



THINKING MORE LIKE A PATIENT

A major information explosion is just the tip of the iceberg in the paradigm shift that is taking place between pharma, marketers and the patients that they serve. **James Chase** asks experts from across the patient-to-pharma spectrum how the industry can negotiate the new environment to successfully put patients first



James Chase
Editor in chief, MM&M



MarlaJan DeFusco
BSN, RN, CPN, Children's Hospital of Philadelphia; Lupus patient



Fred Latasa
SVP marketing, WebMD



Melva Covington, MD
Project leader, research and development, Sanofi



ALL PHOTOS: DAN D'ERRICO

James Chase (MM&M): What does patient-centricity mean to each of you?

Marc Sirockman (Artcraft): I was a pharmaceutical rep down in South Jersey, I carried the bag, and back then the focus was calling on the healthcare provider, and the physician was the one that wrote. So that was our target. A lot has changed in the industry. To me, patient centricity is really helping patients with understanding disease state management, adherence/compliance, all the issues they face each and every day.

Fred Latasa (WebMD): I've also seen at WebMD over the last 16 years that the relationship between health information, and the patient, and the doctor has dramatically changed. For us, what patient centricity means today, is really looking at everything we do through the lens of the patient. Everyone has looked at health in terms of the way that we define health for patients — newly diagnosed, diagnosed, living with that risk, etc. — but that's not being patient-centric. The patient doesn't think of themselves that way. So, for us, the biggest challenge to being more patient-centric is how do we engage the patient and deliver information in a way that's going to resonate with who that patient is and what they're experiencing?

Jacob Agris, MD (Bayer): My background is actually more traditional medicine engineering. To me, patient-centricity means different things in different processes and points in things I do. What does it mean when you're talking about development? What does it mean

to the patient further out? And maybe the most important thing is what does it mean right now when we're looking at an age where you pick up your cell phone and you have as much computing power as many of us had in whole universities? There's a transfer in the power of information from the physician to the patient. "Do I really want this drug or this treatment? I already checked it on Google and, you know, this is what I want from you as my physician."

Campbell Howard, MD (Novartis): I'm doing new drug development, and I've seen an awful lot of change in the healthcare system. But the concept of the patient-centric for me, in drug development

at least, is not so much recruitment, but patient retention. And the patient, I think, makes the decision not only to get into a trial, but more important to staying in the trial. That involves knowledge about the disease for which they're involved in the trial. So, the issue for me is ... is patient-centered medicine good because it takes the physician out of being in control, or is it not so good? I think if you've got a lot of gray hair like I do, you would probably be hesitant to be an advocate for the patient making too many decisions. But the healthcare system is so screwed up that I believe that the patient now has to be functional.

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Todd Kolm
Senior vice president of strategy, WEGO Health



Campbell Howard, MD
Senior medical director, clinical indication leader, Novartis



Jacob Agris, MD
Director, global clinical development, Bayer HealthCare



Marc Sirockman
Executive vice president & general manager, Artcraft Health



Melva Covington, MD (Sanofi): I have the honor of working with an excellent organization, particularly in what we're doing around patient engagement. It's interesting in terms of what we're doing, because we're not only taking an external approach, but we're looking internally at our structures and our systems. So really, it's looking at the entire lifecycle development process. It's about engaging patients, their families, and communities throughout the entire process, and understanding that what is valuable in the context not only of that patient, but the environment in which they live, is crucially important.

“We all want the same thing, which is to feel better and get back to as much of a normal life as we can”

— MarlaJan DeFusco, Lupus patient

MarlaJan DeFusco (Lupus patient): For the past nine years, I've been a registered nurse at the Children's Hospital of Philadelphia. I've also been a patient there. I was born with Tetralogy of Fallot. By the time I was six, I'd had four open-heart surgeries. I, apparently, drew the short straw in the family gene pool because, at 26, I was diagnosed with systemic lupus, Behcet's disease, and an array of other autoimmune diseases. Most recently, a mass was found in my left breast, and I will probably undergo a double mastectomy within the next couple of months. Patient-centricity, to me, I guess, means realizing that no disease is “one size fits all”; and no one will undergo the same treatments. No one will have the same outcomes. We all want the same thing, which is to feel better and get back to as much of a normal life as we can. But a treatment that might work for you could be the absolute wrong thing for me, and I've seen that a lot. There might be pressure from certain pharmaceutical companies or other outlets for doctors to give certain medications without really looking at the patient, looking at the lab work, looking at tests and seeing if that really is the right drug for them, and I think they need to bridge the gap. It's about doing what is right for the patient.

Todd Kolm (WEGO): While I was at Pfizer, one of my primary focal points was the recognition that patients are taking more control of their health, and that a company like Pfizer isn't necessarily the primary source of information about these products anymore. For me, it was an alarm bell that said: This is an opportunity. We need to

understand the patient perspective better, and to do that, we need to, obviously, talk to real patients, but we also need to understand their whole journey. And so, for me, patient-centricity is born out of listening. It's about understanding that patients are people, that data represents individuals, and that those individuals are not the same. Industry is embracing that patients are in control. People are going to own their health, so recognize that. Invite them to the table.

James Chase (MM&M): The pharma industry has always developed products that improve and extend the lives of patients. So why is there now such an increased emphasis on the patient? Why are we now sitting around a table discussing how to do this better? Why wasn't it the focus before now? What has changed?

Todd Kolm (WEGO): In the past, the roads were always paved, the masses were predictable, and maps were printed. The roads would take you straight to the physician and straight through the physician. Now, we're kind of off-road. There are many ways information's going to flow and if there are people actively seeking it, the industry's recognizing that they're going to get it. So, in a sense, industry's recognizing that, number one, it's got to give up a little bit of the control that it's always had, and then the second is that people are going to go out and seek this information, and so, if you're not there, you're not providing them with the services that they need.

Melva Covington, MD (Sanofi): I would agree. And I think that it's not linear. It's really the convergence of different forces. We've improved our healthcare system to the extent to which we have a lot of technology, but that's also driven up the cost of actual care.

Also, technology and the way people use technology has absolutely changed the dynamics of engagement. Our ability to really understand that from an industry perspective and engage is critical.

The third thing that's happened is the decision makers are coming to the table with very different goals, and I think that, when you have that convergence of information, conversion of action, conversion of engagement, it forces different and dynamic things in the marketplace.

Fred Latasa (WebMD): The perfect storm was the expression that came into my mind. It's all these things that you said coming together, and also there are some basic things. People are living longer. People are working longer. People want to feel better. And they have access to more information.



Jacob Agris, MD (Bayer): I see an information overload to the physician. New drugs are costing a fortune for many reasons. So we've got to decide, when it comes back to payers and you're looking at outcome measure, why should I pay for this new drug? So, I think some of it's going to be genetics that drives your care, and we're going to want to own that. There's fear of just handing it out and other markers that help us decide who should be treated for what. So, physician choice is plummeting, and with the information overload, it's giving the patient more say.

Melva Covington, MD (Sanofi): I totally agree. As we, particularly in the US, focus more on these accountable-care organizations, there's the tension between not only what one does in terms of treating or providing care, but also to be able to have a system in which whatever it is that you do, you can trace that to measured improvements.

MarlaJan DeFusco (Lupus patient): From a patient perspective, we're now demanding more. The information's out there, either reputable or not. We're able to look it up and learn more about our own disease processes. With lupus and a lot of other diseases, I could subsist on high-dose steroids for the rest of my life, but in five years, I'll have no hips, my blood pressure will be through the roof and I'll be a shaky mess. There's so many side effects, and now we just want something to give us more of a quality of life. Benlysta was the first FDA-approved medication specifically for lupus that wasn't a steroid, that wasn't antimalarial, that was specifically for that, and it doesn't work for everyone. It's very expensive. I'm fortunate that I'm able to get it, but there's so many out there suffering that aren't, and what or who decides, "Well, we're going to focus on cancer instead of this?"

Jacob Agris, MD (Bayer): How they decide is pretty simple. They look for the largest number of people that have a medical need. Orphan diseases have a separate pathway through the FDA to encourage development in this area. But [in general] they're going to target areas that have true medical need and have a large number of patients.

Fred Latasa (WebMD): I'm going to be provocative here. We've been talking about patient-centricity through the lens of pharma, through you guys marketing drugs. But to me, pharma is only one piece to a much larger puzzle. I'm not anti-pharma, don't get me wrong. But I feel a big part of what has changed is that there's so much more to the patient than just taking a pill. I think people are looking at

their health in a much broader context. The conversation is much bigger than pharma and the drugs coming to market.

Marc Sirockman (Artcraft): But ultimately, you are educating the patient. You're giving the patient choices. Back in the day, whatever a physician wrote or said was the word. But now that people are getting empowered and are not happy with some of the therapy that they're getting, they're looking, and they're asking questions.

MarlaJan DeFusco (Lupus patient): I mean, I'm a realist. I know I'm not going to be how I was at 22 and that I have all these issues. But what I want may not be what he wants.

“Now that people are getting empowered, they're looking, and they're asking questions”

— Marc Sirockman, Artcraft Health

Marc Sirockman (Artcraft): Correct, but you're looking for a combination of medications, or therapies, or somebody to talk to, and a healthcare provider doesn't really share the same goals. There's not enough time, sometimes, for the physician to get into this conversation. So let's figure out a way to put the patient in the center. Let's get clear, actionable, relevant, engaging conversations with those patients, and let's figure out, what is our angle? Because I think there's amazingly smart people here that come together to look at this. But pharma is restricted on what we can say. But when you look at it and you listen to the patients, they're challenged, and what we need to do is figure out a way to match them up.

Todd Kolm (WEGO): And what further complicates it, is that patients don't understand how restricted pharma is. So it actually looks like...

Marc Sirockman (Artcraft): ... it looks like they're not listening.

Todd Kolm (WEGO): That's right. And so, if you could understand the patient, explain your own limitations, but understand their own perceptions and have a dialogue like we're having here, that's a lot different than just a focus group or bringing someone in and eliciting that through one little piece, and that's it.

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James Chase (MM&M): So what's the one thing that each of you would like to see the industry do in the next year or two to improve patient centricity? How can pharma make this happen?

Marc Sirockman (Artcraft): I'd like to see pharma creating what I would consider as a comprehensive plan for the patient from the very beginning of their experience to the very end of their experience and have that two-way communication with them. So, creating material that's simple, easy to read, easy to digest, that really fits their need throughout the journey they're going through.

Fred Latasa (WebMD): To build on that, is to figure out what they're solving for in terms of the patient. So, the pill solves for one thing, but the patient is solving for something greater. If pharma could embrace or have a point of view on what they're solving for some patient types, and really bring forth a greater solution, to be more relevant.

“The emphasis should be on providing accurate information at the patient's educational level”

— Campbell Howard, Novartis

Jacob Agris, MD (Bayer): Pharma needs to get the patient perspective early on in the Phase 2, Phase 3 studies, and to move forward with the patient-centric opinion later on. In the past, pharma concentrated on getting the buy-in of the physician, and then it shifted a little bit to the bigger buyers like hospitals, or managed care, and all the other things we deal with. But the shift has got to be to get the patient's trust, buy-in, and that they desire that treatment to the point where they know, as you said, what to expect, what to do for the treatment, and what to look out for. It's selling on that they're believing that's what they need for their body, and their problem, and their life.

Campbell Howard, MD (Novartis): Yes, I think the future and the emphasis now should be on providing accurate information at the patient's educational level so that the patient is more aware of alternatives to the treatment options that are available, and also is provided sources for getting additional information, whether it be the internet and the blogs, or support groups, advocacy groups, government, organizations, or insurance companies. That information, I think, isn't

always readily available. I'm also a big advocate for access to health-care. The more people that have access to care, the more opportunity there is to improve the quality of life and the quality of health, and all we have to do is figure out how to pay for it, but that's politics. I mean, we all know how we could pay for it in the room here, but we get away from the politics, and that's what the problem is.

Melva Covington, MD (Sanofi): It would be nirvana if pharma could be immersed in making sure that there is diversity in representation at clinical trials or in observation research, to the extent that it reflects the population that's impacted, whether that's based on, again, age, gender, lifestyle, ethnicity, culture, the diversity of culture.

MarlaJan DeFusco (Lupus patient): Again, just to bridge that gap between pharma and patient, I think the biggest thing is education. I know you [pharma] guys aren't marketing, but the industry needs to find a way to bring some education to that advertising/marketing piece so we know what we're getting into.

Todd Kolm (WEGO): I would agree there is a need to educate. There is also a need for dialogue. While there's a lot of science to share, it needs to be conveyed in human terms, and so, that might not always be directly to that end user. It might actually need to be filtered through the intelligent, articulate patient. Someone like them, the Marlas of the world, so that, in order to reach, let's say, the broader lupus community, you might need to go through these influencers. Pharma should recognize the power of the patient care well, embrace that, and use them appropriately.

And besides simplifying information, another thing is also the tone. Pharma has to have a very professional tone. But Marla was selected by the community as “the most hilarious health activist.” Her blog is called Luck Fupus, okay? And the tone is one of, “Damn this disease, but I'm going to pour my heart and soul out and filter this information through the lens and through the aura of humanity,” but also of humility and humor...

MarlaJan DeFusco (Lupus patient): ... and lots of bad words.

Todd Kolm (WEGO): And that's something that is going to get across. It's going to resonate. It's going to connect. Because, when you're diagnosed with something, you're going to look to people who are wearing similar shoes. ■