****Clinical Sequence Evidence-Generating Research Consortium

**CSER Parental Patient Measures – post-ROR Follow-up #1 (0 - 4 weeks post-RoR)**

Proposed by: multiple CSER Working Groups

Version 1.4, Dated 7/16/2018

## Feelings about Genomic Testing Results (FACToR) – Parent

*Citation:*

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*.

1. How **upset** did you feel about your child’s genetic test result?
2. How **happy** did you feel about your child’s genetic test result?
3. How **anxious or nervous** did you feel about your child’s genetic test result?
4. How **relieved** did you feel about your child’s genetic test result?
5. How **sad** did you feel about your child’s genetic test result?
6. How **frustrated** did you feel about recommendations for your child's care based on the genetic test?
7. How **uncertain** did you feel about what your child’s genetic test result means for your child?
8. How **uncertain** did you feel about what your child’s genetic test result means for other family members’ risk of disease?
9. How much did you feel that **you understood clearly your child’s choices** for care based on the genetic test result?
10. How **concerned** did you feel that your child’s genetic test result would affect his or her ability to get or keep health insurance?
11. How **helpful** was the information you received from your genetic test result in planning for your child’s future?
12. How **concerned** did you feel that your child’s genetic test result might make it hard for them to get or keep a job?
13. How **guilty** did you feel about your child’s genetic test result?
14. How **much loss of control** over your child’s life did you feel because of your child’s genetic test result?

## Perceptions of Uncertainties in Genomic Sequencing (PUGS) (PARENT)

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| *Citation: Biesecker BB, Woolford SW, Klein WMP, Brothers KB, Umstead KL, Lewis KL, Biesecker LG, Han PKJ. PUGS: A novel scale to assess perceptions of uncertainties in genome sequencing. Clin Genet. 2017 Aug;92(2):172–179. PMCID: PMC5462880*  *Parental Perceptions of Uncertainties in Genome Sequencing (PUGS)* | | | | | | | |
| **Rate how certain you feel about the following aspects of your child’s sequence results:** | | | | | | | |
|  | **Very**  **Uncertain** | |  | | | **Very**  **Certain** | |
| **1. What my child’s test results mean for his/her health** | **1** | **2** | | **3** | **4** | | **5** |
| **2. What actions I need to take based on my child’s test results** | **1** | **2** | | **3** | **4** | | **5** |
| **3. How my child’s doctor may use the results to improve my child’s health** | **1** | **2** | | **3** | **4** | | **5** |
| **4. Whether I am worried or concerned about my child’s test results** | **1** | **2** | | **3** | **4** | | **5** |
| **5. Whether my child’s test results revealed something alarming** | **1** | **2** | | **3** | **4** | | **5** |
| **6. Whether my child’s test results disrupted my life** | **1** | **2** | | **3** | **4** | | **5** |
| **7. Whether I can trust my child’s test results** | **1** | **2** | | **3** | **4** | | **5** |
| **8. Whether my child’s test results are accurate** | **1** | **2** | | **3** | **4** | | **5** |

## Patient Reported Utility (PrU)

*Citation:*

**PARENTAL PERSONAL UTILITY SCALE (PrU) —FINAL VERSION 17 items**

***Set survey to randomize items to avoid order effects***

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| 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 |
| Help with my child’s life planning | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Inform plans for my child’s school or career | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Inform my child’s decisions about having children | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Use for testing a future pregnancy, if appropriate | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help me or our family mentally prepare for the future | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help to better understand my child’s health | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Contribute to my child’s self-knowledge | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help me cope with my child’s health risks | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help me feel more in control of my child’s health | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help me feel more in control of my child’s life | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Simply to provide information | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Satisfy my curiosity about my child | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help my child use social programs, like resources and services | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Improve communication with my family members | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Feel good about helping the medical community | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Feel good about having information for family members | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Feel good about taking responsibility for my child’s health | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

## Understanding (novel)

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

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

## Information seeking V1

*Citation: Read CY, Perry DJ, Duffy ME. Design and psychometric evaluation of the Psychological Adaptation to Genetic Information Scale. J Nurs Scholarsh. 2005;37(3):203–208. PMID: 16235859*

**INSTRUCTIONS**: This version and version 2 (see next page) can be alternated at post-ROR follow-up 1, 0-3 weeks post ROR. Your site may also choose one version to use for the whole cohort at follow-up 1. Please administer this survey to all patients/parents who received diagnostic or uncertain (VUS) findings with regards to the primary indication for testing, as well as to participants who received secondary findings.

**Information sources Version 1 for Post-ROR Follow Up #1**

What sources, if any, do you think you are likely to use to find more information about the genetic test results you received today? Please write below.

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

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

1=strongly disagree, 6=strongly agree

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

1 2 3 4 5 6

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

1 2 3 4 5 6

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

1 2 3 4 5 6

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

1 2 3 4 5 6

**INSTRUCTIONS:** This version and version 1 (see above) can be alternated at post-ROR follow-up 1, 0-3 weeks post ROR. Your site may also choose one version to use for the whole cohort at follow-up 1. Please administer this survey to all patients/parents who received diagnostic or uncertain (VUS) findings with regards to the primary indication for testing, as well as to participants who received secondary findings.

**Information Sources Version 2 for Post-ROR Follow-up 1**

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 today?

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

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

None

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

1=strongly disagree, 6=strongly agree

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

1 2 3 4 5 6

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

1 2 3 4 5 6

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

1 2 3 4 5 6

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

1 2 3 4 5 6

## Satisfaction with mode of communication of results

OF NOTE: “Your Child’s” below can be replaced by “Your” for adult centers

PREFERRED :

As a reminder, you received your child’s genetic tests results [PRG: in-person OR over the phone OR over videoconference OR by email].

SECOND OPTION:

How did you receive your child’s genetic test results?

* In-person
* Over the phone
* Over a videoconference
* By email
* Other, please specify: [PRG: FREE TEXT]

*Variable*: Satisfaction with mode of communication of results

*Origin*: Novel

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

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

OPTIONAL: [PRG: If select somewhat or very dissatisfied, ask:] Why were you not satisfied receiving your child’s genetic test results this way? [PRG: FREE TEXT]

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

* Yes
* No

[If yes to above Q:] Which of the following ways would you have preferred to receive your child’s genetic test results? [PRG: don’t show mode by which parent received results as a response option]

* In-person
* Over the phone
* Over a videoconference
* By email
* Other, please specify: [PRG: FREE TEXT]

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

* Yes, please explain: [PRG: FREE TEXT]
* No

## Overall satisfaction with results

*Variable*: Overall satisfaction with results

*Origin*: Novel

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

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

OPTIONAL: [PRG: If select somewhat or very dissatisfied, ask:] Why were you not satisfied? [PRG: FREE TEXT]

1. Overall, how much information did you receive about your child’s genetic test results?

* Too much
* About right
* Too little

*Name of scale*: Patient Assessment of Communication Effectiveness (PACE); Novel measure

Adapted from Mazor 2016 and Street 2016; Novel

*Citation #1: Mazor KM, Street RLJ, Sue VM, Williams AE, Rabin BA, Arora NK. Assessing patients’ experiences with communication across the cancer care continuum. Patient Educ Couns. 2016 Aug;99(8):1343–1348. PMCID: PMC4931971*

*Citation #2: Street RL, Mazor KM, Arora NK. Assessing Patient-Centered Communication in Cancer Care: Measures for Surveillance of Communication Outcomes. J Oncol Pract. 2016 Dec;12(12):1198–1202. PMCID: PMC5455589*

[PRG: if parent received results by email, DO NOT SHOW Qs 6-10]

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

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |
| 1. I was treated with sensitivity and respect. | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ |
| 1. I felt listened to. | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ |
| 1. The clinical team checked to make sure I understood the information. | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ |
| 1. I trust the clinical team. | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ |
| 1. The clinical team explained complicated topics well. | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ |
| 1. I got clear, understandable information. | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ |
| 1. I received too much information to understand. | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ |
| 1. It was hard to make sense out of the information. | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ |
| 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. | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ |

[PRG: if parent received results by email, DO NOT SHOW Qs 15-19]

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