



# AMERICAN SOCIETY OF HEMATOLOGY

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June 13, 2019

Nancy Potok  
Chief Statistician  
Office of Management and Budget  
9257 New Executive Office Building  
725 17<sup>th</sup> Street NW  
Washington, DC 20006  
OMB-2019-0002

RE: Request for Comment on the Consumer Inflation Measures Produced by Federal Statistical Agencies

SUBMITTED ELECTRONICALLY VIA [www.regulations.gov](http://www.regulations.gov)

Ms. Potok:

The American Society of Hematology (ASH) is pleased to offer comments in response to the Request for Comment on the Consumer Inflation Measures Produced by Federal Statistical Agencies. We appreciate the opportunity to provide these comments to the Office of Management and Budget 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 sickle 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 states have created a barrier to health care access

### 2019

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for individuals with SCD.

Medicaid has historically paid 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.<sup>1</sup> This, and a lack of sufficient knowledge about SCD, means that there is a limited supply of providers trained to treat this population. As a result, SCD patients frequently rely on care from emergency departments at a high-cost and without the possibility of continuity of care.

The Society appreciates 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 in response to the request for comment with the SCD population in mind.

### **Request for Comment on the Consumer Inflation Measures Produced by Federal Statistical Agencies**

ASH is concerned that a change to the measure used to adjust the poverty line each year for inflation could further limit access to care for the SCD population. The Administration is proposing to use an alternative index, such as the chained Consumer Price Index (CPI) or the Personal Consumption Expenditures Price Index (PCEPI); however, both proposed measures rise more slowly than the current measure, the CPI for Urban Consumer (CPI-U), ultimately resulting in a lower poverty line.

ASH is actively working to help improve access to care for individuals with SCD and believes that everyone should have access to affordable health care, from prevention, to treatment, to end-of-life care. The Society, however, feels strongly that the proposal to use a lower inflation measure to calculate annual adjustments to the federal poverty line could cause many individuals with SCD to lose access to Medicaid, and potentially be left with no insurance coverage. As outlined above, the SCD population already faces many barriers to access to high-quality health care and the Society believes that this proposed rule, if finalized, would further limit access to care.

The majority of child and adult Medicaid and Children's Health Insurance Program (CHIP) enrollees qualify based on income. If this proposed change is finalized, it is estimated that more than 300,000 children would lose comprehensive coverage through Medicaid and CHIP; additionally, more than 250,000 adults who gained Medicaid coverage from the Affordable Care Act's (ACA) expansion would lose it. It is likely that many of these individuals would fall into the "coverage gap," meaning their incomes are too high for Medicaid and too low to qualify for

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<sup>1</sup> Zuckerman, Stephen, Laura Skopec, and Marni Epstein. Medicaid Physician Fees after the ACA Primary Care Fee Bump. Urban Institute. March 2017.

marketplace tax credits, leaving them with no health insurance.<sup>2</sup> Again, ASH is opposed to this proposed change because of the possibility of increasing the number of uninsured individuals, especially those who may have sickle cell disease.

Thank you for the opportunity to provide comments in response to the Request for Comment on the Consumer Inflation Measures Produced by Federal Statistical Agencies. 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](mailto: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

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<sup>2</sup> Aron-Dine, Aviva, and Matt Broaddus. Poverty Line Proposal Would Cut Medicaid, Medicare, and Premium Tax Credits, Causing Millions to Lose or See Reduced Benefits Over Time. Center on Budget and Policy Priorities. May 22, 2019.