This form is used in the child death review process to gather detailed information about children who die as the result of a life-limiting condition. Its primary purpose is to enable CDOP to review all children's deaths in this category in their area in order to understand patterns and factors contributing to children's deaths. Please complete those questions on which you hold information. If you do not have information for a particular item, please tick “Not known”.

Information on this form will be shared with other professionals for the purposes of the child death review process. All professionals are entitled to share this information without contravening laws on data protection. All information gathered will be stored securely and statutory safeguards (s251) are in place to allow the legal transfer, storage, analysis of identifiable data.

**Identifying details** **- to be removed for the purposes of anonymisation prior to discussion at the CDOP:**

|  |  |  |  |
| --- | --- | --- | --- |
| Name |  | Date of birth  (dd/mm/yyyy) | / / |
| URN |  | Date and time of death | Date: / /  Time: **:** (24hr) |
| Postcode |  | | |

**Life limiting / life-shortening conditions** are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers. These conditions fall into 4 main categories as described below:

|  |  |  |
| --- | --- | --- |
| Please select the category that most closely fits this child’s condition: | ☐ Life-threatening conditions for which curative  treatment may be feasible but can fail: *Where*  *access to palliative care services may be*  *necessary when treatment fails or during an acute*  *crisis, irrespective of the duration of that threat to*  *life. On reaching long term remission or following*  *successful curative treatment there is no longer a*  *need for palliative care services. Examples:*  *cancer, irreversible organ failure of heart, liver*  *kidney*  ☐ Conditions where premature death is inevitable:  *Where there may be long periods of intensive*  *treatment aimed at prolonging life and allowing*  *participation in normal activities. Examples: Cystic*  *Fibrosis, Duchenne’s Muscular Dystrophy*  ☐ Progressive conditions without curative treatment  options: *Where treatment is exclusively palliative*  *and may commonly extend over many years.*  *Examples: Battens Disease,*  *Mucopolysaccharidoses*  ☐ Irreversible but non-progressive conditions causing  severe disability: *Leading to susceptibility to health*  *complications and likelihood of premature death.*  *Examples: Severe Cerebral Palsy, Multiple*  *disabilities such as following brain or spinal cord*  *injury, complex healthcare needs and a high risk of*  *an unpredictable life-threatening event or episode*  ☐ Other *(please specify)*  ☐ Not known | |
| Was there an End of Life Care Co-ordinator for this child? | ☐ Yes  ☐ No  ☐ Not known | |
| Was there an End of Life Medical Lead for this child? | ☐ Yes  ☐ No  ☐ Not known | |
| Was there an Advance Care Plan in place for the child? | ☐ Yes  ☐ Discussion in progress at time of child’s death, but  not yet implemented or agreed | |
| ☐ No: | ☐ Opportunity offered to family and declined  by them  ☐ Professionals with appropriate skills not  available to support advance care planning  discussions  ☐ Professionals with appropriate knowledge  not available to support advance care  planning discussions  ☐ Professionals with appropriate relationship  not available to support advance care  planning discussions  ☐ Other  ☐ Not known |
| Was the Advance Care Plan discussed with the child directly (if appropriate)? | ☐ Not appropriate (inadequate capacity)  ☐ Yes  ☐ No, appropriate but not discussed *(please give*  *reason)*  ☐ Not known | |
| Was there a symptom management plan in place for the child? | ☐ Yes  ☐ No  ☐ Not known  ☐ Not applicable | |
| Were there any specific prescribing or drug delivery issues? | ☐ Yes *(please specify)*  ☐ No  ☐ Not known  ☐ Not applicable | |
| Was use made of a cold bedroom / cold cot after death? | ☐ Yes  ☐ No *(please give reason)*  ☐ Not known | |
| Please record notably ‘good’ elements of end of life care. *(NICE NG61 and accompanying quality standard (QS160) can be used to benchmark good end of life care).* |  | |
| Please record any areas which could be improved? |  | |