



**INSTRUCTIONS FOR THE SEMI-ANNUAL
FOLLOW-UP
GENERAL INTERVIEW QUESTIONS (12/15/2011)
(GEN, VERSION 1, 4/23/2012)**

I. General Instructions

The semi-annual follow-up general interview questions (GEN) are completed during the semi-annual follow up interview following the semi-annual follow-up core questions (SAF). The GEN interview is **not** administered to proxy respondents or contacts who answer the SAF questions about the ARIC study participant, nor is the GEN interview administered to ARIC participants who refuse the SAF.

II. Detailed Instructions for Each Item

- 0a. Enter the date of the interview. This date should fall between the scheduling windows on the Participant Tracing Report.
- 0b. Enter the staff ID for the telephone follow-up interviewer ID.

A. GENERAL INTERVIEW

Script: "Now I would like to ask some questions about your health that ARIC has not asked you before."

- Q1.a-d These questions refer to conditions and diagnoses mentioned by the participant's physician or other health professional. Do not define or describe these conditions. If the participant has not heard the term or does not know the meaning of the condition, enter as No.
- e1-e3 For the conditions that the participant reports as being diagnosed by a physician, ask how old the participant was when first told of this condition, and enter the age in years. If unsure, enter the participant's best estimate.
- 2. The participant defines feeling sleepy "most" of the day. If asked to clarify, the interviewer can ask whether the participant feels tired, sleepy, or is dozing off throughout much of the day.
- 3. This question is asked regardless of the answer to question 2. Answers are entered as 0 through 31
- 4. If asked by the participant about sleep-walking, probe whether "punching, moving the arms in the air, making running movements, shouting or screaming" also occurs. If no, enter No and go to Question 5.

Participants may refer to the present, their childhood. If a participant is not acting out dreams at present but did so as a child, enter Yes to Item 4, "less than 3 times in total" in Item 4.a., and enter the age in years when the this started.

5. Enter Yes for either shaking as a fine motion or a large shaking. Trembling of the hands or fingers that occur only when the participant holds an object in his/her hand is entered as a Yes.
6. If the participant is unsure of the answer, enter No.
7. The purpose of this question is to identify gout diagnosed by a physician. If the participant indicates that he/she has gout, probe whether they were told by a physician. If no or uncertain, go to Question 8.
- 7b. The purpose of this question is to determine how long ago approximately since the participant received treatment for gout using yearly units. The interviewer can define "health care" as "any treatment for gout that you received from a health care provider." Probes include "in the past 12 months", "more than 12 months ago", "two years ago", etc. If the participant provides you with a date, subtract as needed and enter the correct number. For example if you are conducting the interview on Feb 1, 2012, and the participant reports that it was "some time during 2008", enter 4 years. If the participant reports in the **past 12 months**, enter 0. For example on Feb 1 2012, the participant reports "Halloween" (Oct 31 2011), even though that date is "last year", it occurred less 12 months ago.
8. This question assesses how many teeth the participant has lost in the past 10 years only. Provide the year from 10 years ago, if the participant needs help.

PHYSICAL ABILITY

Script: "These next few questions ask about how well you typically function on your own, that is without help from another person or special equipment. For each activity I mention, please tell me how much difficulty you have performing the activity when you are by yourself and without the use of special equipment."

Note: Canes and walkers are considered special equipment.

The following questions and their format are not familiar to the ARIC participant from previous AFU interviews and require the interviewer to gently train the respondent by verbal instructions, particularly in the selection of the most appropriate category from the ones offered by the interviewer.

9. Read: "Because of a health or physical problem, how much difficulty do you have walking for a quarter of a mile (about 2 or 3 blocks)? Would you say No difficulty, some difficulty, much difficulty, or you are unable to do it?"

Because the participant does not have response cards, read the response options for each following activity (questions 10 – 20) until you are confident the participant recalls the response categories (no difficulty, some difficulty, much difficulty, unable to do it). If in the course of asking about the remaining physical activities the participant provides answers that deviate from the response categories requested, repeat the refrain (Would you say no difficulty, some difficulty, much difficulty, or you are unable to do it?), or use another form of probing. The most helpful type of probing in this case would be channeling, such as "If you had to choose, which would you say: No difficulty, some difficulty, much difficulty, or you are unable to do it?" If a neutral form of channeling does not work it may be necessary to bracket the perceived level of difficulty reflected in the participant's response, such as, "does that mean

some difficulty or much difficulty ..."? As for any interviewing technique, do not suggest an answer or paraphrase the respondent's words.

If a participant responds "Don't Know or Do Not Do", probe to determine if this is due to a health or physical problem. For example, if the participant responds "My wife prepares all of my meals", ask **"Is that because you are not able to prepare meals?"** If the answer is "No, I just don't do it," choose "Don't know or do not do". However, if s/he says, "My arthritis is so bad my daughter prepares all my meals," choose "Unable to do".

Complete items 9 through 20, and then read the following script as a transition to asking questions 21-31:

Script: "I will now ask you several questions concerning the health care you received in the past six months."

To assist the participant, provide him/her with the month and year six months prior to the day of the interview. Example: If the interview is conducted on October 15, 2012, the time period is between April 2012 and the interview.

CONTINUITY OF CARE

21. This question evaluates the participant's perception of continuity of the medical care he/she received during the 6 months before the interview. After reading the question, please tell the participant that they should select their response from the following four options: "Always", "Most of the time", "Sometimes", or "Rarely or never" If the participant states that he/she did not see a physician or health care provider in the past six months, select response "Did not see a doctor or health care provider in the last 6 months" and Go to question 23.

If the participant states that their usual source of care is a practice rather than a single doctor/ nurse/physician's assistant, please rephrase the question to say the following: "Over the past 6 months, when you received medical care, how often did you go to the same healthcare provider? This can mean the same doctor, the same nurse practitioner or physician's assistant, or the same group of doctors who practice together".

22. This question asks about the number of times that participants saw their "usual doctor or health care provider." If asked by the participant, the interviewer states that "usual doctor" is the person who provides most of the medical care. Usual care doctor may be a primary care provider, or it may be a specialist whom the participant is seeing frequently for a specific medical problem. If a person is seeing multiple physicians regularly, usual care refers to the physician/health care provider whom the participant sees for majority of his/her health problems. If the participant is having difficulty understanding what is meant by usual care, another way to frame the question is to ask which doctor they would go to when a health problem arises.

ACCESS TO CARE

23. This question asks about delay in receipt of medical care in the six months prior to the interview. The participant is asked to recall if there was any occasion during this time period

(prior six months) when they wanted to seek medical care, but did not do so at the time that they needed it. This question does not ask for the reason in delay of care. Go to item 26 for those who answer “No” to this question or refuse to answer this question.

24. This question is directed at study participants who answered “Yes” to the previous question (item 23). It aims to clarify whether the participant delayed getting care because of financial constraints. Enter “Yes” or “No” for each of the three types of medical care in question including: 24a) obtaining care from a health care provider for any reason other than mental health; 24b) mental health care and counseling (including medications); 24c) care provided by a nursing home. Participants currently residing in a nursing home may respond “Yes” or “No” to category 24c, as they may have postponed nursing home admission during the past 6 months.
25. For participants who answered “Yes” to question 23, this question assess reasons, other than financial constraints, why participants delayed or did not obtain care at the time that they felt that they needed it. Please read each reason slowly and enter “Yes” or “No” for each.

COORDINATION OF HEALTH CARE

26. This question establishes whether the participant received care from a healthcare provider other than their usual care provider. As was explained for item 22, the term “usual care” often refers to the usual place where a person receives sick or routine care, or a usual person who provides that care. For some, the source of usual care will be a primary care provider, for others that may be a specialist whom they are seeing frequently for a medical problem.
27. This assesses if the participant’s usual healthcare provider was aware of the details of care provided by other health care providers from whom the participant received care in the six months preceding the interview. Please select “do not know” option if the participant is not aware of the extent to which their usual care provider was informed about the care they received from other providers.
28. This question pertains only to those who answered “yes” to item 26. It aims to establish whether any one person or team of individuals helped coordinate the care that the participant received. It is possible that the study participant may not be aware of his or her health care coordination. Please enter No if the participant states that no one coordinated their care, or if they do not know if anyone coordinated their care. Please go to item 30a.
29. This question should only be asked of participants who answered “yes” to question 28 to assess the level of satisfaction with the coordination of care that they received.

HEALTH CARE SATISFACTION

30. This question evaluates the level of their satisfaction with the medical care that they received in the prior six months, as assessed by the items listed in a-f.

Script: “I will now ask you about your satisfaction with the medical care that you received in the past six months. There are six questions for which you can give me one of the following four answers: never, sometimes, usually, or always.”

Please read response categories slowly and carefully, and repeat the response categories after each question, if necessary.

31. This question assesses participants' overall level of satisfaction with health care that they received. The question applies to all health care including specialists, primary providers, etc. received during that time period.

VERIFICATION OF CONTACT INFORMATION UPDATE (CIU) FORM

"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."

These include the participant's name, address, and phone number(s), as well as information on the contact people and the name of a follow-up proxy. 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 entered as:

OLD MAILING ADDRESS: NEW MAILING ADDRESS:

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

Any changes to the information in the CIU must be entered in the database. The interviewer who updated the computer file enters his/her ARIC Staff Code Number.

CLOSURE SCRIPT:

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

B. ADMINISTRATIVE INFORMATION

13. sAFU general interview questions completion status. Enter the code that describes whether or not the sAFU general interview questions were completed.
 - A. **Complete**: Direct contact was made within the given time frame. The contact provided all the questionnaire information they could offer. The contact is not required to answer every questionnaire item to have completed the interview.
 - B. **Partially complete, contact again within window (interruptions)**: Direct contact was made, but the questionnaire could not be fully administered due to an interruption – not because of a refusal. This status is not a final status, as the interviewer will be attempting another contact to continue the interview. The final sAFU General Interview Questions Completion Status for the given time frame must be a. Complete, or c. Partially complete; unable to complete within window (done).
 - C. **Partially complete, unable to complete within window (done)**: Direct contact was made, but the questionnaire could not be fully administered in the given time frame.