****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.
 | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ | ⭘ |