

What does a technology enabled patient concierge mean to the orphan drugs industry?**Harsha K Rajasimha**

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Traditional clinical research paradigms relying solely on brick and mortar in-person engagement between researchers and patients have failed to provide the scale and efficiencies needed in orphan products development. Patients with rare disease are geographically sparsely distributed globally, are already burdened by the disease they carry, often genetic and debilitating, are often dependent on a caregiver to take paid time off to support them, yet are still willing to travel across the globe to access a life-saving or altering treatment options such as gene therapies. But it is unfair to expect them to do so when it is really not necessary in this day and age of Telemedicine, Digital Health, and wearable devices. Unique to rare diseases R&D are patient registries and natural history studies. These multi-year studies are often necessary prerequisites for orphan product development as patients demonstrate significant heterogeneity of symptoms with limited medical literature and understanding of their physiological and molecular underpinnings. The traditional process of patient education, engagement, informed consent, screening, enrollment, retention, and evidence generation needs an overhaul. It is not just introducing digital tools and

elements into the centralized brick-and-mortar paradigm. It is about finding and meeting patients where they are in the global communities through online social channels and multi-modal engagement. I will demonstrate how such as technology enabled patient concierge is helping connect patients with registries, natural history studies, clinical trials, other global resources and experts based on their specific needs.

Biography

Harsha K Rajasimha is a precision medicine data scientist by training with 17+ years of experience spanning academia, the National Institutes of Health, FDA, healthcare and life science consulting, and multiple startups. He is a social entrepreneur focused on accelerating the research and development of diagnostics and therapies for rare and common diseases. He has founded numerous international organizations to address these challenges. He is pioneering human-centric technology innovation to accelerate online recruitment of diverse patients for clinical research in a range of diseases including rare, chronic, infectious, and neurobehavioral disorders. He has authored 17+ publications, book chapters, and patents.

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