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Social Media Company Matches Sponsors with Patients to Advise on Trial Design Evidence Program

By Bill Myers and Leslie Ramsey

An innovative social media company is developing a new model for matching trial sponsors with patients and caregivers who can offer ideas for making trials more patient-focused.

Inspire, an Arlington, Va.-based social media company, has built a community of 1.5 million people sharing information, opinions and support in therapeutic areas ranging from advanced breast cancer to wound healing.

In addition to connecting people with similar health interests, Inspire is now matching drug sponsors with what it calls virtual patient advisory boards, using the company's 225 disease-specific online communities to identify members that can help guide development of clinical trials.

"There was like an 'aha' moment for us," says Robert Gardner, senior director of business development. "The lightbulb goes off and you go, wait a second, we can connect these two things together."

It's an old story in clinical trials but it's becoming especially acute as the drug industry moves into precision medicine, Gardner says.

"It's a huge problem across all pharma, and one of the main reasons is that pharma is not including the patient voice in the protocol," he says. "They decide all these things without including the patient ... and they wonder why they can't recruit. It's not because you can't find the patients and caregivers, it's because you set up a protocol that isn't feasible for them. You haven't asked them anything."

Virtual patient advisory boards can help fill that gap, Gardner says. The model, which is evolving as Inspire navigates its first contract, begins with an invitation to participate sent out to members of the appropriate Inspire communities.

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To create a board for a sponsor of a series of trials on stages of heart failure, Inspire will reach out to about 30,000 members, aiming to get at least 200 responses, says Jeff Terkowitz, Inspire's vice president of product. Those that accept will receive a sponsor-developed questionnaire that asks about such issues as protocol intensity — is there too much testing or too many office visits in the trial — and reducing patient burden.

The sponsor is looking for any factors that it wouldn't normally be aware of, Terkowitz says. Do trial participants need reimbursement for bus fare, parking or child care? Is the location accessible and are instructions easy to follow? The goal is to make it as easy as possible for patients to participate in the trial and to retain patients once they have been recruited and enrolled.

He tells the story of one mother who nearly withdrew her child from a trial over frustration at not being able to locate the correct office in a large hospital complex. The room had been changed, and signage didn't clearly direct participants to the new location.

Once the membership of the virtual advisory board is set, Inspire sets up an invitation-only online community that participants check into once a month to respond to the sponsor's queries as it develops the trial protocol. Participants in the heart failure advisory board sign on for a 12-month commitment.

Advisory board members receive a $50 honorarium for each month they check in and respond to questions. More than that, Terkowitz says, they get a say in shaping the future of clinical trials that may someday benefit them.

In addition to the heart failure trial, Inspire is in discussion for three other advisory boards — one on idiopathic pulmonary fibrosis, one on prostate and bladder cancers and a third on liver diseases.

The work isn't cheap — drug companies pay a fee ranging from $175,000 for a three-month advisory board to $600,000 for a one that is year-long — unless you think about how much a sponsor might have to spend to put together an actual patient advisory board amongst scattered populations for rare diseases.

"This isn't just 'nice to have' research," Gardner says. It's "actionable, informative research that healthcare companies can take and apply to their clinical development," he says. "The reason why we're doing all this is to help make clinical outcomes better."