



December 7, 2022

# Long COVID Follow-up Survey

## Introduction

Thanks for taking time to complete the follow-up survey for the CHASING COVID Cohort study. This should take 15-20 minutes of your time. When you finish the survey, you'll be directed to resources with accurate and up-to-date information about COVID-19. This survey may look a little different from previous surveys. The aim of today's survey is to focus on symptoms, and whether or not you have ever or have recently had COVID. You will receive a \$20 Tremendous gift card for completing the survey. Tremendous offers over 700 redeeming options, including Visa virtual gift cards, Amazon, Target, Starbucks, various charities, and more. Now you can choose which type of gift card you receive.

## **Contact Information**

- 1) If no phone number on file as of V12, skip to next question: We have this number for text message reminders. Is this correct?: [Enter phone number on file from V12]
  - a) Yes, this is correct
  - b) No
  - c) Don't know / Not sure
- 2) If no or don't know or no phone number on file: What is a good phone number where we can reach you? (We will never share your information with anyone. Standard messaging rates may apply.)
  - a) Phone Number: \_\_\_\_\_
  - b) Please confirm your phone number: \_\_\_\_\_\_

### Sociodemographics

- 3) Are you currently...? (Source: <u>BRFSS, 2019</u>; C3, V0-V12)
  - a) Employed for wages
  - b) Self-employed
  - c) Out of work for less than 1 year
  - d) Out of work for 1 year or more
  - e) A homemaker
  - f) A student
  - g) Retired





- 4) *If out of work*: Are you receiving unemployment benefits, or have you filed for unemployment benefits? (Source: C3, V0-V12)
  - a) Yes, I am receiving unemployment
  - b) Yes, I have filed for and am waiting to hear about eligibility
  - c) Yes, I have filed for and am waiting to receive unemployment
  - d) No, I am not receiving, filing or eligible for unemployment
  - e) No, my unemployment benefits expired
  - f) Don't know / Not sure
- 5) In the past month (since ADD Qualtrics DD/Mon/YY), have you experienced a significant personal loss of income as a result of COVID-19? (Source: C3, V0-V12)
  - a) Yes
  - b) No
  - c) Not applicable
- 6) *If yes experienced a personal loss of income:* Which of the following contributed to a personal loss of income? **Please select all that apply.** (Source: C3, V0-V12)
  - a) I was fired / laid off
  - b) I was given time off without pay (not fired, but not working)
  - c) I was given time off with reduced pay (employer provided benefits)
  - d) My hours were reduced
  - e) I could not work and care for or educate a child in my household
  - f) I felt I was at high risk and did not want to leave my home
  - g) My business temporarily closed
  - h) My business permanently closed
  - i) I was sick
  - j) I was in quarantine or isolation
  - k) I was in the hospital
  - l) Other: \_\_\_\_

### Healthcare Access, Insurance Status

- 7) During the **past 12 months**, have you had either a flu vaccine that was sprayed in your nose or a flu shot injected into your arm? (Source: <u>BRFSS, 2019</u>; C3, V0, V9, V11)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 8) During the past 12 months, has anyone else in your household received a flu vaccine that was sprayed in the nose or a flu shot injected into the arm? (Source: adapted from <u>BRFSS</u>, 2019; C3, V11)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
  - d) Not applicable, I do not live with anyone else





- 9) During the **past 12 months**, have you received a tetanus shot? (Source: adapted from <u>BRFSS, 2019</u>; C3, new question in V13)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
  - d) Not applicable, I do not live with anyone else

## **Pre-Existing Conditions and Symptoms**

- 10) Has a doctor, nurse, or other health professional ever told you that you had any of the following? **Please select all that apply** (Source: adapted from <u>BRFSS, 2019</u> to include additional risk factors; C3, V0, additional risk factors added in V9, V11)
  - a) A heart attack, also called a myocardial infarction
  - b) Angina or coronary heart disease
  - c) Type 2 diabetes
  - d) High blood pressure
  - e) Dyslipidemia (abnormally elevated cholesterol or fats (lipids) in the blood)
  - f) Cancer
  - g) Asthma
  - h) Chronic obstructive pulmonary disease, C.O.P.D., emphysema or chronic bronchitis
  - i) Kidney disease (not including kidney stones, bladder infection or incontinence)
  - j) Chronic liver disease, including cirrhosis
  - k) HIV/AIDS
  - l) Immunosuppression
  - m) Autoimmune condition
  - n) Depression
  - o) Post-traumatic stress disorder or PTSD
  - p) An anxiety disorder
  - q) Chronic fatigue syndrome
  - r) Mononucleosis
  - s) A traumatic brain injury
  - t) Migraines
  - u) Insomnia or another sleep condition
  - v) Dysautonomia (disorder of the autonomic nervous system (ANS) function)
  - w) Any other condition that you haven't told us about:\_\_\_\_
  - x) I have not been told that I have any of the above conditions [exclusive]
- 11) If yes to asthma: Do you still have asthma? (Source: <u>BRFSS, 2019</u>; C3, V0, V9, V11)
  - a) Yes
  - b) No
  - c) Don't know / Not sure





- 12) If yes to any health condition, excluding cancer: How old were you when a doctor, nurse, or health professional told you that you had the following... (Source: adapted from <u>BRFSS</u>, 2019; C3, V11)
  - a) [prepopulate list of responses endorsed above excluding cancer] \_\_\_\_\_ years old
- 13) *If yes to cancer*: You've told us that you have had cancer. We would like to ask you a few more questions about your cancer.

What type(s) of cancer? **Please select all that apply.** (Source: adapted from <u>BRFSS, 2019</u>; C3, V11)

- a) Bladder
- b) Blood
- c) Bone
- d) Brain
- e) Breast
- f) Cervix / cervical
- g) Colon
- h) Esophagus / esophageal
- i) Gallbladder
- j) Kidney
- k) Larynx / windpipe
- l) Leukemia
- m) Liver
- n) Lung
- o) Lymphoma / Hodgkins' disease
- p) Melanoma
- q) Mouth / tongue / lip
- r) Nervous system
- s) Ovary (ovarian)
- t) Pancreas / pancreatic
- u) Prostate
- v) Rectum / rectal
- w) Skin (non-melanoma)
- x) Skin (don't know what kind)
- y) Soft tissue (muscle or fat)
- z) Stomach
- aa) Testis / testicular
- bb) Thyroid
- cc) Uterus (uterine)
- dd) Other: \_\_\_\_\_
- ee) Don't know / not sure
- ff) I have not been told that I have any of the above conditions [exclusive]
- 14) *If yes to cancer*: How old were you when you were diagnosed? (Source: adapted from <u>BRFSS</u> 2019; C3, V11)





- a) [prepopulate types of cancer endorsed above] \_\_\_\_ years old
- 15) Are you <u>currently</u> experiencing any of the following symptoms? **Please select all that apply.** (Source: C3, V4-V12, new items added in V5 and V11)
  - a) Shortness of breath
  - b) Difficulty walking more than 15 minutes
  - c) Difficulty running / exercising
  - d) Fatigue

e) Fatigue after an activity (e.g., doing dishes, which is sometimes called post exertional malaise)

- f) Headache
- g) Trouble concentrating / brain fog
- h) Dizziness
- i) Irritability
- j) Erratic heartbeat
- k) Gastro-intestinal issues
- I) Low-grade fever
- m) Muscle aches (myalgia)
- n) Loss or altered taste
- o) Loss or altered sense of smell
- p) Waxing and waning of some or all of my initial symptoms
- q) Difficulty sleeping
- r) Something else:\_\_\_\_
- s) I am NOT experiencing any of the symptoms above [exclusive]

### Vaccine

- 16) If not fully vaccinated in previous (V5-V12): Have you been fully or partially vaccinated against COVID-19 with a vaccine that has received FDA approval or emergency use authorization? (Source: C3, V5-V12, question modified in V8)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 17) If yes or don't know to fully or partially vaccinated in this survey: How many doses of the primary vaccine series did you receive? Primary vaccine series means either a 2-dose mRNA COVID-19 vaccine series (Moderna or Pfizer) or a single dose of Johnson & Johnson COVID-19 vaccine. If you received booster doses please do not include them here. (Source: C3, V8-V12)
  - a) 1
  - b) 2
- 18) If reported receiving 1 dose only or 2 doses in this survey: When did you receive your first dose of the COVID-19 vaccine? Your vaccination card should have the date of your first shot. (Source: C3, V8-V12)





- a) Enter date: Month Day Year lookup
- b) Don't know / Not sure
- 19) *If don't know exact date*: What month did you receive your<u>first dose</u> of the COVID-19 vaccine? (Source: C3, V7.1 V12)
  - a) Enter date: Month Year dropdown options
  - b) Don't know / Not sure
- 20) *If don't know month*: Do you recall the season in which you received your <u>first dose</u> of the COVID-19 vaccine? (Source: C3, V8 V12)
  - a) Enter date: Season & Year dropdown options
  - b) Don't know / Not sure
- 21) If reported receiving 2 doses in this survey: When did you receive your second dose of the COVID-19 vaccine? Your vaccination card should have the date of your second shot. (Source: C3, V8-V12)

Please note that you entered [*piped text of first dose date*] as the first COVID-19 vaccine date. Please make sure the date of your first dose is before the date of your second dose. If the first dose date is wrong, please go back to change the date.

- a) Enter date: Month Day Year lookup
- b) Don't know / Not sure
- 22) *If don't know exact date*: What month did you receive your <u>second dose</u> of the COVID-19 vaccine? (Source: C3, V8-V12)
  - a) Enter date: Month Day Year lookup
  - b) Don't know / Not sure
- 23) *If don't know month*: Do you recall the season in which you received your <u>second dose</u> of the COVID-19 vaccine? (Source: C3, V8-V10)
  - a) Enter date: Season & Year dropdown options
  - b) Don't know / Not sure
- 24) *If yes to vaccinated in V13:* Do you know which COVID-19 vaccine you got? (Source: C3, V5-V12, question modified in V11)
  - a) Pfizer/BioNTech
  - b) Moderna
  - c) AstraZeneca-Oxford
  - d) Johnson & Johnson / Beth Israel Deaconess
  - e) Novavax
  - f) Other: \_
  - g) Don't know / Not sure





- 25) If reported full vaccination previously or in V13: Since your **last survey (on** ADD Qualtrics DD/Mon/YY**)**, have you received a COVID-19 booster? (Source: C3, V8-V12, question modified in V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 26) If yes to booster since last survey: Since your last survey (on ADD Qualtrics DD/Mon/YY), which most recent booster dose did you receive? (Source: C3, V8-V12, question modified in V12)
  - a) Pfizer/BioNTech
  - b) Moderna
  - c) AstraZeneca-Oxford
  - d) Johnson & Johnson / Beth Israel Deaconess
  - e) Novavax
  - f) Other: \_\_\_
  - g) Don't know / Not sure
- 27) *If received booster since last survey*: When did you receive your <u>most recent</u> booster dose for the COVID-19 vaccine? (Source: C3, V8-V12, question modified in V12)
  - a) Enter date: Month Day Year lookup
  - b) Don't know / Not sure
- 28) If don't know exact date: What month did you receive your <u>most recent</u> booster dose for the COVID-19 vaccine? (Source: C3, V8-V12, question modified in V12)
  - a) Enter date: Month Year dropdown options
  - b) Don't know / Not sure
- 29) If received a booster since last survey: Was your <u>most recent</u> booster dose an <u>omicron-specific</u> COVID-19 booster? This may also be known as the "bivalent" or "updated" booster. (Source: C3, V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 30) If no/don't know to getting the booster: Now that boosters are available, will you: (Source: C3, V11-V12)
  - a) Immediately get the booster
  - b) Delay getting the booster
  - c) Never get the booster
- 31) *If no to booster:* Which of the following influenced your decision to not get a booster? **Please select all that apply.** (Source: C3, V9-V12, additional reasons added in V12, V13)
  - a) I recently got a booster
  - b) I don't believe I need an additional booster dose





- c) There is not enough evidence that the booster dose is effective
- d) I'm not yet eligible for the booster dose
- e) I'm not sure if I'm eligible for the booster dose
- f) Short-term side effects
- g) Long-term side effects
- h) Whether other people I know also get it
- i) I think that other people should get it before me
- j) I need more information about the booster dose
- k) I already had COVID
- I) I recently had COVID
- m) I don't think I am at risk for getting COVID
- n) I have a medical condition which prevents me from getting boosted
- o) Issues accessing a booster dose at a time (or venue) that works for me
- p) Issues accessing a specific vaccine booster dose versus the one that is available
- q) Lack of FDA full approval (Johnson & Johnson vaccines)
- r) I plan to get a booster, but haven't had time yet
- s) I'm worried that there will be fees or other costs if I get the booster
- t) I'm scared of needles
- u) Other: \_
- v) None of the above [*exclusive*]
- 32) *If yes to booster*: What motivated you to get the booster dose(s)? **Please select all that apply**. (Source: C3, V9-V12)
  - a) I believe the vaccine effectiveness due to my primary vaccine could be waning
  - b) I'm concerned about new coronavirus variants such as Delta and Omicron
  - c) It is required for travel outside the US
  - d) It is required by my employer
  - e) It is required by my school/university
  - f) I want to visit my family
  - g) I want to help reduce the burden on the healthcare system
  - h) I want to help end the pandemic as soon as possible
  - i) I believe it is effective
  - j) It will help protect me
  - k) It will help protect others around me
  - I) I trust the FDA emergency use authorization and approval process
  - m) Other: \_\_\_\_\_
- 33) If no/don't know to getting the vaccine: Now that the vaccine is available to everyone 6 months or older, will you: (Source: C3, V2-V12, question modified in V5, V8, V9, and V12):
  - a) Immediately get the vaccine
  - b) Delay getting the vaccine
  - c) Never get the vaccine
- 34) *If delay or never get vaccine*: Which of the following influenced your decision NOT to get a vaccine? **Please select all that apply**. (Source: C3, V5-V12, reasons added in V6, V7, V8)





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- a) Short-term side effects
- b) Long-term side effects
- c) Vaccine effectiveness
- d) Whether other people I know also get it
- e) I think that other people should get it before me
- f) I need more information about the vaccine
- g) I already had COVID
- h) I don't think I am at risk for getting COVID
- i) I have a medical condition which prevents me from getting vaccinated
- j) Issues accessing a vaccine at a time that works for me
- k) Issues accessing a specific vaccine versus the one that is available
- I) Lack of FDA approval (Moderna and Johnson & Johnson vaccines)
- m) Other: \_
- n) None of the above [*exclusive*]

35) *If immediately get the vaccine*: What motivates you to get the vaccine? **Please select all that apply**. (Source: C3, V5-V12, reasons added in V8, V9, V10, V11)

- a) I'm concerned about new coronavirus variants such as Delta and Omicron
- b) It is required for travel outside the US
- c) It is required by my employer
- d) It is required by the school where I am a student
- e) I want to avoid getting COVID-19
- f) I want to visit my family
- g) I want to help reduce the burden on the healthcare system
- h) I want to help end the pandemic as soon as possible
- i) I believe it is effective
- j) It will help protect me
- k) It will help protect others around me
- I) I trust the FDA emergency use authorization and approval process
- m) Final FDA approval for Pfizer and Moderna vaccine in adults
- n) Other: \_\_\_\_\_

### **Testing and Diagnosis**

We've been asking you periodically if you've ever had COVID, but we want to make sure our information is correct.

- Have you ever had COVID or a positive/reactive test? (Source: C3, V8, question modified in V11)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 37) Have you had COVID or a positive/reactive test **in the last 9 months (since** *ADD Qualtrics DD/Mon/YY***)**? (Source: C3, new question in V13)





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- a) Yes
- b) No
- c) Don't know / Not sure
- 38) Since you completed your last survey (on ADD Qualtrics DD/Mon/YY), have you taken a viral test for COVID-19? A viral test can show if you are currently infected. Viral tests (PCR or rapid tests) identify virus in samples from your respiratory system, such as swabs from the inside of your nose or a saliva sample. (Source: C3, V0-V10, V12, question modified in V1 and V13)
  - a) Yes
  - b) No, but I tried and was unable to get a viral test for COVID-19
  - c) No, because I did not need or try to get a viral test for COVID-19
  - d) Don't know / Not sure
- 39) If have taken viral test: Since you completed your last survey (on ADD Qualtrics DD/Mon/YY), were any of your viral tests an **at-home rapid** test? (Source: C3, new question in V13)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 40) If selected yes was tested or tried to get a test: What motivated you to get or try to get a test for COVID-19? Please select all that apply. (Source: C3, V2-V10, V12, reasons added in V3, V4, V5)
  - a) I was experiencing COVID-like symptoms
  - b) I was in contact with someone who had or was suspected to have had COVID-19
  - c) I needed to get a test for **work** (e.g., working in a healthcare or congregate living facility)
  - d) I needed to get a test for school
  - e) I belong to a priority population (e.g., having an underlying health condition)
  - f) I attended a gathering with more than 10 people (e.g., a church or protest)
  - g) Prior to a healthcare visit or procedure
  - h) Prior to seeing friends or family
  - i) After seeing friends or family
  - j) Prior to traveling
  - k) After traveling
  - I) I was just curious
  - m) Other: \_\_\_\_\_
- 41) If yes to viral test: Since you completed your last survey (on ADD Qualtrics DD/Mon/YY), were any of your viral (PCR or rapid) test(s) positive/reactive? (Source: C3, V4-V12, question modified in V5)
  - a) Yes
  - b) No
  - c) I am still waiting for test results
  - d) Don't know / Not sure





- 42) If yes to positive/reactive viral test: Since your **last survey (on** ADD Qualtrics DD/Mon/YY**)**, when was your positive viral (PCR or rapid) test? If you had more than one positive test since your last survey, please enter the date of your first positive test. An approximate date is okay. (Source: C3, new question in V13)
  - a) Enter date: Month Day Year lookup
  - b) Don't know / Not sure
- 43) If don't know/not sure about positive/reactive viral test date: Since your **last survey (on** ADD Qualtrics DD/Mon/YY), what month was your first positive viral (PCR or rapid) test? (Source: C3, new question in V13)
  - a) January 2022
  - b) February 2022
  - c) March 2022
  - d) April 2022
  - e) May 2022
  - f) June 2022
  - g) July 2022
  - h) August 2022
  - i) September 2022
  - j) October 2022
  - k) November 2022
  - I) December 2022
  - m) Other: \_\_\_
  - n) Don't know / Not sure

#### **Symptoms**

- Since you completed your last survey (on ADD Qualtrics DD/Mon/YY), have you had any of the following symptoms? Please select all that apply. Please do not include side effects that you experienced after receiving a COVID-19 vaccination or booster (usually occurring 24-48 hours after receiving a vaccination or booster). (Source: C3, V0-V12, symptoms added in V2, V6)
  - a) Headache
  - b) Cough (new since you completed your last survey)
  - c) Coughing up phlegm
  - d) Coughing up blood
  - e) Sore throat
  - f) Fever
  - g) Muscle aches (myalgia)
  - h) Chills
  - i) Repeated shaking and chills
  - j) Runny nose
  - k) Nasal congestion
  - I) Sneezing





Follow-up Questionnaire for the

Communities, Households and SARS-CoV-2 Epidemiology (CHASING) COVID Study

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- m) Chest pain
- n) Shortness of breath
- o) Itchy eyes
- p) Eye pain
- q) Loss or altered sense of smell of smell (new since you completed your last survey)
- r) Loss or altered sense of taste (new since you completed your last survey)
- s) Rash
- t) Stomach ache
- u) Nausea
- v) Diarrhea
- w) Vomiting
- x) I have not had any of these symptoms [exclusive]
- 45) *If selected any symptom:* Have you seen or called a physician or health care professional for any of these symptoms? (Source: C3, V0-V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 46) If selected any symptom: Since you completed your **last survey (on** ADD Qualtrics DD/Mon/YY**)**, were you hospitalized for any of these symptoms? (Source: C3, V0-V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 47) If reported COVID in last 9 months or if reported a positive/reactive viral test in V13: Did you have [populated with each of the following symptoms] before or after your <u>most recent</u> COVID infection? (Source: adapted from <u>NICE</u>; C3, V11)

Please check all time periods that you experienced that symptom	Before your most recent COVID infection	1 month after your most recent COVID infection	3 months after your most recent COVID infection	6 months after your most recent COVID infection	I didn't experience it at any of those times [ <i>exclusive</i> ]
Fever					
Fatigue					
Pain					
Cough					
Breathlessness					
Chest tightness					
Chest pain					
Palpitations					
Brain fog, memory/					
concentration loss					
Headache					





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Sleep disturbance			
Delirium			
Dizziness			
Loss or change to			
your sense of			
taste/smell			
Pins and			
needles/numbness			
Joint pain			
Muscle pain			
Symptoms of			
depression			
Symptoms of			
anxiety			
Abdominal pain			
Nausea			
Diarrhea			
Anorexia/loss of			
appetite			
Digestive disorders			
Tinnitus			
Earache			
Sore throat			
Skin rash			

## Recovery

If positive/reactive viral test in v13: You are seeing the following questions because you previously reported having had COVID-19. The questions ask about your experience recovering from COVID-19. Now we would like to ask you about things you might have tried to improve your symptoms the time(s) you had COVID.

- 48) If positive/reactive viral test in V13: Have you tried any of the following for COVID symptoms? Please select all that apply. (Source: C3, V11, option added in V13)
  - a) Symptoms eventually went away with time
  - b) Medication to reduce symptoms
  - c) Diet modifications
  - d) Physical therapy
  - e) Respiratory therapy (e.g. breathing exercises)
  - f) Respiratory assistance (e.g. inhaler, oxygen)
  - g) Occupational therapy
  - h) Monoclonal antibodies
  - i) Paxlovid





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- j) Molnupiravir
- k) COVID-19 vaccination
- I) Vitamins or herbal supplements
- m) Other: \_\_\_\_\_
- n) I still have symptoms
- o) I didn't have symptoms [exclusive]
- p) None of the above [exclusive]
- 49) *If yes to any resource:* Did you find [*prepopulate list of responses endorsed above*] helpful for reducing COVID symptoms? (Source: C3, V11)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 50) If positive/reactive viral test or yes to ever COVID in V13: Since you completed your **last** survey (on ADD Qualtrics DD/Mon/YY), were you prescribed antiviral medications (Paxlovid or Molnupiravir) to help with COVID symptoms? These are generally taken as pills for 5 days. Please select all that apply. (Source: C3, V11-12, question modified in V13)
  - a) Paxlovid
  - b) Molnupiravir
  - c) Other: \_\_
  - d) I was not prescribed an antiviral medication [exclusive]
- 51) *If prescribed Paxlovid:* When were you prescribed Paxlovid? **Please select all that apply.** (Source: C3, new question in V13)
  - a) Within 5 days of a positive/reactive test
  - b) 6-90 days after a positive/reactive test
  - c) 3 or more months after a positive/reactive test
  - d) Don't know / Not sure
- 52) *If prescribed Paxlovid:* For the time(s) when you took Paxlovid, was Paxlovid prescribed for more than 5 days? (Source: C3, new question in V13)

	Yes	No	Don't know / Not sure
Within 5 days of a positive/reactive test			
6-90 days after a positive/reactive test			
3 or more months after a			
positive/reactive test			
Don't know / Not sure			

53) *If prescribed Paxlovid:* For the time(s) when you took Paxlovid, did you take all the **Paxlovid** pills in your prescription? (Source: C3, new question in V13)

Yes	No	Don't know / Not sure





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Within 5 days of a positive/reactive test		
6-90 days after a positive/reactive test		
3 or more months after a		
positive/reactive test		
Don't know / Not sure		

- 54) *If prescribed Paxlovid:* Did you find Paxlovid helpful for reducing COVID symptoms? (Source: C3, V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 55) *If prescribed Molnupiravir:* When were you prescribed Molnupiravir? **Please select all that apply.** 
  - a) Within 5 days of a positive/reactive test
  - b) 6-90 days after a positive/reactive test
  - c) 3 or more months after a positive/reactive test
  - d) Don't know / Not sure
- 56) *If prescribed Molnupiravir:* For the time(s) when you took Molnupiravir, was Molnupiravir prescribed for more than 5 days? (Source: C3, new question in V13)

	Yes	No	Don't know / Not sure
Within 5 days of a positive/reactive test			
6-90 days after a positive/reactive test			
3 or more months after a			
positive/reactive test			
Don't know / Not sure			

57) *If prescribed Molnupiravir:* For the time(s) when you took Molnupiravir, did you take all the Molnupiravir pills in your prescription? (Source: C3, new question in V13)

	Yes	No	Don't know / Not sure
Within 5 days of a positive/reactive test			
6-90 days after a positive/reactive test			
3 or more months after a			
positive/reactive test			
Don't know / Not sure			

- 58) *If prescribed Molnupiravir:* Did you find Molnupiravir helpful for reducing COVID symptoms? (Source: C3, V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure





- 59) *If prescribed Other antiviral:* When were you prescribed [*prepopulate text response of 'other' in prescribed antivirals question*]? **Please select all that apply.** (Source: C3, new question in V13)
  - a) Within 5 days of a positive/reactive test
  - b) 6-90 days after a positive/reactive test
  - c) 3 or more months after a positive/reactive test
  - d) Don't know / Not sure
- 60) *If prescribed Other antiviral:* Did you find [*prepopulate text response of 'other' in prescribed antivirals question*] helpful for reducing COVID symptoms? (Source: C3, V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 61) *If positive/reactive viral test result in V13:* When you had COVID or a positive/reactive test, did you receive monoclonal antibodies, which are given intravenously in a health care setting? (Source: C3, V11-V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure

# Long-haul specific section

The following questions ask about experiences you may have had with COVID or long COVID. Even if you do not currently have COVID or long COVID, it is important to us to collect this information to better understand the experiences of long COVID among participants.

- 62) If skipped V4-V12 or don't know/no in response to long-haul questions in V4-V12: Some people report having persistent coronavirus symptoms, weeks and months after they first became sick. These people are sometimes known as COVID "long-haulers" or having "long-haul symptoms" or "long COVID". Some evidence suggests this can happen to people even if they did not have a positive antibody test. Do you think of yourself as a COVID "long-hauler"? (Source: C3, V4-V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 63) If people haven't previously identified they have long-haul by a doctor in V10-12: Have you been told by a **doctor** that you might have long COVID? "Long COVID" means having persistent coronavirus symptoms, weeks and months after someone first became sick. (Source: C3, V10-12)
  - a) Yes
  - b) No





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- c) Don't know/not sure
- 64) Would you describe yourself as having "long COVID", that is, you are still experiencing symptoms more than 4 weeks after you first had COVID-19, that are not explained by something else? (Source: <u>ONS, V11</u>; C3, V11-V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 65) *If yes or don't know to self-identified long-hauler (Q62 or Q64) or told by a doctor:* The following question is about your experience with long-haul symptoms or long COVID.

When did your initial symptoms start? (Source: C3, V4-V12)

- a) December 2019
- b) January 2020
- c) February 2020
- d) March 2020
- e) April, 2020
- f) May 2020
- g) June 2020
- h) July 2020
- i) August 2020
- j) September 2020
- k) October 2020
- l) November 2020
- m) December 2020
- n) January 2021
- o) February 2021
- p) March 2021
- q) April 2021
- r) May 2021
- s) June 2021
- t) July 2021
- u) August 2021
- v) September 2021
- w) October 2021
- x) November 2021
- y) December 2021
- z) January 2022
- aa) February 2022
- bb) March 2022
- cc) April 2022
- dd) May 2022
- ee) June 2022
- ff) July 2022





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- gg) August 2022
- hh) September 2022
- ii) October 2022
- ii) November 2022
- kk) December 2022

If self-identified long-hauler or told by a doctor in V13 or previously: Since you previously reported having had COVID or long COVID in this or another survey, it is important to us to collect this additional information to better understand the experiences of long COVID among participants. The details of your experience with COVID or long COVID are important to us. This section may take a little more time to complete.

- 66) If self-identified long-hauler or told by a doctor: How would you describe your long COVID when it was the absolute worst? (Source: C3, V11, responses modified in V13)
  - a) No impact on activities of daily living
  - b) Little impact on activities of daily living
  - c) Little to moderate impact on activities of daily living
  - d) Moderate impact on activities of daily living
  - e) Moderate to severe impact on activities of daily living
  - f) Severe impact on activities of daily living
- 67) If some impact on activities of daily living: You answered that during the worst period of time your long COVID had [insert response], what was the total duration of that worst period of time? Please answer even if ongoing, and tell us how long you have been feeling this way. (Source: C3, V11)
  - a) Less than a week
  - b) Between a week and a month
  - c) 1 month to 6 months
  - d) 6 months to a year
  - e) More than a year
- 68) If ever had COVID or long COVID: Since you had COVID, have you been diagnosed with any medical conditions? Please select all that apply. (Source: C3, V7, expanded list of conditions in V11)
  - a) Postural orthostatic tachycardia syndrome (POTS)
  - b) Hypertension / high blood pressure
  - c) Myalgic encephalomyelitis/chronic fatigue syndrome (ME / CFS)
  - d) Dysautonomia (disorder of the autonomic nervous system (ANS) function)
  - e) Any heart condition
  - f) Any lung or pulmonary condition
  - g) Seizures
  - h) Guillain-Barre Syndrome
  - i) Parkinson's disease
  - j) Alzheimer's disease
  - k) Blood clots





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- l) Depression
- m) Anxiety
- n) Migraines
- o) Abnormally elevated cholesterol or fats (lipids) in the blood (Dyslipidemia)
- p) Insomnia
- q) Traumatic brain injury
- r) Other mental health diagnosis: \_\_\_\_\_
- s) Anything else: \_\_\_\_\_
- t) I have not been diagnosed with any of the above conditions [*exclusive*]
- 69) *If ever had COVID or long COVID:* Compared to when you first got sick with COVID, how do you feel right now? (Source: C3, V4-V12)
  - a) Worse than I felt initially
  - b) About the same
  - c) Somewhat better
  - d) Much better, but not totally really recovered
  - e) Totally recovered

f) I did not mean to identify as a long hauler [*option shown only for those who self-identified or said they were told by a doctor that they had long COVID*]

g) Don't know / Not sure

If did not mean to identify as a long-hauler, skip to Q76.

70) *If selected "Totally recovered" and ever identified as a long-hauler:* The following question is about your experience with long-haul symptoms or long COVID.

How long did your symptoms last? (Source: C3, V11)

- a) Less than a week
- b) Between a week and a month
- c) 1 month to < 6 months
- d) 6 months to a year
- e) More than a year
- 71) If reported at least one vaccine dose and ever self-identified as long-hauler or told by a *doctor:* Do you think your long haul symptoms have improved since you were vaccinated? (Source: C3, V7-V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
  - d) Not applicable
- 72) If reported at least one booster and ever self-identified as long-hauler or told by a doctor: Do you think your long haul symptoms have improved since you were boosted? (Source: C3, V11-12)
  - a) Yes





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- b) No
- c) Don't know / Not sure
- d) Not applicable
- 73) If ever self-identified as long-hauler or told by a doctor: Have you tried any treatments for long-haul COVID symptoms? Please select all that apply and/or feel free to list any additional treatments that are not included. (Source: C3, V7-V12, question modified and additional options added in V11)
  - a) Symptoms eventually went away with time
  - b) Medication to reduce symptoms
  - c) Diet modifications
  - d) Physical therapy
  - e) Respiratory therapy (e.g. breathing exercises)
  - f) Respiratory assistance (e.g. inhaler, oxygen)
  - g) Occupational therapy
  - h) Monoclonal antibodies
  - i) Paxlovid
  - j) Molnupiravir
  - k) COVID-19 vaccination
  - I) Vitamins or other herbal supplements
  - m) Other \_\_\_
  - n) I didn't have symptoms [exclusive]
  - o) None of the above [exclusive]
- 74) *If yes to any resource:* Did you find [*prepopulate list of responses endorsed above*] helpful for reducing long-haul COVID symptoms? (Source: C3, V11-V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 75) *If ever self-identified as long-hauler:* Have you had difficulty finding a doctor to treat your long-haul COVID symptoms? (Source: C3, V7-V12)
  - a) Yes
  - b) No
  - c) Don't know/not sure

## Quality of Life

- 76) Since your **last survey** (*on* ADD *Qualtrics DD/Mon/YY*), how much difficulty do you have engaging in daily activities (or household responsibilities) because of physical, mental, or emotional problems? (Source: adapted from <u>BRFSS</u>; C3, V1-V12)
  - a) No difficulty
  - b) Some difficulty
  - c) A lot of difficulty
  - d) Don't know / Not sure





Under each heading, please select one response that best describes your health TODAY (Source: <u>Euro Qol 5D</u>; C3, V11)

- 77) Mobility
  - a) I have no problems in walking about
  - b) I have slight problems in walking about
  - c) I have moderate problems in walking about
  - d) I have severe problems in walking about
  - e) I am unable to walk about
- 78) Self-care
  - a) I have no problems washing or dressing myself
  - b) I have slight problems washing or dressing myself
  - c) I have moderate problems washing or dressing myself
  - d) I have severe problems washing or dressing myself
  - e) I am unable to wash or dress myself
- 79) Usual activities (e.g. work, study, housework, family or leisure activities)
  - a) I have no problems doing my usual activities
  - b) I have slight problems doing my usual activities
  - c) I have moderate problems doing my usual activities
  - d) I have severe problems doing my usual activities
  - e) I am unable to do my usual activities
- 80) Pain or discomfort
  - a) I have no pain or discomfort
  - b) I have slight pain or discomfort
  - c) I have moderate pain or discomfort
  - d) I have severe pain or discomfort
  - e) I have extreme pain or discomfort
- 81) Anxiety or depression
  - a) I am not anxious or depressed
  - b) I am slightly anxious or depressed
  - c) I am moderately anxious or depressed
  - d) I am severely anxious or depressed
  - e) I am extremely anxious or depressed
- 82) We would like to know how good or bad your health is TODAY. This scale is numbered from 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine. Select the number to indicate how your health is TODAY. (Source: <u>Euro Qol 5D</u>; C3, V11)

[Scale from 0 to 100]





The next set of questions is about fatigue.

83) Please select the extent to which you agree with the following statement. This refers to your usual way of life within **the last week**. (Source: <u>Fatigue Severity Scale</u>; C3, V11)

Scale: ["Strongly disagree (1)"; "disagree (2)"; "somewhat disagree (3)"; "neither disagree nor agree (4)"; "somewhat agree (5)"; "agree (6)"; "Strongly agree (7)"]

- a) My motivation is lower when I am fatigued
- b) Exercise brings on my fatigue
- c) I am easily fatigued
- d) Fatigue interferes with my physical functioning
- e) Fatigue causes frequent problems for me
- f) My fatigue prevents sustained physical functioning
- g) Fatigue interferes with carrying out certain duties and responsibilities
- h) Fatigue is among my most disabling symptoms
- i) Fatigue interferes with my work, family, or social life

The next few questions ask about difficulties in thinking or remembering that can make a big difference in everyday activities. This does not refer to occasionally forgetting your keys or the name of someone you recently met, which is normal. This refers to confusion or memory loss that is happening more often or getting worse, such as forgetting how to do things you've always done or forgetting things that you would normally know. We want to know how these difficulties impact you. (Source: <u>BRFSS</u>; C3, V11)

- 84) During the **past 12 months**, have you experienced confusion or memory loss that is happening more often or is getting worse?
  - a) Yes
  - b) No
  - c) Don't know / Not sure

#### If no, skip to Q90.

- 85) During the **past 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? Would you say it is...
  - a) Always
  - b) Usually
  - c) Sometimes
  - d) Rarely
  - e) Never
  - f) Don't know / Not sure





- 86) As a result of confusion or memory loss, how often do you need assistance with these dayto-day activities? Would you say it is...
  - a) Always
  - b) Usually
  - c) Sometimes
  - d) Rarely
  - e) Never
  - f) Don't know / Not sure
- 87) When you need help with these day-to-day activities, how often are you able to get the help that you need? Would you say it is...
  - a) Always
  - b) Usually
  - c) Sometimes
  - d) Rarely
  - e) Never
  - f) Don't know / Not sure
- 88) During the **past 12 months**, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities outside the home? Would you say it is...

IS...

- a) Always
- b) Usually
- c) Sometimes
- d) Rarely
- e) Never
- f) Don't know / Not sure
- 89) Have you or anyone else discussed your confusion or memory loss with a healthcare professional?
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 90) Would you say that in general your health is: (Source: <u>CDC's Healthy Days Measure</u>; C3, V2-V12)
  - a) Excellent
  - b) Very Good
  - c) Fair
  - d) Poor
- 91) Now thinking about your physical health, which includes physical illness and injury, for how many days during the **past 30 days** was your physical health <u>not good</u>? (Source: <u>CDC's</u> <u>Healthy Days Measure</u>; C3, V2-V12)
  - a) \_\_\_\_\_ Number of days from 1-30





- b) None
- c) Don't know / Not sure
- 92) Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the **past 30 days** was your mental health <u>not</u> good? (Source: <u>CDC's Healthy Days Measure</u>; C3, V2-V12)
  - a) \_\_\_\_\_ Number of days from 1-30
  - b) None
  - c) Don't know / Not sure
- 93) During the **past 30 days**, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work or recreation? (Source: <u>CDC's</u> <u>Healthy Days Measure</u>; C3, V2-V12)
  - a) \_\_\_\_\_ Number of days from 1-30
  - b) None
  - c) Don't know / Not sure
- 94) During the **past month (since** *ADD Qualtrics DD/Mon/YY***),** other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise? (Source: <u>BRFSS, 2019</u>; C3, V3-V12)
  - a) Yes
  - b) No
  - c) Don't know / Not sure
- 95) If yes or don't know to any physical activities or exercises: How many times per week or per month did you take part in this activity during the past month? (Source: BRFSS, 2019; C3, V3-V12)
  - a) \_\_\_\_ Times per week
  - b) \_\_\_\_ Times per month
  - c) Don't know / Not sure
- 96) If yes or don't know to any physical activities or exercises: And when you took part in this activity, for how many minutes or hours did you usually keep at it? (Source: BRFSS, 2019; C3, V3-V12)
  - a) \_\_\_\_ Number of hours
  - b) \_\_\_\_ Number of minutes
  - c) Don't know / Not sure

## Anxiety & Risk Perception

- 97) *If ever had COVID:* How worried are you about getting sick from COVID-19 **again**? Would you say: (Source: C3, V3-V12)
  - a) Not at all worried
  - b) Not too worried
  - c) Somewhat worried





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- d) Very worried
- 98) *If never indicated COVID diagnosis:* How worried are you about getting sick from COVID-19? Would you say: (Source: C3, V0-V12)
  - a) Not at all worried
  - b) Not too worried
  - c) Somewhat worried
  - d) Very worried
- 99) In the past month (since ADD Qualtrics DD/Mon/YY), how often have you been bothered by the following problems (Source: adapted from the GAD-7 and PHQ-8; C3, V0-12 for GAD and V1-V12 for PHQ-2 and V2-V12 for PHQ-8)

Have you been bothered by	Not at all	Several days	Over half the days	Nearly every day
Feeling nervous, anxious, or on edge				
Not being able to stop or control worrying				
Worrying too much about different things				
Trouble relaxing				
Being so restless that it's hard to sit still				
Becoming easily annoyed or irritable				
Feeling afraid as if something awful might				
happen				
Little interest or pleasure in doing things				
Feeling down, depressed or hopeless				
Trouble falling or staying asleep, or sleeping too				
much				
Feeling tired or having little energy				
Poor appetite or overeating				
Feeling bad about yourself - or that you are a				
failure or have let yourself or your family down				
Trouble concentrating on things, such as, reading				
the newspaper or watching television				
Moving or speaking so slowly that other people				
could have noticed? Or the opposite - being so				
fidgety or restless that you have been moving				
around a lot more than usual				

### Administrative

- 100) Would you like to receive the \$20 gift card incentive for your time participating in the survey?
  - a) Yes
  - b) No





### **End Survey**

Thank you for taking the time to complete this follow-up survey. You will hear from us in approximately three months with the next follow-up survey. In the interim, we may periodically reach out to invite you to participate in short surveys with only a few questions or any other studies you may be eligible for. A confirmation email with the details has also been sent to you. For resources related to mental health, substance use, violence, and food banks in your area, please visit our website, <a href="https://cunyisph.org/cunycovidfacts/">https://cunyisph.org/cunycovidfacts/</a>.

For up to date and accurate information about COVID-19, please visit our website, https://cunyisph.org/cunycovidfacts/ or visit CDC.gov.

For up to date and accurate information about the COVID-19 vaccine, please visit CDC. <u>https://www.cdc.gov/coronavirus/2019-ncov/vaccines/faq.html</u>

If you have any questions, reach us here: <a href="mailto:covid@sph.cuny.edu">covid@sph.cuny.edu</a>

# **Automated Response**

Thanks for completing this follow-up survey with the CHASING COVID Cohort study. We will email you a \$20 *Tremendous* gift card to the email address that you provided within 3 business days. As part of this longitudinal study on COVID, we can learn a lot from your experience and insights and appreciate your participation. The CHASING COVID Cohort study includes participants from all across the country.

If you have any questions about your participation in the study, or need to contact our team, email us at <u>covid@sph.cuny.edu</u> or call 917-740-8714.



