



MANAGING HEALTHCARE THROUGH SOCIAL NETWORKS

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Surveys show an increased reliance on physician and patient social networks, which promise to transform healthcare management. But challenges such as privacy and data accuracy remain.

Part of being successful, according to Ralph Waldo Emerson, is “leaving the world a bit better and knowing that even one life has breathed easier because you lived.” Karen Parles, founder of lungcanceronline.org, certainly met both those criteria. After being diagnosed with non-small-cell lung cancer in 1998, Parles launched the site and ran it until she died in February 2009. The site continues to provide advice and hope to those suffering from all forms of lung cancer.

Parles’s site was one of many to benefit from participation in Health 2.0, a movement that began in 2004 in response to a growing reliance on the Internet as a source of health information. Health 2.0 leverages social software to promote collaboration among patients, caregivers, medical professionals, and other health stakeholders.¹ Since the movement’s inception, healthcare social networks have grown to such a degree that research has begun focusing on user patterns, including how often and why users turn to online health tools.

This interest is not undeserved. Healthcare social networks provide an active platform for sharing ideas, discussing symptoms, and debating treatment options—tasks that together promise to improve patient care. But these networks also raise concerns: Is participatory medicine a benefit or a danger? What about loss of privacy or inaccurate information? What do social networks offer that traditional healthcare resources cannot provide? Answers to these questions will determine how to use technology to its best advantage in improving healthcare.

USER MOTIVATION

Health issues are a primary concern for most people. In January 2009, the Health Engagement Barometer² published the results of a survey asking US citizens to report their involvement in health issues. The survey revealed four categories:

- *Health involved.* Is involved in health but does not necessarily gather or share information (80 percent).
- *Health informed.* Gathers and shares information more than once per week (33 percent).
- *Health engaged.* Identifies condition and treatment by actively gathering and sharing health information and advocating a point of view (39 percent).
- *Health info-ential.* Is involved in all the previous categories (22 percent).

The last category is perhaps the most significant because it shows that roughly one of every five individuals surveyed were most likely to influence their own or others' healthcare decisions and that 88 percent of those surveyed turn to other sources to validate physician information.² All this data points to an increasing demand for health content and strongly suggests that, as an inexhaustible source of information, the Internet could satisfy that demand.

According to the technology acceptance model, successful use relates to a person's intent to apply the technology, which in turn depends on how that person perceives its usefulness and ease of use.³ In the context of online health tools, *perceived usefulness* is the degree to which a person believes that the technology will aid in accessing and understanding online health-related information, while *perceived ease of use* is the degree to which a person believes that using the technology will require very little effort.

A survey of US citizens conducted in December 2008 by the Pew Internet Project (www.pewinternet.org) found that 61 percent have looked online for health information, and an iCrossing survey⁴ corroborated those findings. As Figure 1 shows, 63 percent of the iCrossing survey respondents reported performing searches at least once a month, 11 percent once a week, and 12 percent two or more times a week.

Figure 2 shows the variety of health- and wellness-related factors that led iCrossing survey respondents to search online for health information.⁴ Of these respondents, 75 percent researched a specific condition, disease, or symptom, and 41 percent used the Internet to attempt self-treatment. In a June 2009 survey by the Pew Internet Project,⁵ 44 percent of respondents found their most recent search had a minor impact on their own or another's healthcare management; 13 percent saw a major impact; and 42 percent stated that they or someone they know had been helped by following medical advice or using health information on the Internet.

These statistics imply a bright future for health-specific social networks. Personal attributes, such as Facebook experience, and network attributes, such as a user-friendly interface or free access, will also influence the perceived usefulness and ease of use of healthcare social networks.

USER CHARACTERISTICS

Healthcare social networks can be either physician or patient oriented. *Physician social networks* provide an online technical infrastructure for doctors to share clinical cases, images, videos, and medical knowledge. *Patient social networks* emphasize direct patient support, promoting disease awareness, and positive and proactive behaviors to stay healthy while living with a disease. Both network types can greatly enhance healthcare management.

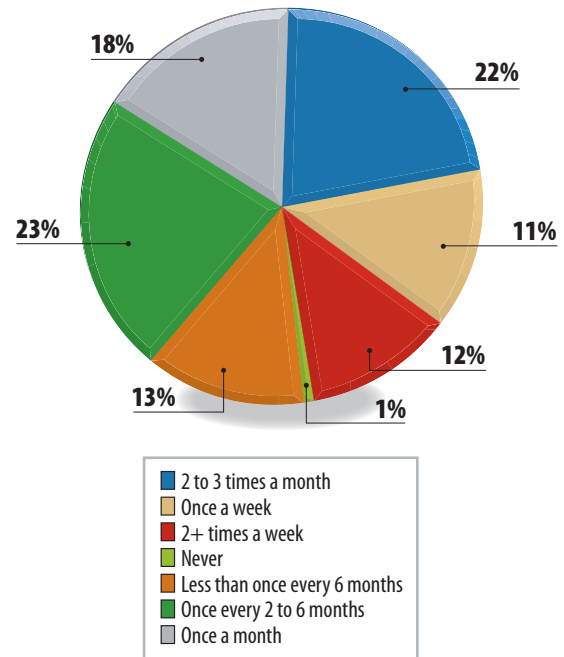


Figure 1. Results of a survey to determine how often people search for health- and wellness-related information online. Of those surveyed, 63 percent had attempted to access online information at least once a month in the past 12 months (n = 644).

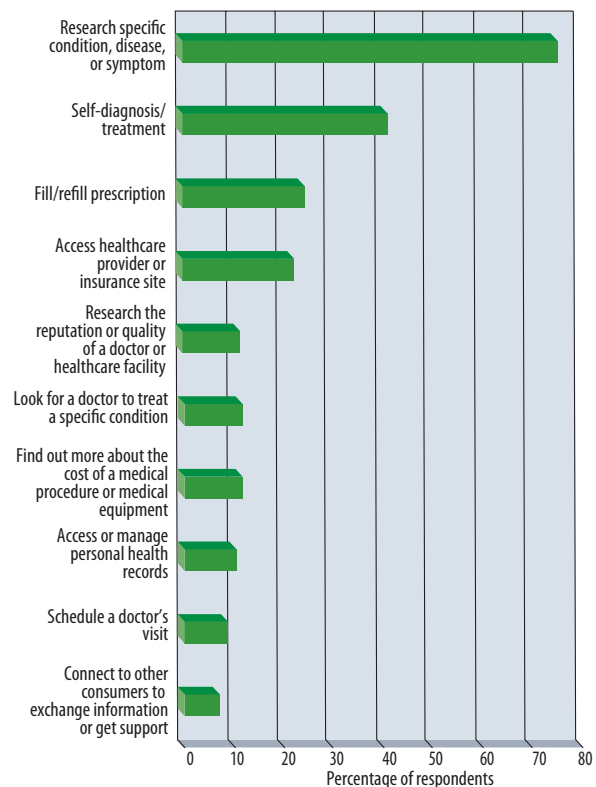


Figure 2. Health- and wellness-related factors prompting consumers to go online in the past 12 months (n = 633).

Table 1. Actions taken by physicians as a result of online research.

Actions taken	Percentage of respondents
Conduct further research myself	48
Print out information or direct a patient to a website to learn more	45
Recommend a patient change behavior or habits (in lifestyle, for example)	38
Recommend further testing based on symptoms	32
Change patient's medication in some way	31
Initiate treatment, such as writing a prescription for a new treatment course	30
Ask the opinion of another colleague	28
Request more information about a product or medication	25

Physician networks

The large number of physicians attracted by physician social networks is surprising. Manhattan Research, a global pharmaceutical and healthcare market research company, found that 60 percent of US physicians use or plan to use a physician social network.⁶ These platforms bring thousands of physicians together to exchange the latest in medical advances. Sermo (www.sermo.com) is the largest online physician community, with more than 112,000 members representing 68 specialties as of March 2010; members' average age is 47, and their average experience level is 13 years. Other popular physician social networks such as Ozmosis (www.ozmosis.com) and DoctorNetworking (www.doctornetworking.com) reported anywhere from 3,000 to 10,000 physician members each as of September 2009.

Members seem largely satisfied with the networks. Of those surveyed by Manhattan Research,⁶ 89 percent deemed the Internet "essential" to their professional practice. In a 2009 survey of physicians by Hall & Partners,⁷ 86 percent responded that they use the Internet to search for health, medical, or prescription drug information and that they depend on the Internet more than any other resource; over half of these physicians belong to a physician social network, with the majority belonging to Sermo.

Table 1 shows the Hall & Partners survey respondents' actions as a result of their online research. The survey also found that 69 percent of the physicians trust clinical information online, and 73 percent consider the Internet to be a standard part of their practice.

This growing reliance on the Internet is consistent with the findings of another Manhattan Research study,⁸ which found that participation in physician social networks almost doubled from 2008 to 2009. The study also forecasts that demand will continue to grow as physicians

find new uses for social media in providing and improving healthcare.

Benefits. In a physician social network, physicians exchange views about drugs, devices, and treatment options and can use their knowledge from daily practice to ask and answer specific clinical questions that are not obvious in the medical literature. The premise is that gathering and sharing information about new clinical findings, drug treatments, and patient care can bring unprecedented benefits to the medical community: physicians can better solve problems, collaborate on difficult cases, and predict future events through a network than they could individually or even in a small group.

Such networks are particularly useful for nearly 75 percent of the office-based physicians in solo or small practices, who often find it difficult to contact other doctors. According to founder Daniel Palestrant, Sermo's value is in providing a way for its members to make better, faster decisions informed by real-world feedback. A medical doctor in the remotest location can collaborate instantly with thousands of colleagues and draw from their combined experience. Because this information is available 24/7, the benefit to patients can be instantaneous as well.

Physician social networks also influence healthcare institutions that monitor doctors' conversations and use them in decision-making. Networks such as Sermo receive funds from industry, the US government, and financial institutions, all of which are interested in early indicators that could affect healthcare, such as symptoms of an impending epidemic. In the past, only a few experts have been able to provide this insight, but these entities can glean information directly from communities of thousands, using an analysis of physicians' feedback to plan future investments. Palestrant alludes to the "collective voice" of physicians nationwide and their ability to influence the healthcare and financial industries, as well as regulatory bodies. Instant feedback from peers can embolden a physician to be more proactive in improving patient care—providing a physician's voice not previously heard.

Finally, physician social networks contribute to the emergence of trends and insights in medications, devices, and treatment. Physicians can discuss ongoing research and help speed the process of bringing advances to patient care. For example, according to the Sermo website, in January 2008, Nature Publishing Group (NPG) and Sermo announced a partnership to make the content in NPG journals accessible to Sermo members; NPG in turn would be able to view comments on its publications. This symbiotic relationship is a novel and relatively effortless way to improve medical research and publishing.

Concerns. Trust is a major issue in relying on network information: How do you gauge the accuracy of an anonymous posting or the poster's expertise on that topic? Some

networks offer a peer review system to ensure content validity. Physicians on Sermo, for example, rank each observation's pertinence, and Sermo offers financial incentives to encourage evaluative commentary. Other networks, such as Within3 (www.within3.com), reveal members' identities so that other posters can measure the usefulness of specific comments in light of a physician's background.

Most networks also require that physicians verify their credentials, such as state license, before becoming a member, or they accept members only by invitation. The expectation is that physicians will trust the platform more if they are invited to join by other physicians they know and trust. Within3 follows the by-invitation model and checks the identity and credentials of new users at registration to ensure the community's integrity.

Networks are also taking steps to ensure individual privacy. Sermo hides physician information, and Within3 lets members decide how much personal information to share. Both networks strive to provide knowledge free of outside influence in a safe, easy-to-use environment that costs nothing to join.

Patient networks

Patient social networks support e-patients worldwide by promoting disease awareness and positive and proactive behaviors to stay healthy while coping with disease. E-patients or e-caregivers—friends or family members—can access content, connect with others, or collaborate with others in exploring treatment options or other concerns.⁹

PatientsLikeMe is a patient network with more than 58,000 registered patients as of March 2010. Its cofounder, James Heywood, recognized that doctors often answer medical questions but do not cover how a condition will affect the patient's everyday life. The site attempts to fill that gap, even making its members' medical records available to anyone else on the site and providing free tools for patients to track their medications, symptoms, and health outcomes. Data is stored in easy-to-read charts, allowing members to search for medical profiles that most closely match their own. According to Benjamin Heywood, also a cofounder of PatientsLikeMe, the site's value stems from the patient's knowledge of how he or she is doing relative to the rest of the world (www.patientslikeme.com). A patient can compare parameters such as disease progress, treatment, and dosage level—information that would never be available outside the network.

Table 2 shows the PatientsLikeMe members classified according to condition. "Estimated US prevalence" gives an idea of how many other US citizens have the same disease and thus might benefit from the network.

Benefits. Patient networks offer a highly interactive way to exchange information about disease. In the past, patients had to resort to reading case studies and statistics,

Table 2. PatientsLikeMe members' conditions and estimated US prevalence.

Condition	Registered patients	Estimated US prevalence
Amyotrophic lateral sclerosis	4,382	30,000
Multiple sclerosis	17,608	400,000
Parkinson's disease	4,767	500,000
HIV/AIDS	2,645	1,000,000
Mood disorders	14,316	20,000,000
Progressive supranuclear palsy	100	10,000
Multiple system atrophy	340	25,000
Devic's disease (neuromyelitis optica)	220	15,000
Fibromyalgia/chronic fatigue syndrome	12,502	7,000,000
Epilepsy	1,024	3,000,000
Organ transplants	813	200,000

which were often impersonal, hard to understand, and only partially relevant to a particular patient. Networks, in contrast, provide almost limitless knowledge about symptoms and treatments in a supportive environment.

Patient networks can also lower the anxiety level of patients and caregivers, particularly for newly diagnosed patients who are unsure of their future. Such patients need a variety of information quickly and without interruption. Between doctor's appointments, patients can contact other patients to gain enough knowledge to ask the right questions about treatment, symptoms, and life care. According to Matthew Holt, organizer of the annual Health 2.0 conference, healthcare has traditionally focused on acute events, but illness is ongoing sometimes over long periods (www.businessweek.com/magazine/content/08_50/b4112058194219_page_2.htm).

Patient networks empower their members to open dialogs among themselves freely and honestly, which often has unexpected consequences. Patients can tell one another where to go for treatment or report drug side effects directly to regulators, circumventing pharmaceutical companies. E-patients can share their health-related experiences, personal research and stories, pictures, and videos to encourage and inform others. Writing and multimedia posts help e-patients express themselves creatively and enhance motivation.

Like mainstream social networks, patient networks make people feel less isolated. J. Glen House, who founded Disaboom for people with disabilities, observed that patient social networks can be vital for those who cannot leave their homes and who feel alone in their health struggles (www.disaboom.com). Disaboom members—100,000 as of March 2010—make plans to watch

movies with one another but remain at home, chatting online while watching. For these house-bound patients, the network provides a social life they might not otherwise have.

Inspire (www.inspire.com), sponsored by the National Organization for Rare Disorders, unites people with the same disease. Being able to meet others with a similar medical condition and learn from them assures patients that they are not alone and motivates them to fight their disorder. For caregivers and families, meeting other families in the same situation can help lower stress.

Patient networks can also promote new treatments. The aim of CureTogether (www.curetogether.com), which has more than 7,200 registered patients as of March 2010, is to help people anonymously track and compare health data and collaborate with scientists to accelerate research. Pharmaceutical and insurance companies, universities, and research labs have purchased data from patient networks with their members' consent—revenue that feeds back into the network. Those purchasing the data also benefit by acquiring and being able to analyze information not available elsewhere, such as data from PatientsLikeMe related to various chronic diseases. Advertising is another source of revenue, as are the fees that drug companies pay to recruit participants for clinical trials. The benefit to patients is the hope that their actions are furthering progress toward a cure.

Concerns. As in physician social networks, the biggest concern is trust. To what extent can people trust the content of patient social networks? Most medical advice and comments come from users, and sites do not verify their validity before publication. Patient social networks try to identify the content source as being a medical professional or patient, but that is the extent of any accuracy check. Patients believe in the wisdom of crowds, which is the essence of social networks. Patient social networks explicitly announce that their content should not be a substitute for professional medical advice, diagnosis, or treatment and recommend that patients seek a physician's advice.

Privacy is also a concern. PatientsLikeMe warns individuals before they register that their personal records will be visible to others and that drug or insurance companies can pay for access to the aggregated information. Patients must feel that the benefits outweigh misgivings about loss of privacy because they openly share medical records, often with photos and names attached. For these patients, privacy takes a back seat to the hope that some exchange will help them improve their health or find a better treatment. Nonetheless, the disclosure of personal information can be a motive for discrimination and the consequences can be serious, such as thwarting a job search. Some patient social networks like HeartPatients (www.heartpatients.com) let patients control who can see what personal information they post.

The creation of communities with a common interest is the essence of online social networking. What distinguishes physician and patient social networks from other online communities is the motivation for interaction: professional interest for doctors and coping with disease or disability for patients.

System designers must understand the nature of this motivation and how it plays out. Physician and patient social networks must offer broad access to all functions, motivate participation, and encourage best practices. Developers should implement applications that promote ethical behavior and prevent unauthorized content use. Users should have the option to conduct both private and public communication and to control access to their personal information. Any system design must thoroughly address trust and privacy issues. Interaction support, access to a wide variety of functions, and data portability are also critical requirements. Interaction will benefit from OpenSocial, a set of common application programming interfaces developed by Google to interoperate on multiple platforms¹⁰ and to connect different social networks related to particular diseases or supporting interests. Data portability¹¹ calls for open standards and other technologies that enable users to export their identity-related information, such as membership numbers, contacts, personal details, and videos.

New methods are needed to navigate across physician and patient social networks and to facilitate the interoperability of content objects and person-to-person networks.¹² The Semantic Web, which represents the future of Health 2.0, will enable people and objects to interconnect by allowing context-sensitive searching. The social Semantic Web will use tagging as a way to aggregate information, and to organize and analyze social media content.¹³

The ultimate aim of physician and patient social networking is to let e-patients, doctors, and caregivers quickly find health information that matches their specific interests. Cicero stated, "In nothing do men more nearly approach the gods than in giving health to men." It should be the aim of networking technology to do likewise. **■**

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