To friend or not?
New insights about social networks in the life sciences industry
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To friend or not? New insights about social networks in the life sciences industry

With half a billion Facebook members and 75 million Twitter users speaking about products and opinions, there is an overload of stories about companies using internet enabled social networks – or groups of people on a specific World Wide Web address who share, modify, and view information – to reach consumers. These formidable numbers – and a healthy dose of hype – suggest that companies would do well to “tweet, friend, or get out of the way.” But in the life sciences industry, things are not that simple and the line between hype and hope is a thin one. On one side, mounting restrictions on communication with patients and physicians make access to these groups attractive and 65 percent of surveyed life science professionals say their company is using or plans to use social networks in some capacity. On the other hand, industry regulations limit interaction between life sciences companies and their customers, raising questions about the social networks’ usefulness, at least as a marketing channel.

These questions may explain why more than one third of life sciences professionals say they have no plans to use online social networks in any capacity, and of those that do, regulatory uncertainty is cited as the largest barrier.

Off-the-cuff judgments about new technologies are seldom solid ones. According to Gartner’s Hype Cycle (depicted in figure 2), new technologies are sometimes heralded as “transformational” and then discarded after a few public failures. Subsequently, truly transformational technologies tend to demonstrate themselves after the hype has subsided. Social networks may be travelling along this well-trodden path, currently residing in the “peak of inflated expectations” where the hopeful tout them as the way to market to customers. In reality, however, social networks are not a new way of putting out messages but a tool that provides customer centric information, communications, and collaborations that companies can use to support strategy. In the life sciences industry, social networks are already improving applications such as market research, physician relations, clinical trials, and medical education and are demonstrating utility beyond mere marketing channels, but as powerful tools that have the potential to – combined with the right application – add value.

Understanding how companies can use social networks may point the industry toward what Gartner calls “the plateau of productivity” – the time when life sciences companies effectively use social networks to interact with external communities. To examine the impact of social networks on the life sciences industry, we interviewed life sciences executives and social networking subject experts. We also surveyed professionals in the drug, device, and diagnostics space, selecting for marketing and compliance professionals who are using or planning to use social networks to fulfill a business objective.

### Figure 1. Life sciences companies’ plans to adopt social networks

During the past 12 months, have you/use your business unit/use your company used an online social network to seek or disseminate information?

<table>
<thead>
<tr>
<th></th>
<th>Currently use</th>
<th>Plan to use</th>
<th>No, and no plans</th>
</tr>
</thead>
<tbody>
<tr>
<td>You</td>
<td>55%</td>
<td>47%</td>
<td>38%</td>
</tr>
<tr>
<td>Your business unit</td>
<td>17%</td>
<td>23%</td>
<td>21%</td>
</tr>
<tr>
<td>Your company</td>
<td>27%</td>
<td>30%</td>
<td>41%</td>
</tr>
</tbody>
</table>

35 percent had no plans to use in any capacity.
We sought to understand six fundamental questions:
1. How are social networks adding value now?
2. How prevalent is the use of social networks in the industry?
3. What kinds of networks are being used, and for what?
4. What are the key barriers to social networking use?
5. How should the smart organization think about using social networks?
6. How should they govern and manage social networking initiatives?

Figure 2. Gartner Hype Cycle

1. **Technology trigger**: A potential technology breakthrough kicks things off. Early proof-of-concept stories and media interest trigger significant publicity. Often no usable products exist and commercial viability is unproven.

2. **Peak of inflated expectations**: Early publicity produces a number of success stories—often accompanied by scores of failures. Some companies take action; many do not.

3. **Trough of disillusionment**: Interest wanes as experiments and implementation fail to deliver. Producers of the technology shake out or fail. Investments continue only if the surviving providers improve their projects to the satisfaction of early adopters.

4. **Slope of enlightenment**: More instances of how the technology can benefit the enterprise start to crystallize and become more widely understood. Second- and third-generation projects appear from technology providers. More enterprises fund pilots; conservative companies remain cautious.

5. **Plateau of productivity**: Mainstream adoption starts to take off. Criteria for assessing provider viability are more clearly defined. The technology’s broad market applicability and relevance are clearly paying off.
Using social networks

Social networks are not new, but the reach of the internet allows them to form faster and go further than before. Unlike static websites, online social networks are more dynamic because they are controlled by many instead of a few. Physicians’ and patients’ activity on social networks is changing healthcare\textsuperscript{16} and causing manufacturers to take note. At a time when regulatory constraints are placing access to these groups at a premium, the communities where they discuss diseases and treatments are becoming an increasingly attractive venue for the industry. The hope is that companies would eventually integrate into the conversations between external scientists, physicians, and patients (see figure 3); however the lack of regulatory clarity, considered by industry professionals to be the biggest barrier to social network use, may limit this scenario.\textsuperscript{17} Still, even if companies cannot fully integrate with communities, they may still be able to opportunistically participate in social networks of the future. (See figure 3.)

Figure 3. Life science companies participation in social networks now and in the future

Patients/consumers
- One in three Americans who research their condition online use social networks

Physician and researchers
- 60 percent of physicians are using or are interested in using social networks for professional purposes

Life sciences companies
- 65 percent of surveyed professionals say they are using or have plans to use social networks – 41% say their company has used social networks
The industry is currently looking to the Food and Drug Administration’s (FDA) expected guidelines on social networks use to shed more light on future directions. Regardless, companies now and in the future can choose between three basic approaches to using online social networks: passively collecting information, actively communicating by asking direct questions and pushing out information, or collaborating to produce something of value. (See figure 4).

While social networks help life sciences companies collect information, communicate, and collaborate, online communities can be an attractive tool only to the extent that they add replacement value (making existing processes faster and cheaper) or incremental value (potentially developing new processes and insights). Table 1 highlights cases where social networks are, in fact, improving data collection, communication, and collaboration.

Figure 4. Life sciences manufacturers can use social networks for collecting information, communicating, or collaborating
Table 1. Real world applications and value of social networks

<table>
<thead>
<tr>
<th>Application</th>
<th>Use</th>
<th>Example social network</th>
<th>Replacement value – making existing processes better</th>
<th>Incremental value – adding new insights and processes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Collect Information</strong></td>
<td>Market research</td>
<td>Sermo panels, Medscape Physician Connect, Inspire</td>
<td>Reduces the cost and cycle time of face to face physician and consumer panels</td>
<td>Non KOL physicians offer alternative research insights</td>
</tr>
<tr>
<td>Clinical trial feasibility</td>
<td>iGUARD</td>
<td></td>
<td>Reduces the cycle time of feasibility projections that had been based on epidemiology literature, electronic medical records, and historical experience</td>
<td>Improves the accuracy and allows companies to sample a broad range of potential enrollees that may have been missed</td>
</tr>
<tr>
<td>Pharmacoeconomic research/outcomes</td>
<td>PatientsLikeMe, iGUARD</td>
<td></td>
<td>Replaces phase IV and foundation registries</td>
<td>Identifies patient outcomes that are vital for comparative effectiveness research</td>
</tr>
<tr>
<td>Consumer insight</td>
<td>Inspire, iGUARD</td>
<td></td>
<td>Reduces the time and cost of identifying and gathering information from patients/caregivers.</td>
<td>Represents higher order, authentic feedback from patients/caregivers</td>
</tr>
<tr>
<td><strong>Communicate</strong></td>
<td>Physician relations</td>
<td>Sermo (AskRx), Medscape Physician Connect, Ozmosis, SpineConnect</td>
<td>Reduces the cost of traditional sales force and medical science liaisons. Reduces the cycle time with which physicians receive information necessary for prescribing.</td>
<td>Allows companies to channel information to physicians who are otherwise unreachable by sales force</td>
</tr>
<tr>
<td>Community relations</td>
<td>Inspire, PatientsLikeMe</td>
<td></td>
<td>Direct communication to patients/caregivers about life science company public interest initiatives</td>
<td>Improves communications between life sciences companies and patients; in the case of Inspire, improves foundation, patient, and company communication</td>
</tr>
<tr>
<td>Clinical trial recruitment</td>
<td>Inspire, PatientsLikeMe, CureTogether, iGUARD</td>
<td></td>
<td>Reduces costs of clinical trial recruitment</td>
<td>Can gather feedback on clinical trial protocols</td>
</tr>
<tr>
<td><strong>Collaborate</strong></td>
<td>Compound identification</td>
<td>PD2</td>
<td>Increases the potential number of collaborations</td>
<td>Compound portals such as PD2 open access to novel, lead compounds that may not be found through traditional channels</td>
</tr>
<tr>
<td>Medical education</td>
<td>SpineConnect, Ozmosis, Sermo, Medscape Physician Connect</td>
<td></td>
<td>Reduces the cost of medical education events</td>
<td>Changes the way physicians receive their training and learn about innovative products</td>
</tr>
<tr>
<td>Patient mobilization</td>
<td>Inspire</td>
<td></td>
<td>Reduces need for ad hoc communications and issue ads</td>
<td>Enables better cooperation between companies, foundations, and patients</td>
</tr>
</tbody>
</table>
Collecting data from online social networks

People are individual data stores, and as online social networks link them to each other, people can become part of a dynamic data warehouse. Social networks can be faster, cheaper and higher-fidelity data sources than traditional outlets such as post-market registries, market research panels, and static databases. (See Table 2.) For example, professional networks like Sermo and Ozmosis provide access to practicing physicians’ attitudes and knowledge about current medical practices, lessening the need for traditional market research.19 (See Sermo case study). Patient networks like Inspire, PatientsLikeMe, Curetogether, dailystrength, and MedHelp are rich sources of patients’ insights and clinical data. (See PatientsLikeMe case study). Furthermore, as Craig Lipset, director of clinical research at Pfizer said, “The patient is the ultimate aggregator of information,” so social networks can generate epidemiological and clinical data sets previously dispersed between doctors’ charts, electronic medical records, and oral histories.20 When it comes to collecting data, companies can utilize third party social network vendors such as Inspire, PatientsLikeMe, and Sermo who offer both the data and the analytical assessment to interpret sentiment. In other cases, there are a variety of vendors such as Nielsen or BuzzMetrics who can track data, especially sentiment, across multiple social networks.

Data from social networks may also be more inclusive than traditional sources. For example, Quintiles Inc.21 built iGUARD, an online social network of 2 million people who receive medication alerts and post comments about their prescription drugs. Depending on the condition and the subscribed population, the iGUARD network has the potential to provide a statistically representative sample of people with a particular condition. Using this network, Quintiles can query the iGUARD network to determine the probability of finding specific clinical trial subjects rather than using medical records or historical clinical trial databases. The data allows them to model the pool of available subjects and understand the trade-offs between criteria stringency and enrollment time. (See iGuard case study).

Table 2. Select social network and their data

<table>
<thead>
<tr>
<th>Social network</th>
<th>Description</th>
<th>Research uses</th>
</tr>
</thead>
</table>
| Sermo          | Online network of >100,000 physicians who anonymously post about medical practice and clinical issues | • Quantitative analysis of product mentions and sentiment  
• Physician market research and perspectives through surveys, panels, interviews |
| PatientsLikeMe | Online network of >65,000 patients across 19 conditions who track information in detailed personal health records (PHRs) and then are able to share data with the community leading to aggregated patient data sets | • Health outcomes research  
• Comparative effectiveness research  
• Utilization and adherence research  
• Market research |
| iGUARD         | Online network of 2.2 million users who track medication and receive safety alerts from the network | • Health outcomes research  
• Comparative effectiveness research  
• Utilization and adherence research  
• Market research |
| Inspire        | Online community of >160,000 patient/caregiver members with over 70 partnerships with non-profit foundations | • Clinical trial recruitment  
• Patient perspectives and decision-making  
• Health outcomes research  
• Patient outreach and education |
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With looming patent expirations and drying up pipelines, online social networks could provide access to new ideas, product concepts, and innovations.

Communicating with online social networks

Millions of patients use networks such as Facebook, WebMD, MedHelp, and Inspire to discuss their personal medical conditions, share ideas and experiences, and exchange support. At the same time, thousands of physicians are on Sermo, Ozmosis, SpineConnect, and WebMD discussing new therapies, their perceptions of new products, and the practice of medicine. As life sciences companies move toward patient-centricism, and industry sales forces increasingly lose access to physicians, engaging on social networks offers an attractive solution. One of the difficulties life science companies face, however, is that physicians and consumers are reluctant to engage with companies on social networks. Furthermore, not all social networks are appropriate for communicating everything to everyone all the time – it is important to understand the rules of the road.

First, people tend to reject advertising on social networks, typically turning to this medium for specific, timely information that is otherwise unavailable. Online communities, therefore, are better venues for information than for marketing. Second, timing is everything. This makes social networks relevant during an acute event where uncertainty is high such as crisis situations, difficult-to-solve medical cases, during a new drug launch or indication, or after a patient receives a diagnosis.

Companies should also consider that people behave differently in various online communities. For example, Facebook, typically a recreational venue, may be more useful for fundraising than for discussions about diseases or therapies, whereas patient-activists are more likely to discuss advocacy and treatment in online communities like PatientsLikeMe and Inspire, making them “among the most efficient places on the web for recruiting patients for clinical trials,” according to Craig Lipset.

Finally, people turn to online social networks when they want information from people in similar circumstances, so authenticity is required for companies who are typically not considered trustworthy or peers. Establishing the right kind of chemistry can be as simple as allowing physicians to speak with other physicians and patients to speak with other patients. For example, in response to physician demand, Pfizer and Sermo developed a service called AskRx, which allowed physicians to request scientific information from medically trained Pfizer personnel.

Collaborating with online social networks

Physicians and scientists are exploring ways of collaborating with each other through online social networks to solve cases and improve the practice and science of medicine. An often cited example of this involves the online network Sermo. An ER physician wanted to know how to remove a serrated blade from a patient’s thumb without further damaging tissue and posed the question to the Sermo network. Within hours, the community came up with the answer: use a drinking straw split sideways to lever the blade out of the patient while protecting the adjacent tissue. Collaborating with physicians as they learn from each other through online social networks may make the medical education process required for complex devices and therapies more efficient. In addition, online community physician peer-to-peer learning may be more valuable than the current medical education model based on the industry’s Key Opinion Leaders (“KOL”). With looming patent expirations and drying up pipelines, online social networks could provide access to new ideas, product concepts, and innovations.
Collaborating can be tricky because medical experts typically have good offline networks and need an added incentive to go to an online social network. Syndicom spent eight years trying to integrate their SpineConnect platform into spine surgeons’ daily workflows. Now, because 1600 spine/neuro surgeons are members of SpineConnect, the platform can help medical device companies collaborate with online networks of spine surgeons to improve learning on new devices and methods. For example, companies with new, complex surgical devices are collaborating with spine surgeons on SpineConnect to verify that their surgical customers’ patient selection and case planning are appropriate for selected products. (See SpineConnect case study). By making this service available as part of sales support, companies may determine that their products are used only when likely to be successful.

While not as specialty-specific as SpineConnect, Ozmosis is driving a similar company-physician collaboration model. Through a private and secure knowledge sharing platform, Ozmosis helps companies virtually bring together speakers and key opinion leaders in advance of a drug launch. After launch, when physicians have questions about the new therapy, the larger community can access these experts. According to Joel Selzer, CEO of Ozmosis, “medical education and clinical research is typically done at high cost and with mixed results – Ozmosis can reduce those costs and improve outcomes by reducing needless travel and providing a more collaborative education and knowledge sharing environment.” (See Ozmosis case study).

Social networks may help companies develop new medical treatments. Although a social network of external and internal researchers is not yet a reality, Eli Lilly has achieved the first steps through The Lilly Phenotypic Drug Discovery Initiative, or PD2 portal. PD2 scientists submit the chemical structures of investigational compounds through Lilly’s secure portal, and if a compound is considered novel, they are invited to physically test it against Lilly’s proprietary assays. The scientist gains access to a sophisticated toolkit of laboratory tests, and in return, Lilly has first rights to an exploratory deal on promising compounds.

Although potentially more difficult than physician collaborations, patient collaborations are possible. For example, in the face of changes to Medicare coverage of DEXA (Dual energy X-ray absorptiometry) scans, Amgen, a manufacturer of a potential anti-osteoporosis therapy, and the National Osteoporosis Foundation, worked with Inspire’s osteoporosis community to understand consumer sentiment. The survey was clearly presented as being on behalf of the NOF and Amgen. Despite the presence of a manufacturer, 27 percent of the osteoporosis community responded. Interestingly, 60 percent of respondents said they believed enough in early screening to lobby their representatives, demonstrating how companies can work with foundations to mobilize patients. (See Inspire case study).
Using social networks poses a significant risk in the life sciences industry, where public miscommunication could lead to, at best, regulatory scrutiny, and at worst, patient deaths. On the whole, risks vary depending on the activity in which the company is engaging and the audience of the social networks. Although by no means risk-free, collecting data is one of the least risky activities because most social network users agree to exchange some of their data in return for the free use of a social network. Additionally, privacy can be preserved either by allowing users to remain anonymous or by collecting data from third party social networks that scrub their users’ identities before submitting data to their life sciences’ clients.

Communicating involves significant regulatory risk. The FDA, which tightly regulates many scientific or commercial communications to physicians and consumers, worries that conversation could result in off-label promotion, unfair or unbalanced portrayals of therapy risks and benefits, and failure to report adverse events. Life sciences companies should also consider that communication on social networks is highly public and democratic, which allows small issues to escalate into public incidents. Although companies cannot easily control social networks, they may be held accountable for content, even if it is created by patients or physicians. Furthermore, obtaining FDA pre-clearance for content that may change in real-time introduces a myriad of additional challenges. That being said, communication between doctors and company medical personnel, especially when unsolicited and for the purposes of education, poses less regulatory constraints if it is considered scientific exchange, although safeguards still have to be taken to ensure that the conversation does not become promotional.

Because of the risks of intellectual property loss and the possibility of off label conversations, expert collaborations have to manage the trade-offs between open collaboration and the risks of bringing in everyone. To this end, Sermo allows physicians to collaborate anonymously, but uses proprietary technology to verify physicians’ credentials. Ozmosis suggests that one key to collaborative success lies in disclosing physicians’ names and credentials. SpineConnect lists participants’ names, residencies, fellowships, publications, board certifications, and clinical trial experience.

Given these considerations, the FDA plans to issue clarifying guidelines by the end of 2010, but these will only be guidelines. Half of surveyed industry professionals expect that confusion about how to engage with social networks will persist. Given the shifting nature of social networks, the industry will likely combine regulatory guidance with experimentation. Nearly 60 percent of surveyed professionals who use or plan to use social networks will invest ahead of formal FDA guidance.
Finding value in the networks

Despite the considerable hurdles, surveyed professionals are eager to use social networks, especially as new brands get launched — compared to mature brands, more people associated with new brands (brands launched less than three years ago) plan on using social networks (36.7 percent versus 22.7 percent). (See figure 5).

However, companies must consider how to get value from social networks across the organization, not just as a promotional tool. While the wealth of opportunities is exciting, success is situational and depends mainly on determining objective and audience, the investment strategy, and intelligent risk management.

“For some brands, social marketing makes sense, however, in many cases, a customer-centric website is all the brand really needs,” said Marc Schwartz, director of multi-channel marketing, Established brands at Pfizer. Table 3 highlights some of the ways the life sciences industry can use social networks to meet specific objectives.

**Determining objective and audience**

Though companies could use social networks to collect information, communicate, and collaborate, they should not do so unless they match a business objective and there is an external audience who can both further that business objective and actually want to use a social network. "For some brands, social marketing makes sense, however, in many cases, a customer-centric website is all the brand really needs," said Marc Schwartz, director of multi-channel marketing, Established Brands at Pfizer.
Table 3. Objectives of social networks across the research and commercial organization

<table>
<thead>
<tr>
<th>Function</th>
<th>Objective (audience)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Collect information (from)</td>
</tr>
<tr>
<td>Sales and marketing/medical affairs</td>
<td>• On use of a therapeutic (from consumers and physicians)</td>
</tr>
<tr>
<td>R&amp;D</td>
<td>• On side effects and efficacy (from consumers and physicians)</td>
</tr>
<tr>
<td></td>
<td>• On new targets and compounds (from scientists)</td>
</tr>
<tr>
<td></td>
<td>• On the feasibility of clinical trials (from patients)</td>
</tr>
<tr>
<td>Corporate/ public relations</td>
<td>• About product and company concerns (from consumers, investors, and physicians)</td>
</tr>
<tr>
<td>Compliance/ regulatory</td>
<td>• On incidence and type of adverse events (from patients and physicians)</td>
</tr>
<tr>
<td></td>
<td>Communicate (to)</td>
</tr>
<tr>
<td>R&amp;D</td>
<td>• Clinical trials, and research opportunities and protocols (to physicians and researchers)</td>
</tr>
<tr>
<td></td>
<td>• Clinical trial opportunities (to consumers)</td>
</tr>
<tr>
<td>Corporate/ public relations</td>
<td>• Clinical trial results (to the public and investment community)</td>
</tr>
<tr>
<td></td>
<td>• Crisis updates (to consumers, investors, and physicians)</td>
</tr>
<tr>
<td></td>
<td>• Quarterly earnings and results (to the public and investment community)</td>
</tr>
<tr>
<td>Compliance/ regulatory</td>
<td>• Safety alerts and product recalls (to the public/regulatory agencies)</td>
</tr>
<tr>
<td></td>
<td>Collaborate (with)</td>
</tr>
<tr>
<td>Sales and marketing/medical affairs</td>
<td>• Training sessions on patient selection and case planning (with physicians)</td>
</tr>
<tr>
<td>R&amp;D</td>
<td>• Develop new products (with scientists, clinicians, and consumers)</td>
</tr>
<tr>
<td></td>
<td>• Review research methods and insights (with scientists, clinicians, and patients)</td>
</tr>
<tr>
<td>Corporate/ public relations</td>
<td>• Run clinical trials (with clinicians and patients)</td>
</tr>
<tr>
<td>Compliance/ regulatory</td>
<td>• Report and follow up on adverse events (with consumers, physicians, patients, and regulatory agencies)</td>
</tr>
<tr>
<td></td>
<td>• Report and follow up with compliance issues (with consumers, physicians, patients, and regulatory agencies)</td>
</tr>
</tbody>
</table>

Consumers will use social networks when their healthcare providers can’t sufficiently respond,\(^5^1\) when they feel isolated or stigmatized by their disease, and when, according to Jamie Heywood, chairman and co-founder of PatientsLikeMe, they “wake up every day and think about their condition.”
As for a willing audience, assuming every patient and physician wants to use a social network is shortsighted. Consumers will use them when their healthcare providers can’t sufficiently respond, when they feel isolated or stigmatized by their disease, and when, according to Jamie Heywood chairman and co-founder of PatientsLikeMe, they “wake up every day and think about their condition.” Consequently, patient-directed social networks are centered on high-impact conditions such as cancer, chronic conditions that require injectables, long-term maintenance such as diabetes, or conditions such as depression that carry a social stigma. (See figure 6.) Physicians, especially older ones that are isolated by the demands of their practice, want to use social networks to collaborate with colleagues without intrusion from manufacturers and patients and are more likely stay active on the network if it helps them do their job.

Socially networked people may use multiple networks for different purposes. A good rule of thumb is that people’s purposes on social networks move from recreational to transactional as the information they seek becomes more sensitive and decisions they make become more consequential. (See figure 7.) When people want precise health information from a specific group of colleagues or health peers, their purposes are transactional, and they use specialized communities; 55 percent of consumers go online to research their prescription medication, but only 5 percent use Facebook or Twitter. Despite this, half of surveyed industry professionals indicate they have used or want to use Facebook.

With all of these considerations about objective and audience, companies also need to know if they’ve succeeded. A variety of metrics can help to measure success, including community engagement, new collaborations, information metrics, trial enrollment, cost avoidance, new scripts, and time saved.

Figure 6. Patients use social networks for high impact conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oncology</td>
<td>30</td>
</tr>
<tr>
<td>Endocrinology</td>
<td>25</td>
</tr>
<tr>
<td>Psychiatric and behavior</td>
<td>20</td>
</tr>
<tr>
<td>General health</td>
<td>15</td>
</tr>
<tr>
<td>Inflammation and autoimmune</td>
<td>10</td>
</tr>
<tr>
<td>Rare/and or severe disease</td>
<td>5</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>5</td>
</tr>
<tr>
<td>CNS</td>
<td>5</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>5</td>
</tr>
<tr>
<td>Orthopedic</td>
<td>5</td>
</tr>
<tr>
<td>Ob/gyn</td>
<td>5</td>
</tr>
<tr>
<td>Infectious disease</td>
<td>5</td>
</tr>
<tr>
<td>Allergies/asthma</td>
<td>5</td>
</tr>
</tbody>
</table>

Dedicated social networks on the World Wide Web
Investing for success

Social networks require investment to ensure success (timely and constant content and attention), mitigate failure (neglected networks can be worse than building nothing) and manage ongoing risks (dedicated monitoring and high-level accountability). According to Deloitte’s “Tribalization of Business” study, which looks at social networks across a variety of industries, more than one third of surveyed companies who created their own online communities employed between two and five full time equivalents (FTEs) to run them, and further research suggests that even this is not considered sufficient. However, few surveyed life sciences respondents have a budget for social networks; on average, these companies devote about five percent of their marketing budgets to online communities.

The decision to “buy, build, or borrow” a network ultimately hinges on objective, audience, resources, and risks but it’s probably true that if you build it, they will not come. Given the costs and experience required, life sciences companies should consider buying or borrowing a network by collaborating with or sponsoring a third party network. While brand visibility is lower on third party sites, they have lower startup and maintenance costs and enjoy more trust. In addition, the use of third party networks whose mission is to care and feed communities helps companies avoid building an online ghost town. If companies do decide that it is worth it, either for their brand or because they want to control access to the network or its information, they can consider building a branded network on a proprietary platform or a pre-existing platform such as Facebook.

Companies who wish to collect information may have an easier time buying or borrowing a third party network because collecting social network information typically does not require company or therapy branding. Many third party networks have taken time to carefully cultivate trust among the network. Furthermore, they have the experience to maintain users’ privacy but still preserve the integrity of their insights. According to Brian Loew at Inspire, “we receive requests from companies that want to have a site, but they do not want the responsibility or they do not have the expertise. We are experts in this area and know how to build and moderate a patient community.”
Communicating on social networks is not as straightforward. In some cases, a company may want to establish their own branded voice on social networks. For example, because journalists, analysts, and other media parties already use Twitter in their daily life, companies can typically brand their own presence on this established platform. In other cases a company may want their own communication channel without an external platform’s constraints and so may build their own blog. However, in other cases, when companies want to communicate with patient or physician stakeholders that may already be engaged, working with a third-party social networks may be a better way to meet them on their own turf.

Collaborating on a company-built network helps control information collection and intellectual property leakage, but external collaborations can lose some of their value if brought in-house. Companies can strike a balance by building a secure company branded site on a third party network. For example, medical education collaborations on physician social networks typically involve a company-identified portal where members of the network are invited to participate. This allows companies to collaborate with an external social network but still maintain control.

Managing risk
Companies should manage social network risks pertaining to the enterprise as a whole including finance, technology, brand, reputation, regulatory, and compliance risk among others. Although, different platforms and different investment strategies offer differing degrees of risk exposure, companies should consider that they are participating in forum that is, in essence, difficult to control. Even so, companies do not appear to be establishing clear, written policies – only half of surveyed respondents say they have a social networks policy and 43 percent had no guidelines for managing adverse events that may appear on a social network. 71

![Figure 8. Your own or someone else’s: Density of company branded and third party networks and demonstrated uses
](chart.png)
Oversight needs may also vary depending on the application. Compared to expert collaborations, collecting information from a third party site, may be a relatively lower regulatory-risk proposition but require more alliance management. Communication, on the other hand, requires considerable risk management focused on FDA oversight, brand, and reputation risk. Likewise, governing collaboration may encompass all of the former considerations as well as a watchful eye on intellectual property issues.

Despite the risks, companies want to be flexible enough to start new social network initiatives that accommodate an ever-changing business environment. One way to allow experimentation but retain control is to allow individuals within the company to easily start social networking initiatives within certain guidelines while establishing a small oversight group with the authority to monitor initiatives. As initiatives progress, the oversight group monitors adverse events and measures performance, keeping the initiatives honest while also keeping a close eye on any potential problems. This way, a centralized group provides standards, trains users, and allocates resources but lets people use their judgment to nimbly respond to events on social networks.

In addition, by combining centralized governance with an “options thinking” approach, companies can partially mitigate financial risk. Here the governing body has an option at a pre-agreed point in time to invest or remove an initiative. This limits start-up costs and keeps initiatives small to start. As time goes on, some initiatives will succeed and they can be funded commensurate with their value. Given the rapidly changing state of social networks, some will fail. With regular checkpoints, executives can select for the “fittest” initiatives. Additionally, by centralizing oversight of social networks initiatives, the oversight team can make sure each department benefits from information that comes through these initiatives and therefore increase the total value of each initiative.

Figure 9. Governing survival of the fittest

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Procter and Gamble’s Old Spice “Smell Like a Man, Man” campaign used funny, customer personalized videos and disseminated them on social networks demonstrating how companies can get close to their customers and improve sales. According to *Brandweek*, sales have jumped 55 percent between May and July 2010, and more than 100 percent in the month of July alone – a fact that experts say closely correlates to their use of social networks.73

The chances of the life sciences industry finding similar commercial success using this model are less likely. Life Sciences companies manufacture complex products and are subject to strict guidelines on how they can approach their customers. Furthermore, patients and physicians use social networks to inform decisions that have higher impact than the choice of consumer goods. This raises the stakes considerably on company engagement.

But, social networks do have value since the life sciences industry needs information from people, people need information from the industry, and the industry needs to collaborate outside their walls. Online social networks of physicians, patients, and scientists offer companies an unprecedented opportunity to collect information, communicate important information, and collaborate externally. Some of this is happening right now in the industry. (See figure 10.)

**Figure 10. Demonstrated and emerging industry social network use**

<table>
<thead>
<tr>
<th>Target</th>
<th>Collecting information</th>
<th>Communicating</th>
<th>Collaborating*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Industry analysts/public/media</strong></td>
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<td></td>
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<tr>
<td>1</td>
<td>Company Twitter</td>
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<td>2</td>
<td>Company Blog</td>
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<td>3</td>
<td>IGUARD</td>
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<td>4</td>
<td>Inspire</td>
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<tr>
<td>5</td>
<td>PatientsLikeMe</td>
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<td>6</td>
<td>Sermo</td>
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<td>Medscape physician connect</td>
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<td>8</td>
<td>Ozmosis</td>
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<td>9</td>
<td>SpineConnect</td>
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<td>10</td>
<td>PDsquare**</td>
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*While almost all 3rd party social networks collaborate with their stakeholders this figure documents instances where companies are collaborating with the network.

**Because it is currently a one-to-one portal PD squared does not meet the strict definition of a social network.

1. Twitter’s real-time aggregation of news and current events makes it useful in times of crisis and for journalists and analysts
2. During the May Tylenol recall, the BTW blog posted their CEO’s letter of apology and received comments from parents
3. Companies that are clients of Quintiles can leverage iGUARD, a network of 2 million patients to optimize clinical trial protocols
4. Companies such as BMS, Amgen, and Pfizer are working with INSPIRE communities to collect patient information, learn from the communities, and recruit of clinical trials
5. Companies like UCB and Novartis are sponsoring communities to understand patient reported outcomes. PLM also offers a service where companies can interact with patient advocates.
6. Companies are using Sermo’s market research offerings to collect information in an asynchronous format. Sermo’s AskRx pilot demonstrated pull communication capability
7. Companies can track sentiment analysis across the community and start discussions. Physician connect is also experimenting with company blogs
8. Companies are working with Ozmosis to open speakers privately trained on the Ozmosis platform to the broader Ozmosis network
9. Lilly is working with academic scientists to increase innovation and collaborate on new drug development initiatives
As regulatory clarity emerges and more companies innovate with social networks, these tools have the potential to underpin business development, clinical trials, research, human resources, marketing, medical affairs, and other strategic parts of the life sciences value chain. The technology is new and the uncertainty is high, so tomorrow’s disruptive innovations might look different than today’s increments. Flexibly investing with an options approach gives organizations a “multiple shots on goal” strategy and the flexibility to adjust as the landscape shifts.

Until the future rolls around, executives are tasked with taking advantage of today’s realities. The mature organization will likely know the social networks relevant to their business units and have ways of linking them to their business strategies. They can then understand how to measure various initiatives, how to govern, remain compliant, and stay flexible. Less mature organizations should consider the risks and exposures and whether they should have some presence on social media, for example a rapid feed account (such as Twitter) and an automated report of their company’s mention on social networks by using what are known in the social media world as “listening platforms.”

Even if companies and their constituents do not harmoniously exist on many social networking platforms, the industry and the public can and should still interact on these communities. According to one executive in a major global pharmaceutical company “we should be on social networks because it is our duty to give the public information about their medicine. Our responsibility is to make sure we give them all the information we have.”
Social networks can help companies execute market research cheaper and faster.

Example: Life sciences companies can conduct in-depth research using Sermo’s online panel approach
- Acquiring first-hand knowledge from physicians is typically a slow, expensive process for life sciences companies.
- Brand teams want actionable data on demand.

Social networks and applications
Sermo, an online network with over 100,000 medical practitioners, offers physicians a place to speak to other physicians confidentially. Companies can use a Sermo Panel to conduct market research. Because the discussion takes place over several days, questions can be followed up on and doctors can participate in off-peak hours.

“Market research is a tremendous opportunity. You can wrap up research in a week or two and it costs only a fraction of what traditional market research normally costs.”
– Len Starnes, Head of Digital Marketing and Sales, General Medicine, Bayer Schering Pharma

Learnings and potential impact
- Conducting research via online panels allows flexible and asynchronous feedback – companies can revise content and add questions based on the conversation.
- Fast and inexpensive data from social networks leads to increases in the iterative cycle of questions and answers leading to better understanding of a topic.
- Panel output can be compared to community-wide sentiment analysis and a quantitative survey can be used to gain additional insight.
- Frequent iterations can lead to a higher breadth of research and faster decision-making.

Social networks can help companies determine the right patient reported outcomes.

Example: Using PatientsLikeMe data, a biotechnology company can better analyze real world efficacy of its injectable
• A biotechnology company that has the leading therapeutic in a highly competitive chronic disease area is trying to understand patient reported outcomes and progression across all classes of therapies.

Social networks and applications
• PatientsLikeMe is a site that hosts over 65,000 members who suffer from severe conditions such as Amyotrophic lateral sclerosis, Epilepsy, Multiple Sclerosis, and others.
• The site allows patients to input their data, track progress over time and share experiences.
• The availability and the openness with which data is shared allows patient reported data to be aggregated and has even enabled patient-led observational studies.

Learnings and potential impact
• By surveying the entire patient community across therapies, the potential partner can understand and quantify patient viewed, real world differences in safety and efficacy of currently marketed therapies.
• The potential partner can work with PatientsLikeMe to add data input functionality to the desired community and determine what the right parameters are for measuring comparative effectiveness.
• Ultimately, the results could end up in a peer reviewed publication.
• This pilot, if pursued, has the potential to define comparative effectiveness outcomes and help determine meaningful patient centered outcomes.

“By understanding how patients are using and faring on their products, life sciences companies can truly become patient centric.”
– Jamie Heywood, Chairman and co-Founder, PatientsLikeMe

Social networks can provide data to speed up clinical trials.

**Example: Quintiles can leverage their subsidiary social network, iGUARD, to speed up clinical trial recruitment**
- Quintiles’ client was conducting a Phase III trial in treatment resistant depression that, due to slow enrollment, was delaying filing and registration.
- The client needed to understand the factors that were delaying recruitment and adjust inclusion/exclusion criteria to improve enrollment without compromising the therapy signal to noise ratio.

**Social networks and applications**
- iGUARD is a patient/consumer network of over 2 million patients with a diverse array of conditions who use the network to track their medications and pose questions to each other.
- Using this network, Quintiles was able to poll a sample of patients with treatment resistant depression and ask them to fill out a patient reported depression rating scale.

**Learnings and potential impact**
- A large, dynamic network is useful to obtain customized data and can result in findings that would have taken more time and money using electronic health records, historical databases, or paper-based surveys.
- Within three days, surveying the network showed that the inclusion criteria was rejecting 95% of the treatment resistant depression population.
- Additionally, by using the full distribution curve, Quintiles could perform a sensitivity analysis revealing that a slight adjustment in criteria could increase recruitment eight fold.
- Using this analysis, the company and Quintiles was able to increase enrollment 5-10 fold in less than two months.

“We do not need a lot of engagement to meet our objectives and we don’t expect a lot of intensity. When a patient registers for iGUARD and they get an alert, we have a 40 percent response rate over patients that have not had an alert.”

— Hugo Stephenson, CEO iGUARD

“With a large enough network we can start to ask questions that we were never able to ask before, like how does a 2pt change in a rating scale change recruitment feasibility.”

— Hugo Stephenson, CEO iGUARD
Social networks can engage physicians to help improve the adoption of new products.

Example: Because SpineConnect’s specialized surgical network is extensively used by spine surgeons, it can help companies collaborate with peer-to-peer learning and improve product adoption

- NuVasive wanted to increase the adoption of their new minimally invasive XLIF associated technology through peer-to-peer training that reached the broadest group of spine surgeons.

Social networks and applications

- Syndicom’s SpineConnect is a 1,600 spine surgeon’s a specialized collaborative social network.
- Physicians will participate in a network if it integrates with their workflow and provides access to experts and data across the globe.
- NuVasive and Syndicom launched a private discussion group focused on training surgeons on XLIF, which evolved into SpineConnect’s Technology Fellowship program where experienced surgeons train 5-6 fellows through instructional cases and online surgeries.

Learnings and potential impact

- An online learning environment that provides access to experts and data, and also bridges geography, can potentially improve the adoption of new products.
- Adoption rates may be contingent on physicians’ patient selection and case planning. According to Syndicom sponsored research, fellowships and virtual collaboration improves adoption by 30 percent compared to traditional models.

“Adoption is slow unless surgeons feel confident. Failure comes from poor patient selection and poor case planning – [SpineConnect] helps connect surgeons to experts that can help.”

– Scott Capdevielle

Social networks can help companies facilitate peer-to-peer learning.

**Example: Companies can coordinate pre-launch education and post-launch peer-to-peer learning on Ozmosis**

- Life sciences companies with a product in development can use social networks as an inexpensive, inclusive and compliant way to facilitate peer-to-peer education and collaboration around upcoming product launches

**Social networks and applications**

- Ozmosis, a provider of knowledge management solutions, operates a general practice physician network composed of verified physicians who share knowledge and clinical experiences with each other on a social network platform.
  - HCP
  - Profiles
  - Social
  - Search
  - Micro-Blogging
  - Activity Feeds
  - Web Meetings
  - Networking

- The Ozmosis platform can be used to host private sites to educate and train key opinion leaders and speakers before new product launches.
- Post launch, selected healthcare professionals (including Ozmosis physician members) can be invited to participate in a clearly identified learning community with trained peers.

“Create private, virtual networks to enhance collaboration and increase interaction all at a lower total cost.”

— Joel Selzer, CEO Ozmosis

**Learnings and potential impact**

- Successful programs on the Ozmosis platform require:
  - Each trained physician to verify their identity and disclose affiliations;
  - 3-6 month lead time to organize content, prepare experts, schedule live events and secure medical/legal approvals;
  - Client resources to support community moderation, answer clinician questions and submit content for discussion.

“Our goal is to accelerate the adoption of new products by ensuring that education and training takes place in a more timely and effective manner for all parties.”

— Joel Selzer, CEO Ozmosis

Sources: Deloitte Research Interviews, Ozmosis website
Social networks can help companies mobilize patients by collaborating with medical foundations.

**Example: Amgen worked with the National Osteoporosis Foundation (NOF) and Inspire’s patient communities to mobilize patients to lobby for access to early bone density screening (DXA)**

- Because Amgen was developing an osteoporosis treatment Denosumab, Amgen’s Government Affairs department needed to understand patient sentiment about Medicare DXA cuts and DXA access.

**Social networks and applications**

- Inspire is a diverse community of over 190 groups covering conditions such as oncology and osteoporosis. The site draws in over 1.4 million unique posts and 500,000 unique visitors monthly. Seventy of these groups collaborate with leading health organizations like the NOF, and are connected by conditions such as cancer, osteoporosis, and diabetes.
- Amgen worked with the NOF and Inspire to develop a survey to understand patient sentiment.
- The survey was sent out with disclosure of the sponsors and their purpose.

**Learnings and potential impact**

- The survey was sent to 2,000 members and had a 27% response rate.
- A significant portion of respondents said they would be willing to connect with their representative regarding their opinion on DXA scan access.

**“They see this as an opportunity to work with the non-profit foundations and a good way to strengthen ties”**

– Brian Loew, CEO Inspire.com

“**The key lesson is that if a pharmaceutical company is transparent, it can engage patients.**”

– Brian Loew, CEO Inspire.com
Endnotes


2 Companies like Dell, Starbucks, and Proctor and Gamble are using them to improve their brand, company reputation, and get their customers’ feedback. Dell hosts a blog, Dell2Dell and a collaborative social network called IdeaStorm to improve customer service, Starbucks’s MyStarbucksIdea has solicited thousands of customer ideas for improvement and is seamlessly linked to branded Facebook and web pages. Procter and Gamble has a centralized social media hub that engages stakeholders in research and development of new and existing brands.

3 There are many different ways to define an online social network. According to the Journal of Computer-Mediated Communication, social networks are “web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system.” Others may define bulletin boards and forums as social networks. However all definitions involve a group of people, shared content, and a single meeting place.


6 “Life Sciences Professionals Social Networks Survey Findings,” Deloitte Research, July 2010. To supplement qualitative findings, Deloitte surveyed life sciences industry professionals who are involved in marketing and/or compliance and risk management to get attitudes and behaviors relating to social network use in the industry. 208 people employed in the pharmaceutical, biotechnology, medical device, and diagnostics industries were recruited between June 22, 2010 and July 6, 2010 to take part in a web-based questionnaire. Professionals with marketing and compliance and risk responsibilities were selected based on their company’s core business and their day-to-day roles, and then asked to self describe their title and function. Respondents were categorized as “marketing” or “risk management” based on degree to which they were involved in brand management and risk and compliance in their day-to-day jobs. The web based questionnaire consisted of 35 questions about the use and perceptions of social networks in their company and business units and was divided into a section focused to marketing professionals and a separate section focused to risk management professionals. All 208 were asked demographic questions and then asked about their plans to use social networks. 72 respondents had no plans to use social networks and were terminated. The rest of the questions focused on the 136 people who indicated that they either used or had plans to use social networks either in their company or in their business unit. All 136 were asked questions related to risk and compliance however, 102 people involved in brand management were asked specific questions about specific strategy and use of social networks.

7 Based on our executive interviews, there has been a significant increase in interest at the Life Sciences company C-suite and board level in social networking in the last 12 months. In one global organization, the CEO got interested and is mandating global effort to train senior managers and above on social networking.

8 According to Doug Black, Executive Director of Strategy Development Group, Merck & Co., Inc., “The adoption of social networking as a channel of communication will be slow in our industry. We take great care to communicate within regulatory guidelines and to engage in exacting product surveillance. It is unclear how those business requirements will be consistent with the admittedly less formal nature of social networking communication.”


According to Clay Shirky, professor at New York University, author of “Here Comes Everybody: The Power of Organizing Without Organizations” and “Cognitive Surplus: Creativity and Generosity in a Connected Age,” the business model in general is changing across industries as well as in the Life Sciences industry: “Social networks isn’t detailing and marketing. It’s really the use of networks to get smart people to fix pharma problems.” Len Starnes, Head of Digital Marketing and Sales, General Medicine, Bayer Schering Pharma believes that social networks may have a transformative effect on the industry: “Social networks have broad applicability: patent cliff, decreased ROI on sales force, and the drying pipeline.”

Social networks can be both internal and external to the company – this study focuses on the use of social networks to engage with external stakeholders.


“FDA: internet ad guidance is coming,” Medical Marketing & Media 1 May 2010. For a full list of FDA concerns that may be addressed in pending guidelines, see “Promotion of Food and Drug Administration-Regulated Medical Products Using the Internet and Social Media Tools; Notice of Public Hearing,” Federal Register: September 21, 2009 (Volume 74, Number 181)

For example, because of its price and access to physicians on demand, Sermo allows brand managers who might ordinarily conduct market research through focus groups and physician panels to conduct quick initial studies online and rapidly add follow-on physicians’ market research.

According to Lipset, work still needs to be done to compare patient reported data to traditional methods such as electronic medical records (EMRs) and physician solicited questionnaires.

A contract research organization that runs a significant number of industry trials.


Among surveyed physicians, 60 percent are interested in using social networks for professional purposes, and approximately one out of every six U.S. physicians are members of Sermo – Manhattan Research, Taking the Pulse v9.0, Sermo website About us http://www.sermo.com/about/introduction accessed April 2010.

Several top companies are trying to move toward patient centricism. For example, UCB recently announced it was moving to become more patient centric (“UCB accelerates transition to become patient-centric global biopharmaceutical leader with decision to exit the primary care market in the U.S.” Press Release 29 January 2010), and Pfizer is changing its clinical trial structure to do so.

In 2009, doctors willing to see pharmaceutical sales representatives decreased by 20 percent while the number of doctors who refused to see any sales representatives increased by 50 percent, according to ZS Associates 2010 AccessMonitor report.


“Facebook Takes a Dive: Why Social Networks Are Bad Businesses,” Time 1 April 2009, furthermore interviews conducted with executives at patient and physician social networking sites confirm that the advertising model is unsustainable.

“Communication works best when there is an event that requires substantial new information like a drug launching,” according to Daniel Palestrant, CEO of Sermo and “by the time patients see their doctor their particular case is individualized and static web pages are no longer useful - that is when they turn to social networks.” according to Hugo Stephenson, CEO of iGUARD.
For example, an ER physician posted a question on Sermo.com asking how to remove a serrated saw from a patient’s hand and received advice from a multitude of physicians, including the selected answer: use a longitudinally cut straw to “shoehorn” the blade out — McGuire, Stephen “MM&M: All Stars Media Brand of the Year: Sermo” Medical Marketing and Media 1 January 2008.

According to Clay Shirky, social networks are an active medium and people will reject messages on social networks that they may passively accept over television, radio, print, and the internet. Echoes Jonathan Richman, author of the blog “Dose of Digital” and director of Strategic Planning for Bridge Worldwide, “Some marketers want to broadcast messages on social networks the way they would use television, but, with a few exceptions, regardless of how many fans or members, social networks will never be as good a broadcast medium as you want it to be because people can talk back”. Instead of messages from companies, people are looking for information and opinion from their peers. Deloitte’s State of the Media Democracy Survey, 4th Edition, details that 55 percent of US consumers agree with the statement that “online consumer reviews and ratings influence my buying decisions more than any type of online advertising.”


An analysis of the top Facebook pages in oncology and cancer showed that the “I bet I can find 1,000,000 people who hate cancer fan page” had over one million fans whereas a group page entitled “’Gleevec’ or ’Glevec’—the drug that saved me” had less than 200 members.


According to one study, traditional physician social networks, typically constructed around academic influencers and “Key Opinion Leaders” are not as useful for improving adoption of a new product as social networks constructed around “sociometric” influencers, or physicians identified by the community based on practice rather than reputation. These results suggest that physicians depend on their self-identified peers for the use of new products more than “KOLs” and academic experts — Iyengar, Van den Bulte, Valente “Opinion Leadership and Social Contagion in New Product Diffusion,” The Wharton School University of Pennsylvania 9 January 2010.

“No Refills” The Atlantic July/August 2010.

According to Scott Capdevielle, CEO and founder of Syndicom, “we have so many fellowship groups who use SpineConnect for their training because fellowship directors can create a SpineConnect group and train the community without having to personally answer every case that comes their way.”

According to Capdevielle, “It is very difficult to get a spine surgeon’s attention; it takes a lot of investment, but if you can connect physicians with experts in their fields, and you can help them get their work done, you can facilitate the conversation and understand what they need.” Follows JD Kleinke, a Syndicom investor, “the original network all trained with each other using the traditional social network, but what drives it after that is the platform.”

These numbers are according to Syndicom, who estimate that this represents 65 percent of the U.S. market.

According to SpineConnect, 11 percent of patients selected for new procedures are not indicated, which can lead to an unfavorable experience with a new product, slowing its uptake.

Ozmosis is a provider of social powered knowledge management solutions that helps U.S. licensed and verified physicians learn from and connect with colleagues they trust. Ozmosis offers client companies products that leverage both the social network and the knowledge management platform and therefore can help with both external and internal social networks.

In order to comply with medical education regulations, all company trained peer educators are identified as such.

“The FDA has signaled its readiness to crack down not just on social networks, but also internet search, by issuing 14 warning letters to companies whose Google search ads were considered unbalanced because they promoted the therapy without giving equal weight to the potential side effects, Nature Biotechnology 27, 405 (2009) doi:10.1038/nbt0509-405.
For a full list of FDA concerns that may be addressed in pending guidelines, see “Promotion of Food and Drug Administration-Regulated Medical Products Using the Internet and Social Media Tools; Notice of Public Hearing,” Federal Register: September 21, 2009 (Volume 74, Number 181).


“FDA: internet guidance is coming,” Medical Marketing & Media 1 May 2010.

For example, Novartis received a warning letter from the FDA regarding its Facebook share widget for Tasigna. According to the FDA, Facebook users who share the widget were sharing misleading information because the widget “makes representations about the efficacy of Tasigna but fails to communicate any risk information associated with the use of this drug”. Part of the reason for the misleading information is because the widget only displays a small portion of what is called metadata, text embedded into a website that is visible to search engines but not most viewers. The FDA action against Novartis has set a precedent where all content; including metadata, should be shared with the FDA prior to dissemination.”


According to Hugo Stephenson, CEO of iGUARD, a medication tracking social network, “people turn to [online] social networks for specific information when they have a problem their health care provider cannot answer.”

Joel Selzer, CEO of Ozmosis and Daniel Palestrant, CEO of Sermo, both said their members tend to be older and removed from their training peers. Ozmosis addresses the “specific pain going from a collaborative environment in their residency to their practice where they are seeing patients 24/7 and have limited interactions with peers.”

According to Daniel Palestrant “as the model evolves, Sermo is looking to move from things that doctors want to things they need, and from the recreational to the vocational” in order to increase and retain membership.

Deloitte Research Catalogue of Life Sciences Social Network Sites: Social networks existing by therapeutic areas as of Spring 2010 were determined as follows: Based on a sample of life sciences relevant social networking sites, to understand the totality of social networking activities that impact life sciences companies, and who was driving them, we surveyed the World Wide Web for social networks that met the following criteria: (1) Relevant to the use of therapeutic agents/med devices (typically networks about a condition which has a prescription, or in some cases, an OTC medical therapy) (2) English speaking (3) contain content that the audience can create or modify AND/OR that allows the audience to engage (with others and/or the sponsor) through their associated interest in the content (e.g., Youtube channels). Social networks created on a unique platform (for example Sermo or UCB’s community “Chronsandme”) and pre-existing platform networks such as Facebook, Twitter, and YouTube were considered.

Each distinct Facebook page, Twitter feed, and YouTube channel was counted as a separate network. In some cases, a network was counted as a single network even if split by therapeutic area (e.g. PatientsLikeMe has 18 separate communities) because it is sponsored by one distinct company and has one single landing page.

As a check for exhaustion, the list was cross checked against a common list of healthcare and pharmaceutical social media site – the “Dose of Digital Pharma and Healthcare Social Media Wiki” (http://www.doseofdigital.com/healthcare-pharma-social-media-wiki/ accessed May 15, 2010). Despite the cross checks and key word searches, there are no assurances that all sites were captured and are subject to change over time.

According to Nowell Outlaw, founder of FacetoFace Health, his typical user turns to the site immediately after a diagnosis and is thinking “all I want is to speak to someone who has lymphoma like me — e.g., same diagnosis, same care pathway and ask them how they fared, and I do not want to go to WebMD. If I go to a message board, it takes a long time before people reply or the right people because health care is not a hobby.” According to both Joel Selzer, CEO of Ozmosis and Daniel Palestrant, CEO of Sermo, activity on both physician social networks spiked during the flu pandemic.


Deloitte Research Analysis.

In some cases, industry executives want to know if the community is working. According to Starnes, “Ahead of ROI there are KPIs that measure engagement such as number of members, numbers of posts, number of links, and types of questions.”
1/3 of executives say that getting people to engage and participate is one of the biggest obstacles to social networks in business, which in turn, depends on fresh content and active discussions. – Moran, Edward “The 2009 Tribalization of Business Study,” 2009 Deloitte Beeline Labs and the Society for New Communications Research.

According to Colin Foster, director of social media at Novartis, teams that build or sponsor a social network have to have the ability to commit resources to an endeavor that should last far longer than the particular team. “Brands will create a program for 6–12 months and turn over without thinking how to sustain the community — this has potential to make the community angry and destroy value.”

Many companies require social networking initiatives to be approved by director level personnel, and in some cases, the CEO of the business unit signs off on new social networking initiatives.


“In addition to executive interviews which suggested that home grown sites are difficult to establish from both a content, popularity, and a risk perspective, other Deloitte work has shown that attempts to move an existing community to a company branded site has not in the past not work. For examples of companies that have fallen victim to the “build it and they will come” myth, see p 192-195, Gossieux, Francois and Edward Moran. “The Hyper-Social Organization: Eclipse Your Competition by Leveraging Social Media,” New York: McGraw Hill 2010.

According to Nowell Outlaw potential users often pose a familiar question before joining: “Who owns your site,” and they ask for the same reason: “if it is an insurance company or a pharmaceutical company, I do not want them to have our information.” In addition, the 2010 Deloitte Consumer Survey showed that manufacturers are one of the least trusted sources of information about treatment efficacy and side effects. “2010 Survey of Health Care Consumers: Key Findings, Strategic Implications,” Deloitte Center for Health Solutions, May 2010.

“Twitter is about news, not social media,” Information Week 5 May, 2010.

Deloitte Research Catalogue of Life Sciences Social Network Sites (see above for methodology).

“Life Sciences Professionals Social Networks Survey Findings,” Deloitte Research, July 2010; however for risk questions, used a subset of individuals who said they were responsible for managing risk on social networks (n=40).


“Old Spice Campaign Smells Like a Success, Too,” Brandweek 25 July 2010.

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