Enquiries

The confidential enquiry into maternal and child health (CEMACH)

A M Weindling

A review of the history of confidential enquiries

The Confidential Enquiry into Maternal and Child Health (CEMACH) was established in April 2003. It replaces CESDI (the Confidential Enquiry into Stillbirths and Deaths in Infancy) and CEMD (the Confidential Enquiry into Maternal Deaths); this gives it a truly perinatal focus, but its remit is now wider and includes all childhood death. This paper reviews the history of confidential enquiries, some of the principle findings of CEMACH's predecessors, and the methodology and aims of CEMACH.

THE HISTORY OF CONFIDENTIAL ENQUIRIES

The current system of confidential enquiries started in 1952, just four years after the inception of the NHS. Before that, maternal deaths were reported to the Ministry of Health on an ad hoc basis.[1] The first report of CEMD covered 1952–54, capturing 77% of maternal deaths during that period. From 1985–87 onwards, a single report was published triennially for the whole of the United Kingdom.[2] The purposes of the CEMD were to assess the main causes of maternal deaths and, through the identification of avoidable causes, to reduce maternal morbidity and mortality by recommending improvements in clinical care and service provision; it also indicated directions for future research and audit.

CESDI was established in 1992, after the Department of Health directed that the 14 regions of England should undertake perinatal mortality surveys. CESDI's remit was to improve understanding of the causes of death in late fetal life and infancy—that is, from 20 weeks post-conception to one year after birth. Its aim was to reduce mortality by identifying suboptimal patterns of practice and service provision related to those deaths and to make recommendations for improvement. Combining CEMD and CESDI, CEMACH retains this regional organisation and these overall aims.

There are two other national confidential enquiries: the National Confidential Enquiry into Perioperative Deaths (NCEPOD) and the Confidential Enquiry into Suicides and Homicides (CISH). All the confidential enquiries now fall under the umbrella of the National Institute of Clinical Excellence (NICE).

All confidential enquiry reports describe the conclusions of audits of their work by those involved in that field. The reports have been authoritative and have influenced clinical practice. Their frequency of publication is determined by the rate of occurrence of the events described. In the United Kingdom there are an estimated 957 500 pregnancies a year* and between 300 and 400 maternal deaths a year (giving a maternal mortality rate of 11.4 deaths per 100 000 maternities over the most recent period reported, 1997–99; see box 1):[3] reports on maternal deaths are published every three years. The scale of the work undertaken by CESDI was quite different. About 10 000 deaths occur annually between 20 weeks gestation and 1 year of age in England, Wales, and Northern Ireland (644 940 live births and stillbirths in 1999; perinatal mortality rate 7.9 per 1000 live births) and reports are published annually. It is of course not possible to have an enquiry about all these deaths and CESDI has always had a rolling programme, identifying specific criteria for detailed confidential enquiry. Table 1 summarises some of CESDI's previous work programmes.

*The figure combines pregnancies that resulted in a live birth at any gestation or a stillbirth at or after 24 weeks (known as ''maternities'', of which there are about 708 000 a year), legal terminations, spontaneous abortions, and ectopic pregnancies, and is likely to be an underestimate.

Confidential enquiries are driven by a desire to improve care and a great many people are involved.[2] CEMACH has a central office with a permanent staff of six and there are managers in each of the regions of England and Wales, who are responsible for individual enquiries. Each enquiry panel for a death that fulfils pre-set criteria comprises clinicians from relevant specialties, who are independent of the hospital where the patient died and who are unaware of the clinicians concerned with the patient's care—one of the regional managers' tasks is to ensure that the case notes are anonymised. The results of these enquiries are then collated.

CESDI's early projects often lacked controls and denominator information, which limited their interpretation and generalisability.[3] However, the study of Sudden Unexpected Deaths in Infants,[4 5] the Antepartum Term Stillbirth Study,[6] and the study on babies at 27 and 28 weeks gestation[6] have included information about controls. Other CESDI projects have used a focus group methodology (for example, reports on shoulder dystocia,[6] ruptured uterus,[6] planned home delivery,[6] anaesthetic complications and delays,[8] breech presentation,[8] and the onset of labour (all undertaken in 1994–95) and stillbirths (undertaken in 1996–97)[9]).

SOME FINDINGS OF CEMACH'S PREDECESSORS

The CEMD reports showed a fall in maternal deaths due to abortion from 153 in 1952–54 to one in 1994–99, attributable to the legalisation of abortion. Between the same periods, maternal deaths from haemorrhage fell from 188 to nine because of oxytocic injections, ultrasound diagnosis of placenta praevia, and improved intensive care. Death due to thromboembolism, which remains an important cause of maternal mortality, fell from 138 to 46 over this same 40 year period.[10] After 1993, there was improved case ascertainment through linking data with that provided by the Office for National Statistics. Table 2 summarises major causes of maternal deaths and their rates.[11]

Table 1 Some CESDI work programmes.

Enquiry topic	Year of study	Annual report in which findings reported
Intrapartum related deaths >2.5 kg	1993	2nd
Intrapartum related deaths >1.5 kg	1994–95	4th
''Explained'' sudden unexpected deaths in infancy	1993–96	5th
''1 in 10'' sample of all deaths >1 kg	1996–97	6th
All deaths 4 kg and over	1997	6th
Case control studies		
Sudden unexpected deaths in infancy	1993–96	3rd and 5th and the CESDI SUDI studies[4]
Antepartum term stillbirths	1995	5th
Project 27/28	1998–2000	8th

There is a fuller summary in the CESDI 8th annual report.[9]

Box 1 Classification of maternal deaths

Maternal deaths are defined as deaths of women while pregnant or within 42 days of delivery, miscarriage, or termination of pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes. Maternal deaths are classified as:

- Direct (deaths resulting from obstetric complications of the pregnant state (pregnancy, labour, and puerperium), from interventions, omissions, incorrect treatment, or from a chain of events resulting from any of the above).
- Indirect (deaths resulting from previous existing disease or diseases that developed during the pregnancy and not due to direct obstetric causes but aggravated by the physiological effect of pregnancy).
- Late (deaths occurring between 42 days and one year after termination of pregnancy, miscarriage, or delivery that are due to Direct or Indirect maternal causes.
- Coincidental (previously known as Fortuitous) deaths (those due to unrelated causes which happen to occur in pregnancy or the puerperium).

In 1994–95, 52% of 873 deaths related to intrapartum events were found to have received suboptimal care and the intrapartum related mortality rate was 0.95 per 1000 live and stillbirths;[12] by 1999, the intrapartum related mortality rate had decreased to 0.62.[9] There is, however, no room for complacency. The 1999 CESDI report warned about a failure to recognise that fetal growth failure was a precursor of many stillbirths. It was necessary to repeat recommendations that had been made in 1997 and 1998: there is a need to improve the quality of maternity records to enable clear identification of risk factors and appropriate management plans during the ante- and intra-partum periods.[9]

Several CESDI reports have commented on the use of fetal monitoring. The 1997 CESDI report showed a failure of use and/or interpretation of the cardiotocograph (CTG) in more than half of deaths that occurred intrapartum.[12] A focus group on the ruptured uterus reported that 26% of comments on substandard care related to fetal monitoring.[13] The following year, a ''4 kg and over'' survey also found deficiencies in the interpretation of CTGs.[14] CESDI consequently recommended that every hospital offering intrapartum care should train and update staff regularly in the use of CTGs, and standards were developed:[15–17]

- Basic provision of electronic fetal monitoring (EFM) facilities should be 2–4 machines per 1000 deliveries.
- A guideline on the use of EFM should be available in every unit.
- Continuous EFM should be used in selected high risk pregnancies.
- If EFM is used, fetal blood sampling should be available.
- In situations of suspected fetal compromise, umbilical cord pH should be measured at delivery.

One of CESDI's last projects was ''Project 27/28—An enquiry into the quality of care and its effect on the survival of babies born at 27–28 weeks''.[7] This major piece of work aimed to identify patterns of practice and service provision that were considered to have contributed to the deaths of babies born at 27 and 28 weeks gestation born between 1 September 1998 and 31 August 2000. It collected denominator data, set out standards, and used a case-control study approach to make recommendations for the better care of these very vulnerable infants. During the study period the neonatal mortality rate in this group was 12%. The Project made 16 recommendations for standards at a national and commissioning level and 64 at Trust level. These included recommendations about:

- Avoiding super-ovulation and multiple pregnancies when assisted reproductive techniques are used.
- Ensuring that units have a system to identify mothers who are at risk of preterm delivery at booking and during antenatal care and that these mothers should receive appropriate consultant care.
- A specialist high risk team to manage the labour and delivery of the baby of 28 weeks and less.
- Appropriate guidelines, which should include communication issues between professionals, the management of infection in the mother and baby, and thermal, respiratory, and cardiovascular support of the baby.
- Managed clinical networks and appropriate staffing levels.

Both the CEMD and CESDI have drawn attention to public health messages. In 1996, CESDI promoted key messages from the SUDI (Sudden Unexpected Deaths

Table 2 Major causes of maternal deaths per million maternities notified to the CEMD: United Kingdom 1985–99[11]

	1985–87	1988–90	1991–93	1994–96	1997–99
Total maternities (n)	2268766	2360309	2315204	2197640	2123614
Direct causes					
Thrombosis and thromboembolism	14.1	14.0	15.1	21.8	16.5
Pregnancy induced hypertension	11.9	11.4	8.6	9.1	7.1
Haemorrhage	4.4	9.3	6.5	5.5	3.3
Amniotic fluid embolism	4.0	4.7	4.3	7.7	3.8
Early pregnancy	7.9*	7.6	5.2	6.8	8.0
Sepsis	4.4	5.5	6.4	6.4	6.6
Uterine trauma	2.6	1.3	1.7	2.3	1.0
Other	9.3	5.9	4.3	0.9	2.3
Anaesthetic	2.6	1.7	3.5	0.5	1.4
Indirect causes					
Cardiac	10.1	7.6	15.9	17.7	16.5
Psychiatric†	–	–	–	4.1	7.1
Other	37.0	31.0	27.0	39.1	35.3
Malignancies‡	–	–	–	–	5.1
Total direct and indirect causes	98.2	100.1	98.1	121.9	114.0
Coincidental causes	11.3	16.5	19.9	16.4	10.8
Late causes	–	20.3	19.9	32.8	50.3

Including sepsis in early pregnancy.
†Until 1993–96 counted as ''coincidental''.
‡Until 1997–99 not classified separately.

Box 2 Key health messages from the SUDI studies[18]

Back to sleep
Babies should be put down to sleep lying on their backs, unless there is a substantial medical reason not to do so. Sleeping on the back is preferable to sleeping on the side, and sleeping on the front should be avoided.

Feet to foot; head uncovered
Babies should sleep in such a way that their head does not become uncovered during sleep. This is most easily achieved by putting a baby to sleep with his or her feet close to or touching the foot of the cot. Blankets are preferred to duvets, and should be tucked in so that the baby's head is exposed and uncovered without a hat.

Not too hot
Although it is important to prevent a baby becoming cold, becoming too hot is also a danger. Room heating is not required at night except when the weather is very cold. Babies' bedrooms should be at a temperature overnight which is comfortable for a lightly clothed adult (usually 16–20°C).

Smoke-free zone
Cigarette smoking in pregnancy and around babies increases the risk of cot death. Although giving up would be the best option, a baby will be partly protected if his or her sleeping place is regarded as a smoke-free zone, whether the baby is asleep there or not.

Prompt medical advice
The risk of cot death may be reduced by seeking prompt medical advice for babies who become unwell, particularly those with a raised temperature, breathing difficulties and who are less responsive than usual. A proportion may have acute infections amenable to treatment.

Bed sharing for comfort, not sleep
While it is likely to be beneficial for parents to take their baby into bed with them to feed or comfort, it is preferable to place the baby back into a cot to sleep. This is especially important if the parents smoke or have consumed alcohol.

in Infancy) studies (box 2).[19] In 1998, the CEMD gave clear advice on the correct use of seat belts by pregnant women (box 3).[10]

A review of trends in reproductive epidemiology by the CEMD has shown a steady increase in the proportion of deliveries by caesarean section: 3% in the 1950s, 10% in the early 1980s, 15% in 1994–95, and over 18% in 1997–99.[18] This increase has implications both for the health of mothers and for the healthy survival of their children. The most recent CEMD publication highlighted 20-fold increased mortality rate among the most disadvantaged.[3] These issues, which cut across the interests of different groups of patients, are areas that CEMACH will be able to address.

THE FUTURE

The CEMD and CESDI were previously managed by the Department of Health. In 1996, the management of CESDI was taken over by a consortium of royal colleges. Now NICE provides most of the funding. However, the profession still runs CEMACH and its management board comprises members nominated by the Royal Colleges of Paediatrics and Child Health (RCPCH), Obstetrics and Gynaecology (RCOG), Pathology (RCPath), Midwives (RCM), Anaesthetics (RCA), and the Faculty of Public Health.

CEMACH will continue to review the causes of deaths related to pregnancy and those occurring during infancy, but will also include children up to the age of 16 years. Furthermore, as the change in title implies, the new enquiry will be concerned with morbidity as well as mortality.

There will be three sections, each headed by a National Advisory Group, which will advise on the content of the programme of work. One section will continue the work of the CEMD, considering the problems of pregnancy. The next edition of the triennial report, covering the period 2000–02 is being prepared and data are being collated for 2003–05 report. The last CEMD report identified suicide as a leading cause of maternal death—there were 28 such deaths, compared with 35 due to thrombosis and thromboembolism and 15 due to pregnancy induced hypertension. This is the sort of issue where work undertaken by the new Confidential Enquiry might be linked with that of an existing one, CISH.

The second section of CEMACH will take on the work of CESDI: the present programme considers the problems of the diabetic mother and her infant, using a case-control approach. Diabetes is the most common pre-existing medical disorder complicating pregnancy in the United Kingdom, affecting approximately four per 1000 pregnancies. The St Vincent Declaration[20] stated that every diabetic pregnancy should have a near normal outcome, but in the UK, where the background perinatal mortality rate is 7.9/1000, the perinatal mortality rate of pregnancies complicated by maternal diabetes varies between 36.1 and 42.8 per 1000.[21–23] A survey by CEMACH has found that facilities available to pregnant diabetic women appear to be variable throughout the UK. CEMACH has set standards, and appointed panel chairs; the confidential enquiries are about to start.

The third of CEMACH's sections will consider the problems of childhood. This latter task is potentially broad and challenging. The precise area has not yet been decided, but it is likely to cross professional boundaries, perhaps involving social services and education. The methodology will continue to be based on confidential enquiries around individual cases and it will be case-controlled. Whatever the precise problems of childhood that are to be considered, CEMACH is determined to make a difference to the lives of children. Many of the CESDI and CEMD reports are available on the CEMACH website (www.cemach.org.uk).

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Correspondence to: Professor A M Weindling, Department of Child Health, University of Liverpool, Neonatal Unit, Liverpool Women's Hospital, Crown St, Liverpool L8 7SS, UK; a.m.weindling@liv.ac.uk

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Box 3 Recommendations for use of seat belts in pregnancy[10]

All pregnant women should be given advice about the correct use of seat belts as soon as their pregnancy is confirmed:

- Above and below the bump, not over it.

Three-point seat belts should be worn throughout the pregnancy, with the lap strap placed as low as possible beneath the ''bump'', lying across the thighs with the diagonal shoulder strap above the bump lying between the breasts. The seat belt should be adjusted to fit as snugly as comfortably possible and, if necessary, the seat should be adjusted to enable the seat belt to be worn properly.

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NEWS AND NOTES FROM THE UK

Care in the community

I think that she must be about 145 cm tall, perhaps 40 kg, and about 60 years old. She might have been taller before, but now her legs bow and her back is hunched over. She's dressed in dirty, but not filthy, clothes which are nearly, but not yet, rags. However, none of these features are what you'd notice first about her. In fact, at first you don't see her diminutive figure at all—you hear her, from a good block or two away, because she's playing a drum.

The drum, supported by a strap around her neck looks fairly new and well cared for. Unlike the tin drum my grandad gave me for Christmas when I was five—thus endearing both him and me to my parents—this is a real drum, a cylinder with the same depth as diameter, real resonance and a deep, booming note.

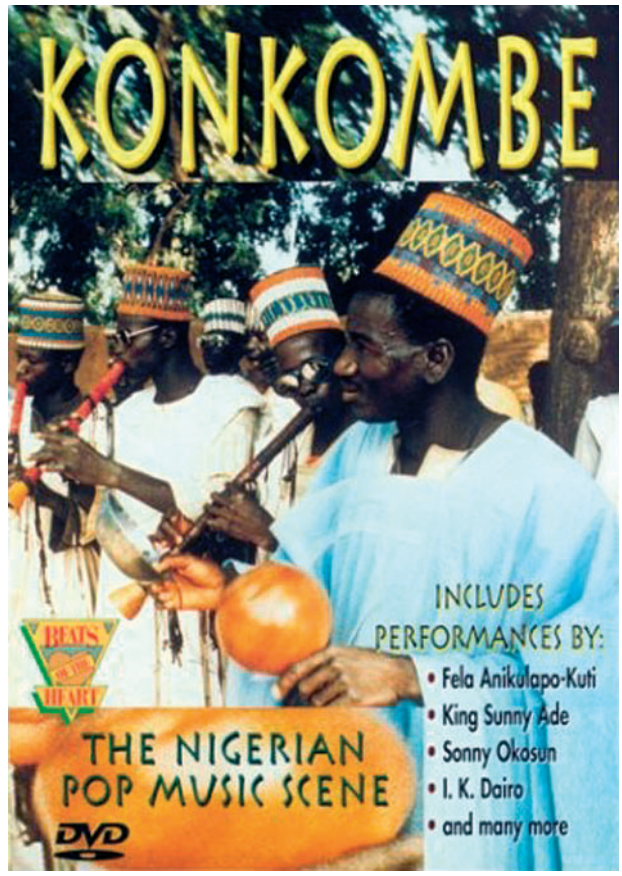
The rhythm is strictly 2/2 march. No complex quickstep of waltz here; no pretentious 5/4 or fussy 6/8—just 2/2, because that is the way she is walking. As I say, you can hear her from a block or two away, giving you enough time to work through ''What on Earth?...'', then ''Maybe it's…'', then ''No it can't be…'', and finally ''Well, it really is!'' When she gets really close you can tell that she's also singing, if you can describe a monotonal ''La, la, la'', in time with the beat of the drum singing.

If she spots you watching she'll pause, smile a broad smile with not many teeth, and give you a burst of drumming at a faster rate—not, for the moment, constrained by her walking pace.

The deal is that you give her a few pence for her playing and she goes away. Except that she is so obviously enjoying her playing that you are reluctant for her to leave; it is such a simple—but noisy—pleasure. The cynic would have it that she is playing to be a nuisance, so that you give her money to stop disturbing you. Her eyes, her slurred speech, her apparent difficulty hearing, and her childish laughter tell a different story: That she's probably enjoying this, probably a good deal more than you or I enjoy most of the things that we do. If you do a little dance with her metronomic beat, she'll laugh fit to cry, as if you've just told the world's funniest joke, or passed wind on live television.

This is a real live case of care in the community. Only here you get to choose if you are going to be a NIMBY—Not In My Back Yard—by paying just a few pence a day. You don't worry yourself about where she sleeps, or washes or eats, because she seems pretty happy, doesn't she?

An evil thought enters my mind. I see the consequences of (don't) care in the community coming home to roost, in Downing Street in the late eighties, where those policies were



engineered. I see a hundred, no, a thousand of these ladies wandering by each day, each with a voice in the shape of a drum, each pounding out their own happy rhythm.

A drum isn't the same as a voice in a democracy, but it can be a lot of fun as this lady has shown me. The lingering questions remain, however. Where on earth did she get such a good drum, and where can I get hold of a job lot?

I D Wacogne
Ian Wacogne is a consultant in general paediatrics at Birmingham Children's Hospital