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# Internet Health Resources

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**Health searches and email have become more commonplace, but there is room for improvement in searches and overall Internet access**

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# Summary of Findings

## Half of American adults have searched online for health information.

Fully 80% of adult Internet users, or about 93 million Americans, have searched for at least one of 16 major health topics online. This makes the act of looking for health or medical information one of the most popular activities online, after email (93%) and researching a product or service before buying it (83%).

<b>Health Topics Searched Online</b>	
In all, 80% of American Internet users have searched for information on at least one major health topic online. Many have searched for several kinds of information.	
<b>Health Topic</b>	<b>Internet Users Who Have Searched for Info on It (%)</b>
Specific disease or medical problem	63%
Certain medical treatment or procedure	47
Diet, nutrition, vitamins, or nutritional supplements	44
Exercise or fitness	36
Prescription or over-the-counter drugs	34
Alternative treatments or medicines	28
Health insurance	25
Depression, anxiety, stress, or mental health issues	21
A particular doctor or hospital	21
Experimental treatments or medicines	18
Environmental health hazards	17
Immunizations or vaccinations	13
Sexual health information	10
Medicare or Medicaid	9
Problems with drugs or alcohol	8
How to quit smoking	6

Our finding represents a substantial enlargement of the population we have called online “health seekers” in the past. Previously, we have reported that 62% of Internet users said “yes” when we asked if they look for health or medical information online. For the first time, we prompt respondents with questions about specific health topics, to give a fuller portrait of what Americans are looking for online. Not surprisingly, the number of health seekers increased when we asked Internet users more specific questions.

This Pew Internet & American Life Project report is based on the findings of a daily tracking survey on Americans' use of the Internet and an online survey about Internet health resources. All numerical data was gathered through telephone interviews conducted by Princeton Survey Research Associates between November 25 and December 22, 2002, among a sample of 2,038 adults, aged 18 and older. For results based on the total sample, one can say with 95% confidence that the error attributable to sampling and other random effects is +/- 2%. For results based Internet users (n=1,220), the margin of sampling error is +/- 3%. Online essays and responses were collected from 1,971 Internet users between May 31 and August 17, 2002.

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### **Health seekers go online to become informed, to prepare for appointments and surgery, to share information, and to seek and provide support.**

We conducted an online canvassing of Internet users to find out in more detail the kinds of things they do online and the impact it has on their health care. From the nearly 2,000 responses we received, we can construct a detailed portrait of the many kinds of activities health seekers do online.

Among other things, Internet users:

- Search for health information at any time of the day or night.
- Research a diagnosis or prescription.
- Prepare for surgery or find out how best to recover from one.
- Get tips from other caregivers and e-patients about dealing with a particular symptom.
- Give and receive emotional support.
- Keep family and friends informed of a loved one's condition.
- Find humor and even joy in a bad situation.

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### **Women are the primary consumers of online health information.**

Women are more likely than men to seek health care and health information, so it is no surprise that they lead the way with Internet health. Some 85% of online women have searched for at least one of these 16 health topics, compared to 75% of men. Wired women are also considerably more likely than wired men to have sought information on multiple health topics.

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### **Health searches are not an everyday thing for most Internet users.**

Although very large numbers of Internet users conduct health searches, most do so infrequently. Eight out of ten of those who have conducted health searches say they do so every few months or less frequently than that. Indeed, on a typical day, just 6% of Internet users look for health or medical information online (by contrast, 49% use email, 19% research a product or service, and 5% buy a product online). More than half of those who recently conducted searches did so on behalf of someone else — a spouse, child, friend, or other loved one — not for themselves.

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### **Internet users find support in online groups and email.**

In addition to information searches, Internet users are increasingly going to disease- or situation-specific support sites and using email to discuss health issues with family, friends, and (to a lesser degree) doctors.

- More than half (54%) of Internet users, or about 63 million Americans, have visited a Web site that provides information or support for people interested in a specific medical condition or personal situation.
- About a third (30%) of email users, or about 32 million Americans, have exchanged health-related email with friends, family members, and doctors. At this point, only a small portion of patients communicate with their doctors online, but those online survey respondents who do say email streamlines tasks like scheduling prescription refills and follow-up appointments.

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### **Health seekers report that their health information and services improve and that their relationships with their doctors change.**

Internet users report two effects of online health resources: better health information and services, and different (but not always better) relationships with their doctors.

- Three-quarters (73%) of health seekers say the Internet has improved the health information and services they receive.
- Some online survey respondents say that doctors are receptive to Internet research; others are cautioned to avoid any online health information.

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### **Health seekers want access to more information, but they can't always find what is already available online.**

When asked what is missing online, e-patients and caregivers came up with a list that was both inspirational and disappointing. Many current Internet health users want to expand access to information-laden sites that are currently closed to non-subscribers, while other users wished for items that already exist, but apparently go unnoticed or unfound to them. Examples include:

- More information on drug interactions
- Diagnostic tools or symptom finders
- Electronic medical records and test results
- More information for caregivers
- More ways to connect with local resources
- Doctor-patient email
- More information on a doctor's background

## Summary of Findings

<b>What E-Patients Do Online: Summary of Findings at a Glance</b>
Half of American adults have searched online for health information.
Health seekers go online to become informed, to prepare for appointments and surgery, to share information, and to seek and provide support.
Women are the primary consumers of online health information.
Health searches are not an everyday thing for most Internet users.
Internet users find support in online groups and email.
Health seekers report that their health information and services improve and that their relationships with their doctors change.
Health seekers want access to more information, but can't always find what is already available online.
Source: Fox, Susannah, and Deborah Fallows. <i>Internet Health Resources</i> . Washington, DC: Pew Internet & American Life Project, July 16, 2003.

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About the Pew Internet & American Life Project: The Pew Internet Project is a nonprofit, non-partisan think tank that explores the impact of the Internet on children, families, communities, the work place, schools, health care, and civic/political life. The Project aims to be an authoritative source for timely information on the Internet's growth and societal impact. Support for the project is provided by The Pew Charitable Trusts. The project's Web site: [www.pewinternet.org](http://www.pewinternet.org)

About Princeton Survey Research Associates: PSRA conducted the surveys that are covered in this report. It is an independent research company specializing in social and policy work. The firm designs, conducts, and analyzes surveys worldwide. Its expertise also includes qualitative research and content analysis. With offices in Princeton, New Jersey, and Washington, D.C., PSRA serves the needs of clients around the nation and the world. The firm can be reached at 911 Commons Way, Princeton, NJ 08540, by telephone at 609-924-9204, by fax at 609-924-7499, or by email at [ResearchNJ@PSRA.com](mailto:ResearchNJ@PSRA.com)

# Part 1.

## Internet Health Resources

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### The number of health seekers continues to increase.

The Pew Internet & American Life Project first began tracking Internet behavior relating to health in March 2000. At that time, 54% of all U.S. Internet users, or about 50 million American adults, said “yes” when we asked if they looked for health or medical information online. We dubbed these Internet users “health seekers.” Since that time, the numbers have been steadily rising. By March 2003, 66% of Internet users, or 77 million American adults, said they go online to look for health or medical information.

In December 2002, we explored this general question about health and medical searches in a more detailed way. We elaborated on our question to ask respondents if they had done searches for a number of specific health and medical topics, e.g., “Have you ever looked online for information about exercise or fitness? For information about immunizations or vaccinations?” These reminders apparently prompted some Internet users about certain health-related searches they had done online, and it is not surprising to note that the number of health seekers rose dramatically. Eighty percent of adult Internet users, or almost half of Americans over the age of 18 (about 93 million), say they have researched at least one of those specific health topics at some point.

“Health seekers” — Internet users who search online for information on health topics, whether they are acting as consumers, caregivers, or e-patients

While everyone agrees that the number of health seekers is rising, the way to establish that number is a matter of debate. Recent reports, one by the Center for Studying Health System Change<sup>1</sup> and another by a team of Stanford researchers,<sup>2</sup> have estimated a lower population of health seekers by limiting the scope of their survey questions. We deliberately keep the timeframe open, asking if respondents had “ever” searched for a health topic, because it has been our observation that once an Internet user has been successful in an online endeavor, she will return to it the next time she has a similar problem or question, no matter how much time has lapsed between the searches. We also do not limit respondents to thinking exclusively about their *own* health concerns since our past research shows that more than half of Internet health searches are conducted *on*

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<sup>1</sup> Tu, Ha and J. Lee Hargraves. “Seeking Health Care Information: Most Consumers Still On Sidelines.” (Center for Studying Health System Change: March 2003.)

<sup>2</sup> Baker, Laurence; Todd Wagner; Sara Singer; and M. Kate Bundorf. “Use of the Internet and E-mail Health Care Information.” (Journal of the American Medical Association: May 14, 2003—Vol. 289, No. 18.)



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*behalf of someone else.* Indeed, for most Americans, health is a family affair, not a solitary activity. Finally, for the first time, we asked questions of respondents about 16 specific health topics, rather than just asking them about general health searches, and this drove up the number of Internet users who say they have searched for health-related topics online.

We do not mean to imply, however, that an increase in the use of Internet health resources is a cure-all. The Center for Studying Health System Change makes an excellent point when they write about how “significant challenges lie ahead in educating consumers about trade-offs among the cost, quality, and accessibility of care.”<sup>3</sup> Even if more Americans do gain access to the Internet and online health information, low health literacy limits many Americans’ ability to understand what is available online.<sup>4</sup>

The reason to change our basic questionnaire was simple: We were interested in examining in more detail how health seekers were using the Internet for health interests. Many public officials, advocate groups, health researchers, and interested citizens have asked us for more detailed information about the types of health information searches people do online. They ask: Which health topics are people most interested in? How do people apply the fruits of their online research to their health and health care? How do people communicate about their health issues online; using email, message boards, chats? What kind of impact do these communications have on their lives? And what is missing: What would today’s health seekers like to see developed in the future?

It was our hunch that this would be an opportune moment to ask such questions. While the Internet population has stabilized at about 60% of Americans over the last 2 years, the number of “veteran” Internet users has grown substantially.<sup>5</sup> We know, among other things, that the longer someone has been online, the more effectively she uses the Internet. Veteran users do more things online, feel more confident about their ability to find valuable information on the Web, and report using that information to make decisions in their lives.<sup>6</sup> We wondered how this more experienced population was using the Internet for health care and medical information.

“Veteran” Internet user — someone who has been online for 3 or more years
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The Pew Internet Project conducted two kinds of surveys for this report: First, we invited Internet users to share their stories in an online survey. We posted announcements in four online venues — Braintalk.org, which hosts online patient support groups for neurology; DrGreene.com, a pediatric information site; ACOR.org, which hosts online support

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<sup>3</sup> Tu, 2003.

<sup>4</sup> Baur, Cynthia. “The Internet and Health Literacy: Moving Beyond the Brochure.” In Schwartzberg, J.G., J. VanGeest, C.C. Wang (Editors). Understanding Health Literacy: Implications for Medicine and Public Health. (Chicago: AMA Press, 2004.)

<sup>5</sup> Lenhart, Amanda. “Ever-Shifting Internet Population.” (Pew Internet & American Life Project: April 2003.) Available at <http://www.pewinternet.org/reports/toc.asp?Report=88>.

<sup>6</sup> Horrigan, John. “Getting Serious Online.” (Pew Internet & American Life Project: March 2002.) Available at <http://www.pewinternet.org/reports/toc.asp?Report=55>.

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groups for “everyone affected by cancer and related disorders”; and our own site, [pewinternet.org](http://pewinternet.org). We also placed an announcement in a syndicated newspaper column by Joe and Terry Graedon, called “The People’s Pharmacy.” Nearly 2,000 Internet users answered 20 short-answer questions about whether they use the Internet to research symptoms, email loved ones, connect to online support groups, and communicate with their doctors. Second, in December 2002, we conducted a telephone survey with 2,038 Americans, aged 18 or older, 1,220 of whom are Internet users. In that survey, we asked detailed questions about different kinds of health searches.

## Part 1. Internet Health Resources

**Popular topics include specific diseases and treatments, plus diet and fitness information.**

<b>Health Topics Searched Online</b>		
In all, 80% of American Internet users have searched for information on at least one major health topic online. Many have searched for several kinds of information.		
Health Topic	Internet Users Who Have Searched for Info on It (%)	
	Men	Women
Specific disease or medical problem	54%	72%
Certain medical treatment or procedure	40	54
Diet, nutrition, vitamins, or nutritional supplements	39	48
Exercise or fitness	34	38
Prescription or over-the-counter drugs	29	38
Alternative treatments or medicines	23	33
Health insurance	22	29
Depression, anxiety, stress, or mental health issues	17	25
A particular doctor or hospital	17	25
Experimental treatments or medicines	16	20
Environmental health hazards	16	17
Immunizations or vaccinations	11	14
Sexual health information	12	9
Medicare or Medicaid	8	11
Problems with drugs or alcohol	9	8
How to quit smoking	7	5

Source: Pew Internet & American Life Project December 2002 Survey. N=1,220. Margin of error is ±3%.

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### **Women and well-educated Internet users are the most likely to search for health information online.**

In general, women are more likely than men to have looked online for information on most health topics, especially in such areas as information about a specific disease, alternative treatments, diet, nutrition, vitamins, or nutritional supplements. There are topics which interest men and women equally, such as fitness information, experimental treatments, and environmental health hazards.

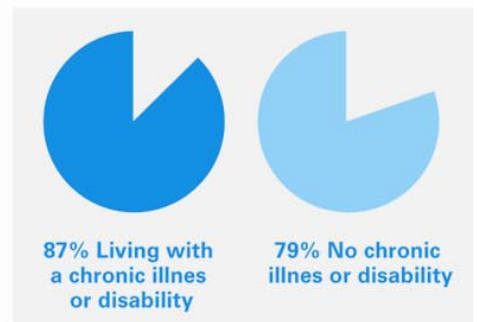
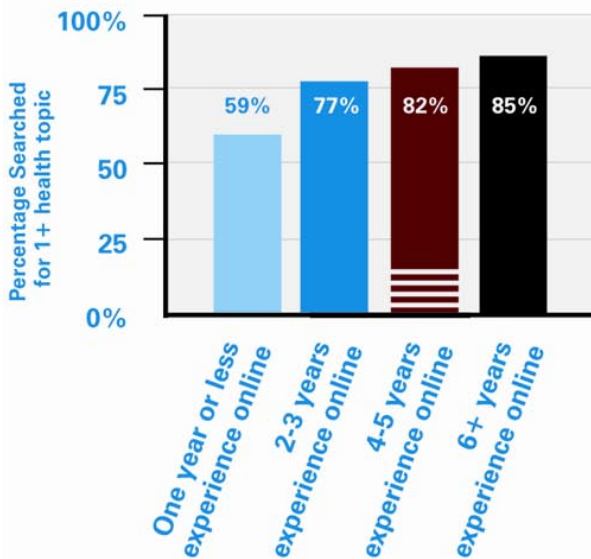
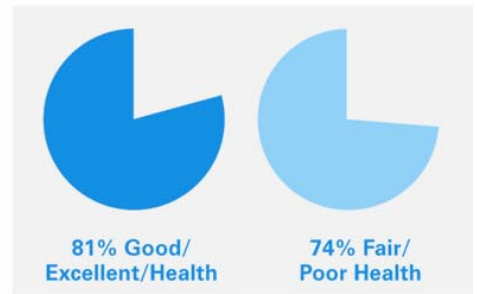
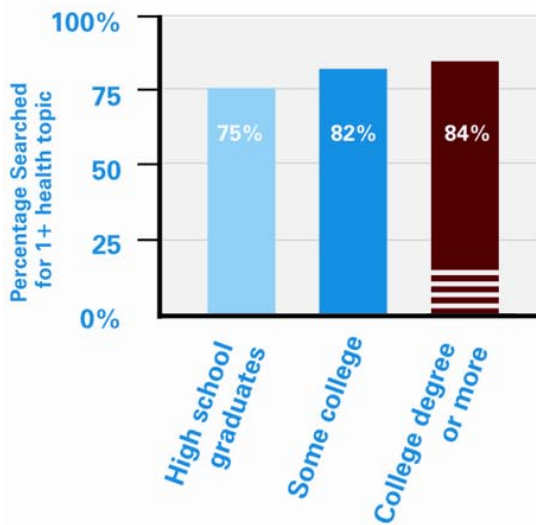
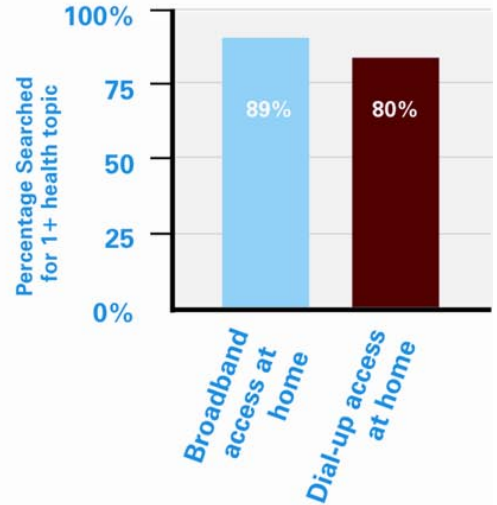
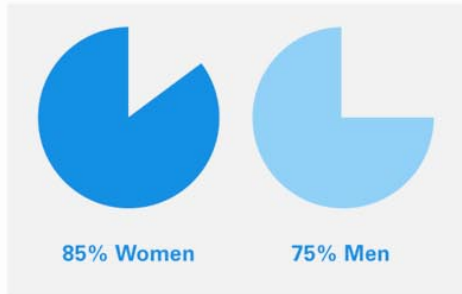
Better-educated and higher-income Internet users are more likely to have searched for health information. Those under the age of 65 are more likely than wired seniors to have looked for health information online (about 80% of Internet users between 18 and 64 years old vs. 70% of wired seniors, age 65+), possibly because most seniors are newcomers to the Internet and therefore less likely to do any kind of search. And, while whites are more likely than African Americans or English-speaking Hispanics to have searched for health information online (82% vs. 76% and 75%, respectively), those differences diminish when other demographic factors are held constant. That is, differences in education levels largely explain why different people are more or less likely to look for health care information online. Those with high educational levels are more likely to be a health seeker than the less educated; race and ethnicity (i.e., whether one is African American or an English-speaking Hispanic) does not affect the likelihood that one is an online health seeker.

Veteran Internet users are more likely than newcomers to have searched for health information – 77% of those with 2-3 years of online experience, compared to 59% of those with less than one year of experience online. And while dial-up users match the general population – 80% have searched for health information – fully 89% of Internet users with a high-speed connection at home have performed such a search.

Broadband users are more likely to search for health information than dial-up users.
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The average Internet user has searched for four of the sixteen health topics we surveyed. Twenty-nine percent of Internet users have searched for at least seven topics. Women are more likely than men to be wide-ranging health seekers; home broadband users are more likely than dial-up users to have searched for seven or more topics.

## Internet users who have searched for at least one health topic



### Specific disease

Sixty-three percent of Internet users have at some point looked for information about a specific disease or medical problem. One respondent to our online survey wrote about a common effect: “Information available on the Internet takes the mystery out of illness and gives the patient a sense of power over his/her condition.” Another respondent shared more dramatic consequences of her search: “As the parent of a child with a very rare neurological syndrome, the Internet was vital to putting the pieces of a puzzle together. It saved my son months of struggle when I found a diagnosis prior to the neurologist he was seeing, who openly admitted she had only heard of the syndrome but never treated a child with [Landau-Kleffner Syndrome].”<sup>7</sup>

As a topic, information about a specific disease or medical problem illustrates well the typical differences among demographic groups. Women are more likely than men to have done such searches (72% vs. 54%). Middle-aged Internet users are more likely than younger or older adult Internet users to have searched (66% of 30-49 year-olds vs. 55% of 18-29 year-olds). College graduates are more likely than those who have not graduated from high school (68% vs. 52%). Internet users who saw a doctor in the past year are more likely to have looked for this type of information than those who did not see a doctor (68% vs. 45%). Those who are living with a chronic illness or disability are more likely than those who are not dealing with a major health problem (85% vs. 61%). And, as we have noted, long-time Internet users are more likely to have searched for information about a specific disease than newcomers (64% of Internet users who have had access for 4-5 years vs. 43% of Internet users who have had access for less than one year).

### Medical procedures and treatments

Forty-seven percent of Internet users have at some point searched online for information about a certain medical treatment or procedure. Caregivers who live with someone who is chronically ill or disabled, a group of searchers who make thorough and frequent use the Internet for health issues, are particularly likely to have searched for information about a specific treatment – 62% have done so. One woman wrote about how she scours the Internet for ways to extend her husband’s life by slowing the progression of Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig’s disease).<sup>8</sup> “There is no expert at treating this disease,” she wrote. “Only experts at diagnosing it.” Internet users often gather information from online sources in order to share in treatment decisions. Another respondent wrote that she brings peer-reviewed medical journal articles to her orthopedist, but adds that, “I do not insist on the procedure, but use the articles as a starting point to discuss new treatment options when we both seem stymied.”

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<sup>7</sup> Landau-Kleffner Syndrome is a rare neurological disorder affecting a child’s comprehension of speech.

<sup>8</sup> ALS is a degenerative neurological disorder primarily affecting the brain and spinal cord.

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### Diet and nutrition

Forty-four percent of Internet users have searched online for information about diet, nutrition, vitamins, or nutritional supplements. Some of these searches are certainly for weight management – indeed, diet sites are among the most popular on the Web, especially during the season for New Year’s resolutions.<sup>9</sup> Other Internet users may be dealing with allergies or conditions like diabetes or high blood pressure that require a special diet. One mother wrote in our online survey said she uses an online gluten-free food list almost daily to help with the dietary restrictions facing her family.

### Fitness

Thirty-six percent of Internet users have searched online for information about exercise or fitness. Internet users between the ages of 18 and 29 are the most likely to have searched for this type of information – 51%, compared to 35% of 30-49 year-olds, 28% of 50-64 year-olds, and just 13% of Internet users age 65 or older.

### Prescription and over-the-counter drugs

Thirty-four percent of Internet users have ever searched online for information about prescription or over-the-counter drugs. Online survey respondents were quite enthusiastic about the details about drugs they can find, whether on a Web site or in online discussions with fellow patients. “I can get first hand knowledge about the drugs I am taking,” one person wrote. “I can find out the side effects and how really useful the drug is and any drug interactions.” Another wrote that when faced with a regimen requiring daily self-injections, she turned to an online support group. “I got a huge amount of support and education when I started on this med,” she wrote. “It took away my fear and apprehension, and answered my questions related to taking this drug.”

### Alternative medicine

Twenty-eight percent of Internet users have searched online for information about alternative treatments or medicines. One respondent to our online survey wrote that she appreciates the information available on pain management sites, noting that massage and acupuncture are among the only treatments that alleviate her “constant pain” from a repetitive stress injury.

### Health insurance

Twenty-five percent of Internet users have searched online for information related to health insurance. Parents are more likely than non-parents to have searched for this type of information – 29%, compared to 23%. One respondent to our online survey wrote that

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<sup>9</sup> Jupiter Media Metrix January 2002 Internet Audience Ratings. Available at: <http://www.comscore.com/press/release.asp?id=270>

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she had read about a new procedure to treat back pain and then consulted her insurance company's Web site to see if it is covered (it was not, so her husband's treatment had to wait).

### Mental health

Twenty-one percent of Internet users have searched online for information about depression, anxiety, stress, or mental health issues. Caregivers who live with a care recipient are more likely than other Internet users to have searched for this information – 37% have done so. Internet users who are living with a chronic disease or disability are also more likely to make these kinds of searches – 37% have searched for mental health information. One respondent to our online survey who is living with depression and borderline personality disorder wrote, "Doctors do not spend enough time explaining or consoling. Reading and learning exactly what my conditions are helps me to cope."

### Particular doctor or hospital

Twenty-one percent of Internet users have searched online for information about a particular doctor or hospital. "The Internet allows me to get a variety of expert opinions from some of our country's top physicians," wrote one Internet user caring for her husband. Another respondent wrote: "I found my doctor by writing a short description of my symptoms and he pre-authorized an immediate appointment with him."

### Experimental treatments

Eighteen percent of Internet users have searched online for information about experimental treatments or medicines. Thirty-seven percent of Internet users living with a chronic disease or disability and 35% of wired caregivers living with a care recipient have done this type of online research. "The doctors do not have the time to remain current in the information about every disorder, so I give the doc the cutting edge information on mine so that I can benefit from new thoughts and therapies," one respondent to our online survey wrote. "I am my own medical advocate."

### Environmental health hazards

Seventeen percent of Internet users have searched online for information about environmental health hazards. "I live in a manufactured home purchased new in 1997," wrote one respondent. "I was diagnosed (Porphyria - 3 forms)<sup>10</sup> in 1998. It was only through the Internet that I was able to learn that the house was making me very ill, supersensitive even for a Porph. It was through these sources that I was able to learn what

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<sup>10</sup> Porphyria is a group of disorders characterized by the accumulation of natural chemicals called "porphyrins" or "porphyrin precursors." Environmental factors can affect the severity of symptoms, which show up in the nervous system or on skin.



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can be done to make the house safer for me.” She is now living in a “detoxed” apartment while her house is made over with safe materials.

### Immunizations

Thirteen percent of Internet users have searched online for information about immunizations or vaccinations. Younger users are more likely to have searched for this information (19% of 18-29 year-old Internet users, compared to 12% of 30-49 year-olds and 7% of 50-64 year-olds). Parents are also more likely (15%, compared to 11% of non-parent Internet users). A number of respondents to our online survey mentioned that they “found out online” about vaccinations that cause other health problems – and some decided to delay vaccinations for their own children.

### Sexual health

Ten percent of Internet users have searched online for information about sexual health information. Nineteen percent of Internet users between 18-29 years old have done so, compared to 8% of 30-49 year-old users. One woman, who had been told by her doctor that a hysterectomy would not affect her sex drive, wrote, “If I had the resources of the Internet then, I would have not had the surgery knowing that this doctor was not telling me the truth about the after-effects and outcomes of hysterectomy.” She has since found out that she is not alone in experiencing diminished interest in sex.

### Medicare and Medicaid

Nine percent of Internet users have searched online for information about Medicare or Medicaid. Not surprisingly, this is the one topic where wired seniors lead every other age group – 19% of Internet users age 65 and older have searched for Medicare or Medicaid information. Twenty-three percent of Internet users living with a chronic disease or disability have researched Medicare or Medicaid online. Twenty-one percent of wired caregivers living with a care recipient have done so.

### Problems with drugs or alcohol

Eight percent of Internet users have searched online for information about problems with drugs or alcohol. Fourteen percent of 18-29 year-old Internet users have done so, compared to 7% of 30-49 year-old Internet users. One woman wrote about her appreciation for Braintalk.org, which hosts online patient support groups for neurology: “Because I am a recovering alcoholic, [Alcoholics Anonymous] meetings have been very important to me in my 18 years of sobriety... Since there isn't a physical meeting close to me, I feel as if this online forum is a life-saver for me.”

### Smoking cessation

Six percent of Internet users have searched online for information about how to quit smoking. Eighteen percent of Internet users with less than a high school education have searched for smoking cessation information, compared to 6% of high school graduates and 4% of college graduates. One fan of the Web site [emphysema.net](http://emphysema.net) (also known as EFFORTS) wrote, "I was diagnosed with emphysema in 1994. I had no idea what that really meant. I knew I needed to quit smoking but didn't really know why. Then I joined EFFORTS a couple years ago and I have learned more about my disease and what I can do for myself than anywhere. I quit smoking and got into an exercise plan and now feel better than ever."

### Domestic violence

In addition to the sixteen topics listed above, we found that 8% of Internet users have searched online for information about domestic violence. Twelve percent of Internet users between 18-29 years old have looked for this type of information, compared to 5% of 50-64 year-old Internet users.

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### Most search every few months, or less often.

But most health seekers search infrequently. Eight out of ten health seekers search "every few months" or less often than that (78%).<sup>11</sup> This updates findings by the Center for Studying Health System Change, whose 2001 survey also found that most Americans had not gathered health information online during the previous year.<sup>12</sup> Our findings also parallel those of the Institute for the Future, which found that the majority (60%) of health seekers are in good health and search infrequently. However, 35% of health seekers are what the researchers termed the "Chronic Stable" and 5% are categorized as "Newly Diagnosed." These Internet users are likely to search more frequently than the "Well."<sup>13</sup>

As we have found in our previous studies, most e-patients are searching when the need arises, often reacting to a symptom or a diagnosis. For example, one respondent to our online survey wrote, "My mother-in-law suddenly began bruising very badly. Medical personnel simply said it was because she was old. I was not satisfied with this answer because the onset was so sudden. Turning to the Internet, I found it was because her aspirin dosage was too high." After consulting with a doctor, this caregiver lowered the aspirin dosage, gave her mother-in-law chewable vitamin C tablets with bioflavonoids, and the bruising cleared up within weeks.

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<sup>11</sup> 2% of health seekers search for health or medical advice or information every day; 4% search several times a week; 14% search several times a month; 32% search every few months; 46% search less often than that.

<sup>12</sup> Tu, 2003.

<sup>13</sup> Cain, Mary M., Jane Sarasohn-Kahn, and Jennifer C. Wayne. "Health E-People: The Online Consumer Experience." (Institute for the Future/California HealthCare Foundation: August 2000). Available at: [http://www.iftf.org/html/researchareas/hc\\_research/chcf/](http://www.iftf.org/html/researchareas/hc_research/chcf/)

## Part 2.

### Email and Support Communities

Internet users support each other online in two major ways: through online communities and through personal emails. In previous studies, the Pew Internet Project has found that 84% of Internet users have contacted online interest groups of varying sorts, from hobbies to politics to religion.<sup>14</sup> Participation in health-related online groups and communities has been steadily rising. In May-June 2001, we found that 36% of Internet users had visited a Web site that provides information or support for people interested in a specific medical condition or personal situation. In September 2002, that number grew to 47% of Internet users, and by December 2002, to 54% of Internet users, or about 63 million Americans.

In addition, about 32 million Americans seek support in a more private form; 30% of email users have sent or received health-related email. About a quarter of email users exchange email with family members about health or medical issues; another quarter do the same with friends. Only 7% exchange emails with doctors or health professionals. Women, better-educated, and more experienced Internet users are more likely to exchange health-related email. Of all those who email about health issues, about 90% find the email useful.

This usefulness and popularity of online support translates into enthusiasm and even passion from e-patients and caregivers for electronic communications. In comments, they describe the value from email and support groups in both emotional and practical terms. A number of themes emerge. On the emotional side, empathy is highly valued; giving support is as important as getting it. On the practical side, support leads to tangible results.

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#### **The Internet connects users to emotional support.**

Email users value connecting with others who can empathize from their own first-hand experience. One respondent to our online survey wrote, “I have met people on support forums that share my concerns and problems. We can ask questions of each other and have understanding that people without our problems can’t possibly understand.” Another wrote, “The Internet put me in contact with others that KNOW what it was and is like living with a disease that can be disabling with many odd symptoms.” And a mother wrote, “Emailing with other mothers of special needs children has been a great way for me to feel linked with women who know what I’m going through.”

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<sup>14</sup> Horrigan, John. “Online Communities: Networks that nurture long-distance relationships and local ties.” (Pew Internet & American Life Project: October 31, 2001.) Available at: <http://www.pewinternet.org/reports/toc.asp?Report=47>

## Part 2. Email and Support Communities

Some respondents to our online survey focus on the less tangible issue of depression. A study published in the December 2002 issue of the American Journal of Psychiatry found that 95% of participants in online support groups for depression said communication with other patients alleviated some depression symptoms.<sup>15</sup> As one e-patient confided, “Just when I think my life is horrible, I read someone else's post and they have it worse...makes me feel better.”

Interestingly, we found that many sought out electronic communications as a way to give as well as receive knowledge. Wrote one, “I am an active participant and information flows both directions. I spend at least an hour a day helping others with their medical concerns.” Another respondent wrote, “As an old timer, I'll help another MS patient with questions that I might know the answer to.” And another goes out of her way to make herself available, “When I sign guest books and what-not, often times people will email me ...almost ALWAYS it's a parent whose child has hydrocephalus<sup>16</sup> and they want to know what their child's future might hold and what insight I may give them as their child grows up.”

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### The Internet also connects users to practical help.

Online support sometimes leads to real results: A recent study of 92 overweight or obese adults showed that individuals who received weekly email counseling lost more weight in a year than similar adults who participated in an Internet weight loss program, but did not receive supportive email.<sup>17</sup> Those who corresponded via email with weight loss counselors lost 4.8 percent of their original body weight – double the loss experienced by the control group.

The good, practical advice is traded on many fronts. One respondent wrote that she corresponds with her sister, “who knows many chronic pain coping techniques.” “Maybe,” offered another, “(we can) discuss more personally some of the things that we can do to ease some of the symptoms that we have.” One AIDS patient explained, “My online correspondence with friends infected with HIV+/AIDS has given me a basis for comparison, as well as tips for staying healthy.” Another respondent wrote about medications, “Patients undergoing drug trials...can compare notes on the Web (like lab rats communicating with each other by tapping on the bars of their cages).”

Email offers efficiencies; it serves as a purely practical tool within many friends-and-family networks for updating groups of people about a loved one's health condition or for offering health information. Wrote one respondent, “My father spent 20 days in the ICU

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<sup>15</sup> Houston, Thomas K., Lisa A. Cooper, and Daniel E. Ford. “Internet Support Groups for Depression: A 1-Year Prospective Cohort Study.” (The American Journal of Psychiatry: December 2002 – Vol. 159, Issue 12.) Available at: <http://ajp.psychiatryonline.org/content/vol159/issue12/>

<sup>16</sup> Hydrocephalus is characterized by a build-up of spinal fluid in the brain.

<sup>17</sup> Tate, Deborah F.; Elizabeth H. Jackvony; and Rena R. Wing. “Effects of Internet Behavioral Counseling on Weight Loss in Adults at Risk for Type 2 Diabetes.” (Journal of the American Medical Association: April 9, 2003 – Vol. 289, No. 14.)

## Part 2. Email and Support Communities

for a subarachnoid hemorrhage<sup>18</sup> in 2002. I was able to communicate with family and friends on a daily basis by sending one email out to all.” “I’ll send articles or links to sites,” wrote one of many, commenting on how electronic communications lets them share the wealth of information they find.

Internet communications cut through all kinds of physical barriers as well, “I often share info via email with people who do not live in close proximity to me.” And it helps create communities of few, far-flung members. One wrote, “I use email a lot. I will ask questions of ...other porphyria patients... They are a wealth of information on a very rare disease.”

Of course, electronic communications isn’t the answer for everyone. Sharing personal medical and health information across the Internet requires a certain leap of faith – or at least a strong sense of privacy and trust. While some e-patients will reach out, using a “patient-matching service”<sup>19</sup> to find someone whose situation is like theirs, through sites like the Association of Cancer Online Resources (acor.org) or the Friends' Health Connection (friendshealthconnection.org); others show concern about writing with online-only correspondents. Wrote one respondent, “I don’t trust people I meet over the Internet enough to give them my email or personal details.” For others, it’s a matter of comfort with the medium. “I can do better in person,” wrote another, in response to a question about whether they use email to discuss health concerns.

“Patient-matching service” – a support network that connects people with similar health problems or personal situations

Two of our respondents best illustrate the sharp contrasts between the advocates for and the stalwarts against using electronic communications. Answering our query seeking information about whether e-patients ever communicate about health issues with people they have met online, one man wrote, “I have over 500 contacts concerning [Huntington’s Disease],<sup>20</sup> all are on line.” This response stands in contrast to another: “ABSOLUTELY NOT. I wouldn’t dare. You don’t know who you are talking to.”

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<sup>18</sup> A subarachnoid hemorrhage is a type of stroke, caused by a break in a blood vessel on the surface of the brain.

<sup>19</sup> See “Matching Services Connect People Who Feel Your Pain,” by Tara Parker-Pope, *The Wall Street Journal*, December 17, 2002.

<sup>20</sup> Huntington’s Disease is a hereditary, degenerative brain disorder.

## Part 3.

### The Internet and Doctor-Patient Dynamics

We wanted to explore some questions about the role of the Internet in people's health care practices and management. For example, how does Internet use fit into people's current habits and patterns of health care?

We found a correlation between visits to health care providers and researching health issues on the Internet. People who visit a doctor or clinic are more likely to have gone online for health information, and vice versa.

In our survey, we found that eight in ten Internet users saw a medical professional in the past 12 months (80%). Of those, 84% have searched online for health information. Of the other 20% of Internet users who didn't see a medical professional in the last 12 months, significantly fewer, 66% have ever searched for health information. This suggests that when people are sick or have health issues rise to the fore, they turn to both their traditional practice of visiting a health care provider and the newer resource of searching the Internet for health information.

Our findings echo a study conducted for the American Academy of Dermatology which found that 67% of patients preferred to go online to research a medical procedure, yet 70% of patients also said that their physician's advice is the ultimate decision-making factor.<sup>21</sup> E-patients are, for the most part, supplementing their doctor's counsel with information gathered from family, friends, medical journals, and the Internet.

We saw two themes emerge from our e-patient surveys: First, people use the Internet to inform themselves about their relevant health care issues and then carry that information to their health care providers. And second, when they carry this information to doctors, they are met with mixed reviews from the doctors.

One respondent related the benefits of her online searches: "Our first visit to the neurologist, when my son was diagnosed with autism<sup>22</sup> was not as devastating as it could have been. My husband and I were well informed and had already figured out the diagnosis by the time we saw the doctor. By being better informed, that first visit was very informative and constructive because we knew the background information, weren't in denial and could discuss therapies and tests in a logical way with the doctor."

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<sup>21</sup> "New American Academy of Dermatology Survey Finds Patients Do Their Homework." Available at: <http://www.aad.org/PressReleases/homework.html>.

<sup>22</sup> Autism is a developmental disorder which affects how a person communicates with and relates to other people. Signs of autism are usually observed by the age of 3.

### Part 3. The Internet and Doctor-Patient Dynamics

Another e-patient summarized, “Knowledge is power. It also helps me to feel prepared to talk with doctors and nurses. I know the terminology and the options.”

For the most part, respondents report that their use of the Internet makes them feel more independent of their doctors, empowers them to ask more informed questions during appointments, and allows them to have less fear of the unknown because of what they learn during their online health research. But their new-found health information from the Internet affects doctor-patient dynamics in a variety of ways. These may be best summarized by one man who wrote in our survey that he had encountered two attitudes: doctors who said they were “partners in my care” vs. those who sent the message “him chief, me Indian.” Some respondents reported going online to test a doctor’s knowledge or to fact check a diagnosis and were pleased to find that their care was indeed excellent, just rushed.

“Every time I visited with the neurosurgeons,” wrote one respondent, “I was well equipped with an incredible amount of information retrieved from countless hours of scanning sources on the Internet. Many times, they became irritated with me for having knowledge of the condition beyond what they chose to share with me. Many times they became defensive and short with me when I would question different aspects of either the information they were giving me, or what I had found out on my own on the Internet.”

Another respondent, after encountering a doubtful doctor, went online to gather testimony from fellow support group members and “was able to let my doctor know that I was not the only one with the odd symptoms I was having.”

E-patients who have encountered negative attitudes from medical professionals either abandon those doctors or keep quiet about their online research. But many echo the sentiment of one respondent who happens to work in a medical facility. This person wrote, “Countless days, weeks, months of suffering are happening to so many patients because doctors refuse to learn new things from the Internet.” Indeed, one defiant health seeker wrote, “Never again will I accept loopy advice such as, ‘There’s no reason for you to be having trouble walking, so it’s not happening.’”

It is not always the case, though, that physicians resist information brought to them by patients after online searches. We did not include physicians in our survey, but in a study of oncologists led by Dr. Paul Helft of the University of Indiana, researchers found that when a patient brings online health information to an appointment, the doctor spends about 10 extra minutes discussing it with them. Oncologists also reported that use of the Internet had the ability to simultaneously make patients more hopeful, confused, anxious, and knowledgeable.<sup>23</sup>

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<sup>23</sup> Helft, Paul R., Fay Hlubocky, and Christopher K. Daugherty, “American Oncologists’ Views of Internet Use by Cancer Patients: A Mail Survey of American Society of Clinical Oncology Members” (Journal of Clinical Oncology: March 1, 2003 – Vol. 21, No. 5.) Abstract available at: <http://www.jco.org/cgi/content/abstract/21/5/942>

### Part 3. The Internet and Doctor-Patient Dynamics

Other e-patients may visit the doctor as infrequently as possible because they do not have health insurance. According to the Census Bureau, 14.6% of Americans (about 41 million, including 8.5 million children) do not have health insurance.<sup>24</sup> Yet they get sick or have health questions, too. As one respondent to our online survey wrote, “I live in a remote rural area — 150 miles from my doctor. I do not have health insurance so I try to make any time spent with my doctor more helpful. If I can rule out or treat issues myself, I can help my physician give me the best health care for the dollar.”

As noted above, a small but enthusiastic number of respondents praise an emerging feature the Internet offers for doctor-patient relations: email correspondence. Only 7% of respondents say they have exchanged email with their doctors, but almost all of these emailers say their electronic correspondence with their doctor has been useful to them in their health care.

Email correspondence between patients and doctors is very efficient in a number of ways:

- Email spans geographic distance. It helps shorten the miles between doctors and patients: patients are sometimes separated from their doctors, particularly specialists, by great distances. One respondent wrote, “The neurologist I most respect and trust practices about 1500 miles from where I live...but when I have questions about therapy or have an important medical decision to make, I discuss it with him via e-mail.”
- Email facilitates ongoing, non-urgent communication. Email takes real-time constraints out of non-critical doctor-patient communications. Wrote one: “My local doc wants me to email him with updates on how a new treatment is working or with questions. I find this to be a convenient way to communicate. We don’t end up playing phone tag; I don’t have to keep calling back, wondering if he ever got the first message. Usually, I get a response within a day or so.” Another echoed, “My neurologist invites his patients to communicate with him via email. I do this when I have the need and he responds within the day or hour, depending on severity of situation.”
- Email can remove the adversarial nature of some discussions. Email can help patients vault over the lines of defense that are often set up between patient and doctor, offering clarity in many situations. One respondent described a typical and clumsy process that email could streamline, “We call and leave information with the nurse/receptionist saying A; she goes to the doctor and says B; she calls us back and gives doctor’s reply to B or sometimes even C! ...but I need an answer to A. Usually, there is at least another phone call before the doctor calls me back to find out what the problem really is.”

In past Pew Internet Project research, we have seen the value of email as an easy way to make arrangements, appointments, and plans for both personal and professional life.<sup>25</sup>

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<sup>24</sup> See <http://www.census.gov/Press-Release/www/2002/cb02-127.html>

<sup>25</sup> Fallows, Deborah. “Email at work.” (Pew Internet & American Life Project: December 8, 2002.) Available at: <http://www.pewinternet.org/reports/toc.asp?Report=79>



### Part 3. The Internet and Doctor-Patient Dynamics

Similarly here, email simplifies the housekeeping details of appointments, prescriptions, and basic questions, especially for patients with complicated cases. One patient living with a chronic disease described using email for “specific appointments and specific advice for clarification, for obtaining duplicate prescriptions, for advance arrangements for personal care during holidays.”

Email helps simplify the housekeeping details of patient-doctor relations.

Amplifying email’s secretarial benefits, many patients with complex medical situations have adapted email to be a kind of open diary or journal from the patient to the doctor. One summarized this matter-of-factly, “My medical oncologist and I communicate via email concerning questions and treatment progress between appointments.” Elaborated another, “I usually update diary highlights for my doctor so that the limited time he is available for consultation will be more meaningful. He, in turn, responds to the emails and often exchanges info to accomplish the same end.”

In addition, both doctors and patients recognize that intense and fast-paced in-person appointments sometimes mean questions are forgotten, answers are mis-remembered. Email serves as a good record-keeper. One respondent wishes she could correspond with doctors by email, “I could comprehensively communicate all of my questions and concerns without feeling rushed.”

But email does have limitations. It lacks the in-person assessment and nonverbal clues of an office visit, like a doctor’s reassuring smile or a patient’s raised eyebrows. In some of our past studies on email’s place in interpersonal relations and in the workplace, we have seen that some people shy away from using email to discuss sticky or sensitive issues. Patient evidence here suggests that people avoid email for the complex and intricate medical discussions, too. One wrote, “Since my surgeon is out of state, I keep him posted on my progress via email in between visits. Of course, he never gives out medical advice over email. Only in person or over the phone. Email is strictly for progress reports so he can stay in the loop of my recovery!”

While many respondents longed for email contact with their doctors (“I only WISH!” was a frequent, resounding sentiment), a number of others echoed some of the worries we hear with any Internet or email use: Some e-patients fret using the Internet for personal or private issues. Wrote one Parkinson’s disease<sup>26</sup> patient, “Not an option for me. I don’t believe that a doctor or health professional can adequately answer an online question. Only doctors and health professionals who can visually assess my person can adequately answer my health questions.” And another, warning that email should play a very limited role, wrote, “I think the Internet is great for information but cannot replace the medical community. Nothing is worth the human relationship with a caregiver.”

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<sup>26</sup> Parkinson’s disease is a progressive neurological disorder characterized by tremors in the hands, arms, legs, or face, as well as impaired coordination and stiffness.

### Part 3. The Internet and Doctor-Patient Dynamics

The medical establishment is beginning to recognize both the potential benefits and pitfalls of using email communications in health care. The few doctors and clinics that are using email already recognize that email communications represent more than a shift in a technology; establishing email use can entail wholesale change in office attitudes and practices, not to mention a serious look at medical and legal ramifications. Those who use email suggest guidelines for a good working system of email, one that requires patients and doctors share common expectations and observe common protocols. For starters, both parties need to agree on —

- the content of emails — what is appropriate to consult about over email
- how to format emails — be clear, use proper identification
- outline turn-around times and expected record-keeping
- privacy and security concerns — who in the doctor’s office can read the emails and respond to them
- compensation — when should doctors charge for online consultations, are they covered by insurance<sup>27</sup>

And the doctors themselves are concerned about the shift in medical and legal, administrative and technological procedures. What is the role of email correspondence in diagnoses; what are the implications of email correspondence in malpractice suits; where do emails fit into patient files; what if emails go astray or end up in the wrong hands?

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<sup>27</sup> For more details, see the Electronic Patient Centered Communication Resource Center, available at <http://134.174.100.34/>

## Part 4.

### Three Particular Groups of Health Seekers

Three different groups of Internet users emerge as noteworthy health seekers: those who use look for health information on behalf of others; those with disabilities; and those who care for others full time.

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#### Most health seekers are searching on behalf of someone else.

A significant 57% of health seekers said the last time they did a health search, they looked for information for someone else. This group is heavily represented by parents, women, healthy people, and the middle aged between 30 and 49 years old.

Parents are more likely than non-parents to have dedicated their last health search to someone else – 65% vs. 50%. Women are more likely than men to say their latest search was at least in part for someone else – 62% compared to 50% of men. Not surprisingly, the characteristic most likely to define a health seeker on behalf of others is the good health of the user: 59% of healthy Internet users look on behalf of others, compared to 32% of those in poor health themselves. And 62% of 30-49 year-olds did research for someone else the last time, compared to 38% of Internet users aged 65 and over.

Women who describe their health as “good” or “excellent” are the most likely Internet users to search on behalf of someone else – 66% have done so, compared to 59% of men in good health.

From our online survey, we discovered a range of reasons why health seekers go online on behalf of others. Among the most important reasons is to get care-giving guidance. For example, one woman wrote about how she used the Internet to span the miles between family members, sharing what she found about end-of-life care. “My father died in January 2002 of lung cancer. My siblings and I are spread across the country and took turns flying to Florida to care for him. Through the Internet I was able to research Hospice and determine that my father was eligible. I asked his doctor to recommend it (none of his many doctors mentioned it to my family). Unfortunately my father was cared for by Hospice for only two weeks before his death.”

Other health seekers said they act as fact-finders on the Internet on behalf of the ill. As one person wrote, “[I] point them to factual sources when they spout old wives tales or home grown remedies.”

## Part 4. Three Particular Groups of Health Seekers

Some e-patients use their newfound awareness of health resources to advocate for loved ones, accompanying them to doctor's appointments and connecting them to other people with the same diagnosis. One person wrote, "Being informed makes it easier for me to be of support to my family and friends in a time of need." Another wrote that online health information helped alleviate some of her husband's concerns about cancer surgery. "It helped him to be prepared for a new way of life," she wrote. "He has also benefited from pointers from others who deal with the same concerns."

Mark Bard of the Manhattan Research Group has coined a term that captures this "searching for someone else" phenomenon. He writes that, when counting the millions of Americans who actively use online health resources, researchers should calculate a much larger "zone of influence"<sup>28</sup> made up of friends, family members, co-workers, and neighbors who also benefit from e-patients' searches. Health care is often a highly social pursuit, not a solitary activity. It is essential to reflect this reality when researching, serving, or creating policies for the health seeker population.

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### **Health seekers who live with a chronic illness or disability actively use the Internet, despite many obstacles.**

A second group that emerged from our data is the small group of Internet users who are living with a disability, handicap, or chronic disease.

Fifteen percent of Americans report in our survey that a disability, handicap, or chronic disease keeps them from participating fully in work, school, housework, or other activities. The likelihood of disability and chronic illness increases with age: 5% of 18 – 29 year-olds live with a disability or chronic illness, and the rate increases with age to 28% of Americans over 65 years old.

Americans living with a disability have among the lowest levels of Internet access in the country. In a survey in the spring of 2002, we found that 38% of Americans with disabilities go online, compared to 58% of all Americans. Of those with disabilities who do go online, a fifth say their disability makes using the Internet difficult. Disabled non-users often face large hurdles in relation to the Internet: They are less likely than other non-users to believe that they will ever use the Internet and less likely than others to live physically and socially close to the Internet. Americans living with a disability are also less likely to have friends or family who go online.

Those who do go online are very active users: Eighty-seven percent of disabled or chronically ill Internet users have searched for at least one health topic. Nearly every topic we asked about was more popular with disabled or chronically ill Internet users than with the rest of the Internet population.

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<sup>28</sup> Manhattan Research, "The Future of e-Health" (2002). Available at <http://www.manhattanresearch.com/signsoflife.pdf>

## Part 4. Three Particular Groups of Health Seekers

Similarly, disabled or chronically ill users are avid online communicators. They are significantly more likely to exchange health-related email with friends – 34%, compared to 20% of non-disabled, healthy email users. The two groups are equally likely to use email to communicate about health issues with family members – about 23%. One in five disabled or chronically ill email users have exchanged email with a doctor, far surpassing non-disabled, healthy users: 19% vs. 6%.

<b>Online Americans living with a chronic illness or disability are fervid health seekers</b>		
<b>Health topics</b>	<b>Non-disabled Internet users (%)</b>	<b>Those with disabilities (%)</b>
Specific disease or medical problem	61	85
Certain medical treatment or procedure	45	66
Diet, nutrition, vitamins or nutritional supplements	42	59
Prescription or over-the-counter drugs	31	55
Alternative treatments or medicines	26	48
Depression, anxiety, stress, or mental health issues	19	37
Experimental treatments or medicines	16	37

Source: Pew Internet & American Life Project December 2002 Survey. N=1,220. Margin of error is ±3%.

### **Home caregivers focus on more urgent concerns, such as treatments, procedures, or drugs.**

A third group that emerged from our data are those who take care of someone living in their household – 11% of Americans live with someone chronically ill or disabled and 70% of that group is a primary or secondary caregiver. Six million home caregivers go online and, when looking for health information, tend to focus on imperatives like treatments, procedures, or drugs.

“Home caregiver” – Respondents were first asked if any member of their household has a disability, handicap, or chronic disease that keeps them from participating fully in work, school, housework or other activities. If they answered yes, respondents were asked if they are responsible for this person’s care.

Wired home caregivers are more likely than the general Internet user population to have searched for information about a specific medical treatment or procedure (62% vs. 47%) and for information about prescription or over the counter drugs (55% vs. 34%). They are also more likely than the general Internet population to have researched mental health information (37% vs. 21%), experimental treatments (35% vs. 18%), and Medicare or Medicaid (21% vs. 9%). Caregivers are, in general, avid online health researchers – they

## Part 4. Three Particular Groups of Health Seekers

are just as likely as non-caregivers to have searched for all the other topics we asked about.

Caregiving duties are more likely to fall to older generations than to Americans under 30. Just 15% of 18-29 year-olds who live with a care recipient say they are primarily responsible for the disabled loved one, compared to about 60% of Americans over the age of 30 who are living with a care recipient.

About half of home caregivers are Internet users, and their lengths of experience reflect the general Internet user population, but they are more likely to have dropped off the Internet for a time. Caregivers are more likely than the rest of the Internet population to go online only from home, possibly because they tend to work somewhat less and perhaps spend more time at home.

Family caregivers probably all have extraordinary stories to share about the good days and the bad days, the lucky breaks and the near-misses, but there is one who stands out in our online survey. She cares for her husband at home, researching each medication before he begins a new prescription and tracking his many health concerns. She is a newcomer to the Internet, but has clearly jumped in with both feet. As she relates, “Hubby has special high rise alternating air pressure mattress. Last year there was a power surge that blew out the motor. This mattress is very important, not only for skin care but his breathing also. Company that originally supplied us with setup no longer dealt in them (Medicaid/Medicare no longer would pay for them). They gave me info to contact company but neither could supply back up motor and this happened two days before Christmas so the repair would take at least a couple of weeks. I went online to eBay and found a used motor at auction for a very reasonable price, reasonable enough so that I could have it sent overnight. Saved the holiday, saved hubby from potential problems and we have a back up in the house should we ever have another problem.”

## Part 5.

### Hope, Validation, and a New Sense of Power

Overall, 73% of health seekers say the Internet has improved the health and medical information and services they receive. And when we asked in our online survey, “On the whole, have the online health resources you have used been helpful, harmful, or somewhere in between?” our respondents shared stories about *how* the Internet has been helpful.

While many cited the maxim “knowledge is power,” many more filled in a picture of the Internet adding a strong measure of psychological and emotional benefit to their health care management. One mother of an autistic child wrote, “It has given me hope for my son. I am not alone anymore.” Another respondent simply stated, “I am less afraid now.”

“I feel more in control of my own destiny and less at the mercy of someone who has many other people to take care of and who asks me when he comes in, ‘What are you here for?’”

One mother told how, when she suspected that her daughter had a serious respiratory infection called RSV, she looked it up online and took her to the emergency room. The doctor at the hospital sent them home with a recommendation to call a pediatrician if the girl’s condition did not improve within three days. But the mother was sure her online research was accurate and saw her pediatrician the next day. The girl did have RSV and stopped breathing at the doctor’s office. The mother wrote, “Her life was saved because I followed my instincts and I only followed my instincts because of what I read about RSV on babycenter.com.”

Respondents who wrote about the harmful effects of the Internet warned that people must watch out for “quacks” and misinformation, especially on discussion forums. One respondent found it “depressing” to read about other people’s problems. Another found the medical information online “too technical” to understand. Others warned that “moderation is key” and health seekers should vet any information they find online with a medical professional. “I’ve found both good and bad resources on the web,” wrote one respondent. “There are a lot of sites that are heavily sponsored by certain pharmaceutical companies and this definitely creates biases. Some sites are simply ill-informed and are passing on incorrect or out of date information.” Another e-patient wrote, “Some websites are very accurate with their medical information. Then there are some that are not. It takes a lot of research to figure out which ones are good, and which ones are selling snake oil.”

## Part 5. Hope, Validation, and a New Sense of Power

### The young are most likely to report benefits

Health seekers in each group who report that their use of the Internet has improved the health and medical information and services they receive (%)

Ages 18-29	80
30-49	72
50-64	71
65+	61

Source: Pew Internet & American Life Project December 2002 Survey. N=1,220. Margin of error is  $\pm 3\%$ .

In our telephone survey, female health seekers are more likely than male health seekers to say the Internet has improved the health and medical information and services they receive (76% vs. 70%). Further, enthusiasm for the Internet among health seekers was inversely associated with age: The younger an online health seeker, the more likely she is to cite benefits from online information. There are no significant differences between health seekers with various levels of education and income. But it seems that health seekers enjoying high-speed Internet access at home are more likely than dial-up users to cite benefits – 81% vs. 71%.



## Part 6.

### Potential for Growth — Up to A Point

If 80% of current Internet users have looked for health information online, what does the future hold? Will the other 20% of current Internet users try a health search some day? Will the 40% of Americans who do not have Internet access some day go online and conduct health research? There is evidence that most Americans, whether they currently have Internet access or not, have a positive outlook when it comes to searching online for health information. We also notice that the more familiar someone is with the Internet, the higher his or her expectations are about online health information. However, there is a significant group of Americans who are completely cut off from online health resources.

Those Internet users who have not yet searched for health information online are most likely to say they just don't have any medical concerns right now or they are satisfied with the information they get elsewhere. They do not seem daunted by the possibility of untrustworthy information or concerned about where they would start looking for health information online.

<b>Why some Internet users have NOT searched for health information</b>			
	<b>Major reason</b>	<b>Minor reason</b>	<b>Not a reason</b>
There are not any health or medical issues that concern me right now	47%	14%	36%
I'm satisfied with the health and medical information I get elsewhere	46	17	34
Much of the information on the Internet cannot be trusted	12	24	61
I would not know where to start looking for such information online	9	18	72

**Source:** Pew Internet & American Life Project Survey, December 2002. N= 453 Internet users who had not yet searched for health information. Margin of error is ±5%.

**New Internet users, and even some non-users, view online health resources in a positive light.**

Many respondents to our online survey reported that they are novice Internet users, often plunging in just to see what they can find. One woman wrote, “Let me start off by saying that a home computer is new for us (thanks to the generosity of family) but I now consider it INVALUABLE.” She especially likes the BrainTalk Communities,<sup>29</sup> hosted at Massachusetts General Hospital, “I have learned more here in the last couple of months than in all the years of dealing with the medical profession (and we have had some very good doctors/nurses and I am VERY proactive).”

Another respondent happened to be answering our survey on the day of her very first health search. “I took my son to a children's neurologist today for the first time. He says my son has short adult syndrome,” she wrote. “This is my first time using the Internet to research an illness.” Her approach was typical of a new health seeker – she just typed “child neurology” into a search engine and began reading, but unfortunately had not yet found any relevant information.

In a September 2002 survey, we asked all Americans if they would expect to find reliable health information online.<sup>30</sup> Eighty-one percent of current Internet users were confident that they could find good health information on the Internet. But a surprising 45% of non-Internet users said they also would expect to get reliable information about health or medical conditions online.

<b>The next time you need reliable information about health or medical conditions, will you be more likely to try to find it online, will you contact a medical professional, or try some other means to get the information?</b>			
	All	Internet Users	Non-Internet Users
Find it online	31%	46%	8%
Contact medical professional	59	47	79
Some other way	8	6	11

**Source:** Pew Internet & American Life Project Survey, September 2002. N=2,092 adults; 1,318 Internet users. Margin of error is ±2% for full sample and ±3% for Internet users.

Most strikingly, Internet users are about as likely to say they will go online the next time they need medical information as they are to contact a medical professional. Nearly half (46%) of Internet users say they will use the Internet next time they need reliable health

<sup>29</sup> See [www.braintalk.org](http://www.braintalk.org).

<sup>30</sup> Horrigan, John and Lee Rainie. “Counting on the Internet.” (Pew Internet & American Life Project: December 29, 2002.) Available at: <http://www.pewinternet.org/reports/toc.asp?Report=80>.

## Part 6. Potential for Growth — Up to A Point

care information. This is statistically the same as the 47% of Internet users who say they will contact a medical professional. Internet users who have already searched for health information are especially enthusiastic – fully 58% of health seekers say they will first go online when they next need reliable health care information; 35% say their first move would be to contact a medical professional. And, in another sign that there is potential for growth in the health seeker population, about one in twelve non-Internet users – 8% – say they will turn to the Internet first when they next need medical information. Those users will probably turn to a trusted friend or family member with online access for this information. And if they eventually do go online, health information will probably be a popular pursuit for those non-users who are already enthusiastic about e-health resources.

As noted above, the Internet population is holding steady at about 60% of American adults. However, of the 40% of Americans who describe themselves as non-Internet users, many in fact have some direct experience with using the Internet and have dropped off. Others live in homes that have Internet connections and are literally offline in an online home. Still other “non-users” find ways to exploit the technology by getting family and friends to send and receive emails for them and do information searches online, even though they themselves remain offline. Thus, when the number of those who live in wired homes and the number of Internet dropouts are considered, the actual size of the population of Americans who have never had any tie – formal or informal – to the Internet is about 24% of Americans. These people are generally the poorer, older segment of the not-online population, and are more likely to be white, female, retired and to live in rural areas.<sup>31</sup> It is these Americans who are least likely to have access to any online health information.

By contrast, the 60% of Americans who do go online are gaining confidence with each passing month. As more users become “veterans,” with three or more years of experience, they are more likely to turn to the Internet if they have a health question.

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### Resources are often hidden in plain sight.

Respondents to our online survey praised the special qualities of the Internet as attractions for new users – one wrote that “anonymity is helpful,” and another wrote, “I can be me without the trappings.” A particularly poignant response came from a respondent who can no longer speak, so the Internet has become a lifeline.

But when asked if there has been anything that they wanted to do using online health resources that they have not been able to do, a popular suggestion was to provide free access to medical journals, most of which are currently available only to subscribers or to those able to pay a fee. The “invisible Web”<sup>32</sup> is truly invisible to many e-patients – search engines cannot gain access to certain pages and online databases that contain vital information.

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<sup>31</sup> Lenhart, 2003.

<sup>32</sup> Sherman, Chris and Gary Price, *The Invisible Web* (CyberAge Books, 2001). See <http://www.invisible-web.net/>

## Part 6. Potential for Growth — Up to A Point

Other popular ideas include:

- More information on drug interactions
- Diagnostic tools or symptom finders
- Electronic medical records and test results
- More information for caregivers
- More ways to connect with local resources
- Doctor-patient email
- More information on a doctor's background
- Better privacy protection
- Less spam, which can limit discussion on list-serves and bulletin boards

Unfortunately, respondents also listed resources that do exist on the Internet, such as a glossary of medical terms or lists of clinical trials, but they just have not been able to find them. Many e-patients wished for “better search engines” or, more generally, “a better way to search for information” since they find most sites accidentally and have no clear way to “save” the searches.

Other studies have also found that health Web sites are not meeting consumers' needs in some key areas. Dr. Christopher N. Sciamanna led a study of 300 health consumers and found that they are satisfied with what they can find online about medications and disease information, but are not satisfied with the Internet's ability to return quality of care information, like provider ratings. These health consumers were also disappointed by the lack of access to their doctors' calendars – they would like to make appointments online.<sup>33</sup>

Harris Interactive's study on behalf of First Health Group Corporation found that consumers see both benefits and drawbacks in health technology.<sup>34</sup> About six in ten consumers agree that information technology will give them a sense of control and empowerment in managing their health. And another 63% believe information technology will save them from making unnecessary visits to the doctor. But about half of consumers say that new information technology will end up being more trouble than doing things the old way. And the majority (77%) believes that doctors will miss subtle clues in online interactions that they would catch in office visits.

However, there are at least a few Internet users who would appreciate the opportunity for online consultations. “I would very much like to communicate with a health professional

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<sup>33</sup> Sciamanna, Christopher N., Melissa A. Clark, Thomas K. Houston, Joseph A. Diaz, “Unmet needs of primary care patients in using the Internet for health-related activities.” (Journal of Medical Internet Research: January 8, 2003.) Available at: <http://www.jmir.org/2002/3/e19/index.htm>.

<sup>34</sup> “The Consumer Health Benefits Survey,” conducted by Harris Interactive for First Health Group Corp.

## **Part 6. Potential for Growth — Up to A Point**

who is not only familiar with my illness, but interested enough to want to assist,” wrote one respondent to our online survey. “I live in a very rural area, the closest town has a population of 1,200; I am the only person my doctor has met who has my illness. He has no time to spare to research for one patient. I am unable to travel so an on-line doctor would be wonderful.”

## Part 7.

### What We Have Learned about Internet Health

The Pew Internet Project, along with other Internet health researchers, has chronicled the growth of the online health sector over the past three years. Here are some of our most important conclusions to date.

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#### Half of American adults have searched for health information online.

About half of all American adults have turned to the Internet for health information. Many Americans who do not have Internet access may ask friends and family to search on their behalf, but about one in four Americans is quite cut off from Internet health resources – they have never had access and they do not live with anyone who has access. Even if they do gain access to the Internet, low health literacy limits many Americans' ability to understand what is available online.<sup>35</sup> And online health information is not just a convenience – a report published in the *New England Journal of Medicine* in June 2003 found that Americans receive about half of recommended medical care.<sup>36</sup> An educated consumer stands a better chance of getting better treatment and the Internet can be a significant resource for that health education process.

An educated health care consumer is likely to get better care.

Just looking at current Internet users, women, those with three or more years of online experience, and those under the age of 65 are more likely to look for health information online. Internet users with a college degree and those who enjoy a high-speed connection at home are significantly more likely to have searched for health information. Those who are dealing with a disability or illness – their own or someone else's – are also more likely to have sought health information online. In this national sample, wealthier Internet users are more likely to be health seekers – Americans living in households with less than \$30,000 annual income are not only less likely to be online, they are less likely to have searched for health information. White Internet users are more likely than African American or English-speaking Hispanic Internet users to have searched for health information, but those differences diminish when other demographic factors are held constant.

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<sup>35</sup> Baur, 2004.

<sup>36</sup> McGlynn, Elizabeth A., Steven M. Asch, John Adams, Joan Keesey, Jennifer Hicks, Alison DeCristofaro, and Eve A. Kerr. "The Quality of Health Care Delivered to Adults in the United States." (*New England Journal of Medicine*: June 26, 2003 – Vol. 348, No. 26.)

## Part 7. What We Have Learned about Internet Health

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### **Popular topics include specific diseases and treatments, plus diet and fitness information.**

Eighty percent of Internet users, or about 93 million American adults, have searched for at least one of sixteen health topics. The average Internet user has searched for four of the sixteen topics. The most popular topics include information about a specific disease or medical problem (63%); information about a certain medical treatment or procedure (47%); and information about diet, nutrition, vitamins, or nutritional supplements (44%). The least commonly searched topics include problems with drugs or alcohol (8%) and smoking cessation (6%).

Internet users also value connecting with others who can empathize from their own first-hand experience. Many go online to give as well as receive emotional support, research notes, and practical tips.

A typical health search is often on behalf of someone other than the Internet user sitting at the computer – many Americans are looking for advice about how to help and comfort a friend, child, spouse, or other loved one.

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### **Most rely on search engines and don't always check the source and date of online health information.**

Experts say that Internet users should set aside ample time for a health search, check a health site's sponsor, check the date of the information, and visit four to six sites. In 2001 we reported that most health seekers go online without a definite research plan, relying largely on their own wits and the algorithms of search engines, to get them to the information they need. The typical health seeker searches every few months or less. She starts at a search site, not a medical site, and visits two to five sites. She spends at least thirty minutes on a search. She feels reassured by advice that matches what she already knew about a condition and by statements that are repeated at more than one site. She is likely to turn away from sites that seem to be selling something or don't clearly identify the source of the information. And about one third of health seekers who find relevant information online bring it to their doctor for a final quality check.

Health seekers turn away from sites that appear to be selling something or don't identify their sources.
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Only about one-quarter of health seekers follow the recommended protocol on thoroughly checking the source and timeliness of information and are vigilant about verifying a site's information every time they search for health information. Another quarter of health seekers check a site's information "most of the time." Half of all health seekers search for medical advice and "only sometimes," "hardly ever," or "never" check the source or date of the information they read online.

## Part 7. What We Have Learned about Internet Health

Some e-patients and caregivers rely more heavily on their peers – online friends and family who trade tips via email or online discussion boards. Fifty-four percent of Internet users, or 63 million Americans over the age of 18, have visited a Web site that provides information or support for people interested in a specific medical condition or personal situation. Thirty percent of email users, or about 32 million American adults, have sent or received health-related email.

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### **Convenience, breadth of information, and anonymity are valued.**

In 2001, 82% of health seekers said they find what they are looking for “most of the time” or “always.” Yet our online survey revealed that some e-patients continue to hunt for information that already exists on the Web – they just haven’t found it. About seven in ten health seekers say their most recent search had some impact on decisions related to their own health care or a loved one’s care. And in this most recent survey, conducted in December 2002, 73% of health seekers say the Internet has improved the health and medical information and services they receive.

In 2000, Internet users reported that one of the most important aspects of online health advice is the fact that it is available at any hour of the day or night, from wherever they are able to log on. Ninety-three percent of health seekers said that convenience is important. Eighty-three percent of health seekers said that it is important that Internet users can get more health information online than from any other sources. And 80% of health seekers said it is important that Internet users can get health information anonymously.

In 2000, Internet users also expressed concern about the security of their personal information. Eighty-nine percent of health seekers were concerned that a health Web site might sell or give away information about what they did online. Seventy-five percent of health seekers said that health Web sites should not be allowed to track users’ activities, compared to 18% who said that would be fine. Sixty percent of Internet users thought 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. Thirty-three percent of Internet users thought it would be a good thing to have online access to their medical records.



# Methodology

This Pew Internet & American Life Project report is based on the findings of a daily tracking survey on Americans' use of the Internet and an online survey about Internet health resources.

Telephone interviews were conducted by Princeton Survey Research Associates between November 25 and December 22, 2002, among a sample of 2,038 adults, 18 and older. 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 percentage points. For results based Internet users (n=1,220) the margin of sampling error is plus or minus 3 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.

New sample was released daily and was kept in the field for at least five days. This ensures that complete call procedures were followed for the entire sample. Additionally, the sample was released in replicates to make sure 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. The overall response rate was 32.8%.

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 2001). This analysis produces 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.

## Part 7. What We Have Learned about Internet Health

An online survey consisting of 20 questions was hosted by Princeton Survey Research Associates. Respondents were primarily recruited from announcements posted on [Braintalk.org](http://Braintalk.org) (hosted by the Department of Neurology, Massachusetts General Hospital); [ACOR.org](http://ACOR.org) (the Association of Online Cancer Resources); [DrGreene.com](http://DrGreene.com) (a pediatric Web site); and on the Pew Internet Project's own [site](#). An announcement was also printed in a syndicated newspaper column entitled "[The People's Pharmacy](#)." In addition to the "official" announcements, individual Internet users posted links to the survey in a multitude of personal emails, listserv discussion groups, and other health-related Web sites.

Respondents were invited to complete the multiple-choice questions and most used the open-ended text boxes to provide more detail. In all, 1,971 individuals' responses were collected and transmitted to reviewers as three spreadsheets. Follow-up interviews with 19 respondents were completed via email.