HEALTH POLICY ISSUE BRIEF

Recommendations to Achieve a More Transparent Health Care System for Consumers

AUTHORS

Kavita Patel, Domitilla Masi, Caitlin Brandt

**ENGELBERG CENTER for
Health Care Reform
at BROOKINGS**

Authors

Kavita Patel
Managing Director, Clinical Transformation
Fellow, Economic Studies

Domitilla Masi
Research Assistant

Caitlin Brandt
Research Analyst

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Abstract

As policy makers, researchers and field experts increasingly consider health care data transparency as a way to drive overall health system improvement, it is necessary to start thinking about how to render health care information more meaningful for consumers. Now more than ever, as they face higher cost-sharing for their care, consumers need the ability to access cost and quality information for a specific provider or service. This brief discusses a number of recommendations to ensure that this data is both available and more effective in informing everyday health care decisions. First, we discuss regulatory barriers that need to be addressed and then, what information consumers will need when making smart health care choices.

Overview

As solutions to address excessive health care costs continue to attract debate, policymakers and researchers believe that increasing **health care data transparency** – the process of providing the public and other critical stakeholders with information on health care prices and quality of care – is key to achieving overall health system improvement. Unlike any other market, consumers of health care do not have ready and user-friendly access to cost and quality information, which means they cannot compare the price or quality for a particular service (knee replacement, diagnostic test, etc.) before they purchase it.[1]

Especially in the current health care environment, where consumers are taking on more of the cost burden through increasing out-of-pocket costs, particularly from the growth of high deductible health plans, they need and want more information.[2] On the provider end, there is also an increasing need for transparency. Just like consumers, physicians have limited price and quality information either on the drugs and devices they prescribe or on other providers, meaning that they too operate with a lack of transparency. However, new models of paying for and delivering care, such as bundled payments, patient centered medical homes and accountable care organizations (ACOs), enforce a new level of provider financial accountability for their patients' care. In turn, physicians have become far more discerning about which providers they partner with and / or refer their patients to.

This brief was prepared by gathering insights through more than twenty expert interviews with key payers, providers, researchers and consumer advocates. It also includes learnings from a recent Brookings event, Enhancing Health System Transparency through Meaningful Health Data Releases. Our goal is to move beyond recommendations designed to merely increase the volume of data available to the public, and propose concrete next steps for rendering more meaningful data to consumers and providers, so they can make better health care decisions. We offer two categories of recommendations: (1) **regulatory issues** that need to be addressed to facilitate meaningful data transparency, and (2) **which** data should be provided, and **how** it should be provided, in order to ensure its effective use by consumers.

A. Regulatory Reforms that Will Enhance Transparency

It's easy to offer up "transparency" as a simple solution to a very challenging problem, but it will be extremely difficult to achieve. If the goal is to change the priority from increasing volume of data to providing more practical and meaningful, attention to regulatory reforms is critical.

1.   Breaking Down Private Payer Data Silos

Private payers – commercial health insurers – have access to a wealth of pricing and performance data for providers in their networks. However, contract agreements usually prohibit sharing this data publicly to prevent compromising pricing information or market power.[3] As a result, consumers are unable to comparison shop across provider, hospital, practice or price, and providers are often making referrals with little to no cost or quality information. To achieve meaningful transparency, pricing and performance data

from various private payers should be aggregated with that of Medicare and Medicaid, and made available for public use.

Some states have already started in this direction. For example, Colorado's all-payer claims database combines claims data from seven health plans.[4] This allows providers and patients to compare health care prices for specific procedures, across location and by specific health plan.[5] More recently, the **Health Care Cost Institute's (HCCI)** Transparency Initiative is combining cost and quality data from four of the country's largest private health insurers - Assurant Health, Humana, Aetna and UnitedHealthcare - to build consumer transparency tools that will launch in 2015. This initiative also involves collaboration with the National Committee for Quality Assurance (NCQA), who will develop appropriate quality metrics and standardize them across participating payers.[6]

We also recommend development of a **national strategy** for implementing common data collection standards and interoperable HIT systems, so as to facilitate the sharing and aggregation of information across different providers and payers. Though a new goal for achieving nationwide electronic medical record (EHR) interoperability has been set for 2017, the Office of the National Coordinator for Health Information Technology (ONC) continues to be criticized from payers and providers for not effetively standardizing interoperability and data sharing guidelines.[7] A proposed solution is to create a public private partnership that will develop an actionable framework for sharing health information. Moreover, providers should be incentivized and rewarded for transitioning to shareable patient-level data.

2.   Creating a Publicly Available Database of Research Findings

Since we are still in the infancy of realizing meaningful health care data transparency, we recommend the creation of a **free, web-based database.** The database would house research findings that would better inform which analyses should be conducted on publicly released health datasets, and which provider information should be extracted. Such a database would provide (1) a centralized location for crowdsourcing research findings and (2) access to research that can be enhanced, further tested and refined. For example, the Agency for Healthcare Research and Quality has created the Systematic Review Data Repository, an open database of systematic reviews of health outcomes, which could provide a template for this effort. Getting perspectives and results from actors outside of the government would help improve trust in the research findings. The release of more refined public datasets are necessary for the creation of meaningful transparency tools that improve the information available to consumers for health care decision-making purposes.

3.   Enhancing Data Integrity While Still Protecting Patient Confidentiality

With the intent of protecting private patient information, specific data is often excluded or removed from publically available datasets. For example, the Centers for Medicare and Medicaid (CMS) have been redacting any Medicare and Medicaid claims data associated with services provided for substance and alcohol abuse.[8] However, withholding this information not only hampers research on this specific patient population, but it also renders all other Medicare and Medicaid data inaccurate (through sample bias) and incomplete for meaningful analysis.[9] Though inconsistent with the agency's rules on the disclosure of substance and alcohol abuse claims data, CMS acted to protect patient confidentiality over the benefits of research. However, if the ultimate goal of meaningful data transparency is to advance health system improvement, a better way must be found to balance these considerations.

From a broader perspective, data protection governance models should be simplified and updated. For example, the regular misinterpretation and misuse of the **Health Insurance Portability and Accountability Act's (HIPAA)** privacy, security and enforcement regulations – developed to safeguard patients' personal health information – hampers data sharing.[10] In fact, the ONC recently called for a need to better educate providers on federal privacy regulations.[11] Current data protection governance models were also developed before the trend toward greater health care data transparency began. These models should therefore be re-

evaluated for how they balance the importance between privacy and broader health system evolution and improvement, especially as more and more patients show a willingness to share data with their physicians and collect health data through wearable devices. For example, in the Medicare Shared Savings Program, as well as numerous other CMS initiatives, only about 2 percent of beneficiaries opted out of sharing their claims data.[12]

B. Presenting Data to Consumers: What Do They Need?

A recent Brookings review of online health care data sources[13] demonstrates that the public and private sector have undertaken a number of efforts to enhance transparency.[14] Though those initiatives have been important for propelling the transparency movement forward, the information being poured into the public domain is still of limited use to consumers when it comes to simple uses like choosing a provider. It is also essential that consumer data are thoroughly cleaned, contextualized and refined.

Below is a discussion of gaps in the data that is currently available, as well as recommendations for how and what information should be made available to consumers to empower them in their provider decision-making abilities. **Figure 1** (page 5) provides a summary of findings based on a recent U.S. Government Accountability Office (GAO) report that identifies what health care information is relevant and understandable to consumers.[15] This information should be taken into consideration when developing new transparency efforts.

1. Sharing Data that is User-Friendly and Can Be Personalized

In a recent report card on transparency, the majority of US states were rated as failing in providing patients with usable consumer websites and provider data.[16] As described in a previous brief, some current transparency efforts provide consumers with data that is too raw and complex to use meaningfully.[17] The GAO report found that consumers find it difficult to ascribe value to large amounts of varying information and intricate numerical information. Instead, future transparency tools should focus on restricting the amount of information provided to the consumer, and on presenting information in a way that facilitates the drawing of comparisons and patterns between providers. At the same time, it is important that the data are not aggregated at a very general level (such as 'high cost' versus 'low cost' providers or 'high performing' versus 'low performing' providers), as this may lead to the exclusion of specific pieces of information that are important to consumers.[18]

For example, the GAO report found that consumers are most receptive to information that pertains to their personal situation, such as the quality and costs for a specific procedure they need. In terms of cost information, consumers need and want to know the out-of-pocket costs they will incur for a service under their specific health plan benefits. It is therefore important that future data transparency tools and cost calculators can be tailored to each consumer's specific circumstance. In regards to quality, consumers are most interested in comparing patient health outcomes and experiences across providers. For example, consumers have been found to be more interested in patient survey ratings of doctors rather than evidence of board certification or that a physician follows evidence-based guidelines for care.[19] Therefore, the quality information provided in these tools should strike an appropriate balance between clinical significance and consumer value. Future tools should also facilitate the provision of data at a convenient time so that consumers can compare and choose services or providers at the time they require care. Ultimately, building transparency tools with more focused pieces of information would also help restrict the overall amounts of information presented down to that which is absolutely necessary for a consumer's decision-making purposes.

2. Providing Quality Data Transparency Alongside Cost Data Transparency

A consistent lack of reliable and standardized metrics to judge the quality of care provided has led to a comparably much faster growth in price transparency than quality transparency. This chasm contributes to a

concern that a rapid growth in cost transparency, coupled with a slow growth in quality transparency, may cause consumers to make critical health decisions based only on price, and not quality. [20] Therefore, outcome-based quality information is absolutely necessary to help consumers make informed decisions. Recent survey data shows that currently almost half of patients not only use physician rating sites, but also state that they would seek more expensive out-of-network physicians if they displayed higher quality and patient experience ratings.[21] As such, the larger issue of creating clinically appropriate and meaningful quality metrics must be tackled by multiple stakeholders including policymakers, payers, providers and patients. This could be encouraged through the creation of a research database, as mentioned above, to crowdsource perspectives on meaningful quality measures. Accessibility of the data won't matter for consumers if the quality of the measurements is low. Information on clinically bad outcomes, such as mortality and complication rates, should be included alongside information on what a provider is doing well. The best providers can be expected to work with the most complicated patients, so negative quality measurements do not provide a full picture of their quality as a provider. For example, Medicare's Nursing Home Compare website, which allows consumers to compare the quality of care provided in nursing homes across the country, includes user-friendly information on the details of inspections and complaints filed against specific nursing homes.[22] The incorporation of this kind of information in new transparency tools could be one meaningful way of helping consumers compare quality across providers.

3. Distinguishing Elective from Emergent/Urgent Health Care Services

When considering what services to include in meaningful transparency tools, being able to distinguish elective from emergent/urgent health care services is important. For example, when compared to urgent services such as emergency room visits, elective services such as standard diagnostic procedures (MRIs, blood tests, colonoscopies) – for which consumers have the time to price shop - benefit more from transparency and should be included.

Figure 1: Information that is Relevant to Consumers When Making Health Care Choices[23]

TYPE OF INFORMATION	DESCRIPTION	EXAMPLES
QUALITY OF CARE		
Patient-reported Outcomes	Health status outcomes self-reported by the patient	- physical and mental well-being - functional status after procedure
Patient Experience	Reports on patient perspectives of the quality of their care, usually obtained through surveys	- how well nurses communicate with patients - the responsiveness of clinicians to patients' needs
COST OF CARE		
Specific Out-of-Pocket Costs	Costs that are not reimbursed by insurance and are the responsibility of the consumer; should ideally be tailored to individual consumer benefit summaries	- Deductibles - Copayments - Coinsurance
OTHER		-
Elective Services	Non-emergency services that will give consumers time to compare price and quality	- Hip replacements - MRIs - Colonoscopies
Explanations of the Data	Explanations of terminology and links to methodology that can increase consumer trust and understanding	- An easy-to-understand glossary - Link to quality metric site (if a third-party)

Conclusion

The achievement of health care data transparency that is meaningful to the consumer trying to shop for appropriate services and/or providers still has a long way to go, but several steps can be taken to move us in the right direction.

First, broad regulatory changes need to take place before this information can be available and used meaningfully. For example, data protection governance models must be re-designed to better reflect the importance of overall health system reform compared to patient and/or payer privacy; and broad data standards must be implemented and the sharing of research findings must be facilitated to continually improve future public data releases.

Second, to ensure that consumers actually use the data to inform their health care decisions, greater thought needs to be given to exactly what data consumers want and need access to, and how to best present it to them. This includes making customizable data on the quality as well as cost of care and on foreseeable elective services available.

Most importantly, it must be emphasized that the ultimate goal of achieving meaningful transparency in the health care sector is only attainable if meaningful health data transparency is considered across all key stakeholders – it should not be only left to consumers to help use transparency to drive health system improvement. Beyond consumers, who we have focused on in this brief, providers, payers, researchers, and policymakers must also be able to meaningfully engage in the use of health care data transparency. Each stakeholder has different data uses, wants, and needs depending on their overall role in the health care market that need addressing.

Notes

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