



Patient E-engagement: A Marriage Made in Cyber Space

In just a few years, the pharmaceutical industry has moved from listening to patients to engaging patients directly and through patient communities.

It wasn't very long ago that industry involvement with social media consisted of only what our experts call "buzz monitoring," or the analysis and interpretation of patients' public comments in online communities. While this practice was a good place to start, the industry is set to take the next step beyond to participate in the more valuable opportunity of engaging in two-way conversations with patients. The industry has made the all-important shift from unengaged listening to deliberate interactions with patients.

According to research conducted by Daniel Ghinn, CEO and director of digital engagement at Creation Healthcare, a new paradigm emerges every year, signaling progress within the industry.

"For example, by 2010 social media pioneers had tackled the challenges of regulatory and adverse event concerns and were wondering what to do next in terms of social media," he says. "In 2011, innovating pharma companies broke free of their online shackles and began testing the boundaries of online patient engagement. By 2012, several companies are wholly participating in purposeful, proactive online engagement with patients and physicians."

For the past three years, Mr. Ghinn's agency has conducted an industrywide research and awards process that has identified best practice examples of companies that have been successfully engaging with consumers. Creation Healthcare has named Boehringer Ingelheim, AstraZeneca, Roche, and Pfizer among the winners of its annual Healthcare Engagement Strategy awards. For the first time in 2012, the majority of award winners were commercial healthcare companies that used social media and digital channels.



“As peer-to-peer networks scale, geography disappears, and the value of the engagement increases.”

BRIAN LOEW / Inspire

"This is proof that the leaders in the pharma and healthcare industry are no longer lagging behind in their adoption of these different channels," Mr. Ghinn says.

The industry is starting to better align its marketing tactics to what e-patients actually want to do, agrees Donna Wray, VP, management advisor, TGaS Advisors.

"Theoretically, an app might be a great thing to get into the hands of a patient, but patients are not using many pharma apps today," she says. "On the other hand, 31% of sites today have limited or no access via mobile devices, according to TGaS Advisors July 2012 Mobile Landscape Study. In fact, only

14% of pharma companies have a version of their sites customized to a smaller mobile screen."

It Takes a Community

Brian Loew, co-founder and CEO of Inspire, has witnessed similar innovative trends taking place in the patient engagement landscape and says more pharma companies are now discussing how to appropriately access patient communities rather than whether they should.

"Between the time we created Inspire seven years ago and today, most pharma com-



“There must be a commitment from senior management and recognition of the value that patient engagement brings.”

NICK HALKITIS / MediciGlobal

panies have become far more understanding and appreciative of the value of patient communities,” he says. “We no longer have to discuss the value proposition with them — they get it.”

Companies that don’t get it, and are reluctant to engage with patients, need to rethink their strategy fast, says Greg Rutherford, senior VP of marketing at Klick Health.

“With less access to physician targets, marketers need to identify new approaches to facilitate appropriate conversations or engagements between physicians and patients,” he says.

More than ever patients are influencing their own outcomes. These days, patients cite that they are most influenced by other patients, care partners, and visits to branded and unbranded sites.

“Compared with just five years ago,

pharmaceutical marketers need to change their targeting focus and percentage of budget allocation efforts when it comes to working with e-patients,” he says. “I think the industry needs to increase its appropriate targeted patient effort allocation with extra attention paid to those patients who influence other patients.”

And unlike other industries — for example the level of customer engagement is significantly less for consumer goods — social media brings a unique value to the healthcare space, says Nick Halkitis, VP, e-marketing and digital strategies, at MediciGlobal.

“For patients whose lives are encumbered by their medical conditions, social media communities are places to share solace, obtain information, and connect with consequential strangers who share a common bond,” he says. “Consumer product companies and the auto

PATIENT ENGAGEMENT BEST PRACTICES ▶

Thought leaders discuss their experiences working with patient communities.



DANIEL GHINN is CEO and of Director of Digital Engagement, Creation Healthcare, an engagement strategy

consultancy specializing in the healthcare and pharmaceutical industries.

▼ For more information, visit creationhealthcare.com.

A best practice is to integrate both offline and online communities. There are patient advocacy groups that bring people together face to face and that also have an online presence or digital engagement component. Pharma companies have worked with these groups in the past, so it is a good way to bring those relationships online to help to create or develop connections with patients in a digital context. For example, we worked on Pfizer’s European Can You Feel My Pain initiative and this is a good example of the way pharma companies are able to use social media to support and strengthen their relationships with advocacy groups around a common cause.

For Pfizer, the cause was patients living with chronic pain and the purpose was to drive the patient voice around the frustration of living with chronic pain and to provide an opportunity to share what the experience is like. The good thing about this initiative was

that it supported Pfizer’s work with patient groups already taking place away from the Internet and it had a strong social media component and connected patients directly together around a common cause. This turned out to be a pretty good partnership in which social media played a role in actually facilitating that connection between patients. Since the campaign was for a European initiative, the company couldn’t create a direct link to the products, but Pfizer wanted to give the patient groups something to empower them. Through extensive research into the types of conversations that were taking place in the social communities, Pfizer identified that chronic pain is one of those disease areas that people can’t really see, so for the patients there is a feeling of isolation. Therefore, Pfizer determined that what this group of patients needed was support from each other.

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BRIAN LOEW is Co-founder and CEO, Inspire, which builds online communities for patients and caregivers and helps life-sciences

organizations connect with them. For more information, visit corp.inspire.com.

We recently worked with the Novartis Institutes for Biomedical Research on a survey of our lung

cancer support group to prospectively assess both patients’ and caregivers’ perceptions of symptoms of an advanced lung cancer treatment as well as interest and willingness to participate in supportive care clinical trials. The survey showed that caregivers noted symptoms to be at higher rates than patients. Also, Novartis was interested to see that these seriously ill patients reported that they were more willing to participate in supportive care trials to evaluate novel methods to manage symptoms. Survey response differences are being evaluated by the researchers.



GREG RUTHERFORD is Senior VP of Marketing at Klick Health, an independent digital health agency

developing digital experiences rooted in strategic and marketing insights, creative thinking, and technological expertise.

▼ For more information, visit klick.com.

I worked for many years in global marketing at Tibotec, a Johnson & Johnson company, where I had commercial launch responsibility for two HIV compounds. We worked closely with HIV patient advocacy groups and I found our interactions extremely productive and important. We learned to speak less and to listen more. We gained insights from the patient perspective as to what info was needed and what drug side effects were difficult to manage. As a result, we focused on making a positive difference. This influenced our clinical programs, our economic thinking, and our messaging.



“With the advent of mHealth, patients are expected and encouraged to take more control over their own healthcare.”

ERIC PILKINGTON / Torre Lazur McCann



“Leaders in the pharma and healthcare industries are no longer lagging behind in their adoption of new channels.”

DANIEL GHINN / Creation Healthcare

industry have reported that they are not seeing the value in social media the same as in healthcare. This is not surprising — patients live with the disease and the disease lives with them; a car and other consumer products do not have that same connection.”

Getting it Right: Planning, Patience, and Maintenance

Embracing the next steps to engaging patient communities will provide companies the

opportunity to get to know their patients and their journeys, but that process takes planning, patience, and the understanding that once a connection is made, it must be maintained.

“In the patient engagement space today, pharma companies should be employing intermediaries, trusted by patients, to engage in meaningful conversations with patients, and be transparent about doing so,” Mr. Loew says.

And several companies have done just that, according to Mr. Ghinn. A common denominator in a few notable campaigns — other than digital — was that they were designed to enable straightforward and honest interaction with patients.

“Credibility, it seems, never goes out of fashion with patients,” Mr. Ghinn says.

What is out of fashion is promotional information that does not add value to the patients’ lives, or a company offering information before adequately doing its homework.

“Pharma companies need to do research to be sure they truly understand patient needs and concerns before engaging with them,” Mr. Rutherford says. “If patient groups feel they are being exposed to promotion, and not valued information, they will turn off and there will be no insights gained.”

Mr. Loew says the industry must also be aware that patients are gaining more power within the healthcare triangle of the patient, physician, and pharmaceutical company interaction continuum.

“In five years, many more patients will demand that their healthcare providers be online, and patients will more fully leverage the information gained from online resources in their plan of care,” he says. “More patients will use online support communities, in higher numbers, and with more sophistication as online communities continue to grow and improve.”

As peer-to-peer networks scale, geography disappears and the value of engagement increases. Patients are often connected for the first time in their lives with others who have the same condition.

“This is perhaps most significant in communities for people affected by rare diseases,” Mr. Loew says. “Some of these communities have become the largest repositories and best concentrations of patients and caregivers for a specific disease.”

However, there is one small drawback to engaging with these e-patients. Because of their online engagement and empowerment in dealing with their disease, they are not broadly representative of the entire population.

“One issue that pharma companies should understand fully is that with online communities, they’re dealing with a self-selected segment of the patient population that is far more engaged and educated about health conditions than the average patient,” Mr. Loew says.

“Therefore, the nature of the sample must be recognized, just as for any research project.”

According to Eric Pilkington, senior VP, digital strategy, Torre Lazur McCann, the industry has to take some critical steps.

“First, companies must accept the fact that patients today are more empowered than ever

GSK Improves Process for Digital Engagement

Global digital services illustrate importance of online communication.

GlaxoSmithKline has partnered with Infosys to optimize digital channels across its global consumer healthcare and pharmaceuticals business lines by creating Global Digital Services, a new shared service that will drive standardized processes and sharing of best practices in creating and securely delivering information across multiple digital channels. The partnership, in association with Fabric Worldwide, a WPP company, will simplify and improve the effectiveness of how GSK delivers digital engagement with consumers and healthcare professionals. The proprietary BLUE (Build, Listen, Understand, Engage) framework of the platform will allow GSK to build digital assets and listen to consumers across an array of digital channels. GSK will be able to use the platform’s advanced analytical capabilities to better understand consumer segments and leverage audience insight to deliver an engaging brand experience. The platform will allow teams to collaborate through superior workflow capabilities, and foster re-use of digital assets. Infosys, in partnership with Fabric Worldwide, will also provide specialized digital marketing services, around brand and agency liaison, and advanced analytics to enable GSK to improve the effectiveness of digital media.

Phil Benton, VP, global digital services at GSK Core Business Services, has been quoted as saying: “We recognize that our customers, consumers, and other external stakeholders increasingly want to engage with us online. Global Digital Services will enable us to provide globally standard processes, scalable assets and advanced analytics to support better and more efficient engagement with these external audiences.”

Source: GlaxoSmithKline



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GREG RUTHERFORD / Klick Health



before,” Mr. Pilkington says. “With the advent of mHealth, patients are expected and encouraged to take more control over their own healthcare. The industry needs to be proactive in ensuring that the information available to the mobilized patient is accurate, easily understood, and balanced.”

Building rapport with patient communities takes significant time. Many pharmaceutical companies have started with good intentions, but fail over the long term because of

lack of planning, vigilant maintenance, or bandwidth.

“Some companies are launching into social media because their competitors are doing so, but they haven’t done the work necessary to be successful,” Mr. Ghinn says. “And once they open up a channel, they expect to get a positive response, but often there is community backlash, and they wonder why. The reality is that the companies that have had success have taken years to build up a reputation and trust.”


Mr. Ghinn says the real pioneer companies, such as J&J, Roche, and Pfizer, have taken little steps over a long period of time to build the trust necessary for effective patient engagement.

“If there is one lesson to be learned, it is to be patient,” he says. “A pharma brand manager may want a campaign that delivers in three months, but engaging in social media takes more time.”

Once these communities are built, for the company to continue to have credibility, the relationship needs to be constantly maintained.

“Maintaining a consistent level of engagement with patients and monitoring the information exchanged can be a daunting task,” Mr. Halkitis says. “There must be a commitment from senior management and recognition of the value that patient engagement brings.”

According to Mr. Rutherford, this buy-in may not come easily at first, as many in pharma still believe that getting close to patients is risky. However, he expects that misconception will continue to wane.

“I think this perceived risk will go away as more and more educated patients engage with their HCPs differently,” Mr. Rutherford says. “I have heard repeatedly that patients ask their doctors for drugs by name, where as a few years ago, this was far less common. Therefore I do not think this trend will weaken. I also have heard that patients will ask their doctors to enroll them in investigational drug studies, suggesting that patient access to information is increasingly more sophisticated. This is why I expect the pharma industry’s level of engagement in e-patient dialogue will increase over time.” 

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E-Patient Engagement is Not Just for Marketing Anymore

Connecting with patients boosts clinical trial enrollment and improves R&D.

Patient communities and social media have more implications for the industry than improved marketing. There are many e-applications for the clinical side from drug development to clinical trials.

For clinical trials, e-patients are changing the conventional model of patient recruitment by the manner in which patients are reached and enrolled for clinical trials. Today, there is a major shift from recruitment to engagement.

This is a profound change that is a positive for the industry and patients, says Nick Halkitis, VP, e-marketing and digital strategies, MediciGlobal.

“Engagement is significantly different from recruitment,” he says. “The word recruitment connotes a more insistent approach to enlisting patients into clinical trials, conversely the term engagement connotes an approach designed to put patients at ease. Engagement is based on information exchange and precisely the model industry needs for clinical trials. In the past two decades, the recruitment approach has done little to engage patients in the process of understanding clinical trials or to address patients’ wariness about clinical trial participation.”

Another reason patient engagement is crucial to clinical trials is that in the past, many companies relied only on the opinions of study sites or physician KOLs, and the input of the patient was often overlooked. Patient voices are critical to planning and implementing an effective patient engagement program, Mr. Halkitis says.

“Only from the patient can we know the challenges of coping each day with a medical condition, and today’s online patient communities provide instant feedback on questions that are general in nature to more in-depth insights related to a clinical trial,” he says. “In real time, data can be collected from these patient communities by various means; from patient polls, online surveys, buzz metrics, and study pre-screening.”

Real-time data from patient communities deliver critical patient insights fast, enabling teams to validate assumptions of others.

Pharmaceutical companies and clinical teams that use the data available from patient community engagement will be able to operate a much more efficient and functional trial.

“Teams that leverage the constant flow of real-time data for protocol design can make quick changes that keep the trial on track,” Mr. Halkitis says. “As a case in point, a recent clinical trial required patients to present with certain criteria, and to have had specific medical testing. A rapid survey of several thousand patients yielded a response in a matter of days, showing that this specific protocol requirement would reduce the viable patient pool significantly. In turn, it was decided that this medical test could be conducted during the screening visit instead.”

Working with and listening to e-patients and patient communities can also identify unmet medical needs, which can help shape the focus of R&D as well as the design of clinical studies, says Greg Rutherford, senior VP, marketing, Klick Health.

“Because e-patients have contact with a

A Social Media Community for MS Researchers

Industry supports social networking for scientists as well as patients.

EMD Serono has provided a grant of \$1.5 million to support the Multiple Sclerosis (MS) Discovery Forum website, a joint project of the MassGeneral Institute for Neurodegenerative Disease (MIND), the nonprofit organization Accelerated Cure Project for MS, and the Max Planck Institute for Molecular Genetics. The site provides an interactive virtual environment for members of the MS research community to engage in online discussions and collaborations to speed the development of treatments. This grant reflects EMD Serono’s ongoing commitment to investing in the understanding of neurological diseases.

The MS Discovery Forum is an impartial space that will afford the MS research community numerous benefits, including access to a custom drug-pipeline database and the MSGene database of MS genetic association studies, the ability to participate in peer-hosted discussion forums and webinars, the ability to share and receive feedback from other researchers on study findings and key learnings and the opportunity to learn about breakthrough findings through original articles by highly regarded science writers.

Source: EMD Serono.

For more information, visit msdiscovery.org.



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GREG RUTHERFORD / Klick Health



“ Engagement is precisely the model that the industry needs for clinical trials.”

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“ For patients involved in online communities, educating themselves about clinical research is key.”

BRIAN LOEW / Inspire



great many patients, they possess the collective view of many when they provide insights,” he says.

Patient communities are also valuable in educating newcomers to the clinical trial process.

“For patients involved in online communities, educating themselves about clinical research is key,” says Brian Loew, co-founder and CEO, Inspire. “We often see new members post multiple questions about enrolling in trials, and it’s clear from their questions that they have very little understanding of what a trial is. More veteran members of the community, who themselves have been through clinical trials, answer the newcomers’ questions. Those answers are often full of tremendous insights

and practical advice that can only come from people who have lived those experiences.”

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HIGHLIGHTS

- ✓ Risk Based Monitoring – What Does it Mean for Your Global Study?
- ✓ Re-Thinking How We Globalize Outsourcing
- ✓ Reducing Risk in Placebo Response in Global Clinical Research
- ✓ Investigator Non-Compliance and Protocol Deviation
- ✓ Social Media Techniques and Mobile Technologies Update
- ✓ Conducting Global Trials for Rare Diseases

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