



Listening to Consumers in a Highly Regulated Environment

How Pharmaceutical Manufacturers
Can Leverage Consumer-Generated Media

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Market Context: The Empowered Consumer

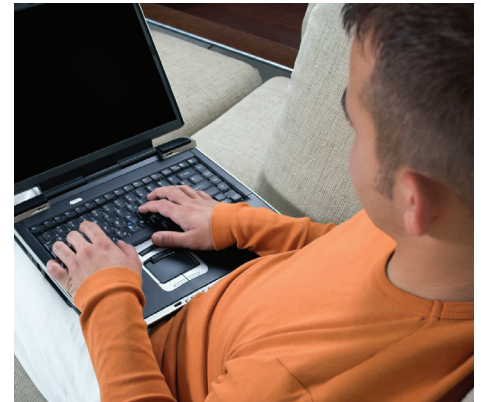
The roles of consumers and corporations have changed significantly since the rise of the Internet. YouTube is only the latest manifestation of a broader trend: consumers have the ability to voice opinions about products and brands, and there is now little standing in their way.

Consumers have come to expect that companies can and should listen to their ideas, requests and questions, and that companies will *react* to this input. A broad range of traditional companies—including Purina, Mattel, American Airlines and Comcast, to name just a few—have quickly learned the importance of listening and responding to what their consumers are saying. Companies are being held to increasingly high standards set by organizations that excel at listening and responding, such as Zappos, Geico, Starbucks, Southwest Airlines and others. These companies are setting the bar not just for their direct competitors, but for all businesses that serve consumers.

Consumers who feel they are not being heard will turn to other channels to share their opinions and express their frustration. Many choose the Internet—and specifically social media sites including discussion boards, blogs and online groups. Specific to healthcare, a Pew Foundation study finds that 39% of patients already use online support groups to discuss medications or

treatments with other patients—and this is a number that can only grow, given the size of the online population today and the increasing number of social media sites just a few clicks away.

Why is social media such a strong resource for patients and caregivers? The anonymity of the Internet affords a comfort level that encourages individuals to share details about their symptoms, treatment history, experiences with their doctors, the efficacy and side effects of medication, the impact of their condition on their own lives and more. At the same time, the ubiquity of the Internet can provide a connection between experienced patients and someone newly diagnosed. That is a powerful draw for anyone new to a particular disease and unsure about what the future holds. Finding a community of individuals who have a shared experience is equally powerful for veteran patients, who return to online discussion again and again to seek and share emotional support as they continue on the path of treatment and living with their condition.



Companies today face an increasingly difficult challenge: how to communicate with consumers in a way that encourages trust and engagement, in an environment where companies' statements and actions are routinely dissected on the Internet for the entire world to see. Pharmaceutical companies (so far) have escaped the most public of lashings; however, patients are taking an increasingly proactive role as healthcare consumers, meaning that pharmaceutical marketers and brand managers now must navigate new and unfamiliar waters. What can pharma companies do to change this dynamic and open a door of communication with today's empowered consumer? The answer to this question is complicated by the heavy regulation around the healthcare industry, but one thing is clear: pharmaceutical manufacturers have a lot to gain by listening to the conversation that is already taking place.

The Challenges of Listening

There can be no doubt that creating a listening culture presents a challenge for many companies, including pharmaceuticals. In certain corners of corporate America, a “listening as liability” mindset has prevailed.

Many companies are intimidated by the procedures that must be put in place for logging consumer feedback, seeing that it gets to the right place and, most importantly, following through.

More than possibly any other industry, the pharmaceutical industry is constrained in how it communicates with its customers—exemplified by the advertising real estate that pharmaceutical companies must allocate to side effects and possible adverse events (AEs) associated with their products. It is completely understandable that the constraints around pharmaceutical companies’ ability to speak to their customers would affect how they listen to their customers. We believe, however, that the two do not need to go hand in hand; that there are ample opportunities for pharmaceutical manufacturers to listen to their customers, and to better serve the public and gain competitive advantage by doing so.

Social Media and Adverse Event Reporting

Any pharmaceutical company considering an entry into the social media space will naturally wonder about discussion of adverse events. Are consumers sharing information online that would indicate an adverse experience? Does social media monitoring trigger the AE reporting requirement?

At this writing, there is no FDA guideline or regulation that specifically covers the content of online discussion in a way that is different from reporting AE information derived from any other source. Current FDA guidelines give four parameters for submitting information about adverse experiences: the pharmaceutical company should have knowledge of (i) an identifiable patient; (ii) an identifiable reporter; (iii) a specific drug or biologic involved in the event; and (iv) an adverse event or fatal outcome. (From FDA’s “Guidance for Industry: Postmarketing Adverse Experience Reporting for Human Drug and Licensed Biological Products: Clarification of What to Report,” issued August 1997; available online at: <http://www.fda.gov/cder/guidance/1830fn1.pdf>.) According to the guideline: “If any of these basic elements remain unknown after being actively sought by the applicant, manufacturer, or licensed manufacturer, a report on the incident *should not be submitted* to the FDA because reports without such information make interpretation of their significance difficult, at best, and impossible, in most instances” (emphasis added). A draft guideline for filing individual case safety reports related to OTC treatments was posted on the FDA website in October 2007; it reiterates these same four parameters and again states that the responsible person should “wait to submit a report on the incident to the FDA until the information is obtained.”

This raises a key question: When adverse experiences are mentioned within consumer-generated media (CGM), do they meet the FDA’s criteria for reporting?

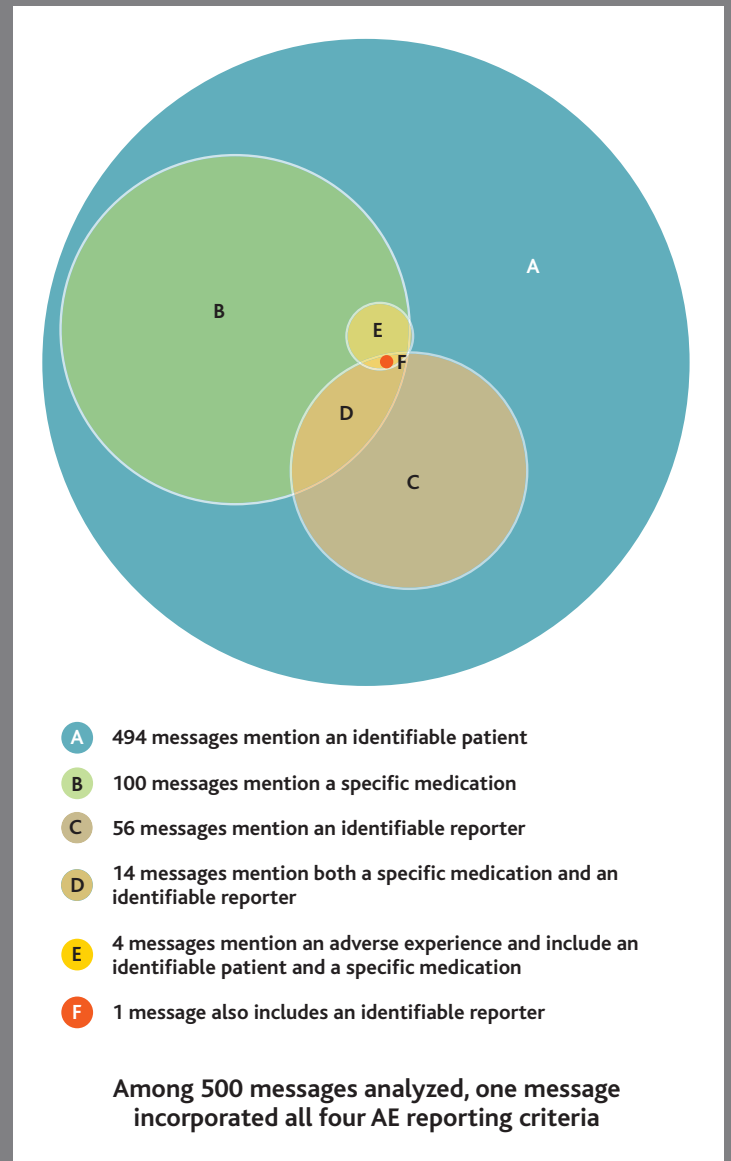
In a recent Nielsen analysis of 500 healthcare-related messages posted online across multiple disease categories, Nielsen’s BuzzMetrics analysts found only
(continued)

one message that incorporated the information needed to meet all four of the FDA's AE reporting requirements (see chart for details). In this message, a caregiver whose mother was taking chemotherapy reported that her mother experienced abdominal fluid retention, noted that this was not a listed side effect of the medication, and inquired in the online community whether this fluid retention might be a sign that the medication was working.

A note on identifiable reporters: Though the FDA guideline does not specify what constitutes an identifiable reporter, the 2007 draft guideline for OTC reporting notes that in order for an AE report to be submitted to the FDA, there should be "sufficient information for the responsible person to follow-up, such as a phone number or e-mail address."

Most online discussion communities discourage the use of personally identifiable information. This is especially true within healthcare communities, where personal privacy is even more carefully guarded. For example, WebMD's Terms and Conditions of Use include the following: "To protect your privacy, you agree that you will not submit any media that contains Personally Identifiable Information (like name, phone number, e-mail address or web site URL) of you or of anyone else." Other websites use similar language to caution participants against revealing personal information.

In the recent analysis of 500 messages, Nielsen's BuzzMetrics analysts found that 56 messages (11%) contained identifying information that could be used to reach out to an individual to follow up on a possible AE report. It is important to note that all of these messages came from Yahoo! or Google groups, rather than from discussion boards. Groups use their members' e-mail addresses as their online identification; this is a key difference from discussion boards, which use less identifiable screen names for members' online ID. This use of e-mail addresses provides contact information that could be used to follow up with a reporter to gather the details that would be needed for an AE report.



It is clear that a pharmaceutical company that aggressively monitors social media may pick up the occasional AE within patient/caregiver online discussion. Nielsen Online's experience is that this happens very rarely, with a volume that is entirely manageable within companies' broader AE monitoring programs.

The Benefits of Listening

Following are just a few examples of the learning opportunities social media research presents:

Understand patients' questions

Patients who are new to a medication often have questions about how and when to take it. In many cases, these questions may not occur to the patient during the initial doctor visit. Patients often turn to the experiences of others within the online community for answers. Understanding the questions that typically come up can inform the language used in brand packaging inserts, patient education materials, Web site content, DTC marketing and even conversations between sales reps and doctors.

Learn about patients' experiences using the product

Is the packaging hard to open? Does the patch fail to peel away from the protective backing—or fall off too easily after it is applied? Is the eye dropper too short to get the last dose of medication out of the bottle? This type of feedback can quickly bubble to the surface within online discussion.

Avoid response bias

A challenge of market research is overcoming respondent bias. Following

consumer conversations that are taking place naturally in the online environment allows researchers to avoid respondent bias by studying the full scope of consumer feedback—the good, the bad and the ugly. This can be a humbling experience and in some cases brand managers will need to brace themselves for what they will learn. However, many marketers believe that a proactive approach to learning about issues being discussed is preferable to reacting to an issue already snowballing within consumer discussion.

Expand the feedback base

The sheer number of patients and caregivers who are participating in online discussion creates an opportunity to collect data from a much larger sample than is often possible through survey or focus group research.

Answer questions the brand team didn't think to ask

Even the best survey instruments cannot uncover the answers to unasked questions. But if consumers are talking about issues outside of what is expected, listening to their online discussion is a great way to learn about the topics that are driving that conversation. Having this knowledge can inform brand strategy or help shape traditional market research efforts to further explore these consumer issues.

Case Study

A few months after the launch of a new prescription that used an innovative administration mechanism, patients began reporting difficulties that were related to its adhesive application mechanism but not to the medication itself. The first accounts of these experiences surfaced in online discussion forums four months before another media outlet picked up the story, and nine months before a major national media outlet reported on it. When the Institute for Safe Medication Practices (ISMP) reported on these difficulties, it cited messages posted by patients and caregivers from “several online message boards” in its alert.

From the very first consumer-generated messages on this issue, patients and caregivers shared details about their experiences, as well as tips and potential solutions for ways to work around the application difficulty, such as putting the medication in the freezer briefly to make it easier to apply. Ultimately, the pharmaceutical company marketing the medication was able to go back to its manufacturing partner and work to resolve the issue.

Getting Started

For companies ready to take a more active role in the process of listening to consumers, but not sure where or how to start, the following steps can provide a roadmap to leveraging the digital space:

Listen to the conversation

This advice may seem obvious, but for companies wondering how to take advantage of the rich learning opportunities in social media, this is the best place to start. There are many ways to approach this important first step:

Head online to a discussion board and start reading. Marketers could easily start with any of the large health sites—WebMD, Revolution Health, iVillage, Healthboards.com, etc. Most discussion sites are organized into smaller forums by disease category, allowing patients and caregivers to congregate into affinity groups—making it easy for pharma managers to find relevant discussion too. Those concerned about the content of online conversations can start with a disease category different from what they work on. Online discussion boards are public places, and members understand that any information shared there is publicly accessible, so reading the information shared in these communities is not a violation of members' privacy.

Conduct an online search on the brand.

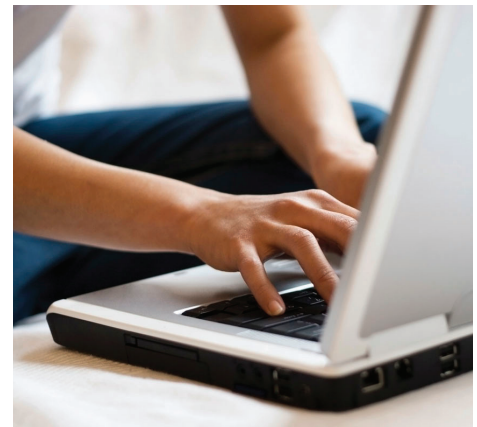
Start by scrolling through the first 20 or 30 search results. How many of these are written by consumers? (The answer may surprise you.) Marketers reviewing online search results should note that these are the very same search results that patients and caregivers will find if they search the same terms.

Visit Wikipedia and see what information has been posted about the brand.

Hint: Wikipedia entries typically include both an "article," which is often more reference-based, as well as "discussion" that usually incorporates consumers' input. Brand managers will want to be sure to read both.

Check for consumer-created videos about the brand.

From serious how-to videos to personal stories and testimonials to spoofs on anything from marketing to side effects, many pharmaceutical marketers are surprised to learn how many healthcare-themed videos are already online. For many brands, snippets from news or other television coverage have been posted in addition to consumer-generated videos. In searching for online videos, marketers will want to search on both their own brands as well as competitors.



Those who are ready for a more broad-ranging analysis (or simply do not have time to monitor the discussion themselves) may want to consider enlisting a third-party service, such as Nielsen Online, to provide this information.

Facilitate the conversation

For companies comfortable listening to the conversation, a next step to consider is helping to build the community in which consumers will congregate. GlaxoSmithKline has already done this with myalli.com, the Web site for its over-the-counter weight loss product, alli™. In addition to product information, how-to's (in both text and video) and assessment tools to help consumers determine whether alli is right for them, the site also incorporates a very popular moderated discussion forum. As of late April 2008,

the alli discussion boards boasted nearly 220,000 messages written by more than 189,000 registered users, and the site is adding new users at a rate of 300+ every day. That is an incredible community of people supporting and encouraging one another to continue using the product—and an amazing opportunity for GSK to listen to its consumers.

The alli message boards engage independent moderators to review all messages before they are posted to the site. (There may be a delay of up to 24 hours before new messages are posted.) The moderators are compensated for their time, but “the opinions are their own,” according to the site. Employing this type of moderated discussion is a great way to facilitate the conversation while also ensuring that the messages posted do not veer off in an inappropriate direction. A moderator would also have the ability to screen for and follow up on messages that indicate an adverse experience with a product.

In addition to launching a discussion community (or instead of this approach, for companies that are not ready), there are other options for helping to facilitate consumer discussion:

Go where the audience is. A brand team might consider partnering with an existing discussion site to sponsor a subforum for discussion related to its brand or disease category. This

type of community may benefit from the participation of a third-party moderator—someone clearly identified as affiliated with or representing the brand—who will take part in the discussion, answer questions and provide information, and generally keep an eye on what is being said.

Provide materials that will help patients better understand their condition and its treatment, and have a more informed discussion with their doctors. There are several options a brand manager might consider, such as a brief questionnaire that helps patients quantify their symptoms prior to a conversation with the doctor, or a listing of questions that patients with a particular condition typically ask, which the patient could use as a discussion guide. (Depending on the disease category, these could even be divided into stages based on the treatment cycle.)

Share condition information or how-to’s for treatment in the form of one or more podcasts that can be downloaded from the brand’s website. This brief video format allows patients to watch again and again and to take the information along with them for viewing at a convenient time.

Incorporate the voices of actual patients through personal stories on the brand site. These could include success stories, treatment milestones,

“Patients are taking an increasingly proactive role as healthcare consumers, meaning that pharmaceutical marketers and brand managers now must navigate new and unfamiliar waters.”

tips on living with and managing a condition, challenges faced and overcome. Text is the traditional format for these types of stories, but marketers may want to consider the power and influence of a video in which a patient tells his or her own story directly to others facing the same treatment and prognosis.

Allow and encourage patients to link to these resources from other sites.

Patients and caregivers are hungry for information about the conditions that affect their daily lives, and they will actively share what they find with others.

Join the conversation

Social media is here to stay. Web 2.0 is a fact of life. Corporate blogging is becoming a reality. Is there a role in this space for someone who openly represents a pharmaceutical company? It may be hard to imagine this as a possibility within healthcare. But there was a time when automotive executives could not imagine allowing a corporate blog—and today, both GM and Toyota have successful, popular blogs led by high-ranking corporate executives.

Another company that is successfully blogging today—and is a little closer to home for pharmaceuticals—is Johnson & Johnson (www.jnjbtw.com). Editor Marc Monseau notes in his introduction that creating this blog was “a big step” for J&J. One can only imagine the planning and

debate that took place behind the scenes prior to launching the blog—and the number of different groups that needed to be involved in the discussion, from Communications to PR to Legal.

J&J’s blog does have its limitations, and these are clearly spelled out on the site. There are certain subjects the authors will not talk about. The blog allows comments, but all comments are reviewed before being posted, and comments about certain subjects—including comments about products sold by J&J operating companies and about any ongoing legal matters—are not likely to be posted. The editor does note that comments not posted on the site may be forwarded to others within Johnson & Johnson for follow-up as appropriate. In addition, the site is more strongly focused on the consumer products side of J&J’s business than on the pharmaceutical side.

In the blog’s introduction, editor Marc Monseau writes that after reading other blogs for just a few months, “it’s clear to me how important it is not just to watch, but to join in productively. Doing that will take some unlearning of old habits and traditional approaches to communicating—and I will have to find my own voice.” Monseau’s thoughts provide a concise summary of not only the value of joining the conversation, but also the challenges inherent in doing so.

“A proactive approach to learning about issues being discussed is preferable to reacting to an issue already snowballing within consumer discussion.”

How might pharmaceutical companies join the conversation?

Consider starting a blog. Although it may take time to research, gain approval for and launch a pharmaceutical-branded blog, marketers who raise the idea within their companies may find that they are not alone in thinking about leveraging this platform on behalf of their organization. There is no doubt that launching a blog will take work and planning—marketers who start now may just be able to make it happen down the road.

Appoint someone from the brand team to take an active role in online discussion as an *identified* representative of the brand. Under no circumstances should pharmaceutical companies try a “stealth” approach—there is a high likelihood that this approach will be discovered and the potential damage to the brand’s reputation is great. (In fact, legislation enacted in the U.K. in May 2008 makes it a criminal offense for a brand representative to falsely represent him/herself as a consumer in online discussion.) Having a brand representative active in the online community creates an opportunity to share information about clinical trials or new research, point individuals to a patient-assistance program, provide answers or additional

input when questions (or misinformation) are shared, and even suggest that individuals follow up with their doctors if they mention unusual treatment effects. When this is done with an open, honest, straight-forward approach, members of the online community tend to appreciate the fact that a company cares enough about its consumers to meet them on their own turf.

For any company, taking steps to begin listening to social media discussion can be a challenging task, and this is especially true in the highly regulated pharmaceutical industry. But the potential rewards are powerful: companies stand to gain a better understanding of their consumers’ authentic voices, their successes and frustrations, their actual experiences. Patients can share in the benefits by having their voices heard and their needs better understood. Many companies outside of the pharmaceutical industry are already seeing the benefits of listening to—and, in some cases, participating in—consumers’ online discussion. Within pharma, a handful of companies have found ways to listen to and take part in the world of social media. For other healthcare companies, though the challenges in getting started may seem particularly steep, the potential rewards can be well worth the effort.



About the Author

As Research Director, Healthcare, Melissa Davies oversees integrated Nielsen Online research and analytics for the company’s healthcare

practice, which serves the top 15 largest pharmaceutical companies in the U.S. as well as many other healthcare clients. In this role, Melissa has managed research projects to study patient/consumer perceptions about multiple disease categories, emerging and established treatments, and key marketplace issues affecting the healthcare industry. Melissa joined Nielsen Online as a Senior Analyst with BuzzMetrics, which provides monitoring and insights based on online consumer-generated media (CGM).

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