NCMD

National Child Mortality Database

Knowledge, understanding and learning to improve young lives

National Child Mortality Database
Parent, Patient and Public Involvement Stakeholder Advisory Group
Terms of Reference

Document Version: 2.0

Version History

Date	Document Version	Document Revision History	Document Author/Reviser
22nd May 2018	**1.0**	**Initial draft**	**Vicky Sleap**
9th July 2018	1.1	Revised draft contributed to by collaborators	Vicky Sleap
25th January 2019	1.2	Governance Structure added	Kate Hayter
2nd September 2019	1.3	Membership list added, Governance Structure updated, Patient and Public Involvement changed to Parent, Patient and Public Involvement	Kate Hayter
7th February 2022	2.0	Membership listed updated; section 2 expanded to include structure of group and purpose of group also updated. Frequency of meetings amended. Revised governance chart included in section 5.	Vicky Sleap

1. Introduction

1.1. The National Child Mortality Database (NCMD) project 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 project team will quality assure, scrutinise and analyse the data derived from the database and provide timely, accurate and informative outputs to relevant stakeholders to facilitate learning and actions to reduce potentially modifiable child mortality.

1.2. The NCMD project 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. Core Parent, Patient and Public involvement (PPPI) in this project is through partner charities; The Lullaby Trust, Sands (stillbirth and neonatal death charity) and Child Bereavement UK (CBUK). The project was initially funded for 4 years from 1st April 2018 and a further one-year extension has been approved giving the project a current end date of 31st March 2023.

The commissioning of this database happened 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,[1] and the revision of national guidance aimed at reducing variability of practice between CDOPs.

The overall aim of this project 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 will collect a minimum dataset from the CDOP reviews of all child deaths in England. The data will be analysed, and informative outputs will be produced to facilitate learning to reduce preventable child mortality.

The aims of this project are 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 project.

The design and outputs from this project will 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.

1.3. 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 project within England. The scope of these TOR is explained further within this document. Programme

---

[1] https://www.gov.uk/government/publications/wood-review-of-local-safeguarding-children-boards

delivery and management of the overall NCMD project is outside the scope of this document.

2. Purpose / Role and Structure of the Group

2.1. The purpose of the group is to work strategically to achieve the following aims:

- To expand, enhance and improve NCMDs engagement with parents, patients and the public (including children themselves) over the lifetime of the programme.
- To ensure meaningful, authentic and demonstrable public engagement in all that we do
- To support bereaved families to share the knowledge, experiences and insight they have gained through their child's life and death.
- To seek a range of perspectives from people from diverse backgrounds with diverse experiences

2.2. The structure of the group will be as follows:

The NCMD has adopted a 3-tiered approach for engagement with our PPPI representatives. This has allowed us to determine which tier(s) can provide appropriate engagement for each specific strand of work or project within the programme. The tiers are defined as follows:

Tier 1: Partner Charities
This tier will be populated by our 3 partner charities, The Lullaby Trust, Sands and Child Bereavement UK. These 3 charities are members of our core Steering Group for the project.

Tier 2: Third Sector Stakeholders
A wide range of other third sector stakeholders representing the interests of bereaved families and/or children's health and well-being.

Tier 3: Families and Patients
Bereaved individuals themselves. This will be parents or other family members who have lost a child or relative under the age of 18. We will also aim to engage with children directly via RCPCH and the Association for Young People's Health.

2.3. The members of the group will be invited to:

- Attend meetings or send a deputy (this may be in person or by online video conferencing; in the event that attendance is not possible written comments can be sent ahead of the meeting.
- Provide a line of communication between the NCMD project and the members of their organisation.
- Advise on the communication of the activities of the NCMD project and the results coming from the programme of work.
- Comment on the details of the programme of work.

3. Membership

3.1. The membership of the group will be made up as follows:

Organisation	Name of Representative
A child of mine	Gayle Routledge
Action on Pre-eclampsia (APEC)	Rowan Grigg
Antenatal Results and Choices (ARC)	Sara Lykke Madsen
Bliss - for babies born premature or sick	Caroline Lee-Davey
Bodie Hodges Foundation	Nicola Rhodes Donna Hodges
Child Accident Prevention Trust (CAPT)	Katrina Phillips Ian Evans
Child Bereavement UK (CBUK)	Ann Chalmers
Child Poverty Action Group	Alison Garnham Lizzie Flew
Compassionate Friends	Ruth Mercier
Coroner’s Court Support Service	Beverley Radcliffe
Da’aro Youth Project	Benny Hunter
Dove House Hospice	Jill Dolman Laura Statham
DSM Foundation	Fiona Spargo-Mabbs
Elliot’s Footprint	Andrea Kerslake
Forget-me-not Hospice	Luen Thompson
Group B Strep Support (GBSS)	Oliver Plumb
Kit Tarka Foundation	Sarah De Malplaquet
Lullaby Trust	Jenny Ward
Multiple Births Foundation (MBF)	Jane Denton
Rainbow Trust	Anne Harris Fiona Rankine

Royal Society for the Prevention of Accidents (RoSPA)	Ashley Martin
Sands (stillbirth and neonatal death charity)	Charlotte Bevan Clea Harmer
SUDC-UK	Nikki Speed
Tommy's	Jane Brewin
You Rise Me Up	Leesa Pattison

3.2. Members of the Parent, Patient and Public Involvement (PPPI) stakeholder group will be present in a representative capacity

3.3. The representative from a particular organisation may change from meeting to meeting, deputies may attend

4. Meetings & Quoracy

4.1. Tier 1 meetings will be held 2-4 times a year. Tier 2 meetings will be held 1-2 times a year.

4.2. For both Tier 1 and Tier 2 meetings, a minimum number of one third of the members of the group are required for decision-making purposes. The quorum must include a minimum number of 1 representative from the NCMD Team at the University of Bristol as the lead organisation and 1 charity representative from The Lullaby Trust, Sands or CBUK.

4.3. Individual members as individuals or on behalf of the organisations they represent may be asked to provide advice between meetings depending upon their availability and expertise.

4.4. Travel expenses (standard class travel) and childcare expenses will be paid but otherwise this is a non-remunerated role.

5. Governance