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RESEARCH BRIEF NO. 18 | MARCH 2017

Consumer-Centric Healthcare: Rhetoric vs. Reality

From patient-centered care to consumer-directed health plans, changes in the delivery, financing, and organization of healthcare and health coverage are increasingly touted as consumer- or patient-centered. But does today's system accurately reflect consumers' true needs and preferences? Have consumers and patients been actively engaged in the development, design, and implementation of these insurance products and delivery system reforms? How can we elevate and validate the voice of the consumer while separating out efforts intended to increase the market share, or bottom lines, of financially vested interests?

As this backgrounder shows, across the continuum of consumer healthcare engagement, we rarely cater to what consumers really want and need. To truly claim the mantle of consumer-centric, stakeholders and interested parties must meet consumers where they are, realize the limitations and barriers many consumers face, and actively work to reduce the consumer's burden of interacting with the health system.

This paper introduces an overarching framework for thinking about the consumer's healthcare engagement continuum, provides evidence of consumers' preferences and needs for each touch point in the life-cycle, shows how our system too often fails to address consumer preferences and needs, outlines how these failings could be addressed, and encourages a discussion of how to elevate, support, validate and authenticate the consumer's voice.

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Why Consumer Preferences and Needs Matter—and Must be Validated

As a starting point, it is important to establish why consumers' preferences and needs matter. The fundamental purpose of the healthcare system is to create health among members of the community. Research is beginning to show that revealing and catering to consumer preferences can lead to better outcomes, more efficient spending and higher patient satisfaction. But we don't want to see stakeholders misappropriate the mantel of consumer- or patient-centric, and we want to avoid using that rhetoric when we are not addressing consumers' true preferences and needs.

In "Patient Preferences Matter: Stop the Silent Misdiagnosis," the authors provide substantial evidence that "preference misdiagnosis" is as harmful to the patient as "medical misdiagnosis."[1] To illustrate their point, the authors describe the experiences of two women. The first woman was wrongly diagnosed with breast cancer at age 58 and underwent an unnecessary surgery. The second woman was correctly diagnosed with breast cancer at age 78, and, although she dreaded undergoing surgery (after having survived heart failure), her doctor insisted she do so. The first is an example of medical misdiagnosis and the latter an example of preference misdiagnosis.[2] After discussing with friends with similar diagnoses, the 78 year old woman realized that a hormone therapy would likely have prevented the cancer from advancing long enough that she would likely die of other causes. She felt intense regret with a surgery that could not be reversed. The authors concluded that if her doctor had given her alternative treatment options she would have been able to make an informed decision and would not have agreed to surgery.[3]

Patient preferences are not just an ethical matter, but also a budgetary one. The evidence shows that patients make different decisions about whether to have tests, treatments or procedures when they are well informed and their preferences are recognized. Some examples include:

- PSA (prostate-specific antigen) test. After receiving information about the limitations and possible false positives of the test, the proportion of patients choosing to be screened dropped from 98 percent to 50 percent.[4]
- Benign prostate disease. When patients were informed that a side effect to surgery was possible sexual dysfunction, 40 percent fewer chose surgery.[5]
- Abnormal bleeding from the uterus. When women were given the option of surgical removal of the uterus or waiting for menopause, the relative reduction in rate of surgery was more than 20 percent.[6]
- Coronary heart disease. A randomized trial of decision aids found a 20 percent reduction in preference for surgical treatment for patients with chest pain diagnosed as stable angina.[7]
- Cardiac arrhythmia. Patients who participated in shared decision-making chose far less-invasive treatments compared to those who did not.[8]
- Back pain. Patients with herniated discs were more than 30 percent less likely to choose surgery when fully informed of their options, while those with spinal stenosis were more than 30 percent more likely to choose surgery.[9]

These examples illustrate the importance of validating consumers' preferences. This means looking beyond consumers' "stated" (aspirational) preferences to also include their "revealed" preferences (actual behavior).[10] While *stated preferences* are what consumers say they will do, *revealed preferences* observe consumers' actual behavior. Sometimes stated and revealed preferences are aligned, for example, in a study of vaccine use in children, 80 percent of respondents stated that they planned to vaccinate and the same percentage actually did.[11] But often consumers are poor predictors of what they actually know or will actually do. For example, consumers overstate their actual knowledge of health insurance terms[12] or their likelihood of using price and quality data.[13]

Further, it is not just doctors or other healthcare providers who fail to understand consumers' preferences or needs. The health insurance industry promotes high-deductible health plans as "consumer-driven" and "consumer-oriented," yet consumers are much less satisfied with these types of plans compared to traditional plans with lower deductibles, and would not recommend them to friends or relatives.[14]

Products, services, or systems that are promoted as consumer- or patient-centric should align with validated consumer preferences. Validation should take into account both stated and revealed preferences, and ensure that these preferences were formed with complete information. For example, if consumers don't understand the extent to which provider quality can vary, they may not seek out reliable quality information.

Finally, it is also important to establish the independence of organizations that purport to represent consumers or patients. For example, at least 83 percent of the nation's 104 largest patient advocacy groups take contributions from the drug, medical device and biotech industries, at least 39 percent have a current or former industry executive on the board, and at least 12 percent have a current or former industry executive in a leadership position on the board, which raises questions about whether they consistently put patients first.[15]

Consumer Healthcare Engagement Points

In addition to ensuring that consumers' preferences and needs have been validated and are not marketing schemes designed to increase market share or profits, we need to adopt a common understanding of the consumer healthcare engagement points (see Figure 1). If we are going to identify ways to better meet consumers wants and needs, we don't want to overlook any aspect of their healthcare experience and we need to reveal the key linkages between them. For example, the health plan a consumer chooses impacts the availability of in-network providers and the cost of treatment options should they need care.

Self-Care

What are Consumers' Preferences and Needs?

For healthy individuals, self care includes eating a balanced diet, exercising regularly, getting adequate sleep, and avoiding high-risk behaviors such as smoking. Americans clearly understand the importance of being healthy and overwhelmingly aspire to lead healthy lives.[16,17] They feel that they are responsible for staying healthy and that their personal lifestyle choices matter.[18]

But what consumers aspire to and what they actually do are two different things. For example, 89 percent say taking personal responsibility for one's health is the best way to stay healthy, 75 percent say they feel they can manage health issues through nutrition, and 64 percent say they will take whatever means necessary to control their own health. However, when it comes to action, only 70 percent say they are actively trying to be healthier, 50 percent say it's a challenge to eat healthy and 66 percent say they don't exercise enough.[19] These statistics show the difference between *stated preferences* and *revealed preferences*.

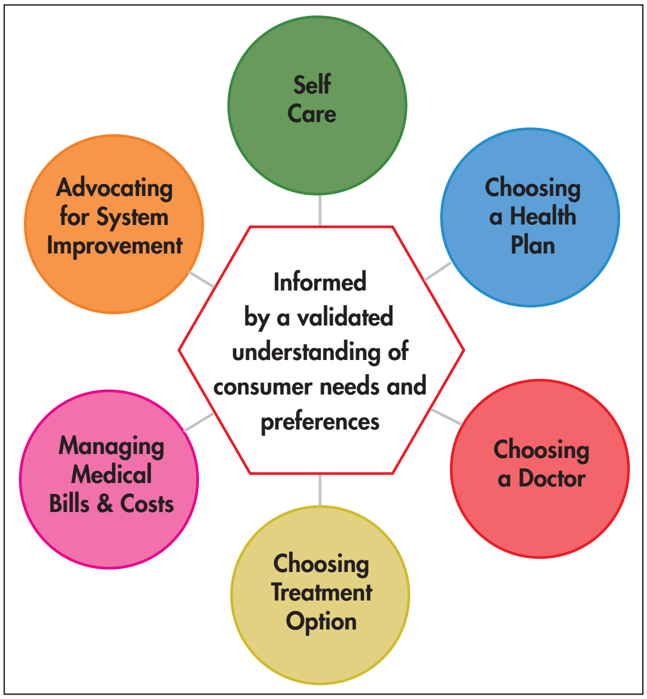
Nearly all U.S. adults in a recent poll expressed concerns that something was interfering and keeping them from being as healthy as they could be. Three quarters of American adults say there is some barrier to being their healthiest self. Most commonly, these barriers are lack of interest/motivation, time, cost, and competing responsibilities.[20]

If becoming active in one's health is hard for healthy individuals, it becomes even more difficult when an individual becomes critically ill or injured.[21] For example, the potential scope of self-care activities after hospital discharge could include taking prescribed medications, sampling and interpreting one's own blood or urinary laboratory values, changing dressings, administering parenteral nutrition, monitoring and adjusting fluid and dietary intake and output, and suctioning one's airway.[22]

Although studies suggest that self-care can lead to cost savings and better outcomes in the prevention and treatment of asthma,[23] chronic obstructive pulmonary disease,[24] diabetes,[25] and other chronic conditions, [26]a key question is how far people are able to participate in their

Figure 1

Consumer Healthcare Engagement Points



own healthcare? While some people are very proactive about their health, many are quite passive or face barriers to self-care.

How Our System Fails Consumers

Social, political, economic and environmental barriers have been identified that inhibit consumers trying to lead healthy lives and exercise personal responsibility.

Studies have shown that consumers are highly responsive to even subtle environmental cues,[27] so large shifts in access, pricing, portion sizes, marketing, and other powerful drivers of eating and physical activity will have major effects on weight.

In part, this is due to the fact we don't have consensus on the right balance between personal responsibility and the role of public "nudges" (or even stronger measures). Policymakers may frame certain public health issues as either an individual responsibility or as an environmental issue resulting in very different policy recommendations.[28] If getting to good health outcomes is the goal, we must not let the framework of personal responsibility use blame, bias, stigma, and discrimination to avoid regulatory or governmental action that would provide necessary supports and interventions that would help Americans to better achieve their aspirations for living healthy lives.[29]

Moreover, when trying to support and incentivize consumers, one-size-fits-none. Providers, health plans, government officials, consumers, and others need to acknowledge that some people are less likely to be active in their self-care[30] and face varying levels of structural barriers to self-care. If a patient feels overwhelmed, has little confidence, and has had experience of failing to manage their health, it can be overwhelming when a doctor tells them that, because of a new diagnosis, they need to make multiple changes to their lifestyle – changing their diet, increasing their physical activity and managing new medications. They may try to make these changes, but when they cannot make all of them, they will most likely make none. By not understanding that a patient like this has limited self-care skills, their doctor has set them up for failure.[31]

How the System Can Better Meet Consumers' Preferences and Needs

The priority must be on additional work to identify and address the social, political, economic and environmental barriers to self-care. With a robust understanding of these barriers, policymakers must then address the challenges of balancing personal and environmental approaches to serve the greater public good, e.g., smoking reductions, the use of seat belts, wearing a bike helmet, clean air and safe drinking water. A nuanced use of behavioral economics, social cues and personal interventions may help improve results.

Providers can help patients identify personal preferences and goals for self-care and barriers that inhibit realizing goals. For some patients, identifying community and employer resources that might address barriers and proven techniques for exercising control can improve outcomes. Health plans should pay for, and health systems should encourage, longer appointments for patients with greater need, and all stakeholders should guide investments in local, community-based services to support them.[32]

Measuring patient activation levels would help health providers target time and resources to patients.[33] We can maximize the value of doctor's appointments for less-activated patients by using specially trained medical assistants, such as health coaches, to meet the patient prior to their appointment to help them formulate their self-care questions for the clinician.[34]

Choosing a Health Plan

What are Consumers' Preferences and Needs?

Health insurance is vital for the health and financial well-being of individuals and families. It is a choice that then affects the consumer's subsequent choice of providers and cost of treatment options. But purchasing health insurance is an extraordinarily complex process.

Most consumers want health insurance—they don't want to "go bare" and they don't believe themselves to be invincible.[35]

When consumers search for health insurance, their top considerations are financial—affordability of monthly premiums, annual deductibles, and annual caps on out-of-pocket expenditures.[36] Despite advancements in how insurance is presented in the Affordable Care Act (ACA) marketplaces, consumers still find it hard to compare health plan costs. They are unfamiliar with plan components, such as premiums, copays, deductibles, coinsurance, and other out-of-pocket expenses, and how these elements form the overall cost of a health plan.[37]

While consumers are concerned about the cost of health insurance, they also don't necessarily want the cheapest plan. They want the plan that provides the best value for their needs that they can afford.[38] However, consumers have difficulty determining which plan would have the highest value for their expected needs. Consumers are skeptical of their ability to shop for high-value, low-cost healthcare. Without actionable, comparative information about health plan cost and quality, consumers tend to give higher consideration to premiums than to their expected out-of-pocket spending.[39]

Among the options for constraining health premium growth, consumers prefer that health insurers use more limited physician and hospital networks. In controlled experiments, given accurate information, a variety of options, and a valid structure for weighing the pros and cons, consumers report they prefer to narrow their provider choices in order to preserve or increase medical benefits.[40] But this work shows that consumers assume the narrow networks are high quality and feature sufficient providers for the full range of covered benefits. Other research shows that consumers may be becoming more willing to choose a narrow-network plan, especially if their preferred physician is part of the network.[41]

Many studies show consumers value having options to choose from, but also want a manageable number of plans.[42] They don't want to be overwhelmed with choices.

Consumers also rank choice of doctor, simplified purchasing, credible and impartial comparative information, and having a trusted adviser for health insurance information high in their preferences and needs.[43]

How Our System Fails Consumers

Navigating their health insurance choices is one of the most difficult tasks consumers face in their lives and they dread it.

No coverage. Perhaps our greatest failure is instances where we fail to provide consumers with even one viable coverage option—for example, those in the coverage gap in states that did not expand Medicaid.[44]

Poor coverage. High-deductible health plans, and so-called consumer-directed health plans, are not affordable for many people. They shift more costs onto consumers, especially lower-income and sicker consumers, causing them to forgo needed care. Stakeholders need to comprehensively contain, not shift, rising health costs, and deal with system-wide waste estimated at 30 percent of total health spending from duplicative, unnecessary, or harmful care. And despite the subsidies available under the affordable care act, many report difficulties finding an affordable health plan.[45]

The illusion of choice. Health insurance companies hurt consumers by confusing and overwhelming them with too many plan options with relatively insignificant differences. A recent study found that when presented with just two health plan options consumers found it very difficult to make an informed decision due to the large number of health plan features. Several studies of Medicare Part D and Medigap plans found that more options made it harder to choose [46] and, as a result, consumers often didn't make the best choices for their circumstances.[47] Presenting complex comparative information greatly decreases consumers' comprehension of information and reduces their ability to make informed choices.[48] Yet this is exactly what we provide.

Failure to provide out-of-pocket cost information. Consumers want to know what they will have to pay out-of-pocket for procedures and services. But because health plan cost sharing is so complex, many consumers default to using premium as their decision-making criteria without understanding the impact of out-of-pocket costs in their circumstances.

Lack of ease of use and simplicity. Consumers know what to expect when they order a product on Amazon or a ride from Uber and wonder why health insurance companies have not caught up in terms of effortlessness and accuracy.

How Can the System Better Meet Consumer Needs?

To truly leverage consumers as shoppers, we must make it easier for them to compare insurance coverage choices. Coverage choices should be restricted to a manageable number, and there should be meaningful differences between the options. Plan features that are allowed to vary should be minimal, in order to make it easier to compare products. For example, states have taken action to simplify plan choice by limiting the number of plans or benefit designs insurers may offer, requiring standardized benefit designs, and adopting meaningful difference standards. Focus groups convened by the Massachusetts Health Connector found that the ideal number of distinct plan designs was six to nine.[49] Previous focus group studies found that consumers wanted four to six insurance carrier options within a tier system that indicated low, medium, and high levels of overall cost sharing.[50]

Coverage options should reflect consumer preferences, for example, making costs more predictable by using co-payments instead of coinsurance and covering more services on a pre-deductible basis.[51]

Once the set of choice has been simplified, consumers prefer information and assistance navigating their health choices from a trusted source. To help healthcare assistors and those comfortable navigating choices on their own, provide consumer-tested, standardized, comparative displays that feature easy-to-understand signals about expected cost-sharing, network quality and breadth,[52] and scope of covered benefits. For example, one study found that placing health plan quality data next to cost information and using a checkmark or blue ribbon helped consumers pick high-value plans regardless of their knowledge level.[53]

Choosing a Doctor

What are Consumers' Preferences and Needs?

The relationship and interactions with one's doctor or other healthcare provider remains the most important healthcare consideration for consumers.[54] While the importance of relationships and interactions is true for all consumers, it was especially true for Hispanics and seniors; and Hispanic consumers found special importance in the relationships between their provider and family.[55]

When choosing a provider, consumers are interested in quality information that reflects elements of patient experience, such as bedside manner and service quality, such as follow-up care and personalized instructions.[56] Consumers prefer doctors or other healthcare providers who spend time with them and do not rush; who listen and show they care about them; who clearly explain what they are doing and what the consumer needs to do later; and who provide clear, helpful information about the consumer's diagnoses and conditions.[57] When consumers are asked about "quality" of their healthcare, they often think about it in terms of the quality of their own provider: treatment is effective (77 percent), treats me well and with respect (74 percent), keeps me fully informed (71 percent), receive the care I expect (69 percent), and treats me as a person not a patient (69 percent).[58]

Convenience is important to consumers. Nearly two-thirds of consumers say they would switch providers for the ability to get an appointment quickly when they need it; and more than half would also switch for the ability to get an appointment at a convenient location.[59] Language is a key provider attribute for Spanish speakers.[60] Spanish speakers often find it hard to communicate with doctors.[61]

To choose a doctor, most consumers (74 percent) continue to rely on opinions and recommendations of friends and relatives.[62]

Many will also use computer searches as a starting point, but lower-income consumers often don't know the precise search terms to use.[63] Many low-income consumers perform searches for indicators that a physician will be respectful, often using the physician's photograph as a proxy.[64]

Consumers report they are most interested in information that reflects elements of the patient experience or service quality. However, only about one-in-four (27 percent) have used online ratings of a doctor's bedside manner or wait time; only 22 percent looked at online ratings of clinical quality to help them decide on a medical provider; and few consumers (14 percent) used data on the cost of care to select a doctor.[65]

Focus groups reveal that consumers don't realize that the quality of healthcare can vary among providers and that may be the reason that clinical proficiency isn't listed more often among their stated preferences.[66] Consumers assumed that some "watch dog" was ensuring that poor performers were kept from practicing.

How the System Fails Consumers

Consumers are not aware of independent, trusted sources of information that they can use to choose among providers that matches their preferences for information on bedside manner, convenience and language. While quality reports capture elements that resonate with experts and healthcare professionals (mortality rates, clinical quality measures), consumers often are more interested in quality information that reflects elements of the patient experience or service quality.

Moreover, patient experience surveys—which could help inform consumers when they are searching for a physician—have been used primarily with Medicare and privately insured populations, leaving the voices of patients in the lowest socioeconomic status underrepresented.[67]

And information is not geared to consumer preferences. For quality and cost information to be meaningful to consumers, it needs to reflect consumer priorities and be presented in a way that makes it accessible and understandable. Even highly motivated consumers are likely to abandon efforts to find information if difficult to find or understand.

Spanish speakers often struggle with language barriers when it comes to understanding insurance terms or in communicating with providers. They often don't ask for resources, even when available, for fear of prejudice against immigrants.

Failure to keep poor performers from practicing. Consumers want to know they can navigate their physician choices safely, without encountering a physician who has lost their license in a nearby state. While rare, it is still too common that physicians' reputations are protected at the expense of patients.[68]

How the System Can Better Meet Consumers' Preferences and Needs

Build the healthcare workforce consumers are looking for by providing training and support to physicians and other providers to better communicate with and understand consumer preferences and needs, and practice shared-decision-making.[69] Hiring a more diverse workforce, making language access a high priority, and even something simple like making more eye contact could greatly improve trust and respect in provider-patient relationships and interactions.

Provide comparative quality information geared to consumers' preferences and make the information easier for consumers to find and use. And remove one consumer choice burden by doing a better job of prohibiting dangerous doctors from practicing.

Make it mobile. Vulnerable consumers use mobile phones for 90 to 95 percent of their internet use, including to access health information.[70]

Opting for and Choosing Among Treatments

What are Consumers' Preferences and Needs?

The vast majority of Americans trust their doctor—86 percent.[71] This often results in patient reluctance to take a more active role in their care (61% are content with having the doctor in control or largely taking control during a visit). Researchers believe that this high level of trust could lead to a biased perception that their doctor would never deliver unnecessary care. For example, despite national estimates that up to one-third of care is duplicative, unnecessary or harmful,[72] more than 90 percent of consumers agreed with the statement that "my doctor would never recommend a test or procedure unless it was necessary."[73]

For many patients, a doctor visit is the best opportunity to become engaged in their own health.[74] In that encounter, consumers want to be heard, understood and given clear directions.[75] Nearly nine in 10 consumers say if their doctor provides them with material when diagnosed with a health condition, they read it as soon as possible.[76]

As a general rule, patients think in terms of outcome preferences (e.g., prevent another heart attack or fixing a sprained ankle) rather than the treatments that can lead to those outcomes. However, as patients become more informed, they become more likely to express a treatment preference.[77] In other words, the more informed a patient becomes the more they are likely to have knowledge of, and opinions about, the treatment options available to them.

Most consumers (95 percent) believe it is important that doctors tell them about the results of medical research when making treatment decisions.[78] However, consumers believe evidence regarding care or treatment that works for most people may not apply to them and want to avoid "one-size-fits-all" or "cookie-cutter" medical treatments.[79] If they don't believe the evidence is relevant to their situation, they may use other criteria to make their treatment decision, such as personal preference or convenience, the doctor's clinical judgment and out-of-pocket costs.[80]

Consumers believe that financial interests may sway how evidence of medical effectiveness is presented by payers and providers; therefore, they have a positive view of government-required public reporting of treatment effectiveness.[81]

Consumers prefer that their provider not consider costs when weighing treatment options.[82] But they want information on their own out-of-pocket costs, believing that they personally should considering costs when weighing evidence and understanding care options.[83] Nine in 10 consumers believe it is important to know their ut-of-pocket expenses for specific services with specific providers, including insurance deductibles, copayments and other cost-sharing.[84] Moreover, consumers want information for a complete episode of care rather than individual services delivered as part of that care.[85] For example, when given a cost estimate for a surgical procedure, they do not want to be surprised by additional costs such as anesthesiologist fees.

Consumers also strongly prefer integrated information that allows them to simultaneously compare quality and cost information for the various options they are considering.[86] When cost information is presented without accompanying quality information, consumers may use price as a proxy for quality—higher cost equals higher quality.

Evidence is mixed with respect to consumer views concerning the relationship between the cost and quality of procedures or services. Several studies show they don't believe they are linked. For example, most consumers (58 to 71 percent) [87] do not believe there is an association between cost and quality in choosing a doctor or medical care. But in the absence of other information about the efficacy of treatment, consumers sometimes report that high costs signals high quality for them.

But consumers express more interest in treatment information than they tend to seek in real life. Fewer than two out of five consumers used price or quality data to inform their decisions in the past 12 months; only 38 percent looked for healthcare quality ratings before they received services, and only 36 percent asked how much their healthcare service would cost in advance.[88] This may be due to "clutter" or information overload. Decision-making research shows that more information does not always improve decision-making, and frequently may actually undermine it.[89] Other explanations include: lack of awareness of provider quality variation, insulation from out-of-pocket expenses at the point of service, and the inadequacy of current information sources.[90]

All income groups are going to the Internet to find information, but lower-income consumers often don't know the precise terms to use.[91] In general, lower-income consumers are less satisfied with existing healthcare resources and spend less time searching for health information.[92]

How Our System Fails Consumers

Our greatest failure is that far too many consumers do not get care they believe they need due to concerns about cost.[93] Many others get care but then struggle to pay the resulting bills (as discussed in the next section).

When patients do receive care, too often that care is not aligned with their preferences. For example, in a study of more than 1,000 office visits in which more than 3,500 medical decisions were made, less than 10 percent of decisions met the minimum standards for informed decision making.[94] Similarly, a study showed that only 41 percent of Medicare patients believed that their treatment reflected their preference for palliative care over more aggressive interventions. [95] There is also significant variation in the use of procedures, particularly those for preference-sensitive conditions, which suggests that patients may receive care aligned not with their values and preferences.

Failure to use informed, shared decision-making is a missed opportunity to reveal patient's preferences and goals. As described above, patients make different decisions about whether to have tests, treatments, or procedures when they are well informed and their preferences are taken into account, resulting in more satisfied patients and better allocation of system resources. This failure may stem from:

- Reimbursement policies that are not aligned with shared decision-making.
- Doctors' perception that consumers don't want to be involved in their treatment options, or cannot understand the options. Physicians believe that 37 percent of their patients want their doctor to make the decisions regarding their medical treatment with input from the patient, but only 7 percent of consumers selected this as the role they wanted doctors to have. Instead consumers are much more likely to want a process that uses joint decision making or the patient makes the decision with input from the doctor.[96]
- Doctors' belief that medical diagnosis is more important than preference diagnosis. Doctors believe that they are already quite good at diagnosing patient preferences, but the evidence shows that there are enormous gaps between what patients want and what doctors think they want. For example, doctors believe that 71 percent of patients with breast cancer would rank keeping their breast as a top priority, yet the actual figure reported by patients is 7 percent.[97] Doctors believe that 96 percent of breast cancer patients considering chemotherapy would rank living as long as possible a top priority, yet the actual figure is 59 percent.[98]

Preference misdiagnosis is widespread. Doctors are highly trained in medical diagnoses, but not in diagnosing patients' preferences, even though the evidence shows that the right treatment—the treatment that the patient wants when fully informed—is dependent on patient preferences.[99] A large body of evidence shows that doctors, in general, are unskilled at diagnosing what patients want.[100] Three types of evidence support this conclusion: studies show how treatment preferences change after patients become well informed; studies of outcome preferences show differences between the outcomes that patients prefer and the outcomes that doctors think they prefer; and studies of geographic variations in care show that the variations can only partially be explained by causes other than the preference misdiagnosis. [101]

Dissatisfaction. When asked to infer their patients' satisfaction with their care, doctors estimated that 76 percent of patients were satisfied, but only 39 percent were.[102] Moreover, vulnerable consumers are three times more likely to feel disrespected by doctors and other providers.[103] Those that feel disrespected are twice as likely to not follow their treatment regimen.

Lack of consumer and patient engagement at the organizational design and governance level. Healthcare organizations such as hospitals, ACOs, clinics, and nursing homes are slow to integrate patient preferences, values, experiences, and perspectives into their design and governance.

Failure to provide publicly reported information geared to consumer preferences. Consumers first need is for information on how outcomes differ across treatment options, public quality reporting is not specific to one's doctor. In choosing a doctor, consumers prefer condition-specific or procedure-specific information reported at the individual physician level, yet most publicly reported quality information is not condition or procedure specific and focuses on the general performance of hospitals, medical groups—not at the individual physician level. [104]

Meaningful price information is hard to obtain prior to receiving care.[105] Shortcomings include:

- Failure to provide integrated cost and quality information. Consumers prefer integrated cost and quality information at the physician level for specific services in a simple, easy-to-access, and easy-to-understand format.

- Public cost reporting is not specific to one's health plan. Consumers want to know their out-of-pocket costs for specific services with specific providers, given their insurance benefits. However, many current public reporting initiatives give total or average charges for specific services—information that is too general to meet the consumer's specific needs.
- Lack of information about complete episode of care. Consumers want information for a complete episode of care rather than individual services delivered as part of that care. If consumers are given a cost estimate for a surgical procedure, they do not want to be surprised by additional costs associated with the procedure such as anesthesiologist fees. Most useful is price information that incorporates any negotiated discounts; is inclusive of all costs associated with a particular service; and identifies consumers' out-of-pocket costs.
- Lack of reimbursement policies and benefit designs that help signal to consumers what high-value care is and makes it financially accessible.

Finally, consumers are generally unaware of comparative quality and cost information. For consumers to be more aware of their options and their costs, reporting entities need to lower the burden on consumers to track down and use information.[106] Lower levels of consumer use of information may reflect issues with the availability of relevant data and the design of the tools to deliver those data, rather than a lack of interest in comparative assessment of quality and costs.

How the System can Better Meet Consumers' Preferences and Needs?

Encourage shared decision-making and train doctors and other health providers in preference diagnosis. Shared decision-making that takes place in a clinical setting discards the notion that the provider is the only person who needs access to available evidence.[107] It often involves the use of patient decision-making aids such as online interactive information and applications, as well as written material in pamphlets or booklets.

And when doctors accurately diagnose patient preferences, an enormous source of waste—the delivery of unwanted services—is eliminated. This is especially true when doctors accurately diagnose the preferences of patients with long-term conditions who are far more likely to keep their conditions under control with fewer hospitalizations and emergency department visits.[108]

In this vein, with the advent of ACOs and other coordinated efforts at multiple levels within health organizations, a concerted effort to change physician and other clinician perceptions and behavior is needed. Such efforts should also include training in medical schools.

Reimbursement and Organizational Changes

Payers and purchasers' reimburse doctors for taking more time with their patients, and health systems can maximize the value of physicians' appointments by using paraprofessionals, such as health coaches, to obtain information about patient preferences and help patients with lower activation levels to understand their medication and follow-up appointment schedules.[109] Health systems should increase their focus towards trying to eliminate preference misdiagnoses, so that patients receive the care they prefer and need. Moreover, benefit designs should be smarter, such as having lower or no copayments for office visits to manage chronic conditions to incentivize patients to seek care and be more active in their treatment regimens. Purchasers' policies can also indicate to healthcare organizations where resources should be allocated, such as support to patient engagement and discharge planning.

Hospital policy changes that can increase patient engagement include enabling families to visit 24-hours a day; bedside rounding—conducting doctor and team rounding at the bedside; having nurses give shift reports at the patient's bedside; patient-centered discharge planning; and electronic health records that patients can access and edit. [110]

Address Consumer Information Needs

Healthcare costs should be integrated (e.g., all out-of-pocket costs based on the consumer's specific insurance plan) and quality information at the physician level. Insurance companies can make this data available and match the insured's out-of-pocket exposure with specific services.

Consumers should be provided with information about the complete episode of care. Consumers want information for a complete episode of care, without surprise medical bills, that identifies their out-of-pocket costs based on the negotiated rates between the insurer and the providers, such as in bundled payment arrangements.

Comparative cost and quality reports should include a variety of techniques to help users comprehend information, understand the relevance to their personal situation, and make choices that reflect both the evidence for a treatment or service options and the consumer's personal preferences.[111]

Evidence shows that consumers are more likely to use comparative cost and quality information if they fall into one of three groups: those with greater financial exposure or with benefit designs that encourage cost-conscious choices (such as reference pricing), those seeking elective procedures, such as joint replacements, and those seeking maternity care or low-complexity, routine procedures such as immunizations, cholesterol screening and colonoscopies. Reporting entities need to do a better job integrating quality and cost information in a way that enables consumers to easily understand and access this information.

Make the information relevant and its display simple. Using less detail in presenting cost information, and putting quality information adjacent to cost information, and indicating higher value with checkmarks or blue ribbon symbols, saved consumers time and was easier for them to understand. Comparative reports should include a variety of techniques to help users comprehend the data, understand their personal relevance, and make choices that reflect a combination of the evidence and their personal preferences.

Manage Medical Bills and Costs

What are Consumers' Preferences and Needs?

Lowering out-of-pocket costs and drug prices are a top priority for Americans. Two-thirds of consumers (67 percent) say lowering the amount people pay for healthcare should be a top priority for the President and Congress; and six in ten (61 percent) say lowering the cost of prescription drugs should be a top priority.[112]

High-deductible health plans are increasingly prevalent in both the employer and individual markets potentially exposing many consumers out-of-pocket costs they can't afford.[113] Since 2006, insurance deductibles have increased by 255 percent.[114]

These out-of-pocket costs are often misaligned with what people can pay. A majority of Americans (59%) don't have enough available cash to pay a $1,000 emergency department bill or even a $500 car repair.[115]

Rising consumer payment responsibility has changed how consumers approach provider visits. In 2015, nine-out-of-10 consumers said it was important to know their payment responsibility prior to a provider visit.[116] Consumers also want to know their payment options with their provider; and when given the option of various payment methods, more than 70 percent of consumer said they preferred to pay with an electronic payment method, including credit or debit cards.[117] Consumers want the convenience of payment options common in other industries. For example, 75 percent of consumers choose to pay their household bills online, including bank bill-pay portals and mobile apps. Two-out-of-three consumers (65 percent) said they wanted to pay their health plan premiums online in 2015 and 57 percent said they wanted the option to schedule automatic deductions for recurring premium payments. [118]

Nearly half of consumers (47 percent) say they will switch providers if cost information and easy billing options were available elsewhere.[119] This may be a case of stated preferences differing from revealed preferences—consumers tend to stick with their providers, especially when they are involved in treatment.

How the System Fails Consumers

Affording healthcare remains a top-of-mind worry for consumers.[120]

The trend toward shifting more costs to consumers through higher copays, coinsurance and high-deductibles burdens consumers and does not lower underlying health costs.

Poor benefit designs mean inadequate coverage for many. High-deductible health plans are causing consumers to cut back on needed healthcare services. They do not go to a doctor, skip getting recommended tests or treatments, don't fill prescriptions, or cut back on preventive care.

Roughly 20 percent of people under age 65 with health insurance reported having problems paying their medical bills in 2015.[121] By comparison, 53 percent of people without insurance said the same. Among those who reported having problems paying their bills despite having insurance, 63 percent said they used up all or most of their savings; 42 percent took on an extra job or worked extra hours; 14 percent moved or took in roommates; and 11 percent turned to charity.

How the System Can Better Meet Consumers' Preferences and Needs

Insurance plans with enormous out-of-pocket costs will not solve the problem of rising health costs. Employers, the government and providers—as well as consumers—must work together to lower the underlying costs of healthcare.

Healthcare providers, hospitals, drug makers and medical-device makers should be encouraged to address high healthcare costs that are not sustainable for consumers. We need to build political support to cut unnecessary spending and reduce prices, not just push the cost onto consumers. And consumers need to support state and federal efforts to gather data in order to understand healthcare spending, see where consumers are experiencing high costs, and determine which markets lack competition or suffer from weak regulation.

As already noted above, health plan designs should be simplified to make costs more predictable by using co-payments instead of coinsurance. And consumers should have access to timely, accurate, and actionable information to help them make decisions and find high-value care. One way to reduce the cost burden on consumers is for insurance companies to adopt more value-based design features that change benefit designs to have lower or no copayments for services such as office visits to manage chronic conditions; or to provide more services on a pre-deductible basis.

Payers and providers should take steps to help consumers avoid losing coverage. For example, payors could identify those who stopped payments early in the past and direct them to auto-pay options whenever possible or issue regular reminders about making payments. They could also reach out to any members they believe are likely to stop making future payments and make sure they understand both the penalties they may face and subsidies they may be eligible for.

Providers also have a role to play. For example, when patients appear to have financial difficulties, their provider could connect them with third-party organizations that may be able to offer payment assistance. Providers also could connect patients to in-house financial counselors or enrollment assistors to ensure that the patients understand subsidies and penalties.[122]

Advocating for Health System Improvements

What are Consumers' Preferences and Needs?

Consumers are the ultimate payers of all health costs. Whether paying through reduced wages for employer sponsored insurance, taxes for public coverage, or out-of-pockets costs for direct care or coverage, consumer dollars are at stake. Yet, when it comes to policy matters and shaping the direction of the healthcare system for which they pay, consumers have relatively no voice, no power, and no seat at the table. In this context, it becomes clear that terms such as consumer-oriented, consumer-driven, and patient-centered were largely developed by others—whether well-intentioned or not—*for* consumers, but not *with* consumers.

Given the imbalance of power in our healthcare system, consumers need a place at the table where decisions are being made about them, their care and the prices they pay.

How Does the System Fail Consumers?

Corporate organizational and governmental regulatory policies often lack institutional mechanisms for consumers to provide input. And when these roles do exist, they almost always lack dedicated resources to support consumer participation and put consumers on a level playing field with other stakeholders.

To maximize consumer engagement while minimizing consumer burden, we need to look across both formal and informal means of ensuring the consumer perspective is included.

Informal pathways include leveraging feedback mechanisms and complaint systems, consumer surveys, real world observations and extrapolating from available data. But we rarely leverage or support these pathways. For example, the vast majority of consumers do not realize that they have a state insurance regulator who can address their insurance problems.[123] Under these circumstances, we must extrapolate from consumer complaint data rather than rely upon it as a faithful representation of how consumers are faring in the healthcare marketplace.

We also see a failure to include consumers in hospital governance structures and legislative taskforces. Further, when these roles exist, consumer members are often under-supported by the absence of funds for transportation, for technical support, and other resources that would make them effective members.

As a result, individuals playing these roles are often outgunned and out resourced by the other stakeholders around the table.

How the System Can Better Meet Consumers' Preferences and Needs?

It is clear that consumers need a place at the table where decisions are being made about the care they receive and the prices they pay. But they need to be supported in this role, with reimbursement for transportation, access to technical assistance and other resources to put them on a level playing field with the other, more powerful, stakeholders.

Emerging evidence suggests that consumer and patient engagement into health system organizational design and governance can be a pathway toward achieving the goals of better quality of care, greater cost efficiency, and improved population health.[124]

South Australia provides a good example of a government-supported consumer-engagement program,[125] to recognize the value of the consumer voice and to provide consumers with a seat at the table. The regulatory framework[126] for implementing the program states it will:

- ensure there are mechanisms in place to actively engage with consumers and the community in order to identify their needs, and also develop appropriate services;
- partner with consumers and the community in the planning, implementation and evaluation of its service;
- strengthen responsiveness to the differing perspectives and needs of a diverse range of consumers and community members;
- provide accessible engagement strategies that are acceptable to a broad range of consumers and the community developing a culturally responsive healthcare system;
- develop a culturally responsive healthcare system; and
- ensure the methods and practice of consumer engagement are guided by current best practice.

One of the program's mechanisms for bringing the consumer voice into policy are "Health Policy Councils," which the Minister for Health can establish "to undertake an advocacy role on behalf of the community, undertake consultancies with the community, and provide advice to the Minister and the Chief Executive in relation to health matters, among other functions."[127]

In the U.S. we have local examples that we can replicate more vigorously. For example, there is a mandate in Massachusetts for hospitals to establish patient and family advisory councils.[128] There are also health systems that build patient and family advisory councils into their operations.[129]

Similarly, government should develop create mechanisms for patients and caregivers to provide input and shape policy. For example, community health centers are required under the Public Health Service Act to have a consumer majority on their board of directors.

Conclusion

Stakeholders from politicians to provider organizations to health plans claim to be dedicated to the wellbeing of the patient and the consumer. And as this report shows, researchers have collected more information about consumer preferences and needs than at any time in history.

Yet this report also shows we still a long way to go. There are still areas where a validated understanding of consumer wants and needs is sparse, such as the barriers to self-care. What's worse, in many instances consumer preferences are known but discounted, ignored, not communicated to the right party, or institutional and cost barriers prevent us from acting on that information. Some of the most egregious examples surfaced in this report are the continued push for high-deductible health plans, failure to simplify health insurance choices, information on provider costs and quality that is insufficient and hard to use, and a scarcity of shared decision-making for treatment options.

We must set a rigorous bar for what constitutes being consumer—or patient-centric—one that closely aligns with validated consumer preferences. This validation takes into account both stated and revealed preferences and ensures that these preferences were formed with complete information.

The good news is that really aligning our health system with consumers wants and needs can lead to better outcomes and greater patient satisfaction, with less waste and fewer unwanted treatments.

A key precursor to this alignment is providing consumers with a place at the governmental or local health system table when decisions are being made about them about the care they receive and the prices they pay. But they need to be supported in this role, with reimbursement for transportation, access to technical assistance and other resources to put them on a level playing field with the other, more powerful, stakeholders.

Many industry stakeholders hide behind the veil of "meeting consumers' needs" and too many patient advocacy groups are either partially or wholly industry funded. In policymaking and programmatic work, we must ensure that a true picture of consumers' wants and preferences has been revealed. If the reality doesn't match the rhetoric, the rhetoric must be discarded.

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Independent Consultant Joe Ditre prepared this report. Thanks to colleagues Lynn Quincy and Tad Lee for their review and editing.

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HEALTHCARE VALUE HUB

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The Healthcare Value Hub takes a careful look at the evidence and consults with experts in order to clarify for advocates, media and policymakers the important cost drivers and the promising policy solutions. Hub Research Briefs, Easy Explainers,infographics and other products are available at our website. Note: This Research Brief was produced when the Healthcare Value Hub was affiliated with Consumer Reports. As of July 1, 2017, the Hub is part of Altarum Institute.

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Support provided by the Robert Wood Johnson Foundation