## Frequently Asked Questions (FAQs) for completion of the Child Death Review – Case Reporting System (CDR-CRS)

August 22, 2016

## SECTION B. PRIMARY CAREGIVER(S) INFORMATION

# If a newborn infant dies in the hospital and was never discharged from the hospital after birth, isn't the primary caregiver "Institutional Staff"?

No. The primary caregiver is the person who has *legal* custody of the child. Unless the infant was removed from the biological mother's custody or the mother gave up her legal rights before the infant's death, the correct entry for primary caregiver when an infant dies before leaving the hospital is the infant's biological mother.

# Who should be designated caregiver 1 and who is caregiver 2 when both parents have joint custody of a child and the child spends equal time with each parent?

In this case, code the mother as caregiver 1 and the father as caregiver 2. Whenever 2 parents are active caregivers, code the mother as caregiver 1 and the father as caregiver 2.

## SECTION C. SUPERVISOR INFORMATION

# If a toddler and the supervisor are both in the house, but in distant rooms, is the child considered supervised?

No, this child is not considered supervised and C1 should be marked "No, but needed". Supervision is defined as the action or process of watching and directing what someone does. Supervision of a child is determined by how close the supervisor is to the child and if they can see or hear the child.

Children less than six years old require constant or close supervision most of the time. If the supervisor can neither see nor hear the child the child, consider the child not supervised.

## What about when a child and supervisor are both sleeping, is the child supervised?

If the child was asleep (or supposed to be asleep) at time of incident and the supervisor was also asleep, and if the incident occurred during the night (when you would expect families to be sleeping), the child would be considered "supervised."

However, if the supervisor is sleeping during the day or evening hours when they should be supervising the child, no alternative supervisor is assigned, and the child is awake (or wakes up) and is fatally injured, document this in C15 by indicating that the supervisor was impaired (check C15 = yes; and check "asleep").

Supervisor sleeping at time of incident is only considered an impairment if the incident occurred at a time of day that is not typical for the supervisor to be sleeping.

# If the baby is sleeping in a "safe" space, then the time shouldn't matter. New Moms often try to nap while baby is sleeping.

We do not expect that parents will watch their infants while they are sleeping. If an infant is placed in a safe sleep environment (e.g., crib, no soft bedding, pillows, etc) for a nap during the day and the supervisor is home and naps at this time, we would consider this child supervised because the parent has provided a safe environment and there is no risk that an infant will awake and wander off into a hazard.

# What about parents who do shiftwork? Sometimes a night shift working parent will supervise the children during the day while the other parent is working. If the kids are napping and the parent is also asleep, is the child supervised? Is the supervisor impaired by sleep?

In general, night shift workers who need to sleep during the day should ensure alternative supervision for their young children during the day so they can get needed sleep. The hazard for adults who plan to nap when the children nap is that toddlers may wake up and wonder off while the parent is sleeping. In addition, adults need adequate periods of deep sleep during which time they may not hear a child. If a parent works nights and is sleeping during the day while sole supervisor of (a) young child(ren) and the child is fatally injured, code C1. "yes" if the supervisor was in proximity that they could have seen or heard the child, or "no, but needed" if not. Then, code C15 as supervisor impaired by sleep.

# In what circumstances would a child be considered supervised (C1=yes), but the supervisor impaired by absence (C15= yes, absent)? Wouldn't the absence of the supervisor mean that, by definition, the child was unsupervised?

By definition, if the supervisor was absent, the child would be unsupervised. However, when the answer to question C1 (Did the child have supervision at the time of incident leading to death) is: "No, but needed" or "unable to determine" you are asked to answer all the questions for Section C, including C15 (At time of incident was supervisor impaired). So, you may have a situation where the child was not supervised due to the supervisor being absent, but the team determined supervision was needed (C1=no, but needed). In this case C15 would be checked yes, and absent would be indicated here.

# Co-sleeping infant death. The parents awoke at 7:30am and child was deceased. Child was in between the parents. Parents were drinking alcohol and smoked marijuana prior to death, would this still be considered impairment due to sleep?

In this case, for question C1, the infant is considered supervised, presumably they all went to sleep during the night, and the parents were within proximity to see and hear the infant. For question C15, at the time of incident, was the supervisor impaired, mark "yes" and specify all responses that apply (i.e., drug impaired, alcohol impaired, asleep).

## SECTION D. INCIDENT INFORMATION

# What guidance is there for determining time lapsed between incident and time of death when related to sleeping death.

For D2 (approximate time of day that incident occurred), if the time the incident occurred is not known but it can be determined that the incident occurred in the am (midnight until noon) or pm (between noon and midnight) mark AM or PM (leave hour of day blank) For example, parents checked on baby at 12:30 am, and baby was fine. When they checked again at 5:30am, baby was dead. Check AM in D2. In this case, for D3 (Interval between incident and death) mark unknown, since the number of hours (minutes, hours, days, etc) is required if hours is checked. Without knowing the number of hours, unknown is the most accurate response.

## SECTION F. OFFICIAL MANNER AND PRIMARY CAUSE OF DEATH

# What is the difference between the answer to F2a. Immediate cause of death (as written on the death certificate) and the answer to F6. Primary cause of death?

## What if the immediate cause of death listed on the death certificate is not listed as a response option for F6, What do we code?

F6 is used to identify whether the death resulted from an injury or illness (medical cause) for the purpose of completing the most appropriate risk factor details in Section G. This risk factor information is important for guiding possible prevention strategies. Consequently, the primary cause of death marked here may not be the same as the immediate cause of death listed on the death certificate.

## SECTION G. DETAILED INFORMATION BY CAUSE OF DEATH

How should we answer G1i, where all possible protective measures for motor vehicle or transport injuries are listed? Only one measure might be appropriate given the circumstances and sometimes, none of these apply (e.g., child pedestrian killed while crossing the street).

For this question, something should be checked FOR EACH PROTECTIVE MEASURE. If the measure is not applicable, check "not needed."

## SECTION H2. WAS THE DEATH RELATED TO SLEEPING OR THE SLEEP ENVIRONMENT

# If an infant is placed in a co-sleeper on the adult bed and the cause of death is mechanical asphyxia due to unsafe sleep...how should the incident sleep place be identified? adult bed or other: co-sleeper

In this case, code as "other" and specify "infant co-sleeper." In addition, identify death as related to a consumer product (H3 = yes) and describe information on the make and type of co-sleeper (e.g., placed on adult bed, attached to side of adult bed) as well as the circumstances in H3a.

## SECTION I. ACTS OF OMISSION OR COMMISSION

## Section I only applies to injury deaths, right?

Although injury deaths, both unintentional (accidents) and intentional injury deaths are most likely to be related to acts of omission or commission, Section I should be considered for ALL deaths.

Most natural deaths will not be related to acts of omission or commission, but the potential for failure to seek or provide medical care, or religious practices to contribute to a death should be considered and documented when appropriate.

Even when the specific cause of a child's deaths is undetermined or unknown, acts of omission or commission that directly cause or indirectly contribute to the death might be identified and when they are, should be documented.

#### In question I1, when should we check "Probable"?

Check "probable" if the team is not certain that an act of omission or commission directly caused or indirectly contributed to the child's death, but there is evidence suggesting such a link. Use of this "probable" category is particularly relevant to deaths due to unknown or undetermined causes such as sudden unexpected infant deaths in the sleep environment, particularly if hazards in the sleep environment are noted (e.g., bed-sharing, soft bedding, sleeping on surface not intended for infant sleep).

## In question I2, what is the distinction between the options of "Poor/absent supervision," "Child neglect," and "Other negligence"?

All three of these categories reflect failures to act on the part of a child's parent or caregiver to protect a child from harm. If the team agrees that the failure to act meets the definition of neglect, select this option.

Sometimes, teams cannot reach consensus that a failure to act constitutes neglect so the options of poor/absent supervision and other negligence can be used when this is the case. Use poor/absent supervision when a caregiver's failure to supervise, provide alternative appropriate supervision, or engage in other behavior that causes or contributes to the injury death of a young child and the team does not feel that the lapse of supervision meets criteria to be classified as child neglect. Use other negligence for failures to act that are not related to supervision. For example, this category should be used for sudden unexpected infant deaths when hazards are documented in the sleep environment when the team does not feel that the circumstances meet the criteria to be classified as child neglect.

# Why is there not an option for "unsafe sleep environment" in question I2? We always code this as "Other"

Failure to provide a safe sleep environment is an act of omission on the part of a parent or caregiver and in a future revision might be added to the current list of options for I2. In the current list of options, infant deaths related to unsafe sleep conditions for which the circumstances do not meet the team's criteria for child neglect should be classified as "other negligence".

The "other" option should be reserved for acts other than the ones listed that are not committed by a parent or caregiver. For example, deaths of adolescents where high risk behaviors (e.g. ingesting drugs or alcohol, reckless driving) cause or contribute to the death should be classified as other.

# How about a case with an older child with severe asthma who dies after having an asthma attack because his inhalers were empty and there is a long history of the parents not keeping his meds on hand.

This scenario meets the definition in Section I of child neglect: "An act of omission on the part of a parent or caregiver that results in harm to a child."

This should be coded I1. Act of omission/commission = "Yes," I2. Act = "child neglect" and in I8. Child Neglect, mark "failure to seek/follow treatment.

# Defining broadly, if you are warned of the dangers of bumper pads and leave them in the crib, is it an act of omission or commission?

Section I does not ask you to identify if the act was one of omission or commission as sometimes the line between the two can be difficult to distinguish as evidenced in this question. In this case, we view this as an act of omission – the omission being that the parents failed to protect the child by removing the

hazard (bumper pads). As such, 11 should be checked "yes." And, depending on the circumstance of the infant's death, 12 would be coded either "child neglect" (if the child died of suffocation with face in the bumper pads or the team agreed that the circumstances of death met the criteria for child neglect), or "other negligence" (if bumper pads were not directly responsible for the child's death but reflect one or more hazards in the sleep environment).

## If a child is co-sleeping with parents under influence of drugs and/or alcohol, we consider that child neglect under acts of omission or commission. Is that appropriate? Yes.

## Where does failure to protect infant from known risk factors go?

These deaths are typically acts of omission and should be identified in Section I as such. Check section I a either "yes" or "probable" and I2 as "poor/absent supervision," "child neglect," or "other negligence," depending on the circumstances of the death and the definitions/description provided in the Guidance document.

## Is child abuse to be used only if the assailant is a bioparent?

No, child abuse is defined as an act on the part of a parent (biological, step, adoptive, etc) *or* caregiver, that results in harm to the child.

# Mental Illness or untreated mental illness is not technically an act but is it unreasonable to suggest that when considering omission/commission it should be captured in terms of suicide?

Suicide is an act of commission and Section I should be completed for every suicide death. Question I1 = "yes," and question I2 = Suicide, caused; Child Neglect contributed. Then in I8 mark "Failure to seek/follow treatment." The history of mental illness should also be documented in Section A. Child Information, question A20. Child had a disability or chronic illness. Mark Mental health/substance abuse, then specify the mental illness diagnosis.

## SECTION K. PREVENTABILITY

# Do we have to have documentation of education of parents about safe sleep to call that kind of death preventable?

No. A child's death is considered to be preventable if an individual or the community could reasonably have done something that would have changed the circumstances that led to the child's death. Safe sleep information is widely available in the US. If, however, a new parent did not or might not have access to this information, the community has a responsibility for trying to fill this gap. This is the primary purpose of child death review – to understand the circumstances of child deaths so that prevention strategies can be identified.

# If I child had received care (hospitalization for suicide attempt) and had been released with a warning from doctors that he was a high suicide risk, but dad did not remove lethal means from home (guns left unsecured) would you consider that to be preventable?

Yes, absolutely. In this circumstance both the parents and community have a responsibility to prevent this death. Why was the child released, when doctors knew he was a high suicide risk? Were community resources not available to keep him in the hospital? Given this high risk, why did father not secure weapons?

# What if a parent sought care for a child who was suicidal and had a hx of mental illness, but the child committed suicide? Would you consider this death preventable?

In this case, additional information will provide direction to the

team in classifying preventability. If the child was actually receiving care, then the team may reasonably decide the death was not preventable. However, if care was sought but not available for some reason related to community access (e.g., parents couldn't afford care, care not available in community), then the death would still be considered preventable. The responsibility for preventability extends beyond the parents to the community.

## **GENERAL CDR-CRS QUESTIONS:**

## Do you recommend completing the data during the actual reviews?

Depending on the protocol for each state/local review process, certain data might be obtained and entered prior to the multidisciplinary review.

# Is it the expectation that during a review that the team would use the data entry tool and follow through question by question hoping to discuss each one and not skip any?

No, this is not the expectation, nor is it recommended. Strictly going through the tool during a review meeting will likely inhibit discussion and discourse that is so critical for and effective review. We view the data entry form as a tool. It can be used to enhance and facilitate discussion as well as identify areas for improvement in information collection, when possible. It will be helpful if someone familiar with the CRS data tool attends the meeting. Once each team member has shared their information and the general discussion is winding down, questions that have not already been discussed should be raised and answers, if known can be documented.

## **MISSING VS. UNKNOWN**

# If the team doesn't discuss the question - the data would be "missing"? Only "unknown" would be used if team discussed but didn't have answer? This is correct.

The CRS was developed so that when you open a record to start data entry on a new death, all the fields are blank, that is they are set to "missing." As you enter the information from your review you change the response in that field from missing to whatever answer you choose.

The response option of Unknown should be used in situations when your team has discussed the question but the information necessary to answer it was not available to anyone. For example, question C15. At time of incident was supervisor impaired? The response options are: Yes, No, U/K. If the review team attempted to obtain this information, the attempt was discussed but nobody was able to obtain it, marking unknown is the correct response.

A missing response indicates that the question was skipped during data entry or not discussed/ mentioned during the review.

## DATA DICTIONARY

## What is the data dictionary, where is it located/how to access it.

The data dictionary is the document that provides instruction on how to answer each of the questions in the CDR-CRS. When you are logged in to the CRS, the data dictionary information for the question is immediately available if you click on the "?" next to the question. The entire data dictionary document is available online at: <u>https://www.childdeathreview.org</u>, Tools and Resources tab under "Tools for Teams" link.

## What is the "Data Quality Priority Variables Definition and Guidance" document? How is it different from the data dictionary?

This guidance document lists all the priority variables identified by the Data Quality Workgroup in 2016 and provides definitions and guidance for completing each variable. It is intended as a streamlined reference for specific guidance on completing the priority variables with the goal of increasing consistency within and across states when answering these questions in the CRS. It does not replace the data dictionary. For questions about completing all other questions in the CRS, you must refer to the CRS data dictionary.

The guidance for the priority variables will be available within the CRS, by clicking on the "?" next to the question, as well as in the updated data dictionary in 2017.

## DATA QUALITY INIATITIVE WEBINAR JUNE 2016

## How do I access the archived webinar? Are the slides available?

The webinar and slides are available at: <u>https://www.childdeathreview.org/</u> in the Tools and Resources tab, "Archived webinars/presentations" link.