

NCMD

National Child Mortality Database

Knowledge, understanding and
learning to improve young lives

National Child Mortality Database Programme Steering Group

Terms of Reference

Document Version: 2.0

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 from collaborators	Vicky Sleap
28 th January 2019	1.2	Further revised draft	Sylvia Stoianova / Vicky Sleap
25 th June 2019	1.3	Further revision and final for publication on the NCMD website	Sylvia Stoianova
6 th February 2020	1.4	Change of membership	Sylvia Stoianova
9 th December 2020	1.5	Change of membership	Sylvia Stoianova
23 rd August 2023	2.0	Revised following commencement of new contract for NCMD Programme	Vicky Sleap

Chair:**Prof Karen Luyt****NCMD Director, Professor of Neonatal Medicine, University of Bristol****Members:**

Vicky Sleaf	NCMD Deputy Director
Sylvia Stoianova	NCMD Deputy Director
Tom Williams	NCMD Data Manager
James Harle	NCMD Senior Communications and Engagement Officer
Ghazala Jones	NCMD Administrator
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Dr David Odd	NCMD Lead Epidemiologist
Dr Joanna Garstang	NCMD Clinical Advisor, Chair of Association of CDR Professionals
Dr James Fraser	NCMD Clinical Advisor, Chair of NCMD Professional Advisory Group
Prof Peter Fonagy	Director of Mental Health Programmes, UCL Partners
Ann Chalmers	Chief Executive, Child Bereavement UK
Julie Hartley	Prevention and Practice Improvement Officer, Sands
Jenny Ward	Chief Executive, The Lullaby Trust
Charlotte McClymont	Children and Young People Programme Manager, UCL Partners
Abi Miranda	Head of Early Years and Prevention, Anna Freud
Rob Taylor	Managing Director, QES
Caroline Rogers	Associate Director, HQIP
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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). It is delivered by the University of Bristol in collaboration with, Cardiff University, Birmingham University, UCL Partners, the Anna Freud Centre and QES. Parent, patient and public involvement in this programme is through the Lullaby Trust, Sands and Child Bereavement UK (CBUK). The programme was initially funded for 5 years and 3 months from 1st April 2018 to 30th June 2023. The current contract is for a further 3 years from 1st July 2023 to 30th June 2026.

The overall aim of this 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. The data is analysed, and informative outputs are produced to facilitate learning to reduce preventable child mortality.

The NCMD programme collects data from CDOP reviews of all children in England who are live born and die before their 18th birthday irrespective of the cause of death, place of death or their gestational age at delivery.

The design and 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.

Purpose of the group

To oversee the delivery and development of the NCMD programme to ensure it meets its objectives to:

- Capture, analyse and disseminate appropriate data and learning from child death reviews.
- Drive the quality of child death review at every stage through benchmarking and quality improvement (QI) methodology.
- Study and analyse the patterns, causes and associated risk factors of child mortality in England, providing information to target preventative health and social care and to assist in policy decisions.
- Develop a sustainable model after the lifetime of the programme.

Accountability

The group reports directly to HQIP and NHS England, the commissioner and the funder of the NCMD programme respectively.

Scope of the Group

1. Guide the development of the NCMD to collect data on child death reviews.
2. Ensure the bereaved family's "voice" is fully heard and acted upon in all aspects of the work. This includes design, conduct and communication about the programme.
3. Monitor targets related to proportion of deaths entered and reviews completed by each CDOP.
4. Assist with the interpretation and analysis of data submitted from CDOPs, including areas of good practice in collecting accurate data.
5. Listen to and support bereaved families and implement interventions aimed at preventing premature mortality and identify areas where improvements in practice could be made.
6. Ensure agreed protocols are in place for information sharing and keeping content confidential and secure.
7. Advise on changes to the programme which may have high impact on timelines and budget.
8. Assess programme progress and report on progress to HQIP and/or NHS England.
9. Provide advice and guidance on issues facing the programme.
10. Assist with resolving issues and risks.
11. Use influence and authority to assist the programme in achieving its outcomes.
12. Respond in a timely manner to requests for information related to the programme from appropriate agencies (e.g. the Department of Health and Social Care).

Role of Members

Members review programme direction and make decisions to ensure that:

- Partners work together to support the success of the programme and make sure that no single interest will undermine the programme.
- All risks are assessed and managed well, putting in place actions and contingency plans for all high impact risks.

- The time and resources needed for the programme objectives are available.
- Recording of programme information is accurate and coherent.
- The progress of the overall programme is monitored, and any remediable action is undertaken.
- The purpose, progress and achievements of the programme are communicated to all stakeholders consistently and in a timely way.

Meetings and Quoracy

Meetings will be held quarterly. They will be organised by the NCMD Administrator and chaired by the NCMD Director.

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 5 members.

Secretariat

The NCMD Administrator will provide the secretariat for the meetings. Papers for sign-off at meetings should be circulated with the agenda at least a week in advance to allow time for members to familiarise themselves with the content.

Review of Terms of Reference

The TOR will be reviewed every 12 months.

Management and Governance Structure for the NCMD Programme

