

PatientsLikeMe

www.patientslikeme.com

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Description

PatientsLikeMe is an e-health 2.0 application that provides an effective means of managing and understanding chronic conditions. Users are able to monitor their progress using clinically validated scales, share treatment and symptom information, and participate in research related to ALS, Multiple Sclerosis, Parkinson's Disease, HIV/AIDS, and Mood Conditions. PatientsLikeMe empowers patients to control their disease by providing a platform to "[collect] and [share] real world, outcome-based patient data and [establish] data-sharing partnerships with doctors, pharmaceutical and medical device companies, research organisations, and non-profits".³⁷ Furthermore, PatientsLikeMe provides a platform connecting patients with leading scientists, permitting individuals to participate in clinical research trials. Dr Paul Wicks, Resident Researcher at PatientsLikeMe, told this researcher that "studies conducted with PatientsLikeMe have gone from design stage to journal publication around ten times faster than research using existing methods".

The concept behind PatientsLikeMe enables patients to share real-time information on treatments and symptoms. Newly diagnosed individuals were said to be eager to learn from fellow patients what treatments were available as well as what did and did not work. The organisation was founded by three brothers who graduated from Massachusetts Institute of Technology in 2005. One of the brothers was diagnosed with ALS (or Lou Gehrig's Disease) and it became immediately apparent that there was no means to quickly (and easily) connect with other patients to discuss the effects of various treatments.

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Further, the founders concluded that by sharing quantitative patient data, in a productive and secure way, this information could actively contribute to advancing medical research. Thus, PatientsLikeMe seeks to offer a means by which a patient can track and better understand their chronic conditions whilst sharing that information with fellow patients, healthcare professionals, industry and research organisations.

Technology

PatientsLikeMe.com was launched in March 2006. The web service is unique in that it offers its members tools to track and manage their condition, thus personalising the service. To ensure the accuracy and effectiveness of the reporting tools, healthcare professionals and research scientists were consulted during development phases. What resulted was a unique algorithm that tracks the average duration and severity of symptoms. PatientsLikeMe technology also enables its users to track and manage disease-specific outcomes and treatment effects. Specifically, the algorithm takes into account the effects of over-the-counter medications, prescription drugs, specialised equipment and general health treatments and presents these findings in an illustrative format to be shared among the community members.

To take full advantage of the site's tools and features, users are required to complete a series of questions used to generate a report, which charts their progress and calculates percentile curves. This output is then compared (with full transparency) against other users with similar conditions to establish whether their progress is slow, average, or rapid - information which doctors are typically unwilling to share with patients. In addition, the advanced treatment tracking system records dosage, frequency and user satisfaction ratings.

Other sophisticated tools have been developed to 'match' patients based on demographic and disease characteristics so members can find and interact with others with similar interests and conditions. Registration to the website is free but mandatory, and upon membership, users can create a profile, where fellow members can post comments and participate in a message board forum to achieve a greater sense of community. Members can also interact privately.

Business model

PatientsLikeMe receives funding from private investors and business angels. Since the website does not serve adverts and membership is free, the organisation relies on investors and partnerships with healthcare providers. CommerceNet and Omnidyar Network were initial investors in PatientsLikeMe, and the founders secured a Series A finance agreement worth \$5 million in February 2007 with Collaborative Seed & Growth LLC and Invus LP. Currently, the organisation is looking to partner with non-profit organisations and the pharmaceutical industry, as the stakeholders believe those organisations could gain insight into real world data generated from the site's users.

PatientsLikeMe covers operating costs through partnerships with relevant organisations that extract anonymous and aggregated patient data to be utilised in medical and life science research. Typical partners include healthcare providers, pharmaceutical and medical device companies, non-profit

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organisations and research firms. Members are aware of these agreements as the PatientsLikeMe team makes known their 'openness philosophy'. The website makes clear that profile data - or 'personally identifiable data' - is used for research purposes. The privacy policy gives details on the types of data this includes, such as treatment regimens, primary and secondary outcome scores, and biographical information. The intention is that the sharing of this data will drive product developments as well as advancements in medical research.

PatientsLikeMe.com currently serves 500,000 page views each month. Though membership figures are not disclosed, the number of new members is said to be growing at a rate of 15-30% per month. ALS is the oldest community on PatientsLikeMe; it includes 5% of all patients diagnosed in the US and acquires roughly 10% of all newly diagnosed ALS patients each year. Additionally, forums participation is quite active with 28,000 posts spanning 3,700 topics in total since launch.

PatientsLikeMe does have an international presence, however, the bulk of its members are from the US. Membership is comprised of: 70% from US, 10% from UK, 5% from Canada, 5% from Australia and New Zealand, and 10% from the rest of the world. There are plans to increase the size and diversity of the communities in early 2008 in hopes of establishing an even greater international presence and richer repository of patient data.

Prognosis

Web 2.0 has been referred to as a 'disruptive technology' whereby its effect resonates at a societal level, not just at the technical level. In the case of PatientsLikeMe, an organisation that has already been awarded the title 'Next Disruptor' by Business 2.0 Magazine and CNN Money, the service utilises the Internet to democratise patient data and accelerate medical research.³⁸ Namely, the organisation seeks to break down the barrier between the silos of rich, real world patient data generated from e-health 2.0 applications and that data acquired through traditional mechanisms in clinical research. As previously mentioned, the PatientsLikeMe team mobilises the data acquired through their web service by anonymising and aggregating it for use in research and development endeavours in the medical device, pharmaceutical and non-profit sectors.

PatientsLikeMe has been successful in acquiring a solid user base as well as making known their intentions with current and prospective partners. The website makes clear their 'openness philosophy' which states that the organisation shares patient data in a quest to help advance the development of new treatments. PatientsLikeMe collaborates with R&D teams on a global scale - "speeding up the pace of research and fixing a broken healthcare system", according to the website. Thus, the contribution of PatientsLikeMe to the medical and life science research fields goes well beyond the mission of this one e-health 2.0 application. The organisation is challenging privacy regulations and proprietary tactics that hinder existing research efforts. Therefore, PatientsLikeMe challenges its users to divulge information and data. The organisation's stakeholders assert that democratising patient information improves patient-doctor dialogues and decreases the time required to bring treatments to market.

To be associated with such an undertaking - to expose rich data repositories for product development and research - is potentially an exciting opportunity for the medical and pharmaceutical industries as

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well as government bodies albeit a lucrative prospect. Bridging UGC from e-health 2.0 applications with medical and drug research requires strict terms and conditions to be put in place, but once established the publicity from involvement could become viral.

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