Chronic Disease and the Internet

March 24, 2010

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http://pewinternet.org/Reports/2010/Chronic-Disease.aspx

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Summary of findings

Adults living with chronic disease are disproportionately offline in an online world.

Recent survey data from the Pew Internet Project and the California HealthCare Foundation show that adults living with chronic disease are significantly less likely than healthy adults to have access to the internet:

- 81% of adults reporting no chronic diseases go online.
- 62% of adults living with one or more chronic disease go online.

People managing multiple diseases are less likely to have internet access:

- 68% of adults reporting one chronic disease go online.
- 52% of adults living with two or more chronic diseases go online.

These findings are in line with overall trends in public health and technology adoption. Statistically speaking, chronic disease is associated with being older, African American, less educated, and living in a lower-income household. By contrast, internet use is statistically associated with being younger, white, college-educated, and living in a higher-income household. Thus, it is not surprising that the chronically ill report lower rates of internet access than other adults. However, when all of these demographic factors are controlled, living with a chronic disease in and of itself has an independent, negative effect on someone's likelihood to have internet access.

The internet access gap creates an online health information gap.

Looking at the population as a whole, 51% of American adults living with chronic disease have looked online for any of the health topics included in the survey, such as information about a specific disease, a certain medical procedure, prescription or over-the-counter drugs, or health insurance.

By comparison, 66% of adults who report no chronic conditions use the internet to gather health information.

Lack of internet access, not lack of interest in the topic, is the primary reason for the gaps. In fact, when demographic factors are controlled, internet users living with chronic disease are slightly *more* likely than other internet users to access health information online.

Health professionals dominate the information mix.

More than any other group, people living with chronic disease remain strongly connected to offline sources of medical assistance and advice:

- 93% of adults living with chronic disease ask a health professional for information or assistance in dealing with health or medical issues.

- 60% ask a friend or family member.
- 56% use books or other printed reference material.
- 44% use the internet.
- 38% contact their insurance provider.
- 6% use another source not mentioned in the list.

By comparison, adults who report no chronic conditions are significantly *more* likely to turn to the internet as a source of health information and *less* likely to contact their insurance provider.

However, the social life of chronic disease information is robust.

Interestingly, there are two activities which stand out among people living with chronic disease: blogging and online health discussions. When other demographic factors are held constant, having a chronic disease significantly increases an internet user's likelihood to say they work on a blog or contribute to an online discussion, a listserv, or other online group forum that helps people with personal issues or health problems.

Uptake for these activities is low overall, but those who have participated often praise the information they find. For example, one person wrote, "[An] online support group helped me learn about the disease and provided comfort in knowing that my symptoms were not 'just in my head,' and helped me take steps to adjust to living with a chronic condition." Another shared, "I live in a small town and it is helpful to be able to use the internet to find others that have the same condition as I do."

Living with chronic disease is also associated, once someone is online, with a greater likelihood to access user-generated health content such as blog posts, hospital reviews, doctor reviews, and podcasts. These resources allow an internet user to dive deeply into a health topic, using the internet as a communications tool, not simply an information vending machine.

The impact of online health information may be muted among people living with chronic disease.

Thirty-six percent of adults living with chronic disease say they or someone they know has been helped by following medical advice or health information found on the internet, which is significantly lower than the 45% of adults with no chronic disease.

Very few adults, regardless of health status, say they or someone they know has been harmed by following medical advice or health information found on the internet. Two percent of adults living with chronic disease report such harm, compared with 3% of adults with no chronic disease.

However, when asked if the health information found in their last online session had an impact on their own health care or the way they care for someone else, those who are living with chronic disease are significantly more likely than other internet users to say yes, their most recent inquiry made a difference.

The internet is like a secret weapon – if someone has access to it.

The deck is stacked against people living with chronic disease. They are disproportionately offline. They often have complicated health issues, not easily solved by the addition of even the best, most reliable, medical advice.

And yet, those who are online have a trump card. They have each other. This survey finds that having a chronic disease increases the probability that an internet user will share what they know and learn from their peers. They unearth nuggets of information. They blog. They participate in online discussions. And they just keep going.

Acknowledgements

This report is the result of collaboration between the Pew Internet Project and the California HealthCare Foundation.

The Pew Internet & American Life Project is an initiative of the Pew Research Center, a nonprofit "fact tank" that provides information on the issues, attitudes and trends shaping America and the world. The Project is nonpartisan and takes no position on policy issues. Support is provided by The Pew Charitable Trusts. Lee Rainie, Aaron Smith, and Kathryn Zickuhr provided editorial guidance and support throughout this project.

The California HealthCare Foundation is an independent philanthropy committed to improving the way health care is delivered and financed in California. Veenu Aulakh seeded and nurtured this research project, including an upcoming California-only report.

All quantitative, numerical data is based on a December 2008 national telephone survey conducted by Princeton Survey Research Associates International (PSRAI).

PSRAI is an independent firm dedicated to high-quality research providing reliable, valid results for clients in the United States and around the world. Evans Witt and Jennifer Su guided the quantitative research, overseeing interviews of 2,253 respondents, age 18 and older, in both English and Spanish, including 502 cell phone interviews.

All stories and quotes from consumers are based on qualitative surveys fielded in the summer and fall of 2009 on PatientsLikeMe and HealthCentral.

PatientsLikeMe is a free online community for patients with life-changing conditions to monitor and share the course of their disease. While patients interact to help improve their outcomes, the data they provide helps researchers, doctors and industry learn how these diseases act in the real world. Paul Wicks and Michael Massagli adapted and fielded a series of questions to a sample of members drawn from the Fibromyalgia, HIV, and Mood Disorders communities for a total of 258 completed surveys.

HealthCentral is a collection of condition and wellness websites providing clinical information, tools, and mobile applications. The sites provide a platform for over 3,000 bloggers, 200 expert patients, and millions of people sharing real-life experiences about specific conditions such as diabetes, asthma, and heart disease. Ted Smith and his patient analytics team adapted and fielded a series of questions to a sample of HealthCentral's audience for a total of 996 completed surveys.

In addition, Jane Sarasohn-Kahn, Gilles Frydman, and "E-patient Dave" deBronkart provided peer review comments before publication.

The authors would especially like to thank all the people who took the time to respond either to the telephone or the online surveys. Your responses are a gift and deeply affected our understanding of what life is like with chronic disease.

Main Report

Adults Living with Chronic Disease

Adults at every stage of life, in good health or poor health, say they use online resources to connect with each other and make better-informed decisions. In a prior report, “The Social Life of Health Information,” the Pew Internet Project and the California HealthCare Foundation reported on how the general population uses the internet to gather and share health advice.[1] The current study focuses on people living with chronic diseases.

According to the Centers for Disease Control (CDC), nearly half of adults in the U.S. are living with at least one chronic illness. [2] These diseases are among the top killers in the U.S. and represent a significant portion of health care spending.[3]

Online health resources play a supporting role in many people’s lives as they pursue better health and navigate the health care system, either as passive recipients of advice or as active “partners in their care.”[4] Disease-specific patient networks, which have been called “the chicken soup of the internet,” present an opportunity for people to harness social media tools not only for emotional support but to find practical tips and to weigh treatment options.[5] There is also a significant investment being made in the Nationwide Health Information Network, which is meant to bring together streams of medical information and ensure its secure exchange between health care consumers and providers.[6] However, the question remains: Are online health resources reaching the population most in need?

A national telephone survey, conducted in December 2008, asked about the following five chronic diseases: high blood pressure, lung conditions, heart conditions, diabetes, and cancer. This collection of diseases encompasses the most common conditions affecting Americans, but is narrower than the one used by the CDC, for example. This survey finds that 36% of adults in the U.S. say they are living with at least one of those five conditions and 13% say they have two or more.

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[1] Susannah Fox and Sydney Jones, “The Social Life of Health Information” (Pew Internet & American Life Project and the California HealthCare Foundation: June 11, 2009). See: http://www.pewinternet.org/Reports/2009/8-The-Social-Life-of-Health-Information.aspx

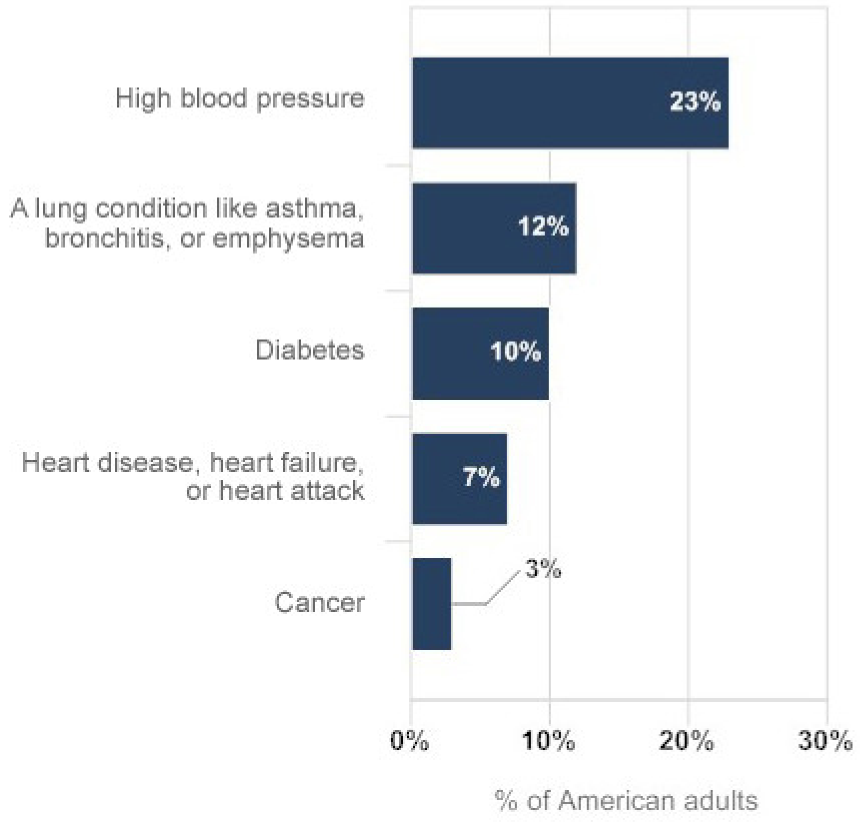
[2] Centers for Disease Control: Chronic Disease at a Glance 2009. See: http://www.cdc.gov/nccdphp/publications/AAG/chronic.htm

[3] Gerard Anderson, “Chronic Conditions: Making the Case for Ongoing Care” (Partnership to Fight Chronic Disease: November 2007). See: http://www.fightchronicdisease.com/news/pfcd/pr12102007.cfm

[4] Carol L. McWilliam, “Patients, persons or partners? Involving those with chronic disease in their care” (Chronic Illness: 2009; 5: 277-292). See: http://chi.sagepub.com/cgi/content/abstract/5/4/277

[5] Jane Sarasohn-Kahn, “The Wisdom of Patients: Health Care Meets Online Social Media” (California HealthCare Foundation, April 22, 2008). See: http://www.chcf.org/topics/chronicdisease/index.cfm?itemID=133631

[6] Office of the National Coordinator for Health Information Technology and the Agency for Healthcare Research and Quality are collaborating on this initiative: http://healthit.hhs.gov



Americans with chronic diseases

36% of adults say they have at least one of the following five chronic conditions. 13% of adults say they are living with two or more chronic conditions.

Source: Pew Internet & American Life Project Survey, November-December 2008. N=2253. Interviews conducted in English or Spanish. Margin of error is ±2%.

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The broader footprint of chronic disease emerges when loved ones are taken into account. This survey finds that 29% of adults say that although they do not have a chronic disease, someone close to them has a chronic medical condition such as asthma, diabetes, heart disease, high blood pressure, or cancer. Since half of health searches are conducted on behalf of someone else,[7] the social life of chronic disease information may be more wide-

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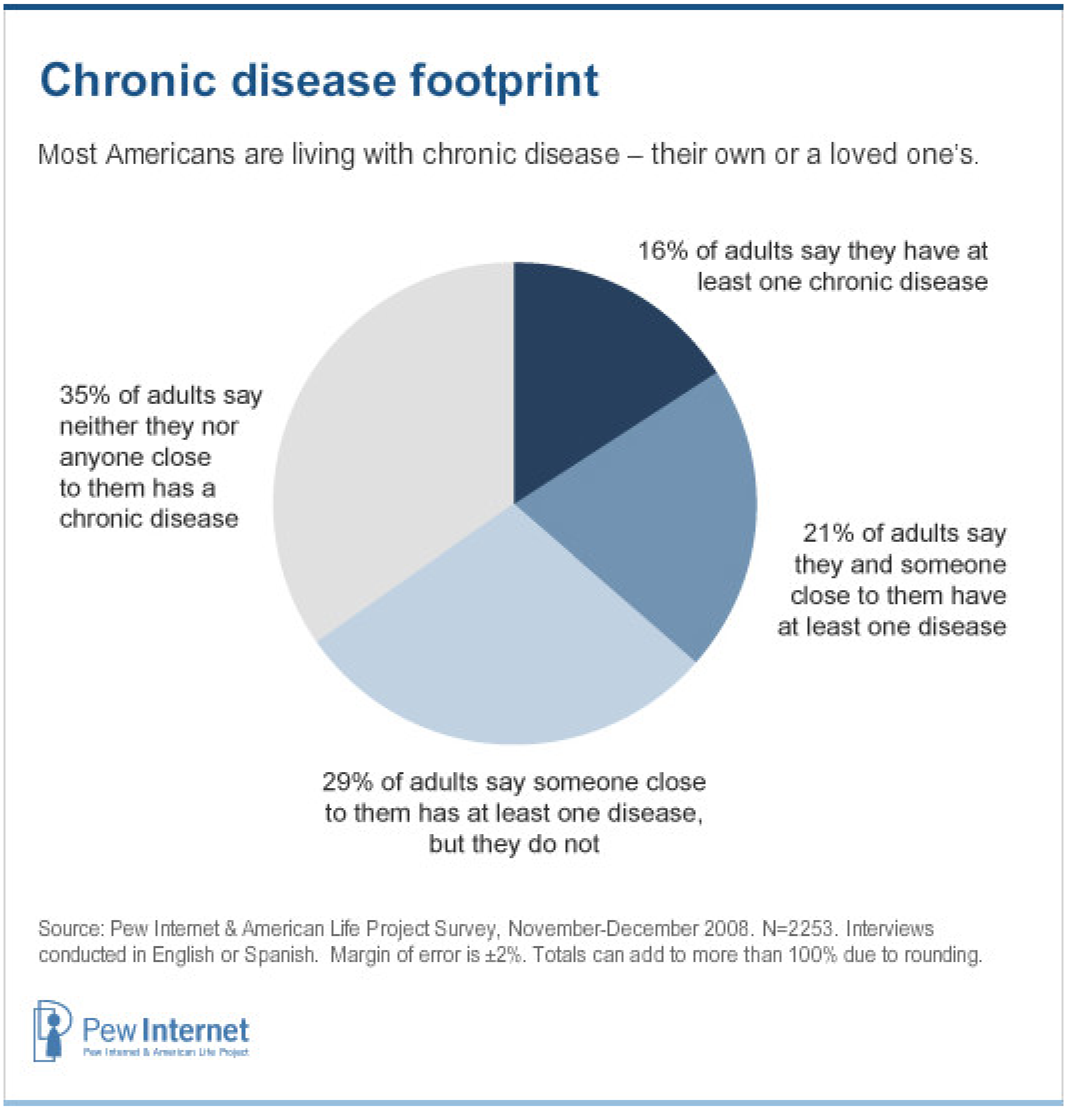
[7] 41% of internet users who have looked online for health information say their last search was related to their own health; 43% say it was related to someone else's health or medical situation; 9% say it was for both themselves and someone else.

ranging than might be suspected by looking only at the population of adults who live with these conditions. A forthcoming report from the Pew Internet Project will focus on family caregivers.



Chronic disease footprint

Most Americans are living with chronic disease – their own or a loved one's.

Source: Pew Internet & American Life Project Survey, November-December 2008. N=2253. Interviews conducted in English or Spanish. Margin of error is ±2%. Totals can add to more than 100% due to rounding.

One internet user may collect information to send to multiple friends and relatives, hoping to jump-start an interest in that person's health. As an e-patient wrote, "Both my brother and sister are diabetics. Neither is very concerned or tries hard to avoid foods that are bad for them. I send them reprints and copy anything I find. I am a pest but they need it. I also have a 58-year-old friend who is afraid to know his [A1C] numbers.[8] I also bombard him. Not knowing is no longer an excuse."

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[8] The "A1C" is a laboratory test used to monitor blood glucose levels over a 2- to 3-month interval. Someone's A1C numbers are a key indicator for diabetes management. For more information, please see: http://diabetes.niddk.nih.gov/dm/pubs/overview/

Internet access

The Pew Internet Project defines the internet user population by asking two questions:

> Do you use the internet, at least occasionally?
> Do you send or receive email, at least occasionally?

Those who answer "yes" to either question are included in the analysis as internet users. According to this definition, three-quarters of adults in the U.S. go online.[9] Yet, internet penetration drops as illness is added to the picture. Fully 81% of adults reporting no chronic conditions go online, compared with 62% of adults living with one or more chronic disease. The more diseases someone has, the less likely they are to have internet access: 68% of adults living with one chronic condition go online, compared with 52% of adults living with two or more chronic conditions.

These findings are in line with overall trends in public health and technology adoption. Statistically speaking, chronic disease is associated with being older, African American, less educated, and living in a lower-income household.[10] By contrast, internet use is statistically associated with being younger, white, college-educated, and living in a higher-income household.[11]

Thus, it is not surprising that the chronically ill report lower rates of internet access than other adults. However, when all of these demographic factors are controlled, living with a chronic disease in and of itself has an independent, negative effect on someone's likelihood to have internet access.

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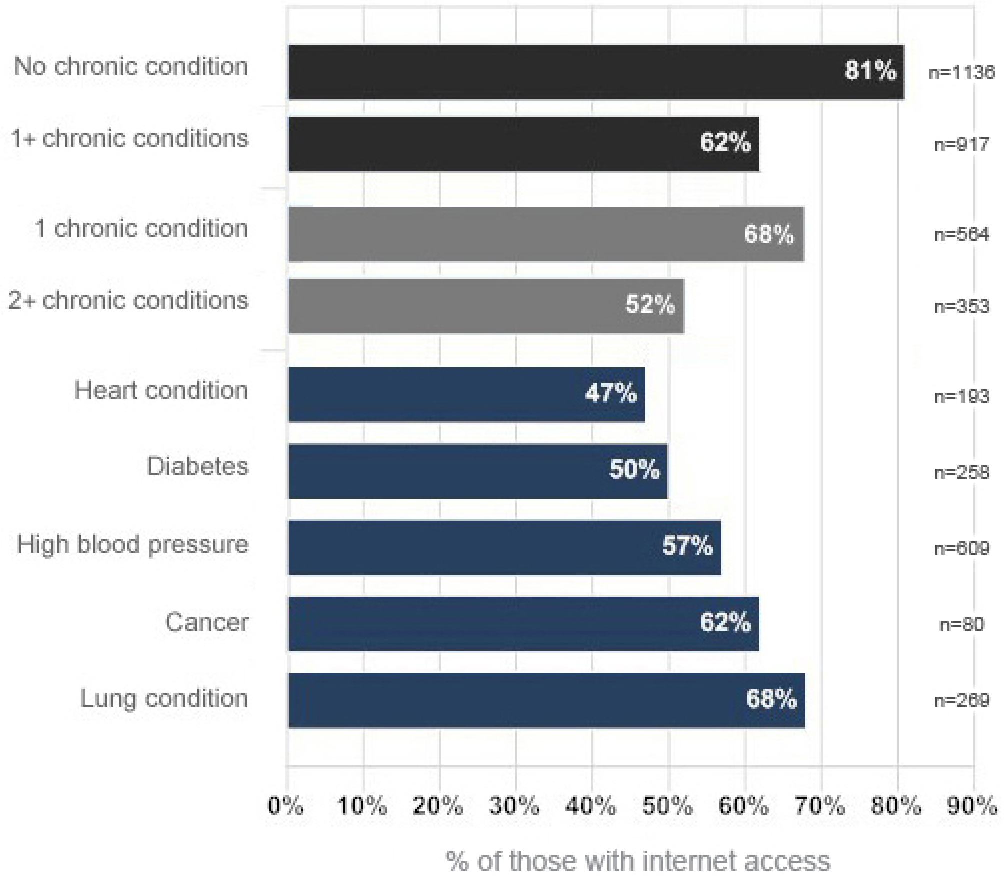
[9] Internet penetration rates increase, particularly for African American adults, when wireless access is taken into account. John Horrigan, "Wireless Internet Use" (Pew Internet & American Life Project: July 22, 2009). See: http://www.pewinternet.org/Reports/2009/12-Wireless-Internet-Use.aspx

[10] The MacArthur Research Network on Socioeconomic Status and Health lists extensive publications on this topic: http://www.macses.ucsf.edu/ The Mobilizing Action Toward Community Health project, a collaboration between the Robert Wood Johnson Foundation and the University of Wisconsin Population Health Institute, includes an interactive guide to health factors: http://www.countyhealthrankings.org/health-factors

[11] Lee Rainie, "Internet, broadband, and cell phone statistics" (Pew Internet Project: January 5, 2010). See: http://www.pewinternet.org/Reports/2010/Internet-broadband-and-cell-phone-statistics.aspx

Internet access by condition

The percentage of adults in each group who go online. Overall, 74% of adults in the U.S. go online.



Source: Pew Internet & American Life Project Survey, November-December 2008. N=2253. Interviews conducted in English or Spanish. Margin of error is ±2%. Note: Margins of error are higher when comparing subgroups.

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The remainder of this report focuses on three groups of adults in the U.S.: those living with at least one of the five chronic disease (the broadest group, encompassing those living with one, two, or more conditions); those living with two or more conditions (who provide the starkest contrast); and those who report having none of the diseases named in the survey.

The Demographics of Chronic Disease

Adults living with chronic disease are likely to be age 50+ and living in lower-income households.

	No conditions	1+ conditions	2+ conditions
Sex			
Men	48%	46%	44%
Women	52	54	56
Race/Ethnicity			
White (non-Hispanic)	69%	70%	70%
African American (non-Hispanic) (n=225)	11	15	17
Hispanic (n=199)	12	8	7
Other	6	5	4
Age			
18-29	22%	12%	5%
30-49	36	24	14
50-64	24	32	34
65+	16	30	45
Education			
Less than high school	14%	19%	27%
High school diploma	32	34	33
Some college	26	26	24
College graduate	26	21	16
Household income			
Less than $30,000	27%	34%	43%
$30,000-$49,999	18	16	14
$50,000-$74,999	13	11	10
$75,000 or more	25	16	10
Don't know/refused	20	22	23
Number of respondents	**N=1136**	**N=917**	**N=353**

Source: Pew Internet & American Life Project Survey, November-December 2008. N=2253. Interviews conducted in English or Spanish. Margin of error is ±6%.

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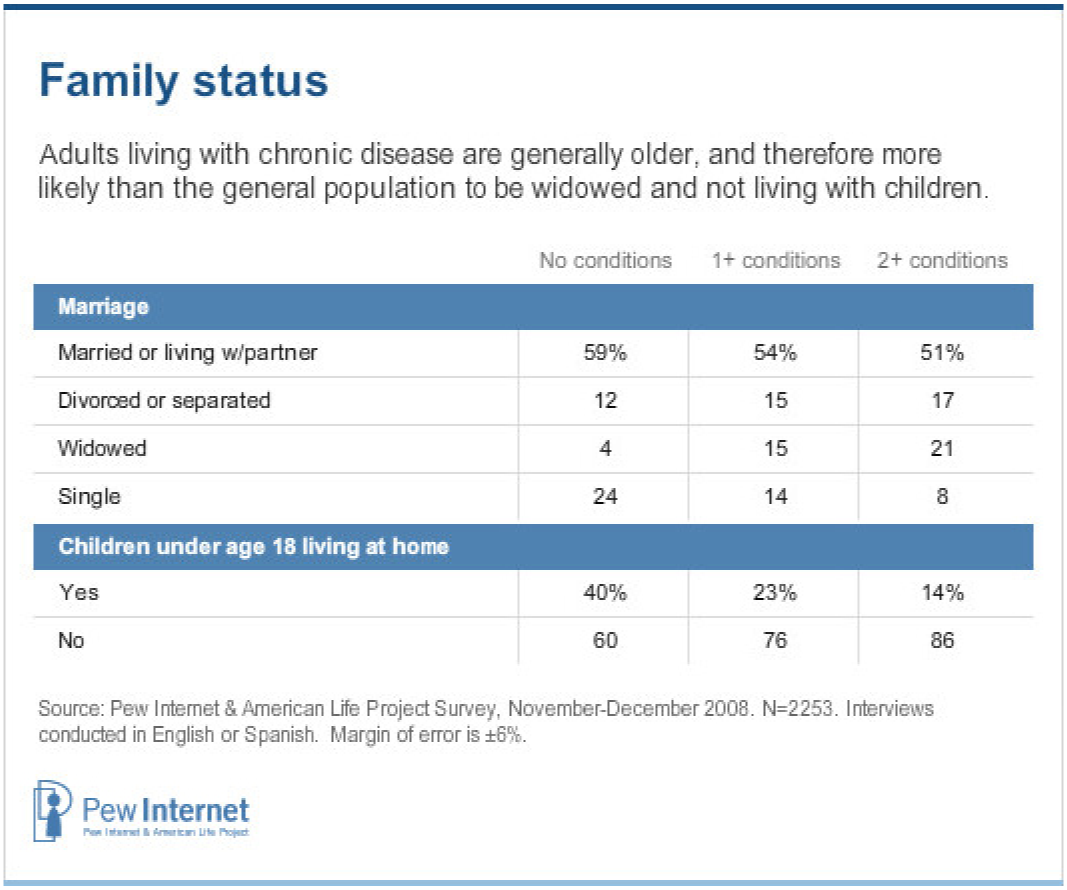

Family status

Adults living with chronic disease are generally older, and therefore more likely than the general population to be widowed and not living with children.

	No conditions	1+ conditions	2+ conditions
Marriage			
Married or living w/partner	59%	54%	51%
Divorced or separated	12	15	17
Widowed	4	15	21
Single	24	14	8
Children under age 18 living at home			
Yes	40%	23%	14%
No	60	76	86

Source: Pew Internet & American Life Project Survey, November-December 2008. N=2253. Interviews conducted in English or Spanish. Margin of error is ±6%.

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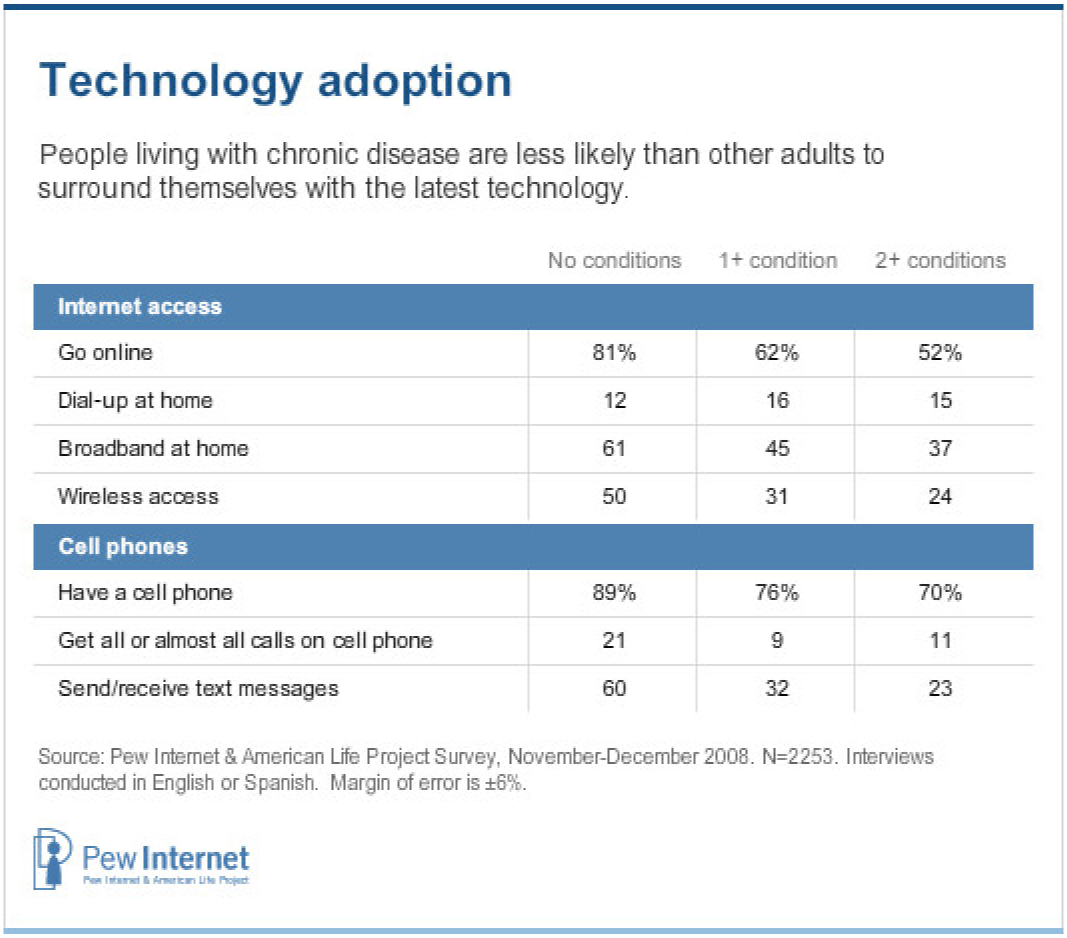

Technology adoption

People living with chronic disease are less likely than other adults to surround themselves with the latest technology.

	No conditions	1+ condition	2+ conditions
Internet access			
Go online	81%	62%	52%
Dial-up at home	12	16	15
Broadband at home	61	45	37
Wireless access	50	31	24
Cell phones			
Have a cell phone	89%	76%	70%
Get all or almost all calls on cell phone	21	9	11
Send/receive text messages	60	32	23

Source: Pew Internet & American Life Project Survey, November-December 2008. N=2253. Interviews conducted in English or Spanish. Margin of error is ±6%.

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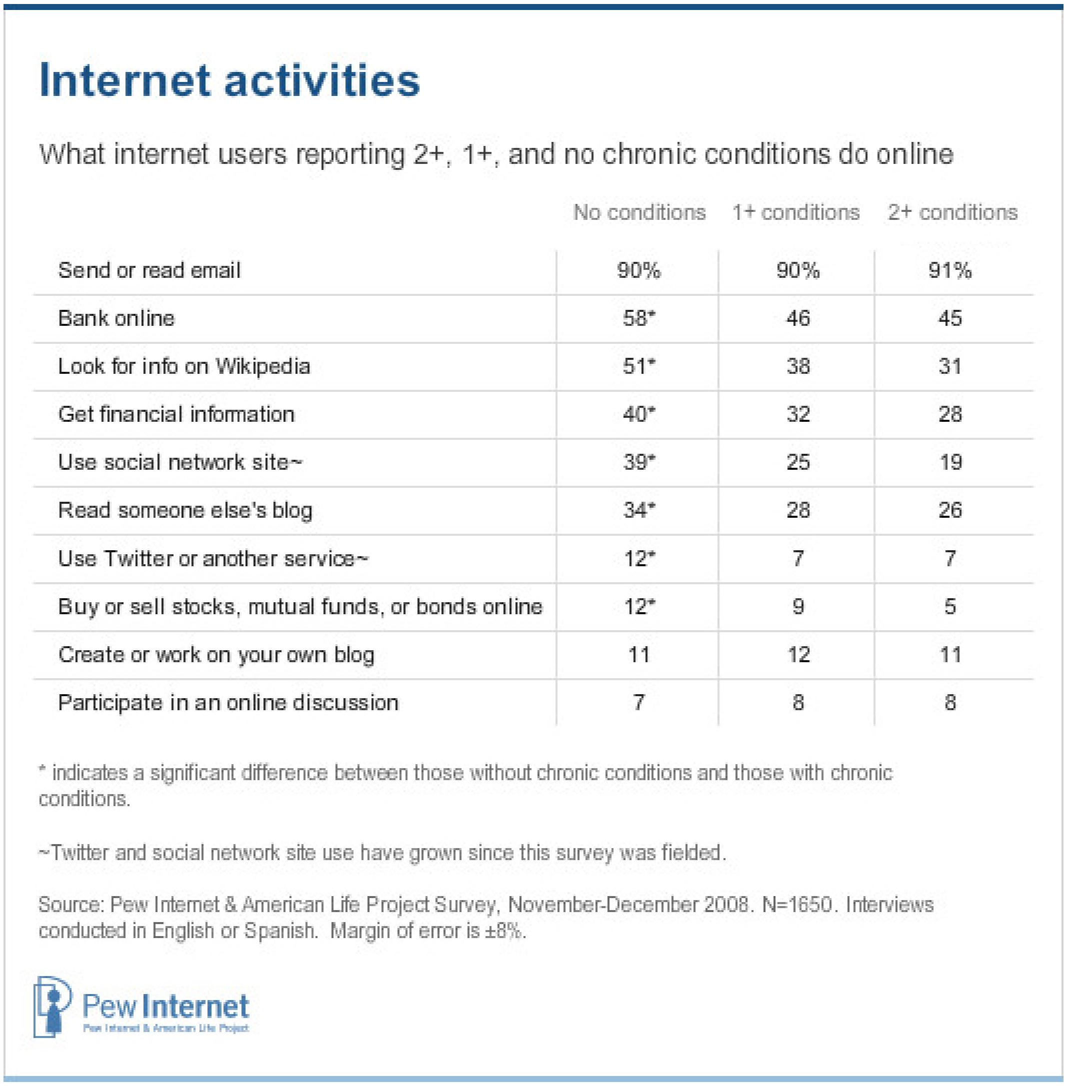
Online activities

Internet users living with chronic disease generally stay in the shallow end of the online activities pool. They are less likely than internet users who report no chronic conditions to bank online, look for information on Wikipedia, use a social network site, or get financial information online.

Two activities stood out in the analysis, however: blogging and participating in an online discussion. Holding all other variables constant, living with chronic disease increases the probability that an internet user will say they work on a blog or contribute to an online discussion, a listserv, or other online group forum that helps people with personal issues or health problems. These resources allow an internet user to dive deeply into a health topic, using the internet as a communications tool, not simply an information vending machine.



Internet activities

What internet users reporting 2+, 1+, and no chronic conditions do online

	No conditions	1+ conditions	2+ conditions
Send or read email	90%	90%	91%
Bank online	58*	46	45
Look for info on Wikipedia	51*	38	31
Get financial information	40*	32	28
Use social network site~	39*	25	19
Read someone else's blog	34*	28	26
Use Twitter or another service~	12*	7	7
Buy or sell stocks, mutual funds, or bonds online	12*	9	5
Create or work on your own blog	11	12	11
Participate in an online discussion	7	8	8

* indicates a significant difference between those without chronic conditions and those with chronic conditions.

~Twitter and social network site use have grown since this survey was fielded.

Source: Pew Internet & American Life Project Survey, November-December 2008. N=1650. Interviews conducted in English or Spanish. Margin of error is ±8%.

To understand the patterns of technology use among adults, the Pew Internet Project has used statistical techniques to isolate the factors associated with an adventurous engagement in a wide range of online activities. We have consistently found that the older someone is, the less likely they are to sample all that the internet has to offer, as are those with less education and lower incomes.[12] In addition, the more an internet user is tethered to a stationary, home internet connection, the less likely they are to venture far and wide online.[13]

While a majority of internet users have wireless internet access,[14] just one-quarter of internet users living with two or more chronic diseases have such access. People living

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[12] Sydney Jones and Susannah Fox, "Generations Online in 2009" (Pew Internet Project: January 28, 2009). See: http://www.pewinternet.org/Reports/2009/Generations-Online-in-2009.aspx

[13] John Horrigan, "The Mobile Difference" (Pew Internet Project: March 25, 2009). See: http://www.pewinternet.org/Reports/2009/5-The-Mobile-Difference--Typology.aspx

[14] Lee Rainie, "Internet, broadband, and cell phone statistics" (Pew Internet Project: January 5, 2010). See: http://www.pewinternet.org/Reports/2010/Internet-broadband-and-cell-phone-statistics.aspx

with chronic disease are likely to be advanced in age, living in lower-income households, and lagging behind the general population in technology adoption. Once again, statistical techniques show that in addition to these factors, the presence of chronic disease has a small but significant negative effect on wireless adoption.

Daily internet use

In order to capture a picture of a typical day online, we ask each respondent, “Did you happen to use the internet yesterday?” It turns out that 60% of internet users living with chronic disease are online on a typical day, compared with 74% of internet users who report no chronic diseases.

This gap carries over into online activities. For example, email is nearly universal, but just 44% of internet users living with two or more chronic diseases and 56% of internet users living with one disease send or receive email on a typical day, compared with 61% of internet users who report no chronic diseases. This pattern is repeated in all the other activities included in this survey. Most internet users living with chronic disease have not made the internet a part of their daily routine and continue to rely on offline information and communications resources.

Health information

Looking at the population as a whole, 51% of American adults living with chronic disease have looked online for any of the health topics we ask about, such as information about a specific disease, a certain medical procedure, prescription or over-the-counter drugs, or health insurance.

By comparison, 66% of adults who report no chronic conditions use the internet to gather health information and 44% of adults living with two or more conditions do so. (Throughout the remainder of the report, the term “e-patient” is used to describe an internet user who has looked online for health information.)

Lack of internet access, not lack of interest in the topic, is the primary reason for the gaps. In fact, statistical analysis finds that, once online, having a chronic disease has a positive effect on someone’s propensity to look online for health information. Education and type of access (broadband or wireless) are still the strongest predictors for seeking health information online but the more diseases an internet user reports, the more likely they are to seek advice online, independent of all other demographic factors.

The motivations to go online for health information are probably as varied as the topics people research. People living with chronic disease are likely to be managing multiple conditions, filling multiple prescriptions, and visiting multiple doctors.[15] In fact, a Harris Interactive study found that 17% of people living with chronic conditions reported receiving conflicting information from providers and 18% reported having duplicate tests

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[15] Anderson, 2007

or procedures performed.[16] And again, the internet can be an information vending machine for some users and a powerful communications resource for others, depending on the nature of their illness or their level of interest in a certain topic.

Health topics

There is almost a universality of interest in the following health topics, no matter someone's health status. Chronic disease increases someone's propensity to look for information about many of these topics, though not all. In addition, information seeking for many of these topics is driven by key demographic factors such as being female, holding a college degree, having broadband at home. These influences are noted in the text below.

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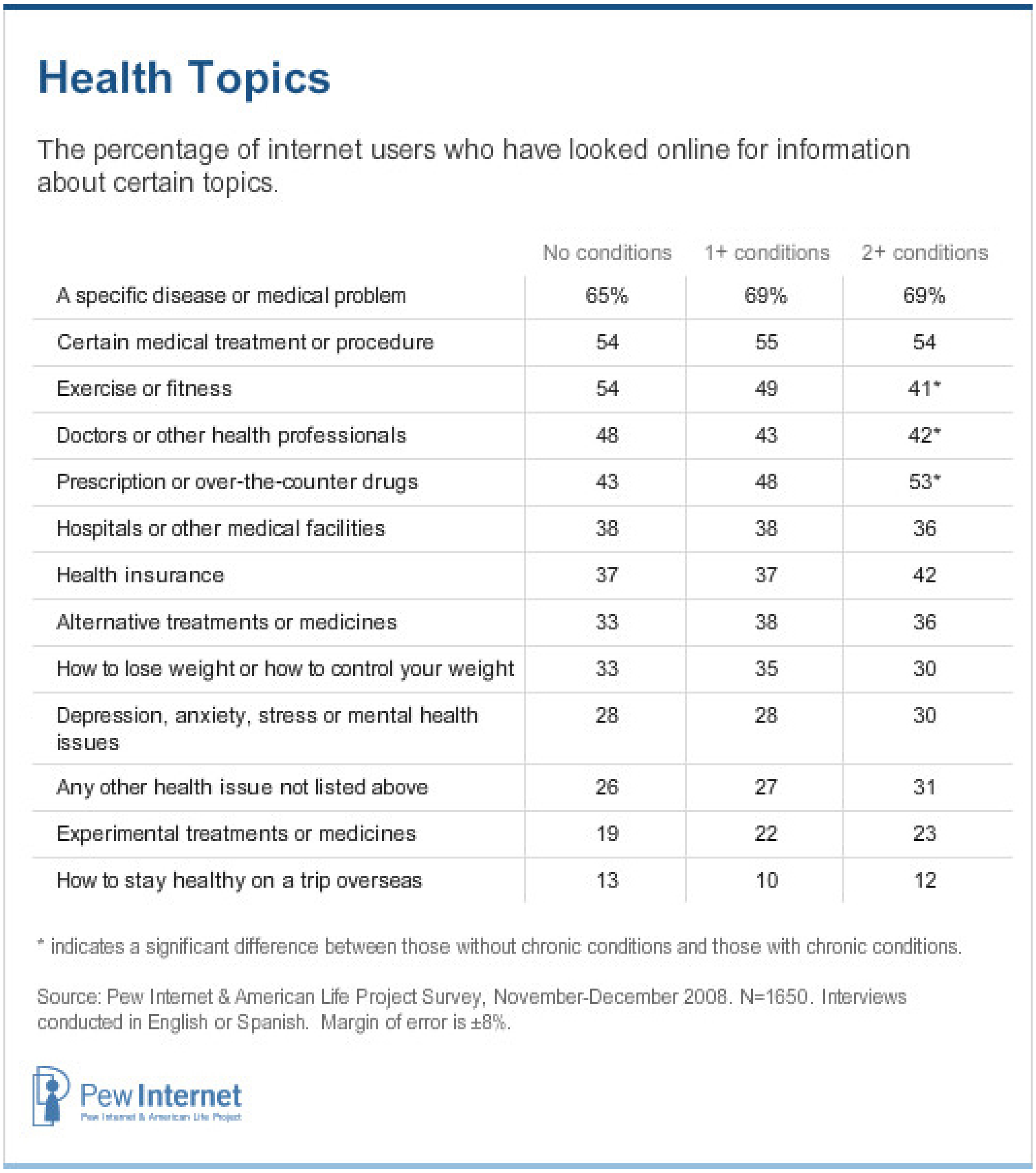
[16] Harris Interactive, "Chronic Illness and Caregiving." (2000).



Health Topics

The percentage of internet users who have looked online for information about certain topics.

	No conditions	1+ conditions	2+ conditions
A specific disease or medical problem	65%	69%	69%
Certain medical treatment or procedure	54	55	54
Exercise or fitness	54	49	41*
Doctors or other health professionals	48	43	42*
Prescription or over-the-counter drugs	43	48	53*
Hospitals or other medical facilities	38	38	36
Health insurance	37	37	42
Alternative treatments or medicines	33	38	36
How to lose weight or how to control your weight	33	35	30
Depression, anxiety, stress or mental health issues	28	28	30
Any other health issue not listed above	26	27	31
Experimental treatments or medicines	19	22	23
How to stay healthy on a trip overseas	13	10	12

* indicates a significant difference between those without chronic conditions and those with chronic conditions.

Source: Pew Internet & American Life Project Survey, November-December 2008. N=1650. Interviews conducted in English or Spanish. Margin of error is ±8%.

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Specific disease or medical problem

Overall, 69% of internet users living with chronic disease report that they have looked online for information about a specific disease or medical problem, compared with 65% of internet users who report none of the chronic conditions named in the survey. This does not represent a significant difference between the two groups. However, among internet users, being female, having a college degree, or having home broadband access increases the likelihood to look for this type of information online. Chronic disease also slightly increases the probability that an internet user will look online for information about a specific disease or medical problem.

One e-patient wrote about receiving an unexpected diagnosis and needing specific information, on her own time: “[The] doctor just called on the phone and said I had it and did I have any questions. I was in too much shock at that moment and was crying and emotional so I couldn't think of anything to ask. Later, I got on the internet and went to many sites that gave me very good and helpful information. My fears were calmed somewhat. I am still confused about the disease and have many questions so I have scheduled an appointment with the doctor.”

Certain medical treatment or procedure

55% of internet users living with chronic disease report that they have looked online for information about a certain medical treatment or procedure, compared with 54% of internet users who report none of the chronic conditions named in the survey. Again, this does not represent a meaningful difference, but statistical analysis finds that being female, having a college degree, having home broadband access, or living with chronic disease all increase an internet user’s likelihood to look online for this type of information.

One e-patient wrote about her motivation to find out everything she could about her condition: “If I had not done my own research then I would have not known to request the surgery that saved my hip. I learned early to do my own research and not rely on the doctor. By my own family doctor’s admission, I knew more than he did by the time I was done.”

Exercise or fitness

49% of internet users living with chronic disease report that they have looked online for information about exercise or fitness, compared with 54% of internet users who report none of the chronic conditions named in the survey. This gap represents a significant difference between the two groups. In addition, being young, non-white, female, or college-educated are each predictors for doing online research about this type of information.

Those chronically-ill internet users who do search for this type of information online can find valuable insights to help them manage their illness. One respondent wrote that, rather than finding any new treatments for her condition during her most recent foray online, she found new exercises to try to alleviate both her physical symptoms and her mental state: “I am under a lot of stress and don’t know what to do about it.”

Prescription or over-the-counter drugs

48% of internet users living with chronic disease report that they have looked online for information about prescription or over-the-counter drugs, compared with 43% of internet users who report none of the chronic conditions named in the survey. This is the one topic which is significantly more popular among internet users living with chronic disease than among non-chronic internet users, which is in line with studies conducted by Manhattan

Research.[17] Statistical analysis shows that the presence of chronic disease has an independent effect on someone's likelihood to seek information about drugs – the greater the number of diseases reported, the greater the interest in this type of information. In addition, a college degree, broadband, or being female are each associated with a propensity to do online research about prescription or over-the-counter drugs.

Many respondents to the qualitative survey report looking up new prescriptions, either for themselves or on behalf of a loved one. Typical of this theme is the e-patient who wrote, "I always look up new prescriptions and check if new pills will interact with the many that I am already taking."

Doctors or other health professionals

43% of internet users living with chronic disease report that they have looked online for information about doctors or other health professionals, compared with 48% of internet users who report none of the chronic conditions named in the survey. This represents a statistically significant difference between the two groups. In addition, among internet users, being female, having a college degree, or having home broadband access increases the likelihood to look online for information about doctors and other health professionals.

For those chronically ill internet users who do look for this information on the internet, shopping for a doctor online is still a new concept for many people. The information available about health professionals fell short of expectations for one respondent, but she does have a wish list for the future: "I would love it if doctors were rated and blogged about so the majority of patients wouldn't end up with bad doctors or that doctors would try harder because they know that they are being reviewed."

Health insurance

37% of internet users living with chronic disease report that they have looked online for information related to health insurance, including private insurance, Medicare or Medicaid, the same percentage as internet users who report none of the conditions named in the survey. Once again, being female, having a college degree, or having home broadband access increases an internet user's likelihood to look online for information about health insurance.

None of the respondents to the qualitative survey mentioned using the internet to get information about health insurance (it is likely that those living with chronic illness are in touch with their insurance providers on a fairly regular basis by telephone or mail, and are already deeply familiar with their plan and coverage). Nearly all of the responses who did mention health insurance expressed frustration, some using language that cannot be printed here.

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[17] Manhattan Research, "The Online Pharmaceutical Information-Seeking Landscape." See: http://www.manhattanresearch.com/research/white-papers/consumer-digital-pharma-landscape.aspx

Hospitals

38% of internet users living with chronic disease report that they have looked online for information about hospitals or other medical facilities, the same percentage as those who report none of the chronic conditions named in the survey. Statistical analysis shows that the presence of disease in someone's life has an independent, positive effect on their likelihood to look online for this type of information. Being female, having a college degree, or having home broadband access increases an internet user's likelihood to look online for this type of information.

One respondent told about how, before seeking treatment, she searched online for a list of local hospitals and reviewed the doctors listed on each website. As she writes, "Some were eliminated based on past negative experiences. I eventually chose a hospital with which I had previous excellent care."

Alternative medicine

38% of internet users living with chronic disease report that they have looked online for information about alternative treatments or medicines, compared with 33% of internet users who report none of the chronic conditions named in the survey. Statistical analysis shows that having wireless access is strongly associated with a propensity to look online for this type of information. Having a college degree, being female, or living with chronic disease are also associated, but to a lesser degree, with looking online for information about alternative treatments.

Many chronic e-patients wrote about their online research related to alternative treatments. The following is a typical comment shared in the qualitative survey: "I have learned other ways to keep my blood pressure in control, e.g. deep breathing and relaxation, so I don't depend entirely on drugs."

Mental health

28% of internet users living with chronic disease report that they have looked online for information about depression, anxiety, stress or mental health issues, the same percentage as those who report none of the chronic conditions named in the survey. Statistical analysis shows that, among internet users, as the number of chronic diseases someone has increases, the more likely they are to seek information online about mental health issues, independent of other factors. Being young or being female are also associated a propensity to do this type of research online.

Coping with mental health issues was a theme threaded through many of the online essays, including this quote: "I love to be able to talk to others who know how bad depression can be from their own experiences."

Weight loss

35% of internet users living with chronic disease report that they have looked online for information about how to lose weight or how to control their weight, compared with 33% of internet users who report none of the chronic conditions named in the survey. Being young, non-white, female, or college-educated are each predictors for doing online research about this type of information, as is having wireless internet access. Chronic illness is not correlated with seeking this type of information.

One e-patient wrote about how she hopes to lose weight and lower her high blood pressure but her diet searches have been in vain: “All I ever get back or find is ‘stay away from salt.’ Well, I don't use salt and I watch what I buy that has salt already in it. All I want is a diet to follow where I'm not eating like a rabbit and can enjoy eating.”

Another e-patient living with diabetes wrote, “I have a hard time fighting to remember to not eat carbs. [Certain websites] have been extremely valuable to keeping me on line and always coming back to my goals.”

Experimental treatments

22% of internet users living with chronic disease report that they have looked online for information about experimental treatments or medicines, compared with 19% of internet users who report none of the chronic conditions named in the survey. Statistical analysis shows that as the number of chronic diseases someone has increases, the more likely they are to seek information online about experimental treatments, independent of other factors.

One respondent shared that she found herself caught between her medical doctor and her chiropractor, who each dismissed the other’s advice about experimental treatments. She writes, “I was able to find how the two treatments would be complementary if performed correctly. Once I gave my doctors this information they both felt more comfortable with the other doctor’s way of treating me.”

Immunizations for travel

10% of internet users living with chronic disease report that they have looked online for information about how to stay healthy on a trip overseas (such as immunizations and shots), compared with 13% of internet users who report none of the chronic conditions named in the survey. Having a wireless connection, being non-white, or living in a lower-income household each increase an individual’s propensity to look online for this type of information.

None of the respondents to the qualitative survey wrote about this health topic.

Any other health topic

27% of internet users living with chronic disease report that they have looked online for information about any other health issue, not included in our list, compared with 26% of internet users who report none of the chronic conditions named in the survey.

This question was included as a catch-all to be sure everyone who has done online health research is included in the analysis. The essays collected in the qualitative surveys are a window into the variety of health information sought online from home remedies to nutritional information to smoking cessation tips.

Few are engaged daily or even weekly with online health resources.

The vast majority of internet users living with chronic disease (83%) look online for health information. However:

- 81% of internet users living with chronic disease say they go online and do something related to health *less often than once a week.*
- 10% say they do so once a week.
- 5% say they do so every few days.
- Only 3% say they go online and do something related to health once a day or more.

These findings match the habits of the general population of internet users: 81% of all internet users say they go online and do something related to health less often than once a week.

Similarly, Harris Interactive has found that 25% of internet users "often" look for information online about health topics, compared with 38% of internet users who "sometimes" look and 36% of internet users who "hardly ever" or "never" look online for health information.[18]

It appears that online health research is generally conducted episodically, on a need-to-know basis. People living with chronic disease, much like everyone else, are busy working and socializing, hoping to avoid the need to investigate a new diagnosis or treatment. Frequency is not necessarily an indication – in either direction – for the quality of someone's engagement with online health resources.

Chronic disease requires a focus on one's own health questions.

Not surprisingly, e-patients living with one or more chronic diseases are often focused on their own concerns: 51% say their last online health inquiry centered on their own medical situation. Thirty-four percent say their last health search focused on someone

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[18] Harris Interactive's Healthcare News, Volume 8, Issue 8, August 2008. See: http://www.harrisi.com/news/newsletters/healthnews/HI_HealthCareNews2008Vol8_Iss8.pdf

else’s concerns. Eight percent volunteer that their last inquiry was on behalf of both themselves and someone else.

By comparison, e-patients who report none of the chronic diseases recorded in this survey are likelier to say their last health search focused on someone else’s concerns. Thirty-seven percent say they were looking on behalf of themselves, 47% say they were looking on behalf of another person, and 10% volunteer that the last search was for both themselves and someone else.

Statistical analysis bears out this observation. If someone is dealing with a chronic disease they are more likely than other e-patients to research their own questions, regardless of their age, education level, or other demographic variables.

Health professionals dominate the information mix.

More than any other group, people living with chronic disease remain strongly connected to offline sources of medical assistance and advice.

When asked, "Now thinking about all the sources you turn to when you need information or assistance in dealing with health or medical issues, please tell me if you use any of the following sources..."

- 93% of adults living with chronic disease ask a health professional, such as a doctor.
- 60% ask a friend or family member.
- 56% use books or other printed reference material.
- 44% use the internet.
- 38% contact their insurance provider.
- 6% use another source not mentioned in the list.

By comparison, adults who report no chronic conditions are significantly *more* likely to turn to the internet as a source of health information and *less* likely to contact their insurance provider:

- 83% of adults who say they have no chronic conditions ask a health professional, such as a doctor, when they need medical assistance or information.
- 64% ask a friend or family member.
- 60% use the internet.
- 52% use books or other printed reference material.
- 29% contact their insurance provider.
- 5% use another source not mentioned in the list.

Statistical analysis shows that living with a chronic disease has a significant, independent effect on someone’s likelihood to stick with offline sources. In fact, although other factors, such as advanced age, are associated with a reliance on offline health resources, having a chronic disease is the strongest predictor of all the variables included in the analysis.

The qualitative survey yielded many stories about how the internet is a supplement, not a substitute, for the care and advice people receive from health professionals. One breast cancer survivor wrote about how she uses the internet to prepare for appointments: "I was never great about asking my doctor the questions that needed to be asked. Now I ask away and never go without asking what's important about my health and anything I just want to know."

Other research bears out this finding. Over the course of three national surveys conducted by the National Cancer Institute, researchers found that "the public's trust in physicians as their preferred source of health information has remained high and, if anything, increased from 2002 to 2008." When respondents were asked where they went first for cancer information, however, the internet was their top choice. In fact, even as trust in physicians remained steady and trust in the internet decreased, the use of the internet as a first stop for respondents seeking health information rose over time.[19]

There is also evidence that people living with chronic disease are discriminating about what sites they visit, when they do go online. A 2006 survey by the Pew Internet Project found that e-patients living with chronic conditions were also more likely than other internet users to go to trusted sites instead of relying on a general search engine to answer their questions.[20]

In the current study, one e-patient wrote, "I hesitate to say 'internet' because I am very picky on the resources I use. I prefer using websites that are written for professionals dealing with the disease because they don't 'talk down' to me."

Another e-patient wrote, "I send links of relevant articles to my friends and/or family and have many discussions with my husband and 19 year old son… I am a pretty good diagnostician. However, the best advice I give is 'You should see a doctor about that!'"

People living with chronic conditions have good reason to be careful about health information: the consequences of missed opportunities can be very serious. One respondent told about how, in 2003, she heard disturbing news about a medication she was taking. She went to a major disease-specific, consumer-oriented website and found nothing about it. As she wrote, "Now the drug comes with warnings about heart related issues. Would have been nice to know about those things years ago when they kept denying that there was a problem."

Once they find health information online, most talk it over with friends and family.

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[19] Bradford W. Hesse, Richard P. Moser, and Lila J. Rutten, "Surveys of Physicians and Electronic Health Information." (*New England Journal of Medicine*: 2010 Mar 4;362(9):859-60.)

[20] Susannah Fox, "E-patients With a Disability or Chronic Disease." (Pew Internet Project: October 8, 2007). See: http://www.pewinternet.org/Reports/2007/Epatients-With-a-Disability-or-Chronic-Disease.aspx

Most internet users, once they find health information online, usually talk with someone about it, regardless of their health status. Two-thirds of e-patients living with chronic disease (66%) say they usually talk with a friend, a spouse or partner, a family member, a co-worker, or a medical professional. The pattern is the same among e-patients who report no chronic disease.

One respondent to the online survey wrote, “I research everything and then discuss with my doctor and family who have to deal with my condtion.” Another shared that, because of her online research, “I am better able to give intelligent answers to my doctor's questions on my health generally.”

Social media and health

More than half of e-patients living with chronic disease consume user-generated health information.

The Pew Internet Project has tracked the internet’s role in decision-making, finding that many people use online resources to compare their options.[21] Social media’s influence is on the rise as more and more people look for advice from peers as well as experts.[22] The idea is that, if people can pool knowledge and learn to track their own health metrics, such as their weight or cholesterol counts, they can make better choices and have better health outcomes.[23]

Among e-patients living with chronic disease:

- 37% have read someone else's commentary or experience about health or medical issues on an online news group, website, or blog.
- 25% have consulted rankings or reviews online of hospitals or other medical facilities.
- 25% have consulted rankings or reviews online of doctors or other providers.
- 22% have signed up to receive updates about health or medical issues.
- 13% have listened to a podcast about health or medical issues.

Overall, 57% of e-patients living with chronic disease have done at least one of the above activities. These findings mirror patterns in the general population: e-patients living with chronic disease are about as likely as the general population of e-patients to tap into user-generated health content. [24] However, statistical analysis shows that when age, education,

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[21] Lee Rainie, Leigh Estabrook, and Evans Witt, “Information Searches That Solve Problems.” (Pew Internet Project: December 30, 2007) See: http://www.pewinternet.org/Reports/2007/Information-Searches-That-Solve-Problems.aspx

[22] Edelman, “Health Engagement Barometer.” See: http://www.engageinhealth.com/

[23] Thomas Goetz, *The Decision Tree: Taking Control of Your Health in the New Era of Personalized Medicine* (2010)

[24] Fox and Jones, 2009. See also: Forrester Research’s Social Technographics Ladder: http://www.forrester.com/Groundswell/ladder.html

and type of internet access are controlled, living with chronic disease increases the likelihood that an internet user will consume user-generated health content.

In the modern world, blogs and other online meeting grounds provide a way for people to share information, emotional support, and practical advice.[25] This is the 21st century version of the age-old instinct to seek solace in the community. Thomas Jefferson captured the sentiment in a letter to a friend in 1786, "Who then can so softly bind up the wound of another as he who has felt the same wound himself?"[26]

On a more practical level, one e-patient wrote, “I was having problems sleeping [because of] hip pain. Through this site I received info about proper ways to set up my bed and since then have been sleeping so much better.”

Another respondent wrote, “I read the Gluten Free Forum daily for about a year before I really got my celiac disease under control and felt fully informed. You can't call your gastroenterologist everytime you buy a new product.”

By contrast, another e-patient does not find the community aspect of online health information to be useful, writing, “I don’t find chat rooms helpful because most people are sharing how horrible they feel and I am beyond that. I have bad days but I feel dragged down when I whine about them or listen to others talk about their problems with doctors, family, etc. I don’t have those problems.”

One in five e-patients living with chronic disease create online health content.

Among e-patients living with chronic disease:

- 7% of chronic e-patients have tagged or categorized online content about health or medical issues.
- 7% have posted comments, queries, or information about health or medical matters in an online discussion, listserv, or other online group forum.
- 6% have posted a review online of a hospital.
- 5% have posted a review online of a doctor.
- 4% have shared photos, videos or audio files online about health or medical issues.
- 6% have posted comments about health on a blog.

Overall, 20% of e-patients living with chronic disease have done at least one of the above activities, which matches the general population of e-patients.

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[25] Regina Overberg, et al. “How Breast Cancer Patients Want to Search for and Retrieve Information From Stories of Other Patients on the Internet: an Online Randomized Controlled Experiment” (Journal of Medical Internet Research 2010; Mar 09; 12(1):e7). See: http://www.jmir.org/2010/1/e7/HTML

[26] Letter from Thomas Jefferson to Maria Cosway, 1786: http://www.pbs.org/jefferson/archives/documents/ih195811.htm

Despite the fact that only a subset of chronic e-patients take part in these activities, it is worth noting once again that, when other demographic factors are held constant, living with chronic disease increases the probability that an internet user will contribute to the online conversation. Specifically, chronic disease increases the likelihood to work on a blog, to post comments on a blog, or to contribute to an online discussion, a listserv, or other online group forum that helps people with personal issues or health problems.

One e-patient wrote, “I spend a lot of time looking for information on the internet. It has been an invaluable resource for me. In addition, I keep a blog so that I can keep all my information in one place. Having a rare disorder along with chronic pain, I need all the help I can get – but I do great. I have a full time job, and participate in many activities, including a half marathon in May – and many of the things I have learned have been from the internet.”

Social network sites

The tendency among chronically ill internet users to stick to the straight and narrow online carries over into other forms of social media. Social network sites such as MySpace and Facebook are becoming mainstream destinations for many internet users, particularly younger adults, but less so for people living with chronic disease.

As of September 2009, 47% of internet users say they use a social network site, up from 35% in December 2008, when this survey focused on health and health care was conducted. There has been a modest growth of interest in this activity among older adults over the last year: 15% of internet users age 65 and older now use social network sites, compared with 7% in December 2008. Therefore, the following numbers may be slightly lower than the current uptake of social tools among people living with chronic disease.

As further context, these findings are in line with the HINTS 2008 survey, which noted a strong inverse relationship between social network site use and age. Internet users between ages 18-24 years-old were 47.8% more likely to be part of a social network site than internet users age 65 and older.[27]

In December 2008, 25% of internet users living with chronic disease said they use a social networking site like MySpace and Facebook. Of those:

- One in four has followed their friends’ personal health experiences or updates on the site.
- One in five has posted comments, queries, or information about health or medical matters.
- One in five has gotten any health information on the sites.

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[27] Bradford W. Hesse, “Technology-Mediated Social Participation in Health and Health Care.” (Health Communication and Informatics Research Branch, National Cancer Institute, National Institutes of Health: January 18, 2010). See: http://www.tmsp.umd.edu/position%20papers/technology%20mediated%20social%20participaiton%20in%20health,%20Hesse%20%282010%29.pdf

- One in ten has started or joined a health-related group on a social networking site.

Seven percent of internet users living with chronic disease use Twitter or another service to share updates about themselves or to see updates about others. Of those, very few have posted comments, queries, or information about health or medical matters.

Online support groups

Eight percent of internet users living with chronic disease say they participate in an online discussion, a listserv, or other online group forum that helps people with personal issues or health problems. This mirrors the 7% of internet users who report no disease who participate in online support groups.

The National Center for Health Statistics recently found a similarly low uptake for online discussion groups devoted to health information. Three percent of adults aged 18-64 say they had used an "online chat group" to learn about health topics in the past year.[28]

However, holding all other variables constant in the current survey, living with chronic disease increases the probability that an internet user will participate in online discussions.

The few people who have used such groups often praise the information they find. As one person wrote, "[An] online support group helped me learn about the disease and provided comfort in knowing that my symptoms were not 'just in my head,' and helped me take steps to adjust to living with a chronic condition."

Another e-patient wrote, "I live in a small town and it is helpful to be able to use the internet to find others that have the same condition as I do."

Impact of online health resources

About one in six online health inquiries have a major impact on a chronic e-patient's health care or the way they care for someone else.

When asked, "Did the health information you found in the last time online have a major impact on your own health care or the way you care for someone else, a minor impact, or no impact at all?"

- 16% of e-patients living with chronic disease say their most recent inquiry had a major impact.
- 41% say it had a minor impact.
- 39% say their most recent inquiry had no impact.

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[28] Cohen, RA, Stussman, B. "Health information technology use among men and women aged 18-64: Early release of estimates from the National Health Interview Survey, January-June 2009." Health E-Stats. National Center for Health Statistics. February 2010.

By comparison, 11% of e-patients who report no chronic conditions say their last online health inquiry had a major impact on their own care or the way they care for someone else. The two groups come out even overall: 57% of both groups, regardless of their health status, say their last online health inquiry had any impact, major or minor.

Indeed, the following comment succinctly illustrates the disappointment of many people regarding online health resources: “The last time I went online for health information, I did not find the information I needed.” Another respondent wrote about how online health research may not bring earth-shattering revelations, but plays an important role in his life: “The information didn’t change anything I am doing, but it made me feel more educated.”

However, statistical analysis reveals that living with chronic disease does have a fairly strong positive effect on someone’s likelihood to report that online health information has made an impact on their care or the way they care for someone else.

One e-patient wrote, in reference to the impact of her last online search for health information, “It let me know I wasn’t alone in my pain or diagnosis. It gave me a place to share and be open....to ask questions...to get and to give support.”

Another e-patient shared that her last online health inquiry had a major impact on her well-being: “I was having pretty severe side effects from one particular drug I was taking but it was working very well in controlling my symptoms. However, while pain control was good, my fatigue was crushing. I did online searching to see what others have tried in that regard and used that information to visit with my doctor. Together we found another medication that helped which also did not create severe side effects. I find I take a more proactive approach to my healthcare because of what I am able to find out before a doctor visit.”

Of the e-patients living with chronic disease who say their most recent query had an impact, either major or minor:

- Two-thirds say the information found online affected a decision about how to treat an illness or condition.
- Half say it changed the way they cope with a chronic condition or manage pain.
- Half say it changed their overall approach to maintaining their health or the health of someone they help take care of.
- Half say it lead them to ask a doctor new questions, or to get a second opinion from another doctor.
- Half say it changed the way they think about diet, exercise, or stress management.
- One-third say it affected a decision about whether to see a doctor.

These findings match the responses of the general population with one notable, but unsurprising, exception: pain or chronic condition management. Thirty percent of e-patients who report no chronic conditions say their last online health query changed the way they manage pain or cope with a chronic condition, compared with half of e-patients living with chronic disease. It is worth noting that there are people living with chronic pain who are not included in this survey's definition of the chronic disease population since we ask only about heart conditions, lung conditions, high blood pressure, diabetes, and cancer. Thus, the percent of chronically ill e-patients whose pain or condition is affected in part by information they find online is likely even higher.

One e-patient living with chronic pain wrote that the social aspect of her online community helps her cope: "I can't talk to my family or friends and have them truly understand what I am dealing with. [Online] I can get great advice, and be encouraged to go another day when I am having the worst pain day of my life. It is a wonderful place to be when there is no other place to turn to."

Apropos of asking a doctor new questions, one e-patient wrote, "I like to keep up to date with the latest research on my illnesses. That way if something new comes up that I want to try I can ask my doctor about it."

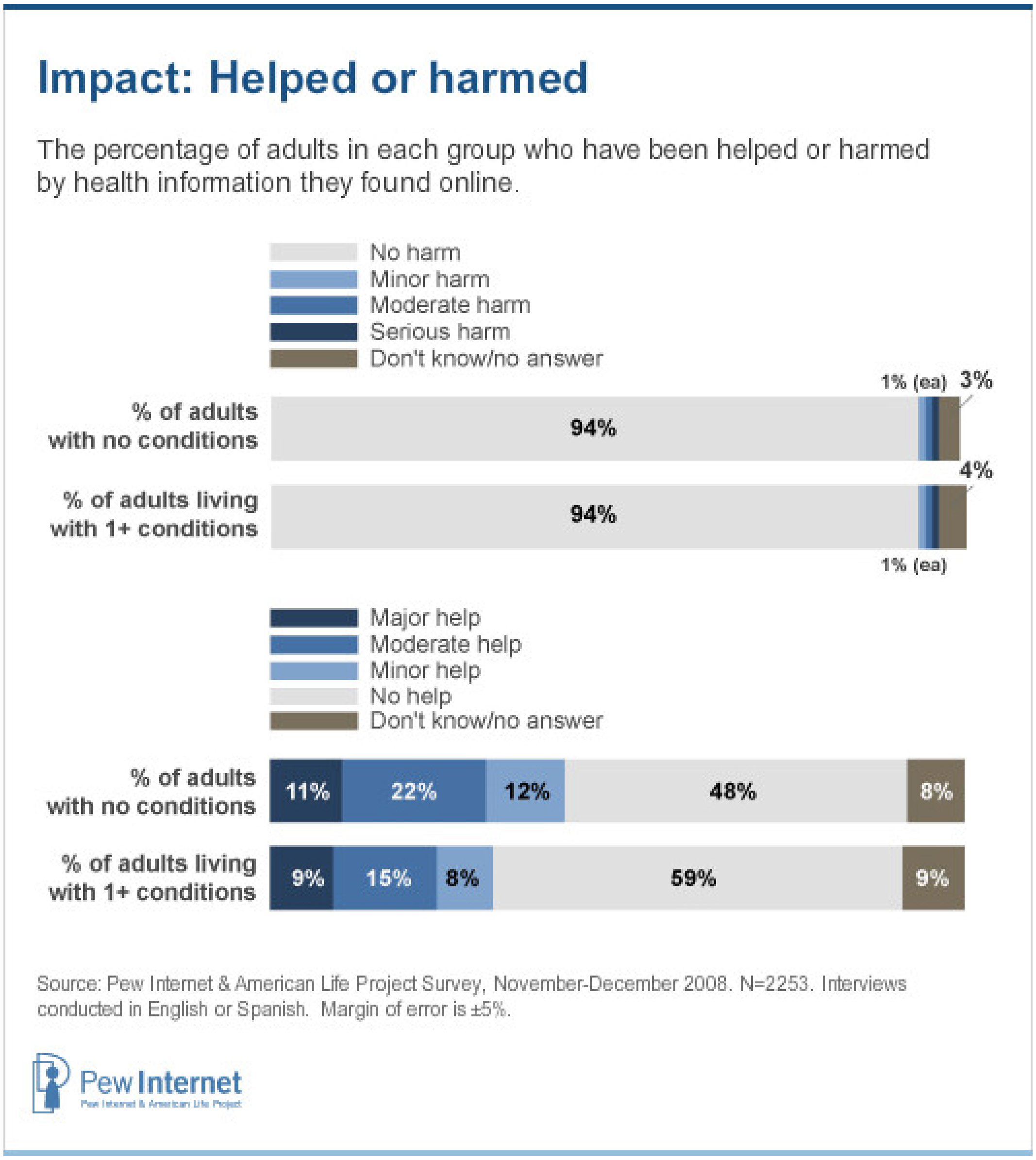
One third of adults living with chronic disease say they or someone they know has been helped by online health advice.

Because we are interested in the internet's impact on the entire population, we asked the following question of all adults, not just internet users:

> Have you or has anyone you know been helped by following medical advice found on the internet?

Thirty-six percent of adults living with chronic disease say they or someone they know has been helped by following medical advice or health information found on the internet, compared with 45% of adults reporting no diseases.

Very few adults, regardless of health status, say they or someone they know has been harmed by following medical advice or health information found on the internet (2% of adults living with chronic disease, compared with 3% of adults with no chronic disease).



Impact: Helped or harmed

The percentage of adults in each group who have been helped or harmed by health information they found online.

Source: Pew Internet & American Life Project Survey, November-December 2008. N=2253. Interviews conducted in English or Spanish. Margin of error is ±5%.

While one would expect chronic e-patients to be more likely to say they have been helped by information they find online, people living with chronic disease are surrounded by thorny issues which may not be as easily solved as the health questions posed by people dealing with more run-of-the-mill concerns. When the stakes are high or the outlook is grave, help may be more measured and breakthroughs few and far between. In addition, someone dealing with a new, life-changing diagnosis has different information needs and expectations than someone who is already living the long, hard slog of a chronic condition.

Indeed, one person wrote, “I keep looking to find something new to help me function better but new information doesn't come very quickly. The most helpful use of the internet is getting new research articles.”

Another e-patient warned about the dangers of online health information: “It's important to be able to distinguish between reliable and unreliable sources of information on the Internet. Because of my background, I am usually able to do that… I know quite a few people who, in my opinion, have been harmed by bad health information. However, they tend to be people who rely unquestioningly on opinions of friends and/or so-called alternative health practitioners and do NOT take the time to conduct their own research.”

In some cases, basic advice is what makes the difference. One woman wrote, “I was having very little progress in controlling my and my husband’s sugar count as we are diabetics. After looking at various websites we are doing much better at staying active, eating reduced portions and controlling the amount of carbohydrates. We have found the best times to take our various medicines [and] we get good reminders on how we can make changes to improve our health.”

Conclusion

The deck is stacked against people living with chronic disease. They are disproportionately offline. They often have complicated health issues, not easily solved by the addition of even the best, most reliable, medical advice.

And yet, those who are online have a trump card. They have each other. This survey finds that having a chronic disease increases the probability that an internet user will share what they know and learn from their peers. They unearth nuggets of information. They blog. They participate in online discussions. And they just keep going.

The online essays contributed by members of the HealthCentral and PatientsLikeMe communities speak to the potential of online health resources to make a significant impact in people’s lives. The telephone survey results show just how far the field must go to reach the millions of adults who are still searching for answers.

Methodology

This report is based on the findings of a daily tracking survey on Americans' use of the Internet. The results in this report are based on data from telephone interviews conducted by Princeton Survey Research Associates between November 19 to December 20, 2008, among a national sample of 2,253 adults. For results based on the national sample, one can say with 95% confidence that the error attributable to sampling and other random effects is plus or minus 2.3 percentage points. For results based on internet users (n=1,650), the margin of sampling error is plus or minus 2.7 percentage points. For results based on adults living with chronic disease (n=917), the margin of sampling error is plus or minus 5 percentage points. In addition to sampling error, question wording and practical difficulties in conducting telephone surveys may introduce some error or bias into the findings of opinion polls.

A combination of landline and cellular random digit dial (RDD) samples was used to represent all adults who have access to either a landline or cellular telephone. Both samples were provided by Survey Sampling International, LLC (SSI) according to PSRAI specifications. Numbers for the landline samples were selected using standard list-assisted RDD methods from active blocks (area code + exchange + two-digit block number) that contained three or more residential directory listings. The cellular samples were not list-assisted, but were drawn through a systematic sampling from dedicated wireless 100-blocks and shared service 100-blocks with no directory-listed landline numbers.

New sample was released daily and was kept in the field for at least five days. The sample was released in replicates, which are representative subsamples of the larger population. This ensures that complete call procedures were followed for the entire sample. At least 10 attempts were made to complete an interview at sampled households. The calls were staggered over times of day and days of the week to maximize the chances of making contact with a potential respondent. Each household received at least one daytime call in an attempt to find someone at home.

In each contacted household in the landline sample, interviewers asked to speak with the youngest male currently at home. If no male was available, interviewers asked to speak with the youngest female at home. This systematic respondent selection technique has been shown to produce samples that closely mirror the population in terms of age and gender. For the cellular sample, interviews were conducted with the person who answered the phone. Interviewers verified that the person was an adult and in a safe place before administering the survey. Cellular sample respondents were offered a post-paid cash incentive for their participation. All interviews completed on any given day were considered to be the final sample for that day.

Non-response in telephone interviews produces some known biases in survey-derived estimates because participation tends to vary for different subgroups of the population, and these subgroups are likely to also vary on questions of substantive interest. In order to compensate for these known biases, the sample data are weighted in analysis.

A two-stage weighting procedure was used to weight this dual-frame sample for each weighting. A first-stage weight of 0.5 was applied to all dual-users to account for the fact that they were included in both sample frames. All other cases were given a first-stage weight of 1. The second stage of weighting balanced sample demographics to match population parameters. The sample was balanced to match population parameters for sex, age, education, race, Hispanic origin, region (U.S. Census definitions), population density, and telephone usage. The basic weighting parameters came from a special analysis of the Census Bureau's 2007 Annual Social and Economic Supplement (ASEC). The population density parameter comes from 2000 Census data. The cell phone usage parameter came from an analysis of the July-December 2006 National Health Interview Survey.

Table 1 on the following page is the full disposition of all sampled telephone numbers. At PSRAI it is calculated by taking the product of three component rates:

- Contact rate – the proportion of working numbers where a request for interview was made
- Cooperation rate – the proportion of contacted numbers where a consent for interview was at least initially obtained, versus those refused
- Completion rate – the proportion of initially cooperating and eligible interviews that were completed

Thus the response rates for the land line sample were 21%. The response rates for the cellular sample were 25%.

Table 1:Sample Disposition

National			
Landline	Cell		
20,826	5,357		Total Numbers Dialed
1,274	81		Non-residential
1,050	9		Computer/Fax
6			Cell phone
8,171	2,111		Other not working
1,606	134		Additional projected not working
8,719	3,022		Working numbers
41.9%	56.4%		Working Rate
535	45		No Answer / Busy
826	422		Answering Machine / Voice Mail
85	56		Other Non-Contact
7,273	2,499		Contacted numbers
83.4%	82.7%		Contact Rate
429	192		Callback
4,803	1,461		Refusal
2,041	846		Cooperating numbers

28.1%	33.9%		Cooperation Rate
83	82		Language Barrier
	190		Child's cell phone
1,958	574		Eligible numbers
95.9%	67.8%		Eligibility Rate
207	72		Break-off
1,751	502		Completes
89.4%	87.5%		Completion Rate
20.9%	24.5%		Response Rate

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