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A Frost & Sullivan Executive Brief

The Most Effective Way to Identify Better Outcomes When Using Limited Patient Populations

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The National Organization for Rare Disorders estimates that about one in 12 Americans has a rare (or orphan) condition. The Genetic and Rare Diseases Information Center, a project of the National Institutes of Health's National Center for Advancing Translational Sciences, maintains a list of about 7,000 conditions that affect fewer than 200,000 people in the United States; of these, only about 500 have a specific diagnosis code in the International Classification of Diseases.

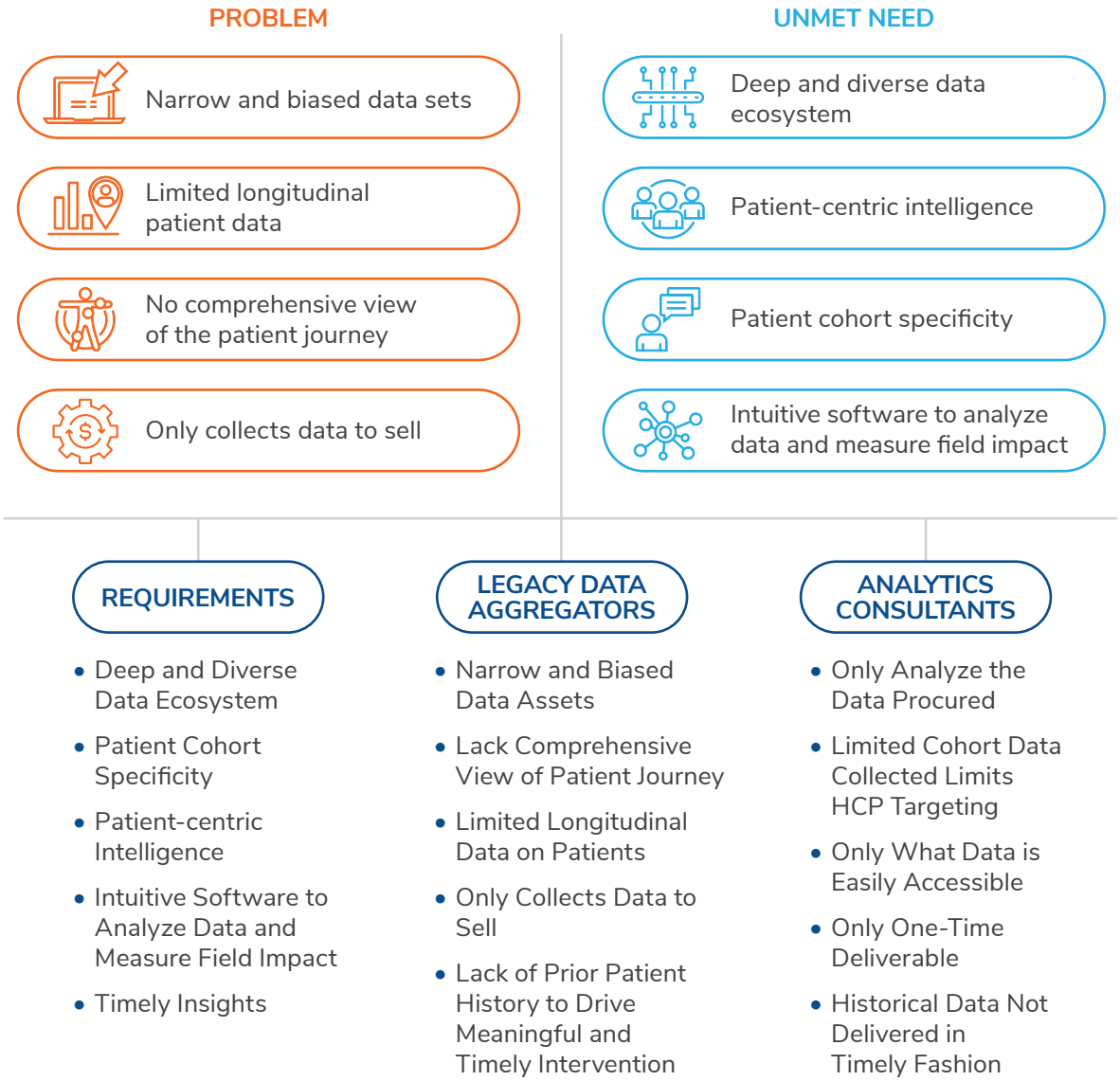
Some patients with complex care pathways may have been underdiagnosed or misdiagnosed, or have not yet begun a therapy. Even for well-known conditions, the diagnostic pathway is not always direct, but can be predictable. Most commercial healthcare databases lack the depth and breadth of patient-level insight or the sophistication to flag those who are receiving or may benefit from novel therapies (many specialty pharmacies that handle orphan drug prescriptions do not even share data). This puts pharmaceutical and biotechnology companies at a disadvantage as they try to understand where to target their efforts. Identifying predictable patterns in the signals on the patient journey can support commercial teams to focus earlier on patients where they can make a difference.

Mapping the Healthcare Journey

Electronic medical records, administration enrollment and billing systems, health surveys, fitness wearables, and social media are creating healthcare data at a volume and speed never before seen. This so-called Big Data is a treasure trove for commercial teams; the problem is that much of the information is locked in silos created by the variety of public and private systems (hospitals, community health centers, individual providers, and health plans) that generate and collect it. An additional complication is the fact that many people have no regular provider relationship, at best seeking care only in an emergency department.

Defining or viewing a specific patient population is the first step in identifying a clinical opportunity. This traditionally involves a long list of database requests for prescriptions and very limited provider-patient data; usually, requests are iterative and require refinement, resulting in multiple back-and-forth conversations. Analytics consultants are at the mercy of a third-party data aggregator, as Exhibit 1 shows. They are only as good as the collected data.

Exhibit 1: Legacy Data Aggregator Limitations



A true patient population is larger than the number enrolled in a clinical trial or on a registry. The challenge is finding a better way to identify them. Technological advances allow for a more nuanced understanding of disease, drilling down to individual-level variations and smaller subgroups based on genetic subtype, variation in therapy response, and/or social and environmental disparities. The result is much more robust patient data and the ability to more precisely identify those who may have rare conditions to deliver on the promise of precision medicine.

Optimal care is the goal for any health system, but cost obviously plays a role in many decisions. In an already overburdened system with limited resources, breakthrough or emerging therapeutic medicines may not be a priority consideration. So how can a commercial team clearly communicate the value of an innovative treatment for a limited patient population? The answer is an actionable, evidence-based program that convinces a broad range of stakeholders—each with a unique definition of value—that a treatment merits adoption. A comprehensive data set allows an analytics team to effectively map a treatment journey (including when, where, and from whom) and quickly identify the patients and physicians who are most likely to benefit from a novel therapy.

Constructing a True Healthcare Encounter Data Map

Commercial teams rely on alerts, or what are traditionally known as "rep triggers," to intercept patients at key stages in disease progression. Each healthcare encounter generates data about a symptom, test, diagnosis, or treatment. When data from different visits, or providers, is combined, it is easier to find commonalities or matching points that trigger an alert. This requires sophisticated software to reconcile all medical record numbers and other internally assigned identifiers from different source systems; unfortunately, most commercial datasets miss the patterns that could indicate a rare condition.

An ideal system must be able to receive continuous, near real-time clinical intelligence about initial diagnoses, relapses, or disease progression, and collect accurate patient history, including age, previous morbidities, and previous provider encounters. Understanding the common patterns in the diagnostic journey of the patient population with a specific condition can provide early signs of what signals to look for in identifying the types of patients to focus on. Utilizing advanced analytics to identify the signals that matter on the patient journey can empower commercial teams to be more efficient and effective. But they must be built on detailed, nuanced data, with cohort-specific patient population filters to ensure exact target identification at specific moments and the ability to enrich signals with patient history.

Necessary elements include:

- a customizable alert impact tracker;
- transparency in alert rules, logic, and geographic distribution of incoming alerts; and
- user views of the impact of alerts (tracing the path from alert to engagement to changes in the provider treatment modality).

Conclusion

Pharmaceutical and biotechnology companies are paying more attention to rare diseases because of lucrative government incentives, relatively low commercialization costs, and the likelihood of successful outcomes. Even in the midst of the COVID-19 pandemic in 2020, the U.S. Food and Drug Administration reported that it approved 32 novel drugs and biologics with orphan drug designation; in the Center for Drug Evaluation and Research, 31 of 53 novel drug approvals were orphan-designated products.

In this multibillion-dollar industry, a company may only have limited experience with a disease or be entering a completely new therapeutic area; a succinct alert map of patient encounter data is a valuable asset. Commercial teams evaluate a mapping vendor based on:

- **Broad visibility**: a deep-data ecosystem that captures diverse signals for large populations and an array of clinical encounters.
- **Accuracy**: data modeling that eliminates false negatives and positives in alerts.
- **Speed**: the frequency of alerts on patient treatment at optimal phases.
- **Evolution**: new features in alerting software and new data sources that continually elevate the system.
- **Expertise**: years of experience in identifying highly complex patient cohorts and translating clinical patient journeys.

The information coming to the commercial team must be actionable and presented in an easy-to-understand display. Important attributes include:

- Precision patient cohort filtering and insights
- Diagnostic history
- Comorbidities
- Past procedures
- Previous therapy administration (or a combination of diagnosis, procedure, and drug criteria)
- Gender and age
- Provider, National Provider Identifier (NPI) number, or specialty
- Sequence of events
- The ability to identify the same patient throughout a journey (i.e., has the patient previously appeared in an alert?)
- Complete provider contact information so the commercial team can communicate effectively
- Real-time intelligence (e.g., timely, actionable alerts)

Healthcare is a dynamic, ever-expanding ecosystem; companies must be able to react quickly to clinical practice and policy levers that could create opportunities. It is imperative for the commercial field team to find new methods of working with payers and advocacy groups while addressing a patient's diagnosis and treatment journey. The right technology built on the right data provides that mechanism.

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