Should Healthcare Organizations Use Social Media?

A Global Update

CSC | Business Solutions Technology Outsourcing
Social media is the process of people using online tools and platforms to share content and information through conversation and communication. It is drastically changing the way that we communicate and you should not underestimate its ability to work for or against your organization.

Globally, healthcare organizations are already using social media as an important tool to connect consumers and providers as well as to inform product development. The experience of early adopters demonstrates that social media can be used to accomplish healthcare goals in four broad areas:

- Communications
- Information sharing
- Clinical outcomes
- Speed innovation

In considering what to do with and about social media, healthcare organizations cannot afford to take a “wait-and-see” approach or you may soon find yourself trying to catch up with competitors. Even if you do not currently have an active social media presence, your employees and customers are already using social media and may be sharing information about you. At minimum, organizations need a “protective” policy and an outreach program to educate employees and customers about appropriate social media use. More broadly, organizations should develop an overarching strategy that leverages social media to help influence customers and accomplish strategic healthcare goals.

We offer the following recommendations:

1. You cannot afford to take a “wait-and-see approach.” Although some believe social media is a passing fad, we believe it is here to stay and the sooner your organization develops an active presence, the less distance you will have to make up later.

2. You should have a social media policy, minimally, to protect against security, privacy or ethics breaches by your employees or customers. You should also offer staff education. Training and outreach are necessary to ensure that staff fully comprehends and is able to carry out the policy.

3. Use social media to go where your customers are. Listen to what others are saying about your organization, your product(s) and your brand(s). Monitor the social media activities of others in your market, and use social media to listen to what others are saying about your competition.

4. Consider starting where many organizations start. Use social media to enhance marketing, branding, recruitment, reputation management, customer relations and customer service. However, take care to educate yourself first on what is allowable under existing laws in your country.

5. You don’t have to develop a full-blown social media strategy now, but eventually you will need one. Start now but start small and monitor outcomes. Ask what your organization should be doing now to anticipate a more widespread use of social media to help accomplish key health care goals. Then expand your social media activities into new areas of value.

6. Recruit social media managers internally. Distribute responsibilities among staff that know your organization, are Internet-savvy and are excited about using social media to benefit your organization. Keep social media content accurate and current.
INTRODUCTION

Social media may present the most important change in the way we communicate since Johannes Gutenberg invented the printing press in 1440. We are only just beginning to understand the impact social media can have on business in general and on healthcare in particular.

In less than a decade, hundreds of millions of people globally have become active users of social media sites — the most popular of all Internet destinations. Social media is a radically different way to communicate because it breaks through three barriers that previously were major limiting factors: geography, time and cost.

Social media is changing the way organizations think about communicating with customers and accomplishing their business objectives. The train has left the station. Few think social media is a passing fad. Thus, healthcare organizations must now answer two main questions:

1. What am I going to do about social media?
2. What am I going to do with social media?

Regarding the first question, it is critical that all healthcare organizations develop a social media policy. Even if you do not currently have an active social media presence, your employees and your customers are actively using social media now. You need both a “protective” social media policy and an outreach program to educate your employees and customers about appropriate social media use. A recent global survey of over 4,000 IT security practitioners across industries revealed that almost two-thirds believe that social media poses a significant business risk to their organization. Yet, only 29% said they have adequate controls in place to manage that risk.¹

Regarding the second question, we believe healthcare organizations should be developing a social media strategy now. What is your organization going to do with social media now and what are your aspirational goals? What strategic business goals will you advance using social media? If you take a “wait-and-see” approach now you may soon find yourself trying to catch-up with others in your market.

The recommendations we offer at the end of this paper apply to all healthcare organizations. Especially in the United States, social media currently tends to be located in marketing, communication and recruiting departments, but it is beginning to spread throughout organizations. In European countries where there is less competition for patients, uses are more diverse. Other departments — particularly those involved in reimbursement, finance, clinical improvement and product development — should proactively focus on how social media can help advance organizational goals. To this end, consider the 15 healthcare business goals identified in Table 1. This paper describes best practices from early adopters that illustrate how healthcare companies have employed social media to accomplish these goals.

Table 1. Healthcare Business Goals Advanced by Social Media

<table>
<thead>
<tr>
<th>Communications</th>
<th>Information sharing</th>
<th>Clinical outcomes</th>
<th>Speed innovation</th>
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<tbody>
<tr>
<td>4. Reputation management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Consumer relations</td>
<td></td>
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</table>


Social Media²

- Allows a wide variety of content formats (text, photos, video)
- Is device indifferent (computers, tablets, mobile/smartphone devices)
- Facilitates speed and breadth of information dissemination
- Provides one-to-one, one-to-many and many-to-many communication
- Allows communication to take place in real time or asynchronously over time
- Extends engagement by creating real time events, extending online interactions offline or augmenting live events online
- Allows different levels of engagement
WHAT IS SOCIAL MEDIA?

There are many definitions of social media. No one is definitive. We took the most frequently used words in 30 social media experts’ descriptions of the concept (see Figure 1) and use them in our working definition.

**Social media** is the process of people using online tools and platforms to share content and information through conversation and communication.

The speed at which social media has been adopted in one short decade is without parallel. Facebook was famously launched in a Harvard University dormitory in 2004 and at the end of 2011 counted 845 million users worldwide. Twitter was launched in 2006 and had over 200 million accounts by early 2011.1 Every day, the world tweets the equivalent of 8,123 copies of Tolstoy’s *War and Peace*.2 Social media sites are among the most popular internet websites throughout the world (Table 2). On average, global consumers in Australia, Brazil, France, Germany, Italy, Spain, Switzerland, the United Kingdom and the United States spent nearly a quarter (22%) of their online time using social media sites in April 2010.3

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**Familiar Examples of Social Media Sites**

- **Facebook** — A social networking website that allows users to create a personal profile, connect with others, exchange messages, and join common-interest user sites.
- **Mass Multiplayer Online Role Playing Games** — Online games connect players from all over the world and enable interaction and collaboration.
- **YouTube** — A media sharing platform that allows users to view and share videos with a global audience.
- **Twitter** — A micro-blogging site that allows users to communicate with each other and share information through short (140 characters) messages, or “tweets.”
- **Wikipedia** — A free online encyclopedia that anyone can edit. One of the most comprehensive sources of knowledge online, but reportedly, also a frequent source of misinformation.
- **Weblogs/Blogs** — Tumblr, WordPress, Blogger and others allow users to generate their own content, whether it is image based, video based, or the plain old written word, which they can share with anyone they want.

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**Table 2. Most Popular Internet Destinations**

<table>
<thead>
<tr>
<th>Website/Brand</th>
<th>Percent of World’s Internet Population Visiting</th>
<th>April 2010 Time Per Person (hh:mm:ss)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Google</td>
<td>82%</td>
<td>1:21:51</td>
</tr>
<tr>
<td>MSN/WindowsLive/Bing</td>
<td>62%</td>
<td>2:41:49</td>
</tr>
<tr>
<td>Facebook</td>
<td>54%</td>
<td>6:00:00</td>
</tr>
<tr>
<td>Yahoo</td>
<td>53%</td>
<td>1:50:16</td>
</tr>
<tr>
<td>Microsoft</td>
<td>48%</td>
<td>0:45:31</td>
</tr>
<tr>
<td>YouTube</td>
<td>47%</td>
<td>0:57:33</td>
</tr>
<tr>
<td>Wikipedia</td>
<td>35%</td>
<td>0:13:26</td>
</tr>
</tbody>
</table>

*Source: Nielsenwire, 2010*4

*Includes AU, BR, CH, DE, ES, FR, IT, GB and USA only.*
BUSINESS USE OF/ATTITUDES TOWARD SOCIAL MEDIA

A 2010 survey of 2,100 Harvard Business Review subscribers from around the world found that nearly two-thirds of represented organizations are using, or plan to use, social media. A 2009 – 2010 survey of the top 100 Global Fortune 500 companies found that most reported having a presence on Twitter (65%), Facebook (54%) and YouTube (50%) and a third (33%) indicated having a corporate blog.

The attitudes expressed by HBR subscribers are instructive and paint the following picture. On the one hand, most believed social media is “not a passing fad” and that “the use of social media by our organization will grow significantly over the next few years.” In slightly more than four out of 10 organizations “social media is an important component of our overall marketing strategy” and “using social media is integral to our overall company goals and strategy.” On the other hand, most agreed that “our organization has a significant learning curve to overcome before we can utilize social media” and one-half believed that “until we are able to clearly measure the impact of social media, it will not be taken seriously in our organization.” Four out of 10 said that use of social media is a “tactical rather than strategic” decision in their company and only about one-third agreed that “social media has been designated as a high priority by our organization’s executives.” Of course another way to understand this finding is that, at this early stage, as many as one third felt that executives in their organization consider social media a high priority.

When asked which departments are responsible for developing their organization’s social media strategy, seven out of 10 identified marketing, but only 16% said IT and 12% said customer service. We think this suggests a two-fold problem. First, organizations “silo” social media in marketing departments to their own detriment. And two, as Avinish Kaushik, Google’s Analytics Evangelist has said, “Too many companies have not evolved from what I call ‘shout marketing’ — think TV, newspapers, magazine ads — to influence by initiating and participating in conversations with consumers.” The use of social media should be about much more than the application of a traditional marketing campaign into a new space. Rather, at heart, social media is an opportunity to build relationships, start conversations and learn from your customers.

HOSPITAL, CONSUMER AND PHYSICIAN USE OF SOCIAL MEDIA

Hospital Social Media Use

Healthcare organizations have been slower to adopt social media than other business organizations. Thus far, hospitals, as a group, have higher adoption rates than other sectors of the healthcare economy. As a cohort, hospitals in Europe are leading in their adoption of social media. In particular, more hospitals in the Netherlands and the United Kingdom use social media than hospitals elsewhere in Europe, the United States or Australia (see Table 3). In the United States, a close look at the hospital industry reveals significant heterogeneity in use: Large, urban, nonprofit/private, teaching hospitals and children’s hospitals are the highest adopters (see Table 4).

Table 3. Social Media Use Among Hospitals Internationally, 2009 - 2011

<table>
<thead>
<tr>
<th>Social Media Use</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Adopters</td>
<td>Netherlands, United Kingdom, Norway, Sweden</td>
</tr>
<tr>
<td>Mid-Range Adopters</td>
<td>United States, Austria</td>
</tr>
<tr>
<td>Low Adopters</td>
<td>Australia, Switzerland, Germany</td>
</tr>
</tbody>
</table>

Source: Engelen, 2012 and Cadogan, 2011

Table 4. Social Media Use in U.S. Hospitals

<table>
<thead>
<tr>
<th>Hospital characteristics</th>
<th>Percentage of U.S. Hospitals that Use Social Media</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of beds</td>
<td></td>
</tr>
<tr>
<td>6-69</td>
<td>15%</td>
</tr>
<tr>
<td>100 - 399</td>
<td>26%</td>
</tr>
<tr>
<td>&gt;399</td>
<td>42%</td>
</tr>
<tr>
<td>Ownership type</td>
<td></td>
</tr>
<tr>
<td>Private, nonprofit</td>
<td>30%</td>
</tr>
<tr>
<td>Investor-owned, for profit</td>
<td>13%</td>
</tr>
<tr>
<td>Government, federal</td>
<td>24%</td>
</tr>
<tr>
<td>Government, nonfederal</td>
<td>13%</td>
</tr>
<tr>
<td>Teaching status</td>
<td></td>
</tr>
<tr>
<td>Major</td>
<td>58%</td>
</tr>
<tr>
<td>Minor</td>
<td>31%</td>
</tr>
<tr>
<td>Nonteaching</td>
<td>16%</td>
</tr>
<tr>
<td>Location</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>27%</td>
</tr>
<tr>
<td>Rural</td>
<td>10%</td>
</tr>
<tr>
<td>Primarily treats children</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>58%</td>
</tr>
<tr>
<td>No</td>
<td>19%</td>
</tr>
</tbody>
</table>

Source: Thaker, Nowacki, Mehta, Edwards, 2011
Research indicates that consumers are increasingly going online and to social media sites to get health information. One report estimates nearly half of European healthcare consumers in Spain, Italy, France, Germany and the United Kingdom (150 million or approximately 47% of the total population) used the internet to find health information in 2010, up from 112 million in 2007. A separate 2009-2010 survey of roughly 1,000 healthcare consumers and physicians in France, Germany, Italy and Spain found that consumers ranked Facebook as their fourth most popular online source for health information. The majority of these consumers (65%) indicated that they trust information from social media venues. In the United States, a domestic population survey conducted in 2010 found that almost 60% of adults seek health information online, but only about 7% go to social network sites for health information. Most adults with a health issue seek information, care or support the old fashion way: from a health professional (70%), from friends and family (54%), and from others with the same health condition (20%).

Thus far, across countries, social media usage has been especially popular among teenagers and younger adults, but there are some signs that the trend is beginning to catch on among older adults.

**Consumer Social Media Use**

**Physician Social Media Use**

Social media use is gaining traction among healthcare professionals globally. Research indicates that some practitioners use social media in their professional lives to locate educational information and communicate with their peers. In the 2009-2010 survey of healthcare consumers and physicians in France, Germany, Italy and Spain described above, most doctors reported using the internet and some social media tools to locate and share health-related information. Physician respondents reported using physician portals (70%), Wikipedia (55%) and video sharing sites such as YouTube (23%) in their professional lives. A separate survey conducted in 2009 among 1,125 physicians in France, Germany, Italy, Spain and the United Kingdom, found online video use was even higher, with almost half of respondents (46%) indicating that they watch online videos for professional purposes. In a more recently published survey of 935 Australian healthcare practitioners, 9.5% of respondents reported that they used social media tools in their professional lives.

In the United States, social media use is somewhat higher among physicians than consumers. More physicians use social media in their personal lives than in their professional lives. Physicians in the latter group use social media to locate educational information and communicate with their peers. Physician interaction with patients using social media is less common, although physicians report that patients are increasingly initiating contact through these channels.
How do U.S. Healthcare Organizations Use Social Media? Best Practice Examples

A number of groups, including providers, patients, payers, life science organizations and others, are already using social media in a number of innovative ways within the healthcare sector.

Social media offers an important set of tools to open communication between providers and consumers, often by going to where consumers are.

Marketing

For many groups, social media has become part of their overall communication and marketing strategy. For instance, German drug maker Boehringer-Ingelheim maintains presences on Facebook, Twitter and YouTube and uses the sites to share news, promote events and public awareness campaigns, and represent the company before a global audience. Consistent with Facebook's open wall requirement, visitors to Boehringer-Ingelheim's page are invited to post comments on the company's wall, but are reminded, in a good humored way, that the space is not intended as "a forum to discuss technical queries regarding specific pharmaceutical products, medical conditions or as a substitute for professional medical advice."[21]

In the United States, Kaiser Permanente has maintained an active presence on multiple commercial social network sites for several years, as has Mayo Clinic. In July 2011, Mayo launched its own “Online Health Community” which is a Facebook-like social media site open to all comers. Within a week, 1,000 people had joined. By late September there were over 7,000 members. Metrics vary for evaluating the impact of social media, but the organization indicated that it was pleased with the response rate. Mayo encourages visitors to its website to upload their photo, watch health videos and stories from patients, meet and join a "community of members with a shared purpose," and participate in or just listen to discussions and conversations on shared health interests. The first page of the website is inviting; it clearly and briefly states why visitors might want to become members: "the benefits of joining are to meet others with similar health interests, share stories, learn, find support, and hear about Mayo Clinic."

Workforce Recruitment

“Social recruitment” is a popular use of social media in large corporations. Sodexo, for example, is a very large global company that has pioneered methods of using social media for workforce recruiting and talent acquisition. Recruiting at the management level and above for hospitals is a main staple of its business. Sodexo uses social recruiting to fill hospital positions in food services management, facilities management and environmental services. The company also uses social recruiting to find and attract registered dieticians to hospitals. Sodexo was recognized with an excellence award for innovative use of social media in 2009 and the company was named recruiting department of the year in 2010. Its social media strategies reduced annual recruitment advertising costs by $300,000.

Brand Management

In countries where it is permissible under existing laws, groups can also use social media and professional networking sites to, directly and indirectly, promote their brands and services. For instance, Switzerland-based pharmaceutical company Roche provides cancer educational resources for Doctors.net.uk. The site has 189,240 members and is the largest physician network in the United Kingdom.[22] Such sponsorship allows the company to interact with one of their target audiences, position themselves as a thought leader and improve their brand recognition.

In the United States, Children's Hospital Boston uses Facebook, Twitter and YouTube to demonstrate its focus on patients and their families by sharing patients' stories and weekly photos. The hospital also maintains a pediatric healthcare blog, called “Thriving,” where clinicians and staff write about various timely health news topics and address questions that are highly relevant to patients and their families. Because “Thriving” is a blog, others can respond and communicate with each other, taking the discussion in sometimes unpredictable directions.
Reputation Management/Customer Relations
While social media presents a new forum for consumers to vocalize their dissatisfaction with companies or service providers, it also provides companies with a new opportunity to manage customer relations and protect their public images. With the rise of social media, organizations can expect to hear more from their customers. Consumers are increasingly airing comments and complaints in public forums, especially when they feel their issues have been ignored through traditional channels. For instance, a group of patients in the United Kingdom launched a Facebook group to protest the closing a midwife unit; the group has amassed over 600 members and received media attention. Such activities are not unique to the United Kingdom. According to Australian consumer watchdog group CHOICE, consumers who have been unable to resolve their issues through customer service department find that posting their complaints on Facebook and Twitter gets better results. As a CHOICE spokesperson put it, the underlying message to consumers is “don’t get mad, get tech savvy if you want to be heard.”

By actively tracking mentions on popular social media sites, groups can proactively intervene to repair strained customer relations and protect their reputations. For example, in the United States, Cigna staff regularly monitor social media channels for comments about the health plan. When negative comments are found, staff reach out and offer assistance to the individual in resolving their issue. Cigna customer experience officer Ingrid Lindberg believes this is a very important activity because negative comments can be influential. “At the end of the day, people do trust what friends or family tell them. With the advent of social media, everybody out there is one of my friends or family,” she said. Similarly, in the United Kingdom, National Health Service (NHS) Direct staff also use social media to listen to what is being said about them and engage with customers. “We knew that conversations are happening about NHS Direct on Twitter,” says Roger Donald, head of digital delivery. “We felt it was better to engage with people interested in our service on Twitter than to ignore it.”

Consumer/Patient Education
Social media offers a new opportunity to communicate evidence-based health knowledge to consumers and patients and to disseminate evidence-based medicine to health professionals. The education possibilities inherent to the use of social media could breathe new life into the consumerism movement.

Some providers are beginning to take advantage of social media to share information with patients and consumers. For instance, a surgical center in the United Kingdom maintains a YouTube channel and posts short educational videos on common health conditions to serve as a reliable source of information for patients. Thus far, the videos have received a warm reception by patients and the YouTube channel has attracted thousands of viewers.

Other providers are taking advantage of multiple social media platforms to educate and engage with patients. A five-doctor center for ear and airway disorders in Budapest, Hungary uses Facebook to share information with patients and one doctor maintains a blog to educate patients about ear, nose and throat issues. A Spanish hospital employs a similar social media strategy. In addition to taking advantage of Facebook and Twitter to share information, it also publishes an informative healthcare news blog in three languages and hosts an interactive forum. Through the forum, patients can interact with physicians, as well as fellow patients, have their questions answered and learn how to manage their conditions. In the United States, a 10-doctor obstetrics and gynecology practice shares information with patients on Facebook, Twitter and YouTube, as well as other platforms. Dr. Jeff Livingston, a member in the practice says, “With Twitter, I can point my patients in the direction of articles and blog postings and things interesting from an OB/GYN perspective.”

Dr. Livingston reports that, as a result of this social media use, his patients are better educated and come to appointments more prepared.

Health Professional Education and Collaboration
Information sharing and interaction over social media provides opportunities for learning, professional development and collaboration among healthcare professionals. For instance, healthcare professionals and others from across the globe come together on Twitter fortnightly to discuss medical journal publications. Known as “Twitter Journal Club,” the discussion is open to all interested parties and brings groups together regardless of geographic location or specialty. Earlier this year a discussion of “A Surgical Safety Checklist to Reduce Morbidity and Mortality in a Global Population” by Haynes et al brought together doctors,
surgeons, nurses, medical students and others from across the United Kingdom, United States and Europe. One of the authors of the paper, Atul Gawande, MD from the United States participated in the discussion as did Suzette Woodward, D. Prof, Director of Patient Safety at the NHS National Patient Safety Agency in the United Kingdom.\textsuperscript{31}

In addition, a growing number of doctors and other clinicians use professional networking sites, such as e-HealthSpace in Australia, Coliquio and Doox in Germany, Doctors.net.uk and Doc2Doc in the United Kingdom, and Sermo and Doximity in the United States, to converse and share information with colleagues near and far. For instance, Coliquio is one of the largest German-speaking physician networks, serving Germany, Austria and Switzerland with more than 58,000 members. Similar to other physician networking sites, Coliquio allows members to consult with colleagues about complicated cases, new treatments, emerging research and other topics relevant to their profession. “Risk from vaccination for yellow fever booster in the elderly” and “persistent fever in pneumonia” are just some of the topics that have been discussed on the site.\textsuperscript{32} Members can also upload patient radiological pictures and solicit feedback from peers. The site advertises that members can expect to receive a considerable amount of feedback from colleagues and to quickly locate answers to their questions (often within 24 hours).

Community Creation
Online healthcare groups — virtual communities — are popping up with little if any regard to geographic or cost barriers thanks to such social media sites as Facebook and Twitter. In addition, an increasing number of health condition-specific sites have been created and are under development for the purpose of encouraging information sharing and, importantly, to provide a context for giving and getting support. Through patient networking sites such as PatientsLikeMe in the United States, HealthShare in Australia, LeukaNet in Germany, HealthUnlocked in the United Kingdom and TuDiabetes internationally, patients and caregivers form communities of people with like conditions, create profiles to document details of their health condition, review others’ profiles, share advice on treatments and provide motivational support. A great attraction of such social media sites is that people experiencing similar problems can find each other with an ease never before dreamt possible. Even patients with the rarest of diseases can find others like them. Some patient communities also partner with respected healthcare foundations, disease associations and charities, which help moderate forum discussions, answer users’ questions and ensure that reliable information is available.

In addition to providing patients with encouragement and support, research has shown that participation in online communities can have beneficial effects for participants. For this reason, some providers and other groups encourage patients to participate in such interactions. Headspace, Australia’s National Youth Mental Health Foundation, provides young people with online (via an online community) and real-world spaces (through headspace centres) to connect and locate mental health support.\textsuperscript{33} The Raboud Academic Medical Center in the Netherlands launched its own online community to specifically serve their young adult cancer patients in 2009. The site connects patients and encourages them to interact, post questions, share feelings and spread knowledge. Users also have the option of blogging, posting pictures and sharing videos. Research indicates that the community has had a positive impact on the population: The hospital has seen fewer unscheduled hospital visits, higher levels of patient satisfaction, and “more confident young patients.”\textsuperscript{34}
Wellness
Some groups use social media to promote wellness and healthy lifestyles among healthcare consumers. In particular, Facebook creates an efficient forum to connect with teenagers and young adults, given the popularity of the site among the age group. For instance, Lyn Familton, a clinical nurse specialist in New Zealand, administers a Facebook page to provide sexual health education and engage with patients. The page provides a means of distributing youth-focused health messages. In addition, using the private message feature, Facebook can also serve as a reliable method of contacting individual patients if traditional contact information is outdated. Nurse Lyn reports that the page has served as “an invaluable tool for reaching and ensuring the engagement of a difficult-to-access cohort.”

A nurse in the United Kingdom employs a similar strategy to educate patients on Twitter.

In the United States, the health plan Aetna uses Facebook, and other sites, to connect with college-aged members and share educational information about alcohol use, physical fitness, sexual health and smoking cessation.

Patient and Population Monitoring
Some physicians use social media to check-in with patients between office visits. For instance, in addition to emailing and texting with her patients, Dr. Jennifer Dyer, a former pediatric endocrinologist, maintained an active presence on Facebook and was “friends” with a small number of her former patients with whom she had close relationships. She says patients already saw her as approachable and felt comfortable talking to her, but that because she was on the site, she could also see what was happening in their lives and identify potential risk factors for discussion. All of this helped to make office visits more efficient because there was less need to discuss background information. “I could do more high quality treatment problem solving during the visit because I was already up to speed,” she said.

Social media sites are also beginning to be used to collect patient-reported data for monitoring individuals and populations with chronic conditions. Researchers at Children’s Hospital Boston collected hemoglobin A1c data from members of the international diabetes community TuDiabetes. They conducted a privacy-secured “data donation drive” and obtained information from over 1,000 voluntary participants from among TuDiabetes members in 32 countries. The results for U.S. users mirrored those in a national survey conducted by the U.S. Centers for Disease Control and Prevention, leading the researchers to conclude that social networks may be an “efficient platform” for collecting data for disease surveillance.

Care Management/Care Coordination
Some groups are beginning to leverage the popularity of social media sites to aid in patient care management and care coordination. For instance, in the United States, University of Iowa Children’s hospital recently launched a Facebook application that seeks to improve medication adherence among teenage kidney transplant patients. Using data taken from the hospital’s electronic health record system, a mobile application was populated with information on patients’ medications and dosage instructions. When a patient logs on to the site their medication data appears on their personal (not publicly accessible) Facebook page to help them remember what drugs they need to take that day.

In addition, efforts are underway to create secure online communities to galvanize providers, informal caregivers, family and friends around the care of individual patients. For instance, NHS East of England recently partnered with Cambridge Healthcare to create “How Are You?,” a social network site capable of securely connecting patients with providers, informal caregivers, family and friends.

Launched earlier this year, the site prompts patients to “tell us how you’re feeling” and enter periodic updates on their health status. In addition to sharing updates, users can also create a personal health record and securely share their information with whomever they chose. The site also allows patients to communicate with their caregivers securely and even offers a video chat feature. Tracking patient updates on the site can help providers, informal caregivers and loved ones monitor a patient’s wellbeing and alert them to when a patient may be in need of extra help or additional encouragement.
Clinical Trial Recruitment

Social media can be used to aid in soliciting volunteers for clinical trials. For instance, MediciGlobal, a United Kingdom and U.S.-based patient-recruitment firm, recently used Facebook to recruit participants for an upcoming clinical trial. In doing so, the company was able to reach an audience of over 750 million users of various ages and successfully surpassed enrollment targets in only six months.

As trends continue to shift away from conducting large trials on “block buster” drugs and towards conducting smaller trials on population-tailored drugs, social media may become an even more valuable tool for recruitment. As the focus narrows, locating patients for who meet the criteria for participation in trials is expected to become more difficult. Social media, with its abundance of condition-specific online patient communities, provides a captive audience of potential volunteers. For instance, in the United States, Novartis partnered with PatientsLikeMe in 2008 to recruit participants for a multiple-sclerosis drug clinical trial. The site sent messages to 8,000 members of the multiple sclerosis community to inform them of the trial, which led to 1,500 web hits on the Novartis site and an increase in study registrations.

Research Collaboration

Social media helps to bring diverse groups together which can aid in research collaboration and accelerate breakthroughs. For instance, a group of online gamers successfully mapped out the structure of an enzyme (M-PMV) believed to be responsible for HIV replication. The model had eluded scientists and automated computer programs for 15 years but was solved by gamers playing “Foldit” in three short weeks. “Foldit” prompts players to break down the model of three-dimensional structure of proteins, rewarding more accurate depictions with higher points. The goal in creating the game was to incorporate human reasoning into the decoding process.40

Surveillance, Analysis, Product Development

In addition to directly benefiting participants, patient interactions on social media can also provide life science organizations and other healthcare stakeholders with useful information for product development. Most notably, discussions occurring on patient networking sites provide insight into disease progression, how medications and devices are used, their effectiveness, their side effects, and unmet patient needs. De-identified patient data aggregated from these sites is being used to inform the development of the next generation of prescription drugs, medical devices and other interventions.

For instance, HealthUnlocked in the United Kingdom leverages support from various patient groups and disease associations to maintain 18 disease-specific patient communities. Community members are able to connect and share knowledge and experiences with other members. With patients’ consent, data collected from discussions is shared with certain groups for research purposes. Thus far, the site has collaborated with doctors, hospitals, patient groups, disease associations and charities, and is beginning to work with pharmaceutical companies. The site, which was established in 2009, had roughly 10,000 members in 2011. Most members (99%) consent to having their information shared to promote learning.

In addition, some third parties sponsor communities on the U.S.-based patient site PatientsLikeMe to encourage patient interaction and collect information on specific topics of interest. In 2010, Belgium-based biopharmaceutical company UCB sponsored the establishment of an epilepsy community on the PatientsLikeMe social media site for U.S. patients. There, members of the community are encouraged to share information on their symptoms and treatments, as well as daily progress in controlling seizures and meeting treatment goals. They also have the option of completing quality of life surveys on topics such as the status of their cognitive, physical and social functionality, and can document and report adverse events associated with UCB treatments. According to UCB Executive Vice-President and Chief Medical Officer Iris Loew-Friedrich, “We believe this community will be a source of information that will allow us to better understand people living with epilepsy and may help us design clinical programs that incorporate real-world patient needs and experiences in a measurable way.”41
We have discussed many ways social media can benefit organizations. However, there are risks involved as well. Organizations using social media face losing control of their message. Once a comment or “tweet” is posted, anyone can respond. While some users may share positive feedback, the door is also open to negative comments, which, however unfounded, can taint an organization’s reputation. In addition, social media can expose organizations to privacy, security and ethics breaches, even if the organization does not have a formal social media presence. Clinicians and staff may inappropriately share confidential information about patients and the organization. Sharing protected health information violates HIPAA and can have serious ramifications for the individual as well as the organization. Social media also raises new ethical questions about patient/provider relationships. Both patients and providers navigate social media channels; interactions on these sites are blurring traditional boundaries. Some fear this could negatively impact patient care by impairing providers’ professional judgment. Some providers also fear that interactions with patients on social media sites could expose them to malpractice lawsuits if their comments are misinterpreted.

A number of outstanding issues impede the use and reach of social media in healthcare.

**Language and Cultural Barriers**

On a basic level, the vast language and cultural differences separating populations present a significant barrier. Even if a social media solution is developed that can be used internationally, it still has to be translated into several languages. However, given that different countries have different cultural traditions and habits that affect the management of healthcare, it will be difficult to develop such a solution.

**Reimbursement Barriers**

In addition to the risks discussed above, time and payment issues hamper some physicians’ and organizations’ use of social media. The reimbursement model for doctor-patient social media interactions remains a sorely unresolved topic given that many doctors, especially in the United States, are presently not compensated for their time spent on social media.

**Return on Investment (ROI) Barriers**

Lack of evidence with regard to the payback of social media may detract some organizations from moving ahead with their strategy. The use of social media in healthcare is a relatively new phenomenon and very much an evolving practice. Positive anecdotal evidence abounds from organizations that have taken the leap, but little formal evidence is yet available to demonstrate the return on investment of social media use.

**Consumer Barriers**

Thus far, use of social media remains more popular among younger adults than older adults. Lower use of social media among older adults may hinder organizations’ efforts to connect with a target audience. Older adults are more likely to have a chronic condition and are one of the groups that could benefit most from the increased interaction and support that social media can offer.

While social media continues to gain popularity, some individuals in all age groups remain skeptical. Among other
things, disinterest in social media could be prompted by concerns for privacy and the perception of security risks. If individuals fear that it is not safe to share personal information in online discussions, this could dissuade individuals from using social media sites for healthcare purposes.

Legal and Regulatory Barriers
Legal and regulatory requirements, including a lack of formal guidance, restrict some organizations’ use of social media, especially among physicians and some life science organizations. In the case of the former, existing laws in certain countries, such as Germany, prohibit advertising healthcare and serve to limit the ways in which providers can use social media. With regard to the latter, lack of clarity regarding how pharmaceutical companies are permitted to use social media hinders the use of sites by many drug makers.

Due to the lack of guidance available, many pharmaceutical companies remain wary of social media. For instance, many companies deleted or significantly pared down their corporate Facebook pages after the site revised its commenting policy last year. Pharmaceutical companies had previously been afforded special dispensation to disable commenting features on their brand posts. When the privilege was largely revoked in August 2011, it prompted many companies to leave the site. Much of the concern surrounding open walls pertains to a fear that users will comment about adverse events and/or share incorrect or off-label information related to pharmaceutical products, which the company must then report to the proper oversight agencies. Many also fear that the company could be held liable for user-posted content on social media pages.

Some regulatory agencies, recognizing pharmaceutical companies’ interest in social media, have begun to issue guidance on how it may be used. After much anticipation, the U.S. Food and Drug Administration (FDA) released its first guidance late last year which addressed how to handle requests for unapproved or off-label information made on social media sites. Notably, it establishes that firms may respond (in a very prescribed manner) to such requests if they specifically pertain to their products. However, the guidance is very limited in scope, dealing with only one of many uses of social media. FDA officials report that additional guidance is currently being developed. However, elsewhere in the international community, there is less interest in developing platform-specific guidelines to govern pharmaceutical companies’ use of social media. For instance, in Europe, the European Medicines Agency has indicated that it has no plans to develop its own guidance on the topic.

PROTECT YOURSELF BY ESTABLISHING A SOCIAL MEDIA USE POLICY

Taken together, these factors may give pause to anyone seriously considering a social media launch. However, precautions can be taken to address these issues and mitigate risks. Establishing policies to govern employees’ use of social media is a critical step that organizations must take to protect themselves. The American, Australian, British and New Zealand Medical Associations, Kaiser Permanente and Mayo Clinic in the United States, and Hospital Sant Joan de Deu in Spain are just some of the groups that have already crafted policies. Minimally, an effective social media policy should reiterate that individuals must adhere to legal requirements, federal regulations, and corporate policies and procedures in their social media use and that patient privacy and confidentiality standards apply in all settings, including the Internet. Policies should clarify what information can and cannot be published on social media sites, and encourage individuals to keep the content of postings professional and respectful of colleagues and patients. Kaiser Permanente in the United States has established a social media policy which may serve as a useful guide for others to consult in crafting their own policy. The document is clearly written, specific and provides readers with best practice examples. In addition, Pfizer Canada has developed a flow chart to help staff consider how to respond (or not respond) to various social media posts.

Posting public disclaimers can also be useful to ensure that users do not construe information taken from a social media site as medical advice, that the information users share on the organization’s sites will be publicly available and may be used for marketing purposes, and that the organization reserves the right to oversee and monitor user activity. In addition, provider organizations may also wish to direct users to call for assistance rather than seek assistance through social media pages in the event of a medical emergency. For instance, Children’s Hospital Boston warmly invites visitors to join discussions, but also warns that, among other things, offensive comments will be removed. Their disclaimer is presented in both legal terms and “plain English” for easy comprehension. Dr. Bertalan Mesko, a medical doctor and blogger in Hungary, clearly outlines the purpose and conditions of use for visitors to his blog. His disclaimer informs readers that the purpose of the site is to share reputable medical research. In doing so, “it is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her physician.” He invites feedback on posted content, but cautions that spam and/or inquiries for medical advice will not receive a response and warns that inappropriate comments and advertisements will be deleted. Patients with a medical problem are directed to see their doctor.
As healthcare organizations consider what to do with and about social media, we offer the following advice:

1. You cannot afford to take a “wait-and-see approach.” Although some believe social media is a passing fad, we believe it is here to stay and the sooner your organization develops an active presence, the less distance you will have to make up later.

2. You should have a social media policy, minimally, to protect against security, privacy or ethics breaches by your employees or customers. You should also offer staff education. Training and outreach are necessary to ensure that staff fully comprehend and is able to carry out the policy.

3. Use social media to go where your customers are. Listen to what others are saying about your organization, your product(s) and your brand(s). Monitor the social media activities of others in your market, and use social media to listen to what others are saying about your competition.

4. Consider starting where many organizations start. Use social media to enhance marketing, branding, recruitment, reputation management, customer relations and customer service. However, take care to educate yourself first on what is allowable under existing laws in your country.

5. You don't have to develop a full-blown social media strategy now, but eventually you will need one. Start now but start small and monitor outcomes. Ask what your organization should be doing now to anticipate a more widespread use of social media to help accomplish key health care goals. Then expand your social media activities into new areas of value.

6. Recruit social media managers internally. Distribute responsibilities among staff that know your organization, are Internet-savvy and are excited about using social media to benefit your organization. Keep social media content accurate and current.

Social media is here. Healthcare organizations are using it as an important tool to connect consumers and providers. Early adopters show through numerous examples that social media can be used to influence customers and accomplish strategic business goals. Your organization needs both a social media policy and a social media strategy. You cannot afford to take a “wait-and-see” approach or to sit idly by while the social media revolution overtakes the information revolution and radically changes the way we communicate and accomplish healthcare goals.

USEFUL LINKS
Webicina provides medical social media resources on over 80 medical topics in over 17 languages. [http://www.webicina.com](http://www.webicina.com)
Andrew Spong provides updated links on pharma’s use of social media and regulatory matters. [http://delicious.com/andrewspong](http://delicious.com/andrewspong)

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