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? ○ Yes ○ No ○ 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?

☐ U/K for all

Symptom	Present w/in 72 hours of death		
	Yes	No	U/K
Cardiac			
Chest pain	○	○	○
Dizziness/lightheadedness	○	○	○
Fainting	○	○	○
Palpitations	○	○	○
Neurologic			
Concussion	○	○	○
Confusion	○	○	○
Convulsions/seizure	○	○	○
Headache	○	○	○
Head injury	○	○	○
Psychiatric symptoms	○	○	○
Paralysis (acute)	○	○	○
Respiratory			
Asthma	○	○	○
Pneumonia	○	○	○
Difficulty breathing	○	○	○

Symptom	Present w/in 72 hours of death		
	Yes	No	U/K
Other Acute Symptoms			
Fever	○	○	○
Heat exhaustion/heat stroke	○	○	○
Muscle aches/cramping	○	○	○
Slurred speech	○	○	○
Vomiting	○	○	○
Other, specify:	○		

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? ☐ U/K for all

Symptom	Present more than 72 hours of death		
	Yes	No	U/K
Cardiac			
Chest pain	○	○	○
Dizziness/lightheadedness	○	○	○
Fainting	○	○	○
Palpitations	○	○	○
Neurologic			
Concussion	○	○	○
Confusion	○	○	○
Convulsions/seizure	○	○	○
Headache	○	○	○
Head injury	○	○	○
Respiratory			
Difficulty breathing	○	○	○
Other			
Slurred speech	○	○	○
Other, specify:	○		

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 Yes	No	U/K
Blood disease			
Sickle cell disease	○	○	○
Sickle cell trait	○	○	○
Thrombophilia (clotting disorder)	○	○	○
Cardiac			
Abnormal electrocardiogram (EKG or ECG)	○	○	○
Aneurysm or aortic dilatation	○	○	○
Arrhythmia/arrhythmia syndrome	○	○	○
Cardiomyopathy	○	○	○
Commotio cordis	○	○	○
Congenital heart disease	○	○	○
Coronary artery abnormality	○	○	○
Coronary artery disease (atherosclerosis)	○	○	○
Endocarditis	○	○	○
Heart failure	○	○	○
Heart murmur	○	○	○
High cholesterol	○	○	○
Hypertension	○	○	○
Myocarditis (heart infection)	○	○	○
Pulmonary hypertension	○	○	○
Sudden cardiac arrest	○	○	○
Neurologic			
Anoxic brain injury	○	○	○
Traumatic brain injury/ head injury/concussion	○	○	○
Brain tumor	○	○	○
Brain aneurysm	○	○	○
Brain hemorrhage	○	○	○
Developmental brain disorder	○	○	○

Condition	Diagnosed Yes	No	U/K
Neurologic (cont)			
Epilepsy/seizure disorder	○	○	○
Febrile seizure	○	○	○
Mesial temporal sclerosis	○	○	○
Neurodegenerative disease	○	○	○
Stroke/mini stroke/ TIA-Transient Ischemic Attack	○	○	○
Central nervous system infection (meningitis or encephalitis)	○	○	○
Respiratory			
Apnea	○	○	○
Asthma	○	○	○
Pulmonary embolism	○	○	○
Pulmonary hemorrhage	○	○	○
Respiratory arrest	○	○	○
Other			
Connective tissue disease	○	○	○
Diabetes	○	○	○
Endocrine disorder, other: thyroid, adrenal, pituitary	○	○	○
Hearing problems or deafness	○	○	○
Kidney disease	○	○	○
Mental illness/psychiatric disease	○	○	○
Metabolic disease	○	○	○
Muscle disorder or muscular dystrophy	○	○	○
Oncologic disease treated by chemotherapy or radiation	○	○	○
Prematurity	○	○	○
Congenital disorder/ genetic syndrome	○	○	○
Other, specify:	○		

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
☐ Cardiac device placement (implanted cardioverter defibrillator (ICD) or pacemaker or Ventricular Assist Device (VAD))
☐ Heart surgery
☐ Interventional cardiac catheterization
☐ Heart transplant
☐ 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

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:

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)):

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

h. In the 72 hours prior to death was the child taking any prescribed medication(s)?
○ Yes ○ No ○ U/K
If yes, describe:

i. Within 2 weeks prior to death had the child:

	N/A	Yes	No	U/K
Taken extra doses of prescribed medications	○	○	○	○
Missed doses of prescribed medications	○	○	○	○
Changed prescribed medications, describe:	○	○	○	○

j. Was the child compliant with their prescribed medications?
○ N/A ○ Yes ○ No ○ U/K
If not compliant, describe why and how often:

k. Was the child taking any of the following substance(s) within 24 hours of death?
Check all that apply:
- ☐ Over the counter medicine
- ☐ Recent/short term prescriptions
- ☐ Energy drinks
- ☐ Caffeine
- ☐ Performance enhancers
- ☐ Diet assisting medications
- ☐ Supplements
- ☐ Tobacco
- ☐ Alcohol
- ☐ Illegal drugs
- ☐ Legalized marijuana
- ☐ Other, specify:
- ☐ U/K

If yes to any items above, describe:

l. Did the child experience any of the following stimuli at time of incident or within 24 hours of the incident?
☐ U/K for all at time of incident
☐ U/K for all within 24 hours of incident

Stimuli	At Incident Yes	At Incident No	At Incident U/K	Within 24 hrs of Incident Yes	Within 24 hrs of Incident No	Within 24 hrs of Incident U/K
Physical activity	○	○	○	○	○	○
Sleep deprivation	○	○	○	○	○	○
Driving	○	○	○	○	○	○
Visual stimuli	○	○	○	○	○	○
Video game stimuli	○	○	○	○	○	○
Emotional stimuli	○	○	○	○	○	○
Auditory stimuli/startle	○	○	○	○	○	○
Physical trauma	○	○	○	○	○	○
Other	○			○		

If yes to physical activity, describe type of activity:
At Incident | Within 24 hours of Incident

Other specify:
At Incident | Within 24 hours of Incident

m. Was the child an athlete? ○ N/A ○ Yes ○ No ○ U/K
If yes, type of sport: ○ Competitive ○ Recreational ○ Unknown
If competitive, did the child participate in the 6 months prior to death? ○ Yes ○ No ○ U/K

n. Did the child ever have any of the following **uncharacteristic** symptoms during or within 24 hours after physical activity? Check all that apply:
- ☐ Chest pain
- ☐ Confusion
- ☐ Convulsions/seizure
- ☐ Dizziness/lightheadedness
- ☐ Fainting
- ☐ Headache
- ☐ Palpitations
- ☐ Shortness of breath/difficulty breathing
- ☐ Other, specify:
- ☐ U/K

If yes to any item, describe type of physical activity and extent of symptoms:

o. If child age 12 or older, did the child receive a pre-participation exam for a sport?
○ N/A ○ Yes ○ No ○ U/K
If yes:
Was it done within a year prior to death? ○ Yes ○ No ○ U/K
Did the exam lead to restrictions for sports or otherwise? ○ Yes ○ No ○ U/K
If yes, specify restrictions:

Questions p through v: Answer if "Epilepsy/Seizure Disorder" is answered Yes in question e above (Diagnosed for a medical condition)

p. How old was the child when diagnosed with epilepsy/seizure disorder?
Age 0 (infant) through 20 years: _____
☐ U/K

q. What were the underlying cause(s) of the child's seizures?
Check all that apply:
- ☐ Brain injury/trauma, specify:
- ☐ Brain tumor
- ☐ Cerebrovascular
- ☐ Central nervous system infection
- ☐ Degenerative process
- ☐ Developmental brain disorder
- ☐ Inborn error of metabolism
- ☐ Genetic/chromosomal
- ☐ Mesial temporal sclerosis
- ☐ Idiopathic or cryptogenic
- ☐ Other acute illness or injury other than epilepsy
- ☐ Other, specify:
- ☐ U/K

r. What type(s) of seizures did the child have? Check all that apply:
- ☐ Non-convulsive
- ☐ Convulsive (grand mal seizure or generalized tonic-clonic seizure)
- ☐ Occur when exposed to strobe lights, video game, or flickering light (reflex seizure)
- ☐ U/K

s. Describe the child's epilepsy/seizures. Check all that apply:
- ☐ Last less than 30 minutes
- ☐ Last more than 30 minutes (status epilepticus)
- ☐ Occur in the presence of fever (febrile seizure)
- ☐ Occur in the absence of fever
- ☐ Occur when exposed to strobe lights, video game, or flickering light (reflex seizure)

t. How many seizures did the child have in the year preceding death?
○ 0/never ○ 1 ○ 2 ○ 3 ○ More than 3 ○ U/K

u. Did treatment for seizures include anti-epileptic drugs?
○ Yes ○ No ○ U/K
If yes, how many different types of anti-epilepsy drugs (AED) did the child take?
○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ More than 6 ○ U/K

v. Was night surveillance used?
○ Yes ○ No ○ U/K

M. SUID AND SDY CASE REGISTRY

1. Is this an SDY or SUID case? ○ Yes ○ No — If no, go to Section N

2. Did this case go to Advance Review for the SDY Case Registry?
○ N/A ○ Yes ○ 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? ○ Yes ○ No ○ U/K

5. Was a specimen sent to the SDY Case Registry bio-repository?
○ N/A ○ Yes ○ No ○ U/K

6. Did the family consent to the SDY Case Registry?
○ N/A ○ Yes ○ No ○ U/K

7. Categorization for SDY Case Registry (choose only one):

- ○ Excluded from SDY Case Registry
- ○ No autopsy or death scene investigation
- ○ Incomplete case information
- ○ Explained cardiac
- ○ Explained neurological
- ○ Explained infant suffocation (under age 1)
- ○ Explained other
- ○ Unexplained, possible cardiac
- ○ Unexplained, possible cardiac and SUDEP
- ○ Unexplained, SUDEP
- ○ Unexplained infant death (under age 1)
- ○ Unexplained child death (age 1 and over)

8. Categorization for SUID Case Registry (choose only one):

- ○ Excluded (other explained causes, not suffocation)
- ○ Unexplained: No autopsy or death scene investigation
- ○ Unexplained: Incomplete case information
- ○ Unexplained: No unsafe sleep factors
- ○ Unexplained: Unsafe sleep factors
- ○ Unexplained: Possible suffocation with unsafe sleep factors
- ○ 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:

- ☐ Soft bedding
- ☐ Wedging
- ☐ Overlay
- ☐ Other, specify: