



issue brief

Improving Quality Health Care: The Role of Consumer Engagement

There is an emerging consensus in the health policy community that informed and engaged consumers have a vital role to play in improving the quality of care that the U.S. health system delivers to patients. The expectation is that when consumers are armed with the right information, they will demand high-quality services from their providers, choose treatment options wisely, and become active participants and self-managers of their own health and health care. Yet the choices before consumers when they attempt to navigate the health system can be dizzying—from how to select health plans and providers to the pros and cons of alternative treatment options. In fact, the choices are becoming increasingly complex along with the health care system itself. The pressing question for the policy community is: How can we ensure that consumers have the tools and information they need to play the active role we are asking of them?

A growing body of research is beginning to provide answers to that question, but there are also substantial gaps in the research. This report attempts to identify the most important of those gaps. It is the product of a colloquium sponsored by the Robert Wood Johnson Foundation (RWJF) at which a select group of health policy experts presented five white papers on different aspects of the consumer engagement issue. Summary briefs of each white paper are available

from RWJF and AcademyHealth. Working discussions at the meeting produced a series of recommendations for facilitating consumer engagement and a roadmap for future research. Both are outlined here.

This overview report illustrates both the complexity of the many ways that consumers interact with the health care system and the varying opportunities for engagement. Consequently, there are unlikely to be simple policy solutions to enhancing consumer engagement. But as the white papers and the discussions at the colloquium attest, two things are clear: First, consumer engagement holds great potential to spur health quality improvements. Second, it must not be viewed as a silver bullet, since consumers have neither the power nor the skills to transform health care systems on their own. Change will require a joint effort on the part of consumers, providers, payers, insurers and policy-makers.

Background

The source, content and distribution of the health quality information that is currently available to consumers all vary widely. For example, comparative information on quality performance for health plans has been available for some time in the form of the Health Plan Employer Data and Information Set (HEDIS) measures. Performance information on hospitals, nursing homes and home health agencies has recently been made publicly available, and



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efforts are underway to produce performance information on physicians. The development of best practice guidelines for a number of conditions has also led to a systematic assessment of treatment options and their associated outcomes. Educational materials have been developed for patients to help them make informed decisions about certain treatment options and improve their compliance with the regimens involved. Yet the development, dissemination and consumer use of these materials has proceeded in a somewhat haphazard manner, and there are a number of gaps where more information is needed. A better understanding of how consumers interact with the health care system may provide a foundation for identifying opportunities for enhanced engagement and empowerment around quality.

Despite the explosion in information resources to help consumers, the structure of the health care system itself may hinder engagement. As has been documented extensively, the system is too difficult to navigate. For patients faced with a recent diagnosis, the confusing web of conditions, screenings and treatments can be overwhelming and impenetrable. Furthermore, decisions are not made in a vacuum. Various support tools are available through practitioners and insurers, yet the inter-related nature of the health care system affects consumers' ability to engage. For example, consumer choices of hospitals and physicians are often limited by health plans under specific plan options.

These issues were covered at the RWJF colloquium, which was held in February 2007. Discussions at the event were shaped by the following five white papers:

- One focuses on the question of what it will take to activate consumers so they can be engaged in quality improvement.
- Two examine the roles of consumers at different points in the health care system, such as when they are choosing health plans and providers, and when they are deciding on treatment options.
- A fourth analyzes opportunities for quality improvement as consumers navigate an increasingly complex health care system.
- The final paper considers the degree to which consumer choice is appropriate and the expectations for consumers to be involved in decision making.

Consumer Activation

Consumers today are expected to choose among a variety of health plans, wade through cost and quality information on providers, and make sense of complicated medical information on services and treatments. In addition, they are expected to manage their chronic conditions and seek preventive treatments and advice from providers. In most cases, consumers are not taking on all of the behaviors expected of them. Learning to foster those behaviors—to activate consumers as agents for their own health care—will be a difficult process.

Thus far, the primary approach to improving consumer interactions with the health care system has been to provide more and better information, along with financial incentives to reward engagement. But there are problems with these approaches. For example, the provision of information itself might not motivate consumers sufficiently. This is because some of the new behaviors we expect of consumers run counter to how they were socialized to behave, require new skills or knowledge, or mean changes in lifestyle or habits.

Behavioral theories focus on changing one behavior at a time. In the case of increasing consumer activation in health care, most consumers have numerous behaviors that need to be changed and concentrating on one behavior at a time may be overwhelming. However, activation may be a single construct that underlies and determines a whole range of behaviors. Hibbard has developed a Patient Activation Measure (PAM) that assesses patients' knowledge, skill and confidence in managing their health and health care. The model describes four stages of activation that people go through in the process of becoming fully competent managers of their own health and health care. These stages predict a number of health behaviors, such as diet and exercise, compliance with drug regimens, and using quality information.

While the PAM holds promise, measuring activation is in its early stages. Much more research needs to be done to determine whether activation is a single construct or a bundle of different but possibly related factors, such as knowledge and expectations. Future research should continue to examine activation and explore whether it is one construct or several that need to be studied separately.

Hibbard's theory indicates that activation is fluid and identifying factors that change, spur or deter activation may result in changing a whole range of health behaviors. If true, this would result in a radical shift in the way we approach changes in health behavior, moving from a focus on individual behaviors to an approach that seeks to activate consumers. This may also suggest that different approaches will be successful at different stages of activation. Participants at the RWJF colloquium discussed the need to move from a one-size-fits-all approach to providing information to one that is more tailored to consumers at different stages of activation. Some also suggested the need to take into account differences in racial and ethnic backgrounds and literacy levels.

Building on that line of thinking, it becomes important to understand how external factors, such as the structure of the health care system, provider characteristics and costs, might affect consumer activation. Would giving providers information about patient activation result in better and more appropriate communication? While providers are frustrated with patients who are not activated or compliant with treatment plans, many are also uncomfortable with highly activated patients who may be overly aggressive. Educating providers to understand the power of patient activation and involvement in care might ensure their participation. Then there is the role of costs in engaging consumers. More research is needed on that front to determine things such as the effect of consumers' financial exposure in cost-sharing arrangements on activation and decision making. Participants agreed that increasing activation may be facilitated by a broader array of changes in the health care system than just those targeted at consumers.

Consumer Decision Making

Consumer decision making is an important part of consumer activation. During the meeting, participants discussed the ways in which consumers make decisions, specifically looking at their decisions about health plans, providers and treatments. There appears to be significantly more research into consumers' choice of health plans than providers. But people appear to respond in similar ways to information about plan and provider choices. Much less is known about how consumers make treatment choices.

Unlike most other consumer decisions about health care, the choice of a health plan is typically made prior to becoming ill. The major factors involved in this choice include the provider panel and financial considerations, such as premiums and co-payments. In contrast, quality of care is a more salient factor in the choice of provider, since consumers are usually shielded from price differences among providers by insurance. Research has shown satisfaction may also play a significant role in the choice of providers.

In addition, consumer decision making may be affected by external constraints. Employers may limit the number of choices and manipulate the premiums and co-payments. Consumers making choices about treatments are constrained by access to information. They generally cannot make treatment decisions alone; they rely on the medical expertise of providers and others for information about their options and potential outcomes.

Health Plan Choice

Although consumers may not have a detailed understanding of the differences between health plans, they do seem to choose high-quality health plans, even in the absence of formal quality reporting. Among a relatively small group of consumers, however, quality reporting, in the form of health plan report cards, does seem to influence plan choice.

When choosing a health plan, research indicates that consumers tend to evaluate options based on access to specific doctors and specialists, costs (including out-of-pocket premiums and co-payments), quality of providers in the panel and their communication skills and courtesy, and the administrative burden of a plan. Evidence regarding consumers' use of specific process measures of performance, such as HEDIS scores, is mixed. They seem to use satisfaction measures, especially the responses of people similar to themselves, in making choices. They also tend to use quality information to avoid bad choices rather than to make good choices.

Studies that examine consumer choice and quality reveal that people from different population subgroups may value certain health plan quality attributes and respond

to information on health plan quality differently. Socioeconomic characteristics such as race, ethnicity, gender and income all appear to affect how consumers perceive information, what information they prefer and what choices they ultimately make. In addition, consumers choosing a plan for the first time rely more on quality information than those who have already chosen a plan and might be facing a decision to change health plans.

Research has shown that consumers are also sensitive to price when choosing a health plan. Interestingly, quality information seems to increase the responsiveness to price. Perhaps that is because consumers do not use price as a proxy for unobserved indicators of quality when they are provided with quality information directly.

Provider Choice

Although there is less research on provider choice than on health plan choice, there have been findings that consumers tend to choose high-quality providers. Consumer choice of primary care physicians appears to be based more on quality, while choice of specialist physicians is often influenced more by referring physicians. Consumers generally do not use cost as a determinant in provider choice because insurance shields them from price differences among providers.

Findings on the impact of quality report cards about providers are mixed. At best, they appear to have a minimal impact on consumer choice. The literature shows that report cards are difficult for consumers to understand and remember, and few physicians acknowledge using public report cards when making referrals.

Similar to consumer choice of health plans, the factors in consumer choice of providers vary across population subgroups. Demographic and socioeconomic characteristics appear to influence the selection process, the information used and the ultimate choice of provider. As with health plans, consumers tend to use quality information to avoid poor quality providers rather than to seek out the best quality.

Treatment Choice

Good treatment decisions require good information, careful attention to values and consideration of tradeoffs. The quality of

treatment decisions has significant implications for quality of care. It can improve compliance and quality of life during the course of treatment and positively affect health outcomes.

The research on consumer choice of treatment shows that neither patients nor providers follow a particularly rational approach. There is considerable variation in the extent to which patients are interested in being a part of the treatment decision-making process at all. Moreover, among those who are interested in participating, there is also variation in how they want to participate. Patients are not routinely involved in ways they want to be.

Not surprisingly, research suggests that socioeconomic factors influence medical decision making. However, preferences vary within as well as between groups. Individual preferences also vary over time. Among the many factors that influence treatment preferences are the involvement of family members, deference to authority figures (i.e., physicians), physicians' behavior, previous experience with medical treatments and the presence of dependents. In general, patients are more likely to want to be involved in medical decision making over time; as they become more knowledgeable.

Wennberg and colleagues have documented significant practice variation by geographic area that does not appear to be explained by differences in patient characteristics. These practice variations have raised questions about the quality of clinical decision making. There has been surprisingly little research comparing the effectiveness of different treatment options. This means that there is little information to assist patients in choosing among different treatment options. In the absence of sound evidence about treatment options, doctors make different assumptions. Patients are often poorly informed about their options and the implications of different treatment choices, and many do not even know they have choices.

In their white paper, Sepucha and Mulley identify two different types of practice variation. The first is unwarranted variation, which includes variation resulting from unknown outcomes due to insufficient research, different levels of access to

resources and expertise, parochial perspectives, and faulty interpretation of evidence. The second is warranted variation, which can result from clinical differences among patients, their individual preferences about health outcomes, and their willingness or unwillingness to consider short-term effort (or discomfort) to achieve longer-term benefits. They suggest that reducing unwarranted variation will improve the quality of treatment decisions.

A number of aids and tools have been developed in the past decade to assist in decision making, but they are not widely used. Some of the reasons posited include fears that patients will choose more costly or inappropriate treatments, lack of physician time and space in the clinical setting, and the belief that patients are not interested in or are not able to cope with the information. However, participants at the RWJF meeting agreed that enhancing choice is likely to improve quality and outcomes. One promising opportunity to increase patients' participation in treatment choice could be to develop measures of treatment choice to incorporate in pay-for-performance initiatives.

Discussion

The evidence shows somewhat limited use of quality information by consumers to make informed decisions about health plans, providers and treatments. But the good news is that there has been growing activity over time.

The reasons for limited impact of quality information on decisions are unclear: Is quality information not being used because consumers do not value quality? Is the information not provided in a way that consumers can understand or act on? Or, are the current measures not meaningful to consumers because they don't address aspects of quality that consumers care about?

Quality measurement is still in a relatively rudimentary stage, and more work needs to be undertaken to develop measures of quality that are relevant. This means developing measures that not only indicate whether something is done correctly but whether the correct thing is being done. We need better measures of underuse, overuse and efficiency, in addition to measures that track the appropriateness of care across an episode (multiple visits) and between different providers. In order for

these broader measures to be accepted by providers, better means of attributing outcomes to particular providers are needed. Also, care needs to be taken to risk adjust measures where appropriate, so that providers who take on more complex cases are not penalized.

The relationship between cost and quality is still not well developed, and more research is needed to understand the empirical relationship and the extent to which consumers can distinguish between the two. While consumers may think of cost as a proxy for quality, in reality the relationship is much more complex. In addition, research needs to determine whether patients would choose more costly treatments if given a greater role in treatment decisions. This is clearly a concern among policy-makers, but there is no evidence proving or disproving it.

The relationship between use of quality information and disparities is complex. While research has shown that minorities are more likely to see lower-quality providers, they are also more likely to use information from formal sources, which could help reverse this trend. However, unless other efforts are made to increase quality across the board, the use of report cards may increase disparities as people with more choices seek out better quality providers, either because they have better insurance or better access to alternative providers. Significantly more research is needed to disentangle these issues.

Navigating the Health Care System

While providing better information and helping consumers make better choices is a laudable goal, some have questioned whether the current health care system facilitates or impedes consumer engagement. The concept of patient navigation has been used in a variety of ways and contexts, but here we use it to denote “the process(es) by which patients and/or their caregivers move into and through the multiple parts of the health care enterprise in order to gain access to and use its services in a manner that maximizes the likelihood of gaining the positive health outcomes available through those services.” Patient navigation is actually a series of complex processes and interactions. Participants at the RWJF meeting agreed that the system is not currently structured to facilitate patient maximization as much as it is struc-

tured to reflect provider silos. There was widespread agreement among meeting participants that high-quality care is dependent upon successful navigation of the system.

While historically there have been health care systems that supported improved patient navigation, these systems do not seem to have appeal in the marketplace. Consumers seem to prefer solo practitioners that provide the illusion of complete free choice of providers, even though these practice settings make integration harder. Some participants suggested that this is because the field has not done a good job of documenting the benefits of coordination or successful navigation. Defining quality broadly and developing measures that incorporate aspects beyond technical quality within a single visit will be vital to educating consumers and providers about the importance of coordination.

Simply restructuring the system is probably not sufficient to facilitate improved patient navigation. The culture of health care also has to change. That is, patients need to be seen as partners in care, and they need better education about what to do and why it will make a difference. As one meeting participant pointed out, patients don't challenge the system and advocate for improved quality because “they don't know they're allowed to, they don't know how, they don't think it will make a difference, they may not feel up to it, and they may not possess the resources to do it.” Educating and activating patients will be essential to facilitating navigation.

Most quality measures are narrow process measures and do not measure quality across an episode of care that may span different types of settings with multiple providers. Participants agreed that further development of measures that track patients as they navigate the health care system is needed, along with measures that assess patient navigation. Also needed are studies that document the financial and health benefits of successful navigation and the pitfalls of poor navigation.

Appropriate Consumer Choice

In the current system, patients are not often informed shoppers with respect to their doctors, hospitals and health plans. This is due to a number of factors, including lack of relevant data and other constraints. However, there are few who

would seriously argue that people should not be encouraged to choose the doctors, hospitals and plans they think will serve them best. In contrast, there is controversy about the best ways for physicians, health plans and others to interact with patients when it comes to determining the medical care they should or should not receive. There is a long tradition of physicians taking responsibility to diagnose disease and determine how to treat it, with the patient's role simply being to comply with the recommended treatment.

Fowler and Stilwell argue that medical decisions have two components: a set of options that a reasonable person would consider given the medical situation and the weights or utilities that an individual patient would assign to the pros and cons associated with those options. Guidelines provide a decision path, but don't take into account individual choice or preferences. Participants at the RWJF meeting noted that there may be a conflict between consumer choice and pay for performance when quality is defined and measured as compliance with guidelines. Therefore, they suggested that performance measures include the quality of decision support as a critical component of quality.

There was broad agreement among participants that the culture of the health care system needs to change from a hierarchical order to one marked by shared decision making. There is a long-standing tradition of paternalism in medicine, where the doctor is at the top of the hierarchy. Informed consent is seen as a critical component of ethical care, and providers are trained and take great pains to ensure informed consent. However, as one participant noted, "there is a difference between informed consent and informed choice." Informed consent occurs after treatment decisions have been made. In fact, patients and providers often move down a path of diagnoses to treatment without even recognizing the earlier points in the process when decisions can be made. Closer attention to these potential decision points and better information may facilitate shared decision making.

Several participants suggested that physicians are not the right partners to support shared decision making. This is because there may be a divergence of interests between physician and patient, especially

in the current payment environment where more services frequently equal more payment. More research is needed on the comparative effectiveness of different treatment options, the impact of incentives on provider behavior and the potential for shared decision making.

Summary and Next Steps

The RWJF colloquium sparked a wide-ranging discussion of the potential to engage consumers to improve quality at different points of entry into the health care system. At several times during the discussion, participants went back to the overarching question: Why are we talking about consumer engagement? Consistently, the answers they came up with were that engaged consumers make better choices, are more likely to avoid negative or sub-optimal outcomes, and are better able to recognize and stop inappropriate or poor-quality care. Increased consumer engagement leads to increased compliance, cooperation and commitment to health. In addition, informed consumers will likely advocate for better quality and reasonable cost, enhancing the value of their care.

Participants recognized the multidimensional nature of quality, acknowledging that it is not well defined or measured and that it may be different for patients and providers. Consumers are interested in "what is good for me," not what is good in general. This may lead to different decisions than the guidelines would suggest. More research is needed to account for the individual variation in values and preferences.

Many participants questioned whether it was realistic to believe that activating consumers would result in improved quality in the current system. Some suggested that the system needs to change. For example, the right information needs to be more readily available to allow consumers to make decisions. While there has been significant progress toward developing quality measures for public reporting, many of these measures may not be relevant for consumer decision making. They often focus on areas where there is widespread agreement about optimal processes or outcomes. They also focus more frequently on whether an activity was done correctly, not on whether it should have been done. Meanwhile, providers need to understand the benefits of consumer activation and

help consumers become more engaged, which will require time and effort.

Participants acknowledged that the current health care system is not consumer friendly. When asked to identify some important activities that could be done to facilitate consumer engagement, they put forward a number of ideas:

- Develop consumer-friendly, patient-centered aids to support decision making and navigation and insert them in a "just-in-time" and "in-the-right-place" manner to be useful to people as they go through the health care system
- Activate consumers to become more involved in preference-sensitive decisions that affect care and quality of life and give them tools—both existing tools and new tools—that will assist them in making choices that effect outcomes and costs
- Urge providers to value, promote and embrace engaged consumers
- Educate providers about the differences in patients' readiness, ability and willingness to participate in self-management of their chronic medical conditions; test the use of simple activation assessment tools, such as PAM, by providers; develop and test additional methods of increasing patient activation
- Develop and test different mechanisms to assist patient navigation through the health care system across episodes of care and across the continuum of health care services, then evaluate the effectiveness of these strategies in improving quality, cost and satisfaction with care in diverse patient populations and communities
- Continue to collect data on outcomes, such as functional status, health-related quality of life, patient experience and patient activation, and feed this back to providers so they can change and modify care processes
- Develop payment systems that reward providers for shared decision making, patient satisfaction and patient-centered care
- Conduct research on when engagement has occurred, under what circumstances and whether it can be translated to other settings

- Develop and pilot projects to engage and inform consumers about making preference-sensitive treatment choices; evaluate the most effective and efficient implementation methods
- Explore possible benefit designs that support better consumer decision making and address cost growth

Participants also identified a number of research gaps in the consumer engagement literature:

- There is a need for more research about ways that information can be framed, packaged and delivered to patients at the time they need it in order to support decision making. How can health care quality performance data be turned into information that is understood and used by consumers in making choices for ambulatory care, hospital care, surgery, long-term care and rehabilitation? What information is most relevant to patients and families? When should they receive this information? Researchers should also identify information needs for minorities, the elderly and other subgroups.
- Research is needed on the question of whether quality report cards are the right strategy. Are they appropriate for all environments and conditions or only some? Can they be improved? Do we have to improve content? Do we have to improve format? What would it take for quality report cards to be valued and used as “consumer reports” for health care?
- What is the relationship between informed choice about treatments and informed choice about costs? Will informed consumers choose more expensive care or less expensive care?
- What is the impact of disengaged consumers on costs and health outcomes? Conversely, can we document the material benefits to the system that come from engaging consumers?
- How can we develop better performance and quality-of-care measures?
- In which environments are better decisions made (e.g., hospitals, clinics, doctors’ offices, other settings)?
- What works to engage consumers? How can we develop evidence of what consumers really care about, recognizing that consumers are not homogeneous?
- What are effective strategies for consumer engagement from other industries?
- What is the impact of consumer engagement on disparities in the quality of care that the system delivers to patients?
- To what extent do patients and their families currently serve as the primary source of continuity within a complex continuum of care and treatment? Are

there system improvements that can be made to facilitate coordination and seamless transitions between sites of care and health care providers?

- How do trends in cost containment affect choices?

There was wide agreement at the RWJF meeting that consumer engagement has the potential to address a number of problems in the U.S. health care system, particularly in improving patient safety and treatment decision making. However, consumers have neither the power nor the skills to change health care systems by themselves. Change will require a coordinated effort on the part of consumers, providers, payers, insurers and policy-makers.

We are just beginning to scratch the surface of what is needed to create a patient-centered health care system. It is critical to better understand how consumers become engaged and make decisions. There is also clearly a need for sound empirical data that adds to our knowledge base and leads to the development of practical applications that can reliably improve the medical decision-making process for patients.

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