



INSTRUCTIONS FOR THE FOLLOW-UP CANCER QUESTIONNAIRE (09/29/2016) (FCQ, VERSION 2, 09/29/2016)

I. General Instructions

The follow-up cancer questions (FCQ) are completed 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.

II. Detailed Instructions for Each Question

When the interviewer makes contact with someone on the telephone (may or may not be the participant), read the following script.

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

Determine the participant's availability and vital status.

If the interviewer is notified that the participant is DECEASED, offer condolences. Go to Section D. ADMINISTRATIVE INFORMATION question 8 and enter a. Complete. If the participant or follow-up proxy ("respondent") is available, greet them with the following script.

Script: "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] cancer diagnosis and treatment?"

- 0a. Enter the date of contact or the date the status determination was made.
- 0b. Enter the staff ID for the telephone interviewer ID or the staff ID that made last contact attempt.

A. STATUS

1. Result of contact for the interview. Enter the contact status code that describes whether or not the interview was completed and the person interviewed.
 - a. **Participant contacted, agreed to be interviewed**
 - b. **Contact, refused to be interviewed**
 - c. **Proxy/Informant contacted**
 - d. **Other person contacted**
 - e. **Contact pending; continue to attempt to contact**
 - f. **Contact not possible**
- a. Participant contacted, agreed to be interviewed: Contact was made with the participant and he/she agreed to be interviewed. The interview was done with the participant or someone who assisted the participant in answering the questions, i.e., not a proxy.

Action: Begin interview at question 3.

If the interview is interrupted or the participant requests the interview be done at another time complete D. ADMINISTRATIVE INFORMATION question 8 and enter b. Partially complete, contact again. The interviewer will continue to attempt to contact at a later date.

- b. Contact, refused to be interviewed: Contact was made with the participant, follow-up proxy, or other informant, but he/she refused to be interviewed. If this interview was refused, go to Section D. ADMINISTRATIVE INFORMATION question 8 and enter a. Complete.
- c. Proxy/Informant contacted: Contact was made with follow-up proxy or other informant who is knowledgeable and able to answer the interview questions on behalf of the participant (e.g., relative, spouse).

Action: Begin interview at Question 2. If the respondent is unable to provide reliable information about the participant at Question 3 go to Section D. ADMINISTRATIVE INFORMATION question 8 and enter a. Complete.

- d. Other person contacted: Contact was made with a person who has not been explicitly identified as a follow-up proxy who may not be familiar with detailed health of the participant (e.g., acquaintance).

Action: Begin interview at Question 2. If the respondent is unable to provide reliable information about the participant at Question 3 go to Section D. ADMINISTRATIVE INFORMATION question 8 and enter b. Partially complete, contact again. The interviewer will continue to attempt to contact the participant or follow-up proxy who is knowledgeable and about to answer the interview questions on behalf of the participant at a later date.

If the interviewer is unable to contact the participant, the proxy, or another person knowledgeable and able to answer the interview questions about the participant, go to Section D. ADMINISTRATIVE INFORMATION question 8 and enter a. Complete.

- e. Contact pending; continue to attempt to contact: Contact pending.
Action: No action necessary; save and close form. Further attempts will be made to complete the interview.
- f. Contact not possible: Neither the participant, the proxy, nor another person was able to be contacted.

Action: No action necessary; save and close form.

A. STATUS (QUESTION 1)	D. ADMINISTRATIVE INFORMATION (QUESTION 8)	EXPLANATION
A	A	The participant was successfully contacted and the entire interview was completed.
A	B	The participant was successfully contacted and agreed to be interviewed but the interview is incomplete or was not done at all due to interruptions. This may be a temporary status if it is possible that the interview may be completed at a later date.

B	A	The participant has indicated that s/he does not wish to be contacted.
A	C	The participant was successfully contacted but the interview was not done and is not completed.
C	A	The participant's proxy or informant was successfully contacted and the entire interview was completed.
D	A	Other person was successfully contacted by phone or in person, and the entire interview was completed.
E	--	1. Attempts are being made to locate the participant, but so far neither the participant nor another reliable source has been contacted. 2. Reliable information (e.g. from a relative, employer, etc.) indicates that the participant is living, but direct contact has not yet been made. It is possible that contact will be made through further efforts. For example, "temporarily away" would fit in this category.
F	--	Neither the participant nor another source of information was contacted that could provide reliable data.

2. Indicate whether the participant deceased. If yes, go to Section D. ADMINISTRATIVE INFORMATION question 8 and enter A. Complete.

B. CANCER INFORMATION

3. Determine whether the respondent is able to answer health questions. If the respondent is unable to answer these questions, try to identify another contact person who might be able to provide this information. If another contact person is identified, go to Section D. ADMINISTRATIVE INFORMATION question 8 and code as 'Partially complete; contact again' and get contact information for the person. If another contact person is not available, go to Section D. ADMINISTRATIVE INFORMATION question 8 and code as 'Partially complete; unable to complete questionnaire'.

Script: "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."

4. This question asks the participant/informant to recall a diagnosis of cancer. If the participant/informant does not recall a diagnosis of cancer, go to Section D. ADMINISTRATIVE INFORMATION question 8 and enter a. Complete.

If the participant/informant responds that they do not know if there was a diagnosis of cancer, you may use the probe "On a previous ARIC call, you reported that you were diagnosed with <<insert first cancer type reported on the follow-up call>> in <<insert first cancer diagnosis year reported on the follow-up call >>. Do you recall that diagnosis?"

If the participant/informant responds no and the participant reported a second (and third) cancer on a previous ARIC call, treat this response as a 'No'. Go to Section D. ADMINISTRATIVE INFORMATION question 8 and enter a. Complete.

If the participant/informant responds no, and the participant also reported a second (and third) cancer on previous ARIC calls, you may use the probe "On a previous ARIC call, you reported that you were diagnosed with <<insert second/third cancer type reported on the follow-up call>> in <<insert second/third cancer diagnosis year reported on the follow-up call >>. Do you recall that diagnosis? If the participant /informant does not recall the any of the previously reported diagnoses, treat this response as a 'No'. Go to Section D. ADMINISTRATIVE INFORMATION question 8 and enter a. Complete. If the participant does recall a diagnosis of cancer, proceed with the questionnaire.

4.a.-4.a.1. These questions ask about the location of the first reported cancer. Select the part of the body from the drop down list, or specify if the body part is not on the list.

If the participant/informant reports uterine or endometrial cancer, select Uterus

If the participant/informant reports a non-melanoma skin cancer, go to question 5.

If the participant/informant reports a cancer location that's not listed (i.e. cervical cancer or cancer of the cervix), select "Other" from the drop down list for question 4.a. and record the response in question 4.a.1.

The participant/informant may be non-specific about the type of cancer. For example, they may report a "female cancer", "cancer of the womb", or "blood cancer". If the participant is non-specific about the type of cancer, you may use the probe "Could you be more specific?" If the participant does not give a more specific response, select "Other" from the drop down list for question 4.a. and record the response in 4a1.

If the participant reports a diagnosis of leukemia, their cancer was likely diagnosed with a blood test, not a biopsy. However, in some cases, people with leukemia may have a biopsy/surgery as part of their treatment. Continue with the script, but be aware that these participants may say "no" to the biopsy and surgery questions, and they may mention a blood test.

4.a.2. This question is for the Interviewer only and asks whether the participant/informant reported the first cancer on a prior FCQ. If the participant did not previously report the first cancer on a prior FCQ ('No'), go to question 4b. If 'Yes', continue with questionnaire.

4.a.3. This question is for the Interviewer only and asks whether more information is needed regarding biopsy for the first cancer cancer. If the participant reported that they did not have a biopsy for the first cancer or provided complete information about the biopsy date, doctor and medical facility on the prior FCQ ('No'), go to question 4e5. If more information is needed because the participant reported a biopsy for the first cancer on the prior FCQ, but provided incomplete or incorrect information about the biopsy date, doctor or medical facility ('Yes'), continue with questionnaire.

4.b. This question asks the participant/informant to recall if they had a biopsy to confirm the cancer. If the participant does not recall having had a biopsy ('No') and the first cancer was not previously reported on a prior FCQ (4.a.2 is 'No'), go to question 4f. If the participant does not recall having had a biopsy ('No') and the first cancer was previously reported on a

prior FCQ (4.a.2 is 'Yes'), go to question 4.e.5. If 'Yes', continue with questionnaire.

4.c. Enter the approximate date of the biopsy in month/year format.

4.d.-4.d.4. Record the name and address of the doctor who performed the biopsy in questions 4.d.-4.d.4.

4.e.-4.e.4. Record the name and address of the medical facility where the biopsy was performed in questions 4.e.-4.e.4. If the first cancer was not previously reported on a prior FCQ (4.a.2 is 'No'), go to question 4f. If the first cancer was previously reported on a prior FCQ (4.a.2 is 'Yes'), continue with questionnaire.

4.e.5. This question is for the Interviewer only and asks whether more information is needed regarding surgery for the first cancer. If the participant reported that they did not have a surgery for the first cancer or provided complete information about the surgery date, doctor and medical facility on the prior FCQ ('No'), go to question 4j. If more information is needed because the participant reported a surgery for the first cancer on the prior FCQ, but provided incomplete or incorrect information about the surgery date, doctor or medical facility ('Yes'), continue with questionnaire.

4.f. This question asks the participant/informant to recall if they had surgery for the cancer. If the participant does not recall having had surgery ('No'), go to question 4j. If 'Yes', continue with questionnaire.

Some participants may not recall having a biopsy or surgery to treat their cancer, especially if the diagnosis was a long time ago. If the participant says "no" to both the biopsy and surgery question, you may use the probe "How was your cancer treated?" or "What treatment did you have for your cancer?" You do not need to record all treatments described. Only record if the participant has had surgery as a treatment.

4.g. Enter the approximate date of the surgery in month/year format.

4.h.-4.h.4. Record the name and address of the doctor who performed the surgery in questions 4.h.-4.h.4.

4.i.-4.i.4. Record the name and address of the medical facility where the surgery was performed in questions 4.i.-4.i.4.

4.j. This question asks the participant/informant to recall if a doctor ever said the cancer metastasized, spread or got worse. If the participant does not recall this ('No'), go to question 4.m. If 'Yes', continue with questionnaire.

4.k. Enter the approximate date the doctor said that the cancer metastasized, spread or got worse in month/year format.

4.l.-4.l.8. These questions ask about the body part where the cancer spread. Please check all that apply. If 'Other', specify in what part of the body the cancer spread on notelog of question 4.l.8.

4.l.9.-4.l.9.d. Record the name and address of the doctor/facility that the participant visited for their cancer progression.

4.m. This question asks the participant/informant to recall if a doctor ever said the cancer was no longer detectable, in complete remission, or cured after treatment. If the participant/informant does not recall this ('No'), go to question 5. If 'Yes', continue with questionnaire.

4.n. This question asks the participant/informant to recall if a doctor ever said the cancer recurred or came back. If the participant does not recall this ('No'), go to question 5. If 'Yes', continue with questionnaire.

4.o. Enter the approximate date the doctor said that the cancer recurred or came back in month/year format.

4.p.-4.p.4. Record the name and address of the doctor/facility that the participant visited for their cancer recurrence.

5.-5.p. These questions are only completed if the participant/informant reports a second diagnosed cancer.

5. This question asks the participant/informant to recall a second diagnosis of cancer. If the participant/informant does not recall a second diagnosis, go to Section C. PERMISSION TO OBTAIN MEDICAL RECORDS RELEASE FORM question 7.

If the participant did not report a second cancer diagnosis on a follow-up call and the participant/informant responds that they do not know if there was a diagnosis of cancer, treat this response as a 'No'.

If the participant did report a second cancer diagnosis on a follow-up call and the participant/informant responds that they do not know if there was a diagnosis of cancer, you may use the probe "On a previous ARIC call, you reported that you were diagnosed with <<insert second cancer type reported on the follow-up call>> in <<insert second cancer diagnosis year reported on the follow-up call >>. Do you recall that diagnosis?"

If the participant/informant responds no and the participant did not report a third cancer on a previous ARIC call, treat this response as a 'No'. Go to C. PERMISSION TO OBTAIN MEDICAL RECORDS RELEASE FORM question 7. If 'Yes', continue with questionnaire.

If the participant/informant responds no, and the participant also reported a third cancer on a previous ARIC call, you may use the probe "On a previous ARIC call, you reported that you were diagnosed with <<insert third cancer type reported on the follow-up call>> in <<insert third cancer diagnosis year reported on the follow-up call >>. Do you recall that diagnosis? If the participant /informant does not recall the second or third previously reported diagnoses, treat this response as a 'No'. Go to C. PERMISSION TO OBTAIN MEDICAL RECORDS RELEASE FORM question 7. If 'Yes', continue with questionnaire.

5a.-5.a.1. These questions ask about the location of the second reported cancer. Select the part of the body from the drop down list, or specify if the body part is not on the list.

If the participant/informant reports uterine or endometrial cancer, select Uterus

If the participant/informant reports a non-melanoma skin cancer, go to question 6.

If the participant/informant reports a cancer location that's not listed (i.e. cervical cancer or cancer of the cervix), select "Other" from the drop down list for question 5.a. and record the response in question 5.a.1.

The participant/informant may be non-specific about the type of cancer. For example, they may report a "female cancer", "cancer of the womb", or "blood cancer". If the participant is non-specific about the type of cancer, you may use the probe "Could you be more specific?" If the participant does not give a more specific response, select "Other" from the drop down list for question 5.a. and record the response in 5.a.1.

If the participant reports a diagnosis of leukemia, their cancer was likely diagnosed with a blood test, not a biopsy. However, in some cases, people with leukemia may have a biopsy/surgery as part of their treatment. Continue with the script, but be aware that these participants may say "no" to the biopsy and surgery questions, and they may mention a blood test.

5.b. This question asks the participant/informant to recall if the second cancer diagnosis was a result of the first cancer. If the participant confirms ('Yes'), go to question 6. If 'No', continue with questionnaire.

5.b.1. This question is for the Interviewer only and asks whether the participant/informant reported the second cancer on a prior FCQ. If the participant did not previously report the second cancer on a prior FCQ ('No'), go to question 5c. If 'Yes', continue with questionnaire.

5.b.2. This question is for the Interviewer only and asks whether more information is needed regarding biopsy for the second cancer. If the participant reported that they did not have a biopsy for the second cancer or provided complete information about the biopsy date, doctor and medical facility on the prior FCQ ('No'), go to question 5f5. If more information is needed because the participant reported a biopsy for the second cancer on the prior FCQ, but provided incomplete or incorrect information about the biopsy date, doctor or medical facility ('Yes'), continue with questionnaire.

5.c. This question asks the participant/informant to recall if they had a biopsy to confirm the cancer. If the participant does not recall having had a biopsy ('No') and the second cancer was not previously reported on a prior FCQ (5.b.2 is 'No'), go to question 5g. If the participant does not recall having had a biopsy ('No') and the second cancer was previously reported on a prior FCQ (5.b.2 is 'Yes'), go to question 5.f.5. If 'Yes', continue with questionnaire.

5.d. Enter the approximate date of the biopsy in month/year format.

5.e.-5.e.4. Record the name and address of the doctor who performed the biopsy in questions 5.e.-5.e.4.

5.f.-5.f.4. Record the name and address of the medical facility where the biopsy was performed in questions 5.f.-5.f.4. If the second cancer was not previously reported on a prior FCQ (5.b.1 is 'No'), go to question 5g. If the second cancer was previously reported on a prior FCQ (5.b.1 is 'Yes'), continue with questionnaire.

5.f.5. This question is for the Interviewer only and asks whether more information is needed

regarding surgery for the second cancer. If the participant reported that they did not have a surgery for the second cancer or provided complete information about the surgery date, doctor and medical facility on the prior FCQ ('No'), go to question 5k. If more information is needed because the participant reported a surgery for the second cancer on the prior FCQ, but provided incomplete or incorrect information about the surgery date, doctor or medical facility ('Yes'), continue with questionnaire.

5.g. This question asks the participant/informant to recall if they had surgery for the cancer. If the participant does not recall having had surgery ('No'), go to question 5.k.

Some participants may not recall having a biopsy or surgery to treat their cancer, especially if the diagnosis was a long time ago. If the participant says "no" to both the biopsy and surgery question, you may use the probe "How was your cancer treated?" or "What treatment did you have for your cancer?" You do not need to record all treatments described. Only record if the participant has had surgery as a treatment.

5.h. Enter the approximate date of the surgery in month/year format.

5.i.-5.i.4. Record the name and address of the doctor who performed the surgery in questions 5.i.-5.i.4.

5.j.-5.j.4. Record the name and address of the medical facility where the surgery was performed in questions 5.j.-5.j.4.

5.k. This question asks the participant/informant to recall if a doctor ever said the cancer metastasized, spread or got worse. If the participant does not recall this ('No'), go to question 5.n. If 'Yes', continue with questionnaire.

5.l. Enter the approximate date the doctor said that the cancer metastasized, spread or got worse in month/year format.

5.m. -5.m.8. These questions ask about the body part where the cancer spread. Please check all that apply. If 'Other', specify in what part of the body the cancer spread on notelog of question 5.m.8.

5.m.9.-5.m.9.d. Record the name and address of the doctor/facility that the participant visited for their cancer progression.

5.n. This question asks the participant/informant to recall if a doctor ever said the cancer was no longer detectable, in complete remission, or cured after treatment. If the participant/informant does not recall this ('No'), go to question 6. If 'Yes', continue with questionnaire.

5.o. This question asks the participant/informant to recall if a doctor ever said the cancer recurred or came back. If the participant does not recall this ('No'), go to question 6. If 'Yes', continue with questionnaire.

5.p. Enter the approximate date the doctors said that the cancer recurred or came back in month/year format.

5.q.-5.q.4. Record the name and address of the doctor/facility that the participant visited

for their cancer recurrence.

6.-6.p. These questions are only completed if the participant/informant reports a third diagnosed cancer.

6. This question asks the participant/informant to recall a third diagnosis of cancer. If the participant/informant does not recall a third diagnosis, go to Section C. PERMISSION TO OBTAIN MEDICAL RECORDS RELEASE FORM question 7.

If the participant did not report a third cancer diagnosis on a follow-up call and the participant/informant responds that they do not know if there was a diagnosis of cancer, treat this response as a 'No'

If the participant did report a third cancer diagnosis on a follow-up call and the participant/informant responds that they do not know if there was a diagnosis of cancer, you may use the probe "On a previous ARIC call, you reported that you were diagnosed with <<insert third cancer type reported on the follow-up call>> in <<insert third cancer diagnosis year reported on the follow-up call >>. Do you recall that diagnosis? If the participant /informant does not recall the diagnosis, treat this response as a 'No'.

6a.-6.a.1. These questions ask about the location of the third reported cancer. Select the part of the body from the drop down list, or specify if the body part is not on the list.

If the participant/informant reports uterine or endometrial cancer, select Uterus

If the participant/informant reports a non-melanoma skin cancer, go to question 7.

If the participant/informant reports a cancer location that's not listed (i.e. cervical cancer or cancer of the cervix), select "Other" from the drop down list for question 6.a. and record the response in question 6.a.1.

The participant/informant may be non-specific about the type of cancer. For example, they may report a "female cancer", "cancer of the womb", or "blood cancer". If the participant is non-specific about the type of cancer, you may use the probe "Could you be more specific?" If the participant does not give a more specific response, select "Other" from the drop down list for question 6.a. and record the response in 6.a.1.

If the participant reports a diagnosis of leukemia, their cancer was likely diagnosed with a blood test, not a biopsy. However, in some cases, people with leukemia may have a biopsy/surgery as part of their treatment. Continue with the script, but be aware that these participants may say "no" to the biopsy and surgery questions, and they may mention a blood test.

6.b. This question asks the participant/informant to recall if the third cancer diagnosis was a result of the first or second cancer. If the participant confirms ('Yes'), go to C. PERMISSION TO OBTAIN MEDICAL RECORDS RELEASE FORM question 7. If 'No', continue with questionnaire.

6.b.1. This question is for the Interviewer only and asks whether the participant/informant reported the third cancer on a prior FCQ. If the participant did not previously report the third cancer on a prior FCQ ('No'), go to question 6c. If 'Yes', continue with questionnaire.

6.b.2. This question is for the Interviewer only and asks whether more information is needed regarding biopsy for the third cancer. If the participant reported that they did not have a biopsy for the third cancer or provided complete information about the biopsy date, doctor and medical facility on the prior FCQ ('No'), go to question 6f5. If more information is needed because the participant reported a biopsy for the third cancer on the prior FCQ, but provided incomplete or incorrect information about the biopsy date, doctor or medical facility ('Yes'), continue with questionnaire.

6.c. This question asks the participant/informant to recall if they had a biopsy to confirm the cancer. If the participant does not recall having had a biopsy ('No') and the third cancer was not previously reported on a prior FCQ (6.b.1 is 'No'), go to question 6g. If the participant does not recall having had a biopsy ('No') and the third cancer was previously reported on a prior FCQ (6.b.1 is 'Yes'), go to question 6.f.5. If 'Yes', continue with questionnaire.

6.d. Enter the approximate date of the biopsy in month/year format.

6.e.-6.e.4. Record the name and address of the doctor who performed the biopsy in questions 6.e.-6.e.4.

6.f.-6.f.4. Record the name and address of the medical facility where the biopsy was performed in questions 6.f.-6.f.4. If the third cancer was not previously reported on a prior FCQ (6.b.1 is 'No'), go to question 6g. If the third cancer was previously reported on a prior FCQ (6.b.1 is 'Yes'), continue with questionnaire.

6.f.5. This question is for the Interviewer only and asks whether more information is needed regarding surgery for the third cancer. If the participant reported that they did not have a surgery for the third cancer or provided complete information about the surgery date, doctor and medical facility on the prior FCQ ('No'), go to question 6k. If more information is needed because the participant reported a surgery for the third cancer on the prior FCQ, but provided incomplete or incorrect information about the surgery date, doctor or medical facility ('Yes'), continue with questionnaire.

6.g. This question asks the participant/informant to recall if they had surgery for the cancer. If the participant does not recall having had surgery ('No'), go to question 6.k. If 'Yes', continue with questionnaire.

Some participants may not recall having a biopsy or surgery to treat their cancer, especially if the diagnosis was a long time ago. If the participant says "no" to both the biopsy and surgery question, you may use the probe "How was your cancer treated?" or "What treatment did you have for your cancer?" You do not need to record all treatments described. Only record if the participant has had surgery as a treatment.

6.h. Enter the approximate date of the surgery in month/year format.

6.i.-6.i.4. Record the name and address of the doctor who performed the surgery in questions 6.i.-6.i.4.

6.j.-6.j.4. Record the name and address of the medical facility where the surgery was performed in questions 6.j.-6.j.4.

6.k. This question asks the participant/informant to recall if a doctor ever said the cancer metastasized, spread or got worse. If the participant does not recall this ('No'), go to question 6.n. If 'Yes', continue with questionnaire.

6.l. Enter the approximate date the doctor said that the cancer metastasized, spread or got worse in month/year format.

6.m.-6.m.8 These questions ask about the body part where the cancer spread. Please check all that apply. If 'Other', specify in what part of the body the cancer spread on notelog of question 6.m.8.

6.m.9.-6.m.9.d. Record the name and address of the doctor/facility that the participant visited for their cancer progression.

6.n. This question asks the participant/informant to recall if a doctor ever said the cancer was no longer detectable, in complete remission, or cured after treatment. If the participant/informant does not recall this ('No'), go to C. PERMISSION TO OBTAIN MEDICAL RECORDS RELEASE FORM question 7. If 'Yes', continue with questionnaire.

6.o. This question asks the participant/informant to recall if a doctor ever said the cancer recurred or came back. If the participant does not recall this ('No'), go to C. PERMISSION TO OBTAIN MEDICAL RECORDS RELEASE FORM question 7. If 'Yes', continue with questionnaire.

6.p. Enter the approximate date the doctor said that the cancer recurred or came back in month/year format.

6.q.-6.q.4. Record the name and address of the doctor/facility that the participant visited for their cancer recurrence.

C. PERMISSION TO OBTAIN MEDICAL RECORDS RELEASE FORM

The medical release form is sent to a physician only after the participant provides consent to release medical information to ARIC.

Script: "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. This question requests permission to send the release form to the participant. If the participant's response is "No", do not send the release form. The release form should contain all facilities provided by the participant (e.g. pertaining to all

biopsies, surgeries, metastases, and/or recurrences) on the first and second FCQ.

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."

D. ADMINISTRATIVE INFORMATION

8. Cancer interview questions completion status. Enter the code that describes whether or not the cancer interview questions were completed.
 - a. **Complete:** Direct contact was made. The contact provided all the questionnaire information they could offer. The contact is not required to answer every questionnaire question to have completed the interview.
 - b. **Partially complete, contact again:** Direct contact was made, but the questionnaire could not be fully administered due to an interruption – not because of a refusal. This status is not a final status, as the interviewer will be attempting another contact to continue the interview. The final status must be a. Complete, or c. Partially complete; unable to complete questionnaire (done).
 - c. **Partially complete, unable to complete questionnaire (done):** Direct contact was made, but the questionnaire could not be fully administered.