

CESDI

Confidential Enquiry into Stillbirths and Deaths in Infancy

6th Annual Report

Focusing on:

**The '1 in 10' Enquiries 1996-97
The '4kg and over' Enquiries 1997
Perinatal Pathology
Record Keeping
and
Developing the Enquiries**



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APPENDIX 1

Members of the Project 27/28 Working Group
Members of the Communications Working Group
Members of the Rapid Report Form Working Group
Members of the Classification Working Group

APPENDIX 2

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PREFACE

We are pleased to publish this 6th Annual Report of the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI), the third for which the Maternal and Child Health Research Consortium have had responsibility.

The launch of the National Institute for Clinical Excellence (NICE) on 31st March 1999, has meant that henceforth the Enquiry will come within its overall remit. We very much welcome the opportunity to work through NICE towards a national agenda in setting and improving the standards of patient care.

These new arrangements mean that the National Advisory Body (NAB), which has been under the able chairmanship of Lady Shirley Littler, has now been disbanded. The overall direction, in terms of strategic development of the programme, and the skills and hard work of NAB members, have been greatly appreciated by the Consortium, the CESDI Secretariat, and not least by myself as Chairman. The role that they have played since the inception of CESDI is reviewed in Chapter Seven, and we wish to record our sincere thanks and hope that we can call upon individual members of the NAB for their expertise in the future when appropriate.

A variety of aspects of the work of the Enquiry are included in this 6th Report. The excellent ascertainment rates of indexed cases is maintained and is a result of the hard work of our regional and district co-ordinators.

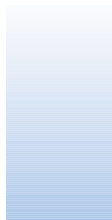
The Confidential Enquiry programme featured in this Report was held on a 1 in 10 randomised selection of all deaths during 1996 and 1997, and has identified new groups for further in-depth study by the Enquiry in future programmes of work.

Whilst previously much emphasis has been placed on the deaths of preterm and small babies, the study of deaths in babies weighing 4.0 kg or more has highlighted some important issues in patient management and assessment, particularly in labour.

When deaths do occur, a detailed postmortem examination can often produce an explanation. The information obtained is only as good as the quality of the postmortem performed. Our review of postmortem reports suggest there is scope to improve the quality of postmortems and the need to reconsider the establishment of regional specialist pathology services.

Finally, it is encouraging that there have been many attempts by the professional bodies to implement the previous CESDI recommendations. We hope that the lessons and recommendations within this report will likewise be disseminated widely and implemented.

Professor Robert W Shaw
Chairman, Executive Steering Group
Maternal and Child Health Research Consortium



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MEMBERS OF THE MATERNAL & CHILD HEALTH RESEARCH CONSORTIUM (MCHRC) EXECUTIVE STEERING GROUP

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Yorkshire - Ms Lesley Anson	Oxford - Ms Irene Boller
Trent - Ms Sue Wood	South Western - Ms Rosie Thompson
East Anglia - Ms Jane Baker	West Midlands - Ms Donna Drinkall
North West Thames - Ms Stephanie Roberts	Mersey - Ms Grace Edwards
North East Thames - Ms Dawn Saunders	North Western - Dr Jean Sands
South East Thames - Ms Patricia Hanson	Wales - Ms Jane Stewart - Ms Judith Hopkins
South West Thames - Ms Julia Chachere (until October 1998) - Ms Sharon Hackett (from November 1998)	Northern Ireland - Dr Maureen Scott - Ms Terry Falconer

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In addition to the above named people, we would also like to acknowledge the considerable contribution of the many district co-ordinators and others based throughout England, Wales and Northern Ireland, who, often without recognition and in their own time, undertake work for CESDI.

INTRODUCTION

1.1 HISTORY

The Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) was established in 1992 to improve understanding of how the risks of death in late fetal life and infancy, from 20 weeks of pregnancy to one year after birth, might be reduced. CESDI attempts to identify risks which can be attributed to suboptimal clinical care.

In 1991 the Department of Health directed that the fourteen 'Regions' of England should undertake Perinatal Mortality Surveys. CESDI was subsequently organised on this regional basis with separate arrangements for Wales and Northern Ireland. Each region is autonomous and has a full-time co-ordinator together with varying numbers of support staff. The network of CESDI has remained despite organisational changes in the NHS during 1994-95 and 1998-99.

In the first instance, CESDI was funded directly by the Department of Health and supervised by a National Advisory Body (NAB), under the chairmanship of Lady Littler. In April 1996 responsibility for the management of CESDI was assumed by the Maternal and Child Health Research Consortium (MCHRC). This group was established by the Royal College of Obstetricians & Gynaecologists, Royal College of Paediatrics & Child Health, Royal College of Pathologists and the Royal College of Midwives, to oversee the running of the Enquiry. The National Advisory Body advise the Consortium. In addition, to involve other key disciplines and professions in the Enquiry, a Professionals' Steering Group (PSG) was established to provide further advice to the Consortium. As from April 1st 1999 CESDI will be one of the four National Enquiries under the umbrella of the National Institute for Clinical Excellence (NICE). This will facilitate the setting of consistent clinical standards. Chapter 7 contains a review of CESDI and the NAB from 1992 - 1997, written by Lady Littler.

In England, Wales and Northern Ireland there are some 10,000 deaths annually occurring between 20 weeks gestation and 1 year of life. These deaths are notified to the regional co-ordinator, and a sub-set are anonymised and reviewed by a specialist panel within the region. The data is collected by district co-ordinators, using a rapid reporting notification system (RRF). The success of CESDI is highly dependent on the goodwill of these co-ordinators.

Regional data and enquiry findings are collated and analysed by the central Secretariat to provide a national overview. Results are published in the CESDI Annual Report.

1.2 THE WORK OF CESDI

CESDI is tasked to provide an overview of the numbers and causes of stillbirths and infant deaths, together with a detailed enquiry into

specific sub-sets. Depending on the subject various additional approaches are used: case control studies where the cause is unknown or risk factors need to be assessed, focus group work to provide greater detail and overview of rare events. Table 1 summarises the enquiry programme, case control studies and focus group work to date and the topics highlighted in the various past Reports.

Part of CESDI's work is to evaluate the effect of its recommendations. A review of the effectiveness of the dissemination of its findings was undertaken in 1998 and this is discussed in Chapter 8. Audits have been carried out looking at the standards of postmortem reporting (Chapter 5) and a national multidisciplinary survey of the provision of education in the use and interpretation of CTGs is currently underway.

Table 1 The work programmes of CESDI

	Year of study	Findings Reported
Enquiry Topic		
Intrapartum related deaths >2.5 kg	1993	2nd Annual Report
Intrapartum related deaths > 1.5 kg	1994-1995	4th Annual Report
'Explained' Sudden Unexpected Deaths in Infancy ²	1993-1996	5th Annual Report
1 in 10 sample of all deaths >1kg excluding post-neonatal deaths and major anomalies	1996-1997	6th Annual Report
All deaths 4 kg and over	1997	6th Annual Report
Case Control Studies		
Sudden Unexpected Deaths in Infancy ¹	1993-1994	3rd Annual Report
Sudden Unexpected Deaths in Infancy ¹		Due for Publication late 1999
Antepartum Term Stillbirths ³	1995	5th Annual Report
Project 27-28	1998-2000	To be reported
Focus Group		
Shoulder dystocia	1994-1995	5th Annual Report
Ruptured uterus	1994-1995	5th Annual Report
Planned home delivery	1994-1995	5th Annual Report
Audits		
Post-mortem reporting	1994-1995	6th Annual Report
CTG education		To be reported

¹ 3 Regions (South Western, Yorkshire, Trent)

² 5 Regions (South Western, Yorkshire, Trent, Northern, Wessex)

³ 1 Region (West Midlands)

1.3 ENQUIRY PROCESS

The detailed methodology applied by the multidisciplinary panels was described in the 1st and 2nd Annual Reports. Each panel consists of experts from a number of disciplines including, as a minimum, an obstetrician, paediatrician, midwife, specialist perinatal/paediatric

pathologist, general practitioner and an independent chairperson. Other parties with appropriate expertise may also be involved. Panel members are sent anonymised case-notes prior to the meeting. At the meeting itself they produce a summary of the case and complete a standard CESDI form. This includes comments on suboptimal care, each item of which is graded according to the following system:-

- Grade 0 - No suboptimal care.
- Grade 1 - Suboptimal care, but different management would have made no difference to the outcome.
- Grade 2 - Suboptimal care - different management *might* have made a difference to the outcome.
- Grade 3 - Suboptimal care - different management *would reasonably have been expected to* have made a difference to the outcome.

The panel assigns an 'Overall Grade' together with comments on the completeness of the record and on the pathological findings (determined by the extended Wigglesworth, fetal/neonatal and obstetric classification).

1.3.1 **Validation of Enquiry findings**

The exact process followed by a panel varies between regions. To address the validity of the confidential enquiry process a fifth of all enquiries in 1995 were submitted to a second panel in a different region. The findings of this study are reported in the 5th Annual Report and concluded that at least three quarters of cases subjected to Panel enquiries were given a similar overall grade when subsequently reviewed by another Panel. However, a more detailed review of the Panel reports found that the subject of the comments was the same in only half of all enquiries.

1.3.2 **A structured approach to Enquiry work**

The findings of the above exercise led to the development of a much more structured enquiry form and process for the current project. Project 27/28 focuses on babies born at between 27 and 28 weeks gestation, and Confidential Enquiries will be held on all early neonatal deaths of babies born at this gestation and an equivalent number of controls (babies who are born at this gestation and survive beyond 28 days). Knowledge of the outcome of the case, i.e. whether the baby died or survived, inevitably affects opinion, and therefore all panel members who are responsible for assessing the obstetric part of the case, will be blind to the outcome. A more detailed description of Project 27/28 is found in Chapter 9.

1.4 **CONTENTS OF THIS REPORT**

1.4.1 **'1 in 10' and '4kg and over' - Enquiries**

As it is only possible to enquire on a small fraction of the losses reported to CESDI, it was decided to sample as broad a range as possible to obtain an overview. This would inform decisions regarding further programmes. This was the basis of the 1 in 10 programme and the findings are reported in Chapter 3.

Large babies are known to be associated with difficult deliveries, fetal distress, shoulder dystocia, and with gestational and pre-pregnancy diabetes in the mother. In 1997 all babies that died weighing 4 kg and over were subject to a confidential enquiry and the results are reported in Chapter 4.

1.4.2 Postmortem reporting - Audit

In 1993 CESDI issued guidelines on perinatal postmortem examinations, which were formally endorsed by the Royal College of Pathologists and distributed to all pathologists. An audit of postmortem reports was carried out by a panel of specialist perinatal pathologists in 1993/94 and at that time 57% of reports sampled appeared to have followed CESDI guidelines. Following this study, two further audits were carried out, focusing on the postmortem reports from the Intrapartum Deaths study (1994/95), and the 1 in 10 programme (1996/97). The findings of these audits are outlined in Chapter 5.

1.4.3 Consent issues when requesting a postmortem

In the last few years increasing attention has been directed towards informed consent. CESDI through the NAB (Chapter 7) has always benefited from significant contributions from parental representation and involvement. This led directly to the initiation and production of a leaflet on the topic of postmortem for parents. This is a sensitive area that health professionals need to be well informed on and following the success of the parental leaflet it was decided to produce one for the professional on the issues regarding requesting consent. This is now available and is mentioned in Chapter 5.

1.4.4 Record keeping

Record keeping is a vital part of communication and of care. CESDI has repeatedly drawn attention to this and a review of the panel's assessments of the standards of record keeping is described in Chapter 6.

1.5 CHANGING PRACTICE

The findings of CESDI need to be acted on as well as understood. In our last Report (5th) there was a review of how the Royal Colleges and other statutory bodies responsible for training and accreditation are responding to the recommendations of the 4th Report which focused on intrapartum deaths. This review has been updated in Chapter 8.

1.6 VIEWS OF THE NATIONAL ADVISORY BODY

The NAB have been consulted about this Report and are in general agreement with its findings and recommendations.

ACKNOWLEDGEMENTS

Members of the Consortium Executive Steering Group, the Secretariat, the National Advisory Body, the Professionals' Steering Group and the various working groups are listed in the Report. While it has been the prime responsibility of the Secretariat and the Executive Steering Group to produce the Report, they gratefully acknowledge the invaluable input made by the National Advisory Body to the Report as a whole, as well as the other contributors named in the footnotes to individual chapters.

RAPID REPORT FORM RETURNS - 1997

2.1 INTRODUCTION

The Rapid Report Form (RRF) is the CESDI notification system first used in 1993. Its purposes are:

- to obtain a dataset for each death within the CESDI range between 20 weeks' gestation and one year of life
- to provide information as soon as possible after the death in support of the enquiry process.

The RRF data collection forms for 1996 and 1997 are reproduced in Appendix 3.

A national collection of mortality statistics is also conducted by the Office for National Statistics (ONS) based on registered deaths of babies born from 24 weeks onwards. This comprises socio-demographic and occupational details and is collected from the Registrar of Births and Deaths. As registration of death is statutory these figures form the gold standard for comparison with the RRF returns. The content of the latter is of a clinical nature.

2.2 NOTIFICATIONS TO CESDI

2.2.1 Ascertainment levels of CESDI

Table 2.1 shows the deaths reported by the RRF system compared to those reported by statute to ONS for England and Wales and to the General Register Office (GRO) for Northern Ireland. Since 1993 when CESDI started, the ascertainment level of the RRF system has steadily increased.

Table 2.1: Comparison of Rapid Report Form returns 1993-1997 with registration data (ONS & GRO)

Year	England, Wales and Northern Ireland										
	Stillbirths			Neonatal deaths			Postneonatal deaths			Overall difference	
	RRF	Registration	%	RRF	Registration	%	RRF	Registration	%	N	%
1997	3619	3571	1.3	2706	2641	2.5	1257	1326	-5.2	44	0.6
1996	3688	3699	-0.3	2785	2755	1.1	1253	1372	-8.7	-100	-1.3
1995	3698	3747	-1.3	2714	2809	-3.4	1156	1328	-13.0	-316	-4.0
1994	3747	3946	-5.0	2749	2817	-2.4	1199	1376	-12.9	-444	-5.5
1993	3726	3966	-6.1	2755	2926	-5.8	1242	1442	-13.9	-611	-7.3

In 1997 the numbers reported by CESDI are shown to exceed the registered numbers of stillbirths and neonatal deaths. This may be due to non registration or due to duplication of some records.

The matching exercise involves a complete match on all selected data items. Following this the remaining cases are systematically examined to see which cases match most closely. There was still a small number of cases which could not be positively matched by both CESDI and ONS/GRO: 272 cases reported by CESDI and not matched with ONS cases and 244 cases reported by ONS and not matched with CESDI cases.

Complete identification of post neonatal deaths has always been the most difficult to achieve for CESDI and this has improved from 86% in 1993 to 95% in 1997.

Registering births and deaths

There is a statutory requirement to register live births regardless of gestation, and stillbirths from 24 weeks' gestation onwards. At birth the classification of live or stillbirth depends on whether 'signs of life' are present. This is a subjective observation especially at early gestations between 18 and 24 weeks. For example a fetus delivered at 19 weeks showing signs of life is an early neonatal death and should be registered. However, the same fetus not showing signs of life would not need to be registered and ONS would consequently be unaware of this loss. It would however be counted as a late fetal loss (a death occurring between 20 and 24 weeks gestation) by CESDI.

There are several reasons why the birth may not be registered. Firstly concerns regarding upsetting the parents by registering the loss as a live birth and subsequent death. Secondly these deaths may be perceived to 'add' inappropriately to perinatal mortality statistics. Given the subjective definition of 'signs of life' it is likely that variation in the practice of registration of such events exists.

Data items on the RRF

The response rate to 29 specific questions on the RRF was assessed and on average had increased by 4.4% (93% to 97.4%) between 1996 and 1997. In general completion of questions considered important were high, for example - case definition (98.9%), date delivered (100%), date of death (99.9%), sex (100%), Wigglesworth classification (99.9%), weight (99.7%), region of residence (98.9%), number of fetuses and birth order (99.9%)

2.2.2 Stillbirth and neonatal death rates

Table 2.2 shows the number of deaths reported to CESDI via the RRF system between 1993 and 1997. They are classified according to late fetal loss, stillbirths, neonatal and postneonatal deaths and are also expressed as rates using the relevant denominators. The stillbirth rate and perinatal mortality rates have decreased significantly for the first time since 1993. The trend is based on the figures excluding legal abortions.

Table 2.2: Rapid Report Returns 1993-1997

	England, Wales and Northern Ireland									
	1993		1994		1995		1996		1997	
	Numbers	Rate	Numbers	Rate	Numbers	Rate	Numbers	Rate	Numbers	Rate
Legal abortions	-	-	-	-	959	-	1102	-	1299	-
Late fetal loss (excl legal ab.) <i>legal abortions</i>	1495	-	1573	-	1553	-	1659	-	1774	-
Stillbirths¹ (excl legal ab.) <i>legal abortions</i>	3726	5.3	3747	5.4	3698	5.5	3688	5.4	3440	5.1
Perinatal deaths¹ (excl legal ab.) <i>legal abortions</i>	-	-	5897	8.5	5829	8.6	5898	8.7	5503	8.2
Neonatal deaths² (excl legal ab.) <i>legal abortions</i>	2755	4.0	2749	4.0	2714	4.0	2785	4.1	2648	4.0
Postneonatal deaths² <i>legal abortions</i>	1242	1.8	1199	1.7	1156	1.7	1253	1.9	1257	1.9
Total Reports - RRF	9218		9268		10080		10487		10418	
Live births	696133		688545		671861		674071		666370	

¹ Rate per 1000 live births+stillbirths
² Rate per 1000 live births

Sources:
 Live births: GRO & Child Health System, N Ireland
 ONS, England & Wales
 Deaths: RRF 1996

Classification of legal abortions

Since 1995 CESDI has collected information on legal abortions. For the first two years the RRF did not distinguish between a legal abortion and a case of late fetal loss, stillbirth or early neonatal death. For example, if a late fetal loss was legally aborted, it could be reported as a late fetal loss or a legal abortion but not both. In 1997 the RRF separated out the question on legal abortion to enable categorisation as late fetal loss, stillbirth or early neonatal death as well as being identified as a legal abortion. Figure 2.1 shows the proportions of legal abortions for each case definition. The effects of these changes on stillbirth, perinatal and neonatal death rates are shown in Table 2.2.

Figure 2.1: Legal abortions (1299) by case definition of the RRF returns (10418) - 1997

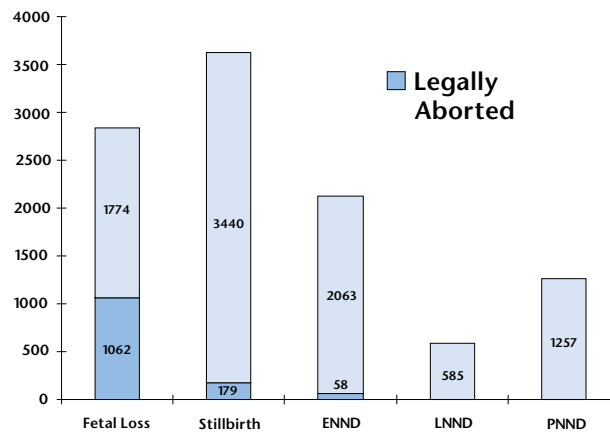


Table 2.3 shows the deaths and mortality rates for singleton and multiple births.

Table 2.3: Stillbirth and Neonatal deaths for singleton and multiple births 1993-1997

	England, Wales and Northern Ireland				
	1993	1994	1995	1996	1997
Total live births	696133	688545	671861	674071	666370
Singleton	678676	670734	653278	655834	647279
Multiple	17457	17811	18583	18237	19091
Stillbirths					
Singleton	3422	3390	3340	3329	3251
Multiple	297	355	356	350	358
Unclassified	7	2	2	9	10
Neonatal deaths					
Singleton	2267	2259	2213	2258	2228
Multiple	477	477	487	517	472
Unclassified	11	13	14	10	6
Stillbirth rate ¹					
Singleton	5.0	5.0	5.1	5.1	5.0
Multiple	16.7	19.5	18.8	18.8	18.4
Neonatal mortality rate ²					
Singleton	3.3	3.4	3.4	3.4	3.4
Multiple	27.3	26.8	26.2	28.3	24.7

¹ per 1000 singleton/multiple live & stillbirths Sources: GRO & Child Health System, N Ireland

² per 1000 singleton/multiple live births ONS, England & Wales RRF 1997

2.2.3 Cause of death

A breakdown of the cause of death as defined by the extended Wigglesworth classification (Appendix 2) for stillbirths, neonatal and postneonatal deaths is shown in Figures 2.2, 2.3, 2.4.

The main causes of death remain the same as in 1996 for each of the three groups, stillbirths, neonatal and postneonatal deaths.

For stillbirths (Figure 2.2), the largest proportion was unexplained antepartum fetal death (n=2562, 70.8%). The most common identifiable causes of death were congenital malformation (n=452, 12.5%) and intrapartum related (n=352, 9.7%).

For neonatal deaths (Figure 2.3), the main cause of death was immaturity (n=1360, 50.3%), followed by congenital malformation (n=664, 24.5%)

For postneonatal deaths (Figure 2.4), the three most common causes of death were Sudden Infant Death (SIDs n=378, 30.1%), congenital malformation (n=344, 27.4%) and infection (n=200, 15.9%).

Figure 2.2 Stillbirths in England, Wales and N Ireland by Wigglesworth classification in 1997

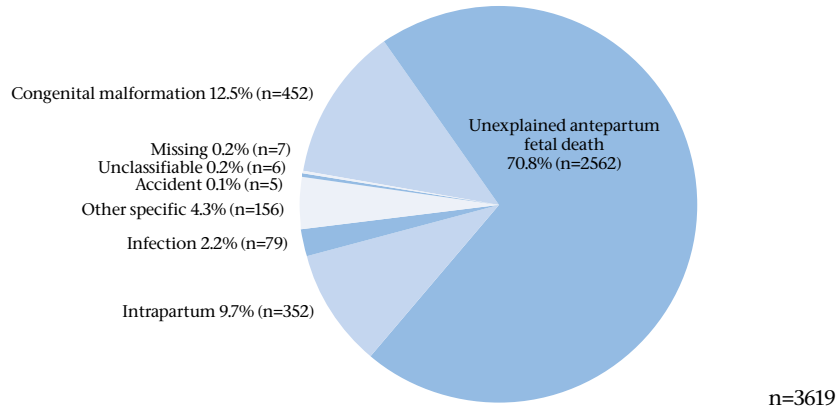


Figure 2.3 Neonatal deaths in England, Wales and N Ireland by Wigglesworth classification in 1997

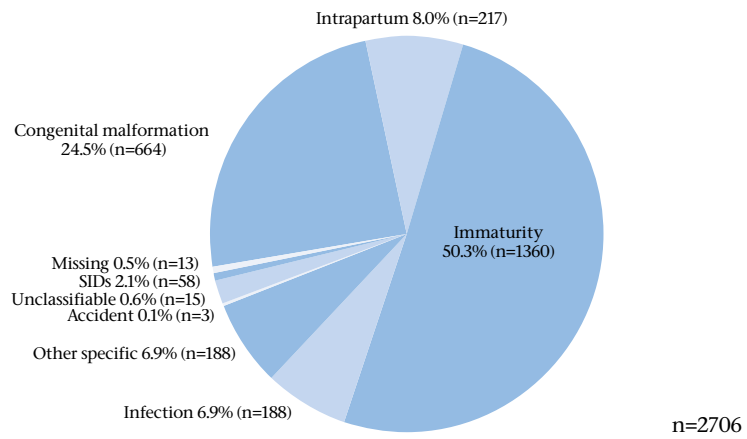
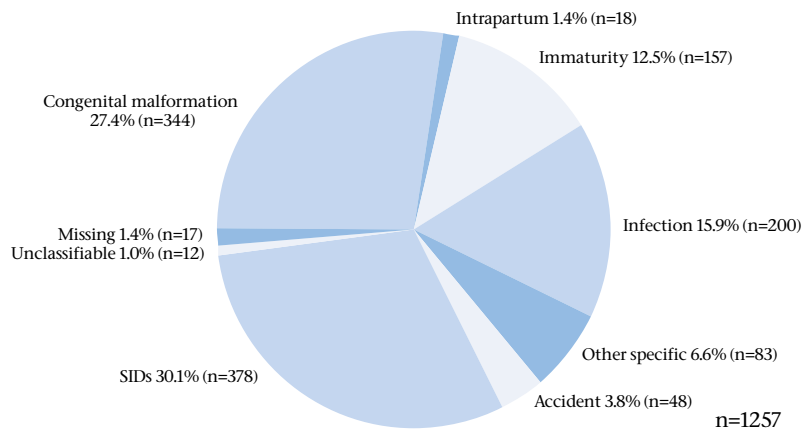


Figure 2.4 Postneonatal deaths in England, Wales and N Ireland by Wigglesworth classification in 1997

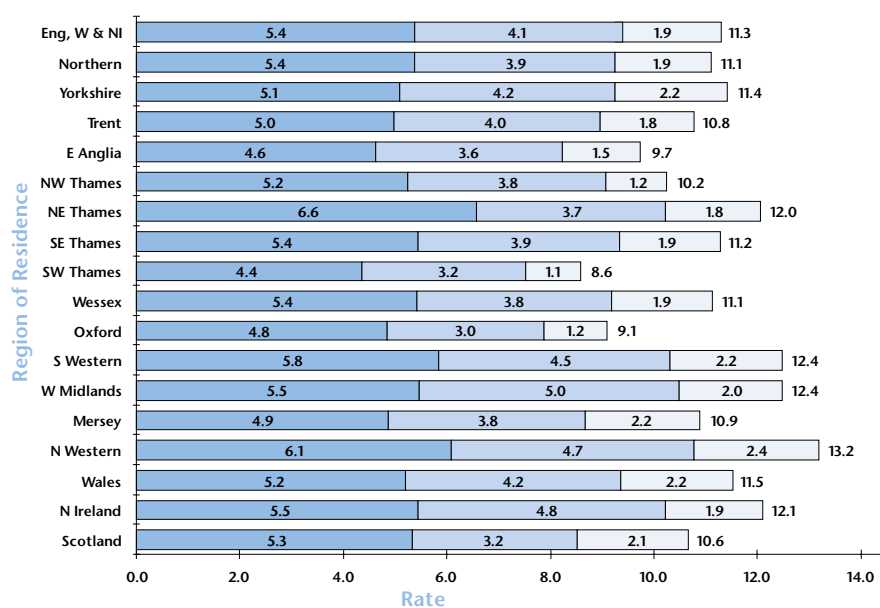


2.2.4 Mortality rates - Regional variation

Stillbirth, neonatal and postneonatal mortality rates by CESDI region of residence of mother in 1997 are shown in Figure 2.5. The source of the denominator data was from ONS (1997) and Northern Ireland GRO (1997). The ONS data pertaining to England was classified according to the current eight NHS Executive Regional Office boundaries and needed to be converted into the relevant 14 CESDI regions. Due to boundary changes, however, the conversion for some regions, notably South Western and Wessex are not exact. These crude mortality rates are *not* indicators of standards of care and should *not* be interpreted as such.

The combined mortality rate (stillbirths, neonatal and postneonatal deaths per 1000 total births) was calculated for each region (Figure 2.5). This varied between 8.6 and 13.2 deaths per 1000 total births. For comparison, figures have been added from the Scottish Stillbirth and Infant Death Report 1997.

Figure 2.5 Stillbirth¹, neonatal², postneonatal² and combined¹ mortality rates by CESDI region of residence of mother 1997.



¹ per 1000 live births and stillbirths

² per 1000 live births

Sources: RRF 1997

ONS 1997

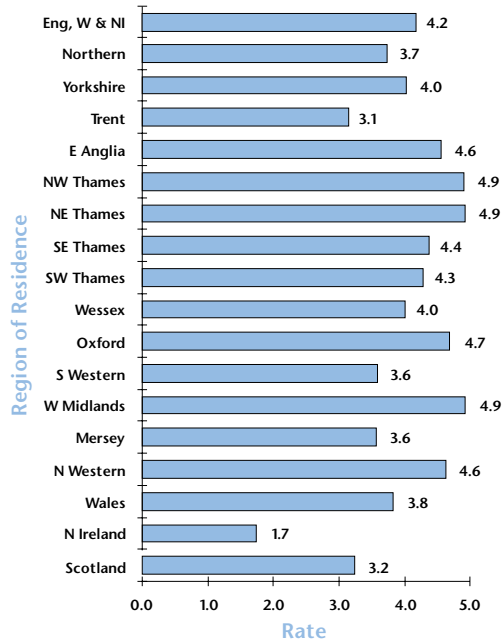
N Ireland GRO 1997

Scotland annual reports 1997

2.2.5 Late fetal loss rates - Regional variation

CESDI is the only source of data at this gestation (20+0 to 23+6 weeks) nationally in England, Wales and Northern Ireland. There is thus no means of validating the accuracy of these figures. Late fetal loss rates according to CESDI region of residence of the mother are shown in Figure 2.6. These figures include legal abortions. It is likely that reporting practices are responsible for this variation.

Figure 2.6 Late fetal loss rates¹ by CESDI region of residence of mother - RRF 1997



¹per 1000 live births + stillbirths + late fetal losses

Sources: RRF 1997

ONS 1997

N Ireland GRO 1997

Scottish Annual Report 1997

2.2.6 Postmortem rates

The numbers and rates of postmortem examination for late fetal losses, stillbirths, neonatal and postneonatal deaths from the 1997 RRF returns are shown in Table 2.4. The overall average postmortem rate for England, Wales and Northern Ireland was 54% and ranged from 44% to 65%. Stillbirths (62%) were the category most likely to have a postmortem and neonatal deaths the least likely (41%).

The rates for previous years are shown in Table 2.5 and 1997 shows the lowest rates since 1993.

Of the 5665 postmortems performed in 1997, 672 had been requested by a coroner. The reasons for failure to perform a postmortem in 4351 cases were examined: requested but refusal by parents or family (2568, 25%); not requested (1714, 17%); permission given but not performed (69, 0.7%). No information about postmortem was available in 402 deaths reported to CESDI.

Table 2.4: Postmortems of late fetal losses, stillbirths, neonatal and postneonatal deaths by CESDI region.

REGION	Late fetal deaths (inc abortions)		Stillbirths		Neonatal deaths		Postneonatal deaths		All deaths	
	Number	% PM	Number	% PM	Number	% PM	Number	% PM	Number	% PM
S Western	135	71.1	220	72.7	155	46.5	77	66.2	587	64.6
Wessex	152	73.0	199	69.8	139	49.6	71	54.9	561	63.8
NW Thames	218	64.7	224	67.4	169	52.7	58	56.9	669	61.9
SW Thames	173	65.3	180	63.9	103	48.5	34	64.7	490	61.2
Oxford	157	74.5	167	65.3	104	38.5	38	47.4	466	60.9
Northern	140	66.4	187	64.2	132	46.2	77	61.0	536	59.9
Wales	124	70.2	175	62.9	138	40.6	73	60.3	510	58.2
SE Thames	225	54.7	281	65.8	209	45.0	113	69.0	828	58.0
Trent	183	65.0	283	62.2	233	40.8	110	56.4	809	55.9
N Ireland	36	38.9	132	63.6	107	47.7	35	57.1	310	54.5
E Anglia	153	55.6	157	60.5	125	42.4	41	46.3	476	52.9
Yorkshire	173	59.0	217	56.7	180	29.4	88	54.5	658	49.5
N Western	241	42.3	318	52.2	231	37.7	117	65.0	907	47.5
NE Thames	278	43.9	366	54.6	215	33.5	112	51.8	971	46.5
W Midlands	344	50.6	372	58.9	337	30.6	141	40.4	1194	46.3
Mersey	104	29.8	141	54.6	129	42.6	72	47.2	446	44.2
NATIONAL	2836	57.5	3619	61.6	2706	40.7	1257	56.2	10418	54.4

Source: RRF 1997

Table 2.5: Levels of postmortem performed, 1993 to 1997

National	Late fetal loss	Stillbirth	Neonatal deaths	Post neonatal deaths	All deaths
	%PM	%PM	%PM	%PM	%PM
1997	57.5	61.6	40.7	56.2	54.4
1996	63.5	62.8	44.0	57.4	57.4
1995	57.5	64.1	46.0	57.5	56.6
1994	58.7	67.5	46.7	59.5	58.8
1993	54.2	66.7	47.6	60.3	58.1

2.3 SUMMARY OF RAPID REPORT FORMS 1997

1. **Total births and deaths:** Live births in England, Wales and Northern Ireland totalled 666370 in 1997. A total of 10418 deaths were notified to CESDI, comprising 1299 legal abortions, 1774 late fetal losses, 3440 stillbirths, 2648 neonatal deaths and 1257 postneonatal deaths.
2. **Stillbirths:** The stillbirth rate was 5.1 per 1000 total births. This is significantly lower for the first time since 1993.
3. **Perinatal mortality rate:** 8.2 per 1000 total births. This is significantly lower for the first time since 1994.
4. **Neonatal deaths:** The neonatal death rate was 4.0 per 1000 live births and remains unchanged.
5. **Postneonatal mortality rate:** 1.9 per 1000 live births and remains unchanged.
6. **Singleton births:** The stillbirth rate was 5.0 per 1000 singleton total births and the neonatal death rate was 3.4 per 1000 singleton live births.
7. **Multiple births:** The stillbirth rate was 18.4 per 1000 multiple total births and the neonatal death rate was 24.7 per 1000 multiple live births.
8. **Regional mortality rates:** The combined (stillbirth, neonatal and post-neonatal) mortality rate for England, Wales and Northern Ireland was 11.3 per 1000 total births and ranged from 8.6 to 13.2 within the CESDI regions.
9. **Postmortem examinations:** The overall postmortem rate for England, Wales and Northern Ireland was 54.4% (range: 44.2% - 64.6%). Within the various categories of death, the highest postmortem examination rate was 61.6% for stillbirths (range: 52.2% - 72.7%); the lowest rate 40.7% for neonatal deaths (range: 29.4% - 52.7%). There has been a small but definite fall in postmortem rates since 1993.

ACKNOWLEDGEMENTS

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Thanks are due to :

Nirupa Dattani , Senior Research Officer, ONS

Nicola Cooper , Research Officer, ONS

Terry Falconer, N Ireland CESDI Co-ordinator

3.1 INTRODUCTION

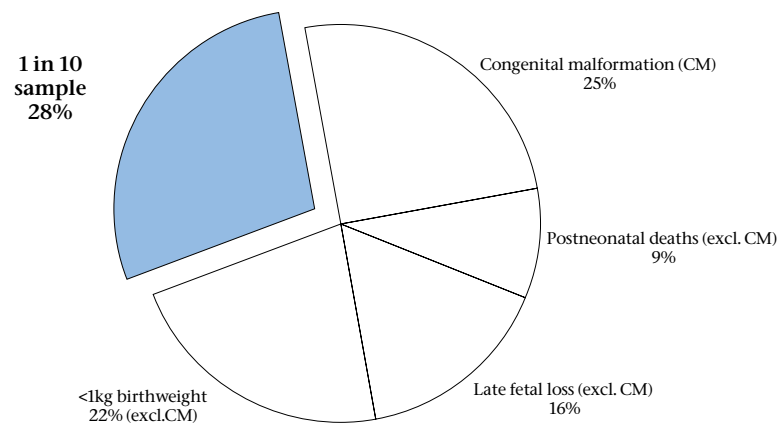
From the start of CESDI it was recognised that there would be a limit to the number of enquiries that could be undertaken annually. On average up to 5% of the cases reported to CESDI are subject to Confidential Enquiry every year. A rolling programme of topics is an essential part of the CESDI process. The initial choice of intrapartum deaths was made because it was expected to contain a high proportion of deaths in which clinical care was relevant to death. Sudden unexpected deaths were chosen because of general public concern aroused by the issue.

As only a small fraction of the losses were covered, it was decided to sample as broad a range as possible to obtain an overview. This would facilitate decisions and methods involved in further programmes. Criteria for the sampling frame were all losses reported to CESDI excluding:

- age at death greater than 27 completed days
- weight at birth less than 1kg
- fetal death before 24 completed weeks of pregnancy
- known major congenital abnormality at the time of notification

The total sample frame was expected to be around 5000. The sample was randomly selected on a 1 in 10 basis by a computer programme based in each Region. The reasons for excluding post neonatal deaths were because of the difficulties in ascertainment of these cases most of which die outside the hospital. The low birth weight babies were excluded because even with optimal care a significant proportion would inevitably die. Major congenital malformations were excluded for similar reasons. Thus the sampling frame was approximately a quarter of all the losses reported to CESDI.

Figure 3.1 The '1 in 10' sample in relation to all losses notified to CESDI.



The enquiry process has been described in Chapter 1. In brief, the panels reviewed all aspects of care and recorded instances where they felt care was suboptimal. These instances are subsequently referred to as notable factors.

For each notable factor the panel assigned:

- a 'who' 'what' and 'when' category

- grade of the standard of care
 - 0 - No suboptimal care
 - 1 - Minor suboptimal care
 - 2 - Moderate suboptimal care
 - 3 - Major suboptimal care

- grade of the relevance to death
 - 0 - Not relevant
 - 1 - Possibly relevant
 - 2 - Probably relevant
 - 3 - Almost certainly relevant

For each case the panels assigned:

- the cause of death according to the three classification methods used by CESDI (see Appendix 2).

- An overall grade relating the care to the final outcome
 - 0 - No suboptimal care
 - 1 - Suboptimal care but different management would have made no difference to the outcome
 - 2 - Suboptimal care but different management might have made a difference to the outcome
 - 3 - Suboptimal care where different management would reasonably have been expected to have made a difference to the outcome

The enquiries were selected from all deaths occurring between January 1st 1996 and December 31st 1997.

3.2 RESULTS

3.2.1 Number of enquiries held

In 1996 to 1997 there were 5930 notifications of deaths to CESDI of babies fulfilling the above criteria for being a potential enquiry subject. Enquiries were held on 573 babies in 1996 to 1997. The mandatory absence of a link between enquiry and notification via the RRF to the Central Secretariat precludes further explanation of the discrepancy between the 573 enquiries and the 593 anticipated.

3.2.2 Description of the 573 cases

The weight and gestational distribution are shown in Figures 3.2 and 3.3. The median weight was 2.350 kg and range 1.000kg to 4.730kg. The median gestational age at birth was 36 completed weeks (range 24 to 42 weeks). There were 311 (54%) cases less than 37 weeks and 6 (1%) cases at 42 weeks and above.

Figure 3.2 Birthweight distribution for the '1 in 10' enquiry programme

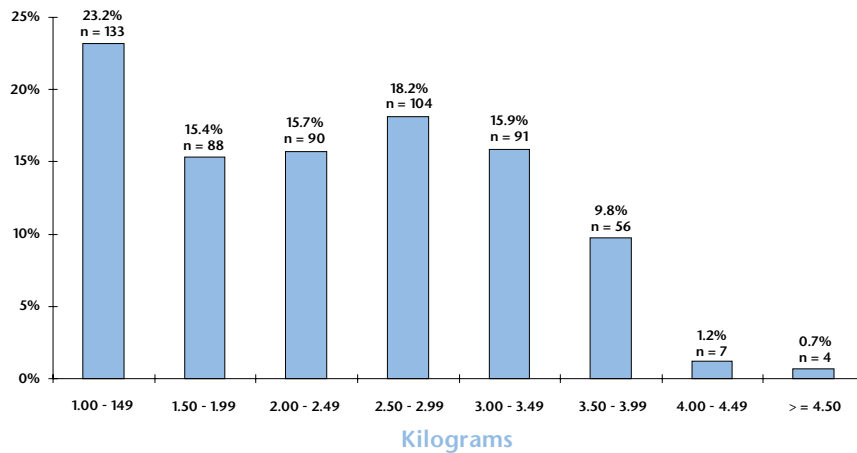
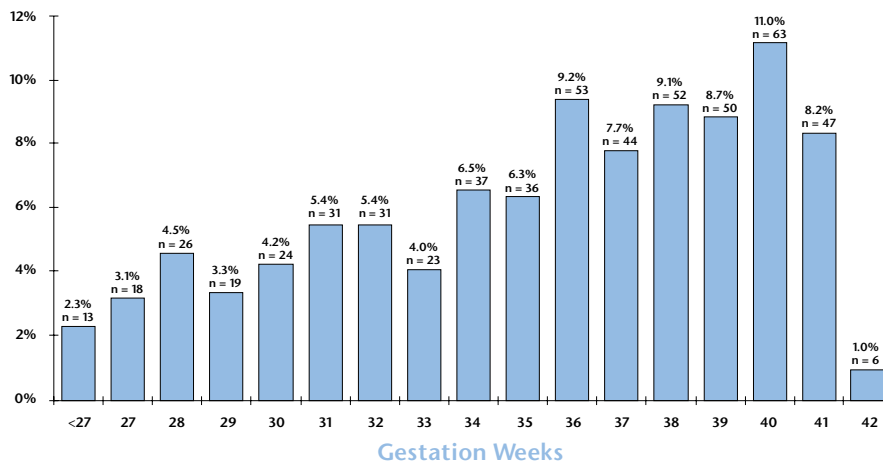


Figure 3.3 Gestational age distribution for the '1 in 10' enquiry programme



There were 422 (74%) stillbirths, 103 (18%) early neonatal deaths and 47 (8%) late neonatal deaths. One case, a baby found in a plastic bag, could not be classified.

There were 30 (5%) babies associated with a multiple pregnancy (28 twins, 2 triplets).

The majority of women (347, 61%) had uncomplicated pregnancies with no identifiable prepregnancy condition.

Postmortems were performed on 345 (60%) of cases. Of these 94% (326/345) were full postmortems. The panels found that the results of the postmortem modified the provisional clinical assessment in 15% (52/345) of cases. However, this is in the context of cases where congenital malformations had been excluded. It also does not emphasise the positive contribution that a negative postmortem can make. The reasons for no postmortem were parental refusal (164/228, 72%), failure of the professional to request (35/228, 15%), not known (29/228, 13%).

3.2.3 Cause of death

The cause of death for the 422 stillbirths and 150 neonatal deaths as defined by the extended Wigglesworth classification (see Appendix 2) applied by the panels at the enquiry is shown in Figures 3.4 and 3.5.

Figure 3.4 Cause of death using extended Wigglesworth Classification - 422 stillbirths

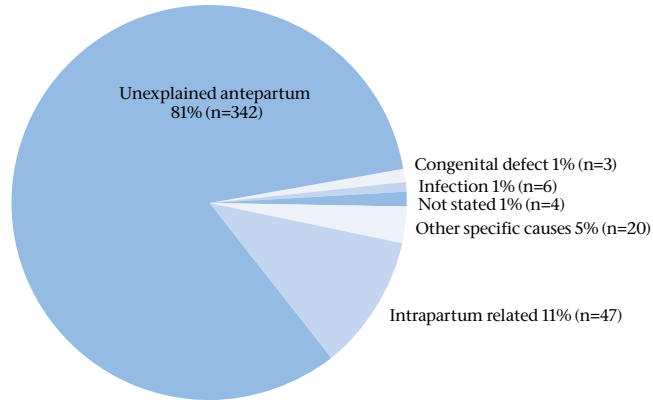
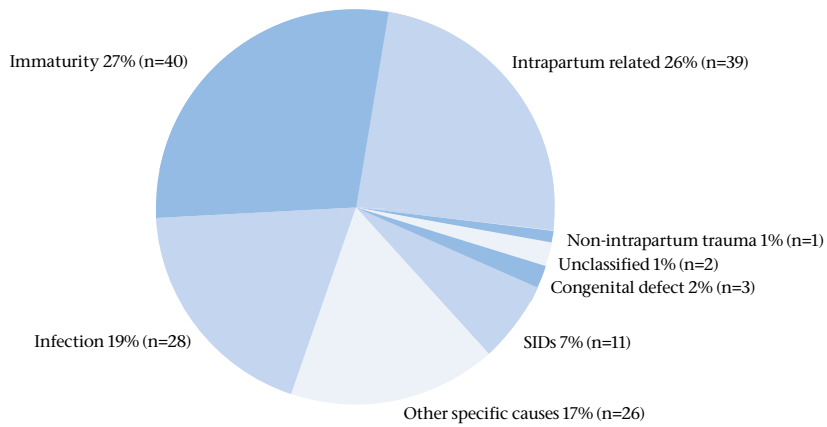


Figure 3.5 Cause of death using extended Wigglesworth Classification - 150 neonatal deaths



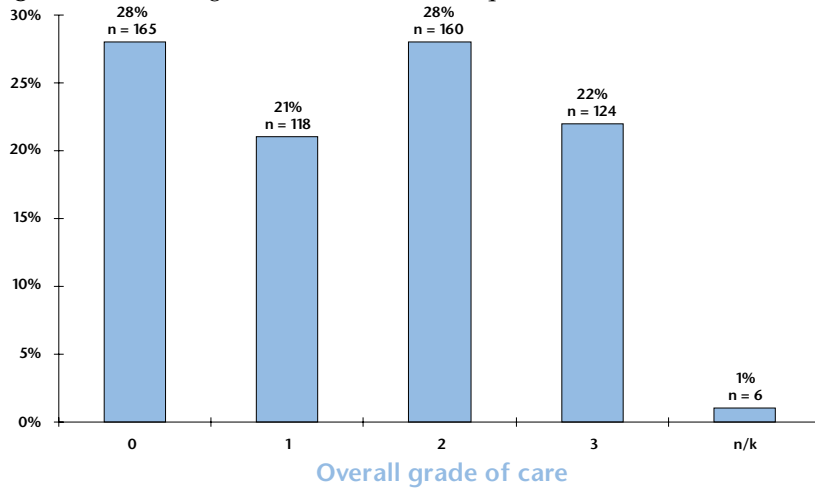
For stillbirths, unexplained antepartum death (342/422, 81%) and intrapartum related death (47/422, 11%) were the major causes.

For neonatal deaths, intrapartum related death (39/150, 26%), immaturity (40/150, 27%) and infection (28/150, 19%) were the major causes.

3.2.4 Panel findings

The overall grades of care are shown in Figure 3.6. Half were given an overall grade 2 (160) or grade 3 (124). The proportion of Enquiries with a grade 2 or 3 classified by Region varies between 19% and 67%. The variation in panel grading is discussed in Chapter 9. There were 1646 notable factors made on the 573 cases.

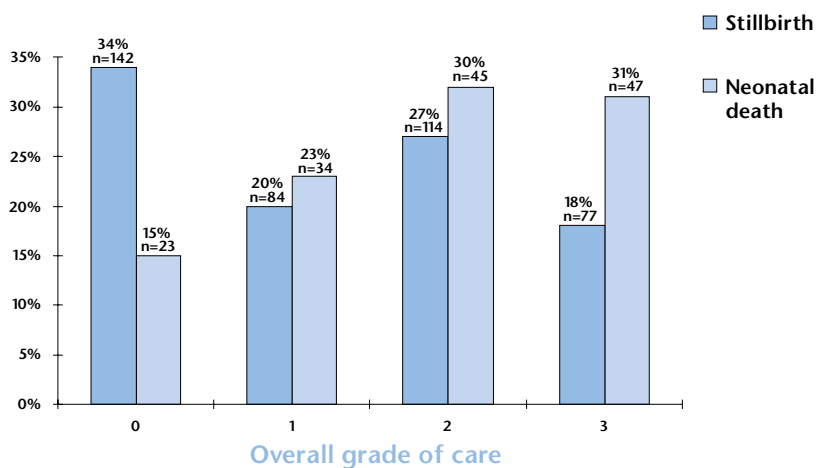
Figure 3.6 Overall grade of care '1 in 10' enquiries



3.2.4.1 Type of death and overall grade

The deaths were classified as stillbirths or neonatal deaths (Figure 3.7) and the distribution of overall care grades compared. A greater proportion of grade 2 (30%) and 3 (31%) were associated with the neonatal deaths compared with the stillbirths (27% grade 2, 18% grade 3).

Figure 3.7 Overall grade of care stillbirths vs neonatal deaths

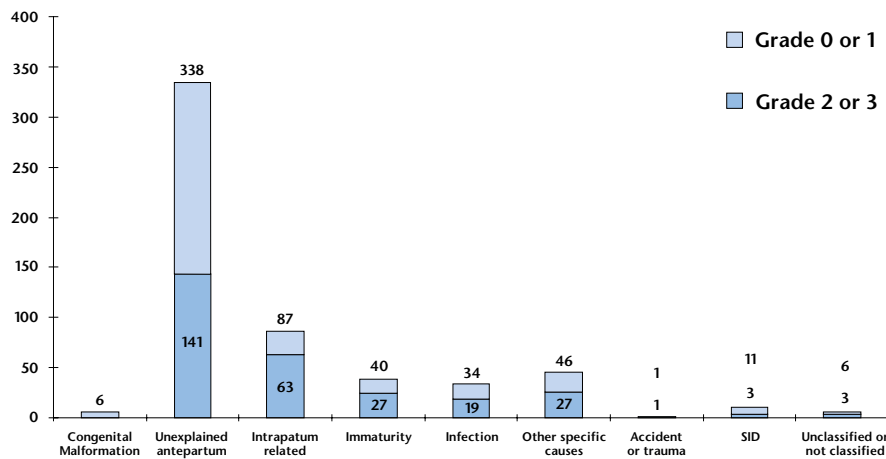


Overall grade of care was not known in 1% (5) stillbirths and 1% (1) neonatal death. The deaths were classified according to singleton or multiple. A greater proportion of grade 2 (9/30, 30%) and 3 (10/30, 33%) were given to the multiple pregnancies than to the singleton pregnancies (grade 2 (146/543, 27%) and grade 3 (119/543, 22%)(Table 3.1).

3.2.4.2 Cause of death and overall grade

These were classified according to cause of death (Extended Wigglesworth) and overall grade (Figure 3.8). Overall the greatest number of grade 2 and 3 (141) were in the unexplained antepartum category. However, intrapartum related deaths had the highest proportion of overall grade 2 or 3 (72%, 63/87), as compared to 42% (141/338) for unexplained antepartum deaths. The proportion of grade 2 or 3 in the smaller classes, immaturity (27/40, 68%) and infection (19/34, 56%) were also notable.

Figure 3.8. Cause of death and overall grade of care



Overall grades were not given for 4 unexplained antepartum cases. Using the other classification systems other categories were identified and the proportion of grade 2 or 3 described (Table 3.1).

3.2.4.3 Clinical conditions and overall grade

Clinical conditions are not necessarily the cause of the death. Rhesus isoimmunisation may be present but may not be the definitive cause of the death of the baby. The classifications used in CESDI refer to cause of death and are hierarchical. For example, infection may have been present but if congenital abnormality was the cause of death then the baby would not be counted in the infection category. Thus the number in a 'cause' category is usually less than the prevalence of the condition.

A basic data set was completed in association with the enquiry on the case describing pre-existing conditions. The panel was asked to identify the presence of a condition but not to confirm its absence. The accuracy of this is subject to the diligence at the time of the panel to complete this request. For example, 13% of enquiries did not state the presentation.

From these data various conditions were identified: gestational diabetes, pre-existing diabetes, previous stillbirth or infant death, multiple pregnancy, breech presentation and induction.

The occurrences of these conditions were identified and the proportion of overall grades 2 and 3 in these groups is described in Table 3.1. These overall grades do not relate directly to these conditions as other associated factors may have influenced the assessment.

Table 3.1 Cause or associated condition, occurrence in the '1 in 10' sample and proportion with overall grade 2 or 3

Cause of death or condition in pregnancy	Occurrence	Overall Grade 2 or 3 n (% of occurrence)		
Cause of death				
Unexplained antepartum fetal death	342	141	(41%)	
Antepartum Haemorrhage	103	45	(44%)	
Intrapartum death	87	63	(72%)	
Infection (maternal/baby)	34	19	(56%)	
Pre-eclampsia	31	20	(65%)	
Rhesus Isoimmunisation	4	4	(100%)	
Condition				
Pre-existing diabetes	16	12	(75%)	
Gestational diabetes	18	11	(61%)	
Past bad Obstetric History	27	16	(60%)	
Presentation	Breech	60	33	(55%)
	Cephalic	428	204	(48%)
	Other	9	6	(67%)
	Not stated	76		
Multiple pregnancy	30	19	(63%)	
Singleton pregnancy	543	265	(49%)	
Induction	274	128	(47%)	
Spontaneous labour	212	114	(54%)	

3.2.5 The contribution of stillbirths to the '1 in 10' enquiry

Of the 573 cases in the '1 in 10' enquiry, nearly three quarters (422; 74%) were stillbirths. The great majority of stillbirths occurred in the antepartum period with 11% occurring during labour (Table 3.2). The gestational range of the stillbirths was similar to the overall '1 in 10' group (range 26 (one case) to 42 (four cases) weeks), with a median gestation of 36 weeks. The lack of cases at very preterm gestations is understandable given the birth weight criteria set for the '1 in 10' enquiry.

This group is 6% of the 7329 stillbirths reported to CESDI in 1996-1997.

Table 3.2 '1 in 10' stillbirths by Extended Wigglesworth Classification

Extended Wigglesworth Classification	Stillbirths	
	Number	(%)
Congenital abnormality	3	(1%)
Unexplained antepartum fetal death	342	(81%)
Intrapartum asphyxia/anoxia/trauma	47	(11%)
Infection	6	(1%)
Specific causes (eg twin-twin transfusion, hydrops)	20	(5%)
Unclassifiable/Not specified	4	(1%)
Total	422	

3.2.5.1 Was there an explanation or cause for the stillbirth?

Three ways of identifying cause or explanation are reviewed: the classification at panel, the recorded risk factors at the panel assessment, and the postmortem findings.

Classification at panel

Three classifications are used in CESDI at the panel assessment (Extended Wigglesworth, Obstetric (Aberdeen) and Fetal and Neonatal). Essentially the names are self-explanatory with the Obstetric designed to identify 'maternal' causes and the Fetal and Neonatal identifying 'fetal' causes.

Congenital malformations (a category common to all classifications) were excluded from the Enquiries, so the distribution of underlying cause does not reflect their contribution in this gestational and weight range. None of the classification systems were particularly helpful in answering the question of explanation or cause of stillbirth. Identifiable causes accounted for: 17% using Wigglesworth, (Table 3.2); 21% using the Obstetric (Aberdeen) Classification (Table 3.3) and 16% using the Fetal and Neonatal Classification (Table 3.4).

In addition antepartum haemorrhage (a process rather than a diagnosis) accounted for 19% of the stillbirths.

The difficulties of devising a classification of perinatal mortality that satisfies obstetricians, neonatologists, pathologists and epidemiologists is well known (Wigglesworth J. 1980). The classification systems identify cause of death rather than pre-existing clinical conditions. Terms such as 'Antepartum Asphyxia' and 'Intrapartum Asphyxia' are not helpful in that they fail to clarify the underlying pathology giving rise to the asphyxia.

Table 3.3 Cause of death using Obstetric (Aberdeen) Classification

Obstetric (Aberdeen) Classification	Stillbirths	
	Number	(%)
Congenital abnormality	3	(1%)
Rhesus disease	2	(0.5%)
Pre-eclampsia	26	(6%)
Antepartum haemorrhage	80	(19%)
Mechanical factors	10	(2.5%)
Maternal Disease including infection	24	(6%)
Specific fetal conditions (eg twin-twin transfusion, hydrops)	22	(5%)
Unexplained or unclassifiable	255	(60%)
Total	422	

Table 3.4 Cause of death by Fetal and Neonatal Classification

Fetal and Neonatal Classification	Stillbirths	
	Number	(%)
Congenital abnormality	3	(1%)
Rhesus disease	2	(0.5%)
Antepartum asphyxia	347	(82%)
Intrapartum asphyxia	41	(10%)
Infection	5	(1%)
Miscellaneous (eg twin-twin transfusion, hydrops)	16	(3.5%)
Unattended/undocumented	8	(2%)
Total	422	

Risk factors at first antenatal visit or during pregnancy

Each enquiry was asked to complete a minimum data set from the case notes regarding the presence or absence of risk factors. A review of these concluded that whilst the majority of the fetal deaths occurred in 'low risk' women, a significant minority had fetal risk factors which were recognised either at the first antenatal visit (26%) (Table 3.5) or during the antenatal period (39%) (Table 3.6).

The results obtained are subject to the accuracy of note keeping (considered to be unacceptable in 33% (138/422) and the diligence of the panel to look for the

factor in the notes. They are likely to underestimate the true existence of 'risk factors'. However, the absence of a 'control' group in the enquiries precludes determining the relative risk of these 'risk factors' with a stillbirth.

Table 3.5 Fetal risk factors present at the first antenatal visit (422 stillbirths)

Fetal risk factors	Stillbirths	
	Number	(%)
None	318	(75%)
Maternal diabetes	15	(4%)
Hypertension	16	(4%)
Subfertility	19	(5%)
Other risk factors	54	(13%)
Total	422	

Table 3.6 Fetal risk factors arising during pregnancy (more than one risk factor might occur in a given pregnancy) (422 stillbirths)

Fetal risk factors	Stillbirths	
	Number	(% of 422 cases)
None	259	(61%)
Gestational diabetes	13	(3%)
Hypertension and/or proteinuria	84	(20%)
Vaginal bleeding after 20 weeks	36	(9%)
Other risk factors	55	(13%)
Total	447	

Postmortem findings

Postmortems were performed on 60% of the stillbirths (251/422). In the great majority of cases this was a 'full' postmortem (236/252; 94%). However, it should be noted that in 31 of the 252 cases (12%) that did have a postmortem performed the diagnosis was altered on the basis of the findings.

3.2.5.2 Was there evidence of suboptimal care in the stillbirth group? A review of the notable factors

For the 422 stillbirths, there were 1091 notable factors identified of which 756 factors were graded 2 or 3. These were due to either a failure to recognise a problem (30%), or a failure to act appropriately when a problem was identified (50%) or a failure in communication (15%) (see Table 3.7). The majority of these examples of suboptimal care took place in the antenatal period (31% outside hospital and 39% inside

hospital) (Table 3.8). Nevertheless, 18% of the examples of criticism related to care provided in labour (Table 3.8).

The 'post death' and 'neonatal' timing of notable factors related predominantly to suboptimal care and were not contributory to the death, for example the handling of follow up arrangements for the mother, incorrect counselling, and poor postnatal care. However, there were some notable factors describing a lack of any attempt at resuscitation, despite the presence of a fetal heart near to the point of delivery.

Not surprisingly, the professional group most commonly implicated in these examples of suboptimal care were the obstetrician (49%), followed by the hospital midwife (18%) (Table 3.9). The general practitioner and community midwife were each responsible in 6% of examples (Table 3.9).

The notable factors attributed to the pathologist generally relate to standards in the autopsy report.

Table 3.7 What was the problem? (756 notable factors graded 2 or 3)

What was the problem?	Grade 2 or 3 Noteable factors	(%)
Failure to act appropriately	377	(50%)
Failure to recognise problem	226	(30%)
Communication failure	116	(15%)
Failure to supervise	15	(2%)
Lack of human resource	7	(1%)
Factor not stated	15	(2%)
Totals	756	

Table 3.8 When did the problem occur? (756 notable factors graded 2 or 3).

When did the problem occur?	Grade 2 or 3 Noteable factors	(%)
Antepartum - inside hospital	298	(39%)
Antepartum - outside hospital	234	(31%)
Intrapartum	134	(18%)
Post death	73	(10%)
Neonatal	6	(1%)
When not stated	11	(1%)
Total	756	

Table 3.9 Who was involved? (756 notable factors, graded 2 or 3)

Who was involved?	Grade 2 or 3	
	Notable factors	(%)
Obstetrician	369	(49%)
Hospital midwife	137	(18%)
Family of patient	72	(10%)
Community midwife	48	(6%)
General Practitioner	43	(6%)
Other (professional)	25	(3%)
Pathologist	13	(2%)
Organisation	14	(2%)
Anaesthetist	4	(1%)
Paediatrician	8	(1%)
Person involved not stated	23	(3%)
Total	756	

3.2.5.3 Were the stillbirths avoidable? The overall grade

Whilst it is clear that a diagnosis was not evident in the majority of the stillbirths, it is nevertheless reasonable to examine whether the stillbirths were avoidable given the prevalence of suboptimal care. Thus, each assessment panel finished the confidential enquiry process by giving an overall grade of care to the case. This was usually the highest grade given in the case to individual examples of suboptimal care. The results are shown in Figure 3.7. Nearly half (45%) had an overall grade 2 or 3.

3.2.6 Losses other than stillbirths in the '1 in 10' enquiry

Numerically, stillbirths dominated the '1 in 10' enquiry programme; however, a review of other categories (intrapartum related deaths, multiple pregnancies, antepartum haemorrhage, pre-eclampsia, rhesus disease) found that the proportion of grade 2 or 3 within these smaller groups with the exception of antepartum haemorrhage ranged between 60% and 75% (Table 3.1).

These conditions range from those likely to be encountered by all general obstetricians (pre-eclampsia) to those where specialist care (diabetes and rhesus iso-immunisation) is called for.

The findings relating to intrapartum related deaths were similar to those reported in the 4th Annual Report published in 1997.

3.3 CONCLUSIONS

The objective of the '1 in 10' programme was to aid in informing decisions and methods involved in future enquiry programmes.

The main points are:

Stillbirths:

1. Stillbirths are the single greatest group contributing to deaths between 20 weeks and one year of age (35% of all losses reported to CESDI). The stillbirth rates for England, Wales and Northern Ireland had a downward trend up to the mid eighties and have remained unchanged in this decade (around 5.4/1000 total births). The '1 in 10' programme reviewed stillbirths in the restricted weight range where neonatal survival would be expected if delivery had taken place before the fetal demise.

2. There was no evidence of a specific cause in the majority of stillbirths. This is not surprising given the limited information on fetal health that is routinely collected in 'low risk' pregnancies. The wide diversity of pathologies amongst the causes identified suggested a multifactorial basis. Further case control studies will help determine the risk factors and the aetiology of stillbirths.

3. Although most of the stillbirths are classified as 'unexplained' the event is often thought of as 'unavoidable'. A review of these cases has shown that this is often not the case (45% grade 2 or 3). Whilst this may be an over emphasis of the relationship between care and outcome (see Chapter 9) it is clear that this is a priority area for ensuring high standards of antenatal care. To aid in drawing up appropriate guidelines a qualitative evaluation of the 1091 notable factors associated with the 422 stillbirths will be undertaken by CESDI in 1999.

4. Lack of knowledge of the cause does not imply that stillbirth rates cannot be reduced. For example, placing a baby on its back is an important factor leading to a reduction of Sudden Infant Death Syndrome (SIDS, 'Cot death') and yet the cause of this condition remains unknown. It is possible that a relevant social or behavioural intervention may one day contribute to significantly reducing stillbirths. However, currently there is a need for further research into the identification of the relevant risk factors. The study of antepartum term stillbirths was a pilot study for future work in this area (SATS, 5th Annual Report).

Intrapartum deaths

5. Intrapartum related deaths represent 15% of the '1 in 10' group. Of the major causes of death, intrapartum related deaths have the greatest proportion of grade 2 and 3 (73%). The panel findings were similar to those in the 4th Annual Report (a review of all intrapartum related deaths occurring in 1994 to 1995) which was published in 1997. There

has not been time for the recommendations to have any effect on clinical practice. However, it is clear this area in particular remains a priority for review in subsequent years.

Specific obstetric conditions

6. There were several areas highlighted for further evaluation, in particular pre-existing diabetes, gestational diabetes, multiple pregnancy and pre-eclampsia. Management of breech presentation was also criticised and would benefit from further assessment.

7. The '1 in 10' sample precluded accruing adequate numbers of very rare events such as deaths from rhesus isoimmunisation. However, those reviewed were consistently found to have problems associated with care. A focus group approach where all such deaths reported to CESDI (an estimated 20 to 30 occurring annually) are reviewed centrally would disclose if there were any specific practical issues needing to be highlighted.

Paediatric care

8. There were 99 grade 2 or 3 notable factors made pertaining to the paediatric management of the 573 cases enquired. Description of the main paediatric clinical issues in the '1 in 10' programme is under review.

The Enquiry method

9. The current classifications in CESDI are relevant for investigating cause of death. However, ready identification of co-existing maternal, fetal and neonatal conditions in addition to the cause of death is needed. A review of the ways of introducing coding of information collected on the rapid reporting form is underway. Easy and efficient identification of important clinical conditions is a priority for CESDI.

10. The variation in the grading assessments by panels is of concern (Chapter 9). This issue has been addressed in the second pass panel exercise (5th Annual Report) and the need for the provision of consistent standards and a structured panel enquiry form was identified. This has now been incorporated into the existing programme, Project 27/28 (Chapter 9).

REFERENCES

1. Wigglesworth J. Monitoring perinatal mortality: a pathophysiological approach. Lancet 1980; ii: 684-6

ACKNOWLEDGMENTS

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4

THE '4KG and over' ENQUIRIES 1997

4.1 INTRODUCTION

Large babies are known to be associated with an increased frequency of difficult deliveries, fetal distress, shoulder dystocia and gestational and pre-existing diabetes in the mother. All babies that died weighing 4kg and over were subject to a confidential enquiry organised by CESDI. Babies who died after the first month (postneonatal deaths) were excluded, but those with congenital malformations were included. The enquiry process has been described in Chapter 1.

4.2 RESULTS

4.2.1 Number of enquiries held

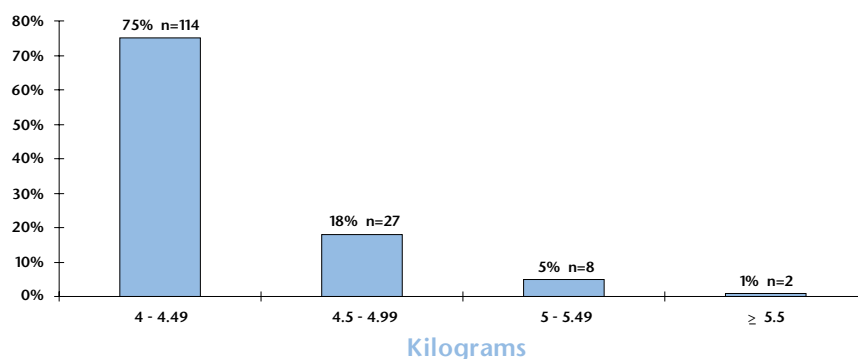
Enquiries were held on 151 singleton babies weighing 4kg and above who were stillborn or died within 28 days of delivery in 1997. There were 151 such deaths notified to CESDI via the Rapid Report Form (RRF). The mandatory absence of a link between enquiry and notification via the RRF to the central Secretariat precludes exact matching between the RRF and the enquiry case. This group represent 1.4% of all the losses reported to CESDI in 1997 (151/10,418).

In addition there were 47 postneonatal deaths with a birthweight of 4kg and over reported via the RRF; these were not included in the enquiry process.

4.2.2 Description of the 151 enquiry cases

The weight distribution of the 151 babies is shown in Figure 4.1. Three quarters were between 4 and 4.49kg with only 6% weighing 5kg and over.

Figure 4.1. Birthweight distribution of the 151 babies dying in 1997 weighing 4kg and over



Ninety-one (60%) were stillborn, 42 (28%) were early neonatal deaths and 18 (12%) were late neonatal deaths. There were no multiple births in this group. A postmortem was performed in 92 (61%) of these babies.

The median gestational range at birth was 40 completed weeks (range 33 to 43). There were 6 (4%) cases less than 37 weeks and 11 (7%) cases at 42 weeks and above.

The majority (86, 57%) of these women had uncomplicated pregnancies with no identifiable pre-pregnancy condition. There was one maternal death.

4.2.2.1 Gestational and pre-existing diabetes

Mothers with pre-existing diabetes accounted for 4 cases; all were stillbirths dying at 33, 35, and two at 38 weeks respectively. These represented 3.5% (4/114) of the total losses reported to CESDI for mothers with pre-existing diabetes. Mothers with gestational diabetes accounted for 12 losses (10 stillbirths dying at 36 to 41 weeks, and 2 neonatal deaths delivered at 41 and 42 weeks). These represented 9% (12/134) of the total losses reported to CESDI for mothers with gestational diabetes. The gestational diabetes had been identified prior to the death in all 12 cases. It is notable that seven out of twelve gestational diabetic losses were born after 40 weeks' gestation.

4.2.3 Cause of death

The cause of death for the stillbirths and neonatal deaths as defined by the extended Wigglesworth classification (see appendix 2) applied by the panels at the enquiry is shown in Figures 4.2 and 4.3.

Figure 4.2. Cause of death using extended Wigglesworth Classification - 91 stillbirths

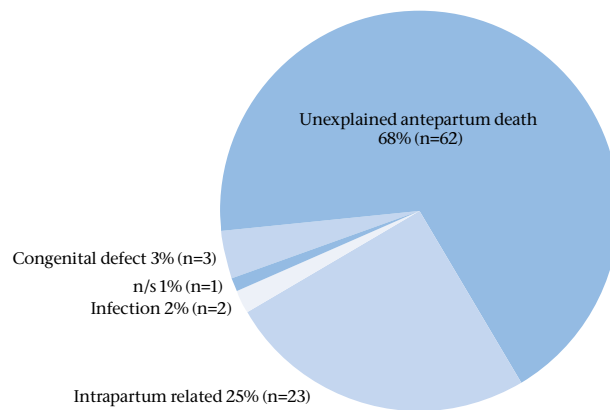
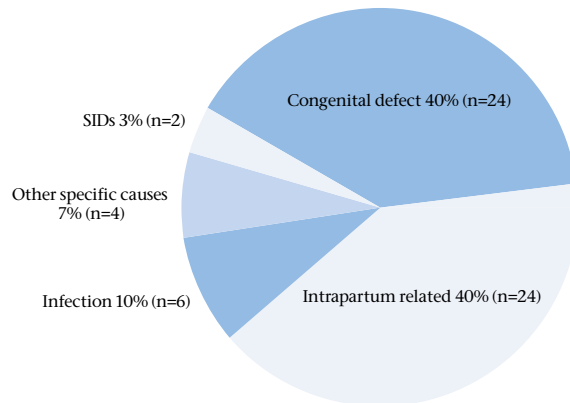


Figure 4.3. Cause of death using extended Wigglesworth Classification - 60 neonatal deaths



For stillbirths, unexplained antepartum death (62/91, 68%) and intrapartum related death (23/91, 25%) were the major causes. For neonatal deaths, congenital malformations (24/60, 40%) and intrapartum related death (24/60, 40%) were the major causes.

These figures are in broad agreement with information from the RRF: stillbirth causes - unexplained antepartum death (51/85, 60%), intrapartum related death (25/85, 29%); neonatal death causes - congenital malformations (32/66, 48%), intrapartum related death (25/66, 38%)

4.2.3.1 Intrapartum related deaths (47, 31%)

This accounted for nearly a third of the losses of large babies. There were 7 cases of shoulder dystocia, 8 of uterine rupture and 7 difficult attempted operative vaginal deliveries. The last review on fatal shoulder dystocia found that three quarters of all cases weighed 4kg and above (5th Annual Report).

4.2.3.2 Congenital abnormalities (27, 18%)

There were 26 babies (3 stillbirths and 24 NND) where the cause of death was a congenital abnormality.

There were 11 prenatal diagnoses, most at 19 to 21 weeks (congenital diaphragmatic hernias (3); posterior urethral valve (1); hydrocephalus (1); hypoplastic left heart (1); Meckel Gruber (1) with a minority in the third trimester (hypoplastic left heart (1) ileal atresia (1) spina bifida (1) and Apert's syndrome (1)).

Sixteen did not have the diagnosis made until birth or at postmortem. This group included congenital heart disease (8); inborn errors of metabolism (3); chromosome disorder (1); sacrococcygeal teratoma (1); Hirschsprungs (1); hydrocephalus (2).

Cardiac anomalies comprised the largest group of the abnormalities (10/27). There were 5 cases of hypoplastic left heart, 3 transpositions of the great vessels, 1 Ebstein's anomaly and 1 aortic stenosis. Only 2 were recognised antenatally.

There were 7 other deaths in which congenital anomalies may have contributed to their death but was not thought to be causative.

4.2.3.3 Infection (8, 5%)

There were 8 infants (2 stillbirths, 6 neonatal deaths) in whom infection was the main cause.

Of the 6 neonatal deaths, three acquired an intrapartum infection and died within 48 hours (1 Group B Haemolytic streptococcus, 2 culture negative). One child collapsed at home on day 8 and at postmortem was found to have a bacterial meningitis though all cultures were negative. A fifth child died on day 14 with disseminated herpes simplex virus infection and a sixth baby presented at 11 days with Group B streptococcus and was subsequently found to have galactosaemia.

4.2.3.4 Intracranial haemorrhage (4, 3%)

This is not a specific category of death but at review 4 cases of intracranial haemorrhage contributing to the death of these babies were identified. Three were associated with difficult deliveries and one appeared unrelated to the delivery.

4.2.4 A comparison of the causes of death for babies weighing 4kg and over at birth and those 2.5kg to 3.9kg.

The risk of the various causes of death (extended Wigglesworth) in relation to the weight of the baby at birth was calculated using data on all deliveries in England and Wales (Office of National Statistics (ONS)) in 1997 and the Rapid Report Form returns in 1997. The relative risk of the various causes was determined (Table 4.1). Postneonatal deaths were included in this data set.

Table 4.1. Cause of death up to 1 year of life (Extended Wigglesworth) by birthweight (Risks per 1000 total births based on 544,082 total births 2.5 to 3.99kg and 72,945 total births 4kg and over in England, Wales and N.Ireland)

Cause of death	4kg and over		2.5kg - 3.9kg		RR (95% CI)
	no (%)	Risk	no (%)	Risk	
Congenital Malformation	50 (25%)	0.69	489 (22%)	0.90	0.76 (0.57 - 1.02)
Unexplained Antepartum	51 (26%)	0.70	776(35%)	1.43	0.49 (0.37 - 0.65)
Intrapartum	51 (26%)	0.70	272 (12%)	0.50	1.40 (1.04 - 1.89)
Infection	18 (9%)	0.25	171 (8%)	0.31	0.79 (0.48 - 1.28)
Other, specific	6 (3%)	0.08	128 (6%)	0.24	
Accident /trauma	0		34 (2%)	0.06	
SID	20 (10%)	0.27	296 (14%)	0.54	0.50 (0.32 - 0.79)
Unclassifiable or Not classified	2 (1%)	0.03	23 (1%)	0.04	
Total	198 (100%)	2.71	2189 (100%)	4.02	0.68 (0.58 - 0.78)

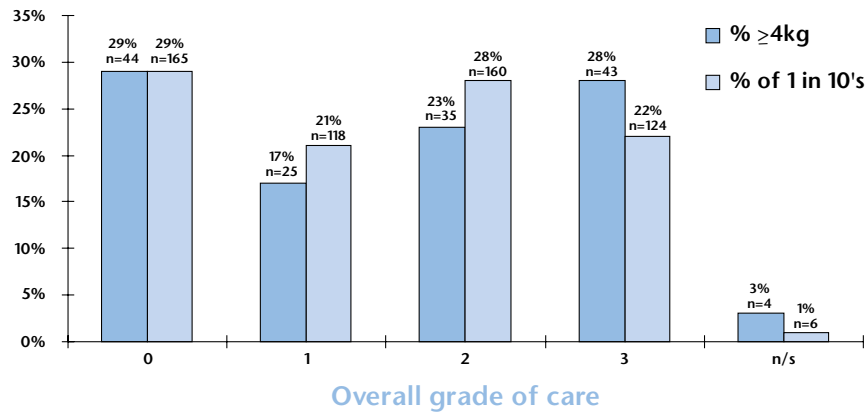
Overall the large babies were *less* likely to die than the smaller babies. However, the large babies were more likely to die from intrapartum related factors and less likely to die from unexplained antepartum factors and sudden infant death. Deaths from congenital abnormality were similar in both weight groups. The increased risk of unexplained antepartum death in smaller babies is likely to be due to the association with growth restriction. These figures highlight the importance of the risks of labour for big babies.

4.2.5 Panel findings

4.2.5.1 Overall grades

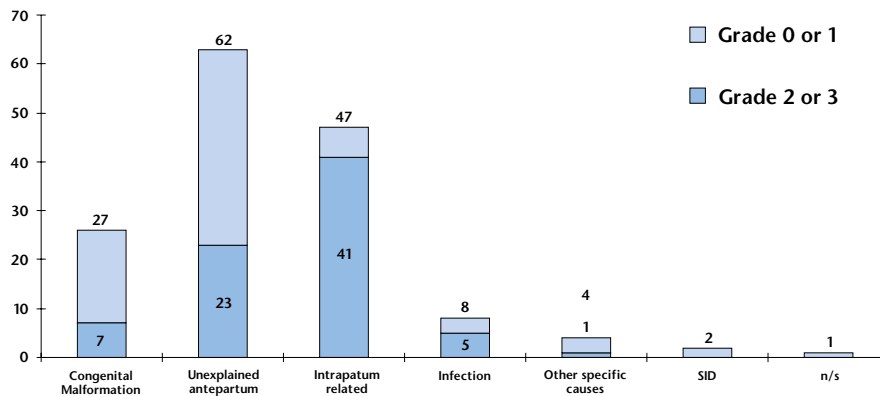
The overall grades of care as defined in chapter 3 are shown in Figure 4.4 together with those of the '1 in 10' enquiry sample.

Figure 4.4. Overall grade of care comparing '≥4kg' with '1 in 10' enquiries



These were classified according to cause of death using the extended Wigglesworth classification (Figure 4.5). Intrapartum related deaths attracted the greatest number (41) and proportion (41/47, 87%,) of overall grade 2 or 3, as compared to 37% (23/62) for unexplained antepartum deaths and 26% (7/27) for congenital malformations.

Figure 4.5 Overall grade according to the cause of death



4.2.5.2 Notable factors mentioned by the panels

There were 475 notable factors mentioned by the panels, of which only the 328 notable factors given a grade 2 or 3 (ie significant or major suboptimal care) are addressed here. They have been classified according to the type of problem and the time in the pregnancy when it occurred (Tables 4.2 and 4.3).

Most of the notable factors concerned the obstetrician (133, 41%), the midwife (82, 25%) and the paediatrician (37, 11%). A minority pertained to general practitioners (15, 5%) and anaesthetists (2, 1%). There were very few notable factors involving the mother or her family (11, 3%). The other notable factors related to the organisation (13, 4%), 'other' professionals (14, 4%) or were unstated (21, 6%).

Table 4.2 What was the problem? (328 notable factors graded 2 or 3)

What was the problem?	Grade 2 or 3 notable factors	
	n	(%)
Failure to act	155	(47%)
Failure to recognise	99	(30%)
Communication failure	43	(13%)
Failure to supervise	9	(3%)
Lack of human resource	10	(3%)
What not stated	12	(4%)
Total	328	(100%)

Nearly half of the notable factors (155, 47%) were classified as a failure to act appropriately with failure to recognise the problem (99, 30%) being the second commonest reason (Table 4.2).

Most notable factors referred to the antenatal (134, 41%) and the intrapartum (122, 37%) periods. In the neonatal period, most notable factors relate to care in the hospital (46, 14%) rather than in the community (2, 1%) (Table 4.3).

Table 4.3 When did the problem occur? (328 notable factors graded 2 or 3)

What was the problem?	Grade 2 or 3 notable factors	
	n	(%)
Antepartum	134	(41%)
Intrapartum	122	(37%)
Neonatal inside hospital	46	(14%)
Neonatal outside hospital	2	(1%)
Post death	11	(3%)
When not stated	13	(4%)
Total	328	(100%)

4.2.5.3 Notable factors attributed to obstetricians and midwives

A review of the individual notable factors pertaining to obstetricians and midwives revealed considerable overlap. The notable factors graded 2 and 3 have therefore been described jointly. Some of the notable factors were attributed to more than one grade of midwife or of obstetrician thus explaining the difference between the total of 215 notable factors and 169 'mentions' in Table 4.4

Table 4.4 What was the area of concern relating to obstetricians/midwives?

Notable factor	No of mentions
ANTENATAL	
Failure to recognise/act on macrosomia	15
Failure to recognise/act on high risk factors	11
No plan of management/inappropriate plan	8
Failure to diagnose/act on gestational diabetes	9
Failure to recognise abnormal CTG	3
Failure to diagnose fetal abnormalities	3
Communications (including record-keeping)	10
General	6
INTRAPARTUM	
Failure to recognise/act on high risk situation	6
Inappropriate use of Syntocinon	8
Fetal surveillance problems, including CTG interpretation	25
Poor management of labour	5
Inappropriate mode of delivery	10
Delay in delivery	9
Problem with shoulder dystocia	2
Inappropriate grade of staff involved	6
Communication failures	11
POSTNATAL/POST-DEATH	
Failure to perform investigations following stillbirth	4
Communications	3
General	3
ORGANISATIONAL/HUMAN RESOURCE PROBLEM	
	9
LACK OF SUPERVISION	
	3
TOTAL	169

A series of examples of cases of sub-optimal care follows. (Some details have been changed to protect confidentiality, but the essential points remain).

Failure to recognise/act on macrosomia

This was the commonest antenatal comment. Many related to the particular circumstances in which the size of the baby was disregarded, for example in women with a previous uterine scar.

Para 2 (LSCS for twins). Booked at Hospital 1, transferred to care of Hospital 2 at 35/40. Induced for post-maturity at 42/40. Ventouse

delivery attempted, mother very pale. Unable to deliver vaginally, so LSCS done, when uterine rupture discovered. Floppy infant, BW 4.78Kg, died a few hours later.

Panel comment: Despite frequent antenatal visits, the fetal macrosomia went unnoticed.

Failure to diagnose/act on gestational diabetes

Many comments related to the failure to appreciate the significance of impaired glucose tolerance, for example when biochemistry was noted to be grossly abnormal at 37 weeks 'immediate' review rather than a 'routine' appointment should have occurred.

Para 1. 91Kg at booking. GTT at 37 weeks abnormal. To be discussed with consultant, diabetic nurse aware. 3 days later, result discussed with Registrar. Appointment made for diabetic clinic. Admitted at term with meconium stained liquor. Fetal death diagnosed. Induction followed by normal delivery.

Panel comment: Grossly abnormal GTT at 37 weeks' gestation - no urgent action taken. Should have been delivered at this point.

Fetal surveillance problems, including CTG interpretation

The vast majority of comments relate to general care in labour and were not specific to the size of the baby. Fetal surveillance problems were the commonest, with CTG interpretation as the basis of the most frequent criticism.

20 year old primigravida, normal pregnancy. Admitted at term+14 in labour. Reactive CTG with some early brief decelerations. CTG discontinued for patient to use bath. Two and a half hours later, CTG recommenced. Profound bradycardia seen with large variable decelerations. 15 minutes later seen by SHO - VE 3cm, thick meconium draining. Half an hour later seen by Registrar - cord prolapse diagnosed. Immediate LSCS. Resuscitation abandoned at 25 minutes.

Panel comment: CTG very abnormal 50 minutes before delivery - needed to be delivered immediately.

Inappropriate mode of delivery/delay in delivery

There were several instances of failure to recognise that a prolonged second stage may be associated with mechanical problems because of a large fetus. The unwise attempts at vaginal delivery reflected the inexperience of the staff at the time of delivery.

30 year old primigravida. Late booking at 35 weeks. Prostin and Syntocinon induction at term. Meconium stained liquor noted at 9cm dilatation. Two and a half hours later, fully dilated, meconium liquor draining. CTG shows early decelerations. No descent of presenting part, no expulsive urge. Decided to wait one hour for descent. Contractions irregular, Syntocinon increased. 3 hours later, ineffective pushing, presenting part not advancing. Half an hour later, decision for forceps delivery. Further half an hour later forceps delivery of head. Suprapubic pressure required to deliver body. Birthweight >5Kg. Failed attempt to resuscitate.

Panel comment: Total failure to recognise obstructed labour. This was a four and a half hour second stage with little or no descent.

4.2.5.4 Notable factors attributed to paediatricians

There were 37 notable factors (2 and 3) relating to 22 babies (4 stillbirths and 18 neonatal deaths). Some factors were attributed to more than one grade of paediatrician, explaining the difference between the total of 37 notable factors and 32 'mentions' in Table 4.5

Table 4.5 What was the area of concern relating to paediatricians?

Notable Factor	No of Mentions
Delay in paediatrician being present at delivery	4
Poor resuscitation	7
Failure to recognise/diagnose specific conditions	7
Inappropriate management/treatment	8
Documentation/communication problems	5
Inappropriate transfer	1
TOTAL	32

A series of examples of cases of sub-optimal care follows.

Delay in paediatrician attending delivery

A number of comments related to the late arrival of a paediatrician, despite being called in advance of the delivery, or because they were not called when they should have been.

Para 1. Poor antenatal attender. Admitted in spontaneous labour. Bradycardia developed just prior to second stage of labour. Forceps delivery of pale, shocked infant. Cardiac massage commenced, oxygen given via bag and mask. Paediatrician arrived 6 minutes after delivery.

Panel comment: Paediatrician not present at delivery. Recorded in notes that s/he was called prior to delivery starting.

Poor resuscitation

There were repeated concerns relating to basic skills, particularly about delay or difficulty in intubation.

23 year old primigravida. Uneventful pregnancy. Admitted for induction for post-maturity. CTG criteria not met, transferred to Labour Ward, decision made for LSCS. Thick meconium at delivery. Paediatrician not present until 3 minutes of age. Baby transferred to SCBU with meconium aspiration++. Intensive therapy withdrawn on Day 6. Baby died soon afterwards.

Panel comment: a senior paediatrician should have been present at delivery as the paediatrician concerned appeared to be very inexperienced and had difficulty with intubation.

Failure to recognise/diagnose specific conditions

There were two areas highlighted: pneumothorax at the time of resuscitation, and the significance of heart murmurs in the neonate. A recent study (Ainsworth et al 1999) suggested that 50% of murmurs in the neonate have an organic cause. Echocardiography may be indicated.

Para 6. Uneventful pregnancy. Admitted with history of decreased fetal movements at 37 weeks. CTG satisfactory, but few fetal movements. Elective LSCS planned for next day. Baby delivered in poor condition. Loud cardiac murmur noted. Baby transferred to SCBU. Transferred to paediatric cardiology unit. Ebstein's anomaly diagnosed. Poor prognosis, died 2 days later.

Panel comment: There was a delay of 4 hours 30 minutes in recognising cyanotic heart disease, despite the loud murmur noted after delivery.

There were 5 babies who were found to have had pneumothoraces following resuscitation. Two of these were stillbirths.

It should be remembered that in any infant with a significant pneumothorax the heart rate may be extremely difficult to detect, and will in most cases only be found once the pneumothorax has been drained. Failure to diagnose a pneumothorax may result in the infant being labelled as a stillbirth. From this small sample there is a clear message to reinforce the teaching around "failure of a baby to respond to resuscitation." Having excluded other causes of failure to respond to resuscitation, it is of paramount importance to exclude pneumothorax.

Inappropriate management/treatment

There was a wide spectrum of comments in this group, ranging from inadequate doses of antibiotics or other drugs to ambivalence about whether or not to resuscitate a particular baby.

Documentation/communication problems

Failure to make adequate records featured in the criticisms of paediatric care. Communication between hospital and community staff was also criticised. The issues are similar to those raised in chapter 6 on standards of record-keeping.

4.3 CONCLUSIONS

Babies weighing 4kg and over are less likely to die than babies in the weight range 2.5 to 4kg during pregnancy and up to the first year of life. The main reason for this is that the latter group includes more unexplained antepartum deaths which are associated with growth restriction. However, the large babies are more likely to die intrapartum than the smaller babies. The true contribution of gestational diabetes to the deaths of these large babies cannot be assessed from the present data.

- Particular attention should be given to suboptimal care issues related to care in labour for big babies.

Diabetes and pre-existing diabetes

Only 3% of this group were from mothers with pre-existing diabetes and 8% of the cases related to known gestational diabetes. These deaths were predominantly stillbirths.

A review of the diabetic cases found that mature stillbirths (4 in this group) still occur despite apparently satisfactory control. The optimum timing of delivery continues to be debated, but these deaths all occurred prior to 38 completed weeks.

The contribution from undiagnosed gestational diabetes cannot be assessed in the absence of pathological investigation, but some studies have suggested that as many as 25% of babies weighing over 4kg have elevated cord blood insulin levels (Weiss et al 1984). It was also notable that 7 of the 12 losses in the gestational diabetic group were delivered after 40 weeks.

Antenatal care

Failure to recognise or act appropriately in a case with a suspected large baby was the commonest antenatal comment. However, there are differing views as to what is appropriate under these circumstances. Routine induction for suspected large babies is not recommended (Irion O and Boulvain M 1998), although this systematic review was underpowered to demonstrate relevant benefits. Elective caesarean section is also not recommended (Rouse et al 1996), but this is based on decision analysis rather than large randomised control trials. Should ultrasound estimation of fetal weight be recommended in a clinically suspected large baby? Probably not, as the inaccuracy of ultrasound estimates have been well documented. Indeed, it is possible that estimating fetal weight by late ultrasound may do more harm than good by increasing intervention rates. Clinical estimation and an experienced mother's own estimate both appear to be as good as ultrasound (Hall et al 1996).

The inaccuracy of estimating weight in utero inevitably means that actions directed at a 'big' baby will often be applied to babies of normal weight. Thus until accurate methods are available no specific recommendations can be made.

However:

- if a large baby is suspected then this fact should be communicated clearly to the team caring for the woman in labour.

Intrapartum care

The vast majority of comments relate to general care in labour and were not specific to the size of the baby. Fetal surveillance problems were the commonest, with CTG interpretation as the basis of the most frequent criticism. It is notable that there were 7 cases of shoulder dystocia in this group. Prolonged second stages and inappropriate choices for the mode of delivery were also often described. The unwise attempts at vaginal delivery may well reflect the inexperience and/or the lack of supervision of the staff at the time of delivery.

Thus with a clinically suspected large baby:

- the delivery team should be alert for delay in late labour. This includes careful documentation with the use of a partogram to monitor the progress of labour
- the delivery team should be alert for the possibility of shoulder dystocia and follow their local protocol
- experienced staff should decide on and undertake or directly supervise any instrumental delivery

All delivery suites should have:

- clear protocols for the management of shoulder dystocia (5th Annual Report)
- a high level of awareness and training of all birth attendants in the management of shoulder dystocia
- 'Fire drills' for the training of staff in the management of shoulder dystocia.

Care of the newborn

The most frequent adverse comment was delay in resuscitation for 4kg and over babies. Reasons included delay in the arrival of the paediatrician; difficulties in intubation; failure to identify pneumothorax; and lack of basic skills. These problems may be equally common in smaller babies.

All delivery suites should ensure that:

- there are clear protocols for calling a paediatrician
- the attending paediatrician has adequate experience in resuscitation skills

Paediatricians on call for the labour ward:

- must attend promptly when called urgently
- must be aware of the possible consequences of difficult deliveries including potential co-existing cerebral trauma
- having excluded other causes of failure to respond to resuscitation, must be alert to the possibility of pneumothorax

The significance of heart murmurs in the neonate is highlighted:

- echocardiography may be indicated in the presence of a heart murmur in the neonate

REFERENCES

1. Ainsworth SB, Wylie JP, Wren C
Prevalence and clinical significance of cardiac murmurs in neonates
Arch Dis Child 1999; 80: F43 - F45
2. Confidential Enquiry into Stillbirths and Deaths in Infancy
5th Annual Report
Maternal and Child Health Research Consortium, (1998) London
3. Hall MH
Guessing the weight of the baby
Br J Obstet Gynaecol (1996); 103, 734-736
4. Irion O, Boulvain M
Induction of labour for suspected fetal macrosomia (Cochrane Review)
In: The Cochrane Library, Issue 1, 1999. Oxford: Update Software

5. Rouse DJ, Owen J, Goldenberg RL, Cliver SP.
The Effectiveness and Costs of Elective Cesarean Delivery for Fetal
Macrosomia Diagnosed by Ultrasound
Journal of the American Medical Association (1996); 276:1480-86
6. Weiss PAM, Hofmann H, Purstner P, Winter R & Lichtenegger W.
Fetal insulin balance, gestational diabetes and post partal screening.
Obstet Gynecol (1984) 64, 65-68

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PERINATAL PATHOLOGY

5.1 INTRODUCTION

Asking recently bereaved parents for permission for a postmortem examination to be carried out is not easy, but such an examination may be the only way to provide answers to important questions posed, either by the parents, or by those caring for mother and baby. In some cases, the postmortem examination may answer the question “Why did my baby die?”, in others, it may exclude a number of possible causes of death or specific abnormalities and answer the question “Will it happen again?” and “How likely is it to recur?”.

Postmortem-derived information also makes an important contribution to reviews of perinatal death at national level.

If postmortem examination after perinatal death is to achieve these objectives, it is important that we are able to perform the examination on a high proportion of deaths and that the examination is carried out to a high standard. CESDI has produced information leaflets for parents (1993 and 1998) which, in conjunction with discussions with their baby’s carers, may help them understand the possibilities and limitations of the examination.

Informed consent is what parents are asked to give and earlier this year, CESDI supplemented the parental information leaflet by producing The Fetal and Infant Postmortem, Brief Notes for the Professional (Appendix 4). Its aim is to help those requesting permission for postmortem examination anticipate some parents’ questions and outlines good practice in a number of important areas relating to the fetal and infant postmortem. Copies of the leaflet were circulated to all hospitals in England, Wales and Northern Ireland, and further copies can be obtained from the CESDI Secretariat.

Because the well conducted postmortem examination can provide such important information after perinatal death, maintaining high standards of performance is important. Guidelines for perinatal postmortem were presented in the first CESDI Report (1993) and subsequently issued by the Royal College of Pathologists. An audit of postmortem reports was carried out by a panel of specialist perinatal pathologists in 1993-4. At that time 57% of 218 reports appeared to have followed the CESDI guidelines and 59% were rated as adequate or good. Two further audits were carried out during last year looking at reports from the Intrapartum Death Study in 1994-5 and the ‘1 in 10’ Sample Study of 1996-7.

5.2 AUDIT OF POSTMORTEM REPORTS ON INTRAPARTUM RELATED DEATHS 1994-1995

In 1994-1995 there were 1266 enquiries on normally formed infants weighing 1.5 kg or more whose deaths were related to intrapartum events and occurred in the first 28 days of life. There were 734 postmortems (58% of total). To review the trends in the standard of the reports an audit was carried out on 200 reports in early 1994 and 200 reports in late 1995.

Four Paediatric Pathologists undertook the audit. The documentation available for each case was the Rapid Reporting Form, the Regional Co-ordinator's summary of the case, the Confidential Enquiry Panel assessment form and the autopsy report which had been submitted to the Panel. All documents were anonymised before receipt.

The quality of the postmortem reports was assessed using a modification of the CESDI Pathology Audit Form 1993 (Figure 5.1). The 1993 form had contained items specified later in the minimum guidelines for postmortem investigation of CESDI deaths. The following aspects were audited:

- documentation of body measurements and organ weights
- external and internal description, placenta description
- undertaking of histology and relevant investigations
- summary of findings
- the pathologist's commentary

The subjective aspects were graded as good, adequate, poor or absent. A set of agreed pre-determined criteria for each section had to be fulfilled to categorise the section as adequate or higher. A scoring system using 5 point increments was applied to the audit form giving a maximum possible score of 145. The final score determined the overall category as poor (<70), adequate (70 - 109) or good (110 - 145).

Figure 5. 1: Form used for audit of pathology reporting

CESDI PATHOLOGY AUDIT FORM 97		
C.Enq.No:	Gestational Age:	Date of death:
Stillbirth/Neonatal Death	Age at death:	
Status of Report:	Provisional / Final	
Seniority of Pathologist:	Consultant / S.R. / Reg. / S.H.O. / N.K.	
Turnaround Time:	<6 weeks / > 6 weeks / N.K.	
P.M. Quality		Score
Clinical history:	missing / poor / adequate / good
External measurements:	none / CR / Ch / HC / FL / body weight
Organ weights:	none / lungs / heart / liver / brain / kidneys
	others (No. =)
	expected weights
External description:	missing / poor / adequate / good
Internal Description:	missing / poor / adequate / good
Placental Description:	missing / poor / adequate / good
Histology:	missing / poor / adequate / good
	lung / heart / liver / brain / kidney
	others (No. =)
Investigations:	Radiology Y / N / Nrec / Req.	
	Bact / Virology Y / N / Nrec / Req.	
	Genetics Y / N / Nrec / Req.	
	Others Y / N / Nrec / Req.
Summary:	missing / poor / adequate / good
Comment:	missing / poor / adequate / good
Total Score	

5.2.1 Findings of the audit

The 400 cases audited relate to intrapartum related deaths and represent 3.5 % of all postmortems reported to CESDI in 1994-1995.

There were 56 incomplete, missing or provisional reports which were excluded from the analysis (Table 5.1). There was considerable variation in the quality of reporting throughout 1994 and 1995 with final scores ranging from 20 to the full mark of 145. The mean score was 74 in 1994 and 81 in 1995 (Table 5.1).

Table 5.1: Quality Category of Autopsy Reports by Year

	1994	1995	Total
Incomplete	9	20	29
Provisional	19	11	30
Complete and final	173	171	344
Poor	81 (47%)	67 (39%)	148 (43%)
Adequate	66 (38%)	68 (40%)	134 (39%)
Good	26 (15%)	36 (21%)	62 (18%)
Mean score (range)	74 (25-145)	81 (20-145)	

Overall 47% in 1994 failed to reach the minimum acceptable standard compared to 39% in 1995 (Table 5.1). The reasons for this were largely because of poor scores for the subjective elements of the report. Some or all of body measurements and of major organ weights were stated in 95% and 94% respectively. Additional organ weights had been taken in 90% (Table 5.2). Missing or poor external descriptions occurred in 54% of reports and for internal descriptions this figure was 45% (Table 5.2).

Table 5.2: Number of cases in each Score Group by Section of Report for 1994/1995

Section of Report	No. scoring 0		No. scoring 5		No. scoring 10		No. scoring 15	
	1994	1995	1994	1995	1994	1995	1994	1995
External Measurements	11	7	31	15	131	149	-	-
5 Major Organ Weights	12	9	53	19	108	143	-	-
Other Organ Weights	17	17	156	154	-	-	-	-
Expected Weights	134	128	39	43	-	-	-	-
External Description	5	6	94	79	39	50	35	33
Internal Description	7	6	74	67	55	62	37	36
Placental Description	63	67	55	46	36	39	19	19
Histology Quality	39	23	67	63	33	48	34	37
Histology 5 Major Organs	84	78	-	-	89	93	-	-
Histology Other Organs	95	63	78	108	-	-	-	-
Investigations	107	95	-	-	66	76	-	-
Summary	43	45	66	57	46	36	18	33
Commentary	73	47	54	51	29	43	17	30

Total No of Cases in 1994 = 173; in 1995 = 171

Histology of the five major organs was taken in just over half of cases. There was a trend for additional organs to be examined in 1995 (63%) compared to 1994 (45%). Adequate reporting of histology improved from 39% in 1994 to 50% in 1995 (Table 5.2). Adequate description of the placenta was available in 33% of reports with minimal change between 1994 and 1995.

Relevant investigations increased from 38% in 1994 to 44% in 1995 (Table 5.2). A commentary was present in 58% in 1994 and 73% in 1995. There was an improvement in the proportion having an adequate or good content from 46% to 58% (Table 5.2).

5.2.2 **Summary of the audit**

In 1994 and 1995 the Confidential Enquiry Panels met several months after the death and so it was disappointing that 56 of 400 Confidential Enquiry Panels had only incomplete or provisional postmortem reports available.

The results show that there has been an improvement, albeit a small one, between early 1994 and the end of 1995, across the range of indices used for assessing the quality of postmortem reports. This ranged from the recording of objective data to the provision and adequacy of commentaries.

However, there is still considerable need to improve observational, diagnostic, and interpretative skills as an 'adequate commentary' was available for 43% of the 1995 cases and 'adequate reporting' of histology in 50%.

5.3 **A REVIEW OF A SAMPLE OF AUTOPSY REPORTS FROM THE '1 IN 10' ENQUIRIES**

As a supplementary to the detailed audit of postmortems from the 1994 and 1995 studies, a pilot study of the contribution of the postmortem to the '1 in 10' Sample Study conducted over 1996 and 1997 was also performed. Fifty postmortem reports of stillbirths coming to Confidential Enquiry during 1996 or 1997 were reviewed together with the clinical history summary made at the confidential Enquiry and the pathology component of the enquiry form. This review was undertaken by a single paediatric pathologist.

5.3.1 **Findings of the review**

Of these 50 cases, there was incomplete data in 4 and these were excluded. Of the remaining 46 cases, 36 (78%) were macerated stillbirths and classified as antepartum asphyxial deaths, unexplained; 5 were intrapartum asphyxial deaths, 4 of which were considered unexplained and 1 associated with pre-eclamptic toxemia; the remaining 5 cases were various single case examples including a congenital abnormality, an infection and idiopathic hydrops.

24 cases were considered to have an overall clinical suboptimal grade of 0 or 1, 22 cases of grade 2 or 3.

Pathology - adequacy

According to the check box on the pathology part of the Enquiry form, the postmortem reports were considered adequate in all cases. However, review of the reports and other comments made by the Enquiry panels showed that there were specific criticisms of the postmortem by the panel members in seven cases (15%). Histology was not performed in four, all of which appeared to be final reports. In three, no interpretation of the postmortem findings was made and important conclusions or statements omitted which would have provided additional information for clinicians.

These included:

- well documented birth weight and organ weights but failure to recognise that the indices showed growth retardation
- description of velamentous cord insertion but no consideration of whether this was a possible cause of an unexplained antepartum haemorrhage
- no estimate of maceration and possible timing of fetal death - whether this was an intrapartum or antepartum death remained unclear.

Pathology - contribution to the Enquiry

The check box on the pathology form indicated that the postmortem did not modify or contradict the clinical assessment in any case. Review confirmed that there was no indication that the major Wigglesworth category was altered except possibly in one where a discharge letter from consultant to GP attributed intrapartum death to infection, which was not confirmed at postmortem nor classified as such by panellists. That there were relatively few Wigglesworth category changes in this review compared with the study as a whole is probably due to the very high proportion of category 2 cases. Changes from category 2 to other categories would already have taken place at the enquiry stage, prior to this review process.

However, there were seven cases (15%) in which postmortem findings or conclusions contributed to the panel discussion. In four unexplained antepartum stillbirths, growth restriction, clinically undiagnosed, was identified (in addition to the case where IUGR was present but was not identified by the pathologist). In three cases, potential clinical diagnoses were confirmed or excluded: a true knot of the cord positively excluded as the cause of death; a diagnosis was shown to be intra-partum asphyxia, not infection; a tentative clinical diagnosis of infection was confirmed.

Other positive findings but which did not affect panel discussion were found in four cases (8.7%): unsuspected unilateral renal hypoplasia; features that suggested but that did not prove infection as the underlying cause of a case of idiopathic hydrops; the presence of chronic villitis of unknown aetiology in two cases of unexplained antepartum stillbirth.

5.3.2 **Summary of the review**

This review examined only a small proportion of postmortem reports (50/345) from the '1 in 10' Enquiry, predominantly stillbirths.

The findings reinforce the previous detailed audit and show that there is still a significant proportion of fetal postmortem reports that are issued without the basic elements such as histology. Additionally, it also illustrates that reports which are descriptive and/or simply record indices such as weights, are also inadequate and may not contribute as fully as they might to the clinical understanding of a case. Interpretation of the pathology in the context of the clinical history is critical.

Furthermore, it emphasises that the postmortem frequently provides additional positive information, even if that information does not alter, fundamentally, the clinical diagnosis of the underlying cause of death. This study suggests that the most common positive finding in the unexplained antepartum stillbirth is unsuspected growth restriction. This does not imply criticism of current antenatal care, but does suggest that improved detection of growth restriction might allow appropriate monitoring and possible prevention of a significant proportion of deaths currently considered unavoidable.

5.4 **CONCLUSIONS**

The perinatal postmortem can make an important contribution to our understanding of some deaths and have a potentially important audit function of both obstetric and neonatal management, within individual units and at a national level. If the postmortem is to fulfil these functions then it is important that the examination itself is of a high standard. Well conducted examinations produce more and better clinically relevant information than those of a poor standard (Cartlidge et al. 1995). We must, then, ensure that the postmortem itself is audited.

For this report two audits have been carried out. The first (Section 5.2) examined two sets of the reports of postmortems done on babies whose deaths were enquired into as part of the Enquiry programme into Intrapartum Deaths. It compared the reports from 200 deaths early in 1994, shortly after guidelines for postmortem examination had been issued by the Royal College of Pathologists, with 200 performed towards the end of 1995 when all pathologists might have been expected to have been familiar with the guidelines.

The audit highlights the marked variability of standard of postmortem reports on perinatal deaths. There was a small improvement in standard between the two groups; in 1994 those graded poor fell from 47% to 39% in 1995, but there is clearly much room for improvement. Attention is drawn to the paucity of descriptive detail. Failure to take samples for histological examination frequently contributed to the poor standard of reports despite the improvement in the number of organs sampled. The standard detail of reporting histological findings overall was disappointing. Perhaps a checklist of essential points covering descriptive and histological details could be drawn up by the specialist reviewers to remind general

pathologists about factors which are important and helpful in assessing the death.

Failure to examine the placenta continues to be a problem and labour wards should have policies in place that will ensure that all stillbirths and most if not all neonatal deaths will have their placentae examined (CESDI 4th Report p51-52).

The usefulness of a conclusion/commentary and a clinically-related summary is still not appreciated and continuing education is the only remedy here.

An audit of a small sample of postmortem reports from the '1 in 10' Sample Study was also carried out. Whilst the Confidential Enquiry process considered the reports adequate, there were, nevertheless, specific criticisms in 15%. Again, histological examination was omitted from a number of reports and pathological findings were not interpreted for clinicians.

Twenty four per cent of the reports contributed new, clinically relevant information. Failure of postmortem to change the Wigglesworth category on all but one case (at most) was not surprising in this small review. Primarily this was because the review examined mainly stillbirths in category 2. Postmortem tends to move cases from category 2 into other categories such as malformation, infection or specific condition (category 1, 5 and 6 respectively).

Another audit of postmortem reports examined the reports for those postmortems carried out in Wales as part of the All Wales Perinatal Survey (Vujanic et al. 1998). They compared the findings with those of an earlier study (1996 v 1993) and found a marked improvement in standards in all categories of fetal and infant deaths. Overall, the proportion of reports above the minimum standards increased from 54% to 93%. Part of this improvement was the result of transfer of babies to a Specialist Centre for postmortem; however, the standard was also raised throughout the region, with non-regional centres achieving the minimum standard increasing to 69% from 28% previously. Awareness of the importance of the examination as a result of guidelines and easy communication with specialists can, of itself, improve standards of postmortem reports.

A well conducted postmortem on a perinatal death can clearly make an important contribution to perinatal care. In order to maximise this contribution, it is important that postmortem examination is done on a substantial majority of (preferably all) perinatal deaths. The proportion of deaths where postmortem is done has fallen in recent years. Parents and, perhaps as importantly, clinicians will quite rightly maintain a critical eye on any investigation that is performed and certainly one that carries such emotional overtones as the postmortem. They will only be requested if they are clearly perceived as giving important information and it is unforgivable if a low standard of postmortem and reporting contributes to the decline of the procedure. An additional factor is the seniority of the person

requesting the postmortem. The NCEPOD enquiry into perioperative deaths in babies and children (Campling et al. 1990) showed a positive relationship with seniority. This success is not just because of status, but because he/she is more likely to have a clearer view about why postmortem is so important in that particular circumstance.

In order to assist junior staff, midwives and nursing staff as well as junior medical staff, CESDI has drawn together some Guidelines for Professionals to draw attention to the sort of things they need to know when they discuss the subject of postmortems and consent with parents, and to alert them to some of the questions parents may have. Some of these relate to local arrangements, others to legal requirements and consent to the procedure, as well as to the procedure itself and what happens afterwards. The Guidelines indicate the many reasons for doing a postmortem examination, the sort of information obtained and highlights what individuals need to know about local practices before being drawn into discussion of postmortem examinations with bereaved parents.

REFERENCES

Campling EA, Devlin HB, Lunn JN (1990) The report of the National Confidential Enquiry into Perioperative Deaths 1989. London 1990: p104

Cartlidge PHT, Dawson AT, Stewart JH, Vujanic GM (1995) Value and quality of perinatal and infant postmortem examinations: cohort analysis of 400 consecutive deaths. *Brit Med J* 310 :155-158

Guidelines for post mortem reports (1993) The Royal College of Pathologists, London

Vujanic GM, Cartlidge PHT, Stewart JH (1998) Improving the quality of perinatal and infant necropsy examinations: a follow up study. *J Clin Pathol*: 850-853

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6

RECORD KEEPING

6.1 INTRODUCTION

Record keeping is a vital part of the care and communication process, and the quality of the record keeping reflects the skills and safety of the practitioner. Good records should provide clear evidence of the care planned, the decisions made and the care delivered, and as such, should be a product of good teamwork.

Unfortunately, documentation is sometimes viewed separately from the rest of the care being given; an optional extra to be fitted in if time allows. Giving such low priority to what should be considered an integral part of patient care, can have serious implications. If events do not get recorded as they occur, or as soon as possible after, important details may be omitted and communication between professionals impeded as a consequence.

Previous CESDI Reports have drawn attention to deficiencies in communication and their significant contribution to sub-optimal care, with poor and illegible case notes being a significant part of the problem. As part of the '1 in 10' confidential enquiry, the standard of record keeping was once again commented upon.

The panels were asked an open question with regard to the standard of record keeping observed in each of the case notes. They were not given any specific standards for use as an audit tool, but panel members would have been familiar with any record keeping guidelines issued by their own professional bodies.

The question, "Was the standard of record keeping adequate in this case?" required a 'Yes/No' answer, followed by a free text area for further comment.

6.2 RESULTS

Out of 573 enquiries, the panels answered 'NO' in 194 (34%) cases and made additional comments in 176 of these. Sometimes there were multiple problems identified within one comment and having itemised all these problems, there were 210 in total. Table 6.1 shows how the comments were categorised.

Table 6.1: Problems with record keeping identified from comments made by the panels

	No. of comments where problem mentioned	% of all problems (n=210)
Insufficient detail/No plan of care	97	45%
Absent dates, times and signatures	29	14%
Missing documentation	27	13%
Errors and inaccuracies/retrospective additions	27	13%
Badly organised notes	16	8%
Illegible hand-writing	14	7%
Total number of problems mentioned	210	100%

6.2.1 Insufficient detail/No plan of care

This was the most frequently mentioned problem. The panels often commented on the lack of written detail and sub-standard record keeping of some or all professionals involved in a case:

“Inadequate fetal heart recordings. Record keeping not adequate according to recognised midwifery guidelines”

“Documentation used and method of record keeping sub standard.”

“No record of FH on partogram whilst in second stage for over 2 hours (CTG recording inadequate at this point)”

There were many additional references made to the lack of clear documentation regarding any decisions made and the subsequent plan of care once complications had been identified:

“There was no record of antenatal planning. There was no decision making during labour recorded eg the reason for not doing a LSCS and none of the subsequent decisions were adequately documented”

Deficient documentation is not only of concern because it hinders communication between professionals involved in a case but it also has legal implications. In the medico-legal setting, the approach of ‘if it is not recorded, it has not been done’ is generally adopted.

6.2.2 Absent dates, times and signatures

This category included incidences where dates and times were missing from notes making it difficult to follow the sequence of events. Entries were frequently unsigned and it was often impossible to determine the status of the professionals giving the care:

“Crucial times, dates and signatures missing”

“Panel unable to assess who giving care eg. Speciality and grade”

Being unable to identify the status of individuals was a significant problem for the panels. Trying to make an accurate assessment of the level to which individuals were, or indeed should have been, involved in a case, was often very difficult.

6.2.3 **Missing documentation**

Panels often referred to incomplete, missing or lost records, making it impossible to get a complete representation of the case:

“The maternal history and antenatal information was incomplete”

“ There were a lot of notes missing, the records were not in sequence and made it extremely difficult to follow”

“Part of labour notes lost”

It is unclear from the comments exactly why some of the documentation was missing. In general, every effort is made by the regional coordinators to obtain full sets of photocopied anonymised notes, so it can only be assumed that some of the original notes must have been lost. Indeed, there was one incident where the panel commented not only on the missing documentation, but also that it was someone else's partogram that had been included in the notes.

Sometimes sections of the notes were missing from the referring hospital, where two or more units were involved:

“Antenatal records from referring hospital missing at end of pregnancy”

6.2.4 **Errors and inaccuracies/retrospective additions**

This category included not only errors with written documentation but also inaccuracies with computerised entries:

“Sloppy details and often frankly inaccurate.”

“Computer generated notes were particularly poor”

A large proportion of the comments in this category referred to retrospective additions and alterations to the notes. Of course, it is permissible to amend notes after the event, provided that they are dated, timed and signed appropriately¹. However, it is unclear whether this was fully acknowledged by all panels:

“Records were amended without explanation....”

“Notes had been written retrospectively by both the midwives and the obstetricians.”

“The original history was inadequate. Additions were made to the notes, but not signed or dated. The notes are difficult to read. There was no plan of care postnatally.”

6.2.5 Badly organised notes

These comments generally referred to the notes being out of sequence and often muddled, making them confusing and difficult to follow. This is of concern as the regional coordinators take great care to organise the notes as logically as possible:

“The notes were out of sequence, and were confusing. Obstetric and medical notes were kept separately.”

One way to overcome this problem would be to use a well-designed universal record. The National Maternity Record Project² has already produced the antenatal section of a uniform record such as this, and it is currently being used in about 30 units around the UK. Both the labour and postnatal sections of the record are still under development.

6.2.6 Illegible handwriting

There were references not only to the poor legibility of the documentation in this category, but also to the fact that some entries were not written in black ink, giving poor quality photocopies:

“Poor legibility of GP notes with idiosyncratic use of abbreviations”

“Illegible handwriting. Not comprehensive record keeping”

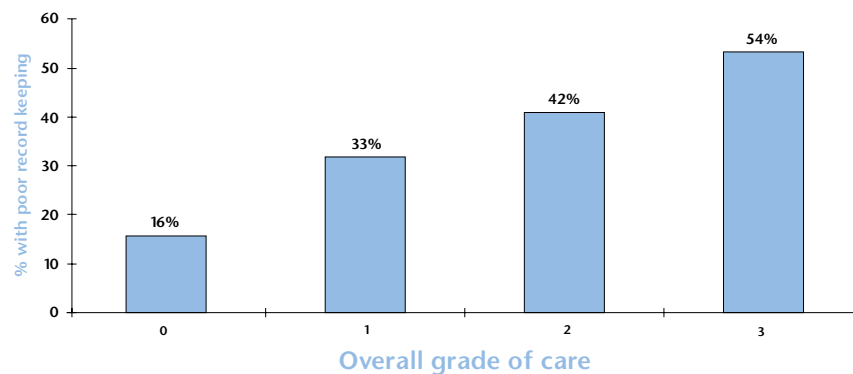
“Notes difficult to read in places - due to poor writing and possible blue biro”

6.3 OVERALL GRADE AND POOR RECORD KEEPING

Figure 6.1 shows the relationship between the overall grade of care given to each case and inadequate record keeping as assessed by the panels in the ‘1 in 10’ enquiries.

It is clear from Figure 6.1 that the highest proportion of notes with poor record keeping (54%), were in the Grade 3 category of sub-optimal care. However, it would be wrong to assume that this means that poor record keeping and poor care always occur together. In fact in 16% of the cases where panels found no evidence of suboptimal care, poor documentation was still observed.

Figure 6.1: Relationship of grade of care to poor record keeping - ‘1 in 10’ enquiries



One possible reason for the high rate of inadequate record keeping in Grade 3 cases could be that the enquiry process relies on the content of the case notes to assess the standard of care. If the panel have to grade the care using incomplete information, this may influence them to award a higher grade of sub-optimal care to the case.

6.4 CONCLUSIONS

Poor record keeping occurred in a third of all enquired cases. The major problem identified from the comments was a failure to document events adequately. This has significant medico-legal consequences and highlights an area of care and communication that could easily be improved at minimal cost.

Obviously, this review only includes cases where a death occurred, and therefore may not be representative of record keeping in general.

The lead from the UK Central Council for Nursing, Midwifery and Health Visiting on its production of 'Guidelines for records and record keeping' (1998) is to be commended.

6.5 RECOMMENDATIONS

It would appear that the recommendations of previous reports with regard to record keeping remain unchanged. These were that:

“ All professionals should make clear and adequate notes. The standard should be that which enables a colleague coming new to the case to be properly informed.” (paragraph 9.3.10. of 3rd Report and 9.4. of 5th Report)

“ The quality of maternity records needs to be improved to enable clear identification of risk factors and documentation of management plans for these during both antepartum and intrapartum periods. These would be facilitated by a well-designed, universally used national maternity record.” (paragraph 10.2.4. of 4th Report and 9.4. of 5th Report)

REFERENCES

1. UKCC - Guidelines for records and record keeping - 1998
2. National Maternity Record Project
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CESDI AND THE NAB

7.1 THE ROLE OF THE NAB

Between 1992 and March 1996, the original, rather large NAB advised Health Ministers on the annual programme of CESDI, prepared the annual report and generally supervised CESDI. When in April 1996 the management of CESDI was contracted to the MCHRC, the reconstituted NAB advised the Consortium on the CESDI programmes and annual reports, on proposals for CESDI research and evaluation and on proposals for guidelines designed to improve clinical care for pregnant women and infants. Thus, the NAB retained a broad policy input into the work of CESDI which was not simply left to the professional bodies themselves. The present NAB consists of an independent (lay) Chair, nine health professionals and three parental voices.

The members of NAB have always acted in a personal capacity, not as delegates for any particular interest. Individual members sit on panels and focus groups and, increasingly, help to draw up the protocols for the annual programme and to prepare draft chapters of the annual reports. Many of them will continue to provide help and advice to the MCHRC.

The NAB will cease to exist after March 1999 when CESDI is brought within the ambit of the National Institute for Clinical Excellence, but it is understood that there will be no diminution of the value placed on expert and independent professional and patient (i.e. from parents) advice in the new environment. This is important.

7.2 DEVELOPMENTS IN CESDI SINCE 1992

NAB members consider that the following themes have been crucial to the success of CESDI so far and will be important in its future development:

- the regional / central organisation of CESDI;
- the choice of the annual programme;
- the contribution that parents may make to CESDI;
- the implementation of CESDI findings.

7.3 THE REGIONAL / CENTRAL ORGANISATION OF CESDI

It was always the intention that CESDI should be regionally based but operate within a national programme.

The methodology of CESDI has improved considerably over the years. The rapid reporting system now works to a high degree of accuracy. While confidential enquiry conducted by different panels is inevitably a subjective process, assessments of sub-optimal practice in CESDI are becoming more similar over time. Focus groups at national level - a CESDI innovation - consider the accumulation of cases of small groups of deaths such as shoulder dystocia and prepare recommendations.

At all levels the different professionals concerned with CESDI are finding it an increasingly valuable part of their own professional experience to pool their knowledge of the causes of these tragic deaths. Over time they have become less defensive of particular professional interests, perhaps more critical of professional colleagues, and more ready to take an interdisciplinary view.

The regional organisation of CESDI makes it more extensive and complicated than other confidential enquiries. Experience shows that this has helped in the dissemination of the findings. Moreover, in broad terms, the educational value of regional panels for the professionals in the regions is more valuable than the consistency of results that would come from a national enquiry panel. (Extreme judgments by panels can be balanced in the national assessment of findings.) A degree of variation in panel judgments may indeed have some advantages. What is interesting and relevant to CESDI in many cases is not so much the degree of blame - whether sub-optimal practice in a case is graded 1, 2 or 3 - as the types of failures involved. These are related predominantly to professional care, but parental care, social circumstances and organisational issues are also involved; and each requires judgments about how the risk of the same types of failures can be reduced in future.

Experience shows that diversity in the judgments made by different panels has not only drawn particular attention to areas where the professional bodies could usefully draw up new guidelines, but that it can also lead to ideas for further improvements and a shift of the mean standard of care over time.

Experience also shows the need for a strong and dedicated team of regional coordinators and for the central secretariat, while small, to be adequately staffed to perform its tasks, including the management of CESDI funds. NAB members consider it important that this experience and goodwill, both regionally and at the centre, is maintained under the new arrangements and that full and continuing use should be made of the valuable stores of CESDI data.

7.4 THE CHOICE OF CESDI PROGRAMMES

Because the number of deaths in the CESDI range is some 10,000 it was accepted from the start that the focus of confidential enquiry would change from time to time as progress was made. The right time to change is about every two or three years.

The 1993 to 1995 programme was designed to have some interest for all those, professionals and parents, concerned with CESDI: the theme was why apparently normal babies who would be expected to do well had not survived. It covered intrapartum related deaths of babies above specified weight levels in all NHS regions; sudden unexpected deaths in infancy in a few selected regions with appropriate epidemiology and pathology resources (the SUDI studies); and a study into normally formed antepartum stillbirths in one region (the SATS study). Late fetal losses were also counted for the first time.

The 1996/1997 programme included a '1 in 10' random sample of deaths of babies weighing at least 1000 grams up to age one month, plus (in 1996) some second pass panel work and (in 1997) special projects concerned with sub-groups of deaths. This was seen as a means of identifying future programmes.

The current area of focus is babies born at 27-28 weeks gestation. Most of these babies are expected to survive, so variations in care will have an impact on the outcome.

7.5 THE INVOLVEMENT OF PARENTS IN CESDI

In almost all deaths in the CESDI age range the mother, who has a unique knowledge of and relationship with the baby, survives. The circumstances of the family and the home also influence the baby's chances of survival. Parents want to know why their baby died and to help other parents avoid the same experience. Voluntary organisations, notably the Stillbirth and Neonatal Death Society (SANDS) and The Foundation for the Study of Infant Deaths (FSIDS) which support bereaved parents, want to contribute to CESDI. The question is how to make the best use of what parents and voluntary organisations can contribute while preserving essential confidentiality.

Taking this by stages, in 1992 an ad hoc group of parental representatives chaired by a NAB member accepted that there could be no feed-back of the results of confidential enquiry in individual cases. However, it emphasised the need for early feed-back to parents from the local perinatal case discussions. The NAB later recommended that the anonymised results of those discussions should also be made available to the regional confidential enquiry panels. Also in 1992, under the chairmanship of a NAB member, a leaflet on postmortem examinations was developed for bereaved parents: this was reviewed in 1998 and is in regular use throughout the U.K.

In 1993, the SUDI project included a case control study which involved interviewing the parents of the dead baby and of four control babies. The SATS study included interviews with the parents and two controls. In its 3rd Report, the NAB concluded that in the CESDI age group parental interviews of index babies and controls were an essential source of information not otherwise available and recommended that they should be used wherever possible.

The present NAB includes three 'parental voices' who play a full part in all its work. They have paid particular attention to the implementation of CESDI findings and to the improvement of communications and understanding between professionals and parents and - which is equally important - vice versa, and between the professionals themselves. It is hoped that the literature survey described in Chapter 8 will provide information about good practice in communications and suggestions for future work and parental involvement in CESDI.

7.6 IMPLEMENTATION OF CESDI FINDINGS

It was a major weakness of CESDI in its first four years that the NAB

could publish findings and recommendations to Health Ministers but had no power or responsibility for implementation.

Many of the most important CESDI findings and recommendations relate to matters of professional practice. As the 2nd Report said: "The main failures from the 1993 enquiries, as the panels themselves recognised, were not those of lack of equipment, but of human beings and the particular circumstances in which they found themselves. The human factors included insufficient skills, inappropriate attitudes and apparent lack of senior accountability. Thus three common themes - communication failure, training issues and the need for clear clinical guidelines - apply to all the NAB's recommendations including those relating to risk assessment and management of clinical problems and emergencies". These themes have recurred in subsequent Reports.

The need is to ensure that the lessons learnt from CESDI are translated into specific and focused advice and action, in particular for and by health professionals. Better training or better supervision for professionals - or indeed other recommendations flowing from CESDI findings - obviously have resource implications. However, improvements should be set in the context of clear and auditable clinical guidelines and standards. The bodies directly responsible for professional practice and training must be involved in implementing such recommendations whether singly or, increasingly, as shown in Chapter 8, as part of multi-disciplinary initiatives. Care in CESDI is interdisciplinary and optimal results are achieved by maximising team work between the different disciplines involved in care.

The 1996 contract with the MCHRC therefore gave high priority to the development and issue of guidelines to improve clinical care for pregnant women and infants. It also required that a proportion of CESDI research funds be spent on the evaluation of the way in which CESDI findings have affected professional practice.

Recent Reports have made specific recommendations for consideration by the Colleges and the professional bodies responsible for clinical training and practice. At the request of the NAB the 5th Report also included for the first time the responses made by these bodies to recommendations in the 4th Report which had focused on enquiries into intrapartum death. Progress was regarded as highly encouraging.

7.7

CONCLUSION

NAB members are encouraged by the progress made by CESDI so far and wish every success to those who will carry forward its work.

ACKNOWLEDGEMENT

Author:

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CHANGING PRACTICE

8.1 DISSEMINATING THE INFORMATION

The findings of CESDI are important to both individuals and the professional bodies. The messages are wide ranging and are applicable to the entire spectrum of health workers, ranging from doctors, midwives, nurses and health visitors to coroners, and at times they are particularly relevant to parents. The appropriate dissemination is therefore of paramount importance.

In 1998 a study was commissioned from the Office for Public Management on the dissemination of CESDI findings to professionals. It found that awareness of CESDI is very high amongst midwifery professionals, and senior clinicians and managers in other specialities, but that awareness falls for front line staff, and in particular for paediatric and neonatal staff. It appeared that the main source of awareness is the Annual Report, and direct involvement in CESDI activities such as data collection and attending panel enquiries. Encouragingly, the Annual Report was rated highly by those surveyed, and the consistency of message, whilst criticised by some, was generally considered important in that key messages are seen to be reinforced. Some of those surveyed questioned the validity and reliability of the data, and it was apparent that many professionals are unfamiliar with the CESDI methodology.

The survey found that the current dissemination process is patchy. It works well for Health Authorities, where the Report is targeted at the Director of Public Health, but in Trusts, dissemination is variable. Frontline staff rarely had access to Annual Reports, and there appeared to be confusion as to who was responsible for disseminating copies of Reports. Trusts which have direct contact with Regional Co-ordinators identified this as a positive and powerful way of communicating CESDI messages. The impact of CESDI findings and recommendations was very difficult to quantify, but the general view was that CESDI reinforces and repeats key concerns and messages.

A number of areas for action are being considered in response to the findings above. In particular, improving the dissemination of CESDI information within Trusts is a key objective, and new mechanisms for distributing CESDI information, such as through a "key contact" network are being explored. With the aim of trying to improve the awareness of CESDI's objectives, processes and mechanisms, the CESDI Website, which will contain background information, the Executive Summary and updated news on Project 27/28, and other ongoing work, is in development. CESDI Reports and articles are to be referenced wherever possible through Medline. Presentation of the findings of the Reports, the new programme and ongoing research to regional and national meetings are another, direct, attempt to reinforce awareness of the CESDI mechanisms and process.

Closer links are being forged with each of the parent Colleges, through the representatives of the ESG, and links with other Colleges such as the RCN and RCGP have also been improved. The current work programme, Project 27/28, requires involvement by neonatal staff in the collection of data, and it is hoped that this, together with a concerted effort to disseminate information in a more targeted way, will improve awareness of CESDI in these specific groups.

As the survey illustrated, CESDI information is better received and acted upon when the recipients have had personal contact with CESDI staff, and therefore Regional Co-ordinators have an important role in dissemination, and the use of Regional Reports and regional meetings is encouraged.

It is clear from the survey that whilst many professionals are aware of the findings of CESDI, particularly at a more senior level, the dissemination process can be improved. Action is being taken at both central and regional level, and this will be ongoing. One of the roles identified for the new National Institute for Clinical Excellence (NICE) is to disseminate guidelines, examples of best practice and audit findings. In "A First Class Service - Quality in the new NHS" (Department of Health, July 1998) the importance of the National Confidential Enquiries is stressed, and a key role for CESDI will be in contributing towards the development of appropriate NICE guidance and ensuring effective clinical governance locally, and CESDI looks forward to working with NICE in this.

8.2 FEEDBACK FROM READERS OF THE FIFTH CESDI REPORT

Last year, a reader questionnaire was enclosed with the Annual Report. Whilst the response rate was a little disappointing (to date some 200 forms have been returned out of a possible 3000) the findings do give some indication of the readership of the Report and the areas which were considered to be of most use by those who responded.

The highest number of responses were from midwives (15% of total responses), midwifery managers and midwifery lecturers (both 10%). Overall more responses were received from senior professionals than from junior staff.

93% of respondents found the report very useful or mostly useful and 89% of respondents found the recommendations very useful or mostly useful. 62% of respondents had read previous CESDI Reports.

The questionnaire found that 96% of respondents considered that it was useful to have a personal copy, although 80% would make the copy available to other colleagues in their department/hospital.

All chapters were considered either very useful or mostly useful by a large proportion of respondents. In particular the Conclusions chapter scored very highly in this category.

The comments received were also of interest. In general comments were very positive. The educational value of CESDI's work was

highlighted in a number of comments, in particular by midwives and midwifery lecturers. Typical comments included “the reports inform midwifery education” and “this will be a very useful resource for teaching student midwives”.

Other respondents highlighted the need to improve the CESDI process “...Assessors should be blinded to outcome and randomly given normal outcomes. It might bring them down to earth a bit”. As mentioned elsewhere in the Report, one of the features of the new project, focusing on premature babies, is the blinding to outcome of the assessors and the introduction of control cases.

The use of cases as examples was also commented on, and it was felt that specific case histories are needed to enable the reader to assess whether care is sub-optimal.

One or two suggestions were made about the layout and style, such as producing page numbers in the table of contents, but the general view was that the size and length of the Report was about right. Placing this Report, and future Reports on the Web was also suggested, and this will be pursued.

8.3 IMPLEMENTING THE FINDINGS

The 5th CESDI Report included, for the first time, the responses of the Royal Colleges and statutory bodies responsible for training and accreditation, to CESDI recommendations, particularly in relation to intrapartum deaths. Again, each Royal College and statutory body has been approached and asked for its response to the recommendations in previous CESDI Reports, and the following is a summary of the replies:

8.3.1 **The Royal College of Midwives**

The Royal College of Midwives is committed to ensuring that the recommendations of the Fifth Annual Report are disseminated as widely as possible. An action plan has been drawn up to ensure that this takes place and this includes the presentation of the findings of the report to the Heads of Midwifery Advisory Group, the Education Advisory Group, the RCM Boards in England, Wales, Scotland and Northern Ireland, and to the RCM Council. In addition to encouraging debate through these presentations, the RCM will continue to publish an annual article in their journal “Midwives” which is sent to over 95% of all practising midwives in the UK.

The RCM has addressed specific focus group issues of the Fifth Annual Report that particularly relate to midwifery. The RCM have spoken on the Fifth Report at several study days, and as part of a conference on the management of obstetric emergencies a specific slot in the programme was held on the management of shoulder dystocia. The RCM were concerned that the focus group on home births raised many issues for midwives. As a result, the RCM are compiling a publication for midwives on delivering babies at home, in which all CESDI recommendations relating to home birth will be highlighted and discussed. The booklet will be published in the spring.

The Advanced Life Support in Obstetrics (ALSO) course has now been running in the UK for three years. This course updates midwives, obstetricians, anaesthetists, GP's and paediatricians in the management of all obstetric emergencies including neonatal resuscitation. Following the Fourth and Fifth CESDI Reports, the RCM is recommending that all NHS Trusts in the UK explore the possibility of sending midwives on these courses. To date almost 700 midwives have attended ALSO courses.

8.3.2 **The Royal College of Nursing**

The Royal College of Nursing (RCN) has been proactive in disseminating information to its paediatric nurse members following concerns that the work of CESDI was not reaching paediatric nurses. These activities include ensuring that these issues were included on the agenda of the various paediatric nursing groups. In addition the midwifery advisor for CESDI was asked to write an article for the RCN journal Paediatric Nursing which has over 10,000 subscribers, and this was published in December 1998.

The RCN Midwifery Society has a CESDI Regional Co-ordinator as a member of its steering group; there is feedback during the course of the meetings, and the newsletter regularly carries articles about CESDI.

The issue of the CESDI Report's findings and its relevance to nursing and midwifery education has been raised with the statutory bodies for nursing, midwifery and health visiting as well as in the RCN's own educational Institute. In all the RCN's educational activities the importance of education and record keeping, and evidence based practice is emphasised.

The RCN have convened meetings with the Director of CESDI, and senior nurses and midwives, including the Chairs of the Paediatric Intensive Care Forum and Paediatric Nurses Managers Forum, and with representatives of the Neonatal Nurses Association and the Association of British Paediatric Nurses. CESDI publications such as the postmortem leaflet for parents have been commented on by RCN members.

8.3.3 **The Royal College of Obstetricians and Gynaecologists**

The recommendations of the Fourth and Fifth Report have been discussed on a number of occasions, and several initiatives have been undertaken.

The Department of Health have funded two relevant National Evidence-based guidelines on the Induction of Labour, and the Use and Interpretation of Electronic Fetal Monitoring. In addition, guidelines already under development include Induced Abortion and Antenatal Care.

A guideline on Induction of Labour was published in July 1998, and a guideline on Ectopic Pregnancy is underway.

The Report of the RCOG/RCM Working Party 'Towards Safer Childbirth - Minimum Standards for the Organisation of Labour Wards' which embraces many important issues, including consultant supervision in the labour wards, has been revised and published.

A national Sentinel Audit on Caesarean Section is in preparation.

8.3.4 **The Royal College of Paediatrics and Child Health**

The Royal College of Paediatrics and Child Health is working with the Royal College of General Practitioners to develop "stem cell posts", which will be suitable for doctors going into paediatric training, or training for general practice. This will increase the availability of posts for GP trainees giving experience in paediatrics. Currently hospital visits are done by the RCPCH in conjunction with a representative of the RCGP, to ensure that GP trainees get adequate and appropriate paediatric training.

As part of a drive to improve the quality and uptake of the CME Programme, the RCPCH now has an officer and a committee for continuing professional development.

The RCPCH has worked with the Royal College of Obstetricians and Gynaecologists to produce guidelines for resuscitation of babies at birth. There are increasing numbers of advance life support courses with practical teaching in resuscitation and attendance on these courses is encouraged for trainees, and as part of CME for consultants.

Work has just been completed with the Faculty of Accident and Emergency Specialists which has resulted in the production of a document giving guidelines as to best practice for the management of children in accident and emergency departments.

The use of parent held personal child health records is strongly encouraged by the College and the Health Services Committee has been pressing the Department of Health to produce a standardised version.

The advent of the NHS Direct system, if properly applied, may help parents in the assessment of the severity of a baby's illness.

8.3.5 **The Royal College of Pathologists**

The CESDI programme has the inevitable effect of increasing obstetric awareness of the need for specialised perinatal pathology services. Moreover, there have been calls for better pathological categorisation of sudden infant deaths, especially with respect to a medico-legal standpoint.

The College is monitoring the effect of these developments on available manpower resources. It is aware of the potential difficulties regarding medical recruitment into paediatric pathology, and it is looking into this.

8.3.6 **United Kingdom Central Council for Nursing, Midwifery and Health Visiting**

The Midwifery Council considers all reports received which relate to maternity care and midwifery services in the UK. At its meeting in July 1998, the Committee considered a paper which highlighted a number of recommendations which appeared to be common to several of the recently published reports on maternity care and services. Among the issues which were regularly identified were poor record keeping, problems with communication, problems with guidelines and a number of issues related to clinical care and education.

It was agreed that some exploratory work should be undertaken into the recurring problems and into ways in which the Council could encourage midwives to take action to address the concerns. A short research project has been commissioned which will draw together evidence of recurring themes from a wide range of sources, including the CESDI Reports. A report resulting from the research will be considered by the Council and an appropriate way forward agreed at that stage.

8.3.7 **Faculty of Public Health Medicine**

Public health practitioners are involved in the many excellent study days held by CESDI Regional Co-ordinators which are so useful for disseminating CESDI recommendations and maintaining local interest in the Enquiry.

There are clear advantages to linking maternal and child health data systems and having a proper denominator base on which to support its findings but, in addition, the important objective of defining and pointing to inequalities of care and outcome will be strongly enhanced. The Sudden Infant Death Syndrome (SIDS) work has been particularly important in this respect.

8.4 **CHANGES IN PRACTICE AT LOCAL LEVEL**

Whilst responses to CESDI recommendations from the Royal Colleges and other statutory bodies are encouraging, evidence of changing practice at local level as a result of CESDI findings is also essential. Effective changes in local practice can often be cheap and relatively easy to implement.

One example of this is the introduction of a regular, multi-disciplinary 'fire-drill style' training programme for the management of rare emergencies such as shoulder dystocia and eclampsia, as recommended in previous Annual Reports. We are aware of several units that have adopted this approach to training and although it is difficult to audit its effect on mortality due to the rarity of such events, it has proved to be very successful as a confidence building exercise with staff.

By simulating these emergency situations, clear, concise instructions of the urgent action required by all members of the team can be given, and by practising these 'drills' on a regular basis, the team are more confident of following the correct procedure should the real event occur. Moreover, in the light of the increasing litigation surrounding obstetrics, Hospital Trusts have a responsibility to ensure that their staff are adequately trained and thus likely to act correctly and effectively in such emergency situations.

8.5 ONGOING WORK

8.5.1 **The current enquiry programme - Project 27/28**

The current programme addresses the care of premature babies, and is known as Project 27/28. Four new components have been introduced: collection of denominator data, enquiries on survivors, a structured assessment form and the provision of a 'standards' document at panel. Chapter 9 - CESDI - Developing the Enquiries describes these in further detail.

8.5.2 **Audit of CTG Education**

The Fourth CESDI Annual Report made a number of recommendations regarding intrapartum care, in particular concerning the training of personnel in the use and interpretation of CTGs. Following this up, CESDI is conducting a survey of all maternity units in England, Wales and Northern Ireland to assess the availability to midwives and obstetricians of CTG training. Questionnaires will be sent to all Heads of Midwifery and District Tutors for the RCOG. The aim of this audit is to review the provision of education in CTG use and it is anticipated that the final report will be complete by late 1999.

8.5.3 **Communications Review**

Good communication is an essential component of the trust that exists between parents and health professionals. It becomes increasingly important in situations leading to a poor outcome. Deficiencies in this area can have wide ranging consequences including the loss of trust in the health system in future pregnancies. The National Perinatal Epidemiology Unit (NPEU) has been commissioned to undertake a review of the contribution that communication failures make to stillbirths and infant deaths. This will include a literature search, a review of relevant panel enquiry comments and interviews with personnel who have assessed in research studies parental views following bereavement. This work is in response to the deficiencies in communications as noted repeatedly by panel enquiries (17% relating to intrapartum enquiries, 4th Annual Report; 15% in the enquiries relating to stillbirths, Chapter 3). The findings will facilitate the design of further work by CESDI in this area.

8.6 FUTURE WORK

8.6.1 **Focus Group work**

One of the benefits of assembling information on a national scale is to determine whether there are general lessons that can be learned about

the management of rare events. A review of all 1266 intrapartum related deaths from 1994/95 has been undertaken to identify other suitable topics for specific focus groups. It is proposed that further focus groups be undertaken, the subjects being: deaths associated with breech presentation and anaesthetic difficulties. The findings of the Focus Groups will be included in the 7th Annual Report.

8.6.2 Socio-economic factors and cause of death - linking RRF to registration data

Inequalities in health are at the forefront of the national agenda, and a proposal is being developed to link Rapid Report Form data with socio-economic data from the Office for National Statistics (ONS). This link has two objectives: firstly to improve rapid ascertainment of deaths at Region, and secondly to look at the association between socio-economic factors and cause of perinatal and infant death. The recent reorganisations of the Regional Health Authorities have introduced difficulties in the linking of CESDI and ONS data but work is underway to resolve this issue.

8.6.3 Classification of Information

The current classifications in CESDI are relevant for investigating cause of death. However, ready identification of co-existing maternal, fetal and neonatal conditions in addition to the cause of death is needed. A review of the ways of introducing coding of information collected on the rapid reporting form is underway by a working party. Easy and efficient identification of important clinical conditions is a priority for CESDI.

8.7 OTHER PUBLICATIONS

8.7.1 *Sudden Unexpected Deaths in Infants - The CESDI study 1993-1996*
Later this year CESDI is going to release a separate publication covering the studies on Sudden Unexpected Deaths in Infants (SUDI) from 1993 to 1996. Previous parts of these studies have been covered in various Reports and publications and this book describes the findings in their entirety.

8.7.2 *The Fetal and Infant Postmortem - Brief Notes for the Professional*
This is a leaflet which was issued by CESDI this year and is designed to help health professionals in requesting a postmortem examination (Chapter 5, Appendix 4).

REFERENCES

1. Department of Health. A First Class Service - Quality in the new NHS. July 1998.

ACKNOWLEDGEMENT

Author:

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DEVELOPING THE ENQUIRIES

CESDI was established to improve understanding of the causes and to quantify the risks of death in late fetal life and infancy, from 20 weeks of pregnancy to one year after birth. CESDI collects quantitative and qualitative information at a national level. This provides epidemiological data which contributes to understanding of cause and to identification of suboptimal clinical care.

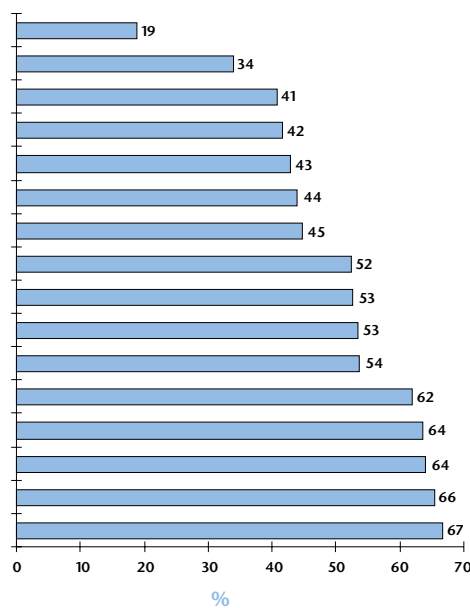
9.1 ASSESSMENT OF THE QUALITY OF INFORMATION PROVIDED BY THE ENQUIRIES

A critical step in the interpretation of the information produced is an assessment of the completeness, accuracy and quality of the primary data. The following description highlights how this has been achieved since 1992.

9.1.1 The validity of opinion and assessment of standards by the panels

It is commonly said that no two clinicians can agree over the management of a patient. It also seems that they cannot agree over standards of care. In part this is because there is often no definitive solution to a particular clinical problem. The panel judgements in CESDI enquiries reflect individual health professionals' opinions, and therefore it is not surprising that there is variation in the grades given. This in part explains the variation in the Regional distribution of overall grades in the '1 in 10' programme where the proportion of assessments given grade 2 or 3 ranged from 19% to 67% (Figure 9.1). The national picture combines the findings at 16 regions, thereby 'averaging' out the extremes.

Figure 9.1: Proportion of assessments given grade 2 or 3 by CESDI region (anonymised)



However, this variation leads many to question the process and its final conclusions.

Can variation in Regional panel assessment be reduced? CESDI panels are now given a 'standards' document, which is used in the assessment of care. It is likely that there will not be universal acceptance of the 'standards' provided - however, their function in the panel setting is to define consistent thresholds for the assessment process.

The setting of national standards is a relatively new initiative and, although they are based on the best possible evidence, significant parts of the statements comprise 'expert' opinion. Inevitably some will be difficult to implement locally and it is important to identify the reasons. The peer review system at a Regional level in CESDI is particularly well placed to do this.

9.1.2 **Overall grade - how accurate a measurement is it?**

The panel is asked to address the likelihood that suboptimal care contributed to the final outcome. It is well known that knowledge of an intervention leads to overemphasis of its effect. A review of randomised control trials in obstetrics and gynaecology (Schultz et al 1995) showed that knowledge of the intervention by assessors led to a 40% increase in the measured 'effect' of the intervention. It is likely that awareness of outcome by the panels does influence the resultant grade, and thus over stresses the relationship between care and death.

The difficulties in determining the accuracy of the grading system have wider implications in two important contexts: predicting perinatal health outcomes and communication with the media.

The first three enquiry programmes (intrapartum deaths; the 1 in 10 sample; and the over 4kg group) included only deaths; knowledge of the outcome was inevitable. Summarising the findings on the basis of the overall grade could lead to unattainable expectations of outcome.

The messages of CESDI are targeted at the health profession but the findings are frequently reported in the general press ranging from the Times to Private Eye. Reporting will not dwell on the process but will concentrate on sound bites such as 'two in three babies' deaths in hospitals are avoidable' (a typical distillate of the 4th Annual Report). Superficial conclusions and public alarm make good news, yet it remains a priority that CESDI must address standards of care.

9.1.3 **Recording and collating opinion - the need for consistent standards and a structured form**

Recording and collating 'opinion' on a national basis is a complex task. In 1996 CESDI undertook a major exercise with a repeat review of a fifth of all its panel assessments (Second Pass Panel Exercise; 5th Annual Report). This confirmed that agreement by panels is greatest in situations of poor care. It also highlighted inconsistencies in the identification of the many problem areas. As a response to this the current enquiry programme has introduced a more structured approach to the process.

9.1.4 **Limitations of enquiring on deaths alone - the need for comparative data in survivors.**

An enquiry panel is asked to judge whether a failure of care significantly contributed to the death. The accuracy of the conclusion cannot be tested. It is possible that similar failures of care occur in cases in which the child survived. To quantify the contribution of suboptimal care requires equivalent information on survivors as well as deaths.

Are controls always necessary? The reason for the introduction of CESDI was the need to identify the reasons for perinatal and infant deaths (most are unknown). Although on a national scale (10, 000 losses annually) these losses appear to be 'frequent' they are relatively rare (for example stillbirth rate 5.6 per 1000 total births; sudden infant death rate 1.2 per 1000 livebirths). A case control approach is often the most appropriate study for investigating multiple risk factors for these events as prospective studies may be impractical.

However, the focus group work in CESDI did not examine controls. Their purpose is to provide unique and practical overviews of rare events. The reports generate the need for further evaluation of the topic. They are especially useful for topics where there are fewer than a hundred occurrences annually and where there are general lessons that can be learned about the management of rare events.

9.1.5 **Future developments**

The limitations of record keeping are described in chapter six. Inaccuracies and failure to record events will preclude an effective assessment of the events contributing to death. It is likely that future enquiries will seek information in addition to that of the case notes to address this issue.

The approach of distributing the cases nationally for assessment rather than regionally is currently under review. This is aimed at addressing the problems of variation in Regional assessment.

'All relevant hospital doctors and other health professionals will be required to participate in the work of the National Confidential Enquiries'. (A First Class Service; NHS Executive 1998). The current arrangements for participating in the assessment process will be reviewed to enable full participation.

9.2 **PROJECT 27/28 - THE CURRENT ENQUIRY PROGRAMME**

Prematurity is the major cause of neonatal deaths, especially in the very low birth weight group of less than 1.5kg which accounts for 1-2% of births and approximately half of neonatal deaths. This group is also a major contributor to long term neurological disability. Despite growing professional and public interest in the care given to babies born before 32 weeks' gestation little is known about their epidemiology. This is because gestational age at birth is not routinely collected on all live births in the United Kingdom. Our national data on livebirths is derived from registration information; there is no appropriate denominator data for gestation.

CESDI is currently identifying all babies born in the 27 to 28 weeks gestational range in England, Wales and Northern Ireland. This group of babies will provide denominator data for survival figures. A sample of the national population of survivors will be randomly selected for enquiry.

9.2.1 **Aims and objectives of Project 27/28**

- 1 To identify all babies born alive in England, Wales and Northern Ireland between 27 and 28 weeks gestation and to identify whether they survived or not.
- 2 To provide a cohort of all livebirths between 27 and 28 weeks, from which the survivors for enquiries will be randomly selected
- 3 To undertake a confidential enquiry on all early neonatal deaths and an equivalent number of the survivors in this gestational range
- 4 To address the association of care given in pregnancy and up to the first seven days of life with the survival of babies in the key gestational range 27 - 28 weeks
- 5 To provide a national and regional audit of a series of obstetric and perinatal standards

9.2.2 **Key Components:**

- Cases:** All early neonatal deaths of babies born at 27+0 to 28+ 6 weeks gestation
- Controls:** A baby who lives to at least 28 days after birth
- Excluded babies:** Those with major congenital malformations, since the care of these babies does not reflect 'routine' care.
- Selection process:** A random selection from the national cohort of all livebirths at 27+0 to 28+6 weeks with frequency matching for multiple births and completed weeks gestation.

To ensure a consistent definition of the gestation of the baby at birth, a dating algorithm based on menstrual history and the first ultrasound scan performed prior to 20 weeks is used.

9.2.3 **Identification of all babies in the range 26+0 to 29+6 weeks:**

Clinical identification at delivery and/or admission to neonatal units
Specially designed recording logs have been introduced into every labour ward and neonatal unit in England, Wales and Northern Ireland. At delivery there may be a discrepancy between the gestation estimated by different methods. To ensure accurate identification of all liveborn infants at 27 to 28 weeks a wider initial identification range band was chosen. All babies with a clinical gestation estimate in the range 26+0 to 29+6 weeks are identified and a minimum data set is recorded in the log book at birth and for every admission to a neonatal unit in the first 28 days of life.

Collection of logs - a monthly process

Each hospital has named individual(s) responsible for the completion and forwarding of the logs to the CESDI Regional Co-ordinator on a monthly basis. At Region the data is entered electronically on to a Regional Summary Database and forwarded monthly to the Central secretariat where it is entered into the National Summary Database. The dating algorithm is applied by the Regional Co-ordinator based on information from the units. No names are held electronically; potential duplication is prevented by the application of a unique national number at birth.

Regional Feedback - a monthly process

Summary statistics are provided from the Central Secretariat to the Regions on a monthly basis. This will rapidly identify any major underreporting in the process and aids in ensuring an effective collective system.

Validation of the numbers reported - maximising ascertainment levels

Logs were introduced into both labour wards and neonatal units to maximise identification of these babies. Although many data items are duplicated, the process ensures as complete an identification as possible.

The lack of any other source of national gestational data precludes a 'gold standard' to validate the process. However, some Regional surveys do collect gestation (eg via Child Health Systems) and these will be used to check ascertainment.

9.2.4 Randomisation selection process for the Enquiries

An equivalent number of enquiries will be undertaken on survivors and on early neonatal deaths.

As there were no accurate estimates for the number of babies born at 27 and 28 weeks gestation, data was extrapolated from the Trent Region (1991-1993). On this basis probabilities were determined which would select an equivalent number of deaths and survivors. The two groups are frequency matched for completed gestational weeks and multiple pregnancies.

Within the first six months of the project it has become obvious that the prior probabilities were incorrect. There were considerably more babies being born and surviving at this gestation than had been anticipated. This is probably due to changes in survival rates in the last eight years. Similar improved survival rates were found in the UK Neonatal Staffing Study (Newsletter no 6, 1999) This emphasises the need for current accurate information regarding gestation. Without this it is impossible to identify whether outcomes could reasonably be expected to be better.

9.2.5 The Confidential Enquiry Process

The antenatal care and the first seven days of care are assessed in the Confidential Enquiry process in Project 27/28. As in previous

programmes the assessment is made by a regional multidisciplinary panel comprising a neonatologist, an obstetrician, a midwife, a neonatal nurse and a pathologist who have not been involved with the case. Other disciplines such as anaesthesia, general practice and public health may also be present if appropriate.

Three new developments have been introduced: a 'standards' document; a structured enquiry form; and 'blinding' of the assessors of care up to and including delivery.

The 'standards' document acts as a guideline and should improve consistency of the assessment. The source for the evidence relating to the standards is provided in the document.

The structured Enquiry Form has designated sections (obstetric, neonatal, pathological and general). Each section addresses specific questions and the topics addressed are outlined in Table 9.1.

Table 9.1 Specific topics addressed by the Enquiry:

<p>Obstetric:</p> <ul style="list-style-type: none">• Administration of steroids• Management of chorioamnionitis• In utero transfers• Fetal surveillance antenatally and in labour <p>Neonatal:</p> <ul style="list-style-type: none">• Resuscitation• Early thermal care• Use of surfactants• Ventilatory and cardio-vascular support• Management of infection• Transfers in the first seven days of life <p>Pathology:</p> <ul style="list-style-type: none">• Standard of post mortem report• Personnel undertaking report• Contribution of post mortem to modification of clinical assessment• Neuropathological findings <p>General</p> <ul style="list-style-type: none">• Communication with parents• Communication between maternity and neonatal staff• Participation in trials• Record keeping• Deficiencies in organisation

As well as factual assessments, opinions on standards of care are also sought with the opportunity for comment. The panels continue to give an overall grade but do so independently for obstetric and

neonatal aspects of care. If the care is thought to be substandard then the relevance to the outcome of the pregnancy is queried.

For each death or survivor obstetric care is assessed in the absence of knowledge of the outcome of the case. It is not feasible to blind the neonatal or pathological assessments.

9.2.6 **Timescale of Project 27/28**

The logs were piloted in five Regions from May 1st 1998. Formal data collection using these logs began in all sixteen Regions on September 1st 1998. The monthly cycle of unit to Regional Co-ordinator to Central Secretariat has been in progress since September. The logs and the Enquiries will continue for a minimum of two years from September 1st 1998.

The Enquiry form was piloted by a snapshot panel exercise in all Regions. Enquiries on six babies (four early neonatal deaths and two survivors) were held such that eight Regions examined the same three enquiries. This identified ambiguous questions which have subsequently been corrected.

9.2.7 **Numbers involved**

With an anticipated 400 cases and 400 controls over this two year period the study has a 80% power to detect an odds ratio of 2.5 or more for risk factors with a prevalence of between 4% and 90% in the survivors.

9.2.8 **The anticipated findings**

These will include:

- the provision of accurate survival figures for babies in the 27 to 28 gestational range
- a national audit of effective practices such as the administration of steroids and surfactants
- identification of associated risk factors with the loss of babies at this gestation
- a survey of transfers, both in -utero and ex-utero with the underlying indications.
- a review of the main issues associated with the provision of care with premature babies at this gestation
- a description of the variations in the provision and standards of pathology services

9.3 **THE REGIONAL CO-ORDINATOR NETWORK - A CORE COMPONENT OF CESDI**

A core component of CESDI is the network of full-time Regional Co-ordinators and support staff. This unique network gathers clinical information. Incorrect data is more likely to be recognised 'at source' and a 'regional' approach facilitates the provision of accurate and reliable information. This cascade system provides an effective dissemination pathway at both a National and Regional level. Geographical variations can be identified and questioned.

Since the start of CESDI there have been three reorganisations of the Regional Health Authorities, the last on April 1st 1999. Although these are aligning with other Government Offices and serve important administrative functions, many significant clinical activities continue to relate to the smaller sized Health authorities, for example the postgraduate deaneries, Regional College advisors within the RCOG and the RCPCH.

The CESDI Regional structure facilitates other important collaborative work in related areas such as low birthweight baby outcomes (North Western), regional audit of unexplained stillbirths (Mersey), a neonatal encephalopathy study (Trent), a Baby Follow-up study - randomised trial of two methods of data collection (Wessex) and the Neonatal Audit Group (Northern Ireland).

Many of the Regional Congenital Anomaly surveys work in conjunction with the CESDI network and achieve consistently higher ascertainment than a centralised reporting system (Northern, Mersey). This feature is utilised by ONS to improve the central ascertainment rates.

Most CESDI Regions produce a Report relating to their own region. These often include maternity and neonatal information relating to individual trusts which may be the only reliable information for local maternity statistics. Although the Department of Health issue NHS Maternity statistics for individual trusts and the original Regional Health Authorities using the Hospital Episode Statistics system, it acknowledges the problems of limited coverage (only two thirds of deliveries generated a HES record in 1994-5). Over a third of maternity units are not computerised (Kenny N, Macfarlane AJ 1997) and although all child health departments use some form of computer system many are outdated. The CESDI network forms a suitable model to collect this long overdue information.

The CESDI Regional structure contributes significantly to the feedback process. A cascade approach to dissemination is particularly effective and this is discussed in Chapter 8. Regional meetings and workshops form important educational forums with exchange of good practices that have developed in response to the CESDI findings.

9.4 ACKNOWLEDGEMENTS

The development of Project 27/28 took place over several months during 1998 and involved many people. The Secretariat would like to thank members of the Project 27/28 Working Group, listed in Appendix 1, who generously gave their time and expertise during this development phase. In addition, the Secretariat very much appreciated the help received from many others, including the Regional Co-ordinators who piloted the project, and those people who took part in the workshops, snapshot panels, and numerous meetings which helped to finalise the project.

REFERENCES

Kenny N, Macfarlane AJ.

The use of computerised information systems in maternity units in England and Wales.

Midwives 1997; 110: 204-6

NHS Executive.

A First Class Service, Quality in the New NHS.

Dept. of Health, June 1998

Schulz KF, Chalmers I, Hayes RJ, Altman DG.

Empirical evidence of bias. Dimensions of quality associated with estimates of treatment effects in controlled trials.

JAMA 1995;273:408-12

UK Neonatal Staffing Study. Newsletter no 6. January 1999

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CONCLUSIONS

10.1 INTRODUCTION

CESDI is now under the umbrella of the National Institute for Clinical Excellence (NICE), thereby re-emphasising its role in improving standards of care. Over the years CESDI has pioneered different approaches to gathering and interpreting information on a national scale in a variety of topics in maternity, neonatal and infant care. Much of the present Report summarises the lessons that have been learnt in this process and discusses the way forward.

The remit of NICE includes the setting and implementation of national clinical guidelines, as part of clinical governance. NICE will be concerned to establish a balance between autonomy and innovation of clinicians at a local level and the centralised direction of best practice. However, at the heart of the matter is the need for effective practices to be implemented and for harmful practices to be minimised. The peer review system at regional level that is the basis of CESDI is an ideal model for future work in this area. National standards, guidelines and variations in practice are evaluated by representative bodies in a confidential setting.

Good quality information is essential to decision making, but there are large and very basic gaps in national statistics relating to maternity and infant care.

Gestation at birth is probably one of the most crucial data items needed. For too long we have relied on weight as a surrogate measure. Prematurity is the single greatest contributor to perinatal mortality and morbidity, and the absence of gestational data precludes accurate description of trends in survival. Local studies are not sufficient. Within six months of the start of Project 27/28 it became apparent that Regional figures had significantly underestimated the numbers of premature babies (27-28 week gestation) being born and surviving in 1999. This may be due to rapid changes in effective care. If this is so it becomes even more essential that the information is readily available. There are numerous examples of effective practices (eg the administration of surfactant) which should probably be implemented nationwide.

10.2 THE '1 in 10' ENQUIRIES

The purpose of the '1 in 10' programme was to sample a broad range of losses reported to CESDI to inform future work programmes. The findings highlight the need for review of general standards in antenatal and intrapartum care (Chapter 3).

Stillbirths

- Stillbirths are the single largest group contributing to deaths between 20 weeks and one year of age (35% of all losses reported to CESDI)

- The terms ‘unexplained’ and ‘unavoidable’ are often used for stillbirths, yet enquiries revealed large numbers of potentially avoidable factors (45% had an overall grade 2 or 3)
- Whilst the majority of fetal deaths occurred in ‘low risk’ women, a significant minority had fetal risk factors which were recognised either at the first antenatal visit (26%) or during the antenatal period (39%)
- A postmortem modifies the clinical assessment in 15% of cases. The contribution of a ‘negative’ postmortem is also stressed (Chapter 5)
- Because of the magnitude of this category further evaluation of the comments and panel findings made in the enquiries on the 422 stillbirths is in progress. This will facilitate future guidelines and work in this area

Intrapartum deaths

- Intrapartum related deaths represent 15% of the ‘1 in 10’ group (the largest cause of death after ‘unexplained’ and haemorrhage)
- Care in labour is an area that particularly stands out in the need to review practice (72% had an overall grade 2 or 3). It will be important to re-visit this issue in subsequent years

Specific obstetric conditions

- Other specific areas of obstetric practice have also been highlighted for further review (at least 55% of each area had an overall grade 2 or 3): pre-existing diabetes, gestational diabetes, multiple pregnancy, pre-eclampsia and management of breech presentation

Other important clinical conditions

- The current pathological classifications used by CESDI are relevant for investigating the cause of death. However, there is also a need to identify co-existing maternal, fetal and neonatal conditions. Work on how to collect such information is in progress (Chapter 8)

10.3 THE ‘4KG and over’ ENQUIRIES

General

- Babies weighing 4kg and more are significantly less likely to die than smaller babies during pregnancy and up to the first year of life
- However, these large babies are significantly more likely to die intrapartum: particular attention should be given to suboptimal care issues related to labour

Gestational diabetes and pre-existing diabetes

3% of this group were from mothers with pre-existing diabetes and 8% related to gestational diabetes. The contribution from undiagnosed gestational diabetes could not be assessed in the absence of further investigation.

Because of the small numbers only limited conclusions can be drawn but particular recommendations include :

- better supervision and early recourse to insulin treatment in the hyperglycaemic subject
- if a large baby is suspected, other risk factors (positive family history, recurrent glycosuria etc) should be sought and, if found, followed up by a formal glucose tolerance test

Antenatal Care

● Failure to recognise or act appropriately in a case with a suspected large baby was the commonest antenatal factor noted by the Enquiry panels. Many related to the particular circumstances in which the size of the baby was disregarded, for example in trials of scar

- If a large baby is suspected clinically, this fact should be communicated to the team caring for the woman in labour

The inaccuracy of estimating weight in utero precluded other specific recommendations.

Intrapartum Care

Most comments related to general care in labour and were not specific to the size of the baby. Fetal surveillance problems were the commonest, with CTG interpretation as the basis of the most frequent criticism. Delay in delivery and inappropriate choices for the mode of delivery was the second commonest criticism. Unwise attempts at vaginal delivery may reflect the inexperience of the staff at the time of delivery.

Thus with a clinically suspected large baby:

- the delivery team should be alert for delay in late labour. This includes careful documentation with the use of a partogram to monitor the progress of labour
- the delivery team should be alert for the possibility of shoulder dystocia and follow their local protocol
- experienced staff should decide on and undertake or directly supervise any instrumental delivery

All delivery suites should have:

- clear protocols for the management of shoulder dystocia (5th Annual Report)
- a high level of awareness and training of all birth attendants in the management of shoulder dystocia
- 'Fire drills' for the training of staff in the management of shoulder dystocia

Care of the newborn

The most frequent adverse comment on paediatric care was delay in resuscitation for babies of 4kg and over. Delays in the arrival of the paediatrician, difficulties in intubation, failure to identify pneumothorax and lack of basic skills were the particular issues highlighted.

All delivery suites should ensure that:

- there are clear protocols for calling a paediatrician
- the attending paediatrician has adequate experience in resuscitation skills

Paediatricians on call for the labour ward:

- must attend promptly when called urgently
- be aware of the possible consequences of difficult deliveries including potential co-existing cerebral trauma
- having excluded other causes of failure to respond to resuscitation, be alert to the possibility of pneumothorax

Postnatal care

The significance of heart murmurs in the neonate is highlighted

- echocardiography may be indicated in the presence of a heart murmur in the neonate

10.4

DEVELOPMENTS IN THE ENQUIRY PROGRAMME

Recording and collating 'opinion' on a national basis is a complex task. The variation in panel assessments has led many to question the process. In 1996 CESDI undertook a major exercise in which a fifth of all its panel assessments were repeated (Second Pass Panel Exercise; 5th Annual Report). Consistency was greatest in situations of poor care but inconsistencies were highlighted in the identification of many problem areas, often due to the relatively unstructured approach to recording of panel opinion.

The limitations of enquiries on deaths only and the lack of comparative data have been described.

As a response to this the current enquiry programme, Project 27/28 has introduced:

- collection of denominator data
- enquiries on survivors
- blinding of the outcome for pre-delivery assessors
- a structured enquiry form
- a 'standards' document at the enquiry

Project 27/28

Prematurity is the major cause of neonatal deaths, especially in the very low birth weight group of less than 1.5kg which accounts for 1-2% of births and approximately half of neonatal deaths. This group is also a major contributor to long term neurological disability. Despite growing professional and public interest in the care given to babies born before 32 weeks' gestation, little is known about their epidemiology. This is because gestational age at birth is not routinely collected on all live births in the United Kingdom. Our national data

on livebirths is derived from registration information; there is no appropriate denominator data for gestation.

CESDI is currently identifying all babies born in the 27 to 28 weeks gestational range in England, Wales and Northern Ireland. This group of babies will provide denominator data for survival figures.

Aims and objectives of Project 27/28

- 1 To identify all babies born alive in England, Wales and Northern Ireland between 27 and 28 weeks' gestation and to identify whether they survived or not
- 2 To provide a cohort of all livebirths between 27 and 28 weeks, from which the survivors for enquiries will be randomly selected
- 3 To undertake a confidential enquiry on all early neonatal deaths and an equivalent number of the survivors in this gestational range
- 4 To address the association of care given in pregnancy and up to the first seven days of life with the survival of babies in the key gestational range 27 to 28 weeks
- 5 To provide a national and regional audit of a series of obstetric and perinatal standards

The protocol for Project 27/28 is described in further detail in Chapter 9.

10.5 PERINATAL PATHOLOGY

Asking recently bereaved parents for permission for a postmortem examination is not easy and guidance on this issue is given in a new leaflet entitled: 'The Fetal and Infant Postmortem, Brief Notes for the Professional' (In full at Appendix 4).

The perinatal postmortem can make an important contribution to our understanding of some deaths but to do so it needs to be of a high standard. Guidelines for the reporting of postmortems were presented in the first CESDI report and subsequently issued by the Royal College of Pathologists. An audit of reports of postmortems on intrapartum related deaths between 1994 and 1995 demonstrated marked variability in standards. The results show that there was a small improvement, between early 1994 and the end of 1995, across the range of indices used for assessing the quality of postmortem reports. This ranged from the recording of objective data to the provision and adequacy of commentaries. However, there is considerable need to improve observational, diagnostic, and interpretative skills as:

- poor or missing histology frequently (56%) contributed to the low standards of reports
- an 'adequate commentary' was available for 35%

10.6 RECORD KEEPING

Record keeping is a vital part of the care and communication process. The quality of record keeping reflects the skills and safety of the practitioner. Good records should provide clear evidence of the care planned, the decisions made and the care delivered. Good teamwork is essential to this process.

- Poor record keeping, as judged by the Enquiry panels occurred in a third of cases
- The major problem was a failure to document events adequately. This has major medico-legal consequences and highlights an area of care and communication that could be improved at minimal cost

Two previous recommendations made by CESDI are reiterated:

- All professionals should make clear and adequate notes. The standard should be that which enables a colleague coming new to the case to be properly informed (3rd and 5th Reports)
- The quality of maternity records needs to be improved to enable clear identification of risk factors and documentation of management plans for these during both antepartum and intrapartum periods. These would be facilitated by a well-designed, universally used national maternity record (4th and 5th Reports)

10.7 ORGANISATION OF CESDI AND THE NATIONAL ADVISORY BODY

CESDI has undergone several re-organisations but the National Advisory Body has been a constant presence. Since 1992 it has been chaired by Lady Littler and has always had major input from lay members as well as professionals. As CESDI becomes part of NICE the NAB completes its term of office.

The key themes that have underpinned the success of CESDI so far and which will be important in its future development are:

- the regional/central organisation of CESDI
- the choice of the annual programme
- the contribution that parents make
- implementing the findings

10.8 DISSEMINATION OF THE FINDINGS

The messages of CESDI are wide ranging and are applicable to the entire spectrum of health workers. Dissemination of these messages is therefore of paramount importance. In 1998 a study was commissioned from the Office for Public Management on the dissemination of CESDI findings to professionals (Chapter 8).

- Awareness of CESDI was very high amongst midwifery professionals, and senior clinicians and managers, but was much lower for front line staff, especially for paediatric and neonatal staff

The current work programme, Project 27/28, closely involves neonatal staff and will help to address this issue. In addition, NICE has a

commitment to publish guidelines and encourage national audit. The dissemination of the findings of CESDI will be strengthened by participation in this process.

10.9 CHANGING PRACTICE

The 5th CESDI Report included, for the first time, feedback from the Royal Colleges and statutory bodies responsible for training and accreditation, particularly in relation to intrapartum deaths. This exercise has been repeated (Chapter 8). There are now encouraging advances. In particular the RCM will issue a publication for midwives on delivering babies at home; this highlights all CESDI recommendations relating to home birth.

The RCN has been particularly proactive in disseminating information to its paediatric nurse members following concerns that the work of CESDI was not reaching this group.

Two of the four National Evidence-based Guidelines undertaken by the RCOG on behalf of the Department of Health are in direct response to the findings of CESDI: Induction of Labour, and the Use and Interpretation of Electronic Fetal Monitoring. The Joint Working Party Report "Towards Safer Childbirth - Minimum Standards for the Organisation of Labour Wards" was published in February 1999 and covers many important issues including consultant supervision in labour wards.

The Royal College of Paediatrics and Child Health (RCPCH) is working with the Royal College of General Practitioners to develop 'stem cell posts', aimed at training for doctors entering specialist paediatric practice or general practice. This will increase the availability of such posts for GP trainees. The RCPCH has worked with the Royal College of Obstetricians and Gynaecologists to produce guidelines for resuscitation of babies at birth. There are increasing numbers of advance life support courses with practical teaching in resuscitation. Attendance at these courses is encouraged for trainees, and as part of CME for consultants. Together with the Faculty of Accident and Emergency Specialists the RCPCH has produced guidelines on best practice for the management of children in accident and emergency departments.

10.10 THE FUTURE

CESDI looks forward to being part of NICE and brings to this organisation a unique ability to provide national clinical data on maternity, neonatal and infant health. Confidential and other assessment of this data by representative bodies will have an important role in the improvement of national standards and the implementation of clinical governance.

ACKNOWLEDGEMENTS

Particular thanks are due to the considerable contribution of the district co-ordinators and the many others based throughout England, Wales and Northern Ireland, who, often without recognition and in their own time, undertake work for CESDI.



GLOSSARY

AETIOLOGY

The science of causes, especially of disease.

ANONYMISATION

The removal of information that would identify babies, family members, professionals and institutions.

ANTEPARTUM STILLBIRTH

Death of a baby before the onset of labour.

BIAS

Any effect at any stage of investigation that tends to cause results to depart systematically from the true values. Examples include observer bias due to differences among observers recording study results; and selection bias where systematic differences occur between selection of cases and controls.

CASE CONTROL STUDIES

Case control studies compare exposures in people who have a particular disease or outcome with those who do not.

CONFIDENTIALITY

Information given in confidence may be used only for the purposes for which it is given and may be disclosed for other purposes only in exceptional circumstances. There are legal and ethical duties to maintain confidentiality in the NHS. The principles on which CESDI data are collected are that the identities of the panels, the professionals involved, and the mothers and families of the babies which died will be anonymous within the enquiry. As a result it is not possible to release panel reports to outside agencies on any identifiable or individualised basis.

CONFIDENTIAL ENQUIRY

Enquiry by peer groups, including experts in the field, into the cause of, and the factors surrounding, a death where strict confidentiality is observed at all stages of the process. It is a form of clinical audit, with an important difference that the feedback or 'closing of the audit loop' is via reports on the general findings, and not direct feedback to those involved with the individual cases subjected to enquiry.

CONFIDENCE INTERVALS (CI)

A range of values about which there is a 95% chance that it includes the true value. For example, if the stillbirth rate is 5.4 per 1000 total births and the 95% confidence intervals are 5.3 to 5.5 per 1000 total births, then there is a 95% chance that the actual stillbirth rate lies between 5.3 and 5.5 per 1000 total births.

CONGENITAL MALFORMATION/ANOMALY

A physical malformation (including biochemical abnormality) which is present at birth.

CONTROL

As used in a case control study or randomised controlled trial, 'control' means person(s) in a comparison group that differ only in their experience of the disease in question. If matched controls are used they are selected so that they are similar to the study group, or cases, in specific characteristics. eg. Age, sex, weight.

DENOMINATORS

The population at risk in the calculation of a rate or ratio. Examples relevant to CESDI include number of all live births as denominator for neonatal mortality rate, and birth weight distribution of all live births for birth weight specific mortality calculations.

EARLY NEONATAL DEATH

Death during the first week of life (0-6 completed days inclusive).

FETAL DEATH (based on WHO recommended definition)

Death prior to complete expulsion or extraction from its mother of a recognisable fetus, irrespective of duration of pregnancy. After separation, the fetus does not show any evidence of life.

GESTATION

The time from conception to birth. The duration of gestation is measured from the first day of the last normal menstrual period.

GESTATIONAL DIABETES

A carbohydrate intolerance of variable severity with onset, or first recognition during pregnancy.

GRO

General Register Office - the official statistics collection body for Northern Ireland.

HOSPITAL EPISODE STATISTICS (HES)

The HES is a national data collection system, introduced in April 1987 to replace the Hospital Inpatient Enquiry. It covers all specialties and is based on consultant episodes (a period of care under one consultant). The HES for maternity includes a 'tail' with maternity data. For a delivery the episode includes data for each baby as well as the mother. CESDI has not yet made use of HES data in a routine way in its enquiries so far.

INFANT DEATH

Death in the first year following live birth; on or before the 365th day of life (366th in a leap year!).

INFANT MORTALITY RATE - see Mortality Rates.

INTRAPARTUM DEATH

Intrapartum means during labour, between the onset of (effective) contractions and ending with completion of delivery of the baby. If a baby is born without signs of life, but also without maceration (the skin and other changes that occur a varying length of time after death in the womb), there is a strong presumption that death occurred during labour. There are exceptions in both directions which require judgement on the timing of death in relation to the presumed onset of labour.

LATE FETAL LOSS

For CESDI, a late fetal loss is defined as a death occurring between 20 weeks + 0 days and 23 weeks + 6 days. If gestation is not known or not sure, all births of at least 500g are reported, (at least 300g from 1.1.96). Late fetal loss and stillbirth are distinguished by gestational age at the time of delivery which is not necessarily the time of death.

LEGAL ABORTION

Within CESDI, this is the term used exclusively to describe deliberate ending of a pregnancy, under the provisions of the current law (1967/92 Act of Parliament), with the intention that the fetus will not survive.

LIVE BIRTH

Delivery of an infant which, after complete separation from its mother shows any signs of life.

There is no recognised gestation or weight qualifier in UK law on Birth Registration, so that any birth at any gestation or birth weight which fulfils these criteria should be registered as a live birth.

MORTALITY RATES

- i) **Infant mortality rate**
Deaths under the age of 1 year following live birth, per 1000 live births
- ii) **Perinatal mortality rate**
The number of stillbirths and early neonatal deaths (those occurring in the first week of life) per 1000 live and stillbirths
- iii) **Neonatal Death rate**
The number of neonatal deaths (ie occurring within the first 28 days of life) per 1000 live births
- iv) **Postneonatal mortality rate**
Number of infants who die between 28 days and less than 1 year per 1000 live births.
- v) **Stillbirth rate**
Number of stillbirths per 1000 of total births (live births and stillbirths)
- vi) **Late fetal loss rate**
Number of late fetal losses per 1000 of total births (live births and stillbirths)

NEONATAL DEATH

Death before the age of 28 completed days

NOTIFICATION OF BIRTH

By law all births must be notified to the District Medical Officer (now Director of Public Health) in England and Wales and the Chief Administrative Medical Officer in Scotland and Northern Ireland within 36 hours of their occurrence

NON REGISTRABLE DEATH

A fetus delivered before the end of 24 completed weeks of pregnancy without signs of life

ODDS RATIO (OR)

This is a measure of the excess risk or degree of protection given by exposure to a certain factor. An odds ratio of greater than one shows an increased risk and less than one shows a protective effect.

ONS (Formerly OPCS)

Office of Populations Censuses and Surveys - merged with National Statistics Office to become Office for National Statistics on 1 April 1996.

PERINATAL DEATH

Fetal deaths after 24 completed weeks gestation and death before 6 completed days

PERINATAL MORTALITY RATE - see Mortality Rates.

POSTNEONATAL INFANT DEATH

Death between 1 month and 1 year of age. (28 days and over, up to 1 year).

POSTNEONATAL MORTALITY RATE - see Mortality Rates.

REGISTRATION OF BIRTH

A statutory requirement for all births in England, Wales & Northern Ireland within 42 days.

REGISTRATION OF DEATH

Time limit for registration in England, Wales & Northern Ireland is 5 days.

SHOULDER DYSTOCIA

Shoulder dystocia is used to describe a range of difficulties encountered in the delivery of the baby's shoulders. Discrepancies in the definition and the use of terms such as 'mild' or 'severe shoulder dystocia' have led to variations in reported incidence.

STILLBIRTH

- i) Legal definition; England and Wales
A child which has issued forth from its mother after the 24th week of pregnancy and which did not at any time after being completely expelled from its mother breathe or show any other signs of life
- ii) Legal Definition: Northern Ireland
A stillbirth 'means the complete expulsion from its mother after the 24th week of pregnancy of a child which did not at anytime after being completely expelled or extracted breathe or show any other evidence of life'.

SUDDEN INFANT DEATH SYNDROME (SIDS)

(1969 Seattle definition): The sudden death of an infant or young child, which is unexpected by history, and in which a thorough postmortem examination fails to demonstrate an adequate cause of death.

With few exceptions SIDS occurs in the first year of life. It is also known as cot death.

SUDDEN UNEXPECTED DEATH

A sudden death, unexpected from the previous history. The term is applied to other age groups as well as to a small number of deaths in infancy and early childhood. It includes both explained and unexplained



APPENDIX 1 - CESDI WORKING GROUPS

MEMBERS OF THE PROJECT 27/28 WORKING GROUP

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APPENDIX 2 - EXTENDED WIGGLESWORTH CLASSIFICATION

- Category 1. Congenital defect/malformation (lethal or severe):** Only **lethal** or potentially lethal congenital malformation should be included here. **Serious biochemical abnormalities** such as **Tay Sach's disease** and any known single gene defects known to have a high risk of death should be included.
- Category 2 Unexplained antepartum fetal death:** Most late fetal losses should be coded here. Where a live born baby dies due to problems during the antepartum period, code this as 'other specific causes'.
- Category 3 Death from intrapartum 'asphyxia', 'anoxia' or 'trauma':** This category covers any baby who would have survived but for some catastrophe occurring during labour. These babies will tend to be normally formed, stillborn or with poor Apgar scores, possible meconium aspiration or evidence of acidosis. Very premature infants (those less than 24 weeks gestation) may be asphyxiated at birth, but should not be entered in this category as a rule.
- Category 4 Immaturity:** This applies to live births only, who subsequently die from structural pulmonary immaturity, surfactant deficiency, intra ventricular haemorrhage, or their late consequences - including chronic lung damage.
- Category 5 Infection:** This applies where there is clear microbiological evidence of infection that could have caused death, e.g. maternal infection with Group B streptococci, rubella, parvovirus, syphilis etc; or in the case of a baby dying with overwhelming sepsis.
- Category 6 Due to other specific causes:** Use this if there is a specific recognisable fetal, neonatal or paediatric condition not covered under the earlier categories. Examples include:
- 1) **fetal** conditions; twin-to-twin transfusion and hydrops fetalis;
 - 2) **neonatal** conditions; pulmonary haemorrhage, pulmonary hypoplasia due to prolonged loss of liquor (primary hypoplasia being classed as a malformation), persistent transitional circulation (in the absence of infection, aspiration or surfactant deficiency), blood loss unassociated with trauma (e.g. vasa praevia);
 - 3) **paediatric** conditions; malignancy and acute abdominal catastrophe (such as volvulus without antecedent congenital malrotation).

Category 7 Due to accident or non-intrapartum trauma: Confirmed non-accidental injury should be coded here. If only suspected, code as a sudden unexpected death cause unknown (category 8)

Category 8 Sudden infant death, cause unknown: This will include all infants in whom the cause is unknown or unsuspected at the time of death. Modification due to post mortem information should be notified later.

Category 9 Unclassifiable: To be used as a last resort. Details must be given if this option is ticked.

Details Please add any information that relates to the diagnosis of the cause of death, particularly where there is more than one contributory factor, or in cases of uncertainty.



APPENDIX 2 -EXTENDED WIGGLESWORTH CLASSIFICATION



APPENDIX 2 -EXTENDED WIGGLESWORTH CLASSIFICATION

APPENDIX 3 - RAPID REPORT FORMS - 1996 and 1997

CESDI (Confidential Enquiry into Stillbirths and Deaths in Infancy)

Notification Form - 1998

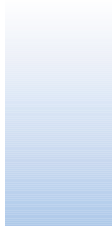
Survey Number: [REDACTED]

1. How was this case classified? (tick all that apply) *Stillbirth*

Late fetal loss (20th-23rd weeks) Stillbirth (24+ weeks) Early Neonatal Death (age 0 - 8 days) Late Neonatal Death (age 7 - 27 days) Fetal Neonatal Death (28 to 364 days)

2. Legal Abortion? (Under 1987/92 Abortion Act) YES NO

MOTHER	BABY / INFANT	
3. Mother's surname	23. Baby's surname	
4. First Name	24. First name	
8. Hospital No.	25. Hospital No.	
6. Mother's usual residential address at time of delivery/birth	26. Baby's residential address at time of death if different from Q8.	
7. Postcode	27. Postcode	
9. Mother's date of birth	28. Sex of fetus/baby	
9. Ethnic group of mother	29. Birth Weight (kg)	
10. Parity	30. Place of death	
THIS PREGNANCY		
11. What was first day of the Last Menstrual Period (LMP)	31. Date and Time death was FIRST diagnosed	
12. What was the agreed starting Estimated Date of Delivery (EDD)	32. Timing of death	
13. Gestation at birth	33. Signs/symptoms at birth	
14. Date and Time of delivery / birth	34. Discharge notes after birth	
16. Intended place of delivery at booking	35. CAUSE OF DEATH - CLINICAL DETAILS	
18. Actual place of delivery	a. Main diagnosis	
17. Reason for change between planned and actual place of delivery	b. Other diagnosis or conditions in clinical notes	
18. Number of fetuses / babies this pregnancy	c. Maternal diagnosis or conditions affecting delivery	
19. Birth Order This Fetus / Baby	d. Obstetrical diagnosis or conditions affecting delivery	
20. Maternal history	e. Obstetrical diagnosis or conditions	
21. Presentation just prior to delivery	36. EXTENDED WIGGLSWORTH CLASSIFICATION	
22. Mode of Delivery	37. FETAL AND INFANT CLASSIFICATION	
38. OBNETRSC CLASSIFICATION		
39. POST MORTEM (ALL TOPSY)		
40. Date CESDI form completed		



APPENDIX 3 - RAPID REPORT FORMS - 1996 and 1997



APPENDIX 4 - THE FETAL AND INFANT POSTMORTEM



APPENDIX 4 - THE FETAL AND INFANT POSTMORTEM



APPENDIX 4 - THE FETAL AND INFANT POSTMORTEM



APPENDIX 4 - THE FETAL AND INFANT POSTMORTEM

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