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Insights

FEATURE

Striving to become more patient-centric in life sciences

What it really takes to optimize patient trust and health outcomes

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DELOITTE CENTER FOR HEALTH SOLUTIONS

In a world where the consumer is increasingly becoming more empowered, life sciences companies should challenge the status quo and embrace opportunities to adopt a wide range of patient-centered approaches presented by an emerging ecosystem.

Executive summary

Stakeholders are recognizing the need for consumer participation in health care decision-making, personalized therapies, and incorporating the patient perspective in product development and approval, but the science around engaging patients and the elements that make up a patient-centered approach is still evolving. The Deloitte Center for Health Solutions set out to understand where the industry is in this journey. We interviewed 27 executives from life sciences companies (primarily biopharma, a few medtech) and patient advocacy/disease research organizations. (See sidebar, "About the research" for more information.)

We identified three waves of patient-centricity in the life sciences industry:

1. **Commercialization:** Most companies we spoke to admitted that their commercial teams and approaches were furthest along when it came to assessing their efforts around patient-centricity.

2. **In the R&D phase:** The consensus seemed to be that to advance patient-centric approaches, companies need to begin much earlier, and explore patient-engagement strategies in the research and development (R&D) phase.

3. **An enterprisewide approach:** As the true value of patient-centricity can be difficult to quantify, a small number of companies we spoke with are focusing on measuring progress toward a more systematic approach or culture-change throughout the organization.

We found four critical strategies that life sciences companies should consider as they evolve their patient-centricity focus:

1. Identify concrete objectives around incorporating the patient perspective into different processes throughout the life cycle and operationalize them

2. Track progress toward delivering (sometimes nontraditional) key performance indicators (KPIs) and return on investment (ROI)

3. Harness digital and data analytics opportunities to engage the patient and collect data on patient outcomes as well as their unmet needs

4. Form deeper collaborations within the industry, with advocacy groups, clinicians, and health

ABOUT THE RESEARCH

The Deloitte Center for Health Solutions interviewed 27 executives from life sciences companies (primarily biopharma, a few medtech) and patient advocacy/disease research organizations.

Industry representatives included chief patient officers (CPOs), patient engagement leads, heads of R&D and commercial leaders, as well as leaders from external affairs and medical affairs from a mix of small, midsized, and large biopharma companies, and a few from the medical device industry.

Senior executives from leading nonprofit patient advocacy organizations that we spoke to focused on a range of diseases and conditions.

plans—and leverage lessons learned from other industries that excel at customer-centricity such as retail and consumer technology.

Our research shows that companies should not only embrace this enterprisewide approach of embedding patient-centricity efforts but also prepare to participate in an emerging ecosystem where disease foundations, patient advocacy groups, health plans, health systems and physicians, regulators, competitors, and technology and wellness companies are all better connected so that the patient is at the center.

Companies that are unable or unwilling to deepen these collaborations could find it difficult if not impossible to participate in a future health care system that is driven by empowered and informed patients.

Understanding patient-centricity

Consumer demand to participate in health care decision-making, the movement toward personalized therapies, and regulators' mandate to incorporate the patient perspective into the product development and approval process are some of the drivers of patient-centricity strategies in the life sciences industry. Many life sciences companies will say they are patient-centric, given that they are making and marketing products for patients. However, the patient perspective has traditionally been viewed through the lens of the

WHAT IS PATIENT-CENTRICITY?

We did not find one standard definition of patient-centricity or patient engagement, or a standard framework or approach. Some companies called their initiatives in this space patient-centricity while others preferred the words patient engagement or patient-focused. A 2016 FasterCures report emphasized the need to craft a common language around the issue of patient-centricity. The report notes that the diversity of terms and definitions can be confusing when trying to move forward and identify the essential elements of what makes an activity patient-centered.[1]

However, many of our respondents tend to agree on what patient-centricity is *not*:

- **It's not a public relations or externally focused initiative:** Many life sciences companies have formed alliances and partnerships with outside organizations, and that is important. But many leading companies have, in recent years, tried to look within the company and change the culture and incorporate processes, methodologies, and metrics to drive change.
- **It's not just about being better engaged with patients as study subjects:** Getting patient input into studies is foundational, but it cannot be the entire strategy. Patient-centricity is not just about making clinical trials more friendly to get faster enrollment and get to market faster, though that is part of it. As one patient engagement leader told us, "Talking to patients about clinical trials is not patient-centric if you are just doing the study you want, looking at what you think is important. It's not interviewing patients to check a box, or cherry-pick what you want to hear, or confirm your bias."
- **It's not one size fits all:** Our interviewees felt that companies DO have to reinvent the wheel—as patient-centricity will look different for every company. As one interviewee said, "We are smart, we do things well. So, we have to do our own pilots. If (our competitor) is doing it, how can we do it better, and our way? Most companies are like that. Not just us."

physician, the regulator, or the health plan. The patient engagement leaders we spoke with acknowledged operationalizing and implementing a truly patient-centric approach requires a scientific methodology which is still in development. We learned about many different approaches through our research, and saw that companies are at various stages of implementing their strategies.

Overwhelmingly, the patient engagement leaders we interviewed agreed that they need a strong operating model and clear metrics to work toward. Many companies have short term ROI metrics they are tracking, such as improved recruitment and retention in clinical trials, fewer trial amendments, or greater brand loyalty, but some companies are pushing their teams to think through nontraditional and longer-term metrics. These include measures such as making the R&D process more patient-centric and improving patient satisfaction and outcomes. These metrics are discussed in more detail below.

So how are some of the companies we spoke with advancing patient-centricity? It starts with a defined strategy and a strong operating model. Figure 1 illustrates some examples of patient centricity initiatives that have been executed against these strategies.

Challenging the status quo: Advancing patient-centric approaches

RECOMMENDATION NO. 1: IDENTIFY AND OPERATIONALIZE STRATEGIC OBJECTIVES AROUND THE PATIENT PERSPECTIVE

In striving for a more patient-centric approach, some of our interviewees said they faced several barriers. Some in the company thought that with all the regulations around product development and collecting patient data, it is better to take a less risky approach to ensure compliance. Others were told by their teams, "I know this space, I know the patients," and didn't think anything more needed to be done. Even as companies got further along in adapting and evolving the culture and process, they were often stymied by competing or changing priorities and limited resources.

It's not enough, they all said, to have a strong vision or support from leadership, although it's important. Employees need informed messages and scientifically validated tools underscoring the importance of patient-centricity from the top down, but they also need direction and resources to incorporate patient-centric practices and methods in their day-to-day jobs. They should understand how these patient-centric practices are connected to corporate objectives that impact overall organizational performance. This is the key to moving from patient-centricity wave 1 (where the patient engagement focus is centered on commercial) to wave 2 (where companies are starting earlier to incorporate methods), and ultimately being able to achieve wave 3: truly getting to an enterprisewide approach to patient-centricity.

The industry leaders we interviewed told us that companies need to be willing to accept a certain amount of risk to advance patient-centric initiatives. As one interviewee told us, "Legal, compliance, and regulatory issues are good excuses to stick with the status quo, but we have to move past that. It IS risky to be patient-centric. You also have to think about what you'll actually be able to do with patient feedback, because if you talk to patients, and they give you feedback and you don't act on it, they are going to know." Many of our interviewees emphasized the importance of telling patients what is feasible, and what is not.

"The patient is our end user" is a phrase we heard from several of our industry interviewees. But many also told us that over the years, their

FIGURE 1

Examples of patient-centricity in action

Action	Example
Conduct studies to figure out patient preferences directly from the patient	A biopharmaceutical company conducted a preference study to understand the differences between physician and patient preferences for desired outcomes. Physicians regarded a "pain-free" response as most important. Patients, however, felt this outcome was unrealistic. They cited rapid relief, headache relief, and sustained response as more achievable and desirable. The company used this information to refine the benefit-risk assessment approach.[2]
Study patients at different points along the treatment journey	A large biopharmaceutical company hired an ethnographer to capture insights on how sickle cell anemia patients cope with acute and chronic pain. These insights are currently being used to develop a patient-reported outcome as a primary endpoint for a Phase III clinical trial.[3]
Partner with advocacy groups to build trust and gain insights	A small biotech company focused on a rare condition told us they have had success partnering with a patient advocacy group to cohost events where patients are invited to attend and participate in a Q&A with physicians. The research team learns by hearing what the patients ask about and what concerns they have. The leader we interviewed said, "While we are focused on white blood cell count, patients were saying they want to stop itching at night so they can sleep better." A Cambridge-based biotech company collaborated with the Parent Project Muscular Dystrophy (PPMD) and used the latter's patient preference study to get accelerated approval for the first disease-modifying therapy for Duchenne muscular dystrophy.[4]
Increase transparency throughout the process of therapy development and beyond	To increase transparency and improve the sharing of aggregate trial results with patients, one biopharma company said it is working to carve out time at conferences to present research in a patient-friendly way. Another biopharma company is working to make its clinical trial website patient-friendly and creating an alumni network so that trial participants can stay in touch or help inform future trial participants.
Use digital solutions as a supplement to hearing directly from the patient (see Recommendation 3 for more on digital strategy)	There is often no substitute for talking directly to patients: One patient engagement leader from a large biopharma company told us that at one point during the research process, the team was collecting passive movement data from a group of patients via wearables. If a patient was up and moving more, the team assumed this meant he or she was experiencing fewer symptoms. However, one patient told them that she was a writer, and if she was feeling better, she was able to sit at her computer and write. Without that information from the patient, the company might have assumed the inactivity signaled a poorer outcome when the opposite was true. Patients, providers, and sponsors may view the risks and benefits of an intervention differently.
Focus holistically on the drivers of health that impact patients and communities	We heard a few companies mention the drivers of health (factors outside the traditional health care system that impact our health, such as education, employment, access to healthy food, transportation, stable housing, meaningful relationships, and a sense of community). There is a growing opportunity for life sciences companies to focus more broadly on their role in addressing patient needs that impact the patient's full and optimal participation, beyond the traditional focus on access, adherence, and financial support for medications.[5]

Source: Deloitte analysis.

"Legal, compliance, and regulatory issues are good excuses to stick with the status quo, but we have to move past that. It *is* risky to be patient-centric. You also have to think about what you'll actually be able to do with patient feedback, because if you talk to patients and they give you feedback and you don't act on it, they are going to know."

— ***Life sciences executive***

FDA AS A CATALYST FOR CHANGE

Many of our interviewees told us that their organizations' approach toward patient-centricity depends on the stand the FDA takes. One stakeholder commented that when her company first met on patient-focused drug development years ago, the main topic of conversation was, what will the FDA do and how can we prepare? It is clear from the FDA's guidance to date that the agency is not only interested in a therapy's biological impact, but also wants companies to demonstrate that they are collecting data on the impact of the condition on the patients' functioning and quality of life, as well as their experience with treatments, input on which outcomes are important to them, and patient preferences for outcomes and treatments.[6]

Many of the industry and advocacy organizations we interviewed told us that if the FDA wants it, it will happen. However, many also said that although the FDA is an important catalyst, there are health technology assessment bodies such as the Institute for Clinical and Economic Review (ICER) and those outside the United States using measures of patient value in their frameworks as well. As the demand to demonstrate value continues to gain momentum, companies should think beyond regulatory requirements, and use some of these same techniques to their advantage.

company faced barriers to truly integrating the patient perspective into every aspect of their product development and commercialization process. Some believe a lot depends on how the US Food and Drug Administration (FDA) approaches patient-centricity (see sidebar, "FDA as a catalyst for change"). Many cited barriers in taking the vision from leadership and translating it into tasks that can be quantified and evaluated. While all life sciences employees might hear the messaging from leadership, clinical development teams are typically focused on getting trials done and products through the regulatory process. Commercial teams are often focused on meeting the needs of physicians and payers as well as patients. The actual work of engaging patients may only be a small part of their day-to-day job. A few companies we spoke to had set up a cross-functional governance structure, set objectives at every level within the company, and were taking a knowledge management approach for sharing lessons learned and leading practices. As one industry patient engagement leader put it, "To be successful, you need commitment from the top, and champions all along the way."

What's the best way to operationalize patient engagement?

In our interviews, we heard a few different perspectives on the role of a CPO and patient-focused staff in companies, as well as how a company should balance a centralized approach vs. integrating patient-centricity into all functions and

at all levels of the company. When it came to defining an operating model, some companies followed a top-down approach, while others followed more of a bottom-up approach. Ultimately, a balance of both seems to be the most effective.

- **Top-down:** Several companies decided to designate a CPO to signal the importance of patient-centricity to both the internal and external markets. The CPO was responsible for championing cultural change throughout the organization, defining patient engagement initiatives, and influencing other functional areas to implement them. A few companies told us that once patient-centricity was embedded throughout the organization, there would no longer be a need for a CPO. Others told us that CPOs struggled to achieve these goals due to a lack of direct line authority over functional leadership, and/or a lack of sufficient resources to drive change (see sidebar, "Making the most of the CPO").

- **Bottom-up:** Some companies assembled cross-functional teams with dedicated

MAKING THE MOST OF THE CPO

Some companies value the role of the CPO, while others have a different structure. However, the CPO does seem to be an emerging role. Our conversation with CPOs and other patient engagement leaders led us to identify potential improvement opportunities for this still-evolving role:

Sponsorship, authority, and accountability: The extent to which a CPO can exert influence depends on the reporting structure, whether s/he has appropriate budget, staff, and resources, and has a say in the product development process. Having a CPO report to the CEO or executive leadership seems to improve the odds of CPO-led enterprisewide success in driving patient-centricity. The CPO should signal to the entire company that the CEO and executive leadership team put these cultural and process changes high on their agenda. The CPO role can help show colleagues the evidence that working directly with patients and listening to their perspective is valuable along the entire value chain.[7] But, without a budget, staff, and clear metrics that the CPO has accountability for and that are transparent throughout the company, the role risks being a figurehead vs. truly leading meaningful change. Further, the CPO should have the authority to influence individuals on core business teams, even if those individuals do not report directly to the CPO.

Communication: A CPO can be viewed as an influencer with a broader understanding of the product development life cycle. Internally, CPOs have found success in setting up cross-functional patient engagement leadership teams to identify key points of intersection where patient engagement could be additive or more effective. One large pharmaceutical company we spoke with has taken this a step further by deploying a dashboard to track the inclusion of the patient perspective throughout the product life cycle.

External partnerships: Besides influencing internal leaders, a CPO who speaks for patients and not brands can also act as a trustworthy partner for patient advocacy groups and other industry leaders. These groups often have valuable data, relationships with patients, and connectivity. The CPO can help bring the right levels of expertise to build trusted partnerships with them. By and large, life sciences companies still tend to work in silos and are not always willing to partner with other companies and share learnings. CPOs can also share lessons learned with other patient engagement leaders within industry.

individuals within each function. These individuals thought through how their processes were or were not incorporating the patient perspective or informed by patients. For processes where there was room for improvement, the individual functional representatives outlined metrics they could target. As the team hit various milestones in its work, it tracked and tweaked the metrics. Whether or not a company opts to have a CPO, it can be important to have designated champions and a reporting structure that enables executive leadership to track progress in the early stages of the transition to a more patient-centric approach.

RECOMMENDATION NO. 2: TRACK PROGRESS AGAINST KPIS AND ROI GOALS

How do you measure the success of patient engagement initiatives?

Whatever the operating model looks like, and whether a company has a CPO or not, our interviewees agree that different functions and teams must have specific metrics to track. However, our interviewees concurred that patient-centricity is hard to quantify, so companies should be prepared to look beyond short-term measures. It's not always possible to tie a specific ROI to these

initiatives. More mature companies acknowledged that they have grappled with the idea of truly shifting the mindset of the company away from traditional ROI measures (i.e., adherence, sales data, number of prescriptions, etc.). But they also said it can be difficult to get everyone to understand the importance of metrics such as patient satisfaction, better clinical trial experience for patients, and the evolving nature of the methodologies.

John Bridges, a professor at Johns Hopkins University, has focused his research on establishing a list of priorities that physicians undervalue compared to patients. In studies on patients with schizophrenia, these include improved satisfaction, independence, physical health, activities of daily living, and work capacity. His research shows that physicians tend to overvalue decreased psychotic symptoms, improved self-confidence, improved capacity for communication and emotion, and decreased mistrust and hostility. Patients and

"Financial decision-making is important. Eventually people need to see the ROI; they need to see the value in dollars. But that often comes later and is a long-term goal. The long-run metrics will be very different than short-run metrics. Every company and team must have a north star. We have to keep the transformation of health care and health outcome improvement metrics in mind and accept that we might not see that for a long time."

— ***Life sciences executive***

physicians engaging in shared decision-making around treatment can improve outcomes and increase patient satisfaction. But, patient-focused drug development can be helpful in the wider context of selecting endpoints in clinical trials, making regulatory decisions, and developing new treatments.[8]

Some companies have tried to tie ROI to specific metrics along the value-chain, and others have focused on process measures that indicate progress toward becoming a patient-centric organization.

Metrics and measures companies are looking at to track ROI against patient-centricity goals

MAKING METRICS MATTER

Jessica Scott, MD, Head of R&D Patient Engagement Office, Takeda Pharmaceutical Company, told us one strategy her team is using to embed the mindset of including the patient perspective in R&D is to require all global program teams to include a Patient Engagement activity as a KPI. Last year, the team set a goal to have

SPECIFIC PATIENT-CENTRICITY METRICS RELEVANT TO ROI IN R&D:

- **Recruitment and retention:** Did patient feedback and input improve clinical trial design in the highest priority studies?
- **Cycle time:** Did incorporating patient input enable a faster trial (i.e., through fewer protocol amendments)?
- **Trial outcomes:** Did the trial address a patient identified outcome?
- **Patient satisfaction:** Did the collection and implementation of patient insights lead to improved patient experience in clinical trials?

GENERAL PROCESS MEASURES:

- **Early patient input:** Were patient advisory boards executed? Were patient surveys or questionnaires collected?
- **Patient voice:** Do we have a consistent process so that every label embeds the patient voice? Do we have processes in place that allow us to capture insights, from the patients, the caregivers, and the people who serve them?
- **Cultural change:** What were the results of surveys and assessments of employees of the company? Are individuals sharing best practices within and across functions?

R&D PROCESS MEASURES:

- **Product design:** Can we use information gleaned from research into patient insights to improve our Target Product Profile?
- **Protocol design:** Have we created metrics that assess patient cocreation for protocols? Did we talk to them about the trial design and answer all their questions/address concerns?
- **Transparency:** How are we sharing aggregate trial results with patients?
- **Continued engagement:** Do we have a website for clinical trial participants? Is it patient-friendly and easy to understand?

employees fulfill three patient-themed activities that would bring the individual employee closer to patient perspectives, and this year's KPIs require each global program team to include a patient engagement activity goal. Next year, all teams will need to have an overarching road map for engaging patients and patient communities ("Patient Engagement Plan"). Scott said, "Our innovative model of creating a push and pull by tying Patient Engagement requirements to KPIs is resonating across the organization. We are connecting patient activities to every global team while giving the teams flexibility with the activities they come up with—without being prescriptive. We want to allow for teams to be really innovative and to focus on activities that are of value to the development of the compound."

RECOMMENDATION NO. 3: HARNESS DIGITAL AND DATA ANALYTICS OPPORTUNITIES TO ENGAGE PATIENTS, IMPROVE THEIR EXPERIENCE, AND COLLECT DATA ON OUTCOMES AND UNMET NEEDS

Life sciences companies are slowly but increasingly adopting and creating digital transformation. It's not easy—and will likely require new platforms and new ways of working. Many of our industry interviewees said that patients are progressively demanding more personalized approaches and better health care experiences, and digital tools can help respond to these demands.

Digital technologies are helping to enable patients to control their health care information and partner in their care decisions. Remote sensors capturing patient data could provide better outcomes data to life sciences companies and health care stakeholders, and behavioral "nudges" could improve patient adherence to treatments or lifestyle. As software and health care converge to create digital therapeutics, this new breed of life sciences technology is helping to transform patient care and deliver better clinical outcomes while addressing unmet patient needs. A better understanding of patient-specific disease characteristics could enable more effective, targeted interventions. We learned in previous Deloitte research that some companies are exploring the use of artificial intelligence for precision engagement by tailoring behavioral nudges to an individual's needs and challenges.[9] The STEP UP study, led by the University of Pennsylvania, is an example of what can result from combining wearables with gamification to encourage overweight and obese adults to become more physically active.[10]

A well-defined, patient-centric digital strategy will likely help companies build trust and gain insights and loyalty. Some of the companies we spoke with are thinking about the role they will play in this transformation, recognizing that traditional strategies of reaching the patient through the physician will likely not be as effective in the coming years. Companies that are not actively preparing to take on a new role as a partner run the risk of not engaging patients and possibly losing relevance in the evolving ecosystem.

Interviewees who were knowledgeable about digital transformation in their organizations told us that before deploying digital tools, organizations should articulate what they want to accomplish with them. Many told us about teams that got excited about having a digital strategy for a problem that did not necessarily demand a digital solution. They stressed the importance of having a clear objective to align the right tools with the right business functions and keeping patient preference and ease of use in mind. The right digital strategies have the potential to result in faster recruiting and better retention for clinical trials, as well as better collection of real-world data that matters to patients. They could also improve treatments and outcomes, and can help in identifying unmet needs. Some of these needs could include those related to the drivers of health that are outside the traditional health care system.

Some of our interviewees noted that patients are interested in adopting digital technologies and becoming owners of their health and well-being. Deloitte's 2018 Survey of US Health Care Consumers shows 60 percent of surveyed consumers say they are willing to share personal health data (generated from wearable devices) with their doctor to improve their health. The use of tools for measuring fitness and health improvement goals jumped from 17 percent in the overall population from 2013 to 42 percent in 2018, according to our survey results.[11] Wearables, sensors, other connected devices, and mobile apps are driving a new level of connectivity between patients and physicians, possibly enabling earlier intervention or even prevention in some cases.

Although there is much excitement about a world where patients are empowered by data and digital tools, the health care ecosystem of today is not set up that way. A patient armed with data and tools is still unlikely to be truly empowered if the underlying workflows and systems the health care ecosystem has traditionally relied on don't change. Based on our interviews with industry patient engagement leaders, we've identified potential success factors for a patient-centric digital strategy:

- **Create a patient journey map** to identify high touch points to improve patient experience and outcomes. Companies should start early and proactively collaborate with the right partners including consumer technology or digital health companies, advocacy groups, and providers in order to create a seamless approach to collecting patient data. Partnering is more likely to result in user-friendly tools.[12]

- **Have a plan (and the analytics capabilities to go with it) to use the enormous amount of data that's being generated.** Companies should work toward proactively identifying methodologies and establishing leading practices to collect and process relevant data. An executive we spoke with at a large pharmaceutical company pointed out the increasing adoption of data lakes to store and process data, collected from various sources, in real time. Some efforts have already gone into making patient data more interoperable such that different data sets can be combined. However, this can require some level of harmonization, which is possible only if different stakeholders show willingness to collaborate.

- **Think through data ownership and use considerations.** Many stakeholders strongly believe that patients own their data, and policies such as the General Data Protection Regulation (GDPR) in Europe empower patients to become ultimate decision-makers for the use of their data. If companies are using the data in ways that can benefit patients, either through research or providing a more tailored experience, they likely need to have clear policies and procedures in place to communicate this to patients if they want them to opt in to sharing. According to the latest Deloitte Survey of US Health Care Consumers, only 39 percent of US consumers are willing to share their blinded data with organizations that conduct health care research.[13] Being transparent about the benefits of sharing data and establishing trust by being transparent about the use of data is critical.

RECOMMENDATION NO. 4: COLLABORATE MORE DEEPLY AND LEARN FROM OTHER INDUSTRIES

Life sciences companies are one part of the ecosystem, and no one stakeholder can overhaul the traditional health care system alone. Patients want biopharma and medical device companies to develop effective and transformative drugs and devices. The industry should partner with other stakeholders, including patient advocacy groups and health systems, to better serve patients. Based on our interviews, we identified strategies for each stakeholder to improve outreach and collaboration

with other stakeholders to work toward a more patient-centric system.

One area that a small number of interviewees mentioned was the importance of working with community organizations to address the needs of the underserved. Some predicted this would be a continued area of focus for the industry, and an issue that will not be easily solved. Life sciences companies will likely need to partner with trusted entities in the community, including physicians and clinicians, community health workers, patient advocacy groups, and nonprofit organizations, to name a few.

Collaboration with patient advocacy groups

Patient advocacy groups vary greatly in their mission, goals, and overall structure. The ones we spoke with all focused on strategies to address their conditions by directing and funding research, raising awareness for the disease or condition, and helping patients understand treatment and care options. Many helped raise funds to support patient services, and some have influenced moving the research agenda forward and driving data strategies. These groups pilot innovative methods to advance research paradigms. As discussed in Deloitte's 2018 research on master protocols—adaptive, collaborative clinical studies that enable simultaneous evaluation of more than one drug for individuals with specific diseases—are largely driven by nonprofit patient advocacy groups, along with the National Institutes of Health (NIH) and academic institutions.[14]

Several success stories of how biopharma and advocacy groups have partnered are in the public domain. The Cystic Fibrosis Foundation has shown how nonprofits can provide funding as well as bring patients to trials.[15] In addition to funding, some advocacy groups have created important data-sharing initiatives. The Muscular Dystrophy Association (MDA) has a data hub that helps connect patients to trials faster and helps them find out more about the natural history of the disease.[16] Advocacy groups have created patient registries and have served as data conveners by forming consortia.

Some representatives from the advocacy groups we spoke with were eager to reach out to people in the industry outside of the external affairs or patient advocacy realms. They pointed out that many patient groups are driving and accelerating research and that they want to more meaningfully interact with leadership in R&D and other areas of the industry, who can advance the integration of the patient perspective and implement that perspective in the clinical process. Some advocacy groups told us that learning to understand and align with the industry's business model has helped them succeed. The limitations of clinical trials and availability of finite resources present a strong case for collaborations of this nature.

Collaboration within the industry

We heard about and researched many examples of powerful precompetitive initiatives among pharma companies. Some of these initiatives enable a more streamlined approach to gaining insights from the data. The Michael J. Fox Foundation brought together four large pharmaceutical companies in a consortium to provide critical safety data of LRRK2 inhibitors for Parkinson's disease, which has enabled continued development of this drug class.[17] The companies participating in this *LRRK2 Safety Initiative* shared tool compounds to address and

understand the safety profile of LRRK2 kinase inhibitors. This is an example of how some companies are sharing data to improve collective understanding, and ultimately get treatments to patients faster.

Some of our interviewees spoke about helpful conveners, such as the Patient Focused Medicines Development (PFMD), the Drug Information Association (DIA), the European Patients Academy (EUPATI), Transcelerate, and the Clinical Trials Transformation Initiative (CTTI). Many of these organizations are bringing industry and other stakeholders together and are advancing scientifically valid metrics to assess patient perspective data.[18] But many interviewees acknowledged that the industry has a long way to go to truly advance meaningful partnerships, and it is still difficult to let go of the traditional, often siloed, ways of doing research. One patient advocacy organization executive told us, "We don't necessarily need another app, or another registry. What we need is to come together and create shared tools: It would be cheaper, faster, higher quality, and more accepted by patients. If we truly put patients at the center we'd cut through the clutter."

The wider ecosystem: Learning from other industries on how to improve the consumer experience

New entrants with consumer-friendly solutions have disrupted almost every industry. While, of course, not every technology-focused company can easily or readily develop a safe, effective drug or medical device, several disruptors in health care have made some of the biopharma executives sit up and take notice (see sidebar, "Taking a page out of the consumer-centric industry book").

Many of the executives from the biopharma companies we spoke with recognized that they had a lot to learn from other industries, including the consumer-centric technology and retail companies that most people likely use on a daily or weekly basis. These companies have figured out a way to make the consumer experience seamless. A few were actively seeking advice from these companies or having their employees going through their trainings. Some digitally maturing biopharma companies have recruited chief digital officers (CDOs) from the retail and fashion industries, expecting that they will provide fresh perspectives to typically conservative and risk-averse companies. One CDO leveraged his fashion industry experience to change the approach to patient engagement. He structured his team like a magazine outlet, hiring editors, librarians, and copywriters to run a digital campaign.[19]

TAKING A PAGE OUT OF THE CONSUMER-CENTRIC INDUSTRY BOOK

Kathy Giusti, patient advocate and cochair of the Kraft Precision Medicine Initiative, a partnership between the Robert and Myra Kraft Foundation, Harvard Business School, and the Broad Institute of MIT and Harvard, is a pioneer in the precision medicine movement. She frequently discusses the need for the life sciences industry to learn from industries and organizations that have mastered the consumer experience.[20]

Early on in the initiative, Giusti and her team realized the need to reach more patients and encourage them to share their data. She has looked to organizations outside of pharma that have been successful at the direct-to-consumer business model. Business techniques her team has employed include developing an emotive brand to draw people in, using more social media, employing jargon-free language, and simplifying everything from the registration process to the questions patients get asked to create a better end-to-end consumer experience. The result is the team has a larger, deeper pool of data to draw on and drive progress in new therapies.[21]

Patient-centricity is key to the future of health

Deloitte's future of health vision looks ahead to the year 2040, and what will emerge in the next 20 years that will dramatically reshape the life sciences and health care industry. Greater data connectivity; interoperable and open, secure platforms; and increasing consumer engagement are key elements that are expected to shape the future of health.[22] By 2040, the consumer—rather than health plans or providers—will determine when, where, and with whom he or she engages for care or to sustain well-being. Over the next 20 years, all health information will likely become accessible and—with appropriate permissions—broadly shared by the consumers who own it.

Life sciences companies should consider how to earn the trust of these empowered consumers. Taking the time to understand the perspective across the patient journey is central to supporting healthy behaviors, achieving better health outcomes, and improving the patient experience. The industry executives we spoke with were aware that misaligned incentives, resistance to evolve, and increasing costs continue to bog down the US health care system. To achieve patient satisfaction and strong health outcomes, players in the health care ecosystem should prepare for disruption and innovation. If life sciences organizations can apply the strategies we found in our research to bring patient centricity to the forefront, there will likely be greater opportunity to improve health, build trust, and improve connectivity with patients.

Endnotes

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