



HCHS/SOL Question by Question Instructions, Informant Interview Form, (IIEA/IISA), Version A

I. Background

The purpose of the informant interview is to better define the factors associated with the onset of a fatal event, including the participant's location and activity at onset, circumstances related to the onset, symptoms, history of medical treatment, and use of various medical services. This form is required for out-of-hospital deaths for which the cause of death is suspected to be a HCHS/SOL endpoint of interest.

The interview with next of kin is potentially difficult because of the sensitive nature of a relative's death. Care should be taken to be aware of the sensitive nature of the interview and the informant's response to the questions. No interview should take place less than 30 days following the participant's death. On the other hand, very distant events may be difficult to recall. The need to provide time for grieving should be balanced with the idea that the sooner the interview takes place, the more details the informant is likely to accurately relate. If possible the informant interview should take place no sooner than 30 days since the death of the participant but within 6-9 months of death.

The person to whom the *Informant Interview* is administered will generally be identified in one of three ways:

1. The person is listed as the "next of kin" on the participant's death certificate.
2. The person had been designated by the participant as a "contact" or "proxy."
3. The person is indicated by a previous informant as someone who has additional information regarding the participant's death.

II. Interview Questionnaire

The questionnaire is divided into seven sections. Section A is concerned with circumstances surrounding the death such as important time intervals. Section B addresses specific aspects of the decedent's medical history. Section C is concerned with acute symptoms at the time of death. Section D covers specifics of emergency medical care that the decedent may have received. Sections E and G are concerned with identifying additional informants and closing the interview. The Section F, the last section, is your assessment of the reliability of the interview.

Almost all questions have multiple choices for answers; however, if necessary the interviewer can write any additional information or comments that may be important to understanding the response in the note logs. When reading questions to the informant, the interviewer should fill in the name of the decedent where appropriate.

For the purposes of this questionnaire, "death" is defined as the point at which the decedent stops breathing on his/her own and never recovers. Thus, the onset of death for someone who is resuscitated or ventilated is the point at which he/she last breathes spontaneously. He/she may recover several times after resuscitations, but the last cessation of breathing is considered "death". Death is not the time "pronounced dead". If someone is "found dead", timing of death

may be estimable if the time since last the decedent was last seen alive was short. However, if long, timing of death may be unknown.

If informant says at the start of the interview that he/she does not know anything about the death, gently attempt to have the informant to start the interview and try to complete. If the informant is obviously not comfortable or helpful, gracefully end the interview.

III. Question by Question Instructions

Establish contact with the informant by reading the following script:

“Hello, my name is (interviewer’s name) with the HCHS/SOL study. I’m calling (name of informant) regarding (name of decedent) involvement with the HCHS/SOL study, a medical study in which (name of decedent) was enrolled. “

Once the interviewer has established contact with an informant, the interview begins with the interviewer the following script:

I want to express our condolences for your loss. We understand that you have been identified as someone who can help us complete our documents for (decedent name). I need to ask you a few questions about the circumstances surrounding (name)’s death. Would now be a good time to talk?

If the informant responds this is not a good time, try to reschedule and record this information on the informant tracking form. If the informant indicates s/he does not want to participate in the interview, ask them if there is someone else who may be able to answer a few questions about the circumstances surrounding the (name)’s death. Record the information if provided and thank them prior to ending the call. Record this information on the informant tracking form.

Q1 Before we get started could you please tell me what was your relationship with the deceased?

This question asks for the relationship of the informants to the decedent. Make sure not to reverse this; for example, “She was my mother” should be answered “daughter/son”. “Other relative” includes aunt, uncle, cousin, in-law, and grandparent.

Section A. Circumstances Surrounding Death

The purpose of this section is to record information about the circumstances, symptoms, and timing surrounding the death. This section is very important to the classification of these out-of-hospital fatal events.

Introduce this section by saying the following:

“Now, I would like to ask you about the circumstances surrounding (insert decedent’s name) medical history.”

Q2 Please tell me about his/her general health, health on the day s/he died, and about the death itself.”

Ask the informant to provide details regarding the circumstances surrounding the participant’s death. Allow the informant to recount what happened in his/her own words. Transcribe this

narrative as close to work-for-word as possible, using short phrases, abbreviations, etc. where appropriate. If the informant does not offer this information on his/her own, probe neutrally for symptoms, order, and timing of relevant occurrences, medical care, etc. The description of the incidents preceding the death is extremely important for diagnostic and endpoint review purposes. Pay particular attention in recording the following information:

Circumstances

- General or usual health of decedent prior to final events, major chronic illnesses.
- Nursing home or other care? What changed if anything before death?
- Was the death witnessed? Or could have decedent been heard if s/he had cried out?
- Any emergency actions taken.

Symptoms

- Symptoms particularly whether or not there was pain
- Specifically ascertain whether or not there was pain and if so where.
- When describing the occurrences surrounding the death itself, be sure to differentiate between the onset of the last symptoms, the death, and the participant's being pronounced dead.
- Don't ask about risk factors (smoking, diabetes, hypertension)

Timing

- Timing around death. Timing should be clear, in terms of minutes/hours between events. Key is the timing from onset of symptoms or last seen alive until cessation of breathing.
- If the decedent was found dead, note as clear as possible the timing since last know alive and death.
- Make sure the description includes the timing of relevant occurrences and the symptoms experienced.
- Timing between incidents should be clear in minutes or hours.

After completing Q2, transition to the rest of the form by stating the following before going to Q3:

"Some of the remaining questions may repeat information already provided, but it helps us to ask these items specifically."

Q3 Where was (insert decedent's name) when s/he died? (Mark only one response.)

Indicate at what location the decedent died. If the response is "other", attempt to discern where and include location under "specify". Mark only one response.

Q4 Was anyone present when s/he died?

Indicate whether or not someone was present at the time of the participant's death. This question should be answered "yes" whether the person present was the informant or someone else. "Present" is defined as being within **sight** of the deceased at the time of death. For example, someone was lying next to the decedent in bed, sitting in a chair in the room, etc. "Not Present" would be the correct response if no one was in the decedent's room at the time of his/her death, or someone left the decedent alive and returned to find him or her deceased, etc.

If the informant indicates someone was present at the time of death, skip to Q7.

If not, continue with Q5.

Q5 Was anyone close enough to hear (insert decedent's name) if s/he had called out?

Indicate whether, though no one was physically present (i.e., in the same room) when the participant died, someone was close enough to have heard the participant if s/he had called out just before his/her death.

Q6 How long was it between the time (insert decedent's name) was last known to be alive and the time s/he was found dead?

Ask the informant how long it was between when the participant was last known to be alive and when s/he was found dead. Do not initially read the choices aloud to the informant. If the informant answers, mark the informant's response. If the informant hesitates, read the intervals in order, starting with the shortest. Record "Unknown" if the participant does not know or refuses to answer.

Skip to Q8.

Q7 Please tell me who was present. (Mark all that apply.)

If the informant indicated in Q4 that someone was present when participant died, ask the informant who was present, wait for response, and mark appropriate answer. If the informant hesitates, read the list and mark correct answer.

Q8 When was the last time you saw (insert decedent's name) prior to his/her death?

Ask the informant how much time passed between when s/he last saw the participant alive and the time of the participant's death. Do not initially read the choices aloud. If the informant answers, mark the informant's response. If the informant hesitates, read the intervals in order, starting with the shortest. Record "Unknown" if the informant does not know or refuses to answer.

Section B. Medical History

Transition into this section by saying the following:

"The next few questions concern (insert decedent's name) medical history."

Q9 Was s/he restricted to home, able to leave home only with assistance or great effort, or was his/her activity unrestricted?

Ask the question as written and record the appropriate response. This question refers to any history of restriction from the decedent's usual day-to-day activities and excludes the circumstances immediately surrounding the participant's death.

Q10 Was s/he hospitalized within the four weeks prior to death?

Ask the informant if the decedent was hospitalized for **any** reason within the four weeks prior to his/her death.

Q11 What was the reason for the hospitalization?

Ask the informant the reason for the hospitalization. Do not read the list. You may need to probe

to obtain pertinent details. Mark the most appropriate answer based on the informant's response. If "Other" is indicated, specify in informant's own words.

Q12 What was the date of the hospitalization?

Enter the date of the hospital admission. If decedent was hospitalized more than once in the four weeks preceding his/her death or stayed in more than one hospital, record the most recent on the form.

Q13 What was the name and location of the hospital?

Collect and record the name, city, state, country of the hospitalization identified in Q11.

Q14 Was (insert decedent's name) seen by a doctor any other time in the last four weeks prior to death?

Ask the informant if the participant was seen by a physician for any reason in the four weeks prior to his/her death.

Q15 What was the name and address of this doctor?

Collect and record the name and address of the physician the participant saw within four weeks of his/her death.

Section C. Symptoms

Transition to this section by saying the following:

"The next set of questions deals specifically with acute symptoms such as pain, discomfort that (insert decedent's name) may have experienced at the time of his/her death."

Q16 Did s/he experience pain, discomfort or tightness in the chest, left arm or jaw?

Ask the informant if the participant experienced pain, discomfort or tightness in the chest, left arm, or jaw. This includes symptoms that were part of or followed the final episode of acute symptoms. Record response. If the response is "No" or "Unknown", skip to Q22.

Q17 Did the pain, discomfort or tightness specifically involve the chest?

Ask the informant if the pain, discomfort or tightness specifically involved the chest. Record response.

Q17a Did (insert decedent's name) ever take nitroglycerin for this pain?

Ask the informant if the decedent ever took nitroglycerin for chest pain.

Recall that nitroglycerin is a heart medication (under the trade names Nitrospan, Nitrostat, and Tridil, amongst others). It is used as a medicine for chest pain (angina, and heart disease) in tablets, ointment, solution for intravenous use, transdermal patches, or sprays administered under the tongue. Other names include Trinipatch, Transderm Nitro, Nitro-Dur, Nitrolingual Pump Spray, Natispray.

Q18 Were these episodes new, or had they occurred previously?

Ask the informant if this episode of pain, discomfort or tightness was new or if the participant had previously experienced similar symptoms. If the informant responds “new symptoms”, go to Q22.

Q19 Were the episodes getting longer or more frequent?

Ask the informant if the episodes of pain, discomfort, or tightness had been getting longer or more frequent. Record response.

Q20 Were the episodes getting more severe?

Ask the informant if the episodes of pain, discomfort, or tightness had been getting more severe. Record response.

Note if the responses for Q19 and Q20 are “No or Unknown”, go to Q22 (skipping Q21).

Q21 Over what period of time did these episodes become longer, more frequent, or more severe?

Ask the informant over what period of time these episodes became longer, more frequent, or more severe. Do not initially read the responses aloud to the informant. Record the informant’s response. If the informant hesitates, read the intervals in order starting with the shortest. Record “Unknown” if the informant does not know or refuses to answer.

Q22 Did s/he experience shortness of breath?

Ask the informant if the participant experienced shortness of breath in the weeks or months leading up to his/her death. Record the informant’s response.

Q22a Did s/he have shortness of breath while at rest?

Ask the informant if the participant experienced shortness of breath while at rest in the weeks or months leading up to his/her death. Record the informant’s response.

Before asking Q23, gently prepare the informant for this sensitive nature of the question by saying:

“I apologize if this next question sounds hard or if it makes you uncomfortable. Please be assured we respect your feelings about this unfortunate event.”

Q23 How long was it from (insert decedent’s name) last episode of symptoms to the time that s/he stopped breathing on his/her own?

Ask the informant to indicate the interval of time between the participant’s last episode of pain, discomfort, or tightness and his/her death. Mark the shortest interval known to be reliable. Do not initially read the choices aloud to the informant. If the informant hesitates, read the intervals in order starting with the shortest. Record “Unknown” if the informant does not know or refuses to answer.

Section D. Emergency Medical Care

Transition into this next section of the questionnaire by saying the following:

“The next few questions are concerned with emergency medical care (insert decedent’s name) may have received prior to or at the time of death. You may have already given this information in an answer to an earlier question. Since it is important to obtain information specifically on emergency medical care, I hope you don’t mind if these questions seem repetitive.”

Q24 Was a physician, ambulance or other emergency medical team called?

This question refers to anyone calling a physician, ambulance or other emergency medical team. If the informant responds that someone called the fire department, record YES.

Q24a How long was it from the time the last episode of symptoms started to the time that medical assistance was called for?

Read the question, wait for response and mark the shortest interval known to be true. If informant hesitates, read the list. Timing is from the onset of the last episode. The following example would be coded as 24 hours or less: “decedent began having chest pain and nausea the night before, but ambulance was not called until the next morning.”

Q24b How long was it from the time medical care was called to the time when it arrived?

Ask the informant to estimate this time interval. Wait for a response and mark the shortest interval known to be true. If the informant hesitates, read the list.

Q25 Were resuscitation measures, such as CPR attempted?

The informant may not be familiar with CPR or the procedure of closed chest massage. If this is the case, tell the informant that CPR is a procedure used to resuscitate (restore breathing or revive) persons who are experiencing heart attacks and have no pulse or breath. It usually involves mouth-to-mouth resuscitation with compression of the chest to circulate the blood.

Q26 Was (insert decedent’s name) taken to the hospital, emergency room or any other emergency care facility?

Ask the informant if the decedent was taken to the hospital, to the emergency room, or to another emergency care facility because of his/her condition. This includes visits to a hospital emergency room whether or not it resulted in a hospitalization. This excludes instances when the participant went to a clinic or physician’s office or was already hospitalized when the event occurred.

Section E. Additional Informants

Q27 Is there anyone else we could contact who might be able to provide additional information about the circumstances surrounding (insert decedent’s name) death or his/her usual state of health?

This question asks if there is any person who may be able to provide additional information about the events leading up to the death or the death itself. For example, a spouse may know

most about the three days prior to death, while a co-worker may have actually witnessed the death.

Q28 How is s/he related to the deceased?

This question asks for the relationship of the person indicated in Q26 to the decedent. "Other relative" includes aunt, uncle, cousin, in-law, grandchild, etc. "Other" includes any relationship not listed.

Q29 What is the name and address of this person?

Collect and record this information.

Section F. Closing

Close the interview by thanking the informant for his/her time and reiterating how much the quality of our research depends on the cooperation of people like him/her. Ask the informant if s/he has additional questions. End the interview by saying the following:

"Thank you very much for your assistance in this study. Do you have any questions? Thanks again for your help."

Section G. Reliability

This section is to be completed immediately after the interview is closed.

Q30 On the basis of these questions, give your rating of reliability of the interview.

- Select **Good** when it is your opinion that the interview provided accurate and complete information to be used in evaluating the death, history, and symptoms.
- Select **Fair** when it is your opinion that the interview provided reasonably accurate and reasonably complete information to be used in evaluating the death, history, and symptoms.
- Select **Poor** when it is your opinion that the interview did not provide accurate or complete information to be used in evaluating the death, history, and symptoms.