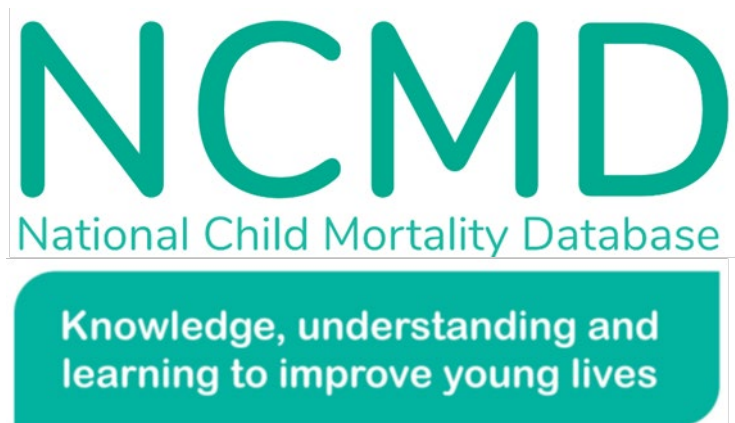




**National Child Mortality Database
Parent, Patient and Public Involvement Stakeholder Advisory Group
Terms of Reference**

Document Version: 4.1

Version History

Date	Document Version	Document Revision History	Document Author/Reviser
22nd May 2018	1.0	Initial draft	Vicky Sleaf
9th July 2018	1.1	Revised draft contributed to by collaborators	Vicky Sleaf
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 Sleaf
23rd August 2023	3.0	Revision and update following award of new contract	Vicky Sleaf
2nd November 2023	3.1	Membership listed updated	Gaja Wright
22nd March 2024	3.2	Document finalized	Vicky Sleaf
28th May 2025	4.1	Changes to language of the document with the term "Tier" removed and replaced with "Group". New additions made to section 2.1 on the purpose of the group and 2.3 on what group members will be invited to do. Governance diagram also updated with terminology changes. Membership list updated.	Vicky Sleaf
26th June 2025	4.1	Discussed at Partner Charity Meeting and approved subject to the inclusion of an additional line explaining how we will engage with young people. This has been included in Section 2.3	Vicky Sleaf

1. Introduction

- 1.1. The National Child Mortality Database (NCMD) programme was 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 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 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. Core Parent, Patient and Public involvement (PPPI) in this programme is through partner charities; 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 programme received funding for a further 3 years from 1st July 2023 to 30th June 2026.

The overall aim of the programme is to drive improvement in the quality of health and social care for children in England and to help reduce premature mortality. The data will be analysed, and informative outputs will be produced to facilitate learning to reduce preventable child mortality.

The aims of this programme 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 programme.

The design and outputs from this programme 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 PPPI strand of work within the NCMD programme. The scope of these TOR is explained further within this document. Delivery and management of the overall NCMD programme 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
- To develop and maintain a charity network to include charities that support bereaved families, or those who have an interest in the health and well-being of children.

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

The NCMD approach for engagement with our PPPI representatives is through three groups. This allows us to determine which group(s) can provide appropriate engagement for each specific strand of work or project within the programme. The groups are defined as follows:

Group 1: Partner Charities

This group will be populated by our 3 partner charities, The Lullaby Trust, Sands and Child Bereavement UK. These 3 charities are also members of the NCMD core Steering Group for the programme.

Group 2: Charity Network

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

Group 3: Bereaved Families

Bereaved individuals themselves. This will be parents or other family members who have lost a child or relative under the age of 18.

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 programme and the members of their organisation.
- Advise on the communication of the activities of the NCMD programme and the results coming from the programme of work.
- Comment on the details of the programme of work.
- Suggest areas of work of interest to PPPI stakeholders that NCMD could undertake.
- Review the NCMD PPPI workplan on a regular basis to ensure accountability.
- Collaborate with NCMD on charity campaigns that relate to recommendations in NCMD thematic reports and other outputs.
- Use their existing networks of children and young people to share messages from NCMD as appropriate. This will be discussed and agreed with Partner Charities in each case.

3. Membership

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

Organisation	Name of Representative
2Wish	Emma Kneebone
A child of mine	Gayle Routledge
Action on Pre-eclampsia (APEC)	Rowan Grigg
Autism Action	Tracey Parsons
Antenatal Results and Choices (ARC)	TBC
Association of Young People's Health	Kirsty Blenkins
Bliss - for babies born premature or sick	Caroline Lee-Davey
Bodie Hodges Foundation	Nicola Rhodes Donna Hodges
Chasing the Stigma	Justyna Lisiecka
Child Accident Prevention Trust (CAPT)	Katrina Phillips Ian Evans
Child Bereavement UK (CBUK)	Maninder Hayre
Child Poverty Action Group	Alison Garnham Lizzie Flew
Compassionate Friends	Ruth Mercier
Da'aro Youth Project	Sarah Robson Benny Hunt
Disabled Children's Partnership	Cath Lunt
Dove House Hospice	Jill Dolman Laura Statham
DSM Foundation	Fiona Spargo-Mabbs
Elliot's Footprint	Andrea Kerslake Lucy Harvey
The Foundation for Infant Loss Training	Chantal Fowler Lockey

Forget-me-not Hospice	Lis Meates
Group B Strep Support (GBSS)	Oliver Plumb Jesicca Fuller
Jessie May Children's Hospice	Helen Williams
Kid Rapt	Carol Ainge
Lullaby Trust	Jenny Ward Kate Holmes
National Children's Bureau	Alison Penny
National Children's Hospitals Bereavement Network	Catherine LeRoy
Papyrus UK	Kate Heneghan
Race Equality Foundation	Tracey Bignall
Rainbow Trust	Anne Harris Fiona Rankine Tomaz Czarnecki
Royal Life Saving Society (RLSS) UK	Porcha Treanor
Royal Society for the Prevention of Accidents (RoSPA)	Rebecca Guy Rhian Reynolds
Sands (stillbirth and neonatal death charity)	Clea Harmer Julie Hartley
Sepsis Trust	Katie Hobday Ron Daniels
Shared Health Foundation	Sam Pratt Angie Ouattara
SUDC-UK	Nikki Speed
The Compassionate Friends	Ruth Mercier
Tommy's	Jane Brewin
Willow Wood Hospice	Callie Harrop
You Rise Me Up	Leesa Pattison
NHS CYP (LD Programme)	David Gill Teresa Randon

- 3.2. Members of the 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. Group 1 meetings will be held 2-4 times a year. Group 2 meetings will be held 1-2 times a year.
- 4.2. For both Group 1 and Group 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 representative from a partner charity (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

