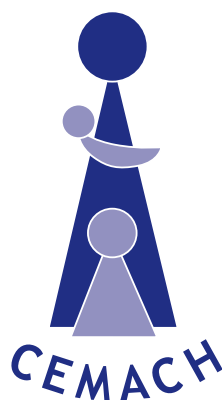


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# Confidential Enquiry into Maternal and Child Health

*Improving the health of mothers, babies and children*



## CHILD HEALTH ENQUIRY

## CHILD DEATH REVIEW

## Report on Case Ascertainment and Data Acquisition

October 2007

## CEMACH CHILD HEALTH ENQUIRY CHILD DEATH REVIEW

### Executive Summary

- CEMACH is studying the feasibility of applying confidential enquiry methodology in the sphere of child health. A Child Death Review was conducted in 2006 where data was collected on all child deaths in the south west, west midlands and north east of England, Wales and Northern Ireland.
- The study used local networks both to become aware of cases and gather the data. In this report we present the levels of case ascertainment and data acquisition achieved, which in general were high. However completion of the full dataset requires waiting for statutory processes to be completed (e.g. police investigations, coroners inquests and post mortems where necessary).
- There are similarities between this study and the legislated remit of Local Safeguarding Children Boards which commences in April 2008. The core dataset developed by CEMACH for its study should provide a helpful foundation for the content of the dataset collected by LSCBs as part of their national statistical return. However some further adaptation would be beneficial.
- Most significant would be adaptations to enable the core dataset to be used to highlight “unexpected” deaths as defined in “Working Together to Safeguard Children” (HM Government 2006) for the purpose of selecting cases for in-depth review.
- We also compare the nature and volume of similar work in relation to infants that die before 28 days of age. LSCBs may wish to refer to CEMACH’s ongoing perinatal mortality surveillance work: <http://www.cemach.org.uk/Programmes/Maternal-and-Perinatal/Maternal-and-Perinatal-Mortality-Surveillance.aspx> in considering their data collection arrangements on the deaths of children from birth to 28 days in order to minimise duplication of existing data collection systems. Our specific recommendations for LSCBs are set out on pages 9 and 10 of this report.
- The full report on the Child Death Review will be produced in April 2008.

## Introduction

CEMACH is performing a Child Death Review as part of a programme of activity commissioned by the National Patient Safety Agency (NPSA). The Child Death Review is a feasibility study on the use of national confidential enquiry methodology in respect of the deaths of children. The aim is to identify lessons for general application from assessing individual cases. The Child Death Review involved the collection of a core dataset on all child deaths that occurred during the calendar year 2006 in five regions (South West, West Midlands, North East, Wales and Northern Ireland). Up to 150 of these, selected from across the regions and age ranges involved in the study, will be subject to multidisciplinary panel review.

Local Safeguarding Children Boards (LSCBs) were legislated for in the Children Act 2004. Their function is fully explained in “Working Together to Safeguard Children” produced by HM Government in April 2006. In addition to conducting serious case reviews and coordinating with coroners’ inquests and police enquiries, LSCBs are required to host Child Death Overview Panels which will collect data on all deaths and assist the LSCB in investigating all “unexpected” death(s) from April 2008. 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” (“Working Together to Safeguard Children” HM Government 2006).

CEMACH has endeavoured to coordinate reports from the Child Death Review so that they can be of maximum use to Local Safeguarding Children Boards. However since the Child Death Review was already running when “Working Together” was published, the CEMACH dataset will need further tailoring in order to best meet the needs of LSCBs. “Working Together” requires a nationally agreed minimum dataset to form the basis of a new statistical return to be made by LSCBs and the CEMACH dataset is under evaluation in this regard by the Department for Children, Schools and Families. To this end we report here upon:

- the ease of case acquisition of the CEMACH dataset using the method we have adopted (local networks)
- the completion rates of each component of the dataset

and make recommendations for LSCBs based upon the experience of conducting the Child Death Review.

The full report of the CEMACH Child Death Review will be issued in April 2008.

### Method

Data for the Child Death Review were gathered by the CEMACH regional managers using clinical contacts in each hospital in their region and a network of other local contacts that they established. This typically included coroners, police (including youth offending teams and prisons), other emergency services, health and safety executives, social workers and general practitioners. Local regional managers also trawled through local newspapers and other media sources in attempts to ensure comprehensive case acquisition. The local regional managers were assisted by voluntary regional clinical leads who helped convene the multi-disciplinary panels and assisted the liaison with local LSCBs.

For patients aged 29 days to 17 years and 364 days, when the regional manager became aware that a death had occurred, basic descriptive details (the “Notification dataset” – Table 1) were recorded and the regional contacts were then used to assist in completing the core dataset.

**Table 1: Notification Dataset**

Date of Notification	Doctor's Name
Caller Identity	Carer of Child at time of death
Contact Telephone No	Brief Summary of death
Name of Child	Place of Birth
Sex of Child	Mother/Father/Carer Name
Date of Birth	Home Address
Date of Death	Post Code
Place of Death	G.P Name
Contact Telephone No of place of Death	GP Address and telephone number

The core dataset consists of:

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

It is largely constructed as a series of stem questions which point to relevant supplementary questions for further detail where appropriate. Copies are appended to the first interim report available at: <http://www.cemach.org.uk/Publications/Child-Health/Child-Death-Review.aspx>.

These data were entered onto the CEMACH database regionally and analysed centrally. The analysis included a cross reference against ONS death registration data to assess the level of case ascertainment. Deaths occurring before midnight on the 31<sup>st</sup> December 2005 and after midnight on the 31<sup>st</sup> December 2006 do not form part of the analysis. The database was closed for the purposes of this interim analysis (and report) on the 31<sup>st</sup> May 2007.

## Results

### *How many deaths did CEMACH discover?*

Table 2 shows the number of cases notified by the regional CEMACH teams, and compares this to ONS data for 2004 and 2006 (deaths of child residents within those regions).

**Table 2: Numbers of deaths by region involved in the Study**

Region	ONS 2004 deaths in children 28 days to 18 yrs resident in the region	Deaths in 2006 Notified by regional Child Death Review team	ONS 2006 Currently registered Deaths of Resident Children
North East	170	181	32
Northern Ireland	105*	101	71
South West	220	243	80
Wales	170	169	99
West Midlands	330	266	184
<b>Total</b>	<b>995</b>	<b>960</b>	<b>466</b>

\*ONS does not collate data from Northern Ireland

### *What proportion of the total number of deaths did CEMACH know about?*

Table 2 shows lower numbers of deaths in the west midlands than might have been expected. Data acquisition may have been poorer there due to the late entry of that region into the study. Other regions had benefited from a run up to the study in late 2005 during which clinical networks were established. The system of local networks allows notification of deaths before registration and hence is quicker than notification to ONS. Nevertheless completion of the dataset requires data dependent upon other statutory processes such as police investigations, coroner's inquests and post mortems.

### *How well did CEMACH complete the dataset?*

In the first interim report relating to this study, the database relating to deaths occurring in the first quarter of the study was presented as it stood some four months later. For this report a copy of the database was used which related to the entire year of data collection and which closed 5 months after the last possible eligible entry into the study. We now report much greater data completion rates for the study as whole (Table 3) than those in the first interim report.

**Table 3: Completeness of data collection**

	Notification only			In progress		Core data set complete	
	Total	n	%	n	%	n	%
First interim report	242	86	35.5	70	28.9	86	35.5
This report	960	17	1.7	92	9.6	851	88.6

The database included a field which was used to indicate whether the regional manager felt that data collection in that case was complete (all relevant data ascertained and entered). This helps with the distinction of blank fields where data is known not to exist, from those where data is thought to exist but has not yet been found out. At the time that the database was closed for analysis, data collection in each case could therefore have been in one of three states of completion:

- Only notification data available
- Some data entered but the data entry was not considered complete when the database was closed for the preparation of this report
- All relevant data had been ascertained and entered into the database by the time it was closed for the preparation of this report.

This explains why some elements in the dataset have been less comprehensively determined than others. The completion rates are summarised in the appended table (appendix 1). The intention is to inform expectations for these variables, should they be included in any future national statistical return (assuming that future data collection would be based upon comparable methods to those used by CEMACH in this study).

In general, completion rates for the variables within the dataset are high, particularly for elements relating to medical and developmental history. Notable exceptions are parental and neonatal details which may not have been considered relevant by clinicians in all cases and therefore may not have been present in the documents reviewed. Substantial amounts of data are available even in cases where the researchers had not signed the data off as “complete”. In such cases, recent medical history, social circumstances and coroner / other post mortem procedures are noticeably less complete than the other variables.

### *How accurate is the data CEMACH collected?*

The analysis of the dataset will include a variety of “cleaning” procedures including contextual checks and other data validation procedures. The impact of these will be presented, along with the results of the analysis, in the final report.

## Relationship of the CEMACH Child Death Review to “Working Together to Safeguard Children”

### *Issues common to CEMACH and “Working Together”*

The main areas in “Working Together” where the work of CEMACH may be most helpful to LSCBs are in sections 7.50 - 7.56. These cover the responsibility of the Child Death Overview Panels to review the deaths of all children in the area for which they are responsible.

The results of the CEMACH multidisciplinary panel reviews will form part of the final report of our enquiry in April 2008. However this report on case ascertainment and data acquisition is particularly relevant to the responsibility of the Child Death Overview Panel to:

- Collect and collate an agreed minimum data set and, where relevant, seek information from professionals . . . (7.55)
- Organise and monitor the collection of data for the nationally agreed minimum data set, and make recommendations (to be approved by LSCBs) for any additional data to be collected locally (7.55)

### *Aspects specific to CEMACH project*

There are some differences between the CEMACH project and the remit of Child Death Overview Panels (CDOPs).

- CEMACH has a background in health. Whilst we have attempted to reflect the needs of other agencies involved in the welfare of children, CEMACH acknowledges that there may be limitations in how well we have met those needs.
- CEMACH’s work is confidential. By contrast Child Death Overview Panels may not be able to work and report anonymously in this way.
- Collaboration with the CEMACH Child Death Review is largely voluntary. Some of the challenges posed by working on a voluntary basis may not be shared by LSCBs whose function is legislated.
- The CEMACH Child Death Review has been on deaths of children from 28 days to 18 years whereas CDOPs will cover all child deaths. Deaths between birth and 28 days of life will represent a significant part of the CDOP workload (e.g. 43% in 2004 in the regions involved in the CEMACH Child Death Review).

**Table 4: Number of Deaths in the Child Death Review vs Number of Deaths in the Perinatal survey for calendar year 2004 by region involved in the CDR.**

Region	Neonatal Deaths 2004 (Perinatal Death Review CEMACH)	Annual deaths in 2004 amongst children 28 days to 18 yrs (ONS)	Ratio of number of deaths neonates: older children
North East	89	170	1:1.9
Northern Ireland	81	105*	1:1.3
South West	165	220	1:1.3
Wales	98	170	1:1.7
West Midlands	304	330	1:1.1
<b>Total</b>	<b>737</b>	<b>995</b>	<b>1:1.4</b>

\*ONS does not collate data from Northern Ireland

- It should be noted however that CEMACH has an existing, well-established and quite separate surveillance programme on deaths up to 28 days of life. This programme has its own dataset and annual national report including regional and trust-specific analyses. A copy of the dataset is available at: <http://www.cemach.org.uk/Programmes/Maternal-and-Perinatal/Maternal-and-Perinatal-Mortality-Surveillance.aspx>. The majority of these deaths occur in hospital.
- The CDOPs may need the core dataset they use to help identify the cases which should be subject to more in-depth review. The CEMACH dataset was not designed for this purpose. Cases for more in-depth review in this study were selected evenly from defined age groups in the five regions involved rather than because the deaths, at first sight, gave any cause for concern.



## Recommendations for a National Statistical Return in Relation to Local Safeguarding Children Boards.

We expect to be able to make further recommendations that would be of interest to LSCBs when we issue our report on the Child Death Review in April 2008. This will include the results of our analysis of the CDR dataset. At this stage we have a number of recommendations in the light of “Working Together” and based upon our experience of case ascertainment and data acquisition in the CEMACH CDR.

1. “Working Together” defines an unexpected death in terms of the time interval before death during which death could be anticipated. In this respect data submitted at registration (the time interval between onset and death on the medical certificate of the cause of death) is not reproduced in the CEMACH core dataset. This omission should be corrected.
2. The CEMACH Child Death Review working group have found the core dataset, as published, to be somewhat limited in collecting potentially useful information in relation to primary care. To this end additional work is being conducted which will be presented in the final report. At this stage we would recommend the collection of additional data items such as:
  - whether the child was registered with a GP
  - for deaths due to disease, how many attendances / visits were made by the primary care team in the 30 days prior to the death.
3. CEMACH experience and expert advice suggests that it is necessary to collect a different dataset for neonatal deaths (i.e. those occurring within the first 28 days of life) than that adopted for the Child Death Review. The factors commonly involved with deaths of neonates tend to be different from those involved with older children. It is likely that LSCBs will need to collect different data for such deaths to ensure the maximum opportunity to learn from these deaths.
4. Case acquisition (“notification”) using the local networks is quicker than through registration data provided by ONS, principally because registration may be appropriately and justifiably delayed by post mortem processes, coroner’s enquiry, police investigation or where death occurs overseas. However the completion of the core dataset is necessarily and inevitably delayed until these other processes are complete. Non-natural deaths (which are all, at some level, avoidable) are easily recognised from both the notification and the core datasets before the latter is completed in its entirety. LSCBs may benefit from having their own brief notification dataset to enable rapid reporting of child deaths and to start the process of completion of the full core dataset. Registration data may then be valuable at a later stage for checking whether full ascertainment of child deaths has been achieved.
5. Unexpected deaths relating to hospital care are only really teased out through multidisciplinary panels. It is considered essential that clinicians with the relevant expertise are involved in the selection of these cases.

6. The diversity of causes of death in childhood and the variation in workload between LSCBs mean that nationally aggregated data and local feedback are essential if the benefits of LSCBs are to be realised.
7. LSCBs may wish to consider developing the core dataset to enable it to be used to provide markers for cases that should be subject to more indepth review.
8. We found that the knowledge and experience gained by our regional managers, covering populations in excess of 1.5 million, were valuable in achieving consistency and quality in the completion of the dataset. This may suggest that some LSCBs would benefit by organising their data collection for child deaths on a joint basis with other LSCBs. This also has the potential to assist LSCBs in the interpretation of trend information.

## Appendix 1:

### *Completeness of data on 31<sup>st</sup> May 2007*

Parameter	Overall completion rate. (n=960)
<b>Summary of demographic information.</b>	
Sex	98.4%
Postcode	97.4%
Date of birth	99.7%
Date of death	100%
Ethnic group	94.7%
Place of Death (registration)	90.6%
Death certificate data	89.4%
Maternal occupation	65.6%
Paternal occupation	62.7%
<b>Medical / Developmental History</b>	
Birthweight	66.3%
Gestational Age	70.4%
Multiple Birth	87.1%
Mothers DOB	62.3%
<b>Conditions present at death</b>	
All data in this category	100%
<b>History of medical conditions</b>	
All data in this category	100%
<b>Presence of developmental delay, impairment or disability</b>	
Special educational support	90.6%
All other data in this category	100%
<b>Medication prescribed prior to death</b>	
All medication data	100%
Surgery within the last 30 days	93.6%
Hospitalisation for 3 months prior to death	93.5%
Visit to primary care within previous 3 months	97.4%
Mode of death	91.8%
Place of death (CEMACH)	93.3%
<b>Summary of Social circumstances of child</b>	
Living Arrangements	92.7%
Member of a traveller community?	94.3%
Asylum Seeker?	94.4%
On child protection register	94.3%
Looked after by local authority	94.4%
Legal order	93.1%
Assessed under section 17 of the Children Act	93.6%

## Case Ascertainment and Data Acquisition

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### Circumstances of Non Natural Death

Whether specific non natural factors were involved	100%
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### Processing of death

Who completed original certificate	89.4%
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Whether coroner consulted	57.7%
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Whether a pathologists post mortem was performed	62.2%
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Whether a paediatric pathologist was involved in any post mortem	34.6%
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Who gave final certification	85%
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Whether police investigation in progress	46.8%
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Whether death subject to a local enquiry	89.6%
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Whether specific records were reviewed by CEMACH	100%
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#### Notes:

1. Completion rate derived by "non null" data entry / ("null" plus "non null").
2. Some data points have been left out of this table e.g. free text variables, explanatory variables (where varying denominators apply which are not yet available), or where the relevant completion rate implies what the data are.

## Acknowledgement

The Child Death Review has only been possible because of the widespread commitment, enthusiasm and cooperation of many professionals working both with and for children. The study has been developed and is coordinated by a working group whose members are:

<u>Name</u>	<u>Representing</u>
<b>Regional Clinical Leads</b>	
Dr Angela Bell	Northern Ireland (neonatologist)
Professor Peter Fleming	South West (neonatologist)
Dr James Fraser	South West (intensivist)
Dr Fiona Reynolds	West Midlands (intensivist)
Dr Moira Stewart	Northern Ireland (community)
Dr Allan Wardhaugh	Wales (intensivist)
Dr Martin Ward-Platt	North East (neonatologist)
Dr Barbara Fulton	North East (intensivist)
Dr Anthony Harnden	Royal College of General Practitioners
Ms Sue Dunstall	NSPCC (policy adviser) & NACECH Member
<b>CEMACH Regional Managers/ Project Co-ordinators:</b>	
Ms Lisa Hydes	West Midlands
Ms Julie Maddocks	West Midlands/North West
Ms Marjorie Renwick	North East
Mrs Dawn Roberts	Wales
Ms Rosie Thompson	South West
<b>CEMACH – Central Office:</b>	
Mr Naufil Alam	Data Analyst
Dr Jessica Berentson-Shaw	Assistant Director of R & D
Mr Richard Congdon	Chief Executive CEMACH
Ms Shona Golightly	Director of R & D
Mrs Rosie Houston	Projects Manager
Professor Deirdre Kelly	NACECH Chair
Mrs Alison Miller	Programme Director
Dr Gale Pearson	Clinical Director, Child Health Enquiry
Professor Michael Weindling	Chair CEMACH Board

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