

**NYCKidSeq – Parental Baseline Survey**

**v. 9/3/2020**

Date of survey completion: \_\_ \_\_ /\_\_ \_\_ /\_\_ \_\_

 MM DD YY

Who is administering this survey?

* Jessica Rodriguez
* Nicole Yelton
* Jessenia Lopez
* Estefany Maria
* Other

How was this survey administered?

* Phone
* In-Person

Based on child’s current age, choose appropriate PEDS-QL set of questions:

* Infant ( 1-12 months)
* Infant ( 13-24 months)
* Toddler (ages 2 - 4)
* Young child (ages 5 - 7)
* Child (ages 8 - 12)
* Teens (ages 13 - 18)

Start Time: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

End Time: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Relationship to Child

Ask which parent/guardian would like to take the survey, keeping in mind that the parent/guardian will have to be the same person who 1) signed the baseline consent, 2) will be present for all study visits and 3) will answer all surveys (BL, ROR1, and ROR2).

1. What is your relationship to (child’s name)?

* Mother
* Father
* Legal Guardian

I. NYCKidSeq Participation

History of Genetic Testing

 “In this first section, we are interested in learning about why you have decided to take part in this study. We will ask you a little about your history with genetic testing, and how you feel about the results you might get from your child’s testing.”

1. Has anyone in your family (including yourself and your child) ever had a genetic test? (CHOOSE ONE ONLY)
* Yes
* No
* Don’t Know
* PREFER NOT TO ANSWER

IF YES:

2a. Who in your family (including yourself and your child) has had a genetic test? Select all that apply.

* Myself
* My child enrolled in this study
* The child’s other biological parent
* My other child not enrolled in this study
* Other family member (do not need to specify who)
* PREFER NOT TO ANSWER

2b. Before you or anyone in your family received genetic testing, did you meet with somebody (either a doctor or a genetic counselor) to learn about the genetic test that was ordered?

* Yes
* No
* Don’t know
* PREFER NOT TO ANSWER

2c. If you met with someone, was it for all the tests you received, or some of them?

* All the tests
* Some of the tests
* Don’t know
* PREFER NOT TO ANSWER

Parent’s Expectations

"In this next section, we will ask you how useful you believe your child's test results will be in making future decisions." [USE RESPONSE CARD]. We know you have not yet received the results, but we want to know what you expect may happen when you do get them.

1. Please indicate how useful you think your child’s results will be for the following purposes. [DO NOT READ ALOUD “DON’T KNOW” RESPONSE OPTION. CHOOSE IT IF RESPONDENT OFFERS IT]

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Not at all useful | A little useful | Somewhat useful | Neutral | Useful | Very useful | Extremely Useful | Don’t Know |
| 1. Help with my child’s life planning
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Inform plans for my child’s school or career
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Inform my child’s decisions about having children
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Use for testing a future pregnancy, if appropriate
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Help me or our family mentally prepare for the future
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Help to better understand my child’s health
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Contribute to my child’s self-knowledge
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Help me cope with my child’s health risks
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Help me feel more in control of my child’s health
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Help me feel more in control of my child’s life
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Simply to provide information
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Satisfy my curiosity about my child
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Help my child use social programs, like resources and services
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Improve communication with my family members
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Feel good about helping the medical community
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Feel good about having information for family members
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Feel good about taking responsibility for my child’s health
 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |

Objective Understanding

1. I know you have not yet been given the results of your child’s genetic test. However, do you think they will show whether your child’s condition is definitely caused by something in his/her genes?
* Yes
* No
* Not sure/don’t know
* Refused
1. Do you think that when you get the results of the genetic test, it will give you a genetic explanation for your child’s condition/symptoms?
* Yes
* No
* Not sure/don’t know
* Refused

II. Healthcare

 “Next, we would like to learn about your experiences getting medical care for your child.”

Access to care

1. Has there been any time in the last 12 months when you wanted or needed your child to see a doctor or health care professional and did not?
* Yes
* No
* Refused

IF YES:

6a. Why did your child not see a doctor or health care professional when you wanted or needed them to in the last year?   I could not afford it.

* It was too difficult to get there.
* I do not like doctors and avoid going.
* I did not want to get bad news.
* I did not have time.
* I decided to take care of it on my own.
* I decided to wait and see if the problem would go away on its own.
* The doctor was not available to see my child.
* PREFER NOT TO ANSWER

Experience with telehealth

Adapted from:

*Polinski JM, Barker T, Gagliano N, Sussman A, Brennan TA, Shrank WH. Patients' Satisfaction with and Preference for Telehealth Visits. J Gen Intern Med. 2016;31(3):269-275. doi:10.1007/s11606-015-3489-x*

1. Is this your first time using telehealth services (medical care delivered by high definition video and audio) at any health care provider?

❏ Yes

❏ No

7a. If No, how many times have you used TeleHealth previously? \_\_\_\_\_\_\_\_\_

BRIEF Health Literacy Survey [USE RESPONSE CARD]

1. How often do you have someone (like a family member, friend hospital/clinic worker or caregiver) help you read medical materials?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Always | Often | Sometimes | Occasionally | Never | Refused |

1. How often do you have problems learning about your medical conditions because of difficulty understanding written information?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Always | Often | Sometimes | Occasionally | Never | Refused |

1. How often do you have a problem understanding what is told to you about your medical condition?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Always | Often | Sometimes | Occasionally | Never | Refused |

1. How confident are you filling out medical forms by yourself?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Not at all | A little bit | Somewhat | Quite a bit | Extremely | Refused |

Subjective Numeracy Scale (SNS-3) [USE RESPONSE CARD]

## “For each item, rate yourself on the scale from ‘Not at all good (1)’ to ‘extremely good (6).’”

1. How good are you at working with fractions “Not at all good (1)’ to ‘extremely good (6)’”

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Not at all1 | 2 | 3 | 4 | 5 | Extremely good6 | Refused |

1. How good are you at figuring out how much a shirt will cost if it is 25% off? “Not at all good (1)’ to ‘extremely good (6)’”

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Not at all1 | 2 | 3 | 4 | 5 | Extremely good6 | Refused |

1. How often do you find numerical information to be useful? ‘Never (1) to Very Often (6).”

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Never1 | 2 | 3 | 4 | 5 | Very Often6 | Refused |

TECHNOLOGY COMFORT:

*Adapted from:*

*Bunz U. The Computer-Email-Web (CEW) Fluency Scale-Development and Validation. Int J Hum Comput Interact. 2004; 17(4):479–506.*

<https://sypher.cci.fsu.edu/NCA2001fluency2.pdf>

On average, how often do you use the internet? By this, we mean using your browser for a specific set of tasks or activities. We do not mean how many times you launch your browser per day.

1. More than 9 times/day
2. 5 to 8 times/day
3. 1 to 4 times/day
4. A few times a week
5. Once a week
6. Once a month

How comfortable do you feel using computers, in general?

1. Very comfortable
2. Somewhat comfortable
3. Neither comfortable nor uncomfortable
4. Somewhat uncomfortable
5. Very uncomfortable

How comfortable to you feel using the Internet?

1. Very comfortable
2. Somewhat comfortable
3. Neither comfortable nor uncomfortable
4. Somewhat uncomfortable
5. Very uncomfortable

How satisfied are you with your current skills for using the Internet?

1. Very satisfied – I can do everything that I want to do
2. Somewhat satisfied – I can do most things I want to do
3. Neither satisfied nor unsatisfied
4. Somewhat unsatisfied – I can’t so many things I would like to do
5. Very unsatisfied – I can’t do most things I would like to do

ACESS TO TECHNOLOGY:

*Adapted from CSER Access to Care questions;*

Do you have access to the Internet in your home?

* Yes
* No

IF YES:

What device do you use to access the Internet at home? (Check all that apply)

* Computer/Laptop
* Smart phone
* Tablet/iPad
* Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

If yes, has there been any time in the last 12 months when you were home and wanted or needed to use the Internet but were unable to access it?

* Yes
* No

IF YES:

Why could you not access the Internet?   (Open ended)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Health Care System Distrust Scale [USE RESPONSE CARD]

“For each item, rate how much trust you have in the Health Care System from ‘Strongly disagree (1)’ to ‘Strongly agree (5) By Health Care System we mean: insurance companies and drug companies. We are not including people such as doctors, nurses, specialists, x-ray technicians, medicines, or office staff. We are just talking about the organizations.”

1. The Health Care System does its best to make patients’ health better.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Refused |

1. The Health Care System covers up its mistakes.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Refused |

1. Patients receive high quality medical care from the Health Care System.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Refused |

1. The Health Care System makes too many mistakes.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Refused |

1. The Health Care System puts making money above patients’ needs.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Refused |

1. The Health Care System gives excellent medical care.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Refused |

1. Patients get the same medical treatment from the Health Care System no matter what the patient’s race or ethnicity.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Refused |

1. The Health Care System lies to make money

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Refused |

1. The Health Care Systemexperiments on patients without them knowing

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Refused |

## III. Your Child’s Health

##  “In this next section, we will ask you about your child’s health and how much care he/she needs.”

* We would like know how good or bad your child’s health is TODAY.
* This line is numbered 0 to 100.
* 100 means the best health you can imagine.

0 means the worst health you can imagine.

* Mark an X on the scale to indicate how your child’s health is TODAY
* Now please write the number you marked on the scale in the box below



**How good is your child’s health TODAY? [SHOW SCALE]**

**24. YOUR CHILD’S HEALTH TODAY =**

**How good was your child’s health in the LAST MONTH?**

**25. YOUR CHILD’S HEALTH in the LAST MONTH =**

26. Quality of Life Ascertainment

 “The following is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month [USE RESPONSE CARD]

0 if it is never a problem

1 if it is almost never a problem

2 if it is sometimes a problem

3 if it is often a problem

4 if it is almost always a problem

We understand that some children may not be able to do all of things that we will ask you about. We ask the same questions of all parents regardless of their child’s health condition.

There are no right or wrong answers. If you do not understand a question, please ask for help.”

Parent proxy – PedsQL Infant (1 – 12 months)

*In the past ONE month, how much of a problem has your child had with …*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| PHYSICAL FUNCTIONING *(problems with...)* | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Low energy level | 0 | 1 | 2 | 3 | 4 |
| 2. Difficulty participating in active play | 0 | 1 | 2 | 3 | 4 |
| 3. Having hurts or aches | 0 | 1 | 2 | 3 | 4 |
| 4. Feeling tired | 0 | 1 | 2 | 3 | 4 |
| 5. Being lethargic | 0 | 1 | 2 | 3 | 4 |
| 6. Resting a lot | 0 | 1 | 2 | 3 | 4 |
| PHYSICAL SYMPTOMS *(problems with…)* | Never | Almost Never | Some- times | Often | Almost Always |
| 1. Having gas | 0 | 1 | 2 | 3 | 4 |
| 2. Spitting up after eating | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty breathing | 0 | 1 | 2 | 3 | 4 |
| 4. Being sick to his/her stomach | 0 | 1 | 2 | 3 | 4 |
| 5. Difficulty swallowing | 0 | 1 | 2 | 3 | 4 |
| 6. Being constipated | 0 | 1 | 2 | 3 | 4 |
| 7. Having a rash | 0 | 1 | 2 | 3 | 4 |
| 8. Having diarrhea | 0 | 1 | 2 | 3 | 4 |
| 9. Wheezing | 0 | 1 | 2 | 3 | 4 |
| 10. Vomiting | 0 | 1 | 2 | 3 | 4 |
| EMOTIONAL FUNCTIONING *(problems with…)* | Never | Almost Never | Some- times | Often | Almost Always |
| 1. Feeling afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling angry | 0 | 1 | 2 | 3 | 4 |
| 3. Crying or fussing when left alone | 0 | 1 | 2 | 3 | 4 |
| 4. Difficulty soothing himself/herself when upset | 0 | 1 | 2 | 3 | 4 |
| 5. Difficulty falling asleep | 0 | 1 | 2 | 3 | 4 |
| 6. Crying or fussing while being cuddled | 0 | 1 | 2 | 3 | 4 |
| 7. Feeling sad | 0 | 1 | 2 | 3 | 4 |
| 8. Difficulty being soothed when picked up or held | 0 | 1 | 2 | 3 | 4 |
| 9. Difficulty sleeping mostly through the night | 0 | 1 | 2 | 3 | 4 |
| 10. Crying a lot | 0 | 1 | 2 | 3 | 4 |
| 11. Feeling cranky | 0 | 1 | 2 | 3 | 4 |
| 12. Difficulty taking naps during the day | 0 | 1 | 2 | 3 | 4 |
| SOCIAL FUNCTIONING *(problems with…)* | Never | Almost Never | Some- times | Often | Almost Always |
| 1. Not smiling at others | 0 | 1 | 2 | 3 | 4 |
| 2. Not laughing when tickled | 0 | 1 | 2 | 3 | 4 |
| 3. Not making eye contact with a caregiver | 0 | 1 | 2 | 3 | 4 |
| 4. Not laughing when cuddled | 0 | 1 | 2 | 3 | 4 |
| COGNITIVE FUNCTIONING *(problems with…)* | Never | Almost Never | Some- times | Often | Almost Always |
| 1. Not imitating caregivers’ actions | 0 | 1 | 2 | 3 | 4 |
| 2. Not imitating caregivers’ facial expressions | 0 | 1 | 2 | 3 | 4 |
| 3. Not imitating caregivers’ sounds | 0 | 1 | 2 | 3 | 4 |
| 4. Not able to fix his/her attention on objects | 0 | 1 | 2 | 3 | 4 |

Parent proxy - PedsQL Infant (13 - 24 months)

*In the past ONE month, how much of a problem has your child had with …*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| PHYSICAL FUNCTIONING *(problems with…)* | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Low energy level | 0 | 1 | 2 | 3 | 4 |
| 2. Difficulty participating in active play | 0 | 1 | 2 | 3 | 4 |
| 3. Having hurts or aches | 0 | 1 | 2 | 3 | 4 |
| 4. Feeling tired | 0 | 1 | 2 | 3 | 4 |
| 5. Being lethargic | 0 | 1 | 2 | 3 | 4 |
| 6. Resting a lot | 0 | 1 | 2 | 3 | 4 |
| 7. Feeling too tired to play | 0 | 1 | 2 | 3 | 4 |
| 8. Difficulty walking | 0 | 1 | 2 | 3 | 4 |
| 9. Difficulty running a short distance without falling | 0 | 1 | 2 | 3 | 4 |
| PHYSICAL SYMPTOMS (problems with…) | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Having gas | 0 | 1 | 2 | 3 | 4 |
| 2. Spitting up after eating | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty breathing | 0 | 1 | 2 | 3 | 4 |
| 4. Being sick to his/her stomach | 0 | 1 | 2 | 3 | 4 |
| 5. Difficulty swallowing | 0 | 1 | 2 | 3 | 4 |
| 6. Being constipated | 0 | 1 | 2 | 3 | 4 |
| 7. Having a rash | 0 | 1 | 2 | 3 | 4 |
| 8. Having diarrhea | 0 | 1 | 2 | 3 | 4 |
| 9. Wheezing | 0 | 1 | 2 | 3 | 4 |
| 10. Vomiting | 0 | 1 | 2 | 3 | 4 |
| EMOTIONAL FUNCTIONING (problems with…) | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Feeling afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling angry | 0 | 1 | 2 | 3 | 4 |
| 3. Crying or fussing when left alone | 0 | 1 | 2 | 3 | 4 |
| 4. Difficulty soothing himself/herself when upset | 0 | 1 | 2 | 3 | 4 |
| 5. Difficulty falling asleep | 0 | 1 | 2 | 3 | 4 |
| 6. Crying or fussing while being cuddled | 0 | 1 | 2 | 3 | 4 |
| 7. Feeling sad | 0 | 1 | 2 | 3 | 4 |
| 8. Difficulty being soothed when picked up or held | 0 | 1 | 2 | 3 | 4 |
| 9. Difficulty sleeping mostly through the night | 0 | 1 | 2 | 3 | 4 |
| 10. Crying a lot | 0 | 1 | 2 | 3 | 4 |
| 11. Feeling cranky | 0 | 1 | 2 | 3 | 4 |
| 12. Difficulty taking naps during the day | 0 | 1 | 2 | 3 | 4 |
| SOCIAL FUNCTIONING (problems with…) | Never | Almost Never | Some- times | Often | Almost Always |
| 1. Not smiling at others | 0 | 1 | 2 | 3 | 4 |
| 2. Not laughing when tickled | 0 | 1 | 2 | 3 | 4 |
| 3. Not making eye contact with a caregiver | 0 | 1 | 2 | 3 | 4 |
| 4. Not laughing when cuddled | 0 | 1 | 2 | 3 | 4 |
| 5. Being uncomfortable around other children | 0 | 1 | 2 | 3 | 4 |
| COGNITIVE FUNCTIONING (problems with…) | Never | Almost Never | Some- times | Often | Almost Always |
| 1. Not imitating caregivers’ actions | 0 | 1 | 2 | 3 | 4 |
| 2. Not imitating caregivers’ facial expressions | 0 | 1 | 2 | 3 | 4 |
| 3. Not imitating caregivers’ sounds | 0 | 1 | 2 | 3 | 4 |
| 4. Not able to fix his/her attention on objects | 0 | 1 | 2 | 3 | 4 |
| 5. Not imitating caregivers’ speech | 0 | 1 | 2 | 3 | 4 |
| 6. Difficulty pointing to his/her body parts when asked | 0 | 1 | 2 | 3 | 4 |
| 7. Difficulty naming familiar objects | 0 | 1 | 2 | 3 | 4 |
| 8. Difficulty repeating words | 0 | 1 | 2 | 3 | 4 |
| 9. Difficulty keeping his/her attention on things | 0 | 1 | 2 | 3 | 4 |

Parent proxy - PedsQL Toddler (ages 2-4)

*In the past ONE month, how much of a problem has your child had with …*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| PHYSICAL FUNCTIONING *(problems with…)* | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Walking | 0 | 1 | 2 | 3 | 4 |
| 2. Running | 0 | 1 | 2 | 3 | 4 |
| 3. Participating in active play or exercise | 0 | 1 | 2 | 3 | 4 |
| 4. Lifting something heavy | 0 | 1 | 2 | 3 | 4 |
| 5. Bathing | 0 | 1 | 2 | 3 | 4 |
| 6. Helping to pick up his or her toys | 0 | 1 | 2 | 3 | 4 |
| 7. Having hurts or aches | 0 | 1 | 2 | 3 | 4 |
| 8. Low energy level | 0 | 1 | 2 | 3 | 4 |
| EMOTIONAL FUNCTIONING *(problems with…)* | Never | Almost Never | Som times | Often | Almost Always |
| 1. Feeling afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling sad or blue | 0 | 1 | 2 | 3 | 4 |
| 3. Feeling angry | 0 | 1 | 2 | 3 | 4 |
| 4. Trouble sleeping | 0 | 1 | 2 | 3 | 4 |
| 5. Worrying | 0 | 1 | 2 | 3 | 4 |
| SOCIAL FUNCTIONING (problems with…) | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Playing with other children | 0 | 1 | 2 | 3 | 4 |
| 2. Other kids not wanting to play with him or her | 0 | 1 | 2 | 3 | 4 |
| 3. Getting teased by other children | 0 | 1 | 2 | 3 | 4 |
| 4. Not able to do things that other children his or her age can do | 0 | 1 | 2 | 3 | 4 |
| 5. Keeping up when playing with other children | 0 | 1 | 2 | 3 | 4 |

|  |
| --- |
| *\*Please complete this section if your child attends school or daycare* |
| SCHOOL FUNCTIONING *(problems with…)* | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Doing the same school activities as peers | 0 | 1 | 2 | 3 | 4 |
| 2. Missing school/daycare because of not feeling well | 0 | 1 | 2 | 3 | 4 |
| 3. Missing school/daycare to go to the doctor or hospital | 0 | 1 | 2 | 3 | 4 |

Parent proxy - PedsQL Young Child (Ages 5-7)

*In the past ONE month, how much of a problem has your child had with …*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| PHYSICAL FUNCTIONING *(problems with…)* | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Walking more than one block | 0 | 1 | 2 | 3 | 4 |
| 2. Running | 0 | 1 | 2 | 3 | 4 |
| 3. Participating in sports activity or exercise | 0 | 1 | 2 | 3 | 4 |
| 4. Lifting something heavy | 0 | 1 | 2 | 3 | 4 |
| 5. Taking a bath or shower by him or herself | 0 | 1 | 2 | 3 | 4 |
| 6. Doing chores, like picking up his or her toys | 0 | 1 | 2 | 3 | 4 |
| 7. Having hurts or aches | 0 | 1 | 2 | 3 | 4 |
| 8. Low energy level | 0 | 1 | 2 | 3 | 4 |
| EMOTIONAL FUNCTIONING (problems with…) | Never | Almost Never | Some- times | Often | Almost Always |
| 1. Feeling afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling sad or blue | 0 | 1 | 2 | 3 | 4 |
| 3. Feeling angry | 0 | 1 | 2 | 3 | 4 |
| 4. Trouble sleeping | 0 | 1 | 2 | 3 | 4 |
| 5. Worrying about what will happen to him or her | 0 | 1 | 2 | 3 | 4 |
| SOCIAL FUNCTIONING (problems with…) | Never | Almost Never | Some- times | Often | Almost Always |
| 1. Getting along with other children | 0 | 1 | 2 | 3 | 4 |
| 2. Other kids not wanting to be his or her friend | 0 | 1 | 2 | 3 | 4 |
| 3. Getting teased by other children | 0 | 1 | 2 | 3 | 4 |
| 4. Not able to do things that other children his or her age can do | 0 | 1 | 2 | 3 | 4 |
| 5. Keeping up when playing with other children | 0 | 1 | 2 | 3 | 4 |
| SCHOOL FUNCTIONING *(problems with…)* | Never | Almost Never | Some-times times | Often | Almost Always |
| 1. Paying attention in class | 0 | 1 | 2 | 3 | 4 |
| 2. Forgetting things | 0 | 1 | 2 | 3 | 4 |
| 3. Keeping up with school activities | 0 | 1 | 2 | 3 | 4 |
| 4. Missing school because of not feeling well | 0 | 1 | 2 | 3 | 4 |
| 5. Missing school to go to the doctor or hospital | 0 | 1 | 2 | 3 | 4 |

Parent proxy - PedsQL Child (Ages 8-12)

*In the past ONE month, how much of a problem has your child had with …*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| PHYSICAL FUNCTIONING *(problems with…)* | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Walking more than one block | 0 | 1 | 2 | 3 | 4 |
| 2. Running | 0 | 1 | 2 | 3 | 4 |
| 3. Participating in sports activity or exercise | 0 | 1 | 2 | 3 | 4 |
| 4. Lifting something heavy | 0 | 1 | 2 | 3 | 4 |
| 5. Taking a bath or shower by him or herself | 0 | 1 | 2 | 3 | 4 |
| 6. Doing chores around the house | 0 | 1 | 2 | 3 | 4 |
| 7. Having hurts or aches | 0 | 1 | 2 | 3 | 4 |
| 8. Low energy level | 0 | 1 | 2 | 3 | 4 |
| EMOTIONAL FUNCTIONING *(problems with…)* | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Feeling afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling sad or blue | 0 | 1 | 2 | 3 | 4 |
| 3. Feeling angry | 0 | 1 | 2 | 3 | 4 |
| 4. Trouble sleeping | 0 | 1 | 2 | 3 | 4 |
| 5. Worrying about what will happen to him or her | 0 | 1 | 2 | 3 | 4 |
| SOCIAL FUNCTIONING (problems with…) | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Getting along with other children | 0 | 1 | 2 | 3 | 4 |
| 2. Other kids not wanting to be his or her friend | 0 | 1 | 2 | 3 | 4 |
| 3. Getting teased by other children | 0 | 1 | 2 | 3 | 4 |
| 4. Not able to do things that other children his or her age can do | 0 | 1 | 2 | 3 | 4 |
| 5. Keeping up when playing with other children | 0 | 1 | 2 | 3 | 4 |
| SCHOOL FUNCTIONING (problems with…) | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Paying attention in class | 0 | 1 | 2 | 3 | 4 |
| 2. Forgetting things | 0 | 1 | 2 | 3 | 4 |
| 3. Keeping up with schoolwork | 0 | 1 | 2 | 3 | 4 |
| 4. Missing school because of not feeling well | 0 | 1 | 2 | 3 | 4 |
| 5. Missing school to go to the doctor or hospital | 0 | 1 | 2 | 3 | 4 |

Parent proxy - PedsQL Teens (Ages 13-18)

*In the past ONE month, how much of a problem has your child had with …*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| PHYSICAL FUNCTIONING *(problems with…)* | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Walking more than one block | 0 | 1 | 2 | 3 | 4 |
| 2. Running | 0 | 1 | 2 | 3 | 4 |
| 3. Participating in sports activity or exercise | 0 | 1 | 2 | 3 | 4 |
| 4. Lifting something heavy | 0 | 1 | 2 | 3 | 4 |
| 5. Taking a bath or shower by him or herself | 0 | 1 | 2 | 3 | 4 |
| 6. Doing chores around the house | 0 | 1 | 2 | 3 | 4 |
| 7. Having hurts or aches | 0 | 1 | 2 | 3 | 4 |
| 8. Low energy level | 0 | 1 | 2 | 3 | 4 |
| EMOTIONAL FUNCTIONING (problems with…) | Never | Almost Never | Some- times | Often | Almost Always |
| 1. Feeling afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling sad or blue | 0 | 1 | 2 | 3 | 4 |
| 3. Feeling angry | 0 | 1 | 2 | 3 | 4 |
| 4. Trouble sleeping | 0 | 1 | 2 | 3 | 4 |
| 5. Worrying about what will happen to him or her | 0 | 1 | 2 | 3 | 4 |
| SOCIAL FUNCTIONING *(problems with…)* | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Getting along with other teens | 0 | 1 | 2 | 3 | 4 |
| 2. Other teens not wanting to be his or her friend | 0 | 1 | 2 | 3 | 4 |
| 3. Getting teased by other teens | 0 | 1 | 2 | 3 | 4 |
| 4. Not able to do things that other teens his or her age can do | 0 | 1 | 2 | 3 | 4 |
| 5. Keeping up with other teens | 0 | 1 | 2 | 3 | 4 |
| SCHOOL FUNCTIONING (problems with…) | Never | Almost Never | Sometimes | Often | Almost Always |
| 1. Paying attention in class | 0 | 1 | 2 | 3 | 4 |
| 2. Forgetting things | 0 | 1 | 2 | 3 | 4 |
| 3. Keeping up with schoolwork | 0 | 1 | 2 | 3 | 4 |
| 4. Missing school because of not feeling well | 0 | 1 | 2 | 3 | 4 |
| 5. Missing school to go to the doctor or hospital | 0 | 1 | 2 | 3 | 4 |

IV. Impact of Your Child’s Health on Lifestyle and Other Factors

Cost Utility Measures

 “In this next section, we will ask you questions about how much care your child needs.”

1. Do you currently have a person you consider your child's primary care doctor or pediatrician, or a place you go where your child sees a primary care doctor or pediatrician? (CHOOSE ONE ONLY)
	* Yes- one primary care doctor
	* Yes- not one doctor, but sees a pediatrician at a place
	* No (Proceed to question 27)
	* DON’T KNOW (Proceed to question 33)
	* PREFER NOT TO ANSWER (Proceed to question 33)
	* Other, specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

27a. In the last 6 months, how many times did your child see that primary care doctor? (CHOOSE ONE ONLY)

Enter # of Times (Specify:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)

None

DON’T KNOW

PREFER NOT TO ANSWER

27b. On average, how long does it take you to get to your child's primary care doctor's office from your child's home? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Enter number of MINUTES)

27c. On average, how much time do you (and your child) spend at your child's primary care doctor's office? Please include both the time you wait to see your child's doctor and the time the doctor spends with your child. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Enter number of MINUTES)

26d. Usually what form of transportation do you use to get to your child's primary care doctor's office? (CHOOSE ONE ONLY)

Public Transportation

Ambulette/ Access-a- Ride

Friend or Family drives us

Taxi

Walking

Other (Specify:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)

I drive myself

DON’T KNOW

PREFER NOT TO ANSWER

1. In the last 6 months, how many times did your child visit specialist doctors? That is, how many visits did your child make to doctors other than your child's primary care doctor? (CHOOSE ONE ONLY)
	* Enter # of Times (Specify:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)
	* None
	* DON’T KNOW
	* PREFER NOT TO ANSWER
2. In the last 6 months, how many times did your child go to an emergency room? (CHOOSE ONE ONLY)
* Enter # of Times (Specify:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)
* None
* DON’T KNOW
* PREFER NOT TO ANSWER
1. In the last 6 months, how many times was your child admitted to the hospital? That is, how many times did your child spend more than 24 hours in the hospital and not just in the emergency room? (CHOOSE ONE ONLY)
	* Enter # of Times (Specify:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)
	* None
	* DON’T KNOW
	* PREFER NOT TO ANSWER
2. In the past 6 months, how many times did your child see a mental health provider, such as a psychologist, psychiatrist, or social worker? (CHOOSE ONE ONLY)
	* Enter # of Times (Specify:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)
	* None
	* DON’T KNOW
	* PREFER NOT TO ANSWER

Insurance Status

1. Is your child covered by health insurance or some other kind of health care plan? (Include health insurance obtained through employment or purchased directly as well as government programs like Medicare and Medicaid that provide medical care or help pay medical bills) (Check one)
* Yes (Proceed to question 31a)
* No (Proceed to question 31b)
* DON’T KNOW (Proceed to question 32)
* PREFER NOT TO ANSWER (Proceed to question 32)

32a. IF YOUR CHILD IS COVERED: What kind or kinds of health insurance or health care coverage does your child have? (Check all that apply)

* Private health insurance, employment based
* Private health insurance, directly purchased
* Government plan, Medicare
* Government plan, Medicaid
* Government plan, Military health care
* Other type of insurance (Please Describe): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_[GET AS MUCH INFORMATION AS POSSIBLE SO WE CAN RECATEGORIZE LATER)
* No coverage of any type.

32b. How long has it been since your child last had health coverage? (CHOOSE ONE ONLY)

* 6 months or less
* More than 6 months, up to and including 1 year
* More than 1 year
* DON’T KNOW
* PREFER NOT TO ANSWER
1. Are your child's prescription medications covered (at least partially) by some kind of health insurance? (CHOOSE ONE ONLY)
* Yes
* No
* DON’T KNOW
* PREFER NOT TO ANSWER
* Other, specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
1. Do you provide care to your child specifically due to her/his physical or mental health problems, care that you do not think you would have to do if she/he were in good health? Some examples of type of care are dressing, bathing, helping use the bathroom, carrying or moving your child, feeding, helping take medications, and making the house safe.
* Yes
* No → Continue to section “Race and ethnicity”
* DON’T KNOW
* PREFER NOT TO ANSWER

34a. How long have you been providing this type of care to your child?

* Less than a month: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ weeks
* Less than a year: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ months
* More than a year: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ years
* DON’T KNOW
* PREFER NOT TO ANSWER

34b. On how many days per week do you usually provide this type of care to your child?

* 1 day
* 2 days
* 3 days
* 4 days
* 5 days
* 6 days
* 7 days
* DON’T KNOW
* PREFER NOT TO ANSWER

34c. How much time during the last week did you spend on household activities like cooking or cleaning that you would not have to do if she/he were in good health?

* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ hours during the last week*\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

34d. How much time during the last week did you spend on taking care for your child’s needs like dressing, bathing, taking to the bathroom, feeding, helping with medicines that you would not have to do if she/he were in good health?

* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ hours during the last week*\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

34e. How much time during the last week did you spend on practical support for your child like getting outside the house, getting to doctors, getting them help from others like relatives or aides, making the house safe and taking care of financial things (such as insurance) that you would not have to do if she/he were in good health?

* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ hours during the last week*\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

34f. Besides your care or support, does your child also receive care from a professional caregiver at home?

* No
* No, but she/he is on a waiting list for professional care at home for \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_hours per week
* Yes, for\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ hours during the last week*\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

34g. Besides your care or support, does your child receive care on a voluntarily basis from others (family members, friends or neighbors)?

* No, I am the only informal caregiver
* Yes, from \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ [number] other informal caregivers, in total for \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ hours during the last week*\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

34h. Did you completely or partly give up paid work to provide care to your child due to her/his physical or mental health problems ?

* No, I did not have paid work before
* No, I still perform the same amount of paid work
* Yes, for \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(number) fewer hours per week since \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(year) *\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

34i. Did you completely or partly give up unpaid work to provide care to your child due to her/his physical or mental health problems ?

* No, I did not have unpaid work before
* No, I still perform the same amount of unpaid work
* Yes, for \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(number) fewer hours per week since \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(year) *\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

34j. Did you give up free time to provide care to your child due to her/his physical or mental health problems?

* No, I did not have free time before
* No, I still spend the same amount of time other things
* Yes, for \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(number) fewer hours per week since \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(year) *\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

34k. Suppose you did not have to provide this care anymore. How would you spend this time?

More paid work:

* No
* Yes: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_hours per week*\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

More unpaid work:

* No
* Yes: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_hours per week*\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

More free time to do other things:

* No
* Yes: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_hours per week*\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.*
* DON’T KNOW
* PREFER NOT TO ANSWER

VI. Race, Ethnicity and Ancestral Background

 “For this next set of questions, we will ask you about your race, ethnicity, and where your family is from. A major goal of this research is to increase diversity in genomic research so that new advances in genomic medicine are available to everyone. To do this, we need to understand how people in our study identify with different racial and ethnic categories. We will not share your answers with your doctors or anyone else at (Mount Sinai/Montefiore).”

 Country of Origin of Child

1. Where was your child born? (country) \_\_\_\_\_\_\_\_\_\_\_
* DON’T KNOW
* PREFER NOT TO ANSWER

Country of Origin of Child’s Biological Parents and Grandparents

1. Where was the CHILD’s Biological MOTHER born? (country)\_\_\_\_\_\_\_\_\_\_\_\_
* DON’T KNOW
* PREFER NOT TO ANSWER
1. Where was the CHILD’s Biological MOTHER’s MOTHER born? (country)\_\_\_\_\_\_\_\_\_\_\_\_
* DON’T KNOW
* PREFER NOT TO ANSWER
1. Where was the CHILD’s Biological MOTHER’s FATHER born? (country)\_\_\_\_\_\_\_\_\_\_\_\_\_
* DON’T KNOW
* PREFER NOT TO ANSWER
1. Where was the CHILD’s Biological FATHER born? (country)\_\_\_\_\_\_\_\_\_\_\_
* DON’T KNOW
* PREFER NOT TO ANSWER
1. Where was the CHILD’s Biological FATHER’s MOTHER born? (country)\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* DON’T KNOW
* PREFER NOT TO ANSWER
1. Where was the CHILD’s Biological FATHER’s FATHER mother born? (country)\_\_\_\_\_\_\_\_\_\_\_\_\_
* DON’T KNOW
* PREFER NOT TO ANSWER

Race and Ethnicity

1. What category or categories best describe your child? Check all that apply.
* American Indian, Native American, or Alaska Native
* Asian
* Black or African American
* Native Hawaiian/Pacific Islander
* White or European American
* Middle Eastern or North African/Mediterranean
* Hispanic/Latino(a)
* Prefer not to answer
* Unknown/none of these fully describe my child
1. What category or categories best describe the child’s biological mother? Check all that apply.
* American Indian, Native American, or Alaska Native
* Asian
* Black or African American
* Native Hawaiian/Pacific Islander
* White or European American
* Middle Eastern or North African/Mediterranean
* Hispanic/Latino(a)
* Prefer not to answer
* Unknown/none of these fully describe me
1. What category or categories best describe the child’s biological father? Check all that apply.
* American Indian, Native American, or Alaska Native
* Asian
* Black or African American
* Native Hawaiian/Pacific Islander
* White or European American
* Middle Eastern or North African/Mediterranean
* Hispanic/Latino(a)
* Prefer not to answer
* Unknown/none of these fully describe me

VII. Demographics

 “Lastly, we would like to ask you a few questions about your and your child’s background. As a reminder, none of your responses will be seen by your providers and will NOT impact your care or services at (Mount Sinai/Montefiore)”

Sex of Child

1. What sex was your child assigned at birth, on the original birth certificate? (Check one)
* Female
* Male
* Prefer not to answer
1. How does your child describe themselves? (Check one)
* Female
* Male
* Transgender
* Do not identify as female, male, or transgender
* Prefer not to answer

Age of Parent

1. What month and year were you born?

 MM: \_\_\_\_ YYYY: \_\_\_\_\_\_\_\_

* Prefer not to answer

 Zip Code

1. What is your zip code? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefer not to answer

Language

1. Do you speak another language besides English?
* Yes
* No
* Prefer not to answer

**49a.** How well do you speak English?

Native English-speaker

Very well

Well

Not well

Prefer not to answer

**49b**. What language do you prefer to speak with your child’s doctors?

English (Proceed to question 55)

* Spanish (Proceed to question 55)
* Another language (Proceed to question 54a)
* I am equally comfortable discussing my child’s medical care in both English and another language (Proceed to question 55)
* Prefer not to answer

**49b1.** [If “another language”]: Please tell us which language you prefer to speak with your child’s doctors:

* Vietnamese
* Chinese (Mandarin, Cantonese, or other Chinese language)
* Tagalog
* German
* French
* Korean
* Russian
* Arabic
* Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefer not to answer

Marital Status

1. What is your marital status? (CHOOSE ONE ONLY, DON’T READ CHOICES UNLESS PARTICIPANT DOES NOT OFFER ONE OF THESE OPTIONS ON THEIR OWN)
* Currently married
* Widowed
* Divorced
* Separated
* Part of an unmarried couple
* Never married
* Don’t know
* PREFER NOT TO ANSWER

Education Level

1. What is the highest grade or level of school you completed or the highest degree you received? (Check one)
	* Less than high school (less than 9th grade)
	* Some high school (9th to 12th grade), no diploma
	* High school graduate (diploma or GED or equivalent)
	* Some post-high school training (college or occupational, technical, or vocational training), no degree or certificate
	* Associate (2-year) college degree, or completed occupational, technical, or vocational program and received degree or certificate
	* Bachelor’s degree (for example: BA, AB, BS)
	* Graduate or professional degree (for example: MA, MBA, JD, MD, PhD)
* Don’t know
* PREFER NOT TO ANSWER

Income

1. What was your household’s total family income (before taxes) from all sources in the last year? (Check one)
* Less than $5,000
* $5,000 to $9,999 (monthly $416 to $833, biweekly $208 to $416)
* $10,000 to $14,999 (monthly $833 to $1,249, biweekly $416 to $624)
* $15,000 to $19,999 ($1,249 to $1,666 , $624 to $833)
* $20,000 to $24,999 ($1,666 to $2,083 , $833 to $1,041)
* $25,000 to $29,999 ($2,083 to $2,499 , $1,041 to $1,249)
* $30,000 to $39,999 ($2,499 to $3,333 , $1,249 to $1,666)
* $40,000 to $49,999 ($3,333 to $4,166 , $1,666 to $2,083)
* $50,000 to $59,999 ($4,166 to $4,999 , $2,083 to $2,499)
* $60,000 to $69,999 ($4,999 to $5,833 , $2,499 to $2,916)
* $70,000 to $79,999 ($5,833 to $6,666 , $2,916 to $3,333)
* $80,000 to $99,999 ($6,666 to $8,333 , $3,333 to $4,166)
* $100,000 to $119,999 ($8,333 to $9,999 , $4,166 to $4,999)
* $120,000 to $139,999 ($9,999 to $11,666 , $4,999 to $5,833)
* $140,000 or more ($11,666 to + , $5,833 to +)
* DON’T KNOW
* PREFER NOT TO ANSWER
1. How many people (children and adults) were supported by this income in the last year? \_\_\_\_\_\_\_
2. How many people (children and adults) live in your household?\_\_\_\_

The Coronavirus or COVID-19 pandemic has impacted many of us. We would like to understand how it may have impacted you.

Were you diagnosed with COVID-19 (novel coronavirus) by a lab test or a healthcare professional?

* 1       No *(Skip to Q about family and friends)*
* 2      Yes
* 888 Don’t know
* 999 Refused

If yes, was it in the last 6 months?

* 1     Yes
* 2      No
* 888 Don’t know
* 999 Refused

Did you need to stay in the hospital because of COVID-19?

* 1       No
* 2       Yes
* 3       Yes and you had to be on a breathing machine or in intensive care.
* 888 Don’t know
* 999 Refused

How many of your close family members or friends were diagnosed with COVID-19? \_\_\_\_ *(skip to Q about impact on health care access)*

Due to COVID-19 did any of them….

 …have to stay in the hospital or have to be on a breathing machine or in intensive care?

* 1      Yes
* 2      No
* 888 Don’t know
* 999 Refused

….pass away from it?

* 1      Yes
* 2      No
* 888 Don’t know
* 999 Refused

In the last 6 months, how much did the pandemic impact your access to health care, including medical and mental health treatment? This could include your appointments were moved to telehealth or your appointments or prescriptions were delayed or cancelled resulting in an impact on your health.

* 1         Not at all
* 2         A little bit
* 3         Somewhat
* 4         Very much
* 5         Extremely
* 888 Don’t know
* 999 Refused

 In the last 6 months, how much did the pandemic affect your level of stress (including worrying, feeling anxious, sad, angry, or having trouble sleeping)?

* 1       Not at all
* 2       A little bit
* 3       Somewhat
* 4       Very much
* 5       Extremely
* 888 Don’t know
* 999 Refused

In the last 6 months, did the pandemic impact your income? This could include making it harder to meet all your needs like buying food or paying all your bills, more than before the pandemic.

* 1       Not at all
* 2       A little bit
* 3       Somewhat
* 4       Very much
* 5       Extremely
* 888 Don’t know
* 999 Refused

***THANK YOU! YOU HAVE FINISHED THE SURVEY.***