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Inside Rare Disease Pharmacy: Lessons in Personalizing Care

Today's guest post comes from Bansi Nagji, Chief Executive Officer at PANTHERx Rare.

Bansi explores how the emerging model of "Rare Pharmacy" addresses the challenges rare diseases pose to patients, caregivers, and the healthcare system. His perspective highlights the role of hyper-personalization, empathy, and data in improving outcomes for individuals with rare and orphan conditions, while also pointing to lessons that may extend across the broader healthcare landscape.



[Click here to learn more about PANTHERx's approach to hyper-personalization.](#)

Read on for Bansi's insights.

Inside Rare Disease Pharmacy: Lessons in Personalizing Care

By Bansi Nagji, Chief Executive Officer, PANTHERx Rare

If a retailer can predict what you'll buy next, or a streaming service can anticipate the right show for you tonight, imagine what's possible if we could harness that same power of personalization in rare disease care. Off-the-shelf models seldom work because of the complexity, uncertainty, and novel nature of most rare disease patient journeys. Hyper-personalization, which goes beyond traditional segmentation to truly tailoring care at the individual level, offers a path forward.



But before diving into the possibilities, let's examine what makes rare diseases different.

Walking in rare shoes

At some point, everyone has likely been a patient, a caregiver, or both. For those working in healthcare, this provides a baseline of empathy and understanding for the patients we support. But, by definition, very few people truly understand what it's like to live with a rare disease. As you would expect, rare conditions with no clear treatment protocol can cause frustration and despair for patients, caregivers, healthcare professionals (HCPs), and patient advocacy organizations.

Imagine struggling with a condition that no one can diagnose, let alone offer appropriate treatment. You battle ongoing anxiety and uncertainty. Then, when you are finally diagnosed, you will likely start therapy that is complex, expensive, and new. There are very few people like you. In fact, you may not have anyone in your network who has any experience with this disease. You feel isolated, vulnerable, and overwhelmed.

Now let's examine a caregiver's perspective, this time for a pediatric patient. You may need to weigh your child regularly or complete frequent lab tests to maintain proper titration or dosing. In addition to the stress that comes from caring for a child with a rare condition, you also play the role of home nurse—monitoring adherence, mixing medicines or injecting them, and managing inventory of medications and other supplies.

Each time we speak with one of our patients, we have a new appreciation for the hope, intensity, and persistence it takes to live with or care for someone with a rare condition.

Applying lessons from rare across healthcare

While rare diseases impact a relatively small number of patients, there are important lessons that inform the foundation of hyper-personalization that can be applied to other sectors of healthcare:

- **Every patient has an individual journey.**

Why "rare" is rare



"Rare" is codified by the **Orphan Drug Act** of 1983.

Defines a health condition affecting **fewer than 200,000** patients.

Over 7,000 rare diseases collectively impact **over 25 million** people in the U.S.

~93-95% of rare diseases do not currently have an FDA-approved treatment.

One-size-fits-all ends up fitting no one well. More targeted interventions, therapies, and care models can yield better outcomes with improved satisfaction.

- **Empathy is more powerful than sympathy.**

Compassion is a great place to start, but until we deeply understand what a patient is going through, we cannot fully satisfy their needs and optimally support them.

- **Specificity and nuance matter—data hold the key.**

Improved adherence rates, cost savings, and reduced hospitalizations are some of the positive outcomes that can happen when all relevant stakeholders align on the shared truth of the data.

Rare pharmacy: A new frontier

In the latter part of the 21st century, specialty pharmacy emerged as distinct from traditional pharmacy due to therapeutic and clinical advancements. Today, we are at a similar inflection point, with a new breed of specialty pharmacy coming forward to focus exclusively on those living with rare and orphan conditions: Rare Pharmacy.

Rare pharmacies have experienced teams of pharmacists, nurses, and care coordinators who dedicate significant attention to each patient. Hyper-personalization and close collaboration with a patient's HCP enable us to leverage clinical data, behavioral insights, and patterns in patient journeys to proactively anticipate needs, remove barriers, and deliver interventions to the right patient at the right time.

Since many rare therapies are high cost, it is in all stakeholders' interest to ensure that a therapy is dispensed to the appropriate patients who are then counseled, closely monitored, and supported collaboratively by the rare pharmacy and referring physician to increase therapeutic success. While incredibly complex, getting it right saves money, improves outcomes, and reduces patients cycling in and out of therapy.

Rare care is healthcare at its best

Founded in 2011, PANTHERx is the largest independent specialty pharmacy focusing solely on rare and orphan therapies. Our model, shaped by the daily realities of rare diseases, gives us the privilege of engaging with patients more deeply and more often than most pharmacies to provide individualized care to each patient. Yet we don't do it alone—we partner with pharmaceutical manufacturers on custom therapy programs and with HCPs to help our shared patients navigate this complex rare journey.

Hyper-personalization offers tantalizing possibilities—in rare disease and beyond. My hope is that today's patient journey examples and insights can serve as inspiration for us all to continue striving to deliver healthcare at its best. [Click here](#) to learn more about PANTHERx's approach to hyper-personalization.

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