Denise Myshko

Patient Recruitment *in the* Online Era

Recruiting patients for clinical trials continues to be challenging. Social media may just be the answer.

Despite the time, effort, and money spent on improving patient recruitment and retention, these two areas of clinical development remain among the biggest challenges facing the industry.

The impact of recruitment challenges is significant. The delays in patient recruitment for clinical trials account for an average of 4.6 months lost per trial, according to one source. When calculated, this is an annual cumulative loss of 26 years, on average, for each company. According to a recent report from Cutting Edge Information, clinical trials last 42% longer than expected in Phase I, 31% longer in Phase II, and 30% beyond planned deadlines in Phase III — all because of recruitment delays.

Now Web-based communications — and specifically social media — are significant tools for patient enrollment. Industry experts say patients can be enrolled faster and less expensively than other methods. Patients are more actively seeking health information online, and they are more engaged. In fact, 73% of online U.S. adults have looked for health information online, according to Pew Research Center's Internet & American Life Project.

Social media represents a potential opportunity, but there are a lot of things that need to be in place in an organization for this to happen, says Pat Connelly, head of digital strategy and communications, at Millennium: The Takeda Oncology Company.

"Finding ways to use the strong presence of patient advocacy groups on a platform such as Facebook is a great place to start with patient recruitment efforts," he says. "We should be partnering with academic centers to create educational materials we can distribute via social channels to encourage participation in clinical trials. Posting videos on YouTube and tweeting the praise of clinical research are great ways to begin to demystify the process."

In fact, social media efforts can be very effective for recruiting specific patient population. Quintiles recently issued a report that highlighted some of the company's efforts, including an observational research study with 425 patients with chronic obstructive pulmonary disease (COPD) from its online patient community. The first digital patient was enrolled in the study in six minutes with the last patient confirmed in only nine calendar days.

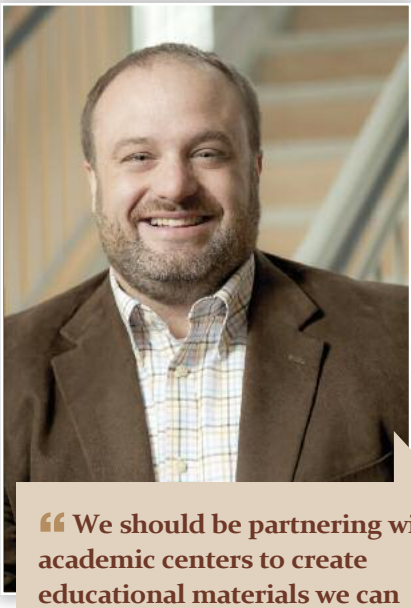
In another example, a 1,255-patient women's health study in which Quintiles developed a custom communication plan to reduce the number of patients who become lost to follow up or drop out of the study entirely. The customized communication program kept patient engagement high and resulted in a 59% increase in the retention rate for the duration of the study.

Matt Stumm, principal, creative and media strategy at BBK Worldwide, says social media is a great way to reach specific patients.

"We've seen a lot focus on specific disease categories," he says. "This is the beauty of using online mediums and specifically social media. Patients aren't looking for general information. Patients are looking for something very specific and tailored for them. We've been having a lot of success in having messages that are tailored to a specific audience."

Mr. Stumm adds that driving people to these messages isn't difficult.

"People are using social media; it is part of their daily lives," he says. "We can get the message into the stream of information in the form patients are comfortable with."



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>
> **PAT CONNELLY** / Millennium

Because there is more competition for patients, trials with smaller patient populations often struggle to enroll completely.

Neil Weisman, executive VP and general manager at Blue Chip Patient Recruitment, says social media is an ideal place to reach smaller patient populations.

"With smaller, harder to reach patient populations, the normal tricks don't work and they are cost prohibitive," he says. "Smaller patient populations are more in tune with each other, and there is a greater sense of community. Patients value each other's opinions and talk about each other's experiences."

Mobile Technology

Patients are using mobile technology more and more to access the Web, but the industry isn't ready, says Liz Moench, president and CEO of MediciGlobal.

"While patients are already gravitating to mobile technology and all of our websites are being programmed for both mobile and tablet compatibility along with the Web, the clinical teams actually still need convincing that mobile technology is here," she says. "It will take another 12 to 18 months for the industry to get where it needs to be."

She stresses that mobile doesn't just include smartphone use, but also tablets.

"Some say the traffic is about 60% on mobile devices in terms of patients' use of technology," Ms. Moench says.

Social media and mobile go hand-in-hand, Mr. Stumm says.

"People are no longer sitting down at their computer to catch up on the news and their social networks," he says. "They are accessing all the information they need on their phones; they're constantly plugged in."

Mr. Stumm adds that there are technical aspects that can optimize a program for mobile platforms and how a user will access information on smartphones or tablets.

"If we ask 15 prescreening questions on a mobile device, people will leave," he says. "We have to employ different tactics. One of the things we started to do was a prescreener that prequalifies a potential study participant so that when he or she finishes someone will call, and this further qualifies the person because we understand he or she is on a phone."

Using Social Media Effectively

Mr. Connelly says the advantages of using

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social media for patient recruitment is extending reach and awareness.

"Facebook has potential because of the sheer enormity of the platform's reach," he says. "It is becoming the communication norm for people. As people's participation in this platform increases so will their interest in receiving more information, such as health, over the channel. Companies are running more and more global clinical trials and 80% of Facebook's users are outside of North America. There is a potential here to get the word out about clinical trials for rare diseases quicker and with a more engaged audience."

Facebook, especially, has made connectivity with patients easier, Ms. Moench agrees.

"Search engine traffic is declining," she says. "Facebook is being accessed more often and is being accessed from a mobile device. Each month there is an increase. What is wonderful about Facebook is that it allows patients to form communities of what we call consequential strangers. They bond because they share a common illness, daily struggles, and shared experiences in a way that no one else can understand. These have become very powerful forums of dialogue and learning."

Ms. Moench says before MediciGlobal embarks on a recruitment program, the company will assess the "buzz metrics," the conversations, the issues, and the concerns that come through on social media.

"The patient communities on Facebook have decentralized patient advocacy and the power that was once wielded by the organized advocacy groups has shifted and become decentralized into the hands of hundreds of patient organizers who share their own information," she says. "It is not all about fundraising. It's about living on a daily basis."

Ms. Moench says she has had success using Facebook for patient recruiting.

"For example, a Swiss-based biotech used Facebook in three cohorts for a rare disease," she says. "This was a study that was in rescue, and we met the timelines to the point that they finished the entire three cohorts of the study five weeks ahead of schedule even though they were already behind the timeline by nine months. We could never have achieved these results without social media."

Mr. Weisman says as companies are looking to target verticals, they have to make sure that the message is provided to the right people at the right time.

Blue Chip Patient Recruitment has worked with patient advocacy groups to communicate messages via social media.

"In some instances, this means creating IRB-approved posts and partnering with local advocacy group chapters or community site administrators to share those messages on their sites," Mr. Weisman says. "The organizers of the page post our approved messages to encourage dialogue in their communities. In other cases, there will be a forum area, which is another opportunity for us to communicate. We create posting and response strategies to ensure we have IRB approval on every possible scenario that could happen if we post in an active community."

One challenge, Mr. Stumm says, is that often patients, depending on the condition, don't know what information is reliable.

"People don't know what information to trust or who to engage with and people don't have the time to figure this out," he says. "We've created a social media hub where we're finding the best and most reliable resources — we've researched them and feel comfortable with the information that they are providing — and we've consolidated that information in our application."

The retention and engagement tool is called Health Info Gizmo, a flexible, audience-specific mobile application that helps to inform, engage, and motivate individuals within a condition specific and clinical study community.

Available as a downloadable mobile application for smartphones as well as through mobile Web, Health Info Gizmo provides general and or study-specific information based on the viewing audience.

Best Practices

Mr. Stumm says using social media is like using any other media, those involved have to have an understanding of how it works.

"Companies have to have a firm understanding of not only the technical aspects, but how to handle risks that come up, how to write for the medium, how to message for that medium, and so on," he says. "Twitter, for example, has a limited number of characters."

Mr. Stumm says for social media to be successful, companies have to have people who are dedicated to the project.

"Running a social media program is time-consuming," he says. "It's better not to have the same person who is also running three other components of the program managing the social media program."

Mr. Weisman adds that because there is no clear guidance, social media is an issue with not just the patient recruitment industry but for healthcare marketing in general.

"The FDA hasn't necessarily provided clarity on what is okay and what is not," he says. "Pharma companies are still interpreting how to use social media in a variety of different ways. From our experience, this spans the gamut. On one hand, we have clients that don't want us to go near social media. On the other hand, we have clients that view social media as an effective way of reaching patients. There is a great span in pharma companies in how legal and regulatory departments have to deal with not only how social media's role in clinical trials but within its overall corporate policy."

Mr. Weisman stresses before opening a communication stream it's important to have prepared answers and responses that are preapproved by an IRB.

"The worst thing in a social media setting is forcing users to wait for an answer while we wait for IRB approval of a response to a user's comment," he says. "Given that every patient-facing communication needs to be approved, having prepared scenarios enables us to act quickly to avoid any patient-reported outcomes, potentially negative chatter among community members, or misinformation spreading."

Mr. Weisman says it is important to work closely with the site and page organizers to be nimble in an interactive community.

"The reality is that if a response is not made within 24 hours, there could be a potential crisis," he says.

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