

IFIC Instructions (QxQs)

This table summarizes changes to the IFI QxQ as of 06/04/2024

Question in IFI QxQ	Description of Changes in IFI QXQ
Q7, pg. 4	<ul style="list-style-type: none"><li data-bbox="678 468 946 499">• Add clarifications

Informant Interview Form Instructions (IFI)
IFI, Version C, 05/05/2014
QxQ, 06/04/2024

I. GENERAL INSTRUCTIONS

The purpose of the informant interview is to obtain information about possible CHD events to classify cause of death. The interviewer can use the following person(s) to complete an informant interview: Follow-Up Proxy, Contact Person 1, Contact Person 2 or Contact Person 3 as listed on the CIU (Contact Information Update Form). Another potential contact is the Informant listed on the Death Certificate. The interview is potentially difficult because of the sensitive nature of the decedent's death. Even if the informant initially claims no knowledge, begin the form to see if the questions can be answered.

While the interviewer is conducting the interview, the responses can be recorded on paper and then entered into CDART, or the data can be entered into CDART in real time. Either way is acceptable as long as all data get entered into CDART.

Out of respect, wait around two months after the death before conducting the informant interview. If there is a known time that the informant would like to be contacted, attempt to make contact during those requested times. Generally, try 3-4 times by phone, leaving detailed messages on how to follow up. Pursuance of phone calls is determined by the interviewer and any detailed information they may have about the informant. This can be assessed on a case-by-case basis. In short, there is no mandatory number of phone call attempts to complete the interview. As long as the interviewer makes a meaningful effort to contact the informant; the interviewer will determine when to cease contact. If unsuccessful in reaching the informant(s), medical records can be used to complete the IFI.

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 enter in the appropriate note log any additional information or comments that may be important to understanding the informant's response. For these questions, the interviewer should enter the responses of the informant. For questions asking the informant to specify names, if more than one answer is given, enter 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 estimated if the time since last seen alive was short. However, if time since last seen alive was long, timing of death may be unknown.

The interviewer should be familiar with skip patterns and nature of each question. This is easiest by entering the form in CDART in real time. 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.

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 and answer all questions the best you can. The description of the events preceding the death (Q20) 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 interviewer determines that all contact efforts have been exhausted, the final screening result code is entered in the Result Code box in CDART.

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 the date of hospitalization. If the decedent was hospitalized more than once or stayed in more than one hospital, record the most recent date on the form, and then list all dates and hospital details in the note log. The purpose of questions 7 and 8 is to ensure every CHD related hospitalization will be abstracted. These questions are a prompt for the IFI interviewers so that further investigation is done and the records for that reported hospitalization have been requested per ARIC protocol. Once the records are received, abstract the record per site and ARIC procedures.
8. Record the name, city and state of the hospitalization recorded in (Q7).
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 for the informant, if required.
15. Synonyms for heart attack are "myocardial infarction", "MI", coronary occlusion.
16. Coronary artery bypass grafting (CABG) involves surgery bypassing the blocked coronary arteries with vessels removed from the arm or leg. Informants may refer to this as a bypass, double bypass, triple bypass or quadruple bypass. Balloon dilation, balloon angioplasty or PTCA are other terms for angioplasty. Bare metal stents are simple metal mesh tubes that can be used in the coronary arteries. Drug-eluting stents are the most common type of stents used in the coronary arteries. Informants may refer to this as stents and may not know the type. Atherectomy is a procedure to remove plaque buildup in arteries. Percutaneous Coronary Intervention (PCI) is a general term used to describe a procedure that restores blood to the heart. 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 such as whether the informant is speaking of heart valve issues, heart rhythm issues, heart failure, etc.

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. a. This includes the final, fatal event under consideration.
- b. History of Cigarette Smoking. A positive history would be 100 cigarettes or more in a lifetime. Do not consider cigar or pipe smoking.
- c. 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. Probe neutrally for symptoms, order and timing of events, medical care, etc. Record these important items verbatim. When describing the events surrounding the death itself, be sure to differentiate between the onset of the last symptoms, the death (recalling ARIC 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./23. These questions ask whether anyone was present at the time of the decedent’s death (defined 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 Q12, 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 Q26 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./37. Read the questions, wait for response, and mark appropriate answer. If informant hesitates, read the list and mark correct answer.
38. Any mode of transportation (ambulance, private car) 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 someone else actually witnessed the death. (Note: If the answer is “yes”, an interview will need to be carried out with this individual if listed as a contact, proxy or informant of the decedent.)
- 41./42. Fill in as much information as is known.

Close the interview by thanking the informant for taking the time to provide the sensitive information and state that our research depends on it. Also express gratitude for the many years of participation and dedication to the ARIC study that the participant has given. Express condolences for their loss.

F. RELIABILITY

- 43.-46. Complete this section immediately after completing the interview.
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 proxy, select 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 ID number of the 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 (heart attack) 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 chest pain, left arm pain, jaw pain as outlined in Question 26.
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.