

# 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: 1.5

#### VERSION HISTORY

Date	Document Version	Document Revision History	Document Author/Reviser
22 <sup>nd</sup> May 2018	1.0	Initial draft	Vicky Sleap
9 <sup>th</sup> July 2018	1.1	Revised draft following comments from collaborators	Vicky Sleap
28 <sup>th</sup> January 2019	1.2	Further revised draft	Sylvia Stoianova / Vicky Sleap
25 <sup>th</sup> June 2019	1.3	Further revision and final for publication on the NCMD website	Sylvia Stoianova
6 <sup>th</sup> February 2020	1.4	Change of membership	Sylvia Stoianova
9 <sup>th</sup> December 2020	1.5	Change of membership	Sylvia Stoianova

**Chair:****Prof Karen Luyt****NCMD Principal Investigator, Consultant Neonatologist and Reader in Neonatal Medicine, University of Bristol****Members:**

Vicky Sleaf	NCMD Manager, job-share
Sylvia Stoianova	NCMD Manager, job-share
Tom Williams	NCMD Data Analyst
Lacia Ashman	NCMD Senior Communications and Engagement Officer
Kate Hayter	NCMD Administrator
Prof Peter Fleming	Professor of Infant Health and Development Physiology, University of Bristol, NCMD PAG Chair
Prof Jenny Kurinczuk	Professor of Perinatal Epidemiology, University of Oxford
Prof Peter Blair	Professor of Epidemiology and Statistics, University of Bristol
Dr David Odd	NCMD Lead Epidemiologist
Prof Peter Fonagy	Director of Mental Health Programmes, UCL Partners
Sarah Harris	Director of Bereavement Support and Education, Child Bereavement UK
Charlotte McClymont	Head of Programmes, UCL Partners
Rob Taylor	CEO, QES
Charlotte Bevan	Senior Research and Prevention Advisor, Sands
Dr Clea Harmer	CEO, Sands
Jenny Ward	Chief Executive, The Lullaby Trust
Yvonne Silove	Associate Director, HQIP
Sarah Walker	Programme Manager, HQIP

**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. Parent, patient and public involvement in this programme is through the Lullaby Trust, the Stillbirth and Neonatal Deaths Charity (Sands) and Child Bereavement UK (CBUK). The programme is funded for 4 years from 1<sup>st</sup> April 2018 to 31<sup>st</sup> 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,<sup>1</sup> and the revision of national guidance aimed at reducing variability of practice between CDOPs.

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

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<sup>1</sup> <https://www.gov.uk/government/publications/wood-review-of-local-safeguarding-children-boards>

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 NCMD programme collects data from CDOP reviews of all children in England who are live born and die before their 18<sup>th</sup> birthday irrespective of the cause of death or place of death or their gestation 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 the Healthcare Quality Improvement Partnership (HQIP) and NHS England, the commissioner and the funder of the NCMD programme respectively.

### **Scope of the Group**

1. Guide the implementation 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 make sure 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 University of Bristol Principal Investigator.

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 TORs will be reviewed every 12 months.

# NCMD Governance Structure

