Confidential Enquiry into Maternal and Child Health

CEMACH

Why Children Die:
A Pilot Study 2006

Children and Young People's Report

May 2008

young ncb

national children's bureau
making a difference

CEMACH Mission Statement

Our aim is to improve the health of mothers, babies and children by carrying out confidential enquiries on a nationwide basis and by widely disseminating our findings and recommendations.

Copies of the full report of the CEMACH study can be bought or downloaded from www.cemach.org.uk

The work reported here was undertaken by CEMACH and funded by the National Patient Safety Agency and the Department of Health, Social Sciences and Public Safety of Northern Ireland. The views expressed in the report are those of CEMACH and not necessarily those of its funding bodies.

The recommendations shown in this report were arrived at after a careful consideration of the available evidence. They do not override healthcare professionals' individual responsibility to make best decisions for the patient, in consultation with the patient and/or guardian or carer.

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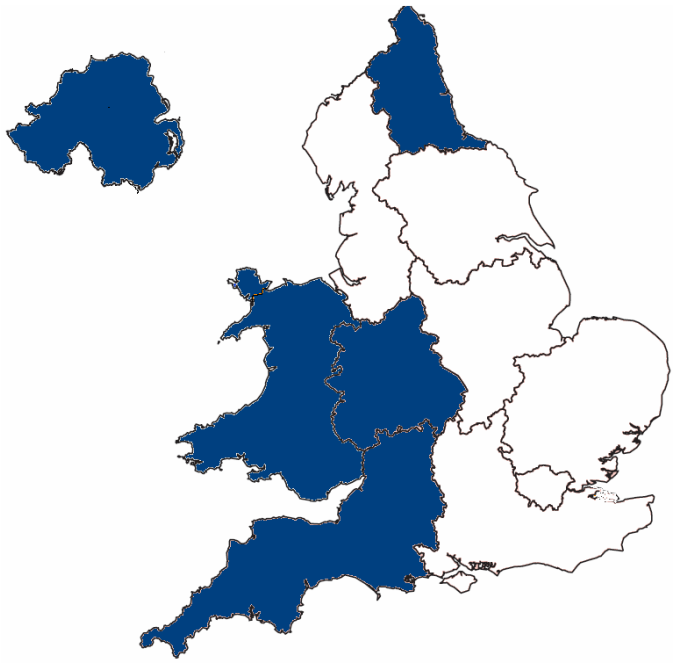
What is CEMACH?

CEMACH stands for the Confidential Enquiry into Maternal and Child Health. CEMACH carries out research across the country and makes recommendations about things that can affect the health of pregnant women, mothers, babies, and children and young people.

More information can be found on their website - www.cemach.org.uk

What is the report about?

This report is part of a study, the 'Child Death Review', which looked at why children die. The study took place in 3 regions in England, and the whole of Wales and Northern Ireland, in 2006. These regions are highlighted in the map below.



This is the first study looking at children in this way, but these kinds of studies have already helped to improve care for pregnant women and babies in the United Kingdom.

The main aims of the Child Death Review were to:

- identify all the children under the age of 18 who died in 2006 (in the regions above),
- collect specific bits of information on each of the deaths,
- look at why those children died, and see whether their deaths could have been avoided, and
- to see whether it would be possible to do more work or studies in this area, in this way.

The study looked at the information provided by doctors and other professionals (like the police, or social services) about what caused a child's death. To understand why children die, the study also involved looking at (if possible) what kind of life the child who had died had had, whether he or she had had any other problems with their health, as well as other things that could have added up to make him or her less healthy.

The study shows that there are some things that need to be improved, and the final report makes suggestions for how people can work together to make sure children can be healthier and safer.

How was the study done?

Three regions of England – the North East, South West and West Midlands – and the whole of Wales and Northern Ireland were involved in the Child Death Review.

The study recorded the deaths of all children who died in these different regions, and all who were living in the regions even if they had died somewhere else. It included all deaths of children and young people between 28 days and 18 years that happened between January 1st 2006 and December 31st 2006.

After a death had occurred and had been reported to CEMACH, detailed information about the child (if available) and how they had died was collected to provide a better picture of what happened.

A database was kept in each region to store this information, before it was looked at in more detail by CEMACH.

Some cases were selected to go forward to a panel to be looked at in more detail. The cases were examined in a panel from a different region to where the child had lived and died, in order to protect their identity. Also, in order to protect the identity of the child and family, any information that could be used to identify them, like names or places, were removed from the cases that went to these panels.

Who was involved in the study?

The study involved lots of different people, from medical experts to young people.

Consultation with young people

The National Advisory Committee for Enquiries into Child Health (NACECH) and the Patient Information Advisory Group (PIAG) thought it was important to ask children and young people what they thought about some of the issues around collecting information on child health, especially the deaths of young people aged between 14 and 18 years in this way. So, together with the National Children's Bureau (NCB), CEMACH held two events with young people aged between 14 and 20. The young people were from St. Marylebone School and Barnet FE College.

24 young people in total took part. They were asked questions about what areas of health were important to them, things that were important to consider when reviewing cases and what questions should be asked in order to get a good idea of what happened leading up to a child or young person's death.

All of the young people were asked to review three cases taken from the study.

The young people asked a lot of practical questions and told the researchers some of the things that should be looked at more closely to get a better idea of how the young people had died. For example, some of these questions involved looking in more depth at their recent health history, and asking for more information from friends and relatives about the young person's emotional and physical well-being.

The young people thought that it was important to not include too much personal detail about the children or young people involved in the cases in order to protect their identities.

They felt that they had learnt a lot about some of the dangers facing young people, particularly around drug and alcohol abuse and traffic accidents as a result of looking at some cases included in the review. They thought that just reading about the cases would help other people understand some of the issues as well, and might help stop similar things happening in the future.

Finally, the young people said that the Child Death Review was an important piece of work, which could help educate children and young people about living healthier lives, and could help prevent deaths that could be avoidable. They also said that the public, including children and young people, should know more about CEMACH's work in this area, and that the Child Death Review should be available to anyone. They thought it was important that CEMACH involves young people in the future, so that they could help inform the way that CEMACH works.

A copy of the report from these consultations with the young people can be downloaded from www.cemach.org.uk.

The Panels

The regional panels were made up of:

- a doctor specialising in children's health in hospitals
- a doctor specialising in children's health in the community
- a pathologist - someone who's job it is to find out what causes a person's death
- a general practitioner (GP) – the kind of doctor you would see at your local doctor's surgery
- a nurse
- 2 people who don't work in medicine

Other people were also asked to be on the panel, if they had special knowledge. For example:

- if a child was less than a year old, a Health Visitor and someone specialising in the health of new born babies.
- for children aged 1 – 9 years, a Health Visitor or School Nurse.
- for children aged 10 – 17 years, a School Nurse.
- someone specialising in a certain area of medicine, such as a surgeon or someone who works with children with heart conditions.
- a nurse who works with children or in the community.
- someone representing the Child and Adolescent Mental Health Service (CAMHS).
- a social worker, paramedic, someone who takes x-rays or someone from the police.

Each panel meeting looked at 3 to 4 cases. Each case was discussed by the panel, who had to look for different things that could have contributed to the death, and decide whether it could have been prevented. The information from the panels was also entered onto a database and looked at in detail by CEMACH.

What the study found

Key findings and recommendations

There were several key findings that came out of this process, both positive and negative, about the actual process used and about healthcare and health issues for young people. After looking at the key findings, CEMACH have come up with some recommendations for what could help to reduce the number of child deaths. Overall it was decided that this method of reporting worked well and could help when Local Safeguarding Children Boards (LSCBs) (people who investigate unexpected deaths of children) to put some of the lessons learnt into practise. It could help people to learn from reviews both locally and nationally.

With more resources, CEMACH could review more child deaths. It could also review more cases if more information and notes from different services were available, and investigate specific problems in local areas and services.

Key Finding 1: It was useful to collect data this way

The local networks that CEMACH used to detect and record deaths were quicker than the usual process of registration. What was recorded gave a good picture of what actually happened to the child, and helped to show things that could have been avoided. It is important to collect information this way so that we can learn more about how to prevent child deaths.

Recommendation:

- *More studies like this should be done in order to find out more about how to prevent children's deaths.*

Key Finding 2: Lots of children were well cared for

There were lots of examples where, even though a child's death couldn't be prevented, everything possible was done by the doctors involved.

Key Finding 3: Problems in recognising serious illnesses in children

In some cases, serious illnesses weren't noticed by doctors in local surgeries or hospitals, especially if the doctors involved didn't have any special knowledge of children's health.

The young people who were involved in the consultation with the NCB before the study was completed said that drug and alcohol abuse and suicide were serious health issues that were important issues to them. The panels found that most of the children and young people who died following suicide or because of drug or alcohol abuse were not in contact with mental health services.

Recommendations:

- *Doctors, nurses and other medical staff, especially in local services and Accident and Emergency (A & E) departments, should be trained in how to look after sick children.*

- *Medical staff should make sure that parents and carers feel comfortable and know how to get help if a child gets more ill after having seen a doctor.*

- *There should be ways of telling if something is wrong with a child as early as possible, for example, an 'early warning scoring system'.*

- *Children and young people who have self harmed should have support from specially trained nurses and doctors, both when they are first diagnosed and afterwards.*

Key Finding 4: Missed appointments make a difference

The panels found that there were cases where a patient did not turn up to an appointment with a doctor, and this was not rearranged or followed up. If the child had attended these appointments, or if a doctor or nurse had followed up the missed appointment, the child might not have died. It is especially important to make this effort with children.

Recommendation:

- *When a child or young person doesn't attend an appointment with any health service, they should be contacted and the appointment should be rearranged.*

Key Finding 5: Palliative Care (care being provided to children who will not recover from their illness)

Some children died as a result of an illness such as cancer or cystic fibrosis that could not have been cured, but could have been made less unpleasant for the child. 73% died in hospitals, whilst only 2.6% died in hospices (special centres for very ill children that can provide specialist care and improve their quality of life). This shows that more work can be done in improving the care of these sick children, to make sure that they can feel happy and comfortable whilst they are still alive.

Recommendation:

- *Children who have an illness that will eventually lead to their death should be given help in order to die somewhere they feel comfortable, such as in their homes or in a hospice.*

Key Finding 6: Recording and reviewing child deaths should be ongoing

The information collected on all of the deaths helped CEMACH to see public health issues relevant to children.

For example, the study found differences relating to ethnic backgrounds. More children from a Pakistani or Black African background died than white children, whereas fewer children from an Indian background died. There were also more deaths amongst children from poorer backgrounds, or where there were fewer opportunities. More non-white children were murdered than white children, although the difference was very small. Where children lived also made a difference; more children died in the North East and Northern Ireland than in other regions. All of this information could help to improve children's health, if the study is continued.

Recommendations:

- *Information should continue to be collected about deaths of newborn babies. This information should be provided to local healthcare services so that they can focus on improving the situation.*

- *As many child deaths as possible should be looked at using in-depth study and panels as was done in the CEMACH Child Death Review. These will help inform governments to plan how best to make the lives of children and young people healthier and safer.*

Key Finding 7: Children's deaths can be complicated

77% of deaths happened because the child was already ill. Sometimes (in 35% of the certificates looked at by panels) information that appeared on the death certificate was incorrect. It is important therefore that coroners (the people who confirm why someone died) work together with local services to find out exactly why a child died.

Recommendation:

- *Coroners should work together with Local Safeguarding Children Boards (people who investigate sudden unexpected deaths of children) to make sure that the real reason for a child's death is found out, and to see whether it could have been prevented.*

Key Finding 8: The role of the local doctors

There were examples of both good care and care that should be improved for children. 23% of children's deaths were caused in part by something that could have been prevented by good local care. For example, immunising them against diseases (such as measles), diagnosing what is wrong, making sure their care continues, and identifying teenagers who could be at risk, are all things that could help prevent a child's death.

Recommendation:

- *Local health care workers must be able to recognise serious illnesses in children, identify teenagers who could be in danger of harming themselves or being harmed and make sure that children are protected against diseases.*

To obtain further copies of this report please go to www.cemach.org.uk

Copies of the full report of the CEMACH study can also be bought or downloaded from www.cemach.org.uk

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