World Trade Center Health Registry

Follow-up COVID-19 Survey

Instructions:

- **Please fill in circles completely using a black or blue ink pen.** → **Example:** ○ ● ○
- **Written answers should be printed in capital letters.** → **Example:** J A 1 2

This survey contains questions that will help the Registry understand how the COVID-19 (or coronavirus disease 2019) pandemic has affected your life and your health. Although it is sometimes referred to as coronavirus, we will use COVID-19 throughout this survey.

1. Please enter today's date:

M M / D D / Y Y Y Y — 2 0 2 _

2. What is your date of birth?

M M / D D / Y Y Y Y

3. What sex were you assigned at birth?

- ○ Female
- ○ Male
- ○ Neither female nor male

4. Did you ever have COVID-19?

- ○ Yes
- ○ No → *Go to Question 20*

5. How do you know you had COVID-19? *Select all that apply.*

- ○ Confirmed by a positive PCR test at a testing site, clinic or with a health care provider
- ○ Confirmed by a positive rapid test or home test
- ○ A health care provider suspected I had COVID-19, but I did not take a test
- ○ Based on an antibody test
- ○ Other reason (please specify):

_____

6. When do you think you first got COVID-19? *If you do not remember exactly, please put your best estimate.*

M M / Y Y Y Y — 2 0 2 _

7. Do you think you had COVID-19 more than once?

- ○ Yes
- ○ No → *Go to Question 9*

8. When do you think you most recently got COVID-19? *If you do not remember exactly, please put your best estimate.*

M M / Y Y Y Y — 2 0 2 _

9. When you had COVID-19, which of the following symptoms did you have? *Select all that apply. Please select any symptom that started or got worse during the period you had COVID-19. If you had COVID-19 more than once, please refer to your most significant illness experience.*

- ○ No symptoms → *Go to Question 18*
- ○ Fever/sweats/chills or shaking
- ○ Shortness of breath (trouble breathing)
- ○ Cough
- ○ Wheezing
- ○ Chest pain/discomfort/tightness
- ○ Nausea/vomiting/diarrhea/abdominal pain
- ○ Muscle/joint pains or aches
- ○ Fatigue
- ○ Congestion or runny nose
- ○ Headache
- ○ Sore throat
- ○ Loss of taste or smell
- ○ Confusion/trouble thinking or concentrating/brain fog
- ○ Other (please specify):

_____

→ *Go to Question 10*

10. For how long were you unable to function as normal due to COVID-19 symptoms?

- ○ I was always able to function as normal
- ○ One to three days
- ○ Four to six days
- ○ At least one week, but less than two weeks
- ○ At least two weeks, but less than four weeks
- ○ At least four weeks, but less than 12 weeks
- ○ 12 weeks or more

11. Which of the following did you do because of your symptoms? *Select all that apply.*

- ○ I saw a health care provider in person, such as in a clinic, doctor's office, urgent care or emergency room/department.
- ○ I spoke to a health care provider by phone, video or email.
- ○ I called **911** or other emergency services with concerns about my symptoms.
- ○ I self-isolated or quarantined at home.
- ○ None of the above.

12. Were you admitted to a hospital because you had COVID-19 or symptoms of COVID-19? *Do <u>not</u> count times you were hospitalized for a reason not related to COVID-19 and later tested positive for COVID-19 in the hospital.*

- ○ Yes, one time
- ○ Yes, multiple times
- ○ No → *Go to Question 15*

13. How long were you hospitalized for COVID-19? *If you were hospitalized more than once for COVID-19, please think about your longest stay in a hospital for COVID-19 to answer this question.*

- ○ Less than 24 hours
- ○ More than 24 hours, but less than one week
- ○ At least one week, but less than two weeks
- ○ At least two weeks, but less than four weeks
- ○ At least four weeks, but less than eight weeks
- ○ More than eight weeks

14. While you were hospitalized for COVID-19, were you <u>ever</u>: *(Select all that apply.)*

- ○ Admitted into an intensive care unit (ICU)
- ○ Intubated/put on a ventilator
- ○ Given oxygen (by mask or nose)
- ○ Put on kidney dialysis
- ○ None of the above

15. Did you have any of the following problems <u>more than 12 weeks</u> after your COVID-19 illness started? *Select all that apply. Please only consider symptoms that are not explained by another reason.*

- ○ Unusual tiredness or fatigue
- ○ Difficulty breathing, shortness of breath or cough
- ○ Confusion/trouble thinking or concentrating/brain fog
- ○ Altered sense of taste or smell
- ○ Muscle or joint pain
- ○ Trouble sleeping
- ○ Lightheadedness upon standing
- ○ Anxiety or depression
- ○ Other problem (please specify):

  _____

- ○ None of the above → *Go to Question 18*

16. Are you <u>currently</u> experiencing these symptoms?

- ○ Yes
- ○ No

17. How much have your health care providers helped you to lessen these symptoms?

- ○ A lot
- ○ Somewhat
- ○ A little bit
- ○ Not at all
- ○ Not applicable – I have not seen a health care provider for these symptoms

This space is intentionally blank.
Please go to Question 18 on the next page.

18. **Have you been told by a health care provider that you may have a new condition, illness or disability because of COVID-19?**
    - ○ Yes
    - ○ No → *Go to Question 20*

19. **What new condition, illness or disability does your health care provider think you may have because of COVID-19?** *Select all that apply.*
    - ○ Post-viral fatigue
    - ○ Post-COVID syndrome (or long COVID)
    - ○ A blood clot in the leg, heart, lung or brain
    - ○ A heart condition (for example, angina, heart attack or congestive heart failure)
    - ○ A lung condition
    - ○ A stroke (cerebrovascular disease)
    - ○ A condition affecting the mind or brain (for example, depression, anxiety or other conditions such as dementia)
    - ○ A condition affecting the nervous system outside of the brain
    - ○ A condition affecting the kidneys
    - ○ Thyroid disease
    - ○ High blood pressure or hypertension
    - ○ Diabetes or high blood sugar
    - ○ Arthritis (including osteoarthritis or rheumatism)
    - ○ Cancer or a malignant tumor (including leukemia)
    - ○ Other (please specify): _____

20. **Thinking about your physical health, which includes physical illness and injury, for how many days during the last 30 days was your physical health not good?**

    ☐☐ days

21. **Thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the last 30 days was your mental health not good?**

    ☐☐ days

22. **For how many days did poor physical or mental health keep you from doing your usual activities during the last 30 days?**

    ☐☐ days

23. **Compared to before the beginning of the COVID-19 pandemic, would you say your physical health is now better, worse or about the same?**
    - ○ Better
    - ○ Worse
    - ○ About the same

24. **Compared to before the beginning of the COVID-19 pandemic, would you say your mental or emotional health is now better, worse or about the same?**
    - ○ Better
    - ○ Worse
    - ○ About the same

25. How many COVID-19 vaccine doses have you received?

- ○ Zero doses → *Go to Question 27*
- ○ One dose
- ○ Two doses
- ○ Three doses
- ○ Four or more doses

26. We would like to know when you received your COVID-19 vaccine doses including any booster doses. Using your COVID-19 vaccination card, please add the month and year you received each COVID-19 dose and the vaccine brand of each dose to the table below. If you do not have your vaccination card, your best estimate is fine.

	Month and Year of Vaccination	Vaccine Brand
Dose 1	M M / Y Y Y Y: ___ / 2 0 2 ___	○ Pfizer-BioNTech (Comirnaty) ○ Moderna (Spikevax) ○ Johnson & Johnson (J&J)/Janssen ○ Other (please specify): _____
Dose 2	M M / Y Y Y Y: ___ / 2 0 2 ___	○ Pfizer-BioNTech (Comirnaty) ○ Moderna (Spikevax) ○ J&J/Janssen ○ Other (please specify): _____
Dose 3	M M / Y Y Y Y: ___ / 2 0 2 ___	○ Pfizer-BioNTech (Comirnaty) ○ Moderna (Spikevax) ○ J&J/Janssen ○ Other (please specify): _____
Dose 4	M M / Y Y Y Y: ___ / 2 0 2 ___	○ Pfizer-BioNTech (Comirnaty) ○ Moderna (Spikevax) ○ J&J/Janssen ○ Other (please specify): _____
Dose 5	M M / Y Y Y Y: ___ / 2 0 2 ___	○ Pfizer-BioNTech (Comirnaty) ○ Moderna (Spikevax) ○ J&J/Janssen ○ Other (please specify): _____
Dose 6	M M / Y Y Y Y: ___ / 2 0 2 ___	○ Pfizer-BioNTech (Comirnaty) ○ Moderna (Spikevax) ○ J&J/Janssen ○ Other (please specify): _____

27. Before the COVID-19 pandemic, did you ever have any of the following conditions? *Select all that apply. Do not count those you developed during or after the pandemic.*

- ○ Cardiovascular disease or a heart condition
- ○ Cancer
- ○ Chronic kidney disease
- ○ Chronic liver disease
- ○ Chronic disease of the respiratory system (for example, asthma or chronic bronchitis)
- ○ Cystic fibrosis
- ○ Dementia or other neurological conditions
- ○ Disabilities
- ○ Immunodeficiency, or taking medication that suppresses the immune system
- ○ Mental health conditions (for example, depression, schizophrenia spectrum disorders or substance use disorders)
- ○ Sickle cell disease or thalassemia
- ○ Solid organ or blood stem cell transplant
- ○ Tuberculosis
- ○ None of the above

28. In the last 12 months, did you delay medical care that you needed?

- ○ Yes
- ○ No → *Go to Question 32*

29. What kind of medical care was it that you needed but delayed or did not get in the last 12 months? *Select all that apply.*

- ○ Preventive care (for example, annual physical or dental cleaning)
- ○ Diagnostic procedure
- ○ Care for a chronic condition
- ○ Medical specialist visit
- ○ Surgical procedure
- ○ Prescription medication
- ○ Care to address pain
- ○ Care for a mental health-related issue
- ○ Cancer screening (please specify):

  _____
- ○ Other type of care (please specify):

  _____

30. Why did you delay or not get the medical care that you needed in the last 12 months? *Select all that apply.*

- ○ Could not get an appointment soon enough
- ○ Too afraid to go to the clinic/doctor's office
- ○ Worried about getting sick with COVID-19 while getting care
- ○ Believed the care needed could be safely postponed
- ○ Unable to get to your clinic/doctor's office (transportation)
- ○ Did not know where to get medical care/test/treatment
- ○ Did not have time
- ○ Concerned about the cost of getting care
- ○ No insurance or not covered by your insurance
- ○ Different language from the doctor, nurse, receptionist
- ○ Could not get time off from work
- ○ Could not get child care or help caring for another family member
- ○ Elective procedures postponed due to COVID-related surges, staffing shortages, or government policies
- ○ Other reason (please specify):

  _____

31. Did the medical care that you delayed include any of your 9/11-related health conditions certified by the World Trade Center Health Program (WTCHP)? *Certification of a 9/11-related health condition means the federal WTCHP determined your condition to be eligible for treatment through the WTCHP.*

- ○ Yes
- ○ No
- ○ Not applicable – do not have a 9/11-related health condition certified by the WTCHP

32. Were you without health insurance at any point since the COVID-19 pandemic began?

- ○ Yes
- ○ No → *Go to Question 34*

33. How long were you without health insurance since the COVID-19 pandemic began?

☐☐☐ weeks **OR** ☐☐ months

34. Since the start of the COVID-19 pandemic, have you been diagnosed by a health care provider with any of the following mental health conditions? *Select all that apply. Do not include diagnosed mental health conditions that you had prior to the COVID-19 pandemic.*

- ○ Depression
- ○ Post-traumatic stress disorder (PTSD)
- ○ An anxiety disorder other than PTSD
- ○ Problems with your use of alcohol or drugs
- ○ Other mental health problems, including problems with your nerves or emotions
- ○ I have not been diagnosed with a mental health condition since the COVID-19 pandemic started

35. Below is a list of problems that people sometimes have in response to stressful experiences like the COVID-19 pandemic. In the last 30 days, how much were you bothered by:

	Not at all	A little bit	Moderately	Quite a bit	Extremely
a. Repeated, disturbing, and unwanted memories of your experiences related to the COVID-19 pandemic?	○	○	○	○	○
b. Feeling very upset when something reminded you of your experiences related to the COVID-19 pandemic?	○	○	○	○	○
c. Avoiding memories, thoughts, or feelings of your experiences related to the COVID-19 pandemic?	○	○	○	○	○
d. Avoiding external reminders of your experiences related to the COVID-19 pandemic (for example, people, places, conversations, activities, objects, or situations)?	○	○	○	○	○
e. Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?	○	○	○	○	○
f. Loss of interest in activities that you used to enjoy?	○	○	○	○	○
g. Feeling jumpy or easily startled?	○	○	○	○	○
h. Having difficulty concentrating?	○	○	○	○	○

36. During the last 30 days, about how often did you feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. So sad that nothing could cheer you up?	○	○	○	○	○
b. Nervous?	○	○	○	○	○
c. Restless or fidgety?	○	○	○	○	○
d. Hopeless?	○	○	○	○	○
e. That everything was an effort?	○	○	○	○	○
f. Worthless?	○	○	○	○	○

37. How often is someone available:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. To take you to the doctor if you need to go?	○	○	○	○	○
b. To have a good time with?	○	○	○	○	○
c. To hug you?	○	○	○	○	○
d. To prepare your meals if you are unable to do it yourself?	○	○	○	○	○
e. To understand your problems?	○	○	○	○	○

38. Please indicate to what extent each of the following statements describes your feelings.

	Yes	More or less	No
a. I experience a general sense of emptiness.	○	○	○
b. There are plenty of people I can rely on when I have problems.	○	○	○
c. There are many people I can trust completely.	○	○	○
d. There are enough people I feel close to.	○	○	○
e. I miss having people around.	○	○	○
f. I often feel rejected.	○	○	○

Questions 39 to 41 are about sensitive topics and they might make some people uncomfortable. If a question upsets you, you do not have to answer it. Remember that all of your answers are kept private.

39. Since January 2020, have you experienced the death of someone close to you?

- ○ Yes
- ○ No → *Go to Question 42*

Questions 40 and 41 will help us understand how you are coping with grief. If you experienced the death of more than one person you were close to, please think about the loss that impacted you most.

40. Did this happen…

- ○ Less than six months ago → *Go to Question 42*
- ○ Six to 12 months ago
- ○ More than 12 months ago

41. Thinking about the loss that impacted you most:

	No, not at all	Yes, somewhat	Yes, a lot
a. Are you having trouble accepting the death of your loved one?	○	○	○
b. Does your grief interfere with your life right now?	○	○	○
c. Are you feeling cut off or distant from other people since your loved one died, including people you used to be close to, like family or friends?	○	○	○
d. Are you having thoughts about the death of your loved one that really bother you?	○	○	○
e. Are there things you used to do when your loved one was alive that you do not feel comfortable doing anymore or that you avoid? *This might include not doing things you used to enjoy together or avoiding talking about them.*	○	○	○

This space is intentionally blank.
Please go to Question 42 on the next page.

42. During the last 30 days, how many hours of actual sleep did you get most nights?

- ○ Less than four hours
- ○ Four hours
- ○ Five hours
- ○ Six hours
- ○ Seven hours
- ○ Eight hours
- ○ Nine hours
- ○ 10 hours
- ○ 11 or more hours

43. During the last 30 days, how would you rate your sleep quality overall?

- ○ Very good
- ○ Fairly good
- ○ Fairly bad
- ○ Very bad

44. In the last 30 days, how often did you feel excessively or overly sleepy during the day?

- ○ Never
- ○ Rarely (once a month)
- ○ Sometimes (two to four times a month)
- ○ Often (five to 15 times a month)
- ○ Almost always (16 to 30 times a month)

45. In the last 30 days, how often did you take any medication to help you fall asleep or stay asleep? *Include both prescribed and over-the-counter medications.*

- ○ Never
- ○ Some days
- ○ Most days
- ○ Every day

46. During the last 12 months, have you experienced confusion or memory loss, other than occasionally forgetting the name of someone you recently met?

- ○ Yes
- ○ No → *Go to Question 50*

47. During the last 12 months, has your confusion or memory loss happened more often or gotten worse?

- ○ Yes
- ○ No

48. During the last 12 months, as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills?

- ○ Always
- ○ Usually
- ○ Sometimes
- ○ Rarely
- ○ Never

49. Have you or anyone else discussed your confusion or memory loss with a health care professional?

- ○ Yes
- ○ No

This space is intentionally blank.
Please go to Question 50 on the next page.

50. Since the start of the COVID-19 pandemic, were you ever employed or self-employed?

- ○ Yes
- ○ No → *Go to Question 58*

51. What type of setting(s) have you worked in since the start of the COVID-19 pandemic? *Select all that apply.*

- ○ At home
- ○ In a medical setting (hospital, clinic, doctor's office, urgent care center, nursing facility, laboratory, etc.)
- ○ In an office or apartment building
- ○ In a private household or households (home health care, nanny, housekeeper, etc.)
- ○ In a setting with regular customer interaction (delivery, material transport, retail, food service, restaurant, hotel, pharmacy, etc.)
- ○ Public or private transit (railroad, bus, taxi, limousine, rideshare, etc.)
- ○ In the community as a first responder (police, EMS, firefighter, National Guard, etc.)
- ○ In a warehouse or manufacturing factory
- ○ In a school or instructional setting
- ○ In an institutional setting (correctional facility, prison, shelter, etc.)
- ○ Outside (gardening, agriculture, fishing or hunting, construction, road work, crane operator, etc.)
- ○ Other (please specify):

_____

52. Since the start of the COVID-19 pandemic, did you work outside the home to provide an essential service (for example, health care provider, first responder, essential retail)?

- ○ Yes
- ○ No → *Go to Question 56*

53. Since the start of the COVID-19 pandemic, how long have you worked or did you work in an essential role?

☐☐ months

54. On the days you have been working since the start of the COVID-19 pandemic, how often has your job required face-to-face contact with other people in an indoor setting? *If you had more than one job, please answer this question for the job you worked at the longest or consider to be your main job.*

- ○ None of the time
- ○ Some of the time
- ○ Most of the time
- ○ All of the time

55. How often have you been able to maintain a 6-foot distance from others at your workplace? *If you had more than one job, please answer this question for the job you worked at the longest or consider to be your main job.*

- ○ None of the time
- ○ Some of the time
- ○ Most of the time
- ○ All of the time

56. Are you now doing the same job you were doing at the time the COVID-19 pandemic began?

- ○ Yes → *Go to Question 58*
- ○ No

57. What are your reasons for not working in the same job? *Select all that apply.*

- ○ I retired
- ○ I was laid off, furloughed, or put on temporary unpaid or paid leave by my employer
- ○ I was no longer able to do my work or run my business because of restrictions associated with the COVID-19 pandemic
- ○ My employer went out of business or closed temporarily due to the COVID-19 pandemic
- ○ I stopped working because I am at high risk for complications associated with COVID-19
- ○ I was concerned about getting or spreading COVID-19
- ○ I was recovering from COVID-19 or caring for someone who had COVID-19
- ○ Other reason(s) not related to COVID-19
- ○ Other reason(s) related to COVID-19 (please specify):

_____

58. Has your household experienced any of the following financial difficulties because of the COVID-19 pandemic? *Select all that apply.*

- ○ Unable to pay the rent or mortgage
- ○ Unable to pay the gas, oil or electricity bills
- ○ Unable to pay the telephone (including cellphone) or internet bills
- ○ Unable to buy groceries because of lack of money
- ○ Asked to move out or threatened with eviction or foreclosure
- ○ Experienced homelessness
- ○ None of the above

59. How does your household's wealth now compare to your household's wealth before the beginning of the COVID-19 pandemic? *Wealth is the difference between your assets (such as savings, stocks, home equity), and debts (such as mortgage, credit card, and student loans).*

- ○ There has not been a change
- ○ My household's wealth has decreased
- ○ My household's wealth has increased

60. Please indicate how much you agree or disagree with each of the following statements.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. I tend to bounce back quickly after hard times.	○	○	○	○	○
b. I have a hard time making it through stressful events.	○	○	○	○	○
c. It does not take me long to recover from a stressful event.	○	○	○	○	○
d. It is hard for me to snap back when something bad happens.	○	○	○	○	○
e. I usually come through difficult times with little trouble.	○	○	○	○	○
f. I tend to take a long time to get over setbacks in my life.	○	○	○	○	○

This space is intentionally blank.
Please go to Question 61 on the next page.

61. As a result of the COVID-19 pandemic, I experienced this change:

	Never	To a very small degree	To a small degree	To a moderate degree	To a great degree	To a very great degree
a. I changed my priorities about what is important in life.	○	○	○	○	○	○
b. I have a greater appreciation for the value of my own life.	○	○	○	○	○	○
c. I am able to do better things with my life.	○	○	○	○	○	○
d. I have a better understanding of spiritual matters.	○	○	○	○	○	○
e. I have a greater sense of closeness with others.	○	○	○	○	○	○
f. I established a new path for my life.	○	○	○	○	○	○
g. I know better that I can handle difficulties.	○	○	○	○	○	○
h. I have a stronger religious faith.	○	○	○	○	○	○
i. I discovered that I'm stronger than I thought I was.	○	○	○	○	○	○
j. I learned a great deal about how wonderful people are.	○	○	○	○	○	○

62. What are the last 4 digits of your Social Security Number? *This information is requested to help confirm that this survey was completed by the enrollee it was sent to. This information will remain strictly confidential. If you would like to provide this information over the phone, please call us at 866-692-9827.*

63. Do you have any additional comments about your COVID-19 pandemic experience?

This is the end of the survey. Thank you for completing the Follow-up COVID-19 Survey.
We appreciate your input and will keep your answers confidential.

Please return the completed survey in the provided envelope.
If the envelope was not included or was lost, call us at 866-692-9827.