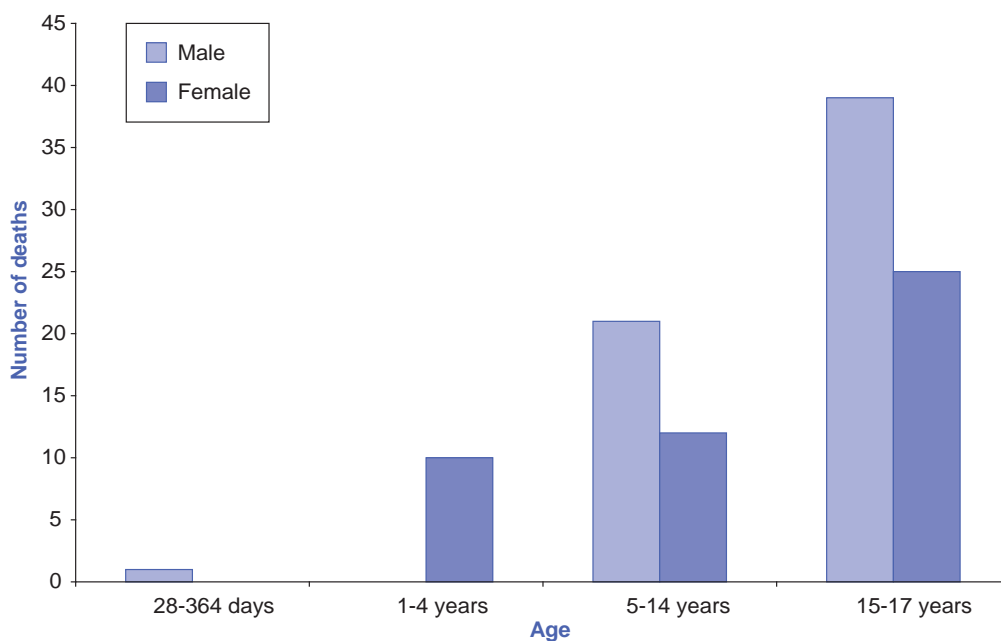
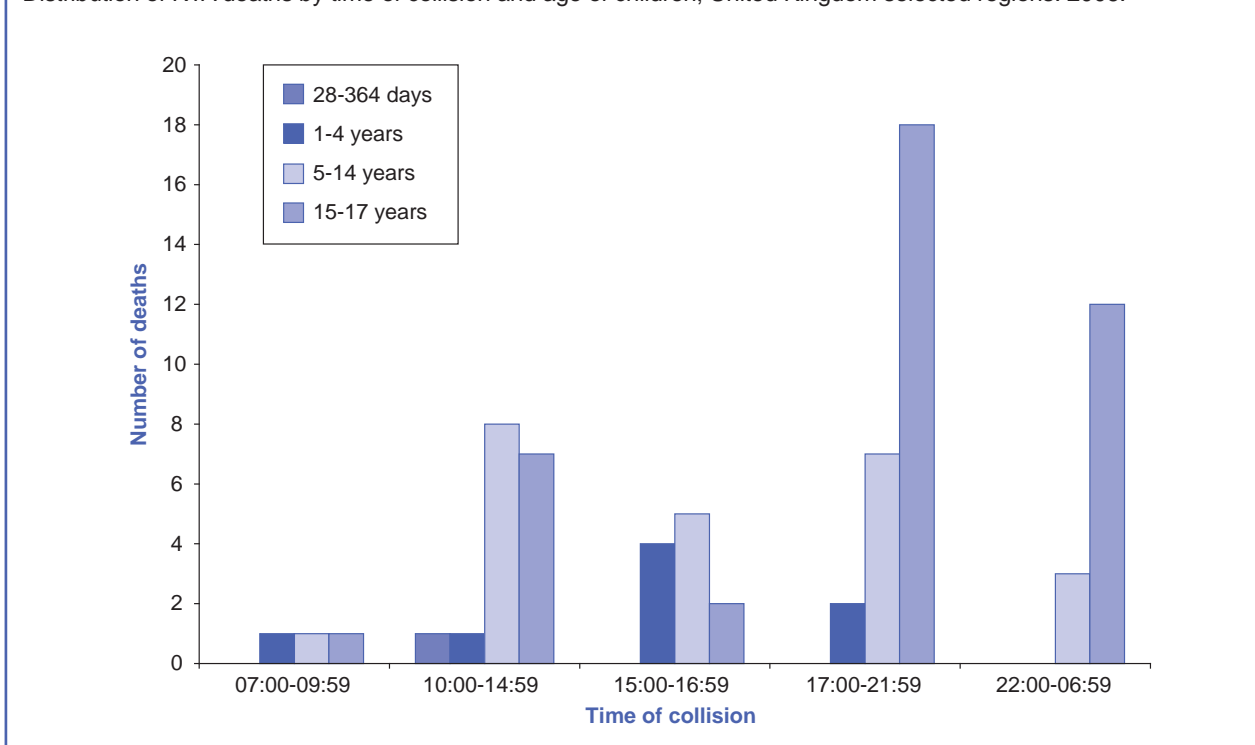


Figure 5.10

Distribution of RTA deaths by time of collision and age of children; United Kingdom selected regions: 2006.



Much of the complete data entry in the explanatory fields for road traffic accidents were positive assertions from the regional managers that they could not obtain the requested information. The low acquisition of data is probably linked to the difficulty panels experienced in providing police / highway agency reports. Nevertheless in 27/108 deaths ascribed to road traffic accident the child who died was a pedestrian. The site of the accident was defined in 19/27.

Sixty-three percent (12/19) of the child pedestrian deaths in this study were reported as being related to “zig zag” areas, however it would be wrong to draw any firm conclusions from these relatively small overall numbers. There were no positive breath test results recorded amongst the drivers involved in these accidents

There were 76 instances where the child who died was described as a driver / passenger and four positive breath test results reached the dataset relating to the drivers of these vehicles. In 5/76 instances in-vehicle restraints were known to be absent and in 11/76 further cases in-vehicle restraints were present but not used.

In eight instances the child who died was riding a bicycle and in only one of these cases was the child wearing a helmet.

5.6.2 Suicide

In this study, suicide was the largest single category of non-natural deaths after road traffic accidents. The rates (shown in Table 5.5) were higher than recently reported by ONS¹⁰ but such low numbers meant that the 95% confidence intervals as shown in Table 5.5 are wide. Our data for Wales may not be different from the 1995 to 2004 rate quoted, for example. Furthermore, inter-regional comparisons should be based on more than just one year’s data and more than just three regions of England. CEMACH acquired suicide data in a different way to ONS. The question of whether each case was a suicide was a distinct data point and not an interpretation of an entry on the death certificate. Furthermore since we quote a significantly higher rate of child suicide in Northern Ireland we should point out that rates in Scotland, Wales and Northern Ireland are

5. Analysis of the deaths

already known to be higher than England and specifically that in response to the number of suicides in Northern Ireland, the Department of Health, Social Services and Public Safety (DHSSPS) published 'Protect Life - A shared vision - the Northern Ireland suicide prevention strategy and action plan 2006-2011' in October 2006. Substantial additional funding has been allocated to support implementation of the strategy. Suicide prevention remains a top priority for health and children's social care services in Northern Ireland.

Table 5.5
Comparison of suicide rates as ascertained by ONS/NISRA and CEMACH Child Death Review

		Data source	
		ONS/NISRA* (1995-2004)	CEMACH Child Death Review (2006)
Age- specific suicide rate per 100 000 live children aged 11-17	England	0.3	0.9 [0.52, 1.69]
	Wales	1.5	2.2 [0.98, 4.90]
	Northern Ireland	3.6	5.6 [3.02, 10.42]

* England and Wales data provided by the Office for National Statistics (ONS), Northern Ireland data provided by the Northern Ireland Statistics Research Agency (NISRA).

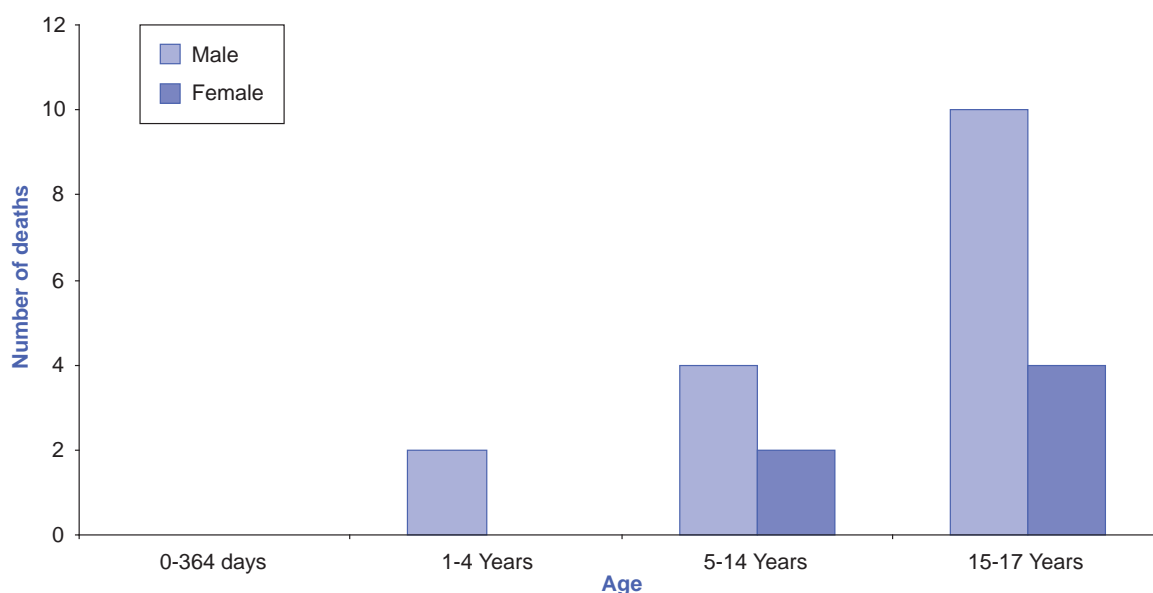
Confidence Intervals not available for ONS or NISRA data.

There were 26 cases (19 boys, 7 girls). The predominant method used was hanging or strangulation (20 cases), with poisoning and jumping accounting for three cases each. Only a quarter of the cases were known to have current or past mental health problems. All the children were aged 12 or over, six (5 boys, 1 girl) were under 15. There was a hint of a seasonal pattern (peak in March / April).

5.6.3 Drowning

For children dying by drowning (22), analysis revealed a substantial effect of age (Figure 5.11). This cause of death did not appear to be dominated by very young children (who may plausibly fall into water when unable to swim, for example in un-enclosed domestic swimming pools), but rather by older children, especially boys, who may drown in a wide variety of circumstances including marine or boating incidents.

Figure 5.11
Gender distribution of deaths from drowning; United Kingdom selected regions: 2006.



The number of deaths from falls (16), fire or burns (12), homicide (12) or substance abuse (8) were not exceptional. No child died unintentionally from poisoning. Of the 12 cases where death was the consequence of fire / burns, fire alarms were known to be absent in two cases. Of the eight deaths due to substance abuse, the child was known to “substance abuse services” in two cases.

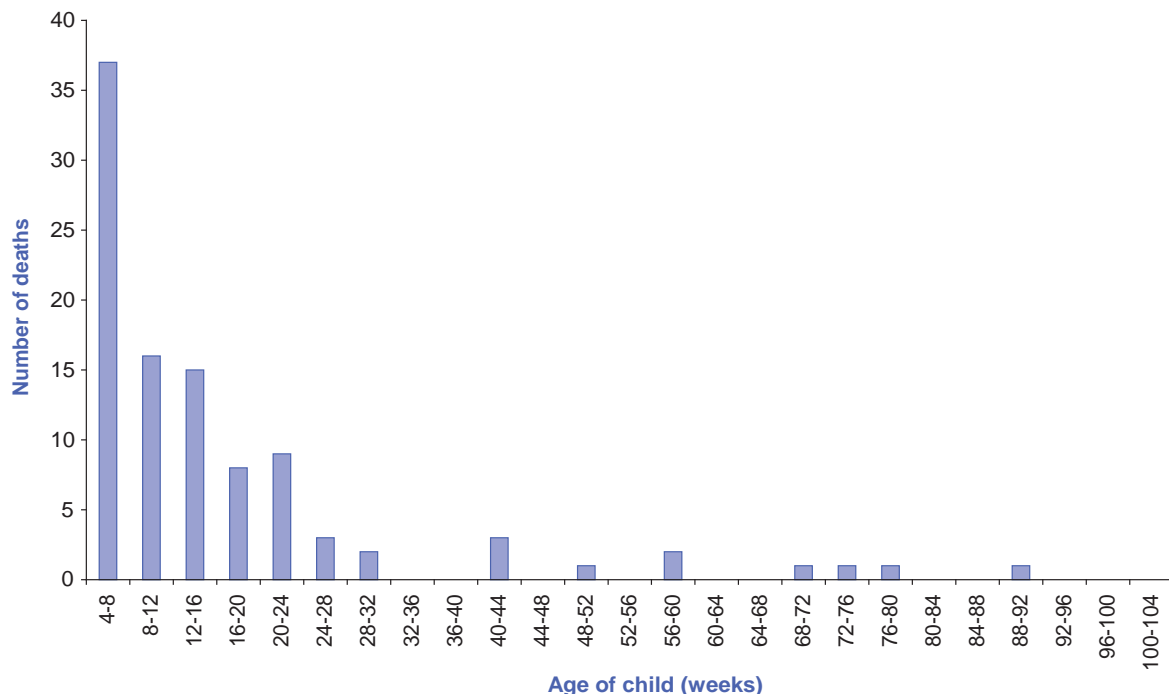
5.6.4 Sudden Unexpected Deaths in Infancy (SUDI)

There were 100 deaths classified as SUDI, (10% of the deaths in the study). Using the ONS data for live births in the CEMACH regions gives a rate of 0.5 per 1000 live births which is the same as that in current UK literature. 60 of the cases were male and 39 female and there was one case where no data was available. A non-restrictive definition was used that allowed children over 12 months of age (that is, not technically ‘infants’) to be categorised in this way if they fulfilled the usual criteria for the diagnosis (which is a diagnosis of exclusion). Of these deaths, 15 (11 males, 4 females) were more than a year old. The classification of a baby as a SUDI may be subject to revision after an inquest, or a panel review might come to a different conclusion, so this category of death has to be accepted with some caution in this analysis.

The age distribution of SUDI in this dataset was markedly different to the peak at three months that has normally been seen in previous investigations (Figure 5.12). While remembering that our dataset did not include deaths under 1 month, it emerged that the modal age of death was between 4 and 8 weeks, with more in this category than in the entire 8 to 16 week age group.

Figure 5.12

Deaths in children classed as Sudden Unexplained Death in Infancy (SUDI) by age of child; United Kingdom selected regions: 2006.



A quarter of the deaths due to SUDI were in babies born at less than 37 weeks or weighing less than 2500g. The Child Death Review did not include on-site death scene evaluations as advocated by some researchers in this field. However the core dataset was created in full knowledge of the factors still significantly associated with SUDI such as those linked to deprivation (e.g. parental smoking), sleeping position when put down,

co-sleeping, drug and alcohol use and sleeping on a couch. Complete data were available on 95 of these deaths and showed that there were smokers in the household in 75%. Co-sleeping occurred in 56% of cases at the time of death. Only 18% were sleeping in a cot but 85% had been put to sleep on their back, perhaps reflecting success in the uptake of this strategy (which reduces the chances of cot death) as a result of a publicity campaign. Post mortem investigations may have later “explained” 10 of the deaths as diagnoses of specific infections (8) and congenital heart disease (2). Two cases were ascribed to overlaying (1) or wedging (1) on the death certificates.

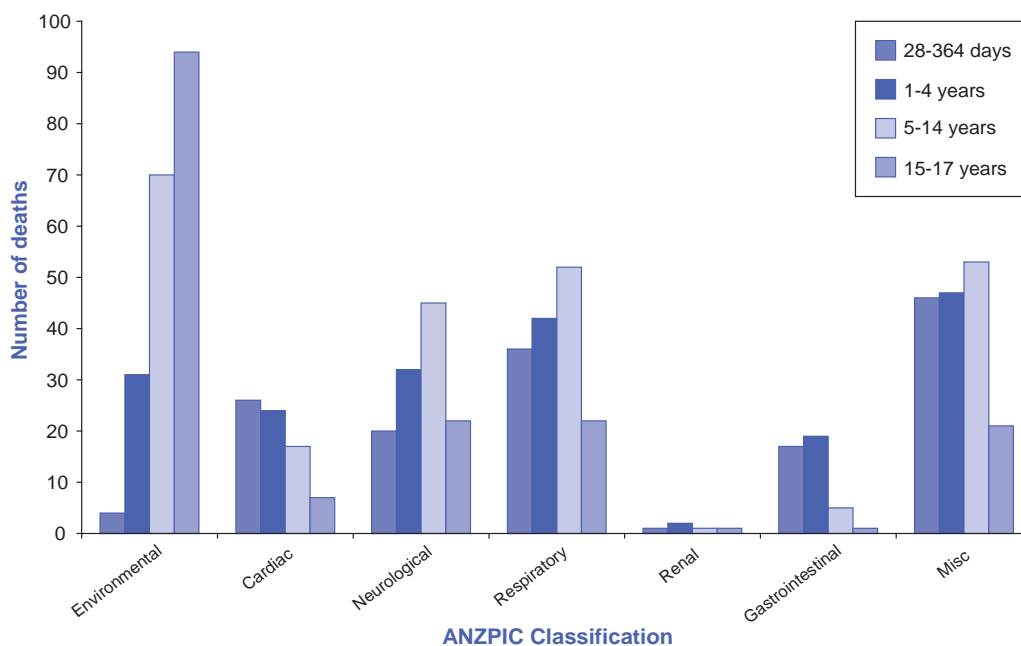
5.7 Natural causes of death

‘Natural causes’ included all disease processes and congenital anomalies, although for the purposes of this chapter SUDI deaths were analysed separately. Natural causes accounted for three quarters of all child deaths.

We used the ANZPIC classification to examine the age distribution of deaths from ‘environmental’, cardiac, neurological, respiratory, renal, gastrointestinal and miscellaneous causes. Figure 5.13 gives ‘natural’ causes some perspective in relation to ‘environmental’, or non-natural, causes; and includes SUDI for comparison as well. There was little variation by gender.

Figure 5.13

ANZPIC Classification of deaths by age; United Kingdom selected regions: 2006.



5.7.1 Infection

Infectious diseases are not allowed as “primary diagnoses” in the ANZPIC system. An analysis of the text entries from death certificates revealed that infection was relevant in 20% of the deaths overall (29% of the natural deaths). The greatest number was in the 1 to 4 year old age group.

Table 5.6
Age distribution of deaths involving infection

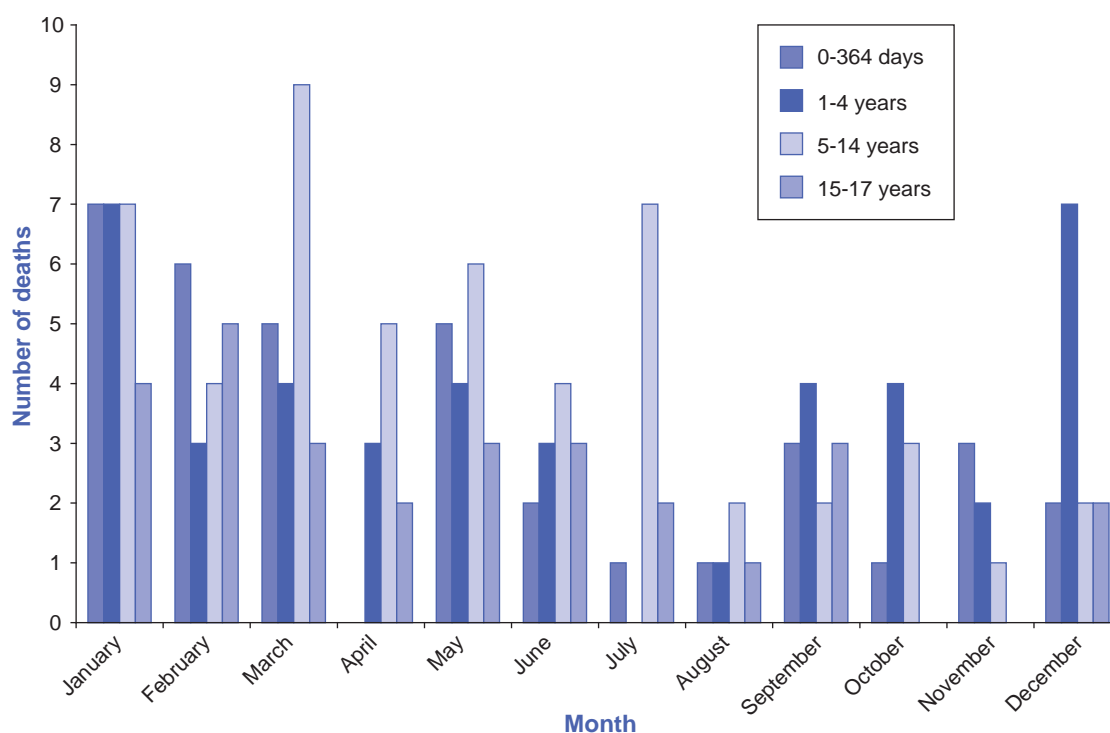
	Male	Female	TOTAL
28 - 364 days	24 (50)	24 (50)	48 (100)
1 to 4 years	27 (43)	36 (57)	63 (100)
5 to 14 years	23 (43)	31 (57)	54 (100)
15 to 17 years and 364 days	13 (45)	16 (55)	29 (100)
TOTAL	87 (45)	107 (55)	194 (100)

5.7.2 Respiratory causes and seasonality

When all causes of natural death were considered together, there was no evidence of any seasonality. However when respiratory deaths were identified separately, a seasonal effect became apparent. This looked strongest among the under fives.

Figure 5.14

Seasonal distribution of deaths classified to occur as from respiratory causes by ANZPIC; United Kingdom selected regions: 2006.



5.7.3 Premorbid disease

A significant proportion of deaths occurred in children with long term disabilities. 307 out of 957 children (32%) in the core data had some developmental delay, impairment or disability and 735 out of 957 children (77%) of the children had previous history of a medical condition, or some sort of developmental delay / impairment / disability. A high proportion of these cases had clearly life limiting illness. 73% of these deaths occurred in hospital, 19% at home and 3% in hospices. When all deaths were considered, 66% occurred in hospital, 18%

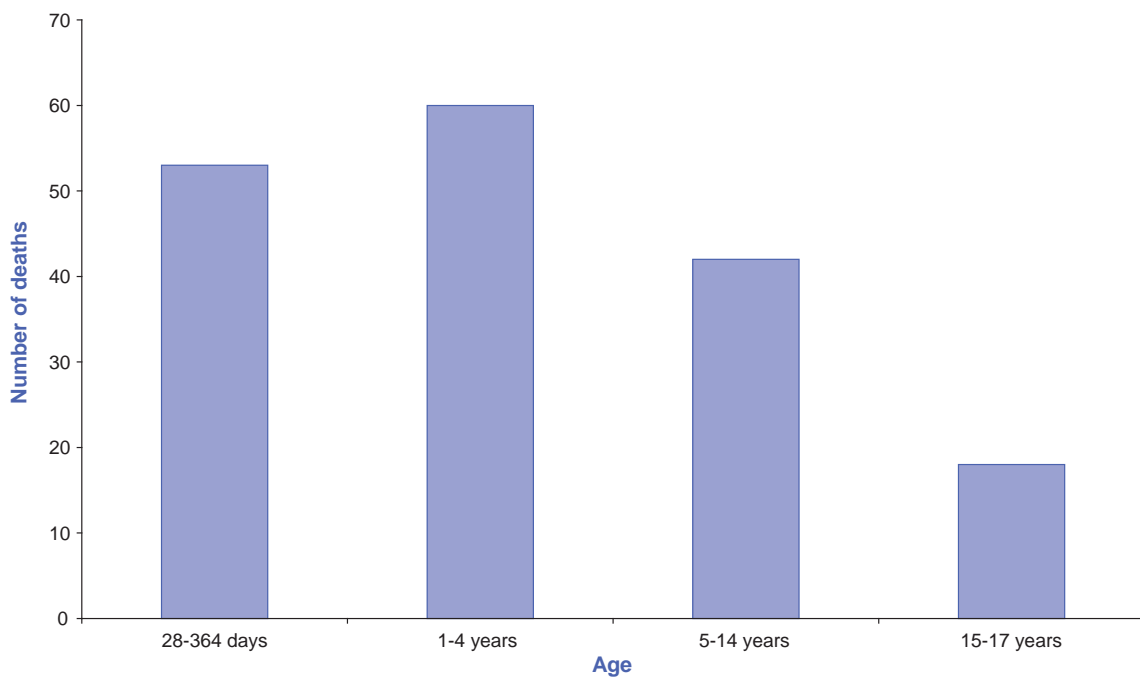
at home and 2% in hospices. Deaths in hospice or at home were more common in the presence of life limiting illness but the low proportion of hospice deaths implies an opportunity to improve practice when potentially life limiting illness is recognised.

5.7.4 Congenital anomaly

173 children who died had congenital conditions. Congenital anomalies are an important cause of childhood death which persist well beyond infancy. Deaths from congenital anomalies in this study were concentrated among pre-school children, while the tail of the distribution extended right into adolescence.

Figure 5.15

Age distribution of child deaths where there was a congenital condition at the time of death; United Kingdom selected regions: 2006.



5.7.5 Cerebral palsy

Similarly we found that many children with cerebral palsy who died had survived into their teenage years.

Table 5.7

Age distribution of children with cerebral palsy: Children aged 28 days to 17 years and 364 days:
United Kingdom selected regions: 2006

Age	Number of deaths in children with cerebral palsy
28 days to under 1 year	1
1 - 4 years	12
5 - 14 years	25
15 - under 18 years	12
TOTAL	50

Seventy-five per cent of these children died from respiratory failure and in 10% death was sudden, possibly associated with epilepsy.

5.8 Conclusions

Across the five pilot regions, there were substantial differences in rates of child death, especially among 15 to 17 year olds, with considerable ethnic variation as well. We have highlighted the contribution of road traffic accidents, and obtained data suggestive of continuing change in the epidemiology of Sudden Unexpected Death in Infancy. We found high rates of childhood suicide and striking differences in homicide rates between ethnic groups. The other data give a foretaste of analyses that will become possible when national data, collected with similar rigour, are aggregated.

Invited commentary: A Pathologist's perspective

Marian Malone

Panels reported access to the conclusions of 42 post mortems and were required to assess the contribution they made to the understanding of the case. They felt that there were “new and extremely important additional factors” revealed in 19 cases. There were “Major” factors in one case and “significant” factors in five cases. To expand upon this contribution the post mortems were recalled for review.

In this heterogeneous group, all post mortems had been carried out on the instructions of HM Coroner, apart from one which was a consented hospital post mortem in a 6 year old boy with known T cell acute lymphoblastic leukaemia.

The level of detail in the clinical history provided to the pathologist varied from a high level of detail in possible criminal cases under investigation by the police to a few lines from the Coroner's Officer in some cases, the most notable example of the latter being “An eight year old girl with cerebral palsy and a two day history of vomiting who had been prescribed antibiotics and who had arrested in front of her parents”.

Pathologists varied in their practice as to whether or not they included the clinical history with their report. In four cases the history was not included. It is of interest that these cases were all performed by paediatric pathologists, and may reflect their experience of families taking issue with details in the clinical history (which are irrelevant in interpretation of the findings) when furnished with copies of the post mortem report on their child. The recent Royal College of Pathologist's guidelines on post mortem examination, which post dates the cases under review, recommends that the clinical history be included with the report.

Of the 33 post mortems that were successfully recalled, 12 were carried out by paediatric pathologists, 10 by adult forensic pathologists, 10 by NHS general consultant pathologists, and one by a neuropathologist. Referral patterns were broadly consistent, with perinatal deaths referred to paediatric pathologists and more adult-type, potentially criminal cases, referred to forensic pathologists. Road traffic accidents and natural deaths in older children tended to be referred to NHS general consultant pathologists. An exception was a baby who had choked on a plastic bag, where the post mortem was performed by an adult forensic pathologist. In most Coroners' jurisdictions such a case would be referred to a paediatric pathologist.

Post mortem reports were detailed with appropriate weights and measurements and reference to centile charts where appropriate. Discussion with other experts was instituted as appropriate, for example, in the sudden unexpected death of a 10 month old in which the pathologist identified a chronic subdural haemorrhage. The post mortem was stopped and resumed on the following day with the assistance of a paediatric forensic pathologist. In another case, the sudden unexpected death of a 16 year old boy, the heart was retained by the forensic pathologist and sent to a specialist cardiac pathologist with an interest in Sudden Adult Death Syndrome. The single case performed by a neuropathologist provided a very detailed report on a rare hereditary neuropathological disorder. Further clinical details were obtained to assist in interpretation of findings where appropriate, particularly in forensic cases. Histology was carried out and reported appropriately. Ancillary investigation in the form of microbiology, virology, radiology and toxicology was appropriate and discussed with experts where interpretation was difficult.

A clinicopathological correlative summary with discussion and analysis of interpretative issues was provided in most cases. There was some discrepancy in the cause of death given in infants dying suddenly and unexpectedly. In one case, a 10 month old baby, one of twins, was found dead in his cot in the afternoon. Although post mortem examination showed old subdural haematoma, ageing haemorrhage in the spinal canal and chronic retinal haemorrhages, the cause of death was still given as “Sudden Unexpected Death in Infancy”. In another case, a 7½ month old baby found dead face down in his cot in the early evening: the cause of death was given as “Sudden Infant Death

Syndrome” without discussion of the role of prone sleeping in sudden infant death. In a further case of an 18 month old baby, whose clinical history was not included in the report, the findings were of petechial haemorrhages on the lower neck and upper chest, petechial haemorrhages over the thymus, heart and lungs, widespread haemorrhagic oedema of the lungs and bilateral suppurative otitis media with a heavy growth of *Haemophilus influenzae* from the middle ear swab - the cause of death was given as ‘Unascertained’. This highlights the difficulty of achieving standardised definitions in this group of subjects, a difficulty which is not confined to the UK but is international with disagreement among experts as to how best to classify these deaths.

Reports were dated in 23 cases and undated in 10. In those cases where the final report was dated it was issued between one week and 21 weeks after the date of the post mortem with an asymmetric, possibly bimodal distribution with 12 cases reported within five weeks and six cases reported between 9 and 14 weeks. This may reflect complexity of cases and/or the workload of pathologists.

In 26 cases, there was a specific comment in the report regarding which organs and tissues had been retained for further examination. In one case there was a reference to consent for organ / tissue retention or disposal, although in this case the relatives’ wishes were not known. The period under investigation antedates the Human Tissue Act which makes it a legal requirement to record this information.

It was not clear from the pathology reports which cases had gone to inquest, and it is possible that some cases had not yet gone to inquest at the time of retrieval of the data. Of note are four cases of deaths occurring suddenly and unexpectedly in the course of an overwhelming infection. In the case of a 15 month old boy who died from pneumococcal meningitis and otitis media, no inquest appears to have been held. In the case of a 12 year old girl dying of Pantan-Valentine Leukocidin (PVL) positive *Staphylococcus aureus* pneumonia, an inquest was held at which the Coroner took evidence from an independent consultant paediatrician regarding this rare form of pneumonia. A verdict of death from natural causes was returned. The study also included a case of a 6 year old boy who died of acute influenza A pneumonia. An inquest was held at which the Coroner returned a verdict of death by natural causes. In the case of a 3 year old girl who died of a Group A Streptococcal empyema of the lung and acute necrotising tonsillitis, an inquest was not held but the parents were referred to a consultant paediatrician to whom the patient’s clinical notes, the post mortem report and a letter from the parents listing a number of questions were sent, asking him to help the parents with their queries. There is clearly variation in how these cases are dealt with, at the discretion of the individual Coroner. All are deaths from natural causes but the ongoing consultation and imminent reform of the regulations surrounding deaths referred to HM Coroner seeks to address these issues, taking cognisance of relatives’ concerns regarding treatment and standardising the process.

It is noted that in six cases, there was implicit or explicit criticism of the autopsy report by the panels with the implication that it fell short of best practice. Further review of these cases indicates that the concern relates not so much to the cause of death as to the failure of the pathologist to draw attention to findings around wider issues, particularly social issues, or issues related to professional healthcare. It is important in this context to recognise the function and brief of the Coroner’s pathologist and also the constraints within which he/she works, in particular the frequent lack of adequate clinical information at the time of the autopsy examination. The post mortem is but one part of the process, and the cause of death is presented to the Coroner as an opinion which the Coroner is free to accept or reject. Its purpose is to inform the Coroner’s decision as to whether or not to hold an inquest to explore wider issues. The pathologist is not judge and juror. The Royal College of Pathologists recommends a clinicopathological summary as part of best practice, meaning a correlation between the history as provided and the macroscopic findings at post mortem. In these sensitive cases it is important that the pathologist does not suborn the role of the Coroner or unnecessarily complicate the process by raising concerns which can subsequently prove to be unfounded. It is a question of providing a full, detailed, accurate and informative report. The proposed reform of the Coroner’s system seeks to redress some of these issues.

6. Primary care

Anthony Harnden and Richard Mayon-White

Learning points

- Avoidable factors were found in 19 of the 82 deaths where the GP was involved with evidence of failures in primary care services.
- Timely and complete immunisation of children is one of the most important aspects of prevention in primary care. There were deaths that could have been prevented if a vaccine had been given on time and following specialist advice.
- GPs should be alert to the child who re-presents on three or more occasions during the course of an evolving illness.
- Primary care records could be improved by noting the time, as well as the date, of consultations and telephone calls.
- The medical concept of an “at risk” child should be extended to all children with chronic disease and a register of such children could be kept by all practices as part of the Quality and Outcomes Framework (QOF).
- Children with epilepsy should have at minimum an annual review including a medication review in primary care.
- Children with an exacerbation of asthma should be reviewed within a few days of starting a short course of oral steroids to assess response to treatment.
- It is important that GPs are proactive in contacting the family following the diagnosis of a serious illness such as childhood malignancy.
- With adequate resources it is possible to deliver high quality palliative care for children in the community.
- Teenagers who died from unnatural causes were more likely to have had previous injuries than those who died of natural causes.

A child's death is a rare event in primary care. Vaccination, antibiotics, improved nutrition and warm housing have done much to prevent children's illness and to reduce their severity. Because they are now so uncommon all child deaths have a significant impact on those working in primary care. Primary care has a special place in the care of children: the early diagnosis of infection or malignancy, delivery of vaccines, the management of chronic disease such as asthma and epilepsy, recognising the at risk child, supporting the child with multiple disabilities, helping the child who is terminally ill. Furthermore primary care practitioners, - GPs, health visitors, school nurses, practice nurses and receptionists - have an essential role in communicating with families, in preventing as well as managing child death.

We undertook a study within this review to look at the factors associated with primary health care. We examined the questions about primary care that were included in the core dataset. In the North East region, the primary care records had been requested for all children who died, which gave the opportunity for a more detailed examination of the primary care factors in this region. We developed standards from the North East region's records to apply to the general practice management of a sample of cases from the other regions. We looked particularly for fatal factors that could be prevented by primary care practitioners, and for examples of good practice. One purpose of this detailed examination was to identify information that could be collected from primary care for future reviews of child deaths.

6.1 Methods

In the core dataset, the primary care questions were whether the child had been seen in primary care in the three months before death, and whether the health worker was a GP, health visitor, school nurse or practice nurse. We explored whether seeing a primary care practitioner was related to the age of the child or the cause of death. When the cause of death had several parts, we chose the main cause of death from a primary care perspective to identify events or illnesses that had a direct link to the child's death. For example, children who died with pneumonia after a long-standing disability with congenital heart disease, were classed as dying from pneumonia, with a sub-categorisation of having a serious underlying medical condition.

Initially, we were given the core dataset for 154 child deaths that occurred in the North East region in 2006. By visiting the CEMACH office in Newcastle, we examined the medical records collected for these children in order to understand the relationship between what was recorded in the primary care records and was entered into the core dataset and collected by the reviews conducted by expert panels. We checked the files for every child to see if there were primary care records available, and assessed how useful the primary care records were as a source of information. Unlike the core dataset, the primary care data was not limited to the three months before death. We looked particularly for whether the records showed the degree of primary care involvement in the fatal illness and events leading to death, whether the primary care records suggested that the children might be at risk and whether there were differences from other sources of information.

The forms of primary care involvement that we sought were:

- Whether the GP was consulted for the fatal illness or injury, including attendance at, and certification of death.
- Diagnosis in the early stages of the fatal condition.
- Management of the fatal condition including referral to, and correspondence with, hospital(s).
- Care at home for chronic fatal conditions.
- Preventive medical interventions if appropriate for the fatal condition (e.g. vaccinations).
- Features suggesting a risk of the fatal condition.

We summarised the sequence of primary care events (consultations and treatments) that were relevant to the cause of death, and considered whether there were elements that might have contributed to the death and whether there were examples of good practice.

In addition to the primary care involvement in the fatal condition, we examined the primary care records in order to:

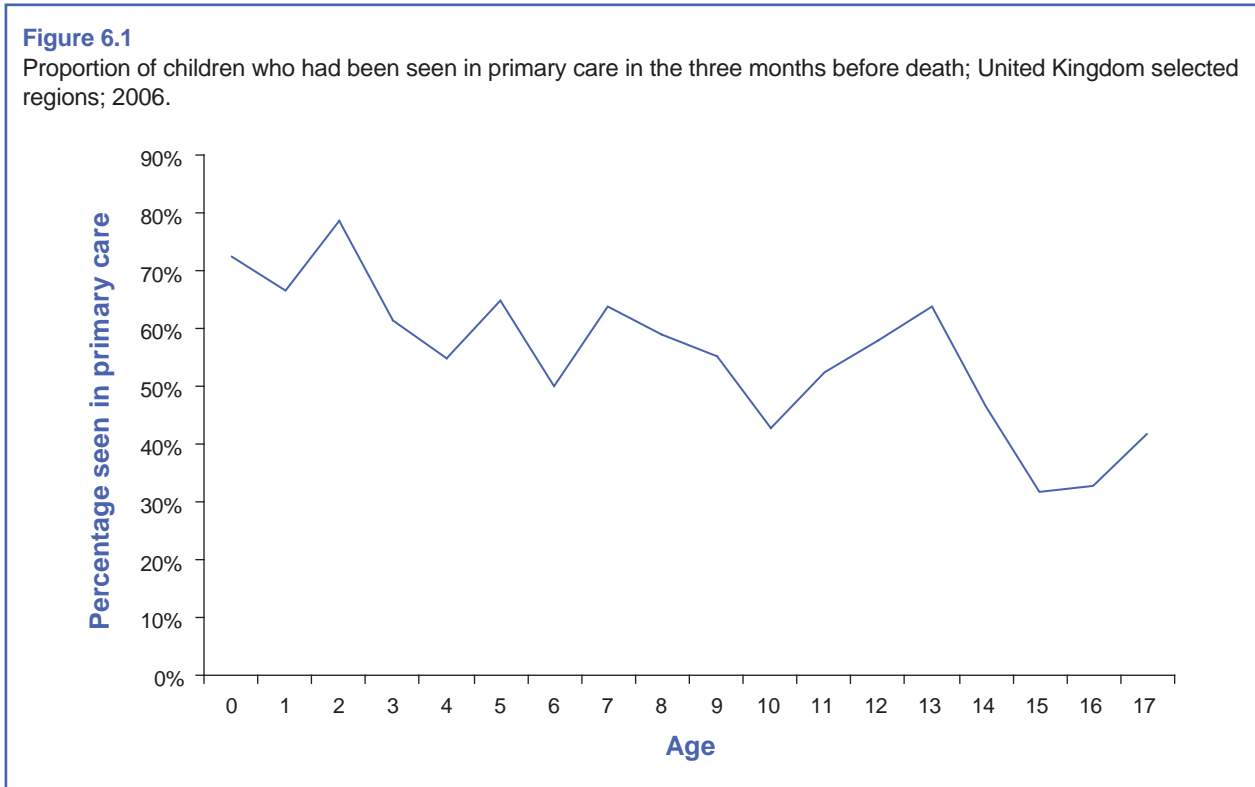
- assess whether the primary care records had been a good source of information about the child's death;
- count the number of times that the child had been seen in the year before death;
- assess the number of consultations for injuries;
- look for evidence of missed appointments;
- look for difficulties in coordinating care;
- record whether the children had their routine vaccinations according to the national schedule.

From the North East region's primary care records, we were able to develop themes of GP involvement, which could be illustrated by case histories. The other regions sent us the anonymous primary care records of 76 cases that had had panel reviews. We examined these other regions' cases in the same manner as the North East cases to see if the findings and themes were the same. The evidence that we found that deaths could have been avoided by better primary care was used to reinforce the review panel decisions described in Chapter 8 (on avoidable factors in the deaths).

6.2 Results

6.2.1 Primary care involvement in the last three months of life.

Of the 957 children in the core dataset, 769 had information on whether they were seen in primary care in the three months before death. In 84 (11%) of the 769 children with information, there was no opportunity for the child to be seen in primary care because the child remained in hospital from birth to death, or because the child had only recently come to the UK and was not registered with a GP. Considering those 686 children on whom there was information and were registered in primary care, 397 (58% of those with information) had been seen in primary care in the three months before death. The proportion seen in primary care varied with age from 72% for those who died in infancy to 33% for children who died at the age of 16 years (Figure 6.1).



In the North East region, where the records for their 154 cases were examined from a primary care perspective, we were able to reduce the proportion of cases without information about primary care consultations during the three months before death from 16 (10%) to only two (1%) cases .

The GPs were the most common primary care practitioners seen in the last three months: including children who were seen by more than one type of practitioner, 328 out of 397 (83%) were seen by GPs. Forty-one children were seen by more than one type of primary care practitioner in the last three months (for example, health visitor, practice nurse, school nurse); in 35 of the 41 cases, a GP was one of the practitioners seen. In 15 cases, the type of primary care practitioner was unreported.

6.2.2 GP involvement

In the 154 cases that occurred in the North East region, we also assessed whether the primary care team had been involved in the fatal illness or event. There were 46 cases in which one or more of the primary care team had played a part as summarised in Table 6.1 below. These cases were used to determine the themes of primary care involvement on the cases reviewed by panels.

Table 6.1

Primary care involvement in child deaths: Children aged 28 days - 17 years and 364 days:
North East England: 2006

GPs' actions	Cause of death	Number of deaths
Diagnosis and response to an acute illness	Acute infection	7
	Other acute illness	2
Management of chronic illness	Asthma	1
	Epilepsy	3
Diagnosis, support and palliative care for cancer	Cancers	13
Support & palliation for congenital and neonatal disabilities	Pneumonia and other complications of disabilities	17
Failure to prevent	Invasive pneumococcal disease	2
Recognition of at risk teenagers	Suicide	1
TOTAL		46

In 90 of the 154 cases, GPs and other primary care practitioners were not involved in the fatal illness or event: road traffic and other accidents (33), children directly under hospital care (28), sudden deaths in infancy and similar conditions (22), overdoses and suicides (5) and two children who were visiting from abroad. In seven cases, a GP could have been involved: two with meningitis who went directly to hospital, one with epilepsy and four children with disabilities. In 11 cases, the GP involvement was unknown.

6.2.3 Value of GP records

The primary care records were available for 93 (60%) of the 154 North East region cases examined. These records were copies of the notes made by GPs, practice nurses, school nurses and health visitors (where available) plus copies of letters that GPs had received from hospitals and other specialist units. Most GP records have been computerised, with summaries of the events, medications and correspondence. If these records were clear and complete, they were judged to be good sources of evidence (77 records [83%]). The other 16 records were incomplete and/or difficult to study, and could not be used to assess the events leading to death.

6.2.4 Vaccination records

There were 80 children over the age of two months with primary care records which included their vaccination histories. There were only 57 (71%) who were vaccinated according the national schedule; 20 had delayed one or more vaccinations in the first year of life and three had missed MMR immunisation. In 10 cases, the delay was only one to two months, so 70 out of 80 (88%) would have been recorded being covered against diphtheria, tetanus, pertussis, polio and Haemophilus influenzae type b by the age of one year – not far short of the national rate of 91%. A factor in the delay and missing vaccinations was the presence of congenital and/or neonatal disorders, present in 12 cases.

6. Primary care

6.2.5 Previous injuries

The records identified that 28 children had had injuries in the past, unrelated to the cause of death but requiring medical treatment. The records included reports from Accident and Emergency departments as well as treatments given in primary care premises. In eight GP records, it was not possible to say whether the child had had a previous injury. Twelve of the 28 children had had more than one injury – all twelve had good quality GP records. Ten of the 12 children who had had more than one injury died “unnatural” deaths: three in road traffic accidents, two fell off buildings, one drowned, one was assaulted, one committed suicide, one inhaled vomit when drunk and one took an overdose of drugs. Restricting consideration to children aged 10 to 17 (for broadly similar time to have injuries) and children with good GP records, the difference between the children who died unnatural deaths and others was striking: 8 out of 14 teenagers who died unnatural deaths had had two or more previous injuries compared with one out of 18 teenagers who died from natural causes (Fisher’s exact test: $p=0.002$).

6.2.6 Missed appointments and coordination of care

Seventeen children had missed one or more appointments in primary care or hospital (and known to primary care) in the three months before death. Five of these children were at risk teenagers. Three others died from epilepsy and one from asthma, suggesting that missed appointments may be an indication of risk.

It was not possible to systematically assess the primary care role in coordinating care. In the majority of cases with non-acute conditions requiring secondary care, the direction of care and liaison between services appeared to be decided with little or no involvement of GPs. However, there were a few cases in which the health visitor or GP had had to make strong efforts in order to get appropriate care for their patients.

6.3 Primary care themes

These themes have been developed from the 154 cases in the North East and the 76 panel cases where GP records were available. Primary care information also contributed to the avoidable factors considered in Chapter 8.

6.3.1 Immunisation

Timely and complete immunisation of children is one of the most important aspects of prevention in primary care. These cases illustrate three key points within this theme.

A boy who was born 10 weeks prematurely was seen by the GP at 11 weeks of age with a cough and raised respiratory rate. A viral chest infection was diagnosed and arrangements were made for him to be reviewed the following day. His symptoms worsened and he presented to hospital where he developed increasingly severe respiratory failure and died four days later. A post mortem examination revealed death was due to whooping cough. The child had not yet received his first set of immunisations.

Primary care teams should be fully aware that it is strongly recommended infants receive their first set of immunisations at eight weeks of age regardless of whether their birth was premature. Premature infants may be at increased risk of infection and delay in immunisation may result in catastrophic consequences. It is difficult to know whether receiving the first pertussis immunisation at eight weeks would have attenuated the illness and prevented this child’s death but high levels of herd immunity protect the most vulnerable children in a community.

A nine month old boy had severe congenital heart disease which had already required surgery. He had four respiratory infections, two managed by the GP at home and two that had resulted in hospital admissions. Although he had received his primary immunisations his hospital consultant wrote to the GP when he was six months old recommending he was given pneumococcal vaccine. This was never acted upon. On the day that he died, he had been 'chesty' but well enough to play in the morning but he deteriorated rapidly and later died of an overwhelming pneumococcal septicaemia.

At the time of this study conjugate pneumococcal vaccine was recommended for certain groups of at risk children although not yet in the routine schedule. So the consultant was correct in recommending immunisation and the GP should have ensured that it was given. There are many examples of children (such as those who have had their spleen removed) who require additional vaccines to prevent serious infection. It is good practice for the specialist to write to the GP with recommendations and for the GP to ensure timely administration of the vaccines.

A previously healthy eight month old girl developed chickenpox. She was seen by the GP on three occasions: for diagnosis, review of poor fluid intake and because of increasing drowsiness and dehydration. On the third occasion she was sent to hospital. Her condition rapidly deteriorated and 12 hours after admission she died from bacterial septicaemia as a complication of chickenpox.

There are a number of childhood vaccines that are available but not in the current UK immunisation schedule. Before a vaccine is introduced its safety, lack of interaction with other vaccines, cost effectiveness and public acceptability must all be demonstrated. This case illustrates an example of a disease (chickenpox) that can be prevented by a vaccine which is administered in other countries but not yet in the UK. At the time of writing, the body responsible for recommending immunisation policy (Joint Committee on Vaccination and Immunisation (JCVI)) is weighing up the evidence.

6.3.2 Diagnosis

Diagnosis, management and communication form the bedrock of every GP consultation for an acute illness. Whilst precision of diagnosis may not be possible, it is critical that GPs remain alert to symptoms and signs which could represent serious illness. These cases illustrate three examples of the evolution of a fatal illness first presenting acutely in primary care.

A 12 year old girl presented to her GP with symptoms of a flu-like illness which were poorly described but had lasted a week. She had coughed up blood on the day of presentation and her mother was alarmed. The GP recorded a temperature of 40.4°C and a clear chest on examination but thought she was hyperventilating and anxious. A diagnosis of a viral infection was made and the child was told to breathe into a paper bag to help the presumed hyperventilation. The GP wrote that a chest XRay would be considered if the haemoptysis persisted. A date but not a time of consultation was recorded. She was taken to the hospital at 9.25am the next day but died shortly afterwards of staphylococcal pneumonia.

This child had a rapidly evolving secondary bacterial infection which was misdiagnosed and inappropriately managed by the GP. A combination of a preceding viral illness, high pyrexia, rapid breathing and haemoptysis should signal serious respiratory illness in a child even in the absence of chest signs. If there was uncertainty, a pulse oximetry reading may have been a helpful addition to the examination. There was no recorded time of GP consultation making it difficult to assess the rapidity of evolution of illness in the last 24 hours of life.

A 10 year old boy presented to his GP with a five day history of fever and tiredness. He had a red throat and large lymph gland in his neck. The boy returned after three days of antibiotics still feeling unwell. The GP noted no new findings but arranged for a review the following week when the glandular swelling had resolved and the boy was feeling better. Two weeks later the boy returned complaining of more fatigue and feeling unwell. He was pale and more lymph glands were palpable. A hospital outpatient appointment was arranged but six days later he developed spontaneous bruising and was admitted to hospital where a diagnosis of acute leukaemia was made. He died a year later.

Serious illness may also present over a few weeks in primary care. During the early presentation of malignancy, children may have short periods of time when they appear better. GPs should be alert to the child who represents on three or more occasions during the course of an evolving illness. An acute referral to secondary care or blood and radiological investigations should be considered.

A two year old boy, who had a narrowing of the aorta (the main blood vessel coming from the heart) repaired as an infant, presented to the GP with sudden onset abdominal pain. A thorough examination revealed abdominal distension with absence of bowel sounds. An immediate referral to hospital ensued but emergency surgery was unsuccessful. He died during the operation because of an internal hernia which had cut off the blood supply to the small bowel.

It may not be possible in primary care to make an accurate diagnosis of a child who is acutely unwell. But this case illustrates an example of an acutely ill child who was appropriately managed by the GP.

6.3.3 Chronic disease management

Continuity of care is especially important in children with chronic disease. Primary care is well placed to deliver this care. Since the inception of the Quality and Outcomes Framework (QOF) in 2004, GPs have demonstrated an ability to deliver high quality management of chronic disease. An example is included in Chapter 10 (Good practice). Although some of the disease specific indicators – such as an annual asthma review – are inclusive of children, there is no specific requirement to register and regularly review all children with chronic disease.

A nine year old girl who died suddenly at home had cystic fibrosis and spastic quadriplegia. She had GP care delivered from the same practice throughout her life. The whole primary health care team offered support and advice in the first year of life about a range of issues including feeding, development, chest infections, diarrhoea and seizures. Over the course of the girl's life the primary care notes included clear records of communication to hospital specialists, a care planning agency and a charitable grant-giving body for disabled children. The GP provided written fitness to travel certifications for the family on request. As well as good coordination of care there was evidence that the child had regular reviews in the practice of medication, respiratory infections, diet and development.

This case illustrates a good example of high quality primary care that it is possible to deliver to children with chronic disease and disability. The evidence of teamwork, communication, family support and medical review are impressive and set a high standard of care which children and their families should receive.

A 10 year old boy with epilepsy was found dead at home. Apart from a home visit ten months earlier for a respiratory infection, there were no recorded GP consultations over a four year period leading up to his death. Yet there were three hospital admissions for seizures in his last six months of life. A hospital doctor had written to the GP and parents advising on a change in the dose of anticonvulsant medication following an admission and arranged for the child to be reviewed at an outpatient appointment. Subsequently the boy failed to turn up to two hospital appointments. The GP was notified but no further action was recorded.

Whilst sudden death in epilepsy is a recognised complication of the disease and is not necessarily avoidable, the primary care in this case was poor. Children with epilepsy should have at minimum an annual review including a medication review in primary care. Children with chronic illness who do not attend hospital appointments should be followed up by the primary health care team to discover the reasons for non-attendance and to ensure the child is not missing out on important medical care.

An eight year old girl who was born prematurely had asthma first diagnosed when she was two years old. Initially she had hospital outpatient care but from the age of three her medical management was delivered in primary care by GPs and practice nurses. There was recorded evidence of annual reviews including height, peak flow measurements, checking of inhaler technique and a clinical management plan. Eight days before she died she presented to the GP with an asthma attack and oral steroids were prescribed. She failed to turn up for a review appointment the day before she died. She suddenly became blue at home, her parents took her directly to A&E but she suffered a cardiac arrest and could not be resuscitated.

Childhood asthma can be unpredictable and cause a sudden severe deterioration during an exacerbation. Children should be reviewed within a few days of starting a short course of oral steroids to measure response to treatment.

6.3.4 Palliative care

The care of children who are dying requires medical competence, teamwork, sensitivity, communication and availability. Whilst palliative care is difficult to do well, if it is the child and parent's wish, every effort should be made to allow the child to die in their home environment. There may be facilities available in some localities that allow a child to die in a hospice whilst still receiving continuity of care from their GP.

A five year old girl who was born prematurely and had mild developmental delay presented to her GP on three occasions over a two week period with headache, earache and vomiting. No specific diagnosis was made nor arrangements for review. She fell and was seen in the local hospital emergency department where it was noted she had an ataxic gait. Following an overnight admission she improved and was discharged. But three weeks later she became drowsy and ataxic and was directly readmitted to hospital where investigation revealed a brain tumour. Five months later she died in hospital of complications of treatment. There was no further GP involvement.

It is important that GPs are proactive in contacting the family following the diagnosis of a serious illness such as childhood malignancy. Although the initial management may be hospital based, the security of knowing there is primary care support available may help facilitate community care when required at a later stage of the child's illness. The knowledge that the GP is interested and caring may be all that is required immediately following diagnosis.

6.3.5 At risk teenagers

Teenagers are a difficult group to cater for. They tend to access health care in an unstructured way. One way primary care can help is grasping the opportunity to offer preventative health care advice whenever a teenager is seen.

A 17 year old boy hanged himself at home. He had a history of suicidal thoughts which began years previously. He was admitted to hospital with an alcohol overdose aged 13 years and reviewed afterwards by a child psychiatrist and family therapist. The psychiatrist wrote to the family for follow up arrangements but they did not reply and no further action was taken. He had annual reviews by the GP for his asthma in the four years leading up to his death. It was recorded that he was using his inhaler too frequently and always running out. There was no mention of his psychological state or care in the GP records.

There was an opportunity to enquire about this boy's emotional state at his annual asthma reviews. Whenever a teenager is seen in primary care there is an opportunity to enquire broadly of the teenager's physical and mental well being from the point of view of the teenager. The priority agenda for the teenager and the primary care professional may differ and it is the responsibility of the professional to be aware of this.

A 16 year old boy lived with his grandmother because of suspicions of child abuse when he was much younger. He was seen over a six year period by the child psychiatric team suffering with depression. When he was 13 years old he took an overdose of paracetamol medication because of being bullied at school. On the night before his death he had been out with friends. The next morning, he was found on the sofa by his grandmother, who was unable to rouse him. He was pronounced dead at home and post mortem examination showed he died of a codeine and alcohol overdose. According to his records he had last been seen by a GP six years earlier.

This vulnerable and at risk teenager had no contact with primary care. Yet he had been seen on a regular basis by the child psychiatric team and there were problems at school. There might be an opportunity in primary care to have a register of all children with mental health problems. There are also opportunities to develop a systematic way for schools to communicate with primary care when there are mental health concerns.

6.4 Avoidable factors in primary care

The deaths for 154 children in the North East region and 76 children in other regions who had had panel reviews were assessed for avoidability from a primary care perspective. The categories were defined in the same way as the panel decisions on avoidability, but without the sub-categories, because the assessment was of the role of primary care services rather than of other agencies.

Avoidable factors were those where there were identifiable failures of primary care services with direct responsibility for the child. Examples were failure to vaccinate a child, failure to recognise the severity of a respiratory infection, failure to manage asthma according to guidelines, failure to closely follow up a depressed child at risk of self-harm.

Potentially avoidable factors were those where the child died from a disease that had a significant risk of a fatal outcome, but primary care practitioners would expect most children to survive, or a death caused by extrinsic factors that were potentially modifiable. Examples were meningococcal infection, congenital heart disease that was not detected at birth, and drowning at home where the primary care team could have recognised that the family was vulnerable.

Unavoidable factors were those for which the cause lay wholly outside the influence of primary care.

These definitions were applied to two groups of children: 82 where the GP had been involved in the fatal condition, and 62 where the primary care team had not been involved in the fatal condition but had seen the child within the previous 12 months, and might have intervened in a way that could have affected the outcome of the fatal condition. The results are shown in Table 6.2 below:

Table 6.2
Avoidability in relation to Primary Care: Children aged 28 days to 17 years and 364 days:
United Kingdom selected regions: 2006

	General Practitioner involved in fatal condition	Primary care not involved but has seen child in last 12 months
Avoidable	19	3
Potentially avoidable	21	29
Unavoidable	42	30
TOTAL	82	62

6.5 Conclusions

In the three months before death, more than half of the children had been seen in primary care, most often by a general practitioner. However, GPs were involved in the events leading up to death in less than a third of cases. In the deaths where GPs were involved, avoidable factors were identified in about a quarter. Primary care teams played an important role in supporting children and their families in palliative care at home.

Primary care records were a useful source of information, especially when the records were on computers because medical events were accurately summarised. The primary care records showed that there may be delays in vaccinating vulnerable children, and the vignettes illustrate that this can be critical. There may be opportunities to improve the timely diagnosis of serious illness. Children who died from unnatural causes were more likely to have had two or more injuries earlier in their lives than children who died of natural causes, suggesting “accident proneness” was a risk factor. Missed appointments and poor coordination appeared to be risk factors in children who died of chronic diseases (asthma and epilepsy). Primary care records could be improved by noting the time, as well as the date, of consultations and telephone calls in all cases.

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7. A description of cases that went to panel

Gale Pearson

The headline result of the panel data in this study was that avoidable factors were found in 26% of cases and potentially avoidable factors in a further 43% of cases. The aim of this and the following chapter is to present some of the detail behind this finding.

7.1 How representative are the cases that were considered by panels?

Since only a sample of deaths were subjected to multidisciplinary panel enquiry, there was not a comprehensive review of all deaths and those due to any given diagnosis or cause would not all be subject to the same level of scrutiny. The sample was intended to provide a cross section of ages and an even geographical distribution of cases. It should not be automatically assumed that the sample is representative of the parent population. The results are therefore presented merely to indicate what can be achieved by a confidential enquiry into child deaths. Nevertheless the panels were able to derive patterns of avoidability, which are discussed in Chapter 8.

The sample of cases that were considered by panels compared to its parent population (the core dataset) as shown in Table 7.1.

Table 7.1

Comparison of core and panel datasets: Children aged 28 days to 17 years and 364 days:
United Kingdom selected regions: 2006

		Core dataset (Percentage)	Panel dataset (Percentage)
Region	North East England	154 (16)	26 (21)
	South West England	228 (24)	32 (26)
	West Midland England	301 (31)	38 (31)
	Wales	163 (17)	12 (10)
	Northern Ireland	111 (12)	16 (13)
	TOTAL	957 (100)	124 (100)
Sex	Male	512 (54)	64 (52)
	Female	431 (46)	60 (48)
	TOTAL	943 (100)	124 (100)
Age	28 days to under 1 year	240 (25)	23 (19)
	1 - 4 years	226 (24)	31 (25)
	5 - 14 years	260 (27)	41 (33)
	15 years to 17 years, 364 days	231 (24)	29 (23)
	TOTAL	957 (100)	124 (100)
Non-natural Death		220 (23)	33 (27)

7.2 The distribution of avoidable factors

26% of cases, where a judgement could be made, contained avoidable factors. These were graded as described in Chapter 3. Most frequently this was an “identifiable failure in the child’s direct care by any agency, including parents, with direct responsibility for the child”. In a further 43% of cases there were potentially avoidable factors. These cases were most commonly described as “Where intrinsic factors were the principal factors leading to the death” or “Where there were potentially modifiable factors extrinsic to the child”.

Table 7.2

Summary of 119 panel determinations, grading the most avoidable factor by the definitions in chapter 3.

Category of associated factor	Total deaths (N)	Number of cases known to have life limiting illness (N)	Hospital deaths (N)	Community deaths (N)	Sub category level of avoidability	Number of deaths (N)
Avoidable	31	3	19	12	1a	19
					1b	8
					1c	4
					TOTAL	31
Potentially avoidable	51	21	44	7	2a	1
					2b	1
					2c	18
					2d	21
					2e	10
					TOTAL	51
Unavoidable	37	34	26	11	3a	1
					3b	4
					3c	32
					TOTAL	37
TOTAL	119	58	89	30	n/a	119

Although there were avoidable factors in a greater proportion of community deaths, the majority of deaths occurred in hospitals. Avoidable factors were less often found in cases where life limiting disease was known to be present.

7.3 Avoidability and location of death

Using death certificate data, 91 (72%) of panel cases died in hospital. This was a similar proportion to that recorded in the core dataset. When the location of the collapse or incident that caused death or lethal injury was considered the allocation changed from “hospital” to “community” in a similar proportion of cases (to that in the core dataset) and from “home” (given on the death certificate) to “hospital” in one.

The community locations of death (CEMACH definition) were in the homes of carers or relatives (43/67), public places 23/67 and a special school (1/67). The hospital locations were as shown in Table 7.3.

Table 7.3

Within-hospital locations of death (CEMACH definition panel cases): Children aged 28 days to 17 years and 364 days: United Kingdom selected regions: 2006.

Within-hospital location	Number of deaths
Paediatric Intensive Care Unit	22
Paediatric ward	20
Neonatal Intensive Care Unit	4
General Intensive Care Unit	3
Children’s hospice	2
Adolescent Unit	2
Accident & Emergency Department	1
High Dependency Unit	1
Special Care Baby Unit	1
Operating theatre	1
TOTAL	57

7.4 How the children died

There was a considerable diagnostic diversity in the cases considered by panels. In most deaths the causes were illnesses, but the sample also included cases of accident / trauma, assault, suicide and homicide. An acute physical illness was a specified feature in 84/126 (67%) of panel cases and in 51% of these it was associated with proven or suspected infection. 60/126 (48%) panel cases had congenital or chronic illnesses that were relevant to the death some of which would be expected to shorten life expectancy whenever they occurred. These can be grouped as shown in Table 7.4.

Table 7.4

Congenital or chronic illnesses relevant to the death: Children aged 28 days to 17 years and 364 days:
United Kingdom selected regions: 2006

Condition	Number of Cases
Congenital (non genetic)	10
Oncological (related to cancer)	10
Genetic syndrome, non chromosomal	9
Congenital heart disease	8
Completion of neonatal illness	6
Asthma	5
Genetic syndrome, chromosomal	5
Gastrointestinal/Liver	2
Neuro or neuromuscular degenerative	2
Undiagnosed	2
Renal	1
TOTAL	60



Invited commentary: A public health perspective

Shona Golightly and Jean Chapple

What do confidential enquiries have to offer?

Public health is about improving and protecting the health of groups of people, rather than about treating individual patients. Public health practitioners look at “the bigger picture” and then take action to promote healthy lifestyles, prevent disease, protect and improve general health, and improve healthcare services. Confidential enquiries are one tool that can tell us what actions can and should be taken to prevent deaths and improve health.

Health services have a long history of using confidential enquiries to improve care. A Confidential Enquiry into Maternal Deaths began in England and Wales more than 50 years ago. Initially, it concentrated on purely clinical issues. As the number of deaths began to fall, it was realised that clinical events might be the final part of a fatal pathway that started with the background of the mother and the circumstances in which she lived. Thus, maternal mortality reports started also to take into account what happened before the woman came into antenatal care.

The public health improvements that have resulted from the work of other Confidential Enquiries illustrate the potential benefits. Deaths in childbirth have plummeted over the last 50 years. While we cannot prove that confidential enquiries have caused this fall directly, we can list positive actions that have resulted from the enquiries such as the benefits of blood pressure and urine protein measurement during routine prenatal care, the need to assess women for postpartum depression at regular intervals, the promotion of pre-conception counselling for women with pre-existing medical problems and advice on how to wear a car seat belt in pregnancy.

The existing Confidential Enquiries have demonstrated that clinicians feel ownership in the enquiry process. Indeed, case ascertainment suggests that compliance with reporting to CEMACH is extremely high despite the enquiry not being statutory. The positive association is strengthened by the perceived benefits of participating in the review process and in the feedback from regular national and local reports. Clinicians actively participate in panel meetings and take the lessons they learn there back to their own units.

Inevitably, this report shows that some deaths are due to problems with clinical care. But more importantly, many have their roots in the intrinsic and extrinsic factors particular to childhood and development. As with the other Confidential Enquiries, we cannot learn lessons from deaths until all those involved provide information from their own field. The challenge for public health is to ensure that all agencies participate equally to build a complete picture. In a multidisciplinary panel, all panel members are ‘lay’ for some parts of the discussion outside their own particular area of work and so are in a privileged position of being able to ask the simple but awkward questions that may get to the heart of the problem and its solution. Once comprehensive participation is achieved, we can begin to assess the current epidemiologic profile of death in children, identify problems with clinical care, make policy recommendations, and hopefully improve our children’s health.

What does this report tell us?

Around 3000 children between the age of 28 days and 18 years die in England, Wales and Northern Ireland each year. This report, which gives an epidemiological overview, contains detailed information on 957 deaths (the core dataset) occurring in 2006 in five regions. We therefore have a description of the magnitude of the problem and can identify the causes of death. Since multidisciplinary panels reviewed 126 deaths in detail, we can also start to identify avoidable factors and to aggregate these findings to draw lessons for wider practice.

The findings of this report contain important information for everyone looking after or working with children. It is clear that not all the deaths in this report could have been avoided. However, from the detailed expert assessment of 126 deaths, the panels determined that 26% of deaths contained avoidable factors. Due to the nature of the study, this percentage cannot be extrapolated to the wider population, but it does indicate substantial room for improvement. Already common themes have emerged in relation to avoidability that point to potential remedies.

The report also highlights the large proportion of childhood deaths that occur after the neonatal period and which may have their origins in pregnancy and child birth, e.g. those due to cerebral palsy and other congenital conditions. Whilst an early death may have been predetermined from birth for these children, examples of good practice from the report highlight the need to commission care that helps families faced with caring for these vulnerable individuals.

Where do we go from here?

This report offers a great achievement in public health, as it is the first time in the UK that we have detailed public health intelligence on a large sample of children's deaths. It also identifies avoidable factors in a subset of these deaths, and in doing so, confirms it is feasible to conduct a National Confidential Enquiry into children's deaths to partner those already successfully established in maternal and perinatal deaths. The public health significance of a National Confidential Enquiry into children's deaths would be immense and an enormous opportunity to reduce mortality and improve children's health.

The most immediate challenge at a national public health level will be to find a way to integrate CEMACH's work with the newly established Local Safeguarding Children Boards (LSCBs). There is a crucial opportunity to collect important data on children's deaths, in a standardised format, to understand the epidemiology of childhood mortality. It is clear there needs to be consistency and standardisation across LSCBs and aggregation at a regional and national level for it to serve the purpose of identifying major issues and trends in child mortality. This study also shows that a useful, relevant, and practical classification system for children's deaths is urgently needed to maximise the benefit from such data. This development will require expertise in both data collection and analysis. Using the experience of CEMACH in this area will be critical. The challenge will be to build upon the information that CEMACH has produced and scale up the process to a national level.

LSCBs are also required to set up Child Death Overview Panels to look at all child deaths. These will differ substantially from the CEMACH Child Death Review panels. The reviews will not be confidential and will concentrate primarily on deaths of children in their local area. The national initiative to set up review processes has its origins in high profile child abuse cases where there was clear evidence that information was not shared between agencies. Safeguarding boards, social workers, and the police may well wish to concentrate on such cases. However, cases of death due to non-natural causes are relatively rare when road traffic accidents are excluded. When the 40% of child deaths that occur in the neonatal period are added, the proportion of deaths to abuse and neglect will decline further. There is a risk that a purely epidemiological focus on medical causes of death and the failings of health care services, whilst encouraging participation among the doctors and nurses on the panel, will cause non-clinical members of the panel to lose interest. Similarly directing discussion to non-natural deaths and their causes outside the health care system risks making clinicians feel that attending a panel is not a good use of their time. It is vital that chairs of overview panels find the right balance so that all panel members feel that they both contribute to the discussion and take back lessons for their own professional groups and organisations.

Conclusion

“A sixteen year old unmarried primigravida from social class V has an antepartum haemorrhage at 28 weeks’ gestation followed by spontaneous labour and the premature delivery of an infant who rapidly develops respiratory distress syndrome and dies on the second postnatal day. The post mortem examination demonstrates hyaline membrane disease and intraventricular haemorrhage...”

The paediatricians will see death in terms of pathophysiology. The obstetricians will consider that the infant died from maternal antepartum haemorrhage with its predictable complications. The pathologist tends to be impressed more by the final event than the initial one, and will attribute death to the intraventricular haemorrhage. The epidemiologist may observe that the pregnancy could have had a different result had not the girl had such an unpromising social background. And the girl’s mother, with some truth and equal conviction, will see the boyfriend as the cause of the whole unhappy episode.” (Source unknown)

Fortunately the death of a child is a relatively rare event in the UK, but each represents an individual tragedy. Immunisation, antibiotics, and improved living standards have done much to reduce child mortality. This report indicates that further improvements are possible. The findings also indicate that the best approach to achieving these improvements is a public health model which combines the social, environmental, and medical approaches to examine childhood deaths from multiple disciplinary and professional angles.

8. “Avoidable factors”

Gale Pearson and Anthony Harnden

8.1 Introduction

When individual cases are considered, the potential to avoid deaths in children is clear. The review panels graded the contributory and avoidable factors that they determined as described in Chapter 3. This chapter presents vignettes that have been selected to represent patterns of avoidable factors that were observed amongst the cases. It should be noted that many of the vignettes that have already been used in earlier chapters of this report, were also considered to contain avoidable factors. These were often further examples of the points made in this chapter (examples not repeated here).

8.2 Recognition of severity of illness

One of the most important clinical skills required of doctors and other health professionals is an ability to recognise severe illness in a child. To do this well requires training, experience, good judgement, and a willingness to review and consult when necessary. A clinician can only make a good judgement if he or she is in a position to assess the evidence of the child's illness. This involves taking a clear and full history and making an appropriate examination of the child. It also requires a recognition and self awareness of the limitations of the clinician's knowledge and expertise. A competent clinician will always seek advice if there is uncertainty.

Competence extends to communication with parents and children. An acute illness is usually evolving and it is important to recognise that even in a child with an apparently minor illness, deterioration may occur quite rapidly. Parents should be provided with information, and given opportunities for further medical consultations should their child's condition deteriorate. In a child with a severe illness, it is a failure of communication if parents are left with an impression that, having already sought medical advice, they would be a nuisance if they asked again for advice during the same illness.

Avoidable factors were frequently found in cases where children with febrile illnesses required multiple assessments from healthcare providers with little or no training or experience in the medical care of children. The impact of recent NICE guidance in this field remains to be assessed.

The parents of a seven month old child presented twice to hospital A&E in the 40 hours before admission. Their first concerns were that the baby had been unwell for three days with a fever and refusing food. The A&E junior doctor wrongly ascribed the fever to a routine immunisation six days previously. They came back 12 hours later because the baby was drowsy and difficult to rouse. The fever was no longer present and the child was not admitted. 24 hours later when brought to the hospital a third time, the baby had extensor posturing and a high pitched cry. A lumbar puncture investigation confirmed meningitis. Problematic seizures later lead to intensive care admission. The baby died when coning (herniation of the brain into the spine) occurred as a result of cerebral swelling from meningitis. The death was not considered by any local enquiry nor formally referred to the Coroner.

Children can become acutely ill at any hour of the day or night and parents may access healthcare advice from a number of different agencies including GP surgeries, NHS direct, out of hours centres, accident and emergency departments, district hospitals, and from relatives and friends. Increasingly, parents are offered telephone advice. Levels of experience and standards of care vary considerably and it is an important challenge to ensure that high standards of care for children are applied uniformly throughout the health service.

There were a number of issues arising within the theme “failure to recognise severity of illness” which we believe were avoidable factors contributing in part to the child's death.

8.2.1 Failure to understand the importance of the history

There may be one or several critical factors in the history of the illness which are crucial in treatment decisions. The review has demonstrated that in some circumstances a child may die if these key history points are not elicited or understood. It is not uncommon for children to take an overdose of a drug: in young children, the overdose is usually accidental, but teenagers may intentionally overdose on drugs and alcohol. The recognition of the potential severity of the effects of the overdose relies upon three key history points: the time of ingestion, the substance(s) ingested and the amount ingested, although it may be difficult to elicit all this information. Relatively small amounts of commonly obtained drugs such as paracetamol or iron can lead to death in children over a short number of hours, despite the child appearing well on initial presentation. Deaths such as these are avoidable if the correct course of action is taken by the doctor seeing the child for the first time in an accident and emergency department.

A teenager took a potentially lethal overdose. When the overdose was discovered she was brought to A&E and was seen by a senior house officer. She gave an honest history in relation to the type and amount of drug ingested. The doctor did not check that the dose involved was potentially lethal. She was sent home without arrangements for follow up (contravening NICE Guidelines on Self Harm (2004)). Her condition deteriorated over the next two days. When she re-presented to A&E, there was a critical failure to recognise the severity of her symptoms and a consequent significant delay in medical management. She collapsed whilst waiting in the A&E and started to convulse. She died later in intensive care.

8.2.2. Failure to examine or interpret physical signs correctly

It requires considerable skill to elicit and correctly interpret physical signs in children. But all doctors involved in the care of children should ensure they possess and refine these skills. We have found, throughout this review, examples of failure to make thorough examinations and correctly interpret clinical signs. In some cases these failures have made significant contributions to the child's death. For example rapid breathing – tachypnoea – can be a critical sign of respiratory distress and requires investigation. Although respiratory rate may rise with fever, it is wrong to attribute tachypnoea to fever without giving consideration that the child may have a serious underlying condition such as pneumonia.

A three year old girl died unexpectedly from empyema (a collection of pus in the space between the lung and the chest wall). She had been described as “previously well” but the panel found records that she was markedly underweight. She presented to A&E in a district general hospital with fever and shortness of breath. Although her initial symptoms were sufficiently severe for the triage nurse to place her in the resuscitation room and administer a nebuliser (inhaler used for asthma), a junior doctor underestimated them and inappropriately attributed her rapid breathing to her fever and the fever to an ear infection. There was no documentation to suggest or confirm that her chest was examined (despite her breathlessness). She was not seen by paediatric or senior staff, but was discharged home on oral antibiotics and died overnight. The diagnosis was made at post mortem.

8.2.3. Failure to recognise complications

A 10 year old severe asthmatic became unwell at home. Her parents were so worried that they did not wait for the ambulance. She was driven to A&E in the back of her father's car and was critically ill on arrival. She was blue, barely breathing and had a dangerously slow pulse. She was ventilated and at first showed a good response to treatment. She then deteriorated, leading to cardiac arrest. This was due to a pneumothorax (a well known complication where an air leak compresses the lung). The pneumothorax was only detected and treated late (after cardiac arrest) when surgical emphysema (air under the skin) was discovered during the resuscitation. Although cardiac output was restored, severe hypoxic brain damage had occurred which proved fatal.

8.2.4. Failure of clinical supervision

In some cases, the errors concerned were repeated and compounded by the fact that the principal assessment was being performed by a junior doctor with no postgraduate training in paediatrics in settings where there was no supervision by an experienced specialist/paediatrician.

A six month old girl died from overwhelming pneumococcal meningitis. Treatment was withdrawn in the face of extensive irreversible brain damage. The family had brought their baby to the hospital accident and emergency department twice in the 24 hours prior to admission and they saw junior emergency department staff on each occasion.

8.2.5. Delay in referral or treatment

The usual consequence of a failure to recognise the severity of a child's illness was a failure to initiate appropriate therapy in a timely manner or to refer to an appropriate specialist.

A 10 year old boy at known risk of high blood pressure for medical reasons had treatment delayed by four hours when he presented to A&E with clear symptoms and signs of hypertensive encephalopathy (brain swelling as the result of uncontrolled high blood pressure). The A&E triage system failed - the initial assessment of risk was wrong - and the case notes were misplaced for one hour. Nurses failed to measure his blood pressure and did not recognise the severity of the encephalopathy. He started to convulse when attempts were eventually made to control his blood pressure. His cranial CT scan was misinterpreted as normal by a neurosurgical registrar. He died from obstructive hydrocephalus despite late emergency transfer for surgical intervention.

A 17 year old boy was assaulted whilst on a night out with his girlfriend. He refused to go to hospital with paramedics and was left in the street. 20 hours later he attended A&E complaining of headache. Cranial CT scan showed two discrete intra cerebral bleeds. Neurosurgical supervision (not available at that hospital) was not thought necessary but he was admitted for observation. 36 hours later he became confused and agitated. A further CT scan showed further bleeding and pressure from the expanding haemorrhage displacing the brain. He was transferred to the neurosurgical centre and operated on immediately but his brain remained swollen afterwards and the swelling did not respond to treatment. A few days later brain stem death was confirmed.

8.3 Compliance with appointments

The attempts of NHS Trusts to meet performance targets in respect of out-patient appointments are confounded by patients who "DNA" (Do Not Attend). Hence NHS Trusts are reluctant to offer out-patient appointments to patients who do not comply. In some cases, very little lenience is shown. However the issues related to children are more complex because missed appointments may be due to the parents or guardians, competing commitments, and family problems.

When reviewing the records of children who had died, panels repeatedly encountered instances where children who had failed to attend out-patient appointments on one or more occasions were not followed up, with deleterious consequences. The panels were particularly critical of instances where the "failure to follow up" occurred in the context of a referral to Child and Adolescent Mental Health Services (CAMHS) (where non compliance is likely to be symptomatic of the problem under review) or where the failure to issue further out-patient appointments was the result of a Trust policy that was felt to unfairly disadvantage the child. Of course fatality is naturally a rare consequence of the failure to provide follow up out-patient appointments and it would be difficult to prove a causal relationship between the two events. Nevertheless the practice violates point 7.6 of the core standards of the National Service Framework for Children. The next two vignettes illustrate the issues relating to the quality of the service that concerned panels.

A 10 year old boy was known to children's social care services as a "Child in need". His mother was depressed, his father was an unemployed alcoholic and he had two siblings with behavioural problems. He had a history of hyperactivity and bed wetting. He was first referred to Child and Adolescent Mental Health Service (CAMHS) by his GP. The referral was rejected after a multi disciplinary team determined that "a lot of resources are already in place to help his family address his behaviour". He was referred to CAMHS again by a consultant community paediatrician concerned about his impulsive, aggressive and violent behaviour (which including several episodes of fire setting) combined with poor academic performance. The referral referenced the concerns of the boy's school nurse and social worker. On this occasion CAMHS wrote to the home address, requesting that the parents contact the department to arrange an appointment. When no contact was made they wrote to the family and the referring paediatrician saying that the offer of an appointment was being withdrawn on the assumption that "the family no longer require the help of our service or have found help elsewhere". In the four years prior to his death, this boy attended one A&E department on 10 separate occasions. He was "knocked down by a car" on four separate occasions and sustained fractures, lacerations and scalds by asserted mechanisms that were not always obviously consistent with the extent of his injuries. The possibility of inflicted injury was never considered. He died in hospital two years later after sustaining a serious head injury when he fell from scaffolding whilst trespassing on a building site. By this time he was no longer under the care of the community paediatrician, this facility having also been withdrawn after he failed to attend clinic appointments on two occasions.

The following vignette is a reproduction of a letter found in the case notes of a girl who died from an asthma attack. The attack occurred on a background of poor control of her symptoms and the letter shows how paediatricians can be frustrated when they are bound by Trust policy but dependant upon parents in order to provide their service:

“Dear (general practitioner), Further to my initial outpatient letter relating to this girl with her recent significant asthma symptoms and signs, we had hoped to review her again early in outpatients having made a change to her daily inhaled steroid regime.

It seems unfortunately that she has not been brought to our outpatients on (a date) and now (a second date) and I am now required by our current hospital Trust policy to stop sending any further routine review appointments for her.

I need to inform you however that as she continues on a significant daily regime of treatment for her asthma, she would need to be under the careful monitoring of her family doctor, so if you feel or the parents feel that we should be reviewing her again and they would be happy to bring her, we will organise a further review appointment at the request of any family doctors.

I will copy this letter to her family to keep them informed of the present position.

Yours sincerely, (Consultant paediatrician)”

8.4 Poor communication

Panels noted that poor communication was a recurrent feature in cases where there was direct or indirect involvement of health and social care professionals. This could be between such professionals and the family or between agencies (both in life and after death) and between staff. Poor communication between care agencies often involved children’s social care services both in the provision and receipt of information and poor communication was often the result of (or accompanied by) poor documentation.

For example, considering the death after a drug overdose of a teenage girl, who was well known to children’s social care services following a long history of behavioural problems compounded by allegations of sexual abuse, the panel listed the following factors as relevant to the death and scored them as indicated:

- Children’s social care services failure to ensure appropriate information sharing and convene timely child protection case conference. (Directly and overwhelmingly important factor in the death).
- Lack of effective multi-agency work to differentiate causation of child’s problems. (Directly and overwhelmingly important factor in the death).
- Availability (in the home) of potentially dangerous medication to facilitate suicide attempt. (Directly and overwhelmingly important factor in the death).
- Failure of emergency department hospital staff to respond appropriately to an earlier suicide attempt. (Probably a significant factor among the events leading up to the death).

As described already, in many cases the panels had to weigh the interaction of multiple factors despite being asked to grade the most avoidable.



A full time mother, suffering from depression, had several children (some with psychiatric problems) and then an unplanned baby. The health visitor had expressed concerns about apparent self neglect and poor hygiene in the house and potential neglect of the children. The baby did not thrive (and should have been referred for investigation) and all the immunisations were given late because of failure to attend appointments. The eventual referral to children's social care services was considered late and was prompted by an episode when the mother tried to have the baby taken into care. It came just before a national holiday and a strategy meeting was planned too late afterwards (three months). The baby's death was considered to be from a particular medical illness which is fatal if not treated but has a very high survival rate if it is. The symptoms leading up to the death were felt to have been misinterpreted by the mother and, on the night when death occurred, the baby was not checked overnight until he was found dead late in the morning. Other members of the primary care team had not been aware of the health visitor's concerns.

8.5 Single service issues

As one might expect, there were cases where the panel were principally critical of a particular service.

8.5.1 Primary care

A GP discussed a baby with increasingly severe respiratory symptoms in a telephone call to the paediatricians at the local hospital during which urgent admission was arranged. However, in a decision that was heavily criticised by the panel, he then sent the child home to await an ambulance to take him to hospital. During this time, respiratory and cardiac arrest occurred. Attempts at resuscitation were commenced by a neighbour and continued by the ambulance crew before a cardiac output was eventually restored half an hour after arrival at hospital. Intensive care was withdrawn later due to devastating brain damage.

8.5.2 Hospital care

A teenager had a benign brain tumour of a type known to be likely to cause "hydrocephalus" (accumulation of cerebrospinal fluid in the head) because it can obstruct the flow of this fluid through the brain. His hydrocephalus had been treated using a drain connected to a reservoir (normally used to assist the introduction of medication into the cerebrospinal fluid). This system relies on external tapping with a needle to release the fluid when required. Normally such cases have a permanent system ("shunt") which allows the fluid to drain elsewhere in the body. His final admission was precipitated by worsening hydrocephalus. The pressure in his head was known to be high because it was measured via the reservoir. A plan was made to convert to a more conventional shunt the following day. Overnight he deteriorated, collapsed and died as the build up of pressure recurred and caused herniation of the brain stem into the spinal cord. The panel felt a "shunt" should have been used from the outset and were very critical of the decision to delay urgent surgery.

8.5.3 Children's social care services management

A teenage girl in an apparently stable long term foster placement committed suicide. The act appeared to have been precipitated by a missed visit with the natural mother with whom she had not lived for several years. At review the panel were critical of the time taken to detect and act upon the original acts of sexual abuse. This was compounded by a previous foster placement with a relative who was a schedule one¹¹ offender himself. The review panel considered that the girl's behavioural difficulties were symptomatic of the original psychological trauma.

8.5.4 Probation Service

A 16 year old girl and three other members of her family were killed in an arson attack committed by her ex-boyfriend – a 31 year old who had been released early from prison for killing his previous girlfriend by attacking her with a mallet. He was in breach of his licence conditions at the time that he committed the arson attack and the review panel were unable to discern what steps if any had been made to supervise the licence.

8.6 Public information

The most straightforward learning opportunities come from cases where a single highly avoidable factor occurred in isolation.

A five year old boy, who could not swim, drowned whilst playing unsupervised in the sea. Bystanders attempted unsuccessfully to resuscitate him.

A young boy, old and tall enough to travel without a booster seat, was a back seat passenger in a car which was involved in a head on collision with another car. He was not wearing a seat belt at the time and died from multiple injuries. The other three occupants of the car had seat belts on at the time and were not injured. There was no suggestion of poor driving conditions, visibility or other road hazards. Neither driver had been drinking.

A critical lapse in parental supervision was a recurrent feature in accidental and traumatic child death in the younger age groups.

A single mother, who had three children under the age of four, briefly left her one year old baby in a shallow bath. When she returned she found the baby lying face down in the water. Attempts at resuscitation continued in the ambulance on the way to hospital but by the time circulation was restored brain damage had occurred and ultimately proved too severe for him to survive.

A mother had recently changed her six month old baby's nappy on a mat on the floor. She left the room to answer the telephone. During the telephone call, she heard the baby cry. When she went to check on the baby she saw it lying on its front and thought that it was asleep. She carried on with her conversation and then went back to check on the baby approx 10 minutes later. At that point the baby was not breathing and a nappy sack was trapped in its mouth/nose. The ambulance and local GP, who managed to attend, attempted resuscitation but later confirmed death at the scene.

Invited Commentary from the College of Emergency Medicine

Ian Maconochie and Ffion Davies

This important study has looked at the quality of care delivered to a sample of children who died in 2006, 126 of whom were studied in detail; some children died as a consequence of life limiting illnesses, and some from conditions in which factors were identified that may have contributed to their demise. The draft report makes key recommendations relating to service delivery to improve the future care of children based on these findings. CEM hopes that the comments below will help realise those recommendations, and may be useful in rephrasing or adding to, some of the CEMACH recommendations.

Children account for a significant part of the workload for Emergency Departments (EDs); 25% of patients attending emergency departments in the UK are children, comprising 3.5 million attendances per year (England).

From the Emergency Department's point of view, key findings of this report include: failure to take a detailed history, inability to recognise a seriously ill child with subsequent failure to take appropriate action, deficient communication in encouraging parents to seek further medical help should it be required, and lack of senior clinical supervision. The failings of Emergency Departments (EDs) included those of triage, prioritisation, process (eg "notes lost"), nursing and medical. The commonest finding was that of inability of junior doctors working in EDs to recognise serious illness and poor provision of senior ED doctors (registrars or consultants) to provide a safety net for this.

The College of Emergency Medicine (CEM) is fully aware of these inadequacies in UK EDs. An internal document is available from CEM "Emergency Care 2015 – Building on the Evidence), a review of the EM workforce was undertaken in October 2007, and the next version of The Way Ahead (a document with recommendations for service and workforce) is due in October 2008.

EDs have been historically staffed by junior doctors with little supervision. Although CEM workforce plans (for the previous and future decade) will make the junior / senior doctor ratio much more safe, this takes many years to achieve in practice. The skills of Emergency Nurse Practitioners and General Practitioners are being increasingly utilised, as a workforce which is more stable than the junior doctor tier.

Medical school prepares graduates very poorly for paediatric emergency care. Paediatric placements are short, and are focussed on chronic disease. Most Foundation Year 1 programmes do not include paediatrics. Therefore the Foundation 2 and Stem Year 1 and 2 doctors who work in EDs are under-skilled in assessing sick children. Increasingly these doctors work in the ED for 4 months at a time, so their paediatric skills improve little during their period of employment. While there is little that can be done about this situation, creation of safety nets for seriously ill children at local level is entirely possible. This includes:

- in-post training (the DH DVD "Spotting the Sick Child" is designed for this purpose)
- utilisation of departmental guidelines (common ones include a 'no discharge of young infants without senior ED or paediatric approval' rule, or 'no discharge of patients over 10 years with overdose of drugs, whether accidental or not')
- shoulder-to-shoulder support by senior ED and paediatric doctors
- rules around telephone advice, which is fraught with danger if the information given to the senior ED doctor or paediatric doctor is wrong. Advice without a face-to-face assessment of the child, or advice by a junior paediatric doctor, can be discouraged.

The College of Emergency Medicine has recognised the requirement to provide PEM skills for training grade EM doctors for over 20 years; this training period has recently increased (since August 2007) to incorporate 6 months focussed and supervised training in managing children at ST3 level, as well as ongoing exposure

to children for the following 3 years of training. Paediatric resuscitation courses are a mandatory element to their training. The RCPCH and CEM have liaised extensively to produce a curriculum and competency based program for ST3-6 training.

The third level of expertise in EDs comes from doctors with sub-speciality training in Paediatric Emergency Medicine (PEM). This is recognised in its own right by PMETB, so that consultant level accreditation can be undertaken by trainees from either an Emergency Medicine or Paediatric background. This is addition to the mandatory core training for EM senior trainees.

The recommendations in the Services for Children in Emergency Departments (produced by the Intercollegiate Committee for Services for Emergency Departments, involving key Royal Colleges and Associations, including CEM) advise that for every emergency department seeing over 16 000 children per year, there should be such a specialist employed, to ensure that structured teaching, guideline development and supervision can be achieved.

This Committee is submitting a proposal for a national audit on the standards of delivery of care to children in emergency departments, which will further improve the care of children, to enhance data already collected by the Healthcare Commission on the hospital and Emergency Department care of sick children.

Other work that has been conducted to influence the delivery of care for children includes the DH document 'The acutely or critically sick or injured child in the District General Hospital: A team response' published in October 2006. NICE guidance provides care pathways to improve the care of children; notable paediatric guidelines for the management of seriously ill child in Emergency departments include the early management of head injury (updated 2007) and the feverish guidelines for managing in 2007. These may have an influence on paediatric mortality and morbidity.

The purpose of all these activities is to reduce the attributable factors which may have been involved in the deaths of the children noted in the CEMACH report. The ultimate aim is to ensure that all children receive the optimal care in emergency departments. This is the case in most instances (the vast majority of the 3.5 million cases per year).



Invited commentary: A hospital care perspective

James Fraser

The Child Death Review study and its findings are particularly relevant to the secondary and tertiary health care community. The headline findings in this regard are:

1. The majority of children's deaths (66%) were in hospital (death certificate data).
2. Avoidable factors were identified in 21% of the hospital deaths reviewed by panel (place of death defined by death certificate). Potentially avoidable factors were found in 49% of the hospital deaths reviewed by panel.

These conclusions immediately pose very real and significant challenges to all those involved in hospital paediatric practice.

This study identifies where children died in hospital. As might be expected, most children are dying on either a tertiary paediatric intensive care unit (33%), in the Emergency Department (27%) or on a children's ward (18%). Some children died on the neonatal intensive care unit (10%). Interestingly, only 2% of deaths occurred in hospices. Of note, 7% of children died on an adult intensive care unit, although closer analysis reveals that the majority of these patients are teenagers aged between 16 and 18 years. This group of deaths would be an interesting subset to investigate prospectively in further detail. This study has also demonstrated that a high proportion of deaths in hospital may occur in children with long term disabilities. 307 out of 957 children (32%) in the core data had some developmental delay, impairment or disability, and 735 out of 957 children (77%) also had some previous history of a medical condition. 60 out of the 126 children (47%) discussed at panel review also had a history of sensory, motor impairment or learning difficulty. In at least a proportion of such cases one might expect end of life to occur either in the hospice or the home setting. The fact that it does not, may imply an inadequate provision of hospice beds, or the failure of paediatricians to discuss end of life issues in a sensitive and proactive fashion.

Chapter 8 eloquently gives examples of real life vignettes, which powerfully illustrate the recurring themes in hospital practice in relation to children's deaths. Many of the issues have also been highlighted in the 2007 Health Care Commission Report entitled 'Improving Services for Children in Hospital'¹². They include:

- **Failure to recognise a sick child** – this has implications for the training of health care professionals, the supervision of junior medical staff, and the empowerment of experienced allied health professionals and of parents to question decision made by junior doctors.
- **Poor medical care delivered by professionals with inadequate paediatric expertise/exposure** – in 8% of hospital Trusts, surgeons carrying out elective surgery did not perform enough work with children to maintain their skills (HCC data). This has implications for Strategic Health Authorities, Commissioners and Trusts to ensure that each region has a network of sustainable services that is safe for children.
- **Failure of hospital Trust services to identify and discriminate 'at risk' children amongst those who 'do not attend' out-patient clinics** – it seems obvious that children are unable to bring themselves to their clinic and yet they are the ones penalised by Trust policies commonly driven by performance targets. This has implications for effective child advocacy, 'safeguarding children' procedures, and for coordinated inter-agency teamwork between primary care, education, secondary care and children's social care services.

- **Failure / lack of regional operational policies** – a child's care pathway is too frequently determined by the decisions of an individual clinician without national guidance and best practice. This has implications for regional centres to put in place operational policies that standardise practice, and for Commissioners to ensure that such systems are in place.
- **Failure of hospital teams to properly respond to the event of a death with respect to correct referral to the Coroner's service, information giving to the pathologist, ongoing liaison with the bereaved family, and the conducting of a standard child death review** – every child's death is a tragedy and demands that lessons are learnt. This has implications for hospital Trust governance teams and, as of April 2008, for Local Safeguarding Children Board (LSCB) Child Death Overview Panels to ensure that statutory requirements in these regards are followed.
- **Failure of attending clinicians to correctly complete the Medical Certificate of the Cause of Death** – this has implications for ONS data, which in turn invalidates national data relating to children's deaths.

This report also informs the logistical challenges that will meet those that take on responsibility for undertaking child death reviews in the future. In straightforward cases, the core dataset takes 10 minutes to complete, although some effort must be made to source parental demographic details. In more complicated cases, for example a death due to a road traffic accident, some investigative work is required to complete the core dataset. In the South West, multi-professional panel reviews were held in relation to all children who died, that enabled the completion of the core dataset in an informed manner at one sitting. The convening of such panels - be it within local hospital or at LSCB level - is extremely labour intensive and will require properly resourced administrative support to arrange meetings, prepare and photocopy relevant documentation, and to process minutes. Although such an undertaking is now a statutory responsibility for all agencies, central funding from the Department of Health will assist this process. Finally, there may have been an assumption by LSCBs that their work in relation to unexpected deaths would, in the main, revolve around 'Sudden Unexpected Deaths in Infancy'. This study clearly demonstrates that sensitive liaison with hospital Trusts will be vital to ensure that avoidable factors relating to the many unexpected deaths that occur in hospital are properly investigated.

An enquiry of this type will inevitably focus on issues that require attention, although it should be emphasised, as other commentators have already done, that there were many examples of excellent care that came to light through the panel enquiry process. It is also important to recognise that a child's death rarely, if ever, results from a single sentinel event but from multiple factors that interplay in complex but often predictable fashions. Thankfully, the death of a child is a rare event, but because of this, 'learning' is often difficult as patterns cannot be identified. This emphasises the need for data relating to children's deaths being collected over a large population and in a standardised fashion. Lastly, effective action in response to identifying 'avoidable factors' can only really come about through local engagement with those immediately involved with the care of the deceased. A 'bottom-up' approach by doctors and nurses on the front line has always delivered more than high-handed directives from those several steps removed from the issues. This will be the challenge for Local Safeguarding Children Boards as they take on these responsibilities in the future.

Invited commentary: From the Royal College of Paediatrics and Child Health
Sue Hobbins and Andrew Boon

The death of any child is a tragic event, but much more so if it was potentially preventable and especially so if the death was due to deficiencies in the care provided for the child by doctors and other health professionals.

This important study has found that a quarter of child deaths could have been prevented and that a major factor was shortcomings in the recognition and management of the acutely ill child.

What can be done to rectify this situation? The ability to identify a sick child is a skill which may come with experience, but unfortunately health professionals, particularly those working primarily with adults often miss the relatively subtle signs of compensated shock or impending collapse in children. There are now a number of validated scoring systems such as the PEWS (Paediatric Early Warning System)^{13,14} score which can reliably identify the acutely ill child. Greater awareness and use of such scoring systems could undoubtedly improve the recognition of children who have a significant risk of dying. A training DVD "Spotting the Sick Child"¹⁵ on the recognition of the sick child in conjunction with the RCPCH, was commissioned and circulated by the Department of Health.

There is a need for improved training of all doctors and health professionals in the management of the acutely ill child. It is already a requirement for all hospital staff caring for children to have regular Paediatric Resuscitation training¹⁶. This should be extended to include general practitioners, practice nurses, ambulance crew and paramedics together with nursing staff in Accident and Emergency departments.

The RCPCH (Royal College of Paediatrics and Child Health)¹⁷ has responsibility for postgraduate medical education, continuing medical education and maintenance of standards for the training of all doctors working in paediatrics and child health in the UK. It aims to ensure high quality care for patients by promoting the highest standards of medical practice.

The College has produced a number of Competency Framework documents for each year of general paediatric training and subsequent subspecialty training including emergency medicine. Communication skills and the recognition of the sick child are highlighted¹⁸:

- "recognise case histories which suggest serious or unusual pathology"
- "recognise the diseases and host characteristics which make certain presentations life-threatening."

Similarly **A Framework of Competences for Level 3 Training in Paediatric Emergency Medicine – July 2006**¹⁹ is for doctors who have completed Higher Specialist Training in Paediatrics or Accident and Emergency Medicine and wish to sub-specialise in Paediatric Emergency Medicine.

The interim report **Aspiring to Excellence, Finding and Recommendations of the Independent Enquiry into Modernising Medical Careers**²⁰ led by Professor Sir John Tooke proposes that the training of general practitioners should be increased to five years. This is strongly supported by the RCPCH and the RCGP, who agree that this will help give all doctors some training in Paediatrics.

Lord Darzi, a surgeon and health minister was appointed by the Prime Minister to lead a review of the NHS in 2007. The document '**Our NHS Our Future: NHS next stage review - Interim report**'²¹ was published in October 2007. One of the stated aims was for PCTs to be responsible for developing greater ease of access for patients with their GP. The Darzi regional children's pathway groups have identified this as one

area of difficulty for children and any improvement on access to medical care is to be welcomed. The final report is due in the Spring 2008.

The publication **Services for Children in Emergency Departments April 2007 Report of the Intercollegiate Committee for Services for Children in Emergency Departments**²² was written with the involvement of the Association of Paediatric Emergency Medicine, British Association of Emergency Medicine, British Association of Paediatric Surgeons, College of Emergency Medicine, Joint Royal Colleges Ambulance Liaison Committee, Royal College of General Practitioners, Royal College of Nursing. To quote from the document: "The purpose and scope of this document is to improve the experience and outcomes of children and families in Emergency Departments (EDs). However, this care should not be seen in isolation, but as part of a network of services providing "urgent care". Care before and after the emergency visit is also considered. While the remit of this document is centred on EDs, it would be impossible, and inappropriate, to ignore issues in the patient's journey that involve other emergency settings in the community, and the ambulance service."

This report seeks to inform the following: policymakers, commissioners of emergency services and urgent care, and more importantly the providers of services, in particular Chief Executives, Medical Directors and clinicians.

The National Institute for Health and Clinical Excellence (NICE) "is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health". NICE produces guidance which includes the appropriate treatment and care of people with specific diseases and conditions. The NICE guidance on Feverish Illness in Children²³ is a document which is clear and unambiguous. It gives simple algorithms for use by both non-paediatric and paediatric professionals and parents and carers. It particularly highlights the need to "take account of parents' and carers' anxiety and instinct" when assessing the febrile child. However this is especially true for any unwell child.

Despite there being a wealth of accessible training materials, documents and guidelines there remains a lack of awareness.

The LSCB (Local Safeguarding Children Boards) Child Death Review Panels have been charged with continuing the process of scrutinising all child deaths. They should also ensure that there is a sustained improvement in the recognition and management of the acutely ill child by promoting training and the use of these readily available training materials

The Deaneries in addition to PMETB throughout the UK have a responsibility for the education of doctors. There are clear guidelines on what is required by an Educational Supervisor and these clinicians must ensure their trainees are not only aware of training opportunities but are actually observed to demonstrate their skills in the clinical setting. Similarly there is a need for nursing clinical supervision which is promoted by the Royal College of Nursing. "The concept of clinical supervision in the workplace was introduced as a way of using reflective practice and shared experiences as a part of continuing professional development (CPD). It has the support of the Nursing and Midwifery Council (formerly the UKCC), and fits well in the clinical governance framework, whilst helping to ensure better and improving nursing practice."

There need to be appropriate and readily available experienced professionals to support inexperienced trainees both in medicine and nursing. Frontline staff must have this support and have the ability to recognise when they need to ask for help. Services for Children in Emergency Departments April 2007²² states "that a whole-systems approach to the provision of urgent care should be taken to ensure a smooth patient journey". This highlights the need for good communication and coordination of services and is a key theme running through the document.

Modelling the Future²⁴ is a major RCPCH project to develop a vision of how children's services could be delivered in the future. The first part of the project is now complete and the consultation report available. This document is designed to act as a template for use in the reconfiguration of paediatric services. It addresses the need for co-location of urgent care centres, emergency departments and in-patient departments, competencies of first line paediatric workforce and the need for networks and robust commissioning. Finally, it recognises the need for implementation of the Children's NSF⁶.

9. Further interpretation of panel findings

Gale Pearson

9.1 Characteristics of the children that died

In the analysis of the core dataset we found that 32% of the children who died had some sort of developmental delay, impairment or disability prior to death. Amongst the cases that went to panel, there were three cases where sensory, motor, learning and chronic illness deficits were graded as an overwhelmingly important factors in relation to the death. In each case there was a severe life limiting congenital problem. Sensory impairments were also recognised in a further 24 cases but were judged in each case to have been “Known to be present but not relevant to the death”. Motor deficits were “directly and overwhelmingly important” factors in four further deaths, three of whom died from respiratory disease in the context of severe debilitation. Two were survivors of neonatal units with severe neurological sequelae and one had a central neurodegenerative disorder and the other a deteriorating neuro-muscular disorder. Similar debilitation was “probably a major factor but one of several” in a further nine deaths. Such debility increases the likelihood of respiratory illness (the most common mode of death in these cases).

Mental illness was felt to be the overwhelming factor in one death (which appears as a vignette in Chapter 8) although concerns in this regard were expressed by panels in another 13 cases where its contribution could not be reliably estimated.

9.2 Medication and drugs

Concentrating upon the drugs taken by the child as opposed to the parent, alcohol consumption was mentioned in nine panel cases and in three it was associated with the use of other illegal drugs (cannabis twice and cocaine once). In the four cases where the alcohol was significant in the death there was clear evidence of disordered thought and behaviour. There was one suicide by hanging where alcohol was present and in the other three cases there was a clear disregard of personal safety in relation to the death. All the alcohol associated deaths were traumatic. There were three other panel cases where death was due to deliberate drug ingestion (two suicide, one parasuicide).

The other medications described in the panel reports related to the treatment of the associated illnesses or the terminal illness itself.

9.3 Patterns in the events leading to death

In 58 cases there were factors external to the child, relevant to the death, which did not fit within the categories anticipated in the reporting tool. These were entered as free text in the reports of the panels’ deliberations. Since no stipulation was put upon the panels in how to choose, select or prioritise these factors, these entries might reflect the interests / biases and behaviour of panel members as well as the nature of the records they reviewed. In 11 such cases the “extrinsic factor” was considered to be directly and overwhelmingly involved in the cause of death. Not surprisingly these were all considered to include avoidable or potentially avoidable factors. In eight cases, the extrinsic factor was “probably major but one of several”. Again these were all felt to include avoidable or potentially avoidable factors.

In 34 of the 58 cases, the additional factors were multiple and in many cases were likely to have compounded in terms of their relevance to the death. As the following vignettes illustrate this was sometimes because of an accumulation of risk factors:

An ex-premature baby died in infancy. No medical explanation was found. The death was classified as a Sudden Unexplained Death in Infancy (“SUDI”). Multiple known risk factors were present. She was sleeping on a sofa; her parents were smokers who were known to drink alcohol excessively. There was extreme social deprivation (the family had recently been homeless). The records stated that the parental relationship was unstable with neither parent employed, and one of the parents suffered from a psychiatric illness. The child had been put to sleep on her back and was not co-sleeping.

Other cases read more like a “system error”. This term is used when there are many different components to a problem which individually can be graded. Typically in a system error, each component on its own could have been overcome given optimal circumstances and treatment in all other respects. However the combination of errors is insurmountable and leads to the poor outcome. In one case, where a teenager died five days after developing respiratory symptoms, there was no post mortem but the panel had access to information from bacterial cultures which implied the cause of the fatal illness. They were able to identify the following potential components of a system error:

- *A past medical history of a condition that causes similar symptoms raised the possibility that there was an assumption of recurrence.*
- *Patient assessed by a junior doctor in Accident & Emergency. ECG (heart trace) abnormality not recognised.*
- *Sent home with increased treatment for the wrong condition.*
- *Recommendation for future consultant review but no appointment made.*
- *When the patient re-attended several days later it was to a different unit with fewer resources.*
- *The new symptoms and observations indicated a worrying condition, but the case was assessed as non-urgent.*
- *There was a long delay before medical review by a junior doctor.*
- *The referral for admission was “bounced” between doctors from different specialties, who did not review the patient and therefore had to rely on the junior doctor’s assessment.*
- *The care of the patient was handed over to a ward team with an inaccurate cursory note in the record.*
- *There was no response to abnormal investigation results.*
- *Two overnight reviews by junior doctors were made when the patient’s symptoms were very serious. Neither resulted in any further action being taken.*
- *No nursing notes entries were made overnight.*
- *The next day a consultant recognised the severity of the illness. Admission to intensive care was arranged but it still took two hours for the patient to reach there.*

The patient died within 12 hours of intensive care admission despite optimal treatment from that point.

Further insights into the panels' view of these cases can be obtained by looking at the serious factors which they described. By far the most frequent concerns were directed at the conduct of adults in relation to the children. They focussed on:

- Failing to supervise the children adequately, which in this sample was as frequent as acting as an assailant.
- Sleeping arrangements in cases of Sudden Unexplained Death in Infancy (SUDI).
- Being the source of access to drugs involved in the death.
- Taking drugs or alcohol themselves whilst responsible for looking after children.
- Poor decision making (such as allowing a teenager to play off-road in a motor vehicle that wasn't roadworthy).
- Delay in recognising that children were ill.
- Driving badly.
- Smoking.

Surprisingly, when looked at in this way, concerns about the parents applied to a minority of cases, although panels were particularly critical of some parents.

The reporting tool proved adequate in most instances to summarise the panels' opinions in relation to the agencies involved with the child (including carers). However there were additional "serious" factors defined in free text entries in relation to health care, the influence of teenage peers, action or inaction by children's social care services, probation service (failure to supervise a banning order) and poor inter-agency working.

9.4 Safety barriers

Absence or failure of a barrier or safety device was relevant in 7/126 cases. In three of the seven it was the direct and overwhelming factor in the death. These sorts of cases include lack of fencing around ponds and swimming pools and unprotected machinery or mechanical apparatus. The absence of a protective barrier was "probably significant" in one further road traffic accident. Other cases related to "absence or failure" of a smoke detector, a barrier above a ravine and the tether on a flotation aid that keeps it attached to its user. All seven cases were assessed by panels as including avoidable factors including three where the identifiable failures were in the child's direct care by someone with direct responsibility for the child. This interpretation is significant since any potential remedial action could be defined as being the remit of a supervising adult as much as the institution or agency that could have fitted or maintained a barrier.

9.5 In-vehicle restraints

Similarly the probable misuse of an in-vehicle restraint was "probably a major feature" in one of the cases reviewed by panels. However, such misuse was also known to be present in a further two cases. In one of these, its relevance could not be further assessed due to lack of access to the relevant documentation (police report). In the other, the pattern of injury strongly implied that the child had slipped out of the shoulder component of the restraint before the collision. However, members of the public had extricated the child from the car before emergency services arrived, making this assertion difficult to prove.

9.6 Clothing

Failure to wear safety clothing e.g. life jackets and cycle helmets was relevant to three of the deaths reviewed by panels.

9.7 Panels' comments in relation to Coroners' Inquests

Some panels (but not all) were fortunate enough to include a Coroner. This greatly added to the perspective and weight of their conclusions. However, even when a Coroner was not present, panels were frequently commented on issues relating to Coroners' inquests. In most, but not all cases, this was because of perceived variation in deciding in which cases to conduct an inquest. For example, panels in the South West tended to expect deaths after cardiac surgery to be subject to mandatory inquest using a paediatric pathologist. However, there were also other cases that panels felt should have been subject to a Coroner's inquest that were not.

In other cases, panels raised medical issues that they felt should have been brought out in the Coroner's inquest.

Lastly, panels sat without access to the Coroner's conclusions in eleven instances and this severely hampered their ability to consider avoidable factors. More information could have been gleaned from these cases if the study had continued.

9.8 Panels' comments in relation to death certificates

It is important to distinguish a "Death Certificate" (issued by a registrar of births, deaths and marriages) from a "Medical Certificate of the Cause of Death" which is issued by a doctor and in health care parlance often referred to as a "Death Certificate". Panels knew the diagnoses entered on the medical certificate of the cause of death in 95/126 cases. They noted that it was inaccurate in 33. There were 11 errant classifications in terms of significance (the position of a diagnosis on the certificate) and 22 cases where an additional diagnosis should have been entered on the certificate. In terms of relevance these were minor (6), significant (2), major (9) and direct and overwhelming (5). This is entirely consistent with the importance panels attributed to the contribution made by post mortem investigations, bearing in mind that the medical certificate of the cause of death may be issued prior to a post mortem.

One of the concerns about poorly completed medical certificates of the cause of death and subsequent coding and grouping is that greater weight can be given to the proximate causes of death as opposed to root causes. For example, a child who suffers a perinatal brain injury that results in cerebral palsy may well die of respiratory infection in the teenage years. The immediate cause of death may be 'pneumonia' or 'aspiration', but the underlying cause is "cerebral palsy", and the root cause may lie in an obstetric complication such as placental abruption. Some of this information was captured on the core dataset; however judgements about the relevance of early life events to later deaths could only properly be made by the confidential enquiry panels.

Guidance for doctors on how to complete a death certificate has been reproduced. This guidance can be found as Appendix D.

Invited commentary: A Coroner's perspective

Aidan Keith Cotter

These are my personal views. They must not be thought to be in any way the views of the Coroners' Society of England and Wales and they should not be assumed to be representative of all or indeed any other of Her Majesty's Coroners.

The CEMACH Child Death Review has impressed me enormously. Too often as one of Her Majesty's Coroners I deal with tragic deaths where there is evidence of "missed opportunities" often due to a failure of communication between the different people who have cared for the deceased. Other contributors have emphasised the importance of effective communication and I add my voice to theirs. This review will improve the situation.

As one of Her Majesty's Coroners I am an independent judicial officer. This means that it is not possible for me to work in partnership with other organisations. I am always willing to help but at all times I need to preserve my independence. In over twenty years as one of Her Majesty's Coroners I have found that this concept is not easily understood by other professionals.

At the time of writing this contribution I have seen only a draft of the study. That draft contains some implicit criticism of Her Majesty's Coroners. To my mind, those criticisms are based upon two things:

1. A lack of understanding of our role.
2. A lack of understanding of our powers.

I do not mean this as a criticism of the other contributors. A similar lack of understanding exists among almost all professional people in England and Wales and exists to a very marked degree in successive governments.

The first criticism is that we do not go far enough in our work.

It may help to explain our role:

Her Majesty's Coroners are independent judicial officers. Our job is to hold inquiries in public regarding certain types of death and to determine in each such case:

- a. Who the deceased is**
- b. How, when and where he came by his death**
- c. The particulars required by the Registrar of Births, Deaths and Marriages.**

Section 8 Coroners Act 1988²⁵ lists the deaths with which we are concerned.

Section 19 and 20 Coroners Act 1988²⁵ gives us the authority to order post mortem and special examinations for the limited purposes of determining the medical cause of death in so far as it is relevant for the purposes of the Inquest and whether an Inquest should be held.

Many people would like Her Majesty's Coroners to go much further and use their powers to obtain other benefits. Here are just some of the things other people would like us to do:-

1. Obtain, record and distribute statistical evidence for the use of government departments, families, academics and specialist groups.
2. Take DNA from all bodies which pass through our hands so as to help police forces to solve crimes,

- to clear unmerited suspicion and to provide evidence which might exonerate convicted criminals.
3. Allow pathologists to remove body parts for the benefit of medical research and teaching hospitals.
 4. Remove body parts for the benefit of living people, e.g. cornea, skin and bone in addition to the harvesting of organs.
 5. Authorise such action as may be of assistance for research into such matters as:
 - a) Sudden Unexpected Death in Infancy (SUDI)
 - b) Child death
 - c) Sudden Adult Death Syndrome
 - d) Sudden death in epilepsy
 - e) Heart disease.
 6. Ensure that the full medical facts are determined at the Inquest.

These are just a few examples. There are many more instances where Her Majesty's Coroners are asked either to do things or to allow things to be done in their name which go beyond our statutory powers. In every case, the people who ask are honest, caring and professional. They are not asking for themselves but because they believe that it is for the public benefit.

There is a huge temptation as one of Her Majesty's Coroners to agree and to do things (either directly or indirectly) which I believe are for the common good. Not only would I be doing something which I think is for the public good, but I would at a stroke become universally popular and be considered wise, compassionate and politically correct.

I will not do these things because I do not have the legal authority to do so.

The review also contains implicit criticism of the fact that there can be inconsistency between Coroners as to when an Inquest is considered necessary.

To a large degree, this is a direct result of the requirement that a Coroner holds an Inquest touching any death which is **unnatural**. Sadly, neither the Coroners Act 1988 nor the Coroners Rules 1984 provide any statutory definition of either the word **unnatural** or the word **natural**. None of the Judges in the High Court, the Court of Appeal, the House of Lords or the Court of Human Rights in Strasbourg has produced a definition of either word. The nearest we have to a definition is a statement in the Court of Appeal that:

An unnatural death is a death which is not natural.

Add to that difficulty, the obvious fact that what was natural in 1907 may clearly not be natural in 2007 bearing in mind the advances in medical knowledge and resources. Things change all the time. At present, deaths from cigarette smoking are considered natural whereas deaths from the effects of heroin or cocaine are still considered unnatural. I expect that by the year 2027 the position will be reversed.

Further, different people have different views as to what is natural.

Finally, when considering inconsistencies between Coroners, one needs to take into account both geography and resources. In Birmingham and Solihull I have my own court available all day and every day. Further facilities are made available to me by Birmingham City Council when needed. My jurisdiction comprises over 1.25 million people but they are within a small area which is served by easy travel arrangements. If I think that an Inquest may be appropriate then I hold an Inquest. Contrast that with the position of one of Her Majesty's Coroners who has no court and can only hold an Inquest on those few days when the Magistrates Court, County Court or Crown Court feel able to lend him a court.

The population of another jurisdiction may well be less than a quarter of mine but spread over a much greater area and one where travelling is far more difficult. In some jurisdictions it can take a family four hours to travel to a Coroner's court and then four hours back home. Families are not always happy to travel eight hours for a Hearing which often would only last for thirty minutes.

Inconsistency could be reduced to a minimum if the government would provide proper leadership for Her Majesty's Coroners and proper resources. There have been three major reviews of the Coronial System in 1936, 1974 and 2001. Each of them was commissioned by the government of that day. Each of them concluded that the Coronial Service was significantly under resourced and under funded. No government has made the slightest attempt to tackle the problem. The situation is getting worse not better.

10. Examples of good practice

Gale Pearson and Anthony Harnden

By virtue of having access to comprehensive copies of all the records relating to the children's lives, the panels were able to highlight many examples of good practice. The vignettes that follow represent a small sample of them.

To the bereaved, death often seems to either have been sudden, too short to have allowed time to prepare and to say goodbye, or too drawn out, so that memories of the event are dominated by concerns over the potential suffering and pain involved.

In instances of sudden unexpected collapse or death, the panels found many examples in which they were driven to comment on the high standard of attempts by various agencies to prevent death and resuscitate the child.

A young child was a back seat passenger in a car which was involved in a high speed frontal collision in a rural area. The ambulance arrived quickly. The patient was in shock (in the medical sense this refers to the consequences of blood loss). Paramedics assisted his breathing and gave fluids by an intravenous drip during a rapid evacuation to hospital. His pulses became impalpable in the A&E department and he went into cardiac arrest. Attempted resuscitation went so far as thoracotomy and internal cardiac massage to regain cardiac output. Then attempts to control internal bleeding in the abdomen meant taking him to the operating theatre where he died despite the efforts that were applauded by panel.

At the other extreme there were also many examples of considerate and comprehensive terminal or palliative care.

A 12 year old boy died from cancer. After a characteristic presentation, the diagnosis was made quickly and treatment was planned along national guidelines. However he suffered many complications of chemotherapy and his tumour progressed before radical surgery was carried out. Subsequent chemotherapy was also poorly tolerated. The further recurrence of his tumour was treated in a palliative fashion. Throughout this time he remained under the care of the palliative care team from the children's hospital but also involving the local community nurse. His palliative care lasted for six months during which time he remained at home. He died at home in the care of both his parents. The panel were impressed with the quality of his analgesia, the extent of treatment that was provided in the home and the level of communication between all agencies involved.

A teenage boy was blind and deaf and had learning difficulties and severe cerebral palsy all attributed to birth asphyxia. His loving family had access to specialist community nurse support and three different sources of respite care (including children's social care services) coordinated by his general practitioner and local paediatrician. Assisted transport was provided to allow attendance at special school. Terminal lung disease required palliative care in a hospice which was considerably negotiated including liaison with his primary care team. Specialist pain relief was provided. He died with dignity in the presence of his family. The hospice's care and support continued after death right up until the funeral and subsequent support was offered to the family from several quarters. The panel felt that this was an excellent example of effective multi-agency professional support working with the family.

The next case also illustrates a good example of high quality primary care that it is possible to deliver to children with chronic disease and disability. The evidence of teamwork, communication, family support and medical review are impressive and set a high standard of care which children and their families should receive.

A nine year old girl who died suddenly at home had cystic fibrosis and spastic quadriplegia. She had GP care delivered from the same practice throughout her life. The whole primary health care team offered support and advice in the first year of life about a range of issues including feeding, development, chest infections, diarrhoea and seizures. Over the course of the girl's life the primary care notes included clear records of communication to hospital specialists, a care planning agency and a charitable grant giving body for disabled children. The GP provided written fitness to travel certifications for the family on request. As well as good coordination of care there was evidence that the child had regular reviews in the practice of medication, respiratory infections, diet and development.

There were other examples of good practice in primary care particularly where extensive coordination and liaison of services had been required.

A 10 year old boy presented to his GP two years prior to his death following a short episode of vomiting blood. He was referred to hospital and underwent investigations which found him to have cancer. He underwent chemotherapy and radiotherapy and initially made a good response to this treatment. However, his tumour recurred after 18 months. During the last six months of his life he received palliative care at home delivered by nurses and the GP with good records of communication between hospital, GP, nurses and family. There were no further hospital admissions although he was reviewed on the children's ward. He was visited at home regularly and the GP was in attendance immediately following his death.

The care of this child illustrates that shared responsibility between hospital and primary care and good teamwork can allow a child's death to be managed very well in the community without the necessity for hospital admission.

A 15 year old boy, who had spastic quadriplegia and epilepsy, suffered recurrent chest infections during the last few years of his life. During his last year, the GP records demonstrated active involvement in the boy's medical care. The GP saw the boy fifteen times in the surgery and visited him on four occasions in his home. There were eight records of telephone consultations between the GP and the family. There were no hospital admissions. There were good records of care plans and discussion with parents. The boy died in a hospice from a chest infection cared for by the GP. The GP saw the family during and after death.

There were also other cases which attracted praise from panels when good practice could be identified.

An ex-premature baby, the seventh of eight children, was the survivor of extensive complications of prematurity. He had quadriplegic cerebral palsy, with epilepsy and scoliosis. He was blind and deaf and immobile but survived until the age of 6 with intermittent severe chest infections related to a poor cough reflex and inadequate clearance of his chest secretions. This was aggravated by severe gastro-oesophageal reflux (persistent, largely unnoticed regurgitation allowing inhalation of stomach contents). The family had extensive needs in terms of social support and the child was eventually fostered in the face of accusations of neglect. The school nurse on the review panel pointed out that at this point the family had been expected to attend follow up appointments from 12 different sources. Failure to attend these clinics was part of the criticism levelled at the family. The community paediatrician involved had her good practice cited by the panel because she served as the key / lead carer in this child's care. This included trying to coordinate the various specialties involved and even, on one occasion, having to write a letter of remonstrance and admonishment to a colleague whose failure to communicate with other health care staff included his secretaries refusing to speak to community nurses stating that they were "only allowed to talk to the family".

Invited commentary: From the Health Care Commission

Maddie Blackburn

First and foremost, I feel it is important to reinforce the importance that should be attached to child death reviews. This work by CEMACH is emerging as a most constructive, sensitive and important pilot / feasibility report which uses the same high quality focus that CEMACH has historically given to maternity reviews. Equally the draft report pays due regard to the responsibilities set out in "Working Together to Safeguard Children" (2006), Chapter 7.6 to 7.57 with particular reference to the functions of the Child Death Overview Panel which are set out in Chapter 7.55.

It is also excellent that children's participation has been included in the development of the Child Death Review, particularly children and young people with special needs and a diversity of ethnic backgrounds. This work highlights the ethical issues and sensitivities surrounding the collection of information on child health. I would recommend extension of this work by including children and young people throughout England, Wales and Northern Ireland and not just from London and Greater London in the interpretation dissemination and implementation of its recommendations. Perhaps, in the first instance, in the development of a child-friendly version of the report.

LSCBs should aggregate the findings from all child deaths, collected according to a nationally agreed minimum dataset. CEMACH commendably produced a report on "Case Ascertainment and Data Acquisition" in September 2007 and I am encouraged to learn that they are sharing the lessons that they have learned with the Department for Children Schools and Families in the development of templates for collecting child death information. The CEMACH dataset was developed from the Arizona Child Fatality Review. In my view wherever possible (without breaching confidentiality) it would be helpful, to include some reference to parental mental or physical health problems, which may impact on the child's emotional and physical development. Continued collaboration between CEMACH and the DCSF is likely to help ensure consistency on how the minimum dataset will be used locally and nationally.

The most obvious limitation of this pilot / feasibility study is that it did not cover all of England. This could have created problems with case ascertainment and data collection. If the death of a child, resident in the pilot study region, occurred elsewhere within England then the review team may not find out about it. Hopefully this risk can be avoided when the data is collected in future post April 2008 although it may persist for deaths occurring abroad. An inclusive approach has been adopted to enrolment in this feasibility study (for example with regard to children who reside in one region and die in another region) and considerable effort made in the analysis to ensure that there are no duplicate recordings of the same death. In the future, unique identifiers for each child born in the UK will assist in this specificity. It is clear from children and young people who die in young offenders institutions or who have been known to YOTS that recording of these deaths is carefully cross-referenced. Experience has taught me that in such environments there are often questions about the recording of deaths of "Looked after Children" who die out of their authority.

With the shortage of health visitors and an increasing focus on their public health remit, I hope that the child death review panels from April 2008 will be able to have sufficient health visitor expertise across the country to provide their important contribution. The authors make reference to missing records. Given the emphasis on the health visitors' use of Parent Held Records, there will have been (and will remain) difficulties for health visitors in providing additional records about the child or young person. Hopefully the National Programme for Information Technology will ensure coterminous record keeping in future which includes the health visitor's documentation.

It is imperative that the intensity of workload and case scrutiny applied in this study is acknowledged, in spite of the restriction of work and cases imposed on this pilot review. There will be significant resource implications on LSCBs who may have to deal with a large number of deaths and which will not be able to review each in this detail. Particularly in areas where there may not be access to the expertise of all the specialists referred to in the CEMACH methodology. One is mindful that many of the pilot reviews relied on the generosity and time given voluntarily and willingly by professional staff which will arguably not continue after April 2008.

I welcome the suggestion of noting the root cause of illness, which may impact on a subsequent child's death; e.g. the child who has meningitis which leads to cerebral palsy but subsequently dies of pneumonia etc in his or her teens. Similarly, ascertaining both the mode and location of death (questions 22 and 23 on the core dataset, see Appendix B) using the core datasets are vital. The additional depth CEMACH proposes in respect of this analysis is to be supported.

The age of consent to treatment is such a "hot issue" and one which frequently challenges doctors and other health professionals alike. I think it would be helpful to see a representative picture in the child death review. I would favour future analysis differentiating children below and above the legal age of consent, even if the sample of young people in this group is reduced. For example: Five- eleven, Eleven- up to sixteenth birthday and 16-18 years.

7% of child deaths were on adult intensive care units and 1% on adult wards. This is a topical matter and clearly one that arises regularly in discussions regarding young people with mental health problems. It may prove challenging trying to establish the contribution made by professionals in such settings.

The use of vignettes is a powerful method of presenting a qualitative analysis in terms of avoidable factors. The authors describe the selection criteria for vignettes but CEMACH should be encouraged to subject more cases to panel review and to include more references to what constitutes appropriate management so that the proportion of cases where professional practices are questionable can be determined. Clearly this would require delicate re-drafting and legal advice prior to the final publication.

The second joint chief inspector's review on children's safeguards highlighted the delays in the LSCBs receiving Coroners' reports. It is clear that the development of LSCBs and any proposed revision to Coroners' working practices should be carefully coordinated not least in respect of deaths in children.

It should be noted that, at the time of writing, the Department for Children, Schools and Families, had reviewed these data sets and their associated forms. Drawing on the CEMACH work and the findings from the Warwick University led study of LSCBs, DCSF has developed a set of templates for LSCBs to use when collecting information about child deaths in accordance with "Working Together". CEMACH has been a key participant in this review.

Invited commentary: Perspective of a children's advocate

Peter Fleming

The full implementation in April 2008 of the Children Act 2004 will for the first time require local authorities, health care providers, police and other statutory and voluntary agencies to routinely review the circumstances and causes of all deaths in childhood in England and Wales. The potential and actual value of such review processes has been widely recognised in the understanding and prevention of maternal deaths, unexpected infant deaths and perinatal deaths. In the USA and Australia, comprehensive child death review programmes have made major contributions to the identification of potentially preventive factors such as the fencing of domestic pools and the use of child cycle helmets.

The investigation of perioperative and maternal deaths in the UK has focused mainly on medical care and related issues, but the investigation of unexpected infant deaths has shown the importance of a broader investigative process, involving information sharing and exchange of views between professionals with expertise in a range of disciplines including social care, education and police as well as health.

Such assessments are most likely to be of value in understanding factors contributing to unexpected deaths, deaths in the community, or those deaths in hospital for which social, economic or environmental factors in the community may have contributed.

Assessment and comparison of figures for the proportion of childhood deaths in different countries attributed to various categories is complicated by the different ways in which the data are published. Table 10.1 shows the proportion of childhood deaths attributed to trauma in published data from the USA in 2004²⁶ and from Belarus²⁷ over the period 1980-2000, showing remarkable similarities over a long time period.

Table 10.1

Proportion of childhood deaths certified as being due to trauma (accidental and non-accidental) in the USA in 2004 and in Belarus 1980-2000

Age range (Years)	USA (2004)	Belarus (1980-2000)
1 to 4	42	34
5 to 9	43	52
10 to 14	44	44

In the study from Belarus, there was clear evidence that, as the total childhood mortality rates fell over this time period, there was a steady rise in the proportion of deaths related to trauma. Thus improved child health, with reduced disease-related mortality rates have not been accompanied by parallel falls in deaths from trauma – either accidental or non-accidental.

Death certificate data from the UK from 1998-2000 (ONS) suggest that throughout childhood around 30-40% of deaths are unexpected, including those due to previously unrecognised identifiable causes and those that remain unexplained, together with both accidental and non-accidental trauma.

As noted in this report and as shown previously in the reports from the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI), the information given on death certificates is very limited, and commonly inaccurate.

In a study from the Oxford record linkage system, Petrou and colleagues (2006)²⁸ showed that, for the period 1979-1988, the mortality rates per 1000 population at risk rose significantly with decreasing socioeconomic status of parents, for each age group (0-6 days, 7-27 days, 28-365 days, and 1-10 years) of children under the age of 10. Overall the mortality rates (13.1/1000) for children in social class V (parents unskilled) was more than 85% higher than for children in social class II (managerial and professional).

The data collected in the present study confirm the particular vulnerability of children growing up in conditions of social, economic, educational or emotional deprivation.

The present study, although not intended to be statistically representative of all childhood deaths in the UK, gives a broad picture of some of the potentially important factors that may contribute, and raises important issues concerning the possibility of prevention for many such deaths – both in hospital and in the community.

Perhaps the most striking feature of the reports from the child death confidential enquiry panels is the high proportion of the deaths – across all ages, and in all settings – both community and hospital – in which potentially preventable factors were identified. Whilst it would be inappropriate to suggest that in the absence of these factors the deaths might not have occurred, it is nevertheless striking that for between 60 and 70% of the deaths potentially contributory avoidable factors were identified.

The nature of the preventable factors identified, whilst not surprising, emphasises the importance of appropriate adult supervision of children. In 21 of the deaths the panels identified aspects of the conduct of the responsible adults as potentially contributory, including equal numbers (five each) in which lack of supervision or assault by a responsible adult contributed to the death. Further potentially preventable examples of lack of appropriate adult supervision included children not using seat belts whilst in vehicles, or not using helmets when cycling.

The twelve child deaths that resulted from motor vehicle collisions in the “zig zag” zone adjacent to pedestrian crossings suggests that greater awareness – both for child pedestrians and for drivers - of the hazards around such crossings might have important public health benefits.

The unexpectedly high number of deaths from suicide, and the relationship between alcohol and drug use and deaths from trauma and suicide raise further important issues of potential prevention. Surprisingly, many of the children who committed suicide were not previously known to mental health services, but, as noted below, there was a worrying lack of follow-up particularly by mental health services of children and families who had been referred but failed to attend appointments.

The broadly based approach – including the investigation of the precise circumstances of road traffic collisions by accident investigation teams, plus careful consideration of any preceding factors in the child – (e.g. behavioural problems, hearing difficulties, learning difficulties) – together with medical or social factors in the background emphasised the potential complexity of any interventions aimed at preventing such deaths.

Whilst direct potentially preventable contributions to childhood deaths by acts of commission or omission by healthcare professionals were unusual (total of five instances identified), indirect contributions from the organisation or provision of care were far more common. Many panels commented upon the frequency with which children who died had previously been identified as recurrent non-attenders or “DNAs” at hospital and community appointments. In this regard the practice of many hospital Trusts of insisting that no further appointments be sent to children who have failed to attend on two occasions requires urgent revision. Children seldom attend appointments without parents or carers, and thus failure to attend is seldom the fault of the child. It was clear from several case reviews that, despite the difficulties in doing so, additional attempts to make contact and maintain medical supervision of children who were recurrent non-attenders might have made a difference to the outcome.

As recognised by the perceptive and thoughtful young people consulted in the early stages of the project, the careful and thorough investigation of childhood deaths is likely to lead to greater insights into the nature, causes and potential prevention of such deaths, and the present study has confirmed this perception, and shed considerable light upon appropriate processes.

11. CEMACH Child Death Review and “Working Together”

Richard Congdon, Anne Aukett, Fiona Reynolds, Dawn Roberts

11.1 CEMACH Child Death Review and LSCB responsibilities in England under “Working Together”

The purpose of this section is to identify areas where the experience gained by CEMACH in carrying out the child death review (and its ongoing perinatal mortality surveillance system - see section 11.11 below) may be of value to LSCBs in England in fulfilling their new responsibilities under Chapter 7 of “Working Together to Safeguard Children”.

Under “Working Together” LSCBs, either working on their own or jointly with other LSCBs, are required to establish a local Child Death Overview Panel (CDOP). Most of the issues covered below will in practice be the responsibility of the CDOP acting as a subcommittee of one or more LSCBs. The section identifies both LSCB and CDOP roles as the responsibility of the LSCB.

The CEMACH Child Death Review applied confidential enquiry methodology in which independent expert panels review the case notes from adverse outcomes to assess whether there were avoidable factors. The results are aggregated to provide learning opportunities for those responsible for organising and providing care. LSCBs will collect data and carry out reviews to ensure that an appropriate local response and local learning have occurred. Appendix E describes in more detail the different responsibilities and processes involved.

Whilst recognising the significant differences between these approaches, there are some areas where the CEMACH Child Death Review may be helpful including:

- collection of information about each child death according to a nationally agreed minimum dataset
- reviewing data on all child deaths, including identification of public health issues
- in-depth evaluation of specific cases.

11.2 Datasets

Three datasets contributed to the total information collected for the CEMACH Child Death Review:

- notification dataset
- core dataset collected on all deaths and
- data collected in the Multidisciplinary Case Review Form (MCRF) for those cases subject to in-depth panel review.

It should be noted that, at the time of writing, the Department for Children, Schools and Families, had reviewed these data sets and their associated forms. Drawing on the CEMACH work and the findings from the Warwick University led study of LSCBs, DCSF has developed a set of templates for LSCBs to use when collecting information about child deaths in accordance with “Working Together”. CEMACH has been a key participant in this review.

11.3 Notification dataset

CEMACH regional offices collected a “notification dataset” with basic descriptive details. This provided information to exclude duplicate notifications and commence the collection of the core dataset, often from multiple sources. There was some local variation, but a notification dataset is set out below for illustrative purposes.



Box 11.1

Notification dataset

- Date of notification
- Caller identity
- Contact telephone no
- Name of child
- Sex of child
- Date of birth
- Date of death
- Place of death
- Contact tel no of place of death
- Doctor’s name
- Carer of child at time of death
- Brief summary of death
- Place of Birth
- Mother/Father/Carer name
- Home address
- Postcode
- GP name
- GP address and telephone number

The new ‘notification of child death’ template developed by DCSF has drawn on this dataset. It has been amended to include contacts with agencies such as children’s social care services, police and education. LSCBs may wish their person designated to be notified of all child deaths (paragraph 7.52, “Working Together”) to collate the required information on all child deaths.

11.4 Core dataset

11.4.1 Design

The CEMACH core dataset consisted of

- demographic and death certificate data
- previous medical /developmental history
- social circumstances
- circumstances if a “non-natural” death
- other relevant information related to local investigation and record keeping.

It was largely constructed as a series of stem questions which pointed to relevant supplementary questions for further detail where appropriate. It can be downloaded from the CEMACH website at www.cemach.org.uk.

The information in the core dataset enabled CEMACH to extract epidemiological information. This is similar to the following functions (paragraph 7.55 “Working Together”) of the LSCBs:

- “organising and monitoring the collection of data for the nationally agreed minimum dataset and
- identifying any public health issues... and their implications for both the provision of services and for training.”

The experience of using the CEMACH core dataset has assisted the development of the nationally agreed minimum dataset referred to in “Working Together”. The templates which will be used to collect the information required for LSCB purposes may however need more multi-agency information, for example details of schools attended and the involvement of other agencies, e.g. family centres, nurseries, youth offending services and voluntary organisations, along with more information about the family and other members of the household.

11.4.2 Ongoing review of core dataset

CEMACH and its predecessor body have, since 1992, collected a core dataset on neonatal deaths (i.e. deaths of babies from 0 to 28 days old - see section 11.11). This is amended and updated every year to ensure its continued relevance. In the same way, it is likely to be useful if the nationally agreed minimum dataset for child deaths required in “Working Together” were to have a similar mechanism for periodic update to respond to changing needs and circumstances.

11.4.3 Matching core data collection to the age of the child

As described more fully in section 11.11, CEMACH collects a different dataset of core information on neonatal deaths. This reflects the different circumstances and information needs for deaths at this age compared to the older child.

There are also, to a lesser extent, varying needs for information about deaths as the child gets older. Information about the maternal obstetric history and the birth becomes harder to gather and, usually, less relevant, the older the child. It is important to consider this in the design of the dataset. Those responsible for gathering the information may otherwise find themselves having to make considerable effort to obtain data of little likely relevance. The experience of the CEMACH Child Death Review was that parental and neonatal details became less fully completed for older children.

11.4.4 Collecting the data in the core dataset

Information for completion of the CEMACH dataset came from many sources, including general practitioners, health visitors, emergency departments, ambulance services, acute and community paediatricians, palliative care nurses, coroners’ officers, police, children’s social care services, schools and many other sources. Coordination of data collection through one committed and knowledgeable person, i.e. the CEMACH regional manager, was essential in facilitating this process.

11.4.5 Using the core dataset to provide epidemiological information

The CEMACH study covered up to approximately 30% of England, Wales and Northern Ireland. The total number of deaths on which information was collected was 957. This provided an opportunity to identify major epidemiological issues in child mortality as set out in Chapter 5 of this report. Collection of information on this scale assists in the identification of common themes requiring further investigation.

There are 150 LSCBs in England. A typical LSCB may experience around 30 child and neonatal deaths in a year. “Working Together” suggests that neighbouring LSCBs may wish to share a CDOP, as experience shows that the optimum sized population to be served should be greater than 500,000. Such an approach is helpful in enabling important local themes to be identified in analysing the deaths.

There would also be additional value if data collected by LSCBs for local purposes were analysed in a national system. This would enable local data to be reviewed within the context of national issues and trends.

11.5 Multidisciplinary Case Review Form dataset

The Multidisciplinary Case Review Form (MCRF) was used to both support in-depth review of individual cases and achieve aggregation of the results of in-depth reviews.

The MCRF was not intended to replace the professional expertise of those involved in the review. It was however helpful in providing a mechanism for ensuring that avoidable factors were identified and for structuring a discussion around such factors in an organised manner.

The additional data collected on an individual case via the MCRF as a result of in-depth review was included in the overall Child Death Review database. This meant that the information collected via the core dataset and that collected via the MCRF were held as a single overall record.

As a result of the CEMACH enquiry, experience has been gained of the MCRF as a tool for data collection. Modifications in the light of experience of panels may assist LSCBs in decisions on how best to gather information for in-depth reviews. If the results of such analyses were stored on a database with the core data on all deaths, this would assist LSCBs in identifying trends and extracting lessons from their child death review processes. It would, of course, be extremely powerful if a common format were used across the country to facilitate the aggregation of learning points at a national level from such in-depth local reviews.

11.6 Identification of deaths for further review

“Working Together” sets out a full process for detailed local review of all unexpected deaths (defined in Chapter 7.6 of that document), in order, inter alia, to assess whether the death may have been preventable and whether there were lessons to be learned. Section 7.50 of “Working Together” identifies the responsibility of CDOPs to support their LSCB in ensuring learning from all child deaths.

The CEMACH Child Death Review found avoidable factors in approximately half of the natural deaths falling outside “Working Together’s” definition of an “unexpected” death. These included deaths in hospital from natural causes as well as non-natural deaths. There are, therefore, many opportunities for learning and improving practice both from unexpected deaths and from deaths falling outside this definition. This finding clearly indicates that, for LSCBs to be as successful as they could be in identifying preventable factors, as many child deaths should be reviewed in as much depth as possible. This supports the statutory requirement in the Children Act 2004 that all child deaths should be reviewed and LSCBs should use the aggregated review findings to inform local strategic planning on how best to safeguard and promote the welfare of the children in their area.

11.7 Reviews of individual deaths

Multidisciplinary panel reviews of individual deaths, with access to case notes in addition to information from the core dataset, were essential for the identification of avoidable factors in the CEMACH study. The role of the chair was important in ensuring that all panel members were able to have their say and contribute to the development of a consensus about the case.

The range of professionals to be involved in reviews of individual deaths is described fully in “Working Together”. This issue has also been looked at in depth in the forthcoming Warwick University led study of “early starter” LSCBs²⁹. An observation from the CEMACH study on this aspect relates to the high number of deaths that occur in hospital. Should the designated paediatrician for unexpected deaths be a community paediatrician, he/she may find it helpful to draw on the expertise of a paediatrician with experience in the management of the relevant acute childhood disease.

Enquiry staff involved in obtaining information for panels found the emotional content of their work demanding and stressful at times and it is important to ensure that they are appropriately supported. This is likely to also apply to reviews carried out via LSCB processes.

11.8 Independence

Panel reviews for the CEMACH study, in common with most confidential enquiries, were conducted on a multidisciplinary basis completely independent of the geographical area in which care was provided.

This level of independence enabled enquiry panels to identify avoidable factors without concern as to any potential medico-legal implications, e.g. where the quality of clinical care may have been an issue. This is a key consideration for the review of deaths in hospital and/or from natural causes. The result is that confidential enquiries were able to identify avoidable factors in a high proportion of deaths.

It may not normally be practical for the local review processes set out in “Working Together” to attain the level of independence of the confidential enquiry process. In many situations, locally conducted reviews can be very effective in identifying shortcomings in care and the presence of avoidable factors.

It may nonetheless be worthwhile for LSCBs to keep under review whether there would be any benefits locally from enhancing the level of independence in their review processes. This would be relevant to deaths in hospital as well as in the community.

The CDOP Chair is required not to “be involved in providing direct services to children and families in the area” and may therefore be able to ensure that an appropriate emphasis is placed on the level of independence in the oversight of child deaths in a local area, particularly where the CDOP covers more than one LSCB.

11.9 Aggregation of themes at a local level

LSCBs, through their CDOPs, have responsibility for aggregation of the lessons learned from analysis of the core dataset on all deaths and reviews of individual unexpected deaths in their area.

Aggregation of results and identification of themes and lessons is a major and integral part of national confidential enquiry methodology. The principal mechanisms CEMACH used for this purpose in its Child Death Review were:

- an analysis of a core dataset for all deaths
- the use of a structured questionnaire in the MCRF used to gather common data from those cases that were subject to in-depth panel reviews
- a database specifically developed for the study and
- the input of the Clinical Director for the review who kept in touch with the in-depth reviews and had an overview of the whole process.

LSCBs may wish to use a similar approach to this to assist in enabling them to aggregate themes and lessons learned at a local level. The nearest match to the role of the CEMACH Clinical Director might be the designated paediatrician for unexpected deaths in childhood and/or the Chair of the CDOP.

11.10 A national perspective

CEMACH would welcome an opportunity to explore ways of integrating its national confidential enquiry work on child deaths with LSCB child death review processes. This could assist the development of learning from the review of deaths at both local and national levels.

Resources for national confidential enquiry work on child deaths are severely limited and permit only a small sample of child deaths to be reviewed. It would help CEMACH to make maximum use of the limited resource available to it, if it could access suitably anonymised information from the core dataset and full multi-agency notes collected by LSCBs. In return, CEMACH would be able to provide LSCBs with the opportunity, along with other stakeholders, to propose topics for consideration for confidential enquiry input to topic selection. Additionally, the findings of national confidential enquiries could be useful to LSCBs in analysing and interpreting their own local positions.

To take forward this idea, CEMACH could develop a brief proposal for such potential collaboration and would hope that such an initiative would be welcomed.

11.11 Neonatal mortality

Neonatal deaths (i.e. those between birth and 28 days) represent over 40% of all child deaths. They usually occur in hospital amongst babies who have never left hospital, although there are unexpected deaths in the community in this age range. In 2005, there were 2,149 such deaths in England. This would amount to an average of 14 neonatal deaths per LSCB. As part of its confidential enquiry contract with the NPSA, CEMACH carries out ongoing surveillance of these deaths. CEMACH provides reports for all NHS providers and neonatal networks to enable them to track their rates over time and compare themselves to others. Further there is a national annual report which brings together findings on important trends and enables focus topics to be explored where a particular priority or need emerges.

CEMACH collects a different dataset, via its “Perinatal Death Notification” (PDN) form, on these deaths compared to the dataset it developed for the Child Death Review for deaths of children aged over 28 days. The information needed to understand deaths in the first few weeks of life is usually very different to the information needed for deaths later in childhood. The dataset is available at: <http://www.cemach.org.uk/Programmes/Maternal-and-Perinatal/Maternal-and-Perinatal-Mortality-Surveillance.aspx>.

CEMACH has considerable expertise in the development of datasets and databases and in ensuring accurate and comprehensive data collection for neonatal deaths. CEMACH therefore believes that there needs to be further consideration of its role in this area and how CEMACH might support LSCBs in carrying out their functions in respect of neonatal deaths. The additional cost of liaising with LSCBs and PCTs to provide them with notification data on each death and of provision of periodic trend reports should be modest. Whilst it is essential with national data systems to ensure strong local ownership through appropriate networking and feedback arrangements, this service to LSCBs/PCTs could be part of a centrally mandated solution to minimise bureaucracy and administrative costs. This could work in tandem with the responsibility placed on all LSCBs in “Working Together” to ensure the ongoing review of all neonatal deaths in their area – and to carry out, where required, in-depth investigations of unexpected deaths or serious case reviews into neonatal deaths.

11.12 Northern Ireland

In Northern Ireland it is proposed that a regional Safeguarding Board for Northern Ireland (SBNI) will be established by statutory provision to make arrangements to safeguard the welfare of children and young people.

The arrangement proposed is similar to that adopted in England and Wales under the Children Act 2004 but is customised to take into account the particular needs of Northern Ireland. It will operate on the premise that safeguarding children requires a multidisciplinary approach, working together across agency boundaries and promoting an ethos of safeguarding communities supported by state intervention when necessary. Safeguarding in the context of the SBNI will go beyond the traditional concept of child protection responsibilities. As part of

its remit the SBNI will have a role in analysing information in relation to child deaths in Northern Ireland and co-operation with regional and national initiatives such as CEMACH will be a consideration of this area of work. It is anticipated that the SBNI will be established in shadow form at around the time of the publication of this report.

CEMACH will seek to liaise with SBNI in a collaborative way.

11.13 Wales

The Welsh Assembly Government is considering the implementation of an all Wales solution. A dataset will be collected on all child deaths. One or two overview panels will be established to include experts from all the relevant agencies including health, social care, police and education, which will review all child deaths in Wales.

CEMACH wishes to continue to develop the child health enquiry in Wales and to work in partnership with the all-Wales child death review system.



Invited commentary: The local authority perspective

Sarah Webb

Local authorities are responsible for ensuring that LSCBs are established and effective in their area. Local authorities are also the lead agency, together with police, in investigating child abuse. The local authority leads in child protection for our 30,000 children registered in England as subject to a multi-agency child protection plan³⁰ and over 100 children a year die from abuse or neglect². Some – but not most – child deaths result from abuse or neglect. The CEMACH pilot has found 26% of panel-reviewed child deaths as having “avoidable” factors and a larger number than previously expected, due to “neglectful” behaviour by adults. In this context, the local authority has an important role to play in the child death review process, albeit their responsibilities in the initial rapid response to child deaths will usually be less than that of health and police.

Local authority role

Local authorities incorporate a wide range of services of relevance in reviewing child deaths. “Children’s social care” now describes the work of local authorities in exercising their social services functions with regard to children. Such children’s services typically include family support and child protection services. Local authorities also provide services to adults such as mental health or social care, wherein information about adults responsible for children who die may be relevant to the child death review. Local authorities also provide support to schools, and their education services may have relevant information. Schools each hold their own recording systems which the local authority should be able to access but such systems will need to be agreed in advance between LSCBs, local authorities and schools.

In considering the role of the local authority, as for each agency in the process of child death review, an understanding of the complexity of the organisation will assist in ensuring appropriate participation. For example, in respect of the choice of case records to be submitted to the overview panel, or deciding the most appropriate staff to attend child death overview panels. The process of child death review is likely to work best if there is one point of communication for child deaths in each local authority to facilitate and coordinate appropriate information exchange (see paragraph 7.52, “Working Together” on the role of designated person to whom all notifications of child deaths should be sent).

Process issues: The local authority pilot panel experience

During the CEMACH pilot, local authority representatives formed part of the multi-agency panels. The process was very much eased by the support of CEMACH and multi-agency working was a positive experience in itself, in terms of improved understanding of roles and the realisation of more effective outcomes for children through joint working and the sharing of information. Local authorities did not appear to be involved in the compilation of information for the core datasets, which were appropriately health care led, but this may have resulted in some information being missing at that early stage.

It is regrettable that there were a large number of local authority records missing from the material examined during the panels. In local authorities the developing transfer from paper to electronic records should ease the practical difficulties in release of records but during the transitional phase disclosure problems may continue.

Even though the local authority representatives on the panels provided a unique social care and education perspective to the cases, their contribution was inevitably limited for some. For example in chronic illness cases, due to little understanding of the complex medical history. Nevertheless if, for efficiency, cases were grouped into subject areas (such as lessons for hospitals, road safety or child protection) and reviewed by smaller panels, then it would be at the expense of a potential child welfare / protection perspective.

The local authority perspective regarding “proportionality” and “evidence base” for outcomes in this pilot may well be shared with others. Is the time spent reading mounds of agency records on children who have died, proportionate to the time spent examining other aspects of the safeguarding children process? The answer may well currently be “No”, as we have yet to input more time on other aspects of safeguarding. Furthermore the pilot has focussed on one part multi-agency reviewing of the overall process, but it has not piloted whether LSCBs can make “S.M.A.R.T.” (**S**pecific, **M**easurable, **A**chievable, **R**ealistic and **T**imely) recommendations, nor whether, if the recommendations are indeed implemented, they will make a significant difference in preventing some child deaths. So although we might be hopeful that the recommendations can help to prevent deaths, as with the “back to sleep” campaign, the end product must be tested as this work develops, through government providing coordination, audit, research and support.

Findings of the pilot: Implications for the local authority

Many aspects of failure of care and poor decision making (e.g. no bicycle helmet/seat belt and lack of supervision to children) could constitute neglect. Like many other aspects of prevention, we should tackle this at an individual, as well as a societal / strategic / governmental level. The local authority could work together with health colleagues to educate the public in basic safety measures, as well as giving advice to individual, often disaffected, families. The local authority could also play a role, together with health visitors, schools nurses and teachers, in providing safeguarding education at an individual and community level for example in respect of co-sleeping and smoking in SUDI.

It became clear to local authority representatives during the study that there is no easy system to choose cases to prioritise for review. Whereas we previously focussed upon deaths which were unexpected or unexplained, experience taught that it was difficult to predict which cases would contain lessons to reduce deaths or significant “avoidable” factors contributing to the deaths.

For local authority staff working with vulnerable children, suicide - of which there were a staggering 26 cases is another area in which social care and other professionals can play a role in support and prevention.

The role of LSCBs is widening almost on a monthly basis, with government advocating that their new guidance on a broad range of issues from knife crimes to “e safety” should fall to the remit of LSCBs. In many respects this is to be welcomed, just as the widening of the term “child protection” into “safeguarding” is a logical step. But in being clear about accountability and responsibility for safeguarding matters, such as child death reviewing, we must differentiate the separate but related functions of LSCBs (coordinating, safeguarding and ensuring effectiveness) compared to Children’s Trust Boards (who commission services for children). As “Working Together” states in respect of safeguarding, “The LSCB is not ... an operational body or one which delivers services to children ... the children’s trust has a wider role in planning and delivery of services”. If Child Death Overview Panels make child safety service recommendations to Children’s Trusts, or to other specific bodies such as Strategic Health Authorities, they will need to firstly agree the nature of that relationship in terms of appropriate requests and responses.

Section 11 of the Children Act 2004 and S175 of the Education Act 2002 place a duty on “..organisations and individuals to ensure that their functions are discharged with regard to the need to safeguard and promote the welfare of children”. This is the statutory basis for our safeguarding work currently and could provide a lever for organisations to comply with recommendations for actions and services to prevent child deaths.

Sufficient resources must be provided by government if LSCBs are made to adopt this wider safeguarding role, as previously they have depended upon small pooled budgets for minimal running costs to respond to child abuse and neglect.

There is a need for consistency and standardisation across LSCBs and Child Death Overview Panels in terms of terminology, for example, a child death case discussion is not a strategy (S47 consideration) meeting. Also in terms of recording - how and by whom, will information gathered at the various stages be recorded and where will that be held and retained, under which recording policy.

Independence is an important issue for LSCB agencies including local authority staff. “LSCBs must be able to challenge organisations as necessary, and to speak with an independent voice”² During panels, despite the anonymisation of records, when the identity of an institution or professional was (very occasionally) inadvertently recognised, this rendered the panel members contribution more difficult and less objective.

Accountability is an issue requiring careful clarification. To whom are the panels’ decisions on contributory factors accountable? And who is responsible if recommendations for prevention are made, but not carried through (and, for example, children continue to die from “preventable” road accidents)?

Invited commentary: The Police perspective

Richard Henson

During the planning of policing operations and in our response to critical incidents the preservation of life is a priority of policing. The investigation of death, be it homicide, road traffic related and even the sudden and unexpected cases, consumes significant policing time and resources.

Police have developed extensive processes and skills in high profile areas such as murder. A corresponding investment has been made in developing a professional and systematic national approach that is contained within the imaginatively titled, Association of Chief Police Officers (ACPO) 'Murder Manual'. In recent times we have also collated intelligence and invested substantially in analytical product to make positive interventions into specific types of homicide and criminal violence. An example being recognising the links between domestic violence and homicide, that has seen the implementation of new strategies to prevent and reduce these terrible incidents.

The investigation of childhood death, particularly those termed "Cot Death", "SIDS" or "SUDI" (Sudden Unexplained Death in Infancy) presents police with different challenges. Striking a balance between a forensically driven criminal investigation and a sensitive sudden death enquiry on behalf of the Coroner created a genuine dilemma. There is no typical circumstance and responding officers were often totally unaware of prevailing social and medical circumstances. Some would be aware of high profile cases from the media where "Shaken Baby Syndrome" was a factor. More recently, highly publicised appeals have focussed attention upon the complexities of this area and reduced the confidence of many professionals. These factors compounded the overall situation that was at best ad hoc and inconsistent in both response and practice. Although some guidance was available prior to the publication of the report of the working group chaired by Baroness Kennedy, it has now been updated.

ACPO guidance has been published and accepted nationally and investment has been made in training and ensuring that the police response to SUDI is enlightened, sensitive and appropriate. Strategic forces such as the Metropolitan Police Service developed a coordinated response (Project Indigo) between its Child Abuse Investigation Command and partners. Guidance identified the level of officers suitably qualified to investigate these incidents. Considerable thought and consultation has been made into developing protocols, materials and occupational support to this service. This has resulted in a systematic open-minded investigative method.

The keystone of these investigations is the partnership approach. Operational experience and feedback confirm the value of this joint investigation method in collecting information from the carers and parents and conducting joint home visits. The relationship with health professionals is particularly important in the early stages of SUDI investigations especially in interpreting the emerging information that informs the decision making process. Unfortunately the availability of health professionals to fully engage in the joint home visit has been inconsistent. The debate as to who from health should attend and when, is still very much open. Without entering the intricacies of commissioning, funding and medical role, I would like to reassert that in those open cases where there is no obvious major crime scene, police investigators wish to visit the place of the child's last residence at the earliest opportunity. Feedback from colleagues is almost universal in wishing to conduct the visit with an experienced health professional. The rationale is that in these tragic and unusual circumstances, a multidisciplinary approach provides the best opportunity in relation to the examination of the major environmental influences on the child immediately prior to death. It also provides the most professional approach for continuing support and explanation to the family, interpretation of medicines and sleep scenes and ultimately identifying the reason why the child died.

Fast-time sharing of information, joint interviewing of carers and joint home visits are all part of a professional investigation that seeks to establish the factors that have contributed and caused the death. This coordinated approach also has the benefit of providing the grieving families with the most appropriate response to their circumstances and can identify particular matters where support services are required.

That has not only provided grieving families with a professional approach but also allowed the collection of data and the identification of “high-risk” factors.

Almost in parallel to the response to SUDI, the Children Act 2004 established Local Safeguarding Children Boards with a statutory duty for agencies to cooperate and proactively safeguard children in their areas. In particular, the response to childhood death was included and the need for a partnership approach enshrined.

The requirements in relation to the multi-agency rapid response to the unexpected death of a child are being developed. Most progress has been made in relation to SUDI. Other areas of unexpected childhood death, mostly in non-hospital settings such as homicide, suicide and road traffic collisions will see variations in the operation of rapid response especially in cases where forensic scene examination is required, particularly in major criminal investigations, where the rapid response will be unlikely to follow the route of multi-agency home visits and paediatric coordination. The challenge for the police service and the LSCB in these cases will be to facilitate a comprehensive and timely information exchange and to identify other children in need or at risk as a result of the incident.

A strategic overview of all child deaths is a welcome development and the police service acknowledges the core membership role it has on the panels. There is already a culture of review in existence within policing, particularly in the context of homicide and other serious crime. This can run in parallel to the investigative process and Senior Investigating Officers are familiar with its process and benefits and can bring this transferable as a skill to the child death overview panel. Police also will be able to provide specialist members where required for cases where factors such as road traffic collisions are present.

Consistency and credibility are essential if this overview activity is to be valuable in terms of achieving safeguarding objectives. Four key outcome areas have been identified and overview must be undertaken with these in mind.

1. Improving understanding of patterns of childhood death;
2. Improving the response to childhood death;
3. Improved recognition of neglect or abuse leading to childhood death and;
4. Improved interagency working to prevent childhood death.

The CEMACH Child Death Review has proved to be a timely project. I was fortunate to be able to participate on one of the panels and my experience of the process was positive. The highly structured process following The ‘Assessment of Contributory Factors’ booklet encouraged the panel to remain focused with stimulating discussion and explanation before agreement of scoring and written comment. The role of the chair was pivotal to facilitating the process but not in such a way as to either dominate or dictate decisions. The direct contribution of experts, specialists and experienced practitioners from relevant professional backgrounds ensured that any myopic and protectionist tendencies were marginalised. This professional multidisciplinary approach to reviewing the cases was extremely relevant and gave the panel the confidence to challenge, identify and discount factors and to produce credible outcomes in recommendations for the particular cases we reviewed.

Some of the recommendations would stand alone but I feel that some would obtain more weight if they were features of other similar reviews and aggregated in regional or national conclusions.

It is important for panels to remind themselves of their role, which is not to reinvestigate the death in a tribunal style setting but to identify areas of risk to children and to use the findings to recommend solutions and best practice to reduce areas of critical risk to children.

The establishment of a National Core Dataset and some fundamental criteria for case review are critical areas to agree upon so that LSCBs can prioritise and implement recommendations with confidence.

The CEMACH panels had the advantage of cases being anonymous and chosen from regions where the panel membership was not based. Additionally, not dealing with neonatal cases reduced around about 40% of the type of cases that a LSCB panel would need to consider. Even so the findings of the panels that approximately 30% of the cases contained avoidable factors of such significance is remarkable. Without the space to delve more deeply into this finding I will simply use it to link with the rationale behind the establishment of LSCBs and their responsibility to develop more proactive and sophisticated alliances to safeguard and protect children.

The police service has changed to embrace these new developments. We are committed to learning from experience and recently have developed partnerships and an approach to better respond to childhood death that would have been unthinkable only a few years ago. The challenge now is to realise the potential that the child death overview panels will produce in relation to reducing untimely and unnecessary death in childhood.

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Index of figures

Figure number	Title	Page number
<i>Figure 3.1</i>	Summary of CEMACH Child Death Review pilot study design.	8
<i>Figure 5.1</i>	Age distribution of all child deaths in the core dataset; United Kingdom selected regions: 2006.	18
<i>Figure 5.2</i>	How the final core dataset of 957 cases was derived.	19
<i>Figure 5.3</i>	Age and gender distribution of all children in the core CEMACH dataset; United Kingdom selected regions: 2006.	20
<i>Figure 5.4a</i>	Child death rate per 10,000 live children: children aged 28 days to up to 17 years 364 days; United Kingdom selected regions: 2006.	21
<i>Figure 5.4b</i>	Child death rate per 10,000 live children: children aged 15 to 17 years 364 days; United Kingdom selected regions: 2006.	22
<i>Figure 5.5</i>	Age distribution of child deaths by mode of death; United Kingdom selected regions: 2006.	24
<i>Figure 5.6</i>	Child death rate per 10,000 live children by ethnic group; selected England regions: 2006.	25
<i>Figure 5.7</i>	Number of cases by deprivation quintile (based on postcode residence); selected England regions: 2006.	26
<i>Figure 5.8</i>	Percentage gender distribution of non-natural deaths; United Kingdom selected regions: 2006.	26
<i>Figure 5.9</i>	Age distribution of children who died from Road Traffic Accidents (RTA); United Kingdom selected regions: 2006.	27
<i>Figure 5.10</i>	Distribution of RTA deaths by time of collision and age of children; United Kingdom selected regions: 2006.	28
<i>Figure 5.11</i>	Gender distribution of deaths from drowning; United Kingdom selected regions: 2006.	29
<i>Figure 5.12</i>	Deaths in children classed as Sudden Unexplained Death in Infancy (SUDI) by age of child; United Kingdom selected regions: 2006.	30
<i>Figure 5.13</i>	ANZPIC Classification of deaths by age; United Kingdom selected regions: 2006.	31
<i>Figure 5.14</i>	Seasonal distribution of deaths classified to occur as from respiratory causes by ANZPIC; United Kingdom selected regions: 2006.	32
<i>Figure 5.15</i>	Age distribution of child deaths where there was a congenital condition at the time of death; United Kingdom selected regions: 2006.	33
<i>Figure 6.1</i>	Proportion of children who had been seen in primary care in the three months before death; United Kingdom selected regions; 2006.	39

Index of tables and boxes

Table/box number	Title	Page number
<i>Table 5.1</i>	Estimated death rate per 10,000 live children by region; children aged 28 days to 17 years 364 days; United Kingdom selected regions: 2006.	21
<i>Table 5.2</i>	Location of deaths in hospital	22
<i>Table 5.3</i>	Cases which were reclassified from a hospital location to a community location	23
<i>Table 5.4</i>	Causes of non-natural deaths: Children aged 28 days - 17 years and 364 days: United Kingdom selected regions: 2006.	27
<i>Table 5.5</i>	Comparison of suicide rates as ascertained by ONS/NISRA and CEMACH Child Death Review	29
<i>Table 5.6</i>	Age distribution of deaths involving infection	32
<i>Table 5.7</i>	Age distribution of children with cerebral palsy: Children aged 28 days to 17 years and 364 days: United Kingdom selected regions: 2006.	34
<i>Table 6.1</i>	Primary care involvement in child deaths: Children aged 28 days to 17 years and 364 days: North East England: 2006.	40
<i>Table 6.2</i>	Avoidability in relation to primary care: Children aged 28 days to 17 years and 364 days: United Kingdom selected regions: 2006.	46
<i>Table 7.1</i>	Comparison of Core and Panel Datasets: Children aged 28 days to 17 years and 364 days: United Kingdom selected regions: 2006.	47
<i>Table 7.2</i>	Summary of 119 panel determinations, grading the most avoidable factor by the definitions in Chapter 3.	48
<i>Table 7.3</i>	Within-hospital locations of death (CEMACH definition panel cases): Children aged 28 days to 17 years and 364 days: United Kingdom selected regions: 2006.	49
<i>Table 7.4</i>	Congenital or chronic illnesses relevant to the death: Children aged 28 days to 17 years and 364 days: United Kingdom selected regions: 2006.	50
<i>Table 10.1</i>	Proportion of childhood deaths certified as being due to trauma (accidental and non-accidental) in the USA in 2004 and in Belarus 1980-2000.	79
<i>Box 11.1</i>	Notification dataset	83



Appendix A

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Appendix B

CEMACH Child Death Review core dataset

The core dataset is available to download via the CEMACH website www.cemach.org.uk.

Appendix C

CEMACH Child Death Review Panel Proforma

The multidisciplinary review panel proforma is available to download via the CEMACH website www.cemach.org.uk.



Appendix D

Guidance for Doctors Certifying Cause of Death

Title	Guidance for Doctors certifying Cause of Death	October 2007
Version	1	Review date: October 2009

Referring Deaths to the Coroner

If you are the doctor in attendance at or immediately after the death of a child, you are required to examine the child and confirm (“certify”) that life is extinct. This is required whether or not the death is to be reported to the Coroner.

The following categories of deaths should routinely be referred to the Coroner:

1. You suspect death may have been due to or contributed to by: Accident, suicide, injury, poisoning, violence, neglect, industrial disease (even if the contributory event occurred a long time ago – e.g. a patient in hospital for several months after a near-fatal episode of trauma, who subsequently dies of an infection, or a patient who dies of complications of quadriplegia from a motorcycle accident 20 years ago – these deaths must be reported to the Coroner).
2. Deaths which are unexpected, or for which the cause is not yet known
3. Deaths occurring during an operation, or before full recovery from anaesthesia

If you are at all uncertain as to whether or not you should certify, you should discuss the case with the Coroner before issuing the medical certificate of cause of death (MCCD).

You may only ever issue a medical certificate of the cause of death if you were (one of) the doctor(s) who cared for the patient during the illness from which they died. If you have **neither** seen the patient within the last 14 days **nor** seen the body after death, you need the Coroner’s permission before you can certify.

If you are considering making a referral to the Coroner it is most important that you do not ask the parents for permission to carry out a post-mortem examination before doing so, as the Coroner may order a post mortem examination even if the parents have refused consent.

How to complete the cause of death section – part 1

- On line 1(a) record the immediate cause of death. It can be the sole entry in the cause of death section if that condition is the only condition causing death e.g. meningococcal septicaemia
- On line 1(b) record the disease, injury or complication that gave rise to 1a.
- If 1(b) in turn resulted from a further condition, record that condition on line 1(c)
- The MCCD has 3 lines in part 1 for the sequence of events leading directly to death. If you want to include more than 3 steps in the sequence you can do so by writing more than one condition on a line, indicating clearly that one is due to the next
- The *lowest* entered record should document the event/condition that initiated the fatal sequence. The lowest entered record will have caused all the conditions on the lines above it.
- The condition entered on the lowest line of part 1 is usually selected as the *Underlying Cause of Death* if the certificate has been filled out correctly. The underlying cause is used as the basis for most routine statistics. ONS codes all of the causes on the certificate, and this multiple cause data is used for some statistical purposes (for example the number of deaths to which MRSA contributed) and can be made available for research within ethical and confidentiality constraints.
- For live-born infants dying within the first 28 days of life, a different certificate is required.

How to complete the cause of death section – part 2

Record all other diseases, injuries, conditions or events that contributed to the death, but were not part of the direct sequence, in Part 2.

Results of investigations waited

If you know the disease that caused your patient's death e.g. bacterial meningitis, but are still awaiting results of laboratory investigations for further detail, you can complete the MCCD. However, you should indicate that information may be available later. This can be done by circling '2' on the front of the MCCD for autopsy information or by ticking box 'B' on the back for results of investigations.

Common errors

1. Avoid terminal events, modes of dying and other vague terms. The immediate cause of death should not be the mechanism of death e.g. cardiac or respiratory arrest, syncope or shock
2. Avoid organ failure (e.g. Congestive Cardiac Failure, renal failure) alone. Always report their aetiology on the lines below.
3. Avoid 'Natural Causes' and 'Sepsis'.
4. Never use abbreviations or symbols.
5. If the case is discussed with the Coroner and he declines involvement, then a consented PM may still be requested by the clinician.
6. When a hospital PM is requested, then the involved clinician may still complete a MCCD before the PM, and circle '2' on the front of the certificate as indicated above.

Reference

Guidance for Doctors certifying Cause of Death; Office for National Statistics Death Certification Advisory group, April 2005.

Appendix E

Analysis of CEMACH & LSCB Child Death Reviews

Issue	CEMACH	LSCB
Area covered	CEMACH carries out enquiries at national, regional and local level. The Child Death Review covered Wales, Northern Ireland and three English regions.	CDOPs recommended to cover at least 500,000+ people.
Dataset	Developed for feasibility study and referred to in “Working Together” - would expect to further develop for any future studies.	Required to use a nationally agreed minimum dataset. This is currently being developed by a group appointed by the DCSF, including participants in the CEMACH study.
Selection of cases for more in-depth review	For this pilot study, selected to ensure spread geographically and by age of child. (Future child health enquiries likely to be topic based with emphasis on issues where child deaths considered likely to be avoidable.)	In effect, three main types: - Serious case reviews - Reviews of “unexpected deaths” as defined by “Working Together”. - Reviews of other deaths deemed locally to merit in-depth review.
Review of individual deaths	Multidisciplinary enquiry panel. Use of structured questionnaire to assist panel to decide if death “avoidable”, “potentially avoidable” or “unavoidable” and to provide basis for aggregation of avoidable factors. This was the “Multidisciplinary Case Review Form”(MCRF), available from the CEMACH website on www.cemach.org.uk . Consensus conclusions about any avoidable factors relevant to the death.	1. Serious case review if necessary – as detailed in Chapter 8 of “Working Together”. 2. Review of unexpected deaths including multidisciplinary case discussion convened and, as described in Chapter 7 of “Working Together”, chaired by the designated paediatrician for unexpected deaths with site visit for unexpected deaths in non-hospital settings. 3. Other in-depth reviews.
Independence of review process	Cases put into a national pool and then reallocated to a different region to the one in which the death occurred to ensure complete independence.	Review processes are local and units and local providers may be reviewing their own cases.
Access to information	Case notes only with copies of any internal investigations requested.	Responsibility for LSCB to “collect and analyse information about each (child) death” is set out in S.I. 2006 No 90.
Confidentiality	All case notes anonymised; all reports anonymised (but see “cause for concern”).	Review and reporting on individual case not anonymous.

<p>Aggregating lessons for general application</p>	<p>Aggregation of lessons from review of individual deaths is a central aspect of confidential enquiry methodology.</p> <p>Public health lessons are derived from analysis and interpretation of findings from common dataset for all deaths and the MCRF.</p> <p>Avoidable factors mainly derived from analysis and interpretation of information from the MCRFs completed for each case reviewed by panel.</p> <p>Identification of themes based on review of many cases.</p>	<p>LSCB has responsibility for establishing CDOP to undertake an overview of all child deaths in their area and to pull together patterns and trends in local child mortality and lessons to be learned.</p>
<p>Key roles for collating findings</p>	<p>Oversight of all cases with assessed avoidable factors by Clinical Director. Key role in interpreting findings to identify themes.</p>	<p>LSCB Chair, CDOP Chair, designated paediatrician for unexpected deaths.</p>
<p>Cause for concern</p>	<p>Scope in exceptional circumstances for Clinical Director to get back to provider and suggest local review of case.</p>	<p>CDOP to refer back to LSCB Chair where, on the basis of available information, further enquiries may be needed.</p>







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