



The World Health Care Congress Speaker Live Chat Series TRANSCRIPT

Ben Heywood, co-founder, president and director, PatientsLikeMe



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Ben Heywood will be a featured presenter at the [6th Annual World Health Care Congress](#), April 14-16, 2009 in Washington, D.C. Visit www.patientslikeme.com to learn more about his company and the social networking movements in health care.

Moderator: Welcome to today's chat with Ben Heywood, co-founder, president and director of PatientsLikeMe. We are happy to start taking your questions.

Mike_D: PatientsLikeMe is one particular application of the social networking movement. Could you have envisioned when the Internet really began taking shape more than a decade ago that people would be using it for such a purpose?

Ben Heywood: I think this latest movement on the web - of users driving the content, users aggregating together to solve problems is something that would have been hard to imagine in the early internet days - but it definitely a huge part of the future potential power of this medium.

Moderator: What does PatientsLikeMe do?

Heywood: At PatientsLikeMe, we build online communities of patients with life-changing illnesses where patients are sharing detailed health information - outcomes, symptoms, and treatments over time. What makes us different and valuable is that the information is structured to help inform treatment decisions and what is working in the real world.

GH: What determines what diseases or conditions are added to your site?

Heywood We are currently in ALS (Lou Gehrig's disease), MS, Parkinson's Disease, HIV, and Mood (Depression, Bipolar, and Anxiety) as well as a number of small orphans diseases.

We choose our conditions from feedback from patients, what illnesses we think we can make the biggest impact in, as well as business considerations.

Kylia: What are some ways for marketers to engage with user-driven content effectively without pushing their product/service in ways that turn off patients?

Really the first step is listening... Patients want to know that the industry creating the products that impact their lives are listening and understanding their needs.

Next up is really engaging in the dialogue - take the lessons learned from listening and engage with patients in a dialogue about their needs and your products.

JimTate: The recent Health 2.0 conference had no patients or patient advocates to present their view of the new technologies. Why?

Heywood: Unfortunately, patients are often under represented in the healthcare dialogue. That is part of what is so exciting about PatientsLikeMe - patients now have the ability to drive change, make their issues central to the dialogue.

Pg1: in addition to patients, who has leveraged the data collected by PLM?

Heywood: We are working with researchers - both internally and a number of research institutions as well as industry - pharma, device companies, and health plans. We list our partnerships on our site as part of our pledge around transparency.

Mitch: Ben, what channels are you pursuing to broaden PLM's influence as a patient-centric, social networking site? Why should healthcare delivery systems get involved with PLM?

Heywood: I think one of the areas we have expanded into earlier than we thought was in the payer/health plan space. Payers are looking at PatientsLikeMe as a lighter-weight disease management platform. A peer-based DM, sort of like an online version of AA (the most successful peer-based DM program around).

Giovana_Quigley: Do you foresee the number of conditions addressed being increased over time?

Heywood: Absolutely - our goal is to reach 1 million patient by the end of 2012 covering 100s of conditions.

Roburban: Do physicians contribute to this site?

Heywood: Yes, we have had some physician contribution... However, we really are patient-centered, so we haven't focused to really engage clinicians yet.

However, we know this data is being used in clinical practice - so the shared information from patients are definitely informing docs.

Also, we have a Doctor Visit Sheet for patients to use their profile as part of the clinical discussion.

Ultimately, treatment decisions need to be between a patient and their doctor. We think that the information on our site, and using our site, only enhances this patient doctor relationship.

GH: Can you say more? What business considerations?

Heywood: Our business model is really about engaging industry into these communities - so one consideration as we look at new diseases is for whom this will help make better products. First and foremost, we need to make communities that help patients - so that is always our first consideration.

Foneil: What kind of information/feedback have you received from your users in terms of impact of the tools on the site?

Heywood: We get a lot of amazing feedback from our users from... depression patients who say using the site keeps them out of the hospital to a patient in MS that said that the site saved her life as her doc over-prescribed one of her medications.

All in all - patients definitely feel like this empowers them to a significant degree.

MK: Given the vast amount of online 'sites' and resources now available to many people for condition-specific issues, what is the unique contribution that you believe Patients LikeMe offers?

Heywood: What is really great about PatientsLikeMe is that we aren't just a forum. We are really focused on structured quantitative longitudinal health data (a mouthful). This data is a really great source of new evidence for both research, clinical practice, and industry.

Don: Do you have any pediatric conditions on the site?

Heywood: Not yet - but we have discussed many internally. Keep your eyes out over the 18 months.

Lisa: How will you reach that goal?

Heywood: With a lot of hard work... we have assembled an amazing team, from technology to user experience, to our R&D team that designs the medical ontology of our communities.

Nancy_Richardson: Do you moderate discussions with patients?

Heywood: We have community managers... but our model is really around light weight moderation - there is a blog post on our moderation philosophy at blog.patientslikeme.com

Fred: How do we integrate patient experiences like those on your site into the more local mainstream health care discussions?

Heywood: I think this is already happening. As I mentioned, we know that doctors are using this information as part of their clinical practice.

Jeanne: Are there concerns about privacy related to social networking in this area?

Heywood: We have a unique take on privacy... well outlined in our Openness Philosophy (a link is on our home page). We talk openly with our patients about the risks of sharing health information - but we (as do our members) feel the benefits out weigh the risks.

Pg1: Can you elaborate on how payers would leverage PLM as a DM platform?

Heywood: The discussions we are having is around offering PatientsLikeMe as a service to their members - we have seen some strong anecdotal evidence that patients are using healthcare more efficiently by learning from other patients experiences and data.

Bill54: Will you seek patients outside of the US?

Heywood: Right now we are English based site - so the bulk of our members are in the US (70+%)... However, we have patients from over 50 countries

Kylia: Do you think that with patient-centered content on the rise, the paradigm of healthcare delivery in the US will change? Patient/Healthcare professional relationships?

Heywood: I think we are evolving to a more collaborative approach to healthcare, and an empowered patient only makes that more effective.

Jsmall: The social networking concept seems really powerful with patients who have like conditions. Do you see it having the same potential with providers?

Heywood: Yes, definitely... A company called Sermo has an incredibly strong physician community.

Lisa: What governance is used to decide to make treatment info/decisions available to others?

Heywood: As I mentioned earlier, we have a very open model. Patients who are members of our site are sharing their information with all the other members at the individual profile level... additionally, approximately 10% of the members share their information with the world. Also, all of the aggregated data is made available for everyone to learn from.

Star: Today's healthcare is fragmented and leaves much to be desired [on many fronts]. How to trim the fat and deliver the clean product for the benefit of the patients/consumers IYO?

Heywood: First off listening to patients is very effective in this regard. Another phenomenon we are seeing is that by understanding what they can control and not control (through others experiences/data), our members use healthcare more efficiently - eliminating a lot of the costs that come from seeking answers.

Giovana_Quigley: What has been the reaction of providers and medical societies to the information on PLM website?

Heywood: Very positive - the AMA asked us to speak to them recently.

Mitch: How do patients engage with one another and is there a clinical moderator to ensure that potentially harmful misinformation is not disseminated within a group?

Heywood: Our community is very effective at weeding out false claims. The power of the open model is that every piece of data, every forum topic, every claim is drillable back to the individual patients profile - this is a very effective means of accountability. It also allows users to check for themselves.

Houstonchick: How much do you find the patient's doctors influence their choices of where to get treated, rather than self-researching or friends?

Heywood: Doctors are obviously (and should be) a big part of this equation. However, patients are definitely more in control of the process with the information they get on PatientsLikeMe.

Debbiek: I don't know much about your site at this point. Do you bring in medical experts to work with the various disease state communities on their questions?

Heywood: Our research team engages clinical experts (and expert patients) when they are designing the medical ontology of a given community/disease state. I encourage you to check out what we are doing - seeing is believing.

MK: What about best practices, the experience of care, in addition to best products?

Heywood Absolutely, if you think about our MS community - now 8500 patients strong - it represents the clinical practice of most of neurologist in the US. This is ultimately a long term real world outcome study in each of the communities.

We have tons of examples of how patients are improving their health from the information on our site and by just participating.

Craig: Can you describe your business model?

Heywood: Our business model is really centered on insights and access. The insights that patients gain from using our site are also useful to the company who make the products these patients are using. We want to measure the value of their products in the real world.

Craig: How do you insure that information shared is evidenced based?

Heywood : Our R&D team has extensive experience in health research and a diverse set of healthcare experience - from genetics, clinical practice, social statistics, neuropsychological, etc.

Giovana_Quigley: At this point PLM is focused on disease-related information. Do you foresee PLM expanding to the health and wellness space?

Heywood: We are really focused on the 1/3 of healthcare which is what we term 'life-changing' illnesses. Health and wellness may spring from this over time - I always found it interesting that my brother at the end of his life was a incredibly disable man, but ultimately incredibly healthy.

That is not something that is explored much. BTW - my brother had ALS.

Nancy_Richardson: Any concerns about liability of information shared by patients with each other?

Heywood: There could be some risks and we are straight forward with our members about those risks. We do know from our members that the benefits outweigh the risks.

Fred: Do you think that the folks who use PLM would also be the ones to use online, real time, on demand physician virtual visits?

Heywood: Perhaps - i thin there is definitely a potential for patients to get a second opinion about their treatment paradigm - or more of a quality check.

Kylia: It seems that there is more authenticity with PatientsLikeMe representations of their lives than with other social networking sites?

Heywood We work hard to help patients share the relevant health information that informs their personal health choices, is clinically relevant, and can make a long term impact on the treatment of their disease through research and industry engagement.

S_M_Greene: To what extent, though, do you think providers' resistance to highly empowered patients will continue? Some are put off by patients who come in asking lots of questions and armed with lots of information.

Heywood: I think this is going away. A more informed patient ultimately is a better treated patient.

Debbiek: We've done some research in the social networking space, and the chief challenge is aggregating the data you can glean from the dialogue. How do you accomplish this?

Heywood: In our communities, patients are sharing structured health information including outcomes, symptoms, and treatments over time. We are not in the anecdote business.

Pinaki: What real value have pharma companies derived from this so far?

Heywood: Really understanding how their products are experienced in the real world. What is the value patients are getting? Those that really embrace this information will ultimately make the best products and services to meet patients' needs.

Lisa: Regarding privacy and social policies, do you also monitor and edit as needed?

Heywood: Again, we have a light weight moderation approach. Also, for our forums, we have more of an aspiration model... i.e. an ideal PatientsLikeMe member...

Pinaki: Curious if the FDA has had any interest in patientslikeme in trying to regulate it?

Heywood: We are engaging the FDA in determining the most valuable use of this data for that agency. We will also allow our patients to directly submit Adverse Events to the Medwatch+ program directly from their PatientsLikeMe accounts.

Kathleen: Do you partner with any of the voluntary health agencies like the MS Society?

Heywood: We have a handful of partnership with disease non-profits.

Lisa: And in turn a more compliant patient?

Heywood: We think that using our site makes patients more compliant... we are working on several pilots to prove this out.

pg1: I am a relatively new community member and do find that the information on treatment, outcomes and symptoms is valuable. I was surprised at the level of social networking by some in the community, though. were you?

Heywood: Not at all... patients have looked for support forever, and the online forum is another means for that.

Nancy_Richardson: What about concerns from sponsors about liability?

Heywood: Pharma in particular has some concerns about engaging - particularly around adverse events. That is why we are working with the FDA on our patient submitted a/e data.

We have products that make it very easy to engage... For example, we have a keyword monitoring service called PatientsLikeMe Listen™ that illuminates the sentiment of our community are a particular subject.

Star: Surprised that you'd define someone w/ALS [that too at the terminal stage] incredibly healthy?

Heywood: He didn't get sick much, his skin was very healthy, primarily because he ate this incredible goop (my term) that my mother made for his feeding tube.

Qian: What tool do you use for patient to share structured information?

Heywood: The community itself is that tool...

Kathleen: What are the age demographics of your patients?

Heywood: Our population tends to skew a little bit younger, but in general matches the disease population as a whole pretty well.

Eric: What are some advancements/upgrades we can expect from your site in the future?

Heywood: We just released forum tagging - which will help structure the discussions on our site. Also, we just upgraded the Doctor Visit Sheet and treatment reports to make them more useful for patients.

We will continue to build out more communities... so keep checking in (and make requests if you have them).

Thanks everybody for the great questions... I really enjoyed the chat. Please say hi to me at the conference in April! Looking forward to it.

Moderator Thanks so much for attending our chat with Ben. Our hour is up. We really appreciate your participation. We will email you a transcript of the chat.