

How the “Power of Why” Can Improve Adherence Rates in Rare Disease

Best-selling author and motivational speaker, Simon Sinek, is best known for his 2009 Ted Talk challenging organizations to set aside their list of product benefits and features to focus on the core purpose of their existence. He asks, WHY are you motivated to do what you do every day? Sinek suggests that organizations that can successfully communicate their “WHY” are able to inspire others to take action and promote long-lasting change.

Why should pharmaceutical manufacturers in the rare disease space channel and communicate their inner WHY to patients? Because it’s how we can improve the adherence rate of orphan drugs from a low 60%, which the industry has accepted as the norm, to a high 90%. Serving as a key indicator that patients are receiving full value of their therapy, adherence rate is an extremely important metric to frequently analyze and improve.

Start with the “Why” To Co-Create With Your Patients

In the value-driven healthcare environment, improving adherence requires a new approach to patient understanding, support and engagement. Engaging patients at various stages of their therapy journey helps manufacturers identify obstacles and challenges in order to drive awareness programs, education, and support services that promote better adherence and health outcomes.



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

Collaborative feedback loops also help manufacturers 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.

“There are only two ways to influence human behavior: you can manipulate it or you can inspire it.”

Simon Sinek, Author of “Start With Why”

Continuity of Rare Care

Patients not only need assistance with adherence challenges, but with managing required lifestyle, nutritional or physical modifications that are necessary for patient compliance — behaviors that are difficult to influence, track or control. Oftentimes patients do not know how to make long-lasting changes to their everyday life that would best benefit their therapy. This is where your WHY can make a difference. For example, if your

organization's WHY is to improve the quality of life of MS patients, your support programs should include actionable steps like providing tools to help with mobility in the home or a list of recommended recipes that align with their dietary regimen. Patients will become your biggest advocates if you can inspire them to build new, life-changing habits for themselves.

EVERSANA recently partnered with Noom, the world's leading behavior change company, to increase medication adherence and improve health outcomes for the millions of patients suffering from rare diseases. Noom's program is based on cognitive behavior therapy that leverages human coaches and artificial intelligence. The partnership combines EVERSANA's fully integrated patient services model with Noom's digital therapeutic platform to give patients the personalized support they need to create life-changing habits and generate positive outcomes.

Innovative Support for Innovative Therapies

Innovative therapies have brought hope to many facing the burden of rare disease. Now we need to apply the same degree of innovation into our ongoing therapy support services. Only through that lens can we achieve ongoing patient adherence and ultimately improved medical outcomes.

EVERSANA recently helped a client with a first-to-market orphan drug. The

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therapy was for a complex disease with adherence challenges and our client needed to establish and maintain leading market share in an increasingly competitive segment. With an integrated commercial platform, we created a single access point for all onboarding and patient support, established dedicated patient service coordinators and coordinated care for each patient, including wraparound education and support, and home care. Our client saw great results, including 95.3% patient compliance, 94.5% patient loyalty and 96% patient satisfaction.

EVERSANA also helped a global manufacturer deliver a new injectable therapy indicated to treat a devastating, ultra-rare disease. EVERSANA's experienced supply chain team developed and deployed an Urgent Access Program comprised of a configurable system of storage facilities with cold-chain capabilities. Patients anywhere in the contiguous United States now receive their life-saving therapy in less than eight hours, 24/7, 365 days a year. This solution has resulted in more than 1,000 patient lives saved to date.

An Empowered Journey

Today's "patient-as-consumer" culture empowers patients to demand high-value, personalized outcomes delivered on their own terms. To keep up momentum, patients must continually feel motivated and inspired by their patient service care team.

According to Sinek, inspiration first begins with employees. He states, "Employees represent an opportunity to inspire..." At EVERSANA, we embody a culture fully committed to our patients and our own WHY: "I am Patient-Minded. I act with the patient's best interest in mind." Understanding the significance of WHY we do what we do — not just what or how we do it — is a core cultural belief the entire EVERSANA team lives by each day.

To achieve this, EVERSANA purposefully built a patient-centered ecosystem of integrated services that will not only keep patients informed and empowered along their journey but will generate positive outcomes to demonstrate real-world evidence of therapeutic success. Delivering best-in-class patient experiences that positively impact adherence involves a comprehensive suite of coordinated and intertwined services that solve challenges and impact the metrics that matter most. That's a WHY we can all get on board with. ^{PV}

EVERSANA is the leading independent provider of commercial services to the life-sciences industry.
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