



# Transparency in Health Care

A Priority Roadmap for Consumer Engagement





# Table of Contents

**Executive Summary** ..... 3

**Transparency in Health Care  
A Priority Roadmap for Consumer Engagement** ..... 6

Framing the Issues ..... 6

Specific Consumer Information Needs ..... 6

Opportunities to Better Support Consumer Choice in Health Care ..... 9

Action Steps to Improve Consumer Engagement ..... 14

**Conclusion** ..... 19

# Executive Summary

## Introduction

Consumers face a number of decisions about their health care – such as selecting a health plan, choosing a doctor, or determining a course of treatment – and they often make these decisions on the basis of inadequate information. As a result, consumers struggle in a number of ways.

First, they may not understand how choosing a health plan affects the financial burdens they face in getting the health care they need. Second, more than half of Americans are unaware of the large cost and quality differences that exist between providers in their area, and few know in advance what costs they will face from undergoing treatment, or how their choice of the doctor or hospital will affect their pocketbook or the quality of the outcomes.

Perhaps most important, patients are often ill-equipped to have a meaningful discussion with their doctors or other providers about which course of treatment would be best for them. Faced with these gaps in information, consumers may make poor choices that lead to unnecessary spending, lower quality care, and outcomes that aren't in line with their own goals and preferences.

Providing high-quality information to consumers through well-designed tools, as well as other resources to help them interpret that information, can address these issues and empower consumers to make superior choices. Having adequate information can also help to protect consumers from financial surprises, such as learning after the fact that a given provider is out-of-network and that treatment that has already been provided will not be covered by the insurer. The need to address the potential for unwelcome financial surprises is especially important as plans move toward increased cost sharing, narrower networks, and restrictions on pharmaceutical formularies.

Recognizing these issues, the Network for Excellence in Health Innovation (NEHI) interviewed experts, reviewed existing research and literature, and convened a panel of thought leaders. The process enabled NEHI to identify the most critical consumer information needs; evaluate how well current tools and resources are supporting consumers in making key choices; and propose specific recommendations for policymakers and other stakeholders to improve the availability of information, tools, and resources to support optimal health care decisions. This document summarizes the findings and recommendations presented in a longer [report](#), *Transparency in Health Care: A Priority Roadmap for Consumer Engagement*.

# Specific Consumer Information Needs

NEHI identified specific sets of information that consumers need when making key health care decisions (Figure 1). In general, consumers want cost, quality, and treatment information that is highly personalized to their situations, goals and preferences, and delivered at the point of decision-making.

**FIGURE 1.** Consumer Information Needs

CHOOSING A PLAN	CHOOSING A PROVIDER	MAKING A TREATMENT DECISION
<p>Estimate of total annual costs based on enrollee demographics and individualized health status including premiums, deductibles, and other cost sharing by service type</p> <p>Makeup of provider networks so consumers can quickly determine which plans include consumers’ desired providers</p> <p>Depth of provider networks – e.g. percentage of physicians within a certain radius that participate in each plan</p> <p>Prescription drug formularies and coverage levels by tiers, so consumers can quickly determine whether their medications will be covered, and their cost sharing obligations</p> <p>Consumer experience ratings</p> <p>Access to in-person help through a navigator or assistor</p>	<p>Total expected out-of-pocket cost for the episode reflecting plan negotiated rates and patient-specific cost sharing</p> <p>Summary quality ratings with option to access greater detail for measures in the following areas:</p> <ul style="list-style-type: none"> <li>• Patient safety</li> <li>• Patient experience</li> <li>• Outcomes</li> <li>• Adherence to evidence-based practices</li> </ul>	<p>Range of medically valid options and supporting evidence</p> <p>Potential risks and benefits of each option; concurrence with patient’s goals, preferences, and values</p> <p>Process for ensuring coverage (preauthorization requirements, etc.)</p> <p>Comparative out-of-pocket costs</p> <p>Complexity of treatment regimen</p> <p>Potential burden on patient and family members</p>

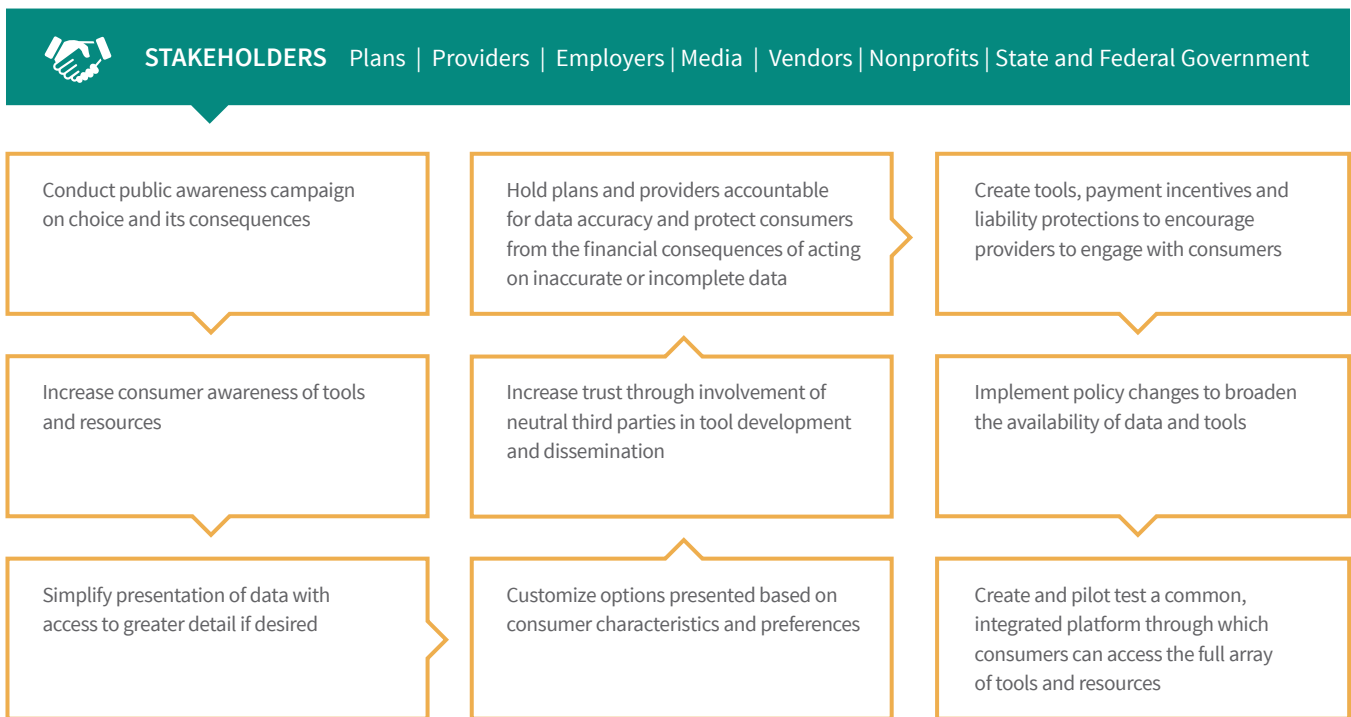
A number of key gaps must be filled to address these information needs. First, consumers need to be made aware that there is a range of choices they can make that will significantly affect the costs and quality of care that they receive. The existing tools that support consumer decision-making need to be improved, and consumers need to be made aware of these tools and encouraged to use them. Second, the information presented to consumers must be valid, credible, and tailored to their specific conditions, needs, and insurance coverage. All relevant stakeholders should make this information available so that it can be incorporated into decision-making tools. Third, providers must be engaged in helping consumers weigh treatment options including potential risks and benefits, concurrence with goals and preferences, and costs. Fourth, improvements in information availability and superior tools must be extended to all consumers, wherever they receive their care and whatever form of insurance they have, including none at all.

## Recommended Actions to Better Support Consumer Choice in Health Care

Tools and resources to meet these information needs are rapidly expanding, but much work remains to be done. Information must be conveyed in a manner that is more relevant to consumers' unique situations, and made available at the point of decision-making. All stakeholders – health plans, public and private payers, creators of transparency tools, and others – must work to improve the accuracy, ease of use, and accessibility of information and tools for all types of consumers. Additionally, stakeholders should also work together to increase consumer awareness of choice in health care, and how different choices can vary considerably in terms of cost, quality, and concurrence with goals and preferences. It is important for public policy to support these goals by providing financial support for development and implementation of new tools and resources. Where appropriate and desirable, policies may be needed to make certain that stakeholders provide consumers with the information they need.

Specifically, NEHI's research identified nine recommendations for stakeholders to improve consumer access to information necessary for optimal health care decisions (Figure 2).

**FIGURE 2.** Action Steps to Better Support Consumer Decision-Making



Although much of the onus to better engage consumers in decision-making will necessarily fall on health plans and providers, policymakers can play a key role in making sure that consumers can get the information they need. Specifically, policymakers can encourage the dissemination and implementation of best practices for creating meaningful transparency tools; implement protections for consumers who make decisions based on inadequate or inaccurate information; build on existing tools at the state and federal level; and incorporate incentives for providers in value-based payment arrangements to support shared decision-making with patients. Research compiled by NEHI suggests that these initiatives could lead to better quality of care, greater consumer satisfaction, and far better use of the nation's health care resources.

# Transparency in Health Care

## A Priority Roadmap for Consumer Engagement

### Framing the Issues

People need basic information about quality and costs to make critical decisions about their health care, but all too frequently that information is lacking. Although vast quantities of information are gathered, curated, and provided to consumers in other aspects of their lives – for example, in online shopping services such as Amazon.com – it is far harder for them to gain access to or understand details of their health coverage or health care. Picking a health plan, determining the quality and cost of their health care providers, and understanding the choices they face in undergoing different types of medical care, all constitute major information challenges for consumers. These challenges are arguably growing as both health care and insurance choices become more complex, and as consumers bear a heftier share of the cost of care.

The Network for Excellence in Health Innovation (NEHI) sought to identify the most critical information needs that consumers have when choosing their health plans, providers, and treatment options. NEHI also evaluated how well current tools and resources are helping consumers make these choices and identified specific recommendations for policy-makers and other stakeholders that would result in meaningful improvements to transparency initiatives to better support individuals in making optimal health care decisions.

To accomplish these goals, over a four month period NEHI reviewed existing research and literature; interviewed over 30 experts representing consumers, researchers, plans, and providers; and convened an expert panel to identify issues and propose solutions. This report summarizes conclusions reached from this work.

### Specific Consumer Information Needs

In surveys, consumers say that they are particularly interested in improving their ability to determine the level of out-of-pocket costs that they may incur; to find an in-network provider; to find a plan that covers their prescription drugs; and to obtain help in choosing a treatment option.<sup>1</sup> Accomplishing any of these objectives involves considerable complexities for consumers.

#### Choosing a Health Plan

Testing by Consumers Union found that individuals struggle to make sense of their health insurance options and dread going through the annual process of choosing a plan.<sup>2</sup> These feelings often drive consumers to take shortcuts that can lead to suboptimal choices.

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When available, however, consumers will use well-designed online tools that explain key terms in plain language and offer simple side-by-side comparisons of key plan parameters. These key “choice criteria” include total annual cost of the plan to an individual or family, combining premiums and out-of-pocket spending; cost sharing by service type, such as for an outpatient physician visit or hospitalization; composition of plan provider networks; contours of prescription drug formularies; and ratings of consumer experience. Ideally, the information provided to assist consumers should be customizable for an enrollee’s demographics and health status. For example, an older adult with multiple chronic conditions, and multiple providers, has different information needs than does a younger, comparatively healthier person.

In addition, some consumers want even more details than others, and appreciate the ability to delve more deeply into plan quality ratings, coverage rules and limits, and other plan features that are discussed more fully below. Even with tools that greatly simplify the presentation of information, however, other consumers will still need access to trained navigators or assistants who can guide them through the options.

### **Choosing a Provider**

As discussed more fully below, consumers are generally not aware of the enormous variations in both quality and pricing within health care. Nonetheless, tools to assist consumers in choosing providers based on price and quality have proliferated. Public payers, health plans, employers, and other purchasers recognize the importance of engaging consumers in seeking high value care, and are increasingly offering tools and resources that present both price and quality data for providers in their networks.

The highest priority information need for consumers in choosing a provider is an estimate of the total out-of-pocket costs for a *given episode of care* – not just the price for a *discrete procedure*. For example, a person undergoing joint replacement surgery needs to understand the costs of the entire episode, from preparation for surgery all the way through to rehabilitation, rather than just the cost of the surgery itself. The episode price should reflect the negotiated reimbursement rate between the plan and the various providers involved, as well as the consumer’s specific cost-sharing responsibility.<sup>3</sup>

Consumers also want to know which providers offer the highest quality care. “Quality” incorporates measures of patient safety, such as rates of hospital acquired infections; patient experience, such as what percentage of patients would recommend a particular provider; outcomes, such as mortality rates; and adherence to evidence-based practice, such as the percentage of heart attack patients receiving clot-busting drugs within 30 minutes of arrival in the emergency department.

However, some consumers want the ability to access even greater detail about quality. For them, it is critical to provide clear explanations of what is being measured, how and by whom. For example, clarity and understanding can be enhanced by taking such steps as substituting simple language like “blood clot” for “thrombosis;” clarifying whether the measure has been derived from patients’ health records, claims data, or some other source; and noting whether the measure has been validated by an independent entity such as the National Quality Forum.



## Choosing a Treatment

Patients’ individual preferences for different outcomes, and the tradeoffs they may be willing to make in risks versus benefits, should clearly be part of treatment decisions. But physicians often fail to inform patients that there are multiple treatment options.<sup>4</sup> As knowledge increases about the underlying genetic and other differences among patients – and differences in the genetic and other signatures of their diseases – the importance of making patients aware of their treatment options also grows.

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But simply providing information and evidence for patients to evaluate on their own is not sufficient. Instead, providers need to engage patients in conversations to review options and evidence; to talk through the risks and benefits of treatment options; and to discuss these in the context of patients’ and families’ goals and preferences. These shared decision-making tools and strategies are discussed further below.



## Opportunities to Better Support Consumer Choice in Health Care

### Increase Awareness of Choice and its Consequences

Consumers face many knowledge gaps as they try to navigate the health care system. Arguably the most critical is a lack of understanding that they have choices and that because of the considerable variation within all aspects of care and coverage, these choices can make a significant difference in terms of cost, quality, and outcomes. Some of these choices may only become more critical and complex for consumers in the future, especially if there is less standardization of health plans, more reliance on health savings accounts, or other changes that will affect the already complicated status quo.

Health care is expensive, and although health insurance premiums are growing more slowly than in prior decades, they are high and rising.<sup>5</sup> At the same time, patients' out-of-pocket, cost sharing obligations – the deductibles and coinsurance that they pay on top of premiums – rose from an average of \$422 per year in 2004 to \$747 in 2014.<sup>6</sup> Such trends reinforce the importance of helping consumers understand their choices and how these choices differ in terms of cost and quality.

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A 2015 nationally representative survey showed that 57 percent of insured Americans and 47 percent of uninsured Americans were unaware of the wide price variation that occurs among local providers for the same service.<sup>7</sup> Many consumers also harbor the misperception that all providers offer high quality care when, in fact, measures of process, outcomes, and patient experience can vary widely. And when confronting the need for treatment, patients often believe there is a single “right” course of treatment even when multiple valid medical options exist. In sum, the gap between the reality of health care and health coverage, and consumers' perceptions of it, is vast, making it a ripe area for new approaches that can better educate consumers and assist them in understanding their choices.

### Promote Awareness and Use of Tools

Although many tools have already emerged to help consumers in making a range of health care decisions, awareness and use of these tools is low. For example, a highly rated web-based tool developed by the state of New Hampshire provides comparative information on out-of-pocket costs for various episodes of care under different health insurance plans, but early evaluations have found that only one percent of state residents have used it.<sup>8</sup> Similarly, only 2.4 percent of eligible enrollees used Aetna's Member Payment Estimator – a web-based tool that provides real-time, personalized, episode-level price estimates – in its second year.<sup>9</sup>

Quality ranking tools are also little used, with consumers in focus groups reporting that the information provided does not address their concerns and is not presented in a consumer-friendly manner.<sup>10</sup> And, as noted above, providers rarely engage in shared decision-making with patients to jointly review medical evidence about different treatments and patients' own preferences about care and outcomes.<sup>11</sup>

Part of the reason for low use of all of these tools is lack of usability and relevance of the tools themselves.<sup>12</sup> For example, very few tools provide quality data on physicians at the procedure level, and many of the pricing tools provided by states present charge data rather than the rates negotiated by insurers that would actually be reflected in a patient’s medical bill. A recent evaluation of state tools to help with provider choice based on data sources, content and usability gave only three an A grade out of 49 rated.<sup>13</sup>

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### **Recognize Variation in Cognitive Ability and Health and Math Literacy**

Consumers also struggle to make sense of the complex information needed to weigh plan, provider, and treatment options, which generally involve multiple features, costs and benefits. Consumers can have cognitive limits in their ability to process information, especially when it involves comparing options with multiple and variable features. Faced with this challenge, many consumers will take shortcuts – for example, selecting a health plan mainly because they recognize the brand name of the insurance company – or choose not to make a decision at all.

Many consumers also lack basic health literacy, defined as the degree to which they have the capacity to obtain, process, and understand basic information needed to make appropriate decisions regarding their health. A major 2004 study by the then-named Institute of Medicine estimated that nearly half of all American adults – 90 million people – had difficulty understanding and using health information.<sup>14</sup> What’s more, data from the National Literacy Survey show that about half of consumers lack the basic mathematical skills necessary to interpret numbers that are embedded in written materials.<sup>15</sup> For example, consumers may not understand the implications of having to pay a percentage of the cost of each service (“coinsurance”) versus a flat dollar amount (“copayment”). These findings have significant implications for the way data are presented in tools to support consumers across the spectrum of decisions they face in health care.

### **Develop Specific, Valid, and Credible Information**

When consumers evaluate information in the context of health care decision-making, the information must be specific to their situation, and they must trust the sources of information provided. However, quality and cost information can be imperfect: confusing at best and suspect at worst.

The tools that are most useful in helping consumers gauge costs calculate their out-of-pocket costs by coupling the payment rates that have been negotiated between payers and providers with consumers’ specific cost sharing liabilities. For example, Aetna’s Member Payment Estimator provides the expected amount that the patient would have to pay different providers, accounting for both the negotiated payment rates and cost

sharing. Some other decision-making tools, however, merely provide an average payment amount across all health plans, and do not feature the specific payment amounts that have been negotiated by individual plans and the specific cost sharing requirements faced by enrollees.

Quality ratings can be equally unhelpful, in part because different rating schemes will often yield different results. For example, an analysis of five hospital quality assessment tools found that they each used different measures, patient populations, and reporting periods, and thus produced different rankings for any given diagnosis.<sup>16</sup> With results varying as widely and as often as they do, quality ratings can be confusing or even suspect for consumers.

Who or what is making the quality data available to consumers also matters. The 2015 National Health Care Trust Survey, undertaken by the MassINC Polling Group and published by PARTNERS+simons, shows that although consumers place high levels of trust in their providers, only 49 percent of consumers say they trust their insurance plans.<sup>17</sup> In general, many consumers worry that plans, and even employers, present information in such a way so as to steer them to the lowest cost options rather than the highest quality ones.

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## Health care decisions that are based on inaccurate or incomplete data can be hazardous for patients.

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Decision-making tools also can be biased depending on the source, such as when information is provided by an entity that stands to gain financially by the choice of a particular treatment option. For example, a decision aid to support a patient in deciding whether to have a hip replacement or continue with physical therapy could be biased if development of the decision aid was funded by the manufacturer of the hip implant.

### **Ensure that Information is Accurate, Complete, and Current**

Health care decisions that are based on inaccurate or incomplete data can be hazardous for patients. Multiple studies have found inaccuracies in provider directories that are published by health plans. Physicians or other providers may be presented as in-network when, in fact, they are not participating in the plan or accepting new patients. Provider phone numbers or locations may be inaccurate.<sup>18</sup> Consumers may wind up picking the wrong health insurance plan for themselves as a result, or may be forced to switch providers to avoid high cost sharing amounts for going out-of-network.

What's more, neither health plans nor providers typically disclose to consumers that even if they use a particular preferred provider such as an in-network hospital, the plan may not cover the full complement of providers involved in the care episode, such as anesthesiologists or radiologists. One recent study found that although 99 percent of emergency department visits were to in-network hospitals, 22 percent of them involved out-of-network physicians.<sup>19</sup> Although more than a dozen states, such as New York and Texas, have taken steps to protect consumers from the financial consequences of the "surprise bills" that ensue from such out-of-network care, many others have not.

Health plans' prescription drug formulary information can suffer from deficiencies as well. A study by the American Cancer Society Cancer Action Network found that 27 percent of a sample of qualified health marketplace plans offered on the Affordable Care Act health insurance marketplaces provided cost sharing information for cancer drugs in web-based tools that did not match the information in other plan documents.<sup>20</sup> The information that health plans provide consumers can also omit important information about drugs that are covered under the medical benefit, as opposed to the pharmacy benefit, such as many injectable medications for cancers or other conditions.<sup>21</sup>

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### **Engage Providers in Helping Consumers Weigh Treatment Options**

One of the most trusted sources of information in making health care decisions is the consumer's physician or other care provider, but these individuals are not currently trained, rewarded, or equipped with the necessary information to help their patients make high value decisions that accord with their preferences. As a result, shared decision-making in U.S. health care remains more the exception than the rule. In a study of more than 1000 office visits in which more than 3500 medical decisions were made, fewer than 10 percent of decisions met the minimum standards for informed decision-making.

When it comes to discussing treatment costs with patients, many providers are especially ill-equipped. Some may not know which health plans patients are enrolled in and what out-of-pocket costs they face for treatments; others may believe that it is inappropriate to discuss cost, and patients may be reluctant to bring up the subject.<sup>22</sup>

In discussing treatment options, many physicians may automatically assume a more paternalistic role, and may unconsciously impose their own values, biases, and preferences to steer patients in particular treatment directions. Physicians may also lack the training to engage in shared decision-making with patients, or the time to do so. Meanwhile, patients often avoid questioning their physicians because they believe that they lack the necessary knowledge to engage in conversations about treatment options, or have a fear of being labeled "difficult."<sup>23</sup>

What's more, in health systems in which payment is still mainly conducted on a fee-for-service basis, little incentive exists for providers to undertake a process that might lead to the provision of less care. For example, Group Health found that the use of shared decision-making with patients eligible for hip and knee replacements lowered the rate of surgery, as patients and their providers jointly agreed to forego or postpone surgery in favor of other interventions, such as weight loss to relieve joint pain. As a result, the health plan saved 12 to 21 percent for those patients.<sup>24</sup> Avoiding surgery can benefit providers operating in a capitated system like Group Health, but constitutes lost revenue in the more typical fee-for-service environment.<sup>25</sup>

A range of shared decision-making tools have become available in recent years to help clinicians communicate the risks and benefits of viable treatment options and help patients sort through which best meet their goals and preferences. These include, among others, those produced under the Wiser Choices Program at the Knowledge and Evaluation Research (KER) Unit at the Mayo Clinic and the Center for Shared Decision Making at Dartmouth-Hitchcock Medical Center. Federally-funded research agencies, including the Agency for Health Care Research and Quality, have also developed tools to support patient and provider decision-making.<sup>26</sup> What's more, under a provision of the Affordable Care Act, the Medicare program is now testing two new Beneficiary Engagement and Incentives Models of care delivery, known as the Shared Decision Making Model and the Direct Decision Support Model.<sup>27</sup>

Research has shown that the use of shared decision-making tools and processes has tangible benefits to patients and the health care system as a whole. A comprehensive review of 86 studies found that patients who used decision aids had a greater knowledge of their illness and treatment options, more accurate assessments of risk, and a greater probability of receiving care aligned with their goals and preferences.<sup>28</sup> Although all shared decision-making tools must continually be updated as medical evidence changes, it is clear that many have been developed, and their broader use throughout the health care system should be actively incentivized and encouraged.

### **Make Decision Tools Available to All**

Despite the rapid expansion of tools and resources available to support consumer decision-making in health care, some segments of the population only have access to substandard tools or lack access to tools altogether. Although federal and state governments have created tools to support the purchase of qualified health plans on insurance exchanges, as well as Medicare Part D plans, most of the millions of individuals in employer-sponsored plans and Medicare Advantage still must wade through complicated written materials and look at each plan network and formulary separately.

It also bears noting that some 20 million or more in the United States remain uninsured, and may face full charges from providers rather than rates that are negotiated with those providers by health plans. With few if any tools to assist them in sorting through quality and cost issues, only rarely can such individuals obtain information in a way that would help them make decisions about their health care.

### **Consolidate Information**

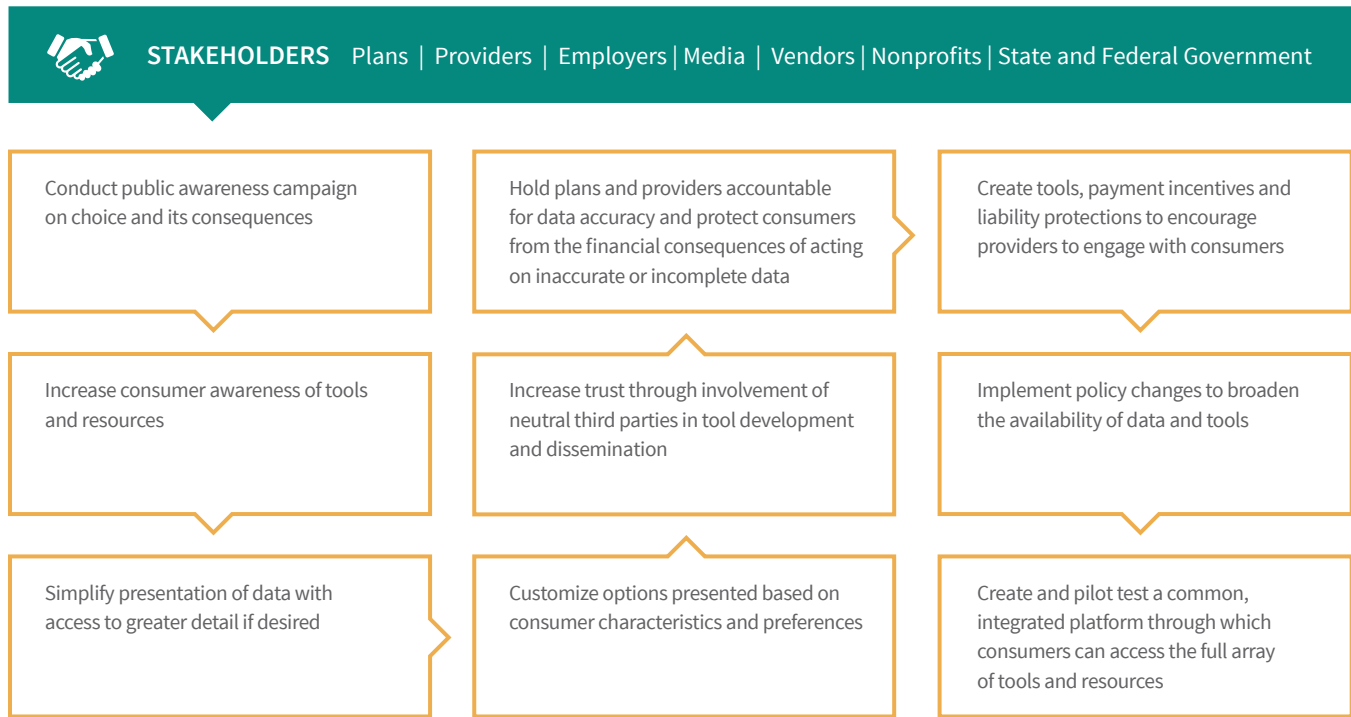
The information that consumers need to support choosing plans, providers, and treatment options is currently spread across multiple sources and types of tools, whereas, in reality, many of these decisions can be interlinked. A patient whose genetic profile shows her to be at high risk for breast cancer, for example, may want to pick a health plan on the basis of which providers are in-network; what her out-of-pocket costs might be for going out of network; and what treatment options would be covered. Seldom is such information readily available in one place, or at the time that a consumer might most want it.

For example, tools that present quality and cost information on the physicians in a plan's network are typically only provided once the consumer has enrolled in a plan, even though such information should be key criteria in plan selection. Measures of network adequacy – for example, how many physicians in a given specialty are covered by a plan – can be hard to discern in the information provided by many health plans during open enrollment. As a result, for patients with multiple chronic illnesses or high-cost conditions, few if any existing tools will provide all the information they might want at the time they need it, to make a fully informed decision in picking a health plan.

## Action Steps to Improve Consumer Engagement

NEHI’s research identified nine specific opportunities for improving the tools and creating other resources for supporting and engaging individuals in making health care decisions (Figure 2).

**FIGURE 2.** Action Steps to Better Support Consumer Decision-Making



- 1 Health plans, providers, employers, the government, media, and non-profit organizations (e.g. The Clear Choices Campaign) should collaborate on a public education campaign to promote awareness of the fact that choices exist in health care and that there are potential consequences to these choices.**

Increasing awareness of variation, choice, and the potential consequences will require a multi-pronged educational effort by stakeholders across the spectrum of health care. Some examples of efforts that could be expanded or replicated are as follows:

- A number of large health insurers have provided claims data to the Health Care Cost Institute, a non-profit entity, that has in turn published studies highlighting price variation within and across markets.<sup>29</sup> These and other studies could be publicized further.
- General Electric (GE) promotes a suite of tools to help its employees understand plan, provider, and treatment choices. Multiple avenues are used, including educational sessions during open enrollment, electronic communications targeted to specific employee needs, and individual in-person assistors. More employers could replicate GE’s approach, and comparable suites of tools could be developed and made available to people who work for smaller businesses and may not have access to such sophisticated tool sets as GE’s.

- The Choosing Wisely Campaign, an initiative of the American Board of Internal Medicine Foundation in partnership with *Consumer Reports*, has developed patient-friendly materials based on medical specialty societies' recommendations that doctors and patients should question the need for certain procedures. Such efforts to engage patients in decision-making around procedures and tests that have a high rate of overuse, and that may be unnecessary or even harmful, should be expanded.<sup>30</sup>

**2 Health plans, providers, government, employers and others must increase efforts to make consumers aware of the full array of tools and resources available to support decision-making and increase their utility by targeting information to the individual's specific needs at the point of decision-making.**

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Health plans, employers, providers, and others need to refine and improve the decision-making tools available to consumers, and do more to make consumers aware of them. Decision-making tools must meet consumers' desire for information that is tailored specifically to them and their needs. For example, tools should be able to present information customized to individuals' unique health status and demographics, such as differentiating between a young active candidate for a hip replacement and one who is elderly and more sedentary.

Health plans and employers also must not simply promote provider selection tools at the time of open enrollment, but should also push them to consumers at various points of decision-making – for example, when a patient is referred for specialty care and needs to know more about choices among specialists and treatment options. Otherwise, consumers often forget that the tools are available or how to use them when they need them.

Finally, providers need to be educated in shared decision-making processes, make decision aids available to patients, and engage them in dialogue about their options. Group Health employed multiple approaches to educate physicians in how to engage patients in shared decision-making processes and reinforced the positive impact of using these tools by reporting data back to physicians on tool use and associated changes in service use.<sup>31</sup> In addition, one of the most important aspects of the development of shared decision-making tools is user testing to make sure patients come away from the process with a clear understanding of the options and their risks and benefits, and that the ultimate decision is congruent with their goals and preferences.

**3 Tool developers across the spectrum should structure consumer tools to account for the wide range of consumer sophistication in terms of health and math literacy when presenting data.**

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As noted above, evaluating options in health care often involves sorting through numbers and multiple decision criteria – for example, weighing whether it is better to have a lower premium and higher cost sharing (deductibles and coinsurance), or vice versa. Consumers also may stumble over information that seems to be conflicting – for example, when a hospital has earned an “excellent” rating on patient satisfaction, but is also shown to have a high rate of complications.



Tool developers must take these complexities and the impact on consumers into account by simplifying the presentation of data as much as possible. The most effective plan chooser tools, such as the one built by *Consumer Checkbook* to support the Missouri exchange, provide a single cost estimate for each health plan that combines both premium and cost sharing responsibilities. This number reflects health and demographic characteristics – such as age, self-reported health status, and whether the individual is a smoker – entered into the tool by the user. The tool also provides a graphical presentation of network depth, showing a bar comparing the percentage of physicians that are in-network within a certain geographic radius across health plans.<sup>32</sup> However, despite the advanced metrics that *Consumer Checkbook* takes into account, it does not use personalized prescription drug usage to generate the cost sharing amounts in its out-of-pocket cost estimate. This fact underscores that there is room for improvement even in highly rated existing consumer tools.

An area of uncertainty that may call for further research is how best to combine information for consumers about providers' prices and quality. The highly rated state tools created by New Hampshire and Colorado have separate sections for price and quality information and no combined representation of "value."<sup>33</sup> According to the Catalyst for Payment Reform's specifications for provider choice tools, price and quality information should at a minimum be presented on the same page, but ideally combined into a single measure of value. However, value is an elusive concept for many consumers, who may associate the word "value" with inferior care. Further testing and analysis of different approaches in communicating cost and quality information is warranted.

Research has shown that consumers respond best to simplified presentations using "word-icons" that combine shape, color and text to quickly convey information.<sup>34</sup> An example would be the typical presentation of product ratings in *Consumer Reports*, or a "traffic light" scheme that labeled choices as red for stop, yellow for caution, or green for go.

4

**To help consumers and their providers personalize their health care decisions, tool developers should allow consumers to easily refine and sort the options based on their demographic profiles, health status, and expressed preferences.**

As noted previously, health care is becoming increasingly individualized, particularly with the advent of treatments tailored to patients' specific genetic characteristics or to the underlying genetics of their disease. Tools to support shared decision-making must account for not only patients' different physical characteristics, but also their specific needs and preferences.

One approach that tool developers could consider using is Multiple Criteria Decision Analysis (MCDA) to create support and structure for decision-making.<sup>35</sup> This technique can be used to personalize the options presented to those that best meet consumers' expressed preferences, health status and demographic characteristics.

For example, a shared decision-making tool could be devised that would display treatment options based on patients' preferences for specific outcomes, their desire to avoid adverse events, a given treatment's impact on their work productivity, and their projected out-of-pocket costs. A similar approach can be used for picking health plans. Plan options could be offered to consumers that include their physicians of choice and be sorted by total annual expected cost – as does the tool described above for Missouri's health insurance exchange. Provider choice tools can also display provider options by the distance that consumers say they are willing to travel, and then sort them by which ones offer "high value" care.

5

**Plans and providers can enhance consumer trust in tools by increasing the role of the federal and state governments; neutral third parties, such as the National Quality Forum; and others in providing, certifying, and evaluating tools.**

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As noted above, tools and information can lack credibility with consumers, depending on the source and the associated potential for bias. These issues are often addressed when tools are provided by reliable sources like states or the federal government, or in partnership with trusted media.

For example, the state of New Hampshire has developed a well-regarded tool that provides estimates of episode costs based on claims data that health plans are required to report to the state’s all-payer claims database.<sup>36</sup> The Federal Employee Health Benefit plan has contracted with *Consumer Checkbook* to provide its plan chooser tool, as have a number of state exchanges.

In the case of information about quality, using measures endorsed and/or provided by the National Quality Forum, the Centers for Disease Control and Prevention, or the Joint Commission, ensures comparability across providers and credibility. With respect to decision aids and other shared decision-making tools, Washington State has adopted a certification process for the tools that can serve as a model for other states.<sup>37</sup> Decision aids are submitted to the state health authority for initial review and then passed to an expert panel for final approval as appropriate. This process was developed with multi-stakeholder input, and built on work from the International Patient Decision Aids Standards Collaborative.

Regardless of the source of the data, credibility can also be enhanced by consumer engagement in tool development and user testing. Consumers often have different needs and priorities than what tool developers initially assume.

6

**Federal and state governments should develop accountability mechanisms to ensure that information provided by plans and providers is accurate, complete, and up-to-date.**

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Laws in place in states such as New Jersey and Washington require health plans to conduct regular reviews and updates to ensure that provider directories are accurate. Some states offer consumers protections from surprise bills – for example, California and Florida prohibit physicians from “balance billing” patients for emergency care (i.e., the practice of billing out-of-network patients any differences between what the plan is willing to pay and the providers’ full charges.) Colorado goes even further by requiring health plans to cover the care provided by non-network providers in an in-network facility as if they were also in-network, and thus hold their members harmless in both emergency and surprise billing situations.

New York has surprise billing protections on top of strict disclosure rules that require health plans to maintain accurate and regularly updated provider directories and provide clear statements and examples of how bills are calculated. New York also requires hospitals to provide lists of the plans they participate in, and to indicate whether their employed or contracted physician groups participate in these plans. Also, at the point of scheduling a hospital service, New York physicians must disclose whether the other physicians involved in providing care accept a given patient’s insurance.<sup>38</sup> More such protections are arguably needed at the federal and state levels.

7

**Public and private payers, providers, governments, and non-profit organizations need to work together to create a suite of tools, payment incentives, and liability protections, to encourage providers to engage in shared decision-making with patients on treatment decisions.**

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Health care systems, along with medical schools, specialty societies, and other organizations that provide continuing medical education, should give doctors and their staffs training and resources to engage with patients in making high value health care decisions. Public and private payers can also promote shared decision-making by incorporating into value-based payment programs various National Quality Forum (NQF)-endorsed measures, as they become available, that are related to the use and quality of shared decision-making processes. These measures will seek to capture patients' level of knowledge of their conditions and the options for treating them, as well as the degree to which their treatment goals were met.

To further incentivize use of shared decision-making tools and processes, state governments and medical malpractice insurers can provide liability protections and liability insurance premium discounts to providers who use certified decision-making tools. Although the legal framework to support shared decision-making is still in its infancy, some states have made progress. For example, in addition to legislation that supports the certification process described above, Washington State extends certain legal protections to physicians whose patients sign an acknowledgement that patient decision aids were used during the signing of informed consent documents prior to treatment.

8

**Tool developers including health plans, federal and state governments, and commercial vendors, should take action to broaden the availability of high quality tools and resources across different segments of the population.**

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The Affordable Care Act's creation of qualified health plans and insurance marketplaces gave rise to "plan chooser" tools designed to help consumers shop for health plans. Lessons derived from this experience should now be applied by public and private payers across different insurance markets, regardless of potential legislative changes to the ACA. These lessons include the need to have formularies and provider directories that are integrated into the tools supporting easy comparisons across plans; the provision of a single annual cost estimate incorporating both premiums and a personalized estimate of cost sharing; and a "sorting" and screening mechanism that filters the number of options presented to only those that best meet the consumer's needs. Creating a federal data hub of standardized plan information could support the development of plan chooser tools to serve a broader range of consumers, beyond those who have access to exchange plans.

Although the negotiated rates between plans and providers are the basis of information provided to consumers in many plan tools, requiring or otherwise incentivizing plans and providers to disclose this information could improve its accuracy, as well as its availability to states and independent tool developers. In the past, health plans resisted these disclosures, arguing that the proprietary discounts they negotiated with provider networks give them a competitive edge. However, many plans are now contributing data that is incorporated into the tools of states, non-profits such as the Health Care Cost Institute, and private vendors such as Castlight.

The all-payer claims databases that form the basis for many state pricing transparency tools could benefit from federal standards and submission requirements, which would make it easier for health plans that operate in multiple states to submit data and could bring in data from self-insured employers (since the U.S. Supreme Court has ruled that individual states cannot compel employer-sponsored plans to submit this information).

Finally, although the federal government and many states have laws requiring pricing transparency for hospitals, these laws need to be expanded to apply across the spectrum of provider types. The information also must be made more accessible, particularly to uninsured populations who may have no other sources from which to obtain it.

**9 Public and private payers should work with tool developers to create and pilot test a common, integrated platform, through which consumers can access a full array of tools and resources to support choices of health plans, providers, and treatments.**

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Plan enrollees are not the only ones to gain from better access to the information they need to make high value decisions that meet their goals and preferences. Good decisions also benefit public and private payers by leading to lower costs, higher quality of care, and increased satisfaction. An integrated suite of tools and resources would accommodate the fact that choices regarding plans, providers, and treatments are interrelated.

A form of “one stop shopping” would lessen an individual’s confusion about where to go for information. Optimally, such a tool would be designed to push information out to consumers when an inquiry or claim indicates a specific need. For example, a diagnosis of asthma and a prescription for an asthma drug, could trigger the provision of information on treatment options and self-management strategies. In turn, at the next open enrollment period, an enhanced decision-making capacity could point a patient to health plans or providers with particularly high ratings for asthma treatment.

As noted above, some payers, purchasers, and employers, such as General Electric, have moved in this direction, but many others have not. Medicare, for example, has distinct websites for plan choice, provider quality, and provider price, and with the exception of the new models that are testing approaches to shared decision-making, no across-the-board support for treatment choice. Most of the rest of the health care system does not afford any comprehensive or integrated decision-making supports to consumers.

## Conclusion

High quality tools and resources can empower consumers to make health care choices that produce superior results and match their individual needs, preferences, and values. Adequate information also helps to protect consumers from unexpected out-of-pocket costs, an imperative as plans move towards narrower networks and formularies.

The availability of tools and resources to support plan, provider, and treatment choice is rapidly expanding, but much work needs to be done. Information must be made more relevant to consumers’ unique situations. The accuracy, ease of use, and accessibility of information among all types of consumers must be improved. A multi-stakeholder educational campaign is needed to increase consumer understanding of choice in health care. Mechanisms should be developed to push tools out to consumers at the point of decision-making.

Although many of these tasks will necessarily fall to health plans and health care providers to accomplish, policy-makers can support these efforts as well. They can encourage the dissemination and implementation of best practices for creating meaningful transparency tools; implement protections for consumers who make decisions based on inadequate or inaccurate information; build on existing tools at the state and federal level; and incorporate incentives for providers in value-based payment arrangements to support shared decision-making with patients. These initiatives would arguably lead to better quality of care, greater consumer satisfaction, and far better use of the nation's health care resources than a system that leaves millions of Americans effectively in the dark.

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## About NEHI

NEHI is a national nonprofit, non-partisan think tank and membership organization focused on enabling innovations that lead to better health care, smarter spending, and healthier people. We count nearly 100 premier health, health care and health services organizations among our members, including patient groups, hospitals and health systems, health plans, employers, universities and companies in the pharmaceutical, biotechnology, medical device, health technology, and health services sectors. We offer a unique forum for our members to confer across sectors and collaborate on solutions to some of the toughest issues in health and health care. We conduct independent, objective research and thought leadership to move ideas into action within the policy realm and the private sector. Our membership informs our work, and our work informs our members, setting the stage for constructive change.

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