

Informant Interview Form Instructions (IFI)

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I. GENERAL INSTRUCTIONS

The purpose of the informant interview is to obtain information about possible CHD events in order to classify cause of death. The interview with next-of-kin (or the cohort's proxy if the next-of-kin is not available or not useful in obtaining cohort death information) is potentially difficult because of the sensitive nature of a relative's death. Even if the informant initially claims no knowledge, begin the form to see if the questions can be answered.

The interviewer should enter the information required on the first page before the contact is made with the informant, though some of the informant data may need to be filled after contact, such as relationship to the decedent. In some cases the informant may change after calling, as in the case where a spouse is to be contacted but the actual informant is a son or daughter. A record of interviewer should put the data and time of each call, any explanatory notes, a result code for each call, and the interviewer's assigned code number. Eight attempts to contact an informant should be made over a two-week period. If no contact is made, repeat in a month.

The questionnaire is divided into six sections. Section A is concerned with the decedent's medical history, including previous hospitalizations. Section B addresses the events immediately surrounding the fatal event, and Section C is concerned with the symptoms the deceased experienced prior to the event. Section D addresses emergency medical care that may have been provided at the time of death, and Section E asks for information on other potential informants. Section F asks the interviewer about the reliability of the information obtained during 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 margins next to the interviewer to write out descriptions of the death or the decedent's state of health as related by the informant. For these questions, the interviewer should write word-for-word (in Short phrases, abbreviating) the response of the informant. For questions asking the informant to specify names, if more than one answer is given, write all responses.

When reading questions to the informant, the interviewer should fill in the blanks with the name of the decedent. For example, "I'd like to start by asking about _____'s medical history" should be read "I'd like to start by asking about Mr. Smith's medical history."

The interviewer needs to know thoroughly the ARIC definition of death to complete the interview accurately. "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 seen alive was short. However, if long, timing of death may be unknown.

The interviewer should be familiar with skip patterns and nature of each question. Several questions are similar, with only subtle differences. The interviewer must make the distinction clear to the informant. Such questions may sound repetitive and are easier if clarified.

If informant contradicts a previous answer, probe to clarify and correct if obviously wrong.

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

Ask for next-of-kin record during the interview if appropriate but get written permission only if needed. Written release need not be witnessed. Attached is an example of a release form for written permission.

Finally, the interviewer is responsible for reviewing and editing the Informant Interview Form thoroughly following the interview. Review every question and the skip patterns carefully. Every question must be answered unless skip patterns indicate otherwise. The description of the events preceding the death (Q2) is extremely important for diagnostic purposes. Make sure that the description includes the timing of events and the symptoms experienced.

II. DETAILED INSTRUCTIONS FOR VARIOUS QUESTIONS

0. Result Code: When the IFIC has been successfully administered, or the supervisor determines that all contact efforts have been exhausted, the final screening result code is circled in the RESULTS CODE BOX on the "Record of Calls" form, and entered in this field.

A. HISTORY

1. 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.
2. This question refers to any restriction from the decedent's usual day-to-day activities. It excludes the events at death.
3. "Being cared for" refers to attendant medical care because of disability or sickness.
4. Fill in as much information as is known by informant. If the informant asks why this is needed, explain that it may be important to get additional information from the nursing home, with permission, to understand the cause of death.
5. Any hospitalization for any reason is "yes".
6. Read the list and mark appropriate answer(s). If "other" is marked, specify in informant's own words.
7. Date of hospital admission. Record date of hospitalization. If decedent was hospitalized more than once or stayed in more than one hospital, record the most recent on the form, then list all dates, names, cities and states of other hospitalizations on a separate piece of paper. If exact days are unknown, fill in month and year. Missing values are indicated by "=" (equal sign) in appropriate

field. (Note: an HRA form will need to be completed for each hospitalization for “heart attack” or “heart surgery” within 28 days of death, regardless of day of discharge. If a cohort case, obtain an

HRA for each hospitalization. If not a cohort member, obtain an HRA for each hospitalization, if from a catchment area hospital, regardless of day of discharge. Each hospitalized event for “heart attack” or “heart surgery” occurring within 28 days of death and the death event should have different ID numbers.

8. Record the name, city and state of the hospitalization recorded in Question Seven.
9. Refers to any encounter with a physician for any reason in the month preceding death including final symptoms.
10. This should be the most recent. If more than one physician seen, provide names and addresses of most knowledgeable two.
11. Record name and address of decedent’s “usual” physician. If same as most recently seen (Q10), record “same”.
12. This question refers to chest pain from heart disease at any time before death. Angina or angina pectoris or a heart attack would be considered “yes” responses. Pain in the left arm or shoulder, jaw, or upper abdomen is considered equivalent to chest pain.
13. Refer to list of names for nitroglycerin if informant hesitates. Nitroglycerin is usually administered as a small tablet placed under the tongue but may be taken as a pill, an ointment, or as “skin patch”.
14. Be aware that this refers to past history and does not include the fatal event under consideration (emphasize ever) and clarify to the interviewee, if required.
15. Synonyms for heart attack are “myocardial infarction”, “MI”, coronary occlusion.
16. Coronary bypass involves surgery bypassing the blocked coronary arteries with vessels removed from the arm or leg. “Balloon dilation” or “PTCA” are other terms for angioplasty. A cardiac catheterization, coronary angiography, or angiogram for diagnostic purposes without angioplasty should be answered “no”.
17. If yes, specify the condition in the informant’s own words. Hypertension does not qualify here as a heart disease or condition. Conditions recorded in this section should not be conditions directly related to or resulting from past MI recorded in Q14. Probes may be needed.
18. A stroke is a brain hemorrhage or ischemia (blockage of blood flow) also known as cerebrovascular attack, cerebral hemorrhage, or blood clot on brain.
19. This includes the final, fatal event under consideration.
- 19 a. History of Cigarette Smoking. A positive history would be 100 cigarettes or more in a lifetime. Do not consider cigar or pipe smoking.
19. b. History of Diabetes. Either a physician or medical person telling them they had diabetes or high blood sugar.

B. CIRCUMSTANCES SURROUNDING DEATH

20. Narrative: Write out as close to word-for-word as possible, using short phrases. Probe neutrally for symptoms, order and timing of events, medical care, etc. Record these important items verbatim; try to limit the narrative to the space provided. When describing the events surrounding the death itself, be sure to differentiate between the onset of the last symptoms, the death (recalling definition of death), and being “pronounced dead”.
21. “Present” is defined as being within sight or sound of the deceased at the time of death; for example, Present: lying next to in bed, in next room and could be heard, left decedent alone momentarily. Not Present: in another room out of sight and sound, outside out of sight and sound, left decedent alive and returned after 5 minutes, talked to on phone sometime right before.
22. These questions ask whether anyone was present at the time of the decedent’s death (defined
23. above). If the decedent died in his/her sleep with someone nearby; Question 22 should be answered “Yes”.
24. Mark the shortest interval known to be reliable. If the informant hesitates, read the intervals in order starting with the shortest.
25. This question refers to the place where the decedent died, as defined in the general instructions. Read the question, wait for a response, and mark appropriate answer. If the informant needs prompting, read the list. If the informant says “in the hospital” ask if he/she died in the emergency room. If yes, mark appropriate response.

C. SYMPTOMS

26. We are primarily interested in acute symptoms, not chronic. Thus, if a person had been generally fatigued for a month and then had chest pain one hour before death, it is the chest pain that was the last episode. Similarly, if someone had a long history of angina but, not having acute pain, suddenly collapsed and stopped breathing, the onset of the final episode was the time of collapse. If the death occurred while sleeping or while someone was within hearing range of the decedent, the interval between onset and death is considered to be instantaneous. If the decedent was found dead (no one close enough to see or hear him/her), the onset may be unknown.

Onset of last episode is defined as being at that point in time when new symptoms cause a change in activity. If the symptom is chronic (e.g., longstanding exertional chest pain), there must be a change in severity or frequency. Symptoms might be stepwise (e.g., one chest pain, then a more severe one an hour later). In this case it is the first pain, if it was new and caused a change, that is the onset of the final episode. The final episode for someone who collapses again began at the first collapse. Interviewers will have to probe and define onset specifically for each informant.

The difference between Q12 and 26 is the time period referred to. In Q26, the time is specific: within 3 days of death. In 12, the decedent could have experienced pain at any time prior to death. If Q26 is answered “no” skip to Q30, as Q27-29 refer to an episode of pain with 3 days of death.

The location of the pain or discomfort referred to in Q12 and 26 is specific. If the pain was experienced at sites other than the chest, (left arm or shoulder or jaw), the answer should be “no” If the informant is unsure, but is leaning toward a “yes”, then proceed as with a “yes”.

If decedent was found dead, Q26 must be answered either “yes” or “unknown”. If the decedent was found dead, most of the answers will be “unknown”. In this case, skip quickly through, verifying that the answers are unknown.

27. The option “yes” is checked if the pain occurred anywhere in chest within 3 days of death.
28. A list of names of “nitroglycerin” preparations is provided in the medication list and should be consulted if informant isn’t sure or offers a brand name.
29. This is a crucial question for timing of death. Use the definition provided above for death and onset of the final episode in order to clarify timing. Read the question, wait for response, and mark the shortest interval known to be true. If the informant hesitates read the list and mark the appropriate response. The informant may have given a time interval when answering Q26. If so, the interviewer may want to preface the question stating the time interval and asking for confirmation (e.g. “You mentioned that ____ had chest pains two days before he died. Is that when the chest pain began?”).
30. This question asks about any symptoms other than pain or discomfort in the chest. The timing of onset of these “other” symptoms is crucial. After each “yes” answer, probe to make sure the onset was within 3 days, and that the condition was not longstanding or “usual”. Read the list slowly and fill in the appropriate answers.

D. EMERGENCY MEDICAL CARE

Read the introductory statement. If an ambulance service (or other emergency medical service such as a fire department) was mentioned earlier, the interviewer may want to preface questions with a statement acknowledging that such information was given.

31. This question refers to calling for help. If no one was called, skip to Q35.
32. This question is to determine whether help was called for symptoms, or after informant knew decedent was already dead.
33. Read 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 E (24 hours or less): “decedent began having chest pain and nausea the night before, but ambulance was not called until the next morning.”
34. Read the question, wait for response and mark appropriate answer. If the informant hesitates read the list and mark the shortest time known to be true. Be sure informant understands difference between Q33 and Q34.
35. 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.
36. Read the questions, wait for response, and mark appropriate answer. If informant hesitates,
37. read the list and mark correct answer.

38. Any mode of transportation (ambulance, private care) sufficient for a “Yes” answer.

39. Fill in as much of the answer as is known.

E. ADDITIONAL INFORMATION

40. This question asks if there is any person who may be able to provide additional information about the event 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 actually witnessed the death. (Note: If the answer is “yes”, an interview will need to be carried out with this individual.)

41-42 Fill in as much information as is known.

Close the interview by thanking the informant and repeating how much the quality of our research depends on the cooperation of people like themselves. After closing the interview, fill in Section F (Reliability) and Section G (Administrative Information).

F. RELIABILITY

43-46. Complete this section immediately after completing the interview. Remember to fill in your code number.

47. The final script may ask the informants to provide consent in order that other sources of information may be contacted. Indicate the informant’s response. For those who are not a next-of-kin enter the code for “Not applicable”.

G. ADMINISTRATIVE INFORMATION

48. Date of Data Collection: Record the date the informant interview was completed.

49. Method of Data Collection: Record whether the interview was completed by recording informant responses first on the paper form, or directly into the computer.

50. Code number of the person completing this form. Record the unique ID number of the person (ARIC staff) completing this form.

Appendix A

What Reviewers Want to See in IFI Narratives

1. General/usual health of decedent prior to final events, major chronic illnesses, including whether or not there was a history of MI or coronary disease.
 - Don't ask about risk factors (smoking, diabetes, hypertension).
 - Nursing home or other care? What changed, if anything, before death?
2. Circumstances and timing around death.
 - Timing should be clear, in terms of minutes/hours between steps. Key is the timing from onset of symptoms or last seen alive until cessation of breathing.
3. Symptoms, particularly whether or not there was pain, and signs
4. Was the death witnessed? Or could have decedent been heard if s/he had cried out?
5. For found dead, make sure timing since last known alive and death is as clear as possible.
6. Any emergency actions taken.