

INNOVATIONS CONFERENCE -- PATIENTSLIKEME

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CLIFFORD: Hi. I'm Dave Clifford from PatientsLikeMe. I'm gonna talk about patient value in online communities a bit from our experiences as well as the use of some of the things that we do in a patient community for researchers and clinicians.

So this is Stephen Heywood and he is the middle brother of the two founders of PatientsLikeMe.

And we started out as an ALS -- I've been in the U.K. a lot so I say motor neuron disease, so pardon me if I slip, flip back and forth -- an ALS community. So Stephen was diagnosed with ALS in his late twenties. He came from a family of engineers.

And I don't know how many of you hang out with engineers but when engineers see a problem they try and break it down into component parts and solve the problem.

So because there were three engineers in the family, they just figured that biologists and doctors didn't know what they were doing and if they used engineering techniques instead, they could come up with a cure for ALS before Stephen passed away.

One of the components of this was creating an institution called the ALS Therapy Development Institute, which is a non-profit that has done an enormous amount of mouse work in retesting every available therapeutic that was -- that has gone through a phase one clinical trial for patients with ALS in a more rigorous mouse study and were unable to replicate the results of any of the previous mice studies that led to them being approved for human trials by up-powering the studies and -- and introducing more manufacturing controls into the process.

In -- in doing clinical development and doing clinical trial development, one of our founders divorced from his wife and was using a dating site while at the same time trying to do clinical trials recruitment.

And said, you know, I can find someone between 26 and 29 in five miles of my house who loves "Star Trek." (LAUGHTER) What I can't do is find someone like my brother anywhere in the country using any sort of publicly available data.

So that's one of the reasons that the patient community that we built does things like measure data. And for the patient, we want to be able to answer this question, which is given my status, what's the best outcome I can hope to achieve? And how do I get there?

And a lot of online communities provide what I would call sort of folk wisdom or heuristic knowledge, knowledge that's not necessarily evidence. Evidence is driven by aggregated data over time, replicated.

So what we built was we built a community for people to share their folk wisdom online and see if it accrued and aggregated to the point where it was creating evidence and data.

So how did we do that? Well, one, we started by breaking down the question, what is my status? So in ALS there's a tool called the ALSFRS and it's got these four domains: walking, breathing, hands -- hand usage, and speaking-, sort of crudely.

And when a patient comes to our site, we administer them the ALSFRS. They fill it out on their initial entry into the site. And we also give them a quality of life tool, which correlates with the RAND of 36, for any of you who care about these sorts of things -- which measures their wellbeing and their productivity. And we code that into mild, moderate, severe or non-categories.

And then, as the patient continues to engage in the site, unlike a traditional registry where a patient sort of takes their data and throws it over a fence and maybe someone somewhere in the world accesses them for a clinical trial and they don't know their status at the time that they try to access them for the clinical trial, we have this data longitudinally.

So we look at the patient journey. Because if a patient's going to be, you know, at the early part of the journey, getting married after some onset of the disease, having difficulties walking, having difficulties using their arms, in ALS they're gonna be at the end of the journey too.

So it's sort of a one-way train, unfortunately. But the patient who's down at the end can teach the patient who's just diagnosed a tremendous amount about the disease if you're creating ontologies for them to share that data well and share their knowledge well.

So I'm gonna go to the site, ideally, and show you where we are today. So we went from this -- to this community of justALS. We have about -- I can show you right now.

So we have about 4,741 patients with ALS. The largest trials in ALS on drugs are generally done in populations of hundreds. We get about 10 percent to 20 percent of all newly diagnosed ALS patients in the United States coming to use the site.

So we started in ALS but as you can see here, we now have 115,000 patients or people who have signed up for the site in 500-plus conditions. That number's actually probably about 1,000-plus.

So if we were to look for something like bursitis, which is a knee injury, we have about 122 patients who have bursitis.

But some of our best patient populations are in diseases with complex presentation and complex etiology, difficult to determine cause and a wide presentation. So these are diseases where patients really don't know what to expect.

And as you can see there, we've got about 24,729 patients who have come to our site looking for information on multiple sclerosis.

Until April of this year, we had 11 patient communities. We opened this up to a way where you can come to the site with any condition. So you can see that there's a much, much larger, broader patient population now.

And one of the reasons we have such numeracy in MS was because we did do some target research to, or targeted outreach to people with multiple sclerosis.

And this is what a patient profile looks like when you talk about data. This is a patient who chose to make their data public. About 15 percent of all users make their data public to everyone else.

The other 85 percent of users, their data is shared with members of PatientsLikeMe.

That's sort of the transaction cost we impose on our users for using the platform. We say if you're going to use these tools for self-monitor then what you have to do is help other people out. If you're gonna get information from other people, you need to help other people out.

Although we are a for-profit company, we consider ourselves a not-just-for-profit company. We're a for-profit company with a social mission.

So this is a tool that they have called InstantMe. And I can show you six months of this user's data. So he began really robustly using InstantMe in August it looks like. We've launched an app so that people can use this on their mobile device. So this might be a user who's using InstantMe from their mobile all the time.

It's a five point scale with sort of a Twitter feed attached to it, 140 characters, and we can do natural language processing on what makes it -- what makes a person with multiple sclerosis's very bad days different from what makes their -- what makes their very -- their very good days very good. Sorry.

We track weight, relapses and MSRS, which again, is the primary outcome rating scale.

But then you hear some of the other things that we ask patients to come back and tell us about: anxiety, depression, fatigue, insomnia and pain are asked to all of our users. And then there are specific outcomes that they can choose to track -- choose to monitor in each condition.

This is -- these are little areas where their multiple sclerosis affects this person. They also -- it also looks like they have problems with acid

reflux, balance problems, exercise issues.

They're tracking some of the side effects from their drugs and symptoms. Then you can go down and you can see what treatments they take and why they take the treatments and what kinds of treatments they are.

So there's a lot of data here. We were one of the first organizations to look at creating -- taking a tool that's used in engineering project management, the Gantt chart, which is what this is here and then put it up against their symptoms.

So you can look and you can say, OK, what drug are they taking. They're taking Gabapentin. Is that Gabapentin effective or is not effective? And you can scroll through their various symptom scores while they're -- and make those comparisons.

All this data is stored. So we have all of this data on the backend in longitudinal data tables. So for a given user who's using the site, where we can -- where we provide that aggregated de-identified information to other organizations, we can have some -- anywhere from eight columns, which is age, gender, primary condition, you know, what they filled out when they first signed up and never came back, to 800 columns.

Our codebook for epilepsy is 25 pages long.

So that sort of talks about what users can do on the site. But then there's what benefit they get out of it. And I'll flip ahead again. So this is a -- what we call our symptom stacker or symptom sandwich.

And if you go to WebMd and you look in multiple sclerosis or if you go to NHS Choices or if you go to a lot of different places where you can get patient information on what it's like to have multiple sclerosis, they'll give you this list of symptoms, this being things that you can expect to have when you have multiple sclerosis.

And they won't attach any sort of probability to any of those things. So you don't know -- you know that at some point you might be depressed. At some point you might have bowel problems or brain fog or pain or sexual dysfunction.

But you don't know what the likelihood is of you as someone with multiple sclerosis having any of those things. So this provides more context for a patient to get their information.

And for any piece of information they provide, that you saw in the patient profile, when they give us that information we have a philosophy called, give something-get something.

So when a patient fills out a questionnaire, their outcome is immediately reflected in -- against the distribution of all other people with that condition at that point in time.

So if you come and you say, you know, today my brain fog is moderate, it's gonna give you a histogram that shows how many people have moderate brain fog, how many people have mild brain fog, how many people have severe -- severe brain fog. And that can inform your dialogue with your clinician, for example.

Here's another example, what patients get out of the site. So this is a user who for years had been taking 10 milligrams of baclofen on a regular basis to treat spasticity in their legs.

Spasticity and stiffness in the legs is a common problem with multiple sclerosis. It can greatly impair walking. They were taking 10 milligrams because their neuro said you don't need more than 10. More than 10 milligrams is gonna cause weakness in your legs.

They came to the site. They looked at the bar chart distribution of how much baclofen an average multiple sclerosis user uses and they saw that, in fact, they were down near the bottom of that distribution.

They went back to their neurologist and said, you know, here's some data that I got from this multiple sclerosis community I'm a part of. Here it is in a -- in a graph rather than here's something someone told me online on 2diabetes.com or here's something I found by looking at, you know, another community forum.

Sometimes doctors like to see data and charts to put things in context and perspective. Not always, some doctors don't like that but some doctors prefer knowing what a distribution might actually look like.

Again, in HIV, there's a lot of peer-to-peer positive support messaging. So this is a person who was encouraging another member to medication adherence while they were having side effects from the drugs that they were taking.

Protease inhibitors really knock the wind out of you. They're not fun drugs to take. But at the same time, they bring your viral loads from 802,000 to 74. So when someone says that and can show their CD4 chart to another patient, or show their viral load chart to another patient in that context then it's immediately, we think, a more powerful teachable moment.

People with RLS, you know, all of these things if we were on the site showing you this and this person was talking about Requip or Mirapex, those immediately link to the treatment page for Mirapex or for Requip.

So a person who's interested in learning more about the drug can just click a button and see a tremendous amount of additional information about the utilization of that drug in the real world. We measure adherence burden, cost, side effects.

So this is what we do, these are the choices we made as a community, and this is how we're gathering data.

So when you think about online communities, don't just think about them as places where people get together and talk. Think about them as robust data sources when they're created that way.

You can purposely -- purposively create these things to serve as a patient reported outcomes measures platform, as a clinical informatics platform so they're not just places to go for people to talk to each other.

And we found that if you give people data in the context of talking to each other, it makes communications more powerful.

So this is an example of people with epilepsy on our site, so users with epilepsy. We had a client who was interested in what they got out of using the site.

And we found that because we asked them what sort of seizures they had when they were tracking their seizures in a seizure diary, we went from people saying things like, I've got some fuzzy-wuzzies, which was a term that some people with epilepsy use to describe their seizures, to I have a partial tonic-clonic seizure and its severity is five.

Or in -- and because of that they can manage their condition better. Because of recording they know what's normal and what's abnormal and the sorts of seizure presentations they have.

There have been a number of patients, for example, who said, you know, I'm -- I'm having deja vu a lot lately. And deja vu, if you have epilepsy, is a sign of seizure onset.

So these people who were just having deja vu over and over again and weren't telling their neurologist are now saying I'm having seizures more frequently than I thought I had seizures.

A lot of these people, because they understand the side effects of their medication better, they understand how medication might cause drowsiness in some cases, emotional lability in others, are more adherent to their medication because they're better understanding about what to expect and what's caused by drugs and what's not caused by drugs.

So it limits misattribution of things like nausea if someone's taking a drug and saying, OK, you know, I never -- I've -- I've been taking this drug for this many years and I'm experiencing nausea today. What's the likelihood that my nausea today is being caused by this drug? Pretty low, so I'm going to keep taking it.

Eighteen percent of users of PatientsLikeMe have fewer E.R. visits. And that's out of our total epilepsy population, not out of our patient population with epilepsy who were hospitalized in the previous year or in the previous period.

So the -- the appropriate question to ask from a research perspective is did you have fewer hospitalizations than did before? And how many hospitalizations did you have before and how many hospitalizations have you had in the last interval?



Unfortunately, we didn't ask that question. We do -- we're still learning how to do research better.

And 20 percent insisted on seeing a specialist, which, we think, also drives a lot of these changes.

So when you go from a -- we did another study on adherence to guidelines, where we looked at the guidelines that AAN put out for epilepsy treatment. And we asked patients, did your doctor do this the last time you went and saw them?

And we saw that massive changes in adherence to guidelines between G.P.s, who sometimes 50 percent of the time followed the standard -- followed the guidelines that AAN put out and epileptologists who were following the guidelines, 90-95 percent of the time.

Because we have a private messaging function and there's social function to the site, I think two percent of survey respondents, or one percent of survey respondents got engaged to be married as a side effect of using the site.

(LAUGHTER)

Just to talk about the research that you can do because of this and, hopefully, this video will work. There was a paper that was published in Neurology Journal about the -- about lithium delaying the progression of ALS.

And this user, Humberto-from-Brazil, started tracking the outcome scores of every user who is using lithium on the site after they said they were starting to use -- every user of lithium who had ALS on the site.

So he was tracking their ALSFRS scores in a Google spreadsheet. We said that's probably not good because they're probably not controlling for all these other things, so let's do this rigorously.

And because we have outcome scores from before their -- before the date that they started taking the drug, we could match that user's progression...

Is this going to work? This is not going to work. I can show you during the demo.

What we did was we matched the users progression against all the other users in the database that had similar progression and were able to create a linear model and see if there was deviation from that model that was driven by the use of the intervention.

So there wasn't -- it turned out that the initial paper wasn't successful. We had 10 times as many people on drug and 30 times as many controls in our trial, in observational data, than the original trial did.

This impaired study recruiting for other studies that were looking at doing this. This cost us (inaudible) four months of a research assistant's time, or four months of a head of research's time. The other trials cost millions of dollars to run.

Just in case you were wondering if we got it published, we got it published in "Nature Biotechnology" -- reasonable journal score. And this is an open access article so -- because we had users contributing their data to it. We didn't want the users to contribute their data to it and then not be able to see the results of the study.

We got "Nature Biotech" to make this article open access for anyone. So you can go and download it now. That was sort of our major cue in the process.

That's all I have. So if you have...

(END IN PROGRESS)

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