



January 30, 2023

The Honorable Xavier Becerra  
Secretary of Health and Human Services  
U.S. Department of Health and Human Services  
200 Independence Avenue SW  
Washington, DC 20201

The Honorable Chiquita Brooks-LaSure  
Administrator Centers for Medicare and Medicaid Services  
U.S. Department of Health and Human Services  
200 Independence Avenue SW  
Washington, DC 20201

**Re: Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2024 (CMS-9899-P)**

Dear Secretary Becerra and Administrator Brooks-LaSure:

The Cystic Fibrosis Foundation thanks the Department of Health and Human Services (HHS) for the opportunity to comment on the Notice of Benefit and Payment Parameters (NBPP) for 2024 proposed rule. The Cystic Fibrosis Foundation is a national organization dedicated to curing cystic fibrosis (CF). We invest in research and development of new CF therapies, advocate for access to care for people with CF, and fund and accredit a network of specialized CF care centers.

Cystic fibrosis is a life-threatening genetic disease that affects close to 40,000 children and adults in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. If left untreated, infections and exacerbations caused by CF can result in irreversible lung damage, and the associated symptoms of CF lead to early death, usually by respiratory failure. Through careful, aggressive, and continuously improving disease management, the average life expectancy for people with cystic fibrosis has risen steadily over the last few decades. This milestone reflects over 50 years of hard work to improve CF treatments, develop evidence-based standards of care, and encourage adherence to a lifetime of chronic care. However, this system of care and the improvements in length and quality of life for those with CF can only be realized if patients have access to adequate and affordable insurance.

Thank you for the opportunity to submit comments on the Notice of Benefits and Payment Parameters for 2024 Proposed rule. The CF Foundation provides the following recommendations.

## **Network Adequacy**

As noted in our 2023 Notice of Benefits and Payment Parameters comments, the CF Foundation commends HHS for reexamining federal network adequacy standards for plans offered through the Federally Facilitated Marketplace (FFM). We are encouraged by the extensive requirements and oversight procedures implemented in the final 2023 NBPP and that HHS is revisiting the appointment wait time standards. In 2023 final rule, HHS delayed implementation of this standard until 2024, citing concerns about compliance burden on issuers. Establishing standards specifying the maximum number of days enrollees may be required to wait for a provider appointment will add an important dimension to network adequacy review that is not captured by other network rules. Individuals with CF rely on access to a network of specialized providers that are critical for obtaining high-quality care. In CF, waiting too long to see a specialist could give a pulmonary exacerbation time to develop and become life threatening and timely access to providers is essential for maintaining patients' health. We support HHS's approach to collect data from specialists on what would be appropriate for their patient population before setting such a long wait standard.

Furthermore, as HHS considers how to improve network oversight further, the CF Foundation urges the department to scrutinize networks for their ability to provide culturally- and linguistically-competent care. This should include, among other things, a rigorous assessment of whether a network includes sufficient providers with appropriate language proficiencies, and/or provides sufficient access to appropriate language services, to ensure individuals with limited English proficiency can obtain timely care in their preferred language. It also means networks must ensure access to culturally appropriate care that reflects the diversity of enrollees' backgrounds and is attuned to traditionally underserved communities, including people of color, immigrants, and LGBTQ individuals. Further, to enable consumers to identify the plans and providers likely to meet their needs, qualified health plans (QHPs) must be required to indicate in their provider directories the languages, other than English, which are spoken by a provider and/or their staff.

## **Prohibiting Mid-Year Terminations for Dependent Children Who Reach Maximum Age**

In the proposed rule, HHS would codify the requirement to provide more clarity for participating issuers that dependent children maintain coverage until the end of the plan year in which they turn 26. For families that receive advanced premium tax credits (APTCs), the marketplace makes eligibility determinations for the entire plan year. For young adults with cystic fibrosis enrolled on a marketplace plan with their families, there is a chance the APTCs are more generous or the plan is more robust than if the individual enrolls on their own. Furthermore, this prevents young adults with CF who have high cost of care from restarting their cost-sharing requirements mid-year, which could add significant out-of-pocket expenses. The CF Foundation strongly supports finalizing this requirement.

## **Special Enrollment Periods**

The CF Foundation strongly supports the proposed changes to expand special enrollment periods (SEPs). These issues will be particularly important given the upcoming changes related to the continuous coverage provisions for the COVID public health emergency and transition to marketplace coverage.

First, current rules allow a consumer who knows they will lose non-marketplace coverage within the upcoming 60 days to use a SEP to select a marketplace plan in advance of the loss of coverage. HHS is proposing to modify the loss-of coverage SEP to permit exchanges to require QHPs issuers to start coverage one month earlier in case where the old coverage ends before the end of the month. The CF Foundation strongly supports this provision as it will allow consumers to start coverage sooner and avoid a gap.

In addition, HHS is proposing to extend the loss of coverage SEP enrollment window following loss of Medicaid coverage from 60 days to 90 days, in order to provide consumers more time to reestablish eligibility for Medicaid coverage or enroll in a marketplace plan. We strongly support this proposal, as it will minimize gaps in coverage. Separate from this proposed rule, we strongly support HHS's announcement of a temporary Exceptional Circumstances SEP for those losing Medicaid or CHIP coverage due to the unwinding of the Medicaid continuous enrollment condition from March 31, 2023 to July 31, 2024 for Marketplaces using the Federal platform.

Finally, as HHS evaluates potential changes and improvements to SEPs in future rulemaking, the Department is considering whether to provide an SEP to consumers whose providers leave their network mid-year. Significant network changes, whether it is initiated by the QHP issuer or the provider, can occur at any point during the year. The Department notes that under Medicare Advantage (MA), individuals affected by a significant change in their plan's provider network are eligible for an SEP that permits re-enrollment into another MA plan or Traditional Medicare. The CF Foundation believes that an enrollee who is impacted by a provider contract termination to be someone who is experiencing an exception circumstance, and should be eligible for a new SEP. Access to an accredited CF care center is critical for obtaining medically necessary and high-quality care for people with CF. If the CF care center's hospital or health system terminates its contract with a QHP, patients should be eligible for an SEP so they can find a plan that meets their care needs.

### **Standardized Plan Options**

Standardized health plan designs could offer numerous advantages to people with CF. We strongly support HHS's implementation in 2023 to require issuers to offer at least one standardized plan at every product network type, metal level, and in every services area where the issuer also offers non-standardized plans.

Requiring plans to adhere to uniform cost-sharing parameters promotes informed decision-making: the shared standards reduce consumer confusion and make it easier to draw meaningful comparisons based on variables such as plans' premiums and network composition and design. In addition, standardization improves affordability in the marketplace by ensuring that consumers always have access to at least one plan that exempts certain important services and drugs from deductibles. We also support requiring plans to use fixed copays instead of coinsurance, which is often more affordable for people with CF.

Due to these benefits, we strongly support HHS to finalize its proposal to limit the number of non-standard plans that insurers can offer. As noted in the proposed rule, the number of plans available to consumers through the marketplace has increased dramatically over time, estimating shoppers seeking 2023 coverage were tasked with choosing among well over 100 plans, on average. Limiting the number of non-standardized plans would reduce the risk of choice overload while making it easier for consumers to make informed choices for themselves, and the CF Foundation strongly supports this limitation. In the states that have already limited non-standard plan offerings, there is no indication such limits have reduced competition, insurer participation, or plan innovation.

### **Advance Premium Tax Credit Changes**

Under the Affordable Care Act (ACA), APTC eligibility is determined using both the consumers attested income and tax return data provided by the Internal Revenue Service (IRS). Currently, exchanges must treat missing tax data as though it is inconsistent with attested income and thus creates a data matching issue. There are many reasons why tax data may not be available at no fault of the consumer, and this

current policy disproportionately affects low-income consumers, The CF Foundation supports HHS’s proposal to allow exchanges to rely on attested income to determine APTC eligibility.

Furthermore, HHS proposes to modify the rules for denying APTC to consumers who have failed to file a tax return and reconcile APTC received in the past. Rather than denying APTC when the IRS indicates a consumer has failed to reconcile APTC for a single year, exchanges would only deny APTC when the IRS reports a consumer has failed to reconcile for two consecutive years. The CF Foundation strongly supports this change in policy.

The proposed APTC eligibility changes will help ease the cost burden for people with CF who rely on the individual marketplace for coverage and likely help prevent or minimize loss of coverage.

### **Standards for Agents, Brokers, and Web-brokers**

The CF Foundation strongly supported HHS’s final rule changes in the 2023 NBPP that tightened standards of conduct for agents, brokers, and web-brokers, as well as increased transparency, clarification of standards and prohibited business practices, and conflict of interest disclosures. We appreciate HHS further requiring agents, brokers, and web-brokers to document that the eligibility information contained in a consumer’s application has been reviewed and confirmed to be accurate, as well as requiring these entities to document that they received consent from the consumer to provide assistance in the first place. Agents and brokers generally have not duty to act in the best interest of consumers, and therefore we appreciate the steps HHS is taking to improve consumer experience and mitigate the risk.

However, more action can be done. As mentioned in our 2023 NBPP comments, agents and brokers should also have an affirmative duty to screen and refer consumers for Medicare and Medicaid eligibility, so that individuals who qualify for such coverage are not instead routed to private insurance products, as sometimes happens now.

### **Copay Accumulator Programs**

The CF Foundation is disappointed HHS has failed to address copay accumulator adjustment policies in this proposed rule. Accumulator programs prevent third-party payments from counting towards deductibles and out-of-pocket limits and therefore increase out-of-pocket costs for patients—which can cause people with CF to forgo needed care and lead to adverse health outcomes. According to a survey conducted by George Washington University of over 1,800 people living with CF and their families, nearly half reported delaying or forgoing care— including skipping medication doses, taking less medicine than prescribed, delaying filling a prescription, or skipping a treatment altogether—due to cost concerns.<sup>1</sup> Because CF is a progressive disease, patients who delay or forgo treatment face increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

Accumulator programs also place additional financial strain on people with CF who are already struggling to afford their care. More than 70 percent of survey respondents indicated that paying for health care has caused financial problems such as being contacted by a collection agency, filing for bankruptcy, experiencing difficulty paying for basic living expenses like rent and utilities, or taking a second job to make ends meet. And while three quarters of people received some form of financial assistance in 2019 to pay for their health care, nearly half still reported problems paying for at least one CF medication or service in that same year.

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<sup>1</sup> [https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs\\_policy\\_briefs](https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs)

We understand the challenge insurers face in managing the rising cost of drugs, and that copay assistance programs mask bigger cost and affordability issues in the health care system. However, cost containment strategies that further burden patients are unacceptable. Accumulators are especially challenging for a disease like CF, which has no generic options for many of the condition's vital therapies. The situation has become even more dire as a company that manufactures CF therapies recently reduced the amount of copay assistance available for people enrolled in accumulator programs.

Therefore, we urge HHS to include a provision in the final rule requiring insurers and pharmacy benefit managers (PBMs) count all copayments made by or on behalf of an enrollee toward the enrollee's annual deductible and out-of-pocket limit.

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The CF Foundation appreciates the opportunity to provide comments on the proposed rule. We look forward to working with HHS on these critical issues to ensure access and affordability for people with CF.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight', with a stylized flourish at the end.

Mary B. Dwight  
Chief Policy & Advocacy Officer  
Senior Vice President, Policy & Advocacy  
Cystic Fibrosis Foundation