

What Information Do Consumers Want And Need?

A synthesis of research to date, plus interviews with health plan managers and consumer advocates.

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PROLOGUE: When T.S. Eliot asked, "Where is the knowledge we have lost in information?" he was referring to the peculiar fact that gains in information do not always lead to greater knowledge; indeed, too much information, or information of the wrong kind, can erode knowledge. Many consumers confront such a challenge when choosing a health plan: There is often an abundance of information available, but much of it is irrelevant to the decision-making process. This should come as no surprise, for, as Susan Edgman-Levitan and Paul Cleary note in this paper, little is actually known about what kinds of information consumers need to make decisions. Here they review recent findings in this area and conclude with recommendations to improve the accessibility and usefulness of health plan information for consumers.

Few are better qualified for this task than these authors. They have both devoted considerable portions of their professional lives to issues surrounding patients, consumers, and health care information. Their expertise was recently recognized by the Agency for Health Care Policy and Research when they were selected as coprincipal investigators for that agency's Consumer Assessment of Health Plans Study. Edgman-Levitan is executive director of the Picker Institute in Boston and an instructor at Harvard Medical School. Cleary, who has published more than 150 journal articles and book chapters, is professor of health policy at Harvard with joint appointments in the Medical School and the School of Public Health. He also is editor of the *Milbank Quarterly* and research director at the Picker Institute.

ABSTRACT: This paper reviews information from surveys and focus group studies about how consumers define high-quality care and the types of information they want when making decisions about which health plan to join. The authors also interviewed consumer advocacy groups and persons responsible for disseminating health plan information to Medicare enrollees in various types of managed care plans to learn about the types of plan information that Medicare enrollees most often request. They describe the types of information that should be made available to consumers and the challenges involved in making this information understandable and useful.

CONSUMER INFORMATION ON health plans must be publicly available, understandable, and relevant to the decision making process, if consumers are to fulfill the role envisioned for them by those who tout the virtues of the health care marketplace. A number of sources now exist that are useful in monitoring and evaluating hospital and ambulatory care outcomes. These include traditional quality assurance and utilization review mechanisms, as well as a variety of newer methods, such as the Health Plan Employer Data and Information Set (HEDIS), developed and used by the National Committee for Quality Assurance (NCQA).¹

However, as sources of information for consumer decision making, these measures and instruments generally are hampered by two limitations: They rely only on medical or administrative records as sources of information, and they define "quality" in terms of a relatively narrow range of technical processes and physiological outcomes.² In short, these sources to date have omitted the patient's perspective in defining and determining health care quality, a perspective that is seen as increasingly important.³ A recent manifestation of this recognition is the NCQA's mandate under HEDIS 3.0 that health plans survey their members, using a common instrument, about their experiences with their health plans. In conjunction with this, the Agency for Health Care Policy and Research (AHCPR) is funding a project known as the Consumer Assessment of Health Plans Study (CAHPS) to develop a standard, state-of-the-art instrument for assessing the quality of care provided in ambulatory care settings of all types.

The aim of this paper is to inform efforts, such as those by the NCQA and AHCPR, to improve the content, design, and availability of consumer information. To that end, our research was guided by several questions: What constitutes quality of care in the view of consumers? What types of quality information do consumers need or want to make health care choices? What *are* some of the obstacles that consumers face in obtaining useful information? Our research *was* conducted for an Institute of Medicine (IOM) committee on choice and managed care for Medicare beneficiaries. Thus, we de-

voted considerable energy to identifying the needs of that population. Nonetheless, our findings should be applicable to efforts to improve the quality of consumer information generally.

In spite of the importance of issues surrounding consumer choice in health care, there is little previous research to build on. Here we synthesize findings from the literature, several research projects recently conducted by various organizations (both private and public), and interviews that we conducted with staff at insurance companies, managed care organizations, and consumer advocacy groups. Since we discuss a variety of projects with different aims and methods, we provide more detail below, as the projects are introduced in the text.

What Types Of Information About Quality Do Consumers Want?

Health plans are increasingly making information about quality of medical care publicly available. Reports describing such information often are referred to as “report cards.” We do have some assurance that information and satisfaction with care play important roles in the decision-making process, both the decision to enroll and the decision to remain in a given plan.⁴ However, we know relatively little about what information consumers would like to see in such reports and how they interpret and make decisions based on the information.

In 1994 the NCQA, in collaboration with the Picker/Commonwealth Program for Patient-Centered Care and AHCPR, conducted research to learn more about consumers’ attitudes toward report cards. The work, the Consumer Information Project, included a review of the literature and focus groups with a broad range of consumers (including Medicare recipients).

■ **What consumers want.** This work and our review of summaries of focus groups conducted by other groups suggest several broad points about what measures are important to consumers and what sources are most trustworthy.

First, consumers say that they would use information on how a plan works, what it costs, the covered benefits, the quality of care, and overall satisfaction with care if it were available. They seem to be most interested in information about costs of coverage, technical competence, the information and communication provided by physicians, coordination of care, and access.

When it comes to sources of information, consumers show two distinct preferences. Perhaps not surprisingly, they want an unbiased, expert source of judgment about health care quality. However, consumers want to know how others “like them” evaluate care,

and many trust the evaluations of family members and friends more than any other source of data, including "expert" opinion. Opinions varied about the appropriate balance between summary and detailed information.

Another noteworthy observation is that consumers often raise many of the same issues debated by experts in quality measurement. Some members of focus groups expressed concern, for example, about the source and quality of the data, the size of the population (denominator) and the survey sample, and the validity of the data.

Results from these focus groups and other studies suggest that consumers are interested in knowing about other consumers' evaluations of health care providers or systems. However, we do not have much data on exactly what type of information would be most useful. Different types of consumers—for example, healthy persons or those with chronic diseases—have different informational needs. Not everyone has the interest or ability to evaluate detailed information, which is an issue of particular importance with an elderly population. Furthermore, to our knowledge, no one has distinguished the information needs of the general consumer from those of the health care decisionmaker in a family—that is, the person responsible for choosing the health benefits.

■ **Past evaluations.** In addition to recent work on report cards, there also has been extensive research on the ways quality can be measured best using patient surveys. Patient satisfaction with medical care is perhaps one of the most commonly measured patient attitudes, and work in this field has increased markedly in the past decade or so.⁵ There is an extensive literature on both the determinants and the consequences of patient satisfaction.⁶ Almost all of the instruments used to assess patients' satisfaction with their care assess important aspects of care. However, many of the instruments used in earlier studies were not based on careful assessments of how patients define and perceive quality and did not explicitly incorporate patients' priorities. For example, many patient satisfaction scales place substantial emphasis on amenities (such as attractiveness of waiting areas, parking, and hospital food), whereas when consumers are asked to define the most important aspect of quality care, they do not place a high priority on those features.

■ **A new instrument.** An early activity of the Picker Institute was an evaluation of the existing measures and the development of a new instrument to assess the quality of hospital care, from the patient's perspective. The development process included a thorough review of the literature as well as numerous focus groups with patients, their families, other laypersons, and health professionals in order to elicit directly ways in which people defined and evaluated

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care. We also conducted pilot interviews with patients and their families around the country. Subsequently, we had patients and health professionals critique the types of questions that we asked about the quality of hospital care and tell us about the priority that they gave to the different aspects of care that we asked about.⁷

In the focus groups we asked about patients' experiences of illness and hospital care. We asked many types of people about their experiences in hospitals, what was important to them, and what affects them either positively or negatively. On the basis of that work, we defined several dimensions of care, that we think capture how consumers define quality and reflect the most salient processes of care for which they might want comparative assessments.⁸ For hospital inpatients, the dimensions are as follows: respect for patients' values, preferences, and expressed needs; coordination of care; information, communication, and education; physical comfort and pain management; emotional support and alleviation of fear and anxiety; involvement of family and friends; and transition and continuity to the home or community.

The Picker Institute and its collaborators have conducted similar studies to develop measures for ambulatory care. Focus groups have been used to identify the needs of ambulatory patients receiving care in emergency rooms, private doctors' offices, hospital outpatient clinics, community health centers, and managed care plans. Ambulatory care patients are concerned about a somewhat different set of care needs than hospital patients are: access to care; coordination of care; information, communication, and education; respect for patients' values, preferences, and expressed needs; emotional support and the alleviation of fear and anxiety; and patients' experiences with specific processes of care, such as waiting times in the office, assistance from office staff, tests and procedures, and follow-up care and information.

Multiple focus groups conducted with Department of Veterans Affairs (VA) patients from different geographic regions confirmed the dimensions of quality identified by earlier Picker Institute work as being most important to patients. The VA National Customer Feedback Center and Department of Quality have established them as the “customer standards” for all VA hospitals.

What Do Medicare Beneficiaries Want To Know?

We have only limited data about how Medicare beneficiaries make decisions to join managed care plans and their needs for information to support those decisions. Beginning in 1993 the Office of Inspector General (OIG) of the U.S. Department of Health and Human Services (HHS) began surveying Medicare beneficiaries enrolled in or recently disenrolled from health maintenance organizations (HMOS) to better understand enrollment procedures and service quality issues from the perspective of beneficiaries. The intent of the study was to identify areas that need improvement and to suggest methods that the Health Care Financing Administration (HCFA) could use to monitor these areas in the future.⁹ Although that study was not intended to identify information that beneficiaries might use to select a plan, certain areas of performance or perceptions of service were strongly correlated with disenrollment. Comparative information about these areas might be helpful to beneficiaries in their initial selection of plans. The questions most predictive of beneficiaries' future disenrollment included the following: (1) Were complaints taken seriously by the doctor? (2) Did their primary HMO doctors provide Medicare services, admit them to the hospital, or refer them to specialists when needed? (3) Did they perceive that their HMOs are giving too high a priority to holding down the cost of medical care instead of to giving the best medical care? (4) Did they perceive their health worsening as a result of the medical care that they received in their HMO? (5) Did they experience long waits in their primary care doctors' offices?

In addition to this study, several private organizations have conducted focus groups with Medicare beneficiaries about related issues that provide some insights, and inferences can be made about the kind of information that Medicare beneficiaries would want about managed care.

■ **Kaiser Foundation study.** In a 1995 study conducted for The Henry J. Kaiser Family Foundation, senior citizens expressed much mistrust and anger about managed care and believed that elders are being forced to accept a lower standard of care to increase health care profits and reduce the government's budgetary problems.¹⁰ The study found that few consumers, especially the elderly, understand how managed care works, except in market areas with high levels of managed care penetration.

Focus group participants in that study, however, were interested in comparative data on benefits and quality of care and descriptive information about how managed care plans function. They wanted information about how to choose a provider and wanted to see

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specific information about primary and specialty providers, including information on training, a physician’s gender, location, and patient satisfaction information. They also were concerned about how much choice they have with respect to hospitals.

Much of the information that they requested is descriptive: How does managed care work? What are their rights? How do you choose a doctor? How do you switch physicians? What happens if you need experimental treatments? Where are centers or clinics located, and what are their hours?

These focus group participants also were interested in satisfaction information, but they expressed concerns about the utility of general satisfaction ratings. Most talked about the need to understand the source of information: the value system, beliefs, and intelligence of the person or people from whom it was acquired. Word-of-mouth information from family members and friends was viewed as more trustworthy than summary satisfaction scores. Participants were more interested in the opinions of their family members, friends, or neighbors than in those of their coworkers.

■ **Consumer Information Project.** As reported earlier in this paper, findings from the 1994 Consumer Information Project were similar to the focus group findings described above—both for all consumers and for Medicare beneficiaries who participated.

It is also noteworthy to point out that many found the typical information about how to pick a doctor confusing. Many elderly and chronically ill participants in the Consumer Information Project focus groups also made negative comments about the information provided to them about access. They did not want summary satisfaction ratings, because they could not interpret another person’s tolerance for waiting times for appointments or in the waiting room. They wanted to know the number of days or the time spent waiting in the office so that they could judge for themselves. They also wanted to know about access to information over the phone so that they could avoid an appointment, if possible.

Again, these consumers—some of whom were low-income patients with little education—wanted to know the source of the information, the size of the population measured, the sample size, and how the results compared with national norms. They also remarked that some measures (such as the percentage of women over age fifty who have had mammograms or the percentage of children

who had been immunized) reflected personal behavior and social problems as much as the quality of a health plan.

Chronically ill and retired focus group participants had more concerns about the comprehensiveness of the coverage and the referral process for specialty care. They also were interested in the communication skills of their providers and in good access. In an interesting counterpoint to a 1993 study by Shoshanna Sofaer and Margo-Lea Hurwicz that found that 60 percent of Medicare beneficiaries switched managed care plans to preserve their preexisting relationship with doctors, they showed mixed loyalty to their physicians.¹¹ For some, comprehensive coverage was more important than the ability to remain with their primary care provider. These participants also expressed more interest in the ratings of satisfaction from family members and friends than from consumers in general. They also wanted detailed ratings of overall satisfaction rather than aggregate groupings of the "satisfied" versus the dissatisfied."

The elderly were not interested in evaluations of services that they would not use, such as pediatric immunizations. They wanted information that assessed and compared care that persons of both sexes were likely to receive and that was relevant to their age and health status.

■ **RTI study.** The Research Triangle Institute (RTI) is now conducting a study to develop and test prototype information materials for Medicare and Medicaid beneficiaries.¹² The findings from their focus groups and case studies are similar to the findings from other focus groups and to those from interviews that we conducted with state health insurance counseling programs and advocacy groups. Consumers expressed interest in structural measures, that is, the scope of benefits, premiums, and how the plan works; survey-based measures such as access to care, communication/interpersonal skills, experiences with the physician/hospital/member services; and assurances that data have been collected and analyzed by an independent third party.

The RTI report also suggests that Medicare beneficiaries would like more guidance to direct them toward a particular choice. It suggests that the development of composite measures or scores that summarize information on aspects of care such as access, communication, and coordination of care might be helpful. Once again, participants found the information received from family members and friends to be more helpful and trustworthy than information received from other sources and also wanted to see more detailed information about the experiences of plan members "like them."

■ **Focus group limitations.** Although focus groups represent only a modest first step in more rigorous research programs, they

can be very informative in highlighting the types of issues that are of interest to consumers. The results of focus groups conducted to date are particularly interesting because certain themes, summarized above, emerge consistently. They are inherently limited in several important ways, however. First, they cannot provide information about how generalizable the results are. For example, although persons with chronic conditions were included in many of the groups described, those most in need of high-quality, comprehensive care—the disabled, the chronically ill, and those who are cognitively impaired—may be the least likely to participate in focus groups. Second, the importance consumers ascribe to certain types of information may not correspond to the importance of the information in influencing actual decisions.¹³

Views Of Plan Managers And Consumer Advocates

To supplement the findings reported above, we interviewed staff at state insurance counseling programs, consumer advocacy groups, HMO managers of Medicare programs, and patient relations managers for large individual practice associations (IPAs) and prepaid group practice plans to learn more about the type of information most often requested and to find out what kind of information seemed most helpful to potential Medicare enrollees or their families. We also interviewed a benefits manager from a large national employer about how information is disseminated to retirees.¹⁴

Those interviews suggest that Medicare beneficiaries have many of the same concerns as most new enrollees in managed care plans. They often do not understand what managed care is and express concern that it represents “second-class care.” Cost is a major concern, as is overall quality of care.

The managers of Medicare HMO programs agreed with focus group findings about the topics about which beneficiaries want information. They also report that the most frequent benefit questions focus on prescription benefits, home care and long-term care coverage, dental and foot care services, and out-of-plan coverage, especially in plans in the Northeast or Midwest with large “snow-bird” populations.

Many programs have established free, long-distance telephone hot lines, one-on-one counseling sessions, newsletters, and other types of educational presentations to provide Medicare beneficiaries with information. However, our efforts to contact these services revealed several things. Many were extremely difficult to find; it required an assertive, determined person to locate many of the counseling or information services. Also, several insurance commission phone numbers required working through a maze of voice mail, only

to end up with a recorded message asking the caller to leave a name and phone number. Finally, many staff with whom we spoke expressed concern about making subjective recommendations, or even providing information about what to look for in a plan, for fear of “influencing” beneficiaries or of “being censored by health plans.”

All of the managers from managed care plans interviewed indicate that their plans use a combination of written materials, educational group presentations, face-to-face meetings, and benefits hot lines to inform and educate Medicare beneficiaries about their plans. Some plans sponsor fairs and have support groups for caregivers as another way of providing information to the elderly population.

Some plans are testing interactive computer methods of presenting information to consumers and purchasers that present different “layers” of information depending on decisionmakers’ interests. Layered information allows the user to look at global information about a plan and then view more specific information about a plan, a center, or a provider, or specific patient populations, defined by demographic variables or diagnostic groups. Anecdotal information from an interview about these interactive systems revealed that the elderly are using the patient satisfaction information much more than expected. Formal transaction data reports about the use of the information kiosks designed by HealthPartners in Minneapolis may be available in 1997.

In spite of the potential advantages of print and computer presentations of information, several Medicare product managers said that consumers frequently request face-to-face meetings to discuss benefit and plan options. Consumers apparently feel that such meetings allow them to assess the credibility of the staff and information.

Recommendations

A great deal more needs to be known about the information needs of all consumers, especially Medicare beneficiaries and the chronically ill. Many consumers are asking the right questions about data collection and sampling. However, we have only a limited understanding about the kinds of information consumers ultimately may find most helpful.

■ **Basic Information.** Many studies have shown that Medicare beneficiaries need basic information on how Medicare and managed care work as well as a better understanding of their rights in managed care plans before they can make informed choices.¹⁵ Sofaer illustrated the impact of misunderstandings here when she estimated that 10 to 15 percent of Medicare beneficiaries have duplicative policies that entail significant out-of-pocket expenses.¹⁶

Consumers need comparative information about all health care

delivery options, not just managed care, to make educated decisions. Making an informed choice about managed care requires an understanding of the differences between managed care and fee-for-service plans and the availability of comparable information about both types of plans upon which an intelligent decision can be based.” The lack of objective, comparative data about various types of health plans makes it even more difficult for Medicare beneficiaries to behave as informed consumers.

■ **Satisfaction ratings.** Many consumers say that they are not interested in overall satisfaction information because they do not know how to interpret it or whether it is biased. Health care administrators and clinicians also told us this in early focus groups conducted by the Picker/Commonwealth Program for Patient-Centered Care. Patient surveys should allow patients to report about their experiences with a plan’s health care, as well as to rate their overall satisfaction. Correlating patients’ reports about their experiences with satisfaction ratings can elucidate patients’ priorities for different aspects of care and predict which aspects of care will influence disenrollment. Combining these reports about experiences and different evaluations of care may increase the usefulness of these kinds of data to consumers.¹⁸

■ **Access, cost, and quality.** Much of the available information about the informational needs of Medicare beneficiaries suggests that they need more and better information to evaluate the trade-offs among access, cost, and quality. A Medicare manager from one of the largest and oldest managed care plans in the country talked to us at length about how value-conscious and shrewd potential Medicare enrollees have become, making almost actuarial decisions to compare how much they might save or lose, depending on their personal health care needs and utilization history.

Consumers on fixed incomes pay close attention to their out-of-pocket expenses and would benefit greatly from a method of determining those costs that reflect their own health problems. Sofaer and Bruce Davidson developed a way of providing information to Medicare beneficiaries and their family members that allows them to make informed choices about the best plan for them, depending on their health status.¹⁹ The illness-episode approach provides consumers with comparative data about out-of-pocket and premium costs and benefits for representative conditions, such as hypertension, diabetes, and prostate cancer.

■ **Peers’ experiences.** Our findings also suggest that consumers want information about how others like them fare in the health care system. The incorporation of patients’ experiences with care, satisfaction, and outcomes data into the illness-episode approach could

become a very useful way of providing information for people with chronic health problems.

■ **Care by provider groups.** Many Medicare beneficiaries may have few choices among plans, and the same plan may have different arrangements with physicians and hospitals and, in some instances, may even have differences in the services that they provide in the same geographic area. In the future, information that allows consumers to evaluate the care provided by different provider groups may be the most valuable to consumers. We think that collecting and presenting these levels of data will become increasingly important. Devising cost-effective methods of collecting valid center- and physician-level data will be a major challenge in the future.

■ **Usefulness to consumers.** There is little question that providing the kind of information that we have described here could be very informative. It is not clear, however, how much information consumers want or can interpret. Many elements of information that consumers said would be useful are complicated and difficult to present and interpret. For example, even providing rudimentary information about financial and contractual arrangements between plans and providers in a comprehensible manner would be extremely difficult.²⁰ The task of integrating and synthesizing that, as well as other types of information across multiple health plans, would be onerous, even for a sophisticated health services researcher. It would be impossible for many Medicare beneficiaries. How then, should we proceed?

■ **Efforts to improve information.** AHCPR and the Kaiser Family Foundation are sponsoring research and conferences to better understand the information needs of all types of health care users. In the CAHPS project, referred to earlier, teams of researchers are designing and evaluating report formats for presenting information from consumer surveys and other quality information, such as HEDIS indicators, as well as plan descriptions and benefits. HCFA and AHCPR are jointly sponsoring a special study of how to assess the experiences of Medicare beneficiaries and present that information in a way that is most useful to other beneficiaries. These studies will evaluate the way consumers interpret and use the information when making actual plan choices. A similar process could be used to evaluate the presentation and use of a more comprehensive data set. This effort to collect national comparative data will serve as the vehicle for capturing and presenting information to the Medicare population in the future.

Making the right choice of a health plan is extremely important to older Americans. Older consumers need to establish a relationship with a physician and understand how to get the best care for their

limited dollars. Their health care needs are likely to be more extensive than those of younger patients. Continuity of care and good communication with a doctor are likely to improve their subjective well-being and functional status.

Helping Medicare beneficiaries make the right decision and making them comfortable with new organizational and financing arrangements will require providing them with the kind of information that they value and can interpret.

Medicare enrollees may be less likely to change their choice of providers if they are initially given better information. They also will be better consumers in general if they understand their rights under managed care and how to make the plan work for them.

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NOTES

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