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| **About the Measure**  |
| **Domain:** | Sickle Cell Disease Pregnancy |
| **Measure:** | Sickle Cell Disease Phenotype Consensus Definitions  |
| **Definition:** | Sickle cell disease complications include physical symptoms and phenotypes that are characteristic of the disease. |
| **Purpose:** | Consensus definitions for sickle cell disease complications are intended to help standardize diagnostic criteria and facilitate data comparison and integration. |
| **Essential PhenX Measures:** | NA |
| **Related PhenX Measures:** | NA |
| **Measure Release Date:** | NA  |

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| **About the Protocol**  |
| **Protocol Release Date:** | TK Team to Add |
| **PhenX Protocol Name:** | Sickle Cell Disease Phenotype Consensus Definitions  |
| **Keywords:**  | Sickle cell disease, SCD, complications of sickle cell disease |
| **Protocol Name from Source:** | Definitions of the phenotypic manifestations of sickle cell disease.  |
| **Description:** | This protocol summarizes the consensus definitions for the complications of sickle cell disease described in Ballas et al. (2010).  |
| **Specific Instructions:** | None  |
| **Protocol:** | **Sickle Cell Disease Phenotype Consensus Definitions**The article by Ballas et al. (2010) provides concise consensus definitions for 62 sickle cell disease complications organized according to organ or system involvement. The authors also provide diagnostic criteria, severity index, classification, and references for each complication. |
| **Selection Rationale:** | The PhenX Sickle Cell Disease Pregnancy Working Group (WG) selected the consensus definitions from Ballas et al. (2010) as the gold standard to date for classifying sickle cell disease phenotypes. The WG recommended it be included in Supplemental Information (instead of the PhenX Toolkit) because it is a well-established reference instead of a formal data collection protocol.  |
| **Source:**  | Ballas, S. K., Lieff, S., Benjamin, L. J., Dampier, C. D., Heeney, M. M., Hoppe, C., Johnson, C. S., Rogers, Z. R., Smith-Whitley, K., Wang, W. C., & Telen, M. J.; Investigators, Comprehensive Sickle Cell Centers. (2010). Definitions of the phenotypic manifestations of sickle cell disease. *American Journal of Hematology*, *85*(1), 6–13. https://doi.org/10.1002/ajh.21550 |
| **Availability:** | Available |
| **Life Stage:** | Infant, toddler, child, adolescent, adult, senior, pregnancy |
| **Language:** | English |
| **Participant:** | Not applicable; consensus definitions were developed by a Working Group of sickle cell disease experts. |
| **Personnel and Training Required:** | See Ballas et al. (2010) for details. |
| **Equipment Needs:** | See Ballas et al. (2010) for details. |
| **General References:** | Bernard, G. R., Artigas, A., Brigham, K. L., Carlet, J., Falke, K., Hudson, L., Lamy, M., Legall, J. R., Morris, A., & Spragg, R. (1994). The American-European Consensus Conference on ARDS. Definitions, mechanisms, relevant outcomes, and clinical trial coordination. *American Journal of Respiratory and Critical Care Medicine*, *149*(3, Pt. 1), 818–824. <https://doi.org/10.1164/ajrccm.149.3.7509706> |
| **Mode of Administration:** | NA |
| **Derived Variables:** | None |
| **Requirements:** |

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| **Requirements Category** | **Required (Yes/No):** |
| Major equipment | No |
| Specialized training  | Yes |
| Specialized requirements for biospecimen collection  | No |
| Average time of greater than 15 minutes in an unaffected individual | No |

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| **Annotations for Specific Conditions:** | None |
| **Process and Review:** | NA |