



# Patient/Caregiver Empowerment

The industry's intensifying focus on patient-centricity is transforming its engagement strategies with all stakeholders.

**P**atient empowerment is creating a shift in not only marketing but also clinical strategies for the industry. As patients take more control of their healthcare decisions and needs, they are inadvertently forcing the healthcare environment around them to change. As physicians evolve their approach to focus more on meeting the demands of information from digital savvy patients, and the demand for quality patient outcomes from payers, the life-sciences industry has started to follow suit. In the years to come, a focus on customer experience and engagement will become an increasingly larger portion of the value proposition for products and brands. To provide this value, the industry will need to up its game in terms of relationships, communication, and developing strategies that address the needs and expectations of today's patients, as well as caregivers, providers, and payers.

Patient engagement has been called the "Blockbuster Drug of the Century" because of its potential power, says Vera Rulon, direc-



The industry needs to rethink how it does business; companies need to be where people are, and that's on their smart phones.

**VERA RULON**  
Pfizer Medical

## FAST FACT



ACCORDING TO THE WORLD HEALTH ORGANIZATION, THE US SPENT MORE ON HEALTH CARE PER CAPITA (\$8,608), AND MORE ON HEALTH CARE AS A PERCENTAGE OF GDP (17.9%) THAN ANY OTHER NATION IN 2011. IN SPITE OF ALL THIS INVESTMENT, THE COMMONWEALTH FUND RANKED THE US LAST IN THE QUALITY OF HEALTHCARE AMONG SIMILAR COUNTRIES.

Source: SAS

tor, external medical communications, Pfizer Medical.

"This power stems fundamentally from access to information: information about a disease, about healthcare providers, treatments and medicines, and about personal health information," she says. "The industry is starting to recognize that patients aren't standing still, and are already re-defining the shift in the industry's strategies, creating many intriguing examples of organizations re-orienting themselves to become more patient centric."

There are several new themes running through the patient-centric dialogue, including knowledge sharing, patient programs,

and new research techniques. Silos need to be eliminated, integration and partnering will be key, and the buzzword "patient centric" will become not only a corporate philosophy, but also a solid business model.

On the road to this evolution, the industry will want to focus on three basic tenets. To create an integrated approach to patient care and engagement, the industry needs to better understand the emotional insights and overall root causes for patient decisions.

"We as pharma tend to focus and base our decisions on facts, data and science; however, patients' decisions are often purely emotional," says Christine Sakdalan, VP, patient centric strategy and solutions, Novo Nordisk. "We need to shift our strategy to focus on the emotional insights into patients' behavior, unmet needs, and the barriers to treatment."

Ms. Sakdalan says organizations are incor-



We'll continue to see the industry focus on developing predictive models and clinical decision support tools to match the right patients to the right medications.

**RUCHIN KANSAL**  
Boehringer Ingelheim  
Pharmaceuticals

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## Industry Outlook

Our industry experts talk about the importance of digital capabilities in the patient-centric model.

### SANJAYA SHUNGLU

Director of Marketing,  
Infinity Pharmaceuticals

Two significant trends in healthcare have raised the importance of a digital presence in the patient-centric paradigm. First, the increase in cost sharing with patients has led to a much larger group of patients demanding transparency and involvement in care decisions. Second, the rapidly growing mobile digital medium has led to the proliferation of information literally at the patient's fingertips. Together, these trends make mobile digital a cornerstone of interaction between each of the engaged participants: HCPs, patients, payers, and manufacturers, leading to an involved patient. It is widely believed that that this increased involvement leads to improved care management and patient outcomes.



### BRIAN GOFF

Executive VP and  
President, Hematology,  
Baxalta Inc.

With the explosion of health content online, patients and caregivers have unprecedented access to information that can inform their decisions related to treatment and management of their condition(s). Emerging digital platforms offer a unique new venue for peer engagement and dialogue, and at the same time offer a brand new opportunity for our industry to connect and engage with the community. As we consider how we can improve our support for patients, our industry must understand how our audiences choose to engage in the online community and what we can offer on these channels that is useful to their journey without making information access too complicated. At Baxalta, we've re-engineered many of our programs and offerings with a view toward digital and mobile use by our

communities. For example, we've introduced a number of "apps" and mobile-optimized destinations that can help patients or caregivers track treatments, understand disease management and engage with peer groups. Further, we're using these integrated digital channels to improve information access to more diverse, cross-cultural patient communities around the world. With an appreciation for what patients want and how they want to engage, we have a tremendous opportunity to participate in the increasingly robust and globally-integrated online health community.



### VERA RULON

Director, External  
Medical Communications,  
Pfizer Medical

We have all seen data on the rise of the use of smartphones and digital technology as the new way of communicating. This phenomenon is global. New business models, such as Uber in transportation, are disrupting longstanding models. Uber's and other disruptive models share a common theme: they build around the needs of the customer and not the needs of the service provider. They use digital approaches to connect customers and providers, to make customers' lives easier. Healthcare and the life sciences are no different. From redesigning how we do clinical trials, to supporting a person's management of a disease, we need to rethink how we do business to be where people are, and that's on their smartphones, using wearables, and doing research online.

### CHRISTINE SAKDALAN

VP, Diabetes Marketing, Patient Centric  
Strategy and Solutions, Novo Nordisk

It's paramount, and it's critical we are on top of this. Digital is a relevant and timely way to connect with patients. However, content and relevance are still



Just as paramount. Content still needs to be emotionally charged, relevant, and impactful or it won't drive a change in behavior.

We need to tap into the opportunity in the EMR space as this is at the point of care where education and engagement is critical and probably most relevant. Digital is also a way to be able to support the patient after they leave the HCP office as this channel has become one of the key drivers for how patients become informed and educated.

### GAIL COHEN

Executive Director, Corporate  
Communications, Acorda Therapeutics

There's no denying that healthcare has gone virtual. In fact, according to Google one in every 20 searches is for health-related information. Digital communication has the power to improve access to information for patients and the industries that serve them, and eliminate barriers to patients' access to care. Digital tools and social media are cost-effective solutions that can help to identify patients who may benefit from therapies and speed clinical trial recruitment, which can cut down on costs and development timelines. This is especially critical for smaller companies with limited funding.

At Acorda, we're leveraging digital technologies to open the lines of communication with patients. We recently created a digital strategy and innovation department, a dedicated part of the company focused on developing groundbreaking digital initiatives. For example, our MSself app helps multiple sclerosis (MS) patients manage their symptoms and the website for our MS therapy Ampyra is personalized based on each user's behavior.

porating this focus into their strategies and business planning processes, and organizations, like Novo Nordisk, have made patient centricity more than a buzzword by incorporating an intentional focus and discipline into their organizational structures.

"At Novo Nordisk, while patient focus is an expectation with every employee as well as part of the Novo Nordisk Way, we have also decided to invest in having a dedicated team focused on improving patient care, education, engagement, and their overall experience,"

she says. "Some companies even have a chief patient officer or a chief experience and engagement officer."

To bring more value to the patient experience, Ms. Sakdalan says the industry needs to help patients with tools that make their

journey easier. Another place that serves as a benefit for patients is information around reimbursement.

“When it comes to patient affordability, the more that we can provide transparency and healthcare literacy, the more value we can deliver,” she says. “Everything we do is based on the journey of the patient. We focus on each phase of their journey, on their needs and desires, and on areas of their journey where we can make the most impact.”

Many other companies have also started to

provide patients with the right tools to help improve their outcomes — a big step in the right direction for patient-centric experience. Companies recognize the value of offering personalized information to help patients manage their diseases and adhere to their medications.

“Technology has played a huge role in helping to personalize information, giving patients more control over their health,” says Ruchin Kansal, executive director and head, business innovation at Boehringer Ingelheim Pharmaceuticals. “With this, we’ll continue

to see the industry focusing on developing predictive models and clinical decision support tools to match right patients to the right medications. Further, the industry will continue to invest in enhancing the patient experience through services and solutions, including investments in digital health tools and partnerships with health tech companies.”

There are three important steps companies have been implementing to add substantial value to the patient consumer, says Sanjaya Shunglu, director of marketing, Infinity Phar-

## Industry Outlook

Experts discuss how to fill the unmet needs of a patient-centered paradigm.



**TIM FISHER**  
Ph.D., VP Social Science and Healthcare Practice, in-sync

There will be increased recognition of the need for more tailored, individualized communication at specific moments in the patient’s journey. In other words, rather than focusing on messages that resonate with the patient’s experience in a general way, there will be a need for targeted communication that helps patients make sense of particular situations they encounter and that communicates in ways that are more compatible with the patient’s psychological state at those specific points in time. This will produce more convincing messages that reflect patients’ genuine preferences in how they want to receive information.



**TRACY FOSTER**  
President, Lash Group, a part of AmerisourceBergen

The shift to patient-centricity is here and patient engagement matters. When we put the patient at the center, we’re able to better identify their needs, determine how best to empower them and, ultimately, help them to reach the best health outcome possible. We’ve been watching three key trends: patient access and affordability, value based payment models, and quality improvement initiatives. Each of these factors is highly dependent upon patient engagement in order to deliver outcomes and value to the overall

healthcare system. Programs designed to effectively impact patient engagement are shifting: from product-specific education to services that address a patient’s needs more holistically, including affordability and access, adherence support, transportation needs, etc.; from one-way communication approaches to multiple modalities supporting patient, caregiver, and healthcare provider interaction; from a one-size-fits-all approach to customized patient care plans that put patients in the driver’s seat and make them a part of their decision making team.



**PAUL O’NEILL**  
President, Ogilvy CommonHealth Wellness Marketing, part of Ogilvy CommonHealth Worldwide

The current paradox of healthcare decision making lies in the fact that patients are far more involved in, or in control of, decisions regarding their care, but their traditional sources of “authority” are becoming less accessible as time with healthcare professionals and others is under continued pressure. While information is readily available through alternative sources such as the Internet and social media, patients are often ill equipped to sort through the barrage of often contradictory and incorrect information. Informed does not necessarily equate to knowledgeable.

Responsible healthcare marketers have responded to this growing need by attempting to provide understandable and balanced information and resources to help patients become more well-versed in the critical considerations in their healthcare decision-making.



**BRETT HUSELTON**  
VP, Commercial Strategy & Opportunity Development, United BioSource Corp.

Today’s patients are more proactive and better informed than ever before. With the extensive variety of communication channels at their fingertips, we must provide a multi-channel approach to give patients options and tailor communications to their needs and schedules. Web-based programs, including mobile applications, allow patients to dictate timing and interventions. As patients travel through their daily lives, mobile apps allow them to record real-time information. We can expect to see more apps connecting with monitoring devices to collect information on how and when patients take their medication, activity levels, sleep behaviors, vital signs, and key lab indicators. Regardless of communication channel, patient materials will need to be increasingly strategically planned and distributed at points in therapy when specific information is most relevant to a patient’s individual situation.



**ARYEH LEBEAU**  
Executive VP, Client Services, Remedy Health Media

Pharma has helped usher in an era where patients play a highly active role in shaping healthcare. Brands are no longer content to limit digital DTC efforts to straightforward brand promotion and basic disease information. Bulked-up brand sites are now aimed at truly engaging patients — both

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maceuticals. First, there has been broad and deep adoption of new data sources and advanced research methods to delve underneath stated patient needs. Second, companies have expanded efforts to educate the diverse constituents, helping them gain accurate and complete information as well as valuable input from their support network. And third, industry is taking rapid steps toward implementing information and support programs, along with resources that complement direct care teams, such as nurse hotlines, medical information websites, to help

them make complex decisions that encompass both emotional and physical variables.

“The industry has taken these and other significant steps to be more patient-centric in its approach to providing patients the right info in a timely manner,” Mr. Shunglu says.

Across healthcare communities, patients have made it clear in recent years that they want to play an active role in their care and make joint decisions with their doctor to manage their conditions in the way that works best for their individual needs. It is critical for com-

panies to listen carefully and fully understand the patient journey so that they can deliver the kind of support patients are expecting.

“At Baxalta, we place patient interests at the very center of all we do to ensure we’re delivering solutions and support that provide meaningful benefit,” says Brian Goff, executive VP and president, hematology, Baxalta. “Through our many years of engagement with people in the hemophilia and rare diseases communities, for example, we’ve learned how much they value individualized support that

prospective and those already on script. Token reference materials have transformed into a wealth of instructional videos, patient stories, and interactive tools. With increased support of social efforts and unbranded disease education, pharma has acknowledged that moving patient conversation forward by any means — whether with an HCP or among themselves — is a win.

#### LAURA MOORE

**Health Psychology Specialist,  
Atlantis Healthcare**

True patient empowerment requires more than just education when it comes to managing one’s health. It requires us to acknowledge and address the underlying motivators and barriers that influence how patients and caregivers think about the illness and treatment. We need to understand the beliefs that drive patient behaviors along their journey, and make patients active participants in improving adherence to their prescribed treatment. Likewise, it’s important to support family and friends in their roles as patient proxies, caregivers and in taking care of themselves. Input and engagement from the HCP is also important, but only as part of a broader communications plan that includes all stakeholders.

#### JOHN SKOLIS

**Director of Digital Strategy, Cambridge  
BioMarketing Group**

We are in the midst of a second industrial revolution driven by dramatic advances in digital technology, capability, and interaction. Nowhere will its impact be more immense than in patient-driven healthcare. From health tracking to EMRs to on-demand healthcare, digital resources are empowering pa-

tients to become more engaged in their healthcare decision-making. This is impacting the course of care by creating more educated and independent patients among populations afflicted by all epidemics, including those living with ultra-rare diseases. For healthcare professionals, these disruptive new models are opening new engagement opportunities with patients and nurturing deeper interactions with adjacent care providers under a more comprehensive healthcare model. The digital convergence will continue to shape and define this powerful new patient-centric paradigm.



#### AL TOPIN

**President, HCB  
Health — Chicago**

Although the call for patient empowerment continues to grow and patient-centricity is the new war cry, one area continues to be overlooked. Certainly, patients and caregivers should and must be an important part of their own medical team, but what’s often missing is a quarterback. Complex comorbidities, unfathomable insurance coverage, and the growing intricacy of treatment procedures have created an obstacle course for HCPs, much less patients and caregivers. Someone needs to step up and be the guide.

Several future trends show promise. Specialized clinics will increase their comprehensive patient support and begin to demonstrate improved outcomes. The growth of independent case workers who are able to assemble the various puzzle pieces into an understandable picture will flourish, at least for families that can afford the additional cost. Volunteer advocate groups and agencies will attempt

to provide the same support for those families who cannot. Unfortunately, despite the growing power of patients and caregivers and the increasing support of manufacturers, the complexity and frustration of managing a patient’s total care plan will only increase.



#### RACHAEL WYLLIE

**CEO, CRF Health**

We have an expectation of communicating through e-solutions, and the benefits that these technologies can bring to healthcare and

drug development are huge. Using technology that patients are already familiar with such as smartphones, means that patients can report on their health in a way that easily fits into their everyday schedule, improving the accessibility and usability, and making it simpler for them to meet their obligations, such as participating in a clinical trial. Together these factors improve the patient’s overall experience, boosting compliance and increasing the quality of the feedback and data captured. Sponsors and caregivers are not left out, constant access to data means they get a clearer picture of a patient’s health that is not limited to just site visits. At the same time, they can be alerted to and respond to any issues or concerns immediately. With modern technology now firmly embedded in people’s lives across all generations we are in a prime position to implement more audience-appropriate solutions in our programs. This not only puts patients at the heart of healthcare, but also enables us to maintain our focus on quality data and efficiency.

## Industry Outlook

Delivering valuable patient-centric programs will become SOP for the industry in the years to come. Experts provide their insights on how best to address patient and physician services.



**JOE ABDALLA, R.PH.**  
Chief Commercial  
Officer, TrialCard

Physicians must advocate for a brand program. This is incredibly vital as the onset of pay-for-performance reimbursement models force physicians to focus heavily on patient outcomes. Offering proof of effectiveness speaks volumes for a brand in this scenario, as succinct data that demonstrates success is the most powerful mechanism to engage physicians and increase their propensity to recommend a treatment to future patients. Integrated program strategies that capture patient-reported outcomes and communicate them to physicians provide tremendous value by helping inform treatment plans that ultimately result in greater patient success.



**DAVID BALDERSON**  
Global VP, Safety  
Operations, Sciformix

While traditional approaches to understanding patient needs such as market research and focus groups still have their place, the 21st Century patient typically uses the digital environment to research their disease and treatment options and are often just as happy discussing their condition with a fellow patient online as they are with their own doctor. Companies must continue to expand the use of digital media to not only provide information, but also to listen to patients' and HCPs' comments, sug-

gestions, product benefits, and product safety information. Programs within companies must record the AEs, but in addition these programs should also attempt to understand the information coming from patients and HCPs.



**JAY BOLLING**  
CEO, PulseCX

In today's world, patients and physicians have easy access to most of the information they need to make necessary decisions. Gone are the days when marketers and sales people had to deliver the product's features and benefits, as our customers typically have this information already — and may not perceive "us" as the most credible source of this information. Today's point of differentiation in healthcare sales/marketing is about creating positive customer experiences (CX) and helping HCPs and patients navigate the myriad interactions throughout their disease/treatment journeys. Key "moments of impact" in the customer journey are the critical or decisive times on which much depends — the make-or-break moments when, if all goes well, the customer will continue the journey and take the desired action to write a prescription, talk with their doctor, initiate therapy, etc. It's time we stop "selling" — maybe not literally, but certainly figuratively. If the industry wants to engage target audiences and truly add value beyond the pill, we must move away from pushing brand features and benefits to create immersive customer experiences.

can help reduce the burden of the disease on their daily lives. This is why we continually strive to improve our support programs to help them navigate their healthcare journey."

For example, Baxalta's NAVA program — a personalized support website, call and live chat center available 24/7 for patients with hemophilia — offers educational resources and support, and access to peer advisors, others with hemophilia, who serve as useful resources truly understanding their journey.

"We believe that patient interests will con-

tinue to be an increasingly important part of the treatment decision process," Mr. Goff says. "Our focus on patient-inspired innovation and engagement programs will help us continue to improve our own offerings to better prepare patients to make informed decisions."

Other examples, offered up by Ms. Rulon, include the newly launched Get My Health Data Campaign whose aim is to empower patients through access to health information. This campaign is being coordinated by the National Partnership for Women and Families



As an industry, we need to be part of the patient-centric solution.

**CHRISTINE SAKDALAN**  
Novo Nordisk

and has a wide range of sponsors. Another example, Open Notes, which started at the Robert Wood Johnson Foundation, gives patients access to their doctors' notes.

"While there was skepticism at first, both physicians and patients engaged in Open Notes have come to realize that being fully informed engenders trust and enables better care," Ms. Rulon says.

At Novo Nordisk, the company is focused on the patients' experience, but also on their caregivers and allied healthcare professionals such as pharmacists, nurses, and PAs.

"We aim to improve on topics that are relevant to patients and HCPs such as affordability, cost, and burden of diabetes, and the overall impact to the healthcare system," Ms. Sakdalan says. "These are broader topics that affect the patient and increases the burden on them in general. We need to be part of the solution as an industry."

### New Paradigms in Patient Centricity

There are several emerging trends that are creating new paradigms within the industry: new ways to research and understand the patient, increased knowledge sharing, and collaboration with patient advocacy groups.

At Janssen Research & Development, the company has developed a novel scientific approach, called disease interception, which seeks to address genetic susceptibility and environmental triggers in people at-risk of developing disease so that not only can it help patients living with the disease, but it can intervene earlier and prevent progression to disease. Called disease interception, the approach will integrate innovative science, novel therapeutics, precision diagnostics, and new business models to nurture solutions that intercept disease.

Janssen R&D's first area of focus, T1D research, will use the rapidly emerging science of immune diagnostics and precision intervention to provide the foundation to intercept

# CUSTOMER-LEVEL COMMUNICATIONS in a Digital Age



*Contributed by:*  
Marc Sirockman, Executive  
Vice President & General  
Manager at Arcraft Health

If you look at the topics in the 2016 Year in Preview Top 10 Trends, you'll notice a few common threads. One is digital technology, and that should come as no surprise, given the exponential rate of advancement.

From wearable devices and mobile apps that help us manage our health goals to blogs and social media sites that provide us a forum to share lifestyle information and individual health experiences, what might have been considered science fiction a generation ago is now a reality. We're connected online, not just on computers, or even mobile phones, but also through social forums, devices, and anything else you can equip with sensors and WI-FI.

This technology is just scratching the surface. Each of these resources is gathering information in regards to our personal patterns and is developing and collecting our story one click or search at a time. In other words, the availability of data is producing actionable insights into customer-level behavior.

## Our relevancy

Digital technology is transforming every area of the life sciences industry, from research and development through patient education and follow-up. Given the multitude of challenges pharmaceutical marketers face today, such as providing access to the inaccessible and reaching both the community at large and its subpopulations, digital may seem like the answer to our prayers.

There is a danger in it, though. If we're not careful, we run the risk of reducing patients to the sum of their data, which brings us to the second recurrent theme, patient-centered care and personalizing the healthcare experience.

Healthcare consumerism is no longer just a trend, it's the status quo. Patients want to be at the center of their care. And their healthcare providers (HCP) want them to be there as well. That makes it doubly important for pharmaceutical marketers to deliver patient-centered solutions.

## The patient perspective

This is not to say that technology is an immovable barrier between the HCP and the patient. In fact, when used properly, technology has the potential to actually enhance these relationships.

Think how much better an HCP would be able to address the concerns and needs of patients if he or she could identify their journey to that point and understand their mindset based on their background, medical history, and personal motivations.

Also think about social and influence mapping and how important it could be to get thought leadership and new treatments into the hands of HCPs so that they can be informed and educated on potentially lifesaving treatments for their patients.

We as pharma marketers can leverage digital technology to create better accessibility for the HCP and patient and deliver better content and communication that are targeted and clear for the individual audience. A key here is that you can't just put information out there and expect people to understand it.

So how can we avoid the barriers and get to this scenario?

## Clear communication

All of the information available to help patients and caregivers make decisions about their health or to aide HCPs in discussing viable treatment options won't do any good if that information is inaccurate or difficult to understand.

In fact, information that is misinterpreted can be just as dangerous as no information at all. It puts the patient's health and pharma's reputation at risk.

While this sounds obvious, it's more difficult than many realize. According to the National Assessment of Adult Literacy, only 12% of adults have proficient health literacy.

## Personalized experiences

Think about the insights we have into our customers and their experiences. Take it a step further and recognize now that we need to transform and evolve our communication strategies.

Take for example a middle-aged man who has recently been diagnosed with high chole-

sterol following a routine physical. We already know if he is in the 12% of adults with health literacy challenges based on his LinkedIn profile and profession. We also know what appeals to him by his search history, Amazon purchases, and Facebook posts.

The real question is to what extent will we use this information to personalize the healthcare experience for his patient journey to help with adherence and educate his loved ones about his future outcomes and treatment decisions.

The ideal communication strategy changes depending on the personal needs of the individual patient.

## Conclusion

In an era when we are faced with decreased resources, no see physicians, and downsized budgets, we need to make every dollar and every initiative count. Making digital strategies a base operation and key player in any omni channel strategy rather than an added project will enhance your customer-level communication and put the patient perspective at the center of the initiatives concerning them. It's not enough to have access to big data—it's how you use that data through digital solutions that will ultimately have the greatest impact on patient outcomes and marketing objectives.



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other diseases that have immunological underpinnings.

In addition to efforts in T1D, Janssen plans to pursue other disease areas that demonstrate great scientific opportunity, concentrating on diseases with high unmet need, where Janssen has deep expertise and understanding of emerging science, and where there are broader cross-disease applications for scientific learnings going forward.

“The time is now for a major paradigm shift in our industry,” says Dr. Kevin Wildenhaus, behavioral science leader at Johnson & Johnson. “We need to prioritize efforts in developing Disease Interception solutions that essentially prevent, delay, or inhibit progression of disease as an integral part of the healthcare continuum. To make this shift from “diagnose-and-treat” disease-based care to “predict-and-preempt” health-based care will mandate a new model of teamwork.”

For consumers specifically, disease interception will require them to no longer be “patients” but active “participants” in their health, he says. They will need to own their good health, work collaboratively with their providers and embrace industry advances and emerging technologies for early screening and ongoing monitoring of disease risk.

Sharing information on diseases as well as products will become a new role for the industry, and a valued one, Ms. Rulon says.

“From a life-sciences perspective, patient-centric thinking means sharing information not only about our products and the research supporting them, but also about our knowledge base of diseases,” she says. “Many people don’t realize that pharmaceutical companies have extensive, highly valuable bases of knowledge about diseases. Finding ways to share this knowledge will accrue to the benefit of patients and industry alike.”

Digital communication has become a key tool for the industry to reach audiences and share information efficiently, Ms. Cohen says, especially when working with advocacy groups and patients. There is a renewed emphasis on two-way communication between advocacy groups and patients, and the industry, and working through patients’ trusted sources is beneficial to the industry. For example, many patient advocacy organizations are closely connected to the communities they serve and are keenly aware of challenges in the clinical trial process. These advocacy organizations have sophisticated communications channels, which can alert patients of medical research and help them identify trials most targeted to their disease.

“At Acorda, we’re partnering with research foundations and advocacy groups like the Michael J. Fox Foundation’s Fox Trial Finder to communicate the importance of research and

to accelerate our clinical trials,” Ms. Cohen says.

Also, industry and regulators are leveraging patient-reported outcomes to evaluate therapeutic benefit and improve clinical trial design. The idea of incorporating patient perspectives into the drug development process has been gaining momentum with programs like the FDA’s Patient-Focused Drug Development program and the Clinical Trials Transformation Initiative.

### Patient-Centric Research

More productive collaboration between patient groups and sponsors will lead to more efficient and quality-driven data, but the industry needs to revamp its patient research practices to best understand the empowered patient and his or her behaviors. Continuing to work closely with patient advocacy groups can help biotech companies gather better data on the patient experience.

“These organizations have intimate connections to patients, families, and physicians, and the insights we need to inform our understanding of the patient journey,” Ms. Cohen says. “Five years ago, the extent of biotech’s involvement with patient groups was limited, but with the new emphasis on patient-focused drug development and through initiatives like the 21st Century Cures Act, patient groups have more influence across the development continuum.”

Research can only be truly useful if it is responding to a relevant unmet patient need; therefore, early and consistent patient engagement in the clinical research process is critical to design and deliver new offerings that provide truly meaningful benefit and improve lives, Mr. Goff says. In recent years, Baxalta has delivered a number of new therapies, improved and simplified tools for administration and developed new patient resources in direct response to feedback from its communities.

“We have been engaged with the hemophilia community for more than 60 years, and in that time, have learned a lot about what patients and their caregivers value, and how they want to manage their condition,” he says. “This dialogue is what drives our ongoing innovation — we are gaining feedback on the most pressing unmet needs and are actively responding with new strategies and therapies that can help relieve the burden of these conditions.”

Understanding the patient’s mindset through benefit-risk assessment can help bio-

The time is now for a major shift: we need to develop solutions that essentially prevent, delay, or inhibit the progression of disease.

**DR. KEVIN WILDENHAUS**  
Janssen Research  
& Development



We’ve learned how much patients value individualized support that can help reduce the burden of the disease on their daily lives.

**BRIAN GOFF**  
Baxalta



tech companies and regulators tailor clinical trial design, identify potential therapeutic risks, and define meaningful treatment benefits. Developing appropriate scientific methodologies for assessing patient views on disease burden can be translated into new and effective drug development tools, such as qualified patient-reported outcomes and biomarkers.

Acorda Therapeutics used patient feedback to determine the primary focus for outcomes for its multiple sclerosis treatment.

“It was only through reaching out and interviewing people who had been in our early phase studies, and in working with patient advocacy groups to access patients in their networks, that we eventually settled on walking impairment as our outcome measure for Ampyra, which is FDA approved to treat walking in multiple sclerosis patients,” Ms. Cohen says. “This was a symptom for which we could identify a strong, consistent and measureable improvement over a large cohort of patients. And we knew from our frequent interaction with patients that it had a significant impact on their lives.”

Bringing in the emotional element of the patient journey is a new trend that will help further identify behaviors in a more targeted manner. According to Tara Herington, director of patient services, Infinity Pharmaceuticals, says a big change in patient research in

# Innovation keeps the wheels turning.



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recent years has been to uncover the full set of patient needs both personal and disease related. Further, with the uptake of EMR and the availability of big data, industry is well poised to develop a detailed quantification of the patient journey. Importing advanced psycho-social techniques from academia will

help in addressing many of the “why’s?” that underlie behavior.

“Taken together, putting the patient at the center and combining the impact of psycho-social methods with big data analytics will yield superior insights,” Ms. Herington says.

At Novo Nordisk, the company focuses on

emotional insights derived from ethnographic research, looking at patients’ routines and patterns through keeping a diary, observing them in their own environment, and projected techniques.

Examples of projective techniques include, asking patients to draw a picture of how they

## Industry Outlook

Experts offer ways for the industry to revamp its patient-research practices to best understand the new era of digital patients.



**CRAIG BAKER**  
Executive VP, Noble

We ask our clients to test our products with their patients, letting the patient decide which is best. We recently conducted a study with researchers at Auburn University. Our research found that 61% of patients don’t fully read the Instructions for Use (IFU) document, 90% of patients who used a training device during the beginning of treatment rated the training device at least seven out of 10, and 74% reported that in hindsight they should have used a training device. The healthcare industry needs to focus on helping patients through their treatment journey, making sure to properly train them and alleviate the stress and anxiety that comes with using self-administrative devices.



**KATE CALLAN**  
VP, Tonic Life Communications

To me, there is no better feedback mechanism than social media and blogger relationships. While traditional market research certainly has its place, it is often capturing insights on a moment in time or a specific topic or patient segment. Whether building our own direct relationships with online advocates to provide ongoing feedback to patient programs, or leveraging survey tools from online patient communities, the industry has a huge opportunity to engage in real-time, two-way conversations with patients in a way we never have before. In having the ability to speak directly to patients, we are able to better understand how chronic illnesses impact their entire lives and develop tools to help them achieve the goals they set out for themselves — goals that are often more lifestyle focused. Today,

healthcare marketers and communicators have the ability to build long-term relationships with actual people who live with these conditions at various points in their journey. This allows us to build authentic programs that are tailored to and evolve through each stage of the disease journey.



**JAY CARTER**  
Senior VP, Director of Strategy Services, AbelsonTaylor

The old version of the patient journey is closer to a healthcare transaction analysis. That work gives the “who” but not the “why.” Two large consumer studies conducted by our organization have shown conclusively that patients regularly lie in the process of the talking with everyone, notably friends, family, peers, and of course market researchers. The reason why is pretty obvious. Health is critically important to patients, and honest discussions about health and wellness reveal deep vulnerabilities. It’s logical that the patient will lie. It is important for the marketer to understand the core vulnerabilities that are hidden by the patient, and use ethnographic tools to uncover and address those vulnerabilities.



**TODD DURNIK**  
Senior VP and General Manager for USA, LabStyle Innovations Corp.

Technology is shifting healthcare away from being driven by discreet events such as an office visit, diagnostic test, or procedure to a daily process for patients fueled by real, actionable data in real time. In many cases patients can now see their data before their physician, research the implications, and engage their care in a much deeper fashion. The industry must understand how patients collect, compile, and comprehend data

relating to their condition. A connected patient will have a social media circle, see company sponsored content, read blogs, and even dive into peer-reviewed content. This process leaves a digital trail that can be followed. Mapping the trail from the patient’s perspective is imperative and can be accomplished with big data analytics to develop predictive models of behavior.



**LEO FRANCIS**  
Chief Strategy Officer, Avant Healthcare

Noteworthy, is the evolving active participation of patients in advocacy, education, and collaborative forums with pharmaceutical manufacturers to better understand patients’ healthcare journeys. More and more we are seeing, for example, patient advisory boards — analogous to physician advisory forums, groups of informed individuals that represent a diversity of age and geography, with a connection to the broader patient community beyond their own personal disease experience. These patients share their insights and knowledge on a range of topics, including the design and implementation of clinical studies, patient advocacy activities, and reimbursement programs. With the massive expansion into mobile in our lives, one area to consider are the ubiquitous mHealth apps. mHealth is here, but it’s only being slowly embraced by the pharmaceutical industry. To remain relevant and competitive, the pharmaceutical industry needs to supply “technology-based patient support,” which may have an increasingly valued place in improving outcomes and the patient journey.

**LISA HUNT**  
Senior VP, Director of Patient Engagement, Natrel

Patients are now informed and engaged. They no longer follow doctors’ orders without conducting

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felt when they were told they have diabetes or how they felt when they were told they had to be on an injectable.

“These types of techniques will get to the emotions and barriers that we may not understand if we just ask straightforward market research questions,” Ms. Sakdalan says. “We

need to understand how to engage with patients in their own time, in their own space, and in their preferred channels vs. forcing ourselves to them. We need to get on their agenda and the best way to do this is understanding their needs through effective market research techniques.”

“Pfizer studies patient experiences, prefer-

ences, and perceptions of unmet needs in order to identify what is important to patients,” Ms. Rulon says. “As we develop new treatments, we also look at associated changes to patient care and the delivery system, especially as they relate to unmet needs for patients, both individually and in groups.” **PV**



extensive research on their own. Patients and caregivers turn to the Internet to look for education, tools, and resources, and to find other people who have been there, know what it is like, and know what to do. It's important to take a different approach to conducting patient research now. That means a deep dive — right into the entire personal journey of patients and their extended care team. This will help us better understand their attitudes, behaviors, barriers, and motivators from the point of diagnosis through treatment initiation and adherence. We need to know how, when, and why they make decisions. We can only meet the needs of all stakeholders after we understand the insights and truths of the journey each one is on.



**NAREDA MILLS**  
Senior VP, Nursing  
Services, Ashfield Clinical

The patient journey carries great importance but industry must remember it is not a one-size-fits-all experience. There needs to be more research focus on the persona of patients and caregivers, and how they receive and process information. Many factors influence a patient's journey along the way from beliefs about their disease and treatment to health literacy and access to needed medications and specialty care. More resources are now allocated to understanding and providing customized individual journeys for patients to ensure they and caregivers receive the type of message they need, when they need it, in a format that will have impact on them as an individual.

**JENNIFER PETERS**  
Chief Experience Officer, Greenphire

Understanding the patient perspective and their



needs sounds obvious, but this should be at the heart of the trial development process. After all, they have firsthand knowledge of what it is like to live with a certain condition(s) as well as attend study visits and undergo procedures while managing an illness, families, careers, etc. Identifying what would be valuable for the patient by working with them, as well as patient representatives and associations, is likely to increase compliance and retention, which in turn, results in higher quality study outcomes. To do this, sponsors need to interact with patients to determine how and when they want to be involved, or how the trial will impact them. At the same time, this interaction can't be solely based on scientific understanding of a medical condition and the patient's health status. We need to take a more holistic viewpoint of patients and understand the direct implications that this journey has on them. For example, can we be sure that we are getting a patient's complete buy-in to a research program if they are disgruntled that their reimbursement for travel is three months late in being paid? The fact is that something as simple and as easily overlooked as financial reimbursement can have huge implications for patients, and it is important that we understand their journey as a whole to really maximize participation.



**GRAHAM REYNOLDS**  
VP, Marketing and  
Innovation, West  
Pharmaceutical Services

Patient-centric research is critical at all stages of the drug product lifecycle, including administration. For injectable therapies, research that includes patient feedback on how a drug will be delivered will better guide the development of systems that promote greater patient adherence and outcomes.

It is important to develop drug delivery systems that are intuitive and easy to use. Many well-intentioned drug delivery devices are underutilized because of barriers to administration, some which could be addressed through proper education and training. Now with human factors testing and analysis, pharmaceutical manufacturers can gain insight into a user's preferences and behaviors, and those findings can translate into design elements of the drug delivery system. By gaining detailed information on the emotional and physical needs at different points in the patient journey, pharmaceutical manufacturers can shift from a product-centric focus to a patient-centric focus that encourages adherence and can help improve outcomes.



**OMAR SHOHEIBER**  
Chief Market  
Access Officer,  
Guidemark Health

I don't think individuals in the industry are looking at the problem through the right lens and consequently they are not coming up with the right strategies or correct tools. They need to look at the problem through the lens of behavioral economics and social sciences, and to dig deeper to understand what influences patient behavior. Consequently, when designing interventions to modify patients' behaviors, it is important to apply motivational interviewing techniques and adult learning principles. Motivational interviewing techniques give the healthcare professional the skills needed to uncover the true behavioral drivers and allow for a meaningful and deliberate intervention strategy. On the other hand, adult learning principles provide the best tools to move patients along a continuum of knowledge and skills to help them better manage their own diseases.