COVID-19 Participant Experience (COPE) Survey

What should I know before participating?

The *All of Us* Research Program is interested in understanding the changes in your experiences and health during the time of the coronavirus disease 2019 (COVID-19) pandemic. Help us learn more by completing this survey. Participating in this survey may help researchers around the world understand better the impact of COVID-19 during this challenging time. The *All of Us* Research Program will repeat this survey throughout the pandemic.

The questions in this survey may be sensitive and may cause worry or anxiety. Remember your privacy is very important to us. Your name and identity will be separated from your answers before information is shared with approved researchers.

No one will monitor your answers in real time. But, based on your answers, the system may suggest free phone and text resources to help you.

You can choose not to answer any question at any time. This survey will take approximately 8 to 10 minutes to complete.

- Yes, I still want to take the survey. No, I do not want to take the survey.
- Yes, I would like to take the survey at a later time.
- No, I do not want to take the survey.

Please answer each question as honestly as possible. We are looking for your own answers, and not what you think your doctors, family, or friends want you to say.

Don't feel like you must spend a long time over each question. The first answer that comes to you is usually the best one. If you aren't sure how to answer a question, choose the best answer from the options given. Some questions also let you say if you don't know an answer or would rather not answer. Some of the questions may be sensitive. You can choose not to answer any question.

_____
Social Distancing Experiences

The following questions ask about your experiences with social distancing and other risk-prevention measures such as wearing a face mask or face covering when around other people not in your home. Social distancing means keeping at least six feet of space between yourself and other people outside of your home.
_____

In the past month, have recommendations for socially distancing caused stress for you?[1]
- A lot
- Somewhat
- A little
- Not at all

Thinking about your social habits, in the last 5 days:
I have stayed home all day, including not going to a supermarket or any other place of business. I went outside but otherwise stayed at home.[2]
- None of the days (0 days)
- A few days (1-2 days)
- Most days (3-4 days)
- Every day

Branching Logic: when "None of the days (0 days)," "A few days (1-2 days)," or "Most days (3-4 days)" selected, then:

Thinking about your current social habits, in the last 5 days:
I have gone to my workplace or volunteer site that is outside my home.[2]
- None of the days (0 days)
- A few days (1-2 days)
- Most days (3-4 days)
- Every day
  Branching Logic: when "A few days (1-2 days)," "Most days (3-4 days)," or "Every day" selected, then:
  How often did you wear a face mask or face covering?[2]
  - Never
  - Sometimes
  - Most of the time
  - Always
  - Not applicable

Thinking about your current social habits, in the last 5 days:
I have attended social gatherings of LESS than 10 people.[2]

- ○ None of the days (0 days)
- ○ A few days (1-2 days)
- ○ Most days (3-4 days)
- ○ Every day
  Branching Logic: when "A few days (1-2 days)," "Most days (3-4 days)," or "Every day" selected, then:

  How often did you wear a face mask or face covering?[2]
    - ▪ Never
    - ▪ Sometimes
    - ▪ Most of the time
    - ▪ Always
    - ▪ Not applicable

Thinking about your current social habits, in the last 5 days:
I have attended social gatherings of MORE than 10 people but LESS than 50 people. In the next question, we will ask about gatherings greater than 50 people.[2]

- ● None of the days (0 days)
- ● A few days (1-2 days)
- ● Most days (3-4 days)
- ● Every day
  Branching Logic: when "A few days (1-2 days)," "Most days (3-4 days)," or "Every day" selected, then:

  How often did you wear a face mask or face covering?[2]
    - ▪ Never
    - ▪ Sometimes
    - ▪ Most of the time
    - ▪ Always
    - ▪ Not applicable

In the last 5 days, I have attended social gatherings of MORE than 50 people.[2]

- ● None of the days (0 days)
- ● A few days (1-2 days)
- ● Most days (3-4 days)
- ● Every day
  Branching Logic: when "A few days (1-2 days)," "Most days (3-4 days)," or "Every day" selected, then:

  What was the purpose of the large gathering?[2]
    - ❏ Family gathering (wedding, graduation, funeral etc.)
    - ❏ Religious/spiritual gathering
    - ❏ Community events (concerts, sporting events etc.)

❏ Political rally/protest
❏ Other
Please specify.[2]

_____

How often did you wear a face mask or face covering?[2]
- Never
- Sometimes
- Most of the time
- Always
- Not applicable

Thinking about your current social habits, in the last 5 days:
I have gone on shopping trips or outings that were "just for fun."[2]
- ○ None of the days (0 days)
- ○ A few days (1-2 days)
- ○ Most days (3-4 days)
- ○ Every day

   Branching Logic: when "A few days (1-2 days)," "Most days (3-4 days)," or "Every day" selected, then:

   How often did you wear a face mask or face covering?[2]
   - Never
   - Sometimes
   - Most of the time
   - Always
   - Not applicable

Thinking about your current social habits, in the last 5 days:
I have visited nursing homes or long-term care facilities (outside of work duties).[2]
- ○ None of the days (0 days)
- ○ A few days (1-2 days)
- ○ Most days (3-4 days)
- ○ Every day

   Branching Logic: when "A few days (1-2 days)," "Most days (3-4 days)," or "Every day" selected, then:

   How often did you wear a face mask or face covering?[2]
   - Never
   - Sometimes
   - Most of the time
   - Always
   - Not applicable

Thinking about your current social habits, in the last 5 days:
I have been in close contact with someone who is in a risk group for COVID-19 (adults age 50+, people with chronic medical conditions like heart, lung, liver, or kidney disease, diabetes, high blood pressure, or a suppressed immune system). This includes someone inside or outside of your home.[2]

- None of the days (0 days)
- A few days (1-2 days)
- Most days (3-4 days)
- Every day
- I don't know

Thinking about these activities in the last 5 days, my social interaction with people outside my home was[2]

- A lot less than before COVID-19
- Somewhat less than before COVID-19
- About the same as before COVID-19
- More than before COVID-19
- A lot more than before COVID-19

How often in the past month were you doing the recommended pandemic hygiene, like washing hands frequently, avoiding touching your face, covering coughs, wearing a mask, and avoiding frequently touched surfaces in public places?[2]

- All of the time
- Most of the time
- Sometimes
- Rarely

_____

COVID-19 Related Symptoms & Treatment

The next questions ask about your experience with COVID-19 or flu-like symptoms.

_____

In the past month, have you been sick for more than one day with a new illness related to COVID-19 or flu-like symptoms?[1]

- Yes

  Branching Logic: when "Yes" selected, then:

  Approximate date of onset[1]

  _____

  Which of the following symptoms did you have? (Select all that apply)[1]
  - ❏ A fever/feverish
  - ❏ Chills or shivers (feeling too cold)
  - ❏ Unusual fatigue
  - ❏ Unusually strong muscle pains/aches

- ❏ Skipping meals
- ❏ Persistent cough (coughing a lot for more than an hour, or 3 or more coughing episodes in 24 hours)?
- ❏ Sore or painful throat
- ❏ Difficulty breathing or shortness of breath
- ❏ Unusually hoarse voice
- ❏ Unusual chest pain or tightness in your chest
- ❏ Runny or stuffy nose
- ❏ Loss of smell or taste
- ❏ Unusual eye soreness or discomfort (e.g., light sensitivity, pink eye, or excessive tears)
- ❏ Raised, red, itchy, welts on the skin or sudden swelling of the face or lips
- ❏ Headache
- ❏ Dizziness or light-headedness
- ❏ Confusion, disorientation, or drowsiness
- ❏ Unusual abdominal pain or stomachache
- ❏ Diarrhea
- ❏ Nausea
- ❏ Red/purple sores or blisters on your feet, including your toes
- ❏ None of the above

Branching Logic: when "Yes" selected, then:

Are there other important symptoms you want to share with us?[1]
- ○ Yes
  Branching Logic: when "Yes" selected, then:
  Please specify:[1]
  _____
- ○ No

What medical care did you receive? Please select all that apply.[3]
- ❏ I did not speak with a healthcare professional and recovered at home
- ❏ I spoke with a healthcare professional and wasn't admitted to the hospital
- ❏ I was admitted to the hospital for at least one night
  Branching Logic: when "I was admitted to the hospital for at least one night" selected, then:
  What breathing treatment did you receive? Please select all that apply.[3]
  - ❏ I did not receive breathing treatment
  - ❏ Oxygen (through an oxygen mask or tube under my nose, no pressure applied)
  - ❏ Oxygen (through an oxygen mask, which pushes oxygen into your lungs)

❏ A breathing machine (ventilator) with a tube down my throat
❏ Other breathing treatment
Branching Logic: when "Other breathing treatment" selected, then:
What other breathing treatment did you receive? Please specify:[3]
_____

● No

Have you EVER been near someone that you know, or suspect, had COVID-19 (such as co-workers, family members, or others)? Select all that apply.[3]
❏ Yes, known COVID-19
❏ Yes, suspected COVID-19
❏ Not that I know of

Do you know personally someone who has died from COVID-19?[4]
● Yes
Branching Logic: when "Yes" selected, then:
We are sorry to hear about your loss. If you are willing, please share with us your relationship with who has died. Please select all that apply.[4]
❏ Spouse, partner, boyfriend, girlfriend
❏ Parent
❏ Grandparent
❏ Child
❏ Sibling (brother or sister)
❏ Co-worker
❏ Friend
❏ Neighbor
❏ Other
Branching Logic: when "Other" selected, then:
Please specify.[4]
_____

❏ Prefer not to answer
● No

Do you think you have had COVID-19?[3]
● No
● Yes
● Maybe
Branching Logic: when "Yes" or "Maybe" selected, then:
When did your symptoms begin?[3]
○ January or February 2020
○ March or April 2020
○ July or August 2020
○ September or October 2020

_____

COVID-19 Related Testing

The next questions ask about your experiences with testing for COVID-19 in the past month. You will have the chance to share how many tests you've had, if any, your reasons for getting tested, challenges with testing, and of course, your test results.

_____

Were you tested for COVID-19 in the past month?[1] & [3]
- No
- No, I tried and was unable to be tested
- Yes

Branching Logic: when "No, I tried and was unable to be tested" or "Yes" selected, then:

Did you have difficulty with the following aspects of getting a test? Please select all that apply.[1] & [3]

❏ Finding a doctor (I didn't know where I could get the test)
❏ Getting an appointment at a convenient time
❏ Affording the test
❏ I don't have insurance
❏ My insurance doesn't cover the test
❏ The insurance co-pays/deductibles were too high
❏ Wait time for an available appointment
❏ Taking time off from work
❏ I did not have transportation
❏ I did not have childcare
❏ The test was not available at the doctor's office, clinic, or hospital
❏ I did not meet criteria to be tested
❏ I did not have any difficulty getting a test
❏ Other
   Please specify.[1] & [3]

   _____

Branching Logic: when "Yes" selected, then:

How many times have you been you tested?[1] & [3]

   _____

Was the test(s) for COVID-19 positive?[1] & [3]
- ○ Yes
- ○ Yes, some
- ○ No, all were negative or inconclusive
- ○ Waiting for results for at least some tests
- ○ Unknown

How were you tested? Select all that apply.[1] & [3]
- ❏ Nasal swab
- ❏ Throat Swab
- ❏ Blood Sample

What was your reason(s) for testing? Please select all that apply.[1] & [3]
- ❏ I was experiencing COVID-19 symptoms
- ❏ I needed to get a test for work or school
- ❏ I needed to get a test in order to get other health care services
- ❏ I belong to a high-risk population (e.g., have an underlying health condition)
- ❏ I was in contact with someone who had or was suspected to have COVID-19
- ❏ I had to comply with travel mandates (e.g., crossing state lines, international travel)
- ❏ I had no symptoms, but testing was available
- ❏ Other
  Please specify. [1] & [3]

  _____

- ● I don't know

_____

Vaccine Perceptions

The next questions ask you about your **perception of** vaccination **against influenza (**"the flu") or COVID-19.

Did you receive the flu vaccination in the past month?[5]
- ● Yes
- ● No
  Branching Logic: when "No" selected, then:
  Do you plan to get the flu vaccine this season?[5]
  - o Yes
  - o No
  - o I'm not sure yet
  - o No, I received it more than a month ago

When a COVID-19 vaccine is available, how likely are you to want to receive vaccination?[6]
- ● Very likely
- ● Likely
- ● I do not know yet
- ● Unlikely
- ● Very unlikely
  Branching Logic: when "Likely," "I do not know yet," "Unlikely," or "Very unlikely" selected, then:

What factors might make you less likely to get the vaccine? Please select all that apply.[6]
- ❏ I will not get/am never sick.
- ❏ It is just a virus/not fatal/not necessary.
- ❏ I never get vaccinated.
- ❏ I do not trust the vaccine.
- ❏ I do not want to pay for it.
- ❏ My region is not a high risk area.
- ❏ Vaccination location is not convenient.
- ❏ It depends on the risks/adverse events.
- ❏ Vaccination is worse than being ill.
- ❏ I have not thought about it yet.
- ❏ I am not in a risk group with underlying conditions.
- ❏ I need more information first.
- ❏ It will not help.
- ❏ I have already had COVID-19
- ❏ I am going to let others getting it first (herd immunity)
- ❏ Do not know yet
- ❏ Other
  Please specify.[6]

  _____

_____

COVID-19 Related Impact

The following 8 questions ask about the social and financial impact of COVID-19 on your life during the past month. Please choose the answer that best applies to your situation.

Do you have a child(ren) that are currently enrolled in childcare centers, schools, or colleges?[7]
- ● Yes
  Branching Logic: when "Yes" selected, then:
  In the past month, did you have a child(ren) enrolled in childcare centers, schools, or colleges that are learning remotely because of COVID-19?[7]
  - ○ Yes, at home full time
  - ○ Yes, at home part of the time
  - ○ Yes, but not at home
  - ○ No, at care, school, or college full time
    Branching Logic: when "Yes, at home full time" or "Yes, at home part of the time" selected, then:

Compared with when they were in person at school or a childcare center, how much time are you spending on care and supervision of your children?[7]
- ▪ Much more
- ▪ A little more
- ▪ About the same
- ▪ A little less
- ▪ Much less

Compared with when they were in in person school or a childcare center, how much time are you spending on helping your children with learning activities provided by their schools or childcare center?[7]
- ▪ Much more
- ▪ A little more
- ▪ About the same
- ▪ A little less
- ▪ Much less

- ● No

What is your current employment status? Please select 1 or more of these categories.[8]
- ❏ Employed for wages (part- time or full-time)
- ❏ Self-employed
- ❏ Out of work for 1 year or more
- ❏ Out of work for less than 1 year
- ❏ A homemaker
- ❏ A student
- ❏ Retired
- ❏ Unable to work (disabled)
- ❏ Prefer not to answer

How has the COVID-19 outbreak affected you in the past month? Please select all that apply.[1]
- ❏ Worked remotely or from home more than you usually do
- ❏ Worked more hours than usual
- ❏ Worked reduced hours
- ❏ Was not able to work due to COVID-19 related illness
- ❏ I became unemployed
- ❏ Had difficulty arranging for childcare
- ❏ Incurred increased costs for childcare expenses
- ❏ Worked with children at home with me
- ❏ Income or pay has been reduced
- ❏ Not paid at all
- ❏ Had serious financial problems
- ❏ None of the above

Not including yourself, how many other people live at home with you?[8]

_____

Branching Logic: when 1 or more is entered in response, then:
Think of other people who live with you. How many are under the age of 18 years?[8]

_____

What type of household do you live in?[9]
- Studio
- One-bedroom apartment
- Two-bedroom apartment
- Three-bedroom (or more) apartment
- Townhouse
- Free-standing house
- Nursing home, or rehab facility
- Homeless
- Other
  Branching Logic: when "Other" selected, then:
  Please specify.[8]
  _____
- Prefer not to answer

In the past month, have you experienced the following as a result of COVID-19? Select all that apply.[1]
- ❏ Not enough money to pay rent
- ❏ Not enough money to pay for gas
- ❏ Not enough money to pay for food
- ❏ Not enough money to pay for medications
- ❏ Did not have a regular place to sleep or stay
- ❏ None of the above

In the past month, have the following behaviors increased in your household? Select all that apply.[1]
- ❏ Interpersonal conflict with family members or loved ones
- ❏ Snapping at or yelling at family members
- ❏ Interpersonal conflict with friends or coworkers
- ❏ None of the above

In the past month, to cope with social distancing and isolation, are you doing any of the following? Please select all that apply.[1]

- ❏ Taking breaks from watching, reading, or listening to news stories, including social media
- ❏ Increasing watching, reading, or listening to news stories, including social media
- ❏ Taking care of your body, such as taking deep breaths, stretching, or meditating
- ❏ Engaging in healthy behaviors like trying to eat healthy, well-balanced meals, exercising regularly, getting plenty of sleep, or avoiding alcohol and drugs
- ❏ Making time to relax
- ❏ Connecting with others, including talking with people you trust about your concerns and how you are feeling
- ❏ Contacting a healthcare provider
- ❏ Delayed medical care for conditions other than COVID-19
- ❏ Smoking more cigarettes or vaping more
- ❏ Drinking alcohol
- ❏ Using prescription drugs (like valium, etc.)
- ❏ Using non-prescription drugs
- ❏ Using cannabis or marijuana
- ❏ Eating high fat or sugary foods
- ❏ Cutting or self-injury
- ❏ Over exercise
- ❏ Eating more food than usual
- ❏ Eating less food than usual
- ❏ None of the above

_____

Anxiety and Mood

In the next questions, you have an opportunity to share with us how you have been feeling in the past two weeks.

Over the last 2 weeks, how often have you been bothered by the following problem:
Feeling nervous, anxious, or on edge[10]

- ● Not at all
- ● Several days
- ● More than half the days
- ● Nearly every day

**Over the last 2 weeks, how often have you been bothered by the following problem:
Not being able to stop or control worrying**[10]
- Not at all
- Several days
- More than half the days
- Nearly every day

**Over the last 2 weeks, how often have you been bothered by the following problem:
Little interest or pleasure in doing things**[11]
- Not at all
- Several days
- More than half the days
- Nearly every day

**Over the last 2 weeks, how often have you been bothered by the following problem:
Feeling down, depressed, or hopeless**[11]
- Not at all
- Several days
- More than half the days
- Nearly every day

**Over the last 2 weeks, how often have you been bothered by the following problem:
Thoughts that you would be better off dead or of hurting yourself in some way**[11]
- Not at all
- Several days
- More than half the days
- Nearly every day

Branching Logic: Pop-up appears when "Several days," "More than half the days," or "Nearly every day" is selected:

If this is how you feel, think about getting help. There are people who can help 24/7. Text the Crisis Text Line at 741741 or Call the National Suicide Prevention Lifeline at 1-800-273-8255.

Health Basics

The next questions ask about circumstances that affect your general health which might change over time.

If you know it, what is your blood group?[12]
- A
- B
- AB
- O
- I don't know my blood group for certain
- Prefer not to say

Are you currently pregnant?[13]
- No
- Yes
  Branching Logic: when "Yes" selected, then:
  Are you currently receiving prenatal care?[5]
  - Yes
    Branching Logic: when "Yes" selected, then:
    How has your prenatal care changed since COVID-19? (If you became pregnant during COVID-19, compare to any prior pregnancies if relevant.) Select all that apply.[5]
    - ❏ It is the same as before COVID-19
    - ❏ Some visits are virtual (over the phone or computer)
    - ❏ The visits are less frequent
    - ❏ I have to go to the visits alone
    - ❏ I became pregnant during COVID-19 and visits are similar
    - ❏ Prefer not to answer
    - ❏ Other
      Please specify.[5]

      _____
  - No
  - Prefer not to answer
- Not sure
- Prefer not to answer
  Implementation note: this question does not appear for participants whose biological sex is not "Female."

Are you covered by health insurance or some other kind of health care plan?[14]

- Yes

  Branching Logic: when "Yes" selected, then:

  Are you currently covered by any of the following types of health insurance or health care plans? Select all that apply.[14]

  - ❏ Insurance purchased directly from an insurance company (by you or another family member)
  - ❏ Insurance through a current or former employer or union (by you or another family member)
  - ❏ Medicare, for people 65 and older or people with certain disabilities
  - ❏ Medicaid, Medical Assistance, or any kind of government-assistance plan for those with low incomes or disability
  - ❏ TRICARE or other military health care
  - ❏ Veterans Affairs (VA) (including those who have ever used or enrolled for VA health care)
  - ❏ Indian Health Service
  - ❏ Any other type of health insurance or health coverage plan

    Branching Logic: when "Any other type of health insurance or health coverage plan" selected, then:

    Please specify.[14]

    _____

  - ❏ I don't have health insurance, self-pay
- No
- Don't know
- Prefer not to answer

To learn more about COVID-19: https://www.cdc.gov

If you or someone you care about needs help:

Disaster Distress Helpline: 1-800-985-5990 (press 2 for Spanish), or text TalkWithUs for English or Hablanos for Spanish to 66746. Spanish speakers from Puerto Rico can text Hablanos to 1-787-339-2663.

National Suicide Prevention Lifeline: 1-800-273-TALK (8255) for English, 1-888-628-9454 for Spanish, or Lifeline Crisis Chat. https://suicidepreventionlifeline.org/talk-to-someone-now/

National Domestic Violence Hotline: 1-800-799-7233 or text LOVEIS to 22522

National Child Abuse Hotline: 1-800-4AChild (1-800-422-4453) or text 1-800-422-4453

National Sexual Assault Hotline: 1-800-656-HOPE (4673) or **Online Chat**

The Eldercare Locator: 1-800-677-1116 **TTY Instructions**

Veteran's Crisis Line: 1-800-273-TALK (8255) or **Crisis Chat** or text: 8388255

NIMH Getting Help page: https://www.nimh.nih.gov/health/find-help/index.shtml

For more information on mental health topics and research:
https://www.nimh.nih.gov/health/index.shtml

Thank you for answering these questions. Providing this information will help researchers better understand experience and health during a health crisis that is affecting the world. Your privacy is very important to us. Your name and identity will be separated from your answers before information is shared with approved researchers. The information is used for research purposes only and will not be shared with law enforcement.

Sources

[1] CDC/NIH Common Data Element Bank
[2] Michigan COVID-19 Social Distancing Survey
[3] COronavirus Pandemic Epidemiology (COPE) Consortium Tool
[4] Nurses' Health Study COVID-19 supplement
[5] Developed for *All of Us* - COPE surveys
[6] Dutch Mexican Flu Study
[7] RAND American Life Panel
[8] Developed for *All of Us* - Basics
[9] National Health Care for the Homeless Council (NHCHC)
[10] GAD-7
[11] PHQ-9
[12] C-19 CORSET app
[13] Developed for *All of Us* - Overall Health
[14] National Health and Nutrition Examination Survey (NHANES)