

INSTRUCTIONS FOR COVID-19 C4R WAVE 2 INTERVIEW WITH PROXY OF LIVING PARTICIPANTS (08/18/2021) (CV2L, Version 1.0, 07/08/2021)

I. General Instructions

For majority of study participants, this form is completed during the Annual or Semi-Annual Follow-up for all interviews with the proxy of living study participant. It can also be completed outside of a follow-up interview; that is at the field center's discretion. The Annual or Semi-Annual follow-up interview is conducted first, followed by the CV2P interview, which is designed to collect data on testing, diagnosis, preventive behavior and hospitalizations associated with the COVID-19 caused by infection with the SARS-CoV-2 virus.

This is a second wave of the administration of the COVID questionnaire. Participants or their proxy/informant should have completed the COVP or COVL questionnaire approximately one year ago. For participants (proxy/informant) who did not provide consent for future COVID calls during the COVP or COVL interview (question 8 on the COVP/COVL is recorded as "No"), the COVID Wave 2 interview should not be administered to them. You will find red texts that read "COVID Wave 2 interview should NOT be administered" next to the participant ID field in the annual and semi-annual tracing sheets in CDART.

Please make sure that there is not already a CV2L form recorded in previous CYs in CDART, before proceeding to administer a CV2L questionnaire. When a form was started but the interview needs to be rescheduled, the interviewer should go back to the original occurrence of the form and make updates to the same occurrence when they call the proxy/informant back at a later date. Do not create a new occurrence of the form.

II. Detailed Instructions for each Item.

ADMINISTRATIVE INFORMATION

- 0a. Enter the date on which the CV2L was administered.
- 0b. Enter the staff ID for the person who administered the CV2L.
- 0c. Record whether this form is completed during the Annual or Semi-Annual follow-up call. Select "Neither" if the questionnaire is being collected outside of a follow-up call.
- 0d. Use either the annual or semi-annual tracing sheet in CDART to ascertain if the participant has ever reported having a diagnosis of COVID-19. This information would have been recorded in the CEL, if the infection resulted in a hospitalization, or on the COVP or COVL forms. It is important to answer either 'Yes' or 'No' to this question in order to set future skip patterns correctly, so do not leave this field blank.

0e. If this form is administered as part of the AFU/sAFU read the script: "Now I am going to ask a few question about experiences [name] may have had with COVID-19."

If this form is administered separately from the AFU/ sAFU, read the script: **"We are calling to ask** a few questions about experiences [name] may have had with COVID-19. Responses to this survey will contribute to a better understanding of the COVID-19 infection and the way it affects people. Is this a good time to talk?"

If the proxy/informant answers "Yes" and the answer to question 0d is "Yes", skip to question 11. If the proxy/informant answers "Yes" and the answer to 0d is "No", the form skips to question 1. Otherwise, proceed to question 0f.

- 0f. Read the question as listed. If the proxy/informant answers "No", save and close the form. If the proxy/informant answers "Yes", proceed to question 0g.
- 0g. Read the question as listed and record the date provided by the proxy/informant. Read the script: "Thank you, I will call again." Save and close the form.

COVID-19 SELF-REPORT

 Date of last call is the date of completion of form COVP or form COVL, or, in absence of the COVP or COVL, date from the most recent AFU or sAFU form. This date is also made available in the CDART Tracing Sheet. Most ARIC participants will have had a dry blood spot test for COVID-19. This test and any results from it that the participant would have received from ARIC should not be considered in this response.

Skip to question 7 if the answer is "No" or "Unsure". Use the notelog for recording comments made if the participant is unsure if they had a COVID-19 test done.

- 2. Please read the question and then verbally offer the different types of tests listed on the form. Select any and all types that the proxy/informant reports. If the type of test a proxy/informant reports is not listed, select other and then type in what the proxy/informant said in question 2e1.
- 3. Here also, please do not consider results from the ARIC dry blood spot testing. If the answer is "No" or "Unsure, skip to question 5. Use the notelog for recording comments made if the proxy/informant was unsure of test results.
- 4. Enter the approximate date in month/year format if the specific day is unknown. Skip to question 11 after proxy/informant responds. If the proxy/informant does not remember the date, set special missing value for this field and skip to question 11.
- This question should be answered by proxy/informants who responded "No" or "Unsure" to question
 Date of last call is the date of completion of form COVP or form COVL, or, in absence of the COVP or COVL, date from the most recent AFU or sAFU form..
- 6. Enter the approximate date in month/year format if the specific day is unknown. Skip to question 11 after proxy/informant responds. If the proxy/informant does not remember the date, set special missing value for this field and skip to Q11.

- 7. Date of last call is the date of completion of form COVP or form COVL, or, in absence of the COVP or COVL, date from the most recent AFU or sAFU form. If the answer is "No" skip to question 30.
- 8. Please read aloud all response options and record a response of "Yes" or "No" for each listed reason. If the reason provided is not listed, select "Yes" for question 8h and record the reason provided in question 8h1.
- 9. This date does not need to be provided with accuracy to the day; month will be sufficient. If the proxy/informant does not remember the date, set special missing value for this field.
- 10. Please read aloud all response options and record a response of "Yes" or "No" for each listed option. For option 10c Other, say aloud, "Is there any other way [name] could have contracted COVID-19?"

COVID-19 RE-INFECTION

Please read the script: "You have reported that you know or think that [name] has had the COVID-19 infection. The following questions ask about possible re-infections [name] may have had since that first COVID-19 infection."

- 11. If the response is "No", skip to Q16
- 12. This date does not need to be provided with accuracy to the day; month will be sufficient. If the proxy/informant does not remember the date, set special missing value for this field.
- 13. Please read aloud each response option and mark "Yes" or "No". For option 13d Other, say aloud, "Is there any other way [name] could have contracted COVID-19?"
- 14. Please read aloud all response options and mark the one selected by proxy/informant using the drop-down menu.
- 15. We are not anticipating more than three COVID-19 infections in any of the participants. Please use the notelog if there should be additional ones.

COVID-19 HOSPITALIZATION

Questions 16-22 refer to participant's experience while hospitalized due to a COVID-19 infection (as reported by proxy/informant).

Please read the script: "I now want to ask you about COVID-19 hospitalizations that [name] may have had recently."

16. This question is about any COVID-19 related hospitalizations that may have occurred since the last COVP call, SAF call, or sAFU call, whichever was most recent. This date information will be available in the tracing sheet. For responses "No" or "Unsure" skip to question 23. Please note that hospital admission for COVID-19 may have been reported in the course of an AFU or SAF interview

in response to a question formulated differently ("... was [name]) hospitalized or did [name] stay in a hospital observation unit for any reason that you have not yet mentioned?")

If in the course of an AFU or SAF interview the proxy/informant mentions a COVID-19 related hospitalization, let the proxy/informant know that you will return to that information, proceed with the AFU/SAF interview, and then transition into the CV2P interview from the beginning (without changing the order of administration). The information on Hospital Name, City, State can be carried over (need not be asked again).

- 17. Please include all hospitalizations since March 1, 2020. The time frame for this question is March 1, 2020 until the present.
- 18. This date should be the date of arrival at the hospital. It does not need to be provided with accuracy to the day; month will be sufficient. If the proxy/informant does not remember the date, set special missing value for this field.
- 19. This question pertains to the location of the first COVID-19 hospitalization. Please use the dropdown menu for hospital name requested in question 19a. If the hospital is not on the drop down list, enter the hospital name, city, and state in question 19a1.
- 20. The possible response range for this question is 1-365 nights
- 21. Please read aloud the script that precedes questions 21a-21d. For each question 21a-21d, response options are "Yes", "No", "Do not know". Valid range of response for questions 21a1, 21b1 21c1 and 21d1 is 1-365 days.
- 22. Please read aloud all response options and mark the one selected by the participant. Instead of reading aloud 'other', say, **"Was there somewhere else that [name] went directly after hospitalization?"**

COVID-19 SYMPTOMS

The next two questions (Q23-Q24) refer to symptoms associated with a COVID-19 infection.

- 23. This question is most applicable to the first COVID-19 infection. This does not need to have been a COVID-19 hospitalization. Response options are "Yes", "No", "I do not remember". If the answer is "No" or "I do not remember", skip to question 25.
- 24. Please read aloud the question and response options (e.g. "Would you say that the symptoms [name] experienced did not at all prevent him/her from his/her daily activities, prevented a little bit, somewhat, quite a bit, or very much"?) and select the appropriate response from the drop-down menu. "I do not remember" is an appropriate response.

COVID-19 RECOVERY

The following questions Q25-Q29 pertain to the most recent COVID-19 infection the participant experienced. For most that will have been their one and only COVID-19 infection.

- 25. Please skip to Q27a if the response if "No" or "Unsure".
- 26. Record number of days it took for the participant to recover to their usual state of health from their COVID-19 illness. The valid response range is 0-999 days.
- 27. Please read aloud the script that precedes questions 27a-27j and then read the questions in sequence. For each question 27a-27j, select "Yes" or "No" as the response option.
- 28. Please select one of the response options: "Not at all worried", "A little worried", or "Very worried".
- 29. For this question, if the proxy/informant chooses to share additional observations about [name]'s COVID-19 recovery, record them in question 29a. A possible response may be for example, "my (wife's) COVID-19 experience was worse than my (friend's, etc.)".

COVID-19 VACCINE

30. Any of the vaccines approved on the US market are acceptable. The question pertains to the participant having had received at least one dose of the vaccine. Skip to question 34 if the response is "No" or "Unsure"

Questions 31-36 pertain to vaccinations received at any time.

- 31. This pertains to the last of the originally scheduled vaccination(s) received. If the proxy/informant states that the participant has received a COVID-19 booster vaccination, record the date in the notelog. This date does not need to be provided with accuracy to the day; month and year will be sufficient
- 32. Any of the vaccines approved on the US market are acceptable. The question pertains to the participant having had received at least one dose of the vaccine.
- 33. If the proxy/informant does not recall how many doses of the vaccine [name] received, please ask them if [name] has a COVID-19 vaccination record, a card he/she received after their first vaccination. Information about the number of doses received will be noted on that record. Record in the notelog if the proxy/informant reports the participant received a COVID-19 booster vaccination.
- 34. Flu vaccinations may have been lower this year than in previous years, so it will not be unexpected to receive "No" responses. The August 2020 time frame may not be relevant for when this questionnaire is administered in the Fall 2021, However the time frame since August 2020 will be pertinent.
- 35. No specific time frame is provided
- 36. No specific time frame is provided
- 37. Please read the question as stated. Some proxy/informants may be reluctant to let others know that their loved ones/care recipients live alone. If asked why we would like to know about [name]'s living circumstances, you may respond that we are interested in how living circumstances may affect a person's health. It is acceptable for a proxy/informant to refuse to answer this question. A participant who lives in a retirement community, assisted living, or nursing facility is not living alone.

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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.

Please read the following script: "In the next part, there will be some questions that we may have already asked during a previous interview. We would like to ask them again here."

COVID-19 LONELINESS AND STRESS

Questions 38a-38c are to be asked if the response to Q0c is not "Semi-Annual Follow-Up". The reason for that is that this set of questions will have just been asked during this same interview session.

- 38. Please read the script "For each of the following questions, please provide the response that describes [name]'s life. The response options are often, sometimes, or hardly ever." Then read questions 38a, 38b and 38c as listed. If the proxy/informant 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 proxy/informant "would you say this is hardly ever, sometimes, or often?"
- 39. Please read the question as stated. Is the proxy/informant asks what is meant by "hard times", ask them to consider what it means to him/her. Then ask if he/she how they agree with the statement that [name] can bounce back quickly after hard times and select the appropriate response from the drop-down menu.

COVID-19 PANDEMIC IMPACT ON BEHAVIOR

Questions 40-50 pertain to general health status of study participants at this time as compared to the time before the COVID-19 pandemic (March 2020). For most of the questions, there is a direct request for this comparison.

Please read the script: "The following questions ask about how [name]'s activities may have changed since the start of the COVID-19 pandemic in March 2020."

- 40. Any level of walking is acceptable as long as the proxy/informant considers this a form of exercise that the participant engages in.
- 41. For this question, the examples are just guidelines. If a person can do any vigorous activity (not necessarily those specified in the question), then record the question as "Yes". Other examples of vigorous activity could be "brisk walking", or "yoga." These additional tasks can be performed even by those participants who live in retirement communities or assisted living facilities. If the proxy/informant states that [name] does not do vigorous activities, the interviewer should ask "Is [name] able to do vigorous activities?"
- 42. Movies or shows can be watched on any medium TV, streaming, etc. The question is a proxy for sedentary behavior.

- 43. This question asks about average alcohol consumption (per week). Any type of alcohol is acceptable.
- 44. Snacks can include any type of food that is consumed between meals. If the participant states that they now snack more frequently but not necessarily a greater amount than prior to the COVID-19 pandemic, please select "more" as the response.

Do NOT ask Question 45 and Question 46 if Question 0c= "Semi-Annual Follow-Up". The reason for that is that this set of questions was asked just prior on this same Semi-Annual Follow-Up call.

- 45. The amount of weight change in relation to the time prior to the COVID-19 pandemic does not need to be provided.
- 46. This question asks if the weight change was intentional.
- 47. This question asks about overall health status now as compared to the time before the COVID-19 pandemic.
- 48. Response to this question can include naps as well as sleep at night.
- 49. The purpose of this question and the subsequent Q50 is to ascertain proxy/informant's perception of participant's memory. If asked to clarify, indicate that we are asking about whether the participant has more difficulty remembering things (e.g. phone numbers, names of people they just met) than before the COVID-19 pandemic.

If the response is "No", save and close the form.

50. We want to know if the symptoms of memory loss experienced by the participant now are worse than before the COVID-19 pandemic.

CLOSURE SCRIPT:

"Thank you very much for contributing for the past 30 years to the ARIC study and its mission of 'Research with Heart'!"