



AMERICAN SOCIETY OF HEMATOLOGY

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January 14, 2019

Seema Verma
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2408-P
7500 Security Boulevard
Baltimore, MD 21244-1850

SUBMITTED ELECTRONICALLY VIA regulations.gov

RE: Medicaid Program; Medicaid and Children's Health Insurance Plan (CHIP) Managed Care (CMS-2408-P)

Administrator Verma:

The American Society of Hematology (ASH) is pleased to offer comments on the proposed rule outlining changes to the Medicaid Program. We appreciate the opportunity to provide these comments to the Centers for Medicare and Medicaid Services (CMS) on how this proposed rule will impact our members and the patients they serve, specifically individuals with sickle cell disease (SCD).

ASH represents over 17,000 clinicians and scientists worldwide, who are committed to the study and treatment of blood and blood-related diseases. These disorders encompass malignant hematologic disorders such as leukemia, lymphoma, and multiple myeloma, as well as non-malignant conditions such as sick cell anemia, thalassemia, bone marrow failure, venous thromboembolism, and hemophilia. In addition, hematologists are pioneers in demonstrating the potential of treating various hematologic diseases and continue to be innovators in the field of stem cell biology, regenerative medicine, transfusion medicine, and gene therapy. ASH membership is comprised of basic, translational, and clinical scientists, as well as physicians providing care to patients in diverse settings including teaching and community hospitals, as well as private practice.

Background: The Current State of Sickle Cell Disease

There are an estimated 100,000 individuals with sickle cell disease (SCD) living in the United States. The majority of these patients are covered by Medicare or Medicaid or are dual-eligible. Unfortunately, there is little published data on SCD beneficiaries, but estimates from the Centers for Disease Control and Prevention show that about 50 – 60 percent of SCD patients (50,000 – 60,000) nationwide are on Medicaid, while there are about 20,000 SCD patients on Medicare. Individuals with SCD experience painful health crises, which, if untreated, have the potential to cause severe complications, including stroke, acute chest syndrome, organ damage, and in some cases, premature death. For comprehensive care to manage their condition, individuals with SCD need access to a range of specialists to help prevent and treat these potential complications. Unfortunately, low reimbursement in Medicaid and differing coverage policies by state have created a barrier to health care access for individuals with SCD.

2019

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Medicaid has historically paid physicians lower fees than both Medicare and private insurance plans for the same services. As of July 2016, Medicaid programs paid physicians' fees at 72 percent of Medicare rates. This, and a lack of sufficient knowledge about SCD, inevitably has created a limited supply of specialists trained to treat this population which frequently leads these individuals to seek care from emergency departments at a high-cost and often leads to fragmented care.

The Society would also like to note that both Congress and the Department of Health and Human Services (HHS) have recently taken steps to advance policies to protect and improve the care received by SCD patients. Current federal programs that highlight the care of individuals with SCD include:

- The Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection Program;
- The National Academies of Sciences, Engineering, and Medicine's Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action, requested and funded by the Office of Minority Health at HHS; and,
- The Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program through the Health Resources and Services Administration (HRSA).

Additionally, more recently, the National Institute of Health launched the Cure Sickle Cell Initiative through the National Heart, Lung, and Blood Institute, and on December 19, 2018, the President signed the "Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018," which authorizes the SCD data collection program at CDC and reauthorizes the existing SCD Treatment Demonstration Program at HRSA.

Based on the background provided and knowing of the ongoing and recent interest in SCD by the federal government, ASH provides the following comments on the proposed rule with the SCD population in mind. ASH is very concerned that, if finalized, this rule could further limit access for these patients.

Comments on the Proposed Rule

First, ASH is concerned that by allowing states the authority to set their own minimum adequacy standards for Medicaid managed care plans, states will create too narrow of a network; for example, if finalized, the new policy could allow a state to establish a network that would exclude access to a particular provider type and/or a particular type of service. Current regulation requires states to establish time and distance standards with a requirement that states establish quantitative minimum adequacy standards for specified health care providers and long-term services and support (LTSS) providers. Under the existing network adequacy standards, states have to consider the anticipated Medicaid enrollment, expected utilization of services, the numbers and types of network providers required to provide services, the geographic location of network providers and Medicaid enrollees, considering the distance, travel time and means of transportation typically utilized by enrollees. ASH recognizes that CMS's intention to promote flexibility by allowing states to set standards for their Medicaid managed care plans is consistent with the agency's desire to streamline requirements and reduce administration burden. ASH supports these efforts to reduce burden but is concerned about how this policy could limit patient access.

Therefore, to avoid narrow networks, ASH recommends CMS set a minimum federal network adequacy standard that could be based on a variety of factors similar to those currently in place. This minimum standard is needed to maintain a consistent level of network adequacy across states and to ensure appropriate patient access to Medicaid services. Patients should not face further access challenges because their state establishes narrow network requirements. ASH would welcome the opportunity to further define the minimum standard in a way that both increases state flexibility and protects access.

Secondly, ASH opposes the proposal to give states the authority to define "specialist" in the way that is most appropriate for their programs. Without a minimum federal standard, it would be possible for a state to choose not to qualify a hematologist as a "specialist." This would reduce incentives for managed care organizations to contract with a robust array of hematology providers. Again, if implemented, this proposal would result in substandard

networks and inconsistent patient access across states. This would be particularly problematic when patients see physicians in other states, as is common in metropolitan areas like New York and Washington, DC. ASH recommends CMS articulate a definition of specialist that states could further expand, but not limit.

Thank you for the opportunity to provide comments on the proposed rule outlining changes to the Medicaid Program. We welcome the opportunity to discuss these comments with you and your team. If you have any questions or require further clarification, please contact Leslie Brady, ASH Policy and Practice Manager at lbrady@hematology.org or 202-292-0264.

Sincerely,

A handwritten signature in black ink, appearing to read "Roy L. Silverstein". The signature is fluid and cursive, with the first name "Roy" being the most prominent.

Roy L. Silverstein, MD
President