GRANTMAKERS IN HEALTH

CONSIDERING QUALITY:

Engaging Consumers to Make Better Health Care Decisions

ISSUE BRIEF NO. 27

JANUARY 2007

BASED ON A GRANTMAKERS IN HEALTH ISSUE DIALOGUE

WASHINGTON, DC

EXECUTIVE SUMMARY

CONSIDERING QUALITY:

Engaging Consumers to Make Better Health Care Decisions

On May 19, 2005, Grantmakers In Health (GIH) convened nearly 50 grantmakers and leaders in the field of health care quality to discuss the challenges inherent in developing quality information, as well as how consumers use such information. This Issue Brief examines the potential of consumers to use information to select high-quality health services and to become drivers of quality improvement at the systems level. There are three broadly used mechanisms for connecting consumers to information: report cards on health plans and providers, decision support aides, and the Internet. Health foundations can play an important role in developing and disseminating quality information for consumers. They can support the development of quality indicators; assess the effectiveness of information technology, including the Internet; and fund advocacy efforts to ensure consumers have the information needed to make appropriate health care choices.

The average American faces an increasingly complex array of health care decisions. These include choosing health insurance plans, selecting practitioners, learning about medical conditions, and being party to decisions about treatment options. Federal and state government agencies, health plans, employers, unions, advocacy groups, and others are collecting and disseminating information. At the same time, the number of tools available to consumers, such as report cards, Web sites, and decision aids, has proliferated.

Informed consumers are viewed as an important part of the solution to concerns about costs, access, and quality in the health care system. Information about the quality of health care can help consumers make purchasing decisions, and empower them to make choices consistent with their personal preferences, needs, and values. At a broader systems level, quality information can create new incentives for health plans and provider organizations to compete on performance by making care more accessible, effective, and efficient.

Even though extensive information is available, consumers often have difficulty interpreting and using it. Health care decisions require consumers to use information that includes technical terms and to compare multiple options simultaneously. For example, as consumers consider specific quality measures, such as how frequently heart attack patients received beta-blocker treatment, they must think about other important factors, such as cost or accessibility. They also must weigh factors according to individual values, needs, and preferences.

Consumer information about health care must be available, understandable, and relevant. The clarity of health information and how it is presented can influence how consumers understand and use it. Information also must be designed to accommodate differences in consumer characteristics, such as English proficiency and literacy level. Materials can be made available in a variety of languages and at reading levels that are understood by most individuals. Information needs to be relevant to the decisions people need to make. While consumers want unbiased, expert information, they also want to know how others like them evaluate care (Agency for Healthcare Research and Quality 2005). Finally, quality information also needs to be widely disseminated and available through organizations that consumers trust.

There are a variety of mechanisms for providing consumers with information about health care quality, including:

- **Report cards:** Report cards, which provide comparative information on health plans and providers, are being disseminated by employers, business coalitions, government agencies, and others to help consumers understand how their options rate with respect to the technical quality of care or consumers' experiences. The impact of report cards, however, is mixed. Study results are difficult to extrapolate as they tend to focus on a specific geographic area or on one or two specific quality measures. In addition, research shows that only half of those who see report cards use the information (The Henry J. Kaiser Family Foundation 2004).
- **Decision support tools:** Decision aids can be used to help consumers understand the likely outcomes of treatment options by presenting a balanced picture of the available evidence. This may encourage them to think about their values as they relate to the risks and benefits of treatment options, and help them take a more active role in decisions about care. In controlled trails, decision aids have been shown to improve knowledge about treatment options, create more realistic expectations about treatment, reduce frustration with the decisionmaking process, and encourage consumers to be more active decisionmakers.
- **On-line resources:** The Internet is transforming the way consumers access and use health care information. Estimates suggest that the number of health-focused Web sites varies from between 10,000 to 100,000, while an estimated 70 million Americans use the Internet to retrieve health information (Institute of Medicine 2001). Consumers can search the Web for health care facilities and providers, find comparative quality information, research specific conditions and learn about treatment options, and find information about healthy lifestyles. In addition, health information is available quickly and in many formats, such as interactive Internet applications or downloadable publications.

Helping consumers access and interpret health information fits into the mission of many foundations. Health grantmakers can help make quality information accessible by supporting the dissemination of publications that guide consumers through the decisionmaking process and that present comparative quality information in an understandable, consumer-friendly format. They can also support organizations that maintain the Web sites consumers turn to for information.

Foundations are uniquely positioned to support the spread of information technology as a vehicle for health information. For example, they can fund the development of technology to collect data on quality. They can also assist in the development of Web-based applications that improve the flow of health information and patient-provider communication, as well as fund research on the impact of such technology.

Finally, foundations can support advocacy organizations to ensure consumers have the information they need to make appropriate health care choices. Funders can also encourage consumers and patient groups to become involved in health care quality issues such as increased use of evidence-based treatment guidelines and the development of policies to improve health care quality.

Sources

Agency for Healthcare Research and Quality, *Talking to Consumers about Health Care Quality,* <http://www.talkingquality.gov>, March 1, 2005.

Institute of Medicine, *Crossing the Quality Chasm* (Washington, DC: National Academy of Science, 2001).

The Henry J. Kaiser Family Foundation, *National Survey on Consumers' Experiences with Patient Safety and Quality Information* (Menlo Park, CA: 2004).

FOREWORD

As part of its continuing mission to serve trustees, executives, and staff of health foundations and corporate giving programs, Grantmakers In Health (GIH) convened a group of experts from philanthropy, research, practice, and policy on May 19, 2005 to explore how to effectively engage consumers in decisions about their health and health care.

During the Issue Dialogue, health grantmakers and experts from the field participated in an open exchange of ideas and perspectives on how quality is assessed and how the resulting information is disseminated to the public, as well as how consumers use information in the decisionmaking process. The meeting also explored strategies for funders to effectively support consumers and shared lessons from foundation-supported activities already underway.

Special thanks are due to those who participated in the Issue Dialogue, but especially to presenters and discussants: Nanette Falkenberg, a consultant with the Tides Foundation/Community Clinics Initiative; Marybeth Farquhar, health scientist administrator at the Agency for Healthcare Research and Quality's Center for Quality Improvement and Patient Safety; Tom Ferguson, senior research fellow for on-line health at the Pew Internet & American Life Project; Judith Hibbard, professor in the Department of Planning, Public Policy, and Management at the University of Oregon; Karen Menichelli, executive vice president at the Benton Foundation; Ann Monroe, president of the Community Health Foundation of Western and Central New York; Dana Mukamel, senior fellow at the University of California, Irvine's Center for Health Policy Research; Karen Sepucha, senior scientist in the Health Decision Research Unit at Massachusetts General Hospital; and Lisa Payne Simon, director of the Health and Technology Program at the Blue Shield of California Foundation.

Anne Schwartz, vice president of GIH chaired the Issue Dialogue. Katherine Treanor, GIH program associate, planned the program and wrote this report with editorial assistance from Anne Schwartz and Todd Kutyla, communications manager at GIH. Lise Rybowski of The Severyn Group also contributed to this report.

Support for the Issue Dialogue and this Issue Brief was provided by Aetna Foundation, Inc.; Agency for Healthcare Research and Quality; California HealthCare Foundation; and Consumer Health Foundation.

TABLE OF CONTENTS

INTRODUCTION

The average American now faces an increasingly complex array of health care choices and decisions. These include choosing health insurance plans, selecting health care practitioners, learning about specific medical conditions, and being party to complex decisions about treatment options.

At the same time, the amount of information available to consumers has exploded. Report cards, Web sites, decision aids, and other tools have proliferated. Federal and state government agencies, health plans, employers, unions, advocacy groups, and others are collecting and disseminating information. The New York Times *and other major newspapers have even segmented their bestseller lists to reflect the growing number of personal advice books, many of which are health titles. A 2001 survey found that 38 percent of adults sought health information from a source other than their doctor (Tu and Hargraves 2003). In a 2005 survey, eight in ten Internet users reported looking for health information on-line (Fox 2005).*

The average American now faces an increasingly complex array of health care choices and decisions.

The Rationale for Providing Quality Information to Consumers

Consumers are now being viewed as integral to the solution of longstanding concerns about costs, access, and quality in the U.S. health care system. They are challenged to select providers and plans that are high performing and cost effective. They are challenged to become more engaged in their own care, by taking charge of preventive actions and self-managing chronic conditions. And they are being asked to become vigilant actors in assuring health care safety (Hibbard 2005).

To take on these roles, however, consumers not only need to be involved, they must be informed. But what can be expected of the typical consumer? How can consumers effectively use information on health care quality? What are the expectations about what they will do if they are better informed?

Providing information to consumers empowers them to make choices consistent with their personal preferences, needs, and values. Traditionally, the course of diagnosis and treatment was made by the physician who was assumed to be acting in the best interest of the patient. Patients were not always consulted about their desires and priorities or may not have been fully engaged in deciding a course of treatment. Many patients, however, have become frustrated with this model because it can result in a course of treatment that does not reflect their personal preferences regarding risks and benefits. At the Issue Dialogue, for example, researcher Karen Sepucha shared stories about men with prostate cancer who had different preferences with respect to symptom relief and future sexual functioning that implied fundamentally different treatment options.

Giving more information to consumers, at a time when it is relevant and in a form that is understandable, is one way of breaking down asymmetry in the physician-patient relationship. It is also viewed as a way of creating a health care system that is patient-centered, one of the six aims for the U.S. health care system articulated by the Institute of Medicine (IOM) in its seminal report, *Crossing the Quality Chasm* (2001).

The act of engagement and having responsibility for decisionmaking are also seen as intrinsically valuable. That is, because people want to make these decisions, the system as a whole should respect and support their ability to do so. A recent survey, for example, found that 52 percent of consumers want to make final treatment decisions for themselves or a family member, and an additional 38 percent want to make treatment decisions jointly with their doctor (California HealthCare Foundation 2005). At the Issue Dialogue, Karen Sepucha, senior scientist at Massachusetts General Hospital, commented on the large body of literature indicating that "when patients understand that there's a decision to be made and that what they care about matters, they want to play a bigger role. Before that, they want to delegate more to their doctor."

In his book, *Complications* (2002), surgeon Atul Gawande speaks from both the physician and patient perspective about the value of respecting patient autonomy and the difficulty of doing so in fast-paced clinical settings. He talks about the importance of patients questioning their doctors and insisting on explanations. But he also mentions that physicians have obligations as well for "taking on burdensome decisions when patients don't want to make them, or guiding patients in the right direction when they do."

Changes in morbidity, particularly the growing prevalence of chronic disease, and the shift in patterns of care from inpatient to outpatient settings, have placed more of the burden of care on to consumers. With patients now managing their own care, they need new kinds of information and tools. As Judith Hibbard, a researcher in the field of consumer decisionmaking, noted at the Issue Dialogue, "We know that people with chronic illness, through their day-to-day choices and behaviors, largely determine their own ability to function, as well as their health outcomes. And patients who understand this, and have the knowledge and skills to self-manage, fare a lot better than people who lack these skills."

Finally, at a broader systems level, informed consumer decisionmaking may create new incentives for health plans and provider organizations to compete on performance by making care more accessible, effective, and

The act of engagement and having responsibility for decisionmaking are also seen as intrinsically valuable.

With patients now managing their own care, they need new kinds of information and tools.

DEFINING AND MEASURING QUALITY

> ***"We know that, in health care, improvement does not occur until we start to measure things and we have some way of knowing where we are."***
>
> — *Judith Hibbard*

The IOM defines quality as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (IOM 2001). Its key dimensions are:

- *safety:* avoiding injuries to patients from the care that is intended to help them;
- *effectiveness:* providing services based on scientific knowledge and avoiding overuse and underuse of services;
- *patient-centeredness:* providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide clinical decisions;
- *timeliness:* reducing waits and sometimes harmful delays for those who receive and those who provide care;
- *efficiency:* avoiding waste, including equipment, supplies, and energy; and
- *equity:* providing care that does not vary in quality because of personal characteristics such as gender, race, ethnicity, or socioeconomic status.

This definition encompasses both technical aspects of care and the degree to which it comports with patient preferences.

While health care quality measurement is a developing science, there are some generally accepted measures that reflect how care is being delivered and how patients have responded to that care. Clinical performance measures look at how well providers treat or prevent illness. These include process measures such as receipt of preventive care, provision of counseling regarding healthy behaviors, or screening for treatable conditions. For example, the Health Plan Employer Data and Information Set (HEDIS), developed by the National Committee for Quality Assurance (NCQA) to compare how well health plans perform in key areas, includes outcome indicators such as beta-blocker treatment after a heart attack, control of high blood pressure, breast cancer screening, antidepressant medication management, childhood and adolescent immunizations, and smoking cessation.

Measures have also been developed about other aspects of the delivery system. Measures of accessibility, such as appointment wait times and how long it takes for someone to answer the telephone, reflect how easily and quickly consumers receive care. Measures of experience reflect patient opinion about the health plan or provider and the care and services received. This includes patients' ratings as well as reports on their interactions with a doctor or nurse and their ability to get needed information from their plan or provider. One survey from the Agency for Healthcare Research and Quality's (AHRQ) has become the national standard for assessing individuals' experiences with health plans. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan Survey includes more than 40 questions that ask consumers to report on and rate their experiences with aspects of care such as access, communication, timeliness, administrative ease, and courtesy.

Finally structural measures, such as board certification and accreditation, are also used to measure quality. These indicate whether a provider, plan, or institution has systems or organizational traits that are associated with or considered minimum standards of high-quality care (AHRQ 2005).

efficient (California HealthCare Foundation 2005). Providing more information to consumers can put pressure on plans and providers to improve technical aspects of health care quality such as postsurgical complications, and to place a higher priority on things that consumers care about such as wait times for appointments. Proponents of consumer-directed health plans, for example, argue that consumers, armed with information about costs and quality, will select plans and providers that are the best match for preferences about costs, quality, access, and amenities, thus creating incentives for plans to compete for patients on these dimensions.

Making Information Useful

Shaller and his colleagues suggest that consumers "will use [quality information] if it is relevant to their concerns and packaged and disseminated so they can easily obtain, trust, understand, and apply it" (Shaller et al. 2003). Realizing the potential of consumers to use such information requires that they are educated about the concept of health care quality and when they have a stake in knowing about it. It also requires that information be understandable, relevant to the particular decision being made, comparable on the dimensions they care about, widely accessible, and available from trustworthy and neutral sources. In short, it is not a question of taking existing information off the shelf and getting it into the hands of consumers. Rather the task requires understanding consumers: what they already know, what they would like to know more about, how they process information, and who they trust.

Health care decisions often require consumers to use information that includes technical terms and to compare multiple options on several variables. For example, in selecting a health plan, a consumer might have access to information on specific quality measures, such as how frequently heart attack patients received beta-blocker treatment, as well as other important factors, like costs or accessibility. Plan selection implicitly asks them to assign weights

At a broader systems level, informed consumer decision-making may create new incentives for health plans and provider organizations to compete on performance by making care more accessible, effective, and efficient.

The task requires understanding consumers: what they already know, what they would like to know more about, how they process information, and who they trust.

to these various factors according to individual values, needs, and preferences. In each case, the consumer is "likely in an arena where the choice is important but the information is unfamiliar, and the amount of information may exceed information processing skills" (Hibbard and Peters 2003).

In fact, most individuals can process only a limited number of factors at one time. As the number of factors increases, an individual's ability to use all information presented decreases (Hibbard and Peters 2003). Specifically, consumers can only keep five to nine concepts in short-term memory at one time, and most only remember about 10 percent of what they read or hear (California HealthCare Foundation 2005).

To reduce the cognitive effort required to make difficult decisions, consumers are more likely to focus on familiar terms or ideas, and take mental short cuts (California HealthCare Foundation 2005). As Judith Hibbard noted at the Issue Dialogue, "what people don't understand, they think is less important." Additionally, they often equate high prices with high quality. To help consumers understand and apply information, lay terminology is critical. She also noted that "if you want to get people's attention, if you want them to use quality information, use language they understand." Graphic techniques can also help consumers process complex multivariate data. For example, presenting provider performance information in rank order, using symbols that are inherently meaningful such as stars and letter grades, and summarizing all important information on one page (Hibbard 2005).

Consumers also need tools to apply information. In its simplest form, this means providing instructions on how to use report cards, Web-based comparison tools, or similar products (FACCT 1999). But they also need to develop the skills to function adequately in the decisionmaker role (Hibbard 2004a).

Another challenge lies in designing information for those with low literacy, limited English proficiency, or whose cultural values (for example views about deference to be accorded physicians and other authority figures or the role of family members in decisionmaking) differ from the mainstream. These populations and others, such as the elderly, are at increased risk of not understanding health care information and often require additional assistance interpreting and applying information. For example, more than half of elderly Medicare beneficiaries reported having difficulty understanding comparative information about Medicare health plan options (Hibbard 2001). In fact, compared to the under 65 population, older Medicare beneficiaries made three times more errors in interpreting comparative information.

One-on-one counseling or peer coaching, can be particularly helpful in reaching these groups. A number of consumer and advocacy organizations support information intermediaries who provide personal counseling to consumers and guide them in using health information. For example, in

MEASURING CONSUMERS' ABILITY TO ACT

Patient activation refers to patients having the knowledge and skills to self-manage, collaborate with providers, maintain their ability to function (and prevent declines), and access appropriate and high-quality care. To measure levels of patient activation, Hibbard and colleagues developed a 13-item scale that represents four levels of activation:

- *Stage one:* Patients begin to believe their role in their own care is important.
- *Stage two:* Patients learn enough and have sufficient confidence to act on their own behalf.
- *Step three:* Patients take action and are able to stay the course under stress.

These measures are being developed as a tool to help providers work with individual patients by, for example, targeting care plans to their capabilities; as well as patient populations, for example, by segmenting by activation level (Hibbard 2004b).

> *What people don't understand, they think is less important… If you want to get people's attention, if you want them to use quality information, use language they understand.*

California the state Health Insurance Counseling and Advocacy Program assists consumers and their families with Medicare problems. Trained and registered volunteer counselors provide information on Medicare, Medicare supplemental insurance, managed care, and long-term care planning. Community education and some legal services are also available. Other venues that may serve this function include libraries, senior centers, state and local social service agencies, and community health centers. Lay health outreach workers can also be trained to assist consumers in using quality information.

MECHANISMS FOR CONNECTING CONSUMERS TO INFORMATION

Discussion at the Issue Dialogue focused on the promise and challenge of different mechanisms for providing consumers with information about health care quality. These included report cards on health plan and provider performance, decision support aids, and on-line communication between patients and providers, and among patients.

Report Cards on Health Plan and Provider Performance

Report cards, tools providing comparative information on plans and providers, are being disseminated by employers, business coalitions, government agencies, and health plans to help consumers understand how their options rate with respect to the technical quality of care or consumers' experience of care. Despite the growing availability of these tools, relatively few consumers actually use report cards. In fact, a 2004 consumer survey by The Henry J. Kaiser Family Foundation found that only a third of consumers had seen report cards of any kind (although this represented an increase from 27 percent in 2000.) To date, report cards have been used primarily to convey quality information about health plans, large provider groups, and hospitals. Limited information is available on long-term care providers, such as nursing homes, home health agencies, and hospices. Collecting quality information on individual providers has been difficult, with the largest barriers being patient privacy and cost, although some work is underway.

Literature on the impact of report cards on consumers is mixed. It is difficult to extrapolate from studies limited to a specific geographic area or focused on one or two quality measures. Studies that engage consumers with hypothetical choices may not be relevant to real-world settings (California HealthCare Foundation 2006). Moreover, seeing a report card is not enough. In the Kaiser survey noted above, only half of those who had seen report cards used the information in some way.

It is also difficult to know whether report cards have reached their full potential because of inadequacies in their design or because consumers are not motivated to use them, preferring to rely on informal or personal sources of information. In examining the report cards describing the same health plans, Hibbard and her colleagues found inconsistencies in how the plans were rated, which may also contribute to consumer confusion. Additional research on report cards has found that the amount of new information delivered may also affect consumers' ability to use it (Hibbard 2001).

Researchers have been testing whether improvements in design can make a difference, experimenting with data displays that summarize information and do some of the cognitive work so that readers can more easily and quickly understand, interpret, and use data. For example, in a report comparing complications and mortality rates among hospitals in Madison, Wisconsin, several design strategies were employed to increase the report's impact on both consumers and hospitals. These included presenting information in rank order, with performance displayed from best to worst; creating colored bands to distinguish the higher performers from the lower performers; and using plus and minus signs to represent the hospital's performance in each category.

Consumers were influenced by the Madison report and it stimulated quality improvement on the part of the area's hospitals. Consumers exposed to the public report were able to immediately identify high-performing hospitals in the region and retained that perception of the hospitals two years later. The hospitals whose performance was publicly reported were more likely to improve their performance because of concern about their reputations (Hibbard 2005). These factors are consistent with a growing body of evidence that report cards have desirable effects on the provider community.

In New York State, where outcomes for coronary artery bypass graft surgery have been reported for all surgeons each year since 1991, close to two-thirds of managed care plans in the state now look at the reports and use them in their contracting decisions. As a result, researchers found that surgeons with better reported outcomes experienced an increase in market share (Mukamel 2005). More recently, Mukamel and her colleagues found that this statewide report card also helped to reduce disparities in care between black and white patients. Prior to release of the public information, black Medicare beneficiaries were less likely to receive care from high-quality surgeons (as measured by the risk-adjusted mortality rates of their patients); after publication, the probabilities for black and white patients were the same (Mukamel 2004/2005).

Another tool that has the potential to improve quality is pay-for-performance (P4P). As a tool to motivate provider behavior change and improve care, P4P uses financial bonuses to reward hospitals and providers for their performance. Under a Medicare demonstration program initiated by the Centers for Medicare and Medicaid Services (CMS) in 2003, for example, the highest performing hospitals receive bonuses and the lowest performing hospitals may be penalized. Performance in the demonstration is based in specific evidence-based quality measures for heart failure, heart attack, coronary artery bypass graft surgery, and hip and knee replacements (Kahn et al. 2006). The results of this demonstration are mixed, with performance

Consumers exposed to the public report were able to immediately identify high-performing hospitals in the region and retained that perception of the hospitals two years later.

among the hospitals varying. For example, scores for major teaching hospitals caring for heart attack patients were higher than for nonteaching hospitals. And rural hospitals were among the lowest in caring for these patients. Researchers reviewing Medicare P4P data conclude that "although the quality measures are evidence-based and supported by clinical science, collapsing measures into composite scores and specifying bonus and penalty formulas require policy choices for which there is not scientific foundation" (Kahn et al. 2006).

Consumer report cards potentially become even more valuable under a P4P scenario. Standardized measures can enhance quality information and make it easier for consumers to compare hospitals or physician groups (Bodenheimer et al 2005). As a result, consumers may select higher performing providers. P4P programs can also offer financial rewards to providers for meeting specific goals, such as provision of preventive care services and increased patient satisfaction. These outcomes may influence both consumers and providers, ultimately leading to improved quality of care.

Decision aids can be used to help consumers understand the likely outcomes of alternate treatment options by presenting a balanced picture of the available evidence, to think about their values as they relate to the risks and benefits of treatment options, and to take a more active role with their provider in decisions about medical care.

Decision Support When Making Treatment Choices

One way to assist consumers in making health care choices is to provide them with decisionmaking aids. Kasper and his colleagues note that it is "possible to provide tailored information to a patient so that he or she can better determine his or her known preferences for treatment. The result is a patient better able to work with a physician to mutually decide on the best treatment strategy, that is, make a shared medical decision" (Kasper 1992). Decision aids are interventions (including brochures, videotapes, or interactive Web-based programs) that have been developed to improve communication between health professionals and patients, as well as to increase patients' involvement in making decisions about their health care. Decision aids can be used to help consumers understand the likely outcomes of alternate treatment options by presenting a balanced picture of the available evidence, to think about their values as they relate to the risks and benefits of treatment options, and to take a more active role with their provider in decisions about medical care.

Karen Sepucha of Massachusetts General Hospital suggested at the Issue Dialogue that decision aids are most appropriate for preference-sensitive decisions, such as treatments for breast or prostate cancer, where "there's an opportunity for patients to be involved and almost a need." In those cases, where there is evidence that different treatments might be reasonable options, such aids can help patients understand and assess those options in light of their personal values and preferences.

The process of decision support starts with first helping patients understand that there is a decision to be made.

LEARNING HOW TO COMMUNICATE WITH CONSUMERS

An excellent resource on how to interpret and present quality information to consumers is AHRQ's *TalkingQuality* Web site, www.talkingquality.gov. Developed by a consortium of researchers, sponsors of reporting projects, and other experts from the field, *TalkingQuality* is designed to educate and support organizations that are communicating to consumers about the performance of health plans and providers.

The purpose of the site is to help those publishing quality information with a comprehensive reference on what works best for consumers as well as ready access to state-of-the-art materials. The *TalkingQuality* Web site explains how to plan and implement a reporting project, what content to include, how to present complex information, when and how to promote and distribute reports, and how to evaluate your project. In addition to suggesting resources for additional information and support, the site offers examples of reports that illustrate useful concepts.

While recognizing that consumers need to know about quality at every level of the health care system, the current site primarily refers to the development of quality reports on health plans, health systems, and large provider groups. A searchable database of report cards published over the past 10 years is also available on the Web site.

In controlled trials, decision aids have been shown to improve knowledge regarding options, create more realistic expectations about treatment options, reduce frustration with the decision-making process, and encourage individuals to be active as decisionmakers.

Other steps include conveying the time frame in which that decision needs to be made (removing, for example, any unwarranted sense of urgency to make decisions more quickly than necessary), and providing the opportunity for patients to clarify their own values (that is, how they would feel about different outcomes). Overall, the process is intended to help people understand what they can and cannot control.

Studies indicate that these aids are feasible, appreciated by patients, and effective. A systematic review of decision aids conducted by the international Cochrane Collaborative found significant benefits. In controlled trials, such decision aids have been shown to improve knowledge regarding options, create more realistic expectations about treatment options, reduce frustration with the decisionmaking process, and encourage individuals to be active as decisionmakers (California HealthCare Foundation 2006). Much remains to be learned, however, about how best to design, implement, and deliver this kind of decision support.

Going On-Line

The Internet is transforming how consumers access and use health care information. The last several years have seen a huge increase in the number of health-focused Internet sites. While estimates vary, as many as 70 million Americans now use the Internet to retrieve health information and there may be as many as 100,000 health-focused Web sites (IOM 2001). Consumers are using the Internet to search for health care facilities and providers, find comparative quality information, research a specific illness or disease, learn about treatment options, and connect to both providers and other patients in on-line forums. With on-line medical guidance systems, like WebMD, consumers can easily access information about symptoms they are experiencing or learn about specific conditions. Other sites allow users to read reviews of prescription drugs written by patients who have used the medications. As Tom Ferguson of the Pew Internet & American Life Project noted at the Issue Dialogue, "we're in a period of transition between a system of 20th century health care based on the uninformed isolated doctor-dependent patient and 21st century health care built around the net-savvy, well-connected, highly autonomous end user." Ferguson argues that the empowered educated Internet user will drive system change by essentially righting the traditional power imbalance between physicians and patients. Another Issue Dialogue participant noted, however, that "on-line communities are a good source for emotional support but they can also be a source for misinformation." Others commented that consumers can become overwhelmed by the volume of on-line information.

We're in a period of transition between a system of 20th century health care based on the uninformed isolated doctor-dependent patient and 21st century health care built around the net-savvy, well-connected highly autonomous end user.

E-mail between patients and providers is also now facilitating the exchange of clinical information, and is often more convenient and less time-pressured (Ferguson 2005). To date, though, only a small number of physicians offer e-mail interaction (IOM 2001). In part this reflects the fact that few plans pay providers for such encounters.

OPPORTUNITIES FOR FOUNDATIONS

Foundations can support health care improvement by building on the IOM's finding that consumers influence health care and its quality through their purchasing decisions and by becoming active partners in their own care. Quality improvement also fits into the mission of many foundations as they seek to improve the health and health care of their communities. Health grantmakers can help make quality information accessible, support the development of information technology to collect and disseminate information, and support efforts to help consumers understand their health care choices and integrate quality into decisions. Particularly at the local level, they can also support skill development in informatics, quality improvement, and the design of patient-centered care for health leaders who can move these issues within institutions, agencies, and systems of care.

As noted at the Issue Dialogue by Ann Monroe of the Community Health Foundation of Western and Central New York, "engaging people goes far beyond data." Grantmakers do not necessarily need to create a strategic initiative on consumer information, patient engagement, and decision support. Rather, they may enter this work as it relates to specific health care issues, sectors, or populations. The Community Health Foundation, for example, began work on quality information as part of its focus on the needs of frail elders in its community, eventually supporting a project that assists families in making appropriate end-of-life decisions.

Making Information Accessible

Consumers can only use quality information if they have access to it. Grantmakers can play a critical role by sponsoring research to gain a better understanding of what information people can use and how to deliver it most effectively. The Commonwealth Fund, for example, has supported a broad body of work to collect and present quality information. For example, research supported by the fund found that many of the Web sites that consumers turn to for information on health care providers have missing or out-of-date information, as well as limited search capabilities. By making measures of provider quality available, such tools, when up to date, can help consumers in the selection process and lead to more informed care choices. These findings spurred a grant to NCQA to develop an advisory group to create standards for physician directories. Based on the advisors' recommendations, the Midwest Business Group on Health conducted a demonstration project in which a group of Chicago-based health plans, hospitals, and physician organizations implemented the recommended standards and evaluated the cost and value of doing so. This work yielded a blueprint for creating

Grantmakers can play a critical role by sponsoring research to gain a better understanding of what information people can use and how to deliver it most effectively.

physician directories that meets NCQA-recommended standards.

Another way to make information accessible is to produce and disseminate it. California HealthCare Foundation has a strong track record in the area of quality measurement and reporting. An integral part of this work has been to educate consumers about health care quality and to make comparative quality information readily available. The foundation has developed a rich array of strategies, educational materials, and tools to help Californians make informed health care decisions. Specifically, the foundation supported the development of Web sites such as the California Nursing Home Search Web site and CalHospitals.org.

CalHospitals.org allows consumers to learn about patient experiences at California hospitals. Using a patient-centered approach, this survey tool measures eight aspects of hospital performance, including respect for patients' preferences and expressed needs, coordination of care and integration of services, information and education, physical comfort and pain relief, emotional support and alleviation of fears and anxieties, involvement of family and friends, experience with safe medical practices, and transition to home and continuity of care. To elicit information from patients and their families, the survey asks question such as:

- Were you treated with respect and courtesy and as a partner in the health care process?
- How organized and efficient were doctors and nurses?
- Did hospital staff explain treatment options and test results clearly and completely?
- Overall, how would you rate the hospital?
- Would you recommend the hospital to your friends and family?

The surveys are administered at 200 California hospitals. Hospital information is available in both English and Spanish and is organized by city, county, and ZIP code. A printed report of the findings, *What Patients Think of California Hospitals,* is also available.

A third approach is to harness the power of the media to engage consumers and facilitate communication at the community level. The Benton Foundation teamed with the Robert Wood Johnson Foundation to fund Sound Partners, which seeks to increase public awareness of specific health issues and facilitate the public's involvement in making decisions affecting health and health care. Through its grant program, Sound Partners stimulates partnerships between public broadcasters, community organizations, and other media entities to equip consumers with the tools needed to participate in community problem-solving around health issues. For example, in Philadelphia, Pennsylvania local television station WHYY and the Caring Community Coalition partnered to improve care for individuals with chronic and

California HealthCare Foundation has developed a rich array of strategies, educational materials, and tools to help Californians make informed health care decisions.

terminal illnesses. The collaboration promoted patient-centered care and clear communication among patients, families, and health care providers. Success stories were presented on WHYY's television series *Circle of Care*. A toolkit and on-line resource directories were also created for consumers.

Supporting Information Technology

Information technology plays a large role in making health care information accessible to the public. Foundations are uniquely positioned to support the spread of information technology and assist in the development of Web-based applications that can improve access to health information and even improve patient-provider communication. To begin, foundations can assess the effectiveness of Web-based health resources. The Henry J. Kaiser Family Foundation, for example, conducted surveys to find out how consumers are using the Internet. Such findings can assist in creating more user-friendly Internet sites and on-line quality tools. The foundation's 2004 *E-Health and the Elderly: How Seniors Use the Internet for Health* survey, for example, identified the most frequently researched health topics. It found that seniors who go on-line discuss what they learned with their doctors, and found that of seniors using the Internet many consider e-mail a valuable communication tool.

To advance scientific knowledge regarding the effectiveness of interactive applications to promote health behavior change and chronic disease management, the Robert Wood Johnson Foundation developed its national Health e-Technologies initiative. This grant program supports development and research of technological applications for health care such as the Internet, interactive TV, voice response systems, personal digital assistants, and CD-ROMs. Program grantees are evaluating the effectiveness of tools to improve patient-provider communication, contain costs, provide reliable health information, reduce medical errors, and enhance the efficiency of the health care system. For example, the researchers are evaluating the potential of technology to improve chronic disease management and quality of care in the Cleveland, Ohio region. This project will evaluate the effectiveness of the Cleveland Clinic Foundation's Internet portal for diabetic patients. The research will determine if a portal approach to diabetes management can influence patient outcomes and if additional interventions can encourage greater technology adoption and patient compliance. In addition, the outcomes from this study may be generalized to other chronic diseases and health maintenance.

Assessing the effectiveness of existing and emerging technologies is another important role for foundations. The Blue Shield of California Foundation's Center for Technology and Health supports research on the impact of information technology. In 2001,

Foundations can assess the effectiveness of Web-based health resources.

Tools such as RelayHealth can help improve health care quality by increasing patient access to providers in nonemergency situations. It can also improve consumer satisfaction by reducing appointment wait times and unnecessary physician office visits, as well as enhancing access to prescription medications, when needed.

the center supported an evaluation of RelayHealth, an on-line patient-provider communication tool. RelayHealth facilitates clinical consultations about nonurgent medical symptoms via its Internet program webVisit and medication prescriptions via the eScript program. Evaluation of the impact of RelayHealth used by patients and providers in the Blue Shield of California health plan network revealed reductions in both office-based care and total cost of care. Additionlly, physician and patient surveys showed that the majority of both groups found the service easy to use, satisfying, and preferable to an office visit. Tools such as RelayHealth can help improve health care quality by increasing patient access to providers in nonemergency situations. It can also improve consumer satisfaction by reducing appointment wait times and unnecessary physician office visits, as well as enhancing access to prescription medications, when needed.

The Blue Shield of California Foundation also supports the California Technology Assessment Forum, which encourages a communitywide evaluation of the safety and efficacy of new and emerging technologies. These assessments are then shared with stakeholders, primarily physicians and health plans, to help them determine whether a new technology is actually better than, or even as good as, existing alternatives. While the Web site is currently focused on physicians and those who make coverage decisions, the foundation is exploring ways to make this information accessible to consumers to support them in participating in decisions with their providers.

Foundations can also support programs that improve access to information for vulnerable or hard-to-reach populations. The Tides Foundation, for example, is collaborating with The California Endowment and Blue Shield of California Foundation to encourage and support the use of technology in community health centers. Through this program, community clinics have increased their capacity to track and manage patients with chronic diseases as well as their ability to assess and improve the quality of care they deliver. An important component of the program is the use of disease registries that allow community clinics to efficiently track chronic disease patients. At a basic level, registries allow clinics to track the treatments and services received by patients and to track provider performance. They also allow clinics to provide feedback to patients. For example, some of the more sophisticated programs allow a provider and patient to sit at the computer together and graphically look at a patient's progress. Registries can also track organization-wide progress against selected evidence-based guidelines.

Information technology also allows community clinics to link patient encounter data with evidence-based medicine. At the Issue Dialogue, Nannette Falkenberg of The Tides Foundation, described how, in Alameda County, California, encounter data is linked to practice guidelines to generate quarterly performance reports. The reports allow providers and patients to see how each facility is doing on selected practices. Data can also be sorted demographically and used to report variations in performance based on specific populations.

The Markle Foundation's Information Technologies for Better Health initiative aims to accelerate consumer use of information technologies in ways that improve health and health care. Under this initiative, the foundation provided support to the Comprehensive Health Enhancement Support System (CHESS) to evaluate ways in which underserved women with breast cancer use and benefit from a computerized patient support system. CHESS provides women with up-to-date health information, software to help weigh treatment options, and 24-hour access to medical experts and other patients via the Internet. The positive evaluation results have led to the program's use as a tool for breast cancer patients in rural areas.

In collaboration with the Partners Healthcare System and FACCT (Foundation for Accountability), the Markle Foundation also supported the Patient Accessible Electronic Medical Record project. This program has examined the implications of linking patients and physicians to medical records via the Internet. Preliminary findings from the project indicate that while most patients find the tool useful for administrative tasks, such as renewing prescriptions and requesting referrals, a significant proportion are unsure about whether it improves the quality of communication, affords adequate privacy, or saves time. On the other hand, doctors and administrative staff are relatively enthusiastic about the tool, although they have some concerns, such as the fact that doctors are not financially compensated for their time spent responding to patient e-mails. Analyses are also underway on how this Internet tool might enhance the quality of care by altering patient behavior. For example, providers could send electronic reminders to take medication. The tool may also help patients to identify and correct errors in their own medical records in collaboration with health professionals.

Consumer Advocacy

Grantmakers can also ensure that consumers have the information they need to make appropriate health care choices by supporting advocacy organizations. In response to changes in the Medicare program, for example, The California Wellness Foundation awarded a three-year grant to California Health Advocates (CHA) to ensure that California Medicare beneficiaries have access to accurate information on changes to the Medicare program, such as the addition of a prescription drug benefit. With this $150,000 grant, CHA is establishing a centralized office in Sacramento to enhance the Medicare education and advocacy activities provided by the state's Health Insurance Counseling Advocacy

Grantmakers can also ensure that consumers have the information they need to make appropriate health care choices by supporting advocacy organizations.

Programs (HICAPs). HICAPs are staffed by volunteers and provide telephone assistance and one-on-one counseling to Medicare beneficiaries and their families.

Under the Allies for Quality initiaive, grantee organizations used a variety of strategies to bring quality information to consumers, including using community health workers, known as promotoras; training community health care champions; and engaging community and state stakeholders on health care quality issues.

Foundations such as California HealthCare Foundation are supporting and encouraging consumers and patient groups to become involved in health care quality issues. Through its Allies for Quality, a three-year, $2 million program begun in 2001, the foundation awarded grants to eight advocacy organizations throughout California. The program's goals were to increase consumer awareness of health care quality problems, increase consumer and patient use of existing quality measurement tools, promote the use of evidence-based treatment guidelines by consumers, improve patient interactions with providers and the health care system, and develop and implement policies to improve health care quality. Grantee organizations used a variety of strategies to bring quality information to consumers, including using community health workers, known as promotoras; training community health care champions; and engaging community and state stakeholders on health care quality issues. For example, the Women's Information Network Against Breast Cancer (WIN ABC) is empowering newly diagnosed breast cancer patients at Martin Luther King University and Harbor/UCLA Medical Centers to demand quality breast cancer care according to evidence-based guidelines and improve their interactions with providers. Another grantee, the Community Health Workers/Promotoras Network is working in partnership with the Ernesto Galarza Applied Research Center at the University of California, Riverside to improve the quality of care received by Latinos by supporting community health worker and promotora programs. Specifically, the network is enhancing promotoras' awareness of health quality and building their capacity to address health quality issues in their communities.

CONCLUSION

Accurate, relevant information on plans, providers, and treatments can help health care consumers make choices that are consistent with their values, needs, and concerns. Information can empower consumers to become active participants in their care and forge partnerships with physicians and other providers. Although many consumers rely on family and friends for health care recommendations, they are increasingly turning to federal, state, and local agencies; employers and business coalitions; and provider organizations for trustworthy information.

Consumers also need clear reasons to care about health care quality and time and training to use available tools effectively. They need to understand that quality varies and that being smart about quality can help them get better care (FACCT 1999).

Challenges exist to gathering and standardizing health care information, as well as presenting it in formats that consumers can easily use. The effect of empowered and informed consumers, however, is clear. Those who use quality information to make decisions about their care and who actively engage in their care often have improved health outcomes. They also have higher rates of satisfaction with the care they receive.

Grantmakers can use their position in the health care community to promote the use of quality information by consumers. They can contribute to the broader body of quality knowledge by supporting the development and distribution of consumer-friendly information on provider-level quality, the effectiveness of medical treatments, and other factors important to consumers; funding research that evaluates the effectiveness of this information; and sharing their expertise and networks with report developers. They can support advances in information technology that improve collection and dissemination of quality information. They can also fund technology aimed at enhancing patient-provider communication and facilitating more informed treatment decisions. Finally, health foundations can actively support consumer advocacy organizations that educate the public about health care and its quality, as well as assisting consumers in using available information in their health care decisions.

APPENDIX: INFORMATION RESOURCES FOR CONSUMERS

There are many sources of information that consumers can use in making critical health care decisions. This appendix describes some of the major public and private sector information sources on health plans, hospitals, nursing homes, home health agencies, and hospices.

Choosing a Health Plan

Consumers with employer-based health coverage, as well as those with Medicare or Medicaid coverage may need to select a health plan. Quality report cards and Web-based information are the most common forms of health plan data. Consumers may need this information only once a year, during open enrollment, or when seeking a new primary care physician or specialist care.

One tool to assist consumers in selecting a health plan is NCQA's HealthChoices Web site, www.healthchoices.org, which makes HEDIS results accessible to consumers. This on-line health plan report card allows consumers to research and evaluate health plan performance in five areas: access to services, qualified providers, staying healthy, getting better, and living with illness. Users can search for and compare the quality of health plans at the state or ZIP code level, by plan name, or by type of coverage (HMO, PPO, POS). Accreditation outcomes (excellent, commendable, accredited, provisional, and denied) are also provided.

The HealthChoices Web site also features a physician directory to help consumers identify doctors in their area who meet standards of care established in three program areas (diabetes, heart, and stroke) and physician practice groups that use up-to-date information and systems to enhance patient care. NCQA; the American Diabetes Association; the American Heart Association/American Stroke Association; and the employer coalition, Bridges to Excellence, jointly developed the programs.

A set of national report cards is produced by CMS, whose interactive Web site, www.medicare.gov, offers tools to guide Medicare beneficiaries through the process of comparing and choosing Medicare health plans and prescription drug plans, as well as hospitals, dialysis facilities, nursing homes, and home health care agencies. The health plan and prescription drug plan tools allow consumers to search by state, county, or ZIP code. The site provides beneficiaries with detailed information about plans available in their area. Health plans can be compared based on service area, cost, and doctor and hospital choice, as well as benefits such as inpatient hospital care, inpatient mental health care, skilled nursing facility care, home health care, outpatient and preventive services, prescription drug coverage, and medical supplies. Drug plans can be compared based on monthly premium, annual deductible, cost sharing, and drug formularies.

The Medicare Web site also allows consumers to compare health plan quality. Information is available on experience measures (wait times, overall rating of a plan and its care, physician communication, and access to specialists) and process measures such as percentage of beneficiaries receiving influenza shots, routine care for diabetes, mammograms, and beta blockers after a heart attack. In addition, the site indicates why people disenroll from health plans, including the percentage of people who chose to leave based on difficulties accessing services or issues of costs and benefits.

The business community collects and disseminates quality information that is used both in purchasing negotiations with health plans or medical groups, and to encourage employees to make health care purchasing decisions based on quality. Large employers, for example, often provide employees with report cards that help them compare the quality as well as the costs and benefits of their health plan options. The Pacific Business Group on Health (PBGH), a coalition of 50 large businesses that provide health coverage to more than 3 million people, provides information about the quality of health plans, medical groups, and other providers directly to consumers through its HealthScope Web site, www.healthscope.org.

Choosing a Hospital

Many patients seek information about hospitals after a diagnosis. Some comparative quality information is now available for consumers to use in selecting among institutions. In April 2005, the federal government launched Hospital Compare (www.hospitalcompare.hhs.gov), a Web-based tool that allows consumers to compare hospital care for adults with three common diagnosis: heart attack, heart failure, and pneumonia care. Hospital Compare presents measures on how often hospitals provide the recommended care to get the best results for patients with these conditions. Developed jointly by CMS; hospital, provider, and quality organizations; and consumer groups, Hospital Compare is the latest in a series of Web-based comparative tools available through CMS.

Health care purchasers, such as large employers and business coalitions, can also be a source of comparative hospital information for consumers. For example, the Leapfrog Group for Patient Safety (www.leapfroggroup.org) is an initiative driven by health care purchasers working to improve the safety, quality, and affordability of health care. Launched in 2000, Leapfrog is supported by The Business Roundtable, the Robert Wood Johnson Foundation, and its employer members. Together its members purchase health benefits for more than 34 million people. The group's hospital quality improvement program has been rolled out in 23 regions across the country, covering about 1,600 of the 6,000 U.S. hospitals.

To assist consumers in making health care decisions, the Leapfrog Group makes the hospital survey results publicly available on its Web site. This database can be searched at the ZIP code level. Results show consumers which Leapfrog Group practices have been implemented, and their success rates, at participating hospitals that have provided data on implementing the group's quality and safety improvement practices. The Leapfrog Group also provides extensive educational information to consumers on its quality and safety practices and how to factor them into making health care decisions.

Choosing a Nursing Home, Home Health Agency, or Hospice

When selecting a nursing home or other long-term care provider, consumers most often seek information on the quality of care provided and a facility's characteristics. They think about their personal needs and seek facilities consistent with their values, such as those with a religious affiliation. They may also visit facilities and meet the caregivers (nurses, certified nursing assistants, and therapists), watch the care that is given, and see firsthand the quality of the living conditions and the general environment. Additionally, consumers talk to their doctors, ask friends about their experiences, and contact state quality improvement organizations for more information.

CMS's Nursing Home Compare, www.medicare.gov/nhcompare, and Home Health Compare, www.medicare.gov/hhcompare, provide detailed information on long-term care providers, including state inspection reports and quality data. Consumers can search these databases by state, county, ZIP code, or facility name. Nursing Home Compare provides information on facilities that are Medicare or Medicaid certified. Its information comes from two sources. The first is CMS's Online Survey, Certification, and Reporting (OSCAR) database, which includes nursing home characteristics (such as type of ownership and number of beds), health deficiencies issued during the three most recent state inspections, and information on recent complaint investigations. The second source is the Minimum Data Set (MDS) Repository, which is based on resident assessments. It assesses residents' physical and clinical conditions and abilities, as well as preferences and life care wishes. The measures have four intended purposes: to help facilitate consumer choice, to give consumers information about the care at nursing homes where they or family members already live, to get consumers to talk to nursing home staff about the quality of care, and to give data to nursing homes to help them with their quality improvement efforts.

CMS's Home Health Compare also gives consumers information about Medicare-certified home health agencies. The Web site has information about home health agency characteristics such as Medicare-covered services offered (nursing care, physical therapy, occupational therapy, speech therapy, social services, and home health aides), the agency's initial date of Medicare certification, and its type of ownership.

The quality measures provided by Home Health Compare inform consumers about how well home health agencies provide care for some of their patients. The measures provide information about patients' physical and mental health and whether their ability to perform basic daily activities is maintained or improved. The quality data on the Web site comes from the Home Health Outcome and Assessment Information Set (OASIS). Information is collected from home health agencies about patients' health; how they function; the skilled care, and social, personal, and support services they need; as well as their living conditions. Home health staff gather the information by observing the patient and his or her home, and by talking with the patient and caregivers.

The California Nursing Home Search, www.calnhs.org, program allows consumers to find quality information on nursing homes, home health agencies, and hospices throughout the state. The goals of the site are to help consumers choose the right nursing care for their needs and improve that care through public disclosure of ratings. It is maintained by the California HealthCare Foundation and the University of California, San Francisco. California Nursing Home Search began in 2002 with a Web site that offered information and ratings on nursing homes. The Web site was updated in 2004 to include profiles and ratings of home health agencies and hospices. It also offers consumers information on other care options and help in making decisions.

The California Nursing Home Search Web site provides comparative ratings of long-term care facility performance on important measures of quality. The rating system used on the site was designed to be consumer friendly. Nursing homes receive one, two, or three stars based on how well each performs on important measures of quality compared to all other facilities in the state. The measures are grouped into four ratings categories: staffing, facility quality, quality of care, and finances and cost. Each of these categories contains detailed items for which individual ratings are provided. For example, in the staffing category, consumers can learn a facility's total number of nursing staff, nursing staff turnover, and nursing staff wages. In the quality of facility category, consumers can learn about the home's number of federal deficiencies, number of state deficiencies and citations, and number of complaints.

The home health and hospice sections of the Web site also provide comparative ratings of organizations' performance on measures of quality and assist consumers in interpreting the findings. As in the nursing home portion of the site, home health and hospice providers receive scores based on how well they perform on specific quality measures. For home health agencies the measures are quality of care, quality of life (such as getting better at walking or moving around and getting better at bathing), and clinical care (such as getting better at taking medications correctly or having received urgent, unplanned medical care). Only one measure is available for hospices: quality of facility.

SOURCES

Agency for Healthcare Research and Quality, *Talking to Consumers about Health Care Quality*, <http://www.talkingquality.gov>, March 1, 2005.

Bodenheimer, Thomas, Jessica May, Robert Berenson, et al., *Can Money Buy Quality: Physician Response to Pay for Performance* (Washington, DC: Center for Studying Health System Change, 2005).

California HealthCare Foundation, *Consumers in Health Care: Creating Decision Support Tools That Work* (Oakland, CA: 2006).

California HealthCare Foundation, *Consumers in Health Care: The Burden of Choice* (Oakland, CA: 2005).

Edgman-Levitan, Susan, and Paul Cleary, "What Information do Consumers Want and Need?" *Health Affairs* 15(4):42-56.

Falkenberg, Nanette, Tides Foundation/Community Clinics Initiative, remarks at Grantmakers In Health Issue Dialogue, *Considering Quality: Engaging Consumers to Make Better Health Decisions*, May 19, 2005.

Farquhar, Marybeth, Agency for Healthcare Research and Quality, remarks at Grantmakers In Health Issue Dialogue, *Considering Quality: Engaging Consumers to Make Better Health Decisions*, May 19, 2005.

Ferguson, Thomas, Pew Internet & American Life Project, remarks at Grantmakers In Health Issue Dialogue, *Considering Quality: Engaging Consumers to Make Better Health Decisions*, May 19, 2005.

Ferguson, Thomas, *Found on the Net; What e-Patients Do Online*, <http://www.fergusonreport.com/articles/fr00904.htm>, April 27, 2005.

Foundation for Accountability, *Consumers and Quality: What do They Know? What do They Want? Results from FACCT Consumer Research: 1996-2000* (Portland, OR: 2004).

Foundation for Accountability, *Sharing the Quality Message with Consumers* (Portland, OR: 1999).

Fox, Susannah, *Health Information Online* (Washington, DC: Pew Internet & American Life Project 2005).

Gawande, Atul, *Complications: A Surgeon's Notes on an Imperfect Science* (New York, NY: Picador, 2002).

Hibbard, Judith H., University of Oregon, remarks at Grantmakers In Health Issue Dialogue, *Considering Quality: Engaging Consumers to Make Better Health Decisions*, May 19, 2005.

Hibbard, Judith H., "Moving Toward a More Patient-Centered Health Care Delivery System," *Health Affairs*, Web Exclusive, October 7, 2004a.

Hibbard, Judith H., Jean Stockard, Eldon R. Mahoney, et al., "Development of the Patient Activation Measure: Conceptuality and Measuring Activation in Patients and Consumers," *Health Services Research*, 39(4):1005-1026, August 2004b.

Hibbard, Judith H., and Ellen Peters, "Supporting Informed Consumer Health Care Decisions," *Annual Review of Public Health* 24:413-433, 2003.

Hibbard, Judith H., Paul Slovic, Ellen Peters, et al., "Is the Informed-Choice Policy Approach Appropriate for Medicare Beneficiaries?" *Health Affairs* 20(3):199-203, May/June 2001.

Hibbard, Judith H., University of Oregon, testimony before the U.S. Senate Finance Committee, June 19, 2001.

Institute of Medicine, *Crossing the Quality Chasm* (Washington, DC: National Academy of Science, 2001).

The Henry J. Kaiser Family Foundation, *National Survey on Consumers' Experiences with Patient Safety and Quality Information* (Menlo Park, CA: 2004).

Kahn, Charles, Thomas Ault, Howard Isenstein, et al., "Snapshot of Hospital Quality Reporting and Pay-for-Performance Under Medicare," *Health Affairs* 25(1):148-162, January/February 2006.

Kasper, Joseph F., Albert G. Mulley, and John E. Wennberg, "Developing Shared Decision-Making Programs to Improve the Quality of Health Care," *Quality Review Bulletin* 18(6):183-190, June 1992.

Menichelli, Karen, Benton Foundation, remarks at Grantmakers In Health Issue Dialogue, *Considering Quality: Engaging Consumers to Make Better Health Decisions*, May 19, 2005.

Monroe, Ann, Community Health Foundation of Western and Central New York, remarks at Grantmakers In Health Issue Dialogue, *Considering Quality: Engaging Consumers to Make Better Health Decisions*, May 19, 2005.

Mukamel, Dana, University of California, Irvine, remarks at Grantmakers In Health Issue Dialogue, *Considering Quality: Engaging Consumers to Make Better Health Decisions*, May 19, 2005.

Mukamel, Dana B., David L. Weimer, Jack Zwanziger, et al., "Quality Report Cards, Selection of Cardiac Surgeons, and Racial Disparities: A Study of the Publication of the New York State Cardiac Surgery Reports," *Inquiry*, 41:435-446, Winter 2004/2005.

Sepucha, Karen, Massachusetts General Hospital, remarks at Grantmakers In Health Issue Dialogue, *Considering Quality: Engaging Consumers to Make Better Health Decisions*, May 19, 2005.

Sepucha, Karen R., Floyd J. Fowler, and Albert G. Mulley, "Policy Support for Patient-Centered Care: The Need for Measurable Improvements in Decision Quality," *Health Affairs*, Web Exclusive, October 7, 2004.

Shaller, Dale, Shoshanna Sofaer, Steven D. Findlay, et al. "Consumers and Quality-Driven Health Care: A Call to Action," *Health Affairs* 22(2):95-101, March/April 2003.

Simon, Lisa Payne, Blue Shield of California Foundation, remarks at Grantmakers In Health Issue Dialogue, *Considering Quality: Engaging Consumers to Make Better Health Decisions*, May 19, 2005.

Tu, Ha T., and J. Lee Hargraves, "Seeking Health Care Information: Most Consumers Still on the Sidelines," *Issue Brief: Findings from HSC*, No. 61 (Washington, DC: Center for Studying Health System Change 2003).

ABOUT GIH

With a mission to help grantmakers improve the health of all people, Grantmakers In Health (GIH) seeks to build the knowledge and skills of health funders, strengthen organizational effectiveness, and connect grantmakers with peers and potential partners. We help funders learn about contemporary health issues, the implications of changes in the health sector and health policy, and how grantmakers can make a difference. We generate and disseminate information through meetings, publications, and on-line; provide training and technical assistance; offer strategic advice on programmatic and operational issues; and conduct studies of the field. As the professional home for health grantmakers, GIH looks at health issues through a philanthropic lens and takes on operational issues in ways that are meaningful to those in the health field.

Expertise on Health Issues

GIH's Resource Center on Health Philanthropy maintains descriptive data about foundations and corporate giving programs that fund in health and information on their grants and initiatives. Drawing on their expertise in health and philanthropy, GIH staff advise grantmakers on key health issues and synthesizes lessons learned from their work. The Resource Center database, which contains information on thousands of grants and initiatives, is available on-line on a password-protected basis to GIH Funding Partners (health grantmaking organizations that provide annual financial support to the organization).

Advice on Foundation Operations

GIH focuses on operational issues confronting both new and established foundations through the work of its Support Center for Health Foundations. The Support Center offers an annual two-day meeting, The Art & Science of Health Grantmaking, with introductory and advanced courses on board development, grantmaking, evaluation, communications, and finance and investments. It also provides sessions focusing on operational issues at the GIH annual meeting, individualized technical assistance, and a frequently asked questions (FAQ) feature on the GIH Web site.

Connecting Health Funders

GIH creates opportunities to connect colleagues, experts, and practitioners to one another through its Annual Meeting on Health Philanthropy, the Fall Forum (which focuses on policy issues), and day-long Issue Dialogues, as well as several audioconference series for grantmakers working on issues such as access to care, obesity, public policy, racial and ethnic health disparities, and health care quality.

Fostering Partnerships

Grantmakers recognize both the value of collaboration and the challenges of working effectively with colleagues. Although successful collaborations cannot be forced, GIH works to facilitate those relationships where we see mutual interest. We bring together national funders with those working at the state and local levels, link with other affinity groups within philanthropy, and connect grantmakers to organizations that can help further their goals.

To bridge the worlds of health philanthropy and health policy, we help grantmakers understand the importance of public policy to their work and the roles they can play in informing and shaping policy. We also work to help policymakers become more aware of the contributions made by health philanthropy. When there is synergy, we work to strengthen collaborative relationships between philanthropy and government.

Educating and Informing the Field

GIH publications inform funders through both in-depth reports and quick reads. Issue Briefs delve into a single health topic, providing the most recent data and sketching out roles funders can and do play. The GIH Bulletin, published 22 times each year, keeps funders up to date on new grants, studies, and people. GIH's Web site, www.gih.org, is a one-stop information resource for health grantmakers and those interested in the field. The site includes all of GIH's publications, the Resource Center database (available only to GIH Funding Partners), and the Support Center's FAQs. Key health issue pages provide grantmakers with quick access to new studies, GIH publications, information on audioconferences, and the work of their peers.

DIVERSITY STATEMENT

GIH is committed to promoting diversity and cultural competency in its programming, personnel and employment practices, and governance. It views diversity as a fundamental element of social justice and integral to its mission of helping grantmakers improve the nation's health. Diverse voices and viewpoints deepen our understanding of differences in health outcomes and health care delivery, and strengthen our ability to fashion just solutions. GIH uses the term, diversity, broadly to encompass differences in the attributes of both individuals (such as race, ethnicity, age, gender, sexual orientation, physical ability, religion, and socioeconomic status) and organizations (foundations and giving programs of differing sizes, missions, geographic locations, and approaches to grantmaking).

GRANT
MAKERS
IN
HEALTH

1100 CONNECTICUT AVENUE, NW
SUITE 1200
WASHINGTON, DC 20036
TEL 202 452 8331 FAX 202 452 8340
www.gih.org