

FOLLOW-UP VISIT: Forms F2 and F3 — COVID Impact Survey

Instructions for the Center

This updated 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.

This form should be used by participants who have completed v2 of the initial F2/F3 forms (released in July 2022). It reflects complex and recurring biological and psychosocial factors associated with the pandemic, including vaccinations, repeat infections, evolving understanding of the long-term impacts of COVID-19 particularly on cognitive function, and broader psychosocial stressors which occurred in the same timeline as the initial and subsequent waves of the pandemic. In addition, it is recognized that many of these aspects of the COVID-19 pandemic may have been experienced differently person to person as well as community to community. The survey is intended to capture experience since the last form completion date.

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. Centers will need to provide information to participants about local vaccination availability for unvaccinated participants that request information.

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. This information may prove to be extremely useful in our understanding of the impact of such a pandemic on the aging population today and the future.

Note that persons who have completed only v1 (June 2020) of the F2/F3 form should complete one visit with the v2 (July 2022) F2/F3 form before proceeding to this follow-up form at a subsequent visit. Moreover, to clarify timelines and history of COVID-19 infections and vaccinations with participants, it may be useful to have the participant's prior responses to their most recent F2/F3 form when completing this follow-up form.

FOLLOW-UP VISIT: Form F2 — COVID Impact Survey—Participant

ADRC: _____ PTID: _____ Form date: ____/____/____ Examiner's initials: _____

<p>Mode:</p> <p>☐ 1 In-person</p> <p>☐ 2 Remote (reason): ____</p>	<p>Key (remote reason): 1=Too cognitively impaired</p> <p>2=Too physically impaired</p> <p>3=Homebound or nursing home</p> <p>4=Refused in-person visit</p> <p>5=Other</p>
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For Clinical Staff

Is the participant's CDR® > 0.5?	☐ 0 No
	☐ 1 Yes
Who will be filling in the F2 Participant form?	☐ 1 Participant
	☐ 2 Co-participant
	☐ 3 Clinician
Will a co-participant complete the F3 form?	☐ 0 No
	☐ 1 Yes

FOLLOW-UP VISIT: Form F2 — COVID Impact Survey—Participant

ADRC name: _____ Participant 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 has presented multiple 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 alright 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.

Section 1 — COVID-19 infections

1. Have you ever tested positive for COVID-19 and/or been diagnosed with COVID-19 by a healthcare provider?
 - ☐ 0 No (**SKIP TO QUESTION 9**)
 - ☐ 1 Yes, based on a positive test for acute infection
 - ☐ 2 Yes, presumed COVID-19 diagnosis by healthcare provider but not tested
 - ☐ 8 Decline to answer (**SKIP TO QUESTION 9**)
 - ☐ 9 Unsure/unknown (**SKIP TO QUESTION 9**)
2. If 100% is feeling perfectly normal (*fully recovered from your COVID-19 symptoms*), what percent of normal do you feel?

%

(IF QUESTION 2 = 100%, SKIP TO QUESTION 3)

2a. If not 100%, why are you not feeling perfectly normal?

3. Over the past month, how often did symptoms from past or current COVID-19 infection(s) affect your daily life?
 - ☐ 1 Never
 - ☐ 2 Seldom (1-2 days per week)
 - ☐ 3 Sometimes (3-4 days per week)
 - ☐ 4 Often (5-6 days per week)
 - ☐ 5 Every day
 - ☐ 8 Decline to answer

Section 2 — Recent COVID-19 infections

4. Have you tested positive for COVID-19 and/or been diagnosed with COVID-19 by a healthcare professional since your last visit?
 - ☐ 0 No (**SKIP TO QUESTION 8**)
 - ☐ 1 Yes
 - ☐ 8 Decline to answer (**SKIP TO QUESTION 8**)
5. How many distinct episodes of COVID-19 infection have you had *since your last study visit*?
 - ☐ 1 One
 - ☐ 2 Two
 - ☐ 3 Three or more
 - ☐ 9 Unsure/unknown

Examiner's Initials: _____

Section 2 — Recent COVID-19 infections*continued...***5a.** When did your first COVID-19 infection since the last study visit begin (*month/year*)?

(88/8888 = Decline to answer, 99/9999 = Unknown)

____ / ____

5b. What was the duration of symptoms from that first COVID-19 infection?

- | | |
|---|---|
| ☐ 0 Never had symptoms | ☐ 4 > 4 weeks |
| ☐ 1 < 1 week | ☐ 5 Not yet recovered (<i>symptoms persist to the present</i>) |
| ☐ 2 1-2 weeks | ☐ 8 Decline to answer |
| ☐ 3 2-4 weeks | |

(IF QUESTION 5 = ONCE (ONLY DIAGNOSED ONCE), SKIP TO QUESTION 6)**5c.** When did your most recent COVID-19 infection begin (*month/year*)?

(88/8888 = Decline to answer, 99/9999 = Unknown)

____ / ____

5d. What was the duration of symptoms from your most recent COVID-19 infection?

- | | |
|---|---|
| ☐ 0 Never had symptoms | ☐ 4 > 4 weeks |
| ☐ 1 < 1 week | ☐ 5 Not yet recovered (<i>symptoms persist to the present</i>) |
| ☐ 2 1-2 weeks | ☐ 8 Decline to answer |
| ☐ 3 2-4 weeks | |

6. During any of your COVID-19 infections since your last study visit, did you lose the ability to smell or taste, experience lower ability to determine smells or tastes, or experience episodes of unprovoked, unfamiliar, or strange smells or tastes?

- | | |
|---|--|
| ☐ 0 No (SKIP TO QUESTION 7) | ☐ 8 Decline to answer (SKIP TO QUESTION 7) |
| ☐ 1 Yes | ☐ 9 Unsure/unknown (SKIP TO QUESTION 7) |

6a. When did you first experience changes in smell or taste (*month/year*)?

(88/8888 = Decline to answer, 99/9999 = Unknown)

____ / ____

6b. How long did it take to recover smell and taste fully?

- | | |
|--------------------------------------|---|
| ☐ 1 < 1 week | ☐ 4 > 4 weeks |
| ☐ 2 1-2 weeks | ☐ 5 Not yet recovered (<i>symptoms persist to the present</i>) |
| ☐ 3 2-4 weeks | ☐ 8 Decline to answer |

7. During any of your COVID-19 infections since your last study visit, did you experience new problems with thinking, remembering, or concentration (*e.g., brain fog*)?

- | | |
|---|--|
| ☐ 0 No (SKIP TO QUESTION 8) | ☐ 8 Decline to answer (SKIP TO QUESTION 8) |
| ☐ 1 Yes | ☐ 9 Unsure/unknown (SKIP TO QUESTION 8) |

7a. When did you first experience changes in thinking, remembering, or concentration (*month/year*)?

(88/8888 = Decline to answer, 99/9999 = Unknown)

____ / ____

7b. How long did it take to recover changes in thinking, remembering, or concentration?

- | | |
|--------------------------------------|---|
| ☐ 1 < 1 week | ☐ 4 > 4 weeks |
| ☐ 2 1-2 weeks | ☐ 5 Not yet recovered (<i>symptoms persist to the present</i>) |
| ☐ 3 2-4 weeks | ☐ 8 Decline to answer |

Section 3 — COVID-19 medical care**8.** Did you ever seek medical care for COVID-19 since your last visit?

- ☐ 0 No (**SKIP TO QUESTION 9**)
☐ 1 Yes

- ☐ 8 Decline to answer (**SKIP TO QUESTION 9**)
☐ 9 Unsure/unknown (**SKIP TO QUESTION 9**)

8a. Since your last visit, did you receive any type of outpatient treatment for your COVID-19 infection such as monoclonal antibody treatment, oral antiviral, subcutaneous injection of antiviral, or other treatment?

- ☐ 0 No (**SKIP TO QUESTION 8b**)
☐ 1 Yes

- ☐ 8 Decline to answer (**SKIP TO QUESTION 8b**)
☐ 9 Unsure/unknown (**SKIP TO QUESTION 8b**)

8a1. When did you receive this outpatient treatment (*month/year*)?

(88/8888 = Decline to answer, 99/9999 = Unknown)

____ / ____

8b. Since your last visit, what was the highest level of medical care you received for COVID-19?

- ☐ 1 Phone consultation or virtual care visit (**SKIP TO QUESTION 9**)
☐ 2 In-person physician or urgent care visit (**SKIP TO QUESTION 9**)
☐ 3 Emergency department (**SKIP TO QUESTION 9**)
☐ 4 Hospitalized but not the intensive care unit (ICU)
☐ 5 Hospitalized, including a stay in the ICU and/or ventilator support (*breathing tube in your throat*)
☐ 8 Decline to answer (**SKIP TO QUESTION 9**)
☐ 9 Unsure/unknown (**SKIP TO QUESTION 9**)

8c. Since your last visit, how many times have you been admitted to the hospital for COVID-19?

- ☐ 1 Once
☐ 2 Twice
☐ 3 Three or more times
☐ 9 Unsure/unknown (**SKIP TO QUESTION 9**)

When were you admitted to the hospital for COVID-19? If you were hospitalized more than once since your last visit, please report the 3 most recent hospitalizations.**8c1.** Month/year of most recent hospitalization:

(88/8888 = Decline to answer, 99/9999 = Unknown)

____ / ____

8c2. How many days were you hospitalized?

(888 = Decline to answer, 999 = Unknown)

(IF ONLY HOSPITALIZED ONCE, SKIP TO QUESTION 9)**8c3.** Month/year of next most recent hospitalization:

(88/8888 = Decline to answer, 99/9999 = Unknown)

____ / ____

8c4. How many days were you hospitalized?

(888 = Decline to answer, 999 = Unknown)

(IF ONLY HOSPITALIZED TWICE, SKIP TO QUESTION 9)**8c5.** Month/year of next most recent hospitalization:

(88/8888 = Decline to answer, 99/9999 = Unknown)

____ / ____

8c6. How many days were you hospitalized?

(888 = Decline to answer, 999 = Unknown)

Section 4 — COVID-19 vaccinations**9.** Have you received at least one vaccination against COVID-19 since your last visit?

- ☐ 0 No (**SKIP TO QUESTION 10**)
☐ 1 Yes

- ☐ 8 Decline to answer (**SKIP TO QUESTION 10**)
☐ 9 Unsure/unknown (**SKIP TO QUESTION 10**)

9a. Since your last visit, how many COVID-19 vaccine doses have you received?

- ☐ 1 One: Partial vaccination (one dose of two-dose series)
☐ 2 One: One booster (**SKIP TO QUESTION 9d**)
☐ 3 Two: Two-dose series without booster
☐ 4 Two: More than one booster (**SKIP TO QUESTION 9d**)
☐ 5 Three: Two-dose series with one booster
☐ 7 Four +: Two-dose series with more than one booster
☐ 8 Decline to answer (**SKIP TO QUESTION 10**)
☐ 9 Unsure/unknown (**SKIP TO QUESTION 10**)

9b. When did you receive your first COVID-19 vaccination since your last visit (month/year):

(88/8888 = Decline to answer, 99/9999 = Unknown)

____ / ____

9b1. Which COVID-19 vaccine did you first receive?

- ☐ 1 Pfizer
☐ 2 Moderna
☐ 3 Janssen (Johnson & Johnson)

- ☐ 4 Other (**SPECIFY**): _____
☐ 8 Decline to answer
☐ 9 Unsure/unknown

9b2. Did you experience any symptoms within 5 days of your first COVID-19 vaccination?

- ☐ 0 No (**SKIP TO QUESTION 9c**)
☐ 1 Yes

- ☐ 8 Decline to answer (**SKIP TO QUESTION 9c**)
☐ 9 Unsure/unknown (**SKIP TO QUESTION 9c**)

9b3. Which of the following symptoms did you experience after your first vaccine? (**SELECT ALL THAT APPLY**)

- ☐ 1 Sore arm

9b3a1. Number of days sore arm lasted:

(999 = Uncertain, 777 = Continued through now)

- ☐ 1 Flu-like feelings (*fever, chills, tiredness, or "malaise"*)

9b3b1. Number of days flu-like feelings lasted:

(999 = Uncertain, 777 = Continued through now)

- ☐ 1 New problems with memory, thinking, or concentration

9b3c1. Number of days new problems with memory, thinking, or concentration lasted:

(999 = Uncertain, 777 = Continued through now)

- ☐ 1 Decline to answer

- ☐ 1 Unsure/unknown

9c. When did you receive your second COVID-19 vaccination since your last visit (month/year)?

(If Question 9a = 1 (one dose, no booster), skip to Question 10. If decline to answer, enter 88/8888. If date unknown, enter 99/9999.)

____ / ____

9c1. Which COVID-19 vaccine did you receive?

- ☐ 1 Pfizer
☐ 2 Moderna

- ☐ 3 Other (**SPECIFY**): _____
☐ 8 Decline to answer
☐ 9 Unsure/unknown

9c2. Did you experience any symptoms within 5 days of your second COVID-19 vaccination?

- ☐ 0 No (**SKIP TO QUESTION 9d**)
☐ 1 Yes

- ☐ 8 Decline to answer (**SKIP TO QUESTION 9d**)
☐ 9 Unsure/unknown (**SKIP TO QUESTION 9d**)

Section 4 — COVID-19 vaccinations*continued...***9c3.** Which of the following symptoms did you experience after your second vaccine? **(SELECT ALL THAT APPLY)**☐ **1** Sore arm**9c3a1.** Number of days sore arm lasted:
(999 = Uncertain, 777 = Continued through now)

☐ **1** Flu-like feelings (*fever, chills, tiredness, or "malaise"*)**9c3b1.** Number of days flu-like feelings lasted:
(999 = Uncertain, 777 = Continued through now)

☐ **1** New problems with memory, thinking, or concentration**9c3c1.** Number of days new problems with memory, thinking, or concentration lasted:
(999 = Uncertain, 777 = Continued through now)

☐ **1** Decline to answer☐ **1** Unsure/unknown**9d.** When did you receive your first COVID-19 booster vaccination since your last visit (month/year)?

(If Question 9a = 3 (two-dose series without booster), skip to Question 10. If decline to answer, enter 88/8888. If date unknown, enter 99/9999.)

____ / ____

9d1. Which COVID-19 vaccine did you receive?☐ **1** Pfizer☐ **2** Moderna☐ **3** Other (**SPECIFY**): _____☐ **8** Decline to answer☐ **9** Unsure/unknown**9d2.** Did you experience any symptoms within 5 days of your first COVID-19 booster vaccination?☐ **0** No (**SKIP TO QUESTION 9e**)☐ **1** Yes☐ **8** Decline to answer (**SKIP TO QUESTION 9e**)☐ **9** Unsure/unknown (**SKIP TO QUESTION 9e**)**9d3.** Which of the following symptoms did you experience after your first booster vaccination?
(SELECT ALL THAT APPLY)☐ **1** Sore arm**9d3a1.** Number of days sore arm lasted:
(999 = Uncertain, 777 = Continued through now)

☐ **1** Flu-like feelings (*fever, chills, tiredness, or "malaise"*)**9d3b1.** Number of days flu-like feelings lasted:
(999 = Uncertain, 777 = Continued through now)

☐ **1** New problems with memory, thinking, or concentration**9d3c1.** Number of days new problems with memory, thinking, or concentration lasted:
(999 = Uncertain, 777 = Continued through now)

☐ **1** Decline to answer☐ **1** Unsure/unknown**9e.** When was your most recent COVID-19 vaccination/booster (*month/year*)?

(If Question 9a = 2 or 5 (only one booster received), skip to Question 10. If decline to answer, enter 88/8888. If date unknown, enter 99/9999.)

____ / ____

Section 5 — Impact of COVID-19

10. 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)*?

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

11. On a scale of 1-5, since the last visit, how disruptive has the COVID-19 pandemic been to your everyday life?

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

12. On a scale of 1-6 *(with 1 being "I can shake off stress" and 6 being "Stress eats away at me")* how would you rate your ability to handle stress?

- ☐ 1 "I can shake off stress"
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 "Stress eats away at me"
- ☐ 8 Decline to answer

13. In the past year, on a scale of 1-6 with 1 being "no stress" and 6 being "extreme stress" how would you rate the amount of stress in your life *(at home and at work)*?

- ☐ 1 "No stress"
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 "Extreme stress"
- ☐ 8 Decline to answer

14. On a scale of 1-5, since the last visit, how much has COVID-19 changed your willingness to participate in clinical research if it requires in-person visits to the research clinic?

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

FOLLOW-UP VISIT: Form F3 — COVID Impact Survey—Co-Participant

ADRC: _____ PTID: _____ Form date: ____/____/____ Examiner's initials: _____

Mode:

- ☐ 1 In-person
☐ 2 Remote (reason): ____

Key (remote reason): 1=Too cognitively impaired
 2=Too physically impaired
 3=Homebound or nursing home
 4=Refused in-person visit
 5=Other

Instructions for the Center

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 has presented very new challenges for us all, and we would like to learn about your experience. We also would like to learn how COVID-19 may have affected 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 alright 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, since the last visit, how isolated or cut off from family and friends have you felt due to the COVID-19 pandemic?
 - ☐ 1 Not at all isolated
 - ☐ 2 A little isolated
 - ☐ 3 Somewhat isolated
 - ☐ 4 Very isolated
 - ☐ 5 Extremely isolated
 - ☐ 8 Decline to answer
2. On a scale of 1-5, since the last visit, how disruptive has the COVID-19 pandemic been to your everyday life?
 - ☐ 1 Not at all disruptive
 - ☐ 2 A little disruptive
 - ☐ 3 Somewhat disruptive
 - ☐ 4 Very disruptive
 - ☐ 5 Extremely disruptive
 - ☐ 8 Decline to answer
3. On a scale of 1-5, since the last visit, how often have you felt that you were unable to control the important things in your life?
 - ☐ 1 Never
 - ☐ 2 Almost never
 - ☐ 3 Sometimes
 - ☐ 4 Fairly often
 - ☐ 5 Very often
 - ☐ 8 Decline to answer
4. On a scale of 1-6 (*with 1 being "I can shake off stress" and 6 being "Stress eats away at me"*), how would you rate your ability to handle stress?
 - ☐ 1 "I can shake off stress"
 - ☐ 2
 - ☐ 3
 - ☐ 4
 - ☐ 5
 - ☐ 6 "Stress eats away at me"
 - ☐ 8 Decline to answer
5. In the past year, on a scale of 1-6 (*with 1 being "no stress" and 6 being "extreme stress"*) how would you rate the amount of stress in your life (*at home and at work*)?
 - ☐ 1 "No stress"
 - ☐ 2
 - ☐ 3
 - ☐ 4
 - ☐ 5
 - ☐ 6 "Extreme stress"
 - ☐ 8 Decline to answer

Examiner's Initials: _____

6. Since the last visit, regarding your feelings of connectedness with friends and family during the COVID-19 pandemic, did you feel or have you felt...

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

7. Since the last visit, 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

	No	Yes	Decline to Answer
8. Since the last visit, what kind of care assistance, if any, has become harder to access?			
8a. Respite by family or friends	☐ 0	☐ 1	☐ 8
8b. Paid respite by care agencies	☐ 0	☐ 1	☐ 8
8c. Day activity programs	☐ 0	☐ 1	☐ 8
8d. Overnight or extended-stay respite care	☐ 0	☐ 1	☐ 8
8e. Ability to find skilled residential facility placement	☐ 0	☐ 1	☐ 8
8f. Medical care including physician appointments	☐ 0	☐ 1	☐ 8
8g. Other (SPECIFY): _____	☐ 0	☐ 1	☐ 8
9. On a scale of 1-5, since the last visit, how much has the COVID-19 pandemic 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 Not at all			
☐ 2 A little			
☐ 3 Somewhat			
☐ 4 Very much			
☐ 5 Extremely			
☐ 8 Decline to answer			
10. On a scale of 1-5, since the last visit, how much has the COVID-19 pandemic changed your own personal willingness to participate in clinical research, irrespective of whether in-person or telephone/remote visits are used?			
☐ 1 Not at all			
☐ 2 A little			
☐ 3 Somewhat			
☐ 4 Very much			
☐ 5 Extremely			
☐ 8 Decline to answer			
11. 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:			

