## 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? O Yes O No O 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?  c. At any time more than 72 hours preceding death did the												the
Sumatom	Present	w/in 72 h	ours of	death Prese	nt w/in 7	2 hours	of death		•			-th
				death Trese				-Jp.c				aun
				Other Acute Symptoms	res	NO	U/K					
•	_				_	0	_		_	_	_	
-	_	_	_			_	-	•	_			
•	_		-		_	_	_	•	0			
Palpitations	0	0	0				_	•	0	0	0	
Neurologic				Slurred speech	0	_	0	Neurologic				
Concussion	0	0	0	Vomiting	0	0	0	Concussion	0		0	
Confusion	0	0	0	Other, specify:	0			Confusion	0		0	
Convulsions/seizure	0	0	0					Convulsions/seizure	0	0	0	
Headache	0	0	0					Headache	0	0	0	
Head injury	0	0	0					Head injury	0	0	0	
Psychiatric symptoms	0	0	0					Respiratory				
Paralysis (acute)	0	0	0					Difficulty breathing	0	0	0	
Respiratory		_	_					Other				
Asthma	0	0	0						0	0	0	
Pneumonia	Õ	Õ	Õ					Other, specify:	0			
	this death a homicide, suici to terminal illness?  the child have a history of a U/K for all  Symptom  Cardiac  Chest pain  Dizziness/lightheadedness Fainting Palpitations  Neurologic  Concussion  Confusion  Convulsions/seizure  Headache  Head injury  Psychiatric symptoms  Paralysis (acute)  Respiratory	this death a homicide, suicide, overdon to terminal illness?  The child have a history of any of the feature of the child have a history of any of the child have a history of any of the feature of the child have a history of any of the feature of the child have a history of any of the feature of the child have a history of any of the feature of the child have a history of any of the feature of the child have a history of any of the feature of the child have a history of the feature of the child have a history of the feature of the child have a history of the feature of the child have a history of the feature of the child have a history of	this death a homicide, suicide, overdose, injury to terminal illness? Yes No the child have a history of any of the following a U/K for all  Symptom Present w/in 72 h  Cardiac Yes No Chest pain O Dizziness/lightheadedness O Fainting O Palpitations O Concussion O Concussion O Confusion O Convulsions/seizure Headache Head injury Psychiatric symptoms O Paralysis (acute) Present Illness Present w/in 72 h  Cardiac Yes No Chest pain O C	this death a homicide, suicide, overdose, injury with the tot terminal illness?  Yes No U/  The child have a history of any of the following acute con U/K for all  Symptom Present w/in 72 hours of Cardiac Yes No U/K  Chest pain O O  Dizziness/lightheadedness O O  Fainting O O  Palpitations O O  Neurologic  Concussion O O  Confusion O O  Convulsions/seizure O O  Headache Head injury O O  Paralysis (acute) O O  Respiratory	this death a homicide, suicide, overdose, injury with the external cause as the only and to terminal illness?	this death a homicide, suicide, overdose, injury with the external cause as the only and obvious to terminal illness?	this death a homicide, suicide, overdose, injury with the external cause as the only and obvious cause to terminal illness?	this death a homicide, suicide, overdose, injury with the external cause as the only and obvious cause of death of to terminal illness?  O Yes O No O U/K If yes, go to Section H2  The child have a history of any of the following acute conditions or symptoms within 72 hours prior to death?    U/K for all	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 to terminal illness?  Yes No U/K If yes, go to Section H2    C. At any time more than 72 child have a history of any of the following acute conditions or symptoms within 72 hours prior to death?    U/K for all	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 to terminal illness?  Yes No U/K If yes, go to Section H2  The child have a history of any of the following acute conditions or symptoms within 72 hours prior to death?  With child have a history of any of the following acute conditions or symptoms within 72 hours prior to death?  With child have a personal history of a	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 mont to terminal illness?	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 to terminal illness? Yes No U/K If yes, go to Section H2  the child have a history of any of the following acute conditions or symptoms within 72 hours prior to death?    U/K for all

d. Did the child have any prior serious	injuries (e.g. nea	r drownin	g, car accident	, brain injury)?				
Oyes Ono Ou	J/K If ye	s, describ	e:					
e. Had the child ever been diagnosed Condition	Had the child ever been diagnosed by a medical professional for the following?  Condition Diagnosed		U/K for all Condition	Diagnosed				
Blood disease	Yes	No	U/K	Neurologic (cont)	Υ	res	No	U/K
Sickle cell disease	0	Ö	0	Epilepsy/selzure disorder	_	0	Ö	Ö
Sickle cell trait	0	0	0	Febrile selzure	(	0	0	0
Thrombophilia (clotting di	sorder)	0	0	Mesial temporal scierosis		0	Ö	Ö
	oolder)	_	0	Neurodegenerative disease		Ö	ŏ	0
Cardiac	am O	0	0		,	~	ŏ	Ö
Abnormal electrocardiogra	am O	0	0	Stroke/mini stroke/	`			0
(EKG or ECG)	tion O	0	0	TIA-Translent Ischemic Attack	,	_	_	0
Aneurysm or aortic dilatat	_			Central nervous system infection	'	0	0	0
Arrhythmia/arrhythmia sy		0	0	(meningitis or encephalitis)				
Cardiomyopathy	0	0	0	Respiratory		_	_	_
Commotio cordis	0	0	0	Apnea		0	0	0
Congenital heart disease		0	0	Asthma		0	0	0
Coronary artery abnormal	lity 🔾	0	0	Pulmonary embolism		0	0	0
Coronary artery disease	0	0	0	Pulmonary hemorrhage	(	0	0	0
(atheroscierosis)				Respiratory arrest	(	0	0	0
Endocarditis	0	0	0	Other				
Heart fallure	0	0	0	Connective tissue disease	(	0	0	0
Heart murmur	0	0	0	Diabetes	(	0	0	0
High cholesterol	0	0	0	Endocrine disorder, other:	(	0	0	0
Hypertension	0	0	0	thyroid, adrenal, pituitary				
Myocarditis (heart infection	on) O	0	0	Hearing problems or deafness	(	0	0	0
Pulmonary hypertension	0	0	0	Kidney disease	(	0	0	0
Sudden cardiac arrest	0	0	0	Mental Illness/psychiatric disease	(	0	0	0
Neurologic				Metabolic disease	(	0	0	0
Anoxic brain Injury	0	0	0	Muscle disorder or muscular	(	0	0	0
Traumatic brain injury/	0	0	0	dystrophy				
head injury/concussion	n			Oncologic disease treated by	(	0	0	0
Brain tumor	0	0	0	chemotherapy or radiation				
Brain aneurysm	0	0	0	Prematurity	(	0	0	0
Brain hemorrhage	0	0	0	Congenital disorder/	(	0	0	0
Developmental brain diso	_	0	0	genetic syndrome				
				Other, specify:	(	0		
If a more specific diagnosis	is known provide	any addit	onal Informatio	n:				_
		,						
If any cardiac conditions ab	ove are selected, v	vhat card	ac treatments o	fid the child have? Check all that apply:				
☐ Cardia	c ablation			☐ Heart surgery		leart tr	ransplan	t
☐ Cardia	c device placemen	t		Interventional cardiac		Other,	specify:	
(Im	planted cardioverte	r defibrilla	itor (ICD)	catheterization		U/K		
	pacemaker or Vent							
	•			cousins, grandparents or other more distant relatives)	9			od relative (siblings,
with the following diseases, condition	ons or symptoms?		U/K for all					ts, uncles, cousins,
Y N U/K Deaths				Y N U/K Symptoms		gran		s) had genetic testing?
O O Sudden unexpec	ted death before a	ge 50		O O Febrile seizures			O Ye	5 O No O U/K
Heart Disease				O O Unexplained fainting				
O O Heart condition/h		e before	age 50	Other Diagnoses		If yes, describe what test and/or		
O O O Aortic aneurysm				O O Congenital deafness		for wi	hat disea	ase and results:
O O Arrhythmia (fast	_	lythm)		O O Connective tissue disease				
○ ○ ○ Cardiomyopathy			O O Mitochondrial disease					
○ ○ ○ Congenital heart	disease			O O Muscle disorder or muscular dystrophy				
Neurologic Dise	389			○ ○ ○ Thrombophilia (clotting disorder)				
O O Epilepsy or convi	ulsions/selzure			Other diseases that are genetic or				
O O Other neurologic	disease			run in families, specify:		Was	a gene i	mutation found?
If sudden unexpected death	n before age 50, de	scribe (fo	r example, SID	S, drowning, relative who died in single and/or			○ Ye	5 () No () U/K
unexplained motor vehicle a	accident (driver of	car)):						

h. In the 72 hours prior to death was the child taking any prescribed medication(s)?							k. Was the child taking any of the following substance(s) within 24 hours of death?						
Oyes Ono Ou/K							Check all that apply:						
If yes, describe:								Over the counter medicine	☐ Supplements				
							[	Recent/short term prescriptions	☐ Tobacco				
I. Within 2 weeks prior to death ha	ad the d	hlld:		N/A Yes	No I	U/K		☐ Energy drinks	☐ Alcohol				
Taken extra doses of prescrib					0		[	Caffeine	☐ Illegal drugs				
Missed doses of prescribed n	nedicatio	ons		00	0 (	0	[	Performance enhancers	☐ Legalized marijuana				
Changed prescribed medicat	ons, de	scribe:		0 0	0	0		Diet assisting medications	Other, specify:				
j. Was the child compliant with th	eir pres	cribed m	edicatio	ns?			1		□ U/K				
ON/A OYes ON	O	J/K					If yes	to any Items above, describe:					
If not compliant, des			ow ofter	1:									
		•											
I. Did the child experience any of	the follo	wing stir	null at tir	ne of inciden	t or with	in 24 hours	of the incident? U/K for all at time of incident						
		At Incide				of Incident							
Stimuli	Yes	No	U/K	Yes	No	U/K							
Physical activity	0	0	0	0	0	0		If yes to physical activity, describe	type of activity:				
Sleep deprivation	0	0	0	0	0	0		At Incident With	nin 24 hours of incident				
Driving	0	0	0	0	0								
Visual stimuli	0	0	0	0	0	0							
Video game stimuli	0	0	0	0	0	0							
Emotional stimuli	0	0	0	0	0	0							
Auditory stimuli/startle	0	0	0	0	0	0							
Physical trauma	0	0	0	0	0	0		Other specify:					
Other O							- 1	At Incident With	nin 24 hours of incident				
m. Was the child an athlete?	0	N/A	OYes	O No C	U/K								
		If yes,	type of	sport: O	Compe	etitive C	Recrea	tional OUnknown					
		If c	ompetiti	ve, did the ch	ilid parti	clpate in the	6 month	s prior to death? O Yes O No	O u/k				
n. Did the child ever have any of the following uncharacteristic symptoms during or						o. If ch	lid age 12 or older, did the child recei	ve a pre-participation exam for a sport?					
within 24 hours after physical a	activity?	Check	all that a	pply:				ON/A OYES ON	O U/K				
☐ Chest pain		☐ Hea	dache				If ye	5:					
☐ Confusion		☐ Palp	itations				Wa	s it done within a year prior to death?	○ Yes ○ No ○ U/K				
☐ Convulsions/seizure		Sho	rtness o	f breath/diffic	ulty brea	breathing Did the exam lead to restrictions for sports or otherwise? O Yes O No (							
☐ Dizziness/lightheadedness ☐ Other, specify:								If yes, specify restrictions:					
☐ Fainting		□ u/ĸ											
If yes to any Item, describe type													
Questions p throug	gh v: A	nsweri	f "Epile	epsy/Seizu	re Diso	order" is an	swere	I Yes in question e above (Diag	nosed for a medical condition)				
p. How old was the child when dia	gnosed	with epi	lepsy/se	zure	r. What	t type(s) of s	elzures o	lid the child have? Check all that app					
disorder?					[	Non-conv	ulsive		In the year preceding death?				
Age 0 (infant) through 20 years: ————								i mai selzure or	O 0/never O 2 O More than 3				
□ u/ĸ						genera	ilized ton	ic-cionic seizure)	O1 O3 O U/K				
q. What were the underlying cause(s) of the child's seizures?								sed to strobe lights,	u. Did treatment for seizures include				
Check all that apply:					_ ا		jame, or	flickering light (reflex selzure)	anti-epileptic drugs?				
☐ Brain injury/trauma, specify: ☐ U/K									OYes ONo OU/K				
						. Describe the child's epilepsy/selzures. Check all that apply			If yes, how many different types of anti-				
☐ Cerebrovascular				clerosis		Last less			epilepsy drugs (AED) did the child take?				
☐ Central nervous system		diopathic		-				minutes (status epilepticus)	O1 O4 O More than 6 O2 O5 O U/K				
Infection				s or injury				ence of fever (febrile selzure)	O3 O6				
						_		nce of fever					
								sed to strobe lights, video	v. Was night survellance used?				
☐ Inborn error of metabolism		J/K				game,	or flicker	ing light (reflex selzure)	OYes ONo OU/K				

M. SUID AND SDY CASE REGISTRY										
1. Is this an SDY or SUID case? O Yes O No	If no, go to Section N									
Did this case go to Advance Review for the SDY Case Registry?	3. Notes from Ad	vance Review meeting:								
O N/A O Yes O No										
If yes, date of first Advance Review meeting:										
4. If autopsy performed, did the ME/coroner/pathologist use the SDY	Autopsy Guldance or	Summary? OYes	ONo	Ou/k						
5. Was a specimen sent to the SDY Case Registry bio-repository?	6. Did the family	consent to the SDY Case Registry?								
ON/A OYes ON0 OU/K	0	O N/A O Yes O No O U/K								
7. Categorization for SDY Case Registry (choose only one):										
○ Excluded from SDY Case Registry ○ Explained	d cardiac	Explained other	0	Unexplained, SUDEP						
O No autopsy or death scene investigation	d neurological	O Unexplained, possible cardiac	0	Unexplained infant death (under age 1)						
O Incomplete case Information O Explained	d Infant suffocation	O Unexplained, possible cardiac	Unexplained child death (age 1 and over)							
(under	age 1)	and SUDEP								
8. Categorization for SUID Case Registry (choose only one):										
<ul> <li>Excluded (other explained causes, not suffocation)</li> </ul>		If possible suffocation or explained suffocation, select the primary mechanism(s)								
O Unexplained: No autopsy or death scene investigation		leading to the death, check all that apply:								
O Unexplained: Incomplete case information		☐ Soft bedding								
O Unexplained: No unsafe sleep factors		□Wedging								
O Unexplained: Unsafe sleep factors		Overlay								
Ounexplained: Possible suffocation with unsafe sleep factors		☐ Other, specify:								
O Explained: Suffocation with unsafe sleep factors										