December 30, 2024

Re: PRMR MUC 2024-074-Median Time to Pain Medication for Patients with a Diagnosis of Sickle Cell Disease (SCD) with Vaso-Occlusive Episode (VOE)

The Sickle Cell Disease Partnership[i] (Partnership) is a multi-sector public policy and advocacy collaboration of patient advocates, health care providers, biopharmaceutical manufacturers, and other health care stakeholders committed to advancing policies that will improve the lives of those living with Sickle Cell Disease (SCD).

As you know, SCD is the most common inherited blood disorder in the United States,[ii] affecting approximately 100,000 individuals. Individuals living with SCD face severe health complications, including recurring pain crises, infection, acute chest syndrome, lung problems, severe and chronic pain, and stroke. Because individuals with SCD have sickle-shaped red blood cells, their red blood cells get stuck in blood vessels, block blood flow, deprive tissues of oxygen, and deteriorate organs.[iii] This leads to severe pain crises and, oftentimes, admission to the Emergency Department (ED). SCD primarily affects Black and Hispanic individuals, and individuals with SCD experience racial disparities, provider biases, and inequities in their care.[iv] Individuals with SCD ultimately have an estimated life expectancy that is 20 years shorter than the average expected life expectancy in the United States.[v]

Given inadequacies in comprehensive health care and treatment, individuals with SCD tend to visit the ED more often than the average population,[vi] and 75 percent of the 222,612 estimated yearly average number of ED visits by individuals with SCD (1999-2020) were due to a complaint of pain.[vii] Unfortunately, today there are no national metrics to assess the proportion of patients impacted by the quality of timely ED care.

Mindful of the frequency of ED visits by individuals with SCD and the lack of any metrics to assess the timeliness of ED care, the Partnership supports the American Society of Hematology's (ASH) new quality measure in the Hospital Outpatient Quality Reporting Program (HOQR) and the Rural Emergency Hospital Quality Reporting Program (REHQR), entitled: *Median Time to Pain Medication for Patients with a Diagnosis of Sickle Cell Disease with Vaso-Occlusive Episode (VOE)*. Using Digital-Electronic Health Record Data, ASH's proposed quality measure will assess the median time, in minutes, from when an individual with SCD arrives to the ED until the individual is first administered pain medication during the ED encounter. This will apply to encounters for all patients who have a principal encounter diagnosis of SCD with VOE, regardless of age.

The Partnership believes adopting a quality measure is an essential first step in enabling stakeholders to assess the national trends in management of SCD in the ED and to evaluate whether EDs across the country are meeting evidence-based guidelines for pain management, as set forth by ASH[viii] and the National Heart, Lung and Blood Institute.[ix] Assessing the timing to

administration of pain management for adult and pediatric patients presenting to the ED with SCD will not only impact pain management, but has the potential to also impact admission rates, length of ED stay, hospital length of stay, and patient satisfaction.[x]

The Partnership recognizes that this proposed quality measure is not exhaustive and may not address all aspects of care needed in an ED when an individual with SCD presents. Over the longer term, the Partnership urges CMS to consider how it can continue to further advance quality measures – and policies generally – to ensure all individuals with SCD have access to high-quality, comprehensive, and coordinated health care. Better managing the natural history of an individual's SCD is integral in order to keep more individuals with SCD out of the ED.

We look forward to continued collaboration on this SCD policy. Please reach out to Advisors to the Partnership, Josh Trent (Josh.Trent@LeavittPartners.com), Clay Alspach (Clay.Alspach@LeavittPartners.com) or Liz Hassett (Elizabeth.Hassett@LeavittPartners.com), with any questions or to further discuss.

Sincerely,

The Sickle Cell Disease Partnership

[i] https://www.sicklecellpartnership.org/
[ii] https://www.hematology.org/education/patients/anemia/sickle-cell-disease
[iii] https://www.cdc.gov/sickle-cell/complications/pain.html#:~:text=Sickled
[iv] https://pubmed.ncbi.nlm.nih.gov/36400531/
[v] https://www.cdc.gov/sickle-cell/data/index.html
[vi] https://www.jscimedcentral.com/public/assets/articles/hematology-3-1037.pdf
[vii] https://www.ajpmfocus.org/article/S2773-0654(23)00095-0/fulltext
[viii] https://ashpublications.org/bloodadvances/article/4/12/2656/460974/American-Society-of-Hematology-2020-guidelines-for
[ix] https://www.nhlbi.nih.gov/sites/default/files/media/docs/sickle-cell-disease-report%20020816_0.pdf
[x] https://ashpublications.org/blood/article/142/Supplement%201/7201/504559/Delayed-Management-of-Sickle-Cell-Disease-Vaso; https://pubmed.ncbi.nlm.nih.gov/28375958/; https://pubmed.ncbi.nlm.nih.gov/25834959/