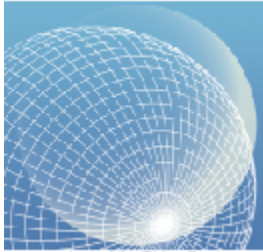


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& Internet
American Life
PROJECT

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Vital decisions

*How Internet users decide what information to trust
when they or their loved ones are sick*

*Plus a guide from the Medical Library Association about smart
health-search strategies and good Web sites (Page 32)*

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Acknowledgment

This report is built around the phone survey work of the Pew Internet & American Life Project done by our polling partner Princeton Survey Research Associates that focused on Internet users who look for health information online. The main survey for this report involved phone interviews with 500 “health seekers” in the summer of 2001. PSRA has done all the project’s surveys since its inception in January 2000, and its executives and staff have been our creative collaborators in every step of the project’s work.

This report also contains information and insights from two online focus groups that were put together by Harris Interactive. The Medical Library Association contacted us after the release of our first report about online health information in November 2000 and has been an invaluable resource since then. Dr. Tom Ferguson, a senior research fellow at the Pew Internet Project, helped us to focus even more closely on the consumer experience and contributed key insights at every stage of research.

About the Pew Internet & American Life Project

The Pew Internet & American Life Project creates and funds original, academic-quality research that explores the impact of the Internet on children, families, communities, the workplace, schools, health care, and civic and political life. The project is an independent, nonpartisan organization that aims to be an authoritative source for timely information on the Internet’s growth and its impact on society. The project is fully funded by The Pew Charitable Trusts.

About Princeton Survey Research Associates

Princeton Survey Research Associates 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

About Harris Interactive

Harris Interactive (Nasdaq: HPOL) is a worldwide market research and consulting firm, best known for The Harris Poll and its pioneering use of the Internet to conduct scientifically accurate market research. Strengthened by its recent merger with Total Research Corporation, the company now combines the power of technology with international expertise in predictive, custom, strategic research. Headquartered in the United States, with offices in the United Kingdom, Japan and a global network of local market and opinion research firms, the company conducts international research with fluency in multiple languages. For more information about Harris Interactive, visit <http://www.harrisinteractive.com/>.

About the Medical Library Association

The Medical Library Association is an educational organization of professionals, providing quality information for improved health. Founded in 1898, MLA represents more than 1,100 institutions and 3,800 individual members in the health sciences information field. For more than a century the Medical Library Association has served society through its members and programs, by providing quality information for better health care, the education of health professionals, the conduct of research, and the public's understanding of health care issues.

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Summary of Findings

In November 2000, the Pew Internet & American Life Project reported that 52 million American adults relied on the Internet to make critical health decisions. We now find that 73 million American adults use the Internet to research prescription drugs, explore new ways to control their weight, and prepare for doctor's appointments, among other activities. Many say the Internet has helped them or someone they know and very few report harmful effects from acting on bad information they found online.

However, there has been a drumbeat of warnings about the quality of online health information and there is cause for concern about whether consumers are finding the very best advice online. While others have looked at online content and charted its deficiencies, the Pew Internet Project focused on users and asked them how they decide what information to believe and what advice to act on. If indeed there are problems with the quality of online health information, do consumers use sensible strategies to separate the good from the bad?

In a national survey conducted March 1-31, 2002, the Pew Internet Project found that 62% of Internet users, or 73 million people in the United States, have gone online in search of health information. For shorthand purposes, we call them "health seekers" throughout this report. About 6 million Americans go online for medical advice on a typical day. That means more people go online for medical advice on any given day than actually visit health professionals, according to figures provided by the American Medical Association.

Experts say that Internet users should check a health site's sponsor, check the date of the information, set aside ample time for a health search, and visit four to six sites. In reality, most health seekers go online without a definite research plan. The typical health seeker starts at a search site, not a medical site, and visits two to five sites during an average visit. 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.

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.

Health seekers seem to look for specific answers to targeted questions and are generally cautious about making decisions based on the information they find. They often use the information in making important decisions about interacting with their doctors, getting

diagnoses, and treatments. But the ease of using the Internet and the abundance of health information online are not changing their entire approach to health care.

Some 72% of online women have gone online for health information, compared with 51% of online men. And 71% of Internet users between 50 and 64 years old have gone online for health information, compared with 53% of those between 18 and 29. Those with more education and more Internet experience are more likely to search for medical advice online. There are no significant differences between whites, African Americans, and Hispanics when it comes to online health research.

In a special survey of 500 Internet users who go online for health care information, conducted June 19-August 6, 2001, we found the following:

Disease information, material about weight control, and facts about prescription drugs top the list of interests for health seekers. We also see big increases in use of the Internet for mental health information and sensitive medical topics.

The list below suggests the variety of things health seekers do online. We also asked for the first time about alternative medicine and saw that substantial numbers of Internet users go online for such material.

- 93% of health seekers have gone online to look for information about a particular illness or condition.
- 65% of health seekers have looked for information about nutrition, exercise, or weight control.
- 64% of health seekers have looked for information about prescription drugs.
- 55% of health seekers have gathered information before visiting a doctor.
- 48% of health seekers have looked for information about alternative or experimental treatments or medicines.
- 39% of health seekers have looked for information about a mental health issue such as depression or anxiety (up from 26% in August 2000).
- 33% of health seekers have looked for information about a sensitive health topic that is difficult to talk about (up from 16% in August 2000).
- 32% of health seekers have looked for information about a particular doctor or hospital.

A typical health seeker searches for medical information only occasionally, and she relies on search engines and multiple sites

The typical health seeker is a sporadic user of online medical information. More than half of health seekers (58%) do health searches every few months or even less frequently. A typical seeker goes online to see what she can find without getting advice about where or how to search from anyone, including medical professionals or friends. She visits several sites during a typical search and does not have a favorite site.

Successful searches, varying impacts

Even without any outside help, the typical health seeker feels it is quite easy to get the information she needs. Eighty-two percent say they find what they are looking for “most

of the time” or “always.” Fully 61% of health seekers, or 45 million Americans, say the Internet has improved the way they take care of their health either “a lot” or “some.” This is a significant increase from an August 2000 Pew Internet Project poll that found that 48% of health seekers, or 25 million Americans, said the Internet improved the way they take care of themselves.

One in three health seekers know someone who has been appreciably helped by following medical advice or health information they found on the Internet. Just 2% of health seekers know someone who has been seriously harmed by following medical advice or health information they found on the Internet.

The impact of their online searches

In most cases, the information they find online is helpful as they make decisions about how to take care of themselves or loved one. Overall, when we asked these health seekers about their most recent search for information, 68% said it had some impact on their decisions related to their own health care or a loved one’s care. About 16% said it had a major impact on their own health care routine or the way they helped care for someone else; 52% said the information had a minor impact; 31% said it had no impact at all.

Different degrees of vigilance about the information health seekers find on the Web

Respondents fall into three broad groups. About one quarter are vigilant about verifying a site’s information, another quarter are concerned about the quality of the information they find but follow a more casual protocol, and half rely on their own common sense and rarely check the source of the information, the date when the information was posted, or a site’s privacy policy.

Perhaps one of the reasons why health seekers are generally casual in their approach to verifying online information is that they trust the online environment. Fully 72% of health seekers say you can believe all or most of the health information online. Indeed, 69% of health seekers say they have not seen any wrong or misleading health info on the Web, while 28% of health seekers say they have seen bad information.

Credibility killers: Why health seekers turn away from Web sites

Still, 73% of health seekers have at some point rejected information from a Web site during a health search for one reason or another. Here are the major reasons they cite for turning away from a site:

- 47% of health seekers have decided not to use information they found because the Web site is “too commercial and seemed more concerned with selling products than providing accurate information.”
- 42% of health seekers have turned away from a health Web site because they couldn’t determine the source of the information.
- 37% of health seekers have turned away from a health Web site because they couldn’t determine when the information was last updated.

- Other reasons for turning away: no visible “seal of approval,” sloppy or unprofessional design, or the presence of bad information (as judged by the health seeker or the health seeker’s own doctor).

Health seekers still rely on doctors for guidance

While there is great concern in the medical establishment that e-patients are self-diagnosing and self-medicating because of the information they can find online, only a modest number of Internet users say they are substituting online information for doctor’s advice. One in five health seekers (18%) say they have gone online to diagnose or treat a medical condition on their own, without consulting their doctor.

Despite reports that doctors are upset with patients who march into the examining room with Web printouts, our respondents tell a different story. When we asked health seekers about their most recent episode of online searching, 37% say they talked to a doctor or other health care professional about the information they found during their search. Of those who talked to an expert, 79% say their doctor was interested in the information found online. Just 13% who talked to their doctor got the cold shoulder and report that the health care professional was “not too interested” or “not at all interested.” Of those who chose not to talk to a health care professional, most deemed the topic too insignificant to seek expert advice. Just 2% of health seekers who did not talk to a doctor say it was because they didn’t think their doctor would listen.

Table of Contents

Acknowledgment	2
Summary of Findings	4
Table of Contents	8
Main Report: The search for online medical help	
Introduction.....	10
Part One: A basic profile of health seekers	
Who is searching for health information online?.....	11
Part Two: Hot topics	
Weight control and prescription drug information are high on the list of health interests	12
Part Three: Search strategies	
Most go it alone	14
Most use a search engine and visit a few sites.....	14
A small number consult one favorite site	14
Most are occasional users	15
Many are looking on behalf of someone else	15
New symptoms spur research for individuals.....	15
Searching from home to answer a specific question.....	16
Part Four: Evaluating the quality of health information	
The recommended way to assess medical material	17
Health seekers' basic presumptions.....	17
If it fits with what they've already heard, they believe it	18
When they read the same facts at different sites, health seekers' trust in those sites grows.....	18
Health seekers' information assessment screens	19
Commercialization and search engines.....	20
A typology of health seekers.....	20
Vigilant health seekers.....	20
Concerned health seekers.....	21
Unconcerned health seekers.....	21
Health seekers still rely on doctors for guidance and fact-checking	21
Part Five: Results	
Successful searches.....	23
Part Six: Impact	
Health information's impact	25

Part Seven: Email, support groups, and personalization

Few go beyond Web searching27
Few take advantage of personalization28

Part Eight: Health searches for someone else

Searching on behalf of someone else29
Continual caregivers30
Parents30

Appendix: Medical Library Association guide

Finding and evaluating health information on the Web.....32
Top ten most useful consumer health Web sites.....35
Recommended cancer Web sites38
Recommended diabetes Web sites.....39
Recommended heart disease Web sites41

Methodology43

Main Report: The search for online medical help

Introduction

Tens of millions of Americans turn to the Internet when they need help with health problems. Health professionals are often apprehensive about the reliability of online health information and wonder how consumers can possibly find good advice in the untamed wilderness of the Internet. In an environment where any quack can create a credible-looking Web site and promote all manner of questionable “cures,” how can Internet users know what information will most benefit them? What signals of quality should they seek?

Some experts warn about another danger – that the best information is not even on the Internet. An exhaustive study by the California HealthCare Foundation and RAND Health found “substantial gaps in the availability of key information” relating to breast cancer, depression, obesity, and childhood asthma available through English- and Spanish-language search engines and Web sites.¹ Another study, funded by the Robert Wood Johnson Foundation, echoed RAND’s cautionary tone after comparing the 25 most popular health Web sites’ adherences to quality codes, peer review, and external advisory boards.² And the American Medical Association (AMA) has taken the position that online health information is never a substitute for a physician’s experience and training, suggesting that Americans make a new year’s resolution to “trust your physician, not a chat room.”³

Widespread skepticism among medical providers has not deterred the remarkable growth in the number of people seeking medical information online. More Americans research health information online on an average day than visit health professionals. About 6 million Americans go online for medical advice on a typical day, whereas the American Medical Association estimates that there are an average of 2.75 million ambulatory care visits to hospital outpatient and emergency departments per day and an average of 2.27 million physician office visits per day. So we set out to examine how Internet users search for information, how they establish its credibility, and how they decide to act on it. We used several approaches. We surveyed 500 Internet users who go online for health care information. This special sample, surveyed June 19-August 6, 2001, portrays the overall habits and attitudes of those Americans who use the Internet for medical information and advice. We also gained insights from two online focus groups conducted on October 15, 2001, by Harris Interactive. In one group, six participants with special needs discussed how they use the Internet to manage their chronic illnesses and care for their loved ones. In the second group, ten participants representing the general

¹ Berland, Gretchen K., et al., “Health Information on the Internet: Accessibility, Quality, and Readability in English and Spanish,” *JAMA*, May 23/30, 2001, Vol. 285 No. 20. Available at:

<http://jama.ama-assn.org/issues/v285n20/ffull/joc02274.html>

² Eng, T.R. “The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care.” Princeton, NJ: The Robert Wood Johnson Foundation, 2001.

³ American Medical Association, “AMA Suggests Resolutions for a Healthy New Year.” Dec. 20, 2001, press release.

population discussed how they use the Internet to take better care of themselves and their loved ones.

Part One: A basic profile of health seekers

Who is searching for health information online?

In a national survey conducted March 1-31, 2002, the Pew Internet Project found that 62% of Internet users, or 73 million people in the United States, have gone online in search of health information. Women are more likely than men to have researched a medical question online. Some 72% of online women have sought medical information online, compared with 51% of online men. Those in the middle age groups are more likely to turn to the Internet for health information than those under 30 or over 65. College-educated Internet users are more likely to search for medical advice online than those with a high school education. Longtime users are more likely than Internet newcomers to look online for health tips. Interest in health information cuts across ethnic and racial groups in a relatively equal way – white, black, and Hispanic Internet users are equally enthusiastic for such material.

Fifty-seven percent of health seekers describe themselves as in “good” health. Twenty-nine percent of health seekers say they are in “excellent” health and 14% say they are in “fair” or “poor” health. By comparison, the National Center for Health Statistics reports that 37% of Americans assess their health as “excellent,” 31% say it is “very good,” 23% say it is “good,” and 9% say their health is “fair” or “poor.”⁴ Not surprisingly, those in fair or poor health search for medical advice more frequently and on more topics than those in better health.

On a typical day, 5% of all Internet users – about 6 million Americans – go online to look for health information. There are few differences in the population of Internet users who searched online “yesterday”; men, women, old, young – all were equally likely to look for medical advice. However, it seems that those with more online savvy may be more accustomed to answering a health question online – 7% of Internet users with three or more years of experience search on a typical day, compared with 2% of Internet users with just six months of experience online.

Health Seekers	
<i>Those who have gone online for health information or medical advice.</i>	
<i>Internet Users</i>	<i>%</i>
All	62
<i>Gender</i>	
Women	72
Men	51
<i>Age</i>	
18-29	53
30-49	63
50-64	71
65+	58
<i>Education</i>	
Less than high school	44
High school graduate	57
Some college	61
College graduate	69
<i>Race</i>	
White	62
Black	61
Hispanic	60
<i>Internet Experience</i>	
Less than 6 months	46
6-12 months	53
2-3 years	57
3+ years	68

Source: Pew Internet & American Life Project Survey, March 1-31, 2002. Margin of error is ±3%.

⁴ National Center for Health Statistics’ “National Health Interview Survey.” Available at: <http://www.cdc.gov/nchs/about/major/nhis/released200202.htm>

Part Two: Hot topics

Weight control and prescription drug information are high on the list of health interests

Almost every health seeker (93%) has looked at one time or another for information about a particular illness or condition. Roughly two thirds of all health seekers have looked for information about nutrition, exercise, or weight control. In our August 2000 survey, 13% of health seekers said they had sought information about just “fitness and nutrition.” The new survey shows a big increase when weight control is added to this list. Those who describe their health as “fair or poor” are more likely than those in excellent health to have looked for information about nutrition, exercise, or weight control.

Two thirds of all health seekers (64%) have looked for information about prescription drugs. Those who have seen a doctor in the past year are more likely to use the Internet to research a certain drug than those who have not consulted with a doctor. In our August 2000 survey, only 10% of health seekers said they had purchased medicine or vitamins online.

As with other aspects of online shopping, there are more browsers than buyers. Part of the reason for this is that many people prefer to make their actual purchase in stores. Others are worried about the security of their credit card information. Nonetheless, the Web is increasingly important to “window shoppers” – those gathering consumer information, doing price comparisons, checking out alternative purchases.

More than half of all health seekers have gathered information before visiting a doctor. Health seekers dealing with a chronic disease or disability are more likely to do their homework before a doctor’s appointment. One member of the Harris Online focus group living with fibromyalgia said, “I can at least go into the doctor’s office with a good knowledge of what is going on and ways of treatment.”

Nearly half of all health seekers (48%) have looked for alternative or experimental treatments or medicines. Those who have been treated for a serious illness in the past year are more likely to have done this – 62%, compared with 48% of those who have escaped such a diagnosis. One focus group participant who is living with a chronic condition said, “I hope to find new ways to treat myself without using medication.”

Hot Topics for Health Seekers	
<i>Weight control is near the top and self-diagnosis is near the bottom</i>	
	%
Looked for information about a particular illness or condition	93
Looked for information about nutrition, exercise, or weight control	65
Looked for information about prescription drugs	64
Gathered information before visiting your doctor	55
Looked for information about alternative or experimental treatments or medicines	48
Looked for information about a mental health issue like depression or anxiety	39
Looked for information about a sensitive health topic that is difficult to talk about	33
Looked for information about a particular doctor or hospital	32
Diagnosed or treated a medical condition on own, without consulting your doctor	18

Source: Pew Internet & American Life Project Health Callback Survey, June 19-Aug. 6, 2001. Margin of error is ±4%.

Another chronically ill participant agreed, saying, “Most doctors are not up to date on alternative methods.”

Thirty-nine percent of health seekers have looked for information about a mental health issue such as depression or anxiety. Those who have visited an emergency room for medical treatment in the past year are more likely to have looked for mental health information online – 49%, compared with 37% of health seekers who have not been to the emergency room. In August 2000, 26% of health seekers said they had ever looked for this type of information. Although our survey ended August 6, 2001, this increased interest in mental health information probably accelerated in the wake of the September 11 terrorist attacks. As an indication of this, Michelle Pruett, media director for the National Mental Health Association, says the association’s Web traffic increased by 50% from September to October and the top destination was “Coping with Disaster,” an information page for helping children deal with disaster-related anxiety.

Similarly, 33% of health seekers have looked for information about a sensitive health topic that is difficult to talk about, which is a big jump from the 16% of health seekers who said they had done this in August 2000. Men are more likely than women to have done this – 38% of male health seekers, compared with 29% of female health seekers.

Frequent health seekers are more likely than occasional seekers to have tried every activity we asked about, from looking for weight control tips to diagnosing a medical condition on their own. For example, 74% of health seekers who go online at least several times a month have looked for information about nutrition, exercise, or weight control. Fifty-nine percent of Internet users who go online every few months or less have done this. Not surprisingly, health seekers who say the Internet has improved the way they take care of themselves are also more likely to have gone down all sorts of avenues in pursuit of medical advice – and to have found the right information the last time they did a search.

Part Three: Search strategies

Most go it alone

To get a picture of Internet users' actual behavior, we asked health seekers to relate details about their most recent information search. Most health seekers (86%) just plunged right in to see what they could find rather than asking anyone for advice about which Web sites to use. Of the 14% of health seekers who asked someone for advice, most followed that counsel at least a little bit. However, 41% of health seekers who got advice said they ended up finding the information they wanted on their own.

Friends and Family	
<i>Just 14% asked for advice about where to look for online health information</i>	
<i>Advice Seekers</i>	<i>%</i>
Asked friends	38
Asked family	38
Asked doctor or nurse	25
Asked someone else	8

Source: Pew Internet & American Life Project Health Callback Survey, June 19-Aug. 6, 2001. Margin of error is ±4%.

Most use a search engine and visit a few sites

In keeping with other research into health seekers' habits,⁵ we found that the vast majority (86%) visit multiple sites when looking for health information and do not have one favorite site. Most start at a general, non-specialty Web site – a search engine or a portal. They surf to other sites after finding information or links to them on the general site. The typical range of sites visited is two to five. Eighty-nine percent of health seekers who visit multiple sites say that, in general, they start at a site like Yahoo or the AOL home page. Just 8% of health seekers who visit multiple sites say they are most likely to start at a specialized health site like WebMD.com.

Last time they searched for health advice, those who used a search query on a search engine were more focused on getting the information fast than finding a trusted name – 45% started at the top of the search results and worked their way down; 39% read the results list and then clicked on the items that seemed to be the most relevant; and just 12% clicked on a site because they recognized the sponsor or name.

A small number consult one favorite site

About one in three health seekers (29%) has bookmarked health-related Web sites or saved them as a “favorite place” for consultation again and again. Frequent and enthusiastic health seekers are more likely to have health-related bookmarks, as are those who saw a doctor in the past year.

When asked if they have one favorite site, 14% of health seekers said yes. Of that small group, 35% named WebMD. Other sites named by these “favorite-site” health seekers include the Mayo Clinic site, the National Institutes of Health, InteliHealth, Medline, and DrKoop.com. One online focus group participant who is a fan of WebMD commented, “I know it so well it is just easier to go to it every time I have a question.”

About one quarter of health seekers with one favorite site say they first went to it because of a personal recommendation, usually from a friend or family member, and a small number got the tip from a doctor or other health professional. Another quarter of

⁵ Harris Interactive Health Care News, Volume 1, Issue 21, June 26, 2001.

favorite-site health seekers saw an advertisement for the site. The third quarter found it through an Internet search, and another 12% just came across their favorite site while surfing the Web. One focus group participant said that he ended up getting good advice from health chat rooms recommended by “close friends who thought they would help.”

Health seekers with a favorite site are often rewarded for their focused approach. Of the 41% of health seekers who went to a specialized health site or health portal site the last time they went online for health information, about half (53%) said the site delivered exactly what they needed. Thirty-seven percent of these focused health searchers went on to other sites.

For some health seekers, the need for detailed, specialized information is vitally important. One focus group participant who is living with 18% lung capacity put it this way: “Most commercial sites have the basics of an illness. I am beyond basics.”

Features of a Favorite Site	
<i>14% of health seekers go back to one specific site – here's why.</i>	
<i>Favorite-Site Health Seekers</i>	<i>%</i>
Site is easy to navigate	30
Trust advice and information on site	25
Site specializes in a particular health condition of interest	14
Site was recommended by friends or family	13
Like certain features of site	7
Site was recommended by doctor or other health care provider	6

Source: Pew Internet & American Life Project Health Callback Survey, June 19-Aug. 6, 2001. Margin of error is ±4%.

Most are occasional users

Most health seekers are only occasional visitors to health and medical sites. Fifty-eight percent of health seekers use the Internet to look for medical advice or health information every few months or less. Forty-two percent of health seekers search for health information at least several times a month – 4% do so every day, 13% search several times a week, and 25% search several times a month. Those in excellent health are less likely to haunt health Web sites than those who describe their health as good, fair, or poor.

Many are looking on behalf of someone else

Worrying about someone else’s health issue is the No. 1 motivation for health seekers to go online for medical advice, whether for a friend, spouse, child, or parent. Eighty-one percent of health seekers have gone online because someone they know was diagnosed with a medical condition. In addition, 38% of health seekers have gone online because they are caring for someone else. Indeed, when asked about their last online health search, half of health seekers say they were looking on behalf of someone else. (See the separate section on caregivers, Page 29.)

New symptoms spur research for individuals

Fifty-eight percent of health seekers have gone online because they themselves were diagnosed with a new health problem. Other important motivating factors include being prescribed a new medication or treatment; dealing with an ongoing condition; having unanswered questions after a doctor’s visit; and deciding to change diet or exercise habits.

The middle age groups (30-49 years old) are more likely than young health seekers or senior health seekers to be motivated to go online for all these reasons, except one. Older health seekers are more likely to go online for information about how to deal with an ongoing medical condition, such as diabetes or high blood pressure. Not surprisingly, those in less-than-excellent health are more likely to go online to research a new diagnosis or medication. There are few differences, however, when it comes to feeling underserved by a health professional – no single group is more motivated than another to go online because they had unanswered questions after a doctor’s visit.

Searching from home to answer a specific question

The great majority of health seekers went online from home the last time they searched – 80% of health seekers. Just 16% of health seekers went online from work the last time and 4% said they went online from somewhere else, such as a library or a friend’s house. As one at-home mother said in an online focus group, “If I did work, I would probably be too embarrassed to look up stuff online.” Another focus group participant echoed her concern, saying, “I know we monitor the use of the Net at work and I have seen it work against people.”

The last time they went online for health information, 62% of health seekers researched a specific illness or condition. When we asked what illness or condition they searched for, 12% of this subgroup of disease-researching health seekers said they were researching cancer. Other commonly named illnesses included diabetes, heart condition, arthritis, mental health, and conditions affecting the skin, kidneys, lungs, the brain, and bone density. The rest of those who looked for information on a specific illness revealed a wide range of concerns, from spider bites to autism.

Health seekers with one illness in mind were quite focused the last time they went online for information. They tended to be looking for information about medications or treatments for that particular illness, for details about the symptoms of that illness, and for the disease’s prognosis.

The last time they went online for health information, 14% of health seekers sought information about specific doctors, hospitals or medicines. This is a notable increase from our August 2000 survey, which found that 9% of health seekers had searched for a specific doctor the last time.

Fourteen percent of health seekers sought information about fitness, nutrition, or general wellness the last time they went online for health information. Ten percent of health

Motivations <i>Reasons why health seekers have gone online for medical advice</i>	
	%
Someone you know being diagnosed with a medical condition	81
Being diagnosed with a new health problem of your own	58
Being prescribed a new medication or course of treatment	56
Dealing with an ongoing medical condition, such as diabetes or high blood pressure	47
Having unanswered questions after a doctor’s visit	47
Deciding to change your diet or exercise habits	46
Being a caregiver to someone else	38

Source: Pew Internet & American Life Project Health Callback Survey, June 19-Aug. 6, 2001. Margin of error is ±4%.

seekers sought information about a specific surgical or diagnostic procedure. Ten percent of health seekers went looking for basic health care news.

Part Four: Evaluating the quality of health information

The recommended way to assess medical material

A substantial majority of health seekers do not follow the verification protocols recommended by experts such as the Medical Library Association when searching for information. The MLA recommends that searchers identify each site’s sponsor, check the date of the information posted, and verify that the material is factual information, not opinion. The California HealthCare Foundation recommends that consumers take ample time to search for health advice, visit four to six sites, and discuss the information with a health care provider before making a treatment decision. Advocates for privacy, such as the Center for Democracy and Technology, recommend reading a site’s privacy policy very carefully – and writing a protest email to any site that doesn’t post a policy.

In fact, most health seekers go online without a fixed destination in mind. The typical health seeker starts at a search site, not a medical site, and visits two to five sites. 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.

Respondents seemed to fall into three groups – about a quarter of them are vigilant about verifying a site’s information, another quarter are concerned but follow a more casual protocol, and about half mostly avoid the kind of search strategies experts recommend. And although health seekers are generally wary about revealing their identity online or having their activities tracked, only about one in five have checked a site’s privacy policy.

Health seekers’ basic presumptions

Health seekers generally start their searches in a confident frame of mind – and this might be the reason that so many avoid digging into the background of the information they are retrieving. Fully 72% of health seekers say you can believe all or most of the health information online. Part of the reason for their upbeat assessment might stem from the fact that 69% of health seekers say they have not seen any wrong or misleading health info on the Web – although 28% of health seekers have seen bad information. It should be noted that consumers’ radar is not as highly tuned as a health professional’s –

Evaluating Information	
<i>Why some have turned away from a health information site.</i>	
<i>Health Seekers</i>	<i>%</i>
Site was too commercial	47
You couldn't determine the source of the information	42
You couldn't determine when information was last updated	37
Site lacked endorsement of a trusted independent organization	30
Site appeared sloppy or unprofessional	29
Site contained information you knew to be wrong	26
Information disagreed with own doctor's advice	20

Source: Pew Internet & American Life Project Health Callback Survey, June 19-Aug. 6, 2001. Margin of error is ±4%.

consumers may not be aware of what is *not* readily found on the Web. It also could be the case that health seekers are so pleased with the convenience of getting health information online that they forgive any shortcomings of online medical advice. In our August 2000 survey, 93% of health seekers said it is important that they can get health information when it is convenient for them. One focus group participant said the Internet makes it “so easy to look up things” and “go deeper into the problem” that she frequently uses it to check her doctor’s diagnosis or her mother’s advice.

If it fits with what they’ve already heard, they believe it

In most cases, health seekers decide to believe what they read online because it fits with the facts they already know. Nine out of ten health seekers who found the information they were looking for the last time they searched said the health information mostly agreed with what they already thought or knew. Only 4% of successful searchers said the information mostly disagreed with what they knew, and 7% of successful searchers said they found information that both agreed and disagreed with what they knew. In an online focus group, one participant said, “When I had surgery I found a lot of information that corresponded with what the doctor had told me. It made me feel more at ease.” Another participant living with a chronic disease explained why he continues to read and re-read online health information, saying, “I want to read everything I can locate regarding my disease on any site I locate. [It] is mostly rehashing but [I] often find a new tidbit or two.”

At the same time as they are relying on online information that confirms what they already believe, most health seekers also pick up new insights about medical conditions or treatments when they do their searches. Eight out of ten successful searchers said they learned something new the last time they went online for health information.

When they read the same facts at different sites, health seekers’ trust in those sites grows

If a site confirms what they already know or they found similar information on multiple sites, health seekers were more confident in those sites. Of the health seekers who visited two or more sites during their last search and found what they were looking for, two thirds (67%) say the multiple sites provided mostly the same information. A majority of multiple-site searchers who found similar information on different sites say the similarities gave them more confidence in the sites – 49% say it gave them a lot more confidence, 38% say it gave them a little more confidence. Eleven percent of multiple-site searchers who saw similar information say it did not give them more confidence.

A participant in an online focus group said that he trusts information more if he sees it on more than one site, saying, “There is a lot of bogus info out there but at least it is a starting point.” Another participant said, “On the Internet you can get four or fifty different opinions and if they are all the same advice your doctor gave you, you can relax and not wonder if he was right or if his info is dated.”

It is important to note that some health-related content is syndicated and may appear on multiple sites. Consumers may think they have verified a piece of information by reading

two sources, but in fact may have simply re-read the same material from the same syndicate at two different Web sites. For example, Well-Connected reports about common diseases and wellness issues have appeared on WebMD, CBS HealthWatch, MDConsult.com, and Discovery Health.⁶

One third of multiple-site searchers (30%) say the different Web sites they visited provided different information. The fact that they found different information at different places had a smaller effect on health seekers than the similarity of information had on searchers. One fourth of multiple-site searchers who had found differing opinions say the differences gave them less confidence in the Web sites – 6% say it gave them a lot less confidence and 17% say it gave them a little less confidence. Three-quarters of these multiple-site searchers (76%) say it did not give them less confidence in the sites. Perhaps this reflects recognition by health seekers that there is often not uniform advice from the medical establishment about how to treat some medical conditions.

Health seekers' information assessment screens

Other researchers have spelled out the factors that potentially affect a user's decision to visit a certain Web site. For example, the Utilization Review Accreditation Commission (URAC), a nonprofit accreditation organization, asked health seekers to rate the importance of various features to be found on health Web sites. Its survey found that a "seal of approval," links to related sites, interactive tools, and a list of sponsors would increase consumer trust in a health Web site.⁷ In a more general survey conducted for Consumer WebWatch, 80% of Internet users said it is "very important" that a site is easy to navigate. Just 19% of Internet users said that a seal of approval is "very important" when it comes to deciding whether to visit a site.⁸

Since many surveys have asked questions in the abstract ("Which of the following do you think is the most important attribute for a health related Web site to have?"), we decided to ask health seekers to describe steps they had actually taken to check facts or reject a Web site's advice.

When users are asked about the reasons they have rejected information from a health Web site, many report that they have taken the expert advice to heart. They turn away from sites that do not identify the source or date of the information. But they add a few tests of their own. E-patients say that overt commercialism is the No. 1 reason they have turned away from a site. Forty-seven percent of health seekers have decided not to use information they found because the Web site was too commercial and seemed more concerned with selling products than providing accurate information.

In the Harris Online focus group, health seekers were asked what factors make them feel a particular resource is not trustworthy. An overabundance of advertising, particularly

⁶ See <http://www.well-connected.com/rreports/doc999full.html>

⁷ URAC/Harris Interactive, "Consumers and Health Web Sites," May 17, 2001.

⁸ Princeton Survey Research Associates, "A Matter of Trust: What Users Want From Web Sites," April 16, 2002. Available at: http://www.consumerwebwatch.org/news/1_abstract.htm

“pop-up” ads, made a few participants’ lists of negative factors. One woman took a hard line and said, “If a site has a shopping cart I don’t go back.”

Health seekers also pay attention to what many experts believe is one of the most important factors in judging the quality of online health information – they look for the source.⁹ Forty-two percent of health seekers have turned away from online information because they couldn’t determine the source or author of the information. Not every e-patient looks for the source every time she goes online, however. When asked if they check the source, 58% of health seekers who go to multiple health Web sites say they do so “most of the time” or “always.” Fifty-five percent of health seekers who consult one favorite site say they have checked the source of the information on that site. When thinking about what would make him trust a site, one focus group participant said he looks for the name of “a reputable doctor that I have seen on television or who has printed articles in notable journals.”

Men are more likely than women to blame a site’s sloppy or unprofessional design as the reason for turning away from the information. Younger health seekers are also more influenced by the site’s design than older users. Otherwise, there were no notable differences among demographic groups for the other information quality signals.

Commercialization and search engines

Overt commercialism erodes the credibility of health sites, but what about subtler influences? Consumer WebWatch, a project partly funded by the Pew Charitable Trusts, found that only 39% of Internet users knew that some search engines are paid to list some sites more prominently than others. When told about the practice, 80% of Internet users said it was important for search engines to disclose these arrangements. But only 30% of Internet users said they are less likely to use a search engine that accepts money to promote certain sites and fully 56% of Internet users said it makes no difference to them.¹⁰

A typology of health seekers

Vigilant health seekers

About one quarter of health seekers say they always check the source, date, and privacy policy on a health Web site. These Vigilant health seekers are more likely than other types of health seekers to say the Internet has improved the way they take care of their health – 72%, compared with 63% of Concerned health seekers and 54% of Unconcerned health seekers. This group seems to approach the search for health information quite methodically, trusting search engines to some degree, but clicking on a recognized name more often than the other two groups. Vigilant health seekers are more likely to take their time and visit many sites during a typical search. Seventy percent of Vigilant health seekers spent more than half an hour online during their last foray, compared with 52% of Unconcerned health seekers who devoted that much time. Thirty-one percent of Vigilant

⁹ See the Medical Library Association’s “Guide to finding and evaluating health information on the Web” at the end of this report.

¹⁰ Princeton Survey Research Associates, see note 8 above.

health seekers went to four or five sites the last time, compared with 16% of Unconcerned health seekers who did the same. Vigilant health seekers are by far the most likely to talk to a health care professional about what they found online – 51% of Vigilant health seekers did so the last time they searched for health information, compared with 25% of Unconcerned health seekers.

Concerned health seekers

Another one quarter of health seekers say they check the source, date, and privacy policy of a health Web site “most of the time.” This group seems to trust the search engines to return good results more than the other two groups. Concerned health seekers are the most likely to start at the top of the search results list instead of reading the explanations or looking for a trusted name.

Concerned health seekers are as likely as Vigilant health seekers to go online because they are dealing with an ongoing medical condition. Concerned and Vigilant health seekers are also equally likely to have turned away from a health site because they could not determine the source or author of the information.

Unconcerned health seekers

About half of all health seekers say they check the source, date, and privacy policy of a health Web site “only sometimes,” “hardly ever,” or “never.” They are the least likely to say the Internet has improved the way they take care of their health. Unconcerned health seekers are the least likely group to be living with a chronic illness like diabetes or high blood pressure. Unconcerned health seekers are, not surprisingly, the least likely to have turned away from a health site because they could not determine the source or author of the information – 31%, compared with 52% of Vigilant health seekers. Unconcerned health seekers seem to be in a hurry – they are more likely than the other groups to visit between one and three sites and to spend less than half an hour on a typical search for health information. Unconcerned health seekers are also the least likely to talk to a medical professional about what they found online.

Health seekers still rely on doctors for guidance and fact-checking

A small minority of health seekers is going online instead of seeing a doctor. Fourteen percent of health seekers say they’ve gone online because they didn’t have time to see a doctor. Eight percent say they have gone online because they couldn’t get a referral or an appointment with a specialist. Asked in a different way, a total of 18% of health seekers say they have gone online to diagnose or treat a medical condition on their own, without consulting their doctor. Those who have been treated for a serious illness in the past year are more likely to use the Internet to self-diagnose, as are those who have gone to the doctor at least once in the past year, so these are not necessarily people who reject a doctor’s advice altogether. They are supplementing their care with advice gleaned from the Internet. For example, one focus group participant who is living with a chronic illness said that he finds health Web sites “help clarify some of the things I don’t quite understand” after a doctor’s appointment.

However, another participant in an online focus group lauded the Internet's ability to help him avoid the doctor's office: "When I get sick, I know what to do to get rid of the cold without going to the doctor." Another said, "I don't see a doctor unless I am really sick. If I have any questions I check out Internet sites."

After their most recent health search, more than one third of successful searchers (37%) talked to a doctor or other health care professional about the information they found online. Two thirds of successful searchers (63%) said they did not talk to a health care professional about what they found – mostly because the health seeker deemed the topic too insignificant to seek expert advice. This finding is consistent with an August 2000 Pew Internet Project survey and may reflect consumers' confidence in their decision-making abilities rather than a fear of rejection by their doctor or their rebellion against a doctor. Just 2% of those who did not talk to a doctor say it was because they didn't think their doctor would listen.

Indeed, health professionals seem to be receptive to those consumers who bring in the information they find online. Thirty-one percent of those who talked to their doctor say he was "very interested" and 48% say their doctor was "somewhat interested" in the information found online. Just 13% of successful searchers who chose to talk to their doctor got the cold shoulder and report that the health care professional was "not too interested" or "not at all interested." Despite the American Medical Association's cautions to consumers against online information¹¹, a 2001 Harris Interactive poll¹² found that doctors are using the Internet to increase their medical knowledge and improve the care they provide to patients. It is therefore not surprising to hear that more and more doctors are receptive to patients going online to gather more information.

When we asked focus group participants about their relationships with their doctors, most confirmed the positive trend toward receptive doctors. One participant said he talks to his doctor about what he finds online because "sometimes I just need his reassurance I interpreted my info correctly." However, another participant had a different experience when she brought in Web printouts, relating that her doctor "got mad, like I didn't trust him. Actually, I didn't. So I changed doctors."

Health care professionals also were likely to agree with the information a successful searcher found online. Eighty-two percent of health seekers who discussed what they found with a health care professional said the doctor or nurse agreed with the information.

Health seekers who say the Internet has improved the way they take care of their health are more likely to talk with a doctor about what they found online. Forty percent of these enthusiastic health seekers did so, compared with 30% of those who are less keen on Internet health information.

¹¹ See <http://www.ama-assn.org/ama/pub/category/1905.html>

¹² "The Increasing Impact of eHealth on Physician Behavior," Harris Interactive Health Care News, Volume 1, Issue 31, November 13, 2001.

Of the 63% of successful searchers who did not talk to a health care professional about what they found, 43% say the topic wasn't a health issue that required a visit or phone call with a doctor. Seventeen percent say they had done the research on someone else's behalf and therefore did not discuss it with a health professional. Twelve percent say they didn't think the information was worth mentioning. Eight percent say they were checking on their doctor's diagnosis, so they already had his or her opinion on the topic. For example, one participant in an online focus group said she usually goes to see her doctor when she's not feeling well and then goes online "to see if he is on track with his information."

Seven percent of successful searchers who did not talk to a health care professional about what they found say they haven't had time to see the doctor about it yet. Small numbers of health seekers say they forgot to bring it up, thought the doctor wouldn't listen, or say it was too difficult to talk about with a health care professional.

Part Five: Results

Successful searches

Eight in ten health seekers found most or all of the information they looked for online the last time they searched. Fourteen percent of health seekers say they just ran out of time and had to stop looking, whether or not they had all the answers they needed. A very small minority of health seekers (6%) said they couldn't find the information they were looking for and gave up.

Successful Searchers			
<i>Younger health seekers are more likely to say they find the health information they are looking for online</i>			
	18-29	30-49	50-64
Found most or all the information last time you searched	84%	79%	74%
Always find the information you are looking for	37	23	19

Source: Pew Internet & American Life Project Health Callback Survey, June 19-Aug. 6, 2001. Margin of error is ± 4%.

Age is a factor associated with successful searching. The youngest health seekers (18-29 years old) are more likely to say they "always" find the information they are looking for online. Younger users are no more likely to have found one favorite site or other stratagem – they were easier to please, more confident of their search skills, or both.

Health seekers who are living with a chronic disease or disability are most likely to say they gave up before finding the right information, possibly because they are looking for more detailed or rarer kinds of material. Success did not depend on whether the health seeker has one favorite site or visits many different sites – the vast majority of both groups found what they were looking for.

Health sites please users more than they please health care professionals. The results of the California HealthCare Foundation/RAND study demonstrated those concerns: "Only half of the topics that the expert panels thought were important for consumers were

covered more than minimally.”¹³ In addition, they found that most of the content was written at a high school or college reading level – much higher than the sixth-grade reading level recommended by experts concerned about consumers’ ability to understand the information. However, some of our respondents suggested that high-level writing may inspire trust in the site. One participant in our online focus group said, “When I can only half understand what they’re saying, I start to feel they’re competent.”

The vast majority of health seekers who found the information they were looking for said it was easy to find – 61% said it was “very easy” and 33% said it was “somewhat easy.”

The California HealthCare Foundation/RAND study recommends spending at least 30 minutes on a search to be sure a health seeker has delved deeply into a topic. During a typical search, most health seekers exceed the recommended time allowance. The last time they went online for health information, 12% of health seekers spent less than 15 minutes and 27% spent between 15 and 30 minutes. Thirty-five percent of health seekers spent between a half hour and an hour online. Nineteen percent of health seekers spent one to two hours online and 7% spent more than 2 hours online the last time.

The last time they went online for health information, 51% of successful searchers said they found the information they needed on a site they were already familiar with or had used in the past. Forty-four percent of successful searchers said they found the information on a site they had never heard of before. Three percent of successful searchers said they had found the information on both familiar and unfamiliar sites.

Those in excellent health are more likely to have chanced upon relevant health information – probably because they do not need to search very frequently and are less familiar with health sites. Those in less-than-excellent health are more likely to have visited a familiar site and found what they needed, as are people who search for health information more frequently.

¹³ Berland (2001).

Part Six: Impact

In a survey in January 2002, we asked Internet users whether they themselves had dealt with an illness in the past two years. Seventeen percent said yes, and about one in four of those Internet users say the Internet played a key role in the way they took care of themselves. Women were twice as likely as men to report that their use of the Internet played an important or crucial role in their coping with sickness. And those aged 50-64 were more likely than other age groups to report a significant impact from their use of the Internet.

In our special survey of health seekers, 61% of respondents say the Internet has improved the way they take care of their health either “a lot” or “some.” This is a significant increase from an August 2000 Pew Internet Project poll that found that 48% of health seekers said the Internet improved the way they take care of themselves. Indeed, about 45 million Americans now say the Internet has improved the way they take care of their health, compared with 25 million Americans who said that in August 2000.

Health information’s impact

Health seekers are mostly going online to look for specific answers to targeted questions. Often, this information helps them make informed decisions, but it rarely induces them to make a wholesale change in their approach to health care.

Most of those who have completed successful searches report that the impact of those searches was modest. Of the health seekers who found the information they needed the last time they went online for medical advice, 16% say the information had a major impact on their own health care routine or the way they care for someone else; 52% say the information had a minor impact; 31% say it had no impact at all. The impact was equally felt among all groups – old, young, men, women, college-educated or not. Those who searched on behalf of a loved one were as likely to say the information had an impact as those who searched for answers to their own health questions.

Information’s Impact	
<i>Successful searchers who say online health information...</i>	%
Affected a decision about how to treat an illness or condition	44
Led them to ask a doctor new questions or get a second opinion	38
Changed approach to maintaining own health or health of someone they care for	34
Changed the way they think about diet, exercise, and stress	30
Changed the way they cope with a chronic condition or manage pain	25
Affected a decision about whether to see a doctor or not	17

Source: Pew Internet & American Life Project
Health Callback Survey, June 19-Aug. 6, 2001.
Margin of error is ±4%.

In an online focus group, one participant said online information helped identify a major neck problem that a doctor later confirmed. Yet another participant said she turned to the Internet after a “painful joint replacement in my foot. I [then] knew about the recovery period and what I could or could not do.”

Of the successful searchers, 44% said the information they found online affected a decision about how to treat an illness or cope with a medical condition. Again, there was no significant difference between those who searched on behalf of someone else and

those who searched on behalf of themselves. The only topics that prompted dramatically different answers from these two groups were diet, exercise, and stress. Forty-one percent of health seekers looking for information for themselves say they changed the way they think about diet, exercise, and stress based on what they found online. Just 20% of health seekers looking on behalf of someone else felt the same way.

About one in three health seekers know someone who has been significantly helped by following medical advice or health information they found on the Internet. Fittingly, those most in need are most likely to reap the benefits of online health information. Fully 51% of those who have been treated for a serious illness in the past year say they or someone they know was significantly helped by following advice they found on the Internet.

In an online focus group, one woman said, “When I was pregnant, [online health information] eased my worries, making it an easier and less stressful pregnancy.” Based on what she read online about the risks and trade-offs of prenatal testing, this health seeker decided not to go through with amniocentesis to find out if the baby had Down’s syndrome.

Another focus group participant, who is living with a chronic condition, found that online research improved her quality of life in ways that her doctor deemed too insignificant to mention. “My hair fell out in gobs for years,” she said. “I found out on the Web that the medication I was on did that. Only then did [my doctor] say yes, he knew it could do that. I had told him previously about the hair loss.” This focus group participant was unhappy that her doctor had omitted key information from their conversations, but she was grateful to members of her online support group who posted the truth.

Just 2% of health seekers know someone who has been seriously harmed by following medical advice or health information they found on the Internet. While this small number may cheer advocates of online health information, it serves as a warning for e-patients who may rely too heavily on the advice they find on the Web. For example, in a case reported in the March 2002 issue of *Pediatrics*, a one-year-old boy suffering from diarrhea was brought to an emergency room. A clinician incorrectly advised his parents to stop giving him solid foods, but to provide fluids for rehydration. The parents independently searched online and found similar advice on an unidentified Web site, so they continued the treatment recommended at the hospital. Over the next few days, the child became increasingly weak and eventually was admitted to the hospital, where he recovered.¹⁴ Of course, it was a medical professional who made the first mistake, but the inaccuracy on the Web site exacerbated the problem.

¹⁴ Reported in iHealthBeat on March 28, 2002. Available at <http://www.ihealthbeat.org>.

Part Seven: Email, support groups, and personalization

Few go beyond Web searching

Most health seekers stuck to Web searching the last time they went online for health information, but 3% communicated online with a health care professional, such as a doctor or nurse. Another 3% communicated with a Webmaster of a particular health Web site, while yet another 3% communicated with members of an online support group at some point in their last online search.

These small numbers are consistent with an August 2000 Pew Internet Project survey which found that 9% of health seekers said they had ever used email or gone to a Web site to communicate with a doctor or a doctor's office. However, when asked if they would like to communicate with their doctor online, health seekers in an online focus group were very receptive – as long as the doctor actually replied in a timely manner. As one man who does exchange email with his doctor said, "It is faster to call." A 2002 Harris Interactive poll found that 90% of Internet users would like to email their doctor's offices – and 37% would be willing to pay for the service.¹⁵ As further evidence that email is gaining a foothold, a 2001 Harris Interactive poll found that many doctors were initially skeptical about the benefits of online tools, but were pushed by patients to start using email and now say it has increased patient satisfaction.¹⁶

Just one in ten health seekers has ever participated in an online support group or email list for people concerned about a particular health or medical issue. This activity showed little increase from last year – in both the August 2000 and June-August 2001 surveys, 9% of health seekers say they have ever participated in an online support group. Frequent health seekers are more likely to have joined an online support group – 13% of those who look for health information several times a month or more have done so, compared with 6% of those who look every few months or less.

In an online focus group discussion about why they do not participate in support groups, health seekers cited privacy concerns and the need for a "loving voice" instead of an on-screen note. One woman said, "It seems a bit personal to be chatting about things like that, plus you are exposed in a way on the Internet. Anyone could see what you wrote. Confidentiality is a real big thing with me." But other participants say the benefits outweigh the risk, and one argued, "But it's not like they know you, or will ever see you, so why not?"

Though the numbers are small, those who are most in need are more likely to take advantage of online support groups. Ten percent of health seekers in fair or poor health consulted an online support group the last time they searched for health information, compared with just 1% of those in excellent health. And 14% of those in fair or poor health have ever participated in an online support group, compared with 5% of those in excellent health.

¹⁵ Harris Interactive Health Care News, Volume 2, Issue 8, April 10, 2002.

¹⁶ Harris Interactive Health Care News, Volume 1, Issue 31, November 13, 2001.

Instead of treating the Internet as a vast library, some health seekers are joining online communities that allow them to provide support and keep up with the latest research. In an online focus group, one man living with emphysema said he spends eight hours per day online, scouring Web sites and passing on his knowledge to other members of his online support group, Efforts.¹⁷ He is grateful to the group for giving him hope, especially in the early days of his diagnosis, saying, “Knowledge is key in living with a progressive and fatal disease. I know pretty much what will take my life. Now I am learning how to hold it off.” Another focus group participant's sister has epilepsy and was thinking about getting pregnant, so they dropped into an epilepsy support group to get advice before talking to her doctor about it. Indeed, 33% of health seekers have looked for information about a sensitive health topic that is difficult to talk about – some people feel more comfortable asking strangers or believe that someone who has been in their situation will advise them better than a health professional can.¹⁸

There is evidence that peer support can not only improve the way someone feels but cut costs as well. A randomized study of 580 people with chronic back pain showed that those who participated in an email discussion group with other patients and three expert moderators experienced less pain and saw their doctor less than those who did not participate.¹⁹

“Online patient-helpers” can work in concert with a doctor’s advice to improve care, as well. For example, Karen Parles, who did not smoke, was shocked by a diagnosis of terminal lung cancer at the age of 38. A librarian, she used her skills to research a new treatment and to share her concerns with an online support group, the Lung-Onc mailing list. Group members reassured her about lung surgery and gave her tips on how to sleep on sore ribs during recovery. After going through successful treatment for her own cancer, Parles created a clearinghouse of online information so that others could benefit from her research: lungcanceronline.org. Most Americans will hopefully never need such specialized resources – indeed few health seekers have sought out such support online – but those who do use it are forever grateful.²⁰

Few take advantage of personalization

Only 8% of health seekers have set up a personal profile at a favorite health Web site or customized a health Web site so they receive only the information they are most interested in. Those who saw a doctor in the past year are more likely to have personalized a health Web site, as are those who believe the Internet has improved the way they take care of their health.

¹⁷ <http://www.emphysema.net/>

¹⁸ “E-Patients Prefer eGroups to Doctors for 10 of 12 Aspects of Health Care,” published in The Ferguson Report, Number 1, March 1999. Available at <http://www.fergusonreport.com/archives/idx9903.htm>

¹⁹ Kate R. Lorig et al., “Can a Back Pain E-mail Discussion Group Improve Health Status and Lower Health Care Costs?” Archives of Internal Medicine. April 8, 2002. Vol. 162, No. 7. Available at <http://archinte.ama-assn.org/issues/v162n7/abs/loi10219.html>

²⁰ Adapted from “Online Patient-Helpers and Physicians Working Together,” by Dr. Tom Ferguson, which appeared in the British Medical Journal on November 4, 2000. Available at <http://bmj.com/cgi/content/full/321/7269/1129>

About 14 million Americans, or one fifth of all health seekers, have ever signed up for an electronic newsletter that emails the latest health news or medical updates. Those in fair or poor health are more likely to do so – 30% have signed up, compared with 17% of those in good health and 16% of those in excellent health. Those who have seen a doctor in the past year are more likely to have signed up, as are those who believe the Internet has improved the way they take care of their health.

Part Eight: Health searches for someone else

Searching on behalf of someone else

In January 2002, we conducted a national survey of Internet users, asking if they had helped another person deal with a major illness or health condition in the last two years. A substantial 39% of Internet users said yes, they had done that, and about one in four say their use of the Internet played a key role in the way they took care of that loved one. Therefore, it is not surprising that a large subset of health seekers are those who have gone online because someone they know was diagnosed – 81% of health seekers are included in this group. Indeed, the “last time” they went online for health information, 50% of all health seekers searched on behalf of someone else and 47% were looking for information for themselves. Another 2% of health seekers went online to do health research the last time, not necessarily with anyone in mind.

Health seekers take responsibility for all sorts of relatives and friends. Ten percent of health seekers searched on behalf of a child the last time they went online for medical advice, 10% for a spouse, 9% for a parent, 10% for another relative, 8% for a friend, 2% for a patient or client, and 1% for someone else. Those in the middle age groups are more likely than those in their twenties or senior citizens to search on someone else’s behalf. Men are more likely than women to do a health search for their spouse or partner.

E-patients whose last search was on someone else’s behalf were more likely to be problem solving or reacting to a specific situation than those who were looking on their own behalf. Seventy-two percent of “for someone else” health seekers looked for information about a specific illness or condition compared with 53% of “self” health seekers. More “for someone else” health seekers looked for information about cancer and a certain treatment or medication, which supports the notion that a community often coalesces around someone who is dealing with a chronic illness like cancer. Friends and family educate themselves, forming an ad hoc support group. Indeed, these “for someone else” health seekers encompass a wider population than just parents and direct caregivers for the chronically ill. Focus group participants said they had searched for all sorts of people – a roommate with heartburn, a sister with skin problems, a mother who needed diabetic recipes, and a friend whose child was recently diagnosed with attention-deficit disorder. Said one participant, “I went to Ask Jeeves to find out about some symptom my mom was having and it described the symptoms as that of an ulcer-related problem. She went to the doctor and sure enough, she had three of them!”

Even e-patients living with a chronic illness become information gatekeepers for their friends and family and therefore caregivers in their own way. One chronically ill focus group participant said she searches on behalf of family members, including an adult daughter who has lupus.

Continual caregivers

Thirty-eight percent of health seekers have gone online for health information because they are caring for someone else. This is a different group from those who told us that they occasionally searched for someone else. Not surprisingly, women and people in the “sandwich generations” are more likely to identify themselves as caregivers. Forty-one percent of women health seekers have gone online as a caregiver compared with 33% of men. Thirty percent of health seekers in the 18-29 age cohort have gone online as a caregiver, compared with 43% of 30-49 year-olds, 38% of 50-64 year-olds, and just 13% of health seekers over the age of 65. As an illustration of the “sandwich generation” dilemma, one focus group participant had recently looked up teething information for his baby and disease information for his father.

One in ten health seekers lives with someone who has a disability, handicap, or chronic disease. These caregivers are likely to act on what they find online and are more likely than non-caregivers to research drugs or alternative therapies online. Caregivers are almost twice as likely to ask a doctor new questions based on what they find online and are more likely to say they have been “significantly helped” by online health information. Indeed, the Internet had played an important or even crucial role for 25% of Internet users who had helped another person deal with a major illness in the past two years.

Parents

Four in ten health seekers are the parent or guardian of children under age 18, living at home. (Note that parents are no more likely to be health seekers than non-parents – about four in ten Internet users are parents.) Parents seem to take their health research responsibilities quite seriously, but may not adhere to all the search and validation strategies recommended by experts. For example, parents are less likely than non-parents to look to see who provides the information on a health Web site. However, parents are more likely than non-parents to visit four or five sites and to spend more time online during a search (usually between 30 minutes and an hour). Parents are also more likely than non-parents to talk to their doctor about what they found online. Parents take a more deliberative approach to search engine results and are more likely to read the explanations of a search engine result instead of just starting at the top and working down.

In an online focus group, parents gave a range of reasons for going online for health information. One mother said she uses the Internet to try to “avoid lugging four kids to the doctor for something that I can take care of with over-the-counter medication.” Another mother goes online to see if her teenager is faking his illness to avoid school – if his symptoms check out, she takes him to the doctor. But someone else sounded a note of caution, saying, “If it's the kids, then doctor is first.” All of the parents in the focus group said they appreciated knowing more about what to expect about their child's

illness, whether it was a teenager's mononucleosis, a baby's croup, or a young athlete's torn ligament. These parents say they research homeopathic cures and ways to prevent illness, often starting at a search engine and then checking the information against what they find at trusted sites like WebMD, Babycenter.com, or Kidsdoctor.com. The repetition of information makes them feel it's on target – or at least a starting point for further discussions with their doctors.

Appendix

Editor's note: Since this report raises so many questions about how consumers search for health information online, we asked the Medical Library Association to provide not only a guide to finding information but also examples of the best health Web sites their librarians have found. Included in this guide are general starting points as well as specific sites for cancer, diabetes, and heart disease.

Medical Library Association: **A User's Guide to Finding and Evaluating Health Information on the Web**

Millions of Americans search for health information on the Web every year. Whether the health information is needed for personal reasons or for a loved one, millions of health-related Web pages are viewed by millions of consumers. Sometimes the information found is just what was needed. Other searches end in frustration or retrieval of inaccurate, even dangerous, information.

This guide outlines the collective wisdom of medical librarians who surf the Web every day to discover quality information in support of clinical and scientific decision making by doctors, scientists, and other health practitioners responsible for the nation's health. This guide is supported by the Medical Library Association (MLA), the library organization whose primary purpose is promoting quality information for improved health and whose members were the first to realize that not all health information on the Web is credible, timely, or safe.

The guide is presented in three brief sections. The first section, "Getting Started," provides tips on filtering the millions of health-related Web pages through the health subsets of major search engines and using quality electronic finding tools developed by the U.S. government to do an initial screen of Web sites for further examination. This section is followed by a set of guidelines developed for evaluating the content of health-related Web sites. The final section provides additional information of interest to consumers searching for health-related information on the Web.

Getting Started

As many people have discovered, clicking on a favorite search engine and entering a disease or medical condition can often result in hundreds, even thousands, of "hits." This can be discouraging. Here are a few ideas for filtering the available Web pages to a manageable number:

1. If you are using a search engine such as Google or Yahoo, take advantage of the health subsets of these services for your search. Learn how to use the advanced searching features of the sites so that you can combine terms to make your retrieval more precise. For example, entering the term "cancer" and "chemotherapy" linked together is more powerful and precise than trying

to read through all the hits found by simply entering the general term “cancer.”

2. Become familiar with the general health information finding tools such as [MEDLINEPlus](http://www.medlineplus.gov) (<http://www.medlineplus.gov>), produced by the National Library of Medicine, or [Healthfinder](http://www.healthfinder.gov) (<http://www.healthfinder.gov>), from the U.S. Department of Health and Human Services, which can get you started by pointing you to good, credible health information quickly. The [Medical Library Association's "Top Ten" list](http://www.mlanet.org/resources/medspeak/topten.html) (<http://www.mlanet.org/resources/medspeak/topten.html>) is another device to help you start your search with a highly selective list of quality health information sites trusted by medical librarians.
3. When you have found sites that look relevant, use the guidelines below to help you decide whether the information is as credible, timely, and useful as it looks.

Content Evaluation Guidelines

1. Sponsorship

- Can you easily identify the site sponsor? Sponsorship is important because it helps establish the site as respected and dependable. Does the site list advisory board members or consultants? This may give you further insights on the credibility of information published on the site.
- The Web address itself can provide additional information about the nature of the site and the sponsor's intent.

A government agency has **.gov** in the address.

An educational institution is indicated by **.edu** in the address.

A professional organization such as a scientific or research society will be identified as **.org**. For example, the American Cancer Society's Web site is <http://www.cancer.org/>

Commercial sites identified by **.com** will most often identify the sponsor as a company, for example Merck & Co., the pharmaceutical firm.

- What should you know about **.com** health sites? Commercial sites may represent a specific company or be sponsored by a company using the Web for commercial reasons – to sell products. At the same time, many commercial Web sites have valuable and credible information. Many hospitals have **.com** in their address. The site should fully disclose the sponsor of the site, including the identities of commercial and noncommercial organizations that have contributed funding, services, or material to the site.

2. Currency

- The site should be updated frequently. Health information changes constantly as new information is learned about diseases and treatments through research and patient care. Web sites should reflect the most up-to-date information.
- The Web site should be consistently available, with the date of the latest revision clearly posted. This usually appears at the bottom of the page.

3. Factual information

- Information should be presented in a clear manner. It should be factual (not opinion) and capable of being verified from a primary information source such as the professional literature, abstracts, or links to other Web pages.
- Information represented as an opinion should be clearly stated and the source should be identified as a qualified professional or organization.

4. Audience

- The Web site should clearly state whether the information is intended for the consumer or the health professional.
- Many health information Web sites have two different areas – one for consumers, one for professionals. The design of the site should make selection of one area over the other clear to the user.

Additional Help

The [Health on the Internet Foundation Code of Conduct](http://www.hon.ch/HONcode/) (HONcode) for medical and health Web sites (<http://www.hon.ch/HONcode/>) specifies eight principles intended to hold Web site developers to basic ethical standards and to make sure consumers always know the source and purpose of the data they are reading. Participation is voluntary throughout the world, but sites displaying the foundation's symbol are generally considered credible sources of information. Unfortunately, the number of sites participating is small.

Much of the health-related information that you find may seem to be written in a foreign language because of the highly technical terminology used in the health professions. To

help you use and understand medical terminology on the Web, the Medical Library Association has published a brochure called "Deciphering Medspeak" which is available without charge in individual copies from the Medical Library Association by sending an email to info@mlahq.org or by visiting the MLA Web site at www.mlanet.org. For bulk orders, please call 312-419-9094, Ext. 14, or email mlafa@mlahq.org.

Health sciences librarians at hospitals and academic medical centers throughout America stand ready to help consumers with do-it-yourself search assistance or will assist by performing professional searches of the Web for consumer and professional medical literature. If you don't know whether your community has a health sciences library, please call the Medical Library Association at 312-419-9094.

Medical Library Association "Top Ten" Most Useful Consumer Health Web Sites

[Centers for Disease Control and Prevention](http://www.cdc.gov/) (<http://www.cdc.gov/>), an agency of the Department of Health and Human Services, is dedicated to promoting "health and quality of life by preventing and controlling disease, injury, and disability." Of special interest to the consumer are the resources about diseases, conditions, and other special topics arranged under "Health Topics A-Z," and "Travelers' Health," with health recommendations for travelers worldwide. There are also sections on health topics in the news and health hoaxes. Information is also available in Spanish.

[Healthfinder](http://www.healthfinder.gov) (<http://www.healthfinder.gov>) is a gateway consumer health information Web site whose goal is "to improve consumer access to selected health information from government agencies, their many partner organizations, and other reliable sources that serve the public interest." Menu lists on its home page provide links to online journals, medical dictionaries, minority health, and prevention and self-care. The developer and sponsor of this site is the Office of Disease Prevention and Health Promotion, Department of Health and Human Services, with other agencies that also can be linked to via the site. Access to resources on the site is also available in Spanish.

[HealthWeb](http://healthweb.org) (<http://healthweb.org>) is a site established by librarians and information professionals from major academic medical institutions in the Midwest. Consumers can search the site either by entering search terms or by selecting one of the many alphabetically listed medical subjects. When a medical subject is selected, users can go into more depth by using the left side of the screen to select narrower subjects or categories. The site also provides "User Guides" developed to help consumers use Internet resources more effectively.

[HIV InSite](http://hivinsite.ucsf.edu/) (<http://hivinsite.ucsf.edu/>) is a project of the University of California San Francisco (UCSF) AIDS Research Institute. Designed as a gateway to in-depth information about particular aspects of HIV/AIDS, it provides numerous links to many authoritative sources. Subjects are arranged into "Key Topics" and the site may also be searched by key words. Many items are provided in full text, and information is available in English and Spanish.

[MayoClinic](http://www.mayoclinic.com) (<http://www.mayoclinic.com>) is an extension of the Mayo Clinic's commitment to provide health education to patients and the general public. Editors of the site include more than 2,000 physicians, scientists, writers, and educators at the Mayo Clinic, a nonprofit institution with more than 100 years of history in patient care, medical research, and education. A new format, which recently debuted, has added interactive tools to assist consumers in managing their health. This site supersedes the previous site, Mayo Clinic Health Oasis.

[Medem](http://medem.com) (<http://medem.com>), a new site launched in the fall of 2000, is a project of the leading medical societies in the United States. Some of the founding societies include the American Medical Association, the American Academy of Pediatrics, and the American College of Obstetricians and Gynecologists. The site was developed to provide "a trusted online source for credible, comprehensive, and clinical healthcare information, and secure, confidential communications." The "Medical Library" is divided into four major categories: Life Stages, Diseases and Conditions, Therapies and Health Strategies, and Health and Society.

[MEDLINEplus](http://medlineplus.gov) (<http://medlineplus.gov>) is a consumer-oriented Web site established by the National Library of Medicine, the world's largest biomedical library and creator of the MEDLINE database. An alphabetical list of "Health Topics" consists of more than 300 specific diseases, conditions, and wellness issues. Each Health Topic page contains links to authoritative information on that subject, as well as an optional link to a preformulated MEDLINE search that provides journal article citations on the subject. Additional resources include physician and hospital directories, several online medical dictionaries, and consumer drug information available by generic or brand name.

[National Women's Health Information Center](http://www.4women.gov/) (<http://www.4women.gov/>) is a gateway to selected women's health information resources. Its purpose is to provide a single site on the Web where women can locate reliable, timely resources about "prevention, diagnosis, and treatment of the illnesses and health conditions that affect them." It is sponsored by the U.S. Public Health Service's Office on Women's Health and provides access to a variety of women's federal and private-sector resources. An alphabetical "Health Topics" menu simplifies searching. Information is available in both English and Spanish.

[NOAH: New York Online Access to Health](http://www.noah-health.org/) (<http://www.noah-health.org/>) is a unique collection of state, local, and federal health resources for consumers. NOAH's mission is "to provide high-quality, full-text information for consumers that is accurate, timely, relevant, and unbiased." Information is arranged in alphabetical "Health Topics" which are then narrowed to include definitions, care and treatment, and lists of information resources. Information is available in both English and Spanish, and the majority of items are provided in full text.

[Oncolink^R : A University of Pennsylvania Cancer Center Resource](http://oncolink.upenn.edu) (<http://oncolink.upenn.edu>), provides information on the various forms of cancer and issues of interest to cancer patients and their families. The site may be searched by key

words or by menus, including disease-oriented menus and medical specialty-oriented menus. Major areas covered are cancer causes, symptom management, clinical trials, psychosocial support, cancer FAQs (frequently asked questions), and global resources for cancer information.

Medical Library Association Recommended Cancer Web Sites

[American Cancer Society](http://www.cancer.org) (<http://www.cancer.org>) supports education and research in cancer prevention, diagnosis, detection, and treatment. Its Web page provides news, information on types of cancer, patient services, treatment options, sections on children with cancer and living with cancer, and cancer statistics. Site is also available in Spanish.

[Association of Cancer Online Resources](http://www.acor.org) (<http://www.acor.org>) has a mission to provide "varied and credible" information to cancer patients and those who care for them through the "creation and maintenance of cancer-related Internet mailing lists and Web based resources." ACOR currently offers access to nearly 100 public email cancer support groups, as well as ACOR-supported Web sites.

[Cancer Care, Inc.](http://www.cancercare.org) (<http://www.cancercare.org>) is a nonprofit organization "whose mission is to provide free professional help to people with all cancers through counseling, education, information and referral, and direct financial assistance." Maintains links to support, educational, treatment, and information services. Site is also available in Spanish.

[CancerNet - National Cancer Institute](http://cancernet.nci.nih.gov) (<http://cancernet.nci.nih.gov>). Produced by the National Cancer Institute of the National Institutes of Health, it provides information on types of cancer; treatment options; clinical trials; genetics, causes, risk factors and prevention; testing; coping, and support resources. It also provides free access to the PDQ® and Cancerlit databases. Site is also available in Spanish.

[Families of Children with Cancer](http://www.fcco.org/resources.html) (<http://www.fcco.org/resources.html>), located in Toronto, Canada, is a support and advocacy group for families living with the effects of childhood cancer. Its Web page has a wide variety of links to Internet information sources on pediatric cancer including basic information, treatment and research centers, community organizations, personal Web pages, and a chat support line.

[Intercultural Cancer Council](http://icc.bcm.tmc.edu) (<http://icc.bcm.tmc.edu>). Produced at the Texas Medical Center in Houston, this Web page has as its goal the elimination of "the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States." It provides news, press releases, links to cancer information sites, and a calendar of upcoming events.

[Oncolink](http://oncolink.upenn.edu) (<http://oncolink.upenn.edu>) is a collection of Internet resources on the prevention and treatment of cancer maintained by the University of Pennsylvania Cancer Center. Includes news, book reviews, disease, and patient support links.

[Women's Cancer Network](http://www.wcn.org) (<http://www.wcn.org>) is the official site of the Gynecologic Cancer Foundation – physicians "dedicated to preventing, detecting and conquering cancer in women." It has information on the organization, the types of cancer that affect women, cancer risks for women, and a search engine to locate gynecologic oncologists. There are also links to related sites, publications, and support groups.

Medical Library Association Recommended Diabetes Web Sites

[American Diabetes Association](http://www.diabetes.org) (<http://www.diabetes.org>) is the leading nonprofit health organization dedicated to diabetes. The mission of the organization is “to prevent and cure diabetes and to improve the lives of all people affected by diabetes.” To accomplish this, the American Diabetes Association funds research, publishes scientific findings, and provides information and other services to people with diabetes, their families, health care professionals, and the public. The site contains basic information about diabetes, such as healthy living choices, insulin reactions, exercise, and diet. Other features include diabetes in the news, online shopping, ADA-sponsored events, and a section for health care professionals.

[Ask NOAH about Diabetes](http://www.noah-health.org/english/illness/diabetes/diabetes.html) (<http://www.noah-health.org/english/illness/diabetes/diabetes.html>) is a subsection of a unique and widely used site sponsored by a consortium of libraries in New York known as NOAH (New York Online Access to Health). An extensive collection of full-text consumer health information is easily accessible by clicking on the appropriate topic on the main diabetes page. From there, the user can continue to click on subcategories under each main heading. Information is available in English and Spanish, and there are categories for gender-specific, age-specific, and race-specific issues.

[Centers for Disease Control and Prevention](http://www.cdc.gov/diabetes/) (CDC) (<http://www.cdc.gov/diabetes/>), an agency of the Department of Health and Human Services, is dedicated to promoting the “health and quality of life by preventing and controlling disease, injury, and disability”. The Diabetes Public Health Resource page contains links to information on professional conferences, frequently asked questions (FAQs) about diabetes, projects such as the National Diabetes Education program, links to related sites on diabetes, news and information, publications and products, descriptions of state-based programs, and statistics about the disease. The target audience for this site is adults, both consumers and professionals. Spanish language information is also included. Users of the site can easily connect to the CDC home page to look up other subjects via “Health Topics A-Z.”

[Diabetes 123](http://www.diabetes123.com/) (<http://www.diabetes123.com/>) is an organization whose mission is “to be the world leader in online diabetes care, improving the quality and reducing the cost of care by increasing the understanding of, and providing traditional and innovative products and services for, the treatment of all types of diabetes.” In addition to the main site at *diabetes 123*, the organization also sponsors the *Children with Diabetes* site and *The Diabetes Monitor*. The main site is presented as an online magazine, and the home page serves as a table of contents to a variety of options, such as news and research articles, educational feature articles, chat rooms and other people connections, an “ask the diabetes team” section, and an online store. Although this site does accept advertising, it subscribes to the HONcode principles of the Health On the Net Foundation, as do the two related sites sponsored by diabetes 123.

[Children with Diabetes](http://www.childrenwithdiabetes.com) (<http://www.childrenwithdiabetes.com>) is sponsored by the Diabetes 123 organization and considers itself to be “the online community for kids, families and adults with diabetes.” Like the parent site at *diabetes 123*, the home page is like a table of contents for the remainder of the site pages, offering options similar to *diabetes 123*, but focused primarily on the needs of children with diabetes.

[The Diabetes Monitor](http://www.diabetesmonitor.com/) (<http://www.diabetesmonitor.com/>) is a site that is “monitoring diabetes happenings everywhere in cyberspace.” Sponsored by Diabetes 123, it provides a registry of diabetes-related Web sites around the world. Each entry in the list includes the name and URL for a specific Web site, along with a sentence or two describing the contents of that site. In addition to the “Diabetes Registry,” the home page has links to news about diabetes, as well as links to the other two sites sponsored by Diabetes 123. A separate site called [Diabetes Monitor: Four Star Sites](http://www.diabetesmonitor.com/fourstar.htm) (<http://www.diabetesmonitor.com/fourstar.htm>) provides a more selective list of diabetes Web sites that have been judged to be the best by a panel of Webmasters of such sites.

[Joslin Diabetes Center](http://www.joslin.harvard.edu/) (<http://www.joslin.harvard.edu/>) is a site provided by one of the leading diabetes clinics in the United States. Affiliated with Harvard Medical School, the Joslin Web site is aimed at patients and professionals. The “Managing Diabetes” section has a library of information for patients, discussion boards, descriptions of patient programs and camps for children with diabetes, and a store to purchase books and videos on various aspects of the disease. Other sections of the site provide information about the Joslin Diabetes Center, professional education, and research. The “Diabetes News” area has current updates about legislative activities, press releases, and the latest news in diabetes care and research.

[Juvenile Diabetes Research Foundation International](http://www.jdf.org/) (<http://www.jdf.org/>) is dedicated to fostering research to find a cure for diabetes. The site includes information about JDRF-sponsored research, its chapters and affiliates, ways to support JDRF, its publications, and its legislative activities. A *kids online* section provides links to a variety of materials directed at children and teens, with an index divided into specific age groups. A quarterly online magazine called Countdown For Kids is one of these links. Launched in 1996, its goal is to provide news, help, inspirational tools, educational tools, and fun for kids ages 8 and up.

[National Institute of Diabetes & Digestive & Kidney Diseases](http://www.niddk.nih.gov/) (<http://www.niddk.nih.gov/>) is a government-supported site highlighting the work of the NIDDK, one of the National Institutes of Health. NIDDK is dedicated to conducting and funding research on diabetes and digestive and kidney diseases, and the Web site devotes approximately one third of its content to diabetes and its related diseases. Consumer health information is organized into an A-Z list. “Easy-to-read” versions and Spanish-language versions are included for many of topics. In addition to consumer health information, the site also provides information about research and funding opportunities, clinical trials, health education programs, NIDDK laboratories, and reports about planning and congressional activities.

Medical Library Association Recommended Heart Disease Web Sites

[American Heart Association \(AHA\)](http://www.americanheart.org) (<http://www.americanheart.org>). This is the official Web site of the American Heart Association, with links to the [American Stroke Association](http://strokeassociation.org) (<http://strokeassociation.org>), a division of the AHA. The “Heart and Stroke A-Z Guide” provides a broad spectrum of information, including warnings signs for heart disease and stroke, an easy-to-use reference guide, a legislative action package, family health information (nutrition, exercise, children, programs or books), risk awareness for patients, scientific and professional information, solicitation options for volunteers, local AHA chapters, and donations. There is information on everything from scientific guidelines to training guides to ads for the *Jump Rope for Heart* program or *The American Heart Walk*. Of special note are the public advocacy pages with legislative priorities. Sponsorship is clear, content is factual, and policy briefs are clearly identified as such.

[American Heart Association Women’s Web site](http://www.women.americanheart.org) (<http://www.women.americanheart.org>). Since heart disease and stroke affect one out of every two women, the AHA has developed a site focused on women’s heart-related information needs entitled “*Take wellness to heart.*” Special features include a “talk to us” component in which women share personal stories, “register now” feature to receive emails with links to new features and information, and the ability to enroll in personal management programs.

[Congenital Heart Information Network](http://tchin.org) (<http://tchin.org>). This site provides high-quality information for children and adults with congenital heart disease, their families, and health professionals. It is an international organization that aims to provide reliable information, support, and research to families of children with congenital and acquired heart disease, adults with congenital heart defects, and professionals who work with them. Proudly subscribing to the HON code, it has won so many awards it includes a special link to list them. Elements include portraits of patients, a teen lounge area, local chapter links, email options, and lists for family support.

[Heart Information Network](http://heartinfo.org) (<http://heartinfo.org>). The Center for Cardiovascular Education is affiliated with this site. It is an independent, educational site that provides a wide range of information and services to heart patients and others interested in learning about lowering risk factors for heart disease.

[March of Dimes Birth Defects](http://modimes.org) (<http://modimes.org>). The March of Dimes Foundation sponsors this site, which focuses on birth defects with emphasis on congenital heart disease. An array of information is provided from fact sheets, health statistics, research centers, support groups, programs, local chapters (searchable by ZIP code), and the organization’s national ambassador program.

[Mayo Clinic Heart Center](http://www.mayoclinic.com/home) (<http://www.mayoclinic.com/home> or <http://www.mayohealth.org/home>). Experts of the Mayo Clinic offer extensive information on coronary artery disease, preventing heart disease, high blood pressure,

circulatory problems, and methods of treatment and prevention. Selecting Heart & Blood Vessels under Condition Centers or Diseases & Conditions A-Z provides links to qualitative information and further links. The site fosters taking charge of one's health via scorecards, planners, etc.

[National Center for Chronic Disease Prevention and Health Promotion](http://www.cdc.gov/nccdphp/)

(<http://www.cdc.gov/nccdphp/>). Part of the CDC, this agency's purpose is to enable people in an increasingly diverse society to lead long, healthy, satisfying lives. Since heart disease and stroke are the first and third leading causes of death in the United States, cardiovascular disease (CVD) prevention and health promotion programs are major priorities. The *Cardiovascular Health* page provides international, national, and state-level programs, along with statistical information and fact sheets. In 1998, the CDC received funding for states to develop comprehensive cardiovascular health programs; this agency coordinates these efforts.

[National Center for Health Statistics \(NCHS\)](http://www.cdc.gov/nchs/html) (<http://www.cdc.gov/nchs/html>).

NCHS is the federal government's principal agency for vital statistics and health statistics. A search for data on heart disease retrieved more than 2,100 primary statistical documents. It is *the* source for health statistics, surveys, and analysis. With legislative authority and mandates, it now also provides advice and information alerts for individuals. Internet users can now sign up for specific listservs to stay current with new statistical information on heart disease.

[National Heart, Lung and Blood Institute \(NHLBI\)](http://www.nhlbi.nih.gov) (<http://www.nhlbi.nih.gov>).

Part of NIH, this agency provides leadership for a national program in diseases of the heart, blood vessels, lung and blood, blood resources, and sleep disorders. Since October 1997 it also has administrative responsibilities for the NIH Woman's Health Initiative. The site provides an array of basic and specific heart and vascular disease information, covering topics such as high blood pressure, cholesterol, and obesity, and offers resources for Latino users. A lengthy list of the agency's reports and scientific documents is available, and the agency maintains its own database of clinical trials and studies seeking patients.

[NOAH: New York Online Access to Health](http://www.noah-health.org) (<http://www.noah-health.org>).

Although this site covers a broad range of health topics, the heart disease and stroke pages are so extensive they must be included on this list. The table of contents for this section alone is 12 printed pages. In addition to basic information, care, and treatment, the site includes AHA state chapters and *Heart links*, a *Mended Hearts* support group, hospital ratings of cardiac units nationwide, and capabilities for the blind or the visually handicapped to use the site.

Methodology

This report is based on the findings of a survey of Americans about their use of the Internet. Most of the results in this report are based on data from telephone interviews conducted by Princeton Survey Research Associates between June 19, 2001, and August 6, 2001, among a sample of 500 Internet users, 18 and older, who have ever gone online to look for health or medical information. 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 4 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.

Interviews for this survey were completed from a pre-screened sample of Internet users who in past surveys had identified themselves as seekers of health information on the Internet. Once the household was reached, interviewers asked to speak with the individual who had recently completed a telephone survey. Once the targeted person was on the phone, a few screening questions were asked to make sure that person had in fact gone online to look for health or medical information.

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. The final response rate for the callback portion of this survey is 54%.

This report also contains the results of a national tracking survey conducted by Princeton Survey Research Associates between March 1, 2002, and March 31, 2002, among a sample of 2,410 adults ages 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 on Internet users, the margin of error is plus or minus 3 percentage points.

In addition to the survey results, this report contains quotations from two online focus groups conducted by Harris Interactive. Harris Interactive recruits participants for its qualitative research through the Harris Poll Online and its Qualitative Research Specialty Panel. This panel includes individuals who have expressed an interest in participating in both traditional and online research. When recruited, interested participants complete a screening questionnaire. This information is then used to recruit targeted and low-incidence audiences for both online and offline qualitative research projects.