Help Us Solve
The Cruel Mystery
LUPUS™
FOUNDATION OF AMERICA

July 31, 2026

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

RE: Medicaid Program; Community Engagement Requirement for Certain Individuals [CMS-2454-IFC]

Submitted electronically via https://www.regulations.gov/commenton/CMS-2026-2047-0002

Dear Administrator Oz:

The Lupus Foundation of America appreciates the opportunity to provide comments on the Centers for Medicare & Medicaid Services' (CMS) interim final rule (IFR) with comment period implementing Medicaid community engagement requirements for certain individuals.

The Lupus Foundation of America is the nation's leading organization dedicated to solving the mystery of lupus while improving the quality of life for all people affected by the disease. Through research, education, support services, and advocacy, the Foundation serves individuals and families impacted by lupus in communities across the United States.

An estimated 1.5 million Americans are living with lupus, a chronic, complex autoimmune disease that can damage virtually any organ system and disproportionately affects women, particularly Black, Hispanic/Latina, Asian, Native Hawaiian and Pacific Islander, and Indigenous women. Lupus is often unpredictable, with periods of relative stability interrupted by flares, new or worsening organ involvement, treatment complications, and other changes in health status. As a result, the impact of lupus on a person's ability to work, attend school, provide care for others, or participate in the community may fluctuate substantially over time.

These realities are central to the implementation of Medicaid community engagement requirements. A person living with lupus may be able to work or participate in other qualifying activities during one period, while experiencing significant symptoms or functional limitations during another, all of which can be unpredictable. Fatigue, pain, cognitive symptoms, mobility limitations, organ involvement, treatment side effects, frequent medical appointments, laboratory monitoring, and disease flares may affect an individual's ability to work consistently or comply with recurring reporting, verification, and documentation requirements.

The Lupus Foundation of America is particularly concerned that implementation of the IFR would place individuals with lupus at risk of losing Medicaid coverage. The work reporting requirements included in the IFR go far beyond the framework established by Congress in P.L. 119-21. The restrictive policies in the IFR – most notably provisions narrowing the definition of medical frailty and eliminating the state option to use sworn attestations – could dramatically worsen outcomes for people living with lupus while at the same time increasing administrative and financial burdens on patients, health care providers, and states. The ability to work at a particular point in time should not be treated as evidence that a person with lupus does not experience significant health-related limitations or treatment burden. Similarly, the absence of a specific diagnosis code, administrative record, or formal disability determination should not be treated as evidence that a person does not have significant health needs that affect their ability to comply with recurring administrative requirements.

Medicaid coverage is critical for many people with lupus. Access to rheumatologists and other specialists, prescription medications, laboratory monitoring, infusion services, hospital care, and other services are essential to controlling disease activity and preventing irreversible organ damage. Even temporary interruptions in coverage can disrupt treatment plans, exacerbate adherence and treatment compliance challenges, delay care, create medication access challenges, and increase the risk of disease flares, hospitalization, and other serious complications, all of which lead to worse outcomes and increased costs not only for lupus patients but also the health care system.

The Lupus Foundation of America therefore urges CMS to implement the community engagement framework in a manner that recognizes the unpredictable, fluctuating, and multisystem nature of lupus. Implementation should ensure that individuals living with lupus do not lose Medicaid coverage because the nature of the disease makes it difficult to assess a person's ability to meet community engagement requirements or because lupus prevents a person from being able to navigate complex administrative requirements during periods of active disease, treatment intensification, or significant health-related limitations.

The Foundation's recommendations are as follows:

- Remove the "significantly impairs" standard from the medically frail exclusion or, if CMS retains the standard, provide clear guidance ensuring that states evaluate lupus and other fluctuating, episodic, and multisystem conditions broadly and consistently.
- Ensure that medically frail determinations consider the full clinical context of lupus, including disease activity, flares, organ involvement, treatment burden, medication side effects, frequent appointments and laboratory monitoring, and functional limitations.
- Preserve meaningful opportunities for self-attestation and other accessible methods of demonstrating health-related circumstances when administrative data are unavailable, incomplete, delayed, or insufficient.

- Minimize repetitive documentation requirements for chronic and ongoing health conditions and avoid placing unnecessary burdens on individuals with lupus and their health care providers and caregivers.
- Ensure that reporting and verification requirements account for the unpredictable nature of lupus, including periods of disease flare, treatment changes, hospitalization, recovery, and other changes in health status.
- Establish clear, easily understandable, and timely notices and meaningful opportunities to correct errors, submit additional information, demonstrate eligibility, and appeal adverse determinations.
- Ensure that eligible individuals with lupus do not lose coverage because of missed notices, administrative errors, inaccessible systems, documentation delays, or other procedural barriers.
- Encourage consistent administration of caregiver-related policies, including implementation of the caregiver exclusion and outreach efforts directed toward individuals whose caregiving responsibilities may affect their status under the community engagement framework.
- Continue engaging patients, caregivers, providers, states, plans, and other stakeholders as implementation proceeds so that operational challenges can be identified and addressed before they result in inappropriate coverage loss.

The Lupus Foundation of America believes that the success of the community engagement framework should be measured not only by whether states establish processes to administer the requirements, but also by whether eligible individuals can successfully maintain access to the coverage and care they need. For people living with lupus, continuity of Medicaid coverage can be the difference between maintaining disease control and experiencing a preventable flare, treatment interruption, hospitalization, or irreversible organ damage.

CMS Should Strengthen Medically Frail Protections for People Living with Lupus

For individuals living with lupus and other serious or complex health needs, the medically frail framework will be one of the primary mechanisms for ensuring that community engagement requirements do not apply in circumstances where a person's health status, treatment burden, or functional limitations make compliance inappropriate or impracticable.

Lupus presents unique challenges for the administration of health-based protections. Unlike conditions that may produce consistent and readily observable functional limitations, lupus can vary significantly over time. An individual may experience periods in which symptoms are relatively controlled, followed by a sudden flare involving severe fatigue, pain, cognitive difficulties, mobility limitations, or serious organ involvement. The individual may continue to work or participate in other activities during periods of relative stability while simultaneously managing a substantial and ongoing medical burden.

The Foundation recognizes that the IFR establishes an exclusion pathway for individuals who are medically frail or otherwise have special medical needs, and that CMS is implementing the statutory categories enacted by Congress. However, the Lupus Foundation of America is concerned that an overly narrow interpretation of the medically frail exclusion fails to account for these realities. A framework that focuses primarily on permanent incapacity or the inability to work will exclude people with lupus who experience significant health-related limitations that are episodic, fluctuating, or treatment-related. Without additional guidance and safeguards, overly narrow or inconsistent implementation would place individuals with significant health needs at risk of avoidable coverage loss, higher health care costs and worse health outcomes.

The relevant question should not be solely whether an individual can work at a particular point in time. Rather, CMS should ensure that states consider whether the individual's health status, disease activity, treatment demands, and functional limitations affect the individual's ability to consistently comply with recurring community engagement, reporting, verification, and documentation requirements.

The Lupus Foundation of America further encourages CMS to recognize that claims and administrative data may not fully capture the impact of lupus. A diagnosis code may establish that an individual has lupus but may not demonstrate the severity of current or future disease activity, the impact of fatigue or cognitive symptoms, the burden of treatment, or the effect of a recent flare on an individual's ability to comply with program requirements. Conversely, the absence of a particular claim or data point should not be treated as evidence that an individual does not have significant health-related needs.

CMS should therefore require states to use a flexible, clinically informed approach to medically frail determinations that considers the full context of an individual's health status. States should have the ability to consider appropriate clinical information, patient-reported information, treatment history, and other relevant evidence rather than relying exclusively on rigid diagnostic or administrative criteria.

CMS Should Preserve Meaningful Opportunities for Self-Attestation and Minimize Documentation Burden for People with Lupus

The IFR establishes a verification framework intended to determine whether beneficiaries satisfy community engagement requirements or qualify for applicable exclusions and exemptions. The Lupus Foundation of America supports the use of reliable information already available to states when that information accurately and adequately reflects an individual's circumstances. A data-first approach may help reduce unnecessary administrative burden and avoid requiring beneficiaries to repeatedly provide information that can be verified through existing sources.

However, administrative data will not always capture the realities of living with lupus. Claims data may establish that an individual has a lupus diagnosis or has received medical care, but may not reflect the severity of current or future disease activity, the impact of fatigue, pain, cognitive symptoms, or other manifestations, the occurrence of a recent flare, or the

cumulative burden of treatment and disease management. Employment data may not reflect whether an individual has experienced intermittent absences, reduced hours, changes in work capacity, or difficulty maintaining employment because of unpredictable disease activity. Medical records may also not fully capture the day-to-day functional impact of lupus or the practical challenges of responding to recurring administrative requirements.

These limitations are particularly important because lupus is a highly variable disease. A person may experience a significant flare or change in disease activity that is not immediately reflected in administrative data. An individual may have recently changed medications, begun a new treatment, experienced a hospitalization, or developed new organ involvement. The absence of a corresponding data point should not be treated as evidence that the individual does not have significant health-related needs or does not qualify for an applicable exclusion or protection.

The Lupus Foundation of America therefore urges CMS to preserve meaningful opportunities for self-attestation and other accessible methods of demonstrating an individual's circumstances when reliable administrative data are unavailable, incomplete, delayed, or insufficient. Self-attestation can serve as an important safeguard when available data do not accurately reflect the realities of living with lupus.

The Foundation also encourages CMS to reinforce the verification hierarchy established in the IFR. States should evaluate whether an individual qualifies as a specified excluded individual before assessing compliance with community engagement requirements or exceptions, and, once exclusion status is verified, the exclusion should take precedence even if the state has also collected information related to compliance. This hierarchy is important because it reduces unnecessary compliance checks, limits duplicative administrative interactions, and helps ensure that individuals who are not subject to the requirements are not exposed to avoidable reporting, verification, or documentation burdens. CMS should also ensure that individuals have meaningful opportunities to provide additional information, correct incomplete records, and resolve discrepancies before coverage is denied or terminated.

The Foundation is similarly concerned about the cumulative burden associated with documentation requirements. While individual requests for documentation may appear reasonable in isolation, repeated requests for verification can create significant challenges for beneficiaries, caregivers, providers, and state agencies alike, particularly when individuals living with chronic diseases or disabilities are required to obtain records from multiple providers, respond to repeated information requests, or repeatedly verify circumstances that have already been established. These requirements may also create unintended burdens for clinicians and health care providers, who should not be placed in the position of repeatedly generating documentation for conditions that are chronic, long-term, or already reflected in existing records, and excessive documentation requirements may consume clinical resources, increase administrative workload, and divert attention away from patient care without meaningfully improving program integrity.

The Lupus Foundation of America therefore encourages CMS to minimize repetitive documentation requirements for chronic and ongoing health conditions and to avoid requiring

beneficiaries to repeatedly establish circumstances that have already been verified. States should be encouraged to use information already available through Medicaid systems and other public programs whenever possible and should not require individuals to repeatedly submit the same information through multiple administrative processes.

CMS Should Ensure that Community Engagement Requirements Reflect the Fluctuating Nature of Lupus

The Lupus Foundation of America recognizes that the interim final rule provides multiple pathways through which individuals may satisfy community engagement requirements. Multiple pathways are important because individuals may work, attend school, participate in training, provide care, or engage in other qualifying activities in different ways and at different times.

For people with lupus, however, the ability to participate in these activities may fluctuate significantly. An individual may work full-time during a period of relative disease stability and later need to reduce hours, take leave, or temporarily stop working during a significant flare, treatment change, hospitalization, or period of increased disease activity. These changes should not be viewed as evidence that an individual is not engaged in their community or is unwilling to work.

Lupus can affect an individual's ability to maintain a consistent schedule. Severe fatigue, pain, cognitive symptoms, joint involvement, organ disease, treatment side effects, and other manifestations may affect the number of hours an individual can work or the activities in which they can participate. These limitations may change over time and may not be predictable in advance.

The Foundation urges CMS to ensure that states recognize the realities of variable and fluctuating participation. A person with lupus should not be placed at risk of losing Medicaid coverage because their participation changes during a period of active disease or increased treatment burden, particularly when the individual remains otherwise eligible for Medicaid.

The Foundation further encourages CMS to ensure that states account for the relationship between lupus-related health needs and participation. For example, an individual may be able to work but need frequent time away from work for medical appointments, laboratory monitoring, infusions, or treatment-related care. Another individual may work remotely or have a flexible schedule because of the unpredictable nature of their disease. These arrangements should not be treated as evidence of a lack of meaningful engagement.

Reporting, Notices, Appeals, and Procedural Safeguards Must Minimize Coverage Loss for People with Lupus

The Lupus Foundation of America is concerned that reporting requirements, verification activities, notices, appeals processes, and other procedural requirements could become significant drivers of Medicaid coverage loss for eligible individuals with lupus.

People living with lupus may experience periods in which disease activity or treatment burden makes it difficult to respond to administrative requests within a specified timeframe. A person may be hospitalized, experiencing a severe flare, undergoing a treatment change, recovering from a medical procedure, or managing significant symptoms when a notice or documentation request is issued.

In these circumstances, a missed deadline may reflect a temporary health-related limitation rather than a failure to comply with program requirements. The Foundation urges CMS to ensure that states do not treat an inability to respond promptly during a period of active disease as evidence of ineligibility or noncompliance.

Notices should be clear, accessible, and actionable. They should explain why the notice was issued, what information is required, how information may be submitted, what deadlines apply, what consequences may result from failing to respond, and how the individual may obtain assistance. These protections are particularly important for people with lupus because cognitive symptoms, severe fatigue, pain, treatment side effects, and other manifestations of the disease may affect an individual's ability to understand or respond to complex administrative communications.

The Foundation encourages CMS to ensure that a notice stating that a state is "unable to verify" an individual's circumstances does not function as a presumption of noncompliance. An inability to verify information may result from incomplete data, delayed records, inconsistent administrative systems, unavailable documentation, or a beneficiary's temporary inability to obtain information during a period of illness.

Individuals should be given meaningful opportunities to provide additional information, correct errors, and demonstrate that they satisfy applicable requirements or qualify for an exclusion or protection before coverage is terminated.

Appeal rights are an essential safeguard against inappropriate coverage loss. However, appeal rights are only meaningful if individuals understand how to exercise them and have sufficient time and support to do so. CMS should ensure that states provide accessible appeal processes and reasonable opportunities for individuals with serious health conditions to respond to adverse determinations.

The Foundation also urges CMS to ensure that reinstatement processes are timely, predictable, and accessible. When an individual is subsequently determined to have satisfied a community engagement requirement, qualified for an exclusion or protection, or otherwise remained eligible for Medicaid, coverage should be reinstated promptly and retroactively as appropriate to prevent gaps in care and unpaid medical claims.

For people with lupus, a gap in coverage can have serious consequences. Loss of coverage may interrupt access to medications, specialist appointments, laboratory monitoring, infusion services, and other care necessary to control disease activity and prevent complications. CMS should therefore treat the prevention of procedural disenrollment as a central implementation objective.

Effective Implementation Requires Accessible Systems and Lupus-Specific Monitoring

The systems used to implement community engagement requirements will determine whether people with lupus can successfully maintain coverage. Reporting platforms, notices, call centers, verification systems, appeals processes, and other administrative tools must be accessible and capable of accommodating individuals whose health status may fluctuate over time.

CMS should encourage states to provide multiple ways for beneficiaries to receive information, submit documentation, report compliance, request assistance, and exercise appeal rights. These pathways should include online systems, telephone support, mail, mobile-accessible platforms, and in-person assistance where appropriate.

Individuals should not lose coverage because of technology limitations, inaccessible systems, system errors, or difficulty navigating complex administrative processes. Similarly, administrative system failures should not be treated as evidence of beneficiary noncompliance.

The Foundation also encourages CMS to establish transparent monitoring of the real-world effects of implementation. Oversight should evaluate not only whether states have established required processes but also whether eligible individuals are losing coverage because of administrative barriers.

The Foundation encourages CMS to engage patients, caregivers, clinicians, patient organizations, such as the Lupus Foundation of America, and other stakeholders as implementation proceeds. People living with lupus and the clinicians and caregivers who care for them can provide important insight into how administrative requirements interact with disease flares, treatment changes, organ involvement, and the day-to-day realities of managing a complex chronic disease.

Conclusion

The Lupus Foundation of America recognizes the importance of ensuring that Medicaid programs are administered effectively and that statutory requirements are implemented in a clear and workable manner. At the same time, we urge CMS to ensure that implementation does not place eligible individuals with lupus at risk of losing essential health coverage.

For people living with lupus, continuous Medicaid coverage is essential to accessing the specialists, medications, laboratory monitoring, and other care necessary to manage disease activity and prevent serious complications. Interruptions in coverage can delay care, disrupt treatment, increase the risk of flares and hospitalization, and contribute to irreversible organ damage all of which lead to increased costs and worse health outcomes.

The Lupus Foundation of America urges CMS to implement the community engagement framework in a manner that recognizes the unpredictable and fluctuating nature of lupus. CMS should strengthen medically frail protections, preserve meaningful opportunities for self-attestation, minimize repetitive documentation requirements, ensure accessible reporting and

appeal processes, and monitor the real-world impact of implementation on individuals with lupus.

The Lupus Foundation of America appreciates the opportunity to comment on this interim final rule and urges CMS to ensure that implementation protects continuity of coverage and care for people living with lupus.

Sincerely,

Patrick Wildman
Sr. VP, Advocacy and Government Relations