Patient Influencers as a Means to Patient Centricity

By Leilani Graham

On the Internet, people might not know you are a dog, but they do know if you are an “influencer.” Patient influencers speak out about their patient experience via social media. They have built a dedicated group of followers that, in some way, are connected to their own disease or therapeutic area. These followers trust the influencer to provide accurate, unbiased, useful and perhaps entertaining information tailored to their needs. Influencer communications are not unidirectional; influencers create a community by engaging in conversations with their followers (including other influencers).

Influencer marketing works through influential people rather than directly contacting the target market as a whole. It identifies the individuals that have influence over potential customers, and orients marketing activities around these influencers.

Traditional social media marketing campaigns target a population of people who share a common interest, e.g., a disease. Influencer marketing campaigns target the influential people within that community so those people can pass the message along to their followers, along with the influencer’s credibility. The influencer’s followers will also include people the marketer did not identify in the target population. Ideally, the message will spread virally, as it ricochets through other influencers and the entire target population.

Patient influencers are already communicating with their followers about disease symptoms, current treatments (effectiveness, side effects, dosages, etc.), and clinical studies — the entire patient, caregiver, family and community experience related to the disease. Influencer marketers just add new information about their product — or clinical study — to the mix, employing patient influencers to ensure that the message propagates quickly through the target population.

Why Should We Work with Patient Influencers?

Most patients say they prefer to hear about new clinical studies through their physicians, but marketing a clinical study through physicians has three major obstacles. First, most physicians are not participating in a specific clinical study, are unlikely to know about the trial, and, even if they do know about it, are unlikely to refer their patients to a study site. Second, most physicians at a heathcare provider that is conducting that clinical study are not investigators on that trial and are not thinking about that trial for their patients — they are very, very busy and have other priorities. Third, many investigators in a clinical study do not have the time, the attention, or the systems in place to discuss that clinical study with all their eligible patients. This dynamic is why social media has emerged as an important way to communicate directly with patients. Influencer marketing, given the right conditions, is simply a more effective form of social media marketing.

How Do We Find Patient Influencers?

Patient influencers, by definition, are highly visible on general-purpose social networks like Facebook, Instagram, Reddit and Twitter; patient-oriented networks like Inspire, Patients Like Me, and CureTogether; disease-specific networks like BSCM (breast cancer), DiabetesMine (diabetes), and Preeclampsia Forum (preeclampsia); websites hosted by patient advocacy groups like the American Cancer Society, the National Parkinson
Foundation, and the Mesothelioma Applied Research Foundation; and physician networks like Medscape, Sermo and Doximity.

Find the influencers by searching for relevant hashtags, querying support groups, working with the relevant patient advocacy group, reading popular blogs, and asking patients in the specific indication. A very rare disease might have only a few patient influencers, each with a double-digit number of followers, while a common disease might have hundreds of influencers, each with hundreds, thousands or even tens of thousands of followers.

**How Should We Vet Patient Influencers?**

Influence is a function of scope and effectiveness. The best influencers have the most followers AND have the most influence over their followers. Most social media platforms provide follower numbers. To judge effectiveness, look at the content of the posts and the likes, retweets, reposts, replies, etc., that show patients are reading and engaging with the posts. Characteristics of the influencer are also important — what is their connection to and experience with the disease? If possible, also look at their followers — are they also influencers? What do their posts look like?

In addition to influencers on social media, also consider influencers in the non-digital world — leaders of support groups, churches, schools and government agencies— especially for rare diseases, for which no stone can be left unturned.

You probably want to work with influencers that post uncontroversial content that appeals to a diverse audience, and, obviously, supports clinical research.

Many patient influencers make resumes, recommendations and other material available online or upon request. WEGO Health, Clara Health, Stanford MedicineX, Professional Patient Advocates in Life Sciences, and other organizations certify patient influencers.

**How Should We Work with Patient Influencers?**

Effective influencers are proud of their integrity and their contributions to their community. You must persuade them that your message will enhance their credibility and help their community. An influencer who does not thoughtfully vet your message will probably not be an effective messenger.

Influencers have limited bandwidth to help recruit patients for clinical studies, so you might have to compete for their attention. Good influencers will think of their relationship with you as a partnership. They will expect you to listen to their advice, and so you should, because they are the experts in communicating with their communities.

Influencers will not want to repeat the same text over and over again. They can craft variations in their own words and messages that are less direct than “Join this clinical study.” As you proceed, your influencers will have their “ear to the ground,” so pay attention to what they hear.

If you want to assemble a patient (and caregiver) advisory group for your clinical study, consider including patient influencers. They can represent not only their own perspectives but also those of their community of followers. They also have experience articulating the priorities and issues of their community.

Many of the best patient influencers expect to be compensated like anyone else who provides a valuable professional service.

Influencers are two-edged swords — expect them to tell the truth about your clinical study, as they understand it, whether the news is good or bad. They will view any attempt to
deceive, manipulate or keep them in the dark as a betrayal, and you do not want patient influencers as enemies.

**Does Patient Influencer Marketing Actually Work?**

According to a study by WEGO Health, the answer is a clear “yes.” When marketed to by patient influencers, 87% of patients will ask their physician about the information, and 85% will share that information with people they deem as potentially interested.

The following case studies illustrate the effectiveness of working with patient influencers, especially when they contribute to the design of the patient recruiting program:

**Case Study 1: Autoimmune Disease**

When reviewing a prescreener for a client’s slow-enrolling autoimmune trial, we noticed they were asking patients to rate their pain from the previous week. We consulted a top influencer in the field, who told us that patients with autoimmune conditions often have sporadic pain, so reporting last week’s pain was missing a lot of eligible patients.

After our client restructured the pre-screener, they saw an influx of qualified patients, and filled the trial in just 21 days, seven days earlier than the trial’s original enrollment deadline.

**Case Study 2: Juvenile Idiopathic Arthritis**

One of our clients initiated a first-in-human clinical study within a disease indication known to afflict only 80 patients worldwide. According to the patient influencers we consulted, 70% of people diagnosed with the rare disease were first misdiagnosed with another rare, but more common disease: juvenile idiopathic arthritis.

By partnering with patient influencers in the juvenile arthritis community, we achieved over one million impressions on Twitter alone, quickly filling the study with qualified patients.

**Case Study 3: Lupus**

One of our clients was four weeks into a 12-week recruitment period for a lupus clinical study. Within three weeks on social media, we identified over 3,000 leads, with over 25% through influencer marketing, and completed enrollment.

**Conclusion**

Influencer marketing is a proven technique in many fields, including patient recruiting for clinical studies. By partnering with patient influencers, study sponsors can effectively engage with the patient population, quickly and economically find patients for the study, and enhance the effectiveness of other recruiting methods.

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