NCMD

National Child Mortality Database

Knowledge, understanding and learning to improve young lives

National Child Mortality Database
First Annual Report
2019

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HQIP

Healthcare Quality Improvement Partnership

Acknowledgements

The National Child Mortality Database (NCMD) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. NCAPOP is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies www.hqip.org.uk/national-programmes

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1. EXECUTIVE SUMMARY

This is the first annual report of the National Child Mortality Database (NCMD) programme. NCMD is a 4-year programme commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The programme was established and is delivered by the University of Bristol, in collaboration with the University of Oxford, University College London (UCL) Partners and the software company QES. It also includes representation from bereaved families through the NCMD charity partners: Child Bereavement UK, The Lullaby Trust and Sands.

The new NCMD national system collates data collected by Child Death Overview Panels (CDOPs) in England from reviews of all children, who die at any time after birth before their 18th birthday. There is a statutory requirement for CDOPs to collect this data and to provide it to NCMD. The purpose of collecting this information, via the NCMD national data collection system, is to ensure we are able to learn from deaths, that learning is widely shared and that actions are taken, locally and nationally, to reduce preventable child deaths in the future. This will be achieved by the publication of annual reports and additional thematic reports, which will include key messages and recommendations informed by the data and in consultation with the NCMD stakeholder professional and public representation groups.

This report covers the first year of the programme (1st April 2018 – 31st March 2019) and is intended to be of general interest to professionals, bereaved families and the public.

The report describes the background for the development of the NCMD programme, its aims, objectives and governance structures, the details of the implementation of the NCMD web-based platform and scope of the national data collection system and data flows. It also focuses on the additional projects

undertaken by the NCMD team in engaging and supporting the child death review (CDR) partners and in data linkages with other national data collection and service improvement systems.

The NCMD programme receives input from a multi-partner steering group and multi-professional advisory groups, which includes representatives from national organisations, charities and family representatives. The NCMD programme acknowledges that parent, patient and public involvement (PPPI) in safety and improvement programmes is vital to ensure that their perspectives inform development and progress. The programme has established and actively engaged a PPPI Group in communicating the progress in developing the system and sought members' feedback on the information materials used by the programme. This group includes representation from charities who support children of all ages as well as parents. The PPPI Group members will be actively involved in the development and implementation of the NCMD quality improvement plan, work on which will begin in the second year of the programme.

A set of milestones were achieved in the first year of the programme:

- Governance and operational structures were developed ensuring bereaved families and professionals who care for children are fully represented at the very core of this programme.
- A communications plan was developed, which focused on effective engagement through the NCMD website, social media and presentations at national events, such as, NHS England implementation events and webinars, and the National Network of Child Death Overview Panels (NNCDOP) Annual Conference. This has involved raising awareness about NCMD to CDR partners and specialist professional organisations e.g. Royal Colleges.
- A legal basis for collecting and holding data in NCMD was established.
- A set of supplementary reporting form questions was updated and expanded to collect information from those people who provided services to the child and their family during life and after death. This work was carried out with the involvement of experts from around the country who helped in guiding key questions (Appendix 1).
- The NCMD web-based platform was designed and built. A pilot was carried out to test the system, which resulted in the provision of valuable feedback from CDOPs that enabled appropriate adjustments to be made before going live. The team worked with members of the NCMD Steering Group, PPPI Group, Professional Advisory Group and CDOPs to ensure that when the system was launched it met the needs of all stakeholders.
- Data linkage collaboration was set up with the Perinatal Mortality Review Tool (PMRT), with the aim to support professionals by reducing the number of forms they need to complete to provide information for both data collection systems. Progress was made in mapping both national data sets and setting up the principles and plans for the technical work required.
- An NCMD pilot phase was completed where CDOPs tested NCMD by entering information into the system and providing feedback on what works and what needed changing.
- After the successful completion of the pilot, the NCMD system went live on 1st April 2019, as planned.

2. INTRODUCTION

The National Child Mortality Database (NCMD) programme is currently funded from 1st April 2018 to 31st March 2022 and has been commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

The programme is led by the University of Bristol, in collaboration with the National Perinatal Epidemiology Unit (NPEU) at University of Oxford, UCL Partners and the software company QES. In addition, the programme benefits from the involvement of the NCMD charity partners: The Lullaby Trust, Sands and Child Bereavement UK.

Child death review (CDR) processes were made mandatory for Local Safeguarding Children Boards (LSCBs) in England in 2008 for all child deaths up to the age of 18. The overall purpose was to understand why children die and to put in place interventions to protect other children and prevent future deaths.

In 2018, the Department of Health and Social Care (DHSC) published new and revised statutory and operational guidance related to CDR. The new guidance requires all CDR partners to gather information from every agency that has had contact with the child, during their life and after their death, including health services, children's social services, police, and education services. This is done using a set of statutory CDR forms.

Once completed, the statutory CDR forms are provided to the local Child Death Overview Panel (CDOP) meeting, where the information is independently reviewed. CDOPs are groups of professionals who meet several times a year to review all the child deaths in their area. The CDOP must then supply specific information to the NCMD programme via a web-based platform.

The purpose of collecting this information from all over England, via the NCMD national data collection system, is to ensure that deaths are learned from, that learning is widely shared and that actions are taken, locally and nationally, to reduce preventable child deaths in the future.

The mission of the NCMD programme is to use "Knowledge, Understanding and Learning to Improve Young Lives".

2.1. Background and context

2.1.1. International context

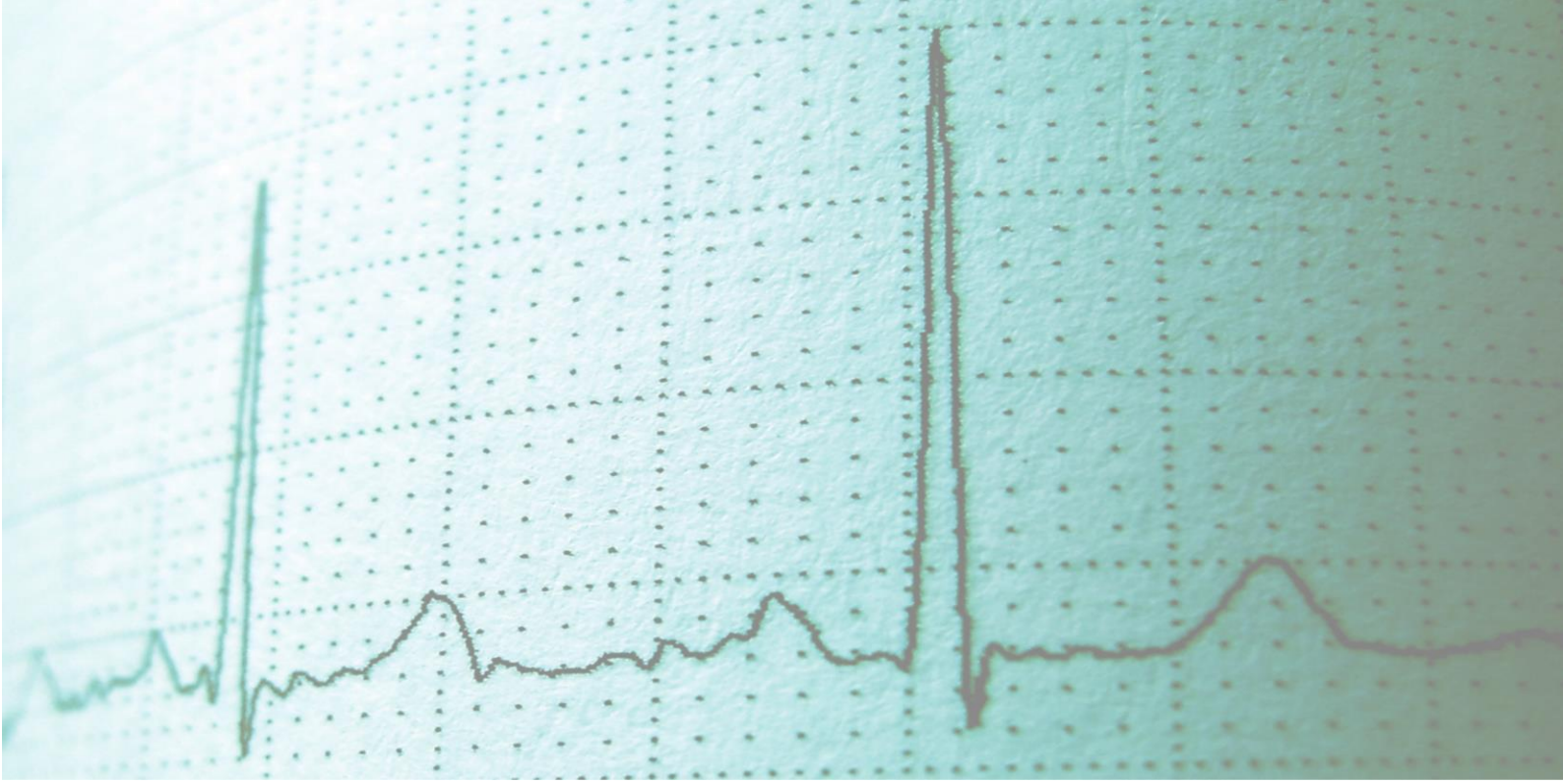
The UK has not kept pace with comparable countries in reducing the deaths of babies and children under five and has dropped several positions in European Union rankings of child mortality since 1990[1]. The international position for the UK is similar for all deaths of children under the age of 18[2]. This is despite multiple processes to review and understand the deaths of children, some of which have been long established. These include:

- Hospital morbidity and mortality discussions
- CDOPs
- Serious case reviews
- Multi-agency or single-agency learning reviews
- Mothers & Babies: Reducing Risk Through Audit and Confidential Enquiries (MBRRACE-UK): perinatal confidential enquiries
- Child Health Clinical Outcome Review Programme
- NHS England regional operational delivery networks

In addition, multiple reviews have been undertaken and reports written providing advice and guidance on what should happen when a child dies. Many of the processes laid out in these reports are aimed at identifying learning and improving outcomes for children. They include:

- Review of the Serious Incident Framework (2015)
- Report of the Morecombe Bay Investigation (2015)
- Review into the Role and Function of Local Safeguarding Children Boards (2016)
- Review of the Sudden Unexpected Death in Infancy Guidance (2016)
- CQC Report: Learning, Candour and Accountability (2016)
- Children and Social Work Act (2017)
- Working together to Safeguard Children (2018)
- Child death review statutory and operational guidance (2018)
- Planned introduction of Medical Examiners (2019)

[1] Office for National Statistics, 2017
[2] Viner et al, 2014



2.1.2. Challenges in learning from deaths

The CDR process was implemented in 2008 and from its inception it was the responsibility of the Local Safeguarding Children Boards (LSCBs) to carry out the process. There are 152 LSCBs across England and each one works in a slightly different way.

This meant that the way the CDR process operated across the country varied significantly, both in terms of what data was collected and how deaths were reviewed. In addition, there was no national collation or analysis of the CDOP information. This meant that the understanding of how and why children die, and what might be done to reduce the number of children dying in the future, was very limited.

In addition, the context in which the CDR process operates changed significantly in the last decade. This includes:

- The introduction of Duty of Candour for health organisations
- Changes in legislation around data protection and freedom of information
- The occurrence of high profile child deaths in healthcare institutions, such as those that occurred at Morecombe Bay[3]

As a result, CDOPs and those involved in CDR now operate in a much more complex environment.

In addition, the communication between CDOPs and other agencies was poor and there was a lack of good quality information coming out of the CDR process.

During the CDR Database Development Project, parents felt that in order for something positive to emerge from the tragic death of their child, there needed to be better national learning. They implicitly understood the valuable contribution that a national database would make to the achievement of this goal.[4]

[3] Kirkup (2015)
[4] Kurinczuk et al (2016)

2.2. Aims and objectives of NCMD

2.2.1. Aims

Improvement of child survival starts with high quality standardised review processes of each child death, pragmatic data collection of review data, intelligent analysis and systematic dissemination of learning and conclusions to key audiences capable of effecting change.

The overall aim of the NCMD programme is to drive improvements in the quality of health and social care for children in England and to help reduce premature mortality.

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.

2.2.2. Objectives

- To capture, analyse and disseminate appropriate data and learning from CDR.
- To 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 developments.
- To drive the quality of CDR at every stage through benchmarking and quality improvement (QI) methodology.
- To develop a sustainable model for data collection after the lifetime of the programme.

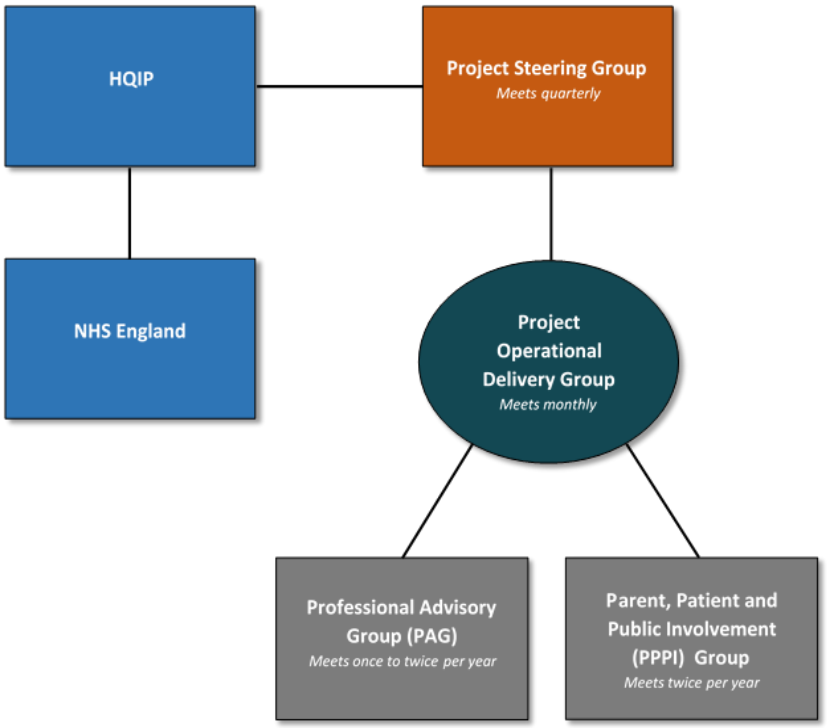
2.3. Scope of the programme

The CDR process collects data on all children, regardless of how short their lives, who die before their 18th birthday. It does not collect data on babies who are stillborn.

2.4. Governance

There are two strands to the governance process for the NCMD programme of work. The first is input from the programme's Steering Group and Professional Advisory Group, which include representatives from national organisations, charities, parents and patients (see Figure 1). The second is regular contract review meetings, to report progress against our deliverables and to ensure the contract is proceeding on time and to budget.

Figure 1: NCMD Programme organisational structure



2.4.1. Programme Operational Delivery Group

The NCMD programme team meet monthly to discuss and agree the details on the course of action set by the Steering Group. For instance, this group develops the NCMD analysis plan, communication strategies, as well as approaches for data linkage and stakeholder engagement.

2.4.2. Programme Steering Group

The Programme Steering Group guides and oversees the implementation of NCMD. Through representative membership of three bereavement charities the voices of bereaved parents are fully heard and acted upon in all aspects of the work. It also drives engagement and alignment across the partner organisations and facilitates the dissemination of key programme information (https://www.ncmd.info/governanceterms-of-reference/).

2.4.3. Professional Advisory Group (PAG)

The PAG acts as an independent expert advisory group to the NCMD programme and plays a key role in determining priority themes for the analysis and reporting on specific causes of deaths as well as the annual updating of the supplementary reporting forms. It includes representatives from a wide range of organisations and professional bodies (https://www.ncmd.info/governanceterms-of-reference/).

2.4.4. Parent, Patient and Public Involvement (PPPI) Group

The PPPI Group was set up and led by Professor Jenny Kurinczuk. The first PPPI meeting was held in September 2018 as a joint stakeholder consultation meeting with the Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries (MBRRACE-UK) Perinatal Mortality Review Tool (PMRT) team as the same stakeholders were being consulted for both programmes of work.

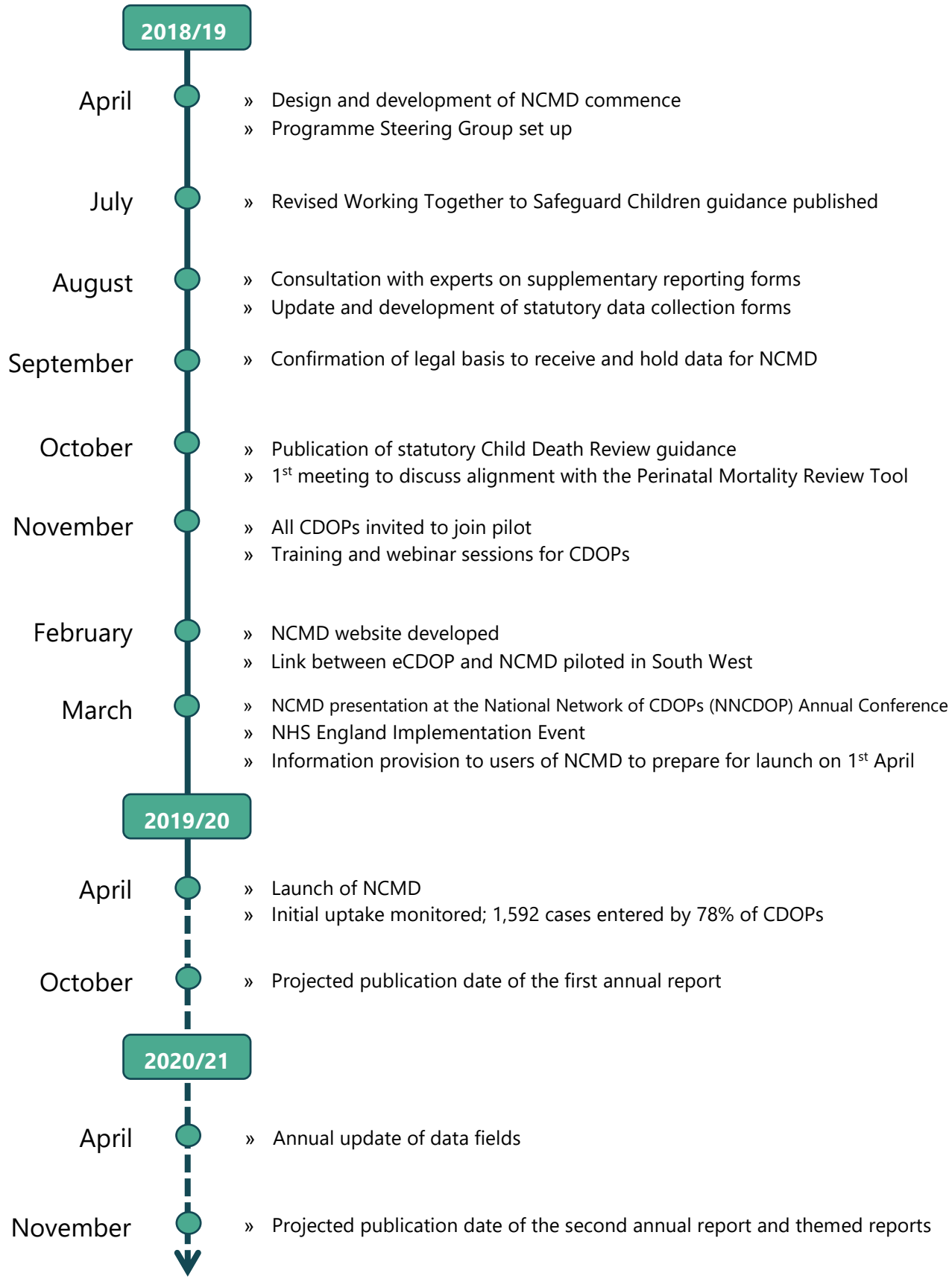
The first meeting was an opportunity to introduce the NCMD programme to the stakeholders, and discuss its purpose, progress and planned outputs and activities. 40 stakeholders attended representing relevant charities and voluntary groups, royal colleges and professional associations such as the Child Accident Prevention Trust and the Royal Society for the Prevention of Accidents. The unanimous view by the attendees was that they found this joint meeting format very helpful and time efficient.

> "As the UK's leading charity working to reduce the number of children killed, disabled or seriously injured in accidents, we welcome the opportunity to participate in the work of the National Child Mortality Database, not only with health professionals and researchers but critically with bereaved parents and those who support them.
>
> Our experience shows that it is vital to share learning about the changing risks to children's safety and wellbeing. It is only by working together nationally to understand the circumstances of these tragic events that we can ensure effective preventative action and potentially life-saving engagement with all families."
>
> *Katrina Phillips*
> *Chief Executive, Child Accident Prevention Trust (CAPT)*

3. NCMD PROGRAMME – IMPLEMENTATION AND DELIVERY

The NCMD programme was delivered in a phased approach in the first year. Figure 2 below summarises the main phases and milestones of the NCMD programme implementation.

Figure 2: NCMD programme milestones



3.1. Legal basis for NCMD to collect and hold data

The legal basis was established for the holding, processing and transferring of data into NCMD. This resulted from legal consultation initiated in the first year of the programme.

Section 16 (M) of the Children Act 2004 requires the analysis of information about child deaths. CDR partners meet this requirement by providing data to NCMD via their CDOPs. The legal basis for this is established through the following two documents:

Working Together to Safeguard Children (2018)
https://www.gov.uk/government/publications/working-together-to-safeguard-children--2

Child Death Review Statutory and Operational Guidance
https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england

3.2. Information Governance

The security of personal and sensitive information is of vital importance to the programme. The NCMD programme team carried out a detailed data protection impact assessment (DPIA) at the very start of the programme, as soon as the data collection forms were finalised, and before the data collection system was launched on 1st April 2019. The DPIA was approved by:

- Programme Steering Group
- University of Bristol's Information Governance and Information Technology departments
- The NCMD programme team
- QES
- HQIP

Following its completion, the DPIA, along with the risk register and information governance checklist have been regularly reviewed and updated as part of the routine governance processes within the project. These documents will continue to be reviewed and amended as appropriate over the lifetime of the programme.

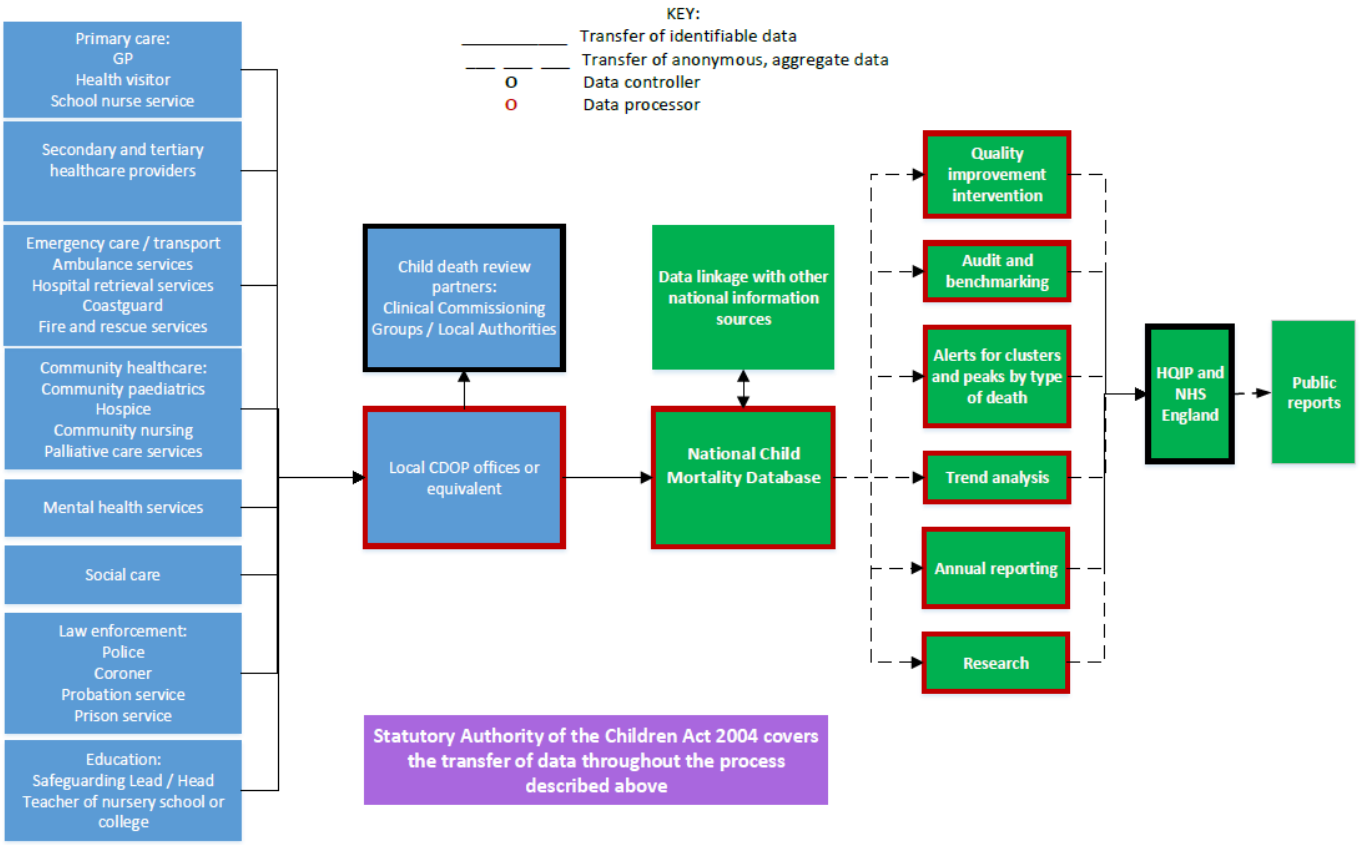
The NCMD programme will be providing evidence for NHS Digital's Data Security and Protection Toolkit, which is being coordinated and submitted by the Bristol Medical School.

In addition, everyone employed by the NCMD programme and involved in the programme (including the NCMD partners) has signed the NCMD confidentiality agreement irrespective of whether they have access to personal identifiable data and information or not. This is because it is expected the information shared during programme meetings will be sensitive in its nature and potentially disclosive where small numbers or specific cases are concerned.

3.3. Data flows

Figure 3 outlines the flows of data through the CDR process.

Figure 3: Child death review process data flows



3.4. Consultation on supplementary reporting forms

Information on children who die is provided to CDOPs by those professionals who knew the child during life or had contact with the family immediately after the death. Professionals are required to complete the statutory forms and submit them to the relevant CDOP office.

The data completed on the forms is then processed by CDOPs and fed into the NCMD system. This either happens by data entry via a secure web-based portal or, for those CDOPs using a CDOP case management tool, the data is automatically linked with the NCMD web-based platform.

There are three core and 20 supplementary forms used in the child death review process.

The three core CDOP forms, previously known as 'Forms A, B and C', are now known as the 'notification', 'reporting' and 'analysis' forms respectively. One of the first pieces of work required was to update and develop the supplementary reporting forms as they had been published by the Department for Education (DfE) back in 2010. The forms were amended to ask more detailed questions on specific types of death to enable a finer granularity than was originally captured.

The supplementary reporting forms were not used consistently by CDOPs as evidenced by feedback received from CDOPs. It was also found that some questions were irrelevant and other important questions were not included in the forms. In addition, some CDOPs had developed their own supplementary reporting forms, which were more comprehensive, to enable their panels to adequately review the deaths of their residents. Therefore, the aim at the start of the NCMD programme was to look at updating and expanding these forms to ensure they met the needs of CDOPs and to collect relevant, useful and standardised information to inform learning and understanding.

Many of the original supplementary reporting forms remain but have been updated (see Table 1). There are also new areas which were not previously covered by supplementary reporting forms (e.g. Asthma and Anaphylaxis, also see Table 1). These new areas reflect some of the most common causes of death amongst children and map to the categorisation of death classification system used on the statutory analysis form.

Table 1: Supplementary Reporting Forms

Violent or maltreatment related deaths	Updated
Suicide or self-harm (including alcohol or substance misuse)	Updated
Trauma or other external factors	New
Vehicle collisions	Updated
Drowning	Updated
Falls	New
Deaths resulting from injuries sustained from a falling object	New
Deaths as a result of fire, burns or electrocution	Updated
Poisoning	Updated
Death of a child with an Oncology Condition	New
Asthma and Anaphylaxis	New
Acute Epilepsy	New
Diabetic Ketoacidosis	New
Cardiac: Congenital or Acquired	New
Other Chromosomal, genetic or congenital anomaly (not including cardiac)	New
Deaths on a Neonatal Unit	New
Death of a child with a life-limiting condition	Updated
Infection	New
Sudden Unexplained Deaths	Updated

During this development phase, it became apparent that there were several questions which ideally should be asked of all deaths, usually related to services provided to the child during their care pathway. It was therefore decided to develop a care pathway reporting form which would contain questions to be answered for every child, except those who die on a neonatal unit. The care pathway for children dying on a neonatal unit is quite different and the questions related to that are included within the Deaths on a Neonatal Unit supplementary reporting form.

This work was carried out with the involvement of experts from around the country who helped in guiding key questions (see Appendix 1 for details of the experts involved in this piece of work).

CDOPs were given the opportunity to comment on the data fields during the pilot phase of the programme.

3.5. Development of the NCMD web-based platform

Many CDOPs use a bespoke case management tool called eCDOP to manage their local caseloads and as of the end of March 2019, 66% (62/93) of CDOPs are using this system.

The programme was required to establish:

- A database on which all information collected would be held. This is the NCMD data collection system.
- A secure, web-based platform for users to enter data into NCMD which was free to use (for those CDOPs that do not use eCDOP).
- A link between eCDOP and NCMD, such that users of eCDOP could enter data into eCDOP, which it would then automatically upload onto the NCMD data collection system.

The web-based platform is an entry portal for CDOPs to enter all the information collected on the statutory forms throughout the whole review process. Work on the development of the web-based platform for the programme commenced in April 2018 and the test platform was ready for use in October 2018.

3.6. NCMD pilot

3.6.1. South West pilot

The first phase of the pilot was for the web-based platform to be tested within the South West Child Death Enquiries Office and that started on 1st October 2018.

An issue log was established with QES on which all feedback received during the pilot was recorded. Meetings with QES took place monthly to review the log and discuss any issues arising. This also provided an opportunity to discuss as a group which feedback related to changes needed in the system and which represented additional training for individuals in how to use the system.

3.6.2. Roll out of pilot to the rest of England

Following the first phase of the pilot, QES released a second version of the web-based platform which resolved initial issues prior to other CDOPs joining the pilot. The second phase of the pilot focused on security (ethical hacking and GDPR compliance) and stress testing (creating 136,472 test CDRs). This gave the wider CDOP community the chance to validate the system's functionality, which began on 1st November 2018 with all CDOPs in England invited to join the pilot.

Each CDOP was provided with a briefing paper including information about the pilot and instructions on how to take part. 14 CDOPs and 81 users signed up to use the web-based platform (see Appendix 2 for details of the CDOPs that joined the pilot). This created 137 cases on the test system during the pilot which resulted in 1071 user logins.

3.6.3. eCDOP users

eCDOP users were informed that when NCMD was launched they would not need to access it directly as their data would be uploaded from eCDOP automatically. However, the NCMD team received enquiries from eCDOP users who wanted to take part in the pilot as they were interested to know what the system looked like and wanted to support the programme by entering cases through the web-based platform during the pilot.

They were therefore also set up as users on the web-based platform for the duration of the pilot.

In January 2019, the linkage between eCDOP and NCMD was piloted by the South West Child Death Enquiries Office for the 4 CDOPs they cover.

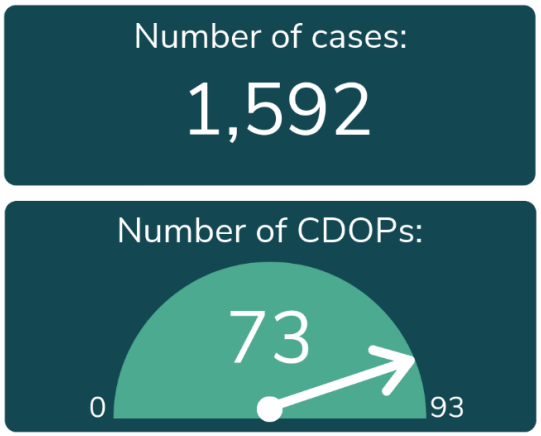
3.6.4. Pilot success and launch of NCMD

The NCMD web-based platform officially launched on 1st April 2019, as planned. A press release was issued by NHS England and shared by the University of Bristol and national media to announce and publicise the launch.

By the end of April 2019, 78% (73/93) of CDOPs in England had inputted cases into NCMD resulting in 1,592 cases entered. This significantly exceeds the uptake targets set by HQIP for the first month of the programme, a testimony to a successful start of the programme and to the engagement and commitment of CDOPs (see Figure 4). One quarter of CDOPs who had entered a case on NCMD by 30th April 2019 did so using the NCMD portal, demonstrating good uptake by those not using the eCDOP case management tool.

Following publication of new statutory guidance, many CDOPs are in the process of transitioning into new arrangements. For some this will include merging with neighbouring CDOPs and commissioning and setting up new processes in order to be compliant with the new requirements. It is expected that at the end of this period of transition, all CDOPs will be inputting cases into NCMD. The NCMD team will continuously monitor uptake and will introduce a minimum ascertainment threshold to set the standards for the reportability of data sets. Monthly data quality monitoring reports will be implemented with an initial focus on capturing data quality issues and providing feedback to CDOPs. Regular communications with CDOPs will ensure issues in uptake and data quality are addressed and solutions identified as early in the data collection process as possible.

Figure 4: Number of cases entered on NCMD and number of CDOPs who entered data between 1st and 30th April 2019



4. ADDITIONAL PROJECTS AND ALIGNMENT WORK

4.1. Helping CDR professionals implement the new CDR statutory and operational guidance

4.1.1. New national guidance for the child death review process and new bereavement information for parents

In 2018, DHSC published new and revised statutory documents related to CDR (see Table 2). Members of the NCMD programme team were involved in the writing of these documents, which was beneficial for ensuring that NCMD was compliant and able to be used to support professionals to implement the new guidance.

Table 2: Published documents relating to CDR process

Document	Publication Date
Working Together to Safeguard Children	July 2018
Statutory CDR forms	September 2018
Child Death Review Statutory and Operational Guidance	October 2018
When a Child Dies: A Guide for Parents and Carers	December 2018

4.1.2. Implementation and training events

Following the start of the pilot phase of the programme, Dr Karen Luyt, Professor Jenny Kurinczuk and Vicky Sleap took part in three implementation events and two webinars arranged by NHS England to publicise NCMD and help CDR professionals to understand the new requirements. It was recognised that in order to ensure that complete and accurate data is submitted to NCMD, those providing the data to CDOPs needed to be supported and have a better understanding of the process.

The events were by invitation only and were focused on tertiary children's hospitals where most deaths in England occur. Those invited were medical directors, mortality leads, clinical leads of Operational Delivery Networks, CDOP chairs and designated doctors. The aim was to provide a forum for these professionals to meet and establish relationships to enable delivery of the requirements.

The events and webinars were well attended with over 400 people taking part overall. The slides and presentations from these events have been published on the FutureNHS Collaboration Platform.

Vicky Sleap gave two workshops at the Association of Independent LSCB Chairs (https://www.lscbchairs.org.uk/) Conference in November 2018 to inform this important group of stakeholders (as CDR partners) about NCMD and to advise them how they can fulfil their obligations under the act through the transfer of data to NCMD.

QES ran three webinar sessions for eCDOP users to explain the new updates to the eCDOP system and its linkage to NCMD. Vicky Sleap joined two of these sessions to answer questions from users about NCMD and the new data fields, supplementary reporting forms and guidance.

Professor Peter Fleming and Vicky Sleap presented at the National Network of CDOPs Annual Conference in March 2019. This was to increase awareness of the NCMD programme and provide information to CDOPs and other users to prepare for the launch.

4.2. Alignment with the Perinatal Mortality Review Tool (PMRT)

A collaboration led by MBRRACE-UK was commissioned by HQIP to develop, implement and maintain a national standardised PMRT building on the work of the DHSC (then Department of Health) / Sands Perinatal Mortality Review 'Task and Finish Group'. The PMRT has been designed with user and parent involvement to support high quality standardised perinatal reviews on the principle of 'review once, review well'.

The PMRT is used by professionals working in hospitals to support them in conducting CDR meetings for babies who die at 28 days after birth or earlier and those babies who die later than 28 days but have spent their entire life in hospital.

The CDR meeting is the third stage of the statutory CDR process and, for neonatal deaths and in-hospital neonatal deaths, CDR teams should use the PMRT to conduct their reviews. Comprehensive information is collected during the review process, although there is no complete alignment between the PMRT (developed in 2017) and NCMD (developed and based on the CDOP process in 2018). The NCMD and PMRT teams were sensitive to the fact that professionals should not be submitting the same information twice; therefore, work began this year on alignment of the two programmes to avoid unnecessary duplication.

This is a large and ongoing piece of work, with both legal and technical considerations, however both teams are committed to resolving these issues and further updates on this work will be forthcoming in the 2019-20 year.

4.3. Alignment with the Healthcare Safety Investigation Branch (HSIB)

HSIB began carrying out maternity investigations from 1st April 2018. Their maternity investigation programme is part of a national action plan to make maternity care safer and they undertake approximately 1,000 independent maternity safety investigations to identify common themes and influence systemic improvements.

There is some overlap between the cases reviewed by HSIB and those reviewed by CDOPs. Both processes review babies who die from hypoxic ischaemic encephalopathy (HIE) and neonatal deaths at up to 7 days of life (where delivery was after 37 weeks' gestation and not including those with an antenatally diagnosed congenital anomaly). In cases which are reviewed by HSIB, their investigation replaces the Hospital Trust Root Cause Analysis investigation. HSIB investigations are carried out with the consent of the family involved.

Discussions are ongoing about how to bring these processes into alignment and the NCMD programme team expect to be able to issue guidance on this to professionals in the coming months.

5. LOOKING FORWARD

In line with the objectives outlined on page 10, the focus for the next year will be to:

- Optimise data collection to ensure complete data submission by all CDOPs and improve data accuracy and completeness. CDOPs will be provided with routine analysis and benchmarking statistics including recommendations for improvements in the data collection and completeness.

- Develop the analytical methodology to categorise and understand potentially modifiable factors, which will form the basis for future QI work to inform improvements on outcomes with the overall aim to reduce child deaths.

- Develop and publish the NCMD second annual report on 2019/20 data, which will focus on the analysis of trends in child deaths by population characteristics (i.e. age, gender, ethnicity), causes of death and associated risk factors. The annual report will also include key learning messages and recommendations from the completed reviews and is provisionally planned to be published in the autumn of 2020.

- Develop and publish thematic reports on 2019/20 data. Themes will be suggested and discussed by appropriate groups, including the PAG, and will depend on whether the data will be representative enough to draw meaningful conclusions from. Potential themes could focus on data quality and completeness and deaths of premature babies.

- Implement a system for the analysis and reporting of statistically significant peaks and clusters of deaths nationally and by location.

- Ensure that the views of bereaved families remain central to our decision-making processes by working with the PPPI group to inform our data analysis and quality improvement work. This group will co-produce Stage 2 of our QI plan which relates to identifying the key improvement messages from the data and supporting the implementation of QI using exemplars and best practice case studies. They will also help to write our family focused communications.

- Work with professional stakeholders on enhancing data collection for selected conditions of interest e.g. emerging contributory factors or causes of death.

- Continue to align work with the PMRT, to help streamline neonatal mortality review processes.

- Explore data linkage to other relevant health databases to help expand our knowledge on why and how children die in England.

- Further develop networks and collaborations with other national agencies to enhance the granularity and completeness of the data and to support professionals in making the notification processes streamlined and remove duplication of paperwork.

- Further engage with the Royal Colleges (for example, with the National Neonatal Audit Programme at the Royal College of Paediatrics and Child Health and the Asthma and COPD Audit Programme at the Royal College of Physicians) and Public Health (for example, with Public Health England's National Disease Registration Service) for the purposes of data linkages to support the evidence needed to develop the NCMD QI strands of work.

- In addition, opportunities might be explored for collaboration with other mortality review programmes such as the National Mortality Case Review Programme (NHS Improvement's adult death review programme) and the Learning Disabilities Mortality Review (LeDeR) Programme.

6. IN QUOTES

Jenny Ward

Chief Executive, The Lullaby Trust

"NCMD has come into being this year, and with it there are great possibilities for the future. This brings together work done locally to be able to give us a national picture, which is vital for SIDS deaths given the lower numbers we now see."

Dr Clea Harmer

Chief Executive, Sands

"NCMD is gathering momentum and to see the work it's achieved in the first year is extremely encouraging. The death of a child brings the hardest heartbreak imaginable; from now on there will be national learning from those deaths and an opportunity to protect future lives."

Vicky Sleap

NCMD Manager, University of Bristol

"The commissioning, development and launch of NCMD represents the culmination of years of work by dedicated professionals across multiple organisations. The commitment and enthusiasm of CDOPs in particular has contributed hugely to its success. It will be a powerful tool in our arsenal to identify how to reduce the number of children that die."

Rob Taylor

Managing Director, QES

"We have been exceptionally pleased with the smoothness of the roll out of NCMD, there have been minimal usage issues despite high volumes of user interactions and data. The system was fully quality assured and tested and ready ahead of schedule. It has been a pleasure for us to collaborate on this important programme."

7. WITH THANKS

This Annual Report was prepared by:

The NCMD Team

- Dr Karen Luyt, Programme Lead
- Professor Peter Fleming, PAG Chair
- Vicky Sleap & Sylvia Stoianova, NCMD Managers
- Tom Williams, NCMD Data Analyst
- Kate Hayter, NCMD Administrator
- Matt Grek, Communications Consultant

With contributions from:

The Programme Steering Group Members

- Charlotte Bevan, Sands
- Dr Clea Harmer, Sands
- Dr Katie Koehler, Child Bereavement UK
- Professor Jenny Kurinczuk, University of Oxford
- Charlotte McClymont, UCL Partners
- Professor Mike Roberts, UCL Partners
- Rob Taylor, QES
- Jenny Ward, The Lullaby Trust

8. GLOSSARY OF TERMS

CDOP	Child Death Overview Panel
CDR	Child death review
CDR partners	Child death review partners (Clinical Commissioning Groups and Local Authorities)
DHSC	Department of Health and Social Care
DfE	Department for Education
eCDOP	Bespoke case management system for child death reviews
HQIP	Healthcare Quality Improvement Partnership
HSIB	Healthcare Safety Investigation Branch
LSCB	Local Safeguarding Children Board
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries
NCMD	National Child Mortality Database
NNCDOP	National Network of CDOPs
NPEU	National Perinatal Epidemiology Unit, at University of Oxford
PMRT	Perinatal Mortality Review Tool
QES	IT Partner in the NCMD collaboration
QI	Quality Improvement
UCLP	UCL Partners, QI Partner in the NCMD collaboration

9. REFERENCES

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APPENDIX 1

In the consultation on the supplementary reporting forms, expert advice and input was provided by:

Name	Title / Organisation
Mr Kristian Aquilina	Consultant Paediatric Neurosurgeon, Great Ormond Street Hospital
Professor Peter Blair	Professor of Epidemiology and Statistics, University of Bristol
Dr Kate Brown	Consultant Intensivist and Associate Professor, Great Ormond Street Hospital and University College London, London
Dr Ronny Cheung	Clinical Director, Healthy London Partnership Child Death Review Programme. Consultant Paediatrician, Evelina London Children's Hospital.
Professor Tim Coats	Professor of Emergency Medicine, University of Leicester
Commander Stuart Cundy	Metropolitan Police Service, NPCC Homicide Working Group (Chair)
Dr Ffion Davies	Consultant in Emergency Medicine, Leicester Royal Infirmary
Professor Charles Deakin	Honorary Professor of Resuscitation and Pre-Hospital Emergency Medicine, University of Southampton
Antoinette Edwards	Executive Director, Trauma Audit & Research Network (TARN)
Professor Peter Fleming	Professor of Infant Health and Developmental Physiology, University of Bristol
Professor David Gunnell	Professor of Epidemiology, University of Bristol
Dr James Fraser	Consultant in Paediatric Intensive Care, Bristol Royal Hospital for Children
Dr Emily Harrop	Consultant in Paediatric Palliative Care & Interim Medical Director, Helen & Douglas House, Oxford
Simon Hester	Head of Safeguarding, South Western Ambulance Service
Dr Michelle Hills	Consultant in Paediatric Palliative Medicine, Leeds Teaching Hospitals NHS Trust/Martin House Hospice Care for Children and Young People
Dr Phil Hyde	Director of Children's Major Trauma, Southampton General Hospital
Dr Richard Iles	Consultant in Paediatric Respiratory Medicine, Evelina London Children's Hospital
Professor Jenny Kurinczuk	Professor of Perinatal Epidemiology, Director of the National Perinatal Epidemiology Unit (NPEU)
Dr Andrew Lux	Consultant Paediatric Neurologist, Bristol Royal Hospital for Children
Dr Karen Luyt	Consultant and Reader in Neonatal Medicine, University of Bristol
Dr Martin McCabe	Clinical lead for Childhood, Teenage and Young Adult Cancer, National Cancer Registration and Analysis Service. Clinical senior lecturer in Paediatric, Teenage and Young Adult Cancer, University of Manchester
Dave Marshall QPM	Director, Dave Marshall Consultancy Ltd

Sara Nelson	Deputy Director of Transformation for Children and Young People and Good Thinking Programmes at Healthy London Partnership
Dr May Ng	Consultant Paediatric Endocrinologist, Chair of Association of Children's Diabetes Clinicians UK
Dr David Odd	Consultant Neonatologist, Southmead Hospital, Bristol
Professor Mark Peters	Professor of Paediatric Intensive Care, UCL Great Ormond St Institute of Child Health
Cathryn Rodway	Programme Manager & Research Associate, National Confidential Inquiry into Suicide and Safety in Mental Health, University of Manchester
Dr Barney Scholefield	NIHR Clinician Scientist, University of Birmingham and Consultant in Paediatric Intensive Care Medicine, Birmingham Women & Children's Hospital
Professor Peter Sidebotham	Emeritus Professor of Child Health, Warwick Medical School
Dr Martin Ward Platt	Clinical Lead for the National Congenital Anomaly and Rare Disease Registration Service and Consultant Paediatrician at the Royal Victoria Infirmary, Newcastle
Dr Amber Young	Consultant Paediatric Anaesthetist and Lead Children's Burns Centre, University Hospitals Bristol NHS Foundation Trust

APPENDIX 2

CDOPs which took part in the NCMD pilot prior to April 2019:

- Bromley
- Cambridgeshire
- Chester and Cheshire West
- Doncaster
- Dorset
- Dudley
- Gloucestershire
- Hertfordshire
- Leeds City Council
- Nottinghamshire
- Sandwell
- Shropshire
- Swindon and Wiltshire
- West of England

Knowledge, Understanding and Learning To Improve Young Lives.

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