**CDOP Notification Form guidance for CDR professionals**

**How to complete a Child Death Notification form effectively**

To submit a new child death notification for Sussex please complete the notification form found via the public eCDOP link: <https://www.ecdop.co.uk/PANSussex/Live/Public>

**Initial information – Childs Details**

The initial fields on the notification form relate to the details of the child who has died. This information should be available from their notes. Inclusion of a valid NHS Number is vital to ensure that both the CDOP and the NCMD do not double count any deaths that might be notified more than once. In rare circumstances, the child may not have an NHS number, if this is the case, please note this in the notification details section of the form and explain the reason why.

**The second and third section – Other significant household and family members**

The second section of the form relates to the mother’s details. This is particularly important to complete in the case of neonatal deaths, or for babies who die after 28 days but have spent their entire life in hospital. For these deaths, obtaining details of the mother’s pregnancy and the care she received is vital to being able to conduct a good review of the baby’s death. The maternal NHS number is very important for enabling data linkage between NCMD and other data sources e.g. BADGERNet to enhance data quality and enable comprehensive analysis.

The third section of the form relates to other significant members of the household. This is important in order to understand the family background and the household circumstances. The child death review process is holistic and therefore looks at all aspects of the child’s life, so understanding who else is in the child’s environment is important. At notification stage, it is sufficient to include immediate family / household members and anyone else the child had regular contact with e.g. grandparents etc.

**Details of death**

The suspected cause of death is an essential field to provide at the point of notification. This is so that the immediate decision-making can be as effective as possible. In most cases there will be some idea of why the child died, even if it is not confirmed. For these cases you should record what cause(s) of death are being considered at that stage. The information you write in this box is not ‘set in stone’ and will not be used for analysis directly, but it will enable the coding team at NCMD to understand what “type of death” this might be (e.g. malignancy, infection, prematurity, cardiac anomaly) for real-time surveillance. Where the child dies and the cause of death is not known, then it is helpful to describe the circumstances of the presentation e.g. previously well child, sudden collapse at home of unknown cause etc.

Information relating to COVID-19

For the questions related specifically to COVID-19, the information should be available from the medical history taken at the point of presentation or from tests performed at the hospital. It is worth bearing in mind that some children are presenting with abdominal symptoms rather than respiratory symptoms and, although the significance of this is not yet known, any abdominal symptoms should also be documented in this section.

**Case management section**

The case management section is very useful for the CDOP administrator to know what has happened with the case so far. If the person completing the notification form does not know the answer to these questions, they should attempt to find out. Involvement of the coroner and/or medical examiner is an important piece of information for the CDOP to know at an early stage. Likewise, whether or not a JAR has been triggered is also important. This is particularly so in cases where a JAR should have been triggered at the point of death but was not. For some CDOPs their administrators will have a role in following this up to ensure that the JAR happens at the earliest possible opportunity if it was not triggered appropriately to begin with.

**The notification details box**

The notification details box is a free text box and there is no limit to the amount of information you can put into this section. You can write as much as you need. For cases where there is a hospital discharge summary, you can simply cut and paste the summary section into this box if it is well completed. Likewise, if you have conducted a JAR, you can cut and paste the details of your JAR report or letter to the pathologist into this section.

**IMPORTANT:** Please do not say “see attached document” as, although CDOP will be able to see this, NCMD cannot and therefore the death will not be able to be reviewed by the NCMD coding team. Anything you want NCMD to be able to see **must** be included in this free text box. The kinds of things that are useful to include are:

* A description of the medical and/or mental health conditions the child had.
* A description of the circumstances in which the child actually died. This is important even if it is a child with a life-limiting condition or a neonatal death.
* A basic description of what interaction they had with services. This might be minimal if the child dies suddenly and did not have any pre-existing medical conditions. This will include non-health services e.g. social care and police. Statements about what didn’t happen are as helpful as those about what did e.g. the child was not known to social care or the police.
* For children with life-limiting conditions, it is helpful to see what advance care planning there was and what community services they had access to, as this will help the CDOP to know what other agencies they might need to contact for information.

**Example of ‘notification details’**(child with a life-limiting condition): *The child had been diagnosed with a brain tumor 6 months prior to his death, following a two week history of headaches and vomiting. They presented to the GP and was referred to paediatrics for further investigation. At that time, a scan revealed an astrocytoma. The child was referred to the oncology service and received treatment, However unfortunately the disease progressed and, following discussion with the family, it was decided that they would be re-orientated to palliative care. An advance care plan was completed with the family and their choice was for the child to die at home. They were discharged home one week before death with a package of community nursing support and some medication for pain relief. On the day before death, they deteriorated and required some additional pain relief. They died the following morning with parents present*.

**The alert function**

Designed to enable CDOPs to notify where there could be an immediate risk to others’ lives, this function enables the NCMD to take prompt action and alert the wider health and social care sectors to prevent death.

**When should I use this function?**

* Any deaths where COVID-19 is known or suspected or any death where the virus or lockdown restrictions may have been a factor.
* Any death where an urgent, national public safety message is required e.g. home safety for children such as the use of blind cords and nappy sacks etc.
* Any death where there is a problem with a product design e.g. car seats.
* Any death where there has been an equipment malfunction, adverse drug reaction or other sentinel event in relation to the child’s death.

**What happens when I complete this box?**

* Each alert is reviewed individually, together with any other information submitted in the notification.
* A decision is made about whether and what action should be taken.
* This decision will be based on how many cases are affected by the issue and the severity of the problem. *Please provide as much detail as you have available on each case to enable us to decide what action we should take*.
* If action is required to prevent further death, NCMD will communicate safeguarding messages and work with key organisations to share them across the sector. Where appropriate, we will also report the incident to NHS England and other national bodies to consider further action such as public health messaging eg the MHRA Yellow Card System.
* Finally, we also maintain and report an aggregate summary of this data to NHS England so that they can determine the scale of the issue and consider any further actions at national level.

**IMPORTANT:** When using our alert, please ensure that you also continue to follow all existing local and national guidance already in place.

**The final section**

The final section is about agency contacts and referral information. When completed well, it can give CDOPs’ a comprehensive list of all those professionals who cared for the child during their life and immediately after their death. It is this list which enables the CDOP administrator to carry out the rest of the process. Without it, gathering information on the child is very challenging.

This should be completed as comprehensively as possible. Even if you don’t know the contact name and number within an agency (but you know they were involved with the child), you should put ‘YES’ in the name and contact details box so the CDOP administrator can try and find out who to go to for more information.

For the referral section, please complete this information so the CDOP office can come back to you for more details if needed.