Patient Centricity, Transparency, & Pharma’s Reputation

Getting Beyond Lip Service

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“Nobody knows you’re a paid Patient Opinion Leader on the Internet!”
ViiV Healthcare, a pharmaceutical company specializing in the development of therapies for HIV that was created as a joint venture by GlaxoSmithKline, Pfizer and Shionogi in November 2009, recently emerged as the most reputable pharmaceutical company in a PatientView survey of more than 2,000 global patient groups.

**Patient Centricity & Reputation**

Patient rated companies based on six indicators of corporate reputation:

1. patient centricity
2. patient information
3. patient safety
4. useful products
5. transparency
6. integrity

Patient centricity was key to ViiV Healthcare’s reputation rating. Manuel Goncalves, Head of Government Affairs, Patient Advocacy, Community Partnerships, Access, and Communications at ViiV Healthcare, told BioPharma Dive:

“We collaborate with the HIV community, including patient groups, to develop meaningful treatment innovations, improve access to our medicines and support communities most affected by the disease through programs that have a direct and sustainable impact. How we do it is by engaging with and listening to the HIV community to better understand their concerns and challenges, learn about their priorities and challenges, and consider new ways to address them.”

As an example of ViiV’s patient-centric approach, on February 4, 2015, the company announced the launch of ACCELERATE!, a four-year, $10 million initial investment to fuel a concerted community response to the HIV epidemic among Black Men who have Sex with Men (MSM) in Baltimore, Maryland and Jackson, Mississippi, two U.S. cities hard hit by HIV/AIDS.

The goal for this initiative is to help speed up community-driven solutions to increase access and engagement in supportive HIV care and services by Black MSM.

**Patient Centricity and Profitability**

A recent eyeforpharma “Industry Healthcheck” survey of 1600 pharma executives found that 85% of respondents agreed that patient-centricity is the best route to profitability (see Figure 1, top right), although one respondent said there is a “huge gap and disconnect here between intent and action.”

ViiV is not the only pharmaceutical company with a patient-centric focus. Sanofi’s Anne C. Beal, M.D., MPH, was the first Chief Patient Officer to be appointed by a top 10 biopharmaceutical company. “Dr. Beal's appointment will help ensure the patient perspective advances our approach to meeting the unmet needs of patients,” said Pascale Witz, Executive Vice President, Global Divisions and Strategic Development at Sanofi.

**Defining Patient Centricity**

In December, 2014, Dr. Beal gave a presentation at the 11th annual Patient Summit USA conference, where she described the three pillars of Sanofi’s patient-centric strategy (also see Figure 2, page 2):

1. **Input and Understanding**: Utilize patients’ input to get a better sense of their needs, so we can design and deliver solutions that help fulfill them
2. **Solutions and Outcomes**: Engage and support patients and other stakeholders, ensuring the solutions that we deliver enhance their lives and improve outcomes
3. **Culture and Community**: Involve and support our employees to create an engaged community and patient-centric culture

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When asked at the conference to define patient centricity, Dr. Beal said: "We have to be honest. We are making this up as we go along. What I’m saying to my team and people we are working with is there is no one way to do this.”

Whatever the definition, according to Beal there must be a commitment to engaging patients and improving outcomes.

Listen to this two-minute PharmaGuy Audio Snippet to hear more from Dr. Beal: http://bit.ly/1DCeYjV

Transparency

Another “buzz” word/phrase popular in the pharmaceutical industry these days is “transparency.” There’s definitely a need for transparency within any patient-centric strategy and Sanofi’s Dr. Beal specifically mentioned transparency as key to her company’s patient-centric policy.

At SMI’s Social Media in the Pharmaceutical Industry conference in January, 2015, Nick Broughton, Managing Director, Havas Lynx Medical, spoke of “implementing social media ethics” in the pharmaceutical industry.

One of the principles Broughton espoused was “the first obligation is to act morally, not just compliantly. There’s no defense if you make a mistake, especially in social media. When the rules are not clear—and often they’re not—you have to rely on moral principles to make decisions that you can justify.”

Transparency was one of the moral principles discussed by Broughton and several other presenters at the conference. Everyone at the conference, I’m sure, would agree with what the EFPIA (the European Federation of Pharmaceutical Industries and Associations) has to say about transparency:

“The pharmaceutical industry recognises that it has a responsibility to show leadership in advancing responsible transparency.”

Theory vs. Practice

The problem, however, is that transparency is good in theory, but not in practice. This was evident when the discussion focused on revealing payments to patient bloggers and “Consumer/Patient Opinion Leaders” (COLs/POLs) who “contribute” content to pharma-owned sites.

POLs are pharma’s “secret sauce” for social media marketing. POLs have the benefit of already being part of the “conversation,” which neatly solves the marketer’s problem of how to “join the conversation.”

There may be hundreds of patients out there on social networks who are paid thousands of dollars by pharmaceutical companies to be spokespeople or contributors to online branded drug or unbranded disease awareness campaigns.

This came up during a presentation at the conference by a German MS patient blogger/journalist who spoke of her contribution to “Living Like You,” a Novartis Pharma AG website, Facebook page, and Twitter account driven by a “community” of patient bloggers.

“Our team of bloggers are real people with MS, facing similar triumphs and challenges and finding unique ways to live fulfilling lives that can inspire a movement,” says the site.

After the presentation I asked the presenter what I thought was a simple question: “I assume you are paid to contribute articles to Living Like You. Does Novartis reveal this on the site?”

That started a heated discussion and some people tried to rephrase my question as a criticism of patient bloggers receiving payment for their work. “Shouldn’t bloggers get paid for contributing?” was the gist of the counter-argument, which I viewed as a non-issue—there’s nothing wrong with getting paid to deliver a service. But shouldn’t the relationship between pharma and paid patient bloggers be revealed?

That’s one of the questions asked in the Pharma Marketing News Patient Opinion Leader survey, which attempts to gain insights on issues involving

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Can Big Data Analytics Help Pharma Deliver “Patient-Centric” Services?

88% of respondents to eyeforpharma’s Industry Checkup survey believe that better use of real world/big data is vital to the future of the pharmaceutical industry. Some data analytics experts such as Sumit Prasad, Manager at Mu Sigma believe that big data tools can help pharma companies implement a “truly patient-centric” model, which is also important to the future of the industry.

“To implement a truly patient-centric model,” says Prasad, “it is crucial to understand the complex journey through the healthcare system and explore how patients’ experiences at each stage of this journey can be enhanced. Making this concept a reality is not as hard as it may sound. Every patient interaction generates reams of structured and unstructured data.

“With the right combination of big data tools, skills and platforms, pharmaceutical companies can harness this data and generate actionable insights. In turn, these will go a long ways towards identifying patient preferences and formulating future strategies” (source: http://sco.lt/75N0XR).

IMHO, with big data it is possible to be TOO patient-centric. Let me explain...

Suppose, for example, that a pharmaceutical company has an Rx coupon that reimburses patients for the co-payment made when filling a prescription for their product. This is a common practice. In return, patients provide some personal information—name, physical address, email address, etc.—when applying for the coupon. With this information—and permission from the patient—the pharma company can send the patient notices and further offers via US postal mail or email.

A pharma company can use this data in combination with social media monitoring to implement a patient-centric program to help improve health outcomes of patients enrolled in the coupon program.

It’s possible, for example, for a pharma company to monitor individual patient conversations on social media to determine if a patient is engaging in a lifestyle that counteracts the effect of the company’s drug. A Chantix patient, for example, may admit to smoking a cigarette. Combining that with data such as email addresses collected via the couponing program, Pfizer could remind the patient -- via private channels such as email -- that smoking while on Chantix is not recommended. Such reminders could improve outcomes and be patient-centric, but maybe TOO patient-centric!

NOTE: If you think this is a fantasy, read this comment from Geno Germano, Group President, Global Innovative Pharma Business, Pfizer, from a guest Forbes blog post (http://onforb.es/1zLFscN): “Through digital information, it’s possible to offer supportive health information when we are open to making positive changes, like quitting smoking. Only five percent of unaided quit attempts are successful, yet quitting is one of the best things people can do for their health. Through information, we can more effectively reach people when they are ready to change, engage the support of friends and family, and connect them to the guidance of a healthcare professional, a relationship shown to double quit success rates.”

transparency and conflicts of interest that may arise when pharma companies pay individual POLs to help them engage with patients online. The survey asks questions such as:

• What best practices should govern pharma’s collaboration with POLs?
• Should the industry develop guidelines for their interactions with POLs via social networks (e.g., develop a “Patient Opinion Leader Transparency Policy”)?

You are invited to respond to this survey here: http://tinyurl.com/2fr784u After taking the survey, you will be able to see a summary of responses to date.

Is It Obvious?
Meanwhile, the counter-argument to the question at the conference was “It’s obvious. Everyone knows these people must be paid.” No, it's not. Readers could infer that a “team of contributors” means that

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bloggers are contributing content not for monetary gain but for recognition or for purely altruistic reasons such as helping other patients.

The counter-arguers emphasized that there is nothing wrong with patient bloggers being paid by Novartis to “contribute” content to Living Like You and readers don’t mind if they are paid—it would not bias them against the content. Then why all the heat about my suggestion that Novartis should reveal this payment on the site?

Unfortunately, the response to my suggestion was confrontational and not so pretty, which is unfortunate considering that the MS patient blogger made the point that “not to accept a critical thought is not so pretty.”

The other side of the coin is transparency by patient/consumers contributors. Should the MS blogger reveal to her blog readers that she gets paid for contributing content to the Living Like You site? She should, IMHO, if she encourages her readers to visit the site (i.e., promotes the site on her blog). In any case, whether or not she does this is up to her, but Novartis should encourage her to be transparent—assuming that Novartis is transparent about it as well.

The pharma industry should follow the example of Janssen, which encourages its patient partners to be transparent about the relationship. The company is offering patient advocacy groups a free “Social Media Toolkit” to help them “articulate and voice their points of view.” Janssen’s statement titled “Absolute transparency” in regard to the distribution of this toolkit is a good model for other pharma companies to follow for disclosing ties to patient bloggers working on their behalf.

Here’s what Janssen has to say about transparency:

“Janssen is fully aware of the potential pitfall of conflict of interest posed by pharmaceutical companies and patient groups working together. That is why Janssen stipulates that such collaborations may only take place in absolute transparency, with contractual documents specifying the scope and modalities of the interaction.

“Each year, Janssen companies post on their websites a list of all patient groups receiving contributions and educational grant funding. Each entry includes a description of the project and its objectives. The company also encourages patient groups to post this information on their sites as well.”

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