American Society of Hematology
Helping hematologists conquer blood diseases worldwide

2026
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July 30, 2026

Mehmet Oz, MD, MBA
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Blvd.
Baltimore, MD 21244

Submitted electronically via Regulations.gov

Re: Medicaid Community Engagement Requirement for Certain Individuals Interim Final Rule (CMS-2454-IFC).

Dear Administrator Oz:

The American Society of Hematology (ASH) appreciates the opportunity to provide comments on the Medicaid Community Engagement Requirement for Certain Individuals Interim Final Rule (CMS-2454-IFC). We wish to express our serious concerns regarding the Centers for Medicare & Medicaid Services' (CMS) interpretation and application of the medical frailty exemption for individuals with serious or complex medical conditions under the new Medicaid community engagement requirements.

ASH represents more than 18,000 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. Our mission is to foster high-quality, equitable care, transformative research, and innovative education to improve the lives of patients with blood and bone marrow disorders.

CMS-2454-IFC and its authorizing statute recognize that any community engagement requirement must include exceptions for certain classes of individuals whose medical frailty precludes employment, enrollment in school, or ability to volunteer for 80 hours per month. On behalf of clinicians and patients, ASH urges CMS to reconsider medical frailty exemptions for those with

serious or complex medical conditions.

Congress specifically stated that individuals with serious or complex medical conditions be classified as medically frail to protect those beneficiaries from losing their Medicaid coverage. Importantly, this category is one of five independent sub-categories of medical frailty in the statute, and—unlike the sub-categories addressing physical, intellectual, or developmental disabilities—it contains no language specific to functional or activities-of-daily-living limitation. Sickle cell disease, hemophilia, and blood cancers are all serious or complex medical conditions, which affect individuals' ability to work particularly at certain points in their treatment. Ahead of the interim final rule being released, ASH provided a list of ICD-10 codes for these conditions to CMS in a letter dated April 10, 2026, to assist the Agency with defining those conditions that could be exempt. However, CMS, in the interim final rule requires that to be exempt, beneficiaries with serious or complex medical conditions will only be considered medically frail based on their condition if that condition significantly impairs their ability for community engagement, in lieu of providing specific diagnosis codes. Congress did not envision this second prong of the medical frailty test, and it grafts a functional-impairment standard onto a statutory category that contains no such element.

As finalized, CMS failed to establish a uniform standard for states to evaluate whether individuals with serious or complex medical conditions can meet the community engagement requirement. This rule builds separate bureaucratic hurdles for patient access to care in each state and creates a conflict of interest for physicians who will be forced to become gatekeepers to Medicaid insurance coverage. This final rule will have consequential, measurable, and negative impacts on clinicians and Medicaid beneficiaries.

Congress also directed CMS to implement this provision in a manner that exemptions should be assessed based on available data. However, the final rule imposes severe administrative tasks on physicians, nurses, staff, and medical practices that will reduce the time that should be devoted to patient care. Medical practices are already overwhelmed with administrative requirements related to prior authorizations, letters to appeal denials of insurance coverage, and coordinating care with co-treating physicians. Establishing a situation in which physicians must also help patients manage paperwork requirements that are not medical in nature – determining capability to be engaged in various employment situations – is unrealistic. This situation is exacerbated by the fact that in many areas of the country, patients travel between states to receive appropriate and timely care. Travel between states for medical care will require compliance with differing standards for making community engagement determinations. For example, Medicaid beneficiaries with rare diseases like sickle cell disease often travel across state lines to access specialized care that is not available in their home state. While the home state Medicaid plan remains the payer for health care services, the physician and healthcare system where the patient is treated will likely bear the documentation burden imposed by the patient's home state. Maintaining Medicaid coverage for these beneficiaries may require time consuming coordination among home-state Medicaid agencies, and out-of-state providers to document exemptions or satisfy reporting requirements. Specialty care providers, including hematologists, may be asked to complete exemption forms, submit medical records, and respond to repeated documentation requests by the home state Medicaid plan.

This additional administrative burden will divert clinical resources from patient care and may delay access to medically necessary services. For patients with rare diseases, even brief interruptions in Medicaid coverage will disrupt access to specialized care, create hurdles in receiving disease-modifying therapies, and slow or eliminate essential treatments, increasing the risk of preventable complications and hospitalizations.

These decisions, coupled with patient education that physician practices will undertake will profoundly affect the administrative burden placed on physicians. We can assume that medical practices will be where patients turn for help in understanding the community engagement requirements and processes, as by the very nature of the requirements, the decisions are based on medical determinations. It is also true that there are no evidence-based

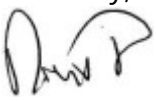
metrics that can be used to measure objectively a patient's fitness for community engagement. This will result in individual physicians and medical practices inserting their own opinions, along with their coding practices and medical evidence. This would adversely affect the doctor-patient relationship, establishing the clinician as a gatekeeper for determining whether someone receives the care they need and introducing the prospect of making a decision that can be harmful to the patient's overall wellbeing.

Consider the case of a hypothetical patient fighting leukemia or another blood cancer. The patient is constantly in and out of a hospital for appointments, chemotherapy cycles, blood transfusions, and addressing downstream symptoms like infection, fever, and pain. This patient is presumably already fighting administrative battles regarding obtaining referrals and navigating diagnostic and therapeutic procedures. Now they must be concerned that proper documentation exists related to their capability of employment, and potentially they must collect this documentation in some circumstances. If the patient crosses state lines for specialized care, the administrative burden is effectively doubled. Such a patient may have some good days, yet they may also be impaired for extended periods of time, making regular employment or community engagement impossible. Determining whether a sick, unemployed individual is capable of community engagement based on a "good day" would be both inaccurate and morally hazardous. Clinicians do not have full visibility on the impact of the disease, personally and professionally or nor do they understand the demands of the patient's employment, and therefore, clinicians should not be forced to be the arbiter of this subjective and non-medical issue, with loss of access to care being the consequence of a judgment.

The internal final rule does not capture Congressional intent in drafting and enacting the underlying statute. Congress intended for state Medicaid agencies to take on the administrative burden of determining capability of community engagement. But instead, the interim final rule assigns this responsibility by default to already overburdened clinicians and medical practices without giving any sufficient direction about how to decide about community engagement capability.

ASH thanks CMS for the opportunity to share these comments on the interim final rule for the Medicaid Community Engagement Requirements. Should you have any questions or require further information, please contact Myra Masood, Manager, Policy and Practice at mmasood@hematology.org.

Sincerely,



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