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| **About the Measure** | |
| **Protocol Id** | 870201 |
| **Domain:** | SCD Research Working Group 5: Psychosocial and Social Determinants of Health Specialty Collection |
| **Measure:** | Sickle Cell Disease Health-Related External Stigma |
| **Definition:** | Stigmatization due to health status or chronic disease burden is referred to as health-related stigma and involves devaluation, judgement, or social disqualification of individuals based on health condition. This protocol specifically addresses stigma associated with sickle cell disease. |
| **Purpose:** | Stigma can cause detrimental effects on the health of individuals, especially those with chronic disease burden. Effects can include negative social consequences such as status loss, employment discrimination, impairment of healthcare interactions, and reduced physiological and psychological well-being. |
| **Essential PhenX Protocols:** | Sex Assigned at Birth [11601] Current Age [10101] Ethnicity and Race [11901] Gender Identity [11801] Sex Assigned at Birth [11601] Current Age [10101] Ethnicity and Race [11901] Gender Identity [11801] |
| **Related PhenX Protocols:** | Sickle Cell Disease Health-Related Internal Stigma - Adolescent and Adult [870301] Sickle Cell Disease Health-Related Stigma - Child [870101] Discrimination [210302] Sickle Cell Disease Health-Related Internal Stigma - Adolescent and Adult [870301] Sickle Cell Disease Health-Related Stigma - Child [870101] Discrimination [210302] |
| **Measure Release Date:** | May 26, 2023 |

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| **About the Protocol** | |
| **Protocol Release Date:** | May 26, 2023 |
| **Protocol Review Date:** | NA |
| **PhenX Protocol Name:** | Sickle Cell Disease Health-Related External Stigma - Adolescent and Adult |
| **Protocol Name From Source:** | Sickle Cell Disease Health-Related Stigma Scale (SCD-HRSS) |
| **Protocol Availability:** | Available |
| **Keywords:** | Stigma; external; sickle cell disease; SCD; health status; Sickle Cell Disease Health-Related Stigma Scale; SCD-HRSS; emotion; Psychosocial; chronic; chronic disease; pain |
| **Description:** | The Sickle Cell Disease Health-Related Stigma Scale (SCD-HRSS) is a 30-item self-administered questionnaire that measures the amount of external stigma experienced by SCD patients (specifically, related to pain). |
| **Specific Instructions:** | The Psychosocial and SDoH Working Group recognizes that these instruments were not developed using inclusive language. The WG recognizes that investigators may want to implement the protocols with appropriate language, but caution that changes should not otherwise alter the items.  This scale is designed to be completed with sickle cell disease (SCD) patients who experience pain as a complication of their disease. It was designed in the United States and may require adaptations for use with SCD populations outside of the United States. |
| **Protocol:** | **SCD Health-Related Stigma Scale**  Please select the number that best reflects your agreement with each statement below.  5 = Strongly Agree 4 = Somewhat Agree 3 = Neutral 2 = Somewhat Disagree 1 = Strongly Disagree  **In the following 10 statements, the word "people" refers to people in general, not members of your family.**   |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | | 1.\* | People believe that someone with sickle cell pain is as mentally and emotionally healthy as the average person. | 5 | 4 | 3 | 2 | 1 | | 2. | People believe that it is mostly the patients fault when his/her pain does not get better. | 5 | 4 | 3 | 2 | 1 | | 3.\* | People are sympathetic when they hear about my pain condition. | 5 | 4 | 3 | 2 | 1 | | 4. | People believe that sickle cell is used as an excuse to get pain medication. | 5 | 4 | 3 | 2 | 1 | | 5.\* | People understand the suffering experienced by someone with chronic pain. | 5 | 4 | 3 | 2 | 1 | | 6. | I feel embarrassed to tell people that I cannot do something because of my pain. | 5 | 4 | 3 | 2 | 1 | | 7. | People think less of someone who is unable to work because of sickle cell. | 5 | 4 | 3 | 2 | 1 | | 8. | People believe that having sickle cell pain is a sign of weakness. | 5 | 4 | 3 | 2 | 1 | | 9. | People think that someone taking prescription pain medication on a regular basis is a "drug addict". | 5 | 4 | 3 | 2 | 1 | | 10. | When people hear that someone has sickle cell pain, they think that person is also likely to have mental or emotional problems. | 5 | 4 | 3 | 2 | 1 |   **In the following 10 statements, the word "doctor" refers to all of the doctors you have seen for sickle cell pain.**  5 = Strongly Agree 4 = Somewhat Agree 3 = Neutral 2 = Somewhat Disagree 1 = Strongly Disagree   |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | | 1.\* | Most doctors believe that there is a real physical cause for sickle cell pain. | 5 | 4 | 3 | 2 | 1 | | 2. | Doctors think that people with sickle cell exaggerate their pain. | 5 | 4 | 3 | 2 | 1 | | 3. | Many doctors think that people with sickle cell pain want more pain medication than is necessary for their physical pain. | 5 | 4 | 3 | 2 | 1 | | 4. | Doctors think that sickle cell pain is mostly a mental or emotional problem. | 5 | 4 | 3 | 2 | 1 | | 5.\* | Most doctors think that people with sickle cell use pain medication appropriately. | 5 | 4 | 3 | 2 | 1 | | 6.\* | Most doctors think that people with sickle cell complain about their illness about as much as people with other medical conditions. | 5 | 4 | 3 | 2 | 1 | | 7. | Many doctors believe that people with sickle cell could be more physically active if they wanted. | 5 | 4 | 3 | 2 | 1 | | 8. | Many doctors think that people with sickle cell are less emotionally stable than people with other medical problems. | 5 | 4 | 3 | 2 | 1 | | 9. | Many doctors think that people with sickle cell pain are "drug addicts". | 5 | 4 | 3 | 2 | 1 | | 10. | Most doctors would prefer not to treat people with sickle cell disease. | 5 | 4 | 3 | 2 | 1 |   **In the following 10 statements, the word "family" refers to the people who are most important and significant to you.**  5 = Strongly Agree 4 = Somewhat Agree 3 = Neutral 2 = Somewhat Disagree 1 = Strongly Disagree   |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | | 1.\* | My family understands that I have physical pain. | 5 | 4 | 3 | 2 | 1 | | 2. | My family thinks I need less pain medication than I take. | 5 | 4 | 3 | 2 | 1 | | 3. | My family feels that I exaggerate how much I hurt in order to get out of doing things that I dont want to do. | 5 | 4 | 3 | 2 | 1 | | 4.\* | My family understands that I can use only as much pain medication as is medically necessary. | 5 | 4 | 3 | 2 | 1 | | 5. | My family thinks that I could be more physically active if I wanted. | 5 | 4 | 3 | 2 | 1 | | 6. | My family thinks that by taking pain medication on a regular basis, I have become a "drug addict". | 5 | 4 | 3 | 2 | 1 | | 7.\* | My family understands that sickle cell is a real medical condition. | 5 | 4 | 3 | 2 | 1 | | 8. | I feel that my family has less respect for me since I have sickle cell. | 5 | 4 | 3 | 2 | 1 | | 9. | My family thinks that sickle cell pain is more of a mental or emotional problem than a physical problem. | 5 | 4 | 3 | 2 | 1 | | 10. | My family feels embarrassed to tell people that I have sickle cell. | 5 | 4 | 3 | 2 | 1 |   Scoring: Each subscale score is the sum of the 10 items in the subscale scale. Be sure to use recoded items in scoring (Range: 10-50). Items to be reverse coded are marked with an asterisk (\*).  The total score is the sum of all four subscale scores (Range: 40-200). Higher total Sickle Cell Disease Health-Related Stigma Scale (SCD-HRSS) total scores or subscale scores indicate higher levels of perceived stigma. |
| **Selection Rationale:** | The Sickle Cell Disease Health-Related Stigma Scale (SCD-HRSS) is a standardized, reliable, and valid instrument used to collect information about external sources of stigma experienced by patient populations with sickle cell disease due to their health-related condition. |
| **Source:** | Jenerette, C., O'Brien, J., Jaja, C., Carvalho, E. S. S., Brewer, C., & Hickman, R. L., Jr (2022). Psychometrics of the Sickle Cell Disease Health-Related Stigma Scale-Short Form. Western journal of nursing research, 1939459221142164. Advance online publication. doi:10.1177/01939459221142164 |
| **Language** | English |
| **Participant:** | Adult, adolescent with sickle cell disease |
| **Personnel and Training Required:** | None |
| **Equipment Needs:** | None |
| **Standards** |  |
| **General References:** | Bediako, S. M., Lanzkron, S., Diener-West, M., Onojobi, G., Beach, M. C., & Haywood, C. (2014). The measure of sickle cell stigma: Initial findings from the Improving Patient Outcomes through Respect and Trust study. Journal of Health Psychology, 21(2), 808-820. doi:10.1177/1359105314539530  Bulgin, D., Tanabe, P., & Jenerette, C. (2018). Stigma of sickle cell disease: A systematic review, Issues in Mental Health Nursing, 39(8), 675-686. doi:10.1080/01612840.2018.1443530  Jenerette, C., Brewer, C.A., Crandell, J., & Ataga, I. (2012). Preliminary validity and reliability of the Sickle Cell Disease Health-Related Stigma Scale. Issues in Mental Health Nursing, 33(6), 363-369. doi:10.3109/01612840.2012.656823 |
| **Mode of Administration:** | Self-administered questionnaire |
| **Derived Variables:** | None |
| **Requirements:** | |  |  | | --- | --- | | **Requirement Category** | **Required (Yes/No)** | | **Major equipment** | No | | **Specialized training** | No | | **Specialized requirements for biospecimen collection** | No | | **Average time of greater than 15 minutes in an unaffected individual** | No | |
| **Annotations for Specific Conditions:** | None |
| **Process and Review:** | Not applicable |