# Transforming Recruitment for Clinical Trials via Patient Social Networks



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Patient-focused social networks are transforming how clinical research is done – and none too soon. Patient recruitment for clinical trials is the Achilles heel of pharma. 45-50% of clinical trials experience recruitment delays, and 70-80% never fully enroll. We all know the associated costs: Every month of recruitment delays leads to extra costs of keeping all those sites open longer, and of course every month that you delay getting a drug approved is millions in foregone revenue.

But this is not a problem of consumer demand. Consumers with chronic diseases want to hear from the companies doing clinical trials. They just don't actually hear from them, or about trials for that matter. In a 2013 survey to members of MyMSTeam.com, our social network for people facing Multiple Sclerosis (MS), 85% responded positively to the question, "If we at MyMSTeam identify trials that might be relevant to you, would you want us to notify you?" These responses included such comments as, "My neurologist doesn't do trials, so I never hear about clinical studies," and, "I don't want to hear about every trial in MS, just the ones that would work for me."



MyMSTeam Survey, October 2013. N = 350

That's the inherent problem: Most methods of reaching out to notify people about clinical trials are not relevant. They are traditional mass marketing techniques: Ads, direct mail, TV, posters, even banner ads on WebMD – and exactly none of these are targeted. So you're taking this mass market bludgeon, if you will, to a real niche problem, where you're trying to find a needle in a haystack. The way to be smarter in that outreach is through patient social networks, where you know those niche audiences and you can get the right message to the right person at the right time.

### WHAT KINDS OF SOCIAL NETWORKS WILL ENGAGE WITH PHARMA?

Many pharma and biotech companies are regularly approached by groups who call themselves social networks. But what do you look for to determine if it's a true social network? Look for these four characteristics in a partner.

First, social networks have personal stories. What is it that draws us to Facebook? It's the fact that we know the people on

there, we know their backgrounds. we're interested in seeing the continuing page-turning of their stories and the chance to interact with them draws us back. In health, this is even more critical. We have a social network for women diagnosed with breast cancer - MvBCTeam.com - and each one of these women shares deeply personal stories about when they were diagnosed and how they went through their treatment, their reconstruction, and their resumption of normal life. These stories create a personal connection. They give hope, validation and perspective - not something the healthcare system is set up to consistently deliver.

#### Social networks are dynamic.

You should see posts and comments every few minutes from real people, not editorially driven content from a community moderator. On a social network. you actually see social interaction and proof of a real personal connection. You see empathy through people giving each other a "hug" or a "like." You see immediate and thoughtful responses from others who care

about you – and this happens every few seconds, not once a week.

Social networks have pictures of real people. Pictures matter quite a lot because they are a sign of trust. If you go to a community and there are no pictures, it's not really a social network. It's as simple as that. Pictures are one of the best and easiest markers for real community. People don't have to share their real names on our social networks if they don't want to, and we never share their personal information outside the social network. But most people typically do share their names and photos because it's a safe, password-protected, and monitored social network.

Social networks have high "MAU." High user engagement is the most critical aspect of a social network. Ask this question: What is your percentage of monthly active users (MAU)? Look for double-digit percentages. MyMSTeam.com has 52% MAU; this means that out of the 24,000 people with multiple sclerosis who have joined MyMSTeam, literally half of them are active on a monthly basis, and most of them

are active on a weekly or even daily basis. When we reach out to them about an MS trial that could be relevant to them, the response is strong and immediate because they are so engaged. Most health websites - WebMD.com or Herceptin.com, for example, or a disease foundation's website - only have about 5% monthly active users (MAU) or less. People might go to these sites, but it's not something that's part of their regular habit, so they may not be around when you are trying to notify them about a trial.



#### BEST PHARMA PRACTICES FOR ENGAGING SOCIAL NETWORKS

So now that you know what to look for in a health social network, how should you as a pharma company engage with them? Here are a few best practices to follow.

Be targeted – drop the mass marketing approach. Precisely identify your targets. If you're recruiting for a breast cancer clinical trial, partner with the social network to find the people for whom it's relevant – for example, women with Stage 2 IDC who are Her2 negative and live near one of your trial sites. There is no need to spam every woman with breast cancer with news about a trial if it doesn't fit them.

Let the social network do the talking. Have the social network you're partnering with do the outreach. At the DIA 2014 50th Annual Meeting, we shared a case study where we partnered with Biogen Idec to help recruit patients for a trial in relapsing MS. We explained how MyMSTeam identified the members who met the basic inclusion criteria for the trial and lived near a site, and

how MyMSTeam emailed those members letting them know about the trial. We don't put ads on our social network announcing a trial. We send targeted emails that our members know will be relevant. Which leads me to the third best practice...

Always personalize your message and be very transparent. When we partner with pharma companies, we clearly state that we've partnered with and have received financial compensation for working with them. People will appreciate and opt in to receiving emails like this: "The reason we're reaching out to you, Mary, is because we

have identified a trial for women

with Stage 2, IDC who are Her2 negative just like you, and there's a study site open near you. We've partnered with Pharma Company X and receive financial compensation for communicating this trial. To learn more and see if you may be eligible, click here." In the MS case study with Biogen Idec, one email like this generated as many qualified candidates in just 24 hours as all 30 open trial sites had generated in seven weeks.

Think Beyond Patient
Recruitment. The other thing
we've learned is that you can do
a lot more with social networks
than just patient recruitment.

Now our opportunity is to engage real people facing these chronic conditions while designing the trial and selecting sites. Clinical research involves providing a high-touch, high-cost service to the "consumers" who agree to join the trials. Yet clinical research is one of the last remaining services that rarely, if ever, consults its consumers about their needs. Show candidates what you're planning to do in the trial. If there's an option between bi-weekly visits versus monthly visits with a sleepover, show them those options and see which ones

# Personal and Transparent



Many members of MyMSTeam have urged us to do more to share information about relevant MS clinical trials as they arise. We've recently partnered with Biogen Idec to share news of the ALLOW study which focuses on people with relapsing-remitting MS who are currently taking a standard interferon beta (IFN-β) therapy such as AVONEX® (interferon beta 1b), BETASERON® (interferon beta 1a), or Rebif® (interferon beta 1a).

find out if you are eligible

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they're more likely to actually sign up for and stay in. And before your finalize where you put your sites for a trial, conduct a fast. cheap survey of a social network to see where there would be real interest in a specific trial, and even check to see which physicians those folks have on their teams and potentially see if they would participate in the trial. If you want to move the needle on patient enrollment and retention, you've got to get patient input early and often.

#### GETTING THROUGH YOUR LEGAL AND COMPLIANCE **DEPARTMENT**

Certainly, this can raise some questions: What about adverse 16 event reporting? What about people talking about the trial? We have worked through these issues with several different pharma and biotechs now and the process has been surprisingly straightforward to handle. Have the social network you are partnering with do it. It is easy to automatically track mentions of an adverse event related to a trial drug. At MyHealthTeams we never share the personally identifying information of our members, but if we see an adverse event we can share that anonymously with our pharma partner.

> As for people talking about a clinical trial, our members are smart and their willingness to learn is high so we educate them about the right way - and the wrong way - to engage with others about a trial. We make sure they understand how they could taint

the trial if they talk about it. Then we actually monitor what they say, and if somebody says something that could damage or taint a trial. we reach out to them, remove that post or comment and explain to them why it was removed. It's rarely a problem, as long as you explain the rationale for it.

#### WHAT THIS MEANS GOING **FORWARD**

It's not long before the primary way people learn about a clinical trial is through a patient social network. Mass marketing is too blunt a tool for patient recruitment. Social networks with highly engaged members facing chronic conditions offer the best way to reach exactly the right people for a trial. Just like any consumer service, eventually people will easily evaluate the trial options put before them - so getting their input early will be key. Partner with the social network, be totally transparent, and seek ways to get member input on trial design and site selection too – in addition to recruiting for the trial. We're finally at the point where several biotechs and pharmaceutical companies are successfully doing this, and not just talking about it at conferences. This is great news for the industry and for people facing chronic conditions. •

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is the co-founder and CEO of MyHealthTeams, a company that creates social networks for specific chronic conditions. In the past three years MyHealth-Teams has launched social networks for 5 different conditions and grown from 35 members at launch, to over 100,000 members today. Eric is passionate about empowering patients and believes that if you are diagnosed with a chronic condition or disease, it should be easy to find the best people around to help you. You can follow him on twitter @ejpeacock