



INSTRUCTIONS FOR THE SEMI-ANNUAL FOLLOW-UP GENERAL INTERVIEW QUESTIONS (02/23/2015) (GND, VERSION 1, 01/05/2015)

I. General Instructions

The semi-annual follow-up general interview questions (GND) are completed during the semi-annual follow up interview following the semi-annual follow-up core questions (SAF). The GND interview is **not** administered to proxy respondents or contacts who answer the SAF questions about the ARIC study participant, nor is the GND 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 Semi-Annual (Participant) Tracing Report.
- 0b. Enter the staff ID for the telephone follow-up interviewer ID.

A. Chronic Pain

Introduce this section by saying **“I would like to ask about pain you may have experienced.”** and proceed to ask Question 1. After asking “When was the last time you experienced pain?” do not read the response categories to the participant but rather record the participant’s response in the best fitting of the categories (a - f) provided. If the participant’s response is ambiguous or does not correspond to one of the response categories provided, probe the participant’s response according to the categories listed. For example, if the response is “Several days ago,” the probe could be: “Would you say that the last time you experienced pain was within the past week, or was it more than week but less than a month ago?”. If the participant says, “I really don’t experience pain”, please follow up with “Would you say the last time was more or less than 6 months ago?” and go from there.

If asked to clarify the type of pain we ask about or its location, indicate that we are asking about any kind of pain, in any part of the body.

In Question 2 slightly emphasize “...the last time you experienced pain,” so that participants do not refer to the worst pain they experienced.

In asking Question 3 do not read the answers, but record the participant’s response in the best fitting of the response categories (a - g) provided. “Several times per week” refers to pain experienced less often than daily, but more often than once per week. If the participant’s response is ambiguous or does not match one of the response categories provided, probe the response according to the categories listed.

B. Unintentional Weight Loss

Script: “Next I will ask you a few questions about weight loss.”

The time frame for this question is 12 months prior to the interview. If the response to Question 4 is YES, ask how much lower the weight is now than one year ago (Question 5) and whether the participant was trying to lose weight (Question 6). If more than 10 pounds were lost in the last 12 months (YES to Question 4), but more than 10 pounds were regained during the same time period, code ‘000’ in Question 5 to indicate that the participant’s current weight is not lower, but the same or higher than it was a year ago. The weight (loss) reported should be recorded in pounds as integers (and no decimal places) in Question 5. If the difference in weight is reported in fractions of a pound, please round down, without engaging the respondent for clarification; e.g., 0.5 pounds should be recorded as 000; 1.5 pounds should be recorded as 1.

If the response to Question 4 is NO, go to Question 7. If the participant does not know if more than 10 pounds have been lost during the last 12 months, enter ‘Unknown’ for Question 4 and go to Question 6 to determine if the unknown weight loss was intentional.

C. Living Arrangements

Script: “Now I would like to ask you a question about your living arrangements. Do you currently live with anyone, such as a family member or a friend, or do you live alone?”

7. Please read the question as stated above. Some participants may be reluctant to let others know that they live alone. It is acceptable for a participant to refuse to answer this question. A participant who lives in a retirement community, assisted living, or nursing facility is not living alone. A participant who lived alone prior to a recent hospitalization, but is currently living with someone (friend, relative, or is in a nursing care facility) should be categorized as not living alone, even if the current living arrangement is considered temporary. If asked why we would like to know about their living circumstances, you may respond that we are interested in how living circumstances may affect a person’s health.

D. Caregiver Burden

Script: “Now I want to ask a few questions about providing care to others.”

8. This question asks whether the participant is a caregiver. Please skip to question 16 if the participant responds that they do not currently provide ongoing care. If the participant responds that they are a caregiver, subsequent questions will allow him/her to provide more information concerning that care.

Script: “If you are providing care for more than one person, the following questions refer to the person for whom you are providing the most care.”

9. ARIC is interested in the care provided to family and friends (informal caregiving). In this question, the term “spouse” can refer to a spouse or a partner. Please use the “other” category if the participant’s response does not correspond to any of the listed response categories (i.e. the relationship between the caregiver and care recipient is other than that of a relative, friend or neighbor).

10. The time frame for this question is an average week out of one month (the most recent month) during which the respondent provided care to another person. Please do not read the response categories to the respondent. He/she will provide a response which should be categorized according to the provided categories.

11a-11b. ARIC would like to know if the care recipient is receiving care because of cognitive impairment or because of a physical disability. Although question 11a focuses on memory loss, please also check the “Yes” response to this question if the responder states that the care recipient has other symptoms of cognitive impairment (for example, s/he is unable to make appropriate decisions or cannot complete a task). It is possible that the care recipient has both a cognitive impairment and needs help with basic functions/daily tasks. If that is the case, please check both response categories. This question is not designed to assess the severity of care recipient’s disability, therefore please check the appropriate response category even if the caregiver states that the care recipient has mild difficulties with their cognition/memory or has a mild physical disability.

12-14: These three questions pertain to the amount of mental, physical, and financial strain that respondents perceive they are experiencing as a consequence of providing care to another person. The responses should be provided on a numerical scale of 1 (no strain) to 5 (extreme amount of strain). If the respondent states that the strain of caregiving has changed over time, please ask for a report of the strain of caregiving as it has been during the past month.

15. To capture the overall caregiving burden, this question refers to care that the respondent is currently providing as well as care they may have provided in the past for another family member or friend. It can be expected that the respondents may have difficulty remembering the exact time when they started providing care to a family member or friend. For that reason the response categories are broad. In the event of multiple separate episodes of caregiving, please prompt the respondent to provide a summary estimate of the total time they have devoted to caregiving.

E. Falls

Script: “Next I will ask you about falls you may have experienced during the past 12 months”

16. Ask the participant if they have fallen in the past 12 months. If they answer “yes” proceed to question 17. If they answer “No” or “Do not remember” then proceed to the administration information for this form.

17. Ask the participant “In the past 12 months, how many times did you fall?” The answers are 1-5, 6 or more or “Do not remember”.

UNLESS the response to question 17 is ‘1’, read the following scrip as a transition to asking questions 18-19.

Script: “Now I am going to ask you about the fall that you thought was the most serious.”

If a participant asks what “most serious” means, indicate that a fall that may have resulted in an injury, medical treatment or a physician visit. If they did not sustain an injury or need medical treatment, then ask them to select one of the falls that they best remember.

If the response to question 17 is not ‘1’, questions 18 and 19 pertain to the most serious fall only

18-19. The answers are Yes, No, or Do not remember.

Thank the participant and proceed to the administration information.

F. Administrative Information

15. 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.