Web Appendix

National Child Mortality Database enhanced child death notification form

The National Child Mortality Database (NCMD) real-time surveillance system was based on an enhanced child death notification form. This was an existing statutory form used within the child death review (CDR) process to notify deaths to NCMD and to ensure the same dataset is collected for every death. It was enhanced by adding a COVID-19 specific module. This module was developed with clinical input and aimed to help identify children who died of or with COVID-19 (confirmed or suspected) and those where COVID-19 may have been a contributory factor in the death for example changes to services as a result of the lock-down which may affect accessibility. NCMD provides ongoing training and support to the Child Death Overview Panels (CDOPs) for how to use the updated notification form and the alert system through webinars, training materials made available online on the NCMD website (https://www.ncmd.info/2020/07/16/guidance-notification-n/) and through the established communication channels.

The enhanced COVID-19 module was designed, developed, tested and deployed into the live system within 10 days and from 1st April 2020 any deaths notified to NCMD were reported using the new child death notification form. A full copy of the revised form with the additional COVID-19 module included can be found at https://www.gov.uk/government/publications/child-death-reviews-forms-for-reporting-child-deaths

Categorisation and coding of deaths notified to NCMD

The information in the enhanced notification form allows for more comprehensive data collection of child death information at the point of notification. A panel of core NCMD clinical and CDR experts was established to carry out daily review and categorisation of all cases notified to the NCMD.

All deaths as notified to NCMD are categorised using one or more of the following broad categories for each notified death:

- Malignancy
- Preterm
- Intrapartum or pre-natal event
- Infection
- Trauma
- Substance Misuse
- Suicide or Self Harm
- Underlying health condition
- Positive Test Child
- Positive Test Mother
- Positive Test Household
- Potential COVID-19 factor
- Insufficient information

Definitions for Cause of Death Categories

Malignancy	Did the child have a known active malignancy?
Preterm	Was the baby born before 37 weeks and died before discharge from hospital?
Intrapartum or pre-natal event	Was the death related to intrapartum or pre-natal events? E.g. Perinatal asphyxia, meconium aspiration, shoulder dystocia
Infection	Was the death related to likely infection/sepsis including bacterial, viral and other organisms?
Trauma	Is the death related to trauma E.g. Possible Non-accidental Injury (NAI), unintentional suffocation/strangulation, Vehicle collision, Drowning, Fire/burns/electrocution, Poisoning (prescription or non-prescription drugs), Medical or surgical complications, Falls, Injuries from falling objects, Animal attack, Natural disaster, Terrorism
Substance misuse	Is the death related to substance misuse / overdose? E.g. Older children who may take drugs recreationally or as a method of potential suicide; Younger children who access medications at home unintentionally
Suicide or self-harm	Is the death the result of apparent suicide or self-harm?

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SUDIC (Sudden Unexpected Death in Childhood)	Was the death sudden and unexpected with no immediately apparent natural cause? (SUDIC)
Underlying health condition	Does this child have a significant underlying health condition? E.g. Asthma, Chronic respiratory condition, Diabetes, Cardiac issues, Renal problems, Gastro-intestinal problems (e.g. short gut), Transplant recipient, Rare disease, Congenital anomalies

This case review and coding process also includes the analyses of free text information from the notification form, which provides detailed account of the events and circumstances of death. In some cases, additional information, either from the CDOPs or the notifying professionals, is requested by the NCMD team to complete the record to help with better and more rapid intelligence. Direct communication between the NCMD clinical team and the clinical staff involved in the care of the children who have died has been welcomed by the staff involved and allows the team to collect more detail more quickly than would otherwise have been possible.
Data collected by NCMD from 1st of April to 30th of June 2019 has been subjected to the same process of categorisation, which has also been applied to data collected on deaths that occurred from 1st of January 2020.

Data linkage and reporting

All child deaths are categorised as definite or potential COVID-19 related, including both direct and indirect factors. These cases are linked to SARS-CoV-2 test results through daily feeds from Public Health England's virology database. This information feeds into daily and weekly official reporting from NCMD to the National Health Service and Public Health authorities in England to inform actions and policies for the health and well-being of children.

The statutory requirement to submit notification of a child death to NCMD within 48 hours of CDOPs being notified means that the information on all child deaths received through the CDR process provides the most complete and real time information on child deaths at a national population level. The median time from a child death occurring to notification to NCMD is 1 day.

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