



NATIONAL HEALTH COUNCIL

March 15, 2024

The Honorable Virginia Foxx
Chairwoman
Committee on Education and the Workforce
U.S. House of Representatives
Washington, DC 20515

Dear Chairwoman Foxx:

On behalf of the National Health Council (NHC), we appreciate your attention to the important issue of employer-sponsored health benefits, which are governed by the Employee Retirement Income Security Act (ERISA). The segment of plans regulated by ERISA comprises a significant number of Americans yet is rarely considered for legislative improvement. This has often led to challenges for people with chronic diseases and disabilities accessing the care they need. ERISA is long overdue for Congressional attention, and we appreciate that the RFI starts this process. Patients need an affordable, functioning employer-sponsored insurance (ESI) system.

Created by and for patient organizations more than 100 years ago, the NHC brings diverse organizations together to forge consensus and drive patient-centered health policy. We promote increased access to affordable, high-value, sustainable, equitable health care. Made up of more than 170 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient organizations. Other members include health-related associations and nonprofit organizations including the provider, research, and family caregiver communities; and businesses representing biopharmaceutical, device, diagnostic, generic drug, and payer organizations.

Importance of the Patient Perspective

As the RFI states an “estimated 153 million employees and their dependents” are covered under ESI plans. It is additionally important to note that many of the people covered by private insurance have disabilities. According to the Department of Health and Human Services, 36.7% of working age persons with disabilities receive health insurance from private sources¹. Our response to the request for information (RFI) is intended to represent the patient's perspective in a discussion that is too often focused only on employers and typically centered around the needs of employees without significant health needs. While it is important that employers have access to information and affordable options to offer coverage to their employees, we must make sure that this coverage is comprehensive and does not increase costs for patients.

¹ [Health Insurance Coverage Among Working-Age Adults with Disabilities: 2010-2018 \(hhs.gov\)](https://www.hhs.gov/health-care/insurance-coverage-among-working-age-adults-with-disabilities-2010-2018)

Request: The NHC requests that the Committee issue additional RFIs or work to assure that patients and patient advocates are directly engaged in future efforts.

NHC's Broad Health Care Cost Priorities

The NHC recommends that Congress' efforts to improve coverage under ERISA focus on assuring that all plans include a basic level of coverage that patients can rely on. The focus should also be on affordability both for employers and employees. The NHC has developed a set of [policy recommendations for reducing health care costs](#). These can serve as a useful guide to efforts to address concerns with ERISA plans and other health care cost concerns. The recommendations are informed by four driving principles. The policies must:

- Promote high-value care;
- Stimulate research and competition for health care products and services;
- Curb costs responsibly; and
- Ensure health equity.

In addition, the NHC has joined in coalition with many patient advocacy groups around [three overarching principles](#) to guide any work to reform and improve the nation's insurance system. These principles state that: (1) health care should be accessible, meaning that coverage should be easy to understand and not pose a barrier to care; (2) health care should be affordable, enabling patients to access the treatments they need to live healthy and productive lives; and (3) health care must be adequate, meaning health care coverage should cover treatments patients need. These are also high-level principles to keep in mind as we embark on efforts to assure patients are protected in ESI.

Responses to Specific Issues Raised in the RFI

Transparency

The health care system is complex and opaque, which too often undermines informed decision-making. The NHC has long advocated for transparency across the health care system from every sector that impacts patients' lives. It is especially important that transparency efforts are focused on access to information that is understandable and actionable for employers and employees.

Cybersecurity and Data Sharing

Patient privacy must be protected, particularly when employers are involved. The RFI points out that there is a gap in privacy protection concerning employers. The NHC supports the concept of engaging the Department of Labor (DOL) in more robust oversight of privacy protections for employees. However, DOL must be adequately resourced to take on this role.

How data gathered by plans is shared and protected is important to patients. The top priority is assuring beneficiaries and employers that data is streamlined, simplified, and secure. Access to data and information is critical for employers to be able to monitor and

manage the coverage they offer their employees as well as to negotiate with plans to manage costs. Removing the prohibition on fiduciaries accessing such information is helpful, but Congress should continue to monitor how this information exchange is working and incentivize appropriate data exchange.

ERISA Advisory Board

While the NHC does not have a position on expanding the authority of the Board, there is a need to assure that there is a patient/beneficiary voice as part of the Board. The NHC recommends that there be dedicated slots on the Board for patients or their representatives. It is also important that the Board be directed to assure that they spend adequate Board time on issues affecting health care. Their mandate is large and there is only so much bandwidth to address all issues. Too often health care is not addressed by the Board. Finally, much like DOL authority to oversee health privacy mentioned above, we must make sure that the Board is appropriately resourced to meet all their roles.

Specialty Drugs

Advances in treatments such as specialty drugs and cell and gene therapy are coming at an unprecedented pace. These new therapies often have significant up-front costs, while the savings can accrue over a lifetime. While the value is often clear, high up-front costs with long-term savings are not something our health care financing system is typically equipped to manage. Too often patients face barriers to specialty drugs that restrict access or interrupt continuity of care. It is vital that Congress supports financing solutions and other structures that work for patients and the health care system.

There are two issues the patient groups have identified as ongoing challenges related to coverage including the increasing prevalence of utilization management, such as step therapy and prior authorization, and strategies such as copay accumulators, copay maximizers, and alternative funding programs (AFPs).

The current application of utilization management can be associated with delays in patient care and the potential for medication adherence issues, potentially resulting in the need for higher cost and more intensive care. We need to ensure that utilization management practices are appropriately used to reduce unnecessary or harmful care while not creating undue barriers to appropriate care. The NHC has developed a series of [Domains and Values](#) on the issues that we urge Congress to use in guiding any utilization management policy decisions.

Additionally, people relying on treatments like specialty drugs may also be steered towards AFPs, often directed there by their employer when they seek advice or assistance. AFPs incentivize health plans to remove coverage for specialty drugs and direct patients to manufacturer patient assistance. This can result in higher out of pocket costs and delayed access, risking the patient's health. In addition, many of these programs raise safety concerns due to practices such as sourcing drugs internationally.

We need to find ways to cover these treatments without pushing patients towards relying on approaches that will harm them financially.

Request: Congress, including this Committee, is currently considering legislation that can address many of these issues such as the Safe Step Act and the HELP Copays Act, and the NHC encourages passage of both bills.

The RFI asks specifically about barriers to entering value-based arrangements to increase access to specialty drugs. The NHC has encouraged outcome-based contracting/value-based arrangements by allowing new flexibilities related to the anti-kickback statute, Stark law, and pricing metric calculations (e.g., Best Price). However, in advancing these flexibilities, policymakers must engage patients and encourage the engagement of patients by eligible entities to ensure that any outcome-based measures reflect the needs and priorities of patients and new safeguards are created in place of existing ones. The purpose of any models should be to expand access to specialty drugs and meet patient-identified needs.

Fiduciary Requirements

It is important that employers have the flexibility to craft plans that meet the unique needs of the employees, particularly for employees with chronic diseases and disabilities. This may mean that they do not always choose the most affordable plan for all employees but the one that is best for the entirety of the employee base. However, as mentioned above, we need to assure that there is an expectation of coverage that is adequate. The committee asks if entities like insurance companies, insurance agents, broker-dealers, third party administrators (TPAs), PBMs, or other service provider should be identified as having fiduciary responsibilities. This is exemplary of how complex the decisions that affect ESI are. As you consider this question, you should form all policies in the best interest of the patient and that employers are getting the best information and guidance to make decisions that benefit their employees.

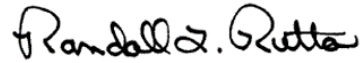
Preemption

The RFI asks how the ERISA preemption should be considered. The ERISA preemption is designed to allow some flexibility for multi-state employers to offer uniform coverage and minimize employer burden in crafting coverage. The NHC appreciates the need for this flexibility and easing employer burden, which can be leveraged to offer better or tailored benefits. However, too often employees are only offered restricted benefits and substandard coverage. If an employer can offer coverage, but only at a minimal level, it is particularly harmful to people with chronic diseases and disabilities who are left paying for needed care that is not covered by their ESI. It is critical to patients that they can rely on a minimum level of coverage that would protect the most needed kinds of care. In other words, uniformity is less important to patients than quality of coverage.

Conclusion

We appreciate your attention to this issue and the opportunity to provide feedback. Please do not hesitate to contact Eric Gascho, Senior Vice President of Policy and Government Affairs, if you or your staff would like to discuss these issues in greater detail. He is reachable via e-mail at egascho@nhcouncil.org.

Sincerely,

A handwritten signature in black ink that reads "Randall L. Rutta". The signature is written in a cursive style with a large initial 'R'.

Randall L. Rutta
Chief Executive Officer