



INSTRUCTIONS FOR THE SOCIAL SUPPORT FORM PROXY VERSION (PWX)

I. General Instructions

The purpose of this form is to assess loneliness, social support, and anxiety that may have resulted from the social/physical distancing imposed in response to the COVID-19 pandemic. This form appears in the event called 'Psychosocial Wellbeing', and data should be entered using form occurrence 1. Note that form occurrence 2 is reserved for future use, so any necessary edits should also be made using form occurrence 1. All ARIC cohort participants who completed Visit 7 are eligible for this questionnaire. Please initially contact the study participant and if possible complete the participant version of this form (PWP) with him/her. If the participant is not able to complete the form, please contact the proxy listed in the CUI form or the last contact person recorded in the tracing sheet and proceed to the PWX form.

Field center staff will keep track of the completed and pending calls.

The need for information gathered through this form is a result of the COVID-19 pandemic. Due to the need for rapid implementation, the Coordinating Center's responsibility in this effort is to create the data collection instrument in CDART and then report on the data collected periodically. The CC is not responsible or involved in the coordination of calls, providing reports to facilitate coordination, linking this information to other sources, or any other logistical support to the field centers. This responsibility falls to each field center.

Text, other than the questions, meant to be read aloud to the participant are in bold and in quotes.

II. Detailed Instructions for each Item

0a. Enter the date on which this interview was attempted or completed. If the interview is interrupted and then resumed, update the date to indicate date of completion.

0b. Enter the staff ID for the interviewer who completed this form.

Read the following opening script:

"Hello. My name is [NAME], and I am calling from the ARIC Study. I am calling to day to ask you a few questions about how [PPT] is doing during the current COVID-19 pandemic. ARIC in person visits have stopped this year. Instead, we are calling to continue our studies of what affects ARIC participants' health and aging. COVID is affecting many people in many ways that are important to understand. Today I would like to ask you about 10 minutes of questions about how [PPT] is dealing with COVID social distancing rules and having to spend more time in your home. Is this a good time to talk?"

If it is a good time to talk, answer 0c 'Yes', continue to question 1.

If it is not a good time to talk, proceed to items 0d through 0f as appropriate and then save and close the form.

The PWX form is updated with new answers to items 0a through 0f until either the form is completed or refused.

A. GENERAL QUESTIONS

Questions 1-6 pertain to the general wellbeing of the participant.

1. We are interested in knowing whether the participant has been told that they were infected with the Cov-SARS-V2 virus.
2. Participants may be concerned about themselves, their families, or have more general worries about how this pandemic will develop and shape the country. All those concerns are appropriate.
3. This question that is a follow-up to Question 2, allows the participant to specify the nature of their concerns.
4. The extent to which the COVID-19 pandemic has changed the participant's life can be interpreted by the participant and by his/her proxy in many different ways. Please include positive responses to physical as well as emotional ways in which the pandemic has had an effect.
5. This question, which is a follow-up to question 4, has two response options: "somewhat" and "very much"
6. The time reference for this question is the past week. Please aloud the three response options: "hardly ever", "some of the time", and "all the time" for each of the conditions (anxious, nervous, fearful). If for any of these conditions, the proxy states that the participant has not at all felt that way, please mark "hardly ever" as the response.

B. MEDICAL CARE

This section refers to medical care the participant may have received in the 6 weeks preceding this interview. Please read aloud the following text: **The following questions are about [participant's name] medical care during the COVID-19 pandemic. Thinking about the past 6 weeks:**

7. This question refers to participant's in-person medical appointments.
8. Several reasons for not attending the appointment are specified. Proxies may state additional ones, which should be entered as free text.
9. In this question we try to ascertain if the participant was not able to purchase medications they needed, for example because they could not get to the pharmacy. Treatments that participants would not have been able to have can include, among others, chemotherapy, radiation therapy, or rehabilitation services.
10. During the COVID-19 pandemic many hospitals are limiting elective procedures and patients are asked to wait longer than expected for those procedures. At the same time, persons with signs and symptoms of serious acute illnesses may be delaying or postponing a visit to the emergency room out of concern for catching the virus. This question aims to capture both situations.
11. Low sleep quality may be due to many reasons, not related to the pandemic. However, the increased worry and stress during this time, may lead to changes in sleep patterns and this in turn may have an impact on overall health. We are asking the proxy to consider participant's normal sleep prior to the COVID-19 pandemic, that is prior to March 1, 2020, and state if in the past 6 weeks that sleep had changed and if so was that somewhat or not at all.

C. UCLA Loneliness Scale

The following three questions are part of the UCLA 3-item Loneliness Questionnaire. This is a standardized questionnaire, therefore we cannot change the way the questions are worded. The response categories also have to be as originally proposed.

Please read aloud the following text: "The following questions ask about your feelings during this time of COVID-19."

Response options are “hardly ever”, “some of the time” and “often”. If the participant states that they do not at all have the feelings stated in any of the three questions, please mark “hardly ever” as the response. If the participant asks about the meaning of a term used in the questions (such as for example, “feeling left out”), please ask him/her to respond to the question according to what that term means to him/her.

D. SOCIAL NETWORK

This section aims to provide information on the number of people that the participant is in touch with during the COVID-19 pandemic.

Please read aloud the following text: **“The following questions ask about how [participant’s name] has been able to stay in touch with family and friends during the COVID-19 pandemic.”**

15. Please read the question as it is stated. For the purpose of this questionnaire we are interested in participants’ living status at the time of this questionnaire administration. Participants may have been living alone prior to the pandemic, but are now living with others. Those participants are not living alone. Conversely, participants may have been living with others prior to the pandemic, but are now living alone. Participants who live in a retirement community, assisted living, or nursing facility are not living alone.
16. Adults are defined as anyone 18 years of age or older
17. Children are defined as less than 18 years of age.
18. Please check all categories of adults living with the participant
19. Ways of staying in touch are listed in question 21
20. Ways of staying in touch are listed in question 21
21. Please mark all the ways in which participants are staying in touch with family and friends.

E. SOCIAL SUPPORT

In this section we are interested in the support that the participant has from family and friends. The first two questions have been asked previously as part of the semi-annual follow-up questionnaire. They are repeated here in the same way that they were asked previously.

Please read aloud the following text: **Now we want to ask you about the kind of support you have from your family and friends during the COVID-19 pandemic.**

22. Please read the question as stated. We would like to know if, during the COVID-19 pandemic, 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 support. Since we will have responses to this question prior to the COVID-19 pandemic, we are interested in knowing if the participants’ social support will have changed as a result of the physical distancing rules during the COVID-19 pandemic and if this will affect a person’s health.

23. Please read the question as stated. We would like to know if the participant now 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.

24. This question aims to ascertain participant’s emotional resilience. Examples of hard times, may

include an illness or death in the family or personal major illness. There are 5 response categories for this question. Please read those aloud. If the participant's proxy has difficulty remembering all of the categories, please give them the option of placing their response on a scale of 1 through 5, where 5 is "never" and 1 is "always".

F. PHYSICAL ACTIVITY

Please read the following script: **"For the following two questions, please think about an average day before the COVID-19 pandemic compared to an average day now."**

25. Physical activity can be defined as any activity that does not include prolonged sitting and may include gardening, walking, or exercising.

26. Sitting can include watching television, reading, writing, etc.

G. CLOSING

27. This is an open-ended question that allows the participant's proxy to express additional concerns that they may have at this time of the COVID-19 pandemic or any questions that may have for the ARIC staff. Please enter responses as free text.

If the contact information of the closest support person who lives outside the home is to be collected at this time, read the script below. Otherwise, save and close the form after thanking the participant for their time according to the script on the screen:

"We have one more question for you. In the past, [PPT] had given us names of family members or friends whom we can contact on [HIS/HER] behalf if we are unable to reach [HIM/HER] after several attempts. The ARIC study has recognized that social connections with people who are close to us are important to our own health. We would like to ask if it would be possible for us to contact the person closest to [PPT] these days to ask how the COVID-19 pandemic is affecting their ability to stay in touch with [PPT]. The questions take about 5 minutes and are for a family member not living with the participant now. Would that be possible?"

H. PERMISSION

28. If the proxy agrees to providing this contact information for the participant, please record this closest support person's contact information in the Psychosocial Wellbeing - Closest Support Person Information (PSI). Please keep in mind that the closest support person who lives outside the home could be the proxy who just completed the PWX interview. If that is the case, complete the PSI form with the proxy and proceed to the Psychosocial Wellbeing - Closet Support Person Questionnaire (PSQ), if the proxy respondent agrees.

If your site is not collecting data from the closest support person, set the field status to "Not applicable." To do this, click the double arrows next to the field, click Field Status, and select "Not applicable" in the dropdown menu.