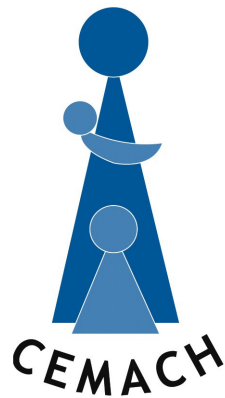


Confidential Enquiry into Maternal and Child Health

Improving the health of mothers, babies and children



CHILD HEALTH ENQUIRY

CHILD DEATH REVIEW

FIRST INTERIM REPORT

September 2006

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**CEMACH CHILD HEALTH ENQUIRY
CHILD DEATH REVIEW
FIRST INTERIM REPORT**

Executive Summary

- CEMACH is conducting a feasibility study into the practicalities and benefits of performing confidential enquiries into child deaths – the Child Death Review.
- This initiative has been welcomed on all sides by Children, Clinicians & Health Care Professionals, Health Service Commissioners, Coroners, the Office for National Statistics, the Department of Health and the Department for Education and Skills.
- The project is timed to be of maximum use to Local Safeguarding Children Boards who will have a statutory obligation to collect and analyse data on all child deaths from April 2008. Discussions are taking place between the Office for National Statistics and the Department for Education and Skills about the possibility of the data being analysed on a national basis.
- In particular, the core dataset has been developed by CEMACH for use by Local Safeguarding Children Boards when collecting data in accordance with “Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children.” (HM Government 2006).
- This interim report is based upon data relating to the first three months of the study (January – March 2006) and describes the progress of the project up until 31 July 2006.
- The pilot is running in 5 CEMACH regions (West Midlands, South West and North East of England, Wales and Northern Ireland) collecting data

on all child deaths aged 29 days – 17 years 364 days as part of a death register. Case ascertainment is validated by cross-referencing against ONS data. Still births and neonatal deaths (up to 28 days) are covered by an established confidential enquiry at CEMACH. Local Safeguarding Children Boards are expected to cover all child deaths from 0 days to 17 years 364 days.

- By July 31st 2006 the 242 deaths in the five regions in the first quarter of the study could be split into three roughly equal groups;
 - Those in which only notification data have been collected so far. In the majority of these cases the explanations are region specific and the data will be complete by the end of the study.
 - Those where much data is entered but the dataset is not signed off as some key fields are awaited. In these cases the researchers are usually waiting for the completion of police investigations or coroners' inquests.
 - Those where data entry is already complete
- The core dataset is proving feasible to complete and assimilate but time is necessarily being allowed for completion of police investigations and coroners' inquests where relevant.
- The age and regional distribution of deaths reported thus far matches predictions based on 2004 ONS data and largely concurs with ONS death registration data for the same period.
- A random sample of up to 150 cases from the register will be selected for multidisciplinary panel review using the confidential enquiry approach to determine "reasonable" avoidable / preventable causes of child death. The multidisciplinary panel reviews are currently underway and will be reported on in the final report early in 2008.

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:

Name

Representing

Regional Clinical Leads

Dr Angela Bell	Northern Ireland (neonatologist)
Professor Peter Fleming	South West (neonatologist)
Dr James Fraser	South West (intensivist)
Dr Barbara Fulton	North East (intensivist/ anaesthetist)
Dr John Henderson	South West (acute)
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 Anthony Harnden	Royal College of General Practitioners
Ms Lucy Thorpe	NSPCC (policy adviser) & NACECH Member

CEMACH Regional Managers/Project Co-ordinators:

Mrs Judith Hopkins	Wales
Ms Lisa Hydes	West Midlands
Ms Julie Maddocks	West Midlands/North West
Ms Marjorie Renwick	North East
Ms Rosie Thompson	South West

CEMACH – Central Office:

Dr Gale Pearson	Clinical Director, Child Health Enquiry
Dr Jana Kovar	National Projects Manager
Mr Richard Congdon	Chief Executive CEMACH
Ms Shona Golightly	Director of Research and Development
Rosie Houston	Projects Assistant
Professor Deirdre Kelly	NACECH Chair
Ms Alison Miller	Programme Director
Professor Michael Weindling	Chair CEMACH Board

We would also like to thank the Office of National Statistics for providing death registration data and Kate Fleming, Senior Data Analyst for providing tables for this report.

Introduction

Confidential enquiries have a long and distinguished history, contributing to major improvements in the delivery of health care across the UK, covering a wide range of specialties. The function of a confidential enquiry is to investigate the detail behind mortality statistics and to identify patterns that imply an opportunity for preventative action in the future. The Confidential Enquiry into Maternal and Child Health (CEMACH) was formed in April 2003 when the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) and the Confidential Enquiry into Maternal Deaths (CEMD) were combined.

CEMACH was set the remit of extending its well-established programme of enquiry work in maternal and perinatal deaths into the area of child health. The National Advisory Committee for Enquiries into Child Health (NACECH) was convened under the chairmanship of Prof Deirdre Kelly in April 2004.

Following an open topic invitation / selection process in 2004, three topics were selected from a total of 45 submitted. These were the review of children's deaths, accidental injury (pre-hospital care of paediatric head injury) and child protection. The first two projects have been given priority and will allow CEMACH to explore the feasibility of conducting confidential enquiry work in child health on a national basis.

The "Child Death Review" is a study running in five CEMACH regions; the West Midlands, South West, North East of England and Wales and Northern Ireland (See Figure 1).

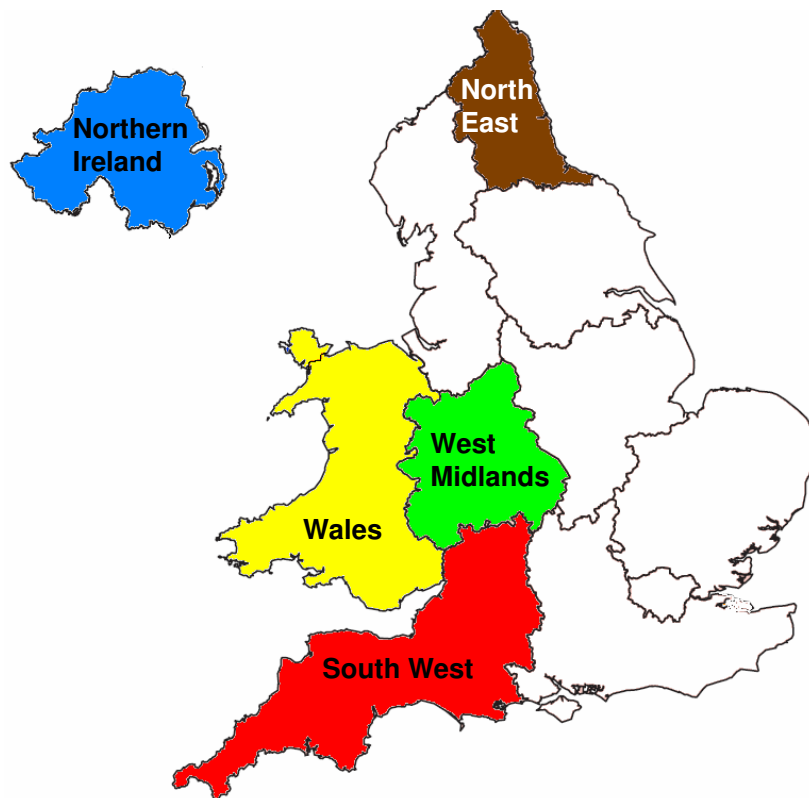


FIGURE 1: CEMACH regions participating in the Child Death Review

The objectives of the Child Death Review are:

1. To identify all child deaths aged 28 days to 18 years (exclusive) in the selected regions during the calendar year 2006
2. To collect “core” data on all those deaths
3. To conduct a detailed review of a subset of the deaths with a focus on identifying preventable and avoidable factors
4. To inform the feasibility of conducting national confidential enquiry work into child deaths

In this way it should be possible to confirm (or otherwise) the cause of death given at registration and to assess the scope for identifying factors over and above that available from registration, relevant to understanding the cause of death.

The Child Death Review receives advice from NACECH and is organised on a practical basis by a working group, which has clinical and CEMACH representatives from each collaborating region. The overall purpose of the working group is to provide operational input into the development and implementation of the Child Death Review project as well as providing drive and enthusiasm for this work.

Multi-centre research ethics approval was obtained 1 July 2005 and the Patient Information Advisory Group (PIAG) granted CEMACH Section 60 approval under the *Health and Social Care Act 2001* on the 12 September 2005. As part of the approval, CEMACH was requested to canvass the assistance and opinions of young people aged 14-18 years into the design and focus of the enquiry. To this end researchers from the National Children's Bureau and CEMACH undertook consultations with 24 young people aged between 14-20 years of age. The emphasis of the sessions was upon gaining ideas and feedback from all participants using creative means. The sessions concentrated on setting the scene and context of the Child Death Review and providing examples of multidisciplinary panel work through individual case studies. In all, the children and young people found the current and proposed work of CEMACH to be valuable and acknowledged that findings of this work could have significant educational and preventative impact.

The project is timed to be of maximum use to Local Safeguarding Children Boards (LSCBs), the establishment of which was legislated for in the Children Act 2004 but whose function, terms of reference and modus operandi are fully explained in "Working Together to Safeguard Children" produced by HM Government in April 2006. The LSCBs will be responsible for local child death review teams which will review all child deaths and respond rapidly to unexpected deaths. The LSCBs will have a statutory obligation to collect data on all child deaths from 1st April 2008. Many are already established and beginning to operate in advance of this date and in the regions where the Child Death Review pilot is operating, local CEMACH clinical leads are liaising closely with them. Developmental work is being undertaken to explore whether the Office for National Statistics will collect and analyse the data on a national basis

and whether CEMACH will be granted access to that data to enable it to conduct confidential enquiries in child health. Meanwhile the development of the CEMACH Child Death Review core dataset has been recognised in “Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children” (HM Government 2006) which requires a nationally agreed minimum dataset for LSCBs.

Reports planned for the Child Death Review Project

Three reports are planned for the Child Death Review project. These are:

- first interim report
- second interim report (Autumn 2007)
- final report (2008).

This is the first interim report. It describes progress to 31st July in respect of deaths that occurred in the first quarter of the study, i.e. from 1st January to 31st March 2006. Its main aims are to report on the feasibility of the arrangements for ascertainment of child deaths in the five pilot sites and the collection of the core dataset. The intention is to advise CEMACH of changes that may need to be made at this stage of the project and to give an initial indication to the DfES of the feasibility of adopting the core dataset used in the CEMACH study for the national minimum dataset to be collected by LSCBs from no later than April 2008.

The second interim report is mainly intended to further assist the DfES in evaluating the core dataset for its use by LSCBs and is expected to contain:

- levels of ascertainment at each pilot site and reasons for variations between them
- conclusions on the feasibility of collection of the core dataset based on the full year's experience
- a discussion of how far the core dataset provides useful information over and above that already available through registration
- an interim evaluation of the usefulness of the core dataset and enquiry review process in assessing avoidability of child deaths.

The final report will draw conclusions on

- the additional epidemiological understanding of factors associated with child deaths as a result of the study
- the overall percentage of avoidable deaths as assessed by the enquiry panels and any recurring patterns and
- recommended topics for in-depth confidential enquiries to be conducted as part of the ongoing CEMACH programme.

The Gantt chart which follows in Figure 2 illustrates the timescales for the Child Death Review.

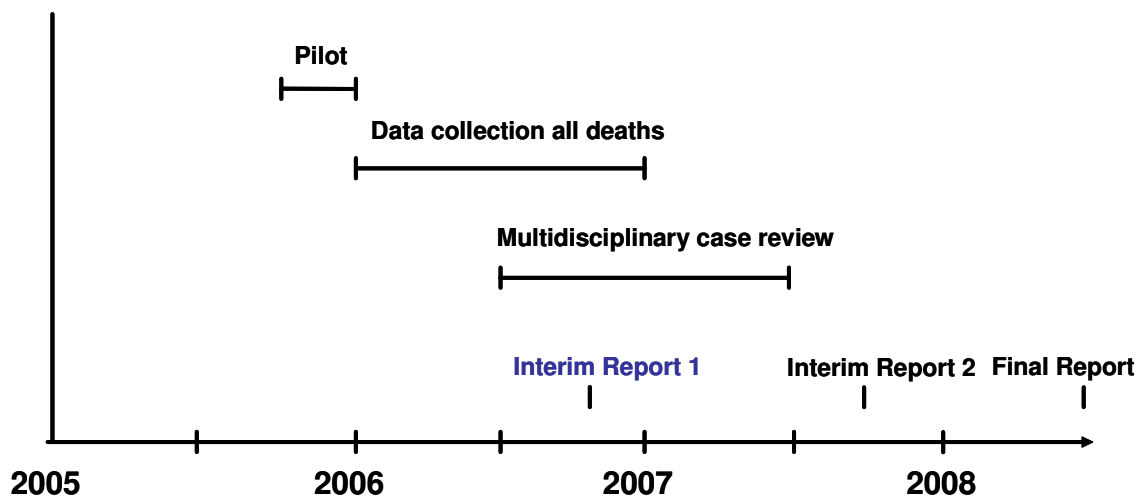


Figure 2: Timescales for the Child Death Review

Method

Data for the Child Death Review are gathered by the CEMACH regional managers using clinical contacts in each hospital in the region and a network of other local contacts that they have established. This typically includes coroners, police (including youth offending teams and prisons), other emergency services, health and safety executives, social workers and general practitioners. The CEMACH regional managers are assisted by a regional clinical lead who is additionally charged with responsibility for liaison with the LSCBs.

For patients aged 29 days to 17 years and 364 days, when the regional manager becomes aware that a death has occurred, basic descriptive details are recorded (“Notification”) and the regional contacts are then used to assist in completing the dataset (Appendix 1). These data are entered onto the CEMACH database regionally and analysed centrally. The analysis includes a cross reference against ONS death registration data to assess the level of case ascertainment.

The Child Death Review core dataset consists of; demographic and death certificate data, previous medical / developmental history, social circumstances, the circumstances surrounding “non-natural” death, and other relevant information. It is largely constructed as a series of stem questions which point to relevant supplementary questions for further detail where appropriate. For an uncomplicated hospital death a full dataset can be completed from the case records, by the attending physician, within about ten minutes.

For the purposes of this review the content of the CEMACH central database on 31st July 2006 was reviewed in relation to deaths that had occurred in the first quarter of the study. Levels of ascertainment and completion of core dataset were interrogated and compared by region.

Cases for multidisciplinary panel review are being randomly selected after being stratified by age into the following groups: 29 – 364 days, 1-4 years, 5-14 years and 15-17 years 364 days.

When a case has been selected for panel review, regional managers and clinical leads use the local network to obtain copies of relevant clinical and other records and anonymise them.

Once the anonymised copy of the records has been assembled they are then sent to CEMACH for distribution. Multidisciplinary panels in each region only review cases from outside their region. The review panels’ constitution is agreed as part of a national framework but is partly dictated by the nature of the cases under review. The essential members of the panel are, an acute care

paediatrician, a community paediatrician (If the acute paediatrician does not cover community care), a pathologist (with paediatric expertise), a general practitioner, a nursing representative and two non-medical representatives. It is highly desirable to also have an LSCB representative. Each panel is convened by the regional clinical lead and works to an agreed proforma / audit questionnaire (Appendix 2). Prior to convening the panel, members produce a brief summary of individual cases to present to their colleagues on the day.

Report: Differences between Regions

Two regions (the North East and South West) piloted data collection from October - December 2005, and all regions (except the West Midlands which joined the study in March 2006) used this “lead in” period to help build up the local networks that are necessary to ascertain when deaths occur. At both regional and national level there has been extensive cooperation across the board. However there are still some small gaps in local networks.

In the South West paediatric deaths were being recorded prior to the CEMACH Child Death Review as part of the South West Region Critically Ill Children Audit and historically, enquiry panels were already being used to look at Sudden Unexplained Deaths in Infancy as part of the Confidential Enquiry into Sudden Deaths in Infancy (CESDI), Sudden Unexplained Deaths in Infancy (SUDI), and South West Infant Sleep Scene (SWISS) studies. Practitioners in the South West hold local child death review meetings on all deaths at which the CEMACH core dataset is completed. In other regions the data collection is co-ordinated centrally by the Regional Managers and posted out to clinicians involved in the care of the child.

In the North East, the Regional Maternity Survey Office manages the CEMACH process for the North East Region and has a multi-agency steering group for the Child Death Project.

In Wales there has been a delay in dataset collection, a consequence of a delay in the appointment of a new CEMACH regional manager. Notifications however,

have not been affected and data entry is projected to catch up with the other regions before the end of the study.

Whilst the West Midlands joined the CEMACH study after its inception it had already been preparing for a similar project. Through local enthusiasm it has proven possible to simultaneously detect and acquire cases whilst establishing the network there. Nevertheless some of the data collection has had to be a later retrospective than in the North East, South West and Northern Ireland.

Report on the first objective:

To identify all child deaths aged 28 days to 18 years (exclusive) in the selected regions

This interim report relates to the content of the CEMACH central database on 31st July 2006 in relation to deaths that had occurred in January to March 2006 inclusive. By July 31st 2006 a total of 242 cases were notified with a date of death between 1 Jan 2006 and 31 March 2006. The regional distribution of cases is shown in table one.

Table One: Regional distribution of cases (deaths of children aged 28 days – 18 years (exclusive) occurring Jan – March 2006)

Region	Total cases known to CEMACH Jan - Mar 2006	Reference figures from ONS Jan – Mar 2006	Annual total deaths in 2004 (ONS)
	n	N	n
NE	37	17	170
NI	33	N/A*	105*
SW	56	55	220
WA	36	27	170
WM	80	74	330

*ONS does not collate data from Northern Ireland

The table shows that the acquisition of cases slightly exceeds those known to ONS by July 31st and broadly matches the rate that might be expected from the ONS annual totals for 2004. Case by case matching will form part of the final report of the child death review.

The age bands for the random selection process for multidisciplinary panel review were chosen with the intention of producing categories with similar

numbers of deaths in each. The actual distribution of cases within these age bands in the first three months of data collection is shown in table two.

Table Two: Regional distribution by age group at death (deaths of children occurring Jan – March 2006)

Region	Total	29-364 days		1-4 years		5-14 years		15-17 years 364 days		Missing	
		n	%	n	%	n	%	n	%	n	%
NE	37	13	35.1	3	8.1	11	29.7	10	27.0	0	0.0
NI	33	9	27.3	7	21.2	11	33.3	6	18.2	0	0.0
SW	56	13	23.2	15	26.8	13	23.2	13	23.2	2	3.6
WA	36	17	47.2	2	5.6	10	27.8	3	8.3	4	11.1
WM	80	27	33.8	12	15.0	27	33.8	14	17.5	0	0.0
Total	242	79	32.6	39	16.1	72	29.8	46	19.0	6	2.5

% are row percentages

Report on the second objective:

To collect “core” data on all the deaths

As might be expected from the description of differences between the regions, at this stage there is considerable regional variation in the status of completion of the dataset. Overall in 86 cases where death occurred between January 1st and March 31st 2006 the database on July 31st still contained notification data only (West Midlands and Wales accounted for 64 of these). The status of core dataset collection at the point data were sampled for this interim report is summarised in Table three.

Table Three: Status of completion of the core dataset by region (as at 31st July) (deaths of children aged 28 days – 18 years (exclusive) occurring Jan – March 2006)

Region	Total	Notification only		In progress		Core data set complete	
		n	%	n	%	N	%
NE	37	1	2.7	15	40.5	21	56.8
NI	33	4	12.1	14	42.4	15	45.5
SW	56	17	30.4	9	16.1	30	53.6
WA	36	36	100.0	0	0.0	0	0.0
WM	80	28	35.0	32	40.0	20	25.0
Total	242	86	35.5	70	28.9	86	35.5

% are row percentages

One of the hypotheses entertained by NACECH was that there would be a difference in case acquisition and core dataset completion dependent upon the location of the death (hospital vs community). Whilst this interim report is for the

first quarter of a year's data collection, the location of the deaths is summarised by age group in table four. A proportion of the "missing" data for this criterion may be cases where the interpretation of the location has been difficult. For example cases where the death and the certification of death have occurred in different locations. The predominant location at death, for cases where it is known, is "in hospital" but this may change as the data is cleaned and the "missing" cases are reallocated.

Table Four: Location of death by age group at death (excluding cases with notification data only) (deaths of children occurring Jan – March 2006)

	Total N=156		29-364 days N=48		1-4 years N=30		5-14 years N=46		15-17 years 364 days N=32	
	n	%	n	%	n	%	n	%	n	%
Acute hospital	76	49%	27	56.3	17	56.7	18	39.1	14	43.8
Community	54	35%	14	29.2	12	40	20	43.5	8	25
Not known	1	1%	0	0	0	0	0	0	1	3.1
Missing	25	16%	7	14.6	1	3.3	8	17.4	9	28.1

% are column percentages

Ease of Collection of the Core Dataset

A survey of the regional managers was also conducted in order to provide feedback on the process of collecting the core dataset. The number of cases where individuals were having to be prompted to complete the dataset, was very low, implying a high level of cooperation within the regional networks and lack of difficulty in collecting the data. Nevertheless in some instances, completion of the dataset can require contact with several different sources.

The explanation for occasions within the database where data were present and yet the core dataset was not yet asserted to be complete, was also sought. The most common cause for delay in signing off the dataset was that the "cause of death" was dependent upon an inquest that was not yet completed (64%). In one case this was due to the wait for post mortem brain histology (which can take over six weeks to process before it can be examined and may have to then be sent long distances for analysis). Delay in ascertaining the NHS number were cited in a further (20%) of cases. In the remaining 14% of cases some other potentially ascertainable data item(s)

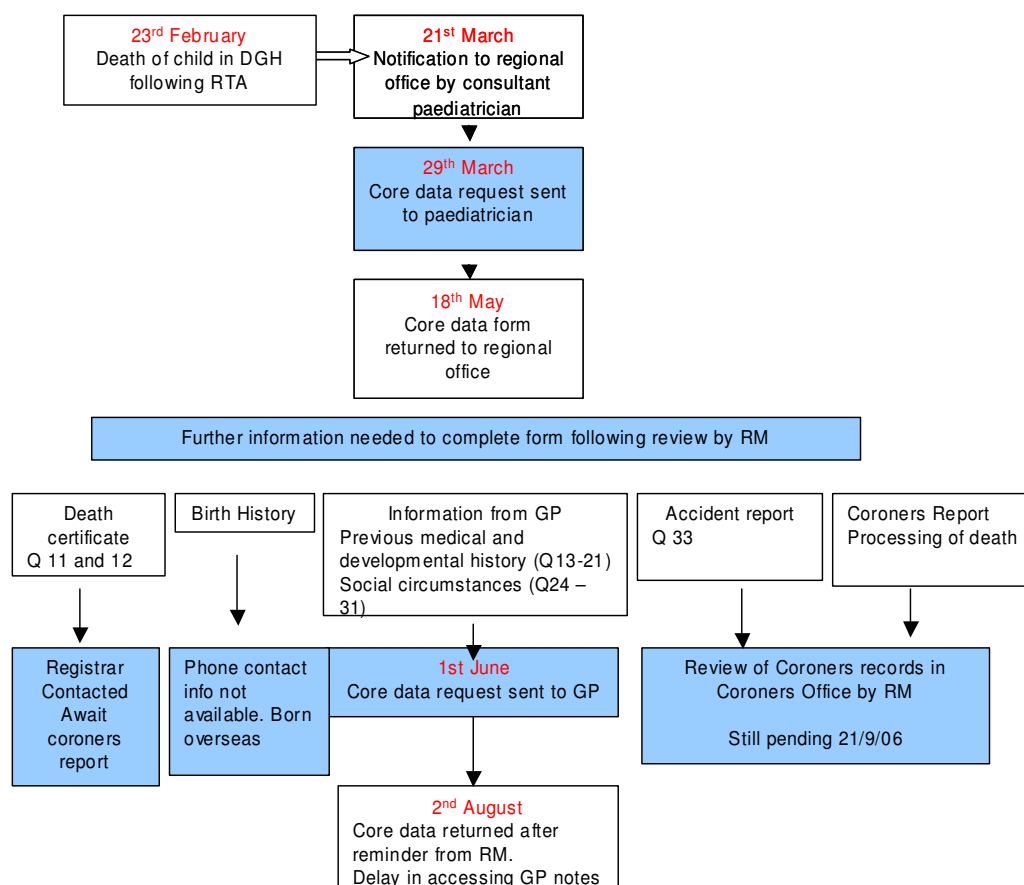
were relevant. There was no pattern to these that would imply difficulty with a particular component of the core dataset.

One region provided, by way of example, their summary percentages on the time taken for the primary contact to return the core dataset (table 5) and a useful vignette (shown in the diagram) of a case where completion of the core dataset has been delayed.

Table Five: Time from request to receipt of core data from main contact.

Time (Days)	%
0-14	43%
15-28	31%
29-42	17%
>42	9%

Vignette:



The core data is still not complete in this case notified 7 months ago.

Report on the third objective:**To conduct a detailed review of a subset of the deaths with a focus on identifying preventable and avoidable factors**

Section D of the core dataset collects information about circumstances surrounding a death that could at some level be considered preventable before, or even without, review by the multidisciplinary panel. In the first quarter of the study one of the factors is mentioned in 27 cases and 98 have a positive assertion that none of the factors were present. In 31 cases (out of 156) there was no positive assertion that one of the designated “non-natural” causes of death was absent (“none of the above”). This was not a defect in completion of the core dataset form, more rather caution on the part of the regional managers in relation to the inquests referred to already. Indeed one further indication of the ease of data collection in respect of the core dataset is that in all bar two of the cases where one of the “non natural” factors was recorded as being relevant in relation to the death, the records also had the supplementary questions relating to the factor completed.

Multi-Disciplinary Panels

The most significant analysis of the cause of death and the identification of avoidable or preventable factors involved in the death is anticipated to result from the work of the multidisciplinary panels. The first multidisciplinary panel took place in Bristol on 25th July 2006, with further panels planned in all regions in the coming year. The audit questionnaire used to record the conclusions of the panels is included as Appendix 2.

Report on the fourth objective:**To inform the feasibility of conducting national confidential enquiry work into child deaths**

Early feedback from the regions with regard the process of setting up the enquiry panels has been positive. One anticipated consideration that has been confirmed, is that it can take a considerable time to gather, photocopy and anonymise case records on the occasions when they are lengthy or complicated. For example, cases where a child dies due to chronic illness or

disability, or additionally when multiple agencies have been involved in the care of the child. There remains a strong desire to obtain comprehensive and complete case notes for the purposes of panel review but in cases where it is clearly not practicable, the regional clinical leads have been given license to determine the best approach to reducing the volume of material to be duplicated and anonymised. Despite these efforts the workload of CEMACH regional managers has shifted so that as much as 50% of their time is now spent in support of the Child Death Review. This translates to a need for approximately 1 WTE administrator per 5 million population. Much of this time relates to the preparation of cases for the multidisciplinary panel review [Vignette].

Not all the parties / institutions and general practitioners caring for children in the regions covered by the study have been prepared to participate in the provision of records. However since LSCB's enquiries will be mandatory they may not experience the same difficulties.

Nevertheless the value of the enquiry part of the child death review is already being confirmed. In a recent meeting of the working group, cases could already be cited where avoidable causes of (or contributions to) death had been identified and lessons learned with regard to issues such as the quality of terminal care in children. There had already been circumstances where a death was revealed by enquiry to be unexpected even though it had been explained superficially by a pre-existing diagnosis. In future reports, CEMACH will be able to report on the proportion of cases reviewed where the conclusions of panels differ from death certificate data.

In some of the cases acquired in the south west there had been difficulty in full participation at local child death reviews on the part of parties whose management might be questioned. These would have largely been resolved by anonymisation and external review but might otherwise persist for LSCB's.

Conclusion

Initial indications are that the Child Death Review will achieve all four of its objectives within the prescribed timescale. The DfES can be reassured that it has proven feasible to assimilate the core dataset although time does have to be allowed for cases that are subject to police investigation and Coroner's inquest. In some cases this is more than the four months that applied in the preparation of this interim report. The difficulties experienced by regional CEMACH managers with regard access to case records and the time taken to prepare them for panel enquiry might not fully transpose to LSCB's whose enquiries will be mandatory. Nevertheless the task has been achievable with considerable investment from CEMACH and the commitment of local networks to participate. Furthermore the advantages of clinical input into reviews are felt to be overwhelming and there is an enormous potential that could be realised by the national amalgamation of the conclusions of the confidential multi-disciplinary panels.

Appendices

The following appendices are available to download from

<http://www.cemach.org.uk/Programmes/Child/Child-Death-Review.aspx>

Appendix 1 Child Death Enquiry - [Core Data set](#)

Appendix 2 Child Death Enquiry – [Multidisciplinary case review pro forma](#)