The Sister Study
COVID-19 Questionnaire
ABBREVIATED

Instructions:

- Please use **DARK BLUE OR BLACK BALLPOINT PEN**.
- Mark only one answer for each question unless otherwise indicated.
- Follow the arrow from your response to find the next question.
- Only write comments in the spaces provided.
- Please keep this questionnaire clean, flat, and dry.
- Do not fold or tear any of the pages.

Fill in the bubbles COMPLETELY for each of the questions in this form.

Like this: ● Not like this: ⊘ ✓

Please write responses in all capital letters and numbers without touching the sides of the boxes.

A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z

1	2	3	4	5	6	7	8	9	0

Thank you very much for taking the time to share your experiences and help us understand the impact of the coronavirus pandemic and response on Sister Study participants' lives. The virus itself and any added stress due to the pandemic response have the potential to affect the long-term health of Sister Study participants.

Because infection rates have varied over time and across the country, and because restrictions—if imposed—have been implemented at different times, it has been challenging to develop a questionnaire that captures each person's full experience adequately. Therefore, some of the questions in this survey ask about your experiences during specific date ranges or milestones related to the pandemic response for most of the country. Others ask about your overall pandemic experience so far, and some ask about your experiences at "the height of the coronavirus pandemic in your area."

Please read each question carefully and give the answer that best fits your situation at that time. Again, thank you.

1. Have you ever been sick with suspected or confirmed COVID-19, whether or not you were tested for active COVID-19 infection at that time?

- ○ No, I have not been sick with COVID-19
- ○ I had a positive COVID-19 test but never felt sick

GO TO QUESTION 5, PAGE 5

- ○ Probably not: I was sick with some of the same symptoms but don't think it was COVID-19.
  If you were sick with this more than once, please report for the time when your symptoms were most similar to COVID-19 (ex. cough, fever, severe fatigue, etc.)

1a. Approximate date you first started feeling sick with this:

MONTH ☐☐ / YEAR 2 0 ☐☐

GO TO QUESTION 2, PAGE 3

- ○ Yes, I was sick with suspected or confirmed COVID-19

If you were sick with COVID-19 more than once, please report for the time you were the most sick.

1b. What was the approximate date you started feeling sick?

MONTH ☐☐ / YEAR 2 0 ☐☐

1c. How many days until you recovered? That is, how many days until you felt well enough to resume your normal activities?

☐☐☐ # DAYS

OR ○ Not yet recovered

GO TO QUESTION 1d ON NEXT PAGE

IF NOT YET RECOVERED:

1c1. Approximately how many days OR weeks have you been sick so far?

☐☐ # DAYS **OR** ☐☐ # WEEKS

1c2. I have not resumed my normal activities due to:
(Please mark all that apply.)

- ○ Acute (short-term) symptoms of COVID-19 (ex. fever, chills)
- ○ Continuing long-term symptoms of COVID-19 (ex. fatigue, other)
- ○ Disability caused by COVID-19 (ex. stroke)
- ○ Other, specify: ☐

GO TO QUESTION 1d ON NEXT PAGE

1d. Were you admitted to the hospital? *Do NOT include visit(s) to the emergency room only.*

- ○ No → **GO TO QUESTION 2**
- ○ Yes → **IF YES:**

1d1. How many days in hospital so far? *Do NOT include days in long-term rehab/rehabilitation facility after hospital discharge.*

DAYS

1d2. Did you go to a long-term rehab/rehabilitation facility after hospital discharge?

- ○ No
- ○ Yes

2. When you were sick with COVID-19 or symptoms similar to COVID-19, which of the following symptoms did you experience? (*If you were sick **with COVID-19 symptoms** more than once, please report for the time you were the most sick.) Please mark all that apply.*

- ○ Fever
- ○ Chills
- ○ Persistent cough
- ○ Unusual shortness of breath or difficulty breathing
- ○ Unusual severe fatigue
- ○ Unusual severe muscle or body aches
- ○ Unusual chest pain or pressure/tightness
- ○ Rash on skin, or red/purple discoloration of fingers or toes
- ○ Headache
- ○ New loss of taste or smell
- ○ Congestion or runny nose
- ○ Nausea or vomiting
- ○ Diarrhea
- ○ Skipped meals (loss of appetite)
- ○ Other significant symptoms, please specify:
- ○ I did not have any symptoms → **GO TO Q3**

2a. Overall, when these symptoms were at their worst, how bad or bothersome were they?

- ○ Not bad at all
- ○ Mild
- ○ Moderate
- ○ Severe
- ○ Very severe

2b. Overall, when these symptoms were at their worst, did they interfere with your daily activities?

- ○ Not at all
- ○ A little bit
- ○ Somewhat
- ○ Quite a bit
- ○ Very much

3. Were you treated with any of the following for your suspected or confirmed COVID-19, or your COVID-19-like symptoms? *(Please mark all that apply.)*

- ○ No, I did not have any of these treatments

Antiviral medications:

- ○ Remdesivir
- ○ Lopinavir/ritonavir (ex. Kaletra)
- ○ Ribavirin (ex. Moderiba, Rebetol)
- ○ Other antiviral drug, specify:

Steroid medications:

- ○ Dexamethasone
- ○ Inhaled corticosteroids (ex. Flovent, Symbicort, Advair)
- ○ Other corticosteroid/steroid, including oral medications (ex. prednisone), specify:

Antibiotics:

- ○ Azithromycin (ex. Zithromax, Z-Pak)
- ○ Other antibiotic (ex. Augmentin), specify:

Pain medications:

- ○ Acetaminophen (ex. Tylenol)
- ○ Regular ibuprofen (ex. Advil, Motrin, Nurofen)
- ○ Lipid-formulated ibuprofen (ex. Flarin)
- ○ Other NSAID (non-steroidal anti-inflammatory; ex. Aleve/naproxen, diclofenac), specify:
- ○ Other pain medications, specify:

Other medications/treatments:

- ○ Chloroquine or hydroxychloroquine
- ○ Plasma transfusion/infusion
- ○ Other medications/treatments, specify:

4. Other than medication, what treatment(s) did you receive for suspected or confirmed COVID-19, or COVID-19-like symptoms? *(Please mark all that apply.)*

- ○ None
- ○ Oxygen and fluids (oxygen flowing through a mask or small nasal tube; no pressure applied)
- ○ Non-invasive ventilation (positive pressure breathing support that pushes oxygen into your lungs through a mask; similar to a CPAP machine)
- ○ Invasive ventilation (breathing support through a tube inserted in the throat; people are usually sedated/asleep)
- ○ Other, specify:

5. Whether or not you had COVID-19 symptoms, have you ever been tested for an ACTIVE COVID-19 infection? This tests for virus causing infection at that time. *(Do NOT include antibody tests, which are blood tests used to measure past infection with COVID-19.)*

○ No → **GO TO QUESTION 6 ON NEXT PAGE**

○ Yes (swab or saliva sample) →

5a. Why were you tested? *(Please mark all that apply.)*

- ○ I had symptoms I thought might be COVID-19
- ○ My healthcare provider requested the test
- ○ I was tested as part of a screening program. For example, workplace testing, pre-surgical testing, testing for travel, community testing, etc.
- ○ I was exposed or potentially exposed to someone who had COVID-19
- ○ I attended a mass gathering, such as a community event, protest, or rally
- ○ Other, specify: _____

5b. Have you ever had a positive test result for COVID-19 infection?

- ○ No
- ○ Still waiting for results

} **GO TO QUESTION 6 ON NEXT PAGE**

- ○ Yes

IF YES:

5c. What was the date of the **first** positive test?

		/	2	0		
MONTH			YEAR			

6. Have you ever been tested for ANTIBODIES to the virus that causes COVID-19? *This tests for COVID-19 infection in the past*.

○ No → **GO TO QUESTION 7**

○ Yes (blood test) →

6a. Have ever you had a positive result to an antibody test for COVID-19?

○ No
○ Still waiting for results } **GO TO QUESTION 7**

○ Yes

IF YES:

6b. What was the sample collection date of the **first** positive antibody test?

		/	2	0		
MONTH			YEAR			

7. Were any of your REGULAR breast cancer screenings or follow-ups *(mammogram, breast MRI, other)* delayed or canceled because of the coronavirus pandemic?

○ No
○ NA } **GO TO QUESTION 8 ON NEXT PAGE**

○ Yes →

7a. How many months was your screening or follow-up delayed?

○ Less than 3 months
○ 3-6 months
○ 7-12 months
○ More than 12 months
○ Has not been rescheduled

7b. Has your delayed or canceled care been completed?

○ No
○ Yes

8. For each time period, please indicate **INDOOR activities you did with people OTHER THAN your household members**: *(Please mark all that apply.)*

Indoor Activities with people other than household members	a. I did not participate in any indoor gatherings or group activities or socialize indoors with people other than my household members	b. I socialized indoors with a few people other than my household members	c. I visited (in the same room) with someone in a nursing home or assisted living facility	d. I participated in group activities at my independent living, assisted living, or other group living community *(ex. dining, classes, social events)*	e. I attended indoor gatherings of **up to 50 people** *(ex. business functions, worship, weddings, funerals)*	f. I attended large indoor gatherings of **more than 50 people** *(ex. indoor concerts, graduations, rallies)*
Jan 1 - Mar 14, 2020 **BEFORE** *the pandemic in most places*	○	○	○	○	○	○
Mar 15 - May 14, 2020 *Initial pandemic-related restrictions*	○	○	○	○	○	○
May 15 - Jul 31, 2020 *Includes Memorial Day and July 4th*	○	○	○	○	○	○
Aug 1 - Sep 30, 2020 *Includes Labor Day*	○	○	○	○	○	○
Oct 1 - Dec 31, 2020	○	○	○	○	○	○
Jan 1 - Mar 31, 2021	○	○	○	○	○	○
Apr 1 - Jun 30, 2021	○	○	○	○	○	○
Jul 1 - Sep 30, 2021	○	○	○	○	○	○
Oct 1 - Dec 31, 2021	○	○	○	○	○	○

IF SELECTED FOR ALL PANDEMIC PERIODS, GO TO QUESTION 10, PAGE 9

9. For each time period, please indicate **how often you wore a MASK/FACE COVERING INDOORS when you were** within (or expected to be within) 6 feet of people **not** in your household**:**

Mask/Face covering— INDOORS within 6 feet	Always	Most of the time	Some-times	Rarely	Never	NA I was always at least 6 feet away
a. Jan 1 - Mar 14, 2020 **BEFORE** *the pandemic in most places*	○	○	○	○	○	○
b. Mar 15 - May 14, 2020 *Initial pandemic-related restrictions*	○	○	○	○	○	○
c. May 15 - Jul 31, 2020 *Includes Memorial Day and July 4th*	○	○	○	○	○	○
d. Aug 1 - Sep 30, 2020 *Includes Labor Day*	○	○	○	○	○	○
e. Oct 1 - Dec 31, 2020	○	○	○	○	○	○
f. Jan 1 - Mar 31, 2021	○	○	○	○	○	○
g. Apr 1 - Jun 30, 2021	○	○	○	○	○	○
h. Jul 1 - Sep 30, 2021	○	○	○	○	○	○
i. Oct 1 - Dec 31, 2021	○	○	○	○	○	○

10. Since the coronavirus pandemic began, have you WORKED (including volunteering) with people NOT in your household, whether at your home (ex. with clients) or elsewhere (ex. in an office with co-workers, customers, patients, students, etc.)?

○ No, I did not work or volunteer → **GO TO QUESTION 12 ON PAGE 10**

○ No, I worked/volunteered entirely remotely (no in-person contact with people other than household members) } **GO TO QUESTION 11 ON PAGE 10**

○ Yes, I worked/volunteered with people not in my household

2020						
10a. My work involved...	**Jan 1 - Mar 14, 2020** **BEFORE** *the pandemic in most places*	**Mar 15 - May 14, 2020** *Initial pandemic -related restrictions*	**May 15 - Jul 31, 2020** *Includes Memorial Day and July 4th*	**Aug 1 - Sep 30, 2020** *Includes Labor Day*	**Oct 1 - Dec 31, 2020**	**NA**
a. **Patient care for patients with suspected or confirmed COVID-19.** *Include patients likely to have COVID-19 based on symptoms or exposure, and patients with a positive COVID-19 test.*	○	○	○	○	○	○
b. **Patient care for patients without suspected or confirmed COVID-19.** *Include care at nursing homes, assisted living, home health, etc. for patients who did NOT have COVID-19 symptoms or a positive COVID-19 test.*	○	○	○	○	○	○
c. **Close personal contact with co-workers, contractors, or clients** *(i.e., routinely worked within 6 feet)*	○	○	○	○	○	○
d. **Face-to-face contact with the public** *(within 6 feet; ex. retail or food service)*	○	○	○	○	○	○
e. **Being alone in a private office** all or almost all of my work hours	○	○	○	○	○	○

2021					
10a. My work involved...	**Jan 1 - Mar 31, 2021**	**Apr 1 - Jun 30, 2021**	**Jul 1 - Sep 30, 2021**	**Oct 1 - Dec 31, 2021**	**NA**
a. **Patient care for patients with <u>suspected or confirmed COVID-19</u>.** *Include patients likely to have COVID-19 based on symptoms or exposure, and patients with a positive COVID-19 test.*	○	○	○	○	○
b. **Patient care for patients <u>without</u> suspected or confirmed COVID-19.** *Include care at nursing homes, assisted living, home health, etc. for patients who did NOT have COVID-19 symptoms or a positive COVID-19 test.*	○	○	○	○	○
c. **<u>Close personal contact</u> with co-workers, contractors, or clients** *(i.e., routinely worked within 6 feet)*	○	○	○	○	○
d. **<u>Face-to-face</u> contact with the public** *(within 6 feet; ex. retail or food service)*	○	○	○	○	○
e. **Being alone in a <u>private office</u>** all or almost all of my work hours	○	○	○	○	○

11. Were you considered an “essential worker?"

- ○ No
- ○ Yes

12. PRIOR to the coronavirus pandemic, did you have health insurance? *Include private, employer, and government plans.*

- ○ No
- ○ Yes

13. What is your CURRENT health insurance status?

- ○ I have health insurance
- ○ I do not have health insurance

14. Since the coronavirus pandemic began, have any of your household members had suspected or confirmed COVID-19?

○ No → **GO TO QUESTION 15**

○ Yes →

14a. Thinking of all of the times a household member had suspected or confirmed COVID-19, what was your highest level of caregiving?

- ○ I was the only caregiver
- ○ I was the primary caregiver, although others helped
- ○ I was not the primary caregiver, but did help with care sometimes
- ○ Others provided all care for household member(s) with COVID-19 but they were not isolated from me within the home
- ○ The household member with COVID-19 was isolated from me within the home or away from our home

15. Since the coronavirus pandemic began, were you exposed to someone NOT living with you (ex. friend, family member living elsewhere, co-worker) with suspected or confirmed COVID-19?

○ No → **GO TO QUESTION 16 ON NEXT PAGE**

○ Yes →

15a. How many people NOT living with you with suspected or confirmed COVID-19 were you exposed to?

☐☐ # PEOPLE

16. Compared to BEFORE the coronavirus pandemic, in general how much of the following do you consume or use NOW?

	More	About the same	Less	a. Did you use before the pandemic?
a. Alcoholic beverages *(including wine coolers, seltzer with alcohol, etc.)*	○	○	○	○ No ○ Yes
b. Tobacco products *(ex. smoking, vaping)*	○	○	○	○ No ○ Yes
c. Marijuana *(ex. vaping, smoking, eating)*	○	○	○	○ No ○ Yes
d. Cannabidiol (CBD)	○	○	○	○ No ○ Yes
e. Recreational drugs *(Do NOT include marijuana or CBD)*	○	○	○	○ No ○ Yes
f. Medicine to help you sleep, either prescription or over-the-counter/non-prescription	○	○	○	○ No ○ Yes
g. Anti-depressants	○	○	○	○ No ○ Yes
h. Anti-anxiety medications	○	○	○	○ No ○ Yes
i. Narcotics, opioids	○	○	○	○ No ○ Yes

17. How has the coronavirus pandemic changed your sleep quality, if at all?

- ○ Significantly worse
- ○ Moderately worse
- ○ About the same
- ○ Moderately improved
- ○ Significantly improved

18. How has the coronavirus pandemic changed how much you sleep, if at all?

- O Significantly less
- O Moderately less
- O About the same
- O Moderately more
- O Significantly more

19. During the HEIGHT of the coronavirus pandemic, how often did you take medicine (prescription or over-the-counter/non-prescription) to help you sleep?

- O Never or very rarely
- O Less than once a week
- O Once or twice a week
- O Three or more times a week

The following eleven questions may seem similar to earlier questions, but they will help us to more fully understand the OVERALL impact the coronavirus pandemic has had on you and any potential for long-term health effects.

Please rate how much the coronavirus pandemic has changed your life in each of the following ways:

20. Routines (ex. work, education, social life, hobbies, religious activities):

- O No change
- O Mild. Change in only one area
- O Moderate. Change in two areas
- O Severe. Change in three or more areas

21. Medical health care access:

- O No change
- O Mild. Appointments moved to telehealth
- O Moderate. Delays or cancellations in appointments or delays in getting prescriptions; changes have had minimal impact on health
- O Severe. Unable to access needed care resulting in moderate to severe impact on health

22. Mental health treatment access:

- ○ No change
- ○ Mild. Appointments moved to telehealth
- ○ Moderate. Delays or cancellations in appointments or delays in getting prescriptions; changes have had minimal impact on mental health
- ○ Severe. Unable to access needed care resulting in severe risk or significant impact on mental health

23. Family Income/Employment:

- ○ No change
- ○ Mild. Small change; able to meet all needs and pay bills
- ○ Moderate. Having to make cuts but able to meet basic needs and pay bills
- ○ Severe. Unable to meet basic needs or pay bills

24. Food Access:

- ○ No change
- ○ Mild. Enough food but difficulty getting to stores or finding needed items
- ○ Moderate. Occasionally without enough food or good quality (ex. healthy) foods
- ○ Severe. Frequently without enough food or good quality (ex. healthy) foods

25. Access to extended family and non-family social supports:

- ○ No change
- ○ Mild. Continued visits with social distancing, regular phone calls, video calls, or social media contacts
- ○ Moderate. Loss of in-person and remote contact with a few people, but not all supports
- ○ Severe. Loss of in-person and remote contact with all or almost all supports

26. Experiences of stress related to coronavirus pandemic:

- ○ None
- ○ Mild. Occasional worries or minor stress-related symptoms such as feeling a little anxious, sad, or angry; mild/rare trouble sleeping
- ○ Moderate. Frequent worries or moderate stress-related symptoms such as feeling moderately anxious, sad, or angry; moderate/occasional trouble sleeping
- ○ Severe. Persistent worries or severe stress-related symptoms such as feeling extremely anxious, sad, or angry; severe/frequent trouble sleeping

27. Stress and discord in the family:

- ○ None
- ○ Mild. Family members occasionally short-tempered with one another; no physical violence
- ○ Moderate. Family members frequently short-tempered with one another or children in the home getting in physical fights with one another
- ○ Severe. Family members frequently short-tempered with one another and adults in the home throwing things at one another, knocking over furniture, or hitting or harming one another

28. Personal diagnosis of suspected or confirmed coronavirus infection (COVID-19):

- ○ None. I did not have COVID-19
- ○ Mild. My symptoms were effectively managed at home
- ○ Moderate. My symptoms were severe and required brief hospitalization
- ○ Severe. My symptoms were severe and required ventilation

29. Number of immediate family members (parents, spouse/partner, siblings, etc.) diagnosed with coronavirus infection (COVID-19):

		# FAMILY MEMBERS

(IF NONE, ENTER '00' AND GO TO QUESTION 30 ON THE NEXT PAGE)

29a. Rate the symptoms of the person who was <u>most sick</u>:

- ○ Mild. Symptoms were effectively managed at home
- ○ Moderate. Symptoms were severe and required brief hospitalization
- ○ Severe. Symptoms were severe and required ventilation
- ○ Immediate family member died of coronavirus infection (COVID-19)

30. Number of extended family member(s) and/or close friend(s) diagnosed with coronavirus infection (COVID-19):

		# EXTENDED FAMILY MEMBERS/CLOSE FRIENDS

(IF NONE, ENTER '00' AND GO TO QUESTION 31)

30a. Rate the symptoms of the person who was most sick:

- ○ Mild. Symptoms were effectively managed at home
- ○ Moderate. Symptoms were severe and required brief hospitalization
- ○ Severe. Symptoms were severe and required ventilation
- ○ Extended family member and/or close friend died of coronavirus infection (COVID-19)

31. Is there anything else you would like to tell us about how the coronavirus pandemic or the response to the pandemic has impacted your life?

Today's Date: ☐☐ / ☐☐ / 2 0 ☐☐

MONTH DAY YEAR

Please check to see that all questions are answered.

Thank you for completing this questionnaire and for your continued participation in the Sister Study.

Please mail this form to us at the address below.
A postage-paid envelope is provided.

The Sister Study, 4505 Emperor Blvd, Suite 400, Durham, NC 27703
phone: 1-877-4SISTER (1-877-474-7837); email: update@sisterstudy.org