



July 30, 2024

The Honorable Diana DeGette
United States House of Representatives
Washington, DC 20515

The Honorable Larry Buschon
United States House of Representatives
Washington, DC 20515

Dear Representatives DeGette and Buschon,

Thank you for the opportunity to provide feedback on your efforts to develop legislation to advance next-generation cures and treatments as well as opportunities to ease burdens pertaining to health information technology. We applaud your commitment to ensuring patients have access to the innovative therapies they need, and that all stakeholders have an opportunity to provide input in this process. We also appreciate your attention to the increasing workforce burden and your efforts to pursue innovative technical solutions to improve data exchange efficiency and quality, thereby easing associated burdens.

The Alliance of Community Health Plans (ACHP) represents the nation's top-performing non-profit health plans improving affordability and outcomes in the health care system. ACHP member companies are provider-aligned health organizations that deliver high-quality coverage and care to tens of millions of Americans across nearly 40 states and D.C. They are leading the industry in practical, proven reforms around primary care delivery, value-based payment and data-driven systems improvement.

Cell and Gene Therapies and Other Emerging Therapies

As you consider policy changes to advance new therapies, we respectfully request consideration of payment and regulatory reforms needed to ensure patients have access to both effective **and** affordable therapies - particularly emerging cell and gene therapies.

Unlike traditional chemical compound medications, cell and gene therapies are a type of precision medicine in which treatments are customized to a patient, often using their own cells. The science is phenomenally exciting but still in its infancy. Accelerated approvals by the Food and Drug Administration (FDA) have been based on smaller cohorts of patients and lack the robust evidence that comes with traditional drug approvals or the nuanced insights of real-world experience over many years.



At the same time, the pricing of these therapies is breathtaking. Two cell and gene therapies recently approved by the FDA carry price tags of \$2.2 million and \$3.1 million. Imagine a small non-profit health plan with 10 sickle cell patients suddenly hit with an unexpected additional \$30 million in medical expenses that needs to be paid up-front. Community health plans could begin to buckle under the massive new costs.

Nationwide, the cost could soar to more than \$200 billion annually, not including the significant associated medical expenses that come with administering such complex treatments. This adds a new challenge for an already straining system.

Given the promise and the peril of these emerging treatments, the situation cries out for Congressional leadership, beginning with substantive hearings on appropriate pricing and financing mechanisms - something ACHP has already [urged Congressional leaders to consider](#). While we are firm believers in the power of a competitive market, the pharmaceutical industry is not, and that necessitates a discussion on guardrails to truly serve patients' needs.

Throughout history, Congress has established a track record of striking compromises in the world of emerging pharmaceuticals. For example, the Hatch-Waxman Act and the Biologics Price Competition and Innovation Act balanced innovation with availability. Now cell and gene therapies provide a fresh opportunity for the federal government, patients, drug makers, clinicians and health plans to come together to determine a path forward on affordable prices and financing for these medical advancements, while ensuring equitable access.

Specifically, ACHP is interested in working with you to:

1. Develop an alternative financing mechanism for approved cell and gene therapies; and
2. Explore reforms to ensure the appropriate use of the FDA's accelerated approval process.

Reducing IT Burden for Provider Directories

As you consider opportunities to build upon the 21st Century Cures Act health IT provisions, we strongly encourage improvements to provider directories. Most consumers looking for a primary care physician or specialist use their health insurance plan's online



directory to find conveniently located, available in-network providers. However, despite dedicating significant resources toward collecting and validating provider information, maintaining provider directories remains a major challenge. This is due to the:

1. varying quality of information health plans receive from providers,
2. lack of provider accountability to ensure updated provider information and
3. absence of reporting standards for payers or providers.

To drastically reduce provider burden and ensure directories are useful for consumers, Congress should legislate a national provider directory, hosted through CMS. This “single source of [provider data] truth” would eliminate the multiple requests providers receive from contracted health plans. Payers and providers would then share accountability -- with providers being held responsible for the accuracy of their own information and health plans being held responsible for pulling that information into their systems in a timely manner.

We thank you again for your request for stakeholder input and reiterate our shared commitment to advancing health care innovations, including ensuring patients have access to safe, effective, and affordable medicines and reducing burden through health IT improvements. Should you have any further questions, please contact Josh Jorgensen, Associate Director, Legislative Affairs at ACHP (jjorgensen@achp.org).

Sincerely,

Dan Jones
Senior Vice President, Federal Affairs
Alliance of Community Health Plans