



NATIONAL CONFIDENTIAL ENQUIRY

HEAD INJURY IN CHILDREN

INFORMATION FOR CHILDREN AND FAMILIES In Northern Ireland

The purpose of this booklet is to provide the families of children who have been admitted to hospital with a head injury, between the 1st September 2009 and 28th February 2010, with information on the CMACE Enquiry into Head Injury in Children.

Overview

Between the **1st September 2009 and 28th February 2010** CMACE will be collecting information (data) on all children and young people under 15 years old who, as a result of a head injury are admitted to hospital. Children who die as a result of their injuries will also be included. The Enquiry is taking place in hospitals across England, Wales, Northern Ireland, the Channel Island and the Isle of Man.

This booklet gives you information about the Enquiry. You do not have to do anything but we think that it is important that you know about it. We hope this booklet answers any questions you may have but if you have further questions please feel free to contact us using the email address or telephone number at the back of the booklet.

Why are we doing an Enquiry on head injury in children?

Head injuries affect children in different ways – some go home after only a short stay in hospital but some may stay in hospital for a long time if their injury has been serious. Sadly, some children even die from head injuries. We hope that by collecting information on the care given to a large number of children with a head injury, care can be improved for other children in the future.

What is CMACE and what do we do?

CMACE stands for the Centre for Maternal and Child Enquiries. CMACE already collects information in all hospitals across the country about things that can affect the health of pregnant women, mothers, babies, and children and young people. From this information CMACE makes recommendations on how things could be improved. More information can be found on their website - www.cmace.org.uk

- Further information for *children and young people* → Page 2.
- Further information for *younger children* → Page 4.
- Further information for *parents and guardians* → Page 5.

Information for children and young people

How will the Enquiry be done?

Most hospitals that look after children in England, Wales and Northern Ireland are involved in the Enquiry. We will count all children and young people (up to 15 years of age) who are admitted to these hospitals or who die because of a head injury between 1st September 2009 and 28th February 2010.

We will collect information about the injuries and how they were cared for. This information will be sent to CMACE. A secure database will store the information. Your details and information about you will not be passed on to anyone else at all under any other circumstances. Some cases will be looked at very closely to see whether anything could have been done differently. We will also look at and report on care that was good.

In all cases we take great care to make sure that no-one knows who was hurt, where they were looked after or by whom. This is what we mean by a "confidential" enquiry. In Northern Ireland we will not include any identifiable details, such as name or address, on the database.

What will happen to your information if it is used for this Enquiry?

This Enquiry does not involve any different treatment, just looking at your information. The information is collected from your hospital notes, not from you directly. Examples of the type of information we are interested in are the results from your scans, what medicine you were given and if you had an operation or not. We are most interested in the early stages of your care.

What happens to the information collected on you and the care you have been given? Is it kept private?

Yes, the information that we collect will be kept very private. Most of the information about you will have a number on it instead of your name. Only the researchers will know what your number is and we keep that information locked away. It will not be shared or given to anyone outside of the research team, or even the team that looked after you in hospital. Your name will never appear in any report or in any other way.

What are the possible benefits of having your information used?

There are no specific benefits to you or your family personally. However we hope that the results of this enquiry will help health professionals provide better services and better information and support to children and their families in the future. So in this way lots of people could benefit from the information we find out.

What do I do if I do not want my information included in the Enquiry?

You do not have to take part in the enquiry, so please tell your nurse or doctor if you do not want your information to be used in this way.

What happens at the end of the Enquiry?

We will publish our findings in a report. We also like to produce a summary for children and young people which we can send out or which you can get from our website.

Did anyone else check that the Enquiry is OK to do?

Before any research is allowed to happen, it has to be checked by a group of people called an Ethics Committee. They make sure the research is fair. This Enquiry has been checked by the Central Manchester Research Ethics Committee (Reference 09/H1008/74).

CMACE also thinks it is important to ask children, young people and their families what they think about some of the issues around collecting this information in this way. So, we have been working with a charity called the Children's Brain Injury Trust (CBIT) to meet with families and talk about these things.

Information for younger children

1 We want to know about your head injury and about how it was cared for while you were in hospital. We won't need to talk to you but will use the information doctors and nurses have written down.

2 We are researchers and our job is to find out information on what makes things better for children who have had a head injury. We will not show anyone else the information we have collected about you or your head injury.

3 When we have finished we will be writing reports. We can send you one if you want us to or you will be able to get one from our website at www.cmace.org.uk.



4 After this project has finished we might like to contact you and your family again about other projects. We would make sure this was ok before we did this.



5 If you, or your parent or carer, want to ask any questions you can ring Rosie Houston on 020 7486 1191. More information can also be found on our website at www.cmace.org.uk



6 Very helpful information about head injury in children is available from organisations like the **Children's Brain Injury Trust (CBIT)**.

You, or your parent or carer, can contact them by calling 01869 341075 or by going to their website www.cbit.org

Further information for parents and guardians

What will the Enquiry into head injury look at?

The Head Injury Enquiry has three parts:

1. The first part is a survey of hospitals and ambulance services to find out about policies and practices for children with head injuries. This does not involve any information on children or parents.
2. The second part is the collection of information on all children and young people (up to 15 years old) who are transferred and/or admitted to hospital between 1st September 2009 and 28th February 2010 because of a head injury. Information will also be collected on the children who die because of their head injury.
3. The third part will involve a group of professionals looking at the care provided to a selection of the children in more detail.

What does the Enquiry involve for your child and you?

You and your child do not have to do anything at this stage: the enquiry does not involve any interviews or questionnaires. During your child's hospital stay we will collect details from their medical notes describing the child's problems and treatments. For example, information will be collected on the type of injury your child had, the time your child arrived at hospital, whether they had any operations and so on. Only information on the first 72 hours of your child's care will be collected.

Will the information collected be kept confidential?

All information which is collected about your child during the course of the enquiry will be kept strictly confidential. Any information that could be used to identify a child, like names or places, will be removed from the records before being used for any purpose.

The results of this research will be published on the CMACE website, will be the subject of presentations at scientific and health related meetings, conferences and workshops. Results will be published in peer-reviewed journals. No children, families, hospitals or staff will be identified from any of this material.

Are there any advantages or disadvantages of your child being involved in the Enquiry?

This Enquiry does not involve any risk for your child. The Enquiry has been approved by the Central Manchester Research Ethics Committee (Reference: 09/H1008/74).

There are no specific benefits to you or your family personally. However we hope that the results from this Enquiry will help the Government, hospitals and health professionals provide better services and information to support children who have had a head injury, and their families. In this way, lots of people could benefit from the information we find out from your child's head injury.

What if I do not want my child's information included in the Enquiry?

If you do not wish your child's details to be included in the Enquiry please inform the doctor or nurse caring for your child. You can also ask to have your child's information removed at any point. Refusing to take part will not affect the care your child receives now or in the future.

Who can give you more information on the Enquiry?

There is one member of staff in every hospital who has particular knowledge about the CMACE Enquiry on Head Injury in Children and they are responsible for collecting the information. Please tell a member of staff if you wish to speak to them.

Further information on head injuries in children

More, very helpful, information about head injury in children is available from support organisations such as the **Children's Brain Injury Trust (CBIT)**:

Tel: 01869 341075

Web: www.cbituk.org

If there are questions that you would still like to ask you may contact the research team at CMACE in London using the contact details on the back of this booklet.

THANK YOU VERY MUCH FOR TAKING THE TIME TO READ THIS BOOKLET

Centre for Maternal and Child Enquiries (CMACE)

Lower ground floor, Chiltern Court, 188 Baker Street
London, NW1 5SD

Tel: 020 7486 1191 **Fax:** 020 7486 6543

Email: headinjury@cmace.org.uk

More information about CMACE can be found on our website: www.cmace.org.uk

CMACE 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.

