



January 27, 2022

The Honorable Xavier Becerra
Secretary
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 2023 (CMS-9911-P)

Dear Secretary Becerra:

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 more than 30,000 children and adults in the United States. 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 Benefit and Payment Parameters for 2023 Proposed Rule, issued by the Department of Health and Human Services (“HHS” or the “Department”).

Network Adequacy

The CF Foundation commends HHS for reexamining federal network adequacy standards for plans offered through the Federally Facilitated Marketplace (FFM). Federal law requires that marketplace health plans maintain an adequate network of providers, and up-to-date online provider directories. These protections are designed to ensure that marketplace enrollees have timely, meaningful access to the care and services they need, as well as accurate information to help them understand plans’ networks and identify the plans and providers most likely to meet their needs. However, we would like the Department to further examine and evaluate the effectiveness of the 30 day wait period for specialists.

Individuals with CF rely on access to an appropriate network of specialized providers is critical for obtaining high-quality care. CF is a genetic disease that causes sticky, thick mucus to build up in organs, including the lungs and the pancreas. In the lungs, the mucus obstructs the airways and traps bacteria leading to infections, extensive lung damage and eventually, respiratory failure. Waiting 30 days to see

their specialist, while it may not rise to the level of an emergency right away, could give an pulmonary exacerbation time to develop and become life threatening. We ask HHS to collect data from specialists on what would be appropriate for their patient population before setting such a long wait standard.

We urge HHS to provide clarity in the final rule about Qualified Health Plans (QHPs) obligation to their enrollees when they are unable to meet time and distance standards or appointment wait time standards. Most people with CF get care at an accredited CF care center that provides multidisciplinary, evidence-based care, and even the most robust networks may be unable to provide services that people with CF require. We urge HHS to make it clear that in situations where rare and specialized services may not be available in network, QHPs must hold their enrollees financially harmless for seeking care from out-of-network or higher tier providers.

Furthermore, we are aware of the contention that a single federal standard related to network adequacy should be rejected and that instead state efforts to define network adequacy should be encouraged. The Foundation does not oppose state efforts, but encourages HHS to ensure there is a federal floor on which states can build.

As the Department considers how to improve network oversight further, we also urge HHS to scrutinize QHP networks' 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, 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.

Finally, the Foundation supports HHS' goal to research the expanded use and availability of telehealth as well as the Department's continuous efforts to collect data on the uses and outcomes of telehealth, including data to measure access and outcomes across different demographic groups. Telehealth should supplement, not supplant, provider networks. The inclusion of telehealth can bring substantial benefit to individuals with CF, and we encourage HHS to include telehealth as an aspect of network adequacy in the future. The decision to use telehealth should be made by the provider and patient based on preference and clinical appropriateness, and plans should not use cost-sharing to steer patients into or out of telehealth. Further, QHPs must ensure that patient referrals to other providers, including specialists, are within network when made by a telehealth provider or through a telehealth visit.

Standardized Options for Marketplace Coverage

Standardized health plan designs could offer numerous advantages to people with CF. We strongly support HHS's proposal 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. Standardized plans can also be a tool for improving coverage affordability. 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 often burdens people with CF.

The effectiveness of standardization in improving access and affordability is apparent in the experience of the nine states and the District of Columbia that have already adopted standardization.¹ We therefore recommend that standardized plans be required in all marketplaces, including state-based marketplaces, where a state-designed standardized plan program does not exist.

Nondiscrimination Based on Sexual Orientation and Gender Identity

LGBTQ people face significant challenges accessing healthcare because of discrimination based on sexual orientation or gender identity. For example, in one survey, roughly 29% of LGB respondents and 73% of transgender respondents felt that medical personnel would likely treat them differently because of their sexual orientation or gender identity.² Discrimination based on sexual orientation or gender identity impedes access to health coverage and care, worsening health outcomes and imposing additional financial costs on those who face such conduct. These harms exacerbate existing disparities experienced by LGBTQ+ individuals, and the current absence of clear federal regulatory protections against such discrimination undermines efforts to address health equity.

HHS proposes to amend six nondiscrimination provisions to prohibit explicit discrimination based on sexual orientation or gender identity.³ As HHS notes, existing law provides ample authority for the revisions, which would simply restore these vital protections to their pre-2020 scope. The Foundation strongly supports these proposals.

Web-broker Website Requirements and Standards for Agents, Brokers, and Web-brokers

We strongly support the Department's proposed additions to this section, especially since agents, brokers and web-brokers have not been required, unlike navigators, to provide accurate and unbiased information to individuals. The Foundation believes the proposed increased transparency, clarification of standards and prohibited business practices, and conflict of interest disclosures will improve consumer understanding when enrolling through these services. The proposed rule would also tighten the standards of conduct for agents, brokers, and web brokers to further protect consumers and give the Department additional grounds for enforcement.

While these changes are a good first step, more can be done. The Department should also consider requiring brokers, who consumers rely on for their professional experience and expertise, to act in the best interest of the individuals they serve. Agents and brokers should also have an affirmative duty to screen 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.⁴ In addition,

¹ <https://www.commonwealthfund.org/blog/2021/state-efforts-standardize-marketplace-health-plans>

² https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf

³ In particular, the proposed rule would strengthen the nondiscrimination protections found at 45 C.F.R. §§ 147.104(e), 155.120(c), 155.220(j), 156.125(b), 156.200(e), and 156.1230(b).

⁴ Straw T. "Direct Enrollment" in Marketplace Coverage Lacks Protections for Consumers, Exposes Them to Harm. Center on Budget and Policy Priorities. <https://www.cbpp.org/research/health/direct-enrollment-in-marketplace-coverage-lacks-protections-for-consumers-exposes>. Published March 15, 2019.

given the risks posed by their financial conflicts, agents and brokers should be required to disclose the amount of their commissions.

Past-due Premiums

In a 2017 rule, HHS permitted issuers to refuse to enroll a consumer who owed past-due premiums to the same issuer until the individual paid the premium debt. This is inconsistent with federal law. The CF Foundation agrees with the Department that this policy imposed a barrier to coverage for individuals with CF who may find their enrollment rejected by an issuer. We support the proposal to revoke the 2017 policy and restore full guaranteed availability rights as provided under the ACA.

Annual Eligibility Redetermination and Reenrollment Hierarchy

The CF Foundation supports the existing policy of automatic re-enrollment as an important safeguard for consumers that promotes continuous coverage and a stable individual market.⁵ Still, marketplace enrollees are usually well-served by returning to the marketplace each open enrollment period to compare their coverage options and update their eligibility information, and there is a risk that enrollees who do not do so will be automatically re-enrolled in plans with higher premiums and cost-sharing than available alternatives.⁶ Therefore, we urge HHS to consider the default assignment for reenrollment to prioritize affordability rather than continuity of issuer or plan.

First, it is currently HHS policy that if the former plan remains available during the new plan year, the enrollee remains in that plan even if a change in market conditions has significantly raised the old plan's cost to the consumer. We recommend HHS change this so when the enrollee is likely better off in a different plan, the enrollee is shifted to that plan unless they opt out.

Furthermore, current HHS policy is that if the former plan is no longer available, the enrollee is shifted to the most similar available exchange plan offered by the same issuer, even if consumer costs are far higher with the new plan. This default assignment rule assumes that the most important fact in most consumers' plan choice involves the carrier and the provider network. Such factors matter to many consumers, including people with CF, but cost burden can often be the higher priority. Therefore, we recommend that HHS prioritize in the default reenrollment hierarchy that when consumer's former plan is no longer offered, keeping the consumer's net premium cost and approximate actuarial value (AV) at levels as close as possible to those in the consumer's plan the previous year.

We appreciate HHS' request for comment on incorporating consumer costs into redetermination and reenrollment and look forward to partnering with the Department as it reevaluates this policy.

Health Equity

The CF Foundation strongly supports HHS' attention to health equity. As we focus on coverage and access to care, we particularly support the strategies to remove barriers to care and coverage for individuals who experience challenges due to social factors, which can lead to disparities in health outcomes.

⁵ For the effects of automatic re-enrollment on continuous coverage, see, e.g., Drake C, Anderson DM. Association Between Having an Automatic Renerollment Option and Reenrollment in the Health Insurance Marketplaces. *JAMA Intern Med.* [10.1001/jamainternmed.2019.3717](https://doi.org/10.1001/jamainternmed.2019.3717). Published September 23, 2019.

⁶ See, e.g., Anderson DM, Rasmussen PW, Drake C. Estimated Plan Enrollment Outcomes After Changes to US Health Insurance Marketplace Automatic Renewal Rules. *JAMA Health Forum.* [10.1001/jamahealthforum.2021.1642](https://doi.org/10.1001/jamahealthforum.2021.1642). Published July 16, 2021.

In July, we joined other advocacy organizations in response to the Office of Management and Budget Request for Information regarding equity and underserved communities.⁷ We support HHS' efforts to collect and disaggregate data to understand how policies impact communities differently and create inequalities in coverage and care. Within QHPs on the marketplace, HHS should first evaluate data currently collected and the process for its collection. Where it is not already being done and where it is possible, QHPs should strive to collect self-reported data on race, ethnicity, gender, disability and sexual orientation. When collecting these data though, it should be made clear why data are being collected and how the data will be used. Individuals collecting this information should undergo cultural competency and skilled communication training to regain trust and minimize the trauma and stigma that underserved communities.

The CF Foundation appreciates the opportunity to provide comment on the Notice of Benefits and Payment Parameters for 2023 Proposed Rule. We look forward to working with the Department on these critical issues to ensure access and affordability for people with CF.

Sincerely,



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Cystic Fibrosis Foundation

⁷ <https://www.cff.org/sites/default/files/2021-10/PPC-Comments-to-OMB-Responding-to-Health-Equity-RFI.pdf>