



*Healthcare Web 2.0 Innovators*

## **PatientsLikeMe Case Study**

### **Business Drivers**

PatientsLikeMe is a digital social network where patients of chronic, life-changing diseases share detailed quantifiable information about themselves, their diseases and their treatments' effectiveness. The goal of the site is to improve quality of life by sharing information.



Patientslikeme's distinguishing feature is the quantification of data and its tools for displaying data to make it actionable. Many sites offer patients the ability to communicate and support each other, but patientslikeme prompts members to quantify many elements of their lives: how long and to what extent they feel a pain, discomfort or improvement, how much of what kind of medication or other intervention they use and the impact of treatment in quantifiable terms. Then the site displays the data in easy-to-understand graphs.

Patientslikeme was founded in 2004 by three engineers from the Massachusetts Institute of Technology, two of whom had a young brother with Lou Gehrig's disease (ALS). They aggressively treated the disease and followed traditional and alternative treatment. Meanwhile their brother became one of the most documented ALS patients in history. The eldest brother was looking at match.com one day and marveling at how people shared personal information for a greater cause. He had an epiphany: "What if people could share information about their health to improve the lives of community members?"

### **Summary of Web 2.0 Activities**

#### **The Facebook for Health Conditions**

It is a truism that people will invest their time and take risks in order to work toward an expected benefit. When it comes to healthcare, patientslikeme is confronting a taboo, that health information is the most personal and potentially embarrassing type of information there is. The site is proving that nothing need be off-limits when the perceived benefit outweighs the potential risk. And the site is inspirational because members mostly have terminal illnesses, and they share information to improve the lives of others.

For example, let's say you have just been diagnosed with a terminal illness, and your life expectancy is five years. On patientslikeme you will find people who are in years two, three and five of that illness. The site's approach to quantifying symptoms, interventions and results enables members to compare cause and effect much more effectively. It enables patients in year four to significantly improve and extend the lives of patients in years one and two. Obviously there is no warranty, but most patients tend to be pragmatic: anything they can do to help others is almost like helping themselves. The site is public, and there are numerous examples of how it creates value for its members.

One of its explicit goals is to demystify illness. Statistics show that "modern" countries have virtually eradicated infectious disease, and the focus of healthcare is shifting away from acute, curable disease to chronic incurable. Therefore, the concept of "terminal illness" will apply to an increasing portion of the population.



## A Revolution in Healthcare

Even more far-reaching: patientslikeme has files patents for tools that can predict life and symptoms probabilistically. Given quantified symptoms a, b and c and interventions x, y and z, they say they can predict major milestones in your life based on other patients' data. The key word here is "probabilistically." You might buck the numbers, but chances are you won't.

Now for the mindblower: DNA and genetic analysis will become more mainstream in the next decade or two. That would mean that everyone would be aware of his or her own "terminal illness." The thought goes, "Every person has genetic weaknesses; we just don't know what they are or how to measure them." Software algorithms will predict our physical life events. We will all become "patients like me." Mind bending, to say the least.

Or, as the website states, "Currently, most health-care data is inaccessible due to privacy regulations or proprietary tactics. As a result, research is slowed, and the development of breakthrough treatments takes decades. . . . When you and thousands like you share your data, you open up the health-care system. . . . We believe that the Internet can democratize patient data and accelerate research like never before."

## Business Model

Patientslikeme is free to members, and it is funded by private sources. The business model may be akin to sermo.com's: patientslikeme sells anonymized data to healthcare providers, pharmaceutical companies and research institutions. Founders are confident that the data will prove to be a gold mine; research on diseases is limited by arduous research processes and patients who participate in clinical trials. Patientslikeme members offer a completely different population, and combining their data and results with that of clinical trials and other traditional processes can provide tremendous insights.

Moreover, patientslikeme members' information is emergent. Traditional research sources are slow and laborious. If you are a patient in year two of an illness, and your life expectancy is four years, you want to improve and/or extend your life now.

## Lessons Learned

- Patientslikeme shows that it is unwise to assume that people will not take risks with PHI. When considering risk, do not neglect the rewards side of the ledger.
- Social networks' organizing principal, people sharing with and helping each other, has infinitely many applications and is potentially transformational.
- Although peripherally relevant to patientslikeme, consider what changes will ensue when everyone will be seen as a terminally ill patient due to DNA and genetic analysis.

## References

Description	Reference
PatientsLikeMe website and community and blog	<a href="http://www.patientslikeme.com">http://www.patientslikeme.com</a>
Social Uses of PHI within PatientsLikeMe community	<a href="http://www.jmir.org/2008/3/e15/HTML">http://www.jmir.org/2008/3/e15/HTML</a>
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