

Harnessing Social Media to Reach Today's Social Media-savvy Rare Disease Patient and Caregiver

For patients with rare diseases, social media conversations are a gateway to uncovering information regarding condition coping and treatment. Likewise, for those who recruit for rare disease clinical trials, social media listening is like a town square – displaying unbiased and unaided conversations that enable all of us to better understand how to connect with those patients for recruitment.

Creating a Virtual Community

Patients with rare diseases are often lost and disconnected from their fellow patients because they lack the same type of resources compared to those with more common diseases. More and more, they and their caregivers are turning to peers on social media, seeking information, sharing experiences and providing support, which establishes mutual trust, bonds and support for those who have been diagnosed with the same disease.

Many in the rare disease community feel geographically isolated, as they may not live near others with the same disease. Additionally, some rare diseases put patients at risk of cross infections, such as cystic fibrosis (CF), where patients could pass on bacteria to each other. These challenging circumstances propel online rare disease communities to great strength, as they're often small in number, but tightly networked with high engagement due to small disease population.

Harnessing Online Connections

For those recruiting patients for clinical trials, the value of social listening from these dynamic communities is the ability to sense the patients' hopes and fears, understand how they seek and process information, and observe pathways discussed and ones taken. This glimpse into patients' and caregivers' lives, if analysed with statistical significance, can quantify behaviours and drivers and reveal potential barriers to treatment and unmet needs.

Analysis of these key findings can identify potential opportunities to inform smarter communication decisions, such as creative development for effective recruitment campaigns and the tailoring of recruitment messaging using lexicons that resonate with patients. Within online forums, it's possible to go directly to where patients frequently have these discussions, answer their questions, conduct awareness and recruit them.

When approaching any social media recruitment campaign, it's important to start by answering some fundamental questions. How are these patients and caregivers interacting with each other on social media platforms? Which platforms are you observing high levels of engagement on around the said condition? Are patients or caregivers congregating in private online support groups, or are they engaging with each other on more public forums and/or patient communities? Is clinical trial recruitment even permitted on a given social media platform? Answering these types of questions will guide your creation and execution of a productive social media advertising campaign targeting rare disease patients.

Direct study advertising on social media is all about the targeting of your ads. Targeting parameters consist of demographics, locations and interests (what patients are following). A study's protocol will dictate demographic targets, and the site locations will be

the geographies you want your ads to show. The disease-related interests of your audience will directly impact the productivity of your social media campaign. Categories of targeting worth exploring are as follows: condition-related interests, patient advocacy groups, scientific journals, symptom-related interests, anything treatment-related, high-rate comorbidities and clinical trial interests. It's important to navigate through the large amount of disease-specific content, and focus on an ROI-based approach to audience building. Direct advertising is just one tool to promote a study on social media. Look for patient groups and communities. Even when they are private, you can approach the group's admins/moderators, describe the study, and ask they share it amongst group members. Patient advocacy groups often have a substantial social media presence. Plug into these trusted patient resources. A multi-tiered approach will lead to better results.

Conclusion

Rare disease patients and caregivers are migrating to social media for answers, resources, and the newest and latest developments in treatments. It's crucial for future recruitment efforts to participate in social media listening from both a tactical and strategic perspective, as listening to and engagement with patients will greatly contribute to and enhance patient recruitment.

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