



INSTRUCTIONS FOR THE SEMI-ANNUAL FOLLOW-UP GENERAL INTERVIEW QUESTIONS (03/16/2016) (GNE, VERSION 1, 12/21/2015)

I. General Instructions

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

1. In general, you are trying to assess the participant's current physical activity levels with a single question. This single question was selected from the ARIC/Baecke Physical Activity Questionnaire, collected at Visits 1, 3, and 5, to obtain a RANKING of participant physical activity levels in comparison to their peers. With similar data collected at Visits 1, 3, and 5, we will also be able to examine changes in physical activity ranking overtime.

Script: “In comparison with others your own age, do you think your physical activity during your leisure time is...”

The focus of this question is to determine how participant’s physical activity levels rank compared to their peers. The five possible response options range from much less to much more.

B. Functional status

In general, you are assessing 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 (i.e., heavy work around the house, walk upstairs without assistance, walk half a mile, or work outside the home).

Script: “Are you able to do your usual activities, such as work around the house or recreation?”

- 2. 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. 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 walking, or performing any form of recreational exercise which they have been able to do until recently, record the question as “No”.

Script: “Are you able to walk half a mile without help? That's about 8 ordinary blocks.”

3. 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 record the question as “Yes” for a participant who reported walking half a mile with the use of a cane or a walker if they are able to use it independently. It is assumed that anyone requiring a second individual to assist ambulating is not able to walk half a mile.

Script: “Are you able to walk up and down stairs without help?”

4. 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 responds that they live in a house (such as a ranch house) where they do not have stairs, say that you want to know if he/she is able to walk up and down stairs if necessary. If the respondent is uncertain, record the question as “No”.

Script: “Are you able to do heavy work around the house, like shoveling snow or washing windows, walls or floors, without help?”

5. 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 the question as “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." If the participant states that they do not perform heavy work, the interviewer should ask again “Are you able to do heavy work?” Additional examples of heavy work can include: carrying heavy loads, gardening, (manually) washing a car. These additional tasks can be performed even by those participants who live in retirement communities or assisted living facilities and may not be exposed to heavy work.

C. Falls

Fear of Falling

These questions should be asked **BEFORE** the “falls in prior 6 months” questions. The purpose of these questions is to determine if participants limit their activities (inside and outside the home) because they are afraid of falling. Regardless of a prior history of falling, older adults are at risk for developing this fear. We ask three overlapping questions for purposes of encouraging the participant to think of different tasks they may conduct inside and outside the home that may limit due to fear of falling. There is no skip pattern. Participants should be asked all three questions.

6. Script: “Are you afraid of falling?”

Please ask the question as written. Please record “Yes” if the participant indicates they are afraid, and “No” if they are not. For participants who indicated “I don't know” or “I don't think so”, record the question as “No”. If participants ask what this means, indicate that you want to know if they avoid activities or choose not to engage in some because they do not want to risk falling.

7. Script: “Do you limit any inside household activities because you are afraid you may fall?”

Please ask the question as written. The purpose of this question is to determine if participants limit activities within their home, including self-care or activities of daily living because they are afraid they will fall. Examples of in-home activities include house cleaning, laundry, bathing, and cooking. Please record “Yes” if the participant indicates they are afraid, and “No” if they are not. For participants who indicated “I don’t know” or “I don’t think so”, record the question as “No”.

8. Script: “Do you limit any outside activities because you are afraid you may fall?”

Please ask the question as written. The purpose of this question is to determine if participants limit activities outside because they are afraid they will fall. Examples of outdoor activities include yard work, walking, climbing a ladder, sports activities, running errands, going out to dinner. Please record “Yes” if the participant indicates they are afraid, and “No” if they are not. For participants who indicated “I don’t know” or “I don’t think so”, record the question as “No”.

Falls

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

A fall is a sudden, unintentional change in position that causes landing at a lower level, on an object, the floor, or the ground. Do not include reported falls that occurred due to sudden paralysis, a seizure, or being pushed.

9. Ask the participant if they have fallen in the past 12 months. If they answer “yes” proceed to question 10. If they answer “No” or “Do not remember” proceed to the question 13.

10. Ask the participant “In the past 12 months, how many times did they fall. The answers are 1, 2, 3, 4, 5, 6 or more, or “Do not remember”.

UNLESS the response to question 10 is ‘1’, read the following script as a transition to asking questions 11-12.

Script: “Now I am going to ask you about your most serious fall during the past 12 months.”

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 9 is not ‘1’, questions 11 and 12 pertain to the most serious fall only.

11-12. The answers are “Yes”, “No”, or “Do not remember”.

D. Cognitive Complaints

Please ask the questions as written. There are no skip patterns. The purpose of these questions is to ascertain participant’s self-reported cognitive abilities. This information can inform on the

demographic, social, and behavioral and comorbid correlates of cognitive aging. The first series of questions (Q13-17) asks participants how well they remember things (their own perception of their memory, their perception of how others feel their memory is performing, and whether they use strategies to help them remember things). Question 18 asks participants about language abilities and whether they have difficulty finding words when having conversations. Question 19 refers to a participant's spatial abilities and difficulties following directions or getting lost in and around familiar neighborhoods. The last series of questions (Q20-22) asks participants about changes in concentration and whether they easily get confused. Asking about cognitive performance in different ways could lead to frustration, but try to encourage participant response by using the clarifications provided below. Please record the question as "Yes" or "No".

13. Do you have any complaints concerning your memory?

For question 13, if asked to clarify, indicate that we are asking about whether they have difficulty remembering things (e.g. phone numbers, names of people they just met).

14. Do other people find you forgetful?

In the scenario where a participant says that others have not yet told them that they are forgetful, the response should be "No".

15. Do you ever forget names of family members or friends?

16. Do you often forget where things are left?

17. Do you often use notes to avoid forgetting things?

For question 17, if asked to clarify, please indicate that we are asking whether the participant feels they have to make notes more often than they used to (i.e. lists for grocery shopping—if you never used to make grocery lists, but need to write them down now more so than before, then the response should be noted as "Yes").

18. Do you ever have difficulties in finding particular words?

For question 18, if asked to clarify, indicate that we are asking about whether they have word finding difficulties when having conversations.

19. Did you ever lose your way in your neighborhood?

For question 19, if asked to clarify, indicate that we are asking about whether they have difficulties following directions and/or get lost in and around familiar neighborhoods.

20. Do you think more slowly than you used to?

21. Do your thoughts ever become confused?

For questions 20-21, if asked to clarify, indicate that we are asking about whether it takes them longer to complete certain tasks because it is difficult for them to concentrate or because they become confused more easily than before.

22. Do you have concentration problems?

For question 22, if asked to clarify, indicate that we would like to know if it is more difficult for the participants to concentrate now? A specific example of concentration problems may be an individual becoming distracted while performing usual tasks (i.e. reading or watching TV). Another example may be an individual who has trouble carrying on a conversation at a social event due to external distractions (i.e. talking or music in the background causes them to lose concentration more quickly than before).

E. Health Questionnaire

The Patient Health Questionnaire (PHQ2) questions are the first two questions of the PHQ9. PHQ2 is an ultra-brief depression screening instrument originally developed from the Primary Care Evaluation of Mental Disorder (PRIME-ED) Procedure. The PHQ2 is not intended to diagnose depression, but may be used to screen for depressive symptoms.

It is important to read the script exactly as written, including using the phrase "...been bothered..." The questions should flow naturally and comfortably; this is best accomplished by being straightforward and direct. Reading from the script helps interviewers achieve these goals and is important for collecting reliable data across field centers. Practice and repetition results in dramatic increases in comfort level among interviewers.

Script: "The following two questions ask about your mood and interest in activities over the past month. Please try to answer with a 'Yes' or 'No' response."

23. During the past month, have you been bothered by feeling down, depressed or hopeless?
The answers are "Yes" or "No".

24. During the past month, have you been bothered by little interest or pleasure in doing things?
The answers are "Yes" or "No".

Troubleshooting: If participants are uncertain how to respond, the examiner should repeat the question exactly as written: "Let me repeat the question. During the past month, have you been bothered by..." If the participant continues to have trouble answering the question, the examiner can first ask about the presence of a symptom, then include information about frequency and nature. For example: "In the past month have you felt down, depressed or hopeless?" If the answer is "Yes" then ask "Did these feelings come and go such that you feel you are back to yourself?" If 'no', they did not resolve or participant is not him/herself, then ask "Did you have these feelings several days or more?" If 'yes', then record "yes" to the question. If they are still unable to respond, record "don't know."

F. 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?"

25. Please read the question as stated above. Some participants may be reluctant to let others know that they live alone. 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. 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.

G. Social Support

Script: “Can you count on anyone to help you when you need to make difficult decisions or talk over problems?”

26. Please read the question as stated. We would like to know if the participant has a friend, neighbor, family member, or someone in the community that they live in or someone who they are in regular contact with whom they can rely on for emotional support and advice. The person does not need to live close to the participant. It is acceptable to refuse to answer this question. This question and the next one will help us assess participants' social network. We are interested in how the presence of social support for emotional and physical needs may affect a person's health.

Script: “Can you count on anyone to help you with daily tasks like grocery shopping, housecleaning, cooking, telephoning, or giving you a ride?”

27. Please read the question as stated. We would like to know if the participant has a friend, neighbor, family member, or someone in the community that they live in who can help them with instrumental activities that may be difficult to perform independently. A response that the participant knows someone who can help them with rides (to the doctor, for example), but that s/he does not have anyone to help with shopping or housecleaning is still a “Yes” response.

F. Administrative Information

28. 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.