

NCRPCD Case Reporting System SDY Module

H. OTHER CIRCUMSTANCES OF INCIDENT - ANSWER RELEVANT SECTIONS																	
1. SUDDEN AND UNEXPECTED DEATH IN THE YOUNG																	
a. Was this death a homicide, suicide, overdose, injury with the external cause as the only and obvious cause of death or a death which was expected within 6 months due to terminal illness? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> U/K If yes, go to Section H2																	
b. Did the child have a history of any of the following acute conditions or symptoms within 72 hours prior to death? <input type="checkbox"/> U/K for all						c. At any time more than 72 hours preceding death did the child have a personal history of any of the following chronic conditions or symptoms? <input type="checkbox"/> U/K for all											
Symptom			Present w/in 72 hours of death			Present w/in 72 hours of death			Symptom			Present more than 72 hours of death					
			Yes	No	U/K				Yes	No	U/K						
<u>Cardiac</u>						<u>Other Acute Symptoms</u>						<u>Cardiac</u>					
Chest pain			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Fever			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Chest pain			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dizziness/lightheadedness			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Heat exhaustion/heat stroke			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Dizziness/lightheadedness			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fainting			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Muscle aches/cramping			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Fainting			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palpitations			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Slurred speech			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Palpitations			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<u>Neurologic</u>						Vomiting			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<u>Neurologic</u>					
Concussion			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Other, specify:			<input type="radio"/>			Concussion			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Confusion			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>							Confusion			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Convulsions/seizure			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>							Convulsions/seizure			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Headache			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>							Headache			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Head injury			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>							Head injury			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychiatric symptoms			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>							Psychiatric symptoms			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paralysis (acute)			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>							Paralysis (acute)			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<u>Respiratory</u>												<u>Respiratory</u>					
Asthma			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>							Asthma			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pneumonia			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>							Pneumonia			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty breathing			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>							Difficulty breathing			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
												<u>Other</u>					
												Slurred speech			<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
												Other, specify:			<input type="radio"/>		

d. Did the child have any prior serious injuries (e.g. near drowning, car accident, brain injury)?

Yes No U/K If yes, describe:

e. Had the child ever been diagnosed by a medical professional for the following? U/K for all

Condition	Diagnosed			Condition	Diagnosed		
	Yes	No	U/K		Yes	No	U/K
Blood disease				Neurologic (cont)			
Sickle cell disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Epilepsy/seizure disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sickle cell trait	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Febrile seizure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thrombophilia (clotting disorder)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Mesial temporal sclerosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cardiac				Neurodegenerative disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Abnormal electrocardiogram (EKG or ECG)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Stroke/mini stroke/ TIA-Transient Ischemic Attack	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aneurysm or aortic dilatation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Central nervous system infection (meningitis or encephalitis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Arrhythmia/arrhythmia syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Respiratory			
Cardiomyopathy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Apnea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Commotio cordis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Congenital heart disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Pulmonary embolism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coronary artery abnormality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Pulmonary hemorrhage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coronary artery disease (atherosclerosis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Respiratory arrest	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Endocarditis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Other			
Heart failure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Connective tissue disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heart murmur	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High cholesterol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Endocrine disorder, other: thyroid, adrenal, pituitary	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hypertension	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Hearing problems or deafness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Myocarditis (heart infection)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Kidney disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pulmonary hypertension	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Mental illness/psychiatric disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sudden cardiac arrest	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Metabolic disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurologic				Muscle disorder or muscular dystrophy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anoxic brain injury	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Oncologic disease treated by chemotherapy or radiation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Traumatic brain injury/ head injury/concussion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Prematurity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain tumor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Congenital disorder/ genetic syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain aneurysm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Other, specify:	<input type="radio"/>		
Brain hemorrhage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
Developmental brain disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				

If a more specific diagnosis is known, provide any additional information:

If any cardiac conditions above are selected, what cardiac treatments did the child have? Check all that apply: None

- Cardiac ablation Heart surgery Heart transplant
 Cardiac device placement (Implanted cardioverter defibrillator (ICD) or pacemaker or Ventricular Assist Device (VAD)) Interventional cardiac catheterization Other, specify:
 U/K

f. Did the child have any blood relatives (brothers, sisters, parents, aunts, uncles, cousins, grandparents or other more distant relatives) with the following diseases, conditions or symptoms? U/K for all

Y N U/K Deaths

Sudden unexpected death before age 50

Heart Disease

Heart condition/heart attack or stroke before age 50

Aortic aneurysm or aortic rupture

Arrhythmia (fast or irregular heart rhythm)

Cardiomyopathy

Congenital heart disease

Neurologic Disease

Epilepsy or convulsions/seizure

Other neurologic disease

If sudden unexpected death before age 50, describe (for example, SIDS, drowning, relative who died in single and/or unexplained motor vehicle accident (driver of car)):

Y N U/K Symptoms

Febrile seizures

Unexplained fainting

Other Diagnoses

Congenital deafness

Connective tissue disease

Mitochondrial disease

Muscle disorder or muscular dystrophy

Thrombophilia (clotting disorder)

Other diseases that are genetic or run in families, specify:

g. Has any blood relative (siblings, parents, aunts, uncles, cousins, grandparents) had genetic testing?

Yes No U/K

If yes, describe what test and/or for what disease and results:

Was a gene mutation found?

Yes No U/K

M. SUID AND SDY CASE REGISTRY

1. Is this an SDY or SUID case? <input type="radio"/> Yes <input type="radio"/> No If no, go to Section N	
2. Did this case go to Advance Review for the SDY Case Registry? <input type="radio"/> N/A <input type="radio"/> Yes <input type="radio"/> No If yes, date of first Advance Review meeting:	3. Notes from Advance Review meeting:
4. If autopsy performed, did the ME/coroner/pathologist use the SDY Autopsy Guidance or Summary? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> U/K	
5. Was a specimen sent to the SDY Case Registry bio-repository? <input type="radio"/> N/A <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> U/K	6. Did the family consent to the SDY Case Registry? <input type="radio"/> N/A <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> U/K
7. Categorization for SDY Case Registry (choose only one): <input type="radio"/> Excluded from SDY Case Registry <input type="radio"/> Explained cardiac <input type="radio"/> Explained other <input type="radio"/> Unexplained, SUDEP <input type="radio"/> No autopsy or death scene investigation <input type="radio"/> Explained neurological <input type="radio"/> Unexplained, possible cardiac <input type="radio"/> Unexplained infant death (under age 1) <input type="radio"/> Incomplete case information <input type="radio"/> Explained Infant suffocation (under age 1) <input type="radio"/> Unexplained, possible cardiac and SUDEP <input type="radio"/> Unexplained child death (age 1 and over)	
8. Categorization for SUID Case Registry (choose only one): <input type="radio"/> Excluded (other explained causes, not suffocation) <input type="radio"/> Unexplained: No autopsy or death scene investigation <input type="radio"/> Unexplained: Incomplete case information <input type="radio"/> Unexplained: No unsafe sleep factors <input type="radio"/> Unexplained: Unsafe sleep factors <input type="radio"/> Unexplained: Possible suffocation with unsafe sleep factors <input type="radio"/> Explained: Suffocation with unsafe sleep factors	If possible suffocation or explained suffocation, select the primary mechanism(s) leading to the death, check all that apply: <input type="checkbox"/> Soft bedding <input type="checkbox"/> Wedging <input type="checkbox"/> Overlay <input type="checkbox"/> Other, specify: