PRECISION MEDICINE MEETS PRECISION PATIENT SUPPORT

HOW PATIENT UNDERSTANDING SHAPED A BETTER, INTEGRATED APPROACH TO ORPHAN DRUG WRAPAROUND SERVICES
Orphan drug therapies used to treat rare diseases navigate a long and costly journey from inception through commercialization. On average, it can take more than 12 years to complete before finally reaching the patient. With mounting time and money invested into a therapy, manufacturers measure commercial success by patient onboarding, reimbursements and adherence – each necessary to recoup the company’s significant investment in research and development.

However, with stakes so high, manufacturers are understandably concerned by a recent report from Global Genes showing therapy adherence in the rare space ranges between only 58 to 65 percent. This leaves many looking to answer the important question of “why is this happening?”

When challenges with acquisition or adherence do occur, manufacturers traditionally research and refine the therapy’s journey through the development process, considering its market access, pricing and distribution. While important, another journey is just as critical, if not more: the unknown and unmet needs of the patient and caregiver journey.

THE FINANCIAL CASE FOR BETTER PATIENT UNDERSTANDING

While certainly complex, the global orphan drug market is booming with sales that are expected to nearly double to $209 billion by 2022, as cited in Evaluate Pharma's 2017 Orphan Drug Report.

Drilling down further, it’s estimated that the average cost for an orphan regimen in 2016 was more than $140,000, compared to only $28,000 for non-orphan drugs. These cost concerns within the orphan drug industry put manufacturers in a defensive position with both patients and payers, who often question prices and demand further justification through health outcomes.

THERAPY EFFECTIVENESS IS IMPACTED BY PATIENT BEHAVIOR

In the value-driven healthcare environment, orphan drug manufacturers are becoming increasingly aware that most therapies require specific lifestyle, nutritional or physical modifications by the patient – changing behaviors that are often difficult to influence, track or control without proper patient insights and data.

According to Global Genes CEO Nicole Boice, there are several misunderstandings about patient communities that contribute to the low adherence rate in rare disease. “A better understanding, ideally, would facilitate a true partnership among patient communities and the industry.”
Boice said. “It would inform the development of support programs that would have a meaningful impact on patients’ and families’ lives. Any time a company truly understands the patient experience and journey, it is a win-win for all involved.”

While many patients and rare disease organizations actively partner with the industry in the development of drugs by sharing their personal and medical data, it is evident that the perception of patients’ needs in the ongoing, and often life-long, treatment process may not be accurate when you acknowledge lagging adherence.

“There is a lack of resources available to address some of the “non-medical” needs of a patient and/or family,” said Boice.

A MORE COMPREHENSIVE APPROACH TO PATIENT UNDERSTANDING EMERGES

Similar to precision medicine, precision support services are now required in today’s healthcare environment.

In 2014, Dohmen Life Science Services, a business process outsourcing company supporting drug manufacturers and their patients, recognized that the industry was underserved by the traditional and fragmented approach to specialty pharmacy and HUB services. The company developed and continuously refines an exclusive distribution model that offers wrap-around coordinated care, patient education and comprehensive support while eliminating the need for multiple middlemen, thereby lowering cost and improving health outcomes.

DLSS leaders say the model, which is rooted in individualized, patient-centered service, positively impacts adherence through multiple measures.

“You’ve got to see the patient as an individual, not a category or community. Patients with the same disease on the same therapy will often have different reasons for nonadherence,” said Linda Newberry-Ferguson, senior vice president of Clinical Navigation with DLSS.

The company’s customized approach to orphan drug program support and wrap-around patient services required an investment in patient understanding of medical, emotional and physical experiences from pre-diagnosis through ongoing medical care.

DLSS calls the process a Patient Journey Map, a research-driven opportunity to bridge the gap in understanding between patients and those who aim to care for them. In specific cases, the insights gathered through the process are leveraged in training programs to help enhance empathy and patient support, and have been used by pre-commercial pharmaceutical teams to help build better connections and lasting relationships within the patient community.
PATIENT UNDERSTANDING DRIVES PROGRAM PERFORMANCE & CONTINUOUS IMPROVEMENT

The DLSS Patient Journey Map provides a 360-degree understanding of the patient and their team of caregivers. The research process centers on the patient viewpoint – what they’re feeling and what challenges they’re facing throughout the progression of diagnosis through ongoing therapy.

Analytical data is complemented by anecdotal insights collected through first-hand interviews with patients, caregivers, doctors and clinical administrative staff about what it’s like to live with and treat patients with the disease. The research process also gleans valued insight through social listening: tuning into conversations that are happening between patients of a rare disease. In all, focusing on what is being communicated in more social, informal settings is helping uncover unmet needs and general sentiment towards disease management from everyone involved – including pharmaceutical companies.

“Often, patients use social forums for questions about the therapy – questions they should be asking their doctor or even the manufacturer of their therapy, but they don’t know how to get in touch,” said Newberry-Ferguson.

Improved adherence cited as one of many benefits

Data and insights captured from patient understanding inform a unique model that offers far more than a HUB and specialty pharmacy model. The results show on average a 90-plus percent patient adherence to the programs administered through this more integrated and patient-focused model.

“We’re not just worried about the shipment and the time and the delivery date,” said Newberry-Ferguson. “That’s incredibly important, but we also care about where they are and what they’re facing. Those patients are more likely to do better, stick to the regime, and take medications like they’re supposed to.”

Tailored emotional care:

The Patient Journey Map reveals factors that commonly impact patient onboarding to ongoing adherence – many go beyond the care regimen, logistics or market access.

“When they learn their diagnosis, some patients are empowered and energized to finally get on a therapy after years of suffering. Other patients react differently,” said Newberry-Ferguson. “They are exhausted from the drawn-out process of searching for an accurate diagnosis, which has eroded their trust in the medical establishment. Those patients typically need more wraparound support from their healthcare providers and pharmaceutical providers to begin treatment and stay adherent.”
Key to the DLSS model is the importance of a one-on-one relationship between the patient and a dedicated Patient Services Coordinator, who are continuously trained to ensure patient empathy and coordinate additional therapies as needed throughout the treatment process.

**Proactive patient support:**
Social media research often identifies the need for custom wrap-around service.

If social listening reveals that patients face certain side effects at certain times, Newberry-Ferguson’s team can proactively ask the patient about that during their regular calls to schedule therapy delivery. For example, a patient with a respiratory disease might experience exhaustion at the end of the day, but might not think to mention that to their patient services team. Through patient journey mapping, DLSS can proactively include education about energy conservation in the regular phone call, sharing practical tips that will improve the patient’s overall experience while taking that therapy.

“Because we have these journey maps, we can anticipate what issues they may face and be prepared to address them before they become an additional burden,” Newberry-Ferguson said. “We can discuss this possibility upfront and help them better prepare.”

**Better logistical support:**
Often simple, yet overlooked logistical issues prevent patients from remaining adherent with a therapy.

“Convenience is a huge factor for many patients who are trying to live a normal balanced life. We’ve found that with certain age ranges it’s better to leverage technology. They just don’t have the time available for phone conversations and we found that they would consciously ignore calls from the pharmacy. Simply switching to text messaging improved adherence,” said Newberry-Ferguson.

**Dosage and handling requirements:**
Patient journey mapping can also help manufacturers understand issues with the therapy itself that could be impacting adherence. For example, patients might share that taking a drug in many small doses is challenging, and that they would stay more adherent if they could take the drug in fewer, larger doses.

“Patients can help the company understand the reality of living with the disease—even if there is a treatment—and how a treatment could be better,” Boice said.

**Mitigate adverse events:**
Using the information from patient journey mapping, the DLSS team can prompt patients to share more information about their experience with the therapy.

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“If we know something is often a problem, we can ask patients, ‘This is something some people have mentioned. How are you?’” Newberry-Ferguson said. “That’s very different from saying ‘Is there anything going on?’ We can tailor the care.”

These ongoing patient conversations help mitigate adverse events. The DLSS model creates strong patient relationships where, for example, the team member can remind the patient to stay on top of healthy habits like drinking a lot of water or avoiding certain foods.

**JOURNEY MAPPING IS A CRUCIAL STEP IN UNTANGLING THE MODERN HEALTH CARE CRISIS**

The astronomical cost of healthcare in the U.S. is just one of many symptoms of a larger problem in a system that doesn’t place enough emphasis on the patient experience. Low rates of adherence drive up costs even further as manufacturers struggle to recover their investment and realize a profit from their years of research and development... dollars that can also help fund future developments. While the system may appear broken, patient journey mapping can help rebuild it.

“Any organization that truly understands the nuances, challenges and complexity of the patients and their experiences in rare disease is an important partner,” concluded Boice.

“These rare disease patients have been through so much already,” said Newberry-Ferguson. “We’ve got to get them what they need, where and when they need it. Adapting to their experiences is a game changer for modern healthcare.”