

Things to note:

- The common survey items have an overall Flesch-Kincaid reading level of 7.2.
- Headers, source information, and notes are for internal purposes only and should not be included in the participant survey.
- These items are designed to be administered on paper or by web. Items will need to be modified if administered by telephone.
- For web survey administration, RTI recommends randomizing the response options for the grids (unless the order of the responses matter [e.g., Question 1]) and select all that apply questions.
- RTI sent the common survey items for Spanish translation on 11/11/20. This translation should be completed within 2 to 3 business days. The translation will be checked by individuals from the Work Group and Steering Committee.
- RTI will develop and provide the CEAL Research Teams with a codebook to ensure consistency in coding.
- The items are organized into two sections. The first includes core survey items that all 11 CEAL Research Teams will include in their surveys. This includes items on:
 - COVID-19 Prevention (4 items)
 - COVID-19 Clinical Trials (6 items)
 - Social Determinants of Health and Demographics (17 items)
- The second section includes 15 optional survey items that the CEAL Research Teams can draw from, if desired.
- CEAL Research Teams are able to use their own comparable demographic items in their ongoing longitudinal surveys, when appropriate.

Thank you,

CEAL TASC

CEAL Common Survey Items: Modules on COVID-19 Prevention, COVID-19 Clinical Trials, and Social Determinants and Demographics

CEAL Objectives and Research Questions

Objective 1: To conduct urgent community-engaged research and outreach focused on COVID-19 awareness and education to address widespread misinformation about COVID-19 and promote an evidence-based response to the disease.

- **Research Question 1:** Who are the trusted sources of information about COVID-19? (Q4)
- **Research Question 2:** Did CEAL increase intentions to get a COVID-19 vaccine? (Q3)
- **Research Question 3:** Did CEAL increase other COVID-19 prevention behaviors? (Q1, Q2)

Objective 2: To promote and facilitate inclusion of diverse racial and ethnic populations in COVID-19 clinical trials (prevention, vaccine, therapeutics), reflective of the populations disproportionately affected by the pandemic.

- **Research Question 1:** Did CEAL increase awareness and knowledge of COVID-19 clinical trials? (Q6, Q7)
- **Research Question 2:** Did CEAL reduce mistrust around participating in COVID-19 clinical trials? (Q10)
- **Research Question 3:** Did CEAL increase intentions and willingness to participate or self-reported participation in COVID-19 clinical trials? (Q5, Q8, Q9)

CORE SURVEY ITEMS

COVID-19 Prevention

Coronavirus Disease 2019 (COVID-19) is a disease caused by the new coronavirus. The first set of questions asks what you think about COVID-19 and how to stay safe from COVID-19.

COVID-19 Prevention Behaviors

Q1. In the past 7 days, how often have you chosen to do each of the following when in public to keep yourself and others safe from COVID-19? *(Do not include things you were required to do, such as wear a mask while visiting a store. Select one response for each row.)*

	All of the time	Very often	Some of the time	Never
Wore a face covering or mask				
Washed my hands with soap or used hand sanitizer several times per day				
Stayed at least 6 feet away from other people who are not from my household				

Source: Adapted for CEAL Program from Center for Economic and Social Research Understanding America Study Coronavirus Tracking Survey. <https://www.phenxtoolkit.org/covid19/source>.

Note: Modified for plain language, clarified “when in public,” reduced from 16 items to 2 items, added one item, “Stayed at least 6 feet away from other people who are not from my household,” and modified response options from yes/no.

COVID-19 Testing Behaviors

Q2. Have you ever been tested for COVID-19?

- Yes
- No

Source: Adapted for CEAL Program from John Hopkins University COVID-19 Community Response Survey. <https://www.phenxtoolkit.org/covid19/source>.

Intentions to Get a COVID-19 Vaccine

The next question asks about a COVID-19 vaccine. A vaccine is a substance that helps protect against certain diseases.

Q3. How likely are you to get an approved COVID-19 vaccine when it becomes available?

Not at all likely						Very Likely
1	2	3	4	5	6	7

Source: Adapted for CEAL Program from DMACS COVID-19 Survey.

<https://detroiturvey.umich.edu/covid-19-survey-and-resources/>.

Note: Modified from “government-approved” to “approved” and changed response options.

Trusted Sources of Information about COVID-19

Q4. How much do you trust each of these sources to provide correct information about COVID-19? (Select one response for each row.)

	Not at all	A little	A great deal	Don't Know
Your doctor or health care provider				
Your faith leader				
Your close friends and members of your family				
People you go to work or class with or other people you know				
News on the radio, TV, online, or in newspapers				
Your contacts on social media				
The U.S. government				
The U.S. Coronavirus Task Force				
[Sites can add other federal, state, or local sources of information]				

Source: Adapted for CEAL Program from DMACS COVID-19 Survey.

<https://detroiturvey.umich.edu/covid-19-survey-and-resources/>.

Note: Modified for plain language. Reduced from 10 items to 5 items. Added items for “your faith leader,” “The U.S. government,” and “The U.S. Coronavirus Task Force.” Added a “Don’t Know” response option.

COVID-19 Clinical Trials

Now we are going to ask you some questions about COVID-19 clinical trials.

A **clinical trial** is a kind of research study. Clinical trials study if treatments or vaccines are safe for people and if they work like they are supposed to.

Right now, clinical trials are being done across the U.S. to see if new treatments and vaccines for COVID-19 work to keep people healthy.

COVID-19 Clinical Trial Registration or Enrollment Behaviors

Q5. Have you ever signed up for a COVID-19 clinical trial?

[Programming Note: Can select both yes options, but if select no, cannot select yes options.]

- Yes, I signed up for a clinical trial for a COVID-19 vaccine. [\[GO TO Q10\]](#)
- Yes, I signed up for a clinical trial for a COVID-19 treatment. [\[GO TO Q10\]](#)
- No, I have never signed up for a COVID-19 clinical trial. [\[GO TO Q6\]](#)

Source: Developed for CEAL Program by TASC.

Self-Reported Awareness and Knowledge about COVID-19 Clinical Trials

Q6. Are you aware of COVID-19 clinical trials that are being done?

[Programming Note: Can select both yes options, but if select no or not sure, cannot select yes options.]

- Yes, clinical trials for COVID-19 vaccines [\[GO TO Q7\]](#)
- Yes, clinical trials for COVID-19 treatments [\[GO TO Q7\]](#)
- No [\[GO TO Q8\]](#)
- Not sure [\[GO TO Q8\]](#)

Q7. Do you know what to do to sign up for a COVID-19 clinical trial in your area?

- Yes
- No
- Not sure

Source: Developed for CEAL Program by TASC.

Willingness and Intentions to Register or Enroll in a COVID-19 Clinical Trial

We have a few more questions about COVID-19 clinical trials.

Again, a **clinical trial** is a kind of research study. Clinical trials study if treatments or vaccines are safe for people and if they work like they are supposed to.

Right now, clinical trials are being done across the U.S. to see if new treatments and vaccines for COVID-19 work to keep people healthy.

Q8. How willing are you to sign up for a clinical trial for a COVID-19 vaccine?

Not at all willing						Very willing
1	2	3	4	5	6	7

Source: Developed for CEAL Program by TASC.

Q9. How likely are you to sign up for a clinical trial for a COVID-19 vaccine?

Not at all likely						Very Likely
1	2	3	4	5	6	7

Source: Developed for CEAL Program by TASC.

Trust Regarding COVID-19 Clinical Trials

Q10. Below are sources of information of COVID-19 clinical trials. How much do you trust each of these sources to give correct information? (Select one response for each row.)

	A great deal	A fair amount	Not very much	None at all	No opinion
The U.S. government					
Your doctor or health care provider					
Your local health care clinic or hospital					
University hospitals					
Companies that make drugs for medical use					
People who do research					

Source: Developed for CEAL Program by TASC.

Social Determinants of Health and Demographics

The next set of questions asks about you and your household.

Access to Health Services

Q11. When was the last time you saw a doctor or other health care professional for a physical or regular check-up? Do not include visits when you were sick.

- Never
- Within the past 12 months/1 year
- 1 to 2 years ago
- 3 to 4 years ago
- 5 to 9 years ago
- 10 years ago or more

Source: Adapted for CEAL Program from PhenX Toolkit Social Determinants of Health Core Collection. <https://www.phenxtoolkit.org/protocols/view/270101>.

Note: Modified for plain language and to specify “regular” check-up.

Q12. Is there a place that you usually go when you are sick?

- Yes [\[GO TO Q13\]](#)
- No [\[GO TO Q14\]](#)
- Don't Know [\[GO TO Q14\]](#)

Source: DMACS COVID19 Survey. <https://detroitssurvey.umich.edu/covid-19-survey-and-resources/>.

Q13. What kind of place do you go most often for medical care?

- Clinic or health center
- Family doctor
- Hospital ER
- Urgent care clinic at a hospital
- Urgent care clinic not at a hospital
- Retail Center (for example, in a drug store)
- Some other place
- There is no one place I go to most often for medical care

- [We encourage sites to add additional response options as needed]

Source: Adapted for CEAL Program from DMACS COVID-19 Survey.

<https://detroiturvey.umich.edu/covid-19-survey-and-resources/>.

Q14. Do you have any kind of health insurance or health care plan?

This includes health insurance you get from your job or school, that you buy yourself, and programs like Medicare and Medicaid.

- Yes [\[GO TO 15\]](#)
- No
 - [If No, ask:] Did you lose health care coverage because of the COVID-19 pandemic? [\[GO TO Q16\]](#)
 - Yes
 - No
- Don't Know [\[GO TO Q16\]](#)

Q15. What is the primary kind of health insurance or health care plan that you have now?

- Private health insurance through a job or school
- Insurance bought through a government exchange such as healthcare.gov
- Insurance bought from a health plan or company
- Medicare
- Medi-Gap
- Medicaid
- CHIP or kid's state insurance
- Military health care
- Indian Health Service
- [\[Sites can add other response options as needed\]](#)
- Other _____
- Don't know

Source: Adapted for CEAL Program from DMACS COVID-19 Survey.

<https://detroiturvey.umich.edu/covid-19-survey-and-resources/>.

Q16. The COVID-19 pandemic may cause challenges for some people, whether they get COVID-19 or not. In the past month have you or your family experienced any of the below challenges? (Select one response for each row.)

	No, this is not a challenge	Yes, this is a minor challenge	Yes, this is a major challenge
Getting the health care I need (including for mental health)			
Having a place to live			
Getting enough food to eat			
Having clean water to drink			
Getting the medicine I need			
Getting to where I need to go			
[sites can add other challenges]			

Source: Adapted for CEAL Program from DMACS COVID-19 Survey.
<https://detroiturvey.umich.edu/covid-19-survey-and-resources/>.

Note: Modified for plain language and reduced from 7 to 5 items. Modified to ask about “getting enough food to eat” and “having clean water to drink” separately (vs. “Getting food, water, and other household supplies”).

Spoken Languages

Q17. Do you speak a language other than English at home?

- Yes
 - o What language(s)? _____ [recommend sites create list of languages relevant to their area to avoid coding of responses]
- No
- Prefer not to answer

Source: Adapted for CEAL from the 2020 American Community Survey.
<https://www2.census.gov/programs-surveys/acs/methodology/questionnaires/2020/quest20.pdf>.

Reading Ability

Q18. How often do you need someone to help you read written information from your doctor or drug store?

- Never
- Rarely
- Sometimes
- Often
- Always

Source: Adapted for CEAL program from Morris, N.S., MacLean, C.D., Chew, L.D., & Littenberg, B. (2006). The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. *BMC Family Practice* 7, 21.
<https://doi.org/10.1186/1471-2296-7-21>

Note: Modified for plain language.

Demographics

Q19. What month and year were you born?

Month: _____
Year: _____

Source: Provided by CEAL Assessment and Evaluation Work Group.

Q20. What is your gender?

- Man
- Woman
- Transgender female or trans woman
- Transgender male or trans man
- Nonbinary, genderqueer, or genderfluid
- I would describe my gender as: _____
- Prefer not to answer

Source: PhenX Toolkit; Harvard T.H. Chan School of Public Health Social Risk Factors for COVID-19 Exposure Questionnaire.
<https://mfr.osf.io/render?url=https://osf.io/bves6/?direct%26mode=render%26action=download%26mode=render>.

Q21. Which of the following best describes how you think of yourself?

- Gay
- Lesbian
- Straight (that is, not gay or lesbian)
- Bisexual
- Other
- Prefer not to answer

Source: PhenX Toolkit; All of Us Research Program Participant Provided Information (PPI) Version December 17, 2018. <https://www.phenxtoolkit.org/protocols/view/11701>.

Q22. Are you Hispanic or Latino? [sites to include their own examples of countries, if desired]

- No
- Yes
- Prefer not to answer

Source: Adapted for CEAL from United States Census 2020 Questionnaire. <https://www.phenxtoolkit.org/protocols/view/11901>.

Note: Modified for plain language and to be a yes/no question (vs. asking respondents to specify origin).

Q23. Which of the following best describes your race? Please select all that apply.

- White
- Black or African-American
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- Prefer not to answer

Source: Modified for CEAL from DMACS COVID-19 Survey. <https://detroiturvey.umich.edu/covid-19-survey-and-resources/>.

Q24. What is the highest degree or level of school you have completed?

- Less than high school
- Some high school
- High school graduate or GED

- Associate's or technical degree (for example, AA or AS)
- Bachelor's degree (for example BA, BS, or AB)
- Graduate degree (for example MA, PhD)
- Prefer not to answer

Source: PhenX Toolkit; Harvard T.H. Chan School of Public Health Social Risk Factors for COVID-19 Exposure Questionnaire.
<https://mfr.osf.io/render?url=https://osf.io/bves6/?direct%26mode=render%26action=download%26mode=render>.

Note: Modified to clarify that these are highest degrees/levels completed (vs. "in progress").

Q25. In 2019, what was your total household income before taxes?

- Less than \$15,000
- \$15,000 – \$19,999
- \$20,000 – \$24,999
- \$25,000 – \$34,999
- \$35,000 – \$49,999
- \$50,000 – \$74,999
- \$75,000 – \$99,999
- \$100,000 and above
- Prefer not to answer

Source: PhenX Toolkit; Harvard T.H. Chan School of Public Health Social Risk Factors for COVID-19 Exposure Questionnaire.
<https://mfr.osf.io/render?url=https://osf.io/bves6/?direct%26mode=render%26action=download%26mode=render>.

Note: Modified to add more categories for low income levels and collapsed categories for higher income levels.

Q26. How many people live or stay in your household right now? Include yourself, any other adults, and any children.

_____ people

Source: Modified for CEAL from Pulse Survey. <https://www.census.gov/data/experimental-data-products/household-pulse-survey.html>.

Note: Modified for plain language.

Q27. Which of the below describes your situation right now? (Select all that apply.)

- Working for pay—part time (less than 40 hours a week)
- Working for pay—full time (40 hours a week or more)
- Working without pay (for example, as an intern)
- On leave from work
- Unemployed and looking for a job
- Unemployed and NOT looking for a job
- Retired from work
- Staying at home, taking care of the home or of others
- Not able to work because of a disability
- Going to school
- Other: _____

Source: PhenX Toolkit; The Coronavirus Health Impact Survey (CRISIS) v3 Adult Self-Report Baseline Current. https://www.phenxtoolkit.org/toolkit_content/PDF/CRISIS_Baseline_Adult.pdf.

Note: Modified for plain language, removed “laid off or lost job,” added “unemployed and NOT looking for a job,” “working without pay (for example , as an intern),” and differentiated between “part time” and “full time” work.

OPTIONAL SURVEY ITEMS

Perceived Risk and Severity of COVID-19

Q28. How likely is it that these things will happen in the next 6 months? *(Select one response for each row.)*

	Not at all likely 1	2	3	4	Very Likely 5	Already happened
I will get COVID-19.						
If I get COVID-19, I will have to go to the hospital.						
If I get COVID-19, I will make someone else sick.						

Source: Adapted for CEAL Program from John Hopkins University COVID-19 Community Response Survey (Elizabeth Stuart, Coronavirus and mental health measurement working group). <https://www.phenxtoolkit.org/covid19/source>.

Note: Modified for plain language and revised scale. Reduced from 6 to 3 items.

COVID-19 Testing Behaviors

[Programming Note: If you opt to include these items, they should be asked after Q2 for only those who respond “Yes” to Q2.]

Q29. How easy or hard was it to get the COVID-19 test?

- Very easy
- Easy
- Hard
- Very hard

Q30. How many times did you get the COVID-19 test?

- One
- Two
- Three
- Four or more

Q31. What were the results of the COVID-19 test?

- I had COVID-19
- I did NOT have COVID-19

- Do not have results yet
- Prefer not to answer

Note: Added “prefer not to answer” response option.

Q32. Why have you not been tested for COVID-19? (Select all that apply.)

- I haven't felt sick.
- I felt sick, but I didn't feel sick enough to get tested.
- I felt sick, but my health care provider told me to just stay at home and away from other people.
- I was told that testing wasn't available.
- I didn't have a way to get to the testing location.
- I didn't have the money to pay for a test.
- I didn't know where to go to get tested.
- I didn't have someone to watch my children or other people in my care so I could go get tested.
- I couldn't take time off work to get tested.
- I'm afraid that a positive test result will mean that I have to miss work.
- I'm afraid to get a COVID-19 test.
- I don't trust researchers.
- I don't trust the government.
- Other reason: _____

Source: Adapted for CEAL Program from John Hopkins University COVID-19 Community Response Survey. <https://www.phenxtoolkit.org/covid19/source>.

Note: Modified for plain language and to include “I'm afraid that a positive test result will mean that I have to miss work,” “I'm afraid to get a COVID-19 test,” “I don't trust researchers,” and “I don't trust the government.”

Reasons for Getting/Not Getting a COVID-19 Vaccine

Q33. Why would you get a COVID-19 vaccine? (Select all that apply.)

- I want to keep my family safe.
- I want to keep my community safe.
- I want to keep myself safe.
- I have a chronic health problem, like asthma or diabetes.

- My doctor told me to get a COVID-19 vaccine.
- I don't want to get really sick from COVID-19.
- I want to feel safe around other people.
- I believe life won't go back to normal until most people get a COVID-19 vaccine.
- Other: _____

Source: Adapted for CEAL Program from AP-NORC May 18 Topline.
<https://COVID-19.parc.us.com/>.

Note: Modified for plain language and changed format to check all that apply.

Q34. Why would you NOT get a COVID-19 vaccine? (Select all that apply.)

- I'm allergic to vaccines.
- I don't like needles.
- I'm not concerned about getting really sick from COVID-19.
- I'm concerned about side effects from the vaccine.
- I don't think vaccines work very well.
- I don't trust that the vaccine will be safe.
- I don't believe the COVID-19 pandemic is as bad as some people say it is.
- I don't want to pay for it.
- I don't know enough about how well a COVID-19 vaccine works.
- Other: _____

Source: Adapted for CEAL Program from AP-NORC May 18 Topline.
<https://COVID-19.parc.us.com/>.

Note: Modified for plain language, added item "I don't know enough about how well a COVID-19 vaccine works," and changed format to select all that apply.

Beliefs about Taking Part in COVID-19 Clinical Trials

For the next few questions, we want to know your beliefs about taking part in COVID-19 clinical trials.

Q35. How much do you agree or disagree with each statement? (Select one response for each row.)

Taking part in a clinical trial for a COVID-19 vaccine would...

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Make me feel like I am helping keep other people healthy where I live.					
Help find a vaccine for COVID-19.					
Help <u>people like me</u> get a vaccine for COVID-19.					

Q36. How much do you agree or disagree with each statement? (Select one response for each row.)

If I were to get COVID-19, taking part in a clinical trial for a COVID-19 treatment would...

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Make me feel like I am helping keep other people healthy where I live.					
Help find a treatment for COVID-19.					
Help <u>people like me</u> get a treatment for COVID-19.					

Source: Adapted for CEAL Program from Janet Yang, Z., McComas, K., Gay, G., Leonard, J. P., Dannenberg, A. J., & Dillon, H. (2010). From information processing to behavioral intentions: Exploring cancer patients’ motivations for clinical trial enrollment. *Patient Education and Counseling*, 79(2), 231–238. <https://doi.org/10.1016/j.pec.2009.08.010>

Note: Modified to be COVID-19 specific and for plain language; reduced from 10 items to 2 items; added item about “people like me.”

Barriers to Participating in COVID-19 Clinical Trials

Q37. Why would you NOT take part in a clinical trial for a COVID-19 vaccine? (Select all that apply.)

- I don’t trust researchers.

- I don't trust the government.
- The COVID-19 vaccine may not be safe.
- I don't have a way to get to the trial.
- I don't believe clinical trials are important.
- I don't understand what will happen to me.
- It will cost me money.
- It will cost me time.
- Vaccines in general are bad for you.
- I have health problems that prevent me from taking part in a clinical trial.
- Other reason: _____

Source: Developed by the CEAL Assessment and Evaluation Work Group based on findings from Ford, J. G., Howerton, M. W., Lai, G. Y., Gary, T. L., Bolen, S., Gibbons, C. G., Tilburt, J., Baffi, C., Tanpitukpongse, T. P., Wilson, R. F., Rowe, N. R., & Bass, E. B. (2008). Barriers to recruiting underrepresented populations to cancer clinical trials: A systematic review. *Cancer*, 112(2), 228–242.
<https://acsjournals.onlinelibrary.wiley.com/doi/full/10.1002/cncr.23157>

English Proficiency

[Programming Note: If you opt to include this item, it should be asked after Q17 for only those who respond “Yes” to Q17.]

Q38. How well do you speak English?

- Very well
- Well
- Not well
- Not at all

Source: Adapted for CEAL from the 2020 American Community Survey.
<https://www2.census.gov/programs-surveys/acs/methodology/questionnaires/2020/quest20.pdf>.

Food and Housing Insecurity

Q39. Since March 2020, how often have you been worried about running out of food and not having enough money to buy more?

- Not at all

- Some of the time
- Most of the time
- Close to every day

Q40. Since March 2020, how often have you been worried about not being able to pay your rent or mortgage?

- Not at all
- Some of the time
- Most of the time
- Close to every day

Source: Modified for CEAL from items provided by CEAL Assessment and Evaluation Work Group Co-Chair Dr. Ornelas.

Demographics

Q41. Were you born in the U.S.?

- Yes
- No
- Prefer not to answer

Source: Provided by CEAL Assessment and Evaluation Work Group Co-Chair Dr. Ornelas.

Q42. How many people under 18 years old live or stay in your household right now?

_____ people

Source: Modified for CEAL from Pulse Survey. <https://www.census.gov/data/experimental-data-products/household-pulse-survey.html>.

Note: Modified for plain language.