

INSTRUCTIONS FOR THE ANNUAL FOLLOW-UP TRACING FORM AND  
QUESTIONNAIRE, AFU, VERSION D, 3/3/93  
PREPARED 9/23/93

## I. GENERAL INSTRUCTIONS

Annual follow-up of the ARIC Study cohort is used to (1) maintain contact and correct address information of cohort participants and (2) ascertain interim medical events between the three-year comprehensive examinations. Annual follow-up contacts are scheduled approximately every 12 months after the participant's clinic examination. Each follow-up is completed by telephone (preferred) or in person (if necessary). The follow-up call in contact year 07 is preceded by a letter sent by mail about two weeks in advance of the call.

Two data collection forms are used in completing the annual follow-up. The ARIC Annual Follow-Up Tracing Form is a computer-generated paper form which contains a "Participant Tracing Information Sheet" used to update selected tracing information. The ARIC Annual Follow-Up Form contains a "Record of Calls" cover page for use in contacting a participant, the Annual Follow-up Questionnaire used to record vital status information and to gather information on the participant's cardiovascular health since their clinic visit, functional status and major life events, and a "Hospitalizations" section to record information on any hospitalizations. The questionnaire should always be completed on paper and then batch-entered into the local database.

Contact Year 07 AFU will also include the scheduling of the third clinic visit. If the participant refuses or does not show for a visit in Contact Year 07, scheduling should also be attempted in Contact Years 08 or 09.

## II. ANNUAL FOLLOW-UP PROCEDURES

### A. Contacting Procedures and Rules

Either the Coordinating Center or the field center staff will periodically generate the ARIC Annual Follow-Up Tracing Forms for a group of participants. This form contains the tracing information needed to contact the participant.

The "Contact Year Date Range" appearing on the "Record of Calls" is determined as follows:

The Target date is the one-year anniversary of the participant's first clinic visit.

The Earliest date falls six months prior to the Target date.

The Latest date falls six months after the Target date.

For example, if a participant's clinic visit occurred on 11/14/86, then the target date for contact year 2 is 11/14/87. The earliest date of contact is 5/14/87, and the latest date is 5/13/88. In future years, these dates include the same month and day:

<u>Contact Year</u>	<u>Earliest</u>	<u>Target</u>	<u>Latest</u>
02	5/14/87	11/14/87	5/13/88
03	5/14/88	11/14/88	5/13/89
04	5/14/89	11/14/89	5/13/90
05	5/14/90	11/14/90	5/13/91
06	5/14/91	11/14/91	5/13/92
07	5/14/92	11/14/92	5/13/93
08	5/14/93	11/14/93	5/13/94
09	5/14/94	11/14/94	5/13/95

The initial call for annual contact should be no more than three weeks or so before the target date except in contact year 07, in which the contact can be made up to 4 months earlier to aid clinic scheduling. Ideally, the contact should take place as closely as possible to the "Target" date. If for some reason contact is not made until after the "Latest" date, this contact must be assigned to the following Contact Year. This procedure is described in more detail in the section on vital status below.

The "Participant Tracing Information Sheet" contains detailed information to be used in contacting the participant. It is generated as part of the tracing form. Refer to the separate protocol section on tracing for special procedures to use in difficult cases.

As mentioned previously, the first step in the contacting procedures in contact year 07 is a letter sent to the participant about two weeks prior to the first attempted phone call. Before placing the phone call, the interviewer assembles the participant's computer-generated tracing form, the Annual Follow-up (AFU) form, the accompanying question-by-question instructions, and an appointment calendar for scheduling Visit 3.

NOTE: Cohort participants who have moved outside of the study area are still traced and interviewed, and hospitalization or death information is obtained if necessary.

## B. Performing the Interview

Form sections are typically completed in the following order:

- 1) Record of Calls
- 2) Questionnaire
- 3) Hospitalizations
- 4) Appointment scheduling (if due)
- 5) Tracing Form: Verification of Tracing Information

If a clinic appointment is to be scheduled with more than one respondent during a single call, it may be easier to conduct all interviews first and then schedule appointments together.

Each of these sections is described below.

### 1. Record of Calls

The Record of Calls is used to keep track of attempts to contact a participant and appointment scheduling. One line should be used for each attempted contact, and a result code is assigned. Two types of TRC form (Record of Call form) are used, one for annual follow-up calls which lead to scheduling of a clinic visit (contact year 07, 08 or 09) and one for the remaining years. The TRC used in the first case contains two panels at the bottom of the form, one used to record Result Codes and one for Appointment Codes. TRC forms used during contact years which do not lead to appointments have a single panel, namely the Result Codes, as described below. Assigning the code is very important, as the code may be necessary for determining the final vital status in the event that the participant is not successfully contacted. Result codes for contacts (with possible final codes indicated by \*) are:

- 01: "No Action Taken" - No attempt has yet been made to contact the participant.
- 02: "Tracing" - Attempts are being made to locate the participant, but so far neither the participant nor another reliable source have been contacted.
- \*03: "Contacted, Interview Complete" - The participant was successfully contacted by phone or in person, and the entire interview, including the questionnaire and hospitalization information was completed.
- \*04: "Contacted, Interview Partially Complete or Rescheduled" - The participant was successfully contacted by phone, letter, or in person, but the interview is incomplete or was not done at all. This may be a temporary code if it is possible that the interview may be completed at a later date within the same contact year.
- \*05: "Contacted, Interview Refused" - The participant was successfully contacted by phone, letter, or in person, but the interview was not done and will not be completed at a later date within the same contact year.
- 06: "Reported Alive, Will Continue to Attempt Contact This Year" - 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 during this same contact year through further efforts. For example, "temporarily away" would fit in this category.
- \*07: "Reported Alive, Contact Not Possible This Year" - Reliable information indicates that the participant is living, but direct contact has not yet been made. This code should be

used only if repeated contact attempts have been made, or when it has been determined that it is not possible that contact will be made during this same contact year.

- \*08: "Reported Deceased" - Reliable information indicates that the participant has died.
- \*09: "Unknown" - Neither the participant nor another source of information has been contacted in a manner sufficient to provide reliable vital status data during the specified date range.
- \*98 "Does Not Want Any Further Contact" - The participant has requested that s/he does not wish to be contacted any more by the ARIC study. This code alerts staff that no additional contacts should be attempted during the same contact year. Notes should be kept on the record of calls to describe the nature of the refusal. The recruitment supervisor at each field center determines the type of action to be taken at the following contact anniversary date, e.g., a polite letter, post card, or an alternative which is sensitive to any known reasons for this participant's desire not to be contacted again by the study.

For Contact Year 07, appointment codes (with possible final codes indicated by \*) are:

- \*00: Appointment scheduled
- 01: Appointment deferred (by clinic staff), e.g., needs Saturday clinic; school vacation; some other work conflict; etc.
- 02: Appointment pending due to sickness or other concerns/condition of the participant. Typically needs a flag or date for re-contacting by staff.
- \*03: Moved outside of the study area (participant does not need to be recontacted to make an appointment, but will be contacted annually for follow-up).
- \*04: Re-scheduled many times, unlikely to complete appointment (but has not yet formally refused).
- \*05: Appointment refused, but willing to do annual follow-up. Record reason for refusal for entry into a DES note log.
- \*06: Refused clinic visit and does not want any further contact by ARIC staff. Record reason for refusal for entry into a DES note log.
- 07: Unable to locate.
- \*08: Deceased.

Supervisor Review: The follow-up supervisor is responsible for reviewing cases of ambiguity or difficulty. Among these are:

- a. Refusals (attempt conversion).
- b. Difficult contacts or other non-completes. In particular, the supervisor decides when it is no longer practical to continue to investigate a person. All possible alternatives must be exhausted for this decision to be made.
- c. Undocumented deaths. If a death is reported for which no death certificate can be located, the supervisor reviews the case and attempts to resolve it. If no death certificate is ultimately located, including an NDI search, the vital status may be changed to "Unknown".

## 2. Questionnaire

Once the participant is called, the interviewer begins by reading the following script:

INTRODUCTION: "Hello, this is (YOUR NAME) from the ARIC Study. May I please speak with (NAME(s) OF PARTICIPANT(s))?"

DETERMINE PARTICIPANT'S AVAILABILITY AND VITAL STATUS.

IF DECEASED, OFFER CONDOLENCES, AND THEN DETERMINE THE DATE AND LOCATION OF DEATH (STARTING WITH ITEM 4) AND CONTINUE WITH THE SECTION ON HOSPITALIZATIONS (Section H). AT END OF INTERVIEW, INFORM THE RESPONDENT OF THE POSSIBLE NEED FOR SOMEONE FROM THE ARIC STAFF TO CONTACT A FAMILY MEMBER LATER ON, AND ASK WHEN WOULD BE THE BEST TIME TO CALL.

WHEN PARTICIPANT IS ON THE LINE (CY08, CY09), READ: "Hello, this is (YOUR NAME) from the ARIC Study and I'm making our annual contact call. I would like a few minutes of your time to find out about your health in the past year (lead in to item 6.)"

WHEN PARTICIPANT IS ON THE LINE (CY07), READ: "Hello, this is (YOUR NAME) from the ARIC study and I'm making our an annual contact call. I would like a few minutes of your time to find out about your health in the past year and to schedule your next visit for an examination at the ARIC Field Center (lead in to item 6.)"

Instructions for the Annual Follow-up questionnaire are given below:

**A. VITAL STATUS**

1. Date of status determination:

		/			/		
Month			Day		Year		

The date of status determination is the date on which the participant's final vital status became known to the interviewer (see item 2 below). THIS DATE MUST FALL DURING THE PARTICIPANT'S CONTACT YEAR, i.e., no earlier than the "Earliest" date given on the Tracing Form and no later than the Latest Date on that form. It is generally the last date on the "Record of Calls."

2 & 3. Final Status / Information obtained from:

Record the final vital status of the participant for the present contact year, and indicate the source of that information. THE RESPONSE TO ITEM 3 MUST CORRESPOND TO ITEM 2 AS SHOWN ON THE FORM. Thus, if item 2 is "C" then item 3 must be "A," "B," or "C". Similarly, if item 2 is "R", then item 3 must be "D," "E," or "F." If item 2 is "D," then item 3 must be "G," "H," or "I." After completing item 3, follow the corresponding skip rule indicated for that response.

Example: If the participant was contacted over the phone, record as:

<p>2. Final Status: (Circle one below)</p>	<p>3. Information obtained from: (Circle one corresponding choice below)</p>	
<p>Contacted and alive    C</p>	<p>Phone Personal Interview Letter</p>	<p>A } Go to Item 6, Screen 2 B } C } Go to Item 30, Screen 7</p>
<p>Contacted &amp; Refused    F</p>	<p>_____</p>	<p>Go to Item 41, Screen 11</p>
<p>Reported alive    R</p>	<p>Relative, spouse, acquaintance Employer information Other</p>	<p>D } E } Go to Item 30, Screen 7 F }</p>
<p>Reported Deceased    D</p>	<p>Relative, spouse, acquaintance Surveillance Other (National Death Index)</p>	<p>G } H } Continue to Item 4 I }</p>
<p>Unknown    U</p>	<p>_____</p>	<p>Go to Item 41, Screen 11</p>

In this situation, continue the interview by going to item 6 on screen 2

If direct contact is not made, but a reliable source of information has provided a status of "Reported alive" or "Reported deceased" in item 2, then hospitalization information may be obtained from this source. It is important that the source's identity be recorded in the call record.

The following are the criteria for each final status:

Contacted and alive (C): The participant has been directly contacted in some way by the ARIC Field Center during the present contact year. This contact preferably takes the form of a phone call or personal interview (so that the entire questionnaire can be administered), but a letter written by the participant is also acceptable for assigning this status. In this last case, it is obviously not possible to ask the remaining questions on the form. Note that this status corresponds to a final result code of 3, 4, or 5 on the "Record of Calls."

Contacted and refused (F): The participant has been directly contacted in some way by the ARIC Field Center during the present contact year, but he/she refused to answer the annual follow-up questions.

Note: In Year 07, do not confuse this AFU status with refusing an appointment (code 05 of appointment codes). "Contacted and refused" as a final status refers to the AFU questionnaire only.

Reported alive (R): Reliable information indicates that the participant is living, but direct contact has not yet been made. If this is the final status, it is therefore implied that it is not possible that contact will be made during this same contact year. Since one would generally continue to make attempts at a direct contact up until the "Latest" date, it is reasonable that the "date of status determination" would fall on or just before that "Latest" date, when this is the final status. Note that this status corresponds to a final result code of 7 on the "Record of Calls." Reliability of the information is evaluated by supervisor review. It is therefore important to document the source in as much detail as possible.

Reported Deceased (D): Reliable information indicates that the participant has died. In this case, the "date of status determination" is the date on which the death became known to the ARIC Field Center, NOT the date of death. Note that this status corresponds to a final result code of 8 on the "Record of Calls." Reliability of the information is evaluated by supervisor review. It is therefore important to document the source in as much detail as possible.

Unknown (U): Neither the participant nor another source of information has been contacted in a manner sufficient to provide reliable vital status data. In this case, the "date of status determination" is either the date on which the unknown status is being assigned, or the participant's "Latest" contact date for the specified contact year, whichever is earlier. Note that this status corresponds to a final result code of 9 on the "Record of Calls."

NOTE: ONCE A FINAL STATUS HAS BEEN ASSIGNED AND ENTERED INTO THE DATABASE, IT CANNOT BE CHANGED DURING THE SAME CONTACT YEAR WITHOUT WRITTEN AUTHORIZATION FROM THE COORDINATING CENTER. THEREFORE, A FINAL STATUS CODE SHOULD NOT BE ASSIGNED UNTIL THE END OF THE CONTACT YEAR OR UNTIL IT BECOMES OBVIOUS THAT THE STATUS CANNOT CHANGE. AS DESCRIBED ELSEWHERE, A DEATH OCCURRING AFTER A CONTACT BUT BEFORE THE END OF THE CONTACT YEAR IS ASSIGNED TO THE NEXT CONTACT YEAR.

Examples:

1. It is Contact Year 2. The participant cannot be contacted, nor can any reliable information be found regarding his vital status. His baseline visit was on 3/5/87, and his "Latest" CY 02 date is 9/4/88. Record as:

<u>Contact Year</u>	<u>Date of Status Determination</u>	<u>Status</u>
2	9/4/88	U

2. It is Contact Year 3. The participant cannot be contacted, nor can any reliable information be found regarding his vital status. His status in CY 02 was "Unknown," as determined on 6/28/88. His baseline visit was on 1/23/87. Record as:

<u>Contact Year</u>	<u>Date of Status Determination</u>	<u>Status</u>
3	6/28/88	U

3. It is Contact Year 2. The participant's baseline visit was on 2/24/87. His "Latest" date is 8/23/88. Neither the participant nor a reliable source can be located. Finally, on 8/25/88 (one day after the "Latest" date), the participant is located and interviewed. The interview must be recorded under Contact Year 3, and the status for CY 2 is "Unknown." Record as:

<u>Contact Year</u>	<u>Date of Status Determination</u>	<u>Status</u>
2	8/23/88	U
3	8/25/88	C

4. It is Contact Year 2. The participant's "Earliest" date is 2/12/87 and his "Latest" date is 2/11/88. The participant was contacted on his "Target" date, 8/12/87, and the questionnaire was administered routinely. One month later, his obituary is seen in the newspaper. The death may not be reported until the next Contact Year. Record as:

<u>Contact Year</u>	<u>Date of Status Determination</u>	<u>Status</u>
2	8/12/87	C
3	2/12/88	D

A death investigation may, however, be started at any time.



## B. Death Information

4-5. If the participant has died, attempt to secure the date and location (city/county, state) of death from the source of information, whether it is a relative or an obituary. Take steps to begin a death investigation by initiating a Cohort Event Eligibility Form. Obtain as much information as possible from the informant on items 4 and 5. For example, if only the year and month of death are known, record them, (and not the day). Similarly, if the state is known, but not the city/county, record as much information as is available. Continue with Item 30, Section H (HOSPITALIZATIONS).

## C. General Health

The time frame for the next set of questions in Sections C - G is since the last Annual Follow-up (AFU) call. Generally this is about 12 months. Exceptions to this could result from one or more missed AFU contacts. The most recent contact will rarely have been the last field center visit. It is important that the participant understand the time frame.

6. Read the question and the response categories verbatim, substituting the date on which the participant was most recently contacted (directly) where indicated.

## D. Chest Pain on Effort

7. If the participant has reported chest pain during previous interviews, but none since the last contact, select NO and skip to Item 20; otherwise enter YES and continue with Items 8-16. These refer to the 'pain or discomfort in [the] chest' that the participant reported during the most recent (telephone) interview. Confirm that the pain was during the correct time interval. Note all skip patterns.

8-13. These questions refer to the usual characteristics of the pain or discomfort. Unequivocal answers need not be probed; but answers such as "occasionally" or "sometimes" should be probed by a question of the type: "Does this happen on most occasions?" Skip rules must be adhered to.

8. The answer must be interpreted strictly. If pain is experienced only during some other form of exertion (e.g., cycling, stair climbing, lawn mowing), it must be recorded "No."

13. Sternum: the breast bone. To locate upper, middle and lower, divide the breast bone into thirds, starting at the neck and working down.

Left anterior chest: the front rib cage to the left of the sternum (breast bone) and below the clavicle (collar bone).

Left arm: includes the area below the clavicle (collar bone)

and above the left hand.

Other: include here all other locations, such as the left shoulder (clavicle and above), neck and jaw, or other locations beyond the above defined regions.

14. 'It' refers to the pain/discomfort being described in Item 13. If there is a positive response to this question, select YES and also record the location of pain in item 13f.
15. 'Doctor' refers to a medical doctor in a clinic, hospital or private practice.
16. Read the question, but do not read the response categories. If there is more than one diagnosis, and heart attack is listed among the diagnoses, select 'H' (heart attack). If 'heart attack' is not given, but 'angina' and 'other heart disease' are, select 'A' (angina). If 'heart disease' and 'other' are both given, select 'D' (heart disease).

#### E. Possible Infarction

These three items refer to 'a severe pain across the front of [the] chest lasting for half an hour or more' which has occurred only since the last (telephone) contact.

17-19. Ask the questions exactly as printed. For the response to Item 17 to be positive, the pain must have been severe, located across the front of the chest, and have lasted for a minimum of half an hour. Refer to Item 15 for the definition of a 'doctor'. Skip rules must be observed for the questions to make sense.

#### F. Intermittent Claudication

20-28. Refer to leg pain since last contact only. Ask questions exactly as they are printed; interpret answers strictly.

22-24, 26-28. These questions refer to the usual characteristics of the pain or discomfort. Unequivocal answers need not be probed; but answers such as "occasionally" or "sometimes" should be probed by question of the type: "Does this happen on most occasions?" Skip rules must be adhered to.

#### G. Stroke/TIA

29. Here we are specifically looking for a physician diagnosis of stroke or TIA. Light stroke, minor stroke or small stroke would all be considered appropriate synonyms resulting in a "Yes" response if participant was told by a physician. If the participant is unsure, record as "No."

#### H. Hospitalizations

The purpose of questions 30 and 31 is to determine whether it is

necessary to complete the "Hospitalizations" section after the questionnaire has been completed. Generally, these questions are asked directly of the participant. However, if direct contact is not made, but a reliable source of information has provided a status of "Reported alive" or "Reported deceased" in item 2, then questions 30 and 31 may be asked of this source. If speaking with an informant, replace the words "Were you" with "Was \_\_\_\_\_ (participant)". The term "hospitalized" includes staying overnight in any acute or chronic care facility which excludes nursing homes. Only inpatient care should be included, e.g., ER or outpatient visits not involving an overnight stay are coded as NO. If the participant or informant is unsure, doesn't know or can't provide information about the overnight hospitalization(s) for heart attack (Item 30) or other condition (Item 31), select the response category UNKNOWN.

30. Question 30 is intended to specifically enhance the participant's or informant's recall about cardiovascular-related hospitalizations. The term 'heart attack' refers to the person's admitting diagnosis, not the discharge diagnosis. For example, the response to Item 30 would be YES for a person admitted to a hospital overnight to rule out a suspected heart attack. Frequently, such a patient is discharged with a diagnosis of something other than a heart attack, for example, tachycardia (uneven heart rate) and esophageal reflux (indigestion). In other words, admissions to "rule out", as well as discharge diagnoses of a heart attack, are both coded YES.

31. This question asks the participant/informant to recall overnight hospitalizations in acute or chronic care facilities, such as hospitals, for any other condition.

#### I. Functional Status

Provide a transition statement such as, "Next I would like to find out whether you can do some physical activities without help. By 'without help,' I mean without the assistance of another person. These questions refer to the last 4 weeks."

This time frame is different from the previous section on hospitalizations. In general, you are trying to assess the participant's current functional status. This time period (i.e., the last 4 weeks rather than the day of the interview) has been chosen because we do not want to document decreases in functional ability that might be due to temporary conditions such as a headache, a cold or the flu, or a sprained ankle, etc. The intent of these questions is to record the individual's overall ability to perform the various activities covered (i.e., heavy work around the house, walk upstairs without assistance, walk half a mile, or work outside the home).

32. For this question, the examples are just guidelines. If a person can do any heavy work (not necessarily all of the things specified in the question), then record YES. Other examples of heavy work around the house could be "cutting the grass with a hand or power mower" (but not a riding lawn mower), or "painting walls or wallpapering."

33. The focus of the question is on the participant's ability to walk up and down stairs without the assistance of another person. If the participant says something like, "We have a ranch house, so I don't have to go up stairs," say that you want to know if he/she is able to walk up and down stairs. If the respondent is uncertain, code as NO.

34. Again, the emphasis is on the ability to do the activity, in this case, to walk half a mile. The concept of help in this item refers to persons helping. Therefore, the use of equipment would not be considered assistance and you would code YES for a participant who reported walking half a mile with the use of a cane. One, it keeps the definition consistent with those in Items 32 and 33. Two, it is assumed (and was the experience in Framingham) that anyone requiring either a second individual to assist ambulating or the use of a rehabilitative device (such as a three-pronged cane or walker) is not able to walk half a mile.

35. The focus of this question is whether the ability to work outside the home has been primarily compromised due to poor health (i.e., the participant is completely unable to engage in his or her occupation).

If NO, determine if the poor health and the resultant disability were due to heart disease (Item 35b). Regardless of the response, skip Item 36 and go to Item 37a.

If YES, go to Item 36a.

If the participant (1) does not work outside the home or (2) is not capable of working but would normally not be working outside the home (e.g., a homemaker, retired, or unemployed and not looking for work), code as NOT APPLICABLE, skip Item 36, and go to Item 37a.

In 35.b., if asked about the meaning of "a heart problem," do not interpret nor offer a medical explanation, but rather let the participant decide whether s/he is "unable to work because of a heart condition or heart disease."

36. The focus of question 36a is absence from work anytime within the four weeks prior to the interview for at least half a day because of illness. If this occurred (YES for Item 36a), determine how many days the participant was absent from work (Item 36b). The maximum number of days not worked is 28.

37. The focus of this question is to determine whether the ability to pursue one's normal activities around the house has been compromised by poor health.

For example, you would code as NO a homemaker who is no longer able to clean house or perform the usual daily activities. If NO, determine if this is due to a heart problem (Item 37b), and go to Item 39, skipping Item 38. If asked about the meaning of "a heart problem," do not interpret nor offer a medical explanation, but rather let the participant decide whether s/he

is "unable to work because of a heart condition or heart disease." If a participant indicates that s/he is able to carry on with the usual activities around the house but is not able to do his/her usual recreational activities -- such as bowling, walking, any form of recreational exercise -- code NO, determine in item 37b if this is due to a heart problem, and go to item 39, skipping item 38.

However, you would code as YES a retired brick layer (who is physically incapable of laying bricks) but who is able to do his usual retirement activities such as gardening or housework. Continue with Item 38a.

38. The focus of question 38a is a reduction in the participant's usual activities (in contrast to a cessation of these activities in Item 37) during the four weeks prior to the interview because of poor health. The reduction in activities had to occur for at least half a day. If this occurred (YES for Item 38a), determine on how many days the participant had to reduce his or her activity level (Item 38b). The maximum number of days of reduced activity is 28.

39. The time frame for Item 39a is 12 months prior to the interview. If the response is YES, ask how much lower the weight is now than one year ago (Item 39b) and whether the participant was trying to lose weight (Item 39c). If more than 10 lbs were lost in the last 12 months (YES to Item 39a), but more than 10 pounds were regained during the same time period, code '000' to indicate that the participant's current weight is not lower, but higher than it was a year ago.

If the response to Item 39a is NO, go to Item 40a.

If the participant doesn't know if more than 10 pounds have been lost during the last 12 months, enter 'U' for UNKNOWN, skip Item 39b and determine if the unknown weight loss was intentional (Item 39c).

40. The purpose of this question is to update marital status and to determine if one or more people close to the participant has died in the last 12 months.

Read Item 40a and then all the response categories. If the response is MARRIED or NEVER MARRIED, record the appropriate letter, skip Item 40b and go to Item 40c. If the response is WIDOWED, DIVORCED, or SEPARATED, record the appropriate letter and determine how long ago the event took place (Item 40b). Do not read the response categories, but probe if the participant's response is sufficiently unclear for you to select a category.

Read Item 40c to all participants, inserting the word [else] if the participant lost his or her spouse (i.e., WIDOWED in Item 40a) within the last year (Item 40b).

If the response is YES, determine how long ago the person died. The time frame must be no more than 12 months ago. If the participant volunteers that more than one 'close' person died

within the last 12 months, determine when the most recent death occurred.

If the participant volunteers that the deceased was a pet, code YES and replace the word "person" with the word "pet" in Item 40d. Complete the response to Item 40e as Pet, but do not read the question out loud. If there were no deaths (NO or DON'T KNOW) within this time period, go to Item 41. If YES, determine how this person was related to the participant (Item 40e). Do not read the response categories.

## J. Administrative Information

41. The person at the clinic who has completed this form must enter his/her code number in the boxes provided.

## 3. Hospitalizations

### A. Collection of data

If there was a positive response to Items 30 and/or 31, read the following script to the respondent/informant: 'For each time you were (he/she was) a patient over night in a hospital, I would like to obtain the reason you were (he/she was) admitted, the name and address of the hospital, and the date when you were discharged.' Abbreviations can be used for local hospitals.

42-44. Following the questionnaire, record information on all hospitalizations reported since the time of last contact. Use the Hospitalizations section of the Annual Follow-Up Form. This is a long question that will have to be obtained in parts. Use neutral probes to elicit all hospitalizations. For the (first) overnight stay, record the reason for the hospitalization (Item 42a), the hospital name, city, and state (Item 43a), and the discharge date (month and year) of the hospitalization (Item 44a). Probe for additional hospitalizations and follow the directions for the first hospitalization. There is space to complete 6 hospitalizations. If there are more than 6, record and enter the 6 most relevant to ARIC. List the others on a separate sheet, so all can be transmitted to surveillance. If the person was hospitalized overnight more than 6 times, select those with heart disease or stroke as reasons for hospitalization.

45. If any hospitalizations are reported, enter H beside the appropriate letter corresponding to each hospitalization. That is, if 3 hospitalizations are reported, enter H for items a, b, and c. Send a copy of the Hospitalizations page(s) or screen printouts to the surveillance supervisor and check the appropriate boxes for "Transmit to Surveillance." The surveillance staff will investigate each hospitalization. If a reported hospitalization cannot be found, the surveillance supervisor will notify the staff person responsible for annual follow-up, who then changes the "H" to "N". Be certain that

the "H" changed corresponds exactly to the hospitalization in question (for example, if the second hospitalization is actually an outpatient visit, item b. H should become b. N ).

If direct contact is not made, but a reliable source of information has provided a status of "Reported alive" or "Reported deceased" in item 2, then hospitalization information may be obtained from this source. It is important that the source's identity be recorded in the call record.

#### B. Linkage between Annual Follow-up and Event Investigation

Certain procedures are necessary to insure that any deaths or hospitalizations that are encountered during AFU contact attempts are brought to the attention of the Surveillance Event Investigation staff, and vice-versa.

The surveillance staff is to be notified of every cohort hospitalization and an investigation should be initiated. The hospitalizations sheet provides a check box to indicate that the information has been transmitted to the surveillance staff.

#### 4. Verification of Tracing Information and Appointment Scheduling

##### A. Visit 3 Scheduling Not Needed

For AFU contacts for which a clinic visit not being scheduled (contact years other than 07, 08, 09), choose the appropriate ending:

END (talking to participant): "Thank you very much for answering these questions. We will call you in about a year (see you at the clinic)." Proceed to Verification of Tracing Information.

END (if participant deceased): "We may need to contact a family member later. When would be a good time to call in that case?" DO NOT proceed to the Verification of Tracing Information.

END (otherwise): "Thank you very much for answering these questions. We will call \_\_\_\_\_ in about a year." DO NOT proceed to the Verification of Tracing Information.

##### B. Scheduling Visit 3 Appointment

You may want to schedule all appointments in a household together. Below is a prototype script:

"Now let's decide on your clinic appointment date(s). This ARIC clinic visit will be much like the one you had three years ago. You may remember that it takes 3 to 4 hours, and you will be asked to fast for 12 hours before you come in unless you have a medical reason not to. We also can provide a taxi, if you need transportation. We have some openings in (MONTH). Our appointment times are at (TIMES). Is there a day or time that

would be best for you?"

1. IF RESPONDENT(S) IS UNABLE TO SCHEDULE APPOINTMENT AT THIS TIME, INDICATE ON RECORD OF CALLS, SPECIFY REASON AND PROSPECTS FOR RECONTACTING, AND GO TO CLOSING (SECTION 5).
2. IF RESPONDENT IS UNWILLING TO SCHEDULE A CLINIC VISIT, INDICATE ON RECORD OF CALLS, AND VERIFY TRACING INFORMATION.

"I'm sorry you are unwilling to come back for a third exam. We would, however, like to continue calling you once a year. As we've done in the past, we would like to verify the information we have on how to contact you. Let me make sure that I have your full name." (ADMINISTER PART A OF THE VERIFICATION OF TRACING FORM. THEN GO TO CLOSING, SECTION 5.)

3. IF APPOINTMENT IS MADE, RECORD DATE AND TIME ON RECORD OF CALLS. CIRCLE THE APPROPRIATE APPOINTMENT CODE ON THE RECORD OF CALLS. THIS CODE WILL BE ENTERED AS ITEM 46 OF THE ANNUAL FOLLOW-UP FORM ON THE DES.

Refer to page 4 for an explanation of the Appointment Code values. Refusal codes (05 and 06) should have the participant's reason for refusing entered into a notelog for item 46.

Appointment codes should be updated on the DES as appropriate, given changes in the participant's status.

- a. CONTINUE WITH FASTING INSTRUCTIONS.

"We ask that you fast for the visit unless you have a medical reason not to. Do you take insulin for sugar diabetes or have any other reason that you cannot fast for 12 hours?"

IF NO

IF YES

Since your appointment is at \_\_\_\_\_, you should begin fasting the night before. This means nothing by mouth but water and essential medications. We do encourage you to drink plenty of water. As with your previous exam, you will be given a snack at the clinic.

There is no need for you to fast.

- b. ASK ABOUT SPECIAL NEEDS.

"Will you need any assistance getting around the clinic or do you have other special needs we should know about?" IF YES, INDICATE ON RECORD OF CALLS AND INFORM CLINIC.



c. REVIEW MEDICATION SURVEY PREPARATIONS.

"We will want to ask you about your use of medicines, vitamins or supplements. This includes ALL medicines including: 1) prescription drugs from your physician or dentist; 2) prescription drugs you may have received from other people, such as friends or relatives; and 3) over the counter medicines bought at a drug store or supermarket, such as medicines for colds, vitamins, minerals, and the like. We ask that you bring the containers so that we can copy information from the labels. Please bring in the bottles of any medications you have taken in the TWO weeks before your appointment. For vitamins and supplements, we are interested in a longer time period. Please bring in the bottles or containers of the vitamins or supplements you have taken in the FOUR weeks before your appointment. If you don't have the container, please bring the prescription or the loose pills or capsules. A bag to carry them will be in the packet mailed to you."

d. GIVE RESTRICTIONS ON DONATING BLOOD PRIOR TO THE CLINIC VISIT.

"Please do not donate blood during the week before your clinic appointment. If it becomes necessary to give a pint of blood or plasma within 7 days of your appointment, please call the field center and reschedule your appointment."

e. RESOLVE ANY QUESTIONS OR CONCERNS.

"Do you have any questions?"

f. UPDATE MAILING ADDRESS (VERIFY TRACING INFORMATION).

"Finally, this is a good time to verify your mailing address to make sure that all the material you need for the clinic appointment reaches you. This will only take a few more minutes. Let me make sure that I have your full name (Mr. \_\_\_\_\_'s full name). (ADMINISTER THE VERIFICATION OF TRACING INFORMATION FORM.) "You should receive your packet in a few days and we will see you on \_\_\_\_\_. If it is necessary to change your appointment or you think of any (other) questions, please call the clinic."

5. Closing

NO ADDITIONAL INTERVIEWS

"Thank you for your time.  
Good-bye."

ADDITIONAL INTERVIEWS

"Now I would like to interview  
(NAME). Thank you for your  
time."

IF THE PARTICIPANT IS AVAILABLE, RETURN  
TO THE BEGINNING OF THE ANNUAL FOLLOW-UP  
INTERVIEW. IF THE NEXT PARTICIPANT IS  
UNAVAILABLE, DETERMINE WHEN HE/SHE MIGHT  
BE CONTACTED.

"Is there a date and a time that would  
be best for me to speak with (NAME)?"

RECORD DATE AND TIME ON RECORD OF CALLS

6. Tracing form: Verification of Tracing Information

Verify the items on the Verification of Tracing Information sheet for  
contact next year by saying: "You have previously provided us with  
information on how to contact you. To help us contact you next year,  
please tell me if the information I have is still correct." These  
include the participant's name, address, and phone number(s), as well  
as (except in CY07) the information on the two contact people provided  
during the clinic visit. The current data on file appear on the left  
hand side of the page, with blank spaces for corrections or changes  
provided on the right side. Information only needs to be entered in  
these blanks in the case of changes to the data. For example, a  
change of mailing address would be recorded as:

MAILING ADDRESS:

Highland View Apts.  
Apt. 73A  
3465 Highland Lane  
Chapel Hill, NC 27514

MAILING ADDRESS:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

ANY CHANGES TO TRACING INFORMATION MUST BE RECORDED ON THE UPD FORM IN  
THE VISIT 3 DATA MANAGEMENT SYSTEM.

Data should be updated on the UPD form as necessary immediately after  
the follow-up contact, but only by someone certified in use of the  
ARIC Data Entry System. The interviewer who updated the computer file  
enters his/her ARIC Staff Code Number on the Verification of Tracing  
Information Sheet.