Clear both forms

NACC
National Alzheimer's Coordinating Center

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.

Clear co-participant form

NACC
National Alzheimer's Coordinating Center

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?	**NO**	**YES**	**Decline to answer**
7a. Respite by family or friends	0 ☐	1 ☐	8 ☐
7b. Paid respite by care agencies	0 ☐	1 ☐	8 ☐
7c. Day activity programs	0 ☐	1 ☐	8 ☐
7d. Overnight or extended-stay respite care	0 ☐	1 ☐	8 ☐
7e. Ability to find skilled residential facility placement	0 ☐	1 ☐	8 ☐
7f. Medical care including physician appointments	0 ☐	1 ☐	8 ☐
7g. Other (SPECIFY): ____________________	0 ☐	1 ☐	8 ☐

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.**