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CHAPTER

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Empowering Consumers to Make Informed Choices

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INTRODUCTION

Observers of the American health system are concerned that quality of care is inconsistent and somewhat poor. Research reports often highlight patterns of inadequate care, but virtually no one—doctors, managers, or patients—is able to determine who provides the best care for any particular problem, and virtually no organizations—hospitals, health plans, or medical groups—receive any financial reward for providing high-quality care.

The Foundation for Accountability (FACCT) was formed in 1995 to introduce new mechanisms to measure and reward quality care. FACCT was created by purchasers and consumers who sought better information about the quality of the care they were buying or receiving and who believed that widely available quality information would mitigate marketplace trends that rewarded low prices but seemed to ignore the quality of care provided. They sought to create a market in which excellence would

be rewarded, and healthcare organizations would have an incentive to improve.

FACCT's mission is to ensure that Americans have clear, accurate information about quality they can use to make better healthcare decisions. To accomplish this goal, FACCT has defined numerous consumer-focused quality measures, implemented them in market regions across the United States, and developed tools for helping people interpret and use the information. These three activities are tightly related: quality measures are no good unless the data are widely and reliably collected, and the data are not useful unless decision makers—purchasers and consumers—care about it and can understand what it means. This chapter examines one approach to sharing information about healthcare quality with the American public and argues that a common, rigorous approach can rapidly achieve desirable changes in the healthcare marketplace.

RATIONALE

Since 1965, the United States has experienced repeated efforts at healthcare reform, typically engineered around attempts to extend insurance coverage or constrain expenditures. The nation has enjoyed some success in these efforts, most notably the creation of Medicare and Medicaid, the recent Children's Health Insurance Program, and the introduction of prospective payment and managed care financing arrangements. In 1993 and 1994, President Clinton attempted to extend these successes with comprehensive reform, which he characterized as an effort to ensure "health security" for all Americans (Health Security Act of 1993).

Many of these national reform initiatives included design features that were intended to ensure that Americans received high-quality care. Yet these elements of the reform package were typically of secondary importance and have not proven effective (Brook, Kamberg, & McGlynn, 1996; Milgate, 1994). In March 1998, the President's Advisory Commission on Consumer Protection and Quality found the following:

Several types of quality problems in health care have been documented through peer-reviewed research. They include the following:

Avoidable errors: Many Americans are injured during the course of their treatment and some die prematurely as a result. For example, a study of injuries to patients treated in hospitals in New York State found that 3.7% experienced adverse events, of which 13.6% led to death and 2.6% permanent disability. A national study found that from 1983 to 1993, deaths due to medication errors rose more than twofold with 7,391 deaths attributed to medication errors in 1993 alone.

Underutilization of services: Millions of people do not receive necessary care and suffer needless complications that add to healthcare costs and reduce productivity. For example, an estimated 18,000 people die each year because they did not receive beta blockers following a heart attack.

Overuse of services: Millions of Americans receive healthcare services that are unnecessary, increase costs and often endanger their health. For example, an analysis of hysterectomies performed by a sample of health plans in 1990 found that nearly one in five was inappropriate.

Variation in services: There is a continuing pattern of wide variation in healthcare practice including regional variations and small-area variations. This is a clear indicator that the practice of healthcare has not caught up with the science of healthcare to ensure evidence-based practice in the United States (President's Commission, 1998).

More recently, the Institute of Medicine Roundtable on Managed Care reported the following:

Serious and widespread quality problems exist throughout American medicine. These problems, which may be classified as underuse, overuse, or misuse, occur in small and large communities alike, in all parts of the country, and with approximately equal frequency in managed care and fee-for-service systems of care. Very large numbers of Americans are harmed as a direct result. Quality of care is the problem, not managed care. Current efforts to improve will not succeed unless we undertake a major, systematic effort to overhaul how we deliver healthcare services, educate and train clinicians, and assess and improve quality (Chassin & Galvin, 1998).

Remarkably, these comments only repeat and amplify observations that were initially made around World War II. Millenson recently summarized the failure of the health professions and institutions to correct persistent, serious quality deficiencies (Millenson, 1997).

NEED FOR PARADIGM SHIFT

Today, we again are grappling with difficult decisions in organizing care and arranging for its financing, and we remain reluctant to address the quality deficiencies of the healthcare system. Healthcare administrators and purchasers are attempting to fine-tune managed care and make modest adjustments in financing arrangements, but they do so without serious attention to the remarkable social, cultural, and technological forces that are reshaping American life. One reason for this disconnect between health services and other aspects of economic and social life is the persistent exclusion of American consumers from the evaluation and design of healthcare.

In addition, medical technology and biomedical information have grown at an exponential rate. Today, there are 4,000 or more peer-reviewed scholarly publications, and any illusion that an individual physician can be master of all relevant clinical information has been retired (Hunt & Newman, 1997; Rennie, 1998). Similarly, the growing complexity of medicine mandates that effective care requires partnerships among diverse and substantial teams, which in turn require coordination and management.

Finally, these trends are compounded by growing consumer activism and impatience. The interest of state and federal legislators in managed care regulation and the "patient bill of rights" testify to the influence of an anxious public. Public concerns about the quality of care at the end of life (Lo, 1995; Lynn et al., 1997; The SUPPORT Principal Investigators, 1995), about patient safety and medical error (Ross, 1999), and about access to emergent treatments all reflect the urgency of engaging the American consumer in a more candid dialogue about the quality of healthcare services.

Healthcare leaders have responded to some of these trends with piecemeal experiments. The quality improvement movement

has imported industrial management and analytic techniques, and it has some important psychological and local impact. However, the broad patterns of healthcare delivery and outcome appear to be unaffected (Blumenthal & Kilo, 1998; Shortell, Bennett, & Byck, 1998). Hospitals and managed care plans have been subject to elaborate and expensive accreditation programs that examine structural and procedural conditions, but even advocates of these programs have noted their modest impact on ensuring and improving quality. The federal government and the AMA have made a serious effort to document best practices and encourage conformity to practice guidelines; both initiatives have been shelved.

PARAMETERS OF CHANGE

What mechanisms can now be considered for reengineering U.S. healthcare to put it on the road to higher-quality care and service? How can the decades-long pattern of variable and inadequate performance be corrected? It is worth noting that all attempts, until now, have relied on the insights and goodwill of healthcare and policy leaders. The approach has been limited to a "top-down" strategy of quality improvement and healthcare reform. Despite well-intentioned efforts, no leading healthcare organizations have demonstrated their ability to help patients achieve outcomes of recognized importance to the public. Perhaps it is time that these questions are put to the public to humbly ask for instruction on how best to meet their needs.

Ethically, sociologically, and clinically, the U.S. healthcare system cannot improve until consumers are able to become full partners in its management and operation. The healthcare system can provide quality care only when it learns to listen to the needs of the people it serves and is prepared to reorganize its resources in response to those needs.

To achieve this objective, the healthcare system must work with its public to establish a quality lexicon. We will need a common language to discuss our expectations of those who provide healthcare services, and a common metric will be needed that tells us if those expectations are being met. Most important, this vocabulary and set of metrics must be defined by those

served. The healthcare system will not be altered if professionals persist in conversing only with those who share their training, values, and expertise.

By establishing a common vocabulary and measurement language, we can begin to support individuals' ability to seek the healthcare arrangements that they judge best. Patients, consumers, and families can be permitted to select where to seek their care based on relevant, understandable information about quality performance. In the face of clear and relevant information about public expectations, providers and plans will seek to excel on those dimensions used by consumers and purchasers to make selections.

This approach to building a consumer-centered, market-based healthcare system assumes that we can solve several daunting problems:

- Learn what the public cares about.
- Develop reliable, valid measures of the desired quality and service constructs.
- Gather relevant data across all relevant service entities.
- Compile and represent the data in a way that is understood and used by a critical mass of Americans.
- Communicate quality and service performance in a realistic personal choice context that addresses concerns about costs, benefits, and plan rules.
- Communicate personal decision-making information in a context that addresses broader societal healthcare challenges and shapes a successful national health policy.

A FRAMEWORK FOR COMMUNICATING WITH THE PUBLIC ABOUT QUALITY HEALTHCARE

What Does the Public Want?

In 1996, HCFA engaged FACCT to develop an organizing framework for the representation of quality performance information (Bethell, Lansky, & Read, 1997). To develop this Consumer Information Framework, FACCT first researched all available

consumer communication templates. These were analyzed and condensed into four conceptually distinct approaches, organized as follows:

1. Health states model (e.g., getting better, living with illness, staying healthy)
2. Type of measure model (e.g., process, outcome)
3. System competencies (e.g., prevention, acute care)
4. Satisfaction concepts only

These models were tested with more than 400 consumers drawn from a variety of settings across the United States, including Medicare and Medicaid beneficiaries, commercially insured consumers with both managed care and non-managed care experience, and people both with and without chronic disease. These investigations identified five quality constructs of widespread public interest (Box 11-1, p. 272). These five quality domains are inclusive; that is, they accommodate all of the important quality concerns as indicated by respondents.

Each of these five domains can be deconstructed into component concepts, each of which may be represented by quantitative measures. The "Living with Illness" domain, for example, is made up of four subcategories that address important competencies of chronic disease care:

- *Appropriate care*: conformity to practice guidelines and commonly accepted standards of care
- *Education and teamwork*: effectiveness of patient and caregiver teaching
- *Help for daily living*: helping patients minimize adverse symptoms and maximize daily functioning
- *Experience of care*: patient ratings of access, communication, and service quality

Each of these subcategories is in turn comprised of individual performance measures. "Appropriate care," for instance, could include whether severe asthmatic patients possess and know how to use a peak flow meter or inhaler, or whether diabetic patients have had regular assessments of their feet or hemoglobin A_{1c} level.

BOX 11-1**THE BASICS**

Delivering the basics of good care—doctor care, rules for getting care, information and service, satisfaction

STAYING HEALTHY

Helping people avoid illness and stay healthy through preventive care, reduction of health risks, early detection of illness, education

GETTING BETTER

Helping people recover when they are sick or injured through appropriate treatment and follow-up

LIVING WITH ILLNESS

Helping people with ongoing, chronic conditions (e.g., diabetes, asthma) take care of themselves, control symptoms, avoid complications, and maintain daily activities

CHANGING NEEDS

Caring for people and their families when needs change dramatically because of disability or terminal illness—with comprehensive services, caregiver support, hospice care

This hierarchical structure has several advantageous features:

- Users with particular interests may populate the structure with measures of special relevance to them, while retaining the conceptual and methodological integrity of the model.
- Users with interest in greater detail may use layered technologies—such as Internet Web sites—to probe performance issues of personal concern.

- Users with differential abilities to gather data may implement selected branches of the hierarchy and phase in additional content areas over time.

Tailoring: How Can We Develop Measures?

The Consumer Information Framework can be effective only if the information content it conveys is meaningful, relevant, and sound. A nine-stage process is recommended for qualifying measures for inclusion in the Framework. Critical qualification tasks include the following:

1. Assess relevance of topic to consumers and purchasers.
2. Compile expert opinion on quality measurement in topic area.
3. Solicit consumer and patient judgments on dimensions of quality for topic area.
4. Synthesize expert and consumer quality criteria.
5. Develop technical measurement definitions, including case identification, measure specifications, and methods recommendations.
6. Review measurement proposal with experts and consumers.
7. Conduct field trials in different types of settings.
8. Revise measurement proposal as necessary.
9. Publish technical specifications for data collection and communication of quality measures.

Two elements of this process are most important. First, the question “what is quality care?” must have a working definition that reflects the values, preferences, and experiences of patients, families, and the community at large. Typically, patients will include a strong desire for quality measures to reflect expert judgment regarding best practices and contemporary standards of care. They will also emphasize an involvement of patient and family in decisions, the quality of communications between providers and patients, and the commitment of the providers to help patients manage their own care. In addition, patients often

highlight the effectiveness of care in achieving desired outcomes, such as symptom relief, functioning, and clinical benefit to a greater degree than do experts.

As one AIDS patient stated:

Overall health status is what's really important because that's a function of the anti-(retro)viral treatment. It's a function of having mental health services. It's a function of preventing opportunistic infections. All those come together to indicate to me that everything is being done but without mental health coverage or care, I would get depressed. I'm on antidepressants. Without that kind of situation, I think that would make my physical health worse and I know it does. So, it's all interrelated (FACCT focus group, 1998).

Second, emphasis is placed on the importance of testing data collection methods and reporting strategies before publication of measurement specifications, and the need to conduct such trials in multiple settings. As the healthcare system continues to change, quality measures must be available to permit comparisons across settings of care and types of financing systems, both to help consumers understand systematic consequences of alternative structures and to help policy makers evaluate alternative strategies. If the content of quality measures is based on patients' experiences and their values, they will remain relevant as the financial and delivery system arrangements evolve.

Where's the Data?

Some authorities argue that systematic quality assessment and public disclosure must await improvements in clinical information systems (Eddy, 1998). This argument reflects two fallacies. First, it presumes that relevant quality information is principally available in the record-keeping systems of providers and health plans and that such information is more relevant or reliable than alternatives. The authors are unaware of any evidence to support this view. On the contrary, clinical record keeping in paper charts is notoriously incomplete and inaccurate, often reflecting economic incentives, variations in clinical interpretation,

and competing administrative requirements (Palmer & Nesson, 1982; Romano & Mark, 1994; Solberg et al., 1990). The clinical record typically fails to document quality in the domains of concern to patients, such as functioning, symptom level, independence, counseling, or communication. The medical record often fails to record public health interventions of substantial concern to purchasers, such as immunizations, cholesterol checks, or mammograms that may be provided by various community service agencies (IPRO, 1998). Second, the clinical record may report activities of healthcare professionals without noting if they ever reached the patient or had the intended consequences. Medications may be prescribed and not taken; specific counseling provided but not understood (Ickovics & Meisler, 1997; Morse et al., 1991; Sackett, & Haynes, 1976). Whether the impact of professional interventions should be considered as a performance measure (policy versus technical) is an issue unto itself. However, relying solely on the clinical record for capturing information on effectiveness would be a deterrent to any quality strategy.

Instead, we recommend that performance data be gathered from multiple sources that respond to different needs: transaction data that describe key services rendered, medical chart data that reflect objective biological measures, and patient reports that reflect symptoms, functioning, and the patient's experiences of care.

Across studies, patients report that they value each of these types of information. In a series of studies, FACCT asked patients to rate the relative importance of alternative types of quality performance information. In each study, patients were shown proposed quality measures of specific, relevant aspects of care. For persons with diabetes, for example, proposed measures included frequent testing for the hemoglobin A_{1c} and lipid levels, the attainment of desirable levels of hemoglobin A_{1c}, and adequacy of access to specialists and necessary medical materials, such as test strips. Patients provided ratings of their relative importance as follows:

- Whether or not recommended care processes are followed: 1.00 (index)

- Whether or not the desired patient outcomes are achieved: 0.81
- Whether or not patients report satisfaction with care: 0.60

This approach suggests that the evolution of measurement approaches should happen simultaneously, not in sequence. We should develop and implement measures of processes, outcomes, and experience of care in parallel in an effort to minimize bias. If society focuses exclusively on one or another domain, it will present a distorted picture of healthcare performance to the public and possibly influence markets in undesirable ways.

Communicating Quality Performance to the Public

The Consumer Information Framework involves the aggregation of discrete performance data into summary scores that are relevant and understandable to the general public. The process of organizing individual measures into consumer "information" involves these major steps:

- Organizing individual measures into reporting categories and subcategories
- Transforming each item into a standardized value that permits comparison and summation
- Aggregating multiple items into summary scores
- Reporting summary scores to the public in one or more media

Each of these activities involves both policy and methodological decisions, each of which may affect the ranking of healthcare organizations and, ultimately, their economic success. These are summarized briefly here to suggest both that public healthcare performance information can be produced in a systematic and logical fashion and that legitimate policy debates may be necessary.

Organizing Measures into Categories

There are many ways to define the conceptual categories to be

characteristics of the organizations being profiled, (2) based on the nature of the reported data, (3) based on expert theories about healthcare quality, or (4) based on consumer healthcare experiences or values. The categories in the Consumer Information Framework provide a uniform vocabulary that is accessible and interpretable to most consumers. It is a template that accommodates most currently available performance measures as well as those in development. Over time and for various audiences, users can add or drop measures and retain a stable approach to communicating with the public.

The top-level categories of the Framework provide potential standards for public information, but they are not adequate for any but the most superficial reporting systems. Many consumers prefer more detailed performance information than those available at the highest level of aggregation. FACCT has developed a second-level set of (sub)categories that map three or four subcategories associated to each top-level category. A robust design feature of the framework is the flexibility it affords each data collection/reporting project. Individual reporting projects may have reasons to develop alternative subcategories that better meet the needs of specific audiences. For example, a target population with established diseases may wish the "Living with Illness" category to accommodate subcategories such as overall ratings of "diabetes care," "asthma care," and so on.

Once a set of policy-defined reporting categories has been established, the available performance measures must be assigned to each category. The assignment is nontrivial. For example, is the HEDIS measure of *whether beta blocker medications are prescribed following myocardial infarction* properly regarded as an intervention for a chronic disease—thus belonging to "Living with Illness"—or an expected element of acute care best grouped with "Getting Better"? Is *counseling asthma patients about important lifestyle changes* a dimension of "Staying Healthy" or "Living with Illness"?

When measures are matched to reporting categories, psychometric analyses (e.g., measures of reliability and factor analysis) must then be conducted for the proposed groupings. Users need to be confident that the summary categories they report send an accurate signal to consumers about the informa-

Transform Raw Performance Data into Standardized Scores

The goal at this stage is to transform individual quality measures to a common metric and common scale before aggregation. This often includes two steps:

1. *Standardization of individual scores to a common metric:* This is especially necessary when combining rate- versus score-based measures.
2. *Translation of each standardized score to a common scale so that it is appropriate for entry into the summarization and weighting process:* Translation is also important so that the score for each plan is easily understood.

Translating standardized scores to an understandable scale—such as a 0 to 100 scale—will usually involve the determination of which value should represent a “0” performance score (bottom end of the scale) and which value should represent a “100” score (top end of the scale). One option is to assign the *best score* (100) to the best performing organization in a region, and assign the *worst score* to the worst performing organization. Such relative anchor scores can be misleading, particularly if the absolute differences in performance are small. A second option is to assign the *highest value* to a computed “best possible” score (e.g., if every respondent answered “excellent” to every question asked, that organization would achieve 100). Consumers generally prefer the second approach because it provides absolute performance information, but it can be difficult to establish a “best possible” score for some clinical measures (e.g., cholesterol level).

Selection of the comparison benchmarks and the anchor values for transforming the data can have a substantial impact on the consumer’s perception of healthcare system performance. As health plans, providers, and consumer advocates understand these decisions, they often become significant policy debates.

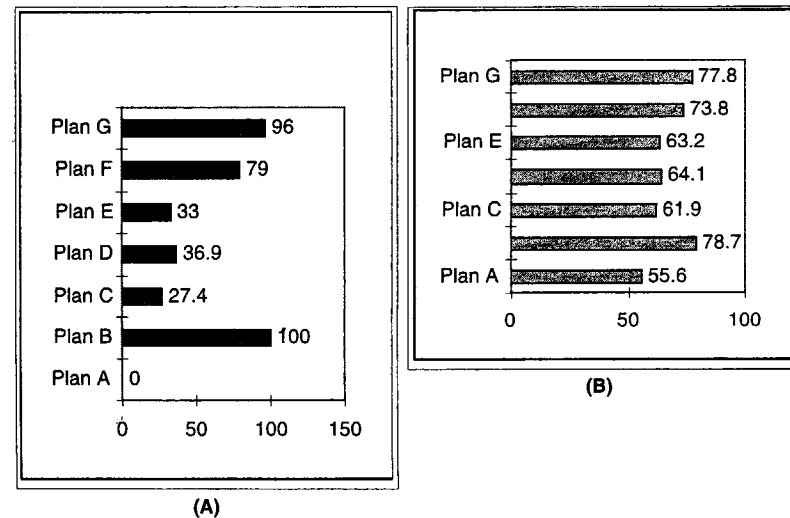
Figure 11-1 illustrates the different apparent performance of seven health plans in caring for asthmatic patients, based on the use of relative or absolute anchor values.

Aggregate Individual Scores into Summary Scores

Each performance measure has presumably been assigned a weight

FIGURE 11-1

Apparent performance of seven healthcare plans in caring for asthmatic patients. **A**, Relative comparison; **B**, absolute comparison.



now scored on a 0 to 100 scale. In general, it is assumed that measures will be combined using a simple additive model of the form:

$$\text{Score} = (wt_1 \times \text{measure}_1) + (wt_2 \times \text{measure}_2) + \dots$$

Determining the appropriate weights is a sensitive and powerful policy decision, because the ultimate ranking of organizational performance will be affected by the relative importance of each component measure.

At least three types of criteria could affect the assignment of weights:

1. Consumer (user) utilities
2. Expert valuation
3. Statistical properties of the measure

Some experts express concern that consumers will give preference to measures of customer service rather than to measures

of desired outcomes. In FACCT's early investigations, we found high agreement between experts and consumers (approximately 85%), with the latter giving modestly higher weight to functional outcomes and elements of communication and relationship with providers. In the case of patients diagnosed with HIV and AIDS, for example, there was strong agreement on the importance of measures of viral load testing and the availability of antiretroviral therapies, but patients argued that poor relationships with providers compromised their willingness to comply with any clinician recommendations and thus deserved primacy in the weighting scheme.

A policy commitment to assess and incorporate consumer utilities in the weighting scheme raises additional questions. Should a quality report, targeted for a particular insurance class or cultural group, use weights generated specifically by that group? Should personal decision aid technology (e.g., interactive Internet sites or computer kiosks) permit each person to assign his or her own weights?

Expert weighting could be applied and based on a variety of criteria. Clinicians tend to advocate weights proportional to expected physiological impact—so maintenance of a diabetic patient's low blood glucose is rated more important than patients' rating of physician communication skills. Social scientists may assign weights based on expected public health impacts or relative cost-benefit, so mammograms for women aged 50 to 64 are weighted higher than well-child visits for grade school-age children.

In addition, weights may be determined by *attributes of the measures* themselves. For instance, the reporting system may choose to systematically weight clinical outcomes higher than overall satisfaction. If the reporting agency wishes to reward organizations that achieve consistency in their performance—as well as high average performance—measures may be weighted inversely by the variance in the distribution of the measure. For example, two health plans may each achieve an average satisfaction rating of 75%, but one does so by having higher numbers of members offering ratings of “very good,” whereas the other has a wider range of members across the entire range from “excellent” to “poor” and thus a higher standard deviation associated

with the same mean. These variances could be used to give additional weight to the more consistent performer.

The selection of these weights does have a meaningful impact on public rankings. In one comparison of using equal weights (.33, .33, .33) versus unequal weights (.2, .5, .3) when aggregating three measures into an asthma score for seven health plans, the choice of weighting schemes altered relative ranks either one or two places for all but the first- and second-ranked plans.

Symbolism and Reporting of Summary Scores

Given a set of performance scores, users still face numerous design decisions affecting the communication of the data to the public. Key issues include the following:

- Should data be presented as numbers, as symbols, or as words? People vary widely in their comfort and understanding of each of these formats. If data are represented numerically, publishers must be careful to avoid misrepresentation of small differences as statistically meaningful or different. Consumers often indicate an interest in being told which performance levels indicate good or poor performance. If data are represented with symbols, publishers must recognize that they are losing data. Auto workers, for example, have complained that a reporting system using one, two, or three stars (where one or three represent statistically significant differences from the mean) hides absolute performance and inevitably clusters too many health plans into an uninterpretable “two-star” category.
- Should publishers indicate confidence intervals or sampling errors? Attempts to represent measurement uncertainty seem important to researchers and the health plans that are being compared, but confuse most consumers. When applied to aggregate scores, these adjustments require additional, complex decisions regarding the treatment of unequal sample sizes, treatment of within-plan variation, and the calculation of composite standard errors. These convoluted analyses

can create perverse incentives for health plans, encouraging smaller sample sizes and even lower performance. By adding uncertainty to the consumer's ability to interpret the data, these adjustments also have the unfortunate consequence of lessening the consumer's confidence in the entire reporting enterprise (Hibbard, Slovic, & Jewett, 1997).

- Should publishers tell a story when presenting data? Communications theorists agree that data without context is not helpful (Rodgers, 1999). Yet providing an interpretive context inevitably reflects the publisher's own agenda. Important policy questions need to be addressed to guide the presentation of data. Should the "story" indicate that quality performance is generally lower than desired or that it varies inexplicably? Should it provide the consumer with tools and ideas for self-advocacy when navigating the health system? At a minimum, quality categories and the words used to describe them must be carefully tailored to accurately reflect the information content being presented. We can easily mislead people into thinking information is included in scores when it is not and vice versa.

HOW CAN QUALITY INFORMATION BE INTEGRATED WITH OTHER IMPORTANT FACTORS?

Most consumers evaluate numerous aspects of a product or service when making a decision. Price, features, and quality are all important. For health plan or provider decisions, additional constraints may come into play—such as the number of choices made available by their employer or public sponsor, specific geographic and access considerations, or the importance of maintaining current relationships. Quality information must be arrayed in a specific choice context.

In general, four categories of information should be presented to consumers when making these marketplace decisions, and consumers should be aided in evaluating the trade-offs among these four considerations. In addition to quality information, consumers should understand the following:

- *Costs*: What will each of the available options cost the consumer, including co-pays, deductibles, and premium contributions? Optimally, this information can be estimated for the individual subscriber, based on previous utilization experience.
- *Benefits*: What coverage is available from each of the available options?
- *Rules*: What barriers to care exist that may affect the subscriber? Particular concern has been voiced about continuity with current doctors, access to preferred medications, and opportunities to see specialists without primary care referral.

Numerous initiatives are under way to develop decision models and decision support systems to assist consumers in evaluating their own needs and selecting health plans and provider relationships. Some efforts involve computer-assisted decision aids; others involve in-person "choice counseling" either one-on-one or through a "town hall" format.

HOW CAN CONSUMER DECISION MAKING SHAPE SUCCESSFUL NATIONAL POLICY?

This chapter argues that consumers can be given substantial, relevant, and valid information upon which to make important healthcare decisions. We identify a concise framework for organizing performance information and discuss both the methods for constructing meaningful performance scores and the context within which such data should be communicated.

There is a risk that consumers are not interested in quality information, have not valued such information as has been made available, or may overvalue service performance at the expense of clinical performance. These are serious concerns and heighten researchers' obligations to evaluate the impact of consumer information strategies, both to improve the various technologies described here and to avoid unnecessary or irresponsible policy initiatives.

Yet the mere tabulation and presentation of individual performance data is unlikely—*prima facie*—to stimulate new

marketplace behaviors. Consumers have not previously been informed about the workings of healthcare or the legitimacy of their expectations for high-quality care. They have not been encouraged to inquire about performance or to make meaningful decisions about their care.

FACCT continuously conducts interviews, focus groups, and quantitative surveys of American consumers. We are constantly reminded of the pressing and anxious desire of consumers for guidance on navigating the healthcare system and for ensuring that they can get high-quality care. Over time, we have seen that a simple framework, reflecting careful technical work, can help people gain a common understanding of how healthcare works and how they can look for the best care for themselves. Numerous organizations have embraced the Consumer Information Framework—ranging from the State of Michigan to the “big three” auto companies to *Newsweek* magazine. Despite slow progress in improving the availability of quality data, there seems to be great interest in using a common vocabulary and technical toolkit for educating the public about quality.

However, the inadequacy of quality data presents a profound challenge. Communications messages without meaningful content is just “spin.” Government agencies and purchasers will need to explore new ways of acquiring quality information that matters to people. Certainly, the Internet will provide an opportunity for broad distribution of quality data and, perhaps, for inexpensive collection of patient evaluations of their care. But the likelihood that quality data will be slow in coming suggests that quality leaders will need to start focusing their efforts on educating patients to advocate for themselves, to give them tools to recognize and demand high-quality care in their own lives, and thereby send a message to providers, insurers, employers, and governments that their accountability remains to the public and for the public’s well-being.

The present market environment poses serious barriers to effective consumer choice and to the prospect of rewarding excellence in healthcare. A strategy of systematic disclosure of healthcare system performance, coupled with coordinated and thoughtful public education, has the potential to accelerate necessary changes in the healthcare system.

REFERENCES

- Bethell C, Lansky D, Read D. *Reporting quality information to consumers. A report to the Health Care Financing Administration*. Portland, OR: Foundation for Accountability, December 1997.
- Blumenthal D, Kilo CM. A report card on continuous quality improvement. *Milbank Quarterly* 1998; 76(4):625–648.
- Brook RH, Kamberg CJ, McGlynn EA. Health system reform and quality. *JAMA* 1996; 276(6):476–480.
- Chassin MR, Galvin RW. The urgent need to improve healthcare quality: Institute of Medicine National Roundtable on healthcare quality. *JAMA* 1998; 280:1000–1005.
- Eddy DM. Performance measurement: problems and solutions. *Health Affairs* 1998; 17(4):7–25.
- FAACT focus group. San Francisco, CA, August 15, 1998.
- Health Care Security Act of 1993*. A bill to ensure individual and family security through healthcare coverage for all Americans in a manner that contains the rate of growth in healthcare costs and promotes responsible health insurance practices, to promote choice in healthcare, and to ensure and protect the healthcare of all Americans.
- Hibbard JH, Slovic P, Jewett JJ. Informing consumer decisions in healthcare: implications from decision-making research. *Milbank Quarterly* 1997; 75(3):395–414.
- Hunt RE, Newman RG. Medical knowledge overload: a disturbing trend for physicians. *Health Care Management Review* 1997; 22(1):70–75.
- Ickovics JR, Meisler AW. Adherence in AIDS clinical trials: a framework for clinical research and clinical care. *J Clin Epidemiol* 1997; 50:385–391.
- IPro. Audit Report: 1997 Medicare HEDIS® 3.0/1998 Data. <http://www.hcfa.gov/quality/3i2.htm>
- Lo, B. Improving care near the end of life: why is it so hard? *JAMA* 1995; 274(20):1634–1636 (editorial).
- Lynn J, et al. Perceptions by family members of the dying experience of older and seriously ill patients. *Ann Intern Med* 1997; 126(97):97–106.
- Milgate K. Health reform and accountability for quality. *QRC Advis* 1994; 10(7):8.
- Millenson ML. *Demanding medical excellence: doctors and accountability in the information age*. Chicago: The University of Chicago Press, 1997.

- Morse EV, et al. Determinants of subject compliance within an experimental anti-HIV drug protocol. *Soc Sci Med* 1991; 32:1161-1167.
- Palmer RH, Nesson HR. A review of methods for ambulatory medical care evaluations. *Medical Care* 1982; 20(8):758-781.
- President's Advisory Commission on Consumer Protection & Quality in the Health Care Industry. Quality First: Better Health Care for All Americans. Final Report, March 13, 1998. <http://www.hcqualitycommission.gov>
- Rennie D. The present state of medical journals. *Lancet* 1998; SII:18-22.
- Rodgers AB. *Making quality count: a national conference on consumer health information. Conference summary.* February 1999. HCFA contract 500-97-P511.
- Romano PS, Mark DH. Bias in the coding of hospital discharge data and its implications for quality assessment. *Medical Care* 1994; 32(1):81-90.
- Ross PE. Nine mistakes doctors make. *Forbes* 1999; 9:116-118.
- Sackett DL, Haynes RB (eds). *Compliance with therapeutic regimens.* Baltimore: Johns Hopkins University Press, 1976.
- Shortell SM, Bennett CL, Byck GR. Assessing the impact of continuous quality improvement on clinical practice: what it will take to accelerate progress. *Milbank Quarterly* 1998; 76(4):593-624.
- Solberg LI, et al. The Minnesota project: a focused approach to ambulatory quality assessment. *Inquiry* 1990; 27:359-367.
- The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatment (SUPPORT). *JAMA* 1995; 274(20):1591-1598.