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| **About the Measure** | |
| **Domain:** | Sickle Cell Disease Pregnancy |
| **Measure:** | Multidisciplinary Care for Sickle Cell Disease Pregnancies |
| **Definition:** | Multidisciplinary care for pregnant people with sickle cell disease includes a medical care team with expertise in obstetrics, hematology, pediatrics, pulmonology, and nursing. |
| **Purpose:** | Establishing a multidisciplinary care team with standard protocols has been demonstrated to reduce mortality rates for pregnant people with sickle cell disease. |
| **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:** | Multidisciplinary Care for Sickle Cell Disease Pregnancies |
| **Keywords:** | NA |
| **Protocol Name from Source:** | Asare et al. (2017). |
| **Description:** | This protocol summarizes that implementation of multidisciplinary care reduces mortality in pregnant people with sickle cell disease in low-resource settings. |
| **Specific Instructions:** | The Working Group notes that while this was performed in a low-resource setting, it is applicable to other settings as well. As this paper shows, multidisciplinary care can impact outcomes and a description should be included of the composition of the care team involved in the research. |
| **Protocol:** | **Multidisciplinary Care for Sickle Cell Disease Pregnancies**  The article by Asare et al. (2017) describes the motivation, process, and results of a clinical trial testing the impact of a multidisciplinary care team on sickle cell disease pregnancies in low-resource settings. The authors demonstrate that a multidisciplinary care team including expertise in obstetrics, hematology, pediatrics, pulmonology, and nursing decreased maternal and perinatal mortality by 89.1% and 62.2%, respectively. Supplemental information included with the article outline intervention strategies and a checklist for managing acute chest syndrome. |
| **Selection Rationale:** | The PhenX Sickle Cell Disease Pregnancy Working Group (WG) selected the approach and interventions outlined in Asare et al. (2017) as the gold standard for reducing maternal mortality in low-resource settings. The WG recommended it be included in Supplemental Information due to investigator burden and requirements for assembling a multidisciplinary team with appropriate expertise for the research setting. |
| **Source:** | Asare, E. V., Olayemi, E., Boafor, T., Dei-Adomakoh, Y., Mensah, E., Ghansah, H., Osei-Bonsu, Y., Crabbe, S., Musah, L., Hayfron-Benjamin, C., Covert, B., Kassim, A. A., James, A., Rodeghier, M., DeBaun, M. R., & Oppong, S. A. (2017). Implementation of multidisciplinary care reduces maternal mortality in women with sickle cell disease living in low-resource setting. *American Journal of Hematology*, *92*(9), 872–878. <https://doi.org/10.1002/ajh.24790> |
| **Availability:** | Available |
| **Life Stage:** | Adolescent, adult |
| **Language:** | English |
| **Participant:** | Pregnant women with sickle cell disease |
| **Personnel and Training Required:** | Clinicians with expertise in obstetrics, hematology, pediatrics, pulmonology, and nursing. |
| **Equipment Needs:** | See Asare et al. (2017) for equipment requirements. |
| **General References:** | Asare, E. V., DeBaun, M. R., Olayemi, E., Boafor, T., & Oppong, S. A. (2022). Acute pain episodes, acute chest syndrome, and pulmonary thromboembolism in pregnancy. *Hematology. American Society of Hematology. Education Program*, *2022*(1), 388–407. https://doi.org/10.1182/hematology.2022000376 |
| **Mode of Administration:** | Not applicable |
| **Derived Variables:** | None |
| **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:** | None |
| **Process and Review:** | NA |