



INSTRUCTIONS FOR THE SEMI-ANNUAL FOLLOW-UP GENERAL INTERVIEW WITH PROXY (01/21/2026) (GLX, VERSION 1, 01/21/2026)

I. General Instructions

The semi-annual follow-up general interview questions (GLX) are completed during the semi-annual follow-up interview, following the administration of the semi-annual follow-up core questions (SAF). It is the proxy version of the GNL form and should be completed only if the participant is living and the interview is conducted with a proxy, informant, or other respondent instead of the participant. If consent for the SAF interview is not obtained, neither the GNL nor the GLX form will be administered.

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. Falls

Script: “Next, I will ask you about falls [name] 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 proxy if the participant has fallen in the past 12 months.

B. Traumatic Brain Injury

Script: “Next, I will ask you about any head injuries [name] may have experienced in the past 12 months which led him/her to seek medical care. A head injury may also be referred to as a concussion or traumatic brain injury. Head injuries may happen from a fall, motor vehicle crash, or being hit by something or someone.”

- 8. Ask the proxy if the participant has experienced a head injury (also referred to as a concussion or traumatic brain injury) which led them to see a physician or seek emergency room or hospital care in the past 12 months. If they answer “Yes”, proceed to question 8a. If they answer “No” or “Don’t know”, proceed to the question 12a.
- 8a. Ask the proxy “In the past 12 months, how many times did [name] have a head injury which led him/her to seek medical care?” The answers are 1, 2, 3, 4, 5, 6 or more, or “Don’t know”.

C. Digital Access

Script: “Next, I will ask you about [name’s] internet use in the past month and year.”

If sites feel that Questions 12a-12c are confusing for respondents, sites may choose to adapt the wording to clarify or explain the meaning of “the Internet”. For example, Question 12a may be read as, “In the last month, has [name] used a device, such as a smartphone, computer, tablet, to access the Internet for household activities (e.g., shopping, paying bills)?” Wording adaptations may also be applied to Questions 12b and 12c, as needed.

- 12a. Record whether the participant has used the Internet for any household activities in the last month. Proxy who states the participant has not done this, but that a family member, friend, or caregiver has done this for them, should be marked as “No.”

Internet use for conducting household activities includes shopping for groceries or personal items (e.g., toiletries that you can buy at the grocery or drug store) and paying bills or doing banking.

- 12b. Record whether the participant has used the Internet for any connecting with others in the last month. Internet use for connecting with others includes use of social networking sites (e.g., Facebook, LinkedIn) and video calls with family or friends (e.g., Zoom, FaceTime).

- 12c. Record whether the participant has used the Internet to manage any health-related tasks in the last year. Emphasize that Q12c is asking about “the last year,” in contrast to the previous two questions, which asked about “the last month.”

Proxy who states the participant has not done this, but that a family member, friend, or caregiver has done this for them, should be marked as “No.”

Internet use to manage health-related tasks including having a telehealth visit, refilling prescriptions, changing medical appointments, getting test results, requesting referrals or prescriptions, contacting your healthcare provider, learning about a health condition, or handling health insurance matters (e.g., finding out what is covered, comparing plans or providers, finding out about bills, filing a claim).

If the proxy does not know the answer to question 12a, 12b, or 12c, mark them as “Don’t know”.

D. Alcohol Consumption

Script: “Next, I am going to ask you about [name’s] consumption of wine, beer and drinks made with hard liquor.”

13. Current alcohol consumption (yes/no). If the proxy asks, or if the answer is not explicit, “presently” is defined as within the last 6 months.

E. Arthritis

Script: “The next questions are about arthritis.”

15. For the question about arthritis, read the script in Question 15. If the proxy responds “No” or “Don’t know”, record the response and go to Question 16a.

If the proxy responds with indirect responses, such as “They said [name] has rheumatoid”, include this as a “Yes” response to being told the participant had “arthritis”. If the proxy responds “Yes”, proceed to 15h and read the script regarding location of arthritis.

If the proxy avoids the yes/no response or responds with “I don’t know”, probing is permitted. The interviewer could ask, “Do you recall [name] seeing a doctor or other healthcare provide for pain in his/her joints that was not from an acute event such as a fall or injury?” If the proxy reports this occurred or may have occurred, repeat the question or rephrase it. For example, the interviewer could say “Do you recall if they said [name] had arthritis in the joint?”

- 15h. Ask the proxy to report in which areas of the body the participant has arthritis. When recording responses, use the joint location categories included on participant version of this form whenever possible (e.g. Feet or ankles, Knees, Hips, Back, Neck, Shoulders, Hands or wrists), based on the proxy’s description.

F. Unintentional Weight Loss

Script: “I would like to ask you a few questions about [name’s] weight loss to track potential changes.”

If there are concerns that some of these questions about weight loss have been asked previously, the interviewer can respond by saying, **“You may have been asked some of these questions before, but it is important to make sure we have accurate information and to track potential changes that could have occurred since you were last asked these questions.”**

- 16a. Read the question as written. If the response to question 16a is “Yes,” go to question 16c. If the response to question 16a is “No,” go to question 20. If the proxy does not know whether the participant has lost more than 10 pounds during the last 12 months, enter ‘Unknown’ for question 16a and go to question 16c 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.

- 16c. Read the question, recording whether the participant was trying to lose weight or not.

G. Physical Ability

Script: “These next few questions ask about how well [name] typically functions on his/her own. Do not include difficulties due to a temporary condition like a broken limb. Can [name] do the following activities without help from another person or special equipment, such as a cane or walker?”

- 20-31. Examples of special equipment include canes, walkers, lift chairs, and motorized beds. If a device is used to aid in physical mobility (e.g. walking, balance, transferring in and out of bed or chairs) it is considered special equipment.

If the proxy reports the participant using special equipment or assistance, ask whether the participant can perform the activity without that equipment or assistance. If the proxy says they use equipment but do not truly need it (e.g., “[Name] keeps a cane with him/her, but he/she doesn’t need it”), ask **“Would [name] be able to do this without the cane/equipment?”**

The available response categories are “Yes”, “No”, “Does not do” and “Don’t know”. The option “Does not do” must NOT be read aloud and should only be selected if the proxy volunteers that the participant does not do the activity.

If the proxy responds, “[Name] doesn’t do that,” the interviewer should probe to determine if this is due to a health or physical problem. For example...

- For preparing meals (Question 25) or managing money (Question 26), if the proxy responds, “[Name’s] wife does that,” ask, **“Is that because [name] is not able to (prepare meals or manage the bills/bill paying)?”** If the answer is “No, [Name] just doesn’t do it and has never done it,” choose “Does not do.” However, if the proxy says, “[Name] can’t keep up with that anymore,” or “[Name’s] arthritis is so bad his/her daughter started doing it,” choose “No.”
- For standing up from an armless chair (Question 30), if the proxy says the participant is in a wheelchair or paralyzed or the participant is bedbound so they don’t do this, the answer would be “No” they cannot do this. If the proxy says, “All of the participant’s chairs have arms, so he/she hasn’t tried,” probe to ask if they use the arms of the chair to push themselves up. If they use the chair, a person, or other support to stand, choose “No” they cannot do without help or equipment. If they only have chairs with arms and they stand from the chair without using the chair to push themselves up, then choose “Yes” they can do it. If they don’t do it, it should generally be due to a physical problem, meaning there are few, if any, reasons to choose “Does not do”.
- For stooping, crouching, or kneeling (Question 31), if the proxy says the participant doesn’t do, probe to ask “Is there a reason [name] does not do [task]? If they are afraid they would not be able to get back up if they get on the floor, the response should be “No”, not able to do.

Script: “The following three questions are about bathing, using the toilet, and incontinence. Although these are normal, everyday activities and functions, we understand these may be sensitive topics”

32-33. The available response categories are “Yes,” “No,” “Does not do” and “Don’t know”. The option “Does not do” must NOT be read aloud and should only be selected if the proxy volunteers that the participant does not do the activity.

If the proxy volunteers **“[Name] doesn’t do that,”** probe to determine whether this is due to a health or physical problem. For example, if the proxy says the participant doesn’t bathe, the interviewer could ask “Does someone help him/her bathe or shower, including sponge baths?”

If the proxy indicates the participant uses assistance or equipment (e.g., grab bars, shower chairs, adult briefs) or reports completing the activity only with help from another person, clarify their ability to perform the activity on their own: **“Would [name] be able to do this on his/her own without help from another person/without the grab**

bar/equipment?" Record "Yes" only if the participant can perform the activity independently.

32. Note that sponge-bathing counts as bathing as long as the participant completes it independently.

Examples:

- If the proxy says, "[Name's] spouse helps him/her with bathing now," ask: **"Is that because [name] is not able to bathe himself/herself, or is it just something [name's] spouse helps with?"**
 - If the proxy indicates the participant **cannot** perform the activity due to a physical or health limitation, record **"No."**
 - If the proxy indicates the participant **does not perform** the activity for reasons unrelated to ability (e.g., "[name] has never bathed himself/herself, but not because he/she can't"), record **"Does not do."**

L. Incontinence Question

34. The question pertains to an average day. You may want to acknowledge that this may be a sensitive question to ask, but incontinence is something that many adults have to manage, although this can cause embarrassment and distress and is difficult to discuss. According to the CDC, approximately 50% of non-institutionalized adults 65 years or older report either bladder or bowel incontinence.

Lack of bladder control is understood as urgent urination/inability to get to the bathroom in time or inability to hold the urine during the day or at night. There are many types of incontinence, including stress incontinence (e.g., bladder leakage when coughing), urge incontinence (i.e., an urgent, and often frequent, need to urinate), or persistent urine leakage due to incomplete bladder emptying. Lack of bowel control is understood as accidentally passing stool or not being aware of the need to pass stool.

If the proxy does not answer "Yes" or "No" and instead says the participant uses "*Depends*" or a similar product, set special missing value for the question and record in the notelog the word "Depends." Similarly, if the proxy answers "Yes" or "No," but also volunteers that the participant uses Depends or a similar product, record the Yes/No response and also record in the notelog the word "Depends."

If the proxy refuses to respond to this question, record "Don't know".

M. Administrative Information

35. 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.