



# INFORMANT INTERVIEW - ENDPOINTS

ID NUMBER:

FORM CODE: IFI  
VERSION: 2.0 10/23/2020

Event \_\_\_\_\_

Occurrence # \_\_\_\_\_

0a. Collection Date:   /   /

0b. Staff Code

**Instructions:** The informant interview form is completed for each informant for an eligible death as determined by the SPIROMICS endpoints investigation protocol.

0c1) Decedent's name: \_\_\_\_\_

0d2) Informant name: \_\_\_\_\_

0e3) Date of death:   /   /

0f4) Age at death:

0g5) Date of birth:   /   /

0h6) Place of death: \_\_\_\_\_

0i7) Informant interview attempted for the:

- Primary Informant<sub>1</sub>
- Secondary Informant<sub>2</sub>
- Additional Informant<sub>3</sub>

0j18) Attempts made to contact informant when there was no answer:

- First attempt<sub>1</sub>
- Second attempt<sub>2</sub>
- Third attempt<sub>3</sub>
- Fourth attempt<sub>4</sub>
- Fifth attempt<sub>5</sub>

*"Hello, my name is (interviewer's name) with the SPIROMICS study. I'm calling (name of informant) regarding (name of decedent)'s involvement with the SPIROMICS study, a medical research study in which (name of decedent) was enrolled and participated."*

[Once it is established you are speaking with the informant, continue with the script below. If the informant is not available determine a time to call back. If the interviewer determines that the person they are speaking with is knowledgeable of the circumstances surrounding the decedent's death, the interview with this person should continue. See procedure manual for more details.]

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*"I'm sorry for your loss. We understand that you might be able to help us complete our documents for (decedent), particularly the circumstances surrounding (his/her) death."*

09) "Is now a good time to talk?"

- 1  No<sub>0</sub>
- 9  No - Do not contact again<sub>3</sub> → **End Form**
- 2  Yes - Thank you. If you have any questions, please ask me<sub>1</sub>. → **Skip to 10**
- Yes - Mailed in form<sub>2</sub> → **Skip to 10**

029a) When would it be convenient to call back?   /   /

10) Before we get started could you please tell me what your relationship was with (*insert name of decedent*)? (Respondent was deceased's...)

- Spouse<sub>1</sub>
- Daughter/Son<sub>2</sub>
- Parent<sub>3</sub>
- Friend<sub>4</sub>
- Workmate<sub>5</sub>
- 7  Other<sub>6</sub>

10a) If other, please specify: \_\_\_\_\_

**A. CIRCUMSTANCES SURROUNDING DEATH**

"I'd like to ask you a few questions about (*decedent's name*)'s medical history and the events leading up to (*his/her*) death."

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

Record a brief synopsis of the events surrounding the death as relayed by the informant:

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

12) Please tell me who was present.

- 4a 12a) Self  No<sub>0</sub>  Yes<sub>1</sub>
- 4b 12b) Health care person(s)  No<sub>0</sub>  Yes<sub>1</sub>
- 4c 12c) Other person(s)  No<sub>0</sub>  Yes<sub>1</sub>

## B. MEDICAL HISTORY

“I’d like to ask you a few questions about (*decedent’s name*) medical history.”

6 13) Was (*he/she*) hospitalized within the four weeks prior to his/her death?

No<sub>0</sub> → **Skip to Item 17**

Yes<sub>1</sub>

9  Unknown<sub>2</sub> → **Skip to Item 17**

7 14) Reason for the hospitalization:

7a 14a) Unknown  Yes<sub>1</sub> → **Go to 15**  No<sub>0</sub>

7b 14b) Respiratory  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 14c**

7b1 14b1) Emphysema, Chronic Bronchitis, or chronic obstructive pulmonary disease (COPD)  Yes<sub>1</sub>  No<sub>0</sub>

7b2 14b2) Pneumonia  Yes<sub>1</sub>  No<sub>0</sub>

7b3 14b3) Other respiratory problem  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 14c**

14b3a) Specify other respiratory: \_\_\_\_\_

7c 14c) Cardiac  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 14d**

7c1 14c1) Heart Attack  Yes<sub>1</sub>  No<sub>0</sub>

7c2 14c2) Heart Failure  Yes<sub>1</sub>  No<sub>0</sub>

7c3 14c3) Other cardiac problem  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 14d**

7c3a 14c3a) Specify other cardiac problem: \_\_\_\_\_

7d 14d) Cancer  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 14e**

7d1 14d1) Lung  Yes<sub>1</sub>  No<sub>0</sub>

7d2 14d2) Other cancer  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 14e**

7d2a 14d2a) Specify other cancer: \_\_\_\_\_

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7e14e) Other condition  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 15**

7e114e1) Specify other condition: \_\_\_\_\_

815) What was the date of the hospitalization?   /   /

16) What was the name and location of the hospital?

916a) Name of hospital: \_\_\_\_\_

916b) Street address of hospital: \_\_\_\_\_

916c) City of hospital: \_\_\_\_\_

916d) State of hospital: \_\_\_\_\_

916e) Zip code of hospital: \_\_\_\_\_

1017) Was (insert decedent's name) seen by a doctor any other time in the last four weeks prior to death?

No<sub>0</sub> → **Go to 19**

Yes<sub>1</sub>

Unknown<sub>2</sub> → **Go to 19**

18) What was the name and address of this doctor?

1118a) Name of doctor: \_\_\_\_\_

1118b) Street address of doctor: \_\_\_\_\_

1118c) City of doctor: \_\_\_\_\_

1118d) State of doctor: \_\_\_\_\_

1118e) Zip code of doctor: \_\_\_\_\_

18f) Phone number of doctor: \_\_\_\_\_

### C. SYMPTOMS

"Now I'd like to talk about specific symptoms (*decedent's name*) might have experienced just prior to (*his/her*) death."

1219) Did (*he/she*) experience an increase in shortness of breath?

No<sub>0</sub>

Yes<sub>1</sub>

9 Unknown<sub>2</sub>

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<sup>13</sup>20) Did (*he/she*) experience increased coughing?

No<sub>0</sub>

Yes<sub>1</sub>

<sup>9</sup> Unknown<sub>2</sub>

<sup>14</sup>21) Did (*he/she*) experience increased mucus or sputum production?

No<sub>0</sub>

Yes<sub>1</sub>

<sup>9</sup> Unknown<sub>2</sub>

#### D. EMERGENCY MEDICAL CARE

"I now have a few questions about 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, and I apologize if these questions seem repetitive, but it is important to obtain information specifically on emergency medical care."

<sup>15</sup>22) Was a physician, ambulance or other emergency medical team called?

No<sub>0</sub>

Yes<sub>1</sub>

<sup>9</sup> Unknown<sub>2</sub>

<sup>17</sup>23) Was (*decedent's name*) taken to the hospital, emergency room or any other emergency care facility?

No<sub>0</sub>

Yes<sub>1</sub>

<sup>9</sup> Unknown<sub>2</sub>

#### E. CAUSE OF DEATH

<sup>18</sup>24) To the best of your knowledge, what was the reason for the death?

<sup>18a</sup>24a) Unknown

Yes<sub>1</sub> → **Go to 25**       No<sub>0</sub>

<sup>18b</sup>24b) Respiratory

Yes<sub>1</sub>       No<sub>0</sub> → **Go to 24c**

<sup>18b1</sup>24b1) Emphysema, Chronic Bronchitis,  
or chronic obstructive pulmonary  
disease (COPD)

Yes<sub>1</sub>       No<sub>0</sub>

<sup>18b2</sup>24b2) Pneumonia

Yes<sub>1</sub>       No<sub>0</sub>

<sup>18b3</sup>24b3) Other respiratory cause

Yes<sub>1</sub>       No<sub>0</sub> → **Go to 24c**

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24b3a) If other, specify: \_\_\_\_\_

18c24c) Cardiac  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 24d**

18c124c1) Heart Attack  Yes<sub>1</sub>  No<sub>0</sub>

18c224c2) Heart Failure  Yes<sub>1</sub>  No<sub>0</sub>

18c324c3) Other cardiac problem  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 24d**

18c3a24c3a) If other, specify: \_\_\_\_\_

18d24d) Cancer  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 24e**

18d124d1) Lung  Yes<sub>1</sub>  No<sub>0</sub>

18d224d2) Other  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 24e**

18d2a24d2a) If other, specify: \_\_\_\_\_

18e24e) Other condition  Yes<sub>1</sub>  No<sub>0</sub> → **Go to 25**

18e124e1) If other, specify: \_\_\_\_\_

## F. ADDITIONAL INFORMANTS

1925) Is there anyone else we could contact who might be able to provide additional information about the circumstances surrounding (*decedent's name*) death or (*his/her*) usual state of health?

No<sub>0</sub> → **Go to Closing Script and Q28**

Yes<sub>1</sub>

9  Unknown<sub>2</sub> → **Go to Closing Script and Q28**

2026) How is (*he/she*) related to (*decedent's name*)?

Spouse<sub>1</sub>

Daughter/Son<sub>2</sub>

Parent<sub>3</sub>

Friend<sub>4</sub>

Workmate<sub>5</sub>

7  Other<sub>6</sub>

20a26a. If other, please specify: \_\_\_\_\_

27) What is the name and address of this person?

2127a) Name of this person: \_\_\_\_\_

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2127b) Street address of this person: \_\_\_\_\_

2127c) City of this person: \_\_\_\_\_

2127d) State of this person: \_\_\_\_\_

2127e) Zip code of this person: \_\_\_\_\_

27f) Phone number of this person: \_\_\_\_\_

**G. CLOSING SCRIPT**

“Thank you very much for your assistance in this study. This information is very important for advancing our understanding of lung disease. Do you have any questions? Thanks again for your help.”

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

2228) On the basis of these questions, give your rating of reliability of the interview.

Poor<sub>0</sub>

Fair<sub>1</sub>

Good<sub>2</sub>

**I. COORDINATOR SUMMARY**

2329) Please provide a narrative summary of the conversation with the informant, describing any pertinent details that may not have been captured by this form that will aid the adjudication committee in determining any circumstances and underlying conditions that may have contributed to a participant’s death in addition to determining the ultimate cause of death.

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