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WHITE PAPER

ESTIMATING THE COSTS OF GENE THERAPIES FOR SICKLE CELL DISEASE IN A NATIONAL ALL-PAYER RISK POOL



Key Findings

Under base-case assumptions (5% of the SCD population eligible, 5% annual uptake, 25% rebate), funding an all-payer risk pool for Casgevy and Lyfgenia would cost approximately $0.11 per member per month (PMPM) across a 337-million-member insured population — roughly $1.32 per member per year. To put this in context, this would equal $13,200 a year for an employer that had 10,000 lives in their plan.

Sensitivity analyses produced a PMPM range of $0.02 to $0.22, with uptake as the primary driver of variability and rebate depth as a secondary lever.

Even at the high end of the range, the per-member cost of covering both approved SCD gene therapies through a national risk pool appears financially manageable for the payer system in aggregate.

These estimates cover two therapies for a single condition. Extending the model to the full pipeline of approved and near-approval CGTs would meaningfully increase the total PMPM, and risk-adjusted contributions would redistribute—not reduce—that cost across payers.

The State of CGT Access and Financing

Cell & Gene Therapies (CGT) offer potentially curative treatment to patients with chronic and hereditary conditions but carry high price tags, sometimes as high as $3 million per patient. This paper focuses on two of the financial barriers most relevant to payers: the concentration of cost in a single upfront event, and the mismatch between who pays and who benefits over time. First, many cell and gene therapies are one-time treatments with significant upfront costs. The cost of these therapies combined with the rare and unpredictable nature of these diagnoses leads to unexpected costs that can be unaffordable for many managed care plans. Second, given the significant volume of coverage transitions—sometimes called churn—in the US health insurance marketplace, any long-term potential savings to be gained from these curative treatments may not be realized by the primary payer, a challenge sometimes referred to as "risk portability." It is estimated that 1 in 5 Americans disenroll from their insurance plan every year.[i] Such coverage transitions are well documented across all payers, including employer sponsored insurance, Medicaid, and Medicare Advantage.[ii, iii, iv]

Market-based solutions have emerged to help payers and plan sponsors manage the financial risk of gene therapies, including specialty stop-loss products designed specifically for ultra-high-cost therapies like CGT.[v] Traditional stop-loss insurance remains a well-established tool for catastrophic claims generally but was not built with single-dose, multimillion-dollar therapies in mind. Challenges such as lasering out known patients, coverage renewals, and an inability to address risk-portability make stop-loss coverage less than ideal for meaningful and sustainable coverage of a quickly growing list of FDA-approved CGTs.[vi] Policy discussions among stakeholders have frequently cited the need to manage risk portability across payers.[vii] One proposal recently put forth to overcome both challenges for CGT access is to create a national risk pool. This proposal would create an all-payer risk pool that provides coverage for some or all CGTs for qualifying patients.[viii, ix]

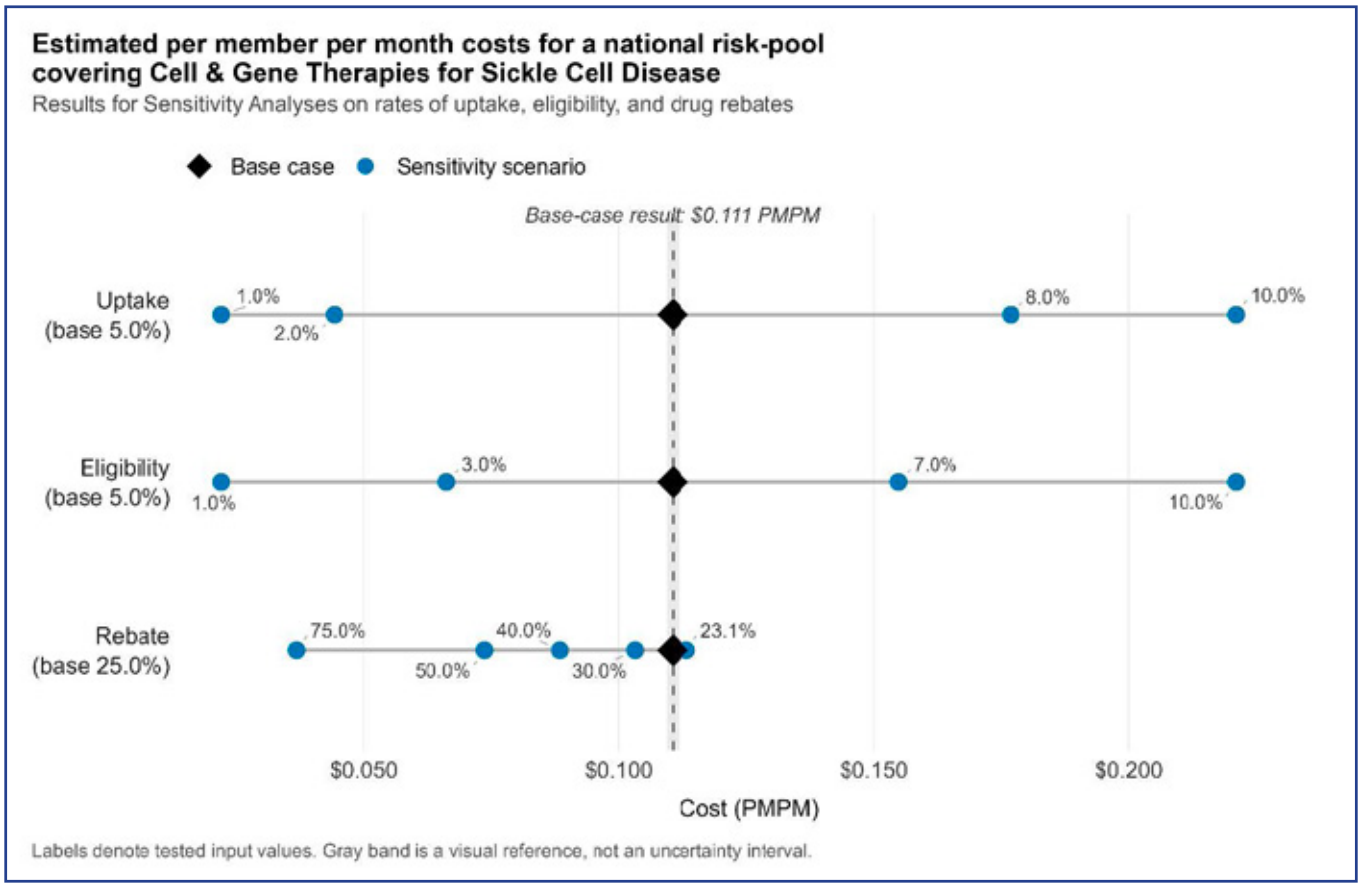
Under a national risk pool model, all public and private health payers would contribute a certain amount of money per member per month (PMPM) in exchange for all of their beneficiaries having access to the CGT. The policy relies on the principle that the conditions treated by CGTs are so rare that aggregating the risk and cost for these treatments across the entire insured population is the only affordable mechanism to pay for these innovations while still obtaining the long-term societal benefits associated with these curative therapies. Successful implementation of such a policy requires further exploration of many questions, including whether contributions should be risk adjusted, what treatments are covered by the risk pool, whether the risk pool pays for the entire episode of care or only the product cost, and how patient eligibility is determined. However, to explore the feasibility of this policy solution, we need reasonable estimates of PMPM costs that would be needed to sustainably fund the national risk pool. To further explore this idea, AMCP conducted preliminary analyses to estimate the PMPM costs of two gene therapies for sickle cell disease (SCD)—Casgevy and Lyfgenia—under a mandatory all-payer national risk pool model.

Estimating PMPM Costs for Sickle Cell Gene Therapies

Based on an insured population of 337,000,000,[x] we estimated total PMPM costs under a few key assumptions. First, we assumed that there were 90,000 individuals with SCD in the United States, and that only 5% of this SCD population was in fact eligible (based on existing estimates) for one of the two existing gene therapies on the market. Second, the cost of treatment for Lyfgenia and Casgevy were estimated using the available list prices ($2,200,000 and $3,100,000, for Casgevy and Lyfgenia, respectively) along with an assumed rebate of 25%. This rebate estimate is a conservative assumption based on the minimum statutory rebate required for participation

in the Medicaid program. Given the CGT Access model currently operated by the CMS Innovation Center and other ongoing negotiation programs, the rebate amount for these products may in fact be higher than 25%. In the absence of a clear market signal, we also assumed that the market share for each product was exactly 50%. Finally, given established concerns around the rate of uptake of these products, challenges with accessing institutions that can administer the product as well as patient concerns around potential side effects, we estimated a conservative uptake of only 5% per year. That is, we assumed that only 5% of all patients eligible to receive CGT for SCD will actually access an institution and undergo treatment each year. We conducted several sensitivity analyses to evaluate the robustness of our assumptions and estimated the results in various scenarios.

Under our base scenario, only 225 individuals received CGT for SCD each year, at an average net cost of $1.9 million, resulting in a total net cost of just over $447 million per year. To fund a risk pool that can adequately pay for such expenses, the fee incurred for every insured member per month was approximately 11 cents. When varying the uptake rate in the base scenario—which assumed a 25% rebate—the range of PMPM estimates was as low as $0.02 with an uptake rate of 1% and as high as $0.22 with 10% uptake. Variation in the proportion of individuals with SCD who were eligible to receive treatment from 1% to 10% produced PMPM estimates ranging from $0.02 to $0.22. We also tested varying the rebate amounts from the statutory Medicaid rebate at 23.1% all the way to a 75% ceiling and found that the PMPM estimate varied from $0.11 at 23.1% rebates to $0.04 PMPM with a 75% rebate rate.



These estimates indicate a generally affordable PMPM for SCD gene therapies in an all-payer risk pool, though there is significant variation described in the sensitivity analyses. While the estimates assumed utilization equal to 5% of eligible patients per year, current utilization is far below that, about 1%.[xi] As a result, our standard assumptions may overestimate the number of patients who receive treatment through this model. However, it is very likely that expanded access will lead to greater utilization than is currently observed.

Sensitivity analyses were run based on varying one variable at a time holding the others constant, but in reality, these will be compounding factors. Implementation of an all-payer risk pool will likely involve the negotiation of outcomes-based contracts, meaning that overall discounts may also fluctuate over time based on patient outcomes.

Successful implementation of a national risk pool will require several additional challenges. First, improvements in accessibility of CGT will require an overhaul of the buy-and-bill system that currently makes these drugs challenging for hospital systems to stock and safely administer. Second, the implementation of a national risk pool can facilitate long-term follow-up for monitoring safety and efficacy, which many CGTs may require. Finally, a rigorous, transparent, and stakeholder-driven process will be needed to screen approved CGTs that are eligible for inclusion into the national risk pool.

Our estimates are merely preliminary and do not consider the possibility of risk adjusted payments—where PMPM costs are tied to relative likelihood of payers' utilization—or other innovative contracting arrangements. Inclusion of additional therapies will result in a higher PMPM, depending on the nature and size of the additional therapy.

Conclusion

The preliminary analysis suggests that an all-payer national risk pool is a financially plausible mechanism for funding gene therapies in sickle cell disease, with per-member costs that fall well within the range payers routinely absorb for far less transformative interventions. The model's appeal is structural as much as financial: by aggregating risk across the entire insured population, it addresses both the affordability challenge facing individ
ual payers and the risk portability problem created by coverage transitions.

Translating this concept into policy will require stakeholders to resolve several design questions that materially affect both cost and equity:

- **Scope of covered therapies** — whether the pool covers only SCD gene therapies, all approved CGTs, or a defined subset based on criteria such as prevalence, cost, or clinical profile
- **Scope of covered services** — whether the pool pays for the product alone or the full episode of care, including pre-treatment workup, administration, and post-treatment monitoring
- **Patient eligibility** — how clinical criteria are defined, who adjudicates them, and how eligibility interacts with existing payer utilization management
- **Contribution structure** — whether payer contributions are flat PMPM or risk-adjusted based on expected utilization, and how outcomes-based contracting flows through to contribution levels
- **Administration** — which entity operates the pool, how funds are collected and disbursed, and how the model interacts with existing federal programs including Medicaid, Medicare, and the CMS Innovation Center's CGT Access Model

AMCP will continue to convene managed care pharmacy stakeholders to examine these questions and to model PMPM implications across a broader set of currently approved and pipeline gene therapies. The financial case for a national risk pool is stronger than commonly assumed.

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