The Doctor as the Second Opinion and the Internet as the First

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Abstract

People are increasingly using the Internet for health information, a phenomenon which is increasingly being incorporated under the term of "Dr. Google". Many people are using Dr. Google as their "first opinion" and their doctor as the "second opinion". Using the Internet for a first opinion can be problematic due to misinformation and inaccuracies, misinterpretation of valid information, and the fears that can arise due to lack of medical knowledge, inexperience, and limited perspectives. When people do visit their doctor, some do not disclose the fact they already received their first opinion from Dr. Google. People may make significant health decisions after consulting Dr. Google – oftentimes decisions in their best interest. The result at other times: People may suffer needlessly since their fears, concerns, misunderstandings, and misinterpretations are not addressed by the very people with the expertise and skills to assist them. The worst scenarios occur when people are satisfied with Dr. Google and do not seek further medical help when it is in fact warranted. Currently, a pernicious disconnect hovers and exists between people who use the Internet for health information and medical professionals who care for them. The medical profession could alleviate this disconnect if it provides leadership in 1) establishing standard guidelines for systematically talking to people.
about their Internet research, and 2) ensuring credible medical websites become the “gold standard” that people use.

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Health, medicine, doctors, patients, Internet, websites, search

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**Introduction**  
In many domains, the Internet has dramatically changed how consumers get the information and services they need. In finance and travel, the Internet provides consumers with the information and self-service model that they can use to make their own decisions and perform transactions themselves.

Professional medical care has evolved from the family doctor making house calls into the current in-flux system. In healthcare, unlike many other domains, the traditional doctor-patient relationship has not been disintermediated by the Internet. Instead, a distinct shadow system exists largely in parallel with professional healthcare system - the use of the Internet by healthcare consumers for diagnosis, education, and support.

**The Infiltration of the Internet for Health**  
The initial use of the Internet for health was for online support groups through listservs and discussion forums [11]. As the Internet evolved, patients expanded their Internet use to learn about a disease or condition, to determine whether professional medical care is needed and what options exist, and to get a diagnosis, as well as for support and to identify other people in similar situations.

Eighty-four percent of American adult Internet users, or about 160 million people, looked for health or medical information online in 2007, up from eighty percent in 2006, according to a 2007 Harris poll [7]. The Pew Internet and American Life Project similarly reports that eighty percent of Internet users in the U.S. have researched health and medical advice online [2]. As Internet use increases globally, the use of the Internet for health is likely to increase as well.

**The Impact of Poor Health Literacy Skills**  
Most patients who engage in online activities do so without the knowledge, experience, and detachment of medical providers. Due to poor health literacy skills, many patients “cannot understand or act upon [medical] information,” whether received online or during a doctor’s visit [10]. Components of health literacy include many skills pertinent to the use of the Internet, such as evaluating information for credibility and quality; analyzing relative risks and benefits, and locating health information [3].

Poor health literacy is compounded by poor information literacy skills, lack of education or guidance about how to use the Internet for health purposes, and the desire for miracle cures and easy solutions. While highly reliable health resources are available online, some information is of poor quality, misleading, or outright dangerous [5]. For example, a recent YouTube video that has been viewed thousands of times depicts a treatment that claims to reverse the effects of Alzheimer’s disease [6]. In another instance, a
woman’s extensive online search located a cure for her husband’s ALS; doctors have yet to sanction a cure [6].

While some people start looking for health information at well-known and established websites, such as MayoClinic.com and WebMD.com, most health information seekers, just like seekers of other types of information, start at a general search engine such as Google or Yahoo when researching medical advice [2]. This has led to common references to “Dr. Google” and that “Google is the de facto second opinion” [6, 13, 14].

Often health information searches display mixed quality results that include advertisements and sponsored links that are barely discernable from other search results. People choose which links to follow with little guidance other than their ranking in the results page. Using websites that may be of mixed quality, people may reach conclusions or act upon what they read without the knowledge, experience, detachment, or health literacy skills to make an informed decision. They may make decisions in isolation, without the benefit of expert medical professionals who can make accurate diagnoses and guide informed decisions.

**The Internet Has Become Many People’s First Medical Opinion**

People who search the Internet have vast amounts of health information available to them immediately and at any time of day. Many turn to the Internet readily to look up symptoms, to diagnose a problem, and determine what to do about it, including the basic question as to whether professional medical care is needed at all. For many of these health information seekers, the Internet provides, not their second opinion but, in fact, their first [14]. When they receive professional medical care after first using the Internet, the physician’s advice becomes relegated to the “second opinion”.

In some cases, the first opinion is the only opinion. Someone may determine that a doctor’s visit is not needed or learn how to treat a health problem on their own. A symptom checker can advise when immediate attention is needed for a possibly serious health problem, but a doctor provides further exploration of symptoms and signs, an appropriately focused physical exam, and any testing that may still be necessary before an assessment and differential diagnosis can be accurately produced. Doctors can misdiagnose, too, but the Internet has many limitations as a screening tool. No data really exists about the frequency with which a doctor’s appointment is needed but not scheduled.

In many cases, the first opinion from the Internet leads to seeking the second opinion. Frequently, the first opinion is not communicated to doctor. The lack of communication occurs in both directions; patients often do not talk about their research and diagnosis, and doctors rarely inquire about their patients’ Internet use, focusing instead in the usual stereotypical manner of addressing symptoms and making a diagnosis [6].

**Why Physicians Don’t Ask**

One reason physicians may not ask is that they are not trained or incented to integrate discussions about patients’ Internet research into their practice [4]. Initiatives such as pay-for-performance may have the unintended adverse consequence of reducing the already often limited provision of patient education [1, 12].
Another reason physicians don’t ask is lack of time during appointments. Yet another is the negative image of patients who are confrontational because they already are convinced of their diagnosis or who walk in armed with the “enthusiastically clutched ream of internet printouts” [6, 15].

Some physicians may feel that a patients’ Internet research is not relevant since they must rely on their own expertise, patient interviews, and diagnostic procedures regardless of what the patient found online.

**Why Patients Don’t Tell**
The negative image of the patient who has reams of printouts or who confronts the doctor is more mythical than real. In fact, many patients never bring printouts, and more significantly, they don’t disclose their online health research to their doctor, even when they have found that first opinion, or are confused or scared by what they read or believe they might have [2].

The reasons patients don’t disclose their Internet research include not wanting to appear stupid, not being comfortable with the pronunciation or definition of medical terminology, wanting to test the doctor’s knowledge or diagnostic skills, or wanting to see if the doctor’s opinion agrees with their own or with Dr. Google’s [8]. Another major reason is that they aren’t asked by their doctor and they don’t know whether it is disrespectful to bring up, or how to bring it up.

Many people don’t want to voice their worst fears or come across as a “cyberchondriac,” a term that was coined to describe people who believe they have a disease that they read about online [6]. Their disinclination to talk about what they read is compounded by the vulnerability patients experience by having to ask health-related questions while attired in a paper gown and knowing that there is limited time for their appointment.

**The Consequences**
Thus, patient’s Internet research and the doctor’s visit largely remain disconnected even though patients, doctors, and most creators of health websites all share the same purpose: to help patients become healthier. Since a strong doctor-patient relationship is partially based on trust, undisclosed research can erode the patient’s trust in the doctor without the doctor even being aware of it.

The lack of discussion about the use of the Internet on both parts can lead to problems following a doctor’s visit. A common example of this is when the fears and concerns a patient had prior to the visit are not addressed and incite more worry or further research. For instance, a patient who sees a doctor with a pre-conceived diagnosis and who receives a different diagnosis may be skeptical of the accuracy of the doctor’s diagnosis if the original one was not considered or explicitly tabled.

Since the lack of health literacy skills can lead to poor comprehension and retention of information during a doctor’s visit, many patients leave the doctor confused and ill-informed. While there are ways the consultation can be restructured to mitigate this [12], currently many patients leave their doctor without enough of the answers they were seeking, and, hence, immediately go online to conduct another search for Dr. Google’s third opinion. Without recommendations or assistance from the doctor in locating high quality and relevant
information, patients conduct their research in isolation, just like with any research they did prior to the doctor’s visit. Once again, the patient didn’t ask and the doctor didn’t tell.

**True Story: A Mother Diagnoses Whooping Cough Incorrectly**

Mary Ann P. went online because her 10-year-old daughter had a cough that had persisted for six days, and had kept her out of school. She was looking for potential home remedies to help calm the cough so that her daughter would be more comfortable, be able to rest, and recover.

As a result of her Internet search, she discovered that her daughter’s symptoms were similar to those of whooping cough. One website she went to even had an audio clip of a coughing child with whooping cough, which sounded just like her daughter’s cough.

Based on what she read and heard online, Mary Ann wondered if the effectiveness of her daughter’s babyhood immunization was fading.

Armed with this information, Mary Ann took her daughter to see a nurse practitioner during the "sick kid" drop-in hour the morning after looking online. Mary Ann didn’t tell the nurse practitioner she had looked online because she wanted her to observe her daughter’s symptoms and make her own diagnosis based on her training and experience. Mary Ann also did not want to "sound stupid" if her whooping cough suspicion was more farfetched than she thought.

Mary Ann was told that her daughter just had a cold and a bad cough. She was relieved, of course, although wondered if the time and worry from her Internet research had been worthwhile. Her daughter got better quickly; if she hadn’t, Mary Ann’s worries about a diagnosis of whooping cough could have persisted and she would have returned once again. If the health professional had asked, it would have been easy for Mary Ann to voice her concerns and she might have even learned more about the diagnostic process the nurse practitioner used so that she would know more about diagnosing whooping cough.

**True Story: A Patient Brings Critical Medical Information to a Doctor and Nurse about Treatment for Bat Bites**

One morning Diana C. woke up to find a bat in her bedroom. Not knowing that bats should be captured and tested for rabies, she "batted" it out a window. The next day she noticed marks on her shoulder. When they reddened and became itchy, she searched online and identified the marks as a bat bite by measuring the distance between the teeth on a life size picture of a bat and comparing that to the marks on her shoulder. She learned that a bat bite can eventually prove fatal if not treated within 48 hours, and she went to the emergency room for appropriate treatment.

Diana told her doctors what she found online - seeking confirmation that it was, in fact a bat bite, and insisting on getting both the first doses of the vaccine plus the rabies immunoglobulin, within the 48 hour post-bat exposure time frame. Diana's Internet first opinion got her to the emergency room. The doctor’s second opinion confirmed the first opinion, and Diana significantly contributed to her own treatment, bringing accurate information to the doctor about what she needed for definitive prevention, in case the bat was
carrying rabies, since bat bites are not common in her region. She also provided directions from her online information for the nurse who washed the area. Diana and the professionals who treated her arguably benefited from her online research.

**True Story: A Patient Panics from What She Finds Online**

Julie Z. thought she had symptoms consistent with uterine cancer based on a symptom checker she used when she had unexplained symptoms. She was able to make an appointment with her doctor for a week after detecting the first symptoms, but in that interim, she searched the Internet relentlessly, scaring herself “to death” by the information she found about severe cases.

Julie tried to talk to her doctor about the information she read online about uterine cancer, “but all he said was, ‘We cannot know until we do the biopsy’, which may have been medically true but didn’t calm my fears,” Julie related. “My anxiety led me to search obsessively. Plummeting [into] the depths of the Internet is far more responsive to my needs since I can openly search on any topic that I can think of related to my concern.”

Julie’s test results came back negative. She and Diana shared the benefits of using the Internet to prompt them to go for medical evaluation, but Julie also suffered one of the same consequences as Mary Ann, since the information she found was frightening. Julie’s doctor could have recognized and responded more to her concerns, but Julie tried to be respectful of his time and did not disclose the extent of her fears, or of her obsessive online searching.

**What Can Patients Do To Use the Internet More Effectively**

The “empowered healthcare consumer” refers, in part, to the patient who uses the Internet judiciously and safely. The term also implies that, through knowledge about health problems and what to do about them, the burden on the medical system is reduced.

Little training or education is available to “empower” healthcare consumers; many develop skills on their own due to persistence, determination, or need. Patients rarely receive specific guidance on how to use the Internet generally or for using it for health particularly. Poor health literacy, which impacts patients in their adherence to prescriptions and a multitude of other ways, can be somewhat mitigated by better education by doctors and other health professionals. The provision of education could even take advantage of blocks of time such as prior to a doctor’s appointment in a waiting room.

Most importantly, patients can be given guidance in how to integrate their Internet research with visits to their healthcare providers. Patients are only rarely invited to bring information or resources they have identified with them for a doctor’s visit. It would assist patients if they were told whether to bring printouts or questions arising from their Internet research, how to bring up online research with their physician, or even the optimal point in the consultation. Ideally some of this type of information exchange or discussion can take place outside the confines of a consultation, but, as of yet, many physicians do not have email contact with patients.
**What Can Doctors Do?**

Doctors can acknowledge that many of their patients quite likely went online before a visit. Doctors can specifically address the difference between presenting symptoms and presenting a diagnosis acquired through online research. Finally, doctors can ask about any lingering concerns about the diagnosis or treatment.

Doctors can also provide recommendations of health websites to use. A doctor’s advice can save a patient time and effort in searching and can lead directly to websites with high quality information. Furthermore, doctors can provide guidance about health website quality indicators and reliable sites to use in general.

Doctors are themselves often users of the Internet, and the more they use it for their own and their patients’ health concerns, the more knowledgeable and adept they become. For those who haven’t, performing general searches on the same types of conditions that they treat patients for would allow them to see what their patients would see. Doctors can also learn about patients’ perspectives and their experiences of illness through discussion forums and patient blogs. Some doctors even write their own blogs or create websites for their practice. But with the growth of medical literature, doctors have less time than ever before. Even small amounts of time devoted to helping their patients find beneficial websites could benefit those patients; this could be facilitated by medical societies rather than each doctor bearing the responsibility.

Questions from patients arising from their Internet research need to be addressed by doctors. Doctors are afraid of being inundated with information that is irrelevant or even just too much information, whether it is before, during, or after an appointment. Since each doctor might have a preferred way to handle this, this can be decided within a practice and communicated in advance to patients.

**Health Websites Need to Be Designed to Meet Patient’s and Doctor’s Needs**

A “gold standard” for health websites must emerge that both patients and doctors can trust to provide accurate, current, and relevant health information that are designed to meet the needs of patients with different needs and health literacy skills. “Gold standard” health websites require user experience professionals to design and evaluate targeting not only the patients who use the sites but the doctors who will get a “secondary” experience by virtue of their patients.

Web 2.0 and the now touted Health 2.0 are not a panacea for helping patients in their use of the Internet and may even be disadvantageous for patients who do not distinguish between expert- and user-generated content. Specialized medical search engines exist but are in limited use. Accrediting agencies, such as HONcode and URAC, also exist but most people don’t know about them and therefore don’t check websites for their seals indicating compliance with the accrediting agency’s standards [5]. In fact, people rarely check at all for quality indicators, sources, or dates on health websites [2].

Certainly, quality seals, information about sources, the date material was created, and any funding or sponsorship can be made more apparent and noticeable on health websites. Especially as the barriers become lower for creating websites, quality indicators become more important for the public’s protection. Yet this only
works if quality indicators are expected by healthcare consumers or required by some regulatory action.

Agencies such as HONcode and URAC look at many factors in accrediting a site, but don’t include usability or the user experience. “Gold standard” health websites will instead focus on the patient’s firsthand and the doctor’s secondhand experience. Professional medical societies and government agencies may ultimately be best suited to develop standards and guidelines because they have the most at stake. Regulatory requirements will provide the most consistent consumer protection.

In addition to better design, the websites themselves can provide guidance on how to use the website safely and more effectively and in conjunction with professional medical care. This type of guidance rarely occurs presently, other than when a symptom checker recommends seeing or contacting a doctor or visiting an emergency room.

**Conclusions**

“Don’t ask” and don’t tell” have had dubious benefits in other domains. Doctors benefit if their patients are more knowledgeable and less confrontational or fearful. Patients benefit if they are more knowledgeable and have better relationships with their doctors. These should become shared goals supported by medical societies since all parties benefit.

To date, acknowledgement of the extent to which patients are going online is lacking within the medical community. More information is needed into the reasons that patients are relying heavily on the Internet, using it for their first opinion, and far too often keeping the information they discover about their potential or probable diagnoses and their fears to themselves.

Changes in what doctors and other health professionals do, what patients learn, and how health websites are designed can each contribute to safer use of the Internet for health and better integration with professional medical care. In order to create further strategies you first need insights into the underlying reasons for patients’ actions.

Initiatives such as electronic medical records (EMRs) receive attention and funding because the efforts are aimed at both reducing healthcare costs and improving patient care. Yet there is debate that the use of EMRs improves the quality of patient care [9].

Many questions need to be answered, such as what types of information best help patients, how to develop and promote a “gold standard” for health websites that is supported and endorsed by the medical community, how health literacy can be improved, and how patient-doctor consultations can better integrate patient’s Internet research activities in ways that benefits patient and provider. With eighty percent or more of Americans, across all ages, and many people in other countries as well, using the Internet for health information, research and funding should be directed for efforts in the public domain to harness patients’ use of the Internet and ways to connect their Internet use with the professional medical community.

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References


