Discussion Paper

Demanding Value from Our Health Care: Motivating Patient Action to Reduce Waste in Health Care

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Explanation of contents: The following discussion paper includes two appendixes that are intended as companion and complementary items to the main text. They can also be used as pull-out, standalone resources for a variety of audiences.

This discussion paper can be accessed at: www.iom.edu/PatientsForValue.

Demanding Value from Our Health Care: Motivating Patient Action to Reduce Waste in Health Care

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Health care costs have doubled as a share of the economy over the past three decades (Martin et al., 2012), causing stress on family, employer, and government budgets. Furthermore, these expenses contain substantial waste and often do not improve patient health. One important way to improve this situation is by engaging patients and the public around value. There are numerous challenges to achieving this goal, including several unanswered questions about how best to routinely approach patients on the issue. Yet, some insights are developing. First, the success of value initiatives depends on their understanding of, and connection to, patient goals, motivations, values, and aspirations. To further engage people around value requires that comparative cost and quality information is available and comprehensive enough to support individuals' care decisions. Finally, value needs to be embedded in all aspects of health care decisions—from incentives to benefit design—to support patients and consumers as they seek to increase the value they achieve from their care. Given the size of the task, effective change will require coordinated efforts from all stakeholder groups.

WHY IS IT IMPORTANT TO ENGAGE PEOPLE IN HEALTH CARE VALUE?

In recent years, concerns have been growing about the rising cost of health care. In 2012, health care will consume an estimated 18 percent of the economy, or almost $2.8 trillion. Moreover, costs are increasing rapidly, having risen by 88 percent in the last decade (Martin et al., 2012). These rising costs stress family, employer, and national budgets. Rising health care costs have eaten away at income gains for the last decade, leaving a family's real wages essentially flat. In the same time frame, insurance premiums for families and individuals have more than doubled (Auerbach and Kellermann, 2011). These cost problems can be quite acute for those struggling with serious medical conditions, with 40 percent of such patients reporting that health care costs are a serious financial problem for them or their families (NPR, RWJF, and Harvard, 2012). If this type of spending produced outstanding results, it could potentially be justified. However, the health care system contains substantial waste that does not improve patient health and produces little value.

Greater engagement of patients and the public has the potential to transform every dimension of health care. This is especially true for improving health care value. Focusing care

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[1] Participants in the Value Incentives Learning Collaborative of the IOM Roundtable on Value & Science-Driven Health Care. While the manuscript reflects contributions from the authors, authorship does not imply endorsement of every point expressed in the document. In addition, although the individuals who provided assistance submitted many constructive comments and suggestions, they were not asked to endorse the final draft of the discussion paper before its release.

on patient needs can promote higher-quality care and better use of resources, which has been demonstrated in several prior studies. For example, several studies have found that patient-centered communication is associated with fewer diagnostic tests and lower costs (Epstein et al., 2005). Another study found lower use of health care services and lower overall cost with physicians who employ a patient-centered practice style (Bertakis and Azari, 2011). Furthermore, studies of shared decision making have found that patients who receive thorough information on benefits and risks tend to choose less-invasive treatments; one study found that well-informed patients were 20 percent less likely to choose surgery than other patients (O'Connor et al., 2009; Stacey et al., 2011). These examples demonstrate the impact that patients and consumers can have on improving health care value when they are involved in their own care.

Patients and consumers may be increasingly receptive to beginning a conversation about value. While most Americans are generally happy with their specific coverage and care, most also see the need for improvements to the overall system (Blendon et al., 2011; RWJF, 2011). For example, 65 percent of Americans grade the quality of their care as an A or a B; approximately the same percent rate the overall quality of American health care as grade C or below (Blendon et al., 2011). Moreover, changes in the structure of health insurance, such as the shift toward high-deductible health plans, have increased the level of costs borne directly by patients and consumers. In 2010, 30 percent of workers had an individual deductible of $1,000 or higher for their employer-sponsored insurance (KFF and HRET, 2011). On a national level, policy discussions have begun to focus on defined-contribution plans, like premium support and vouchers, amid growing anxiety about the ability to control ever-rising health care costs (Haskins et al., 2011).

Another opportunity to engage people in value lies in the growing interest in, and ability of the public to look for, information that can guide their decisions in many aspects of their lives. In a recent survey, almost 60 percent of individuals were willing and able to do detailed research before buying a car, and 50 percent do so before buying a major appliance (Lynch and Smith, 2011). While decisions in health care are different from decisions about consumer goods, there are some similar principles at play. Accordingly, there are signs that consumers are increasingly looking for health care information. In 2011, 80 percent of Internet users looked online for some type of health information (Fox, 2011). Before a doctor's visit, patients are looking for information to help them better explain their symptoms, while after the doctor's visit, they are looking for information to better explain what the doctor said and alternative treatment options. People's growing interest in accessing health information presents a new opportunity for engaging conversations around value.

While certain initiatives have reported success in involving people in improving health care value, more work needs to be done to understand how to engage patients consistently. Several themes are beginning to emerge from research and practice on strategies for communicating and discussing value and applying those insights to care decisions. This paper highlights key lessons learned about engaging people in value: the need to understand what patients view as value; the need to ensure the availability, utility, and use of cost and quality information; and the need to provide more than just information to support patient value decisions. These lessons can be the basis for the continuing work that needs to be done.

Further information about ways to engage patients in value is included in Appendix A, which summarizes this information in short document intended for broad accessibility. Appendix

B contains selected resources that have been developed on care cost, quality, and value for patient and consumer decision making.

WHAT ARE THE KEY CHALLENGES IN INVOLVING PEOPLE IN HEALTH CARE VALUE?

Given the unsustainable path of growth in health costs, attention needs to be focused on improving health care value. Fundamentally, value is what is gained for a given cost. Yet, this simple definition is complicated by the fact that different stakeholders have different perspectives on what procedures, treatments, technologies, and care practices are valuable and how valuable they are (IOM, 2010). Given the importance of patient perspectives in the health care system, definitions of value should consider how care improves patients' overall health, their quality of life, their experience of care, and the overall health of the public.

One challenge is that many patients and consumers are reluctant to talk about value (Hibbard and Sofaer, 2010; RWJF, 2011). In some cases, value can be perceived as a code word for rationing, implying that care may be cheapened or that patients would have less time with their clinicians (RWJF, 2011). These perceptions translate into tepid support for incentives that encourage people to consider value when selecting clinicians, health care organizations, or medical treatments.

Another challenge is that many individuals are unsure about the usefulness of detailed research into health care options. One survey found that 40 percent of people were uncertain that they could find a better-qualified doctor through detailed research while 60 percent were not confident that they could reduce the cost of health care by shopping around (Lynch and Smith, 2011). Part of the reason that many individuals believe research will not improve their health care options is the common perception that all hospitals or clinicians are of similar quality—or even that all health care meets minimum quality standards (Blendon et al., 2011; Carman et al., 2010; Hibbard and Sofaer, 2010; KFF, 2008, 2011). If quality does not vary, there is little to be gained by careful research of different health care options. Yet, multiple studies have shown that wide differences exist in the quality of care delivered by different hospitals and physicians. These quality differences occur independently of cost—sometimes better-quality care cost more, but often it costs less.

Several other challenges exist when seeking to engage patients in health care value. Unlike the decision to purchase a consumer good, health care decisions can be made under very difficult circumstances when patients are under physical, mental, and emotional stress. It is unlikely that an individual suffering a heart attack is going to research hospitals while in an ambulance. In addition, patients vary in their need to make major health decisions. In a given year, most people will use few health care services—in 2008, half of the population accounted for 3.1 percent of the total health care costs (Cohen and Yu, 2011). On the other hand, patients who deal with chronic diseases like diabetes or high blood pressure will continue to struggle with their disease for years or decades and will need to devote ongoing attention to managing these conditions. These patients will respond differently to incentives and may have different views on health care value than a patient facing an acute health care condition (Loewenstein et al., 2012). Finally, making decisions about value can be very difficult and therefore is only done by the most engaged and motivated patients (Hibbard and Sofaer, 2010). Understanding the challenges patients face is fundamental to promoting engagement in health care value.

One Patient's Struggle to Find a Physician

Mr. A, a previously healthy 37-year-old man, suffered a heart attack 3 years ago and was diagnosed with several unusual cardiac conditions. He developed a relationship with a cardiologist at a large health center in his area and appreciated his physician's attention to adverse effects from medication. In the spring of 2009, Mr. A's cardiologist moved to another area, requiring him to select a new clinician for his care. As he looked for a new physician, he couldn't find the information he wanted. He disliked the top physician lists, feeling that they weren't asking the questions he cared about, and struggled to find basic information on many of the cardiologists in his area. Further, as his conditions were unusual, he questioned whether the general findings reported on many websites would actually apply to someone like him. His story highlights the issues that many patients have in learning about potential clinicians and the need to customize information to different patients.

SOURCE: Howell, 2009

FIRST LESSON LEARNED: UNDERSTAND WHAT PATIENTS VIEW AS VALUE

One important lesson is that the success of value initiatives depends on their understanding of, and connection to, patient goals, motivations, values, and aspirations (Rollnick et al., 2008). A person's internal motivations can be a powerful resource for long-term change (Wiegand, 2011). This underlines the importance of discovering a patient's goals and how they fit into the value discussion.

Misconceptions often exist about what patients view as value. In seeking to improve the patient-centeredness of care, some health care organizations and providers have focused on aspects such as food and hotel-like amenities (Rau, 2011). Yet, previous studies have found that substantial differences often exist between the factors providers believe are important to people and the factors patients identify as valuable (Hibbard and Sofaer, 2010). Summaries of this research have found that patients value many aspects of their care, including technical performance but also including other factors (Bechtel and Ness, 2010). The factors patients consider when evaluating health care can be categorized into the following groups:

- Patient-centeredness;
- Affordability and accessibility;
- Communication and information;
- Courtesy and emotional support (from all members of staff);
- Efficiency in the use of patients' time with good coordination between all care elements;
- High technical quality; and
- Structure and facilities in which care is delivered (Sofaer and Firminger, 2005).

One theme that consistently runs through these categories is that people value a personal relationship with their clinician (RWJF, 2011). Individuals prefer a continuous relationship with someone who knows about them as a person, understands their history, and communicates with them. This type of patient-centered relationship also has been associated with positive health outcomes. In one study, HIV patients who felt that their provider knew them as a person were more likely to take antiretroviral therapy, adhere to that treatment, and have better outcomes (Beach et al., 2006).

Another area that patients consider in their value calculus is whether their doctor stays up to date with the latest medical evidence. Focus group research has found that patients are generally supportive of medical evidence and efforts to identify the treatments that produce the best results for patients. However, research also shows that patients can become concerned about medical evidence if it is seen as limiting their options, since more care, especially newer care, can be perceived as better. Further, consumers may believe that evidence-based guidelines only apply to the average patient and are inflexible (Carman et al., 2010). Patients, therefore, weigh the interaction between options, new knowledge, and customization to their condition in deciding the value of new medical evidence.

Beyond value in medical care, there are emerging lessons about what consumers value in health insurance plans. Focus groups have found that consumers do not define value in health insurance based solely on price. Rather, consumers also account for a plan’s covered medical services and how much they would pay out of pocket for those services (Quincy, 2012).

Yet, patients are not homogeneous in their views. Opinions about value vary from state to state, from town to town, and from individual to individual. As recognized by the concept of shared decision making, the right answer for a given patient depends on his or her personal characteristics, values and goals, and support networks.

SECOND LESSON LEARNED: MAKE SURE THE BEST INFORMATION IS EASY TO FIND AND USE

Another important lesson in engaging patients in value is that comparative cost and quality information should be available and comprehensive enough to support individuals’ care decisions. Too often, beyond anecdotes and stories, individuals have little trusted information that they can use to make decisions. Even among patients who are engaged, it is frequently unclear where to go for reliable sources of information about their providers, hospitals, or health plans (Howell, 2009).

Current cost- and quality- reporting efforts have gained limited traction with the public—few people know about them, and fewer use them in making decisions (Fung et al., 2008; KFF, 2008; Lynch and Smith, 2011). One survey found that approximately 14 percent of respondents noted that they had seen and used information comparing the quality of different health insurance plans, doctors, or hospitals (KFF, 2008), while another found that less than 30 percent of individuals research potential physicians (Lynch and Smith, 2011).

Challenges in Applying Information to Care

One reason for the limited use of reported information is that information is routinely presented in a way that is not meaningful to people. Complex information that cannot be applied easily to an individual’s health care situation will not be used (Hibbard and Sofaer, 2010; Hibbard et al., 2012; Hibbard and Peters, 2003; Shaller Consulting, 2006; Vaiana and McGlynn, 2002). The presentation of the information may be as important as the information itself—the context, language, graphics, and format of information help people use it easily (Hibbard and Sofaer, 2010; Vaiana and McGlynn, 2002).

Several factors can affect whether people use reported information, such as whether they have multiple health care options in their geographic area, whether financial incentives encourage patients to seek high-value providers or health care organizations, and whether their physicians or family recommend a particular provider (Blendon et al., 2011; KFF, 2011; Lynch and Smith, 2011; Sinaiko, 2011; Sinaiko and Rosenthal, 2011; Tu and Lauer, 2009). Another factor is the salience of the presentation; statistics may not be as powerful as anecdotes or personal examples when individuals are making health care decisions (RWJF, 2010). One study found that patients presented with statistical information made different decisions than those presented with statistical information and a single contradictory anecdote—the number of patients choosing a given treatment dropped by 20 percentage points when they were given an anecdote that contradicted the statistics (Fagerlin et al., 2005). This highlights the need to deliver information in a way that resonates with people's goals and preferences.

There are specific concerns when information is presented online. Given the ubiquity of the Internet as an information source, more health care value information is increasingly presented there. Online information is of varying quality and comprehensiveness, ranging from basic consumer reviews—where patients write about their experiences—to complex sites with objective quality and value measures which can present very technical material. Given how common review sites are in other aspects of everyday life, it is likely that their prevalence in health care is going to increase over time.

In considering online information, it is important to recognize that people from different age groups have differing interest in using online information sources for health care decisions (Lynch and Smith, 2011). When considering how to display cost and quality information online, there are several best practices gained from focus group and survey research. First, a simple, uncluttered format with easily understandable information tends to be preferred by most people. All terms should be explained clearly, especially those whose meaning depends on one's perspective. Second, building trust is important as conflicts of interest are a common concern—individuals want to know the source of information as well as the sponsors who provided financial support (RWJF, 2010).

Another factor that influences people's use of health information is the complexity of the information and the technical language used to describe health care options, from health plans to treatments. Understanding the terminology and concepts needed to make value decisions can be daunting, especially when that information is presented in complex and lengthy documents. These problems are compounded for the nearly half of all American adults with lower rates of health literacy (IOM, 2004). Even for those with higher levels of health literacy, focus group research finds that common health benefit terms—like deductible, co-insurance, and out-of-pocket limits—can be difficult to apply, making comparison shopping and informed selection difficult for consumers (IOM, 2012; Quincy, 2012).

In the specific case of providing cost and price information, several considerations are relevant. Without useful information about quality, consumers can equate higher cost with higher quality (Hibbard et al., 2012; Mehrotra et al., 2012). For example, one survey of California residents found that 35 percent believed higher price was associated with better care, while 65 percent assumed the care was probably about the same, regardless of price (Shannon, 2011). If this perception leads more people to seek high-cost providers, then cost reports without quality information have the potential to increase costs. To prevent this problem from occurring, cost information needs to be meaningfully integrated with information about the quality of health care services and providers to highlight that higher-quality care can be delivered at lower cost

(Carman et al., 2010; Hibbard and Sofaer, 2010; Hibbard et al., 2012; Mehrotra et al., 2012; Sinaiko and Rosenthal, 2011).

When providing price and cost information, many patients and consumers are specifically interested in their estimated out-of-pocket cost. Yet, several factors make it difficult to provide estimates of out-of-pocket costs. It is rarely known what health care services are needed for a specific health condition; each health plan tends to use a different benefit structure with different levels of cost sharing; and the negotiated rates for services are rarely disclosed for proprietary, antitrust, or contractual reasons. As an example, in a Government Accountability Office survey of 19 Colorado hospitals, none was able to provide a complete estimate of the consumer's cost for a full knee replacement (GAO, 2011). Without such basic information, people have little ability to seek better value.

Finding the Price of Care

Finding the price of a particular treatment or test can be very difficult. Brad, a student from North Carolina, experienced this problem after developing a sinus infection. As Brad had a high-deductible, catastrophic insurance policy that covered only four physician visits a year, he was very concerned about the cost of treating this condition. His physician prescribed lab work and a CT scan, but Brad knew that his insurance would not cover the CT scan. At first, he asked admissions for the price. Admissions didn't know, so they called the imaging department, which also didn't know. Finally, admissions found the price of a sinus CT scan ($900) in a little-used black binder. Brad declined the CT scan, but went to the lab. Unfortunately, his physician had referred Brad to a lab that was out of network for his insurance. A month later, he received a bill for $478. Brad learned that when looking for medical care, even routine services, finding the cost of care is frequently the biggest challenge.

SOURCE: Shah, 2010

Strategies for Success

These factors speak to the need to simplify information to highlight what the consumer needs to know, when they need to know it (Quincy, 2011; RWJF, 2011). To be useful for decision making, information must be available just in time, immediately understandable, and applicable to the health care situation under consideration. A study of 70 health plan report cards concluded that the most useful report cards presented information in a form that consumers could understand at a glance and then explore more deeply if interested (Cronin, 2011). Meeting this goal often requires involving people in the design of reporting schemes to understand their preferences and needs (Bechtel and Ness, 2010; Quincy, 2012; Shaller Consulting, 2006). Several other industries outside of health care have developed sophisticated methods for translating complex information to a public audience in a format that can be used for decision making. These methods can provide inspiration for new health care communication strategies that are usable and accessible to patients and the public.

Customizing Messages Increases Their Potential Usefulness

While information is important in itself, the more customized the information is to a particular patient, the more likely it is to be used. As an example, one study looked at how likely patients were to take a particular cholesterol medication (a statin). Some patients were given a generic guide to cholesterol, while others received feedback customized to their knowledge about cholesterol, their beliefs and values, and the barriers they identified to taking a medication. At the end of 6 months, 70 percent of the patients who received the more customized messages were still taking their medication, compared to 61 percent of those who received generic materials.

While this is a clinical example, the same principle is true for information about value. Adapting the message to an individual's beliefs, knowledge, and goals will be more likely to succeed than offering generic information.

SOURCE: Stacy et al., 2009

As different populations have different needs, preferences, and abilities, strategies customized to meet those needs are more likely to succeed (Kling et al., 2008; RWJF, 2011; Wiegand, 2011). People vary in their ability to manage their health, the family and community resources they can draw upon for their care, and their motivations and interest to be involved in their care. Some people, including those struggling with serious conditions, are very well informed about their care options, follow clinical research, and play an active role in their care. Those patients taking an active role in their care will have different information needs (and respond to information differently) than less-engaged patients (Hibbard and Cunninghan, 2008; Hibbard et al., 2004). To engage individuals who are currently less activated in health care, initiatives may need to encourage small steps, start where people are, and measure and assess their progress (Hibbard and Tusler, 2007).

Another opportunity for expanding the availability of value information is by involving clinicians in this effort. Clinicians are trusted sources of information for many patients, and people often turn to them for help in making decisions. As such, their involvement is critical in moving toward increased patient engagement. However, those clinicians, often in primary care, many times lack the information they need to help their patients with value decisions. Although such discussions require substantial time and effort, clinicians receive few incentives for undertaking these important conversations. In addition, clinicians have few practical tools at their disposal for discussing value with their patients, further limiting their ability to engage in these efforts.

Similarly, families and caregivers can play an important role in discussing value with patients. Families, friends, and caregivers are a key source of information that people use in making decisions. People often value the recommendations or opinions of friends and family over objective data about the quality of providers (Sinaiko, 2011). Further, families and caregivers can play an important role in decision making, from choosing what clinicians to visit to selecting treatments and scheduling physician visits. As such, they also need to be involved in value conversations and given tools they can use in having conversations with their loved ones.

Policy Implications

An improved understanding about how to provide health care quality and cost information has implications for several current initiatives. These include efforts to communicate health benefit information in state health insurance exchanges, especially the proposed "coverage facts label," as those materials are designed to assist consumers in making health insurance purchasing decisions (AHIP and BCBSA, 2011; IOM, 2012; NCQA, 2012; Quincy, 2012). These also include public reporting efforts to help patients and consumers make informed selections of clinicians and health care organizations, such as Hospital Compare, Physician Compare, and private-sector initiatives. Finally, other improvement initiatives, like Partnership for Patients, depend on public engagement strategies to increase awareness and attention to patient safety.

THIRD LESSON LEARNED: INFORMATION ALONE IS NOT ENOUGH

A third lesson for engaging people in value is that information alone is not enough to support health care value decisions. In fact, simply supplying more information is unlikely to focus attention on health care value. Rather, multiple strategies are needed to support patients and consumers as they seek to maximize the value of their care.

One reason that multiple strategies are needed is that most health care decisions are complex and are made under considerable uncertainty. In complex situations, people tend to use rules of thumb to make decisions and tend to stick with default options (Halpern et al., 2007). In addition, in complex situations people often will delay decisions or not make them altogether, thereby staying with the status quo, if the situation becomes overly complex (Kling et al., 2008).

One example of complexity in health care decision making is in health benefit arrangements. Health benefits can often be complex, with different levels of cost sharing for different types of care. For instance, some high-deductible plans specifically provide preventive

Supporting Chronic Disease Management

Many patients in America have long-term, chronic diseases, like diabetes or asthma, that require them to take medications for long periods of time. Many people stop taking their medications regularly, which can cause their disease to get worse because it's not being treated properly. To improve this problem, Pitney Bowes redesigned its prescription drug program. It lowered the amount that employees had to pay to fill prescriptions to treat diabetes and heart disease. As a result, more employees stayed on their medications. For employees with diabetes, pharmacy costs were lowered 7 percent, emergency room visits were reduced by 26 percent, and insurance costs for diabetes patients were reduced by 6 percent. While financial incentives are only one factor affecting an individual's health care behavior, thoughtfully designed incentives can support patients as they seek to maintain their health.

SOURCE: Choudhry et al., 2010a; Mahoney, 2005 coverage and chronic care maintenance at low or no cost sharing to encourage preventive care. Yet, a recent study found that many people with high-deductible plans still use preventive services less than people with plans with lower deductibles even though preventive care is specifically exempted from the plan's cost-sharing requirements (Beeuwkes Buntin et al., 2011). This suggests that the more complex the incentive structure, the more difficult it will be to achieve the desired effect.

Strategies for Success

One way to support consumer decisions about value is providing financial incentives that reward quality and value in health care. Yet, these incentives will not be successful unless they are designed with an understanding of how people actually respond to financial motivators (Loewenstein et al., 2012). For example, simply increasing the proportion of costs that are paid by patients will lower their use of health care, but may not focus attention on high-value care (Chernew et al., 2008; Choudhry et al., 2010b; Hsu et al., 2006).

Behavioral economics has shown that the way that people actually respond to incentives may be different than predicted by traditional economic theories (Loewenstein et al., 2012). In practice, people react to incentives according to several common factors that can be predicted (Volpp et al., 2009b). For example, people are adverse to loss (they have stronger feelings about losing a given amount of money than gaining the identical amount), they are optimistic about their chances of success, and they tend to focus on the present over the future. These findings have substantial implications for designing more effective health care incentives that help people meet their health and health care goals (Volpp et al., 2008a). For example, incentives that reward people in the same time frame as a given action will be more successful—an annual reward will likely not encourage someone to exercise three times a week or take a pill once a day (Volpp et al., 2008b, 2011). Rather, more frequent incentives may needed to support those types of behaviors. In short, the structure of the incentives is as important as their size. While these general rules are true, different populations respond in distinct ways to incentives, meaning that incentives need to be customized to be effective (Choudhry et al., 2010a, 2011; Volpp et al., 2009a).

Lottery Rewards for Medication Adherence

There are new ways to encourage people to take health-promoting actions. In a study at the University of Pennsylvania, participants at risk for stroke and bleeding were prescribed the drug warfarin and given a reminder device. The device did something else, too—it kept track of whether participants had taken their medication as planned, and then entered them into a daily lottery. The lottery structure was a 1-in-5 chance of winning $10 each day, and a 1-in-100 chance of winning $100 each day. Participants were told every day if they had won, or if they would have won if they'd taken their medication as their prescription indicated. The study found that the number of missed doses went down dramatically. Health outcomes also improved, although only during the course of the study. Why was this successful? The incentive provides quick rewards. It also incentivizes people who are averse to loss, since no one wants to miss out on winning the lottery.

SOURCE: Volpp et al., 2008b

Another strategy for success recognizes that information can be more useful if embedded into decisions, especially in default options. As noted earlier, the default option can have a big impact on patient behavior. Customizing default options makes it easier to apply quality and value information to a care situation while ensuring that individuals continue to have choice in their health care options. Several research studies have shown that thoughtful use of default options, as well as other methods of embedding information in decisions, can be effective in promoting health and high-value care (Keller et al., 2011; Wisdom et al., 2010).

Policy Implications

New forms of benefit design, such as value-based insurance design and reference pricing, seek to shape incentives according to value. The lessons learned about incentives have implications for health care payers designing consumer financial incentives, from consumer-directed health plans to tiered benefit structures to value-based insurance design. They have further implications for employers seeking to incorporate incentives in their health and wellness programs. Finally, given the importance of default options, these should be carefully considered for state health insurance exchanges, employer-based plans, and public programs.

CONCLUSIONS

Engaging and investing patients in health care value will require coordinated action from all stakeholder groups. For each stakeholder group, the three lessons learned have different implications, as noted in the list below.

Patients, Consumers, the Public

- Researchers have found that the quality and value of medical care varies substantially among doctors, hospitals, communities, and other parts of health care—even among highly reputable physicians and other providers.

Clinicians

- Different choices are appropriate for different patients, and clinicians cannot provide high-value care without engaging patients to understand their goals, values, and motivations.
- Clinicians play an important role in discussing cost and quality information with patients.

Health Care Payers (Insurers and Employers)

- Incentives have been shown to be effective if they are thoughtfully designed to reward and encourage greater value.
- Engaging patients in developing incentives can improve their effectiveness by understanding patient needs, motivations, and goals.

System

- Consumers and patients often lack the information they need on quality and value to compare and evaluate health care options—from clinicians to treatments to hospitals.
- Cost and quality need to be improved overall to ensure the sustainability of the health care system.
- Given the size of the problem, everyone involved in the health care system—patients, doctors, hospitals, employers, and others—needs to work for a high-quality, high-value system.

States

- Insurance exchanges offer an opportunity to promote value, provide more information on cost and quality, and offer other tools to help consumers and patients make decisions.

Researchers and Research Funding Agencies

- Research is needed to better understand effective ways to engage people around value.
- More research needs to be done to create practical tools that can be used by patients, their families and caregivers, and clinicians in conversations about value.

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Appendix A

Motivating patient action on waste in health care

What have we learned?

Motivating patient action on waste in health care

What have we learned?

Health care costs have risen rapidly, stressing family, employer, and national budgets, yet these expenses often do not improve patient health and contain substantial waste. One way to reduce waste and improve overall health care value is engaging patients and the public. While questions still exist on how to routinely involve patients in health care value decisions, several key lessons are known. Implementing these lessons can help increase patient and consumer involvement in health care and improve the value of health care for the nation.

ENGAGING PATIENTS IN HEALTH CARE VALUE | Lessons Learned

1. Understand what patients view as value

Improving value depends on understanding and connecting to patient goals, motivations, and values.

2. Make sure the best information is easy to find and use

Information on quality and cost should be easy to find and comprehensive enough that individuals can truly understand and use it.

3. Information is not enough

Information alone is not enough to support high-value decisions, but multiple strategies are needed to support patients as they seek to increase the value of their care.

This document serves as a companion item to the Institute of Medicine Discussion Paper *Demanding Value from Our Health Care: Motivating Patient Action to Reduce Waste in Health Care* by Margaret O'Kane et al. The full Discussion Paper can be found online at www.iom.edu/PatientsForValue. For more information contact, vsrt@nas.edu.

ENGAGING PATIENTS IN HEALTH CARE VALUE | Key Messages

Patients, consumers, and the public

- *Researchers have found that the quality and value of medical care varies substantially among doctors, hospitals, and communities—even among highly reputable physicians and other providers.*

Clinicians

- *Different choices are appropriate for different patients, and clinicians cannot provide high-value care without engaging patients to understand their goals, values, and motivations.*
- *Clinicians play an important role in discussing cost and quality information with patients.*

Employers and insurance companies

- *Incentives have been shown to be effective if they are thoughtfully designed to reward and encourage greater value.*
- *Engaging patients in developing incentives can improve their effectiveness by understanding patient needs, motivations, and goals.*

Health care dystem

- *Cost and quality need to be improved overall to ensure the sustainability of the health care system.*
- *Consumers and patients often lack the information they need on quality and value to compare and evaluate health care options—from clinicians to treatments to hospitals.*
- *Given the size of the problem, everyone involved in the health care system—patients, doctors, hospitals, employers, and others—needs to work for a high-quality, high-value system.*

States

- *Insurance exchanges offer an opportunity to promote value, provide more information on cost and quality, and offer other tools to help consumers and patients make decisions.*

Researchers and research funding agencies

- *Research is needed to better understand effective ways to engage people around value.*
- *More research needs to be done to create practical tools that can be used by patients, their families and caregivers, and clinicians in conversations about value.*

What can be done about rising health care costs?

The cost of health care is becoming increasingly unaffordable for many patients, families, businesses, and the nation. In the past decade, insurance premiums for families and individuals have more than doubled. Yet, the situation will not improve by cutting costs across the board—that would eliminate waste but also the treatments, screenings, and prevention that make people healthier. For this reason, the goal should not be to cut costs, but to improve the value of health care overall. In basic terms, this means that patients receive the best-quality care for their money.

While it is easy to talk about value, it is much harder to measure and improve it. Value means different things to different people and groups—physicians, insurance companies, manufacturers, employers, and patients have different perspectives on what is valuable in health care. Even when agreeing that something is valuable, different groups of patients will consider different treatments or medical services more or less valuable. Given that patients are key and central participants in the health care system, value should always include the patient's perspective, accounting for how care improves the patient's health, quality of life, and overall experience.

Why is it important for everyone to be engaged in the value of health care?

In addition to the fact that engaging patients is the right thing to do, greater engagement of patients, people, and the public has the potential to improve health care value. Studies have shown that when patients are involved in decisions and weigh risks and benefits, they choose fewer tests and treatments, and overall costs are lowered. Involving patients and consumers can have a powerful impact in improving health care value and making sure that resources are devoted to areas that improve patient health.

Engaging patients and consumers in health care value is an urgent priority. Changes in the structure of health insurance, such as the rise of high-deductible health plans, have increased the level of costs borne directly by patients and consumers. These changes require patients and consumers to play a greater role in considering the value of care.

Yet, there are opportunities to better involve patients in health care, especially people's growing willingness and ability to research many aspects of their lives. In a recent survey, almost 60 percent of individuals were willing to do detailed research before buying a car (and were able to find useful resources for this purpose) and 50 percent do so before buying a major appliance. While health care is different from buying a car or appliance, people's growing interest in research and ability to do so change the way they consider health care decisions.

While some strategies for involving people in health care value have succeeded, there are many unanswered questions and challenges, and there is room for improvement. However, much is now known on effective ways to team with people to discuss value, deliver better value, and help with health care decisions.

What are the key challenges to engaging people more effectively in health care value?

Understanding the challenges that patients face is fundamental in expanding their engagement in health care value. In general, making decisions based on health care value is difficult work and generally only done by the most involved and motivated patients. There are several other challenges that prevent its consideration.

Concerns about rationing

Many people are reluctant to talk about getting better value for their care. There is often a fear that value is a code word for rationed, cheap, or low-quality care. As a result, support for programs that encourage people to consider value when selecting clinicians or treatments is limited.

One patient's struggle to find a physician

Mr. A, a previously healthy 37-year-old man, suffered a heart attack 3 years ago and was diagnosed with several unusual cardiac conditions. He developed a relationship with a cardiologist at a large health center in his area and appreciated his physician's attention to adverse effects from medication. In the spring of 2009, Mr. A's cardiologist moved to another area, requiring him to select a new clinician for his care. As he looked for a new physician, he couldn't find the information he wanted. He disliked the top physician lists, feeling that they weren't asking the questions he cared about, and struggled to find basic information on many of the cardiologists in his area. Further, as his conditions were unusual he questioned whether the general findings reported on many websites would actually apply to someone like him. His story highlights the issues that patients have in learning about potential clinicians, and the need to customize information to different patients.

Source: Howell, 2009.

Lack of resources and tools

While people may conduct detailed research before buying a smartphone or a stove, few individuals do so when choosing a physician or considering medical treatments for a disease—some recent surveys suggest that less than 30 percent of patients research potential physicians before selecting one. One reason is the lack of clear, reliable resources. It is very difficult for patients to find the price or what they can expect to pay out of pocket for treating a disease. As noted in the earlier survey, 40 percent of patients indicated that they were uncertain that they could find a better-qualified doctor through more research while 60 percent were not confident that they could reduce the cost of health care by shopping around.

Few know how much quality varies

There is a widespread perception among patients that quality does not significantly vary between different hospitals or clinicians, with many believing that all health care must meet some minimum quality standards. Careful shopping seems unnecessary if all health care is expected to be of a certain quality. Yet, research has shown that wide differences exist in the quality of care delivered by different hospitals and physicians.

High prices can be seen as better quality

Without information on the quality of health care, most people are inclined to believe that a higher price means better care. Research suggests that this is not true. Expensive care is not necessarily better quality than inexpensive care; in fact, the opposite is often true. This shows the need to link prices and quality information together.

Difficult conditions for making decisions

Unlike other consumer decisions, health care decisions are often made under very difficult circumstances. For example, it is unlikely that an individual suffering a heart attack is going to research hospitals while in an ambulance. Moreover, patients who deal with chronic diseases like diabetes or high blood pressure will need to devote ongoing attention to managing and making decisions about these conditions. Patients managing these types of health conditions will respond differently to incentives and may have different views on health care value than patients facing other types of health conditions.

First lesson learned: Understand what patients view as value

One lesson is that the success of value initiatives depends how well they connect with and include patient goals, desires, and motivations. A person's internal motivations can be a powerful resource for long-term change. This is why it is important to discover a patient's goals and motivations.

There are often misconceptions about what patients view as value. Some organizations and hospitals have tried to become more patient-centered by focusing on customer service and food, for instance. Yet, this is not necessarily in line with what studies show patients want and care about. Instead, patients want medical care

- centered around their needs and values;
- that is affordable and accessible;
- with good communication and information;
- where all staff members show courtesy, respect, and emotional support;
- that is efficient in the use of their time and well coordinated between all clinicians;
- of high technical quality; and
- with adequate facilities.

Most patients desire a personal relationship with their care provider. Patients want someone who knows them and their history, listens to them, and communicates well. When patients have a high-quality relationship with a clinician, health outcomes can improve. In one study, HIV patients who felt their provider knew them as a person were more likely to take antiretroviral therapy, adhere to that treatment, and have better outcomes.

Patients also want their doctors to be on top of the latest science, and are generally supportive of research efforts to improve medical knowledge. However, research also shows that patients can become concerned about medical evidence if they think it might limit their

Customizing messages increases their potential usefulness

While information is important in itself, the more customized the information is to a particular patient, the more likely it is to be used. As an example, one study looked at how likely patients were to take a particular cholesterol medication (a statin). Some patients were given a generic guide to cholesterol, while others received feedback customized to their knowledge about cholesterol, their beliefs and values, and the barriers they identified to taking a medication. At the end of 6 months, 70 percent of the patients who received the more customized messages were still taking their medications, compared to 61 percent of those who received generic materials.

While this is a clinical example, the same principle is true for information about value. Adapting the message to an individual's beliefs, knowledge, and goals will be more likely to succeed than offering generic information.

Source: Stacy et al., 2009.

options or if the evidence is perceived to create inflexible guidelines. Patients want the latest and best information, but want to maintain choice and autonomy.

Beyond value in medical care, there are emerging lessons about what consumers value in health insurance plans. They evaluate health plans not only on price, but also on the services that are covered and how much they would pay out of pocket for those services.

Yet, patients are not uniform in their views. Opinions about value vary from town to town and from state to state. The right answer for any individual depends on their personal characteristics, values and goals, and supports.

Second lesson learned: Make sure the best information is easy to find and use

A second lesson is that information should be easy to find and comprehensive enough so that individuals can truly understand and use it. Too often, it is hard to find reliable sources of information on health care providers, hospitals, or health plans. People then turn to the stories or opinions of their friends and family.

Existing cost and quality reports are frequently difficult to use, with information frequently presented in a confusing format or with confusing language. People will not use information they cannot easily understand. To be useful, the reports should use clear graphics and plain language to help people find what they need to know.

Other factors can affect whether people use reported information. In some areas of the country, people may have only one health care option to choose from, so there is little to gain from research. In addition, many individuals prefer to use stories, personal examples, and information that speaks directly to their own individual situation, rather than statistics, for making health care decisions.

Frequently, the information is very complex and difficult to understand, from medical terminology to health insurance benefit arrangements. Understanding the terms and concepts can be challenging, especially when they are placed within a lengthy document. Even for those familiar with health care, common health benefit terms—like deductible, co-insurance, and out-of-pocket limits—can be difficult to apply in everyday value decisions. This complexity makes comparison shopping and informed selection difficult.

Finding the price of care

Finding the price of a particular treatment or test can be very difficult. Brad, a student from North Carolina, experienced this problem after developing a sinus infection. As Brad had a high-deductible, catastrophic insurance policy that covered only four physician visits a year, he was very concerned about the cost of treating this condition. His physician prescribed lab work and a CT scan, but Brad knew that his insurance would not cover the CT scan. At first, he asked admissions for the price. Admissions didn't know, so they called the imaging department, which also didn't know. Finally, admissions found the price of a sinus CT scan ($900) in a little-used black binder. Brad declined the CT scan, but went to the lab. Unfortunately, his physician had referred Brad to a lab that was out of network for his insurance. A month later, he received a bill for $478. Brad learned that when looking for medical care, even routine services, finding the cost of care is frequently the biggest challenge.

Source: Shah, 2010.

These challenges highlight the need to provide simple, clear information any time a consumer needs it. To be useful for decision making, information must be

- available just in time;
- immediately understandable;
- trustworthy, disclosing the sources of all information, including financial sponsors;
- applicable to the health care situation under consideration; and
- customized to the needs, preferences, and skill sets of different people.

Lotteries help people adhere to treatment

There are new ways to encourage people to take health actions. In a study at the University of Pennsylvania, participants at risk for stroke and bleeding were prescribed the drug warfarin and given a reminder device. The device did something else too—it kept track of whether the participants had taken their medication as planned, and then entered them into a daily lottery. The lottery structure was a 1 in 5 chance of winning $10 each day, and a 1-in-100 chance of winning $100 each day. Participants were told every day if they had won or if they would have won if they'd taken their medication as their prescription indicated. The study found that the number of missed doses went down dramatically. Health outcomes also improved, although only during the course of the study. Why was this successful? The incentive provides quick rewards. It also incentivizes people who are averse to loss, since no one wants to miss out on winning the lottery.

Source: Volpp et al., 2008.

Besides published cost and quality information, people value talking to trusted individuals when making health care decisions. For example, many people would like their health care provider to help them consider complex health care decisions. However, many clinicians, often in primary care, lack the practical tools, time, and incentives they need to take on these conversations. Similarly, families, friends, and caregivers can play an important role in helping patients consider value, yet they may also not have the tools they need.

Third lesson learned: Information is not enough

A third lesson is that information alone is not enough to support high-value decisions. Rather, multiple strategies are needed to support patients and consumers as they seek to increase the value they achieve from their care.

As mentioned earlier, most health care decisions are complex and are made under considerable uncertainty. In complex situations, people tend to use rules of thumb to make decisions and tend to stick with default options. In addition, people often will delay decisions or not make them altogether. This will occur even if patients are unhappy with the current situation and would prefer to make a change.

Supporting patients with chronic diseases

Many patients in America have long-term, chronic diseases like diabetes or asthma that require them to take medications for long periods of time. Many people stop taking their medications regularly, which can cause their disease to get worse because it's not being treated properly. To improve this problem, Pitney Bowes redesigned its prescription drug program. It lowered the amount that employees had to pay to fill prescriptions to treat diabetes and heart disease. As a result, more employees stayed on their medications. For employees with diabetes, pharmacy costs were lowered 7 percent, emergency room visits were reduced by 26 percent, and insurance costs for diabetes patients were reduced by 6 percent.

Source: Choudhry et al., 2010a; Mahoney, 2005.

One way to support consumer decisions about value is providing financial incentives that reward considering quality and value. Yet, these incentives will not be successful unless they are designed with an understanding of how people actually respond to financial motivators. As patients pay more for health care, they cut back on all of their health care—whether it is of high value (like insulin for a patient with diabetes) or not.

How do people actually respond to financial incentives? People have stronger feelings about losing a given amount of money than gaining the identical amount, they are optimistic about their chances of success, and tend to focus on the present over the future. Incentives that account for these human factors (like the lottery example) have a greater chance of success. For example, a payment at the end of the year may not encourage someone to exercise three times a week, as the pain of exercising is immediate while the reward is far in the future. Finally, different types of patients respond differently to incentives. To have a better chance of success, incentives need to be customized to particular health care situations and to specific patients' capabilities, preferences, and needs.

For more information, please consult the following resources:

Benefits of Centering on Patients

Beach, M. C., J. Keruly, and R. D. Moore. 2006. Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *J Gen Intern Med* 21(6):661-665.

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This document serves as a companion item to the Institute of Medicine Discussion Paper *Demanding Value from Health Care: Motivating Patient Action on Waste in Health Care*[1] which was authored by:

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[1] The views expressed in the Discussion Paper are those of the authors and not necessarily of the authors' organizations or of the Institute of Medicine. This Issue Brief and the paper are intended to help inform and stimulate discussion. They have not been subjected to the review procedures of the Institute of Medicine and are not a report of the Institute of Medicine or of the National Research Council.

Appendix B

Examples of Quality and Cost Reporting

Varied sites exist for consumer information

Examples of Quality and Cost Reporting

Varied sites exist for consumer information

Examples of Quality Reporting

Resource	Description
AHRQ Chartered Value Exchanges *www.ahrq.gov/qual/value/lncveover.htm*	The Agency for Healthcare Research and Quality (AHRQ) organizes a network of multi-stakeholder, community-based organizations. Examples of organizations that publish quality measures and statistics include - Kansas City Improvement Consortium's Quality Health Together: *www.qualityhealthtogether.org* - Maine Health Management Coalition's Get Better Maine: *www.getbettermaine.org* - Utah's HealthScape: *www.utahhealthscape.org*
AHRQ Health Care Report Card Compendium *www.talkingquality.ahrq.gov/content/reportcard/search.aspx*	The AHRQ provides a variety of resources to help reporting organizations publish quality information. As a part of this initiative, AHRQ has assembled a comprehensive list of quality reports, searchable by subject, state, sponsor, data type, and other criteria.
Care About Your Care *www.careaboutyourcare.org*	The website provides printable handouts with tips for consumers on how to get better health care. A highlighted resource is the Robert Wood Johnson Foundation's "Comparing Health Care Quality: A National Directory," which provides quality reports available from around the nation. The website also provides a list of additional resources to find quality care.
CMS Hospital Compare *www.hospitalcompare.hhs.gov*	Medicare's hospital compare tool allows users to compare quality measures from hospitals located within or around any given zip code. The website also publishes Medicare payment information.

This resource guide serves as a companion item to the Institute of Medicine Discussion Paper *Demanding Value from Our Health Care: Motivating Patient Action to Reduce Waste in Health Care* by Margaret O'Kane et al. The full Discussion Paper can be found online at www.iom.edu/PatientsForValue. For more information, contact vsrt@nas.edu.

Consumer Health Ratings *www.consumerhealthratings.com*	This online resource is provided as a free, public service by the Dahlen Company, and consolidates quality rating information for hospitals, providers, nursing homes, home health agencies, and other health care providers.
HealthCare.gov *http://www.healthcare.gov*	Created by the Affordable Care Act, this will be a one-stop resource for quality information. The website currently links to Partnership for Patients and Medicare Physician, Hospital, Nursing Home, Home Health, and Dialysis Facility Compare.
HealthGrades *http://www.healthgrades.com*	Users search for doctors (including by specialty), dentists, and hospitals in a given area. Published information includes provider demographics, accepted insurance, and whether they are accepting patients. Quality metrics are self-reported patient survey data. These surveys also generate "stars" that rank a provider from 1–5 stars.
Joint Commission Quality Check *www.qualitycheck.org/consumer/searchQCR.aspx*	This website provides a search engine so users can find Joint Commission accredited health care organizations.
Leapfrog Group Hospital Quality Compare *www.leapfroggroup.org/cp*	The website publishes self-reported overall patient safety ratings, with four bars that indicate progress toward meeting Leapfrog's standards.
NCQA Clinician Directory *www.recognition.ncqa.org*	NCQA provides a search engine to find physicians, broken down by state, who have met the criteria for NCQA recognition programs.
NCQA Health Plan Report Card *www.reportcard.ncqa.org/plan/external*	The website is a directory of health plans searchable by name, state, zip code, and plan type. NCQA provides the plans' overall accreditation status. Users can then compare plans to learn further details.
UCompareHealthCare *www.ucomparehealthcare.com*	Users can search for physicians, hospitals, senior care, insurance, clinics, and pharmacies by zip code. The website has a "compare" function so users can look at selected health care providers side by side. Hospital and nursing home profiles include quality measures such as patient satisfaction.
U.S. News & World Report Health Plans *www.health.usnews.com/health-plans*	Users can search for how health plans are ranked, broken down by state. The website includes articles that define health insurance terminology and tips on how to pick the best plan.

Examples of Cost Reporting*	
Resource	**Description**
FAIR Health *www.fairhealth.org*	The website helps insurers calculate out-of-network costs and at allows consumers to examine the reimbursement process. Other tools for consumers include a glossary of terms and videos that help explain the reimbursement process.
Healthcare Blue Book *http://healthcarebluebook.com*	This online tool allows users to find standard prices for a variety of procedures based upon their zip code. The website calculates average prices based upon local billing and medical payment data.
Hospital Price Reporting *Various resources available*	In several states, hospital associations are publishing price information for consumers. Examples include - Colorado: *www.cohospitalprices.org* - Wisconsin: *www.wipricepoint.org*
Insurer Price Reporting *Various resources available*	Some insurers provide information to their members on the cost of health care services, and allow users to calculate out-of-pocket expense estimates. Examples include - Aetna Member Payment Estimator - Anthem Care Comparison
State Price Reporting *Various resources available*	Several states publish not only quality information for providers and hospitals within the state, but also the prices for treatments and services. Examples include - New Hampshire Health Cost: *www.nhhealthcost.org* - Massachusetts' MyHealthCareOptions: *www.hcqcc.hcf.state.ma.us*

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* Several highlighted initiatives were first identified in the October 24, 2011 U.S. Government Accountability Office report, *Health Care Price Transparency: Meaningful Price Information Is Difficult for Consumers to Obtain Prior to Receiving Care*.