



## Policy Brief

December 6, 2019



### Trump Administration Moving Forward on Price Transparency

On November 15<sup>th</sup>, the Trump Administration released [two rules](#) to advance price transparency in health care. The first rule finalizes CMS' policy in the Outpatient Prospective Payment System (OPPS) CY 2020 proposed rule for hospitals to post their standard charges for all services and the payer-specific negotiated rates for 300 shoppable services. The second is a proposed rule requiring insurers to post their beneficiaries' out-of-pocket costs for in-network providers. The American Hospital Association and other trade organizations have [challenged this in court](#). Although the outcome of these policies remains to be seen, price transparency will continue to be a top priority of the Trump Administration and policy makers. Below are top highlights from the rules. Additional resources on the final rule can also be found below in the AHPA Resources section.

#### Final Rule for Hospitals to Post Standard Charges

Starting on January 1, 2021, hospitals must post all of their standard charges in a machine-readable format and their negotiated rates for 300 shoppable services in a consumer-friendly way (70 selected by CMS and 230 for hospitals to choose). The required standard charges include the gross charge or chargemaster and the discounted cash price for all self-pay consumers. Not included in the proposed OPPS rule, yet finalized in this rule, is the requirement for hospitals to post the de-identified minimum and maximum payer negotiated rate for each shoppable service. CMS also added that they will allow internet-based price estimator tools to fulfill the requirement to post negotiated rates in a consumer-friendly way.

## Proposed Rule for Insurers to Report Out-of-Pocket Costs

In tandem with the final rule, CMS released a proposed rule for insurers to post similar information about their beneficiaries' out-of-pocket costs. If finalized, insurers will be required to make public their beneficiaries' cost-sharing liability, accumulated amount spent and out-of-network allowed amount for an item or service. The rule proposed the information be shared through an Internet-based self-service tool but did not specify a date this would take effect.



## Gene Therapy Makes Breakthroughs, but Barriers Remain

A year ago, spinal muscular atrophy, sickle cell anemia and inherited retinal disease had few, if any, forms of effective treatment. As 2019 comes to a close, biotechnology companies can celebrate a banner year in breakthrough treatment for these diseases thanks to new applications of [CRISPR-Cas9](#) gene editing technology. However, new medical frontiers have shed light on complex issues. Below is more about emerging policy considerations in the gene therapy landscape.

### What Should Health Care Systems Know?

Despite the unprecedented benefits of gene therapy, cost, quality and access barriers are still present. All sectors of the health care industry must now contend with the challenges of these powerful and pricey new treatments, including complex [ethical issues](#).

**Gene therapy has shattered cost records.** In a year where drug pricing reform is dominating headlines, Novartis' Zolgensma hit the market with a [cost of \\$2.1 million](#). Zolgensma is a one-time noncurative treatment for spinal muscular atrophy in individuals under two years old, earning it the title of "Most Expensive Drug Ever." The drug costs more than six times the lifetime cost of insulin for type 1 diabetes and antiretroviral drugs for HIV. Luxturna for inherited retinal disease lists at \$425,000 *per eye*, while [Oxbryta](#) for sickle cell will list for \$125,000 per year. Patients are [advocating for these drugs](#) while figuring out how to afford the steep prices—even at insurer discounts.

**Gene therapy is very new.** Patients were [treated with CRISPR](#) for the first time in the United States in 2019. That means Congressional and regulatory oversight is still in its early stages. The National

Institutes of Health scaled back [oversight of gene therapy](#) trials this year, raising some concerns about the quality of newly approved drugs. As with any new treatment, long-term effects will not be understood for quite some time and practitioners must be educated on the risks and benefits for their patient populations.

**Current gene therapy often targets rare disease.** The rarity of the diseases matched with novel therapeutic applications makes institutional knowledge of gene therapy relatively scarce. While the CRISPR technology is considered simple among the science community, the administration of gene editing therapy can be significantly more complex depending on disease stage or manifestation.



### **AMA Updates Best Practices for LGBTQ Patients**

The American Medical Association (AMA) has released [updated policies](#) to better protect and provide care to patients within the LGBTQ community. Regardless of ethnicity, [LGBTQ patients](#) experience higher rates of chronic illness, increased exposure to violence and lower life expectancies than their peers. During its November meeting, the AMA underscored its [longtime opposition](#) to providers engaging in so-called “[conversion therapy](#)” (which seeks to change an individual’s sexual orientation) and announced that it will advocate for legislation banning the practice. The AMA also called for fully-inclusive Electronic Health Records (EHR) for transgender patients and increased provider education on caring for the LGBTQ community.

#### **Banning “Conversion Therapy”**

The AMA is committed to working for a federal ban on “conversion therapy.” Sometimes called “reparative therapy,” the practice attempts to change a patient’s sexual orientation or gender identity, despite a [lack of credible evidence](#) supporting the practice. Treatments often include [unethical practices](#) such as food or liquid deprivation, electric shocks, chemically-induced vomiting and verbal abuse. Patients undergoing the experience show increased rates of depression, PTSD and suicidal ideation. Despite opposition from the medical community, [31 states](#) currently have no legislation protecting patients from the practice—something the AMA hopes to change with forthcoming model legislation.

#### **Creating Inclusive Health Records**

The AMA also recommends supporting the [voluntary inclusion](#) of transgender patients’ preferred names and clinically-relevant, sex-specific anatomy (including transition history) within the EHR. Without this information, providers often have difficulty preparing for patient visits, particularly for new patients.

Transgender patients currently face high rates of discrimination and harassment in medical settings and often [forgo care](#) for fear of further harmful experiences, exacerbating incidents of chronic disease and HIV complications. The AMA believes that more inclusive EHRs will increase providers' ability to mitigate the health disparities faced by these patients.

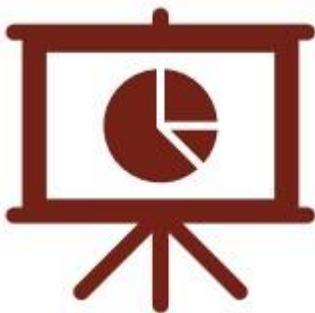
### **Supplemental Nutrition Assistance Program (SNAP) Rule Enforces Work Requirements**

Initially proposed in February, the Department of Agriculture released a [final rule](#) on SNAP that will make it more difficult for states to waive work requirements for able-bodied adults without dependents. This rule will remove an [estimated 755,000 individuals](#) from the food assistance benefit. [AHPA commented](#) on the proposed rule, opposing the limitations placed on state SNAP administrators and the implementation of additional barriers. The rule is effective April 1, 2020.

### **Continuing Resolution Funds Government Thru Dec. 20**

On November 21<sup>st</sup>, the President signed a [continuing resolution](#) to temporarily fund federal agencies through December 20<sup>th</sup>. The short-term spending bill extends current funding levels to government agencies, includes a pay raise for military servicemembers and provides funding for the 2020 census. The President maintains his request for additional border wall funding; a similar demand led to the [record-breaking](#) government shutdown. Despite this, lawmakers remain hopeful that Congress will be able to pass a full-year funding bill before the December deadline.

### **AHPA Resources**



#### **OPPS/ASC Final Rule**

[Webinar Recording](#)  
[Presentation Slides](#)  
[Final Rule Outline](#)

#### **Price Transparency Final Rule**

[Detailed Summary](#)  
[Key Highlights](#)



## **A Look at the Federal Register**

### **Price Transparency Requirements for Hospitals to Make Standard Charges Public**

CMS released the long-awaited final rule ([84 FR 65524](#)) implementing President Trump's Executive Order on price transparency in health care. This rule finalized policies that require hospitals to publish their payer-negotiated rates for 300 shoppable services in a consumer-friendly format. The final rule is effective January 1, 2021.

### **Transparency in Coverage**

The Internal Revenue Service, along with the Departments of Treasury and Health and Human Services, released a complementary price transparency proposed rule ([84 FR 65464](#)) requiring insurance providers to publish cost-sharing liability and out-of-pocket expenses for beneficiaries. Comments are due January 14, 2020.

### **TRICARE to Further Align with OPPTS/ASC**

The Department of Defense released a proposed rule ([84 FR 65718](#)) that seeks further alignment between TRICARE reimbursement and the Outpatient Prospective Payment System by adopting the Ambulatory Surgical Center (ASC) and Cancer and Children's Hospital payment rates. Comments are due January 29, 2020.

### **Community Preventive Services Task Force (CPSTF) Call for Recommendations**

The CDC-supported CPSTF has issued an RFI ([84 FR 66198](#)) seeking recommendations on priority issues in public health and evidence-based interventions addressing them. The CPSTF evaluates these interventions and recommends based practices to solve pressing public health problems. Comments are due January 23, 2020.

### **Supplemental Nutrition Assistance Program (SNAP) Work Requirements**

The Department of Agriculture issued its final rule ([84 FR 66782](#)) on work requirements for able-bodied adults without dependents, reducing the level of discretion given to states to waive them. The rule also limits the carryover of discretionary exemptions.

## **IN OTHER NEWS**

[Five Takeaways from the Fifth Democratic Debate](#) – Axios

[Hospital Groups Sue to Block Price-Transparency Rule](#) – WSJ

[Does Gavin Newsom Have the Answer to Democrats' Health Care Fights?](#) – Politico

[Trump Says U.S. States Will be Able to Buy Prescription Drugs Abroad](#) – Reuters

[Big Study Casts Doubt on Need for Many Heart Procedures](#) – AP

[AHA Statement on the 20<sup>th</sup> Anniversary of “To Err is Human”](#) – AHA

[Judge Halts Trump's Insurance Mandate for Immigrants](#) – Politico

[Confronting Bias and Discrimination in Health Care—When Silence Is Not Golden](#) – JAMA

[Trump Administration Will Provide HIV Prevention Drug for Free to Uninsured](#) – STAT