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| **About the Measure** | |
| **Domain:** | Sickle Cell Disease: Psychosocial and Social Determinants of Health |
| **Measure:** | Medication Adherence |
| **Definition:** | Adherence is the extent to which a person’s behavior aligns with their healthcare providers’ recommendations. |
| **Purpose:** | Patients who have higher adherence, often have better health outcomes. This includes taking medications, less frequent chronic disease complications, hospitalizations, Emergency Room visits, and overall lower healthcare costs. |
| **Essential PhenX Measures:** | Not applicable. |
| **Related PhenX Measures:** | Not applicable. |
| **Measure Release Date:** |  |

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| **About the Protocol** | |
| **Protocol Release Date:** |  |
| **PhenX Protocol Name:** | Medication Adherence |
| **Keywords:** | Medication, adherence, sickle cell disease, medicine, medicines, prescription, routine, psychosocial |
| **Protocol Name from Source:** | PROMIS® Scale v1.0 - Medication Adherence |
| **Description:** | The PROMIS® (Patient-Reported Outcomes Measurement Information Systems) Medication Adherence Scale is a 12-item questionnaire that measures medication adherence behavior, rate, and related barriers. It is a Likert-style questionnaire that asks the participant to select a response that best describes their medication adherence habits. |
| **Specific Instructions:** | Please note that individuals may need to complete multiple forms if they are on multiple medications.  The PhenX Working Group recommends this PROMIS® protocol. To use PROMIS® instruments, please visit: [www.healthmeasures.net](https://www.healthmeasures.net/) for Terms of Use and additional information related to [scoring](https://www.healthmeasures.net/score-and-interpret/calculate-scores), validity, and interpretation. |
| **Protocol:** | PROMIS® Scale v1.0 - Medication Adherence  **Medication** **Adherence**  Please answer the following questions about this medicine: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(specify) **OR** about medicines you take for this condition: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(specify).  **Please respond to each question or statement by marking one box per row.**   |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | |  |  | **Less than once per day** | **Once per day** | **Twice per day** |  | **Three or more per day** | | MedAdFRQ | How many times per day are you supposed to take this medicine?....... | [ ]  1 | [ ]  2 | [ ]  3 |  | [ ]  4 | |  |  | **Strongly disagree** | **Disagree** | **Neither agree or disagree** | **Agree** | **Strongly agree** | | MedAd1 | I know how to take this medicine as recommended....... | [ ]  1 | [ ]  2 | [ ]  3 | [ ]  4 | [ ]  5 | |  |  |  |  |  |  |  | | MedAd2 | I understand why I need to take this medicine....... | [ ]  1 | [ ]  2 | [ ]  3 | [ ]  4 | [ ]  5 | |  |  |  |  |  |  |  | | MedAd3 | I believe it is important to take this medicine....... | [ ]  1 | [ ]  2 | [ ]  3 | [ ]  4 | [ ]  5 | |  |  |  |  |  |  |  | | MedAd4 | I believe this medicine is working....... | [ ]  1 | [ ]  2 | [ ]  3 | [ ]  4 | [ ]  5 | |  | **In the past 7 days …** | **Never** | **Rarely** | **Sometimes** | **Almost always** | **Always** | | MedAd5 | I took this medicine as recommended....... | [ ]  1 | [ ]  2 | [ ]  3 | [ ]  4 | [ ]  5 | |  |  |  |  |  |  |  | | MedAd6 | I remembered to take this medicine....... | [ ]  1 | [ ]  2 | [ ]  3 | [ ]  4 | [ ]  5 | |  | **In the past 7 days …** | **Never** | **Rarely** | **Sometimes** | **Almost always** | **Always** | | MedAd7 | I did not take this medicine because it caused side effects that bothered me.......  *Note: Please select “Never” if you have no side effects*. | [ ]  5 | [ ]  4 | [ ]  3 | [ ]  2 | [ ]  1 | |  |  |  |  |  |  |  | | MedAd8 | I stopped taking this medicine because I thought I did not need it....... | [ ]  5 | [ ]  4 | [ ]  3 | [ ]  2 | [ ]  1 | |  |  |  |  |  |  |  | | MedAd9 | I did not take this medicine because of the cost....... | [ ]  5 | [ ]  4 | [ ]  3 | [ ]  2 | [ ]  1 | |  |  | **Not at all** | **A little bit** | **Somewhat** | **Quite a bit** | **Very much** | | GP5 | I am bothered by the side effects of treatment.......  *Note: Please select “Not at all” if you have no side effects.* | [ ]  5 | [ ]  4 | [ ]  3 | [ ]  2 | [ ]  1 | |  |  |  |  |  |  |  | | FT12 | The cost of my medicine has been a financial hardship to my family and me....... | [ ]  5 | [ ]  4 | [ ]  3 | [ ]  2 | [ ]  1 |   19 February 2020  © 2019-2020 PROMIS Health Organization (PHO) |
| **Selection Rationale:** | The PROMIS® v1.0 Medication Adherence scale is a freely available questionnaire that measures medication adherence behavior, rate, and related barriers. |
| **Source:** | Peipert, J. D., Badawy, S. M., Baik, S. H., Oswald, L. B., Efficace, F., Garcia, S. F., Mroczek, D. K., Wolf, M., Kaiser, K., Yanez, B., & Cella, D. (2020). Development of the NIH patient-reported outcomes measurement information system (PROMIS) medication adherence scale (PMAS). *Patient Preference and Adherence*, *14*, 971-983. <https://doi.org/10.2147/ppa.s249079> |
| **Availability:** | Available |
| **Life Stage:** | Adult Adolescent |
| **Language:** | English |
| **Participant:** | Adult, Adolescents, and Caregivers |
| **Personnel and Training Required:** | None |
| **Equipment Needs:** | None |
| **General References:** | Badawy, S. M. (2021). Clinical trial considerations in sickle cell disease: Patient-reported outcomes, data elements, and the stakeholder engagement framework. *Hematology*, *2021*(1), 196-205. <https://doi.org/10.1182/hematology.2021000252> |
| **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. |