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| **About the Measure** | |
| **Domain:** | Sickle Cell Disease: Psychosocial and Social Determinants of Health |
| **Measure:** | Transition Readiness |
| **Definition:** | This measure assesses readiness of teenagers to transition from pediatric care providers to adult providers. |
| **Purpose:** | This measure can be used to assess if a patient is prepared to transition to adult care and to facilitate conversations between patients, parents, and physicians. |
| **Essential PhenX Measures:** | Current Age (10101); Educational Attainment - Individual (11001) |
| **Related PhenX Measures:** | Self-efficacy in Sickle Cell Disease (820401) |
| **Measure Release Date:** | TBD |

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| **About the Protocol** | |
| **Protocol Release Date:** | TBD |
| **PhenX Protocol Name:** | Sickle Cell Disease Transition Readiness Assessment |
| **Keywords:** | Not applicable. |
| **Protocol Name from Source:** | American Society of Hematology Sickle Cell Disease Transition Readiness Assessment Template |
| **Essential PhenX Protocols** | Not applicable. |
| **Related PhenX Protocols:** | Not applicable. |
| **Description:** | The American Society of Hematology Sickle Cell Disease Transition Readiness Assessment Template is a self-administered questionnaire to help assess the adolescent/young adult’s knowledge and skills regarding his/her hematologic condition and its management. The assessment template covers Transition and Self-Care Importance and Confidence (three questions), Disease Knowledge (nine questions), Medication Management (six questions), Appointments (eight questions), Insurance (two questions), and Privacy (one question).  This American Society of Hematology Sickle Cell Disease Transition Readiness Assessment Template is intended for use by both adolescents and adults for the following purposes:  **For Adolescent Patients**  The tool should be used for the pediatric care team or other clinicians caring for youth to begin the conversation about the youth’s needed skills to manage his/her hematologic health and health care. This tool indicates the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice.  **For Adult Patients**  This tool should be utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal management of the medical condition(s). |
| **Specific Instructions:** | The form should be completed by the patient and is intended to help assess the adolescent/young adult’s knowledge and skills regarding their hematologic condition and its management. For Adolescent Patients, the form should be used by the pediatric care team or other clinicians caring for youth to begin the conversation about the youth’s needed skills to manage their hematologic health and health care. The form indicates the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice. For Adult Patients, the form should be utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal management of the medical condition(s).    The form should be accompanied by a Sickle Cell Disease Clinical Summary available at:  <https://www.hematology.org/-/media/hematology/files/clinicians/guidelines/scd-clinical-summary_2022_v2.pdf>.  This form provides a medical record summary that indicates essential clinical information specifically related to the clinical condition that is to be included in the patient’s medical record upon transfer to the adult practice. These forms should be completed, signed, and dated on the last page by the referring provider and patient/family. The patient and/or family should review and give the completed form to the new adult health care provider. |
| **Protocol:** | |  |  | | --- | --- | |  | **American Society of Hematology**  **Sickle Cell Disease Transition Readiness Assessment Template**  Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you want to learn more about. If you need help completing this form, please ask your parent/caregiver. |  |  |  |  | | --- | --- | --- | | Date: | Name: | Date of Birth: | | Transition and Self-Care Importance and Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel now* | | |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | How important is it to you to manage your own health care? | | | | | | | | | | | | | | | | | | | | | | 0 (not) | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | | | 10 (very) | | How confident do you feel about your ability to manage your own health care? | | | | | | | | | | | | | | | | | | | | | | 0 (not) | | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | 10 (very) | | | How confident do you feel about preparing for/changing to an adult doctor before the age of 22? Not Applicable | | | | | | | | | | | | | | | | | | | | | | 0 (not) | | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | 10 (very) | |  |  |  |  |  |  | | --- | --- | --- | --- | --- | | My Health ***Please check the box that applies to you right now.*** | No, I do not know | No, but I am learning to do this | Yes, I have started doing this | Yes, I always do this when I need to | | Disease Knowledge | | | | | | | I know what type of sickle cell disease I have. |  |  |  |  | | I know my medical needs and can explain them to someone. |  |  |  |  | | I know what a hematologist is and why I go to one. |  |  |  |  | | I know what to do in case of a medical emergency. |  |  |  |  | | I understand what causes a pain episode. |  |  |  |  | | I understand how drugs, alcohol and tobacco affect sickle cell disease. |  |  |  |  | | I have friends that I can talk to about sickle cell disease. |  |  |  |  | | I know about necessary screening exams (echo annually, kidney function annually, retinal exams, etc.). |  |  |  |  | | I know how to get blood work and x-rays. |  |  |  |  | | Medication Management | | | | | | | I know what my medications are for. |  |  |  |  | | I know the names and doses of my medications. |  |  |  |  | | I remember to take my medications without my parent reminding me. |  |  |  |  | | I fill prescriptions before I run out of medications. |  |  |  |  | | I am aware of what hydroxyurea is and how it prevents sickling of my red blood cells. |  |  |  |  | | I know how to prevent a pain episode and what to do if I have pain. |  |  |  |  | | Appointments | | | | | | | I make my own doctors’ appointments. |  |  |  |  | | I know how to get medical care when the doctor’s office is closed. |  |  |  |  | | I fill out my own medical history form. |  |  |  |  | | I keep track of my own medical information. |  |  |  |  | | I keep track of my doctors’ and other appointments. |  |  |  |  | | I make a list of questions before my visit with my doctors. |  |  |  |  | | I answer questions on my own during medical visits. |  |  |  |  | | I arrange my own transportation to medical appointments. |  |  |  |  | | Insurance | | | | | | | I carry my own insurance card. |  |  |  |  | | I understand my insurance plan. |  |  |  |  | | Privacy Information | | | | | | | I understand how health care privacy changes at age 18, when I am legally an adult. |  |  |  |  | |
| **Selection Rationale:** | The American Society of Hematology Sickle Cell Disease Transition Readiness Assessment was developed to facilitate conversations between patients, parents, and physicians as the patient transitions to adult care. |
| **Source:** | The American Society of Hematology Sickle Cell Disease Transition Readiness Assessment Template is available for download from the American Society of Hematology website. |
| **Availability:** | Available |
| **Life Stage:** | Adolescents and adults |
| **Language:** | English |
| **Participant:** | Adolescents with sickle cell disease |
| **Personnel and Training Required:** | None |
| **Equipment Needs:** | None |
| **General References:** | None |
| **Mode of Administration:** | Self-administered questionnaire |
| **Derived Variables:** | Not applicable. |
| **Requirements:** | |  |  | | --- | --- | | **Requirements 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:** | Not applicable. |
| **Process and Review:** | Not applicable. |