

# CESDI

Confidential Enquiry into Stillbirths and Deaths in Infancy  
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# Executive Summary

of the  
**8th**  
Annual  
Report

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Focusing on:  
Stillbirths  
European Comparisons of Perinatal Care  
Paediatric Postmortem Issues  
Survival Rates of Premature Babies – Project 27/28

Since 1992, the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) has been dedicated to improving outcomes in maternal and infant health. It collects accurate clinical data in perinatal and infant medicine on a unique scale throughout England, Wales and Northern Ireland. This has been especially important for rare events such as intrapartum deaths, stillbirths and cot deaths. These have a major impact on parents and health professionals, but occur so infrequently that only limited lessons can be learnt from individual events. The ability to derive general guidance is one of the key features of CESDI.

The 8th Annual Report of CESDI addresses a series of topics that are of major current concern. A series of recommendations are made to address the deficiencies that have been identified.

#### **Infant and perinatal mortality – England, Wales and Northern Ireland 1999**

In 1999 there were 648,409 total births in England, Wales and Northern Ireland, a figure that has been declining since 1991. The Rapid Reporting Form is the notification system used by CESDI since 1993: 10,139 deaths were notified in 1999. These comprised: 1558 legal abortions; 1679 late fetal deaths; 3216 stillbirths; 2502 neonatal deaths; and 1184 postneonatal deaths.

Completeness of ascertainment is assessed using data from the Office for National Statistics (ONS) as the 'gold standard'. This is based on Death Notifications collected by the Registrar of Births and Deaths. The proportion of ONS deaths reported by CESDI rose from 93% in 1993 to 99% in 1996 and has remained around this level since. Postneonatal deaths are the most difficult category to collect as many occur within the community, but ascertainment here has ranged from 86% in 1993 to 96% in 1998 and was 93% in 1999.

In 1999 the stillbirth rate was 5.0/1000 total births, the neonatal death rate was 3.9/1000 live births, the postneonatal death rate was 1.8/1000 live births and combined death rate (stillbirth, neonatal and postneonatal) was 11.1/1000 total births.

#### **Intrapartum related death rates 1993–99**

Although there were no significant changes in overall perinatal outcomes since 1993 there was a significant downward trend in intrapartum related deaths. These deaths account for 5% of the notifications received by CESDI and have been a major topic of review. The 4th Annual Report (1997) found that, in 1994 to 1995, half of these cases had been associated with suboptimal care that was likely to have contributed to the outcome. A series of recommendations were made regarding training, assessment and supervision of health professionals involved in caring for women and babies in labour. Many initiatives at national and local level have occurred in response to these and it is pleasing to see a downward trend in deaths of this type. The number and rate of deaths in this category, weighing 1 kg and

over, have fallen from 529 (0.77/1000 total births) in 1993 to 398 (0.62/1000 total births) in 1999.

#### **Stillbirths 1996–97 – a review of antenatal and postnatal care**

Stillbirth is the commonest category of deaths reported to CESDI, accounting for nearly a third of deaths up to 1 year of life. Many are classified as 'unexplained' but this does not equate with 'unavoidable'. An earlier CESDI programme examining stillbirths born in 1996–97 found that nearly half had suboptimal care that might have contributed to the outcome. This Report contains a further qualitative review of the comments made by the panel assessors. The key areas of concern included: antenatal risk assessment and referral practices throughout pregnancy; recognition and management of the growth restricted baby; fetal movement issues (as reported by the mother and acted on by the profession); communication (lack of planning, poor documentation); lifestyle issues (smoking, poor attendance).

The commonest area of concern in the postnatal period was the quality of the postmortem reporting. Failures in follow-up investigations and subsequent communication were also identified.

The Report recommends that:

- All maternity professionals should have an easily accessible, robust protocol to assist in ascertaining maternal and fetal risk throughout pregnancy.
- Health professionals involved in maternity care should be vigilant in identifying and communicating risk factors to specialist services.
- Plans for antenatal management in complicated pregnancies should be made in conjunction with a senior colleague.
- Parents should be counselled on postmortem to allow a well-informed choice.
- Guidelines on postmortem issues, investigations and bereavement support should be readily available to all staff.

The Report includes a commentary on future directions that may impact on reducing unexplained stillbirths. It discusses the problems of the current classification systems as used by CESDI and highlights the need for awareness and early detection of growth restriction.

#### **European standards of care**

CESDI is pleased to welcome a European initiative to evaluate whether differences in perinatal mortality rates reflect differences in standards of care. This issue was addressed in ten countries by the Euronatal Study.

Perinatal deaths were defined as babies born after 28 completed weeks and excluded neonatal deaths prior to 34 weeks. 1619 such deaths in 10 European countries

between 1995–98 were reviewed. The assessors were provided with a summary of care and were unaware of the country of origin. A series of 50 explicit audit criteria were agreed. An overall grade of care was applied to each case; this was identical to that used by CESDI (0 = no suboptimal care; 1 = suboptimal care not affecting the outcome; 2 = suboptimal care that might have affected the outcome; 3 = suboptimal care that is likely to have affected the outcome).

CESDI had already assessed the English cases as part of its own '1 in 10' programme (1997). CESDI used the medical record rather than a summary and an unstructured appraisal rather than agreed audit criteria. However the findings were remarkably similar (grade 2 or 3 Euronatal 53%; CESDI 50%). England was at the extreme of the range of the proportion of cases assigned grade 2 or 3 (32–53%). Despite the potential biases of the methodology, these findings identify areas of maternity care which deserve further study.

Two areas of concern highlighted in all participating countries were the management of the growth restricted baby and the need for interventions related to smoking cessation.

#### **Use of intrapartum monitoring 1999 – survey**

A review by CESDI of intrapartum related deaths occurring in 1994 to 1996 found that failures in the use and interpretation of cardiocographs was present in more than half of cases. This led to the recommendation of regular training and the provision of local protocols in this area. The Department of Health commissioned the Clinical Effectiveness Support Unit of the Royal College of Obstetricians and Gynaecologists to produce a national guideline on the topic and this was published in May 2001. The preparatory work included a survey of electronic fetal heart monitoring (EFM) in the UK in 1999. The results are published in this report and key points include:

- provision of local guidelines on EFM was available in 74% of units;
- use of EFM in high risk labours was variable;
- use of umbilical cord blood analysis was variable (68% units routinely performed this following emergency caesarean section);
- an admission trace was used routinely on all women in 79% of units.

CESDI recommends the implementation of two national guidelines related to labour ward practice which have been published in 2001:

*Induction of Labour: Evidence Based Clinical Guideline No 8*, RCOG Press 2001

*The Use of Electronic Fetal Monitoring: Evidence Based Clinical Guideline No 9*, RCOG Press 2001

#### **Survival rates of babies born between 27 and 28 weeks' gestation in England, Wales and Northern Ireland 1998–2000**

Prematurity is the main cause of neonatal deaths. Data on gestational age is routinely recorded on all births but is not collected centrally or published routinely for England or Northern Ireland. Thus it is not possible to provide national data on survival after preterm delivery. One of the key aims of the recent CESDI programme, Project 27/28, was to provide this data for babies born at 27<sup>+0</sup> to 28<sup>+6</sup> weeks. At this gestation most babies should survive, and differences in standards of care may make a significant contribution to the outcome. A notification process was introduced in maternity units (294) and neonatal intensive care units (149) between September 1998 and August 2000. The survival rates to day 28 of the 3522 babies are reported here.

Most babies (3101, 88%) survived to day 28. This is almost double the rate observed 15 years ago. Regional rates ranged from 80% to 92%. The median age at death was 2 days with 31 babies dying on the labour ward.

#### *Ex-utero transfers*

Following delivery 854 (24%) babies were transferred to another unit at least once within 28 days (regional range 4–41%). Within the first 24 hours of birth, 283 (7%) were transferred (regional range 0–16%). Survival was greater in transferred babies (94%) than in the non-transferred babies (86%), suggesting that the more compromised babies were less likely to be transferred.

#### *Place of birth*

A pragmatic classification of type of unit was used based on the presence of a neonatal intensive care unit and its referral pattern for babies born at 27–28 weeks. Nearly two-thirds (63%) of the babies were born in a unit with a neonatal service receiving routine referrals; and a further 28% were born in units with a neonatal intensive service which would manage babies at this gestation but did not accept referrals routinely. Seven percent of babies were born in units with no neonatal intensive care facility.

Care was provided by a large number of neonatal units managing a relatively small number of babies rather than by a few units managing large numbers. There is on-going debate on the degree to which neonatal services should be centralised. This study cannot answer this question directly because it does not adjust for case mix, clinical risk and illness severity. However it shows that babies survive equally well regardless of the type of hospital in which they are born.

#### *NHS number at birth – the potential to produce routine survival figures for premature babies*

CESDI welcomes the introduction, by May 2002, of the application of the NHS number at birth rather than at registration. If birth details, including gestation, are then linked to national infant mortality information, survival rates adjusted for gestation could be provided routinely.

CESDI recommends that the Departments of Health in England and Northern Ireland consider supporting this as a routine data set.

#### **Perinatal pathology – an update on issues surrounding the postmortem**

This year has witnessed the professional and public anguish that accompanied the Bristol and Alder Hey Inquiries. Postmortem practice, which in the past was deemed to be acceptable to the profession, has been acknowledged to be unacceptable to the public. A series of reports from various bodies including the public Inquiries have been published; this Report aims to distil the essential messages of these. The following generalisations can be made:

- Trusts must ensure that parents are provided with better information about the postmortem examination.
- All professionals who discuss the postmortem with parents must be fully informed about the process.
- The consent process requires that the postmortem is fully explained including all options regarding tissue or organ retention.
- Pathologists should be fully aware of the constraints on the use of tissue indicated by the consent process.
- In postmortems required by law (Coroner's postmortems) parents should be informed of the reasons for requiring a postmortem examination by law, of its location and of the retention of any tissue or organs.

Considerable further work is underway by the relevant bodies and organisations. In the shorter term, a Code of Practice governing the postmortem examination is under consideration together with a standardised consent form with an accompanying information leaflet specific to infants and children. In the longer term, the law is likely to be clarified, notably the 1961 Human Tissues Act, and the operation of the Coroner's system will be subject to review. The establishment of a more open and transparent framework, in which both professionals and parents are better informed, will significantly improve the climate within which the postmortem system operates.

#### **Changing practice - Clinical Negligence Scheme for Trusts**

Implementing the lessons from previous Enquiry findings is fundamental to improving practice and subsequent outcomes. In previous reports CESDI has invited a number of organisations, both national and regional, to describe how the findings of CESDI have impacted on their practice and future strategies. This year the Clinical Negligence Scheme for Trusts (CNST)

has been invited to respond. This organisation has contributed to establishing risk management in the NHS within England since 1996. Childbirth involves the highest number and highest cost of claims. CNST promotes a series of standards drawn from a variety of sources including the Confidential Enquiries. The implementation of these is discussed.

#### **The future – a time to progress**

CESDI is one of four Confidential Enquiries that come under the umbrella of the National Institute of Clinical Excellence (NICE). An external review was conducted in 2000 to inform NICE of how these Enquiries should be developed to maximise their use within the National Health Service.

Recommendations included that the programmes should concur with the health targets of the Government; the methodology should be able to support the recommendations made (incorporation of controls and relevant denominators); and the assessments should be as objective and evidence-based as possible.

With these in mind, the care of diabetic pregnancies will be the next subject for the CESDI programme. It is planned to establish a process for the notification of all diabetic pregnancies which will provide the denominator.

The review noted the considerable overlap between the areas covered by the Confidential Enquiry into Maternal Deaths (CEMD) and by CESDI and recommended that these organisations should work together. This will be particularly useful in the light of the forthcoming National Service Framework for children, which includes maternity services. From inception, CESDI has always been required to change its focus on a regular basis and it looks forward to extending its remit and scope to encompass women and children's health. Constructive learning and improving practice and outcome will remain at its core.

#### **Acknowledgements**

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

A full copy of the 8th Annual Report can be obtained from:

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