

**TeleKidSeq – Parental Return of Results #2 (RoR2) Survey**

**v. 10/17/20**

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

MM DD YY

Who is administering this survey?

* **Jessica Rodriguez**
* **Nicole Yelton**
* **Jessenia Lopez**
* **Estefany Maria**
* **Karla Lopez**
* **Other (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

How was this survey administered?

* **Telephone**
* **In-Person**
* **Videoconference**

Any changes in zip code or phone number?

* **Yes, zip code changed**
* **Yes, phone number changed**
* **Yes, both changed**
* **No, nothing has changed**
* **[If yes zip code or if yes both], what is your current zip code?**
* **[If yes phone or if yes both], what is your current phone number?**

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)**

Which arm of the study was the subject randomized to?

* **Screen-Share**
* **NO Screen-Share**

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

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

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

Relationship to Child

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

* Mother
* Father
* Legal Guardian

## I. Six months post-ROR Retention

Prompt: “As you remember, about six months ago you met with a genetic counselor to review your child’s genetic test results. The following questions will ask you about what was discussed during that session and about your understanding of your child’s results.”

1. Can you please tell me, in your own words, what were the results of the genetic test? **[OPEN RESPONSE]**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

***PROBE to distinguish, if necessary, between primary vs. secondary findings***

***PROBE to obtain sufficient information to code “positive,” “negative,” or “uncertain”: “Did the results of the test explain your child’s symptoms?”***

Please answer “yes,” “no,” or “not sure/don’t know” to the following questions:

1. The result of the genetic test means my child’s condition is definitely caused by something in his/her genes.

* **Yes**
* **No**
* **Not sure/don’t know**

**PROBE to distinguish if the parent is unsure because they didn’t understand the result or the result of the test was unclear.**

* + **“When you say \_\_\_\_[unsure/don’t know], what do you mean?”**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* + **If need further clarification, ask: “Is it that you didn’t understand the results or that the test didn’t give you a clear answer?”**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* **Refused**

1. The result of the genetic test gave me a genetic explanation for my child’s condition/symptoms.

* **Yes**
* **No**
* **Not sure/don’t know**

**PROBE to distinguish if the parent is unsure because they didn’t understand the result or the result of the test was unclear.**

* + **“When you say \_\_\_\_[unsure/don’t know], what do you mean?”**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* + **If need further clarification, ask: “Is it that you didn’t understand the results or that the test didn’t give you a clear answer?”**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* **Refused**

1. At this time, there is no genetic explanation for my child’s condition/symptoms.

* **Yes**
* **No**
* **Not sure/don’t know**

**PROBE to distinguish if the parent is unsure because they didn’t understand the result or the result of the test was unclear.**

* + **“When you say \_\_\_\_ [unsure/don’t know], what do you mean?”**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* + **If need further clarification, ask: “Is it that you didn’t understand the results or that the test didn’t give you a clear answer?”**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* **Refused**

1. The result of the genetic test means we still don’t know if my child’s condition is genetic or not.

* **Yes**
* **No**
* **Not sure/don’t know**

**PROBE to distinguish if the parent is unsure because they didn’t understand the result or the result of the test was unclear.**

* + **“When you say \_\_\_\_[unsure/don’t know], what do you mean?”**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* + **If need further clarification, ask: “Is it that you didn’t understand the results or that the test didn’t give you a clear answer?”**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* **Refused**

## II. Perceived Understanding

* + 1. Genetic test results can be complicated. How much did you understand about the results that were given to you? Please rate your understanding on a scale of 1 to 5, where 1 means “very little or none of it” and 5 means “you understood almost all or all of it.”

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Very little or none of it  1   | 2   | 3   | 4   | You understood almost all or all of it  5   |

* **Refused**
  + 1. “If you needed to explain your child’s genetic test results to someone else, how confident would you feel doing so?” Answer on a scale of 1 to 5, where 1 is “not confident at all” and 5 is “completely confident.”

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Not confident at all  1   | 2   | 3   | 4   | Completely confident  5   |

* **Refused**

Understanding

9. How well do you understand your child’s test results?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Not at all**  **** | **A little bit**  **** | **Moderately**  **** | **Quite a bit**  **** | **Extremely**  **** |

* **Refused**

## III. Information Seeking Behavior

Prompt: “Next, we will ask you about the resources you may have used after your return of results session to help you understand your child’s genetic test results.”

1. Which of the following sources, if any, did you use to find more information about the genetic test results you received at your last visit? Please rate the usefulness of the sources you used. (Check all that apply)

**1=not useful at all, 5=very useful**

☐ **Family or friends 1 2 3 4 5**

☐ **Facebook 1 2 3 4 5**

☐ **Support groups 1 2 3 4 5**

☐ **My/my child’s other doctors 1 2 3 4 5**

☐ **Internet Search, i.e. Google, Pub Med, etc. 1 2 3 4 5**

☐ **Books and other print media 1 2 3 4 5**

☐ **Information provided by the doctor who 1 2 3 4 5**

**ordered my child’s genetic test**

☐ **Written materials that your 1 2 3 4 5**

**genetic counselor provided**

☐ **Other (please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ 1 2 3 4 5**

☐ **None**

☐ **Refused**

10a. [if internet search selected] If you used the internet to search for information about the results, please list any web sites you found helpful: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

INSTRUCTIONS: Please administer at follow-up 2, 5-7 months post ROR. Please administer this survey to all patients/parents who received diagnostic (positive) or uncertain (likely positive VUS) findings with regards to the primary indication for testing, as well as to participants who received secondary findings.) FOR THOSE WITH NEGATIVE FINDINGS SKIP TO Q15

Please rate your level of agreement or disagreement with the following statements.

**1=strongly disagree, 6=strongly agree**

1. **I understand how I and/or my child came to have this gene change.**

**1 2 3 4 5 6**

* **Refused**

1. **I understand the health risks my relatives face because of this gene change.**

**1 2 3 4 5 6**

* **Refused**

1. **I understand the chances I have of passing this gene change on to my children.**

**1 2 3 4 5 6**

* **Refused**

1. **I feel that I can explain to other people what having this gene change means.**

**1 2 3 4 5 6**

* **Refused**

## IV. Adherence to Medical Follow Up Recommendations and Other Patient-Initiated Actions

Medical Actions and Follow Through on Recommendations [ADMINISTER TO ALL]

Prompts:

For patients with a positive OR VUSfinding:

“You will now be asked about what you did after you received your child’s genetic test results, including whether you shared the results with other health care providers.”

For patients with a negative finding:

“Your child’s genetic test results from participating in this study were negative. However, we would still like to know whether you talked to doctors or other healthcare providers about your child’s test result and anything you did after you received their negative result.”

## Did you discuss your child’s genetic test results with your child’s doctors or health care providers?

* **Yes**
* **Not yet but I plan to**
* **No and I don’t plan to (if selected, skip to Q15c)**
* **Refused**

**15a.** If yes, please indicate which doctors or health care providers you have shared the results with.

* **Primary care provider/pediatrician**
* **Oncologist**
* **Cardiologist**
* **Neurologist**
* **Other specialist(s) \_\_\_\_\_\_\_\_\_**

**15b.** If yes, did the doctor or health care provider make any recommendations based on the test result?

* **Yes**
* **No**
* **I don’t know/don’t remember**
* **Refused**

**15b1.** If yes, what were the recommendations?

1. Medication
   * **Start**
   * **Stop**
   * **Change (*e.g*., stop taking one medication and start another one or increase or decrease the dose or frequency)**
   * **Not applicable**
2. Additional non-genomic medical tests for screening, monitoring, or diagnosis (*e.g*., blood test, imaging such as x-ray, MRI, etc)
   * **Start**
   * **Stop**
   * **Change (*e.g*., increase or decrease the frequency)**
   * **Not applicable**
3. Referrals to consult with other doctors or specialists
   * **Yes** 
     + **If yes, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**
   * **No**
   * **Stop seeing other doctors or specialists (Please specify: \_\_\_\_\_\_\_\_\_\_)**
   * **Not applicable**

iv. Referral to a non-MD health professional

* + New consultation with one or more of the following (please check all that apply):
    - **Audiology**
    - **Dental**
    - **Genetic counselor**
    - **Psychologist**
    - **Other (Please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)**
    - **Not applicable**
  + Stop seeing other non-MD health professional **(Please specify: \_\_\_\_\_\_\_\_\_\_)**

1. Referral for mental health support
   * **Mental health**
   * **Social support**
   * **Palliative care**
   * **Not applicable**
2. Referral for therapeutic services
   * **Speech therapy**
   * **Occupational therapy**
   * **Physical therapy**
   * **Other (Please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)**
   * **Not applicable**
3. Lifestyle changes
   * **Change diet**
   * **Change exercise**
   * **Start taking vitamins and supplements**
   * **Change alcohol consumption**
   * **Stop smoking**
   * **Other (Please specify: \_\_\_\_\_\_\_\_\_\_)**
   * **Not applicable**

**15b2.** Have you followed the recommendations?

* + - * **Yes**
      * **No but I plan to**
      * **No and I do not plan to**
      * **Refused**

**15b2a.** If yes, which ones? \_\_\_\_\_\_\_\_\_\_\_\_

**[PRG: Drop-down menu for Medication, Medical, Other, Lifestyle, with associated response line(s) as indicated below each response category]**

* Medication

1. **Please specify which medication(s): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

* Medical

**a. New consultation with a medical specialist**

**Please specify which specialty(ies):**

**b. New consultation with a non-MD health professional**

**Please specify which non-MD health professional(s): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**c . New consultation for therapeutic service**

**Please specify which therapeutic service(s): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**d. Any additional laboratory testing?**

**Please specify which type of lab test(s): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**e. An imaging test (such as x-ray, MRI, etc.)**

**Please specify which type of imaging test(s):**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**E2. If yes, what is the frequency?**

* **One time only**
* **Recurring**
* Other
* Lifestyle

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**15b2b.** If “No and I do not plan to” [follow the recommendations], Why not? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**15c.** If “no and I don’t plan to,” [discuss the results with my child’s providers] why not?**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Satisfaction with mode of communication of results**

**Taken from ROR1 survey. It was added to assess if communication preferences have changed after participants had chance to review materials sent to family by genetic counselor after visit, via email.**

Satisfaction with mode of communication of results

RESEARCH COORDINATORS - CHOOSE THE SENTENCE IN WHICH THE RESULT WAS RETURNED:

Prompt to participants:

Telehealth services is medical care delivered by high definition video and audio. Sometimes, you can see digital/electronic images that a provider displays on your device. This is called “screen sharing.”

“As a reminder, you received your child’s genetic tests results via **telehealth** with screen sharing.”

“As a reminder, you received your child’s genetic tests results via **telehealth with no screen sharing**.”

**16.** How satisfied were you with receiving your child’s genetic test results this way?

* **Very satisfied**
* **Somewhat satisfied**
* **Somewhat dissatisfied**
* **Very dissatisfied**
* **Refused**

15a. [If select somewhat or very dissatisfied, ask:] Why were you not satisfied receiving your child’s genetic test results this way? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**17.** Would you have preferred to receive your child’s genetic test results in a different way?

* **Yes**
* **No**
* **Don’t know**
* **Refused**

**17a.** [If yes to above question:] Which of the following ways would you have preferred to receive your child’s genetic test results?

* **Over the phone**
* **By mail**
* **By email**
* **In person**
* **Other, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**18.** Is there anything else you wish you could change about how your child’s genetic test results were communicated to you in the TeleKidSeq Study?

* **Yes, please explain: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**
* **No**
* **Don’t know**
* **Refused**

V. Patient-Initiated Actions Attributable to Genomic Testing [ADMINISTER TO ALL]

Prompt: “Next, we will ask you about the changes you have made to you or your child’s lifestyle and perhaps other aspects of your life based on your child’s genetic test results.”

1. Have you made any changes in your/your child’s health care or lifestyle, not based on medical recommendations made by your doctor or health care provider?
   * Yes
   * No
   * Refused

**19a.** If yes, what kind of changes did you make on your own?

* + Changed diet
  + Changed exercise
  + Started taking vitamins and supplements
  + Changed alcohol consumption
  + Stopped smoking
  + Stopped seeking diagnostic testing
  + Stopped medication

What medication did you stop on your own? \_\_\_\_\_\_\_\_\_\_\_

* + Other, specify \_\_\_\_\_\_\_\_\_\_\_\_
  + Refused

1. Did you change your/your child’s insurance based on the results of the genetic testing?
   * Yes
   * No
   * Refused

**20a.** If yes, what kind of change?

* + - * Buying new or buying more life insurance
      * Buying new or buying more disability insurance
      * Buying new or buying more long term care insurance
      * Other, specify\_\_\_\_\_\_\_\_
      * Refused

1. Have you made any other changes to your lifestyle based on the results of the genetic testing?
   * + - Yes
       - No
       - Refused

**21a.** If yes, what kind of change?

* Changed job
* Reduced time or quit job
* Moved closer to hospital
* Other, specify: \_\_\_\_\_\_\_\_\_
* Refused

Seeking genetic counseling for future family planning

1. Are you or your partner pregnant now?
   * Yes
   * No
   * Don’t know / not sure
   * Not applicable
   * Refused

## [ONLY ASK OF PARTICIPANTS WHO RECEIVED A POSITIVE OR LIKELY POSITIVE VUS FINDING. OTHERWISE SKIP TO Q 24] Since the genetic diagnosis was made, have you received counseling from your OB/GYN, reproductive genetic counselor, or primary care provider to discuss how your/your child’s diagnosis might affect future pregnancies?

* Yes
* Not yet but I plan to
* No, and I don’t plan to
* Not applicable
* Refused

**23a.** If “No and I do not plan to”, Why not? \_\_\_\_\_\_\_\_\_\_\_

## Based on your child’s test results, have other family members had genetic testing?

* + Yes
  + No
  + Don’t know / not sure
  + Not applicable
  + Refused

VI. Family Communication

Instructions: **Family Communication is to be administered for ALL PATIENTS. We feel that participants will still find it important to communicate to other family members that their genetic work-up was negative.**

Prompt: "In this next section, we will ask you questions about sharing information about your child’s genetic test results with your biological family members."

1. Since receiving your child’s study results, have you shared the information with any biological family members (blood relatives)?

* **Yes**
* **I didn’t share this information with anyone [PRG: if selected, skip to Q25f]**
* **I haven’t shared this information yet, but plan to in the future [PRG: if selected, skip to Q25h]**
* **I don’t have blood relatives to share this information with [PRG: if selected, skip to next section Q26]**
* **Refused**

[IF YES]

**25a.** Since receiving your child’s study results, have you shared the information with any of the following blood relatives?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Yes** | **No** | **N/A** | **Refused** |
| **My child’s other biologic parent [PRG: only show for parents of pediatric patients]** | **⚪** | **⚪** | **⚪** | **⚪** |
| **My child(ren)** | **⚪** | **⚪** | **⚪** | **⚪** |
| **My siblings** | **⚪** | **⚪** | **⚪** | **⚪** |
| **My parents** | **⚪** | **⚪** | **⚪** | **⚪** |
| **My other biological family members**  **[If select “Yes”:] Please specify who: [PRG: FREE TEXT]** | **⚪** | **⚪** | **⚪** | **⚪** |

**25b.** On a scale of 1 to 5, how important were each of the following reasons for sharing your child’s genetic test results with blood relatives?

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Not at all important (1)** | **2** | **3** | **4** | **Very Important (5)** | **Refused** |
| **To give my blood relatives information about their genetic risk** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **To encourage my blood relatives to have genetic testing** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **The doctor/genetic counselor encouraged me to share the information with blood relatives** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **So my relatives could make family planning decisions** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **To share the information I learned because I thought it was interesting** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **To share my feelings about my genetic test results** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **So I could get help from blood relatives with coordinating and planning for things like appointments and other health-related responsibilities (for example, going to doctors’ appointments, getting child care, getting transportation, etc.)** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |

**25c.** Are there any other reasons that influenced your decision to share the results with blood relatives? [PRG: FREE TEXT]

**25d.** What type of information did you share with blood relatives? Please check all that apply.

* **General information about the study results**
* **Detailed information about the genes they tested**
* **My relative’s risk of having a condition**
* **Information about the possibility of being treated unfairly based on the study results**
* **Recommendations of ways to prevent illness**
* **Recommendations for more screening and testing**
* **Feelings about the study results**
* **Other, please specify: [PRG: FREE TEXT]**
* **Refused**

**25e.** How did you share information about the genetic test results with your blood relatives? Please check all that apply.

* **In person**
* **By phone**
* **By letter**
* **By email**
* **Through social media**
* **Other, please specify: [PRG: FREE TEXT]**
* **Refused**

[IF ‘I didn’t share this information with anyone’]

**25f.** On a scale of 1 to 5, how important were each of the following reasons for not sharing your child’s genetic test results with blood relatives?

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Not at all important (1)** | **2** | **3** | **4** | **Very Important (5)** | **Refused** |
| **I don’t want to worry or upset them** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **I would have to talk to a blood relative I’m not close to/prefer not to talk to** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **I don’t have contact information for my blood relatives** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **I have privacy concerns about sharing this information with my relatives** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **I don’t know how to explain the genetic results to my relatives** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **I don’t think this information is useful for my relatives** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **I’m having trouble coping with my/my child’s results** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **I’m overwhelmed with my/my child’s health** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **I’m worried that my relatives will treat me/my child differently** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |

**25g**. Are there any other reasons that influenced your decision not to share the results with blood relatives? [PRG: FREE TEXT]

[IF ‘I haven’t shared this information yet, but plan to in the future’]

**25h.** On a scale of 1 to 5, how important are each of the following reasons for sharing your child’s genetic test results with blood relatives?

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Not at all important (1)** | **2** | **3** | **4** | **Very Important (5)** | **Refused** |
| **To give my blood relatives information about their genetic risk** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **To encourage my blood relatives to have genetic testing** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **The doctor/genetic counselor encouraged me to share the information with blood relatives** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **So my relatives could make family planning decisions** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **To share the information I learned because I thought it was interesting** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **To share my feelings about my genetic test results** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |
| **So I could get help from blood relatives with coordinating and planning for things like appointments and other health-related responsibilities (for example, going to doctors’ appointments, getting child care, getting transportation, etc.)** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** | **⚪** |

**25i.** Are there any other reasons that will influence your decision to share the results with blood relatives? [PRG: FREE TEXT]

**25j**. What type of information will you share with blood relatives? Please check all that apply.

* **General information about the study results**
* **Detailed information about the genes they tested**
* **My relative’s risk of having a condition**
* **Information about the possibility of being treated unfairly based on the study results**
* **Recommendations of ways to prevent illness**
* **Recommendations for more screening and testing**
* **Feelings about the study results**
* **Other, please specify: [PRG: FREE TEXT]**
* **Refused**

**25k.** How will you share information about the genetic test results with your blood relatives? Please check all that apply.

* **In person**
* **By phone**
* **By letter**
* **By email**
* **Through social media**
* **Other, please specify: [PRG: FREE TEXT]**
* **Refused**

## VI. Use of Communication Tool Post-ROR

**Prompt FOR SCREEN SHARE**: “In this section, we will ask you to share your feelings about how your child’s results were communicated to you. As a reminder, your genetic counselor used screen sharing to display images on your device. She then provided you provided you with a print out/copy by email of what was shown to you on the screen.”

**Prompt FOR NON-SCREEN SHARE:** “In this section we will ask you to share your feelings about how your child’s results were communicated to you. As a reminder, your genetic counselor held up visuals to the camera for you to see. She then provided you with a print out/copy by email of the results and resources.”

1. Did the resources that was used by the genetic counselor help you to understand your child’s genetic test results?

* Yes
* No
* Don’t Know/Unsure
* Refused

1. Have you used the print out/copy of the resources to explain your child’s test results to your child’s physician or other health professionals?

* Yes
* No
* Don’t Know/Unsure
* Refused

1. Have you used the print out/copy of resources to explain your child’s results to your family members?

* Yes
* No
* Don’t Know/Unsure
* Refused

1. How many times have you looked back at the print out/copy of the resources in the past 6 months?**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ times**

* Don’t Know/Unsure
* Refused

Patient Reported Utility (PrU)

Prompt: "In the next section, we will ask you questions about how useful your child's test results have been in making future decisions."

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Please indicate how useful you find the following outcomes of your child’s test result: | | | | | | | |  |
|  | **Not at all useful** | **A little useful** | **Somewhat useful** | **Neutral** | **Useful** | **Very useful** | **Extremely useful** | **Refused** |
| 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 |

Decision Regret (TeleKidSeq ONLY) – *FOR POSITIVE SECONDARY FINDINGS ONLY*

[DO NOT ASK RESPONDENT THIS QUESTION. COORDINATOR TO MARK THIS QUESTION BASED ON TEST RESULTS RECEIVED]

Did the child receive any positive secondary findings? □ Yes □ No *(Skip to Your Child’s Health Section)*

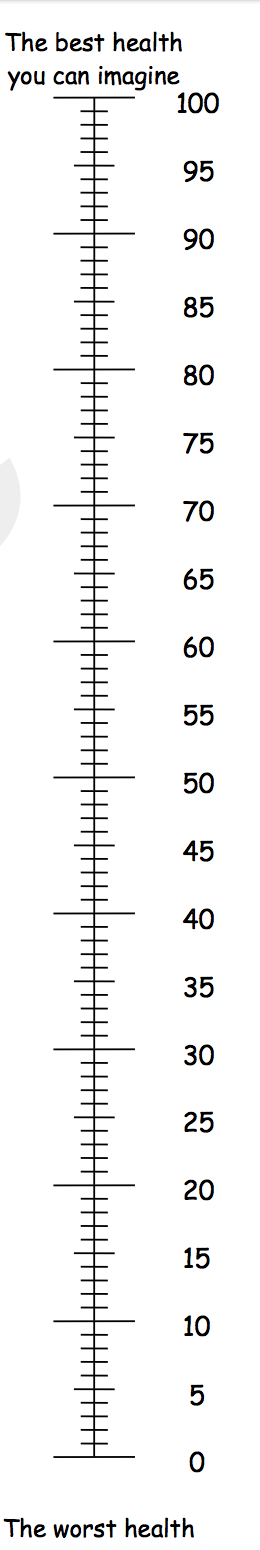
Prompt: “Please reflect on your decision to choose to receive secondary findings for your child. Please show how strongly you agree or disagree with these statements by choosing a number from 1 (strongly disagree) to 5 (strongly agree) which best fits your views about your decision.”

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Strongly Disagree** | **Agree** | **Neither Agree Nor Disagree** | **Disagree** | **Strongly Agree** | **Refused** |
| 1. **It was the right decision** | **1** | **2** | **3** | **4** | **5** | **6** |
| 1. **I regret the choice that was made** | **1** | **2** | **3** | **4** | **5** | **6** |
| 1. **I would go for the same choice if I had to do it over again** | **1** | **2** | **3** | **4** | **5** | **6** |
| 1. **The choice did me a lot of harm** | **1** | **2** | **3** | **4** | **5** | **6** |
| 1. **This decision was a wise one** | **1** | **2** | **3** | **4** | **5** | **6** |

## IX. Your Child’s Health

Prompt: “In this next section, we will ask about your child’s health and development.”

Quality of Life Ascertainment – Visual Analog Scale

* + - * **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**

1. How good is your child’s health TODAY?

YOUR CHILD’S HEALTH TODAY =

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

YOUR CHILD’S HEALTH in the LAST MONTH =

1. Quality of Life Ascertainment - PedsQL

Prompt: “The following page 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 | Some- times | 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 | Some- times | 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 | 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** |
| **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 caregiversems with** | **0** | **1** | **2** | **3** | **4** |
| **2. Not imitating caregiversems with childrenght** | **0** | **1** | **2** | **3** | **4** |
| **3. Not imitating caregiversems with** | **0** | **1** | **2** | **3** | **4** |
| **4. Not able to fix his/her attention on objects** | **0** | **1** | **2** | **3** | **4** |
| **5. Not imitating caregiversattentio** | **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 | Some- times | 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 | 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** | **0** | **1** | **2** | **3** | **4** |
| SOCIAL FUNCTIONING *(problems with…)* | Never | Almost Never | Some- times | 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 | Some- times | 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 | Some- times | 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 | Some- times | 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 | 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 | 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 | Some- times | 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 | Some- times | 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 | Some- 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 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** |

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

Cost Utility Measures

Prompt: “In this next section, we will ask you questions about the level of 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 76)**
   * **DON’T KNOW (Proceed to question 76)**
   * **PREFER NOT TO ANSWER (Proceed to question 76)**
   * **Other, specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

[If yes]

**55a.** 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**

**55b**.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)

**55c**. 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)**

**55d**. 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 80a)**
* **No (Proceed to question 80b)**
* **DON’T KNOW (Proceed to question 81)**
* **PREFER NOT TO ANSWER (Proceed to question 81)**

**60a.** IF YOUR CHILD IS COVERED: What kind or kinds of health insurance or health care coverage do they 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**
* **PREFER NOT TO ANSWER**

**60b.** IF YOUR CHILD IS NOT COVERED: 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**
* **Other, specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**
* **DON’T KNOW**
* **PREFER NOT TO ANSWER**

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 “Feelings and perceptions of genetic test results”
* **DON’T KNOW**
* **PREFER NOT TO ANSWER**

**62a.** 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**

**62b.** On how many days per week do you usually provide 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**

**62c.** 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**

**62d.** 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**

**62e.** How much time during the last week did you spend on practical support for your child like getting outside the house, getting to doctors, organizing help, 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**

**62f.** 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**\*\*Surveyor can ask # hours/day and #days/week and calculate for respondent.
* **Yes, for\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ hours during the last week**
* **DON’T KNOW**
* **PREFER NOT TO ANSWER**

**62g**. 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**

**62h.** 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**

**62i.** 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**

**62j.** 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**

**62k.** 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**

## VII. Feelings and Perceptions Toward Genomic Test Results

Feelings about Genomic Testing Results (FACToR)

Prompt: “Parents may have lots of different reactions to their child’s genetic test results. **The following questions ask about how you, as a parent, felt after receiving your child’s genetic test results. Please indicate how much you had each specific feeling** in the past week **by circling the one answer for each question: *not at all, a little, somewhat, a good deal*, or *a great deal*.** There are no right or wrong feelings or responses.”

1. **How** upset **did you feel about your child’s genetic test result?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** happy **did you feel about your child’s genetic test result?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** anxious or nervous **did you feel about your child’s genetic test result?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** relieved **did you feel about your child’s genetic test result?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** sad **did you feel about your child’s genetic test result?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How**frustrated**did you feel about recommendations for your child's care based on the genetic test?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** uncertain **did you feel about what your child’s genetic test result means for your child?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** uncertain **did you feel about what your child’s genetic test result means for other family members’ risk of disease?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How much did you feel that** you understood clearly your child’s choices **for care based on the genetic test result?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** concerned **did you feel that your child’s genetic test result would affect his or her ability to get or keep health insurance?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** helpful **was the information you received from your genetic test result in planning for your child’s future?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** concerned **did you feel that your child’s genetic test result might make it hard for them to get or keep a job?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** guilty **did you feel about your child’s genetic test result?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

1. **How** much loss of control **over your child’s life did you feel because of your child’s genetic test result?**

* not at all
* a little
* somewhat
* a good deal
* a great deal
* REFUSED

*THANK YOU! YOU HAVE FINISHED THE SURVEY.*