



FOLLOW-UP CANCER QUESTIONNAIRE

ID NUMBER:

FORM CODE:

DATE: 09/29/2016
Version 2.0

ADMINISTRATIVE INFORMATION

0a. Completion Date: / / 0b. Staff ID:

Month Day Year

Instructions: This form is administered during a separate telephone interview from the annual or semi-annual follow-up contact or following the annual or semi-annual follow-up interview. This form should be completed for participants who have ever reported a diagnosis of cancer from Visit 1 through the last completed Follow-up interview. The Date is the day the contact was made or is the date the status determination was made. Special missing values are allowed for cases where the response "Don't know", "Refused", "Unknown", or "N/A" is not listed as an option.

INTRODUCTION SCRIPT: "Hello, this is [your name] from the ARIC Study. May I please speak with [name of contact]?"

"Hello [name of respondent]. This is [your name] and I am from the ARIC Study. On a previous ARIC follow-up telephone call in [year] you [name] indicated that you [name] had been diagnosed with cancer. May I have a few minutes of your time to ask about your [name's] cancer diagnosis and treatment?"

A. STATUS

1. Result of contact for the interview (*select one*)
- a. Participant contacted, agreed to be interviewed... → **GO TO QUESTION 3**
 - b. Contacted, refused to be interviewed → **GO TO QUESTION 8**
 - c. Proxy/Informant contacted.....
 - d. Other person contacted
 - e. Contact pending; continue to attempt to contact.. → **SAVE AND CLOSE FORM**
 - f. Contact not possible → **SAVE AND CLOSE FORM**
2. Is the participant deceased?
- Yes → **GO TO QUESTION 8**
- No

B. CANCER INFORMATION

3. Are you able to answer some questions about your [name's] health?
- Yes
- No → **GO TO QUESTION 8**

“The ARIC study has collected cancer information for many years, which has been helpful to cancer research. We are interested in learning more about the risk factors for and causes of cancer so that we may prevent or develop better treatments for it in the future. The additional information we are now requesting will help us further our understanding of cancer.”

First diagnosed cancer

4. Do you recall that you [name] had a diagnosis of cancer?

Yes
No → **GO TO QUESTION 8**

4a. In what part of the body was your [name's] first cancer located?

- Brain
- Breast
- Bladder
- Colon & Rectum
- Esophagus
- Kidney
- Leukemia
- Liver
- Lung
- Melanoma
- Non-Hodgkin lymphoma
- Oral Cavity (anywhere in the mouth, including the tongue and lips)
- Ovary
- Pancreas
- Prostate
- Skin (non-melanoma) → **GO TO QUESTION 5**
- Thyroid
- Uterus
- Other → **GO TO QUESTION 4a1**

4a1. Specify in what part of the body the first cancer was located if not in drop down list:

4a2. **[DO NOT ASK; FOR THE INTERVIEWER]** Has the first cancer been reported on prior FCQ?

Yes
No → **GO TO QUESTION 4b**

4a3. **[DO NOT ASK; FOR THE INTERVIEWER]** Is more information regarding biopsy needed for this cancer?

Yes
No → **GO TO QUESTION 4e5**

4b. Did you [name] have a biopsy to confirm the cancer?

Yes
No → **IF QUESTION 4a2 is 'Y', GO TO QUESTION 4e5;
IF QUESTION 4a2 is 'N', GO TO QUESTION 4f**

4c. Approximate date of biopsy: /
Month Year

4d. Name and address of the doctor who performed the biopsy:

4d1. Name: _____

4d2. Address: _____

4d3. City: _____ 4d4. State:

4e. Name and address of the medical facility where you [name] had the biopsy:

4e1. Name: _____

4e2. Address: _____

4e3. City: _____

4e4. State: → **GO TO QUESTION 4f if QUESTION 4a2 is 'N'**

4e5. **[DO NOT ASK; FOR THE INTERVIEWER]** Is more information regarding surgery needed for this cancer?

Yes

No → **GO TO QUESTION 4j**

4f. Did you [name] have surgery for this cancer?

Yes

No → **GO TO QUESTION 4j**

4g. Approximate date of surgery: /
Month Year

4h. Name and address of the doctor who performed the surgery:

4h1. Name: _____

4h2. Address: _____

4h3. City: _____ 4h4. State:

4i. Name and address of the medical facility where you [name] had the surgery:

4i1. Name: _____

4i2. Address: _____

4i3. City: _____ 4i4. State:

4j. Has a doctor ever said this cancer metastasized, spread or got worse?

Yes
No → **GO TO QUESTION 4m**

4k. What was the approximate date a doctor said that this cancer metastasized, spread or got worse?

/
Month Year

4l. In what part of the body did the cancer spread? Please check all that apply.

- 4l1. Adrenal Gland
- 4l2. Bone
- 4l3. Brain
- 4l4. Liver
- 4l5. Lung
- 4l6. Lymph Nodes
- 4l7. Peritoneum (abdominal cavity)
- 4l8. Other → **If Other, specify in what part of the body the cancer spread on notelog**

4l9. Name and address of the doctor/facility that treated you for the cancer metastasis:

4l9a. Name: _____

4l9b. Address: _____

4l9c. City: _____ 4l9d. State:

4m. Has a doctor ever said the cancer was no longer detectable, that you [name] were in complete remission, or that you [name] were cured after treatment?

Yes
No → **GO TO QUESTION 5**

4n. Has a doctor ever said the cancer recurred or came back?

Yes
No → **GO TO QUESTION 5**

4o. What was the approximate date a doctor said that the cancer recurred or came back?

/
Month Year

4p. Name and address of the doctor/facility that treated you for cancer recurrence:

4p1. Name: _____

4p2. Address: _____

4p3. City: _____ 4p4. State:

Second diagnosed cancer, if applicable

5. Have you [name] ever been diagnosed with a second cancer?

Yes
No → **GO TO QUESTION 7**

5a. In what part of the body was the second cancer located?

- Brain
- Breast
- Bladder
- Colon & Rectum
- Esophagus
- Kidney
- Leukemia
- Liver
- Lung
- Melanoma
- Non-Hodgkin lymphoma
- Oral Cavity (anywhere in the mouth, including the tongue and lips)
- Ovary
- Pancreas
- Prostate
- Skin (non-melanoma) → **GO TO QUESTION 6**
- Thyroid
- Uterus
- Other → **GO TO QUESTION 5a1**

5a1. Specify in what part of the body the second cancer was located if not in drop down list:

5b. Was the diagnosis of the second cancer a result of the diagnosis of the first cancer?

Yes → **GO TO QUESTION 6**
No

5b1. **[DO NOT ASK; FOR THE INTERVIEWER]** Has the second cancer been reported on prior FCQ?

Yes
No → **GO TO QUESTION 5c**

5b2. **[DO NOT ASK; FOR THE INTERVIEWER]** Is more information regarding biopsy needed for this cancer?

Yes
No → **GO TO QUESTION 5f5**

5c. Did you [name] have a biopsy to confirm the cancer?

Yes
No → **IF QUESTION 5b1 is 'Y', GO TO QUESTION 5f5;
IF QUESTION 5b1 is 'N', GO TO QUESTION 5g**

5d. Approximate date of biopsy: /
Month Year

5e. Name and address of the doctor who performed the biopsy:

5e1. Name: _____

5e2. Address: _____

5e3. City: _____ 5e4. State:

5f. Name and address of the medical facility where you [name] had the biopsy:

5f1. Name: _____

5f2. Address: _____

5f3. City: _____

5f4. State: → **GO TO QUESTION 5g if QUESTION 5b1 is 'N'**

5f5. **[DO NOT ASK; FOR THE INTERVIEWER]** Is more information regarding surgery needed for this cancer?

Yes

No → **GO TO QUESTION 5k**

5g. Did you [name] have surgery for this cancer?

Yes

No → **GO TO QUESTION 5k**

5h. Approximate date of surgery: /
Month Year

5i. Name and address of the doctor who performed the surgery:

5i1. Name: _____

5i2. Address: _____

5i3. City: _____ 5i4. State:

5j. Name and address of the medical facility where you [name] had the surgery:

5j1. Name: _____

5j2. Address: _____

5j3. City: _____ 5j4. State:

5k. Has a doctor ever said this cancer metastasized, spread or got worse?

Yes
No → **GO TO QUESTION 5n**

5l. What was the approximate date a doctor said that this cancer metastasized, spread or got worse?

/
Month Year

5m. In what part of the body did the cancer spread? Please check all that apply.

- 5m1. Adrenal Gland
- 5m2. Bone
- 5m3. Brain
- 5m4. Liver
- 5m5. Lung
- 5m6. Lymph Nodes
- 5m7. Peritoneum (abdominal cavity)
- 5m8. Other → **If Other, specify in what part of the body the cancer spread on notelog**

5m9. Name and address of the doctor/facility that treated you for the cancer metastasis:

5m9a. Name: _____

5m9b. Address: _____

5m9c. City: _____ 5m9d. State:

5n. Has a doctor ever said the cancer was no longer detectable, that you [name] were in complete remission, or that you [name] were cured after treatment?

Yes
No → **GO TO QUESTION 6**

5o. Has a doctor ever said the cancer recurred or came back?

Yes
No → **GO TO QUESTION 6**

5p. What was the approximate date a doctor said that the cancer recurred or came back?

/
Month Year

5q. Name and address of the doctor/facility that treated you for cancer recurrence:

5q1. Name: _____

5q2. Address: _____

5q3. City: _____ 5q4. State:

Third diagnosed cancer, if applicable

6. Have you [name] ever been diagnosed with a third cancer?

Yes
No → **GO TO QUESTION 7**

6a. In what part of the body was the third cancer located?

- Brain
- Breast
- Bladder
- Colon & Rectum
- Esophagus
- Kidney
- Leukemia
- Liver
- Lung
- Melanoma
- Non-Hodgkin lymphoma
- Oral Cavity (anywhere in the mouth, including the tongue and lips)
- Ovary
- Pancreas
- Prostate
- Skin (non-melanoma) → **GO TO QUESTION 7**
- Thyroid
- Uterus
- Other → **GO TO QUESTION 6a1**

6a1. Specify in what part of the body the third cancer was located if not in drop down list:

6b. Was the diagnosis of the third cancer a result of the diagnosis of the first or second cancer?

Yes → **GO TO QUESTION 7**
No

6b1. **[DO NOT ASK; FOR THE INTERVIEWER]** Has the third cancer been reported on prior FCQ?

Yes
No → **GO TO QUESTION 6c**

6b2. **[DO NOT ASK; FOR THE INTERVIEWER]** Is more information regarding biopsy needed for this cancer?

Yes
No → **GO TO QUESTION 6f5**

6c. Did you [name] have a biopsy to confirm the cancer?

Yes
No → **IF QUESTION 6b1 is 'Y', GO TO QUESTION 6f5;
IF QUESTION 6b1 is 'N', GO TO QUESTION 6g**

6d. Approximate date of biopsy: /
Month Year

6e. Name and address of the doctor who performed the biopsy:

6e1. Name: _____

6e2. Address: _____

6e3. City: _____ 6e4. State:

6f. Name and address of the medical facility where you [name] had the biopsy:

6f1. Name: _____

6f2. Address: _____

6f3. City: _____

6f4. State: → **GO TO QUESTION 6g if QUESTION 6b1 is 'N'**

6f5. **[DO NOT ASK; FOR THE INTERVIEWER]** Is more information regarding surgery needed for this cancer?

Yes
No → **GO TO QUESTION 6k**

6g. Did you [name] have surgery for this cancer?

Yes
No → **GO TO QUESTION 6k**

6h. Approximate date of surgery: /
Month Year

6i. Name and address of the doctor who performed the surgery:

6i1. Name: _____

6i2. Address: _____

6i3. City: _____ 6i4. State:

6j. Name and address of the medical facility where you [name] had the surgery:

6j1. Name: _____

6j2. Address: _____

6j3. City: _____ 6j4. State:

6k. Has a doctor ever said this cancer metastasized, spread or got worse?

Yes
No → **GO TO QUESTION 6n**

6l. What was the approximate date a doctor said that this cancer metastasized, spread or got worse?

/
Month Year

6m. In what part of the body did the cancer spread? Please check all that apply.

- 6m1. Adrenal Gland
- 6m2. Bone
- 6m3. Brain
- 6m4. Liver
- 6m5. Lung
- 6m6. Lymph Nodes
- 6m7. Peritoneum (abdominal cavity)
- 6m8. Other → **If Other, specify in what part of the body the cancer spread on notelog**

6m9. Name and address of the doctor/facility that treated you for the cancer metastasis:

6m9a. Name: _____

6m9b. Address: _____

6m9c. City: _____ 6m9d. State:

6n. Has a doctor ever said the cancer was no longer detectable, that you [name] were in complete remission, or that you [name] were cured after treatment?

Yes
No → **GO TO QUESTION 7**

6o. Has a doctor ever said the cancer recurred or came back?

Yes
No → **GO TO QUESTION 7**

6p. What was the approximate date a doctor said that the cancer recurred or came back?

/
Month Year

6q. Name and address of the doctor/facility that treated you for cancer recurrence:

6q1. Name: _____

6q2. Address: _____

6q3. City: _____ 6q4. State:

C. PERMISSION TO OBTAIN MEDICAL RECORDS RELEASE FORM

“As part of the ARIC Cancer Study, we would like permission to retrieve copies of your [name’s] medical records from all of the doctors and medical facilities involved in your [name’s] cancer diagnoses and treatments. We would also like permission to retrieve and store your [name’s] tissue samples taken during cancer care. This will help us conduct future research on different tumor types.

If you agree to do this, I will send you a form that tells your [name’s] physician or medical facility that you [name] authorize the ARIC Cancer Study to get this information from them. Once you sign the form and mail it back to me, I will contact your physician’s office or medical facility.”

7. May I send you this release form and an addressed envelope for you to mail it back?

Yes
No

D. ADMINISTRATIVE INFORMATION

8. FCQ Completion Status:

a. Complete
b. Partially complete; contact again
c. Partially complete; unable to complete questionnaire (done)

CLOSURE SCRIPT:

Talking to participant/informant: "Thank you very much for answering these questions. You have previously provided us with information on how to contact you. To help us contact you in the future, please tell me if the information I have is still correct." [Update the CIU form as necessary.]

If participant deceased: "Thank you very much."

Otherwise: "Thank you very much."