

The e-Patient e-Volution

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Interpret-her

In October of 2004, the first web 2.0 conference was held. Hi-tech luminaries from all walks of Internet life convened to discuss the revolution that creative and information sharing and collaboration would have on how people use the Internet. Today, we know that the “who’s who of the Internet” which attended that meeting underestimated what the next three years would bring, and today, giants such as Microsoft, Yahoo, Time Warner and J&J as well as creators of the largest first generations of healthcare portals are all scrambling to understand and engage the empowered e-patient consumer.

Today, the consumer has embraced these tools to have their voice and choice heard by all who choose to listen, often to the dismay of their physicians, healthcare providers, medical equipment users and big pharma. While organizations focus on how to control and monitor the patients, these e-empowered families and caregivers are focusing on how to build, grow and nurture global networks of support, filling the gap they see in their healthcare delivery.

So we must ask ourselves... do we want to join them and learn with them as partners or continue to focus on only the efficiencies that technology can provide us? How the industry responds to this question will forever change the way patients view their role and healthcare’s role.

The ‘Father’ of e-Patient Research

In 2007, an important research paper begun in 2000 by Tom Ferguson MD and posthumously finished by his *e-Patients Scholars Working Group* was published. Dr. Ferguson’s white paper and the ongoing research begun in 2000 by the Pew Internet & American Life Project³ pose challenging questions and suggest that those involved in the delivery of healthcare services must rethink some of their most fundamental assumptions about doctors and patients. To quote MIT’s Sherry Turkle, “Instead of asking how these new technologies can help us make the familiar processes of medical care more efficient and effective, we should ask ourselves how these new technologies are changing the way we deal with one another...how are they changing our fundamental notions of who we are and what we need to do and who we should do it for? What new doors are they opening for us?”⁴

Social Media – Redefining e-Patients Relationships

Webster’s defines relationship as the connection between two or more people or groups and their involvement with one another, especially with regards to the way they behave toward and feel about one another.⁵ Social media can be viewed as an umbrella term that defines the online technologies and practices that people use to share opinions, insights, experiences, perspectives and the media itself.⁶

If viewed through these two different lenses – the first being the actual connection and shared interest two or more people have and the second, the technology facilitators of connections and shared interests, a clearer picture of what the healthcare community will need to do to satisfy the e-patients new way of building, nurturing and sustaining relationships emerges.

So has technology and other current trends changed the definition of what a relationship is or can be? Are relationships built on trust with only those that we know and have worked with or who have helped us in the past? Are the tried and true persons and institutions that people looked to for answers still being viewed as trusted sources? As you will see, our traditional concept of what constitutes a relationship, inadequately describes how the e-wired world views relationships. There is little evidence

that we will be returning to the past. Or as a famous Greek philosopher once said “there is nothing as permanent as change”!

My Relationships...Anyone Like ‘Me’!

Forums, chat sessions, blogs, social network and community web sites allow e-patients to connect, share, but most importantly learn from each other when, where and how they want. This ability would not be near as disruptive to every industry if it were not for three other simultaneous trends which have been evolving tandem with these facilitators of talk. The first being a decline in trust in traditional institutions which people previously looked to for guidance, and the second; the ability to review, rate and provide opinions and stories relating to one’s personal experience with products, services and people performance. Lastly, add the ability to find these collective views easily and you have the perfect industry disruptive storm.

The Trust Factor Disruptor

In 2007, the 7th annual Edelman Trust Barometer, an international study conducted with 2000 opinion leaders in 11 countries, found that “trust in a person like me, rose dramatically to surpass doctors and academic experts for the first time... trust in “a person like me” increased from 20% in 2003 to 68% today. Opinion leaders also consider rank-and-file employees more credible spokespersons than corporate CEOs (42% vs. 28% in the U.S.).

“We have reached an important juncture, where the lack of trust in established institutions and figures of authority has motivated people to trust their peers as the best sources of information about a company, its products and its services,” said Richard Edelman, president and CEO, Edelman. “Companies need to move away from sole reliance on top-down messages delivered by elites toward fostering peer-to-peer dialogue among consumers (in healthcare’s case e-patients, their families and their caregivers) and employees, activating a company’s most credible advocates.” ⁷

In December of 2006, Time Magazine declared its *Person of the Year* to be you, me and everyone else who contributes content to the new media venue. “... look at 2006 through a different lens and you'll see another story, one that isn't about conflict or great men. It's a story about community and collaboration on a scale never seen before. It's about the cosmic compendium of knowledge Wikipedia and the million-channel peoples' network YouTube and the online metropolis MySpace. It's about the many (the patients) wresting power from the few (the doctors, hospitals and healthcare delivery system) and helping one another for nothing and how that will not only change the world, but also change the way the world changes.” ⁸

For industries, institutions and companies who are still bound in hierarchical management silos of power with corresponding P&L responsibility this shift in human behavior demands a new view of “who’s in control” and an analysis of how they organize, compensate and manage every aspect of their business. It requires a new way of communicating, selling, developing and in some cases distributing product and service care, information and education.

The Rate and Review Disruptors

The ability to rate and review retail products and services are common place, but the data on the real impact of these web based capabilities is just beginning to emerge. Studies by comScore, Kelsey and Deloitte's Consumer Products Group are confirming what online opinion

sites had hoped and what face-to-face, word of mouth recommenders have always known – that recommendations do influence consumer as well as business behavior. 9

So does this translate to healthcare you may be asking? The answer is yes. A quick look at the below graph indicate the impact of Rate& Review disruptors.

Online Review Influence on Purchase Decision	
October 12-18, 2007	
Source: comScore, Inc./The Kelsey Group	
Percent of Review Users Identifying Review as Having a Significant Influence on their Purchase	
Service	Purchase
Restaurant	79%
Hotels	87%
Travel	84%
Automotive	78%
Home	73%
Medical	76%
Legal	79%

Source: comScore 9

If the above data doesn't convince the e-patient naysayer that this is definitely not a trend, an online visit to RevolutionHealth.com, the healthcare consumer driven web site founded by Steve Case, the co-founder of AOL or a look at one of the 100,000 physician reviews on RateMDs.com will demonstrate that like it or not, the e-patient is going to have his/her opinions heard.

The e-Patient Profile

Today, it is estimated that half of all the US adults on the Internet have looked for health information on the net, making this the third most popular online activity. E-Patients (those looking for guidance for their own illnesses or for their ailing family and friends) report that their online activity has resulted in "better healthcare information and services" and a different relationship with their doctors and healthcare providers. 10 Different may be good or bad, and will depend on how open physicians and their institutions are and how they integrate this new brand of patient into their patient care planning.

So who is the typical e-patient? She is predominantly female (THE healthcare gatekeeper and CMO (Chief Medical Officer) for herself and her family). The e-patient is a member of two of the largest consumer segments – the Boomer and Traditionalists groups. She is educated, computer savvy and passionate about finding the help to meet her needs. We also know she is more vocal, will describe in greater detail the problem she is facing and is more connected than her male counterpart so meeting her needs will carry the added benefit of extending a physician's, organization's or company's product and service brand and offerings across a wider network. Additionally, we know that she is more likely be burdened with the caregiver role, one that makes her more active in her online role, one that sees her taking on the role of online host, advisor and community elder. She often creates her own web site or

blog about the condition she is caring for and more often than not, she posts content to help others and respond to question.

Beyond the caregiver, we know that those patients facing chronic and life threatening conditions are most likely to be active e-patients. For the three C's reading this article, these situations translate into revenue generation from the surgeries, medications, equipment and medical devices needed to deliver patient treatment.

What Do We Need to Do?

With the above knowledge in hand AND collaboratively with e-patients, a strategic plan for leveraging the collective brain and desire of the e-patient can be created. A Plan which allows the e-patient to:

- Become a valuable renewable resource managing much of their own care
- Help professionals improve the quality of their services
- Participate in entirely new kinds of clinician-patient collaborations
- Initiated patient research
- Self-manage their care

And, a Plan which incorporates strategies that integrate electronic tools which facilitate:

- The search for information
- The exchange of information between family, friends and net 'peers'
- Guidance from online, 'sponsored' patient-helpers
- Participation in online support groups
- Shared research among other online e-patients who suffer the same debilitating illness
- Medical Guidance in areas as diverse as drug interactions and risk assessment
- Interactions with online health professionals
- Fee for service medical consultation and advice
- E-chat with physicians and clinicians

Lastly, a Plan that recognizes the benefit that e-patients provide, such as:

- Placing a human face on medical information
- Practical day-to-day illness management advice
- 24/7 coverage
- Support for the incurable
- Special research, knowledge for rare conditions
- A resource for those with limited professional care
- Up to date information on state of the art care and findings for their condition
- Supplemental healthcare service, not replacement service ¹¹

Product & Service Innovation - THE e-Patient Opportunity

The marketing and media companies quickly saw the revenue potential from the aggregation of hundreds of thousands e-patient eyeballs, but many healthcare companies look to their Communication and PR departments to come up with a strategy to 'deal with the e-patient'. The three "Cs" in most companies are missing THE key opportunity being offered, that of product and service development, improvement and differentiation and patient driven research which can result from the collective sharing and creative problem solving offered by the e-patients' global brain. The collective, unfiltered

voice of these patients are yelling and in some cases, literally dying to be heard. All that needs to be done is to listen – truly listen.

The above is easier said than done. It will require a new model of clinical care. It will demand new processes and procedures and it will demand that ivory towers and ego's be set aside for the good to be maximized. Not a small order, but with or without these changes, the e-patient will have their way and embrace with their dollars and referrals those that lay down the welcome mat and invite them into exclusive world.

References

- 1 *e-Patients, how they can help us heal healthcare*, Thomas Ferguson MD & the e-Patient Scholars Working Group, <http://www.acor.org/e-patients/>
- 2 *Health Online: How to Find Health Information, Support Groups, and Self Help Communities in Cyberspace*, Harper Collins, 1996, Thomas Ferguson, MD
- 3 Pew Internet & American Life Project *Health Reports 2000* to present
http://www.pewinternet.org/PPF/r/26/report_display.asp
- 4 "An interview with Professor Sherry Turkle:", Open Door: Ideas and Voices from MIT, MIT Alumni Association, July/August 2003. <http://alumweb.mit.edu/opendoor/200307/turkle.shtml>
- 5 MNS Encarta, Dictionary, Relationship. Web Retrieval, April 13, 2008
http://encarta.msn.com/dictionary_1861699964/relationship.html
- 6 Wikimedia, Social Media. Web Retrieval April 13, 2008
http://en.wikipedia.org/wiki/Social_media
- 7 Press Release "A person like me" January 23, 2006. Web Retrieval , April 13, 2008
<http://www.edelman.com/news/showone.asp?id=102>
- 8 Time Magazine, December 13, 2006, *Time's Person of the Year*: Author Lev Grossman. Web Retrieval April 14, 2008
<http://www.time.com/time/magazine/article/0,9171,1569514,00.html?ref=klasshop...?ref=Klasistanbul.Com>
- 9 Online Consumer-Generated Reviews Have Significant Impact on Offline Purchase Behavior, Study comScore/Kelsey group study, November 29, 2007. Web Retrieval, April 14, 2008.
<http://www.comscore.com/press/release.asp?press=1928>
- 10 The First generation of e-patients, *bmj.com*, May 15, 2005. Tom Ferguson, MD & Gilles Frydman,
- 11 *e-Patients, how they can help us heal healthcare*, Thomas Ferguson MD & the e-Patient Scholars Working Group, Page 55-57, <http://www.acor.org/e-patients/>