Why is health data transparency important?
Much has been written about the apparent disconnect between the relatively high rate of health care spending in the United States and the relatively substantial deficiencies in the quality and access of care provided. In order to close this gap, more needs to be known about which expenditures provide the greatest value in terms of quality of care, treatment outcomes and access to care. At a minimum, determining value requires measurement of health care price and quality data. Reporting the data in a way that is accessible and meaningful to researchers, consumers and policymakers has the added potential to encourage health care purchasing decisions based on value.

Who needs the data and why?
Consumers, providers, insurers, employers, researchers, and state and local governments can all benefit from greater health data transparency. Across the board, greater access to health care price and quality information gives stakeholders the ability to manage and evaluate data-driven quality improvement efforts and the ability to make informed decisions regarding care utilization and costs. At the same time, each of these stakeholders has legitimate concerns about increased transparency ranging from privacy concerns to measurement reliability to increased costs associated with data collection, reporting, and monitoring. For a more detailed analysis of stakeholder perspectives see pages 2 and 3.

The ACA and transparency
• Increases data collection and public reporting for hospitals, physicians, nursing homes, skilled nursing facilities and long-term care facilities.
• Makes Medicare claims data available to states and to certain “qualified organizations” to help identify high quality doctors and hospitals.
• Establishes the Patient-Centered Outcomes Research Institute (PCORI) to perform comparative effectiveness research using quality metrics.
• Sets minimum data collection standards for state run exchanges, including standardizing the electronic transmission of health care claims, enrollment and benefit data.
• Requires transparency from health insurers who must demonstrate compliance with the medical loss ratio and must justify premium increases in excess of 10%.

Public and private support for greater transparency
Support for greater health data transparency has been growing among both the public and private sectors. While multiple federal agencies have been collecting, housing and disseminating both process and outcome measures for several years (mainly through voluntary reporting efforts led by federal-state partnerships), it is only recently that coordinated efforts have been made to release and share the data publicly. Both the current and former Presidential administrations have directed federal agencies to increase transparency and data sharing.

In 2006, the State of Ohio passed legislation (HB 197) requiring hospitals to report a series of hospital performance measures and service charges to the Ohio Department of Health (ODH). More recently, the Governor's Office of Health transformation (OHT) has indentified standardized performance measurement and public reporting as an important health system performance initiative.

Commercial insurers have responded to the call for greater transparency by offering enrollees password-protected access to price and/or quality information; some offer limited access to the general public. In addition, the majority of insurers participate in The National Committee for Quality Assurance (NCQA), a private, non-profit organization dedicated to improving health care quality that regularly tracks and reports on the quality of care delivered by the nation’s health plans. In 2011, Aetna, Humana, Kaiser Permanente, and UnitedHealth Group pooled financial resources and 10 years of medical claims data to create the non-profit Health Care Cost Institute to analyze the data and identify the drivers of health spending.

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>What data they need</th>
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| Consumers           | • Accurate total and out-of-pocket cost of an episode of care  
                     • Access to easy-to-understand provider quality of care and outcomes information  
                     • Secure medical records  
                     • Cost of medications  
                     • Knowledge about treatment benefits and risks |
| Providers           | • Standard metrics for assessing quality of care  
                     • Outcomes or performance based payment  
                     • Reduced paperwork  
                     • Knowledge of prices paid to hospitals, labs, specialists, etc., to inform patients |
| Insurers/Payers     | • Standard metrics for assessing provider quality and patient outcomes  
                     • Patient compliance data  
                     • Consumer involvement in care decisions  
                     • Reduction in inappropriate or unnecessary medical services  
                     • Information on total cost of treatment |
| Employers           | • Standard metrics for assessing provider quality  
                     • Patient compliance data  
                     • Health status, needs, and goals of employees  
                     • Risks and benefits of treatments and drugs  
                     • Employee participation in wellness programs |
| State Government    | • Standard metrics for assessing provider quality  
                     • Patient compliance data  
                     • Consumer involvement in care decisions  
                     • Reduction in inappropriate or unnecessary medical services  
                     • Information on total cost of treatment  
                     • Provider capacity  
                     • Data on population health |
<p>| Researchers         | • Claims data and/or electronic health records from which to glean patient and provider demographics as well as clinical, financial, and utilization information (e.g. cost and quality metrics, process measures, utilization data, service volumes, patient satisfaction, etc) to inform research studies |</p>
<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Why they need it</th>
<th>Concerns of increased transparency</th>
</tr>
</thead>
</table>
| Consumers   | • Accurate total and out-of-pocket cost of an episode of care  
• Access to easy-to-understand provider quality of care and outcomes information  
• Secure medical records  
• Cost of medications  
• Knowledge about treatment benefits and risks  
• To make informed care decisions  
• To be able to “shop” for medical services and medications  
• To drive and evaluate quality improvement efforts  
• To support data-driven management of patient health care cost and utilization | • Disclosure of personal medical information  
• Information overload/confusion  
• Unfair, inaccurate, or unreliable quality measurement methodologies  
• Loss of patient-physician confidentiality  
• Reductions in payments  
• Additional cost and time to meet reporting requirements, some of which may not lead to better outcomes  
• Patients may delay or avoid care once they know the cost  
• Patients may not follow doctor recommendations if less expensive options are available  
• To drive and evaluate quality improvement efforts  
• To support data-driven management of patient health care cost and utilization  
• To inform contracting decisions with providers |
| Providers   | • Standard metrics for assessing quality of care  
• Outcomes or performance based payment  
• Reduced paperwork  
• Knowledge of prices paid to hospitals, labs, specialists, etc., to inform patients  
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• Reductions in payments  
• Additional cost and time to meet reporting requirements, some of which may not lead to better outcomes  
• Patients may delay or avoid care once they know the cost  
• Patients may not follow doctor recommendations if less expensive options are available  | • Disclosure of proprietary discounts and fee schedules will compromise trade secrets  
• Lack of trust from providers and consumers  
• Potential liability for violating privacy laws  
• Price transparency may lead to higher prices by potentially reducing the incentive to bid aggressively and by facilitating possible collusion among insurers and hospitals, particularly in markets where there is little competition |
| Insurers/Payers | • Standard metrics for assessing provider quality and patient outcomes  
• Patient compliance data  
• Consumer involvement in care decisions  
• Reduction in inappropriate or unnecessary medical services  
• Information on total cost of treatment  
• To support data-driven management of client health care cost and utilization  
• To inform contracting decisions with providers  
• To assess plan performance, understand medical expense trends, identify workforce health risks, develop targeted health programs, evaluate how they are spending their health care dollars, and predict future health-related expenditures  
• To inform contracting decisions with insurance vendors  
• To allow for data-driven policymaking and legislative efforts  
• To support data-driven management of state employees’ health care cost and utilization  
• To assist with state regulation of insurers and providers  
• To inform contracting decisions with insurance vendors  | • Disclosure of proprietary discounts and fee schedules will compromise trade secrets  
• Lack of trust from providers and consumers  
• Potential liability for violating privacy laws  
• Price transparency may lead to higher prices by potentially reducing the incentive to bid aggressively and by facilitating possible collusion among insurers and hospitals, particularly in markets where there is little competition  
• Additional cost and time to regulate and monitor reporting activities  
• Possible loss of control over Medicaid provider payment rates if CMS decides to require publicly-available rate justifications |
| Employers   | • Standard metrics for assessing provider quality  
• Patient compliance data  
• Health status, needs, and goals of employees  
• Risks and benefits of treatments and drugs  
• Employee participation in wellness programs  
• To assess plan performance, understand medical expense trends, identify workforce health risks, develop targeted health programs, evaluate how they are spending their health care dollars, and predict future health-related expenditures  
• To inform contracting decisions with insurance vendors  | • Ability to share data with researchers while adequately protecting patient data and privacy  
• Data use fees can be a deterrent to health services research |
| State Government | • Standard metrics for assessing provider quality  
• Patient compliance data  
• Consumer involvement in care decisions  
• Reduction in inappropriate or unnecessary medical services  
• Information on total cost of treatment  
• Provider capacity  
• Data on population health  | • Ability to share data with researchers while adequately protecting patient data and privacy  
• Data use fees can be a deterrent to health services research |
| Researchers | • Claims data and/or electronic health records from which to glean patient and provider demographics as well as clinical, financial, and utilization information (e.g. cost and quality metrics, process measures, utilization data, service volumes, patient satisfaction, etc) to inform research studies  
• To enhance health services research to support data-driven improvements in care  
• To identify disparities in health care  
• To perform observational studies using claims and other datasets  
• To conduct evaluations of patient care processes  
• To measure impact of payment reforms on quality and cost of care  
• To foster new research ideas  | • Ability to share data with researchers while adequately protecting patient data and privacy  
• Data use fees can be a deterrent to health services research |
Impacts of greater transparency

Impact on consumer decision-making
Thus far, greater access to price and quality measures has not significantly impacted consumer health care decisions. Many consumers have limited understanding of price and quality data or are unaware that such data is publicly available. In addition, consumers who try to access data often find that it is voluminous and difficult to understand and use. Research shows that patients tend to rely more on their physician’s advice about where and from whom to seek medical care or on a provider’s reputation than on the price differential among providers.

Impact on health care spending
The effect of price transparency on spending for health care services is mixed, scant, and still emerging. Many consumers have limited incentive or ability to shop around for care. The majority of published prices are averages that do not account for confidential, negotiated rates between insurers and providers. Consumers have limited knowledge of total costs and/or out of pocket costs, making it difficult to compare the actual cost of care before undergoing treatment.

The lack of coordination and consistency among transparency initiatives minimizes the potential for transparent price and quality data to reduce health spending by placing significant operational and financial burdens on provider organizations that must meet multiple and varied reporting requirements. However, health quality data that is transparent to providers, consumers and health plans provides important support for cost-saving payment methodologies that pay for value, not volume, of service.

Impact on quality of care and outcomes
Systemic reviews of the evidence that publishing care performance measures improves quality of care have yielded inconsistent results. Rigorous evaluation of public reporting systems’ impact on quality of care is lacking. While evidence suggests that publicly releasing performance data stimulates quality improvement efforts among hospitals and physicians, the impact of reporting on effectiveness, patient safety, and patient-centeredness is inconsistent and uncertain.

The role of policymakers
State government leaders can support greater transparency by:
• Assisting with the development of standardized metrics and policies for price and quality transparency consistent with nationally accepted standards and consistent across programs.
• Supporting the coordination of health information technology/exchange with quality measurement and reporting
• Assessing the return on investment and impact of transparency efforts on outcomes, access, and cost
• Making transparency a requirement for state license renewals for insurers, health care facilities, and providers
• Requiring or incentivizing all health plans and providers with state contracts to participate in price and quality transparency efforts
• Collaborating with large employers to leverage support for transparency efforts, both locally and statewide.
• Monitoring prices to prevent collusion among insurers and/or providers

State legislators can support greater transparency by:
• Mandating that health plans and employers make price and quality data available to plan enrollees.
• Mandating that health care providers and facilities disclose prices.
• Providing funding for public-private partnerships to pilot transparency projects

More work is needed to make the most of health data
In the last decade, there has been a proliferation of public and private reporting of health care costs and quality data — some mandatory, some voluntary. Unfortunately, the result has been what some consider an unwieldy, inconsistent set of quality reporting measures. The problem is compounded by a lack of institutional resources and expertise to perform meaningful analysis on the data being collected. While there have been many commendable efforts in recent years to harmonize and streamline quality and performance measures across reporting organizations, more work needs to be done to reduce the data collection burden on providers and to lessen confusion among data users.