



National Organization  
for Rare Disorders



August 14, 2020

Honorable Alex Azar  
Secretary  
Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Honorable Steve Mnuchin  
Secretary  
Department of the Treasury  
1500 Pennsylvania Avenue, NW  
Washington, DC 20220

Honorable Eugene Scalia  
Secretary  
Department of Labor  
200 Constitution Avenue, NW  
Washington, DC 20210

**Re: Grandfathered Group Health Plans and Grandfathered Group Health Insurance Coverage Proposed Rule (RIN 1210-AB89)**

Dear Secretaries Azar, Mnuchin and Scalia:

Thank you for the opportunity to submit comments on the Grandfathered Group Health Plans and Grandfathered Group Health Insurance Coverage ("grandfathered group coverage") proposed rule issued by the Departments of the Treasury, Labor, and Health and Human Services (the "Tri-Agencies" or the "Departments").

The undersigned organizations represent millions of patients facing serious, acute, and chronic health conditions across the country. Our organizations have a unique perspective on what patients need to prevent disease, cure illness, and manage chronic health conditions. Our diversity enables us to draw upon a wealth of knowledge and expertise that can be an invaluable resource in this discussion. We urge the Departments to make the best use of the knowledge and experience our patients and organizations offer in response to this proposed rule.

In March of 2017, our organizations agreed upon three overarching principles<sup>1</sup> to guide any work to reform and improve the nation's healthcare system. These principles state that: (1) healthcare should be accessible, meaning that coverage should be easy to understand and not pose a barrier to care; (2) healthcare should be affordable, enabling patients to access the treatments they need to live healthy and productive lives; and (3) healthcare must be adequate, meaning healthcare coverage should cover treatments patients need, including all the services in the essential health benefit (EHB) package.

In 2019, many of our organizations submitted comments in response to the Departments' Request for Information (RFI) regarding grandfathered group coverage.<sup>2</sup> In those comments, we wrote that "[a]ny effort to relax the 2015 definition of grandfathered plans would be unacceptable for our patients" because it would violate these principles.

In the proposed rule, the Tri Agencies observe repeatedly that weakening standards could be exploited to allow grandfathered group coverage to change to such an extent that it could not reasonably be described as being the same coverage offered at the time of the enactment of the Affordable Care Act (ACA). We agree that such changes run counter to the plain language and intent of the ACA, and under the same reasoning, we strongly disagree with the proposal to award grandfathered group coverage new discretion to increase cost sharing for their enrollees while avoiding the application of the ACA's core consumer protections. We oppose these changes and urge that they not be finalized.

#### *Grandfathered Plans Lack Essential Patient Protections*

Our organizations recognize and respect the commitment that Congress made when enacting the ACA to allow people to keep their existing plans. At the same time, grandfathered group coverage poses significant risk to the patients we represent because, by definition, these plans offer coverage that does not include key patient protections.

Grandfathered group coverage is not required to adhere to annual limitations on cost-sharing and is not required to cover preventive services without cost-sharing including co-pays, co-insurance and deductibles, as ACA-compliant plans are required to do. Preventive services are cost-effective and are key to early detection and treatment for cancer, heart disease, diabetes and many other serious and chronic illnesses.

Additionally, grandfathered plans may exclude coverage for patients who are eligible to participate in clinical trials. Access to clinical trials is also critically important. Individuals with challenging forms of cancer or other life-threatening illnesses typically choose to participate in clinical trials when they

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<sup>1</sup> Healthcare reform principles. Available at:

<https://cengage.com/mda/file/kSgnXK91pJZ/052820%20Healthcare%20Principles42logos.pdf>.

<sup>2</sup> Comments on CMS-9923-NC: Request for Information Regarding Grandfathered Group Health Plans and Grandfathered Group Health Insurance Coverage, March 27, 2019. Available at:

<https://www.lung.org/getmedia/2149f755-55b0-4bf5-826a-69d16d1c0030/health-partner-comments-re-5.pdf>.

conclude (in consultation with their physicians) that the trial provides the best odds of a successful clinical outcome when compared to other existing therapies. Further, ensuring coverage for those seeking to participate in a clinical trial recognizes that there is a greater public good to encouraging increased patient participation in clinical research.

Unlike small-group health plans that are fully compliant with the ACA's consumer protections, grandfathered small-group coverage is not required to provide coverage of essential health benefits (EHB). Prior to the establishment of the EHB protections, patients and consumers frequently found themselves enrolled in plans that failed to provide coverage for the care they might rely on to maintain their health or treat illnesses. Patients with serious illnesses discovered they were not covered for new and innovative treatments, while those with chronic illnesses were often denied coverage for life-improving, sometimes even life-saving, medication. Many of these individuals did not realize at the time of their enrollment that they had selected a plan that did not meet their health care needs, let alone provide adequate coverage for a new diagnosis.

This risk of consumers being confused about what they can expect from their coverage is perhaps more acute now than it was prior to the ACA. Because new employees and their beneficiaries may enroll in grandfathered group coverage, consumers who previously were insured by a non-grandfathered plan — and who may have grown to expect that the ACA's protections apply as a matter of course — may start a new job only to find themselves enrolled in coverage that does not cover EHB and requires significant cost-sharing for preventive services.

#### *The Proposed Rule Lacks Evidence to Support Changes*

The Departments acknowledge that the changes they propose may cause enrollees in grandfathered group coverage to face increased out-of-pocket spending, and that the people most likely to shoulder this new burden are those who already have higher medical expenses and out-of-pocket costs — individuals with preexisting conditions and the kinds of chronic illnesses experienced by the patients we represent. The economic impact analysis conducted by the Departments further estimates an increase in adverse health outcomes from beneficiaries foregoing treatment because of an unaffordable increase in cost sharing, or inability to access non-covered treatments. Though the Departments "anticipate" the overall economic impact of the proposals will be minimal, this assertion does little to justify the rule change. The Departments concede there is an "overall lack of information and data" that renders them "unable to accurately determine" the impact of their proposals and caution that "there is a large degree of uncertainty" in their understanding of the effects of the proposed rule on enrollee cost-sharing.<sup>3</sup>

If, after years of experience with grandfathered group coverage and following the completion of an RFI process specifically intended to inform these deliberations, the Departments do not have sufficient information and data to predict the effect of their proposed changes to grandfathered group coverage on the very people enrolled in such coverage — and particularly, the effects on enrollees with preexisting conditions — we respectfully suggest they should not proceed with the rulemaking process. In the absence of adequate justification for the proposed changes — which appear likely to disadvantage consumers with preexisting conditions in ways the ACA's full slate of consumer protections were designed to prevent — they should not be finalized.

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<sup>3</sup> The Departments also acknowledge that they "cannot accurately predict the number of grandfathered health plans and group health insurance coverage that would retain their grandfather status" as a result of the new flexibilities the Departments propose to extend.

Thank you for the opportunity to provide these comments. Please contact Hannah Green with the American Lung Association at [hannah.green@lung.org](mailto:hannah.green@lung.org) for any follow up.

Sincerely,

American Cancer Society Cancer Action Network

American Heart Association

American Lung Association

American Kidney Fund

Arthritis Foundation

Cancer Support Community

Cystic Fibrosis Foundation

Epilepsy Foundation

Hemophilia Federation of America

Leukemia & Lymphoma Society

National Health Council

National Hemophelia Foundation

National Kidney Foundation

National MS Society

National Organization for Rare Disorders (NORD)

Pulmonary Hypertension Association

Susan G. Komen

The AIDS Institute