

**TeleKidSeq – Parental Return of Results #1 (RoR1) Survey**

**v. 10/17/2020**

*IF A PARTICIPANT IS VISIBLY UPSET AFTER THE ROR SESSION WITH THE GC AND BEFORE THE ROR1 SURVEY*

“I can see you are upset at this moment and that is OK. Parents can have many different reactions to learning their child’s genetic test results. Here are some tissues and water. Please take a few minutes to yourself. If you would like I can come back and see if you are ready to complete the survey that is part of this study visit.”

1. If participants says they are fine with continuing, allow them a minute or two to compose themselves and begin the survey.
2. If participants says they would like a little more time, allow them 5 minutes of privacy. If when you return they say they are ready to complete the survey, begin to administer it.
3. If participants says they are unable to complete the survey at this time, ask for a time when you can call them later that day (or the next if it is already late in the day) to complete the survey by phone.

*IF A PARTICIPANT BECOMES VISIBLY UPSET DURING THE ROR1 SURVEY*

“I can see you are upset at this moment and that is OK. Parents can have many different reactions to learning their child’s genetic test results. Here are some tissues and water. Please take a few minutes to yourself. If you would like I can come back and see if you are ready to continue the survey then.”

1. If participants says they are fine with continuing, allow them a minute or two to compose themselves and begin the survey.
2. If participants says they would like a little more time, allow them 5 minutes of privacy. If when you return they say they can continue the survey, resume administering it.
3. If participants says they are unable to resume the survey at this time, ask for a time when you can call them later that day (or the next if it is already late in the day) to finish the survey by phone.

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

Who is administering this survey?

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

How was this survey administered?

* Telephone
* In-person
* Videoconference

Any changes in zip code or phone number since last study visit?

* No
* Yes, new contact information:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Which arm of the study was the subject randomized to?

* Screen Share
* No Screen Share

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

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

* + 1. What is your relationship to (child’s name)?
* Mother
* Father
* Legal Guardian

## I. Objective Understanding

Prompt: “Today, 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 this session and about your understanding of these results.”

2. 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:

3. 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

7 . 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 it1 | 2 | 3 | 4 | You understood almost all or all of it5 |

* **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 all1 | 2 | 3 | 4 | Completely confident5 |

* **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. Understanding of Medical Follow Up and Actionability

Report of whether medical follow up is recommended

**10.** Were any recommendations made based on the test result?

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

10a. 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
		1. 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
		1. Referrals to consult with other doctors or specialists
	+ Yes
		1. If yes, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
	+ No
	+ Stop seeing other doctors or specialists (Please specify:\_\_\_\_\_\_\_\_\_\_)
	+ Not applicable
		1. Referral to a non-MD health professional
	+ New consultation with one or more of the following (please check all that applies):
* Audiology
* Dental
* Genetic counselor
* Psychologist
* Other (Please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)
* Not applicable
	+ Stop seeing other non-MD health professional
		1. Referral for mental health support
	+ Mental health
	+ Social support
	+ Palliative care
	+ Not applicable
		1. Referral for therapeutic services
	+ Speech therapy
	+ Occupational therapy
	+ Physical therapy
	+ Other (Please specify: \_\_\_\_\_\_\_\_\_\_)
	+ Not applicable
		1. Lifestyle changes
	+ Change diet
	+ Change exercise
	+ Start taking vitamins and supplements
	+ Change alcohol consumption
	+ Stop smoking
	+ Other (Please specify: \_\_\_\_\_\_\_\_\_\_)
	+ Not applicable

Report of whether family members should receive genetic testing

11. Based on your child’s test results, did your genetic counselor recommend that other family members consider getting genetic testing?

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

Seeking genetic counseling for future family planning

12. Are you or your partner pregnant now?

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

13. [ONLY ASK OF PARTICIPANTS WHO RECEIVED A POSITIVE OR LIKELY POSITIVE VUS FINDING. OTHERWISE SKIP TO Q 15] Based on your child’s genetic test results, did the genetic counselor recommend that you see your OB/GYN, reproductive genetic counselor, or primary care provider to discuss how your child’s diagnosis might affect any future pregnancies?

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

14. [ONLY ASK OF PARTICIPANTS WHO RECEIVED A POSITIVE OR LIKELY POSITIVE VUS FINDING. OTHERWISE SKIP TO Q 15] Will you seek counseling from your OB/GYN, reproductive genetic counselor, or primary care provider to discuss how your child’s diagnosis might affect any future pregnancies?

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

14a**.** If “No and I do not plan to”, Why not? **\_\_\_\_\_\_\_\_\_\_\_**

## IV. Satisfaction

Prompt: “In this next section, we will ask you how satisfied you feel with the way your child’s results were returned as well as your overall experience with the results you received.”

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.”

15. 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? **\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

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

* Yes
* No
* Don’t know
* Refused

16a. [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: **\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

17. 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

Perceptions of Satisfaction and Usefulness of Telehealth Delivery:

***Adapted from 26-item Telemedicine Satisfaction and Usefulness Questionnaire (TSUQ), validated in low-literacy English and Spanish:***

***Bakken S, Grullon-Figueroa L, Izquierdo R, et al. Development, validation, and use of English and Spanish versions of the telemedicine satisfaction and usefulness questionnaire. J Am Med Inform Assoc. 2006;13(6):660-667. doi:10.1197/jamia.M2146***

**Satisfaction scale: 1, strongly disagree to 5, strongly agree.**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Strongly Disagree** | **Disagree** | **Neither Agree nor Disagree** | **Agree** | **Strongly Agree** | **Refused** |
| 1. In general, I am satisfied with the telehealth system
 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. The telehealth equipment is easy to use
 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. It was easy to learn to use the equipment
 | 1 | 2 | 3 | 4 | 5 | 6 |
| **21.** My privacy is protected during video visits | 1 | 2 | 3 | 4 | 5 | 6 |
| **22.**Video visits are a convenient form of healthcare delivery for me | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. Video visits save me time
 | 1 | 2 | 3 | 4 | 5 | 6 |
| **24.** My genetic counselor answers my questions | 1 | 2 | 3 | 4 | 5 | 6 |
| **25.** My genetic counselor deals with my child’s problems  | 1 | 2 | 3 | 4 | 5 | 6 |
| **26.** My genetic counselor engages me in my child’s visit | 1 | 2 | 3 | 4 | 5 | 6 |

**Overall satisfaction with results**

**27**. Overall, how satisfied are you with your child’s genetic test results?

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

**27a.** **[If selects somewhat or very dissatisfied, ask:]** Why were you not satisfied? **\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**27b.** Overall, how satisfied are you with the materials that your genetic counselor used to explain your child’s genetic test results?

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

27c. **[If selects somewhat or very dissatisfied, ask:]** Why were you not satisfied? **\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

1. Overall, how much information did you receive about your child’s genetic test results?
* Too much
* About right
* Too little
* Don’t know
* Refused

Please tell us about your experience receiving your child’s genetic test results.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Refused |
| 1. I was treated with sensitivity and respect.
 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. I felt listened to.
 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. The clinical team checked to make sure I understood the information.
 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. I trust the clinical team.
 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. The clinical team explained complicated topics well.
 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. I got clear, understandable information.
 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. I received too much information to understand.
 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. It was hard to make sense out of the information.
 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1. I felt I had the information and support available to me to answer any questions I had after receiving my child’s genetic results.
 | 1 | 2 | 3 | 4 | 5 | 6 |

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree | Not Applicable | Refused |
| 1. I felt comfortable asking questions and voicing my concerns.
 | 1 | 2 | 3 | 4 | 5 | 6 | **7** |
| 1. The clinical team helped me cope with any uncertainty or unknowns.
 | 1 | 2 | 3 | 4 | 5 | 6 | **7** |
| 1. It was hard to ask questions about this information.
 | 1 | 2 | 3 | 4 | 5 | 6 | **7** |
| 1. I felt comfortable talking about sensitive issues or embarrassing subjects with the clinical team.
 | 1 | 2 | 3 | 4 | 5 | 6 | **7** |
| 1. The clinical team noticed when I had problems understanding.
 | 1 | 2 | 3 | 4 | 5 | 6 | **7** |
| 1. I had questions about this information that I was unable to ask.
 | 1 | 2 | 3 | 4 | 5 | 6 | **7** |

Patient Reported Utility (PrU)

Prompt: "In the next section, we will ask you questions about how useful your child's test results will be 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** |  | **Very useful** | **Extremely useful** | **Refused** |
| **44. Help with my child’s life planning**  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **45. Inform plans for my child’s school or career** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **46. Inform my child’s decisions about having children** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **47. Use for testing a future pregnancy, if appropriate** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **48. Help me or our family mentally prepare for the future** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **49. Help to better understand my child’s health** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **50. Contribute to my child’s self-knowledge** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **51. Help me cope with my child’s health risks** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **52. Help me feel more in control of my child’s health** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **53. Help me feel more in control of my child’s life** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **54. Simply to provide information**  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **55. Satisfy my curiosity about my child** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **56. Help my child use social programs, like resources and services** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **57. Improve communication with my family members**  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **58. Feel good about helping the medical community** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **59. Feel good about having information for family members** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| **60. 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 Information Seeking Behavior section)*

Prompt: “Please reflect on your decision to choose to receive secondary findings for your child. Please tell me 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** | **Disagree** | **Neither Agree Nor Disagree** | **Agree** | **Strongly Agree** | **Refused** |
| **61. It was the right decision** | 1 | 2 | 3 | 4 | 5 | 6 |
| **62. I regret the choice that was made** | 1 | 2 | 3 | 4 | 5 | 6 |
| **63. I would go for the same choice if I had to do it over again** | 1 | 2 | 3 | 4 | 5 | 6 |
| **64. The choice did me a lot of harm** | 1 | 2 | 3 | 4 | 5 | 6 |
| **65. This decision was a wise one** | 1 | 2 | 3 | 4 | 5 | 6 |

## VI. Information Seeking Behavior

**66.** Which of the following sources, if any, do you think you are likely to use to find more information about the genetic test results you received? (check all that apply)

**☐** Family or friends

☐ Facebook

☐ Support groups

☐ My/my child’s other doctors

☐ Internet Search, i.e. Google, Pub Med, etc.

☐ Books and other printed materials

☐ Information provided by the doctor who ordered my child’s genetic test

☐ Written materials that your genetic counselor provided

☐ Other (please specify)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

☐ None

INSTRUCTIONS: Please administer this survey to all participants 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. DO NOT ASK OF PARTICIPANTS WITH NEGATIVE FINDINGS.

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

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

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

 1 2 3 4 5 6

* Refused

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

1 2 3 4 5 6

* Refused

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

1 2 3 4 5 6

* Refused

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

1 2 3 4 5 6

* Refused

**INSTRUCTIONS: Please administer these next set of questions to both participants in the screen share study arm AND the non-screen share study arm.**

**Prompt FOR SCREEN SHARE:** 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.” The genetic counselor used telehealth with screen sharing capabilities to use visuals to explain your child’s genetic results to you. In this section, we will ask you to tell us how helpful the visuals were to you.

**Prompt FOR NON-SCREEN SHARE:** Telehealth services is medical care delivered by high definition video and audio. The genetic counselor used telehealth and visuals to explain your child’s genetic results to you. These visuals were held up to the camera for you to see. In this section, we will ask you to tell us how helpful the visuals were to you.

How helpful were the visuals in...

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | Extremely Helpful | Very Helpful | Neutral | Unhelpful | Extremely Unhelpful | Refused | Not applicable |
| **71.**  explaining your child’s test results to you | **1** | **2** | **3** | **4** | **5** | **6** | **7** |
| **72.** reducing your anxiety about your child’s test results | **1** | **2** | **3** | **4** | **5** | **6** | **7** |
| **73.** explaining the next steps for your child’s care | **1** | **2** | **3** | **4** | **5** | **6** | **7** |

 The genetic counselor will be e-mailing or mailing you a copy of these visuals. How helpful do you think the visuals will be in…

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | Extremely Helpful | Very Helpful | Neutral | Unhelpful | Extremely Unhelpful | Refused | Not applicable |
| **74.**  your ability to share your child’s test results with your family? | **1** | **2** | **3** | **4** | **5** | **6** | **7** |

Thank you. Next, we will ask your opinion about the information provided to you and how it was provided:

**75.** Would you say that the information presented was:

* Hard to understand
* Easy to understand
* Just right
* Refused

**76.** Would you say that the amount of information presented was:

* Too much
* Too little
* Just right
* Refused

**77**.  Did the pictures help you understand the information better?

* Yes
* No
* Not sure/Don’t Know
* Refused

**78.** Could you see the pictures clearly?

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

## V. 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. 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 after receiving your child’s genetic test results by choosing 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. Please answer these as best as you can right now.”

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

[DO NOT ASK – COORDINATOR TO MARK] **Was the set of COVID questions answered in the baseline survey? Yes/No**

[DO NOT ASK RESPONDENT CORONAVIRUS QUESTIONS, IF THEY ALREADY ANSWERED THESE IN THE BASELINE SURVEY]

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

***You have completed the survey. Thank you!***