



SEMI-ANNUAL FOLLOW-UP FORM

ID NUMBER:

STUDY YEAR SEQ #

FORM CODE: SAF
VERSION: A - 7/15/10

ADMINISTRATIVE INFORMATION

Oa. Completion Date: / /
Month Day Year

Ob. Staff ID:

Public reporting burden for this collection of information is estimated to average 6-15 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: **NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0281)**. Do not return the completed form to this address.

Instructions: This form should be completed during the interview portion of the participant's **semi-annual** follow-up. ID Number, Contact Year, and Name must be entered above. Code the correct entry clearly above the incorrect entry. For "multiple choice" and "yes/no" type questions, circle the letter corresponding to the most appropriate response. If a letter is circled incorrectly, mark through it with an "X" and circle the correct response.

A. VITAL STATUS

1. Date of status determination: / /
Month Day Year

2. Final Status (choose one)

3. Information obtained from (choose one)

Contacted and Alive C Phone A → **Go to Question 6**
 Personal Interview / Proxy Interview B → **Go to Question 6**
 Letter C → **Go to Question 17**

Contacted and Refused F → **Go to Question 31**

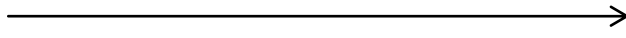
Reported Alive R Relative, spouse, acquaintance D
 Employer information E **Go to Question 17**
 Other F

Reported Deceased D Relative, spouse, acquaintance G
 Surveillance H **Go to Question 4**

Other (National Death Index) I

Unknown

U



Go to Question 31

B. DEATH INFORMATION

4. Date of death: / /
Month Day Year

5. Location of death:

a. City/ County

b. State:

If deceased. skip to Question 17.

C. GENERAL HEALTH

“I would like to start with some questions about your health that ARIC has not asked you before:”

6. Have you ever been told by a physician that you that had gout?

Yes
No → **Go to Question 7**
Unknown..... → **Go to Question 7**

a. How old were you when a physician first told you had gout?

 Age in years

b. When was the last time you had to get health care for your gout?

 Age in years (*for the QxQs: within the year = 0 years*)

7. Have you ever been told by a doctor or heath professional that you had/have Parkinson’s disease?

Yes
No → **Go to Question 8**
Don’t know → **Go to Question 8**

a. How old were you when you were first told you had Parkinson’s disease?

 Age in years

b. Are you currently being treated for Parkinson’s?

Yes
No → **Go to Question 8**
Don’t know → **Go to Question 8**

“The ARIC study would like to ask the physician to tell us more about your health. If you agree to do this I will send you a form that tells your physician that you authorize the ARIC study to get this information from your doctor. Once you sign that form and mail it back to me I will contact your physician’s office.”

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

Yes

No

d. What is the name and address of the doctor who is seeing you for Parkinson’s disease

Name: _____

Address: _____

D. QUALITY OF LIFE

Use of the SF-12 form for AFU call. (Copied from <http://www.bellmorept.com/SF-12%20Health%20Survey.pdf>)

Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by filling in the bubble that best represents your response.

1. In general, would you say your health is: ① Excellent ② Very Good ③ Good ④ Fair ⑤ Poor

2. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?	①	②	③
b. Climbing several flights of stairs?	①	②	③

3. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

	Yes	No
a. Accomplished less than you would like	①	②
b. Were limited in the kind of work or other activities	①	②

4. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	Yes	No
a. Accomplished less than you would like	①	②
b. Didn't do work or other activities as carefully as usual	①	②

5. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home, and housework)?

① Not at all ② A little bit ③ Moderately ④ Quite a bit ⑤ Extremely

6. These questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the **past 4 weeks**....

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a. Have you felt calm and peaceful?	①	②	③	④	⑤	⑥
b. Did you have a lot of energy?	①	②	③	④	⑤	⑥
c. Have you felt downhearted and blue?	①	②	③	④	⑤	⑥

7. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

① All of the time ② Most of the time ③ Some of the time ④ A little of the time ⑤ None of the time

E. HEALTH CARE UTILIZATION

8. "Now I will ask you some questions about your health since the last time we contacted you on (mm/dd/yyyy). Since that time and compared to other people your age, would you say that your health has been excellent, good, fair or poor?"

- Excellent
- Good
- Fair
- Poor

9. When you get sick or need advice about your health, what kind of place do you go to most often – a clinic, doctor’s office, emergency room, or some other place?

- Clinic or health center A
- Doctor’s office or HMO B
- Hospital emergency room C
- Hospital outpatient department D
- Other, specify: _____ E
- Doesn’t go to one place most often F
- Don’t know G

10. In the past 12 months, was there any time when you delayed getting medical care when you needed it?

- Yes
- No → **Go to Question 12**
- Refused → **Go to Question 12**
- Don’t know → **Go to Question 12**

11. What reason(s) did delay getting medical care in the past 12 months when you needed it?

- | | Yes | No |
|--|--------------------------|--------------------------|
| a. You couldn’t get through on the telephone..... | <input type="checkbox"/> | <input type="checkbox"/> |
| b. You couldn’t get an appointment soon enough..... | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Once you got there, you had to wait too long to see the doctor..... | <input type="checkbox"/> | <input type="checkbox"/> |
| d. The clinic/doctor’s office wasn’t open when you could get there ... | <input type="checkbox"/> | <input type="checkbox"/> |
| e. You didn’t have transportation..... | <input type="checkbox"/> | <input type="checkbox"/> |
| f. You did not have health insurance..... | <input type="checkbox"/> | <input type="checkbox"/> |

12. During the past 12 months, was there any time when you needed any of the following, but didn't get it because you couldn't afford it?

	Yes	No
a. Prescription medications	<input type="checkbox"/>	<input type="checkbox"/>
b. To be seen by doctor	<input type="checkbox"/>	<input type="checkbox"/>
c. Mental health care or counseling	<input type="checkbox"/>	<input type="checkbox"/>
d. Nursing home care	<input type="checkbox"/>	<input type="checkbox"/>
e. Surgery	<input type="checkbox"/>	<input type="checkbox"/>

13. To help pay for medical care, do you NOW have:

- a. Health insurance or a health plan, such as Blue Cross/Blue Shield or a HMO Y/N/U
- b. Medicare Y/N/U
- c. Medicaid Y/N/U
- d. Other Y/N/U

14. How often do you have a routine physical examination that is not for a particular illness, but for a general check-up? (At least once every five years, less than once every five years, do not have routine physical examinations, unknown)

15. During the last year, have you not received a doctor's care or prescription medications because you needed the money to buy food, clothing, or pay for housing? YES/NO

16. Which of these is the main problem that caused you difficulty, delay, or not receiving needed health care?

- a. Can't afford care
- b. Insurance company won't approve, cover, or pay for care
- c. Pre-existing condition
- d. Insurance required a referral, but couldn't get one
- e. Doctor refused to accept my insurance plan
- f. Medical care too far away
- g. Can't drive/ don't have car/ no public transportation available
- h. Too expensive to get there
- i. Hearing impairment or loss
- j. Hard to get into building
- k. Hard to get around inside building
- l. No appropriate equipment in office
- m. Couldn't get time off work
- n. Didn't know where to get car
- o. Was refused services
- p. Didn't have time or took too long
- q. Other

F. HEALTH CARE SATISFACTION

17. In the last 12 months, how many times did you go to a doctor’s office or clinic to get care for yourself? Do not include times you were hospitalized or went to an emergency room.

Enter number of times → **IF 0, Go to Question 17**

18. In the last 12 months, how often did doctors ...

	Never	Sometimes	Usually	Always
a. listen carefully to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. explain things in a way you could understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. show respect for what you had to say?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. spend enough time with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. In the last 12 months, how often did nurses ...

	Never	Sometimes	Usually	Always
a. listen carefully to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. explain things in a way you could understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. show respect for what you had to say?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. spend enough time with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Using a number from 0 to 10, where 0 is the worst health care possible and 10 is the health care possible, what number would you use to rate all your health care in the last 12 months?

21. Does this health care provider have office hours at night or on weekends? Yes/No

II. How difficult is it to get appointments with this health care provider on short notice, for example, within one or two days? Would you say it is:

- a. very difficult
- b. somewhat difficult
- c. not too difficult
- d. not at all difficult

22. If you arrive on time for an appointment, about how long do you usually have to wait before seeing a medical person at your health care provider?

- a. Less than 5 minutes
- b. 5 to 15 minutes
- c. 16 to 30 minutes
- d. 31 to 59 minutes
- e. 1 to 2 hours
- f. More than 2 hours

23. How difficult is it to contact a medical person at your health care provider over the telephone about a health problem? Would you say it is:

- a. Very difficult
- b. Somewhat difficult
- c. Not too difficult
- d. Not at all difficult

24. How satisfied are you with the professional staff at your health care provider's office? Would you say that you are:

- a. Very satisfied
- b. Somewhat satisfied
- c. Not too satisfied
- d. Not at all satisfied

25. Overall, how satisfied are you with the quality of care received from your health care provider. Would you say that you are:

- a. very satisfied
- b. somewhat satisfied
- c. not too satisfied
- d. not satisfied at all

G. ADMISSIONS

26. Since our last contact on (mm/dd/yyyy), have you stayed (Did [name] stay) overnight as a patient in a hospital?

- Yes
- No → **Go to Question 17D**
- Unknown..... → **Go to Question 17D**

a. Were you (Was [name]) hospitalized for a heart attack since our last contact on (mm/dd/yyyy)?

- Yes
- No
- Unknown.....

b. Were you hospitalized for a stroke, slight stroke, transient ischemic attack or TIA?

- Yes
- No
- Unknown.....

c. Since we last contacted you on mm/dd/yyyy, were you hospitalized for heart failure or congestive heart failure?

- Yes
- No
- Unknown.....

If "Yes" to 17a, 17b or 17c, add to "HOSPITALIZATIONS" section G and return.

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

- Yes
- No
- Unknown.....

If No or Unknown: Go to Question 18.

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

- Yes
- No
- Unknown.....

If No or Unknown: Go to Question 18.

What is the name and address of this medical facility ?

e1. Name: _____

e2. Address: _____

e3. What was the approximate date? /
M M Y Y Y Y

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

Yes

No → **Go to Question 27**

For DECEASED, REPORTED ALIVE, or CONTACTED BY LETTER statuses, go to Question 31.

28. Are you currently staying in a nursing home?

Yes

No

H. HOSPITALIZATIONS

“For each time you were (he/she was) a patient in a hospital, I would like to obtain the reason you were (he/she was) admitted, the name of the hospital, and the date. When was the first time you were (he/she was) hospitalized since our last contact with you (him/her) on (mm/dd/yyyy of last contact)?” *Fill in, probing as necessary. Probe for additional hospitalizations.*

29a. Hospitalization Reason:

29b. Hospital Name, City, and State:

29c. Month and Year: /
M M Y Y Y Y

30a. Hospitalization Reason:

30b. Hospital Name, City, and State:

30c. Month and Year: /
M M Y Y Y Y

31a. Hospitalization Reason:

31b. Hospital Name, City, and State:

31c. Month and Year: /
M M Y Y Y Y

32a. Hospitalization Reason:

32b. Hospital Name, City, and State:

32c. Month and Year: /
M M Y Y Y Y

33a. Hospitalization Reason:

33b. Hospital Name, City, and State:

33c. Month and Year: /
M M Y Y Y Y

34a. Hospitalization Reason:

34b. Hospital Name, City, and State:

34c. Month and Year: /
M M Y Y Y Y

35a. Hospitalization Reason:

35b. Hospital Name, City, and State:

35c. Month and Year: /
M M Y Y Y Y

I. 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 in an emergency department, or as an outpatient."

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

Yes
No → **Go to Question 29**

37. Did you have:

a. Coronary bypass?

Yes
No

b. Other heart procedure?

Yes Specify: _____
No

c. Carotid endarterectomy?

Yes

No → **Go to Question 29**

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 neck or legs?

Yes

No

38. Since we last contacted you on (mm/dd/yyyy) have you had a balloon angioplasty or stent on the arteries of your heart, neck, or legs?

Yes

No → **Go to Question 30**

Did you have:

a. Angioplasty or stent of the coronary arteries of your heart:

Yes

No

b. Angioplasty or stent in the arteries of your neck:

Yes

No

c. Angioplasty or stent of the lower extremity arteries:

Yes

No

J. INTERVIEW

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

39. Did you take any medications during the past two weeks for:

a. High blood pressure?

Yes

No

Unknown

b. High blood cholesterol?

Yes

No

Unknown

c. Diabetes or high blood sugar?

Yes
No
Unknown.....

d. Heart failure?

Yes
No
Unknown.....

[Closure script]

K. ADMINISTRATIVE INFORMATION

40. Does participant (still) live within official ARIC study boundaries?

Yes
No
Unknown.....

41. Will your center (still) be able to get his/her records via community surveillance?

Yes
No

42. Result code:

Result Codes

- 01 – No Action Taken
- 02 – Tracing (Not yet contacted any source)
- 3A – Contacted, Interview Complete by Cohort Member
- 3B - Contacted, Interview Complete, Proxy/Informant
- 04 – Contacted, Interview Partially Complete or Rescheduled
- 05 – Contacted, Interview Refused
- 06 – Reported Alive, Will Continue to Attempt Contact This Year
- 07 – Reported Alive, Contact Not Possible This Year
- 08 – Reported Deceased
- 09 – Unknown
- 98 – Does Not Want Any Further AFU Contact

L. MEDICATION ADHERENCE

Questions modified from the Sueta Medication Survey, Version 7

43. How convinced are you that it is important to take your heart medicines every day? Circle one.
Not important 0 1 2 3 4 5 6 7 8 9 10 Very important

44. How difficult is it for you to pay for your heart medicines? (Very difficult, Somewhat difficult, Not difficult, Easy)

45. In the last year, how often did you miss your heart medicines? (Often, Sometimes, Rarely, Never)

46. In the last year, have you “stretched” (take less of) your heart medicines to make it last longer? (Often, Sometimes, Rarely, Never)

47. In the last year, how often did you run out of your heart medicines? (Often, Sometimes, Rarely, Never)

48. If you ran out, what were the reasons? Check all that apply: Cost, Lack of transportation to get heart medicines, Forgot, Other____)

Morisky Scale Questions[5]

49. Do you ever forget to take your medicine? Y/N

50. Are you careless at time about taking your medicine? Y/N

51. When you feel better, do you sometimes stop taking your heart medicine? Y/N

52. Sometimes if you feel worse when you take the heart medicines, do you sometimes stop taking it?
Y/N