

Precision Medicine Meets Precision Patient Support

In the value-driven healthcare environment, orphan drug manufacturers are becoming increasingly aware that improving adherence requires a new approach to patient understanding and support. Take for example the required lifestyle, nutritional or physical modifications often necessary for patient compliance — behaviors that are difficult to influence, track or control without proper patient insights and ongoing therapy support services.

New Research Calls Attention to Unmet Patient Needs

In a recently released white paper, Precision Medicine Meets Precision Patient Support, clinical care experts, along with insights from patient advocacy leaders, highlight a more comprehensive approach to better patient understanding.

“Precision medicine has brought hope to many facing the burden of rare disease. Now we need to apply the same degree of precision-based research into our ongoing therapy support services,” says Kathi Henson, Chief Patient Support Officer at Dohmen Life Science Services (DLSS). “Only through that lens can we achieve ongoing patient adherence and ultimately improved medical outcomes.”

As one advocacy expert highlights, “A better understanding, ideally, would facilitate a true partnership among patient communities and the industry. 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.”

Patient Insights Inform New Model for Orphan Drug Therapy Support Services

The paper highlights the DLSS Patient Journey Mapping process, which provides orphan drug manufacturers valuable insights into the medical, emotional, and physical experiences of the patient and caregivers, from pre-diagnosis through ongoing medical care. The process is then used to develop and continuously improve an exclusive distribution model that offers wrap-around, coordinated care, patient education, and comprehensive support.

Contributed by



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Dedicated, Consistent Care to Improve Outcomes and Drive Continuous Improvement

When applied to multiple orphan drug support programs, the approach has resulted in 90%-plus patient adherence, compared with far lower industry standards of only 58% to 65%.

Key to the DLSS model is the one-on-one relationship between the patient and a dedicated Patient Services Coordinator, who is continuously trained to ensure patient empathy and coordinate additional therapies as needed throughout the treatment process.

“We’re not just worried about the shipment and the time and the delivery date,” shares Linda Newberry-Ferguson, SVP of Clinical Navigation, DLSS. “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.”

Patient Journey Mapping also helps man-

ufacturers understand potential 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. Manufacturers also cite fewer adverse event challenges, thanks in large part to proactive patient outreach based on research cited concerns in the therapeutic journey.

“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,” advocacy experts explain.

The Economics of 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. Increasing reputational and payer pressures will require the industry to create more value through better outcomes. Improving adherence, through precision patient support, will lower cost while helping manufacturers recoup their investment after years of research and development — all to the ultimate goal of better rare disease patient care. PV

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Visit www.dlss.com/news to read Precision Medicine Meets Precision Patient Service to learn more.



LOST IN TRANSITION

We've all played telephone. The game where information passes from one player to the next until the end result is unrecognizable. As a game, it's funny. When treating rare disease, it's not. Drugs move down a chain of middlemen, generating confusion and expense along the way. Patient adherence suffers, quality of care diminishes, manufacturers miss out on vital feedback and cost goes up. Imagine if you could cut past all that. We did.



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