

My Patient on MySpace: E-patients and the Evolution of Healthcare on the Web

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INTRODUCTION:

The Internet has revolutionized the way in which information is transmitted, interpreted, and updated. In the four decades since its inception as a simple link between two computers in California, the Internet has expanded to reach over one billion individuals.¹ Meanwhile, the United States healthcare system, the trillion dollar behemoth, continues to lag behind when it comes to technology. Electronic medical records are still used by only a minority of physicians, practices, and health systems. Despite the incredible infrastructure of the Internet and World Wide Web, information does not flow freely as lots of individual parties have held sway over common interests and goals.

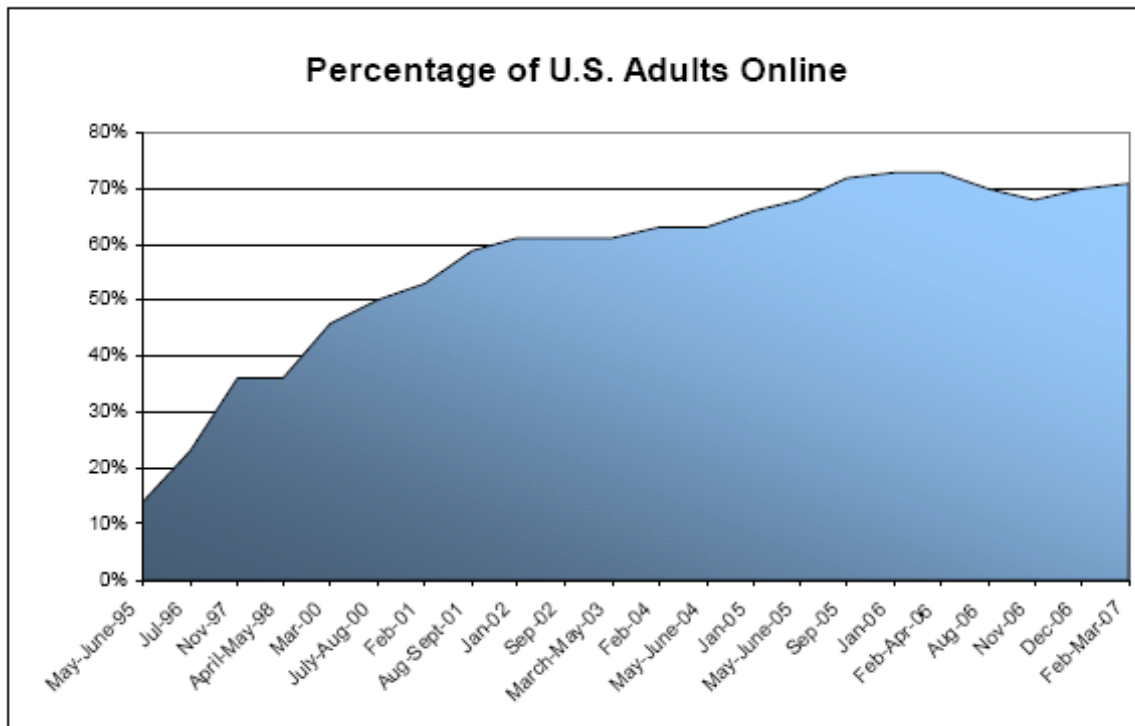
Patients, however, are bypassing this outdated system and finding novel ways to utilize the Web to manage their illnesses, bolster their medical knowledge, and provide support to others. These individuals are driving change in the healthcare marketplace using technology, and they require the attention of all parties involved. The Internet has the potential to revolutionize a very inefficient system, empowering e-patients, driving self-care and promoting wellness and prevention.² Physicians, especially have “underestimated the benefits and overestimated the risks of online health resources for patients.”³ Physicians and the healthcare system as a whole must recognize the Internet’s influence on today’s patients. Understanding that e-patients are complex and that they have an important role to play in the current healthcare marketplace is crucial to fixing a broken system.

The Rise of the Internet & Online Health

The Internet grew ploddingly since its inception in 1969 through a Department of Defence program known as ARPAnet.⁴ Guided by the National Science Foundation it reached universities by the early 1980’s.⁵ Following the creation in 1991 of the World Wide Web by CERN a European nuclear research organization, the Internet expanded dramatically.⁶ The 1990’s marked the commercialization of the Web. Mosaic, the first popular Web browser appeared in 1993 when the Internet had just over a million users. Despite the Dot-com bubble crash growth continued as Web grew from 18,000 sites in 1995 to over 100 million by 2006.⁷ Currently it is estimated that over 1.3 billion individuals worldwide have Internet access and over 70% of the U.S. population is online (Figure 1).⁸

Before the rise of the Web, the online health world was based on bulletin boards and newsgroups.⁹ Some of the earliest health websites such as WebMD, DrKoop.com, and MedHelp.com appeared during the Internet boom of the 1990’s. These sites were fairly one-dimensional and static, providing basic health information, news and lots of commercial content as well. While many sites dissolved after the Internet bubble burst in

2000, a few survived and have evolved to compete in today's online healthcare marketplace.



Source: Pew Internet & American Life Project Surveys, March 2000-March 2007. All surveys prior to March 2000 were conducted by the Pew Research Center for People & the Press. For 1995, internet users include those who ever use a home, work or school computer and modem to connect to computer bulletin boards, information services such as CompuServe or Prodigy, or computers at other locations. For 1996 to 1998, internet users include those who ever use a home, work or school computer and modem to connect with computers over the internet, the World Wide Web, or with information services such as America Online or Prodigy. For 2000 to 2004, internet users include persons who ever go online to access the Internet or World Wide Web or to send and receive email. For 2005, internet users include those who at least occasionally use the internet or send and receive email.

Figure 1: Percentage of U.S. Adults Online From 1995 to 2007. (Source= Pew Internet & American Life Project)¹⁰

E-PATIENTS

Anywhere from 120 to 160 million U.S. residents use the Web for health related information.^{11,12} A 2007 Harris Interactive poll estimated that 84% of all online adults have searched the Web for health information, an increase of 37% over 2 years.¹² Another recent survey revealed that more patients go to the Internet rather than their physicians for health and wellness related information (59% vs 55%).¹³ Despite this, patients still view their primary physicians as their most trusted resource.

Why use the Web?

Convenience, accessibility and cost are the obvious ones. Information is literally at the fingertips of patients. They do not have to resort to print material in a textbook or journal, or even a visit to their physician's office to obtain health information. There are plenty of reliable sources on the Internet and free access is available to many journals, government, and medical group sites. Material presented on the Internet is often easier to digest as it is more likely to be in layman's terms. It can also be difficult for a physician to provide complex medical information in any understandable language especially given all the limitations in our time.

E-patient Demographics:

In trying to understand e-patients it is necessary to look at the demographic breakdown of these users. In general, e-patients are more likely to be better educated, younger, earn higher incomes, and Caucasian. A 2004 survey of patients in three urban clinics in Buffalo demonstrates some of the distinctions that predict who is likely to be a health browser and who is not (Table 1).¹⁴ As would seem obvious these resources are most frequently used by the youngest health consumers (18 to 34 year olds) and also more commonly by men.¹⁵ However in the Buffalo study, women were just as likely to use Web as men, but more often used the Internet to search for health information (37% vs. 27%).

Table 1: Buffalo Urban Clinic Study¹⁴ (2004), n=315:

	Used the Web	Used Web for Health
No College	35%	18%
Attended College	76%	50%
Not Employed	44%	27%
Employed	69%	43%
Black	43%	28%
White or other race	62%	37%
Medicaid	33%	20%
Medicare	53%	37%
Commercial Insur.	62%	38%

Another study looked at Internet use among radiation oncology patients at three sites at the University of Pennsylvania.¹⁶ Results revealed that in an academic center, 42% of those patients had searched for cancer-related information online, 25% at a community hospital, and 5% at a Veterans Administration hospital.

Categorizing E-patients:

The Pew Internet & American Life Project has spawned numerous studies and publications on the topic of online healthcare users. An early study of online health consumers categorized these e-patients into three distinct groups: The Well, The Acutes, and The Chronics.¹⁷ This schema has proven useful in looking at the diversity and

complexity of patients and their needs when it comes to health seeking behavior on the Web. Each of these groups also play different roles on health websites, from purely obtaining information to providing content and support.

The Well are generally healthy individuals who occasionally use the Web to look for wellness and prevention information such as nutrition, exercise, stress. They also search on behalf of others with medical conditions: their family, friends, and colleagues. The Acutes are those with newly diagnosed conditions from minor illnesses such as a UTI to serious diseases such as HIV, diabetes, or cancer. They also represent individuals with an acute change in a stable chronic condition. When they use the Web, they conduct intensive, broad searches and spend a significant amount of time trying to obtain as much information as possible.

The Chronics are individuals with chronic illnesses or disabilities. They not only manage their own health using online tools, but they also tend to be involved in content production, running online support groups, and advising the newly diagnosed. They regularly use the Internet and tend to go to familiar sites. It appears that The Well comprise 60-65% of all e-patients, The Chronically Ill 30-35%, and the Acutes only about 5%. When it comes to Internet traffic The Acutes are responsible for almost half, while The Well represent only about 15%.¹⁸ A recent study (2008) looking at the frequency of use of the Web for health and wellness-related information illustrates a similar distribution (Figure 2).¹⁵ Thirty-six percent of respondents searched for online health content less than monthly, 40% searched a few times a month, and 23% reported weekly use.

FREQUENCY OF SEARCHING FOR HEALTH- AND WELLNESS RELATED INFORMATION ONLINE

How often do you generally search for health- and wellness-related information online? Please select one answer.
Base: Respondents who have used Internet resources to find or access health- and wellness-related information in the past 12 months (n=644)
Source: iCrossing

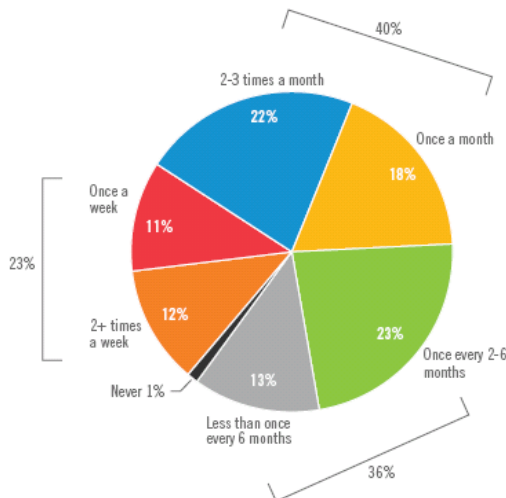


Figure 2: Frequency of Searching for Health and Wellness Related Information Online (Source: iCrossing, 2008) ¹⁵

What do Patients Search for Online?

The iCrossing survey revealed that of the health-related topics searched the most common were symptoms, treatments, and specific diseases or conditions (Figure 3).

TYPES OF HEALTH- AND WELLNESS-RELATED TOPICS SEARCHED FOR ONLINE

What type(s) of health- and wellness-related topics do you search for online? Please select all that apply.

Base: Respondents who have used Internet resources to find or access health- and wellness-related information in the past 12 months and who have ever searched for them online (n=633)

Source: iCrossing

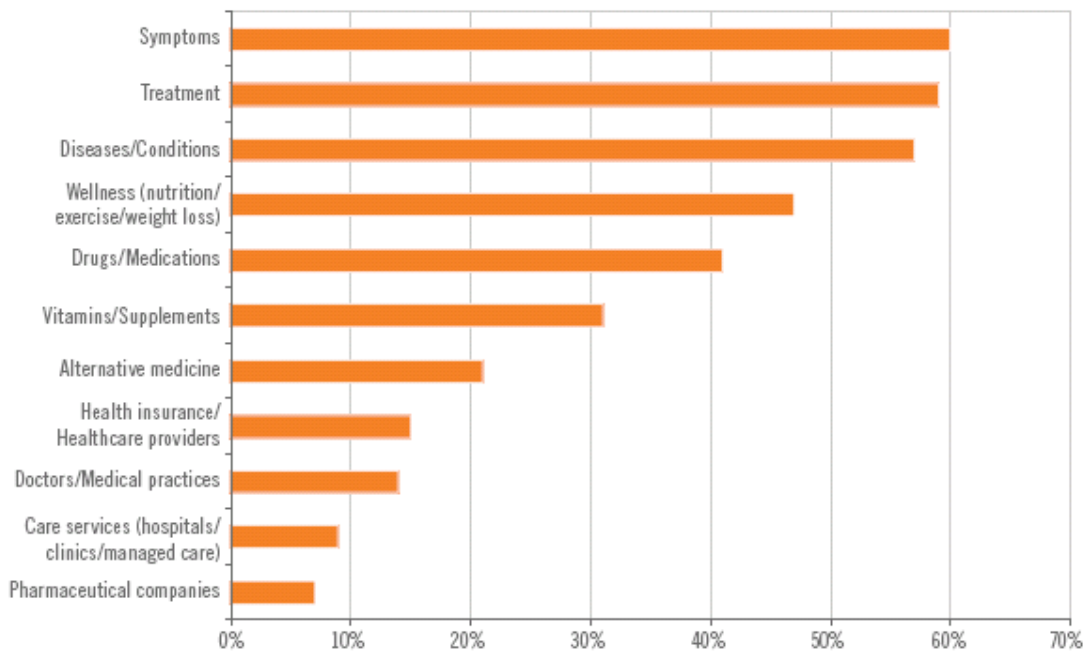


Figure 3: Types of Health-and Wellness-Related Topics Searched For Online (Source: iCrossing, 2008) ¹⁵

Women tended to search for these topics more than men. Men however were more likely to look up topics such as vitamins and supplements, and health insurance providers and doctors. As expected adults over 45 were more likely to search for disease-specific information compared to younger individuals. The iCrossing study found that 75% of users were prompted to go online because of a specific diseases, conditions, or symptoms. Forty-one percent went online to self-diagnose or self-treat a condition, and about 25% went to the Web to fill or refill a prescription or access a healthcare provider or insurance site.

The Internet and Healthcare Decision-Making

Another study looked at the effect of online content on health decision. About 3000 patients with a disability or chronic illness were surveyed in 2007.¹⁹ Fifty-four percent of respondents had used the Web, and 86% of these individuals were e-patients. Seventy-five percent reported finding content that affected their treatment decisions. Additionally, 69% asked their physician a new question or sought a second opinion based on this online content. Online health content appears to not only have a significant influence on medical decision making, but it also affects the physician-patient relationship.

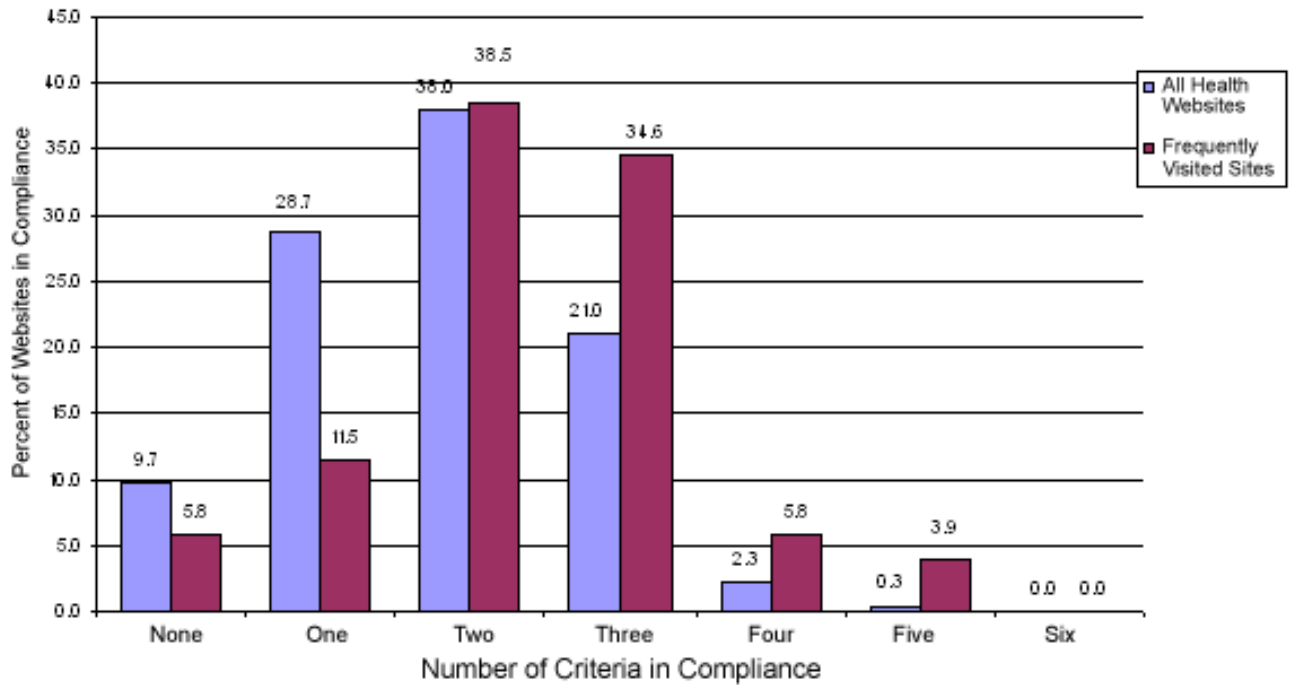
A study in the Archives of Internal Medicine in 2003 looked specifically at this topic.²⁰ Of those surveyed, 31% had used the Internet for health-related information in the past year. Sixty-seven percent reported that their physicians reacted positively when presented with online content, while 7% reacted negatively. Fifteen percent reported that their physician “acted challenged,” and this was more likely if the patient was uninsured (48% vs. 12%). The study concluded that physician reactions and communication skills heavily influenced the physician-patient relationship when it came to presentation of health information from the Internet. Patients however did realize that there were adverse effects of Internet use. Thirty-nine percent of respondents were concerned that using the Web may lead to unnecessary doctor’s visits and 37% thought it may put more demands on their physician’s time. Twenty-two percent thought this information could interfere with the physician-patient relationship.

Quality and Reliability of Health info on the Web:

Assessing the quality and reliability of online health information has been a difficult task and there remains significant variability in these measures.^{21,22} Given the nature of the Web, the rapidity of information turnover, the sheer volume of content, it is has been very difficult to create appropriate tools to gauge quality and accuracy.²³ A British Medical Journal study of an epilepsy-support group website indicated that only 6% of information posted was factually wrong when reviewed by professionals. Patients using this site, when surveyed, overestimated the prevalence of inaccurate information with approximately half believing over 25% of information posted was inaccurate. On the other hand, 95% thought that inaccurate information did not negatively affect their experience.²⁴ In a Harris Interactive poll in 2007, 86% of e-patients found online health information reliable and only 26% found online medical information “very reliable.”¹² A 2004 study reported that 81% of e-patients thought they had the ability to find “high quality” information online, but 72% were concerned about its reliability.²⁴ Thirty-five percent thought they were either very good or excellent at determining the reliability of online health information.

As part of the *Healthy People 2010* initiative, the Office of Disease Prevention and Health Promotion (ODPHP) established a national objective of increasing the proportion of health-related websites that disclose information to better assess the quality of these sites.²⁵ The six criteria outlined in this objective were: 1) information on the identity of

the website sponsors, 2) the purpose of the site, 3) the authorship or source of the health information provided, 4) policies for protecting the confidentiality of users' personal information, 5) how the site is evaluated, and 6) how often the health content is updated. In 2006, The ODPHP then assessed adherence to these recommendations, using a sample of 102 out of 3,608 active health-related sites. About half of the sites assessed were randomly sampled from a pool of 213 “most frequently visited” sites which represented 60% of health-related Web traffic. The other half were sampled from the remaining sites. The study revealed that none of the sites were compliant with all six disclosure criteria and less than 3% of all sites were even compliant with four (Figure 4).

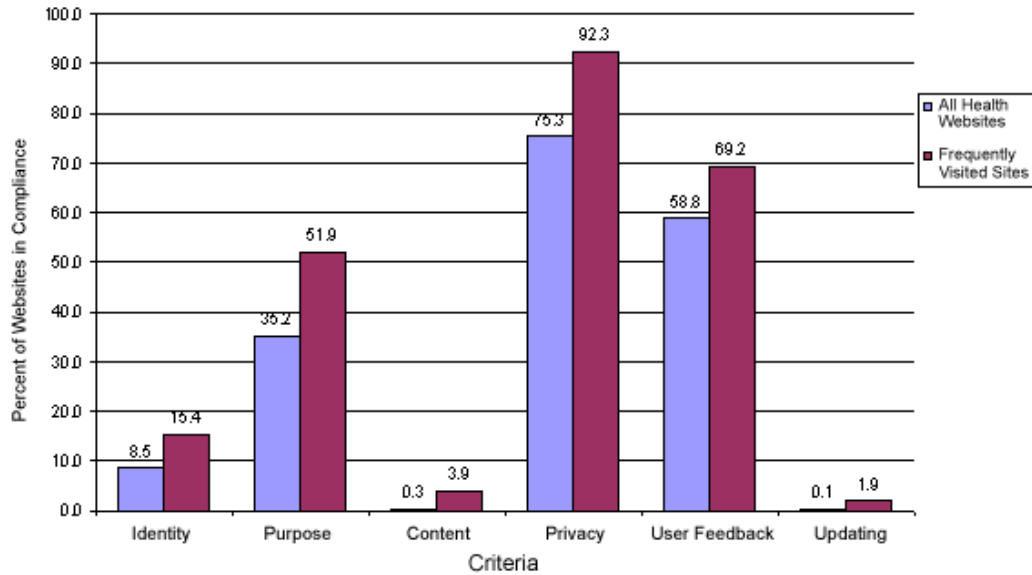


Source: Computations by Mathematica Policy Research, Inc.

Note: All percentages shown are weighted.

Figure 4: Percent of Sampled Websites With Number of Criteria in Compliance. (Source: ODPHP)²⁵

The more popular sites were generally more compliant. Across the board, sites did not comply well with disclosing sponsors, content sources, and methods of content updating (Figure 5).



Source: Computations by Mathematica Policy Research, Inc.

Note: All percentages shown are weighted.

Figure 5: Percent of Websites in Compliance According to Individual Criteria (Source: ODPHP)²⁵

To counter these trends the Medical Library Association provides a guide to evaluating health-related information on the Internet found at: <http://www.mlanet.org/resources/userguide.html>.²⁶ Additionally the Health On The Net Foundation is a neutral accrediting organization for health-related websites.²⁷ A logo pictured in Figure 6 can be found on accredited sites.



Figure 6: Health On The Net Foundation Accreditation Logo.

Where do E-patients go for Information on the Web?

When e-patients were asked about sites, and Web tools they used within the past year, search engines such as Google and Yahoo! were the most commonly cited (Figure 7) at 65%.¹³ They were followed by Healthcare portals such as WebMD and YahooHealth! reported by 45% of e-patients.

ONLINE TOOLS, SERVICES AND RESOURCES USED TO LOCATE OR ACCESS HEALTH- AND WELLNESS-RELATED INFORMATION IN THE PAST 12 MONTHS

Which of the following online tools, services and resources have you used to locate or access health- and wellness-related information in the past 12 months? Please select all that apply.

Base: Respondents who have used Internet resources to find or access health- and wellness-related information in the past 12 months and who have ever searched for them online (n=633)

Source: iCrossing

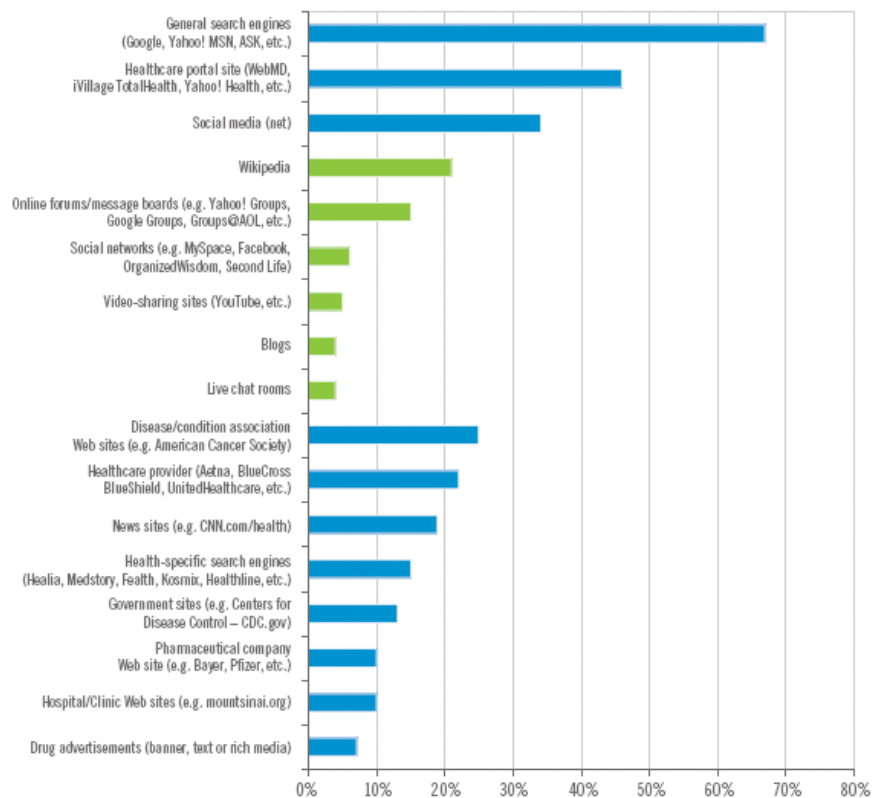


Figure 7: Online Tools, Services and Resources Used To Locate or Access Health- and Wellness-Related Information in the Past 12 Months. (Source: iCrossing, 2008)¹³

Health 2.0/Web 2.0: The Future of Health on Internet

Social media sites were used by about 35% of respondents in the iCrossing study, the most prominent being Wikipedia (Figure 7). These tools and technologies, also known as “Web 2.0”, are quickly becoming mainstream and taking over the Internet universe because of their ability to bring people together in a constructive and interactive environment.²⁸ Web 2.0 is a term coined by Tim O’Reilly a prominent tech blogger and online publisher. More than a physical entity, Web 2.0 represents the idea of an interactive, collaborative online world in which individuals surfing the Web not only view content, but are a part of its creation and evolution as well. The Internet is no longer a simple, one-way source of information. The novel concept driving this most recent

iteration of the Web is user-generated content. Two of the most popular Web 2.0 sites MySpace and Facebook count over 70 million users in their midst.²⁸ Within these sites there are interest groups that focus on many specific areas of health from weight loss, to depression and cancer. On the back of the explosion of Web 2.0-themed sites health-focused, “Health 2.0” sites are emerging.

Health2.0/Web 2.0 Technologies Defined

Among the Web 2.0 tools available, the most applicable to health-related content from a patient perspective include wikis, blogs, social search engines, podcasts, vodcasts, and both social networking and virtual communities.^{30,31} Wikis, the most commonly cited Web 2.0 tool used by e-patients are collaborative websites with open content, accessible, and free to edit by anyone. Wikipedia, the most prominent wiki, has spawned several health-focused versions such as Ganfyd.org, FluWikie, and AskDrWiki.com. Blogs, short for weblogs, are online journals or Web diaries that are focused on specific topics with news, general information and links. Diabetesmine and Thefurrymonkey are both excellent examples of patient-generated blogs focusing on Type 1 diabetes and non-Hodgkin lymphoma respectively. Social search engines depend on user generated tags and community/common-interest based search parameters to filter online content. OrganizedWisdom is a hybrid in that it integrates user generated site recommendations and organizes them within specific health topics termed “wisdom-cards” that are subsequently reviewed by physicians. In this form, it represents a truly collaborative tool where lay-persons and professionals can create useful health-related web content. Podcasts (audiocasts), and vodcasts (videocasts) are both tools generated for and by the health-consuming Web user which can be actively used for social communication through websites such as Youtube. As mentioned earlier, social networking communities such as Facebook and MySpace are being used to house support groups. Based on these models more focused health-related online communities such as PatientsLikeMe, Tudiabetes, and DailyStrength have come into being. Second Life a virtual community with 1.3 million active users also hosts a variety of health-related, user-generated areas. The American Cancer Society hosted the “Second Life Relay for Life” in 2007 which paralleled its annual real world charity run.³² Virtual runners from all over the world generated \$118,000 for the organization through this event.

CONCLUSION

The Internet has revolutionized the way in which information is published, accessed, and transmitted. With the incredible pace at which the Web has grown and evolved, the larger healthcare community has not truly recognized its effect on health-related information delivery. Today’s patients have much greater access to this content and it affects their opinions and decision making more than we really understand. Just as more traditional forms of media such as radio and TV shaped the views of the public for years, the Internet has very quickly taken their place, however with much greater potential. The accessibility, interactivity, and ability to harness collective intelligence with the rise of Web 2.0 has made the Internet a truly powerful tool. It allows patients and their caregivers unprecedented access to medical information that once was available only to

medical professionals. There remain issues with quality and accuracy of content, however with all things on today's Web, what is outdated and factually incorrect eventually gets discarded. E-patients are shifting the traditional paradigm of the physician as the gatekeeper of health information who has total control of all health decisions.² Information is empowering patients and giving them the opportunity to become more involved in their own health and wellbeing. These patients are adopting technologies to reach this goal, but it remains up to physicians and the healthcare system to encourage and guide them in this process.

“Health 2.0 is about redefining the role of consumers in our health life. We are experiencing a sea change in consumer attitude, a growing understanding that we must be our own best advocate for personal and family health. We no longer live in a one-source world where we can rely solely upon a physician to inform our decisions about health.

Men and women are flocking to the Internet in increasing numbers looking for health information. We want access to multiple points of view on conditions, treatments, exercise and nutrition to make better decisions about our health. The vision of someone armed with the right information--with the power to make personal health decisions--is a compelling one. But this vision cannot be achieved without addressing a central flaw in the current system - our focus on patients, rather than people. Online and offline, we are not fully acknowledged as multi-dimensional people who desire and pursue an active role in our health lives.” – Keith Schorsch, The Health 2.0 Blog³³

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