

# Patient2Patient, LLC.

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## **PATIENT2PATIENT WHITE PAPER:**

### **HEALTH CRISIS ON THE NET – “HOW WE ARE FIXING THE HEALTH CARE SYSTEM.”**

#### **THE INTERNET HEALTH LANDSCAPE**

Ninety Million U.S. adults currently seek disease specific information on the Internet.<sup>1</sup> This *Online Patient Community*, by definition, represents individuals facing serious medical problems who desperately seek the medical information and resources scattered across the Internet. This group primarily consists of patients, caregivers and family members.<sup>2</sup>

The Internet is a treasure trove of health information and resources. Members of the Online Patient Community look for diverse health information over a variety of topics. The typical health seeker has searched for 5 topics and more than one-third of health seekers have searched for 7 or more topics. The primary categories for health seekers are specific disease information, treatment information, diet/nutrition/supplements, drug information, alternative treatments and medicines and doctor/hospital information. (Pew Internet, May 2005)

#### **THE CHALLENGE FOR PATIENTS**

Anyone who has used the Internet to find health information knows that a search for disease information can return anywhere from hundreds to thousands to millions of listings. A recent search for “Breast Cancer” on Google, the most commonly user search engine for health, returned over 33 million listings. A similar search on Yahoo Health returned over 6,500 listings. A refined search on Yahoo Health for “Breast Cancer Symptoms and Diagnosis” returned 27 pages of results.

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<sup>1</sup> The general U.S. adult population seeking health information, support, products, and services online represents some 95 million people. (Pew Internet and American Life Project Survey; May 2005).

An earlier Pew Internet study (2002) found that within this group of 95 million people seeking health information, 91% of these users, (90 million people) are looking for disease-specific information.

<sup>2</sup> A majority of health information seekers (54%) are looking for information for someone else, while (43%) are seeking information for themselves. (Harris 2002)

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The problem online health users face is not limited to the overwhelming number of listings provided by search engines. As described by Matthew Sullivan, Editor of Search Engine Week: *"If its not on the first page it might as well be invisible."*(New York Times, 11/6/06)

In other words, Internet health users rarely get beyond the first page of results. For members of the Online Patient Community this means that they never even know about information and resources that may be important, or even critical to their treatment and recovery.

As an example, one of the featured sites in Patient2Patient's Parkinson's WebGuide is [www.plwp.org](http://www.plwp.org). (Patients Living with Parkinson's). PLWP is one of the best overall websites for Parkinson's disease information. But [www.plwp.org](http://www.plwp.org) doesn't appear within the first 15 pages of search results for the Treatments subcategory under a search for "Parkinson's disease" on Google. For most patients this site does not exist.

And what about the quality of the sites patients do find from search results?

Danny Sullivan, Editor of *Search Engine Watch*: "Anybody who looks for something on any search engine and thinks the results are the best or most impartial results, or that they came back completely organically is totally mistaken." (New York Times, 11/ 6/ 2006)

And there is yet another problem: A Pew Internet and American Life Project found in 2005 that *only 38% of Internet searchers* were aware of a distinction between paid and unpaid search results.

Clearly, the difficulties patient face in trying to even find a useful health site are enormous. But finding a health site is not the end of a patient's difficulties:

Each website requires the user to learn and understand the layout and navigation of the particular site, determining who is sponsoring the site (i.e. commercial, non-profit, hospital, pharmaceutical etc...), whether the information is pertinent and geared to the user's level of understanding, what privacy guidelines the site follows and the credentials of the individual/group who is posting the information. It is generally impossible for the user to know if the information is current, or how often the site updates its information.

The whole process is exceedingly difficult and draining, particularly where the user has a serious illness or is the caregiver for someone with such an illness.

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Ultimately, over the course of an illness, patients need to find information on a host of issues that confront them. Patient2Patient has identified more than 20 different issues that most patients and their families face over the course of their illness, regardless of their particular disease.<sup>3</sup>

## **THE IMPACT**

The impact of all these difficulties was summarized in the Rand Report on the "Quality of Health Information On the Internet" (May 2001) which found that:

**"Search engines are inefficient tools for locating relevant health information."** The Rand study concluded that Internet Health users have only *"a one in five chance* of finding information pertinent to their search." (Italics added)

The Rand study highlighted the difficulties faced by Internet health users:

- Only one-third of the links provided information relevant to the users search
- Different search engines provided different sets of links, and that on average only 11 % of the web sites listed by a top ten search engine appeared on the top-ten list of another search engine
- One-half of the information contains material that is promotional but is not clearly labeled as such
- It difficult and time consuming to locate the information within a relevant site
- Most websites contain information and are written at a level that is difficult for most users to understand<sup>4</sup>

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<sup>3</sup> Disease background and treatment information, clinical trials, specialty doctors and hospitals, online and local support groups, medication and drug contraindication databases, medical dictionaries, alternative and complementary resources, diet and nutrition, caregiver resources, local and national organizations, financial, legal and insurance resources, health news sites, newsletters and medical journals.

<sup>4</sup> The Rand Study's Recommendations included:

- Refer consumers to the best sites
- Help patients distinguish between useful and non-useful Web sites;
- Recommend condition-specific sites that may be useful to groups of patients.

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These findings were echoed in a joint report issued by URAC (Utilization Review Accreditation Commission) and Consumer WebWatch, (2004)<sup>5</sup> as well as a Robert Woods Johnson Foundation report on eHealth.<sup>6</sup>

## **THE BOTTOM LINE – 81 MILLION US ADULTS**

More recently, in May 2006, Jupiter Research issued a report on the current ability of Internet health users to find health information on the Internet:

Five years after the Rand Study, the Jupiter found that *only 16% of Internet Health Users are able to find the health information they are seeking online.*

In other words - in the five years from 2001 to 2006, with the advent of extraordinary developments in Internet technology, the ability of patient's and caregivers to find critical health information on the Internet *has grown worse.*

The Jupiter Research report finding that only 16% of Internet Health Users are able to find the health information they are seeking online means that of the 90 million US adults seeking disease and condition information online, more than **81 million** people (84%) are not able to find the critical information and resources that exist on the Internet.

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<sup>5</sup> The Joint Report was based on an online health information Summit attended by health information specialists and officials from government, health care, corporations and health organizations from across the U.S. (Patient2Patient participated in the Summit).

The Summit report recommended:

- Creating consumer-directed tools to support health information needs;
  - Identifying the search needs and capabilities of a diverse group of users;
  - Creating models for offering education on how to conduct health searches; and
- Developing search engine capabilities to refine searches based on user needs and content quality.

<sup>6</sup> The Robert Woods Johnson Foundation Study on eHealth concluded that:

- Consumers face a major difficulty in selecting the most appropriate sites from among the hundreds or thousands that appear in a search result;
- The growing array of eHealth sites makes the search process extremely daunting
- Consumers require guidance and tools for appropriate resource evaluation

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**Neither the Rand study of 2001 or the Jupiter Research study of 2006 considered or gauged the degree to which patients are not even aware of significant health information and resources available online.**

**The founders of Patient2Patient believed in 2001 that the Rand report highlighted an enormous and inexcusable failure – Tens of millions of people, patients and caregivers, who desperately needed health information and resources, but could not find it.**

**This is why they formed Patient2Patient and began the development of Patient Medical WebGuides™ .**

**The fact that this situation has gotten worse from 2001 to 2006 serves to illustrate that search technology, as represented by standard search engines, health search engines and “refined” health search results has not provided a solution, and apparently cannot provide a solution, to this problem.**

## **PATIENT2PATIENT’S SOLUTION**

**Patient2Patient, LLC is the first company to develop an online library of Patient Medical WebGuides™ that provide patients with a detailed guide to the best Internet medical, resource, support and Website information for their specific illness. (Think “Zagat’s for Alzheimer’s disease on the Internet”).**

**Patient2Patient’s Medical WebGuides™ are the first online resource available to Internet health users that provide a comprehensive solution to the enormous problem they face in locating and using Internet health information. Each Patient Medical WebGuide is an interactive “book,” focused on a particular disease that provides detailed analysis and profiles of the best Websites on the Internet for that particular disease. The detailed site information in each Patient Medical WebGuide is divided into twenty different topic areas that provide quality information and resources on the range of issues patients face during their illness. Users are provided with a choice of Websites orientated to their experience and level of understanding for every topic.**

**The topics in each Patient Medical WebGuide include: Disease background and treatment information, clinical trials, specialty doctors and hospitals, online and local support groups, medication databases and medical dictionaries, alternative and complementary resources, diet and nutrition,**

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caregiver resources, local and national organizations, financial and legal resources, health news sites, newsletters, medical journals and more... The twenty topics covered in each Patient Medical WebGuide make it the most comprehensive guided source of disease and resource information on the Internet.

Each Website description outlines the useful information to be found on the Website and how to navigate to this information, provides the user with information on the site's sponsor, the content provider's medical credentials and provides the site's privacy policies.

Every Patient2Patient Medical WebGuide includes extensive patient oriented text that assists each user in understanding and applying the information and resources that they find in the WebGuide to their own situation. Our Patient Medical WebGuides are prepared using the same strict credibility guidelines that the federal government uses on its health websites. Each WebGuide is reviewed by a Board Certified Medical doctor who specializes in the disease being researched. And all the Patient Medical WebGuides are developed under the supervision of our Medical Board of Directors.

In creating our Patient2Patient Medical WebGuides our professional health and medical staff use proprietary search and selection criteria that utilize established government and medical standards for credibility, as well as additional criteria that incorporate usability, style, substance, tone, etc...

Patient2Patient's Business-to-Business model is to build its library of Patient Medical WebGuides to license to managed care companies, physicians, corporations and other healthcare stakeholders. The cost of the entire library of Patient Medical WebGuides will be less than what most companies currently pay for a single source of medical content that only covers a few topics of concern to patients. Patient2Patient's Consumer model is based on advertising and subscription sales.

At the present time over 1,000,000 people have access to our Patient Medical WebGuides through our first commercial client, the National Rural Electric Cooperative Association. The Patient Medical WebGuides have received an extraordinary response from patients and caregivers.

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