OMB#: 0925-0281
Exp. 03/31/2014

ANNUAL FOLLOW-UP FORM

ID NUMBER: ☐☐☐☐☐☐☐ FORM CODE: A F U DATE: 11/19/13 Version 2.0

ADMINISTRATIVE INFORMATION

0a. Completion Date: ☐☐/☐☐/☐☐☐☐ (Month / Day / Year) 0b. Staff ID: ☐☐☐

Instructions: *This form should be completed during the interview portion of the participant's follow-up. 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]. My name is [your name] and I am from the ARIC Study. May I have a few minutes of your time to ask about your recent health?"

A. STATUS

1. Result of contact for the interview *(select one)*
   - a. Participant contacted, agreed to be interviewed.... ☐ → **GO TO QUESTION 17**
   - b. Participant contacted, refused to be interviewed... ☐ → **GO TO QUESTION 71**
   - c. Proxy/Informant contacted ..... ☐
   - d. Other person contacted ..... ☐
   - e. Contact pending; continue to attempt to contact ... ☐ → **SAVE AND CLOSE FORM**
   - f. Window closed; unable to contact ..... ☐ → **SAVE AND CLOSE FORM**

2. Is the participant deceased?
   - Yes..... ☐
   - No ..... ☐ → **GO TO QUESTION 29**

B. DEATH INFORMATION

3. Death reported by: (select one)
   - Relative/Spouse/Acquaintance..... ☐
   - Surveillance..... ☐
   - Other (e.g., Obituary, Social Security Administration) ..... ☐

4. Date of death: ☐☐/☐☐/☐☐☐☐
Month Day Year

5. Location of death:

a. City: _____ c. State: ☐☐

b. County: _____

6. Are you able to answer some questions about any hospitalizations that occurred since our last contact with [name] on [mm/dd/yyyy]?

Yes..... ☐ → **GO TO QUESTION 7**
No ..... ☐

6a. Is there someone else who could answer these questions?

Yes - person located..... ☐
Yes - reschedule remainder of interview..... ☐ → **GO TO QUESTION 71**
No ..... ☐ → **GO TO QUESTION 71**

HOSPITALIZATIONS FOR HEART ATTACK / CONDITION / STROKE (for deceased participants)

7. Was [name] hospitalized for a heart attack, or heart condition, or stroke since our last contact on [mm/dd/yyyy]?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 10**

8a. Hospital Name, City, State: ☐▼

8a1. Specify hospital name, city, and state if not in drop down list: _____

8b. Approximate date of hospitalization: ☐☐/☐☐☐☐
Month Year

Second hospitalization, if applicable

9a. Hospital Name, City, State: ☐▼

9a1. Specify hospital name, city, and state if not in drop down list: _____

9b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

OTHER HOSPITALIZATIONS (for deceased participants)

10. Did [name] stay overnight as a patient in a hospital for any other reason since our last contact?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 14**

11a. Hospitalization Reason: _____

11b. Hospital Name, City, State: ☐▼

11b1. Specify hospital name, city, and state if not in drop down list: _____

11c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

Second hospitalization, if applicable

12a. Hospitalization Reason: _____

12b. Hospital Name, City, State: ☐▼

12b1. Specify hospital name, city, and state if not in drop down list: _____

12c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

Third hospitalization, if applicable

13a. Hospitalization Reason: _____

13b. Hospital Name, City, State: ☐▼

13b1. Specify hospital name, city, and state if not in drop down list: _____

13c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

OUTPATIENT TREATMENT (for deceased participants)

14. Was [name] admitted to an emergency room or a medical facility for outpatient treatment since our last contact?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 71**

15. Was this related to a heart problem or difficulty breathing?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 71**

16a. Hospital/Medical Facility Name, City, State: ☐▼

16a1. Specify hospital/medical facility name, city, and state if not in drop down list: _____

16b. Approximate date of admission: ☐☐/☐☐☐☐ → **GO TO QUESTION 71**
Month Year

C. GENERAL HEALTH

17. Now I will ask you some questions about your health. Over the past year, compared to other people your age, would you say that your health has been excellent, good, fair or poor?

Excellent ..... ☐
Good..... ☐
Fair ..... ☐
Poor..... ☐

[QUESTIONS 18-20 MOVED TO MCU FORM]

21a. Are there times when you wake up at night because of difficulty breathing?

Yes..... ☐
No ..... ☐

21b. Do you have trouble breathing or shortness of breath when hurrying on a level surface?

Yes..... ☐
No ..... ☐
Unable to Walk..... ☐ → **GO TO QUESTION 22**

21c. Do you have trouble breathing or shortness of breath when walking at ordinary pace on a level surface?

Yes..... ☐
No ..... ☐

21d.Do you stop for breath when walking at your own pace?

Yes..... ☐
No ..... ☐

21e.Do you stop for breath after walking 100 yards on a level surface?

Yes..... ☐
No ..... ☐

21f. Do you have to walk slower than people of your own age on a level surface because of shortness of breath?

Yes..... ☐
No ..... ☐

22. Do you have difficulty breathing when you are not walking or active?

Yes..... ☐
No ..... ☐

23. Do you usually have some cough or wheezing?

Yes.....☐
No .....☐

[QUESTIONS 24-25 MOVED TO MCU FORM]

26. Do you have pain in your legs caused by a blockage of the arteries?

Yes.....☐
No .....☐

27. Do you often have swelling in your feet or ankles at the end of the day?

Yes.....☐
No .....☐ → **GO TO QUESTION 28**

27a. Is the swelling in your feet or ankles gone in the morning?

Yes.....☐
No .....☐

28. Since we last contacted you, has a doctor said you had cancer?

Yes.....☐
No .....☐ → **GO TO QUESTION 36**

28a. Can you tell me in what part of the body the most recently diagnosed cancer was located?

_____

28b. What is the approximate date the cancer was diagnosed?

☐☐/☐☐☐☐
Month Year

DOCTOR INFORMATION FOR CANCER

"Please provide the contact information of the doctor you most recently visited for your cancer."

28c. Contact information of the doctor you last saw for your cancer:

28c1. Doctor Name: _____

28c2. Clinic or Institution Name: _____

28c3. Address: _____

28c4. City: _____ 28c5. State: ☐☐

28c6. Approximate date: ☐☐/☐☐☐☐
Month Year

"The ARIC study would like to ask your health care providers to tell us more about your cancer diagnosis and treatment. If you agree to do this, I will send you a form that tells your providers that you authorize the ARIC study to get this information from them. Once you sign

that form and mail it back to me, I will contact your health care providers."

28d. May I send you this release form and an addressed envelope for you to mail it back?

Yes..... ☐ → **GO TO QUESTION 36**
No ..... ☐ → **GO TO QUESTION 36**

D. CARDIOVASCULAR EVENTS

29. May I ask you some questions about [name's] health?

Yes ..... ☐ →**GO TO QUESTION 36**
No..... ☐

29a. Is there someone else we can ask?

Yes, person located..... ☐→ **GO TO QUESTION 36**
Yes, reschedule remainder of interview..... ☐→ **GO TO QUESTION 71**
No ..... ☐→ **GO TO QUESTION 71**

RECENT HEART FAILURE DIAGNOSIS

[QUESTIONS 30-35 MOVED TO MCU FORM]

36. Since we last contacted you [name] on [mm/dd/yyyy], has a doctor said you [name] had a heart attack?

Yes..... ☐
No ..... ☐→ **GO TO QUESTION 40**

37. Were you (Was [name]) hospitalized at that time?

Yes..... ☐
No ..... ☐→ **GO TO QUESTION 40**

HOSPITAL INFORMATION FOR HEART ATTACK

38a. Hospital Name, City, State: ☐▼

38a1. Specify hospital name, city, and state if not in drop down list: _____

38b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

Second hospitalization, if applicable

39a. Hospital Name, City, State: ☐▼

39a1. Specify hospital name, city, and state if not in drop down list: _____

39b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

40. Since we last contacted you [name], has a doctor said you [name] had angina, angina pectoris or chest pain due to heart disease?

Yes.....☐
No .....☐

[QUESTIONS 41-44b MOVED TO MCU FORM]

45. Since we last contacted you [name], has a doctor said that you [name] had a blood clot in your lungs or a pulmonary embolus?

Yes.....☐
No .....☐→ **GO TO QUESTION 48**

46. Were you (was [name]) hospitalized for a blood clot in your lungs or a pulmonary embolus at that time?

Yes.....☐
No .....☐→ **GO TO QUESTION 48**

HOSPITALIZATION FOR BLOOD CLOT IN LUNGS

47a. Hospital Name, City, State: ☐▼

47a1. Specify hospital name, city, and state if not in drop down list: _____

47b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

48. Since we last contacted you [name], has a doctor said that you [name] had a stroke, slight stroke, transient ischemic attack, or TIA?

Yes.....☐
No .....☐→ **GO TO QUESTION 51**

49. Were you (was [name]) hospitalized for this stroke, slight stroke, transient ischemic attack, or TIA?

Yes.....☐
No .....☐→ **GO TO QUESTION 51**

HOSPITALIZATION FOR STROKE OR TIA

50a. Hospital Name, City, State: ☐▼

50a1. Specify hospital name, city, and state if not in drop down list: _____

50b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

E. ADMISSIONS

51. Since our last contact, were you (was [name]) hospitalized or did you [name] stay in a hospital observation unit for any reason that you have not yet mentioned?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 57**

HOSPITALIZATION FOR OTHER REASON

52a. Hospitalization Reason: _____

52b. Hospital Name, City, State: ☐▼

52b1. Specify hospital name, city, and state if not in drop down list: _____

52c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

HOSPITALIZATION FOR OTHER REASON

53a. Hospitalization Reason: _____

53b. Hospital Name, City, State: ☐▼

53b1. Specify hospital name, city, and state if not in drop down list: _____

53c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

HOSPITALIZATION FOR OTHER REASON

54a. Hospitalization Reason: _____

54b. Hospital Name, City, State: ☐▼

54b1. Specify hospital name, city, and state if not in drop down list: _____

54c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

HOSPITALIZATION FOR OTHER REASON

55a. Hospitalization Reason: _____

55b. Hospital Name, City, State: ☐▼

55b1. Specify hospital name, city, and state if not in drop down list: _____

55c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

HOSPITALIZATION FOR OTHER REASON

56a. Hospitalization Reason: _____

56b. Hospital Name, City, State: ☐▼

56b1. Specify hospital name, city, and state if not in drop down list: _____

56c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

EMERGENCY ROOM/MEDICAL FACILITY INFORMATION

57. Were you (Was [name]) seen at an emergency room or a medical facility for outpatient treatment since our last contact on [mm/dd/yyyy]?

Yes.....☐
No .....☐→ **GO TO QUESTION 60**

58. Was this related to a heart problem or difficulty breathing?

Yes.....☐
No .....☐→ **GO TO QUESTION 60**

59a. ER/Facility Name, City, State: ☐▼

59a1. Specify ER/Facility name, city, and state if not in drop down list:_____

59b. Approximate date ☐☐/☐☐☐☐
Month Year

60. Since our last contact, (Did [name] stay) have you stayed overnight as a patient in a nursing home?

Yes.....☐
No .....☐

61. Are you (Is [name]) currently a resident of a nursing home or long-term care facility?

Yes.....☐
No .....☐

F. INVASIVE PROCEDURES

Next I am going to ask about various types of surgery and medical procedures. We are interested in those that occurred in the hospital, or as an outpatient.

62. Since we last contacted you [name] on [mm/dd/yyyy], have you (has [name]) had any surgery on your [name's] heart, or the arteries of your [name's] neck or legs, not counting surgery for varicose veins?

Yes.....☐
No .....☐→ **GO TO QUESTION 64**

63. Did you [name] have:

a. Coronary bypass?

Yes.....☐
No .....☐

b. Other heart procedure?

Yes.....☐ → Specify: _____
No .....☐

c. Carotid endarterectomy?

Yes.....☐
No .....☐→ **GO TO QUESTION 63e**

d. Site:

Right.....☐
Left.....☐
Both.....☐

e. Other arterial revascularization?

Yes.....☐ → Specify: _____
No .....☐

f. Any other type of surgery on your heart or the arteries of your [name's] neck or legs?

Yes.....☐
No .....☐

64. Since we last contacted you [name] on [mm/dd/yyyy], have you (has [name]) had a balloon angioplasty or stent on the arteries of your [name's] heart, neck, or legs?

Yes.....☐
No .....☐→ **Go to Question 65**

Did you [name] have:

a. Angioplasty or stent of the coronary arteries of your [name's] heart:

Yes.....☐
No .....☐

b. Angioplasty or stent in the arteries of your [name's] neck:

Yes.....☐
No .....☐

c. Angioplasty or stent of the lower extremity arteries:

Yes..... ☐
No ..... ☐

Angioplasty or stent facility information

d. Facility Name, City, State: ☐▼

e. Specify Facility name, city, and state if not in drop down list:_____

f. Approximate date ☐☐/☐☐☐☐
Month Year

G. INTERVIEW

Now I would like to ask about medication use during the past four weeks.

65. Did you [name] take any medications prescribed by a health professional during the past four weeks?

Yes..... ☐
No ..... ☐ → **Go to Question 66**

Did you [name] take any prescribed medications for:

a. High blood pressure or hypertension?

a. .....Yes ☐
b. .....No ☐

b. High blood cholesterol?

a. .....Yes ☐
b. .....No ☐

c. Diabetes or high blood sugar?

a. .....Yes ☐
b. .....No ☐
c. .....

d. Heart failure?

a. .....Yes ☐
b. .....No ☐

e. Asthma?

a. .....Yes ☐
b. .....No ☐

f. Chronic bronchitis or emphysema?

a. .....Yes ☐
b. .....No ☐

g. Chest pain or angina?

a. .....Yes ☐
b. .....No ☐

h. Abnormal heart rhythm?

a. .....Yes ☐
b. .....No ☐

i. Blood thinning?

a. .....Yes ☐
b. .....No ☐

j. Stroke?

a. .....Yes ☐
b. .....No ☐

k. Mini-stroke or TIA?

a. .....Yes ☐
b. .....No ☐

l. Leg pain while walking or claudication?

a. .....Yes ☐
b. .....No ☐

m. Depression?

a. .....Yes ☐
b. .....No ☐

Next I would like to ask you about your regular use of aspirin. This includes aspirin alone or in a combination with another drug, such as aspirin in a cold medicine. By regular use, I mean taking aspirin at least once a week for several months.

66. Do you [name] regularly take any aspirin or aspirin-containing products including Alka-Seltzer, cold and allergy medication or headache powder? This does not include acetaminophen (for example, Tylenol), ibuprofen (for example, Advil, Motrin or Nuprin), and naproxen (for example, Aleve).

Yes.....☐
No .....☐

66a. Do you [name] regularly take medicine for pain or inflammation that does NOT contain aspirin? This would include Tylenol, Advil, Motrin, Nuprin, Midol, or Ibuprofen among others.

Yes.....☐
No .....☐

[Questions 67-68 deleted]

Next, I have a few miscellaneous questions.

69. Do you (Does [name]) now smoke cigarettes?

Yes ..... ☐
No ..... ☐

70. Please tell me which of the following describes your [name's] current marital status:

Married ..... ☐
Widowed ..... ☐
Divorced ..... ☐
Separated ..... ☐
Never Married ..... ☐

H. ADMINISTRATIVE INFORMATION

71. AFU Completion Status:

a. Complete ..... ☐
b. Partially complete; contact again within window (interruptions) ... ☐
c. Partially complete; unable to complete within window (done) ..... ☐

CLOSURE SCRIPT:

If participant deceased: "We may need to contact a family member later. When would be a good time to call in that case?"

OMB#: 0925-0281
Exp. 03/31/2014

MEDICAL CONDITIONS UPDATE FORM

ID NUMBER: ☐☐☐☐☐☐☐ FORM CODE: M C U DATE:11/19/2013 Version 1.0

ADMINISTRATIVE INFORMATION

0a. Completion Date: ☐☐/☐☐/☐☐☐☐ (Month / Day / Year) 0b. Staff ID: ☐☐☐

0c. Person being interviewed:

Participant ..... ☐
Proxy/informant/Other person..... ☐ → **GO TO QUESTION 6**

Instructions: *This form is updated during the interview portion of the participant's follow-up. Any medical condition question which has already been answered 'Yes' should not be asked. Special missing values are allowed for cases where the response "Don't know", "Refused", "Unknown", or "N/A" is not listed as an option.*

SECTION I – This section is asked of the participant only

1. Since we last contacted you, has a doctor said you had high blood pressure?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 2**

1a. Date: ☐☐/☐☐/☐☐☐☐ (Month / Day / Year)

1b. CY: ☐☐

2. Since we last contacted you, has a doctor said you have diabetes or sugar in the blood?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 3**

2a. Date: ☐☐/☐☐/☐☐☐☐ (Month / Day / Year)

2b. CY: ☐☐

3. Since we last contacted you, has a doctor told you that you had chronic lung disease, such as bronchitis, or emphysema?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 4**

3a. Date: ☐☐/☐☐/☐☐☐☐
Month Day Year

3b. CY: ☐☐

4. Since we last contacted you, has a doctor said you had asthma?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 5**

4a. Date: ☐☐/☐☐/☐☐☐☐
Month Day Year

4b. CY: ☐☐

5. Since we last contacted you, has a doctor said that you have peripheral vascular disease or intermittent claudication?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 6**

5a. Date: ☐☐/☐☐/☐☐☐☐
Month Day Year

5b. CY: ☐☐

SECTION II – This section is asked of the participant or the proxy/informant/other person

6. Since we last contacted you [name], has a doctor said that you [name] had heart failure or congestive heart failure?

Yes..... ☐ → **GO TO QUESTION 7a**
No ..... ☐

7. Since we last contacted you [name], has a doctor said that your [name's] heart is weak, or does not pump as strongly as it should, or that you had fluid on the lungs?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 12**

7a. Date: ☐☐/☐☐/☐☐☐☐
Month Day Year

7b. CY: ☐☐

DOCTOR INFORMATION FOR HEART FAILURE/WEAK HEART

8. Name and address of the doctor you [name] saw:

8a. Name _____

8b. Address _____

8c. City: _____ 8d. State: ☐☐

8e. Approximate date: ☐☐/☐☐☐☐
Month Year

If speaking to the participant: **"The ARIC study would like to ask your doctor to tell us more about your health. If you agree to do this, I will send you a form that tells your doctor that you authorize the ARIC study to get this information. Once you sign that form and mail it back to me, I will contact your doctor's office."**

If speaking to the proxy/informant/other: **"The ARIC study would like to ask [name's] doctor to tell us more about his/her health. If you agree to do this, I will send [name] a form that tells the doctor that [name] authorizes the ARIC study to get this information. Once [name] signs that form and mails it back to me, I will contact the doctor's office."**

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

Yes.....☐
No .....☐

If the participant agrees to receiving and signing the release form, remember to update the PHF form when the release form is sent to the participant, and then again when the release form is received back.

HOSPITAL INFORMATION FOR HEART FAILURE/WEAK HEART

10. At that time, were you (Was [name]) hospitalized or did you [name] stay in a hospital observation unit?

Yes.....☐
No .....☐→ **GO TO QUESTION 12**

11a. Hospital/Medical Facility Name, City, State: ☐▼

11a1. Specify hospital/medical facility name, city, and state if not in drop down list: _____

11b. Approximate date of admission: ☐☐/☐☐☐☐
Month Year

12. Since we last contacted you [name], has a doctor said you [name] had an irregular heart beat called atrial fibrillation, or atrial fibrillation on a heart scan or electrocardiogram tracing?

Yes.....☐
No .....☐

13. Since we last contacted you [name], has a doctor said that you [name] had a blood clot in a leg or deep vein thrombosis?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 16a**

14. At that time, were you (was [name]) hospitalized or did you [name] stay in a hospital observation unit for a blood clot in a leg or deep vein thrombosis?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 16a**

HOSPITALIZATION FOR BLOOD CLOT IN LEG

15a. Hospital Name, City, State: [▼]

15a1. Specify hospital name, city, and state if not in drop down list: _____

15b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

PERSONAL NEUROLOGIC HISTORY

If speaking to the participant: **"Since we last contacted you, have you been told by a doctor or health professional that you have:"**

If speaking to the proxy/informant/other: **"Since we last contacted you [name], has [name] been told by a doctor or health professional that he/she has:"**

16a. Alzheimer's Disease?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 16b**

16a1. Date: ☐☐/☐☐/☐☐☐☐
Month Day Year

16a2. CY: ☐☐

16b. Parkinson's Disease?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 16c**

16b1. Date: ☐☐/☐☐/☐☐☐☐
Month Day Year

16b2. CY: ☐☐

16c. Memory loss or cognitive impairment?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 16d**

16c1. Date: ☐☐/☐☐/☐☐☐☐
Month Day Year

16c2. CY: ☐☐

16d. Dementia, vascular dementia, or hardening of the arteries of the brain?

Yes..... ☐
No ..... ☐ → **SAVE AND CLOSE FORM**

16d1. Date: ☐☐/☐☐/☐☐☐☐
Month Day Year

16d2. CY: ☐☐

CLOSURE SCRIPT:

If proxy/informant/other person contacted: "Thank you very much for answering these questions. We will call _____ in a few months."

10. Do you live with this person?

Yes..... ☐
No ..... ☐

11. How much mental or emotional strain is it for you to provide this care?

No strain..... ☐→ **GO TO QUESTION 15**
Low amount of strain..... ☐→ **GO TO QUESTION 15**
Moderate amount of strain.... ☐→ **GO TO QUESTION 15**
A lot of strain ..... ☐→ **GO TO QUESTION 15**
Extreme amount of strain ..... ☐→ **GO TO QUESTION 15**

12. Are you currently receiving care on an ongoing basis from a family member or friend to help with a chronic illness or disability? This would include any kind of help such as companionship, dressing or bathing, arranging care, or providing transportation.

Yes..... ☐
No ..... ☐→ **GO TO QUESTION 15**

13. How are you related to the person who is providing care for you?

Spouse..... ☐
Friend..... ☐
Neighbor..... ☐
Parent/Grandparent..... ☐

14. Do you live with this person?

Yes..... ☐
No ..... ☐

C. ADMINISTRATION INFORMATION

15. sAF General Interview Questions Completion Status:

a. Complete..... ☐
b. Partially complete; contact again within window (interruptions)... ☐
c. Partially complete; unable to complete within window (done)..... ☐

CLOSURE SCRIPT:

"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.]

"Thank you very much for answering these questions. We will call _____ in about six months."

OMB#: 0925-0281
Exp. 3/31/2014

CONTACT INFORMATION UPDATE FORM

ID NUMBER: ☐☐☐☐☐☐☐ FORM CODE C I U DATE: 4/20/2011 Version 1.0

ADMINISTRATIVE INFORMATION

0a. Completion Date: ☐☐/☐☐/☐☐☐☐ (Month / Day / Year) 0b. Staff ID: ☐☐☐

0c. Does participant have hearing problem/loss? Yes ☐ No ☐ 0d. Does participant have cognitive impairment? Yes ☐ No ☐

0e. Participant has a spouse in the ARIC study. Yes ☐ No ☐→ **Go to item 0g** 0f. ID number of spouse: ☐☐☐☐☐☐☐

0g. Administrative information:_____

Instructions: *This form is updated any time a participant's information changes.*

INTRODUCTION SCRIPT: "Hello Mr/Mrs [name of participant or proxy]. My name is _____. I would like to verify some of the information we have collected from you [name] in the past. First, your [name's] personal information; I'll read the information we have and you can let me know if anything needs to be changed."

A. VERIFICATION OF IDENTIFYING INFORMATION

1. a. Title: _____

   b. First Name: _____

   c. Middle Name: _____

   d. Last Name: _____

2. Mailing Address:

   a. _____

   b. _____

   c. City: _____

   d. County: _____

e. State: ☐☐

f. Zip Code: ☐☐☐☐☐-☐☐☐☐

g. Is this mailing address your [name's] physical address? (i.e. where you [name] live[s])

Yes ☐ → **Go to item 3**
No ☐

Physical Address:

h. _____

i. _____

j. City: _____

k. County: _____

l. State: ☐☐

m. Zip Code: ☐☐☐☐☐-☐☐☐☐

3. Home Phone Number: (☐☐☐) ☐☐☐-☐☐☐☐ (land line)

4. Cell Phone Number: (☐☐☐) ☐☐☐-☐☐☐☐ Does not use cell phone ☐

5. Email Address: _____ Does not use email ☐

6. Is there another place where you [name] live[s]?Yes ☐

No ☐ → **Go to item 9**

Mailing Address:

a. _____

b. _____

c. City: _____

d. County: _____

e. State: ☐☐

f. Zip Code: ☐☐☐☐☐-☐☐☐☐

7. Phone Number at this second residence: (☐☐☐) ☐☐☐-☐☐☐☐

8. What time of year do you (does [name])live at this second residence?

from month ☐☐ to month ☐☐

9. SSN ☐☐☐-☐☐-☐☐☐☐ *(QxQ: If participant refuses, make field perm. missing)*

B. CONTACT PERSON 1
"Now I would like to verify the information we have for your [name's] contacts. These are the people we can contact if we are unable to reach you [name] I'll read the information we have and you can let me know if anything needs to be changed."

10. a. Title: _____

b. First Name: _____

c. Middle Name: _____

d. Last Name: _____

11. Mailing Address:

a. _____

b. _____

c. _____

d. City: _____

e. State: ☐☐ f. Zip Code: ☐☐☐☐☐-☐☐☐☐

12a. Telephone #1: (☐☐☐) ☐☐☐-☐☐☐☐

b. Telephone #2: (☐☐☐) ☐☐☐-☐☐☐☐

c. Telephone #3: (☐☐☐) ☐☐☐-☐☐☐☐

13. Relationship: ☐▼

13a. Is this person either the primary or secondary contact? *(check only one)*
- ☐ Primary
- ☐ Secondary
- ☐ Neither primary nor secondary

C. CONTACT PERSON 2

14. a. Title: _____

b. First Name: _____

c. Middle Name: _____

d. Last Name: _____

15. Mailing Address:

a. _____

b. _____

c. _____

d. City: _____

e. State: ☐☐

f. Zip Code: ☐☐☐☐☐-☐☐☐☐

16a. Telephone #1: (☐☐☐) ☐☐☐-☐☐☐☐

b. Telephone #2: (☐☐☐) ☐☐☐-☐☐☐☐

c. Telephone #3: (☐☐☐) ☐☐☐-☐☐☐☐

17. Relationship: ☐▼

17a. Is this person either the primary or secondary contact? *(check only one)*

- ☐ Primary
- ☐ Secondary
- ☐ Neither primary nor secondary

D. CONTACT PERSON 3

18. a. Title: _____

b. First Name: _____

c. Middle Name: _____

d. Last Name: _____

19. Mailing Address:

a. _____

b. _____

c. _____

d. City: _____

e. State: ☐☐

f. Zip Code: ☐☐☐☐☐-☐☐☐☐

20a. Telephone #1: (☐☐☐) ☐☐☐-☐☐☐☐

b. Telephone #2: (☐☐☐) ☐☐☐-☐☐☐☐

c. Telephone #3: (☐☐☐) ☐☐☐-☐☐☐☐

21. Relationship: ☐▼

21a. Is this person either the primary or secondary contact? *(check only one)*

- ☐ Primary
- ☐ Secondary
- ☐ Neither primary nor secondary

E. FOLLOW-UP PROXY INFORMATION

"We are asking all our ARIC participants to give us the name of a person that can answer questions about your [name's] health if you cannot. This person will be considered your [name's] "follow-up proxy" for the ARIC Study. Only your ARIC center can contact your [name's] proxy."

22. Is one of the contact people you have already identified going to be this person for you [name]?"

- ☐ Yes
- ☐ No → **Go to item 23**

22a. Which contact person is your [name's] follow-up proxy? .....☐ → **Go to item 27**

1 = Contact #1
2 = Contact #2
3 = Contact #3

Please identify your [name's] follow-up proxy.

23. a. Title: _____

b. First Name: _____

c. Middle Name: _____

d. Last Name: _____

24. Mailing Address:

a. _____

b. _____

c. _____

d. City: _____

e. State: ☐☐

f. Zip Code: ☐☐☐☐☐-☐☐☐☐

25a. Telephone #1: (☐☐☐) ☐☐☐-☐☐☐☐

b. Telephone #2: (☐☐☐) ☐☐☐-☐☐☐☐

c. Telephone #3: (☐☐☐) ☐☐☐-☐☐☐☐

26. Relationship: ☐▼

F. PHYSICIAN INFORMATION

Instructions: *If updating for Annual Follow-up, this form is complete.*
Questions 27 – 32 are asked during the recruitment phone call in preparation for the clinic visit.

"In approximately 6 weeks, we will send you [name] a summary of your study results from this exam visit."

27. Would you like us to also send this summary to your [name's] physician or provider of medical care?
Yes..... ☐
No ..... ☐→ **Go to item 30**

28. a. First Name: _____

b. Last Name: _____

29. Mailing Address:

a. Clinic/Building: _____

b. _____

c. _____

d. City: _____

e. State: ☐☐

f. Zip Code: ☐☐☐☐☐-☐☐☐☐

G. OPHTHALMOLOGIST OR EYE SPECIALIST INFORMATION

"If you [name is] are selected and agree, we will take a photograph of the back of one of your [name's] eyes. If we find a medical condition in your [name's] eye we can send a report to your [name's] eye specialist."

30. Would you like us to send this report to your [name's] eye specialist?

Yes..... ☐
No ..... ☐→ **Form is complete**

31. What is the name of the doctor, ophthalmologist, or eye specialist you [name] saw concerning your [name's] vision?

a. First Name: _____

b. Last Name: _____

32. Mailing Address:

a. Clinic/Building: _____

b. _____

c. _____

d. City: _____

e. State: ☐☐

f. Zip Code: ☐☐☐☐☐-☐☐☐☐

CONTACT INFORMATION UPDATE FORM
Appendix 1

AUNT
BROTHER
BROTHER (IN LAW)
BROTHER (STEP)
COUSIN
DAUGHTER
DAUGHTER (IN LAW)
DAUGHTER (STEP)
EX WIFE
FATHER
FATHER (IN LAW)
FATHER (STEP)
FRIEND
GRAND CHILD
HUSBAND
MOTHER
MOTHER (IN LAW)
MOTHER (STEP)
NEIGHBOR
NEPHEW
NIECE
PASTOR/MINISTER/PRIEST
SISTER
SISTER (IN LAW)
SISTER (STEP)
SON
SON (IN LAW)
SON (STEP)
UNCLE
WIFE
OTHER - SPECIFY IN NOTE LOG

Drop-down menu items for ‘Relationship’ questions on the CIU.

Appendix 2

Follow-Up by Proxy

A very important goal of the Atherosclerosis Risk in Communities (ARIC) Study is to keep track of any major changes in your health. This information is important for answering scientific questions about heart disease and other health conditions. You are the best source of information regarding your health, but there may be times when you are not able to provide these details yourself. We are asking you to provide us with the name of a person that can answer questions about your health if you cannot. This person will be considered your "proxy" for the ARIC Study. The person you designate would only be contacted once per year, should you be unable to respond. Only your ARIC center can contact your proxy.

What is a proxy?
A proxy is someone who can "stand in" for you and tell us about your health when you cannot because of illness.

Why is a proxy needed?
For almost 20 years you have been providing information about your health to ARIC. This important information should not be lost, even when you are unable to provide it yourself.

What does a proxy do?
Should it be necessary we would ask your proxy to answer questions about your health, just like the questions you have been asked each year by the ARIC staff.

Whom should I name as my proxy?
You should select someone who knows you well enough to provide health information about you. For example, your proxy can be the person who has your power of attorney, your legal health care proxy, or your legal next-of-kin (including your spouse, son, daughter, brother, sister, etc).

Am I allowed to change my proxy?
Yes, you may change your proxy at any time by either calling ARIC or by indicating your wishes at your annual ARIC phone call.

Will you give my earlier information to my proxy?
No, all of your information is strictly confidential and will not be provided to your proxy.

What would you like me to do now?
Using the attached form please indicate whom you have chosen to be your proxy. Please indicate his/her name, contact information, relationship to you, sign the form and mail it to the ARIC field center in the enclosed envelope.

We have sent a copy of this form for your own records and one to give to your proxy. This material should be kept by him/her so he/she understands your wishes as a participant in the ARIC Study.

If you have any questions call Mr/Ms. ……. ARIC Study Manager at (xxx) xxx-xxxx

Thank you for your continued dedication to the ARIC Study!

ARIC Proxy Designation Form

Participant Name: _____ ARIC ID: _____
First Last MI

I have named as my proxy: _____
(Name of person you choose as ARIC Proxy)

Relationship:_____

Proxy Address:_____

_____

_____

Proxy Phone Number:_____

He/she has the authority to provide medical information, and/or to sign a Medical Release Form to obtain hospital records or physician records for the ARIC Study.

_____ _____
Participant's Signature Date

_____ _____
Witness Date

Complete only if participant is physically unable to sign: I have signed the Participant's name above at his/her direction in the presence of the Participant and witness.

_____ _____
(Name) (Street)

_____
(City/Town) (State)

Optional: If my ARIC Proxy is unwilling or unable to serve, then I appoint as my Alternate ARIC Proxy:

_____
(name of person you choose as your alternate proxy)

of_____
(street) (city/town) (state) (phone)

OMB#: 0925-0281
Exp. 03/31/2014

DEATH INFORMATION

ID NUMBER: ☐☐☐☐☐☐☐ FORM CODE: D E C DATE: 12/15/11 Version 1.0

ADMINISTRATIVE INFORMATION

0a. Completion Date: ☐☐/☐☐/☐☐☐☐ (Month / Day / Year) 0b. Staff ID: ☐☐☐

Instructions: *This form is completed during the interview portion of the participant's follow up in the event of the participant's death. The Date is the day the contact is made, or is the date the status determination is 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]. My name is [your name] and I am from the ARIC Study. We were saddened to learn of [participant's name] death. Please accept our condolences for your loss. Would you be willing to answer a few questions about [participant's name]?"

A. DEATH INFORMATION

1. Death reported by: (select one)

Relative/Spouse/Acquaintance ..... ☐
Surveillance ..... ☐
Other (e.g., Obituary, Social Security Administration) ..... ☐

2. Date of death: ☐☐/☐☐/☐☐☐☐ (Month / Day / Year)

3. Location of death:

a. City: _____ c. State: ☐☐

b. County: _____

4. Are you able to answer some questions about any hospitalizations that occurred since our last contact with [name] on [mm/dd/yyyy]?

Yes ..... ☐ → **GO TO QUESTION 6**
No ..... ☐

5. Is there someone else who could answer these questions?

Yes - person located ..... ☐
Yes - reschedule remainder of interview ..... ☐ → **GO TO QUESTION 13**
No ..... ☐ → **GO TO QUESTION 13**

B. HOSPITALIZATIONS FOR HEART ATTACK / HEART CONDITION / STROKE

6. Was [name] hospitalized for a heart attack, or heart condition, or stroke since our last contact on [mm/dd/yyyy]?

Yes ..... ☐
No ..... ☐ → **GO TO QUESTION 8**

6a. Hospital Name, City, State: ☐▼

6a1. Specify hospital name, city, and state if not in drop down list: _____

6b. Approximate date of hospitalization: ☐☐/☐☐☐☐
Month Year

Second hospitalization, if applicable

7a. Hospital Name, City, State: ☐▼

7a1. Specify hospital name, city, and state if not in drop down list: _____

7b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

C. OTHER HOSPITALIZATIONS

8. Did [name] stay overnight as a patient in a hospital for any other reason since our last contact?

Yes ..... ☐
No ..... ☐ → **GO TO QUESTION 11**

8a. Hospitalization Reason: _____

8b. Hospital Name, City, State: ☐▼

8b1. Specify hospital name, city, and state if not in drop down list: _____

8c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

Second hospitalization, if applicable

9a. Hospitalization Reason: _____

9b. Hospital Name, City, State: ☐▼

9b1. Specify hospital name, city, and state if not in drop down list: _____

9c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

Third hospitalization, if applicable

10a. Hospitalization Reason: _____

10b. Hospital Name, City, State: ☐▼

10b1. Specify hospital name, city, and state if not in drop down list: _____

10c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

D. OUTPATIENT TREATMENT

11. Was [name] admitted to an emergency room or a medical facility for outpatient treatment since our last contact?

Yes.....☐
No.....☐→ **GO TO QUESTION 13**

12. Was this related to a heart problem or difficulty breathing?

Yes.....☐
No.....☐→ **GO TO QUESTION 13**

12a. Hospital/Medical Facility Name, City, State: ☐▼

12a1. Specify hospital/medical facility name, city, and state if not in drop down list: _____

12b. Approximate date of admission: ☐☐/☐☐☐☐ → **GO TO QUESTION 13**
Month Year

CLOSURE SCRIPT:

"Thank you very much for answering these questions."

E. ADMINISTRATIVE INFORMATION

13. Death Information Completion Status:

a. Complete ..... ☐
b. Partially complete; contact again within window (interruptions) ... ☐
c. Partially complete; unable to complete within window (done) ..... ☐