**CSER HARMONIZED MEASURE REPOSITORY: Patient reported utility (Adult/Parent)**

| **Template topic** | **Definition/Note** |
| --- | --- |
| **Measure name and acronym** | Patient Reported Utility (PRU) |
| **Source citation for original measure** | Kohler, Jennefer N., et al. "Defining personal utility in genomics: A Delphi study." Clinical genetics 92.3 (2017): 290-297. |
| **Category of assessment (construct/ CSER framework location)** | Patient perceptions of the non-clinical utility of genomic sequencing |
| **Conceptional definition and rational for using** | 19-item Survey, instructions have items randomized, this measure is used to assess patients’ perception of utility of clinical sequencing |
| **Operational definition of construct** | “Taken literally, the concept of personal utility describes benefitsbeyond clinical utility. While negative outcomes, or harms, resultingfrom genetic testing cannot be considered “of use” to individuals,patients have also raised concerns about potential harms in the context of personal utility. For example, these harms include potential violation of privacy, discrimination and stigma. Concern about potential harms informs decision-making such as whether to undergo testing. These concerns may lead to patients forgoing testing and its associated benefits.10 Given the importance of harms to test decision-making we investigated them in conjunction with personal utility in this study.”  |
| **Summary of changes made to measure for CSER (“CSER-adapted scale”), if any** | The original measure included a place an additional scale for each question that assessed “utility for other people” such that it assessed personal utility and beliefs about how others will feel about the utility, literacy level lowered, parent language added for parent version. |
| **Time to administer** | 10 min |
| **Target Respondent(s)** | Patient |
| **Age range(s) or respondents** | Originally validated in adults aged 45-65, predominately Caucasian population |
| **Number of items**  | Original Scale: 24 |
| CSER2: 19 |
| **Subscales and items per subscale**  | Original Scale: Anticipatory guidance, immediate benefits, social benefits |
| CSER2: Same as original |
| **Response scale (including anchor labels)** | Original: Required 2 ratings per-item; How plausible is this outcome for you? How plausible is this outcome for others? Scored 1=very implausible,2= implausible, 3=somewhat implausible 4=neutral 5=somewhat plausible, 6=plausible, 7=very plausible |
| CSER2: Please indicate how useful you find the following outcomes of genome sequencing: Scored 1=not at all useful,2= a little useful, 3=somewhat useful 4=neutral 5=useful, 6=very useful, 7=extremely useful |
| **Scoring instructions**  | No suggested scoring but median scores given |
| Choices include, total score, mean item score |
| **Validated cutoff scores, if any** | No cutoff scores suggested |
| **Norms (if available)** | Norms not available |
| **Contact for permission to use/adapt (associated cost)** | NA |
| **Validated administration modes** | Paper/pencil |
|  **Original measure languages available**  | English |
| **Evidence for reliability (provide type and values)** | Reliability evidence not available. |
| **Evidence for validity (provide type and values if available)** | Face validity based on Delphi development method and administration in adults receiving genomic sequencing. Developed to gage non-clinical utility of genomic sequencing specifically |
| **Evidence for sensitivity to change** | Initial search did not identify evidence.  |
| **Relevant references in genetics or genomics** | Initial search did not identify references. |

**Paste original scale below**

**PERSONAL UTILITY SCALE (PrU) —Original version 24 items**

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

| **Please indicate how plausible you find the following outcomes of genome sequencing:** |
| --- |
|  | Very implausible | implausible | Somewhat implausible | Neutral | Somewhat plausible | Plausible | Very plausible |
| **Help one understand one’s health condition better** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Help one cope with one’s health risks** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Improve one’s self-knowledge** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Make one feel good for contributing to research** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Help one or one’s family mentally prepare for the future** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Make one feel good for providing knowledge to one’s family** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Sequencing results are valuable simply because they provide information** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Improve one’s understanding of one’s family** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Inform one’s decisions about having children** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Use for prenatal testing to ensure children do not have condition** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Allow one to organize long-term care** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Satisfy one’s curiosity** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|  |  |  |  |  |  |  |  |
|  **Help one feel more in control of oneself** | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Make one nervous about discrimination; insurance, employment** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Motivate one to get one’s affairs in order** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Spur increased communication with one’s family members** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Sequencing results are valuable no matter what the results are** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Spur feelings of responsibility for one’s children’s health risks** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|  **Lead to greater support from one’s friends and family** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Allow one to take advantage of social programs; advocacy** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|  **Help one feel more in control of one’s life situation** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Help one live more fully** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Inform one’s plans for school or career** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|  **Give one a false sense of security** |  |  |  |  |  |  |  |
| How plausible is this outcome for you? | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| How plausible is this outcome for others | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|  |  |  |  |  |  |  |  |

**Paste CSER adaptation below**

**PERSONAL UTILITY SCALE (PrU) —FINAL VERSION 19 items**

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

| **Please indicate how useful you find the following outcomes of genome sequencing:** |
| --- |
|  | Not at all useful | A little useful | Somewhat useful | Neutral | Useful | Very useful | Extremely useful |
| Help with future life planning  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Inform plans for school or career  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Inform my decisions about having children  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Use for prenatal testing, if appropriate | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help me or my family mentally prepare for the future  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help in understanding my health better  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Contribute to my self-knowledge  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Contribute to understanding of my family**  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help cope with my health risks  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help me feel more in control of my health  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help me feel more in control of my life  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Simply to provide information  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Satisfy my curiosity  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| **Lead to better support from my friends, family or community** | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Help me to use social programs, like resources or 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 my family members | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Feel good about taking responsibility for my children’s health | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

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

**NA**