June 23, 2026

VIA ELECTRONIC SUBMISSION

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

Attention: CMS–2454–IFC

RE: Medicaid Program; Community Engagement Requirement for Certain Individuals (CMS–2454–IFC, RIN 0938–AV98)

Administrator Oz:

Sick Cells appreciates the opportunity to submit comments on the interim final rule with comment period (IFC) implementing the Medicaid community engagement requirement under section 1902(xx) of the Social Security Act.

Sick Cells is a national advocacy organization dedicated to improving health outcomes, access to care, and quality of life for individuals living with sickle cell disease (SCD). More than half of the approximately 100,000 Americans living with SCD[1] are enrolled in Medicaid or the Children's Health Insurance Program[2], making this rule one of the most consequential pieces of federal policy our community will face in the year ahead.

We submitted comments to Secretary of Health and Human Services Kennedy and Administrator Oz in January 2026 urging the Centers for Medicare and Medicaid Services (CMS) to include SCD within its definition of medical frailty for purposes of these work requirements and to prioritize timely identification of SCD beneficiaries within Medicaid programs. We are encouraged that the IFC names SCD directly among the examples of conditions that may significantly impair an individual's ability to comply with the community engagement requirement. We remain concerned, however, that the rule's case-by-case approach to the medically frail exclusion, combined with its documentation and verification requirements, creates meaningful risk of coverage disruption for a population that CMS itself has identified as medically vulnerable. We offer the following comments and recommendations.

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[1] https://www.medicaid.gov/medicaid/quality-of-care/quality-improvement/improving-care-for-sickle-cell-disease.
[2] https://www.medicaid.gov/medicaid/quality-of-care/quality-improvement/improving-care-for-sickle-cell-disease.

I. The Medically Frail Definition Should More Clearly Account for the Episodic and Unpredictable Nature of Sickle Cell Disease

The IFC defines a medically frail individual at proposed § 435.554(c)(5)(i) as one whose physical, mental, or other behavioral health condition significantly impairs their ability to comply with the community engagement requirement, adding that the determination must consider the severity of an individual's condition rather than relying on diagnosis alone. CMS identifies SCD as a condition that would not typically be categorically excluded, placing it among those conditions that could qualify as serious or complex when they significantly impair an individual's ability to meet the requirement.

We appreciate that CMS recognized SCD by name in this preamble discussion. Nevertheless, an individualized severity standard, applied without specific guidance for episodic conditions, is poorly suited to SCD. The effects of this condition do not materialize as a single, stable level of impairment. A person living with SCD may go weeks or months with relatively manageable symptoms, then experience a vaso-occlusive pain crisis that results in an emergency department visit or a multi-day hospitalization with no advance warning. The unpredictability of these episodes is the defining feature of the disease. It does not map cleanly onto a static determination of whether someone can presently perform 80 hours per month of qualifying activity.

We recommend that CMS issue sub-regulatory guidance directing states to treat the frequency and unpredictability of disease exacerbations as relevant evidence of significant impairment for episodic conditions such as SCD in addition to an individual's status at the moment of determination. We further suggest that CMS direct states to explicitly include SCD and its major complications, including but not limited to vaso-occlusive crisis, acute chest syndrome, stroke, and avascular necrosis, in their lists of diagnoses, diagnosis codes, and other health conditions required under § 435.554(c)(5)(ii). Doing so will ensure that frontline eligibility staff are not left to make ad hoc determinations about a complex hematologic disease.

II. Verification Requirements Should Reflect the Realities of How Sickle Cell Disease is Documented and Treated

The IFC permits states to rely on an applicant's statement under penalty of perjury to verify medical frailty only where no reliable information is otherwise available to the state and only on a one-time basis. A state may not later accept a second penalty of perjury statement if the individual's medical frailty status changes or is asserted on a different basis.

For many people with SCD, the most reliable evidence of significant impairment is a pattern of utilization across emergency departments, hospitals, and specialty clinics rather than any single document. Furthermore, that pattern may not be consolidated in any one state's data systems as beneficiaries may move between states or receive care at multiple institutions. We urge CMS to clarify that a documented history of SCD-related hospitalization or emergency care, even where fragmented across providers or systems, constitutes reasonably available documentation sufficient to support a medical frailty determination. We correspondingly call upon CMS to prohibit states from requiring a beneficiary to produce a single consolidated record as a condition of recognizing that history.

We also urge CMS to direct states to accept attestations or documentation from a treating hematologist or sickle cell specialty provider as sufficient evidence of medical frailty for individuals with SCD, given the well documented severity and life limiting nature of the disease, without requiring the additional utilization or functional assessment data that the preamble describes as relevant to other serious or complex conditions.

III. Outreach and Screening Materials Should be Designed with Input from the Sickle Cell Disease Community

The IFC requires states to conduct targeted outreach to applicable individuals and encourages the use of plain language screening questions to identify beneficiaries who may be medically frail. We support this approach, but we are concerned that screening questions designed without input from disease specific communities will fail to surface SCD as a qualifying condition.

We ask CMS to encourage states to consult with national and community-based SCD organizations, including Sick Cells, when developing screening questions and outreach materials. These materials should explicitly reference sickle cell disease as a condition that may qualify for the medically frail exclusion, consistent with its inclusion in the preamble to this IFC.

IV. CMS Should Monitor Implementation Data for Disparate Impact on the Sickle Cell Disease Population

We worry that a verification regime that relies heavily on documentation, when layered onto a healthcare system in which SCD patients already report difficulty obtaining timely diagnoses and consistent care, will result in coverage terminations for individuals who in fact meet the medically frail standard but cannot produce the records a state requests within the timeframes the rule allows.

SCD disproportionately affects Black Americans, a population that already experiences documented disparities in pain management and access to specialty care. We urge CMS to require states to report data allowing CMS to monitor whether individuals with SCD and other conditions disproportionately affecting populations of color are losing coverage at rates inconsistent with the medical frailty exclusion's intended protections as part of their existing data submission obligations under § 435.562. That monitoring data must be made available to the public on a regular basis as well.

Conclusion

Sick Cells appreciates CMS's recognition of sickle cell disease as a condition relevant to the medically frail exclusion and welcomes the opportunity to serve as a resource to the agency as it implements this rule. We respectfully encourage CMS to adopt the recommendations above to ensure that the community engagement requirement does not result in disruptions of coverage for a population that is, by CMS's own observation, medically vulnerable. We would welcome any opportunity to discuss these comments further.

Thank you for your consideration.

Sincerely,

Ashley Valentine

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Co-Founder & President
Sick Cells