

**Pew Internet & American Life Project: Online life report**

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**The online health care revolution:  
*How the Web helps Americans*  
*take better care of themselves***

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Our two projects will also issue a joint report in the coming months that will assess the implications for the Internet health community – both consumers and companies – of the health-privacy rules that will soon be issued by the federal Department of Health and Human Services.

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## **SUMMARY OF FINDINGS**

### ***The Internet's powerful influence on "health seekers"***

**Fifty-two million American adults, or 55% of those with Internet access, have used the Web to get health or medical information. We call them "health seekers" and a majority of them go online at least once a month for health information. A great many health seekers say the resources they find on the Web have a direct effect on the decisions they make about their health care and on their interactions with doctors.**

- 48% of these health seekers say the advice they found on the Web has improved the way they take care of themselves; and 55% say access to the Internet has improved the way they get medical and health information.
- 92% of health seekers say the information they found during their last online search was useful; 81% said they learned something new.
- 47% of those who sought health information *for themselves* during their last online search say the material affected their decisions about treatments and care. Half of these health seekers say the information influenced the way they eat and exercise.
- 36% of those who sought health information *for someone else* during their last online search say the material affected their decisions on behalf of that loved one.

### ***The specific impact***

**For the 21 million health seekers who say they were swayed by what they read online the last time they sought health information, the impact was as follows:**

- 70% said the Web information influenced their decision about how to treat an illness or condition.
- 50% said the Web information led them to ask a doctor new questions or get a second opinion from another doctor.
- 28% said the Web information affected their decision about whether or not to visit a doctor.

### ***For illness, including mental illness, more than for fitness***

**The Internet is a tool for the sick more than it is an educational resource for those who want to stay well.**

- 91% of health seekers have looked for material related to a physical illness.
- 26% have looked for mental health information.
- 13% have sought information about fitness and nutrition, 11% have sought basic news about health care, and 9% have sought information about specific doctors, hospitals, or medicines.

### ***For research, more than interaction with providers***

## ***Pew Internet & American Life: Online life report***

**Most users go to health sites for research and reference purposes. Few use it to communicate with their caregivers or to buy medicine. Most health seekers have been able to get the information they need without making any significant trade-offs by giving up personal information. Thus, it is not clear whether most Internet users will embrace a full range of health-care activities online, such as filling prescriptions, filing claims, participating in support groups, and emailing doctors.**

- 9% of health seekers have communicated with a doctor online.
- 10% have purchased medicine or vitamins online.
- 10% have described a medical condition or problem in order to get advice from an online doctor.
- 21% have provided their email address to a health Web site; 17% have provided their name or other personal information.

### ***A tool for family members seeking help for ailing loved ones and friends***

**A great many are using the Web to gather information on behalf of family and friends. Those who are in excellent health often seek material to help someone else; those who are in less-than-excellent health are more likely to be hunting for information for themselves.**

- 54% of health seekers say they were searching for information on behalf of someone else, including their children, their parents, and other relatives, during the most recent time they went online for health information.
- 43% of health seekers were looking for information for themselves during that most recent visit.

### ***Accessing the Web: A way to get a second opinion***

**When it comes to the most recent time they used the Internet to get health information, most health seekers focused on getting information about an immediate medical problem. And the majority got information in conjunction with a doctor's visit.**

- 70% of health seekers said they went online for information about a specific illness or condition the last time they consulted the Web for health information; 11% were checking out news related to health care, 9% were seeking information about specific doctors, hospitals, or medicines.
- 61% of those who sought information for themselves and 73% of those who sought information for others turned to Web resources in connection with a visit to the doctor.

**More often than not, health seekers consult Web resources after they had been to a doctor, and, presumably after a diagnosis has been given. But the timing of the Web search also depends on the person who is sick. If a health seeker is looking for information on behalf of a loved one, she is very likely to go online *after* a doctor's visit, perhaps to get more information related to the diagnosis. If she is looking on behalf of herself, she relatively likely to go online *before* the doctor's visit, perhaps to**

see what the diagnosis might be. Only a small percentage of health seekers use the Web in lieu of a doctor's visit.

### **Why health seekers like the Internet**

**They appreciate the convenience of being able to seek information at any hour, the fact that they can get a wealth of information online, and the fact that they can do research anonymously.**

- 93% of health seekers say it is important they can get health information when it is convenient for them.
- 83% of health seekers say it is important to them that they can get *more* health information online than they can get from other sources.
- 80% of health seekers say it is important to them that they can get this information anonymously, without having to talk to anyone; 16% of health seekers said they had used the Web to get information about a sensitive health topic that is difficult to talk about

### **Health seekers fear privacy violations**

**Health seekers are very anxious to have their privacy protected. They are afraid of Web sites selling or giving away information about them, about insurance companies learning what they have done online and making coverage decisions based on that, and about their employers learning what they have done. Among the most sensitive to privacy violations are African-Americans, parents, and Internet newcomers (those who first came online less than six months ago).**

- 89% of health seekers are concerned that a health-related Web site might sell or give away information about what they did online; 71% are "very concerned" about such privacy violations.
- 85% of health seekers are concerned that an insurance company might raise their rates or deny them coverage because of the health sites they have visited; 72% are "very concerned" about this possibility.
- 52% of health seekers are concerned that their employer might find out what health sites they have visited. This ranks comparatively low in part because most health seekers are getting their information online from home.
- 63% of health seekers and 60% all Internet users think that putting medical records online is a bad thing, even if the records are on a secure, password-protected site, because they worry about other people seeing their personal information. The rest think it's a good thing because they and their doctors would have easy access to patients' medical records.

### **Privacy policy issues**

**Despite these public sentiments, the health-information privacy regulations soon to be released by the Clinton Administration will probably not cover the majority of the nation's more than 17,000 health-related Web sites. Analysis by the Health Privacy Project suggests that many Web sites do not clearly fall into the three categories of organizations that are covered by the regulations – health care providers, insurance**

## ***Pew Internet & American Life: Online life report***

**companies, and health data clearinghouses (the organizations that process and transmit insurance-claim data). Many of the most common features of health Web sites will not be covered: health assessments, applications for clinical trials, chat rooms and bulletin boards, and personal management tools such as online disease management and patient-generated “medical records.” In the future, health seekers want protection and the right to punish companies that violate their privacy policies.**

- 81% of health seekers think people should be able to sue a health or medical company if it gave away or sold information about its Web site users after saying that it would not.

### ***Health seekers also fear getting inaccurate information***

**The credibility of health information and health advice on the Internet is also a concern. One major reason is that most health seekers are doing general Internet searches for the material they need, rather than relying on recommendations about Web sites from health providers or friends. Compared to other Internet users, health seekers show greater vigilance in checking the source of online information. Health seekers are pretty evenly divided about whether the information they get online is credible.**

- 86% of health seekers users are concerned about getting health information from an unreliable source online.
- 81% of health seekers found the information they wanted through an Internet search, rather than being directed by someone. And 64% of health seekers say they had never heard about the Web sites they ended up consulting before they began the search. 30% of health seekers checked out four or more Web sites during their most recent search.
- 58% of health seekers checked to see who was providing the information at the Web sites they visited the last time then went online for health-related material.
- 52% of users who have visited health sites think that “almost all” or “most” health information they see on the Internet is credible; 44% think that they can believe only “some” online health information.

### ***How women and men differ***

**Women are much more likely than men to seek online health information. Women are more likely to register strong feelings about the benefits of online searches, especially those related to the wealth of information online and the convenience of online searches. And women are more likely to worry about getting unreliable information from the Web. Asked about their most recent search for medical and health information, women were more likely than men to be seeking material related to a specific illness, to be hunting for material related to symptoms, and to be conducting the search after a doctor’s visit. Women are twice as likely as men to be seeking material for a child. However, men and women were equally likely to be seeking information on behalf of a parent or other relative.**

*Pew Internet & American Life: Online life report*

**When men look for information about a specific illness, they are more likely than women to look for material about their own condition and they are more likely to report that their Web search affected their decisions about how to treat the illness. Men are more likely to be seeking material about what happens to someone during an illness and when certain treatments or drugs are administered. They are also more likely than women to have used the Web information they gathered to ask follow-up questions of a medical professional. Men's and women's attitudes about privacy are very similar. However, compared to women, men are slightly more privacy-conscious; they are more likely to have read a Web site's policy. And men are somewhat more eager to take advantage of the fact that they feel anonymous online; they are more likely to have used the Web to search for information about sensitive health issues.**

## **MAIN REPORT**

### ***Introduction***

There is abundant evidence that use of the Internet has played a role in revolutionizing the more than \$1 trillion health care industry in America. Doctors, hospitals, health maintenance organizations (HMOs), insurance companies, and Internet firms are using the Internet to retool the business of medicine. More and more health care providers are interacting with their colleagues via email and are interested in using email and the Web to interact with patients, to locate the most current literature on the effectiveness of specific treatments, and to conduct research themselves, sometimes in collaboration with colleagues on the other side of the world.

At the same time, the surveys of the Pew Internet & American Life Project show that the Internet has become a valued source of health-care information for a substantial number of Internet users. Fifty-two million adult Americans – 55% of the Internet-user population – have turned to Internet sources to seek health information. In this report, we call them “health seekers” because most are in pursuit of information that will help them at a time when they or their loved ones are sick. Patients and their families are using the Internet to help with many aspects of care, but they are most likely to have sought material to find out about the options they have for battling illnesses and the prognoses for those illnesses. In addition, they investigate how to participate in clinical trials for new drugs; they examine reports on the course of diseases; they buy vitamins, download fat-free recipes, use calorie calculators, and search for ways to develop “washboard abs.” Further, they check report cards for hospitals, doctors, and health insurers. Some support each other through disease-specific bulletin boards and trade ideas about how to deal with symptoms with support groups.

This is all taking place in an environment where the burden of responsibility in the health-care system has shifted more to patients. Health maintenance organizations and tighter insurance rules have compelled patients to take more assertive roles in their own care. A typical doctor’s visit has reportedly shrunk to less than 15 minutes, and many patients leave a physician’s office without getting answers to all the questions they have. One 1999 survey by Yankelovich Monitor found that half or more of Americans are not satisfied with the availability of their doctors and not satisfied with the duration of their meetings with their doctors. Not surprisingly, many Internet users have turned to the Web to provide the information they find hard to get from their care-givers and because they are increasingly interested in participating in what the medical community calls “shared decision-making.”

<b>Health Seekers</b>	
Internet users who have gone online for health or medical information	
All Internet users	55%
Online women	63%
Online men	46%
Veteran users (3 or more yrs)	59%
New users (less than 6 mos.)	47%
Online parents	59%
Online non-parents	52%
<i>Source: Pew Internet &amp; American Life Project survey, July-August 2000</i>	

In a comparative sense, more Internet users have sought medical information on the Web than have shopped online (47% of Internet users have done that), looked up stock quotes

## ***Pew Internet & American Life: Online life report***

(44% of Internet users have done that), or checked sports scores (36% of Internet users have done that). Twenty-nine percent of health seekers, or about 15 million people, go online to look for medical information about once a week and 30% go online once per month. Less-healthy people are more likely to seek such information frequently – 32% of those who say they are in less than excellent health go online once per week, compared to 23% of those who say they are in “excellent” health. On a typical day online, about 6% of Internet users are seeking health and medical information. That is more than 5 ½ million Americans.

The health-seeker population is made up of many more women than men. Fully 63% of women with Internet access have sought health information, while 46% of online men have done that. On a typical day, this gender difference is reflected in the fact that 59% of those seeking such information are women.

Health seekers are proportionally more middle-aged than very young or old, with the highest proportions of usage showing up in those between the ages of 30 and 64. Two thirds of women between the ages of 30 and 49 who have Internet access have gone online to get health or medical information. The other demographic trait that distinguishes health seekers is their level of experience with the Internet. The longer someone has had access to the Internet, the more likely it is that she has gotten medical information. Some 59% of those with three years of Internet experience have sought medical information, compared to 47% of those who first went online within the past six months. It is worth noting, though, that this gap between veterans and newcomers is substantially smaller when it comes to health information than it is on many other popular Internet activities.

In our survey, 91% of health seekers reported they were covered by health insurance – the rest said they weren’t covered. That means health seekers are more likely to have insurance than members of the general U.S. population. Some 15.5% of all Americans – adults and children – are uninsured.

The rest of the demographic story about health seekers is notable for what *does not occur*. In contrast to many other online activities, the seeking of health information is equally compelling to all racial and ethnic groups. Similarly, there is no major “income” effect on this activity. The likelihood that someone has gotten health information does not correlate with her household income. Compared to, say, online auctions or online banking, the search for health information is a relatively popular activity with newcomers to the Internet and they are more likely to be members of minority groups and those from households with incomes under \$50,000.

The most significant finding in this survey is that the health decisions made by many health seekers are influenced by the health and medical information they find on the Web. More than four in ten health seekers (41%) say that the material they found during their last online search affected their decisions about whether they should go to the doctor, how to treat an illness, or how to question their physician. Half of all Internet users who have gone online for medical information (48%) say the advice they found on the Web has improved the way they take care of themselves and 55% report that it improves the way they get health care information.

## ***Pew Internet & American Life: Online life report***

In many cases, the timing of the online search for health information, the nature of the search, and the impact of the search depended on who is doing the search. Women and men perform different kinds of health searches online. Those who are in excellent health do different kinds of searches from those who are in less-than-excellent health. And those who are searching for information on behalf of themselves have a different purpose from those who are seeking information on behalf of others, like children, parents, or other relatives. One Internet user sent a testimonial to our site about how online health research has improved his own health care and that of his wife, his children, and his great-aunt – keeping him more up-to-date than their doctor on some medical procedures.

The results in Section One of this report are based largely on two surveys: One uses data from roughly six months of telephone interviewing conducted between March and August 2000, among a sample of 12,751 adults, 18 and older – 6,413 of whom are Internet users. The other was a survey during the summer probing all Internet users' feelings about health privacy. It involved 2,109 persons, 1,101 of whom are Internet users. In addition to this daily tracking poll, we conducted a special survey of 521 Internet users who go online for health care information, the results of which are detailed in Section Two. This special sample, which was conducted August 3-14, portrays the habits and attitudes of the 52 million Americans who use the Internet for medical information and advice.

### **SECTION ONE: ALL INTERNET USERS**

#### ***The reasons people like to go online for health information***

Internet users say that one of the most important aspects of online health advice is the fact that it's available at any hour of the day or night, from wherever they are able to log on. Fully 93% of those who have gotten health information say that convenience is important.

Internet users also like to search a diverse menu of resources – from commercial sites like Drkoop.com to government sites like the federal National Institutes of Health (www.nih.gov). Eighty-three percent of those who have sought health information say it is important that Internet users can get more health information online than from other sources.

<b>Convenience, anonymity, and wealth of information</b>	
Percent of health seekers who say this factor is "very important" to them when it comes to seeking health information online	
You can get information at any time	66%
You can get information anonymously	46%
You can get more information online than from other sources	37%

Source: Pew Internet & American Life Project survey, July-August 2000

Anonymity is also important to Internet users – the search for health information can be conducted without encountering anyone else. Nobody has to know about that bout with depression or an incontinence problem. Eighty percent of health seekers say it's important that Internet users can get health information anonymously.

All these attributes of the Web are especially attractive to women, to parents who have children under 18 at home, and to minorities. And it is easy to speculate why. In addition to being concerned about their own health, many women are also gatekeepers and advocates for the health of those they love. Women, in general, and mothers, in particular, are also

## ***Pew Internet & American Life: Online life report***

among the most stressed for time, so the convenience of looking up health information on the Web is appealing to them. For African-Americans and Hispanics, the Web's appeal might lie in the fact that it is especially empowering to them when they can get information to supplement information from sources such as doctors, clinics, or hospitals.

### ***Privacy concerns about using the Web for health information***

Hospitals, pharmacists, insurance companies, and patients are struggling with the murky issues of medical privacy. Internet users have made it clear that privacy is one of their primary concerns – whether it's their name and address being sold to a marketer or their medical records being handed over to researchers or broken into by crackers (that is, hackers with destructive or illegal intent). Everyone involved with online health care is waiting for new privacy rules that are expected to be released in the next few weeks by the Clinton administration's Department of Health and Human Services (HHS).

There is little legal protection now for health information – online or offline. Unlike financial records, credit reports, and even video rental records, there is no comprehensive federal law that protects the privacy of medical records. State laws are generally considered inadequate for the rapidly changing health care delivery system. That is why Congress specified in the 1996 Health Insurance Portability and Accountability Act that federal rules should be written by HHS in 1999 if Congress itself had not written such rules. The department released draft regulations in November 1999, and received more than 55,000 comments on the draft.

It appears unlikely that the new rules will have a major impact on health Web sites or give significant privacy protections to those who use those Web sites. The regulations may impose some confidentiality standards on certain Web sites and provide new protections for the consumers who frequent such sites. But the regulation will only cover three kinds of health care entities, all of which are related to insurance activities. They will cover providers who electronically transmit insurance claims information, insurers, and the "clearinghouses" that process information for providers and insurers. The draft regulation only covers a select universe of information held by these three entities.

Given the wide range of activities that take place on the more than 17,000 health-related Web sites, and the relatively narrow scope of the regulation, it is likely that a great deal of health information collected on health Web sites will *not* be covered by the new regulation. Many of those Web sites do not fall into any of the categories of organizations covered by the new rules.

Still, the Web sites that will be covered by the new regulation may have to change their practices in significant ways. Among its many provisions, the draft regulation: gives consumers a right to inspect and copy their own health information; requires that consumers

<b>Health privacy</b>	
Percent of all Internet users who say they are "very concerned" a Web site might sell or give away information about what they did online	
All Internet users	69%
Online women	73%
Online men	65%
Online blacks	75%
Online Hispanics	69%
Online whites	68%
Online parents	74%
Online non-parents	65%
New users (<6 mos.)	77%
Veteran users (3+ yrs)	67%

*Source: Pew Internet & American Life Project survey, July-August 2000*

## ***Pew Internet & American Life: Online life report***

receive notice about the use and disclosure of their health information; and gives consumers the right to limit disclosures in many circumstances. (A full explanation of the current state of those regulations and what will not be covered can be found in an article written by Janlori Goldman and Zoe Hudson of the Health Privacy Project entitled “Virtually Exposed: Privacy and E-Health” at [www.healthaffairs.org](http://www.healthaffairs.org) in the December, 2000 issue.)

Internet users will appreciate whatever privacy protections they get, and they appear eager to get as many safeguards as possible. Most Internet users are anxious about their privacy online and this general feeling becomes quite acute when it comes to medical and health information. An overwhelming majority of Internet users and an even greater 89% of health seekers are concerned that a health Web site might sell or give away information about what they did online.

Most health seekers fear reprisals might occur if others knew the kind of information they were examining at health Web sites. Eighty-five percent of health seekers are concerned that an insurance company might raise their rates or deny coverage because of the health sites they have gone to online. In a similar vein, Internet users are afraid that their online health research could have an impact on their job status. More than half of health seekers (52%) are concerned that their employer might find out what health sites they have gone to online. Interestingly, this question elicited the highest level of “not at all concerned” responses in the overall Internet population – 35% – possibly because not all respondents are employed, possibly because these Internet users do not believe their employers will track their online health research. This relatively high level of confidence may also be explained by the fact that most Internet users go online from home when they get for health care information.

African-Americans, Internet newcomers (those who have been online for 6 months or less), and parents with children under 18 showed the highest levels of privacy concerns.

### ***Medical records***

One of the hottest topics among doctors, legislators, and health Web site business leaders is the act of putting medical records online. The American Medical Association not only endorses online technology, but also has helped found Medem, a for-profit technology company that creates Web sites for doctors and would allow for secure communications between patients and offices. Many argue that the ready availability of a patient’s comprehensive medical history would save lives, reduce life-threatening medical errors, and improve the communication between doctors and patients, and doctors and their colleagues. Mark Leavitt, chairman of MedicaLogic/Medscape, Inc., testified before Congress in June 2000 and compared the convenience of online medical records to ATM machines and called on legislators to aid in the fight against the “national problem” of medical errors.

But is the public ready for this step? A majority of Internet users (60%) think that putting medical records online is a bad thing, even if they are on a secure, password-protected site, because they would worry about other people seeing their personal information; 33% think it’s a good thing because they would have easy access to their own medical records. Some 63% of health seekers believe that putting medical records online is more a threat to privacy than it is a benefit. Women, older Internet users, and Internet novices are the most wary of online access to medical records. Sixty-five percent of online women say they would worry

***Pew Internet & American Life: Online life report***

about other people seeing their health records, compared to 55% of online men. Sixty-five percent of Internet users between 30-49 years old are opposed to online medical records, compared to 50% of those between 18-29 years old. Fully 74% of Internet users with less than six months of online experience are fearful of online records, compared to 58% of Internet users with three or more years of online experience.

Men, young people, and more experienced Internet users are the most likely to say online medical records are a “good thing.” Thirty-seven percent of online men see the benefits, compared to 30% of online women. Forty-three percent of Internet users between 18-29 years old say online access would be good, compared to 32% of those between 50-64 years old. Thirty-six percent of those who have been online for three or more years see the advantages of online medical records, compared to 19% of the newest users (less than six months experience).

**SECTION TWO: HEALTH SEEKERS**

***What health seekers want and how they hunt for it\****

Health seekers are mostly interested in investigating specific physical and mental ailments and their searches often are tied to visits to the doctor. However, they do not use the medical establishment or even friends to help guide their online searches when it comes to health care. Most health seekers treat the Internet as a vast, searchable library, relying largely on their own wits, and the algorithms of search engines, to get them to the information they need. Asked about the most recent time they got health-related information online, more than 30% checked out four or more Web sites. Younger health seekers and those with relatively high educations (at least some college-level work) are the most likely to have looked at multiple sites.

Ninety-one percent of health seekers have looked for information about a physical illness or condition and 26% have looked for information about a mental health issue like depression or anxiety. Less-healthy people are more likely to go online frequently for medically-related material and to have sought mental health information on the Web – 30% of those who say their health is less than excellent have sought material about mental illness, compared to 19% of those who say their health is excellent.

<b>The medical information they have sought</b>	
<b>The percent of health seekers who say they have:</b>	
Sought information about a physical illness	91%
Sought information about mental illness	26%
Gotten information about a sensitive topic that is difficult to talk about	16%
Gotten advice from an online doctor	10%
Bought medicine or vitamins online	10%
Used email to communicate with a doctor	9%
Participated in an online support group	9%

Source: Pew Internet & American Life Project health seekers survey, August, 2000

In contrast to their aggressive use of the Internet to do research about specific illnesses, health seekers are much less likely to have interacted with a doctor online, to have searched for general news about health and medicine, or to have bought a medical product or vitamins online. While online pharmacies promote the convenience of ordering online – and some skirt federal laws by dispensing

\* This section is based largely on a special survey of 521 Internet users who go online for health care information.

## ***Pew Internet & American Life: Online life report***

sensitive items such as Viagra without a prescription – most health seekers are not yet using the Web as a substitute for the corner drug store. Only 10% of health seekers have purchased medicine or vitamins online.

Once they have found a useful site, health seekers are likely to go back to it again. Forty-two percent of health seekers have kept a health Web site bookmarked or saved as a “favorite place,” so they can go back to it regularly. Men are more likely to have bookmarked a site than women. And health seekers with more online experience are more likely to bookmark health sites – 45% of those with two or more years of experience have done this, compared to 36% of those with one year or less online experience.

### ***The quality of information: Verify before trusting***

Much of the health information available on the Web is not monitored for accuracy or quality. The Federal Trade Commission estimates that doctors review only about half of the content on health and medical Web sites. There is significant concern – especially on the part of advocates for the chronically ill – that patients may harm themselves based on inaccurate information or products obtained on the Internet. In October, for example, a Web-distributor of a home HIV test kit was brought up on charges of misleading his customers because the Federal Drug Administration did not, in fact, approve the faulty kit he sent to over 600 people in the U.S. The few studies by scholars and medical professionals have raised concerns about the reliability of online information. For instance, a 1999 survey by a team at the University of Michigan of 400 health sites found that half of them had not been scientifically reviewed and that 6% provided incorrect information. A study in 1997 that focused on the recommendations of 41 Web sites on how to deal with children’s fevers found that only four of the sites offered recommendations that were completely consistent with established guidelines in the medical community. Because of such fears, the American Medical Association and other medical groups have mounted major campaign to stress that consumers need to check the quality of information they get online.

Our survey confirms that the vast majority of Internet users are worried about getting bad information online. Fully 82% of those with Internet access – health seekers and nonseekers alike – say they are concerned about getting health information from an unreliable source online. Thus, it is not surprising that 58% of health seekers have looked to see what company or organization is providing the advice or information that appears on a health Web site. Health seekers with more education are more likely to check the source of health information – 61% of those with at least some college education have done so, compared to 46% of those with a high school education or less.

While there is a high anxiety among Internet users about health information online, 52% of users who have actually used health sites think that “almost all” or “most” health information they see on the Internet is credible. Forty-four percent of health seekers think that they can believe only “some” online health information. Just 1% of health seekers say “almost none” of the information is credible. Younger health seekers (under age 40) and those with less formal education are more likely to support the credibility of the health information on the Internet.

***The absolute value of anonymity***

Health seekers report a broad lack of interest in activities that might require them to identify themselves online. They want to be in control of the search for health information and they do not relish giving up personal information in the process. These Internet users would much rather stay anonymous than participate in an exchange about health information online where personal information was given up in return for access to a site or for customized content. In fact, the anonymity of Web searches for health information is sometimes seen by users as preferable to contact with human beings. Some 16% of health seekers have gone online to get information about a sensitive health topic that is difficult to talk about. Health seekers under the age of 40 are also more likely to have done this – 23%, compared to 10% of those over 40.

The vast majority of health seekers are concerned that a health site might disclose what they did online, most worry about their insurance companies or employers finding out what Web sites they have accessed, and most object to the idea of having their medical records posted even on a secure server.

Only 9% of health seekers have participated in an online support group for people who are concerned about the same health or medical issues. This contrasts sharply with another Pew Internet Project survey that found 36% of Internet users who had gone to a support-group site or one that provides information about a specific medical condition or personal situation. Again, it appears that health seekers are much more protective of their privacy than the general Internet population.

***Don't follow me around***

Despite the fact that 89% of health seekers say they are concerned that a health Web site might sell or give away information about what they did online, just 24% of health seekers have clicked on a health or medical Web site's privacy policy to read about how the site uses personal information. Health seekers who have expressed privacy concerns are more likely to have clicked on the privacy policy – 31%, compared to 21% of those who say they are not too concerned about privacy.

Most commercial health Web sites rely on advertising for a large portion of their revenue. Third party ad networks – such as Doubleclick – are interested in tracking and profiling Internet users so that customized ads and content could be placed on their screens. While many of the firms that run health sites say they do not profile based on the health-related material a user has accessed on their site, there is a great deal of concern among privacy advocates that advertisers can have access to sensitive health information without the consumers' knowledge or consent.

<b>Don't track, don't tell</b>	
Health seekers value anonymity because only ...	
21%	have provided their email address to a health Web site
17%	have provided their name or other personal information
<b>and fully ...</b>	
75%	believe Internet firms should not be allowed to track users'

*Source: Pew Internet & American Life Project health seekers survey, August, 2000*

***Pew Internet & American Life: Online life report***

There has not been an extensive review of the privacy policies of the entire universe of health-related Web sites. One important analysis of the 21 most heavily used health sites by the Health Privacy Project in early 2000 showed that several sites warn users that advertisers might have access to information, and that the sites have no "control" over this practice. But most of the policies were silent on the issue of profiling. Unless an Internet user is a very savvy Web surfer, she will never know if she is being tracked and profiled by a health Web site or those that advertise on the site.

Advocates of profiling argue that it brings several advantages to Internet users. They say that it helps Internet companies provide customized information and tailored ads that closely match a user's interests. That helps the user get the information she needs and makes her aware of the products that matter most to her. This eliminates waste and makes it easy and quick for users to get the information they are seeking. Moreover, many point out that the growth of the Internet would not be taking place were it not for the fact that advertising supports the availability of much of the information online.

Yet, most health seekers still have a dim view of profiling. Three out of four health seekers

<b>Heightened privacy concern</b>		
Health-seekers are more likely to be opposed to tracking		
	Health-seekers, when asked about health sites	Internet users, when asked about Web sites in general
Companies should NOT be allowed to track activities	75%	62%
Companies should be allowed to track activities	18%	22%

*Source: Pew Internet & American Life Project, May-June and August 2000*

(75%) think Internet companies that specialize in health or medical information should not be allowed to track the activities of people who visit their Web sites and just 18% of health seekers think Internet companies should be allowed to track activities. These findings show a higher level of concern about tracking among Internet users who visit health sites than among the general Internet population. In our previous study

on trust and privacy online, 62% of all Internet users said Internet companies should not be allowed to track; 22% of all Internet users said companies should be allowed.

Health seekers are not very likely to have traded personal information with health-related Web sites – just 21% of health seekers have provided their email address at a health Web site. Seventeen percent of health seekers have provided their name or other personal information at a health Web site. This is a sharply lower rate of disclosure than takes place in the overall Internet population. In our previous report "Trust and Privacy Online," we noted that 54% of all Internet users had given up their email address and other personal information in return for access to Web sites.

Yet while health seekers are determined to preserve their privacy, few have resorted to guerrilla tactics to get access to Web sites. Just 4% of health seekers have provided a fake name, email address, or other personal information in order to avoid providing real information at a health Web site. In our trust and privacy study, we found that 24% of Internet users have provided a fake name or personal information in order to gain access to a Web site.

## ***Pew Internet & American Life: Online life report***

An overwhelming majority of health seekers (87%) think there should be rules about how health and medical companies on the Internet can track activities. Just 10% don't think rules are needed. Health seekers register slightly more caution about health Web sites' business practices than the general Internet population's attitude toward tracking. In our previous study on trust and privacy online, 81% of Internet users said there should be rules about Internet companies' ability to track. Asked who should set the rules about if and how health companies can track online, 47% of health seekers said Internet users themselves should set rules, 25% said the federal government should set the rules, and 18% said Internet companies should set the rules.

And, in a finding that runs counter to existing federal policy, 81% of health seekers think people should be able to sue a health or medical company if it gave away or sold information about its Web site users after saying that it would not. Under current law, the Federal Trade Commission can take action, but individuals have no federal right to sue.

### ***Case study: The last time each health seeker went online***

To move beyond abstractions and get a picture of Internet users' actual behavior, we asked health seekers to relate details about their most recent foray online for health information. For about one-quarter of respondents, it was a fresh memory. Some 23% of health seekers said the last time they went online to look for medical advice or information was within the last week; 35% said it was in the last month; 31% said it was in the six last months, and 10% said it was sometime more distant in the past than that.

The overwhelming majority of health seekers (83%) said they went online from home the last time they sought medical advice or information on the Internet. Only 14% went online from work.

<b>The youngest patients</b>	
Who is seeking health information for children	
All health-seekers	13%
Women	16%
Men	7%
Under 40 years old	17%
Over 40 years old	9%
<small>Source: Pew Internet &amp; American Life Project health seekers survey, August, 2000</small>	

There are two major reasons health seekers go online for medical information – they are gathering information for themselves or they are gathering it for someone else. Our findings suggest that there are more health seekers looking for information on behalf of someone else than there are health seekers looking for themselves. When asked about their most recent search, 43% of health seekers were hunting for material for themselves and 54% were searching for information for someone else. That 54% breaks down this way: 13% of health seekers were looking for health information on behalf of a child, 8% were looking on behalf of a parent, 15% were looking on behalf of another relative, and an additional 18% were looking for health information on behalf of someone else.

Women were more likely to seek health information on behalf of a child – 16% of women were doing this the last time then went online looking for medical material, compared to 7% of men. However, men were just as likely as women to have been seeking health information on behalf of a parent, another relative, or someone else.

The health seekers in our survey were more likely to be focused on an immediate problem, rather than general information or updates on medical news; 70% went online for

**Pew Internet & American Life: Online life report**

information about a specific illness or condition. Thirteen percent sought information about fitness and nutrition, 11% sought basic news about health care, and 9% sought information about specific doctors, hospitals, or medicines.

Of those who were looking for online guidance about a specific illness or condition, 48% looked up symptoms of that illness, 30% sought information about medicines or treatments, and 29% were trying to find out what happens to people who contract a specific illness.

Because most are so focused on a specific illness, it is not surprising that health seekers seem to use Internet health sites to supplement a doctor's advice or to understand a diagnosis better. Fifty-nine percent of those who sought information on behalf of another person did so after that person had visited a doctor or clinic and 34% of those who sought the information for themselves went online after a doctor's appointment. Those who went

<b>For "yourself" or for another person</b>		
When seeking health information for someone else, most wait until after seeing a doctor		
Percentage of Health Seekers who went online seeking advice...	For yourself	For someone else
before visiting a doctor or clinic	27%	14%
after a visit	34%	59%
instead of a visit	2%	3%
unrelated to a visit	35%	22%

*Source: Pew Internet & American Life health seekers survey, August 2000*

online to seek health information for themselves were just as likely to be looking for this advice independent of a doctor's visit (35%). A very small percentage of health seekers used the Web to get medical advice instead of visiting a doctor or clinic – just 2% of those who sought information for themselves and

3% of those who sought information on behalf of someone else.

The Internet users looking for health advice for their own problems were more likely to have checked the Web before a doctor's appointment – 27%, compared to 14% of those who sought health information for others. Health seekers under the age of 40 were more likely to seek information in preparation for their own doctor's appointment – 34%, compared to 21% of those over 40. Older health seekers were more likely to go online after they had visited a doctor or clinic (41%, compared to 26%).

Health seekers' search for information had a scattershot quality. Three-quarters of those seeking health information were not content to get material from just one Web site. Only 17% in our sample did that. In contrast, half of health seekers (49%) visited two or three Web sites the last time they looked for health information online; 18% of health seekers went to four or five sites and 9% visited six to ten sites; 4% went to 11 or more sites.

Most health seekers were on their own in finding the sites they visited. An overwhelming majority of respondents (81%) said they found the health Web sites through an Internet search and 62% had not heard about the sites they ended up visiting before they began their search. Just 10% of health seekers had heard about the sites through an advertisement they spotted and 6% had gotten a recommendation from a friend or relative. A very few health seekers read about the site in a news article or followed up on a recommendation from a doctor, health insurance company, or HMO.

***Pew Internet & American Life: Online life report***

Once they completed their Web crawling, health seekers liked what they found. Fully 92% of health seekers say the information they found was useful and 81% said they learned something new the last time they went online for health information.

About half of health seekers (47%) who looked for information about their own health situation said the information they found online affected decisions about health treatments or the way they take care of themselves. Of those who said the information had an effect on the way they coped with the ailment, 51% reported that they changed the way they eat or exercise based on what they read online.

Those who sought information on behalf of another person were somewhat less likely to say that information found online affected decisions about the person’s health care. Still, more than a third (36%) of those hoping to help a loved one or friend said the Web resources affected the decisions they made about how to help the patient.

Of those swayed by what they read online, whether it was information for themselves or for someone else, 70% said the information affected their decision about how to treat an illness or condition. Fifty percent said the information lead them to ask a doctor new questions or to get a second opinion from another doctor. And 28% said the information affected their decision about whether to see a doctor.

<b>The healthy really are different</b>		
<b>The percentage of health seekers who...</b>	<b>Those who claim less-than-excellent health</b>	<b>Those who claim excellent health</b>
sought health information for themselves last time	52%	29%
sought health information for someone else last time	44%	68%
go online for health information about once a week	32%	23%
have ever sought mental health information online	30%	19%

*Source: Pew Internet & American Life Project health seekers survey, August 2000*

***The healthy try to help others; the less-healthy try to help themselves***

The health status of those getting medical information online strongly correlates with the reasons a health seeker turns to the Web and on the results of her search. A majority of health seekers describe their health as less than ideal – 49% say it is “good,” 10% say it is “only fair,” and 2% say their health is “poor.” Thirty-nine percent of health seekers describe their own

health status as “excellent.”

The last time they went online for health information, users in less-than-excellent health were more likely to have sought information for themselves than for other people. Fully half (50%) of those in less-than-excellent health say the information they gathered online during their most recent search affected their decisions about health treatments. That compares to 39% of those in excellent health who reported such an impact. Moreover, those in less-than-excellent health were more likely to report their hunt on the Web led them to ask new questions of their doctor or get a second opinion. Fully 52% of them reported such an effect, while 44% of those in excellent health said the online material led them to ask new questions or get a second opinion.

***Pew Internet & American Life: Online life report***

Those in excellent health were more likely to seek advice on behalf of someone else – a child, parent, relative, or another person.

***How women and men differ in their online behavior***

Women are more likely than men to have sought health information online. In general, women more frequently say they have searched for information about illnesses and about illness symptoms. Men are more likely than women to have sought information on behalf of themselves. Men are more likely than women to say their Web search affected their decisions about how to treat a disease. While women are more likely to seek material about the illness that is causing disease symptoms, men are more likely to hunt for information about the prognosis of a disease and what happens to people when they undergo certain treatments or take certain medications.

More often than men, women carry out health searches after a doctor’s visit. Women are also more likely to access online health information on behalf of their children. There are no notable gender differences when health seekers are looking for information on behalf of parents, other relatives, or other people. However, men are more likely than women to have used the Web information they gathered to ask follow-up questions of a medical professional.

Perhaps because they are the most active health seekers, women are more likely to register strong feelings about the benefits of online searches, especially those related to the wealth of information online and the convenience of online searches. And women are more likely than men to worry about getting unreliable information from the Web. Men’s and women’s attitudes about privacy are very similar. However, compared to women, men are slightly more privacy-conscious; they are more likely to have read a Web site’s policy. And men are somewhat more eager to take advantage of the fact that they feel anonymous online; they are more likely to have used the Web to search for information about sensitive health issues. Finally, men are more likely to have bookmarked a health site for future reference (48% to women’s 39%).

<b>A tale of two genders</b>		
Women and men differ in their health-seeking Web searches		
The percent of each gender who have sought information about...	Women	Men
a physical illness	93%	86%
a mental illness	28%	23%
a sensitive health topic that is difficult to talk about	14%	20%
During their most recent online health search looked for information ...		
on behalf of themselves	41%	46%
on behalf of a child	16%	7%
on behalf of a parent	9%	7%
on behalf of another relative	15%	17%
on behalf of someone else	16%	20%
Performed the search for themselves and did it...		
after visiting a doctor	39%	26%
unrelated to a visit to the doctor	31%	42%
Performed the search for someone else and did it ...		
after visiting a doctor	63%	53%
When looking for material about a specific illness, sought information about...		
health conditions that may be related to specific symptoms	51%	42%
what happens to people who get a specific illness or treatment	25%	36%

*Source: Pew Internet & American Life Project health seekers survey, August, 2000*

## ***Pew Internet & American Life: Online life report***

### ***Fervent and engaged health seekers***

Frequent users of health Web sites were more likely to be engaged in online activities that augment their health care. About 59% of health seekers report going online for health information at least once a month. There is not a notable gender difference in this, but age plays a role: 63% of health seekers under age 40 are frequently online for health information, compared to 54% who are over that age. Two-thirds of these frequent health seekers live in households earning less than \$50,000. And frequent health seekers are less well physically than health seekers who use the Web less often. Some 62% of frequent health seekers report being in less-than-excellent health, while 53% of those in excellent health report frequent health searches online.

Internet users who said they go online for health information at least once a month are more likely to participate in an online support group, buy medicine or vitamins online, email their doctor, check a site's privacy policy, describe a medical condition online to get advice, bookmark a favorite health site, verify the source of a site's health information, and look for information about a physical or mental health issue. These highly engaged health seekers are also more likely to say the Internet has improved the way they take care of their health, compared to those who seek online health advice every few months or less often.

## **METHODOLOGY**

This report is based on the findings of a daily tracking survey on Americans' use of the Internet. The results in Section One are based largely on data from roughly six months of telephone interviewing conducted by Princeton Survey Research Associates between March 1, 2000 and August 20, 2000, among a sample of 12,751 adults, 18 and older. Some 6,413 of them are Internet users. For results based on the total sample, one can say with 95% confidence that the error attributable to sampling and other random effects is plus or minus 2.5 percentage points. A special survey of 2,109 adults (1,101 are Internet users) was conducted between July 24 and August 20, 2000 and dealt primarily with health privacy issues. Results in Section Two of this report are based largely on data from a special survey of 521 Internet users who go online for health care information. For results based on this second survey, the margin of error is plus or minus 5 percentage points. In addition to sampling error, question wording and practical difficulties in conducting telephone surveys may introduce some error or bias into the findings of opinion polls.

The sample for this survey is a random digit sample of telephone numbers selected from telephone exchanges in the continental United States. The random digit aspect of the sample is used to avoid "listing" bias and provides representation of both listed and unlisted numbers (including not-yet-listed numbers). The design of the sample achieves this representation by random generation of the last two digits of telephone numbers selected on the basis of their area code, telephone exchange, and bank number.

A new sample was released daily and was kept in the field for at least five days. This insures that the complete call procedures are followed for the entire sample. Additionally, the sample was released in replicates to insure that the telephone numbers called are distributed appropriately across regions of the country. At least 10 attempts were made to complete an interview at every household in the sample. The calls were staggered over times of day and days of the week to maximize the chances of making contact with a potential respondent. Interview refusals were re-contacted at least once in order to try again to complete an interview. All interviews completed on any given day were considered to be the final sample for that day.

Non-response in telephone interviews produces some known biases in survey-derived estimates because participation tends to vary for different subgroups of the population, and these subgroups are likely to vary also on questions of substantive interest. In order to compensate for these known biases, the sample data are weighted in analysis. The demographic weighting parameters are derived from a special analysis of the most recently available Census Bureau's Current Population Survey (March 1999). This analysis produced population parameters for the demographic characteristics of adults age 18 or older, living in households that contain a telephone. These parameters are then compared with the sample characteristics to construct sample weights. The weights are derived using an iterative technique that simultaneously balances the distribution of all weighting parameters.

Throughout this report, the survey results are used to estimate the approximate number of Americans, in millions, who engage in Internet activities. These figures are derived from the Census Bureau's estimates of the number of adults living in telephone households in the

***Pew Internet & American Life: Online life report***

continental United States. As with all survey results, these figures are estimates. Any given figure could be somewhat larger or smaller, given the margin of sampling error associated with the survey results used in deriving these figures.

For the questionnaire used in the creation of this report, please go to our Web site, <http://www.pewinternet.org/> and click on the Main reports page, and then “The Online Health Care Revolution” and then the PDF file of the Health questionnaire.