



## INSTRUCTIONS FOR INFORMANT INTERVIEW - ENDPOINTS IFI, VERSION 2.0, QUESTION BY QUESTION INSTRUCTIONS (QxQ)

### I. GENERAL INSTRUCTIONS

The Informant Interview Form is to be completed for each informant for an eligible death as determined by the SPIROMICS endpoints investigation protocol.

Enter all available information in items 1 – 8 (item 5 will auto populate with date of birth) prior to initiating contact with the informant. If any information for items 1 – 6 is not available from other sources prior to the call (i.e. date of death, place of death, etc.), the informant should be asked if they have that information during the call.

If phone contact with the informant is not possible, this form may be mailed to the informant for completion. In that case, prior to mailing, items 1 - 8 should be completed with information previously known from other sources, but the informant should be instructed to complete any of those with missing data. Then the informant should be instructed to complete items 10-27f. Upon entering the data from the mailed-in form, item 9 should be answered “Yes – Mailed in form”.

**Header Information:** The header information consists of key fields which uniquely identify each recorded instance of a form.

0a. Date of Collection: Record the date the data was collected. Select the date from the pop-up calendar in the data management system (DMS) or type the date in the space provided. Dates should be entered in the mm/dd/yyyy format. In the event that the form has been mailed-in by the informant, the date of collection should be the date the data is entered.

0b. Staff Code: Record the SPIROMICS staff code of the person who collected the data. This code is assigned to each person at each site by the GIC. If you do not have a staff code and are collecting SPIROMICS data, please contact the GIC in order to receive your own individual staff code.

### II. DETAILED INSTRUCTIONS FOR EACH ITEM

Please answer every question on this form.

- Item 1. **Decedent's name:** Enter the decedent's name.
- Item 2. **Informant name:** Enter the informant name.
- Item 3. **Date of death:** Enter the date of death.
- Item 4. **Age at death:** Enter the decedent's age at death.
- Item 5. **Date of birth:** Enter the decedent's date of birth (this field will auto-populate).
- Item 6. **Place of death:** Enter the decedent's place of death.
- Item 7. **Informant interview attempted for:** Select only one option among the three possible choices.
  - Select 'Primary Informant' if this attempt is for the Primary Informant.
  - Select 'Secondary Informant' if this attempt is for the Secondary Informant.
  - Select 'Additional Informant' if this attempt is for an Additional Informant.

- Item 8. **Attempts made with no answer:** Select only one option among the five possible choices.
- Select 'First attempt' if this is the first attempt made to contact informant when there was no answer.
  - Select 'Second attempt' if this is the second attempt made to contact informant when there was no answer.
  - Select 'Third attempt' if this is the third attempt made to contact informant when there was no answer.
  - Select 'Fourth attempt' if this is the fourth attempt made to contact informant when there was no answer.
  - Select 'Fifth attempt' if this is the fifth attempt made to contact informant when there was no answer.

Read the first portion of the script provided on the form. Once it is established that you are speaking with the informant, continue with the rest of the script. If the informant is not available, determine a time to call back. If you determine that the person you are speaking with is knowledgeable of the circumstances surrounding the decedent's death, continue the interview with this person. **See the procedure manual for more details.**

- Item 9. **Is now a good time to talk:** Select only one option among the four possible choices.
- Select No if the informant reports that it is not a good time to talk.
  - Select 'No – Do not contact again' if informant says no and wants no further contact. [Go to END]
  - Select 'Yes – Thank you' and answer any questions informant has if informant agrees to continue. [Go to Q10]
  - Select 'Yes – Mailed in form' if the informant mailed in a completed form. [Go to 10]

- Item 10. **Relationship with decedent:** Select only one option among the six possible choices.
- Select Spouse if the informant is the decedent's spouse.
  - Select Daughter/Son if the informant is the decedent's daughter or son.
  - Select Parent if the informant is the decedent's parent.
  - Select Friend if the informant is the decedent's friend.
  - Select Workmate if the informant is the decedent's workmate.
  - Select Other if the informant is other than those listed above.

Item 10a. **Other relationship with decedent:** Specify the other relationship with the decedent.

## **A. CIRCUMSTANCES SURROUNDING DEATH**

Read the script preceding Q11.

- Item 11. **Synopsis of events surrounding death:** Record a brief synopsis of the events surrounding the death as relayed by the informant regarding the decedent's general health, the decedent's health on the day of death, and about the death itself.

Read the script preceding Q12.

- Item 12. **Who was present at death:** Select the appropriate options in Q12a-Q12c to record who was present at this death.

- Item 12a. **Self:** Select only one option among the two possible choices.
- Select No if the informant was not present at this death.

- Select Yes if the informant was present at this death.

Item 12b. **Health care person(s):** Select only one option among the two possible choices.

- Select No if no health care person or persons were present at this death.
- Select Yes if a health care person or persons were present at this death.

Item 12c. **Other person(s):** Select only one option among the two possible choices.

- Select No if no other person or persons were present at this death.
- Select Yes if another person or persons were present at this death.

## B. MEDICAL HISTORY

Read the script preceding Q13.

Item 13. **Hospitalized within the four weeks prior to death:** Select only one option among the three possible choices.

- Select No if the decedent was not hospitalized within four weeks prior to death. [Go to Q17]
- Select Yes if the decedent was hospitalized within four weeks prior to death.
- Select Unknown if it is unknown whether the decedent was hospitalized within four weeks prior to death. [Go to Q17]

Item 14. **Reason for hospitalization:** Select the appropriate options in Q14a-Q14e to record reasons for the hospitalization. If there were multiple hospitalizations in the four weeks (28 days) prior to death, answer for the hospitalization closest to the date of death.

Item 14a. **Unknown:** Select only one option among the two possible choices.

- Select Yes if the reason for the hospitalization is unknown. [Go to Q15]
- Select No if the reason for the hospitalization is known.

Item 14b. **Respiratory:** Select only one option among the two possible choices.

- Select Yes if the reason for the hospitalization was respiratory.
- Select No if the reason for the hospitalization was not respiratory. [Go to Q14c]

Item 14b1. **Emphysema, chronic bronchitis, or chronic obstructive pulmonary disease (COPD):** Select only one option among the two possible choices.

- Select Yes if the reason for the hospitalization was emphysema, chronic bronchitis, or chronic obstructive pulmonary disease (COPD).
- Select No if the reason for the hospitalization was not emphysema, chronic bronchitis, or chronic obstructive pulmonary disease (COPD).

Item 14b2. **Pneumonia:** Select only one option among the two possible choices.

- Select Yes if the reason for the hospitalization was pneumonia.
- Select No if the reason for the hospitalization was not pneumonia.

Item 14b3. **Other respiratory problem:** Select only one option among the two possible choices.

- Select Yes if the reason for the hospitalization was a respiratory problem not listed.
- Select No if the reason for the hospitalization was not another respiratory problem not listed. [Go to Q14c]

Item 14b3a. **Specify other respiratory problem:** Specify the other respiratory problem.

- Item 14c. **Cardiac:** Select only one option among the two possible choices.
- Select Yes if the reason for the hospitalization was cardiac.
  - Select No if the reason for the hospitalization was not cardiac. [Go to Q14d]
- Item 14c1. **Heart attack:** Select only one option among the two possible choices.
- Select Yes if the reason for the hospitalization was heart attack.
  - Select No if the reason for the hospitalization was not heart attack.
- Item 14c2. **Heart failure:** Select only one option among the two possible choices.
- Select Yes if the reason for the hospitalization was heart failure.
  - Select No if the reason for the hospitalization was not heart failure.
- Item 14c3. **Other cardiac problem:** Select only one option among the two possible choices.
- Select Yes if the reason for the hospitalization was a cardiac problem not listed.
  - Select No if the reason for the hospitalization was not another cardiac problem not listed. [Go to Q14d]
- Item 14c3a. **Specify other cardiac problem:** Specify the other cardiac problem.
- Item 14d. **Cancer:** Select only one option among the two possible choices.
- Select Yes if the reason for the hospitalization was cancer.
  - Select No if the reason for the hospitalization was not cancer. [Go to Q14e]
- Item 14d1. **Lung cancer:** Select only one option among the two possible choices.
- Select Yes if the reason for the hospitalization was lung cancer.
  - Select No if the reason for the hospitalization was not lung cancer.
- Item 14d2. **Other cancer:** Select only one option among the two possible choices.
- Select Yes if the reason for the hospitalization was a cancer other than lung cancer.
  - Select No if the reason for the hospitalization was not a cancer other than lung cancer. [Go to Q14e]
- Item 14d2a. **Specify other cancer:** Specify the other cancer.
- Item 14e. **Other condition:** Select only one option among the two possible choices.
- Select Yes if the reason for the hospitalization was another condition not listed.
  - Select No if the reason for the hospitalization was not another condition not listed. [Go to Q15]
- Item 14e1. **Specify other condition:** Specify the other condition that was the reason for this hospitalization.
- Item 15. **Date of hospitalization:** Record the date of the hospitalization. If there were multiple hospitalizations in the four weeks (28 days) prior to death, enter the date of the hospitalization closest to the date of death.
- Item 16. **Name and location of hospital:** Record the name and location of the hospital in Q16a-Q16e.
- Item 16a. **Name of hospital:** Record the name the hospital.

- Item 16b. **Street address of hospital:** Record the street address of the hospital.
- Item 16c. **City of hospital:** Record the city of the hospital.
- Item 16d. **State of hospital:** Record the state of the hospital.
- Item 16e. **Zip code of hospital:** Record the zip code of the hospital.
- Item 17. **Seen by doctor at any other time in the last four weeks prior to death:** Select only one option among the three possible choices.
- Select No if the decedent was not seen by a doctor at any other time in the last four weeks prior to death. [Go to Q19]
  - Select if the decedent was seen by a doctor at another time in the last four weeks prior to death.
  - Select Unknown if it is unknown if the decedent was seen by a doctor at any other time in the last four weeks prior to death. [Go to Q19]
- Item 18. **Name and address of doctor:** Record the name and address of this doctor in Q19-18f.
- Item 18a. **Name of doctor:** Record the name of this doctor.
- Item 18b. **Street address of doctor:** Record the street address of this doctor.
- Item 18c. **City of doctor:** Record the city of this doctor.
- Item 18d. **State of doctor:** Record the state of this doctor.
- Item 18e. **Zip code of doctor:** Record the zip code of this doctor.
- Item 18f. **Phone number of doctor:** Record the phone number of this doctor.

### C. SYMPTOMS

Read the script preceding Q19.

- Item 19. **Shortness of breath:** Select only one option among the three possible choices.
- Select No if the decedent did not experience an increase in shortness of breath just prior to death.
  - Select Yes if the decedent did experience an increase in shortness of breath just prior to death.
  - Select Unknown if it is unknown if the decedent experienced an increase in shortness of breath just prior to death.
- Item 20. **Increased coughing:** Select only one option among the three possible choices.
- Select No if the decedent did not experience increased coughing just prior to death.
  - Select Yes if the decedent did experience increased coughing just prior to death.
  - Select Unknown if it is unknown if the decedent experienced increased coughing just prior to death.
- Item 21. **Increased mucus or sputum production:** Select only one option among the three possible choices.

- Select No if the decedent did not experience increased mucus or sputum production just prior to death.
- Select Yes if the decedent did experience increased mucus or sputum production just prior to death.
- Select Unknown if it is unknown if the decedent experienced increased coughing just prior to death.

#### D. EMERGENCY MEDICAL CARE

Read the script preceding Q22.

- Item 22. **Physician, ambulance, or other emergency medical team called:** Select only one option among the three possible choices.
- Select No if a physician, ambulance, or other emergency medical team was not called prior to or at the time of death.
  - Select Yes if a physician, ambulance, or other emergency medical team was called prior to or at the time of death.
  - Select Unknown if it is unknown if a physician, ambulance, or other emergency medical team was called prior to or at the time of death.
- Item 23. **Hospital, emergency room, or other emergency care facility:** Select only one option among the three possible choices.
- Select No if the decedent was not taken to the hospital, emergency room, or any other emergency care facility prior to or at the time of death.
  - Select Yes if the decedent was taken to the hospital, emergency room, or any other emergency care facility prior to or at the time of death.
  - Select Unknown if it is unknown if the decedent was taken to the hospital, emergency room, or any other emergency care facility prior to or at the time of death.

#### E. CAUSE OF DEATH

- Item 24. **Reason for death:** Select the appropriate options in Q24a-Q24e to record the reason for the death to the best of the informant's knowledge.
- Item 24a. **Unknown:** Select only one option among the two possible choices.
- Select Yes if, to the best of the informant's knowledge, the reason for the death is unknown. [Go to Q25]
  - Select No if, to the best of the informant's knowledge, the reason for the death is known.
- Item 24b. **Respiratory:** Select only one option among the two possible choices.
- Select Yes if, to the best of the informant's knowledge, the reason for the death was respiratory.
  - Select No if, to the best of the informant's knowledge, the reason for the death was not respiratory. [Go to Q24c]
- Item 24b1. **Emphysema, chronic bronchitis, or chronic obstructive pulmonary disease (COPD):** Select only one option among the two possible choices.
- Select Yes if, to the best of the informant's knowledge, the reason for the death was emphysema, chronic bronchitis, or chronic obstructive pulmonary disease (COPD).

- Select No if, to the best of the informant's knowledge, the reason for the death was not emphysema, chronic bronchitis, or chronic obstructive pulmonary disease (COPD).

Item 24b2. **Pneumonia:** Select only one option among the two possible choices.

- Select Yes if, to the best of the informant's knowledge, the reason for the death was pneumonia.
- Select No if, to the best of the informant's knowledge, the reason for the death was not pneumonia.

Item 24b3. **Other respiratory problem:** Select only one option among the two possible choices.

- Select Yes if, to the best of the informant's knowledge, the reason for the death was a respiratory problem not listed.
- Select No if, to the best of the informant's knowledge, the reason for the death was not another respiratory problem not listed. [Go to Q24c]

Item 24b3a. **Specify other respiratory cause:** Specify the other respiratory cause.

Item 24c. **Cardiac:** Select only one option among the two possible choices.

- Select Yes if, to the best of the informant's knowledge, the reason for the death was cardiac.
- Select No if, to the best of the informant's knowledge, the reason for the death was not cardiac. [Go to Q24d]

Item 24c1. **Heart attack:** Select only one option among the two possible choices.

- Select Yes if, to the best of the informant's knowledge, the reason for the death was heart attack.
- Select No if, to the best of the informant's knowledge, the reason for the death was not heart attack.

Item 24c2. **Heart failure:** Select only one option among the two possible choices.

- Select Yes if, to the best of the informant's knowledge, the reason for the death was heart failure.
- Select No if, to the best of the informant's knowledge, the reason for the death was not heart failure.

Item 24c3. **Other cardiac problem:** Select only one option among the two possible choices.

- Select Yes if, to the best of the informant's knowledge, the reason for the death was a cardiac problem not listed.
- Select No if, to the best of the informant's knowledge, the reason for the death was not another cardiac problem not listed. [Go to Q24d]

Item 24c3a. **Specify other cardiac problem:** Specify the other cardiac problem.

Item 24d. **Cancer:** Select only one option among the two possible choices.

- Select Yes if, to the best of the informant's knowledge, the reason for the death was cancer.
- Select No if, to the best of the informant's knowledge, the reason for the death was not cancer. [Go to Q24e]

Item 24d1. **Lung cancer:** Select only one option among the two possible choices.

- Select Yes if, to the best of the informant's knowledge, the reason for the death was lung cancer.
- Select No if, to the best of the informant's knowledge, the reason for the death was not lung cancer.

Item 24d2. **Other cancer:** Select only one option among the two possible choices.

- Select Yes if, to the best of the informant's knowledge, the reason for the death was a cancer other than lung cancer.
- Select No if, to the best of the informant's knowledge, the reason for the death was not a cancer other than lung cancer. [Go to Q24e]

Item 24d2a. **Specify other cancer:** Specify the other cancer.

Item 24e. **Other condition:** Select only one option among the two possible choices.

- Select Yes if, to the best of the informant's knowledge, the reason for the death was another condition not listed.
- Select No if, to the best of the informant's knowledge, the reason for the death was not another condition not listed. [Go to Q25]

Item 24e1. **Specify other condition:** Specify the other condition that was the reason for this death.

## F. ADDITIONAL INFORMANTS

Item 25. **Anyone else who could provide additional information:** Select only one option among the three possible choices.

- Select No if the informant reports that there is no one else who could be contacted who might be able to provide additional information about the circumstances surrounding the decedent's death or usual state of health. [Go to closing script and Q28]
- Select Yes if the informant reports that there is someone else who could be contacted who might be able to provide additional information about the circumstances surrounding the decedent's death or usual state of health.
- Select Unknown if the informant does not know if there is someone else who could be contacted who might be able to provide additional information about the circumstances surrounding the decedent's death or usual state of health. [Go to closing script and Q28]

Item 26. **Additional informant's relationship with decedent:** Select only one option among the six possible choices.

- Select Spouse if the additional informant is the decedent's spouse.
- Select Daughter/Son if the additional informant is the decedent's daughter or son.
- Select Parent if the additional informant is the decedent's parent.
- Select Friend if the additional informant is the decedent's friend.
- Select Workmate if the additional informant is the decedent's workmate.
- Select Other if the informant is other than those listed above.

Item 26a. **Additional informant's other relationship with decedent:** Specify the other relationship with the decedent.

Item 27. **Name and address of additional informant:** Record the name and address of additional informant in Q27a-27f.



- Item 27a. **Name of additional informant:** Record the name of the additional informant.
- Item 27b. **Street address of additional informant:** Record the street address of the additional informant.
- Item 27c. **City of additional informant:** Record the city of the additional informant.
- Item 27d. **State of additional informant:** Record the state of the additional informant.
- Item 27e. **Zip code of additional informant:** Record the zip code of the additional informant.
- Item 27f. **Phone number of additional informant:** Record the phone number of the additional informant.

## G. CLOSING SCRIPT

Read the closing script and answer any questions. End the interview.

## H. RELIABILITY (to be completed after the interview)

- Item 28. **Reliability of informant's responses:** Select only one option among the three possible choices.
- Select Poor if you feel the reliability of the interview is poor.
  - Select Fair if you feel the reliability of the interview is fair.
  - Select good if you feel the reliability of the interview is good.

## I. COORDINATOR SUMMARY

- Item 28. **Narrative summary:** Please provide a narrative summary of the interview. Describe pertinent details that may not have been captured in the form but could help the adjudication committee members determine circumstances and/or underlying conditions that may have contributed to the decedent's death.

Save and close the form.