**CSER HARMONIZED MEASURE REPOSITORY: Understanding (Adult Version)**

| **Template topic** | **Definition/Note** |
| --- | --- |
| **Measure name and acronym** | * Item #1: Understanding (CSER2 novel scale)
* Items #2-5: Psychological Adaptation to Genetic Information Scale (PAGIS) certainty subscale (subset of 4 items from 6-item subscale)
 |
| **Source citation for original measure** | * Item #1: NA
* Items #2-5: 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
 |
| **Name of construct** | Perceived understanding of test results  |
| **Conceptual definition** | * Item #1: Respondents’ general perception that they understand their test results
* Items #2-5: Respondents’ perception that they understand several specific aspects of their test results, including how they came to have the gene change their test identified, its implications for their relatives’ health risks, and their chances of passing it on to their children, as well as their perception they understand their gene change well enough that they can explain to other people what having it means.
 |
| **Category in CSER framework** | Patient processes |
| **Description of measure** | * Item #1: Respondents’ perceived general understanding of their genetic test results is measured with a single item that asks them to rate the extent to which they understand their test results on a 5-item Likert scale ranging from “not at all” to “extremely.” This item was created for the CSER consortium.
* Items #2-5: Respondents’ perceived understanding of specific aspects of their genetic test results is measured with 4 items adapted from the 6-item certainty subscale of the Psychological Adaptation to Genetic Information Scale (PAGIS). The items assess the extent to which respondents agree or disagree that they understand how they came to have the gene change that was identified, the health risks their relatives face because of the gene change, and the chances they have of passing the gene change on to their children, and the extent to which they agree or disagree that they can explain to other people what having this gene change means. Responses are provided on a 6-item discrete visual analog scale ranging from 1=Strongly disagree to 6=Strongly agree.
 |
| **Operational definition of construct** | * Item #1: Item measures respondents’ perceived general understanding of their genetic test results.
* Items #2-5: According to Read et al. (2005), the items on the certainty subscale of the PAGIS assess respondents’ “perception of accurate knowledge and understanding of what it means to have the disease-related gene” (p. 203-204).
 |
| **Summary of changes made to measure for CSER (“CSER-adapted scale”), if any** | * Item #1: NA
* Items #2-5: The CSER-adapted version of this scale includes 4 of the 6 items from the certainty subscale of the PAGIS. The selected items included 4 of the 5 items with the highest factor loadings from a principal component analysis in Read et al. (2005). The word “gene” in the original items was reworded to “gene change” in the CSER items for accuracy (e.g., “I understand how I came to have this gene” was reworded to “I understand how I came to have this gene change”). In addition, the item “I understand the chances I have of passing this gene along to my children” was reworded to “I understand the chances I have of passing this gene change on to my children.”
 |
| **Time to administer** | * Item #1: < 1 min.
* Items #2-5: 1 min.
 |
| **Target Respondent(s)** | Adult patients  |
| **Age range(s) or respondents** | * Item #1: NA
* Items #2-5: Read et al. (2005) participants ranged in age from “under 18” to “over 85” with a median age in the category of 36 to 45 years old.
 |
| **Number of items**  | Original scale: * Item #1: NA
* Items #2-5: 6 items in original PAGIS certainty subscale
 |
| CSER adapted: * Item #1: 1 (novel item)
* Items #2-5: 4 items
 |
| **Subscales and items per subscale**  | Original scale: * Item #1: NA
* Items #2-5: The 6-item certainty subscale is one of 5 subscales in the 26-item PAGIS. The certainty subscale itself is unidimensional.
 |
| CSER adapted: * Item #1: 1 item
* Items #2-5: one 4-item scale, assumed to be unidimensional.
 |
| **Response scale (including anchor labels)** | Original scale: * Item #1: NA
* Items #2-5: Per Catherine Read (personal communication 2/6/19) and Read et al. (2005) – the PAGIS uses a 1-6 Likert scale (1=strongly disagree, 2=moderately disagree, 3=slightly disagree, 4=slightly agree, 5=moderately agree, 6=strongly agree). The measure was administered in an electronic survey and respondents were not allowed to skip items. Respondents were allowed to respond “don’t know/not applicable” to items.
 |
| CSER adapted: * Item #1: Not at all, A little bit, Moderately, Quite a bit, Extremely
* Items #2-5: 6-point Discrete Visual Analog scale in which 1= “strongly disagree” to 6=”strongly agree.” The interior responses are labeled by the numbers 2 through 5.
 |
| **Scoring instructions**  | Original Scale: * Item #1: NA
* Items #2-5: Because the electronic survey was programmed so that respondents were not allowed to skip items, no data were missing. When respondents checked the “don’t know/not applicable” response (≤ 5% of the observations), median substitution was used. One item on the certainty subscale (not included in the CSER-adapted scale) was reverse scored. Responses were averaged to create a score for which higher scores indicated greater certainty (understanding).
 |
| CSER adapted: * Item #1: Response to single item is score; higher score indicated greater understanding.
* Items #2-5: Responses will be summed, then divided by the number of responses provided, to create a score for which higher scores indicated greater certainty (understanding) Recommended rule for missing data: Require at least 3 responses of 4. The scoring described above is equivalent to using mean imputation for the missing item.
 |
| **Validated cutoff scores, if any** | No known cutoff scores for either item #1 or items #2-5. |
| **Norms (if available)** | Original scale: No known norms for either item #1 or items #2-5. |
| **Contact for permission to use/adapt (associated cost)** | * Item #1: CSER Measures and Outcomes Work Group
* Items #2-5: For any necessary permissions, contact lead author of 2005 paper, Catherine Read (readca@bc.edu). No cost to use this published scale.
 |
| **Validated administration modes** | * Item #1: NA
* Items #2-5: Online survey (Read et al., 2005)
 |
|  **Original measure languages available**  | * Item #1: NA (but translated to English and Spanish for CSER)
* Items #2-5: English
 |
| **Evidence for reliability (provide type and values)** | * Item #1: NA
* Items #2-5: From Read et al. (2005) sample of 323 participants who were 82% female, 91% White, and ranging in age from under 18 to over 85. They completed a web-based survey after having been recruited via electronic mailing lists and websites for people affected by genetic diseases. Internal consistency reliability (Cronbach’s alpha) of .90 for 26-item PAGIS measure and .77 for the 6-item certainty subscale. No study has used a subscale consisting of only the 4 items being used in CSER, so the reliability of this briefer scale is to be determined.
 |
| **Evidence for validity (provide type and values if available)** | * Item #1: NA
* Items #2-5: No known validity data.
 |
| **Evidence for sensitivity to change** | * Item #1: NA
* Items #2-5: No known evidence for sensitivity to change.
 |
| **Relevant references in genetics or genomics** | * Item #1: NA
* Items #2-5: No known references other than the source reference.
 |

**Paste original scale below**

**Item #1: No original scale (novel item)**

**Items #2-5 (from Read et al., 2005)**

1=strongly disagree, 2=moderately disagree, 3=slightly disagree, 4=slightly agree, 5=moderately agree, 6=strongly agree

1. I understand how I came to have this gene.
2. I understand the health risks my relatives face because of this gene.
3. I feel certain that I understand the meaning of having this gene.
4. I understand the chances I have of passing this gene along to my children.
5. I feel that I can explain to other people what having this gene means.
6. I feel confused because I have been given different explanations of what having this gene means.

**Paste CSER adaptation below**

NOVEL ITEM:

1. How well do you understand your test results?

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

SUBSET OF ITEMS FROM PAGIS CERTAINTY SUBSCALE

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

1=strongly disagree, 6=strongly agree

2. I understand how I came to have this gene change.

1 2 3 4 5 6

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

1 2 3 4 5 6

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

1 2 3 4 5 6

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

1 2 3 4 5 6