**CSER HARMONIZED MEASURE REPOSITORY: Information Seeking (Adult and Parent Versions)**

| **Template topic** | **Definition/Note** |
| --- | --- |
| **Measure name and acronym** | Information seeking  |
| **Source citation for original measure** | NA (two versions of a single item measure developed at UCSF by Shannon Rego and Anne Slavotinek in the EDU/ROR working group) |
| **Name of construct** | Information Seeking |
| **Conceptual definition** | The conceptual definition of *health information seeking* from <https://chirr.nlm.nih.gov/health-information-seeking.php> is “Intentional, active efforts to obtain specific information above and beyond the normal patterns of media exposure and use of interpersonal sources (Atkin, 1973; Griffin, Dunwoody, & Neuwirth, 1999)…. Health information seeking is distinguished from information scanning (e.g., Morris, Rooney, Wray, & Kreuter, 2009; Niederdeppe, et al., 2007), which is information acquisition from routine or habitual media use and interpersonal communication. Information scanning is seen as less active and less goal-directed than information seeking.” |
| **Category in CSER framework** | Patient processes |
| **Description of measure** | This measure includes two alternative versions of a single-item measure that gathers data on sources of information respondents perceive themselves to be likely to use to find more information on the genetic test results they received. * The first of these two alternative versions asks for an open-ended response to a question assessing potential sources of information. Responses will need to be coded for quantitative analyses.
* The second of these two alternative versions provides a checklist of 7 possible sources of information along with an “other” option that allows respondents to specify a different source and an option that allows them to report they are not likely to use any sources (“none”).

Note: The measure developed at UCSF by Shannon Rego and Anne Slavotinek and shown in the harmonized measures document also includes 4 items assessing understanding from the certainty subscale of the PAGIS; they are reported on the validation template for measures of “understanding.” These four items are not relevant to the construct of information seeking, and thus are not recommended for inclusion in quantitative psychometric analysis of information seeking. |
| **Operational definition of construct** | The two alternative versions of this item assess sources of information respondents may use to find more information about the genetic test results they received. Respondents may report zero or more sources. Because the measure is administered close in time to return of results, it is focused on respondents’ expectations regarding the sources they are likely to use rather than their actual behavior. This measure may also be conceptualized as assessing respondents’ intended behaviors, linking it to research on theoretical models of health behaviors that include behavioral intentions (a person's subjective probability of engaging in a behavior) as a primary determinant of actual behavior (e.g., the theory of reasoned action or the theory of planned behavior). |
| **Summary of changes made to measure for CSER (“CSER-adapted scale”), if any** | NA: These items were created for the CSER consortium. |
| **Time to administer** | < 1 min. |
| **Target Respondent(s)** | Adult patient, Parent of pediatric patient |
| **Age range(s) or respondents** | NA These items have not been validated.  |
| **Number of items**  | Original scale: NA |
| CSER: Single item, with 2 alternative versions. |
| **Subscales and items per subscale**  | Original scale: NA |
| CSER: NA |
| **Response scale (including anchor labels)** | Original scale: NA |
| CSER: 1 version of this item uses an open-ended response, and the other uses a checklist with a pre-specified set of possible options (7 sources of information, an “other” option that asks respondents to specify the other source, and an option for “none”).  |
| **Scoring instructions**  | Original Scale: NA |
| CSER: Scoring depends on the alternative version of the item used by a site. As a first step, for the version with the open-ended response only, responses will need to be coded for use in quantitative analyses. The responses should be coded into the same 9 categories available in the version with a checklist: family or friends, facebook, support groups, my/my child’s other doctors, Internet search, books and other printed materials, information provided by the doctor who ordered my/my child’s genetic test, other, or none. This step is not needed for the alternative version of the item that includes the checklist.There are several possible scoring options, depending on the research question being addressed: These scoring options include (1) computing the percentage of participants or subsets of participants who select/list individual sources of information; (2) counting the unique sources listed (e.g., as a broad indicator of the breadth or extend to intended information seeking); (3) scoring an individual or related subset of sources as having been selected/listed (e.g., to evaluate associations of selecting/reporting a source/sources with other variables).  |
| **Validated cutoff scores, if any** | NA |
| **Norms (if available)** | NA |
| **Contact for permission to use/adapt (associated cost)** | Shannon Rego and Anne Slavotinek at UCSF; no known cost to use. |
| **Validated administration modes** | NA |
|  **Original measure languages available**  | NA (But developed in English and Spanish for CSER) |
| **Evidence for reliability (provide type and values)** | NA |
| **Evidence for validity (provide type and values if available)** | NA |
| **Evidence for sensitivity to change** | NA |
| **Relevant references in genetics or genomics** | NA |

**Paste original scale below**

**N/A**

**Paste CSER adaptation below**

**Note about versions of items:** This version and version 2 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**

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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**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**

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

**Note that the measure developed for information seeking included one of the two items listed above, plus the following 4 items from the 6-item PAGIS certainty subscale:**

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.

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

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

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

**Paste or list CSER site-specific adaptation/deviation below**