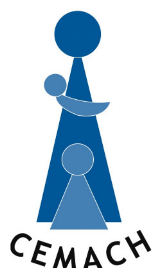

National Confidential Enquiry into 'Head injury in Children' Summary for Stakeholders

1. Introduction

The aim of CEMACH is to improve the health of mothers, babies and children by carrying out confidential enquiries and related work on a nationwide basis and widely disseminating the results. To achieve this, CEMACH carries out ongoing work, such as maternal and perinatal mortality surveillance, and time-limited research projects.

The proposed project into head injury in children is intended to be one of two topics within the national child health enquiry for 2009-2012. It will be based on morbidity rather than mortality, though some deaths due to head injury will be part of the project. The project will contribute to the evidence base concerning the impact of early management (i.e. in the first 72 hours post injury) of head injury in children on outcomes, for example health, social, and educational. The project will identify avoidable factors associated with adverse outcomes.

2. Context for a project into head injury in children

Traumatic brain injury (TBI) is the most common cause of morbidity, mortality, disability and lost years of productive life in children.[1] In 2002, TBI caused 2% of all deaths in those aged 0-14 years, and 30% of deaths due to external causes of injury in 1-14 year olds in England and Wales.[2,3] Prognosis in patients (of all ages) with severe TBI is poor: one study reported that the outcome of approximately 26% of patients admitted to hospital with Glasgow Coma Scale (GCS) score less than thirteen was either death or a persistent vegetative state.[4] Although there are no reliable current figures for the total denominator of patients with a head injury at emergency departments it is estimated that 150,000 UK children under 15 attend hospital every year due to head injury.[1] The rate of intensive care admission related to traumatic brain injury (TBI) ranged from 5.6 cases per 100,000 children in England and Wales to 7.3 per 100,000 per year in Northern Ireland.[5] These figures impact hugely on the individual and their family, and upon the state for the long-term provision of care.

Head injuries have a range of health and social outcomes, which may include disabilities that are either minor or major and include both temporary and permanent conditions. These outcomes encompass intellectual, academic, personality, and behavioural problems.[1] Long term outcome after head injury in childhood is variable and children with even mild head injuries may have persisting cognitive and behavioural problems.[6]

While little can be done by clinicians to alter the primary traumatic injury, effective optimal management to reduce secondary injury can significantly affect outcome.[7] However there is an urgent need to ensure quality service provision, and a need for greater standardisation of practice across the UK centres admitting children with severe TBI. Studies have reported large variation of practice in the UK for this patient group.[8] Less variation in management could have a beneficial effect on outcomes.

The outcome of head injuries therefore depends largely on the extent and nature of primary damage and on the effectiveness of therapy in preventing, or limiting, secondary brain damage.[9] Avoidable factors identified in care which may contribute to the death or unfavourable outcome of a child with a TBI have been noted as: inadequate airway management and insufficient management of hypoventilation,[10, 11] insufficient management of hypotension[7, 9] and poor management of transfers between hospitals.[9, 12-14] The CEMACH project would be well placed to investigate these.

Availability of standards and guidelines on care of head injured children

It is not yet known whether the recommendations in the NICE, SIGN or JRCALC guidelines are being followed by ambulance or acute NHS trusts across England, Wales and Northern Ireland. Many of the recommendations in the guidelines are based on the lowest possible level of evidence and therefore due to the various historical controversies in the pre-hospital and hospital care of head injured there is believed to be a lack of uniformity in practice.[15-17]

Implementation of and adherence to national and local guidelines and care standards related to pre-hospital and hospital care are crucial factors in managing early complications and may be associated with improved outcomes.[18] However although implementation of guidelines is clearly intended to improve patient care, the sheer number of patients with head injury means that any change in policy may have important effects on health services[15] as a result of existing health care infrastructures and operational strategies. There is no way of telling whether the results of published local audits[1,19-24] are representative of hospitals and emergency departments in the UK as a whole with regard to staffing, skills levels, and local protocols. The proposed CEMACH project could be able to ascertain whether the variability reported in the United Kingdom Paediatric Traumatic Brain Injury Study (UKPTBIS)[8] still persists even after the publication of the NICE guidelines in 2007 and earlier international guidelines[28] published in 2003.

Other initiatives

To date there has not been a national study that is specific to head injury in children which tracks the care pathway from scene of injury to intensive care treatment.

3. Project aim and objectives

The aim of this project is to optimise the outcomes for children following a head injury. Specifically the objectives of the CEMACH head injury project are to:

i. Identify and describe current protocols and practice in the pre-hospital and acute management of head injury in children in England, Wales, Northern Ireland, the Channel Islands and the Isle of Man (Scotland have been invited to participate) and to gain an overview of the variation between organisations in the use of and adherence to national guidelines.
ii. Determine the national incidence of head injury in children over the defined period (which includes the peak seasonal months) by collecting basic demographic and clinical information on all children aged between 0 and 15 years (14 years and 364 days) who are admitted to hospital with an isolated head injury (or with a head injury as part of a pattern of injuries) over a pre-identified six month period.
iii. Examine the effectiveness of the early management of head injury in children by reviewing practice against the standards set out in the 2007 NICE and JRCALC guidelines, despite the low level of evidence underpinning some of the recommendations. The project will build on areas where evidence is weak in support of the recommendations made in these guidelines.
iv. Identify avoidable factors and areas of substandard care that may lead to worse outcomes.
v. Generate and disseminate recommendations to healthcare professionals and commissioners on how to improve the care received by children with a head injury prior to and during definitive care.
vi. Engage clinical staff and healthcare providers in increasing awareness of guidelines related to head injury in children.

4. Anticipated benefits of the project

It is anticipated that the project will provide policy-makers with valuable information about the utilisation and feasibility of implementing guidelines in local settings and set the context for further research into the management of severe head injury in children. Additionally it is anticipated that the project will enable barriers to providing a comprehensive paediatric service that complies with clinical guidelines into the management of head injury to be identified. Importantly, the project will provide a much needed up to date national picture on the incidence of head injuries in children that require admission to hospital and inform regional care providers, trusts, and other national health services/ commissioners of the burden that head injury has on their resources.

5. Project design

In brief, the head injury project comprises three modules:

i. A national organisational survey of all ambulance service NHS trusts and acute NHS trusts (Spring 2009)

Purpose: To ascertain current policy, protocols and practice in the pre-hospital management of head injury in children and describe care provision across UK. The surveys will also provide an overview of the variation between organisations with regards to implementation of local and national guidelines specific to the management of children with head injury.

ii. Initial notification on children (up to 15 years old) who are admitted to hospital with or who died from an isolated head injury or a head injury as part of a pattern of injuries (expected September 2009 – February 2010 inclusive)

Purpose: To gain an overview of the national incidence of head injury in children over the defined period by collecting basic demographic and clinical information on a unit log. Cases will be identified prospectively and completed log forms will be sent to CEMACH by the local enquiry coordinators on a monthly basis. The project will include children who have a head injury as part of multiple trauma. Children who were found to be dead upon the arrival of professional medical assistance will be included in module 2 for purposes of gathering incidence data however they will not be reviewed at an enquiry panel.

Data on these children will be collected from Ambulance Services, Emergency Departments, Paediatric Intensive Care and Neurosurgical Units over the pre identified 6 month period. The completed dataset will form the pool from which cases for the enquiry panels will be sampled.

iii. Confidential enquiry panels on a sample of cases (April 2010 – June 2011).

Purpose: To investigate standards of care related to head injury to examine whether the relevant head injury standards are applied in practice, whether adherence to standards make a difference to outcome and whether there is evidence that adverse outcomes could be avoided with better care and if so, how. The cases will be children that died or who were still hospitalised as a result of their head injury at 12 weeks post injury. The controls will be children that were admitted to hospital for their head injury but did not die or who had been discharged home prior to 12 weeks post injury. Children to be included in the panel reviews will be selected using a stratified sampling strategy.[26]

8. Ethics

The methodology for the project is restricted to reviewing medical records against pre defined standards however as access to potentially identifiable data is required. CEMACH's programme of work currently has approval from PIAG under Section 251 (originally enacted under Section 60 of the Health and Social Care Act 2001 (PIAG 4-08(c)/2003) to process patient identifiable information for this project without consent. An extension to the existing approval has been agreed by PIAG for this project following agreement by Central Manchester Research Ethics Committee (Ref 09/H1008/74).

For the purposes of an additional 'follow up' module at six months post injury CEMACH will be submitting a separate application to a Research Ethics Committee.

9. Confidentiality, data handling & protection

As PIAG approval for an extension to section 60 exemption has been granted for the head injury enquiry standard CEMACH practices with regard to confidentiality, data handling and protection with apply. Identifiers will be used to enable additional case notes to be requested from hospitals and the ambulance service. Once this process is complete, however, all identifiers will be removed.

10. Non Accidental Head Injury (NAHI)

Based on previously published incidence rates it is expected that in the six months of data collection in 2009 between 48 to 114 children under 1 year may have a suspected NAHI. This subset of children will be included.

11. Outputs and Dissemination

A CEMACH report on the overall results from each module of the project will be published following completion of the enquiry panels in addition to a number of peer reviewed journal articles. CEMACH also aims to provide individual feedback reports to trusts on the organisational survey data so that they are able to compare themselves to the national picture. Relevant data from the panel enquiries will also be fed back to trusts.

A London based national conference will be held to launch the final report following completion of all modules. The launch will be followed by conferences in the UK nations participating in the project and at regional centres in England. An interactive workshop programme will be developed to further promote the recommendations using case studies where appropriate.

12. Post project review

In order to monitor the uptake of recommendations made in the report a post project review will be undertaken after completion of the project. This will involve a survey to trusts to gain feedback on local uptake of the recommendations and exploration of any barriers to implementation. A report assessing the success of the project, ongoing dissemination and uptake of recommendations, and also exploring further work potential child health for CEMACH, will be produced within 2 years of the final publication.

13. Project timescales

Project Module ➔	1. Organisational Survey - Acute Trusts	1. Organisational Survey - Ambulance Trusts (RH)	2. Descriptive study/core data collection	3. Confidential Enquiry Panels
Planning and development	October 2008 to January 2009	September 2008 to April 2009	October 2008 to May 2009	April 2009 to January 2010
Data Collection OR Enquiry panels	February 2009 to July 2009	May 2009 to August 2009	September 2009 to February 2010	April 2010 to June 2011
Data Analysis (inc cleaning)	August 2009 to November 2009	September 2009 to November 2009	April 2010 to July 2010	August 2011 to November 2011
Writing	December 2009 to March 2009	November 2009 to February 2010	July 2010 to October 2010	October 2011 to March 2012
Dissemination	*From April 2010*	*From April 2010*	*From April 2012 to post project review*	

14. Project management

The **in-house project team** will form the core working group responsible for the operational aspects of the project:

Suzanne Cox *Assistant Director R & D*
Rachael Davey *R&D Administrator*
Rosie Houston *Research Fellow (Child Health)*
Alison Miller *Programmes Director & Midwifery Lead*
Dharmishta Parmar *Data Manager*
Gale Pearson *Clinical Lead*
Rachel Thomas *Regional Manager, London & South East*

A multidisciplinary **external advisory group (EAG)** for the project has been established to advise on the project comprising individuals with an expert knowledge in this area (e.g. pre-hospital, emergency, intensive, and neurosurgical clinical and nursing care). The group reflects the range of stakeholders or groups whose professional activities or care will be covered in this project however it is not expected to be representative of all stakeholders.

Dr Rosemary Arthur	*Consultant Paediatric Radiologist, Leeds*	(Radiology)
Dr Richard Edwards	*Consultant Paediatric Neurosurgeon, Bristol*	(Neurosurgery)
Dr Phil Edwards	*Head of NPHIRU and Senior Lecturer, LSHTM*	(Epidemiologist)
Dr Ian Maconochie	*Consultant in Paediatric A&E*	(Emergency Medicine)
Dr Fionna Moore	*Medical Director, London Ambulance Service*	(Pre hospital care)
Dr Kevin Morris	*PICU Director*	(PICU)
Dr Roger Parslow	*Senior Lecturer, Paediatric Epidemiology Group*	(PICANet)
Dr Robert Tasker	*Senior Lecturer, Department of Paediatrics*	(Neuroscience)
Lisa Turan	*Chief Executive, Child Brain Injury Trust*	(Voluntary Sector)
Gurkamal Virdi	*Assistant Head of Clinical and Audit Research, London Ambulance Service*	
Mark Woolcock	*Emergency Services Specialist – Europe*	(Paramedic)

In addition to these members, the group will be extended to include, for example, a paediatric nurse.

Further information on the project can be obtained from Rosie Houston via rosie.houston@cemach.org.uk or 020 7467 3232

For further information about CEMACH, please go to www.cemach.org.uk

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