



**RECOMMENDATIONS To A Bipartisan Effort To Increase Health Care Price and Information Transparency to Empower Patient, Improve the Quality of Health Care, And Lower Health Care Costs**  
**Submitted by Community Catalyst on March 23, 2018**

Community Catalyst respectfully submits the following comments in response to the stakeholder letter regarding bipartisan efforts to increase health care price and information transparency.

Community Catalyst is a national non-profit advocacy organization dedicated to quality affordable health care for all. Since 1997, Community Catalyst has been working to build the consumer and community leadership required to transform the American health system. With the belief that this transformation will happen when consumers are fully engaged and have an organized voice, Community Catalyst works in partnership with national, state and local consumer organizations, policymakers, and foundations, providing leadership and support to change the health care system so it serves everyone – especially vulnerable members of society.

While we believe transparency is crucial, both at the point of care and point of plan choice, in helping consumers make the health care decisions that are right for them, we also know that transparency alone is not the solution to improving patients’ outcomes and experiences or reducing costs. In fact, only 7 percent of consumers’ out of pocket health care spending is estimated to be on “shoppable” services,<sup>1</sup> suggesting that the purchasing power of consumers has limited ability to drive affordability and quality of care. Improving healthcare for consumers will ultimately require much more than transparency.

In particular, we would like to draw attention to the ways in which a focus on transparency will fail to improve consumers’ experience if it is not also paired with improvements in quality of care and if the unique needs and circumstances of vulnerable patients are not taken into account. To that end, we ask that the Senators consider two overarching principles as you advance these efforts.

- *Efforts to improve transparency should take into account the unique needs of different patient populations, including patients with complex health needs.*  
Efforts to improve price transparency will not be equally effective for all populations. For example, these efforts are often irrelevant for patients who have little choice in their providers, such as patients with complex medical needs, people in plans with closed networks, and people who live in rural areas or areas with provider monopolies. People

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<sup>1</sup>Health Care Value Hub “Improving Value: Who’s the primary target of the intervention? It matters.” Altarum.  
<http://www.healthcarevaluehub.org/improving-value/who-target/>

with rare or complex health needs are likely to face limited choices of providers or treatment options for their condition. These populations also benefit most from care that is well coordinated and grounded in longitudinal relationships with care providers, so changing providers or treatment options to get the best price might actually be harmful for their health outcomes.<sup>2</sup> For people with physical disabilities, the accessibility of the provider's location (for example, is it wheelchair accessible) will likely matter more than the price of a service. The same is true of people with limited English proficiency, who will need to prioritize providers that offer reliable translation services and culturally competent care. Patients in rural or underserved areas may also find price transparency efforts irrelevant if they are not also paired with efforts to improve access to care in these areas. As you continue your work, we ask that you take into account the differing impacts these policies may have on vulnerable and complex patient populations.

- *The end goal of any efforts to improve transparency should be to empower consumers, not penalize them.* While we are supportive of increased transparency, we are strongly opposed to this increased transparency being used as a step towards implementing “consumer directed” health care models that limit consumers’ choice of providers, limit low income people’s ability to access the highest quality care, or expose consumers to increased out of pocket costs. Even with additional information available, many consumers, such as those with chronic illnesses described above, may find it difficult or counterproductive to “shop” for the highest value services or providers. Models of coverage and care that use financial penalties for consumers to make cost-conscious decisions are harmful for patients and often work counter to the goals of lowering costs and improving care. Studies have shown that even small out-of-pocket costs reduce access to care, especially for those with low incomes or chronic illnesses and in some instances lead to an increase in more costly modes of care such as emergency department visits.<sup>3</sup> As the Senate moves forward with its work, we ask that you explicitly oppose strategies that increase financial penalties for consumers.

### **Transparency and Consumer-Centered Quality Measures**

Even in situations where consumers are able to “shop” for care, the goal of consumer choice is meaningless without clear and meaningful information on quality. The drive towards higher value care in the U.S. involves not only lowering costs, but also improving outcomes by ensuring health care dollars are spent effectively on high quality services. Alongside price information, patients should have access to meaningful and easy-to-understand information about the quality of the provider they are considering. This should include patient experience and patient reported

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<sup>2</sup> Frandsen, Brigham D., et.al. Care “Fragmentation, Quality, and Costs Among Chronically Ill Patients.” American Journal of Managed Care. (May 14, 2015) <http://www.ajmc.com/journals/issue/2015/2015-vol21-n5/care-fragmentation-quality-costs-among-chronically-ill-patients>

<sup>3</sup> One study out of Wisconsin found that the addition of a \$10 premium for Medicaid beneficiaries made them more likely to exit the program. This study also found that it was the premium itself and not the amount of the premium that caused people to leave the program, showing that even small out of- pocket costs, like the ones implemented in Indiana, can significantly reduce access to care (Dague, 2014). A study of Oregon’s Medicaid enrollment following cost-sharing changes found similar results, with nearly half of program participants who were surveyed leaving the program following increases in premiums and copayments (Wright et al., 2005).

outcome measures (PROMs) that reflect outcomes meaningful to patients. A strong, consumer-centered quality strategy will be critical for transparency initiatives.

### **Transparency in coverage and benefits**

Consumers should be fully informed about how their coverage works and what their health care costs are so that they can make informed decisions. This information should be easily accessible and explained in a way that consumers can relate to, including common examples, interactive tools, and plain-language descriptions. Transparency of plan information – including ensuring plans provide up-to-date and accurate formularies and provider networks to both prospective and current enrollees – is critical to ensure that consumers have the information they need to choose the best plan. We urge Congress to take the following steps to protect and expand consumer protections and transparency in the following areas:

***Provider networks:*** In response to cost pressures, insurers are increasingly turning to narrow networks and high deductible plans to help restrain premium growth. As consumers navigate this new landscape, they need the right tools and information to choose a health insurance plan that best fits their medical needs and their household budgets. Provider directories are the primary tool available to consumers to determine whether the plan they are selecting has a narrow or broad network and to identify which providers are in their plan. As such, these provider directories should be accessible, accurate and comprehensive to consumers of all social and demographic backgrounds. We urge Congress to hold health plans accountable throughout the year for meeting network adequacy standards--not just at the time of certification. To strengthen current requirements concerning accuracy of provider directories and timely notices of network changes,<sup>4</sup> we urge Congress to require health plans to:

- Submit the criteria they use to select and classify providers into tiers along with provider lists to regulators for evaluation to determine whether the provider networks meet network adequacy standards;
- Keep provider directories easily searchable by tier, product, languages spoken by the provider, disability access, cost-sharing information and specialty and subspecialty providers.

Keeping provider directories accurate and accessible to consumers is not enough to help lower health care cost. Even when consumers do their research ahead of a scheduled service or procedure, they still may receive surprise medical bills. Over the course of two years, nearly one third of privately insured individuals nationwide received a surprise medical bill.<sup>5</sup> Surprise medical bills occur when patients are unknowingly treated by providers outside their health plan's contracted network; for example, an anesthesiologist providing sedation for a procedure or surgery, or a pathologist examining a patient's biopsy.<sup>6</sup> These bills can add up to hundreds or

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<sup>4</sup> 45 CFR §156.230; 45 CFR § 156.230

<sup>5</sup> Consumer Union (2015). Surprise Medical Bills Survey 2015 Nationally-Representative Online Survey. <http://consumersunion.org/wp-content/uploads/2015/05/CY-2015-SURPRISE-MEDICAL-BILLS-SURVEY-REPORT-PUBLIC.pdf>

<sup>6</sup> Kaiser Family Foundation (2016). The Burden of Medical Debt: January 2016 Results from the Kaiser Family Foundation/New York Times Medical Bills Survey. <https://kaiserfamilyfoundation.files.wordpress.com/2016/01/8806-the-burden-of-medical-debt-results-from-the-kaiser-family-foundation-new-york-times-medical-bills-survey.pdf>

thousands of dollars, leaving consumers with little recourse and potentially devastating medical debt. We urge Congress to put in place policies that protect consumers from surprise medical bills. At a minimum, consumers should be held harmless in these following situations: (1) unavailability of in-network providers for a covered service; (2) unexpected utilization of out-of-network care at an in-network facility for a covered service; (3) emergency care; (4) unexpected utilization of out of network care as a result of an inaccurate provider directory.

In the event where a consumer opts to receive care from an out-of-network provider, health plans should provide the consumer with advance balance billing notices that include an estimate of charges for that specific treatment if delivered by an out-of-network provider in comparison to the in-network rate.

***Formularies:*** Keeping prescription drug formularies accessible, comprehensive and easy-to-understand is critical as it allows consumers to make informed decisions about their coverage options. This is particularly true for millions of Americans living with chronic conditions who need access to life-saving medications. Under the Affordable Care Act, health plans have made progress in keeping their prescription drug formularies more accessible and accurate.<sup>7</sup> However, studies have found inconsistency in formulary format display and drug benefit terminology used across plans or insurers, and incomplete disclosure of drug benefit coverage and cost-sharing.<sup>8</sup> As a result, consumers are unable to make apples-to-apples comparisons amongst plans when selecting plans that suit their needs. In addition, many health plans made mid-year formulary changes that reduced drug coverage, moved a covered drug to a higher formulary tier or imposed higher cost-sharing.<sup>9</sup> To lower prescription drug cost for consumers, more can be done to increase the level of transparency of prescription drug coverage. We urge Congress to take the following steps:

- Require the use of standardized formulary display. Formularies should be electronically accessible, accurate and available prior to enrollment. Health plans should be required to publish complete formulary lists that include the full scope of information that a consumer may want to consider when selecting a plan (i.e. tiering structures and cost-sharing requirements for each tier, any restrictions on the manner in which a drug can be obtained, any drugs that are covered as a preventive service without cost-sharing, and coverage of over-the counter medications).
- Prohibit mid-year formulary changes that negatively affect consumer affordability and access to drugs. However, health plans should be allowed to add new products (including generics, biologics and biosimilars) at any time during the plan year.

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<sup>7</sup> 45 C.F.R. § 156.122(d)(1); 45 C.F.R. § 147.200(a)(2)(i)(L); 45 C.F.R. § 156.122(d)(2)

<sup>8</sup> Urban Institute (November 2015). Marketplace Antidepressant Coverage and Transparency. <https://www.urban.org/sites/default/files/publication/72911/2000509-Marketplace-Antidepressant-Coverage-And-Transparency.pdf>; National Partnership for Women & Families (Feb. 2015). Supporting Informed Decision-Making in the Health Insurance Marketplace: A Progress Report. <http://www.nationalpartnership.org/research-library/health-care/supporting-informed-decision-making-in-the-health-insurance-marketplace.pdf>.

<sup>9</sup> Karyn Schwartz (February, 2015). New Analysis: Midyear Formulary Changes in Marketplace Plans Can Significantly Reduce Access to Needed Medications for Patients. <https://catalyst.phrma.org/new-analysis-midyear-formulary-changes-in-marketplace-plans-can-significantly-reduce-access-to-needed-medications-for-patients>

While transparency in formularies is helpful for consumers when selecting plans, more can be done to improve affordability for consumers. Out-of-pocket spending on prescription drugs have decreased on average as a result of the implementation of the Affordable Care Act (ACA).<sup>10</sup> However, people with chronic conditions (such as cancer, digestive disease or mental illness) are likely to spend in excess of \$1,000 or more per year on prescription medications.<sup>11</sup> In a recent survey, the Kaiser Family Foundation found that one in four of those taking a prescription drug skipped doses or cut pills in half due to costs.<sup>12</sup> In addition to improving transparency in formularies, we suggest policies that reduce cost sharing for prescription drugs to improve affordability for consumers. Specifically, we recommend to:

- Cap cost sharing for prescription drugs at no more than \$150 per drug per month; and limit the total out-of-pocket spending for prescription drugs at a specific threshold.
- Eliminate pharmaceutical “gag clauses” that prohibit pharmacists from disclosing to consumers when they could save money by paying cash for their prescriptions instead of using their insurance. A recent study by The Leonard D. Schaeffer Center for Health Policy and Economics found that in 2013, consumers overpaid for their prescriptions 23 percent of the time, with an average overpayment of \$7.69 on those transactions.<sup>13</sup>

### **Transparency in provider billing and collections**

The ACA made important strides towards this goal by establishing new requirements<sup>14</sup> around fair, transparent billing for non-profit hospitals. But these protections don’t extend to other provider types.<sup>15</sup> Congress should continue to require HHS, the Internal Revenue Service, and other federal agencies to improve consumer protections and increase fairness and transparency with regard to provider billing and collections by:

- Broadly sharing information about hospital financial assistance policies (FAPs) on a publicly available, free searchable website such as [healthcare.gov](http://healthcare.gov).

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<sup>10</sup> Health Affairs (2016). Gaining Coverage Through Medicaid Or Private Insurance Increased Prescription Use And Lowered Out-Of-Pocket Spending.

<http://content.healthaffairs.org/content/early/2016/08/16/hlthaff.2016.0091#cited-by>

<sup>11</sup> Kaiser Family Foundation (2016). Examining High Prescription Drug Spending For People With Employer Sponsored Health Insurance. <https://www.healthsystemtracker.org/brief/examining-high-prescription-drug-spending-for-people-with-employer-sponsored-health-insurance/#item-start>

<sup>12</sup> Kaiser Family Foundation (2017). Data Note: Americans’ Challenges with Health Care Costs. <http://www.kff.org/health-costs/poll-finding/data-note-americans-challenges-with-health-care-costs/>

<sup>13</sup> The Leonard D. Schaeffer Center for Health Policy and Economics (2018). Overpaying for Prescription Drugs: The Copay Clawback Phenomenon.

[http://healthpolicy.usc.edu/documents/2018.03\\_Overpaying%20for%20Prescription%20Drugs\\_White%20Paper\\_v.1.pdf](http://healthpolicy.usc.edu/documents/2018.03_Overpaying%20for%20Prescription%20Drugs_White%20Paper_v.1.pdf)

<sup>14</sup> Community Catalyst (2015). Hospital Financial Assistance Policies: A Quick Reference Guide. <https://www.communitycatalyst.org/resources/publications/document/CC-Checklist-R2.pdf> and IRS: New Requirements for 501(c)(3) Hospitals Under the Affordable Care Act

<https://www.irs.gov/charities-non-profits/charitable-organizations/new-requirements-for-501c3-hospitals-under-the-affordable-care-act>

<sup>15</sup> Patient Advocate Foundation (2015). Patient Data Analysis Report 2015.

[http://www.patientadvocate.org/pdar/2015\\_PDAR.pdf](http://www.patientadvocate.org/pdar/2015_PDAR.pdf)



- Exploring options for expanding provider financial assistance and consumer protections against overcharging and problematic collections tactics to a broader range of providers, perhaps through accountable care organization (ACOs) requirements.
- Gathering data and studying the impact of provider billing and collection policies on medical debt. The Consumer Financial Protection Bureau has been doing groundbreaking research on the prevalence of medical debt and its sources, and that research should continue. This work has helped to inform and deepen understanding of how medical debt varies by geography, race, gender, insurance status, and income.<sup>16</sup>
- Expanding financial assistance and billing protections to all hospitals (regardless of ownership status) receiving Disproportionate Share Hospital (DSH) funds.

### **Transparency in prescription drug pricing**

High drug prices are a growing concern for many Americans: One in four of those taking a prescription drug reported skipping doses or cutting pills in half due to costs.<sup>17</sup> For millions of Americans with chronic conditions, access to affordable medications has been a persistent issue.<sup>18</sup> One of the main causes of high costs of prescription drugs is that pharmaceutical manufacturers have taken advantage of their patent rights to set introductory prices--often at excessively high levels-- and dramatically increase certain brand-name drug prices annually.<sup>19</sup>

Secondly, the pharmaceutical supply chain is very complex and involves various intermediary players (including wholesalers, pharmacy benefit managers, retailers, and private and public health insurance entities). The complex web of financial arrangements between these players create opportunities for profit taking at each transaction point and often lacks transparency.<sup>20</sup> To improve transparency in prescription drug pricing, we urge Congress to enact legislation that require pharmaceutical manufacturers to disclose a wide range of information, including: (1) Manufacturer prices offered to other payers; (2) Research and development costs including clinical trial costs; (3) Manufacturing costs; (4) Marketing and advertising costs; (5) Patient financial assistance and rebates; (6) Intellectual property status; (7) Acquisition costs; (8) Pay-for-delay settlements; (9) Regulatory approval costs; (10) State and federal tax benefits; (11) Off-shored profits and jobs; (12) Donations to patient disease advocacy groups; (13) Grants, subsidies and costs paid with public funds or by third parties. This information should be available to the public in a clear, straightforward and timely manner. In addition, pharmaceutical manufacturers should be required to provide advanced notices of price hikes to give time for purchasers to adjust formularies, negotiate price concessions or seek other alternatives.

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<sup>16</sup> Consumer Financial Protection Bureau (2014). Consumer credit reports: A study of medical and non-medical collections [https://files.consumerfinance.gov/f/201412\\_cfpb\\_reports\\_consumer-credit-medical-and-non-medical-collections.pdf](https://files.consumerfinance.gov/f/201412_cfpb_reports_consumer-credit-medical-and-non-medical-collections.pdf)

<sup>17</sup> Ibid. footnote 11

<sup>18</sup> Liz Szabo. "As Drug Costs Soar, People Delay or Skip Cancer Treatments." *NPR Shots*, March 15, 2017. <http://www.npr.org/sections/health-shots/2017/03/15/520110742/as-drug-costs-soar-people-delay-or-skip-cancer-treatments>

<sup>19</sup> Joseph E. Stiglitz. "Prizes, Not Patents." Project Syndicate, March 6, 2007. <https://www.project-syndicate.org/commentary/prizes--not-patents?barrier=accessreg>

<sup>20</sup> The Leonard D. Schaeffer Center for Health Policy and Economics (2017). The Flow of Money through the Pharmaceutical distribution System. [http://healthpolicy.usc.edu/documents/USC%20Schaeffer\\_Flow%20of%20Money\\_2017.pdf](http://healthpolicy.usc.edu/documents/USC%20Schaeffer_Flow%20of%20Money_2017.pdf)

### **Transparency in New Payment and Delivery Models**

Providing clear and accurate information to consumers is important in all aspects of the health care system, not just when it concerns health care prices or choosing private market plans. With the increase in integrated and risk-bearing delivery models, like Accountable Care Organizations, there is a need to ensure transparency around patient participation in these models. Patients should be fully informed of if and how they are being assigned to a new model of care and beneficiaries have a right to know about any new financial incentives that may influence provider behavior and the care that is delivered. Beneficiaries also need to fully understand what they can expect from these models, including attributes that differentiate them from the fee-for-service model, like care coordination, as well as what their rights are under these models and what the grievance and complaint processes are.

### **Transparency in Federal Decision Making Processes**

Finally, just as we believe consumers deserve access to clear and transparent information when it comes to their health coverage and care, consumers also deserve transparency around the federal policymaking processes that impact their care. We ask that the process for designing, testing and evaluating new health care initiatives, including but not limited to CMMI initiatives and 1115 waivers, be done in a transparent manner that includes opportunities for public input; and that related data and evaluations are made publicly available in accessible formats in a timely manner. Patients and other stakeholders should fully understand how federal decisions around health care impact them and have ample opportunity to provide input on this work.

We appreciate the opportunity to provide input on this important topic. Please do not hesitate to contact us at [dgarrett@communitycatalyst.org](mailto:dgarrett@communitycatalyst.org) should you have any questions or if you would like additional information.

Respectfully submitted,



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