



# SEEKING HEALTH CARE INFORMATION: MOST CONSUMERS STILL ON THE SIDELINES

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Contrary to popular belief that Americans avidly seek health information—especially on the Internet—a majority of Americans in 2001 sought no information about a health concern, according to a Center for Studying Health System Change (HSC) study. And, instead of surfing the Internet, the 38 percent of Americans who did obtain health information relied more often on traditional sources such as books or magazines. People living with chronic conditions were more likely to seek information, yet more than half did not. Education is key to explaining differences among people. Those with a college degree are twice as likely to seek health information as people without a high school diploma. As consumers are confronted with more responsibility for making trade-offs among the cost, quality and accessibility of care, credible and understandable information will be critical to empowering consumers to take active roles in managing their care.

# **Empowered Consumers in a Changing Health System**

ountering images of American consumers actively researching personal health concerns, a 2001 survey of U.S. households found that only 38 percent of adults, or 72 million people, sought health information in the previous year from a source other than their doctor (see Figure 1). In contrast, nearly two-thirds of American adults (62%) failed to seek any health information, suggesting significant challenges lie ahead in educating consumers about trade-offs among the cost, quality and accessibility of care.

Driven largely by concerns about rapidly rising health costs, employers are taking steps to make consumers more aware of the true costs of care. For example, the newest product in health insurance, the consumer-driven health plan, is premised on the idea that consumers will be motivated and knowledgeable enough to shop around for the best health care at the lowest possible price. Architects of consumer-driven plans envision empowered consumers balancing the cost of care when deciding which caregiver to see or what treatment options to pursue.

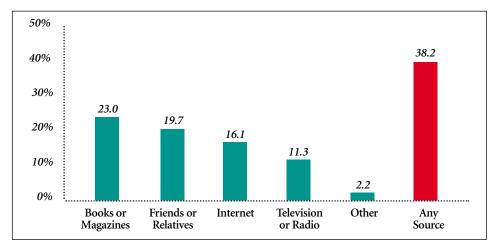
Another consumer-oriented movement, patient-centered medicine, views patients as active and equal partners with caregivers in making treatment decisions. Broader-based developments affecting much larger numbers of consumers, such as increased cost sharing and tiered-provider networks—where patients must decide, for example, whether to pay more out of pocket to go to a more expensive hospital—also require consumers to be more knowledgeable.

While mainstream media portrayals of consumers actively researching health issues and discussing the information with their doctors are common, there has been little reliable national information until now about the extent to which consumers actually seek health information.<sup>1</sup>

HSC's 2000-01 Community Tracking Study (CTS) Household Survey asked adults whether, during the past 12



Figure 1
Where Consumers Seek Health Information

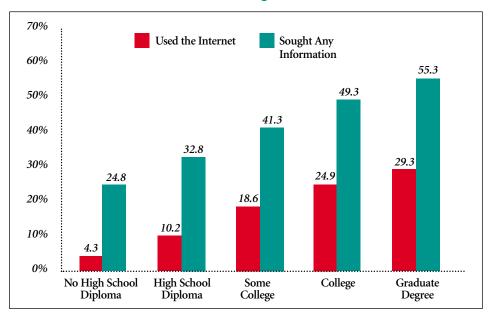


Note: Categories are not mutually exclusive; respondents could select multiple categories.

Source: HSC Community Tracking Study Household Survey, 2000-01

Figure 2
Education Level and Information-Seeking Behavior

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Note: "Any information" includes use of the Internet to find health-related information. These percentages were adjusted for other consumer characteristics shown in Table 1.

Source: HSC Community Tracking Study Household Survey, 2000-01

months, they had looked for or obtained information about a personal health concern from a variety of sources other than their doctor, including books or magazines, television or radio, friends or relatives, and the Internet.

Only one in six consumers turned to the Internet for health information (16%, or 30 million adults). In contrast, nearly one in four adults relied on books or magazines for information (23%, or 44 million adults), and another 20 percent, or 37 million adults, turned to friends or relatives. Only a small segment of consumers is quite active in pursuing health information: About one in five adults used multiple sources to obtain health information.

Some consumers, such as the very healthy, may have no pressing need for

information, and the 78 million adults living with chronic conditions, such as diabetes, asthma or heart disease,² were more likely to seek health information. Forty-two percent of adults with one chronic condition and 45 percent with multiple conditions sought health information, compared with 35 percent of people with no chronic conditions—a surprisingly small gap (see Table 1). Nonetheless, more than half of all people with chronic conditions, or 44 million adults, sought no health information.

## **Level of Education is Key**

Among the personal characteristics affecting whether people are likely to seek health information, level of education is by far the most important (see Figure 2).3 Information seeking rises sharply as the level of education increases: 55 percent of people with a postgraduate education sought health information, compared with only 25 percent of those without a high school diploma. The information gap is even wider for Internet use: People with a postgraduate education are more than seven times as likely as those without a high school diploma to use the Internet as a resource for health information (29% vs. 4%).

Although education appears to exert the strongest influence on informationseeking behavior, other characteristics also come into play. Men are less likely than women, older consumers are less likely than younger consumers and people with low incomes are less likely than higherincome people to seek health information. All of these differences, unlike education, are modest to moderate in magnitude, with one exception: The Internet information gap between elderly Americans and younger ones is sizeable. Only 7.7 percent of people 65 and older used the Internet to find health information, compared with 19.3 percent of people aged 18 to 34.

The overall likelihood of seeking health information does not vary by race/ethnicity, once other personal characteristics are

Table 1
Consumers' Information Seeking and Information Sharing with Doctors<sup>1</sup>

	ALL ADULTS			Adults Who Sought Information and Saw a Doctor	
		SOUGHT HEALTH			
	SOUGHT HEALTH		SOUGHT ANY	MENTIONED	
	Information	FROM MULTIPLE	HEALTH	Information	
ALL	ON INTERNET	SOURCES 21.2%	Information 38.2%	TO DOCTOR 23.7%	
	16.1%	21.270	38.270	23.770	
CHRONIC CONDITIONS		10.1	246	10.4	
None (R)	14.3	19.1	34.6	18.4	
ONE	18.7*	23.2*	42.1*	25.0*	
Two or More	19.4*	25.3*	44.7*	31.0*	
Sex					
Female (R)	18.0	24.2	41.8	24.6	
Male	13.9*	17.7*	34.4*	21.9*	
AGE GROUP					
18-34 (R)	19.3	22.9	41.4	23.9	
35-49	18.5	22.6	39.9	25.0	
50-64	13.2*	19.3*	<i>34.8</i> *	25.7	
65 AND OLDER	7.7*	17.9*	<i>33.5</i> *	18.8*	
EDUCATION					
No High School Diploma	4.3*	11.8*	24.8*	16.3*	
HIGH SCHOOL DIPLOMA	10.2*	16.6*	32.8*	20.3*	
SOME COLLEGE	18.6*	23.7*	41.3*	23.9*	
COLLEGE DIPLOMA	24.9*	29.6*	49.3*	28.8	
GRADUATE EDUCATION (R)	29.3	35.0	55.3	30.1	
FAMILY INCOME					
Less than 200% Poverty	12.0*	18.8*	35.6*	22.9	
200-399%	15.6*	21.2*	37.8*	24.2	
400-599%	17.3*	22.3	40.3	23.4	
600% OR MORE (R)	19.0	22.7	40.3	24.0	
RACE OR/ETHNICITY					
WHITE (R)	16.9	21.0	38.1	24.6	
AFRICAN AMERICAN	12.2*	20.1	37.7	17.9*	
LATINO	13.2*	22.4	39.2	23.7	
OTHER	15.5	23.1	37.7	21.1	

<sup>&</sup>lt;sup>1</sup> Table shows adjusted means derived from a multivariate model that controls for differences in personal characteristics, including age, sex, race/ethnicity, education, income, chronic conditions, health status and health insurance type. For unadjusted means, see Web Table No. 1, Issue Brief No. 61, Consumers' Information Seeking and Information Sharing with Doctors, Unadjusted Means. \* Significantly different from the reference group (R) at p<.05.

Source: HSC Community Tracking Study Household Survey, 2000-01

accounted for. However, minority consumers are somewhat less likely than white consumers to use the Internet as a health information source.

Passive consumers—those who seek no health information on their own—may rely on their doctors to give them all the information they need. Indeed, elderly consumers and those with less education—two of the groups least inclined to seek information actively—do tend to be more trusting of their doctors.<sup>4</sup>

# **Sharing Information with Doctors**

Among the 72 million consumers who sought health information in the past year, only one in five mentioned the information to their doctors. Seventeen percent of information seekers had no doctor visits in the past year, and the remaining 63 percent visited their doctors but did not bring up health information.

When focusing on the smaller subset of consumers who both sought health

information and saw their doctors, 24 percent mentioned the information to their doctors. Two consumer characteristics had a pronounced effect on the likelihood of sharing health information with doctors: the level of a patient's education and the number of chronic conditions—the same factors most strongly associated with seeking health information in the first place. Among other demographic characteristics, being male, elderly and African American are all associated with a lower likelihood of raising health information with doctors.

#### Some Consumers Harder to Reach

While some consumers actively obtained health information, a majority of American adults sought no health information during the previous year. Even among people with chronic conditions, who might be expected to have the most incentive to seek health information, 56 percent sought no information.

Some 32 million people, or 17 percent of all adults, neither sought health information nor saw a doctor in the past year. And 9 million adults had health problems either reporting a chronic condition or fair or poor health status—yet did not see a doctor and sought no health information. Such consumers tend to have less education and lower incomes and are disproportionately uninsured, male and minority than consumers who sought information and saw a doctor. These hard-to-reach people will be at a distinct disadvantage in a health care system that demands more consumer involvement unless aggressive education strategies are targeted toward them.

### **Implications for Policy Makers**

Health care information can be a doubleedged sword, and much depends on the credibility and purpose of the information. Direct-to-consumer drug advertising, for example, often is cited as a factor in spiraling pharmaceutical costs. The explosive growth of e-health as an information channel also is mentioned as a possible cause of rising



#### **Data Source**

This Issue Brief presents findings from the HSC Community Tracking Study Household Survey, a nationally representative telephone survey of the civilian, noninstitutionalized population conducted in 2000-01. Data were supplemented by in-person interviews of households without telephones to ensure proper representation. The survey contains information on about 60,000 people, and the response rate was 59 percent. More detailed information on survey methodology can be found at www.hschange.org.

#### **Web Exclusive**

Supplementary data tables related to this Issue Brief are available online at www.hschange.org.

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consumer demand for various tests, procedures and prescriptions, which may contribute in turn to rising health care costs. Some consumers, including the so-called worried well, may seek too much health information and spur demand inappropriately.

Recent research, however, suggests that more informed patients tend to choose more conservative treatment options for certain conditions, 5 so the assumption that more consumer education leads to greater demands for costly care may be invalid. To help consumers make informed decisions about the trade-offs among the cost, quality and accessibility of health care services, policy makers could take an active role in fostering development of credible and understandable information.

Consumer-centered approaches are likely to be best suited to consumers with more education who are sophisticated in seeking and using health care information. People with at least a college degree comprise only a quarter of the American adult population, so the most receptive audience for consumeroriented strategies may be limited. But even a minority of informed and empowered consumers could spark changes in the health care system that would benefit all consumers.

Many consumer-oriented approaches, particularly consumer-driven health plans, rely heavily on Web-based tools to educate consumers.6 Yet, few consumers currently use the Internet to find health information, and Internet access and proficiency vary widely across consumers. Targeting information toward groups such as the elderly and those with less education will require providing information through multiple channels, only one component of which would be the Internet. Other special efforts, such as making complex health information accessible and understandable to diverse groups, will be needed if passive consumers are to become empowered consumers engaged in managing their own health care.

#### Notes

1. In a 1999-2000 survey of California residents, 38 percent of consumers reported actively looking for health information—the same percentage

found in the CTS survey results reported here. See RAND Health, *Consumers and Health Care Quality Information: Need, Availability, Utility,* California Health Care Foundation (October 2001). An often-quoted survey conducted by the Harris Poll that included only Internet users estimates that 53 percent of all adults sometimes use the Internet to look for health information. This survey, however, had not only a very small sample size (707 respondents) but also a nonrandom, nonrepresentative sample, consisting only of Internet users. See <a href="https://www.harrisinteractive.com/harris\_poll/index.asp?PID=29">www.harrisinteractive.com/harris\_poll/index.asp?PID=29</a>, accessed Jan. 28, 2003.

- 2. Adults in the CTS Household Survey were considered to have a chronic condition if they had been diagnosed with at least one of 11 conditions and had seen a doctor in the past two years for the condition. The list of chronic conditions includes asthma, diabetes, arthritis, heart disease, chronic obstructive pulmonary disease, hypertension, cancer, benign prostate disease, abnormal uterine bleeding and depression.
- 3. Results reported here are derived from a multivariate model (see note to Table 1). Controlling for personal characteristics is important because (a) many demographic factors are correlated with one another, and (b) the need to obtain health information varies by demographic characteristic (e.g., between the young and old).
- 4. See Web Table No. 2, Issue Brief No. 61, Trust, Age, Education and Seeking Health Information.
- 5. Flood, Ann B., et al., "The Importance of Patient Preference in the Decision to Screen for Prostate Cancer," *Journal of General Internal Medicine*, Vol. 11, No. 6 (June 1996); Phelan, Elizabeth A., et al., "Helping Patients Decide About Back Surgery: A Randomized Trial of an Interactive Video Program," *Spine*, Vol. 26, No. 2 (Jan. 15, 2001); Chapman, Gretchen B., Arthur S. Elstein and Kevin K. Hughes, "Effects of Patient Education on Decisions About Breast Cancer Treatments: A Preliminary Report," *Medical Decision Making*, Vol. 15, No. 3 (July-September 1995).
- 6. Gabel, Jon R., Anthony T. Lo Sasso and Thomas Rice, "Consumer-Driven Health Plans: Are They More Than Talk Now?" *Health Affairs*, Web Exclusive (Nov. 20, 2002).