



CRA Insights: Life Sciences

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Navigating the rare disease marketplace: Presenting a cloud-based patient tracking platform

Patient identification: the first step in building the patient funnel

It is well known that developing and marketing products for rare diseases brings unique challenges to biopharmaceutical companies. Disease awareness is low, research costs are high, and there is often no clear regulatory pathway given that products are often first-to-market. Moreover, the relatively small patient populations heighten the importance of patient-finding efforts to ensure that rare disease products reach the patients they are intended to treat. These patient-finding initiatives have three main objectives:

1. Fill existing knowledge gaps in the patient journey – an understanding of a patient's story from symptoms to diagnosis to treatment;
2. Understand the drivers and barriers to diagnosis and/or treatment; and
3. Help rare disease patients receive the correct diagnosis and subsequent treatment.

Successful patient identification initiatives can lead to more patients receiving potentially life-saving or life-changing treatment, thereby achieving a product's full commercial potential.

Patient tracking: an integral part of patient identification

Patient identification is typically accomplished by local team members including sales reps, access managers, and country managers who use various tools and strategies to identify and record newly diagnosed patients. Existing relationships with physicians, established patient registries, and treatment centers are leveraged to learn about patients currently being diagnosed and treated. Additionally, understanding current patient dynamics paints a better picture of the market map that is ultimately used to inform strategies to identify more patients.

Unfortunately, we often see patient identification initiatives that do not employ rigorous follow-on patient tracking, and many identified patients are lost as a result. Patients are lost not only because of drop-offs, switching to a competitor, or low adherence overall but also due to constraints regarding the significant time and resource investment needed for patient tracking and a lack of available patient data. Additionally, regional nuances in how patients are

handled can generate confusion when aggregating findings. A holistic approach is therefore required to integrate patient identification with a robust patient tracking platform, allowing organizations to build and leverage patient maps and detailed patient journeys to connect more patients to care and maintain them on care.

Need for enhanced patient tracking that empowers stakeholders

For many rare and ultra-rare diseases, there may be no more than 100 patients across entire continents, and closely tracking a patient throughout their journey is important – not only to assess drug usage and effect, but also to fulfill a product’s commercial potential. We see that the most effective patient tracking initiatives have two key objectives:

1. Identification of drop-outs, discontinuations and switches by monitoring the flow of patients among medical sites; and
2. Removal of double-counted patients through data audits.

In our experience, rare disease companies often use spreadsheets to collect and consolidate data, which can lead to cumbersome and time-consuming data collection processes, significant disorganization, and validation issues. Such inefficiencies routinely frustrate stakeholders at all levels, from sales representatives seeking to spend less time reporting the data to executives who receive inaccurate status reports. On the other hand, the most successful patient tracking initiatives employ extensive and often large-scale data architecture approaches to data collection, which not only require significant investment but also are time consuming to set up and deploy.

There is a clear need for a patient tracking platform that allows companies to simplify the data collection process by streamlining data entry, using a centralized approach, and assigning ownership. Such a platform would empower stakeholders across functions to make better business decisions. Beyond being integral to patient identification, the platform to track patients could enable accomplishment of several other goals including:

- **Driving diagnosis and treatment:** allowing tracking and trend analysis of seasonal and geographic variations in patient diagnosis and treatment to uncover drivers and barriers and thus enhance diagnosis and treatment rates.
- **Bolstering patient recruitment efforts:** allowing identification of clinical facilities based on tracked patient data to enhance time to treatment initiation and deliver better-informed forecasts.
- **Informing patient journey initiatives:** allowing closer and more methodical monitoring of rare disease patients and helping to understand influencers of patient initiation, retention, and discontinuation.
- **Corroborating other internal and external efforts:** allowing well-informed initiatives such as sales force incentive programs, revenue forecasting, and marketing efforts.

RNnavigator: CRA's online patient tracking platform

To address some of the above-mentioned challenges and needs, CRA has developed RNnavigator – a cloud-based secure platform that provides a tailored approach for rare disease companies to accomplish their patient tracking goals. RNnavigator removes many of the burdens of mapping patients across and within markets through a platform customized for each organization and indication allowing for streamlined, efficient, and accurate data entry and reporting across all business units. The platform provides companies with a single source of data to inform their strategic decisions and support internal processes such as revenue forecasting, opportunity assessments, and commercial optimization. Most importantly, the tool is intended to significantly reduce time for data entry and organization, allowing resources to stay focused on identifying patients and enhancing their access to care.

Streamlined data entry

Companies tell us one of the biggest challenges in creating a functional patient tracking system is collecting de-identified patient data from field team members and consolidating the data in a systematic manner. RNnavigator provides a data entry platform that is customizable and highly intuitive, resulting in fewer data entry errors, less time spent on quality control, and the ability to use compliant data. The platform is code-free, minimizing training costs, and because the platform is already integrated, no time is spent on data consolidation.

Automated reporting

Another challenge rare disease companies face is the time spent reporting on collected patient data. RNnavigator automates this process by allowing the effective integration of data input from field users through multiple systems and browsers and enabling pre-selected self-service analytics, both critical to identifying actionable insights. In our experience, patient identification only yields optimal results if the end-users are enabled and encouraged to generate patient tracking reports on their own with nominal IT support. To further support effective patient identification initiatives, RNnavigator also helps to identify exceptions and reports anomalies that could be easily missed when looked at using unsynchronized spreadsheets. One of the goals of RNnavigator is to create a seamless flow of insight generation without much manual intervention.

Data accessibility for users

Real-time patient tracking with RNnavigator allows a streamlined reporting process for users at every level within the organization and appropriate access to patient data as required. The inherent flexibility of the tool allows reports to be made available across various functions and can integrate data from different systems in a secure manner – complying with GDPR (General Data Protection Regulation) rules for ex-US countries and the Health Insurance Portability and Accountability Act (HIPAA) for patient tracking within the US. RNnavigator ensures that the data is available as a single database, which has been tailored to the needs of the rare disease company and indication.

Conclusion

Rare disease companies require a holistic patient-finding strategy in order to achieve commercial success. However, to succeed in a rare disease market, companies not only need to excel at patient finding but also ensure that identified patients are followed throughout their entire journey. Patient tracking using RDNavigator informs patient identification initiatives and aids companies in understanding patient needs in greater depth, monitoring revenue versus forecast in different markets or regions, and enhancing data analysis to make more effective business decisions. The platform ensures that users in different markets and regions are operating with the same foundational knowledge and using similar modes of data entry, ultimately helping company leaders to navigate the complex world of rare disease commercialization.

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The Life Sciences Practice works with leading biotech, medical device, and pharmaceutical companies; law firms; regulatory agencies; and national and international industry associations. We provide the analytical expertise and industry experience needed to address the industry's toughest issues. We have a reputation for rigorous and innovative analysis, careful attention to detail, and the ability to work effectively as part of a wider team of advisers. To learn more, visit crai.com/lifesciences.

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