



Please note that this archival material was published under Enspektos' former corporate identity.

For more insight and information on a range of health marketing communications-related topics, please visit our educational initiative, the Path of the Blue Eye Project at www.pathoftheblueeye.com.

Envision Solutions Spotlight

Achieving Openness:

**The Art Of Listening, Learning, & Communicating
With People Using Social Networks For Health & Wellness**

RIGHTS AND USE STATEMENT

Envision Solutions, LLC is licensing this content under the Creative Commons License, Attribution 3.0 (<http://creativecommons.org/licenses/by/3.0/>).

Please feel free to use material in this report in blogs, podcasts, presentations, and other content.

You may also e-mail it to your colleagues and others you think will benefit from it.

ABOUT ENVISION SOLUTIONS, LLC

Envision Solutions, LLC is a full-service healthcare marketing communications consulting firm. The company provides innovative products and services to not-for-profit and for-profit organizations. Its core competencies are in the areas of analysis, strategy, training, and content development.

Please visit www.envisionsolutionsnow.com for more information about the firm, or call (212)-501-6101.

CONTENTS

INTRODUCTION	4
I. SOCIAL NETWORKS AND HEALTH: THE CURRENT LANDSCAPE	9
II. FOUR COMMON SOCIAL NETWORK COMMUNICATIONS STRATEGIES	16
III. PREDICTING THE IMPACT OF TWO-WAY DIALOGUE WITH SOCIAL NETWORKERS	40
IV. THE FIVE GOLDEN RULES OF EFFECTIVE SOCIAL NETWORK COMMUNICATION	49
CONCLUSION	65
REFERENCES	66
ACKNOWLEDGEMENTS	67

INTRODUCTION

In 1995, a groundbreaking book appeared by the late Tom Ferguson, M.D., *How to Find Health Information, Support Groups, and Self-Help Communities in Cyberspace*, which provided useful information on how to use the Internet effectively for health-related purposes.[2] Ferguson recognized the Internet was filled with individuals, or “e-patients,” eager to share information and advice on a range of health topics.¹ Using tools such as e-mail and online bulletin boards, these e-patients forged powerful social networks that provided encouragement, support, and practical advice to Internet users.

Today, nearly 15 years later, the Internet has become our most important source of health information.

¹ [Wikipedia](#) defines e-patients as “health consumers who use the Internet to gather information about a medical condition of particular interest to them.”

A Note About Terminology

We define social networks as technology that enables people to collaborate quickly, share information, and learn from others via the Internet. Online forums and listservs were early examples of tools that helped people forge strong social networks online. This report focuses on newly emerged social network sites that combine a range of technologies, including chat services, e-mail, and site-specific tools, such as Facebook [applications](#).

According to a January 2008 study by the digital marketing firm iCrossing, 59% of U.S. adults reported going online to find health content.[4] Technology has been a major reason the Internet has grown in influence. Many people are employing “social” technologies such as blogs, wikis, and online bulletin boards to access health content that is being developed and vetted by their peers.

In addition, people are using social networks. Like the online bulletin boards and listservs that preceded them, social networks are helping people efficiently connect with others around the world.

Health is a major topic on popular social networks such as MySpace (www.myspace.com) and Facebook (www.facebook.com). In addition, health-centric online communities, such as TuDiabetes (www.tudiabetes.com), and Daily Strength (www.dailystrength.com) are growing in popularity. In general, social networks are quickly becoming major destinations for people seeking to find and share health information online.

Medical professionals are also using social networks. For example, PRESENT Diabetes (www.presentdiabetes.com) is a diabetes-focused social network and educational platform for researchers, nurses, and other health professionals. In addition, Sermo (www.sermo.com) and

iMedExchange (www.imedexchange.com) are two examples of physician-only social networks. Doctors are using these sites to collaborate, discuss clinical practice, and forge personal and professional bonds.

As social networks have increased in importance, a range of corporations, non-profit groups, and government agencies in the healthcare industry have begun to consider them a valuable platform for

- Communicating about health topics
- Leveraging the collective wisdom of consumers and health professionals to understand current and future trends in clinical practice, drug safety, and other issues better

Unfortunately, many health organizations are still uncertain about how to communicate effectively with people using social networks. We have developed this report to help the health industry to

- Understand how consumers and professionals are using social networks for health and wellness
- Learn the four major communications strategies health organizations are currently using to communicate with, and learn from, social networkers
- Benefit from first-hand commentary from social networking experts from a number of health organizations, including the Centers for Disease Control and Prevention (www.cdc.gov), TNS Media Intelligence/Cymfony (www.cymfony.com), PatientsLikeMe (www.patientslikeme.com), Sermo and Ignite Health (www.ignitehealth.com)

- Develop an evidence-based strategy for engaging in successful two-way social network dialogue

Navigating This Report

This report is organized into four sections:

I. Social Networks And Health: The Current Landscape

We present a brief overview of how social networks are being used for health and wellness .

II. Four Common Social Network Communications Strategies

We outline four strategies health organizations are using to communicate with, and learn from, social networkers. We also present commentary on each strategy from a range of social networking experts.

III. Predicting The Impact Of Two-Way Dialogue With Social Networkers

We present the results of a study that indicates that engaging in two-way dialogue with social network users can improve relationships with key stakeholders.

IV. The Five Golden Rules Of Effective Social Network Communication

We propose five "golden rules" that health organizations can follow to communicate successfully with social network users.

Topics This Report Does Not Cover

There are many issues related to social network communications that are outside the scope of this report. The most important include

- **Legal And Regulatory Issues:** Health organizations must understand and overcome the legal obstacles to effective social network

communications. This is especially true for highly-regulated companies in the life sciences industry.

- **Privacy:** Many consumers are unaware about the privacy implications of participating in health social networks. Search engines such as Yahoo! and Google regularly index content published on some social networks. As online health expert John Grohol, Psy.D. has noted, "Consumers aren't even always aware of this trail of health bread crumbs they're leaving around the Internet and are surprised when they learn it's been connected to their real life identity." [5] Health organizations should fully understand how privacy issues will influence their communications efforts before engaging social networkers.

Achieving Openness: A Brief Guide

Looking to get started communicating with people using social networks for health and wellness? The most important advice featured in this report appears below.

Listening Should Be The First Step



People using social networks for health purposes are seeking to achieve specific goals. Before communicating with an online community, listen first. Understand why people are participating in the online community and how they expect “guests” or outsiders to behave. See **Part IV** for more.

Let The Evidence Guide You



Many marketers want to know whether engaging in two-way dialogue with people using social networks is worth the effort. The evidence outlined in **Part III** of this report indicates that it is. Let this study, other data, and your instincts guide your social media communications efforts.

The Tortoise Often Wins The Race



Successful social network communications requires extensive planning. It may also take a while to bear fruit. Remember to start slow and remain patient. **Part II** provides information that will help you plan a communications initiative; **Part IV** explains why patience is a virtue.

I. SOCIAL NETWORKS AND HEALTH: THE CURRENT LANDSCAPE

According to a 2008 iCrossing report, 6% of people who go online for health information use social networks.[4] While the young are the most active users of social networks, the networks are also frequented by a significant minority of older Americans. A study conducted by ThirdAge and JWT BOOM in 2008 indicates that 22% of U.S. Internet users 40 and over use social networking Websites.[6]

In addition, research suggests that some people with medical conditions are active users of social networks. For example, a 2007 study by Forrester Research indicates that 15% of people with a medical condition have used a social network.[7]

According to Nielsen Online, MySpace and Facebook received the most number of unique visitors in September 2008. (See **Table 1.**)

Table 1: Top Ten U.S. Social Networking Sites (September 2008)

Social Network	Unique Visitors September 2008 (in millions)
Myspace.com	59,352
Facebook	39,003
Classmates Online	17,075
LinkedIn	11,924
Windows Live Spaces	9,117
Reunion.com	7,601
Club Penguin	4,224
AOL Hometown	3,909
Tagged.com	3,857
AOL Community	3,079
Source: Nielsen Online	

Because of their popularity, MySpace and Facebook are being used by a number of organizations for health communications purposes. For example,

- New Mexico AIDS Services (NMAS) (www.nmas.net) has developed a [MySpace page](#) focusing on HIV/AIDS education. According to NMAS’s Joey Torres, the page reached more than 200 people a month in March 2008.[8]

- In 2007, General Mills partnered with Ellen Degeneres and Susan G. Komen for the Cure, a breast cancer non-profit organization, to launch [PinkTogether](#). This MySpace-based campaign aims to raise awareness about breast cancer and to provide an online community for caregivers, patients, and others impacted by the disease. The site features stories of breast cancer survivors, their families, and friends. Site users can also connect and learn from other women impacted by the disease.
- The U.S. Department of Health and Human Services (HHS) has launched a Facebook group focusing on HIV/AIDS. HHS's AIDS.gov Facebook site has become a rich source of disease-related information from the agency and dozens of other individuals and organizations. An image of HHS's Facebook group appears in **Figure 1**.

Figure 1: AIDS.gov Facebook Page, November 2008



Health-Focused Social Networks

Over the past several years, dozens of health-focused social networks have appeared online. All of these sites provide users with opportunities to connect with, collaborate with, and learn from a range of people, including patients and health professionals. The most successful social networks meet the key needs of online health consumers. The three most important are

- **Accurate online health information.** Most Americans begin their search for online health content using Google and Yahoo![7] Because these sites deliver confusing or inaccurate results, there is a great need for online tools to help people quickly locate highly-relevant, high-quality health information.

- **Connecting with “people like me.”** Online health consumers sometimes pursue connections with those they can relate to from a personal, professional, or situational (i.e., caregivers’, widowers’, new parents’) perspective.
- **Quality health providers and safe medications.** Many with medical conditions (or those caring for them) need unbiased and accurate online information about health providers and drugs.

Figure 2 illustrates how eleven health-related social networks meet the key needs of online health consumers.² See below for more information about each site.

² It is important to recognize that many social networks provide tools that meet multiple needs of online health consumers. For example, PatientsLikeMe (www.patientslikeme.com) helps users connect with others and learn about prescription drug efficacy.



Figure 2: Common Needs Health-Related Social Networks Are Designed To Meet



- **Accurate Online Health Information**

Healia (www.healia.com): Healia is a health-focused online search engine. In March 2008, the company launched Healia Connections. According to Healia, this free service “enables people to get personal support for their health decisions from peers and experienced health professionals.” On Healia, peer-generated content is provided alongside high-quality search results.

OrganizedWisdom (www.organizedwisdom.com): OrganizedWisdom is a “human-powered search engine” that uses consumer and expert editors to highlight and locate quality health and medical content.

WEGO Health (www.wegohealth.com): WEGO Health is a social network that features online health content organized and researched by health experts and its online consumer community. The

site also features blogs, online bulletin boards, and forums organized by health topic.

- **Connecting To People With Similar Personal And Professional Needs**

PatientsLikeMe (www.patientslikeme.com): This social network provides technologies patients can use to connect to others with similar medical conditions. The company reports that it has also introduced an evolving platform that consumers, academic leaders, and industry leaders are using to research real-world experiences with prescription medications.

Inspire (www.inspire.com): Working with a range of health organizations, including the Arthritis Foundation (www.arthritis.org) and the Lung Cancer Alliance (www.lungcanceralliance.org), Inspire builds online communities for patients,



caregivers, and others impacted by disease.

Sermo (www.sermo.com): This physician-only social network has more than 90,000 members. The company reports that doctors “exchange clinical insights, observations, and review cases” on the site.

Nurse Link Up (www.nurselinkup.com): This social network provides nurses with the opportunity to connect with their peers.

Strength for Caring (www.strengthforcaring.com): Sponsored by Johnson & Johnson, this social network features caregiving-related content, expert blogs, and online communities.

Disaboom (www.disaboom.com): This social network for people with disabilities features a number of resources, including forums and groups.

- **Finding High-Quality Providers And Safe Medications**

Health Care Scoop

(www.thehealthcarescoop.com): This social network is produced by the non-profit group Consumer Aware, a holding company of Blue Cross Blue Shield of Minnesota. The site features user ratings of hospitals and health professionals.

iGuard (www.iguard.org): iGuard is an online community providing users with real-time feedback on common (and unusual) drug side effects. Information about drug risks is communicated using a proprietary color-coded system.

The eleven social networks highlighted above represent only a small fraction of sites that cater to the various needs of patients, caregivers and medical

This is because companies such as Ning (www.ning.com) have given people the ability to engage in “do-it-yourself” social networking. With Ning, anyone can quickly create a social network on any topic, condition, or issue. For example, TuDiabetes (www.tudiabetes.com) is a popular Ning-powered health social network.

Although the market is fragmenting, health companies, non-profit groups, and government agencies have been experimenting with ways to engage people using social networks. In **Part II**, we outline four major communications strategies these organizations are currently using.

II. FOUR COMMON SOCIAL NETWORK COMMUNICATIONS STRATEGIES

As discussed in Part I, consumers and health professionals are turning to social networks in increasing numbers. This is partly because many sites are fulfilling some of their key informational and social needs. Evolving social networks have the potential to become powerful communications channels for organizations in the health industry.

Because of this potential, many health industry stakeholders have been watching the evolution of social networks with great interest. However, the majority have been reluctant to communicate with social networkers directly because they are

- Unwilling to risk generating negative feedback or commentary from social network users

What Does Engagement Mean?

Forrester Research has defined engagement as "the level of involvement, interaction, intimacy, and influence an individual has with a brand over time." [1]





- Uncertain about how social network communications efforts will be regulated – this is especially true for marketing executives in the life sciences industry
- Having difficulty determining whether a social network engagement effort will generate sufficient return on investment

Despite these obstacles, some health organizations have begun to experiment with various communications strategies designed to inform and influence people using social networks. We have loosely grouped these approaches into four areas (See **Figure 3**):



- **Broadcast.** Delivering messages to large groups of social networkers via advertising campaigns or other techniques such as sponsorships
- **Research.** Tapping into the collective wisdom of social networks to gain insights about clinical outcomes, shifts in prescribing patterns, attitudes or perceptions, and other topics
- **Seeding.** Creating or mobilizing online communities by
 - Developing a customized social network (Organizations engage in direct dialogue with community members or simply provide a place for people to congregate online.)
 - Leveraging social network tools such as Facebook and MySpace applications.
- Information about MySpace applications can be found [here](#).
- Click [here](#) to learn about Facebook's applications.
- **Conversation.** Participating in two-way dialogue with social network users (This can occur on custom-designed or well-established online communities.) Organizations commonly engage in two types of conversation:

Figure 3: Four Commonly Used Social Network Communications Strategies

Strategy	Description	Engagement Level
 <p>Broadcast</p>	<p>Delivering messages to broad segments of social network community via advertising or other techniques</p>	<p>Low</p>
 <p>Research</p>	<p>Gathering outcomes or other health-related data from a social network community</p>	<p>Moderate</p>
 <p>Seeding</p>	<p>Mobilizing or creating online communities around specific issues, disease states, causes, or health transactions</p>	<p>Moderate → High</p>
 <p>Conversation</p>	<p>Engaging in two-way "corporate" or "personal" dialogue with social network community members</p>	<p>High</p>

- **Corporate.** Dialogue (sometimes anonymous) is largely confined to issues relating to organizational initiatives, current events, and announcements. In some cases, there is overlap between research and corporate style communication. Organizations will sometimes ask questions designed to capture current opinion on health-related issues such as clinical practice or new research studies.

- **Personal.** Conversation is highly personal (i.e., organizational representatives identify themselves to social network users). Organizations engaging in personal dialogue often

- Inject themselves into ongoing conversations about issues of concern to the organization
- Provide direct responses to specific questions or observations posted by community members
- Actively participate in ongoing dialogue – often responding to both positive and negative feedback

Organizations often use different communications strategies simultaneously. For example, a corporation may conduct research by commissioning a survey on a particular health issue and engage social networkers in two-way corporate-style dialogue regarding it.

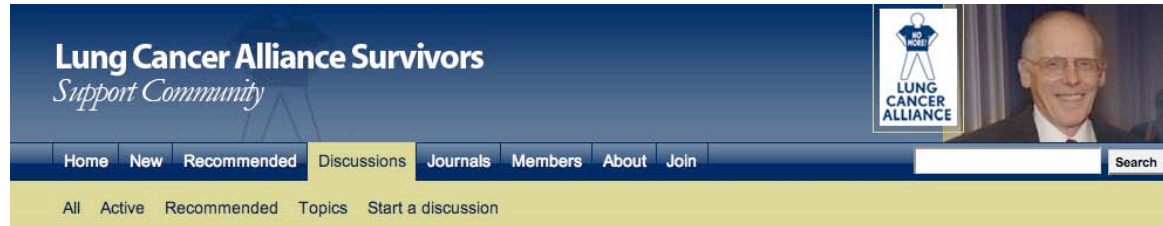
What Does Corporate-Style Conversation Look Like?

Corporate conversation: Often anonymous dialogue that is confined to events, initiatives, news, or other organization-related topics. See below for an example of corporate conversation from a social network produced by Inspire (www.inspire.com) for the National Osteoporosis Foundation (www.nof.org). (Inspire develops health-related social network communities for a variety of non-profit and for-profit organizations.)

The screenshot shows the 'National Osteoporosis Foundation Support Community' website. The header includes the organization's name and logo, along with a navigation menu (Home, New, Recommended, Discussions, Journals, Members, About, Join) and a search bar. Below the header, there are filters for 'All', 'Active', 'Recommended', and 'Post a journal entry'. The main content area features a journal entry titled 'Advocacy Training Meeting in Arizona—Open to Everyone to Attend' by 'Osteo Staff Journal', posted on May 12, 2008. The entry text describes an invitation to an advocacy training meeting in Tempe, AZ, on June 6th, 2008, hosted by the National Osteoporosis Foundation (NOF) and the Arizona Osteoporosis Coalition. The entry has 0 recommendations and includes buttons for 'Recommend' and 'Print'. To the right of the entry, there is a 'You' section with buttons for 'Start a discussion', 'Post a journal entry', 'Meet others like you', and 'Update your profile'.

What Does Personal-Style Conversation Look Like?

Personal conversation: Highly personal (i.e., first-person) conversation with social network users. An example of personal-style dialogue in a Lung Cancer Alliance (www.lungcanceralliance.org) affiliated social network appears below. This community is maintained by Inspire.



I'm noticing some new faces. :-)



By [amymaura](#)
Posted March 28, 2008 at 10:55 am · 9 replies
In [Good news](#)

Greetings!

I have been noticing some new faces recently on posts - and clicking on people's profiles, I see that many people have joined recently. So I went back to my Team Inspire emails, and added up day by day how many new members are registering in our community. So far, since the new site launched, 78 people have registered for the LCA Survivor's Community.

So I just wanted to welcome the new members to our community! You will find that this community will bring you more strength, warmth and hope than you could have imagined. The people in this community inspire me every day to do my job here at LCA, and to do it the best I possibly can!

Best wishes to everyone, and happy Friday. :-)

Amy

2

Recommendations

[Recommend](#)

[Print](#)

You

[Start a discussion](#)

[Post a journal entry](#)

[Meet others like you](#)

[Update your profile](#)

Degrees Of Engagement: From Arm's Length To In The Fray

As illustrated in **Figure 3**, different communications strategies require varying levels of interaction with social network users.

- **Broadcast** and **research** activities allow organizations to communicate with, and learn from, social network users at arm's length or with limited one or two-way conversation (i.e., low to moderate engagement).
- **Seeding** and **conversational** strategies require organizations to be more closely involved with a social network community. For example, those creating a customized social network will have to monitor it closely and may have to respond to community requests directly. (This could require moderate to high engagement).

Organizations engaging social network users choose their communications strategies based on their comfort level and objectives. This is because

- **Sometimes it makes sense to keep one's distance.** Often, health organizations decide they want to reach people using a social network but do not think it is appropriate to insert themselves into ongoing community dialogue. In these situations, using a broadcast communications strategy may be the optimal course of action.
- **Unfiltered real-time intelligence is valuable.** For companies seeking insight and information on health products, services, and issues from social network users, becoming a visible part of the conversation may harm research efforts.

- **Influencing opinion or behavior may be the key objective.** Some organizations may seek to defuse a crisis or improve their standing with key influencers. Achieving these goals often requires a personal touch.

For real-world examples of each communications strategy in action, please see **Tables 2 through 5**.

Table 2: The “Broadcast” Communication Strategy At Work

Social Network (URL)	Description
PRESENT Diabetes (www.presentdiabetes.com)	PRESENT Diabetes features diabetes-related content and conversation on its medical professional-targeted social network. A number of corporations display banner advertisements on the site, including Pfizer and Novo-Nordisk.
TuDiabetes – <i>Word in Your Hand Project</i> (www.onetouchdiabetes.com/sharing/index.html)	<p>In September 2007, Manny Hernandez, founder of the diabetes social network TuDiabetes (www.tudiabetes.com), initiated the <i>Word in Your Hand Project</i> for World Diabetes Day. Hernandez asked TuDiabetes’ members to submit photos with one-word descriptions of their feelings about diabetes. Users submitted more than 120 photographs for the project.</p> <p>LifeScan, manufacturer of the OneTouch blood glucose meter, partnered with TuDiabetes to expand the impact of the project. Currently, LifeScan is using images from the initiative in a OneTouch-related marketing campaign that launched in April 2008.</p> <p>Visitors to the OneTouch Website are directed to a page focusing on <i>Word in Your Hand</i> and TuDiabetes. Click here to view the OneTouch Web page.</p> <p><i>See below for commentary from Hernandez on Word in Your Hand and LifeScan’s support of TuDiabetes.</i></p>

Building A Sustainable Diabetes Social Network

Manny Hernandez, Founder, TuDiabetes.com

Manny Hernandez is the founder of the fast-growing diabetes social network TuDiabetes. See below for his thoughts on why TuDiabetes has grown so quickly and how organizations can partner with social networks like his to "broadcast" their messages in innovative ways.

Q1: Why did you decide to launch TuDiabetes?

A1: First, I have diabetes. Second, I had been a Web Product Manager and Community Specialist for many years. (See his profile on the business-focused social network LinkedIn [here](#).) By the end of 2006, I wanted to apply the concept of social networks to something beyond socializing. I eventually focused it on diabetes, given the emotional and physical connection I have to it.

Initially, we envisioned having an organic community where some people would "hang out" in English and some in Spanish (hence the name, in part). But in spite of the fact that some conversations did start in Spanish, the interface was in English and this left out Spanish-only speakers. Therefore, we waited a bit and started a second community that we also run today called EsTuDiabetes, where the conversations and the interface are both in Spanish. That community is a bit smaller (close to 500 members, as of June 2008), but it's very much as alive as TuDiabetes.com.

Q2: As your social network grows, companies may be interested in having banner advertisements published on TuDiabetes. Would you be interested in this type of marketing activity, or are you searching for a company willing to play a larger role in the community?

A2: We are working on a comprehensive fundraising plan. While we are not discounting traditional banner ads as an option for now, most likely we will be exploring first getting sponsorships and donations from our community. Most likely, there will be more than one sponsorship going on, unless a VERY big one comes along – however, we are very focused on diversifying our funding sources.

Q3: LifeScan's licensing of *Word in Your Hand* is very interesting and goes beyond buying advertising space on TuDiabetes. What attracted you to the OneTouch marketing campaign?

A3: We were approached by LifeScan in February 2008 at the Diabetes Expo in San Francisco. The project caught their attention (they found out about it through YouTube) as a very human and universal way for people to speak about their feelings on diabetes, and they wanted to incorporate it into their [marketing] campaign.

Building A Sustainable Diabetes Social Network

Manny Hernandez, Founder, TuDiabetes.com

A3 (continued): We thought they were a good match as a partner because of how much our members knew them and used their products. Also, Johnson & Johnson (LifeScan, the manufacturer of OneTouch, is a J&J company) is a very well-known and respected trust-mark. The company's [credo](#) contains numerous elements with which we can easily identify.

Ultimately, our mission at the [Diabetes Hands Foundation](#) (the non-profit group we started to run both TuDiabetes and EsTuDiabetes) is "to provide an open space for people touched by diabetes to connect with others in pursuit of a healthy life through support, information, and creative expression." Partnering with LifeScan around *Word in Your Hand* (WIYH) enables us to further our mission by giving the WIYH program more exposure and getting us closer to our vision of a world where people with diabetes no longer feel alone. (For more information about the LifeScan-TuDiabetes partnership, please [click here.](#))

Q4: What lessons have you learned from the OneTouch partnership that you will be applying to future sponsorship opportunities?

A4: We learned five main lessons from the OneTouch partnership:

1. We became more familiar with how these partnerships are developed, since we knew close to nothing about this before. We also learned about these partnerships in the context of the non-profit world, which is a very different environment from the for-profit space.
2. We learned to be patient. Although things moved very quickly, they never went as fast as we expected.
3. We learned that it is important to have good legal counsel when working out the details of a partnership. We got outstanding legal advice from Cobalt LLP (www.cobaltlaw.com), a firm based out of Berkeley.
4. We confirmed that being a small operation does not mean we can't offer something valuable.
5. Finally, we learned that dreams do come true, and that it is important to dream and dream big. If you settle for less, you are leaving opportunities on the table.

Table 3: The “Research” Communication Strategy At Work

Social Network (URL)	Description
<p>Sermo (www.sermo.com)</p>	<p>Sermo is a social network with more than 90,000 physician members. The site is only open to doctors.</p> <p>Sermo has developed several technology platforms that enable organizations to conduct primary research within the social network. The most important are</p> <ul style="list-style-type: none"> ○ HotSpots: Physicians using Sermo are presented with the opportunity to answer organization-developed survey questions about specific clinical topics. (Doctors can also earn continuing medical education credit for learning about specific treatment strategies.) ○ Market Research: Organizations can post questions (and associated surveys) within Sermo on various medical treatment-related issues. ○ Physician Panels: Organizations can invite physicians to participate in intimate online panels to glean further insight into treatment practices and opinions.

Table 3: The “Research” Communication Strategy At Work (continued)

Social Network (URL)	Description
<p>PatientsLikeMe www.patientslikeme.com</p>	<p>PatientsLikeMe is a social network that provides tools consumers can use to connect to people with a range of medical conditions. A key feature of the site is the rich data patients are sharing about their experiences with diseases and specific medications. Organizations are conducting a number of research-related activities on the site, including</p> <ul style="list-style-type: none"> ○ Custom Surveys: Organizations are fielding surveys on PatientsLikeMe to help them understand users’ perceptions and experiences with drugs and disease. Responses are linked to detailed anonymous data on the safety and efficacy of specific medications. ○ Clinical Trial Recruitment: Pharmaceutical companies are beginning to communicate with PatientsLikeMe’s users about ongoing clinical trials. For example, Novartis asked members of the online community to consider participating in FREEDOMS II, a trial of an experimental oral multiple sclerosis medication. ○ Online Focus Groups: Companies have conducted small focus groups with PatientsLikeMe members to determine whether their medications are effective in real-world settings. <p><i>See below for commentary from PatientsLikeMe’s Benjamin Heywood on research-focused social network communications.</i></p>

Leveraging Social Networks To Accelerate Clinical Research

Benjamin Heywood, CEO, PatientsLikeMe

Benjamin Heywood is CEO of PatientsLikeMe, a health-focused social network that encourages users to share information about their experiences with a variety of medical treatments, including pharmaceuticals. He shares his ideas on the value of social networks and how health organizations can benefit from research conducted in sites like PatientsLikeMe.

Q1: Unlike many social networks, PatientsLikeMe does not accept advertising. Why did the company make this decision, and how does PatientsLikeMe generate revenue?

A1: That's true; we have chosen not to pursue an ad-based business model right now. We want to preserve the sanctity of our user experience, and we think that advertising can dilute that. Our revenue model is different from most social networking sites because we're different. We're more of a personal medicine platform that uses social networking functionalities to drive health data-sharing.

That said, PatientsLikeMe generates revenue by taking the information patients share about their experience with disease and selling it in a blinded, aggregated, and individual format to our partners (i.e., companies that are developing or selling products to patients). Because we believe in transparency, we tell our members exactly how we make money, including what we do and don't do with their data.

Q2: Why is it valuable for patients to share treatment-related data with each other?

A2: By sharing personal health data (such as treatments and symptoms), our patient members are illuminating great ideas and new knowledge about how their diseases act in the real world. There's both immediate and long-term value for patients in sharing this information. First, patients can immediately find others just like them by searching by specific treatment regimen details, including dosages and side effects (as well as symptoms, demographic, and other disease-specific characteristics). Additionally, they can learn how to improve their own quality of life by engaging in dialogue about specific data.

The long-term value, and our hope as a company, is that patient-driven data that will change health outcomes, speed up the pace of research, and help fix an inefficient healthcare system.

Leveraging Social Networks To Accelerate Clinical Research

Benjamin Heywood, CEO, PatientsLikeMe

Q3: How does the community correct inaccurate or harmful data?

A3: We have many systems in place to correct inaccuracies, with the emphasis on allowing our community to self-monitor. The most powerful is that you can drill down on every piece of information entered, right back to the patient providing it. This way, there's real accountability at the individual level, and it creates a great self-regulating ecosystem where members identify inaccurate information.

We are also implementing a validation system that asks patients to verify unusual treatment dosages, including those outside of the approved range by the FDA. This will help to not only validate patient supplied information, but also educate patients about the medication they're taking.

All of that said, there's a real balance to strike with assessing data accuracy in a community such as PatientsLikeMe - sometimes seemingly inaccurate outlier data ends up as the most clinically interesting.

Q4: Why do you feel life sciences companies, government agencies, and other organizations should view social networks such as PatientsLikeMe as valid and valuable sources of research on the real-world safety and efficacy of medications?

A4: I can't speak for other social networks, but PatientsLikeMe is specifically designed to help people create better outcomes for their diseases. Because our data collection methodology is based on the answers to clinically and/or functionally valid rating scales (and thus mimics that of clinical trials), our outcomes data captures the real-world course of each patient's disease over time.

When that information is shared within the community, patients can learn how to create the best outcomes and improve their quality of life. When that information is aggregated, it becomes the largest repository of real world outcomes ever in every disease we enter. What research group wouldn't want access to that extensive data set? Additionally, our upcoming treatment evaluation system will focus specifically on the perceived safety and efficacy of medications, giving even more insight into what patients believe are affecting their quality of life.

Leveraging Social Networks To Accelerate Clinical Research

Benjamin Heywood, CEO, PatientsLikeMe

Q5: What tips – especially those regarding privacy – do you have for organizations considering conducting research-related communications activities with people using social networks?

A5: We recommend that each organization read the conversations that people are having on these social networks. The prospect of collective knowledge driving better outcomes is why these people spend hours sharing information with each other. Many of these patients are activists, those who want to drive change, and even participate in clinical trials. The communications, therefore, must address the changing landscape of healthcare and appeal to patients' desire to become more involved with all aspects of the system. The companies that pursue this approach will earn the respect and trust of patients.

Table 4: The “Seeding” Communication Strategy At Work

Social Network (URL)	Description
Facebook – <i>The Pink Ribbon Application</i> (http://apps.facebook.com/pinkribbon)	<p>In September 2007, Susan G. Komen for the Cure launched the Pink Ribbon application on Facebook. Members of the social network were asked to download the application to raise awareness about breast cancer and support Komen.</p> <p>As of May 2008, more than 3 million people had added the Pink Ribbon application to their Facebook profile.</p> <p>The application helped to seed an active and engaged community of Facebook users who promised to help educate others about breast cancer.</p> <p>Members of the Pink Ribbon Facebook group regularly exchange information about their cancer experiences and other topics.</p>
eDrugSearch.com (www.edrugsearch.com)	<p>Launched in January 2007, this San Antonio-based company helps consumers purchase prescription medicines safely online. In February 2008, the company introduced a social network.</p> <p>eDrugSearch.com has benefited greatly from the social network. Most importantly, its customers are spending more time – and purchasing more medications – from the company because of its online community.</p> <p><i>See below for commentary from eDrugSearch.com’s founder Cary Byrd about the benefits of “seeding” a social network.</i></p>

Seeding A Health Social Network To Educate And To Boost Sales

Cary Byrd, Founder, eDrugSearch.com

Cary Byrd, founder of eDrugSearch.com, is on a mission to help consumers save money on prescription medications. Recently, he started a social network that has increased users' engagement with eDrugSearch and significantly increased company revenues. The following are his thoughts on the benefits of seeding a health social network.

Q1: Purchasing drugs online is currently a controversial topic in the United States. Given this, why did you decide to create a Website designed to make it easier to acquire drugs via the Internet?

A1: We started eDrugSearch.com specifically to address the problems associated with buying drugs through the Internet. We wanted to create a safe haven for consumers – a place where they know the pharmacies have proper home-country licensing and third-party accreditations.

One problem has been illegal online pharmacies. There are a lot of rogue pharmacies out there – as you can readily see every day when you check your e-mail, and your spam folder is full of solicitations to buy Viagra and Xanax. Chasing these illegal operations down has been difficult for the U.S. Food and Drug Administration (FDA). It's like policing anything over the Internet – very difficult.

In addition, many mistakenly believe that ordering your Lipitor from a licensed Canadian pharmacy is somehow not as safe as buying it from a licensed U.S. pharmacy. This perception is inaccurate.

eDrugSearch.com has stepped into this controversy to try to clear up the confusion and offer a simple solution – a safe haven where you know the pharmacies have been through a 10-point pre-screening process. You know you don't have to worry about that question. And, that frees you to focus on saving money, which is why you're shopping online in the first place.

I should add that, in addition to the problem of rogue pharmacies, there are obviously consumers out there who are looking to use the Internet to buy prescription drugs illegally – without a prescription. The problem of teenagers illegally purchasing drugs online has gotten a lot of attention – and rightly so. It's a very real problem. But you can't blame the Internet for this, any more than you can blame the highway for traffic accidents. And you can't blame legitimate pharmacies, either.

Seeding A Health Social Network To Educate And To Boost Sales

Cary Byrd, Founder, eDrugSearch.com

Q2: With the health social network universe expanding rapidly, why did it make sense for eDrugSearch to create another one?

A2: It makes sense because the universe IS expanding rapidly – not only in the number of social networks, but also in the number of consumers who incorporate these tools in their lives. We think smaller and smaller niche networks are a natural progression.

As I said in a [byline article](#) on the Health 2.0 blog, an estimated 150 million Americans sought health-related content and services on the Internet in 2007. According to a recent Harris poll, 71 percent of U.S. adults use the Web to search for health information – a number that continues to rise. Prescription drug consumers, in particular, have shown significant interest in blogs and social networks. They relish the opportunity to share their experiences – and their frustrations – with one another.

As pointed out in a white paper produced by Cymfony, Envision Solutions and Seyfarth Shaw in 2007, one reason for the popularity of blogs, forums, and social networks among drug consumers is that they don't trust the information they are getting from pharmaceutical companies.[3] They don't trust DTC advertising. They don't trust the FDA. They don't even trust their doctors quite as much, because relationships with personal physicians just aren't what they used to be 10 or 20 years ago. It's become more transactional – 15-minute appointments, and you better ask all your questions fast before your doctor's out the door.

In this environment, a social network for prescription drug consumers such as the eDrugSearch.com community can fill a very important need. And we're already seeing a very positive response since we launched the community in February 2008.

Q3: How has eDrugSearch benefited from “seeding” a social network for its customers?

A3: The eDrugSearch.com community has generated a big increase in the amount of time visitors spend on the site. Before we launched our social network, most of our visitors bought some - but not all - of their medications through us. We're beginning to form stronger relationships with our members – where they don't just search for a drug and leave. Now, they check out all the features of the site; they really get to know us. One result of this is that more of our members are choosing to order all of their medications through eDrugSearch.com.

Seeding A Health Social Network To Educate And To Boost Sales

Cary Byrd, Founder, eDrugSearch.com

Q4: What are the questions health organizations should ask before deciding to start a social network given how difficult it is to attract users?

A4: The first question I'd ask is, "What will my social network have to offer that others don't?" The second is, "How will it benefit my organization if it is successful?" And the third is, "Am I ready to commit to this for the long haul?" Social networks are trendy at the moment, but the reality is, once you start one, it's a long, hard slog – and not particularly glamorous. You should attempt to measure the expected benefits against the time and resource commitments – which you shouldn't underestimate.

Q5: What about organizations who are unwilling to create their own social network? How can they go about encouraging the growth of online communities in areas they care about?

A5: This is actually a much better way to get started than to just jump in and launch your own social network. When you first move into a new neighborhood, you probably don't want to immediately throw a party – because no one knows you, and that means no one will show up. Wait until you've met the neighbors, gotten the lay of the land, figured out what nights work best for people, and then throw your party. It's the same thing online. So it's a great way to test the waters before starting a social network.

But you certainly don't need to start a social network to have an impact. For most health organizations, a better route is simply to support the communities that healthcare consumers have developed around specific illnesses, interests, or concerns. Become an advertiser, sponsor an event, answer questions – and most importantly, listen. Patient advocates can be your advocates, too, if you are really committed to putting the patient first.

Table 5: The “Conversation” Communication Strategy At Work

Social Network (URL)	Description
Inspire (www.inspire.com)	<p>Inspire develops customized health social networks for organizations seeking to engage in direct communication with their stakeholders. The majority of Inspire-produced online communities were created for non-profit groups.</p> <p>Organizations engage in a mix of “corporate” and “personal” style communication to</p> <ul style="list-style-type: none"> ○ Deliver important content ○ Mobilize key stakeholders ○ Influence attitudes and behavior ○ Allow people with similar interests to connect with each other <p><i>See below for commentary from Brian Loew, CEO of Inspire, on the promise and pitfalls of the conversation-style communication strategy.</i></p>

The Promise Of Two-Way Dialogue With Social Network Users

Brian Loew, Chief Executive Officer, Inspire

Brian Loew is a co-founder of Inspire, a company that has developed numerous customized social networks for a range of health organizations. As he discusses below, Loew believes there is much to be gained by engaging in two-way dialogue with social network users.

Q1: Inspire creates customized social networks for various health organizations. Why do you think there is so much interest in creating an online community from scratch, rather than using existing technologies, such as Facebook?

A1: It's a depth-versus-breadth question. There seem to be a few reasons why health organizations desire to have their own, subject-specific online community. To begin with, they want to create a safe and secure environment, where relevant, private health data can be shared. Facebook is great for many things, but many people do not feel comfortable discussing very personal health-related matters in a forum like Facebook. Branding is a key influencer as well: many health organizations want their brand to be in the forefront; Inspire-developed groups preserve their brand. Advertising is another issue. Many health organizations are uneasy about ads appearing in their environment, particularly ads that they have no control in choosing. On Facebook, this control is lost.

Although online social networks have been around for a few years, most health organizations have been slow to embrace these technologies. Many health organizations are risk-adverse to begin with and are not typically known as early adopters. Nevertheless, health organizations know that they need to enter the world of social networks, so many of them are looking for tools to do so. Many of these organizations do set up groups in Facebook and MySpace, but those broad-based groups typically complement the health-specific groups they create with Inspire or other social networks.

Q2: Many organizations are very leery of engaging in two-way "conversation" style communications with social network users. What's holding them back?

A2: Offering a platform for two-way conversation between an organization and its constituents can be a great thing, but it can also be a double-edged sword in the minds of many health organizations. Occasionally, conversations are negative, and health organizations are wary of opening themselves up to criticism by their constituents. In addition, many organizations see two-way conversations as a loss of control.

The Promise Of Two-Way Dialogue With Social Network Users

Brian Loew, Chief Executive Officer, Inspire

Q3: What are the pros and cons of engaging in “corporate” versus “personal” style communication with social networkers?

A3: We have seen some of our health organization partners engage in both “corporate” and “personal” communications with their community members. The corporate method is useful in conveying information about an organization, such as upcoming events, fundraising, and advocacy. We have observed that using a corporate tone does not always promote two-way conversation. On the flip side, we have seen that when a representative of an organization engages in a more personal style of communication, there is greater interaction from community members, and it is usually positive. To really maximize the use of this personal style, an organization needs to invest some time and effort. We have seen that doing a half-hearted job risks antagonizing and disenfranchising constituents.

Q4: What are the major benefits and drawbacks of engaging in conversation with social network users; is it worth the time and effort?

A4: It is most definitely worth the time and effort! The time and effort needed also depends on the size of the community and its activity level. One benefit of engaging in conversation with your community members is that you learn what those members truly care about, what their concerns are, and what they think of your organization and services. If your organization is ready to receive this feedback, you can use the information to better your services. Engaging in conversation also helps community members feel that they play an important role in making a difference and that there is someone listening to them. The drawback, of course, of engaging in conversation with your community members is that you learn what those people truly care about, what their concerns are, and what they think of your organization and services. If your organization is not ready for this information, it may be difficult to hear what people think.

The cat is out of the bag. Although there are benefits and drawbacks to engaging in conversation with members of social networks, people are going to have these conversations whether an organization is involved or not. It is up to an organization to decide whether they want to be part of the conversation, and to help shape it. What we have discovered is that forward-thinking organizations are quite happy they jumped into the fray: they're learning from their stakeholders, they're helping more people, and they're building stronger bonds than they ever have before.

Some Experts Urge Organizations To Engage In Two-Way Conversation With Social Networkers

For many marketers, the broadcast communications strategy will seem very familiar. Most are well aware of advertising's impact and are comfortable with it, partly because it has well-established metrics. However, some social networking experts believe that engaging in broadcast-style social network communications will not yield maximum benefits. Steve Rubel, an executive at Edelman Public Relations and prominent blogger, is one of them. He argues that "static advertising is no longer viable." He believes "collaboration" is the key to long-term social network communications success.[9]

If Rubel is correct, organizations will have to use communications strategies that require them to engage deeply with social network users. However, as noted above by Brian Loew of Inspire, corporations and non-profit groups are afraid to move down this path.

This may be because they are unsure whether engaging in two-way dialogue with social network users is worth the risk.

In **Part III**, we provide the results of a study indicating that communicating deeply with social network users can result in more positive and productive relationships with key stakeholders and influencers.

III. PREDICTING THE IMPACT OF TWO-WAY DIALOGUE WITH SOCIAL NETWORKERS

In **Part II**, Brian Loew of Inspire (www.inspire.com) outlined some of the benefits of two-way dialogue between health organizations and social network users. He notes that social networkers can provide a wealth of valuable information – if one is willing to cede some control over the conversation.

Although this is sound advice, many health organizations have been reluctant to take it. This is because they are

- Accustomed to maintaining tight control over all communications
- Wary of being exposed to negative commentary
- Unsure how social networkers will react to attempts to engage in two-way conversation

Despite these uncertainties, a number of health industry players, including Pfizer (www.pfizer.com), the American Medical Association (www.ama-assn.org) (AMA), and the Lung Cancer Alliance (www.lungcanceralliance.org) have decided to engage social network users directly. Pfizer and the AMA have been conducting conversations with users of Sermo (www.sermo.com), a physician-only social network. The Lung Cancer Alliance (with the assistance of Inspire) has been actively building and participating in a growing online community of patients, survivors, and caregivers.³

These initial efforts demonstrate that a number of health organizations are more than willing to cede some control over their communications activities and risk being exposed to negative commentary. However, what could these activities tell us about how

³ Inspire produces social networks for a variety of health organizations, including the Lung Cancer Alliance.



social networkers are reacting to efforts by these organizations to engage in two-way dialogue?

To answer this question, Envision Solutions conducted an analysis of discussions between health organizations and people using Sermo- and Inspire-produced social networks. We found that organizations engaging in personal-style dialogue with social networkers were much more likely to have positive and productive interactions with people using these online communities.⁴ See below for more information about this study.

Study Description And Methodology

Between January and March 2008, Sermo and Inspire provided Envision Solutions with access to conversations between eight health organizations and physicians, patients, and caregivers using both social

⁴ See Part II for a definition of personal-style social network communications.

networks. Two types of interactions were analyzed: posts and responses. (See **Table 6** for a description of both conversation types).

Table 6: Description Of Conversations Analyzed In Sermo And Inspire

Conversation Type	Description
Posts	Posts developed by health organizations for social network users.
Responses	Responses by health organizations to ongoing conversations taking place between social networkers.

As outlined in **Figure 4**, we selected 48 Sermo/Inspire-based conversations for analysis because these interactions generated responses from online community users. Each conversation was divided into two categories: personal and corporate. (Please see Part II for a description of personal and corporate-style dialogue.)

Overall, the types of personal conversations conducted by organizations using Sermo and Inspire were very similar. However, there were some differences in the corporate interactions, because market research is a major activity within Sermo. Seven of the 22 corporate conversations analyzed for this study were requests from health organizations using Sermo for physician insight about clinical trials and medical practice.

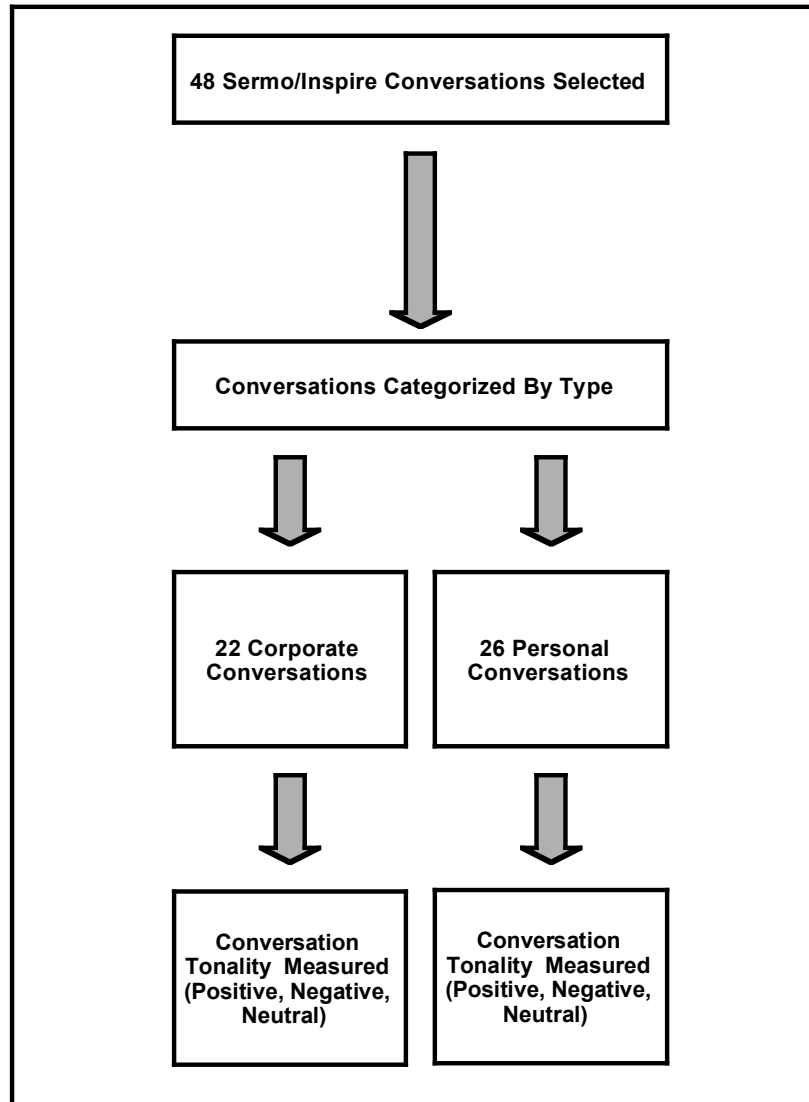
We then analyzed the tonality of each conversation and organized them into three categories:

- **Positive.** The overall conversation was generally positive in tone. In some cases, the dialogue shifted from sharply negative to positive after the community received a (usually personal) response from a health organization.

- **Neutral.** The overall conversation was neither overly positive nor negative in tone. Responses to posts tended to be factual (e.g., in the case of Sermo, some organizations focused on clinical issues).
- **Negative.** The conversation was generally negative in tone; in other words, social network users
 - Launched attacks against the organization or its personnel
 - Complained about an organization or its policies

To aid analysis, we assigned a numerical score to each type of interaction: Positive = 1; Neutral = 0; Negative = -1.

Figure 4: Study Methodology



Study Results

The results of our analysis appear in **Figures 5, 6, 7, and 8**. The tonality line depicted in each graph illustrates the impact of health organizations' dialogue with people using the social networks Sermo and Inspire.

Figure 5 indicates that companies engaging in corporate-style communications receive generally neutral responses from social networkers. The average tonality score of these interactions was **.318**.

Figure 6 shows that personal-style interactions generated mostly positive responses. The average tonality these conversations was **.576**.

Negatively Viewed Organizations Benefit From Personal-Style Conversation

Interestingly, we found that organizations viewed negatively by social network users can benefit from personal-style conversation. **Figure 7** shows the

tonality of six conversations conducted by an organization viewed negatively by Sermo physicians. Overall, they reacted positively its communications efforts. The average tonality score of these interactions was **.667**.

Discussion

The results of this preliminary study indicate that organizations that engage in corporate interactions may be less likely to encounter negative commentary from social network users.

However, there is some evidence these conversations are impacted by the online community's relationship with the organization. As shown in **Figure 8**, a well-regarded non-profit group that engaged in corporate-style conversation with an Inspire-based online community generated more positive than neutral responses.

Figure 5: Tonality (Corporate Conversations)

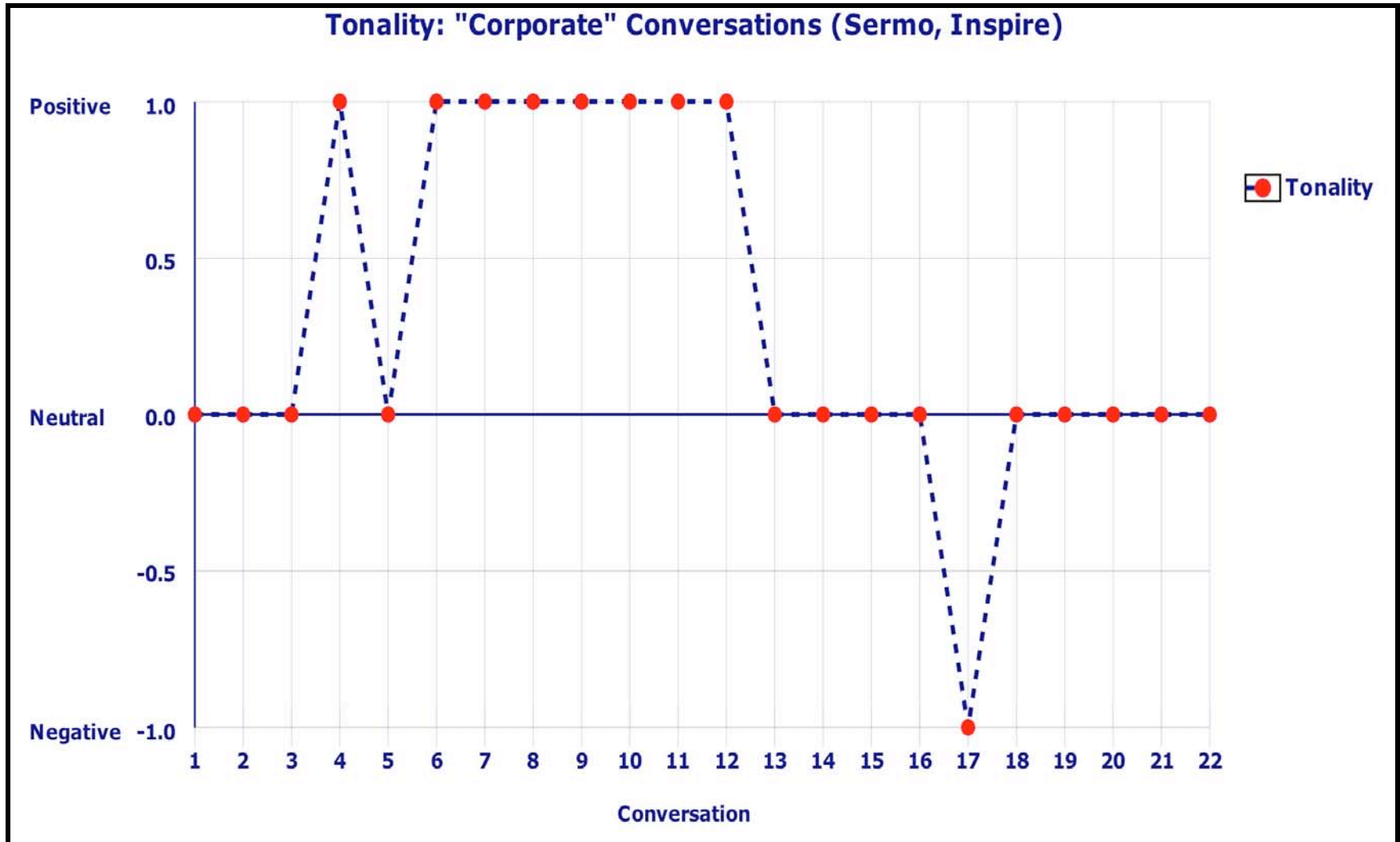


Figure 6: Tonality (Personal Conversations)

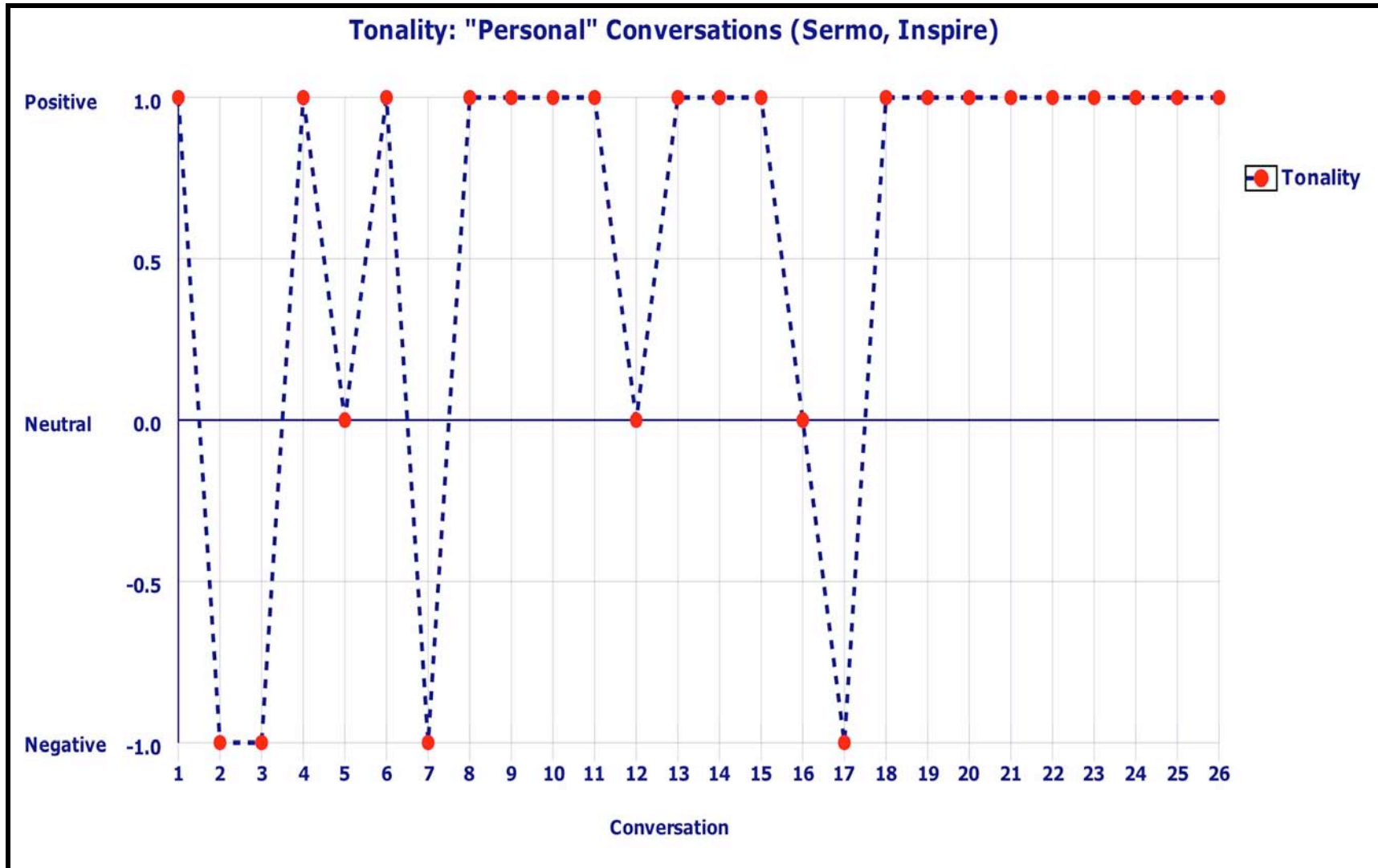


Figure 7: Tonicity Of Personal Conversations By Controversial Organization

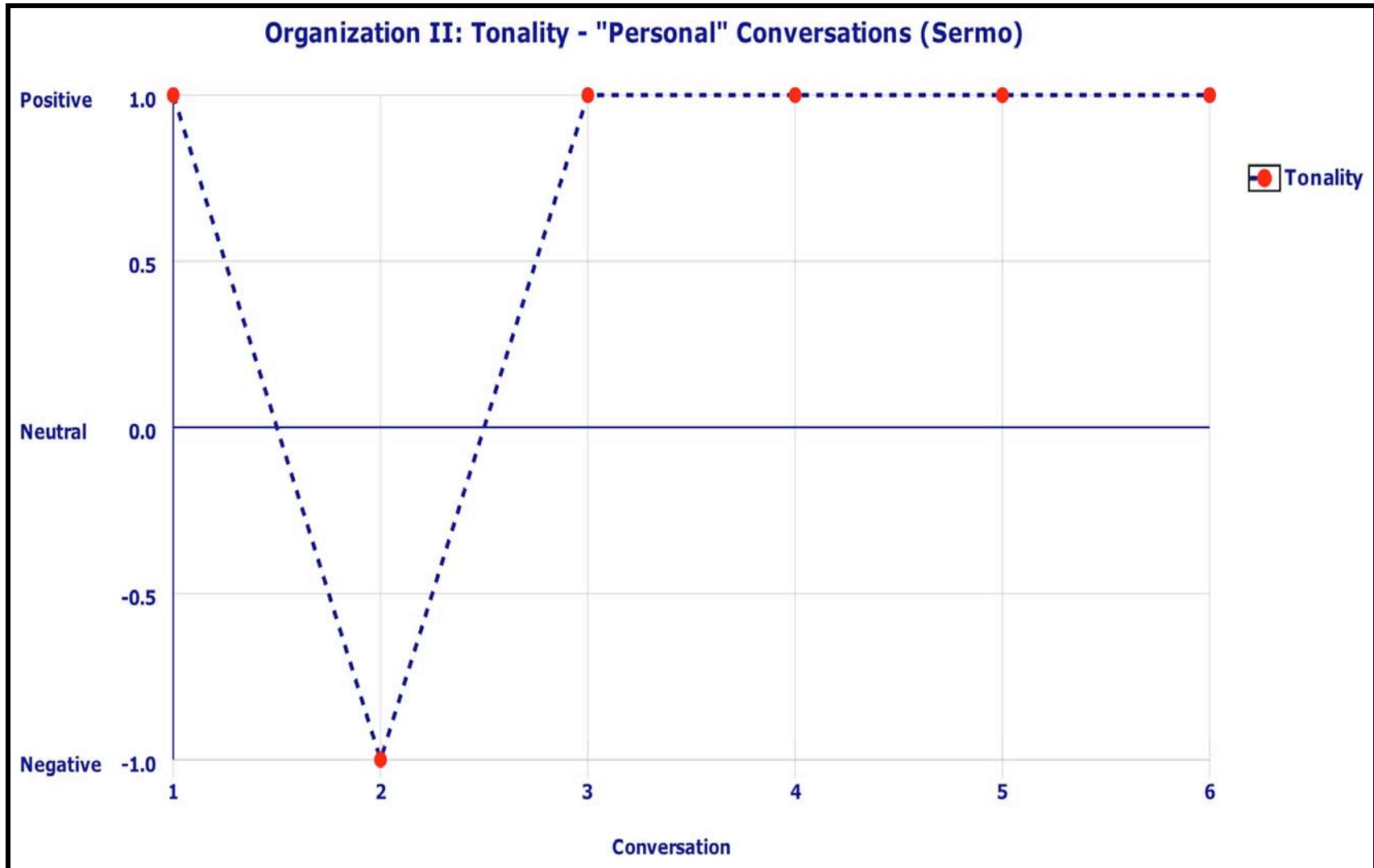
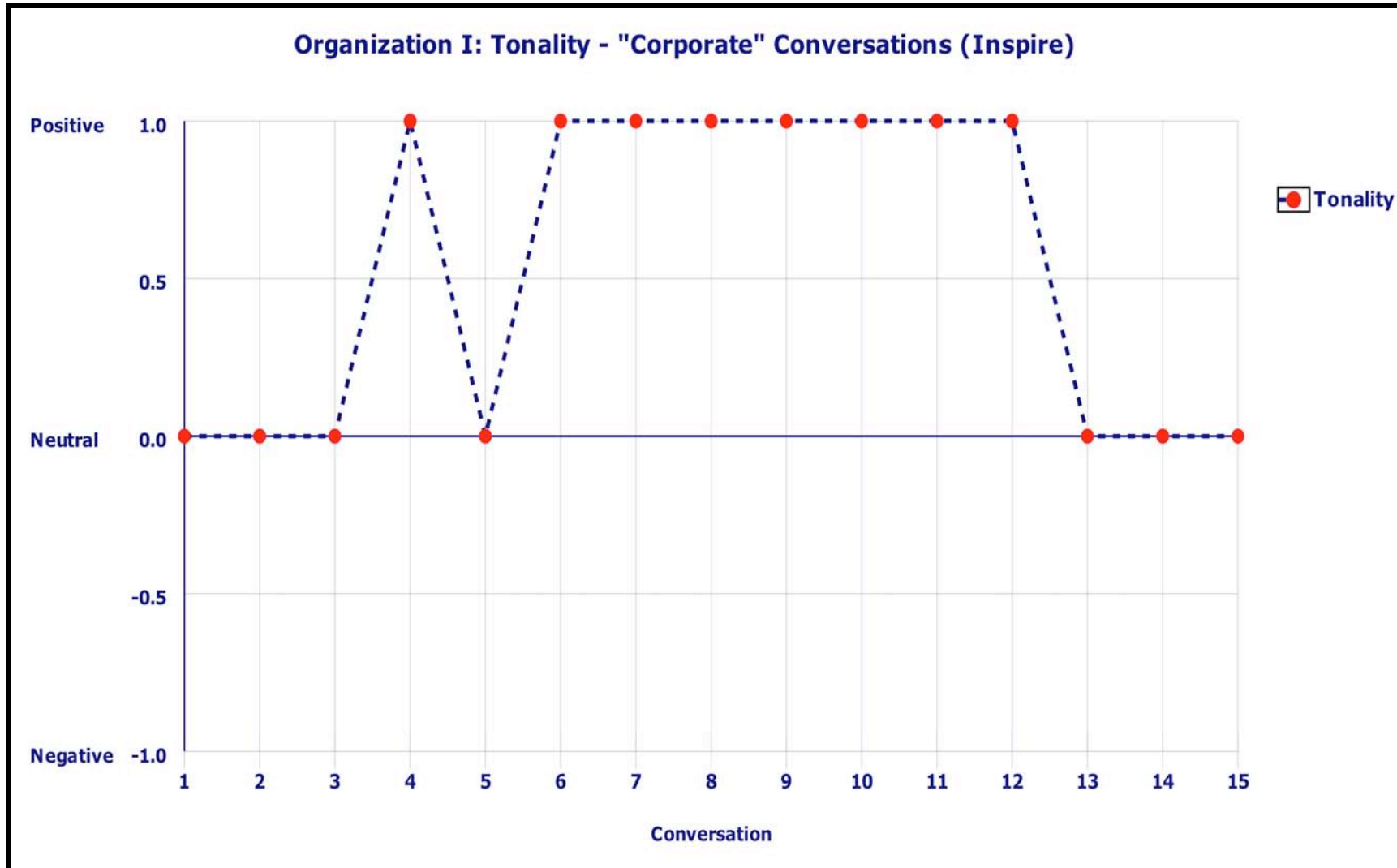


Figure 8: Tonicity Of Corporate Conversations By Well-Regarded Organization



IV. THE FIVE GOLDEN RULES OF EFFECTIVE SOCIAL NETWORK COMMUNICATION

In Parts II and III of this paper, we outlined the major ways health organizations are communicating with social network users. We also provided data that will enable them to predict how social networkers may react to their efforts at two-way dialogue. In this section of the paper, we outline the five “golden rules” of social network communications. After briefly outlining each rule, we provide commentary from five experts with extensive experience in social network development, monitoring, and marketing.

Rule I: Listen First, Speak Second

Before launching a social network communications effort, it is best to spend a lot of time listening to the target online community. Doing so can help a health organization determine

- What issues are important to social network users
- How social networkers typically react to marketing efforts
- Their views on products, services, and issues

Jim Nail, Chief Marketing Officer of TNS Media Intelligence/Cymfony (www.cymfony.com) is an expert about the importance of listening to people using social networks. His company provides a number of products and services designed to help organizations listen to, and understand, people using a range of social technologies. His commentary on the value of listening appears below.

The Value Of Listening

Jim Nail, Chief Marketing Officer, TNS Media Intelligence/Cymfony

Q1: The health industry is eager to communicate with people using social networks. Why is it so important to “listen” to these online communities before communicating with them?

A1: In these communities, people are often asking for advice or looking for answers to questions. By listening first, you can understand what information is valuable to the group and make a positive contribution to the conversation. If you jump right in first with a message you want to communicate, you will likely be out of synch with the style and topics important for the group.

Imagine being at a cocktail party and you approach a group of people who are talking about their kids, and you interrupt to ask if any of them have diabetes and have heard about this new treatment; you’d kill the conversation and likely be perceived as pushy and insensitive. Virtual communities are similar to these real-life communities.

Q2: Please provide some examples of companies or organizations – in any industry – that have instituted effective listening processes.

A2: I’ve long admired Intuit’s Quickbooks small business accounting product for their approach. They early on established discussion boards for technical support and have evolved them into great listening and relationship-building tools. I’ve seen posts where product managers ask the community for input on new product features they would like to see and marketing managers ask feedback on new advertising ideas.

The auto industry, too, has embraced listening. They know a lot of purchase research is done online, and so they gain a lot of insight through listening to the many blogs and boards on auto sites. Toyota, in particular, has done a good job extending their listening process beyond just buyers into owners who are having problems, and then offering help to resolve their issues.

The Value Of Listening

Jim Nail, Chief Marketing Officer, TNS Media Intelligence/Cymfony

Q3: How can organizations put the knowledge they have gained during the listening process to work?

A3: One of the trends we are observing is that multiple groups within companies are now interested in tapping the insights in social networks, blogs, and other online tools to improve their effectiveness. Public relations and marketing executives were early users, since they were looking to identify influential bloggers and consumers with whom they would be communicating. Market research sees the unfiltered spontaneity of these discussions as providing a different perspective on consumer wants, needs, and motivations that classic quantitative or focus group studies can. As noted in the Toyota example above, more and more customer service and consumer affairs organizations are listening to identify and resolve issues for current customers. We are even starting to do work with investor relations professionals who want to track financial discussion boards and competitive intelligence executives who are looking for new threats or opportunities.

Q4: Why is it important to listen throughout a social network communications effort?

A4: At the beginning, insights from social network analysis can help a company craft its message and positioning to resonate better with their target audience. Mid-campaign you get a real-time check on what is working and what is not so that you can make mid-course corrections to improve results. At the end, you will have a good pre- and post-campaign comparison to see exactly how much you have changed the target's attitudes and perceptions so you are well prepared for your next initiative.

Q5: In politics, "It's the economy, stupid" has become a handy reminder for candidates seeking public office. If you were to create a one-sentence slogan focusing on why it is important to listen to social network communities, what would it be?

A5: It would have to be the "The brand lives in the mind of the consumer." Mark Morris, an Executive Vice President at Bates Advertising and my branding mentor from my early career days in the advertising agency business, taught me this concept. Online communities can give you a direct look into the mind of the consumer so you can get a real view of your brand. This view is often less flattering to the brand than a typical survey, and thus sometimes shocking, but allows marketers to connect with consumers on a more authentic basis rather than put out more messages, which consumers ignore as mere spin.

Rule II: Tread Softly And Be Prepared

When, and if, a health organization decides to engage with people using social networks, it is important to proceed carefully, or “tread softly and be prepared.” The listening process should have provided useful intelligence about the social network community’s culture and the issues it believes are important. This information should be leveraged appropriately so that communications efforts are always in line with the expectations of the community.

Daniel Palestrant, M.D., is founder and CEO of Sermo (www.sermo.com), a physician-only social network. Since launching the online community in 2007, he has managed to attract tens of thousands of physicians to the community while keeping them engaged over the long-term. In the commentary below, he explains why he believes it is important to tread softly and be prepared when communicating with, building, and engaging a social network community.

The Importance Of Respecting A Social Network Community's Culture And Expectations

Daniel Palestrant, M.D., Founder And Chief Executive Officer, Sermo

Q1: What does the phrase "tread softly and be prepared" mean to you when considering how health organizations can successfully communicate with people using social networks?

A1: First let me say that because I can speak most authoritatively about my experiences with Sermo, I'll focus my remarks on what we've found in our social network. However, I think this advice can be applied to organizations seeking to communicate with other online communities.

For organizations communicating with the Sermo community, the motto "tread softly and be prepared" is critical to success.

First and foremost, there must be a recognition that an organization has been invited to communicate with physicians by the doctors themselves. Successful organizations acknowledge that "guests" are there by invitation only and can be asked to "leave" at any time. Next, organizations – and those who represent them – must build credibility with the physician community. This credibility is earned over time through multiple interactions, small and great. Third, organizations should present information to physicians that is relevant and new. Often, this requires a change in strategy for many healthcare companies. For example, the physician community on Sermo rejected repackaging promotional or marketing content and clearly expressed a preference for new clinical data and the opportunity to communicate with company liaisons in scientific exchange. This form of two-sided dialogue is proving to be mutually beneficial; it's important to note that this can take time and often requires multiple stakeholders within an organization to accomplish. This is where the "preparedness" piece plays a role. Through our early partnership with Pfizer, we have learned how physicians prefer to communicate with a pharmaceutical company. Pfizer has worked with the physician community to define new modes of interaction that physicians are giving positive reviews. That said, these new interactions – designed from the physicians' perspective for the first time ever – have required the company to develop new processes and procedures.

Our most successful clients present new or relevant clinical data that physicians can use to improve patient care. They also use each interaction to develop continuously a trusting relationship. Over time, they achieve the credibility within the community necessary to glean insights and observations that are simply not possible to uncover in other settings.

Q2: What are the characteristics of a healthy, responsive relationship with a social network community?

A2: Social networks present a powerful, cost-effective source of information, but require a mutual give-and-take – a value exchange. On Sermo, both physicians and healthcare organizations are able to participate in an information exchange that can solve problems and answer questions faster and more accurately than ever before possible.

The Importance Of Respecting A Social Network Community's Culture And Expectations

Daniel Palestrant, M.D., Founder And Chief Executive Officer, Sermo

A2 (continued): The collaborative environment taps into the wisdom of the crowds and the idea that no one physician is as smart as many. Based on our experiences with physicians using Sermo, healthcare companies must do the following to achieve a healthy, responsive community environment:

- **Build credibility.** Healthcare companies should provide full disclosure to get useful and relevant feedback from the community. This includes openly disclosing what they want to know, and why they want to know it.
- **Provide a clear personal identity.** Sermo's clients often designate a physician employee to serve as a representative and resource to physicians in the Sermo community. Because the employee is a peer, the employee has the background to interact effectively with physicians. Clients sometimes have multiple doctors participate, depending on the subject matter and areas of expertise.
- **Ditch the marketing spin.** Provide credible clinical information to the community, free from marketing spin and jargon. For us this means that Sermo clients can't misrepresent their intentions, and they must back up claims with sound clinical information.
- **Keep it relevant.** Physicians using Sermo have limited time to communicate with the community. Because of this, they want insight and the space and freedom to collaborate with each other to solve clinical problems, exchange information on drugs and devices, and improve medical practice. Because of this, we advise client organizations using Sermo to avoid
 - Re-starting conversations that have reached a satisfactory conclusion
 - Posing questions that have already been answered by other community members
 - Requesting advice on problems that have already been solved.
- **Provide timely feedback.** Communities require constant feedback and attention to improve and thrive. Physicians using Sermo can help organizations collect a tremendous amount of information in a short period of time. In exchange, we ask our clients to provide the community with feedback on the information they provide and quickly address questions and issues.

Rule III: It's A Marathon, Not A Sprint

Health organizations considering creating a social network or engaging in two-way dialogue should have a long-term strategy. It can take a while for skeptical social networkers to trust an organization or engage in productive, positive conversation. In addition, building a critical mass of people willing to use a social network created by a health organization can take months – or years.

Maureen Rigney, an executive at the Lung Cancer Alliance (www.lungcanceralliance.org) (LCA), a non-profit dedicated to supporting people living with lung cancer or at risk for the disease, knows the benefits of having a long-term social network communications strategy first-hand.

In the commentary below, she explains why LCA started a social network for its constituents, and why it is important to participate in the social network over a long period of time.

Communicating With Social Networkers Over The Long Haul

Maureen Rigney, Director, Patient Services, Lung Cancer Alliance

Q1: Why did the Lung Cancer Alliance (LCA) decide to use a social network to communicate with its constituents?

A1: Although it is the nation's leading cancer killer, lung cancer has fewer resources than other major cancers. The Lung Cancer Alliance devotes 50% of its efforts to patient support and education and had a toll-free line, one-to-one peer support program, informative Website, and educational materials, but, as a small organization, we recognized there were support needs of our community that we could not meet.

An online social network was appealing, because it would be a resource for support and information, day or night, seven days a week, from a number of individuals located across the country and around the world.

Q2: What were the major initial lessons LCA learned about communicating via a social network?

A2: We merged with an existing message board, and we learned early on that many people are uncomfortable with change. Communication is of utmost importance, and users must be part of change process. It is also vital that people have a place to log comments, suggestions, and complaints, and get rapid response to those postings.

The community must be a place where people feel safe to exchange ideas freely. We take seriously the right to free expression and have only intervened when people tried to take advantage of the site (through advertising or false promises) or postings were to the detriment of the site as a whole. Luckily, we have had to intervene rarely and have found that users of the site will self-monitor postings that may border on inappropriateness.

Q3: Have LCA's interactions with people using its social network changed over time?

Q4: Our interactions with the community are ever-changing! We launched the site less than two years ago – it is, and will continue to be, a work in progress. We know that our community is a place for patients, caregivers, and other interested parties to exchange information and support, and moderate our involvement accordingly. It's very important in an endeavor such as this to be fluid and able to adapt quickly. Again, communication is key.

Communicating With Social Networkers Over The Long Haul

Maureen Rigney, Director, Patient Services, Lung Cancer Alliance

Q5: Why is it important for organizations thinking about working within social networks to be in it for the long haul?

A5: It can take time to build the trust of the community, and to get the word out about it. It is also important – in the case of a psychosocial support community, especially – to be in it for the long haul because over time, users come to rely heavily on the support they get from the social networking site. If the organization were to pull that support for whatever reason, it can have serious emotional consequences for the users.

Particularly with a community that is based around a life-threatening illness, it is important to understand there will be both physical (such as software usage) and emotional challenges throughout the lifetime of the network. It's important to be adaptable to the changing needs of the users while providing a calm and steady presence.

Q6: What three pieces of advice do you have for people in the health industry thinking about communicating via social networks?

A6: My advice to other health organizations is

1. Meta-communication [dialogue between the organization and users] is as (possibly more) important than communication between users.
2. Keep it simple and adaptable (unless the network is for highly technical individuals).
3. Never fail to appreciate the power of the collective voice formed by the network.

Rule IV: Remember, School Is Always In Session

Several years ago, the Centers for Disease Control and Prevention (CDC) began to notice that the Internet was transforming how people found and exchanged health information. Long before many other health organizations were comfortable with social technologies, the agency began to experiment with blogs, podcasts, and virtual worlds such as Second Life (www.secondlife.com). Recently, the CDC has begun to engage with users of social networks. Currently, it is applying lessons learned from its forays into social network communications to transform its online health education efforts.

Although it has learned much, the CDC understands that when it comes to social network communications, school is always in session. To be successful, it is important to remain open to new ideas and perspectives.

In the commentary below, Erin Edgerton, of the CDC's National Center for Health Marketing (www.cdc.gov/healthmarketing), talks about what the agency has learned about public health and health communications from social networkers.

A Public Health Agency Learns From Social Networkers

Erin Edgerton, Content Lead, Interactive and New Media, Centers for Disease Control And Prevention

Q1: Why is the CDC currently using social networks, including MySpace, to communicate about health?

A1: CDC is committed to using emerging channels of communication to provide agency content, tools, and services available when, where, and how users want them. Current research shows that online health information seekers are increasingly turning to “people like me,” making social networking sites in particular, important information dissemination channels.

In November 2007, CDC launched the official [CDC MySpace page](#). Using this as a channel to direct MySpace users to consumer health information, CDC expands the reach of its health impact. In addition, MySpace users can get information on incorporating CDC health messages and graphics into their own pages, empowering our friends to become our advocates. We are also working with several social networks that are devoted to health and/or public health professionals. CDC is currently working on a group page in DailyStrength (www.dailystrength.com) and developing partnerships with Sermo (www.sermo.com) and CaringBridge (www.caringbridge.org).

As CDC expands its use of blogs, podcasts, social networks, and other technologies, we will continue to evaluate these spaces to gauge the impact that online messages are having on real-world behavior. Research and evaluation are critical to interactive media activities at CDC.

Q2: What has surprised CDC most about its social network communication efforts?

A2: We’ve been pleased (but not that surprised) to see that social networks can truly provide a channel for individual interactions between a large government agency and individual health consumers. Building collaborations with new partners and developing communication strategies to empower individuals have been great experiences.

A Public Health Agency Learns From Social Networkers

Erin Edgerton, Content Lead, Interactive and New Media, Centers for Disease Control And Prevention

Q3: What is CDC learning from social networks about public health and health communication?

A3: Regarding public health, information from peers, and “people like me” is an important source for today’s online health information seekers. Participating in social networks gives CDC the opportunity to provide credible science and relevant health messages in the same space where peer-to-peer information-sharing is taking place. Reaching people where they are and bringing them back to CDC.gov for more information has been an effective communication strategy for the agency.

As for health communication, social networks provide opportunities to reach different segments of the public with relevant, meaningful, and influential health messages. By tailoring messaging to match the needs and interests of a particular social network group, CDC’s science can have even more impact on everyday health decisions.

Q4: Has CDC adjusted its communications strategies based on what it has learned in social networks?

A4: As we build our research in social network communications and explore new pilot activities, we will continue to evolve our strategic approach. We will consider ourselves successful when we can achieve a balance between our credible research and health information and new movement towards participatory Internet-based activities. We will continue creating innovative pilots with our partners and building the marketing and communication science behind these interactive channels.

Q5: How will CDC use insights gained from its current social network communications efforts in the future?

A5: The research for CDC’s social networking sites adds to the overarching “CDC 2.0” communication strategy. We will continue to find opportunities to integrate social networks with traditional health education outreach and use new technologies to increase the impact of the agency’s science and research. Ultimately, CDC must participate in online conversations to: increase the dissemination and potential impact of CDC’s science; leverage unique characteristics of emerging channels; reach diverse audiences; facilitate interactive communication and community; and empower people to make healthier and safer decisions.

Rule V: Build A New Yardstick

While there is much excitement in the health industry about social networks, relatively few health organizations have begun to engage people using them. One important barrier is fear. Another is uncertainty about whether a social network communications effort will yield measurable results.

Although they have different objectives, philosophies, and cultures, both non-profit and for-profit health organizations have similar questions about the benefits of a social network communications effort. Most importantly, how should one quantify the return on investment of creating a new social network or engaging in two-way dialogue with stakeholders? An obvious answer is to determine whether the communications initiative resulted in increased sales or donations.

However, it is more difficult to measure the value of non-tangible benefits, such as an improved reputation or more positive relationships with key stakeholders. This will require health organizations to build customized yardsticks that they can use to determine what constitutes success.

In the commentary below, Fabio Gratton, of Ignite Health (www.ignitehealth.com), a healthcare marketing agency that works with a range of pharmaceutical companies, patient advocacy groups, and other organizations, provides his perspective on measurement. While corporate executives will gain the most from his commentary, he has a few words of wisdom for those with non-profit groups.

How To Measure Social Network Communications

Fabio Gratton, Co-founder, Chief Innovation Officer, Ignite Health

Q1: Why have so few organizations in the health industry leveraged the power of social networks to communicate with the public?

A1: There are some obvious factors that are driving this industry's reluctance to use blogs, social networks, and other technologies, including a general lack of understanding of how to leverage them, fear of failure, and [in the case of life sciences companies] the always-present conservativeness resulting from regulatory restrictions. I work with a lot of companies in this industry, and I've found that few have devised a metric system which can effectively measure how this investment will directly and positively impact the brands which they market. Yes, our gut tells us that there is gold in these hills – but it's hard to sell intuition to upper management, and it's even harder to expect a financial commitment without a way to measure the financial return.

So when we reach into our arsenal of analytic models and find ourselves unable to retrieve the right tool for this challenge – we are faced with a difficult choice: either we pull out our reliable hammer and start pounding away with the hope we will extract some bit of meaningful insights from the data or, we dump all the tools on the ground, re-examine their relevance, mine their value where applicable, and begin the process of building a new yardstick that enables us to measure success. This new yardstick is comprised of three elements: (a) new tools and technologies, (b) new types of campaign assets, and (c) [from a commercial perspective] new types of conversion metrics that result in return on investment (ROI) for a brand.

Q2: Why is it so difficult for companies to measure social network communications efforts? Don't they have a wealth of measurement tools they can modify and apply?

A2: Answering this question requires us to look at how we are measuring the effectiveness of interactive campaigns today. For example, a pharmaceutical company's online strategy might consist of employing a variety of tactics to drive users to branded or unbranded Websites. On those sites, the user is presented with information about our product with the goal of (a) informing them about the existence of our product and its associated benefits (e.g., "Awareness"); (b) converting them into new customers (e.g., "Acquisition"); or (c) delivering a service that evolves the visitor into a loyal customer (e.g., "Retention," "Compliance," "Adherence"). For each of these objectives, pharmaceutical marketers can determine what metrics will constitute success and implement tracking mechanisms to capture those metrics accurately.

How To Measure Social Network Communications

Fabio Gratton, Co-founder, Chief Innovation Officer, Ignite Health

A2 (continued): However, the days where we could simply measure click-through rates on a banner ad or traffic volume to a Website are long gone. Simply measuring *quantity* provides a marketer with little insight as to the effectiveness of any particular tactic. The best way to measure a qualified visitor is by defining the desired *conversion metric(s)* and subsequently measuring the campaign's ability to deliver the *highest* number of conversions at the *lowest* possible cost (e.g., "cost-per-conversion"). In the world of e-commerce, conversion is a simple and straightforward concept: *Did the consumer purchase something?*

One of the biggest challenges in measuring the effectiveness of social network communications strategies is getting people to think differently about the metrics that constitute success. Today, we can no longer just measure a conversion at a single point in time; we must be able to measure the level of *engagement* that our strategies create and how that engagement translates into a long-term relationship with our customers. Once we define how to measure engagement, we will also need to determine how to assign a quantifiable value to that engagement. How we measure engagement and how we assign value to the relationships that emerge from that engagement are two distinct but interrelated aspects of a social network strategy, and both must be thoroughly explored to develop a new means of measuring these new tactics.

Q3: Okay, so how should we be measuring our social network focused communications campaigns?

A3: One of the greatest values of communicating with people using social networks is our ability to create *engagement*; however, it can be very difficult to quantify its value. Many published studies cite the power of word-of-mouth – specifically, its ability to influence and motivate people to take action. People tend to listen to, trust, and follow the recommendations of people similar to them more than any other source of communication. That is why user reviews are one of the most powerful tools in influencing consumer-purchasing decisions – whether the reviews are about gadgets, hotels, or prescription medications.

How To Measure Social Network Communications

Fabio Gratton, Co-founder, Chief Innovation Officer, Ignite Health

A3 (continued): There are various ways that one can assign value to engagement. One way is to calculate the average cost-per-conversion for all other tactics, and use it as a benchmark for evaluating the relative value delivered via a social network communications effort. When Ignite has done this, we've been pleased to see that our social network communications efforts have exceeded expectations.

For example, when we set up a social network for one of our clients, we accomplished something very interesting. Our campaign was living in an online environment where people are accustomed to commenting, discussing, and interacting with content. User participation in the social network helped to ignite viral activity that helped our client's message spread to dozens of blogs, each with its own sphere of influence. The farther the message spread, the lower the conversion cost for each subsequent message became. In addition to leveraging influencers and reducing the cost-per-conversion, the viral component of the campaign seeded important keywords throughout the blogosphere that were subsequently indexed by all the major search engines, thus resulting in increased traffic. We also enhanced our rank in search engines as a result of the growing amount of inbound links (part of Google's ranking algorithm).

So, what exactly is the return on investment, and how should we be rethinking our approach to metrics when it comes to social technologies? The simple answer is: *Create engagement*. If you engage your customers, they will interact with your brand longer. The longer they interact, the more time they have to digest your brand's key messages. The more engaging the experience, the more likely they are to tell others about you – on their dime and time. And, the better relationship you build, the more likely they are to come back in the future – without your need to win them over again. Each of these benefits can be classified as distinct metrics that can and should be captured, analyzed, and reported.

Q4: Do you have any tips for people seeking to measure social network communications campaigns effectively?

A4: Well, my advice will be most relevant for corporate marketers, but I think both for-profit and non-profit organizations could benefit from it. As you evaluate the viability of a social network communications strategy, it's important to ask yourself a question: How much more likely is someone to take some beneficial action (e.g., engage in a meaningful dialogue with a healthcare provider) if the person is actively engaged? If the likelihood is high, then it makes sense to create a campaign that will provide people with a place to express themselves and participate in an *experience* – not just an advertisement.

CONCLUSION

Social networks are quickly becoming a favored online destination for patients, health providers and caregivers. Despite this, many health organizations have been unwilling to communicate with social network users because they are uncertain about what strategies will be successful.

In this report, we have provided a wealth of tools and information that has hopefully helped you to

- Understand how the social network universe is evolving
- Recognize and evaluate common strategies health organizations are using to communicate with, and learn from, social network users
- Predict how social networkers may react to attempts by health organizations to engage in two-way dialogue with them

- Apply the five “golden rules” that will aid in the successful planning, implementation, and measurement of a social network communications effort

We are only at the beginning of the health social network revolution. Over the coming months and years, it is likely that social networks will become increasingly influential and important. Health organizations that quickly take advantage of the communications opportunities presented by social networks will surely benefit.



REFERENCES

1. Haven, B., *Marketing's New Key Metric: Engagement*. 2007, Forrester Research.
2. Ferguson, T., *Health Online: How to Find Health Information, Support Groups, and Self-Help Communities in Cyberspace*. 1995, Reading, MA: Addison-Wesley/Perseus Books, 1995.
3. Anonymous, *Connecting with Patients, Overcoming Uncertainty* 2007, TNS Media Intelligence/Cymfony, Envision Solutions, LLC, Seyfarth Shaw, LLP: Watertown, MA.
4. iCrossing, *How America Searches: Health and Wellness*. 2008.
5. Grohol, J. *The Wisdom of Patients Report*. 2008 April 28 [cited 2008 May 5]; Available from: http://www.e-patients.net/archives/2008/04/the_wisdom_of_p.html.
6. Anonymous, *Boomers, Healthcare and Interactive Media*. June 2008, ThirdAge and JWT BOOM.
7. Stromberg, C., *How Consumers Use Social Computing For Health*. 2007, Forrester Research.
8. Gomez, M. *Should MySpace be Your Space?* 2008 March 11 [cited 2008 May 6]; Available from: <http://blog.aids.gov/2008/03/should-myspace.html>.
9. Rubel, S. *The Promise and Peril of Ubiquitous Community*. 2008 May 15 [cited 2008 May 16]; Available from: <http://www.micropersuasion.com/2008/05/the-promise-and.html>.

ACKNOWLEDGEMENTS

Envision Solutions would like to acknowledge the following individuals for contributing commentary, insight, and data for this report:

- Cary Byrd, eDrugSearch.com (www.edrugsearch.com)
- Erin Edgerton, The Centers for Disease Control and Prevention (www.cdc.gov)
- Fabio Gratton, Ignite Health (www.ignitehealth.com)
- Benjamin Heywood, PatientsLikeMe (www.patientslikeme.com)
- Brian Loew, Inspire (www.inspire.com)
- Manny Hernandez, TuDiabetes (www.tudiabetes.com)
- Jim Nail, TNS Media Intelligence/Cymfony (www.cymfony.com)
- Daniel Palestrant, Sermo (www.sermo.com)
- Maureen Rigney, Lung Cancer Alliance (www.lungcanceralliance.org)