

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: 2.2

Date	Document Version	Document Revision History	Document Author/Reviser
22 nd May 2018	1.0	Initial draft	Vicky Sleaf
9 th July 2018	1.1	Revised draft following comments for collaborators	Vicky Sleaf
31 st January 2019	1.2	Further revised draft prior to publication on website	Sylvia Stoianova / Vicky Sleaf
25 th June 2019	1.3	Further revision and final for publication on the NCMD website	Sylvia Stoianova
3 rd August 2020	1.4	Additional member added	Sylvia Stoianova
29 th July 2022	1.5	Members/organisations added and members/organisations removed	Ghazala Jones
4 th October 2023	1.6	Members/organisations added and members/organisations removed	Gaja Wright
29 th February 2024	1.7	Members/organisations added and members/organisations removed	Gaja Wright
25 th April 2024	1.8	Additional members added	Gaja Wright
12 th June 2024	1.9	Additional member added	Gaja Wright

30 th July 2024	2.0	Members/organisations added and members/organisations removed	Gaja Wright
9 th October 2024	2.1	Additional member added	Gaja Wright
20 th November 2024	2.2	Members/organisations added and members/organisations removed	Gaja Wright

VERSION HISTORY

Chair: Dr James Fraser

Members:

Organisation	Name
Association for Child & Adolescent Mental Health ¹	Barbara Maughan
Association of Child Death Review Professionals (ACDRP)	Nicola Needham
Association of Paediatric Palliative Medicine (APPM)	Emily Harrop Anna-Karenia Anderson
British Association for Community Child Health ¹	<i>Pending confirmation of representative</i>
Royal College of Emergency Medicine	Sian Thomas
British Association of Paediatric Surgeons	<i>Pending confirmation of representative</i>
British Association of Perinatal Medicine ¹	Stephen Wardle
British Association of Social Workers	Luke Geoghegan
Children and Young People's Cancer Clinical Reference Group	Rachael Hough
Children's Cancer & Leukaemia Group ¹	Jessica Bate
Children and Young People's Cancer Clinical Reference Group	Julia Chisholm
Children's Commissioner for England	Harriet Waldegrave
College of Paramedics	Will Broughton
Coroners' Society of England and Wales	Victoria Davies
National Director, Children and Young People's Mental Health Services (CYPMHS) Clinical Reference Group (CRG)	Prathiba Chitsabesan
Children and Young People's Mental Health Services (CYPMHS) Clinical Reference Group (CRG)	Tina Irani
Department for Education	Melanie Cawthorn
English Ambulance Services via Association of Ambulance Chief Executives (AACE)	Nicola Albutt, Lucy Gascoigne
Institute of Criminal Justice Studies, University of Portsmouth	John Fox
Institute of Health Visiting	Philippa Bishop
UK Preterm Clinical Network and NIHR Research Delivery Network (Reproductive Health and Childbirth national specialty group)	Nigel Simpson
National Association of Head Teachers	<i>Pending confirmation of representative</i>
National Genetic Risk Expert Group	Nasaim Khan
National Medical Examiner for England and Wales	Alan Fletcher <i>Pending confirmation</i>
National Network of Designated Healthcare Professionals	Peter Green
National Police Chiefs Council	Eamonn Bridger
Office of the Chief Coroner	Cathy Yallop

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

Office for Health Improvement and Disparities	Helen Duncan, Marilena Korkodilos, Lynne Reed
Office for National Statistics	<i>Pending confirmation of representative</i>
Paediatric Critical Care Society	Miriam Fine Goulden
PICANet	Richard Feltbower Sarah Seaton
Police National Child Death Working Group	Eamonn Bridger (see above)
Health & Social Care, Northern Ireland (HSNI)	Sinead Magill
Quality, Patient Safety and Maternity, Department of Health of Social Care	Karen Todd
Royal College of Anaesthetists	John Pappachan
Royal College of Emergency Medicine	Damian Roland
Royal College of GPs	Janice Allister and Bryony Kendall
Royal College of Midwives	Mervi Jokinen
Royal College of Nursing (England)	<i>Pending confirmation of representative</i>
Royal College of Obstetrics & Gynaecology	<i>Pending confirmation of representative</i>
Royal College of Paediatrics and Child Health	Ingrid Wolfe
Royal College of Pathologists	Gauri Batra and Prof Marta Cohen
The National Hub for Child Death in Scotland	Nanisa Feilden, Alison Rennie
Shooting Stars Children's Hospice	Jo Cohen
Trauma Audit & Research Network ¹	Antoinette Edwards
University of the West of England, Health and Social Sciences Department	Dawn Odd
Welsh Child Death Review Programme	Rosalind Reilly
GP/ Public Health Medical Associate	Nikesh Parekh

Background

The National Child Mortality Database (NCMD) programme has been commissioned to collect data, via the child death review process, on all child deaths in England. The NCMD programme team quality assures and analyses all data to provide timely, accurate and informative outputs to relevant stakeholders in order to facilitate learning and actions to reduce 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 delivered by the University of Bristol in collaboration with UCL Partners, the Anna Freud Centre and the NCMD system software provider company QES Ltd (Quality Education Solutions). Parent, patient and public involvement (PPPI) in this programme is enabled through the Lullaby Trust, Sands (Stillbirth and neonatal death charity) and Child Bereavement UK (CBUK). The programme is currently funded until July 2026 with a possibility for an extended funding for a further 2 years until July 2028.

The overall aim of the programme are as follows:

- Capture, analyse and disseminate appropriate data and learning from 100% of child death reviews
- Study and analyse the demographics, patterns, causes and associated risk factors of child mortality in England

- Provide information in a timely fashion that can be used by relevant NHS, health and social care organisations to make policy decisions and interventions with the aim of reducing the number of preventable child deaths
- Produce routine aggregate data tables and benchmarked child mortality data at the local level to support local response by NHS regions and Integrated Care Boards (ICBs)
- Provide information in a timely fashion that can be used by organisations in wider society to make policy decisions and interventions with the aim of reducing the number of preventable child deaths
- Support cross-system work to reduce the number of preventable child deaths, particularly in relation to groups with health inequalities, e.g. those who experience factors which impact on health determinants such as disability, socio-economic status, deprivation and poor housing
- Identify and issue relevant alerts for:
 - modifiable factors in child deaths, both related to the NHS and in wider society
 - clusters of deaths
 - newly emerging causes and risk factors for death
- Produce reports, briefings, present data, share case studies and make recommendations to relevant agencies for implementation
- Drive improvements in the quality of child death reviews, e.g. through training and support for the professionals involved

The Professional Advisory Group provides a formal interface between NCMD and the professional community. Its meetings provide a forum in which organisations can:

- a) raise practical issues with regards to the operation of NCMD
- b) contribute to discussions around themed reports and other data arising from analysis of its database
- c) inform the long term development of its program.

Its membership includes organisations that represent the cohort of children who die and who on a national level can affect policy change.

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 (and vice versa).
2. Advise on how best to promote NCMD activities and outputs arising from its programmes of work.
3. Advise on how best to engage the members of their organisation in the work of the NCMD programme.

Advise on prioritisation and content of NCMD reports.

4. Provide specialist support/advice as required.
5. Attend all meetings (or send a deputy) and be familiar with all circulated content for meetings.

Meetings and Quoracy

1. Meetings will be held 2 times a year.

2. Attendance may be in person or by teleconference facility (e.g. Microsoft Teams).
3. Communication between the NCMD programme team and the membership of the Professional Advisory Group will be via email.
4. All papers / agenda items will be forwarded at least 5 working days in advance of the meeting.
5. All meetings will be minuted. Travel expenses (standard class travel) will be paid.
6. A minimum number of members, i.e. an appropriate quorum and organisations' representatives will be required for decision-making purposes. The minimum number required to be quorate will be 15 members.

Appendix A NCMD Governance Structure

Management and Governance Structure for the NCMD Programme

