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Layout Design: François Louis Nicolet

Composition: Jorge Liácer-Gil de Ramales

Editorial correspondence: Llorenç Pagés-Casas <pages@ati.es>

Advertising correspondence: <novatica@ati.es>

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The New ICT Driven Doctor-Patient Relationship

Jorge-Juan Fernández-García

Web 2.0 tools and the increasingly more widespread use of Information and Communication Technologies (ICT) among the general populace is bringing about a major change in the traditional communication flows between the healthcare system and patients. The possibility for patients to exchange information, consult, check, compare, and even influence the decisions of a healthcare centre is also helping change the way such centres are managed, as well as their strategies for the future. This article describes in detail two success cases (PatientsLikeMe and Patient Opinion) which combine the use of ICT, social networks, and health information exchange.

Keywords: Communication Flows, Doctor-Patient Interaction, Health Information, Healthcare Management, Healthcare Sector Revolution, Online Communities.

Social networks are redefining the relationships between the main players of the healthcare sector in ways that were unimaginable scarcely two years ago. Web 2.0 tools (*blogs, wikis, podcasts, vcasts,...*) are bringing about changes in traditional communication flows.

Innovative business models are behind such initiatives as *PatientsLikeMe*, the online community for patients with pathologies whose physical or mental effects impair quality of life, and *Patient Opinion*, the Website where patients of the British National Health Service (NHS) can share their personal experiences of their interaction with the health services.

1 PatientsLikeMe: A Community Which is Transforming the Way Patients Manage Their Own Health

In December 1998, Stephen Heywood, the son of John B. Heywood <<http://meche.mit.edu/people/faculty/index.html?id=43>>, Sun Jae Professor of Mechanical Engineering of the Massachusetts Institute of Technology (MIT), was diagnosed with amyotrophic lateral sclerosis (ALS)¹. ALS is a degenerative motor neuron disease that causes progressive muscular paralysis, leading to death. The family's first reaction was to go to the Internet. These days everything is just a *google* away, a *google* being a new unit of measurement in the digital world. They found a wealth of basic information about the disease and its prevalence and clinical characterization at sites such as WebMD <<http://www.webmd.com>>. However there were few stories told from the patients' viewpoint, in the first person. This information existed, but it was dispersed over the Internet, mainly on personal Web pages.

As soon as he heard about his younger brother's illness, James Heywood abandoned his career at the Neurosciences Institute (San Diego) to set up a foundation to combat ALS.

¹ Also known as Lou Gehrig's disease after the US baseball star of the 20s and 30s, Lou Gehrig. Other famous sufferers are the British scientist, Stephen Hawking, and Morrie Schwartz, the protagonist of Mitch Albom's bestselling book "Tuesdays with Morrie", 1997.

Author

Jorge-Juan Fernández-García is a graduate in economics from the *Universidad de Oviedo*, holds a Masters in Economic Theory and Political Theory from the London School of Economics and Political Science (LSE), and has completed an Executive Program in Healthcare Management (PADIS) at the IESE Business School. He currently works as a Senior Manager in the world of health sciences consulting (Antares Consulting) where he leads strategic positioning and operational efficiency projects in Spain and Europe. His personal Web page is at <<http://www.jorgejuanfernandez.com/>>.

In 1999, Stephen and James set up the ALS Therapy Development Foundation (ALS TDF) <<http://www.als.net>>, the first not-for-profit biotechnological company in the world. ALS TDF currently employs 13 scientists on a full time basis and receives funding worth 20 million dollars. It is recognized as a cutting-edge research centre that is defining new fields of research in the fight against ALS. It is currently the most active institution in terms of trials of new medicines and treatments targeting ALS.

In 2004 James and his brother, Benjamin, both mechanical engineering graduates from MIT, got together with a former classmate, Jeff Cole, to create a Web page with the aim of bringing together these patient histories told by the patients themselves and helping them monitor the clinical progress of their own illness. They called it *PatientsLikeMe*, a simple but catchy name which, thanks to the participative nature of this type of patients, soon achieved what many social networks take a long time to achieve: scale.

PatientsLikeMe defines itself as: "*the leading treatment and outcome sharing Website for people with life-changing conditions*". The idea is based on a new healthcare model that is "made by patients, for patients". Patients affected by such pathologies are enthusiastic about the project: "*For the first time since I contracted the disease I feel connected*".

The way *PatientsLikeMe* works is simple. The patients choose their community and input their personal data and their symptoms and treatments. Based on that information, the tool enables them to monitor their progress on what is known as a clinically-valid outcome scale. The Website also



Figure 1: Home Page of PatientsLikeMe.

allows patients to select other patients with a similar profile to their own (for example in terms of age, sex, pathological stage) and see what treatment they are receiving and with what results (see Figure 1).

One of the most interesting aspects of PatientsLikeMe is its policy in respect of patient privacy. While other sites promise not to reveal personal information about their customers, PatientsLikeMe has adopted the opposite approach, which also lies at the heart of its business model. They believe that to share and to open up, rather than adopting an exclusive privacy policy, is the best way for patients to be able to monitor their disease, to improve clinical outcomes, and to give a boost to the research efforts of the international community. A description of this unusual policy is to be found on their website in the section entitled "*Openness Philosophy*".

PatientsLikeMe boasts an innovative business model with two important facets: on the one hand, it gathers information about patients, their pathologies, and their treatment. On the other hand, it provides aggregate, anonymous information about symptoms and treatments to researchers, pharmacists, etc. in order to raise the degree of involvement of scientific institutions and pharmaceutical companies in research into these pathologies. These institutions and companies pay for access to these data repositories which are critical in certain phases of clinical trials. This new mode of interaction with the scientific community may usher in a new era in research. Previously it could take around two years to make a questionnaire in the USA and deliver it to the target population. Now, PatientsLikeMe offers the sci-

entific community a repository of data about real patients with a certain disease which is very difficult, not to say nearly impossible, to obtain, even for institutions dedicated to research. Thus it is a case of a win-win model, one in which everyone taking part comes out ahead.

PatientsLikeMe also has a strong investment team: it was initially funded by CommerceNet and Omidyar Network (yes, the founder of eBay). In February 2007 they obtained five million dollars in a first round of funding (*Collaborative Growth & Seed LLC* and *Invus, LP*).

PatientsLikeMe currently has four communities running: ALS, multiple sclerosis, Parkinson's, and HIV/AIDS. In the next two it plans to expand its services years to include over fifty pathologies.

In April 2007 PatientsLikeMe received the FierceHealthIT Top Health IT Innovator Award <<http://www.fiercehealthit.com/innovators/2007/patientslikeme>> given by the online journal FierceHealthIT <<http://www.fiercehealthit.com>>. And in August 2007 it was recognized by Business 2.0 and CNN Money as one of the most important innovations of 2007: "*Next Disruptors: 15 Companies That Will Change the World*" <http://money.cnn.com/galleries/2007/biz2/0708/gallery.next_disruptors.biz2/7.html>.

The Heywood family's fight against ALS was chronicled in the documentary "*So Much So Fast*" <<http://www.westcityfilms.com/smsf.html>> and in the book "*His Brother's Keeper*" <<http://www.jonathanweiner.com/keeper.html>>, selected by the New York Times as one of the 100 notable books of 2004.



Figure 2: Patient Opinión, Opinions of National Health Service Users.

The story ended tragically for one person: Steven Heywood died on November 26, 2006, at the age of 37. But, thanks to PatientsLikeMe, stories like his may end differently in the future.

2 Patient Opinion: Reversal of the Communication Flow in the Health Sector

In 2004, a general practitioner named Paul Hodgkin with a practice in Sheffield (where he still holds surgery once a week) was browsing in eBay. As he scoured the pages in search of products, his attention was drawn to the ratings of the reputations of buyers and sellers: *"as those ratings ensure that eBay users behave honestly, I thought that a reputation system generated by patients could be as powerful as eBay's system and help improve the quality of service of our healthcare institutions"*.

The classical mechanisms that users have to improve the quality of a service are "exit" and "voice" rates². Many health systems use the "exit" of certain players (either hospitals or specific professionals) to increase quality. The other alternative, "voice", has always been limited to complaints and suggestions or satisfaction surveys. Although these may have a positive impact, the fact is that they are asynchronous and any impact suffers from a time lag.

Hodgkin believes that patients see above and beyond what healthcare professionals see. For this reason in September 2005 he decided to create Patient Opinion <<http://www.patientopinion.org.uk>>, a Web page where patients of the British National Health Service (NHS) can go to share experiences of their interaction with the health services (see Figure 2).

Patient Opinion uses Web 2.0 tools to ensure that the voice of patients is heard and that this voice is useful to healthcare organizations, bringing about change where necessary. *"The idea of our organization – says Hodgkin – is based on the belief that to improve health services we need to find new ways to access and learn from the collective wisdom of patients"*.

² "Exit, Voice, and Loyalty is a theoretical concept derived from the work of Albert O. Hirschman which elaborates on two essential options in organizational decline, being exit and voice. The basis concept is as follows: members of an organization, whether a business, a nation or any other form of human grouping, have essentially two possible responses when they perceive that the organization is demonstrating a decrease in quality or benefit to the member: they can exit (withdraw from the relationship); or, they can voice (attempt to repair or improve the relationship through communication of the complaint, grievance or proposal for change)" <http://en.wikipedia.org/wiki/Exit,_Voice,_and_Loyalty>.

The way the page works is simple: users of British hospitals can post their opinions and see those posted by other patients in reference to a specific hospital or service. They can rate the service they have received, set up a dialogue with other patients, see how the hospitals respond to certain opinions aired on the site, and maintain a diary of hospital stays and operations.

On accessing the page, users key in a postal code and, optionally, a service or specialty, which takes them to the options for that service in the selected geographic area, and to the opinions posted by other patients (see Figure 3).

Analysis of these opinions indicates that over 50% of the postings are positive, 25% are critical, and 25% are mixed. All opinions stay on the page for twelve months and are accessible using various search criteria: by hospital, by specialty, etc.

This reversal of the communication flow is one of the most important aspects of the Web 2.0. Where previously some communicated and the rest listened or were simply forced to listen without being able to give their opinion, now a conversation is initiated in which the prime interlocutor is always the end customer, something unprecedented in a sector which is highly intensive in the use of technology but poor in terms of customer orientation.

In this respect, Patient Opinion is not an online "User Care Service", but rather a technology-based merit recognition system. With a total of 350,000 pages visited every month, Patient Opinion generates around 1,000 postings a year per hospital. The hospitals themselves respond to the complaints or requests of their own patients: about 5% of the cases generate a response from the hospital.

How is this different from the traditional complaints or suggestion boxes, which started out as physical boxes before moving onto the Web? They are used in hospitals as a way of collecting users' ideas, suggestions and the like. The difference now is twofold:

- Firstly, all contributions are seen by everyone. In other words, the control of the process is not in the hands of the criticized party (the hospital): the process has changed from a "black box" situation (in which the input and the output is visible, but we do not know what goes on inside) to a situation of procedural transparency.

- Secondly, this greater visibility increases the "cost" of not providing a positive response. This wealth of postings about users' experiences means that all the other users are better informed and, when patients have free choice of doctor (which is the case in Britain), allows them to go to a different surgery.

Patient Opinion is a social sector enterprise (its first re-

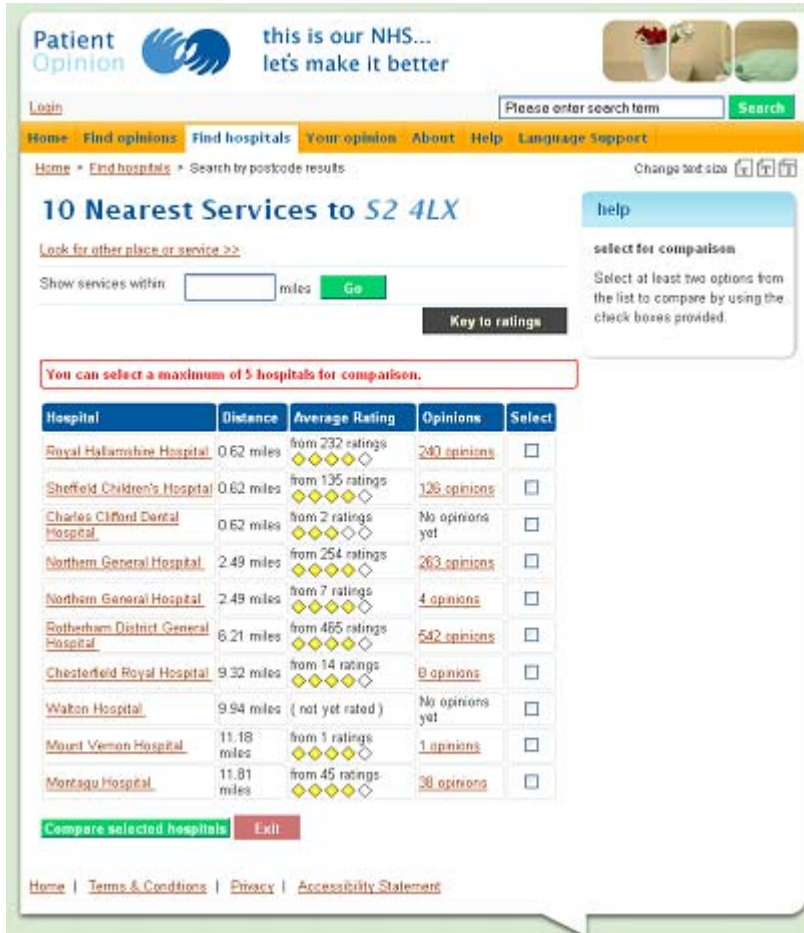


Figure 3. Selection of Hospital by Postal Code.

responsibility is to patients, not to any other interested party or stakeholder) which is funded by subscriptions received from service providers (hospitals) and primary care trusts (PCTs), which use the information they receive to improve quality of service.

This business model (subscription) means that revenue increases as the number of subscriptions grows. This approach allows the enterprise to be free of the tyranny suffered by other similar Internet sites, such as RateMDs <<http://www.ratemds.com>>, which operate under the pressure of having to rely on advertising revenue (which means that the survival of such organizations and their ideas depends on the number of postings they are able to generate).

Patient Opinion's business model is tailored to the needs and incentives of the various players: it is economically viable (in 2007, 90% of the operating budget came from subscriptions and the balance sheet is expected to move into the black in 2009) and it allows the company to concentrate on working with the hospitals rather than meeting the needs of advertisers first (advertisers are the prime stakeholders in a business model based on advertising revenue).

In 2006-07, 9 hospitals or PCTs subscribed to Patient Opinion's services. In 2007-08, the number rose to 30, which represents about 4 million users, between 5 and 8% of the

entire English market.

The results achieved in these first two years of operation are conclusive:

- No hospital has been shut down nor has any doctor been the subject of a lawsuit as a result of Patient Opinion.

- Changes have been made in hospitals as a result of postings made by patients: from such simple things as moving signs inside the hospital so they can be seen by people in wheelchairs, to adapting equipment to meet the needs of older patients.

- The PCTs use this information to monitor the management contracts entered into with the service providers (the hospitals).

- The patients continue to demonstrate their support of the Patient Opinion project because it is the patients themselves who bring about the changes that they believe are necessary.

Patient Opinion was a finalist in the "Yahoo – 2006 Finds of the Year Awards" (Yahoo!'s annual awards for the most interesting and innovative websites of the year), in the Resourceful category <<http://uk.promotions.yahoo.com/finds2006/resourceful/>>. And in August 2007 it reached the last 8 of the *Disruptive Innovations in Health and Health Care: Solutions People*

Want in the ASHOKA (a global association of the world's leading social entrepreneurs) Changemakers Competition <<http://www.changemakers.net/in-us/competition/disruptive>>.

Patient Opinion's next goal is to expand internationally, and it has already made contacts in five countries. Perhaps Spain is one of those five?