



Consumers Don't Know What They Don't Know

All the state-of-the-art health care literacy tools go for naught when faced with such ignorance

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At a time when people make decisions about health care based on input from friends, family, physicians, the Internet, and a myriad of other sources, you can count Charlie Baker as a believer in the positive influence of a steadily swelling stockpile of cost and quality data.

Living in "a world in which there are data available on relative price, mortality, satisfaction" does not change the fact that we still have the same people as before engaged in obtaining and using that information, says Baker, CEO of Harvard Pilgrim Health Care.

Making the data more readily available won't transform the way consumers make health care choices overnight, he adds, but it will have an impact. And to that end, Baker has been one of the pioneers in pushing those data out to his members. Harvard Pilgrim has been frequently cited as one of the leading health plans in the nation when it comes to educating members on quality data. Harvard Pilgrim officials can pore over comparisons of providers of every stripe.

In an attempt to rein in steadily surging health care costs — or at least ensure that management and employees share the burden — managed care organizations around the country have been developing plans with ever-higher out-of-pocket expenses for their members. And that in turn has produced a call for

greater transparency in the way health care services are sold and the quality of the services that are available.

With more of the expense, comes more of the responsibility for choosing providers, shopping for the kind of price and quality that consumers expect when footing the bill. And the new system requires a consumer who understands how to buy health care.

But while the trend toward consumer-directed care gains momentum, the rapid proliferation of ratings and data sources has triggered a growing debate over just how much responsibility people are able to shoulder. Is the average consumer equipped to find the right doctor and hospital for his bypass surgery? Just how much of the information available is laid out in a way that can be understood?

Experts in academia have been taking a close look at health literacy in America and have concluded that this is one area where even relatively well-educated people will have trouble finding their way. Several recent studies have underscored a disturbing confusion among patients when it comes to figuring out medical information. And for tens of millions of Americans who aren't well educated, the task of sorting through the information may well be far beyond their capability.

"Limited literacy"

"If people who are educated have trouble figuring this out — reading hospital bills, prescription labels — then 90 million Americans with limited literacy are going to have more trouble with these tasks," says University of Wisconsin literacy expert David A. Kindig, MD, PhD, lead author of a 2004 study on the subject titled "Health Literacy: A Prescription to End Confusion."

And those literacy facts are likely to collide with the rapid development of consumer-directed plans, says Kindig and his colleagues.

"In a broader sense," they concluded in their study, "many in both the public and private sectors see increased consumer involvement in coverage and care decisions as a major force to improve the cost and quality issues that other approaches have not been able to achieve. If this is the case, the burden for persons with limited health literacy ... will surely increase significantly."

You have to consider that those 90 million Americans — about half of all adults — struggle to read a map, balance a checkbook, or stick to a simple schedule, says Northwestern University's Michael Wolf, PhD, who has studied health literacy.

"Those are easy tasks when compared to the task of interacting with their physicians or navigating their way through the health care system," says Wolf. That 48 percent is also a conservative figure if you think in terms of health literacy, where the jargon and medical terminology are so much more complex. The 90 million also are unlikely to get very far in understanding the online tools that are being created for managing consumer-directed health plans.

"Just making more information available doesn't mean it will be used. I think that many people will not be able to understand much of the information that is presented."

Without a clue

"It's nice to say that the available health information for consumers is adequate to their needs, but the truth is that it rarely is," says Abbie Leibowitz, MD, cofounder and chief medical officer of Health Advocate, which advises patients on health insurance issues.

"We'd like to make health care act like a marketplace, as the marketplace works for other consumer products," says Leibowitz. "Like shopping for a refrigerator. Consumer Reports says this is better, this worst, and that's the approach we're taking. The difficulty is, health is far more complicated. Each patient is unique, bringing pre-existing problems, complicated issues, complex insurance issues as well.

"It's not a bad idea," adds Leibowitz, the former chief medical officer at Aetna. "It's just that we're really embarking on a very broad experiment with the health care system we've created by assuming the consumer can be a more active part of it."

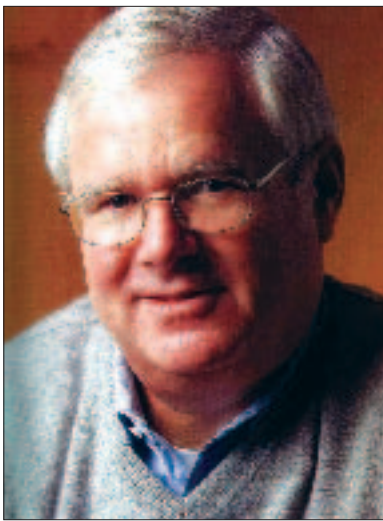
But the system we have is already riddled with communication breakdowns, he adds. Aside from the obvious difficulty of understanding medical lingo, visits can be short and physicians may not always take enough time to communicate effectively.

"Lots of people go online and muck around on the Web," says Leibowitz, "check out their doctor and such." But browsing for information about a condition is nothing like looking for someone to take care of an emergency. "Don't think for a second that people are going to sit down at a computer and start looking up who's the best provider for heart attacks when they have their chest pain. They're going to go to a doctor they know or the nearest hospital."

Most people approach the health care system with the same trepidation that they approach auto mechanics, adds Wolf. Something goes wrong with your car, you take it to a mechanic and trust him to tell you what's needed. With your health, you

go to a doctor and trust him to tell you what's needed. But people still often walk away from their doctor's office without a clue of what they just heard.

"I can't tell you how many calls we get from patients leaving the doctor's office, literally from the office parking lot, saying, I have five prescriptions in my hand but I don't know what to do," says Leibowitz. "Meaningful



"Meaningful participants in their health care decisions?" Abbie Leibowitz, MD, CMO of Health Advocate, a company that advises patients on health insurance issues, asks rhetorically. Consumers, he asserts, "simply aren't." A quarter of adults can't read at fifth grade level.

participants in their health care decisions? That's silly. They simply aren't."

Keep in mind, says Leibowitz, that a quarter of all adults can't read at fifth grade level. But the situation with health literacy is far worse.

"You may be able to read a manual for a wristwatch, but reading anything about your health and understanding medicine is a whole different ballgame. Saying you're now in charge without personal attention and personal help I think is really naive."

The new ratings systems that have sprung up have done little to improve matters.

"Anecdotally," says Wolf, "when we're talking to patients on how they choose their health care, oftentimes ratings are not widely understood. Other, more subjective factors are coming

Physicians not always up to date

Patients who depend on their doctors for help understanding what various hospitals charge for their services are probably not getting the help they want. In Harvard Pilgrim's latest survey, 71 percent said they didn't know where their patients could check out costs. Surprising? It was to Harvard Pilgrim Health Care's CEO, Charlie Baker.

"They hear about costs all day long, every day," says Baker. "That's all I think about all day long. That's all my customers tell me to think about all day long."

But consumers - or at least the 310 people who took the survey - did a lot better, in his judgment. About 85 percent said that they were very or fairly likely to check out a hospital's quality rating before going there and were willing to switch to a higher quality hospital with lower costs. Half of those ready to check into a teaching hospital would reconsider their choice if they had cost and quality data to ponder.

Other findings:

- Ninety-nine percent responded very favorably or fairly favorably to the notion of making cost and quality data available to them; 79 percent of consumers responded very favorably to the idea.
- Physicians also favor the idea. Seventy percent of doctors responded very favorably or fairly favorably; 26 percent responded very favorably.
- Both consumers and physicians say they would use the information to make better health care decisions if it was made available. Seventy-four percent of physicians were very likely or fairly likely to use the data when making referrals; 95 percent of consumers would be very likely or fairly likely to use the information (68 percent responded "very likely").
- Currently more Massachusetts residents compare cost and quality information for buying a car (97 percent), a home (94 percent), furniture (89 percent), groceries (75 percent), and gasoline (68 percent) than do for their medical services (35 percent). (Average annual premiums for insured workers are approximately \$11,000 for a family plan and \$4,000 for an individual.)

Encouraging? Yes, Paul B. Ginsberg, president of the Center for Studying Health System Change, told the Boston Globe. But doubts remain. "These results suggest consumers are talking the talk, but it's uncertain if they'll walk the walk."

into play. Patients are less focused on the quality that is derived from a rating system than they are on the perspective of other family members.

"The ratings system might reflect a complexity of decision-making that many Americans may not apply to health care. The most highly educated individuals are the smart shoppers." But others, without the education or the access to information, "don't have the luxury to be smart shoppers."

"I think it's a huge problem," says Wolf. "The demands of the health care system are already growing for patients." Self-management requires technology skills, an ability to manage and process several pieces of information." And that's a scenario that will probably lead to worse health outcomes, not better.

"There are a lot of concerns that if we keep throwing more onto the pile of patient responsibilities, we should not be surprised when we see health disparities grow and a lot of failures in chronic disease management."

Not all Web sites about health are created equal.

Comparing public sites created by the Centers for Medicare & Medicaid Services, the Leapfrog Group, and the Joint Commission on Accreditation of Healthcare Organizations with third-party sites such as Subimo and WebMD, Forrester Research's Katy Henrickson concludes that "third-party tools were much better than publicly available tools. They use more data sets, had data on more procedures — many more procedures — and had better features and functions. And they're easier to use. Public ones are really looking at heart failure, heart attack, acquired pneumonia, not a lot."

Work in progress

Subimo, for example, used a scenario-based search tool that made it easier for users to find the kind of information that was most helpful to them personally. All of the sites have plans to boost utilization, but they're also pushing for better information.

"It's definitely a work in progress," says Henrickson, and it's steadily building reliance on the Web for more and better health care information.

"We survey consumers about their use of electronic tools. Twelve percent were researching hospital quality," says Henrickson. "And we have certainly noticed increased usage in general of health plan Web sites. We also asked consumers whether doctors and hospitals should be reporting their performance. More than half said yes."

While there are lots of consumers who say they want to be able to seek out the data, Henrickson also understands that there are many consumers who wouldn't use the information even if they had access. That is likely to change gradually as more and more consumers wind up paying for their care or look for ways to navigate a system still fraught with second-rate providers. And as health plans continue to build up tiered networks, steering members to higher quality providers with lower copayments, more consumers will probably get into the swing of things.

"In the scheme of going from infancy to maturity," says Leibowitz, "we've just been born. And we've got a long way to go to make information available in a timely, meaningful way in the way the average consumer can understand."

"I think most of the time the data are nonspecific, general, rather than about specific conditions. Many of the Web sites require you have information about your illness beyond what the individual consumer is likely to have at that time."

Chronic problems

Because huge volumes of data are available from Medicare, much of the information is weighted too heavily toward illnesses common among the old, adds Leibowitz. That makes individual health plans' data less useful to a broad audience. Also, there are chronic problems with a system that can be maddeningly confusing in its interpretation of conditions.

"You can call it chest pain, angina, chronic persistent angina, there are other interpretations. The data is by and large old, years past. It is heavily weighted toward people that do high volume things. You don't get enough information about people who don't do a lot of things, and in turn you don't weight them well."

In that circumstance, a 70-year-old surgeon whose hands may be starting to shake may look better on the Web than a top resident who's been in practice three years and has been trained in the latest techniques.

And whom would you really prefer?

For all its problems, Leibowitz isn't saying that the information shouldn't be posted. It should. Just don't put too much stock in its usefulness.

For the health plans, though, there's no turning back. Yes, the data aren't perfect. Yes, some people will find it hard or even impossible to understand them in their current form. But that current form will undergo enormous improvements in a relatively short period of time — and consumers can only benefit from the data in growing numbers as they become more universally available.

"I don't think we're talking here that people will suddenly and dramatically alter the way they gather information," says Baker. For the last 30 years, he adds, the system has been little better than don't ask, don't tell. That won't change overnight. "But I do think we're going to be in a period of significant transition."

He holds out one particular piece of information as an example.

"Most hospitals collect data on how often they bump surgeries," says Baker, "how they keep to schedules. The variation on this is huge. There are some that almost never bump and others that bump dozens of times a week. It's a pretty good stat, useful to a lot of people. It's not complicated; sort of an indicator of the level of service and the likelihood you'll have the surgery on schedule."

And there's an underlying benefit to the system from providing the data as well, he says. "If you're bumping thousands of surgeries, you're probably working to drive that number down."

Where data and ratings advocates seem to disagree most sharply with the health literacy experts is the ability of an average consumer to grasp what the numbers mean.

Just look at the average baby boomer, says Baker. "Sophisticated, well educated, always looking for value. They

Should government build pipeline for data on quality?

Managed care organizations can contribute a lot to the drive to make quality data available, says Harvard Pilgrim Health Care's CEO, Charlie Baker. But in the fight for full public acceptance, the country may well need a public reporting group that can act as a clearinghouse for easily understood data.

"I think you need the equivalent of a Bureau of Labor Statistics," says Baker, "a place that most people believe is baseline truth. Massachusetts and New Hampshire and Maine, are in various stages of development of single sources of information collected by a public agency — a disinterested third party — which aggregates data and make them available to the public. I view all of this as a .5 and 1.0 version of what will over time become more sophisticated."

In Massachusetts, health care officials have begun posting cost and quality information related to the state's hospitals as an initial effort in an overall drive to push lower-premium, higher-out-of-pocket consumer-driven health plans as a solution for the state's uninsured. The state's Executive Office of Health and Human Services rates hospitals on the data and is working to add more stats on treatments, physician groups, and pharmacies.

The site — www.mass.gov/healthcareqc — employs a menu style listing of the hospitals, with a single dollar sign signifying the least expensive and three such signs marking the most expensive.

The Massachusetts Hospital Association, though, says the state site underscores a key difference of opinion about the data that are being offered up.

"We think the most reliable data are from medical reports, not billing records," says MHA spokesman Paul Wingle. But the state's site, like many third-party sites, relies on billing information.

The problem, he says, is that many hospitals get an unfairly low quality rank because adequate risk adjustment has not been performed. One of the hospitals on the state site, for example, got a poor rating for heart failure because it had a low volume of heart patients with a high concentration of voluntary "do-not-resuscitate" orders. Hospitals that specialize in infection-prone burn victims, he adds, run a risk of looking bad in terms of infection rates.

So the MHA has been backing the Hospital Quality Alliance's emphasis on assessments based on hospitals' ability to follow accepted clinical procedures. And in the meantime, he adds, the association has been using its influence to push health insurers and the state toward its preferred approach to quality.

But, much like Baker, the MHA sees a need for a single, unified approach.

"There's a great deal of discussion on how data is rated," says Wingle. "We hope to settle on a common set of measures."

have been that way as shoppers and users of services their whole lives, and they're just now reaching the point of using a fair amount of health care."

"We don't claim to solve the problem of literacy in the U.S.," says Ann Mond Johnson, founder and CEO of Subimo, which contracts with health plans to make the information available to millions of their members. "However what we're seeing at an increasing rate is that people are more engaged and want to ask

the right questions of their providers. The American consumer is very savvy, and we are selling him short if we say that health care is too difficult for him to understand. We have lots of anecdotal evidence where people have used Subimo's tools and used them for a number of situations — realizing there was another, less invasive surgical option, an alternative to surgery altogether, or deciding where they might want a procedure performed because they realized the local facility may not be the best for them."

That has been borne out in survey groups, she adds, citing "Consumer Demand for Clinical Quality: The Giant Awakes," a study by VHA, an alliance of 2,400 not-for-profit health care organizations.

"The purpose was to understand whether consumers understood concepts of evidence-based medicine," she says. So VHA organized focus groups and, "with a very brief overview, described what evidence-based medicine would suggest take place if someone was brought into the ER for the treatment of a suspected coronary. Consumers understood the concept of evidence-based medicine and best practices and were outraged when they learned — by looking at data — that the best practice may not be followed by all hospitals.

Whether consumers understand everything there is to know about procedures and other quality ratings may be debatable, say the health plans, but there is no mistaking their response to a rating systems when tied to a tiered network of providers.

At Tufts Health Plan, high quality hospitals are available under Navigator, a tiered product, for a \$200 daily copayment versus a \$400 copayment for a nonpreferred hospital, says John Freedman, MD, Tufts' assistant vice president and medical director for medical and quality management. Particularly for patients with time to consider their options — such as where they will deliver a child — there's been a distinct "shift toward lower copayments. The shifts are not enormous, but they are real and they are there." In the process, says Freedman, Tufts has also learned that different consumers have varying appetites for data.

"We've found that there are people who like simplified ratings and there are others that want more in-depth information." So Tufts offers both basic summaries and the option to dig deeper. But it's all part of making the information available to them so they can study, explore, and carry on a more informed dialogue with their doctor. In the end, he says, patients need to become better informed, and this is a practical way to help.

"We're not in a position to be paternalistic," says Freedman. "This is something that we've been actively engaged in, that members have been using, and we've been getting positive feedback," he adds.

But everyone agrees that there is plenty of room for improvement.