This form is used in the child death review process to gather detailed information about children who die as the result of a congenital or acquired cardiac 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:**

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

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| --- | --- |
| Which primary cardiac diagnosis sub-category did this child fall into? *(Please choose* ***ONE*** *option)* | ☐ Medical or acquired heart disease  ☐ Two ventricle structural heart disease without  aortic obstruction  ☐ Two ventricle structural heart disease with aortic  obstruction  ☐ Single (one functional) ventricle structural heart  disease without aortic obstruction  ☐ Single (one functional) ventricle structural heart  disease with aortic obstruction |
| State the name of the cardiac diagnosis here: |  |
| Was the child’s cardiac disease antenatally diagnosed? | ☐ Yes  ☐ No |
| If **no**, please specify when diagnosed. | ☐ Under 1 month  ☐ 1 – 12 months  ☐ After 12 months of age |
| Was there delay in the diagnosis of heart disease at any stage? | ☐ Yes *(please give details)*  ☐ No |
| Did this child have any of the following case complexity risk factors? *(Tick* ***ALL*** *that apply; see NCHDA manual for criteria)* | ☐ Congenital syndrome or genetic syndrome  ☐ Non-cardiac congenital anomaly affecting another  major organ  ☐ Major acquired condition affecting another organ of  the body  ☐ Premature birth <37 weeks gestation  ☐ Very low weight for age meaning below the second  percentile for age |
| Were any of the following cardiac specific risk factors present in the period before he or she died? *(Tick* ***ALL*** *that apply, see NCHDA manual for criteria)* | ☐ Pulmonary hypertension  ☐ Significantly impaired ventricular function  ☐ Significant leak on a heart valve  ☐ Significant obstruction of a heart valve or channel  ☐ Confirmed diagnosis of arrhythmia  ☐ Known major residual cardiac defect following  surgical repair |
| Did this child have a recent major cardiovascular collapse (not related to post-operative period) manifested by: *(tick* ***ALL*** *that apply)* | ☐ Shock with metabolic acidosis leading pH <7.20 or  lactate greater than 3  ☐ Cardiac arrest  ☐ Inotropes in intensive care  ☐ Ventilation in intensive care  ☐ Mechanical circulatory support in intensive care  ☐ Renal support in intensive care |

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| Did the child undergo a cardiac intervention, and if so when? | ☐ Yes *(please list interventions using NCHDA*  *defined specific procedure names with month(s)*  *and year(s))*  ☐ No |
| **For Deaths Following Interventional Treatment** *(answer if the child had an intervention at any time)* | |
| Was there a multi-disciplinary meeting involving all relevant health professionals that documented the plan for intervention? | ☐ Yes  ☐ No |
| If the child had undergone an interventional procedure, how many days elapsed between the procedure and the child’s death? | Number of days: |
| If this was a death following intervention was the child in hospital at the time of death? | ☐ Yes *(please state which hospital)*  ☐ No *(please state location)* |
| If yes, had the child been home in the interim? | ☐ Yes  ☐ No |

|  |  |
| --- | --- |
| Did any of the following confirmed morbidity events happen post intervention? *(Tick* ***ALL*** *that apply)* | ☐ Acute neurological event  ☐ Unplanned re-intervention within 30 days (surgical,  catheter) *(please state name of operation, ideally*  *the NCHDA defined specific procedure)*  ☐ Diaphragm paralysis  ☐ Permanent complete heart block  ☐ Major post-operative haemorrhage  ☐ Cardiac arrest  ☐ Necrotising enterocolitis  ☐ Mechanical circulatory support in intensive care  ☐ Renal support in intensive care  ☐ Prolonged pleural effusion >10 days  ☐ Confirmed major post-operative infection *(please*  *state name of organism)* |
| **For Events Outside the Tertiary Centre** *(answer any that apply irrespective of earlier questions)* | |
| How long before death had the child been discharged from a tertiary centre? |  |
| If at home was the child supported by any of the following measures? *(Tick* ***ALL*** *that apply)* | ☐ Feeding support such as nasogastric tube  ☐ Enrolment in a home monitoring programme from  the tertiary centre  ☐ Monitoring of saturations by the tertiary centre  ☐ Monitoring of weight gain by tertiary centre  ☐ Child was not at home  ☐ No surveillance measures were required for this  child’s condition |
| If outside the tertiary centre did the child have tertiary care provision in place? *(Tick* ***ALL*** *that apply)* | ☐ A named cardiologist  ☐ A named cardiac liaison nurse or cardiac nurse  specialist  ☐ A date for follow up |
| Did the child deteriorate to the point of needing HDU or ICU care in a secondary care hospital? | ☐ Yes  ☐ No |