



COUNCIL FOR AFFORDABLE
HEALTH COVERAGE



The Council for Affordable Health Coverage's Campaign for Transformative Therapies

Barriers to pay for outcomes

Today, medical science is on the cutting edge of innovation with new treatments- like gene therapies- entering the market faster than ever before. Gene therapies target genetic mutations in cells and many times do not simply treat but actually prevent or cure disease. However, because these therapies are complex and costly to develop, they generally carry large upfront price tags. These high prices, combined with the current US reimbursement system that is largely based on volume of sales and standards of care rather than outcomes achieved for patients, means that accessing gene therapies is extremely challenging. Uncertainty by payers about the long-term benefits, risks, and effectiveness among different patient populations receiving these treatments also present roadblocks to reimbursement agreements, where the return on investment of these potential cures may not be evident for many years.

Reforms to encourage VBAs for gene therapies

Value-based arrangements (VBAs; also known as outcomes-based contracts) are contracts between payers and manufacturers in which the manufacturer is reimbursed based on their product's performance. In its basic form-If the gene therapy doesn't work as anticipated, the payer is reimbursed by the manufacturer for all or a portion of the cost of the product.

VBAs also can result in useful real-world efficacy data, particularly valuable for cases regarding rare disease gene therapies, where the clinical trial populations are relatively small.

The Campaign for Transformative Therapies believes that encouraging value-based arrangements for gene therapies is necessary to ensure patients can access these innovative cures. We will work to remove policy barriers that inhibit VBAs for gene therapies in both public and private markets.

CAMPAIGN BACKGROUND

These transformative therapies cannot be effective if they are unable to be accessed by those who need them. By bringing together leading payer, manufacturer, patient, consumer, provider and health care industry leaders, the Campaign is committed to advocating for specific legislative and regulatory solutions that can be brought to the attention of Congress and the Administration.

JOIN US

Contact Sloane Salzberg (Sloane.salzburg@cahc.net) to learn more about how your organization can join CAHC's campaign and advocate for near-term solutions to help ensure access to gene therapies.