Patient-finding excellence: Connection to care

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It is estimated that 400 million people suffer from a rare disease globally, with approximately 7,000 distinct types of rare and genetic diseases identified. On average, it takes eight years before rare disease patients receive an accurate diagnosis and even then, the majority of those diagnosed lack access to approved therapies for targeted treatment. Many of these rare diseases affect children, with irreversible debilitating and painful impact that is often fatal. Thus, it is essential to identify patients early and connect them to treatment as soon as possible to improve patient outcomes.[1]

Patient finding is the foundation of successful rare disease efforts

Finding rare disease patients is an exhaustive and often convoluted process. A disciplined, systematic, and tenacious approach to patient finding is required to maximise the opportunity for a rare disease therapeutic and effectively connect patients to needed care. Yet, many rare disease launches and patient finding efforts tend to stall once the more easily identified patients are identified and placed on therapy (see Figure 1).

Every rare disease has unique dynamics and challenges and there is no single definitive process or data source that can be relied upon to identify and locate all potential patients in a geographic area. Compounding the issue are: the relative scarcity of patient level data in rare diseases, often the lack of definitive and discrete diagnostics, and the differences in medical care and institutions across geographic regions. Accordingly, it is necessary to invest in a disciplined and customised approach to systematic patient finding as early as possible in the product development cycle. Patient finding in rare disease takes time, effort and discipline, but it is a pivotal step in connecting patients to treatment.

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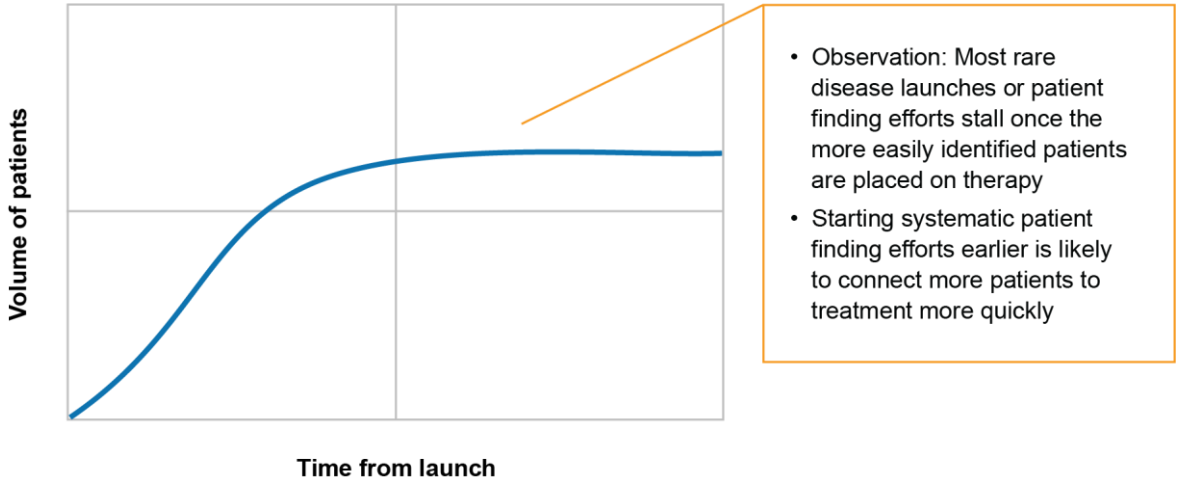
1 https://globalgenes.org/rare-facts/

Figure 1: Most rare disease patient-finding initiatives stall after easy-to-find patients are identified



- There is **no single definitive data source** to identify and locate all potential patients and hence it is necessary to assemble a **tailored approach**
- Patient finding in rare disease takes **time, effort, and discipline** but is **crucial for the ultimate success** of connecting patients to care

Source: CRA

Leverage multiple sources of information in patient finding efforts

As there are multiple potential sources available for finding rare disease patients, it is important to assess the potential value of each data source and how they might be used in concert to develop a targeted approach to patient finding that fits the particular characteristics of the rare disease and geographic market in question. The below list, though not exhaustive, delineates commonly used sources leveraged for patient finding.

- KOL networking
- Patient advocacy groups
- Patient registry and / or epidemiology study
- Electronic medical records
- Digital and social media engagement
- Private insurance plans
- Field force (prospecting)
- Lab data, including genetic testing
- Specific market research

By leveraging information from these sources, it is possible to develop best practices in patient finding specific to the rare disease of focus, covering a spectrum of outputs and deliverables (see Figure 2).

Figure 2: Best practices in patient finding

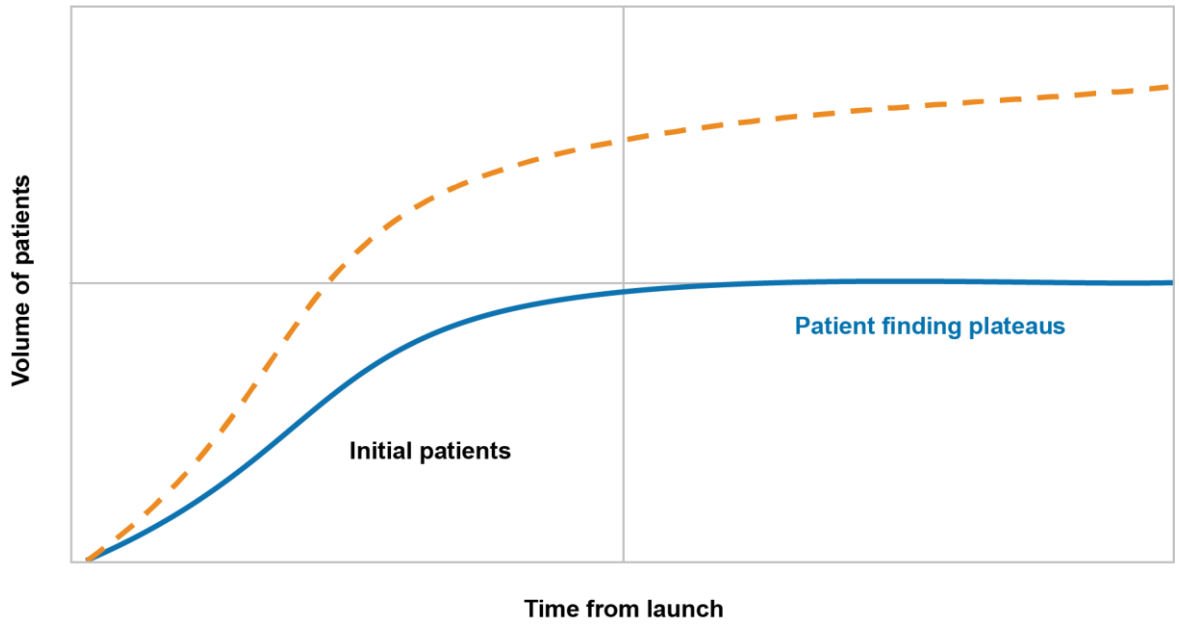
Best Practice	Mechanism	Key Outputs
Thorough market landscape assessment	Knowledge Book	Chapters may include: • Epidemiology • Pathophysiology • Current Standards of Care • Future Market Map • Access & Reimbursement • Thought Leadership • Patient Advocacy Landscape • Insights from Qualitative & Quantitative Market Research
Understand the patient/ physician/caregiver/ payer experience from symptom onset to diagnosis to long-term management	Rare Disease Patient Journey	• Understand the points of care • Identify the physician specialties involved • Determine the key intervention points to find patients and connect to care
Identify the treaters and experts	Thought Leader & Expert Identification, Profiling & Mapping	• Identify, rank, and profile thought leaders in therapy area and market(s) of interest • Customised thought leader database and visual mapping tool
Targeted patient finding efforts	• Advanced Analytics Fingerprinting • Partnership with Patient Advocacy Groups • Advanced Analytics Social Media Listening	• Fingerprinting: Leverage longitudinal claims data analysis to identify undiagnosed patients • Patient Advocacy: Conduct patient ad boards • Social Media: Utilise contextual text mining to identify potential patients
Robust and secure patient tracking process	RDNavigator	• Real-time data collection accessible by all team members • Streamlined reporting via data consolidation and customised report templates

Source: CRA

An established approach to patient finding provides a faster connection to care for patients

Systematic and disciplined investment in effective patient finding can connect patients to care, which is especially important in rare diseases where treatment options have been more limited in the past (see Figure 3). Additional benefits to an integrated approach include the coordinated focus on activities in priority areas, leveraging the individual benefits of different data sources and approaches to deliver a synergistic effort. An integrated approach to patient finding also helps establish clear lines of communication among stakeholders and enables patient tracking to produce robust, actionable data with transparent evaluation of successes and failures via a patient tracking platform (e.g., RDNavigator).

Figure 3: Effective patient finding and tracking can mitigate the stall in patient numbers



Source: CRA

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