

Powerful Tools



The consumer's changing role in health care

By Karen Donelan and Katherine Binns

In the past decade, we have seen the power of the public's ability to say "no" regarding health care. President Clinton arrived with a promise to reform the system, but the public's initially positive response to the idea turned negative as proposals came forth. Health plans, already poised to provide widespread access to managed care,

moved forward with the assurance that business could bring about change in ways that government could not. The public said no again.

What is clear is that the public says yes to health care itself. Americans' consumption of health services is higher than that of all other nations. US per capita expenditures on health care were over \$4,600 in 2001—two or three times greater than many other industrialized nations, according to the international economic organization OECD. Still, the National Opinion Research Center's General Social Survey tells us, a majority thinks we do not spend enough.

What does the public want from its health care services? In what ways do Americans want to be involved in their own care?

For several decades, providers—doctors, nurses, and pharmacists—have been the main agents of information and decision-making in the health care system, and health plans (government- or employer-sponsored) the main source of payment for services. Their relationships with one another, suppliers and government/ employer sponsors of care or coverage, have often caused the patient to be seen as a less important customer than the agent.

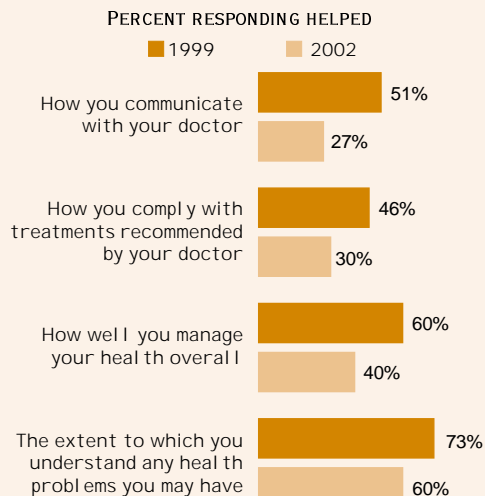
Karen Donelan is senior scientist in health policy, Massachusetts General Hospital Institute for Health Policy. Katherine Binns is senior vice president, Harris Interactive.

Figure 1

Information Impact Is Waning

Questions:

Overall, do you feel that internet health information has helped, hurt or made no difference in each of the following?



Note: Asked of those who said they look for information online about health topics.

Source: Surveys by Harris Interactive, May 25-June 8, 1999 and April 17-May 4, 2002.

Gradually, over the past two decades, we have witnessed major changes in these relationships. Information is more widely available to the general public from a panoply of private and public sources. In a recent survey by the University of California at San Francisco, the Harvard School of Public Health, and Harris Interactive, 31% said they relied often on the media for medical information, versus 35% who relied often on their own physicians.

The consumer's role in paying for care has also been changed, both in traditional and alternative/complementary health settings. Throughout the 1990s consumers became more aware of health plan costs as rising premiums resulted in increased cost-sharing, in both employer-sponsored and government plans. In a 2001 *Health Affairs* article, Jon R. Gabel and colleagues wrote that, despite evidence that increases in out-of-pocket premiums had been offset by savings

elsewhere (the move from indemnity insurance to managed care resulted in lower out-of-pocket costs for many), consumers were still angry when they saw more restrictions from health plans while paying more for their coverage.

The growing power of this increasingly active consumer has been noted. Riding the wave of dissatisfaction about limitations on coverage, pharmaceutical and device companies began taking their case directly to patients. New consumer-directed health plans and benefits are gradually emerging. Several companies are competing to offer medi-

cal decision-making devices, ratings and quality information, and scientific information directly to consumers. At least some consumers now have two powerful tools to wield when it comes to making decisions about their own care—information and money.

What are we learning about consumers as they try to wield these tools? Researchers at the Harvard School of Public Health and Harris have been tracking specific consumer activities in health care since 1998, through a collaborative project known as Strategic Health Perspectives, as well as through several other projects. Data from these studies offer a look into what is happening as the public makes use of its newly acquired information and economic influence in the marketplace.

In a survey conducted in 2000 by Harris Interactive, consumers were asked how involved they would

like to be in decisions about their own care. Two percent of Americans said they wanted doctors to make their decisions for them, 57% wanted to share decisions with doctors, and 41% preferred to make decisions themselves after hearing the pros and cons from doctors.

These responses may have been influenced by how well-equipped—or ill-equipped—people felt to participate in the decision-making process. In the UCSF/HSPH/Harris survey, only 11% of Americans felt they got sufficient health information to make good decisions all of the time, 49% said most of the time, 36% only some of the time, and 3% none of the time.

Presented with a list of information sources and asked to report the frequency with which they used each, 35% said they often consulted their own doctors, 31% the media, 29% friends, 17% their health plans, 13% the internet, and 7% disease support groups.

Though ranked near the bottom, the presence of the internet on this list is significant. In the past five years, the internet, along with direct-to-consumer advertising, has had a noticeable impact in health care, generating considerable debate.

According to Harris Poll trend data, about 67% of Americans now have access to the internet, and about 80% of internet users (52% of the adult population overall) have looked online for health information.

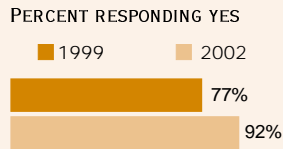
The most common place to start a health information search, employed by 53% of users, is a portal or search engine that allows them to look across multiple sites. Twenty-six percent of respondents said they began with sites devoted to health issues, and 12% with sites that included health as one of many issues. Eight percent could not recall where they started.

Figure 2

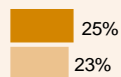
More Ads, Same Demand

Questions:

Have you seen or heard an advertisement for a prescription drug within the past twelve months?



Have you talked to your doctor about a prescription drug you saw or heard advertised?



Did the doctor prescribe the drug or not?



Did you fill the prescription?



Overall, do you feel the drug was effective...?



Source: Surveys by Harris Interactive, May 25-June 8, 1999 and April 17-May 4, 2002.

The most frequent uses of the internet are searches on specific medical issues or symptoms. Annual data since 2000 indicate that 62% of people who searched often or sometimes were looking for information on specific medical conditions. Forty-five percent had researched symptoms they were having, and 43% sought information on specific drugs.

People also went online to find support with a disease (20%) or to seek ratings information about health providers (15%). Fewer than 10% interacted online with providers to get advice, prescriptions or refills, or tried to consult in “real-time” with physicians.

What do consumers do with the information they find? Among the 31% who indicated they had looked for health infor-

mation in the past year, only 50% actually discussed the information they found with their physicians, and only 18% scheduled an appointment completely or partly for this purpose.

Those who had used the internet to look for health information and had brought the information to their physicians were overwhelmingly positive about this experience: 86% in the UCSF/HSPH/Harris survey said the information helped their understanding, 74% found it beneficial to their decision-making, and 62% said it improved communication with their doctors.

Other surveys show, however, that if you ask similar questions of all those who have sought health information online, these proportions decline considerably, and have shown a downward trend over the past four years (see Figure 1). So the message is a mixed one.

Searching for information online requires consumers to be proactive. Americans are also the passive recipients of a substantial amount of health information from the media, and, in recent years, from advertisements for prescription pharmaceutical products directed specifically at them.

From 1999 to 2002, the proportion of the general public that had seen or heard an advertisement for a prescription drug rose from 77 to 92%, according to Harris. There was a slight decrease in a similar time frame in the percentage that thought the ads were a good thing—59% thought so in 2000 compared with 50% in 2002—though the plurality still held this opinion.

Of concern to insurers and policymakers is the rate at which consumers are responding to the ads with new demands for health care services. Despite increased awareness of the ads since 1999, the proportions who talked to their doctors about the drugs and who actually got new prescriptions were essentially unchanged (see Figure 2).

Nonetheless, the ads have had an impact. A study by researchers at Massachusetts General Hospital, published in the March/April 2003 issue of *Health Affairs*, documented that about half of the time, ads encouraged consumers to seek medical help for conditions federal agencies have targeted as high priorities for regular medical care. The question remained as to who paid for any resulting increase in care and how much unnecessary demand was being generated, but there were at least some indications that a \$2 billion investment has paid off by generating increased public awareness of some serious health conditions.

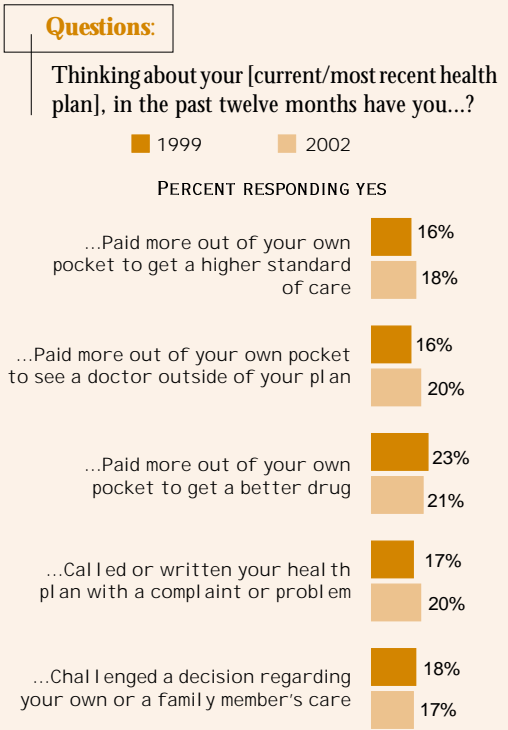
As any observer of health policy debates knows, the prevailing wisdom is that the public wants everything but does not want to pay anything extra to get it. Still, if consumers are going to have market influence, money is a tool that must be wielded by those who have resources. So what do consumers spend their money on in health care? And what else would they spend it on if they could?

This area of survey research is fraught with complexity. Expressed willingness to pay is not the same thing as actual expenditure—on taxes or in the marketplace. But there is some evidence that, while not necessarily happy about it, people are indeed spending money to improve the health care they get.

Figure 3 shows trend data on a number of measures of consumer activity in the health marketplace. In some, we asked if people had spent money out of

Figure 3

Some Willing to Pay, Challenge



Note: Asked of those currently or recently insured.
Source: Surveys by Harris Interactive, May 25-June 8, 1999 and April 17-May 4, 2002.

their pockets beyond insurance coverage on medications or health providers. Others showed customer challenges to drug prices or health plan coverage decisions by their members.

These data do not indicate widespread public uprising and market activity. They do show willingness by a segment of consumers to spend more to get more and willingness on the part of other consumers to demand lower prices. Willingness to spend more is, not unexpectedly, highly correlated with income and education, but not with health status.

It's clear that a lot of extra health spending is done to get around existing rules. Figure 4 shows that as out-of-pocket burdens rise, the proportion of consumers who mistrust key

health stakeholders tends to increase—with the exception of managed care plans, which begin with high levels of distrust. Doctors are relatively immune from the public's blame, but employers, pharmaceutical manufacturers and hospitals all suffer in the public eye.

Not all consumers believe that all health plans or providers are created equal. More than a third of respondents to a March 2002 study indicated there were big differences in quality among the hospitals (37%), health plans (38%), primary care (36%) and specialist physicians (37%) in their local areas. Among the college-educated, those proportions rose

substantially, to 46%, 49%, 49% and 43%, respectively.

It may not be surprising that information and money are being wielded in health care by the more educated and wealthy of our society. Differential access is a problem that plagues the US health care system. Our truest health care

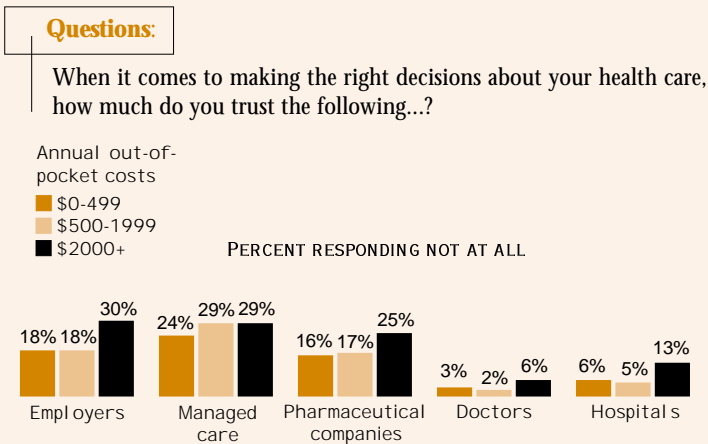
consumers have long been those without insurance, who are trying to get the care they need with limited dollars and full exposure to costs. They certainly use fewer services by any measure. So do people with less comprehensive insurance, higher deductibles and co-pays, or self-paid indemnity plans.

Managed care was supposed to simplify the process, wrap all costs into one lump sum, and make care more accessible. Ironically, the backlash seems to have helped create a newly aware consumer who rejects plan limits and reaches into his or her pocket to purchase the services plans won't cover.

We are gradually discovering what people are willing to pay for and what kind of information and decision-making authority they want. When and if the two come together in informed consumers willing to pay for the care they want, the health care system may be changed in ways none of us can yet imagine.

Figure 4

Trust Tied to Expenses



Source: Survey by Harris Interactive, April 17-May 4, 2002.