

# 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: 1.3

## VERSION HISTORY

Date	Document Version	Document Revision History	Document Author/Reviser
22 <sup>nd</sup> May 2018	1.0	Initial draft	Vicky Sleep
9 <sup>th</sup> July 2018	1.1	Revised draft contributed to by collaborators	Vicky Sleep
25 <sup>th</sup> January 2019	1.2	Governance Structure added	Kate Hayter
2 <sup>nd</sup> September 2019	1.3	Membership list added, Governance Structure updated, Patient and Public Involvement changed to Parent, Patient and Public Involvement	Kate Hayter

### 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. Parent, Patient and Public involvement in this project is through The Lullaby Trust, Sands (Stillbirth and neonatal death charity) and Child Bereavement UK (CBUK). The project is funded for 4 years from 1<sup>st</sup> April 2018.

The commissioning of this database 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 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

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

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

## **2. Purpose / Role of the Group**

2.1 The members of the group will be invited to:

- Attend meetings or send a deputy (this may be in person or by Skype / Teleconference; 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 this group will be made up as follows:

<b>Organisation</b>	<b>Name of Representative</b>
Action Against Medical Accidents (AvMA)	Liz Thomas
Action on Pre-eclampsia (APEC)	Marcus Green
Antenatal Results and Choices (ARC)	Jane Fisher Cheryl Titherly
Association for Improvements in the Maternity Services (AIMS)	Beverly Beech Debbi Chippington Derrick
Best Beginnings	Nilushka Perera
Birth Trauma Association (BTA)	Maureen Tredwell
Bliss - for babies born premature or sick	Helen Kirrane Caroline Lee-Davey
BRIPPA - British and Irish Paediatric Pathology Association	Tamas Martan Elena Pollina
British Association of Perinatal Medicine	Sanjeev Deshpande
British Maternal and Fetal Medicine Society (BMFMS)	Surabhi Nanda Melissa Whitworth
Child Accident Prevention Trust (CAPT)	Ian Evans
Child Bereavement UK (CBUK)	Ann Chalmers Therese McAlorum
DSM Foundation	Fiona Spargo-Mabbs
Group B Strep Support (GBSS)	Jane Plumb
ICP Support (Intrahepatic Cholestasis of Pregnancy Support)	Jenny Chambers
International Stillbirth Alliance (ISA)	Claire Storey
NCT (formerly the National Childbirth Trust)	Sarah McMullen
Neonatal Nurses Association	Denise Evans

Obstetric Anaesthetists' Association and Royal College of Anaesthetists	Felicity Plaats
Royal College of Emergency Medicine	Shammi Ramlakhan
Royal College of Midwives	Mervi Jokinen Rachel Scanlan
Royal College of Nursing	Carmel Bagness Pamela Boyd
Royal College of Obstetricians and Gynaecologists	Anita Dougall
Royal College of Paediatrics and Child Health	Marcia Philbin Rachel Winch
Royal College of Physicians	Clare Wade
Royal College of Psychiatrists	Trudi Seneviratne
Sands (Stillbirth and neonatal death charity)	Charlotte Bevan Clea Harmer Mehali Patel Jessica Reeves
Tamba - Twins and Multiple Births Association	Amy McCarthy Keith Reed
The Lullaby Trust	Francine Bates Jenny Ward
The Multiple Births Foundation (MBF)	Jane Denton
The Royal Society for the Prevention of Accidents (RoSPA)	Ashley Martin
Tommy's	Jane Brewin

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 and Quoracy**

4.1 Meetings will be held 1-2 times a year.

4.2 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 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 child care expenses will be paid but otherwise this is a non-remunerated role.

## 5. Governance

