



American Society of Hematology

Helping hematologists conquer blood diseases worldwide

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2026

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The Honorable Mehmet Oz, M.D.
Centers for Medicare and Medicaid Services
7500 Security Blvd.
Baltimore, MD 21244

Dear Administrator Oz,

On behalf of the American Society of Hematology (ASH), we write to request that you consider the needs of individuals living with complex hematologic conditions as you implement the community engagement requirements of the One Big Beautiful Bill Act (OBBBA) (P.L.119-21).

Section 71119 of the law requires states to impose community engagement requirements for adults in the Medicaid expansion population aged 19–64 (under age 65, $\leq 138\%$ FPL). Enrollees in this population will be required to complete 80 hours of qualifying activities per month (i.e., work, community service, work program, half-time education, or income equivalent) to maintain their Medicaid eligibility. The legislation allows the Secretary to define “medically frail,” “special medical needs,” “physical § disability,” and/or “complex medical condition” to exclude certain Medicaid beneficiaries from the community engagement requirements (P.L. 119-21, Sec. 71119(a); (xx)(9)(A)(ii)(V)).

In a letter dated November 24, 2025, the Society outlined the importance of protections for individuals with complex hematologic conditions who rely upon Medicaid coverage. These individuals regularly require access to highly specialized care appropriate to manage their conditions. Again, ASH writes to emphasize the importance of continuous Medicaid coverage for low-income adults with hematologic conditions.

The Society recommends that Medicaid beneficiaries in active treatment for hematologic malignancies including acute lymphoblastic leukemia, acute myeloid leukemia, myelodysplastic syndromes, lymphoma, and multiple myeloma, and severe classical hematologic conditions including sickle cell disease (SCD), thalassemias and rare hematologic conditions included below be excluded from the OBBBA’s community engagement requirements.

Blood Cancers

For malignant hematologic conditions, such as lymphoma and acute leukemia, the intensity of treatment and length of recovery make it difficult to maintain employment or regular daily activities. Acute leukemias like acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML) are rapidly progressive cancers that need timely and comprehensive medical intervention to optimize survival rates.ⁱ Treatment requires patients to spend more than twelve months in the hospital receiving chemotherapy and specialized care following diagnosis. Hodgkins and non-Hodgkin’s lymphoma are additional examples of cancers that require cycles of chemotherapy from two to nine months depending on severity of disease.ⁱⁱ Multiple myeloma is a rare cancer of plasma cells in the bone marrow.ⁱⁱⁱ Treatment for this malignant condition includes a combination of therapies, including targeted therapy, immunotherapy, and chemotherapy. Cancer treatment often leads to side effects including fatigue, increased risk of infection, cognitive impairment and neuropathy, all of which

can make a patient physically unable to perform job duties or attend school. As CMS directs states to apply a definition of medical frailty to exclude certain populations, it is imperative that individuals who are undergoing active blood cancer treatment are included. Active treatment should be defined to include individuals with relevant diagnosis and procedure codes indicative of ongoing care, including chemotherapy, immunotherapy, or bone marrow transplantation.

Sickle Cell Disease

Approximately 100,000 Americans are living with SCD, an inherited, lifelong disorder, which results in patients' red blood cells becoming rigid and sickle shaped.^{iv} The worst complications include stroke, acute chest syndrome, organ damage, other disabilities, and premature death. People with SCD will often experience a pain crisis or vaso-occlusive (VOC) episode which can cause sudden and severe pain, most commonly in hands, feet, chest, and back.^v Up to 67% of Americans with SCD experience at least three VOC pain crises per year, with the average hospital admission for a severe pain crisis being five days.^{vi} This variability among individuals living with SCD adds to the complexity of the disease and its manifestations, progression, and response to treatment.^{vii} These seemingly random pain crises can have a significant impact on a person's quality of life, including the ability of individuals with SCD to attend and participate fully in school and work on a regular basis. Consistent coverage is necessary for individuals with SCD to avoid or lessen complications that may occur from delayed potential treatment. Due to the unpredictability of SCD the Society recommends that patients be excluded from the community engagement requirements and defined as medically frail if they have a diagnosis code for SCD.

Other Classical Hematologic Conditions

Other rare, classical hematologic conditions, including aplastic anemia, severe hemophilia, paroxysmal nocturnal hemoglobinuria, thalassemia major, refractory immune thrombocytopenic purpura, thrombotic thrombocytopenic purpura, severe hemochromatosis, and amyloidosis should be explicitly recognized for exemption under the definition of medically frail from the community engagement requirement.^{viii} These disorders are characterized by significant clinical burden and functional impairment, including severe fatigue, chronic pain, heightened risk of infection, and the need for ongoing, intensive medical management. Patients frequently require recurrent healthcare utilization, such as transfusions, infusion therapies, and specialized monitoring, which can be unpredictable and time intensive. As a result, individuals living with these conditions may face substantial barriers to maintaining consistent employment, warranting an exemption from the implementation of community engagement requirements.

These conditions stated above should be explicitly included in the Secretary's definition of medically frail; however, such designation should not categorically preclude individuals with these conditions from working or attending school if their health status allows.

Table 1: Complex Hematologic Conditions ICD-10-CM Range

Disease	ICD-10-CM Range
Acute lymphoblastic leukemia	C91.0-
Acute myeloid leukemia	C92.0-
Hodgkin lymphoma	C81.0–C81.9
Non-Hodgkin lymphoma	C82–C86, C88, C96
Multiple myeloma	C90.0-
Sickle cell disease	D57.0–D57.8
Aplastic anemia	D61.0–D61.9
Severe hemophilia	D66–D67
Paroxysmal nocturnal hemoglobinuria	D59.5
Thalassemia major	D56.1 (within D56.0–D56.9)
Refractory ITP	D69.3
TTP	M31.1
Hemochromatosis	E83.11-
Amyloidosis	E85.0–E85.9

We hope to continue to serve as a resource to CMS throughout this process, to ensure that patients with hematologic conditions are appropriately considered and afforded flexibility permitted by law under the Medicaid community engagement requirements. The Society welcomes the opportunity to meet with you and your team to discuss further. In the interim please contact ASH Manager, Policy & Practice, Myra Masood (mamasood@hematology.org) if you require additional information.

Sincerely,



Robert Negrin, MD
President

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- i. <https://ashpublications.org/blood/article/144/Supplement%201/2343/532132/Medicaid-Expansion-and-Cancer-Specific-Survival>
 - ii. <https://ashpublications.org/blood/article/146/Supplement%201/8039/553856/Temporal-trends-and-demographic-patterns-in>
 - iii. <https://ashpublications.org/blood/article/146/Supplement%201/8117/550007/Outcomes-for-Medicaid-recipients-with-multiple>
 - iv. <https://www.cdc.gov/sickle-cell/complications/pain.html>
 - v. <https://pmc.ncbi.nlm.nih.gov/articles/PMC1032958/>
 - vi. <https://pmc.ncbi.nlm.nih.gov/articles/PMC1032958/>
 - vii. <https://doi.org/10.17226/15244>.
 - viii. <https://www.hematology.org/classical-hematology#:~:text=From%20%22Non%2Dmalignant%22%20or,with%20non%2Dcancerous%20blood%20disorders.>