CLL SOCIETY

VIA ELECTRONIC DELIVERY

April 11, 2025

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

RE: Patient Protection and Affordable Care Act; Marketplace Integrity and Affordability [CMS-9884-P]

Dear Administrator Oz,

CLL Society appreciates the opportunity to provide its comments on the Centers for Medicare & Medicaid Services' (CMS') proposed rule refining key processes and protections eligibility, enrollment, and coverage protections within the Affordable Care Act (ACA) Marketplaces ("Proposed Rule").

CLL Society is the largest nonprofit focused exclusively on the unmet needs of patients living with Chronic Lymphocytic Leukemia and Small Lymphocytic Lymphoma (collectively, "CLL"). We are dedicated to addressing the unmet needs of the CLL community through patient education, advocacy, support, and research.

We strive to fulfill our primary mission of ensuring that patients have access to safe and effective treatment options by informing patients and caregivers about the rapidly changing therapeutic landscape, underscoring the importance of clinical trials, supporting, and building patient networks, engaging in research, and educating providers and patients. As an organization, we also recognize that the healthcare landscape extends beyond science, clinical care, and patient support to include the financial realities and access challenges patients face throughout their cancer battle.

Our comments are intended to contribute the lived experience of individuals living with CLL and aid CMS in implementing policies that improve marketplace program integrity without compromising the Administration's "make American healthy again" goal.

Background: CLL/SLL

CLL is a chronic blood cancer of a type of white blood cell called the B-lymphocyte. CLL is both a type of leukemia and a type of non-Hodgkin's Lymphoma (NHL). SLL is simply a different manifestation in which there are not yet a significant number of cancer cells located in the bloodstream. When the cancer is only found in the lymph nodes it is called SLL. When the cancer is found in the bloodstream and possibly elsewhere, including lymph nodes, it's called CLL.

While rare, CLL is the most common leukemia in U.S. adults, with around 21,000 cases diagnosed annually. According to 2024 data from the National Cancer Institute's Surveillance, Epidemiology, and End Results Program:[1]

- An estimated 20,700 new CLL cases were diagnosed in 2024
- CLL accounts for approximately 1% of all cancers in the U.S.
- Approximately 4,400 Americans died from CLL in 2024 (.7% of cancer deaths)
- CLL is most frequently diagnosed in individuals aged 65-74 (32.3%)
- Individuals aged 55-65 account for 22.3% of new cases

CLL is extremely heterogeneous in terms of disease course and progression. Some patients have an aggressive form of the disease, generally identified by genetic expression as higher-risk, experience rapid deterioration, and survive for as little as two years. Others have a less aggressive form of the disease, may never need treatment, and can expect to have a normal life expectancy. For most patients, CLL is indolent and incurable. The goals of therapy are to improve quality of life and prolong overall survival (OS).[2] Today, the median overall survival (OS) from start of front-line therapy is 5 to 15 years, depending on disease features, individual patient factors, and treatment choices. Although CLL patients have more treatment options compared to several years ago, most patients will experience one or more relapses, and many will receive all available agents during their disease course.

---

[1] Chronic Lymphocytic Leukemia — Cancer Stat Facts

[2] Selection of initial therapy for symptomatic or advanced chronic lymphocytic leukemia/small lymphocytic lymphoma - UpToDate

Access to Affordable, Comprehensive Insurance through Marketplace Plans Provides a Lifeline for Many CLL Patients

While the majority of CLL patients are over age 65 and eligible for coverage through Medicare, nearly a quarter of newly diagnosed patients are between 55 and 65 years of age. Asymptomatic individuals who do not require immediate treatment can expect to continue working without significant disruption (other than living with the fact of a cancer diagnosis) due to CLL. This is not the case for symptomatic patients and those requiring treatment.

A 2020 analysis of a long-term study assessing how patients with chronic lymphocytic leukemia (CLL) describes quality of life (QoL) compared to other U.S. populations, and the impact CLL has on daily living, finances, and professional and family relationships.[3] The study included 191 patients with CLL who were enrolled in the Cancer Support Community's online cancer experience registry. The mean patient age was 61 years and the mean time from CLL diagnosis was 6.6 years. One in five patients (19%) reported experiencing a recurrence of CLL. A sizable proportion of CLL patients reported significantly worse quality of life (QoL) than the national average of the U.S. population. In addition:

- 20% of responding CLL patients rated their overall health as poor or fair.
- 30% said that CLL affects their relationships with friends and family.
- 24% were concerned about thinking clearly ("chemo brain" or "brain fog")
- 34% reported that CLL affects their ability to work.
- 42% reported that CLL affects their day-to-day finances.

The most common cancer-related sources of distress reported by respondents centered on physical and future-focused matters. Respondents reported being moderately to very seriously concerned about health insurance and finances (33%) and changes in work, school, or home life (32%).

CLL patients unable to maintain sufficient work schedules to continue receiving employer sponsored coverage rely on ACA marketplace coverage to access the care they need until either extended disability or age enables enrollment in Medicare. For these patients, it is imperative that enrollment processes be clear, predictable, and immediately actionable. In addition, patients need coverage that is both affordable and sufficiently comprehensive to permit a treatment plan

---

[3] https://www.cancersupportcommunity.org/sites/default/files/file/2020-07/CSC_Registry_Report_June_2020.pdf

developed by or in consultation with a clinician with CLL expertise, and access to prescribed medications, tests, and other services.

CLL Society Recommendations as CMS Finalizes its Modifications to Processes and Requirements Related to ACA Marketplace Coverage

CLL Society supports the Administration's goal of reducing fraud and abuse throughout health programs funded or administered by CMS. We are, however, concerned that several of the provisions in the Proposed Rule are likely to disrupt coverage, present administrative and financial burdens to providers, and adversely impact CLL patients and others with chronic conditions. In addition, we expect that implementing the new requirements will be costly to ACA marketplace plans and that those costs will ultimately be borne by the federal government, taxpayers, and patients. We expect many of these processes will reveal instances of individuals inappropriately receiving premium and cost-sharing assistance, including individuals with earnings below what is required to qualify for such assistance. Unfortunately, it is likely that the new requirements will have a net impact of terminating assistance and coverage for more individuals lawfully receiving these benefits.

We urge CMS to reconsider the proposed refinements outlined below:

Shortening the Annual Open Enrollment Period

The Proposed Rule would replace the November 1 through January 15 annual OEP with a reduced 45-day period from November 1 to December 15. CLL Society is concerned that this change would exert a destabilizing force on the individual market. Individuals with chronic conditions are highly motivated to re-enroll in a plan, whereas younger, healthier individuals might be more likely to miss the new deadline and fail to enroll. This could threaten progress toward a functioning, viable, and competitive market that is crucial to CLL patients seeking to choose a plan that suits their financial situation and health concerns.

Reinstating Special Enrollment Period (SEP) Verification Requirements

CMS proposes to require that Federally Facilitated Exchanges (FFEs) conduct pre-enrollment SEP verification of eligibility for five SEP qualifying events -- marriage, adoption, moving to a new coverage area, loss of minimum essential coverage, and Medicaid/CHIP denial. It would also require State-based Exchanges on the Federal platform (SBE-FPs) to conduct pre-enrollment SEP verification for at least 75 percent of new enrollments. CMS proposes that starting with the 2026 plan year, consumers would have their eligibility verified electronically or would be asked to submit documentation to confirm their eligibility for an SEP.

CLL Society is concerned that plans might utilize these processes in a manner that favors individuals with low healthcare costs. CLL patients often face significant physical, financial, and emotional challenges as they navigate their access to care. Treatment side effects, CLL symptoms, and the stressors associated with any cancer diagnosis can quickly overburden families. On balance, program integrity concerns could be addressed with uniform, simplified processes that might include transmitting a notice of coverage discontinuation. Delays in processing enrollment, burdensome documentation requests, and/or multi-step administrative processes for transmitting, reviewing, and assessing documentation create a high potential for delaying necessary care for patients who simply cannot afford treatment disruptions.

Requiring Premiums for Auto Re-enrolled Consumers

CMS proposes changing the annual eligibility redetermination process by requiring Marketplaces to assess a $5 monthly premium for automatically re-enrolled individuals who do affirm or update their eligibility information and are re-enrolled in a plan with a fully subsidized premium. CLL Society understands that CMS seeks to use a pragmatic “carrot and stick” approach to encourage consumers to update eligibility information. The $5 premium is nominal and there is clearly a program integrity interest in maintaining up to date information related to eligibility for subsidized premiums. Unfortunately, we expect that the nominal nature of the $5 premium is counterbalanced by the fact that consumers would have to remember to submit $5 to cover their premium each month. We are concerned that nonpayment of the $5 premium will be a common occurrence and oppose this proposal if this nonpayment would result in termination of coverage.

Removing Re-enrollment Hierarchy Standards

The Proposed Rule provides for removal of the current provision permitting Marketplaces to automatically re-enroll CSR-eligible enrollees from a bronze plan to a silver plan if the silver plan is in the same product, has the same provider network, and has a lower or equivalent net premium as the bronze plan into which the enrollee would otherwise have been re-enrolled.

The higher actuarial value of silver plans makes this provision beneficial to individuals with chronic conditions, including CLL. We understand that CMS is concerned that consumers will feel that their choice was not respected, are confused, or might incur unexpected tax liabilities due to this switch. We believe a simple notice of the re-enrollment change along with a clear process for reverting to bronze coverage would alleviate these concerns while providing consumers with affordable, comprehensive coverage.

Conclusion

CLL Society supports the Administration’s priorities to address adverse selection bias and reduce waste, fraud, and abuse. We appreciate the opportunity to contribute the perspectives of our CLL communities as you work to strengthen access to affordable, comprehensive coverage for all Americans. If you have any questions, please feel free to contact me or Saira Sultan, CLL Society’s Healthcare Advocacy & Policy Consultant, via email at saira.sultan@connect4strategies.com.

Sincerely,

Carly Harrington
Executive Director, CLL Society