

E-patients With a Disability or Chronic Disease

**Just half of adults with chronic conditions
use the internet; but once online, they are
avid consumers of health information.**

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Summary of Findings

Adults living with a disability or chronic disease are less likely than others to go online, but once online, are avid health consumers.

About a fifth of American adults say that a disability, handicap, or chronic disease keeps them from participating fully in work, school, housework, or other activities. Half (51%) of those living with a disability or chronic disease go online, compared to 74% of those who report no chronic conditions. Fully 86% of internet users living with disability or chronic illness have looked online for information about at least one of 17 health topics, compared with 79% of internet users with no chronic conditions.

Health Topics Searched Online			
Health Topic	Percentage of Internet Users Who Have Searched for Information on Each Topic		
	Those Living with a Disability or Chronic Condition	Those with No Chronic Conditions	All
Specific disease or medical problem	73%	62%	64%
Certain medical treatment or procedure	64	49	51
Diet, nutrition, vitamins, or nutritional supplements	53	48	49
Exercise or fitness	46	44	44
Prescription or over-the-counter drugs	51	35	37
A particular doctor or hospital	33	28	29
Health insurance	30	28	28
Alternative treatments or medicines	42	25	27
Depression, anxiety, stress, or mental health issues	30	21	22
Environmental health hazards	24	21	22
Experimental treatments or medicines	30	17	18
Immunizations or vaccinations	13	16	16
Dental health information	16	14	15
Medicare or Medicaid	24	11	13
Sexual health information	11	11	11
How to quit smoking	18	8	9
Problems with drugs or alcohol	8	8	8

Source: Pew Internet & American Life Project August 2006 Survey (N=2,928). The margin of error for comparison of internet users with chronic conditions (n=268) and those who report no disability or chronic condition (n=1,711) is +/- 7%. Significant differences are in bold, blue type.

This Pew Internet & American Life Project report is based on the findings of a daily tracking survey on Americans' use of the internet. All numerical data was gathered through telephone interviews conducted by Princeton Survey Research Associates between August 1-31, 2006, among a sample of 2,928 adults, aged 18 and older. For results based on the total sample, one can say with 95% confidence that the error attributable to sampling and other random effects is +/- 2%. For results based on internet users (n=1,990), the margin of sampling error is +/- 3%. For results based on internet users with chronic conditions (n=268), the margin of sampling error is +/- 7%. Separately, online essays were collected from 1,680 members of Association of Cancer Online Resources in November 2006.

Throughout this report, we refer to internet users who have looked online for health information as “e-patients.” And we refer to those who identify themselves as living with disabilities or chronic disease that prevents them from participating fully in work, school, housework, or other activities as those having “chronic conditions.” This population is characterized by a comparatively greater portion of people age 50 and older and those who do not use a computer on a regular basis.

Those with chronic conditions are more likely than other e-patients to report that their online searches affected treatment decisions, their interactions with their doctors, their ability to cope with their condition, and their dieting and fitness regimen.

In order to capture a portrait of a typical health search, we asked respondents to think about the most recent time they had gone online for health or medical information. Fifty-three percent of all e-patients say their last search had an impact on their own health care or the way they care for someone else; 42% say it had a minor impact and 11% say the last search had a major impact.

However, e-patients living with chronic disease or disability who reported any impact, major or minor, were significantly more likely than other e-patients to describe the following four effects:

- 75% of e-patients with chronic conditions say the information they found in their last search **affected a decision about how to treat an illness or condition**, compared with 55% of e-patients who report no disability or illness.
- 69% of e-patients with chronic conditions say the information **led them to ask a doctor new questions or to get a second opinion from another doctor**, compared with 52% of other e-patients.
- 57% of e-patients with chronic conditions say the information **changed the way they cope with a chronic condition or manage pain**, compared with 36% of other e-patients.
- 56% of e-patients with chronic conditions say the information **changed the way they think about diet, exercise, or stress management**, compared with 42% of other e-patients.

Two effects were reported by statistically equivalent percentages of both e-patient groups:

- 61% of e-patients with chronic conditions say the information they found during their most recent search **changed their overall approach to maintaining their health or the health of someone they help take care of**, compared with 54% of other e-patients
- 36% of e-patients with chronic conditions say the information **affected a decision about whether to see a doctor**, compared with 35% of other e-patients.

E-patients with chronic conditions are less likely than others to start their information queries at search engines.

Fifty-six percent of e-patients with chronic conditions began their last online health inquiry at a search engine; 37% began at a health-related website. This is somewhat different from e-patients who report no disability or illness: 67% of that group starts at a search engine and 27% start at a certain website.

E-patients with chronic conditions are more likely than other health seekers to go online for information about their own conditions.

Not surprisingly, e-patients with chronic conditions tend to devote more attention to their conditions than those who report no serious illness or disability. Fifty-three percent of e-patients with chronic conditions say their last search was in relation to their own health questions, whereas 33% of e-patients with no chronic conditions say their last search was in relation to their own health or medical situation.

E-patients with chronic conditions have mostly positive things to say about their online health searches, but they are more likely than others to report frustration as well.

Most e-patients, including those living with chronic conditions, are likely to identify with positive descriptions of their last search for health information online. The following responses were in line with answers from the general population of internet users who go online for health information.

On the positive side:

- 71% of e-patients with chronic conditions say they felt **reassured** that they could make appropriate health care decisions during their last search for health information online.
- 59% say they felt **relieved** or **comforted** by the information they found online.
- 56% say they felt **confident** to raise new questions or concerns about a health issue with their doctor.
- 55% say they felt **eager to share** their new health or medical knowledge with others.

On the negative side:

- 30% say they felt **overwhelmed** by the amount of information they found online.
- 19% say they felt **confused** by the information they found online.

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- 9% say they felt **frightened** by the serious or graphic nature of the information they found online

One question elicited different responses from the two groups:

- 31% of e-patients with chronic conditions say they felt **frustrated** by a lack of information or an inability to find what they were looking for online, compared with 20% of e-patients who report no chronic conditions.

Most e-patients with chronic conditions do not consistently check the source and date of the health information they find online.

Just 14% of e-patients living with disability or chronic disease say they “always” check the source and date of the health information they find online, while another 18% say they do so “most of the time.” Sixty-seven percent of e-patients with chronic conditions say they check the source and date “only sometimes,” “hardly ever,” or “never.” These figures are not markedly different from the responses provided by other e-patients, although those living with chronic conditions are less likely than those with no chronic conditions to say they “never” check the source and date (13%, compared with 22%).

As we reported in “Online Health Search 2006,”¹ the cause of diminished diligence in checking quality indicators might lie with health websites themselves: A study commissioned by the U.S. Department of Health and Human Services found that just 4% of “frequently visited” health websites disclosed the source of the information on their pages and 2% disclosed how the content is updated.²

The impact of the most recent search for health information was most deeply felt by internet users who had received a serious diagnosis or experienced a health crisis in the past year.

One-quarter of adults (27%) say they or someone close to them has been diagnosed in the last 12 months with a chronic medical condition, such as asthma, diabetes, heart disease, or high blood pressure. One-third (34%) of American adults say they or someone close to them faced a serious medical emergency or crisis in the past 12 months. Members of these two groups who have searched online for health information are more likely than other e-patients to say the information they found had a major impact on their own care or the way they care for someone else.

¹ “Online Health Search 2006” (Pew Internet & American Life Project, Oct. 29, 2006). Available at: http://www.pewinternet.org/PPF/r/190/report_display.asp

² “Report on Objective 11-4: Estimating the Proportion of Health Related Websites Disclosing Information That Can Be Used to Assess Their Quality” (Department of Health and Human Services, May 30 2006). Available at: <http://www.health.gov/communication/healthypeople/obj1104/default.htm>

Summary of Findings

E-patients: Summary of Findings at a Glance
Adults living with a disability or chronic disease are less likely than others to go online, but once online, are avid health consumers.
Those with chronic conditions are more likely than other e-patients to report that their online searches affected treatment decisions, their interactions with their doctors, their ability to cope with their condition, and their dieting and fitness regimen.
E-patients with chronic conditions are less likely than others to start their information queries at search engines.
E-patients with chronic conditions are more likely than other health seekers to go online for information about their own conditions.
E-patients with chronic conditions have mostly positive things to say about their online health searches, but they are more likely than others to report frustration as well.
Most e-patients with chronic conditions do not consistently check the source and date of the health information they find online.
The impact of the most recent search for health information was most deeply felt by internet users who had received a serious diagnosis or experienced a health crisis in the past year.
Source: Fox, Susannah. <i>E-patients With a Disability or Chronic Disease</i> . Washington, DC: Pew Internet & American Life Project, October 8, 2007.

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Acknowledgements

On behalf of the Pew Internet & American Life Project, I would like to acknowledge the following contributions to this study:

Tom Ferguson, MD, coined the term “e-patients” to describe individuals who are equipped, enabled, empowered and engaged in their health and health care decisions. Dr. Ferguson’s book, “E-Patients: How They Can Help Us Heal Health Care” can be downloaded from <http://www.e-patients.net/>

Princeton Survey Research Associates International: PSRAI conducted the telephone survey that is covered in this report. It is an independent research company specializing in social and policy work: <http://www.psrai.com/>

Association of Cancer Online Resources: Special thanks to the ACOR list owners and members who contributed essays about their experiences as e-patients and caregivers. ACOR offers access to 159 mailing lists that provide support, information, and community to everyone affected by cancer and related disorders: <http://www.acor.org/>

About the Pew Internet & American Life Project: The Pew Internet Project is a nonprofit initiative of the Pew Research Center and is funded by The Pew Charitable Trusts to examine the social impact of the internet. The project is non-partisan and does not advocate policy outcomes: <http://www.pewinternet.org/>

Part 1.

34 Million Adults Live With a Disability or Chronic Disease; Half Go Online

People with chronic conditions are likely to be older and less educated than the general population.

Large surveys of Americans generally show that about one-fifth of the adult population live with disabilities or serious chronic conditions.³ Different definitions of disability and chronic illness are sometimes employed in these surveys, but they are relatively consistent in finding that a notable portion of Americans live with these conditions.

Profile of the Chronic Conditions Population			
The "Living with Chronic Conditions" column should read as follows: 56% of adults living with chronic conditions are women; 53% of adults with no chronic conditions are women; 53% of the entire U.S. population are women.			
Demographic Group	Living with Chronic Conditions	No Chronic Conditions	U.S. Population
Women	56%	53%	53%
Men	44	47	47
Age 18-29	8	22	19
Age 30-49	25	40	37
Age 50-64	37	22	24
Age 65+	29	15	17
Less than a high school education	25	10	12
High school diploma	31	34	33
Some college education	27	26	26
College degree or more	18	29	28
Use a computer at work, school, home	52	75	71
Do not use a computer	48	25	29
Use the internet or email	51	74	70
Do not use the internet or email	49	26	30

Source: Pew Internet & American Life Project August 2006 Survey (N=2,928). The margin of error for comparison of adults with chronic conditions (n=538), those who report no disability or chronic condition (n=2,367), and the total U.S. population is +/- 5%. Significant differences are in bold, blue type.

³ In the 2004 American Community Survey, 35 million Americans age 16+ were estimated to be living with a "long-lasting sensory, physical, mental, or emotional condition." (See Table 181 of the Statistical Abstract of the United States: 2007.)

Part 1. 34 Million Adults Live With a Disability or Chronic Disease

In a Pew Internet & American Life nationwide phone survey in the fall of 2006, 17% of American adults answered “yes” to the following question: “Does any disability, handicap, or chronic disease keep you from participating fully in work, school, housework, or other activities, or not?”⁴ That translates to about 34 million adults living with chronic conditions. This population is characterized by a comparatively greater portion of people age 50 and older and those who do not use a computer on a regular basis.

A report by the Centers for Disease Control and Prevention and the Merck Company Foundation estimates that 80% of older Americans live with one or more chronic conditions.⁵ As the population ages, the number of Americans with chronic conditions is certain to grow, consuming more health care and health information along the way.

Those with chronic conditions are less likely to use the internet, but there has been major growth in this population in internet adoption in the past four years. Half of people living with disability or chronic disease use the internet, but once online they are nearly as engaged as the general internet population.

About half (51%) of people living with chronic conditions go online, compared with 74% of those who report no disability or chronic disease. This represents a significant increase since 2002, when we found that 35% of adults living with a disability or chronic disease had internet access, compared with 61% of adults with no chronic conditions. However, despite the relatively faster pace of adoption (a 46% increase among the special-needs population, compared with a 21% increase), these figures illustrate the continuing disparities among U.S. adults when it comes to technology adoption.⁶

<p>“People with chronic conditions” — Adults who have identified themselves as living with a disability or chronic disease that prevents them from participating fully in work, school, housework, or other activities</p>
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Internet users living with chronic conditions are somewhat less likely than other internet users to go online on a typical day (58%, compared with 67% of internet users who report no illness or disability).

The vast majority of all internet users (89%) have internet access from home, regardless of their disability or health status. A division between the two groups is apparent in workplace access, however, since most people with chronic conditions are out of the

⁴ In a survey conducted in 2002, 15% of adults answered yes to that question. See: “Internet Health Resources” (Pew Internet Project: July 16, 2003). Available at: http://www.pewinternet.org/PPF/r/95/report_display.asp

⁵ “The State of Aging and Health in America 2007” (Centers for Disease Control and Prevention and The Merck Company Foundation). Available at: <http://www.cdc.gov/aging/>

⁶ “Disability and the Digital Divide: Comparing Surveys with Disability Data” (University of Montana Research and Training Center on Disability in Rural Communities: June 2006). Available at: <http://rtc.ruralinstitute.umt.edu/TelCom/Divide.htm>

Part 1. 34 Million Adults Live With a Disability or Chronic Disease

workforce.⁷ Just 31% of internet users with chronic conditions go online from work, compared with 54% of internet users who report no illness or disability.

Internet users with chronic conditions who have internet access at home are just as likely as other users to have upgraded to broadband service. Sixty-five percent of home internet users with chronic conditions have some kind of high-speed access, compared with 69% of home internet users with no chronic conditions.

Opportunity: Half of American adults with chronic conditions remain offline, but this study shows that once online, they are likely to be enthusiastic internet users.

Once online, internet users with chronic conditions pursue most online activities at the same rate as other users. Equivalent percentages of each group do the following activities:

- Send or read email (89% of all users)
- Use a search engine (88% of all users)
- Visit a government website (66% of all users)
- Buy or make a travel reservation (63% of all users)
- Get financial information online (41% of all users)
- Send instant messages (39% of all users)
- Look for information about a place to live (39% of all users)
- Pay to access or download digital content (17% of all users)
- Use an online social networking site (16% of all users)
- Sell something online (15% of all users)

Two topics are particularly popular among internet users living with chronic conditions: health and genealogy. Eighty-six percent of internet users with chronic conditions say they look for health information online, compared with 79% of internet users who report no chronic conditions. Thirty-eight percent of internet users with chronic conditions say they research genealogy and family history online, compared with 24% of internet users who report no disability or chronic disease.

People living with disability or chronic disease are very engaged with health care.

Ninety-one percent of people with chronic conditions say they visited a doctor or medical clinic in the previous 12 months, compared with 76% of people with no special needs.

⁷ 23% of adults living with disability or chronic disease are employed full- or part-time, compared with 68% of adults who report no disability or disease.

Part 1. 34 Million Adults Live With a Disability or Chronic Disease

Half (52%) of people living with disability or chronic illness say they or someone close to them faced a serious medical emergency or crisis in the last 12 months, compared with 30% of people with no chronic conditions. Nine in ten adults living with a disability or chronic illness say they are covered by some form of health insurance, essentially the same percentage as the rest of the adult population.

“E-patients with chronic conditions” —
Internet users who have identified themselves as living with a disability or chronic disease and who search online for information on health and health care

Since health care plays a central role in their lives, it is not surprising that internet users living with disability and chronic disease are more likely than other people to have done some research about it online. But on a typical day, e-patients with chronic conditions and those with no chronic conditions are equally likely to look for health information – 8% and 7% do so respectively.

Part 2.

Searching for Answers Online

As in past surveys, we asked respondents to think about the last time they went online for health or medical information, hoping to capture a portrait of a typical health search.⁸

E-patients with chronic conditions are likely to be searching for answers to their own health questions.

Fifty-three percent of e-patients with chronic conditions say their last search was related to their own health or medical situation. Twenty-nine percent of e-patients with chronic conditions say their last search was on behalf of someone else. Thirteen percent of e-patients with chronic conditions volunteered that their last search was both for themselves and for someone else.

By contrast, e-patients with no chronic conditions are likely to be acting in a caregiver role, gathering information on behalf of someone else. Fifty-one percent of e-patients with no chronic conditions say the last time they went online for health or medical information, their quest was related to someone else's situation; 7% say their last search was for both themselves *and* for someone else. Thirty-three percent of health seekers say their last search was in relation to their own health or medical situation.

General search engines still dominate, but e-patients with chronic conditions are more likely than others to turn to trusted health sites.

During their last online health inquiry, 56% of e-patients living with disability or chronic disease began with a search on a general search engine like Google or Yahoo. Thirty-seven percent of e-patients with chronic conditions skipped the search and went right to a specific website they know provides health information.

Opportunity: If health care providers have sites or key words to recommend, e-patients with chronic conditions may be especially receptive.

By contrast, 67% of e-patients with no chronic conditions say their last query began at a general search engine. Twenty-six percent of e-patients with no chronic conditions say their last health information session began by going to a specific health website.

⁸ "Online Health Search 2006" (Pew Internet & American Life Project, Oct. 29, 2006). Available at: http://www.pewinternet.org/PPF/r/190/report_display.asp; "Vital Decisions: How internet users decide what information to trust when they or their loved ones are sick" (Pew Internet & American Life Project, May 22, 2002). Available at: http://www.pewinternet.org/PPF/r/59/report_display.asp

Most e-patients visit two or more sites during a typical online health inquiry.

One in five e-patients, regardless of health status, visited just one site the last time they got health information online. The majority visited two or more sites. The following responses from e-patients with chronic conditions are not statistically different from answers provided by e-patients who report no disability or chronic disease:

- 21% of e-patients with chronic conditions say they visited one site during their last health information session.
- 37% say they visited two or three sites.
- 22% say they visited four to five sites.
- 12% say they visited six to ten sites.
- 1% say they visited 11 to 20 sites.
- 3% say they visited more than 20 sites.
- 4% say they do not recall the number of sites.

Half of e-patients with chronic conditions later talked to a doctor about what they found online.

The Health Information National Trends Survey (HINTS), sponsored by the National Cancer Institute, found a significant disparity between what people say is their preferred source of information about cancer and where they actually go to gather it. In a national survey conducted in 2003, 49% of adults said they would go first to a health care provider if they had a strong need to get information about cancer. In the same survey, however, people who said they had recently looked for cancer information for themselves were likely to say they looked online – 46%, vs. 11% who had consulted a health care professional.⁹

The Pew Internet Project's 2006 survey finds that e-patients living with disability or chronic disease are more likely than other e-patients to take advantage of both online and offline information sources. Fully 49% of e-patients with chronic conditions talked with a health professional about what they found online during their most recent search, compared with 30% of e-patients with no chronic conditions, possibly because those living with chronic conditions are highly likely to have seen a doctor in the past year.

In addition to a telephone survey, which provided all numerical data covered in this report, the Pew Internet Project asked members of the Association of Cancer Online

⁹ See <http://hints.cancer.gov/>

Part 2. Searching for Answers Online

Resources (ACOR) to write essays about their use of internet health resources.¹⁰ Many ACOR respondents describe their doctors as supportive “partners” or “teammates” in their care. As one e-patient wrote, “Fortunately, we had a doctor with a sense of humor and who was not an Ultimate Authority on Everything. He was open to the things we learned online. If he hadn’t been, maybe we’d have changed doctors.” Another e-patient wrote, “With the information I have gathered on the internet...I have used my doctors more as expert consultants...They seem to appreciate that I am an informed and educated patient and are very willing to work with me on that basis. The only downside to this approach is that perhaps they assume that I know more than I do, but then I just go back and do more research.”

However, there is a significant group of e-patients with chronic conditions who do not discuss their online research with a medical professional. It may be that the e-patients do not wish to share their findings or it may be that doctors discourage such conversations. As one person wrote, “I have not found a doctor who wants their patients to use the web.” The 2005 HINTS survey suggests that this perception of disinterested doctors may need to be updated. About half of internet users in that survey said they have ever talked to a doctor, nurse, or other health care provider about online health information, and of those, only 8% encountered a health professional who was “not at all interested.” Fully 73% of e-patients who discussed their online research encountered health professionals who were “very” or “somewhat” interested in their findings.

Opportunity: Health care providers may want to make “Do you ever go online for health information?” a standard question.

E-patients with chronic conditions are likely to use their online health research to aid care decisions, ask new questions of their doctors, and manage chronic conditions.

Just 9% of e-patients with chronic conditions say their last health information query had a major impact on their own health care or the way they care for someone else. Forty-three percent of e-patients with chronic conditions say their last search had a minor impact. Another 43% of e-patients with chronic conditions report that their last search had no impact at all on their own or someone else’s care. These responses are not significantly different from those provided by e-patients who report no disability or chronic disease.

However, e-patients living with chronic disease or disability who reported any impact, major or minor, were significantly more likely than other e-patients to describe the following four effects:

¹⁰ Barbara K. Rimer, Ph.D., dean of the University of North Carolina’s School of Public Health, has led in-depth studies of ACOR members. For example, “How Cancer Survivors Provide Support on Cancer-Related Internet Mailing Lists” (Journal of Medical Internet Research: Vol 9, No 2, 2007). Available at: <http://www.jmir.org/2007/2/e12>

Part 2. Searching for Answers Online

- 75% of e-patients with chronic conditions say the information they found in their last search affected a decision about how to treat an illness or condition, compared with 55% of e-patients with no chronic conditions.
- 69% say the information led them to ask a doctor new questions or to get a second opinion from another doctor, compared with 52% of e-patients with no chronic conditions.
- 57% say the information changed the way they cope with a chronic condition or manage pain, compared with 36% of e-patients with no chronic conditions.
- 56% say the information changed the way they think about diet, exercise, or stress management, compared with 42% of e-patients with no chronic conditions.

Both groups of e-patients reported the following effects to essentially the same degree:

- 61% say the information changed their overall approach to maintaining their health or the health of someone they help take care of, compared with 54% of e-patients with no chronic conditions.
- 36% say the information affected a decision about whether to see a doctor, compared with 35% of e-patients with no chronic conditions.

Opportunity: Online research may be part of a “coached care” program to help people get the most out of their health care.¹¹

One e-patient wrote, “Doctors are always in a hurry. By researching online I can find information that fills in gaps in my knowledge, and allows me to ask better questions of the doctor. I also find out information that the doctor hasn’t shared with me, but it is important for me to understand my disease.”

E-patients with chronic conditions are likely to report strong feelings, both positive and negative, about their online health inquiries.

We gave respondents eight different ways – four positive and four negative – to describe how they felt during their last search for health information online. It is striking that for all e-patients, positive assertions about the impact of their online health searches significantly overshadowed negative responses. The following responses were in line with answers from the general population of internet users who go online for health information:

- 71% of e-patients with chronic conditions say they felt **reassured** that they could make appropriate health care decisions. As one e-patient wrote, “Finding [a specific support group]...was terribly reassuring – it gave me peace of mind that what my

¹¹ “Coached care” is a phrase employed by Sherrie Kaplan, associate dean for Clinical Policy and Health Services at the University of California Irving School of Medicine. For more information, please see “The Prepared Patient: Effective Patienthood Begins With Good Communication” (Health Behavior News Service, September 2007: <http://www.cfah.org/hbns/PreparedPatient/Prepared-Patient-Vol1-Issue3.cfm>).

Part 2. Searching for Answers Online

urologist was doing was the correct course of action, and gave me access to a wealth of information.”

- 59% say they felt **relieved** or **comforted** by the information they found online. Another ACOR member wrote, “After diagnosis, I immediately searched online and immediately found this wonderful list. No one can understand a disease better than someone who has it and has researched it for years.”
- 56% say they felt **confident** to raise new questions or concerns about a health issue with their doctor. One e-patient put it this way, “[Online health resources] helped me take an active role...and follow up rather than being a passive ‘whatever the doctor says’ patient.”
- 55% say they felt **eager to share** their new health or medical knowledge with others. When asked to describe the most significant benefits or upsides of an online health community, an e-patient wrote, “Knowing that you are doing what you can to help others who have come down the path after you, and who are as bewildered as you were when you were on the path.”
- 30% say they felt **overwhelmed** by the amount of information they found online. As one person wrote, “At times I must stop reading and take a break as the information can be overwhelming. Of course having a chronic non-curable disease is overwhelming also. Sometimes repressing reality is therapeutic.”
- 19% say they felt **confused** by the information they found online. Another e-patient wrote, “Each website is a little different...beyond my vocabulary in many cases. But the information is useful.”
- 9% say they felt **frightened** by the serious or graphic nature of the information they found online. As one person wrote, “As someone who is newly diagnosed...it is emotional and a little disturbing to find all these people with such a terrible time with this disease. I don’t have the experience yet to know whether my situation will be the same, better or worse.”

One question elicited different responses from the two groups:

- 31% e-patients with chronic conditions say they felt **frustrated** by a lack of information or an inability to find what they were looking for online, compared with 20% of e-patients who report no chronic conditions.

The frustration highlighted in this survey echoes what we found in previous studies of e-patients living with disability and chronic disease. In a survey conducted in 2001, most respondents found most or all of the health information they looked for online, while 14% said they ran out of time or had to stop looking before finding all the information they sought and 6% of e-patients reported that they could not find the information they sought. Those living with chronic disease or disability were the most likely group to say they gave up before finding the right information, possibly because they are looking for more detailed or rarer kinds of material. As one e-patient wrote, “I have been disappointed when I have had a question and NO ONE responded. I think that this happens with more rare or esoteric issues related to [my disease].”

Most e-patients with chronic conditions do not consistently check the source and date of the health information they find online.

Few e-patients are vigilant about checking key information quality indicators of the information they find online, regardless of health status.

Just 14% of e-patients living with disability or chronic disease say they “always” check the source and date of the health information they find online, while another 18% say they do so “most of the time.” Sixty-seven percent of e-patients with chronic conditions say they check the source and date “only sometimes,” “hardly ever,” or “never.” These figures are not markedly different from the responses provided by other e-patients, although those living with chronic conditions are less likely than those with no chronic conditions to say they “never” check the source and date (13%, compared with 22%).

The Pew Internet Project’s 2006 survey findings stand in contrast to our 2001 survey: e-patients with serious concerns were likely to be vigilant in their attention to the source and date of the information they found.¹²

E-patients may be giving up on a search for a needle in a haystack. The U.S. Department of Health and Human Service’s Office of Disease Prevention and Health Promotion, working with industry experts, identified six types of information that should be publicly disclosed to health seekers: the identity of the site’s sponsors, the site’s purpose, the source of the information provided, privacy policies to protect users’ personal information, how users can provide feedback, and how the content is updated. Of the 102 websites reviewed for the 2006 report, none met all six of the disclosure criteria and only six complied with more than three criteria. Just 4% of “frequently visited” health websites disclosed the source of the information on their pages and 2% disclosed how the content is updated. Less-popular health sites fared even worse: 0.3% of these sites listed their content’s source and only 0.1% disclosed how the content is updated.¹³ As the online health market expands, this issue will most likely grow along with the number of websites available to consumers.

Opportunity: The Medical Library Association (<http://www.mlanet.org/>) provides tips and resources for consumers who want to be sure they are accessing the best information available.

It is important to note that e-patients may have turned to other quality controls in the face of a fruitless search for source and date information. For example, one e-patient wrote, “Having access to medical journal articles and others’ opinions of articles were the reason

¹² “Vital Decisions” (Pew Internet & American Life Project: May 22, 2002). Available at: http://www.pewinternet.org/PPF/r/59/report_display.asp

¹³ “Report on Objective 11-4: Estimating the Proportion of Health Related Websites Disclosing Information That Can Be Used to Assess Their Quality” (Department of Health and Human Services, May 30, 2006). Available at: <http://www.health.gov/communication/healthypeople/obj1104/default.htm>

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that my brother lived much longer than expected and had an improved quality of life. Being able to email world specialists and/or call them for help made a huge difference in his medical care with his local doctors.” Another wrote, “The web-based stuff can point you toward information, but to get solid, in-depth knowledge you need to access a medical library, in my opinion. The problem: Medical libraries are few and far between for most people.”

E-patients with chronic conditions are particularly tuned in to the benefits of following medical advice or health information found on the internet.

Just 4% of e-patients with chronic conditions say they or someone they know has been seriously harmed by following the advice or information they found online, which is about the same percentage of e-patients with no chronic conditions who agree. Forty percent of e-patients with chronic conditions say they or someone they know has been significantly helped by following medical advice or health information found on the internet. By comparison, 29% of e-patients with no chronic conditions say they or someone they know has been significantly helped by online health information.

ACOR members were asked to share a particular incident or story from their own experiences that makes an important point about online health resources. Here are a few of the stories:

- “After diagnosis it seems everyone has the same experience of shock, dismay, etc. Having the ability to speak with others who have experienced the same thing is invaluable. My greatest fear was dying at 46, not seeing my kids get married, and not seeing and holding my grandkids. I guess I automatically assumed the worst, but I think most of us do. Talking to others who have received the same treatment and are surviving fine 10 to 12 years later really gave me hope. Suddenly the diagnosis didn't mean I was going to die young, and I found out that my particular type of leukemia is not only highly treatable, but also has a fantastic cure rate. I went from being anxious and depressed to being hopeful, and that change has made all the difference.”
- “After my hysterectomy, I went for post-op. The gyn who performed the surgery had a pathology report and read the diagnosis (low malignant potential) without explanation, and glossed over it. I went home and immediately searched the term on the internet. Imagine my surprise when the first site in the list was the cancer center at UPenn! Nothing like diagnosing YOURSELF. The doc never mentioned the C word. Through further study, I found [an online cancer group], who sounded the battle cry: ‘Get thee to a gyn-onc.’¹⁴ That was nearly 8 years ago.”
- “I wasn't sure whether or not something I was experiencing was a side affect of treatment, or possibly a symptom of a different illness. I asked my doctor and he didn't think it was a side affect of the treatment, so I looked through the archives of an online community and found someone else had asked the members about the same issue. I learned that many others had the same side affect and their doctors told

¹⁴ “Gyn-onc” refers to a gynecologic oncologist.

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them how to avoid or care for it. I showed my doctor printouts from the online forum and he was appreciative of receiving the information and said he'd share it with his associates in case anyone else had been asked about it.”

- “I have seen pictures of other people suffering from my same disease. A picture is worth a thousand words. I have never seen another person who has my disease face to face.”
- “I have too many stories to recount. My wife was paralyzed from a plasmacytoma wrapped around her spine. This happened gradually, while we were under the care of a hematologist, oncologist, and other doctors. We went from specialist to specialist and it wasn't until she was unable to stand that one finally did the full MRI of the spine that should have been done to start with. They had done MRIs but all too low. Recently on the list a new person described his wife's symptoms. They were identical to what my wife's had been. I advised him to demand a FULL MRI of the spine and they found a plasmacytoma on her spine. They caught it in time to avoid the paralysis my wife has suffered. I feel good about that.”

These stories echo what other researchers and observers have found: The internet can help people engage with health care in new, unexpected, and important ways. A person with diabetes might learn to control their diet through the help of an online guide.¹⁵ A doctor might use a site like Isabel Health Care to diagnosis a rare form of leukemia or an unexpected complication.¹⁶ “Offline” family and friends can join “online” friends in an integrated support group for people with hearing loss.¹⁷ Epilepsy patients can band together to create an information resource that guards against misinformation.¹⁸

¹⁵ See “CalorieKing And Joslin Diabetes Center Team Up to Promote Diabetes Prevention and Management Through Healthy Food Choices” (Joslin Diabetes Center: July 31, 2007). Available at: http://www.joslin.org/1083_4103.asp

¹⁶ “Why Doctors So Often Get It Wrong,” by David Leonhardt (*New York Times*: Feb. 22, 2006). “For doctors, diagnosing gets a technological boost,” by Erin Donaghue (*USA Today*: Sept. 6, 2007). See also: <http://www.isabelhealthcare.com>

¹⁷ “Beyond Hearing: Where Real-World and Online Support Meet,” by Jonathan N. Cummings, Lee Sproull, and Sara B. Kiesler. (Group Dynamics: Theory, Research, and Practice, 2002, Vol. 6, No. 1, 78-88).

¹⁸ “Learning from e-patients at Massachusetts General Hospital,” by John Lester, Stephanie Prady, Yolanda Finegan, and Dan Hoch. (*British Medical Journal*: May 15, 2004). Available at: <http://www.bmj.com/cgi/content/full/328/7449/1188>

Part 3.

Recently Challenged or Diagnosed E-patients

Americans with fresh experiences of serious diagnoses and medical crises are likely to use the internet for health information.

One-quarter of adults (27%) say they or someone close to them has been diagnosed in the last 12 months with a chronic medical condition, such as asthma, diabetes, heart disease, or high blood pressure. One-third (34%) of American adults say they or someone close to them faced a serious medical emergency or crisis in the past 12 months.

These two groups, the recently diagnosed and the recently challenged, constitute a special case. Seventy-one percent of these adults go online and, of those, 84% look online for health information.

“Recent challenged or diagnosed e-patients”
— Internet users who say they or someone close to them has received a serious diagnosis or gone through a health crisis in the last 12 months and who search online for information on health and health care

Older adults, those with less education, and minorities are more likely than other groups to report a recent diagnosis.

Americans age 50 and older are more likely than younger Americans to report a recent diagnosis (31% of those age 50 and older, compared with 21% of those age 30-49 years old). Americans with less education are more likely than those who have graduated from college to have received a serious diagnosis in the past year (35% of those with less than a high school education and 29% of those who have a high school diploma, compared with 21% of college graduates). African Americans and English-speaking Hispanics are more likely than whites to report a recent diagnosis (33%, 42%, and 24%, respectively).

Americans with a recent diagnosis are somewhat less likely to be internet users. Sixty-five percent of recently-diagnosed Americans go online, compared with 71% of those who have not received a serious diagnosis, either their own or someone close to them. Those who are online are likely to be active e-patients. As one e-patient wrote, “My first action when I got home from the hospital with my diagnosis was to get on the internet to find answers to the millions of questions bombarding me.” Others are fortunate to have family and friends available to search on their behalf, as another e-patient wrote: “The night I told my best friend of my diagnosis, her husband went online to find a support list for me.”

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By contrast, everyone seems equally at risk for a health crisis.

The population of adults who report that they or someone close to them faced a serious medical emergency or crisis within the last 12 months looks like the general U.S. population. No one age group stands out, nor does any ethnic group. Adults with college degrees are as likely to report a health crisis as those with less education. However, 80% of recently challenged Americans go online, higher than the average of 70%.

Recently challenged or diagnosed e-patients are more likely than other groups to say their last search had a major impact on their own health care routine or the way they care for someone else.

The impact of the most recent search for health information was most deeply felt by internet users who had received a serious diagnosis or experienced a health crisis in the past year, either their own or that of someone close to them. Fourteen percent of these e-patients say their last search had a major impact, compared with 7% of e-patients who had not received a diagnosis or dealt with a health crisis in the past year.

Recently challenged or diagnosed e-patients report the following effects:

- 59% say the information found in their most recent online search led them to ask a doctor new questions or to get a second opinion from another doctor, compared with 48% of e-patients who had not experienced a health challenge in the past year.
- 46% say the information changed the way they cope with a chronic condition or manage pain, compared with 31% of other e-patients.

Opportunity: Doctors, nurses, website developers, public health advocates and anyone else involved in health information dissemination should be especially tuned in to hard-hit e-patients' interest in gathering data and advice online.

E-patients facing serious challenges are likely to report strong feelings about their last health inquiry.

When recently challenged or diagnosed e-patients describe their last online health inquiry, they seem to have higher highs and lower lows than other e-patients:

- 74% say they felt **reassured** that they could make appropriate health care decisions, which is the same percentage as e-patients with no recent crises in their own lives or in the life of someone close to them.

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- 61% say they felt **confident** to raise new questions or concerns about a health issue with their doctor, which is significantly higher than the 51% of e-patients with no recent crises to report.¹⁹
- 58% say they felt **relieved** or **comforted** by the information they found online, compared with 54% of other e-patients.
- 57% say they felt **eager to share** their new health or medical knowledge with others, compared with 45% of other e-patients.
- 30% say they felt **overwhelmed** by the amount of information they found online, compared with 22% of other e-patients.
- 25% say they felt **frustrated** by a lack of information or an inability to find what they were looking for online, compared with 19% of other e-patients.
- 22% say they felt **confused** by the information they found online, compared with 14% of other e-patients.
- 13% say they felt **frightened** by the serious or graphic nature of the information they found online, compared with 7% of other e-patients.

ACOR members wrote about some of the emotions they feel as they search online for answers. For example:

- “As a parent of a child who, at 3 years old, was diagnosed with Acute Lymphoblastic Leukemia, it’s very overwhelming at the beginning. The child is hospitalized, all kinds of new terms and medical jargon is being thrown at you and you are emotionally overwhelmed and the same time trying to digest information that you never knew existed but has become extremely important to you. Having other parents available to help share their experiences is like having a lifeline.”
- “As the mother of a 4-year-old who was diagnosed with cancer, I was not able to look online or read about the disease until after treatment. I couldn’t handle the emotional turmoil of gaining knowledge which also scared me.”
- “I’ve had to educate myself very quickly – alone. Without the internet medical resources I would be sitting in libraries for time I don’t have, out of my house and without access to the amount and quality of information received [online].”
- “At the time of my diagnosis, my doctor assumed that I had already gone online to pursue treatment options and the standard course of regimens. I hadn’t. I was too overwhelmed and didn’t know where to turn.”
- “Anne has just been diagnosed. We are numb.”

A study published last year in the Journal of Health Communication interviewed newly diagnosed cancer patients about their first eight weeks of treatment and found that one-

¹⁹ The margin of error for comparison of recently challenged or diagnosed e-patients (n=758) and those who report no recent health challenges (n=836) is +/- 5%.

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fifth of patients who had not previously used the internet to gather health information became more active e-patients.²⁰

In addition, newly diagnosed cancer patients who used the internet during those first two months were more likely than non-user patients to ask their doctor questions during their last office visit and to say they have a “partnership” with their doctor. The authors note that the most popular reason for upgrading one’s connection to online health resources was the serious and life-threatening diagnosis of cancer, plus access to either a computer or someone close to them with a computer.

Unfortunately, people facing a serious diagnosis are the most likely group to be offline in an online world, to not only lack internet access, but also to lack friends and family who can go online for them. Americans age 70 and older and people living with chronic disease or disability are likely to benefit from the in-depth, just-in-time information available online, but are among the least likely groups to have access to it.

²⁰ “Relationship of Internet Health Information Use With Patient Behavior and Self-Efficacy: Experiences of Newly Diagnosed Cancer Patients Who Contact the National Cancer Institute’s Cancer Information Service,” by Sarah Bauerle Bass, Sheryl Burt Ruzek, Thomas F. Gordon, Linda Fleisher, Nancy McKeown-Conn, and Dirk Moore. (Journal of Health Communication, 11:219-236, 2006).

Methodology

All numerical data covered in this report is based on the findings of a daily tracking survey on Americans' use of the internet.

Telephone interviews were conducted by Princeton Survey Research Associates International between August 1 to August 31, 2006, among a sample of 2,928 adults, 18 and older. For results based on the total sample, one can say with 95% confidence that the error attributable to sampling and other random effects is plus or minus 2.0 percentage points. For results based on internet users (n=1,990), the margin of sampling error is plus or minus 3 percentage points. For results based on e-patients with chronic conditions (n=268), the margin of sampling error is +/- 7%. 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. More details on the design, execution and analysis of the telephone survey are discussed in the questionnaire associated with this report.

Online essays were collected on a site hosted by Association of Cancer Online Resources (ACOR). Respondents were primarily recruited from announcements posted on the mailing lists hosted by ACOR. In all, 1,680 individuals' responses were collected between November 14 and 20, 2006. Most respondents participate in the ACOR discussions as patients or caregivers and represent 87 of the 159 ACOR online communities.