

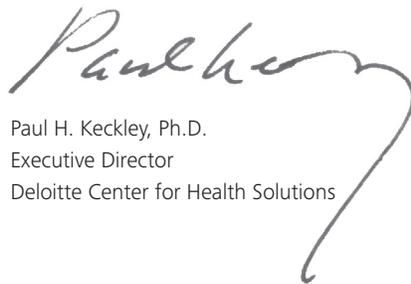
Issue Brief:

Social Networks in Health Care: *Communication, collaboration and insights*

Foreword

At Chirp, Twitter's first ever developers' conference held in April 2010, Twitter announced that people were enrolling at a rate of 50,000 per day and that it had more than 100 million unique users. As of June 2010, Facebook boasts 400 million users and has created its own unique cyber culture. Social networking is to the current era what online access was just 20 years ago – a transformational change in how information is accessed and shared.

In this issue brief, we provide a snapshot of social networking's evolution and explore its current and potential impacts on the health care industry. We believe that social networking is an important trend: Industry stakeholders who do not consider how to incorporate social networks into their future strategies risk being run over on the super-highway of health information sharing.



Paul H. Keckley, Ph.D.
Executive Director
Deloitte Center for Health Solutions

Overview

Public, Internet-based social networks can enable communication, collaboration and information collection and sharing in the health care space. About one-third of Americans who go online to research their health currently use social networks to find fellow patients and discuss their conditions,^{1,2} and 36 percent of social network users evaluate and leverage other consumers' knowledge before making health care decisions.³ Social networks hold considerable potential value for health care organizations because they can be used to reach stakeholders, aggregate information and leverage collaboration.

This issue brief offers a high-level overview of social networking, its industry and societal impacts; describes social networking initiatives in health care; provides key applications by health care sector; compares health care's efforts to other industries and offers industry implications.

1 Manhattan Research's Cybercitizen Health v9.0.

2 Noah Elkin, "How America Searches: Health and Wellness," iCrossing, January 2008.

3 Jupiter Research, *Online Health: Assessing the risks and opportunity of social and one-to-one media*, 2007.



Business use of social networks

Social networks transmit media such as video, web logs (blogs), ratings and reviews, podcasts and audio among a group of people who are linked by a common characteristic, such as friends and family, profession, school, residence and even likes and dislikes. They rely on networked users' connectivity and the Internet's ability to breach time and place to form communities and disseminate information. Although social networks are considered primarily a

recreational tool, they are becoming increasingly important to businesses and organizations. Figure 1 provides some examples of well-known social networks and potential opportunities for business applications.

Social networks hold considerable potential value for health care organizations because they can be used to reach stakeholders, aggregate information and leverage collaboration.

Figure 1: Social network description, usage and applications

Network	Description	Usage	Business Applications
Twitter	140-character news feed	105 million users ⁴	<ul style="list-style-type: none"> Posting press release-like announcements which, in some cases, can supplant traditional news formats
Facebook	Recreational peer-to-peer social network	400 million users ⁵	<ul style="list-style-type: none"> Building fan pages for specific causes, organizations or products Sharing recreation-oriented campaigns
YouTube	Video	6.5 billion views ⁶	<ul style="list-style-type: none"> Posting educational videos and testimonials
Blogs	Internet web diary	112 million blogs ⁷	<ul style="list-style-type: none"> Discussing happenings in an organization (e.g., product launches, executive changes)
LinkedIn	Professional peer-to-peer networking	60 million users ⁸	<ul style="list-style-type: none"> Recruiting talent, announcing staff news
Wikis	Tool that allows groups to create and edit pages of content	47 percent of surveyed Americans have used Wikipedia ⁹	<ul style="list-style-type: none"> Enabling knowledge management
Forums and discussion boards	Online locations to post questions and receive community replies	20 percent of surveyed Americans have posted on bulletin boards ¹⁰	<ul style="list-style-type: none"> Facilitating participants' sharing of experiences and knowledge
Peer-to-peer social network	Organization's own social network, which includes profiles of its members	47 percent of surveyed American adults report using a peer-to-peer social networking site ¹¹	<ul style="list-style-type: none"> Supporting members in therapeutic areas that are high-impact and high-burden

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4 "Twitter CEO Ev Williams' Keynote From Chirp," BusinessInsider.com, <http://www.businessinsider.com/live-twitter-ceo-ev-williams-keynote-from-chirp-2010-4>, accessed June 2010.

5 Facebook Statistics, <http://www.facebook.com/press/info.php?statistics>, accessed June 2010.

6 *YouTube Surpasses 100 Million U.S. Viewers for the First Time*, comScore, March 4, 2009, http://www.comscore.com/Press_Events/Press_Releases/2009/3/YouTube_Surpasses_100_Million_US_Viewers, accessed April 2010.

7 Technorati, *The state of the blogosphere 2008*, <http://technorati.com/state-of-the-blogosphere/>, accessed April 10, 2010.

8 LinkedIn, *About Us*, <http://press.linkedin.com/>, accessed March 10, 2010.

9 The Pew Internet and American Life Project, *Internet Usage Over Time Data ACT103 2008*.

10 The Pew Internet and American Life Project, *Internet Usage Over Time Data ACT53 2004*.

11 Lenhart, Amanda. *The Democratization of Online Social Networks: A look at the change in demographics of social network users over time*. The Pew Internet and American Life Project, October 2009.

To date, social networks have helped a diverse array of businesses and organizations improve their industry, stakeholder and market knowledge by leveraging user feedback and interaction (Figure 2).

Figure 2: Impact of social networks on selected businesses and organizations

Organization	Social networking activity	Impact
Dell	In response to dissatisfied customers in the blogosphere and reports of exploding batteries, Dell Computers launched the Direct2Dell blog to capture customer complaints and IdeaStorm, an online suggestion site.	<ul style="list-style-type: none"> • Direct2Dell helped improve Dell’s customer service by opening a channel for direct customer feedback to upper management – according to Dell, negative mentions of Dell dropped from 50 percent to 23 percent in the year after the launch of Direct2Dell.¹² • IdeaStorm feeds Dell information on its users’ preferences, which assists the product development process.¹³
Starbucks	Starbucks launched MyStarbucksIdea.com to connect to its loyal coffee drinkers and solicit their ideas. ¹⁴	<ul style="list-style-type: none"> • Site visitors submitted 80,000 ideas in 2009; Starbucks implement 53 of them.¹⁵
Independent Financial Advisors	LinkedFA.com is a social network for financial advisors that enables them to engage with investors while remaining FINRA-compliant.	<ul style="list-style-type: none"> • Financial advisors, many of whom typically work from home, can leverage their secure, FINRA-compliant network outside of the office to reach their existing customers and give on-demand advice and perspectives. • LinkedFA.com is also intended to help financial advisors expand their reach and increase their customer base.
Small Business Owners	Foursquare, a location-based social networking site and mobile application, allows registered users to connect with friends and update their location. Points are awarded for "checking in" at venues. Businesses recognize foursquare users with rewards such as complimentary drinks.	<ul style="list-style-type: none"> • Small business owners can get access to customer data and analytics. • Businesses can reach out to and improve interactivity with customers.¹⁶
The Centers for Disease Control and Prevention (CDC)	Given the mission of the CDC and its budget, the organization has been using social networks to help the public share accurate information about health.	<ul style="list-style-type: none"> • During the 2009 flu season, H1N1 YouTube videos were viewed 2.6 million times, podcasts were downloaded 1.5 million times and the CDC Facebook page had over 50,000 followers.¹⁷ • Social media use spikes coincided with outbreaks representing the public’s use of information during the epidemic.
MD Anderson Cancer Center	To better understand its patients’ experience and to improve patient care, MD Anderson has moderated social networks that include “The Cancer Survivor’s Network,” “Ask the Expert” and “The Anderson Network.”	<ul style="list-style-type: none"> • Increased understanding of patient experience helped MD Anderson prioritize their scheduling processes.¹⁸

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12 *Dell and Social Media, Brand Autopsy Blog*, John Moore 2007, <http://brandautopsy.typepad.com/brandautopsy/2007/09/dell-and-social.html>, accessed May 2010.

13 “Dell Hell: The Impact of Social Media on Corporate Communication,” Norbert Elliot’s website, <https://learningspaces.njit.edu/elliott/content/dell-hell-impact-social-media-corporate-communication>, March 2009.

14 “Starbucks’ new blend for stronger standing,” *Seattle Times*, March 20, 2008.

15 *IdeasinAction Blog*, December 8, 2009, <http://blogs.starbucks.com/blogs/customer/archive/2009/12/08/msi-milestone-50-ideas-launched-and-still-counting.aspx>, accessed May 2010.

16 “Foursquare Introduces New Tools for Businesses,” *The New York Times*, <http://bits.blogs.nytimes.com/2010/03/09/foursquare-introduces-new-tools-for-businesses/>, March 9, 2010.

17 *H1N1 Web and Social Media Metrics Cumulative Data Report* April 22, 2009 – December 31, 2009, Division of eHealth Marketing (DeHM) National Center for Health Marketing (NCHM) Centers for Disease Control and Prevention (CDC).

18 Li, Charlene, and Bernoff, Josh. “Groundswell: Winning in a World Transformed by Social Technologies,” 2008.

Similar to their growing importance in other industries, social networks are playing an increasingly prominent role in health care. Fifty-five percent of surveyed Americans get information about a therapy or condition online.¹⁹ Sixty percent of surveyed physicians are interested in using social networks for professional purposes,²⁰ approximately one out of every six U.S. physicians are members of Sermo, an online physicians network²¹ and 65 percent of surveyed nurses indicate they are planning to use social networks for professional purposes.²² Because both consumers and clinicians are using social networks, health care organizations have an opportunity to leverage their influence across multiple audiences.

For example, the website PatientsLikeMe gives consumers a way to track disease progress, access disease information and learn from the real-world experiences of other patients with the same medical condition and to share their findings with patients, health care professionals and industry organizations that are trying to treat the disease. Other consumer-directed sites include MedHelp which, in addition to being a social network, offers a number of tracking tools for pain, weight and other chronic conditions; CureTogether, which helps people anonymously track and compare health data to better understand their bodies, make more informed treatment decisions and contribute data to research; DailyStrength, which allows patients and caregivers to give and receive support; Inspire, which hosts different communities, some of which are co-sponsored by non-profit foundations, to educate and offer support; and FacetoFace Health, a social network that uses a proprietary algorithm to match people with similar diagnoses.

Sixty percent of surveyed physicians and 65 percent of surveyed nurses are interested in using social networks for professional purposes.

As more patients use social networks to track their health conditions and care, industry organizations have an opportunity to interact with the members of these online communities and to leverage “real world” data sets to inform new treatments and care pathways.

- Hospitals increasingly are using social networks for promotional purposes and to gauge consumer experiences with their organizations.
- More than 700 of the U.S.’ 5,000 hospitals have a social media and social networking presence to enhance their ability to market services and communicate to stakeholders.²³
- Cancer centers such as MD Anderson are developing communities to understand how their patients view their care experiences.²⁴
- Government agencies including the Food and Drug Administration (FDA) and the CDC are using social networks to engage the public during product recalls and in H1N1 flu pandemic preparations.²⁵

19 *2010 Survey of Health Care Consumers*, Deloitte Center for Health Solutions.

20 Manhattan research *Taking the Pulse*, v9.0.

21 Sermo website, *About us*, <http://www.sermo.com/about/introduction>, accessed April 2010.

22 Nicholson Kovac Inc, *New Media Usage Study: Healthcare professionals*, February 2010.

23 Hospital Social Network Data & Charts, Bennett Ed. May 22, 2010, <http://ebennett.org/hssl/data>.

24 Li, Charlene, and Bernoff, Josh. “Groundswell: Winning in a World Transformed by Social Technologies,” 2008.

25 *H1N1 Web and Social Media Metrics Cumulative Data Report* April 22, 2009 – December 31, 2009, Division of eHealth Marketing (DeHM) National Center for Health Marketing (NCHM) Centers for Disease Control and Prevention (CDC).

- Almost all of the top pharmaceutical companies, biotechnology firms and medical device manufacturers have some social network presence; some are partnering with third-party social networks such as PatientsLikeMe and Sermo to communicate and collaborate with external stakeholders.

Figure 3 provides examples of some current social network applications in the health care arena.

More than 700 of the U.S.' 5,000 hospitals have a social media and social networking presence to enhance their ability to market services and communicate to stakeholders.

Figure 3: Select social networking applications in health care

Health care application	Participants	Impacted organizations	Representative social networking applications
Maintaining health and wellness	<ul style="list-style-type: none"> • Consumers • Health coaches 	<ul style="list-style-type: none"> • Physicians • Health plans • Wellness facilities • Hospitals • Alternative providers/health coaches • Employers 	<ul style="list-style-type: none"> • WEGO Health offers health activists the chance to advise consumers about their health by reviewing and linking tools on one site. • WebMD offers a social networking platform for both consumer- and physician/expert-moderated health conversations.
Disease management	<ul style="list-style-type: none"> • Consumers • Physicians • Allied health professionals 	<ul style="list-style-type: none"> • Physicians • Retail clinics • Health plans • Device manufacturers • Drug companies • Alternative care providers • Disease management companies 	<ul style="list-style-type: none"> • PatientsLikeMe offers a 24/7 secure login for health plans to enable disease management. • Inspire.com offers patients 24/7 access to peer communities.
Clinical trial recruitment	<ul style="list-style-type: none"> • Consumers • Clinical investigators 	<ul style="list-style-type: none"> • Academic medicine • Drug & biotech companies • Contract Research Organizations (CROs) • Device manufacturers 	<ul style="list-style-type: none"> • Amyotrophic lateral sclerosis (ALS) patients organized their own clinical trial on PatientsLikeMe. • Novartis recruited patients from PatientsLikeMe for its FTY720 multiple sclerosis trials.²⁶ • iGUARD, a wholly owned subsidiary of Quintiles, is a drug review site that leverages its network of participants to model clinical trial feasibility.
Personal Health Records (PHRs)	<ul style="list-style-type: none"> • Consumers • Health professionals 	<ul style="list-style-type: none"> • Drug & device manufacturers • CROs • Academic medicine • Health plans 	<ul style="list-style-type: none"> • PatientsLikeMe and MedHelp allow participants to upload detailed information about their condition and receive information from similar patients.
Health professional training	<ul style="list-style-type: none"> • Physicians • Advanced practice nurses • Allied health professionals 	<ul style="list-style-type: none"> • Drug & device manufacturers • Licensing organizations • Hospitals • Schools 	<ul style="list-style-type: none"> • radRounds offers radiology professionals a community to collaborate and share cases and receive opinions. • Sermo and Ozmosis offer physicians the opportunity to submit cases for community discussion; they fund their sites with manufacturer sponsorships and advertisements.
Public health announcements and campaigns	<ul style="list-style-type: none"> • Consumers • Regulators 	<ul style="list-style-type: none"> • Regulatory agencies • Public health agencies • Local/state/federal government 	<ul style="list-style-type: none"> • The CDC collaborated with DailyStrength and Sermo to inform the public and physicians about flu outbreaks. • In addition, the CDC monitored the conversations and addressed the public on a variety of social networking sites, including Facebook, MySpace, CafeMom, etc.²⁷
Treatment, physician or hospital selection	<ul style="list-style-type: none"> • Consumers 	<ul style="list-style-type: none"> • Drug & device manufacturers • Hospitals • Health plans • Retail clinics 	<ul style="list-style-type: none"> • DailyStrength and FacetoFace Health offer communities and a search engine so that patients can find "matches" to ask advice. • The Mayo Clinic offers the "Sharing Mayo Clinic" blog for patients and physicians to share their stories; it also offers the "Medical Edge" for patient information podcasts and news.

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²⁶ "Pharma's Facebook: Research 2.0: How drug companies are using social networks to recruit patients for clinical research." *Newsweek*, March 10, 2009.

²⁷ *H1N1 Web and Social Media Metrics Cumulative Data Report* April 22, 2009 – December 31, 2009, Division of eHealth Marketing (DeHM) National Center for Health Marketing (NCHM) Centers for Disease Control and Prevention (CDC).

Hurdles to increased use of social networks in health care

Although health care stakeholders are using social networks on a more widespread and frequent basis, the networks' commercial value to specific health care organizations and the industry as a whole remains elusive. Unlike Internet advertisements and traditional marketing tactics, many

businesses have not yet developed robust metrics to measure success and return on investment related to social networks. In addition, regulations limit what industry organizations can say to physicians and consumers. For these and other reasons, health care lags other industries in its social network presence (Figure 4).

Figure 4: Fortune 100 company engagement in social networks²⁸

FORTUNE 100 companies	Blogs	Facebook	Twitter
Telecommunications	75%	100%	100%
Computers, Office Equipment	67%	100%	67%
General Merchandiser	50%	75%	100%
Motor Vehicles and Parts	67%	67%	67%
Specialty Retailers	50%	50%	100%
Food and Drug Stores	17%	33%	50%
Insurance: Property and Casualty	0%	25%	50%
Aerospace and Defense	33%	17%	50%
Commercial Banking	25%	0%	38%
Health care: Insurance and Managed Care	0%	0%	50%
Pharmaceuticals	33%	0%	33%
Petroleum Refining	11%	11%	22%

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Overcoming the following hurdles may accelerate social networks' usefulness in health care:

1. **Risk and liability:** Communications between health care providers and their patients are subject to the Health Insurance Portability and Accountability Act (HIPAA), which limits insurance plans, hospitals and physicians from answering questions on a specific patient's health information across a social network. Additionally, manufacturer communications to consumers and physicians are typically regulated as either labeling or advertisements by the FDA. The original Federal Food Drug and Cosmetic Act did not conceive of the communication and promotion methods available today via social networks and, therefore, the FDA is uncertain as to how manufacturers should proceed:

"...FDA recognizes that the Internet possesses certain unique technological features and that some online tools that may be used for promotion offer novel

presentation and content features. Another emerging issue involves the reporting of adverse event data because such information may initially be revealed using social media platforms in the context of Internet promotion for FDA-regulated medical products."²⁹

The FDA has indicated that it will issue guidance in late 2010 that may address the industry's current level of uncertainty.

2. **Consumer Trust:** The social network venue is rife with misinformation, which might lend itself to consumer trust issues if key health care industry groups are thought to be "manipulating" the free flow of information. Deloitte's *2010 Survey of Health Care Consumers* suggests that health insurance plans and manufacturers are the least-trusted sources of health information, with approximately one-third of respondents indicating that they distrust information from these organizations.³⁰

²⁸ *Social Media Use by Fortune 100 Companies*, Burson-Marsteller, July 29, 2009.

²⁹ Promotion of Food and Drug Administration-Regulated Medical Products Using the Internet and Social Media Tools; Notice of Public Hearing Docket No. FDA-2009-N-0441, October 2009.

³⁰ *2010 Survey of Health Care Consumers*, Deloitte Center for Health Solutions.

3. **Resources:** Operating a social networking site requires time and effort to maintain user engagement and subsequent return. According to Greystone.net, two-thirds of surveyed hospitals have not developed a plan on how to use their existing social networking sites; 70 percent of hospitals surveyed have less than four people devoted to social networking. Even as organizations face daunting challenges to maintain bottom lines and access capital cost-effectively for growth and innovation, the investment in social networking as a core communication channel is an expensive but unavoidable necessity. In most organizations, it likely will be added to traditional budgets for connectivity and communications.

Implications

Social networks enable access to and sharing of information that is essential to the U.S. health care system. As consumers increasingly depend on these networks to help them choose providers, determine a course of treatment and manage their health risks, industry stakeholders will face inevitable challenges in adapting to this new technology, complying with regulations and evaluating/acting upon the potential clinical and business opportunities inherent in social networks.

Decision makers who are considering new or expanded use of social networks should consider that social networks are not a strategy, but a tool that should be evaluated based on a business model's unique social, technical and cultural requirements. As such, some organizations may find little benefit in using social networks – at least at present. In fact, there is a significant risk to engaging with social networks when there is no clear objective for their use or an understanding of the potential avenues for failure.

Social networks are likely to have a significant impact on the future of U.S. health care. Already, these networks are enabling patients to communicate with each other to better manage their treatment and physicians to communicate with each other to better practice medicine. Although their current uses are somewhat limited, industry observers envision a future where social networks are an integral part of the health care landscape. Figure 5 provides examples of potential applications for key stakeholder groups.

As the regulatory environment becomes more defined and innovative organizations demonstrate measurable commercial value from social networks, increasing numbers of health care stakeholders are expected to recognize – and leverage – this transformational technology's role in information acquisition and access. Indeed, social networks are a trend that could change the face of health care information sharing, providing new power for providers and patients alike.

Figure 5: Examples of potential social network use by health care stakeholders

Organization	Implications/ future directions
Professional societies	<ul style="list-style-type: none"> Health care professional societies may be replaced by online networks. For example, Sermo recently represented U.S. physicians as a contributor to the federal Health Care Reform debate.³¹
Nonprofit foundations	<ul style="list-style-type: none"> Foundations may leverage recreational and health care sites to educate their stakeholders and to mobilize them for advocacy and activism.
Public health organizations	<ul style="list-style-type: none"> Social networks may enable public health organizations to quickly reach the public and alert them to policy debates and key decisions such as vaccination drives, quarantines and evacuations.
Hospitals	<ul style="list-style-type: none"> Hospitals may use social media to engage in crisis management, help consumers understand their treatment options and obtain feedback on their services.
Life sciences companies	<ul style="list-style-type: none"> Pharma and biotechnology companies – may increasingly mine physician data from physician networks. Medical device companies – may increasingly use professional networks to train physicians remotely on their products. CROs – may build their own social networks to help with clinical trial feasibility and recruitment.
Federal regulators	<ul style="list-style-type: none"> Given the life sciences' industry's interest in social networks, the FDA may eventually set up pharmacovigilance channels through online social networks.
Health plans	<ul style="list-style-type: none"> Health plans may be able to increase member marketing and education efforts via social networks.

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31 *The Biggest Risk to US Physicians: The AMA*, From the Founder Blog, <http://www.sermo.com/blog?page=2>, July 2009.

Authors

Paul H. Keckley, PhD
Executive Director
Deloitte Center for Health Solutions
pkeckley@deloitte.com

Michelle Hoffmann, PhD
Senior Manager
Deloitte Center for Health Solutions
mihoffmann@deloitte.com

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Contact information

To learn more about the Deloitte Center for Health Solutions, its projects and events, please visit:
www.deloitte.com/centerforhealthsolutions.

Deloitte Center for Health Solutions
555 12th Street N.W.
Washington, DC 20004
Phone 202-220-2177
Fax 202-220-2178
Toll free 888-233-6169
Email healthsolutions@deloitte.com
Web <http://www.deloitte.com/centerforhealthsolutions>

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