

COVID-19 Impact Survey

INSTRUCTIONS FOR THE CENTER

The following COVID-19 survey is an optional form to be filled out by either the participant (if CDR® Dementia Staging Instrument score=0 or 0.5) or co-participant/caregiver on behalf of the research participant (if CDR®>0.5); alternatively, it may be administered by study personnel. Participants may decline to answer questions. If Centers want to obtain information on additional issues related to COVID-19, they may do so locally, but any additional material will not be collected for NACC.

Attached to this participant form is a supplemental form for co-participants/caregivers of participants with a CDR®>0.5. This survey is also optional for Centers. Again, if Centers want to obtain information on additional caregiver issues related to COVID-19, they may do so locally, but this additional material will not be collected for NACC.

These surveys may be administered by Centers in conjunction with, or unique and separate from, annual in-person or telephone UDS visits. The timing and option to participate in collection of this important data is entirely up to the individual Centers that are part of the NIA ADRC Program. Each Center should consider administering these surveys to as many participants as possible through either mail, telephone, video, and/or in-person contacts.

We have tried to capture important scientific information regarding COVID-19 exposure, medical consequences, and impact on social situations; on cognitive, psychiatric, and behavioral issues; and on caregiver burden and related issues. While only a snapshot, this information may prove to be extremely useful in our understanding of the impact of such a pandemic on the aging population today.

COVID-19 Impact Survey: Participant

ADC name: _____ Subject ID: _____ Form date: ____/____/_____
 Examiner's initials: _____

The following COVID-19 survey is an optional form we would like you to fill out (or, alternatively, the survey may be administered to you by research study staff). We are asking these questions because COVID-19 presents very new challenges for us all, and we would like to learn about your experience. We also would like to learn how COVID-19 affects memory and health. As a research participant, you may decline to answer any of these questions, and it is all right to do so, but please answer as many of the questions as you feel comfortable with. Your research center may also have additional questions regarding COVID-19.

<p>1. During the COVID-19 pandemic, have you experienced new or worsening symptoms (see below) that led you to think you had COVID-19 (novel coronavirus) such as fever, cough, difficulty breathing, persistent pain or pressure in the chest, chills, repeated shaking with chills, muscle pain, headache, sore throat, new loss of taste or smell, new confusion or inability to arouse, or bluish lips or face?</p> <p>0 <input type="checkbox"/> No 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> Other (SPECIFY): _____ 8 <input type="checkbox"/> Decline to answer 9 <input type="checkbox"/> Unsure/unknown</p>
<p>2. Have you ever been tested for acute COVID-19 infection?</p> <p>0 <input type="checkbox"/> No, not tested (SKIP TO QUESTION 4) 1 <input type="checkbox"/> Yes, I was tested once (CONTINUE) 2 <input type="checkbox"/> Yes, I was tested more than once (CONTINUE) 8 <input type="checkbox"/> Decline to answer (SKIP TO QUESTION 4) 9 <input type="checkbox"/> Unsure/unknown (SKIP TO QUESTION 4)</p>
<p>3. If yes, on approximately what date(s) did you have the test? If you were tested more than once, please report the 3 most recent dates.</p> <p>3a1. Date of most recent test: _____</p> <p><i>(Enter 88/88/8888 if "Decline to answer" is selected.)</i> (MM/DD/YYYY)</p>

3a2. What type of test did you have?

- 1 Swab of nose or throat
- 2 Blood test
- 8 Decline to answer
- 9 Unsure/unknown

3b1. Date of next most recent test:

(Enter 88/88/8888 if "Decline to answer" is selected. Enter 99/99/9999 if not applicable because only tested once, and SKIP TO QUESTION 4)

__/__/____
(MM/DD/YYYY)

3b2. What type of test did you have?

- 1 Swab of nose or throat
- 2 Blood test
- 8 Decline to answer
- 9 Unsure/unknown

3c1. Date of next most recent test:

(Enter 88/88/8888 if "Decline to answer" is selected. Enter 99/99/9999 if not applicable because only tested twice, and SKIP TO QUESTION 4)

__/__/____
(MM/DD/YYYY)

3c2. What type of test did you have?

- 1 Swab of nose or throat
- 2 Blood test
- 8 Decline to answer
- 9 Unsure/unknown

4. Have you been diagnosed with COVID-19 (you tested positive or were presumed to have COVID-19 by a healthcare provider)?

- 0 No
- 1 Yes, positive test for acute infection
- 2 Yes, presumed COVID-19 by healthcare provider but not tested
- 8 Decline to answer
- 9 Unsure/unknown

<p>5. Were you admitted to a hospital for treatment of COVID-19?</p> <p>0 <input type="checkbox"/> No (SKIP TO QUESTION 7)</p> <p>1 <input type="checkbox"/> Yes, but not the intensive care unit (ICU) (CONTINUE)</p> <p>2 <input type="checkbox"/> Yes, including a stay in the ICU and/or ventilator support (breathing tube in your throat) (CONTINUE)</p> <p>8 <input type="checkbox"/> Decline to answer (SKIP TO QUESTION 7)</p> <p>9 <input type="checkbox"/> Unsure/unknown</p>	
<p>6. If yes, on approximately what date(s) were you admitted to the hospital? If you were hospitalized more than once, please report the 3 most recent dates.</p>	
<p>6a1. Date of most recent hospitalization: <i>(Enter 88/88/8888 if "Decline to answer" is selected.)</i></p> <p>6a2. How many days were you hospitalized? <i>(Enter 888 if "Decline to answer" is selected.)</i></p>	<p>__ / __ / ____ (MM/DD/YYYY)</p> <p>___ days</p>
<p>6b1. Date of next most recent hospitalization: <i>(Enter 88/88/8888 if "Decline to answer" is selected. Enter 99/99/9999 if not applicable because only hospitalized once, and SKIP TO QUESTION 7)</i></p> <p>6b2. How many days were you hospitalized? <i>(Enter 888 if "Decline to answer" is selected.)</i></p>	<p>__ / __ / ____ (MM/DD/YYYY)</p> <p>___ days</p>
<p>6c1. Date of next most recent hospitalization: <i>(Enter 88/88/8888 if "Decline to answer" is selected. Enter 99/99/9999 if not applicable because only hospitalized twice, and SKIP TO QUESTION 7)</i></p> <p>6c2. How many days were you hospitalized? <i>(Enter 888 if "Decline to answer" is selected)</i></p>	<p>__ / __ / ____ (MM/DD/YYYY)</p> <p>___ days</p>
<p>7. On a scale of 1–5, how worried are you that you will get COVID-19 (or, if previously infected, worried that you will get it again)?</p> <p>1 <input type="checkbox"/> 1 = Not at all worried</p> <p>2 <input type="checkbox"/> 2 = A little worried</p> <p>3 <input type="checkbox"/> 3 = Somewhat worried</p> <p>4 <input type="checkbox"/> 4 = Very worried</p> <p>5 <input type="checkbox"/> 5 = Extremely worried</p> <p>8 <input type="checkbox"/> 8 = Decline to answer</p>	

8. On a scale of 1–5, how isolated or cut off from family and friends are you feeling due to COVID-19?

- 1 1 = Not at all isolated
2 2 = A little isolated
3 3 = Somewhat isolated
4 4 = Very isolated
5 5 = Extremely isolated
8 8 = Decline to answer

9. On a scale of 1–5, how disruptive has the COVID-19 pandemic been to your everyday life?

- 1 1 = Not at all disruptive
2 2 = A little disruptive
3 3 = Somewhat disruptive
4 4 = Very disruptive
5 5 = Extremely disruptive
8 8 = Decline to answer

10. Has your household's income been significantly reduced due to COVID-19?

- 0 No
1 Yes
8 Decline to answer
9 Unsure/unknown

11. On a scale of 1–5, since the start of COVID-19, how often have you felt that you were unable to control the important things in your life?

- 1 1 = Never
2 2 = Almost never
3 3 = Sometimes
4 4 = Fairly often
5 5 = Very often
8 8 = Decline to answer

12. Have you noticed any changes in your memory and thinking, depression, anxiety, or behavioral symptoms since the COVID-19 pandemic began (due to need for social distancing, sheltering in place, worries about getting infected, or other causes)?

- 1 No changes (SKIP TO QUESTION 14)
2 Some changes, but nothing out of the ordinary (CONTINUE)
3 A great deal of change (CONTINUE)
8 Decline to answer (SKIP TO QUESTION 14)

13. If yes, please tell us what has changed?	NO	YES	Decline to answer
13a. Memory and thinking	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
13b. Depression	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
13c. Anxiety	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
13d. Behavior	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
13e. Other (SPECIFY): _____	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
<p>14. On a scale of 1–5, how much has COVID-19 changed your willingness to participate in clinical research if it requires in-person visits to the research clinic?</p> <p>1 <input type="checkbox"/> 1 = Not at all</p> <p>2 <input type="checkbox"/> 2 = A little</p> <p>3 <input type="checkbox"/> 3 = Somewhat</p> <p>4 <input type="checkbox"/> 4 = Very much</p> <p>5 <input type="checkbox"/> 5 = Extremely</p> <p>8 <input type="checkbox"/> 8 = Decline to answer</p>			

COVID-19 Impact Survey — Co-participant

ADC name: _____ Subject ID: _____ Form date: ____/____/____

Examiner's initials: _____

The following COVID-19 survey is an optional form we would like you to fill out (alternatively, the survey may be administered to you by research study staff). We are asking these questions because COVID-19 presents very new challenges for us all, and we would like to learn about your experience. We also would like to learn how COVID-19 might be affecting your well-being and your ability to support the research participant as their co-participant/caregiver. You may decline to answer any of these questions, and it is all right to do so, but please answer as many of the questions as you feel comfortable with. Your research Center may also have additional questions regarding COVID-19.

1. On a scale of 1–5, how isolated or cut off from family and friends are you feeling due to COVID-19?

- 1 1 = Not at all isolated
- 2 2 = A little isolated
- 3 3 = Somewhat isolated
- 4 4 = Very isolated
- 5 5 = Extremely isolated
- 8 8 = Decline to answer

2. On a scale of 1–5, how disruptive has the COVID-19 pandemic been to your everyday life?

- 1 1 = Not at all disruptive
- 2 2 = A little disruptive
- 3 3 = Somewhat disruptive
- 4 4 = Very disruptive
- 5 5 = Extremely disruptive
- 8 8 = Decline to answer

3. Has your household's income been significantly reduced due to COVID-19?

- 0 No
- 1 Yes
- 8 Decline to answer
- 9 Unsure/unknown

4. On a scale of 1–5, since the start of COVID-19, how often have you felt that you were unable to control the important things in your life?

- 1 1 = Never
- 2 2 = Almost never
- 3 3 = Sometimes
- 4 4 = Fairly often
- 5 5 = Very often
- 8 8 = Decline to answer

5. Regarding your feelings of connectedness with friends and family during the period of social distancing, do you feel ...

- 1 Less connected
- 2 About the same level of connection
- 3 More connected
- 8 Decline to answer

6. Has the COVID-19 pandemic affected your ability to provide care for the research participant?

- 1 It is easier to provide care
- 2 I am managing the same as always
- 3 It is somewhat more difficult to provide care
- 4 It is extremely difficult to provide care
- 8 Decline to answer

7. What kind of care assistance, if any, has become harder to access?

7a. Respite by family or friends

7b. Paid respite by care agencies

7c. Day activity programs

7d. Overnight or extended-stay respite care

7e. Ability to find skilled residential facility placement

7f. Medical care including physician appointments

7g. Other (SPECIFY): _____

	NO	YES	Decline to answer
0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>	
0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>	
0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>	
0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>	
0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>	
0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>	
0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>	

8. On a scale of 1–5, how much has COVID-19 changed your willingness to allow or encourage your care partner’s participation in clinical research if it requires in-person visits to the research clinic?

- 1 1 = Not at all
- 2 2 = A little
- 3 3 = Somewhat
- 4 4 = Very much
- 5 5 = Extremely
- 8 8 = Decline to answer

9. On a scale of 1–5, how much has COVID-19 changed your own personal willingness to participate in clinical research, irrespective of whether in-person or telephone/remote visits are used?

- 1 1 = Not at all
- 2 2 = A little
- 3 3 = Somewhat
- 4 4 = Very much
- 5 5 = Extremely
- 8 8 = Decline to answer

10. Do you have specific care needs that are not addressed above? Please list any care needs (both yours and the research participant’s) that are not being met because of the COVID-19 pandemic.