

INSTRUCTIONS FOR THE SEMI-ANNUAL FOLLOW-UP GENERAL INTERVIEW QUESTIONS (01/01/2021) (GNH, VERSION 1, 01/01/2021)

I. General Instructions

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

Read the question as listed: "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". If the participant states that they do not know what is the level of physical activity of others their own age, please ask them to think about the physical activity of their friends or family members who are of about the same age.

This question pertains to usual leisure time physical activity and does not refer to physical activity occurring under other circumstances, such as sports activity.

B. Functional Status

This question applies to the participant's current functional status within the last 4 weeks rather than on the day of the interview. We do not want to document changes 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 listed activities (i.e., heavy work around the house, walk upstairs without assistance, walk half a mile, or work outside the home).

Read the question as listed: "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".

Read the question as listed: "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.

Read the question as listed: "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 participant responds that they use a seated stair-lift to get up stairs, but can access and use the lift of their own accord, record the question as "No". If the respondent is uncertain, record the question as "No".

<u>Read the question as listed</u>: "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

<u>Script</u>: "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, a stroke, syncope or fainting, or being pushed.

- 6. Ask the participant if they have fallen in the past 12 months. If they answer "Yes" proceed to question 7. If they answer "No" or "Do not remember" proceed to the question 8.
- 7. 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".

D. Caregiving

- 8. Read the question as listed: "Are you currently receiving care on an ongoing basis to help with chronic illness or disability? This includes any kind of help, such as companionship, help with dressing, bathing, transportation, food preparation."
- 9. This question provides information on the extent to which the person receiving care is in constant contact with the caregiver. It is possible that the caregiver is living in the same dwelling as the care recipient, although the care recipient may spend the day in a full-day care facility. This should still be considered as living with the caregiver. The answer to this question should be "Yes" if the person receiving care is living in a long-term care facility where s/he is receiving care on a regular basis. It should also be "Yes" if the person is living in an assisted living facility. For individuals, who state that they live in a retirement community, the answer will be "Yes" to this question if they also receive help with daily activities, having transitioned to assisted living or to skilled nursing to receive more medical care while remaining in the same community.

E. Social Support

10. This question and the next three questions will help us assess participants' social network. We are interested in the participant's social support for emotional and physical needs. We would like to know if the participant has a friend, neighbor, family member, someone in the community that they live in or someone who they are in regular contact whom they can rely on for emotional support and advice. The person does not need to live close to the participant. It is not necessary to probe if the participant declines to answer this question. Please read the question as stated.

<u>Script</u>: "The next questions are about how you feel about different aspects of your life. For each one, tell me how often you feel that way."

Read questions 11, 12 and 13 as listed. If the interviewee asks about the meaning of a term used in these questions ask them to respond to the question according to what it means to him/her. If an answer does not correspond to the response categories ask the participant "would you say this is hardly ever, some of the time, or often?"

F. Cognitive Complaints

Script: "Now I have a question about your memory."

Please ask the questions as written. The purpose of these questions is to ascertain participant's self-reported memory function. The first question (Q14) is asking participants about their own perception of their memory. Question 15 is asking about whether they worry about their changes in memory function. Asking about memory in many different ways could lead to

frustration, but try to encourage a participant response using the clarifications provided below. Please code the responses as "Yes", "No", or "Do not know".

- 14. For question 14, if asked to clarify, indicate that we are asking about whether they have more difficulty remembering things (e.g. phone numbers, names of people they just met) than usual. Please skip to Q16 if the response to Q14 is "No", or "Do not know".
- 15. For question 15, if asked to clarify, indicate that we are asking about whether you are concerned about your changes in memory.

G. Unintentional Weight Loss

- 16. Read the question as written. If the response to Question 16 is YES, go to Question 17. If the response to Question 16 is NO, go to Question 19. If the participant does not know if more than 10 pounds have been lost during the last 12 months, enter 'Unknown' for Question 16 and go to Question 18 to determine if the participant was trying to lose weight. This will be informative when combined with objective measures of weight from the clinic exams.
- 17. If more than 10 pounds were lost (Yes to Question 16), ask how much lower the weight is now than one year ago (Question 17) and go to Question 18. If more than 10 pounds were lost in the last 12 months (YES to Question 16), but more than 10 pounds were regained during the same time period, code '0' in Question 17 to indicate that the participant's current weight is not lower, but the same or higher than it was a year ago. If the participant reported losing more than 10 pounds in the last 12 months (YES to Q16) and gained back weight, but not as much as they lost, the net result of their loss/gain is recorded in Q17. For example, if they lost 20 pounds in the last 12 months and regained 15 pounds during the same time period, '5' should be recorded in Q17. The weight (loss) reported should be recorded in pounds as integers (and no decimal places) in Question 17. 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 '0'; 1.5 pounds should be recorded as '1'.
- 18. Read the question, recording whether the participant was trying to lose weight or not.

H. Administrative Information

- 19. sAFU general interview questions completion status. Enter the code that describes whether or not the sAFU general interview questions were completed.
 - A. <u>Complete</u>: 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

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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.

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