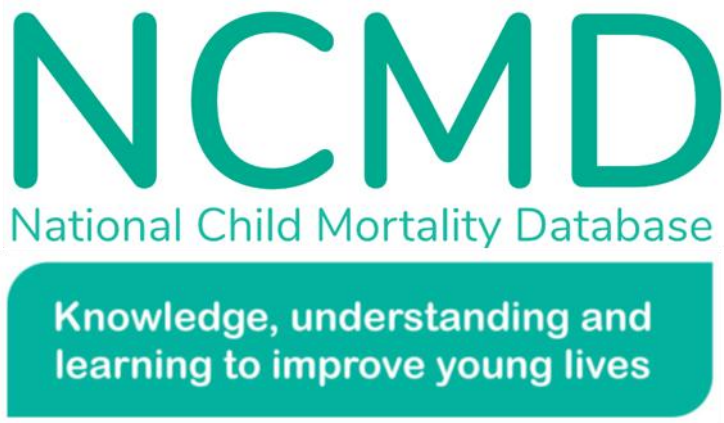


National Child Mortality Database Parent, Patient and Public Involvement Advisory Network Terms of Reference

Document Version: 5.2

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
23rd August 2023	3.0	Revision and update following award of new contract	Vicky Sleap
2nd November 2023	3.1	Membership listed updated	Gaja Wright
22nd March 2024	3.2	Document finalized	Vicky Sleap
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 Sleap
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 Sleap
15th January 2026	5.0	Document updated to reflect changes in structure of PPPI involvement in the programme and a change in collaborating partners.	Vicky Sleap

4th August 2026	5.2	• Added a new section on principles for the Network. • Clarified under section 3 that this Network is advisory only and decision-making sits with the NCMD leadership and governance structure. • Added a new section 3.3 relating to how the Network will engage with children and young people. • In section 4 the membership list has been removed and will be maintained separately. It has been replaced with a general statement about membership of the network. A new section 4.4 has been added to set out the expectations of members of the network. • Section 5 has two new clauses. One about conflict of interest to clarify how these will be dealt with and the other about accessibility and NCMD's commitment to inclusion • A new section 6 has been added to detail chairing and secretariat arrangements. • New clauses have been added in section 7 to clarify governance details.	

22nd October 2026	5.2	The following changes were made in response to feedback from PPPI Advisory Network Members • Section 2 on Principles updated language to include equity • Section 3.2 – additional paragraph added to clarify that the TOR relate to all 3 pillars of the network and to clarify attendance at meetings • Section 3.3 – Additional text added to clarify membership rights and participation of children • Section 3.4 – additional bullet point added to reflect that members can co-produce reports and outputs • Section 4.1 – Amendment made to clarify that membership may include bereaved parents acting in an individual capacity rather than representing organisations • Section 4.4 – Amended to clarify that people can also share their personal lived experience as appropriate • Section 7.1 detail added to make the route of influence between the network and the NCMD steering group clearer and to clarify the role of the Professional Advisory Group.	

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, 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 30thJune2026 and has just been granted a 2 year contract extension from 1st July 2026 to 30th June 2028.

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. Principles

The NCMD PPPI Network will operate in accordance with the following principles:

- Respect for lived experience.
- Equity, inclusivity and diversity.
- Transparency and accountability.
- Collaboration and mutual learning.
- Accessibility and flexibility.
- Meaningful rather than tokenistic involvement.

3. Purpose / Role and Structure of the Network

3.1. The purpose of the Network 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, inclusive and demonstrable parent, patient and public involvement across all aspects of the programme
- To support bereaved families to share the knowledge, experiences and insight they have gained through their child's life and death. This will include sharing their experiences in NCMD thematic reports and other publications as appropriate.
- To seek perspectives from people with a broad range of backgrounds experiences and communities
- 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.
- To communicate learning and safety messages to families and professionals to ensure they have up to date information on how to keep children safe and well.
- For NCMD and members of their charity network to work together to influence policy at a national level by supporting charity campaigns and objectives with data and analysis
- The Network provides advice and recommendations to NCMD. Responsibility for operational and strategic decisions remains with the NCMD leadership and governance structure.

3.2. The structure of the Network will be as follows:

The NCMD approach for engagement with our PPPI representatives is through three interconnected pillars supporting the programme. This allows us to utilise the expertise of each pillar to ensure all perspectives are represented and inform our work.

These Terms of Reference apply to the NCMD PPPI Advisory Network as a whole. The Network is comprised of representatives from all three PPPI pillars and provides a mechanism through which perspectives from partner charities, the wider charity

network, and individuals with lived experience can be brought together to inform the work of NCMD.

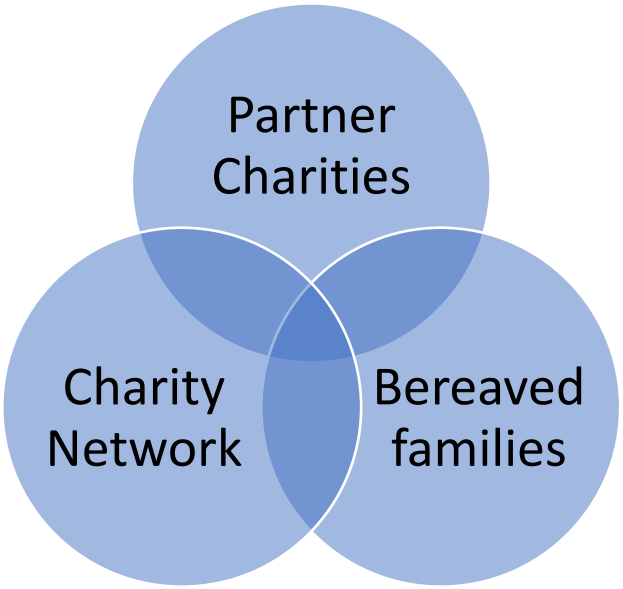
The pillars are defined as follows:

Partner Charity Pillar: This pillar 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 Steering Group for the programme.

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

Lived Experience Pillar: Bereaved individuals themselves. This will be parents, siblings, grandparents or other family members who have lost a child or relative under the age of 18. This pillar will also include children and young people who may not be bereaved but will have an important perspective on issues of relevance to them.

3.3. Engagement with children and young people will be undertaken using age-appropriate methods and, wherever possible, through existing networks and organisations with expertise in youth engagement. Participation will be voluntary and supported in accordance with safeguarding and ethical requirements. Children and young people participating in the Network will be supported to contribute meaningfully to discussions and activities in a manner that is appropriate to their age, experience and preferences.



3.4. The members of the Network 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
- Contribute to the development and dissemination of NCMD reports, publications and outputs where appropriate
- 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.
- Use NCMD data and analysis to support their charity objectives and campaigns and feedback to NCMD on the value/impact of the data.

4. Membership

4.1. Membership will consist of organisations supporting bereaved families and/or promoting child health and wellbeing, together with individuals with relevant lived experience who may participate in a personal capacity. A current membership list will be maintained separately by the NCMD team and reviewed annually.

4.2. Organisational members will participate in a representative capacity. Individuals with lived experience may participate in a personal capacity.

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

4.4. Members are expected to:

- Attend meetings regularly where possible.
- Read papers circulated in advance.
- Share views from their constituency, organisation and/or personal lived experience as appropriate.
- Respect confidentiality where required.
- Declare conflicts of interest.

5. Meetings & Quoracy

5.1. Partner charities will attend the NCMD steering group meeting to regularly advise on matters relating to PPPI. These meetings are held 4 times per year. The terms of reference for this group can be found on the NCMD website.

5.2. Members should declare any actual, potential or perceived conflicts of interest at the start of meetings. The Chair will determine whether any action is required.

5.3. Meetings of this Network will be held two to three times a year. One meeting will be in person and the others will be online. All members from each pillar will be invited to attend.

5.4. A minimum number of 8 members of the Network are required. 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).

5.5. 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.

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

5.7. NCMD is committed to ensuring participation opportunities are accessible and inclusive. Reasonable adjustments will be made wherever possible to support involvement from individuals with protected characteristics and those with additional needs.

5.8. NCMD will seek to ensure that participation by individuals with lived experience is appropriately supported and conducted in a sensitive manner.

6. Chairing and Secretariat

The Network will be chaired by a representative of NCMD. Secretariat support will be provided by the NCMD team, who will coordinate meetings, agendas, records of discussions and actions.

7. Governance

7.1 The NCMD PPPI Advisory Network reports into the NCMD Steering Group through the Partner Charity Pillar. Representatives from the Partner Charity Pillar, who are also members of the NCMD Steering Group, will ensure that key recommendations, themes and actions arising from the Network are shared with and considered by the Steering Group (see Figure 1).

The Professional Advisory Group provides professional, clinical and operational expertise to NCMD. The PPPI Advisory Network provides advice and insight based on lived experience and perspectives from voluntary sector organisations and the public. Both the Professional Advisory Group and the PPPI Advisory Network inform the work of NCMD through separate but complementary routes.

7.2 These Terms of Reference will be reviewed annually, or sooner if required following changes to the NCMD programme, governance structure or membership.

Figure 1: Governance structure for the NCMD PPPI Advisory Network

