

# **The Wisdom of Patients: Health Care Meets Online Social Media**

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*by*

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## About the Foundation

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*“Community is the killer app in health care.”*

— STEVE CASE, REVOLUTION HEALTH  
TO THE WORLD HEALTHCARE INNOVATION AND  
TECHNOLOGY CONGRESS, DECEMBER 2007

## Foreword

When Steve Case founded America Online, it was a Web 1.0 world in which users could search for and read information. The online environment is quickly evolving into what has been called Web 2.0, and the difference for health care consumers is transformational.

Web 2.0 enables “regular” people—not just the technology-savvy—to create content online. Such user-generated content takes the form of photo-sharing, video-uploading, music-downloading, and personal blogging, among other activities supported by social networks. The technologies, called social media, that consumers are using in their daily lives for entertainment, education, and financial management are also a platform for consumers to use for health information and support.

Social media on the Internet are empowering, engaging, and educating consumers and providers in health care. This movement, known as Health 2.0, can be defined as: *the use of social software and its ability to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health.*

Within the environment of Health 2.0, people with chronic health conditions are sharing their stories with each other, not just for emotional support, but for the clinical knowledge they gain from participating with “patients like me” in an online community. Doctors are meeting up online to share quandaries about challenging cases and solutions that work. Researchers are coming together with patients to learn about side effects in real-time to improve therapeutic regimens.

This iHealthReport takes a close look at Health 2.0. Who is using it? How are they using it? What is the impact? How can organizations get involved? Finally we will look to the more distant horizon, where Health 3.0 will eventually unfold.

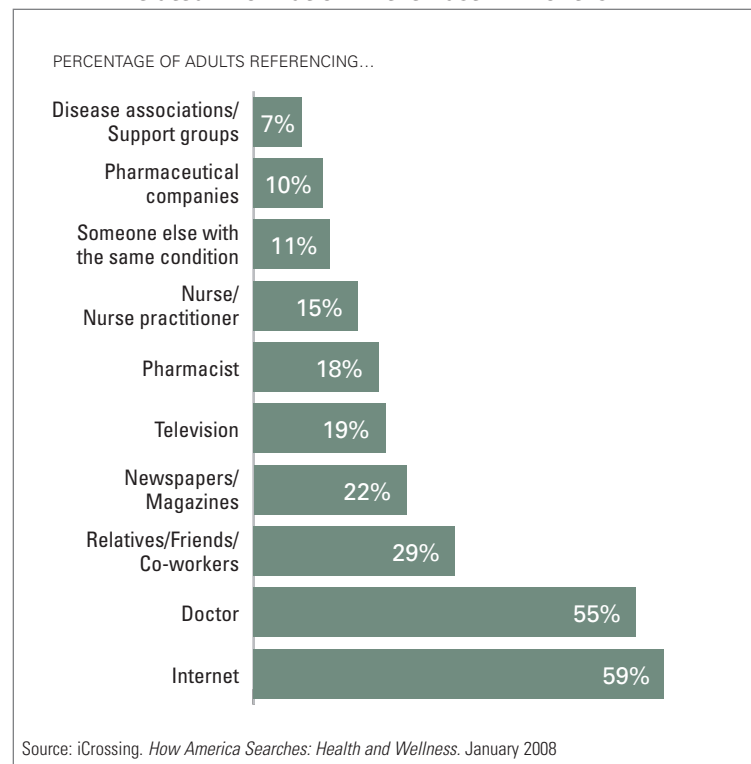
— Jane Sarasohn-Kahn  
THINK-Health

# I. Social Networks Come to Health

*The Internet plays a central role in providing health information. It is also becoming a platform for convening social networks and creating health information.*

AMERICANS USE THE INTERNET TO HELP INFORM decisions in their daily lives—from getting government information on Social Security to job-seeking or selling a car.<sup>1</sup> Increasingly, consumers also rely on the Internet for help with their health care decisions. According to recent surveys, some 60 to 80 percent of Americans have used the Internet to find health information, and as of January 2008, the Internet rivaled physicians as the leading source for health information.<sup>2,3</sup>

**Figure 1. Sources Used to Find or Access Health- and Wellness-Related Information in the Past 12 Months**



The sheer quantity of information on the Web raises its own problems. Jude O’Reilly, an expert in health information exchange online, puts it this way: “A common part of the consumer’s health experience is to face a health challenge, Google it, spend 20 minutes getting totally overwhelmed, and then do what they did in the 1980s: Call a friend and work through their offline social networks.”

This was the impetus behind the emergence of Web-based social networks in the area of health and medicine. The new Web sites facilitate the exchange of health information and personal stories in a way that transcends both medical textbooks and chatting with a friend on the phone—yet offers some of the benefits of both. Consumers are quickly adopting such social networks; one in three Americans used some form of social media online for health in 2007.<sup>3</sup>

Even before the Internet became widely available, there was evidence that social networks had a positive influence on health. In 1979 a large-scale California study showed that people with the lowest levels of social contact had mortality rates two to four-and-a-half times greater than those with strong social networks.<sup>4</sup> Since then, research has found that a stable and supportive social network improves health outcomes for people with a wide range of conditions from heart failure to post-partum depression.<sup>5,6</sup> In addition, social networks have a palliative effect on preoperative pain and anxiety.<sup>7</sup>

The facilitation of social networks through the Internet has infinitely expanded the possibilities beyond the constraints of in-person, localized contacts. Users are linked into networks based on shared interests. Links include general sites, such as MySpace, or specific interest-based networks, such as the MySpace CURE DiABETES group. Other types of tools for online social networking in health include the following:

- Blogs enable users to record text, graphics, and video and to share them with others.
- Online forums allow people to post opinions on subjects of personal interest.
- Podcasts help people create and share audio files.
- Really Simple Syndication (RSS) rapidly disseminates new information.
- Social network services use software to build online social networks for communities of people to share and explore their interests with

others. These Web-based services can involve chat, messaging, email, video, file-sharing, and discussion groups.

- Wikis enable a group of people to record, edit, and verify knowledge on a particular subject collectively.

Together, these base technologies provide the foundation for social networks in health known as “Health 2.0.”

## II. What Is Health 2.0?

*“Groups are remarkably intelligent, and are often smarter than the smartest people in them.”*

JAMES SUROWIECKI, *THE WISDOM OF CROWDS*

THE FIRST GENERATION OF THE INTERNET — WEB 1.0 — has been described as the “read-only Web.”<sup>8</sup> It allowed people to search for information and to read it. The provider of the online information controlled the content. Web 2.0 allowed for interaction, which has led to users’ ability to create information. Users can post and share audio, graphics, text, and video online through sites such as Last.fm, Flickr, Blogger, and YouTube, respectively.

### The Power of Collective Wisdom

The more participants there are in a social network—the foundation of Health 2.0—the more value they create. This is the phenomenon of positive network effects. Some have referred to it as harnessing collective intelligence. In his book *The Wisdom of Crowds*, James Surowiecki notes that “groups are remarkably intelligent, and are often smarter than the smartest people in them.”<sup>9</sup> This is the underlying thesis of the wisdom of crowds: Groups don’t need to be led by the smartest people to be smart. When patients managing the same chronic condition share observations with each other, their collective wisdom can yield clinical insights well beyond the understanding of any single patient or physician. Similarly, when physicians share information with each other online, the results go well beyond the doctor’s lounge—the traditional locale for exchanging clinical experiences and insights.

When the local in-person support group goes global—as is the case when patients and physicians share online—the results can be transformational. “It’s now possible to solicit and aggregate information from people all over the world and arrive at a collective decision with a few clicks of a mouse,” says Surowiecki. On the [PatientsLikeMe](#) Web site, for example, people from many countries convene to share personal information on drug dosages, side effects, and medical histories for multiple sclerosis (MS), as well as other conditions. The collective wisdom on this Web site may rival the body of information that any single medical school or pharmaceutical company has assembled in the field of MS.

The wisdom of crowds does not resist expert opinion—only dependence on a single expert opinion. “Relying on a crowd

rather than an individual improves your chances of finding information that you didn't know was out there," Surowiecki explains. That is especially relevant for people with a newly diagnosed rare disease. They often find themselves relatively alone in their geographic community, without in-person access to patients with the same illness, or a medical community with expertise in treating it.

The phenomenon of the wisdom of crowds has begun to change consumers' relationships with their traditional touchpoints in health: physicians, health plans, suppliers, and pharmacists. By sharing ideas, discussing symptoms, and debating treatment options together, all of these stakeholders gain knowledge that can ultimately improve patient care.

Consumers value the health information they get through social media. According to the 2008 *Edelman Trust Barometer*, people tend to trust "a person like me" more than authority figures from business, government, and media. Furthermore, social networkers—those people who are most likely to share their opinions about companies with friends, colleagues, and the community-at-large—are also more likely to be more health-activated.<sup>10</sup>

However, today's consumer-generated content isn't geared well to supporting decisions, according to Jude O'Reilly of Trusera, an invitation-only network of people looking for health information. "People mine through acres of message boards to get to actionable information. What they're forced to do manually is to work out two very hard problems: first, is this person like me; and second, is this person credible? The process of building trust is laborious."

Critics of social media in health warn that content provided by individuals could lead to adverse effects or even death. Fard Johnmar of Envision Solutions, a company active in social networks and health, argues against this. "The communities that are very active and have a lot of members tend to be self-correcting," he says. "Bad health information

gets driven out. Just like Wikipedia, misinformation doesn't remain 'up' for very long."

This has also been the experience of Amy Tenderich, one of health social media's pioneers. She has found that her community, DiabetesMine, self-polices and self-corrects. She relates an incident in which a medical equipment company attempted to promote a new set of glucose meters in the guise of a public service announcement. A group of DiabetesMine community members quickly critiqued this ploy on the Web site. Says Tenderich, "you cannot get away with that sort of thing nowadays with the prevalence of social networking online. Patients can call your bluff and discuss the issue with each other immediately." She commended the company for responding on the site and becoming part of the conversation.

#### **Daniel Hoch, M.D.**

Neurologist and believer in the wisdom of crowds

Since 1994, Daniel Hoch, a Harvard professor of neurology, has noticed that his patients with epilepsy meet up online at the BrainTalk Communities, a site founded by John Lester at Massachusetts General Hospital.

Dr. Hoch observes that an online group like BrainTalk "is not only much smarter than any single patient, but is also smarter, or at least more comprehensive, than many physicians—even many medical specialists."

More recently, several of his patients have directed his attention to an increase in EEG guided biofeedback to augment treatment of neurologic disorders. With their help, Dr. Hoch is about to embark on a review of this literature and potentially even publish it, including several of the patients as authors. "Their motivation to explore the topic and their knowledge of the general population's perceptions about this technology has been incredibly helpful and insightful," says Hoch.



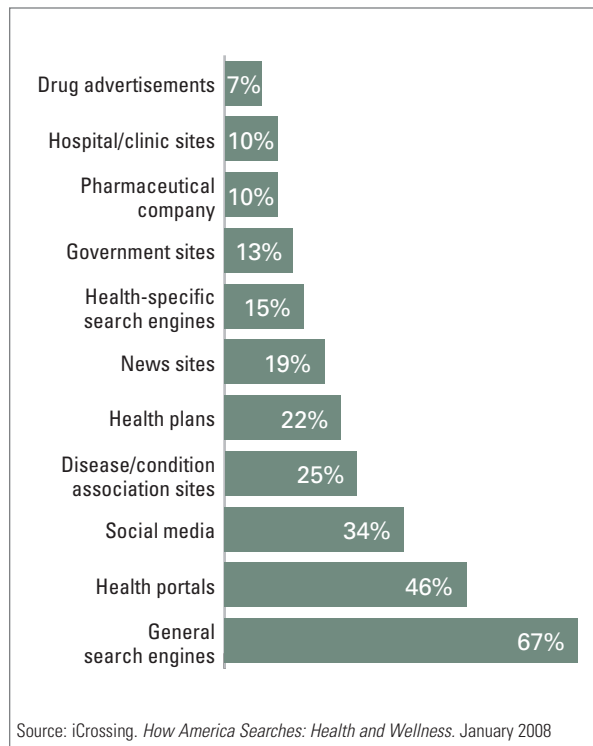
## Who Is Doing What?

“Prosumers” are consumers who actively search for health information, according to Bonnie Becker of Yahoo! Health. She says that 80 percent of health searchers seek information for themselves, while 20 percent are caregivers. For cancer and Alzheimer’s, the proportion of caregivers is higher.

Consumers don’t use just one source for health information online, says Becker. “People leverage on average five information sources per search scenario. They don’t just go to Yahoo! Health, but to Mayo, WebMD, and bloggers’ sites. Consumers reconfirm information all along the Web.”

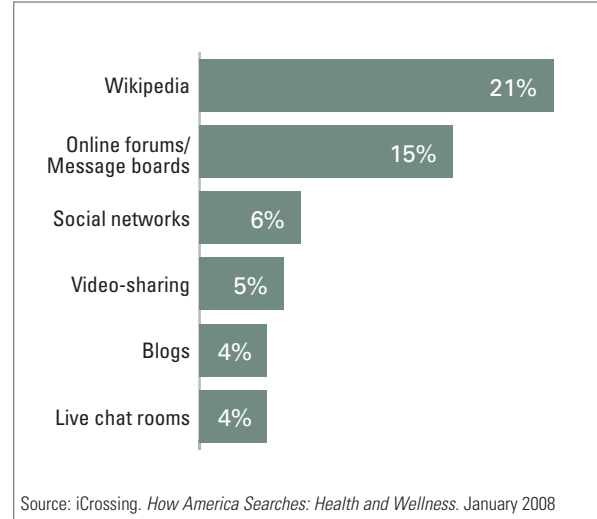
Social networks for health vary greatly in size, but the typical consumer has about 50 people in his or her monthly active social network, according to Ted Smith of MedTrackAlert, a consumer health information company that provides information on the benefits and risks of prescription medications.

**Figure 2. Online Tools and Resources Used to Locate Health Information**



Social media broadly defined covers the online technologies and practices that people use to share opinions, insights, experiences, and perspectives with each other. Within social media, the most common platforms used by online health consumers are shown in Figure 3.

**Figure 3. Social Media Platforms, by Usage**



**Table 1. Examples of Health 2.0 Sites, by Social Media Platform**

PLATFORM	EXAMPLES
Wikis	Wikipedia, FluWiki, WiserWiki
Blogs	DiabetesMine, HealthMatters (Healthline), WebMD
Social networks	OrganizedWisdom, PatientsLikeMe, DailyStrength, SecondLife, Sermo, ReliefInSite, NursesRecommendDoctors, TheHealthCareScoop, MySpace, Facebook
Video-sharing	ICYou, YouTube
Online forums	Yahoo! Groups, Revolution Health Groups, Google Health Groups, Groups@AOL, About Groups, iVillage
Podcasts	Johns Hopkins Medical Podcasts, NIH Podcasts, CDC Travelers Health, dLife podcasts for diabetes

Among all online health searchers is a core of about 20 million who are influential and from whom other health consumers seek out advice. This cadre of “patient opinion leaders” (POLs) are emerging in networks focused on cancer, diabetes, HIV, mental health, and many other chronic conditions.<sup>11</sup>

Why do consumers use social media? Table 2 lists reasons in descending order. Although emotional support is important, it is less so than finding out what others say about a medication or treatment, researching others’ knowledge and experiences, and learning how to manage a condition.

### Using Social Media in Health

Consumers are well ahead of other health stakeholders in adopting social media in health. These early adopters have many lessons to share on how to proceed in this new space.

**Privacy concerns may prevent potential users from getting involved.** When Google Health and Microsoft announced plans to develop personal health records in 2007, some consumer advocates voiced the concerns of consumers.

Health data is as personal as information gets. Many consumers are wary to share health information online, particularly those who haven’t used a credit card for purchasing online and those who are fairly new to the online world. Other consumers, quite knowledgeable about the workings of search portals, ask, “Why should we consumers trust ‘you’ with our health information when you already know so much about us?” The concern is that many companies already have a great deal of power based on the amount of personal information they have about peoples’ search patterns. Some fear that one of these companies could leverage this information in the future for purposes other than those consumers had agreed on.

The emergence of genetic information in health care will ramp up privacy concerns, predicts Robert Coffield, a health lawyer. “As genetic information becomes more commonly used as a part of the health dataset and our health system shifts the focus toward predicting chronic disease, the stakes involved in the inappropriate use of data increase,” says Coffield. “Genetic information and data that can predict chronic disease would have substantial value in a variety of contexts outside of using it for health care.”

**Table 2. Reasons Online Health Information Seekers Used the Internet to Connect with Others**

	PERCENTAGE OF SEEKERS
To see what other consumers say about a medication or treatment	36%
To research other consumers’ knowledge and experiences	31%
To learn skills or get education that helps me manage a condition	27%
To get emotional support	17%
To build awareness around a disease or cause	15%
To share my knowledge of and experiences with a medication or treatment	14%
To share my knowledge of and experience with a health issue	14%
To find consumers’ recommendations and opinions about hospitals and other treatment options	13%
To find consumers’ recommendations and opinions about hospitals and other treatment centers	13%
To find consumers’ recommendations and opinions about doctors	10%
To feel I belong to a group or community	8%
<b>None of the above</b>	<b>22%</b>

Source: JupiterResearch. *Online Health: Assessing the Risks and Opportunity of Social and One-to-One Media*, 2007

Trust between health consumers and social networking sites grows with transparency and openness. However, people in search of health information and support are often willing to trade off aspects of their privacy in exchange for valuable services. Ultimately, consumers want and need to be able to control their level of interaction with the site. This is a central operating principle in user-generated media.

**The upsides to participation by organizations aren't always clear.** Potential users of social media in health often can't quantify in advance what the benefit of participation will be. Joshua Seidman of the Center for Information Therapy, a nonprofit that promotes effective use of information among patients, believes that, over time, more people will adopt social media as a standard part of care processes. He says, "We're creating ways for people to get what they need in a different way than they have been. This could be a hospital realizing it's important to incorporate social media into their Web marketing strategy. For physicians, using social media can create new models for how primary care is delivered."

Measuring a clear return-on-investment for organizations such as health plans and pharmaceutical companies that adopt social media in health often is not straightforward. Will it immediately generate new sales? Probably not. However, social media can benefit the company over the long term in a number of ways: integrating patient care and enabling continuity, enhancing patients' compliance with therapies, building goodwill in communities, providing useful health information to people who opt-in to receive it, and averting costs that would be incurred in more acute settings.

**Legal and regulatory barriers persist between consumers, employers, and suppliers to the industry.** We are in the infancy of case law related to the privacy of social network health information. Coffield anticipates that, "in time, the courts will be looking at whether consumers have an expectation of

privacy regarding such information, and the extent to which the courts might provide protection to this information will have a major impact on the future development and use of social information."

Coffield cautions that employers could potentially access employee's health information on social networks. As we move toward a decentralized model of health information and continuous access to information via social networking, there is concern that employers could monitor such data and interaction. Employment litigation claims often arise as a result of employers monitoring employees' email traffic. Coffield warns, "You can gain a lot of information about a person by reviewing the historical information found on MySpace and Facebook."

For pharmaceutical companies, there are concerns about consumers' ability to review materials online. Chloe Stromberg from Forrester Research raises this issue: "Say an activist posts an unbalanced view of your drug on Wikipedia. The pharma company wants to modify it. This keeps their staff up at night" with concerns about fair balance—the FDA's requirement that drug companies communicate an accurate and fair assessment of risks as well as benefits.

Other legal obstacles perceived by life science companies include the potential for adverse drug events to be reported on a site sponsored by the company, and the risk of off-label drug promotion on that site.

**Organizational culture can impede adoption of social media in health.** The large corporate interests in health care, such as health plans, provider organizations, and large vendors for health information technology, have focused on "big iron." As described by Dr. David Kibbe of the American Academy of Family Practice, big iron is the bias toward centralized mainframe computing, so-called because the computers were housed in room-sized

metal boxes or frames. Big iron has often trumped other IT viewpoints in health care.

Health 2.0 comes from an entirely different vantage point. “We have the World Wide Web,” Dr. Kibbe explains, “and it’s becoming more intelligent in searching. It’s more interactive. There is untold potential for what people might be able to do with self-management and self-care if people had the right information at the right time available to them.”

Big iron’s centralized mentality doesn’t fit with social media. There is a corporate tradition of controlling ‘the message,’ but this is impossible in the social media milieu, points out Fard Johnmar of Envision Solutions. In social networks, users generate content. Furthermore, people are increasingly relying on their peers and less on institutions for health information.<sup>11</sup> Johnmar believes the impact of the Internet on the exchange of health content is forcing the industry to re-examine its assumptions about communications. The engaged consumer is seeking an ongoing dialogue on health—not a one-way, 30-second broadcast TV spot. Health marketers must meet consumers where they live, which is increasingly online and in social networks.

Organizations just entering social media in health will find a daunting array of choices—multiple channels, devices, and formats. Health marketers will need to master the integration of promotion between the “old media” (e.g., television and print) and the “new media” online.

# III. The Business of Social Networks and Health

*There is evidence that consumers will pay for content they perceive to be personally valuable.*

CONSUMERS ARE NOT KEEN TO PAY FOR CONTENT online because they are used to getting free access to a dizzying array of content. However, there is evidence that consumers will pay for content they perceive to be personally valuable. One example is *The Biggest Loser* club, associated with the NBC television program that features overweight participants in a real-life battle to lose weight. The online club, operated by health publishing company Rodale in conjunction with NBC, is funded through member subscriptions. As of March 2008, the club had more than 50,000 members paying \$19.98 a month.

In this early stage of social media in health, business models are evolving and adapting. The market is attracting a flurry of companies. Some are entrepreneurs backed by angel investors and, a few, with venture capital. “With a few exceptions, there hasn’t been a huge amount of venture funds thrown at Health 2.0,” Matthew Holt of The Health Care Blog and the Health 2.0 Conference acknowledges. “There isn’t irrational exuberance for the space among the investment community yet.” Some Health 2.0 entities are among the largest publicly traded companies on the New York Stock Exchange. The biggest players in the space by market capitalization include Google, Microsoft (with MSNHealth), WebMD, and Yahoo! Revolution Health, established by AOL founder Steve Case, is a privately held company building a network of Web sites and partnerships focused on helping consumers take control of their health care. Holt expects different business models to develop as the industry matures.

**Advertising.** Advertising support from health companies, such as plans, providers, and medical device and pharmaceutical companies, seems to be a natural revenue source for Health 2.0 programs. However, consumers online may question their motivation in supporting the sites. There is already advertising from for-profit companies visible on blogs and patient-sponsored forums. Google AdSense reviews an individual’s searches and delivers ads that relate directly to that content. For a chronically ill patient, receiving these ads could be useful. Some patients do want to receive advertising and information “pushed” from trusted sources if they can control the flow of the ads. Targeted advertising by health care organizations is a process that, for example, Google

will understand because of its knowledge about consumers' search behavior.

For health bloggers who write about their own conditions, they must walk a fine line between accepting advertising and avoiding the appearance of "selling out" to corporate interests. There is a tacit agreement between health bloggers and their readers to be responsible and support best practices that honor the health of the consumer. At PatientsLikeMe, the core values are clearly stated: Honor patients, be open, be transparent.

**Data aggregation, knowledge-gaining and -sharing.** Where groups of people come together to aggregate opinions and data, there will be a valuable data stream collected. The value of these data can be monetized in a variety of ways. In the case of PatientsLikeMe, the data can be used (on a patient opt-in basis) for clinical trials and new product development by life sciences and medical device companies. In Sermo, an online physician network where doctors convene to share opinions, companies targeting the physician market can observe and aggregate data to better market to them. This is especially relevant for drug companies whose traditional detailing strategies are being blocked by physicians who decline to take in-person meetings with the pharma sales force. Therefore, consumers who engage with social media in health need to make an educated decision on how much personal information to share, and what their personal return on sharing this information will be.

Another aspect of aggregating data is the concept of intelligent networks. Because of the "wisdom of crowds" phenomenon, networks can get better as more people use them. Two examples are AthenaHealth, which operates an insurance rules engine that improves as more clinicians use the software; and MedBillManager, where consumers enter the real pricing they were charged and, by doing so, the site becomes more robust.

**Information arbitrage.** Sermo, which enables physicians to share insights with each other in a closed network, has a unique business model based on the concept of "information arbitrage." Sermo defines information arbitrage as, "the opportunity that arises when breaking medical insights intersect with the demand for actionable, market-changing events in health care." Sermo targets financial services companies, government agencies, and health companies (especially pharmaceutical marketers), which pay a subscription fee in exchange for being able to post questions on the Sermo site. The subsidization of these clients allows Sermo to make the social network free to physician members. The clients gain access to real-time knowledge about how physicians are dealing with diseases, patient trends, safety and public health issues, and virtually anything physicians comment about on the site.

**Sponsorship.** The evolution of online banking provides a useful analog for potential health organization sponsors of social media health sites. Pioneers in online banking were initially drawn to the concept because of the red-tape and bureaucracy involved with regular banking. What they found is that consumers who embrace online banking have greater satisfaction, generate positive word-of-mouth recommendations, and tend to buy more services from the bank than offline customers.<sup>12</sup>

The health field has followed suit. Blue Cross and Blue Shield of Minnesota's The Health Care Scoop ([www.thehealthcarescoop.com](http://www.thehealthcarescoop.com)) was launched in November 2007. With the tagline "Patient reviews from people like you," the Scoop is an early example of a health plan willing to experiment in the unknown world of social media. As the plan continues to monitor comments on the site, they will be able to incorporate what they learn from their customers into the development of new products. In the longer term, the hard return-on-investment could come from the online feedback that provides real-time market research.

Sponsorship of social media sites can help bond existing customers (whether patient, plan enrollee, or caregiver), bolster trust with the organization, and ultimately drive health product/service sales that benefit both the patient and the company.

**Social networks integrated in health care delivery.**

For stakeholders in patient care, social networks can facilitate the care integration that improves patients' daily management of chronic conditions. Josh Seidman notes that social networks can tie into health management programs for a group of patients dealing with a chronic condition. For diabetes, targeted information can be pushed to patients about HbA1c tests along with cholesterol management support. Resolution Health is a company that monitors the care of health plan members to identify opportunities to improve quality and reduce cost. It integrates social networking into its interventions, develops personalized messages to health plan members, and helps clinicians to improve care.

**Private labeling.** CarePages, part of the consumer-centered health company Revolution Health, offers online support communities created by patients and caregivers. The sites are used as an online rallying point for families and friends supporting a patient. CarePages offers hospitals the opportunity to brand these communities, which extends the offline hospital experience to patients online. By targeting families who are undergoing catastrophic events, the privately labeled CarePages enhance families' relationships with the institution and can inspire positive word-of-mouth beyond these communities.



## IV. What's Next for Social Networks and Health?

*As consumers take on increased responsibility for clinical and financial decisions in health, social networks will be one of many platforms that will support sound decision-making.*

THE EVOLUTION OF SOCIAL MEDIA IN HEALTH WILL BE driven by the growing demand for transparency and openness. As health care costs approach 20 percent of the GDP by 2016, health care financing in the United States will be unsustainable in its current form.<sup>13</sup> Shining a light on the data by which payers and consumers make purchasing decisions can help drive more rational, cost-effective choices.

As consumers take on increased responsibility for clinical and financial decisions in health, social networks will be one of many platforms that will support sound decision-making. Many consumers are already ahead of the health organizations that serve them. How might health plans, providers, and suppliers catch up with consumers?

### Health Ratings

The first generation of consumer health ratings consisted of “best hospital” and “best doctor” rankings in city magazines. For 18 years, *U.S. News and World Report* has published the “Best Hospitals” survey highlighting the country’s leading referral centers by medical specialty. *Consumer Reports* began offering information about “Best Buy Drugs” in 2004, comparing prescription drug brands against generics in a broad range of therapeutic categories. For nearly a decade, HealthGrades has provided online quality ratings on providers, physicians, and long term care to consumers, plans, and payers.

The second generation of consumer health ratings is now materializing. An early entrant is Vitals ([www.vitals.com](http://www.vitals.com)), which combines consumer reviews, peer reviews, and empirical data on a doctor’s quality. One of Vitals’ strategic partners is Castle Connolly, which has been publishing *America’s Top Doctors* since 1991.

New entrants into the ratings game are consumer-facing and—trusted names including Angie’s List (known for home repair service ratings) and Zagat, the famed hospitality rating service.

The immediacy of social networking will enable savvy online consumers to be wise about who is behind health ratings.



Transparency and openness must be the operating principles of these projects.

### **Platforms That Make Health Consumers and Clinicians Peers**

In addition to consumer-generated health ratings, many consumers seek more sophisticated information about care for a chronic or newly diagnosed condition. A 2007 column in *The New York Times* titled “When the Patient Is a Googler” pointedly demonstrated many physicians’ discomfort with patients who enter the exam room armed with computer-generated printouts of Medline, WebMD, and Google searches.<sup>14</sup> In fact, some patients with rare conditions learn more about their malady than their internists or GPs.

Social networks such as Sermo can bring patients together with physicians online in peer-to-peer relationships—a kind of open-source health care. Companies like AmericanWell facilitate interactive conversations between patients and clinicians. Some payers now reimburse for such consults.

### **Knitting Communities Together**

Social networks in health are proliferating so rapidly that there is a need for services that “knit” communities together to enable health consumers to move seamlessly and efficiently through the networks without having to be a member of all the groups that pertain to their illness or interest. Open Social is a set of common application programming interfaces (APIs) for Web-based social network applications that was developed by Google. Open Social will allow social networking sites such as MySpace and Yahoo! to interact, ameliorating the problem of silos of communities competing with each other. WEGO Health, a health information portal, aims to connect communities in this way.

### **Disruptions Through Collaborations**

Collaborations between social media and health stakeholders could benefit patients in unforeseen ways and, at the same time, disrupt traditional

relationships between providers, payers, suppliers, and consumers.

The innumerable start-ups in social media/health in early 2008 remind many analysts of the dot-com irrational exuberance. “There are plenty of start-ups rushing into this space, hoping to profit,” notes Dmitriy Kruglyak of Trusted.MD. “We should expect to see a lot of ‘noise’ and a success rate similar to the dot-com era. Many high-profile and well-funded companies will bomb. Expect some large and well-known companies and institutions to stumble in this changing world. What is certain is that Web 2.0 is highly disruptive to traditional business models. On the other hand, some successes will emerge seemingly out of nowhere. Think Google in 2000.”

Established health care organizations have the opportunity to disrupt traditional business models through collaborating with partners from outside of the health arena. In health, stakeholders are now coming together that never would have in the past. Social networks offer a wide and accepting tent under which disparate parties can work together in targeted ways. Consider the Anthem/Zagat project, which has created a new online survey tool that will allow consumers to share their experiences with their physicians with others.

Physicians could also come together with a national retail clinic and launch a social network project to help consumers use online tools that enable better continuity of care than the episodic clinic model. Large employers might link with a pharmaceutical company to engage in a chronic health management protocol enabled through social media.

Another disruption could come from the sixth-largest company on the Fortune 500 list, General Electric. Within GE are health and content businesses that can be leveraged through media outlets such as *The Today Show*, *NBC Nightly News*, and the company’s many local news outlets. In following its vision of a more informed, engaged

health consumer, GE is planning health offerings that leverage across their media properties and their health businesses such as the Centricity electronic medical record, diagnostic imaging, personalized medicine, and others. The company also has plans for online media including the Your Total Health social network site and Healthline networks, in which NBC Universal has a financial stake.

### **The New Health Company, v 2.0**

Web 2.0 tools may be daunting to traditional companies conscious of shareholder responsibilities and Wall Street quarter-to-quarter pressures. However, entrepreneurs are quite comfortable with the new media. This points to an opportunity to start a *de novo* health care business that could disrupt existing business models in health financing and care.

Consider what a new health plan model could look like using social media. The launch of Carol.com in January 2008 was a seminal market event. Built on Web 2.0 technologies, it promises to do for health care consumers, “what Travelocity did for airline tickets.”<sup>15</sup> Its home, Minnesota, is a state known for health care experimentation and the early adoption of HMOs in the 1960s. For its product launch, Carol.com developed 350 health product “bundles” offered by 30 providers in the state, including some of the highest-quality brands such as HealthPartners, Mayo Clinic, and Park Nicollet Health Services. This is, effectively, a direct-to-consumer health care delivery model. Consumers can review health services by provider and see their potential costs. It is too soon to know whether Carol.com will grow into a full menu of services across all therapeutic categories. For now, this start-up represents a way to bring transparency and openness to health care consumers.

### **Going Mobile**

The social media/health convergence will enable personalization not only in terms of the messaging, but also for preferred modes of delivery and media. The modes for participating in health social networks won't be just Web browsers; they will be portable, such as cell phones and PDAs.

Cell phones are ubiquitous and are an obvious technology for consumers to use in health social nets. Nearly eight in 10 of all adults and two thirds of seniors have cell phones.<sup>16</sup>

Consumers are opting for a multi-platform world. Social networks in health can capitalize on their preferences and engage with them in their daily lives on a continuous basis. The ability to engage with consumers in this way is particularly useful for chronic disease management, where lifestyle behaviors can have a significant impact on a patient's wellness. This is the case with diabetes, obesity, migraine, mood disorders, and other conditions.

### **The New Patient Opinion Leader**

Increasing numbers of people are reaching out to others for more than the kind of support they might have found in the CompuServe health interest groups in the 1980s. They are finding practical solutions to chronic health challenges. Consumer-generated content in health has found a receptive audience in Web 2.0. Patient opinion leaders have emerged in many disease areas. Just as pharmaceutical companies recognize and reward key opinion leaders for their knowledge of patients and prescriptions, the patient opinion leaders will become a key influence on other consumers and, increasingly, the organizations who serve them.

## V. Conclusion

### Web 3.0 and the Future of Health 2.0

As the Internet evolves into Web 2.0, it is natural for technology mavens to envision Web 3.0, otherwise known as the Semantic Web.<sup>17</sup> The Semantic Web is an extension of the World Wide Web in which the semantics (meaning) of information and services available online is defined, enabling the Web to understand and satisfy the requests of people and machines to use that content. Tim Berners-Lee, the developer who invented the World Wide Web and who coined the term, explains its significance. “Most of the Web’s content today is designed for humans to read, not for computer programs to manipulate meaningfully. Computers can adeptly parse Web pages for layout and routine processing—here a header, there a link to another page—but in general, computers have no reliable way to process the semantics.” The computer does not know the meaning of the search terms.

The realization of the Semantic Web would lead anyone searching for health information—clinician, consumer, caregiver—much closer to what they are seeking. The fullness realization of the semantic Web, however, is years away.

In the ongoing journey that is Health 2.0, those people who choose to use social media for managing health and gaining support will find a growing array of tools and modalities—increasingly mobile ones. In the next few years, we will see countless social media projects focusing on specific diseases and sub-specialty areas, built by and for patients, caregivers, and providers. More programs will be devoted to personal health data, through applications that reside on commercial products like Microsoft Health Vault, Google Health, and others. Finally, the ongoing demands of a consumer-driven health marketplace will inspire innovation in applications that integrate clinical and financial information, Quicken-Health style. And ratings sites will grow in number and type.

The proliferation of these health-oriented sites enabled through social media will inevitably lead to consolidation. Ultimately, the users of Health 2.0, through their collective wisdom, will determine whether Health 2.0 provides value to them in their daily lives.

## Appendix A: Portraits of Social Media Health Pioneers

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*“Providers and tool makers realize this is where patients live. To gain their respect, you need to be part of the social media sphere.”*

— AMY TENDERICH, DIABETESMINE

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Disease-specific patient networks provide members with an invaluable type of around-the-clock support. Richard Rockefeller, President of the Health Commons Institute, has called it the “chicken soup of the Internet.”

The “cooks” can be found any hour of the day in Facebook, where more than 500 groups focused on diabetes meet; FLickR, where there are nearly 2,000 photos posted on chemotherapy; and YouTube, where about 36,000 pages are devoted to some aspect of surgery.

The following brief portraits illustrate how social media are meeting peoples’ information and support needs in different, always organic, and often surprising, ways. There are hundreds of examples of pioneers whose early adoption of social media in health live online. These examples are just a sampling of the range of experiences and lessons learned in the first wave of social media and health.

### Social Network-Health Pioneer

Amy Tenderich, Founder

DIABETESMINE

**Social media:** blog

**Target audience:** diabetics, caregivers, providers, payers, industry

Two things about Amy Tenderich positioned her to be a health social networking pioneer. She was a practicing journalist in the information technology industry for many years, and she was diagnosed with Type 1 diabetes five months after her third child was born in 2003.

Like most people, Tenderich hadn’t known that adults could get Type 1 diabetes, and the doctors who treated her in the hospital didn’t seem to know much about it. “I felt like the only person on the planet to get the juvenile disease at this late age. After the diagnosis, I sat on the couch for a day and cried. Then I got off the couch and figured this thing out. The first thing I did was search on the Internet. When it came to reach out to people with diabetes there was nothing that felt real or personal. There wasn’t any place for patients.”

Fortunately, Tenderich’s husband had attended a conference on social media in the early days of blogging. He told her, “You should start a blog about diabetes.”

That was the impetus behind DiabetesMine. Within four months of launching the site, Tenderich was featured as a patient blogger in the *Wall Street Journal’s* “Informed Patient” column. She describes her following as “interactive and passionate. It’s not about the page views alone, but the amount of conversation, which shows the level of people’s engagement. The more personal posts get more comments.”

The users of social network health sites, says Tenderich, “are more than readers—these are community members who you interact with. People are intimate in a way they never would be on a site like WebMD, for example, which offers great information but feels impersonal. You might look there, but you will find the real-life information on a more targeted site.” If you want to find out whether a particular drug really makes people nauseous, “you want to ask other patients directly.”

In fact, Tenderich believes that the big players such as WebMD and Revolution Health are “getting a run for their money by the numerous smaller, more targeted health sites online. People want content very specific to their condition or situation, so they spend more quality, interactive time on blogs and social networks,” says Tenderich.

For the first few years, Tenderich did not accept advertising on her site, but has now begun to accept sponsors that “fit with the mission and vision of the site.” She notes that “It’s a balancing act because, to me, the reason some sites haven’t done well is that they’re too big, too commercial, and appear too much about making money. I think of my site as pioneering and experimental. I always want to keep DiabetesMine’s grassroots feel.”

### Micro-Segmenting for a Deeper Conversation

Jack Barrette, CEO and Founder  
WEGO HEALTH

**Social media:** social/health network, Wiki  
**Target audience:** “prosumers” looking to manage their health

“We want this to be a movement more than a Web site,” Jack Barrette says of his online community, WEGO Health. “We have a passion to help each other.”

WEGO Health is an interactive, constantly updated clearinghouse for online health information. It creates what Barrette calls “expert-supported health communities.” The experts are health and wellness professionals who cover a broad range of health conditions. WEGO Health also solicits contributions from people online and brings the information from experts and consumers together, continually evaluating and ranking the information for each page. It’s a kind of health information democracy: “Everyone has a stake, everyone can join in,” the site invites.

“We find that the ‘prosumer,’ the expert consumer, is most attracted to this concept,” says Barrette. These users are past the point where Google or a general portal can help them. “We’re building pages about general health topics, but digging deeper into, for example, Type 2 diabetes and diet among African-Americans, using videos, tools, and content. We’re micro-segmenting the information. We’re not going to have 1.6 million results like Google, but in-depth content to help our community members get to the best content quickly.”

He adds, “Where the genuine conversation is, that’s where the teachable moment is.”

### Finding a Space for Young Adults with Cancer

Matthew Zachary, CEO and Founder  
I’M TOO YOUNG FOR THIS! FOUNDATION

**Social media:** blogs, forums, social network  
**Target audience:** under-40 cancer patients and caregivers

During his senior year at Binghamton University, Matthew Zachary noticed that his left hand had a pins-and-needles sensation. This was not a welcome symptom for a concert pianist in the midst of organizing theatrical productions. Soon afterward, Zachary was diagnosed with a rare form of pediatric brain cancer called medulloblastoma.

The 21-year-old found himself caught between the worlds of pediatric oncology and adult cancer. “Pediatricians are not used to speaking to their patients since they’re usually little kids,” says Zachary. “It was socially awkward to have conversations with these providers. The institutions were focused on treatment and not quality of life. I didn’t know anyone my age with cancer and was terribly isolated.”

But Zachary rehabilitated himself enough to hike the Grand Canyon with friends, and it made a great difference in his outlook. “By hiking the Grand

Canyon, I realized I could do anything,” he says. “I was not afraid of dying anymore.”

After honing his skills in design, marketing, and IT, Zachary founded the I’m Too Young For This! Cancer Foundation (i[2]y). It is the first national cancer advocacy, research, and support organization working exclusively on behalf of survivors under 40.

Three weeks after i[2]y’s launch, the *New York Times* wrote about the Web site. This was followed by coverage in the *Washington Post*, *Newsweek*, and a host of other national publications. *TIME* magazine included the site in its Best 50 Web sites for 2007. Since then, Zachary was appointed to the Google Health Advisory Council. The foundation is now linked to oncology providers at 300 cancer centers in nine countries.

Zachary’s site brings together cancer advocacy, a place for young survivors to convene and organize, music, commerce, and information. He describes his business model this way: “We have an open source model. We’re free, but we bring you to other resources that are also free.” There are countless little-known sites that can be helpful to young cancer survivors, says Zachary, and “We’re going to tell you about it.”

Zachary credits social networking for enabling him to bring “the cause of cancer-survivors-under-40 to the masses. There are over 1 million young adults with cancer in this country. They’re part of the larger youth culture movement.” He believes that the cancer “establishment” is not helping anymore. His goal is to “make i[2]y the relevant group for the next 30 years.”

## An Ongoing, Live Outcome Study

Ben Heywood, CEO

PATIENTSLIKEME

**Social media:** social/health network, online forum

**Target audience:** patients with ALS, MS, Parkinson’s Disease, HIV/AIDS; caregivers, providers, researchers

“What’s really exciting is what happens when health data gets shared in an open community,” Ben Heywood enthuses about PatientsLikeMe. “Our community breaks down walls of data silos. Here, patients are fundamentally in control of their data.”

PatientsLikeMe, a social network of people with Lou Gehrig’s disease (amyotrophic lateral sclerosis, or ALS) and multiple sclerosis (MS), along with other health conditions. People share very personal data on prescription drug histories, health conditions, side effects, what works and what doesn’t work. The community first launched for people with ALS in March 2006. A year later, PatientsLikeMe added MS and Parkinson’s disease communities.

PatientsLikeMe has amassed a substantial body of research that can advance knowledge about these conditions. The community is now sufficiently large that its patient-reported dataset has been presented at scientific meetings and used in peer-reviewed research studies.

Heywood shares a typical example of someone who recently joined PatientsLikeMe. “Joe” had leg spasticity, a common symptom of MS, which he had tried to manage for ten years. A decade ago, Joe’s doctor prescribed a low dose of Baclofen, a muscle relaxant, insisting that a higher dose would cause problems. Joe had no way to verify the doctor’s claim until he joined PatientsLikeMe and learned that people in the community are taking up to 10 times the dosage prescribed for him. As a result, Joe asked to have his dosage increased and his condition improved.



PatientsLikeMe has users from over 40 countries. Its business model is innovative. The site does not accept advertising. However, says Heywood, “We’re trying to work with pharma and medical device companies to utilize our data through permission-based access to patients to improve the way they use and develop treatments.”

The underlying purpose of the site is to lead to the best health care. Heywood calls PatientsLikeMe “an ongoing, live outcome study. We hope to find the patients in which the treatments work best.”

### Changing Health Behavior

Neal Sofian, Director, Behavioral Interventions  
RESOLUTION HEALTH

**Social media:** social networks

**Target audience:** health plans, employers, providers, consumers

A pioneer in innovative approaches to health for two decades, Neal Sofian, says “It’s so obvious that people learn through the experience of other people.” He started one of the first social networking programs in 1999, focused on cancer.

Previously, he founded an innovative phone coaching health service, the Free & Clear Smoking Cessation Program. “Phone counseling is a great thing,” Sofian found, but, “there is a real tyranny in that a minute is a minute is a minute. How can you make a minute more than a minute? Through social networking.” So he created a network where a coach worked with a group of 20 smokers who supported each other. Sofian calculates this approach led to each coach being able to turn “one minute into 20.”

Since then, he has worked with a range of organizations focused on changing peoples’ health behavior. “Messages are no better than their ability to be acted on,” he warns. “It’s the behavior, stupid!”

Sofian is attempting to make the messaging more interactive. “Right now, most of what we do is

push,” he says. “We’re looking at how to integrate the messages and the media” to personalize them in ways that move people to change health behavior. He and his partner, Dan Newton, merged their social networking health company NewSof into Resolution Health in October 2007. There, they work with clients to bring the lessons of social networking to health plans, employers, and other health stakeholders.

“I want all of this to be completely seamless—whether pushed to you in print, via phone coach, or online,” says Sofian, stressing that no single one of these approaches is a solution in itself. “Ultimately, all of the messages should reside where the patient can see all of the interventions and data.”

## Appendix B. Glossary of Social Media Terms

**Blog:** Short for “Web log,” an online journal consisting of postings. Blogs often link to other Web sites and blog posts, and allow readers to comment on the original post, which enables ongoing discussions.

**Podcast:** A digital recording of a broadcast made available on the Internet for downloading to a personal audio or video player. The word originally derived from a combination of “broadcasting” and “iPod.”

**RSS (really simple syndication or rich site summary):** A family of Web feed formats used to publish frequently updated content such as blog entries, news headlines, and podcasts. An RSS document (which is called a “feed” or “web feed” or “channel”) contains either a summary of content from an associated Web site or the full text.

**Social media:** A set of Internet tools that enable a group of people with common interests to connect with one another to learn, play, work, organize, and socialize.

**User-generated content (UGC):** Also known as consumer-generated media (CGM) and user-created content (UCC), the term refers to various kinds of media content that are produced by end-users.

**Web 1.0:** Refers to the World Wide Web during its first phase of operation. Used to contrast the early era of the Web before blogs, social networks, and wikis—which are part of Web 2.0.

**Web 2.0:** An umbrella term for the second wave of the World Wide Web. Web 2.0 is not a specific technology but refers to the paradigm shift of user-generated content and thin client computing (i.e., data and applications stored on Web servers, where the user has access from any computer via a Web browser).

**Wiki:** A Web site or online resource that allows users to add and edit content collectively.

**Wikipedia:** A wiki that is a free content encyclopedia written collaboratively by contributors.



## Appendix C: More Information on Social Media in Health

The market for social media in health is burgeoning. There are countless sources of information in the field. This very short list includes some of the most useful and sustained sites.

### Health 2.0 Background

Health 2.0 article in The Economist

[www.economist.com/printedition/displaystory.cfm?story\\_id=9719054](http://www.economist.com/printedition/displaystory.cfm?story_id=9719054)

Health 2.0 Conference

[health2con.com](http://health2con.com)

Health 2.0 definition by Scott Shreeve, MD

[scottshreeve.blogspot.com/2007/01/healthcare-20-definition.html](http://scottshreeve.blogspot.com/2007/01/healthcare-20-definition.html)

Health 2.0 Wiki

[health20.org/wiki/Main\\_Page](http://health20.org/wiki/Main_Page)

### Health Social Networks

Daily Strength

[www.dailystrength.com](http://www.dailystrength.com)

Organized Wisdom

[www.organizedwisdom.com](http://www.organizedwisdom.com)

PatientsLikeMe

[www.patientslikeme.com](http://www.patientslikeme.com)

### Health Wikis

Ask Dr. Wiki

[askdrwiki.com/mediawiki/index.php?title=Physician\\_Medical\\_Wiki](http://askdrwiki.com/mediawiki/index.php?title=Physician_Medical_Wiki)

Clinfo Wiki, on health information technology

[www.informatics-review.com/wiki/index.php/Main\\_Page](http://www.informatics-review.com/wiki/index.php/Main_Page)

David Rothman's list of medical wikis

[davidrothman.net/list-of-medical-wikis/](http://davidrothman.net/list-of-medical-wikis/)

FluWiki

[www.fluwikie.com](http://www.fluwikie.com)

Health, in Wikipedia

[en.wikipedia.org/wiki/Health](http://en.wikipedia.org/wiki/Health)

### Patient Blogs

Diabetes Mine

[www.diabetesmine.com](http://www.diabetesmine.com)

Prostate-Help

[prostate-help.blogs.com/prostatehelp](http://prostate-help.blogs.com/prostatehelp)

The Assertive Cancer Patient

[www.assertivepatient.com](http://www.assertivepatient.com)

### Podcasts in Health

Johns Hopkins Medical Podcasts

[www.hopkinsmedicine.org/mediaII/Podcastsinstructions.html](http://www.hopkinsmedicine.org/mediaII/Podcastsinstructions.html)

*New York Times* Health Podcasts

[www.nytimes.com/ref/multimedia/podcasts.html](http://www.nytimes.com/ref/multimedia/podcasts.html)

Podcast Health on HIV/AIDS

[www.podcasthealth.com](http://www.podcasthealth.com)

Portal for Health Podcasts from the U.S. Government (CDC, CMS, NIH, etc.)

[www.usa.gov/Topics/Reference\\_Shelf/Libraries/Podcasts/Health.shtml#vgn-health-podcasts-vgn](http://www.usa.gov/Topics/Reference_Shelf/Libraries/Podcasts/Health.shtml#vgn-health-podcasts-vgn)

Virtual Worlds: discussion on Second Life's role in physical and mental health, *Voices in the Family*, Dr. Dan Gottlieb, February 2008

[www.whyy.org/91FM/voices200802.html](http://www.whyy.org/91FM/voices200802.html)

Many other podcasts are available via iTunes

[www.itunes.com](http://www.itunes.com)

### Video-Sharing in Health

Cleveland Clinic on Google Video

[www.clevelandclinic.org/healthedge/Content/Videocasts.aspx](http://www.clevelandclinic.org/healthedge/Content/Videocasts.aspx)

icYou

[www icyou.com](http://www icyou.com)

YouTube ([www.youtube.com](http://www.youtube.com)) hosts thousands of health-related videos on a broad range of health topics. The site was viewed as a site of health mis-information in a December 2007 commentary in the *Journal of the American Medical Association*.<sup>19</sup>

Many social networking sites, such as

iVillage ([www.ivillage.com](http://www.ivillage.com)) and TauMed

([www.taumed.com](http://www.taumed.com)), enable video-sharing for health and other purposes.

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