



## Straight talk with... Jamie Heywood

Last month, Genentech launched an unusual five-year research pact. The San Francisco subsidiary of the drug giant Roche partnered with Cambridge, Massachusetts-based PatientsLikeMe to mine the online patient network's database of real-world experiences. In exchange for an undisclosed fee, Genentech now has access to nearly all of the information collected by PatientsLikeMe, which currently includes more than 250,000 members with 2,000 different conditions. The hope is that studying the network will help Genentech learn how to stratify patient populations more precisely and measure drug effectiveness better, among other things.

At the helm of PatientsLikeMe is Jamie Heywood, a mechanical engineer by training who devised the idea for the platform ten years ago when he noticed some striking similarities between the information asked of online dating websites and clinical trial portals. With his brother Benjamin and friend Jeff Cole, Heywood founded PatientsLikeMe later that same year. **Nicholette Zeliadt** spoke to Heywood about where the crowdsourcing site stands a decade on from its inception and what this new partnership with Genentech will mean for open-participation research.

### What kinds of information does PatientsLikeMe currently collect?

What we get from the patients is essentially a clinical interview that asks about how the patient is doing, the symptomology of their disease, what drugs they're taking, what novel therapies they're trying, what supplements they're using and even lab values. Functionally, it asks about how they live their life: Are they working? Do they have good relationships? Are they depressed? Our system is capable of both interviewing a patient about their meaningful outcomes and storing that in a computable format so that our partners can do predictive calculations and informatics work on that.

### PatientsLikeMe has partnered with several different drug companies in the past. How is the new deal with Genentech different?

PatientsLikeMe has four basic product offerings. One involves either analyzing our data or surveying patients to get new information to try to answer a specific research question. The second involves building

and enrolling disease-specific community registries for longitudinal observational studies so that a company can learn about the disease, the journey the patients go on, their unmet needs, problems with medicines and treatment issues to understand how to make trials more reliable and easier for patients to be part of. The third is advanced predictive disease modeling where we build tools to predict individual patient outcomes. And now we have Global Network Access, which we just announced and which Genentech is utilizing. Global Network Access is different in that it's a five-year partnership designed not to inform one product or problem but to enable learning throughout the enterprise.

### How did you settle on the five-year timespan for the new collaboration?

We've done about ten major partnerships with pharma, and what we realized was that we can do some things in the short, two- to three-year time frame that are very successful: trial recruiting, health economics outcomes research and building disease registries. But those were at some level inadequate for some of our longer-term ambitions. We said, "Let's be ambitious and talk about how, by understanding the patient's experience, we can invent better ways of doing discovery in health care." I think that required a long-term commitment so that we could learn to work together, because we're inventing a new science, and we have to figure out how that new science should be used in the clinical development process.

### How will PatientsLikeMe change as a result of this partnership?

One thing Genentech wants to understand is, for patients with particular kinds of cancer, what it's like to go through the process to get diagnosed, to go through the different treatment choices, and where there's opportunity to make that better so that patients have better outcomes and experiences. That requires some major upgrades to our system, because the cancer treatment modalities are so different from the other diseases that are currently represented in PatientsLikeMe. Cancer treatment involves combination therapies in specifically timed regimens, and collecting that data—the general regimen and the variations in it—is a complicated user experience and data architecture problem. Therefore, we need to expand the technical capability of the system to manage oncology so that we can understand the side effects and the consequences of those complex treatments.

### How is PatientsLikeMe different from other existing patient-centric data collection efforts?

Almost all of the other approaches are either purely social, which means they run forums and social networks but don't really have a medical informatics framework, or they're technologies that are still building additional silos that only look at one dimension, such as the genome or the microbiome. What we're doing that no one else is doing is focusing on measuring the trajectory of the human experience in a robust and computable way so that we can understand how anything that is done to a patient or that a patient does to himself or herself will affect that person's outcomes.

### What do you want PatientsLikeMe to look like ten years from now?

I think you'll be looking at a global registry with hundreds of millions of individuals that's been translated into every language and normalized to local traditions and that's fully integrated into the medical system so it's part of care and incorporates information from the electronic medical record, imaging, diagnostics and emerging technologies for interrogating biology. Everyone says we have to spend less on health care, and I'm not sure I agree with that—there's nothing more important in life than health. What we need to do is get more value for health care, and value means you have competitive outcomes. And that's what, in our longest dreams, I think PatientsLikeMe begins to bring to bear.