

**Annual Follow-Up Other Form Instructions**  
**AFO Version C : 08/18/2005**  
**QxQ Prepared: 08/19/2005**

**I. GENERAL INSTRUCTIONS**

Annual follow-up of the JHS cohort is used to maintain contact and correct address information of cohort participants, ascertain vital status, and document interim medical and life course events, which have occurred since the last contact. Annual follow-up contacts are scheduled approximately every 12 months based on a schedule that accommodates the date of the baseline clinic visit and reordering of participant "windows" to allow for a three year exam with an approximately equal number of participants. Each routine follow-up is completed by telephone. The only exception to this is when a participant cannot be contacted using all available telephone numbers. At this point, field tracing is initiated and, if located, the participant may be interviewed in person.

The Annual Follow-Up Other (AFO) form is completed as the second of three (or four if the participant has not previously completed any one of Annual Follow Up 1 [AF1], Annual Follow Up 2 [AF2], Annual Follow Up 3 [AF3], or Annual Follow Up Extra [AFE]) annual follow-up forms administered each year. It is completed immediately following completion of the AFU form. The interviewer must be certified and should have a working knowledge of the annual follow-up procedures. S/he should also be familiar with the data entry procedures for electronic version forms and the document titled "General Instructions for Completing Paper Forms" prior to completing this form. ID number, Contact Year, and Name should be completed as described in that document.

Form sections for completing for completing the AFU are generally completed in the following order:

- 1) Annual Follow-Up Record of Calls (ARC)
- 2) Annual Follow-Up Form (AFU)
- 3) Annual Follow-Up Other Form (AFO)
- 4) Annual Follow-Up 1, 2, or 3; Annual Follow-Up Extra (AF1, AF2, or AF3; AFE) **[PLEASE NOTE: THESE FORMS ARE ONLY COMPLETED IF THE PARTICIPANT DID NOT COMPLETE THEM IN A PRIOR YEAR]**
- 5) Appointment scheduling (if due) (See script and Clinic Appointment Form [CLA])
- 6) Contact Form (CON): Verification of participant contact information

**II. SPECIFIC INSTRUCTIONS**

**Please note that while all items have a possible response choice of DON'T KNOW, REFUSED, or MISSING this is not read to the participant. This response option is only to be used by the interviewer when the participant absolutely refused to answer the specific question.**

1. This item is intended to determine whether the participant has taken any medications in the past two weeks (that is, two weeks prior to the annual follow up telephone call) for any heart related conditions. This item may be somewhat difficult for respondents as they may not be aware of all the reasons that they take medications.

Item a. addresses medications for chest pain or angina. These medications may include such things as nitroglycerine, isosorbide mononitrate, isosorbide dinitrate, Ismo and so forth.

Item b. addresses any other heart condition. This can include a wide variety of medications (e.g. for high blood pressure, for irregular heart beat, etc.). We are particularly interested in any medications taken for treatment of congestive heart failure. Therefore, that type of medication is specified in the question stem. However, if the participant does not know why s/he takes the medication but just knows it is for "heart", the answer should be YES.

For each item a. – d., read the question as written and record YES, NO, DON'T KNOW, REFUSED, or MISSING as appropriate. Please read the items as printed and, if the respondent answers "Yes" to Item 1 b., ask her/him to tell you the name of the medication.

If the respondent can not recall the name of the medication, ask her/him if they would get their medication bottle and read the name and dose to you. Record the name of any and all medication(s) (and dosage, if that is provided) in the space provided.

2. This series of questions is intended to identify whether the participant has experienced any of the possible symptoms of congestive heart failure in the past two weeks (that is two weeks prior to the annual follow up telephone contact). For each item a. – e., read the question as written and record YES, NO, DON'T KNOW, REFUSED, or MISSING as appropriate.

If the respondent answers "Yes" to any item a. through e., ask if the respondent has been seen by a health care provider in the past year (from the date of the last contact with the Jackson Heart Study, either by telephone for annual follow up, or if this is the first annual follow up contact, since the baseline clinic examination).

3. This item (3a-d) is intended to identify whether the respondent has had any heart-related diagnostic tests or procedures (3e) performed in the past year (since the last contact with the Jackson Heart Study, either by telephone for annual follow up, or if this is the first annual follow up contact, since the baseline clinic examination). For each item a. through 3., read the question as written and record YES, NO, DON'T KNOW, REFUSED, or MISSING as appropriate.

3a1-3d1. If the participant answers YES to any of the items 3a-3d, ask the respondent to tell you why s/he had the test or procedure done. If using the DMS, the drop down box will provide the specific list of available responses [including an OTHER (SPECIFY)]. If using a paper version of this form, select from the list of responses designated on the form for each item; e.g. Items 3 a-c use one set of response codes, Item 3d and 3e each have their own set of response codes specific to those items.

- 3e. This item (3e) is intended to identify whether the respondent has had any heart-related procedures performed in the past year (since the last contact with the Jackson Heart Study, either by telephone for annual follow up, or if this is the first annual follow up contact, since the baseline clinic examination). Read the question as written and record YES, NO, DON'T KNOW, REFUSED, or MISSING as appropriate.

3e1-3e4. If the response to Item 3e is YES, ask the respondent to tell you what kind of catheterization or arteriogram they had done. That is, was it a carotid arteriogram/catheterization to look at the blood vessels in their neck, a coronary catheterization for the blood vessels around their heart, a renal arteriogram to visualize the arteries going to the kidneys, or a peripheral arteriogram to look at the vessels in their legs.

4. If the participant answers YES to any of the items 3e1-3e4, ask the respondent to tell you why s/he had the procedure done. If using the DMS, the drop down box will provide the specific list of available responses [including an OTHER (SPECIFY)]. If using a paper version of this form, select from the list of responses designated on the form.
5. This item is intended to capture any changes in family history since the last JHS contact. This could be a sensitive question as it asks about deaths of close relatives within the past year. Remind the participant that we are interested in her or his natural parents, full siblings, or natural children only (no half siblings, adopted children, etc). If the answer is YES, proceed to Item 7 to ascertain additional information about the person(s) who died. Otherwise, go to Item 8.

6. This item is intended to detail the relationship, cause of death, and age at death for each family member who died within the year since the last JHS contact. In each column select the type of relationship (mother, father, sibling, child) for Item 7a, the cause of death (cancer, heart attack, stroke, other) in Item 7b, and the age at death in Item 7c. Record age to the nearest year. There are four response options provided. If OTHER, specify in the boxes provided. Items 6-1 through 6-4 allow space for up to four family deaths in the preceding year.
7. This item continues the information of changes in family history to ask about any new diagnoses (having been told by a health care provider) in their family (parents, sibling, children) since the last JHS contact. If YES, proceed to Item 9 to characterize more fully the relationship and diagnosis. Otherwise go to Item 10.
8. In this item, for each person who was told they had a new health condition in the year since the participant's last JHS contact, identify the relationship (8a), diagnosis (8b: high blood pressure, stroke, heart disease, diabetes, cancer, other), and the age (8c) at diagnosis. There are four response options provided. If OTHER, specify in the boxes provided. Items 8-1 through 8-4 allow for up to 4 new family diagnoses in the preceding year.

Initiate the next section by reading the introductory script.

Remind the participant that the time frame for these questions is the past year. If the participant has difficulty or is not clear on the time frame involved say, "that is, from this time last year." Inform the respondent in advance that each item has six possible answers and ask them to listen carefully, selecting the one which most closely matches her/his experience.

9. This item is intended to assess the degree of overall stress the respondent has experienced over the past year. Stress may include any number of things, both positive and negative, as defined by the participant. Avoid interpreting for the participant, but the interviewer may clarify by saying something like "stress might include both good and bad experiences, such as getting a desired, new job or being fired or laid off from a job." Read the question. Provide the response options: NONE, VERY LITTLE, MILD STRESS, MODERATE STRESS, A LOT OF STRESS, EXTREME STRESS. Record DON'T KNOW, REFUSED, OR MISSING as appropriate if the respondent does not select one of the response options.
10. This item is intended to assess the degree of depressed mood experienced by the respondent over the past year. Read the question. Provide the response options: ALMOST NEVER, SELDOM, SOMETIMES, OFTEN, VERY OFTEN, CONSTANTLY. Record DON'T KNOW, REFUSED, OR

MISSING as appropriate if the respondent does not select one of the response options.

11. This item is intended to assess the degree of anxiety experienced by the respondent over the past year. Read the question. Provide the response options: ALMOST NEVER, SELDOM, SOMETIMES, OFTEN, VERY OFTEN, CONSTANTLY. Record DON'T KNOW, REFUSED, OR MISSING as appropriate if the respondent does not select one of the response options.
12. This item is intended to assess the degree of unfair treatment or discrimination experienced by the respondent over the past year. Read the question. Provide the response options: ALMOST NEVER, SELDOM, SOMETIMES, OFTEN, VERY OFTEN, CONSTANTLY. Record DON'T KNOW, REFUSED, OR MISSING as appropriate if the respondent does not select one of the response options.
13. This item is intended to assess the extent of coping with stressors experienced by the respondent over the past year. Read the question. Provide the response options: VERY POORLY, POORLY, FAIR, PREGGY WELL, WELL, VERY WELL. Record DON'T KNOW, REFUSED, OR MISSING as appropriate if the respondent does not select one of the response options.
14. This item is intended to assess the degree of satisfaction with the social support experienced by the respondent over the past year. Read the question. Provide the response options: ALMOST NEVER, SELDOM, SOMETIMES, OFTEN, VERY OFTEN, CONSTANTLY. Record DON'T KNOW, REFUSED, OR MISSING as appropriate if the respondent does not select one of the response options.
15. This item is intended to identify a wide range of possible types of health care providers, both traditional and nontraditional, that the respondent may have seen in the past year (since the last contact with the Jackson Heart Study, either by telephone for annual follow up, or if this is the first annual follow up contact, since the baseline clinic examination). For each item a. through h., read the question as written and record YES, NO, DON'T KNOW, REFUSED, or MISSING as appropriate.
16. This item is intended to determine the participant's current insurance status. Current means as of the day of the interview. Health insurance can include private insurance such as Blue Cross/Blue Shield, or government sponsored programs such as Medicare, Medicaid, or CHAMPUS / TRICARE. Read the question and each the response options. Based on the participants answer, choose one of the following options: YES, NO, DON'T KNOW, REFUSED, or MISSING. Observe the skip pattern based on the participant's response. If

the participant answers NO, go to item 12. For all other responses, go to item 13.

17. This item is intended to determine how long the person has been without health insurance for participants who answered NO, DON'T KNOW, REFUSED, or MISSING to Item 11. Read the question and each the response options. Based on the participants answer, choose one option. After answering this question, go to item 16 (skipping items 13 through 15).
18. This item is intended to determine the current type of health insurance coverage for participants who respond YES or DON'T KNOW to Item 11. Read the question and each response option since a participant may be covered by more than one type of health insurance program. For each response option, record either YES, NO, DON'T KNOW, REFUSED, or MISSING.
19. This item is intended to determine whether the participant has experienced any of the identified changes in health insurance benefits in the past year or since the last annual follow-up call. If the participant has difficulty understanding the time frame involved say, "that is, from this time last year, or the last time we talked with you on the phone". Read the question and each response option. For each response option for items a. through c., record YES, NO, DON'T KNOW, REFUSED, or MISSING, as appropriate.
- 20 This item is used to determine whether the participant has experienced a lapse in health insurance coverage in the past year. Read the question and each the response options. Based on the participant's answer, record YES, NO, DON'T KNOW, REFUSED, or MISSING, as appropriate.
- 21 This item is intended to determine how much the participant is spending out of pocket on medication each month. **Do not include the amount paid by health insurance program.** Make sure that the participant understands the one-month time frame. You may need to clarify with her/him whether they purchase medications each month, or if they receive a 3-month supply via mail order or other mechanism. If the participant buys prescriptions over a 3-month time period, divide the amount by 3 to determine the monthly spending. Read the question and response options and record YES, NO, DON'T KNOW, REFUSED, or MISSING, as appropriate.
22. This item is used to determine whether the participant currently has health insurance coverage that helps pay for prescription medications. Read the question and choose one of the following options: YES, NO, DON'T KNOW, REFUSED, or MISSING, as appropriate.

Observe the skip pattern based on the participant's response. If the participant answers NO, go to item 20. For all other responses, go to item 18.

23. This item is intended to determine whether the person has set co-payment for each prescription filled. A co-payment is an amount that is paid by the person regardless of the actual cost of the medication. For example, generic medications may have a lower co-payment (for example \$10), while a preferred medication (a medication that the insurance company has designated as "preferred" over other similar medications in the same class) may have another payment (say, \$15), and a non-preferred, non-generic medication may have a much higher co-payment (for example, \$30-40). So, the co-payment may vary depending on the type of prescription. This item is only attempting to determine whether the person does have a co-payment option as part of their medication insurance plan. Read the question and response options, recording YES, NO, DON'T KNOW, REFUSED, or MISSING, as appropriate.
24. This item is intended to determine additional detail on the type of medication insurance coverage for participants who answered YES or DON'T KNOW to Item 17. For items a., b., d., f., and h., record YES, NO, DON'T KNOW, REFUSED, or MISSING, as appropriate.

If the respondent answers YES to item b., record the dollar limit on medications in item c.

If the respondent answers YES to item d., record the number of medications s/he is limited to each month in item e.

If the respondent answers YES to item f., record the number of months that must lapse before s/he can refill a prescription in item g. For example, many plans require that participants obtain a 3 month supply and medications cannot be refilled prior to that time.

If the respondent answers YES to item h., record the specific "Other" limitation on her/his prescription medication insurance coverage. Record verbatim the respondent's answer.

The next set of items assesses the participant's use of and experiences when using health services over the past year. Make sure the participant understands the time frame, that is, from this time last year.

25. This item is intended to assess the level of use of primary health care services provided by a doctor, nurse practitioner, or some other health care clinic. Read the question and response options. Notice the skip pattern. If the

participant has not seen a health care provider over the past year, go to item 26. Otherwise, go to item 21.

26. This item is intended to assess the participant's perception of how well the providers listened to her/his concerns during health care encounters. Read the question and response options. Record NEVER, SOMETIMES, USUALLY, ALWAYS, DON'T KNOW, REFUSED, or MISSING, as appropriate.
27. This item is intended to assess the participant's perception of how well the providers explained things in a way the participant could understand. Read the question and response options. Record NEVER, SOMETIMES, USUALLY, ALWAYS, DON'T KNOW, REFUSED, or MISSING, as appropriate.
28. This item is intended to assess the participant's perception of how well the providers showed respect for the client and what he or she had to say during health care encounters. Read the question and response options. Record NEVER, SOMETIMES, USUALLY, ALWAYS, DON'T KNOW, REFUSED, or MISSING, as appropriate.
29. This item is intended to assess the participant's perception of how much time the provider spent with the participant during health care encounters. Read the question and response options. Record NEVER, SOMETIMES, USUALLY, ALWAYS, DON'T KNOW, REFUSED, or MISSING, as appropriate.
30. This item is intended to assess the participant's perception of the quality of care that was provided during health care encounters. Read the question and response options. Record VERY SATISFIED, SOMEWHAT SATISFIED, SOMEWHAT DISSATISFIED, VERY DISSATISFIED, DON'T KNOW, REFUSED, or MISSING, as appropriate.

The next series of items are used to assess barriers to receiving health care.

31. This item is intended to determine the level of difficulty the participant experiences when attempting to get the health care treatments or procedures that the participant believed was necessary or those that were recommended by a health care provider. Read the question and response options. Record A BIG PROBLEM, A SMALL PROBLEM, NOT A PROBLEM, DON'T KNOW, REFUSED, or MISSING as appropriate
32. This item is intended to determine whether the participant has had to forego or go without receiving needed health care because s/he could not pay for it. Read the question and response options. Notice the skip



- pattern. If the participant answers NO, go to item 29. Otherwise, go to item 28.
33. This item is intended to determine the type of care the person did not receive. Read the question and each response option. For items a. through e., record YES, NO, DON'T KNOW, REFUSED, or MISSING, as appropriate. For item e., specify the response given by the participant in the provided space.
  34. This item is intended to assess the participant's confidence in receiving high quality health care when it is needed. Read the question and response options. Record: VERY CONFIDENT, SOMEWHAT CONFIDENT, NOT TOO CONFIDENT, NOT AT ALL CONFIDENT, DON'T KNOW, REFUSED, or MISSING as appropriate.

### **ADMINISTRATIVE INFORMATION**

36. Enter the date of data collection in the provided spaces assuring that all four digits for the year are completed.
37. Specify the method of data collection, by PAPER or COMPUTER.
38. Enter the interviewer code number of the person completing the data collection.