



Peer-to-peer healthcare

Many people – especially those living with chronic or rare diseases – use online connections to supplement professional medical advice

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Summary of Findings

The internet gives patients and caregivers access not only to information, but also to each other.

Many Americans turn to friends and family for support and advice when they have a health problem. This report shows how people's networks are expanding to include online peers, particularly in the crucible of rare disease. Health professionals remain the central source of information for most Americans, but "peer-to-peer healthcare" is a significant supplement.

This report is based in part on a national telephone survey of 3,001 adults which captures an estimate of how widespread this activity is in the U.S. All numerical data included in the report is based on the telephone survey. The other part of the analysis is based on an online survey of 2,156 members of the National Organization for Rare Disorders (NORD) who wrote short essays about their use of the internet in caring for themselves or for their loved ones.

One in five internet users have gone online to find others like them.

Eighteen percent of internet users say they have gone online to find others who might have health concerns similar to theirs.

The most striking finding of the national survey is the extent of peer-to-peer help among people living with chronic conditions. One in four internet users living with high blood pressure, diabetes, heart conditions, lung conditions, cancer, or some other chronic ailment (23%) say they have gone online to find others with similar health concerns. By contrast, 15% of internet users who report no chronic conditions have sought such help online.

Other groups who are likely to look online for people who share their same health concerns include: internet users who are caring for a loved one; internet users who experienced a medical crisis in the past year; and internet users who have experienced a significant change in their physical health, such as weight loss or gain, pregnancy, or quitting smoking.

Some of the most notable interactions involve people who meet online for the first time. There were numerous examples of these powerful long-distance connections in our online survey of patients and caregivers who take part in rare-disease communities. One adult living with a rare condition described how she connected with another patient online, bonded, and then enriched the friendship with in-person encounters: "The first time I met another patient, face to face, I sobbed. I was overjoyed and began to communicate with them on a regular basis and my network grew. "

In the moment of need, most people turn to a health professional for information, care, or support.

When asked about the last time they had a health issue, 70% of adults in the U.S. say they received information, care, or support from a health professional. Fifty-four percent of adults say they turned to friends and family. Twenty percent of adults say they turned to others who have the same health condition.

The majority of health care conversations happen offline: Just 5% of adults say they received online information, care, or support from a health professional, 13% say they had online contact with friends and family, and 5% say they interacted online with fellow patients.

In our online survey, patients and caregivers were asked the same question about the last time they had a health issue. The people living with rare disease who responded to the survey far outpaced all other groups, including those living with chronic conditions, in tapping the wisdom of their peer network. More than half of rare-disease respondents say they turned to family and friends. Another majority say they turned to others who have the same health condition.

A mother of a small child with a rare condition wrote about the lifeline she has found online: “When a disease is so rare and there are no folks in your town, and few in your state who are going through what you are going through, you need a support group that encompasses people from all over the world. Getting to know people through the disorder has been an amazing experience and has created incredibly wonderful friendships and ties.”

People turn to different sources for different kinds of information.

In the national survey, adults were asked which group is more helpful when they need certain types of information or support: health professionals like doctors and nurses or peers like fellow patients, friends, and family. The pattern of their responses was pretty clear: When the issue involved technical issues related to a health issue, professionals held sway. When the issue involved more personal issues of how to cope with a health issue or get quick relief, then non-professionals were preferred by most patients.

Who is more helpful when you need...	Professional sources like doctors and nurses	Fellow patients, friends, and family	Both equally
Times when professionals matter most			
An accurate medical diagnosis	91%	5%	2%
Information about prescription drugs	85	9	3
Information about alternative treatments	63	24	5
A recommendation for a doctor or specialist	62	27	6
A recommendation for a hospital or other medical facility	62	27	6
Times when non-professionals matter most			
Emotional support in dealing with a health issue	30	59	5
A quick remedy for an everyday health issue	41	51	4
Times when the two groups are equally helpful			
Practical advice for coping with day-to-day health situations	43	46	6

Source: Pew Research Center's Internet & American Life Project, August 9-September 13, 2010 Survey. N=3001 adults and the margin of error is +/- 3 percentage points for the full sample.

Many people find the internet to be a valuable tool, whether they are using it to search for a quick answer or gain a deeper understanding of a new treatment option or prescription. As one respondent in the online survey commented, "When time is of the essence, search on the internet is the only way to time travel." The internet is also, as this study shows, a way to tap into our instincts to gather together, help other people, and be helped ourselves.

Acknowledgements

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The California HealthCare Foundation is an independent philanthropy committed to improving the way health care is delivered and financed in California.

All quantitative, numerical data is based on a September 2010 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.

All qualitative data, including the stories and insights provided by caregivers and patients, is based on an online survey of members of the National Organization of Rare Disorders (NORD) in December 2010.

NORD is a non-profit organization dedicated to improving the lives of all patients and families affected by rare diseases through advocacy, education, research, and patient services. NORD sent invitations to a sample of their membership which resulted in 2,156 completed online responses to 14 questions about how they navigate the shoals of living with rare conditions.

I am deeply grateful to the respondents of both the telephone survey and the online survey, all of whom contributed to my understanding of the role of the internet in the new health care landscape. This is the first of a series of analyses planned for these combined data sets.

Peer-to-Peer Health

The internet provides access not only to information, but also to each other.

The Pew Internet Project and California HealthCare Foundation have long been interested in the impact of the internet on health and health care, measuring how many people have access to technology, how they use it to gather information, and what topics are of greatest interest.¹ A primary finding of our research is that health professionals continue to play a central role in most people's lives when it comes to being sick, getting well, and maintaining good health, no matter the level of internet access someone may have.²

However, the internet has not only facilitated increased patients' access to information, but it has also enabled new pathways for patients to find and help each other. Social network sites, blogs, online communities, email groups and listservs, and other tools allow people to express themselves in ways that respond immediately to people. But those messages also persist – and are often searchable and can help patients in the future. People use the internet to find others who share the same interests, whether in politics, hobbies, music, health, or any other topic, no matter where they may live. Social tools also deepen people's connections to groups they join offline and draw them to join new groups formed online. Indeed, 46% of internet users who are active in groups say the internet has helped them to be active in more groups than would otherwise be the case.³

Over the last few years, the popular imagination has been captured by the possibility that people can use digital tools to reorganize segments of society.⁴ A revolution in health care is running along a parallel track, mixing people's instincts to share knowledge with the social media that make it easy, creating what might be called "peer-to-peer healthcare."

Taking the social life of health information to the next level.

This report is based in part on a national telephone survey of 3,001 adults which captures an estimate of how widespread this activity is in the U.S. All numerical data included in the report is based on the telephone survey. The other part of the analysis is based on an online survey of 2,156 members of the

¹ "Health Topics," by Susannah Fox. (Pew Internet Project and California HealthCare Foundation: February 1, 2011). Available at: <http://www.pewinternet.org/Reports/2011/HealthTopics.aspx>

² "The Social Life of Health Information," by Susannah Fox and Sidney Jones. (Pew Internet Project and California HealthCare Foundation: June 11, 2009). Available at: <http://www.pewinternet.org/Reports/2009/8-The-Social-Life-of-Health-Information.aspx>

³ "The Social Side of the Internet," by Lee Rainie, Kristen Purcell, and Aaron Smith. (Pew Internet Project: January 18, 2011). Available at: <http://www.pewinternet.org/Reports/2011/The-Social-Side-of-the-Internet.aspx>

⁴ "The Political Power of Social Media," by Clay Shirky. (Foreign Affairs: January/February 2011). Available at: <http://www.foreignaffairs.com/articles/67038/clay-shirky/the-political-power-of-social-media>

National Organization for Rare Disorders (NORD) who wrote short essays about their use of the internet in caring for themselves or for their loved ones.

NORD represents the approximately 25 million Americans living with a rare disease, which is defined as affecting fewer than 200,000 people in the U.S. The people who participated in the online survey reported a wide array of conditions, such as Marfan's Syndrome, congenital hyperinsulinism, and aplastic anemia, to name just a few. In reading those essays, it becomes clear that the people who responded to the survey have taken the social life of health information to the next level. Many of them forged a long path toward a diagnosis (if they even have one) only to find out that this was simply the start of another journey.

People living with rare disease, their own or a loved one's, have honed their searching, learning, and sharing skills to a fine point. They endlessly scan resources for clues to try to cope with and mitigate the inevitable complications and setbacks that come from rare diseases. What was once a solitary expedition for one person or one family, however, has become a collective pursuit taken on by bands of brothers- and sisters-in-arms who may never meet up in person.

Many Americans turn to friends and family for support and advice when they have a health problem. This report shows how people's networks are expanding to include online peers, particularly in the crucible of rare disease.

“We can say things to each other we can't say to others.”

One in five internet users (18%) have gone online to find others who might have health concerns similar to theirs.

Internet users ages 65 and older are less likely than younger internet users to have done this (10%, compared with 18% of those ages 50-64, for example). Spanish-dominant internet users are also significantly less likely than English-dominant internet users to have looked online for someone with similar health concerns (6%, compared with 19%).

Twenty-three percent of internet users living with chronic conditions have looked online for someone with similar health concerns, compared with 15% of those who report no conditions. In the survey, we asked about chronic conditions in two ways: First, we asked people if they had one of five conditions: high blood pressure, diabetes, lung conditions, heart conditions, or cancer. All of the internet users who had at least one of those conditions are equally likely to have looked online for someone with similar health concerns.

Our second strategy in looking at chronic disease was to ask people if they had any other condition besides the one we mentioned. Some 17% of respondents say they do. It is intriguing that *a greater proportion* of these internet users living with less common, chronic health problems have gone online to find others with similar health concerns. Thirty-two percent of internet users in that group say they have done so, compared with 15% of internet users who have no chronic conditions.

Looking online for someone like you: Health status

Percentage of internet users in each group who have looked online for others with similar health concerns	
All internet users	18%
Caregiver status	
Currently caring for a loved one	26
Not a caregiver	15
Recent medical crisis	
Experienced within past year – self or someone close	23
No recent experience	16
Recent personal health change	
Experienced within past year	24
No recent experience	17
Chronic disease status	
One or more chronic conditions	23
No conditions	15
Disability status	
One or more disabilities (N=439)	20
No disabilities	18

Source: Pew Research Center’s Internet & American Life Project, August 9-September 13, 2010 Survey. N=2065 internet users age 18+. Margin of error is +/- 3 percentage points for the full sample. Margins of error for sub-populations are higher.

Internet users who have experienced a recent medical emergency, their own or someone else’s, are also more likely than other internet users to go online to try to find someone who shares their situation: 23%, compared with 16%. This fits the pattern observed in other research that people going through a medical crisis are voracious information consumers: 85% say they look online for health information, compared with 77% of internet users who have not had that experience in the past year.⁵

Internet users who have experienced a significant change in their physical health, such as weight loss or gain, pregnancy, or quitting smoking are also more likely than other internet users to have looked online for someone like them. This is not new behavior, of course, as any member of Weight Watchers or a new mothers’ playgroup can attest. However, the internet widens the network available to people and allows behavior change to spread in new ways. Ex-smokers can support each other through nicotine

⁵ “Health Topics” (2011).

cravings at any time of the day or night, for example, and studies have shown that the more help someone receives, the more likely they will help someone else.⁶

Rare disease seems to amplify this need to spread one's network far and wide. And this more extended network sometimes can bring special benefits. Patients say they will confide to others in these extended networks in ways that are sometimes hard to confide to their closest family members and friends. A woman living with a blood disorder wrote in the online survey about her support group: "We can say things to each other we can't say to others. We joke about doctors and death. We cry when we need to. Together we are better informed. The support is powerful and empowering."

In a book about rare-disease caregivers, *Uncommon Challenges; Shared Journeys*, one mother wrote, "Before the internet, we were alone. In 1996, when Jacob was born, there was no search engine to offer me any information. Today, because of social media, we are connected with many people who are fighting the same fight as we are. The internet has made our small disease larger and we are able to educate many more people now."⁷

Our national phone survey found that 26% of internet users caring for a loved one say they have looked online for someone with similar health concerns, compared with 15% of internet users who are not currently caring for a loved one, either an adult or a child.⁸ In our online survey, a woman who is the primary caregiver for her husband explained that she used this strategy to try to gain access to facts, insights, and advice that sometimes didn't come from doctors or her immediate circle of contacts. Since she had previously found good information about breast cancer online, she expected to find similar resources about his disease, even though it is a much less common condition than breast cancer. She wrote, "I was looking for the same support that I found on Breastcancer.Org for [his condition]. It is a more difficult reach for information and contact with other individuals dealing with the disease. I hope to see it improve."

The internet can enable connections across distances and among people who may never have met in person. These encounters can have deep and lasting impact on people's health and well-being, particularly among those who thought they would never find someone who shared their particular situation. For example, an adult living with a rare condition wrote, "The first time I met another patient, face to face, I sobbed. I was overjoyed and began to communicate with them on a regular basis and my network grew."

⁶ "Building a Research Agenda for Participatory Medicine," by Susannah Fox (e-patients.net: October 11, 2010). Available at: <http://e-patients.net/archives/2010/10/building-a-research-agenda-for-participatory-medicine.html>
See also: *Connected: The Surprising Power of Our Social Networks and How They Shape Our Lives*, by Nicholas Christakis and James Fowler (2009).

⁷ "A Fighting Chance," by Jordana Holovach, in *Uncommon Challenges; Shared Journeys*. (Siren Interactive: 2011). See: <http://press.sireninteractive.com/>

⁸ The word "caregivers" is used throughout this report to refer to people who, in the past 12 months, have provided unpaid care to a parent, child, friend, or other loved one. Unpaid care for an adult may include help with personal needs or household chores, managing finances, arranging for outside services, or visiting regularly to see how they are doing. Unpaid care to a child includes care for an ongoing or serious short-term condition, emotional or behavioral problems, or developmental problems.

In the Moment of Need

Health professionals, friends, family members, and fellow patients are all part of the mix.

When asked about the last time they had a health issue, 70% of adults in the U.S. say they received information, care, or support from a health professional. Fifty-four percent of adults say they turned to friends and family. Twenty percent of adults say they turned to others who have the same health condition.

The majority of these interactions happen offline: just 5% of adults say they received online information, care, or support from a health professional, 13% say they had online contact with friends and family, and 5% say they interacted online with fellow patients.

The last time you had a health issue, did you get information, care, or support from...	Yes, online	Yes, offline	Yes, both	Not a source
A doctor or other health care professional	1%	65%	4%	29%
Friends and family	1	41	12	44
Others who have the same health condition	1	15	4	77

Source: Pew Research Center's Internet & American Life Project, August 9-September 13, 2010 Survey. N=3001 adults and the margin of error is +/- 3 percentage points for the full sample. Margins of error for sub-populations are higher.

People living with chronic conditions are more likely than those who report no conditions to say they turned to a health professional: 79%, compared with 63%. Both groups are equally likely to say they received information, care, or support from friends and family. One in four people living with chronic conditions (25%) say they got information, care, or support from other people who have the same health condition the last time they had a health issue, compared with 19% of adults who report no chronic conditions. Again, adults who report that they have a condition other than the five named in the survey are the most likely group to turn to fellow patients for counsel. Fully one-third of this group (31%) has done so. In all cases, most of the communication happens offline.

Rare conditions necessitate online consultation with peers.

A significant limitation of the online survey we conducted with NORD is its reliance on a sample of people who have already found a community of those who share their condition. Since it is not a representative sample of people living with rare disease, the responses cannot be directly compared to

the national telephone survey results. However, it is interesting to look at the patterns in the data, and in this case, the patterns are strikingly different from the results we got in the telephone survey.

When asked the same question about the last time they had a health issue, the people living with rare disease who responded to the survey far outpaced all other groups, including those living with chronic conditions, in tapping the wisdom of their peer network. More than half of rare-disease respondents say they turned to family and friends. Another majority say they turned to others who have the same health condition. Much of their interaction with friends, family, and fellow patients or caregivers happens online by necessity, since they are unlikely to live near to the people who share their conditions.

Yet again, it is critical to note that health professionals were the most popular choice even among this highly-networked group of people living with rare conditions. The oft-expressed fear that patients are using the internet to self-diagnose and self-medicate without reference to medical professionals does not emerge in national phone surveys or in this special rare-disease community survey. Advice from peers is a supplement to what a doctor or nurse may have to say about a health situation that arises.

A woman who cares for her husband describes how she relies on both groups to navigate to the information she needs: “We have found that we get helpful info from both doctors and other patients/caregivers. Other patients/caregivers are almost more helpful when it comes to this disease because as a group they have more info than any one individual doctor has. We have gotten info from other patients/caregivers that we've then told the oncologist about so he could look into it. Sometimes we feel like we're educating our doctor more than he is educating us.”

One mother of a now-adult child with a rare condition wrote about how much she values the advocacy group founded by a group of patients. She writes, “Experts who have superior information than the best hepatologists are there to answer our questions. Patients and caregivers are there for each other and no question remains unanswered. I wish we had had this group of 2,000 with us at the beginning.”

A mother of a small child with a rare condition writes about the lifeline she has found online: “When a disease is so rare and there are no folks in your town, and few in your state who are going through what you are going through, you need a support group that encompasses people from all over the world. Getting to know people through the disorder has been an amazing experience and has created incredibly wonderful friendships and ties.”

Health professionals retain their role as experts in a certain field or condition, but in these disease communities, each person is an expert in observing the effects of a disease or a treatment on their own or a loved one’s body or mind. In this way, rare-disease patients and caregivers who gather together online are an example of a “smart” group, the elements of which James Surowiecki described in his book, *The Wisdom of Crowds*: They are diverse and decentralized, yet able to pool knowledge and summarize their observations, no matter how eccentric or individual they may be.⁹

⁹ The Wisdom of Crowds, by James Surowiecki. (Random House: 2004). See: <http://www.randomhouse.com/features/wisdomofcrowds/index.html>

Our findings also echo what has been found in other research. A 2007 study of the Association of Cancer Online Resources found that information exchange, not simply emotional support, was the primary driver for community members. Indeed, “the most common expressions of support were offers of technical information and explicit advice about how to communicate with health care providers.”¹⁰ PatientsLikeMe, an online quantitative personal research platform for patients, has published several studies noting the benefits gained by people who share personal health data and tips about their conditions.¹¹ In one 2010 study, “patients reported making more informed treatment decisions as a result of using the site, particularly around managing side effects.”¹² CureTogether is another example of using patient-contributed data to crowd-source answers to health questions on a wide range of topics.¹³

¹⁰ “How Cancer Survivors Provide Support on Cancer-Related Internet Mailing Lists,” by Andrea Meier, PhD; Elizabeth J Lyons, MPH; Gilles Frydman; Michael Forlenza, MPH, PhD; Barbara K Rimer, DrPH. (Journal of Medical Internet Research: Vol. 9, No. 2). Available at: <http://www.jmir.org/2007/2/e12/>

¹¹ See <http://www.patientslikeme.com/research>

¹² “Sharing Health Data for Better Outcomes on PatientsLikeMe,” by Paul Wicks, PhD; Michael Massagli, PhD; Jeana Frost, PhD; Catherine Brownstein, PhD; Sally Okun, RN; Timothy Vaughan, PhD; Richard Bradley, RN; James Heywood, SB. (Journal of Medical Internet Research: Vol. 12, No. 2). Available at: <http://www.jmir.org/2010/2/e19/>

¹³ “CureTogether - Crowdsourced Patient Experience,” by Alexandra Carmichael. (Ashoka Changemakers: August 24, 2010). Available at: <http://www.changemakers.com/node/88624>

Different Sources for Different Kinds of Information

Professionals or peers? Both.

In March 1999, Tom Ferguson, a medical doctor and self-care advocate, and Bill Kelly, cofounder of Sapien Health Network, fielded a survey of an online patient community which asked members to rate the most useful resource for twelve dimensions of medical care.¹⁴ Online patient groups were rated more useful than health professionals on ten of the twelve aspects of care, such as practical knowledge and help finding other resources, whereas specialists and primary care doctors received higher ratings for diagnosis and managing a condition.

It was a small sample of a single patient group (just 191 respondents), but it served as the inspiration for the following series of questions. In our national telephone survey, all adults were asked which group is more helpful when they need certain types of information or support: health professionals like doctors and nurses or peers like fellow patients, friends, and family.

Who is more helpful when you need...	Professional sources like doctors and nurses	Fellow patients, friends, and family	Both equally
Times when professionals matter most			
An accurate medical diagnosis	91%	5%	2%
Information about prescription drugs	85	9	3
Information about alternative treatments	63	24	5
A recommendation for a doctor or specialist	62	27	6
A recommendation for a hospital or other medical facility	62	27	6
Times when non-professionals matter most			
Emotional support in dealing with a health issue	30	59	5
A quick remedy for an everyday health issue	41	51	4
Times when the two groups are equally helpful			
Practical advice for coping with day-to-day health situations	43	46	6

Source: Pew Research Center's Internet & American Life Project, August 9-September 13, 2010 Survey. N=3001 adults and the margin of error is +/- 3 percentage points for the full sample.

¹⁴ "E-Patients Prefer eGroups to Doctors for 10 of 12 Aspects of Health Care" by Tom Ferguson, MD (The Ferguson Report: March 1999). Available at: <http://www.fergusonreport.com/articles/fr039905.htm>

Accurate medical diagnosis

Health professionals are the overwhelming favorites when it comes to getting an accurate medical diagnosis. Fully 91% of U.S. adults say doctors and nurses are more helpful than other sources, such as fellow patients, friends, and family, when they need a diagnosis. Just 5% of adults say they find advice from friends, family, and other sources more helpful.

People living with rare conditions often struggle to get a diagnosis. In fact, the National Institutes of Health established the Undiagnosed Diseases Program in order to help patients with rare conditions find answers, with the understanding that the exploration of the edges of medicine can provide insights into more common ailments.¹⁵ A diagnosis, however, is just another starting point for most people, especially if they feel more information and advice are needed.

One woman in our online survey of NORD members described how her doctor gave her three pages copied from a medical journal about her condition – and little else. She went home and found an online support group where she learned about the tests she would soon face as part of the next stage of diagnosis. Unfortunately, since she was the first person with this condition to ever be treated at her local hospital, she says she did not receive optimal care. She wrote: “The best piece of information that I learned from other patients was to get to a physician that truly knows how to treat my disease. I pass this along to all of the other patients that I come in contact with. I don't want anyone else to receive the wrong dosage as I did. Other patients are your best source of information when dealing with a rare disease. They are living it and know exactly how you feel.”

Information about prescription drugs

Health professionals are the clear favorite when it comes to gathering information about prescription drugs. Fully 85% of adults say they think doctors and nurses are more helpful than peer sources when they need drug recommendations.

A recent study by the Pew Internet Project and the California HealthCare Foundation reported that 24% of internet users look online for information about drug safety or recalls.¹⁶ Caregivers, women, college graduates, and internet users living with chronic conditions (particularly those with lung conditions) lead all other groups in their interest in drug safety information. Age is also a significant predictor: 29% of Generation X internet users (34-45) say they have done this type of research online, compared with 21% of internet users ages 46-55 years old.

¹⁵ “Medical Detectives Find Their First New Disease,” by Gina Kolata (*The New York Times*: February 2, 2011). Available at: <http://www.nytimes.com/2011/02/03/health/03disease.html>

¹⁶ “Health Topics” (2011).

Information about alternative treatments

When asked who they think is more helpful when they need information about alternative treatments, 63% of adults choose health professionals over other sources. Twenty-four percent of adults say they find the advice of friends, family, and fellow patients more helpful in this case.

A 2008 study by the Pew Internet Project and California HealthCare Foundation found that 35% of internet users have looked online for information about alternative treatments.¹⁷ Women are significantly more likely than men to look online for alternative treatments and medicines (37%, compared with 31%). In addition, adults over the age of 65 are significantly less likely than younger adults to look up alternative treatments and medicines online.

A recommendation for a doctor or specialist

Sixty-two percent of adults say they think health professionals are more helpful than peer sources when it comes to getting a recommendation for a doctor or specialist. Twenty-seven percent of adults prefer to ask friends, family, and fellow patients for this type of advice.

Older adults are much more likely than younger ones to say health professionals' opinions are more helpful: 72% of adults ages 65 and older say this, compared with 56% of 18-29 year-olds, for example.

In our previous report about the health topics people search for online, we found that 44% of internet users look online for information about doctors or other health professionals.¹⁸ Caregivers, women, those with a college degree, and parents with children living at home lead all other groups in looking online for information about doctors or other health professionals. Half of internet users in each of these groups look online for this type of health information.

Generation X internet users (ages 34-45) are the most likely age group to look online for information about health professionals: 51%, compared with 41% of internet users in their 20s and 42% of internet users between 56-64 years old, for example.

A recommendation for a hospital or other medical facility

Health professionals are also preferred by a majority of adults (62%) when it comes to getting a recommendation for a hospital or other medical facility. Twenty-seven percent of adults say they think other sources, such as friends, family, and fellow patients, are more helpful in gathering this type of information.

Again, older adults are considerably more likely than younger adults to turn to health professionals for this type of information: 72% of adults ages 65 and older, compared with 54% of 18-29 year-olds.

¹⁷ "The Social Life of Health Information" (2009)

¹⁸ "Health Topics" (2011).

In our previous report about the health topics people study online, we found that 36% of internet users look online for information about hospitals or other medical facilities.¹⁹ Caregivers, women, those with a college degree, those between 34-45 years old, and parents with children living at home lead all other groups in looking online for information about this topic. Four in ten internet users in each of these groups look online for information about hospitals or other medical facilities.

Emotional support in dealing with a health issue

A clear majority of adults favor friends, family, and fellow patients when they need emotional support in dealing with a health issue: 59% say that, compared with 30% of adults who say they rely on health professionals for such support.

Women are more likely than men to say they rely on friends, family, and fellow patients for emotional support (64% vs. 54%). Younger adults are more likely than older adults to turn to friends, family, and fellow patients for emotional support concerning a health issue: 70% of 18-29 year-olds say this, compared with 64% of 30-49 year-olds, 55% of 50-64 year-olds, and 42% of adults ages 65 and older.

One adult living with a rare condition wrote about the way friends and family formed a safety net around her: “People like to help. And in the face of an incurable, rare, awful disease that leaves me at times helpless, people not only like to help, letting them help is a gift I can give them, a way to take some of the power and fight back against the currently unfightable.”

At the same time, there are patients who described the tenderness and attachment they felt from medical professionals. Another adult living with a rare condition wrote movingly of that experience: “I have been exceedingly lucky to have been loved and supported by so many including the many medical practitioners that I now call friends (as well as colleagues in my continuing care).”

A quick remedy for an everyday health issue

Half of adults (51%) say they find friends, family, and fellow patients more helpful than professional sources when they need a quick remedy for an everyday health issue. Forty-one percent prefer advice from a doctor or nurse.

The gender and age breakdowns are similar to the question regarding practical advice for coping with day-to-day health situations: women and younger adults prefer to gather quick remedies from peers while men and older adults prefer professionals.

One respondent commented, “When time is of the essence, search on the internet is the only way to time travel.”

Practical advice for coping with day-to-day health situations

People are split evenly when it comes to day-to-day care tips: 43% of adults say health professionals are more helpful and 46% of adults say friends, family, and fellow patients are the better source.

¹⁹ “Health Topics” (2011).

Women are more likely than men to rely on friends, family, and fellow patients for practical advice: 51%, compared with 40%.

Older adults are significantly more likely to say health professionals are the more helpful source for coping strategies: 55% of adults ages 65 and older, compared with 45% of 50-64 year-olds, 40% of 30-49 year-olds, and 38% of 18-29 year-olds.

One mother caring for a child with a rare condition wrote, “In my experience of dealing with a rare, serious, and chronic disorder, specialist doctors are typically the ‘go to’ people for medical advice involving medication or surgery ... Sometimes the doctors have not been as knowledgeable about the feeding issues which are of great importance. Sometimes other parents have some really good advice in these areas.” She qualifies that statement, however, noting the seriousness of the situation she and other people face: “We patients and caregivers of patients have to be very careful not to generalize from our experiences. Sharing information about experiences with medications and symptom is very helpful as long as extrapolations are not made.”

Methodology

National Telephone Survey: Methodology

All numerical results in this report are based on data from telephone interviews conducted by Princeton Survey Research Associates International between August 9 and September 13, 2010, among a sample of 3,001 adults, age 18 and older. Interviews were conducted in English and Spanish. For results based on the total sample, one can say with 95% confidence that the error attributable to sampling is plus or minus 2.5 percentage points. For results based on internet users (n=2,065), the margin of sampling error is plus or minus 2.9 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 in the continental United States who have access to either a landline or cellular telephone. Both samples were provided by Survey Sampling International, LLC (SSI) according to PSRAI specifications. The landline sample for this survey was designed to generalize to the U.S. adult population and to oversample African Americans and Hispanics. To achieve these objectives in a cost effective manner, the design uses standard *list-assisted random digit dialing* (RDD) methodology, but telephone numbers are drawn disproportionately from telephone exchanges with higher than average density of African-American and/or Hispanic households. The cellular sample was not list-assisted, but was 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 7 attempts were made to complete an interview at a sampled telephone number. 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 number received at least one daytime call in an attempt to find someone available. For the landline sample, half of the time interviewers first asked to speak with the youngest adult male currently at home. If no male was at home at the time of the call, interviewers asked to speak with the youngest adult female. For the other half of the contacts interviewers first asked to speak with the youngest adult female currently at home. If no female was available, interviewers asked to speak with the youngest adult male at home. 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.

Disproportionate sampling and non-response in telephone interviews can produce biases in survey-derived estimates. The dataset was weighted in two stages. The first stage of weighting corrected for the disproportionate landline sample design and also accounted for the overlapping landline and cellular sample frames as well as different probabilities of selection associated with the number of adults in the household. The second stage of weighting matched overall sample demographics to population parameters. The demographic weighting parameters are derived from a special analysis of the most recently available Census Bureau's March 2009 Annual Social and Economic Supplement. This analysis produces population parameters for the demographic characteristics of adults age 18 or older. These parameters are then compared with the sample characteristics to construct sample weights. The weights are derived using an iterative technique that simultaneously balances the distribution of all weighting parameters.

Following is the full disposition of all sampled telephone numbers:

Table 1: Sample Disposition

Landline	Cell	
53,160	17,075	Total Numbers Dialed
2,613	441	Non-residential
2,430	32	Computer/Fax
21	---	Cell phone
27,936	6,428	Other not working
4,308	311	Additional projected not working
15,852	9,863	Working numbers
29.8%	57.8%	Working Rate
1,436	104	No Answer / Busy
2,734	2,370	Voice Mail
84	17	Other Non-Contact
11,598	7,372	Contacted numbers
73.2%	74.7%	Contact Rate
1,020	1,027	Callback
8,303	4,597	Refusal
2,275	1,748	Cooperating numbers
19.6%	23.7%	Cooperation Rate
158	60	Language Barrier
---	646	Child's cell phone
2,117	1,042	Eligible numbers
93.1%	59.6%	Eligibility Rate

116	42	Break-off
2,001	1,000	Completes
94.5%	96.0%	Completion Rate
13.6%	17.0%	Response Rate

The disposition reports all of the sampled telephone numbers ever dialed from the original telephone number samples. The response rate estimates the fraction of all eligible respondents in the sample that were ultimately interviewed. 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 rate for the landline sample was 13.6 percent. The response rate for the cellular sample was 17.0 percent.

National Telephone Survey: Questions

Q6ab Do you use the internet, at least occasionally? Do you send or receive email, at least occasionally?

CURRENT	
%	74 Yes
	26 No
	* Don't know
	* Refused

Q17 Are you now living with any of the following health problems or conditions...?

	YES	NO	DON'T KNOW	REFUSED
a. Diabetes or sugar diabetes				
Current	11	89	*	*
b. High blood pressure				
Current	24	75	1	*
c. Asthma, bronchitis, emphysema, or other lung conditions				
Current	12	88	*	*
d. Heart disease, heart failure or heart attack				
Current	6	94	*	*
e. Cancer				
Current	2	97	*	*
f. Any other chronic health problem or condition I haven't already mentioned				
Current	17	82	*	1

Q18 In the last 12 months, have you personally faced a serious medical emergency or crisis?

CURRENT	
%	12 Yes
	88 No
	* Don't know
	* Refused

Q20 Is there anyone close to you who has a CHRONIC medical condition, such as asthma, diabetes, heart disease, high blood pressure, cancer, or another chronic condition?

CURRENT		DEC 2008 ²⁰
%	47 Yes	49
	53 No	50
	* Don't know	*
	* Refused	1

Q21 In the last 12 months, has anyone close to you faced a serious medical emergency or crisis?

CURRENT	
%	27 Yes
	72 No
	* Don't know
	* Refused

²⁰ In December 2008, question wording was "Is there anyone close to you who has a CHRONIC medical condition, such as asthma, diabetes, heart disease, high blood pressure, or cancer?"

Q24 Apart from looking for information online, there are many different activities related to health and medical issues a person might do on the internet. I'm going to read a list of online health-related activities you may or may not have done. Have you...

	YES	NO	DON'T KNOW	REFUSED
d. Gone online to find others who might have health concerns similar to yours				
Current internet users	18	82	0	*

Q30 Thinking about the LAST time you had a health issue, did you get information, care or support from... [INSERT; RANDOMIZE]? [IF YES AND INTERNET USER: Did you interact with them ONLINE through the internet or email, OFFLINE by visiting them in person or talking on the phone, or BOTH online and offline?]

	YES, ONLINE	YES, OFFLINE	YES, BOTH	NO, NOT A SOURCE	DON'T KNOW	REFUSED
a. A doctor or other health care professional	1	65	4	29	*	*
b. Friends and family	1	41	12	44	1	*
c. Others who have the same health condition	1	15	4	77	2	*

Q32 Overall, who do you think is more helpful when you need... [INSERT FIRST ITEM] – health professionals like doctors and nurses, OR other sources, such as fellow patients, friends and family? And who is more helpful when you need... [INSERT NEXT ITEM; RANDOMIZE]? READ AS NECESSARY: Professional sources like doctors and nurses, OR other sources, such as fellow patients, friends and family?

	PRO- FESSIONALS	OTHER SOURCES	(VOL.) BOTH EQUALLY	DON'T KNOW	REFUSED
a. An accurate medical diagnosis	91	5	2	2	*
b. Emotional support in dealing with a health issue	30	59	5	4	2
c. Practical advice for coping with day-to-day health situations	43	46	6	3	1
d. Information about alternative treatments	63	24	5	6	1
e. Information about prescription drugs	85	9	3	3	1
f. A quick remedy for an everyday health issue	41	51	4	3	1
g. A recommendation for a doctor or specialist	62	27	6	4	1
h. A recommendation for a hospital or other medical facility	62	27	6	4	1

CARE2 In the past 12 months, have you provided UNPAID care to an adult relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.

[IF RESPONDENT ASKS DOES GIVING MONEY COUNT:] Aside from giving money, do you provide any other type of unpaid care to help them take care of themselves, such as help with personal needs, household chores, arranging for outside services, or other things?

CURRENT	
%	27 Yes
	72 No
	* Don't know
	* Refused

CARE3 Do you provide this type of care to just one adult, or do you care for more than one adult?
Based on those who provide unpaid care to adults [N=790]

CURRENT		
%	66	One adult only
	33	Provide care to multiple adults
	*	Don't know
	*	Refused

CARE4 Is this person a parent of yours, or not?
CARE5 Are any of the adults you care for a parent of yours, or not?
Based on those who provide unpaid care to adults [N=790]

CURRENT		
%	38	Yes, parent
	62	No, not a parent
	*	Don't know
	*	Refused

CARE6 In the past 12 months, have you provided UNPAID care to any CHILD under the age of 18 because of a medical, behavioral, or other condition or disability? This could include care for ongoing medical conditions or serious short-term conditions, emotional or behavioral problems, or developmental problems, including mental retardation.

CURRENT		
%	5	Yes
	94	No
	*	Don't know
	*	Refused

Online Survey: Methodology

The Pew Internet Project adapted questions from our national telephone survey, in consultation with Princeton Survey Research Associates International (PSRAI) and the National Organization for Rare Disorders (NORD). In December 2010, NORD sent invitations to 721 patient organizations, asking them to notify members, as well as 212 individuals who had signed up as "Rare Disease Day Ambassadors." The total number of individuals who were invited to participate in the survey is not known. Since the data are based on a non-random sample of 2,156 internet users, a margin of error cannot be computed, and the results are not projectable to any population other than the internet users in this sample.

Online Survey: Questions

1. What rare disease or condition affects you or a loved one? [OPEN-END]

CURRENT		
%	99	Gave response
	1	No answer

2. Are you the patient or is the patient a loved one?

CURRENT		
%	50	I'm the patient
	36	Patient is a loved one
	6	Both
	9	No answer

What is your relationship to the patient? (If more than one loved one with a rare disease or condition, please select all that apply)

Based on those who have a loved one with a rare disease or condition [N=888]

CURRENT		
%	50	Parent of patient
	22	Spouse/partner
	17	Child of patient
	7	Sibling
	9	Other family member
	2	Friend
	3	Other (Specify)
	4	No answer

Note: Total may exceed 100% due to multiple responses.

Many times when people get sick, their family, friends and even more distant acquaintances come together to provide a kind of care network. Did this happen in your case? Who was in the network and what roles did they play in providing care? Please share any details that come to mind. [OPEN-END]

CURRENT		
%	80	Gave response
	20	No answer

3. How long did it take you or your loved one to get a diagnosis?

CURRENT		
%	50	Within 1 year
	15	1-3 years
	5	3-5 years
	9	5+ years
	11	Other
	10	No answer

Please explain further if you would like. [OPEN-END]

CURRENT		
%	60	Gave response
	40	No answer

4. If you wish, please tell us how you found out about this condition. Was the diagnosis process difficult? What did you learn that you would share with someone facing a similar situation? [OPEN-END]

CURRENT		
%	77	Gave response
	23	No answer

5. Is there a treatment for the rare disease that affects you or your loved one?

CURRENT		
%	52	Yes
	28	No
	20	No answer

If you would like, please give us some information about your search for treatments. Has it been pretty easy or pretty difficult? And how about the treatments themselves? How are they going? Did your care network play a role in finding the treatments or helping administer them? [OPEN-END]

CURRENT
 % 69 Gave response
 31 No answer

6. Is there a research center or clinician working on a possible treatment for the disease that affects you or your loved one?

CURRENT
 % 61 Yes
 16 No
 23 No answer

Please explain further if you would like. [OPEN-END]

CURRENT
 % 52 Gave response
 48 No answer

7. Have you used the internet to find clinical trials?

CURRENT
 % 40 Yes
 40 No
 20 No answer

So others might benefit from your experience, please list any websites or resources you have used to look for clinical trials. [OPEN-END]

CURRENT
 % 37 Gave response
 63 No answer

8. Thinking about health-related activities you may or may not do online, have you...

	YES	NO	NO ANSWER
a. Consulted online rankings or reviews of doctors or other providers	42	38	20
b. Consulted online rankings or reviews of hospitals or other medical facilities	44	36	20
c. Consulted online reviews of particular drugs or medical treatments	60	21	20
d. Posted a review online of a doctor	11	68	21
e. Posted a review online of a hospital	7	72	21
f. Posted your experiences with a particular drug or medical treatment online	20	59	21

What other health-related online activities do you find useful? Please share anything that comes to mind. [OPEN-END]

CURRENT
 % 37 Gave response
 63 No answer

9. Thinking about the last time you had a health issue, did you get information, care or support from any of the following? If so, please tell us if you interacted with them ONLINE through the internet or email, OFFLINE by visiting them in person or talking on the phone, or BOTH online and offline.

	YES, ONLINE	YES, OFFLINE	YES, BOTH	NO, DIDN'T USE THIS SOURCE	NO ANSWER
a. A doctor or other health care professional	4	39	26	10	22
b. Friends and family	5	20	33	18	25
c. Others who have the same health condition	23	8	23	22	24

Please explain further if you would like. [OPEN-END]

CURRENT	
%	15 Gave response
	85 No answer

10. Overall, who do you think is more helpful when you need each of the following kinds of information or advice – health professionals like doctors and nurses, OR other sources, such as fellow patients, friends and family?

	PROFESSIONAL SOURCES ARE MORE HELPFUL	OTHER SOURCES ARE MORE HELPFUL	BOTH EQUALLY HELPFUL	NO ANSWER
a. An accurate medical diagnosis	62	2	15	22
b. Emotional support in dealing with a health issue	5	40	32	23
c. Practical advice for coping with day-to-day health situations	10	33	34	23
d. Information about alternative treatments	22	24	28	26
e. Information about prescription drugs	44	7	26	23
f. A quick remedy for an everyday health issue	19	25	31	25
g. A recommendation for a doctor or specialist	29	10	37	23
h. A recommendation for a hospital or other medical facility	29	10	38	24

We are especially interested in any stories you can tell related to this question. Please share your experiences and insights. [OPEN-END]

CURRENT	
%	24 Gave response
	76 No answer