Background

Price transparency is frequently called out as an important component of any reforms to the U.S. health care system. It is seen by policymakers, both as a way to drive cost conscious consumer choices and as a necessary tool to decode the largely opaque health care marketplace. Health care in the U.S. is regularly
cited as an example of market failure, with a multitude of actors engaging in independent and proprietary negotiations that often drive prices of our public insurance programs. A lack of transparency in this “marketplace” frequently leaves patients and their providers with very little ability to determine the true cost of care (either preemptively or after billing). Prices for health care services and goods vary widely by location, choice of provider, or health insurance plan benefit design, and price transparency means different things to different actors. Because of health care system complexity, it is difficult to distill and share information that would be meaningful and useful to patients and providers.

At a time when patients (increasingly characterized as health care purchasers/consumers) are bearing a rising share of health care costs in the form of copays, deductibles and higher coinsurance amounts, price transparency is seen as vehicle to empower the selection of appropriate and high-value care. The need for transparency in the broader health care market has been highlighted most recently by the practices of pharmacy benefit managers (PBMs). For example, little information is available about the size and frequency of rebates PBMs receive from manufacturers, nor is it understood the extent to which patients experience actual benefits of these rebates and discounts. Price transparency is particularly important to the field of cancer care, as prescription drugs represent a large and costly portion of the oncologist’s therapeutic armamentarium. Inefficiencies in the market are passed down to hospitals, private practices, and ultimately to patients.

This policy brief provides an overview of issues around price transparency, placing special emphasis on their impact for patients with cancer.

Hospital Price Transparency

The Patient Protection and Affordable Care Act (ACA) requires hospitals to make their list prices for all services publicly available online in a machine-readable format. While these public chargemaster lists are an attempt to increase transparency, they are confusing for patients and do not provide them the relevant and actionable information they need to influence their health care decisionmaking. Because of the complex web of care delivery, the result of this federal requirement is an unwieldy itemization of thousands of services and products on an individual hospital website. In order to compare prices, patients must be able to identify the services and products they will require and then check multiple hospital websites to compare list prices. Even if a patient succeeded in accomplishing this difficult comparison, costs that are available to them typically are not relevant; patients do not purchase individual services from hospitals at full price so a chargemaster list does not reflect actual prices available to them. Despite references to patients as health care consumers, a majority of health care is not “shoppable.” Consumers often do not have sufficient information to make an informed decision about what care to choose and from whom as it relates to cost. The federal government has not effectively enforced or monitored this requirement to date.

In an effort to provide patients with clear, accessible information about their standard charges, the Centers for Medicare & Medicaid Services (CMS) issued a final rule requiring hospitals to publicly list the items and services they provide, including through the use of standardized data elements. Beginning in 2021, the final rule will require hospitals to make their standard charges public (including the gross charges, payer-specific negotiated charges, the amount the hospital is willing to accept in cash from a patient, and the minimum and maximum negotiated charges) for all items and services in a machine-
readable file; a separate, “consumer-friendly” file would list the same prices—minus the gross charges—for 300 “shoppable” services. Both would be updated annually.1

While most consumer products can be evaluated based on a product’s quality and cost, in health care a higher list price may not necessarily mean better health care. Most patients are unable to make a determination on quality solely by using price information. In fact, evidence shows the quality of health care does not perfectly correlate with price.2

Drug Price Transparency

Unlike most consumer goods, the drug supply chain is significantly larger and more complex. There are numerous actors in both the delivery and distribution of prescription drugs, including but not limited to: employers, individuals, health plans, PBMs, drug manufacturers, drug wholesalers, group purchasing organizations, and pharmacies. While much attention has focused on a manufacturer’s list (gross) price and/or net price, this does not represent the full story. The flow and distribution of money across the drug supply chain typically are confidential, making it difficult to determine how payments, coupons, and rebates are distributed and utilized. Some experts have concluded that this lack of transparency has incentivized the current system to reward higher drug prices while shifting costs to patients.3

The manufacturer’s list price does not reflect what they are paid and likewise, net price does not represent what the patient pays. A manufacturer’s list price also does not reflect the discounts of price concessions paid to a pharmacy benefit manager or insurer. Nevertheless, both list prices and net prices (which have been increasing) often are used to determine patient cost-sharing. The confidential and proprietary nature of the drug supply chain makes it difficult to determine the extent to which savings achieved through the drug supply chain are passed down to patients.

The Medicaid program has been successful in implementing increased drug price transparency by moving away from average wholesale price (AWP) as a basis for payment in their primary drug pricing benchmark. In 2013, CMS established a single national pricing benchmark based on average drug acquisition costs, known as the National Average Drug Acquisition Cost (NADAC). NADAC provides state Medicaid agencies with a better estimate of prices paid by pharmacies for drugs because it is based upon actual drug purchases. According to CMS, NADAC provides greater accuracy and transparency in how drug prices are established and is generally more resistant to manipulation. To the extent that states consider the NADAC as a reference price when setting their reimbursement methodology, they must submit a State Plan Amendment (SPA) to CMS in accordance with state plan requirements if they decide to use NADAC as a basis for payment.4

Health Plan Transparency

Health plans typically do not pay listed charges set by providers. Instead, each health plan negotiates price with each hospital and provider for every plan. Insurers can have multiple plans with multiple agreements for the same hospital or provider. The prices negotiated between the plan and the provider generally are not known to the patient until they receive a bill or explanation of benefits (EOB) form. Because health plans contract with different networks of doctors, hospitals, and other health care professionals, an individual who obtains health care services must determine if their provider(s) are within the health plan’s network (in-network), which typically results in lower copays and other out of pocket cost. Conversely, if an individual obtains services from a provider not in the insurance plan network (out-of-network) they are likely to pay a higher price.

Concerns for ASCO Members and the Cancer Community

ASCO is concerned that lack of price transparency in the health care system leaves patients without sufficient knowledge or understanding of health care cost implications for themselves and their families. However, ASCO is also concerned with proposals that purport to enhance transparency, but fall short by not providing meaningful information to patients. Oftentimes, the type and amount of information provided to patients is unfamiliar and unwieldy, making it difficult for patients to make informed health care decisions. With rising out-of-pocket costs, patients who do not have information that can better prepare them for the cost of their care may forego or discontinue the necessary treatment for their cancer. ASCO supports testing price transparency as a means for consumer and provider education—and as a way to address the rising cost of health care—but proposals must be implemented through a validated, agreed-upon methodology that is meaningful to patients and not overly burdensome to providers.

Where ASCO Stands

ASCO has outlined the need for greater transparency across the health care system to address concerns with patient access, affordability of care, and the price of drugs.

In a 2017 ASCO Position Statement on Addressing the Affordability of Cancer Drugs, ASCO outlined that transparency efforts requiring manufacturers to disclose costs would allow payers and patients to at least make some informed comparison of the relationship between development costs and price for drug products while exerting public pressure on companies where the two appear to be widely divergent. ASCO supports testing price transparency to provide meaningful information to patients and providers, but such mechanisms should include a validated, agreed-upon methodology for value-based pricing.

ASCO’s Position Statement, Pharmacy Benefit Managers and Their Impact on Cancer Care describes the lack of transparency in which PBMs operate, which includes their financial arrangements with other entities within the supply chain, their rebate arrangements, and the significant fees collected from pharmacy providers. In its position statement, ASCO recommends that CMS leverage its authority by requiring the prohibition of gag clauses and requiring a more stringent and detailed accounting of direct-
and-indirect remuneration fees. Collecting and ultimately publishing such data would help plan sponsors, employers and providers understand the financial arrangements for which they are being asked to contract, ultimately helping to ensure patients are able to be fully informed about price differences and ways to obtain their drugs at the lowest cost. ASCO has supported recent efforts by CMS that label gag clauses as unacceptable.\(^5\)

Additionally, ASCO’s Policy Statement, *On the Impact of Utilization Management Policies for Cancer Drug Therapies* states that payer cost containment policies and their decision-making processes should be transparent.

ASCO has also provided [comments to CMS](https://www.cms.gov/newsroom/press-releases/cms-sends-clear-message-plans-stop-hiding-information-patients) in support of real time benefit tools to provide meaningful information on the value of drug therapies at the point of care.

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