Benefits Insights

Navigating CGT Costs, Coverage and Payment Models

Premier Consulting Partners

Cell and gene therapies (CGTs) are among the most advanced medical innovations available today, offering potential cures for rare, severe and historically hard-to-treat diseases. While cell therapy involves the transfer of a specific cell type into a person to prevent or treat a disease, gene therapy uses genetic material to do the same. Patients generally receive CGTs through injection or infusion in a specialty setting. For example, chimeric antigen receptor (CAR) T-cell therapies are among the best-known cell-based treatments, used primarily for blood cancers, and gene therapies deliver functional genes to correct genetic diseases, such as sickle cell disease.

However, with innovation comes complexity. CGTs can cost hundreds of thousands to several million dollars, challenging both traditional insurance systems and employer health plans. With more CGTs approved by the U.S. Food and Drug Administration every year, they are becoming an important part of modern health care and treatment for patients. As overall health care costs continue to climb, plan sponsors may question how these specialty treatments impact formularies for employer-sponsored health coverage and cost management.

This article explains CGT costs, coverage challenges and emerging payment models to help make these treatments more accessible.

The Cost of CGT

Several gene therapies are priced at over $1 million per treatment, with some, such as those used to treat sickle cell disease, costing $2 million to $3 million per patient. Many cell-based immunotherapies fall into the $400,000 to $500,000 range, not including additional costs related to hospitalization, chemotherapy or specialized procedures. For example, CAR-T cell therapy, a type of CGT, is among the most expensive treatments available today. According to the American Cancer Society, the average cost of CAR-T cell therapy alone can range from $300,000 to $475,000 due to the complexity of how the cells are collected and manufactured. Once again, this figure doesn't even include the costs of hospital admission, tests, procedures and other expenses.

Much of this treatment cost stems from the complexity of developing and manufacturing the therapies themselves. Many CGTs are tailored to individual patients, requiring intricate processes such as tissue procurement, cell modification and specialized laboratory environments.

Another factor driving cost is the "one and done" nature of many CGTs. Unlike traditional treatments that spread costs over months or years, CGTs concentrate their value and expense into a single point in time. This creates a significant financial shock to both insurers and employers, who describe these claims as "lightning strikes," which are rare events that carry high expenditures.

CGT Coverage Challenges

Because CGTs are so costly and often target rare diseases, coverage is not always straightforward. Employer-sponsored health plans, insurers and public programs all confront uncertainties in predicting when claims will occur and how to budget for them. While more plans are authorizing coverage, the financial risk can be enormous. Even one single CGT claim may exceed a plan's expected annual cost projections.

Public programs are also adapting. Medicaid agencies have historically struggled to pay for multimillion dollar therapies, prompting the U.S. Centers for Medicare & Medicaid Services (CMS) to launch the CGT Access Model, a multiyear initiative allowing states to negotiate outcomes based agreements with manufacturers. This model is designed to expand Medicaid coverage for high-cost sickle treatments. This outcomes-based payment approach ties reimbursement to treatment effectiveness, aiming to reduce financial risk while improving access to transformative CGTs (e.g., Casgevy and Lyfgenia) that cost millions. The CMS estimates that 50%-60% of people with sickle cell in the United States have Medicaid coverage, and that the participating states represent about 84% of Medicaid beneficiaries with the condition.

Even Medicare is revising its reimbursement structure. Proposed changes include bundling certain preparatory procedures into overall therapy payment and increasing temporary add on payments for new CGTs—up to 75% of the therapy's cost during the early adoption phase—before transitioning back to standard reimbursement levels. These changes reflect an effort to keep pace with rapid innovation while maintaining affordability.

Despite these improvements, individuals seeking CGTs often require extensive care coordination, prior authorizations and documentation to secure approval. Employer-sponsored overage varies significantly, and access can depend on diagnosis, disease severity, treatment center availability and plan design.

Emerging Payment Models for CGT

To address the financial and operational challenges associated with CGT, payers and policymakers are increasingly implementing new payment approaches designed to improve predictability, reduce financial risk and tie spending more directly to therapeutic value.

As such, several models are emerging as leading strategies, including the following:

- **Outcomes-based agreements**—These agreements link payment to how well a therapy performs in real-world settings. If outcomes fall short, the manufacturer may reduce or return payment. For example, the CMS's CGT Access Model is built on this structure, helping Medicaid programs lower financial risk while ensuring patients can access treatments and improve health outcomes. This model is the first time the federal government has negotiated outcomes-based agreements with CGT manufacturers on behalf of state Medicaid agencies. While the initial focus on the model is on access to gene therapy treatments for people living with sickle cell disease, a genetic blood disorder, other conditions might be added to the model over time.
- **Multipayer and employer risk pools**—Private insurers and employer health plans are exploring pooled risk mechanisms to distribute the financial impact of million-dollar CGT claims across larger groups. Such arrangements help reduce volatility and protect individual employers from sudden, budget-breaking costs. In a supplemental risk pool, a sponsor carves out CGT coverage for its members and contributes a per-member-per-month fee to a third party. This fee would be lower than existing risk pooling since it'd be covered by an entity and open across health plan provider networks.
- **Therapeutic health credit**—Instead of paying the full cost upfront, payers may spread CGT payments over multiple years, similar to loan or subscription models. This approach aligns payment with long-term therapeutic benefit and improves budgeting feasibility. Several states and federal agencies are actively evaluating this model as CGTs become more common. This model spreads the cost of a CGT over several years, increasing the likelihood that a plan will approve treatment, helping preserve long-term affordability for both individuals and their employers.
- **Insurance product**—Deloitte has proposed a model that would structure coverage options for CGTs similarly to group life or other employer-sponsored insurance products, allowing companies to offer protection without creating selection risk. While these models would most commonly be delivered through employer plans, versions could also be developed for the individual market, using mechanisms such as accelerated benefit-style policies, supplemental coverage add-ons or even warranty-like programs that extend financial protection for patients. A CGT-specific insurance product could provide more stable and predictable coverage for million-dollar therapies, reducing the chances of denials, significant out-of-pocket costs or sudden plan changes for employees.
- **Enhanced government reimbursement models**—Federal programs like Medicare are updating their reimbursement policies to better support CGT access. Proposed changes include folding certain preparatory procedures into overall therapy payment and temporarily increasing add-on payments during a designated newness period. The adjustments aim to make coverage more sustainable as more CGTs reach approval.

These payment models reflect a shift toward value-based care and offer promising pathways to reduce financial barriers while expanding access to transformative therapies.

Conclusion

CGTs hold promise for individuals facing some of the most challenging medical conditions, including cancer and advanced diseases. The technology's ability to provide long-lasting or even curative benefits represents a turning point in health care. Despite this promise, CGTs are expensive, difficult to budget for and often require specialized treatment pathways.

The health care system is evolving. From the CMS's CGT Access Model to employer risk pooling strategies and outcomes-based contracts, new payment models are emerging to help make CGTs more accessible and affordable.

Employers play a key role in the advancement of specialty treatments. As plan sponsors, employers provide employees access to an evolving health care system, but must face the financial realities of complex payment models. Understanding the CGT market can empower employers to navigate benefits decisions and plan formularies with confidence. Contact us for more information about employee benefits.
