



National Data Collection Forms – Notes for users.

There are three key stages of documentation to support the child death overview processes:

1. Form A: Initial Notification Form.
2. Form B: Agency Report / Case Record – a case summary to be compiled in a local case review or by the CDOP manager from contributions from individual agencies. This acts as the “input data set” for the Child Death Overview Panel.
3. Form C: Analysis Proforma, output from the Child Death Overview Panel.

The security of any system for transferring the information on these forms must be clarified and agreed with the Caldicott guardian.

1. Form A: Initial notification form. The prompt initial notification of all deaths will be an important part of the process of child death review, whether or not the particular case warrants a “Rapid Response” investigation process. We anticipate that most notifications will be by telephone, and the completion of the notification form will be the responsibility of a member of staff in the local notification office. There is the further option for the notification form to be completed by the notifier and sent by secure fax or email to the CDOP manager. **The security of any system for transferring the information on these forms must be clarified and agreed with the Caldicott guardian.**

Professionals (or occasionally members of the public) who become aware of a child death will be encouraged to contact the office and give whatever information they may have – preferably including the full name, age and address of the child who has died, but people should not be discouraged from informing the notification office of a death because they do not have full information. It is better to receive multiple partial notifications rather than to miss collecting information on a child death.

On receipt of an initial notification of a possible child death the staff in the notification office should promptly attempt to confirm this information by contacting the relevant local agencies who may have been involved. It is important at this stage to obtain as much information as possible – including information on all members of the household, and identifying all key professionals – particularly the child’s General Practitioner and paediatrician if one has been involved. Each relevant agency should be contacted, and given information on the identity of the child, and all members of the household, together with any other relevant contacts or family members. This will allow those agencies that may have information on past history, family or household members to check existing records, particularly any information on prior child protection concerns. Great care will be required to ensure accuracy of identification - to avoid duplication and mistaken identities – of the child who has died and of other

household members. The use of the child’s NHS number as a unique identifier (together with name, address and date of birth) will help minimise the risk of mistaken identity or duplication of notifications.

Having ensured that all relevant agencies are aware of the child’s death, and the relevant agencies are providing appropriate support and care to the family, the next stage of the process will be to ensure that all relevant agencies are involved in preparation for any local case review meeting to investigate and review the circumstances of the case, any contributory factors and the ongoing support needs of the family, and to contribute to the Child Death Overview Panel’s review.

2. Form B: The Agency Report Form / Case Record. This form is sent to agency representatives to enable all relevant information on the case to be collected and collated to form a case summary. This may be compiled in a local case review or by the CDOP manager from contributions from individual agencies. This acts as the “input data set” for the Child Death Overview Panel.

In order to ensure completeness and accuracy of the information collected and reviewed at the local case review meeting – or to inform the discussions between the relevant key local professionals in those cases in which no local case review meeting takes place, all representative from each key agency should complete as much as they are able of form B, drawing on a review of the agency records and discussions with individual practitioners. Some aspects of the form are specific to individual agencies (e.g. health), but all agencies should be able to prepare summaries of relevant information available to them.

There are 6 sections to the form:

A Identifying and Reporting Details

This section will normally be completed by the CDOP administrator from the notification form (Form A) prior to sending out to agency representatives. This identifying information can be separated from the rest of the form in order to anonymise the case prior to distribution to the CDOP members.

B Summary of Case and Circumstances leading to the death

Information is included on the nature and circumstances of the death. For some specific categories of death (e.g. road traffic accidents, apparent suicides, SUDI) further specific information will be gathered as part of the core data set. Additional forms will be distributed as appropriate. As well as the core data items, narrative information on the circumstances leading to the death is included to inform the understanding of the case

C The Child

D Parenting Capacity

E Family and Environment

F Service Provision

Each of these sections contains specific data items as well as space for narrative accounts of the relevant factors relating to the child's death.

In addition to the narrative and questionnaire components, the form should include a brief summary of the relevant positive and negative findings from the post mortem examination (form B-11), (where one has been conducted) as well as a full copy of the final postmortem report and (for deaths of children in hospital or under the care of a secondary/tertiary care team) a copy of the final discharge / death summary.

Once all agency reports are received, the CDOP manager should collate the information onto one form, either through a local case discussion, or in discussion with the individual agency representatives. This collated Form B then forms the case summary and input to the Child Death Overview Panel, and can at that point be anonymised. Where there are any discrepancies or disagreements between agencies as to any of the factual information, this should be noted and where possible, consensus reached.

Recent changes to the coroners' rules will facilitate the sharing of information (particularly police reports and postmortem reports) at this meeting for those deaths subject to coroners' investigations and/or Inquests. For all such deaths, the coroner or coroner's officer should be invited to attend the local case review meeting (as recommended in Chapter 7 of "Working Together"). The information made available, the discussions, and the outcome of the local case review meeting in such cases will provide potentially valuable information to inform the conduct of the inquest, which in most cases we anticipate will take place after the local case review meeting but before the Child Death Overview Panel meeting that review the death. The summary report from the local case review meeting should, in all cases in which the coroner remains involved be copied to the coroner to help inform the Inquest.

3. Form C: Analysis Proforma

The first page provides for identifying details of the case. These details can be removed and replaced by a unique identifier if the Panel is discussing cases anonymously, and in any event should be removed after the Panel meeting in order to ensure that any outputs from the panel are anonymised.

A summary of the case should be completed, along with any identified or agreed cause of death.

The panel should then consider any relevant factors identified from form B in each of the following domains, considering the degree to which any factors may have contributed to the death.

Factors intrinsic to the child

Factors in the parenting capacity

Factors in the family and environment

Factors in relation to service provision

The third section of the form is a categorisation of the child's death using a scheme developed for the CDOP process. This classification is hierarchical: where more than one category could reasonably be applied, the highest up the list should be marked. This will form part of the national core data set and enable analysis of information in relation to different types of death.

The Panel needs to make a decision on the degree to which each death is considered preventable. It is important to recognise that this categorisation is to inform any efforts to reduce childhood deaths, it does not in itself carry any implication of blame on any individual party, but simply acknowledges where factors are identified which, had they been different, may have resulted in the death being prevented.

The final section of the form allows the Panel to identify any lessons to be learnt, recommendations to be made or actions to be taken in response to the review of the death. It is anticipated that in most cases, any individual action in relation to specific case management will have been identified and addressed through the local case discussion or other related processes; the focus of these actions and recommendations are on lessons to be learnt at a population level. The overview panel will have the advantage of being able to review each individual child death in the context of other deaths of children in their area, and to be able to identify any potentially contributory recurrent themes, circumstances, or possible limitations in service provision by one or more agencies. The main public output from the Overview Panel will thus be in summary form - drawing on the information from individual cases and from the overall pattern of events, contributory factors and service provision in their local area.

This will allow the overview Panel the opportunity to develop local recommendations to help reduce childhood deaths, for inclusion in annual reports, and where appropriate, specific ad hoc recommendations (e.g. dealing with particular road or environmental factors). This information, together with both the factual and opinion-based outcomes of the Overview panel reviews will be aggregated in the regional and national reports on the child Death Review process, which will in turn be able to produce more generalisable sets of recommendations aimed at reducing child deaths.