



INSTRUCTIONS FOR COVID-19 INTERVIEW WITH PROXY OF DECEASED PARTICIPANTS (11/10/2020) (COVD, Version 1.0, 05/18/2020)

I. General Instructions

This form is completed during the Annual or Semi-Annual Follow-up for all interviews concerning a deceased study participant. The Annual or Semi-Annual follow-up interview is conducted first, followed by the COV interview, which is designed to collect data on testing, diagnosis, preventive behavior and hospitalizations associated with the newly identified disease called COVID-19 caused by infection with the SARS-CoV-2 virus.

Currently only ONE occurrence of the 'baseline' COVID questionnaire (COVP or COVL or COVD) per participant is expected to be completed in CDART. The CC will inform the field centers when the decision is made on when and how the second administration of the COV-19 interview will be done. Please make sure that there is not already a COV form recorded in previous CYs in CDART, before proceeding to administer a COV questionnaire. When a form was started but the interview needs to be rescheduled, the interviewer should open the same original occurrence of the form to make the updates when they call the participant back at a later date.

II. Detailed Instructions for each Item.

0a. Enter the date on which the COVD was administered.

0b. Enter the staff ID for the person who administered the COVD.

0b1. Record whether this form is completed during the Annual or Semi-Annual follow-up call. If the participant agreed to be contacted once a year (ICT1= "Agree to once per year") but gave permission to be contacted again for future COVID-19 interviews on the last COVID-19 interview call (Q8 on the last completed COVP or COVL form is recorded as "Yes"), leave this question as blank and set the field status as "Not Applicable".

0c. Read the script: **"Next I would like to ask you about any experience [name] had with the new coronavirus and the disease it causes, called COVID-19. Is that okay?"**

If the proxy/informant answers "yes" to question 0c, the form skips to question 1. Otherwise, proceed to question 0c1.

0c1. 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 0c2.

0c2. 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 form.

1. If the proxy/informant responds that the participant had a negative test result or has no reason to believe that the participant had COVID-19, record "No". If the proxy/informant responds that the participant had a positive test result or confirmation by a HCP, record "Yes, definitely". If the proxy/informant believes that the participant had it but had not been tested or has not yet received

test results, or the HCP was unsure, record “Yes, I think so”. If the proxy/informant is not sure, record “Maybe”.

2. If the answer is ‘No’, proceed to question 3. If the proxy/informant is certain the participant had been told he/she had COVID-19, record ‘Yes, definitely’. If proxy/informant is not completely sure that the participant has been told he/she had COVID-19, record ‘Yes, probably or suspected’.

Read the script: **“Please provide the contact information of the doctor who told [name] that he/she had COVID-19.”**”

2a.-2e. Record name and contact information of doctor/clinic/institution where the participant’s COVID-19 test or diagnosis was obtained.

2f. This question is asked only if question 1 or question 2 is recorded as “Yes, definitely”. If answered “No”, skip to question 3. If answered “Yes”, proceed to question 2g.

2g. Record number of days it took for the participant to recover to their usual state of health from their COVID-19 illness.

3. This question asks the proxy/informant to recall whether the participant had a cold or flu-like illness since the last contact. If the proxy/informant recalls that the participant had such illness, record “Yes” for this item and proceed to question 3a. If answered “No”, skip to question 4. The date of the last call/contact can be obtained from the ‘Date of Final Status Determined’ field on both the Annual and Semi-Annual Participant Tracing Sheets.

3a. Enter the approximate date of illness in month/year format if the specific day is unknown.

3b. Record the approximate number of days the participant’s cold or flu-like symptoms lasted.

4. If the proxy/informant answers “No”, skip to question 5. If the proxy/informant responds that the participant had a nasal, saliva, or serum test for COVID-19, record “Yes”. Tests to detect the virus, and also tests to detect antibodies to the virus are recorded as “Yes.” If the proxy/informant does not recall whether the participant had a test, or if the proxy/informant is unsure of the purpose of any tests the participant received, or if the participant’s test result is pending or inconclusive, record “Unsure” and skip to question 5.

4a. Record the number of times that the participant had been tested for coronavirus or COVID-19.

If the proxy/informant indicates that the participant had been tested multiple times, ask the proxy/informant to make a best estimate at how many total times the participant had been tested. If unable to do so, ask “approximately when did the testing start?” and assist the respondent in making a best guess at how many tests that would be.

Read the script: **“Can you provide details regarding his/her first COVID-19 test?”**

4b. Record the date of the participant’s first COVID-19 test.

4c-4c5a. Read each reason for the participant’s first COVID-19 test that is listed in Q4c1-Q4c4 aloud to the proxy/informant and record a response of “Yes” or “No” for each listed reason. If the proxy/informant responds that ‘Someone [name] knew tested positive’, record question 4c2 as

'Yes'. If the proxy/informant reports that the participant had surveillance swabs, or that they had other test reasons that are not listed in question 4c1-4c4, record "Yes" for question 4c5 and specify the reason(s) provided in question 4c5a. Otherwise, record question 4c5a as "No" and skip to question 4d.

- 4d-4d1. Read each answer option in the drop down menu for question 4d aloud to the proxy/informant and record the type of test that the participant received. If reported as nose swabs, record the type of test as nasopharyngeal swab. Dry blood spots collected by finger-prick are recorded as 'blood.' Note that the tests to detect the Sars-CoV-2 virus but also the tests to detect antibodies to the virus can be assayed from different sources of specimen. This question records the type of test according to specimen sampling. If the type of the test that the participant received is not listed, record "Other" and specify the type of the test that they received in question 4d1. If the proxy/informant is unable to identify the type of test, record "Other" and specify a best approximation or record 'unknown' under 4d1.
- 4e. If answered "Yes", skip to question 5. If answered "No" or "Unsure" and the participant had more than one test done (Q4a > '1'), proceed with question 4f. If answered "No" or "Unsure" and the participant did not have more than one test done, skip to question 5. "Unsure" includes if test result is pending or inconclusive.
- 4f. This question is asked only if the participant had more than one COVID-19 test done (if Q4a > '1') and their first COVID-19 test result was not positive. Record "Yes" or "No" for this question based on the participant's response and proceed to question 5.
5. If the proxy/informant responds with "No", skip to question 6. If the proxy/informant responds with "Yes", continue with question 5a.

For standardization of this survey with other cohorts, Q5 is asked as "Did [name] ever had an overnight stay in a hospital for suspected or diagnosed COVID-19?" A 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 ("... were you (was [name]) hospitalized or did you [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 that the participant had 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 COV 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).

- 5a1-5a2. Record the date arrived at hospital in question 5a1 and the date discharged from hospital in question 5a2. If date of arrival and formal admit date are different, record the earlier date. If the proxy/informant is unable to provide exact dates of arrival at hospital or discharge from the hospital, record the approximate dates to the best of the ability of the proxy/informant to provide this information.
- 5b-5b1. Select hospital from drop down list in Q5b. If the hospital is not on the drop down list, enter the hospital name, city, and state in Q5b1.

Read the script "**Next, I have some questions about others who might have lived with [name].**"

6. Record the number of people that live in the participant's household (or the place he/she was

residing). If answered “Lived alone”, skip to question 7. Otherwise, proceed with question 6a. If the participant lived in a Nursing Home or Assisted Living, record “More than three people” and add a notelog for Question 6 to record Nursing Home or Assisted Living.

6a. Record the number of people in the participant’s household (or the place they resided) other than themselves that have been tested for COVID-19? If answered “None”, skip to question 7. Otherwise, proceed with question 6b.

6b. If answered “None”, skip to question 7. Otherwise, proceed with question 6c.

6c. Indicate whether the participant changed their behavior at home because of COVID-19. If the answered “No”, skip to question 7. Otherwise, proceed with question 6c1.

6c1. Indicate whether the participant wore a mask at home.

6c2. Indicate whether the infected person(s) wore a mask at home.

6c3. Indicate whether the infected person(s) stayed away from the participant.

7. Read the question as listed “In [name]’s home, was there anyone who regularly goes outside (e.g., for work)?” For this question, regular activities outside the home include work, school, care-giving, and regularly scheduled meetings or commitments outside the home. ‘Regular’ is defined as daily or several times per week. Do not include going for a walk (even if daily), nor the occasional trips to buy groceries, a medical appointment, or to run sporadic errands.

If answered “No”, skip to question 8. Otherwise, proceed to question 7a.

7a. Indicate whether the participant was able to stay 6 feet away from the person who regularly goes outside.

If a group residence, Assisted Living or Nursing Home staff should be included in answering above questions 7 and 7a.

Read the script **“Thank you for sharing this information with us.”**