**CSER HARMONIZED MEASURE REPOSITORY** **Patient-Initiated Actions Attributable to Genomic Testing**

| **Template topic** | **Definition/Note** |
| --- | --- |
| **Measure name and acronym** | Patient-Initiated Actions Attributable to Genomic Testing |
| **Source citation for original measure** | Novel (developed through iterative process of CUHEP working group leadership) |
| **Category of assessment (construct/ CSER framework location)** | Clinical utility/Patient-centered utility |
| **Description of measure** | Asks whether patients initiated any actions as a result of receiving genetic test results. This is a survey rather than a psychometric measure and thus not appropriate for psychometric validation. However, some of these items may be useful as outcome variables to use in predictive validity analyses. |
| **Operational definition of construct** | NA |
| **Summary of changes made to measure for CSER (“CSER-adapted scale”), if any** | NA |
| **Time to administer** | estimated 00:01:30 plus free text |
| **Target Respondent(s)** | Adult patient and parent of pediatric patient versions |
| **Age range(s) or respondents** | NA |
| **Number of items** | Original scale: NA |
| CSER adapted |
| **Subscales and items per subscale** | Original scale: NA |
| CSER adapted |
| **Response scale (including anchor labels)** | Original scale: NA |
| CSER adapted |
| **Scoring instructions** | Original Scale: NA |
| CSER adapted |
| **Validated cutoff scores, if any** | NA |
| **Norms (if available)** | Original scale: NA |
| **Contact for permission to use/adapt (associated cost)** |  |
|  |  |
| **Validated administration modes** | Examples: Paper and pencil, computer adaptive test, interview |
| **Original measure languages available** | NA |
| **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**

**Paste CSER adaptation below**

**Patient-Initiated Actions Attributable to Genetic Testing**

1. Have you made any changes in your/your child’s health care or lifestyle, not based on medical recommendations made by your doctor or health care provider?
   1. Yes
   2. No

1a. If yes, what kind of changes did you make on your own?

* 1. Changed diet
  2. Changed exercise
  3. Started taking vitamins and supplements
  4. Changed alcohol consumption
  5. Stopped smoking
  6. Stopped seeking diagnostic testing
  7. Stopped medication
     + - What medication did you stop on your own? \_\_\_\_\_\_\_\_\_\_\_
  8. Other \_\_\_\_\_\_\_\_\_\_\_\_

2. Did you change your/your child’s insurance based on the results of the genetic testing?

1. Yes
2. No

2a. If yes, what kind of change?

* + 1. Buying new or buying more life insurance
    2. Buying new or buying more disability insurance
    3. Buying new or buying more long term care insurance

1. Have you made any other changes to your lifestyle based on the results of the genetic testing?
2. Yes
3. No

3a. If yes, what kind of change?

1. Changed job
2. Reduced time or quit job
3. Moved closer to hospital

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

**SouthSeq:** Not administering

**ClinSeq:** “Alternative” version according to harmonized measures Google sheet, but surveys not available