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WHITEPAPER

The critical role of Social Insights for Rare Diseases

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Introduction

Rare diseases affect only a small portion of the human population. In the European Union, rare diseases are classified as those conditions which affect fewer than 50 per 100,000 people, while in the United States they are classified as conditions that affect fewer than 200,000 people.[1] Despite the terminology, the overall prevalence of 'rare' diseases is significant. With up to 8,000 different types, it is estimated that at any given time at least 4% of people across the globe are living with a rare condition.[1]

<50 people per 100,000

In the EU has a rare disease

8,000

Different types of rare diseases

4%

Of the world population has a rare disease

[1] Joszt, L. (2019). Not So Rare: 300 Million People Worldwide Affected by Rare Diseases. *AJMC*. Retrieved from: https://www.ajmc.com/view/not-so-rare-300-million-people-worldwide-affected-by-rare-diseases.

Challenges and Opportunities

For the pharmaceutical industry, developing drugs ('orphan drugs') and value-adding support services for patients with rare diseases presents a distinctive challenge. Several industry leaders view orphan drug development and marketing as a risky undertaking because of the logistical difficulties and a perceived lack of economic benefit. The key factor underlying most challenges is the lack of data. In R&D, this translates to difficulty recruiting patients for clinical trials; for medical affairs, this can lead to difficulty in building a knowledge base; and, for sales and marketing, there may be difficulty identifying the right target segment and making data-driven decisions. The scarcity of robust, large-scale research in rare diseases can also create hurdles at the reimbursement stage of the drug lifecycle; it is much more challenging to demonstrate the value of an orphan drug than more common therapeutics.

However, with challenge comes opportunity.

Therapeutics for more familiar diseases has become a relatively saturated area and there isn't much scope for developing meaningful improvements on existing therapies. On the other hand, rare diseases present opportunities for pharma to achieve real 'breakthroughs' in treatment. On the surface, undertaking research for orphan drug development might seem like an expensive affair. However, clinical studies for orphan drugs often require smaller sample sizes and regulatory bodies are more accepting of low-cost study designs, such as pragmatic trials. Research has shown that orphan drug development costs are only half as much as non-orphan drug development.[2]

[2] Jayasundara, K., Hollis, A., Krahn, M., Mamdani, M., Hoch, J.S. and Grootendorst, P. (2019). Estimating the clinical cost of drug development for orphan versus non-orphan drugs. *Orphanet journal of rare diseases, 14*(1), pp.1-10.

Changes in the marketing and pricing landscape are creating further opportunities. In today's era of value-based pricing, payers are willing to accept high-priced orphan drugs if they have proven high efficacy and the potential to contribute to overall savings for the healthcare system. Niche marketing also comes at a lower cost. Overall, pharma stands to gain commercially, and improve brand recognition, from focusing on the rare disease space.

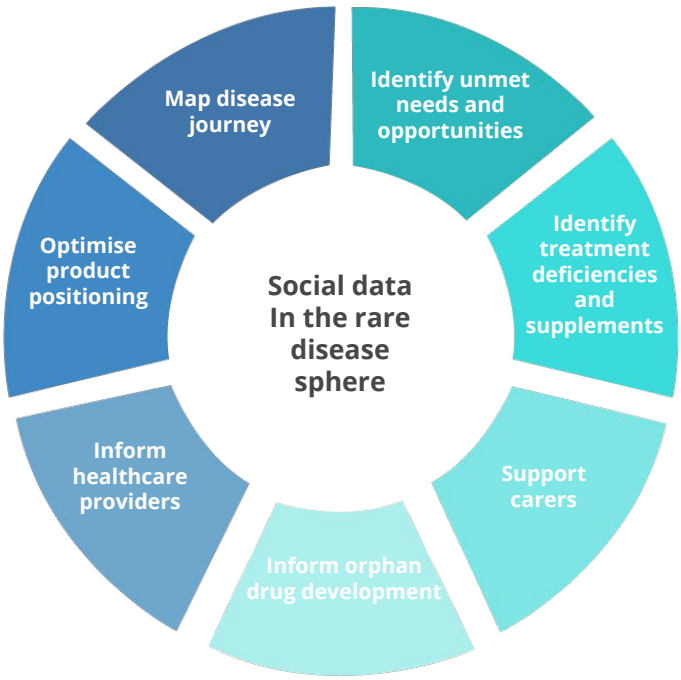
So, how exactly can pharma overcome the challenges within this space to optimise the opportunities?

Advancements in technology and connectivity across the globe make it easier for pharma to overcome the challenges associated with orphan drug development. Real-world data (RWD) analytics, in particular, can help generate insights through technology that were previously unavailable to the industry.

A significant and authentic source of RWD is social media platforms. Patients who are geographically scattered often become 'clustered' onto a single social media platform, which in turn serves as a rich data pool. Social listening – the process of collating and analysing conversations on social media – can serve as a valuable tool for drawing out insights from these forums.

Let's take a closer look at how analysing social data can help pharma – and drive better healthcare for people with rare diseases (*Figure 1*).

Figure 1. How social data can accelerate pharma's efforts in rare diseases



Source: Convosphere

01/

Driving patient-centricity by mapping the rare disease journey

Patient-centricity has been the watchword in the life sciences industry for a few years now. While there is no agreed definition of the term, it generally refers to keeping the patient's feelings and perspective in mind during each stage of the patient journey and product lifecycle. In rare diseases, patient-centricity is particularly important; by definition, since the disease is rare, researcher and clinician understanding of the disease process can be limited. Conversely, patients are often the experts when it comes to rare diseases.

The expertise of patients with rare diseases comes from travelling an obstacle-ridden path as they search for the right diagnosis and management strategy. In the UK, an average rare disease patient consults with five doctors before receiving a final diagnosis, with the number of healthcare professionals being seen ranging from three to ten.[3] Even then, the incidence of misdiagnosis is extremely high, averaging three misdiagnoses per patient. The patient journey reflects a patient's physical and emotional experiences, from the first signs and symptoms of a condition through to a definitive diagnosis and disease management or palliative care. Social media data gathered from online platforms can be collated, analysed and used to chart the patient's needs and emotions at each stage of this journey.

At Convosphere, we have used social listening to map the patient journey for several rare diseases, including mantle cell lymphoma (MCL). Mapping exercises for MCL revealed the key areas of conversation among these groups, along with the emotions associated with these discussions (*Fig. 2*). For MCL, treatment and increasing life expectancy were popular discussions among patients, caregivers, and healthcare providers. Chemotherapy and stem cell therapy were the most discussed treatment types. The overarching emotions associated with these discussions were hope and fear – factors not always considered in patient journey maps that do not utilise social listening or emotional analysis. Understanding these key themes and emotions equips pharma to offer resources that address the psychological needs of patients at different stages of their journey. This can be in the form of educational content for available therapies or links to ongoing clinical trials that patients may wish to be a part of.

Figure 2. Patient feelings associated with different stages of the MCL journey

Source: Convosphere

[3] Muir, E. (2016). *The Rare Reality – an insight into the patient and family experience of rare disease.* [online] London: Rare Disease UK. Retrieved from: https://www.rarediseases.org.uk/media/1588/the-rare-reality-an-insight-into-the-patient-and-family-experience-of-rare-disease.pdf

02/

Identifying unmet needs at each stage of the patient journey

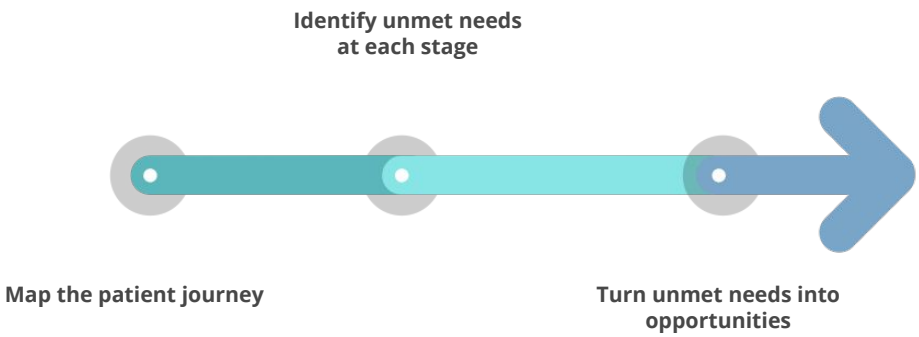
When a patient suffers from a life-depleting or life-threatening disease, their needs go beyond mere diagnosis and treatment. At various stages, patients may require information, education, validation of their symptoms, and even mental health support. The main barrier that patients with rare diseases and their caregivers face is lack of information on their condition. Healthcare providers, being less acquainted with the condition, may not be able to offer information on symptoms and prognosis. Under such circumstances, many patients and caregivers invariably turn to the Internet for more information. Indeed, the act of searching for information on the Internet may serve as a coping mechanism.[4] Most often, such information comes from social media forums dedicated to specific rare diseases. By connecting with others who have the disease, patients and caregivers gain a different perspective of their symptoms and experiences.[5] Importantly, they often feel less isolated after finding people they can relate to. By using social listening tools to map a patient's journey, the pharma industry can attain a holistic view of the patient who is living with the disease, across time.

This enables stakeholders to answer some critical questions:

- What needs do patients have at different stages of the patient journey?
- What needs do caregivers, family and healthcare professionals have at the different stages of the patient journey? Addressing their needs is critical to ensuring patient needs are met.
- What are the different paths the patient can choose and what factors influence their decisions?
- What role can different healthcare personnel (physicians, nurses, counsellors, pharmacists) play at each stage of the journey to influence optimal decision-making?
- How can pharma offer support at each stage, for example, by driving public awareness or educating healthcare providers on drugs or services available for disease management?

Answers to these questions can help pharma identify specific opportunities to improve patient outcomes and quality of life (*Figure 3*).

Figure 3. Mapping the patient journey to identify unmet needs and opportunities

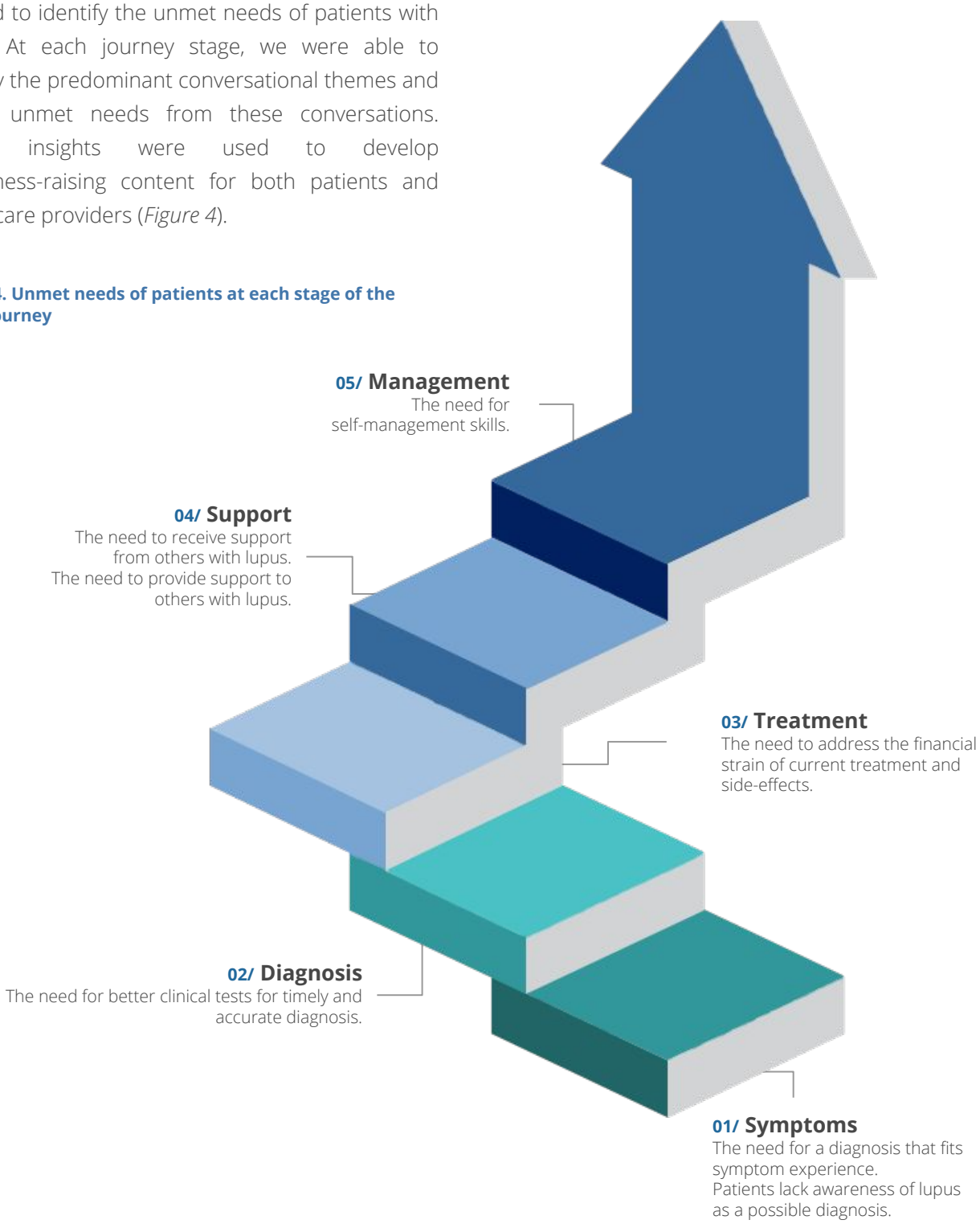


Source: Convosphere

[4] Gundersen, T. (2011). 'One wants to know what a chromosome is': the internet as a coping resource when adjusting to life parenting a child with a rare genetic disorder. *Sociology of health & illness*, *33*(1), pp.81-95.
[5] Barton, K.S., Wingerson, A., Barzilay, J.R. and Tabor, H.K. (2019). "Before Facebook and before social media... we did not know anybody else that had this": parent perspectives on internet and social media use during the pediatric clinical genetic testing process. *Journal of community genetics*, *10*(3), pp.375-383.

We used social listening tools for a key client who wanted to identify the unmet needs of patients with lupus. At each journey stage, we were able to identify the predominant conversational themes and derive unmet needs from these conversations. These insights were used to develop awareness-raising content for both patients and healthcare providers (*Figure 4*).

Figure 4. Unmet needs of patients at each stage of the lupus journey



Source: Convosphere

03/

Providing ‘a disease picture’ that illuminates deficiencies and supplements to current treatment strategies

Fortunately, it is now widely recognised that the management of rare diseases must go beyond attempting to ‘cure’ or stop progression of the disease. Therapy must be directed at helping patients achieve a reasonable quality of life and functioning. When healthcare providers do not have answers to questions related to disease management, patients can often find answers on social media platforms. In the past, social media platforms have been instrumental in identifying new symptoms associated with rare diseases and offering holistic therapeutic advice, such as dietary modifications.[6]

Social listening can help identify the most distressing signs and symptoms of a rare disease, which pharma can utilise to develop management strategies. For instance, we used social listening tools to better understand the unmet needs of patients with multiple sclerosis (MS). By analysing social media conversations around MS treatments, we found that patients were not fully satisfied with currently available treatments and tended to switch medications in search of a more suitable and effective option. Patients associated injectable medications with relapse and oral medications with greater adverse effects. Based on this data, the need of the hour was clearly to search for injectables with improved efficacy and oral medications with fewer adverse effects or, at the very least, to provide information and/or support to patients battling to find a suitable medication.

[6] Kelder, R. (2020). (The Science of Social Listening. Eurkea. Retrieved from: https://www.criver.com/eureka/the-science-of-social-listening

04/

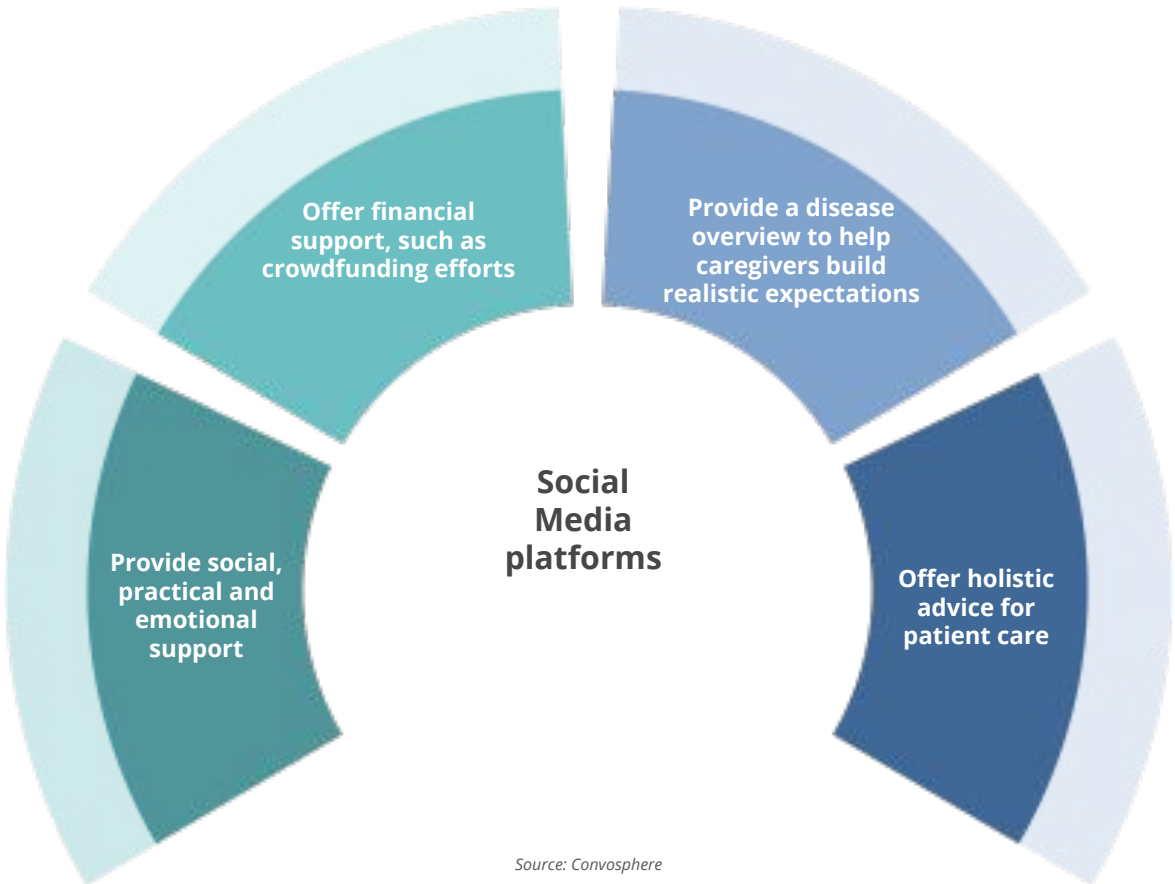
Taking care of the carers

The role of caregivers in the patient journey is increasingly being acknowledged. In caring for a patient with a rare disease, the primary caregiver can endure a significant burden. In prioritising patient needs, carers often make financial and lifestyle adjustments that can take a toll on physical, mental, and emotional health.

Rare disease internet forums can provide social support, improve caregiver self-efficacy, and ease any feelings of isolation caregivers may experience.[7] Similar to the patient journey, social media data can be used to map the caregiver journey and identify the information and support they require at each stage (*Figure 5)*.

Social listening can also help identify the level of awareness and perceptions of caregivers. We used social listening tools to help our client gain insights into awareness surrounding the Respiratory Syncytial Virus (RSV) infection. While usually benign, RSV infection can lead to bronchiolitis in children below one year of age. Social listening data showed that caregiver awareness of disease severity was directly linked to hospitalisation; parents whose children were hospitalised tended to regard the disease as more severe. This insight provided ideas for hospitalisation prevention campaigns.

Figure 5. How social data can help carers



Source: Convosphere

[7] Parker Oliver, D., Patil, S., Benson, J.J., Gage, A., Washington, K., Kruse, R.L. and Demiris, G. (2017). The effect of internet group support for caregivers on social support, self-efficacy, and caregiver burden: a meta-analysis. *Telemedicine and e-Health*, *23*(8), pp.621-629.

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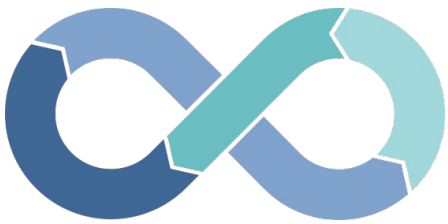
Guiding orphan drug development

The orphan drug development process is associated with several challenges, the most obvious being the identification and recruitment of patients to participate in clinical trials. Even if sufficient patients are identified, it may not be ethical or feasible to assign some of them to a placebo group, when the only hope of a cure may be the experimental drug.

Even prior to trial recruitment, challenges exist, the most significant being identifying a product for experimental use. Only about 10% of all rare diseases have a scientific knowledge base; consequently, it becomes inherently difficult to identify lead molecules or targets for drug development.[8] Another significant challenge is the identification of validated outcome measures. Even though certain biomarkers may be available to monitor disease outcomes, true validation may not be available for use in the disease being studied.[9] Social data can help address each of these challenges (*Figure 6*). By providing information on the disease process, it opens opportunities for pharma to identify targets for the drug development process. Social platforms also allow the opportunity to conduct pre-trial surveys, which can help with the design of validated outcome measures. A recently published paper outlined how researchers used social media to gather information about a rare ocular disease. Using the information gathered, researchers were able to characterise the demographics of the disease and the patient's journey, from symptoms and diagnostic modalities, to treatment options and recurrence data.[10]

Figure 6. Challenges and social data solutions during orphan drug development



Source: Convosphere

[8] Sant Joan de Deau Hospital (2019). A social network connects patients with rare diseases. Retrieved from: from https://www.sidhospitalbarcelona.org/en/share4rare-born-first-social-media-network-connect-patients-caregivers-and-researchers-rare-diseases

[9] ICON (2019). Four Challenges to rare disease drug development. Retrieved from: https://www.iconplc.com/insights/blog/2019/10/24/4-challenges-to-successful-rare-disease-drug-development/index.xml.

[10] Saad, R., Saad, S., Haigh, O., Molinari, D., Labetoulle, M. and Rousseau, A (2021). Using pre-existing social networks to determine the burden of disease and real-life needs in rare diseases: the example of Thygeson's superficial punctate keratitis. *Orphanet journal of rare diseases, 16*(1), pp.1-7.

06/

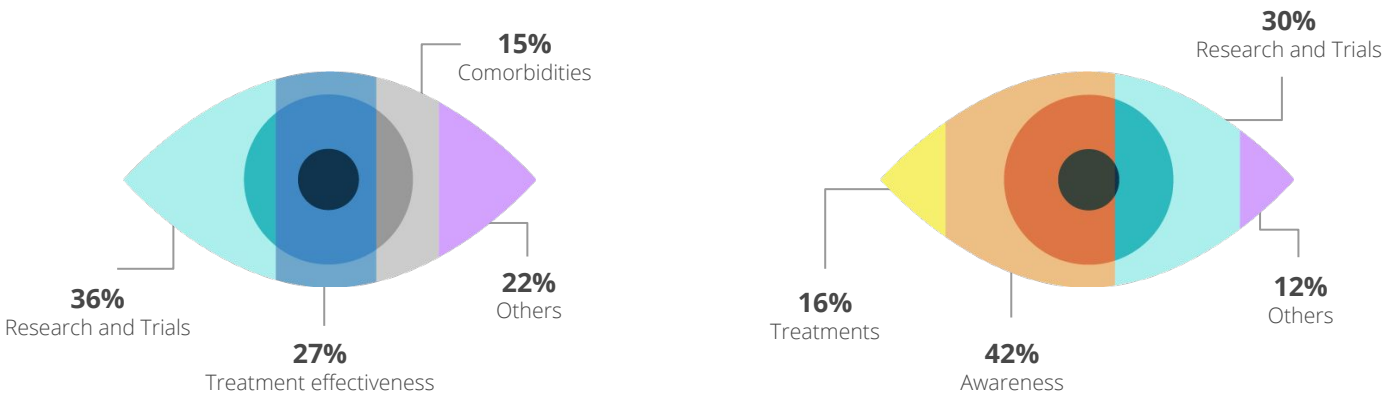
Informing healthcare providers

One of the biggest challenges faced by patients with rare diseases and their caregivers is the quest for a definitive diagnosis. Exploratory surveys have shown that less than one third of all physicians receive training in rare diseases during their medical education.[11] Since healthcare providers, particularly general practitioners, do not see rare diseases on a regular basis, they are unprepared to deal with such a disease when confronted with it. This can be complicated by the fact that patients with rare diseases do not always conform to textbook diagnostic criteria. Indeed, some diseases may not even have established criteria for diagnosis. Consequently, patients may spend several years in the grips of anxiety before they receive a diagnosis.

Online social networks have the potential to serve as a key information source for physicians. The average healthcare provider is believed to spend at least 20 hours per week online, and most of them prefer to access doctor-led social networking sites.[12] However, doctors may not necessarily come across information on specific rare diseases unless they are looking for it. The pharmaceutical industry can use social listening tools to gauge healthcare provider awareness for specific rare diseases. With access to insights generated from social listening tools, pharma can also actively provide physicians with educational content to increase their awareness of the diagnosis and management of rare medical conditions.

To understand the information needs of healthcare providers, Convosphere used different social listening tools to explore the themes emerging in social media conversations for two specific rare diseases: Lymbal stem cell deficiency (LSCD) and Lysosomal storage disease (LSD). While conversation centred around research and trials for both conditions, disease awareness was a far more dominant theme with LSD (*Figure 7)*. Our client used these insights to generate content related to these themes, resulting in improved stakeholder engagement.

Figure 7. Contrasting conversational themes related to LSCD and LSD



Lymbal Stem Cell Deficiency | **Lysosomal Storage Disease**

Source: Convosphere

[11] Ramalle-Gómara, E., Domínguez-Garrido, E., Gómez-Eguílaz, M., Marzo-Sola, M.E., Ramón-Trapero, J.L. and Gil-de-Gómez, J. (2020). Education and information needs for physicians about rare diseases in Spain. *Orphanet journal of rare diseases, 15*(1), pp.1-7.

[12] M3 EU (2014) How do doctors spend their time online? Retrieved from: https://eu.m3.com/PDF/Doctors-Time-Online.pdf

07/

Helping pharma leverage product positioning

Marketing orphan drugs plays an equally significant role as drug development in improving patient's lives. To be truly effective, an orphan drug must have the capacity to reach as many patients as possible. Social listening can help generate the insights required for a successful drug launch and improve the reach of the drug across markets. Social data also plays a key role in identifying and establishing relationships with digital opinion leaders and patient advocacy groups for specific niche diseases; both are important stakeholders for product positioning.

A key factor in leveraging product positioning is understanding and improving levels of healthcare provider awareness. A Convosphere client wanted to gain insights into stakeholder perspectives of Idiopathic Pulmonary Fibrosis (IPF). Using social listening tools, we were able to identify key stakeholder groups who discussed this disease in the context of therapeutics. It was identified that healthcare providers lacked clarity on the treatment options available for the management of IPF. In particular, a lack of palliative care options was identified as a key unmet need and business opportunity. The client modified their marketing efforts accordingly, promoting awareness of available drugs on social media platforms and increasing user engagement.

Social listening tools can also generate insights specific to geographical locations. When we generated social listening insights on Amyloidosis, we found that conversations related to stem cell therapy were limited to the US and UK. The opportunity for similar therapeutic options was still open in other geographic markets. Similarly, in our case study on MS, we found that infusion treatment was more common in the US, whereas oral and injectable drugs were commonly used in Germany. These insights informed better product positioning.

Pharma's Social Data Challenge

While social data can offer numerous benefits, pharma is still wary of adopting it completely because of certain perceived challenges:

Adverse events reporting

The pharma industry is often wary of social media platforms. This is usually out of concern that adverse event reporting could lead to negative publicity. However, the reverse is true. Social media reporting can increase pharma's awareness of adverse events with orphan drugs and prompt opportunities to introduce products with better safety profiles.

Privacy

Although social data is available in the public domain, there might be legal and ethical concerns related to the use of such data. However, a large quantitative survey has shown that most patients with rare diseases are supportive of the use of their personal data, irrespective of their demographics or disease severity.[13]

Expertise

Drawing meaningful insights from social listening requires both technical and industry expertise, which may not always be available in-house for many pharmaceutical companies. It may be necessary to bring in third-party players who can collaborate with pharma to ask the right business questions and help them optimally leverage insights gained through social listening.

Developing actionable insights

Insights obtained from social listening should not merely answer questions, they should provide information that enables pharma to take meaningful action. Unfortunately, due to its highly fragmented and unstructured nature, at least 50% of all social data is pure noise. To generate meaningful, actionable insights, the right social listening tools must be leveraged to ask the right questions in the right context.

Most of the above challenges are centred around a lack of knowledge and experience. Experts in the social listening industry, however, are adept at using social data in a compliant and effective manner and can help pharma overcome these challenges.

[13] Courbier, S., Dimond, R. and Bros-Facer, V. (2019). Share and protect our health data: an evidence based approach to rare disease patients' perspectives on data sharing and data protection-quantitative survey and recommendations. *Orphanet journal of rare diseases*, *14*(1), pp.1-15.

Transforming the Rare Disease Space

Social listening has the capacity to provide the pharmaceutical industry with a 360-degree view of the rare disease patient. The information gained from social data is not just limited to one patient; voluminous datasets can be generated from multiple patients across the globe and historical datasets can be generated by collecting social data insights across different time periods. Essentially, social listening can tackle the main problem underlying many of the challenges in orphan drug development and marketing – lack of data.

To learn more about how Convosphere can help you harness social data to maximise opportunities for the commercial success of orphan drugs, contact us at info@convosphere.com, visit our website www.convosphere.com, or call us at +44 (0) 203 8580235 (UK number) or at +1 332 6001 419 (US number). To stay up to date on the latest in social listening and social intelligence, follow Convosphere on LinkedIn and subscribe to our monthly Social Intelligence Digest newsletter.

Convosphere

Through human-led social data analysis across 45 languages, and with offices around the world, we deliver deep consumer insights that bring our global clients closer to local audiences. Agencies and Enterprises of all shapes and sizes rely on us for our global and multilingual social listening expertise, and the advantage this brings to their business. With clients across a wide range of sectors, we specialise in Pharma & Life Sciences, FMCG, Consumer Electronics and Entertainment. Having our teams on the ground around the world gives us unprecedented access to local data sources in hard-to-reach markets, and the team skilled in generating social intelligence to deliver truly actionable insights at a global scale.

As a social-first insights agency, we recognise that the value of global social listening lies in the impact data driven-decisions can make – and the cultural relevance required to make them actionable. Our approach ensures we do not apply truisms across all markets; rather than trying to fit data into a templated set of predefined results, our methodology allows for new discoveries and nuanced cultural and linguistic differences to emerge. Combined with the experience and capability of our analysts, who combine a passion for cultural trends with unmatched expertise in the latest technologies, this breadth of data provides a significant depth of insight that goes beyond positive and negative sentiment. Gaining a deeper layer of understanding and putting it in context allows our clients to better understand the concerns and preferences of their stakeholders to create more effective strategies and communications.

We can deliver a little or a lot according to our client's business needs, from running global social listening projects to providing strategic recommendations across multiple markets, channels or platforms, including owned social platform analytics and additional datasets to put social conversations in context.

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