

NCMD

National Child Mortality Database

Knowledge, understanding and
learning to improve young lives

National Child Mortality Database Professional Advisory Group

Terms of Reference

Document Version: 1.3

VERSION HISTORY

Date	Document Version	Document Revision History	Document Author/Reviser
22 nd May 2018	1.0	Initial draft	Vicky Sleap
9 th July 2018	1.1	Revised draft following comments for collaborators	Vicky Sleap
31 st January 2019	1.2	Further revised draft prior to publication on website	Sylvia Stoianova / Vicky Sleap
25 th June 2019	1.3	Further revision and final for publication on the NCMD website	Sylvia Stoianova

Chair: Professor Peter Fleming

Members:

Organisation	Name
Association for Child & Adolescent Mental Health ¹	Prof Barbara Maughan
Association of Paediatric Palliative Medicine	Dr Emily Harrop
British Association for Community Child Health ¹	<i>Pending confirmation of representative</i>
Bristol Royal Hospital for Children, Children's Emergency Department	Dr Sian Thomas
British Association of Paediatric Surgeons	Bruce Jaffray
British Association of Perinatal Medicine ¹	Dr Wendy Tyler
British Association of Social Workers	Bob Ashe
Children's Cancer & Leukaemia Group ¹	Dr Antony Michalski
Children's Commissioner	Leon Feinstein
College of Emergency Medicine	Dr Ffion Davies
College of Paramedics	Will Broughton
Institute of Health Visitors	Philippa Bishop
Joint Royal College Ambulance Liaison Committee	<i>Pending confirmation of representative</i>
Office of Chief Coroner	<i>Pending confirmation of representative</i>
National Association of Headteachers	<i>Pending confirmation of representative</i>
National Congenital Anomaly and Rare Disease Registration Service	<i>Pending confirmation of representative</i>
National Police Chiefs Council	Commander Stuart Cundy
NHS England	Anna Rajakumar
Paediatric Intensive Care Society ¹	<i>Pending confirmation of representative</i>
Police National Child Death Working Group	Detective Superintendent Jason Hendy
Public Health England	Dr Helen Duncan and Dr Marilena Korkodilos
Public Health Agency, Northern Ireland	Sinead Magill
Royal College of Anaesthetists	Dr John Pappachan
Royal College of GPs	Dr Janice Allister
Royal College of Midwives	<i>Pending confirmation of representative</i>
Royal College of Nursing	Leila Francis
Royal College of Obstetrics & Gynaecology	<i>Pending confirmation of representative</i>
Royal College of Paediatrics and Child Health	Dr Ingrid Wolfe
Royal College of Pathologists	Dr Gauri Batra
Royal College of Physicians	Clare Wade
Trauma Audit & Research Network ¹	Prof Tim Coats
Scottish Child Death Review Steering Group	Mary Sloan and Harriet Waugh
UCL Partners	Prof Mike Roberts
University Hospital Southampton	Dr Diana Wellesley
Welsh Child Death Review Programme	Dr Rosalind Reilly

¹ Key Clinical groups representing the major causes and places of death

Introduction

The National Child Mortality Database (NCMD) programme has been established to collect a minimum dataset arising from the reviews of all child deaths in England by the child death review process, on behalf of Child Death Overview Panels (CDOPs). The programme team quality assures and analyses the data derived from the database and provides timely, accurate and informative outputs to relevant stakeholders to facilitate learning and actions to reduce potentially modifiable child mortality.

The NCMD programme is funded by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. It is being delivered by the University of Bristol in collaboration with the National Perinatal Epidemiology Unit (NPEU) at University of Oxford, UCL Partners and QES. Patient and Public involvement in this programme is through the Lullaby Trust, Sands (Stillbirth and neonatal death charity) and Child Bereavement UK (CBUK). The programme is funded for 4 years from 1st April 2018 to 31st March 2022.

The commissioning of the national data collection system is happening in the context of significant national changes to the organisation of CDOPs resulting from the recommendations made by Alan Wood, following his review into the Role and Function of Local Safeguarding Children Boards,² and the revision of national guidance aimed at reducing variability of practice between CDOPs.

The overall aim of the programme is to drive improvement in the quality of health and social care for children in England and to help reduce premature mortality through the establishment of the NCMD, which collects a minimum dataset from the CDOP reviews of all child deaths in England. The data is analysed, and informative outputs are produced to facilitate learning to reduce preventable child mortality.

The outputs from this programme provide the data and intelligence to enable strategic focus on the most significant causes and contributory factors in child mortality in England in the medium and long term.

The safe, sustainable and diligent delivery of mortality reviews for children is a complex task involving multiple agencies and processes. The purpose of these Terms of Reference (TOR) is to outline “system” governance arrangements to deliver the NCMD programme within England. The scope of these TOR is explained further within this document. Programme delivery and management of the overall NCMD programme is outside the scope of this document.

Purpose / Role of the Group

The members of the group are asked to:

1. Provide a line of communication between the NCMD programme team and their organisation and its members.
2. Advise on the communication of the activities of the NCMD programme and the results coming from the programme of work.
3. Advise on how best to engage the members of their organisation in the various aspects of the work of the NCMD programme.

² <https://www.gov.uk/government/publications/wood-review-of-local-safeguarding-children-boards>

4. Comment on the details of the programme of work and its execution.
5. Attend all meetings or send a deputy.

Meetings and Quoracy

1. Meetings will be held 1 to 2 times a year. Attendance may be in person or by teleconference facility (e.g. Skype).
2. Communication between the programme team and the membership of the Professional Advisory Group will include email or other electronic communications to all or individual members on an ad hoc basis throughout the programme duration.
3. Individual members may be asked to provide advice relating to their organisation or their personal expertise between meetings depending upon their availability and expertise.
4. Travel expenses (standard class travel) will be paid but otherwise this is a non-remunerated role.

NCMD Governance Structure

